Report of engagement activity with stroke survivors and carers

Introduction

CQC carries out reviews where an aspect of health or social care is of importance across the country and where there are opportunities for organisations to make substantial local improvements. In December 2010 CQC completed a review of services for people who have had a stroke and their carers. The stroke review is based on information from a range of sources, such as from care organisations themselves, and from people who have personal experience of stroke. This document summarises how CQC have sought and taken into account the views of people who use stroke services. This includes engagement activity for this review and also for a planned survey on community rehabilitation services for people who have had a stroke. Engagement activity has focused on people who had their stroke between one and three years ago, although some of the views described in this report relate to experiences of care before that.

Section 1 summarises a workshop held in November 2009 involving people who had a stroke, to get their views on what the review should be focusing on. Section 2 outlines the main findings from focus groups and interviews held in December 2009 with people who have experienced rehabilitation care following a stroke. Work carried out between March and May 2010 via the CQC SpeakOut Network is described in Section 3. This sought opinions about their care from those in diverse groups who have had a stroke (and their carers). Section 4 describes how the review involved people in each local area who have had a stroke, in assessing information provided to people who are transferred home from hospital following a stroke. This local involvement took place during early summer 2010. A summary considers the key messages emerging from all the engagement work associated with the stroke review.
1. Initial Workshop

To help design the framework for the stroke review, a workshop was held on 3 November 2009 in London with people who have had a stroke and their family carers together with representatives from national and local voluntary organisations. The workshop was also attended by the staff working on CQC’s survey of people’s experiences of community rehabilitation services (which is expected to look specifically at the rehabilitation provided following stroke).

The aims of the workshop were to:

- Tell voluntary and representative organisations and people who use services about the review
- Find out what is most important for people who have had a stroke and their families – what makes good care, what can go wrong and how problems can be avoided
- Discuss the framework of questions and indicators which the review will use to assess how well local services are performing
- Help shape the planned Community Health Survey on rehabilitation services for people who have had a stroke. (Other engagement work for this survey is described in section 2 of this report).

WHAT MATTERS MOST ABOUT CARE SERVICES

People at the workshop talked about what makes the difference between good and bad care, and what matters most to people who have had a stroke. What stood out from these discussions was how very different people’s needs are. Each individual who has a stroke has a unique set of needs depending on family and social circumstances, what they want to do (their aspirations), their age and the stroke itself. A number of common factors arose across each of the discussion groups about what matters most about the services people get. Each of these factors is described below

Targeted, simple and well co-ordinated long term support

It was agreed that immediate medical care was very important but almost everyone at the workshop said that people who have had a stroke require much longer term support. A stroke can often result in conditions which can affect a person for the rest of their life. This means making sure that services

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1 This section is an edited version of a report on the workshop which has been available on the stroke review webpage since early 2010. In this version some detail has been omitted, and additional notes have been added towards the end describing how the key messages emerging from this workshop actually affected the way in which the review was carried out.
Stroke engagement

like physiotherapy last long enough, but also that everyone who has a stroke
gets lifelong support.

Stroke is likely to affect an entire family, so families and carers need help as
well as the person who has the stroke. Several people at the workshop did not
think that younger people who have strokes get services targeted to them.
Many people have strokes in the middle of their lives and some even
experience stroke whilst still a child, which is not widely realised.

Most people said that in their experience support was not joined up, and felt
that it was extremely hard to find a way through financial support and benefits,
and the types of social services which those affected by a stroke are entitled
to.

Participants told us that health service staff often see support for people who
have had a stroke in terms of highly skilled teams with specialist medical
expertise. There were some good examples given at the workshop of
voluntary organisations providing a co-ordinating role. Representatives from
these organisations said that services did not need to be high cost: many
involve one-to-one support in simple ways.

One organisation offers personalised practical support to local people who
have experienced a stroke. For example, they will send text reminders for
outpatient appointments as they know that people who have had a stroke may
forget. Or they will go with them to an outpatient appointment so that the carer
does not have to miss work for a day.

One group talked about the need for more advocates for people who have
had a stroke. Often family members are expected to speak on their behalf but
they are also trying to cope with the experience of stroke, and need support
themselves.

Accessing adequate rehabilitation
People also discussed how the physiotherapy they had received had been
very good and said the physiotherapists had really cared for them. One
participant mentioned how the physiotherapists had helped him get out of the
house which was really important to his recovery and commented that he still
keeps in touch with them. The group discussed, however, that physios are
under a lot of pressure and some commented that their physiotherapy service
had been cut-off after a certain period of time.

One stroke survivor felt that whilst in his experience the physiotherapy was
very good in hospital, the physiotherapists never explained the purpose of the
exercises they were given and how they would help. Another participant
highlighted the importance of physiotherapists explaining the reason and
importance of carrying out exercises – particularly when some exercises are
painful or uncomfortable, such as when patients’ legs are strapped down.
The group discussed the value of stroke survivors meeting with people who
have recently had a stroke so that they can help them with carrying out the
exercises and share their experiences.
Staff, understanding and respect
People at the workshop who have had a stroke generally agreed that staff attitudes and understanding in health and social care varied greatly. Some people talked about having a good relationship with a doctor, others commented that staff moved on too quickly, particularly in social services. “Good social care staff seem to move on” “Some staff are great, why can’t they all be?”

As well as recognising individual needs, staff in both health and social care services need to respect the views and wishes of people who have had a stroke and to better understand what it is like to have had a stroke. This can be done through training:

“The Stroke Strategy is fantastic but unless professionals are trained things will carry on as they are”.

Understanding of communication needs
It was argued that the review should pick up on whether services know about people with communication and psychological needs. For instance it is not known how many people in the country have aphasia and systems are not generally in place to track the needs of people with aphasia in the longer term.

“They [the service providers] may have a checklist that includes…..help with dressing, help with eating, mobility help – you may not need these – but may need other things such as help with filling in benefits forms”

“[CQC’s stroke review] should consider how communication difficulties are defined … they should not focus only on how many words a person can produce in a set time, but how the person feels about their communication skills.”

Communication difficulties can lead to other problems if people are not supported. One group reported that some parents with communication difficulties were not supported to discuss their family arrangements and that social services would focus only on whether children were safe or not.

Information and guidance
People at the workshop agreed that it is very important to be told what is going to happen (including the types of services you might get) as soon as you have had a stroke.

A stroke survivor and his carer said that stroke is life changing and frightening, especially if you are the bread-winner. You need to know where to go for practical advice and help, and be given some idea of what will happen afterwards in terms of recovery, plus the implications for your working life.

Some people talked about finding help merely ‘by chance’, and said that they needed help navigating the system.
“You need to someone to go to – a key worker or a link person – who knows who to ask and where you should go for help” “You can’t always take it all in – you may need to be told things again and again”

People also reported that they had ended up paying for services and medications because they had not been told that they could get them free. Others could not get the help they needed to apply for benefits or had not been told about the Stroke Association or other support groups.

Getting into the life you want to lead once you have had a stroke
Many people mentioned the importance of training opportunities, skill development, and pathways back to work (paid or voluntary). However, some said that people have different priorities. When people have a stroke mid-life and with families their personal goals might be engaging in family life again. The experience can break marriages and families up. It is often unrealistic, according to some, to push people back into the jobs they had before having a stroke.

People also discussed the importance of setting goals and being able to get out of their own home and back out into the community as a way of regaining independence and socialising again. They described the importance of emotional support to help them manage with life after a stroke. While some people require specific psychological support, others said how important informal and peer support was to them.

Raising awareness
A few people at the workshop mentioned how important it was to offer advice about prevention and to raise the awareness of stroke. The FAST campaign was praised but some people also said that authorities needed to focus more on black and ethnic minority communities particularly those that had greater risk of having a stroke.

A good service is ....

Joined up - providing a link worker, linking the voluntary and government services
Individualised - understands individual needs and targets help
For ever - doesn’t stop after hospital
Enabling - helps people help themselves
Empowering - helps people to make choices about how they live their lives
DISCUSSION OF THE REVIEW’S THEMES

In the next session, people worked in groups giving their views about three of the key themes that the review will be looking at.

1) Hospital stroke care and discharge

People’s experiences of care in hospital were mixed. In some cases people reported being moved around in hospital from one ward to another without a clear explanation why or in a way which did not seem well organised. One stroke survivor experienced ‘ignorance’ from hospital staff about the effects of his stroke.

A stroke survivor described how despite having no feeling in his left side, he was given a cling-filmed meal which was taken away unopened, and staff did nothing to prevent his left hand getting stuck in the wheelchair wheel.

One participant reported that “medics either write you off totally giving you no hope, or give you false hope”. Most found that Speech & Language Therapy (SLT) was available initially in hospital but that the focus here was often on swallowing problems. This directed resources away from SLT for communication which was felt to be unfair; although it was thought that this may now be changing for the better.

One stroke survivor said that hospital staff go home on Friday afternoon until Monday morning, so rehab activities are not available at weekends. Another said that there were limited places available in the rehab centres for activities such as pottery. It was pointed out that having a range of rehab activities at hospital means you can stay for the day and join in as an outpatient (which is especially useful if there is no day care in the area).

One participant, who had been a Speech and Language Therapist based in a hospital, said that there was not enough space available for rehabilitation. Another felt that hospitals favoured physiotherapy over Occupational Therapy (OT), where less resources were allocated.

A carer said that the intensive physiotherapy received in hospital was not followed up after discharge, and that they had to wait several weeks after going home for home-based physiotherapy to start. She added that physio (once a week for 6 weeks) was not adequate and that, although instruction sheets were given for practising between sessions, there was no ongoing support after that time. As a result she paid for private physiotherapy.

Another participant spoke about the difficulties experienced once back at home and said he never received the aids/adaptations that he was promised and that, as a result, he had to sell his home.

Someone from a stroke voluntary group described how well-organised ‘Early Supported Discharge’ – built around a team of physios, OTs and other...
specialist staff – is really helpful and frees up beds in hospital. She said that people are often very scared after all the help received in hospital to be just ‘dropped’ at home without support.

One participant reported that, while they had heard a lot about personalised services and individual budgets, patients don’t get real choices about what services they want and their preferences in terms of equipment. She also said that for true holistic and joined-up care, reviews of health and social care should be done jointly, rather than separate reviews.

2) Information, advice and support

The sort of things that people want information about include advice about what happens next when you have had a stroke, how to prevent another stroke, financial support that might be available including how to access benefits, and what treatment you can get. People who have had a stroke want information that helps them to make choices about how they live their lives.

A stroke survivor described how when he had a stroke he was declared medically unfit for work, ‘thrown out’ and had nowhere to turn. He went to the Citizens Advice Bureau but they did not have the expertise. On the medical side, he was simply sent home with no support or back up. He was told he would make a full recovery and had his benefits taken away. He said it was not until two years after his stroke that he was referred to the Stroke Association (SA).

People who have had a stroke and their carers want to be given an honest and accurate description of how well they are likely to recover. Often people have been given an artificially positive prognosis, or in other cases very negative.

Several people who have had a stroke said that they needed someone to go to from before they leave hospital, a key worker or link person, who knew who to ask and where you should go for help. This was described as someone to find and try to fill the gaps in services for an individual. Help needs to be at the right time, broken down into digestible chunks (“you can’t always take it all in”) and repeated because stroke can make it very hard to remember things. It takes time to come to terms with a stroke and to take things on board, so information should be given in small amounts at any one time and needs reinforcing over and over again.

Services need to be signposted, but only services that can actually deliver. Signposting services that should be able to help in theory but which are unable to cope with delivering anything is worse than useless, since it raises expectations which then get shattered.

People providing information need to understand that, for many who have experienced stroke, services are bewildering and it is very difficult to see what you might be able to get to fulfil your needs and help you live. They
expressed the view that the voluntary sector is often better than state care services in this regard.

A participant, who was 19 at the time of his stroke, said that he found the Stroke Association by chance. He didn’t know the Stroke Association existed; they paid for driving lessons which he could not afford. His mother paid for his Warfarin tablets for 3 or 4 years before finding out he could get them free. Another survivor said he didn’t find out about car tax exemption until recently.

Getting information on the financial support that is available and how to access benefits is important, but the application process is complicated for anyone, let alone someone recovering from stroke. For example, people told us that the Disability Living Allowance form is long and complex and has to be completed on an annual basis.

Written information is important but not everything. Face to face advice and peer support from other stroke survivors are important sources of information, particularly as many stroke survivors will have aphasia. One person mentioned that when her mother had a stroke, she could find only one leaflet written in the appropriate foreign language.

3) Community care, support and achieving independence

There was strong support for the review looking at these services in the long term – with many participants reporting that services were often ‘cut-off’ after a year.

They said that these services do not need to be high cost – many are provided by smaller scale voluntary organisations and just involve one-to-one support in simple and practical ways e.g. peer support and befriending.

For many who have experienced stroke, services are bewildering and it is very difficult to see what you might be able to get to fulfil your needs and help you live. Someone is needed to find and try to fill the gaps in services for an individual. They can help to ‘navigate’ relevant services and voluntary organisations as currently individuals can feel they discover services ‘by chance’. It is difficult to know which professional can help.

It was felt that there is a need for greater advocacy – currently family members are relied upon to provide this but they are also trying to cope with the experience of stroke and need support. But people also told us that the advocate should be someone independent of health and social services.

People felt that community-based services should be ‘open access’ – allowing individuals to access services again when needed. They also said that support for parents who have had a stroke can be inadequate. Social services will focus on whether children are safe and not seek to offer support beyond this. Those who have experienced strokes and have communication difficulties find they can not challenge this.
People expressed the view that vocational training should not just focus on sending people back to work. People who have had a stroke should not be sent automatically into their old workplace – they are often being set up to fail. Services need to recognise that people who have had a stroke can contribute a lot to society but that they need to be helped to do what they want to and can do.

The group also discussed the importance of involving people who use services in decision making, monitoring, planning and commissioning services and also in service delivery – include both the operational and personal level. Participants also suggested that CQC should look at some outcome indicators to measure success of services e.g. health and well-being, and quality of life.

**WHAT WILL HAPPEN NEXT? – AND IN ITALICS, WHAT DID HAPPEN**

Overall, people at the workshop were supportive of the proposed review and the set of issues it was aiming to look at. In terms of the overall scope of the review, the consensus was that the review should look more at long term support and less at the early stages of hospital care (where a lot of action has been taking place over the last few years).

> The review focused on transfer home from hospital and subsequent care. Stroke treatment in hospital was removed from the scope of the review.

The group also identified a range of issues which the review needs to include in the detailed questions it asks service providers and commissioners. The CQC stroke review team will review the framework against the issues set out in the sections above, as well as the detailed notes taken in each group.

> The review’s data collection forms included questions addressing the issues raised, including for example support for families, and staff training in working with people who have communication difficulties following a stroke.

The group also made some specific comments about the wording of the review themes and questions, as well as about the information analysis tool. Where possible, these will be incorporated directly into the tools the review uses to collect data and assess performance.

> The transfer home information analysis tool incorporated many of the suggestions made in the workshop, both about content/wording and about how to deliver this part of the review.

Some of the comments related to issues outside the scope of the local assessments or which may be difficult to assess through numerical information. Where possible these issues will be addressed in the review’s national report. This report will also provide an opportunity to tell some of the stories people told on the day.
The review’s national report will be shorter than originally envisaged, but will link to other documents, such as this one, which provide more detail.

These comments will also help shape the development of the community health services questionnaire, focusing on rehabilitation for people who have experienced a stroke. In particular it was helpful for workshop participants to emphasise the importance of health and social care professionals setting goals that are meaningful to individuals, and of involving individuals in deciding on these goals.

The community health services rehabilitation questionnaire has been redrafted to reflect the points made in this workshop. However its launch has been postponed until after the 2011 national census.
2. Engagement to help shape the community health rehabilitation care survey

A series of focus groups was held to identify the aspects of rehabilitation care that were most important to patients once they were discharged from hospital and living in the community. These were carried out for CQC by Picker Institute Europe to help develop a new community health rehabilitation survey. The views of three different patient groups were sought: people who had experienced a stroke or transient ischemic attack (TIA), heart surgery or a cardiac event or a hip or knee replacement. This report only describes the engagement with people who have had a stroke or TIA, and is based on a report by the Picker Institute dated January 2010.

Two focus groups were conducted in December 2009; one in Leicester, and one in Sutton Coldfield, West Midlands. A total of ten individuals plus two carers took part in the focus groups. Six had experienced a stroke (or several strokes) and four had experienced a TIA. There were five women and seven men. The groups included three males from black or ethnic minorities. The age range of participants was 34 to 83 years.

In addition, two in-depth telephone interviews were conducted in December 2009 with a male stroke survivor from Birmingham and a female from Farnham in Surrey who had experienced a mini stroke (TIA).

Rehabilitation in hospital

Most participants said that their care in hospital was good or very good, although there were variations in the care and support received. Most stroke survivors reported receiving immediate help from a number of professionals in hospital; this included physiotherapists, speech and language therapists and occupational therapists. Some reported getting daily physiotherapy and speech therapy, and most saw a range of professionals regularly.

A few participants said they saw a social worker in hospital, and several mentioned receiving nutritional or dietary advice. Several participants were unsure what professional they saw or who it was who gave them advice. The shock and the emotional impact of a stroke or TIA meant that people were often confused or upset for some time after the event. Some participants found it difficult to recall the details of their care and several highlighted the loss of confidence and independence caused by this condition.

*The medication is putting it right – physically you are looking alright but mentally you are not.*

(Male stroke survivor, Leicester)

*Yes – I think they did explain it in the hospital and then I had my cousin and my sister who came down to me and kind of explained it to me.*

(Male stroke survivor, Birmingham, telephone interview)

*It’s all about your independence…and if that is taken away*

(Female, TIA, Leicester)
Stroke engagement

Transition between hospital and community services
After the initial shock of a stroke, most participants were keen to leave hospital and return home to continue with their recovery, especially those who had the support of family and friends. Not everybody felt ready to leave hospital or got the support they needed. One participant (with aphasia) described her experience of her first stroke ten years ago when she was discharged, unable to speak and without the use of one hand, with a newborn baby (she experienced stroke as a complication of pregnancy). She had no help or support from professionals, but went to live with her sister as she could not cope unaided during the day when her partner was at work.

Yes because – five months hospital – baby as well – sister – second mum – go there and go home with the baby – I nervous….Yes because with the baby – with one hand – I have got to get better – and change nappies – no help.

(Female stroke survivor, West Midlands)

Her more recent experience of stroke rehabilitation four months ago was more positive and she was getting ongoing support from the Stroke Association. Another participant described her recent experience of a seamless service from the hospital to home, with a physiotherapist, occupational therapist and speech therapist visiting her at home;

It was exactly the same [as in hospital], she came round to my house every week and she did exercises.

(Female stroke survivor, West Midlands)

A carer commented that the ability to make a cup of tea unaided in hospital did not mean that a person could manage at home. Another participant agreed that this test (commonly used by hospitals) was an inadequate indicator of whether he was fit to be discharged;

I didn’t have anything else – all I had to do was make a cup of tea – that is all I did – made a cup of tea in hospital and put the kettle on and had a cup of tea and I was alright.

(Male stroke survivor, West Midlands)

Care Planning
Only three participants had heard of, or been given, a formal care plan. One carer had been invited to attend what sounded like an initial meeting about care co-ordination. She was told that further meetings would be arranged but never heard anything more. Two participants understood the term care plan to mean that they were informed about their rehab arrangements before they left hospital, or they were given appointments on specific days of the week. They did not appear to be involved in care planning discussions on an ongoing basis.

Nobody had a care co-ordinator who looked after all the different aspects of their care on an ongoing basis and several participants thought that a social worker would be suited to a coordinating role. One participant said that he saw a social worker (or OT, he wasn’t sure) when he was in hospital to discuss aids and equipment needed at home and that these were in place when he got home;
Stroke engagement

But I never saw her again – whether or not I needed any more help.
(Male stroke survivor, West Midlands)

Another had a one-off home visit from an unidentified professional;
Once I had left hospital – someone came – asked if I was finding it OK
and was there anything that I couldn’t do and could they help me by
introducing some things to help me.
(Male stroke survivor, West Midlands)

Access to care
All the stroke survivors we spoke to got some rehabilitation, although some
had to wait for it. Most participants said that their aftercare appointments
were made for them, although there was a variation in what rehabilitation
services were arranged and for how long.

Several participants raised the issue of access to services for stroke survivors
whose speech is affected – and who find speaking on the telephone difficult.
One participant described the impatience of the council offices and her GP’s
receptionist as she struggled to get her words out.

Even the doctors – I phoned up the doctors and she couldn’t
understand me so she put the phone down on me – my son went up
there – I got a letter from my doctors apologising and a bunch of
flowers.
(Female stroke survivor, West Midlands)

One male stroke survivor said that he did not use the telephone for several
months after his stroke. This caused problems as rehabilitation appointments
were often cancelled via a last minute phone call.
‘Well, they said that they phoned – because I didn’t answer the phone
– I have started to answer the phone [now] – I didn’t get any messages’
(Male stroke survivor, Birmingham, telephone interview)

Other participants described how they wrote things down or drew pictures
instead of speaking; this clearly requires a patient and engaged listener.
Support of friends and family was vital in being understood.

I mean at the time I couldn’t talk properly it was all coming out slurred
and so she [daughter-in-law] was doing all the questioning.
(Female TIA, Farnham, telephone interview)

Information and Communication
All participants said they were given basic information on stroke and /or TIA
by the hospital. At the time, some participants were in shock or having
difficulty taking in what was happening to them.
I didn’t want to know – I was going through the stroke itself and I was
like – I didn’t want to know about it.
(Male stroke survivor, Birmingham, telephone interview)

Some participants had been given information about organisations and
support groups such as the Stroke Association, and others had found out
themselves. Some wanted this type of support while others got through on
their own, usually with support of close family. The West Midlands focus group participants were all members of the Stroke Association and valued the peer support as well as the information gained from their website and magazine.

*I was very lonely when I had my stroke – all my friends forgot about it – because it's different… I like it [the Stroke Association] because we can have a chat – she lives by me – we have a chat so that is important*

(Female stroke survivor, West Midlands)

Participants were acutely aware of their slurred speech and aphasia, and communication with professionals emerged as an issue for some people, especially in the early days. A few participants raised issues about the communication skills of health professionals when they were in hospital; some felt more sensitivity could have been shown.

*I felt a bit of an idiot – they speak to my wife in one tone, like normal and they speak to me as a different type of person – very loudly for a start and very slowly – but I could understand everything she says. *

(Male stroke survivor, West Midlands)

But examples of listening were also found; one participant said that the district nurse who came to change his dressings understood his complaint and altered her behaviour;

*She did not speak to me at first – but spoke to my wife - but that person was so good that they explained everything to me again- she just felt she needed somebody else to know just in case I didn’t understand. I could hear her talking to my wife and I went ‘Excuse me, I am the person lying down here….she explained everything to me again.*

(Male stroke survivor, Leicester)

**Carers**

These participants agreed that the ongoing support of family and friends is vital for practical and emotional support after a stroke or TIA.

*My family have really been my rock.*

(Female TIA, Leicester)

Participants described how much they relied on this support, and one said she sometimes felt like a burden;

*I sometimes feel guilty because I am young and my family have got to look after me and see if I am alright and drive me there, do the shopping….sometimes I feel a bit of a burden, a bit useless.*

(Female TIA, Leicester)

Carers can feel overloaded. One carer mentioned how a support group in the hospital helped her;

*I found it very difficult to cope…she used to come round and introduce you – and then she used to have meetings I think once a week – where carers could go in and discuss and get some feedback from other stroke victims.*

(Female carer, West Midlands)
**Experience of care received in the community**

Some participants had physiotherapy, speech and language therapy, occupational therapy, a district nurse and a social worker whereas others had very limited support after discharge. Hospital appointments for most participants reduced over time to six monthly or yearly check ups. One participant who had weekly home visits from a physiotherapist, occupational therapist and speech therapist said her experience of rehab this year was much better than her experience 15 years ago. The first time;

*They came round once a week for three times and that was it. My last stroke, they have been absolutely golden, but the first stroke, nothing.*

(Female stroke survivor, West Midlands)

Other participants had more limited experiences of rehabilitation;

*‘I had a bit of physio once I came out of hospital – it wasn’t long before the physio stopped and the speech therapist stopped as well.’*

(Male stroke survivor, West Midlands)

There were gaps in care. One carer commented that she had to arrange physiotherapy for her husband herself, and she investigated private speech therapy when it ended too early. One man who was getting physiotherapy and speech therapy weekly had been promised and even measured up by an occupational therapist for rails in the house, but five months later he was still waiting. This participant also said that appointments were cancelled at short notice, concluding

*It wasn’t well organised – they didn’t have enough on their team.*

(Male stroke survivor, Birmingham, telephone interview)

Some participants had limited contact with rehabilitation professionals, and were given worksheets or exercises to use on their own at home. This approach seemed to suit some people; one person who had just one session of speech therapy at the hospital, followed up by a telephone call, was happy with this arrangement;

*I just had to go and see the speech therapist at the hospital and she gave me a load of sheets which I had to sort of keep practicing over and over again…she rang up about 6 weeks afterwards to see how I was getting on…I think that was enough help because I would have done exactly the same things if I’d gone up to see her again [at the hospital] and in your own place you can sort of keep on doing it rather than do it up there [hospital] particularly on your own you can do it, you know sort of easier.*

(Female, TIA, Farnham, telephone interview)

**Health and Social Care professionals**

Health and social care professionals had an important role to play in rehabilitation care for these participants, especially in terms of reassurance, advice and regular checks after the shock of a stroke or TIA. Although some participants preferred to be in control of their own rehab at home, the input of professionals was regarded as important for keeping people motivated. One participant said;
'There is only so much you can do [at home] if you have got someone you tend to do it, but if you are left alone you will only do so much.'
(Male stroke survivor, Leicester)

Another participant described a growing understanding developing between him and his rehabilitation practitioners. He said that his confidence and assertiveness grew with time;
'I felt that they were in control of it [his recovery] before but now it is kind of like I have taken on a lot of it myself.'
(Male stroke survivor, Birmingham telephone interview)

Personalised care and self management
Participants said that personalised care was important as stroke affects each person differently.

Looking around the table – every stroke victim has a different story because stroke – it is all so different.
(Female carer, West Midlands)
They need to tailor your treatment accordingly instead of just one treatment for everyone.
(Male stroke survivor, West Midlands)

There were examples of a lack of personalised care. One participant kept horses at the time of his stroke and had to abandon this interest – he did not get any help or advice on the possibility of getting back to riding again. Others mentioned a lack of attention to their specific emotional or communication difficulties caused by aphasia.

Some individuals may choose to ‘go it alone’ rather than look to professionals for help. Those who stressed their own role in their recovery appeared to be self-motivated and determined individuals. One participant who had no contact with physiotherapists or social services said of health professionals
I think they have got loads of qualifications but no common sense ….so I think if you are self motivational and you can get out there…go out and do it and just keep pushing yourself.
(Male stroke survivor, West Midlands)

Some participants made permanent changes in their lifestyle including taking regular exercise, trips to the gym, dog walking, cutting smoking and alcohol, reducing spicy food, salt, bring down stress levels and having fewer late nights.

GP care
Most participants said their GP was the key person in terms of their ongoing aftercare and monitoring in the community. All participants said that they found regular contact with their GP was important and reassuring; most had a good or excellent relationship with them.
My GP is brilliant as well - he has made me feel like someone not just a patient…‘he is keeping tabs on everything on the computer – he is my aftercare now.
(Male stroke survivor, Leicester)
A young woman who had experienced several TIA’s said;
‘I’m sure that if my GP had a kettle in his room he would put it on and have a chat – it is that sort of easy talk’.

Most participants said that their GP’s had been made aware of their stroke/TIA via a letter from the hospital. Contact tended to be on an as needed basis for checks and reassurance; most participants said that they would initiate contact with their GP if they were worried and several said their GPs would take the initiative to contact them if they did not attend regularly.

…I go to my doctors once a month – it makes me feel better because he checks me over and it makes me feel better because...he knows me.
(Female stroke survivor, West Midlands)

Monitoring
Participants said that the GP monitored their progress doing blood tests, checking blood pressure, cholesterol, kidney function, monitoring and changing their medication. Some participants monitored themselves at home in terms of cholesterol levels and blood pressure and reported this back regularly to their GP. One participant draws a chart for his GP every month showing his blood pressure readings taken from his own machine. Another keeps a diary of how she feels everyday and takes this to the GP after any incident or seizure. Another participant mentioned her GP looking at her ‘stroke book.’

Although some participants said their GP reviewed their medication on a regular basis, others said they simply followed hospital recommendations. One participant, who hated being on medication, felt that his GP was simply following hospital advice and not listening to him.

Gaps in care
Participants were generally positive about their rehabilitation, although some participants felt that they needed more help or that their rehabilitation ended too early. The emotional impact of stroke did not appear to be addressed by rehabilitation services and many participants found this type of support from family members or after joining their local branch of the Stroke Association or from their GP.

Two people with aphasia made the point that an inability to read due to stroke is not regarded as a health problem. No participants received home care or said they had a social worker on an ongoing basis. One participant with aphasia who lived alone found cooking a problem and got no help learning to read again;

No, they [rehab practitioners] were too busy, so my son went to the shop and he got some (baby) books….Yes [needed help with], reading and writing – cooking and things.
(Female stroke survivor, West Midlands).
People who have had a stroke told us that it is especially important for them to have....

**Personalised care** – as stroke affects everyone differently and can impact on many aspects of a person’s life

**Carers and/or family members** - for emotional and practical support

**Self motivation and determination** - some prefer a self management approach

**Professional support** - the GP is key in providing ongoing aftercare and support

**Understanding of the effects of aphasia** - rehabilitation services must be sensitive to the difficulties involved

**Practical support with day to day activities** - for example help with reading, writing and cooking,

**Support with emotional needs** - after the shock of a stroke

**Peer/mutual support** – via organisations such as the Stroke Association
3. SpeakOut Network views on stroke

SpeakOut is a network of community groups supported by CQC and the University of Central Lancashire. It enables groups who are often not heard to have a stronger voice about the health and social care matters which affect their communities. In 2010 the network expanded and there are now over 80 groups who want to get involved with the work of CQC and a smaller number who want to be kept informed of the work of the network with an option to get more involved when they feel ready.

During spring 2010 six groups in the SpeakOut Network agreed to tell CQC about their communities’ experiences of stroke care. The aim was for the stroke review team to hear about the personal experiences of people who have had a stroke (and their carers) to influence the content of the review and to inform its findings. The idea was to get more information than plain statistics would provide by getting an in-depth knowledge of how people thought they were treated following a stroke. They were asked what they thought mattered in terms of the overall care pathway. The aim was to get feedback on where people thought services worked well and which areas needed more attention.

Six groups in the SpeakOut Network contributed to the review. Three of these groups took part via a series of interviews, and the other three held focus groups. Most people who participated had had a stroke, or had been caring for someone who had had a stroke, within the last five years. The following took part in the research:

<table>
<thead>
<tr>
<th>Group</th>
<th>Location</th>
<th>Form</th>
<th>Participants</th>
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</thead>
<tbody>
<tr>
<td>Gypsies and Travellers (Barnsley Black and Ethnic Minority)</td>
<td>Sheffield</td>
<td>Interviews</td>
<td>6 Males 4 Female carers</td>
</tr>
<tr>
<td>Asian Disabled Association</td>
<td>Derby</td>
<td>Interviews</td>
<td>3 Males 3 Females</td>
</tr>
<tr>
<td>Black Minority Ethnic Elders Forum</td>
<td>Leicester</td>
<td>Focus Group</td>
<td>4 Males 2 Females 1 Female carer</td>
</tr>
<tr>
<td>Health on the Streets (HOTS) Patient Group</td>
<td>Bradford</td>
<td>Focus Group</td>
<td>2 Males 3 Female carers 1 Female awaiting diagnosis (TIA)</td>
</tr>
<tr>
<td>Ed-Bus (Ethnic Minority Families)</td>
<td>London</td>
<td>Interviews</td>
<td>2 Males 1 Female 1 Female carer of child</td>
</tr>
<tr>
<td>Surrey Coalition of Disabled People</td>
<td>Guildford</td>
<td>Focus Group</td>
<td>3 Males 3 Females 2 Female carers</td>
</tr>
</tbody>
</table>
The detailed findings from these interviews and focus groups are described under a series of sub-sections below. Most of these sub-sections refer to the Quality Markers (QMs) used in the National Stroke Strategy (2007). These markers outline the features of a good service and provide a platform to assess where improvements are needed. Note that the scope of the SpeakOut group discussions and the notes that follow is broader than that of the stroke review. In particular they include information about the early stages of the stroke care pathway, such as that provided by ambulance and hospital services. This provides useful context and introduction for the subsequent rehabilitation care, which is the focus of the review.

Information, advice and support (QM3)

“You can’t ask a leaflet questions can you?”
(Male, 52, Traveller, Barnsley Black and Ethnic Minority Interviews)

“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.”  
(Male, 31, Ed-Bus London Interview)

“Don’t know who to ask or where to go.”
(Surrey Coalition of Disabled People)

Information provided was usually in the form of a leaflet. It was generally seen as useful, but as a stroke is such a life changing event, people had questions they wanted to ask but felt they were often not given the opportunity to do so. Some people did not know how to read, and therefore leaflets were really of no use at all.

On leaving hospital many people did not know where to find relevant information and felt they were given little guidance or support on finding help. Some had never heard of the Stroke Association, which could have offered support that was needed. The majority thought more support was needed to become independent again after a stroke. There was also a view that medical staff can be poor at giving information; often thinking things need only be mentioned once. In reality, it takes time to come to terms with a stroke and to take on board any information given, which should be given in small amounts at any one time and needs reinforcing over and over again.

Urgent response (QM7)

“Paramedics came to the house when a neighbour called and it was very good service. He quickly diagnosed the problem, reassured me and called the ambulance straight away. The ambulance people were very kind and treated me with care and respect and I got to the hospital within about 15 to 20 minutes of the stroke happening.”
(Female, 50+, Ed-Bus London Interview)
There was relatively little mention of the ambulance service urgent response. This would suggest that there may have been little recollection of this part of their care, possibly because it occurred such a long time ago, or they were possibly unconscious or in a state of shock at the time. The feedback which was received suggested that the urgent ambulance response was generally positive, with ambulance staff being professional, reassuring and efficient.

People who contacted their GP when they had a stroke reported a range of experience in terms of urgency of response. One said that her GP immediately dialled 999, but others were sent home. Note that many people contributing had their stroke before the “FAST” campaign, which has had a major impact on the initial response to stroke.

**Hospital A&E – assessment (QM8)**

*I was fed up with all the messing about it made me feel even worse.*

(Male, 73, Traveller, Barnsley Black and Ethnic Minority Interviews)

*‘A&E hadn’t done any investigation, no thrombolisation or blood exchange on previous Friday that’s why the stroke happened.’*

(Carer, Ed-Bus London Interview)

Many found the hospital unwelcoming and disorganised, however, this did vary. One person was transferred twice between two hospitals causing a great deal of stress in the immediate hours after their stroke. Some people were informed by a nurse rather than a doctor that they had had a stroke, which was seen as unprofessional and disappointing. There were reports on a few occasions where the person who had a stroke reported that they were not properly diagnosed, as either the doctor did not believe them or there was no investigation done. This raises the issue that some in the medical professions may need more awareness of how to identify a stroke.

**Hospital care – treatment (QM9)**

*I always remember what she told me - she was honest and accurate about my long term prognosis but was always very inspiring.*

(Male, Health on the Streets Patient Group)

*I did not like to be in hospital, you don’t get the rest you need and people don’t treat you with respect, its bad enough to be ill but it makes you feel like a child, the way they talk to you and they don’t know anything about our culture and our needs, I don’t like that hospital the care is rubbish.*

(English Gypsy, 70, Barnsley Black and Ethnic Minority Interview)

The treatment reported of people who have had a stroke in hospital varied from excellent to awful. This tended to depend on the attitudes of the nurses in the wards. Some of the criticisms included nurses being rude and patronising, where others were praised for being professional and encouraging. Some people were made to feel as though it was their fault that
they had had a stroke and others thought they were being rushed through hospital like they were on a conveyor belt.

One area which did keep recurring was language and cultural issues. It was felt that by some, such as the travellers, that their culture was not respected in certain situations. Many said that it was their culture to ‘look after their own’, but due to visiting hours etc, they were not given the opportunity to do so. This caused unnecessary stress for all involved. It was suggested that hospital staff should be taught more about different cultures.

**Hospital rehabilitation – high quality specialist rehabilitation (QM10)**

‘Because I don’t speak English much of this was pointless.’

(Female, 76, Bangladeshi, Asian Disabled Association)

“[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.”

(Male, Asian Disabled Association)

The rehabilitation care in hospital had very positive feedback. Many people praised the rehabilitation services, helping people restore them back to their former physical abilities. However, the areas of concern again were in terms of language. Many of the participants did not claim English to be their first language, and so this caused difficulties, especially when practicing speech therapy. Some staff used cards for picture recognition to help with communication.

**Seamless transfer home (QM12)**

‘There was no communication at all, no coordination of services. We were only told he could not go home to care for himself, we had to sort it out ourselves.’

(Female carer, 32, Gypsy Traveller, Barnsley Black and Ethnic Minority Interviews)

‘Why can’t the hospital contact the community support services and let them know the patient is being discharged and were going home?’

(Health on the Streets Patient Group)

The transfer home of people who had had a stroke in some cases is still far from seamless. Some described it like being ‘passed from pillar to post’. Many found that it was down to themselves or family members to organise the help which was needed, such as physiotherapy or home adaptations.

On the other hand, some claimed they were well advised and cared for on their transfer home. One person who had had a stroke described the care as ‘exactly the same as in hospital’. A common recommendation by those who had had a stroke was that a key worker would be useful to coordinate appointments needed, help them get back to work and working out what they
need to live independently. It was thought this would also relieve some of the stress the families or carers are often put under. Anger and frustration, which is seen as a normal part of recovery, may have less of an impact should a key worker be there to support, build up confidence and enable people to live how they want.

**Long term care and support (QM13)**

‘I was fed up of sitting in my wheelchair all day long – I kept asking for an armchair – but no one noticed - I ended up paying for one myself – it cost me £600 – after 6 years I gave up asking.’  
(Leicester Black and Minority Ethnic Elders Forum Focus Group)

‘If we had relied on the NHS he would still be in a wheelchair.’  
(Carer, Ed-Bus Interview)

There were a lot of views about the quality of long term care for people who had had a stroke. Some felt that they were fortunate to have a very conscientious GP who would provide regular check ups and help organise appointments etc. Others however felt isolated or ignored with no follow up calls or when there were, visits were at irregular times with different people each time. The onus was often on the person who had a stroke or the carer to organise appointments and get there on time. Follow up calls were seen as important and reassuring, especially just after returning home.

One participant said that service providers would only "take notice of you if you make a noise". Whilst another described how she had to pay £55 for private physiotherapy to help her son walk as the NHS physiotherapy simply was not enough.

Many people described having to wait for home adaptations and often had to pay for further private physiotherapy when the NHS finished providing it. The social services could have done more to help with home adaptations and equipment provision according to some. Another aspect of long term care and support is the impact on the families of those who have had a stroke. Children may often be forgotten as much of the parent's time may be taken up with caring for their partner.

**Participation in community life (QM15)**

‘For going home and getting on with life generally I didn’t really get any help but I didn’t ask for any as my wife is very supportive and assisted me as much as she could. I am driving now but got myself back into it. If there is any help for this I was not made aware of it at the time.’  
(Male, 31, Ed-Bus Interview)

‘I do feel lonely because I can’t get out like I used to, it makes me unhappy.’  
(Gypsy, 66, Barnsley Black and Minority Ethnic Group)
The main issue people faced getting back into community life was the feeling of isolation and loss of independence. Many felt that community groups had a positive impact on helping people to socialise again and regain confidence they may have lost. Some found it frustrating that they could not do some things which they were previously able to. Many relied on the community bus to get to appointments, however, this occasionally did not turn up.

Return to work (QM16)

‘I’ve found out about lots of things but have had to do it myself. I can’t use a computer anymore even though I used to be a computer programmer before my stroke.’

(Health on the Streets Patient Group)

‘If you’re not particularly incapacitated, no-one wants to know.’

(Surrey Coalition of Disabled People)

“They 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.”

(Male, Asian Disabled Association)

Experiences of returning to work were generally negative. One participant (wheelchair user) was reportedly offered a desk job but the offer was withdrawn once it was established that mobility changes needed to be made to the office in order to accommodate her. This emphasises how those who have had a stroke do not always get support when trying to return to work, which inevitably can lead to further stress and depression. Key workers and emotional support are therefore seen as very important.

It appeared that many people were not made aware of the financial assistance available to them following their stroke. Some described how the financial advice and forms to complete were over complicated and were required each year, for some this was tiring and stressful.

Emotional support (cross-QM issue)

‘It’s like waking up in someone else’s body, no, in someone else’s life.’

(Surrey Coalition of Disabled People)

‘There wasn’t any help at all with the emotional impact of my stroke, everything was geared to getting me mobile. I think the emotional and psychological side was totally absent.’

(Male, 31, Ed-Bus Interview)

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

(Male, Asian Disabled Association)

An area which was frequently highlighted as being neglected was the emotional care provided to people who had had a stroke, their carers and
their families. The only support some spoke of was that of the nurses and GPs, although this seemed to be due to their caring nature, rather than formal emotional support. Many suggested support in this area would be valuable and could help, and even speed up, recovery if people who have had a stroke are mentally and emotionally supported as well as physically. One woman, who reported she had no emotional support provided, spoke of lack of motivation and often wondered if it was worth the effort trying to make a full recovery. She also reported that all her relationships with people changed after the stroke. Groups such as the Stroke Association and various lunch clubs were seen as valuable, as they provided a forum for people to discuss the problems they are facing.

Some families and carers said that they received little support when a family member suddenly became reliant on others following a stroke. In one case following his stroke, a man became abusive toward his wife, which obviously had a negative impact on both her and their marriage. One mother, whose son had a stroke, did get some counselling and support when she mentioned she was concerned. However, she thinks she only got this as she had a good rapport with the psychiatrist and thought most people would not receive this help. If the person who has had a stroke can see it is affecting their family, due to them having to provide care, it may also increase the stress of the person being cared for, if they feel they are unable to do anything about it.

**Language barriers and culture (cross-QM issue)**

‘No one spoke Gujarati – I was there for 4 months - I felt alone and isolated.’

(Black Minority Ethnic Elders Forum, Leicester)

‘She was afraid and would get upset when we left and the staff didn’t understand our ways there are certain expectations of care in these circumstances, it’s our culture and it’s about the dignity of the person.’

(Carer, 56, Gypsy, Barnsley Black and Minority Ethnic Group)

Many of the participants did not speak English as their first language, with some not being able to speak any at all. This caused some problems with communication for all aspects of rehabilitation and support. It was not only difficult for staff to explain what they were doing and why, but also prevented effective speech therapy to occur through lack of understanding. In many instances, family members were relied upon to act as translators for the person who had had a stroke. This in some cases put extra pressure on the families to be present as much as possible.

Difficulty communicating also has an emotional impact, often leading to loneliness and depression if no one in the hospital talks to you. One person said they felt ‘alone and isolated’ as they spoke Gujarati but none of the hospital staff did.

In terms of culture, groups such as the Gypsies and Travellers often refused treatment as it did not match with their culture. In a follow up interview it was described that much information was withheld from the interviews due to the
community’s mistrust of authorities and they were reluctant to complain to medical staff in case it affected future treatment. This may also have had a significant effect on their usage of services as there is a tradition of ‘looking after your own’, so many people who may have needed help, did not trust or want people to help them. Possible resolutions to this issue involve recruiting people from within the communities to encourage trust and integration, or have key workers who are trusted within the communities. Professionals should be culturally sensitive in terms of visiting hours. One example showed how a nurse agreed for family of a traveller who had had a stroke, to visit after visiting hours to ensure they were not left on their own. This was seen as very important in the travellers’ culture.

<table>
<thead>
<tr>
<th>The things that people told us would really improve their experience of stroke care include ....</th>
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<tbody>
<tr>
<td>Respect our culture – starting with better understanding</td>
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<tr>
<td>Join-up care – which should be seamless and continuous between services</td>
</tr>
<tr>
<td>Give me a key worker – to coordinate my care, and help me get what I need</td>
</tr>
<tr>
<td>Don’t assume I understand/speak English</td>
</tr>
<tr>
<td>Explain things in person – don’t just give me a leaflet</td>
</tr>
<tr>
<td>Provide emotional support - and recognise the impact on the whole family</td>
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</tbody>
</table>
4. Involving people locally in assessing stroke information

The stroke pathway review has included an evaluation of printed information that is provided to stroke survivors (and their carers) around the time that they are transferred home on discharge from hospital. This part of the review, referred to as the transfer home information analysis (THIA), developed from the initial proposal for a discharge information analysis tool which was discussed at the November 2009 workshop (see section 1).

PCTs in England were asked to compile a set of the information documents (leaflets, booklets etc) that would be provided, at or around the time they transfer home from hospital, to someone in their area who has had a stroke that fits a “representative profile”. For each PCT the set of information documents was evaluated in two ways. One of these was an evaluation carried out centrally by CQC. The other, which is the subject of this section of the report, is a local review of the information by a small group of people who have had a stroke and/or their carers.

PCTs were asked to arrange their local review via a stroke support group in their area, either by including it on the agenda of an existing meeting, or setting up a specific session. CQC suggested that the review session should ideally involve between two and six people who have experience of stroke, including some with aphasia. Some PCTs made joint arrangements with one or more neighbouring PCTs for a group to review both/all their information packs.

Feedback to CQC from PCTs suggests that some already had good working relationships with one or more local groups, and were able to arrange for them to undertake the local review of transfer home information fairly easily. However other PCTs commented that the need to arrange the review had encouraged them to improve their previously under-developed relationships with local stroke groups.

146 out of 151 PCTs managed to hold a local review session, nearly all of them between May and July 2010. Approximately 35 held their review jointly with one or more neighbouring PCTs. On the other hand, a few PCTs, mostly covering large geographic areas, held more than one review session. CQC was notified of a total of 1033 people (with stroke or carers) attending the sessions, although this includes some double counting of the same individuals where sessions were held jointly by PCTs. 338 of these people were described as having aphasia or other communication needs, and 176 as having a sensory impairment.

Local review groups were asked to look through the documentation set, and collectively rate on a scale of 1 to 5 how clear and useful the information was regarding seven different aspects (such as how good the information is about reducing the risk of stroke, or how easy the information was to understand). The results from the local reviews are summarised in the chart below:
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.

Most PCT areas were judged to have good information on reducing the risks of stroke and for carers. However, only 40% of the information packs contained good information on local services, and even fewer had good information on money or benefits and making complaints.

PCTs were invited to feedback to CQC any general comments from the local information review sessions, and about half of them (71) did so. Some of the themes recurring in these comments are described below.

The information review process
The review was generally felt to be useful, although a few PCTs mentioned difficulties with the exercise:

The Stroke User Network was pleased to be involved in the review exercise. Participants found it valuable to share their ideas about the type of information they were, or would have wished to have been, provided for them around the period of discharge.

The process proved to be very beneficial with a number of good service improvement points being highlighted and positive peer support within the group

Some of the participants and facilitators found the exercise was complicated by the use of the hypothetical patient profile. In practice, the participants found it difficult to comment on the information without referring to their own experience.

The group reviewing the material felt somewhat overwhelmed by the volume of material presented (normally this would not be given to them all at once)

How the information is provided
The importance of providing the information in the right way, with someone to help explain, was stressed by a number of PCTs:
Having a contact person to explain information within the [local] Stroke Handbook and other literature was seen to be as important as having the information itself, as it allows clients and carers to ask questions for clarification.

The gentleman with aphasia reported that he would prefer someone to come and talk to him about the information in the leaflets. However, some people liked the idea of having the leaflets and reading them over time.

Within the borough, all stroke survivors and their carers are allocated a keyworker. This individual will then sit with the stroke survivor and family and talk them through the information answering any relevant questions.

The information was very comprehensive and an excellent reference but initially requires 'face to face' time to explain and answer specific and immediate questions and anxieties. There is nothing like having someone come and talk to you.

Patients and carers are given too much information at discharge. Carer suggested that information should be given at intervals along with explanations rather than in one go.

Format of the information
Relatively few comments were made about the physical presentation of the information, but they include:

The review showed how important the packaging and design of information is e.g thickness of paper, impacts on ease of handling with restricted movement and mobility

If you have a pack of leaflets they should be numbered with an index sheet at the front so you can choose the ones that you want to read instead of having to look through them all

Carers
A number of suggestions were made for information to be provided differently for carers and stroke survivors:

A strong message that came through from the review was that two sets of information needed to be used. One for the carer, and this should be given out as soon as the patient is in hospital. A patient pack should also be available, but that is tailored to the patients needs and wants, and in a more accessible formats.

Much of the information may be more suited to a carer, particularly since the amount of information that can be comprehended by a patient following a
recent stroke is limited. It was suggested that it may be more helpful to have a ‘patient pack’ and a ‘carer’s pack’.

Generally stroke survivors felt the information needed to be aimed at carers initially as particularly those with aphasia would find it difficult to read

**Proposed action in response to the information review**

It is particularly gratifying that several PCTs noted action that they are taking to address findings from the review:

*The review has been enormously helpful in identifying areas for improvement. We have agreed to continue to work with the group to improve the content and amount of information provided.*

*Locally we hope that the group's comments will be helpful in improving the information that is given in hospital and through community health and social care services and we will be following this up with the providers.*

*We did receive some useful information regarding the format of the material, especially for younger adult strokes and we will share this feedback with the Stroke Association and other local organisations.*

*They felt that although there was a lot of information that some of this was written more in a format that clinical staff would understand rather than the patient. Boxes were too small for patients to write in. We will feed this back to the Trust*

*We will be amending the information leaflets and handbook to take account of the comments made by the user group.*

*The findings from this exercise will be used by the [local] Stroke Modernisation Team to improve the quality and quantity of information given to patients on transfer home.*

<table>
<thead>
<tr>
<th>People want stroke information to be....</th>
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<tbody>
<tr>
<td>Explained to them</td>
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<tr>
<td>Given bit by bit</td>
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<tr>
<td>Easy to handle</td>
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<tr>
<td>Written in “accessible” language</td>
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<tr>
<td>Have a version that contains more detail, which carers could help the stroke survivor to use</td>
</tr>
<tr>
<td>Developed in response to the comments they have raised</td>
</tr>
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Note that following on from the review, some examples of the best stroke information booklets will be made available via the Stroke Improvement Programme website, www.improvement.nhs.uk/stroke/.
Key messages from stroke engagement work

Conclusion

A stroke can be a massive, life changing, out of the blue event, which can see someone go from their ‘normal’ everyday lives to living with significant disabilities. It can affect areas such as speech and communication, which may require specialist rehabilitation. Stroke can also have a huge emotional impact on people who may experience stress, anxiety and depression as consequences. Stroke not only impacts on the person who has had it, but also their families, who may be required to provide care, and could cause financial and relationship difficulties.

Overall, people’s experiences of stroke care varied hugely, and they cope with it in different ways. They require different services and support depending on their circumstances and culture. The quality of care provided, according to people’s experiences, ranged from excellent to poor. The attitude of nurses and doctors was not consistent for all participants, and in some cases there seemed to be a lack of sensitivity or understanding of cultural issues.

The rehabilitation for stroke was generally seen as good, and helped people regain independence and confidence. However, those who could not speak English struggled to get the benefits of many therapies, most notably speech therapy.

One area frequently highlighted as missing from the healthcare pathway was emotional care. The only mention of this was the encouragement received from nurses and care staff, which was appreciated when received. Despite most participants receiving information about stroke, usually in the form of a leaflet, many wanted more explanation, as well as the opportunity to ask questions for reassurance and clarity. This would have helped in cases where people did not feel ready to return home and once they did, felt isolated and depressed.

As expected, people who had had a stroke want to gain as much independence as possible. Some said they received very little support on returning home, returning to work, or learning to drive again. For the majority of cases it was the person who had had a stroke who had to research to find out what help was available to them. Appointments were not always arranged for them by the hospital for when they returned home. A key worker was a frequently suggested way to improve the services, by providing knowledge, support and organisation for the person who had had a stroke and their families.