The Regulation and Quality Improvement Authority

Review of Stroke Services in Northern Ireland

December 2014

Assurance, Challenge and Improvement in Health and Social Care

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The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for regulating and inspecting the quality and availability of health and social care (HSC) services in Northern Ireland. RQIAs reviews aim to identify best practice, to highlight gaps or shortfalls in services requiring improvement and to protect the public interest. Our reviews are carried out by teams of independent assessors, who are either experienced practitioners or experts by experience. Our reports are submitted to the Minister for Health, Social Services and Public Safety, and are available on the RQIA website at www.rqia.org.uk.

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Executive Summary

Stroke can strike anyone, at any age and at any time. In Northern Ireland, approximately two per cent of the population are living with the symptoms of stroke or transient ischaemic attack (TIA).

The Public Health Agency (PHA) ran FAST public information campaigns to raise awareness of stroke signs and symptoms, and what action should be taken if you think someone is having a stroke. Despite a number of campaigns, the review indicated that public awareness in recognising the signs and symptoms of stroke, and knowing what to do, was relatively low. Discussions with stroke survivors revealed a similar finding, that many people did not seek urgent medical attention at the first sign of stroke or TIA.

Since 2008, the Regional Stroke Strategy Implementation Group (RSSIG) has taken forward the implementation of the Northern Ireland stroke strategy with the HSC trusts. While much progress has been achieved, the full implementation of a number of the recommendations from the strategy has not yet been achieved.

The review identified some regional protocols for service delivery is in place. However, the service could benefit from a greater regional approach and the development of a managed clinical network. At the time of the review, the recruitment of service improvement leads in each trust area, offers an opportunity for further progress in this area.

The stroke teams across the trusts were found to be committed and enthusiastic. They are delivering care based on a multidisciplinary approach, demonstrating a genuine sense of teamwork and willingness to provide high quality stroke care.

On arrival at hospital, stroke patients were usually seen quickly, receiving necessary scans. Thrombolytic therapy was available across Northern Ireland. While a regional telephone advice service for thrombolytic therapy has been put in place, it was not being fully utilised in practice at the time of the review.

While most patients were transferred to stroke wards, some were initially transferred to other wards due to bed capacity pressures. In cases where stroke patients were in outlying wards, their level of stroke care and rehabilitation was sometimes not as comprehensive as in a stroke unit.

Rehabilitation was available in all trusts and began as soon as the patient was medically fit. Speech and language, occupational therapy (OT) and physiotherapy were the three main therapies provided, although limited access to psychology and dietetic services were also available in some trusts.

Inequality in access to services was evident in all trusts, between the in-hours and out-of-hours periods. This related to access to imaging, interpretation and reporting of images taken, thrombolytic therapy, TIA clinics and AHP therapies.

The interpretation of early supported discharge (ESD), with the focus on shorter hospital stays, and the provision of this service varied across all trusts. Agreement on a defined model of care associated with discharge planning was required, and development of the ESD and community stroke teams was necessary.

Communication with patients in terms of their condition, treatment and support, as well as the information that is given to them, needs to be improved. This is an area that could benefit from a regional approach.

There was evidence of limited engagement and communication between secondary and primary care. For improved patient outcomes, this is an area that needs to be reviewed and developed.

Specific stroke training, including a competency and skills framework, is now available, but needs to be fully rolled out to all stroke staff. More development is required in relation to stroke training for staff in other parts of the hospitals.

A lot of stroke information was being gathered by trusts; however, the extent of this varied across trusts. Despite the availability of a stroke information management system, there was insufficient data recording using this system. In the absence of accurate information it is difficult to identify areas for service improvements. Trusts should actively record patient data and utilise it to improve services.

RQIA has made twenty two recommendations for improvement in stroke services through the work of this review.

Section 1 – Introduction

1.1 Context for the Review

Having a stroke can be devastating, not just for the person affected, but for family members as well. Stroke can strike anyone, at any age and at any time. A stroke happens when the blood supply to part of the brain is cut off and brain cells are damaged or die. Strokes affect people in different ways, depending on the part of the brain that is affected, how widespread the damage is and how healthy the person was before the stroke. A stroke can damage bodily functions, our thought processes, our ability to learn, and how we feel and communicate.

As part of the review of healthcare in Northern Ireland associated with Transforming Your Care (TYC), the Department of Health, Social Services and Public Safety (DHSSPS) estimated that around 3,000[1] people each year have their lives changed as a result of a stroke. Of those affected, around one third will make a full recovery, one third will die within the first month and one third will have substantial disability, and to varying extents, be left dependent on others for help with everyday activities for the rest of their lives[2].

An early indicator of a stroke is a transient ischaemic attack (TIA). Approximately one in four people who have a stroke report symptoms of a TIA in the week leading up to the stroke. A TIA is often called a 'mini-stroke' and occurs when the blood supply to the brain is interrupted for a short period of time. The symptoms are very similar to stroke, but are temporary, lasting in some cases only a few minutes and always resolved within 24 hours. DHSSPS further estimates that around 1,700[3] people in Northern Ireland suffer a TIA each year.

A range of risk factors linked to health or lifestyle are associated with stroke. Health risk factors include problems such as atrial fibrillation, high blood pressure or high blood cholesterol; while lifestyle risk factors include smoking, obesity or lack of exercise. In many cases stroke can be a preventable and treatable disease and a significant number of strokes could be avoided through simple lifestyle changes or appropriate management of the risk factors.

After the onset of stroke, administering the right treatment at the right time can increase the chances of recovery or a reduction in the damage caused by a stroke. Thrombolysis is a treatment for some types of stroke in suitable patients. Thrombolysis dissolves dangerous clots in blood vessels, improves blood flow, and helps prevent damage to tissues and organs. For most people thrombolysis needs to be given within four and a half hours of the

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[1] Transforming Your Care - http://www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf

[2] DHSSPS Stroke Strategy Consultation document (November 2007) - http://www.dhsspsni.gov.uk/stroke_strategy_consultation_document.pdf

[3] DHSSPS Stroke Strategy Consultation document (November 2007) - http://www.dhsspsni.gov.uk/stroke_strategy_consultation_document.pdf

stroke symptoms starting. The quality of rehabilitation and care provided following a stroke can also help people to regain their independence.

In November 2007, DHSSPS published the Improving Stroke Services in Northern Ireland Consultation document[4], which outlined proposals for improvements in the delivery of stroke services.

On 9 June 2008, following analysis of the consultation exercise, the Minister for Health, Social Services and Public Safety published the Northern Ireland Stroke Strategy – Improving Stroke Services in Northern Ireland[5]. The document sets out 14 recommendations and seven accompanying standards for improving all aspects of stroke care, including prevention, treatment and rehabilitation. The aim was to ensure that stroke patients, their families and carers receive a more responsive, patient focused and effective service, regardless of where they live in Northern Ireland.

The Northern Ireland stroke strategy recognised that preventing strokes from occurring in the first place, offers the best opportunity to reduce the burden of the disease afterwards.

It was recognised that achieving the outcomes would require a significant service re-organisation and re-design. The whole system, including primary, community, secondary, voluntary and independent sectors as well as other statutory bodies, needed to work collaboratively, in partnership to provide a more responsive, patient focused and effective service for stroke patients and their families.

Stroke shares common risk factors with other cardiovascular disease including coronary heart disease and peripheral vascular disease. Following the publication of the stroke strategy, DHSSPS published the Cardiovascular Service Framework in June 2009. The development of the framework was informed by the stroke strategy and the standards set out in the framework were designed to take forward the goals of the strategy.

In 2012, RQIA carried out a review of the implementation of the Cardiovascular Service Framework. The report of that review is available on the RQIA website at the following link - http://www.rqia.org.uk/cms_resources/CVF%20FINAL%20REPORT%2021.11.12%20for%20publication_ISBN.pdf

Since 2008, the Regional Stroke Strategy Implementation Group has taken forward the implementation of the recommendations and standards with HSC trusts. Although the group has been reporting progress to DHSSPS, this review will provide independent assurance on the progress of implementation of the recommendations, and an assessment of the application of the standards within stroke services.

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[4] Improving Stroke Services in Northern Ireland Consultation document - http://www.dhsspsni.gov.uk/stroke_strategy_consultation_document.pdf

[5] Improving Stroke Services in Northern Ireland http://www.dhsspsni.gov.uk/recommendations-stroke-services-in-ni.pdf

1.2 Terms of Reference

This review assessed the implementation of the recommendations and the application of the standards contained in the stroke strategy – Improving Stroke Services in Northern Ireland.

The terms of reference for this review were:

1. To review the progress of implementation of the recommendations contained in the Strategy – Improving Stroke Services in Northern Ireland.
2. To assess the stroke services provided by HSC organisations, against the standards contained in the Strategy – Improving Stroke Services in Northern Ireland.
3. To obtain the experiences of service users and their carers in relation to stroke services provided by the HSC trusts.
4. To report on the findings, identify areas of good practice and, where appropriate, make recommendations for improvements.

1.3 Exclusions

Circulars, guidance, standards, reviews and reports which were issued during the course of the review were not assessed as part of this review but may be highlighted for consideration in the future.

1.4 Review Methodology

The review methodology was designed to gather information about progress towards implementation of the recommendations and assessment of the standards contained within the stroke strategy – Improving Stroke Services in Northern Ireland. The methodology included the following steps:

1. A review of relevant literature set out the context for the review and identified appropriate lines of enquiry.

2. Questionnaires completed by the HSC Board and HSC Trusts, identified progress towards implementation of the recommendations and an assessment of the application of the standards.

3. The views of stroke survivors were a key element of this review. RQIA worked in partnership with the Stroke Association and Northern Ireland Chest Heart and Stroke to set up focus groups to obtain the views of stroke survivors in each of the trust areas. One hundred and eighteen stroke survivors and 12 carers participated in the focus groups.

4. Validation visits to the HSC Board and each of the trusts were undertaken, to meet with practitioners working within the stroke services. These

included representatives from senior management and senior leads responsible for stroke services; consultants, nurses and allied health professionals responsible for the delivery of stroke services; and administrative staff providing support for the stroke services.

5. The initial findings from the questionnaires, validation visits and focus groups were collated, and the results used to inform a stakeholder event held in May 2014. At this event, the initial findings were presented and discussed. Possible approaches to enhance stroke services were then considered. The summit event included representation from each of the trusts, the HSC Board, DHSSPS and other voluntary organisations.

6. Publication of a report, which included the findings from the review and recommendations that may assist in the development of stroke services.

Section 2 – Findings from the Review

2.1 Background to the Findings

The findings from the review are derived from the analysis of the experiences of stroke survivors, written submissions and information provided by the HSC Board and trusts, validation meetings with the practitioners and managers from the HSC Board and trusts, and feedback from the stakeholder event.

2.2 Experiences of Stroke Survivors

An integral part of the review was the views and experiences of stroke survivors who used the trusts' stroke services. To obtain their views, RQIA worked in partnership with the Stroke Association and Northern Ireland Chest Heart and Stroke. Both organisations set up a number of focus groups with stroke survivors, who engaged with RQIA to share their views and experiences.

A total of 118 stroke survivors and 12 carers engaged in the focus groups. The majority of stroke survivors attending focus groups had suffered a stroke within the previous six years, although most had suffered a stroke within the last three years. Only a small number had suffered a stroke more than six years ago, which was prior to publication of the stroke strategy. Their experiences were not used to inform the assessment of the stroke strategy, but rather used as an indicator with stroke care before the publication of the stroke strategy.

An overview of the experiences of stroke survivors is outlined below. These, and other experiences related by stroke survivors are also referenced throughout the report to underpin the findings of the review team.

The Experience of a Stroke

During focus groups, stroke survivors discussed their own personal experiences of having a stroke. The majority of people stated that at the time, they did not know they were having a stroke and did not recognise their symptoms as being a stroke. People recalled having headaches, chest pains, feeling weak or simply not feeling right. In a lot of these cases, people decided to rest, rather than seeking medical attention. As a result, their condition worsened or in severe cases they were unable to move. People who had more severe symptoms of stroke did seek medical attention, but advised they were still unaware they were having a stroke.

Overall, only a small number of people were aware that their symptoms were related to a stroke. They were able to alert others to their condition, and received medical attention.

At the time of their stroke, a number of people were not alone, and some of those with them were able to recognise the symptoms. However, there were a few that still did not recognise the person's symptoms as a stroke. The stroke survivors considered that their lack of recognition of their stroke contributed to their delay in seeking urgent medical attention and subsequently impacted adversely on their recovery.

A common experience recalled by many people, was their lack of memory of the days, and sometimes weeks, following their stroke. It was information provided later by family, friends and healthcare staff that informed them of events following their stroke.

Awareness of Stroke

Everyone was aware of the Public Health Agency's FAST[6] campaign, but advised that this was mainly because of their own personal circumstances. If they had not experienced a stroke, they felt their awareness of stroke would have been considerably less.

People considered that the FAST campaign did raise awareness of stroke and praised this. However, based on their own experiences, they considered that the public's awareness of stroke was not that high. Even with the FAST campaign, they considered that unless people have had personal experience of someone having a stroke, most people would not be confident in recognising or dealing with someone suffering a stroke.

Several people in each focus group reported that it was due to the FAST campaign, that others were able to diagnose their symptoms as being a stroke. Subsequently, this led to emergency medical attention being sought.

Many people in each focus group felt the FAST advertisement was not representative of the symptoms of their stroke. They explained this by describing their own symptoms. Only a few people considered that their symptoms were consistent with those represented in the advertisement. Some people also stated that the advertisement was a little confusing. In particular, a number thought that all symptoms had to be present before a person was having a stroke, which resulted in them not seeking medical attention.

The group highlighted that the FAST campaign indicated that stroke was more likely to affect older people and younger stroke patients were not represented. People considered there was still a lack of awareness that stroke can happen to young people. The group did however, accept that it was difficult to cover all symptoms of stroke in an advert, and trying to cover everything may cause confusion and defeat the purpose of the campaign.

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[6] The Public Health Agency (PHA) launched the FAST public information campaign on Thursday 2 June 2011 to raise awareness of stroke signs and symptoms, and what to do if you think someone is having a stroke. The F.A.S.T. campaign was designed to inform the public about F.A.S.T. – Face, Arm, Speech, and Time to call 999. - http://www.publichealth.hscni.net/news/stroke-campaign-%E2%80%93-act-fast

Getting to Hospital

Awareness of the symptoms of stroke had an impact on the way stroke sufferers travelled to hospital. While most people were taken to hospital by ambulance, there were many that were driven there by family or friends. In several cases, the person having the stroke advised of driving themselves to hospital or to the general practitioner (GP). For patients taken to hospital by ambulance, of those that knew they were having a stroke, several advised that staff in the Emergency Department were waiting for them. They stated the ambulance team had called ahead to advise of their arrival.

Hospital Treatment

Everyone stated they went to the Emergency Department on arrival at hospital. None were admitted directly to the stroke unit. In most cases, people advised of being processed through the Emergency Department quickly; however, these tended to be people who presented with identifiable symptoms of stroke. Others without such symptoms stated they had to wait for several hours in the Emergency Department, as they had not been identified as a medical emergency.

In each of the focus groups, there was at least one person present who had not been diagnosed as having a stroke, or was diagnosed with another condition. These people advised of being discharged or admitted to a general medical ward for further investigation. Several people also discussed their initial assessment in the Emergency Department as not leading to a diagnosis of their stroke and it was not until further tests were taken that their condition was correctly identified.

With the exception of those people who were not initially diagnosed, everyone stated they had received either a computerised tomography (CT) scan, magnetic resonance imaging (MRI) scan, or both during their assessment. For those people with identifiable symptoms of stroke, they received a scan relatively quickly after arrival. In one instance, a participant reported that they were transferred between hospitals as there was no MRI scanner available.

Several people received thrombolysis[7] in the Emergency Department. However, many people believed their inability to identify their symptoms and their delayed presentation at hospital, resulted in them being unable to receive thrombolysis.

Again, with the exception of those people who were not initially diagnosed, everyone was admitted to the stroke ward at some stage during their stay in hospital. Some people stated they were admitted to another ward first, as a bed was not available, but they were transferred later. Some people stated they were discharged, as their stroke was not severe enough to be admitted.

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[7] Thrombolysis is the breakdown of blood clots by pharmacological means, and commonly called clot busting.

While on the stroke ward, most people received multi-disciplinary assessments. People stated they received speech and language, physiotherapy, and occupational therapy assessments. No-one could recall any other type of assessment. Following these assessments, people received varying degrees of speech and language therapy, physiotherapy, and occupational therapy. Some people stated they received treatment every day, while others advised they received it less frequently.

In several cases, people received only one or two therapy sessions during their entire stay. In every group, many people stated that there was a lack of available therapy at weekends and on bank holidays, and felt that this was not acceptable as it impacted adversely on their rehabilitation. Some people stated their relatives had to constantly push to ensure they received adequate therapy while in hospital.

In relation to some of the therapy sessions, in particular physiotherapy, several people stated that it was beneficial for both the patient and carer to be present. A number reported that this was allowed in some trusts, but not in others. Carers stated this was important, as this experience made them more confident in assisting after discharge.

Overall, people were complimentary about the care they received while on the stroke ward. However, they stated that the wards were very busy and staff were often stretched.

Discharge

People expressed differing experiences in relation to their discharge from hospital. People spoke of their appreciation for the role of specialist stroke nurses in all trusts, who many people met prior to discharge. Those patients who had more complex discharge needs, stated they had been involved in several discharge planning meetings and sometimes a staggered discharge was utilised. However, most people advised that they had not been involved in any discharge planning meetings, though some stated they had discussed discharge with the physiotherapist and occupational therapist. Some people advised they did not have any meetings or discussions prior to discharge.

Many people required modifications to their home, and care packages to be put in place before they could return home. While many people remained in hospital until these requirements were put in place, a similar number were discharged without them in place. Many people advised that the proposed modifications were still not put in place several months later.

Support at Home

All focus group attendees advised of input and support following discharge, whether from the community stroke team, physiotherapists, occupational therapists, or social workers. However, the level of input and support varied considerably. Everyone advised that the therapy they received was extremely beneficial to their rehabilitation and recovery.

People continued to be provided with speech and language, physiotherapy and occupational therapy at home. However, the intensity was reduced in comparison to what they received in hospital. Many people only received therapy once or twice a week. Several people stated that they did not always receive the full time they were allocated, and felt that some therapists merely demonstrated the exercises and left it to family members to practice with the patient. They felt this should not be left to family members.

People expressed concern at the total length of time allocated for therapy. Most people stated they only received several weeks of therapy, which would cut off after a maximum of 12 weeks. This was common to all focus groups. Everyone stated this was unacceptable, particularly for younger patients of working age who have more complex rehabilitation needs. People stated they did not understand why a 12 week cut-off existed, and wanted to know who made this decision and on what basis.

People in all focus groups felt they should have received more therapy in order to enhance their rehabilitation and recovery. Many people had to purchase private physiotherapy to continue their rehabilitation. Only a small number had been offered additional therapy after the 12 week period, either through the trust or their GP.

None of the focus group participants received other support, such as counselling or vocational training. Only one person received psychological support arranged through their GP. The majority of people stated that psychological support and counselling would have been beneficial to them and several were not aware that a clinical psychology service should be available.

Many people stated that family members would have also benefited from counselling, in relation to coming to terms with living with and providing support for a stroke survivor. Aphasia survivors stated this was particularly relevant for them, because outwardly, it looked like they were well and families often didn't understand their new disability.

Information

Focus group participants noted the information they received. Everyone advised they were given information at some stage during their stay in hospital, on discharge or at home. However, the amount of information and when it was provided varied. People were given leaflets, booklets and information sheets about stroke, as well as being spoken to about their condition during their time in hospital. Some people felt there was too much information in the leaflets, while others found them useful. The majority of people stated they were somewhat overwhelmed by too much information, given in the initial stages at hospital.

People received further information at the time of discharge and at home, some of which was provided by the Stroke Association and Northern Ireland

Chest Heart and Stroke. Some people stated they could have been given better information on leaving hospital, such as, advice on when to go and see their GP. None of the focus group participants received discharge letters, treatment of care plans, or risk management plans.

In all focus groups, the majority of people stated that information and support for their family was lacking, and advised this was extremely important.

The information that people received was generally limited to the different types and conditions of stroke. Many people considered they should have been given more information on available alternative therapies, and where these services are available.

Many focus group participants were of working age and they stated there was not enough information provided in relation to returning to work and employment. The majority of people would have liked more information on finances and entitlement to benefits.

Voluntary Organisations

All focus group participants were thankful for the work carried out by both the Stroke Association and Northern Ireland Chest Heart and Stroke. They advised they could not have coped if it had not been for the support provided by these organisations. Support groups provided by both organisations were extremely important, as they enabled stroke survivors to meet others going through the same problems. People felt that there should be more linkage between the trusts and voluntary sector.

2.3 Public Awareness of Stroke

In June 2011, the Public Health Agency (PHA) ran an advertising campaign, to raise public awareness about the recognition of the early signs and symptoms of TIA and stroke. The FAST campaign included television, radio and print advertising, such as, leaflets and wallet cards. This was a direct response to Recommendation 1 from the stroke strategy. A subsequent campaign was run in 2013.

Following the second FAST campaign, the PHA undertook an evaluation survey to determine its effectiveness. The results of the evaluation highlighted that 71% of participants had been aware of the FAST advertising campaign and could recall it. However, of the respondents who indicated that they had seen advertisements relating to stroke, only 36.2% were aware of the FAST acronym. The review team considered this was consistent with the comments made by stroke survivors, in relation to their perception of the public's awareness of stroke.

Some of the successes achieved as a result of the FAST campaign were:

- The evaluation highlighted that considerably more people were able to recall the FAST campaign than any other health advertising campaign.

- An ambulance service survey identified an average 30% increase in stroke 999 calls across all trusts.
- The timing of the FAST campaign was coordinated alongside the introduction of thrombolysis across Northern Ireland, and contributed to the increase in thrombolytic therapy rates.

Public awareness following advertising campaigns inevitably declines over time. DHSSPS protocols in relation to health promotion campaigns and the number of other health promotion campaigns being run will present a challenge in maintaining public awareness of stroke and increasing stroke prevention. The PHA and those involved in stroke care will have to consider the most suitable strategy for maintaining or increasing awareness of stroke during future campaigns. The review team would recommend that stroke survivors are engaged with during development of future awareness campaigns.

Recommendation 1
HSC organisations should consider engaging with stroke survivors during the development of future awareness campaigns.

2.4 Organisation of Stroke Services

Stroke is a medical emergency, and early treatment can lead to improved outcomes for patients, and, potentially lower long term costs of care. Although the profile of stroke services is increasing, the review team found that the perception of stroke services did not always reflect the important role it had in patient care. However, this varied across trusts.

In the Belfast Health and Social Care Trust (Belfast Trust), Western Health and Social Care Trust (Western Trust) and the Southern Health and Social Care Trust (Southern Trust), stroke services were seen as a separate entity and not just part of another clinical specialty. In the Western Trust, stroke services fall within the remit of the Primary Care and Older People's Directorates. In the Northern Health and Social Care Trust (Northern Trust) staff indicated that stroke services were beginning to be viewed as a specialist entity. In the South Eastern Health and Social Care Trust (South Eastern Trust), stroke services were a part of the directorate for primary care, elderly and nursing, rather than in an acute medical directorate. Staff were aware of the need for a defined stroke structure and this was noted as being under review. The review team considers that stroke services need to be identified as specialist entities within trusts, to reflect the clinical importance of the service.

The stroke strategy envisaged that patients with symptoms of a stroke or TIA would have access to specialist stroke services, from acute hospital care through to long term community support. Although the trusts were working to deliver services in line with the standards, it was evident that factors such as the geography of trusts, patient numbers, resources and lack of recorded data would prohibit the full achievement of certain aspects of the standards.

RSSIG has been instrumental in launching the stroke strategy and continuing to drive changes within stroke services. The integration and delivery of stroke services, through a regional managed approach, (Recommendation 12), was being taken forward by all trusts through their involvement in the RSSIG.

Regional protocols have been agreed for local management of thrombolysis, TIA assessment, inpatient stroke management plans, discharge planning and community follow up. Some trusts had developed these protocols further, locally. However, information obtained during the review indicated that full implementation of these protocols had not yet been achieved in all trusts.

While much progress had been achieved through the RSSIG, it was generally recognised that this group could not continue indefinitely, as the driver for improving stroke services. Staff across the trusts suggested a regionally managed clinical network[8] to implement improvements in stroke care, share areas of good practice and implement National Institute for Health and Care Excellence (NICE) guidelines and technology appraisals. The review team agreed this was an opportunity for improvement, but acknowledged it presented a challenge when transitioning responsibilities from RSSIG to any new managed clinical network.

The review team was informed that recruitment was underway to establish a service improvement post in each trust, along with a regional coordinator. These roles would include responsibility for implementing regional service improvement initiatives. The review team considered this had the potential to form the basis of a regionally managed clinical network and should be explored further by RSSIG. There was broad support from staff across most trusts for a managed clinical network and the regional management of some aspects of stroke care.

Since the publication of the stroke strategy, further improvements to stroke care have been identified. The review team considered that further improvements to stroke care in Northern Ireland may be achieved, by identifying additional services that would benefit from coordination at a regional or cross trust level. These included:

- telemedicine for thrombolysis
- services for post-stroke spasticity
- agreed protocol for local and regional diagnostic and interventional neuroradiology
- provision of specialist equipment
- progression of competencies and training

Although some of these areas were not included in the stroke strategy, the review team considered that HSC organisations should consider implementing them as they would improve stroke care.

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[8] Managed clinical networks represent a way of working which relies on clinicians being part of a virtual organisation that actively involves patients in service design and focuses on working across boundaries between primary, secondary and tertiary care.

Recommendation 2
HSC organisations should implement additional service improvement initiatives, including telemedicine for thrombolysis, post-stroke spasticity and a protocol for local and regional diagnostic and interventional neuroradiology.

Links with Primary Care

With the unpredictable nature of stroke, the majority of stroke patients had no initial involvement with their GP. Only those patients who presented to their GP with symptoms of a stroke or TIA would have had any primary care input.

Education about the signs and symptoms of a potential stroke, in particular TIA and the need to seek medical input, may increase the number of people attending primary care services. This would reinforce the need for links between primary and secondary care in relation to accessing stroke services.

No evidence of a shared written protocol between primary and secondary care for referral to neurovascular clinics and admission to a specialist stroke unit were presented during the review. However, all trusts had local referral pathways and referenced these as the protocols used. The Northern and South Eastern trusts and the Western Health and Social Care Trust (Western Trust) specifically reference GPs in their pathways and referral documents.

From the trusts' submissions and information provided during meetings, the review team concluded that those involved in secondary care stroke services had only a limited knowledge of the arrangements for stroke care in primary care. There was lack of awareness as to whether GPs maintained a register of stroke and TIA patients.

All trusts were involved with their local Integrated Care Partnership[9] (ICP), which are designed to bring together voluntary agencies with primary and secondary care, to design and coordinate care services. A stroke specific ICP multidisciplinary group in each trust had been established. The review team welcomed this initiative and hoped it would strengthen the links between primary and secondary care and deliver improved referral arrangements and pathways.

Stroke unit

Stroke units are the core of all hospital based stroke services. While a variety of different types of stroke units have been developed, there is evidence that

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[9] Integrated Care Partnerships are collaborative networks of care providers, bringing together doctors, nurses, pharmacists, social workers, hospital specialists, other healthcare professionals and the voluntary and community sectors, as well as service users and carers, to design and coordinate local health and social care services.

the best results come from those which are based in a dedicated ward[10]. Such wards may provide both acute and rehabilitative care.

The review team found no evidence of a regionally agreed model for the delivery of stroke services within stroke units. While the trusts were working towards some regional approaches to stroke services, the models of care and delivery of stroke services varied both between and within trusts. The review team considered this may be related to the geography of the trusts and the patient numbers attending each hospital. It was also evident that there were differences in opinion as to the definition of a stroke unit. This also contributed to the differences in structure and delivery of some stroke services. NICE had defined a stroke unit to be a discrete area in the hospital that is staffed by a specialist stroke multidisciplinary team[11]; however, more recent guidance defines a stroke unit to be an environment in which multidisciplinary stroke teams deliver stroke care in a dedicated ward[12].

Acute stroke units were located in the major hospitals in each trust (reference Figure 1) and each site also provided thrombolytic therapy. These hospitals generally had rehabilitation units on site, and additional rehabilitation units were located in other smaller hospitals in most of the trusts (reference Figure 2).

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[10] Organised inpatient (stroke unit) care for stroke. Cochrane Database of Systematic Reviews 2013, Issue 9. Art. No.: CD000197. DOI: 10.1002/14651858.CD000197.pub3 - http://summaries.cochrane.org/CD000197/organised-inpatient-stroke-unit-care#sthash.ZiamKiCj.dpuf

[11] NICE clinical guideline 68 – Stroke: Diagnosis and initial management of acute stroke and transient ischaemic attack (TIA) – July 2008 - https://www.nice.org.uk/guidance/cg68/resources/guidance-stroke-pdf

[12] NICE clinical guideline 162 – Stroke rehabilitation: Long-term rehabilitation after stroke – June 2013 - http://www.nice.org.uk/guidance/cg162/chapter/terms-used-in-this-guideline

Figure 1 – Locations of Acute Stroke Units

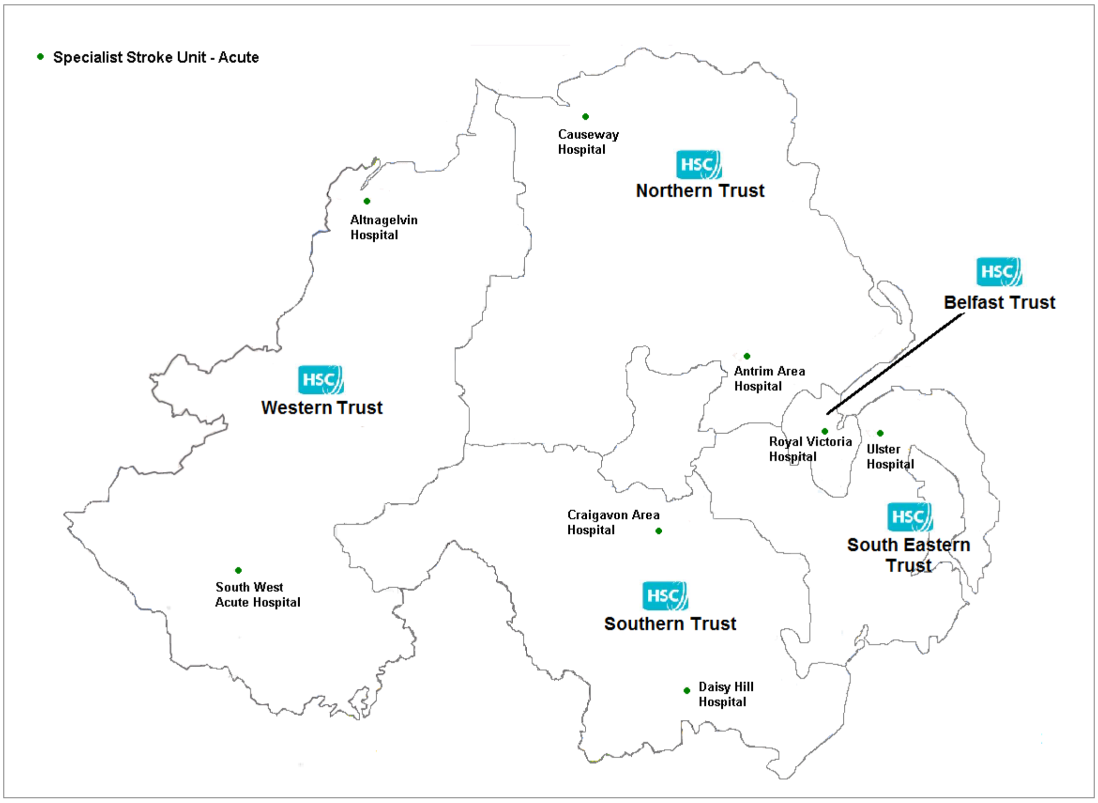
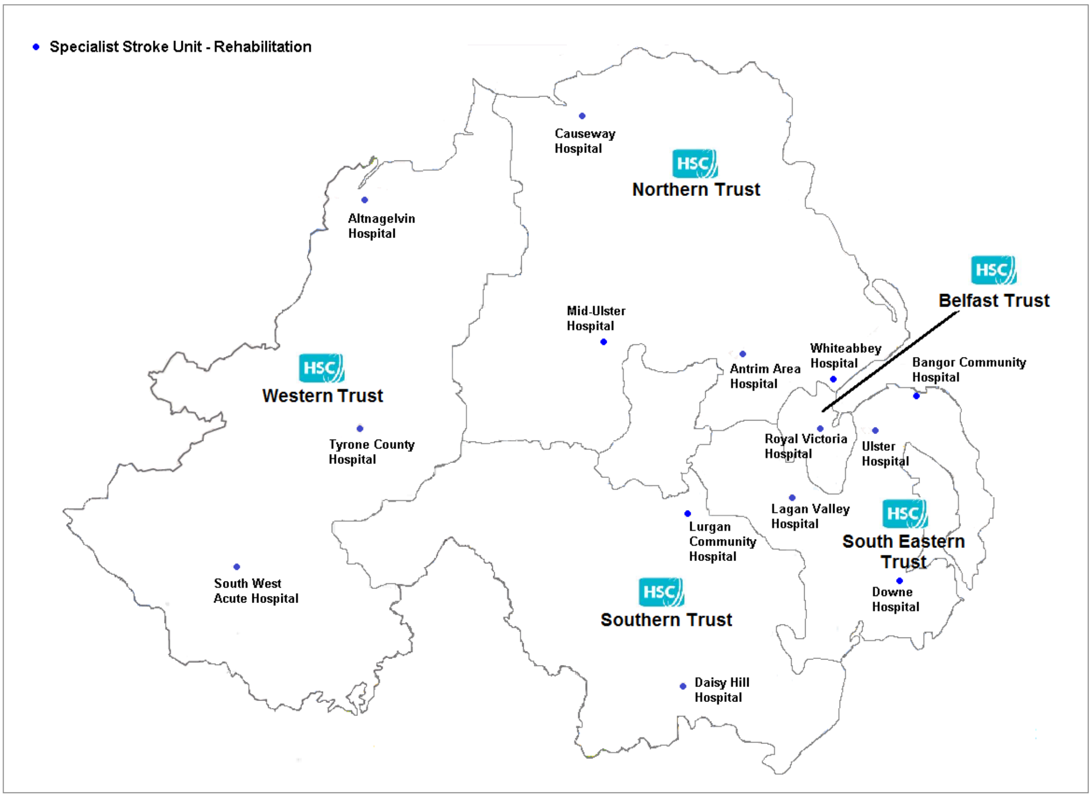


Figure 2 – Locations of Stroke Rehabilitation Units



With the exception of the Northern Trust and part of the Western Trust, the other trusts had an acute stroke unit which was based in a dedicated ward. In the Western Trust, the South West Acute Hospital had a dedicated stroke ward. In the Belfast Trust, stroke services were centralised in the Royal Victoria Hospital, which operated a comprehensive stroke unit model. Both acute and rehabilitative care was provided, with no off-site rehabilitative centres. This model was facilitated by the geography and location of the hospitals within the Belfast Trust. A similar model operated within the Ulster Hospital, where both acute and rehabilitative care was provided. In the other trusts, after the initial acute phase, patients were often transferred to rehabilitation wards in other hospitals.

The review team was conscious of the different models of care being provided across trusts and the rationale for their chosen model. However, in order to achieve better outcomes for patients, agreement needs to be reached on the definition of a stroke unit, and the possibility of developing dedicated stroke wards in line with current best practice.

Recommendation 3

The HSC Board and trusts should reach agreement on the definition of a stroke unit, based on current guidance. The agreed model should be implemented in discrete areas within the acute hospitals, in line with current NICE guidance.

The stroke strategy set the target, that by March 2012, all stroke patients are admitted directly to a specialist stroke unit (Recommendation 5). On arrival at hospital, all stroke patients are initially assessed in the Emergency Department (ED) prior to transfer to the stroke unit, or in some cases discharged.

There was universal recognition across the trusts that stroke patients should be admitted quickly to a stroke unit. However, all trusts advised that while they tried to ensure direct admission to the stroke unit, it was not always achieved. Issues such as the number of admissions, unclear symptoms, bed pressures and delayed discharges all impacted on their ability to admit stroke patients directly to the stroke unit. Subsequently, some patients were being admitted to a medical assessment unit or a medical ward. In all trusts, the stroke teams attempted to identify and repatriate stroke outliers into the stroke unit as early as possible. In the majority of cases, these patients were later transferred; however, a limited number of stroke patients reported that they did not spend any time in the stroke unit.

The pressures in relation to patient flow and competing bed capacity, made it difficult for all trusts to provide designated stroke beds in the stroke units. While it was generally possible to designate one bed for patients who had received lysis therapy, it was not uncommon for other beds to be occupied by non-stroke patients. The review team acknowledged the challenges in maintaining designated stroke beds. However, if the stroke unit is to be the ward of first admission for all stroke patients, and if an appropriate level of therapy intervention is to be provided, capacity on stroke wards needs to be created and protected.

Recommendation 4
Trusts should review their operational protocols for admission, so that more than 90% of acute stroke patients are admitted to the stroke ward as the ward of first admission.

Multidisciplinary Stroke Team

Where care is provided by nurses, doctors and therapists who specialise in caring for stroke patients, working as a co-ordinated team, improved patient outcomes are achievable. Evidence indicates that patients who receive this type of care are more likely to survive their stroke, return home and become independent[13].

The review team found that all trusts were delivering care based on a multidisciplinary approach. Multidisciplinary teams consisting of nurses, doctors and therapists, with the necessary knowledge and skills, were providing care to stroke patients. The teams were meeting at least weekly, or more frequently when required. Throughout the review, the review team came across dedicated and enthusiastic staff working in stroke services in all trusts.

The Belfast, Northern and South Eastern trusts considered their multidisciplinary teams were in line with the requirements of the National Institute for Health and Care Excellence (NICE) guidelines for stroke[14]. However, the review team noted their current provision of psychology input would not be sufficient to provide appropriate support to meet the needs of stroke patients, and considered they would not fully meet the requirements of NICE guidelines for stroke.

The Southern and Western trusts did not consider their multidisciplinary teams were in line with the requirements of NICE guidelines for stroke, as they did not have psychology input as part of stroke services. The Western Trust was planning to recruit a psychologist to the service.

The review team found that stroke teams across the trusts were committed and enthusiastic. There was a genuine sense of teamwork and willingness to provide high quality stroke care.

Staff Training and Development

All trusts provided stroke training to staff working in stroke services. Both in-house and external training was available for nurses, medical and allied health professions (AHP). Staff in all trusts used the Stroke Training and Awareness

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[13] Organised inpatient (stroke unit) care for stroke. Cochrane Database of Systematic Reviews 2013, Issue 9. Art. No.: CD000197. DOI: 10.1002/14651858.CD000197.pub3 - http://summaries.cochrane.org/CD000197/organised-inpatient-stroke-unit-care#sthash.ZiamKiCj.dpuf

[14] NICE clinical guideline 162 - Stroke rehabilitation - Long-term rehabilitation after stroke - http://www.nice.org.uk/nicemedia/live/14182/64098/64098.pdf

Resources (STARS) and the Stroke-Specific Education Framework (SSEF) to develop their core competencies in stroke care. Many staff had also completed university based training in stroke care. AHPs had access to further specific training related to their profession. The review team considered that trusts needed to ensure there was consistent access to stroke training for all nursing, medical, AHP and paramedical staff.

Staff participated in in-house training programmes and multidisciplinary education sessions specific to stroke. Stroke staff also had the opportunity to deliver training to other wards and departments across their respective hospitals. However, in some trusts these opportunities were reducing due to staffing and workload pressures.

Although stroke training was available, there was insufficient evidence presented during the review to conclude that any trust had a formal stroke education and training programme in place for staff. The Belfast and Northern trusts acknowledged this from the outset and advised they were planning to develop a formal stroke education and training programme based on the stroke competency and skills framework. It is essential that stroke units are staffed with appropriately trained nurses and AHPs in order to maintain a high level of care. The British Association of Stroke Physicians (BASP) has published guidance on training for people working in stroke services,

RSSIG had developed the stroke competency and skills framework (Recommendation 13), and in February 2014, forwarded it to the HSC organisations for implementation. Staff acknowledged the new framework; however, it still required full implementation. There were variations in the progress of its implementation across the trusts. Trusts advised that full implementation would be difficult as resources to roll out the framework were not available. The competency and skills framework should be available for all stroke staff and accompanied by appropriate information and training.

Recommendation 5
The Regional Stroke Strategy Implementation Group should receive information from trusts on the progress of the implementation of the competency and skills framework.

2.5 Acute Stroke Care and Hospital Based Rehabilitation

Rapid access to stroke services following a stroke can improve patient outcomes. Therefore, having defined protocols and pathways in place for access to hospital, assessment and treatment are crucial. All trusts submitted evidence of their stroke protocols and pathways, which were unique to each trust. Some pathways appeared to be more comprehensive than others. To achieve more consistency, the review team considered that standardised protocols and pathways across all trusts should be adopted.

Initial Hospital Assessment

On arrival at hospital, all stroke patients are initially assessed in the ED. For patients that were taken to the ED by ambulance, where their symptoms were identified as stroke, a pre-alert was provided from the ambulance. The pre-alert system was available for use in all trusts 24/7. During the in-hours period, the stroke teams in all trusts were waiting for the patient in the ED.

Only the Southern and South Eastern trusts advised that stroke staff also replied to pre-alerts during the out-of-hours period. In the Western Trust, at Altnagelvin Hospital, there are occasions when the stroke consultant is on-site and would respond; however, when they are not available the telemedicine system is used to provide advice. In the South West Acute Hospital, the consultant on-call would attend and occasionally the telemedicine system is used to provide advice. In the Belfast and Northern trusts, the stroke team response was not available during the out-of-hours period. The Belfast Trust had plans in place to move to a 24/7 stroke team response to pre-alerts.

It was reported to the review team that some ED staff were reluctant to get fully involved in the care of stroke patients, and would generally leave things to the stroke nurses. It was not confirmed whether this was due to their level of training and competency in stroke care, or a lack of time available to dedicate to their care. Generally this was not an issue for the stroke team; however, in the cases where the patient was not suitable for thrombolytic therapy, the stroke team often had difficulty getting the ED staff to take back responsibility for processing the patient through the system. Due to capacity issues, it was not always possible for the stroke teams to transfer the patient directly to the stroke unit.

The issue of training and competency in stroke care within the ED was highlighted during focus groups held with stroke survivors. There was at least one person present in each meeting, who had not been diagnosed as having a stroke, or was diagnosed, with another condition in the ED. The review team accepted that a lack of training and competency in stroke care could have contributed to this. The Western Trust advised that ED had received stroke training and lysis training. The Southern Trust confirmed that ED staff had received training in the Recognition of Stroke in the Emergency Room (ROSIER). The Northern Trust advised that ED staff had received training in the safe implementation of thrombolysis for stroke; however, additional stroke training for ED staff was a recognised need, and they were looking at this. The Belfast Trust confirmed that ongoing training for ED staff in stroke recognition and thrombolysis has been provided for several years. The South Eastern Trust provided regular training for ED staff in stroke management and lysis.

In line with assessment pathways, all patients are sent for a CT scan or an MRI scan. The only exceptions were the limited number of patients that had not been diagnosed as having a stroke, or had been diagnosed with another condition. Access to CT and MRI scans was confirmed by the stroke survivors during focus groups.

Daily access to imaging during the in-hours period was available across all trusts, although it was subject to available capacity and the occurrence of unplanned events. Staff advised that occasionally it could be difficult gaining access to an imaging slot, and immediate access to imaging was not guaranteed. Staff reported that some progress had been made towards securing protected imaging slots for stroke requirements.

There was also evidence of inequalities of access between the in-hours and out-of-hours periods. During the out-of-hours periods, access was not always readily available, or provided through the system for on-call radiography. This often resulted in delays in obtaining scans. It was advised that trusts had been requested to improve imaging access, particularly for MRI scanning, at the weekends. The HSC Board also advised that plans were being considered to introduce a second MRI scanner at each of the area hospitals.

Similar inequalities between the in-hours and out-of-hours periods were also reported in relation to the interpretation and reporting of images taken.

The review team considered that the Time is Brain philosophy[15] needed to be the core for stroke care, as delays in assessment and treatment times subsequently decrease patient outcomes.

Thrombolytic Therapy

The review team was encouraged to find that thrombolytic therapy was available across Northern Ireland. All acute stroke units, referenced in Figure 1, provided thrombolytic therapy (Recommendation 2). All trusts, with the exception of the Belfast Trust, were registered with the Safe Implementation of Thrombolysis in Stroke (SITS) collaboration[16]. The Belfast Trust was updating their registration, following the centralisation of stroke services to the Royal Victoria Hospital.

Trusts advised there was a regionally agreed model of care for the delivery of thrombolytic therapy. Although the documentation supplied did not reflect a regional approach, information provided during the meetings about the delivery of thrombolytic therapy was generally consistent with good practice.

The review team noted that the target[17] set in Recommendation 2 of the stroke strategy may not be the most appropriate measurement for thrombolytic therapy. It was also evident that trusts were not recording patient figures against this target, but were recording figures for the door to needle

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[15] Saver JL. Stroke. 2006; 37: 263-266 – The typical patient loses 1.9 million neurons each minute in which stroke is untreated

[16] Safe Implementation of Thrombolysis in Stroke (SITS) collaboration - https://sitsinternational.org/

[17] Improving Stroke Services in Northern Ireland – Recommendation 2 - By 31 March 2011 all acute stroke patients will be appropriately assessed and at least 50% of those clinically suitable for treatment with thrombolysis will be treated within 3 hours of onset of symptoms of stroke.

times. All trusts presented encouraging figures for the numbers of people that received thrombolytic therapy; however, there were variations in the recorded door to needle times across trusts.

Given the variations in the door to needle times, the review team considered there needed to be a clear regional standardised pathway for thrombolytic therapy. The review team further considered that trusts should review the timelines for each stage of thrombolysis, with the aim of identifying process improvements to reduce treatment times. The importance of the Time is Brain philosophy is paramount, as the sooner thrombolysis is administered, the better the outcomes for the patient.

The review team found that thrombolysis was being administered by the consultant on duty at the time. During the in-hours period, consultant cover was provided by the stroke physician or the consultant geriatrician. In the out-of-hours periods, administering thrombolysis was sometimes the responsibility of the medical registrar, the ED consultant or the consultant neurologist. On occasions where the medical registrar was responsible, they would contact the consultant on-call for advice in relation to administration of lysis. In the Southern Trust, arrangements are in place for a consultant led service. When they are not on site, their telemedicine service is used to review scans and examine patients prior to decisions being made for thrombolysis.

Thrombolysis with alteplase is recommended as a possible treatment of acute ischaemic stroke[18]. The review team considered that thrombolysis should only be administered by physicians trained and experienced in the management of acute stroke in thrombolysing centres, in accordance with the marketing authorisation of alteplase. A physician with appropriate training and experience may be defined as a stroke specialist physician or a physician with stroke skills, as per the BASP guidance[19] on the definition of a stroke specialist. It was acknowledged that thrombolysis still needed to be administered to patients, so the current practice should continue in the interim.

Recommendation 6

Trusts should assess the skills and competency of those physicians providing lysis to patients, and provide appropriate training if required.

Specialist stroke nurses were usually available to support the consultant during thrombolysis. However, this was only during the in-hours period. Additional support was also available through the regional telephone advice service, which was funded by all trusts.

All trusts had utilised funding linked with the implementation of the stroke strategy to purchase telemedicine equipment to facilitate thrombolysis. However, only the Southern and Western trusts were regularly using this equipment in practice. It was reported that the current regional service

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[18] NICE - http://www.nice.org.uk/guidance/ta264

[19] British Association of Stroke Physicians - Definitions of a Stroke Specialist Physician - http://www.basp.ac.uk/Portals/2/Definition%20of%20a%20Stroke%20Specialist%20FINAL%20Aug%202011.pdf

consisted of a telephone call for advice via the central hub in the Belfast Trust. Some staff advised that they had sought telephone advice via the regional hub; however, there had been instances when the person providing the advice had lesser experience than them. This contributed to their unwillingness to fully engage with the hub and spoke model for telephone advice as it currently exists.

The review team explored the possibility of each trust contributing to a regional telemedicine service, with the capability to see both the patient and review their imaging, using the equipment already purchased. This was accepted in principle; however, consultants were already involved in either their own hospital rota or trust rota system. They would therefore have difficulty participating in a regional rota system unless their current rota arrangements were reviewed.

The review team considered that trusts needed to move away from their current arrangement of individual hospital lysis implementation teams, to a managed clinical network, with teams supported by a regional telemedicine service. This would require the full utilisation of the already purchased telemedicine equipment and the establishment of a regional telemedicine rota system. A review of the governance arrangements for the telemedicine service would be necessary, and if required, updated to reflect any new arrangements.

In light of the current arrangements, ensuring the safe practice of thrombolysis is a priority. If safe practice is not being achieved, a rationalisation of the number of sites providing thrombolysis should be considered.

The review team considered that trusts need to review their current arrangements for thrombolytic therapy, and adopt a more regional approach to the service for improvements to be achieved.

Recommendation 7

Trusts should review the current arrangements for delivery of thrombolysis to ensure safe practice is being delivered. A regional or cross-trust approach to supporting high quality stroke care, including telemedicine, should be developed.

Investigation of Transient Ischaemic Attack

TIAs are an early indicator of a stroke. Approximately one in four people who have a stroke report symptoms of a TIA in the week leading up to the stroke. Access to appropriate services and early treatment may prevent a stroke. The stroke strategy stated that, by March 2011, 90% of all confirmed TIA patients at high risk of early stroke (ABCD^2 score[20] 6 or 7), are fully investigated in a specialist neurovascular clinic (Recommendation 4).

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[20] The ABCD^2 score is a risk assessment tool designed to improve the prediction of short-term stroke risk after a transient ischemic attack (TIA). - http://www.stroke.org/site/DocServer/NSA_ABCD2_tool.pdf?docID

Across all trusts, there was a universal recognition within the stroke teams of the need to urgently assess and treat high risk patients. TIA clinics were available in all trusts, although their opening times varied. The Belfast, South Eastern, Southern and Western trusts were providing clinics every day, Monday to Friday. In the Western Trust, the venue of the clinics varies between the South West Acute, Tyrone County and Altnagelvin hospitals. The Northern Trust provided Monday to Friday clinics at the Antrim Area Hospital. No trust provided clinics at the weekends.

The South Eastern Trust informed the review team that they had set up a TIA telephone helpline, where GPs could seek advice. The helpline was only available Monday to Friday.

Access to TIA clinics was either via a drop in service, or by referral from the ED or the patient's GP. All trusts used the $ABCD^2$ score to prioritise patients for assessment and subsequent development of treatment plans. High risk patients received further assessment and treatment the same day, or within 2 days. At the weekends, all trusts admitted high risk patients to the stroke ward or an available bed; however, further assessment and treatment were not always available until the Monday.

The review team welcomed the provision of TIA clinics across Northern Ireland; however, there were a number of reservations in relation to current practice. The review team considered that:

- The target set within the stroke strategy should have been 100% of confirmed TIA patients, at high risk of early stroke, to be fully investigated. Despite the target, trusts were investigating all high risk patients on the same day or within 2 days.
- Recognition of high risk TIA condition that needs urgent assessment, in line with the guidance, needed to be promoted more throughout the healthcare environment. Additional guidance on signs and symptoms of TIA and the referral pathways to the clinics should be made available, particularly to GPs and ED staff.
- TIA assessment and diagnosis should be available seven days a week, to eliminate the inequalities of access to investigation and treatment at the weekends.
- Full investigations, including development of subsequent treatment plans, should be conducted on the day of attendance. Given the geography of Northern Ireland, the possibility of a regional network solution for assessment and treatment should be a consideration.
- Access to imaging needs to be improved, particularly for MRI scans.
- Where required, access to the opinions of a senior specialist should be available on the same day as the investigations.
- Appropriate access to immediate anti-coagulation should be available.

There remains a lower recognition of the seriousness of TIAs and the need for urgent medical attention. Early intervention may reduce the risk of a stroke after TIA. Therefore the reorganisation of services to facilitate prompt assessment of people presenting with signs and symptoms of TIA should be a priority for trusts.

Hospital Based Rehabilitation

Following a stroke, good nursing and medical care focuses on assessment and prevention of complications, this begins upon admission to the ward. In all trusts, the majority of stroke patients were admitted to the stroke ward. However, some stroke patients were admitted to other wards, due to bed pressures and capacity issues.

The aim of rehabilitation is to help patients regain as much independence as possible, by relearning skills they have lost, learning new skills, or finding ways to manage any disabilities. Although patients are identified upon admission, rehabilitation usually only begins once the patient is medically stable.

Individualised treatment plans were not being used in line with the standards. However, following the pilot of the stroke passport scheme, patients in the South West Acute Hospital would have received this information. While many patients are involved in the care planning process, they generally do not receive a copy within the stated seven day period. Trusts advised that the reasons for this were the capacity of the patient at the time, individual plans not being resourced or the plan being written up within the medical notes. The review team considered this was an area that trusts should review, as the treatment plan formed an important part of the rehabilitation process.

During the course of the review, it became evident that there was an inequality in the provision of AHP services between patients admitted to a stroke ward and patients admitted to other wards. A less intense level of AHP care was received by patients not on stroke wards. In all trusts there are no AHP services, including assessments or therapies, provided at the weekends.

In the Belfast, Southern and South Eastern trusts, the AHP specialties were part of stroke services. In the Northern Trust therapists were generally dedicated to the stroke wards, although they were part of other services. In the Western Trust, AHP input to the stroke unit varies across disciplines. Speech and language therapists and OTs are allocated to the stroke units, while physiotherapists are allocated to a pool which provides neurological rehabilitation to all neurological patients throughout the hospital.

For stroke patients in outlying wards, therapists would always try and visit them in the ward; however, this was not always possible due to capacity. In the South Eastern Trust, the stroke team would sometimes liaise with other staff to provide therapy for outlying patients, when it was not possible to visit.

Speech and Language Therapy

Communication problems are among the most common effects of stroke. It is estimated that one third of stroke survivors have some difficulty with speaking or understanding what others say. Aphasia, dysarthria and dyspraxia[21] are the three most common communication disorders caused by stroke. These conditions can be treated through speech and language therapy.

On admission to the stroke wards, all patients received an initial swallow test, to determine their swallowing abilities. For patients in outlying wards, this was not a routine assessment as not all nursing staff had been trained to carry it out. This was a recognised training need for ED staff within the Northern Trust, and at the time of the review they were developing a learning tool for nursing and medical staff to access. The Western Trust had introduced training in swallow assessment for nursing staff in the acute medical admissions ward.

For patients that required a specialist swallow test or communication assessment from a speech and language therapist, timescales varied across trusts, but this was generally provided within 2 days. Patients in stroke wards may have been assessed within 1 day, while patients in outlying wards could wait up to 2 days. Following a recent audit of assessment times, the Northern Trust advised that the average wait for a specialist swallow test assessment was 12 hours from referral. The Western Trust was able to provide specialist swallow test and communication assessments for all patients within 3 days, which was in line with the stroke guidance from NICE and the Royal College of Physicians (RCP).

Specialist swallow test and communication assessments from a speech and language therapist were not available at the weekends or during public holidays.

The review team considered an initial swallow test to be a priority, as it had an impact on patient care. Appropriate provision for swallow tests should be available, either by training all staff in how to carry out the test, or by having trained staff available on-call to conduct the tests. A specialist swallow test and communication assessment from a speech and language therapist were a lesser priority.

Speech and language therapy was only provided during the in-hours period. Trusts advised that they had attempted to provide therapy in line with best practice; however, factors such as staff resources and the patient's capacity and motivation, impacted on the level of therapy being provided across trusts. The variation in the level of speech and language therapy being provided

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[21] **Aphasia** is the most common language disorder caused by stroke. It can affect how people speak, their ability to understand what is being said, and their reading or writing skills. It does not affect intelligence. Aphasia can be very mild, and sometimes only affects one form of communication, such as reading. However, it is more common for several aspects of communication to be affected at the same time.
Dysarthria happens when a stroke causes weakness of the muscles people use to speak. This may affect the muscles they use to move their tongue, lips or mouth, control their breathing when they speak or produce their voice.
Dyspraxia is a condition that affects movement and co-ordination. Dyspraxia of speech happens when people cannot move muscles in the correct order and sequence to make the sounds needed for clear speech.

across trusts was emphasised by stroke survivors during focus groups. In the Belfast Trust, group speech and language therapy was being trialled due to lack of resources, and to ensure patients received continuous therapy.

Recommendation 8
Trusts should have appropriate arrangements in place for providing an initial swallow test on admission to a ward.

Physiotherapy

The stroke strategy sets out the timeframe for physiotherapy assessments which should be conducted within 3 days of admission. Trusts advised that this was not always possible, as some patients were not sufficiently medically fit for an assessment to be undertaken. However, most assessments were completed within the 3 day timeframe from admission, or from when the patient was medically fit.

Physiotherapy was provided in all trusts. The level and length of therapy was based on the assessed needs of the patient and their tolerance for therapy, their availability, their motivation for intensive programmes, and the number of staff required for particular therapy sessions.

As part of the hospital based rehabilitation, all stroke patients had access to a hospital gym. The Belfast Trust had a dedicated gym located within the stroke unit. In the South West Acute Hospital, a joint therapy room was located within the stroke ward. In Daisy Hill Hospital, a physiotherapy gym was based in the stroke ward. While a gym was available in the other trusts, it was not always located close to the stroke wards and additional travel time to and from the gym was required. Access to the gym was not always possible for patients in outlying wards which impacted on their rehabilitation. Access to specialist equipment was also an issue for outlying patients, as the equipment was only located on the stroke wards.

Physiotherapy continued for the duration of the patient's stay in hospital, although the intensity generally reduced in line with their improvements. The level of therapy was an area highlighted by stroke survivors during the focus groups, who considered that a lack of therapy at the weekends had an impact on their rehabilitation.

The review team considered that physiotherapy was a key aspect to the rehabilitation of stroke patients, which should not be compromised.

Occupational Therapy

Occupational therapy (OT) addresses the rehabilitation needs of stroke patients, by focusing on adapting the environment, modifying tasks and teaching skills, in order to increase participation in the performance of daily activities.

OT intervention was usually initiated through a referral when patients were considered to be medically fit. Trusts confirmed that OT assessments were generally completed within 4 days of referral, in line with the standards, unless the patient was discharged prior to assessment or if there was insufficient capacity to complete the assessment. Similar to the other therapies, the level and intensity of OT was based on the patient's assessed needs, tolerance and motivation for therapy. The Western Trust considered their inpatient OT service was not adequate to meet the needs of patients, and had submitted a business case for service improvements. However, at the time of the review it had not been approved.

Recommendation 9
Trusts should review the provision of Allied Health Professions services for appropriate stroke patients to determine whether these services should be seven day services.

Other Inpatient Services

Dietetics and psychology are other services being provided to stroke patients when in hospital. All trusts confirmed that patients received nutritional assessments within 2 days of admission. However, the review team considered this may not always be the case for those patients who were medically unfit. Trusts had referral pathways in place for referring patients with nutritional problems to a dietician. The Northern Trust advised that dieticians were providing a lot of support to stroke patients, even though they were not funded for this level of support.

The stroke strategy recommended that psychological screening and treatment for both cognitive impairment and mood disorders should be available to all patients (Recommendation 10). There was recognition from all trusts of the value of clinical psychology in the rehabilitation and long term management of stroke patients. However, this was an area of major unmet need. Some of the trusts had limited psychological support, offering mood and cognitive screening. During focus groups, none of the stroke survivors could recall receiving any psychological assessment or treatment.

In the Belfast Trust a neuropsychologist was providing training to staff within the stroke service, to help them better understand patients' needs. It was noted that the neuropsychologist would also include stroke sufferers in their caseload. However, the level and intensity of involvement was not confirmed.

The South Eastern Trust had a psychologist in post within stroke services, although their remit was to cover both community for direct input, and four hospital sites for assessment and advice as required. The review team considered the volume of work would exceed their capacity to meet the needs of all stroke patients.

The Northern, Southern and Western trusts had limited access to psychology services, and most of the support provided was very much on a good will basis. In the Northern Trust the current allocation of psychology support was not sufficient to provide a good service to all stroke patients.

The Western Trust advised that patients were considered on a case by case basis, and that decisions to refer were taken at multidisciplinary team meetings.

The review team considered that the current provision of psychology services was inadequate across all trusts.

Recommendation 10
Trusts should increase their provision of psychology services for stroke patients.

In light of the challenges faced by trusts in providing hospital based rehabilitation, it may be possible to increase capacity by introducing therapy technicians or assistants into the teams. Such staff could complement the existing therapists to free up their capacity and allow more therapy sessions with patients.

Recommendation 11
Trusts should review the current skill mix within the AHP disciplines and consider the options for increasing capacity within the teams.

2.6 Discharge Planning

Discharge planning is often seen as a key component in the continuation of delivery of patient care. However, it has emerged as a complex area, especially due to increased demand for hospital beds and quicker patient turnaround. All trusts demonstrated a universal acceptance of the benefits of effective and efficient discharge planning.

The concept of early supported discharge (ESD) was introduced as a method of accelerating the discharge of stroke patients from hospital and reducing their length of stay. Research has found that for every 100 patients receiving early supported discharge, six fewer will die or live dependently with daily support from carers[22]. The stroke strategy recognised this and recommended that all trusts have a specialist early supported discharge service in place for stroke patients (Recommendation 6).

The Royal College of Physicians considered an ESD team to be, a team offering rehabilitation in the community replicating stroke unit care. This enables earlier home discharge than would be possible if the team was not available[23].

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[22] Langhorne, P Early Supported Discharge services for stroke patients: a meta-analysis of individual patients' data Lancet 365 P501-6 - http://www.ncbi.nlm.nih.gov/pubmed/15705460
[23] The Royal College of Physicians - National clinical guideline for stroke 2012 - https://www.rcplondon.ac.uk/sites/default/files/national-clinical-guidelines-for-stroke-fourth-edition.pdf

There was variation across trusts as to the interpretation of the ESD team. The Belfast, Northern, South Eastern and Western trusts considered their community stroke teams to be the ESD team. The Belfast and South Eastern trusts advised that without significant funding, the community stroke team did not have the resources to take on a proper ESD role for the number of patients that required this service. At the time of the review, the Western Trust had secured funding for the development of their community team into a dedicated ESD team, and was in the process of recruiting additional personnel to the posts. The Northern Trust, although having a community stroke team, considered the ESD team as a separate team, and advised that they did not have the funding to implement an ESD team.

For the purpose of regional consistency, the review team considered that trusts needed to agree on a defined model of care associated with discharge planning. Whether that was an ESD model of care or a community stroke team model of care. For trusts that provided rehabilitation on multiple sub-acute sites, the review team also considered that they should review their practice against the benefits of having a single rehabilitation unit, supported by a dedicated ESD team.

All trusts had a written policy for the discharge of patients. While the Southern and South Eastern trusts had a specific discharge policy for stroke patients, the Belfast, Northern and Western trusts did not, and utilised their generic trust discharge policy.

All trusts discussed discharge with the patients and also at their multidisciplinary meetings. However, the focus groups with stroke survivors indicated that there were varying degrees of involvement in the discharge planning process. From the information provided by staff, the review team considers that patients may not fully understand what their level of involvement in the discharge planning process should ideally be.

Recommendation 12
Trusts should clearly explain the discharge planning process to patients and indicate to them when they are involved.

To assist in the discharge planning process, the stroke strategy recommended that a specialist stroke coordinator would be available to support patients discharge plan (Recommendation 7). The South Eastern and Western trusts had a specialist stroke coordinator in post. In the Northern and Southern trusts, the roles of the specialist stroke coordinator were being undertaken by specialist stroke nurses. In the Belfast Trust, the specialist stroke nurse delivered the clinical role of the specialist stroke coordinator, while the stroke services manager coordinated the service delivery and development aspects of the role. The Northern Trust was recruiting a coordinator at the time of the review.

The role of the specialist stroke coordinator was outlined during the review, with a wide ranging remit that varied considerably between trusts. The review team considered the role was mostly service development focused with clinical input in the Western Trust, and clinically focused with service development input in the South Eastern Trust. The management and clinical roles were split between the service manager and the specialist nurse within the Belfast Trust. As the post did not exist in the Northern or Southern trusts the role could not be assessed.

Given the extensive remit of stroke coordinators, the review team considered that it would be difficult for them to maintain the current level of involvement and intensity in the long term. With the planned introduction of service improvement leads, the review team considered that the remit for both roles could be more clearly defined.

Depending upon the type and severity of their stroke, some patients will be rehabilitated and be discharged quicker than others. The length of stay in hospital following a stroke varied across trusts. While it is difficult to make comparisons in the length of stay between hospitals, the longest lengths of stay were reported in the Western Trust, where on occasion some patients may remain in hospital for up to nine months. Even for the most complex patients, the review team queried these long hospital stays and queried whether inpatient rehabilitation was necessarily better than rehabilitation in the community.

Recommendation 13
Trusts should review the length of stay of patients in rehabilitation units, with the aim of providing earlier discharge.

During the review, several areas were highlighted that impacted upon patient discharge. With the relatively small geographical area of Northern Ireland, there were many cases where patients from one trust area were being treated in a hospital in another trust. This was particularly frequent for patients in the South Eastern Trust, who were brought to the Belfast Trust when the ED was closed at Lagan Valley Hospital. Similarly, patients living in east and south Belfast were admitted to the Ulster Hospital.

Trusts affected by the cross trust management of patients all raised concerns about the practice. It was reported that following inpatient treatment, transferring a patient back to another trust’s community setting was often an issue. This was due to the limited involvement of both trusts in the discharge planning process, resulting in community services not being in place. While the Belfast and South Eastern trusts had established liaison meetings in relation to discharge planning, it was not clear that this process was working as intended.

Recommendation 14
Trusts should develop an appropriate policy and procedure for the cross trust discharge and transfer of stroke patients.

Trusts advised that discharging patients into the community, although having some minor problems, was easier than cross trust discharge. All trusts reported common problems in relation to discharging patients into the community setting. Availability of medications at discharge and the timely provision of equipment and care packages all contributed to the delayed discharge of stroke patients. Although the discharge of some patients was delayed due to equipment not being available, some patients were also discharged without equipment being available.

In the Belfast, South Eastern and Western trusts, stroke patients would occasionally be discharged into the care of generic community rehabilitation services. However, this only occurred when it was in the best interests of the patient, when the patient had other conditions as well as stroke, and when the multi-disciplinary team agreed dedicated stroke rehabilitation was not required by the patient.

It was identified that the interface between secondary and primary care was limited. The main method of communication about the patient was in most cases, limited to the discharge letter. In some cases a follow up letter was forwarded to the patient's GP by the consultant or specialist stroke nurse.

The review team acknowledged that engagement and communication between secondary and primary care was a necessary aspect of patient care and should be developed. Both secondary and primary care have integral roles and responsibilities in developing this.

Recommendation 15
Trusts should develop improved engagement and communication between secondary and primary care.

2.7 Community Based Care

A stroke is considered to be a long term condition which may impact adversely on a person's life, who may then require ongoing care and support. Evidence demonstrates that targeted rehabilitation after discharge normally benefits patients. In addition to rehabilitation, patients may require other specialist stroke care in the community. The stroke strategy recognised this and recommended that stroke patients have access to appropriate community rehabilitation services, including specialist assessment, advice, support and intervention (Recommendation 8).

Trusts reported that a key factor that had impacted on their ability to fully meet the community services requirements, within the stroke strategy, was that the anticipated funding attributed to year three had not been released.

All trusts, with the exception of the Western Trust, provided rehabilitation services through their specific community stroke teams. The Western Trust utilised their generic rehabilitation team to provide these services. However, once the Western Trust has finalised recruitment to their ESD team, it is anticipated that they would provide specialist rehabilitation services.

Speech and language therapy, occupational therapy and physiotherapy were the key therapies provided to patients in the community. For some patients in the Southern Trust, speech and language therapy was being provided by telerehabilitation[24]. In most cases this was being provided by community therapists, following handover from their hospital colleagues. This treatment generally only lasted for a period of up to 12 weeks. However, arrangements are in place for an extension if required, or referral back into the hospital system, based on the needs of the patient.

During focus groups, stroke survivors advised that in the community, courses of therapy were not as intense as they had been in hospital. They also stated that they only lasted for up to 12 weeks and it was very uncommon to receive an extension. Trusts reported that systems were in place for referral back into the system to continue therapy; however, none of the stroke survivors were aware of this. The Northern Trust advised that therapy was limited to 12 weeks, but they would consider an extension or referral to out-patients. In some cases stroke survivors had to purchase private treatment to continue their rehabilitation.

The review team considered that although there may have been mechanisms in place to extend courses of therapy, this was not communicated appropriately to patients.

Recommendation 16
Trusts should clearly communicate to patients the options for additional therapy provision.

The South Eastern and Western trusts advised of counselling services being provided in the community by the stroke teams. In the Belfast Trust, neuropsychological needs are met through the community stroke team, either by direct contact with the neuropsychologist or indirectly through team management under the supervision of the neuropsychologist. The Northern and Southern trusts advised that they did not provide this service, but would refer to other services based on patient need. None of the stroke survivors advised of receiving counselling in the community after discharge.

Similar to the inpatient psychology input, the Southern and Western trusts did not provide this as part of the community stroke services. The Western Trust was planning to recruit a psychologist to the service. Although the other trusts considered they had provision of psychology services in the community, the review team noted their current provision of psychology input would not be sufficient to provide appropriate support to meet the needs of stroke patients.

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[24] Telerehabilitation is the use of video conferencing equipment, in the clinic at Daisy Hill Hospital and smaller systems installed in patient's own home, to conduct therapy sessions. This video conferencing unit has a very high specification zoom function, which is important for the nature of speech and language therapy work. The unit also has a document reader and laptop attached which allows the therapist to share documents, pictures and other materials with the client on the other end of the link. The initiative enables clients to have more frequent, shorter sessions, and has increased speech and language therapy capacity with the Trust.

During the course of the review, the review team identified several areas of unmet need within community stroke services which were not within the remit of the stroke strategy, including:

- access to post stroke spasticity services
- access to orthotics and other bespoke equipment
- access to orthoptic services
- a lack of self-management programmes and care plans
- a lack of self-referral to services
- access to information on driving assessment
- access to vocational rehabilitation and retraining
- the capacity to provide interventions in residential and nursing homes

After discharge, patients require regular review and appropriate treatment and management of risk factors post stroke or TIA. All trusts advised of six week and six month reviews; however, it was the expectation that longer term reviews would be conducted by the patient's GP. Trusts were unable to confirm whether the longer term reviews were taking place.

Partnership working arrangements with voluntary sector organisations had been established in all trusts. Contractual arrangements were in place with the Stroke Association and Northern Ireland Chest Heart and Stroke, to provide services, information and advice to stroke patients.

An observation identified during focus groups with stroke survivors, was that they were generally unaware that some of the groups they were attending had been funded by the trusts.

Voluntary organisations have developed substantial expertise and resources in relation to stroke, which could be utilised for the benefit of stroke patients. The review team considered that trusts should consider increased partnership working with voluntary organisations.

The stroke strategy recommended that trusts ensure that stroke patients, their carers and other health professionals have an identified point of contact to signpost to the different community services (Recommendation 8). The Northern, Southern and Western trusts advised they provide stroke patients with an identified point of contact. The Belfast and South Eastern trusts advised that signposting and support was provided by any member of the community stroke team.

With the implementation of TYC, more care and rehabilitation will be provided within the community setting. During the review, the review team was informed that three years of transitional funding associated with TYC was to be provided to trusts. The aim of the funding was to support the transition from inpatient treatment, with a reduction in the number of stroke beds, to the provision of more services in the community. The review team welcomed the funding for community services; however, was concerned about the existing funding gap compared to funding outlined in the stroke strategy, and how the service would then cope with the potential increase in demand for community services.

2.8 Secondary Prevention

Some strokes can often be prevented by having a healthy lifestyle and managing certain medical conditions that lead to a higher risk of having a stroke. It has been estimated that by addressing the known risk factors, up to 40% of strokes could be prevented. The stroke strategy recognised that preventing strokes from occurring in the first place, offers the best opportunity to reduce the burden of the disease afterwards.

The general approach to secondary prevention should be based on the type of primary stroke or TIA that has occurred, with subsequent therapy provided accordingly. Re-occurrence may be prevented with appropriate treatment, such as antiplatelet therapy, antihypertensive therapy, anticoagulant therapy or statin therapy. Administering these treatments should be in line with relevant protocols or guidelines.

With the exception of the Belfast and Western trusts, trusts had developed specific protocols for the implementation of antiplatelet therapy, antihypertensive therapy, anticoagulant therapy and statin therapy. The Northern and Southern trusts submitted copies of these protocols. The Belfast and Western trusts advised that guidance on implementation of these treatments was included in their overall stroke protocols.

Following a stroke or TIA as a result of carotid artery stenosis, rapid assessment and management is essential if reoccurrence is to be prevented. With the exception of the Belfast Trust, all trusts had a specific protocol for the assessment and management of carotid artery stenosis. The Northern and Southern trusts submitted copies of the protocols. The Belfast Trust followed the relevant stroke guidance from the RCP.

The review team noted the omission of specific recommendations on the management of atrial fibrillation (AF) from the stroke strategy. AF is the most common sustained irregular heart rhythm and is a major risk factor for stroke, making a person five times more likely to have a stroke. It is estimated that one in five strokes can be attributed to AF, and it is known that patients with AF suffer more severe strokes leading to greater disability and poorer outcomes.

It is particularly important to detect and treat AF quickly following a minor stroke or TIA, if recurrent and more severe strokes are to be prevented. Treatment requires initiating anticoagulant drugs, such as warfarin or a novel agent, unless there are contraindications. Trusts reported varying access to rapid anticoagulation. Some trusts admitted patients to initiate treatment, while other trusts had no defined policy. The review team recommends that all trusts develop appropriate arrangements for the initiation of anticoagulation, to suitable patients with AF.

Recommendation 17

Trusts should develop appropriate protocols for the immediate initiation of anticoagulation, to suitable patients with atrial fibrillation, presenting with stroke or transient ischaemic attack.

Diabetes is a major risk factor for stroke, as high levels of glucose in the blood can damage arteries, making them harder and narrower. Diabetes also increases the risk of the build-up of fatty deposits in arteries, which increases the chances of these blood vessels becoming blocked. If this happens in an artery leading to the brain, it could cause a stroke.

In all trusts, stroke patients were screened for diabetes, either in the ED or the stroke wards. Further testing and monitoring was undertaken during their stay and referral arrangements to specialist diabetic clinics were in place across all trusts.

The stroke strategy states that relevant information, such as test results and identified adverse lifestyle factors, should be provided to patients and their GPs. Trusts advised that such information was provided to patients verbally by staff, during ward rounds or at another suitable time. There was no indication that this information was provided in written format. Trusts advised that GPs received a discharge summary with this information included. The review did not audit discharge summaries to validate that the information included was appropriate.

To assist patients with stroke prevention, the stroke strategy requires that individualised plans for risk management and lifestyle changes are developed and agreed with patients. Trusts advised that patients were involved in the development of these plans; however, no patients received a copy of their plan. During focus groups, no stroke survivors reported being involved in the development of a plan for risk management and lifestyle changes.

Trusts informed the review team that there was either no process in place to facilitate the production of plans for patients or they were not resourced to provide them. The Northern Trust recognised the need for a formal written plan and was planning to develop a suitable document for patients, through the Northern Ireland Multidisciplinary Association for Stroke Teams (NIMAST).

Patients involved in a pilot of the stroke passport initiative in the Western Trust, were the only patients who received written information about risk management and lifestyle changes. The review team would suggest that the outcomes of this pilot are shared with the other trusts.

The review team considered an individualised plan for risk management and lifestyle changes was a core document for secondary prevention. While patients may have been involved in its development, it is still necessary for them to have the information contained in the plan readily available for them to refer to.

Recommendation 18

Trusts should provide all patients with an individualised plan for risk management and lifestyle changes, in line with the requirements of the stroke strategy.

Secondary prevention continues long after discharge from hospital. The stroke strategy envisaged that a risk factor management programme would be available for patients in the primary care setting. The programme was to be supported by protocols for implementing ongoing review.

There were mixed responses to queries about a risk factor management programme in primary care.

- In the Belfast and Western trusts, those involved in secondary care stroke services were not fully aware of the arrangements within primary care, in relation to a risk factor management programme.
- The Southern and South Eastern trusts advised that support and advice was given to patients at review appointments. However, longer term arrangements were the responsibility of their GP through the Quality and Outcomes Framework (QOF).
- The Northern Trust was clear that follow up in primary care was the responsibility of GPs through QOF. The associated stroke and TIA indicators were referenced in detail.

As the Belfast and Western trusts were not fully aware of the arrangements within primary care, they could not confirm whether there were any protocols relating to a risk factor management programme. The other trusts advised there were protocols in place; however, no evidence of these was submitted during the review.

Similarly, the Belfast and Western trusts were unable to confirm whether GPs throughout their trust area maintained a register of stroke and TIA patients. The other trusts informed the review team that GPs did maintain a register of stroke and TIA patients.

2.9 Palliative Care

A stroke carries a significant risk of death, and up to one third of stroke patients will die within one month, following their stroke[25]. It is therefore essential for appropriate palliative care services to be accessible for dying patients. Palliative care is an approach that aims to improve the quality of life for patients and their families, facing the problems associated with life-threatening illness, through the prevention and relief of suffering.

Trusts reported that palliative care was not within the remit of stroke services, and each had a specific palliative care service. The South Eastern Trust advised that palliative care was provided to patients in the stroke units, with

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[25] DHSSPS Stroke Strategy Consultation document (November 2007) - http://www.dhsspsni.gov.uk/stroke_strategy_consultation_document.pdf

onward referral to palliative care services. When dealing with palliative stroke patients, stroke teams referred them to the relevant palliative care teams. All trusts had in place referral protocols to palliative care services. The Belfast, Northern and Southern trusts submitted copies of their referral protocols.

The early identification of palliative care needs can contribute to the quality of life for dying patients. Palliative care training for stroke teams varied across trusts.

- The Belfast Trust advised that stroke team staff had not received palliative care training.
- The Northern Trust had no figures available in relation to the number of staff trained. However, training was made available to all staff and it was also included in their corporate induction programme.
- The South Eastern Trust advised that 40% of staff had received palliative care training.
- The Southern and Western trusts provided ongoing training for staff through a link nurse system. Each stroke ward had a dedicated palliative care link nurse who attended regular training and updates, and brought the learning back to the ward.

Recommendation 19
Trusts should consider the importance of early identification of palliative care needs and ensure that all stroke staff receive palliative care training.

2.10 Communication with Patients and Carers

Communication with stroke patients and their carers is an integral part of care and rehabilitation. They need to be informed of their condition and their prognosis, so they can be involved in establishing rehabilitation goals. The stroke strategy recognised this and recommended that trusts had an effective means of providing information to stroke patients, in a manner tailored to their needs (Recommendation 11).

Trusts provided details about the information they had provided for patients and carers. The type and amount of information varied considerably between trusts. Some of the information was also available in an aphasia friendly format in all trusts. A wealth of information is also available from the Stroke Association and Northern Ireland Chest Heart and Stroke, and trusts made patients aware of it. The Northern and Western trusts commissioned both the Stroke Association and Northern Ireland Chest Heart and Stroke to provide information and advice to stroke patients.

Some areas where trusts considered that they were meeting the communication needs of patients were:

- The Northern and South Eastern trusts provided patients with a stroke information pack on admission and followed up with information on secondary prevention.

- The Belfast Trust had developed a stroke library, consisting of information on stroke, which was made available to patients on request.
- The Southern Trust used an aphasia friendly format communication book for ward patients.
- The Western Trust, at the time of the review, was piloting a stroke passport for use in wards, which was designed to set out the patent's goals.

It was evident that general information about stroke was available; however, it was also evident that the provision of specific individualised information for patients was limited in all trusts. During focus groups, none of the stroke survivors advised receiving copies of individualised information, such as their care plan or their transfer of care document. Most trusts reported that they were not resourced to provide copies of individualised information to patients. The Southern Trust provided patients with a copy of their transfer of care document.

Recommendation 20
Trusts should review their arrangements for the provision of more individualised information to patients.

All stroke survivors were provided with information about stroke during their stay in hospital. However, the majority of people stated they were somewhat overwhelmed by the amount of information provided in the initial stages of their hospital stay. While providing information to patients is essential, the review team considers that trusts should review the timing of when information is provided to patients, and that it should be in line with their recovery and rehabilitation.

Despite the amount of information available, the review team considered that there was no consistency in relation to the information being provided by each trust. This should take account of:

- The areas of good practice in each trust being used as the basis to develop a consistent regional approach.
- Information currently held by the Stroke Association and Northern Ireland Chest Heart and Stroke.
- Experiences of stroke survivors and carers.

This would help patients across different trusts to get consistent information the about different stroke conditions.

Recommendation 21
Health and social care organisations should work together to develop and adopt a regional approach to the provision of information for patients about stroke.

2.11 Stroke Information Management System

Effective improvements in the quality of stroke care can only be achieved by auditing stroke services against evidence based standards. In previous years the trusts had been involved with the Stroke Improvement National Audit Programme and the National Sentinel Stroke Audit[26]. These audit programmes were subsequently replaced by the Sentinel Stroke National Audit Programme (SSNAP). Trusts were not actively inputting into SSNAP. However, the Western Trust was using the SSNAP facility to record stroke data. Their data input was shared across the different disciplines within the stroke service.

The stroke strategy had envisaged that a regionally agreed hospital based stroke register would be in use across the trusts to support service development, research and audit (Recommendation 14). The Stroke Information Management System (SIMS) had been developed for this purpose. SIMS was designed to feed into SSNAP and upload stroke information into the national audit programme, facilitating comparison with other trusts. Although SIMS was available, it was not being utilised by the trusts.

The Southern Trust had implemented a pilot of SIMS. Although they highlighted the benefits of audit data, they advised that it was challenging in relation to data entry. Administrative support was required to complete the data entry. The other trusts raised similar issues about data entry and cited this as the main reason for the delay in fully implementing SIMS. The HSC Board had advised the review team that funding had been supplied to trusts for administrative support in relation to SIMS. Trusts informed the review team that they considered there was inadequate funding to take this process forward. The review team was advised that movement to paperless patient records might impact on the functionality of SIMS. It would be important to ensure that information was provided to SSNAP to facilitate comparison with other services.

Recommendation 22
All trusts should record stroke data on the Stroke Information Management System.

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[26] The National Sentinel Stroke Audit (NSSA), the Stroke Improvement National Audit Programme (SINAP) and the Sentinel Stroke National Audit Programme (SSNAP) were national audits run by the Royal College of Physicians Stroke Programme. These clinical audit programmes aim to improve the quality of stroke care by auditing stroke services against evidence based standards.

Section 3 - Conclusion and Recommendations

3.1 Conclusion

The Northern Ireland stroke strategy recognised that preventing strokes from occurring in the first place, offers the best opportunity to reduce the subsequent burden of the disease. Since 2008, RSSIG has progressed the implementation of the recommendations and standards contained in the strategy, with the HSC trusts.

Although the trusts were working to deliver services in line with the standards, it was evident that factors, such as the geography of trusts, patient numbers, resources and lack of recorded data, would prohibit the full achievement of certain aspects of the standards.

Regional protocols have been agreed for local management of thrombolysis, TIA assessment, inpatient stroke management plans, discharge planning and community follow up. However, the full implementation of these protocols had not yet been achieved in all trusts. Further improvements to stroke care may be achieved by identifying more services that would benefit from a regional or cross trust approach.

Staff across trusts suggested a regionally managed clinical network to implement improvements in stroke care, share areas of good practice and develop training opportunities.

Stroke units are the core of all stroke services. During the review, it was evident that staff in each trust had a different opinion as to the definition of a stroke unit. Such opinions contributed to the structure and delivery of some stroke services. With the exception of the Northern and Western trusts, all trusts had an acute stroke unit which was based in a dedicated ward. The Belfast Trust operated a comprehensive stroke unit model with both acute and rehabilitative care, and included no off-site rehabilitative centres.

Stroke teams across the trusts were committed and enthusiastic, and delivering care based on a multidisciplinary approach. There was a genuine sense of teamwork and willingness to provide high quality stroke care.

Specific stroke training, such as STARS and SSEF, was available for staff to develop their core competencies, to help them become more knowledgeable and skilful in areas of stroke care. RSSIG had developed a stroke competency and skills framework, which had been forwarded to the HSC organisations. The implementation of the competency and skills framework varied across trusts.

On arrival at hospital, all stroke patients are initially assessed in the ED, and where required, received MRI or CT scans. Most patients were transferred to the stroke unit; however, due to bed capacity some were admitted to other medical wards.

Thrombolytic therapy was available across Northern Ireland. However, there needs to be a clear regional standardised pathway for thrombolytic therapy. The timelines for each stage of thrombolysis should be reviewed, with the aim of identifying process improvements to reduce treatment times.

The infrastructure for a regional telephone advice service for thrombolytic therapy was in place; however, in practice this was not being fully utilised. The practice of telemedicine needs to be developed and supported by all trusts.

TIA clinics were available in all trusts, although their opening times varied, and no clinics were provided at the weekends. Across all trusts, there was a universal recognition within the stroke teams of the urgency in assessing and treating high risk patients. High risk patients received further assessment and treatment the same day, or within two days. At the weekends, all trusts admitted high risk patients, with further assessment and treatment being undertaken after the weekend. Some improvements to the services were identified.

Rehabilitation was available in all trusts and began as soon as the patient was medically fit. Speech and language, OT and physiotherapy were the three main areas provided. No service was available at weekends. Dietetics and psychology were other services being provided to stroke patients when in hospital. However, the current provision of psychology services was not sufficient to meet the needs of all patients who required this service in line with clinical guidelines.

All trusts accepted the benefits of effective and efficient discharge planning. There was variation across trusts as to the interpretation of an ESD team. Some trusts considered their community stroke teams to be ESD teams. Trusts need to agree on a defined model of care associated with discharge planning, and develop their ESD and community stroke teams.

Not all trusts had a specialist stroke coordinator in post. In some trusts the specialist stroke nurses were undertaking this role. A review of the role of the specialist stroke coordinator would be required when the posts for the new service improvement leads are filled.

Trusts had discharge protocols in place and discussed patient discharge at multidisciplinary meetings and with patients. Stroke survivors provided limited reference to being involved in discharge planning. Trusts would need to improve information and communication about the discharge planning process.

A key factor that impacted on the trusts ability to fully meet the community services requirements within the stroke strategy was that the anticipated funding attributed to year three had not been allocated. All trusts have specific community stroke teams providing rehabilitation, except the Western Trust who utilised their generic rehabilitation team to provide these services.

Current guidelines recommend that therapy should be ongoing while patients continue to benefit, make functional gains, where goals can be achieved. Rehabilitation therapy provided in the community generally lasted up to 12 weeks, and trusts advised this could be extended. Stroke survivors advised that in the community, these therapies were not as intense as they had been in hospital. They also stated that they only lasted for up to 12 weeks and it was very uncommon to receive an extension. Although there may be mechanisms in place to extend therapies, this was not communicated appropriately to patients. The options for available ongoing therapy need to be clearly communicated.

There was evidence of inequalities in care between the in-hours and out-of-hours periods. This related to access to imaging, interpretation and reporting of images taken, thrombolytic therapy, TIA clinics and AHP therapies. Inequalities in care were also evident between the stroke care provided to patients in stroke wards and stroke care provided to patients admitted to outlying wards. This can only be addressed by admitting all stroke patients to stroke wards.

Secondary prevention measures can reduce the risk of having a stroke. All trusts had protocols relating to secondary prevention, although individualised risk management plans were identified as an area for development. Trusts advised that patients were involved in developing the plans; however, stroke survivors were unfamiliar with this and there was no process in place to provide patients with copies of plans.

From the trusts' submissions and information provided during meetings, it was clear that those involved in secondary care stroke services had only a limited knowledge of the arrangements for stroke care in primary care. There was a need for improved engagement and communication between primary and secondary care services.

Stroke teams did not provide palliative care support, but had referral protocols in place to palliative care teams. All staff in the stroke teams should be provided with palliative care training.

Trusts had general information about stroke available for patients and their carers. Some of it was also provided in aphasia friendly format. However, specific individualised information for patients was limited in all trusts.

Despite the amount of information available, there was no consistency in relation to the information being provided by each of the trusts. A regional approach to the provision of information should be developed and adopted by all trusts.

Despite SIMS being available, there was insufficient data gathering and recording in relation to stroke. Trusts needed to start actively recording patient data and using it to improve services.

RQIA wishes to thank the management and staff from the HSC Board and trusts for their cooperation in taking forward this review.

3.2 Summary of Recommendations

Recommendations

1. HSC organisations should consider engaging with stroke survivors during the development of future awareness campaigns.

2. HSC organisations should implement additional service improvement initiatives, including telemedicine for thrombolysis, post-stroke spasticity and a protocol for local and regional diagnostic and interventional neuroradiology.

3. The HSC Board and trusts should reach agreement on the definition of a stroke unit, based on current guidance. The agreed model should be implemented in discrete areas within the acute hospitals, in line with current NICE guidance.

4. Trusts should review their operational protocols for admission, so that more than 90% of acute stroke patients are admitted to the stroke ward as the ward of first admission.

5. The Regional Stroke Strategy Implementation Group should receive information from trusts on the progress of the implementation of the competency and skills framework.

6. Trusts should assess the skills and competency of those physicians providing lysis to patients, and provide appropriate training if required.

7. Trusts should review the current arrangements for delivery of thrombolysis to ensure safe practice is being delivered. A regional or cross-trust approach to supporting high quality stroke care, including telemedicine, should be developed.

8. Trusts should have appropriate arrangements in place for providing an initial swallow test on admission to a ward.

9. Trusts should review the provision of Allied Health Professions services for appropriate stroke patients to determine whether these services should be seven day services.

10. Trusts should increase their provision of psychology services for stroke patients.

11. Trusts should review the current skill mix within the AHP disciplines and consider the options for increasing capacity within the teams.

12. Trusts should clearly explain the discharge planning process to patients and indicate to them when they are involved.

13. Trusts should review the length of stay of patients in rehabilitation units, with the aim of providing earlier discharge.

14. Trusts should develop an appropriate policy and procedure for the cross trust discharge and transfer of stroke patients.

15. Trusts should develop improved engagement and communication between secondary and primary care.

16. Trusts should clearly communicate to patients the options for additional therapy provision.

17. Trusts should develop appropriate protocols for the immediate initiation of anticoagulation, to suitable patients with atrial fibrillation, presenting with stroke or transient ischaemic attack.

18. Trusts should provide all patients with an individualised plan for risk management and lifestyle changes, in line with the requirements of the stroke strategy.

19. Trusts should consider the importance of early identification of palliative care needs and ensure that all stroke staff receive palliative care training.

20. Trusts should review their arrangements for the provision of more individualised information to patients.

21. Health and social care organisations should work together to develop and adopt a regional approach to the provision of information for patients about stroke.

22. All trusts should record stroke data on the Stroke Information Management System.

Appendix 1 - Abbreviations

Allied Health Professions (AHP)

British Association of Stroke Physicians (BASP)

Belfast Health and Social Care Trust (Belfast Trust)

Computerised Tomography (CT)

Department of Health, Social Services and Public Safety (DHSSPS)

Early Supported Discharge (ESD)

Emergency Department (ED)

General Practitioners (GP)

Health and Social Care (HSC)

Integrated Care Partnership (ICP)

Magnetic Resonance Imaging (MRI)

National Institute for Health and Care Excellence (NICE)

Northern Health and Social Care Trust (Northern Trust)

Occupational Therapy (OT)

Public Health Agency (PHA)

Quality and Outcomes Framework (QOF)

Recognition of Stroke in the Emergency Room (ROSIER)

Regional Stroke Strategy Implementation Group (RSSIG)

Regulation and Quality Improvement Authority (RQIA)

Royal College of Physicians (RCP)

Safe Implementation of Thrombolysis in Stroke (SITS)

Sentinel Stroke National Audit Programme (SSNAP)

South Eastern Health and Social Care Trust (South Eastern Trust)

Southern Health and Social Care Trust (Southern Trust)

Stroke Information Management System (SIMS)

Stroke Training and Awareness Resources (STARS)

Stroke-Specific Education Framework (SSEF)

Transforming Your Care (TYC)

Transient Ischaemic Attack (TIA)

Western Health and Social Care Trust (Western Trust)

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