

Stroke Improvement Plan 2023 - 2028

Equality Impact Assessment – Results

July 2023

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Title of Policy	Stroke Improvement Plan 2023 - 2028
Summary of aims and desired outcome of policy	The vision of the Stroke Improvement Plan is to improve stroke care across the whole patient pathway, developing the priorities identified in the Progressive Stroke Pathway (2022) to support the patient centred prevention, diagnosis, treatment and long-term management of stroke.
Directorate: Division: Team	Health and Social Care Directorate: Healthcare, Quality and Improvement: Clinical Priorities Unit

1. Executive summary

The vision of the Stroke Improvement Plan is to improve stroke care across the whole patient pathway, developing the priorities identified in the Progressive Stroke Pathway (2022) to support the patient centred prevention, diagnosis, treatment and long-term management of stroke.

The incidence of stroke continues to have a significant impact on people in Scotland. The existing Stroke Improvement Plan was published in 2014 and in the last three years, the Covid-19 pandemic has highlighted challenges and opportunities across the entire health care system. The publication of the Progressive Stroke Pathway (PSP) in 2022 set out a vision of what progressive stroke care in Scotland should comprise. The prioritisation and implementation of the PSPs recommendations provides an opportunity for a refreshed Stroke Improvement Plan to reflect this landscape.

The priorities and actions set out in the Stroke Improvement Plan adopt a holistic approach to stroke care across the whole patient pathway, building on work already done through the PSP, Scottish Stroke Improvement Programme reporting and encouraging collaboration and sharing of best practice across service colleagues, stakeholders and our third sector partners.

Our EQIA identified a number of areas where specific efforts to address inequalities throughout the implementation of the plan could be made. These include ensuring that the voices from groups of people are heard, such as those from areas of deprivation, those with intellectual disabilities, those from the LGBT+ community and people with a minority ethnic background who may face inequalities accessing care following stroke and also from the outcomes from stroke, particularly where these groups may overlap each other. The evidence shows that people from these groups

face disparities in accessing care and / or in the quality of care following their experience of stroke.

The vision of the Stroke Improvement Plan is to 'to improve stroke care across the whole patient pathway, developing the priorities identified in the Progressive Stroke Pathway (2022) to support the patient centred prevention, diagnosis, treatment and long-term management of stroke'. Because of this, we do not envision that the plan will have a negative impact on any individual or group, however, it is vital that in the implementation of the actions within the plan, we continue to engage in a robust lived experience process that allows the voices of those listed above to be heard.

2. Background

Stroke remains a major cause of death and disability in Scotland. The number of incident cases of stroke in 2021/22 was reported at 9,589 with 2,157 deaths in 2021. Stroke mortality had fallen over the last ten years¹. In 2021, 3% of adults reported ever having had a stroke². Mortality rates, while higher in Scotland than in the rest of the UK, the gap has reduced over the last fifty years³.

The death rate for cerebrovascular disease (CVD), which includes stroke is higher in the most deprived areas than in the least deprived areas⁴. A Scottish study from 2000 found that poorer socioeconomic circumstance was associated with greater stroke risk, with adverse early-life circumstances of particular importance⁵.

Scotland's disease burden, including cardiovascular conditions is forecast to increase 21% between 2019 and 2043⁶. A study from 2020, suggested that the strokes in the UK were projected to increase by 60% between 2015 and 2035 and that the costs of stroke care in the UK were also set to increase over the same period unless measures to prevent strokes and reduce stroke disability were implemented⁷.

As a result of an ageing population many people are living longer following their experience of stroke and require care and support for significant lengths of time.

3. The Scope of the EQIA

We considered the protected characteristics of: age, disability, severe mental illness, sex and gender, pregnancy and maternity, gender reassignment, sexual orientation, and race,

Therefore, in making its assessment, the Scottish Government has considered relevant evidence relating to the protected characteristics, as well as the potential impact on wider health inequalities.

4. Key Findings

4.1 Age

Stroke is more common in older people and stroke incidence is strongly related to age⁸. 10% of those aged 75 and above in a survey reported ever having had a stroke⁹.

The survey found that the prevalence of stroke was 3% for all adults.

By mid-2043, it is projected that 22.9% of the population will be of pensionable age, compared to 19.0% in mid-2018 with increasing numbers in the 'oldest old' age categories and a doubling of the number of people aged 90 and over between 2019 and 2043¹⁰. This is reflected in the disease burden for Scotland, including cardiovascular conditions, which are forecast to increase substantially for those 65 years old and above, with the largest increases for the 65 to 84 years age group¹¹.

While the incidence of stroke is lower in the under 75s¹², One review study from 2020 indicated that stroke at a young age is an increasing problem with long-term psychological, physical and social consequences with a wide variety of possible underlying risk factors. The same study also reported a higher incidence among young black and Hispanics in the USA¹³.

Older people may face stereotypes in their treatment such as being dependant on others, with failing physical and mental health and their needs may not always be well understood¹⁴, highlighting the need for equality of care to ensure older people do not face barriers to optimal care. It is also recognised that older people, among other groups are less likely to be users of the internet^{15 16} or may be less confident in the use of technology than the general population, and therefore could be adversely affected by increasing use of digital models of care. Innovative, digital means of accessing care have been particularly prevalent during the Covid-19 pandemic and are set to remain in place as part.

4.2 Disability

Stroke has been cited as the single biggest cause of disability in adults¹⁷. It is estimated that 50% of people who have experienced a stroke will live with permanent or chronic disability. This includes the risk of paralysis, aphasia or dysphagia, sensory problems, fatigue and mental health problems¹⁸. 1 in 12 stroke survivors will have to move into a care home because of disability caused by their Stroke¹⁹.

Stroke is associated with health risk behaviors and mitigated by health promoting behaviors, behaviors around diet, exercise, smoking, alcohol and self-management of underlying conditions (such as high blood pressure, high cholesterol, atrial fibrillation and diabetes) can all increase or decrease individual risk of Stroke²⁰. Health behavior has been shown to be shaped by socioeconomic gradients with people experiencing social deprivation smoking more, exercising less and having poorer diets.²¹

Alongside physical disabilities as a result of stroke, intellectual disability is also found to be a diagnoses²². Mortality among people with intellectual disabilities has been reported to be markedly elevated in comparison with the general population and receive poorer quality care²³. A study²⁴ conducted in Scotland, highlighted the potential for people with learning disabilities to be effectively consulted regarding health management and for their views to inform service development regarding stroke cardiovascular disease care.

Stroke research and delivery has traditionally concentrated on acute and early phases of recovery, however there are significant long-term physical and emotional consequences of stroke and many survivors, and their families report unmet needs in relation to these consequences²⁵.

4.3 Severe Mental Illness

It is recognized that mental health disorders play a significant role in the burden of disease in Scotland²⁶. The rate of burden of disease in Scotland due to mental and substance use disorders in the most deprived areas has been reported as 4.4 times the rate in the least deprived areas.²⁷

Individuals living with severe mental illness (SMI) die 10-20 years earlier than the general population, long-term and physical conditions such as stroke contribute substantially to the mortality gap.^{28 29 30} Stroke is 2-3 times more common in people with SMI than the general population³¹. In relation to cardiovascular disease (CVD) patients with SMI have 53% higher odds of CVD than the general population³².

Patients with TIA or minor stroke are at sustained risk of cardiovascular events and medication adherence and smoking cessation decrease by time since TIA³³. Another study also been found that individuals with SMI have lower prescription/referral and adherence to secondary prevention measures including pharmacological, lifestyle and rehabilitation care than equivalent patients without SMI³⁴.

A Scottish study³⁵ found pre-existing severe mental illness was associated with higher risk of stroke and highlighted the need to better understand and address the reasons for this and about how SMIs relates to stroke prognosis and delivery of care. There is therefore, a gap in our understanding of the relationship between SMI's and stroke.

The NHS Race and Health Observatory³⁶, informed by their stakeholder engagement groups suggested Roma, Gypsy and Irish Traveller and Chinese groups may be reluctant to seek help from mental health services due to a lack of trust.

4.4 Sex and Gender

In the Scottish Health Survey 2021³⁷, men reported a higher overall prevalence of stroke compared with women, with 3% of men and 2% of women reported that they had experienced a stroke.

A 2022 study³⁸ noted that the lifetime risk of stroke is higher for women than men and highlighted that most of the data on stroke did not separate sex and gender and

therefore, many of the findings for sex differences may represent the combined impact of both sex and gender. A UK study³⁹ from 2020 found that the incidence of stroke remained higher among men than women, despite several risk factors more strongly associated with the risk of any stroke in women compared to men, particularly type one diabetes, obesity, high blood pressure and atrial fibrillation. In Scotland, in seven out of the ten years, the adjusted mortality rate was slightly higher for females.⁴⁰

A US study highlighted there is limited data on the epidemiology of stroke and risk factors among people who identify as nonbinary and intersex, with the majority of data focusing on binary transgender individuals and suggested changes in how to incorporate sex and gender in research, education, and clinical care were needed⁴¹. A US paper⁴² in 2021 referred to the transgender population experiencing significant stressors that affect cardiovascular health across their lifespan and also highlighted the need for further research on this topic to address gaps in the literature.

4.5 Pregnancy and maternity

Stroke can cause devastating complications during pregnancy; ischemic and hemorrhagic stroke occur in approximately 30 in 100,000 pregnancies⁴³. Women with preeclampsia were found to be at a 6-fold higher risk of stroke. A Swedish study⁴⁴ of more than one million pregnant women found that while the overall risk of stroke was low in women of childbearing age, stroke risk peaked in the peripartum and early postpartum periods.

Women were found to be at an increased risk of stroke due to oral contraceptive use and hormone replacement therapy in a recent study⁴⁵ based on the UK Biobank. UK Stroke Guideline (2023)⁴⁶ recommendations recognise that there is now evidence that oestrogen increases the risk of cardiovascular events including ischaemic stroke both when used by younger women as the combined oral contraceptive and by postmenopausal women as hormone replacement therapy.

4.6 Gender Reassignment

An estimate of the numbers of trans people in Scotland stands at a commonly used figure of 0.5% of the population, just under 24,000 adults.⁴⁷ The Scottish Government's NHS gender identity services: strategic action framework 2022 – 2024 includes a number of recommendations to improve access to and reduce waiting times for these services.

A literary review in 2022⁴⁸ found that while overall, the available data for cerebrovascular disease was equivocal, there seemed to be an increased long-term risk of ischemic stroke in transgender women on gender affirming hormone therapy compared to both sex assigned at birth men and women. The same study found that while data was scarce and not consistent, there seemed to be no increased risk of cardiovascular disease, myocardial infarction or stroke in transgender men on hormone therapy. Another study from 2022⁴⁹ suggested that with regard to risk factors, the effects of gender-affirming hormone therapy on risk of stroke needed to be better quantified, particularly for transgender women.

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Access to health care is a major health determinant for transgender and non-binary individuals⁵². Black and minority transgender and non-binary people are more likely to face barriers and discrimination to and within health care services⁵³. In 2016 the Race Equality Foundation published a briefing paper⁵⁴ which called for improved and equitable access to health services for transgender and non-binary black and minority ethnic people and additional training for all health professionals to support development of this care.

Diagnostic overshadowing can also occur in healthcare treatment of transgender and non-binary people. This is where physical and mental health concerns are tied to their gender/transition status rather than being understood and cared for in isolation⁵⁵.

A literary review from covering a six and half year period⁵⁶ concluded that transgender adults experienced widespread adversity and barriers to safe and equitable healthcare. A paper from 2022⁵⁷ noted that any healthcare approach to transgender people must consider their specific needs, so strategies must be adopted to provide this group with quality, individualized, holistic, and respectful healthcare.

4.7 Sexual Orientation

A Scottish Health Needs Assessment (HNA) research findings report⁵⁸ found LGBT+ people face health inequalities on every measure of wellbeing.

A literary review from 2016⁵⁹ found that gender and sexually diverse populations experience reduced access to quality health care and under-utilization of health care due to individual and systemic discrimination. There is also evidence that LGBT+ people are typically overlooked or excluded from participation and engagement. A US paper⁶⁰ in 2021 referred to the transgender population experiencing significant stressors that affect cardiovascular health across their lifespan and also highlighted the need for further research on this topic to address gaps in the literature. A recent US study⁶¹ found that there was limited data on stroke and risk factors among people who identify as nonbinary and intersex, with the majority of that data focusing on binary transgender individuals. Another US study⁶² from 2021 found that Hispanic and Asian sexual minorities had lower rates of awareness of heart attack and stroke symptoms.

A component of stroke rehabilitation is relationship and sexuality recovery and support. Although this is important element for stroke survivors and their partners, research shows that post-stroke sexuality is rarely discussed in rehabilitation⁶³.

Guidelines⁶⁴ recommend tailored information and access to psychosexual services after discharge and at 6-month and annual reviews for stroke survivors.

4.8 Race

The NHS Race and Health Observatory rapid evidence review⁶⁵ has set out the role of a number of factors in perpetuating health inequalities in ethnic minorities experience of, access to and outcomes across a range of healthcare services.

In a similar finding to the one in Severe Mental Illness section, An Equality and Human Rights Commission research report⁶⁶ indicated barriers to accessing health services for Gypsy / Traveller communities included difficulties registering with GPs, poor staff attitudes and lack of trust of services because of previous experiences. An analysis⁶⁷ of health inequality and ethnicity in Scotland using self-reporting found very stark results for Gypsy / Traveller communities regarding health inequalities and in relation to older women from Indian, Bangladeshi and Pakistani communities.

The British Medical Association, in their response⁶⁸ to the Race Report (2021) from the Commission on Race and Ethnic Disparities (CRED) criticized the report In particular, in its finding that it did not find evidence of structural race inequality as a major factor affecting outcomes and life chances. The Institute of Medicine⁶⁹ has developed a framework to understand racial inequalities in health, this is structured through patient, provider, system and policy level disparities.

Inequalities affecting ethnic minorities over a spectrum of healthcare including access to, uptake of services and quality of care was acknowledged in a 2017 study and cites further sources.⁷⁰ A 2005 study found that ethnic groups have higher rates and more severe cases of stroke⁷¹. The same study found that while outcomes of mortality are higher in ethnic groups, however, inequalities in other clinical outcomes were understudied and not fully understood⁷². In a 2011 study, half of stroke survivors reported unmet needs between 1 and 5 years after experiencing a stroke, with this reporting of unmet needs greater amongst ethnic minorities⁷³. A Danish study⁷⁴ from 2020 found ethnic minorities had a higher risk of stroke and that incidence and post stroke mortality appeared to vary among ethnic minorities compared with those Danish born. It also noted the importance of having good quality registers to support these types of findings. A US study⁷⁵ concluded that risk of stroke recurrence among older Americans hospitalized for ischemic stroke was higher for blacks compared to whites.

A 2018 UK study⁷⁶ found the incidence of first-ever-stroke is higher in the Pakistanis compared with the Whites in Bradford. Stroke was found to be more common in Black people and people from South Asian groups, particularly those in the Pakistani and Bangladeshi ethnic groups⁷⁷. A recent UK study⁷⁸ reported that those from ethnic minorities had earlier onset of an acute stroke and a two to fourfold increase in many stroke-related adverse outcomes and death compared with Caucasian patients.

The British Heart Foundation have highlighted that people from African or African Caribbean backgrounds are at higher risk of developing high blood pressure and having a stroke than other ethnic groups⁷⁹. People from a minority ethnic background

are more likely to live in the most deprived areas of Scotland⁸⁰. They are also likely to face a number of barriers to effective communication about their health. This can include difficulties in accessing healthcare in an appropriate language and cultural context⁸¹. A systematic review of ethnic inequalities in access to, experiences of, and outcomes of digital healthcare was also a recommendation of the NHS Race and Health Observatory work.

5. Recommendations and Conclusion

The EQIA process identified a number of areas where people face variation, differences in accessing services and outcomes following their experience of stroke. As we move forward with the implementation of the Stroke Improvement Plan we will consider how best to address these inequalities.

Regarding age and disability, against a backdrop of an ageing and increasing population of older people with physical and intellectual disabilities, it can be anticipated that there will be a rise in morbidity and mortality from stroke in this group in the future. Tackling risk factors for stroke is Priority 1 in the Stroke Improvement Plan. We will work to prevent stroke, and thus disabling illness, through supporting ongoing primary prevention work commenced in the Heart Disease Action Plan to improve detection, diagnosis and management for the stroke risk factors of high blood pressure, high cholesterol and atrial fibrillation which is person-centred and co-designed.

The recent Scottish study highlights there is gap in our understanding of how those with SMIs experience stroke services.

The Women's Health Plan (2021) makes specific commitment to provide opportunities for optimisation of cardiovascular health and risk reduction across a woman's life course. We will continue to work collaboratively to embed the actions within the women's health plan relevant to cardiac disease and to understand and address the delivery of cardiac services for women in Scotland and where they intersect with stroke care. There is a commitment in the Women's Health Plan (2021) that all women with heart disease will be provided with individualised advice and co-ordinated care to access safe contraception, abortion, assisted conception, pregnancy and gynaecological care.

With the Scottish Health Needs Assessment (HNA) highlighting that those from the LGBT+ community face health inequalities on every measure of wellbeing, there is a gap in our understanding of how LGBT+ people specifically experience stroke care in Scotland. The HNA contains a number of recommendations including training of health staff and the need for inclusivity of services that more broadly, could support positive change for LGBT+ people who have experienced a stroke. Exclusion from participation and engagement in services is also highlighted, while those experiencing gender reassignment were reported to experience widespread barriers to safe and equitable care.

Engagement with South Asian, African and African Caribbean and Gypsy / Traveller communities needs to be culturally sensitive and take into account experiences of discrimination and unconscious bias to inform how services can be tailored to their

needs as well as taking digital literacy support into consideration for a public awareness campaign for stroke. There is a gap in our understanding in how Gypsy traveller communities experience stroke services.

The [Race Equality Framework for Scotland 2016 to 2030](#) also contains a number of goals to support the aim of making Scotland a better, healthier place for everyone and to make real improvements in the lives and experiences of minority ethnic communities in Scotland.

National Stroke Voices

As we move forward to improve stroke care across the whole patient pathway, we will build on the lived experience of the National Stroke Voices to better understand the issues highlighted for these groups to ensure an inclusive approach is adopted to implementing the priorities in the Stroke Improvement Plan.

Priority 2 in the Stroke Improvement Plan focuses on awareness raising to establish the current degree of public understanding of the FAST test (Face Arm Speech Time) to identify stroke symptoms and the action required, and whether certain at-risk groups require different messaging and then to work with third sector organisations to ensure messaging reaches all at-risk groups.

In taking forward these public awareness commitments and the other commitments in the Stroke Improvement Plan, we will work with our stakeholders to make messaging accessible in terms of language, format and medium to reflect the needs of these groups, building on the lived experience of the National Stroke Voices to support positive change for those who have experienced a stroke, to address barriers to engagement and participation and support people to be active partners in their own care.

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The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-83521-014-7 (web only)

Published by The Scottish Government, July 2023

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS1313562 (07/23)

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