

EQUALITY IMPACT ASSESSMENT (EQIA) - RESULTS

Title of Policy	National Action Plan on Neurological Conditions
Summary of aims and desired outcomes of Policy	It is a 5 year plan with an overarching vision to enable everyone with a neurological condition to access the care and support they need to live well, on their own terms.
Directorate: Division: team	Healthcare Quality and Improvement: Planning and Quality: Clinical Priorities

Executive summary

In 2003, it was estimated that there were about one million people in Scotland living with a neurological condition, of whom at least 10% were disabled as a result¹. Neurological conditions account for up to 10% of acute hospital admissions², and 10% of the overall burden of disease in Scotland, as measured by disability-adjusted life years³.

As part of our ambition to help people improve their health and wellbeing, we want everybody with a neurological condition to live well. In September 2017, the First Minister announced that, following discussion between the Minister for Public Health and Sport and the National Advisory Committee for Neurological Conditions (NACNC), the Scottish Government had started work to develop Scotland's first ever National Action Plan on Neurological Conditions.

The National Action Plan has been co-produced with the neurological community to ensure people living with neurological conditions, their families and carers are at the centre of its development. 'Neurological Community' means people living with neurological conditions, their families and carers, those who provide care and support, practitioners, clinicians, academics, NHS Boards, Integration Authorities, third sector and independent care providers.

The following activities have enabled us to acquire an understanding of stakeholders' views and priorities, as well as consider how the plan might impact on people within the neurological community who share certain 'protected characteristics' set out in Part 2 Chapter 1 Section 4 of the Equality Act 2010 or who might be subject to health inequalities caused by socioeconomic disadvantage, as outlined in the Fairer Scotland Duty under Part 1 of the Equality Act 2010.

- the Project Steering Team leading the work comprised individuals representative of the neurological community across Scotland;
- NACNC considered the available evidence found through literature reviews;

- the Health and Social Care Alliance and the Neurological Alliance of Scotland were commissioned to undertake a lived experience survey with people, their families and carers;
- NHS Information Services Division (ISD) produced a report setting out prevalence estimates for neurological conditions in Scotland that included the complexities of determining prevalence;
- NACNC conducted a survey to map Neurological Services in Scotland. This survey described current care and support services and existing gaps in provision;
- NACNC organised three national engagement events involving key stakeholders from across the Neurological Community - people living with neurological conditions, their families and/or carers, clinicians and practitioners from health and social care and support, third sector organisations, researchers and industry; and
- Policy officials involved in the plan's development conducted an exercise to engage with policy teams across the Scottish Government to take account of wider services, policies, strategies and plans.

Background

All public bodies in Scotland, including the Scottish Government, must comply with the public sector equality duty set out in the UK Government's Equality Act 2010, which requires that in exercising functions due regard is given to the need to:

- eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under the Act;
- advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it; and
- foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

The Scope of the EQIA

An EQIA is an important part of the policy making process and applies to both new or revised policies. It helps the Scottish Government to look at how its policies impact on people (positive and negative). In particular, the process identifies the impact of policy on people who share one or more of the protected characteristics.

In making its assessment, the Scottish Government has considered relevant evidence relating to the protected characteristics, as well as the potential impact on health inequalities. Health inequalities are disparities in health outcomes between individuals or groups and arise because of inequalities in society, in the conditions in which people are born, grow, live, work, and age.

Health inequalities are influenced by a wide range of factors including access to education, employment and good housing; equitable access to healthcare; individuals' circumstances and behaviours, such as their diet and how much they drink, smoke or exercise; and income levels.

The potential impact of the National Action Plan on an individual's human rights has also been considered.

Giving due regard to these factors is also intended to help the Scottish Government to meet its duties under the Fairer Scotland Duty, which requires public bodies to reduce inequalities of outcome caused by socioeconomic disadvantage.

Key Findings

This assessment sets out how evidence and analysis has helped shape and inform the development of the National Action Plan on Neurological Conditions, as well as any changes that have been made to policy design as a result.

The National Action Plan will not be condition specific; the use of the term 'neurological conditions' is intended to cover a wide range of conditions, disorders and syndromes affecting the brain, spinal cord, nerves and muscles.

Age

Neurological conditions affect all ages and people may experience the onset at any time in their lives. About one quarter of people aged between 16 and 64 with chronic disability have a neurological condition⁴.

There is increased prevalence in older people, as some conditions particularly affect older people⁵ and others are life-long conditions⁶. Older adults diagnosed with neurological conditions can find their lives completely disrupted. They may already live with other conditions and find it hard to cope with the impact of a neurological condition on top of other symptoms, for example accessing multiple support services⁷.

It is recognised that older people are significantly less likely to have access to the internet than the general population⁸, therefore paper copies of information and support will be required. Information should also be available in a variety of mediums on request, as reduced sight and vision may also be an issue.

Analysis of feedback from stakeholders and evidence gathered during the EQIA highlighted services often fail to understand the changing needs of people with neurological conditions⁹. The National Action Plan therefore places importance on people being partners in their care and support, with services understanding how a person's needs may be affected by the age at which their condition is diagnosed and how those needs progress throughout their life depending on what matters most to the person.

While the National Action Plan is focused on adults (16 years and older), the Scottish Government is undertaking work separately on how to best support children and young disabled people and their families. We have listened to feedback from stakeholders emphasising the importance of improving the transition for young people moving to adult services and the draft National Action Plan contains a commitment to work with key partners to develop policies and procedures for good transitions.

Disability

Overall it is considered that the National Action Plan will have a positive impact on people with disabilities. It focuses on common themes across neurological conditions and seeks to replicate good practice in some areas across the wider system e.g. care pathways for everyone living with a neurological condition.

Many neurological conditions can result in the individual affected potentially being regarded as disabled, as defined within the Equality Act 2010.

Through our work with NHS Information Services Division (ISD) we concluded that it is not currently possible to identify exactly how many people there are in Scotland living with a neurological condition. We have a series of estimates for some (but not all) conditions, some more accurate than others.

The draft National Action Plan contains a commitment to work with ISD and others to improve the breadth of available data. A greater understanding of people's interaction with services based on need, could inform future planning of services and provide a way of measuring performance and outcomes.

Learning disabilities can often be present alongside a neuro-condition, for example epilepsy¹⁰. Cognitive impairments can also manifest in the form of memory and attention problems, lack of perseverance and a limited ability to learn¹¹. Information should be accessible to people with learning disabilities and low literacy. For example, information in easy-read could be considered¹²¹³.

Feedback was received from people with disabilities that participated in the national events held in June 2018. Shorter sessions were organised to reduce the impact on people's fatigue levels. Venues organised by the Neurological Alliance of Scotland were wheelchair accessible and also had hearing loops. However, some people with walking aids found the distance was too far from public transport at some of the venues. People also suggested it would have been helpful to provide ergonomic cups and straws alongside the refreshments. If future events are organised during the latter stages of developing the National Action Plan or this EQIA, these aspects will be taken into account.

Sex

We considered different sources of information to assess the impact of the National Action Plan on males and females, some of which is outlined below. Ultimately the aims of the plan are to ensure everyone with a neurological condition will be able to access the care and support they need to live well, on their own terms – regardless of their gender. We do recognise, however, that some aspects of the plan may indirectly have a bigger impact on women (e.g. a greater proportion of unpaid carers are women, and a greater proportion of care and support staff are women).

In 2017, 45% of all adults aged 16 and over reported living with a long-term condition. The proportion of men (57%) free of long term conditions was significantly higher than women (53%). This is attributable to higher prevalence of limiting long-term conditions among women (34%) than men (29%)¹⁴.

We commissioned ISD to provide information on the gender of people with neurological conditions, and looked at the information to see whether gender was related to certain conditions. If dementia is excluded, men are more likely to die from a neurological condition than women, however, this may be due to the recording or absence of recording of neurological conditions on death certificates.

One in two women and one in three men will develop dementia, stroke or parkinsonism during their life. These findings strengthen the call for prioritising the focus on preventive interventions at population level, which could substantially reduce the burden of common neurological diseases in the ageing population¹⁵.

Pregnancy and Maternity

While the action plan does not refer to pregnancy or maternity, it is acknowledged that there is evidence to suggest that improvements in the care and support offered to people with this protected characteristic that have a neurological condition could only have a positive impact on their ability to live well on their own terms.

Neurological disease in pregnancy is now the second commonest cause of maternal death in the United Kingdom. Many of the pregnant or puerperal women who have died from epilepsy, subarachnoid haemorrhage and other neurological diseases have done so without the benefit of pre-pregnancy counselling, appropriate multidisciplinary care, or timely involvement of neurologists¹⁶.

An audit published in late 2014 on Maternal, Newborn and Infant Clinical Outcome Review Programme produced by MBRRACE-UK (Mothers and Babies: Reducing Risks through Audits and Confidential Enquiries across the UK) highlighted the need for changing the structures of care for pregnant women with pre-existing neurological conditions, as well as those with neurological complications of pregnancy¹⁷.

The National Action Plan contains commitments to work with partners such as NHS Inform to improve the information available on neurological conditions and to encourage NHS Boards and Integration Authorities to consider introducing/strengthening current provision for commonly accessed services including open access clinics for suspected new epilepsy / first seizure patients, that accept referrals from patients, emergency departments and GPs; and rapid access neurology clinics.

Gender Reassignment

In 2016 a Women and Equalities Committee report¹⁸ made over 30 recommendations calling for government action to ensure full equality for transsexual people. This report highlights the difficulties transsexual people may experience, including prejudice and discrimination that affect their ability to access health services.

The new publication *Healthcare Improvement Scotland General standards for neurological care and support: Draft Standards September 2018*¹⁹ set out that the same high level of care and support should be provided for all adults regardless of condition, geographical location, service provider, or an individual's personal

circumstances. The draft National Action Plan includes a commitment to promote and support the implementation of these standards.

ISD does not report statistics from equality data (key national administrative health datasets) for other gender categories such as transsexual. We therefore do not know the number of people who identify as transsexual and who live with a neurological condition. We have asked ISD if information on other gender categories could be included in future datasets.

In gathering other evidence about this protected characteristic we recognise that if transsexual people are taking hormone therapy they may experience migraines or a cerebral aneurysm, that would necessitate their referral to neurological services.

The draft National Action Plan proposes to test generic community neurology teams and that one or more areas will test a new diagnostic support service for migraine. If this is approved, we will highlight the need to ensure services are open to all, and do not incorporate unconscious bias into referral criteria.

Sexual Orientation

ISD does not report statistics from equality data (key national administrative health datasets) about the sexual orientation of people with neurological conditions. We have asked ISD if information on other gender categories could be included in future datasets.

Other evidence enabled us to understand sexual orientation within a wider context. In 2016, the overall proportion of those in Scotland identifying as Lesbian, Gay, Bisexual (LGB) or Other was 2.2%, whilst 2.5% preferred not to respond to the question. Younger people were more likely to identify as LGB or Other. 4.4% of people aged 16 to 24 identified as being LGB or Other, whilst 1.1% of people aged 55 to 64 identified as being LGB or Other and similar proportions could be seen in older age groups²⁰.

In 2014, after age standardisation, the proportion of the 'LGB or Other' group reporting good or very good general health is significantly lower than the rest of the population (65.6% compared with 74.5%)²¹. People who self-report as bisexual have poorer self-assessed health and lower mental wellbeing than average.²²

Between 2000 and 2015, the percentage of people saying that sexual relationships between two adults of the same sex was always or mostly wrong has fallen from 48% to 17%. These changes in attitudes have occurred across most groups in Scottish society, including people brought up in an era when male same sex relationships were illegal (although it remains the case that older are more likely than younger people to hold discriminatory views towards people who are gay or lesbian).²³

We therefore appreciate people that identify as LGB or other within the neurological community in Scotland may experience prejudice and discrimination due to sexual orientation, which in turn may affect their ability to access health services. The draft National Action Plan includes a commitment to promote and support the

implementation of the new Healthcare Improvement Scotland standards that set out people should receive the same high level of care and support regardless of an individual's personal circumstances.

Race

The UK has a culturally diverse population with minority ethnic accounting for 13% of the population²⁴. Population groups with differences determined by culture or ethnicity show differences in terms of illness behaviour and beliefs. These groups also differ genetically, so that some diseases are more prevalent in certain ethnic groups.

Health inequalities are seen between ethnic groups for a number of reasons, These include difficulties in accessing healthcare in an appropriate language and cultural context, plus significant differences in disease patterns and responses to therapy²⁵.

Improving outcomes for the neurological community will be of equal value regardless of ethnicity. There will be a small number of people who may require information in alternative formats if their first or preferred language is not English²⁶.

Religion or Belief

ISD data on neurological conditions did not show religion or belief. Our research found wider evidence to suggest that after the age distribution of religious groups in the general population are taken into account, most of the apparent differences in good/very good general health disappear. Only the lower than average rates for the 'Roman Catholic' and 'Other' groups are significant, at 72.5% and 70.4% respectively²⁷.

Where there are differences, it is not clear how they can be explained, for example whether they can be accounted for by actual differences in the quality of care provided or different cultural expectations and perceptions between population groups or a combination of these factors²⁸.

Cultural values and beliefs may deter people from accessing health services or talking about their long term condition/advanced care planning, a factor that should be respected. We have therefore been mindful of culturally sensitive language throughout to ensure the plan is fair for all.

The aim of the draft National Action Plan to ensure care is more person-centred should help to improve equality for this protected characteristic as some religious groups may have particular needs relating to diet, clothing and religious symbols.

Marriage and Civil Partnership

As this policy or practice does not relate to work, for example Human Resources policies and practices, an assessment against this protected characteristic is not required. However, there is no current evidence to suggest that this group would be negatively impacted by the National Action Plan.

Carers

We acknowledge the key role of unpaid carers and the need to reduce any negative impact on their health and wellbeing. We also acknowledge that a greater proportion of unpaid carers are women. 17% of people aged 50 to 64 provide unpaid care to a relative, friend or neighbour; this compares to 2% of under-25s, 10% of 25-49 year olds and 11% of over-65s.

Support for carers is therefore a key theme which runs throughout the national action plan, and is reflected in a number of the commitments in the plan. We believe these commitments could have a positive impact on the lives of carers.

Homelessness

While there are no commitments on homelessness within the plan, we acknowledge that some neurological conditions can impact on mental health – resulting in a range of social problems such as housing provision.

We believe that the commitments in the plan, which relate to access to timely diagnosis and support would help to alleviate such problems from arising.

Criminal Justice System

While there are no commitments on criminal justice issues within the plan, we acknowledge that some neurological conditions, such as those derived from brain injuries, can impact on mental health – resulting in a range of social and behavioural problems, which can result in contact with the criminal justice system.

We believe that the commitments in the plan, which relate to access to timely diagnosis and support, and raising awareness, would help to alleviate such problems from arising.

Low income/poverty

This is not a specific focus of the plan, but we do acknowledge the relationship between epilepsy mortality and poverty, which is up to three times higher in areas of deprivation compared with other areas.

We believe that the commitments in the plan, which relate to access to timely diagnosis and support, and raising awareness, could help improve outcomes in this respect.

Mental Health

A number of neurological conditions carry a mental health aspect to their symptoms such as Huntington's disease and Medically Unexplained Neurological Symptoms. In addition, there are issues such as anxiety and depression prevalent due to the nature of the nature of chronic conditions.

We believe that the commitments in the plan, which relate to access to timely diagnosis and support could help improve outcomes in this respect.

Rural Areas

There is little information available on the impact of living with a neurological condition in a rural location. However we know that people with neurological conditions such as Epilepsy or MS may be unable to drive and be dependent on public transport to access services, and this is more infrequent in rural areas.

Access to Broadband is patchy in rural areas, and so some parts of the population will have difficulty accessing on-line information resources about their condition, care and support, benefits or other advice.

Both of these factors increase the likelihood that people with neurological conditions will be increasingly dependent on their carers and possibly more isolated.

One neurological condition, Multiple Sclerosis, is associated with increased prevalence in northern parts of the country. We will invite bids that test change in care and support services from rural as well as built up locations.

Recommendations and Conclusion

It is expected that the National Action Plan will have a positive impact on all people in Scotland who are living with a neurological condition. The plan aims to raise awareness within the general population of how neurological conditions can impact on people's lives.

The plan addresses issues of social isolation and seeks to address the inequity of provision of care and support that results from geographical boundaries and local policies.

It is planned that a final EQIA for the National Action Plan will be completed by March 2019 to coincide with its final publication. This enables feedback received during the public consultation exercise held between 13 November 2018 and 8 February 2019 to be taken into account.

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