National Audit Office

the challenge

rehabilitation

response

JOINING FORCES TO DELIVER IMPROVED STROKE CARE

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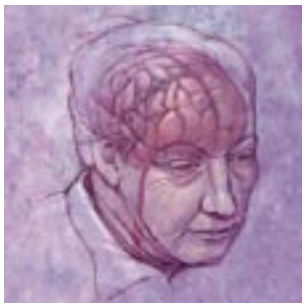


FOREWORD

For many years, stroke was viewed as an inevitable consequence of getting old. For stroke patients, there seemed little to be done, except making them more comfortable. But in recent years experts have identified that much can be done to prevent and treat stroke.

Things have already begun to change. The Older People's National Service Framework, published in 2001, has driven real improvements and the NHS is delivering better treatment and care for stroke, through specialist services, to more people than ever before. Recent developments include the accreditation of stroke as a sub-specialty in 2004, the establishment of a Stroke Research Network to coordinate and champion research in stroke and the integration of stroke policy with other vascular conditions through the Vascular Programme Board.

Strong evidence has also emerged in the past three or four years in favour of key interventions, such as stroke units, immediate scanning for all stroke patients, thrombolysis and Early Supported Discharge. The publication of the National Audit Office report on stroke services in November 2005 was well-timed to capitalise on the opportunity to demonstrate how these recent developments can improve the efficiency and effectiveness of care for stroke patients.

The Department of Health is taking the issues raised by the National Audit Office report seriously and is working to develop a comprehensive national stroke strategy. Stroke is a good example of a care pathway crossing prevention, urgent care, hospital care, community support and social care where the scope for better integration is huge. The challenges are equally big.

That is why we are joining forces through expert project groups who are developing recommendations for the strategy to build momentum and meet these challenges. We have a lot of work ahead of us, but with all the support from voluntary organisations and clinicians, groups and individuals, I am confident we can produce a comprehensive and effective strategy for delivering real improvements in stroke services. The examples in this book show what can be achieved, and it is our aim to make this a reality across the country.

Roger Boyle,
National Clinical Director for Heart Disease and Stroke

INTRODUCTION

Since publishing our report in November 2005, there has been widespread acceptance that the need to improve stroke care is now a national priority. Stroke devastates families and leaves many survivors with serious disabilities. Caring for people who have had a stroke uses a significant proportion of inpatient beds and nursing home places, and as our report showed, ultimately costs the nation around £7 billion every year, with direct costs to the NHS of nearly £3 billion.

Yet we found that each year hundreds of stroke patients were needlessly dying or suffering more serious disablement than might otherwise have been the case, simply because their treatment had not been prioritised in the way it might have been. Furthermore, that the cost of stroke, in both economic and human terms, could be reduced by re-organising and using existing services more wisely and preventing more strokes from occurring in the first place.

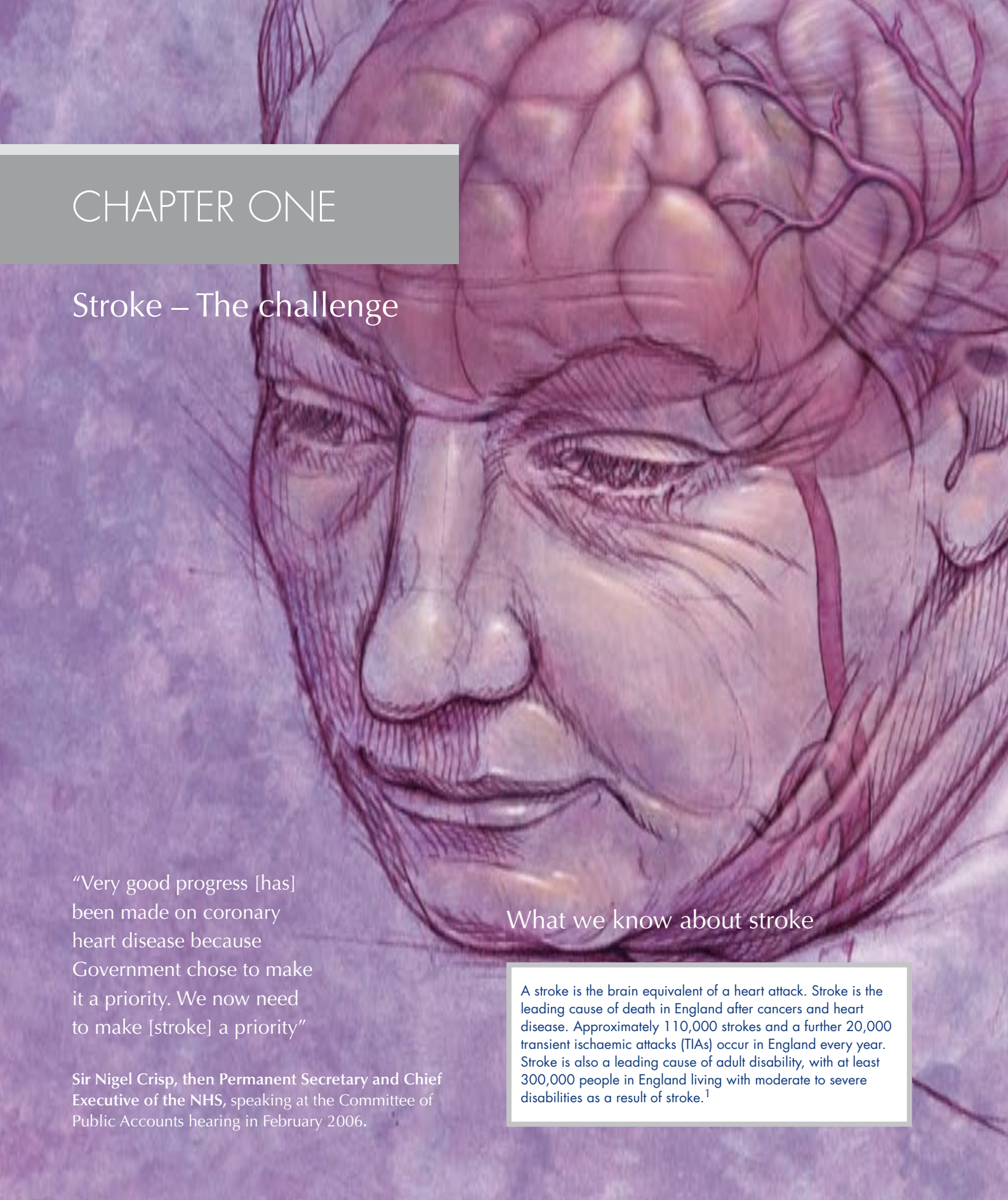
We were heartened at the Department's response and its clear acknowledgement of the need for change, in particular the need:

- To raise public and professional awareness of the best way to manage stroke;
- To improve rapid access to brain scanning alongside interventions; and
- To increase rapid access to acute stroke unit care alongside high quality rehabilitation and post-acute care services.

We have been particularly encouraged by the energy and impetus provided by Professor Roger Boyle since taking on the leadership of the national stroke strategy and the important progress that has already been made by the Department in developing this strategy. We also note the recognition that has been given to learning from the best both nationally and internationally. Indeed, the positive response to our report and the recommendations of the Committee of Public Accounts provided the impetus behind our decision to host a conference on stroke in October 2006. In turn, the sheer energy and commitment that was evident at the conference, and the excellent ideas and examples of good practice debated, led to our decision to try and capture the key messages in this book so that they can be shared more widely.

The NAO's strap line is 'Helping the nation spend wisely'. We hope that implementing the stroke strategy will do just that, resulting in a more efficient and effective use of resources when providing stroke care, and in turn enabling patients to lead more independent lives than they otherwise might have done. Our vision for the NHS is that excellence in stroke care will not be dependent on local leadership and local champions but will be more consistently applied and that patients who suffer a stroke will get the best possible care, regardless of where they live. This book provides a platform for promoting the developing stroke strategy and together we hope these will help this vision become a reality.

Karen Taylor,
Director for Health Value for Money studies, NAO



CHAPTER ONE

Stroke – The challenge

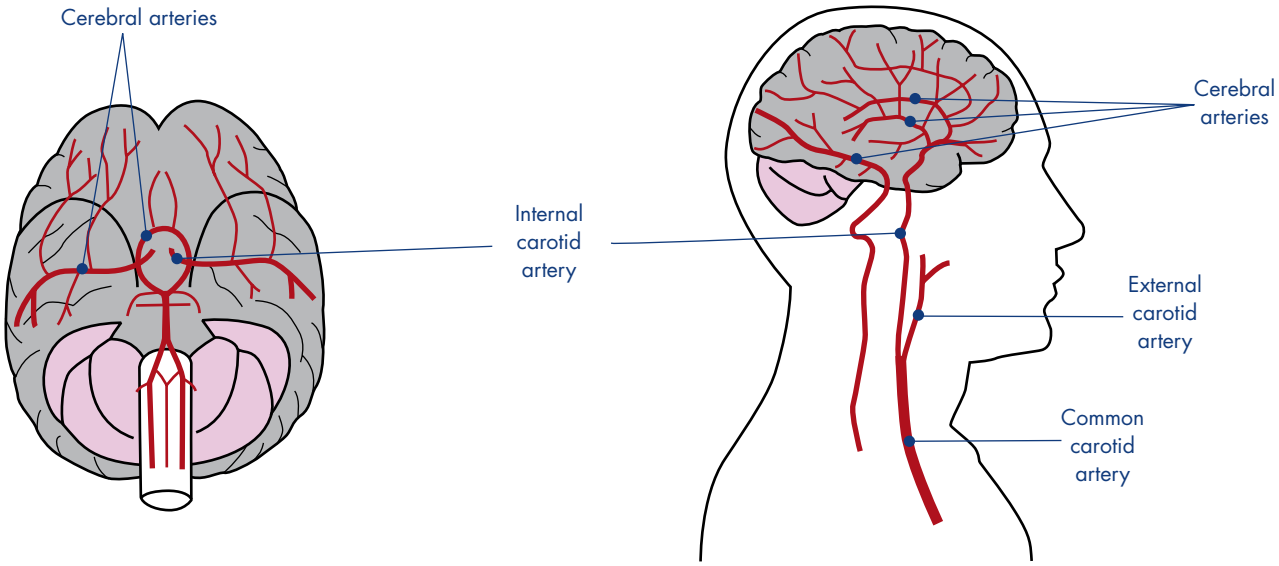
"Very good progress [has] been made on coronary heart disease because Government chose to make it a priority. We now need to make [stroke] a priority"

Sir Nigel Crisp, then Permanent Secretary and Chief Executive of the NHS, speaking at the Committee of Public Accounts hearing in February 2006.

What we know about stroke

A stroke is the brain equivalent of a heart attack. Stroke is the leading cause of death in England after cancers and heart disease. Approximately 110,000 strokes and a further 20,000 transient ischaemic attacks (TIAs) occur in England every year. Stroke is also a leading cause of adult disability, with at least 300,000 people in England living with moderate to severe disabilities as a result of stroke.[1]

1 What is a stroke?



A stroke is a type of brain injury. Most commonly a stroke is caused when blood flowing to the brain is blocked (by a clot or when blood vessels have become too narrow). Strokes of this kind, which account for around 85 per cent of all strokes, are called ischaemic. In a haemorrhagic stroke the blood vessel bursts. In both cases, the disruption of the blood supply to the brain causes brain cells to die.

Strokes range in severity from getting better within 24 hours – known as a transient ischaemic attack (TIA) or a 'mini stroke'– to a stroke which may cause severe brain damage or death. A TIA is a strong warning sign that, unless preventative measures are taken, a further and perhaps major stroke, is likely to occur soon. The impact will vary depending on which part of the brain is affected, how many brain cells have died, how many cells that have been damaged can recover, and if other parts of the brain can take over from the areas that died.

Key symptoms of stroke

Sudden onset of one or more of:

- Weakness or numbness in face, arm or leg, especially on one side of the body;
- Difficulty speaking or understanding;
- Loss of balance or coordination such as difficulty walking.

Risk factors for stroke

- High blood pressure;
- Previous stroke or TIA, or a family history of stroke;
- Atrial fibrillation (irregular heart rhythm);
- High blood cholesterol;
- Diabetes;
- Smoking;
- Advancing age;
- Unhealthy diet.

Stroke is a medical emergency. If you suspect someone is having a stroke, dial 999.

Source: National Audit Office, Reducing Brain Damage: Faster access to better stroke care (HC 452 – Session 2005-2006)

2 Key facts about stroke

- Stroke accounts for 11 per cent of the deaths in England and Wales a year. Between 20 and 30 per cent of people who have a stroke die within a month. Every five minutes someone in England will have a stroke, and around one in four people can expect to have a stroke if they live to 85 years of age. However, awareness of stroke and how to recognise symptoms is low.
- The incidence of, and mortality rates for, stroke and coronary heart disease have declined in recent years, although stroke mortality has declined at a slower rate. Between 1992 and 2002 stroke death rates in those aged under 75 declined by 30 per cent, and heart disease death rates declined by 44 per cent. However the chance of dying from a stroke has remained constant over that time, while the chance of dying from a heart attack has declined by about 1.5 per cent each year.
- There are more than one million people who have had a stroke living in England. Around half of stroke survivors are left dependent on others for everyday activities. Between 20-40 per cent of residents in care homes are likely to be there as a result of stroke.
- The average length of stay in hospital for stroke patients is 28 days. One in five acute hospital beds, and a quarter of long term beds, are occupied by stroke patients.
- Stroke will become increasingly expensive as the number of people living with stroke increases. People aged 65 years and over increased by nearly four million between 1952 and 2002 and the percentage of older people in England is projected to rise from 16 per cent in 2003 to 23 per cent in 2031. The total costs of stroke care are predicted to rise in real terms by 30 per cent between 1991 and 2010.
- Stroke affects young people as well as old: a quarter of strokes occur in people aged under 65.
- People of Afro-Caribbean ethnicity are at higher risk of stroke, especially of having strokes while young.

Source: National Audit Office, Reducing Brain Damage: Faster access to better stroke care (HC 452 – Session 2005-2006)

The cost of stroke to both the NHS and the wider economy is high with much that could and should be done for those who suffer a stroke

Stroke care costs the NHS about £2.8 billion a year in direct care costs – more than the cost of treating coronary heart disease – and costs the wider economy some £1.8 billion more in lost productivity and disability. Additionally, the annual informal care costs (costs of home nursing and care borne by patients' families) are around £2.4 billion.[2]

We found that awareness of stroke and how to recognise its symptoms amongst the general public is low and that more emphasis needs to be given to primary and secondary prevention measures. Emergency response to stroke in acute care is generally lacking and patients should be treated on specialised stroke units with rapid access to brain scans. Following discharge, stroke patients need improved access to rehabilitation and support services.

Overall, we estimated that, each year, more efficient practice could save £20 million, prevent around 550 deaths and ensure that some 1,700 people fully recover from their strokes that would not have otherwise done so.

The critical issues are:

A fast and integrated response

- A fast response to stroke, including rapid access to brain scanning, reduces the risk of death and disability. However, Ambulance Trusts, Accident and Emergency (A&E) departments, Radiology departments and stroke teams often fail to provide an integrated emergency response to stroke.
- Indeed, the Royal College of Physicians Sentinel Audit (2006) shows that 13 per cent of sites in England have arrangements in place with the local ambulance services for emergency or rapid transfer to hospital for stroke patients.
- The clinically optimal model of stroke care is care delivered in a specialised stroke unit and in 2005, 63 per cent of patients were accessing a stroke unit at some point in their hospital stay. However, what constitutes a stroke unit varies considerably between hospitals.
- The transition from hospital to home can be extremely traumatic and a common complaint is that stroke patients feel abandoned. Hospital staff suggested that about half of stroke patients get the services they need in the first six months after discharge, but in the six to twelve months after discharge this falls to around 20 per cent of patients.

Better application of staff and scanning

- Early access to rehabilitation can restore movement, improve recovery and reduce delayed discharges. However, access to professionals such as psychologists, physiotherapists, occupational and speech therapists and social workers is patchy within hospital, and even more so following discharge.
- The number of patients per stroke consultant in 2005 was 640, whereas coronary heart disease consultants had 360 patients each. And the 2006 Sentinel Audit found that, although the number of sessions offered by consultant stroke physicians is increasing, it is still a "long way from the recommendations of the British Association of Stroke Physicians."[3]
- Without a brain scan, treatment cannot commence safely. Research shows that scanning all stroke patients immediately is the most cost-effective strategy. Although most hospitals have access to CT scanners around the clock, in 2004 most stroke patients waited more than two days for a scan. A low priority afforded to stroke patient scanning and a lack of available staff to interpret the scan, once it is done, causes unnecessary delays.
- We estimated that approximately £1.2 million per year was being inefficiently used providing scans to diagnose TIAs after the time when the diagnosis is most useful.

Better application of intervention technologies

- Thrombolytic (clot-busting) drugs can improve patients' chances of recovery after a stroke, but are very rarely part of acute stroke care in England. Currently, less than one per cent of stroke patients in England receive thrombolysis each year, but achieving rates closer to nine per cent could generate net savings to the health service of over £16 million a year, with more than 1,500 patients fully recovering from their strokes each year who would not otherwise have done so.
- We examined the benefits of providing faster access to carotid surgery for TIA patients and estimated that providing surgery within 14 days of TIA could prevent about 250 strokes and yield a net saving to the NHS in care costs avoided of around £4 million, each year.

Improved stroke prevention

- Many people still do not realise that strokes are largely preventable and cannot list the main risk factors, or how to manage them. For example, whilst over three times as many women died of stroke than of breast cancer in England and Wales in 2002, 40 per cent more women mentioned breast cancer than mentioned stroke when asked what the top causes of death were.
- Preventing just two per cent of strokes in England would save around £37 million in care costs.
- If a person has a stroke or TIA this is a major risk for another stroke to follow, yet only a third of people with TIA are seen in a TIA clinic, and the waiting times are still too long.
- GP recognition and referral behaviour around stroke and TIA varies, as do preventative measures – with one in five patients (known to have high blood pressure before their strokes) not on suitable medication prior to their stroke.

In publishing our report, Comptroller and Auditor General and Head of the National Audit Office (NAO), Sir John Bourn said:[4]

> "BY GIVING STROKE THE ATTENTION AND STATUS IT DESERVES, THE DEPARTMENT WILL BE ABLE TO MAKE FINANCIAL SAVINGS TO THE NHS AND THE WIDER ECONOMY. THE NHS CAN HELP PREVENT MORE STROKES AND IMPROVE TREATMENT, CARE AND OUTCOMES BY RE-ORGANISING SERVICES AND USING EXISTING CAPACITY MORE WISELY"

The Committee of Public Accounts questioned the Department of Health on the findings from our report

Following publication of our report in November 2005, the Committee of Public Accounts, the senior Select Committee of the House of Commons, took evidence from Nigel Crisp, the then Chief Executive of the NHS and Accounting Officer for the Department of Health, and other Departmental witnesses.

The Committee then published its own report in July 2006.[5] Significant recommendations that emerged were:

Improving acute care

- All suspected stroke patients should be scanned as soon as possible after arrival at the acute hospital, ideally within three hours, and none should wait more than 24 hours for a scan.
- All A&E and Radiology departments should have protocols in place for the rapid admittance and referral for scanning of stroke patients.
- All stroke patients should be admitted to a specialist stroke unit as soon as possible following a diagnosis of their stroke. Primary Care Trusts should deliver acute stroke care through a stroke unit that meets the national clinical guidelines for stroke.

Improving the workforce

- The NHS should move to a position where there are as many stroke consultants per patient as heart disease consultants per patient.
- The education and training provided to new triage nurses and junior doctors should include awareness of stroke and the need for urgent brain scans for stroke patients.
- The Department should train stroke consultants to interpret scans and make immediate treatment decisions. It should also continue to develop its telemedicine programme so that, by 2007, staff managing stroke patients can access neuro-radiological expertise remotely.

Improving the patient experience

- The Department should evaluate the merits of Early Supported Discharge initiatives and other ways of improving access to therapies, and promote the early adoption of those that can be shown to reduce hospital stay and improve patients' chances of recovery.
- The Department should improve the provision of information to stroke carers, so they become aware of the services available to support them.

Improving prevention

- All providers of primary and secondary care should have protocols in place for the referral of suspected or confirmed TIA patients.
- The Department should run an awareness campaign for stroke, focussing on its symptoms and the fact that it is a medical emergency requiring a 999 response.

On publishing the Committee's report the Chairman of the Committee, Edward Leigh MP, said:[6]

> ***"Until recently, stroke has been treated as going with the territory of growing old and has certainly not been given the same level of priority and resources as coronary heart disease and cancer. It is welcome news that, in the light of the NAO report, the Department of Health has now accepted the need for progress ... and has agreed that implementing the NAO recommendations might save as many as ten more lives a week."***

The Department of Health has launched a programme of work to improve the delivery of stroke care

> ***"The National Audit Office report on stroke services published last autumn was a turning point. It clearly demonstrated that in many respects and in many areas stroke services needed to improve but also, very usefully, it identified the barriers that prevent stroke patients from receiving rapid and responsive emergency care."***

Source: Rosie Winterton, Minister of State for Health Services, speaking at the NAO conference (19th October 2006)

"ONE OF THE THINGS THAT STRUCK ME MOST IS HOW FAST THE DEPARTMENT IS MOVING"

Source: Karen Taylor, Director for Health Value for Money studies, speaking at the NAO conference (19th October 2006)

This is an important time for stroke survivors and professionals who work with stroke patients because work has begun to develop a new national strategy for stroke services. Following a commitment by ministers in November 2005 to examine the best ways to deliver the newest treatments and improve the care that stroke patients receive, the Department began to work with a wide range of stakeholders to look at how to achieve this ambition.

In March 2006 the Department held a conference to launch the development of a stroke strategy and developed six expert project groups to produce recommendations on the content of the strategy. Each of these is led by an independent expert who is working with a team of specialist volunteers to produce recommendations in each of the important areas of services and care for the future. The groups are as follows:

- Public awareness and prevention – chaired by Professor Charles Wolfe.
- TIA and minor stroke services – chaired by Professor Peter Rothwell.
- Emergency response – chaired by Professor Gary Ford.
- Hospital stroke care – chaired by Dr Tony Rudd.
- Post hospital stroke care – chaired by Professor Sally Byng.
- Workforce – chaired by Dr Damian Jenkinson.

Membership of each project group has been carefully selected so that all the relevant people are represented. Representatives from the voluntary organisations The Stroke Association, Connect and Different Strokes are taking a major role in developing the recommendations for the new stroke strategy, along with a number of survivors and carers.

Updates on the work of the groups are posted on the Department of Health website at **www.dh.gov.uk/stroke**

The aims of the strategy are:

- to raise public and professional awareness about stroke symptoms and risk factors and the need for an urgent response, and to improve primary and secondary prevention of those risk factors;
- to ensure that people who suffer TIAs and minor strokes have rapid access to high quality, appropriate diagnostic and treatment services;
- to accelerate the emergency response to stroke and improve coordination between the different agencies and professionals involved, including through improved access to CT scanning;
- to recommend the models of service provision and ways of working in the acute phase of stroke, appropriate to delivering new treatments;
- to ensure support is available to stroke survivors as they transfer from hospital to home and to ensure the long-term support services needed after stroke are provided; and
- to ensure that the workforce is developed, in terms of numbers and skills, to enable the implementation of the strategy.

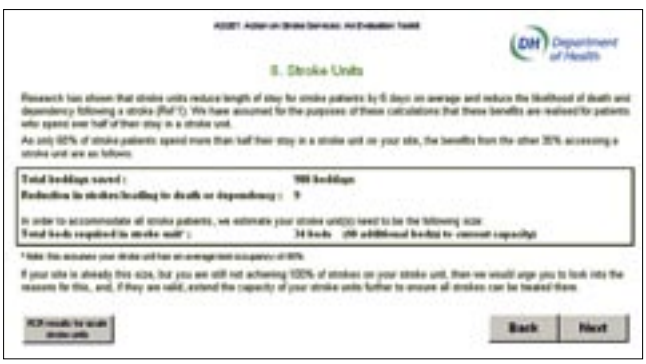
The next stages of development are:

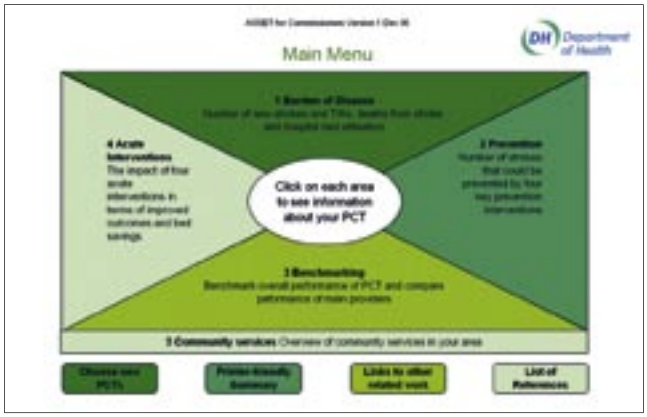
- March 2007 – recommendations from the project groups to go to Ministers
- Summer 2007 – three-month consultation on the strategy
- Autumn 2007 – final strategy published

The Department has developed guidance and tools to support improvements in stroke services

The Government's response to the Committee of Public Accounts gave details of how, as well as developing a new stroke strategy, the Department of Health is responding to the Committee's recommendations. Actions included:

- developing a stroke toolkit, ASSET (Action on Stroke Services: an Evaluation Toolkit), to help health providers understand how they can improve stroke services by reviewing performance compared with other providers (see Appendix 1);





- raising the profile of stroke with commissioners by developing a commissioning guide for stroke. This guide advises commissioners on key issues to consider when commissioning stroke services to ensure a good quality stroke service. This is accompanied by a version of ASSET developed specifically to support commissioners (see Appendix 1);

- asking the National Institute for Health and Clinical Excellence (NICE) to develop a guideline that will cover acute treatment of stroke. This will be published in 2008 and will provide a benchmark against which trusts will be monitored by the Healthcare Commission as part of the Annual Health Check process;
- asking a group of experts to recommend how to overcome cultural and organisational barriers to delivering urgent scanning to stroke patients where appropriate;
- working closely with the Workforce Review Team to ensure that the limitations caused by the current level of stroke consultants are factored into recommendations for planning priorities; and
- improving support for carers. The National Strategy for Carers will be updated and extended, a helpline will be established to offer advice to carers, and an Expert Carers' Programme will be developed which will provide training for carers to develop the skills they need.

Appendix 4 provides full details of the Committee's recommendations and the Department of Health's response.

> ***"When I started on the Heart Programme, the first thing we had to do was to really gather the clinical momentum and buy-in from the various clinical groups dealing with heart disease. And that has not been at all a problem with the stroke community; it was just like pulling a lever and suddenly this huge wash of enthusiasm and pent up frustration emerged into a really positive force. This is [what it] is all about – that you gradually build momentum so that it becomes an unstoppable force (even if money's tight and everyone is being reorganised into different formations) – so in the end, the clinical drive always wins through if you're patient enough, structured enough and reasoned enough in your arguments."***

Source: Roger Boyle, National Clinical Director for Heart Disease and Stroke, Department of Health, speaking at the NAO conference (19th October 2006)

Our conference provided a platform to share leading practice and debate what needs to be done

"THERE IS A SENSE OF PURPOSE AND CONSENSUS IN THIS ROOM AND WITHIN THE STROKE STRATEGY, WITHIN THE DEPARTMENT ITSELF, ACROSS ALL OF US, THAT'S GOING TO LEAD TO PROGRESS FOR ALL STROKE SERVICES"

Source: Joe Korner, Director of Communications at The Stroke Association, speaking at the NAO conference (19th October 2006)

We organised a follow-up conference in October 2006 (Appendix 2). The conference provided an opportunity to discuss the main findings of the Committee of Public Accounts and the Department of Health's response.

Derek Whitehead, who features in our report said:

> ***"I'm a carer and partner for a lady who is totally mentally and physically disabled by multiple strokes. My wife was used as one of the case studies in the NAO report and I thought it was a wonderful report. I also attended the Public Accounts Committee in the Houses of Parliament when the report was analysed and I was most impressed by the way that it was done. Most importantly, what I want to say is that – for the exercises done by the NAO team and the Public Accounts Committee – my heartfelt thanks. It won't help my wife but it will help others."***

Delegates considered presentations from practitioners from across the UK, Australia and Sweden who have innovated stroke services in both acute and post-acute care and who provide the examples of good practice that all services should aspire to deliver.

> ***"Chris Bladin [from Box Hill Hospital in Australia] has given us a standard that we really need to reach in this country and although I'm going to show you some of the efforts we've made to get towards that standard, we're nowhere near that yet."***

Source: Martin Brown, Professor of Stroke Medicine, Institute of Neurology, University College London, speaking at the NAO conference (19th October 2006)

As the Department of Health are currently building a new stroke strategy, and with audits of stroke care continuing, it is increasingly beneficial for all professionals, service users and voluntary sector organisations to continue to be involved in ringing in the changes.

Speaking at the conference Anthony Rudd (Stroke Programme Director, Clinical Effectiveness and Evaluation Unit, The Royal College of Physicians) outlined that audit was an important lever for change, and described how one stroke physician wrote in after the publication of the performance indicators in the 2004 Sentinel Audit to say:

"I'VE BEEN TRYING TO GET THE TRUST TO OFFER SCANNING FOR STROKE PATIENTS FOR 5 YEARS; WITHIN A DAY OF RECEIVING THE AUDIT REPORT THE CHIEF EXECUTIVE HAD CONVENED A MEETING WITH STROKE SERVICES AND RADIOLOGY"

And Edward Leigh MP, Chairman of the Public Accounts Committee, added that stroke care is a subject that resonates with the Committee, and they were committed to revisit the topic to check on progress:

> ***"It was quite clear that so many lives could be improved or saved if we could take action more quickly with strokes. I can assure you that my Committee is unanimous in supporting all and any actions that improve the lives of stroke survivors and their carers. [There] are many people who, if we don't take more action, will suffer appalling disabilities and it may be one of us …"***

We have committed to report to the Committee of Public Accounts again on the progress of stroke services in the coming months and years. Appendix 3 invites you to contact us if you would like to suggest areas that our report could examine, to improve the economy, efficiency and effectiveness with which stroke care is delivered in England.

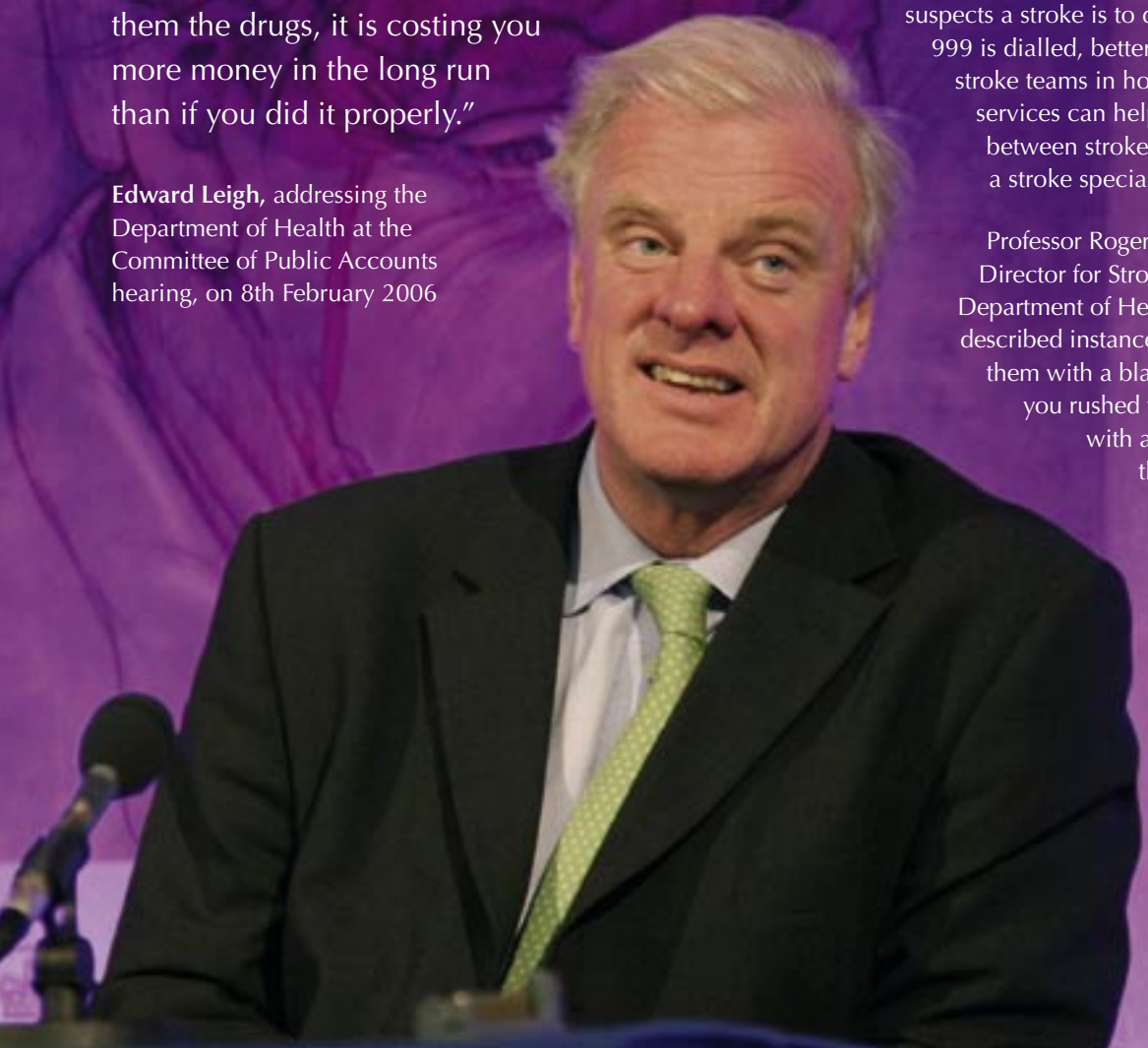
This book is therefore a compendium of our shared knowledge about what works, why and what more can and should be done. There is, of course, a body of literature and research, from both home and abroad, that looks in depth at the functioning of specific interventions and health outcomes. This book does not attempt to compete with this growing body of evidence. Rather, it takes a high-level view, which covers the key managerial issues and critical success factors in delivering stroke care, and it seeks to support the agreed agenda of the Department of Health to re-prioritise stroke care and to make progress against the baseline which is set out by the findings and evidence in our 2005 report.

CHAPTER TWO

Joining forces to respond to stroke

"It seems that even with the resources available to you, because you are not getting people into stroke units quickly enough, giving them a scan, getting them the drugs, it is costing you more money in the long run than if you did it properly."

Edward Leigh, addressing the Department of Health at the Committee of Public Accounts hearing, on 8th February 2006



Stroke is a medical emergency requiring rapid and responsive care

Research shows that a fast response to stroke reduces the risk of death and disability. However, we found that many people do not know how to recognise the symptoms of stroke, or that the correct response if someone suspects a stroke is to dial 999. In cases where 999 is dialled, better coordination between stroke teams in hospitals and ambulance services can help to reduce the time between stroke onset and accessing a stroke specialist.

Professor Roger Boyle (National Clinical Director for Stroke and Heart Disease, Department of Health) said that paramedics described instances where A&E staff greeted them with a blank look of 'why have you rushed this is just somebody with a stroke so there's nothing that can be done here'. However, some ambulance services have established a protocol which enables ambulances to take the patient directly to the stroke unit, bypassing any delay that might occur in the A&E department.

AN ENGLISH TOUR DE FORCE

At the conference Martin Brown (Professor of Stroke Medicine, Institute of Neurology, University College London) described some of the work that he had done with the National Hospital for Neurology & Neurosurgery and the London Ambulance Service to reduce delays in the delivery of stroke patients to a specialised stroke unit:

> ***"When I started thinking about what to do about this problem of stroke I thought there were never any stroke patients who reached hospital in the UK within three hours but we were wrong. We did this study, published in 2002, of 22 district general hospitals in the UK; 37% of stroke patients arrived in hospital in under three hours – nearly all those that called 999. And although they arrived there within three hours, nothing happened to the patients; they didn't see a doctor for many hours afterwards and of course it took forever for them to have a CT scan."***
>
> ***"The London Ambulance Service came to speak to me and said 'shouldn't we be bringing stroke patients to you more quickly?' So we developed this protocol – RAPIDS – a rapid ambulance protocol for identification of stroke. The aim of the work was simply to see if we could improve the delivery of stroke patients to a specialised unit, by educating ambulance personnel and bypassing the block in the A&E department."***

Source: Martin Brown, speaking at the NAO conference (19th October 2006)

As part of the RAPIDS protocol, paramedics were trained to use the stroke identification tool "Face Arm Speech Test" (FAST). This test assesses whether the patient is showing the typical signs of stroke: facial palsy, arm weakness and problems with speech.

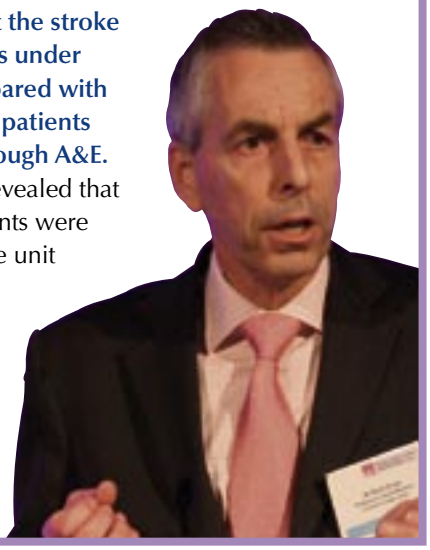
Face Arm Speech Test (FAST) for stroke

	Yes	No	Unable to assess	Affected side Left	Affected side Right
Facial weakness – *Ask patient to smile showing teeth*					
Unequal smile					
Arm weakness – *Lift patient's arm, ask them to hold for 5 secs*					
Arm drifts/falls					
Speech – *Attempt a conversation*					
Slurred speech/ word finding difficulties					

If patient score >1/3 stroke or TIA is likely

Source: Slide from Martin Brown's presentation at the NAO conference (19th October 2006)

Martin Brown's research of the protocol over the last year indicated that ambulance personnel identified stroke as effectively as A&E staff, with both being correct in around 90 per cent of cases. It also found that **the average delay from stroke onset to delivery at the stroke unit was 90 minutes under the protocol, compared with 29 hours when the patients were delivered through A&E.** The research also revealed that 90 per cent of patients were arriving at the stroke unit within two hours of onset through direct ambulance transfer, as opposed to none at all through the A&E.



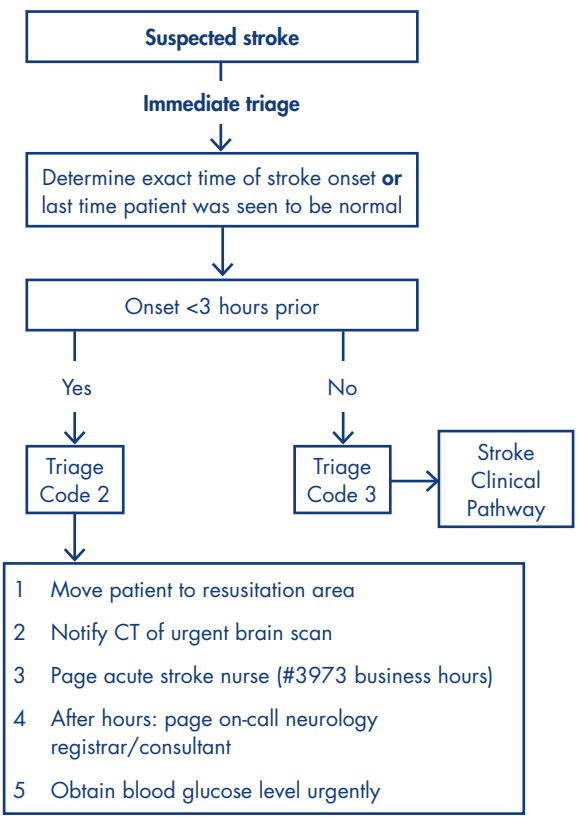
AN AUSTRALIAN TOUR DE FORCE

Professor Chris Bladin (Director, Eastern Melbourne Neurosciences, Box Hill Hospital (Monash University), Melbourne, Australia) provided an example where the interface between paramedics and A&E staff is well constructed. His 'Code Stroke' system is founded on the engagement, education and coordination of paramedics and triage staff. The system involves paramedics utilising a stroke identification tool and then providing prior notification of their arrival with a stroke patient. Chris Bladin found paramedics were correctly diagnosing stroke in the field in 94 per cent of cases. The 'Code Stroke' is coordinated by an acute stroke nurse and enables the patient to be fast-tracked through A&E.

> *"We have developed a CODE STROKE triage system with paramedic pre-notification of hospital arrival. As the ambulance is coming in, the paramedics ring ahead and let us know that they're arriving so that once the patient comes through the front door, we can activate a CODE STROKE. This process very much depends on the triage nurse. They are the key to success as they are right at the front door of the emergency department, are the first to see the ambulance pull up, and are the first person that the trolley passes.*

> *It's very important that they're able to let us know that a stroke patient has arrived – which they do by activating a CODE STROKE. The acute stroke nurse then comes down (or is often waiting at the door, in fact, by that stage) and we're then able to fast track the patients through the A&E department around to the re-susitation area where they quickly have their blood pressure checked and we verify the time of onset of the stroke (time is brain – absolutely critical). By working with the emergency department we're really able to change the culture of acute stroke management to that of a medical emergency."*

Code Stroke flow chart



Source: Slide from Chris Bladin's presentation at the NAO conference (19th October 2006)

The Department of Health's position

The Department has agreed that it is vital for all staff involved in the initial identification of stroke, including triage nurses and doctors, to be well informed about the appropriate response to stroke. It has recognised that a cultural change is necessary and the National Stroke Strategy will emphasise the importance of treating stroke as a medical emergency. One of the project groups developing recommendations for the stroke strategy is considering the development of agreed protocols for the rapid transfer of stroke patients by the ambulance service.

Rapid access to a brain scan is critical for stroke patients

Treatments such as aspirin or clot-busting drugs are dangerous to give to a patient with a haemorrhagic stroke as these increase bleeding tendency and may increase the damage. For this reason, getting an immediate CT scan to diagnose the stroke so that treatment can commence safely is critical.

Speaking at the conference, Joanna Wardlaw (Professor of Neuroradiology and Honorary Consultant Neuroradiologist, University of Edinburgh and NHS Lothian, Western General Hospital) suggested that whilst CT scanning is more widely available in the UK than it was, it is generally seen as being costly.

3 Immediate CT scanning is cost effective, but scans for England's stroke patients are being delayed

CT scanning in stroke – why is it an issue?

- CT scanning seen as costly
- Radiologists in short supply
- Perceived lack of an effective stroke treatment
- General lack of interest in stroke
- Stroke not regarded as a medical priority despite numerous think tanks, etc

Source: Slide from Joanna Wardlaw's presentation at the NAO conference (19th October 2006)

However, a study she carried out in 2004 found that this is not necessarily the case.[7] She examined: whether CT scanning after stroke is cost effective; whether certain patients should be prioritised; and whether the cost effectiveness of CT scanning is dependent on how quickly it is delivered. In order to examine the cost effectiveness of each strategy a decision tree was constructed and populated with evidence from systematic reviews, trials, and observational studies. Information on the cost of scanning and hospital care was also collected, and decision modelling and sensitivity analyses were carried out.

The alternative strategies in the tree reflected alternative ways of using CT scanning – with different prioritisations and treatment opportunities – which ranged from 'Scan all immediately' to 'Do not scan anyone'. The most cost-effective strategy was shown to be 'Scan all immediately'. This strategy achieved the best health outcomes.

Assuming 100,000 stroke patients are admitted to hospital per year across the UK (an under-estimate), 'scanning all patients within 48 hours' would cost an extra £28.5 million; 'scanning the priority cases but everybody else within seven days' would cost an extra £100 million; and 'not scanning anybody' would cost an extra 52 million per year compared to the most cost-effective strategy, which was to 'scan all immediately'.

Our report and the Sentinel Audit found gaps in services, which do not appear for international comparators

Our report found that less than 20 per cent of stroke units have access to scans within three hours of admission. Although most hospitals have the capacity to provide CT scans within 24 hours of admission, in 2004 only 22 per cent of stroke patients had a scan on the same day as their stroke.[8] The Committee of Public Accounts later recommended that all suspected stroke patients should be scanned as soon as possible after arrival at hospital, ideally within three hours, and none should wait more than 24 hours for a scan.[9]

At the conference, Anthony Rudd outlined the results of the 2006 National Sentinel Organisational Audit reporting on the availability of imaging. Aggregated data for England, Wales and Northern Ireland indicated that all 226 hospital sites were offering CT scanning, but only 18 per cent of these were able to provide scanning within four hours. On weekdays the vast majority of trusts were able to do a scan within 48 hours, although seven per cent couldn't, and at weekends 35 per cent were taking longer than 48 hours. Scans for stroke patients are therefore being delayed, even though 'time lost is brain lost'.

4 Scanning all stroke patients immediately produced the best health outcomes at the lowest cost

Total costs (including CT scan) and effect on quality of life for 1000 patients with stroke in a teaching hospital

Scan strategy	Cost £	Quality Adjusted Life Years
All < 48 hours	10,279,000	1982.3
All immediately	9,994,000	1982.4
Scan...[1] < 7 days	11,001,000	1980.7
Scan...[1] < 14 days	12,155,000	1931.9
Scan not at all	10,544,000	1904.2

Source: Slide from Joanna Wardlaw's presentation at the NAO conference (19th October 2006)

NOTE

1 Scan those on anticoagulants, in life a threatening condition or who are candidates for thrombolysis immediately and the rest within.

In contrast, Professor Bo Norrving (Professor in Neurology, Lund University Hospital, Sweden) stated at the conference that Sweden has virtually a 100 per cent delivery rate for CT scans within 24 hours, and Professor Bladin described how all patients at his hospital in Australia have immediate access to scanning.

We found that five times as many MRI scans and over twice as many CT and Doppler scans could be achieved without unfairly compromising necessary scans for other patients. These increases could be achieved by changing, for example, the way scans are planned, managed and carried out, including staffing and time changes.

The Department of Health's position

At the conference, Professor Boyle stated that improving access to scanning is an organisational issue. He noted that the scanners and the expertise in terms of reporting them are there, but that they are often not near to where the patient is at the right time in an accessible way. The Department is taking action to support trusts in the achieving the target of scanning all stroke patients within 24 hours.[10]

Passionate staff with the capacity to carry out, read and interpret scans are critical to delivering acute stroke care

"IT'S EASY TO BE PASSIONATE ABOUT STROKE BECAUSE STROKE CARE IS SUCH AN EASY THING TO DO AND THE OUTCOMES ARE SO FANTASTIC"

Source: Chris Bladin speaking at the NAO conference (19th October 2006)

Despite the successes of Martin Brown's work to reduce delays in the delivery of stroke patients to a specialised stroke unit, his presentation highlighted the availability of services as a significant problem. In some cases this lack of services was a result of there being no stroke consultant. The limited number of health professionals with training in stroke is a barrier to providing high quality care. Indeed, we found that there are 640 patients per stroke consultant per year, compared with 360 per cardiac consultant.[11]

Based on an average district of 250,000 people which would be expected to have about 400 first strokes, 150 repeat strokes and 150 transient ischaemic attacks annually, the British Association for Stroke Physicians recommend that three whole-time-equivalent consultants would be needed to provide 21 sessions a week devoted to delivering a comprehensive stroke service, without including the sessions needed to provide 24 hour cover, seven days a week.

The National Sentinel Organisational Audit 2006 found that the percentage of hospitals with a consultant physician with a special particular responsibility for stroke had risen from 91 per cent in 2004, to 98 per cent in 2006. However, the number of consultant sessions remains particularly low with a median of five sessions per hospital. Stroke coordinators and specialist nurses are present in less than half of trusts, and consultant nurses are only present in nine per cent of trusts. Anthony Rudd noted that there are virtually no consultant level therapists and relatively few stroke specialist therapists. He concluded that there is a major need to increase the amount of specialist medical staff in stroke care.

Additionally, a study by Harbison[12] showed that misdiagnosis of stroke is common in the emergency room and by primary care doctors. Only one in five GPs told us that most of their TIA referrals are subsequently confirmed to be TIAs.[13]

The Public Accounts Committee want fuller use made of scanning capacity

CT scans show whether brain damage is caused by a blocked artery or a haemorrhage into the brain, but there can be delays in getting the diagnosis if no one is available to read the scan once it has been done. Hospitals need to provide not only access to scanning equipment and to radiographers, but also access to staff able to read and interpret the scan itself (such as radiologists, neuroradiologists, or stroke consultants who have been trained in this area). Such access is rarely available 24 hours a day and seven days a week.

The Committee emphasised that in addition to ensuring that stroke has emergency priority with ambulance staff and triage nurses in A&E departments, one of the key requirements for improving scanning capacity for stroke patients is the availability of staff with the necessary skills to carry out, read and interpret scans. Whilst all hospitals have the necessary equipment to carry out scans, the NHS is not presently gaining the full benefit from its investment in this equipment because it is not being used to provide a scanning service for stroke patients that is available 24 hours a day, seven days a week.

AN AUSTRALIAN TOUR DE FORCE

During his presentation at the conference, Professor Bladin described how PACS (Picture Archiving and Communication System) has benefited his stroke unit by enabling diagnoses to be made outside of normal working hours.

> ***"Late night thrombolysis; this is something I do (not frequently but it does happen) as shown here, sitting at my desk late one night. It's actually very simple to use, not sophisticated technology. To help take these calls I've bought a headset which I plug into a cordless phone, so I'm able to keep my hands free to access the computer. Here I have pulled up on my laptop the images of a CT scan of a patient whose has just come into the emergency department and had their CT scan. With the appropriate communication, and particularly with the right people working in the emergency department, thrombolysis can be given quite successfully and I've done this on numerous occasions".***

Source: Chris Bladin, speaking at the NAO conference (19th October 2006)

The Department of Health's position

Professor Wardlaw stated that one of the reasons that access to scanning is an issue is because there is a shortage of radiologists, with 20 per cent of consultant radiology posts across the UK chronically unfilled. At the Committee of Public Accounts hearing, the Department of Health told the Committee it was working to address this problem by making specialist radiological input more accessible, and by training the existing workforce to interpret scans.[14]

The Department has recognised that increasing the number of health professionals with training in stroke is an important factor in increasing the quality of care provided to stroke patients. It has also indicated that as the training programme for stroke consultants takes around a year, there is an opportunity to increase their number relatively quickly. To this end the Department has indicated that it is discussing options for achieving this with relevant bodies.[15]

Additionally, the Department is developing its telemedicine capacity through the implementation of PACS, which will allow scans to be digitally transmitted to staff, who can be off-site, for interpretation.[16]

Patients suffering severe strokes can recover to a near normal lifestyle following thrombolysis

With active management in the initial hours after stroke onset, brain may be saved from further damage. Thrombolysis is a clot-busting treatment that, if administered to eligible (ischaemic stroke) patients within three hours of onset, can clear the blockage causing the damage to the brain, sometimes reversing most or all of the damage.[17] At the conference, Professor Wardlaw reported that thrombolysis reduces death or dependency by 140 per 1,000 stroke patients.

A PERSONAL STORY

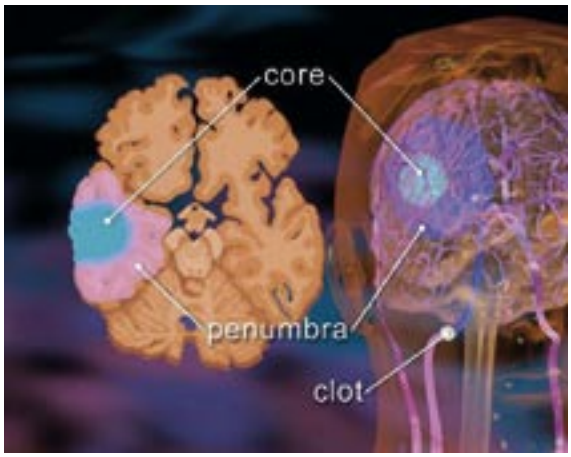
Anthony Rudd described the impact of delivering thrombolysis to a severely affected stroke patient:

> *"I'll just give you a case history: this was a 28 year old man, down from Hull with his wife and two young children, on his first visit ever to London and he was on the top of one of these buses that tour around London, when he suddenly became dysphasic and developed a right hemiparesis. We have a very close relationship with our Ambulance Service but, actually, he did take quite a long time to get there – and I'm not exactly certain why that was the case; normally we get people in much more quickly than that. He had his initial scan at 3 hours and 15 minutes, which was normal. Because he was outside the time window he went into IST 3 (which is a trial testing thrombolysis in the 3-6 hour time window, so outside the normal licence criteria) and he was randomised to receive thrombolysis, which he did at 3 hours and 30 minutes. Within an hour he had fully recovered.*
>
> *Now, this man actually had a really dense hemiparesis, he was severely dysphasic, so I think that this was no way a transient ischaemic attack. I think the thrombolysis actually saved him and he went home virtually fully recovered – although he clearly did have an infarct on the follow up MRI scan – but a dramatic clinical recovery.*
>
> *It only takes a few of these recoveries once you start offering thrombolysis care for you to really start feeling that it has to be something that you always offer to all patients. There is actually very little worse than coming in on a Monday morning when you've been away for a nice weekend and you see somebody sitting on your ward who was admitted on the Sunday afternoon and didn't get thrombolysis."*

Source: Anthony Rudd, speaking at the NAO conference (19th October 2006)

Delivering thrombolysis saves lives

The Ischaemic Penumbra

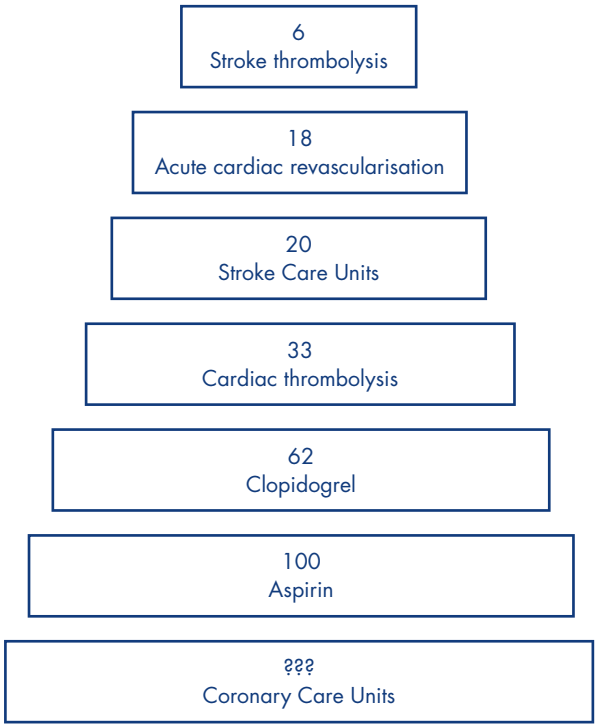


Thrombolysis can save penumbra

Source: Slide from Martin Brown's presentation at the NAO conference, figure in slide courtesy Prof A Buchan (19th October 2006)

Chris Bladin also compared the effectiveness of thrombolysis with other treatments by displaying comparable figures for the number of patients that need to be treated to benefit at least one patient (this is known as the Number Needed to Treat or NNT). At the bottom of his scale was the coronary care unit which by itself actually has no strong evidence to support its effectiveness. Aspirin as a stroke treatment has an NNT of 100 patients, and cardiac thrombolysis, 33. Results from the literature show that for stroke thrombolysis, the NNT is as low as 6 **(see Figure 5)**.

5 Numbers that need to be treated to benefit one patient



Source: Slide from Chris Bladin's presentation at the NAO conference (19th October 2006)

Thrombolysis is being delivered effectively in Swedish and Australian examples

Chris Bladin's hospital is set up to deliver thrombolysis and his presentation emphasised its importance as an effective treatment. Overall, he reported that about one in every four patients will be eligible for thrombolysis at his hospital. Professor Norrving reported that thrombolysis was being actively implemented in Swedish hospitals, with rates of five per cent being achieved.

Chris Bladin reported that at present, up to 15 per cent of ischaemic stroke patients are receiving thrombolysis at his hospital in Australia. A figure that is in line with the most efficient stroke units reported in the literature. He also reported that the proportion of patients returning to a near normal lifestyle following thrombolysis was almost 40 per cent, and that the hospital's average onset-to-treatment time was just under 140 minutes. In order to achieve these outcomes his stroke unit has a number of protocols in place for the use of thrombolysis. These include a medical protocol and a nursing protocol so that all staff know exactly what their role is and how to identify key treatment indicators.

England's stroke services are not matching international examples.

"IT'S NO GOOD JUST KNOWING THAT STROKE NEEDS TO BE TREATED QUICKLY; WE NEED TO CHANGE THE WAY WE BEHAVE"

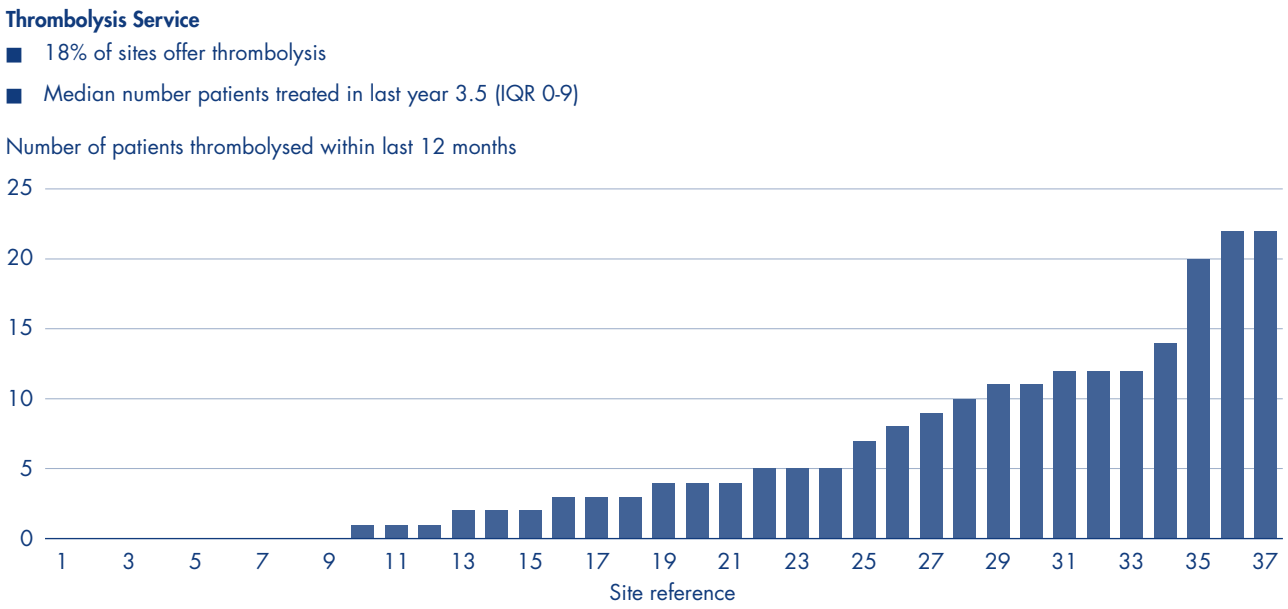
Source: Martin Brown, speaking at the NAO conference (19th October 2006)

Anthony Rudd indicated that whilst 18 per cent of hospitals in the UK have said they can offer a thrombolysis service, a large number of those hospitals have not actually carried any out (National Sentinel Organisational Audit 2006). He reported that the two most active hospitals have thrombolysed 22 patients each during the last year **(see Figure 6)**. Currently, less than 0.2 per cent of stroke patients hospitalised in England, Wales and Northern Ireland are receiving thrombolysis.

It is partly due to delays along the acute care pathway that so few patients receive thrombolysis, as **Figure 7 illustrates.**

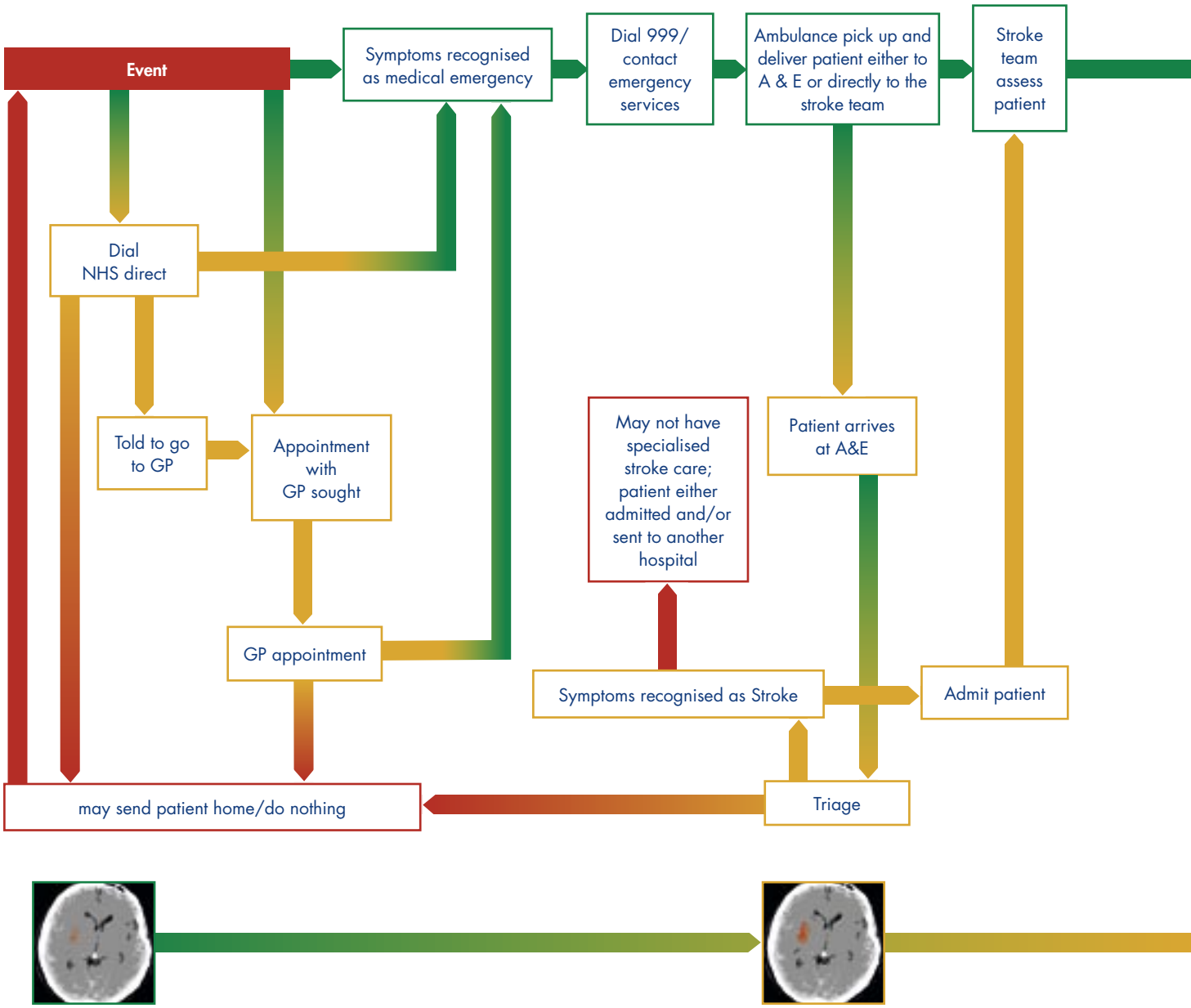
We estimated that achieving a nine per cent rate of thrombolysis in England could generate net savings to the health service of over £16 million a year in care costs avoided, with more than 1,500 patients fully recovering from their strokes each year who would not otherwise have done so.[18]

6 Access to thrombolysis is offered at 18 per cent of sites, but those sites thrombolyse very few patients

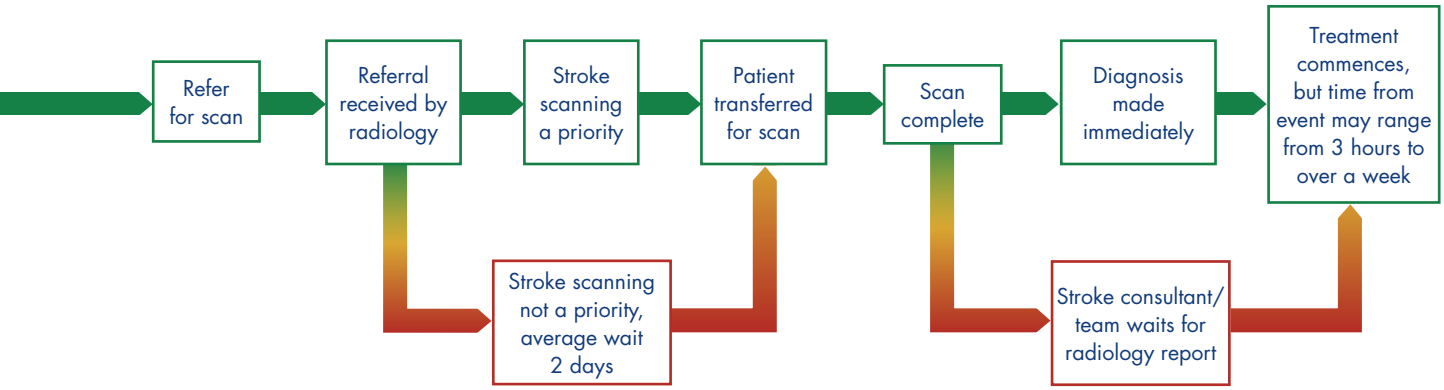


Source: Slide from Anthony Rudd's presentation at the NAO conference (19th October 2006)

7 Several delays can prevent patients receiving urgent medical treatment



Source: National Audit Office, Reducing Brain Damage: Faster access to better stroke care (HC 452 – Session 2005-2006)


Refer for scan
Referral received by radiology
Stroke scanning a priority
Patient transferred for scan
Scan complete
Diagnosis made immediately
Treatment commences, but time from event may range from 3 hours to over a week
Stroke scanning not a priority, average wait 2 days
Stroke consultant/ team waits for radiology report

The Committee of Public Accounts recommended that the Department should benchmark performance on key performance indicators with other leading countries to identify areas where further lessons may be learned. The International Stroke Trial,[19] which recruited patients from many countries around the world, compared outcomes and showed that even when the figures had been adjusted for the severity of the patients, the UK morbidity was significantly worse than the average from the other countries **(Figure 8)**. Anthony Rudd explained that further research would look again at exactly this issue.

SITS (which stands for Safe Implementation of Thrombolysis in Stroke) is an academic-driven, non-profit, international collaboration of medical professionals. An International Stroke Thrombolysis Register and Monitoring Study serves to certify excellence in the therapeutic use of thrombolysis and the registry is available to clinicians across Europe.[20] Members of the SITS Network strongly believe that more patients could be treated with thrombolysis. The purpose of the new project 'SITS 2009 @ 5 per cent' is to reach at least the level of 5 per cent of all stroke patients treated with thrombolysis in each centre and each country within three years. For countries already at this target a higher objective will be set.

8 Stroke outcomes in the UK ought to compare more favourably with other countries in future

Source: Slide from Anthony Rudd's presentation at the NAO conference (19th October 2006)

Patients cared for in a defined stroke unit with organised stroke services are more likely to survive, have fewer complications, return home and regain independence

"I CANNOT DREAM OF A STROKE SERVICE WITHOUT AN ORGANISED STROKE UNIT, IT'S UNTHINKABLE FOR ME; THERE'S NO WAY THAT A STROKE SERVICE CAN BE EFFECTIVE AND WORKING WELL IF WE HAVEN'T GOT THIS AS THE CORE ITEM IN THE MANAGEMENT OF STROKE"

Source: Bo Norrving, speaking at the NAO conference (19th October 2006)

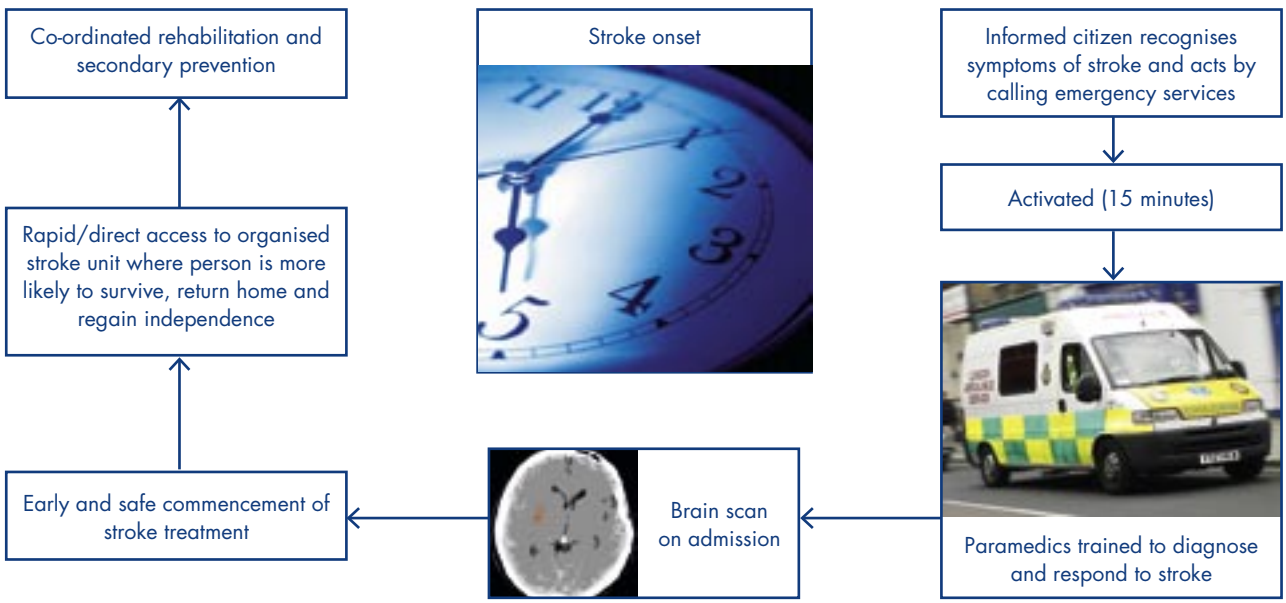
Once a patient has been diagnosed with stroke, the most effective model for acute care is care delivered through an acute stroke unit: a physically separate unit staffed by a multidisciplinary team of stroke specialists including consultants, therapists and nurses trained in the management of stroke.

Responsive care in a stroke unit has been shown to reduce death and disability. If patients can be admitted more quickly into a stroke unit to access specialist acute care, damage and deterioration in their condition can be more efficiently controlled.

The Stroke Unit Trialists' Collaboration showed that by providing stroke unit care rather than general medical care, five out of every 100 people are able to return home independently, two less require institutional care, and three less are likely to die. Langhorne and Dennis (1998) showed that for 100 patients, 26 less bed days would be used if patients were treated in a stroke unit rather than in a general medical ward.[21]

9 Organised acute care, with rapid assessment and access to a stroke unit, is a more efficient way to deliver care that results in better outcomes for the patient

Our vision for acute stroke care



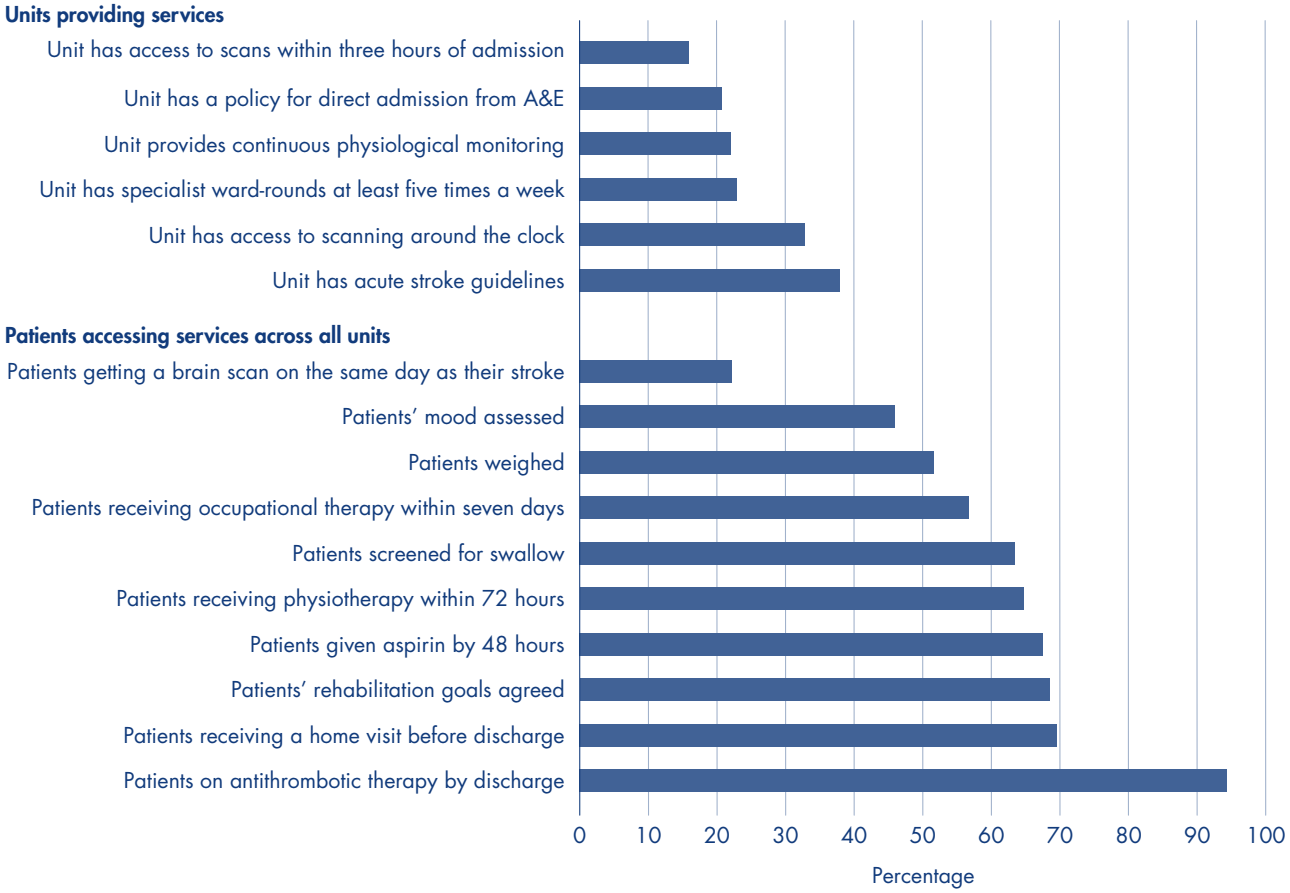
Source: Slide from Helen Rodgers' presentation to the NAO conference (19th October 2006)

Dr Helen Rodgers (Reader in Stroke Medicine, Newcastle) advises:

> *"Those of us who are responsible for managing the throughput of the ward are better able to plan our resources properly if we know who is likely to be going home next week and the week after … and as a result, most of the time, all of the stroke patients within our hospital are able to be cared for on one of our stroke unit beds."*

We showed that patients' access to services across stroke units varied, as did the services provided by different stroke units **(Figure 10)**. One of the most crucial aspects of the stroke unit is access to the therapies that will help the patient recover. The stroke unit should provide access to psychologists, dieticians, physiotherapists, occupational therapists, speech therapists, and social workers. However, access to such professionals can be patchy within and between stroke units, even though access to these services is likely to result in fewer delayed discharges.

10 Service provision varies



Source: National Audit Office, Reducing Brain Damage: Faster access to better stroke care (HC 452 – Session 2005-2006)

NOTE

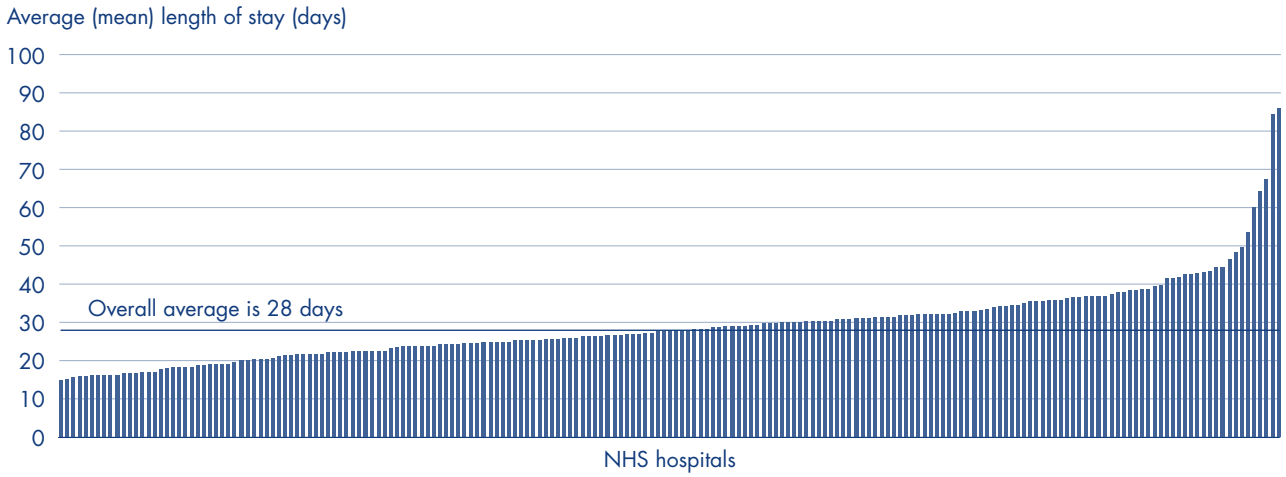
Percentages: Units, above, measure stroke units providing services. Patients, lower, are accessing services across all stroke units.

Our economic modelling suggests that if access to stroke units was increased to 75 per cent of patients, then about 550 deaths could be prevented, and 205 more patients would not be disabled and dependent on discharge from hospital, each year. These benefits could be obtained at no additional cost if the average length of stay on a stroke unit was three days shorter than staying in a general medical ward.[22]

Length of stay for the cohort of patients in the 2004 Sentinel Audit varied considerably, as shown in **(Figure 11)**. Undoubtedly in some hospitals, if not all, there will be opportunities to improve efficiency and therefore length of stay. However, it is critical that this is not the sole measure of quality. Discharge to inappropriate community facilities before the patient is ready will have dire long term consequences, both for the patient and society in terms of the effect on long term dependency and may offset any apparent cost savings from shorter length of stay in hospital.

For instance, the effect stroke units have in increasing independence will impact on the need for nursing home and other specialist aftercare. Our survey of one hundred nursing homes indicated that stroke will have been a contributing factor for entry into care for between 20 and 40 per cent of residents. Our analysis showed that during 2004 around 14 per cent of stroke patients who were living independently pre-stroke went into nursing home accommodation after their stroke. This could be as many as 15,000 people going into nursing homes a year, with an average annual accommodation cost of £22,000 each.

11 Average length of stay varies across hospitals



Source: National Audit Office, Reducing Brain Damage: Faster access to better stroke care (HC 452 – Session 2005-06)

NOTE

Lengths of stay were recorded at each site during the three month period of the Sentinel Audit for a cohort of patients. Each bar refers to one hospital site. Those hospitals that had sample sizes of less than 20 patients were excluded. The data should be interpreted with the understanding that stroke services vary considerably in their operational policies e.g. type of patients admitted and at what stage in their admission they go to the units, and what hospitals qualify as 'discharge'. Not all hospitals contributing to the audit provide acute care and some provide the longer rehabilitation pathway only. Case mix may vary between districts.

A SWEDISH TOUR DE FORCE

Lund-Orup Hospital in southern Sweden: On admission to the outpatient stroke unit, 28 per cent of patients were able to walk upstairs unaided, which increased to 74 per cent at discharge

Sweden has developed some of the leading examples of rehabilitative care. Indeed, at the conference Professor Norrving described some of the features: direct admission to the stroke unit; patients remaining in the stroke unit until discharge; early mobilisation of the patient; ongoing assessment and monitoring of the patient; and the multi-disciplinary rehabilitation team.

According to the Swedish 'RIKS-stroke registry', on average patients take three hours to arrive at the stroke unit (which compares to two days in England).

In Umea, Sweden, even those who have had severe strokes will sit up and move their bodies using specially designed wheelchairs. When they are not engaged in therapy, patients are encouraged to independently use a range of devices that practice mobility, dexterity and memory. Every three to five days patients and their families and staff hold conferences at which rehabilitation goals are discussed. Social services are informed about a new stroke patient as soon as they arrive on the stroke unit.

Stroke patients arrive on Lund's stroke unit within five hours of reaching hospital and within 24 hours of this the occupational therapist and physiotherapist will have assessed their rehabilitation potential. Goals for this will be agreed with the patient in relation to their home living situation.

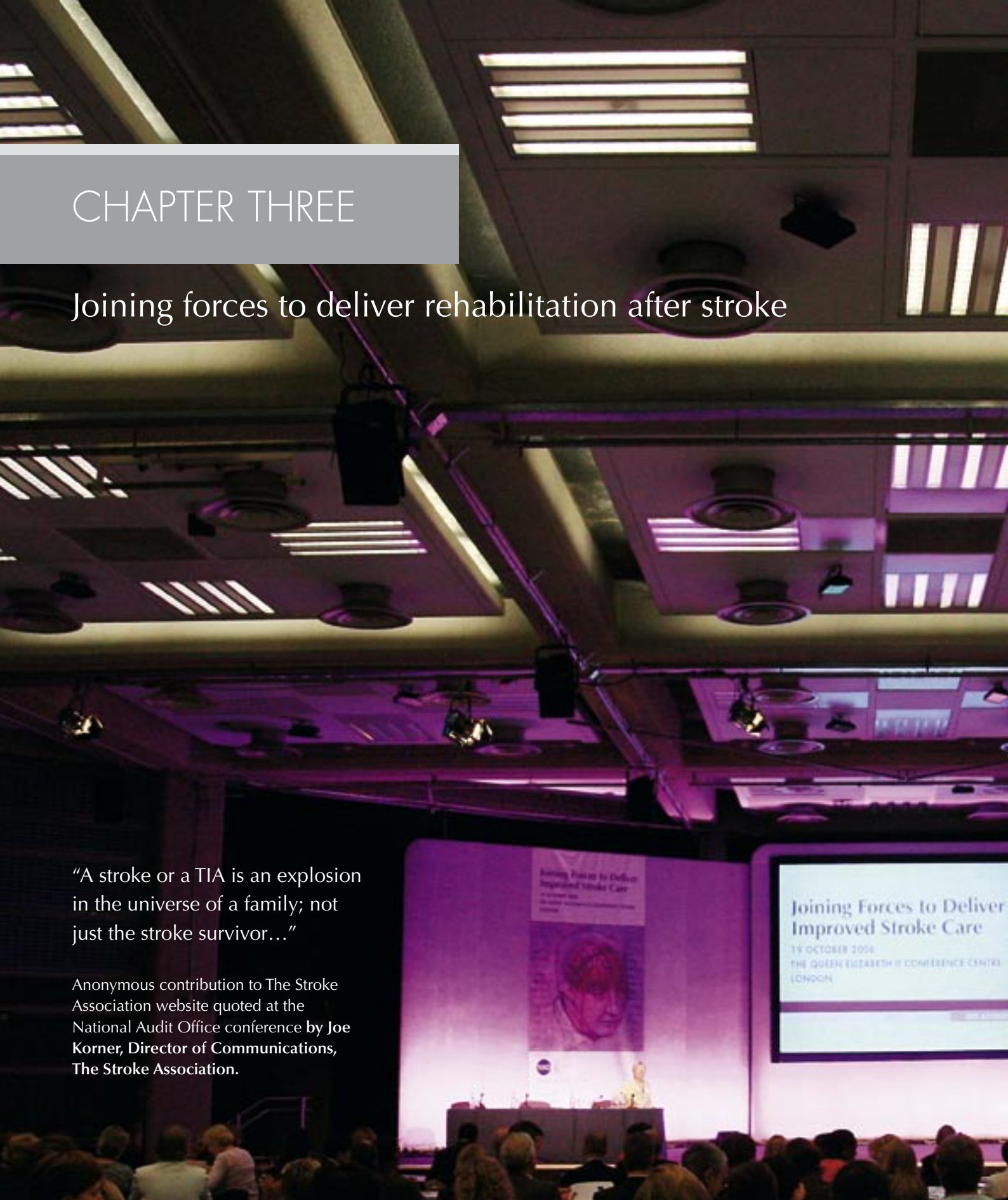
Source: National Audit Office, Reducing Brain Damage: Faster access to better stroke care (HC 452 – Session 2005-2006)

The Department of Health's Position

The Department has agreed that it is desirable for all stroke patients to be admitted to a stroke unit as soon as possible after initial assessment and a commissioning guide has been published to provide Primary Care Trusts with guidance on the commissioning of stroke services. Additionally, the ASSET toolkit for commissioners will enable Primary Care Trusts to model the benefits to be gained from providing appropriate stroke unit care (see Appendix 1).[23]

CHAPTER THREE

Joining forces to deliver rehabilitation after stroke



"A stroke or a TIA is an explosion in the universe of a family; not just the stroke survivor…"

Anonymous contribution to The Stroke Association website quoted at the National Audit Office conference **by Joe Korner, Director of Communications, The Stroke Association.**

During their hospital stay, stroke patients have access to on-call help and care. However, after discharge they have to adjust suddenly to the impacts of the stroke on their life at home. Over a third of stroke patients are left dependent or moderately disabled requiring support, rehabilitation and nursing care.

There are many services commonly needed by people who have had a stroke and are living with some disability or disabilities, such as paralysis, incontinence or problems using and understanding speech or the written word (known as aphasia). For example, physiotherapy, occupational therapy and adaptations of the home, wheelchair and other mobility services, incontinence support, respite support for carers, nursing and social and benefits services may be needed **(see Figure 24)**.

"THE THING THAT STRUCK US MOST FROM THE WORK THAT WE DID WITH PATIENTS AND CARERS WAS THE FEELING THAT ACTUALLY, FOR THEM, THEIR STROKE STARTS THE MINUTE THEY LEAVE HOSPITAL"

Source: Karen Taylor, Director for Health Value for Money studies, speaking at the NAO conference (19th October 2006)

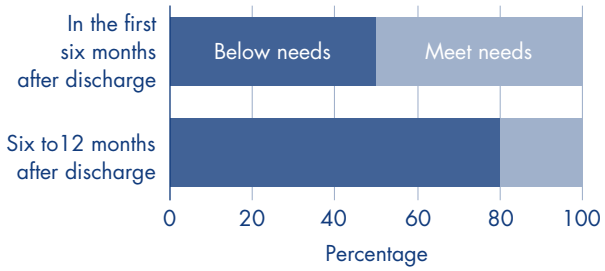
Coordinated care after discharge plays a vital role in helping stroke survivors adjust to the impact of stroke on their life

> ***"What we're trying to do in Newcastle and North Tyneside is to provide a smooth and organised discharge from hospital, with intensive support and rehabilitation – providing both social and rehabilitative care. We're trying to enable people to achieve the maximum potential within their home environment and in order to do this we need to develop very close relationships, not just with patients and carers but between primary and secondary care and between health and social services, otherwise it's very easy for things to go very wrong, very quickly".***

Source: Helen Rodgers, speaking at the NAO conference (19th October 2006)

Coordination in delivering stroke services in good time is vital for people living with stroke in order that they have access to the services they need to be able to cope and live in comfort. However, our survey found that around half of patients receive rehabilitation services that meet their needs in the first six months after discharge, and that this falls to around a fifth of patients in the 6-12 months after discharge **(see Figure 12)**.[24]

12 The proportion of stroke patients receiving rehabilitation services that meet their needs



Source: National Audit Office, Reducing Brain Damage: Faster access to better stroke care (HC 452 – Session 2005-2006)

Successful coordination of post-hospital care includes having a plan in place, before the patient is discharged, covering the services they will need once they have left hospital. However, the division of responsibility between health and social services often acts as a barrier to integrated care and the scarcity of health professionals within the community means that patients do not receive the professional support they need. This is despite the fact that it is in the months and years after discharge that patients, their families, and carers will experience the full impact of the stroke.

The 2006 National Sentinel Organisational Audit data indicates that only 32 per cent of hospitals in the UK have specialist community stroke teams. At the conference, Anthony Rudd therefore suggested that stroke patients may be discharged to services in the community that are not properly equipped to cope with their needs. A particular concern of the Committee of Public Accounts was that community stroke teams are present.[25]

A SWEDISH TOUR DE FORCE

At the Lund Orup hospital in southern Sweden, in 2005, a third of patients received rehabilitation within a few days of being discharged. Some patients attend the outpatient stroke unit, where the goal is to make independent living practicable, for four days a week, for three weeks. They follow an individualised treatment plan which includes sessions with various therapists and group activities that are designed to help their memory, speech, cognitive ability and functional mobility. More intensive rehabilitation is provided for younger stroke survivors at the Lund Orup Department of Rehabilitation, where patients typically stay for five or six weeks and receive 3-4 hours of therapy per day and participate in activities designed to improve their physical abilities.[26]

Information for patients and carers is vital

Joe Korner (Director of Communications, The Stroke Association) drew attention to a Stroke Association campaign called *Nobody Told Me*. He indicated that many stroke survivors tell his organisation that 'nobody told me about what was going to happen, what I should do, what the local services were'. This campaign is therefore focusing on the need to provide adequate information and advice to stroke patients when they are discharged from hospital.

13 The Stroke Association supports stroke survivors and their families, who rely on information and support after a stroke

Views from the stroke frontline

"In August 2005 my incredible, intelligent and fit 71 year old husband suffered a severe stroke. It was a bank holiday Friday and there was no-one to do a CT scan until the Tuesday. He moved beds 8 times before eventually ending up in the stroke unit… He was sent home with no instructions for me, no information on what happens next, no help whatsoever."

Source: Anonymous contribution to the Stroke Association website quoted by Joe Korner at the NAO conference (19th October 2006)

Information for stroke patients needs to take into account the needs of patients with aphasia. In most right-handed people, the left side of the brain controls language and speech. Many people living with a stroke that has damaged this part of the brain will have difficulty communicating. People with aphasia may have difficulty in finding the right words, or may misunderstand what they hear, or they may have perfect comprehension yet be unable to speak. They may also have difficulties with writing or recognising the written word.

The Department of Health's position

> ***"I have been struck again recently by the fact that people can be ignorant of their conditions and it's a tragedy to see people who don't feel that they're getting information but, also don't feel empowered enough to ask for it. I think some of that is to do with the frightening experience of a stroke and compounded by the fact that some people are robbed of their speech and can't express their feelings"***

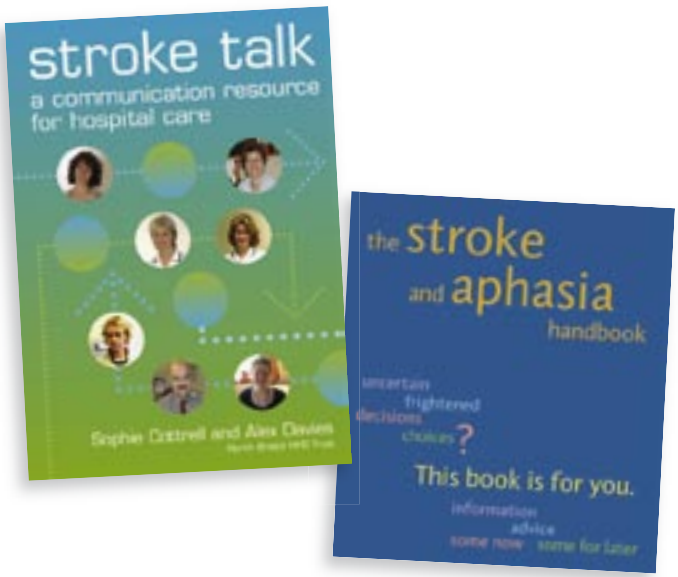
Source: Rosie Winterton, Minister of State for Health Services, speaking at the NAO conference (19th October 2006)

At the conference Rosie Winterton MP, Minister of State for Health Services, announced that the Department of Health are working with Connect – a voluntary organisation that works to promote a better quality of life for people with aphasia – to make sure that each stroke unit in England is provided with a copy of their stroke and aphasia handbook and their new Stroke Talk manual. This is aimed at helping the stroke unit team to communicate effectively with patients during a hospital stay and to explore patients' choices.[a]

Early Supported Discharge can reduce hospital stay and improve the chances of regaining independence

If the patient is discharged to community facilities before they are ready both the patient and society will face dire long-term consequences, in terms of the effect on long-term dependency. This may offset any apparent cost savings from shorter length of stay in hospital.

In its report, the Committee of Public Accounts recommended that the Department of Health should evaluate the merits of Early Supported Discharge initiatives and other ways of improving access to therapies, and promote the early adoption of those that can be shown to reduce hospital stay and improve a patient's chances of recovery.[27]



a For further information about these publications or to order copies, contact Connect, 16-18 Marshalsea Road, London SE1 1HL, email publications@ukconnect.org or visit the Connect website www.ukconnect.org

International studies have demonstrated that Early Supported Discharge services reduce patients' long-term dependency and chances of being disabled at six months. Stroke patients who received Early Supported Discharge have higher levels of independence than those receiving conventional care.[28] Speaking at the conference, Helen Rodgers discussed some of the rationale for adopting Early Supported Discharge:

"A PROLONGED PERIOD OF HOSPITAL REHABILITATION MAY NOT BE IN YOUR BEST INTEREST; IT IS A BORING AND AN ARTIFICIAL ENVIRONMENT WHERE NOT A GREAT DEAL OF TIME IS ACTUALLY SPENT IN REHABILITATION. YOU CAN BECOME QUITE ISOLATED AND DEPENDENT"

In addition, there is poor nutrition, the risk of infection, and the fact that the emphasis is very much upon physical recovery, rather than social or psychological recovery. Helen Rodgers also suggested that home is the most appropriate environment for sustainable and relevant rehabilitation to take place. Rehabilitation in the home empowers the patient by putting them more in control, and there is strong evidence to suggest that the patient will be more likely to drive forward their rehabilitation as a result. Home rehabilitation also provides a greater opportunity to spend time on psychological and social recovery as patients are less isolated and feel more relaxed and more confident about discussing what matters to them.

> ***"I think we can argue that home is definitely the most appropriate place for rehabilitation; it's much better to practice going up and down your own stairs and to gain confidence there, than perhaps go up the three or four steps outside the orthopaedic ward. You're also much more in control of what happens to you in terms of your rehabilitation and there is very strong evidence that if professionals are coming into your own home as a guest then you're much more empowered to say what you want to do and how far you're prepared to go and to set your own goals".***

Source: Helen Rodgers, speaking at the NAO conference (19th October 2006)

AN ENGLISH TOUR DE FORCE

In 1995, Newcastle and North Tyneside Stroke Rehabilitation Services began developing Early Supported Discharge services for stroke survivors, enabling some stroke patients to undergo a substantial part of their rehabilitation in their own homes. This reduced the average length of stay from 22 days to 13 days; there were five per cent more people living at home and six per cent more people independent. The treatment of stroke patients discharged under Early Supported Discharge in Newcastle costs an average of £500 less per patient than those who receive conventional care. In 2005, between 10 and 20 per cent of stroke patients were receiving Early Supported Discharge services in Newcastle.

Much like the Swedish model of care, Newcastle and North Tyneside Stroke Rehabilitation Services' discharge planning starts at the very beginning of a stroke patient's time on a stroke unit, where the patient's ongoing rehabilitation and care needs are assessed to determine whether or not care can be provided at home (**see Figure 14**). If it is appropriate, the patient will be discharged but will receive the same level of rehabilitation services at home that they would have had on a stroke unit, including physiotherapy, occupational therapy and speech and language therapy. A patient-held record is kept in the patient's home and treatment is planned around their specific goals.[29]

Helen reported that a concern with Early Supported Discharge – that it would become difficult when it was appropriate to withdraw and reduce the level of rehabilitation offered to some patients – in fact was not supported by the Newcastle team's experience. Working together with patients and with joint goals made it easier to say when rehabilitation services should begin to diminish.

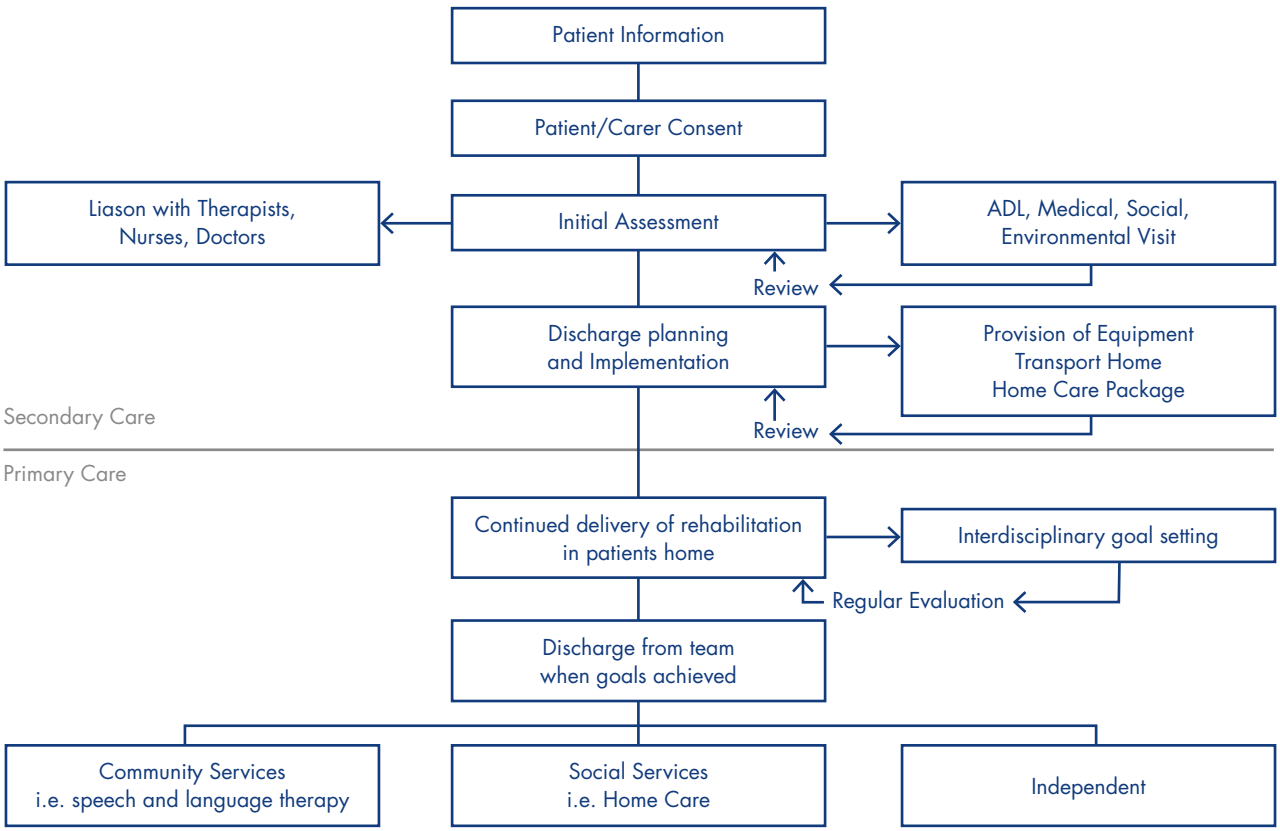
After Helen Rodgers and Bo Norrving had presented their service models, one delegate added:

> ***"It's something [where] the direct payments could work with really well, where the patient controls the budget, so you don't end up in the position where different services refuse to accept the patient."***

Thanks to this delegate for contributing with this comment at the NAO conference (19th October 2006)

14 Coordinating care: The Newcastle Stroke Discharge Team

Pathway of Care



Source: Helen Rodgers' presentation at the NAO conference (19th October 2006)

A HEAVY BURDEN FALLS ON THOSE CARING FOR STROKE PATIENTS

Helen Rodgers began her presentation at our conference with an interesting test for the delegates:

Helen:	"If you had a stroke and were on a stroke unit and I could say 'you can go home shortly and I can provide you rehabilitation and home care at home'; who would like to go home as soon as possible?"
Audience:	(Many hands go up, quickly.)
Helen	"Okay, point taken! If your nearest and dearest who you live with had a stroke and I offered you the same package of care ..."
Audience:	(Laughter)
Helen	"... that they could go home as soon as possible; who would like their nearest and dearest to go home as soon as possible?"
Audience:	(Fewer hands go up, slowly.)
Helen:	"Okay... but that is going to be the issue around supported discharge".

Source: Helen Rodgers' presentation at the NAO conference (19th October 2006)

The Department of Health's position

The provision of an Early Supported Discharge team is one of the interventions included in ASSET. Trusts can use ASSET to see the impact introduction of an Early Supported Discharge team in their area would have on outcomes for their patients and lengths of stay in hospital. ASSET is being used by local NHS trusts to make the case for introducing Early Supported Discharge teams in their area. The Department has stated that more knowledge is needed about the most appropriate rehabilitation model for those who have suffered mild and severe disabilities. It is exploring options for evaluating the services for these groups of stroke survivors and a working group will be established to consider Early Supported Discharge schemes.[30]

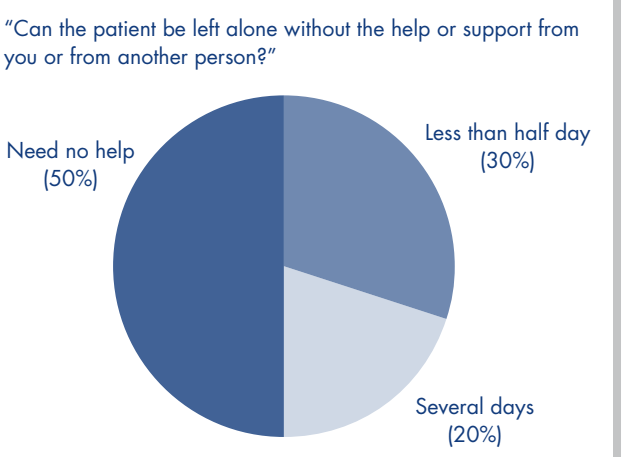
Many families choose to care for stroke sufferers at home, rather than see them go into institutional care

Carers are a vital resource for stroke patients, but the burden of caring for a stroke patient can be great, increasing carer stress. This burden can be even greater when patients do not receive the support they need from health and social services. Decisions about discharging patients need to take these issues and other patient preferences into account.

The impact of carer stress was highlighted in our report where we showed that 28 per cent of carers had experienced problems with their jobs, 63 per cent had problems with their physical health, and 56 per cent had experienced problems with their mental health since becoming a carer of someone with a stroke. Recent research by Patel indicates that providing carers with training improves their psychological outcomes.[31] However, over a third of carers in the Sentinel Audit (2004) did not receive training.

Carers highlighted problems with 40 per cent not getting advice on benefits, 49 per cent not getting support from social services, and 52 per cent not getting support from local health services.[32] The Committee of Public Accounts was concerned that proper support is provided to stroke survivors who live on their own, and may be particularly vulnerable to being overlooked by health and social care services.[33]

15 A large proportion of carers in Sweden could not leave the patient alone for more than half a day



Source: Slide from Bo Norrving's presentation at the NAO conference (19th October 2006)

Speaking at the conference, Professor Norrving indicated that a Swedish stroke registry follow-up study had revealed some of the issues carers of stroke patients are faced with, even in a country seen as a leading provider of rehabilitation for stroke patients. The study found that 30 per cent of carers participated in the patient's rehabilitation; 52 per cent helped the patient with activities of daily living; 62 per cent had taken over many duties in the home; and 14 per cent could almost never practice their previous interests or hobbies.

Professor Norrving reported that surveys carried out in Sweden have shown that patients and carers feel isolated as a result of a lack of continuity following discharge, compounded by limited access to counselling and support. He explained:

> ***"The patients and the carers feel that they are left alone. We are now trying different ways to overcome this. We need to have, by law, a structured Discharge Planning conference. When the patient is discharged to community services, we have a system for the transfer of information. Where hospital facilities permit, we offer the patient a follow-up visit 6-12 weeks after discharge – the patients come to a stroke nurse and are given advice on medications and on problems which have arisen. It's a 30 minute visit. We find this very useful, very fruitful and this is more and more being taken up as a practice across the country."***

Source: Bo Norrving, speaking at the NAO conference (19th October 2006)

The Department of Health's position

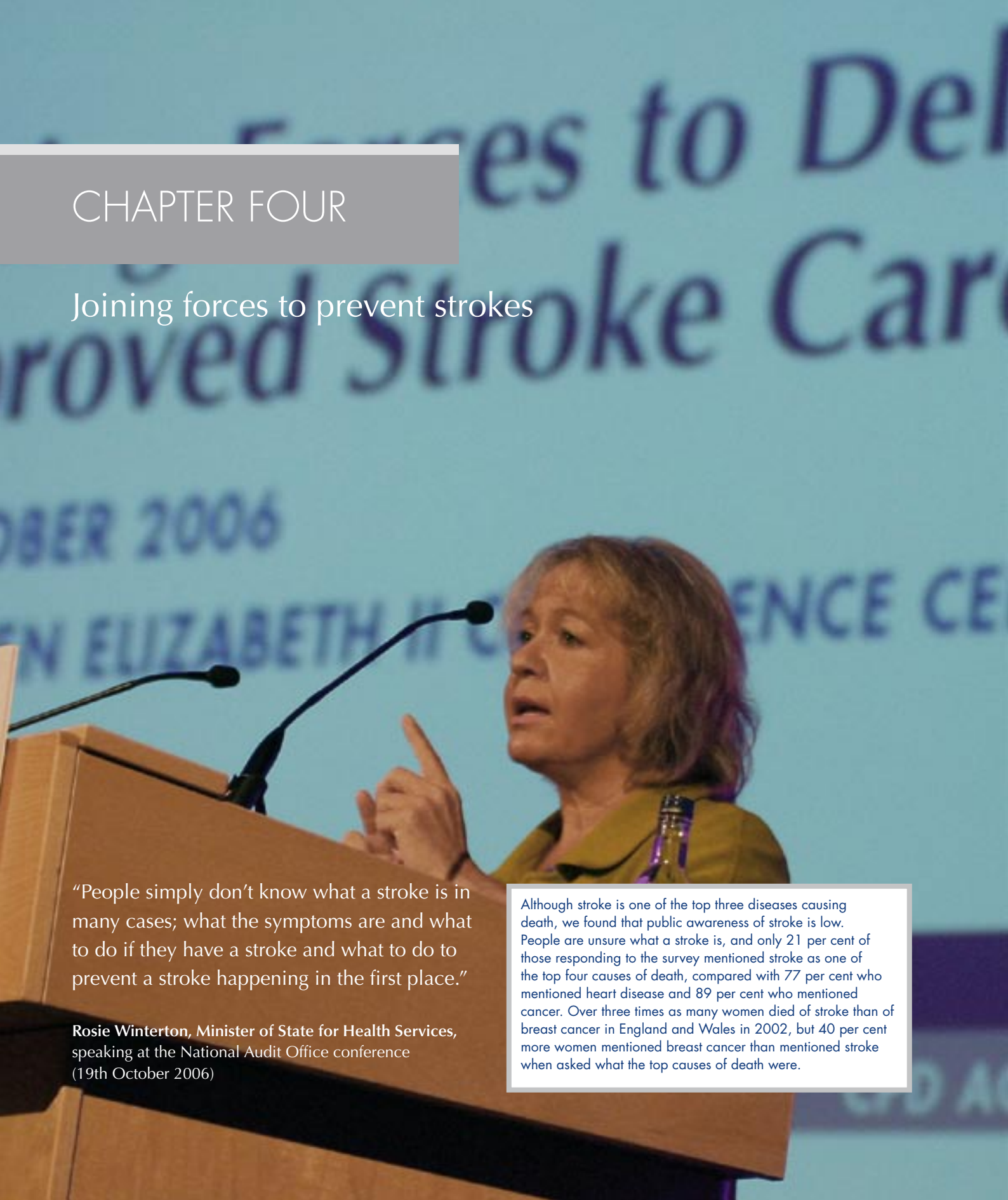
In England, the Department of Health's White Paper *Our Health, Our Care, Our Say: A New Direction for Community Services* (Cm 6737, 30 January 2006), seeks to improve three aspects of support for carers. In particular:

- improving the information available to carers, so they become aware of the services that might support them;
- improving emergency respite, to ensure that care services are available for their loved one during times of crisis or emergency; and
- developing better training for carers to help them undertake their caring role.

In its Treasury Minute response, the Department stated that it has taken action through the National Strategy for Carers to make support available to carers, and to make carers aware that they have the right to a needs assessment. It also stated that a helpline will be established to offer advice and support and that an Expert Carers' Programme will be developed to help carers develop the skills they need.[34]

CHAPTER FOUR

Joining forces to prevent strokes



"People simply don't know what a stroke is in many cases; what the symptoms are and what to do if they have a stroke and what to do to prevent a stroke happening in the first place."

Rosie Winterton, Minister of State for Health Services, speaking at the National Audit Office conference (19th October 2006)

Although stroke is one of the top three diseases causing death, we found that public awareness of stroke is low. People are unsure what a stroke is, and only 21 per cent of those responding to the survey mentioned stroke as one of the top four causes of death, compared with 77 per cent who mentioned heart disease and 89 per cent who mentioned cancer. Over three times as many women died of stroke than of breast cancer in England and Wales in 2002, but 40 per cent more women mentioned breast cancer than mentioned stroke when asked what the top causes of death were.

Public awareness of the causes, risk factors, and symptoms of stroke must be improved

Many people still do not realise that strokes are largely preventable and cannot list the main risk factors for stroke, or how to manage them. Indeed, only one in five respondents to our survey mentioned reducing blood pressure as a way of reducing the risk of stroke.

The Committee of Public Accounts argued that better public awareness is key to preventing more strokes. Preventing just 2 per cent of the strokes that occur in England in a year would save care costs of more than £37 million, over and above the non-financial benefits. In its report the Committee listed some key messages that could be included in a public awareness campaign for stroke **(see Figure 16)**.

16 Elements of a public awareness campaign for stroke

What is a stroke?	■ The equivalent of a heart attack, but in the brain ■ Affects people of all ages; a quarter of strokes occur in under 65s
What is its impact?	■ The biggest killer after heart disease and cancer ■ The biggest cause of adult disability ■ Three times as many women die of stroke than of breast cancer each year ■ Afro-Caribbean and South Asians are at higher risk
What causes stroke?	■ High blood pressure ■ High blood cholesterol ■ Smoking ■ Unhealthy diet ■ People with artrial fibrillation (irregular heart rhythm), diabetes, or who have had a previous stroke or transient ischaemic attack are at higher risk
How can I prevent stroke?	■ Know your blood pressure, and keep it under control ■ Monitor cholesterol levels ■ Eat healthily, including avoiding excess salt ■ Stop smoking ■ Take regular exercise
How do I recognise a stroke?	Sudden onset of one or more of ■ Weakness or numbness in face, arm or leg, especially on one side of the body ■ Difficulty speaking or understanding ■ Loss of balance or coordination
What should I do if I think someone is having a stroke?	Dial 999. Stroke is a medical emergency. Rapid treatment can make a big difference to outcomes.

Source: Figure 3 from the Fifty-second Report by the Committee of Public Accounts Session 2005-2006 – Reducing brain damage: faster access to better stroke care. House of Commons: The Stationery Office Limited, 2006

Seventy-five per cent of contributors to our patient forum indicated that they knew nothing about, or had only a basic awareness of, stroke before it happened. Contributors commonly said they did not know about the causes of and risk factors for stroke and how to prevent it. People also told us about the unexpected impact the stroke had had on their own and their loved ones' lives. Respondents commonly wished they had known:

- what the signs and symptoms of stroke were (e.g. weakness or slurring of speech);
- that stroke is not as broadly understood in the medical community as they had expected;
- that the services they needed after their stroke were difficult to access and they would feel left alone to cope; and
- that urgent action (contacting emergency services rather than their GP; not having to wait for a scan) was so important for the outcomes of the person who has a stroke.

When we asked people what they would do if they experienced "Numbness or paralysis in one arm or leg, perhaps blurred vision and confusion, and maybe slurring of your speech, lasting possibly a few hours but gone away completely and feeling normal the next day", 60 per cent said they would go to or call their GP or NHS Direct; 30 per cent would call an ambulance or go to hospital; and ten per cent would ignore it or phone a friend. In 2005, the Stroke Association launched 'Stroke is a Medical Emergency' – a campaign to raise public awareness of stroke and to encourage people to call 999 if they recognise the symptoms of stroke.

We found that public health campaigns have had modest success in raising awareness of stroke and the least success with ethnic minority and deprived groups. Indeed, whilst other health campaigns on reducing smoking and encouraging healthy eating should have an impact, the link between adopting the behaviours encouraged in the campaigns and reducing the risk of stroke is not generally being made.

For example, 46 per cent of respondents who had heard of the Department's 'Five a Day' campaign thought it related to heart disease, but only eight per cent said it related to stroke – even though healthy eating applies equally to reducing the risk of heart disease and stroke. Respondents to the survey who had heard of the Food Standards Agency's 'Sid the Slug' campaign (which concentrated on reducing salt in the diet as a way of reducing blood pressure) were no more likely than those who had not heard of it to mention that reducing high blood pressure can reduce risk of stroke.

People of Afro-Caribbean and South Asian origin have an increased risk of stroke, as they are more susceptible to high blood pressure, and more likely to have high blood pressure that is resistant to treatment, than other groups. Black respondents were significantly more likely to mention stroke in the top four causes of death than white respondents, but they were less likely to say that they recognised named public health campaigns than white respondents were.

17 The American Stroke Association runs campaigns specifically about stroke

Source: Slide from Joe Korner's presentation at the NAO conference (19th October 2006)

The Committee of Public Accounts recommended that the Department should run an awareness campaign for stroke, focussing on its symptoms and the fact that it is a medical emergency requiring a 999 response. It also recommended that in developing this campaign, the Department should consider how to engage with groups at higher risk of stroke, such as people of Afro-Caribbean and South Asian ethnicity.[35]

The Department of Health's position

In its response to the Committee's report, the Department accepted that awareness of the symptoms of stroke needs to be raised. One of the National Stroke Strategy's project groups will set about developing recommendations on how public awareness of stroke can be raised and what the key messages should be. This work will also include consideration of how best to engage with people of Afro-Caribbean and South Asian ethnicity. The Department also stated that it has identified relevant areas of its existing public health communications activity, and begun to include specific messages about stroke.[36]

Better management of the risk factors for stroke will improve prevention rates

Data from the Sentinel Audit (2004) suggests that risk factors for stroke could be better managed. For example, only 24 per cent of English patients with an irregular heartbeat (atrial fibrillation) pre-stroke were on warfarin, when clinical opinion suggests that at least 75 per cent should have been, and only one in five patients known to have high blood pressure (hypertension) before their stroke were on suitable blood pressure-lowering medication pre-stroke.

If a person has a stroke or TIA this is a major indicator that there is high risk of further stroke, heart attack and other vascular events. The risk of stroke in the seven days following a TIA can be up to 10 per cent – around 45 times the 'normal' risk – and within four weeks of TIA the risk of stroke can be 20 per cent. Additionally, TIAs need to be treated as urgent cases by the ambulance service and NHS Direct, as it is impossible to tell, while they are occurring, whether they are transient attacks or the beginning of a major stroke. Martin Brown outlined how the risk of recurrent stroke is high in the first two weeks after a TIA **(Figure 19)**.

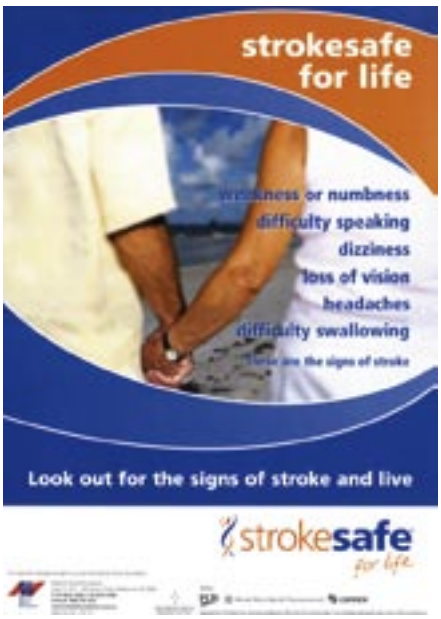
UK national stroke guidelines recommend that all patients with suspected TIA should be assessed and investigated within seven days. However, only a third of people with TIA are seen in a TIA clinic, and the median waiting time is twice as long as the waiting times recommended in the guidelines. At the conference, Martin Brown suggested that in general in the UK, TIA patients are not regarded as requiring admission to hospital and often the patient does not realise that a TIA should be treated as a medical emergency.

18 The National Stroke Foundation in Australia also sought to improve awareness of the symptoms of stroke

Raising public awareness: the strokesafe™ campaign in Australia

The National Stroke Foundation is a not-for-profit organisation that works with government, health professionals, patients, carers and consumers on minimising the impact of stroke on the Australian community. In order to address the escalating rise in the number of strokes occurring it launched the strokesafe campaign™ in September 2004.

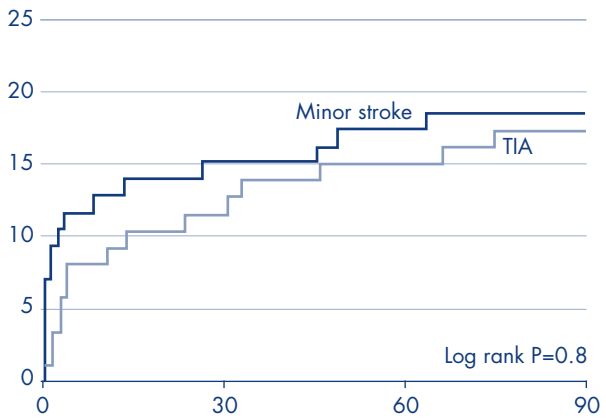
Prior to the launch, every GP in Australia received a strokesafe™ promotional pack which included an educative component and an award for GPs that did the most to keep their patients safe from stroke. strokesafe™ involved a significant television, radio and print campaign supplemented with a public free-phone information line. Calls to the National Stroke Foundation free-phone number increased from around 100 calls a month to over 800 calls in the six weeks of the campaign. Baseline research in 2003 indicated that only half of those aged 40 and over were able to correctly identify signs of stroke. Following the strokesafe™ launch period, the ability to correctly identify at least one sign of stroke had increased from 68 per cent to 73 per cent and awareness of more subtle signs of stroke (such as dizziness and numbness) had increased.



Source: National Audit Office, Reducing Brain Damage: Faster access to better stroke care (HC 452 – Session 2005-2006)

19 Risk of recurrent stroke is highest in the first two weeks after a TIA

Risk of stroke after a transient ischaemic attack (TIA) or minor stroke



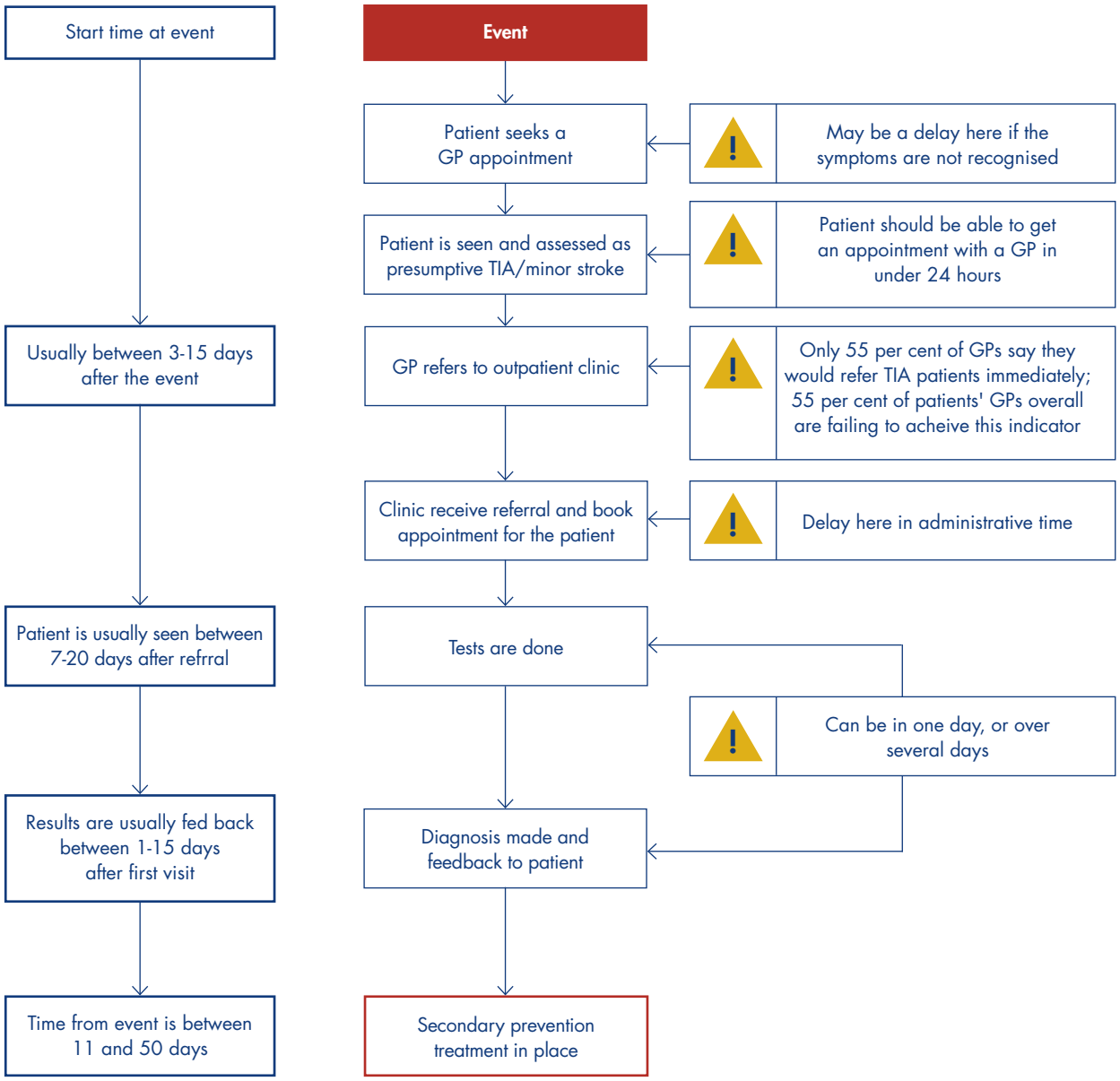
Source: Slide from Martin Brown's presentation at the NAO conference (19th October 2006)

Our analysis of Sentinel Audit data (2004) found that 58 per cent of new patients with TIAs do not get CT scans within two weeks. Delays such as these mean that there are second strokes that could have been prevented **(see Figure 20)**.

Referral to and provision of TIA services in England is patchy

There are stroke-specific performance indicators in the new GP contract that reward the better control and assessment of risk in patients who have already had a stroke or TIA. Over 2004-05 we found that people visiting their GP were more likely to have their blood pressure and cholesterol recorded than was the case in the previous year; that more people who were smokers were receiving cessation advice; and that more people with recorded blood pressure had levels meeting the recommended targets.[37]

20 There are several areas where delays after suspected TIA can hamper effective and efficient stroke prevention



Source: National Audit Office, Reducing Brain Damage: Faster access to better stroke care (HC 452 – Session 2005-2006)

Positive changes were also apparent for secondary prevention activities with trends suggesting that nearly all the desired GP activities, such as measuring and controlling blood pressure and cholesterol in those people who have had a previous stroke or TIA, would soon be achieved. There were exceptions, however, such as a very low referral rate for scans for people who have had a stroke (47.5 per cent in 2004 down to 45.5 per cent in 2005 compared with a target of 80 per cent).

Just over half of GPs we surveyed said they would refer a stroke patient immediately and we found GP referral behaviour varies **(see Figure 21)**. Our analysis of the Sentinel Audit data (2004) showed that risk factors for stroke are not being treated in some patients **(see Figure 22)**.

Reducing the delays in providing preventative interventions to people who have had a TIA or a first stroke can lead to savings for the NHS. When stenosis (narrowing) in the carotid arteries in the neck is found to be the cause of a previous stroke or TIA, surgery to remove the deposits should be performed preferably within two weeks of the stroke or TIA. Yet surgery cannot be performed until a carotid Doppler scan (an ultrasound scan of the carotid arteries) has assessed whether or not surgery is needed. The Sentinel Audit (2004) showed that only half of patients had a Doppler scan within 12 weeks.

Research shows the greatest benefit is from early surgery and there is little or no benefit if surgery is delayed beyond 12 weeks.[38] Our analysis showed that providing surgery within 14 days for TIA patients with stenosis could prevent 250 strokes a year, and save the NHS around £4 million in NHS care costs.

> ***"Imaging for Dopplers: an absolutely critical service if you're running a neurovascular service. Virtually nobody can get access to carotid dopplers within four hours and a lot of people (60 per cent) will take more than 48 hours during the week in order to get a carotid doppler. So even if you're running a neurovascular service, unless you've got your carotid doppler service pretty well tee'd up and the other imaging services, then you are going to be failing some of your patients."***

Source: Anthony Rudd, speaking at the NAO conference (19th October 2006)

21 GP referral behaviour varies

When we asked about referral behaviour, some GPs made the following comments in our survey:

"[There is] no point in rapid referral as [there is] no rapid response"

"[I refer] when I have time to write the letter"

"[I] would not always refer for first TIA"

"I write the letter in the consultation but the patient will wait weeks to be seen so it's pointless really"

"It varies depending on severity of symptoms – usually [I make the referral] within a few hours"

"Information on investigations carried out as in-patients are not effectively communicated to GPs"

Source: National Audit Office Reducing Brain Damage: Faster access to better stroke care (HC 452 – Session 2005-2006)

22 Risk factors for stroke are not being treated in some patients

- Of English patients who had an irregular heartbeat (atrial fibrillation) pre-stroke, only approximately 24 per cent were on warfarin, when clinical opinion suggests that at least 75 per cent should be on warfarin.
- One in five patients were known to have high blood pressure (hypertensive) before their stroke but were not on suitable blood pressure-lowering medication pre-stroke.
- 44 per cent of diabetic patients with stroke were being treated (with angiotension II receptor antagonists or ACE inhibitors) before their stroke when clinical opinion suggests at least 75 per cent should be on either drug.
- For patients who had known heart disease before they had their stroke, 40 per cent were being treated (with an ACE inhibitor or angiotensin II receptor antagonist) when clinical opinion suggests that least 75 per cent of these patients should have been on this treatment prior to their stroke. With Beta Blockers the case was very similar, with 37 per cent of people on the appropriate medication.

Source: National Audit Office, Reducing Brain Damage: Faster access to better stroke care (HC 452 – Session 2005-2006)

In its report, the Committee of Public Accounts recommended that all providers of primary and secondary care should have protocols in place for the referral of suspected or confirmed TIA patients, reflecting the national guidelines for stroke which indicate that all suspected TIA patients should be assessed and investigated within seven days. The Committee also suggested that the indicator in the Quality and Outcome Framework for assessing primary care practices' performance in relation to suspected stroke patients, which simply states "referral for a scan", should be amended to include a time bound element consistent with the national stroke guidelines.[39]

The Department of Health's position

In responding to the Committee of Public Accounts recommendations, the Department has stated that one of the National Stroke Strategy's project groups is looking at improving the provision of rapid access to TIA services and working on options for increasing the speed of referral to surgery.[40]

CHAPTER FIVE

Joining forces with the patient

"We set up a web-based forum for patients and carers to give us their views. Of course, it's selective … but for us it actually brought to life why we were doing this report for the Public Accounts Committee"

Karen Taylor, Director for Health Value for Money studies, speaking at the NAO conference (19th October 2006)

A key objective of the NHS reform agenda is to improve the patient experience by, amongst other things, strengthening the involvement of patients and the general public in shaping the future provision of services. Patient and public involvement and the quality of the patient experience are two important components of clinical governance.

Indeed, as our recent report on *Improving Quality and Safety – progress in implementing clinical governance in primary care* shows, effective clinical governance in primary care can help to ensure the quality of outcomes experienced by patients.[41] The quality of patients' experience depends largely upon:

- fast access to reliable health advice;
- effective treatment delivered by trusted professionals;
- participation in decisions and respect for preferences;
- clear, comprehensible information from practitioners and support for self care;
- attention to physical and environmental needs;
- emotional support, empathy and respect;
- involvement of, and support for, family and carers (for example from voluntary organisations);
- continuity of care, smooth transitions between healthcare providers and 'seamless' delivery of service from the different organisations they come into contact with as they receive care; and
- whether it is straightforward to complain if they are dissatisfied with the service they receive.

'Patient experience' refers to patients' perceptions of the care and treatment they receive, for example the prompt provision of good, safe care in a clean and welcoming environment. Improving patient involvement will create a more positive patient experience. Patients want care professionals who are good communicators and who have sound, up to date clinical knowledge and skills. They also want professionals who are interested, sympathetic, involve them in decisions about their care, give sufficient time and attention and provide advice on health promotion and self care. For instance, most patients responding to patient surveys are positive about their experiences of primary care **(see Figure 23)**.

Under clinical governance, engagement with the patient is based on partnership, with the aim of shifting the balance of power away from a patient-passive relationship towards patient empowerment and establishing a more equal relationship between the NHS and patients where patients become "more active partners in their care".[42] Engagement can take place on different levels from one to one engagement with individual patients to larger scale patient forums or committees. Our evidence indicates that patient and public involvement is relatively less well developed than many other aspects of clinical governance.

23 Key findings from the 2005 primary care patient survey

Positive experiences

92 per cent said they were treated with dignity and respect by the doctor

82 per cent said the doctor listened carefully to them

74 per cent said they definitely had enough time with the doctor to discuss their problem

76 per cent said they had complete confidence and trust in their doctor

85 per cent had complete confidence and trust in other primary care staff

Negative experiences

41 per cent would have liked more say in decisions about medicines

39 per cent of those prescribed new drugs wanted more information about side effects

70 per cent of patients referred to a specialist were not given copies of referral letters

57 per cent of patients who had phoned the practice had had difficulty contacting the practice

Source: Healthcare Commission, Primary Care Trust survey of patients, 2005

Patient voices: the benefit of listening to experience

Patients and carers are in a unique position to bring their experience to bear; practitioners can harness the strength of belief, experience and determination of patients and carers to improve services. One example of a carer who has devoted his time to improving stroke services is Derek Whitehead **(see his Personal Story, overleaf)**.

During our fieldwork, a focus group of carers of people who had had a stroke produced a list of services that were commonly needed, and some experiences of accessing those services **(see Figure 24)**.

Reconnecting with Life: stories of life after stroke

If, as the Department of Health encourages, patients are to be at the heart of healthcare then their views and an understanding of their experiences are crucial to any attempt to reform healthcare services.

Patient stories can make a significant contribution to understanding the patient experience by allowing the patient to recount their experience of illness and of healthcare. Capturing the unwritten and unspoken stories of ordinary people allows those who devise and implement strategies to do so with information and compassion. These stories can also be a valuable teaching aid and listening to them ensures that practitioners are grounded in the reality of what healthcare and healing means.

We teamed-up with Connect to commission 'Reconnecting with Life: stories of life after stroke' – a DVD of short multi-media stories told by people who have experienced stroke. This media-rich blend offers an extraordinary opportunity to disseminate these important stories to a wide audience in a highly accessible form.[43] They can:

- highlight gaps in the system;
- promote education, learning and reconciliation;
- be disseminated more easily to a wider, global audience;
- allow patients' and carers' (and professionals') voices to be heard;
- be created in a spirit of collaboration and partnership; and
- reinforce the place of patients at the heart of care.

All the stories[c] can be seen at **http://www.nao.org.uk/publications/nao_reports/05-06/0506452_interviews.htm** and as part of the Patient Voices programme at **www.patientvoices.org.uk.** Alternatively you can request a free dvd from the NAO by emailing **stroke@nao.gsi.gov.uk**

These stories are intended to serve as an inspiration to people who have had a stroke and to those who provide care for stroke patients.

c Like all the other stories in the Patient Voices programme, the stories are released under a Creative Commons licence, so that they are free for anyone to use for the purposes of healthcare education or quality improvement, provided that appropriate acknowledgement is made and they are not changed or sold.

A PERSONAL STORY

Improving stroke services in Greater Manchester: although it can't help my wife it will help others

During my first year (1949) at university, I met Barbara at a dance on the evening immediately prior to my eighteenth birthday – and it really was love at first sight.

My experience with Barbara's strokes started in 1999.

I agreed to stand as an independent councillor for election in May 1999. Realising that if elected, this would be a major constraint on the activities of our 'golden years', we decided to go on a round-the-world tour. Flying from Singapore to Manchester it became obvious that Barbara's memory was seriously impaired, and over the next few weeks this seemed to get worse.

At first I thought that this was the beginning of Alzheimers Disease, and knowing that there was no cure, I had not the courage to consult the GP. However, our daughter insisted that Barbara was referred to a memory clinic. After 16 weeks the final diagnosis was stroke.

Barbara's condition then remained stable for about another year, until I thought she was having another stroke. I took her to a GP but by the following morning, Barbara was completely paralysed down the left side. She stayed in hospital for about three weeks and there made a remarkable natural recovery.

Barbara had another stroke in 2001 which left her with severe dementia. On one occasion, I went to the Town Hall to drop off some papers, leaving Barbara in the car. In the very brief period I was away, she got out of the car and got on a bus to a town about ten miles away. I searched frantically for her but she was eventually returned by the police, when the bus driver realised that she was completely confused.

To reduce the risk of injury to Barbara, I fitted a gate at the side of the house, (to prevent her roaming) and an extra lock on the front door. However, one day she got out, fell and broke her wrist. I fitted a shop door bell so that if Barbara did open the front door, the door bell rang, attracting my attention.

In the spring of 2003, Barbara had a further massive stroke. She was transferred into hospital, where, although there was a stroke unit, she was placed and remained in, an orthopaedic ward. I have nothing but praise for the hospital's orthopaedic capabilities but it was the wrong ward for Barbara. The physiotherapists worked hard on Barbara and were achieving a significant improvement by the end of three weeks. I was then asked to agree to Barbara going into intermediate care for six weeks of ongoing care. To avoid bed blocking in the main hospital I agreed, providing that the physiotherapy was maintained.

> "...I will do all that is in my power to use available technologies to help other potential victims."

She was transferred but the visiting physiotherapist refused to treat her. The visiting GP said that the care home was not suitable for her and that she should go back to the hospital – but the hospital refused to re-admit her. At the end of her stay in the care home the paralysis seemed irreversible.

At about the same time, I read an article talking about a new stroke drug based on vampire bat saliva (thrombolytic therapy). I contacted the author. From then I have actively campaigned, both locally and nationally, about the use and benefits of thrombolysis.

In the spring of 2005 I discovered that the NAO was working on a report on stroke and I contributed my story (case study 8, page 31). I attended the Public Accounts Committee hearing of the NAO report and when the Department of Health later held a conference, I chaired part of this.

Source: Contributed by Cllr Derek Whitehead MSc BSc, from Cheshire

I co-chaired another conference, of the Greater Manchester Stroke Network, where delegates discussed the benefits of fast stroke care, supported by thrombolysis.

In late 2006, following on from the conference, the Greater Manchester Stroke Group lobbied the Association of Greater Manchester PCTs for an early intervention stroke service for Greater Manchester:

We argued that for planning purposes, in Greater Manchester, we might expect 3,000 suspected stroke cases of whom about 2,500 will be confirmed as having a stroke. If we designed a purpose built system we should aim to thrombolyse 500 patients per year. About 100 of these patients would fully recover who would not do so without thrombolysis. There are potential savings, based on the NAO calculations, of around £2million per year for the health economy in Greater Manchester before taking into account the cost of thrombolysis and there would be very significant additional savings in social care costs due to the decrease in disability.

This motion was approved by the PCT Chief Executives at the end of the year. I am hopeful that this will enable a fast and effective stroke service to be running in 2008.

Resulting from all my activities, I have also been asked (and have agreed) to be the Chair for the Public/Patient Liaison Group for the UK College of Radiographers.

You will understand that we were hoping for many golden years together – but we have been denied this by the horror of stroke. This has been my driving force – for if there is little that I can do to help Barbara other than provide love, care and affection, I will do all that is in my power to use available technologies to help other potential victims.

Until the strokes, I think we had the perfect marriage – a team that was always happy to work together to a mutually agreed end – yes, we did have differences, but by agreement we never slept on them.

24 There are often issues affecting the accessibility of support services for stroke patients

Service or adaptation	Reasons why services are needed by stroke survivors or their carers	Problems encountered when accessing all of these services[30]
GP Hospital in-patient care Hospital out-patient care or clinic visits District nurse Nursing auxiliary Community mental handicap nurse Private nurse Other nurse Health visitor	Many stroke survivors are left with substantial medical and care needs. These include secondary prevention to reduce the risk of a further stroke, and the management of conditions such as diabetes and hypertension. Stroke survivors often also suffer from depression.	■ **Communication:** Accessing services or adaptations often requires communicating with providers by telephone or filling in forms to demonstrate eligibility. However, many stroke survivors suffer from memory loss and confusion and aphasia, which affects their ability to speak, write and understand. *"By the time I get through to somebody at the council on the phone I've forgotten what I want to talk to them about".*
Physiotherapist	Stroke affects the ability of survivors to move and walk. Physiotherapists help survivors to regain some ability to move. They can also teach carers how to position and move patients.	■ **Transportation and mobility:** Stroke survivors may have problems using or affording the transport necessary to reach services such as GPs and social clubs. A step of even a few inches can be an impossible barrier to entering or leaving a building. *"The front of my house has a six inch step into the porch area and the ambulance personnel refused to lift and lower my wife's trolley across this step".*
Chiropodist	Immobility of limbs often results in nails digging into the skin, which can lead to pain and infection.	
Occupational therapist	Many people will be unable to manoeuvre around their homes. Occupational therapists assess and help stroke survivors adapt their homes to match their new needs.	
Home carers Meals on wheels	Following a stroke, it is common for people to find everyday tasks almost impossible because of mobility problems.	■ **Information:** Stroke survivors and their carers frequently state that they are ill-informed about services. *"I've been a carer for 7 years and I've never been told about support groups in my area".*
Incontinence service Laundry service	It is quite common for stroke survivors to experience difficulty in controlling their bladder or bowel movements.	

24 There are often issues affecting the accessibility of support services for stroke patients *continued*

Service or adaptation	Reasons why services are needed by stroke survivors or their carers	Problems encountered when accessing all of these services[30]
Social worker Private home help	Social workers help stroke survivors come to terms with life after stroke and also direct them to other services that they will require.	■ **Individual and changing needs:** The needs of stroke survivors often change over time but the provision of services and adaptations does not always respond to this in a timely manner. *"My husband had to wait 11 months to get a new wheelchair and by the time it was delivered he was dead".* *"We have an average wait of 6 months for an Occupational Therapy assessment".*
Day centre Club for the disabled Other day care Other social club Adult education centre	Many stroke survivors with disability feel isolated. Many also experience communication difficulties due to aphasia and need to participate in activities such as group communication programmes.	
Respite – Local Authority home Respite – convalescent home Respite – hostel for disabled Respite – home for disabled Respite – nursing home Night sitting	Many carers of stroke survivors are elderly or in poor health themselves. Respite care lasts between a few hours and a couple of weeks and provides a temporary break from the strain of caring.	■ **Regional variation:** There is variation in the services available to stroke survivors between different Primary Care Trusts and Local Authorities. *"You can get different services from somebody living in the same street. It all depends on which Primary Care Trust your GP is in".*
Mobility officer Ramp outside house Hand rails outside house Ramp inside house Hand rails inside house Doors altered Stair lift Other alterations to improve access Fitted furniture (kitchen) altered New bathroom or toilet Shower installed Door answering system Other alterations Hoist Wheelchairs	People with mobility and coordination difficulties require a wide range of adaptations to help them perform everyday activities such as bathing, cooking, dressing and walking.	■ **Disability:** Some people with severe disability will be excluded from services because they are too disabled or medically unstable. *"Most support groups can't take people with high needs".*

Source: National Audit Office, Reducing Brain Damage: Faster access to better stroke care (HC 452 – Session 2005-2006)

Understanding these experiences is critical to delivering better services. Bo Norrving[b] explained that the Swedish national quality register, the 'RIKS-stroke registry', plays a vital function in developing the management of stroke care:

> ***"We have a registration in the acute phase and we have a follow-up after three months, which is done either by a questionnaire sent to the patient or by a telephone interview with the patient and about 80% of all patients are actively followed-up. We feel this is essential for the services to have the quality control in-built into the system, so that we know what is happening. We very much take the patient's perspective and carers' roles into focus"***

Source: Bo Norrving, speasking at the NAO conference (19th October 2006)

Helen Rodgers was asked about the arrangements in Newcastle for incorporating patient feedback, and peer support for patients:

Delegate: "I was wondering … about service users, using peer support so people can share experiences of having had a stroke; is that built in to your model or do you cater for that?"

Helen Rodgers: "It certainly is part of our model – we get feedback from all of our patients, both in-patients and people who've received supported discharge and they're very much involved in terms of service development. We also run a course for professionals about stroke and people who've had a stroke are involved as teachers on that course because by actually hearing it first hand, of what the experience was like, it certainly makes you look at what you're doing and how you can improve it."

25 At the conference, Joe Korner relayed some patient experiences collected by The Stroke Association

"Our helpline staff are handling over 2,000 enquiries a month and they're from stroke survivors or their families and carers who are desperate because they're not getting the services they need; they need the advice about what they should be getting. "We hear some terrible stories – we don't, of course, hear some of the good news stories, although I'd like to report on one from yesterday, when I was at the Social Services Conference down in Brighton and we were talking about the transition from hospital back into social care (into the community). One gentleman stood up and he had a stroke on a Saturday night at 11.00pm but it just so happened that the physician in charge of A&E, when he went in, was the stroke physician and they unlocked the scanning room and they gave him a scan within 30 minutes and they were able to thrombolyse him. He was able to make a great recovery. It shouldn't run on luck and that was the key thing and he was aware more than anybody else about how lucky he'd been."

"In August 2005 my incredible, intelligent and fit 71 year old husband suffered a severe stroke. It was a bank holiday Friday and there was no-one to do a CT scan until the Tuesday. He moved beds eight times before eventually ending up in a stroke unit. He was sent home with no instructions for me; no information on what happens next, no help whatsoever."

"They sent her home from the hospital after three and a half hours, the doctor said it might have been a TIA and referred us to the out-patients clinic. I rang the clinic; the soonest they could see him was in three weeks. Then on Tuesday last week I was making her some toast and the colour just drained out of her; she was having another stroke. The doctors at the hospital now say this was a significantly more serious one and there has been damage caused."

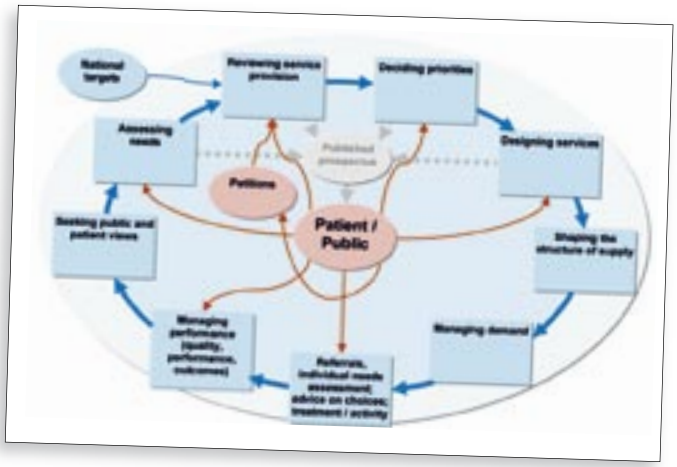
Source: Joe Korner, speaking at the NAO conference (19th October 2006)

b Bo was involved with the recent Helsingborg declaration on stroke management in Europe: For the 2006 Declaration see Cerebrovasc Dis 2007; 23: 229–241 DOI: 10.1159/000097646

The Department of Health's position

At the centre of the commissioning cycle (as outlined in the Department of Health's Improving Stroke Services: a guide for commissioners) is the role of patients and the public, to whom commissioners must be accountable for their commissioning decisions. One of the mechanisms for ensuring accountability is the ability of local people to petition their Primary Care Trust (PCT) for a review of any service they feel needs improvement. In addition, PCTs will be required in future to publish a prospectus which sets out their strategic commissioning intentions. This will help to engage the public, as well as potential service providers. Further details on these involvement mechanisms are available in the full commissioning framework at **www.dh.gov.uk/healthreform**

The Department is working closely with the voluntary organisations that represent stroke survivors and stroke survivors and carers are included on all of the project groups and the steering group developing the national stroke strategy. Members of the Department of Health stroke team have also attended patient forums and events to seek views and to explain what the Department is doing and have been on communications access training to improve the accessibility of Departmental meetings.



GLOSSARY

CT scan	An X-ray scan using Computed Tomography that produces detailed pictures of soft tissues and shows whether the stroke has been caused by a blocked artery or a haemorrhage into the brain.
Doppler scan	An ultrasound scan of the carotid arteries in the neck to check for narrowing or blockage of arteries taking blood to the brain.
Dysphasic	(adj) (Dysphasia or Aphasia (n)) Unable to use or understand language – spoken or written. A partial or total loss of the ability to articulate ideas or comprehend spoken or written language.
GP contract	The General Medical Services contract between PCTs and General Practioners, which was introduced by the Department of Health from October 2003, which stipulates the rewards available for the achievement of certain criteria or indicators in treating patients.
Haemorrhagic stroke	The type of stroke that is caused by a bleed in the brain, causing brain cells to die. Haemorrhagic stroke occurs when a blood vessel bursts inside the brain. The brain is very sensitive to bleeding and damage can occur very rapidly, either because of the presence of the blood itself, or because the fluid increases pressure on the brain and harms it by pressing it against the skull.
Hemiparesis	Weakness, or paralysis, of one side of the body.
Infarct	An area of tissue death due to a lack of local blood supply. For example, in a myocardial infarction there is death of myocardial (heart muscle) tissue due to sudden (acute) deprivation of circulating blood.
Intracerebral haemorrhage	An intracerebral hemorrhage is bleeding in the brain caused by the rupture of a blood vessel within the head. See also Haemorrhagic stroke.
Ischaemic stroke	The type of stroke that is caused by a blockage to local blood flow in the brain, most often by clot inside an artery, reducing blood flow to the brain and causing brain cells to die. This causes a brain infarct or cerebral infarct (see also infarct).

MRI scan	An X-ray scan using Magnetic Resonance Imaging (a more sophisticated technique than CT scanning) that produces detailed pictures of soft tissues and shows whether the stroke has been caused by a blocked artery or a haemorrhage into the brain
(Ischaemic) Penumbra	is an ischaemic brain region in a state of diminished cerebral blood flow that has not yet led to complete infarction and is potentially salvageable.
Primary prevention	Activities that prevent a first-ever stroke or TIA.
Radiology	The branch of medical science dealing with the use of x-rays and other penetrating radiation. Radiologists are qualified to read scans and make an assessment, whereas radiographers are professionals in operating radiological equipment. Neuroradiologists are specialists in the use of x-rays in diagnosis and treatment of disorders of the nervous system (and brain).
Secondary prevention	This refers to activities that prevent a second, or further, stroke or TIA.
Subdural haematoma	(or subdural haemorrhage or blood clot on the brain). A subdural haematoma is a pooling of blood between the dura, which is a leathery membrane just under the skull, and the brain itself.
Telemedicine	Medical services provided remotely, such as using digital radiology technology to send scans electronically to a separate site where they can be read and assessments sent back.
TIA	Transient Ischaemic Attack, or 'mini stroke', where blood flow to the brain is temporarily disrupted, causing symptoms of stroke but they pass quickly (often people recover within minutes). This can be a warning that a more severe stroke is about to happen.
Triage	The process whereby people presenting with disease or illness are assessed, often by nurses or junior doctors in the first instance, and then referred to the appropriate specialist for further treatment when necessary.

CONTRIBUTORS

Thanks to the following

This book was put together by Colin Ross, and edited by Jess Hudson, under the Direction of Karen Taylor.

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- Professor Chris Bladin (Director, Eastern Melbourne Neurosciences, Box Hill Hospital (Monash University), Melbourne, Australia).
- Professor Roger Boyle, and from his team at Department of Health: Anna Norris, Mary Agnew and Marianne Green, who are contactable at: **mb-strokeideas@dh.gsi.gov.uk**
- Professor Martin M Brown, UCL Institute of Neurology, the National Hospital for Neurology & Neurosurgery, London
- Sally Byng and her team at Connect, **www.ukconnect.org**
- Pip Hardy and friends, Pilgrim Projects, **www.pilgrimprojects.co.uk**
- Averil Mansfield, The Stroke Association, **www.stroke.org.uk**
- Bo Norrving, Department of Neurology, Lund University Hospital, Sweden
- Joe Korner, Director of Communications at The Stroke Association, **www.stroke.org.uk**
- Dr Helen Rodgers, Reader in Stroke Medicine, Newcastle University & Honorary consultant stroke physician, Northumbria Healthcare NHS Foundation Trust
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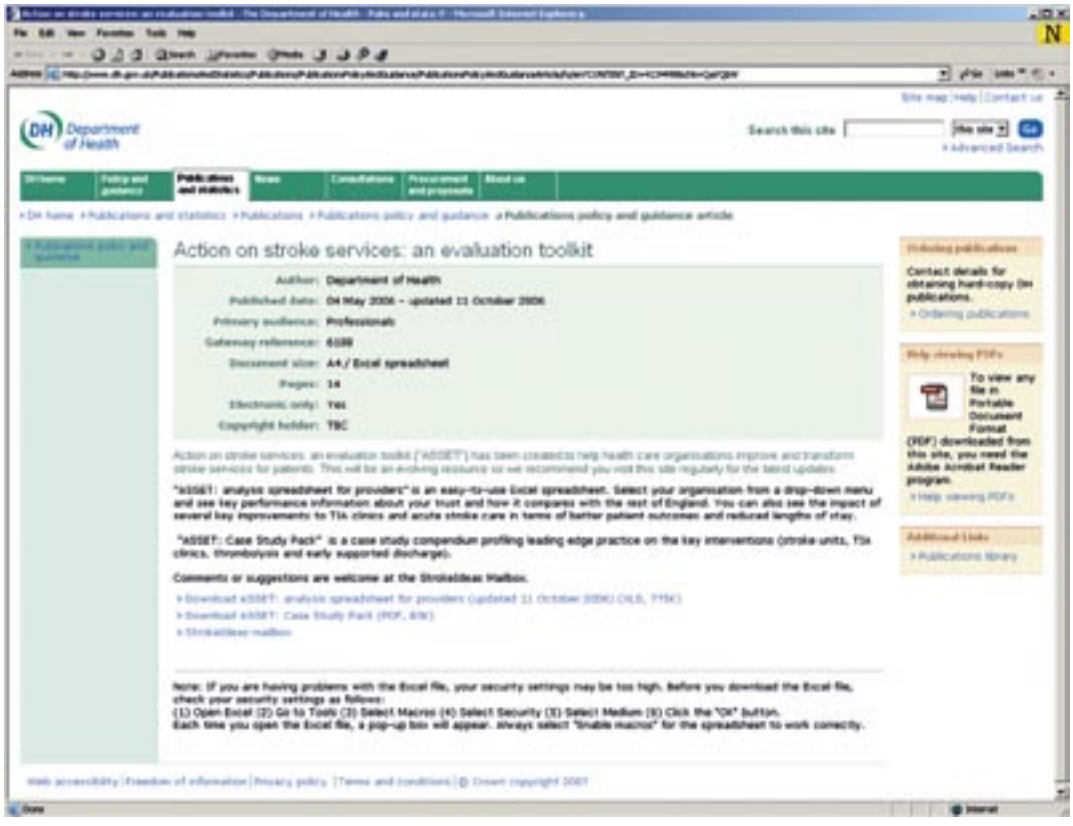
All photographs throughout the publication (not including figures in the report) are courtesy of Justine Desmond Photography.

APPENDIX ONE

Department of Health initiatives to support improvements in stroke care

Action on Stroke Services: an Evaluation Toolkit ("ASSET") for Providers

ASSET for Providers is an interactive resource that is freely available to download at **www.dh.gov.uk/stroke**. It was created to help health care organisations improve and transform stroke services for patients.



The tool allows you to select your own Trust and then displays performance information from HES and the RCP Stroke Audit about your particular site.

The tool then allows you to see the effect that specific interventions would have on patient outcomes and bed days for your Trust.

Action on Stroke Services: an Evaluation Toolkit ("ASSET") for Commissioners

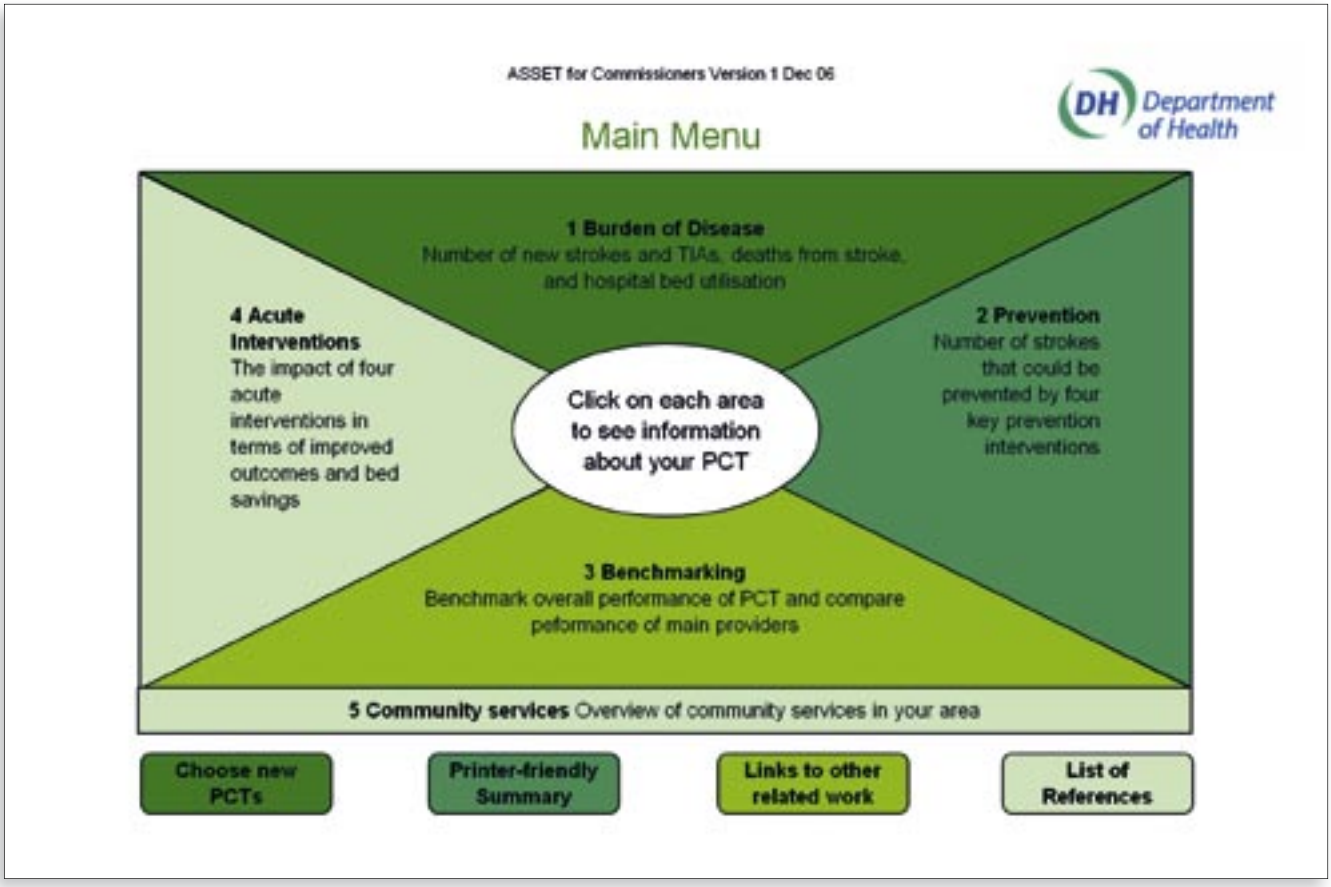
ASSET for Commissioners is a new interactive resource available to download at **www.dh.gov.uk/stroke**. It builds on the success of the original "ASSET for Providers". It can be used to:

1. assess the current demand for services
2. identify scope for preventing future strokes
3. benchmark performance against any other PCTs in the country
4. compare current service provision with best practice
5. demonstrate the tangible benefits that can be realised by improving services

Commissioners can access information on:

1. The burden of disease for each PCT
2. Four key interventions to prevent future strokes
3. Easy-to-use benchmarking by PCT and Provider
4. The impact of four key acute interventions on improved outcomes and reduced lengths of stay
5. Community services

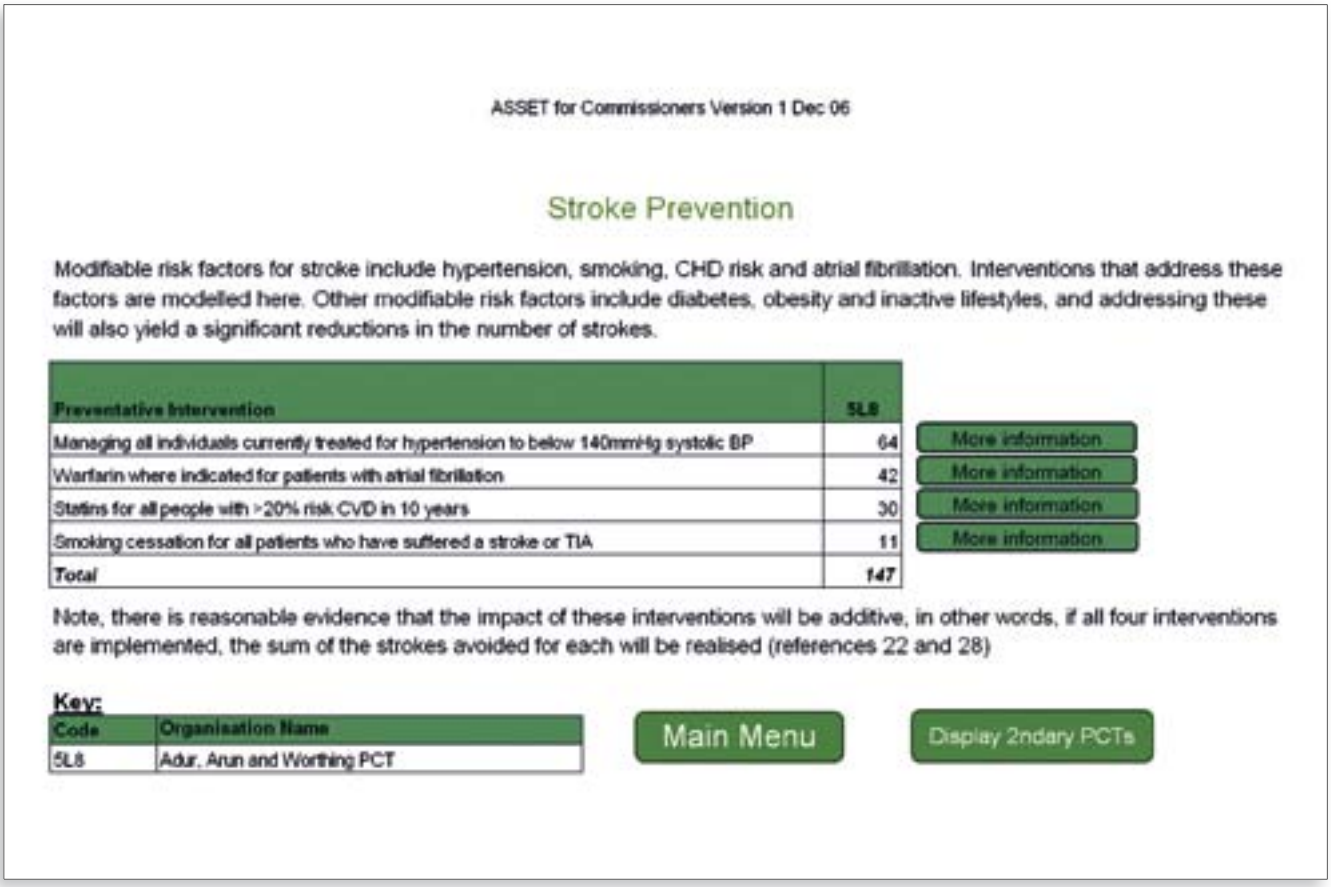
The tool is easy to use and tailored to each PCT – the user simply selects a PCT from a drop down list and follows the onscreen instructions. There is also a function to print out a summary that details all the relevant information.



Stroke Prevention

The tool features four preventative interventions, and estimates the total strokes that could be prevented if each PCT implemented them. These are:

- managing hypertension so systolic blood pressure is below 140 mmHg
- warfarin for patients with atrial fibrillation
- statin therapy for all people with >20% risk of CVD within 10 years
- smoking cessation for all stroke/TIA survivors



ASSET for Commissioners Version 1 Dec 06

Stroke Prevention

Modifiable risk factors for stroke include hypertension, smoking, CHD risk and atrial fibrillation. Interventions that address these factors are modelled here. Other modifiable risk factors include diabetes, obesity and inactive lifestyles, and addressing these will also yield a significant reductions in the number of strokes.

Preventative Intervention	5L8	
Managing all individuals currently treated for hypertension to below 140mmHg systolic BP	64	More information
Warfarin where indicated for patients with atrial fibrillation	42	More information
Statins for all people with >20% risk CVD in 10 years	30	More information
Smoking cessation for all patients who have suffered a stroke or TIA	11	More information
Total	**147**	

Note, there is reasonable evidence that the impact of these interventions will be additive, in other words, if all four interventions are implemented, the sum of the strokes avoided for each will be realised (references 22 and 28)

Key:

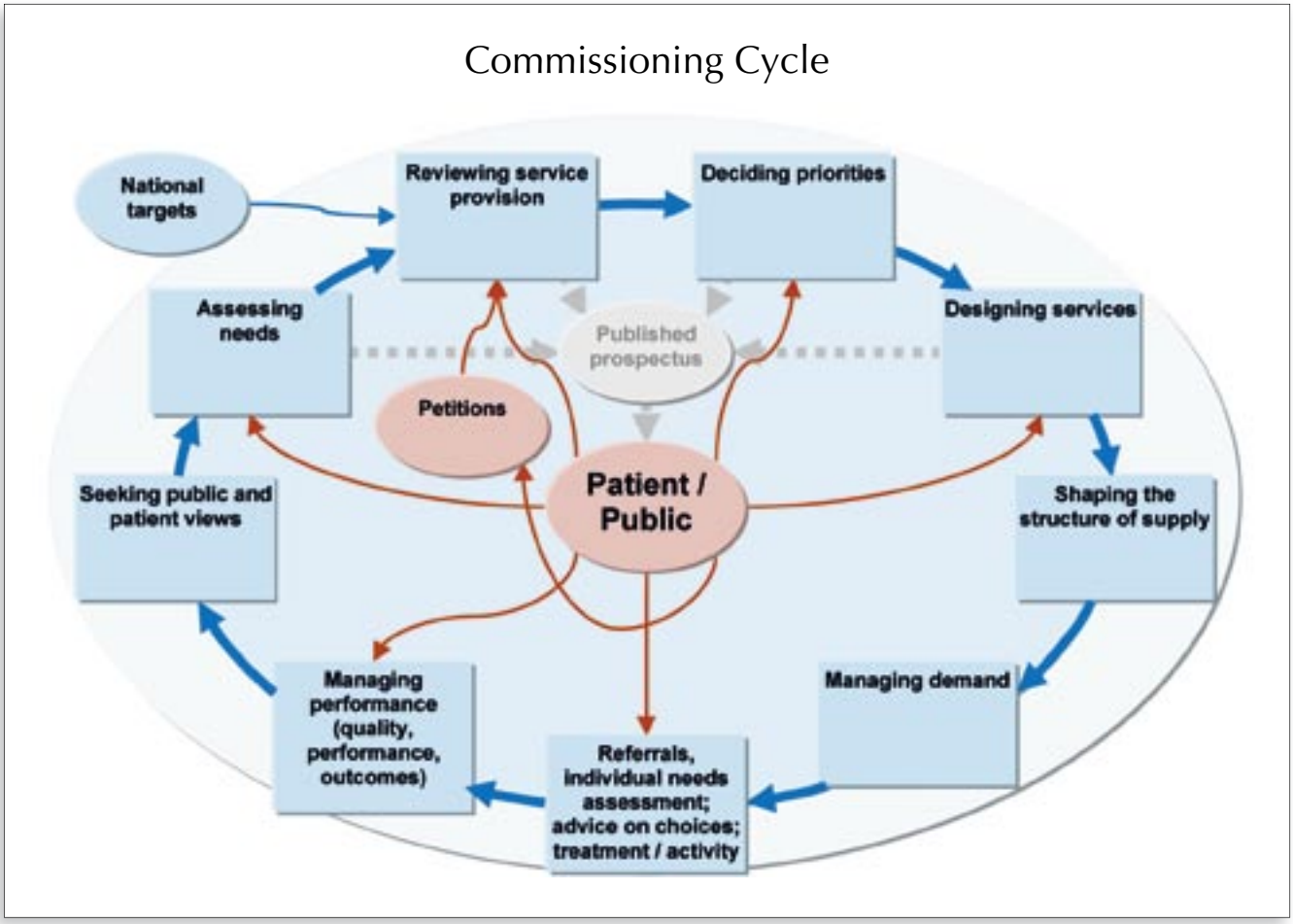
Code	Organisation Name
5L8	Adur, Arun and Worthing PCT

Main Menu

Display 2ndary PCTs

Improved Stroke Services: A Guide for Commissioners

This guide is designed to be of practical use for commissioners as they plan and secure services. It sets out key issues to consider when commissioning stroke services and provides a summary of the more detailed resources available. It draws from emerging themes in the national strategy. It can be downloaded from **www.dh.gov.uk/stroke**



The guide works through the commissioning cycle for stroke and encourages a more integrated approach to health and social care. It highlights some aspects of service that will need to be commissioned across larger areas:

- **Assessing Needs** – Determining the likely local level of need for stroke and TIA services
- **Reviewing Service Provision** – Comparing current service provision and identified needs
- **Deciding Priorities** – Choosing what are the most important services to be offered
- **Designing Services** – Designing the way in which services will be provided and funded
- **Shaping the Structure of Supply** – Making decisions about the large, necessary changes
- **Managing Demand** – Promoting prevention to reduce avoidable and inefficient use of the system
- **Referrals, Individual Needs Assessment, Advice on Choices, Treatment, Activity** – Looking at individual perspectives and providing information
- **Managing Performance** – Using feedback and monitoring to improve the system
- **Seeking Patient and Public Views** – Asking patients and the public what they want from the service

Get involved with the developments at the Department of Health

The Department will be conducting a three-month consultation on the national stroke strategy in summer 2007. This will provide the opportunity to contribute your views on how to deliver improved stroke care.

The Department of Health Stroke team can be contacted via **mb-strokeideas@dh.gsi.gov.uk**

Updates on the development of the strategy and supporting resources can be found at **www.dh.gov.uk/stroke**

APPENDIX TWO

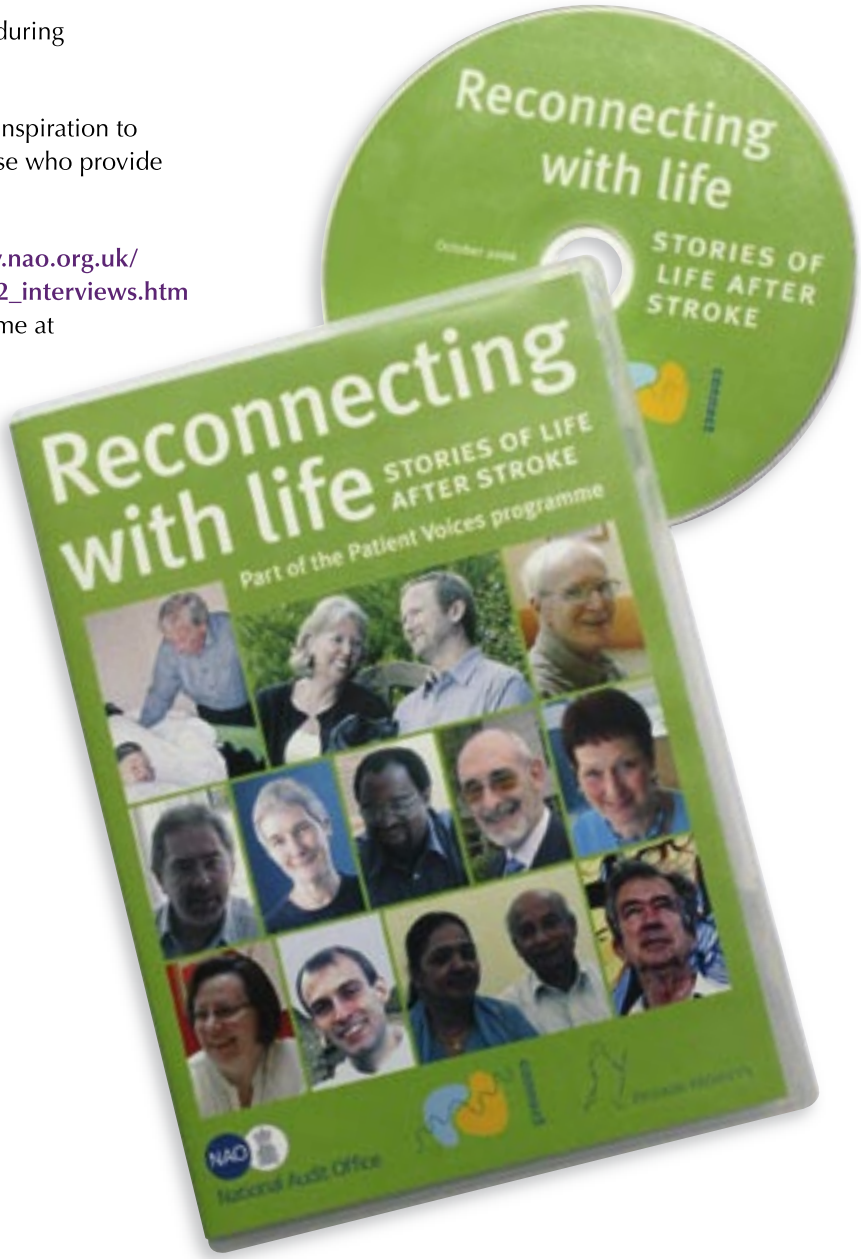
The Conference

Our DVD of patients' stories was shown during our conference.

These stories are intended to serve as an inspiration to people who have had a stroke and to those who provide care for stroke patients.

All the stories can be seen at **http://www.nao.org.uk/publications/nao_reports/05-06/0506452_interviews.htm** and as part of the Patient Voices programme at **www.patientvoices.org.uk**

Alternatively, you can request a free copy of the DVD from the NAO by emailing **stroke@nao.gsi.gov.uk**



Joining Forces to Deliver Improved Stroke Care

19 OCTOBER 2006

THE QUEEN ELIZABETH II CONFERENCE CENTRE

LONDON

CPD ACCREDITED

TOPICS INCLUDE

- Integrating stroke services: challenging the boundaries
- Improving the patient journey in acute and post-acute care: lessons from Australia, Sweden and the UK
- The way ahead: responding to NAO and PAC findings
- Immediate scanning as a cost effective strategy to guide stroke treatment
- Success and progress in surviving stroke
- The 2006 National Sentinel Organisational Audit

PLUS Cast your vote on recommendations for change

KEYNOTE SPEAKERS

- **Rosie Winterton MP**
  Minister of State for Health Services
- **Edward Leigh MP**
  Chairman of the Public Accounts Committee
- **Karen Taylor OBE**
  Director Health VfM Audit, National Audit Office
- **Professor Roger Boyle CBE**
  National Clinical Director for Stroke, Department of Health
- **Dr Anthony Rudd**
  Stroke Programme Director, The Royal College of Physicians

Joining Forces to Deliver Improved Stroke Care

19 OCTOBER 2006 · THE QUEEN ELIZABETH II CONFERENCE CENTRE · LONDON

Faster access to better stroke care would save lives, prevent disability and reduce costs

Recent clinical, technological and organisational developments in stroke care mean that patients who a few years ago would have died or been seriously disabled after their stroke now have a much better chance of making a good recovery, provided they receive fast and effective access to appropriate care.

Stroke care costs the NHS around £2.8 billion a year in direct costs – more than the cost of treating coronary heart disease – and costs a further £1.8 billion in lost productivity and disability with further informal care costs of around £2.4 billion.

In its report, *'Reducing Brain Damage: Faster Access to Better Stroke Care'*, the National Audit Office identified scope for potential savings as a result of more effective practice: some £20 million annually, 550 deaths avoided and over 1,700 people fully recovering from their stroke each year who would not otherwise have done so.

Joining forces

The conference provides a unique opportunity to join the National Audit Office in shaping the future of stroke services.

9.00 Registration and coffee

Morning Chair Professor Averill Mansfield *Chair* The Stroke Association

9.50 Welcome and introduction

Edward Leigh MP *Chairman of the Public Accounts Committee*

10.00 Integrating stroke services: challenging the boundaries

Rosie Winterton MP *Minister of State for Health Services*

Keynote Opening from Rosie Winterton MP

10.10 Reducing brain damage: key messages from the National Audit Office (NAO) and Public Accounts Committee (PAC) reports

Karen Taylor OBE *Director, Health VFM Audit* National Audit Office

- basis for the key findings
- PAC and NAO: recommendations
- commitments given: the Treasury Minute response

10.35 The Way Ahead: responding to the NAO and Public Accounts Committee findings

Roger Boyle CBE *National Clinical Director for Stroke* Department of Health

- background on the national stroke strategy
- progress so far
- next steps

11.00 Questions and answers, followed by coffee and exhibition

IMPROVING THE PATIENT JOURNEY: FASTER ACCESS TO BETTER ACUTE CARE

11.40 Why immediate scanning is the most cost-effective strategy to guide stroke treatment

Joanna Wardlaw *Professor of Neuroradiology and Honorary Consultant Neuroradiologist* Western General Hospitals NHS Trust

- identifying the cause of stroke and distinguishing non-vascular mimic from vascular stroke, or ischaemic from haemorrhagic stroke
- results from an extensive health care modelling exercise determining CT scanning as the most cost effective imaging strategy
- long term functional outcomes and quality of life

12.05 An Australian tour de force

Chris Bladin *Co-Chair* Australian Stroke Trials Network and *Director* Eastern Melbourne Neurosciences

- developing a stroke team: personnel, protocols and passion
- pre-hospital stroke care: paramedics are your best friends
- stroke brain imaging: "time is brain"
- learning to work with the Emergency Department: triage treatment and beyond

12.30 An English tour de force

Martin Brown *Professor of Stroke Medicine* University College London

- time is brain: urgent treatment makes a difference
- the Specialist Acute Stroke Service: what can be offered
- the RAPID5 protocol: the advantages of direct ambulance transfer

12.55 Voting session

☑ *Delegates will be invited to vote on the recommendations proposed by speakers*

13.15 Lunch and networking

Following opening addresses by **Rosie Winterton MP** and **Edward Leigh MP**, the NAO and the Department of Health will provide an update on the actions to date, together with an analysis of the future potential for stroke services, to provide context for the rest of the conference programme. You will hear from practitioners from across the UK, Australia and Sweden who have innovated stroke services in both acute and post-acute care.

You'll be asked to feedback your thoughts on panel recommendations and take part in voting sessions, the results of which will be summarised in a report after the conference.

The conference also includes a summary of the results from the **2006 National Sentinel Organisational Audit** from Tony Rudd, Stroke Programme Director, The Royal College of Physicians, before closing with feedback from the conference suggestions board and closing remarks from The Department of Health.

Drinks reception to celebrate success and network with colleagues

The National Audit Office invite you to a drinks reception after the conference in which you can discuss ideas and network with colleagues.

Afternoon Chair Professor Sally Byng *Chief Executive* Connect

IMPROVING THE PATIENT JOURNEY: FASTER ACCESS TO BETTER CARE AFTER STROKE

14.15 Success and progress in surviving stroke

Joe Korner *Director for Communications* The Stroke Association

- parliament and policy update: what has been happening over the last 18 months?
- increasing public awareness and saving lives: case study examples
- moving forward

14.30 A Swedish tour de force

Bo Norrving *Professor in Neurology* Lund University Hospital, Sweden

- comprehensive stroke units: the core facilities for early care and rehabilitation
- achieving continuity in the subsequent chain of care
- quality control: an integral part of services

14.55 An English tour de force

Helen Rodgers *Reader in Stroke Medicine* Newcastle

- early supported discharge (ESD) services provide co-ordinated discharge and home based rehabilitation and care
- provision of a stroke ESD team can significantly reduce length of stay
- ESD is valued by stroke patients and increases their chances of being independent in the longer term

15.20 Voting session

☑ *Delegates will be invited to vote on the recommendations proposed by speakers*

15.40 Tea and exhibition

16.10 Evidence that stroke services are improving: results from The 2006 National Sentinel Organisational Audit

Anthony Rudd *Stroke Programme Director, Clinical Effectiveness and Evaluation Unit* The Royal College of Physicians

- progress to date and the remaining challenges
- improving stroke services: how stroke professionals can help
- learning lessons from cardiologists

16.55 Audience comments: feedback from suggestions board

Jess Hudson *Manager Health VFM Audit* National Audit Office

17.05 Closing remarks: next steps for moving forward

Roger Boyle CBE *National Clinical Director for Stroke* Department of Health

17.15 Drinks reception and networking

"Until recently, stroke has been treated as going with the territory of growing old and has certainly not been given the same level of priority and resources as coronary heart disease and cancer. It is welcome news that, in the light of the National Audit Office report, the Department of Health has now accepted the need for progress… and has agreed that implementing the NAO recommendations might save as many as ten more lives a week."

Edward Leigh MP, Chairman of the Public Accounts Committee

APPENDIX THREE

Make suggestions for our follow-up study

"I'VE ASKED THE NATIONAL AUDIT OFFICE TO REPORT BACK ON STROKE TO THE COMMITTEE BEFORE THE END OF THE CURRENT PARLIAMENT SO, WITHIN THE NEXT 2 OR 3 YEARS WE WILL COME BACK TO THIS SUBJECT, WE WILL SEE WHETHER ALL THESE REASSURANCES THAT HAVE BEEN GIVEN TO US BY THE DEPARTMENT, HAVE ACTUALLY COME TO FRUITION AND WE WILL HOLD THEM, ON YOUR BEHALF, TO ACCOUNT"

Source: Edward Leigh, Chairman of the Committee of Public Accounts, speaking at the NAO conference (19th October 2006)

We have been asked to compile a second report on the provision of stroke care in England before the end of the current Parliament. Delegates at the conference were invited to make suggestions as to what further issues we should examine. Some of those suggestions included:

"Community services are very threatened at the moment and steps should be taken to protect them."

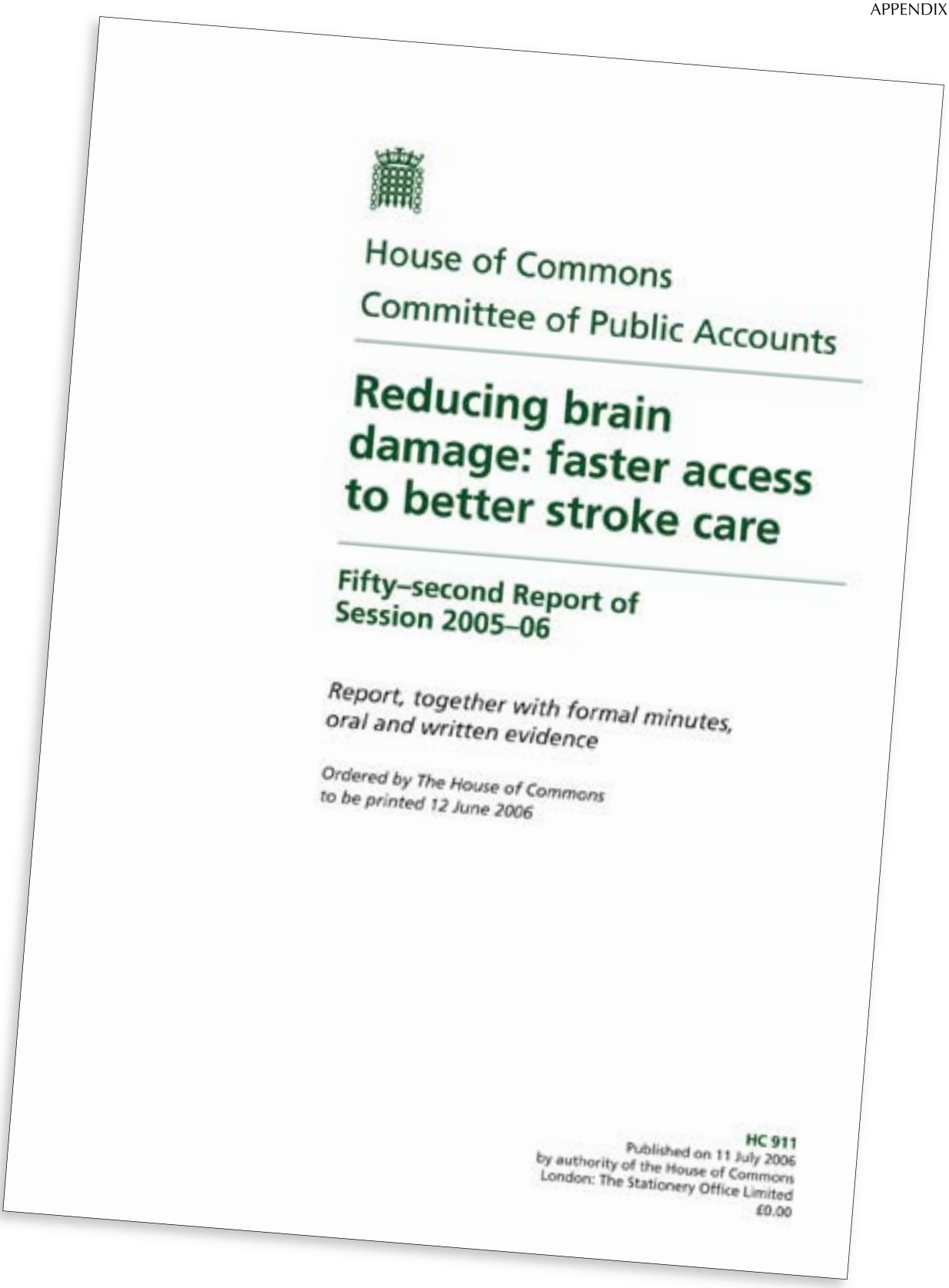
"Has the idea of telemedicine been properly considered, especially in rural areas? A manned teleradiology centre, for example, so CT scan can be assessed?"

"Care for years (care packages) vs Rehabilitation (therapy) for a short period – which is more cost effective?"

"I notice there was very little representation of the key workers who provide rehab (i.e. therapists & nurses) today. They work with patients up to 2 years – are their views heard?"

If you have any suggestions regarding what evidence we should be collecting for our next audit, we would welcome your input.

Please write to: **stroke@nao.gsi.gov.uk**



House of Commons
Committee of Public Accounts

Reducing brain damage: faster access to better stroke care

Fifty–second Report of Session 2005–06

Report, together with formal minutes, oral and written evidence

Ordered by The House of Commons to be printed 12 June 2006

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APPENDIX FOUR

The Government's Treasury Minute response to the Committee of Public Accounts report

Committee of Public Accounts Report Recommendation

1 STROKE IS THE THIRD BIGGEST CAUSE OF DEATH IN ENGLAND, AFTER HEART DISEASE AND CANCER. IT IS ALSO THE LEADING CAUSE OF ADULT DISABILITY. ALTHOUGH HISTORICALLY STROKE HAS BEEN SEEN AS AN INEVITABLE RISK OF GROWING OLD, WITH LITTLE TO BE DONE FOR STROKE PATIENTS OTHER THAN TRYING TO MAKE THEM COMFORTABLE, A QUARTER OF STROKES OCCUR IN PEOPLE UNDER THE AGE OF 65. FAST AND EFFECTIVE ACUTE TREATMENT, AND HIGH QUALITY REHABILITATION, CAN SIGNIFICANTLY REDUCE DEATH AND DISABILITY.

Government's Treasury Minute Response

The Department of Health agrees with this conclusion. Recent evidence has shown that a number of interventions can have a significant impact on the number of people who die or are seriously disabled as a result of a stroke. These include clot-dissolving treatment (thrombolysis) following a computerised tomography (CT) scan to determine the type of stroke suffered; admission to a stroke unit; and early supported discharge.

The Department of Health has responded to this emerging evidence base by developing Action on Stroke Services: an Evaluation Toolkit (ASSET). ASSET is designed to help health providers understand how they can improve stroke services by reviewing performance compared with other providers, and identifying the positive impact on patient outcomes and efficiency from four specific service interventions. Those interventions are thrombolysis, admission to a stroke unit, early supported discharge and rapid referral to carotid surgery via a one-stop Transient Ischaemic Attack (TIA) clinic.

Building on these recent developments, the Department of Health is developing a national stroke strategy to be published in Autumn 2007. This will cover prevention of strokes as well as fast and effective acute treatment and high quality rehabilitation.

Committee of Public Accounts Report Recommendation

II STROKE COSTS THE ECONOMY £7 BILLION A YEAR, INCLUDING £2.8 BILLION IN DIRECT CARE COSTS TO THE NHS. STROKE COSTS THE NHS MORE THAN HEART DISEASE, AND SHOULD RECEIVE THE PRIORITY WARRANTED BY ITS IMPACT AND COST. TO RAISE THE PROFILE OF STROKE WITH COMMISSIONERS AND CLINICIANS, THE DEPARTMENT OF HEALTH SHOULD WORK WITH THE HEALTHCARE COMMISSION AND THE ROYAL COLLEGE OF PHYSICIANS TO DEVELOP BENCHMARKS FOR STROKE CARE – FOR EXAMPLE THE PROPORTION OF SUSPECTED STROKE PATIENTS RECEIVING A BRAIN SCAN WITHIN THREE HOURS, OR THE PROPORTION OF STROKE PATIENTS BEING TREATED ON A STROKE UNIT.

Government's Treasury Minute Response

The Department of Health accepts that the high cost and impact of stroke, together with the more robust evidence base now available, warrant action to ensure that resources are used efficiently to improve outcomes for stroke patients. The National Service Framework for Older People has driven forward significant improvements in stroke services and set a standard that has ensured that there is an infrastructure in place in all hospitals. In light of recent evidence, Ministers have asked Professor Roger Boyle, who implemented the National Service Framework for Coronary Heart Disease, to develop a new national stroke strategy to improve stroke services. Professor Boyle will draw on the experience of addressing similar issues in redesigning the acute care pathway for coronary heart disease to accelerate access to treatment.

The Healthcare Commission funds the Royal College of Physicians (RCP) National Sentinel Stroke Audit, which takes place every two years. This audit includes key performance indicators, including the proportion of stroke patients being treated on a stroke unit, which enables Trusts, and others, to benchmark performance against the national average. The audit continues to evolve and the Department Of Health will be working with the RCP and the Healthcare Commission, as part of the work to develop the national stroke strategy, to consider any future changes.

The stroke toolkit, ASSET, enables Trusts to benchmark themselves against other Trusts in terms of key indicators as well as demonstrating the benefits of improving performance through key interventions. ASSET uses data from the RCP audit as well as data from Hospital Episodes Statistics.

The Department will be raising the profile of stroke with commissioners by publishing a commissioning guide for stroke later in the year, which will advise commissioners on key issues to consider when commissioning stroke services to ensure a good quality stroke service. This will be accompanied by a version of ASSET developed specifically to support commissioners.

The Department of Health has asked the National Institute for Health and Clinical Excellence (NICE) to develop a guideline that will cover acute treatment of stroke. This will be published in 2008 and will provide a benchmark against which Trusts will be monitored by the Healthcare Commission as part of the Annual Health Check process.

Committee of Public Accounts Report Recommendation

III IN MOST EUROPEAN COUNTRIES STROKE IS REGARDED AS A NEUROLOGICAL CONDITION FIRST AND FOREMOST, RATHER THAN AN OLDER PEOPLE'S CONDITION. IN SWEDEN, ON AVERAGE PATIENTS TAKE JUST THREE TO FIVE HOURS TO ARRIVE ON A STROKE UNIT WITH EARLY ASSESSMENT OF AND ACCESS TO REHABILITATION. IN ENGLAND THE MEDIAN TIME TO ARRIVAL ON A STROKE UNIT IS TWO DAYS AND ACCESS TO REHABILITATION IS PATCHY WITHIN AND BETWEEN HOSPITALS. IN LEADING HOSPITALS IN AUSTRALIA, THROMBOLYTIC (CLOT-BUSTING) DRUGS ARE GIVEN TO AROUND NINE PER CENT OF ELIGIBLE PATIENTS COMPARED TO ONE PER CENT IN ENGLAND. THE DEPARTMENT SHOULD BENCHMARK PERFORMANCE ON THESE KEY PERFORMANCE INDICATORS WITH OTHER LEADING COUNTRIES TO IDENTIFY AREAS WHERE FURTHER LESSONS MAY BE LEARNED.

Government's Treasury Minute Response

The Department of Health accepts the importance of learning from the experience of other countries in the development of our strategy. The Department of Health is working with colleagues who helped develop a new stroke strategy in Canada and will consider the examples of good practice in Sweden and Australia highlighted by the Committee. There are also examples in England, as in Australia, of thrombolysis being delivered to a much higher proportion of eligible patients than the national average and of rehabilitation being delivered in a well-coordinated way. Some centres in the UK are world class and the strategy will aim to bring all Trusts up to the level of the best.

Benchmarking against other countries on specific indicators can be unreliable and the World Health Organisation advises caution: "The comparability of data between countries is also limited, owing to difference in definitions and recording practices." However, the Department is keen that data on international best practice is used to inform the development of stroke services in England. For example, the Department is working on a tool for commissioners that will compare the performance of individual hospitals against an aspirational level that has been informed by international best practice.

Committee of Public Accounts Report Recommendation

IV THE LAST CLINICAL AUDIT OF STROKE SHOWED THAT ONLY 22 PER CENT OF STROKE PATIENTS HAD A SCAN ON THE SAME DAY AS THEIR STROKE, AND MOST WAITED MORE THAN TWO DAYS. SCANS FOR STROKE PATIENTS ARE BEING DELAYED, THOUGH 'TIME LOST IS BRAIN LOST', AND RESEARCH SHOWS THAT SCANNING PATIENTS IMMEDIATELY COSTS LESS, AND RESULTS IN BETTER PATIENT OUTCOMES THAN SCANNING LATER. ALL SUSPECTED STROKE PATIENTS SHOULD BE SCANNED AS SOON AS POSSIBLE AFTER ARRIVAL AT THE ACUTE HOSPITAL, IDEALLY WITHIN THREE HOURS, AND NONE SHOULD WAIT MORE THAN 24 HOURS FOR A SCAN. ALL ACCIDENT AND EMERGENCY AND RADIOLOGY DEPARTMENTS SHOULD HAVE PROTOCOLS IN PLACE FOR THE RAPID ADMITTANCE AND REFERRAL FOR SCANNING OF STROKE PATIENTS.

Government's Treasury Minute Response

The Department of Health agrees with the recommendation. The RCP guidelines state "brain imaging should be undertaken as soon as possible in all patients, within 24 hours at most of onset unless there are good clinical reasons for not doing so" and the Department of Health is taking action to support Trusts to achieve this. ASSET reinforces the value of immediate scanning for stroke patients, particularly its importance for delivering thrombolysis, and demonstrates the improvements to outcomes and lengths of stay that can be made by putting a system in place to enable this.

The evidence that scanning stroke patients immediately is the most cost-effective strategy was published in 2004. Stroke services will need time to assimilate this knowledge, although some centres are already routinely providing CT scans within four hours for stroke patients. ASSET highlights the benefits of early scanning as well as the fact that, as most stroke patients receive a brain scan at some point in their stay, providing an early scan will, in most cases, not be an additional cost.

One of the project groups developing recommendations for the national stroke strategy is looking at the emergency response to stroke. This group has been tasked with recommending how to overcome cultural and organisational barriers to delivering urgent scanning to stroke patients where appropriate. Agreed protocols for rapid admittance and referral for scanning are one way of achieving this and some stroke services are already doing this. The group will also cover the need for protocols for rapid transfer of stroke patients by the ambulance service.

Committee of Public Accounts Report Recommendation

V THERE ARE 640 PATIENTS PER STROKE CONSULTANT, COMPARED WITH 360 PATIENTS PER CARDIAC CONSULTANT. THE LIMITED NUMBER OF HEALTH PROFESSIONALS WITH TRAINING IN STROKE IS A BARRIER TO PROVIDING HIGH QUALITY ACUTE CARE AND REHABILITATION. FUTURE WORKFORCE PLANNING TARGETS SHOULD ENABLE THE NHS TO MOVE TO A POSITION WHERE THERE ARE AS MANY STROKE CONSULTANTS PER PATIENT AS HEART DISEASE CONSULTANTS PER PATIENT.

Government's Treasury Minute Response

The Department accepts that increasing the number of health professionals with training in stroke is important to increasing the quality of care and rehabilitation stroke patients receive. For many years, stroke was viewed as an inevitable part of getting old and it is only in recent years that experts have come to a consensus that much can be done to prevent and treat stroke. Stroke has only recently become a medical sub-specialty, unlike coronary heart disease, which has been a major focus of the specialty of cardiology for over 80 years.

The training programme for stroke consultants only takes about one year, which presents opportunities to increase numbers relatively quickly. The Department of Health has begun discussions with the relevant bodies on options to achieve this. One mechanism is to convert vacant geriatric training posts into stroke training posts. Earlier this year the Specialty Advisory Committee for Geriatric Medicine agreed to review the suitability of any unfilled posts for transfer to stroke medicine.

One of the project groups developing recommendations for the national stroke strategy is looking at workforce issues. The group is looking at the full range of health and social care professionals that work with stroke patients, including both their number and their training. The group is considering different models of service provision and ways of working. Stroke teams should have the competencies and skills to deliver high quality care for stroke patients, but local services should have the freedom to determine the composition of the team that best provides those competencies. This may result in a different number of stroke consultant sessions compared to the current numbers of heart disease consultant sessions.

The Department of Health has moved away from setting central workforce planning targets, but is working closely with the Workforce Review Team, who carry out workforce planning on behalf of the NHS in England and the lead post-graduate dean for stroke, to ensure that the limitations caused by the current level of stroke consultants are factored into annual recommendations about planning priorities for the NHS.

Committee of Public Accounts Report Recommendation

VI HOSPITAL STAFF ARE NOT ALWAYS SUFFICIENTLY WELL INFORMED ON HOW TO RESPOND TO STROKE. THE EDUCATION AND TRAINING PROVIDED TO NEW TRIAGE NURSES AND JUNIOR DOCTORS SHOULD INCLUDE AWARENESS OF STROKE AND THE NEED FOR URGENT BRAIN SCANS FOR STROKE PATIENTS. THE DEPARTMENT SHOULD TRAIN STROKE CONSULTANTS TO INTERPRET SCANS AND MAKE IMMEDIATE TREATMENT DECISIONS. IT SHOULD ALSO CONTINUE TO DEVELOP ITS TELEMEDICINE PROGRAMME SO THAT, BY 2007, STAFF MANAGING STROKE PATIENTS CAN ACCESS NEURORADIOLOGICAL EXPERTISE REMOTELY.

Government's Treasury Minute Response

The Department of Health accepts this conclusion. The RCP audit shows that continuing education in stroke for staff on stroke units has improved in recent years, from 74 per cent in 2002 to 92 per cent in 2006 for qualified staff and from 64 per cent in 2002 to 88 per cent in 2006 for unqualified staff. However, in 2006 only 57 per cent of sites had continuing education in stroke for qualified staff on other wards and 55 per cent for unqualified staff.

All qualified nurses and doctors will have a basic awareness of stroke as part of their training. It will be important that all staff, including triage nurses and doctors, involved in the initial identification stage are well informed on how to respond to stroke. This will require a cultural change to ensure that stroke is regarded as urgent and as part of this the national stroke strategy will recognise the importance of treating stroke as a medical emergency. The workforce project group developing recommendations for the strategy are looking at the education and training provided to all staff who work with stroke patients to build on recent improvements.

Training on the interpretation of scans is currently available for a range of clinicians. New roles have been introduced, including advanced and consultant radiographers. This means that radiographers are being trained to interpret and report specific types of scans. Training is also planned for clinicians who are not radiologists, for example, some senior doctors working in A&E Departments will be trained to interpret scans undertaken on suspected stroke patients. The Department of Health is working with NHS Employers on the Large Scale Workforce Change project to ensure that neuroradiology skill development is prioritised. In addition, an imaging workforce strategy is being developed as part of the National Imaging Work Programme. This will be available early in 2007.

Deployment of the Picture Archiving and Communications System (PACS), currently underway, will enable the development of remote reporting via a telemedicine programme. It will enable staff managing stroke patients to access neuro-radiological expertise remotely. PACS should be fully implemented across secondary care services next year.

Committee of Public Accounts Report Recommendation

VII BY INCREASING THE PROPORTION OF STROKE PATIENTS WHO SPEND THE MAJORITY OF THEIR TIME IN HOSPITAL ON A STROKE UNIT BY 25 PER CENT, AROUND 550 DEATHS PER YEAR COULD BE PREVENTED. ALTHOUGH MOST HOSPITALS NOW HAVE SUCH A UNIT, ONLY AROUND TWO THIRDS OF STROKE PATIENTS SPEND TIME ON ONE, AND WHAT CONSTITUTES A STROKE UNIT VARIES CONSIDERABLY BETWEEN HOSPITALS. ALL STROKE PATIENTS SHOULD BE ADMITTED TO A SPECIALIST STROKE UNIT AS SOON AS POSSIBLE FOLLOWING DIAGNOSES OF THEIR STROKE. THE DEPARTMENT NEEDS TO COMMUNICATE CLEAR GUIDELINES FOR AN ACCEPTABLE STROKE UNIT AND PRIMARY CARE TRUSTS SHOULD DELIVER ACUTE STROKE CARE THROUGH A STROKE UNIT. THAT MEETS THESE GUIDELINES. THE DEPARTMENT SHOULD SET CHALLENGING TARGETS TO IMPROVE THE PROPORTION OF PATIENTS TREATED ON A STROKE UNIT.

Government's Treasury Minute Response

The Department of Health agrees that it is desirable that all stroke patients should be admitted to a stroke unit as soon as possible after initial assessment.

The National Service Framework for Older People (2001) has driven forward improvements so that all Trusts that treat stroke patients now have a specialist stroke service. These services were unusual ten years ago. Recent evidence has demonstrated the benefits of that specialist stroke service being delivered on a dedicated ward. There have been significant increases in the number of stroke units since this evidence was published in 2004. The RCP audit shows that between 2004 and 2006 the proportion of Trusts that treat stroke patients that have a stroke unit increased from 82 per cent to 96 per cent. It is expected that the proportion of stroke patients being treated on a stroke unit will also have increased over this period. The results of the second phase of the audit, which covers more detailed clinical data including whether a patient stayed on a stroke unit, will be published in March 2007.

ASSET enables Trusts to model the improvements in outcomes and lengths of stay that can be made by increasing the proportion of stroke patients treated on a stroke unit. Improved care results in shorter stays for patients and the greater patient throughput enables more stroke patients to benefit from stroke unit care. This builds on the information provided through the RCP audit by specifying the benefits to the Trust of driving forward improvements.

The RCP gives guidance on what a stroke unit should include. The RCP highlights five characteristics that have been shown to be markers of stroke unit organisation and their audit records the proportion of units with these characteristics. In 2006, 95 per cent of stroke units had four or all five features compared with 90 per cent in 2004 and 72 per cent in 2002. The RCP has developed six further criteria for assessing the quality of an acute stroke unit using the consensus of an expert working group. The results of the RCP audit show that the proportion of Trusts with a stroke unit meeting five or six of the criteria has increased from 33 per cent to 41 per cent between 2004 and 2006. This shows that there has been progress, but there is still room for improvement.

The stroke commissioning guide that the Department will publish later in the year will assist Primary Care Trusts (PCTs) to ensure that the service they commission meets the appropriate standards by highlighting key issues to consider when commissioning stroke services. The Department of Health is also developing a toolkit for commissioners based on ASSET, which will enable PCTs to model the benefits to be gained by commissioning acute stroke care through a stroke unit that meets the RCP guidelines.

The Department of Health accepts that treatment on a stroke unit should be the norm, with the exception of a small number of patients – for example those receiving palliative care – who may be treated more appropriately in other settings. There are a range of levers for making change happen – from commissioning arrangements and inspections through to patient power and internal pressure from frontline staff working in stroke teams. The Department will be looking at which mechanisms are most suitable to achieve the range of objectives recommended by the expert project groups helping us to develop the strategy.

Committee of Public Accounts Report Recommendation

VIII THE RISK OF STROKE IN THE FOUR WEEKS FOLLOWING A TRANSIENT ISCHAEMIC ATTACK (TIA, 'MINI STROKE') IS AROUND 20 PER CENT. ALL PROVIDERS OF PRIMARY AND SECONDARY CARE SHOULD HAVE PROTOCOLS IN PLACE FOR THE REFERRAL OF SUSPECTED OR CONFIRMED TIA PATIENTS, REFLECTING THE ROYAL COLLEGE OF PHYSICIANS' GUIDELINES THAT ALL PATIENTS IN WHOM A DIAGNOSIS IS SUSPECTED SHOULD BE ASSESSED AND INVESTIGATED WITHIN SEVEN DAYS. THE INDICATOR IN THE QUALITY AND OUTCOME FRAMEWORK FOR ASSESSING PRIMARY CARE PRACTICES' PERFORMANCE IN RELATION TO SUSPECTED STROKE PATIENTS AND WHICH SIMPLY STATES "REFERRAL FOR A SCAN" SHOULD BE AMENDED TO REFLECT THE TIME BOUND ELEMENT IN THE ABOVE PROTOCOL.

Government's Treasury Minute Response

The Department of Health agrees with the recommendation that all primary and secondary care providers should have protocols for the referral of suspected or confirmed TIA patients. The National Service Framework for Older People included a milestone that by April 2004 PCTs should have ensured that every general practice is using a protocol agreed with local specialist services for the rapid referral and management of those with TIA. A review by the Healthcare Commission of progress in implementing the National Service Framework, published in March this year, showed that all of the communities inspected had agreed protocols in place. The Healthcare Commission monitors Trusts' progress in implementing National Service Frameworks as part of their annual review process.

The RCP audit shows that the number of TIA clinics has been increasing and the waiting times for those clinics have been falling. 78 per cent of Trusts now have a TIA clinic compared with 65 per cent in 2004. The average wait for a TIA clinic has fallen from 14 days in 2004 to 12 days in 2006. There is still some way to go to ensure that all patients with a suspected TIA are seen within seven days, but the progress is encouraging.

The Quality and Outcomes Framework (QOF) has proved an important lever in improving the prevention of stroke and the additional 30 points on atrial fibrillation, a key risk factor, are a further welcome development. However, it must be noted that the Department does not have control over amendments to the points and indicators within the Framework. This is negotiated between NHS Employers, the independent employers' organisation, and the British Medical Association. Time bound referral is something to consider through the QOF revisions in future years. However, the first priority must be to ensure rapid access services are in place in all areas of the country. One of the project groups developing recommendations for the national stroke strategy has been tasked with looking at improving services for patients who have had a TIA or minor stroke.

It will also be important to increase GPs' general understanding of stroke to ensure they direct patients experiencing symptoms to call 999. The project group developing recommendations on prevention and public awareness for the national stroke strategy is also considering raising awareness amongst health professionals.

Committee of Public Accounts Report Recommendation

IX BY REDUCING TO 14 DAYS THE MAXIMUM WAITING TIME FOR SURGERY FOR PATIENTS WITH NARROWING (STENOSIS) OF THE CAROTID ARTERIES IN THE NECK, AROUND 250 STROKES A YEAR COULD BE PREVENTED, YIELDING SAVINGS TO THE NHS OF AROUND £4 MILLION. TIA PATIENTS WITH DIAGNOSED STENOSIS SHOULD NOT HAVE TO WAIT LONGER THAN 14 DAYS AFTER THEIR TIA FOR SURGERY.

Government's Treasury Minute Response

The Department of Health agrees with this recommendation. Research shows that the benefit of surgery is maximal when patients undergo surgery within the first two weeks after their TIA.

ASSET demonstrates the improvements in outcomes and lengths of stay that can be achieved though all patients accessing a one-stop TIA clinic within seven days of their TIA, which is the first step to achieving timely surgery. It also provides local data on carotid surgery to enable Trusts to see the average waiting time for a carotid endarterectomy. The RCP is currently conducting a national audit to assess the process of care and outcomes from carotid endarterectomy against the available evidence base, which will provide a fuller picture of the current position.

The project group developing recommendations for the national stroke strategy on services for people who have had a TIA or minor stroke are looking at improving provision of rapid access to TIA services. The group is working on options for ensuring that referral to surgery is much more rapid than is currently the case.

Committee of Public Accounts Report Recommendation

X THREE TIMES MORE WOMEN DIE OF A STROKE THAN OF BREAST CANCER EACH YEAR, AND STROKE IS THE MAJOR CAUSE OF ADULT DISABILITY, BUT PUBLIC AWARENESS OF STROKE AND HOW TO PREVENT IT IS LOW. THE DEPARTMENT SHOULD RUN AN AWARENESS CAMPAIGN FOR STROKE, FOCUSSING ON ITS SYMPTOMS AND THE FACT THAT IT IS A MEDICAL EMERGENCY REQUIRING A 999 RESPONSE. IN DEVELOPING THIS CAMPAIGN, IT SHOULD CONSIDER PARTICULARLY HOW TO ENGAGE WITH GROUPS AT HIGHER RISK OF STROKE, SUCH AS PEOPLE OF AFRO-CARIBBEAN AND SOUTH ASIAN ETHNICITY.

Government's Treasury Minute Response

The Department of Health accepts that awareness of the symptoms of stroke needs to be raised both amongst the workforce and the public. One of the project groups has been tasked with developing recommendations on how public awareness of stroke in general can be raised and what the key messages should be. Consideration of mechanisms for reaching different audiences, including people from African-Caribbean and South Asian communities, will be part of this work.

The Department of Health has funded a project by The Stroke Association to produce and promote information leaflets targeted to the African-Caribbean community. The Department of Health is currently funding a further project by The Stroke Association, targeting South Asian communities, to produce written and recorded information – in Punjabi, Bengali, Gujarati, Urdu and Hindi – about practical steps individuals can take to reduce their risk of stroke. The Food Standards Agency is also working with The Stroke Association on a project looking at the eating habits and salt intake of African-Caribbean, South Asian and Chinese populations.

The Department of Health has identified all the relevant areas of its existing public health communications activity, and has already begun to include specific messages about stroke where appropriate, for example in its tobacco campaigns work. Other channels are being used, like the Department's public facing health promotion magazines (Prime, Your Life, Fit) which carry features about the risk factors, and the signs and symptoms of stroke. Information about stroke has also been updated and given more prominence on the NHS Direct and Direct Gov websites.

Committee of Public Accounts Report Recommendation

XI STROKE SURVIVORS AND THEIR CARERS NEED SUPPORT FROM MANY DIFFERENT HEALTH AND SOCIAL SERVICES, BUT ABOUT 50 PER CENT OF CARERS ARE NOT RECEIVING NEEDS ASSESSMENTS. THE DEPARTMENT SHOULD IMPROVE THE PROVISION OF INFORMATION TO STROKE CARERS, SO THEY BECOME AWARE OF THE SERVICES AVAILABLE TO SUPPORT THEM. COMMUNITY SERVICES SHOULD BE IMPROVED SO THAT PATIENTS IN THE COMMUNITY ARE NOT OVERLOOKED. THE DEPARTMENT SHOULD TAKE INTO ACCOUNT IN PARTICULAR THE NEEDS OF STROKE SURVIVORS WHO LIVE ON THEIR OWN, AND MAY BE PARTICULARLY VULNERABLE TO BEING OVERLOOKED BY HEALTH AND SOCIAL CARE SERVICES.

Government's Treasury Minute Response

The Department of Health agrees with this recommendation. The Government recognises the valuable contribution and the important concerns of carers, and has taken action through the National Strategy for Carers to ensure that the support needed by carers, including those caring for someone who has had a stroke, is available. The Government has given carers a right to an assessment of their needs and taken action to ensure that carers are aware of this right. Some carers will choose not to take up the offer of an assessment, but the Government has provided the framework for needs to be assessed and met.

The White Paper *Our Health, Our Care, Our Say* published in January 2006 sets out a range of further measures to improve support for carers. The National Strategy for Carers will be updated and extended, a helpline will be established to offer advice to carers and an Expert Carers' Programme will be developed which will provide training for carers to develop the skills they need. All these measures will benefit those who are caring for someone who has had a stroke.

High quality community services are crucial to improving outcomes and quality of life for people who have had a stroke. The number of community stroke teams is increasing, although there is still some way to go. The RCP audit shows that the percentage of Trusts in England with a community stroke team increased from 27 per cent in 2004 to 34 per cent in 2006. *Our Health, Our Care, Our Say* sets out a new strategic direction for improving the health and well-being of the population, and focuses on a strategic shift to locate more services in local communities that are closer to people's homes. This focus on community services will benefit stroke patients.

Stroke survivors who live on their own should have equal access to stroke services as other stroke survivors. *Our Health, Our Care, Our Say* recognises the importance of outreach services to support those who find it difficult to access services, which will include those that live alone.

One of the project groups developing recommendations for the national stroke strategy is looking at services for stroke survivors once they have left hospital. This group will be considering the rehabilitation needs of stroke survivors as well as how to improve access to practical support, advice and information for both stroke survivors and carers.

Committee of Public Accounts Report Recommendation

XII MOST OF THE BURDEN OF STROKE OCCURS AFTER DISCHARGE BUT POST-HOSPITAL SUPPORT SERVICES FOR STROKE PATIENTS ARE OFTEN DIFFICULT TO ACCESS. DURING THEIR HOSPITAL STAY PATIENTS HAVE ACCESS TO ON CALL HELP AND CARE BUT ON DISCHARGE THE TRANSITION FROM HOSPITAL TO HOME CAN BE TRAUMATIC. AROUND HALF OF STROKE PATIENTS RECEIVE REHABILITATION SERVICES THAT MEET THEIR NEEDS IN THE SIX MONTHS FOLLOWING DISCHARGE, FALLING TO 25 PER CENT 12 MONTHS AFTER DISCHARGE. THE DEPARTMENT SHOULD EVALUATE THE MERITS OF EARLY SUPPORTED DISCHARGE INITIATIVES AND OTHER WAYS OF IMPROVING ACCESS TO THERAPIES, AND PROMOTE THE EARLY ADOPTION OF THOSE THAT CAN BE SHOWN TO REDUCE HOSPITAL STAY AND IMPROVE PATIENTS' CHANCE OF RECOVERY.

Government's Treasury Minute Response

The Department agrees with this recommendation. The benefits of Early Supported Discharge (ESD) for people with moderate levels of disability as a result of stroke have been demonstrated in research published in 2005. The provision of an ESD team is one of the interventions included in ASSET. Trusts can use ASSET to see the impact introduction of an ESD team in their area would have on outcomes for their patients and lengths of stay in hospital. ASSET is being used by local NHS Trusts to make the case for introducing ESD teams in their area.

However, more knowledge is needed about the best service delivery model for rehabilitation for those with mild and severe disabilities. The Department of Health is currently exploring options for evaluation of services for these groups of stroke survivors. A small working group is being established as part of the strategy work to specifically consider ESD schemes.

The project group developing recommendations on services for stroke survivors once they have left hospital for the national stroke strategy is looking at how to ensure that rehabilitation services, and other support services, meet the needs of people who have had a stroke in the longer term as well as during the transition period.

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