Mind the Gap!

The Third SSNAP Annual Report

Care received between April 2015 to March 2016

Royal College of Physicians

HQIP
Healthcare Quality Improvement Partnership

A description of the front cover of this report

The three paintings Morning, Noon and Night on the front cover of this report are by Richard Creme. The following message is from his wife, Shelly.

Before Richard's stroke we had our own retail business, which was a fashion store that was visited by interesting and influential people. After the stroke, we had to close the business. That was our livelihood and what we loved doing. Stroke changes everything. In an ideal world, your life has structure and a meaning, but everything is taken away from you with the stroke. We used to have a week where we worked, and a weekend where we would visit friends and have fun. Now every day is the same.

Because of Richard's aphasia, it can be hard to know his emotions. But the paintings you see on the front cover are an expression of how he feels emotionally at particular parts of the day. In the morning, when he wakes up, his head is quite confused. It's like a car, the engine needs to tick over. There's a lot going on there. Noon is less busy, and the night is more tranquil, he is more relaxed.

For Richard, the art that he does is his lifeline. Since his stroke, and with him having aphasia, it's really hard for him to communicate. Even I don't know everything that he wants to say. It's like, "give us a clue here!" When he does his art, he switches off from everything else, and it takes his mind to a totally different place.

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Foreword

As the new Chief Executive of the Stroke Association, I am delighted to author the Foreword for the 3rd SSNAP Annual Report 2016. The report contains a wealth of data that will be invaluable in helping to ensure stroke patients receive the care and support they need. I am impressed by the quantity and quality of the information that's collected, but also by the positive attitude of health professionals who rightly view this as a catalyst for service improvement. The case studies illustrate this point and show how real-time data, combined with hard work and commitment, make a real difference to improvements in patient care.

I am also delighted that the stroke community sees the importance of sharing this data in an accessible format with patients and the public. We all work in stroke care because we share a combined passion to improve the quality of life of stroke survivors and their families. The information in this report will help inform people affected by stroke about the level of care they are entitled to. I hope that people will use this and the local reports to push for change nationally and locally.

This report highlights the significant progress that has been made in stroke care over the last three years. We should celebrate the fact that 50 different hospitals across England, Wales and Northern Ireland achieved the highest possible score in one or more quarterly reporting periods between April 2015 - March 2016, equating to a 'world class stroke service.' In the first three quarters of SSNAP scoring starting in July 2013 no hospitals achieved this level. More patients are receiving a brain scan and are seeing a specialist stroke doctor and nurse more quickly. And 81% of hospitals now offer early supported discharge to continue rehabilitation at home compared to 74% in 2014.

However, it is a mixed picture. Fewer patients are benefitting from the FAST message and arriving at hospital within four hours, reducing the opportunity for them to benefit from vital treatments such as thrombolysis. Many patients are not receiving the amount of therapy they need, particularly speech and language therapy which is rarely available to patients 7 days a week. And post-acute care is not being given the attention and resources it needs. Fewer than a third of patients received a six month follow-up assessment. A 2016 survey by the Stroke Association showed that over 45% of stroke survivors felt abandoned after leaving hospital and half of those surveyed rated the support they received for fatigue, memory problems and the emotional effects of stroke as poor or very poor, because they did not receive enough.

We urgently need to address the variations in acute care, and give equal priority to post-acute care so that stroke survivors and their carers are given the right information and support to aid their recovery and life after stroke.

At the Stroke Association, we're delighted that the updated National Clinical Guideline from the Royal College of Physicians continues to raise the bar for stroke care. But we worry that, despite the scale and impact of the condition, stroke is no longer considered a priority by governments and the NHS across the UK. We need to see a renewed national focus on stroke, otherwise there is a real risk that momentum will slow and the best practice that we see in some parts will not become universal. Let's act on this report and use our collective power and capabilities to push for change. Together we can conquer stroke.

Juliet Bouverie, CEO of the Stroke Association

The Stroke Association is the UK's leading stroke charity.
www.stroke.org.uk

Who is this report for?

This report has been written both for those who are directly involved in stroke; clinicians, policy makers, researchers and commissioning bodies, and other people who have been affected by stroke in their personal lives. It has also been designed in a way which should appeal to others with a more general interest in public health, and quality improvement in healthcare.

This report has been written with and designed for stroke survivors and it should prove a powerful resource for patients, carers, and people who campaign for better stroke services. In this year's report we have also included numerous case studies written by clinicians and researchers working in stroke care which outline how they have used SSNAP data to improve the services they provide to their patients. Key findings from important stroke research studies using SSNAP data are discussed by the leading authors in a succinct and understandable way. More details on these studies is provided at the end of this report.

We hope this report will engage, inform, and inspire a wide audience of readers and offer a valuable insight into stroke care in England, Wales and Northern Ireland.

What is SSNAP?

The Sentinel Stroke National Audit Programme (SSNAP) collects data about the care received by nearly everyone admitted to hospital with acute stroke in England, Wales, and Northern Ireland, and compares this to national evidence based standards. SSNAP reports the findings to healthcare professionals providing and managing the services, the organisations that pay for the services, and to the public to enable continuous improvements in stroke care to be made.

Within SSNAP there are two types of audit. The first is a clinical audit, which collects information on the care of patients after they are admitted to hospital until six months following their stroke. This report uses information on patient care collected over the past three years and highlights where progress has been made and where improvements are needed.
The second is an organisational audit, which measures the structure of stroke services. For example the Acute Organisational Audit measures the size and working patterns of the workforce including their availability throughout the week. The inaugural Post-acute Organisational audit measured what kind of rehabilitation services are provided for patients after they leave hospital.

The overall aim of SSNAP is to improve services by:
- helping providers to find out where they need to do better
- enabling those who manage and pay for services to monitor how well providers are doing
- empowering patients, carers, stroke survivors and the wider public to call for improvements by providing information about where they are needed

SSNAP Organisational Audit

- Run every two years
- 100% participation of acute hospitals since 2004
- Focuses on the structures in place to provide stroke care to patients
- Answers key questions such as availability of 24/7 acute interventions, number of stroke beds available, nurse and consultant staffing levels
- First ever audit of stroke services in the community ran in 2015
- This landmark audit reported on the availability and structure of post-acute services within England, Wales and Northern Ireland

SSNAP Clinical Audit

- Collects information on every stroke patient in England, Wales and Northern Ireland
- Over 95% case ascertainment
- 250,000 patients reported on since 2013
- Longitudinal register collecting data from stroke onset to 6 months post stroke
- Over 1000 bespoke reports produced every 4 months
- Composite scoring measures developed
- Results used across the NHS for quality improvement and research purposes

What is the purpose of this report?

The purpose of this Annual Report is to show how the information that we collect in SSNAP provides a very detailed, accurate picture of the characteristics of people who have a stroke and the care that is provided to them in hospital and following discharge. Because SSNAP data covers three years, we are able to look at changes over time, and see where care is improving, and what still needs to be done.

What data is reported on in this report?

This report uses annual level data collected over three years between April 2013 – March 2016. We use results from the Acute Organisational Audit which reported on the structure of stroke services on 1 July 2016. Results from the Post-acute Organisational Audit are also referred to. This audit reported on the structure of post-acute services as at 1 April 2015. The latest periodic clinical reporting period covered stroke admissions between April – July 2016 with results published on 14 November 2016, ahead of the publication date for this report.

What is contained within this report?

In this report, we highlight important aspects of stroke care which have improved or deteriorated over the last three years. We also discuss some other areas of care that have remained stable but don't meet the highest standard. There are some areas of particular concern, for example where hospitals are unable to recruit enough specialist stroke doctors and nurses, or where the numbers of beds are insufficient to ensure rapid access to a specialist stroke unit. There are, however, areas where we can really celebrate progress, such as rapid access to brain scanning for nearly everyone.

In this report we define what a good stroke service should look like and what needs to happen to achieve this. For example having sufficient staffing in the stroke unit regardless of time of day or day of week, or having the most appropriate service structures in place to best serve a local population. We will highlight some of the major challenges in stroke care today and offer some possible solutions.

We have asked stroke experts to tell us how SSNAP data has helped them to improve services or answer research questions, and we have asked stroke survivors and carers to comment on the service they received and how it has affected them. Case studies written by stroke professionals are included throughout the report to provide further insight for the reader and offer expert opinion on some of the most important aspects of stroke care today.

This report is available online, with a full suite of interactive features as well as in-depth case studies, videos and an audiobook version. Go to www.strokeaudit.org/annualreport

Detailed information is available on our website www.strokeaudit.org. The fifth edition of the RCP National Clinical Guideline for Stroke, which is a detailed summary of the research evidence outlining the standard of care we should all be aiming to achieve, is also available at www.strokeaudit.org/guideline

A patient/carer version of the National Clinical Guideline is titled "Care after stroke or transient ischaemic attack: information for patients and their carers". This outlines the care that people should expect to have, and is available at www.strokeaudit.org/Guideline/Patient-Guideline.aspx

1. What aspects of stroke care have improved since 2013?

Introduction

SSNAP began collecting data on stroke patients in 2013 which means we are now in a position to look at the care provided over the last three years, and can report on the findings of detailed analyses.

The data are presented both in terms of how hospitals perform on individual measures (eg the proportion of people who have a specialised swallow assessment within the first 72 hours) and as a composite score, where hospitals are provided with an overall score that summarises all aspects of the care they provide. This allows people to see how one hospital performs compared to another, and whether overall care is improving in that hospital. When we started SSNAP in 2013, no hospitals achieved the highest score possible (A), but in the latest period of reporting (April-July 2016), 42 hospitals achieved this score, indicating a "world class stroke service". Fewer hospitals than ever before are now achieving the lowest possible scores (D and E), which is very encouraging.

However, the NHS is under strain, with difficulties in staff recruitment and concerns about social services funding. This can make it difficult to discharge people home in a timely manner, which can impact on the availability of specialist beds. It is vital that we continue to monitor the quality of care that people with stroke receive, in order to ensure we minimise mortality and disability, and help people return to life after stroke.

What is a stroke?

A stroke occurs when the blood supply to part of the brain is cut off. Stroke remains the third commonest cause of death and the most common cause of complex disability in the UK, and can occur at any age. Most strokes are due to a blood clot suddenly blocking one of the arteries supplying the brain, cutting off the blood supply to part of the brain (ischaemic stroke), while around 1 in 9 are due to a sudden bleed into the brain itself (haemorrhagic stroke). More than 80,000 people each year are admitted to hospital with a stroke in England, Wales, and Northern Ireland and while most people are elderly, a significant proportion are of working age, and of course stroke can affect children and young people too. Most strokes are due to common risk factors such as high blood pressure, irregular heart beat (atrial fibrillation, AF), smoking and high cholesterol but there are rarer causes too.

"Everything went into slow motion, I could not speak, I fell down to the floor. I remember my husband saying "she's had a stroke ring the ambulance". I woke up in a ward, I couldn't walk."
Linda, age 70

Scanning Times

A brain scan is essential in order to make the diagnosis of stroke, in particular to identify the 1 in 9 people who have a haemorrhagic stroke. Acute treatment for ischaemic stroke and haemorrhagic stroke is different, so the sooner the stroke type can be identified, the sooner the patient can receive the right treatment.

There is no benefit in delaying a scan, and it is more cost effective to scan immediately, so it is encouraging to see that more people are having a scan more quickly. Our 2016 guideline now recommends brain scanning within one hour of arrival in hospital so improvements in scan availability will need to continue.

Improvements in scanning times

2013/2014

41.9% of patients received a **brain scan within 1 hour** of arrival at hospital

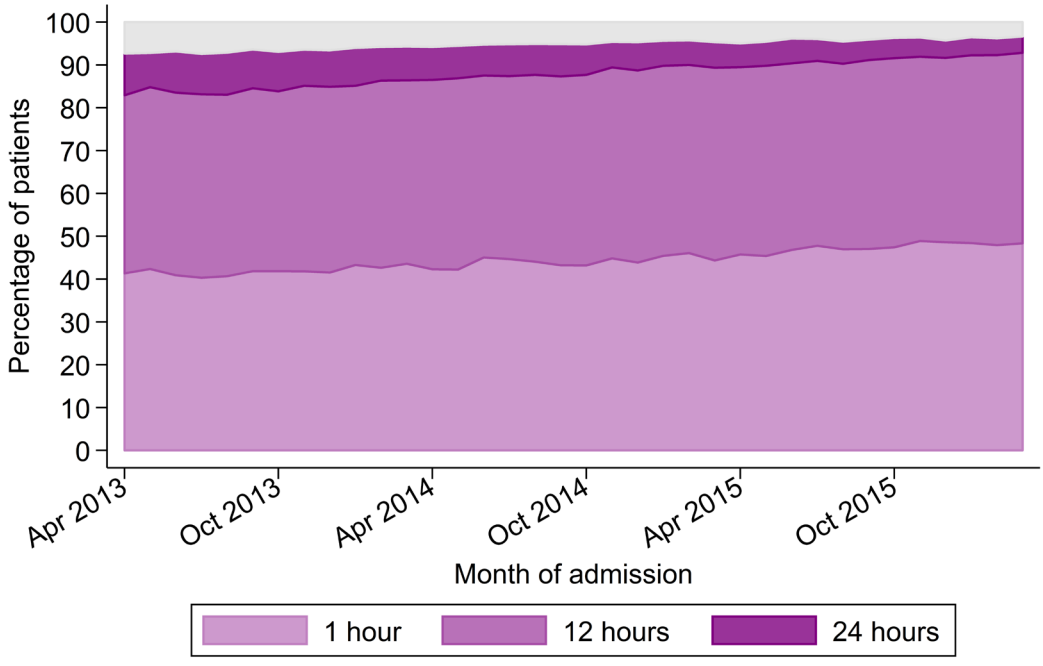
2014/2015

44.1% of patients received a **brain scan within 1 hour** of arrival at hospital

2015/2016

47.5% of patients received a **brain scan within 1 hour** of arrival at hospital

More than **90%** of patients now receive a **scan within 12 hours**



Source: SSNAP Apr 2013-Mar 2016

Figure 1: This graph demonstrates that the percentages of patients scanned within 1, 12 and 24 hours of arrival at hospital has increased over the last three years.

Thrombolysis provision

Thrombolysis is a treatment given to stroke patients that can break down a clot that is blocking blood from reaching the brain. It is not suitable for everyone, but it should be offered to anyone for whom the treatment is appropriate. SSNAP data shows that the total percentage of people thrombolysed (as a proportion of all the strokes admitted) is staying largely unchanged, at around 11%. In some areas, such as London, Thames Valley, and the East of England the proportion is higher, at over 14% suggesting that improvements could be made in the rest of the UK.

More people deemed to be eligible for thrombolysis are now receiving it and the percentage treated within an hour of arrival has also increased. The "door to needle" time (time from arrival in hospital to the time at which the thrombolysis is administered) has also reduced by a few minutes to a median of 55 minutes. This is gratifying, but we know the best outcome for patients is achieved when the time from onset to treatment is as short as possible (for example, research studies show that the outcome for people thrombolysed within 90 minutes of symptom onset is much better than those who receive treatment within 180 minutes) so the more we can do both to reduce the time taken from the start of symptoms to arrival in hospital, and from arrival in hospital to treatment, the less disability people will suffer. We would like to see a target door to needle time of less than 45 minutes, and we know some centres can achieve shorter times than this.

Improvements in thrombolysis provision

2013/2014

74.3% of eligible patients received thrombolysis

2014/2015

80.7% of eligible patients received thrombolysis

2015/2016

84.9% of eligible patients received thrombolysis

What patients are not eligible for thrombolysis?

- People with stroke due to haemorrhage
- People who arrive at hospital more than four and a half hours after stroke onset
- People with abnormalities of blood clotting (including anticoagulant treatment)
- People whose stroke onset time is not known, for example those patients who woke up with stroke

Door to needle time by day of the week and time of day

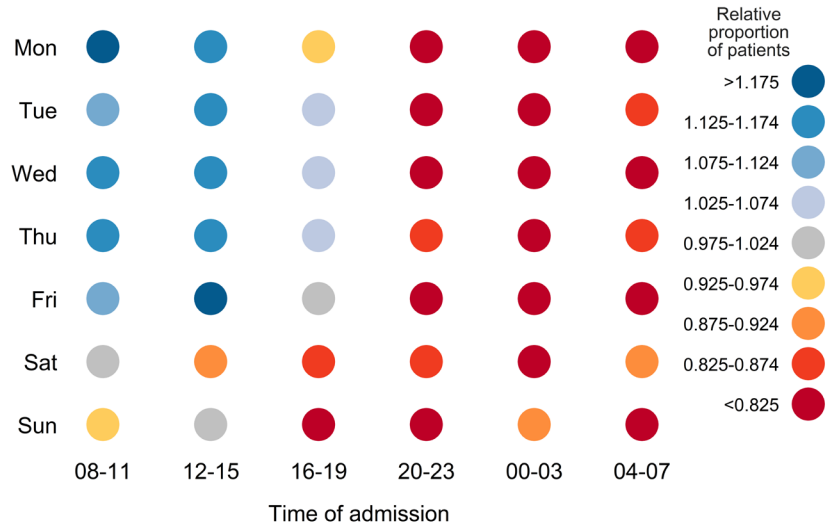


Figure 2: This heat map demonstrates the variation across time of day and day of the week in the proportion of thrombolysed patients who are treated within 60 minutes of arrival. Patients arriving both overnight and at the weekend were less likely to be treated quickly than patients arriving during working hours.

Urgent assessments by stroke specialists

The best way to ensure acute stroke treatments are given in a timely way is for patients to be seen by the specialist stroke teams as quickly as possible. Our research shows that people who do not have these assessments in a timely manner could be at higher risk of developing pneumonia, which is another example of how better care (perhaps perceived as more expensive by providers of care) can not only lead to better outcomes for people but may also be cost saving.

There have been substantial improvements in the proportion of patients being seen by a specialist stroke doctors and nurses within 24 hours of arrival in hospital over the past three years. Most people are being seen on the day of admission, or the next morning, by a stroke consultant, even at weekends. These encouraging results show that hospitals are organising their services to ensure specialist staff see patients quickly after arrival in hospital. This allows much more rapid delivery of the important assessments and treatments that people need.

Around 40% of people with acute stroke cannot swallow safely. Patients with swallowing difficulties (dysphagia) after they have been screened should have a more detailed swallow assessment by a skilled speech and language therapist to ensure that these patients have a management plan in place for keeping hydrated and nourished. This is now being done for a higher proportion of people than in previous years.

Despite these substantial improvements in early acute assessments we are concerned by the current staffing levels of stroke consultant and nurse specialists. We know from the 2016 Acute Organisational Audit that there are many unfilled stroke consultant posts across the country which means not all patients are benefiting from these improvements in early assessments, and it can often depend on when a patient is admitted to hospital. This is discussed in more detail later in this report.

Improvements in specialist assessment timings

2013/2014

2 hours 17 mins median time of arrival to assessment by **stroke specialist nurse**

13 hours 41 mins median time of arrival to assessment by **stroke specialist consultant**

2015/2016

1 hour 30 mins median time of arrival to assessment by **stroke specialist nurse**

12 hours 27 mins median time of arrival to assessment by **stroke specialist consultant**

Improvements in swallow assessments

2013/2014

78.3% of eligible patients had a **swallow assessment** within 72 hours

2015/2016

83.9% of eligible patients had a **swallow assessment** within 72 hours

Importance of early assessments

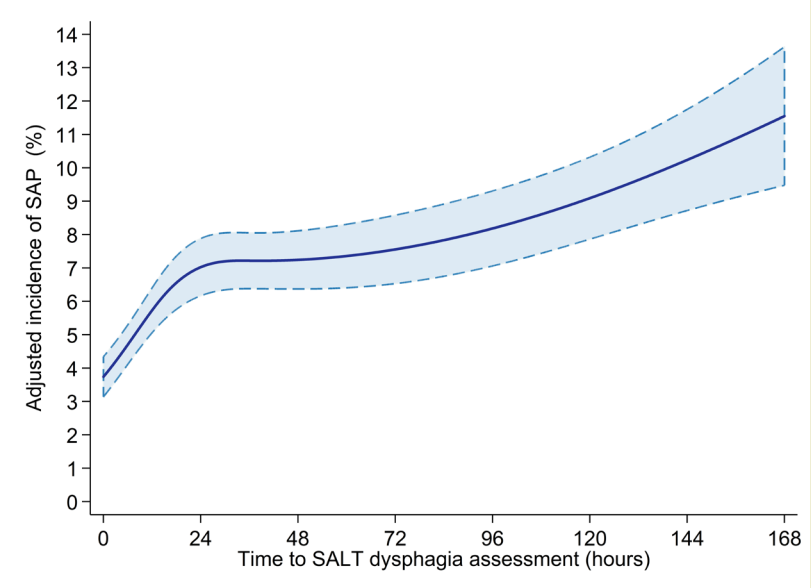
Swallow assessment and pneumonia after stroke

Based on: The association between delays in screening for and assessing dysphagia after acute stroke, and the risk of stroke-associated pneumonia

Pneumonia (infection in the lungs) occurs frequently in people with acute stroke and adversely affects clinical outcomes. It trebles the risk of death, and is associated with worse disability in survivors. The combination of impaired cough and swallowing reflexes, and temporary suppression of the immune system after stroke are believed to be the main causes of the increased risk of pneumonia. Better ways of reducing the risk of pneumonia after stroke are urgently required.

Professor Craig Smith, based at the Greater Manchester Comprehensive Stroke Centre, Dr Ben Bray, of the RCP stroke programme and others, used data from SSNAP to investigate the association between delays in assessing patients' swallowing after stroke and their risk of pneumonia. The study found a strong association between delays in receiving a speech and language therapy (SALT) swallow assessment and of the risk of pneumonia. Delays in SALT swallow assessment beyond 24 hours were associated with a 4% absolute increase in the incidence of pneumonia, after taking account of other patient factors.

Figure 3: Adjusted incidence of stroke-associated pneumonia (SAP) for increasing time to speech and language therapy assessment



This graph shows that the longer it takes for a swallow assessment to be performed for patients after stroke, the higher the risk is of developing pneumonia

These are the first data from a large multicentre national cohort to show that delays in SALT dysphagia assessment are associated with an increased risk of pneumonia after stroke. Expedited SALT dysphagia screening to avoid such delays might therefore be a strategy to reduce the risk of SAP and warrants further study

Therapist assessments and therapy intensity

Therapists are a vital part of the stroke team, and we know that early assessment and provision of specialist stroke therapy can reduce the length of time a person stays in hospital and can help with recovery. It is gratifying to see that for occupational therapy, physiotherapy and speech and language therapy, both the proportion of people seeing a therapist within 72 hours of admission, and the amount of time people are receiving direct therapy has increased.

This improvement reflects innovative changes in working practices, with more weekend working in many centres, and more efficient use of therapists' time. However, as detailed later in this report there is still a significant way to go, particularly for speech and language therapy, and this may reflect staffing numbers on stroke units.

Improvements in early therapy assessments:

2013/2014

86.3% of eligible patients were assessed by an **occupational therapist** within 72 hours

93.3% of eligible patients were assessed by a **physiotherapist** within 72 hours

77.8% of eligible patients were assessed by a **speech and language therapist** within 72 hours

2015/2016

89.3% of eligible patients were assessed by an **occupational therapist** within 72 hours

93.8% of eligible patients were assessed by a **physiotherapist** within 72 hours

85% of eligible patients were assessed by an **speech and language therapist** within 72 hours

"With all the therapy, the exercises were clear. I knew we were making progress, they were keeping an eye on things. They (therapists), all talked to each other, they knew what we were doing with the others, it all happened together"

David, age 62

Care before leaving hospital

Nutrition assessments

We have also seen improvements in the assessments people need before they leave hospital. Malnutrition can be an important problem after stroke, particularly for people who have swallowing difficulties and may be tube fed, so it is good to see an increase in the proportion of people who have an assessment of their nutritional status and are seen by a dietitian if they need to be.

% of patients who are screened for nutrition and seen by a dietitian before leaving hospital if they need to be

2013/2014	2015/2016
65.5%	79.2%

Continence Planning

We have been very concerned in the past by the numbers of people who do not have a proper assessment of continence before being discharged home, and it is good to see substantial improvements. This is an improvement from 3 years ago, but still means that nearly 1 person in 10 who needs one leaves hospital without a continence plan.

Patients requiring a continence plan received one before leaving hospital

2013/2014	2015/2016
15/20	18/20

Mood disturbance

Mood disturbance is unsurprisingly very common following stroke, as are difficulties with memory and concentration (sometimes called cognitive difficulties) and the proportion of people being screened before they go home has also improved.

% of patients who had a mood and cognition screening before leaving hospital

2013/2014	2015/2016
78.6%	89.3%

Care after leaving hospital

People with stroke need to be cared for in a specialist stroke unit and then, where possible, discharged home where they can continue their rehabilitation with the support of a skilled Early Supported Discharge (ESD) team. Not everyone is suitable for ESD at home, although the proportion of people who are suitable can be increased with better provision of home care (sometimes by enhanced home care packages for the first 6 weeks after discharge) and a responsive and well staffed ESD team that includes nurses as well as therapists.

The 2016 SSNAP Acute Organisational Audit reported that 81% of hospitals now have specialist early supported discharge available to them meaning that more patients can return home sooner and receive specialist post-acute care compared to 74% in 2014. We have seen the proportion of people discharged with stroke specialist ESD increase from 25% to 33% between 2013/2014 and 2015/2016, but this is still not as many patients as it could be if this service was available to everyone.

2013/2014

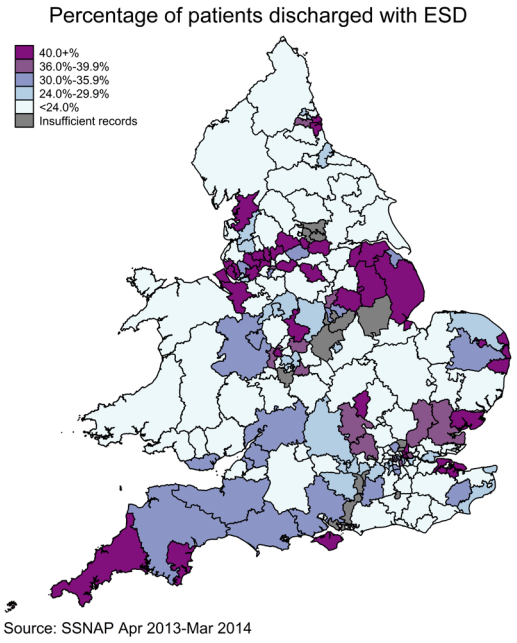


Figure 4: Shows the percentage of patients discharged with ESD by area between April 2013 and March 2014.

2015/2016

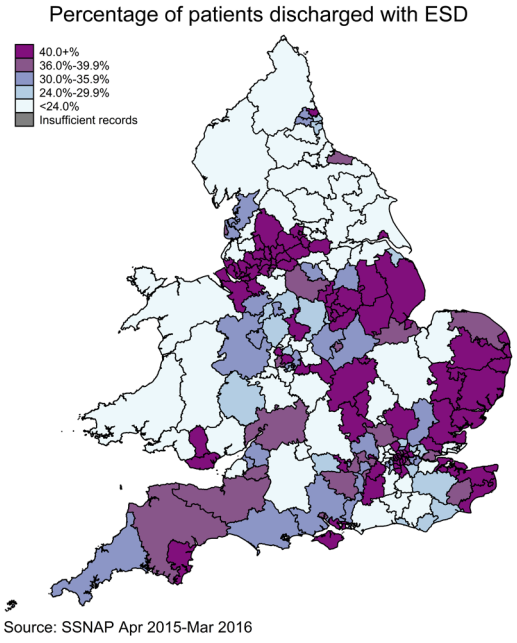


Figure 5: Shows percentage of patients discharged with ESD by area between April 2015 and March 2016.

"I finished physio but I felt after a while that I should try again. I got in touch and they gave me more therapy, she was really good and my walking and balance have improved"

Janet, age 60

2. What are the challenges in stroke care today?

Acting FAST

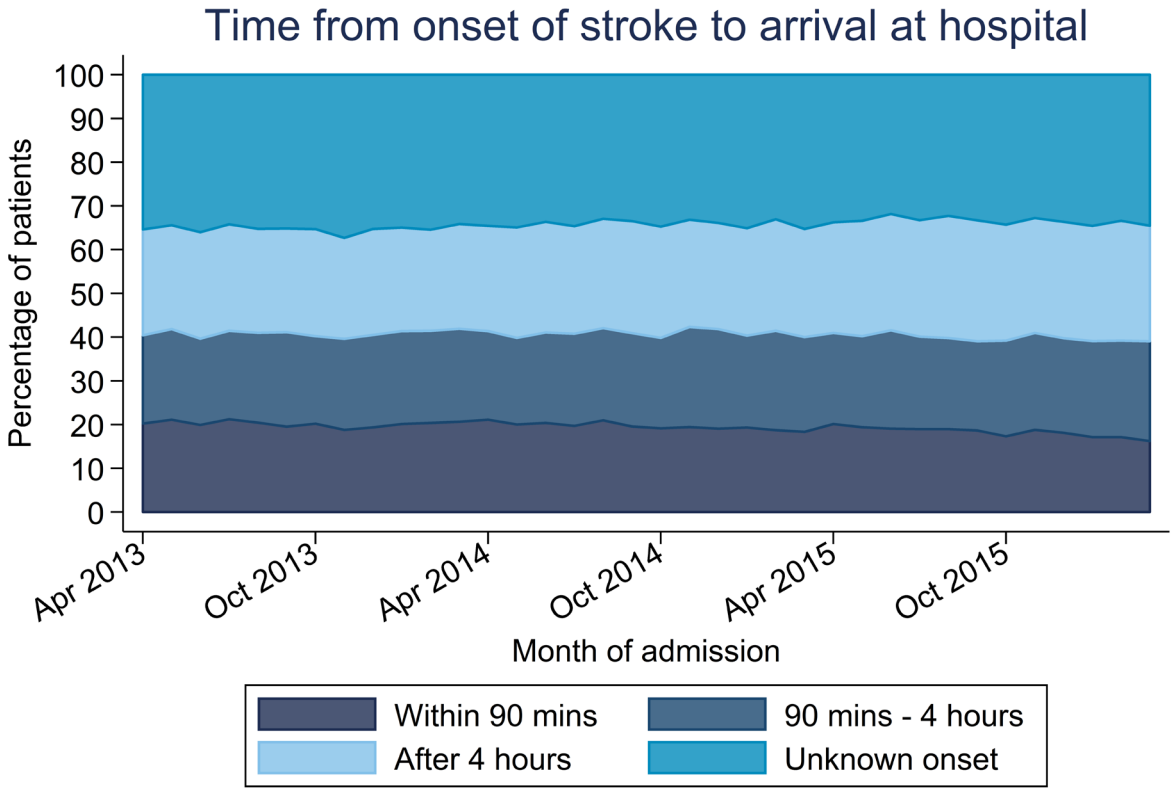
We know that the faster we treat stroke, the fewer deaths there will be and the fewer people who will remain disabled. We have made significant progress in terms of the recognition of stroke symptoms by members of the public (the ACT-FAST campaign has been very successful but the message needs repeating and reinforcing) and in the involvement of paramedics in the design of services to help get patients to the right place as soon as possible.

However, in some areas, access to hospital may be difficult because of long distances, particularly in rural areas, or where ambulance services are under particular pressure. It is worrying to see that fewer patients are arriving in hospital within the 4 hour time window that allows them to benefit from treatments such as thrombolysis, and we need to continue to monitor this. Rapid access to hospital does seem to be possible in some rural areas and we need to understand in more detail what prevents people from getting to hospital quickly.

% of patients who arrived at hospital within 4 hours after stroke onset

(if onset time was known)

2013/2014	2015/2016
63.1%	59.9%



Source: SSNAP Apr 2013-Mar 2016

Figure 6: This graph demonstrates that the percentage of patients arriving at hospital within 90 minutes of stroke onset, and between 90 minutes and 4 hours of stroke onset, has decreased slightly over the last three years.

Treatment of Intracerebral Haemorrhage (ICH)

A haemorrhagic stroke occurs when a blood vessel bursts and bleeds into and around the brain. This is a less common cause of stroke than an ischaemic stroke but over 10,000 people suffered a stroke of this kind between 1 April 2015 and 31 March 2016 in England, Wales and Northern Ireland. People with haemorrhagic strokes have poorer outcomes and effectively treating this type of stroke has proved an immense challenge for stroke professionals.

While we know that many haemorrhagic strokes are very severe and therefore have higher rates of mortality compared to ischaemic stroke, there may be times when it can be treated more effectively. Dr Adrian Parry-Jones used SSNAP data to investigate aspects of care for patients with ICH as described in the case study below.

Treating Intracerebral Haemorrhage (ICH)

Based on: Care-limiting decisions in acute stroke and association with survival

In the UK, intracerebral haemorrhage causes around 12% of strokes but due to its poor prognosis, it accounts for a much higher proportion of deaths. Studies also suggest that 61-88% of survivors remain dependent on others for day-to-day care. Until recently, there were no proven acute treatments for intracerebral haemorrhage. This lack of effective treatments and poor prognosis may be expected to lead to relative pessimism amongst stroke physicians when dealing with this stroke subtype.

In order to better understand this, we used SSNAP data to see whether given similar baseline characteristics and stroke severity, intracerebral haemorrhage patients were less likely than ischaemic stroke patients to be admitted to higher level care and more likely to have end of life (palliative) care commenced. We found that whilst the decision to admit to higher level care was similar between stroke types, intracerebral haemorrhage patients were far more likely to have palliative care commenced.

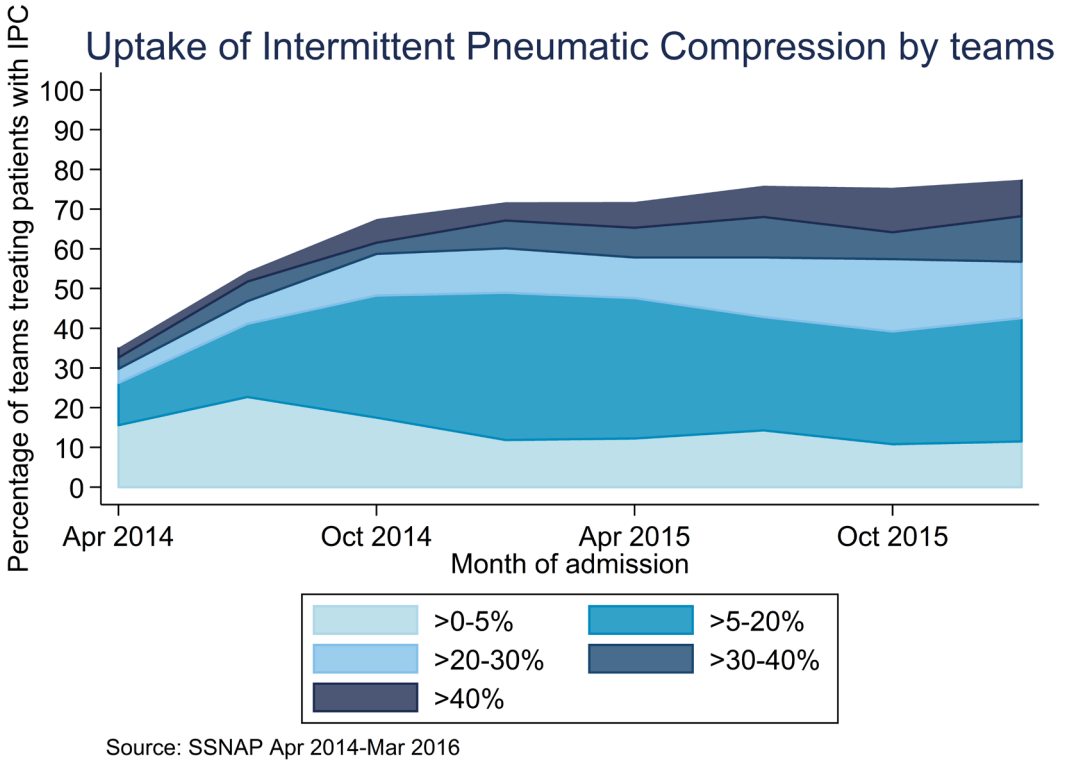
New evidence from the INTERACT2 trial published in 2013 demonstrated that early reduction of blood pressure leads to a reduction in disability at 90 days and improvement in quality of life scores. This intervention is now recommended in the 2016 update of the RCP guideline (www.strokeaudit.org/guideline), and for the first time offers an acute treatment for intracerebral haemorrhage. Along with rapid reversal of anticoagulants in the 10-20% of patients who are admitted to hospital on these medications and referral of carefully selected patients to neurosurgery, blood pressure lowering can be considered part of a bundle of interventions specific to intracerebral haemorrhage that if delivered consistently and effectively will improve outcomes and change perceptions of patients who have this type of stroke.

Ongoing phase 3 clinical trials are testing new interventions for intracerebral haemorrhage. It is therefore hoped that further treatments will become available in the near future, leading to additional improvements in the outcomes of this often devastating form of stroke.

Putting evidence into practice: Intermittent Pneumatic Compression

A common complication of stroke is the formation of blood clots in the veins, often in a person's legs. This is known as deep vein thrombosis. This can be a very serious complication and can even lead to death. In 2012 new evidence emerged in stroke which showed that Intermittent Pneumatic Compression (IPC) can reduce the risk of a person admitted to hospital with a stroke developing a deep vein thrombosis (DVT). IPC is a soft plastic sleeve placed on the patient's legs which provides gentle intermittent compression of the leg veins.

Despite the evidence telling us that this is an effective and potentially lifesaving treatment it is really worrying that only 16.6% of patients were applied IPC this year which is a much lower percentage than we would expect given that around 50% of patients are immobile and can't walk independently after their stroke. Potential reasons for the low uptake in this treatment are discussed by Professor Martin Dennis in the case study on the following page.



Source: SSNAP Apr 2014-Mar 2016

Figure 7: This graph illustrates the uptake of IPC by acute teams over time. More teams are now treating at least some patients with IPC, but we would hope for all teams to treat more than 40% of patients with IPC.

Intermittent Pneumatic Compression in focus

Why are so few patients still not receiving effective Deep Vein Thrombosis (DVT) prophylaxis after stroke?

Based on: The Clots in Legs Or sTockings after Stroke (CLOTS) 3 trial

Venous thromboembolism (VTE), including DVT and pulmonary embolism (PE), is a major cause of avoidable death amongst hospitalised patients. One in three patients with stroke who are immobile will develop a DVT or PE and a third of those dying in hospital will die because of VTE. Although it is unclear whether heparin, or low molecular heparin is useful after stroke, there is now unequivocal evidence from the CLOTS 3 trial published in 2013 that Intermittent Pneumatic Compression (IPC) applied to patients' legs reduces the risk of DVT, and moreover reduces their risk of dying. In 2015 NICE (The National Institute for Health and Care Excellence) recommended that immobile patients with stroke should be offered IPC. Despite this evidence and guidance, the latest data from SSNAP suggest that only a small minority of hospitals in England have effectively implemented this potentially lifesaving treatment. This minority have shown that it is possible to deliver this treatment to a large proportion of immobile patients. Royal Devon and Exeter Hospital are one such example who applied IPC to 64.9% of their patients in Jan-Mar 2016 reporting period.

"We discussed the evidence from CLOTS3 and the NICE guidance in our stroke governance group and decided that it needed consistent implementation within our stroke service. This was greatly helped by the pump-priming support from NHS England, which helped us to make a positive start with changing the culture and expectations for VTE prevention among the medical and nursing staff.
We now regard any VTE on the stroke unit as a rare and unexpected adverse event, which is a great change from the days when we had no evidence about what to do to prevent VTE, and when there was such variation in practice. When the evidence is there, it needs to be promptly implemented."

Dr Martin James - Consultant Stroke Physician, Royal Devon and Exeter Hospital

What are the challenges to IPC implementation?

- Lack of availability of equipment in some Trusts – but it is not expensive!
- Lack of awareness amongst healthcare staff of its benefits
- Lack of clearly defined processes/pathways to identify patients who may benefit and to ensure that IPC is fitted, and applied promptly
- Lack of training of healthcare staff in the use of IPC – but this is freely available on line at www.stroketraining.org
- A false perception amongst some staff that IPC is uncomfortable – staff should try wearing the sleeves themselves. Patients sometimes describe the sensation as being like a massage

With the emphasis generally being placed on improving the safety of our hospitals, and specifically on reducing the risk of VTE, it is puzzling why implementation of IPC, an inexpensive and safe treatment, is so patchy across the UK.

Putting evidence into practice: Intra-arterial Therapy

In ischaemic stroke, where a blood clot is blocking an artery, removal of the blood clot will allow blood to start flowing again to the damaged brain. The usual way of attempting to get rid of the blood clot is by trying to dissolve it, using thrombolysis treatment given directly into a vein in the arm. However, recent studies have shown that direct removal of the blood clot, called thrombectomy or intra-arterial therapy, may be more beneficial in selected patients.

Stroke services should be able to offer patients specialist acute treatments such as thrombolysis which is discussed in detail in section 1 of the report, and thrombectomy, which is an emerging treatment for ischaemic stroke.

Latest figures from SSNAP indicate that very few patients nationally are receiving this treatment. At present there are not many people who have the expertise and experience to provide the service. Working out how to make this treatment accessible to everyone who could benefit from it will be an organisational challenge.

How does it work?

Thrombectomy involves insertion of a thin flexible tube over a guidewire into an artery in the groin, feeding this up into the main blood vessel in the body (the aorta) and then up through the carotid artery in the neck into the blocked artery in the brain. A mesh device is inserted into the artery at the site of the clot, and then pulled back to extract the blood clot and re-establish blood flow.

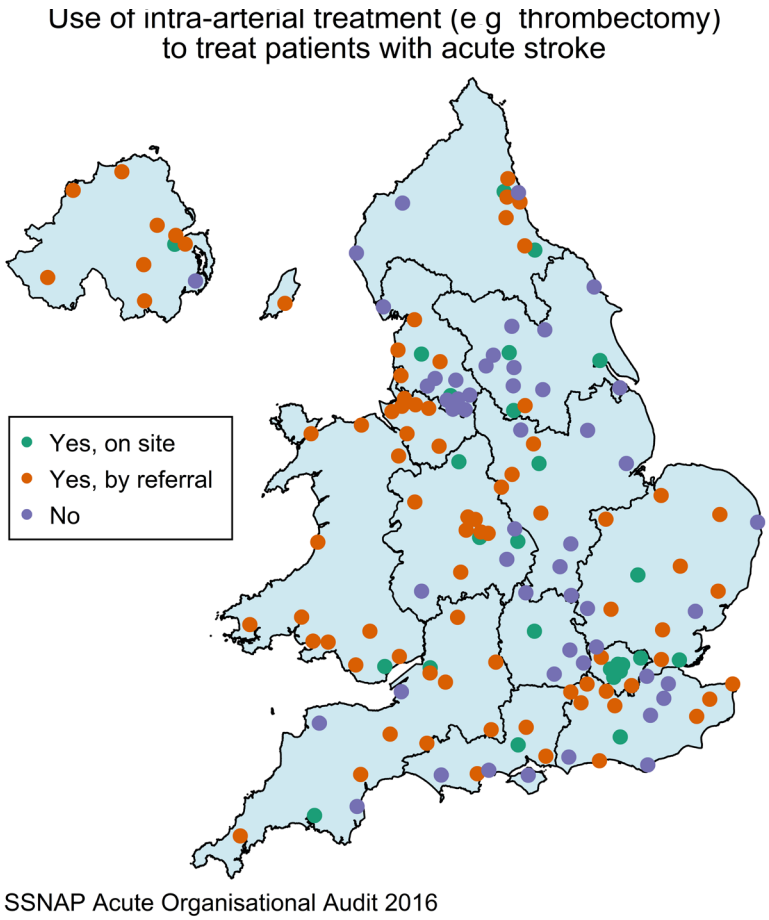


Figure 8: Shows availability of intra-arterial treatment at hospitals treating patients in the first 72 hours. Green dots show hospitals where intra-arterial treatment is provided on site (18%), orange dots are hospitals where intra-arterial treatment is offered by referral to another hospital (50%), and purple dots show hospitals that do not provide intra-arterial treatment on site or by referral (32%).

Providing sufficient therapy to patients

"I thought that I would be speaking again after a short while. I just wanted to get home, I thought it would all be OK"

David, age 57

Therapy in hospital

People really value therapy and the effect it can have on their recovery. Some people, especially soon after stroke, are not well enough for therapy, or get very tired, and cannot tolerate much. Many patients, though, feel they do not get enough therapy on the stroke unit, and spend many hours doing nothing that seems very productive, especially at the weekend. Though it is encouraging to see a slight overall increase in therapy staffing numbers this year, we know that many patients are still not receiving the amount of therapy they need (particularly speech and language therapy). There are still a small number of hospitals with no speech and language therapists.

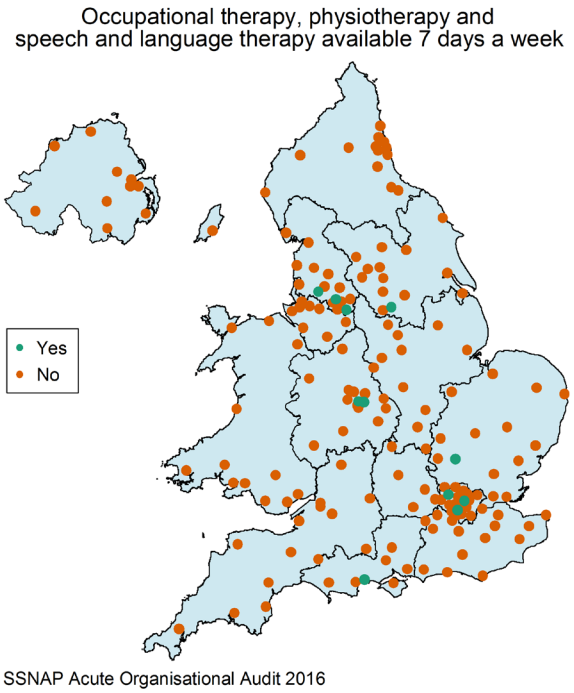
Despite the improvements we have seen in recent years, providing sufficient therapy to all patients remains an organisational challenge for hospitals. All of occupational therapy, physiotherapy, speech and language therapy services are rarely available to patients 7 days a week. However, Dr David Clarke's study on the following page discusses possible ways of increasing the amount of therapy that is provided to patients.

Therapy after leaving hospital

Many people with stroke need further rehabilitation in the community, ideally in their own homes. Early supported discharge (ESD) is a system in which rehabilitation is provided to stroke patients at home instead of at hospital at the same intensity as inpatient care. It can result in better outcomes for patients after stroke and reduce the amount of time that patients spend in hospital. Though 81% of hospitals now have a specialist ESD team available this still means that many patients do not benefit from this highly valued service.

Additionally 2015's Post-acute Organisational Audit revealed that only 29% of ESD teams deliver a 7 day service and there are still substantial delays between discharge from hospital and patients being picked up by an ESD team. This can lead to stroke patients feeling abandoned or alone after being discharged from hospital. There remains work to be done to improve this.

Figure 9: This map has orange dots showing hospitals that don't have occupational therapy, physiotherapy and speech and language therapy available 7 days a week and green dots for those that do



SSNAP Acute Organisational Audit 2016

"There has not been much since therapy has finished. You feel you have just got to learn to get on with it on your own".

Harold, age 78

How can we provide more therapy after stroke?

Based on the paper: "ReAcT study: Why do stroke patients not receive the recommended amount of active therapy?"

SSNAP data identifies units which are performing well across a range of measures including inpatient therapy provision (rated A to E for each therapy). The audit also identifies marked regional and national variation in provision of the recommended amount of inpatient therapy.

A study funded by the National Institute for Health Research (NIHR) led by Dr David Clarke, from the University of Leeds, investigated factors to explain this variation using observations of the day-to-day work of over 200 therapists in eight stroke units across different English regions. The study found eight factors influencing therapy provision; no single factor accounted for why the recommended amount of therapy was not always received. Two of the most important factors identified, which directly impact on therapy provision across all stroke units, were:

1. The amount of time therapists spend in non-clinical activity (such as in information exchange events and meetings)
2. The number of therapists routinely available to provide therapy

Consensus meetings held with expert clinicians in regions not involved in the study confirmed these factors are likely to be common across stroke units in England but are amenable to change as part of local service improvement initiatives.

Royal College of Physicians | Sentinel Stroke National Audit Programme (SSNAP) | www.strokeaudit.org

POST-ACUTE STROKE SERVICES

ENGLAND, WALES & NORTHERN IRELAND

Who does stroke affect?

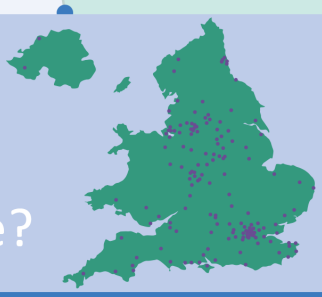
2018 2017 2016 2015 2014 2013 2012 2011 2010 2009

100,000 HAVE A STROKE EACH YEAR

1 IN 7 DIE WITHIN 30 DAYS

SURVIVORS NEEDING POST-ACUTE CARE: **1 MILLION**

What services are there?



604 services providing post-acute stroke care

142 Early Supported Discharge (ESD) Teams enabling stroke patients to return home quicker

QUALITY OF AFTER HOSPITAL STROKE CARE

Needs improving

- **15%** of services commissioned to deliver vocational rehabilitation
- **10 WEEKS** from referral to psychological treatment
- **29%** of Early Supported Discharge teams working 7 days a week

Making progress

- **42%** of services have a time limit to their service
- **60%** of ESD teams treat patients within 1 day of discharge
- **70%** of commissioning areas have at least one team carrying out 6 month reviews

Doing well

- **76%** of eligible services submitting data on how they treat their stroke patients
- **85%** services will re-refer patients if they need to be
- **95%** of services have access to an occupational therapist, physiotherapist and rehabilitation assistant

Financing stroke care

SSNAP Health Economics project

This case study was submitted by Dr Ben Bray, RCP Stroke Programme Research Director

Understanding financial costs is an essential part of managing and improving healthcare. Certainly anyone working in the NHS at the moment can't escape the focus on finances, but making care more cost effective has for a long time been part of the "Triple Aim" of healthcare quality. Getting good quality data about the financial costs of illness is hard, cost effectiveness studies are usually done as part of health technology appraisals rather than to support quality improvement and there is often very little data available about the social care costs of illness.

This year SSNAP has become one of the first national clinical audits in the world to integrate health economics into its regular reports. This is based on a project funded by NHS England that used data from SSNAP and the South London Stroke Register to estimate how much stroke costs health and social care services in the first five years after someone has a stroke. We think that there are lots of ways that this data will be useful: teams will, for example, be able to use the data from SSNAP to put cost data into business plans and work out the potential costs and benefits of improving thrombolysis services and access to early supported discharge.

You can watch a video where Dr Bray discusses the findings and impact of this project using this link https://vimeo.com/187350838

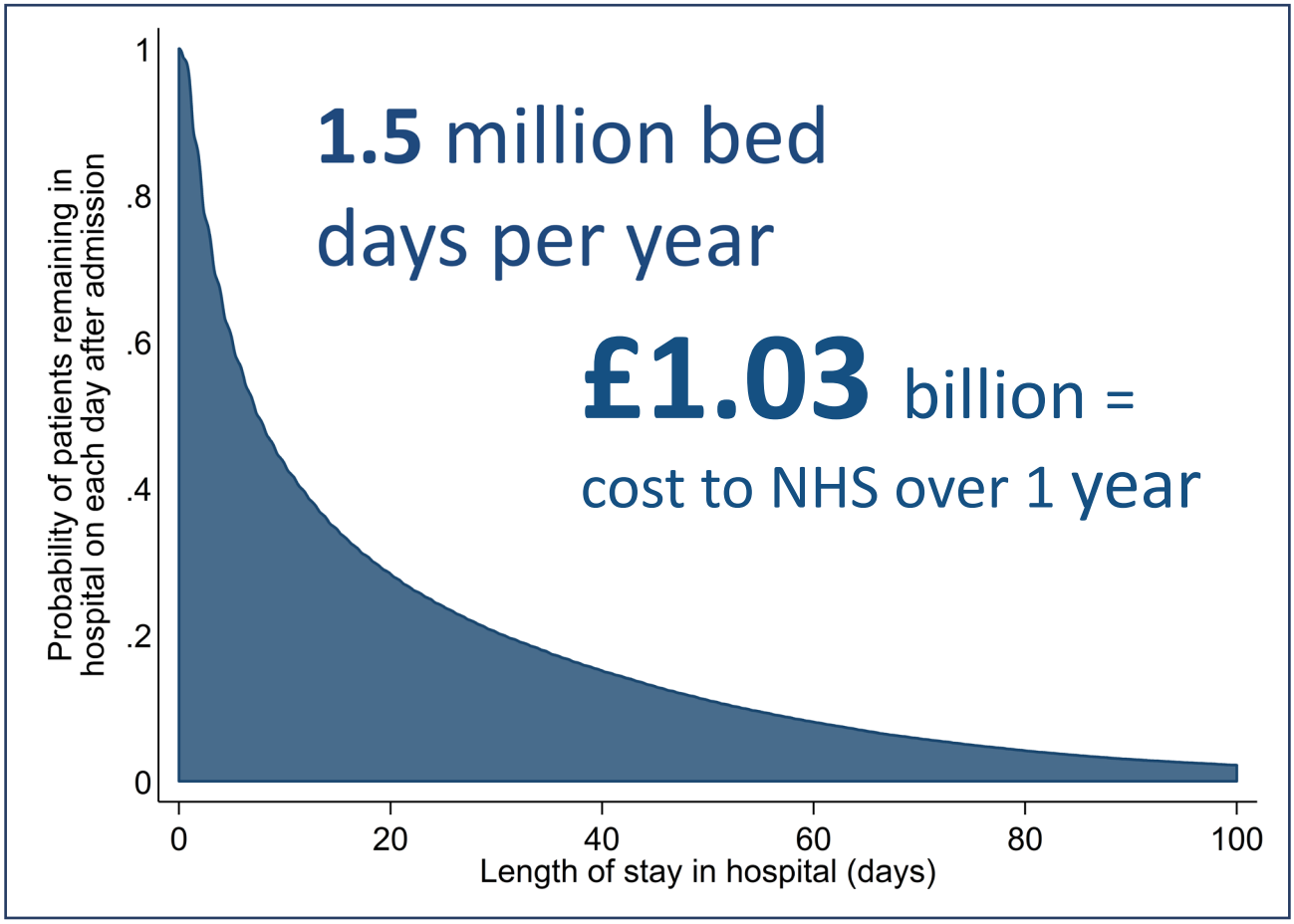


Figure 10: This graph demonstrates the burden of stroke care in the NHS by illustrating the proportion of patients who remain in hospital for different lengths of stay and the cost of treating stroke patients to the NHS over 1 year.

3. What does a good service look like?

Introduction

So far in this report we have looked at some of the encouraging improvements we have seen in stroke care since 2013 and discussed some of the more challenging areas that will require our attention in the future. Next we will investigate what a good stroke service may look like and how this could be structured to best serve patients.

a) Organising care across hospitals within a region

The importance of hyperacute centres

In the past, every local hospital provided stroke care for its local population, but as this generally meant around only one stroke patient would be admitted each day, this model resulted in patients generally being managed by non-specialists because there was insufficient demand to have specialist care around the clock.

The increasing evidence for specialist stroke care, and in particular the impetus to implement thrombolysis, has given us the opportunity to think about how care across a locality (whether a large city such as London or Manchester, or a more rural area such as Thames Valley) is provided, to ensure people have rapid access to the specialist care that they need. A good service has strong links with paramedic services, to ensure rapid access to stroke centres where the stroke specialists are located, and the appropriate staff and infrastructure (beds, scanners, radiology services) to support them.

Patients with stroke need very rapid assessment, with timely delivery of evidence-based care throughout their stroke journey, to discharge and life after stroke. There are a number of different models of how stroke care is delivered, and the right model is designed according to local needs. In the case study on the next page Dr Matthew Burn describes how services in Thames Valley have been reorganised to better serve patients in this region.

Simulation Modelling in focus

Can simulation modelling techniques improve the speed of the stroke pathway?

Based on a study involving the University of Exeter, PenCLARHRC (Collaboration for Leadership in Applied Health Research and Care in the South West), the South West Academic Health Science Network, and 7 regional acute hospitals.

The team used simulation modelling to replicate acute stroke pathways and to ask various 'what if?' questions. The project identified three key areas driving overall thrombolysis rates:

- Speed of the pathway, for example taking FAST-positive patients straight to the scanner rather than going via the Emergency Department
- The importance of ascertaining the stroke onset time (even if this may slow the pathway)
- Confidence in using thrombolysis for patients scanned with time left to thrombolyse

Choosing the best model of stroke services for patients

Based on: Impact of centralising acute stroke services in English metropolitan areas on mortality and length of hospital stay: difference-in-differences analysis

In 2010, Greater Manchester and London centralised their acute stroke services into a small number of specialist "Hyperacute Stroke Units" (HASUs). In Greater Manchester, only patients arriving at hospital within four hours of stroke were eligible for treatment in a HASU; in London, all stroke patients were eligible. In London 93% of patients were treated in a HASU, compared to only 39% of Greater Manchester patients.

In addition, the centralisations were implemented differently: in London, there was:

- greater prioritisation of service standards,
- clinical networks took a more hands-on approach to facilitating change,
- the whole system was launched on the same day.

Patients' length of stay reduced more in both London and Greater Manchester than in the rest of England. However, only London was associated with significantly greater reductions in stroke patient mortality. Therefore, the London centralisation was associated with better patient outcomes. Using national stroke audit data in a study funded by the National Institute for Health Research (NIHR), the researchers analysed the impact of these centralisations on the provision of evidence-based clinical interventions, including rapid access to brain imaging, admission to a stroke unit, and specialist assessments. It was found that, following centralisation, London patients were overall significantly more likely to receive interventions than in Greater Manchester and elsewhere in England. This suggests that centralised systems that admit all stroke patients to HASUs, as in London, are significantly more likely to provide evidence-based care. This may explain why such systems are associated with better patient outcomes.

Restructuring of stroke services in focus

What impact can restructuring of stroke serices have on patient care?

This case study was submitted by Dr Matthew Burn, Consultant Stroke Physician at Wycombe General Hospital and Stroke Clinical Network (SCN) lead for Thames Valley.

Stroke services in Thames Valley were reconfigured in 2010/11 with patients going to a Hyperacute Stroke Unit (HASU) if they arrived at hospital within 4 hours of stroke onset and hence were potentially eligible for stroke thrombolysis. Three hospitals were designated as HASUs, each with 550-700 stroke patients a year. Three other sites were designated Acute Stroke Units and received between 100-350 patients a year.

Evidence since then suggests that better outcomes are achieved with a centralised model, ie taking all patients to a HASU regardless of time of onset. SSNAP data has allowed us to assess the efficacy of the 2010/11 reconfiguration locally. We found a striking difference between the HASUs and non-HASUs particularly for those aspects of care particularly relevant to the first 72 hours of admission.

More recent data has shown that both HASUs and non-HASUs have shown improvement in the non-hyperacute domains, but the non-HASUs have had limited success in improving the hyperacute domains, suggesting that centralisation will be necessary to improve hyperacute stroke care.

This combination of published evidence and local performance data, both telling the same story, prompted commissioners and the Senate to look to develop a centralised model in Thames Valley. The pace of change is variable and is affected by local factors in each area, but the ambition is that all patients with stroke in Thames Valley will be managed on a HASU for the first few days of their admission.

b) Organisation of care within hospitals

The importance of well organised stroke units

A stroke unit is a special ward in a hospital where stroke patients are cared for by a team of professionals (a multidisciplinary team) who specialise in stroke care. There is very robust evidence that stroke units save lives and reduce disability, without increasing costs, so there is no reason to admit a patient with stroke to any other sort of hospital ward, unless they need more specialist care such as the intensive care unit. Once the patient is admitted to the stroke unit, they receive all their nursing care from stroke nurses, are much more likely to see a specialist stroke doctor and stroke therapists, and receive all of their treatments and assessments more quickly. A highly functioning and well organised stroke unit is essential for providing a good stroke service to patients.

Getting to a stroke unit FAST

Patients should go directly to a stroke unit and should arrive there as quickly as possible, certainly within four hours of arrival at hospital, to ensure they receive coordinated care from a specialist stroke team with appropriate facilities. It is a concern that the percentage of patients being admitted directly to a stroke unit within 4 hours of arrival in hospital has not improved over the past three years and still only 83.5% of patients are spending more than 90% of their hospital stay on a stroke unit (our target is 90%). This means that some patients are spending too long in A&E departments or medical assessment units, where they are not receiving specialist stroke care, and where the necessary assessments and treatments are delivered less effectively.

Stroke teams need to investigate how long people are staying in other wards and review work and staffing patterns to see if these delays occur at particular times of the day, for example when fewer staff are available. Having more specialist staff available for longer hours and at weekends can help improve the flow of patients through the system. Some hospitals are reporting increased bed pressures where discharges are delayed making admission to specialist units more difficult. Whiston Hospital's case study gives an excellent example of how SSNAP data can be used to better organise how an acute stroke unit is managed and it could be possible for other hospital trusts to take a similar approach to improving staffing and bed flow at little cost.

% of patients admitted to a stroke unit within 4 hours of arriving at hospital

2013/2014
58.0%

2014/2015
56.8%

2015/2016
58.3%

Using SSNAP data to improve stroke services

The following case study was submitted by Dr Andrew Hill, Stroke Consultant at Whiston Hospital, St Helens and Knowsley Teaching Hospitals NHS Trust.

Being admitted with a suspected stroke can be stressful and bewildering for stroke patients and their families. A simple way to alleviate this and provide high quality stroke care is to try to ensure that patients who have had a suspected stroke are admitted to a specialist ward, and are introduced to and assessed by all the members of the specialist team on the same day that they are admitted. This means that the patient and family can get a timely and well-informed idea of who is providing their care, information about their diagnosis, prognosis, and their initial plan of care.

At St Helens and Knowsley, we realised that SSNAP data is not just useful for examining national performance, but if we used the information real-time we could have a greater understanding of how our service works, and use that information to drive continuous improvement.

We began by looking at our bed capacity: a stroke unit must have an adequate number of beds and policies in place to make sure that when a stroke patient arrives to an Emergency Department that a bed on a specialist stroke unit can be made available immediately. We used information about when stroke patients arrive to hospital, and how long they stayed in hospital, both collected by the audit, to build a model of our unit and work out how big it needed to be in order to do this.

We were next able to use the data to study how long it took everyone in the team to see a patient from their time of arrival. This taught us a lot about barriers to care that we perhaps hadn't considered: promoting very rapid admission to our Hyperacute stroke unit allowed the whole team to work more effectively together and significantly shortened the time to be seen by our team.

We also adjusted both the organisation of the team, and the working hours of our therapy team so that we were better aligned with when the patients arrived (most of our patients present to hospital with their stroke in the late morning or in the early afternoon). For patients and relatives this means that they get an earlier assessment, and a clearer idea of their plan of care. For severe strokes this may mean earlier assessments of swallowing and looking for potential complications such as pneumonia; for mild strokes this may mean plans for discharge being made a day earlier than they may otherwise have been.

We also introduced a review process into every patient's care where our SSNAP data suggested we had not delivered one or more measure of their care, or it was done more slowly than we would like. In that review, we tease out any common themes, brainstorm and quickly implement changes to try to overcome them. This has meant clearer structured documentation, better quality discharge letters, or introducing checking systems. This has meant delivering sustainable changes, and the ability to identify new problems if they occur quite quickly (for example with changes to personnel or other things within or outside the service).

These changes have seen us improve massively on our SSNAP performance from when the audit first began, and we are now consistently amongst the top performing Trusts on the SSNAP audit.

We are very proud to have seen the improvements in our service – feedback from our patients and relatives suggests they are extremely pleased with the service we give, and we are confident we can prove we consistently and efficiently deliver the standards of care set out in NICE and RCP guidance.

c) The importance of staffing

High quality stroke care can only be provided where there are the appropriate specialists available when needed. People with stroke arrive in hospital mainly during the day and late into the evening, although some admissions do occur overnight, and of course through all days of the week.

Stroke Specialist Nurse Staffing

Specialist stroke nurses (often band 6) are often the nurses who attend A&E and undertake initial assessment and management of people with acute stroke. SSNAP data have shown us that current nurse staffing levels are insufficient to provide good care for everyone who needs it, and as we implement the latest National Clinical Guideline for Stroke, it is clear that we will need more skilled nurses rather than less in the future.

Dr Ben Bray, research director of the stroke programme within the Royal College of Physicians, used stroke audit data to show that nurse staffing at weekends impacts stroke mortality within 30 days. The number of patients dying after a stroke is linked to how many registered nurses are working on the stroke unit. The highest risk of death (adjusted hazard ratio) was found in stroke units with the least number of nurses per bed. These findings have major implications for quality improvement and resource allocation in stroke care. The full study is available here http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001705

Stroke Consultant Staffing

A stroke specialist consultant is a physician with expertise in all areas of stroke management including prevention, acute care, and rehabilitation. Following a stroke it is very important that patients are assessed by a stroke consultant as soon as possible to find out what the most effective treatments should be that will maximise their chances of recovery. Throughout a patient's time in hospital a stroke physician will assess the progress made after stroke and review management plans with the wider multidisciplinary team.

The latest SSNAP Acute Organisational Audit results have showed that 40% of hospitals now have an unfilled stroke consultant post which is a very worrying fact. Urgent training and recruitment of consultant stroke physicians is needed in order to ensure this shortage does not worsen further as it is really important that hospitals have sufficient staffing to treat all stroke patients with high quality care.

Developing a 7 day service

People can suffer a stroke at any time of the day and on any day of the week. It is therefore important for hospitals to ensure that there are nurses, therapists, and consultants available 7 days a week to ensure that people who are admitted to hospital with stroke have the best care available at all times. This is a key part of the NHS agenda. It is encouraging to see an increase in the number of hospitals offering daily ward rounds, and occupational therapy and physiotherapy are now available in many hospitals on 7 days a week, but only 20% of acute hospitals are meeting the standard for weekend nurse staffing levels. It is clear that much more work still needs to be done in order for all patients to receive the quality of care they need after their stroke.

A recent research paper by Dr Ben Bray has shown variation in acute stroke care is not only due to what has been called 'a weekend effect', but that specialist healthcare presence is needed every day to ensure that all patients have access to high quality care consistently regardless of the day of the week or time of day they arrive at hospital.

Brain scanning by day of the week and time of day

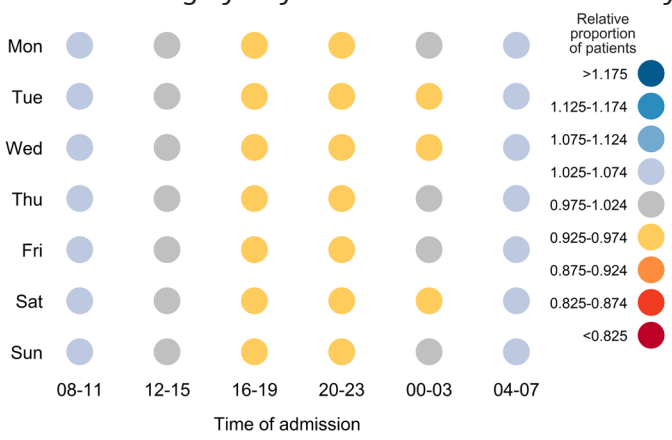


Figure 11: This heat map demonstrates the variation across time of day and day of the week in the proportion of patients who are scanned within 12 hours of arrival at hospital. There is a daily pattern where patients who arrive in the morning are more likely to be scanned within 1 hour than patients arriving in the afternoon and evening.

The "Weekend Effect"

An oversimplification?

Based on paper: "Weekly variation in health-care quality by day and time of admission: a nationwide, registry-based, prospective cohort study of acute stroke care"

There has been a lot of concern and controversy about whether patients admitted to hospital at the weekend receive lower quality care or have worse outcomes – the so called "weekend effect".

Despite the focus on care at the weekends, whether the quality of stroke care varies across the whole week (for example, by varying between days of the week or time of day), had not previously been studied. Using data from SSNAP, the quality of stroke care was mapped out for patients admitted to hospitals in England and Wales with stroke, showing how aspects of care varied across the whole week.

This found that there were not just differences in care between the weekend and the rest of the week, but in fact many aspects of care varied across the whole week. For example, patients waited the longest to be assessed by a physiotherapist or occupational therapist if they had been admitted on a Thursday or Friday, and patients were most likely to receive a quick brain scan if they had been admitted in the morning. This shows that the idea of the "weekend effect" is in fact a major simplification of the variation in care that occurs across the whole week. The study also found that survival rates were no different for patients admitted at the weekend compared to those admitted on a weekday. The main message of the study is that stroke services therefore need to focus on improving care across the whole week, and not only at the weekend.

You can watch a talk by Dr Bray, an author of this paper, that discusses this research and the implications of his findings at the following link: https://vimeo.com/187347196

Availability of psychologists

"The effects were more psychological than physical. I would like more psychology support now; I didn't get any at the time."

Only around 6% of people in hospital with a stroke are reported as needing inpatient psychology input, which is very surprising bearing in mind the burden of low mood and anxiety in hospital, as well as cognitive (attention, memory and concentration) problems reported by service users. However even for this small proportion, the amount of psychology input people receive is small (only receiving any psychology input on an average of 9% of their days in hospital) but this has improved slightly. Access to a psychologist on the ward can help where there are particularly difficult problems, and the psychologist might be able to avoid excessive prescribing of anti-depressants by offering other sorts of treatment as well as proving support and training to the rest of the team.

The 2016 Acute Organisational Audit has revealed that only 6% of hospitals have at least one whole time equivalent (WTE) qualified clinical psychologist for every 30 stroke unit beds. This suggests that only a small number of patients will be able to access input from a psychologist, which contrasts with the high levels of emotional distress reported by patients and their carers following stroke.

Impact of effective psychological treatment after stroke

This case study was submitted by Dr Geoff Hill, Clinical Psychologist in Neuropsychology at South Tees Hospitals NHS Foundation Trust

Andrew was 52 when he had his stroke. He had a number of medical problems including diabetes and arthritis and was also struggling with the loss of his parents and the memories of childhood trauma before the stroke. He was referred by the Stroke Coordinator following his 6 month assessment to the Stroke Neuropsychology team at his local hospital, because of major concerns about his low mood. Andrew said that he felt completely unable to cope since the stroke and had been heavily relying on drinking to block out his emotional pain. Often having suicidal thoughts, he said that if anything further happened to his health he would end his own life. He was very tearful, and felt hopeless.

He was able to engage well with the neuropsychologist to help him understand his distress, and then started on a course of talking therapy. This focused on helping him to explore new, more flexible ways of coping using techniques such as mindfulness. This also supported him to live a richer and healthier life such as eating better, taking regular exercise, starting up his hobbies again, and spending more time with his family and friends.

He quite quickly reported less depression and anxiety, no longer had suicidal thoughts, and was beginning to enjoy life again. He was discharged after 4 months of treatment showing how specialist neuropsychology support can make an enormous difference to peoples' lives.

d) Availability of care in the community

"It was all busy with everyone coming so often. Then it finished, we were expecting it. Then you are on your own, it is scary. But you realise then that you have got to get on with it together" Ruth, 81

A well run stroke service should not only offer patients high quality care in hospital but also provide further therapy, rehabilitation, and support to patients after leaving hospital through early supported discharge and community rehabilitation at home. Evidence shows that rehabilitation at home is cost effective but there needs to be specialist teams in the community able to provide care as soon as someone returns home. These services are highly valued by patients and help recovery.

SSNAP allows us to measure not only the quality of care that people receive in hospital, but also the quality and quantity of rehabilitation services delivered in the community. Most people remain under the care of the community team for around 5 weeks after stroke, but this can be a much shorter time or much longer (25% are under the care of the team for more than 7 weeks). It is good to see that most people are having rehabilitation goals set with them while they are under the care of the team, so they and their carers can participate in deciding what problems need to be addressed and how.

Ongoing support and assessments at six months

The problems experienced by people following stroke change over time. Early on, for example, the emphasis may mainly be on issues such as mobility, speech and swallowing, for many people these problems improve with time and therapy. Six months after a stroke other issues such as fatigue, memory problems, and concerns about returning to work, driving, hobbies and social participation may become more prominent, although many stroke survivors will continue to be very significantly disabled. It is important that even after people are discharged from the community rehabilitation

"I didn't get a six month assessment, but that would be something to look back at, for a mental boost or an incentive"
Hilary, 60

team, people are supported to live as full a life as possible, and a structured, regular assessment of health and social needs at 6 months post stroke and annually is an essential requirement of good stroke care.

A 6 month assessment allows a person with stroke to review with a trained professional how they are getting on, whether they need to make changes to lifestyle or medication and whether further therapy is needed. The six month assessment also provides us with a measure of disability, the modified Rankin scale, which allows us to measure the level of disability amongst our patients at 6 months. Measuring patient outcomes over time is an important tool for improving stroke services.

The 6 month assessment should also include stroke prevention, as following stroke people are at higher risk of further stroke, and so need checks of blood pressure and medication, as well as reinforcement of healthy lifestyle advice. They also need to be able to refer themselves, or be referred, back into appropriate stroke services (for example appropriate therapy services, pain management advice, vocational rehabilitation) and to services provided by voluntary agencies such as the Stroke Association.

% of applicable patients assessed at 6 months after stroke

2013/2014
16.5%

2015/2016
29.9%

SSNAP measures the proportion of people who have had a 6 month assessment and although this is increasing, it is by no means universal. This year only 29.9% of patients who needed one were reported by SSNAP as being assessed at 6 months, and while this is an improvement on previous years, it shows much work is still to be done before 6 month assessments are provided to all patients.

Concluding thoughts

Stroke care has changed beyond recognition in the nearly 20 years that we have been writing stroke guidelines and auditing stroke care. There is widespread recognition now of the need to ACT-FAST when stroke symptoms strike, and paramedics and A&E departments are ready to assess and manage patients quickly, and pass them on without delay to the acute stroke teams that 20 years ago did not exist. CT scanning occurs very rapidly now, and more patients are eligible for, and receive, clot busting treatments. There is much better access to the specialist stroke units that provide the care we know saves lives, and specialist stroke nurses, therapists and doctors are available throughout the day and night.

Yet still there are too many strokes that could have been prevented, and too many people die or are left disabled as a result of stroke. Some hospitals have difficulty providing the level of care that we expect. The cost of not providing good care, both in human and financial terms can be very significant. Commissioners and planners of services need to be aware of the costs of not treating, as well as the costs of treating, when they make their decisions about what stroke care to fund and where.

SSNAP data gives us a very rich picture of stroke care across the NHS, and the rapid feedback of data to hospitals allows them to make changes where their SSNAP results are not as good as they should be, and to continually improve. The data presented in this report has showed where progress has been made, and highlighted aspects of care where there are unacceptable regional variations. Providers and commissioners of services need to address these as a matter of urgency.

This report has not only provided the latest results on stroke care and compared these over time, but also given numerous examples of how SSNAP's rich, robust, and meaningful data is being used for important research studies and by clinical teams working on the ground to improve the quality of care that is provided to their patients. The fact that clinical teams are reviewing and acting on the data available to them to improve patient care in addition to their already busy work schedules is

hugely encouraging and should be celebrated. We hope that this report will inspire others working in stroke to do likewise.

Lastly, the voice of stroke survivors and carers is paramount in all of this; we should be expecting that no less than 100% of our patients receive all the evidence based standards of care, throughout their stroke journey and into life after stroke. We hope that this report has given readers an interesting and lasting insight into stroke and that it will be used in combination with our other available reports as a resource to help campaign for better stroke services in the months and years ahead.

Thanks

We would like to express our thanks to the following people and organisations for their invaluable contribution in producing this report:

Professor Pippa Tyrrell, consultant stroke physician, who has written the clinical commentary for all three SSNAP Annual Reports with prose that is always engaging, informed and accessible.

Richard Creme, an artist and stroke survivor who provided us with the paintings featured on the front cover of this report.

Our patient representatives on the Intercollegiate Stroke Working Party (ICSWP) for their continued support of the programme: Marney Williams, Robert Norbury and Steven Simpson. Their invaluable contribution keeps a patient voice at the heart of what we do as a programme.

Kenny Brown, who graciously contributed photographs of the cover artwork and portrait of the artist.

Gill Pearl and Speakeasy, a charity group for people with aphasia, who have been instrumental in guiding the development of our patient facing reports for a number of years.

The clinicians and researchers who contributed case studies to this report that explain complex areas of healthcare in such a succinct and understandable way.

The hospitals and community teams for continuing to participate in SSNAP, thus ensuring that such rich and robust data is available which can be used to improve stroke services. We want to particularly thank those individuals who work hard every reporting period in submitting these data prospectively so it can be analysed and reported on in a timely way.

Acknowledgements

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We hope that the report can be used to guide, reflect on, and improve stroke care and services in England, Wales and Northern Ireland into the future.

Thank you for reading.
The RCP Stroke Programme

Glossary

Anticoagulant
A type of drug that reduces blood clotting; examples include warfarin.

Atrial fibrillation (AF)
An abnormal heart beat which can result in the formation of blood clots.

Clinical trial
A research study with human participants.

Clinician
A doctor who has direct contact with patients rather than being involved solely in research and teaching.

Computed tomography (CT) scan
An X-Ray technique used to examine the brain.

Continence plan
A plan to help a patient increase their control over bowel and bladder function.

Deep vein thrombosis (DVT)
A blood clot that develops in the large veins usually in the leg.

Door-to-needle time
Term that refers to the time from arrival at hospital or onset of stroke (for inpatient strokes) to the time a patient is thrombolysed.

Dysphagia
Difficulty swallowing.

Early supported discharge (ESD)
A system in which rehabilitation is provided to stroke patients at home instead of at hospital at the same intensity as inpatient care.

Face Arm Speech Test (FAST)
A test used to screen for the diagnosis of stroke or TIA.
https://www.stroke.org.uk/take-action/recognise-signs-stroke

Haemorrhagic stroke
A type of stroke caused when a blood vessel bursts, resulting in bleeding into the brain.

Health technology appraisal
A way of comparing cost-effectiveness of treatments, funded by the NHS.

Incidence
The number of new events (ie stroke) that occurs in a given time period.

Ischaemic stroke
A type of stroke that happens when a clot blocks an artery that carries blood to the brain.

Malnutrition
A condition that develops when the body does not get the right amount of the vitamins, minerals, and other nutrients it needs.

Median
The median is the middle point of a data set; half of the values are below this point, and half are above this point.

Multidisciplinary team
Refers to several types of health professionals working together (physiotherapists, occupational therapists, speech and language therapists, nurses and doctors).

Palliative care
Treating symptoms for end of life care.

Pneumonia
An infection in the lungs partly caused by stomach contents inhaled into the lungs, usually because of dysphagia.

Pulmonary embolism (PE)
A blood clot that develops in the lungs.

Social care costs
Costs associated with the provision of services such as social work, personal care, protection or social support services.

Statin
A type of drug used to lower cholesterol levels.

Systolic blood pressure
The upper figure on the blood pressure reading. If a blood pressure is recorded as 130/80, 130 is the systolic reading and 80 the diastolic.

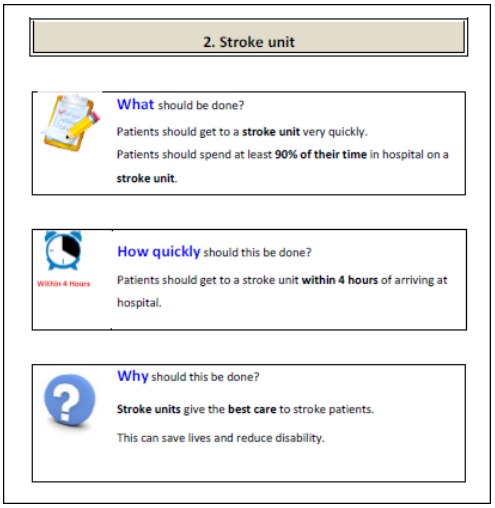
Thrombectomy
Also referred to as **intra-arterial therapy**.
The surgical removal of a blood clot. Thrombectomy is a very new treatment that isn't available in many parts of the country.

Thrombolysis
Treatment with a drug that breaks down blood clots.

Further information on stroke care for patients and carers

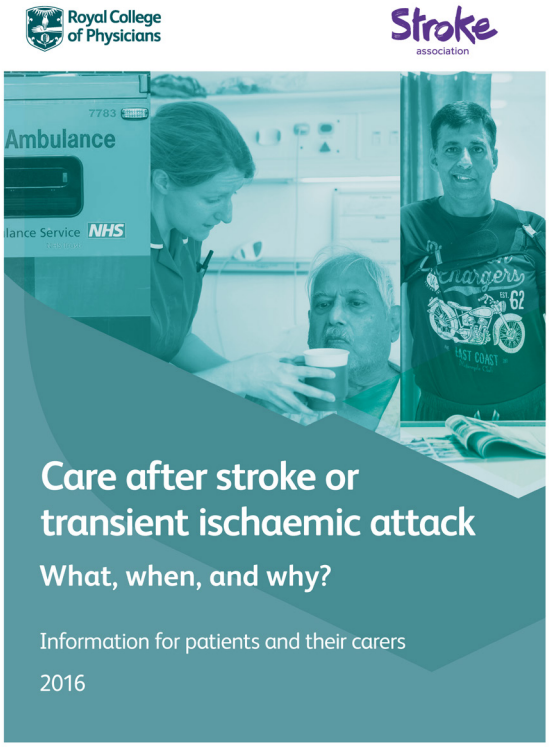
This report is available online, with a full suite of interactive features as well as in-depth case studies, videos and an audiobook version. Go to www.strokeaudit.org/annualreport

SSNAP produces easy access version (EAV) reports every four months which are written specifically for stroke survivors, carers, and people with aphasia. These reports are created for 12 regions within England in addition to Wales and Northern Ireland. This enables readers to ascertain the level of stroke services provided by hospitals in their area in specific aspects of stroke care, and monitor how the levels of care provided to patients are changing over time. These (EAVs) are publicly available on the SSNAP webtool at www.strokeaudit.org/results/regional



SSNAP also produce a patient version of the recently updated 'National Clinical Guideline for Stroke' (2016). This version is written for stroke survivors and their carers but is also useful for anyone who has an interest in stroke care and management. It gives information and advice on the care and treatment of adults after a stroke or TIA (mini stroke). It also has listings of organisations and support groups who can help stroke patients and their families or carers. The patient and carer version of the National Clinical Guideline for Stroke is available to order in hard copy and is also available in alternative formats as a downloadable PDF, interactive online version, ePub/Kindle version, or audiobook.

Please go to the website (https://www.strokeaudit.org/Guideline/Patient-Guideline.aspx) to access the patient version of the 'Guideline'.



Further details on case studies and research referred to in this report

Importance of early assessments: Swallow assessment and pneumonia after stroke
Based on: Bray BD, Smith CJ, Cloud GC, Enderby P, et al, 2016. The association between delays in screening for and assessing dysphagia after acute stroke, and the risk of stroke-associated pneumonia. *Journal of Neurology, Neurosurgery & Psychiatry*, [Epub ahead of print].
http://jnnp.bmj.com/content/early/2016/06/13/jnnp-2016-313356.abstract

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Treating Intracerebral Haemorrhage (ICH)
Based on: Parry-Jones AR, Paley L, Bray BD, Hoffman AM, et al, 2016. Care-limiting decisions in acute stroke and association with survival: analyses of UK national quality register data. *International Journal of Stroke*, 11, 321-31. http://www.ncbi.nlm.nih.gov/pubmed/26763918

For further details, please contact:
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Intermittent Pneumatic Compression in focus
Based on: Dennis M, Sandercock P, Graham C, Forbes J, 2015. The Clots in Legs Or sTockings after Stroke (CLOTS) 3 trial: a randomised controlled trial to determine whether or not intermittent pneumatic compression reduces the risk of post-stroke deep vein thrombosis and to estimate its cost-effectiveness. Health Technology Assessment, 19. http://www.journalslibrary.nihr.ac.uk/hta/volume-19/issue-76#abstract

Further information can be found on the study webpage at http://www.dcn.ed.ac.uk/clots/

How can we provide more therapy after stroke?
Based on: Clarke DJ, Tyson S, Rodgers H, Drummond A, et al, 2015. Why do stroke patients not receive the recommended amount of active therapy? *BMJ Open*, 5, e008443. http://bmjopen.bmj.com/content/5/8/e008443.full

For further details, please contact:
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Financing stroke care
For further details, please contact:
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Simulation Modelling in focus
Further information can be found on the PenCLAHRC webpage
http://clahrc-peninsula.nihr.ac.uk/

Restructuring of stroke services in focus
For further details, please contact:
Dr Matthew Burn: matthew.burn@buckshealthcare.nhs.uk

Stroke Specialist Nurse Staffing
Bray BD, Ayis S, Campbell J, Cloud GC, et al, 2014. Associations between Stroke Mortality and Weekend Working by Stroke Specialist Physicians and Registered Nurses: Prospective Multicentre Cohort Study, *PLOS Medicine.* 11(8) http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001705

For further details, please contact:
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Choosing the best model of stroke services for patients
Based on: Morris S, Hunter RM, Ramsay AIG, Boaden R, et al, 2014. Impact of centralising acute stroke services in English metropolitan areas on mortality and length of hospital stay: difference-in-differences analysis. *BMJ*, 349. http://www.bmj.com/content/349/bmj.g4757

Further information, including accessible summaries of the work, can be found on the study webpage: https://www.ucl.ac.uk/dahr/research-pages/stroke_study

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Using SSNAP data to improve stroke services
For further details, please contact:
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The "Weekend Effect"
Based on: Bray BD, Cloud GC, James MA, Hemingway H, et al, 2016. Weekly variation in health-care quality by day and time of admission: a nationwide, registry-based, prospective cohort study of acute stroke care. *Lancet*, 288, 170-77.
http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(16)30443-3/abstract

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Impact of effective psychological treatment after stroke
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