

Survey of patients 2005

Stroke



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The survey of stroke patients 2005 was designed, developed and coordinated by the NHS patient survey advice centre at



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.

The Healthcare Commission was created under the Health and Social Care (Community Health and Standards) Act 2003. The organisation has a range of new functions and takes over some responsibilities from other commissions. It:

- replaces the Commission for Health Improvement (CHI), which closed on March 31st 2004
- takes over responsibility for independent (private and voluntary) healthcare previously carried out by the National Care Standards Commission, which also ceased to exist on March 31st 2004
- carries out elements of the Audit Commission's work relating to efficiency, effectiveness and economy of healthcare

We have a statutory duty to assess the performance of healthcare organisations, award annual performance ratings for the NHS and coordinate reviews of healthcare with others. We have created an entirely new approach to assessing and reporting on the performance of healthcare organisations. Our annual health check will look at a much broader range of issues in our assessments, enabling us to focus on what really matters.

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Executive summary

The national survey of stroke patients provides an assessment of the experiences of people who have received care and treatment for stroke in England. The survey covers many aspects of the experiences of patients, from diagnosis right through to long term rehabilitation, with particular reference to the aims set out in standard five of the National Service Framework for Older People. It also provides important evidence that can be compared with the findings of the 2004 National Sentinel Audit of Stroke.

Fifty one non-specialist acute hospital trusts in England took part in the survey, drawing up a list of patients who had been admitted, and discharged alive, with a primary diagnosis of stroke between April 1st and June 30th 2004.

More than 1,700 patients were surveyed between October and December 2004.

Key findings

Early management of stroke

The majority (62%) of patients said that they were first told that they had experienced a stroke after being admitted to hospital. Most (89%) believed that their stroke was diagnosed quickly enough. Where there was a perceived delay in diagnosis, 33% of patients believed it was because their GP did not recognise that they had experienced a stroke; 40% said it was because the hospital doctor did not recognise that they had experienced a stroke.

Most patients (90%) believed that they were admitted to hospital quickly enough and almost two thirds of respondents stayed on a specialist stroke unit for most of their stay in hospital.

Care and treatment in hospital

Overall, respondents were satisfied with the care that they received in hospital – 69% rated their care as excellent or very good, 26% rated it as good or fair, and only 4% gave a rating of poor or very poor. The majority of patients had trust and confidence in the doctors and nursing staff treating them, and felt that they were always treated with respect and dignity. However, one in five (21%) thought that they were only sometimes treated in this way. Significant proportions of patients said that they had not always received the help they needed with getting to the toilet on time (34%), eating meals (42%) or washing (33%).

Patients were largely positive about rehabilitation in hospital. Sixty two per cent of those with swallowing difficulties said that they definitely received enough help, 50% of those with speech and communication problems said that they definitely received enough help, and 61% of those with mobility problems said that they definitely received enough help. But, one in four respondents thought that they had not received enough help with their emotional problems when they needed it.

Relationship with health professionals

Around two thirds of patients felt that doctors and nursing staff always answered their questions in a way that they could understand; 30% said that this only happened some of the time and about 7% said that they could not understand their answers at all. Similar responses were received when patients were asked if a member of their family, or someone close to them, had been given enough opportunity to talk to staff.

The survey highlighted the desire of some patients to be more involved in decisions about their care. In fact, 52% of patients said that they had not been involved in decisions about their care as much as they would have liked. This compares with 47% of respondents to the Healthcare Commission's national survey of all inpatients. A higher percentage (54%) of patients who stayed on a stroke unit felt that they there were definitely involved in decisions about their care, compared with those who stayed on other types of wards (39%).

More than a third (36%) of respondents felt that their diagnosis was only discussed with them to some extent, and 16% said that it was not discussed with them at all.

Information

Just over half (55%) of patients said that they understood the information they were given in hospital about their stroke, 30% said that they only understood some of it, and 8% said they understood little or none of it. Forty one per cent were given information about their diet that could help to prevent another stroke and 54% received information about physical exercise. Again, people who stayed on specialist stroke units were more likely to receive this type of information than those on other types of wards.

Twenty three per cent of patients said that the purpose of the medication they were given to take home was only explained to them to some extent and 21% said it was not explained at all. A large percentage (62%) of patients said that they were not told about potential side effects of medication and 35% were not told who to contact if they had concerns after leaving hospital.

Notably, more patients who stayed on a stroke unit said that they received information from hospital staff about local support groups (57%) and national stroke organisations (44%) than those who stayed on other types of wards (36% and 24% respectively).

Care after leaving hospital

There was a significant difference between the percentage of patients who stayed on a specialist stroke unit and felt that their needs and wishes were taken into account when planning rehabilitation (65%) and those who stayed on other types of wards (51%).

Most patients (63%) said that all of the services they needed after leaving hospital, such as occupational therapy, were arranged for them. However, the proportion of patients who said that they did not receive enough help with speech, mobility and emotional problems was higher after leaving hospital. In particular, 41% of patients said that they had not received enough help and support with emotional issues that had been affecting them since leaving hospital.

Ninety per cent of patients thought that their GP was given all the necessary information about the treatment and advice that they had received in hospital – although a small proportion were dissatisfied with the amount, or the quality, of care provided by their GP after leaving hospital.

Conclusion

In general, respondents to the survey were positive about the care and treatment that they received in hospital for stroke. They were particularly positive about how quickly they were diagnosed, with arrangements for services such as occupational therapy and physiotherapy when leaving hospital, and with the provision of equipment or aids to help them at home.

Responses also indicated that patients wanted to be more involved in decisions about their care, wanted more information about different aspects of their care, and wanted more assistance from staff with tasks such as washing, eating and getting to the toilet. The amount of support and information provided to patients after they left hospital was also a key area of concern.

People who stayed on specialist stroke units appeared to be more satisfied with all aspects of their care and treatment than those who stayed on other types of wards. However, more than a third of patients were not treated on specialist stroke units for most of their hospital stay. These findings strengthen arguments for all trusts to provide specialised stroke services in hospital.

About the national patient survey programme

Understanding what people think about the care and treatment they receive is crucial to improving the quality of care being delivered by healthcare organisations. One way of doing this is by asking people who have recently used the health service to tell us about their experiences.

The national patient survey programme, which was taken over by the Healthcare Commission in April 2004, is one of the largest patient survey programmes in the world. It provides an opportunity to monitor experiences of healthcare and is an important part of the Healthcare Commission's new approach to assessment.

The national patient survey programme aims to:

- provide feedback from patients to healthcare organisations, which can be used locally for quality improvement
- gather information about the experiences of people using services to inform performance assessment and the Healthcare Commission's inspections and reviews at a local level
- assess the performance of healthcare providers and monitor the experience of patients at a national level
- allow healthcare organisations to compare their results so that best practice can be shared

The Healthcare Commission has already surveyed patients on topics as diverse as hospital inpatient services, services for children and young people, emergency and ambulance services, and mental health and outpatient services. The programme continues to develop new approaches, different topics and improved partnership working to ensure that we capture a wider range of views from people who use the NHS and independent healthcare services.

More information about the national patient survey programme is available on the Healthcare Commission website at www.healthcarecommission.org.uk, along with copies of our survey reports.

Introduction

Stroke is a major cause of severe disability and the third most common cause of death in the UK. A stroke is a type of brain injury that can affect different people in different ways. There are two main types of stroke – an ischaemic stroke, which occurs when a blockage in a blood vessel stops blood from reaching the brain, and a haemorrhagic stroke, which occurs when a blood vessel bursts allowing blood to leak into the brain. Transient ischaemic attacks (or TIAs) are often described as ‘mini strokes’ and can increase the risk of stroke.

The quality of care being delivered by stroke services has been subjected to greater scrutiny in recent years, with a series of national sentinel audits by the Royal College of Physicians¹ and publication of the National Clinical Guidelines for Stroke.²

The National Service Framework (NSF) for Older People³, published by the Department of Health in March 2001, also raised the profile of stroke services. Standard five in the NSF aims to reduce the incidence of stroke in the population and to ensure that those who have had a stroke get prompt access to integrated stroke care services. It outlines four main components:

- prevention – reducing risk factors across the whole population as well as those at greater risk of stroke
- immediate care – patients who have had a stroke require urgent hospital admission and should be treated by specialist stroke teams within designated stroke units
- early and continuing rehabilitation – early, expert and intensive rehabilitation in a hospital stroke unit improves the long term outcome for patients
- long term support – rehabilitation should continue until it is clear that maximum recovery has been achieved

Obtaining the perspective of the patient is an important and valuable part of the evaluation of health services. The national survey of stroke patients by the Healthcare Commission complements the findings from the national stroke audit. This report summarises the key findings from that survey of patients.

Aim

Relatively few studies have tried to establish the views of patients of hospital stroke care.⁴ The main purpose of this survey was to assess experiences of stroke patients of hospital and post-discharge care in England against some of the aims set out in standard five of the NSF for Older People. At the same time, it provides important evidence to compare with the findings of the 2004 National Sentinel Audit of Stroke.

In addition to this survey, we will also seek feedback from stroke patients and their carers after initial hospital support has ended. A follow up survey is being undertaken with those patients who agreed to be contacted by us again, approximately one year after their discharge from hospital. The Healthcare Commission will report separately on the findings of this follow up survey.

Who took part in the survey?

One in three (51) non-specialist acute hospital trusts in England took part in this survey. A full list of participating trusts is provided in appendix 2. Other trusts were allocated to the parallel national surveys of patients with cancer⁵ or coronary heart disease.⁶

Each trust drew up a list of patients who had been admitted to hospital between April 1st and June 30th 2004, and discharged alive, with a primary diagnosis of intracerebral haemorrhage, cerebral infarction or stroke (not specified as haemorrhage or infarction)*. Each trust was required to have their sample validated by a clinician to confirm that the selected patients had indeed suffered a stroke and were eligible to take part in the survey. The period April to June was chosen so that comparisons could be made with the National Clinical Audit of Stroke, which was being carried out at the same time**.

Questionnaires were posted to 2,786 patients between October and December 2004, together with a covering letter. Up to two reminders were sent to non-responders. Completed questionnaires were received from 1,713 patients, representing a response rate of 65%***.

Of those patients who took part in the survey:

- 56% were men
- 96% were white, 2% Asian or Asian British, 1% black or black British and 0.4% were of mixed race, or from Chinese or other ethnic groups
- the average age was 75 years
- 56% had required help from another person for everyday activities in the previous two weeks
- 70% did not feel they had made a complete recovery from their stroke

* That is, ICD 10 codes: I61, I63 and I64

** Where comparisons are made in the report, the clinical audit figures are based only on the hospital sites in the 51 trusts that participated in this survey of patients exclude those patients who died in hospital

*** Excluding 60 undelivered questionnaires, 55 deceased patients and 21 patients ineligible to take part

Development of the questionnaire

The questionnaire was based on a review of published qualitative studies that focused on the care experiences of stroke patients and their carers, the NSF for Older People, and the National Clinical Guidelines for Stroke. Content validity and sampling issues were considered by an advisory group of experts in stroke (drawn from the intercollegiate working party for stroke at the Royal College of Physicians), researchers at Picker Institute Europe and the Healthcare Commission.

Questions were designed to examine the experiences of patients by asking them whether or not certain events or processes had occurred during a specific period of care. Many of the questions were based on previously validated questions used in the Healthcare Commission's national surveys of inpatients and the NSF for Coronary Heart Disease.

Two questions, developed by Lindley et al⁷, were also used to assess the health status (dependency and recovery) of respondents. A full report on the development, pilot testing and refining of the questionnaire used in this survey is available on the NHS surveys website at www.nhssurveys.org.

Interpreting the results

A quarter (26%) of patients filled in the questionnaire with the help of a friend or relative and 2% with the help of a health professional. A further 16% of questionnaires were completed by a friend or relative on behalf of the patient. Analysis showed that this last group of respondents had a longer average length of stay in hospital (26 days) when compared with those who completed the questionnaire themselves (15 days) or with the help of a friend or relative (22.8 days). It might, therefore, be reasonable to suggest that these respondents were more sick or had a higher degree of cognitive impairment.

With this in mind, the findings of the survey need to be interpreted with some caution. There is evidence that the more sick patients generally tended to give more negative assessments of their care⁸ and that responses tended to be more negative if people have help completing the questionnaire.^{9,10}

We also found that there were lower response rates among women, people from black and minority ethnic groups and those living in more deprived areas. There were also differences in response rates by age group, with those aged 51 to 80 years having significantly higher response rates than patients aged 50 and under, or those aged over 80. See appendices 3 and 4 for more information.

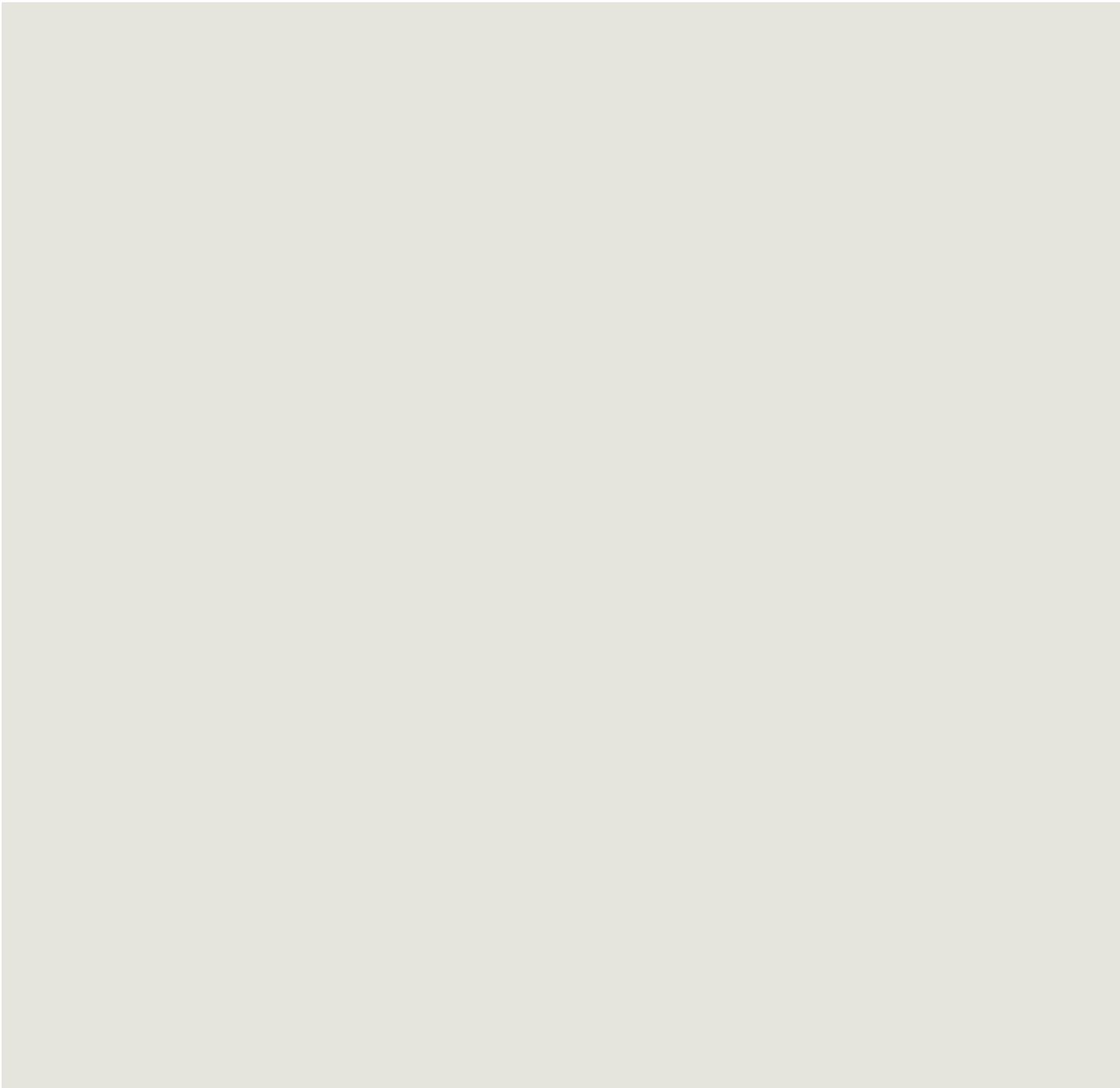
Previous surveys

The national survey of inpatients takes place each autumn and involves patients from all NHS acute hospital trusts in England. In 2004, more than 88,000 patients took part in the survey. A report on the key findings of the survey and more detail about how it was carried out are available on the Healthcare Commission website.

Acknowledgement

The Healthcare Commission would like to thank the patients and carers who responded to this survey, as well as the NHS trusts in England that participated. We would also like to thank Rachel Reeves and Esther Howell for their contribution.

Results of the survey



Early management of stroke[†]

Diagnosis

An early and accurate diagnosis is important in ensuring that stroke patients have the best possible chance of recovery. We asked the question when were people first told that they had experienced a stroke. Just over a third (36%) said that they were told before being admitted to hospital, while the majority (62%) said that they were first told in hospital. A small proportion (2%) of patients reported that they were not told that they had experienced a stroke until after they had left hospital.

Most patients (89%) thought their stroke had been diagnosed quickly enough. Of those who did not think that their stroke had been diagnosed quickly enough, the main reason they identified for the delay was because their GP (33%) or hospital doctor (40%) did not recognise that they had experienced a stroke. Eight per cent thought it was because equipment to carry out tests was unavailable in hospital.

“The GP concerned needs to be able to identify stroke earlier. It was three days before I was in hospital.”

“A whole week elapsed after my wife’s admission to the hospital before we were told she had suffered a stroke. Valuable time was thus lost during which treatment may have saved, or partially saved, the use of her left leg and arm.”

“The morning she rushed me in with my suspected stroke they could not diagnose if a clot or bleed had caused it as the scanner had broken down.”

Admission to hospital

Almost all (90%) of those who responded to the survey felt that they had been admitted to hospital quickly enough. Only 6% thought that they should have been admitted a little sooner and 4% thought that they should have been admitted a lot sooner.

“When I had my stroke in April 2004, I was at home. The doctor came very quickly and I was taken by ambulance to hospital, checked over and put to bed in a stroke ward.”

“The response by the ambulance and the care at hospital on arrival were excellent and could not have been better.”

There is strong evidence to show that patients who are treated on a stroke unit by a specialist stroke team are more likely to survive and to recover more function after a stroke.^{1-3, 11-14} The NSF for Older People proposed that, by April 2004, all hospitals caring for people who have had a stroke should have access to a specialised stroke service providing acute care and rehabilitation.

[†] Percentage figures quoted in the text may not always add up to 100% because of rounding

Results of the survey

The survey showed that, while only a quarter of patients were initially admitted to a stroke unit, almost two thirds (64%) said that they stayed on a stroke unit for most of their hospital stay. This figure was somewhat higher than the figure reported by the 2004 National Sentinel Audit of Stroke for the same trusts in the same period of time. The audit found that just over half (54%) of patients were treated on a stroke unit for most of their hospital stay.

Almost half (49%) of patients were first admitted to an acute assessment ward and 10% said that they had been on an acute assessment ward for most of their stay. A quarter (26%) of respondents stayed on another type of ward or unit (for example, a general ward) for the majority of their time in hospital.

Although we do not know what criteria participating trusts used in allocating patients between specialist and non-specialist wards, the survey evidence suggested that the most dependent patients (for example, those who needed help completing the survey and who had the longest average length of stay) stayed on specialist stroke units. The average length of stay on a stroke unit was 22 days, compared with 14 days for those who stayed on other types of ward.

“I walked into hospital and said I think I have had a stroke and before I knew it I was in a stroke ward.”

“I received no specialist stroke care, and spent most of the time on wards not specialising in strokes, such as an assessment ward, surgical ward and general medical ward.”

Care and treatment in hospital

Quality of care

The survey showed that most patients were satisfied with the care that they received in hospital. The majority (69%) rated the care they received in hospital as excellent or very good. Twenty six per cent rated it as good or fair and only 4% rated their care as being poor or very poor.

Patients who stayed on a stroke unit for most of their hospital stay were more positive about their experiences of care and treatment when compared with those who stayed on other types of wards or units.† Appendix 5 sets out the results for each question by ward type.

The majority of patients had trust and confidence in the health professionals that treated them. Seventy eight per cent said that they always had confidence and trust in the doctors treating them, while 75% said that they always had confidence and trust in nursing staff. Only 5% of patients said they did not have confidence and trust in the doctors or nursing staff treating them.

An analysis of the results by ward type (appendix 5) showed that a higher percentage of patients who stayed on a stroke unit always had confidence and trust in the doctors (83%) or nursing staff (79%) who treated them, compared with those who stayed on other types of ward (70% for both doctor and nursing staff).

“Excellent care, all staff took time and nothing was too much trouble. I cannot speak highly enough of the care from medical and nursing staff.”

A large proportion (92%) of patients thought that all or most of the doctors who treated them knew enough about the treatment of stroke. Similarly, 85% believed that all or most of the nursing staff knew enough about how to treat patients who have had a stroke.

† All differences referred to in this report are statistically significant at the 0.05 level; most are also significant at the 0.01 level.

A significantly higher percentage (14%) of those who had not stayed on a specialist stroke unit felt that none or only some of the doctors knew enough about the treatment of stroke, compared with those (6%) who stayed on a stroke unit. Likewise, 24% of patients who had not stayed on a stroke unit reported that none, or only some, of the nursing staff knew enough about the treatment of stroke, compared with 10% of those who stayed on a stroke unit.

“The treatment I received in hospital because of the stroke I had was overall excellent.”

“One nurse, in a standard ward, thought I was deaf because I could not understand what he was asking me... maybe they might be made aware of stroke patients’ problems understanding if they are to look after them.”

Most patients (79%) felt that they were always treated with respect and dignity in hospital. However, one in five (21%) thought that they were only sometimes treated in this way.

Patients were asked if they thought that there were enough nursing staff on duty to care for them in hospital. More than a third (37%) thought that there were enough nursing staff on duty only some of the time. Their comments also showed that some felt that a lack of nursing staff was sometimes the reason for poorer quality of care, such as not getting enough help with getting to the toilet.

“The nursing staff were stretched to the limit and could have done with more staff.”

“The problem is there is not enough staff to meet the demands of very ill patients.”

“Reaction to patient call alarms was always slow, causing difficulties with toilet needs which were not able to be pre-planned.”

In particular, the survey showed that a significant proportion of patients did not always receive the help they needed from hospital staff with getting to the toilet on time (34%), eating their meals (41%), or with washing (33%). Higher proportions of those who stayed on specialist stroke units reported that they received help with these activities, compared with patients who stayed on other types of wards (appendix 5). For example, 71% of those who stayed on a stroke unit reported that they always received the help they needed with washing, compared with 59% of patients on other wards.

“If I [relative] didn't go to feed her, she was left with her food and did not eat ... she was left to go to the bathroom on her own and many times [she] was wet or dirty.”

A poor diet is a recognised risk factor for stroke, so patients were asked whether they were able to get healthy meals from the hospital menu. Of those patients who ate the hospital food (others were fed by a tube), 60% said that they were always able to get healthy meals. A third of patients said that they were only able to get healthy meals some of the time, while 7% reported that they could not get healthy meals at all from the hospital menu.

Results of the survey

Early rehabilitation

Early and continuing rehabilitation is important for improving long term outcomes for patients.¹⁵ The NSF for Older People recommends that a multidisciplinary assessment should be carried out, and rehabilitation started, within 24 hours of a stroke. According to current guidelines and standards, disability assessment and rehabilitation might include:

- speech and language therapy
- nutritional advice
- physiotherapy
- occupational therapy
- clinical psychology
- bladder and bowel management

The National Clinical Guidelines for Stroke recommend that patients experiencing problems with swallowing fluids or food should be seen by a speech and language therapist. Of those patients who had difficulties with swallowing, 62% felt that they definitely received enough help, while 27% said that they had help to some extent. However, 10% of patients who had difficulty swallowing said that they did not receive help when they needed it.

An analysis by ward type showed that two thirds (67%) of patients who stayed on a stroke unit felt that they had definitely had enough help with swallowing difficulties, compared with half (50%) of those who stayed on other types of wards.

The 2004 National Sentinel Audit for Stroke reported a similar picture. Among the trusts that participated in the audit and the survey, 74% of patients who spent the majority of their stay on a stroke unit had a swallowing assessment by a speech and language therapist within 72 hours of admission. This compared with 55% of patients who stayed on other wards.

Half of those who had speech and communication problems following their stroke said that they had definitely received enough help in hospital. A third (34%) reported that they received help to some extent, while 16% indicated that they did not get help when they needed it.

“Had speech and language therapy almost straight after stroke; good service.”

“More opportunities for speech therapy and family to have access to speak to therapists with patient to determine best ways to improve patient’s speech.”

Again, a higher percentage (56%) of patients who stayed on a stroke unit reported that they had definitely received enough help with speech and communication problems, compared with those who stayed on other types of wards (38%).

The National Clinical Guidelines for Stroke also recommend that a physiotherapist should coordinate therapy to improve movement and increase physical independence. Most (61%) respondents with mobility difficulties said that they had definitely received enough treatment to help improve their mobility. However, almost a third (30%) felt that they had only received enough treatment to some extent. A small proportion (8%) said that they had not received treatment to help improve their mobility.

A higher proportion (16%) of patients who stayed on a non-specialist ward reported that they did not get help to improve their mobility, compared with those who stayed on specialist stroke units (5%).

Psychological impairments, such as mood disturbance, depression and anxiety, are common problems after stroke.

Almost half (48%) of patients said that they had experienced emotional problems, such as confusion or depression, in hospital. Of these people, 40% said that they had definitely received enough help and support with their emotional problems; 36% felt that they had received the help and support that they needed to some extent. However, the survey showed that one in four patients thought that they had not received help with their emotional problems when they had needed it. Again, those who stayed on a stroke unit were more likely to report that they had definitely received enough help and support for emotional problems than those who stayed on other types of wards.

“Hospital staff were excellent; completely understanding and supportive of physical and emotional needs.”

“During her [patient] stay in the stroke unit, her confused state and memory problems were not considered to be a consequence of the stroke and, as such, were not treated by those responsible for her care.”

Relationship with health professionals

Communication

Almost two thirds (63%) of patients felt that doctors always answered their questions in a way that they could understand. The same proportion (63%) felt that nursing staff answered their questions in a way that they could understand.

“The doctors at the hospital and my own GP always took time to explain everything to me, even when I found it a little hard to understand at times. Their patience and caring attitude was greatly appreciated.”

“[Doctors] have been extremely [good] in their professional care, taking great care to explain the treatment thoroughly in a caring and sympathetic manner. They also encouraged me to ask questions and I never felt rushed in their presence.”

However, 30% of patients reported that doctors (and 31% for nursing staff) only sometimes answered questions in a way that they could understand, while 7% said they could not understand answers from doctors at all (6% for nursing staff).

“The doctor in charge of me was only seen three times in three weeks. But no questions were answered. He always said he would see me later but he never did.”

Results of the survey

“The communication between the doctors etc and what is told to the family and patient [needs to be improved]. My father-in-law found it very hard to understand what was being said to him.”

Patients were asked whether a member of their family, or someone else close to them, were given enough opportunity to talk to staff if they wanted to. The majority (61%) said that a member of their family or someone close to them definitely had enough opportunity to talk to staff. However, a third (33%) reported that this was only the case to some extent and 6% said that their family members or others close to them did not have an opportunity to talk to staff.

Two thirds (66%) of those who stayed on a stroke unit reported that a member of their family was definitely given enough opportunity to talk to staff if they wanted to, compared with around half (51%) of those who stayed on other types of wards.

“Everything was explained to my mum [patient]. It was all explained to the family as well.”

“Doctors telling close relatives more about what is going on with the patient instead of telling the patient who cannot speak or understand everything that is told to them. The patient cannot tell the relative what he has been told by doctors.”

“As the relative of a person suffering from a stroke, I would have appreciated the opportunity to speak to the consultant looking after my father when he was at the start of his time in hospital. There were questions I would have liked to ask, but did not get the chance.”

Given that many patients experience communication and cognitive problems following their stroke, there is perhaps a greater risk that hospital staff will talk in front of them as if they are not there. A comparison of the findings from this survey and the Healthcare Commission’s survey of all inpatients would appear to support this assertion.

Ten per cent of patients responding to the stroke survey reported that doctors often talked in front of them as if they were not there, while 28% said that this sometimes happened. In contrast, only 6% of respondents to the inpatient survey reported that doctors often talked in front of them as if they were not there; 22% reported that this sometimes happened.

Similarly, while 28% of respondents to the stroke survey said nurses sometimes, or often, talked in front of them as if they were not there, a smaller percentage (20%) of respondents to the inpatient survey experienced this.

Patients were also asked whether one member of staff said one thing and another said something different during their hospital stay. A third of respondents (34%) said that this sometimes, or often, happened to them. This finding corresponds with the inpatient survey, where 31% of respondents reported that this happened.

“I also found it very upsetting and confusing when different members of senior staff were giving me different information about discharge dates, required treatment etc.”

Involvement in care

The survey highlighted that many people who have had a stroke would like to be more involved in decisions about their own care. Just over half (52%) said that they had not been involved as much as they wanted in decisions about their care and treatment in hospital (including 19% who said they were not involved at all). This compares with 47% of respondents in the Healthcare Commission’s survey of all inpatients.

Analysis by ward type also revealed that a higher percentage (54%) of patients who stayed on a stroke unit said that they had definitely been involved in decisions about their care and treatment, compared with those who had stayed on other types of wards (39%).

Qualitative research has shown that diagnosis and care plans are not always explained in a way that patients and carers can understand and patients are not given enough opportunity to discuss their diagnosis.¹⁶ Almost half (49%) of the respondents said that their stroke diagnosis was fully discussed with them. However, more than a third (36%) thought that it was only discussed to some extent, and 16% said that their diagnosis was not discussed with them at all.

“Before leaving hospital someone should have explained what had happened to me in more detail and how my stroke would affect my life and recovery.”

“Greater discussion could have been had as to the reason or the cause of the stroke.”

“Not knowing much about my condition, I really feel that I would have felt better if I had had more time with the doctors or consultants to give me more detailed information and advice.”

Fifty three per cent of patients who stayed on a stroke unit said that their stroke diagnosis had been fully discussed with them, compared with 42% of those who stayed on other types of wards.

Information

Stroke and treatment

The NSF for Older People recommends that the treatment and care of people who have had a stroke should include the provision of “advice to patients and their carers to help manage the effects of the stroke on their lives” and “information and explanations about the treatment and care needed”. However, previous research indicates that some patients are dissatisfied with the amount and content of the information given to them.⁷

Just over half (55%) of respondents to the stroke survey said that they were able to understand the information they were given in hospital about their stroke. However, 30% reported that they only understood some of the information given to them and 8% understood little or none of it. Seven per cent said that they were not given any information about their stroke during their stay in hospital. A slightly higher percentage (9%) of patients who stayed on non-specialist wards for most of their hospital stay said that they were not given any information about their stroke, compared with those (6%) who had stayed on a stroke unit.

“More information should be given to patients and their families to help understand more about the stroke.”

“I would have liked to be told about my stroke at an early stage instead of waiting until I visited my own GP.”

“It was two months into my stay when I had to ask a doctor for information on my illness as none had been offered.”

Preventing another stroke

Patients who have had a stroke are at increased risk of a further stroke, so preventive measures are an important aspect of the individual care plan. With this in mind, the National Clinical Guidelines for Stroke and the NSF for Older People recommend that all patients and their family members be provided with appropriate information and advice on lifestyle factors, such as smoking and diet.

We asked patients if they were given information about dietary changes that might help prevent another stroke. Forty one per cent said that they were given information, while 43% said they were not. A small proportion (16%) felt that they did not need any information about changes to their diet.

Just over half (54%) of respondents received information from staff before they left hospital about physical exercise. One in three said that staff did not give them any information about physical exercise and 13% said that they did not need it.

Patients who stayed on a stroke unit were more likely to receive information about physical exercise and dietary changes that might help prevent another stroke, when compared with those on other types of wards. Of those who stayed on a stroke unit, 47% said that they received information about changes in their diet and 62% received information about physical exercise. This compared with 30% and 38% respectively of those who stayed on other types of wards.

The majority (71%) of respondents who smoked were given information about stopping smoking before they left hospital. Twenty nine per cent reported that they were not given any such information. There was little difference between the types of wards on this question.

Medication

More than half (57%) of those who were given medication to take home said that a member of staff had explained the purpose of their medicine in a way that they could understand. Almost a quarter (23%) said the purpose of their medicine was explained to some extent, while 21% felt that it was not explained at all.

In comparison, only 7% of respondents to the Healthcare Commission's national survey of inpatients reported that the purpose of their medication was not explained in a way that they could understand.

The majority of patients (76%) said that they were given enough information about how to use their medication, such as when to take it or how long to take it for. Only 10% said that they had not received this information, even though they wanted it.

The survey also highlighted that a large percentage (62%) of patients said that they were not told about potential side effects of their medication, even though a relatively high proportion of them had received information on its purpose and how to take it. Again, this figure was higher when compared with the national survey of inpatients, in which 43% of patients reported that they were not told about potential side effects of their medication.

“I would have liked to have been told that my medicines might cause side effects, as I was a little worried when these manifested themselves.”

“I was not told about possible side effects of my medication or who to contact if I was worried. I had quite worrying, to me anyway, side effects including terrible headaches and muscle aches.”

A comparison of results by ward type showed that a significantly higher proportion of patients who stayed on a stroke unit were informed of the purpose and side effects of their medication, compared with those who stayed on other types of wards.

Contact name

The NSF for Older People recommends that patients and carers be given the name of a stroke care coordinator who they can contact for advice.

The majority (65%) of patients who thought it was necessary to have the name of somebody to contact after leaving hospital were given a contact name. However, a third (35%) were not told who to contact. In comparison, 24% of respondents to the national survey of inpatients said that they were not told who to contact if they were worried about their condition or treatment after leaving hospital.

“I would have liked a contact number after my little stroke. I would have liked somebody to talk to. Being frightened and on your own isn't very nice.”

A much higher percentage (71%) of patients who stayed on a specialist stroke unit were given a contact name, compared with those who stayed on other types of wards (56%).

Results of the survey

Support groups and services

Stroke teams are advised to make links to voluntary organisations and support groups, such as the Stroke Association and Different Strokes, so that they can inform patients who have had a stroke about the support that is available to them. The National Clinical Guidelines for Stroke recommend that patients and their families receive information about the statutory and voluntary organisations offering services specific to their needs as part of post-discharge stroke care.

Forty eight per cent of respondents were given information from hospital staff about local voluntary and support groups for people who have had a stroke. Almost a third said that they were not given this information, but would have liked it, while 21% got their information about local support groups from somewhere else. Forty per cent of patients said that they would have liked information (or website details) from national stroke organisations, but had not received it; 24% got this information elsewhere.

Notably, more patients who stayed on a stroke unit reported that they received information about local support groups (57%) and national stroke organisations (44%) from hospital staff than those who stayed on other types of wards (36% and 24% respectively).

The 2004 National Sentinel Audit of Stroke revealed a similar finding. At trusts that participated in the audit and the survey of stroke patients, 83% of stroke units displayed information for patients about local voluntary agencies. This compared with 58% of rehabilitation units and only 16% of all other wards.

Previous research has shown that stroke patients do not always get enough information about the benefits they are entitled to.^{15, 17} We asked patients if they wanted, and had received, any help from health and social services in relation to obtaining benefits. Despite wanting some help, 27% of respondents said that they had not received any assistance with benefits. Again, an analysis by ward type showed that 38% of those who stayed on a stroke unit received help with benefits, compared with 25% of those who stayed on other types of wards.

“Definitely needed precise information of what assistance could be obtained for home support, benefit claiming and general information for post stroke help.”

The 2004 National Sentinel Audit of Stroke showed that 80% of stroke units at hospital sites that also participated in our survey of stroke patients displayed information on the Benefits Agency. This compared with 60% of rehabilitation units and 22% of all other wards.

Care after leaving hospital

Rehabilitation

The National Clinical Guidelines for Stroke and the NSF for Older People recommend that patients and their carers are prepared and fully involved in planning their future care and rehabilitation in order to ensure a smooth transfer between care settings. Sixty one per cent of patients felt that their own needs and wishes were taken into account when planning their rehabilitation. A third said that their own needs and wishes were only taken into account to some extent, and 6% said that their wishes were not taken into account at all.

“I was very impressed with the after care provided on discharge. Care was well organised and planned to suit my needs.”

“After discharge from hospital you are left to cope by yourself, as well as you can. More follow up care would be nice.”

The survey showed that there was a significant difference between those who stayed on a stroke unit and said that their own needs and wishes were definitely taken into account (65%) and those who stayed on other types of wards (51%).

If patients require any continuing treatment following discharge from hospital, this should be provided without delay by a specialist service in the community, day hospital or outpatient service. Most patients (63%) said that all the services they needed after leaving hospital, such as occupational therapy, were arranged for them.

“It [follow up care] was very good in my case, with follow up appointments for MRI scan, ECG chest x-ray, cardio scan and specialist appointments.”

“Good coordination between hospital and social services.”

However, 15% of patients who needed such services reported that these were not arranged for them. Twenty two per cent said that only some of the services they needed were arranged.

“Astonished that there was no contingency planning or follow up care. No future appointments to assess progress or assessment of mobility.”

“More communication between agencies after discharge from hospital is needed such as social services and home care services. Provision of aftercare very limited.”

A breakdown of the results by ward type highlighted that only 50% of patients who stayed on a non-specialist ward reported that these services were arranged for them, compared with 70% of those who stayed on a stroke unit.

The survey showed that the proportion of patients who said that they did not get enough help with speaking difficulties, mobility difficulties, or emotional problems was higher after leaving hospital than when they were in hospital. Of patients with speaking difficulties, 31% felt that they did not get enough help with speaking difficulties after they had left hospital, while 26% felt that they only received enough help to some extent.

“Since coming out of hospital I have not had any speech therapy like they promised.”

“I was promised speech therapy and promised someone would contact myself and wife about this and other issues, no one has been near me to ask if I’m alright or if I need help.”

Results of the survey

Twenty three per cent of patients said they had not received enough treatment to help improve their mobility after leaving hospital; 30% felt that they only got enough treatment to some extent. A number of patients expressed their dissatisfaction about not receiving any physiotherapy or occupational therapy since leaving hospital. Others felt that these services had not lasted for as long as they were needed.

“I didn't receive enough occupational therapy or physiotherapy. I have only recently started physiotherapy five months after my stroke. I feel this has put my recovery back.”

Other research has also highlighted patients' dissatisfaction with the availability of longer term physiotherapy.^{15, 16} A focus group involving stroke patients and carers revealed that some people found it difficult to understand the time limited nature of therapy that they felt was vital to their recovery⁸. The intensity and duration of therapy required for people who have had a stroke has been contested a great deal. While research has shown that the potential of therapy to influence recovery is limited, there is now evidence that a continuing decline following a stroke can be reversed by further rehabilitation.

It is recognised that the effects of a stroke may involve major changes in lifestyle and identity for people, requiring effective emotional support. However, a large proportion (41%) of respondents to the stroke survey said that they had not received enough help and support with the emotional issues that had been affecting them since leaving hospital.

“It would have been nice to have a counsellor explain the difficulties to expect when I returned home, such as sexual difficulties, mood swings, and depression. There was no-one to tell me that I would have irrational fears.”

A higher percentage of those who stayed on a stroke unit reported that they definitely received enough help with speaking difficulties, mobility and emotional problems after leaving hospital, compared with patients who stayed on other types of wards. However, the difference between these two groups was not as large as the difference reported during their stay.

Local (GP) health services

Another important aspect of a patient's discharge is the transfer of information and responsibility from the hospital to their GP and primary healthcare team. The survey showed that most patients (90%) thought that their GP was given all the necessary information about the treatment or advice they had received in hospital.

Only a small proportion (10%) did not think that their GP was given all the necessary information and some were dissatisfied with either the amount or quality of care provided by their own GP.

“Contact with GP could be better. He didn't know I'd been in hospital until I went to see him approximately three weeks after discharge.”

“The after care and support from the GP was practically non existent. In fact, one doctor told me you have had a stroke now get on with your life.”

Equipment and aids

It is recommended that all necessary equipment or aids, home adaptations or improvements be in place before a patient leaves hospital. The survey showed that nearly half of patients needed some equipment or aids to help them after they had left hospital and the majority (82%) of these patients thought that they had received the equipment and/or aids they needed quickly enough.

“The promptness of the physiotherapy department in providing a hand rail at home, allowing me to leave hospital sooner than I expected (was particularly good).”

“A rail was installed to enable me to get to bathroom easily. It was in place in my bungalow before I arrived home.”

However, 18% of patients reported that they would have liked the equipment or aids sooner. The comments showed that some patients and carers had to arrange equipment or home adaptations that they needed themselves, without help from health and social services.

“No follow up visit from social services after my discharge. My wife phoned and wrote before anyone came to discuss grab rails or any alterations needed in the bathroom.”

“Installation of equipment to assist getting into and out of home was very slow – some items were not suitable.”

Conclusions

This was one of the most extensive surveys of patient views of stroke care in England. It described the experiences of more than 1,700 people who were admitted to hospital between April and June 2004 with a primary diagnosis of stroke.

Positive findings

In general, respondents to the survey were positive about the treatment they received in hospital for their stroke, with 69% rating their care as excellent or very good. The majority reported that they had confidence and trust in the doctors and nursing staff treating them and felt that staff knew enough about the treatment of stroke.

In terms of early care and treatment, most patients said that they were admitted to hospital as soon as required and felt that their stroke was diagnosed quickly enough. A large proportion said that the services they needed after leaving hospital (for example, occupational therapy and physiotherapy) were arranged for them and any equipment or aids they needed were provided as soon as required.

Areas for improvement

Most patients were satisfied with their overall treatment for stroke, but the survey identified some specific areas where the quality of stroke services could be improved.

Involvement in care

Some patients said that they needed to be more involved in decisions about their care and treatment and in discussions about their diagnosis.

Information

More information needed to be given to patients about the side effects of medication, local support groups and national stroke organisations, and on ways to prevent another stroke, for example, through dietary changes and physical exercise.

Care in hospital

Some patients reported that they received insufficient help from hospital staff with getting to the toilet, eating meals and washing. More than a third felt that there were not enough nursing staff on duty to care for them.

Rehabilitation and support

A significant minority of respondents said that they had not received enough help in hospital for speech and communication difficulties, mobility problems or emotional issues. After they left hospital, the percentage of patients who reported that they had not received enough help and support with emotional problems or enough rehabilitation rose further. It is, however, important to note that there is ongoing debate about the benefits of rehabilitation therapy in the longer term.

In comparison with the results of the national survey of inpatients, the results from the stroke survey were less positive. In particular, a higher percentage of respondents to the stroke survey reported that:

- they were not involved as much as they wanted in decisions about their care and treatment
- doctors and nurses sometimes talked in front of them as if they were not there
- the purpose and side effects of their medication were not always explained
- they were not told who to contact if they were worried about their condition or treatment after leaving hospital

Specialist stroke units

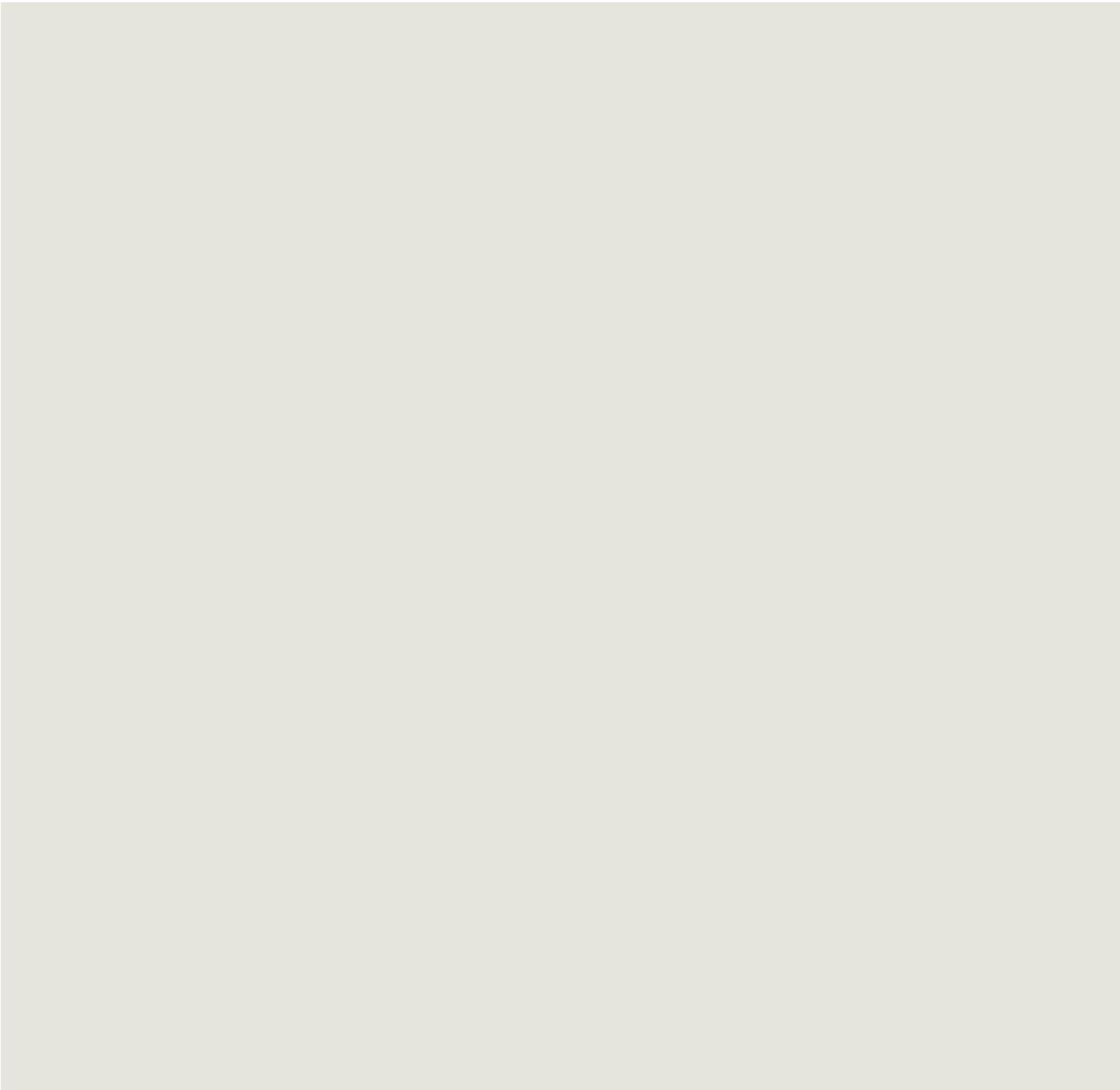
While a large body of research has shown that specialist stroke units have a positive effect on health outcomes, this survey provided evidence that patients were also more satisfied with their care when were treated on a stroke unit. The patients who stayed on a specialist stroke unit reported more positive experiences of their stroke care and treatment compared with patients who stayed on other types of wards. More than a third of patients who responded to the survey said they were not treated on a stroke unit for most of their hospital stay.

These findings strengthen arguments for all hospital trusts to provide specialised stroke services.

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Appendices



Appendix 1

Key result tables

Q1. When were you first told that you had had a stroke?		
	Number	National average %
Before I went into hospital	574	36%
In the hospital	995	62%
After I left hospital	28	2%
Total specific responses	1597	
Don't know, can't remember	59	
Missing responses	57	

Q2. Do you think your stroke was diagnosed quickly enough?		
	Number	National average %
Yes	1414	89%
No	169	11%
Total specific responses	1583	
Don't know, can't remember	87	
Missing responses	43	

Q3. If your stroke was not diagnosed quickly enough, what was the main reason?		
	Number	National average %
My GP did not recognise that I had had a stroke	52	33%
Doctor at hospital did not recognise that I had had a stroke	64	40%
Equipment at hospital to carry out tests was not available	13	8%
Another reason	31	19%
Total specific responses	160	
My stroke was diagnosed quickly enough	926	
Don't know, can't say	66	
Missing responses	561	

Q4. In your opinion, were you admitted to hospital quickly enough?		
	Number	National average %
I was admitted as soon as I thought was necessary	1426	90%
I should have been admitted a bit sooner	94	6%
I should have been admitted a lot sooner	62	4%
Total specific responses	1582	
I was already in hospital when I had a stroke	45	
Don't know, can't say	44	
Missing responses	42	

Q5. When you were first admitted to a bed on a ward, what type of ward was it		
	Number	National average %
Stroke unit	372	25%
Acute assessment ward	728	49%
An intensive care unit	45	3%
Other type of ward, unit	349	23%
Total specific responses	1494	
Don't know, can't remember	151	
Missing responses	68	

Q6. What type of ward were you on for most of your hospital stay?		
	Number	National average %
Stroke unit	984	64%
Acute assessment ward	151	10%
An intensive care unit	17	1%
Other type of ward, unit	396	26%
Total specific responses	1548	
Don't know, can't remember	91	
Missing responses	74	

Appendix 1

Key result tables

Q7. When you had important questions to ask a doctor, did you get answers that you could understand?		
	Number	National average %
Yes, always	888	63%
Yes, sometimes	427	30%
No, I did not get answers I could understand	100	7%
Total specific responses	1415	
I had no need to ask	121	
I was not able to ask	132	
Missing responses	45	

Q8. Did you have confidence and trust in the doctors treating you?		
	Number	National average %
Yes, always	1308	78%
Yes, sometimes	287	17%
No	82	5%
Total specific responses	1677	
Missing responses	36	

Q9. Did doctors talk in front of you as if you were not there?		
	Number	National average %
Yes, often	169	10%
Yes, sometimes	470	28%
No	1036	62%
Total specific responses	1675	
Missing responses	38	

Q10. In your opinion, did the doctors who treated you know enough about the treatment of stroke?		
	Number	National average %
All the doctors knew enough	967	65%
Most of the doctors knew enough	397	27%
Only some of the doctors knew enough	104	7%
None of the doctors knew enough	22	1%
Total specific responses	1490	
Can't say	181	
Missing responses	42	

Q11. When you had important questions to ask nursing staff, did you get answers that you could understand?		
	Number	National average %
Yes, always	875	63%
Yes, sometimes	430	31%
No, I did not get answers I could understand	87	6%
Total specific responses	1392	
I had no need to ask	177	
I was not able to ask	111	
Missing responses	33	

Q12. Did you have confidence and trust in the nursing staff treating you?		
	Number	National average %
Yes, always	1270	75%
Yes, sometimes	338	20%
No	77	5%
Total specific responses	1685	
Missing responses	28	

Q13. Did nursing staff talk in front of you as if you were not there?		
	Number	National average %
Yes, often	112	7%
Yes, sometimes	359	21%
No	1200	72%
Total specific responses	1671	
Missing responses	42	

Q14. In your opinion, were there enough nursing staff on duty to care for you in hospital?		
	Number	National average %
There were always or nearly always enough nursing staff	1034	63%
There were sometimes enough nursing staff	427	26%
There were rarely or never enough nursing staff	177	11%
Total specific responses	1638	
Don't know, can't remember	43	
Missing responses	32	

Q15. In your opinion, did the nursing staff who treated you know enough about the treatment of stroke?		
	Number	National average %
All the nursing staff knew enough	657	44%
Most of the nursing staff knew enough	616	41%
Only some of the nursing staff knew enough	184	12%
None of the nursing staff knew enough	33	2%
Total specific responses	1490	
Can't say	190	
Missing responses	33	

Q16. Were you involved as much as you wanted to be in decisions about your care and treatment in hospital?		
	Number	National average %
Yes, definitely	806	48%
Yes, to some extent	561	33%
No, I was not involved in decisions about my care and treatment	313	19%
Total specific responses	1680	
Missing responses	33	

Q17. Were you able to understand the information you were given in hospital about your stroke?		
	Number	National average %
Yes, I understood most or all of it	916	55%
Yes, I understood some of it	492	30%
No, I understood little or none of it	134	8%
I was not given any information	120	7%
Total specific responses	1662	
Missing responses	51	

Q18. Was your stroke diagnosis discussed with you?		
	Number	National average %
Yes, completely	740	49%
Yes, to some extent	544	36%
No, it was not discussed	240	16%
Total specific responses	1524	
It was not necessary to discuss it	56	
Don't know, can't remember	85	
Missing responses	48	

Appendix 1

Key result tables

Q19. If a member of your family or someone else close to you wanted to talk to the staff, did they have enough opportunity to do so?		
	Number	National average %
Yes, definitely	934	61%
Yes, to some extent	497	33%
No, but they wanted to talk to the staff	98	6%
Total specific responses	1529	
No, but they did not want or need to talk to the staff	67	
I did not want family or friends to talk to the staff	22	
Can't say	51	
Missing responses	44	

Q20. When you needed help from staff getting to the toilet, using a bed pan did you get it in time?		
	Number	National average %
Yes, always	783	65%
Yes, sometimes	315	26%
No, I did not get help when I needed it	99	8%
Total specific responses	1197	
I did not need help from staff	416	
I had a catheter	34	
Missing responses	66	

Q21. When you needed help from staff in eating your meals, did you get it when you needed it?		
	Number	National average %
Yes, always	453	59%
Yes, sometimes	225	29%
No, I did not get help when I needed it	89	12%
Total specific responses	767	
I did not need help from staff	870	
I had a nasogastric, NG, or PEG tube	20	
Missing responses	56	

Q22. Were you able to get healthy meals from the hospital menu?		
	Number	National average %
Yes, always	930	60%
Yes, sometimes	509	33%
No, I could not get healthy meals	102	7%
Total specific responses	1541	
I did not eat hospital food	57	
I had a nasogastric, NG, or PEG tube	23	
Don't know, can't remember	37	
Missing responses	55	

Q23. When you needed help from staff with washing, did you get it when you needed it?		
	Number	National average %
Yes, always	751	67%
Yes, sometimes	276	24%
No, I did not get help when I needed it	102	9%
Total specific responses	1129	
I did not need help from staff	539	
Missing responses	45	

Q24. While you were in hospital, did you get enough help for difficulties with swallowing?		
	Number	National average %
Yes, definitely	344	62%
Yes, to some extent	152	27%
No, I did not get help when I needed it	57	10%
Total specific responses	553	
I did not have any difficulties with swallowing	1098	
Missing responses	62	

Q25. While you were in hospital, did you get enough help with speech and communication problems?		
	Number	National average %
Yes, definitely	416	50%
Yes, to some extent	284	34%
No, I did not get help when I needed it	130	16%
Total specific responses	830	
I did not have any speech or communication problems	839	
Missing responses	44	

Q26. While you were in hospital, did you get enough treatment to help improve your mobility?		
	Number	National average %
Yes, definitely	760	61%
Yes, to some extent	373	30%
No, I did not get help when I needed it	105	8%
Total specific responses	1238	
I did not have any mobility difficulties	428	
Missing responses	47	

Q27. While you were in hospital, did you get enough help and support with any emotional issues that might be affecting you (such as confusion, depression or crying)?		
	Number	National average %
Yes, definitely	326	40%
Yes, to some extent	293	36%
No, I did not get help when I needed it	201	25%
Total specific responses	820	
I did not have any emotional issues	844	
Missing responses	49	

Q28. Sometimes in hospital, a member of staff will say one thing, and another will say something quite different. Did this happen to you?		
	Number	National average %
Yes, often	128	8%
Yes, sometimes	431	26%
No	1103	66%
Total specific responses	1662	
Missing responses	51	

Q29. Did you feel you were treated with respect and dignity while you were in the hospital?		
	Number	National average %
Yes, always	1332	79%
Yes, sometimes	284	17%
No, little of none of the time	67	4%
Total specific responses	1683	
Missing responses	30	

Q30. Before you left hospital, did staff give you information about changes in your diet that might help prevent another stroke?		
	Number	National average %
Yes	644	41%
No	683	43%
I did not need any information	254	16%
Total specific responses	1581	
Don't know, can't remember	82	
Missing responses	50	

Appendix 1

Key result tables

Q31. Before you left hospital, did hospital staff give you information about physical exercise (e.g. walking) that might help prevent another stroke?		
	Number	National average %
Yes	855	54%
No	531	33%
I did not need any information	202	13%
Total specific responses	1588	
Don't know, can't remember	73	
Missing responses	52	

Q32. Before you left hospital, did a member of staff give you information about stopping smoking?		
	Number	National average %
Yes	276	71%
No	114	29%
Total specific responses	390	
I did not smoke	1259	
Don't know, can't remember	24	
Missing responses	40	

Q33. Did a member of staff explain the purpose of the medicines you were to take at home in a way you could understand?		
	Number	National average %
Yes, completely	798	57%
Yes, to some extent	318	23%
No, it was not explained	292	21%
Total specific responses	1408	
I did not need an explanation	123	
I had no medicines to take home	65	
Don't know, can't remember	65	
Missing responses	52	

Q34. Before you left hospital were you given enough information about how to use the medicine(s) (e.g. when to take it, how long to take it for, whether to take it with food)?		
	Number	National average %
Yes, enough information	1054	76%
Some, but not enough	204	15%
No information at all, and I wanted some	134	10%
Total specific responses	1392	
I did not want any information	112	
I had no medicines to take home	70	
Don't know, can't remember	77	
Missing responses	62	

Q35. Did a member of staff tell you about medication side effects to watch for when you went home?		
	Number	National average %
Yes, completely	294	23%
Yes, to some extent	196	15%
No, I was not told about side effects	809	62%
Total specific responses	1299	
I did not need an explanation	203	
I had no medicines to take home	69	
Don't know, can't remember	80	
Missing responses	62	

Q36. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?		
	Number	National average %
Yes	879	65%
No, I was not told who to contact	476	35%
Total specific responses	1355	
Don't know, can't remember	107	
It was not necessary	197	
Missing responses	54	

Q37. Did hospital staff give you information about voluntary and support groups for people who have had a stroke in your local area?		
	Number	National average %
Yes	666	48%
No, but I would have liked some	431	31%
No, but I got the information from somewhere else	289	21%
Total specific responses	1386	
Not sure, can't remember	208	
Missing responses	119	

Q38. Did hospital staff give you information about national stroke organisations or useful websites?		
	Number	National average %
Yes	472	36%
No, but I would have liked some	520	40%
No, but I got the information from somewhere else	313	24%
Total specific responses	1305	
Not sure, can't remember	267	
Missing responses	141	

Q39. Overall, how would you rate the care you received during your hospital stay?		
	Number	National average %
Excellent	556	33%
Very good	606	36%
Good	304	18%
Fair	131	8%
Poor	48	3%
Very poor	23	1%
Total specific responses	1668	
Missing responses	45	

Q40. Were your own needs and wishes taken into account when planning your rehabilitation?		
	Number	National average %
Yes, definitely	727	61%
Yes, to some extent	394	33%
No, my wishes were not taken into account	76	6%
Total specific responses	1197	
I have not had any rehabilitation	403	
Missing responses	113	

Q41. Were the services you needed after you left hospital arranged for you? (e.g. occupational therapist, physiotherapist)		
	Number	National average %
Yes, all the services I needed	695	63%
Yes, some of the services needed	241	22%
No but these services were needed	162	15%
Total specific responses	1098	
It was not necessary	494	
The services were already in place before my stroke	18	
Missing responses	103	

Q42. As far as you know, was your GP given all necessary information about the treatment or advice that you received in hospital?		
	Number	National average %
Yes	1060	90%
No, my GP was not given all the necessary information	119	10%
Total specific responses	1179	
Don't know	471	
I am not registered with a GP	0	
Missing responses	63	

Appendix 1

Key result tables

Q43. After you left hospital, did you get enough help with speaking difficulties?		
	Number	National average %
Yes, definitely	245	43%
Yes, to some extent	149	26%
No, I did not get enough help	173	31%
Total specific responses	567	
I did not have any speaking difficulties	1051	
Missing responses	95	

Q44. After you left hospital, did you get enough treatment to help improve your mobility?		
	Number	National average %
Yes, definitely	483	47%
Yes, to some extent	302	30%
No, I did not get enough treatment	237	23%
Total specific responses	1022	
I did not have any mobility difficulties	590	
Missing responses	101	

Q45. After you left hospital, did you get enough help and support with any emotional issues that might be affecting you (such as confusion, depression or crying)?		
	Number	National average %
Yes, definitely	188	27%
Yes, to some extent	229	32%
No, I did not get enough help and support	292	41%
Total specific responses	709	
I did not have any emotional issues	901	
Missing responses	103	

Q46. After you left hospital, did you get the equipment and, or aids (e.g. a wheelchair, commode or kitchen aids) you needed quickly enough?		
	Number	National average %
Yes, I got it as soon as I thought was necessary	667	82%
No, I would have liked it a bit sooner	74	9%
No, I would have liked it a lot sooner	72	9%
Total specific responses	813	
I did not need any equipment or aids	684	
The equipment/aids were already in place	90	
Missing responses	126	

Q47. Since your stroke have you received help with getting benefits (e.g. disability living allowance, attendance allowance, carer allowance)?		
	Number	National average %
Yes	455	33%
No, but I would have liked help	373	27%
I did not need any help	539	39%
Total specific responses	1367	
I was already receiving benefits	222	
Missing responses	124	

Q48. Who was the main person or people that filled in this questionnaire?		
	Number	National average %
The person who was a patient in the hospital	920	57%
A friend or relative of the patient	260	16%
Both patient and friend, relative together	418	26%
The patient with the help of a health professional	25	2%
Total specific responses	1623	
Missing responses	90	

Q49. Are you male or female?		
	Number	National average %
Male	940	56%
Female	742	44%
Total specific responses	1682	
Missing responses	31	

Q50. Age of respondents		
	Number	National average %
Aged 16-50 years	111	7%
Aged 51-60 years	201	12%
Aged 61-70 years	394	23%
Aged 71-80 years	554	33%
Aged 81 years and over	418	25%
Total specific responses	1678	
Missing responses	35	

Q51. In the last two weeks did you require help from another person for everyday activities?		
	Number	National average %
Yes	927	56%
No	732	44%
Total specific responses	1659	
Missing responses	54	

Q52. Do you feel you have made a complete recovery from your stroke?		
	Number	National average %
Yes	489	30%
No	1134	70%
Total specific responses	1623	
Missing responses	90	

Q53. To which of these ethnic groups would you say you belong?		
	Number	National average %
British	1551	94%
Irish	22	1%
Any other white background	17	1%
White and black Caribbean	1	0%
White and black African	0	0%
White and Asian	2	0%
Any other mixed background	0	0%
Indian	16	1%
Pakistani	12	1%
Bangladeshi	4	0%
Any other Asian background	2	0%
Caribbean	15	1%
African	5	0%
Any other black background	1	0%
Chinese	2	0%
Any other ethnic group	1	0%
Total specific responses	1651	
Missing responses	62	

Q54. Could we send you a survey again in a few months time to ask you about your follow up care?		
	Number	National average %
Yes, and I understand that this does not mean that I would have to take part	1249	79%
No, I would prefer you not to contact me again	333	21%
Total specific responses	1582	
Missing responses	131	

Appendix 2

Participating trusts

Participating trusts

Barnet and Chase Farm Hospitals NHS Trust
Bradford Teaching Hospitals NHS Trust
Bromley Hospitals NHS Trust
Cambridge University Hospital NHS Foundation Trust
Chelsea and Westminster Healthcare NHS Trust
East and North Hertfordshire NHS Trust
East Cheshire NHS Trust
East Kent Hospitals NHS Trust
East Lancashire Hospitals NHS Trust
Gloucestershire Hospitals NHS Trust
Good Hope Hospital NHS Trust
Harrogate Health Care NHS Trust
Hereford Hospitals NHS Trust
Hinchingbrooke Health Care NHS Trust
Ipswich Hospital NHS Trust
Isle Of Wight Healthcare NHS Trust
James Paget Healthcare NHS Trust
Kettering General Hospital NHS Trust
King's College Hospital NHS Trust
Leeds Teaching Hospitals NHS Trust
Medway NHS Trust
Mid Yorkshire Hospitals NHS Trust
North Middlesex University Hospital NHS Trust
Northern Devon Healthcare NHS Trust
Northumbria Health Care NHS Trust
Oxford Radcliffe Hospital NHS Trust
Portsmouth Hospitals NHS Trust
Queen Elizabeth Hospital NHS Trust
Queen's Medical Centre, Nottingham University Hospital NHS Trust
Royal Berkshire and Battle Hospitals NHS Trust
Royal Cornwall Hospitals NHS Trust
Salford Royal Hospitals NHS Trust
Sandwell and West Birmingham Hospitals NHS Trust
Scarborough and North East Yorkshire Health Care NHS
Sherwood Forest Hospitals NHS Trust
South Tyneside Health Care NHS Trust
Southport and Ormskirk Hospital NHS Trust
St Helens and Knowsley Hospitals NHS Trust
St Mary's NHS Trust
Tameside and Glossop Acute Services NHS Trust
Taunton and Somerset NHS Trust
The Lewisham Hospital NHS Trust
The Mid Cheshire Hospitals NHS Trust
The Newcastle Upon Tyne Hospitals NHS Trust
The Royal Wolverhampton Hospitals NHS Trust
United Bristol Healthcare NHS Trust
University College London Hospitals NHS Trust
West Dorset General Hospitals NHS Trust
West Suffolk Hospitals NHS Trust
Winchester and Eastleigh Healthcare NHS Trust
Wrightington, Wigan and Leigh NHS Trust

Appendix 3

Demographics of responders and non-responders

Demographics of responders and non-responders

It is important to compare the response rates for different demographic groups of responders and non-responders to the survey, as the responders may not be representative of all sampled patients.

Sex

The response rate for men (69%) was higher than that of women (60%) and this difference was statistically significant (Chi square=21, df=1, $p<0.001$).

Age

Completed questionnaires were received from:

- 60% of patients aged 16 to 50 years
- 72% of patients aged 51 to 60 years
- 75% of patients aged 61 to 70 years
- 66% of patients aged 71 to 80 years
- 54% of patients aged over 81 years

The differences in response rates between age groups were significant (Chi square=73, df=4, $p<0.001$).

Ethnic group

Information on ethnic background was available for 86% of patients. Of those patients, completed questionnaires were returned by:

- 73% of white patients (n=1623)
- 57% of Asian or Asian British patients (n=36)
- 50% of black or black British patients (n=24)
- 27% of patients of mixed, Chinese patients or other ethnic groups (n=12)

These differences were statistically significant (Chi square=62, df=3, $p<0.001$), although only a small proportion of patients were from non-white ethnic backgrounds.

Deprivation score

The Index of Multiple Deprivation (IMD), 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 their area of residence (i.e. ward).

It was possible to allocate a ward level IMD score to 88% of patients in the sample using their postcode. The mean deprivation score for responders was 24, compared with a mean for non-responders of 27, indicating that those patients living in more deprived areas were less likely to respond. This difference was highly significant ($t=4.7$, $df=2461$, $p<0.001$).

Appendix 4

Analysis by sub group

Analysis by sub group

It was important to examine the extent to which patients' experiences of stroke care were influenced by their demographic characteristics, the severity of their stroke, whether or not their care was managed on a specialist stroke unit, and where they lived. To undertake this analysis, questions were scored using a scale of 0 to 100. A response option that was assigned a score of 100 reflects the most positive patient experience, while a score of 0 indicates the worst experience.

An overall score was calculated for each respondent by taking a mean of the scores to each rated question. Higher mean scores indicated a more positive patient experience. Further analysis is required to unpick this data in detail.

Demographic characteristics

Age

An analysis of variance (table 1) showed that the overall mean score did not differ significantly between five different age groups of respondents suggesting that age did not have a strong influence on patients' evaluations of their experiences of stroke care and treatment ($f=2.2$, $df=4$, $p=0.62$). This finding contrasts with the results of an analysis based on the national surveys of patients, which showed that older patients generally gave higher scores (i.e. answer more favourably about their experience) than younger patients.

Sex

The overall mean score (table 2) was significantly different between men and women, with men rating their experiences of stroke care more positively ($t=4.3$, $df=1709$, $p<0.001$). This finding corresponds to the trust-based surveys of patients, in which men were shown to respond more favourably than women.

Ethnic group

Given that the majority of respondents to the survey (96%) reported they belonged to a white ethnic group, it would not be meaningful to compare the overall mean score by ethnicity, due to the small number of respondents from the other ethnic groups.

Completion of the questionnaire

Recipients of a questionnaire were invited to get help completing it from a friend/carer or a health professional, providing the answers were given from their own point of view. A question was included to identify the main person (or people) who filled in the questionnaire. The overall mean score (table 3) was significantly higher if the patient completed the questionnaire themselves than if the questionnaire was completed by, or with the help of, a friend, relative or health professional. This difference in the overall mean scores was statistically significant ($f=40.4$, $df=3$, $p<0.001$).

Self reported health status

Questions 51 and 52 of the survey – 'In the last two weeks did you require help from another person for everyday activities?' and 'Do you feel you have made a complete recovery from your stroke?' – can be used as a proxy for health status.⁷ The two questions were recoded to one dichotomous variable to indicate two levels of health status:

- recovered (i.e. did not require help from another person in the last two weeks for everyday activities and had made a complete recovery)
- not recovered (i.e. in last two weeks required help from another person for everyday activities and have not made a complete recovery and/or did not require help from another person but had not made a complete recovery)

Table 4 shows the overall mean score was higher for respondents who felt they had recovered from their stroke (82.0), than those who felt that they had not made a complete recovery (69.4). An independent test showed that this difference in the overall mean rating was significant ($t=10.6$, $df=1469$, $p<0.001$).

Length of stay in hospital

Length of stay in hospital can also be used as a proxy for health status or severity of stroke, as it can be assumed (though this is not the only explanation) that those patients who stayed in hospital for a greater length of time had a more severe stroke and therefore a poorer health status. Supporting this hypothesis is the fact that those who needed help in completing the questionnaire had the longest mean length of stay.

The number of days a patient stayed in hospital was calculated using the data on admission and discharge dates supplied by trusts. The variable showing the number of days a patient was in hospital was recoded into a categorical variable, and appropriate categories were determined by percentage quartiles.

The mean score (table 5) was lower for respondents who stayed in hospital the longest (i.e. 31 days or more), suggesting that patients who had a more severe stroke (poorer health status) reported a less favourable experience of their care and treatment. An analysis of variance showed that this difference in the overall mean rating was significant ($f=6.8$, $df=3$, $p<0.001$). However, this needs to be interpreted with some caution, since there is evidence that that responses tended to be more negative if patients had help completing the questionnaire.

Type of ward

As discussed in the report, it is well established that patients who are treated on a stroke unit by a specialist coordinated stroke team are more likely to have better health outcomes. It is reasonable to assume that respondents who stayed on a stroke unit would report a more positive experience of their care and treatment. A one way analysis of variance supported this assumption, as the respondents who stayed on a stroke unit for most of their hospital stay had a higher overall mean score (76.3) than those who stayed on another type of ward (table 6). The difference in the overall mean score was statistically significant ($f=25.4$, $df=3$, $p<0.001$).

Appendix 5 shows the some of the key results for each question broken down by ward type.

Locality

The impact of geographical area on patients' experience of stroke care was calculated by assigning each trust to the appropriate Government office region, and then comparing the mean scores by these nine regions (table 7). Respondents living in the north east had the most positive experiences, with a mean score of 77.8. Patients who stayed in hospital in London had the lowest mean scores (69.6), suggesting a poorer experience of stroke care services. The variation in the overall mean scores between the regions was significant ($f=3.0$, $df=8$, $p=0.002$).

Appendix 4

Analysis by sub group

Table 1. Mean scores by age group

	N	Mean score	Standard deviation	95% Confidence interval for mean	
				Lower bound	Upper bound
Aged 16-50 years	111	71.9	23.0	67.6	76.2
Aged 51-60 years	201	71.5	20.1	68.7	74.3
Aged 61-70 years	394	75.4	18.9	73.5	77.2
Aged 71-80 years	554	73.1	20.1	71.4	74.8
Aged 81 years and over	416	71.6	20.5	69.6	73.5
Total	1676	73.0	20.1	72.0	73.9

($f=2.2$, $df=4$, $p=0.62$)

Table 2. Mean scores by sex

Sex	N	Mean score	Standard deviation	Standard error mean
Male	958	74.8	19.2	.6
Female	753	70.6	21.2	.8

($t=4.3$, $df=1709$, $p<0.001$)

Table 3. Mean scores by who completed the questionnaire

	N	Mean score	Standard deviation	95% Confidence interval for mean	
				Lower bound	Upper bound
The person who was a patient in the hospital	920	77.6	18.1	76.4	78.7
A friend or relative of the patient	260	65.9	20.2	63.5	68.4
Both patient and friend, relative together	418	67.7	21.6	65.6	69.8
The patient with the help of a health professional	25	64.2	21.3	55.4	72.9
Total	1623	73.0	20.2	72.0	73.9

($f=40.4$, $df=3$, $p<0.001$)

Table 4. Mean scores by self reported health status

Health status	N	Mean score	Standard deviation	Standard error mean
Not recovered	1116	69.4	20.5	.61
Recovered	355	82.0	15.5	.82

($t=10.6$, $df=1469$, $p<0.001$)

Table 5. Mean scores by length of stay in hospital

	N	Mean score	Standard deviation	95% Confidence interval for mean	
				Lower bound	Upper bound
5 days or less	426	73.5	20.3	71.6	75.4
6-12 days	500	75.5	19.4	73.7	77.2
13-30 days	444	72.5	19.5	70.7	74.3
31 days or longer	339	69.1	21.6	66.8	71.4
Total	1709	72.9	20.2	72.0	73.9

($f=6.8$, $df=3$, $p<0.001$)

Table 6. Mean scores by ward type

	N	Mean score	Standard deviation	95% Confidence interval for mean	
				Lower bound	Upper bound
Stroke unit	984	76.3	18.8	75.1	77.5
Acute assessment ward	151	71.6	20.5	68.3	74.9
An intensive care unit	17	75.3	16.1	67.0	83.5
Other type of ward or unit	396	66.1	21.6	64.0	68.3
Total	1548	73.2	20.2	72.2	74.2

($f=25.4$, $df=3$, $p<0.001$)

Table 7. Mean scores by locality

	N	Mean score	Standard deviation	95% Confidence interval for mean	
				Lower bound	Upper bound
North east	174	77.8	18.6	75.0	80.6
North west	279	72.2	21.5	69.7	74.8
Yorkshire and the Humber	203	72.5	20.3	69.7	75.3
East Midlands	126	70.1	19.3	66.7	73.5
West Midlands	110	72.4	18.4	68.9	75.8
East of England	186	71.4	21.1	68.3	74.4
London	200	69.6	21.1	66.6	72.5
South east	234	74.2	19.8	71.6	76.7
South west	199	75.6	18.9	73.0	78.3
Total	1711	72.9	20.2	72.0	73.9

($f=3.0$, $df=8$, $p=0.002$).

Appendix 5

Key results tables by ward type

Key results tables by ward type

	Ward type	
	Stroke unit	Other type of ward
Before I went into hospital	36%	37%
In the hospital	64%	60%
After I left hospital	1%	3%

(Chi-square=19, df=2, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes	92%	84%
No	8%	16%

(Chi-square=20, df=1, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
My GP did not recognise that I had had a stroke	43%	28%
Doctor at hospital did not recognise that I had had a stroke	29%	45%
Equipment at hospital to carry out tests was not available	6%	9%
Another reason	22%	19%

(Chi-square=6, df=3, p=0.114)

	Ward type	
	Stroke unit	Other type of ward
I was admitted as soon as I thought was necessary	92%	87%
I should have been admitted a bit sooner	5%	8%
I should have been admitted a lot sooner	3%	5%

(Chi-square=7, df=2, p=0.030)

	Ward type	
	Stroke unit	Other type of ward
Yes, always	66%	55%
Yes, sometimes	29%	34%
No, I did not get answers I could understand	5%	12%

(Chi-square=28, df=2, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes, always	83%	70%
Yes, sometimes	13%	23%
No	4%	7%

(Chi-square=34, df=2, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes, often	10%	10%
Yes, sometimes	26%	31%
No	64%	59%

(Chi-square=4, df=2, p=0.137)

	Ward type	
	Stroke unit	Other type of ward
All the doctors knew enough	70%	55%
Most of the doctors knew enough	24%	32%
Only some of the doctors knew enough	5%	12%
None of the doctors knew enough	1%	2%

(Chi-square=42, df=3, p<0.001)

Appendix 5

Key results tables by ward type

	Ward type	
	Stroke unit	Other type of ward
Yes, always	68%	54%
Yes, sometimes	28%	35%
No, I did not get answers I could understand	4%	11%

(Chi-square=32, df=2, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes, always	79%	70%
Yes, sometimes	18%	23%
No	3%	7%

(Chi-square=18, df=2, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes, often	7%	6%
Yes, sometimes	20%	22%
No	73%	72%

(Chi-square=0.7, df=2, p=0.715)

	Ward type	
	Stroke unit	Other type of ward
There were always or nearly always enough nursing staff	65%	58%
There were sometimes enough nursing staff	26%	27%
There were rarely or never enough nursing staff	10%	14%

(Chi-square=9, df=2, p=0.010)

	Ward type	
	Stroke unit	Other type of ward
All the nursing staff knew enough	49%	33%
Most of the nursing staff knew enough	41%	43%
Only some of the nursing staff knew enough	9%	20%
None of the nursing staff knew enough	1%	4%

(Chi-square=66, df=3, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes, definitely	54%	39%
Yes, to some extent	32%	37%
No, I was not involved in decisions about my care and treatment	14%	24%

(Chi-square=35, df=2, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes, I understood most or all of it	58%	51%
Yes, I understood some of it	30%	29%
No, I understood little or none of it	6%	10%
I was not given any information	6%	9%

(Chi-square=18, df=3, p<0.001)

Appendix 5

Key results tables by ward type

Q18. Was your stroke diagnosis discussed with you?

	Ward type	
	Stroke unit	Other type of ward
Yes, completely	53%	42%
Yes, to some extent	34%	40%
No, it was not discussed	13%	18%

(Chi-square=16, df=2, p<0.001)

Q19. If a member of your family or someone else close to you wanted to talk to the staff, did they have enough opportunity to do so?

	Ward type	
	Stroke unit	Other type of ward
Yes, definitely	66%	51%
Yes, to some extent	29%	40%
No, but they wanted to talk to the staff	5%	9%

(Chi-square=29, df=2, p<0.001)

Q20. When you needed help from staff getting to the toilet, using a bed pan did you get it in time?

	Ward type	
	Stroke unit	Other type of ward
Yes, always	68%	60%
Yes, sometimes	25%	28%
No, I did not get help when I needed it	7%	12%

(Chi-square=11, df=2, p=0.004)

Q21. When you needed help from staff in eating your meals, did you get it when you needed it?

	Ward type	
	Stroke unit	Other type of ward
Yes, always	62%	50%
Yes, sometimes	29%	32%
No, I did not get help when I needed it	9%	18%

(Chi-square=13, df=2, p=0.002)

Q22. Were you able to get healthy meals from the hospital menu?

	Ward type	
	Stroke unit	Other type of ward
Yes, always	62%	56%
Yes, sometimes	33%	35%
No, I could not get healthy meals	6%	8%

(Chi-square=5, df=2, p=0.065)

Q23. When you needed help from staff with washing, did you get it when you needed it?

	Ward type	
	Stroke unit	Other type of ward
Yes, always	71%	59%
Yes, sometimes	24%	25%
No, I did not get help when I needed it	6%	16%

(Chi-square=32, df=2, p<0.001)

Q24. While you were in hospital, did you get enough help for difficulties with swallowing?

	Ward type	
	Stroke unit	Other type of ward
Yes, definitely	67%	50%
Yes, to some extent	27%	30%
No, I did not get help when I needed it	7%	19%

(Chi-square=21, df=2, p<0.001)

Q25. While you were in hospital, did you get enough help with speech and communication problems?

	Ward type	
	Stroke unit	Other type of ward
Yes, definitely	56%	38%
Yes, to some extent	32%	37%
No, I did not get help when I needed it	12%	25%

(Chi-square=31, df=2, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes, definitely	69%	45%
Yes, to some extent	26%	39%
No, I did not get help when I needed it	5%	16%

(Chi-square=66, df=2, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes, definitely	45%	28%
Yes, to some extent	35%	39%
No, I did not get help when I needed it	20%	32%

(Chi-square=21, df=2, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes, often	7%	8%
Yes, sometimes	25%	29%
No	68%	63%

(Chi-square=4, df=2, p=0.172)

	Ward type	
	Stroke unit	Other type of ward
Yes, always	82%	74%
Yes, sometimes	14%	21%
No, little of none of the time	4%	5%

(Chi-square=13, df=2, p=0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes	47%	30%
No	38%	50%
I did not need any information	15%	20%

(Chi-square=37, df=2, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes	62%	38%
No	29%	43%
I did not need any information	9%	19%

(Chi-square=77, df=2, p<0.001)

	Ward type	
	Stroke unit	Other type of ward
Yes	76%	66%
No	24%	34%

(Chi-square=4, df=1, p=0.037)

	Ward type	
	Stroke unit	Other type of ward
Yes, completely	60%	50%
Yes, to some extent	20%	28%
No, it was not explained	20%	22%

(Chi-square=12, df=2, p=0.003)

Appendix 5

Key results tables by ward type

Q34. Before you left hospital were you given enough information about how to use the medicine(s) (e.g. when to take it, how long to take it for, whether to take it with food)?

	Ward type	
	Stroke unit	Other type of ward
Yes, enough information	78%	72%
Some, but not enough	14%	17%
No information at all, and I wanted some	8%	11%

(Chi-square=5, df=2, p=0.086)

Q35. Did a member of staff tell you about medication side effects to watch for when you went home?

	Ward type	
	Stroke unit	Other type of ward
Yes, completely	25%	19%
Yes, to some extent	16%	14%
No, I was not told about side effects	59%	67%

(Chi-square=7, df=2, p=0.029)

Q36. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

	Ward type	
	Stroke unit	Other type of ward
Yes	71%	56%
No, I was not told who to contact	29%	44%

(Chi-square=27, df=1, p<0.001)

Q37. Did hospital staff give you information about voluntary and support groups for people who have had a stroke in your local area?

	Ward type	
	Stroke unit	Other type of ward
Yes	57%	36%
No, but I would have liked some	26%	38%
No, but I got the information from somewhere else	18%	27%

(Chi-square=51, df=2, p<0.001)

Q38. Did hospital staff give you information about national stroke organisations or useful websites?

	Ward type	
	Stroke unit	Other type of ward
Yes	44%	24%
No, but I would have liked some	35%	47%
No, but I got the information from somewhere else	21%	29%

(Chi-square=46, df=2, p<0.001)

Q39. Overall, how would you rate the care you received during your hospital stay?

	Ward type	
	Stroke unit	Other type of ward
Excellent	38%	25%
Very good	37%	35%
Good	17%	21%
Fair	6%	11%
Poor	2%	5%
Very poor	1%	2%

(Chi-square=51, df=5, p<0.001)

Q40. Were your own needs and wishes taken into account when planning your rehabilitation?

	Ward type	
	Stroke unit	Other type of ward
Yes, definitely	65%	51%
Yes, to some extent	30%	40%
No, my wishes were not taken into account	5%	9%

(Chi-square=21, df=2, p<0.001)

Q41. Were the services you needed after you left hospital arranged for you?		
	Ward type	
	Stroke unit	Other type of ward
Yes, all the services I needed	70%	50%
Yes, some of the services needed	18%	29%
No but these services were needed	13%	21%

[Chi-square=34, df=2, p<0.001]

Q42. As far as you know, was your GP given all necessary information about the treatment or advice that you received in hospital?		
	Ward type	
	Stroke unit	Other type of ward
Yes	91%	86%
No, my GP was not given all the necessary information	9%	14%

[Chi-square=6, df=1, p=0.013]

Q43. After you left hospital, did you get enough help with speaking difficulties?		
	Ward type	
	Stroke unit	Other type of ward
Yes, definitely	47%	36%
Yes, to some extent	26%	25%
No, I did not get enough help	28%	39%

[Chi-square=8, df=2, p=0.022]

Q44. After you left hospital, did you get enough treatment to help improve your mobility?		
	Ward type	
	Stroke unit	Other type of ward
Yes, definitely	53%	36%
Yes, to some extent	28%	34%
No, I did not get enough treatment	20%	31%

[Chi-square=25, df=2, p<0.001]

Q45. After you left hospital, did you get enough help and support with any emotional issues that might be affecting you (such as confusion, depression or crying)?		
	Ward type	
	Stroke unit	Other type of ward
Yes, definitely	31%	18%
Yes, to some extent	34%	29%
No, I did not get enough help and support	35%	53%

[Chi-square=19, df=2, p<0.001]

Q46. After you left hospital, did you get the equipment and, or aids (e.g. a wheelchair, commode or kitchen aids) you needed quickly enough?		
	Ward type	
	Stroke unit	Other type of ward
Yes, I got it as soon as I thought was necessary	84%	78%
No, I would have liked it a bit sooner	8%	11%
No, I would have liked it a lot sooner	7%	11%

[Chi-square=4, df=2, p=0.142]

Q47. Since your stroke have you received help with getting benefits (e.g. disability living allowance, attendance allowance, carer allowance)?		
	Ward type	
	Stroke unit	Other type of ward
Yes	38%	25%
No, but I would have liked help	26%	28%
I did not need any help	36%	46%

[Chi-square=20, df=2, p<0.001]

Appendix 5

Key results tables by ward type

Q48. Who was the main person or people that filled in this questionnaire?		
	Ward type	
	Stroke unit	Other type of ward
The person who was a patient in the hospital	56%	58%
A friend or relative of the patient	17%	14%
Both patient and friend, relative together	25%	26%
The patient with the help of a health professional	1%	2%

[Chi-square=3, df=3, p=0.472]

Q51. In the last two weeks did you require help from another person for everyday activities?		
	Ward type	
	Stroke unit	Other type of ward
Yes	59%	50%
No	41%	50%

[Chi-square=11, df=1, p=0.001]

Q52. Do you feel that you have made a complete recovery from your stroke?		
	Ward type	
	Stroke unit	Other type of ward
Yes	26%	34%
No	74%	66%

[Chi-square=9, df=1, p=0.003]

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