Findings from the Pre-consultation on Re-shaping Stroke Services and Next Steps

Re-Shaping Stroke Services

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This document summarises the findings of the pre-consultation engagement activities undertaken during the summer of 2017 in relation to seven proposals for improving stroke services in Northern Ireland.
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SECTION 1: INTRODUCTION AND BACKGROUND

Background

On the 23rd of June 2017 Health and Social Care engaged in a pre-consultation with the general public and a range of specific stakeholders on seven proposals to Reshape Stroke Services in Northern Ireland. This project is one part of the transformation work being undertaken in implementing ‘Health and Wellbeing 2026: Delivering Together’ policy¹.

The seven proposals were developed through the Northern Ireland Stroke Network, which consists of voluntary sector support groups, stroke survivors, clinical staff, Trust service managers, the Health and Social Care Board, the Department of Health and the Public Health Agency.

The seven proposals are:-

1. To provide seven day assessment for patients at an appropriate number of Stroke Units for patients experiencing a suspected TIA.
2. To provide assessment for clot busting treatment ‘thrombolysis’ on an appropriate number of sites.
3. To provide a clot removal service ‘mechanical thrombectomy’ 24 hours a day and seven days a week for suitable patients.

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4. To provide an appropriate number of Hyperacute Stroke Units to deliver specialist early inpatient care to every stroke patient.

5. To establish an appropriate number of Acute Stroke Units, co-located with Hyperacute Stroke Units whenever possible.

6. To provide community stroke services that are resourced to deliver Early Supported Discharge, the recommended amounts of therapy and respond over seven days.

7. To ensure that stroke survivors and carers have timely access to services from both Health and Social Care and Voluntary Sector organisations to optimise recovery.

These proposals were developed in response to the growing evidence of variation in the standards of care delivered to stroke patients throughout Northern Ireland\(^2\), and informed by the 2014 inspection report from the Regulatory Quality and Improvement Authority (RQIA). A review of all the evidence and comparison of local service provision with the required care standards concluded that the organisation of care is sub optimal\(^3\) and that there is now an urgent need to implement a new system of care that is focused on optimising the level of recovery experienced by survivors of stroke.

A “Re-shaping Stroke Task and Finish Group” (the Task & Finish Group) was set up consisting of key stakeholders with four main tasks:-

(i) to deliver the pre-consultation and evaluate the responses;

\(^2\) SNNAP Audit 16/17 Annual Report
https://www.strokeaudit.org/results/Clinical-audit/Regional-Results.aspx

\(^3\) RQIA Stroke services Inspection report - https://www.rqia.org.uk/RQIA/files/b8/b8f067de-3bf7-40c6-9297-b21a41a31811.pdf
(ii) co-design new recommendations on a model for provision of stroke care which is fit for the current and future needs of the people of Northern Ireland;

(iii) undertake a formal consultation on the new model; and,

(iv) Submit the model and responses to the Department of Health for final decision.

This document reports on implementation of the first of these tasks.

What Did We Do?

The Task and Finish Group developed and implemented a comprehensive pre-consultation engagement strategy which included the following key activities. A full list of the schedule of events is detailed in Appendix 4

Key activities:-

- Six public meetings at Local Commissioning Groups within each Trust area in Northern Ireland;
- Five stroke survivor events organised by Northern Ireland Chest Heart and Stroke; and,
- Six public meetings geographically spread across the region
- Seven workshops with Health and Social Care staff.
- Attendance at three local council meetings; and,

A political stake-holders event.

Products:-

- An easy read consultation document, leaflet, an infographic and an animation, FAQs, and press releases;
- Stroke survivor story videos and press articles;
- Platform pieces by eminent experts;
- Creation of a website and an online survey; and,
- An exhaustive communication strategy including the use of social media platforms.

**SECTION 2: OVERVIEW OF RESPONSES**

**Who responded to the online questionnaire?**

Table 1: Breakdown of responses to postal and on-line questionnaire responses

<table>
<thead>
<tr>
<th>Total Number of Surveys returned online/post</th>
<th>Number of responses from MLAs and Local Councils</th>
<th>Number of Organisations responded</th>
<th>Number of Individuals Emails/letters</th>
</tr>
</thead>
<tbody>
<tr>
<td>789</td>
<td>13</td>
<td>60</td>
<td>49</td>
</tr>
</tbody>
</table>

A further 2909 responses were received from groups in Fermanagh which had been pre-completed with a set of prescribed responses.
Figure 1 illustrates the volume of responses received from various counties across Northern Ireland.

**Figure 1: Where did responses come from?**
QUESTION 1

Do you agree with proposal one?

Provide seven day assessment for patients at an appropriate number of Stroke Units for patients experiencing a suspected TIA.

**Figure 2: Question one responses**

<table>
<thead>
<tr>
<th>Agree</th>
<th>Disagree</th>
<th>Neither</th>
</tr>
</thead>
<tbody>
<tr>
<td>298</td>
<td>419</td>
<td>72</td>
</tr>
</tbody>
</table>

Those agreeing with question one made comments recognising:-

- The importance of prompt treatment within 24 hours by specialists as a vital opportunity to prevent a more serious stroke related event.

**Issues raised by those who disagreed**

- The additional travel time required to access a smaller number of Stroke Units may reduce the likelihood of some people attending an outpatient appointment.
- The recommendation that people should not drive after a transient ischaemic attack and therefore the choice of location of services was a key concern related to clinical outcome.
Some people felt the evidence for early treatment after a transient ischaemic attack was not as strong as for other parts of the Stroke Pathway and therefore this recommendation should not be given the same priority for implementation.

QUESTION 2

Do you agree with proposal two?

Provide assessment for clot busting treatment ‘thrombolysis’ on an appropriate number of sites.

Figure 3: Question two responses

Those agreeing with question 2 made comments recognising:

- Current variation in care and suboptimal provision of thrombolysis services in some locations.
- The challenges in maintaining the required workforce and service supports including investigations in multiple locations.

Issues raised by those who disagreed
• Concern that additional travel time might incur harm for some people.
• The need for more detail on location of service to respond from an informed position.
• Fear that services would be removed from their local hospital.
• Some respondents reported they were not convinced by the presentation of the evidence base and how this was translated into an assessment of need across the mixed rural and urban geography of Northern Ireland.

QUESTION 3

Do you agree with proposal three?

Provide a clot removal service ‘mechanical thrombectomy’ 24 hours a day and seven days a week for suitable patients.

Figure 4: Question three responses

Those agreeing with question 3 made comments recognising:-
• The opportunity to prevent stroke related disability presented by the clot removal procedure and the benefits associated with implementing this service on a 24/7 basis.

Issues raised by those who disagreed:-

• All 24/7 services should be offered locally not centralised in the Royal Victoria Hospital.

QUESTION 4

Do you agree with proposal four?

Provide an appropriate number of Hyperacute Stroke Units to deliver specialist early inpatient care to every stroke patient.

Figure 5: Question four responses

Those who agreed made comments recognising:-

• The challenge faced by the health services when providing specialist multidisciplinary stroke services on many sites and the increasingly specialist nature of stroke care, the importance of
early correct diagnosis and the need to safeguard the sustainability of services for the long term

Issues raised by those who disagreed

- Maintenance of all services within their local hospital,
- Healthcare provision for the rural communities,
- The effect of increases travel time particularly given the time critical nature of early stroke treatments.
- Ambulance response time was also noted to be an area of frequent concern.

QUESTION 5

Do you agree with proposal 5?

Establish an appropriate number of Acute Stroke Units, co-located with Hyperacute Stroke Units whenever possible.

Figure 6: Question five responses
Those agreeing with question 5 made comments recognising:-

- The importance of being cared for by a comprehensive specialist multidisciplinary team.
- The potential to reduce the number of inter-hospital transfers, and thus, potential pressures on the ambulance service.
- That these units should be accessible to people across the region of Northern Ireland.

Issues raised by those who disagreed

- Local services for stroke recovery would enable more involvement of the family and carers for recovery.
- Services should be maintained within local hospitals.
- The importance of accessibility of services, travel times and road infrastructure issues.

**QUESTION 6**

Do you agree with proposal six?

Provide community stroke services that are resourced to deliver Early Supported Discharge, the recommended amounts of therapy and response over seven days.
Figure 7: Question six responses

Those agreeing with question six made comments highlighting:

Community stroke services were highly valued by stroke survivors and carers. Health services should be available seven days a week and should be available on an equal basis across the region. This should include access to the full range of professional service required including physiological services

Issues raised by those who disagreed

- Care packages are not always available to support people after an early discharge.
- Concern that stroke survivors may be discharged before they are ready.
- Services may not be required to be available seven days a week.
QUESTION 7

Do you agree with proposal 7?

Ensure that stroke survivors and carers have timely access to services from both Health and Social Care and voluntary sector organisations to optimise recovery.

Figure 8: Question seven responses

Those agreeing with question made comments of support recognising:

- These services are highly valued by stroke survivors, family members, carers and the wider community.
- They are important for bridging the gaps in HSC Trust services.
- They enable people to make a longer term recovery and adapt to life after a stroke.

Issues raised by those who disagreed

- The priority should be to protect local hospital services
- The proposal to involve voluntary sector services in this service provision would be difficult to enforce and implement.
SECTION 3: KEY THEMES

The following sections outline key themes which arose from the combination of the online submissions, stakeholder meetings, letters and email correspondence.

Rural Needs

People in rural communities had particular concerns about the potential impact of changing the locations of hospital stroke services.

These concerns related mainly to road networks and infrastructure, travel times to alternative locations and how this could affect stroke recovery and the potential local economic impact of removing local services. There was a concern that rural communities would be particularly impacted negatively by these proposals.

Response

A rural needs impact assessment will be completed to demonstrate the range and extent of impacts to rural communities and how these impacts can be mitigated.

Carers and Stroke Survivors

Many of the responses contained testimonials of the experiences of those caring for people after a stroke or people who had experience of stroke in the wider family. They supported the case for services that support people in life after stroke and particularly recognised that family members and carers had particular needs at this stage. The important role of family members and support networks during the hospital recovery and after discharge was highlighted. There was some concern
as to whether greater travel distances might detract from the amount of support family members and carers could offer during recovery.

Response

It is recognised that carers and family members make an important contribution to a person’s recovery after stroke and that impacts in relation to this will need to be considered. Further consideration will also be given to improving the provision of long term support.

Ambulance Response

People reported their concerns that ambulance services were not meeting response time standards, particularly in rural communities. There was some concern that the implementation of these proposals would put further pressure on already stretched ambulance resources and would require significant investment in ambulance services to implement.

Response

The development of proposals for the location of services will take account of ambulance response times and identify any investment required to enable the ambulance service to provide a safe and effective service for stroke patients that is timely and reliable.

Workforce Supply

Many individuals and, in particular, professional bodies highlighted the challenges that currently exist in supplying the numbers of health care staff needed. It was highlighted that implementing these proposals would require additional staff especially specialist disciplines and that the availability of these skilled people may limit what can be achieved.
Response

Work is ongoing with advisers to ensure the workforce challenges are fully understood and steps taken to ensure that proposals for the future configuration of services can be fully implemented, cognisant of the workforce supply issues.

Resources

Many responses highlighted that some of the underperformance in the existing system could be attributed to the level of resources that services have received in recent years and that additional investment may be needed in future. They were concerned that the extent and source of this funding was not detailed.

Response

The current performance of stroke services is in part related to the limitations in financial resources available but its efficiency could also be improved through re-configuration. Proposed changes to the system of care will be fully costed.

Impact of Increased Journey Times

A frequent concern expressed was with the provision of some services on fewer sites, which could lead to poor outcomes where there was a delay in receiving time-critical treatments. It was also felt this may be difficult, in particular, for older people or people with pre-existing disabilities and mobility issues. It was posited that this could also create a further pressure on already stretched ambulance service resources.
Response

Maximising the numbers of people who have a good recovery and survived a stroke without disability is the key driver for designing the future model of Hospitals Service Provision for Stroke. In some instances, traveling further for specialist treatment will provide more rapid assessment, treatment or intervention than would be the case if they went first to their local hospital. In other instances, the distances to an alternative may be so great that the person would have a better opportunity for recovery if assessed first at the local hospital and offered first-line treatment there. Detailed analysis will be undertaken to ensure that any proposals will maximise the numbers experiencing a good recovery after stroke.

Loss of Local Services

Many people voiced concern that implementing these proposals may undermine the sustainability of their local hospital.

Response

The focus of the proposals is on improving outcomes for those who suffer a stroke. Assessment of the sustainability of services in any particular location against a defined set of criteria is outside the scope of this review.
Evidence Base

Some respondents felt that the supporting evidence was not specific enough to the Northern Ireland health system and were concerned about the relevance of learning from other regions with differing population demographics and geography. In particular people did not understand the basis of the NHS recommendation for a minimum volume of 600 cases per year for a Hyperacute Stroke Unit and how Northern Ireland could learn from the London and Manchester reconfigurations.

Response

The NHS ‘Stroke Reconfiguration Decision Support Guide’\(^4\) recognise that reliance on smaller stroke units makes it more difficult to operate safe and sustainable rotas of staff on a 24/7 basis. This underpins the recommendation for a minimum volume of 600 admissions per year.

Learning has been sought and continues to be sought from varied healthcare systems nationally and internationally. The London and Manchester reconfiguration publication demonstrated beyond doubt that specialist Hyperacute Stroke Unit care for every stroke patient saved lives, reduced disability and saves money. This publication also demonstrated the benefits centralisation used in urban areas. Many other reconfiguration projects have been undertaken across varied regions in England, including those with remoter rural areas, and all of these have provided valuable learning.

\(^4\) NHS Stroke Reconfiguration Decision Support Guide

Hospital Performance

In cases where the local hospital performance in the National Audit was excellent, people did not understand why there was a need to change the design of services.

Response

Work is ongoing to design a model that optimises the recovery for patients with stroke across the entire region and acknowledges that there is much variation in performance. Audit data demonstrates a trend for larger hospitals to perform more thrombolysis more quickly and we recognise that in some cases a small number of smaller hospitals are providing excellent stroke care. However, all people in our region require access to required investigations, the full range of range of specialist treatments and, access to appropriately staffed stroke units stroke care irrespective of where they live.

Prevention

Responses from several organisations highlighted the great opportunities that exist to reduce the burden associated with stroke through enhanced stroke prevention, in particular, in the diagnosis and treatment of Atrial Fibrillation.

Response

It is recognised that optimising treatment and diagnosis for those with Atrial Fibrillation can make an important contribution to preventing stroke and reducing the burden of stroke in our communities and that GPs play an important role in identifying patients with this condition.
Rehabilitation

Many people described the importance of sufficient amounts and periods of rehabilitation. It was felt there was a lack of psychological support and vocational rehabilitation. Many people provided experiences of difficulties accessing rehabilitation after the acute phase. Staff groups in particular wanted a clear pathway of care for those with complex rehabilitation needs not suitable for the early support discharge programme.

Response

Further investment in rehabilitation is required to ensure that all patients who have had a stroke have the best possible outcome. Improvements in emergency intervention will also reduce the number of people experiencing significant complex disability.

Long Term Support

Many respondents provided details of the benefits received from voluntary sector groups that support people in life after stroke. In some cases, people felt they would benefit from clearer communication between agencies and help to navigate the broad range of services on offer.

Response

Further work is being undertaken in conjunction with voluntary organisations to quantify the needs of stroke survivors during this phase and how best to co-ordinate working with voluntary sector agencies.
Cross Border Co-operation

At both the public meetings and at meetings with local Councils, stakeholders were keen that the Task and Finish Group evaluate fully the potential for co-operation with the Republic of Ireland health system in provision of emergency stroke care. In particular, it was highlighted that this was important in considering the sustainability of Stroke Units close to border regions.

Response

Contact has been made with Health Authorities in the Republic of Ireland and conversations will be continued to explore this issue to the full.

Figure 9, illustrates how frequently these various themes arose within the pre-consultation responses.

Figure 9: Frequency of themes arising within responses

![Pie chart showing frequency of themes]

- Wording of Questions
- Voluntary Role
- Resources
- Retaining Local Services
- Long term support
- Rurality
- Travel Time
- Rehabilitation
- Workforce
- Early Diagnosis
- Carer/Families
- Local Performance
- Evidence
- Other
SECTION 4: CONCLUSIONS AND NEXT STEPS

A very comprehensive programme was delivered that fully achieved the objective of engaging with the identified stakeholder groups and the general public. The findings of this process will inform the ongoing work to design future recommendations, including options for hospital stroke services. It is clear that many people who responded remain to be persuaded of the benefits of reorganising stroke services. Learning and specific evaluations of this process will be considered in designing all future communications and engagement strategies relating to the Reshaping of Stroke Services.

The findings from the Pre-Consultation will be considered by the Transformation Implementation Group and fully taken into account in the development of proposals for formal consultation in 2018.