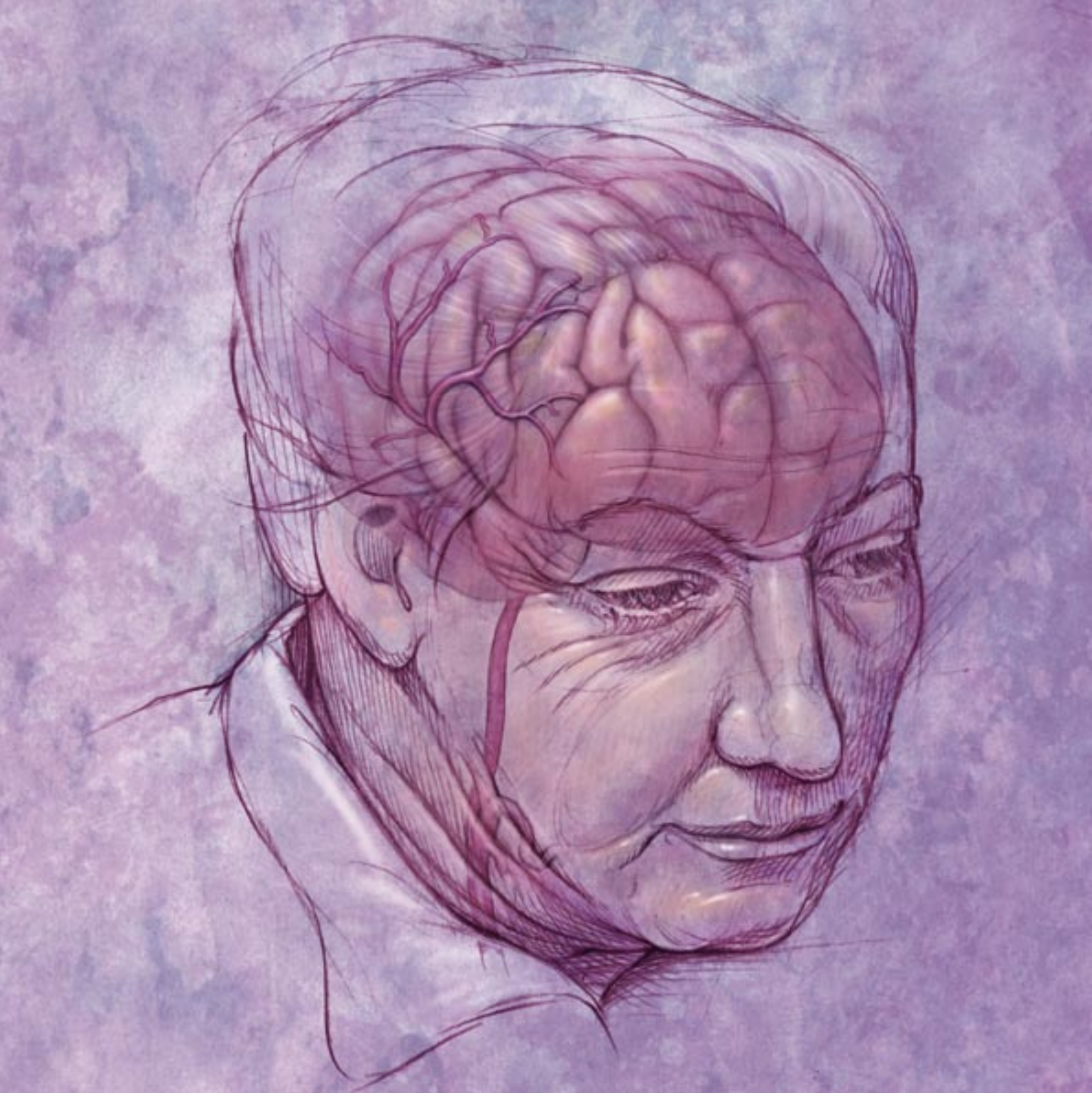

National Audit Office

DEPARTMENT OF HEALTH

Reducing Brain Damage: Faster access to better stroke care

REPORT BY THE COMPTROLLER AND AUDITOR GENERAL | HC 452 Session 2005-2006 | 16 November 2005

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National Audit Office

DEPARTMENT OF HEALTH

Reducing Brain Damage: Faster access to better stroke care

LONDON: The Stationery Office
£11.25

Ordered by the
House of Commons
to be printed on 14 November 2005

This report has been prepared under Section 6 of the National Audit Act 1983 for presentation to the House of Commons in accordance with Section 9 of the Act.

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10 November 2005

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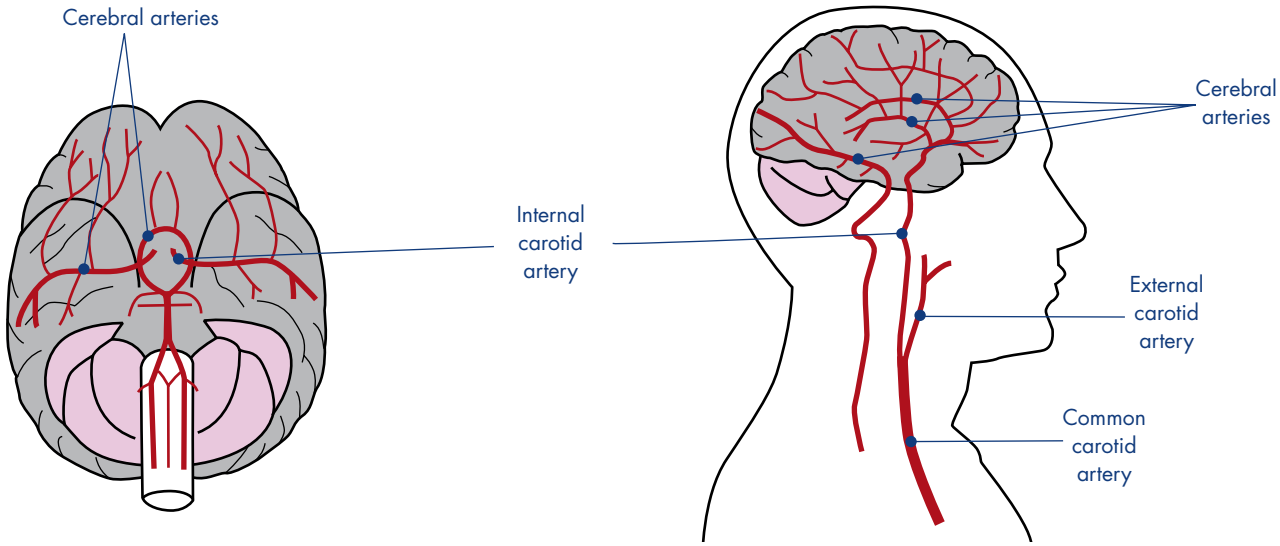
Photographs courtesy of Justine Desmond Photography, and with thanks to the National Hospital of Neurology and Neurosurgery, London.

SUMMARY

1 A stroke is the brain equivalent of a heart attack. Stroke is one of the top three causes of death in England and a leading cause of adult disability. Approximately 110,000 strokes and a further 20,000 transient ischaemic attacks (TIAs) occur in England every year. There are at least 300,000 people in England living with moderate to severe disabilities as a result of 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. **Figure 2** outlines other key facts about stroke.

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

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 for stroke patients the chance of dying from their stroke has remained constant (at around 24 per cent) over that time, while for heart attack patients the chance of dying from their heart attack has declined by about 1.5 per cent each year.
- There are more than 900,000 people who have had a stroke living in England. Around half of stroke survivors are left dependent on others for everyday activities.
- There is high variability in the average lengths of stay across hospitals. The average length of stay is 28 days, which is a reduction from the 34 day average in 2001. At any one time one in five acute hospital beds, and a quarter of long term beds, are occupied by stroke patients.[1] Stroke patients occupy one of the largest numbers of acute hospital bed days – over 2.6 million per year – of any patient group.
- 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.[2]
- Stroke affects young people as well as old: a quarter of strokes occur in people aged under 65. People of African or Caribbean ethnicity are at higher risk of stroke, especially of having strokes while young. Incidence rates of first ever stroke adjusted for age and sex have been found to be twice as high in black people compared with white people.
- 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 than patients that stay on a general medical ward.

Source: National Audit Office analysis

2 The cost of stroke to both the NHS and the wider economy is clearly high, and the number of people living with or at risk of stroke is significant. We therefore examined whether the NHS is providing effective and high quality stroke care services in England, in terms of acute response, rehabilitation and prevention, and whether the Department of Health (the Department) is managing and supporting the programme of stroke care well. Key parts of our methodology included: a public awareness survey; analysis of data on GP practices; a review of the 2004 National Sentinel Stroke Audit (the Sentinel Audit) published by the Royal College of Physicians; a survey of hospitals to update Sentinel Audit data; economic research to model the burden of stroke and the benefits of different interventions and prevention measures; case study visits; and a patient/carer web forum and focus groups. Further details on our methodology are at Appendix 1.

Overall conclusions

3 Historically stroke has been seen as an inevitable risk of growing old, with little to be done for those who suffer a stroke other than trying to make them comfortable. However, recent clinical, technological and organisational developments in acute 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. The Department has responded positively to the emerging evidence base, for example it included some stroke milestones in the Older People's National Service Framework, and there have been real gains in the provision of organised stroke services in NHS hospitals. However, progress in the efficiency and effectiveness of treatment provided to stroke patients varies considerably, with some pockets of excellence but

also areas where the response is not as fast and effective as it could be. Overall we have identified scope for potential savings as a result of more efficient practice: some £20 million annually, 550 deaths avoided and over 1,700 people fully recovering from their strokes each year who would not otherwise have done so. More specifically:

a A key feature of effective stroke care is rapid access to specialised acute stroke services, including timely brain scanning. A delay in treatment increases the risk of death and disability. We identified scope for the NHS to prevent more strokes and drastically improve treatment, care and outcomes by re-organising services within hospitals and using more wisely the capacity that is available.

b For most patients and carers the impact of stroke starts following discharge from hospital. Over a third of stroke patients are left dependent or moderately disabled requiring support, rehabilitation and nursing care. Many patients feel abandoned. 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 care sector means that patients do not receive the professional support they need. As a result there is a reliance on informal carers and the voluntary sector.

c For every patient who experiences a stroke, the cost to the NHS in the UK is around £15,000 over five years, and when informal care costs are included this increases to around £29,000.[3] Campaigns to reduce smoking and improve diet should have a positive impact on primary stroke prevention. However, public awareness of stroke remains very low, as is awareness of the need for an emergency response if stroke is suspected. The new GPs' contract[a] has improved the prevention of stroke although some risk factors are still under-treated. There are also inefficiencies in the organisation of outpatient care where improvements, particularly in accessing scans and specialists, would ensure an appropriate response to transient ischaemic attacks (TIAs) and help prevent secondary strokes.

Key Findings

The Department has encouraged improvements in stroke services but has not given it as high a priority as other conditions

4 In setting out plans for investing in developing and improving health services it was necessary for the Department to set priorities for action due to the limited resources and management time available. The initial priorities focused on cancer and CHD with the Department publishing separate dedicated strategies to modernise services in these areas, and there is evidence of progress in key areas.[4, 5] The framework for delivering stroke care, however, is part (Standard Five) of the *National Service Framework for Older People* (2001). Its inclusion in the Older People's framework has helped kick-start the widespread development of stroke services in most NHS hospitals. There is now scope to give stroke care increased priority given its impact and cost – the costs of stroke care are more than those for heart disease, and a quarter of strokes occur in people aged under 65.

5 In most European countries stroke is regarded as a neurological condition first and foremost, rather than an older people's condition. The Department's *National Service Framework for Long-term Conditions* (2005) focuses on the needs of patients with neurological conditions, including those who have neurological damage as a result of a stroke, although it does not specifically mention stroke other than to state that it is covered in the Older People's National Service Framework. Most people who survive a stroke will live for the rest of their lives with minor to major disabilities as a result, and will be dependent to varying degrees on health and social care. However, less than a fifth of the number of consultant sessions a week that the British Association for Stroke Physicians recommends are currently being provided for stroke patients.

a The General Medical Services contract for GPs sets out a Quality and Outcomes Framework under which GPs' remuneration is determined by how well they perform on a set of clinical outcome indicators for their patients.

6 There have been some welcome developments. In 2004 the Joint Committee on Higher Medical Training accredited stroke as a sub-specialty which means there is now a formal training structure for a career in stroke medicine. Since July 2004, the Department's Vascular Programme Board assumed responsibility for driving improvements in stroke services, and in 2005 the Department established a Stroke Research Network to coordinate and champion research in stroke.

An emergency response to stroke with efficient and effective acute care is generally lacking

7 Research shows that a fast response to stroke reduces the risk of death and disability. Our survey showed that many people do not know how to recognise the symptoms of stroke, or that the correct response if someone is suspected of having a stroke is to dial 999. The Stroke Association has recently introduced a campaign to alert the public to the symptoms of stroke and to call 999 if they suspect someone is having a stroke. The Ambulance Service Association has introduced training and guidance for paramedics in diagnosing and responding to stroke.

8 Coordination between stroke teams in hospitals and ambulance services can reduce the time between when a stroke starts and accessing a stroke specialist. However, only 16 per cent of hospitals have protocols in place with ambulance services for the rapid referral of stroke patients. In some services the protocol enables ambulances to take the patient direct to a stroke unit, helping to bypass any delay that might occur in the Accident and Emergency department.

9 The clinically optimal model of stroke care is care delivered in a specialised stroke unit, but the interpretation of what constitutes a stroke unit varies considerably between hospitals. The Department's 2001 target, that 100 per cent of all general hospitals should have a specialised stroke service by April 2004, has nearly been met in 2005. Hospitals told us that two-thirds of patients had access to good or very good specialised stroke services. However, the extent of clinical services provided varies widely (Figure 8 in main report), for example 54 per cent of dedicated stroke beds are rehabilitation only beds.

10 Overall, the number of patients treated on a stroke unit during their stay in hospital has increased – up from 36 per cent in 2001 to 47 per cent in 2004 – and the mean length of stay has fallen from 34 days in 2001 to 28 days in 2004. Despite this improvement, stroke units are of insufficient size, with only 41 per cent of patients in 2004 spending more than half of their stay there. Economic modelling suggests that if access to stroke units were 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.

11 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 brain imaging to diagnose the type of stroke is crucial because until this has happened treatment cannot commence safely. 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, an audit by the Royal College of Physicians found that in 2004 only 22 per cent of stroke patients had a scan on the same day as their stroke – indeed, most patients waited more than two days. Scans for stroke patients are being delayed, even though 'time lost is brain lost', and recent research shows that scanning all stroke patients immediately is the most cost-effective strategy.

12 CT scans show whether brain damage is caused by a clot or a haemorrhage, but there can be further 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 who can 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.

13 The development in the late 1990's of thrombolytic (clot-busting) drugs, which can reduce mortality and morbidity in eligible patients, was an important step forward in the acute treatment of stroke. Although such drugs have had a conditional license in England since April 2003, thrombolytic treatment is not yet a routine part of acute stroke care despite evidence showing it would benefit a significant minority of stroke patients. In leading hospitals in Australia around nine per cent of patients are thrombolysed and about 40 per cent of these patients then fully recover from their strokes. Rates of thrombolysis in England are below one per cent. Achieving rates of thrombolysis in England in line with those currently being achieved in leading Australian hospitals 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.

14 Current thrombolytic drugs should only be given within a few hours of the onset of stroke and the patient must have a brain scan to determine whether the treatment is possible. The low rate of thrombolysis in England is partly due to a lack of public awareness of the fact that stroke is a medical emergency, and that appropriate treatment within the first few hours can make the difference between recovery and serious disability. It is also partly due to the fact that Ambulance Trusts, Accident and Emergency departments, Radiology departments and specialist stroke teams do not routinely provide an effective, integrated emergency response to stroke that includes rapid triage and access to scanning.

Following discharge patients need improved access to rehabilitation and support services

15 Stroke patients require services and therapies from many disciplines in health and social care. If people do not get good rehabilitation after their stroke, such as early access to physiotherapy to restore movement, their paralysis or weakness can produce stiffness and spasticity which in turn can lead to painful spasms and abnormal posture. Many stroke survivors have difficulty speaking and communicating. However, access to professionals such as psychologists, dietitians, physiotherapists, occupational and speech therapists and social workers can be patchy within and between stroke units, even though access to social work and occupational therapy is likely to result in fewer delayed discharges. This is in strong contrast to the leading examples of rehabilitative care provided in Sweden.

16 A third of acute stroke patients are left dependent or moderately disabled. During their hospital stay, patients have access to on-call help and care, however on discharge they have to adjust suddenly to the impacts of the stroke on their life at home. Hospitals told us that around half of patients receive rehabilitation services that meet their needs in the first six months after discharge, but this falls to around a fifth of patients in the 6-12 months after discharge. Data from South London showed that only 26 per cent of patients in need received physical and occupational therapy and 14 per cent received speech and language therapy 3-12 months after discharge. Early Supported Discharge, facilitated by a multi-disciplinary team, reduces length of stay – thereby increasing inpatient bed capacity – and can help the patient adapt to their life at home.

17 There is also a serious impact on carers which is inadequately addressed. The Sentinel Audit recognises that carers are a vital resource and it is known that carers' morbidity is high, with around one third experiencing problems with their jobs and just under two thirds experiencing physical and mental health problems. Yet in over half of cases in the Sentinel Audit, carers' needs were not assessed, despite carers now having a legal entitlement to request an assessment. Recent research[6] indicates that providing carers with training improves their psychological outcomes. It also reduces the total health and social care costs of the patient and carer, in particular the costs of the patient needing to be re-admitted to hospital. There is scope to increase the numbers of carers receiving training: over a third of carers in the Sentinel Audit did not receive training.

18 There is a lack of coordination of support services for stroke patients after they are discharged from hospital which can leave patients feeling abandoned. The Department has recognised that stroke survivors need to access many different health and social care services, and that the lack of clarity of responsibilities between health and social services is a barrier to the delivery of person-centred care. But these issues are still unresolved 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.

More emphasis is needed on primary and secondary prevention measures

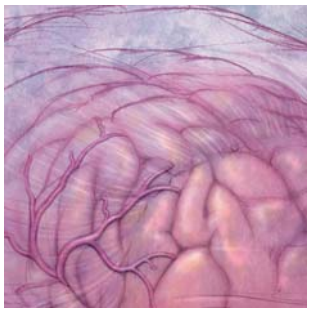
19 Over three times as many women died of stroke than of breast cancer in England and Wales in 2002, but 40 per cent more women mentioned breast cancer than mentioned stroke when we asked them what the top causes of death were. Indeed, many people still do not realise that strokes are largely preventable and cannot list the main risk factors for stroke, or how to manage them. The Department has run national campaigns which highlight the benefits of a healthy diet and lifestyle, and these may help to reduce the incidence of stroke.

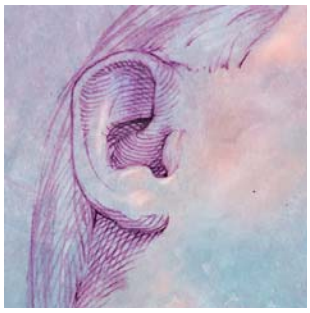
20 GPs have a key role to play in managing risk factors and the new GPs' contract, in place since April 2004, is focussed on issues that have helped to provide better and more systematic prevention of stroke. We found that people on GP lists were more likely to have their blood pressure and cholesterol recorded than was the case a year previously, that more people who were smokers were receiving cessation advice, and that more people with recorded blood pressure had levels meeting the recommended targets.

21 Positive changes were also apparent for secondary prevention activities with trends so far 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 transient ischaemic attack, will soon be achieved (Figure 14 in main report). There are 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).

22 Delays in getting appropriate outpatient treatment for patients who have had a TIA mean that strokes are occurring that could have been prevented; and some preventative interventions, such as surgery on the carotid arteries, are being carried out after the time when they would have been of most benefit. Ultrasound scans can show if a thickening of the carotid arteries in the neck is the cause of a previous stroke or TIA. If that is the case, surgery should be performed preferably within two weeks of the stroke or TIA. Yet the Royal College of Physicians' stroke audit in 2004 showed that only half of stroke patients had an ultrasound scan within twelve weeks, despite the majority of hospitals having scanning available. Providing carotid surgery within two weeks to patients who are indicated for it could prevent around 250 strokes, and result in a net saving to the health service of around £4 million, each year.

23 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 ten per cent – around 45 times the 'normal' risk – and within four weeks of TIA the risk of stroke can be 20 per cent. This increased risk means that patients need to be seen rapidly in a TIA clinic. 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.





RECOMMENDATIONS

24 Clinical guidelines for optimal stroke care are clear and many of the individual components required for effective stroke services are already in place, but that capacity is largely not being utilised. The Department and NHS must now focus on removing the barriers to the delivery of responsive, integrated stroke care, in order to save lives, reduce disability and reduce the cost of stroke to the health service.

Preventing more strokes

a Incidence rates for vascular disease have fallen over the last decade, probably in part because of greater awareness of the benefits of making lifestyle changes such as eating more healthily and taking more exercise. Public health campaigns such as 'Five a Day' have helped to raise awareness of these issues. There is still more to be done, however, to raise awareness of the fact that such lifestyle changes can prevent strokes as well as heart disease, and in particular, that high blood pressure is a key risk factor for stroke. **The Department should refer explicitly to stroke in more of its campaigns (at no or an insignificant additional cost) to ensure that the public and the NHS benefit from preventing more strokes**. For example, preventing just two per cent of strokes that occurred in England last year would have saved care costs of more than £37 million.

b Reducing delays in access to outpatient services, such as diagnostic testing at a neurovascular clinic for patients who have had a TIA, is likely to prevent strokes and hence reduce the overall cost of stroke to the health service. **All Primary Care Trusts should ensure they provide access to an outpatient stroke and TIA service. Primary Care Trusts should also ensure arrangements are in place between GPs and secondary care to ensure outpatients are referred efficiently and effectively**. One way of doing this would be to use the GP contract to lever improvements in the number of TIA patients referred to neurovascular clinics.

Rapid response to stroke

c A key component of effective treatment of stroke is that a suspected stroke should be treated as a medical emergency in the same way a suspected heart attack is. **The Department should work to raise public awareness of the signs of stroke, and the fact that stroke is a medical emergency that requires a 999 response. This should be integrated with the provision of information and guidance to GPs, Accident and Emergency department staff and ambulance staff to prepare for the increased demand and expectations of a more informed public.**

Improving acute care: brain scanning, thrombolysis and acute stroke units

d Greater uptake of thrombolysis would improve stroke outcomes. There are several models of practice that could be adopted to overcome the barriers to delivering thrombolysis routinely for eligible patients. These include: greater use of telemedicine to access expertise in reading brain scans; protocols between Ambulance Trusts and hospitals to ensure that all suspected stroke patients are delivered to a designated hospital that is equipped for thrombolysis; and more widespread training of triage nurses, radiologists and stroke consultants in how to work together to deliver thrombolysis. **The Department should, in conjunction with the National Institute for Health and Clinical Excellence, appraise the costs and benefits of different approaches and provide guidance to the NHS on how to deliver thrombolysis in practice.**

e A key requirement for all acute stroke treatment, including thrombolytic treatment, is rapid access to brain scanning. Our audit revealed existing capacity for scanning stroke patients that is being under-used. **The Department should explicitly address the issue of improving emergency scanning capacity in its strategic work on improving stroke management. For example, it should explore the possibility of the extension of training so that stroke consultants can read scans to a sufficient level to be able to make decisions about immediate acute treatment without having to wait for specialist radiological input.**

f In commissioning stroke care services, **Primary Care Trusts should ensure that acute stroke services are delivered through acute stroke units. As a minimum, all stroke patients should have a stroke care plan and access to specialist staff. The Department should make available best practice guidance on the provision of an acute stroke unit, to reduce regional variations.** 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, reducing morbidity and mortality. This increase in efficiencies should also reduce overall averages for lengths of stay.

Coordinating post-acute support services

g The Department should ensure that its initiatives to support more coordinated and cohesive health and social care services take into account the need for joined-up services to reduce the disabling impact of stroke on peoples' lives following discharge from hospital. Arrangements must be put in place to ensure that where responsibilities are divided between health and social services the responsibility is not neglected by either party. **The Department has set out eleven quality requirements for delivering care to people with long term neurological conditions in its *National Service Framework for Long-term Conditions*. These quality requirements apply to people with neurological damage as the result of a stroke, and commissioners should refer to them in planning post-acute stroke services.**

h Voluntary and community organisations can provide effective long term support for people who have suffered a stroke. Our report *Working with the Third Sector* (HC 75, 2005-06) sets out how government departments can build effective partnerships with such organisations. **The Department should be informed by the recommendations in that report in working more closely with the voluntary sector on the issues surrounding the provision of long term rehabilitation and support services for stroke patients.**

Better management of stroke services

i Stroke costs the NHS more than heart disease. In order to reduce these costs, it is important that commissioners and clinicians in the NHS are as aware of the need to improve the capacity and responsiveness of stroke care services as they have been for higher-profile diseases. **To support this, the Department should work with the Healthcare Commission and the Royal College of Physicians to build on existing guidelines and audit processes. This should include considering appropriate benchmarks for stroke care – for example, for the proportion of suspected stroke patients receiving a brain scan within three hours, or the proportion of eligible patients receiving thrombolysis – as part of its strategic approach to taking forward an integrated vascular care programme.**

j **The Department should take a unified approach to stroke, awarding it appropriate priority and supporting its stroke programme with strong leadership for vascular disease management.** This would build on the *National Service Framework for Coronary Heart Disease*; the stroke section of the *National Service Framework for Older People*; and the quality requirements listed in the *National Service Framework for Long-term Conditions*.

PART ONE
Responding to Stroke

'Time lost is brain lost'

Stroke is a medical emergency. Brain tissue at risk of damage can be saved with active management in the initial hours after a stroke starts. Rapid admission to hospital and access to specialised stroke care, including brain scanning, is vital for ensuring the best possible outcome for stroke patients. The Department of Health has encouraged the development of specialised stroke services and is developing a strategy for improving acute stroke care. However, more needs to be done to address specific barriers and blockages in the system to ensure that aspirational improvements are actually delivered in practice.

1.1 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 occur in England every year. Around two-thirds of people will survive their stroke, but half of them will be left disabled and dependent. Historically stroke has been seen as an inevitable risk of growing old, with little to be done for those who suffer a stroke other than trying to make them comfortable. However, many strokes are preventable and recent developments in the last decade have shown that fast and effective acute treatment and care can save brain from further damage and hence significantly reduce death rates and disability. In some cases clot-busting drugs can effect a complete recovery.

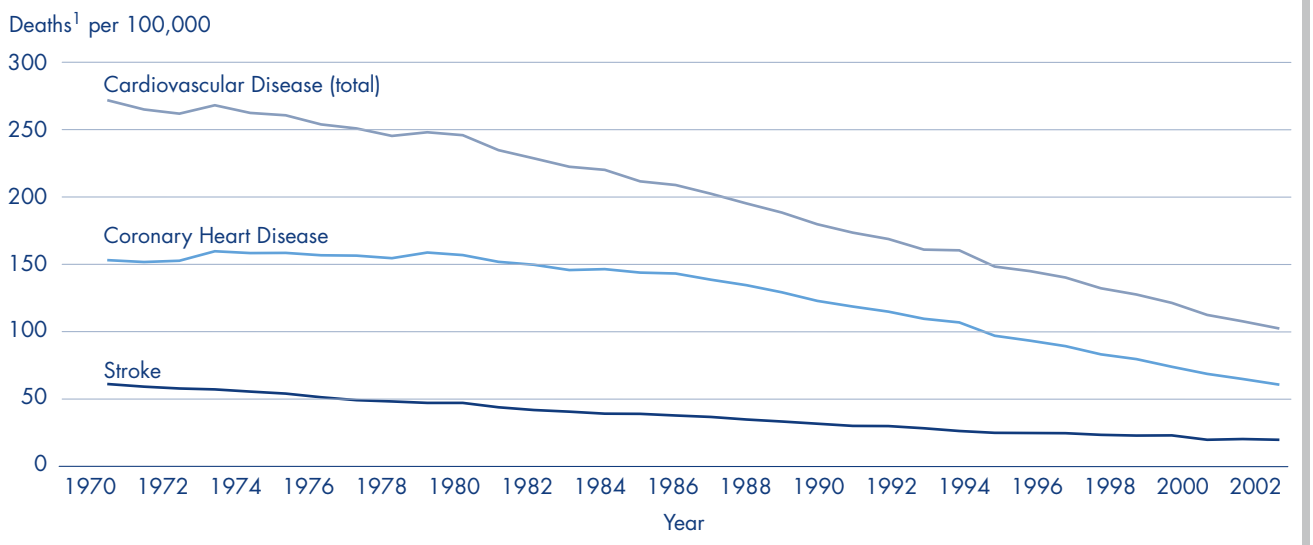
The status awarded to stroke has not been commensurate with other leading diseases, such as heart disease, and more can be done to lever improvements

1.2 The Department has published separate strategies for cancer[7] and for coronary heart disease[8], setting out their strategy to modernise services in these areas. But the framework for delivering stroke care is part of the *National Service Framework for Older People* (Standard Five) (2001), even though the costs of stroke care are more than those for heart disease and a quarter of strokes (approximately 28,000 a year) occur in people aged under 65.

1.3 The Department has had considerable success in improving services for people with coronary heart disease and in decreasing mortality rates. **Figure 3** shows how coronary heart disease mortality rates have fallen at a faster rate than stroke mortality rates, especially since the late 1980s.

1.4 Services for coronary heart disease have been well established and mature for some decades; services for stroke are still in their infancy. For example, by the early 1980s most English district general hospitals had a specialist coronary care unit and at least one consultant cardiologist. In contrast, 1980 saw the publication of the first British clinical trial of stroke unit care (the Edinburgh Stroke Unit trial). The results were inconclusive and it was only later that a consensus on the value of stroke unit care emerged. Thus, the position of coronary heart disease in the health service has had several decades to develop, mature and consolidate whereas stroke, as a specialist service, is a recent concept. A comparison of key elements of coronary heart disease and stroke illustrates the disparity in status and priority that stroke services have historically had **(Figure 4 overleaf)**.

3 Stroke deaths are reducing, but at a slower rate than deaths due to coronary heart disease



Source: National Audit Office analysis of data from the Department of Health

NOTE

1 Death rates are age standardised, for people under 75 years old.

4 Benchmarking stroke service provision against services for coronary heart disease reveals disproportionate differences in resourcing and status

	Stroke	Coronary Heart Disease
Annual direct healthcare costs	£2.8 billion	£1.9 billion
Number of in-patient hospital bed days annually	2.6 million	3 million
Average length of stay	28 days	7 days
Proportion of deaths in England and Wales it caused in 2002	11 per cent	19 per cent
Approximate prevalence of people disabled or dependent as a result	300,000	n/a
Status in the Joint Council for Higher Medical Training	As of 2004, stroke is a sub-speciality	A speciality
Number of trainees registered in England	6	430
Charity research funding in the United Kingdom in the financial year 2000-2001	£2.6 million	£43 million
Number of research posts funded by charities and government agencies in the United Kingdom in the financial year 2000-2001	7	455
Department of Health Research funding 2003-04	£9.4 million	£52 million
Respondents to NAO public awareness survey who listed the disease in the top four causes of death	21 per cent	77 per cent
Number of points in the GP contract allocated specifically to secondary prevention of this condition (plus points awarded for hypertension)	31 (+105)	121 (+105)
Proportion of GPs that have no system or are unsure if they have a system for identifying repeat events	15 per cent	26 per cent
Proportion of GPs with a special interest in the condition	16 per cent	39 per cent
Proportion of GPs that would refer a patient with this condition within a few minutes	55 per cent	94 per cent
Proportion of GPs that have local protocols in place for rapid referral and management of acute cases	73 per cent	86 per cent
Proportion of GPs that have local protocols in place for rapid referral and management of minor cases	71 per cent	92 per cent
Percentage of hospitals with protocols with the ambulance service for managing patients (over and above the regular system)	16 per cent	100 per cent
Percentage of patients seen as an outpatient within 14 days	37 per cent	95 per cent
Percentage of patients treated at some time on a specialist unit	47 per cent	100 per cent
Number of patients per consultant	640	360
Patients discharged with an identified help contact point	48 per cent	86 per cent

Source: National Audit Office analysis, including information from: Department of Health Hospital Episode Statistics, 2003-04. "The economic burden of coronary heart disease in the UK" JLY Liu, N Maniadakis, A Gray and M Rayner, Heart, 2002;88;597-603 (costs adjusted for inflation to 2002-03 prices). Joint College of Higher Medical Training (www.jchmt.org.uk). Pendlebury et al "Under funding of Stroke Research: A Europe-Wide Problem", Stroke, October 2004. National Audit Office Survey of GPs (2005). National Sentinel Audit of Stroke, Royal College of Physicians (2004). Healthcare Commission, Getting to the heart of it – Coronary heart disease in England: A review of progress towards the national standards (2005). The Department of Health Cardiovascular Research Funders' Forum.

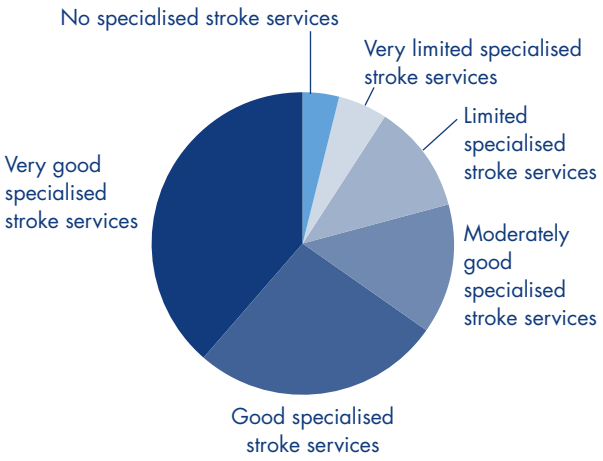
1.5 Appendix 2 summarises key initiatives that relate to stroke care. In December 2004 the Department established a Vascular Programme Board to take forward policy development in vascular disease management in a coordinated way. A stroke sub-group of the Board is developing a strategy for improving stroke services and decreasing stroke mortality rates. This is an important and significant step towards prioritising the management of stroke services and driving forward improvements.

The Department of Health has encouraged improvements, but stroke services vary and many patients have limited access to stroke services

1.6 A key milestone set by the Department in its *National Service Framework for Older People* was that by April 2004, 100 per cent of all general hospitals should have a specialised stroke service. We asked hospitals to rate patients' access to specialised stroke services. The results showed that although nearly two-thirds of patients had access to good or very good specialised stroke services on the day of the survey, over a thousand patients (21 per cent) were judged to have limited, very limited or no such access **(Figure 5)**.

1.7 Evidence-based clinical guidelines from the Royal College of Physicians[9] show that the most effective model for specialised stroke care, shown to save lives and reduce disability for those who survive, is care delivered through a specialised stroke unit: a geographically distinct unit staffed by a multidisciplinary team of stroke specialists, including consultants, therapists and nurses trained in the management of stroke. Stroke units are more successful at preventing complications and shortening the time to starting rehabilitation and benefit all types of patients irrespective of gender, age and severity. A meta-analysis shows an 18 per cent reduction in mortality, a 29 per cent reduction in death or dependence and a 25 per cent reduction in death or need for institutional care in patients treated in a stroke unit compared to a general medical ward.[10] This evidence is recognised internationally, for instance with hospitals in Australia adopting a specific model for delivering stroke services through stroke units **(Case Study 1)**.

5 Hospitals rated patients' access to specialised stroke services



Source: National Audit Office survey of hospitals (2005)

CASE STUDY 1

Adopting stroke unit models in Australia

Gosford hospital's stroke unit is one of 22 units in New South Wales that has been established according to a detailed model devised jointly by clinicians and the state Department of Health. Over the last seven years, average length of stay has fallen from 16 to nine days (compared with 28 days average stay in the UK Sentinel Audit of stroke); mortality has fallen from 24 per cent to 13 per cent (inpatient death was 28 per cent in the Sentinel Audit); discharge to nursing homes has fallen from 30 per cent to 15 per cent (compared to 18 per cent of surviving patients in the Sentinel Audit who were discharged to a residential or nursing home) and referrals for further inpatient stays for rehabilitation have fallen from 40 per cent to 20 per cent, enabling people to have outpatient rehabilitation services instead.

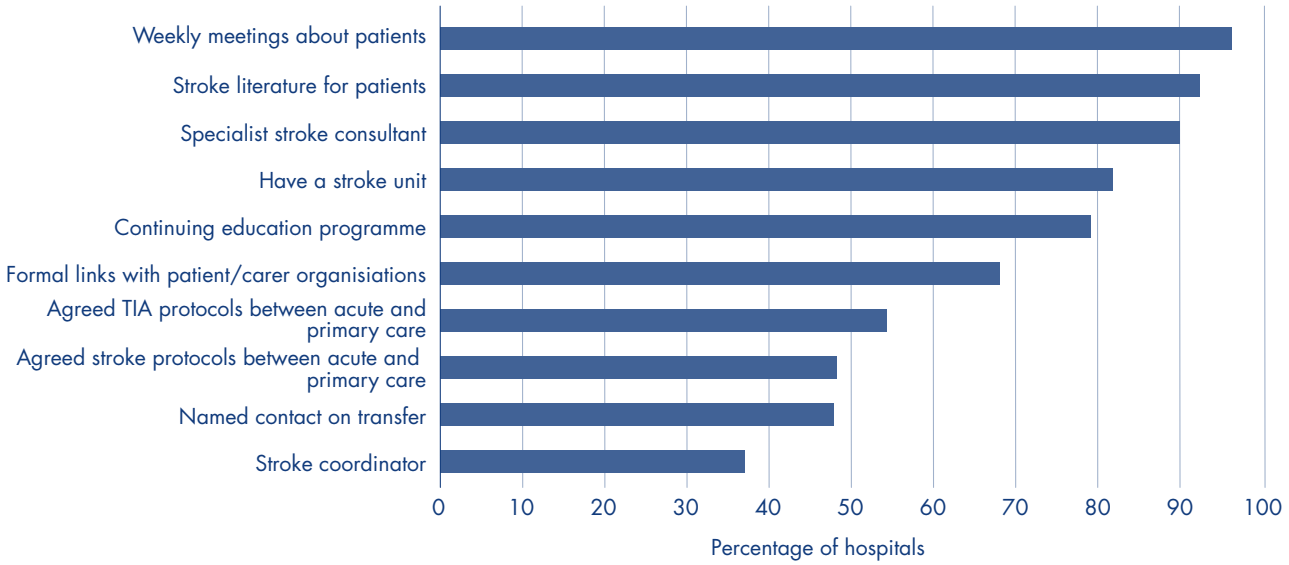
Source: National Audit Office

1.8 The Department recommends that hospital services for stroke should be reviewed using the clinical audit methodology developed by the Intercollegiate Stroke Working Party. The National Sentinel Audit of Stroke (the Sentinel Audit), run by the Royal College of Physicians and sponsored by the Healthcare Commission, was published in 2004. It found that provision of stroke unit care improved significantly over the last three years: more patients are treated on a stroke unit during their stay – up from 36 per cent in 2001 to 47 per cent in 2004 – and the mean length of stay has fallen from 34 days in 2001 to 28 days in 2004, indicating an average saving per stroke patient of six bed days. Appendix 3 shows the key Sentinel Audit results across the UK; England compares favourably with Northern Ireland and Wales.

1.9 Overall, most hospitals are now incorporating some of the organisational features recommended for stroke units, such as having literature available for patients, weekly meetings and a consultant responsible for stroke, as shown in **Figure 6**.

1.10 However, there is regional variation in the percentage of hospitals incorporating the criteria from the service model. There is a lower than average proportion of hospitals in the South with specialist stroke consultants and London has lower than average percentages of hospitals with formal links with patient/carer organisations and hospitals with stroke coordinators **(Figure 7)**.

6 Most hospitals incorporate some organisational criteria from the stroke service model



Source: National Audit Office analysis of Sentinel Audit data

7 Regional variation in the percentage of hospitals incorporating organisational criteria for stroke

The percentage of hospitals that meet the indicated criteria

	London	South	Midlands & East	North	National Total (%)
Weekly meetings about patients	97	97	94	100	97
Stroke literature for patients	94	95	90	95	93
Specialist stroke consultant	94	**82**	95	92	91
Have a stroke unit	**91**	**77**	**87**	78	82
Continuing education programme	**91**	79	76	76	80
Formal links with patient/carer organisations	**53**	**61**	69	**73**	67
Agreed TIA protocols between acute and primary care	**50**	53	55	58	55
Agreed stroke protocols between acute and primary care	**44**	**60**	43	46	49
Named contact on transfer	50	**53**	**43**	49	48
Stroke coordinator	**28**	**44**	**42**	**31**	37

Source: National Audit Office analysis of Sentinel Audit data

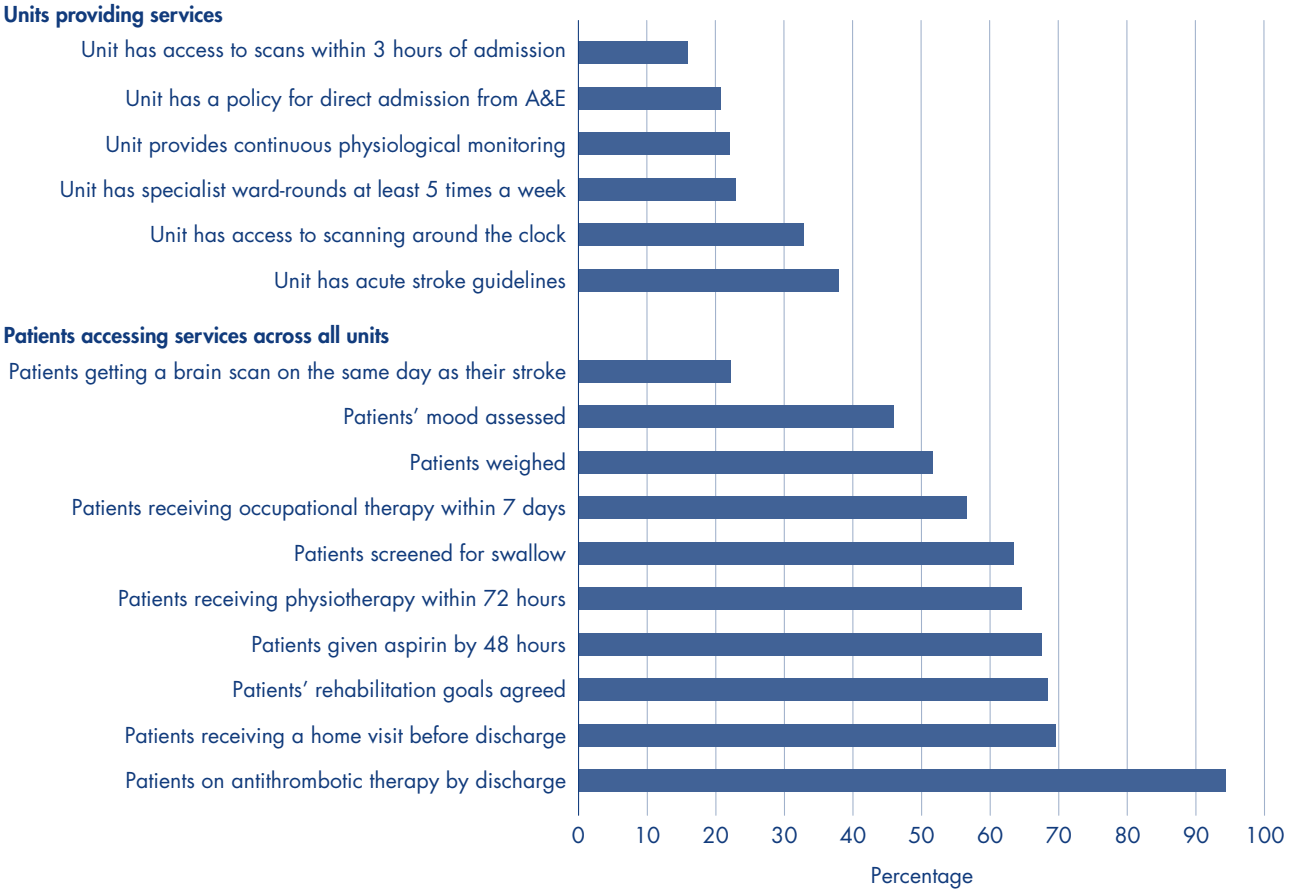
NOTE

Numbers in red show where the regional percentage of hospitals meeting the criteria is 5 percentage points or more below the national average, numbers in green are 5 percentage points or more above the national average.

1.11 Although treatment in a stroke unit is the clinically optimal model of stroke care, the Sentinel Audit showed that stroke units remained of "insufficient size", with no increase in the number of stroke beds between 2001 and 2004. In 2004, around half of eligible patients were treated on a stroke unit at some point and only 41 per cent spent more than half of their stay there. The median time to get admitted to the stroke unit was two days, and 70 per cent of hospitals were using a set of criteria to select which patients could access their stroke unit. We found evidence of some improvement over the last year. Sixty-three per cent of the 5044 stroke patients in the hospitals we surveyed in 2005 were in a stroke unit.

1.12 Service provision in one stroke unit may vary significantly from services in another stroke unit. For instance, just over half of hospitals said that patients could access 'very good specialised stroke services' in their stroke unit and 15 hospitals claimed that patients in their stroke unit had access to limited, very limited or no specialised stroke services. The Sentinel Audit also showed that stroke units varied considerably in terms of providing clinical services for acute stroke management **(Figure 8)**. Indeed, our survey showed that 54 per cent of dedicated stroke beds were rehabilitation only beds.

8 Service provision varies



Source: National Audit Office analysis of Sentinel Audit data

NOTE

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

There are barriers that prevent stroke patients from receiving rapid and responsive emergency care

1.13 Stroke is a medical emergency. Over 25 per cent of stroke patients show significant neurological deterioration during the first 72 hours after admission to hospital. 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. In some patients the impact of this can be to reverse most or all of the damage, sometimes with complete recovery. **Figure 9 (on page 20)** shows that there are several key areas along the critical path at which urgent medical treatment can be delayed. Particular pinch points are: the emergency response and triage; getting a brain scan[b] to diagnose stroke; and accessing the expertise to read the scan and administer treatment.

From onset of stroke to arrival at A&E

1.14 In 2004 the Sentinel Audit showed that only five per cent of hospitals had protocols with the ambulance service for the rapid referral of stroke patients. Our survey in 2005 showed an increase in this, to 16 per cent, although protocols for managing TIA patients were still low at six per cent. Protocols with an ambulance service provide explicit guidance on where the patient should be taken (less than a fifth of hospitals enable stroke patients to access scans within three hours and ambulance staff will not necessarily know which do) and who in the hospital should be notified that a suspected stroke is being brought in. The Face Arm Speech Test was developed in the North East as a paramedic stroke identification instrument. The Ambulance Service Association is implementing the use of the Face Arm Speech Test in other parts of the country and contributed to the expert panel for a 2004 report called *Act Now*[11] which highlights how a coordinated approach can improve patient management and outcomes in acute stroke. This capacity can be drawn upon effectively to reduce delays in the acute stroke pathway, as shown in **Case Study 2** and in **Case Study 3**.

CASE STUDY 2

Treating stroke as an emergency: The Freeman Hospital and the North East Ambulance Service

Paramedics have a protocol to take all suspected stroke patients in Newcastle upon Tyne to the Freeman Hospital, avoiding the city's Royal Victoria Infirmary, because it does not have an acute stroke service. The North East Ambulance Service will arrive within 14 minutes of a 999 call for suspected stroke patients. Paramedics are trained to recognise stroke using the "Face Arm Speech Test" (FAST) which assesses whether the patient is showing the typical signs of stroke: facial palsy, arm weakness and problems with speech.

The latest estimate for the median time from onset of stroke symptoms to presentation at the emergency unit is around 1 hour 12 minutes. Between August 2001 and July 2002, ambulance crews referred 278 suspected stroke patients to the Freeman hospital, of whom 217 (78 per cent) had the diagnosis confirmed as stroke or TIA.[12] Paramedics will notify the stroke unit at the Freeman Hospital that a suspected stroke patient is coming in, which in turn enables a more rapid response once the patient arrives at the hospital as the stroke team are prepared for their arrival and to deliver emergency treatment.

At Accident and Emergency in the Freeman Hospital, patients with suspected stroke who are not brought in directly by paramedics are assessed using the Recognition of Stroke in the Emergency Room (ROSIER) tool, a further development of the FAST test, which reduces misdiagnosis of stroke 'mimics' such as seizures. Using the ROSIER tool, over 90 per cent of strokes were initially recognised as a stroke and 75 per cent of non-stroke mimics were identified correctly as non-strokes.

These management tools reduce the time and manage the pathway between when the symptoms are recognised, arriving at hospital, and then accessing expert stroke care.

Source: National Audit Office

b Computerised tomography (CT scan) or Magnetic Resonance Imaging (MRI) are imaging techniques which allow the assessment of soft tissues – in this case brain tissue. These scans can show whether or not the stroke is caused by a bleed or a clot, and hence, are critical to enabling treatment.

CASE STUDY 3

'Rapid Ambulance Protocol for IDentification of Stroke' (RAPIDS): The National Hospital for Neurology & Neurosurgery and the London Ambulance Service

The National Hospital for Neurology & Neurosurgery and the London Ambulance Service set up a multidisciplinary project to reduce the delay between when the stroke patient was picked up by the ambulance and their actual admission to the Acute Brain Injury Unit in the hospital. The project introduced:

- Simple guidance to ambulance crews on diagnosing acute stroke:

Face Arm Speech Test (FAST) for stroke	Yes	No	Unable to assess	Affected side	
				Left	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

- The protocol that the London Ambulance Service calls the Acute Brain Injury Unit at the hospital to forewarn of a stroke patient arriving
- The protocol that 999 stroke calls are taken directly to the Acute Brain Injury Unit

The project successfully raised awareness of stroke in both the London Ambulance Service and across the University College of London Hospitals; it successfully enabled stroke patients to bypass A&E; and it significantly reduced time from onset to admission.

Source: National Audit Office

Diagnosis and access to stroke specialists

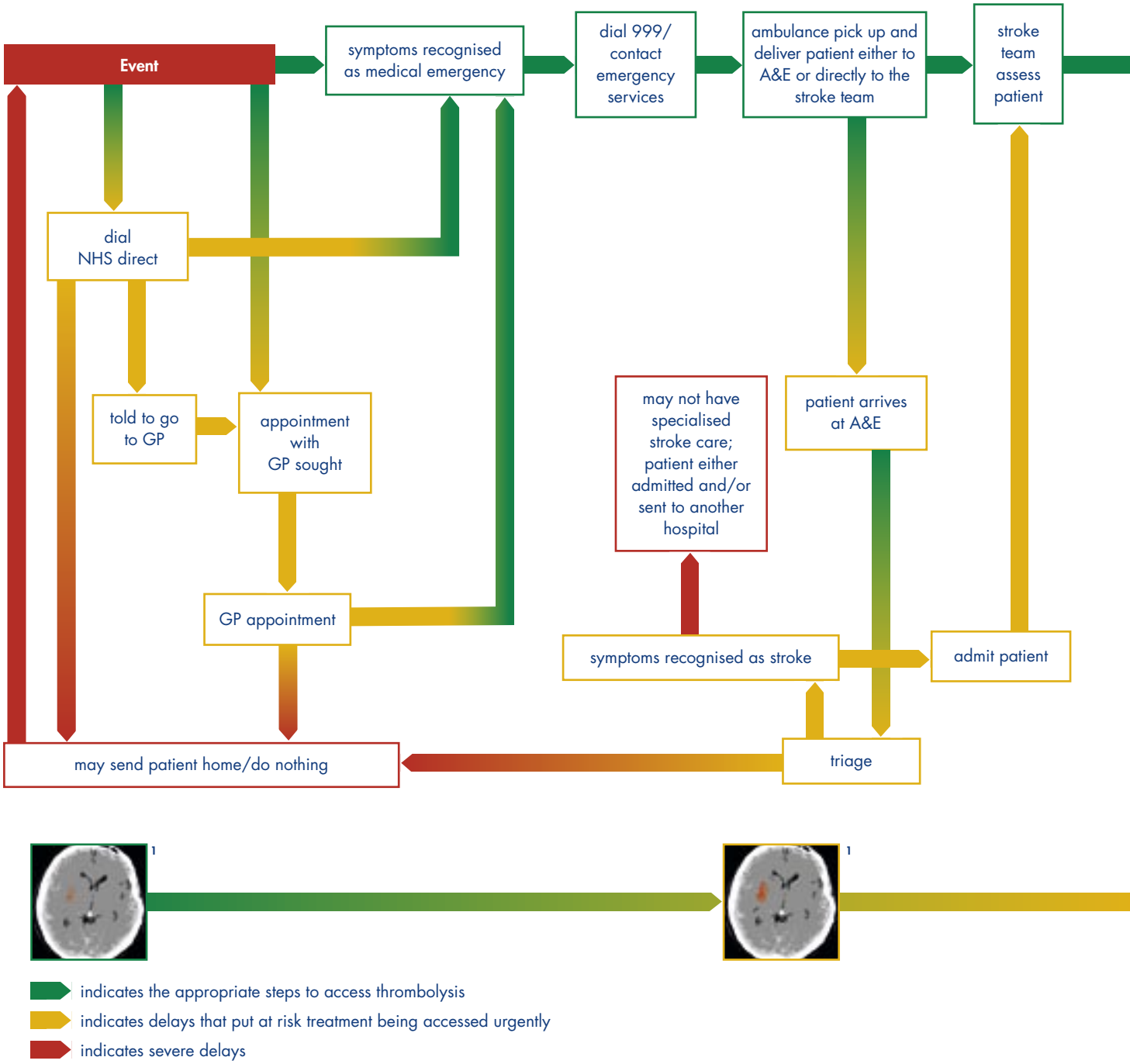
1.15 In many cases of acute stroke where an ambulance has been called quickly after the onset of symptoms, the majority of the delay is likely to be *after* the patient has arrived at hospital.[13] It is partly due to these delays that so few patients receive thrombolysis, although there are also contraindications that mean not all ischaemic stroke patients are eligible for it. However, less than one per cent of stroke patients are receiving thrombolysis annually in England when around nine per cent of stroke patients are receiving thrombolysis in other places, such as in Box Hill hospital **(Case Study 4 on page 22)** in Australia.

Large numbers of acute stroke patients don't get a scan within the critical time period

"my husband was turned away [from A&E] and told to go to his GP - It actually took me two hours to get him up the stairs at home on that particular evening ... he has had another minor stroke and three TIAs" – A carer

1.16 Treatments such as aspirin or thrombolysis may be dangerous to give to a patient with a haemorrhagic stroke as these increase bleeding tendency and may increase the damage. For this reason, getting a CT scan to diagnose the type of stroke is a critical pinch point because until this has happened treatment cannot commence safely.

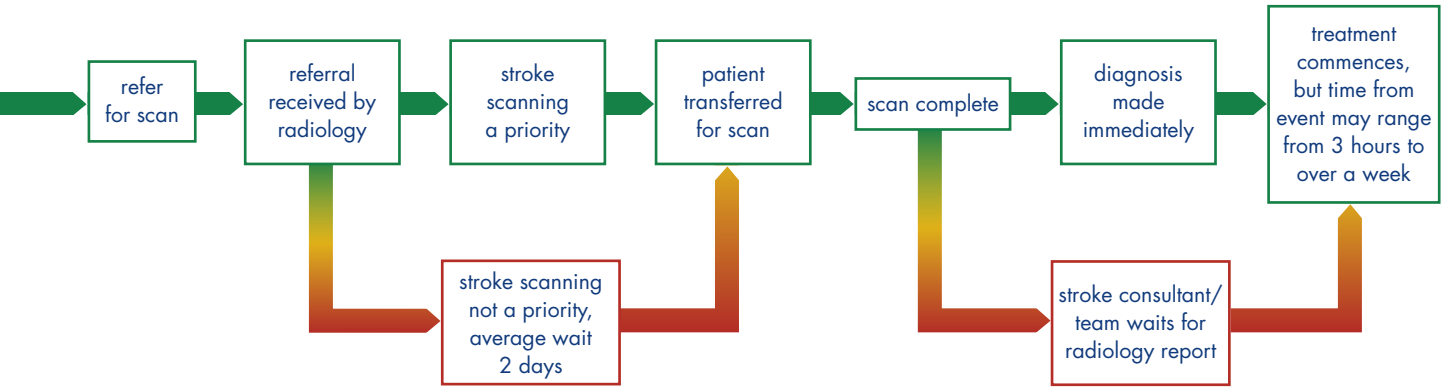
9 Several delays can prevent patients receiving urgent medical treatment



Source: National Audit Office analysis

NOTE

1 With active management in the initial hours after stroke onset, brain may be saved from further damage. The representation of brain damage here is only illustrative.


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

1
1

CASE STUDY 4

Stroke teams in Australia are organised for a fast-stream disease

In leading stroke units in Australia, stroke is treated as a fast-stream disease. This entails:

- Stroke being classified as a medical emergency (ambulance paramedics are trained to diagnose stroke and can notify the hospital when a stroke is coming in)
- Continuing education of triage nurses about the emergency status of stroke and the need for urgent scanning and treatment
- Stroke patients having immediate access to scanning/neuro-imaging
- Stroke consultants and registrars having the neurological expertise to read scans – digital radiology technology enables consultants to see scans immediately off-site and at home if necessary, so radiologists do not need to be involved which speeds up the process
- Availability of thrombolysis
- Commitment to the professional development of the multidisciplinary team. Stroke care is seen as a career with a rewarding mixture of up-skilling opportunities, a committed team has the skills to prevent common complications such as aspiration or pneumonia and care is more acute from day one. The average length of stay across Australia is 11 days compared with 28 days across England.

Recent results from Box Hill hospital showed that 41 per cent of thrombolysed patients fully recovered from their stroke.
Box Hill hospital is a metropolitan hospital serving a population of approximately 800,000 people (13 per cent over the age of 65 years) in the eastern suburbs of Melbourne, Australia. It has a four bed acute stroke unit situated within a 20 bed Neurology ward and admits approximately 300 stroke patients per year. Around ten per cent of ischaemic strokes (nine per cent of all strokes) are thrombolysed. Since the introduction of thrombolysis, staff are now seeing patients, who previously would have been seriously disabled or killed by their stroke, make a full recovery. Additionally, digital scanning capability enables patients to be diagnosed and thrombolysed outside normal working hours because the consultant can access digital images of the scans at home and discuss the diagnosis over the telephone.

Source: National Audit Office

1.17 In fact, a study by Wardlaw and others in 2004 found that scanning patients immediately is the most cost-effective strategy.[14] They found that compared with strategies such as 'scan all within 48 hours of admission' or 'scan only patients with a life-threatening stroke immediately and the remaining within 14 days of admission', the strategy 'scan all immediately' cost the least and provided the best health outcomes. Independent survival increased because appropriate early management was then possible. CT scans distinguish between brain damage caused by a clot – which appears dark on a scan – and haemorrhage – which appears white. But bleeds eventually become darker on a scan so over time, depending on the size of the bleed, the ability to differentiate is lost. This is another reason why scanning quickly is important for stroke. Wardlaw points out that when it comes to scanning "stroke has traditionally been assigned a low priority" and that radiologists, with many demands for CT investigations, might not know the benefits of immediate CT scanning for stroke patients.

1.18 However, only 22 per cent of stroke patients in the Sentinel Audit received a scan on the same day as their stroke. Most waited two or more days. For patients who were registered as requiring an urgent CT scan (within 30 minutes), only 30 per cent actually got the scan on the same day. But nearly all hospitals (91 per cent) have the capacity to be able to provide CT scans within 24 hours of admission. This means that scans for stroke patients are being delayed, even though 'time lost is brain lost'.

1.19 We asked hospitals whether the number of scans achieved met a reasonable potential; we were told 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 (by changing, for example, the way scans are planned, managed and carried out, including staffing and time changes). Over a quarter of respondents suggested that having protocols such as set 'slots' for CT scanners to serve stroke patients would reduce waiting times for scans, and nearly a third said that the scanners should be available more of the time, for instance in the evenings and at weekends.

1.20 The Audit Commission reported in 2001 that in England and Wales around 80 per cent of CT scanners operate for nine hours or less on weekdays. They noted that "radiology departments face increasing pressures to provide out-of-hours services, for instance to support the diagnosis and management of emergency cases, such as suspected stroke". That report also suggests that possible solutions might be to set up on-call arrangements, or adapt to an extended-hours service during the week, or offer a 24-hour seven-day service (which is rare). **Case Study 4** shows how telemedicine (digital technology that allows scans to be read remotely) is being used in Australia; and this approach has also been used in Germany, Austria and North America to facilitate centres delivering thrombolysis. At Western General Hospital in Edinburgh, close links between the radiologists and the stroke unit and training of stroke physicians to read scans is seen as essential in facilitating timely scanning and enabling the thrombolysis of stroke patients **(Case Study 5)**.

CASE STUDY 5

Speeding up access to scans for stroke patients: Western General Hospital in Edinburgh

In most hospitals, consultants must request scans from the radiologist, who will then pass it on to the radiographer. At the Western General Hospital the consultant can go straight to the radiographer with a request for immediate scanning for those patients who might be thrombolysed. Elsewhere the scans are read by general radiologists or neuroradiologists who will then pass on the diagnosis to the stroke consultant, which of course involves a delay. At Western General Hospital some stroke physicians have been successfully trained to read the scans. This means the diagnosis can be reviewed at a later date by the radiologist, but the consultants will be able to initiate treatment immediately, based on their own diagnosis. In any case, general radiologists may not have as up-to-date knowledge on brain scans and stroke diagnosis as that which would be available for specialist stroke consultants.

Source: National Audit Office

Achieving thrombolysis rates in line with those in leading Australian hospitals would deliver savings to the NHS

1.21 Using data on average mortality and recovery rates for thrombolysed patients, we made an indicative assessment of the costs and benefits of delivering thrombolysis to nine per cent of all stroke patients in England. Nine per cent is the rate currently being achieved at Box Hill hospital in Australia **(Case Study 4)**. We used cost data collected by the London School of Economics and Political Science to calculate the costs that would be avoided by the NHS in not having to provide care for those stroke patients who would make a good recovery from thrombolysis, but would not have done so without the treatment. We netted off the cost of providing thrombolysis to nine per cent of all stroke patients. We found that it would cost about £9.9 million a year to provide thrombolysis for these patients, but would save around £26.4 million a year in care costs: a net saving of more than £16 million a year.

The limited numbers of health professionals with training in stroke care is a barrier to delivering high quality care across the country

"[There are] still problems with the ambulance crew who assess TIA as nothing wrong and tell [the patient] to see [their GP at] some time. TIA is serious and needs taking seriously, NHS Direct and other triage systems are also guilty of this" – A GP

1.22 A study in 2003 showed that misdiagnosis of stroke is common in the emergency room and by primary care doctors.[15] Only one in five GPs told us that most of their TIA referrals are subsequently confirmed to be TIAs. More worrying though is if stroke patients are not being recognised as such. Patients and GPs described examples where people were sent home from Accident and Emergency departments, or from GPs' surgeries, when attending with stroke symptoms **(Case Study 6 overleaf)**.

1.23 In England there are currently 86 whole-time-equivalent stroke consultants. This is only 20 per cent of the requirement recommended by the British Association for Stroke Physicians for a specialist-led acute stroke service. 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 two whole-time-equivalent consultants would be needed to provide 16 sessions a week to deliver a comprehensive stroke service. A median of three consultant sessions a week are currently being provided for stroke patients.

1.24 Stroke units also need to be able to attract and retain staff in order to build a high-quality and well coordinated service. The Sentinel Audit warned that "it is of grave concern that only two-thirds of patients have a record made as to whether they are safe to swallow". Difficulty swallowing is a common complication in stroke and aspiration pneumonia and chest infections are serious further complications that can result; staff need to be knowledgeable about how to feed and position a stroke patient appropriately to prevent this. Training on how to care for stroke patients has not been mainstreamed and although sites with stroke units are more likely than other wards to provide continuing stroke education for staff, a significant proportion of stroke patients are managed elsewhere than on stroke units.

1.25 Stroke patients require services and therapies from many disciplines in health and social care. If people do not get good rehabilitation as soon as possible after their stroke, such as early access to physiotherapy to restore movement, their paralysis or weakness can produce stiffness and spasticity which in turn can lead to painful spasms and abnormal posture. However, access to professionals such as psychologists, dietitians, physiotherapists, occupational therapists and social workers can be patchy within and between stroke units, even though access to social work and occupational therapy is likely to result in fewer delayed discharges. The provision of psychological support is particularly low **(Figure 10)**.

CASE STUDY 6

Stroke patient: Eve*, Age 40, South London

Eve is a 40 year old Asian-Caribbean mother of four children who has had three strokes and a heart attack. She has been diabetic for about 9 years and had her first stroke when she was 37 years old. However, at the time of her first stroke doctors thought she had meningitis. It was not until she had her second stroke several months later that she was informed about the first. Eve says that doctors treating her demonstrated a lack of awareness about stroke among younger people. Eve's second stroke was detected when she went to visit her local GP – several hours after the stroke had occurred.

Eve is now disabled and unable to work. She is incontinent, has extreme mobility problems and is paralysed along her right side. She received speech therapy from the local primary care trust after her second stroke and her speech is now almost fully regained. The primary care trust's adult therapy team referred Eve to the Stroke Association, which now provides a family support organiser to visit her approximately every month.

** Name has been changed*

Source: National Audit Office

10 Ranges in the provision of multidisciplinary care

Whole-time-equivalents for staff on stroke units (per ten beds)	Inter quartile range
Qualified nurses/assistants on duty	2.7–3.8
Junior doctor sessions	2.7–7.1
Clinical psychology	0.0–0.1
Dietitian	0.1–0.2
Occupational Therapy	0.7–1.3
Physiotherapy	0.9–1.7
Speech and Language Therapy	0.2–0.5

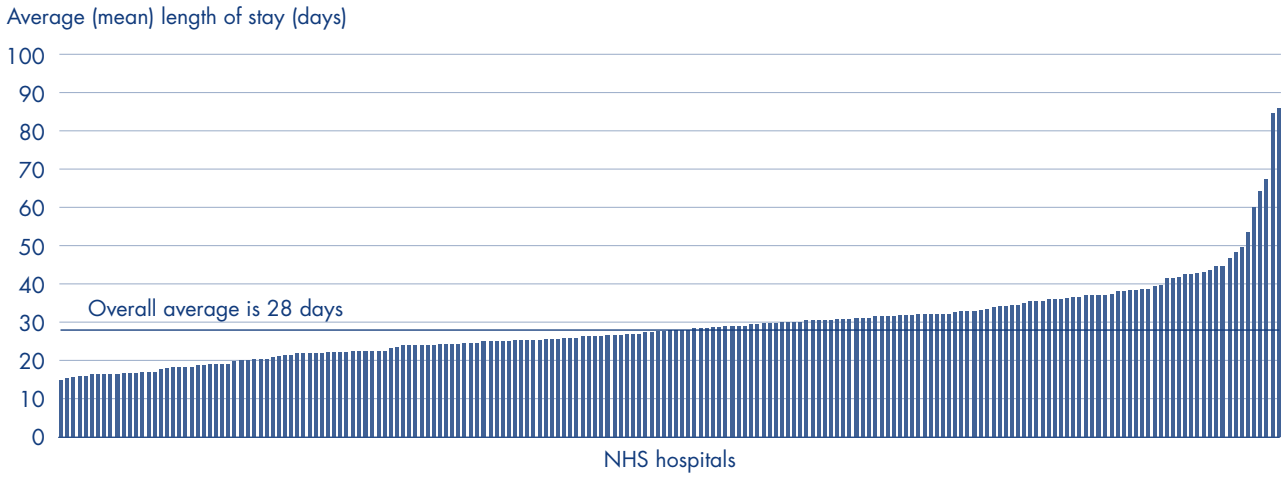
Source: National Audit Office analysis of Sentinel Audit data

1.26 Hospital episode statistics show that the bed days for stroke patients are among the highest, at over 2.6 million bed days in 2003-04, of any patient group. 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. This increase in efficiencies should reduce overall averages for lengths of stay.

1.27 The stroke unit triallists 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.[16] The updated Cochrane Library[17] stroke unit review shows a reduction in length of stay of about 6 days. The Sentinel Audit showed that average length of stay decreased considerably since 2001 by just over 6 days, and that the proportion of stroke patients spending the majority of their stay on a stroke unit increased from 27 per cent to 41 per cent. The decrease in length of stay by 6 days indicates, for the cohort of 7619 patients in the 2004 audit, a saving of around 45,000 bed days. If extrapolated to the 110,000 strokes that occur in England annually, this suggests a saving of 660,000 bed days, which is 1800 bed years – or more simply 1800 beds, to the NHS. At an average cost of £125 per bed day, a reduction of 660,000 bed days represents a saving of over £82 million.

1.28 Length of stay for the cohort of patients in the 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. Mortality can also appear to shorten length of stay (some trusts may have high mortality and have low length of stay) although this also is clearly not a good outcome. Nevertheless fast access to treatment and acute rehabilitation on a stroke unit should reduce mortality, disability and length of stay.

11 Average length of stay varies across hospitals



Source: National Audit Office analysis of Sentinel Audit Data

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.

PART TWO
Life after Stroke

'My stroke starts now'

While responsive, specialised acute care is essential to achieving the best possible outcomes for stroke patients, it is in the months and years following their stroke that most patients will experience the full impact of the event. Many will require considerable levels of rehabilitation, support and nursing care, and will need to access many different health and social care services. Currently these are often not provided in a joined-up manner, which can lead to feelings of abandonment. There is scope for more effective working with the voluntary and community sectors to provide long-term support for stroke survivors.

Most of the burden of stroke is in the cost of rehabilitation and life after stroke

"[I wish I had known] how devastating the effects of a stroke can be, and the effect that it has had on the whole family, the isolation and loneliness" – A patient

2.1 The Department noted in its 1993 'Coronary Heart Disease and Stroke Key Area Handbook' that stroke accounts for a higher proportion of NHS expenditure than heart disease because of the greater burden of disability. Although the average length of stay in hospital for a stroke patient is around 28 days, the costs of stroke are incurred to a larger extent after the patient leaves hospital. The disabling impact of stroke continues for as long as the person who had a stroke lives. A disabled stroke survivor needs continuing support and community care, including social services and primary care; income is lost (by patients who are no longer able to work and also by carers who leave work in order to care for their loved one). We commissioned King's College, London, and the London School of Economics and Political Science to calculate the cost of stroke to the NHS and the economy more widely (Appendix 4 gives further details of their work). **Figure 12** shows the analysis of how the costs of stroke break down, with around £2.8 billion of direct care costs, £2.4 billion of informal care costs (e.g. costs of home nursing borne by patients' families), and a further £1.8 billion of wider economic costs.

2.2 Our survey of a hundred nursing homes indicates that stroke will have been a contributing factor for entry into a care home for between 20 and 40 per cent of residents. Other surveys of nursing homes, in 1985[18] and 1991[19], estimated (respectively) that 14 per cent and 23 per cent of nursing home beds were occupied by people who have had a stroke. The Audit Commission[20] found that out of 55 homes, 19 had less than a 20 per cent complement of stroke patients but 11 homes had over 30 per cent. Information from our survey on the average cost of nursing care (around £420 a week) suggests that if around 20 per cent of nursing home residents are there as the result of a stroke, the total annual care costs for these people will be around £680 million. During the three months of the Sentinel Audit, 662 people in the sample (14 per cent of stroke patients) who were living independently pre-stroke went to nursing home accommodation after their stroke; the annual cost of nursing home care for that group alone will be around £14 million.

12 The burden of illness: a breakdown of the costs of stroke

	£ million
Diagnosis costs	60
Inpatient care costs	530
Outpatient costs	46
Outpatient drug costs	507
Community care costs (including nursing homes)	1,700
Total Annual Direct Care Costs	**2,800**
Informal Care Costs	**2,400**
Income lost due to mortality	480
Income lost due to morbidity	600
Benefit payments	690
Total Annual Indirect Costs	**1,800**
Total Annual Cost	**7,000**

Source: National Audit Office analysis

Living with stroke starts after discharge, but the transition from hospital to home can be extremely traumatic

2.3 Stroke patients and carers told us that the experience of stroke really starts when a patient leaves hospital, as once discharged, patients and carers have to learn to cope with a new way of life. A third of acute stroke patients are left dependent or moderately disabled. Although for the 28 days the average stroke patient spends in hospital on-call help and care is available, on discharge patients have to adjust suddenly to the impacts of the stroke on their life at home.

2.4 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. Coordination in delivering these 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. Appendix 5 gives further details of services stroke survivors need and examples of problems they can have accessing those services.

2.5 We observed how two hospitals in Sweden had put in place integrated care pathways to provide early rehabilitation for stroke patients from a range of providers, including coordinated working with social services at admission and after discharge. A 2001 International Stroke Trial identified Sweden as a leading provider of rehabilitation for stroke patients.[21] Rehabilitation is characterised by:

- Patients commencing **rehabilitation within a few hours of arriving** in hospital
- A strong emphasis on **patient participation** in their own rehabilitation
- Continuing stroke-specific **education of the multidisciplinary team**
- An **integrated care pathway** with a range of providers of rehabilitation

These examples of good practice in providing effective, early and patient-centred rehabilitative care are summarised in Appendix 6.

2.6 Successful coordination includes planning support for the patient after they are discharged from hospital, and planning the support services delivered in the community. In a patient survey[22] conducted by the Stroke Association in 2001, 38 per cent of respondents said they were given a name and number to contact if they needed help after leaving hospital. In 2004 the Sentinel Audit showed an improvement on this, with 48 per cent of patients given a named contact. The Sentinel Audit also showed that prognosis was discussed with 63 per cent of patients and therapy goals with 65 per cent of patients, and in four out of five cases the plan for follow up was discussed with either the patient or carer. Our survey showed that 53 per cent of patients were receiving a care plan, identifying the services they would need, and who was responsible for providing those services.

2.7 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, reducing the length of their stay in hospital and in turn increasing the bed capacity on the stroke unit. International studies have demonstrated that Early Supported Discharge services reduce stroke sufferers' long term dependency as well as their chances of being disabled at six months.[23] Stroke patients who received Early Supported Discharge have a higher independence score than those receiving conventional care[24] **(Case Study 7)**.

CASE STUDY 7

Early Supported Discharge at Newcastle and North Tyneside

In 1995, the median length of stay for eligible patients in Newcastle fell from 22 days to 13 days following the introduction of Early Supported Discharge. 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. Currently between 10 and 20 per cent of stroke patients receive Early Supported Discharge services.

The rationale for providing rehabilitation in the home is that this is the environment that patients need to adapt to for their everyday lives after stroke. Even in designated rehabilitation units patients spend long periods of time inactive or bedridden and often express a desire to return home more swiftly than they are allowed. Additionally, the emotional impact a patient experiences upon discharge appears to be the same irrespective of the stage of the patient pathway at which they leave hospital.

Discharge planning starts at the very beginning of a stroke patient's time on a stroke unit and will assess a patient's ongoing rehabilitation and care needs and determine whether or not these can be provided at home. If it is appropriate, the patient will be discharged but will receive the same level of rehabilitation services at home that they would have on a stroke unit, including physiotherapy, occupational therapy and speech and language therapy. A patient-held record is kept in a patient's home and treatment is planned around their specific goals. There is no time limit for this service and the teams continue to be involved for as long as the patient has some goals that they are able to work with. The average input that a stroke patient receives from the Early Supported Discharge team is 1-2 months.

Source: National Audit Office

People living with stroke need coordinated services from both health and social care, but resources are disaggregated

"We need a seamless transition from hospital to home. I was dumped after weeks of twenty-four-seven care, and it was weeks till therapy was arranged and implemented"
– A patient

2.8 A common complaint that stroke patients make about their care is that they feel abandoned when they leave hospital. Only 27 per cent of hospitals in England have specialist community stroke teams; and the number of community stroke teams across the UK appears to be falling (31 per cent in 2002 and 25 per cent in 2004). One-third of the GPs we surveyed said they did not, as a matter of routine, receive information about the secondary prevention arrangements for their patients, suggesting a lack of coordination between some primary and secondary care services.

2.9 In 2004, 30 per cent of eligible patients did not receive a visit to their home before discharge, which would assess their needs and ability to live there comfortably. This is an improvement since 2001, when 48 per cent of patients said they did not receive one. However, there does not seem to be any improvement in accessing social services before leaving hospital, with 40 per cent of respondents in both years not doing so. Fifty-nine per cent of people in our patient and carer forum who were using social services scored the support provided by those services as four or below on a scale of one ('not providing any support at all') to ten ('providing excellent support').

2.10 The Department recognises in *Action on Neurology*[25] (2005) that the care pathway "includes a range of services from different professionals and organisations spanning health, social care and other sectors. However, barriers between the different professionals, whether real or perceived, often seem to impede the delivery of person centred care". In *Independence, Well-being and Choice: Our vision for the future of social care for adults in England* the Department recognises the need to improve the early identification and response to people's needs through better assessment and information sharing between local councils and NHS services, and the need to ensure a more coordinated response.

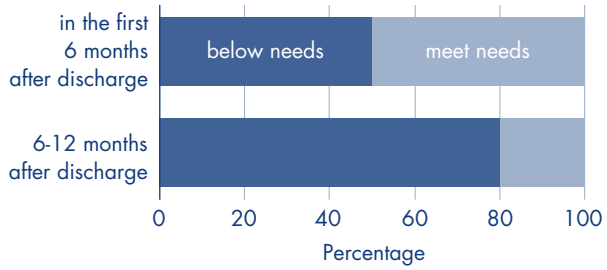
2.11 In 2000, the Audit Commission[26] emphasised the importance of a 'whole systems approach' to delivering person-centred care. This is not currently being achieved, which means patients do not receive a coordinated or cohesive service. The Department is currently consulting on how to improve community health and social care services for everyone through the *Your Health, Your Care, Your Say* consultation, which will consider how services can be better integrated.

Post-hospital support services for stroke survivors can be difficult to access

"I am unsure as to what my entitlements are regarding losing my job as I am unable to work. The forms for benefits claimants should be made easier or they should have benefits officers who are trained to deal with people who have had a stroke"
– A patient

2.12 We asked hospitals to estimate whether stroke services after discharge met patients' needs. Respondents felt unable to give an answer for the service provision beyond 12 months after discharge, but **Figure 13** shows that about half of stroke patients were estimated to be receiving services that met their needs in the first six months and that this fell to about a fifth by 12 months after discharge.

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



Source: National Audit Office survey of hospitals (2005)

2.13 The Picker Institute's survey of stroke patients in 2005, commissioned by the Healthcare Commission, surveyed stroke patients who were in or recently discharged from across 50 hospitals. Questions focussed on the inpatient stay, and did show some positive results, with patients showing satisfaction with their treatment and care. For instance, 90 per cent of patients said they got at least some help with swallowing, 84 per cent got at least some help with speech and communication problems, 92 per cent got help with their mobility, and 76 per cent got at least some help with emotional issues. Although the survey could not capture patients' experience of care once they had been discharged for a significant length of time (although a follow-up survey is planned), it did ask questions about care immediately after they had left hospital. These results were less positive:

- 48 per cent of respondents said that hospital staff did give them information about local voluntary and support groups,
- 69 per cent said they got enough help with speaking difficulties after they left hospital,
- 63 per cent of patients said that all the services they needed after they left hospital were arranged for them,
- 59 per cent said they got enough help and support with emotional issues affecting them after they had left hospital.

2.14 Data from the South London Stroke Register (the most comprehensive source of follow-up information on stroke patients in England) showed that in 2002, 71 per cent of those with clinical need received physical therapy and occupational therapy, and 60 per cent received speech and language therapy, at the onset of their stroke. However, this dropped markedly between three months and one year after stroke. Only 26 per cent of patients in need received physical and occupational therapy and 14 per cent received speech and language therapy during this period.

Stroke survivors require informal care and nursing, and a heavy burden falls on carers

"We are astounded by the lack of assistance our parents have had. My father is 91 years old and Mother 84 ... Everything has been left to us" – A carer

2.15 The Sentinel Audit states that carers are a vital resource for patients and it is known that carers' morbidity is high. The Department has developed a National Strategy for Carers, granting carers the right to request their own needs assessment, and introduced a £450 million Carers' Grant. However, in over half of the cases in the Sentinel Audit the carers' needs were not assessed. In the 2001 patient survey, 59 per cent of patients with carers said their carer received little or no support.
Twenty-eight 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. Carers said they had problems:

- getting advice on benefits (40 per cent),
- getting support from social services (49 per cent) and
- getting support from local health services (52 per cent).

2.16 The burden of care can be very great, and many families will want to care for the person who has had a stroke at home rather than for the stroke sufferer to go into institutional care **(Case Study 8)**. Figure 12 indicates that the economic cost of income lost, benefit payments, and informal care, is around £4.2 billion.

CASE STUDY 8

Barbara has suffered five strokes and Derek is her carer

Before her first stroke, Barbara, a graduate physicist with a talent for water-colour painting, was in good health and led an active lifestyle. Barbara's first stroke occurred in 1999 and caused memory loss. This was followed by another stroke a year later, after which she was paralysed but was able to recover. However, she experienced a third severe stroke in 2001, leaving her with incontinence and dementia but not physically disabled. Barbara experienced two further strokes in 2003, causing her to lose the ability to walk and speak and leaving her left arm paralysed.

Barbara's strokes initially required significant adaptations to her home, including an additional handrail on the stairs and the installation of a rotating seat in the bath. Later, as Barbara's condition worsened, a hospital bed, cyclic pneumatic mattress, ramp and hydraulic hoist were also added to the house. Barbara receives attendance allowance, which partially pays for two visits a day from carers who help clean her and change her bedding. She is also visited twice a week by district nurses who dress the wounds caused by her disability - where the contractions in her hands have caused her fingers to penetrate the flesh on her thumbs. Incontinence support is provided by a weekly service of clean replacement bed linen. In addition Barbara is occasionally visited by a social worker, and by her GP.

By far the greatest provider of care is Barbara's husband of 50 years, Derek, who is also 73 years old and is available for his wife 24 hours a day, seven days a week. The ongoing emotional distress experienced by Derek as a result of caring for his wife is extremely high. However, his burden is somewhat lightened when Barbara is taken into hospital for respite care, for two weeks in every eight weeks, a service which is provided free of charge by Stockport Primary Care Trust, to give carers a break.

Source: National Audit Office

The voluntary and community sector can provide effective support services for stroke survivors but demand outweighs supply

2.17 The impact of a stroke and the amount and kind of disability that results depends upon where in the brain the damage has occurred. However, some parts of the brain can take over from other parts that have died. A stroke affecting the left side of the brain causes symptoms, such as paralysis, on the right side of the body, and in most right-handed people, the left side of the brain controls language and speech. This is why many people living with stroke 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. People with aphasia can be encouraged to re-learn how to communicate: with the right help patients can significantly increase their communication abilities. These kinds of improvements can make the difference for a stroke survivor who wants to be able to work. One stroke survivor told us that she could hardly speak at all initially after her stroke, but that attending an aphasia group had helped her enormously **(Case Study 9 overleaf)**. The Stroke Association provide this kind of support to around 4,000 people a year, which is around a fifth of the number of patients that are discharged with a continuing need for therapy addressing communication problems.

2.18 Voluntary organisations can promote alternative but effective support through events and groups, rather than on an individual basis, and so can deliver services at a significantly lower cost than the nearest comparable type of service provided by the NHS. An external evaluation[27] of the services of Connect, a national charity for people with aphasia, showed that people with stroke and aphasia who participate make statistically significant gains in both their quality of life and communication skills **(Case Study 10 overleaf)**. Through these kinds of opportunities people with aphasia have gained increased confidence and well-being, new interests and skills, regular opportunities to participate in activities outside the home, and have created new and sustaining relationships with other people with aphasia in the process.

CASE STUDY 9

Aphasia Group – Speech and Language Therapy

We visited an aphasia group in North London, run by the Stroke Association and funded by Barnet Primary Care Trust. There is a home visiting programme where volunteers spend one hour per week with a client in their own home to work together on communication skills. Ten volunteers and one paid employee also run 45 therapy sessions a year, each lasting two hours with an average caseload of 30 clients.
These sessions are designed to help clients practise their communication abilities such as reading maps or writing cheques, improving their word-retrieval and word-recognition. The sessions also provide a network of friends in the local community and two hours respite a week for the client's carers.

In total the funding is £21,643 a year, which equates to approximately £16 per client per session, although small donations are also asked of the clients or carers. A private Speech and Language Therapy session would cost around eight times that amount (around £50-100 per hour depending on the complexity of the case).

Source: National Audit Office

CASE STUDY 10

Events at galleries for people with aphasia

The national charity for people with aphasia, Connect, has developed partnerships with arts organisations in London such as the National Portrait Gallery, Dulwich Picture Gallery, the Tate Gallery and others. In partnerships with the galleries, Connect has explained the needs of people with aphasia, enabling the galleries to provide a range of events specifically aimed at people with aphasia, such as art workshops through which they explore the impact of their stroke and disability. This advice on how to make facilities more accessible for people with physical and communication disabilities means the galleries are now also well-placed to enable people with aphasia to participate in mainstream events, which people living with stroke otherwise might not have attempted.

Connect has established strategic partnerships with acute and primary care NHS trusts in the South West and with the Stroke Association to collaborate on a three-year project beginning in 2006 to test how to expand the type of services described here.

Source: National Audit Office

2.19 Stroke sufferers often have unmet needs in areas such as dealing with the trauma of having a stroke and getting ongoing support and ideas for how to manage life with disability. Just under a third of respondents to our patient forum said that they were using voluntary and community services and a third were using social services. Almost half of the people who were using voluntary services rated them as six or above (on a scale of one 'not providing any support at all' to ten 'providing excellent support') compared to a third of users of social services who rated those services as six or above.

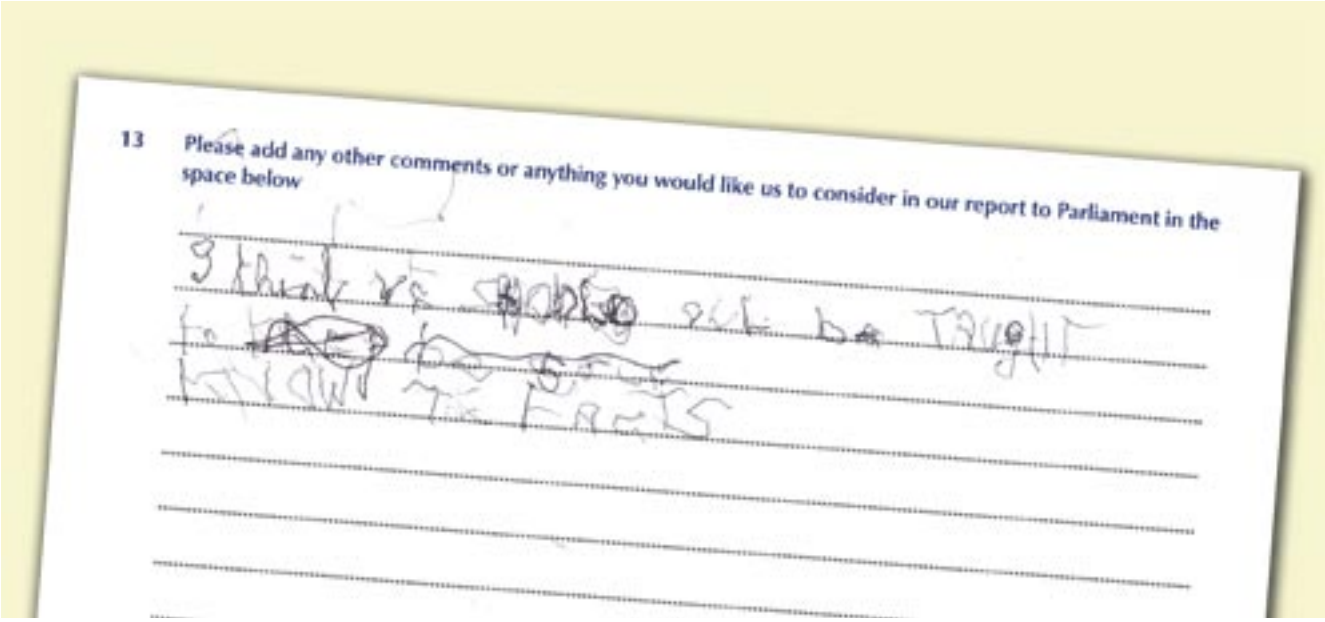
2.20 There is an active voluntary sector presence for supporting people with stroke which some primary care trusts are making use of. However, although around 300,000 people across England are living with disability after their stroke, only around five per cent of families (15,000) are receiving Family Support services from the Stroke Association, which seek to provide emotional support and information on a range of issues including secondary prevention, transport and mobility, and housing and benefits. The Department of Health is currently working with voluntary and community sector organisations and the NHS to develop improvements in the procurement of health services from the third sector.[28]

PART THREE

Preventing Stroke

'I wish I'd known more about the combination of raised cholesterol and hypertension on the blood vessels. I wish I'd known strokes don't only happen to older people'

Many strokes are preventable, and the greatest potential for achieving value for money benefits in stroke care services is in preventing strokes. There are simple ways of preventing first-ever stroke (primary prevention) and in targeting prevention of further stroke in those who have already had previous strokes or mini-strokes (secondary prevention). The new contract for GPs has improved the prevention of stroke, although some risk factors are still under-treated. Public awareness of stroke, and the fact that it is a medical emergency requiring urgent attention, is low. There are also inefficiencies in the organisation of outpatient care: improvements here could prevent strokes in those at high risk.



This is an extract from one respondent to our patient forum, in this case a paper-based response. It reads " I think we should all be taught to know the facts".

There is insufficient public awareness of what a stroke is and its seriousness, how to recognise symptoms and what to do if they occur

"She had been warned about a stroke unless she got her weight and blood pressure down but ignored it saying 'a short life and a gay one'. She is now unable to walk, incontinent, epileptic and has reduced comprehension"
– A carer

3.1 Although stroke is one of the top three diseases causing death, our survey showed that public awareness of stroke is low. People are unsure what a stroke is, and only 21 per cent of respondents to our public 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. Only one in five respondents mentioned reducing blood pressure as a way of reducing risk of stroke.

3.2 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 we asked them what the top causes of death were.

3.3 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"*. Sixty 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; ten per cent would ignore it or phone a friend. Although these proportions do not vary by ethnicity or region, men are more likely to ignore it than women, and older people are less likely to say they would call an ambulance than younger people.

Public health campaigns have had modest success in raising awareness specifically about stroke and the least success with ethnic minority and deprived groups

"I wish I had known what a TIA was prior to my major stroke. I had four of these but did not know what was going on"
– A patient

3.4 The 2004 *Choosing Health* White Paper sets out a range of actions to reduce the number of people who smoke, encourage sensible drinking and encourage healthier eating. Campaigns on reducing smoking and encouraging healthy eating should have an impact, but 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 to our survey 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. Similarly, 50 per cent of respondents 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) thought it related to heart disease, and 11 per cent thought it related to cancer, in comparison with six per cent who thought it related to stroke. Respondents to our survey who had heard of 'Sid the Slug' were no more likely than those who had not heard of it to mention that reducing high blood pressure can reduce risk of stroke. However, those who had heard of 'Sid the Slug' were more likely to mention that cutting down on salt intake can reduce the risk of stroke.

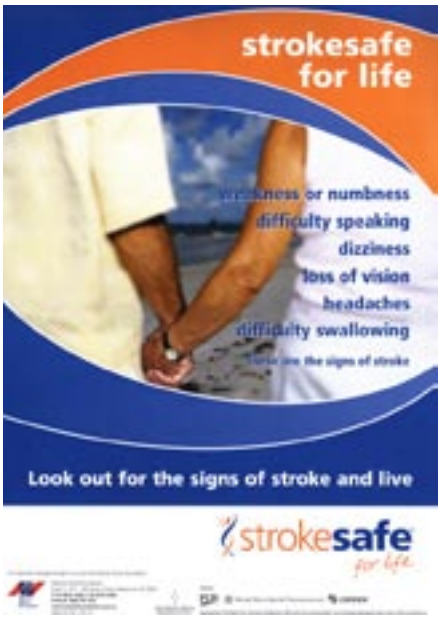
3.5 Improving people's understanding of stroke and teaching the signs of stroke should achieve sustainable changes in attitudes and behaviour that increase the likelihood that acute treatments and preventative measures are initiated. The *Choosing Health* White Paper includes commitments to increase health literacy, focusing first on the most deprived areas and building on existing information resources, such as NHS Direct. The strokesafe™ campaign in Australia was developed to convey the fact that people can be safe from stroke **(Case Study 11)**.

CASE STUDY 11

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

3.6 Incidence rates of stroke are higher in the black population (even after adjusting for social class, age and sex). Black respondents to our public survey 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. Thirty per cent of respondents in the two highest socio-economic groups mentioned reducing blood pressure as a way of reducing the risk of stroke, compared with 19 per cent in the fourth socio-economic group and 15 per cent in the fifth socio-economic group. Sixteen per cent of respondents in the bottom fifth income bracket mentioned reducing blood pressure, compared with 23 per cent across the top four fifths. This variation has implications for future public health campaigns that seek to contribute to the Department's aim, as described in its Public Service Agreement, of achieving a "40 per cent reduction in the inequalities gap, in relation to mortality from heart disease, stroke and related diseases, between the fifth of areas with the worst health and deprivation indicators and the population as a whole".

3.7 Seventy-five per cent of respondents to our patient forum said that they knew nothing about, or had only a basic awareness of, stroke before it happened. When we asked respondents to tell us what they wished they had known before the stroke, they most commonly said they did not know about the causes of and risk factors for stroke and how to prevent it, particularly that it was important to manage high blood pressure. People also told us about the unexpected impact of the stroke on their own and their loved ones' lives. Commonly, respondents 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.

3.8 Stroke consultants estimated that five per cent of patients who initially attend at an outpatient clinic chose not to finish the entire course of their investigations and therefore did not receive feedback on their results and what to do next. At current levels of outpatient treatment this might be 12 people per year per clinic – a total of around 1,500 people a year who are not aware of the importance of the tests and results for initiating therapy that can prevent further, and perhaps major, strokes. This is specifically a problem for people who have a TIA, as the symptoms (which are painless) pass usually within an hour and people will feel 'back to normal' soon after the TIA occurs. It can be easy to put the symptoms down to 'a funny turn' when a TIA is actually a serious event.

The new GP contract and more widespread protocols between primary and secondary care have led to improvements in stroke prevention

3.9 In 2001 the Department published milestones to be achieved by April 2004 which stated that protocols for treating stroke and TIA should exist between all providers of secondary and primary care. The results from our survey of hospitals show that protocols for referring TIA were in place at 55 per cent of hospitals in 2004 and in 76 per cent of hospitals in 2005; and protocols for primary care referral of acute stroke increased from 49 per cent to 60 per cent.

3.10 The Department's new GP contract came into place in April 2004. This awards points (which translate into funding) to GPs for recording particular interventions or treatments they have given to their patients. As a GP increases the delivery of treatments or interventions from a minimum to a maximum threshold of relevant patients, funding increases. We commissioned an examination of the achievement of the indicators in the contract that relate to the secondary prevention of stroke (further details are in Appendix 7).

3.11 Evidence suggests that controlling blood pressure has a significant effect at a population level in terms of preventing first ever stroke. The percentage of patients aged 45 and over who had had their blood pressure recorded increased from 77 per cent in 2004, to 81 per cent by 2005. Of patients who had had their blood pressure recorded, 77 per cent had their blood pressure controlled in 2004 and by 2005 this had also increased to 82 per cent. Many patients (83 per cent in 2004 and 87 per cent in 2005) have a record made of whether they are smokers, and around one in five of those people are smokers. However, smoking cessation advice was given to more smokers overall in 2005 (52 per cent) than in 2004 (38 per cent).

3.12 The stroke-specific indicators in the GP contract relate to controlling and assessing risk in patients who have already had a stroke or TIA. Nationally, the percentage of patients achieving those indicators rose between April 2004 and April 2005 for all indicators except that which asks that GPs refer patients with suspected stroke for an MRI or CT scan **(Figure 14)**.

3.13 The level of improvement in measuring and controlling blood pressure in people who have already had a stroke is likely to significantly reduce the incidence of further strokes. Similarly, if the trend in improving the measurement and control of cholesterol in patients with a history of stroke continues (which is likely) then the maximum threshold should be met in the next twelve months. Patients who have had a non haemorrhagic stroke should be prescribed aspirin or an equivalent anti-platelet drug or warfarin. At a national level the threshold was not met in 2004 or in 2005, but if there is a similar improvement over the next twelve months then the threshold should be achieved by April 2006. The publication of an additional chapter to the Coronary Heart Disease National Service Framework covering arrhythmias and sudden cardiac death is another encouraging sign as atrial fibrillation, the most common arrhythmia, is a major risk factor for stroke.

3.14 There is no evidence to suggest that GPs treat patients with stroke or TIA from rural or deprived areas in a different way from other patients with stroke or TIA. Deprivation or rurality had no effect on whether patients achieved the thresholds in the indicators. Since there have been a number of earlier studies showing differential access to care for patients from deprived areas with coronary heart disease or diabetes, this is a positive result and is in line with the Department's Public Service Agreement target to reduce health inequalities between the most and least deprived areas.

14 Since the introduction of the GP contract, more stroke patients are receiving treatment to prevent a second or further stroke

Indicator description	Threshold	Patients achieving indicator 2004 (%)	Threshold achieved?	Patients achieving indicator 2005 (%)	Threshold achieved?
Newly diagnosed stroke patients referred for MRI or CT	80	47.5	✘	45.5	✘
Stroke or TIA patients with smoking status	90	70.9	✘	91.1	✔
Stroke or TIA current smokers offered cessation advice	70	79.7	✔	91.8	✔
Stroke or TIA patients with blood pressure recorded	80	88.5	✔	94.7	✔
Stroke or TIA patients with blood pressure <=150/90mmHg	70	68.9	✘	80.3	✔
Stroke or TIA patients with cholesterol recorded	90	62.1	✘	77.7	✘
Stroke or TIA patients with last cholesterol <= 5mmol/l	60	41.0	✘	54.9	✘
Non-haemorrhagic stroke or TIA patients taking aspirin or antiplatelet or anticoagulant	90	78.9	✘	84.3	✘
Flu vaccination in the preceding 1st Sept - 31st Mar	85	79.4	✘	86.1	✔

Source: National Audit Office analysis

GP behaviour still varies and needs to be better managed

"My wife had several TIAs which were not recognised as such by several GPs" – A carer

3.15 Thresholds for achieving the indicators are set and apply at individual practice level so a threshold can be exceeded in the overall national sample but not met in a significant number of individual practices. A practice level analysis showed substantial variation. In 2004 the proportion of practices achieving the maximum threshold ranged from five per cent (recording cholesterol) to 88 per cent (recording blood pressure) and in 2005 from 11 per cent (referring for a scan) to 99 per cent (recording blood pressure). The largest increase is seen in recording smoking status where the percentage of practices achieving the maximum threshold increased from 16 per cent in 2004 to 68 per cent in 2005. There are increases for all other indicators except referring for a scan, where 23 per cent of practices achieved the threshold in 2004 but only 11 per cent in 2005. Maximum thresholds for key interventions, such as providing smoking cessation advice, controlling blood pressure and controlling cholesterol were achieved in 94, 89, and 40 per cent of practices respectively.

3.16 Although 70 per cent of GPs in our survey said their practice had a way of identifying patients at risk of first-ever stroke, it is not clear how far these systems are used to actively prevent first strokes. Where there were systems in place they were unlikely to monitor when a patient reaches a certain age: only a quarter of practices do this, even though age is a key risk factor and is easy to monitor. Data from the Sentinel Audit (2004) suggests that risk factors could be better managed **(Figure 15)**.

3.17 The Bournemouth Primary Care Trust and the Royal Bournemouth and Christchurch Hospitals NHS Trust ran a programme to promote better management and primary prevention of stroke; it shows how active engagement with GPs can improve GP awareness **(Case Study 12)**.

15 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 angiotensin 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 at 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 analysis of Sentinel Audit data and advice from the Intercollegiate Stroke Working Party

CASE STUDY 12

Improving GP awareness of stroke: Bournemouth

A specialist nurse in stroke, who held honorary contracts with both the primary care trust and acute trust, was appointed for one year. Funding was obtained from a pharmaceutical company at a cost of approximately £20,000. The nurse visited all 25 GP practices within Bournemouth Primary Care Trust, and worked closely with practice managers to help each practice create registers for those patients considered to be at risk of stroke and TIA. Practice-based lunchtime educational meetings were held at different locations around the trust's catchment area, and the e-booking process for the acute trust's TIA clinic was promoted. As a result of the nurse outreach programme more practices were able to identify patients at risk of stroke and implement a prevention policy; there was higher awareness and use of referral and prescribing practices and protocols and there was an improvement in the number of outpatients appropriately referred to the TIA clinic at the Royal Bournemouth Hospital.

Source: National Audit Office

3.18 Two-thirds of GPs in our survey said they received, as a matter of routine, information about the secondary arrangements for their patients but nearly a third were unsure if their patients received their outpatient appointments. This suggests that even for the patients being referred for scans (less than half of all patients), there are communication breakdowns. Not all of the patients who are referred will have their results fed back to their GPs, and GPs will not necessarily be informed about their treatment and care needs.

3.19 Just over half of GPs said they would refer a stroke patient immediately, and more than a third of GPs are likely to wait more than six hours to refer a patient with TIA. Nearly one in five GPs said they do not refer 20 per cent or more of their TIA or stroke patients. GPs said the likelihood of referring their patients for outpatient appointments would vary, depending on factors such as the severity of the stroke **(Figure 16)**.

16 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 inpatients are not effectively communicated to GPs"

Source: National Audit Office survey of GPs

Removing delays in providing interventions that can prevent stroke would save money

"My mother's scan has taken four weeks to happen although she was seen by the GP on the day of her stroke. He won't do anything until he has seen the results, time during which she should have been receiving treatment"

– A carer

3.20 Nearly a third of the patients who had a stroke in the three months of the Sentinel Audit had had a previous TIA or 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. Symptoms of stroke, however mild, require urgent medical attention because further and more serious strokes can be prevented. The risk of stroke in the seven days following a TIA can be up to ten per cent – around 45 times the 'normal' risk – and within four weeks of TIA the risk of stroke can be 20 per cent. This increased risk means that patients need to be seen rapidly in a TIA clinic. Guidelines published by the Royal College of Physicians state that all patients in whom a diagnosis of TIA is suspected should be assessed and investigated within seven days.

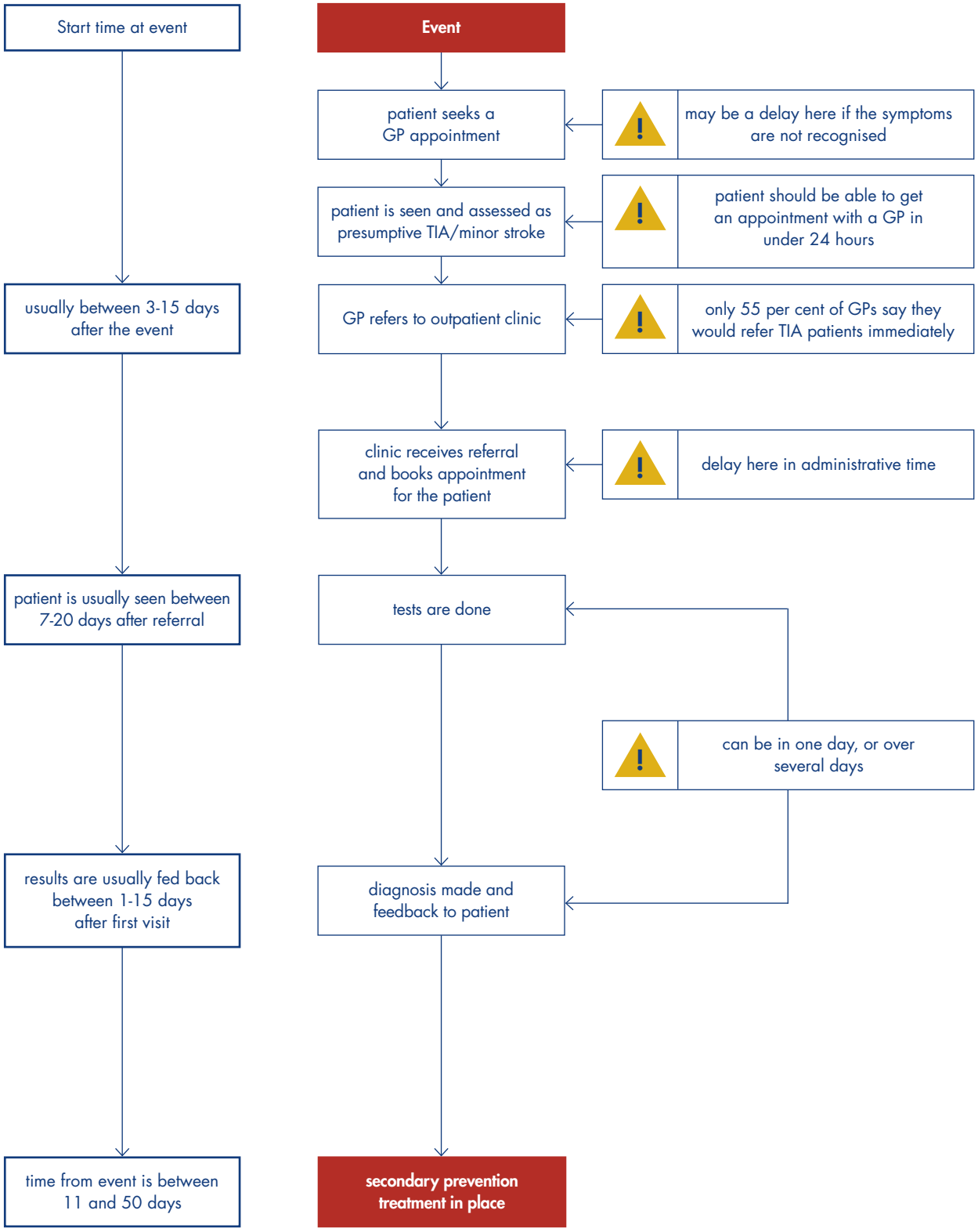
3.21 The Sentinel Audit showed that overall, only a third of people with TIA are seen in a TIA clinic within 14 days. The median waiting time for those that do get an appointment is twice as long as the seven days recommended in the clinical guidelines as the maximum time patients should have to wait. In 2005, the stroke consultants we surveyed confirmed that around half of the patients that get an outpatient appointment will get a CT scan within 14 days of their first visit to hospital. There may well be a delay between the TIA event and the person's appointment with their GP, and if the GP does make a referral to a TIA clinic, they may not make this referral urgently. There may be further delay before patients start their treatment for secondary prevention because they may not get results and feedback on the day of their scan. Although some clinics are run as 'one-stop-shops', some patients can wait up to 14 days after their first visit to the clinic for their feedback and results. **Figure 17** shows how there are several barriers that can preclude getting effective early treatment.

3.22 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.

3.23 The Sentinel Audit also showed that 39 per cent of hospitals had no outpatient scanning of any kind (CT, Doppler, or MRI) available within 14 days and 58 per cent of hospitals cannot provide outpatient CT scanning within 14 days of a TIA. Even where there is scanning capacity, the majority of scans are not made available for stroke outpatients within the critical period (within 48 hours for CT or MRI scans, or within 14 days for Doppler scans) as shown in **Figure 18 on page 42**. Half of the stroke consultants responding to our short questionnaire suggested (unprompted) that better access to CT and Doppler scanning would be a key way of improving the efficiency and effectiveness of TIA clinics.

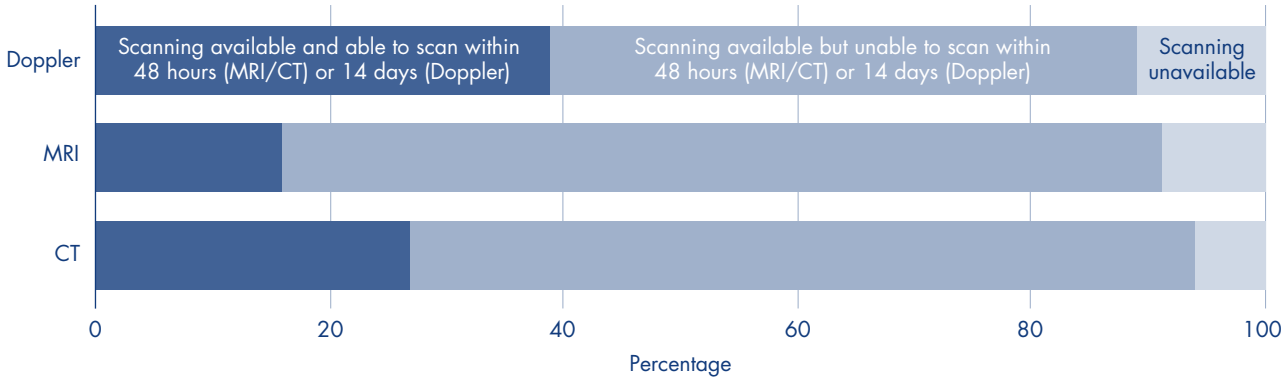
3.24 The Sentinel Audit showed that 58 per cent of new patients with TIAs do not get their CT scans within two weeks. The annual cost of providing those scans outside of the two-week time window is approximately £1.2 million (14,250 scans at a unit cost of £85). This is an inefficient use of those funds because risk of further stroke or other vascular events is highest early after stroke or TIA. Risk of recurrent stroke is high in the first two weeks so delays in being seen in a TIA clinic mean there are second strokes that could have been prevented.

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



Source: National Audit Office analysis

18 There is scope for more efficient use of outpatient scanning capacity



Source: National Audit Office analysis of Sentinel Audit data

Providing better secondary prevention would be cost effective

"The NHS will spend hundreds of thousands on someone post stroke but not a few hundreds in preventative steps".
– A patient

"I was not fully informed that if I ceased taking my medication to control hypertension that I fell into one of the risk factors – had I been told I would have continued taking the medication and I would not be currently disabled" – A patient

3.25 Improvements to acute care, rehabilitation, and service organisation can reduce the cost of stroke services by improving the efficiency with which resources are used and by improving morbidity levels. Better primary and secondary prevention would reduce the annual incidence of stroke and so also reduce costs. For example, the economic modelling we commissioned from King's College, London and the London School of Economics and Political Science showed that:

- If the proportion of patients spending the majority of their time on a stroke unit increased from current levels (around 50 per cent) to 75 per cent, then 550 deaths could be prevented in a year. There would also be an increase of 205 in the number of independent cases at an additional cost of £32 million. If access to stroke units is further increased to 95 per cent then 441 more deaths could be prevented and 163 more cases would be independent at an additional cost of £22 million. However if the average length of stay is three days shorter in stroke units than in general wards then there would not be an increase in costs, with the same number of deaths prevented and same number of increase in the independent cases.
- If the proportion of stroke patients on antiplatelets is increased from the current situation (85 per cent) to 95 per cent, then 17 deaths and 45 recurrent strokes would be prevented. This would also lead to an increase of six independent cases at an additional cost of £56,000 annually.

3.26 We examined the benefits of providing faster access to carotid surgery for TIA patients with moderate to severe stenosis (narrowing of the artery). To provide the maximum benefit, surgery should be performed within two weeks of the TIA.[29] Nearly all TIA patients with stenosis who are referred for surgery in England, however, are not operated on until much later than this. Using data from studies on the efficacy of carotid surgery, and unit cost data collected by the London School of Economics and Political Science, we estimated that providing surgery within 14 days of TIA for patients with stenosis could prevent about 250 strokes a year, and yield a net saving to the NHS in care costs avoided of around £4 million.

Investing in clinical best practice can deliver improvements in meeting high-level targets, although managers and commissioners are not always aware of the potential dividends

3.27 We ran a structured group activity with commissioners and clinicians to look at the issues around effective and coordinated working in providing stroke services. We found that the two groups can appear to each other as separate 'tribes' speaking separate 'languages' where different levers impact on how they appraise priorities and approach resource allocation. Although this was only a small exercise our expert advisers confirm that the issues are commonplace. Clinical evidence generally concentrates on quality improvements for the patient. But if stroke services are to be appropriately prioritised among all the other services being demanded from the NHS, then evidence also needs to be explicit about other impacts such as improvements in service delivery, or the potential for financial benefit as indicated by the example of faster access to carotid surgery in the previous paragraph. This is particularly important from a commissioning point of view, where clear implications of service re-design would need to be explained and justified with references to key strategic and local targets.

3.28 For stroke services, easily identifiable linkages can be made to targets such as re-admission rates (through better secondary prevention) and lengths of stay (through increasing the capacity of stroke units and developing early supported discharge teams), as well as to reducing mortality from cardio-vascular disease (through better primary and secondary prevention, and faster access to treatments such as thrombolysis) which is in the Department's Public Service Agreement in the 2004 Spending Review. Commissioners and clinicians can deliver clinical and management priorities by working together and considering the implications of evidence-based good practice in terms of both patient outcomes and sound financial management.

APPENDIX 1
Methodology

We designed this study to examine whether the NHS is providing effective and high quality stroke care services, and whether the Department of Health is managing and supporting the stroke care programme well. Our study methodology involved the collection and analysis of primary data to provide evidence on public awareness of stroke; the impact of stroke on patients and their carers; the numbers of nursing home residents who have entered residential care as a result of stroke; the behaviour of GPs in managing and preventing strokes and TIAs; the cost of stroke to the health service and the wider economy; and the extent to which hospitals are providing specialised stroke and TIA services and patients are accessing them. We also carried out secondary analysis of the extensive data collected by the Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians and the patient survey data collected by the Picker Institute for the 2005 stroke patient survey commissioned by the Healthcare Commission, as well as reviewing relevant literature and speaking to a wide range of stakeholders such as patients, carers, GPs, consultants, nurses, commissioners, managers and voluntary sector workers. Details of the main strands of our methodology are set out below.

Public awareness survey

We commissioned Ipsos UK to run a telephone survey of the public in February 2005. They provided responses for a representative national sample of 1,650 people in England on questions about stroke, together with demographic information about respondents. This enabled us to gauge overall levels of knowledge of stroke, and to test for statistically significant variations by subgroups such as gender, age, region and socio-economic status. The results of these analyses are used particularly in paragraphs 3.1 to 3.6.

Telephone survey of nursing homes

We conducted telephone interviews in March 2005 with a simple random sample of 100 nursing homes in England. We asked about the care provided for residents with stroke, the number of people who had entered the home as the result of a stroke, and the cost of their care. The results are used particularly in paragraph 2.2.

Survey of members of the British Association of Stroke Physicians

We surveyed members of the British Association of Stroke Physicians in January 2005 via a self-completion questionnaire, and received 90 responses (an approximate 50 per cent response rate for English members). We asked about staffing and the provision of outpatient TIA services. The results are used particularly in paragraph 3.8, 3.21, 3.24 and in figure 17.

Survey of GPs

We commissioned Medix PLC to run a web-survey of GPs, with questions on the primary and secondary prevention of stroke, and the treatment of stroke patients. The survey was run in March 2005. There were 568 respondents. We supplemented this with a further web-survey of 511 GPs to provide benchmark information about the treatment of angina. Medix checks when the summary statistics for the data converge to values that do not significantly change with the collection of more data to ensure that the sample size is sufficient to provide a nationally representative response. The results of these surveys are used particularly in paragraphs 2.8, 3.16, 3.18, 3.19 and figures 4 and 16.

Economic analyses of the cost of stroke, and the benefits of interventions

We commissioned King's College, London and the London School of Economics and Political Science to carry out an economic burden of illness study to calculate the cost of stroke to the NHS and to the wider economy, and to model the costs and benefits of interventions that have the potential to improve stroke care. Further details are given in Appendix 4, and a full report of the work is available on the NAO website **(www.nao.org.uk)**. Special thanks are due to R. Omer Saka MD, MSc, Research Associate, King's College, London, Division of Health and Social Care, for his commitment to this project. The results are used particularly in paragraphs 1.21, 2.1, 3.25-6 and figure 12.

Analysis of anonymised patient records from GP management information systems

We commissioned QRESEARCH, a not-for-profit organisation developed by the University of Nottingham, to examine achievement against the patient outcome indicators for stroke set out in the Quality and Outcomes Framework for primary care practices in the UK. QRESEARCH analysed 2,934,111 patient records for the period 1 April 2004 to 31 March 2005 against these indicators. Further details of the analysis are given in Appendix 7, and the full report from QRESEARCH is available on the NAO website **(www.nao.org.uk)**. The results are used especially in paragraphs 3.9 to 3.15 and figure 14.

Analysis of data from the Sentinel Audit of Stroke

We used the data collected by the Royal College of Physicians for its 2004 *National Sentinel Audit of Stroke*, sponsored by the Healthcare Commission, to examine stroke care provision in England. We should like to thank the Clincal Effectiveness and Evaluation Unit at the Royal College of Physicians for their help in running analyses for England alone, and for responding so helpfully to our requests for additional analyses. The results are used throughout the report.

Web-survey of hospitals

We ran a short web-survey of hospitals in March 2005 to update some of the data in the Sentinel Audit, and to collect responses on some other issues not raised in the Sentinel Audit. We received responses from 192 hospitals (an 86 per cent response rate). The results are used particularly in paragraphs 1.6, 1.11-12, 1.14, 1.19, 2.6, 2.9, 2.12 and figures 5 and 13.

Patient and carer web forum, and carer focus group

We set up an internet-based forum (which we also made available in paper form on request) to enable people who had had a stroke and/or their carers, to answer the question 'what would you like Parliament to know about stroke care?'. We advertised the forum through the British Association of Stroke Physicians and the Stroke Association, and via links from other internet sites such as Connect (the national aphasia charity) and the BBC news health webpages. We received 209 responses. We triangulated these against our other evidence sources to ensure we avoided bias or undue attention to anecdotal evidence in building up a picture of the patient and carer experience of stroke care. We also ran a focus group of carers to explore issues affecting them. The results are used, and quoted in places, throughout the report.

Case study visits and interviews

We identified examples of good practice in stroke prevention, treatment and rehabilitation, and visited centres and organisations in England, Scotland, Sweden and Australia to collect evidence of how barriers to the delivery of more efficient and effective stroke care services were being addressed and overcome. The results are used and illustrated in case studies throughout the report.

Benchmarking of stroke against coronary heart disease

We benchmarked the provision of stroke care in England against the provision of care for patients with coronary heart disease. The results are summarised in Figure 4 in the main report.

Expert group activity

We ran a structured group activity to examine explicitly the different trade-offs that clinicians and commissioners of healthcare services make in designing and delivering stroke care services. The results are used particularly in paragraphs 3.27 and 3.28.

Consultation and expert panel

Our partnerships with the following organisations underpinned our work: The Clinical Effectiveness and Evaluation Unit at the Royal College of Physicians, the Stroke Association, King's College and the London School of Economics, Connect, the British Association of Stroke Physicians, the Intercollegiate Stroke Working Party and the Healthcare Commission.

The Intercollegiate Stroke Working Party acted as a reference panel for this study. We thank them for their time and assistance. The following provided extra individual input to this report, for which we are grateful:

Dr Tony Rudd	Chair of the Intercollegiate Stroke Working Party and Consultant at Guy's and St Thomas's Hospital, London
Professor Derick Wade	Professor and Consultant in Neurological Rehabilitation, Oxford Centre for Enablement
Professor Gary Ford	Professor at the University of Newcastle, Consultant Stroke Physician at the Freeman Hospital and Director of the UK Stroke Research Network
Dr Helen Rodgers	Reader in Stroke Medicine, University of Newcastle

APPENDIX 2

Recent Initiatives in Stroke

2001 The Department of Health published the *National Service Framework for Older People*; Standard Five relates to stroke care, and contains the following milestones for April 2004:

PCG/Ts will have ensured that:

- every general practice, using protocols agreed with local specialist services, can identify and treat patients identified as being at risk of a stroke because of high blood pressure, atrial fibrillation or other risk factors
- every general practice is using a protocol agreed with local specialist services for the rapid referral and management of those with transient ischaemic attack (TIA)
- every general practice can identify people who have had a stroke and are treating them according to protocols agreed with local specialist services
- every general practice has established clinical audit systems for stroke
- 100 per cent of all general hospitals which care for people with stroke have a specialised stroke service as described in the stroke service model

None of these milestones refer to rehabilitation or integration between the different sectors to deliver stroke-specific care. For issues of long term care, the reader is directed to Standard Two, on person-centred care. One of the milestones for this specific standard is to introduce a single assessment process for health and social care for older people by April 2002. There is also a milestone for integrated community equipment and incontinence services.

2004 The Joint Committee on Higher Medical Training (JCHMT) has the authority to oversee training in all medical specialties. Upon recommendation of the JCHMT, a Certificate of Completion of Specialist Training (CCST) will be awarded, which grants entry in the Specialist Register, allowing trainees to practise as a consultant. The JCHMT announced a sub-specialist training programme "in response to the clear need for the NHS to train physicians in the specialist expertise of stroke medicine". Prior to this programme there was no formal training structure for a career in stroke medicine. The training programme expects all stroke specialists to have core knowledge and skills in all areas of diagnosis, investigation and treatment relevant to the care of stroke patients. After satisfactory completion of subspecialty training in stroke medicine, trainees would be eligible to have the subspecialty of stroke medicine included in their entry in the General Medical Contract's Specialist Register, after the award of CCST in their parent specialty.

2004 National Clinical Guidelines for Stroke 2004 (2nd edition), prepared by the Intercollegiate Stroke Working Party. These guidelines provide a framework for best care and are intended for use by clinicians and all members of the multidisciplinary team involved in the management of the stroke patient – both in hospital and in the community. Since the first guidelines were published in 2000, several hundred new references have been published, many indicating major changes in the way stroke care should be delivered (http://www.rcplondon.ac.uk/pubs/books/stroke/index.htm).

2004-05 The Royal College of Physicians' Clinical Effectiveness and Evaluation Unit publish the fourth organisational and clinical audit of stroke services funded by the Healthcare Commission. The project was guided by the Intercollegiate Stroke Working Party. This audit relates to patients admitted from 1 April 2004 to 30 June 2004 and takes place exactly three years since the last audit.

2005 The Department of Health established the Vascular Programme Board to take forward monitoring of the Public Service Agreement target to reduce mortality rates in cardiovascular disease by at least 40 per cent in people under 75, by 2010. The Board created a stroke sub-group to concentrate on improving stroke care, in order that the target remains achievable.

2005 The Department of Health launched the Stroke Research Network (SRN), funded with £20 million over five years, which is part of the UK Clinical Research Network (UKCRN). The SRN Coordinating Centre is based in the Clinical Research Centre, Newcastle University. The aim of the Network is "to facilitate the conduct of randomised prospective trials and other well-designed studies of stroke, including those for prevention, diagnosis and treatment".

APPENDIX 3

Key UK results from the Sentinel Audit

The fourth round of the National Sentinel Stroke Audit (The Sentinel Audit), prepared on behalf of the Intercollegiate Stroke Working Party, was conducted in April 2004 to coincide with the stroke milestones within the *National Service Framework for Older People*. The total number of hospitals participating (the Audit achieved a 100 per cent response rate) was 256, with 220 in England, 20 in Wales, 19 in Northern Ireland and 3 in the Channel Islands.

The organisational audit (part 1) was followed up with a clinical audit of the process of stroke care (part 2) in 2005. The full reports can be found at www.rcplondon.ac.uk The NAO worked with the authors of the Sentinel Audit to generate some further analyses (for English patients only) and the results are captured throughout the report. **Figure 19** provides a summary of some key indicators and the achievement levels across the nation.

19 A summary of key findings from the Sentinel Audit

Percentage of applicable patients:	England	Wales	Northern Ireland	National Average
Treated in stroke unit during hospital stay	47	28	62	46
Spent more than 50 per cent of stay on stroke unit	41	23	55	40
Screened for swallowing disorders within first 24 hours of admission	64	51	66	63
Commenced aspirin 48 hours after stroke	68	73	63	68
Physiotherapy assessment within first 72 hours after stroke	65	49	59	63
Assessment by an Occupational Therapist within seven days of admission	57	55	67	57
Weighed at least once during admission	52	51	49	52
Mood assessed by discharge	46	47	53	47
On antithrombotic therapy by discharge	95	97	98	95
Rehabilitation goals agreed by the multidisciplinary team	69	67	58	68
Home visit performed before discharge	70	69	50	69
Discharged with a high to moderate disability score	20	18	14	19
Discharged with a 'fully independent' disability score	37	39	42	38
Discharged to residential accommodation if living independently pre-stroke	13	10	9	12
Mean (median) length of stay to death or discharge	28 (15)	28 (16)	24 (12)	28 (15)

Source: National Audit Office Analysis of Sentinel Audit data

APPENDIX 4

Economic analysis of the costs of stroke care

1 King's College, London and the London School of Economics and Political Science undertook a 'burden of illness' analysis to calculate the direct and indirect costs of stroke to the health services and the economy more widely. They also developed a model to examine the costs and benefits of potential interventions to improve stroke care. A very brief summary of their methodology is set out below. The full report is available on the NAO's website, at **www.nao.org.uk**.

2 In calculating the burden of illness of stroke, the aim was to develop a snapshot picture of the annual cost of stroke, including **direct** healthcare costs such as inpatient and surgery costs, outpatient costs and community care costs, and **indirect** costs, such economic productivity losses resulting from people being unable to work as a result of their stroke.

3 There are two approaches that can be taken to calculating these costs: bottom-up and top-down. Bottom-up approaches build up a total cost by using information on the unit costs for all resources involved (obtained, for example, from specific local studies) and then grossing up to generate a national picture. Top-down approaches use national published sources of costs (such as the National Schedule of Reference Costs), applying these to the specific population in question. This study used a bottom-up approach supplemented in places with top-down calculations where there was a lack of detailed bottom-up data.

4 The **direct costs** included inpatient costs (costs of diagnosis, tests, inpatient stay, treatments such as thrombolysis, costs of any surgery, physiotherapy, occupational therapy, speech and language therapy, etcetera); outpatient costs (e.g. medical staff time, drug costs); and community care costs (costs of staying in residential homes or sheltered accommodation, adaptations to the home etcetera). The **indirect costs** included loss of productivity due to mortality or morbidity, and benefit payments made to people who have become disabled as a result of their stroke. Similarly, costs of informal care, such as the loss of productivity of carers, have been estimated.

5 Direct costs are calculated by establishing, from epidemiological studies of stroke prevalence and incidence, and from data sources such as the South London Stroke Register, the numbers of people annually falling into each relevant category (e.g. requiring surgery, requiring occupational therapy for a specified period of time) and multiplying these by the appropriate unit cost for that particular resource (e.g. hourly salary cost of a therapist, daily bed cost in a hospital). Indirect costs are calculated using actuarial data on expected average life expectancies of people having strokes at different ages, and calculating earnings that are consequently lost as a result of strokes occurring in people under the age of 65. Data on benefit payments to people who have had a stroke come from official statistics produced by the Department of Work and Pensions.

6 Finally, using data on the efficacy of various interventions (such as taking aspirin, or being treated in a stroke unit as opposed to a general medical ward) from clinical trials, and combining this with information on costs, it is possible to model the likely costs and benefits of different scenarios (such as increasing the proportion of people treated in a stroke unit by a given percentage from the current value). Full details of the modelling work are set out in the King's College and LSE report.

APPENDIX 5

Services needed by stroke survivors

Common services needed by stroke survivors and their carers, and issues accessing those services

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.	

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".*

APPENDIX 6

Rehabilitation of stroke patients in Sweden

Umea hospital in northern Sweden: if patients are medically stable they will be immediately mobilised and are seldom confined to bed

According to the Swedish 'Riks-stroke' stroke register, on average patients take three hours to arrive upon the stroke unit (which compares to two days in England according to the Sentinel Audit). In Umea, 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. After discharge, social services provide training for those patients still requiring further support; training in how to perform everyday tasks is provided either in the patient's own home or in specific training homes, where patients can stay for between three to six weeks before returning home. If a patient requires further assistance, social services will provide them with a home help and some stroke patients will also receive rehabilitation after discharge from a Home Rehabilitation team.

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[31]

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. In 2005 a third of inpatients 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 three to four hours of therapy per day and participate in activities designed to improve their physical abilities.

APPENDIX 7

Examination of GP electronic management information systems

1 On 1st April 2004, the Quality and Outcomes Framework (QOF) was introduced for primary care practices in the UK. The QOF sets out a range of clinical and organisational indicators against which practices are assessed. Achievement against these indicators earns practices QOF points with associated financial rewards. The QOF covers 11 clinical disease areas and one of these is Stroke/Transient Ischaemic Attack (TIA), which includes ten indicators, awarding a total of 31 points. In addition, there are four quality indicators for the management of hypertension, awarding 105 points.

2 The NAO commissioned QRESEARCH to examine the achievement of the indicators relating to stroke and TIA. QRESEARCH is run as a not-for-profit organization developed by the University of Nottingham in conjunction with Egton Medical Information Services (EMIS) – the largest supplier of general practice computer systems in the country. The full report is available at **www.nao.org.uk**; it examines the achievement of the ten stroke indicators for patients across the UK and at practice level. It also investigates the recording of smoking status and smoking cessation advice and blood pressure measurement and control in all patients on the GP lists, as a way of investigating primary prevention activity (before the patient has a stroke or TIA).

3 There were 413 practices with complete data for the entire 12 month period between 1st April 2004 and 1st April 2005. The total number of patients registered with these 413 practices on 1st April 2004 was 2,901,748 and on 1st April 2005 was 2,934,111. The median list size of the 413 practices included in this analysis was 6,324. The vast majority of practices were from England (398 practices), with nine from Wales, five from Scotland, and one from Northern Ireland. Practices within England were spread throughout every geographical region, with at least 23 practices in each region. The age-sex structure of the population in 2004 was similar to the 2001 census.

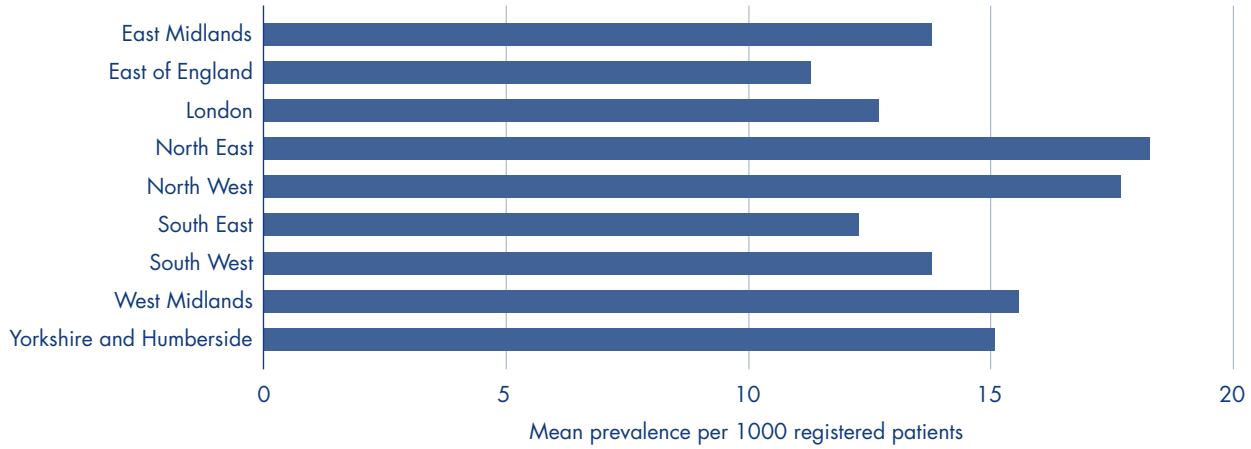
4 Of the 45,538 patients with either a stroke or TIA registered on 1st April 2004, 51 per cent were females and 49 per cent were male. Of all the patients with either a stroke or TIA, 52 per cent were from urban areas, 41 per cent from rural areas and 7 per cent had a missing rurality score; 21 per cent of stroke or TIA patients were from the most affluent quintile and 18 per cent were from the most deprived quintile. The pattern for all these characteristics was similar in 2004 and 2005.

5 For each patient with stroke or TIA, we determined whether they achieved each of ten quality indicators as defined in the contract. We compared levels of achievement at the start of the new contract with the levels achieved at the end of the first year. Results are summarised in Figure 15 of this report and further graphics are presented overleaf.

QRESEARCH make the following recommendations as a result of this work:

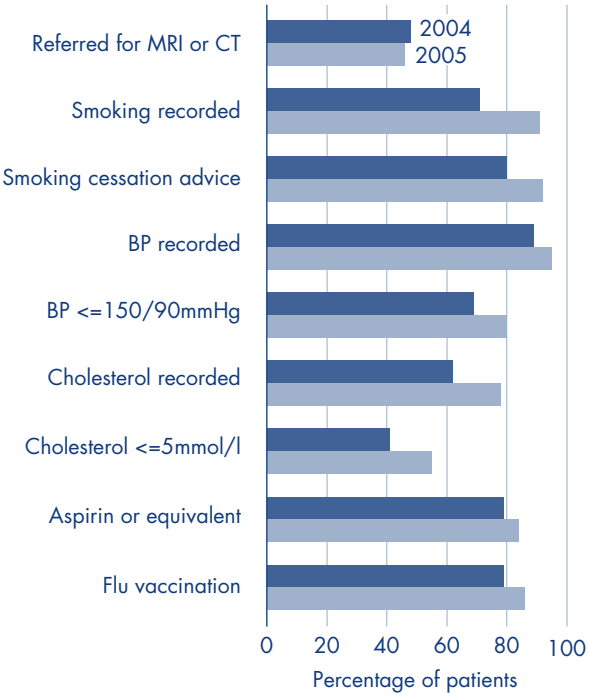
- The rationale for the different number of points attributed to each of the clinical indicators is not entirely clear. This should be reconsidered especially given the under-achievement of indicator 2 (referral for MRI or CT scan) which also happens to be associated with the lowest number of points.
- The Quality and Outcomes Framework should be revised to include better measures of primary prevention of stroke and TIA. This could include the following additional measures:
  - Overall population levels of blood pressure control
  - Overall population levels of smoking
  - Overall population levels of patients who stop smoking
  - Overall population levels of obesity and exercise
- Consideration should be given to stroke prevention in patients with co-morbidities which increase risk of stroke or TIA. This includes patients with atrial fibrillation (who may need aspirin or an equivalent antiplatelet or anticoagulant).
- The indicators could more rigorously address quality issues, for instance the indicator 'referral for a scan' may not trigger the patient actually receiving the outpatient appointment for a full neurovascular assessment. And there is also no time-bound element in this indicator, even though the benefit of the intervention declines over time.

20 Prevalence of stroke or TIA per 1000 registered patients by geographical area in 2005 adjusted by age



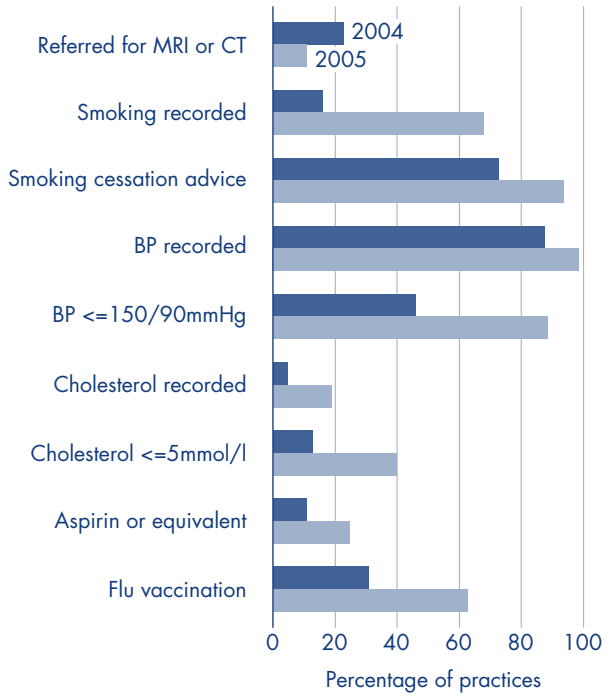
Source: National Audit Office analysis

21 Percentage of patients achieving each indicator



Source: National Audit Office analysis

22 Percentage of practices achieving the maximum thresholds in 2004 and 2005



Source: National Audit Office analysis

GLOSSARY

Antithrombotic therapy	Prevents the blood clotting e.g. aspirin or warfarin.
Aphasia	Partial or total loss of the ability to articulate ideas or comprehend spoken or written language, resulting from damage to the brain caused by injury or disease.
A&E	Ambulance and Emergency departments, where people who require urgent medical attention can access treatment at hospital.
Aspirin (antiplatelet)	A treatment than reduced the stickiness of the blood (platelets) that clump together to form a clot.
Carotid arteries	The arteries in the front of the neck which make up two of the four main blood vessels supplying the brain.
Carotid endarterectomy	The surgery which is performed on the carotid arteries to ease blood flow to the brain.
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 bleeding or a clot in the brain.
Doppler scan	An ultrasound scan of the carotid arteries in the neck to check for ease of blood flow to the brain.
GP	General Practice or Practitioner, for instance a local doctor's surgery in the community.
GP contract	The General Medical Services contract for General Practioners, issued by the Department of Health, 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.
Incidence	This is the number of stroke events that happen in a year (also see *prevalence*).
Ischaemic stroke	The type of stroke that is caused by a narrowed artery or blockage or clot, reducing blood flow to the brain and causing brain cells to die.
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 bleeding or a clot in the brain.
Prevalence	The number of people alive in the population who have had a stroke at any point in time. This differs from incidence in that it includes people who have had a stroke although that stroke event may have been in a previous year.
Primary prevention	This refers to activities that prevent a first-ever stroke or TIA.

Radiology	Is 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.
Sentinel Audit	The Royal College of Physicians published clinical and organisational audit results in February 2005 and in July 2004 respectively. References to the 'Sentinel Audit' refer to either or both of these parts of the National Sentinel Audit of Stroke 2004.
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). Can be a warning that a more severe stroke is about to happen.
Thrombolysis/ thrombolytic treatment	Clot-dissolving treatment (appropriate for ischaemic strokes only) that is given directly into a vein and currently must be administered within three hours. It is the standard treatment for blocked vessels in the heart – to treat heart attack.
Triage	This is the process whereby people presenting with disease or illness are assessed, often by nurses or junior doctors in the first place, and then referred to the appropriate specialist for further treatment when necessary.
Warfarin (anticoagulant)	A treatment (tablet) used to prevent further blood clots.

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