

What do we know about the relationship between neurological conditions and protected characteristics? A short review

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Introduction

Neurological conditions can affect anyone at any time, no matter your age, sex, living situation or gender. They can impact all aspects of your life; how you think, feel, move, work and play. There are more than 600 different types of neurological conditions, ranging from the very rare (affecting less than 1 in 2000 people), to more prevalent conditions you may be more familiar with, such as dementia, Parkinson's or autism. For everyone with a neurological condition, the right support at the right time makes all the difference.

As a community of individuals and organisations committed to improving the treatment, care and support for every person living or affected by a neurological condition, it is in all of our interests to understand the extent to which different conditions affect different people and different socio-demographic groups. At present, we are unable to offer tailored treatment for specific groups, although health outcomes and experience vary across different groups. For example, a survey by (Stonewall, 2018) found 23 per cent of LGBTQ+ people have 'witnessed discriminatory or negative remarks against LGBTQ+ people by health care staff' and one in seven LGBTQ+ staff have avoided treatment for fear of discrimination. Researchers at University College London found that females with dementia receive worse medical treatment than males with the condition. They found that females make fewer visits to the GP, receive less health monitoring, and take more potentially harmful medication (Cooper, et al., 2017).

In addition, Getting it right first time (GIRFT) reports in stroke (Hargroves & and Lowe, 2022), neurosurgery (Phillips & May, 2018) and neurology (Fuller, 2021) have all found significant unwarranted variation in the structure and delivery of services, thereby potentially increasing inequity.

Yet, our understanding of health inequalities across neurological conditions is fairly limited – improving that understanding is absolutely critical to improving neurological health outcomes for all.

The Neurological Alliance recently asked more than 8,500 people affected by neurological conditions about their experience and access to services (The Neurological Alliance, 2022). People could respond either by an online questionnaire, a paper questionnaire, using a 'language telephone line' or via an easy read version. The survey was promoted via Neurological Alliance member organisations, social media and in (predominantly neurology outpatient) clinics.

The research, entitled 'My Neuro Survey', found:

- Females were more likely than males to report greater disruptions to their treatment and care during COVID-19
- Those identifying as Lesbian, Gay or Bisexual were less likely to report receiving information at diagnosis, and when they did, less likely to find it helpful
- Those living in more deprived areas were more likely to report greater impacts of their neurological condition on their quality of life and day to day activities, and more likely to experience pain due to their neurological condition.

Building on this evidence, we conducted a focussed literature review of evidence which indicates how prevalence and incidence of neurological conditions, and access and experience of services may differ for different groups of people with neurological conditions. Our hope is that this evidence would contribute to our understanding of inequalities amongst people with neurological conditions, and deliver much needed insight into how we might be able to reduce these. This report provides a summary of our key findings and recommendations.

We limited our search to the top 10 most prevalent neurological conditions – our hypothesis being that the majority of available literature would be found here. Of course the majority of neurological conditions are rare. It is likely that our understanding of the

relationship between rare neurological conditions and protected characteristics is even lower than is presented here.

We recommend:

- All neurology outpatients have their diagnoses coded so that future audits can be conducted on access to services and outcomes. Coding approaches need to be harmonised nationally, to ensure the validity of this data.
- Funders of research prioritise enhancing our understanding of how the prevalence and incidence of neurological conditions varies across protected characteristics.
- Researchers and publishers encourage publication of data disaggregated by protected characteristic, where possible.
- Providers of services conduct an equity audit of their service to ensure it is accessible, trustworthy and welcoming to all people suspected of or living with neurological conditions. The characteristics of age, sex, race, religion, postcode (as an estimate of deprivation) are usually collected for all patients and need to be used to conduct this audit. The other characteristics are likely to need additional studies.
- Organisations within the voluntary sector review their information and support, research programmes, public involvement activities and people policies to ensure they reflect the principles of equity, diversity and inclusion.
- The Neurological Alliance (England) provides a space for members to share their experiences of embedding equity, diversity and inclusion into their work.
- The UK Government work with voluntary and community groups, people with lived experience and the research community to update key terminology, including definitions used for protected characteristics within the Equality Act 2010.

Methodology

We conducted a focused review of published literature between 2000-2022 to outline the evidence describing the relationship between the protected characteristics of the Equality Act 2010 and the epidemiology, diagnosis, management, experience and outcomes of people affected by neurological conditions. Other factors such as deprivation, settlement status, education and employment were also explored. This report highlights the areas which were significant and/or had a good evidence base.

For pragmatic reasons, we included ten conditions in the research, due to high prevalence and availability of published evidence:

1. Stroke
2. Dementia
3. Migraine
4. Brain and tumour cancer
5. Parkinson's disease (PD)
6. Epilepsy
7. Functional Neurological Disorder (FND)
8. Multiple sclerosis (MS)
9. Traumatic Brain Injury (TBI)
10. Motor Neurone Disease (MND)

We included research conducted with human participants and published in the English language. Research participants were patients, carers, or healthcare professionals and regardless of institutional/environmental setting. Database searches were conducted to cover articles published between 2000 to early 2022. Grey literature, including from the UK Government and arms-length bodies, think tanks, patient organisations, charities and healthcare professional bodies were reviewed where relevant. Articles were excluded if they were reported in book chapters or unpublished theses. Medline (Ovid), CINAHL (Ebsco), PsycINFO (Ebsco), Embase (Ovid), Cochrane Review, Web of Science were used to

conduct the focused academic literature searches. Given the broad scope of our research and feasibility, it was not possible to perform a systematic literature review, and it is therefore possible that some key publications have not been included in this report.

Summary of our findings

		Epilepsy	Migraine	Dementia	FND	MND	MS	PD	Stroke	TBI	Brain tumours
AGE	Quality of evidence	A	A	A	A	B	A	A	A	A	A
	Summary findings	Incidence of epilepsy higher in youngest and oldest age groups.	The prevalence of migraine demonstrates a well-established age-related distribution. Overall, migraine is most prevalent during the productive years of life, ages 20 to 50.	Incidence and prevalence of Dementia increases with age is well documented. The prevalence is 5-7% for people above age 60 years.	FND presentation is most likely in the 4th to 5th decade of life.	ALS incidence increases with age, with peak incidence of 8.3 per 100,000 person-years at ages 70-74 years. Global prevalence is 5.7%, with the prevalence peaking in 80-89-year-olds.	MS usually presents in adults in their twenties or thirties, but it does also present in children, and older adults.	Incidence and prevalence of PD increases with age. Global burden of disease estimated 6.1 million individuals with Parkinson's disease worldwide.	Incidence of both haemorrhagic and ischaemic stroke increases with age. Older patients had a longer time from admission to CT scan. Older age associated with higher risk of in-hospital death and higher 7 day mortality.	TBI prevalence peaks mostly in the older population (80-90yrs old) with a smaller peak in 20-40s. Falls were the most common mechanism of injury in the elderly, and RTAs in young adults. Increasing age is associated with worsening outcome post-TBI and mortality.	Incidence of brain tumours increases with age and peaks mid-late 60s. Meningioma incidence increases until the mid 80s, where it peaks and then declines. Astrocytoma and glioblastoma incidence peaks in the mid 60s to mid 70s and oligodendroglioma peaks in the mid 30s to mid 40s. Mortality and complications

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GENDER REASSIGNMENT	Quality of evidence	C	C	C	C	C	B	C	C	C	C
	Summary findings	There is limited data on the relationship between gender reassignment and transgender issues in patients with epilepsy.	Very limited research in this area. Hormonal treatment associated with male to female transitioning seems to confer increased migraine risk.	No published evidence in this area.	Higher proportion of FND patients are transgender in comparison to that statistic for the population.	No data available	Some suggestion of higher prevalence of MS in genetic males undergoing sexual transformation. Further research is required to see if these findings can be replicated and further elucidate any role for gender reassignment and hormone treatment in MS pathogenesis.	No published data available.	For Ischaemic stroke, transfeminine patients had an incidence rate of stroke and higher risk of stroke.(hazard ratios of 2.3 and 2.9 respectively).	No data available	Cross-sex hormone treated increases risk of meningiomas, prolactinomas and somatotrophinomas. Meningioma incidence higher in transwomen. Somatotrophinoma incidence higher in transmen.

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MARRIAGE AND CIVIL PARTNERSHIP	Quality of evidence	B	B	C	B	C	B	C	B	B	C
	Summary findings	Suggestion that people with epilepsy are less likely to get married, but these findings need replicating.	There is limited published data about the relationship between marriage, relationships and migraine. One large survey reports those with a higher frequency of episodic migraine are more likely to report a 'damaged relationship' or 'relationship break up' than those with fewer migraine days per month	Two qualitative studies found dementia affected relationships, roles, loss of partner and loss of marriage.	Of the patient group, the majority were married.	1 study found lower marital relationship satisfaction and sex life satisfaction in carers/partners of the patients. Found marital relationship satisfaction to be predicted by amount of social support.	Studies suggest an associated risk of divorce among males and the probability of remaining in the same relationship.	No published data available.	Risk of stroke is increased immediately following a divorce for males and females. In those who are divorced or widowed, risk of stroke is increased. Being married had a protective effect for 90day mortality for haemorrhagic stroke.	Varying values regarding divorce rates are available, with some research using focus groups looking at spousal perception and reaction to the injury affecting marriage satisfaction and stability. Post-concussion syndrome was more common in married patients.	Reduction in marriage probability seen across both genders. Beneficial marriage effect on survival decreases with more lethal cancers and higher years already survived.

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PREGNANCY AND MATERNITY	Quality of evidence	A	B	C	C	C	B	C	B	C	B
	Summary findings	There is a complex relationship between pregnancy and epilepsy, including the need for preconception planning, the effects of antiepileptic drugs and seizures on foetal development and pregnancy and the impact of the physiological changes of pregnancy on antiepileptic drug effectiveness.	Episodic migraine frequently typically increases in the first trimester but can be expected to decrease later in pregnancy. Associations between migraine, treatment and miscarriage, pre-eclampsia, congenital anomalies, and low birth weight are not well understood.	No published evidence in this area.	No data available.	One study found no risk association of MND with parity.	Low MS relapse rate during third trimester with a rebound of disease activity in the first 3 months following delivery. Thereafter, the disease activity steadily returned to the level that preceded pregnancy. These findings are replicated across multiple studies. Note only limited data on pregnancy related safety for many of the newer Disease Modifying Drugs. Further research required.	One single review of 74 live births to patient with PD, with advice on symptomatic management.	Risk of stroke is increased during the peripartum and early postpartum period. Also evidence to suggest HTN during pregnancy increases risk of stroke in later life. Increase in prevalence of stroke risk factors and high maternal mortality if stroke occurs.	No published data for incidence, but trauma is known to be the leading cause of nonobstetric maternal mortality. Some research shows no statistically significant difference in mortality compared to non-pregnant controls.	Pre-existing meningiomas rapidly grow during pregnancy due to progesterone and oestrogen but stop after birth. Meningiomas most likely to present in third trimester. If they do develop, gliomas are most often seen in first and second trimester. Pre-existing gliomas seen to increase in volume and size during pregnancy. One study found poor outcomes and maternal death to be associated with unplanned pregnancy and tumours diagnosed during pregnancy.

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RACE	Quality of evidence	B	B	A	B	A	B	B	A	A	A
	Summary findings	Evidence suggests those who do not identify as White are disproportionately affected by epilepsy. Further research required to examine relationship between race and epilepsy incidence, burden and access to care in the UK.	There is limited data on the relationship between race, ethnicity and migraine prevalence, diagnosis or treatment. However, data suggests that prevalence may be higher in Caucasian populations	Abundance of evidence, mainly from North America. Studies on health disparities have emphasised Dementia being under-diagnosed in ethnic and racial groups: African-Americans are less likely to be diagnosed, and diagnosed at a later stage, with more barriers to accessing care after diagnosis.	Of the individuals with FND, there is a higher proportion from Africa and India. In countries with a low % of Indian Population, the % of FND patients from India is surprisingly high. Data for incidence levels for different races could not be found for most countries, Northern Europe reports prevalence rates of approx. 20% and in Asia the prevalence was 10.84 per 1000.	Median prevalence in Europe is 5.4 per 100,000. Prevalence in East/South Asia is 1.0-1.6 per 100,000. Japan had a higher incidence rate (2.2 per 100,000) in comparison to the rest of East Asia. Patients with mixed ethnicity have a lower mortality rate.	The long held notion that the risk of developing MS is highest in White populations is being questioned by newer data, with multiple recent epidemiological studies reporting increasing incidence in Non-White populations.	Incidence of PD reported to be higher in Western than Asian populations but may be due to under-reporting. More studies needed in this area.	For ischaemic stroke, the risk increases in relation to race. Incidence is higher in those of Asian background, followed by Blacks, Hispanics and then White people. Black patients less likely to receive evidenced-based care and lower odds of iv thrombolysis, DVT prophylaxis and other medical therapies. Black patients had a lower in-hospital mortality risk. For haemorrhagic stroke, the incidence is increased in those of an Asian background, followed by White, Black and Hispanics.	In the US black people had the highest incidence of TBI and second highest mortality rate from TBI. North Africa, the Middle East and Central Europe have the highest rates of TBI. Black patients had an increased average length of stay, they also had a lower rate of mortality at an AIS score of 5 than White patients. Black patients were more likely to be discharged to rehabilitation, whereas Hispanic patients were less likely and they also had lower functional outcomes.	Malignant tumours are more likely in white people. Non-malignant tumours are more common in black people. CNS tumour incidence is highest in Northern Europe. However, lack of detection due to poor country socioeconomic status impacts results. Non-Caucasian patients more likely to have post-op complications or require blood

											transfusions post-craniotomy.
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RELIGION AND BELIEF	Quality of evidence	C	B	B	C	C	C	C	C	B	C
	Summary findings	Further research is required to determine whether religious factors are associated with better / worse access to healthcare, or treatment related outcomes.	There is little research exploring the relationship between religious factors and the experience of migraine. Fasting practices may exacerbate migraine.	Few studies exist but highlighted benefit of faith practices in maintaining social relationships.	No data available.	Religion is an infrequently used coping strategy for these patients, with likelihood of using it increasing with age.	Few studies exist, where religious variables were not effective prognostic factors in physical and mental quality of life or psychological adjustment.	Few small studies reporting decrease in religious practice in Parkinson's disease.	Limited research available. One study found possible association between religion and decrease in cardiovascular disease risk factors, which may then decrease cerebrovascular disease risk.	Some research to suggest religious beliefs have a unique role in predicting rehab outcomes but religious practice does not. Spirituality also seen to have a negative link with carer burden. Attending religious services was seen to predict better life satisfaction, greater social participation and less depressive symptoms.	Some evidence to suggest patients find religion/spirituality useful when coping with their disease, with most patients feeling that their religious needs were often overlooked. Also, patients did not want their physician to pray with them as this came across as physician uncertainty.

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SEX	Quality of evidence	B	A	A	A	A	A	A	A	A	A
	Summary findings	Unlikely significant difference in prevalence between male and female. However experience differs, with females affected by catamenial epilepsy and issues surrounding pregnancy and epilepsy control.	Sex has a significant role in prevalence of migraine, with a number of epidemiological studies demonstrating a prevalence in females in some cases over twice that of males	Incidence rates of dementia higher in females upto age 85 years.	Incidence of FND is found to be higher in females, with 75% of those diagnosed being female. However, males are more likely to present acutely to the hospital.	Male to Female ratio for ALS is 2.10:1.00. The exact ratio between males and females varies based on country of origin, but the trend of males being more commonly affected remained. Mortality rate is higher in males.	Incidence and prevalence estimates higher in females, with ratios as high as 3:1 in some regions of Europe.	Incidence rates of Parkinson's disease for males higher than for females.	The risk of ischaemic stroke is higher in females than males and is attributed to a range of factors. Females have a longer life expectancy than males, use of HRT post-menopause, females are more likely to suffer from migraines with aura, use of oral contraceptives and pregnancy. Females had a higher risk of readmission for ishcaemic stroke and mortality. For haemorrhagic stroke, the risk and mortality is higher in males until age 80 where the risk increased for females.	Male predominance of TBI incidence. Mortality is higher in males than females.	Incidence of malignant CNS tumours is higher in males. Incidence of non-malignant CNS tumours is higher in females. Evidence shows meningiomas have oestrogen and progesterone receptors so often grow during pregnancy or HRT. Females have a higher 5-year survival rate.

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SEXUAL ORIENTATION	Quality of evidence	C	B	C	C	C	B	C	C	C	C
	Summary findings	No data could be found demonstrating an association between sexual orientation and epilepsy diagnosis, prevalence, incidence, access to healthcare services or outcomes.	Epidemiological data suggest a possible increased prevalence of migraine in those who do not identify as heterosexuals. No high quality evidence.	No published evidence in this area.	No data available.	No data available	Two European studies indicate that people with MS who identify as LGBTQ have difficulty with access to and engagement with healthcare services.	No published data available.	No data available	No data available	No data available

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OTHER - GEOGRAPHY	Quality of evidence	B	B	A	C	B	A	C	C	C	C
	Summary findings	Evidence from NASH indicates geographical variation in care, particularly for patients attending Emergency Departments due to seizures.	No clear evidence of variation in migraine prevalence across the UK. However likely variation in access to migraine treatment, particularly specialist neurologist advice and CGRP therapy. Further research required.	Dominance of European studies suggesting higher incidence rates in older people in northwestern countries compared with Southern European countries.	No data available.	Incidence is highest in Scotland and lowest in Ireland . Incidence in England varied based on the location within the UK with higher levels of incidence in North West England. Increasing mortality over the past few decades.	Multiple epidemiological studies demonstrate that MS is a geographically-related disease, suggesting that acquired environmental factors contributes to disease pathophysiology.	Limited data outlining geographical variations in PD within the UK. One study reported incidence rates higher in urban population than rural.	Highest incidence of stroke in Scotland, lowest incidence of stroke in England.	No data discussing incidence or prevalence around the UK could be found.	Data available from GBD. England has the highest incidence and prevalence of brain tumours. Greater London has an incidence number in the middle of the values around England, but has the highest prevalence of patients with brain tumours.

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OTHER - DEPRIVATION / SOCIOECONOMIC STATUS	Quality of evidence	A	B	B	C	C	B	C	B	B	A
	Summary findings	Evidence indicates strong correlation between epilepsy prevalence and specific measures of socioeconomic deprivation such as education and training, employment, health and disability, income and crime.	Data suggests an inverse relationship between household income and migraine prevalence	Loneliness and social isolation are well-documented issues among people with Dementia (mostly quoted being Alzheimer's disease). Immobility, transportation difficulties and poor health were reasons cited in literature.	More deprived patients rated their functional weakness higher.	1 study mentioned there was no significant impact of socioeconomic status on MND risk in females.	Association between socioeconomic status and the risk of disability from MS, with individuals from areas of lower socioeconomic status experiencing more severe disease outcomes.	As part of larger study, incidence of PD was found to be lower in more affluent areas of UK.	Countries with higher socioeconomic statuses had a reduced stroke mortality rate. 50% of stroke related deaths in countries of lower socioeconomic status was due to poor management of modifiable risk factors. Increased stroke incidence, risk factors and mortality in socioeconomically deprived areas.	Suggestion that TBI incidence is higher in homeless individuals than the general population, with some research finding lifetime prevalence being 53% for homeless individuals. Mortality rate is higher in those without private health insurance in the US. Uninsured patients less likely to be discharged to rehab.	Higher SES associated with increased glioblastoma risk due to increased exposure to risk factors. Higher SES and income also seen to be associated with increased risk of malignant brain tumours. However, due to having higher SES the age of diagnosis is earlier and so the 5-year prognosis is better. Patients with higher socioeconomic status were more likely to receive treatment, and those with lower statuses had shorter survival times. Mortality risk is increased by 11% in those with economic and social disadvantage.



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OTHER - SETTLEMENT STATUS/IMMIGRANTS	Quality of evidence	C	B	C	C	C	A	C	B	B	C
	Summary findings	Generally, there is a lack of studies on epilepsy and immigration or migrant status, particularly in the UK.	Few studies have explored the effect of settlement status on migraine prevalence.	No published evidence in this area.	No data available.	Potential link to genetic burden in certain countries affecting disease presentation and duration.	Evidence of MS risk modulation when migrating to countries with higher MS prevalence.	No published data available.	Stroke rates are higher in immigrant populations in comparison to nationals, however risk was dependent on immigrant country of origin.	Refugees/asylum seekers report head injuries obtained during traumatic experiences. Immigrants with TBIs were on average younger, more likely to be uninsured and was more likely to be due to an assault. Undocumented immigrants more likely to be discharged to their homes, and less likely to be sent to rehab and had a shorter length of hospital stay.	Some suggestion its related to genetic background and environmental risk factors NOT settlement status, but not enough data to make a conclusion.

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OTHER - EDUCATION AND EMPLOYMENT	Quality of evidence	B	B	A	A	B	A	B	A	A	B
	Summary findings	influence of epilepsy on social outcome is greater than found in other childhood chronic diseases. Research is warranted to investigate the most effective educational, psychosocial and political changes required to reduce this attainment, and achievement gap.	Multiple sources suggest a relationship between low educational status, unemployment and chronic migraine. There is limited data on UK cohorts, and future research should address this.	Low educational attainment is a strong predictor of Alzheimer's disease.	There are varying education levels amongst FND patients. FND patients were more likely to be unemployed due to their illness.	Occupational exposure to lead and electric shocks increased the risk of developing MND. The highest risk of MND was found for fishery workers and hunters. An association between duration of agriculture employment and MND risk has been found.	MS is associated with high rates of unemployment and low educational attainment.	Mixed evidence of effect of education and employment in PD, possibly with job stress as a confounder.	Unemployment and fewer years of education are associated with increased risk of ischaemic stroke. Education level was not seen to be associated with haemorrhagic stroke. Blue-collar workers, long working hours and high levels of strenuous work activity increase risk of haemorrhagic stroke.	Fatal TBIs more likely for steelworkers and roofers as a result of falls, those in mining and construction most at risk of TBI. One study found of their TBI patients, the majority had high school education as their highest level. A proportion of patients need assistance with living a post-recovery. Mortality seen to be higher in retired patients whereas the student group had the best outcomes.	Acoustic neuromas more common in those with higher education levels and in those with medium-income. Post-op a decrease was seen in patients continuing their pre-op jobs. Certain occupations have been linked to increased risk of brain tumour risk.



Abbreviations used: DALY Disability Adjusted Life Years; GBD Global Burden of Disease; SES Socioeconomic status

Below we tease out some key findings where our search indicated there was good evidence (A) to support these. There was significant lack of evidence in many areas, mainly due to lack of research in that particular area, and this is highlighted in the summary table above.

Stroke

Age

Incidence of ischaemic stroke increases with age (Jolink, Klijn, Brouwers, Kappelle, & Vaartjes, 2015), with the majority of stroke occurring above the age of 65. Stroke risk factors (O'Donnell, 2010) and the incidence of haemorrhagic stroke (Stein, et al., 2012) also increases with age.

Increased age is also associated with increased odds of inpatient death and a higher 7-day mortality rate, with the highest number of stroke deaths in the 85 years and older age group. (Office for National Statistics., 2020) Older patients, especially those from care homes had longer times from admission to CT. Studies suggest those with a longer wait are less likely to be thrombolysed or admitted to the stroke unit (Myint, et al., 2016).

Race

In ischaemic stroke, Black males and females have a higher incidence of stroke until the age of 75. Black patients are less likely to receive IV thrombolysis, Deep Vein Thrombosis prophylaxis, discharge antithrombotic, anticoagulants for Atrial Fibrillation and lipid therapy in comparison to white patients. In addition, Black patients receive less evidence based care and were more likely have longer hospital stays but had a lower risk of dying in hospital (Wafa, Wolfe, Rudd, & Wang, 2018).

For haemorrhagic stroke, Asian patients were found to have the highest incidence (van Asch, et al., 2010). The VISTA study found most of their patients to be Caucasian, older,

have larger haematoma volumes, high mortality rate and worse quality of life post haemorrhage. Whereas Black patients have lower admission conscious levels and higher systolic blood pressures. (Krishnan, et al., 2018)

Sex

For ischaemic stroke, over 50% of patients are female with the life-time risk of stroke being higher in females than males (Seshadri, et al., 2006). Females are on average 4 years older than males in the stroke population (Gargano, Wehner, & Reeves, 2009). Age of menopause was seen to be a factor in stroke risk, and use of post-menopausal oestrogen was seen to increase stroke risk (Wassertheil-Smoller, et al., 2003). Females were seen to have a higher risk of readmission within 1 year and mortality rate post-ischaemic stroke (Morton, et al., 2022).

In haemorrhagic stroke, males are likely to be younger, more likely to be smokers and more likely to have a history of alcohol abuse in comparison to females. (Bueno Alves, et al., 2012) (Hsieh, Ang, Ng, Allen, & King, 2016).

Risk of haemorrhagic stroke increased after gestational hypertension, hysterectomy, pre-eclampsia and pre-term birth (Elgendy, Gad, Mahmoud, Keeley, & Pepine, 2020).

Stroke mortality rate of males is higher until age 74, where female mortality rate is then higher (Office for National Statistics., 2020).

Education and Employment

A significant inverse relationship is seen between years spent in education and ischaemic stroke incidence, mortality and risk of recurrence (Jackson, Sudlow, & Mishra, 2018). Low educational level was found to be the single largest behavioural risk factor for hypertension (Yusuf, et al., 2020).

In haemorrhagic stroke, educational level was not seen to be associated with incidence (Xiuyun, Qian, Minjun, Weidong, & Lizhen, 2020). Manual workers, those working long hours regularly and >8hrs strenuous work activity were associated with increased risk of haemorrhagic stroke (Kim, et al., 2013).

Dementia

Age

Both incidence and prevalence of dementia increases with age. The prevalence is 5-7% for people above age 60 years. It is estimated that prevalence will double every 20 years, with an estimated prevalence of 115.4 million by 2050, compared to 35.6 million in 2010 (Prince, et al., 2013).

Race

Most studies focusing on race and ethnicity are from North America. Medicare data shows African-Americans are less likely than Whites to be diagnosed, given the estimated prevalence rates in the United States. Second, when they are diagnosed, African Americans and Hispanics — possibly due to barriers to accessing health care — are typically diagnosed in later stages of the disease, resulting in higher use of health care services and substantially higher costs. Average per-person Medicare payments are 45 percent higher for African-Americans with a dementia diagnosis and 37 percent higher for Hispanics compared with whites who have dementia (Alzheimer's Association, 2013).

Sex

Prevalence of dementia is higher in women than in men (from a review of 11 European population based studies), and another study again concurred this finding with a female excess – mostly after age 75 – was described (Berr, Wancata, & Ritchie, 2005), and confirmed with another epidemiological study published more than a decade later (Fiest, et al., 2016)

Incidence rates of dementia among women are higher, especially above the age of 80. The rates continued to increase with age in women, whereas the increase reached a plateau in men at age 85 (Fratiglioni, Launer, Andersen, & al., 2000).

Geographical variation

Incidence rates vary between studies of dementia and geographical variation. Methodological issues partly account for these differences, but the difference may also be due to possible risk factors such as cardiovascular disease (for example, differences between north and south Europe). Given the available evidence for risk factors of dementia and the pronounced variation in vascular risk factors across regions, there could be parallel variation in the incidence of dementia. The pooled analysis of eight European studies mentioned above suggests a geographical dissociation, with higher incidence rates being found among the 'oldest' of north western countries than among southern countries (Fratiglioni, Launer, Andersen, & al., 2000).

Education and Employment

A systematic review of 247 studies on modifiable factors and their association with dementia found that low educational attainment are strong predictors of incident Alzheimer's disease (Beydoun, Beydoun, Gamaldo, & al, 2014), while Hersi and colleagues' reports also came to similar suggestions that higher educational attainment is associated with a decreased risk of Alzheimer's disease onset. Interestingly, it was also associated with faster cognitive decline. However, the authors felt that some studies were conflicting, and that further research was required to confirm the etiological or protective role (Hersi, et al., 2017).

Migraine

Age

Well-established age-related distribution. Overall, migraine is most prevalent between ages 20 to 50 (Stovner, Zwart, Hagen, Terwindt, & Pascual, 2006) (Ashina, et al., 2021). Good quality data on age and gender distribution found in Global Burden of Diseases, Injuries, and Risk Factors (GBD) studies (Steiner, et al., 2018).

Whilst migraine prevalence doesn't peak until adulthood, there is a suggestion of disparity in service provision for children with migraine living in the UK, with little paediatric headache expertise and services.

Sex

Well established sex differences in migraine prevalence exist. Therefore, sex biases may exist in the diagnosis and treatment of migraine. For example, males are less likely to seek treatment and be prescribed with appropriate treatment for migraine, compared to females (Loder, Sheikh, & Loder, 2015).

Brain tumour and cancer

Age

Incidence of meningiomas increase up until age 85 before it begins to decline. Astrocytoma and glioblastoma incidence peaks in the age group of 65–74-year-olds (Wrensch, Minn, Chew, Bondy, & Berger, 2002).

Age is seen to be an independent risk factor for survival in oligodendrogliomas, with mortality rates increasing with increasing age (Jin, et al., 2021).

Mortality rates are increasing at rate of 1% per year in the over 80s age group (Jin, et al., 2021). 3-month mortality rate, length of stay and rates of perioperative complications were seen to significantly increase in elderly patients in comparison to the younger patient groups post-intracranial meningioma resection (Rafiq, et al., 2021).

Race

There is good evidence to suggest that malignant CNS tumours, gliomas in particular, are two times more common in white people than any other racial group. Non-malignant meningiomas are more common in Black people (Barnholtz-Sloan, Ostrom, & Cote, 2018).

Incidence of CNS tumours is highest in Northern Europe and 'Western countries'. Countries such as the Philippines and India have a quarter of the rate, potentially linked to better access to healthcare and detection services available in countries like the US (Barnholtz-Sloan, Ostrom, & Cote, 2018) (Fisher, Schwartzbaum, Wrensch, & Wiemels, 2007) (Ohgaki, et al., 2004).

African American patients are two times more likely to have a postoperative major cardiovascular complication, pulmonary complication or a urinary tract infection (UTI) in comparison to Caucasian patients post-craniotomy (Thomas, et al., 2021).

Sex

Malignant tumour incidence is higher in males than females. Non-malignant tumour incidence is higher in females than males. 5-year survival after diagnosis of malignant brain tumour is higher in females. For malignant and non-malignant meningiomas, females have a higher 1- and 5-year survival rate than males (Barnholtz-Sloan, Ostrom, & Cote, 2018).

Female meningioma patients had an increased overall survival rate (Riano, et al., 2020), and a decreased risk of developing multiple meningiomas in comparison to males (Ramos-Fresnedo, et al., 2020).

Parkinson's

Age

Incidence and prevalence of Parkinson's increases with age. Global burden of disease estimates that 6.1 million individuals are affected with PD worldwide in 2016, compared to 2.5 million in 1990 (GBD 2016 Parkinson's Disease Collaborators, 2018). This increase is due to an increasing number of older people as a main factor. The prevalence rate of PD doubles every 5-year interval between age 50-69 years and tails off after age 80 (Hirsch, Jette, Frolkis, Steeves, & Pringsheim, 2016).

Sex

Parkinson's UK reported incidence rates for males aged 50- 94 were between 1.3 and 2.4 times higher for males than for females in the same age-group. The incidence rate for the 85-89 age-group continued to rise in males but this trend was not seen in females. The incidence rate for the 90-94 age-group was lower in both males and females than for the 75-89 age range (Parkinson's UK, 2017).

Males have 1.4-3.7 times the risk of developing PD compared to females and the aetiology behind sex differences are thought to be multifactorial; due to neuroprotective effect of oestrogen, genetic factors, differences in brain development / function and in environmental exposure and lifestyle factors (Gillies, Pienaar, Vohra, & Qamhawi, 2014) (Savica, et al., 2013).

Epilepsy

Age

There is a large body of evidence supporting a bimodal pattern of epilepsy incidence by age, highest in the youngest and oldest age groups, and increasing steadily after age 50 years. This is evidenced by multiple sources including the most recent Global Burden of Disease Survey data and is consistent across high-, middle- and low-income settings, globally (Sen, Jette, & Husain Mand Sander, 2020).

Pregnancy

There is a complex relationship between pregnancy and epilepsy, including the need for preconception planning, the effects of antiepileptic drugs and seizures on foetal development and pregnancy and the impact of the physiological changes of pregnancy on antiepileptic drug effectiveness. There is a large evidence base, which is generally outside of the scope of this focused review.

Streamlined systems should be in place to facilitate specialised care in a timely manner for females planning pregnancy or who become pregnant, with regular audit against quality standards.

Socioeconomic status

UK primary care data suggests a correlation between epilepsy prevalence and specific measures of socioeconomic deprivation, including employment and income. People with epilepsy are more likely to live in socially and economically deprived areas and to be educationally disadvantaged (Steer et al, 2014). The impact of seizures on safety within particular work contexts and implications on ability to drive likely explain some extent of this association.

Risk

People living with epilepsy are at a 1 in a 1000 risk of Sudden unexpected death in epilepsy (SUDEP) per year.

The risk factors below have been shown in research to increase the chance of death in people with epilepsy (SUDEP and other causes). Many of these risk factors can change over time, or can be changed to improve seizure control and reduce risks:

- Frequent seizures
- Tonic-clonic seizures (the more frequent these seizures, the higher the risk)
- Nocturnal seizures (seizures at night) and lack of night-time monitoring / someone there to help if you have a seizure
- Not taking your medication as prescribed, or medication changes
- Alcohol or substance abuse
- Depression or psychiatric illness
- Pregnancy
- Intellectual (Learning) Disability
- Infrequent epilepsy reviews and engagement with an epilepsy clinician
- Recent hospital attendance for epilepsy
- Having had epilepsy for over 15 years
- Epilepsy starting before the age of 16
- Male gender
- Younger adult age

(Shankar, Donner, McLean, Nashef, & Tomson, 2017) (SUDEP Action, 2022)

Functional Neurological Disorder (FND)

Age

FND tends to present in the 4th to 5th decade of life. The mean age of onset of the various functional disorders varies slightly based on the condition. For functional dystonia it is 36.4 (Stephen, Perez, Chibnik, & Sharma, 2021), functional movement disorders is 44.7 functional parkinsonism is 45.5 and functional mimics is 49 (Rather & Cavanna, 2020).

Sex

Across all the studies over 50% of patients were female (range: 63.6% - 86.2%)

This was seen for FND, functional dystonias, functional movement disorders and functional limb weaknesses. (Ahmad & Ahmad, 2016) (Garrett, Hodges, & Stahlman, 2020) (Rather & Cavanna, 2020) (Stephen, Perez, Chibnik, & Sharma, 2021) (Stone, Warlow, Deary, & Sharpe, 2020).

Education and Employment

There is a wide range of years spent in education across the people with FND, with roughly equal amounts having completed mandatory education, higher education and tertiary education.

One study found functional motor disorder patients with more time in higher education were more likely to experience non-motor symptoms (Tinazzi, et al., 2020). Educational difficulties are seen in conditions such as functional seizures (Asadi-Pooya, Brigo, Tolchin, & Valente, 2021); however, the relationship of cause and effect can be argued both ways.

40% of FND patients from an Australian FND clinic were unemployed due to illness, this was significantly higher than the base rate as established by the census (Morsy, et al., 2021).

At the 14 year follow-up, 40% of patients were in paid employment and 41% were unemployed due to their health (Gelauff, Carson, Ludwig, Tijssen, & Stone, 2019).

(Stephen, Perez, Chibnik, & Sharma, 2021). From a case-control study using motor FND patient data from SLaM, 24.5% were employed 75.5% were unemployed, 87.5% were employed pre-morbidly and 12.5% were not employed pre-morbidly (O'Connell, Nicholson, Wessely, & David, 2020). In the UK, 45% of patients with functional movement disorder who attended the specialist neuropsychiatry clinic in Birmingham were found to be employed (Rather & Cavanna, 2020). Of patients with functional motor disorders in the U.S. FND clinic, 66% were found to be unemployed at the time of the study (Matin, et al., 2017) (Rather & Cavanna, 2020).

Multiple Sclerosis

Age

There is a well-documented age-related incidence distribution, with peak incidence at working age e.g. (Public Health England, 2020).

Sex

MS occurs more frequently in females than in males, it has been suggested that sex-related factors such as hormonal, genetic and environmental influences may be explanatory (Public Health England, 2020).

There is a suggestion that males have a higher prevalence of primary progressive disease, and show more progression of disability compared to females (Bergamaschi, 2007).

Socioeconomic Status

The UK MS registry has demonstrated that increased deprivation negatively influences the access to disease modifying therapies (DMTs) in England. It is suggested that the lack of access to local MS DMT clinics in deprived areas may contribute to this disparity (Das, et al., 2022).

Employment

MS is associated with high rates of unemployment. Specific physical and mental health limitations confer risk of employment cessation over time, as well as the likelihood of employment initiation. This has implications for rehabilitation interventions to target specific MS related limitations that place patients at greatest risk for work status changes (Julian, Vella, Vollmer, & et al, 2008).

Traumatic Brain Injury (TBI)

Age

Prevalence of TBI increases with age, with the largest peak in the 80-90 age group. However, there is a small peak in the 20-30 age group (Lawrence, Helmy, Bouamra, & et al, 2016).

Age is associated with mechanism of injury, with falls being most common for the older age groups and road traffic accidents being most common for young adults (Peeters, van den Brande, Polinder, & al, 2015).

Increasing age was seen to be associated with increased mortality and worse outcomes post-TBI, with a suggestion that for each 10 years of age, the odds of a worse outcome increase by 40-50%. Also, each 1-year increase in age was associated with a 3% risk of mortality (Hukkelhoven, et al., 2003).

Sex

Incidence is much higher in males than in females (Mollayeva, Mollayeva, & Colantonio, 2018) (El-Menyar, Mekkodathil, Al-Thani, Consunji, & Latifi, 2017) (Saatian, Ahmadpoor, Mohammadi, & Mazloumi, 2018) (Nguyen, Fiest, McChesney, & al, 2016). In the >65 age group, incidence is similar between males and females (GBD 2016 Traumatic Brain Injury and Spinal Cord Injury Collaborators, 2019).

Mortality rates were seen to be higher in males than in females, and although down trending the rate was decreasing faster in females than in males (Kadar, et al., 2019) (Hosomi, Kitamura, Sobue, Ogura, & Shimazu, 2021).

Males were seen to have more complications, both neurological and non-neurological, post-TBI than females (Hosomi, Kitamura, Sobue, Ogura, & Shimazu, 2021).

Education and Employment

Those working in mining, agriculture, forestry and construction were most at risk of TBI (Chang, Guerriero, & Colantonio, 2015). Fatal TBIs are more likely in structural iron/steel workers and roofers with the mechanism of injury being due to falls (Konda, Tiesman, & Reichard, 2016).

The majority of TBI patients had reached high school level education, with less than a third pursuing further education (Paci, Infante-Rivard, & Marcoux, 2017).

Approximately two thirds report cognitive, behavioural and emotional changes and the need for greater community support (Ponsford, Olver, & Curran, 2009). One third of patients experience severe fatigue 6-months post-TBI affecting daily functioning and employment. Mortality was seen to be higher in retired patients, whereas students had the best outcomes at 6-months (Stulemeijer, van der Werf, Borm, & Vos, 2008).

Motor Neurone Disease (MND)

Race

Incidence of Amyotrophic lateral sclerosis (ALS) may depend on ethnic background, with the highest incidence being found in homogenous populations such as the Faroe Islands. Europe has the highest incidence globally (Chiò, et al., 2013) (Marin, et al., 2014).

ALS patients of mixed ethnicities have lower mortality rates (Zaldivar, et al., 2009).

Sex

Incidence of ALS is higher in males than in females (Imam, Ball, Wright, Hanemann, & Zajicek, 2010) (Abhinav K, 2007). Bulbar onset MND was more common in elderly females (Chhetri, Bradley, Majeed, & Lea, 2016). Mortality rates are higher in males than in females, this was found to be consistent across multiple studies and countries in the UK (Day, Scott, Perring, & Doyle, 2007) (Goldacre, Duncan, Griffith, & al., 2010).

Conclusion and recommendations

We hope the evidence from this focussed review will support further deliberation and research into the prevalence, incidence, diagnosis, healthcare utilisation, experience and outcomes of underlying health inequalities for people with neurological conditions.

Lack of system recognition of diagnosis (i.e. a lack of consistent, high quality outpatient coding) in the UK secondary care setting makes it impossible to study this without specific research. This must be addressed.

It is quite clear from our research that there is a scarcity of published research on the management, experience, and outcomes of people with these 10 neurological conditions based on their protected characteristics. Systematic collection of data with improved outpatient coding will enable monitoring of access to services. In addition, there is minimal data to help understand how the relationship between various protected characteristics, particularly gender reassignment, and residential and immigration status, may interact with the prevalence and incidence of neurological conditions or experience of care. This is despite the fact that there is good evidence of poorer outcomes for trans individuals more broadly, along with those of no fixed abode.

We recommend:

- All neurology outpatients have their diagnoses coded so that future audits can be conducted on access to services and outcomes. Coding approaches need to be harmonised nationally, to ensure the validity of this data.
- Funders of research prioritise enhancing our understanding of how the prevalence and incidence of neurological conditions varies across protected characteristics.
- Researchers and publishers encourage publication of data disaggregated by protected characteristic, where possible.
- Providers of services conduct an equity audit of their service to ensure it is accessible, trustworthy and welcoming to all people suspected of or living with

neurological conditions. The characteristics of age, sex, race, religion, postcode (as an estimate of deprivation) are usually collected for all patients and need to be used to conduct this audit. The other characteristics are likely to need additional studies.

- Organisations within the voluntary sector review their information and support, research programmes, public involvement activities and people policies to ensure they reflect the principles of equity, diversity and inclusion.
- The Neurological Alliance (England) provides a space for members to share their experiences of embedding equity, diversity and inclusion into their work.
- The UK Government work with voluntary and community groups, people with lived experience and the research community to update key terminology, including definitions used for protected characteristics within the Equality Act 2010.

Appendix – key definitions

Term	Definition	Source
Race	Race includes— (a)colour; (b)nationality; (c)ethnic or national origins.	Equality Act 2010
Sexual orientation	Sexual orientation means a person's sexual orientation towards— (a)persons of the same sex, (b)persons of the opposite sex, or (c)persons of either sex.	Equality Act 2010
Gender reassignment	(1)A person has the protected characteristic of gender reassignment if the person is proposing to undergo, is undergoing or has undergone a process (or part of a process) for the purpose of reassigning the person's sex by changing physiological or other attributes of sex. (2)A reference to a transsexual person is a reference to a person who has the protected characteristic of gender reassignment.	Equality Act 2010
Ethnicity	"the social group a person belongs to, and either identifies with or is identified	Bhopal R. Glossary of terms relating to

	with by others, as a result of a mix of cultural and other factors including language, diet, religion, ancestry and physical features traditionally associated with race"	ethnicity and race: for reflection and debate. J Epidemiol Community Health 2004;58:441-445.
Settlement and asylum	<p>Asylum seeker: You must apply for asylum if you want to stay in the UK as a refugee.</p> <p>To be eligible you must have left your country and be unable to go back because you fear persecution.</p>	Gov.uk
British nationality	<p>There are six different classes of British nationality:</p> <ul style="list-style-type: none"> • British citizenship • British citizen • British Overseas Territories citizen • British Overseas citizen • British subject • British National (Overseas) • British protected person 	Gov.UK

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