

Special review



Supporting life after stroke

A review of services for people who have had a stroke and their carers

January 2011

About the Care Quality Commission

The Care Quality Commission (CQC) is the independent regulator of health care and adult social care services in England. Whether services are provided by the NHS, local authorities or by private or voluntary organisations, we make sure that people get better care.

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Summary

Stroke can be a devastating and life changing event for people. However, our review found that the extent to which they are supported to cope with life after stroke varies significantly across England. The best services are built around the individual – with their care being planned to take account of the needs, circumstances and preferences of the person who has had a stroke, their carers and family. People in these areas are more likely to experience a smooth and coordinated return home from hospital and to have access to a broad range of services to help them recover from, and cope with, the effects of stroke.

But services in other areas have significant room for improvement. We found that people could not always access the services they need when they need them:

- Early supported discharge, which provides more rehabilitation at home rather than in hospital and is known to achieve better results for people and cut pressure on hospital beds, was available across 37% of areas.
- 32% of primary care trusts (PCTs) did not commission specialist stroke physiotherapy in the community across the whole of their area.
- In 44% of areas, occupational therapy for people who have had a stroke was not always provided by specialist staff with specific training on stroke.
- In 48% of areas, people had to wait two weeks on average until they receive community-based speech and language therapy.
- While most carers were given access to information and advice, in around a third of areas not all carers could access peer support, such as carer support groups or befriending schemes.

Even where services were available, accessing them can be complicated and confusing – at a time of huge emotional upheaval:

- Most people are given an information pack when they leave hospital, but it is often poorly organised – only around 40% of people told us it was easy to find things in them.
- Only 40% of these packs contained good information on local services.
- While 87% of areas provided a helpline, only 26% were available outside office hours.
- 68% of areas provided a named contact to help people plan and organise their care after transfer home from hospital – but in only a half of areas did these contacts look across health, social and community services.

Services do not always adapt well to meet individuals' needs:

- Only 37% of areas provided rehabilitation services to people based in their community, focusing on helping them return to work.
- 38% did not train helpline staff to deal with people who have communications problems caused by stroke, such as aphasia; only 38% involved people with communication problems in the design of their information for stroke survivors.

- Only 34% of areas provided information on stroke in relevant community languages other than English.
- Most areas have fully implemented a stroke pathway that sets out how different services should work together; but only 28% cover mental health services and only 24% specifically mention care homes.
- Around three-quarters of social services could direct people to community-based services to help them with their physical disabilities, but less than half could signpost similar services for people with aphasia.

Services did not always involve people in decisions about their care:

- 72% of areas had a policy in place about transfer home from hospital which said patients and carers should be involved in planning transfer home.
- 71% of adult social services departments provided people with information on how to ask for a re-assessment of their needs.
- 65% of stroke survivors had a care plan for community-based support which included goals they had agreed.
- 39% of people who had a stroke were given a copy of their care plan after they were transferred home from hospital.
- Only 9% of people were offered individual budgets or direct payments within the first six weeks of their returning home.

Services are not always organised to meet people's needs:

- Regular reviews after transfer home provide a key opportunity to ensure people get the support they need – but, while most areas have systems for reviews after 6 weeks, systems for reviews after this are in place in less than a quarter of areas.
- 34% had a framework for joint reviews of people's health and social care needs.

Services have made improvements over recent years in the way they treat people in the initial hours and days that follow their stroke. But they need to improve the care and support they provide in the longer term. We have found wide levels of variation both between and within different PCTs in the accessibility and quality of the care and support provided to people after they have been transferred home. The level of variation we have found is a concern, but it also shows that the barriers to effective care after transfer home can be overcome, and improvements made which can help people who have had a stroke both to recover from, and cope with, life after stroke.

We have identified a number of areas which service providers and commissioners could focus on to drive improvement and where work at the national level could support these improvements.

Key areas for improvement

Primary care trusts, adult social services and providers of services should work together to:

1. Agree and implement a plan to improve services and share good practice with members of their local stroke network, drawing on the results of our assessment of local services (available from www.cqc.org.uk/stroke).
2. Identify and address problems with the availability and accessibility of health and social services highlighted by our assessment.
 - Is community-based rehabilitation available across the area, including physiotherapy, occupational therapy and speech and language therapy?
 - Are these provided by specialist stroke staff?
 - Can people access more specialist services, such as vocational rehabilitation and emotional and psychological support?
 - Are waiting times for services monitored?
 - Can carers access a range of support, including peer support?
 - Does the local stroke pathway cover supporting life after stroke in the long term?
3. Assess progress in the implementation of early supported discharge (ESD) across their area, ensuring that all eligible patients are able to access specialist multi-disciplinary ESD.
 - Do all eligible patients have access to ESD across the PCT area?
 - Do these teams include all relevant specialist staff?
 - Are these teams able to provide intensive community-based rehabilitation?
 - Do patients who are not eligible for ESD still benefit from the systems and working practices set up under ESD?
4. Ensure all people who have had a stroke and their carers are provided with the information they need in accessible formats when they leave hospital, along with support to understand and use it.
 - Is information tailored to people's needs and circumstances – including those of carers and family members?
 - Does it signpost key national organisations and documents?
 - Is it explained to people, not just given to them – preferably by someone who can act as a single point of contact for health, social and other services?
 - Does it include personal space to include diary planning notes?
 - Does it include key local information, such as contact details for local services and a description of the local stroke pathway?

- Is it well presented and organised – short and to the point, with the right look and feel to make it accessible for people with aphasia?
 - Is it developed with advice from people that have experience of stroke?
 - Is it kept up to date?
5. Ensure that the processes used to manage care involve all relevant people and support seamless transitions between services.
- Do processes for managing transfer home involve all relevant health and social care professionals?
 - Are people who have had a stroke, their carers and families involved in planning transfer home?
 - Are systems in place for reviews at 6 weeks/6 months/1 year/annually?
 - Do these reviews cover the full range of health and social care needs?
 - Is it clear who is responsible for ensuring these reviews take place?
 - Do these processes ensure smooth transitions between services and effective sharing of information?
6. Ensure services understand and adapt to people’s individual needs and circumstances, including:
- People who have little or no support from carers or family members (e.g. people living alone)?
 - People in care homes?
 - People of working age?
 - People with family responsibilities?
 - People with aphasia?
 - People from black and minority ethnic communities?

Primary care trusts and adult social services departments should:

7. Ensure that their decisions about the future of services are based on a clear understanding of the needs, experiences and priorities of people who have had a stroke and their carers (including the specific groups listed in recommendation 6).
8. Ensure they have sufficient information to monitor people’s experiences and outcomes once they have been transferred home.
9. Work with GP consortia to ensure that their new commissioning procedures build on the strengths of current arrangements and on the improvements planned following this review.

Service providers should:

10. Ensure that their staff have the training and time to involve people in decisions about their care, and to understand and adapt services to respond to people’s individual needs.

Building on the work of the Stroke Improvement Programme and stroke networks, the Department of Health should help ensure that:

11. Support is in place to complete the implementation of the National Stroke Strategy.
12. The new systems through which health and social services are commissioned and funded support effective models of care, as set out in the National Stroke Strategy, such as early supported discharge and integrated working across health and social services.

The National Institute for Health and Clinical Excellence should:

13. Review the recently published draft stroke standards to see how they can be extended to cover community-based rehabilitation (including ESD), longer-term support and social care services.

For further advice and information on implementing these recommendations see:

- www.improvement.nhs.uk/stroke/ – For good practice and guidance on issues including early supported discharge, community-based services for people who have had a stroke and carers, information, care planning, reviews and stroke in care homes.
- www.stroke.org.uk/, www.ukconnect.org, www.differentstrokes.co.uk/ – For information, advice and publications for people who have had a stroke and carers (including communications and decision-making tools).
- www.rcplondon.ac.uk/clinical-standards/ceeu/Current-work/stroke/Pages/Guidelines.aspx – For the national clinical guidelines on stroke.
- www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_098352 and www.ukfst.org/ – For guidance on stroke education and training.

Introduction

What is stroke?

People have a stroke when an area of their brain is deprived of its blood supply, causing some brain cells to die. Stroke is the third largest cause of death in England and is the biggest single cause of disability in adults. Every year, over 80,000 people in England are admitted to hospital following a stroke. A further 25,000 are admitted following a transient ischemic attack (TIA), which is similar to a stroke, but the symptoms go completely within 24 hours, and many more have a stroke or TIA but are not admitted to hospital. There are more than 900,000 people living in England who have had a stroke, including around 300,000 who live with moderate to severe disability as a result.¹

People of all ages and from all social groups have strokes. While older people are more likely to experience a stroke, one in four strokes occurs in people under the age of 65 years. People living in areas of higher deprivation are more likely to have a stroke, as are people from particular ethnic groups.² The main risk factors for stroke are well understood and include smoking, obesity and high blood pressure.

But to understand the impact of stroke it is important to look beyond its causes and medical effects. As part of this review we spoke to a wide range of people who had experience of stroke, as well as to many groups that represent and support people who have had a stroke. A clear message from this work was that stroke can have a devastating effect on people's lives.

This is partly due to its direct impact on people's ability to move around, think and communicate. But it is also due to its wider impact on people's ability to work, take part in community activities or participate in family life. People's emotional reaction to stroke is also complex and can include grief, loss, confusion, frustration, fear, anxiety and even elation – where people are “just happy that they survived”.

How are services changing?

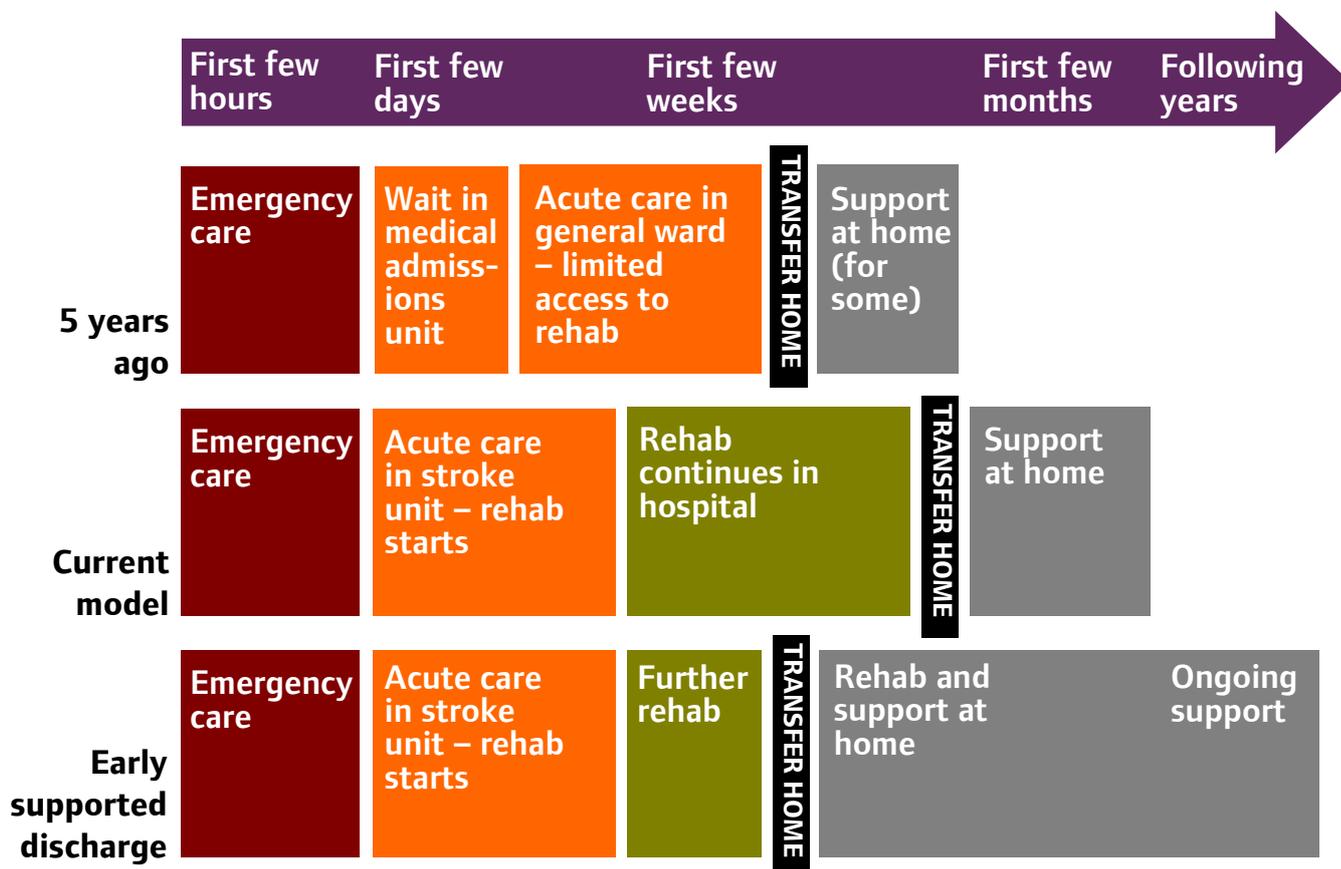
There has been significant national interest in stroke over the last five years, following the National Audit Office (NAO) report, *Reducing Brain Damage: Faster access to better stroke care* (2005), which recommended better access to specialist stroke units, greater use of thrombolysis (clot-busting drugs) to treat relevant strokes, and improved working across acute care, primary care and social services.

Following this, the Department of Health developed the National Stroke Strategy (2007), which set out a framework for delivering effective stroke services, and set up the Stroke Improvement Programme (SIP) and 28 local stroke networks to support its implementation. The SIP carries out a range of activities, which focus on different aspects of the strategy, working through the 28 stroke networks which cover stroke services across England. More recently the National Institute for Health and Clinical Excellence published standards for stroke and the Department of Health set up the Accelerating Stroke Improvement Initiative.

The National Sentinel Stroke Audit, run by the Royal College of Physicians, and the NAO's follow-up report have reported significant progress in many aspects of hospital-based stroke care.¹ For example, more people are now treated in specialist stroke units

and more areas are able to treat patients with thrombolytic drugs, which can reverse the effects of stroke in some patients if received quickly enough. There has also been an increase in the availability of early supported discharge schemes (ESD), where people are able to leave hospital early and receive intense rehabilitation after they have returned home (see figure 1).

Figure 1: How the pathway for people who have had a stroke is changing



There have also been falls in both the number of people having a stroke and in the number who die as a result of a stroke. Between 2003/04 and 2007/08 there has been a 9% fall in the number of people admitted to hospital following stroke and a 21% fall in the number of stroke-related deaths within 30 days of hospital admission.³ More recently there has been an increase in the number of people admitted to hospital following stroke, linked to the success of the FAST campaign, which aimed to improve public awareness of the symptoms of stroke.

But despite this progress, data collected as part of the National Sentinel Stroke Audit shows there is still significant room for improvement in a number of aspects of stroke care, including access to specialist stroke units, thrombolysis, ESD and vocational rehabilitation (which helps people return to work). Also, until this review, there has been little consistent national data on people’s care once they have been discharged from hospital, and limited evidence of progress against the key conclusion of the 2005 NAO report that “patients feel abandoned when they lose the emotional and practical support they receive in hospital”. A recent survey found that almost half of people who have had a stroke had unmet needs for care and that over half wanted more information about stroke.⁴

How we carried out this review

This review looks at the 'pathway' of care experienced by people who have had a stroke (or TIA) and their carers. The review starts from the point people prepare to leave hospital to the long-term care and support people may need to cope with stroke-related disabilities. It looks at both health and adult social care, as well as links to other relevant services, such as local support groups and services to help people participate in community life. The review aims to promote improvement by assessing local services, publishing data and highlighting key national issues.

To ensure that we focused on what matters most to people, we held a workshop with representatives from a number of national patient groups, and we reviewed existing research into people's experiences of stroke services. We have also conducted further research with people from 'hard to reach' groups, including people from particular ethnic communities and people living with high levels of disability, to understand some real life stories of their experiences of stroke. Some of the areas for improvement people who have had a stroke and their carers told us about were:

"My family had to find out about everything – what sort of help I could get – no one came to speak to me."

"I am feeling unhappy because I can't do what I want, being independent. They don't seem to care about that."

"I wish they would just treat you like human beings and explain, give you some time to ask questions and don't use big words."

"My stroke affected my wife emotionally – we should have got more help – at times I could see she was struggling to look after me."

"Because my mother tongue is Urdu I had a lot of difficulties – I couldn't really learn/say much because we couldn't communicate with each other."

"The main thing is respecting people's dignity and you can't do that without knowing our culture properly."

We have been working with a range of local and national stakeholders to develop both our assessment framework and data collection tools for this review. The assessment framework has been discussed with the review's external advisory group, which includes representatives from a range of local and national organisations (see the annex). We have carried out a number of site visits to help develop the review and to ensure that the data collection tools take account of local systems for gathering information.

As the Quality Markers (QMs) set out in the National Stroke Strategy are now well established, they form the basis of our 'assessment framework' for this review. We used the QMs to create a set of 15 scored indicators (see table 1), which we combined to give an overall assessment for each local area. The review has focused on stroke in adults, since guidance on this area is better developed.

Table 1: The scored indicators for this review

Scored indicator	Quality Marker	Chapter of this report
Early supported discharge	10	1. Providing the right care and support
Community-based services	13	
Secondary prevention	13	
TIA care and support	6	
Support for participation in community life	15	
Long-term outcomes of care	13	
Services for carers	13	
Meeting individuals' needs	13	
Range of information provided	3	2. Involving and informing stroke survivors and carers
Signposting, coordination and personalisation	3	
End of life care	11	
Involvement in planning and monitoring	4	3. Working together to deliver effective care
Management of transfer home	12	
Reviews and assessments after transfer home	14	
Working together	17	

We found reasonably strong links between most of the scored indicators. In particular, areas that provided good information and had good systems to direct (signpost) people to the services they needed also tended to have a good range of services available for stroke survivors and carers, and better systems to manage people's transfer home from hospital and review their care afterwards.

In order to review the aspects of stroke care that people have told us are important, we collected additional data from primary care trusts (PCTs) and adult social services departments about the range of services they commission. We also carried out two more detailed exercises.

- An evaluation of printed information that people are given when they are transferred home from hospital. This was carried out in each local area by a group of stroke survivors and carers, who were asked to answer seven questions about how clear, helpful and easy to use they found this information. We then analysed what specific information these packs contained.
- An evaluation of the care provided to a sample of around 25 people in each area who had a stroke and their carers in the six weeks following transfer home, based on the case notes available to PCTs. This looked at how their transfer home had

been organised, whether they had been involved in decisions about their care and how long they had to wait for services.

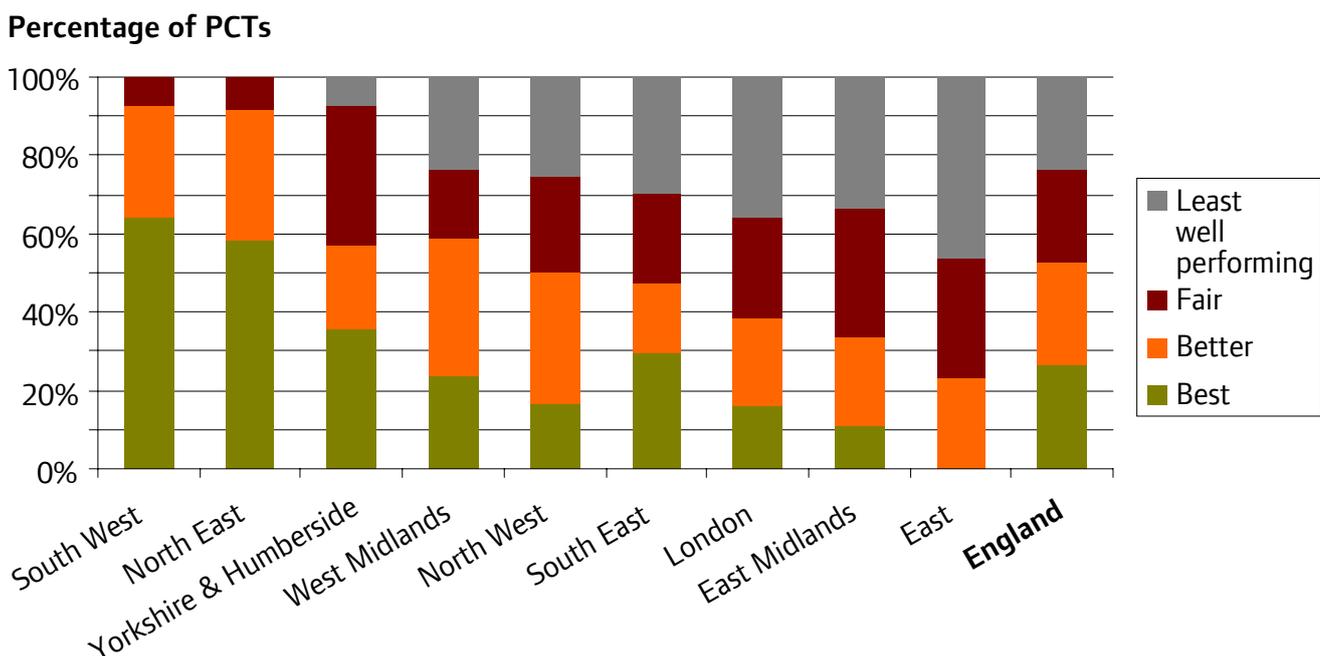
For this review, the areas we used for our assessments were based on the boundaries of PCTs. PCTs are the main organisations responsible for commissioning care for people who have had a stroke and their carers, although local councils, in particular adult social services departments, also have an important role in assessing people’s needs and commissioning a range of community-based support, care and advice services.

We have produced two assessment reports for each area, both of which are available from our website (www.cqc.org.uk/stroke). The first is a summary report designed for people who have had a stroke and their carers, and shows how well the area performs in each of the scored indicators. The second looks in more detail at the data we collected and is designed to help service managers and commissioners identify where they need to improve. These reports also include an overall summary assessment, which groups areas into four categories:

- ‘Best performing’ – on average these areas scored the top 2 marks across 8 or 9 of the 15 scored indicators and only scored low marks in 1 or 2.
- ‘Better performing’ – with more areas of strength than weakness.
- ‘Fair performing’ – with more areas of weakness than strength.
- ‘Least well performing’ – typically scored low marks in 8 or 9 of the 15 scored indicators and only scored high marks in 1 or 2.

Overall, around a quarter of areas were placed in each category, although the results do vary significantly across different parts of England. Performance was generally very good in the North East and South West (where no areas were in the bottom category) and generally good in the West Midlands. Performance in the North West and South East was mixed, with similar numbers of areas scoring well as poorly. Performance in London, the East and East Midlands was generally below average, with many areas rated in the least well performing category (see figure 2).

Figure 2: Variation in overall scores across England



1. Providing the right care and support

People who have had a stroke and their carers need to be able to access a range of services after they have been transferred home. Many will need further community-based rehabilitation, such as physiotherapy, speech and language therapy or occupational therapy. Most people are likely to need support to reduce their chance of having another stroke, such as medication, help to stop smoking or advice on healthy eating. Many stroke survivors and carers also need broader support to help them manage life after stroke, such as the support and advice provided by local stroke and carer groups, or help to take part in community activities.

This chapter looks at the range of services available in different areas, how long people have to wait to get them, and how well they adapt to meet people's needs, such as those related to disability, age and language.

Rehabilitation and early supported discharge

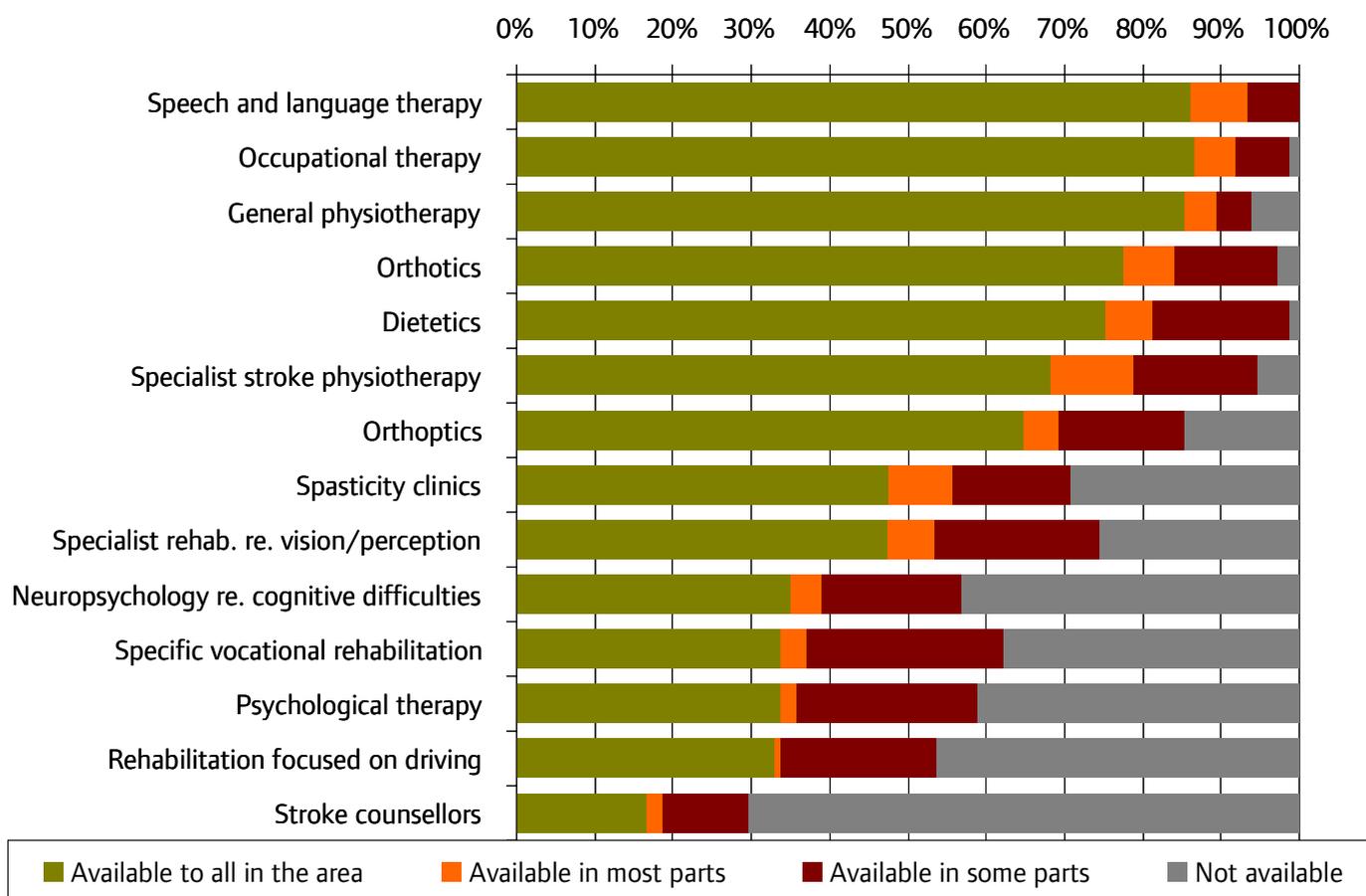
PCTs reported that a range of community-based rehabilitation services were widely available in their area, typically including speech and language therapists, occupational therapists and physiotherapists (see figure 3). Most also provided orthotics (personal equipment, such as ankle supports, to help rehabilitation) and dietetics (specialist advice on diet and nutrition).

However, people in some areas had little or no access to more specialist rehabilitation services, such as vocational rehabilitation (which helps people return to work) and spasticity clinics (which support people with muscular problems). Only two-thirds of PCTs commissioned specialist stroke physiotherapy across the whole of their PCT area, and less than 40% of areas provided good access to psychological therapy or support from stroke counsellors.

Even where services are available, people can wait a long time for them to start. In around 40% of areas, average waits for community-based physiotherapy and speech and language therapy were over 20 days – and in 10% of areas average waits exceeded 50 days. These figures do not only refer to stroke services, as most areas were not able to collect stroke-specific waiting times. The data we collected from a sample of people who have had a stroke gave a more positive picture, but still a quarter of areas reported that the average time it took to provide someone with all the rehabilitation they need was 10 days or more from their return from hospital. Waiting times were shorter for the 'minor' equipment and adaptations that some stroke survivors need once they have been transferred home – with average waits of less than a week in 75% of areas. However, even short delays can result in people staying in hospital longer than necessary, increasing costs and putting pressure on stroke unit beds.

A key element of the national stroke strategy is the implementation of early supported discharge (ESD). ESD provides a greater proportion of rehabilitation in the community rather than in hospital. It is not suitable for everyone, but it is estimated that around 40% of patients could benefit from ESD. Research has shown that ESD is cost-effective and can achieve better outcomes for patients, as well as relieving the demand on beds in stroke units.^{5,6}

Figure 3: Availability of rehabilitation and psychological support



Progress in implementing ESD, however, is limited. Only 18% of PCTs reported that ESD, with access to the full range of specialist staff, was in place across all or most of their area. A further 27% had made some progress, but did not have the full range of recommended specialists across their area. Fifty-five per cent reported that very limited progress had been made – although many of these told us that work was underway to implement ESD, building on existing community stroke teams.

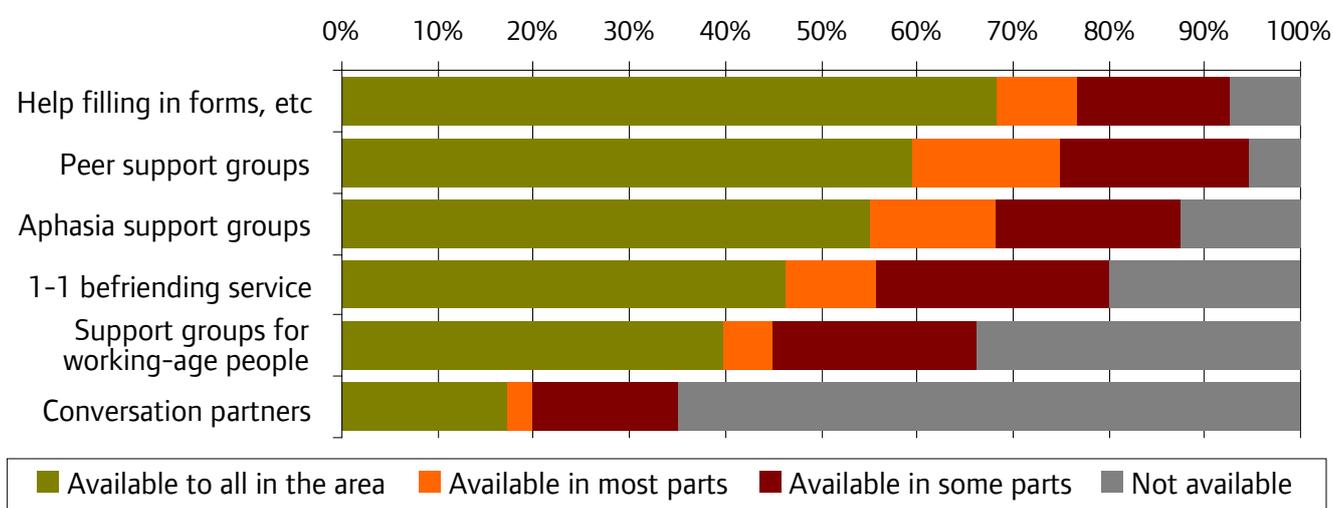
Where ESD is in place, people’s experiences of it varied significantly between areas. For example, while most people receiving ESD only waited a day or two after returning home from hospital before their rehabilitation began, in 20% of areas this wait was, on average, at least five days. The level of rehabilitation provided as part of ESD schemes also varied – in some areas, people on ESD typically received five or more rehabilitation sessions per week; in other areas people typically received one or two sessions per week. In part, these differences may reflect the challenges of delivering ESD in rural areas. While ESD teams are in place in both urban and rural areas, those in rural areas recorded higher average waiting times and lower average levels of rehabilitation. These differences suggest that clearer guidance is required on what constitutes ESD.

Supporting community life

When we spoke to stroke survivors and carers, the aspect that they thought most needed improvement was longer-term support for managing life after stroke. People particularly valued the help and support provided by other people who had experience of stroke.

Most PCTs reported that peer-support groups (usually run by third-sector organisations, sometimes with support from local health or social care services) were available in at least part of the area they cover, but only 60% reported they were available to everyone. Access to specific peer support for people with aphasia, for people of working age or for people in care homes, was more limited (see figure 4).

Figure 4: Availability of support for people who have had a stroke



Note: Conversation partners are schemes that support people with aphasia who are isolated, such as those in care homes.

Most areas had fully implemented a 'stroke pathway', setting out how care should be provided in the days and weeks following stroke – but only about half of these included long-term support, and only around 40% covered housing services or community transport. Only a quarter of local plans looking at opportunities for people with disabilities to return to work (for example, Joint Investment Plans and Pathways to Work) specifically mentioned stroke.

Around 75% of adult social services were able to provide advice on community-based services suitable for people with mobility problems, such as sport, leisure, culture, training and volunteering opportunities. However, only around 40% provided a similar service for people with aphasia. Similarly, while two-thirds of local transport plans addressed physical disabilities, only 43% address communication-related disabilities.

While 55% of PCTs monitored outcomes for people who have had a stroke that are specific to rehabilitation, and 44% monitor whether people are able return home, only 17% look at long-term outcomes, such as people's ability to return to work or ability to participate in community life.

Services can also help people minimise the risk of having another stroke, for example, by making sure they get the right medication and checks. Data collected from GPs

shows that most people do get the right checks, but it also shows variation in the numbers of people who have had a stroke whose blood pressure and cholesterol levels are under control. For example, the proportion whose total cholesterol is within the recommended range varies from 70% to 84% between areas. Work is underway to ensure more people (particularly people with the heart condition atrial fibrillation) are on the right preventative medication.⁷

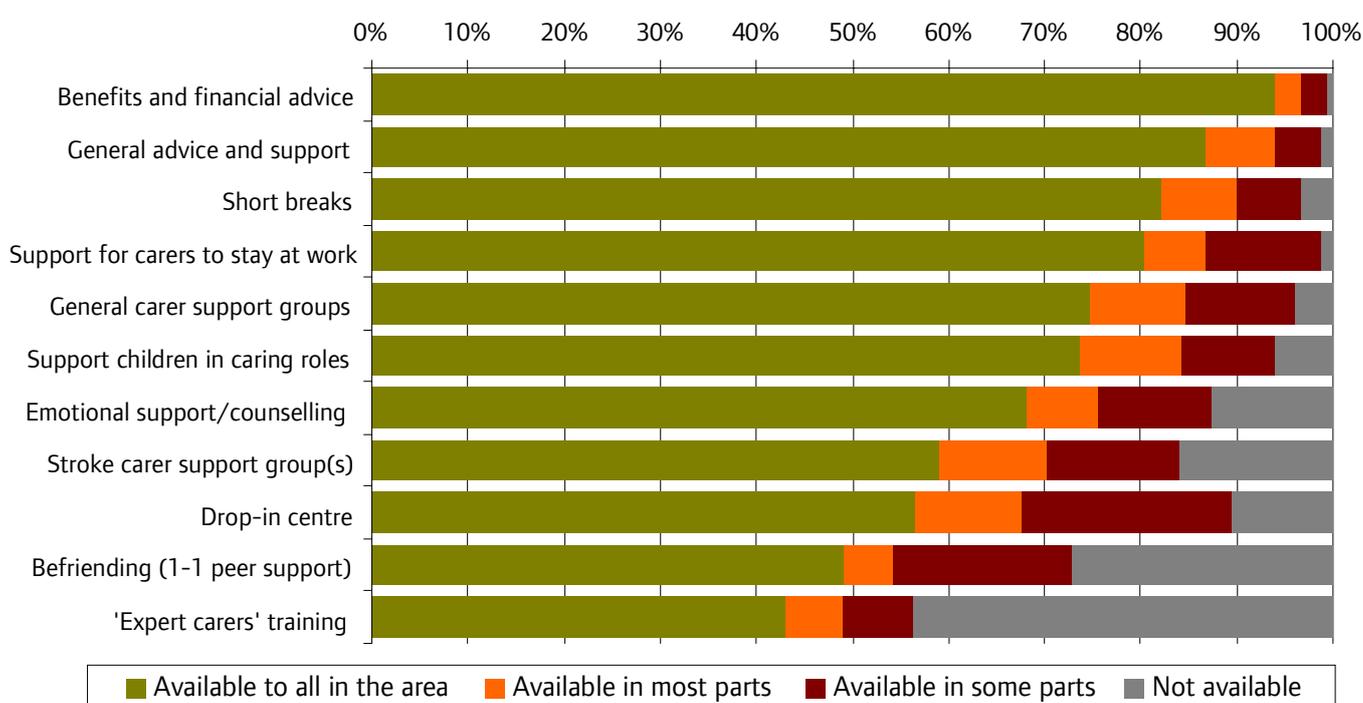
People’s risk of having a stroke also increases following a TIA. Most work to improve treatment of TIA has focused on care in the 24 hours after a TIA, so is outside the scope of this report. We did look at longer-term pathways (policies saying what should happen to people who experience a TIA) and found these are in place in nearly all areas. Nearly all PCTs commission TIA assessment clinics to carry out tests and provide advice to people who have had a TIA. However, these centres are open outside office hours in only 16% of areas and a third of PCTs do not monitor attendance at follow-up appointments.

Services for carers and families

The support that carers receive can help them maintain their independence and cope with life after someone has had a stroke. This support may be provided from a range of organisations including the NHS, social care and the voluntary sector. Social services have a particularly important role as they are responsible for assessing the needs of carers.

Carers in nearly all areas have access to general information, advice on benefits and short breaks. Many also have access to general carer support groups and emotional support. However, access to befriending schemes, drop-in centres and stroke-specific carer groups is more difficult in around a third of areas (see figure 5).

Figure 5: Availability of support for carers



Two-thirds of areas provided information about how to ask for an assessment of carers' needs when people were transferred home from hospital. Around two-thirds of the people whose records we examined as part of our case file tracking exercise had a carer. Half of these carers had been offered an assessment, and 44% were receiving some support.

While nearly all areas had a local stroke pathway, only a quarter of these specifically covered the children of someone who has had a stroke and only 19% included children who have had a stroke. Only a quarter of the information packs put together for after a parent had a stroke included information which had been specifically designed to help children understand stroke.

Meeting individuals' needs

So far this chapter has focused on what support is available in different areas. However, stroke affects people of all ages and from all groups in widely differing ways. It is important that services understand these differences and adapt to meet people's individual needs and aspirations.

A key issue is how well services meet the needs of people with aphasia and other communication-related disabilities. While many areas provided training to relevant staff about communicating with people with aphasia and provided information to people in relevant formats, around 60% of areas did not. In particular, social services and other council services appeared less aware of people's needs associated with communication disabilities than they were for physical disabilities.

Part of our work with stroke survivors and carers focused on people from particular ethnic or cultural groups, such as travellers and Asian communities. While we only spoke to a small number of people in each group a picture did emerge that services could do more to understand and adapt to their needs. For example, communities with a tradition of "looking after your own", could be better supported to do so, rather than focusing on providing services directly from professionals who may find it hard to gain their trust. And the communication problems that often arise from having a stroke can be even more difficult to deal with for people who do not speak English confidently. This is consistent with our other findings. For example, only a third of areas produced information in languages other than English and only about a fifth provided information in Braille, audio or DVD. Similarly, many services provided limited support and information specifically for people of working age.

There have also been concerns over how well staff in care homes understand and respond to stroke. Estimates for the proportion of care home residents who have had a stroke vary from 25% to 45%.⁹ Around 46% of PCTs had provided staff in care homes with some training in issues such as awareness of stroke and communicating with people with aphasia or other communication needs. However, only 24% specifically mentioned stroke occurring in care homes in local stroke pathways and only 10% reported that they have reviewed the quality of care for people in care homes who have had a stroke.

While only a quarter of PCTs have completed an equality impact assessment (EIA) on their plans to implement the National Stroke Strategy, many have carried out work looking at how well they are targeting the needs of some specific groups. For example, 40% have looked at how well they are meeting the needs of people in different age groups, a third have looked at the use of services by different ethnic or cultural groups

and 13% have looked specifically at how well stroke services meet the needs of people with family responsibilities. Where PCTs have looked at these needs, around a half reported that they found issues to address and that they have taken action to deal with them.

Conclusion

Most people were able to access help and advice on preventing future strokes and general support for carers. But access to more specialist services was variable, and in some areas people experienced long waits before care got underway. Early supported discharge is only fully in place in a minority of areas. While most carers could access information and advice, peer support, such as carer support groups or befriending schemes, was not always available.

Services were not always adapting well to meet people's needs, such as the communications needs of people with aphasia or the needs of people who do not speak English.

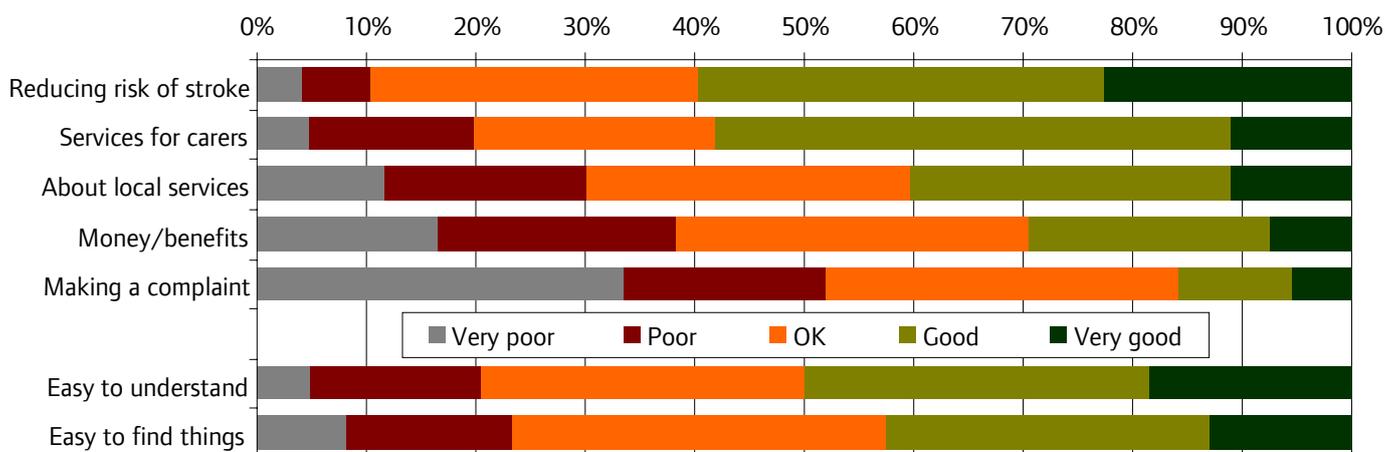
2. Involving and informing stroke survivors and carers

The National Stroke Strategy emphasises the need for information to be provided to stroke survivors and carers, along with support and advice to understand and use it. This chapter looks at these issues, and how well services involved people in decisions to personalise their care and in broader decisions about how services are planned and managed.

Information for people who have had a stroke and carers

As part of this review each PCT was asked to put together the information pack they give to a person with particular needs when they are transferred home. This information was discussed at a local meeting of stroke survivors and carers, who were asked to assess it against seven criteria (see figure 6). Most of these packs were judged to have good information on reducing the risks of stroke, and on services for carers. However, only 40% of these packs contained good information on local services, and even fewer had good information on money or benefits and making complaints.

Figure 6: The views of stroke survivors and carers of the quality of information provided when people are transferred home



Note: This chart shows the conclusions from each discussion group.

We then carried out a further analysis, looking in detail at what information the packs contained and whether they had clear information on who to contact about local services. We found that improvement was needed on:

- Support to return to work (included in 75% of packs).
- Financial benefits (included in 74%).
- Stroke-related cognitive problems, such as memory and concentration (included in 70%).
- Contact details for stroke groups (included in 63%).
- Community transport for people with disabilities (included in 47%).
- Sex and relationships (included in 45%).

- What to do if you have another stroke or transient ischemic attack (TIA) (included in 32%).
- Information on accessing sport and leisure activities (included in 31%).
- Local education, training or volunteering opportunities (included in 28%).
- A glossary of technical terms related to stroke care (included in 23%).

We also found that only 40% of areas gave people information on why and when services will end, and that 29% of adult social services departments do not give people information about how to ask for a re-assessment of their needs.

The size and organisation of the packs also varied widely – ranging from packs of 50 or more leaflets, to single coordinated and well-structured and well-designed booklets (examples of the best stroke information booklets are available via the Stroke Improvement Programme website⁸).

Support and coordination

Stroke is a time of major emotional upheaval, which can impact on people in numerous ways, therefore even the best printed information will not meet most people's needs in full – particularly since these needs will change over time. The figures discussed above are somewhat more positive than the results of the National Audit Office's survey of people who had a stroke. For example, 41% of people they surveyed reported being given information on preventing future strokes and 32% reported being given contact details for a local stroke group.¹ This underlines the importance of the broader process of how information is given, as they suggest that either people are not always given the available information or that they do not always recall what they were given.

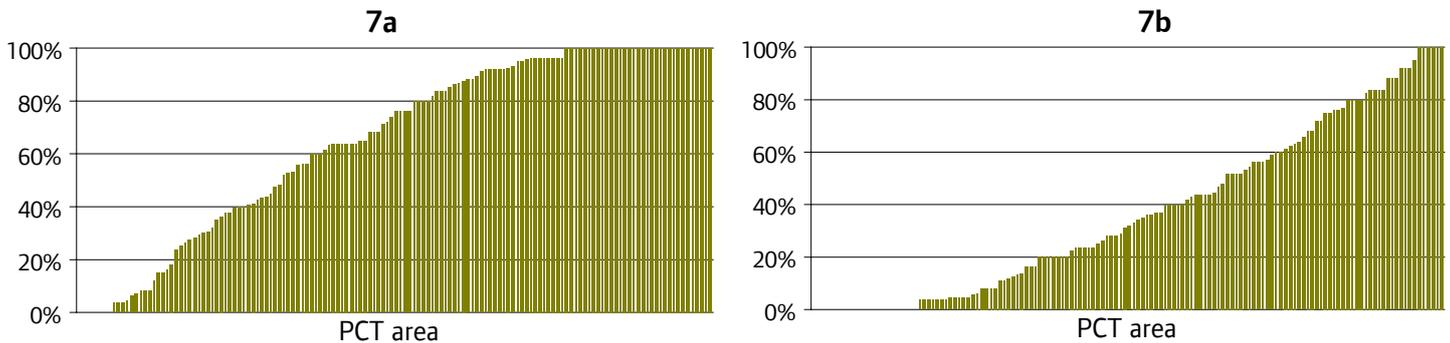
Most services recognise this. Ninety per cent of areas told us that they handed over information to people face-to-face when they are transferred home, giving time to explain it, and 87% of areas provided some sort of telephone helpline. However, the accessibility of these services varied – people were often not given a helpline number when they left hospital after having a stroke, and in 74% of areas helplines are only available during usual office hours.

In all areas, adult social services provided support and advice on issues such as applying for benefits, accessing personal care and managing direct payments and individual budgets (discussed further below). They also provided advice and support to people living with disabilities – although their focus in some areas is more on physical disabilities than those related to communication, as reported in the previous chapter.

In 68% of areas, systems were in place to give people a named contact to help them plan and manage their care after they leave hospital. However the proportion of people given this support varied significantly between different areas (see figure 7). There was also variation in which services these contacts cover:

- 54% of areas provided people with a single contact who looks across health, social and community services.
- In less than a half of areas this support covered services such as community transport, access to leisure facilities or finding training and volunteering activities.
- These contacts can coordinate across different services (for example, ensuring all appointments are on the same day) in 40% of areas.

Figure 7: Percentage of people given a) a named contact on transfer home, b) a copy of their care plan



Most areas also maintained a directory of local services for people who have had a stroke, which covers stroke-specific user groups, peer support services and community-based NHS rehabilitation. However, only 57% of areas' directories covered home care services, and only 14% included privately available community-based rehabilitation.

Again, in around 40% of areas the staff providing the sort of support described above were not given training to help them understand and support people with aphasia. It is also a concern that these services, many of which have been supported through the earmarked stroke funding provided to councils, may not be continued (only 15% of adult social services departments reported that they plan to fully maintain these services, and 62% stated they plan to maintain them 'in part').

Choice and personalisation

One of the main aims of providing the information and support discussed above is to enable people to choose and control the services they receive. However in many areas there are opportunities to involve people more actively in these decisions.

- 72% of areas had policies about transfer home from hospital that involve patients and carers and 50% said patients should agree the goals in their discharge plan.
- Around three-quarters of PCTs provided training for people who have had a stroke on looking after themselves, and most also provided training for carers.
- There is a wide variation in the proportion of people who were given a copy of their care plan (see figure 7b), and in the proportion of people who have agreed the goals in these plans.
- Only 29% of areas tell people how and when they should ask for a re-assessment of their needs after services are withdrawn.

Direct payments and individual budgets enable people who use services to personalise their social care and other services to meet their needs. But take-up remains low in many areas.¹² This may be because, while all adult social services departments provided support and information about direct payments and individual budgets, only in 31% of areas were people who have had a stroke given written information about them when they left hospital. We also found that only 9% of stroke survivors were offered these within the first six weeks of being transferred home (although this may be because long-term care needs for some are not assessed until this stage).

End of life care is an area where listening to people's preferences is particularly important. Eighty-eight per cent of areas reported having a local pathway that covered end of life care. Most of these set out when and how to determine people's preferences for where they would like to die and for the use of 'do not attempt to resuscitate' notices. However, only 36% of areas had an end of life care pathway that takes specific account of communications disabilities. Also, while 75% of areas had pathways that allow fast track transfer out of hospital (to the patient's home, with support, or to a hospice) these arrangements covered weekends in only 59% of areas.

Involvement in planning and monitoring services

We looked at the broader involvement of people who have had a stroke and their carers in decisions about the design and delivery of services. All areas have carried out such work, linked to the implementation of the national stroke strategy, most often through surveys and focus groups. However, this work may not have always included some of the main groups affected by stroke. For example, only 65% of areas have done specific involvement work with people with aphasia, only a third have targeted people who live alone, and only 17% have targeted people in care homes.

Some services could do more to encourage people to engage more in the day-to-day running of services. Only around a third of information packs explained how to complain about stroke services, or to make suggestions for how they could improve. However, around two-thirds of areas did report that they involved people who have had a stroke either on management boards or directly in service delivery, and around half involved carers.

Conclusion

Stroke can be a time of major emotional upheaval for people who have had a stroke, their carers and families. While most people received a good standard of general information on stroke, fewer got clear information on local services or support to help them access services or sort out problems. The way that this support was provided did not always meet specific needs, such as those of people with aphasia, living alone or in care homes. Services in many areas could be doing far more to involve people both in decisions about their care and about the future of stroke services.

3. Working together to deliver effective care

People who have had a stroke, their carers and families may require support from a range of health and social care services, which should adapt as people’s needs and circumstances change. This chapter looks at the systems that underpin how care and support are managed, focusing on whether they support smooth and coordinated service delivery.

Transfer home

One of the most important transitions between services occurs when people leave hospital and return home (either their own home, or to residential care). This transition can be particularly traumatic as people move from a busy hospital environment to life at home. Effective systems for managing this transfer should help to minimise both the stress and anxiety of transfer and any ‘gaps’ between the services people receive in hospital and the support they receive at home.

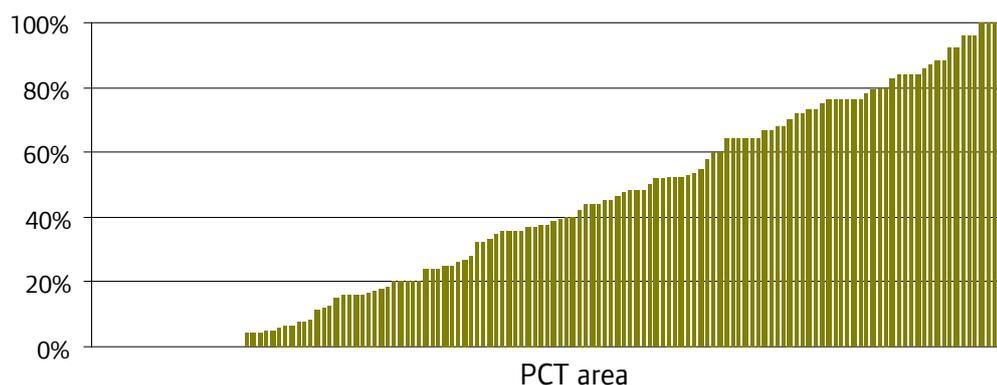
Basic systems to manage the transfer home are in place in most areas. Seventy-seven per cent of PCTs have agreed policies in place (with most or all hospitals in their area) for managing this process and 88% of adult social services departments have staff based in local hospitals to help people prepare for their transfer home.

Even where these policies are in place, they may not function well. In many PCT areas, copies of the plans for transfer home were not routinely received by community-based services. More than a third of people wait more than a week before their full package of community-based rehabilitation is underway and almost a third wait at least a week before they have the basic aids and equipment they need to help them at home.

We are also concerned that almost 12% of people discharged home after a stroke are re-admitted to hospital in an emergency within 30 days of going home, and this figure is significantly higher in some areas (even after taking account of the age and gender of the local population).

It is encouraging that around two-thirds of people get called at home to check that they are coping following their transfer home. However in 10% of areas these calls are not made and, even where they are made, the proportion of people contacted within two days of going home varies widely (see figure 8).

Figure 8: Percentage of people contacted within two days of going home



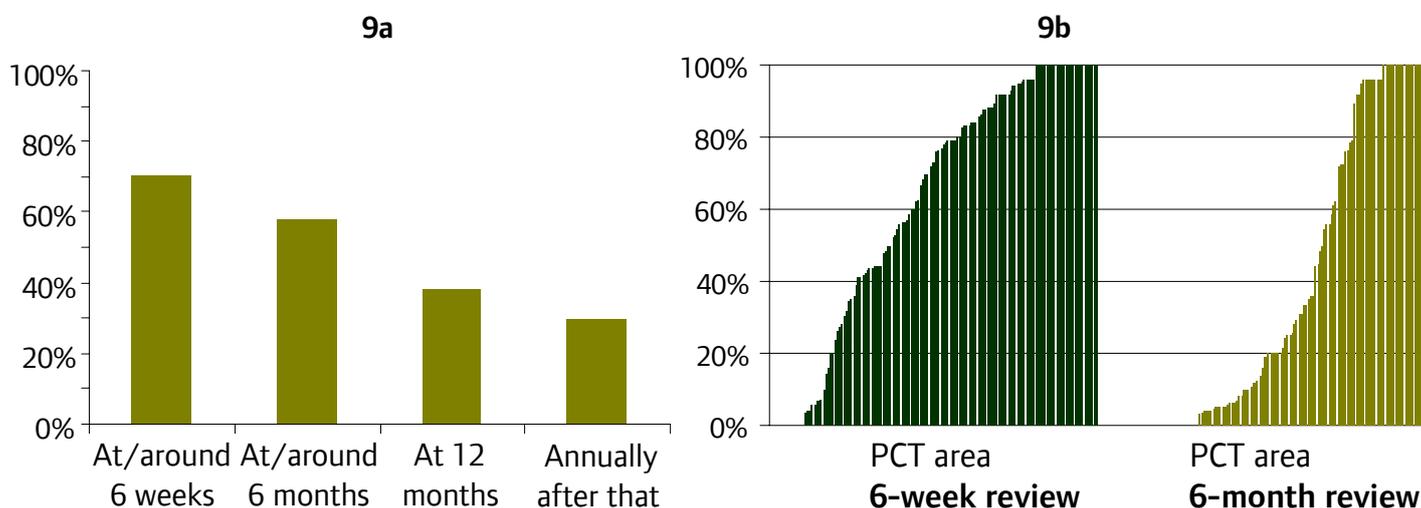
Reviews and assessments

Once people have returned home their needs and circumstances continue to change. Rehabilitation and occupational therapy will need to adjust as recovery progresses. People may need support to adjust their lifestyles to reduce the chance of another stroke, to return to work or to cope with altered roles and relationships and the emotional and psychological impact of stroke. Other needs, including those of carers and family members, are also likely to change as people learn to deal with stroke-related disabilities.

The National Stroke Strategy recognises that people’s needs require regular re-assessment so that these changes can be taken into account. It sets out a framework for reviews to take place six weeks after leaving hospital following a stroke, and again after six months, and then annually. It also states that people should be able to request a review should their needs or circumstances change.

While most PCTs have systems in place for reviews at six weeks, systems for reviews later in the pathway were not well developed (see figure 9a). And even where such systems are in place, it is not always clear who is responsible for ensuring that reviews take place. Overall we found that six week reviews were taking place for around two-thirds of people included in our case file tracking exercise and that reviews at six months were planned to take place for 44%. But we also found significant differences in these figures between PCT areas (see figure 9b).

Figure 9: a) Policies for reviews (percentage of PCTs)
b) Percentage of people for whom a review has taken place, or is scheduled, at six weeks/ six months



PCTs that have policies about carrying out reviews generally reflect good practice. For example, most set out that people who have had a stroke and their carers should be involved in reviews and that robust tools should be used to assess progress. However, we found that only around one in ten of the information packs given to people around transfer home mention these reviews or set out people’s rights to ask for a re-assessment should their needs change.

Work is currently underway to collect better national data on reviews and to produce guidance on what reviews should look like.⁷ Early feedback from this work is positive and is demonstrating that effective review processes can deliver a range of benefits, including reducing emergency re-admissions, improving secondary prevention and providing better support for stroke survivors and their carers.

Working in partnership

If people's experiences of care are to be seamless, then services need to work in a coordinated way. In particular, health and social services both have an important role in planning people's transfer home from hospital and in continuing to assess their needs.

While policies are generally in place to involve adult social services in planning transfer home, there are many opportunities to improve integration of health and social services. For example, only 26% of areas produce information jointly on care and support after stroke and only 34% have a framework for joint reviews of people's health and social needs across most or all of the PCT area. Only 40% of adult social services departments had systems in place to monitor what happens to people who are signposted to other sources of help (rather than being provided with support directly), although a further 36% had plans in place to introduce such systems.

The 28 local stroke networks that cover all parts of England have an important role in developing local stroke pathways and supporting the implementation of the National Stroke Strategy. We are concerned that some adult social services departments have little, if any involvement with these networks – 25% are either not a part of their local network or attended no network meetings during the whole of 2009/10.

There are also opportunities to involve other organisations in the development of local pathways. While nearly all pathways cover hospital care and 79% also cover social care for people living at home to some extent, only 41% cover pathways into mental health services and only 32% specifically cover people who have a stroke in local residential care homes.

Conclusion

While systems for managing people's transfer home from hospital are generally in place, the extent to which people are supported through this process varies significantly. Systems to review care in the weeks, months and years following transfer home provide a key opportunity to check progress and ensure people are getting the support they need. But in many areas these reviews do not take place.

Stroke pathways (policies setting out how care should be delivered) are in place, but do not always cover all relevant services. In some areas social care services have not been fully engaged in the process of designing these pathways.

Conclusions

This review looked at the range and quality of services provided to people who have had a stroke and their carers. We have found wide levels of variation both between and within PCT areas in what services are available, how well people are informed and supported to access those services, and how well these services are organised to meet people's needs.

These differences matter. Stroke is the single largest cause of disability in adults. It can occur to people of all ages and from all groups, but is particularly prevalent among some vulnerable groups, particularly older people. Evidence shows that early access to intense rehabilitation results in people experiencing better outcomes. Providing good support to carers both helps them cope and helps the people they care for maintain their independence. And good information and support should help people navigate through the complex range of relevant services.

It is important that the momentum generated over recent years is not lost. Budgets for services are coming under increasing pressure and significant reorganisation is on the horizon. In particular, PCTs are due to be abolished by 2013 and their capacity to support local improvements will be under strain.

Yet there are reasons for optimism. We are only three years into a 10-year strategy that aimed to transform stroke services. Much has been achieved already and many of the building blocks necessary to achieve that transformation are now in place.

The key outputs from this review are the 151 local assessment reports produced for each PCT area in England. We recommend that everyone involved in local stroke services review these reports and agree and implement an action plan to address their findings. This work should include representatives from all relevant groups and organisations, including:

- Organisations responsible for commissioning services: PCTs, adult social services departments, representatives of people who purchase their care privately and the emerging GP consortia.
- Organisations providing relevant services: acute trusts, community rehabilitation services, stroke support groups, carer support groups, GPs, social workers, housing services, transport services and district nursing services.
- People who have had a stroke and their carers.
- Other members of local stroke networks.

Overcoming the barriers to change

Most action to date has focused on care in the acute end of the stroke pathway. This is understandable, given the strength of the evidence for the effectiveness of care in specialist stroke units and treatment with thrombolytic drugs. Services further down the stroke pathway are more variable. This may reflect a range of factors, including the lack of good data and a clear evidence base for 'what works'. It may also reflect the fact that much of the drive for improvement has come from acute trusts where good data on care has been available for some time. It may also explain, in part, some of the regional differences in performance (see Figure 2 on page 12), such as the mixed

performance across London, where there has been a major reorganisation of hyper-acute services.

This variability also applies to the extent to which social care services have been engaged in stroke improvement work. This may link to the factors described above, but may also reflect a broader range of organisational, financial and cultural barriers. These barriers need to be addressed, not least because improvement in long-term care and support are often identified as a priority by people who have had a stroke and their carers.¹⁰ This work has shown that people do not see a separation between their social care needs and their health needs, and therefore do not expect their support to be separated in this way.

While these barriers are formidable, there are grounds for optimism. This review has provided much-needed data on care after transfer home as well as an opportunity to engage all relevant organisations in improving services. The targeted funding provided to councils to improve stroke services has helped in this respect. We have also found that areas that score well in some aspects of care, such as providing good information and organising care around the individual's needs, tend to score well in other aspects – suggesting that once the basic care processes are working well then performance in other aspects should also improve.

Some of the positive things that stroke survivors told us about their experiences were:

“Anything that I was promised happened and I didn’t have to chase or anything like that. Mostly things happened quite quickly or when they said they would.”

“[My physiotherapist and nurses] were very supportive and kept on telling me that I was improving which helped me mentally. ... [Physiotherapy] was usually the highlight of my day.”

“The information in the leaflets was very comprehensive. The senior nurse made sure that supplies were kept up. There was some verbal information if you asked for it.”

“I always remember what [my therapist] told me – she was honest and accurate about my long-term prognosis but was always very inspiring.”

“[Social services, following a referral from the district nurse] told me what benefits we could be entitled to which helped us a lot financially as I was out of work for a long time.”

The National Stroke Strategy has been well received and has helped drive a range of service improvements through the Stroke Improvement Programme and local stroke networks. There is also evidence-based guidance on the effectiveness and value for money for many of the main aspects of the stroke pathway, particularly in the earlier stages – although there remains a need for clearer guidance on some aspects of community-based rehabilitation, including early supported discharge (ESD), and the provision of long-term support.^{11, 12}

Data systems in the acute sector are also generally well developed and systems such as the Stroke Improvement National Audit Programme (SINAP) do enable data to be collected at and beyond the point that people are transferred home. There are also opportunities to improve how information is shared across organisations by using the NHS number as a unique identifier.¹³ The fact that 90% of areas were able to submit

some data for our case file tracking exercise shows that local data on care after discharge is available (although some areas found it difficult). Work is also underway as part of Accelerating Stroke Improvement to collate data on access to ESD and psychological support and on the use of care plans and reviews.

Much work has also been carried out by the Stroke Improvement Programme and others to identify best practice in many of the areas this review addresses.⁸ Our work has also identified a range of further potential best practice examples which people will be able to follow up within their region or network. To support this, we are publishing the data we have collected with software that allows people to choose their own comparative groups and identify areas that scored well.

The introduction of ESD provides an important opportunity to improve services in many areas. But those not eligible for ESD should also see significant benefits from its introduction – some indirect, through savings in hospital bed-days and from reducing demand for other services. But there should also be benefits through the improved working practices central to successful ESD, such as integrated working across health and social care, smooth systems for transferring people home, effective systems for reviewing progress and focusing on long-term goals aimed to improve people's lives.

Areas for local and national action

While the local assessments should provide the basis for action in each PCT area there are a number of common themes across our findings. Some of these changes are likely to require action at the strategic level, such as introducing new services. But others relate to day-to-day working practices, such as involving the right people in reviews and ensuring people are engaged in decisions about their care, and service providers should implement these as soon as possible. Most are in line with the work of the Stroke Improvement Programme and the recommendations set out by the NAO and the stroke subgroup of the National Quality Forum.ⁱ

Improvements in the commissioning of stroke services also need to take account of the changes set out in the White Paper, *Liberating the NHS*. Stroke is reasonably well placed in this respect. The national strategy has widespread support, all areas have at least a basic stroke pathway in place and data currently exists to cover many aspects of acute- and community-based health and social care. Stroke may therefore be a suitable condition to develop and test the new responsibilities of GP consortia and local authorities.

There is much that can be done at the national level to support these changes. As described above, action to improve both services and data have focused on the earlier parts of the stroke pathway. Further national support is likely to be required to support improvements in the later stages of the pathway.

Such work is already underway through the Stroke Improvement Programme and local stroke networks. CQC will aim to support this through further work – publishing benchmarking data and the tools used to collect it. We will also be working with the Stroke Improvement Programme and local stroke networks to identify and share further good practice, particularly with those areas that scored less well in the review. The data we collected will also be used to help us target our regulatory work.

ⁱ See page 5 for a summary of our local and national recommendations.

However, some of the barriers discussed above will be difficult to overcome and further support may be required. There are a number of aspects of care that we were not able to include in this review and where further work will be required to understand performance and set out a clear way forward. These include:

- Improving services for vulnerable groups, such as people who do not have a carer or family member to help them cope, and people in care homes.
- Care for children who have had a stroke.
- Supporting people who have had a stroke to return to work – such as providing access to vocational rehabilitation and improving employers’ understanding of, and attitudes to, stroke-related disabilities.
- The availability and accessibility of the specialist inpatient rehabilitation services available at a regional level.

CQC is responsible for registering all health and adult social care service providers and ensuring their compliance with relevant regulations, including those related to the availability of suitably trained, qualified, skilled and experienced staff.¹⁴ Skills For Care are currently looking at the training and accreditation of care home staff with respect to stroke, including both caring for people who have had a stroke and recognising and responding to stroke. We will look at the outcome of this for our work, such as in the guidance provided to our inspectors and to care home providers.

In the longer term, the National Commissioning Board (NCB) will have an important role in setting direction for stroke services as it is likely to take over responsibility for national service frameworks and similar initiatives. The National Stroke Strategy has been a significant success and the NCB should ensure that its key elements are incorporated in future guidance on commissioning stroke services. Similarly, the remit of the National Institute for Health and Clinical Excellence is being extended to cover standards for social care. It will need to review the recently published stroke standards to see how they can be extended to cover community-based rehabilitation (including ESD), longer-term support and social care services.

Finally, changes in the way services are funded need to support and reward effective models of care, including integrated working and investment in preventative services. In particular, funding systems need to encourage a long-term approach that recognises the inter-dependencies between services, as there is a significant risk that, as services come under financial pressure, they retreat into more traditional ‘silo’ ways of working.

Significant improvements have been made in stroke services over the last five years, particularly in care in the initial hours and days after stroke. But little has been known about progress in the care provided in the months after stroke until this review. The level of variation we have found is a concern, but it also shows that the barriers to effective care after transfer home can be overcome and improvements made which can help people who have had a stroke both to recover from, and cope with, life after stroke.

Annex – Review Advisory Group

Name	Organisation	Job Role
Lorraine Ayres	Different Strokes	Group Development Manager
Joe Korner	Stroke Association	Director of Communications
Kate Swinburn	Connect – the communication disability network	Research and Policy Manager
Rhoda Allison	The Chartered Society of Physiotherapy	Consultant Therapist in Stroke
Claire Moser	Royal College of Speech and Language Therapy	Policy Officer
Alex Hoffman	Royal College of Physicians	Stroke Programme Manager
Tony Rudd	Royal College of Physicians	Chair, RCP Intercollegiate Stroke Working Party
Dr Judi Edmans	British Association and College of Occupational Therapists	Senior Research Fellow, Division of Rehabilitation and Ageing, University of Nottingham
Dr Richard McManus	Royal College of GPs	Professor of Primary Care Cardiovascular Research
Amanda Jones	Royal College of Nursing	Nurse Consultant
Pam Scoular	Department of Health	Stroke Programme Manager
Will Palmer	National Audit Office	Manager, Health VFM Audit
Kate Burley	Shropshire and Staffordshire Heart and Stroke Network	Director
Sarah Gillham	Stroke Improvement Programme	National Improvement Lead
Jane Barton	Sheffield Health and Social Care NHS Foundation Trust	Consultant psychologist
Elaine Yardley	ADASS/ Nottingham City Council	Director – Access & Reablement
David Roberts	ADASS/ The London Borough of Bromley	Assistant Director
Mimi Konigsberg	ADASS/ London Borough of Hounslow	Director, Community Services
Elaine Cohen	NHS Confederation	Senior Policy Manager
David Haslam	Care Quality Commission	Clinical advisor
Rekha Elaswarapu	Care Quality Commission	Strategy lead

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