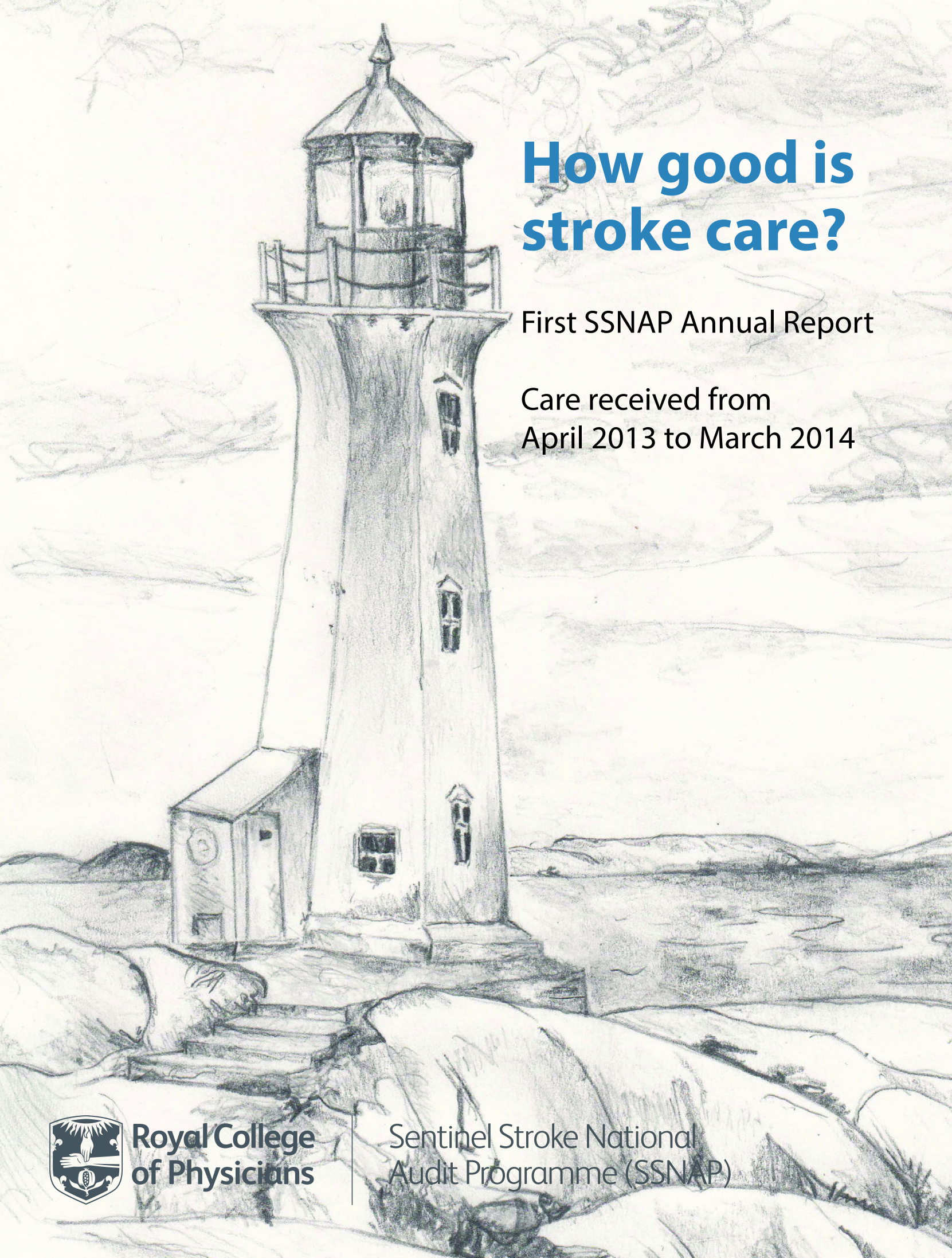


How good is stroke care?

First SSNAP Annual Report

Care received from
April 2013 to March 2014

Royal College of Physicians

Sentinel Stroke National Audit Programme (SSNAP)

"Distant as a light house I felt, shining my inner light for a rescue boat...
In time it eventually came!"

Claire Whitehouse

Claire is an artist and stroke survivor from Bournemouth who suffered a stroke in 2010 at the age of 19. Following her stroke, Claire learned to draw again using her left hand and hopes her image will provide hope and determination for other stroke survivors and their families.

Contents

Foreword

People with stroke need high quality treatment from the moment that the stroke strikes, with rapid transport to a hospital providing excellent acute management and rehabilitation, and care after they return home. While stroke remains a devastating disease, good care makes a real difference to the numbers of people who survive stroke, and the proportion of survivors who make a good recovery.

The Royal College of Physicians has been measuring how well hospitals and community teams care for people with stroke since the turn of the century. Reporting results back to the organisations providing care allows them to make the changes needed to improve, and the Royal College of Physicians' audits have had a very significant impact on improvement of the quality of care since 2000.

In 2010, the audit changed from a retrospective audit of hospital case notes to a prospective audit whereby patient details are entered into a webtool in real time. Information about all aspects of care (acute, rehabilitation and community care) are collected. In addition, these data are linked with mortality statistics.

For the first time, we can link the patients who suffer stroke (their age, associated illnesses and medications) with the speed with which they access acute care, how quickly, how and where they are treated and the amount of rehabilitation they receive, with their level of disability at 6 months and whether or not they die. This information is made public and fed back regularly to the teams caring for patients so that they can see what needs to be improved.

The purpose of this report is to present this wealth of data in the form of questions that patients and their families feel are important. We hope that this information will provide people with the information that they need to understand what happens to people with stroke in the NHS and where improvements need to be made, and will put the more detailed reports that are available on the SSNAP website (www.strokeaudit.org) into context.

Stroke care is improving all the time, but more needs to be done to ensure that every person with stroke gets the highest quality care so that they have the best possible chance of survival with the least possible disability. The SSNAP audit provides information of value to everyone with stroke, their families, the organisations caring for them, and the people who make decisions about the funding and provision of stroke care.

Professor Pippa Tyrrell

Associate Director of the RCP Stroke Programme

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 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 perhaps encourage you to look at more SSNAP information.

What is SSNAP?

SSNAP is a national clinical audit programme. Clinical audits collect information about the quality of services compared to the evidence for what works best for patients and report on the findings to those providing the services, those who pay for the services and the public. The overall aim of SSNAP is to improve services by helping providers to find out where they need to do better, to enable those who manage and pay for services to monitor how well they are doing, and to empower patients, carers, stroke survivors and the wider public to call for improvements with an understanding of 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 using the data collected in SSNAP over the first year of full data collection. This report covers over 74,000 stroke patients who were admitted and/or discharged from hospital between April 2013 and March 2014. There are many more questions which could potentially be answered using SSNAP data, but we wanted to make sure this report was a reasonable length for most of the readers. However, SSNAP produces detailed reports every three months which 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, see page 38 of this report.

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) or a bleed in the brain (haemorrhage). Strokes impact on people in many different ways, depending on the part of the brain that is affected, how widespread the damage is and how healthy the person was before the stroke. For example, a stroke can have an effect on functions such as movement and speech, as well as thought processes and how somebody feels.

- Blockage of one of the arteries to the brain can occur as a result of build up of fatty deposits, making the inner surface of the artery thickened and rough.

- This leads to narrowing of the artery, and formation of blood clots which can break off and block the feeding arteries of the brain. A blood clot can also come from the heart (often in association with an irregular heart beat).

- A brain haemorrhage is bleeding from a ruptured or abnormal artery into the brain itself, sometimes due to high blood pressure. Both types of stroke present with very similar symptoms, and a brain scan is needed to distinguish them.

88% of patients had a blockage (infarction) as the cause of their stroke

11% of patients had a bleed (haemorrhage)

The nurses did explain what a stroke was but I didn't take it in at the time. It wasn't until weeks later that it gradually sank in how much my life had changed.

Bob Norbury, stroke survivor

I had just put my baby daughter to bed and was feeling unwell when I became aware that my left side had gone numb. I tried to tell my wife what was happening and my speech was slurred.

Martin Kelly, stroke survivor

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.
- One in five strokes are fatal. Stroke causes about 7% of deaths in men and 10% of deaths in women.
- In 2010 stroke was the fourth largest cause of death in the UK after cancer, heart disease and and respiratory disease, resulting in almost 50,000 deaths. Click this link for more details and references
- To watch an animated video by NHS Choices showing what a stroke is, click on this link: Stroke: an animation - from NHS Choices

Who has a stroke?

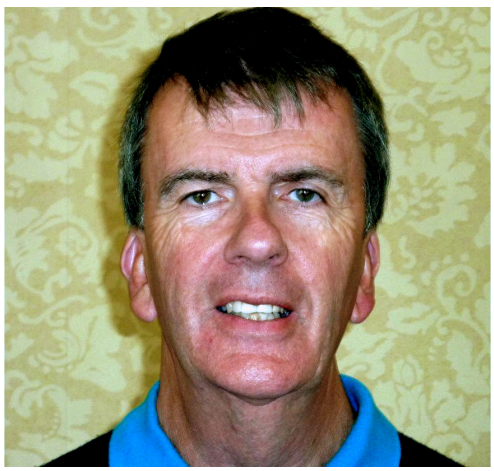
People often think that stroke is only a disease of old age, and although many people with stroke are elderly, a significant proportion are younger. Rarely, even children and teenagers can have a stroke. Most people have other conditions that may place them at higher risk of stroke, for example irregular heartbeat, this is called Atrial Fibrillation or (AF), high blood pressure or a previous stroke or mini-stroke (sometimes called TIA or Transient Ischemic Attack). Good control of risk factors (for example, a healthy life style, not smoking, good control of blood pressure, treatment for AF) can reduce stroke risk whatever your age.

- Stroke affects men and women in equal numbers. Whilst 40% of people who have a stroke are more than 80 years of age, 14% are under the age of 60. Women are on average older than men when they have a stroke, with half of female patients aged 81 years and over compared to 74 years for male patients.
- Over half of patients had high blood pressure (hypertension) before their stroke and over a quarter had suffered a previous stroke or mini-stroke (TIA).
- 18% of patients had a moderate to severe disability before their stroke; 3 out of 5 had no disability at all before their stroke.

Half of stroke patients are female

1 in 7 patients are under 60 years of age when they have a stroke

27% of patients had suffered a previous stroke or mini-stroke



I always thought it was older people who had a stroke. I had mine on my 50th birthday.

Steve Hall, stroke survivor

These graphs show the proportion of patients of different ages who have certain conditions which are risk factors for stroke. The proportion of patients with these conditions tends to increase with age.

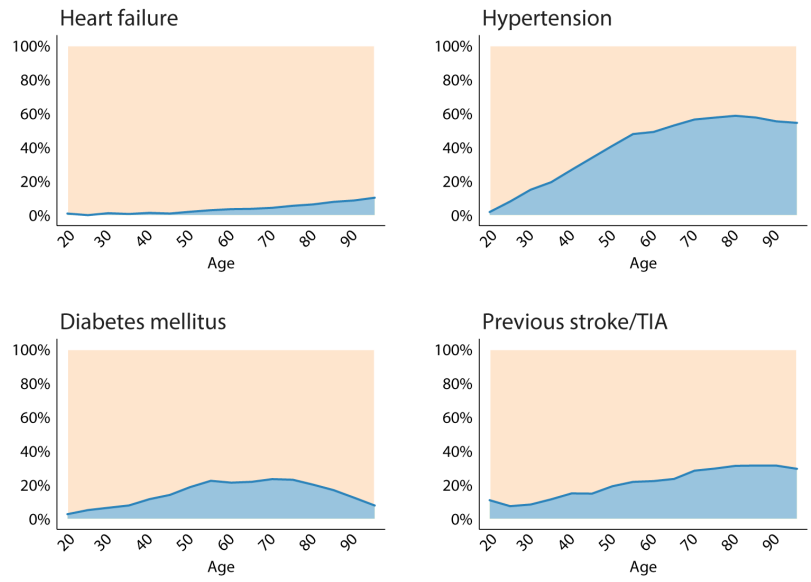


Figure 1: Proportion of patients with other conditions before stroke

This graph shows the differences in numbers of men and women who have stroke within different age groups. For example, there are around 1,000 more men than women who have had a stroke between ages of 70 and 74, but around 1,000 more women than men who have had a stroke between ages of 80 and 84.

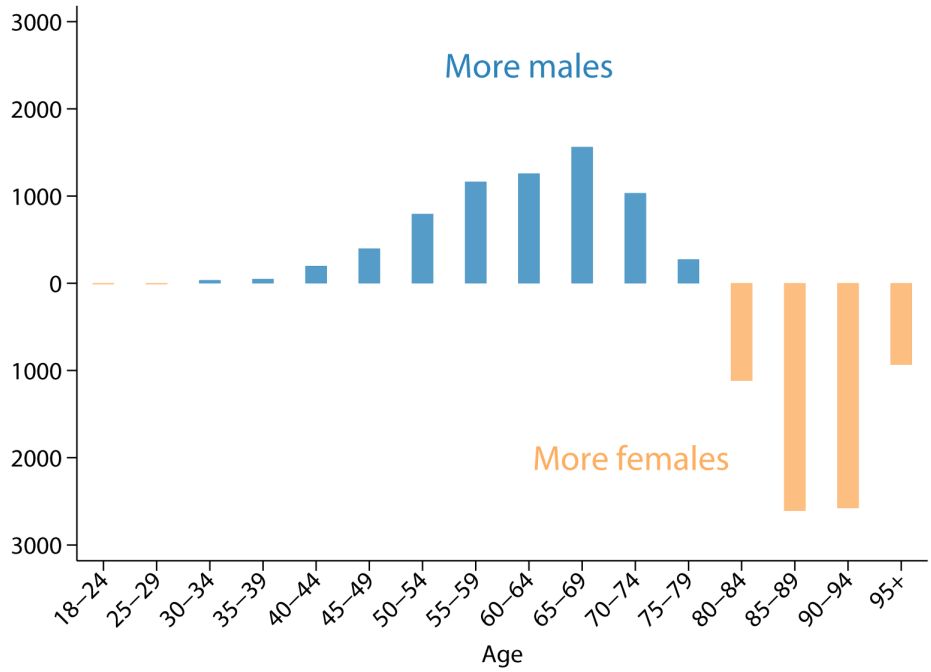


Figure 2: Difference in numbers of men and women who have stroke within different age groups

How many people had an irregular heartbeat (AF) before stroke?

An irregular heartbeat becomes more common as people get older, and it is really important that people take their pulse from time to time, or ask a doctor or nurse to do so, to check the rhythm is regular. If the pulse feels irregular, heart tracing (an ECG) is needed to confirm AF. Some people may need an ECG over a longer continuous period (24 hours or 5 days). People with AF are at significantly higher risk of stroke.

Taking blood thinning drugs (warfarin or one of the new anticoagulant drugs, but not aspirin) can significantly reduce the risk of stroke. Doctors have sometimes been reluctant to prescribe these drugs because of concerns about bleeding, but for most people the benefit of the drugs (stroke risk reduction) greatly outweighs the risks.

What is Atrial Fibrillation (AF)?

Atrial Fibrillation (AF) is a heart condition that causes an irregular and often abnormally fast heartbeat. Some people with atrial fibrillation have no symptoms and are completely unaware that their heart rate is not regular.

1 in 5 stroke patients were known to have an irregular heartbeat (AF) before they had their stroke

More than **half** of patients with AF were not given drugs which could have prevented their stroke

Heart monitoring machines are used to record heart rates and rhythms and look for other abnormalities that may affect normal heart function.

I had a heart attack first,
I did not know they are linked.

Eamon Booth, stroke survivor

- Findings from SSNAP show that, before they had their stroke, one in five patients were known to have an irregular heartbeat. However, less than two in five of these patients with AF were on anticoagulant drugs before their stroke.

- By the time they were discharged from hospital, 93% of patients who should have been given anticoagulant drugs were given them.

- Six months after their stroke, 79% of patients with an irregular heartbeat were taking anticoagulant drugs, meaning one in five patients who should have been taking these drugs were not.

More older people are known to have an irregular heartbeat (AF) before their stroke. However, the older the patient, the less likely they are to be on blood thinning treatment (% anticoagulated).

For example, 15% of 65-69 year olds are in AF with just under half anticoagulated whereas 35% of 95 and overs are in AF with less than a quarter anticoagulated.

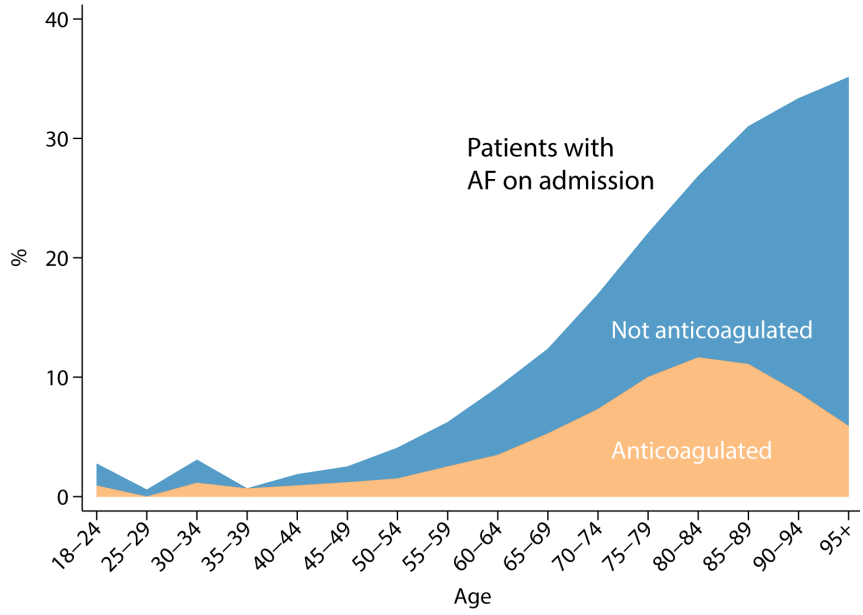


Figure 3: Proportion of patients in AF who are anticoagulated and not anticoagulated in different age groups

Are we acting FAST enough?

It is really important that people with a stroke get to hospital as quickly as possible. If people ACT-FAST 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. Most people come to hospital by ambulance, but sometimes the response in hospital is not as fast as it could be. There is considerable variation across the country in the time it takes people to get expert care, but many more people than previously are now are being scanned quickly, seeing a stroke nurse in A&E, and being admitted to a stroke unit in under 4 hours from arrival.

- The average time between patients first getting symptoms and arriving at hospital is 2 hours and 25 minutes.
- This varies widely though, with the quickest quarter of patients arriving in less than 1 hour 18 minutes, and the slowest quarter arriving after more than 7 hours.
- 82% of patients arrive at hospital by ambulance.
- After arriving at hospital, the average time for a patient to have a brain scan was 1 hour and 22 minutes, to see a stroke nurse was 2 hours and 17 minutes.

This graph shows the time from when symptoms started (onset time) to arrival at hospital, for those patients with a known or estimated onset time. For some patients, particularly those who had their stroke during sleep, the onset time will not be known. 63% is the total proportion of patients who arrived within 4 hours of first experiencing symptoms. The more people who recognise the symptoms of a stroke and know to ACT-FAST, the more these times should shorten.

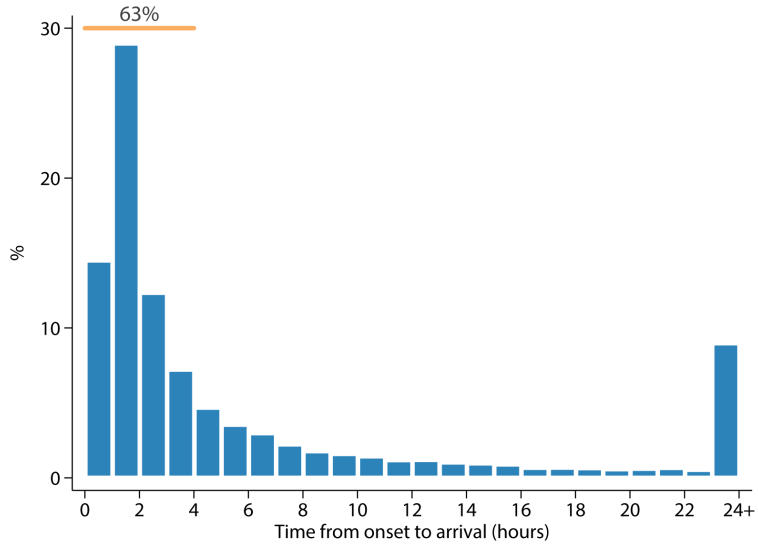


Figure 4: Symptom onset time to arrival at hospital, for patients with known or estimated onset time

This 'heat map' shows the differences in proportions of patients getting a brain scan within 12 hours depending on what time of day and what day of the week they arrived at hospital. There is a very clear difference with patients arriving after 5pm less likely to receive a scan within 12 hours.

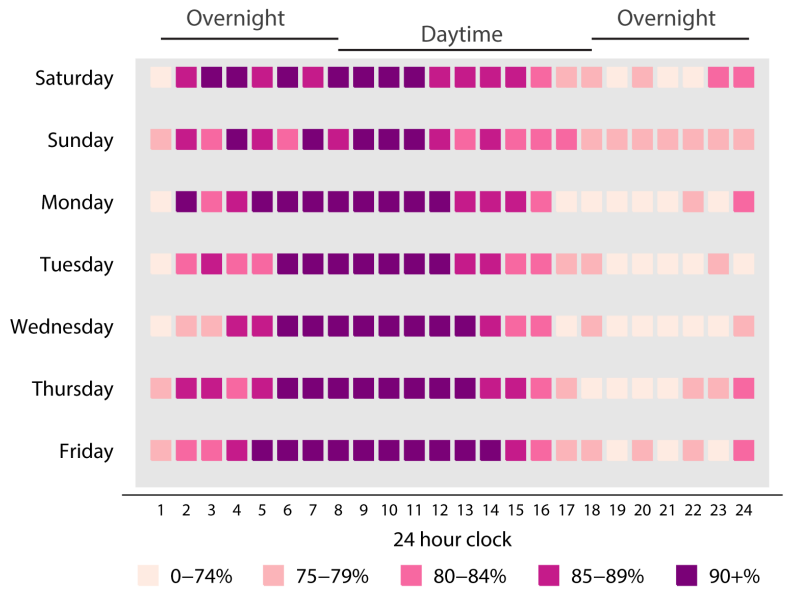


Figure 5: Differences in proportions of patients getting a brain scan within 12 hours of arrival at hospital at each hour of the day and day of the week

Where do stroke patients go for treatment?

It is not surprising that people looked after in a unit where the staff are experts do better than people looked after in a general ward. Research studies have confirmed that being looked after in a dedicated stroke unit with specialist stroke nurses, doctors and therapists means patients are less likely to die, and leave hospital less disabled. Many more people now go straight to dedicated stroke units from A&E but we should be aiming for virtually everyone, whatever the day of the week or time of day, to get to a dedicated stroke unit within 4 hours of arrival in hospital.

What is a stroke unit?

- The best place for the vast majority of stroke patients to go is a stroke unit.
- A stroke unit is a special ward in a hospital where stroke patients are cared for by a team of all professionals (a multidisciplinary team) who specialise in stroke care.
- The core team usually consists of doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, dietitians, therapy assistants, psychologists 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.
- The essential components of care patients receive in the stroke unit they go to immediately after they have a stroke (acute stroke unit) include monitoring of body temperature, blood pressure, oxygen levels and blood sugars, attention to fluid intake and early mobilisation and physiotherapy.
- The other main features are the use of setting goals with patients, multidisciplinary meetings and information and education for both patients and staff. In addition, there are tried and tested methods of dealing with complications and other problems arising from strokes.
- A major review, 'Organised inpatient (stroke unit) care for stroke', found that stroke patients who receive organised inpatient care in a stroke unit are more likely to be alive, independent, and living at home one year after the stroke. The benefits are most apparent in stroke units based in a dedicated stroke ward. Furthermore, there was no associated increase in the length of inpatient stay.

From the SSNAP Acute Organisational Audit, based on the stroke services provided in July 2014, we know that every hospital which routinely admits stroke patients now has a stroke unit. However, there are still variations in the quality of service provision across the country. For instance, there are 5 characteristics which are considered essential for a 'good' stroke unit and only 44% of hospitals currently achieve all 5 of these (consultant physician with responsibility for stroke; formal links with patient and carer organisations; multidisciplinary meetings at least weekly to plan patient care; provision of information to patients about stroke; and funding for training [study leave and days taken]).

This 'heat map' shows the differences in proportions of patients getting to a stroke unit within 4 hours depending on what time of day and what day of the week they arrived at hospital. It shows that there is an increase in the proportion of patients getting to a stroke unit within four hours as the week goes on from Monday, with best performance on Thursday to Saturday. There is also a consistent pattern of a lower proportion of those patients arriving in the early mornings being admitted to a stroke unit within 4 hours compared to those patients admitted during the rest of the same day.

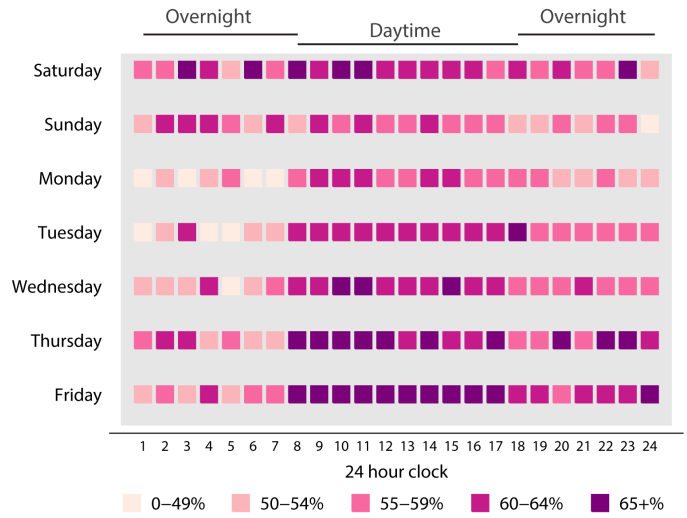


Figure 6: Differences in proportions of patients getting to a stroke unit within 4 hours depending on what time of day and what day of the week they arrived at hospital

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. This map shows the variation in the proportion of patients getting to a stroke unit within four hours.

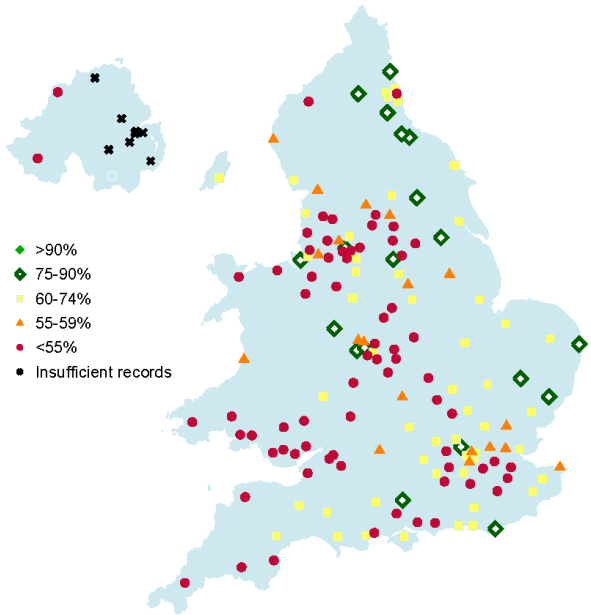


Figure 7: Patients directly admitted to a stroke unit within 4 hours

Are patients getting clot-busting drugs when they need them?

Thrombolysis (or clot busting drugs) has made a very significant change to the way we treat people with stroke. 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. Ideally it is given within 3 hours of symptom onset. In 2005, only about 1% of people with stroke in the UK received thrombolysis, and it was estimated that increasing the proportion to 9% would save £16m each year; we have now achieved 10% across the country and higher in some places.

What are clot-busting drugs?

- Thrombolysis can break down and disperse a clot that is preventing blood from reaching the brain
- Therefore, only patients with a blockage (infarction) can receive it
- Thrombolysis can help around 15 – 20% of all stroke patients
- The main reason more patients who could benefit but do not is that it can only be given within four and a half hours of the onset of symptoms and many patients arrive after this time period

The rate of introducing thrombolysis between 2004 and the present has increased as services have developed to 7 days per week and regions have taken a coordinated approach, providing services operating in partnership between a number of hospitals.

Every hour

a stroke patient receives clot busting treatment

This means 24 patients a day, of which

2 patients a day are saved from being left more disabled than if they were not given clot busting drugs

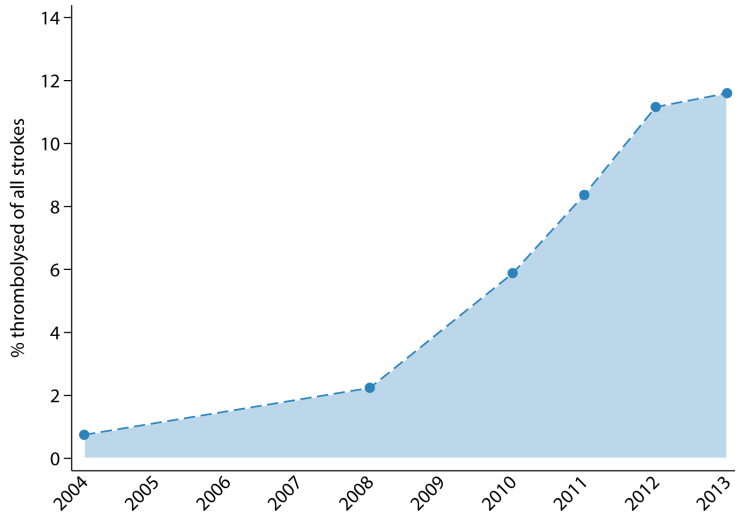


Figure 8: Proportion of patients thrombolysed of all strokes between 2004-2013

A report on stroke by the National Audit Office in 2005 reported on the likely effect in cost effectiveness terms of 9% of patients being thrombolysed: "Using data on average mortality and recovery rates for thrombolysed patients…delivering thrombolysis to nine per cent of all stroke patients ...would [create]…a net saving of more than £16 million a year."

Therefore SSNAP shows that this saving has already being achieved, since 11.6% of all patients between March 2013 and April 2014 received clot busting drugs.

According to the criteria to identify which patients will benefit, three quarters of those eligible patients received thrombolysis. Of patients who received it, the average time between arriving at hospital and receiving thrombolysis was 58 minutes, which is encouraging as the faster it is given the greater the effect.

This 'heat map' shows the differences in proportions of patients getting clot busting drugs when they are medically eligible depending on what time of day and what day of the week they arrived at hospital. It seems that patients arriving in the early hours (before 8am) are less likely to receive clot busting drugs than patients arriving at other times.

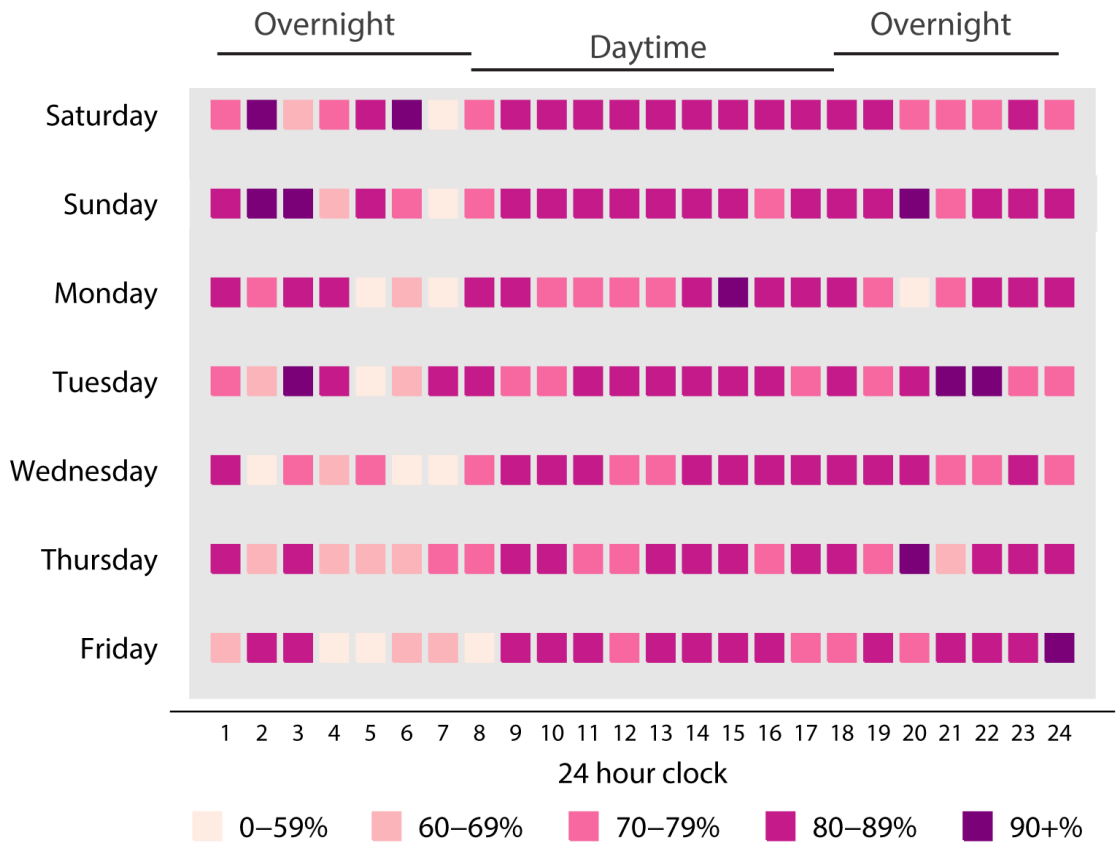


Figure 9: Differences in proportions of patients getting clot busting drugs when they are medically eligible depending on the time and day they arrived at hospital

Is treating patients with clot busting drugs safe?

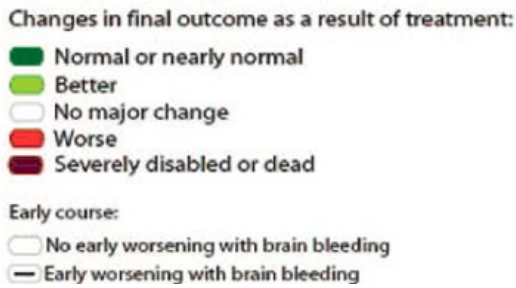
Thrombolysis carries two main risks, brain haemorrhage (bleeding into the brain which can be fatal) and swelling of the mouth and face. Swelling is more common in people taking one type of blood pressure lowering medicine (ACE inhibitor), it needs prompt recognition and treatment and resolves quite rapidly. Brain haemorrhage occurs early after starting treatment and in one person in 100 results in death. This risk is balanced against the benefits of treatment, where risk is more than off-set by an absolute increase in disability free survival of 10% in people treated within 3 hours, and 5% in those treated between 3 and 4.5 hours.

The SSNAP data gives us some information regarding the safety of clot busting drugs (thrombolysis).

- We know that overall 9.5% of patients had a complication following thrombolysis.
- 4.2% of patients had bleeding in the brain (symptomatic intracranial haemorrhage).
- 0.7% of patients suffered rapid swelling, e.g. of the tongue or around eyes (angioedema).
- We also know from the study "Stroke thrombolysis in England: an age stratified analysis of practice and outcome" that older patients have no higher risk of major complications following thrombolysis.

This graphic is taken from a study (separate from SSNAP called Thrombolytic Therapy in Stroke) and shows the outcomes for 100 patients treated with clot busting drugs within 3 hours of stroke:

- 32 get better (including 13 who return to normal)
- 62 have no major change
- 6 have brain bleeding (resulting in no major change for 3, worsening for 2 and death or severe disability for 1)



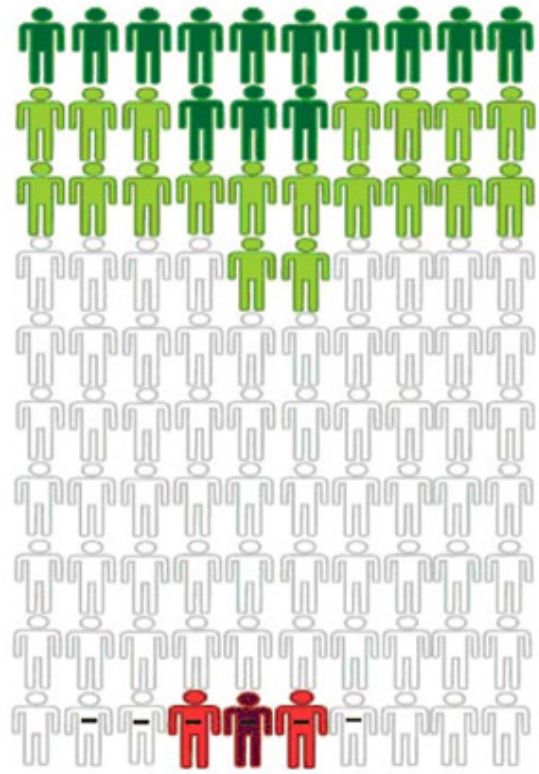


Figure 10: Outcomes for 100 patients treated with clot busting drugs within 3 hours of stroke

The effect was astonishing;
as if a switch had been flicked,
my brain raced into action
automatically checking that my limbs
would move, then I remembered
my name, address, and other key facts
of personal history.

Marney Williams,
stroke survivor

Clot busting drugs are more effective the quicker they are given. So it is important that people with stroke symptoms get to hospital rapidly. Over half of patients are given clot busting treatment less than an hour after arriving at the hospital door.

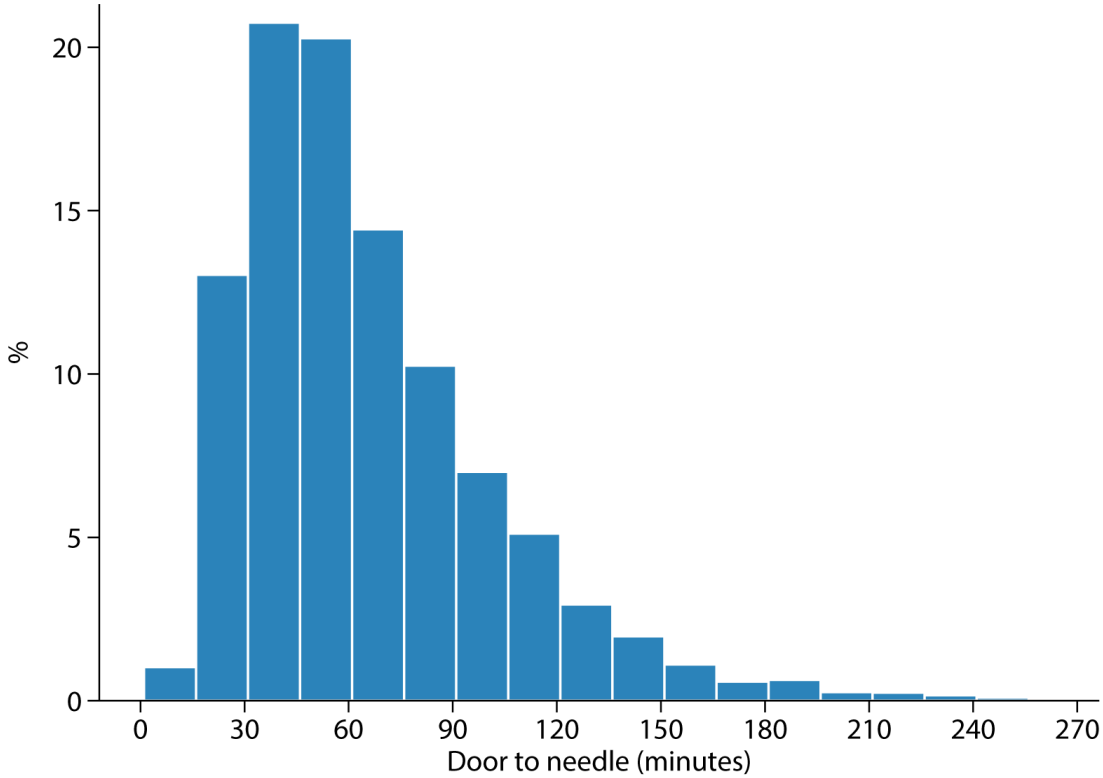


Figure 11: Door to needle times for thrombolysed patients

Why is specialist stroke care important?

People with stroke may face multiple challenges, including difficulty with movement, communication, vision, swallowing, and bladder and bowel control. A swallow check very soon after admission helps avoid choking, and possibly inhaling food and fluids into the lungs. It seems simple things like checking a person is getting the right fluids and nourishment, or making sure incontinence is being managed, still don't happen for everyone. Seeing a specialist stroke consultant within 24 hours of admission to hospital is a good way of making sure the right things are being done promptly, but there is wide variation across the country in how often that happens. Nurse staffing at weekends is often less than in the week which may affect the way people are treated at the weekend and has been shown to affect mortality rates.

Evidence that specialist stroke care saves lives

A recent study using stroke audit data has shown that patients admitted to stroke services with better organised services are more likely to receive high quality care and that patients receiving high quality care have a reduced risk of death in the 30 days after stroke.

Click to see the full article: Organisation of services, process of care and mortality

Another study using stroke audit data evaluated nurse staffing ratios and found that patients admitted to hospitals with the lowest weekend ratios of registered nurses to patient beds had the highest mortality risk. After differences in patient cohorts were adjusted for, patients admitted to a stroke unit with 1.5 registered nurses per ten beds had an estimated 30 day mortality risk equivalent to one excess death per 25 admissions compared to patients admitted to a unit with 3 nurses per ten beds.

Click to see the full article: Association between stroke mortality and number of registered nurses

1 in 4 patients do not have a plan drawn up for them to regain urinary continence when necessary

More than a **third** of patients do not have a swallow screening within four hours of arrival

There are many different aspects of specialist stroke care which contribute to a patient's chances of making a good recovery:

- 64% of patients are screened to check for swallowing difficulties within four hours of arrival at hospital.
- Where there is a problem identified, patients need to have a comprehensive assessment of swallowing ability by a trained person (usually a speech and language therapist or a specially trained stroke nurse). This happens for 78% of patients within 72 hours.
- Seeing a stroke specialist consultant physician is another important part of specialist stroke care and nearly three quarters of patients are assessed by such a doctor within 24 hours and 92% within 72 hours.
- Checking that patients are receiving the right hydration and nutrition has been shown to be a crucial aspect of stroke care. 94% of patients have a nutritional screening by the time they are discharged from hospital. Of the patients who are identified by the screening as being at high risk of malnutrition, 83% are seen by a dietitian.
- Managing continence is important for those patients who are incontinent following their stroke. Around 2 out of 5 patients need to have a continence plan drawn up but a quarter of these patients do not get such a plan.
- It is very important that patients are assessed by a nurse who us specially trained for managing stroke patients as soon as possible. 86% of patients were assessed by such a nurse within 24 hours of arriving at hospital.

It is important that patients are assessed as soon as possible by a stroke specialist consultant physician. This map shows variation in proportion of patents assessed by a stroke consultant within 24 hours of arrival at hospital.

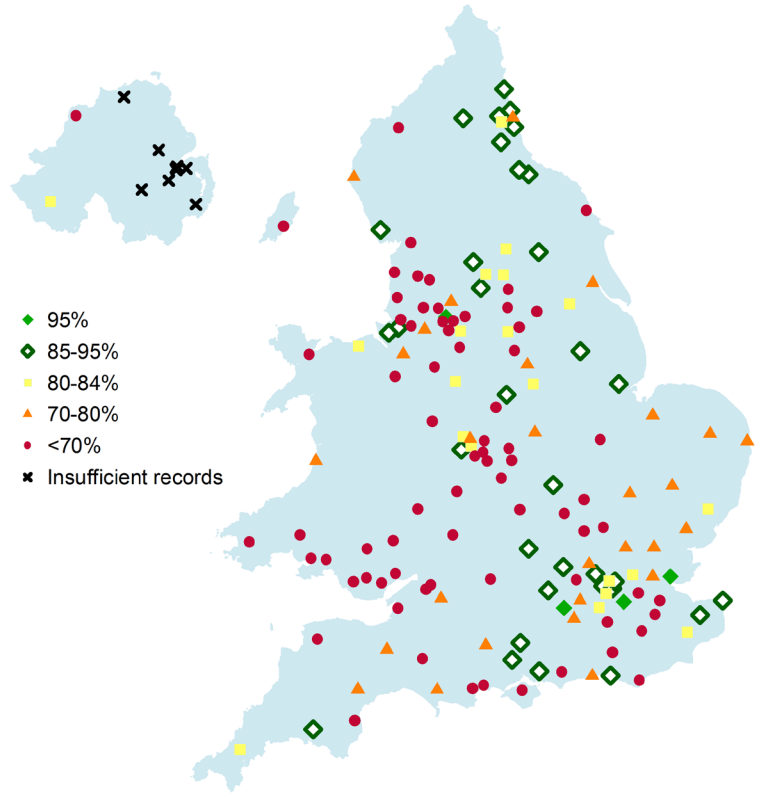


Figure 12: Patients assessed by a stroke consultant within 24 hours

Do patients get enough therapy?

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. One way to give people more therapy would be to get it for longer each day but getting some therapy on more days would make the most difference. There is marked variation in the proportion of patients that therapists think need therapy.

- The amount of therapy received is of major concern to patients and their families.

- Physiotherapy is reported nationally in SSNAP to be required by 85% of patients. Of those patients who need it, they receive an average of 32 minutes of physiotherapy on just over half of their days in hospital.

- This is similar for occupational therapy (which 80% of patients require), with an average session of 40 minutes, but spread across a smaller proportion of days in hospital (45%).

- Just under half of patients (47%) are reported as requiring speech and language therapy. When they receive it, this is on average for 30 minutes per session. However, it is only provided on 28% of the days spent in hospital on average.

- Patients should receive the equivalent of 45 minutes of each therapy a day for 5 days a week. Patients getting more minutes of therapy when they are receiving a session would go some way to achieving this goal, but the biggest improvement needed is for patients to get the therapy more often (on more of the days they are in hospital).

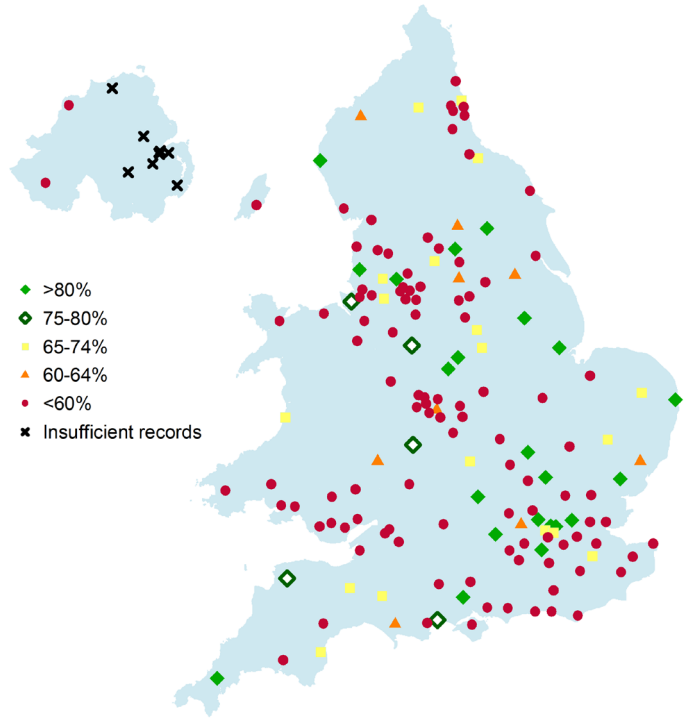


Figure 13: % of target amount of occupational therapy given

There is very significant variation between teams across the country in terms of how much face to face therapy is provided. This is shown for occupational therapy in the map above.

The physios in hospital were brilliant, but the bar was set pretty low. As long as I could get out of bed and climb a flight of stairs then I was ok to go home, actually I was months away from being able to look after myself.

Paul Van Der Kamp,
stroke survivor

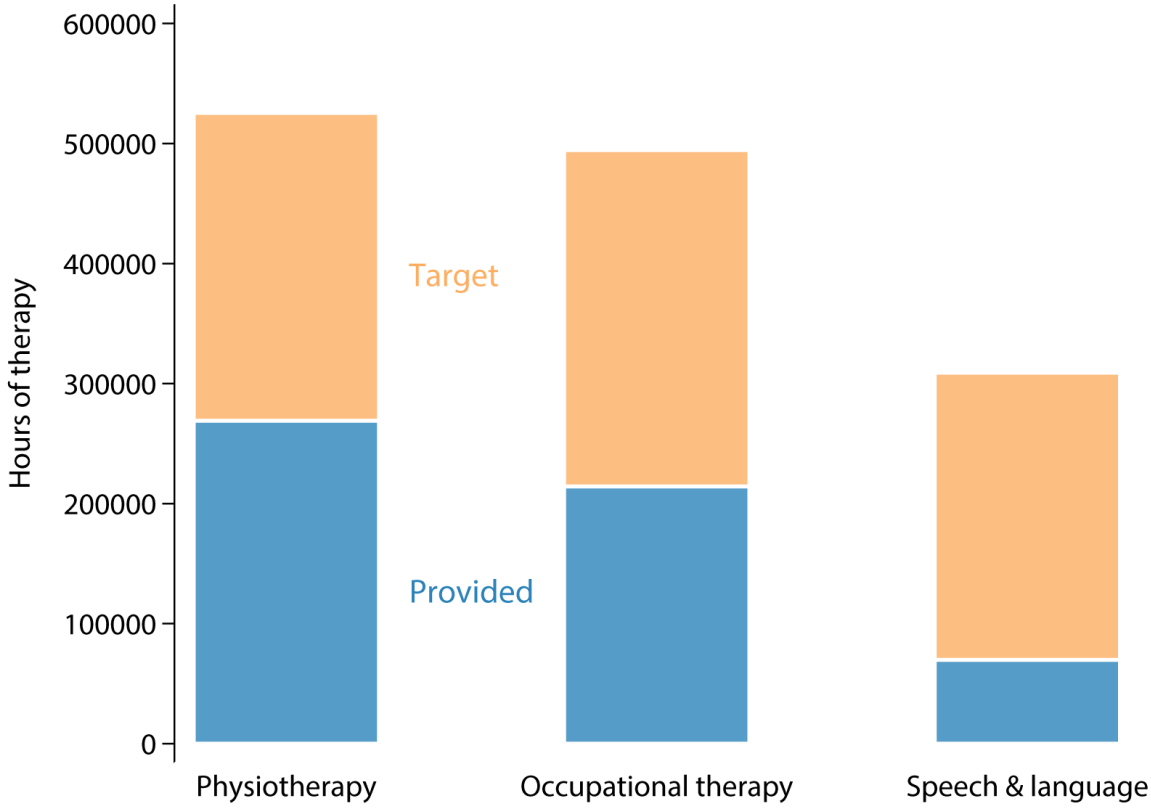


Figure 14: Total hours of therapy provided for all patients across the year against the target number of hours

The graphs above show the number of hours of each therapy given throughout the year to all patients and show this in relation to the target for the number of hours of each therapy which would have been given if every patient who required some amount of therapy received 45 minutes on 5 out of 7 days per week across their entire length of stay as an inpatient.

It should be noted that these results may appear to be worse than the reality because the target is based on the entire length of stay as an inpatient, whereas it will be measured in future across the period of stay that each therapy type was required for (as some patients require a therapy for a while but do not need to continue that therapy for the rest of their time in hospital.)

What is done about silent symptoms after stroke?

Feeling low in mood or anxious is common after a stroke, and it is important that people get the right support early on. Some people have difficulty with attention, concentration and memory, and tiredness can be a problem. These are sometimes called "silent symptoms" because they may not be obvious to others. It is worrying that 25% of people with stroke have not been asked about their mood before they are discharged, and 4 people out of 10 who need support for mood or memory after going home do not get it. Better access to psychology services both in hospital and at home could make a big difference to these troublesome symptoms.

Silent symptoms are the ones which affect the patient's thoughts and feelings, such as their mood.

- 73% of patients who were in hospital for more than 7 days were screened for mood by discharge. This means 27% (8,000 patients) were not screened for mood before leaving hospital.
- 84% of patients were screened for cognition by discharge.
- 5% of patients are reported to require support from a clinical psychologist; a small amount of psychology is received on average nationally (for those who receive it, it is on 6% of days the days they are in hospital). The proportion of patients considered to require support from a clinical psychologist varies widely across teams, with an interquartile range from 0.5% to 11.4% of patients (median 3.6%). This may, however, be more of a reflection of the disparate access to clinical psychologists (the SSNAP Acute Organisational Audit 2014 shows that only 61% of services have access to a clinical psychologist) rather than the actual needs of each team's patients. After discharge 60% of patients are screened for mood and cognition and of those who need support 60% then get it.

1 in 4 stroke patients were not screened for mood by discharge from hospital

60% of patients who need support for mood or cognition after discharge receive the required support

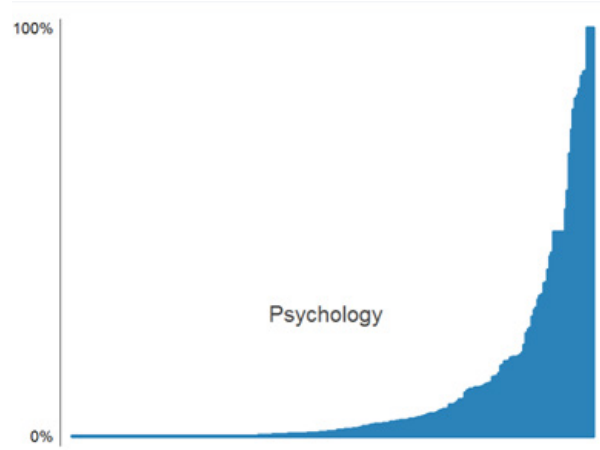


Figure 15: Variation in the proportion of patients considered to require support from a clinical psychologist

This graph shows the variation in the proportion of patients considered to require support from a clinical psychologist by each hospital. Each hospital has a line showing their percentage and the graph shows the majority of hospitals at less than 10%. The halfway point is 3.6%.

I could not understand what to do, Jean's personality and emotions had changed as had her sense of humour. I needed help to understand.

Victor Wright, carer

It is important that patients have their mood and cognition screened in order to identify whether they need support. Across the country, there is variation in the proportion of patients who have mood and cognition screening before they leave hospital, as shown in this map.

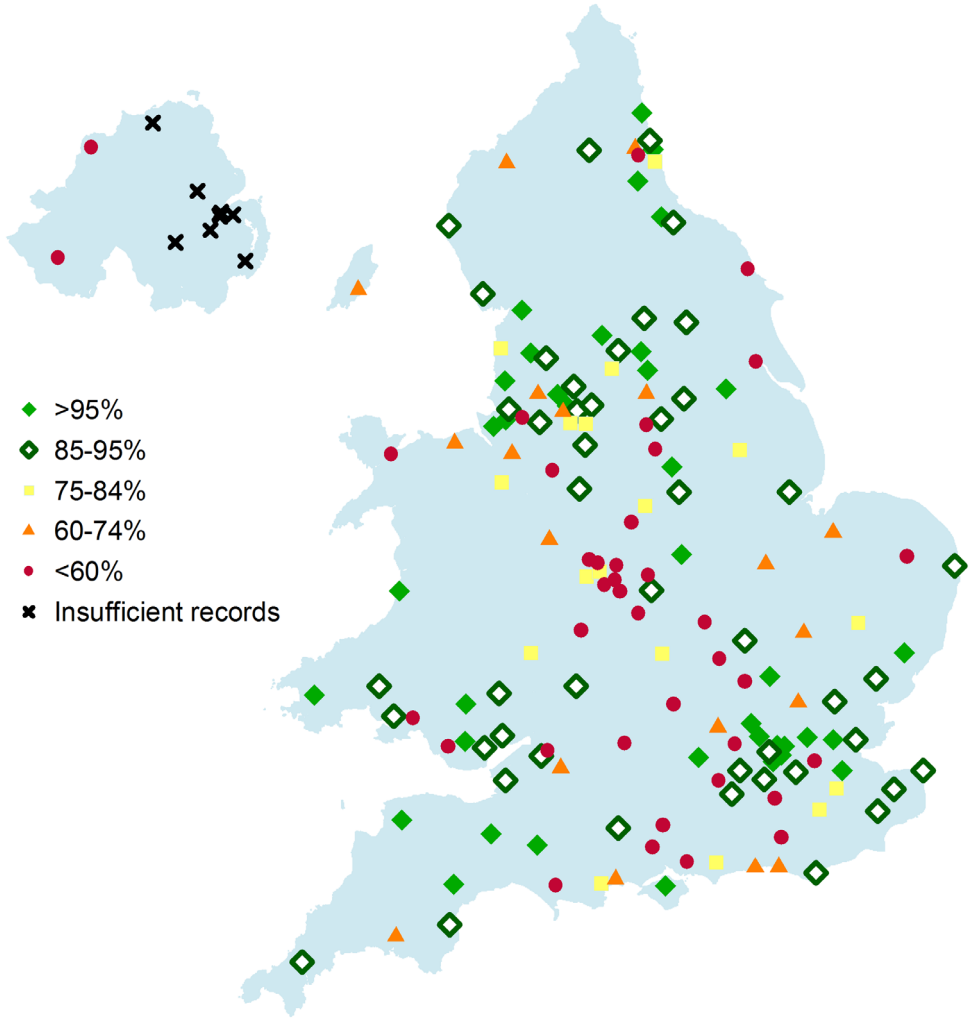


Figure 16: Proportion of patients who have mood and cognition screen before leaving hospital

What are the outcomes for patients?

It is important to measure what happens to patients to see how well treatments are working, and what needs to be improved. Pneumonia is especially common in people with severe stroke, but careful monitoring of temperature and early treatment can help, and early swallow assessment and careful mouth care may help prevent it. There are fewer urinary tract infections (UTIs) now that catheters are avoided where possible. Stroke can be a very serious condition, as judged by the fact that 15% of people die in hospital. Death rates for different hospitals can be compared, carefully correcting for stroke severity and other factors, which provides useful information about what systems of care for stroke work best. Length of stay has dropped considerably since the stroke audits began and many patients are discharged after less than a week. This means that community services need to be as good as possible to continue rehabilitation after discharge.

This is the first time we have been able to collect information on the outcomes for so many patients.

- One important indicator relating to patients outcomes is how long they need to spend in hospital. The length of stay was an average (mean) of 17 days, with a middle value of 7 days (half of patients staying 7 days or less).
- A quarter of patients stayed in hospital for 3 days or less and quarter stayed for 21 days or more.
- Around 1 in 12 patients developed a urinary tract infection (UTI) in the first 7 days in hospital.
- Around 1 in 9 patients developed pneumonia in the first 7 days in hospital.
- Both of these can contribute towards mortality. 15% of patients died in hospital.
- 14% of patients died (either in hospital or after) within 30 days of arriving at hospital.

1 in 12 stroke patients developed a urinary tract infection (UTI) in the first 7 days in hospital

1 in 9 stroke patients developed pneumonia in the first 7 days in hospital

This graph shows the average (mean) length of stay in hospital. The top line is for those patients who were discharged alive and the bottom line for all patients (including those who died in hospital). The decrease over the years shows that, on average, patients now spend a much shorter time in hospital than in 2001.

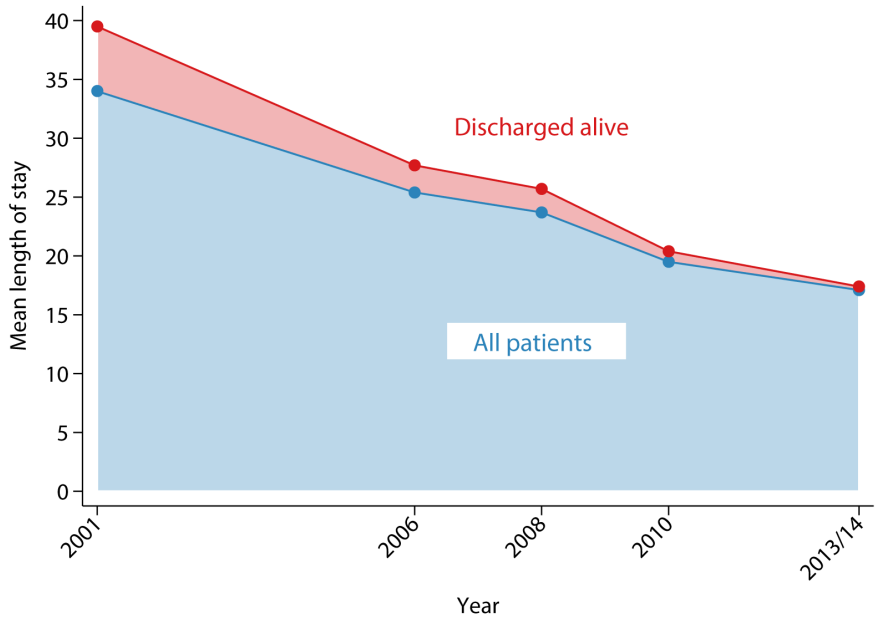


Figure 17: Average (mean) length of stay in hospital

This graph shows the changes in the proportion of patients who die within 30 days of arriving at hospital over the years. 30 day mortality has decreased from 30% in 1998 to around 13% between 2011 and present.

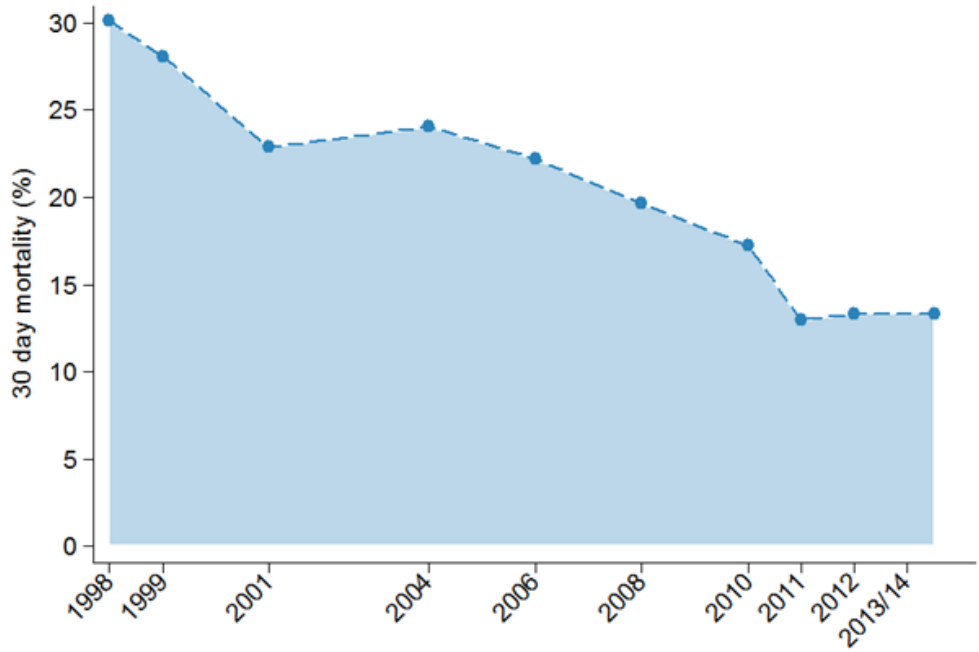


Figure 18: Changes in the proportion of patients who die within 30 days of arriving at hospital over time

What happens when a patient leaves hospital?

While acute care in hospital has improved significantly over the last decade, the transition from hospital to the community remains problematic for many people with stroke. Some people, who were living at home before their stroke, are so disabled that they need to go into a care home. Fortunately, more than half of all patients are able to return to their own home, and many of these have only minor disability, but sometimes people who may need help after they go home do not get it. One third of people leave hospital without a named contact in case

- Over half (55%) of all patients admitted were discharged home and for over a quarter of those discharged home, they went home to a place where they are living alone.

- 11% of patients were discharged to a care home; nearly two thirds of these people were not previously a resident at a care home, and therefore are considered to be 'newly institutionalised' following their stroke.

- A third of patients were not given the name of a person to contact when they left hospital.

- Following stroke, more than a third (37%) of people required help with activities of daily living such as washing and dressing when they left hospital. Whilst 4 in 5 of these patients received help from paid carers, 1 in 5 only received help from informal carers (often relatives). Hospitals do not know the number of social service visits per week planned for 60% of these patients.

- Over half of patients (52%) leave hospital with no disability or only a slight disability. 4,330 patients (6.5%) left hospital with a severe disability.

1 in 5 stroke patients who require help with activities of daily living did not receive any help from paid carers when they left hospital

More than **half** of patients returned to their own home when they left hospital

This graph shows the changes in the percentage of patients who were discharged to a care home between 2004 and present, with a continuous reduction over these years.

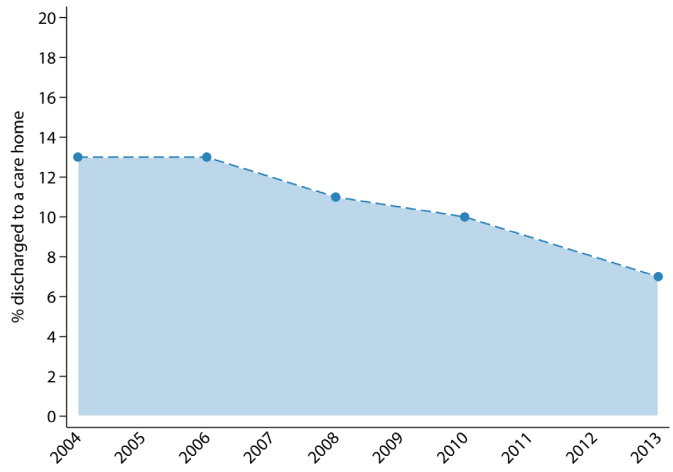


Figure 19: Changes in the % of patients discharged to a care home between 2004 and present

I got a letter saying my speech and language therapy had ended. I wanted to phone her to say it was not finished but I couldn't speak.

Eamon Booth, stroke survivor

Some patients who require help with activities of daily living, such as washing and dressing, do not receive any support from paid carers when they leave hospital, and the extent of this varies across the country, as shown in this map.

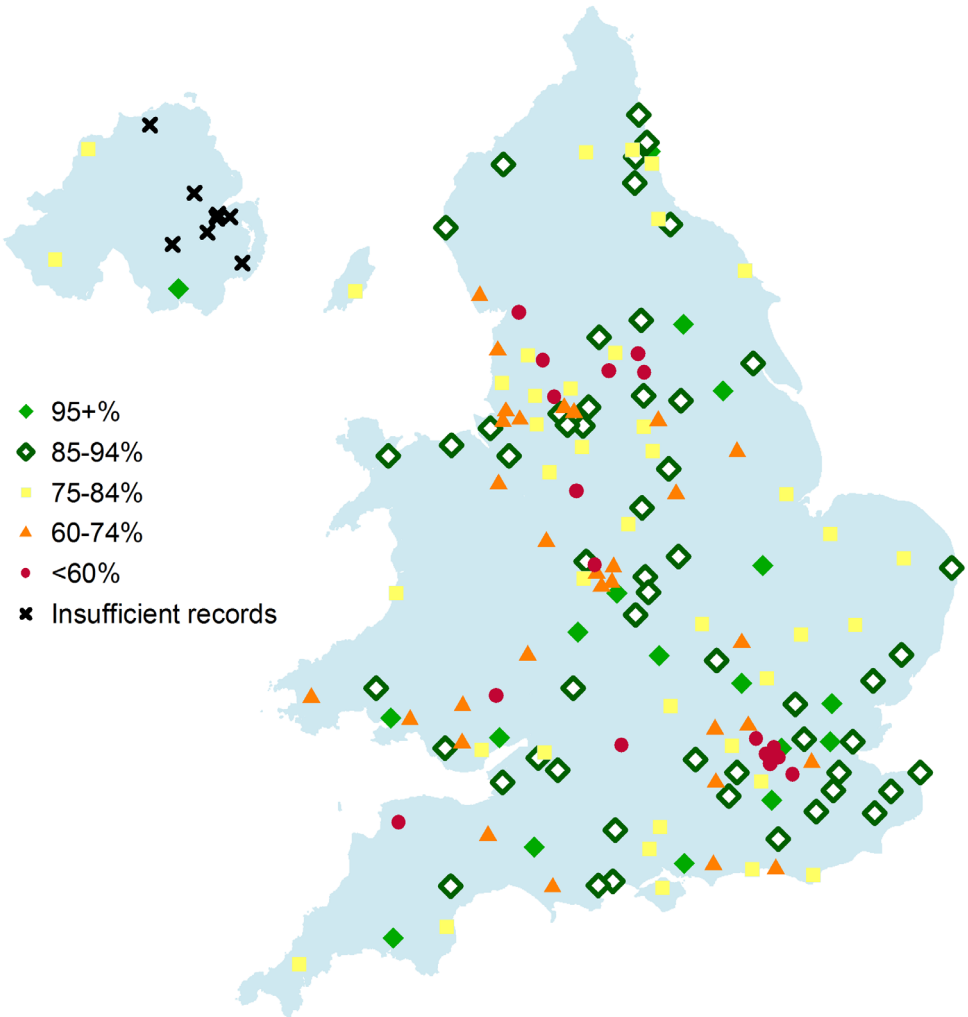


Figure 20: Paid carers available for patients who need help with daily living

What sort of care do patients get in the community?

Many people with stroke need further rehabilitation in the community, ideally in their own homes. Evidence shows that rehabilitation at home is cost effective but there need to be specialist teams in the community able to provide care as soon as someone returns home.

Early supported discharge teams ideally provide the same expertise at home as in the stroke unit, allowing people to get home more quickly, but these are not always available. 40% of people have some support from some sort of specialist team in the community, but access to specialist nursing, speech and language therapy or psychology varies considerably.

- A quarter of patients were discharged with the support of an Early Supported Discharge (ESD) team.
- 40% of patients had support from a stroke specialist team in the community, either an ESD team or a community rehabilitation team.
- 92% of patients under the care of an ESD or community rehabilitation team have rehabilitation goals set. This suggests that these teams promote further recovery after hospital. We need more of these teams to enter data to SSNAP, as currently only 4,667 patients had a completed record out of a possible 23,063.

1 in 4 stroke patients were discharged with support of an Early Supported Discharge team

40% of patients had support from a stroke specialist team in the community

This graph shows how access to Early Supported Discharge has increased between 2008 and present, from just 31% in 2008 to 74% today.

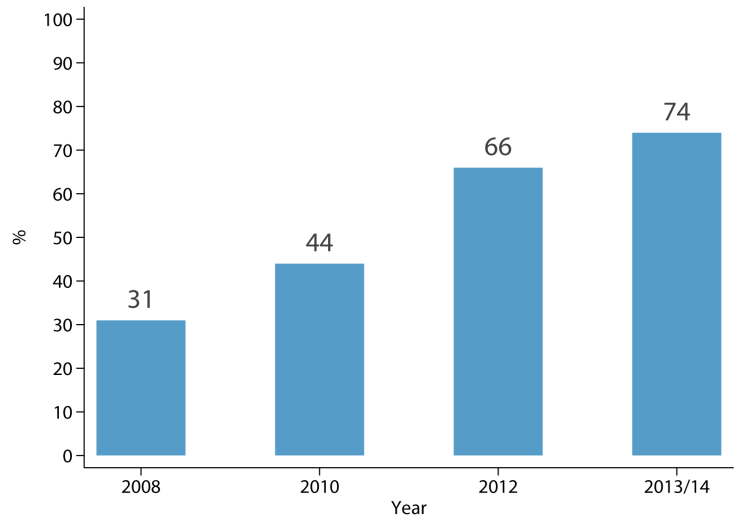


Figure 21: Change in accessability to ESD between 2008-2014

The transition from hospital back to everyday life is fraught with barriers. Community support is variable and inconsistent at best. High quality provision of community services is required to help with this long term condition.

Stephen Simpson, stroke survivor

What is Early Supported Discharge (ESD)?

Early Supported Discharge (ESD) is where patients return home quicker than they would otherwise be able to because they have support from an ESD team. An ESD team treats a patient in their own home. The team is usually made up of different healthcare professionals e.g. nurses and physiotherapists who are often stroke specialists. An ESD team will usually provide intensive treatment at first which will gradually reduce in intensity as the patient recovers.

Access to stroke specialist Early Supported Discharge services is extremely variable across the country, as shown in this map showing the proportion of patients discharged with support from a stroke specialist ESD team.

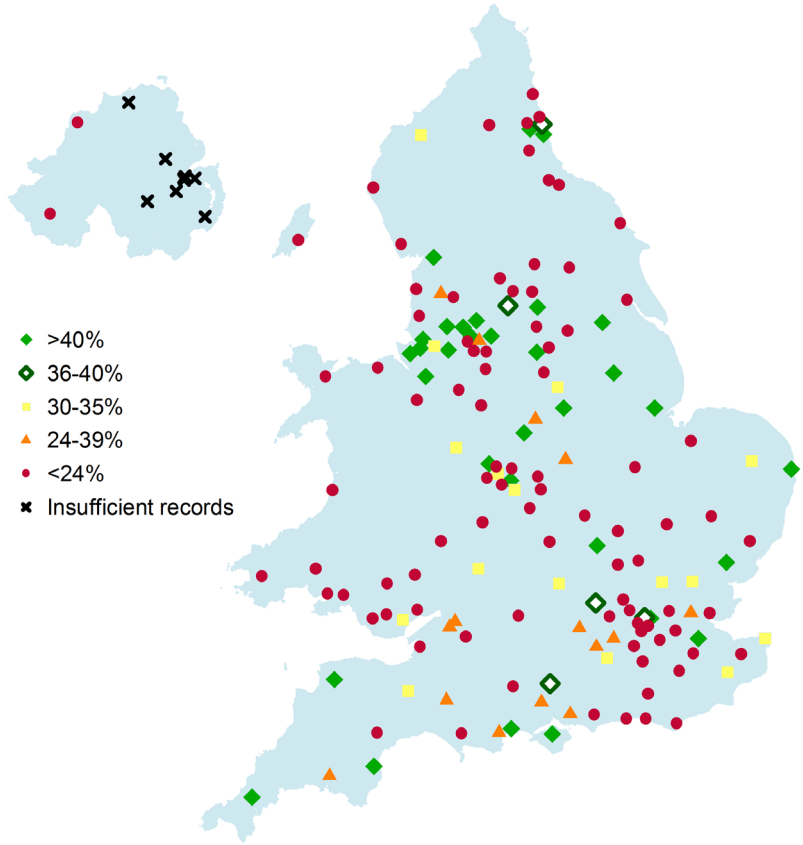


Figure 22: Proportion of patients discharged with support from a stroke specialist ESD team

What do we know about patient recovery six months after stroke?

Stroke recovery takes time, and many people feel that at 6 months following stroke they are just beginning to adjust to what has happened to them. People's needs change over time. An assessment allows a person with stroke to review with a trained professional how they are getting on, whether they need to make changes to life style or medication and whether further therapy is needed. Everyone should have an assessment of their needs at 6 months after stroke, but there is enormous variation in whether people are offered one. An assessment at 6 months also allows us to measure how people have recovered, which is an important measure of the effectiveness of treatment.

- SSNAP presents the first opportunty to get information on the status of a large number of stroke patients at six months after their admission to hospital.

- At present, an increasing number of teams are starting to enter information routinely to SSNAP, but based on the patients who could have had a six month follow-up assessment within the financial year, the rate is less than one in five.

- Therefore the information available is only based on a small subset of patients from the areas where six month follow-up has been routinely entered into SSNAP from an early stage.

- These data show us that at six months, 68% of stroke survivors have either a mild disability or no disability and a third have a moderate to severe disability.

- One in seven stroke survivors had another illness which required hospitalisation since their stroke.

Only **17%** of stroke survivors had an assessment six months after admission which was recorded on SSNAP.

Two thirds

of the stroke survivors we have information about have only a mild disability or no disability by six months after stroke

At 6 months you feel pressured to be "recovered", particularly if problems are not immediately obvious to others, but actually six months is still early in the journey to find your "new normal" and to adjust to, and accept, changes in yourself.

Marney Williams,
stroke survivor

SSNAP is showing huge variation in the proportion of patients who go on to have a six month follow-up assessment. This map shows the proportion of patients admitted to each team who are still alive at six months and had a six month assessment.

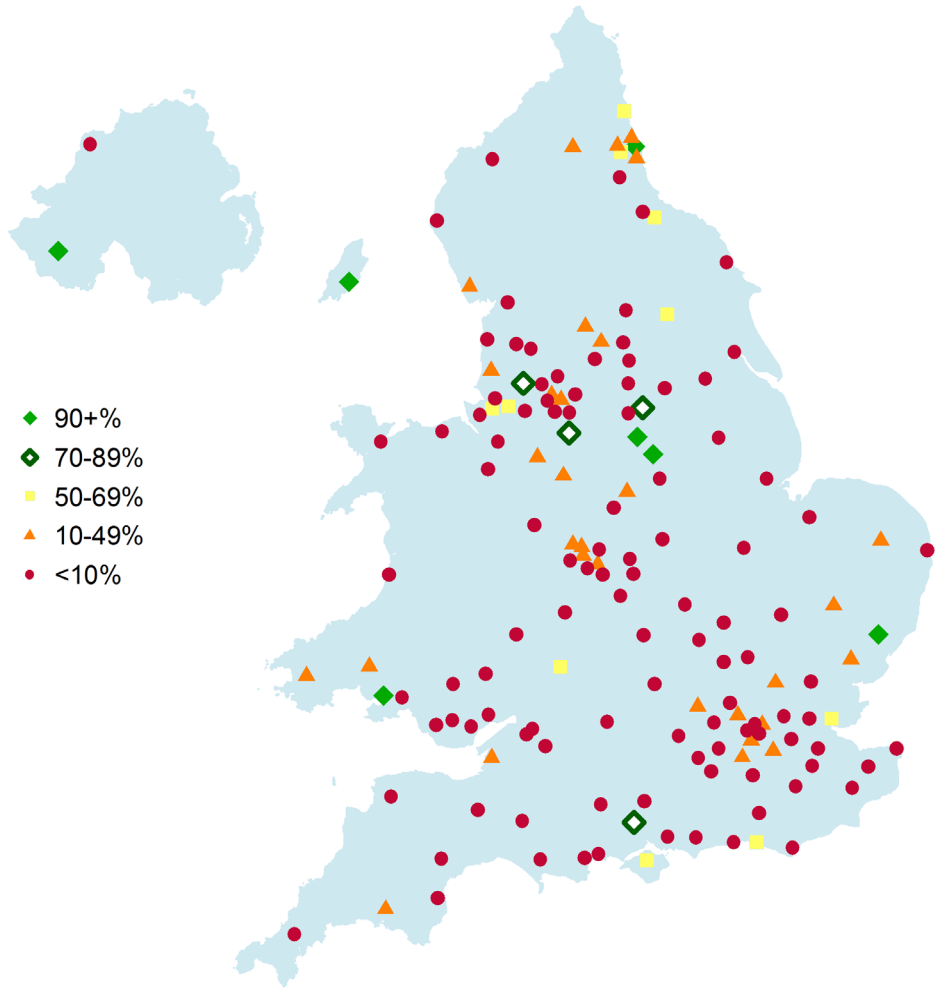


Figure 23: Proportion of patients who have a six month follow-up assessment

What does a patient's care pathway look like?

After a stroke, people need different types of care at different times. In the hours after the stroke, people should be in an acute stroke unit that can provide thrombolysis and other acute treatments. This may be in their local hospital, or may be in a stroke centre that serves several local hospitals. Once the acute phase is over, people are sometimes discharged home, but often need a period of inpatient rehabilitation, usually in their local hospital. They may be discharged home with the early supported discharge team or other community team.

A patient-centred approach?

There are complex pathways for stroke patients, which can comprise multiple acute settings including specialist hyperacute stroke centres, various non-acute and community inpatient settings, Early Supported Discharge teams and community rehabilitation teams, and a wide range of services (including voluntary sector) providing six month follow-up assessments.

SSNAP enables the full pathway of stroke care for each patient to be delineated and a 'transfer tree' created for each participating team to show them the patient journey before their team and after their team. The aggregated data enabled the production of 'patient-centred' results, which complemented 'team-centred' results. (These can be found in the SSNAP quarterly results for those who wish to see more detail.)

Whilst the team-centred results give each team their performance according to the areas of care they were responsible for, patient-centred results give every provider along the pathway results based on what the patient received during their care, regardless of who provided (or failed to provide) the standards in question. The patient-centred approach to data collection and reporting encourages service providers and commissioners to consider how care is delivered across several providers, rather than focusing solely on how well each separate service is delivering care.

1 in 10

patients went to more than one team and had their record entered jointly on SSNAP

More than **half** of patients went to teams across acute and community based care

Everybody's journey is completely different, but it is lifelong for many of us. There are times when you feel you are doing well, then times when everything is static, but I still feel I am improving I can now watch my favourite programmes, but in the past my visual problems prevented me from doing this.

Janet Rockcliffe,
stroke survivor

This flow diagram shows that there are different 'pathways' for stroke patients, with some going straight home and others going to more than one hospital. Some patients get admitted to a care home where they were not previously a resident before they had their stroke.

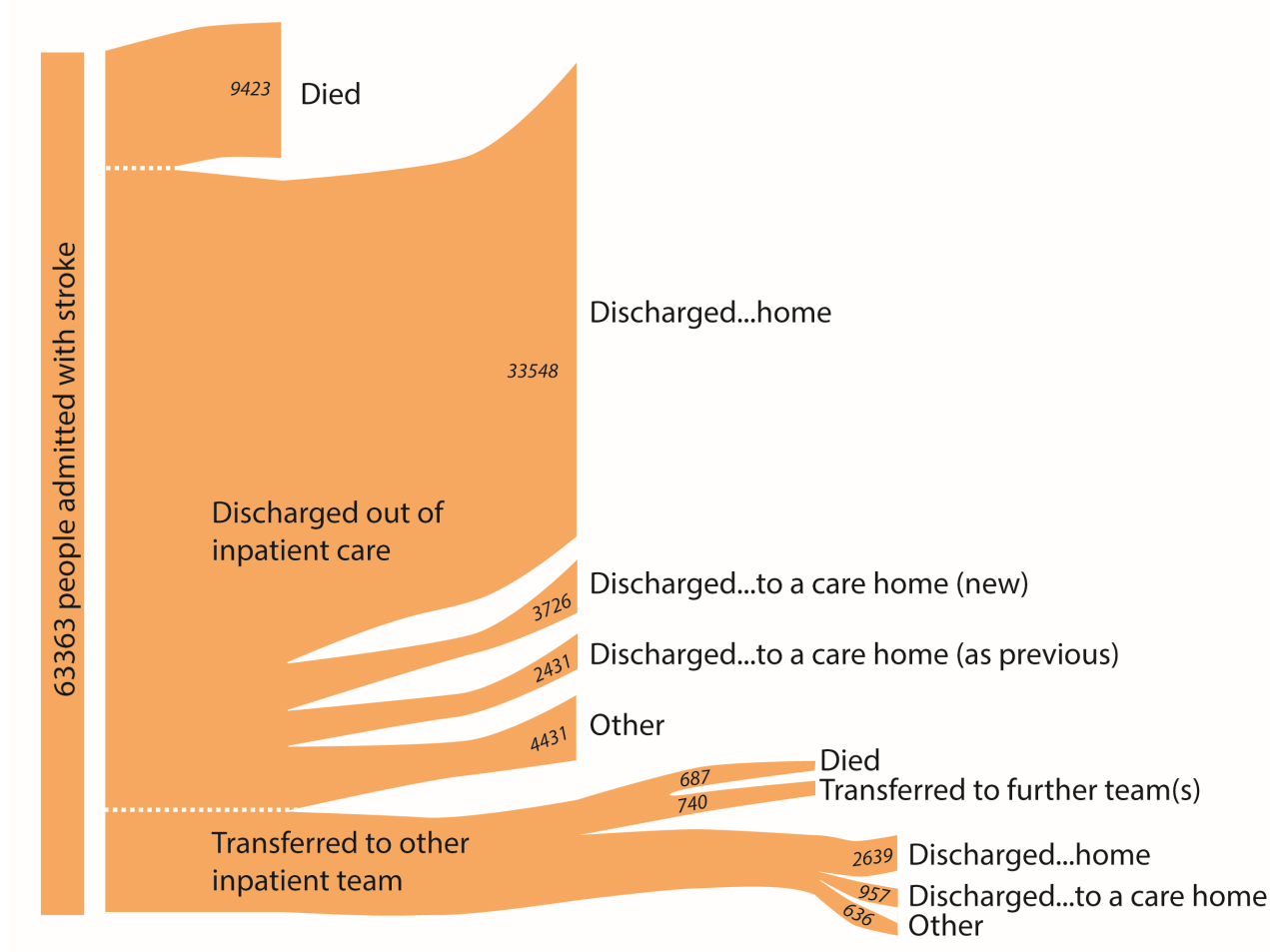


Figure 24: Different pathways followed by stroke patients

How can SSNAP help improve care for stroke patients?

We know that measuring what we do is the best way to monitor the quality of care we offer to people with stroke. We should be aiming for the best care for 100% of the people 100% of the time. Hospitals that submit their stroke data to the SSNAP audit are able to monitor their performance and make changes. We need to check that hospitals are submitting all of their data and not being selective, and we can do this by checking against another national database, Hospital Episode Statistics (HES). The SSNAP database includes over 90% of all the stroke patients admitted in England and Wales since 2013 and because we can now link directly to mortality and levels of disability, for the first time we can measure reliably how what we do affects patient outcome.

SSNAP aims to collect information about the organisation and quality of care and outcomes for every stroke patient in England, Wales and Northern Ireland. The fact that almost every hospital treating stroke patients in the acute phase is taking part, and that over 90% of stroke patients have been included, means that the information we have is highly representative and therefore useful for identifying where improvements are needed.

Each team (hospital or community team) receives their own results in a variety of formats every three months. This enables clinicians, managers and commissioners (funders) to review at high level and in detail about where to set goals for improvement.

The results for each team are provided to the public each quarter, enabling patients, carers, stroke survivors and other interested members of the public to get detailed information about the quality of stroke services and this can be used to press for improvements.

100% of hospitals in England and Wales which directly admit stroke patients are taking part in SSNAP

Information is entered into SSNAP for over

90% of patients

This graph shows how there has been an increase in the proportion of all stroke patients entered into SSNAP each quarter, with over 90% of all stroke patients now being included in SSNAP.

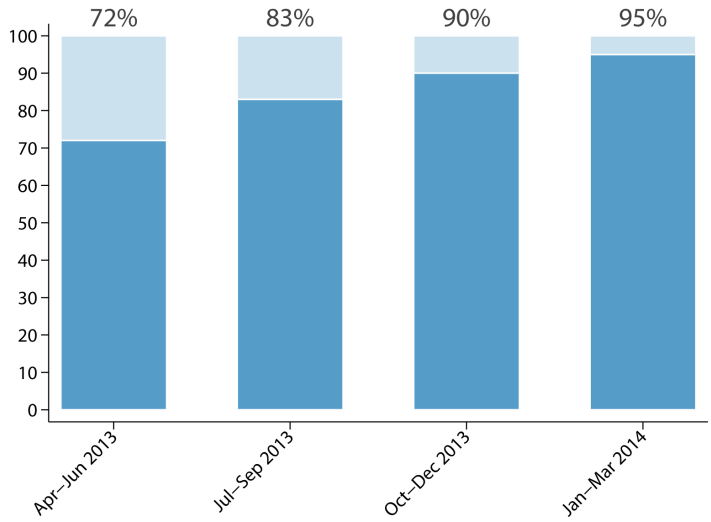


Figure 25: Proportion of all stroke patients entered into SSNAP each quarter

An example of improvements since start of continuous stroke audits

The graph below shows how the proportion of patients being scanned within 24 hours has increased since 2011, as measured in SINAP and SSNAP. Each dot represents a week and there has been consistent improvement. Whilst this cannot be attributed to SINAP or SSNAP, the fact that details of every patient's care (such as brain scanning) are collected and reported back to hospitals and the public continuously may be one factor helping to drive up standard of care for stroke patients.

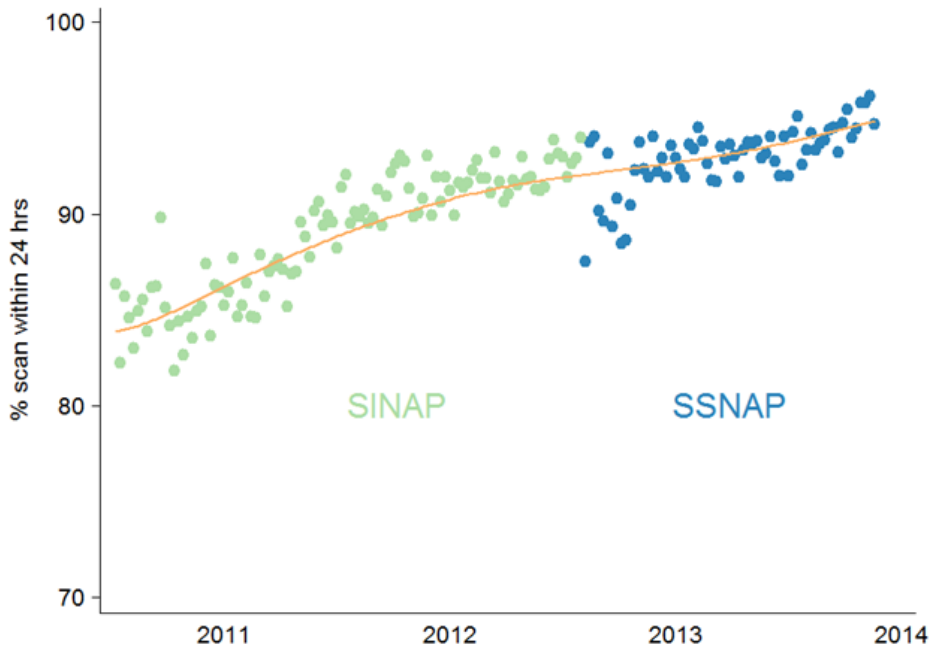


Figure 26: Proportion of patients scanned within 24 hours from 2011-2014

National Clinical Guideline for Stroke – information for patients and carers available as an App

The app for stroke survivors, stroke patients and carers is 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?

The Stroke Programme at the Royal College of Physicians has had a number of articles published using data from the stroke audits. You can find these articles by using the references below:

Bray BD, Ayis S, Campbell J, Cloud GC, James M, et al. (2014) Associations between Stroke Mortality and Weekend Working by Stroke Specialist Physicians and Registered Nurses: Prospective Multicentre Cohort Study. PLoS Med 11(8): e1001705. doi:10.1371/journal.pmed.1001705

Campbell JTP, Bray BD, Hoffman AM, Kavanagh SJ, Rudd AG, et al. (2014) 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 9(2): e87946. doi:10.1371/journal.pone.0087946

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

Bray B, 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.

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

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 Mar;42(2):240-5.

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

Acknowledgements

The RCP Stroke Programme would like to express our gratitude to the following people for their generous support, advice, and commitment, without which we would not have been able to produce this report.

Professor Pippa Tyrrell for writing the clinical commentary for the report in such a fluent and meaningful way; Claire Whitehouse whose powerful drawing we used as the artwork for our front cover; Speakeasy, a charity group for people with aphasia, who provided patient quotes and pictures for the report (for more information on this group, or to donate go to www.buryspeak-easy.org.uk); our patient representatives on the Intercollegiate Stroke Working Party (ICSWP) for their continued enthusiasm and support of the work we do; the Stroke Association who also provided us with patient quotes for inclusion in the report (www.strokeassociation.org); finally we want to thank the teams and individuals participating in SSNAP for their hard work and dedication to submitting prospective and robust data to the audit each quarter. Without this data it would not be possible to produce a report of this kind. 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

This report was written and produced by James Campbell, Professor Pippa Tyrrell, Dr Ben Bray, and Mark Kavanagh.