Survey of patients 2006

Caring for people after they have had a stroke

A follow-up survey of patients

Healthcare Commission

Inspecting Informing Improving

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This follow-up survey of patients was designed, developed and coordinated by the NHS patient survey advice centre at Picker Institute Europe.

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What is the Healthcare Commission?

The Healthcare Commission exists to promote improvements in the quality of healthcare and public health in England. We are committed to making a real difference to the delivery of healthcare and to promoting continuous improvement for the benefit of patients and the public. The Healthcare Commission's full name is the Commission for Healthcare Audit and Inspection.

We have a statutory duty to assess the performance of healthcare organisations in the NHS and award annual ratings of performance, to coordinate inspections and reviews of healthcare organisations carried out by others, and register organisations providing healthcare in the independent sector on an annual basis.

We have created an entirely new approach to assessing and reporting on the performance of healthcare organisations – our annual health check – which will examine a much broader range of factors, enabling us to focus on what really matters to patients and the public.

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Executive summary

A stroke occurs when an area of the brain is deprived of its blood supply, causing some brain cells to die. The effects of stroke vary enormously depending on the type of stroke and the area of the brain that has been affected. While some people will experience mild effects, which will improve in a short time, others may experience more severe effects that last considerably longer.

Approximately 110,000 strokes occur in England each year[1]. Stroke is the third most common cause of death and a major cause of disability in the population. Having a stroke has a tremendous effect on peoples' lives, not only for the patient but also their family, friends or anyone else close to them. To help them cope and learn to live with the long term effects of stroke, patients need rehabilitation, combined with a variety of practical and emotional support.

The framework for delivering stroke care is part of the National Framework (NSF) for Older People published by the Department of Health in March 2001[2]. Standard five sets out national standards and models of care that aim to reduce the incidence of stroke in the population and ensure that those who have had a stroke get prompt access to integrated stroke services.

Obtaining the perspective of patients is an important and valuable way of evaluating healthcare services and assessing progress with the implementation of standards set out in the framework. This is one of the first surveys to follow a group of patients with stroke from their hospital experience through to their return home. It shows that their experiences of care after they left hospital tend to be less positive – in terms of rehabilitation and emotional support – than their experiences of care in hospital, and highlights a number of areas where the quality of follow-up care could be improved.

Method

In the autumn of 2004, we asked 51 NHS acute hospital trusts in England to survey patients who had had a stroke, focusing on their experiences of being in hospital and the care they received following their discharge from hospital. More than 1,700 patients took part. In the summer of 2005, we carried out another survey of the same patients to find out about their care and support approximately one year after discharge. Eight hundred and seventy-five patients responded to the second survey.

Key findings

Patients were positive about some aspects of their care since they have been discharged from hospital. Most patients (83%) had seen their GP about their stroke and almost two thirds (65%) felt that their GP knew enough about the treatment of stroke. Since leaving hospital, almost all patients (96%) had had their blood pressure checked and 88% of patients had had their medicines reviewed by a healthcare professional.

However, overall, patients who responded to the follow-up survey were less positive about the care that they had received since they had left hospital. Two-fifths (42%) of respondents rated their care after leaving hospital as 'excellent' or 'very good' compared with 69% who thought their care in hospital was 'excellent' or 'very good'.

Areas for improvement

There are at least 300,000 people in England living with moderate to severe disabilities as a result of stroke[1]. A significant number of respondents to the survey had difficulty with speaking or mobility following their stroke and many felt that they had not received enough help since they had left hospital.

Coping with the emotional effects of stroke is an important part of rehabilitation. Almost half of the respondents felt they had not had enough help with emotional problems since they left hospital. The survey suggested that more help and support is needed in this area. Many of the respondents to the survey also reported that they wanted to be more involved in decisions about their care and treatment. In comparison with other national surveys, the results from this survey were less positive about this aspect of care, suggesting that more effective ways of communicating with patients who have had a stroke are needed.

More information about stroke and how to prevent another stroke needs to be given to patients as part of their follow-up care. Almost one third of patients (32%) who wanted information from health and social services about stroke said that they had not received any information since they had left hospital.

The survey suggested that many of the people who said that they required help for everyday living were not getting the help that they felt they needed. More than half of those (54%) who reported that they needed support said that they had not received any 'home help' (help with cleaning, washing clothes, etc) and a third (32%) had not received any help with personal care (getting washed and dressed). The survey also showed that more help needed to be given to certain patients when applying for certain benefits.

Carers of people who have had a stroke may also require support. The survey also showed that some patients experienced dissatisfaction with the level of help and support provided to their families or carers.

Finally, the results of this follow-up survey show that those patients who stayed on a unit for people who have had a stroke had a more positive experience of the care and treatment they received after they left hospital when compared with the experiences of those who stayed on other wards. These findings suggest that more needs to be done to promote continuing rehabilitation, emotional support, support for everyday activities and the provision of information.

Next steps

The Healthcare Commission will be developing indicators to support improvement in the care of stroke as part of our assessment of progress in relation to developmental standards for 2006/2007. These indicators will form part of the ongoing assessment of healthcare organisations and will be used to look at how services are improving year on year.

Joint indicators across health and social care will also be developed as outlined in the Government's White Paper, *Our health, Our care, Our say*. These will be focused on outcomes and will be used to assess the provision of services for people with health and social care needs.

Introduction

A stroke occurs when an area of the brain is deprived of its blood supply, causing some brain cells to die. The effects of stroke vary enormously depending on the type of stroke and the area of the brain that has been affected. While some people will experience mild effects, which will improve in a short time, others may experience more severe effects that last considerably longer. More than a third of patients who have had a stroke are left dependent or moderately disabled and require support, rehabilitation and nursing care from several different health and social care services.[1]

This report sets out the key findings from the follow-up survey of patients who have had a stroke and looks at the care they received after they left hospital.

It is widely acknowledged that long term support that meets the needs of patients who have had a stroke, and their carers, is important for maintaining their mental and physical health, ensuring the best possible quality of life and reducing the use of health and social care resources.[3]

Standard five of the National Service Framework (NSF) for Older People, published by the Department of Health in 2001, sets out to reduce the incidence of stroke in the population and to ensure that those who have had a stroke get prompt access to services that are integrated. Support over the longer term is identified as one of the four main priorities for the development of stroke services.

The quality of care being delivered by stroke services has been subject to greater scrutiny in recent years, with a series of national sentinel audits by the Royal College of Physicians. The National Sentinel Audit of Stroke[4] assesses the quality of the organisation and the delivery of multidisciplinary inpatient services in England, Wales and Northern Ireland. The fourth round of the audit was undertaken in April 2004. The audit monitors the milestones of stroke in the NSF for Older People.

Our approach

In the autumn of 2004, we asked 51 NHS acute hospital trusts in England to survey patients who have had a stroke, focusing on their experiences of being in hospital and the care they received following their discharge from hospital. More than 1,700 patients took part.

The aim of this follow-up survey was to find out what patients who have had a stroke thought about the care they received after leaving hospital. The survey provides evidence against which progress in meeting the standards set out in the NSF for Older People can be monitored. It also complements some of the findings from the 2004 National Sentinel Stroke Audit.

More than three quarters of the people who responded to the 2004 survey agreed to participate in the follow-up. The questions that were asked covered the issues that patients who have had a stroke and their families identified as being most important to them.

In total, 1,192 questionnaires were sent to people who participated in the 2004 survey approximately one year after they had been discharged from hospital following a stroke; 875 completed questionnaires were returned, representing a response rate of 75%.

Interpreting the results

The findings from this survey need to be interpreted carefully for two reasons.

Firstly, it is important to remember that the sample is self-selecting. That is, it consisted of people who, in 2004, said they wanted to take part in the follow-up survey. Analysis showed there were lower response rates to the follow-up survey from patients aged under 50 years and over 80 years, those living in more deprived areas, and among those who said they required help from another person with everyday activities and who needed help completing the original survey. Those patients who rated their care as 'fair', 'poor' or 'very poor' in the 2004 survey had significantly lower rates of response to the follow-up survey than those who said the care was 'excellent', 'very good' or 'good'.

Secondly, there is evidence to show that patients with a poorer health status generally give more negative assessments of their care.[5] One in five patients (20%) completed the questionnaire with the help of a friend/relative or healthcare professional, and one in six questionnaires (17%) were filled in by a friend or relative on behalf of the patient. It is reasonable to suggest that these respondents had a poorer health status or had a higher degree of cognitive impairment than those who completed the questionnaire themselves. Analysis showed that those patients who needed help completing the questionnaire had a longer average length of stay in hospital, were less likely to report that their health in the previous four weeks was 'excellent' or 'very good', and were more likely to have had a further stroke.

Understanding differences

When the results from a survey show a difference between two groups, for example men and women, these differences may be real, or may have occurred by chance, reflecting who responded to the questionnaire. We have used statistical tests to determine if differences are real or statistically significant. Where we say that a difference is 'significant', this means that it is highly unlikely that it could have occurred by chance and that there is a real difference between the two groups.

Key findings

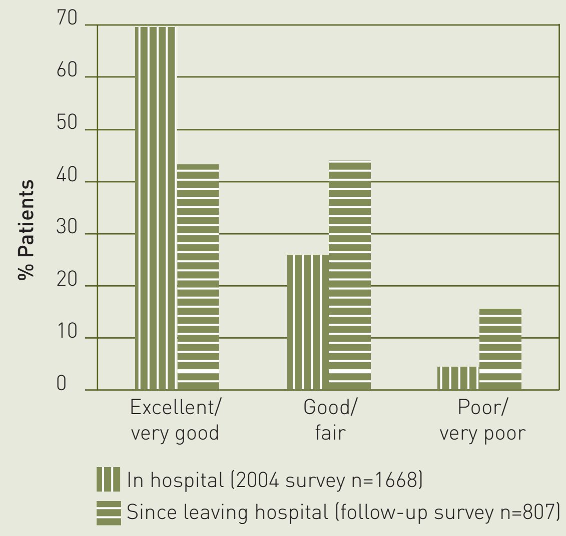
This section presents the key findings from the 2005 follow-up survey of patients who have had a stroke.

Overall care

In general, people who responded to the follow-up survey were not as positive about the care they had received since they had left hospital, when compared with the results of the 2004 survey. In 2004, 69% of respondents rated the overall care they received as being 'excellent' or 'very good', compared with 42% of people in the 2005 follow-up survey (see figure 1).

Figure 1

Overall rating of the care received in hospital and after leaving hospital by people who responded to the survey



Of those people who rated the care they had received in hospital as 'excellent', only 32% said the care they received after they left hospital was 'excellent'.

Patients reported a more positive experience of their overall care since leaving hospital if, among other things, they had a better self-reported health status, lived in the north east of England, had stayed on a unit for patients with stroke during their time in hospital, and had not paid for any private care to help with their recovery.

Rehabilitation therapy

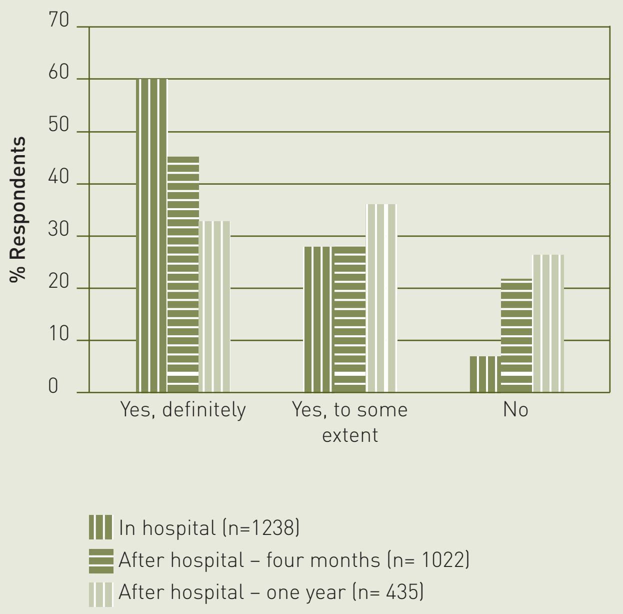
Rehabilitation is important for improving the recovery of patients who have had a stroke and for increasing their independence and ability to undertake daily activities such as dressing and cooking.[1] The National Service Framework (NSF) for Older People recommends that rehabilitation should continue until it is clear that maximum recovery has been achieved. It states that patients reporting a significant disability at six months should be reassessed and offered further targeted rehabilitation if this could help to recover further function. A recent survey of hospitals, carried out by the National Audit Office, estimated that about half of patients receive services for rehabilitation to meet their needs in the first six months after they have been discharged, but only about a fifth of patients receive such services in the six to 12 months after discharge.[1]

By examining data from the 2004 and 2005 surveys, it was possible to assess whether patients felt that they had received enough rehabilitation therapy at three different points in time – while they were in hospital, four months after they were discharged and 12 months after they were discharged.

Treatment to improve mobility

The proportion of patients who felt that they had definitely received enough treatment to improve their mobility declined over time (see figure 2). Of those who had difficulties with mobility, 35% reported that they had definitely received enough treatment to improve their mobility since they had left hospital, although more than a quarter felt that they had not. This finding supports previous research, which has shown that patients are often dissatisfied with the availability of physiotherapy over a longer period. [6-8]

Figure 2
Since you left hospital, have you had enough treatment from the NHS to improve your mobility?



> *"I had two 12 week sessions of group physiotherapy at my local hospital which was very good."*
>
> *"The physiotherapy is very poor ... they just don't seem to be interested to follow up with further treatment."*
>
> *"I have been discharged from (community stroke team) with no consultation when I feel I still need help with speech and mobility."*

It is well known that those who are treated in units for patients with stroke are more likely to survive and recover more function following their stroke.[1,2,4,9] The 2004 survey showed that patients who stayed on such a unit reported more positive experiences of their care and treatment than those who stayed on other types of wards. Those who had stayed on a unit for patients with stroke also reported more positive experiences of some aspects of their follow-up care than patients who had stayed on other wards.

A significantly higher percentage of people (38%) who had stayed on a unit for patients with stroke who felt that they had received enough treatment to improve their mobility since they had left hospital when compared with those who had stayed on other types of ward (29%).

Overall, about 16% of the people who responded to the survey had paid for some private care to help with their recovery following their stroke. People were more likely to have paid for private care if they were in the oldest age group, required help from another person with everyday activities and lived in a less deprived area. A significantly higher percentage of people paid for private care if they felt they had not received enough treatment to help improve their mobility.

"I waited approximately 10 weeks from discharge before getting any home physio. The period of physio help was too short and I did not feel it was of a good quality. I paid for physio privately and was really impressed; this is where the NHS is lacking. There should be a 12 month follow-up of patients to check their physical movement and, if needed, an offer of further physio."

"I have had private treatment for walking since April which I felt I needed."

Help with difficulties with speaking

Many people who have had a stroke may have difficulty with speaking and communicating. They may misunderstand what they hear, be unable to speak despite having perfect comprehension, or have difficulties with writing.[1] The National Clinical Guidelines for Stroke recommend that patients who have problems with communication should be assessed fully by a speech and language therapist and, where achievable goals can be identified, offered appropriate treatment that monitors progress.

Among those respondents who wanted help with difficulties with speaking, the proportion who said they had definitely received enough help decreased in the first few months after leaving hospital, and remained high after this time (see table 1).

Table 1

Help with difficulties with speaking

Did you get enough help with difficulties with speaking?	In hospital	Four months after leaving hospital	12 months after leaving hospital
Yes, definitely	50%	43%	43%
Yes, to some extent	34%	26%	31%
No	16%	31%	26%
Base number	830	567	261

Support with emotional problems

Having a stroke can have a detrimental impact on the psychological and emotional wellbeing of a person. Depression and anxiety are common after stroke[1], and patients can feel abandoned when they lose the emotional and practical support they receive in hospital.[1,9] The NSF for Older People states that support over a longer period for patients who have had a stroke should include the provision of social and emotional support to minimise any loss of independence and to help manage the consequences of stroke. The findings from the survey show that a large number of patients were not getting the support they needed.

The percentage of people who felt that they had not received enough help and support with emotional problems increased over the two surveys. A quarter of people responding to the 2004 survey said that they did not receive enough help and support with emotional problems when they were in hospital, and this increased to 41% about four months after they left hospital. Almost half of the people who responded to the follow-up survey felt that they had not received enough help and support with emotional problems since leaving hospital.

> *"Counselling should be offered to some people who are affected in the short term about the change in their lifestyle and limitations."*
>
> *"It was not explained to me that as well as the physical damage that a stroke can cause, there are also emotional ones. I was fortunate that the physical damage was very small, but the loss of personal drive and desire to work was very hard to take."*
>
> *"I received no information about the emotional side of a stroke which I have suffered from."*

A higher proportion of those who had stayed on a unit for patients with stroke during their time in hospital reported that they had received support for emotional problems after leaving hospital compared with those who had stayed on other types of ward (see table 2). Of those patients who had stayed on such a unit, 44% said that they had not received enough help with emotional problems since they had left hospital, compared with 58% of those who had stayed on other types of ward.

Table 2
Help and support with emotional problems by type of ward

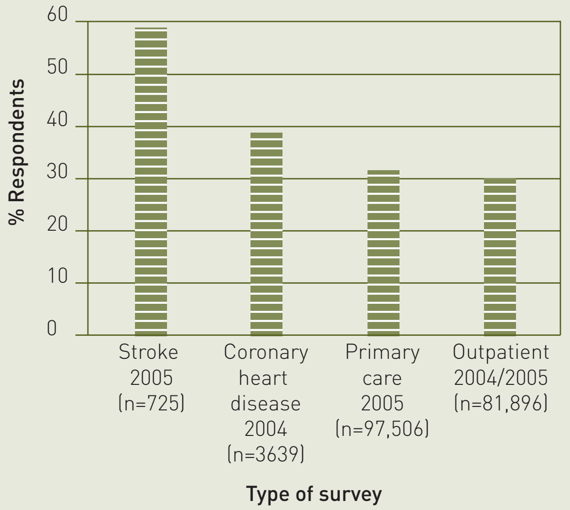
		Since you left hospital, have you had enough help with emotional problems from the NHS?			
		Yes, definitely	Yes, to some extent	No, I did not get enough help from the NHS	Total
Type of ward	Unit for patients with stroke	29%	27%	44%	191
	Other type of ward	13%	29%	58%	84

Involvement in care

More than half (59%) of people who responded to the follow-up survey felt that they had not been involved as much as they had wanted to be in decisions about their own care and treatment since they had left hospital (this includes 15% who said that they had not been involved at all). This is slightly higher than in the 2004 survey, when 52% said they had not been involved in decisions about their care as much as they had wanted to be.

There is a marked, and statistically significant, difference between the responses from patients in these surveys regarding their involvement in decisions about their own care and treatment, when compared with other national surveys of patients (see figure 3). The difference may be explained partly by the fact that many patients will experience difficulties with communication following a stroke and may not be able to articulate their needs as readily.

Figure 3
The percentage of respondents who wanted to be more involved in decisions about their care and treatment in four different surveys of patients



Of the people who wanted to be involved in decisions about the best medicine for them, one in five (20%) said that they had not been involved as much as they had wanted to be, and 35% said they had only been involved to some extent. This compares with 12% in the survey of patients of primary care trusts carried out in 2005, who felt they had not been involved in decisions about their medication as much as they had wanted, and 29% who said they had been involved to some extent.

"My GP involves me in decisions about drugs/side effects and always listens to what I have to say."

"I would like to be informed as to why there was no appointment for outpatients, also why – even without seeing the doctor – sometimes medicine doses are changed and I have to chase it up in case it is a mistake ... I would have liked to discuss it with the doctor, but it isn't considered my concern."

The 2004 survey showed that a significantly higher proportion of people who had stayed on a unit for patients with stroke said they had definitely been involved in decisions about their own care and treatment, compared with those who had stayed on other wards. Unsurprisingly, this difference disappeared following discharge. However, a significantly higher percentage of people who had stayed on such a unit said they had been involved in decisions about the best medicine for them, compared with respondents who had stayed on other wards.

Information

Information about stroke

Published guidelines and standards of care for people who have had a stroke recommend that information should be provided to patients and families about the nature of stroke and its effects.[2,4,9] A lack of information may lead to anxiety and fear, and could prevent patients from being involved fully in decisions about their care and treatment.[10] Of those people who said that they had definitely received enough information about stroke, 70% felt that they had definitely been involved enough in decisions about their own care and treatment. In contrast, of those who said they had not received enough information about stroke, only 17% reported that they had been involved as much as they wanted in decisions about their care and treatment. This suggests that being informed helps patients to become more involved in decisions regarding their own care and treatment.

Of those people who would have liked information from health and social services about stroke, almost a third (32%) said they had not received any since leaving hospital and 35% said that they had only received enough information 'to some extent'. This finding supports a considerable body of evidence on the need to improve the provision of information for patients who have had a stroke and their carers.

Many studies have shown that patients who have had a stroke and their families wish to be informed about all aspects of stroke and the care and support available to them, but are often dissatisfied with the information given.[10-15]

> *"I felt very confused when I left (hospital) as no one gave me information on what had happened to me or how to deal with it."*
>
> *"My husband and I have not been given any information about the stroke or embolism, until the last appointment at outpatients with [name] which was six months after he did the brain operation."*

The 2005 follow-up survey shows that a significantly higher percentage of those who stayed on a unit for patients with stroke reported that they had definitely received enough information about stroke since leaving hospital, compared with those who had stayed on other wards (see table 3). This supports findings from a previous study which showed that patients cared for on such a unit received more information about stroke than those on general wards, and that, after 12 months, these patients were also more likely to report that they were aware of the causes of stroke and the risk of further stroke.[16]

Table 3
Information given to patients about stroke since leaving hospital by type of ward

		Since you left hospital, have health and social services given you enough information about stroke?			
		Yes, definitely	Yes, to some extent	No, but I would have liked some more information	Total
Type of ward	Unit for patients with stroke	36%	38%	26%	351
	Other type of ward	30%	28%	42%	163

Information about the prevention of stroke

Patients who have had a stroke are at an increased risk of further stroke, heart attack and other vascular events.[1,2,9] Guidelines state that all patients should be given appropriate advice on lifestyle factors, such as diet and exercise, to reduce the risk of further stroke.[2,9] The NSF for Older People recommends that information about secondary prevention arrangements are initiated in hospital and continued after discharge with the primary care team. Despite such recommendations, a recent survey of GPs by the National Audit Office showed that one third did not routinely receive information about the secondary prevention arrangements for their patients.[1]

Almost half (48%) of the people who responded to the 2005 follow-up survey said that they had not been given any information about dietary changes that might prevent a further stroke, while 39% said they had not been given information about physical exercise.

> *"More information about how to prevent stroke, the sort of diet to have and exercise to engage in is needed."*
>
> *"I would have liked more information about what exercise I can do, also about diet"*

> *"I have not been given any form of diet or dietary advice."*

Information for families and carers

Information about stroke and advice on how to reduce the risk of another stroke are important[17]. More than two thirds of the people who responded to the survey said that a family member or close friend would have liked such information. Of this group, one third said that a member of their family, or someone else close to them, had not been given enough information about stroke since they had left hospital and 38% said they only received enough information to 'some extent'. This supports previous research, which has shown that carers are often dissatisfied with the amount of information that they are given.

> *"Carers could be made more aware of the needs of their clients following a stroke, such as mobility and help with cutting up food."*

The survey also shows that a significantly higher percentage of families and carers had 'definitely' received enough information about stroke if the patient had stayed on a unit for patients with stroke, rather than another type of ward (see table 4.)

Table 4
The provision of information to the patients' family or carer by type of ward

Since you left hospital, has a member of your family or someone else close to you been given enough information about stroke to help you recover?

		Yes, definitely	Yes, to some extent	No, but they would have liked some information	Total
Type of ward	Unit for patients with stroke	31%	39%	29%	319
	Other type of ward	23%	33%	44%	127

Services provided by GPs

The NSF for Older People recommends that a stroke care coordinator should be responsible for ensuring the smooth transfer of information and responsibility between hospital and community care settings.[2]

The majority of people (83%) who responded to the follow-up survey had seen their GP about their stroke since they had left hospital. Almost two thirds of respondents said that they felt their GP definitely knew enough about the treatment of stroke. However, 29% said this was true only 'to some extent', and 7% felt their GP did not know enough.

> *"My own GP has been excellent. He's always been able to answer my questions and fears. He always makes time to explain things."*

Given that many patients will experience difficulties with mobility following a stroke, it may be difficult for them to get to their general practice. Patients were asked if their GP or nurse had visited them at home the last time they had wanted them to. Of those respondents who had wanted a GP or nurse to visit them at home, the majority (89%) said that they had received a home visit. However, patients living in more deprived areas were shown to have significantly lower average scores for this question, when compared with those living in more advantaged areas, which suggests a more negative experience.

Checks on medication and blood pressure

The regular review of medication is included in standard five of the NSF for Older People in relation to the provision of long term support for patients who have had a stroke. The majority of respondents (88%) said that since leaving hospital, they had seen a healthcare professional, such as a doctor, to review their medication. This survey highlights that although most respondents had received a review of their medicines, a much smaller percentage felt that they had been involved as much as they had wanted to be in decisions about the best medicine for them.

> *"Since I had my stroke in June 2004 and left hospital, I have only seen the stroke doctor once. I feel that a year has passed and they should now review me and my medication."*

High blood pressure is a major risk factor for people who have had a stroke. National clinical guidelines state that all patients should have their blood pressure checked. The GPs' contract includes some indicators specifically related to stroke and the control and assessment of risk in patients who have already had a stroke. Two indicators focus on recording and controlling the blood pressure of patients. Research commissioned by the National Audit Office showed that, since the introduction of the GP contract, more patients are receiving treatment to prevent a second or further stroke, with 95% of patients with stroke having their blood pressure recorded in 2005 compared with 88% in 2004. The report asserts that the level of improvement in measuring and controlling blood pressure in people who have already had a stroke is likely to reduce significantly the incidence of further strokes.[1] Almost all respondents (96%) to our survey reported having had their blood pressure checked by a healthcare professional since they had left hospital.

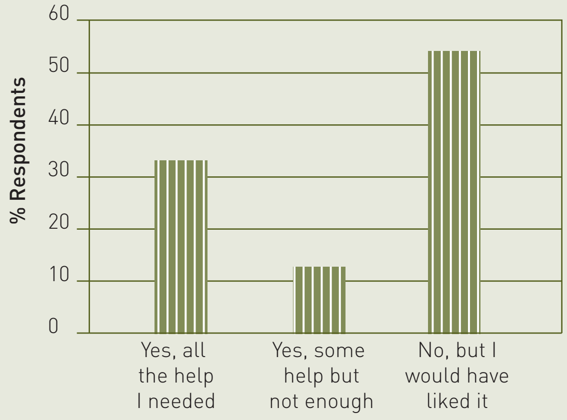
> *"My GP has been very supportive. He has been monitoring my blood pressure and taken total responsibility for my medication and care."*

Support for everyday living

It is widely recognised that the coordination of health, social care and other services is essential for delivering care that is centred on the person who needs it.[1,8,9,18] However, only 27% of hospitals in England have teams of community specialists on stroke and there is evidence that not all patients are receiving a coordinated service.[1]

More than a quarter of the people who responded to the survey wanted 'home help' (for example, help with cleaning and shopping) from social services. Figure 4 shows that a significant minority of people are not getting the support they feel they need, with more than half of these people saying that they would have liked this support but had not received it (it is not known how many of these respondents had received an assessment for home help, which found that they did not need this service).

Figure 4
Have you had any 'home help' provided by social services



Comparing the average scores for this question shows that people who required help from another person with everyday activities and who needed help with completing the questionnaire had significantly higher scores. This means that people who are more dependent on others appear to have a more positive experience. In contrast, people with a higher self-reported health status were less likely to have received home help even though they would have liked it.

> *"Social services could be improved and more home help provided."*
>
> *"I don't think the social services were any help whatsoever."*

Most people who responded to the survey said they did not need anyone from health or social services to help them with personal care, such as getting washed and dressed. Of those who wanted this type of care, about one third (32%) said that they had not received any.

> *"The care package agreed with hospital should be honoured by the social services. It seems that the package agreed is not arranged with cooperation of local social services. This causes conflict when aspects of the package are requested."*

A common complaint made by patients is that they are not aware of the financial benefits available to them, or how to apply for them, and that this may lead to them having problems with their finances.[19] Both of our surveys asked patients if they had received help in applying for benefits from health and social services. In both cases, 45% of those who had wanted help said that they had not received any.

> *"I do wish someone from social services would have advised me on claiming benefits I was entitled to ... I have only had one visit from a social worker and that was approximately four months after having the stroke – none since. My family have had to try to sort things out."*

Support groups

Voluntary and community organisations can provide valuable support over the long term for people who have had a stroke. It is argued that voluntary organisations can deliver services at a much lower cost than a comparable service offered by the NHS as they offer support through events and groups.[1] Guidelines and standards for the care of someone who has had a stroke state that health and social services should ensure that patients and their families are given information about voluntary organisations.[2,9] However, almost half the people (49%) who responded to the survey and who wanted to attend a local stroke support group had not been to one. This may be because there was no group in their local area, because they cannot get there or for other personal reasons. Evidence suggests that the demand for care and support from the voluntary and community sector exceeds supply.[1]

> *"My family have cared for me since leaving hospital and we have been informed there are no stroke support groups in the (name of area), there are some in surrounding areas, but you have to be resident in those areas to attend."*

About a quarter of people who responded (28%) said that they were not aware of a local support group. More than half of the people who responded to the 2004 survey said they had not been given information from staff at the hospital about local voluntary and support groups. Table 5 shows that people were less likely to have been to a support group if staff at the hospital did not provide any information about support groups.

Table 5
The provision of information on support groups by the attendance of patients at support groups

		Have you been to a support group for people who have had a stroke in your local area?		
		Yes	**No, but I would have like to**	**Total**
Did hospital staff give you information about voluntary and support groups for people who have had a stroke in your local area?	**Yes**	58%	42%	84
	No, but I would have liked some	29%	71%	52
	No, but I got the information from somewhere else	59%	41%	32

Only a quarter (26%) of people who responded to the survey said that they had been given information about national stroke organisations since they had left hospital. This compares with 36% of people in the 2004 survey, which suggests that the provision of information about national stroke organisations does not improve once patients have left hospital.

Help and support

Many of the people who survive having a stroke will suffer long term effects and will require continuing care and support from their family.[17,20] The national clinical guidelines state that patients and their carers should have their individual social and support needs reviewed on a regular basis. Results from the 2004 National Sentinel Stroke Audit showed that less than half of carers had their needs assessed separately and only two thirds had received training for the role.

The families or carers of patients who have had a stroke often require help and support from health and social services as the burden of care can be considerable. There is evidence that carers have high levels of morbidity, low self-esteem, emotional distress and poor mental health.[1,9,19,21,22]

Three fifths of the people who responded to the follow-up survey said that a friend or family member wanted or needed support from health and social services. Just under half of these people (46%) reported that a family member or someone else close to the patient had not received any help or support from health or social services.

> *"There should be more support for the carers of stroke victims who are traumatised by events and really only survive on 'automatic pilot' until they can adjust to the situation."*

Again, significant differences were found between patients based on the types of ward on which they had originally stayed (see table 6).

Table 6

The provision of help and support to the family or carer of the patient by type of ward

Since you left hospital, has a member of your family or someone else close to you had enough help and support from health and social services?

		Yes, definitely	**Yes, to some extent**	**No, they have not had any help or support**	**Total**
Type of ward	Unit for patients with stroke	25%	33%	42%	273
	Other type of ward	16%	29%	55%	111

Conclusions

This is one of the first surveys to follow a group of patients with stroke from their hospital experience through to their return home. Together with the findings from the 2004 survey, it provides a picture of recent experiences of stroke services in England in both hospital and community settings.

Overall, people who responded to the follow-up survey were less positive about the care they had received since they had left hospital. Since leaving hospital 15% of patients rated their care overall as 'poor' or 'very poor'. This compares with 4% who rated their care as 'poor' or 'very poor' in the 2004 survey.

Patients were positive about some aspects of care since they had been discharged from hospital:

- almost all patients (96%) said their blood pressure had been checked since they had left hospital and most of them (88%) said that their medicines had been reviewed by a healthcare professional
- almost two thirds of respondents felt their GP knew enough about the treatment of stroke and the majority (89%) of those patients who wanted a home visit from their GP or nurse got one

The results of this follow-up survey show that those people who had stayed on a unit for patients with stroke during their time in hospital had a more positive experience of the care and treatment they received after they had left hospital, when compared with the experiences of those who had stayed on other wards. In particular, higher percentages of patients who had stayed on such a unit reported that, since leaving hospital:

- they had definitely received enough treatment to help improve their mobility
- they had definitely received enough help and support with emotional problems
- they had definitely been involved in decisions about the best medicine for them
- enough information had been given to them about stroke
- a member of their family or someone else close to them had been given enough information about stroke to help with recovery
- a member of their family or someone else close to them had been given enough help and support

It is possible that these differences reflect improved planning for discharge on units for patients with stroke, and a better understanding of the needs of patients who have had a stroke.

Areas for improvement

The survey also highlighted a number of areas where the quality of follow-up care for patients who have had a stroke could be improved:

1. **Continued rehabilitation:** a significant number of people who responded to the survey had difficulty with speaking and mobility following their stroke. Many of these people felt that they had not received enough help with these difficulties since they had left hospital.

2. **Emotional support:** almost half the respondents said they had not received enough help with their emotional problems since they left hospital.

3. **Involvement in care:** the majority of patients said they wanted to be more involved in decisions about their own care and treatment, including decisions about the best medicine for them. The results from this survey were less positive about this than those of other national surveys of patients, suggesting that more effective ways of communicating with patients who have had a stroke are needed.

4. **Support for everyday activities:** the survey suggests that many of those who want support for everyday living are not getting the help they feel they need. Of these people, more than half would have liked some 'home help' and one third said they wanted help with personal care from health and social services but had not received any. Almost half of the people who responded to the survey also reported that a family member or someone else close to them had not received any help or support from health and social services. The survey also showed that more help needed to be given to certain patients when applying for financial benefits.

5. **Information:** more information about stroke and how to prevent a further stroke needs to be given to patients. Patients who had not received enough information about stroke were more likely to feel that they had not been involved enough in decisions about their own care and treatment. As these patients are at risk of a further stroke, information about prevention is important. One third of people who responded to the survey said that a member of their family, or someone else close to them, had not been given enough information about stroke to help with the recovery of the patient.

What are we doing?

The Healthcare Commission will be developing indicators to support improvement in the care of stroke as part of our assessment of progress in relation to developmental standards for 2006/2007. These indicators will form part of the ongoing assessment of healthcare organisations and will be used to look at how services are improving year on year.

Joint indicators across health and social care will also be developed as outlined in the Government's White Paper, *Our health Our care, Our say*. These will be focused on outcomes and will be used to assess the provision of services for people with health and social care needs.

Appendices

Appendix A:
Tables of key results

The tables below show the results for all of the questions that patients were asked. The results reported are those for the average NHS trust in England.

Q1. When you first left hospital, where did you go?	Number of respondents	National average %
Own home	749	87%
The home of a relative or friend	38	4%
Care home (residential/nursing)	25	3%
Rehabilitation unit	24	3%
Warden controlled accommodation (sheltered)	19	2%
Other	7	1%
Total specific responses	**862**	
Missing responses	13	

Q2. Where do you think you should have gone?	Number of respondents	National average %
Own home	717	85%
The home of a relative or friend	38	4%
Care home (residential/nursing)	21	2%
Rehabilitation unit	38	4%
Warden controlled accommodation (sheltered)	23	3%
Other	9	1%
Total specific responses	**846**	
Missing responses	29	

Q3. Where do you live now?	Number of respondents	National average %
Own home	793	92%
The home of a relative or friend	20	2%
Care home (residential/nursing)	22	3%
Rehabilitation unit	0	0%
Warden controlled accommodation (sheltered)	24	3%
Other	2	0%
Total specific responses	**861**	
Missing responses	14	

Q4. After you left hospital, did you need to move house because of your stroke?	Number of respondents	National average %
Yes	41	5%
No	804	95%
Total specific responses	**845**	
Don't know	8	
Missing responses	22	

Q5. Did health and social services help you find the accommodation?	Number of respondents	National average %
Yes	11	27%
No	30	73%
Total specific responses	**41**	
Don't know	1	
Missing responses	1	

Q6. After you left hospital, how long did you have to wait until health and social services found you the accommodation?		
	Number of respondents	National average %
Less than one month	6	55%
One to three months	3	27%
Four to six months	1	9%
More than six months	1	9%
Total specific responses	**11**	
Missing responses	1	

Q7. Following your stroke, have you paid for any private care to help with your recovery?		
	Number of respondents	National average %
Yes	137	16%
No	707	84%
Total specific responses	**844**	
Don't know	6	
Missing responses	25	

Q8. Since you left hospital, have you had enough help with difficulties with speaking from the NHS?		
	Number of respondents	National average %
Yes, definitely	111	43%
Yes, to some extent	81	31%
No, I did not get enough help from the NHS	69	26%
Total specific responses	**261**	
I did not have any difficulties with speaking	438	
Missing responses	27	

(Excludes those who had another stroke)

Q9. Since you left hospital, have you had enough treatment to help improve your mobility (e.g. walking, moving your legs) from the NHS?	Number of respondents	National average %
Yes, definitely	153	35%
Yes, to some extent	161	37%
No, I did not get enough treatment from the NHS	121	28%
Total specific responses	**435**	
I did not have any difficulties with mobility	263	
Missing responses	28	

(Excludes those who had another stroke)

Q10. Since you left hospital, have you had enough help with emotional problems (such as confusion, depression or crying) from the NHS?	Number of respondents	National average %
Yes, definitely	70	23%
Yes, to some extent	89	29%
No, I did not get enough help from the NHS	150	49%
Total specific responses	**309**	
I did not have any emotional problems	380	
Missing responses	37	

(Excludes those who had another stroke)

Q11. Since you left hospital, have health and social services given you enough information about stroke?	Number of respondents	National average %
Yes, definitely	182	33%
Yes, to some extent	196	35%
No, but I would have liked some information from health and social services	179	32%
Total specific responses	**557**	
No information was needed	143	
Missing responses	26	

(Excludes those who had another stroke)

Q12. Since you left hospital, have you seen a health professional (e.g. doctor) to check how you are getting on with your medication (i.e. have your medicines been reviewed)?	Number of respondents	National average %
Yes	713	88%
No	98	12%
Total specific responses	**811**	
Don’t know	19	
I had no medicines to take home	27	
Missing responses	18	

Q13. Since you left hospital, have you been involved as much as you wanted to be in decisions about the best medicine for you?	Number of respondents	National average %
Yes, definitely	291	46%
Yes, to some extent	221	35%
No, I would have liked to have been more involved	127	20%
Total specific responses	**639**	
No, but I did not mind	140	
Don’t know, can’t say	41	
I am not taking any medication	22	
Missing responses	33	

Q14. Since you left hospital, have you had any ‘home help’ provided by social services (e.g. help with cleaning, washing clothes, shopping)?	Number of respondents	National average %
Yes, all the help I needed	70	33%
Yes, some help but not enough	28	13%
No, but I would have liked it from social services	113	54%
Total specific responses	**211**	
I did not need this service	598	
I was already receiving home help	31	
Missing responses	35	

Q15. Since you left hospital, has anyone from health or social services helped you with personal care (e.g. help with getting dressed or washed)?

	Number of respondents	National average %
Yes	117	68%
No, but I would have liked it	56	32%
Total specific responses	**173**	
I did not need this type of help	621	
I was already receiving this type of help	48	
Missing responses	33	

Q16. Have you been to a support group for people who have had a stroke in your local area?

	Number of respondents	National average %
Yes	93	51%
No, but I would have liked to	91	49%
Total specific responses	**184**	
No, I did not want to attend a support group	407	
I am not aware of a local support group	234	
Missing responses	50	

Q17. If you have been to a stroke support group, have you found the activities helpful?

	Number of respondents	National average %
Yes, definitely	46	37%
Yes, to some extent	44	35%
No	34	27%
Total specific responses	**124**	
I have not been to a support group	617	
Missing responses	134	

Q18. Since you left hospital, have you been given any information from health or social services about national stroke organisations or useful websites?

	Number of respondents	National average %
Yes	170	26%
No, but I would have liked some	291	45%
No, but I got the information from somewhere else	186	29%
Total specific responses	**647**	
Not sure, can't remember	136	
Missing responses	92	

Q19. Since your stroke, have you had help from health and social services when applying for benefits (e.g. disability living allowance, attendance allowance, carer allowance)?

	Number of respondents	National average %
Yes	227	55%
No, but I would have liked help	183	45%
Total specific responses	**410**	
I did not need any help	331	
I was already receiving benefits	101	
Missing responses	33	

Q20. Since your stroke, have you received any benefits (e.g. disability living allowance, attendance allowance, carer allowance)?

	Number of respondents	National average %
Yes	290	76%
No, but I should have received benefits	93	24%
Total specific responses	**383**	
No, but I do not need any benefits	301	
I was already receiving benefits	126	
Don't know	29	
Missing responses	36	

Q21. Since you left hospital, has a member of your family or someone else close to you been given enough information about stroke to help you recover?		
	Number of respondents	National average %
Yes, definitely	142	29%
Yes, to some extent	186	38%
No, but they would have liked some information	165	33%
Total specific responses	**493**	
No, but they got information from somewhere else	55	
No information was needed	151	
Missing responses	27	

(Excludes those who had another stroke)

Q22. Since you left hospital, has a member of your family or someone else close to you had enough help and support from health and social services?		
	Number of respondents	National average %
Yes, definitely	92	22%
Yes, to some extent	136	32%
No, they have not had any help or support from health and social services	195	46%
Total specific responses	**423**	
No help or support was needed	261	
Don't know	12	
Missing responses	30	

(Excludes those who had another stroke)

Q23. After you left hospital, how long did you wait for an appointment at the outpatient department?		
	Number of respondents	National average %
Up to one month	155	26%
More than one month but no more than three months	276	46%
More than three months but no more than six months	130	22%
More than six months	41	7%
Total specific responses	**602**	
I have not visited the outpatient department	174	
Don't know, can't remember	64	
Missing responses	35	

Q24. Who was the main person you saw (tick one only)?

	Number of respondents	National average %
A doctor	426	72%
A nurse	56	9%
A physiotherapist	50	8%
An occupational therapist	18	3%
A speech therapist	12	2%
Someone else	33	6%
Total specific responses	**595**	
Don't know, can't remember	4	
Missing responses	25	

Q25. Did the person listen to what you had to say?

	Number of respondents	National average %
Yes, definitely	481	79%
Yes, to some extent	119	19%
No	11	2%
Total specific responses	**611**	
Missing responses	15	

Q26. If you had important questions to ask the main person you saw, did you get answers that you could understand?

	Number of respondents	National average %
Yes, definitely	371	66%
Yes, to some extent	174	31%
No	16	3%
Total specific responses	**561**	
I did not need to ask	41	
I did not have an opportunity to ask	6	
I was not able to ask	5	
Missing responses	10	

Q27. Since leaving hospital have you seen your GP about your stroke?	Number of respondents	National average %
Yes	717	83%
No	142	17%
Total specific responses	**859**	
I am not registered at a GP surgery or health centre	1	
Missing responses	15	

Q28. In your opinion, did the GP know enough about the treatment of stroke?	Number of respondents	National average %
Yes, definitely	463	65%
Yes, to some extent	205	29%
No	47	7%
Total specific responses	**715**	
Can't say, don't know	88	
I have not seen a GP	43	
Missing responses	29	

Q29. The last time you wanted your GP or a nurse to visit you at home did they come?	Number of respondents	National average %
Yes	322	89%
No	40	11%
Total specific responses	**362**	
I have not wanted a home visit	487	
Missing responses	26	

Q30. Since you left hospital, have you had your blood pressure checked by a health professional (doctor, nurse)?	Number of respondents	National average %
Yes	825	96%
No	33	4%
Total specific responses	**858**	
Don't know	10	
Missing responses	7	

Q31. Since you left hospital, have you been given information from the NHS about changes in your diet that might help prevent a further stroke?		
	Number of respondents	National average %
Yes, definitely	220	31%
Yes, to some extent	143	20%
No, I have not been given any information from the NHS	340	48%
Total specific responses	**703**	
Don't know	9	
Missing responses	14	

(Excludes those who had another stroke)

Q32. Since you left hospital, have you been given information from the NHS about physical exercise (walking) that might help prevent a further stroke?		
	Number of respondents	National average %
Yes, definitely	227	33%
Yes, to some extent	200	29%
No, I have not been given any information from the NHS	269	39%
Total specific responses	**696**	
Don't know	16	
Missing responses	14	

(Excludes those who had another stroke)

Q33. Since leaving hospital, how would you rate the care you have received for your stroke from health and social services?		
	Number of respondents	National average %
Excellent	138	17%
Very good	203	25%
Good	191	24%
Fair	154	19%
Poor	77	10%
Very poor	44	5%
Total specific responses	**807**	
Missing responses	68	

Q34. Since leaving hospital, have you been involved as much as you wanted to be in decisions about your care and treatment?	Number of respondents	National average %
Yes, definitely	299	41%
Yes, to some extent	317	44%
No	109	15%
Total specific responses	**725**	
I have not had any care or treatment since leaving hospital	110	
Missing responses	40	

Q35. Who was the main person or people who filled in this questionnaire?	Number of respondents	National average %
The person who was a patient in the hospital	535	63%
A friend or relative of the patient	142	17%
Both patient and friend or relative together	163	19%
The patient with the help of a health professional	10	1%
Total specific responses	**850**	
Missing responses	25	

Q36. Are you male or female?	Number of respondents	National average %
Male	519	59%
Female	356	41%
Total specific responses	**875**	

Q37. Age group calculated from year of birth	Number of respondents	National average %
Aged 16 to 50 years	57	7%
Aged 51 to 60 years	108	12%
Aged 61 to 70 years	224	26%
Aged 71 to 80 years	284	32%
Aged 81 years and over	202	23%
Total specific responses	**875**	

Q38. Following the stroke you had between April and June 2004, have you since had another stroke?

	Number of respondents	National average %
Yes, I've had one stroke since then	61	7%
Yes, I've had more than one stroke since then	36	4%
No	726	88%
Total specific responses	**823**	
Not sure, can't remember	31	
Missing responses	21	

Q39. Overall, how would you rate your health during the past four weeks?

	Number of respondents	National average %
Excellent	38	4%
Very good	140	16%
Good	285	33%
Fair	293	34%
Poor	84	10%
Very poor	19	2%
Total specific responses	**859**	
Missing responses	16	

Q40. In the last two weeks did you require help from another person for everyday activities?

	Number of respondents	National average %
Yes	420	49%
No	435	51%
Total specific responses	**855**	
Missing responses	20	

Appendix B:
Demographics of responders and non-responders

It is important to compare the total proportion of people who responded to the questionnaire (response rate) for different groups of people who did and did not respond to the survey (responders and non-responders). This is because the responders may not be representative of all sampled patients and we need to have an understanding of how the sampling coverage varies.

The analysis showed that there were significantly lower response rates to the follow-up survey from people:

- aged under 51 or over 80 years
- living in more socio-economically deprived areas
- with poorer health status
- who reported a poorer experience of their hospital stay in the 2004 survey

Patients aged under 51 and over 80 years

Completed questionnaires were received from:

- 67% of patients aged under 51 years
- 74% of patients aged between 51 and 60 years
- 78% of patients aged between 61 and 70 years
- 79% of patients aged between 71 and 80 years
- 71% of patients aged over 80 years

Respondents living in more socio-economically deprived areas

The Index of Multiple Deprivation, produced by the Department for Transport, Local Government and the Regions in 2000, was used to compare the responders and non-responders in terms of the socio-economic status of the area they live in. A high Index of Multiple Deprivation score indicates a more socio-economically disadvantaged local council ward.

It was possible to allocate a ward level Index of Multiple Deprivation score to 91% of patients in the follow-up sample using their postcode. Completed questionnaires were returned from 80% of patients from places with an Index of Multiple Deprivation score of 10 or less (n=227), but only 66% of patients from places with an Index of Multiple Deprivation score 40 or higher (n=187).

Respondents with poorer health status

Questionnaires were returned by:

- 72% of patients who had required help from another person with everyday activities in the two weeks before they completed the first survey
- 79% of patients who did not need any help from another person with everyday activities in the two weeks before they completed the first survey

These differences were significant, which implies that those patients who required help with everyday activities, i.e. those with poorer health status, were less likely to respond to the follow-up survey.

People who responded to the 2004 questionnaire were invited to get help to complete it from a friend/carer or a health professional, provided that the answers were given from the point of view of the patient. We can assume that those patients who required help with completing the questionnaire, or who needed somebody to complete it on their behalf, had a poorer health status or higher degree of cognitive impairment:

- of those who completed the 2004 questionnaire themselves, 81% responded to the follow-up survey
- of those who completed the 2004 questionnaire with the help of a friend or relative, 69% responded to the follow-up survey
- of those whose friend or relative completed the 2004 questionnaire on their behalf, 62% responded to the follow-up survey
- of those who completed the questionnaire with the help of a health professional, 47% responded to the follow-up survey

The differences in the response rates between these groups were statistically significant and suggest that patients who needed help completing the 2004 survey (i.e. those who had a poorer health status or were more dependent on others) were less likely to respond to the follow-up survey.

Respondents who rated their overall hospital care as 'fair', 'poor' or 'very poor'

A question was included in the 2004 survey that asked patients to rate the overall care they had received during their hospital stay. Completed questionnaires were received from:

- 76% of patients who rated the hospital care overall as 'excellent', 'very good' or 'good'
- 68% of patients who rated the hospital care overall as 'fair', 'poor' or 'very poor'

This suggests that patients who reported more negative experiences of care in the 2004 survey were less likely to respond to the follow-up survey.

Ethnic group

Information about the ethnicity of patients was based on the self-reported ethnicity of respondents to the 2004 survey, or, if this information was missing, from the information provided by trusts.

Analysis was undertaken to compare the ethnic profile of the sample for the survey of patients with stroke with that of the general population of patients, using hospital episode statistics. For the 51 trusts that took part in the survey of people who have had a stroke, ethnicity was identified for all patients with stroke (ICD-10 codes I61, I62, I63 and I64 diagnosis of intracerebral haemorrhage, cerebral infarction, or stroke not specified as haemorrhage or infarction) appearing in hospital episode statistics (2004/2005, provisional). Only patients admitted between April 1st 2004 and June 30th 2004 were included to match the sampling frame of the survey.

Table 7
The ethnic composition of patients in the survey sample and in hospital episode statistics

	Hospital episode statistics		Survey sample admissions	
Ethnicity	**Number**	**%**	**Number**	**%**
White	3,351	93.80	2323	93.44
Mixed	13	0.40	8	0.32
Asian or Asian British	79	2.20	65	2.61
Black or black British	99	2.80	50	2.01
Chinese	7	0.20	8	0.32
Any other ethnic group	23	0.60	32	1.29
Total	**3,572**	**100**	**2,054**	**100**
Invalid	403	8.23		
Unknown	922	18.83	300	10.77
Grand total (including unknown/invalid)	4,897	100	2,786	100

Table 7 summarises the ethnic composition of patients identified in hospital episode statistics, and that of the sample drawn for the survey. Overall, there is reasonable agreement between the ethnicity of the patients in hospital episode statistics with valid ethnicity codes, and that of the survey sample.

A high proportion of records in hospital episode statistics have an unknown, or invalid ethnic code (27.1% overall) and the proportion of invalid/unknown codes varies quite significantly from trust to trust. These results suggest that, as is generally accepted, information relating to ethnic coding in hospital episode statistics should be interpreted with caution.

The relatively small proportion of patients who have had a stroke from black and minority ethnic groups in both the data from hospital episode statistics and the sample reflects the age profile of patients who have had a stroke (more than 80% of respondents were aged 61 or over). Differences in the response rates between ethnic groups are not statistically significant. However, the small numbers of respondents from black and minority ethnic groups precludes any analysis by ethnicity.

Appendix C:
Analysis by subgroup

It was important to examine the extent to which the experiences of patients were influenced by their demographic characteristics, health status, where they lived, and whether or not their care in hospital was managed on a unit for patients with stroke.

Method

To analyse the results of the survey, questions were scored using a scale of 0 to 100. A response option that was assigned a score of 100 reflects the most positive experience of patients, while a score of 0 indicates the worst experience. An overall score was calculated for each respondent by taking an average of the scores to each rated question. Higher average scores indicate that the experience of patients was more positive.

Overall experience

We looked at the overall experiences of patients to determine if demographic factors had any effect. We found that patients reported a more positive experience of their overall care since leaving hospital (i.e. had significantly higher average scores) if they:

- had a better self-reported health status
- had stayed on a unit for patients with stroke during the acute phase of their care
- did not pay for any private care to help with their recovery
- lived in the north east

Demographic characteristics

We looked at the extent to which the experiences of patients were affected by their demographic characteristics.

Age

We found that, for some of the questions, the average score generally increases with age, indicating that younger patients reported a more negative experience of care (note in some cases the average score declines in the oldest age group). Respondents from the older age groups appeared to have a more positive experience of:

- the help they had received with applying for benefits
- being involved as much as they wanted to be in decisions about the best medicine for them
- receiving a home visit from a GP or nurse
- having their blood pressure checked by a healthcare professional

Results from other national surveys of patients have also shown that older people generally gave higher scores than younger patients. However, for two questions in the follow-up survey, the average score decreased with age, indicating that the experiences of respondents from older age groups were more negative than those from younger age groups. Patients in the older age groups responded more negatively to questions about whether they had received enough information about dietary changes and physical exercise that might help prevent another stroke, when compared with the responses of those from younger age groups.

Gender

Men have significantly higher average scores than women for the questions relating to the provision of information on stroke and on how to help prevent a further stroke.

Socio-economic status of residential area

Respondents living in more socio-economically deprived areas had significantly lower average scores – i.e. a more negative experience of care – than those respondents living in the more advantaged areas for:

- having seen a healthcare professional to check how they are getting on with their medication
- receiving a home visit from a nurse or a GP
- having had their blood pressure checked by a healthcare professional
- being involved as much as they wanted in decisions about their care and treatment

However, those respondents living in more socially advantaged areas reported a more negative experience of the amount of information given to them about dietary changes that might help prevent a further stroke.

Self-reported health status

Patients with a poorer self-reported health status had significantly lower average scores to most questions in the survey. As stated previously, there is evidence that patients with a poorer health status generally give more negative assessments of their care.[5] The questions that did not show a significant difference between groups were those that related to support with everyday activities (i.e. home help, help with personal care, local support group, applying for benefits); home visits from a GP or nurse and whether or not they had had their blood pressure checked.

Help from another person

It is reasonable to suggest that those patients who said they required help from another person with everyday activities had a poorer health status than those who did not require such help. It is therefore not surprising that those respondents who did require help from another person had significantly lower average scores for many questions. However, for two questions (Q14 on home help and Q19 on help with applying for benefits), respondents who did not require help from another person with everyday activities had significantly lower average scores, implying a more negative experience. These two exceptions may be explained by the fact that these patients have a better health status and so may be less likely to be provided with such help, when compared with those patients with a higher level of dependency.

Completion of questionnaire

It is reasonable to suggest that patients who completed the questionnaire themselves had a better health status or a lesser degree of cognitive impairment than those who required help from another person. Analysis showed that those patients who needed help completing the questionnaire had a longer average length of stay in hospital, were less likely to report that their health in the previous four weeks was excellent or very good, and were more likely to have had a further stroke. Significantly lower average scores were found for several questions if the questionnaire had been completed on behalf of the patient, when compared with questionnaires completed by the patient. However, for questions relating to support for everyday activities (for example, home help or help with personal care) those patients who had completed the questionnaire themselves had significantly lower average scores (i.e. a more negative experience) than those who had required help to complete the survey. Again, this finding may be explained by the fact that these patients have a better health status and so may be less likely to be provided with such help, when compared with those patients with a higher level of dependency.

Type of ward

As shown in the key findings section earlier in the report, those respondents whose care was managed on a unit for patients with stroke during their inpatient stay had a more positive experience (i.e. had significantly higher average scores) for many aspects of their longer term care and support, than those who had stayed on other types of wards. This suggests that these units may offer benefits to patients, not only during their hospital stay, but also for the duration of their longer term care and support provided in the community.

Appendix D: Demographics of patients by type of ward

The extent of the difference in demographic characteristics or health status of respondents who had stayed on a unit for patients with stroke compared to those respondents who stayed on another type of ward needs to be considered. These factors may have influenced the experiences of patients of the care and treatment they received.

No significant differences were found between the socio-demographic characteristics of respondents who had stayed on a unit for patients with stroke compared with those who had stayed on other wards. Although the 2004 stroke survey showed that those respondents who had stayed on a unit for patients with stroke had, on average, poorer health status than those who had stayed on other wards, such differences were not apparent in the follow-up survey. There were no significant differences in the health status of respondents who had stayed on a unit for patients with stroke and those who had stayed on other wards, with regard to self-reported health status, whether they had required help from another person with everyday activities, whether they had experienced another stroke, or whether they required help with completing the questionnaire. However, we found that respondents who had stayed on such a unit had a significantly longer average length of stay in hospital (21 days) when compared with those who had stayed on other wards (13 days).

The survey showed that, for some aspects of follow-up care, respondents who had stayed on a unit for patients with stroke during their hospital stay were more positive about their care than those who had stayed on other wards. This analysis shows that such differences in response are not the result of differences in the demographics or health status of patients.

References

1. National Audit Office (2005) *Reducing Brain Damage: Faster access to better stroke care.*

2. Department of Health (2001) *National Service Framework for Older People.*

3. Department of Health (2002) *What makes a good stroke service and how do we get there? National Service Framework for Older People supporting implementation.*

4. Royal College of Physicians (2004) *National Sentinel Audit of Stroke (concise report). Prepared on behalf of the Intercollegiate Stroke Working Party.*

5. Cleary PD, McNeil BJ (1988) *Patient satisfaction as an indicator of quality of care, Inquiry*. 25(1): 25-36.

6. Tyson S and Turner G (2000) *Discharge and follow-up for people with stroke: what happens and why, Clinical Rehabilitation.* 14: 381-392.

7. McKevitt C and Wolfe CD (2000) *Community support after stroke: patient and carer views, British Journal of Therapeutic Rehabilitation.* 7: 6-10.

8. Thomas C, Parry A (1996) *Research on users' views about stroke services: towards an empowerment research paradigm or more of the same? Physiotherapy.* 82: 6-12.

9. Wade, D and the Intercollegiate Working Party for Stroke (2004) *National Clinical Guidelines for Stroke.*

10. Rodgers H, Bond S, Curless R (2001) *Inadequacies in the provision of information to stroke patients and their families, Age and Ageing.* 30: 129-133.

11. Greveson G, James O (1991) *Improving the long-term outcome after stroke – the views of patients and carers, Health Trends.* 23: 161-2.

12. O'Mahony PG, Dobson R, Thomson R et al (1997) *Satisfaction with information and advice received by stroke patients, Clinical Rehabilitation.* 11:68-72.

13. Kelson M, Ford C, Rigge M (1998) *Stroke rehabilitation: patient and carer views.*

14. Chest, Heart and Stroke Scotland (2001) *Improving Stroke Services: Patients' and carers' views.*

15. Anderson S, Marlett NJ (2004) *Communication in stroke: the overlooked rehabilitation tool, Age and Ageing.* 33: 440-443.

16. Drummond A, Lincoln N, Luby L (1996) *Effects of stroke unit on knowledge of stroke and experiences in hospital, Health Trends.* 28: 26-30.

17. Zwygart-Stauffacher M, Lindquist R, Savik K (2000) *Development of health care delivery systems that are sensitive to the needs of stroke survivors and their caregivers, Nursing Administration Quarterly.* 24(3): 33-42.

18. NHS Modernisation Agency (2005) *Action on neurology: Improving neurology services – a practical guide.*

19. Murray J, Ashworth R, Forster A and Young J (2003) *Developing a primary care-based stroke service: a review of the qualitative literature, British Journal of General Practice.* 53: 137-142.

20. Dorsey M, Vaca K (1998) *The stroke patient and assessment of care-giver needs, Journal of Vascular Nursing.* 16: 62-67.

21. Pierce L, Gordon Finn M, Steiner V (2004) *Families dealing with stroke desire information about self-care needs, Rehabilitation Nursing.* 29(1): 14-17.

22. Kerr SM, Smith LN (2001) *Stroke: an exploration of the experiences of informal caregiving, Clinical Rehabilitation.* 15: 428-436.

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