

Scottish Government

Long Term Conditions Framework – Public Consultation.

Stroke Association response

Stroke Association would like to thank the Scottish Government for the opportunity to respond to this consultation.

Stroke Association consulted stroke survivors, professionals and researchers to inform this response.

Executive summary:

The key issue for the Stroke Association is assurance that stroke will retain appropriate, designated policy space. Integration into a Long-Term Conditions Framework must not result in a watering down or deprioritising of existing commitments.

Stroke must be appropriately resourced, retain its own budget and status, and existing commitments must be built upon.

Scottish Government must retain all current civil service stroke policy support apparatus including a dedicated stroke policy lead, dedicated budget to a level commensurate with stroke improvement needs, a stroke improvement team, the Specialty Adviser to the CMO, a National Advisory Committee and so on.

The substantive elements contained within the Stroke Improvement Plan 2023 must remain in place, and progress by Health Boards towards delivery against the Plan's commitments must continue to be supported, encouraged and vigorously pursued by Scottish Government.

1. Do you agree that Scottish Government should move from a condition-specific policy approach to one that has a balance of cross-cutting improvement work for long term conditions alongside condition-specific work?

Our interest is in the likely impact of this move on outcomes for people affected by stroke. While it remains unclear what those impacts will be, we cannot give a clear yes or no to the proposal. What we are sure of, is that a move towards cross-

condition working must not be at the expense of the quality and suitability of care provided to stroke survivors.

The Stroke Association shares the Scottish Government's ambition for patient-centred care that enables people to live longer, healthier, and more fulfilling lives. We believe there are opportunities for collaboration and a more coordinated approach. However, we are deeply concerned that this development raises the prospect of a one-size-fits-all approach to long-term conditions; conditions which vary significantly in clinical pathways, specialisms, and impact on patients' lives. Any new, joined-up approach must be greater than the sum of its parts.

With very little information available on what is, and what is not included in the move from a condition-specific policy approach to one that has a balance of cross-cutting improvement work for long term conditions alongside condition-specific work, it's extremely difficult to offer clear responses.

We would have wished for much greater detail and clarity on what is being proposed structurally and financially; more detail on delivery and accountability mechanisms, and presumably considered information on how the framework aligns and interacts with other strategic documents, such as the NHS Operational Improvement Plan, Population Health Framework, and Health and Social Care Service Reform Framework.

A concern remains that this is at core an over-simplified, bureaucratic improvement to complex systems. There may be potential benefits for some people to aspects of 'cross-cutting improvement work' but there remain many tried and proven benefits to specific attention being given to stroke treatment and care for the more than 10 000¹ people who have a stroke every year in Scotland, and the more than 130 000² people living with the effects of their stroke.

The absolute need for stroke specific attention for a large part of the stroke pathway, including hyper acute and acute treatments and stroke-specific rehabilitation remains, regardless of whatever shape the Long-Term Conditions strategy takes.

The Scottish Government has demonstrated in recent times its understanding of the need to improve stroke treatment and care. Programme for Government commitments in 2019 were followed by the vision of modern stroke care

¹ <https://publichealthscotland.scot/publications/scottish-stroke-improvement-programme/scottish-stroke-improvement-programme-annual-report-2024/>

² <https://www.stroke.org.uk/stroke/statistics>

encapsulated in the progressive stroke pathway in 2022, and the publication of a Stroke Improvement Plan in 2023.

Stroke has had a civil servant devoted solely to stroke policy for only the last three years. Prior to that, stroke policy was shared with heart disease; both clinical priorities served by one person who split their time across both conditions. This move to separation and the investment in personnel to support it was further recognition by the government that stroke did not perform well and needed dedicated policy attention. The benefits have been tangible.

We note the inherent goal of reducing the number of health policy commitments faced by the NHS and other stakeholders. Yet, we cannot suggest any single one of the existing stroke policy commitments that we could consider expendable.

If a similar commitment expressed across several conditions' policy areas can be combined into a more general directive, then that seems sensible. But any dilution of hard-fought, necessary improvements in stroke policy over last few years will be vehemently opposed by the Stroke Association.

At a time when stroke service delivery routinely misses Scottish Government-set desired standards, and the stroke community already feels undervalued, Scottish Government should deliver greater prioritisation of stroke, not less, and Health Boards must deliver against the commitments in the Stroke Improvement Plan 2023.

More than ever, with health and social care under extreme pressure, evidence suggests that stroke improvements can be part of the solution to some of our challenges. More than ever, stroke needs single issue attention, determination and commitment.

Summary

Point 1.

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Stroke must be appropriately resourced. It must retain its own budget and status, and existing commitments must be built upon.

Scottish Government must retain all the current civil service stroke policy support apparatus including a dedicated stroke policy lead, dedicated budget to a level

commensurate with stroke improvement needs, a stroke improvement team, the Specialty Adviser to the CMO, a National Advisory Committee and so on.

The substantive elements contained within the Stroke Improvement Plan 2023 must remain in place, and progress by Health Boards towards delivery against the Plan's commitments must continue to be supported, encouraged and vigorously pursued by Scottish Government.

Point 2. Stroke is a medical emergency. It differs entirely, in that respect, from other chronic conditions. The time-sensitive treatments required for hyper acute and acute stroke and the sheer numbers of people affected, offer absolute justification for stroke-specific policy and resource.

Point 3. Stroke-specific rehabilitation must remain a part of stroke policy and not become absorbed into generic multi-condition rehabilitation programmes.

This feels like the most obvious danger point for stroke patients and stroke policy in a move to a multi-condition 'cross-cutting' approach. Stroke rehabilitation is a specialist area requiring stroke-specific interventions and treatments.

Stroke specialist rehabilitation in line with the National Guideline on stroke needs to be provided promptly in hospital and be available in the community.

Stroke specialist rehabilitation to patient-centred, individually appropriate levels allows patients to be discharged from hospital as soon as they are able. This is good for the patient and frees up much needed hospital beds. It also ensures that the patient maintains gains they have achieved in hospital and can remain living in their own homes.

There is clear and compelling evidence of the benefits of stroke-specific rehabilitation in improving outcomes for patients and offering economic savings for health and social care systems.

Point 4. Stroke Association would encourage investment in a national programme to improve the early detection and treatment of hypertension.

Hypertension is the biggest, single risk factor for stroke. In terms of stroke prevention as well as prevention and management of many other long-term conditions this presents one of the biggest opportunities for a genuine 'cross-cutting' multi-condition initiative.

A 'cross-cutting' multi-condition, hypertension initiative could engender large scale population level health impact, benefitting stroke patients and patients affected by

many other conditions including diabetes, heart disease and kidney disease, as well as people with as yet undetected high blood pressure.

Point 5. In line with other third sector organisations Stroke Association was dismayed at the absence of meaningful discussion before this move to a Long-Term Conditions strategy was enacted.

We would respectfully request meaningful engagement in future developments of the Long-Term Conditions Framework with the Stroke Association and other third sector organisations affected by this change; with particular attention to implementation, resourcing, and accountability mechanisms for delivery of improved services.

2. Are there any improvements in prevention, care or support you have seen in a long-term condition you have, or provide care and support for, that would benefit people with other long-term conditions?

Genuine marked improvements are yet to be realised but we are aware of positive developments arising from a commitment in the 2023 Stroke Improvement Plan, one which offers genuine localised Health Board management accountability for delivery.

"Commitment: Every NHS Board asked to provide an accountable individual from their senior management team to be responsible for the delivery of stroke services in that area across the entire pathway."

As well as this, the requirement for Health Boards to offer six-month reviews to every stroke patient is a very welcome improvement.

3. Do you have any thoughts about how areas for condition-specific work should be selected? This means work which is very specific to a health condition or group of health conditions, rather than across conditions

Around two thirds of all stroke survivors have a disability. The scale, impact and sheer numbers of people affected by stroke - 10,803⁴ Scottish residents had a final diagnosis of stroke in 2023 - demand that stroke retains its status as a condition which absolutely requires condition-specific work.

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4. What would help people with a long-term condition find relevant information and services more easily?

Having localised support offers/opportunities collated and easily accessible would prevent a lot of searching around on the part of those affected by the conditions.

A single point of contact with the relevant professional team(s)

Some stroke services provide a phone number for patients to phone any time after their hospital admission if they have a question, but this is not available everywhere. Our understanding is that this service works well for patients and is rarely abused.

5. What would help people to access care and support for long term conditions more easily?

As above (question 4)

A six-month review after discharge has proved to be a crucial component of Life After Stroke support, and may offer similar benefits for other conditions

Flexibility built into Health Board pathways for patients to refer 'back in' for help and support should they require it.

6. How could the sharing of health information/data between medical professionals be improved?

Implement a 'Once for Scotland' digital approach. Deliver one system for the national health service in Scotland with patient records from any Health Board

available to health and social care professionals in any other Health Board across all work areas from primary care to acute specialist care, and rehabilitation.

The wearisome tale of progress towards procurement of a national AI system in support of the rollout of mechanical thrombectomy is a sore issue for the Stroke Association and for many stroke health professionals.

In a digital age we simply cannot deliver optimum care for patients when Health Boards have data systems that are unable to communicate with each other.

7. What services outside of medical care do you think are helpful in managing long term condition(s)? You may wish to comment on how these services prevent condition(s) from getting worse

Stroke differs from many other long-term conditions in its huge variability of functional and cognitive impairments as well as the emotional impact.

Long-term health monitoring for stroke patients usually relates to underlying conditions which caused the stroke (high blood pressure, diabetes) rather than the stroke itself. This clearly nods to the 'cross-cutting' multi-condition agenda, but the impact of stroke itself also specifically needs looked after. Stroke is a brain attack. The emotional and psychological impact can be enormous.

Peer support and support groups and networks are not a replacement for the psychological and emotional support which every stroke survivor should be availed of. They can, however, be effective for some people. They can be helpful in developing self-esteem for someone who has lost their previous life and may be coming to terms with a new way of living; a new sense of 'who they are in the world'. This in turn encourages some people to more effectively self-manage their condition.

8. What barriers, if any, do you think people face accessing these (non-medical) services?

Stroke differs from many other long-term conditions in its variability of functional and cognitive impairments as well as the emotional impact.

The impacts of stroke combined with factors such as rurality, digital exclusion, health inequalities will prevent some people from accessing services whether online or in-person.

9. What should we know about the challenges of managing one or more long term conditions?

People with long-term conditions have all seen doctors, had tests done and been given a diagnosis of stroke, diabetes, heart failure, COPD, chronic kidney disease et cetera. They then embark on what will often be a lifelong path of medication, hospital appointments, rehabilitation et cetera.

A drive towards simplification of systems must not forget the many challenges and very real difficulties many individuals with long term conditions such as stroke experience daily.

10. What would strengthen good communication and relationships between professionals who provide care and support and people with long-term condition(s)?

11. What digital tools or resources provide support to people with long term conditions?

12. What new digital tools or resources do you think are needed to support people with long term conditions?

13. How do you think long term conditions can be detected earlier more easily?

14. What barriers do people face making healthy decisions in preventing or slowing the progress of long-term condition(s)?

The resolve to maintain best-method, self-management for stroke patients with or without other long-term conditions can be challenging.

Social determinants of health leading to inequities of income, education, employment, housing, limited access to primary care, healthy food, and social support systems all lead to poorer lifestyle choices in preventing or slowing the progress of long-term conditions.

The commercial determinants of health is an important factor here too. Big business thrives on proffering unhealthy choices. It's understandably just easier sometimes to just say 'yes'.

www.bhf.org.uk/scotland/ncd-prevention-a-commercial-determinants-of-health-approach-2024-report.pdf

15. Is there anything currently working well within your community to prevent or slow progression of long-term conditions?

16. How can the Scottish Government involve communities in preventing or slowing the progress of long-term conditions?

17. Are there additional important considerations for people with long term conditions? For example people who; live in deprived areas and rural and/or island areas, have protected characteristics e.g. race, disability, who are in inclusion health groups e.g. homelessness, or who experience stigma due to perceptions of their long term condition e.g. people with dementia?

Early provision of stroke-specific rehab and wrap around care, thereafter, is a recurrent theme across the board - and a major problem for stroke patients in rural and island communities.

18. Given that racism and discrimination are key drivers of inequalities, what specific actions are necessary to address racism and discrimination in healthcare?

19. Is there anything else you would like to raise that was not covered elsewhere in the consultation paper?

One reflective point.

We were grateful to Scottish Government officials for an invitation to attend an online Third Sector engagement event on 20 November. We assumed the event was to float a proposed potential move towards amalgamation of long-term conditions, to canvass opinion from ourselves and other third sector representatives and to gather views as to how different thematic areas might be affected.

Instead of which, the move was presented as effectively done and dusted. Comments were sought to questions around challenges to service users in accessing services (as per the questions in this consultation) rather than first principles such as: 'What does your organisation think of a proposed move to a long-term conditions strategy?' or 'Do you think such a move would benefit patient outcomes?' We were left none the wiser as to what the proposed benefits of this move are.

The process up to this consultation has not been handled well. We remain unclear on some very basic points.

ENDS