Stroke Reform in Northern Ireland

NICHS Stroke Manifesto 2021











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Self-Management



Northern Ireland Chest Heart and Stroke (NICHS) is calling on the Department of Health and the Northern Ireland Executive to act on stroke reform in NI to improve stroke prevention, treatment and care for stroke survivors and their families.

Progress in acting on the outcome of the stroke review consultation was already slow due to political instability and the COVID-19 crisis which have sadly hugely delayed reform. The result is that Northern Ireland continues to live with higher levels of mortality and disability from stroke than it should.

Northern Ireland urgently needs not just to press on with the Stroke Review but with the development of a wider Stroke Strategy that addresses prevention, acute care, rehabilitation and support in the community. Such a strategy would provide a framework for service improvement across prevention, acute care and community care.

This Manifesto outlines a number of key areas which need action now. We can delay no longer.



Stroke Burden

Stroke is a major health issue in Northern Ireland, with around 2,800 people being admitted to hospital and 800 deaths due to stroke per year. In addition there are roughly 38,000 stroke survivors living in our communities. Approximately two thirds of those who survive stroke are left with a life changing disability, which shatters lives for individuals and their families, and places pressure on the NHS, wider service network and on the community.

Sadly, the number of people in NI experiencing a stroke each year is likely to increase in the future because of a growing older population, with three out of four people who experience a stroke being over the age of 65.

The COVID-19 pandemic has had a major impact on stroke. There was a marked drop in hospitalised stroke cases worldwide particularly during the first wave¹. There is growing evidence that people who have a stroke and COVID-19 are likely to be younger than expected. A stroke can strike at any time and at any age and further delay of stroke reform in NI is not acceptable.

Progress so far

NICHS appreciates that progress has been made to improve both prevention of stroke and care for stroke patients in Northern Ireland. This is due in part to changes in lifestyle behaviours, including a reduction in smoking. It is also a result of improvements in early diagnosis of stroke, improved access to thrombolysis, the introduction of thrombectomy, and increased investment into stroke research. However, despite the significant success in reducing premature mortality from stroke, it remains a major cause of death and disability in Northern Ireland. The decline in deaths has plateaued in recent years and inequalities in stroke risk have been further exacerbated by the COVID-19 pandemic.

Further Action and Progress Required

- Invest further in the prevention, awareness and early detection of stroke.
- **Progress** the acute stroke hospital reform.
- **Deliver** a regional and sustainable long term support pathway and care for people affected by stroke.
- **Fairly fund** the voluntary sector. Enable us to help the statutory sector and provide the best services possible for patients.
- **Produce** a partnership NI Stroke Strategy.

Prevention

In recent years much attention has focused on improving the treatment of people experiencing stroke – through thrombolysis and thrombectomy. Important – and indeed lifesaving – as these interventions can be, prevention is clearly better than 'cure'. The Stroke Action Plan for Europe 2018-2030 has four overarching goals. One of these is to reduce the absolute number of strokes by 10% by 2030.

Prevention is at the heart of the NHS Long-Term Plan in England. It includes as a major ambition preventing 150,000 strokes and heart attacks over the next ten years by improving the treatment of high-risk conditions – hypertension (high blood pressure), high cholesterol and atrial fibrillation (AF).



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¹ Ischaemic stroke can follow COVID-19 vaccination but is much more common with COVID-19 infection itself, https://jnnp.bmj.com/content/early/2021/05/20/jnnp-2021-327057

Individuals with these common conditions are more at risk of developing cardiovascular disease (CVD) including heart attack, heart failure, and stroke. Large numbers of people are undiagnosed or under treated, partly because these conditions often have no symptoms. To help tackle this, and to support the Long-Term Plan ambition, NHS England and NHS Improvement have commissioned a national primary care audit – CVDPREVENT.

CVDPREVENT is a national primary care audit in England that automatically extracts routinely held GP data covering diagnosis and management of six high risk conditions that cause stroke, heart attack and dementia: atrial fibrillation (AF), high blood pressure, high cholesterol, diabetes, non-diabetic hyperglycaemia and chronic kidney disease.

Northern Ireland clearly needs to mirror the ambition of the Action Plan for Europe and the Long-Term Plan for England. We have seen how in stroke care the SSNAP audit has driven improvement in stroke services across the acute sector in Northern Ireland. We too need to carry out an audit in primary care. NICHS is calling for an increased focus on prevention, early detection and supporting people to make healthy choices and behaviour changes. We also want to see targeted action to prevent and reduce health inequalities associated with stroke risk and outcomes.

Atrial Fibrillation

There are over 40,000 people on the AF Register and approximately 10,000 who are currently undiagnosed who are at a much higher risk of stroke.

In 2019/20 an inquiry was conducted into AF detection and management in Northern Ireland. This was led by Dr Niamh Kennedy from Ulster University. The study, commissioned by NICHS, engaged with clinicians at every level across Northern Ireland.



Summary of the Key AF Recommendations

Working in partnership with key stakeholders, including the Department of Health we should:



1. Develop an AF strategy for Northern Ireland.



- 2. Aim to identify 85% of people with AF by March 2023 and 90% by 2025.
- 3. Create a clear clinical pathway for AF.



4. Invest in technologies in clinical practice to detect AF and monitor treatment.



5. Increase AF detection rates by targeted case finding based on AF risk factors.



 Address the echocardiograms (ECG) waiting list issue including tackling any workforce issues.



7. Provide information and education to people living with AF.

- 8. Prioritise improving adherence to treatment for existing AF patients to prevent future strokes.
- 9. Commission the Public Health Agency to identify the most effective methods to raise public awareness of AF.

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- 1. Invest further in the prevention and awareness of stroke and increase support to people at risk of stroke including conducting an audit of the current situation in primary care.
- 2. Increase community detection and treatment rates of High Blood Pressure and AF.
- **3**. All key stakeholders should work to adopt the recommendations of the NICHS AF Inquiry.



Progress Stroke Hospital Reform

In 2017, NICHS led stroke pre-consultation meetings and workshops with stroke survivors to inform and influence the stroke reform process. The formal 'Reshaping Stroke Care' consultation on these changes took place two years later in 2019. Seven recommendations for change were identified, including making changes to acute stroke care in NI and creating hyper acute stroke units or HASUs that have been shown to save lives and reduce length of hospital stay for stroke patients in other parts of the UK.

NICHS is calling on the Executive and Department of Health to honour the commitments made before the pandemic.

The 72-hour period post stroke is crucial and current services can be markedly improved.

It is essential that we press on with reform in this area. Specifically, around the areas identified in the consultation;

"A regional model for TIA assessment by March 2020 and implement that model by 2022 to deliver a 7-day service of specialist assessment within 24 hours of symptoms."

Early intervention and support for people who have had a TIA is key to overall improved health outcomes for high risk patients, and to prevent further strokes. We recognise the development of TIA services across Northern Ireland in recent years. We note that meeting the commitment of a comprehensive 7-day service will be a challenge in terms of workforce and service planning.

"By 2022 we will remove the variance in delivering thrombolysis to ensure that patients across NI have timely access to the treatment."



In recent years there have been marked improvements in the thrombolysis rate in Northern Ireland and this is welcome. In addition to reducing variance we need to set goals for overall improvement too. The Long-Term plan for England set a target of 20% by 2025. NI needs to have this as a goal too.

"We will continue to invest in the growth of thrombectomy, increasing hours of operation to Monday – Friday 8am-8pm service by December 2019, and moving to 24/7 service by 2022."

With 132 thrombectomy procedures carried out in 2020, the team at the Royal Victoria Hospital, despite the COVID-19 pandemic, have been remarkable. The thrombectomy service is something the Health Service in NI should be justly proud of and we need to move to 24/7 availability as soon as possible. "We will reshape stroke services by 2022 to establish dedicated hyperacute and acute stroke units underpinned by regional service standards to deliver improved outcomes for stroke patients."

NICHS supports the development of specialised Hyper-Acute Stroke Units, as the evidence demonstrates overwhelmingly that treatment within these units represents the best chance for good outcomes following stroke. The failure to make progress on this is extremely disappointing. At the time of the consultation NICHS called for more information on the six options outlined, not least with regard to the workforce plans. We believe this work has now been carried out.

NICHS Stroke Manifesto The Health Minister needs to: 4. Set a date for the introduction of 24/7 TIA assessment. 5. Set a target of 20% for thrombolysis and a date for its achievement. 6. Highlight the achievement of the Thrombectomy service – and support its development. 7. Make a decision on the number and location of HASUs.



Post Acute Care – Community Care, Rehabilitation and Self-Management

The stroke consultation commitment read:

"The recently published Stroke Association document 'Struggling to Recover' makes six recommendations to improve services. Alongside the reshaping of hospital services, we are committed to driving improvement in rehabilitation and long-term support and will use the Stroke Association's analysis and recommendations as a blueprint to drive that improvement."

NICHS has always been concerned about the apparent vagueness of this proposal and noted that there are no specific time-bound actions included in this commitment.

The Consultation noted that up to 40% of stroke survivors may be suitable for 'Early Supported

Discharge' (ESD) and that only 2 Trusts currently provided access to ESD at that time. It is welcome that funding is committed for the roll out of ESD. NICHS believes that there should be a target date for when ESD will be available to all suitable patients in Northern Ireland.

Recent estimates indicate that about a third of stroke survivors are left with long-term residual disabilities and needs which can persist for many years following the stroke event. This would suggest that there are over 10,000 people across Northern Ireland who may require support with long-term residual disabilities and needs.

It is clear from the Stroke Association report, 'Struggling to Recover' and the experience and knowledge of NICHS staff that there is significant unmet need. It is imperative that this need is met alongside any changes to acute services. This will require a commitment to a detailed plan to ensure people receive the level of support with regard to physiotherapy, etc. in line with NICE guidance. This will require considerable workforce resources.



Enabling the Voluntary Sector to support the Statutory Sector

NICHS have designed services for those who have had a stroke, and for their families, to help at different stages of their journey. We work with local Health and Social Care Trust Teams across Northern Ireland, to deliver these services in an integrated and supportive way.

These services include Stroke Family Support, Taking Control Self-Management, Stroke Activity Groups, Young Stroke Support and the Post Rehab Exercise Programme (PREP). NICHS supports thousands of service users through these services. Only a proportion of these services are supported financially by the statutory sector. In fact, for the eight care services contracts relating to stroke services, the fees received represents less than 50% of the cost of providing them. These are services that the statutory sector has agreed are required to help patients deal with stroke but over half the cost is being met from NICHS charitable funds.



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- 8. Outline a timeline to produce a long-term support pathway and to make ESD available to all who can benefit from it.
- 9. A detailed response to 'Struggling to Recover' including how NICE guidelines are to be met and the detailed workplace plan required to deliver this.
- 10. A commitment to work with the voluntary sector to enable them to support the statutory sector, including details of how the cost of services provided by the voluntary sector can be properly reimbursed.



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