Is stroke care The Second SSNAP improving? Annual Report

Care received from April 2014 to March 2015





Sentinel Stroke National Audit Programme (SSNAP) "I had a stroke in 2011.

I had 8 weeks in hospital.

I couldn't speak, I would open my mouth but it was just rubbish.

I started off writing but I could draw an 'R'.

I could do drawing but not with paint, it was too messy.

Felt pens in sketch books.

It was simple and complex.

I came out and it was weird.

After a month I had speech therapy, it was really good.

Then I had some seizures, it was terrible.

After two years I had an exhibition called 'A Sore Head'.

And a book in April 2015."

Robert Welch

The drawings featured on the front and back cover of this report were taken from Robert's 'A Sore Head' exhibition in 2012.

His book is available from: www.aptstudios.org

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Foreword

Without information and data about stroke services in England, Wales and Northern Ireland there would be no chance of persuading clinicians, commissioners or policy makers that there is still work to be done to ensure that patients can be confident that they will always receive the best possible care, regardless of where they live or when they have their stroke. Progress is being made and I am always encouraged when I visit hospitals and community teams by the energy and genuine commitment to deliver high quality care by the staff working with stroke patients. They do not always get the recognition that they deserve. The work is often difficult and both physically and emotionally draining. We should all be grateful that there are people willing to devote their professional lives to working with people who suffer a stroke.

Stroke and other vascular diseases remain a priority within NHS England, particularly with respect to developing better ways of preventing it. It is estimated that up to 70% of all strokes could be avoided if the risk factors were treated and people adopted healthier lifestyles. It is worth making every possible effort to avoid stroke because however good our services are at treating stroke acutely and in the longer term there will always be people whose strokes are just too severe that the disease shortens their lives or leaves them with long term severe disability. It can be an incredibly cruel disease. So read the section in this report on atrial fibrillation, checking your own pulse and diagnosing and treating high blood pressure and make sure that your friends, colleagues and family do the same.

I want to thank the team who run the SSNAP Programme at the Royal College of Physicians. The work involved in encouraging everyone to get their data in on time and then processing the huge amounts of information in a remarkably short time to produce reports for everyone from commissioners to clinicians and patients is amazing.

Please contact me and the team if you have any comments either on the report or stroke care more generally.

Tony Rudd CBE Stroke Programme Director, Royal College of Physicians London Professor of Stroke Medicine, King's College, London Consultant Stroke Physician, Guy's and St Thomas National Clinical Director for Stroke NHS England London Stroke Clinical Director

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What is this report about and who is it for?

Who is this report for?

This report has been written for everyone with an interest in stroke care, both those who are directly involved with the Sentinel Stroke National Audit Programme (SSNAP) and those who are not. We hope that it will be used by patients, carers and stroke survivors, and people who campaign for better stroke services. Some readers will already be familiar with other reports we have produced; we hope that you find this to be a useful supplement to those reports. Other readers may not have come across SSNAP at all before; we hope that this report provides a valuable insight into stroke care in England, Wales and Northern Ireland, and will encourage you to look at more SSNAP information.

What is SSNAP?

SSNAP is a national audit programme, which means that it collects information about healthcare services to find out if those services are being provided in line with what the evidence says is best for patients. SSNAP then reports the findings to healthcare professionals providing and managing the services, to the organisations that pay for the services, and to the public.

Within SSNAP there are two complementary audits. 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. The second is an acute organisational audit, which measures the structure of stroke services, for example, what kind of services are provided and how many staff they have. This year for the first time, we have also done a post-acute organisational audit, to find out what services are available to stroke survivors 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, and empowering patients, carers, stroke survivors and the wider public to call for improvements by providing information about where they are needed.

What are the aims of this report?

This report aims to answer a number of important questions about stroke and the quality of stroke care in England, Wales and Northern Ireland. The report uses the two years' worth of data now collected by SSNAP to compare performance in key areas of care between 2013/14 and 2014/15, identifying where improvements are being made to stroke care, and which areas need further work.

There are many more questions which could potentially be answered using SSNAP data, but we wanted to make sure this report was easy to digest. SSNAP produces more detailed reports every three months and annually that show how well every stroke service is doing. These are available for anyone to see at: www.strokeaudit.org/results

For details on how you can find out more information about stroke, please see the back pages of this report.

1. WHAT HAS HAPPENED TO ME?

What is a stroke?

A stroke occurs when the blood supply to part of the brain is cut off. It can be caused by a blockage in one of the blood vessels leading to the brain (infarction), known as an ischaemic stroke, or a bleed in the brain (haemorrhage). Strokes impact people in different ways. This depends on the part of the brain affected, how widespread the damage is and how healthy the person was before the stroke. Strokes can affect movement and speech, as well as thought processes and how somebody feels.

Diagnosing a stroke

The diagnosis of stroke is made on the basis of a careful history and examination. The only way to distinguish between an ischaemic stroke and a haemorrhagic stroke is by a brain scan. Most strokes are ischaemic. The proportion of strokes that clinicians designated as "unknown" has fallen slightly this year. This is a good sign, and a reflection of the fact that scans tend to be done sooner now, allowing earlier diagnosis, with very few people not receiving a scan at all.

The left hand scan here shows a large infarct or blockage - the black areas are dead infarcted brain.

The right hand scan shows a haemorrhage - the white areas show the area of bleeding into the substance of the brain. 88%

of patients had a blockage (infarction) as the cause of their stroke

11%

of patients had a bleed (haemorrhage) as the cause of their stroke

1%

of patients did not have their stroke type recorded

Stroke Facts

- Over 100,000 people have a stroke each year in England, Wales and Northern Ireland
- There are approximately 1 million stroke survivors living in England, Wales and Northern Ireland
- Stroke is a leading cause of adult disability. More than half of all stroke survivors are left dependent on others for everyday activities
- 1 in 7 stroke patients died within 30 days after admission to hospital last year
- Stroke is now the third leading cause of death in the UK





How do we know when the stroke occurred?

It is important to know as accurately as possible when the stroke happened. There are some treatments such as thrombolysis, known as a "clot buster", which can only be given within a specified time following an ischaemic stroke. Therefore, it is vital to have as much information as possible about the time of onset of symptoms. For many people, the onset of symptoms is quite obvious: they (or a witness) can report exactly the time at which they became unwell.

Clinicians need to take a very careful history, including from the paramedics who brought the patient in, to ensure that the onset time is as accurate as possible. For one third of people admitted with stroke, the time of onset of symptoms is not known. This means that some acute treatments cannot safely be given to them.

Sometimes symptoms may be less clear. For example, more subtle symptoms of stroke (such as changes in sensation, balance or vision) may not be obvious initially so people are not quite sure when they started. Some strokes are only apparent when people wake from sleep, or occur when they are alone at home, so the onset time is taken as the 'time last seen well'.



Stroke Onset Times

32%

of patients had an unknown stroke onset time

68%

of patients had a precise or best estimate of the stroke onset time



Current research is investigating whether brain scanning techniques can be used to give a better idea of the "age" of a stroke, for example in people who have woken with symptoms, which may help to select some of these people for acute treatments.

Preventable causes of stroke

Atrial Fibrillation

Atrial fibrillation (AF) is a completely irregular heartbeat. People with AF should normally be on anticoagulant drugs to reduce the risk of stroke. Anticoagulants are medicines that help prevent blood clots by interrupting the process involved in the formation of blood clots. Increasing the proportion of people with AF on anticoagulants will reduce the number of people having stroke.

There is a campaign called 'Know Your Pulse' which is trying to get the message across about the importance of early detection and treatment of AF. You can learn how to take your pulse and find out much more information about this important campaign by visiting www.knowyourpulse.org



Hypertension

More than half of people presenting with acute stroke are known to have high blood pressure (hypertension). Lowering blood pressure in those people is a very important way of reducing the likelihood of having a stroke.

54% of stroke patients had known hypertension before their stroke

Atrial Fibrillation Facts

On arrival at hospital

20% of stroke patients are known to have been in AF before stroke

48% of those who need anticoagulant medication are on it before stroke

When leaving hospital

22% of patients discharged alive from hospital are in AF

95% of those who need anticoagulant medication are given it at discharge

Six months after stroke

Almost 20% of patients we know about in AF discharged on anticoagulants are no longer taking them six months later

Simple lifestyle steps such as reducing salt intake and taking more exercise makes a difference, and all adults should have regular blood pressure checks.

Understanding stroke severity

It is really important that people presenting with acute stroke are fully assessed as soon as possible so that everyone understands exactly what effects the stroke has had. A detailed neurological examination, looking at the functions of the brain and nerves, is a vital part of the initial assessment. If this is not done carefully, important problems may be missed and treatments delayed.

NIHSS

The National Institutes of Health Stroke Scale (NIHSS) is the standard way of measuring stroke severity. It is a scoring system (the higher the score the more severe the stroke) and gives a measure of the types of problems people have. It was developed as a simple way of documenting the findings from a neurological examination of people with stroke. There are points for different problem areas; measuring how alert the person is (level of consciousness) and problems with vision, balance, strength, speech, sensation and awareness. Ideally everyone presenting with a stroke should have a NIHSS recorded on admission to hospital as part of routine care.

Completion Rates

In measuring the extent to which every patient is assessed using NIHSS scoring on admission in SSNAP, it can be seen that more clinicians are doing the NIHSS routinely. At the very least, the first question on the NIHSS should be measured: level of consciousness. It is good to see that the proportion of people for whom only this question is answered is falling, and the proportion fully assessed is increasing.

Figure 1: shows the proportions of people suffering different severities of stroke



Figure 2: This graph shows the number of strokes in different age groups

2. WHAT CAN BE DONE ABOUT IT?

Why do we need to Act F.A.S.T.?

It is really important that people with a stroke get to hospital as quickly as possible. If people Act F.A.S.T. and dial 999 as soon as someone appears to have had a stroke, paramedics can assess them quickly and transport them to hospital without delay. Over 80% of stroke patients come to hospital by ambulance, but sometimes the response in hospital is not as fast as it could be.

Getting to hospital

By measuring the time from when someone's symptoms start to their arrival in hospital, it is possible to measure the speed of the response to stroke in the community. This includes the time it takes for the paramedics to bring the person to hospital. By getting data every year it is possible to see whether services are improving. This year there has been a slight overall increase in onset to arrival time which will need to be continuously monitored.

The importance of scanning

A brain scan is vital for making an accurate diagnosis of stroke. An immediate brain scan is also more cost effective than a delayed one. Hospitals need to ensure that people with suspected stroke are scanned as early as possible. Ideally, everyone would be scanned immediately on arrival. It is estimated that around half of all people have symptoms that definitely warrant an immediate brain scan (for example if they are eligible for thrombolysis).

It is encouraging to see the proportion of people having a brain scan within 1 hour improving this year compared with last year. There is no clinical reason to delay a brain scan. The standard is that everyone should be scanned within 12 hours of arrival. This standard was achieved in 88% of people and has improved compared to last year's figure of 85%, which translates into almost 3000 additional patients being scanned within 12 hours this year compared to last. Furthermore, the time between having the stroke and getting thrombolysis has also reduced. Together these suggest that acute stroke teams in hospital are better organised.





Stroke unit admission

A stroke unit is a hospital ward that specialises in treating stroke patients both during the event and in the crucial first few days after. The core team usually consists of doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, therapy assistants, psychologists, dietitians, and social workers. Research has shown that stroke patients treated on a stroke unit do better than those treated on medical wards or general assessment units. Patients are more likely to survive the stroke, have fewer disabilities and be able to live independently if treated on a stroke unit.

Getting to a stroke unit

SSNAP measures how quickly the stroke team responds once the patient is in hospital. The standard is that patients go to a stroke unit as their first ward and do so within 4 hours of arrival. People who get to a stroke unit quickly are more likely to receive the treatment they need in a timely manner. Unfortunately, fewer patients are being admitted to a stroke unit within this timeframe when compared to last year. This is partly because many patients are not being taken to a stroke unit as the first ward of admission. While it may be clinically appropriate for some patients to be admitted to another ward (such as those who need access to the intensive care unit) it is concerning that almost 25% of patients are initially



admitted to another ward such as a medical admission unit. This is not good for patients and is an inefficient use of hospital beds.

It is expected that all patients spend 90% or more of their admission in the stroke unit rather than other wards. This was achieved for 82% of applicable patients, slightly down on last year.

Trusts need to improve access to stroke unit care and ensure that patients are not being moved unnecessarily between areas and staying in non-specialist wards.



Variations in stroke unit admissions

The graphs below show that patients are less likely to be directly admitted to a stroke unit quickly in the early hours and on certain days of the week.



Figure 3: This shows the likelihood of direct stroke unit admissions within 4 hours depending on the time of arrival in the left hand graph and the day of the week in the right hand one

Are patients being admitted to stroke units faster?

Figure 4 shows that over the past year there has been a deterioration in the percentage of patients admitted quickly to a stroke unit as their first ward, falling from 59.8% between July and September 2014 to 53.6% between January and March 2015.



Figure 4: This shows the percentage of patients admitted to a stroke unit as their first ward within 4 hours over the past two years

How effectively is thrombolysis being delivered?

What is thrombolysis (clot busting drugs)?

Thrombolysis is a treatment administered to stroke patients which can break down and disperse a clot that is preventing blood from reaching the brain. Breaking down a blood clot can restore blood flow to the brain, and, if given early enough, can save brain cells from damage and reduce disability. The proportion of stroke patients thrombolysed has increased in recent years and it has made a very significant change to the way stroke patients are being treated.

Who is eligible for thrombolysis?

Not everyone with acute stroke is suitable for thrombolysis (clot-busting) treatment. People with stroke due to haemorrhage, people who arrive at hospital more than 4 and a half hours after stroke onset, and people with abnormalities of blood clotting (including those taking anticoagulant medication) are not suitable for this treatment.

Thrombolysis timings

The proportion of all people having a stroke who receive thrombolysis remained the same as last year (12% of all strokes). Up to 20% of stroke patients are eligible for thrombolysis, but this depends on whether patients can quickly get to a hospital that offers thrombolysis. The quicker thrombolysis is given following a stroke the more effective it is, so the time taken from the onset of symptoms to the time the treatment starts (onset to needle time) and the time taken from arrival in hospital to starting treatment (door to needle time) are both monitored by SSNAP. Ideally all thrombolysed patients would receive treatment within 3 hours of onset as research shows that this will give the best results.

Figure 5 shows that since 2004 the proportion of patients receiving thrombolysis out of all patients has risen dramatically. This is a big long-term improvement.





"I am still blessed and amazed how quickly I have recovered after the stroke. I am nearly back to where I was before. It was a really scary episode but the whole experience from start to finish was very good: I felt that I was looked after by highly skilled stroke specialists consisting of doctors, nurses, therapists and ambulance staff throughout the whole process."

Tina, 38 - patient who received thrombolysis

Figure 6 shows that patients are less likely to receive thrombolysis within 60 minutes if they arrive at hospital "out of hours" (between 20.00 and 07.00 hours).



Figure 6: The percentage of patients who receive thrombolysis depending on their time of arrival

Swallow screening and assessment

One of the most important immediate assessments that should be made when a patient is admitted to hospital is the swallow screen. Around 40% of people with acute stroke cannot swallow safely and are at risk of aspirating food and drink into their lungs leaving them at risk of pneumonia. A swallow screen should be carried out by trained staff with the patient in the correct position.

More patients who needed a swallow screen had one within 4 hours of arriving at hospital when compared to last year which is encouraging. However, this still means that more than 22000 patients who should have received a swallow screen were not given one within 4 hours of their admission.

If a swallow screen detects some problems with swallowing, it may not be appropriate for the patient to eat or drink. They need to have a formal assessment from a speech and language therapist who can confirm whether or not the patient still has a swallowing problem and how best to manage it. Of those who need one, 83% of people are now receiving a formal swallow assessment within 72 hours of arriving at hospital, an improvement on last year.

Swallow screening within 4 hours 2013/2014 64% of patients had a swallow screen within 4 hours if they needed one

2014/2015 68% of patients had a swallow screen within 4 hours if they needed one

Dr Craig Smith, a consultant in stroke medicine at Salford Royal NHS Foundation Trust in Manchester, used stroke audit data to derive a new simple risk score for predicting stroke-associated pneumonia that can be used in a clinical setting. The risk of a patient being diagnosed with pneumonia after stroke is linked to how independent the patient was prior to stroke, as well as the patient's gender, age and stroke severity. The new risk score helps identify those patients most at risk of developing pneumonia.

Smith CJ, Bray BD, Hoffman A, Meisal A, et al. (2015)



Is there age discrimination in stroke care?

In recent years, inequalities of acute stroke care on the basis of patient age have been vastly reduced. Regardless of age on admission, almost all stroke patients are now receiving a brain scan within 24 hours as the graph below demonstrates.



There has also been a reduction in age discrimination with respect to stroke unit admissions. Audit data in 2004 showed that older patients were less likely to be admitted to a stroke unit than younger patients. Stroke units provide the most appropriate care to patients so it is encouraging to see not only a higher proportion of stroke patients being treated in stroke units, but that discrimination on the basis of age has also been eliminated. The graph below demonstrates the reduction in age discrimination for patients admitted to stroke units. It also shows long-term improvement in the proportion of patients being treated in stroke units may be admitted to stroke units.



Emerging treatment: thrombectomy

What is thrombectomy?

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.

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.

At present there are very few people who have the expertise and experience to provide the service. Working out how to make this treatment accessible to everyone who needs it will be an organisational challenge. Below is a picture of a "stent retriever", the mesh device used to extract a blood clot in a thrombectomy. Availability of thrombectomy SSNAP asked units in July 2014 whether their centres provided intra-arterial therapy or whether they could refer people on for this treatment.

13% of centres had some access to intra-arterial therapy (but not 24 hours),

42% did not have direct access but could refer people for intra-arterial therapy.

46% had no access to intra-arterial

therapy at all.

In total it was reported that 295 patients were treated intra-arterially between April 2013 and March 2014.



3. WILL I GET BETTER AND WHAT ARE THE TIMESCALES?

Some people are able to go home very quickly after a stroke, although most would say full recovery does not happen for months or years, even when the stroke has been very mild. Many people need rehabilitation in hospital.

Nurses, speech and language therapists, physiotherapists, occupational therapists, psychologists, dietitians, pharmacists and doctors make up the multidisciplinary team working alongside the patient and their family to try to achieve the best levels of recovery before the patient is discharged home.

Therapy often continues after leaving hospital and is provided by an Early Supported Discharge or Community Rehabilitation Team. Figure 9 shows how long patients have to wait after they're discharged before being treated by an Early Supported Discharge or Community Rehabilitation Team.





Important assessments before leaving hospital

Nutrition

Following a stroke, many people cannot eat and drink safely. These people may need a drip to provide fluids, and sometimes tube feeding to provide fluids, nourishment and medication. Even people without swallowing problems identified in a swallow assessment may not drink or eat enough because they have difficulty seeing or reaching for food and drink, drowsiness or low mood.

Patients who need to have a nutritional assessment should receive one before leaving hospital. They should also be seen by a dietitian if required. This year, a higher percentage of patients were initially screened to identify the risk of malnutrition compared to last year and more of those patients at risk were seen by a dietitian. This means that these important processes of discharge from hospital were achieved for approximately 1000 more patients.

Mood and cognition screening

Many people have low mood after a stroke, may suffer from depression or anxiety, and have difficulties with cognition (for example remembering things, concentrating or being able to plan a task). Sometimes these problems may not be immediately obvious to the ward team or to family and friends, so it is important to screen for them.

82% of those stroke patients who needed mood screening received one before they were discharged. This has improved from 73% last year. 90% of patients who were applicable for a cognition screening before discharge received one this year. This is another improvement on last year's figure, which was 84%. This is encouraging as it means more patients are identified for follow up treatment.



Nutritional screening and dietitian assessment

2013/2014

13/20 patients were screened for nutrition and seen by a dietitian before leaving hospital if they needed to be.

2014/2015

15/20 patients were screened for nutrition and seen by a dietitian before leaving hospital if they needed to be.

"I lost my confidence. I couldn't read or write. My vision was affected. I couldn't socialise. I find it difficult to deal with my frustration."

Eileen, 57

Continence

Managing continence is very important for those who are incontinent following their stroke. In last year's report, SSNAP highlighted that 5 out of every 20 patients who required a continence plan did not have one within three weeks after their stroke. Improvements have been made this year and now this is only occurring for 3 out of every 20 applicable patients.

However, this still represents approximately 5000 patients who needed a continence plan not receiving one within three weeks of stroke, which is very concerning. All patients requiring a plan for continence should receive one within 3 weeks of their stroke.

Continence planning 2013/2014 15/20 patients requiring a continence plan received one before leaving hospital.

2014/2015

17/20 patients requiring a continence plan received one before leaving hospital.

Palliative care

Palliative care (care that is focussed on symptom control and a good death, rather than trying to make someone better) is always a very sensitive and difficult issue. In stroke it is particularly complex because people can become so ill very quickly, and because sometimes it is difficult to distinguish a very severe stroke that might respond to treatment from one that is very unlikely to. Making a palliative care decision is difficult but it is an incredibly important part of stroke care. Making sure that someone's final few days or hours are as comfortable as possible should be a paramount concern for all.



Figure 10: This graph shows the proportion of patients who go into palliative care, broken down by age group and number of strokes

Weekend staffing

The SSNAP Acute Organisational Audit in 2014 investigated the numbers of nurses and therapists available on the stroke unit at different times of the week. Not all therapists were available every day. Ideally, all units would have members of these teams available at least six days a week.



Do staff levels matter?

Dr Ben Bray, research director of the stroke programme within the Royal College of Physicians, used stroke audit data to investigate if nurse staffing at weekends impacted 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. 35% of teams have an occupational therapist available six or seven days of the week

44% of teams have a physiotherapist available six or seven days of the week

8% of teams have a speech and language therapist available six or seven days of the week





This graph highlights that the higher the number of nurses per 10 beds, the lower the risk of death.

Figure 11: shows the number of weekend nurses per 10 beds against adjusted hazard ratio of 30 day mortality of patients admitted on weekends

Care after leaving hospital

What is Early Supported Discharge (ESD)?

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. This means that patients can return home quicker than they would otherwise be able to.

An ESD team is usually made up of different healthcare professionals such as occupational therapists, speech and language therapists, and physiotherapists who are often stroke specialists. The team will usually provide intensive treatment at first which will gradually reduce in intensity as the patient recovers. The Post-Acute Organisational Audit reported that the majority of ESD services are available on only 5 days or less each week. As ESD teams should provide the same level of care to patients that they would receive if in hospital, these teams should provide services every day of the week.

60% of ESD teams deliver a service that is available to patients on 5 days or less.

11% of ESD teams deliver a service that is available to patients 6 days a week.

29% of ESD teams deliver a service that is available to patients on 7 days a week.

Where is ESD available?

ESD can result in better outcomes for patients after stroke and reduce the amount of time that patients spend in hospital. It is a service that many patients value highly. It is therefore seriously concerning that there are some areas in the country where patients do not have access to ESD. The map below uses 2015 Post-Acute Organisational Audit data to highlight regional variation in the availability of ESD services. All areas should be providing ESD for everyone who needs it.



Figure 12: This map shows in light blue those areas which have access to ESD services and pinpoints the location of the service based on the results from the Post-Acute Organisational Audit in 2015 "I feel that ESD would have helped my recovery from stroke. I would have been able to go home sooner but still receive the care I needed. Living at home would have allowed me to be closer to my friends and family during a very difficult period of my life. Unfortunately this service was not available to me. However, if I had lived a few hundred metres further away, it would have been an option. Availability of ESD should not be a postcode lottery."

Bob, 63

Six month assessments after stroke

A six 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. An assessment at six months also allows patient outcome data to be reported on which demonstrates the impact that treatment has had on patients. Measuring patient outcomes over time is an important tool for improving stroke services.

Everyone should have an assessment of their needs at six months after stroke, but there is enormous variation in whether people are offered one. The map below shows those areas where there is at least one stroke service that provides six month assessments to patients, as reported in the Post-Acute Organisational Audit.



4. WHAT HAPPENS NEXT?

Reducing risk factors for stroke

Having a stroke comes as a real shock, and the thought of having another one can be really frightening. 27% of people in SSNAP had had a previous stroke or "mini stroke" (transient ischaemic attack or TIA). While some of these second strokes may be unavoidable, steps should be made to reduce the risk as much as possible by identifying changes that can be made to reduce risk of another stroke. Not knowing why a patient had a stroke (which despite intensive investigations is sometimes the case) can be particularly worrying, although in these cases the chance of recurrence is actually very low. Most people however have risk factors that can be identified. While some risk factors such as age cannot be changed, many risk factors can be treated or the risk reduced by treatment or lifestyle changes.

"My husband's cognitive ability was reduced but speech and language therapy and a lot of concentrated effort reaped huge improvements and contributed to our quality of life. He had eye sight issues and lost the sheer pleasure of getting into the car and going. Not being able to work full time did, however, provide opportunities to do new things like learning to play guitar." Janette (carer)



Lifestyle changes

People who are smokers should give up completely. Exercising more frequently when stroke recovery allows it, together with a healthy diet, also makes a difference. Everyone should have their fasting blood sugar and lipids checked, to exclude diabetes and high cholesterol, and many people will need long term treatment with statins.

People with ischaemic stroke are also treated with antiplatelet drugs (initially aspirin and then usually clopidogrel) to reduce the stickiness of the blood. SSNAP asks whether people were known to have risk factors such as atrial fibrillation or high blood pressure before their stroke.



Concluding thoughts

Stroke is a complex and devastating condition. This report has highlighted that many good improvements in stroke care are being made, but that work remains to be done to ensure that excellent care is available to everyone, both in hospital and in the community. It would not be possible or feasible to answer every question related to stroke in a report of this type, but we feel that the topics we have addressed are some of the most pertinent and important for patients. The pages that follow provide readers with guidance on where additional support and information on stroke can be found. "I have tried to maintain an active lifestyle although this has proved more difficult during the last two years. I have been aware of the need to constrain my diet - this has been reduced recently both in volume and content. I do not smoke and I have a very modest alcohol intake." John, 77



"I make sure I take my medication. I avoid alcohol, red meat or smoking and I ensure I eat lots of vegetables every day. I do regular exercise such as cycling and I maintain a good weight. I had to develop new hobbies and get used to being in a wheelchair although I am getting more independent now."

Glossary

Anticoagulants - drugs that reduce the likelihood of blood clotting

Antiplatelet - a drug that helps prevent the formation of blood clots by affecting the function of certain blood cells; examples are aspirin and clopidogrel

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

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

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

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

Haemorrhagic stroke - bleed on the brain caused by a rupture or burst artery

Hypertension - high blood pressure

Ischaemic stroke - a type of stroke that happens when a clot blocks an artery that carries blood to the brain causing brain cells to die

Lipids - types of fat, cholesterol is a variety of lipid

Pneumonia - lung inflammation caused by infection

Thrombectomy/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 - the use of drugs to break up a blood clot

Useful contacts and websites

Stroke Association (provides practical support to people who have had strokes and their families) Helpline: 0303 3033 100 Website: www.stroke.org.uk

Atrial Fibrillation (information and support materials for people with atrial fibrillation) Helpline: 01789 867 502 Website: www.atrialfibrillation.org.uk/

Carers UK (useful advice and information for carers) Carers Line: 0808 808 7777 Website: www.carersuk.org

Connect - the communication disability network (works with people living with stroke and aphasia) Tel: 020 7367 0840 Website: www.ukconnect.org

Different Strokes (is run by and for younger people who have had strokes) Tel: 0845 130 7172 Website: www.differentstrokes.co.uk

Disabled Living Foundation Helpline: 0300 999 0004 Website: www.dlf.org.uk

Know Your Pulse Website: www.knowyourpulse.org

Relatives and Residents Association (provides information and support for residents of care homes and their relatives) Helpline: 020 7359 8136 Website: www.relres.org

Shaw Trust (a charity which specialises in helping disabled people to return to work) General Enquiries: 01225 716300 Work Programme Enquiries: 0300 2472550 Website: www.shaw-trust.org.uk

Speakeasy (a charity specifically for people with aphasia) Tel: 01706 825 802 Website: http://www.buryspeakeasy.org.uk

Further information on stroke care for patients and carers

SSNAP produces easy access version (EAV) reports every three 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 'National Clinical Guideline for Stroke' (2012). 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. Please go to the website www.rcplondon. ac.uk/guidelines-policy/stroke-guidelines if you would like to order this patient version of the 'Guideline'.

The patient and carer version of the National Clinical Guideline for Stroke is also available as an App. This app is designed specifically for stroke survivors, stroke patients and carers and is available FREE on both android and apple devices. It includes information on preventing stroke, stroke treatment and available support services. Search for RCP Stroke Guideline in the Apple or Android Stores.







How can I find out more?

A number of research papers have been published that use data from SSNAP and from the previous stroke audits. You can find these by using the references below:

Organisation of stroke services

Ramsay AI, Morris S, Hoffman A, et al. Effects of centralizing acute stroke services on stroke care provision in two large metropolitan areas in England. Stroke 2015;46(8):2244-51.

Bray BD, Campbell J, Cloud G, Hoffman A, Tyrrell P, Wolfe CD et al. Bigger, faster? Associations between hospital thrombolysis volume and speed of thrombolysis administration in acute ischaemic stroke. Stroke 2013; 44(11): 162.

Bray BD, Ayis S, Campbell J, Hoffman A, Roughton M, Tyrrell PJ et al. Associations between the organisation of stroke services, processes of care, and mortality in England: prospective cohort study. BMJ 2013; 346:f2827.

Analysing stroke care processes

Smith, CJ., Bray, BD, Hoffman, A. et al (2015) Can a novel clinical risk score improve pneumonia prediction in acute stroke care? A UK multicenter cohort study. J Am Heart Assoc. 2015;4(1): e001307. doi: 10.1161/JAHA. 114.001307.

Parry-Jones A, Paley L, Bray BD, Hoffman A, Martin J, Cloud G, Tyrell PJ, Rudd A, Care-limiting decisions in acute stroke and association with survival: analyses of UK national quality register data (Unpublished) Int. Journal of Stroke ID IJS-07-15-4297.R1.

Bray BD, Campbell J, Hoffman A, Tyrrell PJ, Wolfe CD, Rudd AG. Stroke thrombolysis in England: an age stratified analysis of practice and outcome. Age Ageing 2013 March; 42(2): 240-5.

Bray BD, Hoffman A, Tyrrell P, Rudd A. Measuring stroke care and quality in routine data sets. JAMA Neurol. 2013; 70(1):130-131.

The effect of out of hours working

Bray BD, Ayis S, Campbell J, Cloud GC, James M, et al. Associations between stroke mortality and weekend working by stroke specialist physicians and registered nurses: prospective multicentre cohort study. PLoS Med 2014; 11(8): e1001705. doi:10.1371/journal.pmed.1001705.

Campbell JTP, Bray BD, Hoffman A, Kavanagh S, Rudd AG, et al. The effect of out of hours presentation with acute stroke on processes of care and outcomes: analysis of data from the Stroke Improvement National Audit Programme (SINAP). PLoS ONE 2014; 9(2): e87946. doi:10.1371/journal.pone.0087946.

History of the national stroke audit

Cloud G, Hoffman A, Rudd A. National Sentinel Stroke Audit 1998-2011. Clin Med. 2013; 13(5): 444-448.

Finding the 'age' of a stroke: www.wakeup-stroke.eu

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All pictures are ©Jonathan Perugia except those on pages 6, 8, 10, 25, the F.A.S.T. campaign poster on 11, the stent retriever on 17 and the right hand image on 21.

The pictures of brain scans on page 6 are ©Geoffrey Cloud.

The pictures on page 10, 25 and the right hand image on 21 are taken from the Royal College of Physicians Image Library.

The leaflet entitled 'The Road to Recovery' on page 18 is produced by the Stroke Association.

The 'Know your Pulse' image on page 8 was provided by the Arrhythmia Alliance.

This report was written and produced by Professor Pippa Tyrrell, Mark Kavanagh and Angus Waite, supported by Lizz Paley, Rachel Otago, Emma Vestesson, Victoria McCurran and Dr Ben Bray, and guided by Alex Hoffman and Professor Tony Rudd.

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

