



Royal College of Surgeons
in Ireland



Trinity College Dublin

**National Audit of Stroke Care (NASC)
Irish Heart Foundation in Association with the
Department of Health and Children**

**Community Audit:
National Survey of Community-Dwelling Stroke Patients
and Carers, 2007**

**Prepared on behalf of the Irish Heart Foundation National Stroke
Review Group**

by

**The National Audit of Stroke Care Research Team
(Royal College of Surgeons in Ireland and Trinity College Dublin)**

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National Audit of Stroke Care:

National Survey of Community-Dwelling Stroke Patients and Carers, 2007

Report prepared by the National Audit of Stroke Care Research Team

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This report forms one component of a larger project to systematically and comprehensively determine the current state and need for stroke care in Ireland. As such, it should be read in conjunction with findings from other projects completed in 2006 and Autumn 2007.

Executive Summary

- The specific focus of this sub-report of the National Audit of Stroke Care was a survey of community-dwelling patients post-stroke and their carers. In order to gain comprehensive insight into the experiences of this patient group, the study sample was stratified in a number of ways. Stratification was by geographic location (four hospitals nationally, representative of all acute hospitals in the Republic of Ireland), by patient gender, by age (under and over age 65) and by time since stroke (short-term – 6-12 months post-stroke; and intermediate-term – 24-36 months post-stroke).
- The aim of this survey was to investigate the experiences of patients with stroke and their carers of stroke services post discharge from hospital, and to document current physical and psychological well-being of both groups.
- The study sample was identified through the HIPE scheme, all patients within the relevant timeframes identified and randomly selected according to survey stratification requirements.
- Of 251 eligible patients, a total of 139 patients participated; 101 patients nominated a primary carer, 72 of whom participated in the survey.
- Findings of this survey demonstrate major deficits in the provision of information, support and services to people with stroke and their carers who are discharged to community settings.
- In the acute stage of stroke, half of patients travelled to hospital by private transport. A small number of patients travelled to hospital using public transport. On arrival to hospital, many patients reported delays in A&E. The cumulative effects of these delays in attendance at hospital at the time of stroke are of serious concern, given the critical importance of rapid assessment and treatment to stroke outcome.
- Findings indicate significant shortcomings in rehabilitation services, deteriorating considerably after patients are discharged home. Carers reported that they needed to become 'expert' in managing the patient at home in as context of little or no support from health professionals.
- Comparisons of findings of this survey to a similar survey conducted in the UK indicate many similarities between survey findings. However, where differences are present, Irish patients reported receiving poorer care.
- Many patients reported receiving little or no information about their medicines post hospital discharge, a finding that also emerged in the carer survey. Carers also reported receiving little information about what to expect once the patient came home and little or no information about services or entitlements that might be available to them.
- One in ten carers could themselves be classified as vulnerable. These were almost exclusively women, most of whom were over 65.

The findings from this survey form one of six reports in the overall National Audit of Stroke Care. As such, it should be read in conjunction with findings from other projects completed from September 2006 to September 2007.

Recommendations

- To avert unnecessary delay of patients in A&E, it is recommended that patients with possible stroke be triaged directly to a stroke unit for rapid assessment.
- There is a need for information to be provided in the hospital setting, with opportunities for patients and families to seek additional information and advice if required.
- Following discharge from hospital, there needs to be a liaison function with designated staff who can be contacted for information, guidance or to link with needed services.
- Specific service deficits were noted that should be addressed, e.g., speech and language therapy and psychological support.

[For further discussion with Review Group]

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Chapter 1: Introduction

Heart disease and stroke are leading causes of death worldwide, identified as the first and third leading causes of death, respectively, in the US (Veasie et al., AHA, 2005), and contributing similarly to mortality rates in Ireland (Stroke Council Report, 2000). Two out of 3 people survive their first stroke. However, many are left with long-term disability and consequent needs for healthcare (Hare et al., 2005). Stroke has been identified as one of the major causes of disability in the UK and its consequences are a major source of expenditure for the health services. Physical disability and morbidity resulting from stroke pose a significant burden both at an individual and a societal level. The dramatic onset of physical disability following stroke may also have severe social and psychological consequences, including feelings of worthlessness or hopelessness and other depressive symptoms requiring significant adjustment (Boerner, 2004; Bruce, 2001). The high level of physical and psychological morbidity associated with stroke results in a significant burden for both patients and their carers. On discharge home, patients following stroke frequently have persisting clinical problems including impaired upper and lower limb function, speech and cognitive problems, difficulties mobilising indoors, outdoors and on stairs, and limited independence in self care, depression and social inactivity (Andersen et al 2002). At least three-quarters of all people with stroke are managed in the community, meaning that optimisation of stroke care in the community setting is central to minimising disability from stroke (Russman & Katzan, 2005).

An important input to improving the quality of stroke care received by patients and carers, both in hospital and after returning home, is to ask people who have had stroke about their experiences of the care and treatment they received (Healthcare Commission, 2005). Much of the literature to date focuses on patient experiences of hospital and of transfer from the hospital into the community, with longer-term problems relatively neglected (Hare et al., 2005). A number of postal surveys have been conducted of patients with stroke discharged from hospital to the community in the UK. The focus of these surveys has been on patients' experiences in hospital and of the discharge process (Healthcare Commission, 2005), and of the discharge and follow-up of patients following stroke (Tyson & Turner, 2000). These surveys have indicated generally positive reports from patients of their time in hospital, but rising levels of dissatisfaction once patients were discharged home. Dissatisfaction focused particularly on lack of communication with patients in relation to stroke, lack of involvement in decisions about their care and inadequate rehabilitation and support with emotional problems (Healthcare Commission, 2005). Other findings indicated an overly narrow focus of rehabilitation in hospital, directed at achieving discharge rather than addressing issues of importance to the individual with stroke (Tyson & Turner, 2000). A poor level of service overall was identified in the community, with shortcomings in particular in relation to poor communication from hospital to community services, and frequently poor liaison across community services

(Tyson & Turner, 2000). In a small, qualitative study of patients with stroke living in the community and their carers, Hare et al. (2005) found that the major issues faced were information needs. There was general consensus of need for more comprehensive information from both patients and carers. Many were unclear about the specific roles of different health professionals. There was a lack of contact with services, for example little or no hospital contact. Carers felt they had to become “experts” in dealing with the problems that arose. Ongoing psychological and emotional problems (e.g., fear of another stroke, generalised anxiety) were not being addressed. The care received appeared to be reactive rather than proactive, with patients and carers reporting persisting difficulties that were not being addressed by health professionals. A Cochrane review of information provision to patients with stroke and their carers yielded results limited by variability in the quality of trials conducted to date, with the result that the general effectiveness of information giving has not been conclusively demonstrated (Forster et al., 2002). This review identifies the need for further work that incorporates the expressed needs of patients and carers.

The aim of the National Audit of Stroke Care is to conduct a national stroke audit of hospital and community stroke care for the Republic of Ireland, and to establish the current level and functioning of services available for the care of stroke patients in both public acute hospitals, and in the community in the Republic of Ireland. This is being conducted through a series of six audits/surveys of hospital and community-based stroke services. The community component of this National Audit involves a survey of:

- (i) General practitioners
- (ii) Allied health professionals and public health nurses
- (iii) Patients and carers, and
- (iv) Nursing homes.

This phase of the community audit involves a survey of stroke patients and their carers residing in the community. The survey seeks to investigate the views, experiences and levels of satisfaction of community dwelling stroke patients and their carers in relation to stroke management and service provision post-stroke. Interviews with patients and their primary carers in the community are key to identifying their experience of stroke services after leaving hospital. This component of the community-based audit will seek to reflect the experiences of a range of stroke patients – those recently discharged from hospital and those who have now spent a longer time period post-stroke; those under and over age 65; and those living in urban and rural locations.

This audit of patient and carer experiences of stroke services and management will provide the first contemporary evidence on the status of community-based stroke service provision in Ireland. Findings will provide an important insight into the views, experiences and needs of patients and their carers in relation to stroke. Comparative analysis of patient and carer experiences will also provide information on the potentially different experiences of these groups. These

findings can be used to inform service frameworks and facilitate a more comprehensive and integrated approach to stroke management in the community. Patient and carer experiences of stroke management in Ireland can also be compared with findings from other countries to evaluate quality of care as experienced by these groups, in an international context.

Chapter 2. Methods

2.1. Sample

A sample of 200 patients with a primary diagnosis of stroke, discharged alive from hospital across the Republic of Ireland were the focus of this study, along with their primary carer. Patients were stratified by age [younger versus older (65+)], gender, geographic location [urban versus rural] and time since stroke [early: 6-12 months versus intermediate term: 24-36 months]. Geographic location was stratified by selecting patients post-stroke discharged from specific hospitals in Ireland regionally. In order to address hospital size and geographic location, the hospitals selected for inclusion were the Adelaide and Meath Hospital Incorporating the National Children's Hospital, Dublin, the Midland Regional Hospital at Mullingar, Mallow General Hospital, Cork, and Mayo General Hospital, Castlebar. These hospitals were comparable on key standards to all other public acute hospitals (N=32) in the Republic of Ireland involved in the NASC Clinical Audit (see Appendix 1). Patients whose acute stroke care took place in these four hospitals were included in the survey if they had been discharged alive from hospital within specified time periods, namely, 6-12 months prior to interview (timeframe slightly different for each hospital, depending on interview start date, timeframe was relevant 6 month period between January – October 2006), and 24-36 months prior to interview (relevant 12 month period between January 2004 and April 2005). Identification of patients discharged from these hospitals was through the Hospital In-Patient Enquiry (HIPE) scheme office (ESRI), using the same ICD10 codes as were used for the NASC Clinical Audit (codes I61, I63, and I64 for the 2006 cohort; equivalent ICD9 codes 431, 434, and 436 for the 2004 cohort).

2.2. Measures

Four questionnaires were developed for this survey: a patient questionnaire; a carer questionnaire; a proxy questionnaire for use where a patient was unable/unwilling to take part, but was happy for a relative to take part on his/her behalf; and a carer questionnaire for use where the person with stroke died following discharge from hospital.

2.2.1. Patient Questionnaire (see Appendix 2)

The patient questionnaire addressed a number of areas and comprised standardised assessment instruments, alongside a series of demographic questions and questions relating to the details of the person's stroke, ongoing risk factors for stroke, quality of care, service use, transport issues and employment. The standardised questionnaires incorporated in the survey were as follows:

- (i) The Vulnerable Elders Scale (VES)(Saliba et al., 2001): The VES is a 13-item measure developed from a study of over 6,000 community dwelling medicare beneficiaries over age 65 years (Saliba et al., 2001). A function

based scoring system is employed, which considers age, self-rated health, limitation in physical function and functional disabilities. The range of possible scores is 0-10 with scores of 3 points or more classified as vulnerable. The scale can be administered in less than 5 minutes, and has been shown to have good predictive validity.

- (ii) The Hospital Anxiety and Depression Scale (HADS)(Zigmond and Snaith 1983) – Depression subscale: The HADS is a widely applied 14-item (7 anxiety; 7 depression) self-rating instrument for assessing levels of psychological distress in non-psychiatric patients in medical settings. It focuses on the psychological rather than somatic symptoms of affective (mood and anxiety) disorders. The HADS has been extensively applied in research settings and provides cut-off scores to highlight levels of psychological distress. The depression subscale only was used in this survey. Scores range from 0-21 with lower scores indicating better mental health. Scores less than 8 indicate normal levels, scores of 8-10 indicate possible clinical levels of depression and scores of 11 or above indicate probable clinical levels of depression.
- (iii) The Barthel Index (Mahoney & Barthel, 1965): The Barthel Index is a measure of independence in activities of daily living (ADL). It measures independence/dependence across 10 ADL, with a total score range of 0-100, lower scores indicating higher levels of dependence.
- (iv) Service access: Questions relating to service access were derived from the HeSSOP-2 survey instrument (O’Hanlon et al., 2005) and focused on services potentially available in the community. In each case, patients were asked if they: A. needed the service; B. Availed of it; C. If availed of, was it paid for by the patient (in full or in part); D. If not availed of, would the patient have liked to receive the service; and E. if service wanted, why was it not availed of. The services listed included GP, public health nurse, allied health professionals and social services.
- (v) Quality of care: Questions used in the UK Healthcare Commission National Patient Survey of Stroke Care (2005) were used in this survey to address quality of care. Specifically, the sections of this questionnaire incorporated in the present survey were those relating to diagnosis; admission to hospital; care and treatment in hospital; discharge planning; and care after leaving hospital.

A brief assessment of patient’s cognitive function and language function were conducted to ascertain suitability for inclusion to the survey, in the case of cognitive function, and need for the interview to be conducted by a speech and language therapist, in the case of language function. These assessments were:

- (a) The Abbreviated Mental Test (AMT): The abbreviated mental test score (AMTS) was introduced by Hodkinson in 1972 to rapidly assess patients for the possibility of dementia. Its use in medicine has become more common, e.g., to assess for impaired cognitive function in situations other than dementia. It has been validated mainly in older patient populations.

- (b) The Frenchay Aphasia Screening Test (FAST): The FAST is a brief, validated assessment, which can be used by non-specialists to distinguish aphasia and normal language (Enderby & Crow 1996).

2.2.2. Carer Questionnaire (see Appendix 3)

As with the patient questionnaire, the carer questionnaire comprised demographic questions alongside standardised research instruments. The questionnaires incorporated in the survey were as follows:

- (i) Carer satisfaction with community stroke care questionnaire (Simon et al., 2003): This is a 23-item questionnaire recently developed for use with carers of stroke patients who are cared for at home. Initial reliability and validity data for this measure indicate satisfactory psychometric properties.
- (ii) The Vulnerable Elders Scale (VES)(Saliba et al., 2001): The VES-13 was administered to carers as previously described under “Patient Questionnaires”.
- (iii) The Hospital Anxiety and Depression Scale (HADS)(Zigmond and Snaith 1983) – Depression subscale: The HADS-D was administered to carers as described previously under “Patient Questionnaires”.
- (iv) The IQ-CODE (Jorm, 1994): The IQCODE is a short questionnaire designed to assess cognitive decline in older people. The questionnaire is completed by a relative or friend of the individual being assessed. The measure is used in situations where the individual is unable to undergo direct cognitive testing or screening. In this survey, the IQ-CODE was administered to carers of patients with stroke who had aphasia, where cognitive screening with the AMT might yield spurious or misleading results, indicating false positives or negatives in relation to cognitive function.

2.2.3. Proxy Questionnaire

The proxy questionnaire was an abbreviated version of the patient questionnaire, which excluded questions relating to ongoing risk factors for stroke, the HADS depression questions, the AMT and the FAST.

2.2.4. Carer Questionnaire Form B (patient deceased)

Form B of the carer questionnaire (used when the person with stroke was deceased) was an abbreviated version of the carer questionnaire, which excluded the IQCODE, the VES and the HADS depression questions.

2.3. Design

The survey was a cross-sectional study of a stratified, randomly selected group of patients with stroke discharged from hospital to home alive within two specified timeframes.

2.4. Procedure:

Stroke patients discharged from the four selected hospitals within the relevant specified timeframes were identified through HIPE scheme data, using relevant ICD10 and ICD9 codes. HIPE data in each hospital were stratified further by gender of patient and by age (under or over age 65)(see tabular representation of stratification procedure in Table 2.1). Thus, stratification was by geographic location (addressed by selection of 4 hospitals; N=50 patients required from each hospital); by time since stroke (6-12 months ago versus 24-36 months ago; N=25 in each hospital from each timeframe); by gender (N=25 male and N=25 female from each hospital); and by age (N=25 under 65 and N=25 over 65 in each hospital). In terms of selecting patients for inclusion in each hospital, therefore, the number required in each stratification frame was 6.25, which was rounded to N=7 in each case. Where numbers permitted (e.g., number of older females who had a stroke 24-36 months ago), twice the number of patients needed was randomly selected (N=14). The Patient Information Management System (PIMS) was consulted in each hospital in order to identify the contact details of each of the patients randomly selected from HIPE data. Where PIMS indicated that a patient had died in hospital, or been discharged directly to a nursing home, this patient was replaced by drawing another patient in that category at random from the HIPE data. This process continued until 14 patients had been identified as discharged alive in each case, or until the patients available to select within that category had been exhausted.

Once identified, stroke patients and their carers were sent a pack incorporating a letter of introduction and invitation from their hospital consultant, a letter of invitation and explanation of the value of the audit from the IHF, and a letter of introduction from the research team. The study was outlined as a face-to-face interview of approximately 30 minutes duration. Potential participants were advised that they would be contacted within a week to arrange an interview at a time and location (either at the hospital, or at home) that was convenient for them.

Within a week of letters being sent, telephone follow-up calls were made to ascertain willingness or otherwise of the person with stroke to take part in the survey. Where willing to participate, a suitable time and location for interview were agreed. Availability and willingness of a carer was also ascertained during this telephone call and, where willing to participate, an arrangement was made to interview the carer also. In almost all cases, carer interviews took place at the same time as patient interviews, two researchers conducting interviews in parallel. In each of the four hospitals from which the patient sample was drawn, rooms were made available in which interviews could take place. Patients and carers were invited either to attend the hospital for interview, with taxis provided for transportation, or to have interviews conducted in their home.

Table 2.1. Stratification procedure for patient selection.

| Hospital 1 (N=50) | | | | | | | | Hospital 2 (N=50) | | | | | | | |
|--------------------|------------|---------------|------------|---------------------|------------|---------------|------------|--------------------|------------|---------------|------------|---------------------|------------|---------------|------------|
| 6-12 months (N=25) | | | | 24-36 months (N=25) | | | | 6-12 months (N=25) | | | | 24-36 months (N=25) | | | |
| Male (N=25) | | Female (N=25) | | Male (N=25) | | Female (N=25) | | Male (N=25) | | Female (N=25) | | Male (N=25) | | Female (N=25) | |
| <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) |
| N= | N= | N= | N= | N= | N= | N= | N= | N= | N= | N= | N= | N= | N= | N= | N= |
| 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 |

| Hospital 3 (N=50) | | | | | | | | Hospital 4 (N=50) | | | | | | | |
|--------------------|------------|---------------|------------|---------------------|------------|---------------|------------|--------------------|------------|---------------|------------|---------------------|------------|---------------|------------|
| 6-12 months (N=25) | | | | 24-36 months (N=25) | | | | 6-12 months (N=25) | | | | 24-36 months (N=25) | | | |
| Male (N=25) | | Female (N=25) | | Male (N=25) | | Female (N=25) | | Male (N=25) | | Female (N=25) | | Male (N=25) | | Female (N=25) | |
| <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) | <65 (N=25) | >65 (N=25) |
| N= | N= | N= | N= | N= | N= | N= | N= | N= | N= | N= | N= | N= | N= | N= | N= |
| 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 | 6.25 |

In situations where a carer informed the research team of the death of the person with stroke since coming home from hospital, carers were asked if they would be willing to participate in the survey to provide some information on quality of care up to the time that the person with stroke died. These interviews were conducted by telephone.

2.5. Ethics

Ethical approval was sought from and granted by the hospital ethics committee in each of the four participating hospitals.

2.6. Analysis

Statistical analysis was conducted using SPSS Version 14 for PC.

Chapter 3: Results I: Patients

3.1 Patient profile

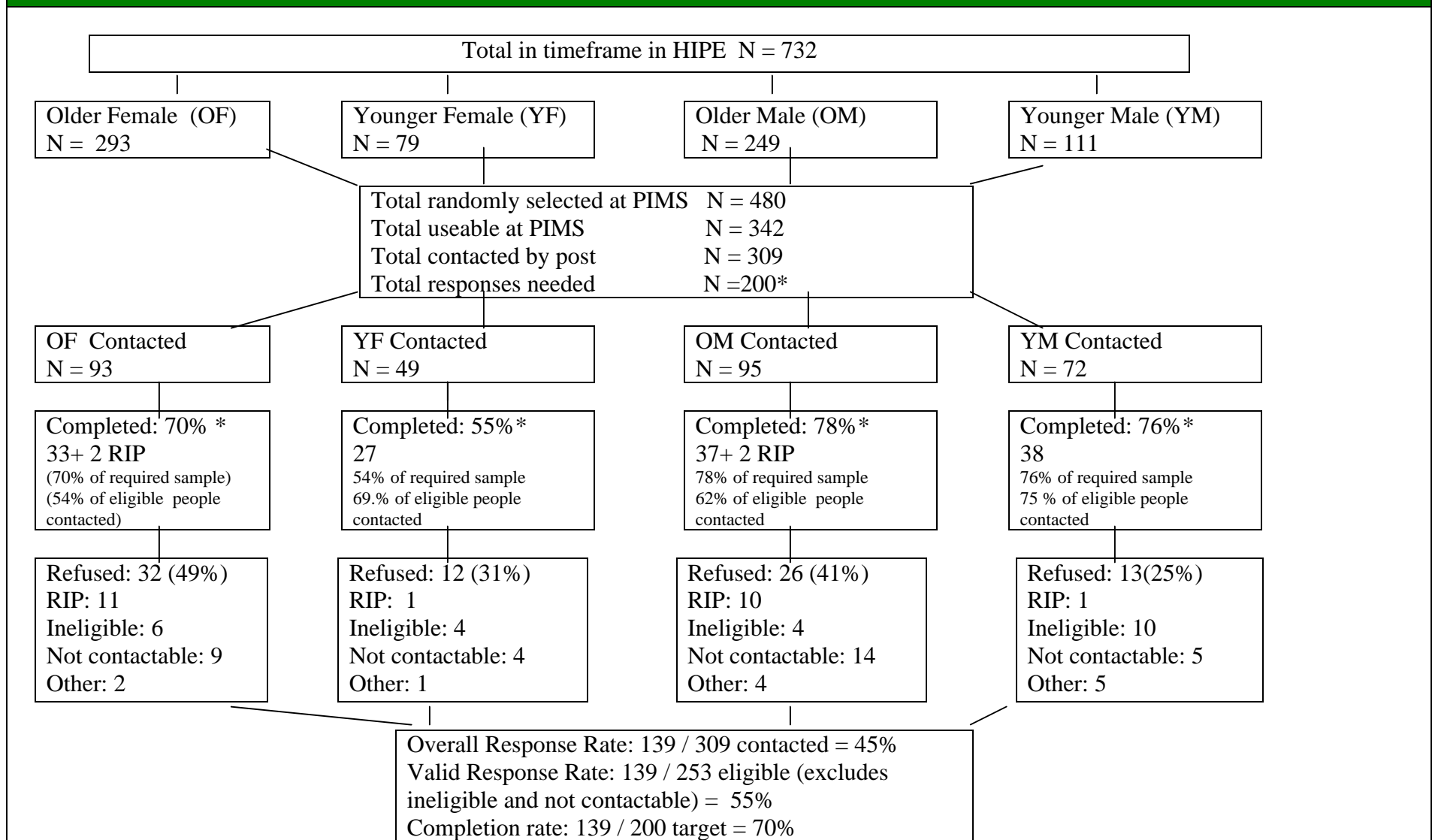
I. Patient participants

Table 3.1.1 illustrates patient response rate. In total, 309 patients were identified through HIPE and contacted by letter forwarded through their attending hospital consultant. On follow-up telephone contact, it became apparent that 56 patients (18%) could not be included in this study. Of these, 32 patients (10% of overall sample) had incorrect contact details and therefore could not be contacted. A further 24 patients (8% of overall sample) were not eligible to participate. This was because they had been discharged to a nursing home (which was not recorded in PIMs) or because the research team were informed that the person had not had a stroke when contacted by telephone. It was not possible to determine how many of those who stated they had not had a stroke represent miscoding in HIPE, inadequate communication about diagnosis by medical staff, or unwillingness by patients to accept or identify themselves as having had a stroke. Twenty-three patients (7% of overall sample) were deceased since returning home. In these cases, the next of kin was invited to participate. Of the 23 patients deceased since hospital discharge, four next of kin (17%) agreed to participate. Of the 253 patients eligible 139 (55%) took part in the study (including 14 interviews completed by proxy (carer) and four interviews with next of kin of patients who were deceased since hospital discharge). This represents 70% of the target sample.

II. Patient Demographic Profile

The demographic profile of the patient sample is detailed in Table 3.1.2. Of the patients who participated in this study, 76 (57%) were men. The mean age of the sample overall was 67 years, age range 28 to 96 years. Fifty two percent of the sample were aged 65 and over. Over half (55%) of the sample interviewed were married, the remainder were widowed (25%), never married (14%) or separated/divorced (6%). Twenty four percent of those interviewed lived alone.

Table 3.1.1 Flow chart of patient response rate



| Table 3.1.2 Participant demographic profile | | | | | | |
|---|----------------------------------|--|-------------------------------|--|----------------------------------|--|
| | 2004 | | 2006 | | Total | |
| Gender | Male 36 (54%) Female 31 (46%) | | Male 40 (60%) Female (40%) | | Male 79 (57%) Female 60 (43%) | |
| Age Mean (SD) | 64 (13.2) Range: 28-96 | | 70 (11) Range: 52-92 | | 67 (12.5) Range: 28-96 | |
| Marital Status | | | | | | |
| Married | 39 (58%) | | 34 (51%) | | 76 (55%) | |
| Seperated / Divorced | 3 (5%) | | 5 (7%) | | 9 (6%) | |
| Widowed | 14 (21%) | | 20 (30%) | | 35 (25%) | |
| Single | 11 (16%) | | 8 (12%) | | 19 (14%) | |
| Living Arrangements | | | | | | |
| Lives Alone | 18 (27%) | | 12 (18%) | | 33 (24%) | |
| Lives with Others | 49 (73%) | | 55 (82%) | | 106 (76%) | |

III. Stroke Risk Factors

One fifth of patients were diabetic (23%). A quarter of patients (26%) were current smokers and over were former smokers (58%). Table 3.1.3 illustrates the change in smoking status of those who smoked at the time of the stroke. Almost half of the sample (48%) did not change their smoking patterns following stroke. Nearly thirty per cent (28%) of patients quit smoking, over one fifth (22%) smoked fewer cigarettes, and nearly one third of the sample (33%) who smoked at time of interview are currently trying to give up smoking.

| Table 3.1.3. Changes in Smoking Pattern (of those who smoked at time of stroke) | | | | | | | | | | |
|---|----------|-----|---------|-----|----------|-----|---------|-----|---------|-----|
| | 2004 | | | | 2006 | | | | Overall | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Smokers that quit smoking following the stroke | 8 | 32% | 0 | 0% | 4 | 33% | 5 | 36% | 17 | 28% |
| Those who smoked less cigarettes per day following the stroke | 4 | 16% | 3 | 33% | 4 | 33% | 2 | 14% | 13 | 22% |
| Those who smoked more cigarettes per | 1 | 4% | 0 | 0% | 0 | 0% | 0 | 0% | 1 | 2% |

| | | | | | | | | | | |
|--|----|------|---|------|----|------|----|------|----|------|
| day following the stroke | | | | | | | | | | |
| Those who have not changed smoking pattern following the stroke | 12 | 48% | 6 | 67% | 4 | 33% | 7 | 50% | 29 | 48% |
| Overall N & % | 25 | 100% | 9 | 100% | 12 | 100% | 14 | 100% | 60 | 100% |

Of those still smoking at the time of interview, Table 3.1.4 illustrates the numbers considering stopping smoking. A majority (56%) were not considering stopping smoking at the time of interview. This was particularly the case for older men.

| Table 3.1.4 Smoking Pattern (of those who smoked at time of stroke) | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|
| | 2004 | | | | 2006 | | | | Overall | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Trying to quit smoking | 3 | 38% | 0 | 0% | 2 | 67% | 1 | 25% | 6 | 33% |
| Actively planning to quit | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% |
| Thinking about quitting, but not planning to | 0 | 0% | 0 | 0% | 1 | 33% | 1 | 25% | 2 | 11% |
| Not thinking about quitting | 5 | 62% | 3 | 100% | 0 | 0% | 2 | 50% | 10 | 56% |
| Overall N & % | 8 | 100% | 3 | 100% | 3 | 100% | 4 | 100% | 18 | 100% |

IV. Medical Check-ups

A majority of patients (82%) reported attending a GP in the last three months and half reported attending a hospital doctor within the last three months (Table 3.1.5). However, 3% of young men reported never having attended a GP.

| Table 3.1.5 Changes in GP and hospital doctor attendance | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|
| | 2004 | | | | 2006 | | | | Overall | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Attended GP in last 3 months | 27 | 75% | 20 | 80% | 18 | 82% | 32 | 89% | 97 | 82% |
| Attended a hospital doctor in the last 3 months | 16 | 47% | 11 | 50% | 10 | 46% | 17 | 55% | 54 | 50% |
| Attended GP in last year | 8 | 22% | 5 | 20% | 4 | 18% | 2 | 5% | 19 | 16% |

| | | | | | | | | | | |
|---|----|-----|---|-----|----|-----|----|-----|----|-----|
| Attended a hospital doctor in the last year | 16 | 47% | 5 | 23% | 11 | 50% | 12 | 39% | 38 | 34% |
| Attended GP in last 3 years | 0 | 0% | 0 | 0% | 0 | 0% | 1 | 3% | 1 | 1% |
| Attended a hospital doctor in last 3 years | 6 | 18% | 6 | 27% | 1 | 5% | 2 | 6% | 15 | 14% |
| Attended a hospital doctor between 3-5 years ago | 1 | 3% | 0 | 0% | 0 | 0% | 0 | 0% | 1 | 1% |
| Never attended a GP | 1 | 3% | 0 | 0% | 0 | 0% | 1 | 3% | 1 | 1% |
| Don't know when they last attended a hospital doctor | 1 | 3% | 0 | 0% | 0 | 0% | 0 | 0% | 1 | 1% |

One-fifth of patients (21%) reported not having their blood pressure checked in the past three months, considerably more reporting that they did not have their cholesterol or diet checked (50% and 78%, respectively)(Table 3.1.6).

| Table 3.1.6 Risk Factor Assessment: Blood Pressure, Cholesterol and Diet | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|
| Health Check in past 3 months | 2004 | | | | 2006 | | | | Overall | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Blood Pressure (N = 119) | 22 | 56% | 21 | 84% | 21 | 88% | 33 | 92% | 97 | 79% |
| Cholesterol (N = 112) | 17 | 47% | 14 | 58% | 13 | 57% | 16 | 44% | 60 | 50% |
| Diet (in past 12 months) (N = 105) | 4 | 12% | 1 | 5% | 6 | 30% | 8 | 23% | 24 | 22% |

3.2. Patient experiences of stroke care:

This section of the results is based on the UK Healthcare Commission survey of patients with stroke (2005). Tables illustrate the findings of the present survey overall and subdivided by age and time since stroke, alongside UK overall survey findings.

I. Diagnosis

Over a quarter of Irish patients (26%) had their stroke diagnosed prior to hospital admission, while almost two thirds were diagnosed in hospital (63%) (Table 3.2.1). These findings are similar to the UK study, although a larger number of Irish patients report being told of their diagnosis after leaving hospital (5%), or don't know/can't remember when they were told (6%).

| Table 3.2.1 Diagnosis: timing of diagnosis of stroke | | | | | | | | | | | | |
|--|----------|------|---------|------|----------|------|---------|------|---------|------|------------|-----|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Told before they went into hospital | 11 | 29% | 8 | 29% | 6 | 24% | 10 | 26% | 35 | 26% | 574 | 33% |
| Told in the hospital | 25 | 66% | 16 | 57% | 16 | 64% | 24 | 62% | 81 | 63% | 995 | 60% |
| Told after they left hospital | 0 | 0% | 3 | 11% | 2 | 8% | 1 | 2% | 6 | 5% | 28 | 2% |
| Don't know/ can't remember | 2 | 5% | 1 | 3% | 1 | 4% | 4 | 10% | 8 | 6% | 59 | 4% |
| Overall N & % | 38 | 100% | 28 | 100% | 25 | 100% | 39 | 100% | 130 | 100% | 1656 | 99% |

II. Admission to hospital

Almost half of patients (47%) travelled to hospital for admission using private transport, 4% of whom drove the car themselves (Table 3.2.2). A similar proportion of patients (45%) were taken to hospital for admission by ambulance. Five per cent of patients travelled to hospital by public transport. Older patients admitted to hospital more recently were more likely to have been transferred by ambulance.

| Table 3.2.2. Admission to hospital | | | | | | | | | | |
|---|----------|-----|---------|-----|----------|-----|---------|-----|---------|-----|
| | 2004 | | | | 2006 | | | | Overall | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Admitted by Private Transport: Other driver | 19 | 51% | 16 | 57% | 15 | 63% | 11 | 27% | 61 | 47% |

| | | | | | | | | | | |
|--|----|------|----|------|----|------|----|------|-----|------|
| Admitted by Ambulance | 14 | 38% | 11 | 39% | 7 | 29% | 27 | 66% | 59 | 45% |
| Admitted by Public Transport | 3 | 8% | 1 | 4% | 1 | 4% | 2 | 5% | 7 | 5% |
| Admitted by Private Transport: Self-drive | 1 | 3% | 0 | 0% | 1 | 4% | 1 | 2% | 3 | 3% |
| Overall N & % | 37 | 100% | 28 | 100% | 24 | 100% | 41 | 100% | 130 | 100% |

A majority (78%) of patients reported that they were admitted to hospital as soon as they thought was necessary, a proportion similar to that found in the UK survey (Table 3.2.3). Almost half of patients (44%) reported experiencing a delay between Accident and Emergency and admission to a ward, 10% of patients reporting that they should have been admitted a lot sooner (compared to 4% of UK patients surveyed).

| Table 3.2.3 Speed of admission to hospital | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | N | % | N | % |
| | N | % | N | % | N | % | N | % | | | | |
| Admitted as soon as they thought was necessary | 24 | 68% | 20 | 76% | 20 | 87% | 32 | 41% | 96 | 78% | 1426 | 85% |
| Should have been admitted a lot sooner | 3 | 9% | 1 | 3% | 2 | 4% | 2 | 2% | 12 | 10% | 62 | 4% |
| Should have been admitted a bit sooner | 7 | 20% | 3 | 12% | 1 | 4% | 3 | 5% | 10 | 8% | 94 | 6% |
| Don't know/can't say | 1 | 3% | 2 | 8% | 0 | 0% | 2 | 2% | 4 | 4% | 44 | 3% |
| Already in hospital when they had a stroke | 0 | 0% | 0 | 0% | 0 | 0% | 39 | 50% | 0 | 0% | 45 | 3% |
| Overall N & % | 35 | 100 | 26 | 100 | 23 | 100 | 78 | 100 | 122 | 100 | 1671 | 101 |

Over a quarter of patients could not recall the type of ward to which they were initially allocated (26%). Almost one third reported staying in an acute assessment ward (28%), 40% reported being admitted to an “other type” of ward. In the UK study, almost half of patients were admitted to an acute ward, while a quarter of patients were admitted to a stroke unit (Table 3.2.4).

| Table 3.2.4. Type of ward to which patients with stroke were admitted | | | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | N | % | N | % |
| | N | % | N | % | N | % | N | % | | | | |
| Acute assessment ward | 8 | 21% | 5 | 29% | 7 | 39% | 5 | 17% | 25 | 28% | 728 | 42% |
| Intensive care unit | 0 | 0% | 0 | 0% | 2 | 11% | 3 | 10% | 5 | 6% | 45 | 3% |
| Other type of ward/unit | 12 | 31% | 7 | 42% | 6 | 33% | 11 | 38% | 36 | 40% | 349 | 20% |
| Rehabilitation ward | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | N/A | N/A |
| Don't know/can't remember | 19 | 49% | 5 | 29% | 3 | 17% | 10 | 35% | 23 | 26% | 151 | 9% |
| Stroke Unit | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | 372 | 21% |
| Overall N & % | 39 | 101% | 17 | 100% | 18 | 100% | 29 | 100% | 89 | 100% | 1645 | 95% |

Almost thirty percent of patients in this survey stayed on an acute assessment ward for most of their stay (27%), a larger proportion (39%) indicating that they stayed on an “other type” of ward, typically described by patients as a “general” ward, while 29% could not recall what type of ward they stayed on (Table 3.2.5). In contrast, 60% of UK stroke patients were cared for in a Stroke unit.

| Table 3.2.5. Type of ward patients cared for majority of hospital stay | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | N | % | N | % |
| | N | % | N | % | N | % | N | % | | | | |

| | | | | | | | | | | | | |
|----------------------------------|-----|------|-----|------|-----|------|-----|------|-----|------|-----|------|
| Acute assessment ward | 4 | 18% | 5 | 36% | 6 | 40% | 6 | 24% | 21 | 27% | 151 | 9% |
| Intensive care unit | 2 | 9% | 0 | 0% | 1 | 7% | 1 | 4% | 4 | 5% | 17 | 1% |
| Other type of ward/unit | 9 | 41% | 6 | 43% | 5 | 33% | 10 | 40% | 30 | 39% | 396 | 24% |
| Don't know/can't remember | 7 | 32% | 3 | 21% | 3 | 20% | 8 | 32% | 21 | 29% | 91 | 6% |
| Stroke Unit | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | N/A | 60% |
| Overall N & % | 22 | 100% | 14 | 100% | 15 | 100% | 25 | 100% | 77 | 100% | 655 | 100% |

In a large proportion of cases, patients could not recall the type of medical specialist under whose care they were managed. Where patients could recall, most (48%) were managed by a consultant geriatrician, followed by consultant physician (19%) consultant neurologist (17%) and consultant in rehabilitation medicine (7%)(Table 3.2.6).

| Table 3.2.6. Medical specialist providing stroke care | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|
| | 2004 | | | | 2006 | | | | Overall | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Consultant Geriatrician | 10 | 46% | 8 | 42% | 14 | 74% | 12 | 38% | 44 | 48% |
| Consultant Neurologist | 7 | 33% | 2 | 12% | 4 | 25% | 1 | 4% | 14 | 17% |
| Consultant in Rehabilitation Medicine (Rehabilitationist) | 3 | 16% | 3 | 19% | 1 | 7% | 1 | 4% | 5 | 7% |
| General Physician (non-geriatrician) | 9 | 38% | 2 | 12% | 3 | 19% | 2 | 7% | 16 | 19% |
| Other | 5 | 25% | 0 | 0% | 0 | 0% | 0 | 0% | 5 | 7% |

A significantly higher proportion of younger patients (under 65) reported being under the care of a doctor in the “other” category than those over 65 ($\chi^2= 6.839$, $df= 2$, $p \leq .05$). There were significant age differences in terms of being under the care of a neurologist ($\chi^2 = 9,383$, $df = 2$, $p \leq .009$) also.

III. Care and treatment in hospital

Similar to findings in the UK survey, almost half of patients (45%) reported involvement in decisions about their care and treatment while in hospital (Table 3.2.7). However, almost twice as many patients in the Irish sample (39%) reported that they were not involved in decisions about their care and treatment compared to the UK patient sample (19%). Similarly, one third of the UK cohort reported being involved to some extent in decision-making, compared to 16% in the Irish setting. Significant differences also emerged between patients aged under and over 65 ($\chi^2=7.45$, $df=2$, $p<0.05$), older patients reporting significantly more involvement in decision-making than younger patients.

| Table 3.2.7 Patient involvement in decisions about care and treatment in hospital | | | | | | | | | | | | |
|---|----------|------|---------|------|----------|------|---------|------|---------|------|------------|------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | N | % | N | % |
| | N | % | N | % | N | % | N | % | | | | |
| Yes, definitely | 13 | 36% | 15 | 56% | 9 | 38% | 20 | 51% | 57 | 45% | 806 | 48% |
| Yes, to some extent | 5 | 14% | 6 | 22% | 3 | 12% | 6 | 16% | 20 | 16% | 561 | 33% |
| Not involved in decisions about their care and treatment | 18 | 50% | 6 | 22% | 12 | 50% | 13 | 33% | 49 | 39% | 313 | 19% |
| Overall N & % | 36 | 100% | 27 | 100% | 24 | 100% | 39 | 100% | 126 | 100% | 1680 | 100% |

Over half of the patients interviewed (52%) understood most or all of the information provided to them in hospital, a quarter understood some information, the remainder either understood little or none (12%), or were given no information (11%)(Table 3.2.8). These findings do not differ considerably from those reported by the UK patient sample.

| Table 3.2.8 Patient comprehension of stroke information provided in hospital | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | N | % | N | % |
| | N | % | N | % | N | % | N | % | | | | |
| Yes, understood most or all of it | 17 | 44% | 14 | 56% | 16 | 64% | 21 | 51% | 68 | 52% | 916 | 55% |
| Yes, understood some of it | 11 | 28% | 6 | 24% | 6 | 24% | 9 | 22% | 32 | 25% | 492 | 30% |
| No, understood little or none of it | 5 | 13% | 3 | 12% | 2 | 8% | 6 | 15% | 16 | 12% | 134 | 8% |
| Not given any information | 6 | 15% | 2 | 8% | 1 | 4% | 5 | 12% | 14 | 11% | 120 | 7% |
| Overall N & % | 39 | 100% | 25 | 100% | 25 | 100% | 41 | 100% | 130 | 100% | 1662 | 100% |

One third of patients (32%) reported that their stroke diagnosis was discussed with them in full, a further 28% reporting that it was discussed to some extent. However, almost one third of patients stated that their stroke diagnosis was not discussed with them (29%). This compares to only 16% in the UK (Table 3.2.9).

| Table 3.2.9 Discussion on stroke diagnosis | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | N | % | N | % |
| | N | % | N | % | N | % | N | % | | | | |
| Yes, completely | 15 | 39% | 7 | 26% | 9 | 36% | 11 | 27% | 42 | 32% | 740 | 44% |
| Yes, to some extent | 8 | 20% | 7 | 26% | 7 | 28% | 15 | 37% | 37 | 28% | 544 | 33% |
| No, it was not discussed | 12 | 31% | 7 | 26% | 6 | 24% | 13 | 32% | 38 | 29% | 240 | 16% |
| It was not necessary to discuss it | 1 | 3% | 1 | 4% | 0 | 0% | 1 | 2% | 3 | 2% | 56 | 3% |
| Don't know/ | 3 | 7% | 5 | 18% | 3 | 12% | 1 | 2% | 12 | 9% | 85 | 5% |

| | | | | | | | | | | | | |
|--------------------------|----|------|----|------|----|------|----|------|-----|------|------|------|
| Can't remember | | | | | | | | | | | | |
| Overall N & % | 39 | 100% | 27 | 100% | 25 | 100% | 41 | 100% | 132 | 100% | 1665 | 101% |

Almost three quarters of patients reported that their family/person close to them was given the opportunity to talk to staff if required (71%). This figure is higher than in the UK (56%)(Table 3.2.10). Of the remaining 29% of patients in the Irish sample, 10% felt that family had limited opportunity to speak with staff, a further 10% were unable to say whether family had been given an opportunity to talk with staff, while 7% reported that their family wanted to speak with staff, but were not afforded the opportunity(Table 3.2.10).

| Table 3.2.10 Opportunity for family to talk with staff | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, definitely | 25 | 64% | 16 | 59% | 20 | 80% | 33 | 79% | 94 | 71% | 934 | 56% |
| Yes, to some extent | 3 | 8% | 7 | 26% | 2 | 8% | 1 | 2% | 13 | 10% | 497 | 30% |
| No, but they wanted to talk to the staff | 5 | 13% | 1 | 4% | 1 | 4% | 3 | 7% | 10 | 7% | 98 | 6% |
| No, but they did not want or need to talk to the staff | 0 | 0% | 0 | 0% | 1 | 4% | 1 | 2% | 2 | 1% | 67 | 4% |
| Did not want family or friends to talk to the staff | 1 | 3% | 0 | 0% | 1 | 4% | 0 | 0% | 1 | 1% | 22 | 1% |
| Can't say | 5 | 13% | 3 | 11% | 0 | 0% | 4 | 10% | 13 | 10% | 51 | 3% |
| Overall N & % | 39 | 101% | 27 | 100% | 25 | 100% | 42 | 100% | 133 | 100% | 1669 | 100% |

A majority of patients reported needing help with daily activities. Forty-three per cent of patients reported not needing help with the toilet. Of those requiring help, 69% of patients reported always getting help when they needed it and 17% sometimes got help when they needed it. These figures reflect those found in the UK.

| Table 3.2.11 Staff help provided for toilet/bed pan use when needed | | | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, always | 22 | 82% | 9 | 60% | 10 | 71% | 15 | 63% | 52 | 69% | 783 | 64% |
| Yes, sometimes | 3 | 14% | 4 | 27% | 3 | 22% | 3 | 13% | 13 | 17% | 315 | 26% |
| No, did not get help when needed it | 1 | 4% | 2 | 13% | 1 | 7% | 4 | 16% | 8 | 11% | 99 | 8% |
| Had a catheter | 0 | 0% | 0 | 0% | 0 | 0% | 2 | 8% | 2 | 3% | 34 | 3% |
| Overall N & % | 26 | 100% | 15 | 100% | 14 | 100% | 24 | 100% | 75 | 100% | 1231 | 101% |

Nearly two thirds of patients did not require any help with eating their meals (64%)(Table 3.2.12). Of the remainder 57% always received help when they needed it. An additional 13% sometimes received help when needed. However, one-fifth (19%) of patients who needed assistance with feeding did not receive help when it was required. These figures were similar to those found in the UK

| Table 3.2.12 Staff help provided for meals when needed. | | | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, always | 8 | 53% | 5 | 62% | 5 | 56% | 9 | 60% | 27 | 57% | 453 | 58% |
| Yes, sometimes | 3 | 20% | 1 | 13% | 0 | 0% | 2 | 13% | 6 | 13% | 225 | 29% |
| No, did not get help when | 4 | 27% | 1 | 13% | 2 | 22% | 2 | 13% | 9 | 19% | 89 | 13% |

| | | | | | | | | | | | | |
|---|----|------|---|------|---|------|----|------|----|------|-----|------|
| needed it | | | | | | | | | | | | |
| Had a nasogastric (NG) or PEG tube | 0 | 0% | 1 | 12% | 2 | 22% | 2 | 14% | 5 | 11% | 20 | 3% |
| Overall N & % | 11 | 100% | 8 | 100% | 9 | 100% | 15 | 100% | 47 | 100% | 787 | 103% |

Thirty-seven per cent of patients did not need help with washing. Of the remainder (Table 3.2.13), 70% received help at least sometimes. The remaining 30% did not receive help when they needed it, in contrast to just 9% of the UK sample.

| Table 3.2.13 Staff provided help with washing when needed. | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, always | 15 | 60% | 9 | 56% | 9 | 50% | 17 | 71% | 50 | 60% | 751 | 67% |
| Yes, sometimes | 3 | 12% | 1 | 6% | 1 | 6% | 3 | 12% | 8 | 10% | 276 | 24% |
| No, did not get help when needed it | 7 | 28% | 6 | 38% | 8 | 44% | 4 | 17% | 25 | 30% | 102 | 9% |
| Overall N & % | 25 | 100% | 16 | 100% | 18 | 100% | 24 | 100% | 83 | 100% | 1129 | 100% |

Of those who had difficulty swallowing (27% of total) 33% did not get help when they needed it. This compares to 10% in the UK (Table 3.2.14)

Table 3.2.14 Staff help provided with swallowing difficulties when needed.

| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
|--|----------|------|---------|------|----------|------|---------|------|---------|------|------------|-----|
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, definitely | 5 | 50% | 3 | 50% | 4 | 40% | 8 | 62% | 20 | 51% | 344 | 62% |
| Yes, to some extent | 2 | 20% | 1 | 17% | 0 | 0% | 3 | 23% | 6 | 16% | 152 | 27% |
| Did not get help when needed it | 3 | 30% | 2 | 33% | 6 | 60% | 2 | 15% | 13 | 33% | 57 | 10% |
| Overall N & % | 10 | 100% | 6 | 100% | 10 | 100% | 13 | 100% | 39 | 100% | 553 | 99% |

While 64% of patients had no speech and communication difficulties, 35% of those who did reported not getting help when they needed it. This compares with 16% in the UK (Table 3.2.15).

Table 3.2.15 Staff help with speech and communication difficulties when needed.

| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
|--|----------|------|---------|------|----------|------|---------|------|---------|------|------------|------|
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, definitely | 6 | 43% | 5 | 56% | 5 | 46% | 11 | 64% | 27 | 53% | 416 | 50% |
| Yes, to some extent | 2 | 14% | 1 | 11% | 1 | 9% | 2 | 12% | 6 | 12% | 284 | 34% |
| Did not get help when needed it | 6 | 43% | 3 | 33% | 5 | 45% | 4 | 24% | 18 | 35% | 130 | 16% |
| Overall N & % | 14 | 100% | 9 | 100% | 11 | 100% | 17 | 100% | 51 | 100% | 830 | 100% |

Forty one per cent did not have any mobility difficulties. Of those who did have difficulties 70% always received help when needed and 14% received some

degree of help. However, one-sixth of patients (16%), twice the number reported in the UK survey (8%), did not receive help when needed (Table 3.2.16).

| Table 3.2.16 Staff help provided with mobility when needed. | | | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, definitely | 14 | 61% | 9 | 60% | 10 | 71% | 23 | 82% | 56 | 70% | 760 | 61% |
| Yes, to some extent | 6 | 26% | 2 | 13% | 0 | 0% | 3 | 11% | 11 | 14% | 373 | 30% |
| Did not get help when needed it | 3 | 13% | 4 | 27% | 4 | 29% | 2 | 7% | 13 | 16% | 105 | 8% |
| Overall N & % | 23 | 100% | 15 | 100% | 14 | 100% | 28 | 100% | 80 | 100% | 1238 | 99% |

Over half of the patients reported not having any emotional issues (53%). Where help was needed, only 23% reported getting help, compared to 40% in the UK (Table 3.2.17). Almost 56% of patients stated that they did not get any help with emotional issues when needed. In the UK, this figure was 25%. Within the Irish patient cohort, a significant age difference was found ($\chi^2 = 10.680$, $df = 3$, $p \leq .014$), patients under age 65 reporting not receiving help when needed significantly more than those over 65.

| Table 3.2.17 Staff support provided to patients with emotional issues when needed. | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, definitely | 3 | 14% | 2 | 22% | 4 | 25% | 5 | 36% | 14 | 23% | 326 | 40% |
| Yes, to some extent | 5 | 23% | 2 | 22% | 4 | 25% | 2 | 14% | 13 | 21% | 293 | 36% |
| Did not get help when needed it | 14 | 63% | 5 | 56% | 8 | 50% | 7 | 50% | 34 | 56% | 201 | 25% |
| Overall N & % | 22 | 100% | 9 | 100% | 16 | 100% | 14 | 100% | 61 | 100% | 820 | 101% |

Nearly 90% of patients reported always being treated with respect and dignity while in the hospital (87%)(Table 3.2.18). Significant age and gender differences were found. ($X^2=7.198$, $df = 2$, $p \leq .03$; $X^2=6.192$, $df = 2$, $p \leq .05$, respectively).

| Table 3.2.18 Respect and dignity for patient in hospital care | | | | | | | | | | | | |
|---|----------|------|---------|------|----------|------|---------|------|---------|------|------------|------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, always | 29 | 76% | 26 | 96% | 21 | 84% | 39 | 93% | 115 | 87% | 1332 | 79% |
| Yes, sometimes | 8 | 21% | 1 | 4% | 2 | 8% | 3 | 7% | 14 | 11% | 284 | 17% |
| No, little or none of the time | 1 | 3% | 0 | 0% | 2 | 8% | 0 | 0% | 3 | 2% | 67 | 4% |
| Overall N & % | 38 | 100% | 27 | 100% | 25 | 100% | 42 | 100% | 132 | 100% | 1683 | 100% |

IV. Discharge Planning

Almost three quarters of the patients interviewed reported that no family conference was suggested or took place prior to patients leaving hospital (74%). There was a significant difference in terms of year of stroke ($\chi^2 = 7.680$, $df = 2$, $p \leq .021$), those having a recent stroke significantly more likely to have had a family conference than those whose stroke was 2-3 years ago.

| Table 3.2.19 Family conference took place/suggested prior to leaving hospital | | | | | | | | | | |
|---|----------|------|---------|------|----------|------|---------|------|---------|------|
| | 2004 | | | | 2006 | | | | Overall | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Yes | 4 | 11% | 3 | 12% | 5 | 21% | 12 | 29% | 24 | 18% |
| No | 32 | 84% | 22 | 85% | 15 | 63% | 26 | 64% | 95 | 74% |
| Don't know/ can't remember | 2 | 5% | 1 | 3% | 4 | 16% | 3 | 7% | 10 | 8% |
| Overall N & % | 38 | 100% | 26 | 100% | 24 | 100% | 41 | 100% | 129 | 100% |

Almost half of the sample reported receiving information relating to diet prior to leaving hospital (44%). However a further 43% reported getting no information,

with less than 10% reporting they did not receive any because they did not need it. In the UK, 15% reported not needing any information (Table 3.2.20).

| Table 3.2.20 Information provided about changes to diet to improve health before leaving hospital. | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes | 19 | 49% | 13 | 48% | 13 | 52% | 14 | 33% | 59 | 44% | 644 | 39% |
| Did not get any information | 16 | 41% | 11 | 41% | 10 | 40% | 20 | 48% | 57 | 43% | 683 | 41% |
| Did not need any information | 3 | 8% | 2 | 7% | 1 | 4% | 6 | 14% | 12 | 9% | 254 | 15% |
| Don't know/ Can't remember | 1 | 2% | 1 | 4% | 1 | 4% | 2 | 5% | 5 | 4% | 82 | 5% |
| Overall N & % | 39 | 100% | 27 | 100% | 25 | 100% | 42 | 100% | 133 | 100% | 1663 | 100% |

Over 50% of patients reported receiving information about physical exercise to improve their health prior to leaving hospital (58%). However, one third of patients reported not getting any information. These findings mirror UK findings. (Table 3.2.21)

| Table 3.2.21 Information provided about physical exercise before leaving hospital | | | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes | 24 | 61% | 15 | 56% | 12 | 48% | 26 | 63% | 77 | 58% | 855 | 51% |
| Did not get any information | 14 | 36% | 10 | 37% | 11 | 44% | 9 | 22% | 44 | 33% | 531 | 32% |
| Did not need any information | 0 | 0% | 2 | 7% | 1 | 4% | 4 | 10% | 7 | 5% | 202 | 12% |
| Don't know/ Can't | 1 | 3% | 0 | 0% | 1 | 4% | 2 | 5% | 4 | 3% | 73 | 4% |

| | | | | | | | | | | | | |
|--------------------------|----|------|----|------|----|------|----|------|-----|------|------|------|
| remember | | | | | | | | | | | | |
| Overall N & % | 39 | 100% | 27 | 100% | 25 | 100% | 41 | 100% | 132 | 100% | 1661 | 100% |

Over 60% of patients stated that they did not smoke (64%) at the time of their stroke (although many had been former smokers (Table 3.2.22). Of those who did smoke 65% received information about stopping smoking but 28% received no information.

| Table 3.2.22 Information provided about stopping smoking prior to leaving hospital | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes | 12 | 75% | 3 | 50% | 7 | 54% | 6 | 75% | 28 | 65% | 276 | 67% |
| Did not get any information | 4 | 25% | 3 | 50% | 4 | 31% | 1 | 13% | 12 | 28% | 114 | 27% |
| Don't know/ Can't remember | 0 | 0% | 0 | 0% | 2 | 15% | 1 | 13% | 3 | 7% | 24 | 6% |
| Overall N & % | 16 | 100% | 6 | 100% | 13 | 100% | 8 | 101%* | 43 | 100% | 414 | 101% |

For a majority of patients, when the purpose of prescribed medication was explained, almost 60% understood it (44% understood it completely and 14% understood it to some extent)(Table 3.2.23). However, 34% of patients reported that the purpose of their prescribed medication was not explained to them. This compares with 18% in the UK.

| Table 3.2.23 Staff explanation on purpose of medicine understandable | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, completely | 20 | 53% | 8 | 32% | 10 | 42% | 18 | 47% | 56 | 45% | 798 | 48% |
| Yes, to some extent | 8 | 21% | 4 | 16% | 2 | 8% | 4 | 11% | 18 | 14% | 318 | 19% |
| No, it was | 9 | 24% | 11 | 44% | 10 | 42% | 13 | 34% | 43 | 34% | 292 | 18% |

| | | | | | | | | | | | | |
|---|----|------|----|------|----|------|----|------|-----|------|------|------|
| not explained | | | | | | | | | | | | |
| Did not need an explanation | 1 | 2% | 1 | 4% | 1 | 4% | 2 | 5% | 5 | 4% | 123 | 7% |
| Had no medicines to take home | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 65 | 4% |
| Don't know/ Can't remember | 0 | 0% | 0 | 0% | 0 | 0% | 1 | 3% | 1 | 1% | 65 | 4% |
| Family member received information on their behalf | 0 | 0% | 1 | 4% | 1 | 4% | 0 | 0% | 2 | 2% | NA | N/A |
| Overall N & % | 38 | 100% | 25 | 100% | 24 | 100% | 38 | 100% | 125 | 100% | 1661 | 100% |

A majority (63%) of patients reported receiving enough information about medicine usage prior to leaving hospital (Table 3.2.24). However, one fifth of patients (21%), reported not receiving information and would like to have received some. This compares with only 8% in the UK.

| Table 3.2.24 Adequate information provided about medicine usage prior to leaving hospital | | | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, enough information | 26 | 72% | 12 | 50% | 13 | 54% | 25 | 67% | 76 | 63% | 1054 | 64% |
| Some, but not enough | 1 | 3% | 3 | 13% | 1 | 4% | 1 | 3% | 6 | 5% | 204 | 12% |
| No information at all, and wanted some | 6 | 17% | 6 | 25% | 5 | 21% | 8 | 22% | 25 | 21% | 134 | 8% |
| Did not want any | 3 | 8% | 1 | 4% | 3 | 13% | 3 | 8% | 10 | 8% | 112 | 7% |

| | | | | | | | | | | | | |
|---|----|------|----|------|----|------|----|------|-----|------|------|------|
| information | | | | | | | | | | | | |
| had no medicines to take home | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 70 | 4% |
| Don't know/ Can't remember | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 77 | 5% |
| Family member received information on their behalf | 0 | 0% | 2 | 8% | 2 | 8% | 0 | 0% | 4 | 3% | N/A | N/A |
| Overall N & % | 36 | 100% | 24 | 100% | 24 | 100% | 37 | 100% | 121 | 100% | 1651 | 100% |

Seventy percent of patients were not informed about potential medication side effects before leaving hospital. This compares to 49% in the UK study (Table 3.2.25)

| Table 3.2.25. Information provided about medication side effects | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, completely | 8 | 21% | 5 | 21% | 4 | 17% | 3 | 8% | 20 | 16% | 294 | 18% |
| Yes, to some extent | 2 | 5% | 0 | 0% | 1 | 4% | 1 | 3% | 4 | 3% | 196 | 12% |
| No, was not told about side effects | 27 | 71% | 15 | 63% | 15 | 63% | 31 | 79% | 88 | 70% | 809 | 49% |
| Did not need an explanation | 1 | 3% | 1 | 4% | 1 | 4% | 3 | 8% | 6 | 5% | 203 | 12% |
| Had no medicines to take | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 69 | 4% |

| | | | | | | | | | | | | |
|---|----|------|----|------|----|------|----|------|-----|------|------|------|
| home | | | | | | | | | | | | |
| Don't know/ Can't remember | 0 | 0% | 3 | 12% | 2 | 8% | 1 | 3% | 6 | 5% | 80 | 5% |
| Family member received information on their behalf | 0 | 0% | 0 | 0% | 1 | 4% | 0 | 0% | 1 | 1% | N/A | N/A |
| Overall N & % | 38 | 100% | 24 | 100% | 24 | 100% | 39 | 100% | 125 | 100% | 1651 | 100% |

Compared to the Irish patient cohort, almost double the number of patients in the UK study reported receiving a contact name from the hospital if they were worried about their condition after they left hospital (53% versus 31%, respectively). Only 4% of the Irish patient cohort reported that this contact name was not needed (Table 3.2.26).

| Table 3.2.26 Contact name provided before leaving hospital if worried about condition post hospital | | | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes | 13 | 34% | 7 | 26% | 9 | 36% | 11 | 27% | 40 | 31% | 879 | 53% |
| Was not told who to contact | 19 | 50% | 18 | 66% | 13 | 52% | 26 | 65% | 76 | 58% | 476 | 29% |
| Don't know/ Can't remember | 3 | 8% | 1 | 4% | 1 | 4% | 2 | 5% | 7 | 5% | 107 | 6% |
| Was not necessary | 3 | 8% | 0 | 0% | 1 | 4% | 1 | 3% | 5 | 4% | 197 | 12% |
| Family member received information on their behalf | 0 | 0% | 1 | 4% | 1 | 4% | 0 | 0% | 2 | 2% | N/A | N/A |
| Overall N & % | 38 | 100% | 27 | 100% | 25 | 100% | 40 | 100% | 130 | 100% | 1659 | 100% |

Over half of patients said that they would have liked some information in relation to voluntary stroke support groups in their area, but did not receive any (52%). One fifth, however, said that while they did not receive the information, they did not want or need it.

| Table 3.2.27 Staff provision of information on voluntary support groups in your local area | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes | 6 | 15% | 1 | 4% | 6 | 27% | 7 | 18% | 20 | 16% | 666 | 42% |
| No, but would have liked some | 19 | 50% | 15 | 60% | 11 | 50% | 20 | 50% | 65 | 52% | 431 | 27% |
| No, but got information from somewhere else | 4 | 11% | 2 | 8% | 0 | 0% | 1 | 3% | 7 | 6% | 289 | 18% |
| Not sure/ Can't remember | 4 | 11% | 2 | 8% | 0 | 0% | 2 | 4% | 8 | 6% | 208 | 13% |
| Family member received information on their behalf | 0 | 0% | 1 | 4% | 0 | 0% | 0 | 0% | 1 | 1% | NA | NA |
| No, did not want information | 5 | 13% | 4 | 16% | 5 | 23% | 10 | 25% | 24 | 19% | NA | NA |
| Overall N & % | 38 | 100% | 25 | 100% | 22 | 100% | 40 | 100% | 125 | 100% | 1594 | 100% |

Over half of patients (53%) also indicated that they would have liked information about national stroke organisations and websites. Provision of information by staff to patients in relation to relevant websites and national stroke organizations was significantly more likely to happen when patients were in the younger age category than for patients aged over 65 ($\chi^2 = 11.834$, $df = 5$, $p \leq .037$) (Table 3.2.28).

| Table 3.2.28 Staff provide information about national stroke organizations/websites | | | | | | | | | | | | |
|---|-----------|-------------|-----------|-------------|-----------|-------------|-----------|-------------|------------|-------------|-------------|-------------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes | 5 | 14% | 0 | 0% | 6 | 28% | 2 | 5% | 13 | 11% | 472 | 30% |
| No, but would have liked some | 21 | 58% | 14 | 63% | 9 | 43% | 19 | 49% | 63 | 53% | 520 | 33% |
| No, but got information from somewhere else | 4 | 11% | 3 | 14% | 1 | 5% | 1 | 3% | 9 | 8% | 313 | 20% |
| Not sure/ Can't remember | 2 | 6% | 3 | 14% | 1 | 5% | 6 | 15% | 12 | 10% | 267 | 17% |
| No | 4 | 11% | 2 | 9% | 4 | 19% | 11 | 28% | 21 | 18% | NA | NA |
| Overall N & % | 36 | 100% | 22 | 100% | 21 | 100% | 39 | 100% | 118 | 100% | 1572 | 100% |

Over two-thirds (69%) of patients rated their stay in hospital as either very good or excellent. This profile is almost identical to that in the UK. Two per cent of patients reported it as poor or very poor (Table 3.2.29).

| Table 3.2.29 Patient rating of care received in hospital | | | | | | | | | | | | |
|--|-----------|-------------|-----------|-------------|-----------|-------------|-----------|-------------|------------|-------------|-------------|------------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Excellent | 12 | 32% | 8 | 31% | 7 | 31% | 18 | 44% | 45 | 35% | 556 | 33% |
| Very good | 11 | 30% | 12 | 46% | 7 | 31% | 13 | 32% | 43 | 34% | 606 | 36% |
| Good | 9 | 24% | 4 | 15% | 7 | 31% | 7 | 17% | 27 | 21% | 304 | 18% |
| Fair | 4 | 11% | 2 | 8% | 2 | 7% | 2 | 5% | 10 | 8% | 131 | 8% |
| Poor | 0 | 0% | 0 | 0% | 0 | 0% | 1 | 2% | 1 | 1% | 48 | 3% |
| Very poor | 1 | 3% | 0 | 0% | 0 | 0% | 0 | 0% | 1 | 1% | 23 | 1% |
| Overall N & % | 37 | 100% | 26 | 100% | 23 | 100% | 41 | 100% | 127 | 100% | 1668 | 99% |

V. Care after discharge from hospital

On discharge from hospital, over one-third of patients reported that they were never given any information in relation to follow-up services (34%). Others reported receiving information in hospital (14%) or some time after hospital discharge (5%), while some patients reported that they did not require any information (8%). Where follow-up services were provided, some patients reported receiving services immediately (39%), others reported a delay of 1-6 months in receiving services (10%), and some received no services at all (24%).

When post-hospital rehabilitation was being planned, 44% of patients indicated that their needs and wishes were taken into account at least to some extent. In the UK the comparable figure was 68% (Table 3.2.30).

| Table 3.2.30 Needs and wishes taken into account or discussed when planning your rehabilitation with health professionals | | | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, definitely | 12 | 32% | 6 | 25% | 6 | 25% | 7 | 21% | 31 | 26% | 727 | 44% |
| Yes, to some extent | 6 | 16% | 6 | 25% | 3 | 13% | 7 | 21% | 22 | 18% | 394 | 24% |
| Wishes were not taken into account | 8 | 22% | 3 | 13% | 6 | 25% | 9 | 26% | 26 | 22% | 76 | 5% |
| Have not had any rehabilitation | 11 | 30% | 9 | 37% | 9 | 37% | 11 | 32% | 40 | 34% | 403 | 25% |
| Overall N & % | 37 | 100% | 24 | 100% | 24 | 100% | 34 | 100% | 119 | 100% | 1600 | 98% |

When asked about services needed after leaving hospital, 39% of patients felt that services were not necessary (compared with 31% of UK patients). A further 40% of patients indicated that all (29%) or some (12%) of the services they needed were arranged. However, 17% of patients considered that services they needed were not put into place, similar to UK cohort findings of 10% of patients (Table 3.2.31).

| Table 3.2.31 Were the services you needed after leaving hospital arranged? | | | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, all the services needed | 11 | 31% | 7 | 30% | 9 | 38% | 8 | 22% | 35 | 29% | 695 | 43% |
| Yes, some of the services needed | 4 | 12% | 2 | 9% | 1 | 4% | 8 | 22% | 15 | 12% | 241 | 15% |
| No, but these services were needed | 8 | 23% | 4 | 18% | 5 | 20% | 3 | 8% | 20 | 17% | 162 | 10% |
| Was not necessary | 12 | 34% | 10 | 43% | 9 | 38% | 15 | 40% | 46 | 39% | 494 | 31% |
| The services were already in place before stroke | 0 | 0% | 0 | 0% | 0 | 0% | 3 | 8% | 3 | 3% | 18 | 1% |
| Overall N & % | 35 | 100% | 23 | 100% | 24 | 100% | 37 | 100% | 119 | 100% | 1610 | 100% |

In terms of communication from the hospital, 81% of patients stated that their GP had been given all necessary information. A further 5% stated that the GP was not given all necessary information, while 14% reported being unsure whether their GP had been informed. In the UK 64% of patients reported that their GP was adequately informed while 29% were unsure (Table 3.2.32).

| Table 3.2.32. Was the GP given all necessary information about national stroke organisations/websites | | | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes | 29 | 81% | 21 | 88% | 17 | 71% | 35 | 83% | 102 | 81% | 1060 | 64% |

| | | | | | | | | | | | | |
|---|----|------|----|------|----|------|----|------|-----|------|------|------|
| GP was not given all the necessary information | 3 | 8% | 1 | 4% | 1 | 4% | 1 | 2% | 6 | 5% | 119 | 7% |
| Don't know | 4 | 11% | 2 | 8% | 6 | 25% | 6 | 15% | 18 | 14% | 471 | 29% |
| Not registered with a GP | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | N/A | N/A |
| Overall N & % | 36 | 100% | 24 | 100% | 24 | 100% | 42 | 100% | 126 | 100% | 1650 | 100% |

Over three quarters (79%) of patients reported having no speech and language difficulties. Of those with speech and language difficulties, one-third reported getting sufficient help (31%), and a further one-fifth (21%) reporting getting some help in this area. However, almost half of those who needed help with speech and language difficulties (48%) reported that they did not get enough help in this area once they left hospital (Table 3.2.33).

| Table 3.2.33 Help with speaking difficulties after leaving hospital | | | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|-------------------|----------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, definitely | 0 | 0% | 2 | 40% | 3 | 38% | 4 | 44% | 9 | 31% | 245 | 43% |
| To some extent | 2 | 29% | 1 | 20% | 2 | 24% | 1 | 12% | 6 | 21% | 149 | 26% |
| Did not get enough help | 5 | 71% | 2 | 40% | 3 | 38% | 4 | 44% | 14 | 48% | 173 | 31% |
| Overall N & % | 7 | 100% | 5 | 100% | 8 | 100% | 9 | 100% | 29 | 100% | 567 | 100% |

Fifty per cent of patients had no mobility difficulties after leaving hospital. Of those reporting mobility problems, 57% reported receiving sufficient help (Table 3.2.34) and 21% received some help. Twenty two per cent of patients felt that they did not get enough treatment for mobility problems once they left hospital.

Table 3.2.34: Help with mobility after leaving hospital.

| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
|-------------------------------------|----------|------|---------|------|----------|------|---------|------|---------|------|------------|------|
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, definitely | 9 | 50% | 7 | 58% | 5 | 38% | 15 | 75% | 36 | 57% | 483 | 47% |
| Yes, to some extent | 2 | 11% | 2 | 17% | 4 | 31% | 5 | 25% | 13 | 21% | 302 | 30% |
| Did not get enough treatment | 7 | 39% | 3 | 25% | 4 | 31% | 0 | 0% | 14 | 22% | 237 | 23% |
| Overall N & % | 18 | 100% | 12 | 100% | 13 | 100% | 20 | 100% | 63 | 100% | 1022 | 100% |

The majority of participants stated that they did not have emotional issues after leaving hospital (64%). In the UK this figure was somewhat lower at 56%. Of those reporting emotional difficulties after leaving hospital, almost three-quarters (70%) reported not getting enough help and support (Table 3.2.35). Remaining patients experiencing emotional difficulties reported either receiving sufficient support (19%) or receiving support to some extent (11%).

Table 3.2.35 Help with emotional issues after leaving hospital.

| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
|--|----------|------|---------|------|----------|------|---------|------|---------|------|------------|------|
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes, definitely | 2 | 12% | 0 | 0% | 2 | 22% | 5 | 33% | 9 | 19% | 188 | 27% |
| Yes, to some extent | 1 | 6% | 1 | 17% | 1 | 11% | 2 | 13% | 5 | 11% | 229 | 32% |
| Did not get enough help and support | 14 | 82% | 5 | 83% | 6 | 67% | 8 | 54% | 33 | 70% | 292 | 41% |
| Overall N & % | 17 | 100% | 6 | 100% | 9 | 100% | 15 | 100% | 47 | 100% | 709 | 100% |

| Table 3.2.36: Need for aids or appliances after leaving hospital | | | | | | | | | | |
|--|----------|------|---------|------|----------|------|---------|------|---------|------|
| | 2004 | | | | 2006 | | | | Overall | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Yes | 7 | 21% | 10 | 40% | 8 | 33% | 23 | 56% | 48 | 39% |
| No | 27 | 79% | 15 | 60% | 16 | 67% | 18 | 44% | 76 | 61% |
| Overall N & % | 34 | 100% | 25 | 100% | 24 | 100% | 41 | 100% | 124 | 100% |

| Table 3.2.37 Current need for aids or equipment | | | | | | | | | | |
|---|----------|------|---------|------|----------|------|---------|------|---------|------|
| | 2004 | | | | 2006 | | | | Overall | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Yes | 5 | 15% | 4 | 17% | 3 | 13% | 9 | 24% | 21 | 18% |
| No | 29 | 85% | 19 | 83% | 20 | 87% | 29 | 76% | 97 | 82% |
| Overall N & % | 34 | 100% | 23 | 100% | 23 | 100% | 38 | 100% | 118 | 100% |

Over one-third of the patient sample (39%) needed aids or equipment after leaving hospital (Table 3.2.36), with 18% of the sample continuing to need these aids/equipment at time of interview (Table 3.2.37). Older patients were significantly more likely to have needed these aids ($X^2=6.946$, $df = 2$, $p \leq .031$). Of those requiring aids or equipment *de novo* after this stroke, a majority (58%) received them as soon as they were necessary. However, a quarter of patients who needed aids and equipment reported that they would have liked to have received them much sooner than they did (Table 3.2.38). Those over 65 were significantly more likely to receive aids and equipment as soon as they were necessary ($\chi^2 = 13.196$, $df = 4$, $p \leq .01$), women also significantly more likely to receive them in a timely manner ($\chi^2 = 10.806$, $df = 4$, $p \leq .029$).

| Table 3.2.38 Provision of aids/equipment after leaving hospital | | | | | | | | | | | | |
|---|----------|-----|---------|-----|----------|-----|---------|-----|---------|-----|------------|-----|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Got it as soon as they thought was necessary | 2 | 22% | 5 | 56% | 5 | 56% | 14 | 66% | 26 | 54% | 667 | 74% |
| Would have | 2 | 22% | 0 | 0% | 0 | 0% | 2 | 10% | 4 | 8% | 74 | 8% |

| | | | | | | | | | | | | |
|---|---|------|---|------|---|------|----|------|----|-----|-----|------|
| liked it a bit sooner | | | | | | | | | | | | |
| Would have liked it a lot sooner | 5 | 56% | 2 | 22% | 4 | 44% | 3 | 14% | 14 | 30% | 72 | 8% |
| The equipment/aids were already in place before stroke | 0 | 0% | 2 | 22% | 0 | 0% | 2 | 10% | 4 | 8% | 90 | 10% |
| Overall N & % | 9 | 100% | 9 | 100% | 9 | 100% | 22 | 100% | 48 | 100 | 903 | 100% |

Over one-third (33%) of patients reported not needing any help from health or social services and 3% were already in receipt of such help prior to this admission to hospital for stroke (Table 3.2.39). However, of the remaining 64% of patients, a sizeable majority (51%) of patients reported that they would have liked help in this area. This compares to less than a quarter (23%) of the UK sample.

Table 3.2.39 Help from health and social services

| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
|---------------------------------------|----------|------|---------|------|----------|------|---------|------|---------|------|------------|------|
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | N | % | N | % |
| | N | % | N | % | N | % | N | % | | | | |
| Yes | 5 | 13% | 1 | 4% | 5 | 21% | 5 | 13% | 16 | 13% | 455 | 29% |
| Would have liked help | 21 | 57% | 13 | 55% | 9 | 38% | 19 | 50% | 62 | 51% | 373 | 23% |
| Did not need any help | 11 | 30% | 8 | 33% | 8 | 33% | 14 | 37% | 41 | 33% | 539 | 34% |
| Was already receiving benefits | 0 | 0% | 2 | 8% | 2 | 8% | 0 | 0% | 4 | 3% | 222 | 14% |
| Overall N & % | 37 | 100% | 24 | 100% | 24 | 100% | 38 | 100% | 123 | 100% | 1589 | 100% |

Forty-one per cent of patients stated that they had received help in the last two weeks for everyday activities (Table 3.2.40). This appears to be rather less than the UK figures (56%). Significant differences were found in terms of age ($\chi^2 =$

3.995, df = 1, p ≤ .05) and gender ($\chi^2 = 6.948$, df = 1, p ≤ .01), with significantly more of those over 65 and females requiring help.

| Table 3.2.40 Receipt of help from another person for everyday activities in the last 2 weeks. (N = 117) | | | | | | | | | | | | |
|--|----------|------|---------|------|----------|------|---------|------|---------|------|------------|------|
| | 2004 | | | | 2006 | | | | Overall | | UK figures | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | | |
| | N | % | N | % | N | % | N | % | N | % | N | % |
| Yes | 12 | 32% | 10 | 40% | 7 | 28% | 23 | 58% | 52 | 41% | 927 | 56% |
| No | 25 | 68% | 15 | 60% | 18 | 72% | 17 | 42% | 75 | 59% | 732 | 44% |
| Overall N & % | 37 | 100% | 25 | 100% | 25 | 100% | 40 | 100% | 127 | 100% | 1659 | 100% |

In terms of overall ratings of community care since leaving hospital, two-thirds of patients (68%) reported these to be good, very good, or excellent (Table 3.2.41). However, a quarter of patients reported them to be poor (19%) or very poor (6%).

| Table 3.2.41 Overall rating of community care received since leaving hospital | | | | | | | | | | | |
|--|----------|------|---------|------|----------|------|---------|------|---------|------|--|
| | 2004 | | | | 2006 | | | | Overall | | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | | |
| | N | % | N | % | N | % | N | % | N | % | |
| Excellent | 3 | 38% | 0 | 0% | 2 | 40% | 3 | 27% | 8 | 26% | |
| Very good | 1 | 12% | 2 | 28% | 1 | 20% | 4 | 36% | 8 | 26% | |
| Good | 1 | 12% | 2 | 28% | 1 | 20% | 1 | 9% | 5 | 16% | |
| Fair | 0 | 0% | 0 | 0% | 0 | 0% | 2 | 18% | 2 | 6% | |
| Poor | 3 | 38% | 2 | 28% | 1 | 20% | 0 | 0% | 6 | 19% | |
| Very poor | 0 | 0% | 1 | 14% | 0 | 0% | 1 | 9% | 2 | 6% | |
| Overall N & % | 8 | 100% | 7 | 100% | 5 | 100% | 11 | 100% | 31 | 100% | |

3.3. General Health: Physical & Psychological status

Table 3.3.1 presents the results from the measures of self-rated health and comparative health, physical function (Barthel Index), vulnerability (VES),

depression (HADS-D), language comprehension (FAST) and cognitive function (AMT).

Self-ratings of health yielded an overall mean score of 2.1, with a possible range of 1-5. On this measure higher numbers indicate poorer health. Thus, patients in this survey were rating their health, on average, as good. Within group comparisons based on time since stroke, age and gender indicated some variation in scores (see tables 3.3.3 and 3.3.5), but no significant differences were found.

On the comparative health scale the overall mean score was 1.8. This measure is scored in the same way as self-rated health, indicating that on average people considered their health compared to other individuals who had a stroke was between good and excellent. No patient stated that their comparative health was very poor. Again, within-group comparisons based on time since stroke, age and gender indicated some variation in scores (see tables 3.3.3 and 3.3.5), but no significant differences emerged.

| Table 3.3.1 Scores based on year of stroke and patient age | | | | | |
|---|-----------------|----------------|-----------------|----------------|-----------------|
| | 2004 | | 2006 | | Overall Scores |
| | Under 65 | Over 65 | Under 65 | Over 65 | |
| | Mean (SD) | Mean (SD) | Mean (SD) | Mean (SD) | Mean Score (SD) |
| Self-Rated Health | 2.4 (0.86) | 2.1 (0.77) | 2.2 (1.05) | 2.0 (8.1) | 2.1 (0.87) |
| Comparative Health | 1.8 (0.90) | 1.8 (0.59) | 1.7 (0.70) | 1.8 (0.57) | 1.8 (0.71) |
| Barthel | 95 (11.87) | 85 (24.41) | 96.0 (8.97) | 88.5 (22.45) | 91.3 (18.5) |
| VES | 2.2 (2.29) | 4.6 (3.01) | 2.8 (2.88) | 4.4 (3.23) | 3.5 (3.01) |
| HADS (depression) | 5.9 (4.20) | 4.1 (3.21) | 6.7 (4.56) | 5.6 (3.19) | 5.6 (3.81) |
| FAST | 9.7 (0.72) | 9 (2.05) | 9 (2.21) | 8.7 (2.03) | 9.1 (1.84) |
| AMT | 9.3 (1.67) | 9.5 (1.07) | 9.3 (1.46) | 8.9 (1.81) | 9.2 (1.57) |

The assessment of physical function using the Barthel Index yielded an overall mean score of 91.3. This measure is scored on a scale of 0-100 (for purposes of this study; can also be scored from 0-20) with higher scores indicating greater independence. Uyttenboogaart et al. (1987) suggest cut-off points on the Barthel

in relation to the different levels of the Modified Rankin Scale. The cut-off for mRS1 (no significant disability despite symptoms) is 95 and for mRS2 (slight disability) is 90. For mRS3 (moderate disability) the suggested cut-off point is 75. A majority of patients (62%) in this sample had no significant disability (Table 3.3.2). However, just over a quarter of the population had moderate (14%) or severe (12%) levels of disability. No significant differences were found with regard to age, gender or year of stroke.

| Table 3.3.2 Barthel Index Scores : Category Membership (n for each category) | | | | | | | | | | | |
|---|---|----------|-----|---------|-----|----------|-----|---------|-----|---------|-----|
| Range of scores | Modified Rankin Scale Category (cut off) | 2004 | | | | 2006 | | | | Overall | |
| | | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | | N | % | N | % | N | % | N | % | N | % |
| 0-75 | Incorporates moderately severe and severe | 3 | 8 | 5 | 21 | 1 | 4 | 6 | 16 | 15 | 12 |
| 76-90 | Moderate disability (75) | 4 | 11 | 5 | 21 | 4 | 17 | 4 | 10 | 17 | 14 |
| 91-95 | Slight disability (90) | 4 | 11 | 4 | 17 | 3 | 13 | 4 | 10 | 15 | 12 |
| 96 + | No significant disability (95) | 26 | 70 | 10 | 41 | 16 | 66 | 25 | 64 | 77 | 62 |
| Total | | 37 | 100 | 24 | 100 | 24 | 100 | 39 | 100 | 124 | 100 |

On the VES scale the overall mean score was 3.5. Higher scores on this measure indicate increased vulnerability, with a maximum score of 10. The suggested cut off point is 3, above which the person is deemed to have increased vulnerability and thus at greater risk of death or physical decline (Saliba et al., 2001). There were significant differences in terms of age category ($\chi^2= 29.959$, $df = 10$, $p \leq .001$) when looking at overall scores, those over 65 significantly more vulnerable than those under 65. Based on a cut-off score of 3 above which a person is deemed to be vulnerable, over half (57%) of the patient population were in the vulnerable range. Levels of vulnerability were significantly higher in women ($\chi^2 = 5.927$, $df = 1$, $p \leq .015$) with 65% of women in the vulnerable category compared to 41% of men.

| Table 3.3.4 VES scores: Category Membership (n for each category) (N = 111) | | | | | |
|--|----------|---------|----------|---------|---------|
| | 2004 | | 2006 | | Overall |
| | Under 65 | Over 65 | Under 65 | Over 65 | |
| Non-vulnerable category | 20 | 9 | 9 | 16 | 54 |
| Vulnerable category | 13 | 16 | 11 | 17 | 57 |

The overall mean score for the depression scale of the HADS was 5.6. Patient scores ranged between 0 and 17, with higher scores indicating increased depression. The suggested cut-off point on the HADS depression scale indicating probable depression is ≥ 8 (Olsson et al. 2005). In this survey, a majority of patients (70%) were not depressed, while 30% had scores in the depressed range. No differences were found in terms of age, gender or year of stroke.

On the FAST (comprehension) the average score is 9.0. The suggested cut off point on this scale is 27/30 for patients over 60 (Enderby et al. 1987). As we employed only 10 items this was translated to a cut off point of 9/10. Using this cut-off, on average patients involved in this survey were not experiencing aphasia. Nineteen patients were below the cut-off score, indicating some speech and language difficulties, while 78% were not. No significant differences were found within the group, based on age, time since stroke, or gender.

Brief cognitive assessment using the AMT indicated an overall mean score of 9.2. The suggested cut-off point for this measure is 8, below which the person is considered to be cognitively impaired (Jitapunkul et al. 1991). Therefore, on average, patients in this survey were not cognitively impaired. However, scores ranged between 3 and 10, with 8% of the sample falling below the cut-off score of the AMT, indicating cognitive impairment. No significant differences were found in terms of gender, age or year of stroke.

3.4. Service Access

Patients were asked about their need for and ability to avail of a range of services in the community. Where services were needed and received, patients were asked whether they had to pay for the service, either in full or in part. Results are presented separately for patients who had stroke in the last 6-12 months and 24-36 months in Tables 3.4.1 and 3.4.2, respectively.

Significant age differences were found in relation to need for public health nurse ($\chi^2 = 7.921$, $df = 1$, $p \leq .005$), home help ($\chi^2 = 11.559$, $df = 1$, $p \leq .001$), meals on wheels ($\chi^2 = 6.333$, $df = 2$, $p \leq .042$), and chiropody ($\chi^2 = 14.390$, $df = 1$, $p \leq .001$), in all cases patients over 65 indicating need for the service to a significantly greater extent than those aged under 65. Significant differences were also found in relation to year of stroke for the following services: public health nurse ($\chi^2 = 4.281$, $df = 1$, $p \leq .039$), occupational therapist ($\chi^2 = 4.445$, $df = 1$, $p \leq .035$), speech therapist ($\chi^2 = 9.833$, $df = 1$, $p \leq .002$) and hospital-based therapist ($\chi^2 = 9.724$, $df = 1$, $p \leq .002$), in each case patients having stroke in the recent past (6-12 months) indicating significantly greater need for these services than those more long-term following stroke (24-36 months).

Significant gender differences were found in relation to public health nurse ($\chi^2 = 6.253$, $df = 1$, $p \leq .012$), home help ($\chi^2 = 11.635$, $df = 1$, $p \leq .001$), and chiropody ($\chi^2 = 5.733$, $df = 1$, $p \leq .017$), in each case women indicating greater need than men.

The profile of most commonly needed services in the long- and short-term patient cohorts were similar (Tables 3.4.1 and 3.4.2, respectively). The most commonly needed services were GP (96%), outpatient medical appointments (66%), optician (57%) and physiotherapy (53%). Of those patients who needed a particular service, the proportion of those who received it ranged between 75%-100% for most services. However, of those who needed hearing services only 50% received them. Similarly only 40% of those who needed counselling and 56% of those who needed psychology services received these services.

Table 3.4.1: Service Access for long-term patients with stroke

| | 2004 | | | | | | | | | |
|--------------------------------------|-------------------|---------------------------------|-----------------------------------|--------------|--------------|------------------|---------------------------------|-----------------------------------|--------------|-----|
| | Under 65 (n = 39) | | | | | Over 65 (n = 28) | | | | |
| | Need % | Receive (% of those who needed) | Paid by (% of those who received) | | | Need % | Receive (% of those who needed) | Paid by (% of those who received) | | |
| Paid in full | | | Paid in part | Medical Card | Paid in full | | | Paid in part | Medical card | |
| GP | 97 | 100 | 32 | 0 | 64 | 89 | 100 | 6 | 6 | 83 |
| Respite care | 16 | 80 | 50 | 0 | 50 | 23 | 83 | 40 | 20 | 40 |
| Public Health Nurse/District Nurse | 27 | 75 | 0 | 0 | 80 | 48 | 92 | 0 | 0 | 78 |
| Personal care attendant | 9 | 33 | 0 | 0 | 100 | 15 | 67 | 0 | 50 | 50 |
| Home Help | 15 | 60 | 33 | 0 | 67 | 41 | 90 | 12 | 12 | 63 |
| Social Worker | 12 | 100 | 0 | 0 | 100 | 23 | 100 | 0 | 0 | 75 |
| Meals on Wheels | 0 | N/A | N/A | N/A | N/A | 8 | 50 | 100 | 0 | 0 |
| Chiropody services | 18 | 67 | 75 | 0 | 25 | 56 | 79 | 30 | 0 | 70 |
| Physiotherapy services | 33 | 83 | 0 | 0 | 67 | 58 | 69 | 14 | 0 | 86 |
| Occupational Therapy | 20 | 100 | 50 | 0 | 50 | 32 | 71 | 0 | 0 | 75 |
| Speech Therapy | 11 | 75 | 0 | 0 | 0 | 4 | 100 | 0 | 0 | 100 |
| Dietician Services | 35 | 83 | 0 | 0 | 60 | 32 | 100 | 0 | 0 | 100 |
| Optician Services | 53 | 72 | 33 | 8 | 42 | 69 | 89 | 25 | 12 | 63 |
| Dental services | 44 | 75 | 43 | 0 | 43 | 27 | 100 | 60 | 0 | 40 |
| Hearing Services | 11 | 75 | 0 | 0 | 100 | 8 | 50 | 0 | 0 | 100 |
| Psychological Services | 11 | 0 | N/A | N/A | N/A | 8 | 0 | N/A | N/A | N/A |
| Counselling Services | 17 | 0 | N/A | N/A | N/A | 8 | 0 | N/A | N/A | N/A |
| Hospital based Therapist, specify___ | 18 | 100 | 0 | 0 | 33 | 17 | 75 | 0 | 0 | 100 |

| | | | | | | | | | | |
|---------------------------------|----|-----|-----|-----|-----|----|-----|-----|-----|-----|
| Hospital based Social Worker | 6 | 100 | 0 | 0 | 100 | 9 | 100 | 0 | 0 | 100 |
| Day Hospital | 0 | N/A | N/A | N/A | N/A | 13 | 67 | 0 | 0 | 0 |
| Day-care | 6 | 100 | 0 | 0 | 0 | 17 | 50 | 0 | 0 | 0 |
| Outpatient appointments Medical | 60 | 100 | 10 | 0 | 60 | 72 | 100 | 0 | 0 | 100 |
| Outpatient appointments Therapy | 6 | 100 | 0 | 0 | 100 | 25 | 83 | 0 | 0 | 0 |
| Other. Specify____ | 3 | 100 | 0 | 0 | 0 | 0 | N/A | N/A | N/A | N/A |

Patients who reported that they needed a service were then asked whether or not they had received the service. In tables 3.4.1 and 3.4.2 the figures for those who received the service are reported as a percentage of those who had originally stated that they needed the service. Of note is that, of patients who had their stroke in 2004 and stated that they needed psychology or counselling services, none received these services. This figure had increased for those patients who had their stroke in 2006 (67-83% depending on age group).

Table 3.4.2: Service Access for short-term patients with stroke

| | 2006 | | | | | | | | | |
|------------------------------------|-------------------|---------------------------------|-----------------------------------|--------------|--------------|------------------|---------------------------------|-----------------------------------|--------------|-----|
| | Under 65 (n = 25) | | | | | Over 65 (n = 42) | | | | |
| | Need % | Receive (% Of those who needed) | Paid by (% of those who received) | | | Need % | Receive (% Of those who needed) | Paid by (% of those who received) | | |
| Paid in full | | | Paid in part | Medical Card | Paid in full | | | Paid in part | Medical card | |
| GP | 96 | 100 | 33 | 0 | 61 | 100 | 97 | 4 | 0 | 96 |
| Respite care | 17 | 100 | 0 | 0 | 33 | 21 | 100 | 20 | 0 | 60 |
| Public Health Nurse/District Nurse | 40 | 100 | 14 | 0 | 71 | 66 | 100 | 0 | 0 | 100 |
| Personal care attendant | 4 | 100 | 0 | 0 | 0 | 11 | 75 | 0 | 0 | 50 |
| Home Help | 13 | 100 | 0 | 33 | 33 | 41 | 100 | 25 | 0 | 67 |
| Social Worker | 20 | 100 | 0 | 0 | 33 | 16 | 100 | 0 | 0 | 100 |
| Meals on Wheels | 4 | 100 | 0 | 0 | 0 | 15 | 80 | 33 | 0 | 33 |
| Chiropody services | 32 | 100 | 89 | 0 | 0 | 62 | 87 | 39 | 0 | 44 |
| Physiotherapy services | 60 | 93 | 22 | 0 | 56 | 62 | 100 | 0 | 0 | 76 |
| Occupational Therapy | 42 | 100 | 0 | 0 | 75 | 43 | 100 | 0 | 0 | 71 |
| Speech Therapy | 44 | 82 | 14 | 0 | 43 | 21 | 100 | 0 | 0 | 100 |
| Dietician Services | 52 | 100 | 25 | 0 | 31 | 41 | 67 | 0 | 0 | 100 |
| Optician Services | 48 | 83 | 25 | 12 | 63 | 58 | 73 | 25 | 0 | 63 |
| Dental services | 36 | 89 | 57 | 0 | 43 | 30 | 100 | 22 | 0 | 67 |

| | | | | | | | | | | |
|-----------------------------------|----|-----|-----|-----|-----|----|-----|----|---|-----|
| Hearing Services | 12 | 33 | 0 | 0 | 100 | 24 | 44 | 67 | 0 | 33 |
| Psychological Services | 28 | 67 | 0 | 0 | 67 | 15 | 83 | 33 | 0 | 33 |
| Counselling Services | 20 | 67 | 0 | 0 | 0 | 13 | 80 | 0 | 0 | 50 |
| Hospital based Therapist, specify | 33 | 88 | 0 | 0 | 100 | 50 | 100 | 0 | 0 | 100 |
| Hospital based Social Worker | 12 | 100 | 0 | 0 | 67 | 18 | 100 | 0 | 0 | 0 |
| Day Hospital | 12 | 100 | 0 | 0 | 100 | 11 | 100 | 0 | 0 | 100 |
| Day-care | 12 | 100 | 0 | 0 | 50 | 16 | 100 | 0 | 0 | 50 |
| Outpatient appointments Medical | 72 | 94 | 13 | 0 | 63 | 63 | 100 | 0 | 0 | 100 |
| Outpatient appointments Therapy | 16 | 100 | 0 | 0 | 100 | 16 | 100 | 0 | 0 | 100 |
| Other. Specify | 0 | N/A | N/A | N/A | N/A | 38 | 100 | 0 | 0 | 0 |

Where services were availed of, patients who had received services were asked to indicate if they had paid for services. For those over 65, services were provided under the medical card scheme in a majority of cases. However, in many cases, those under 65 and those between 65 and 70 paid themselves for services, either in full or in part.

Where patients indicated that they needed a service, but were unable to avail of it, they were asked to outline the reasons for this inability to access a service. Reasons provided are detailed in Tables 3.4.3. The most common reasons reported for not being able to avail of services were that the service was not available or that the patient didn't know about it.

| Table 3.4.3 Service Access: Unable to avail of service | | | | | | | | |
|--|---|--------------------|---|--------------------|---|--------------------|---|--------------------|
| | 2004 | | | | 2006 | | | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | |
| | Wanted to Avail (% of those not availing) | Main Reason Unable | Wanted to Avail (% of those not availing) | Main Reason Unable | Wanted to Avail (% of those not availing) | Main Reason Unable | Wanted to Avail (% of those not availing) | Main Reason Unable |
| GP | 0 | N/A | 25 | Not Helpful | 0 | N/A | 75 | Transport |
| Respite care | 3 | Didn't know | 12 | Not available | 0 | N/A | 12 | Waiting list |
| Public Health Nurse/District Nurse | 15 | Not available | 23 | Not available | 0 | N/A | 12 | |

| | | | | | | | | |
|--------------------------------------|----|-------------------|----|----------------|----|---------------|----|-------------------|
| Personal care attendant | 3 | | 0 | N/A | 0 | N/A | 3 | Didn't know |
| Home Help | 10 | Didn't know | 0 | N/A | 5 | | 5 | Not available |
| Social Worker | 0 | N/A | 0 | N/A | 5 | | 0 | N/A |
| Meals on Wheels | 0 | N/A | 6 | Not available | 9 | Didn't know | 3 | Not available |
| Chiropody services | 7 | Didn't know | 43 | Never heard of | 7 | | 33 | Not available |
| Physiotherapy services | 19 | Not available | 23 | Not available | 18 | Didn't know | 22 | Not available |
| Occupational Therapy | 0 | N/A | 7 | | 0 | N/A | 0 | N/A |
| Speech Therapy | 0 | N/A | 0 | N/A | 7 | | 4 | Transport |
| Dietician Services | 14 | Didn't know/avail | 0 | N/A | 0 | N/A | 14 | Didn't know/avail |
| Optician Services | 25 | Didn't know | 25 | Not available | 21 | Didn't know | 32 | Transport |
| Dental services | 18 | Didn't know | 6 | | 7 | | 0 | N/A |
| Hearing Services | 6 | Didn't know | 0 | N/A | 5 | Not available | 7 | |
| Psychological Services | 9 | Didn't know | 0 | N/A | 22 | Didn't know | 7 | |
| Counselling Services | 12 | Didn't know | 5 | Not available | 20 | Didn't know | 7 | |
| Hospital based Therapist, specify___ | 0 | N/A | 6 | Not available | 6 | Not available | 9 | Transport |
| Hospital based Social Worker | 0 | N/A | 0 | N/A | 0 | N/A | 0 | N/A |
| Day Hospital | 0 | N/A | 6 | Not available | 0 | N/A | 0 | N/A |
| Day-care | 3 | Not helpful | 6 | Not available | 0 | N/A | 0 | N/A |
| Outpatient appointments Medical | 11 | Didn't know | 25 | Not available | 20 | | 20 | Transport |
| Outpatient appointments Therapy | 6 | Didn't know | 6 | Not available | 0 | N/A | 4 | |
| Other. Specify___ | 4 | Didn't know | 0 | N/A | 0 | N/A | 0 | N/A |

Tables 3.4.4 and 3.4.5 indicate the proportion of patients in the survey who had medical card or medical insurance cover. A majority of patients in the over 65 age group (91%) had a medical card, significantly more than in the younger patient group ($\chi^2=18.817$, $df = 3$, $p \leq .001$), reflecting entitlement to a medical card over age 70. Similarly, a higher percentage of patients over 65 had medical insurance cover (42%) compared with patients under 65 years (34%).

Eight people in the overall sample had neither medical card nor private health insurance. All of these were in the under 65 age group.

| Table 3.4.4 Holder of Medical Card | | | | | | |
|---|-----------------|----------|----------------|----------|----------------|----------|
| | Under 65 | | Over 65 | | Overall | |
| | N | % | N | % | N | % |
| Holder of Medical Card | 31 | 56% | 54 | 91% | 85 | 74% |
| On someone else medical card | 1 | 2% | 0 | 0% | 1 | 1% |
| Not covered | 23 | 42% | 5 | 9% | 28 | 25% |
| Overall N & % | 55 | 100% | 59 | 100% | 114 | 100% |

| Table 3.4.5 Holder of private health insurance | | | | | | |
|---|-----------------|----------|----------------|----------|----------------|----------|
| | Under 65 | | Over 65 | | Overall | |
| | N | % | N | % | N | % |
| Private insurance in own name | 13 | 24% | 23 | 43% | 36 | 33% |
| Private insurance through family member | 7 | 13% | 1 | 2% | 8 | 8% |
| Not medically insured | 34 | 63% | 30 | 55% | 64 | 59% |
| Overall N & % | 54 | 100% | 54 | 100% | 108 | 100% |

3.5. Transport Issues / Employment

Issues relating to driving, transportation and employment were explored. Two-thirds of the sample overall were able to drive, with significantly more men than women indicating that they could drive ($\chi^2 = 40.417$, $df = 1$, $p \leq .001$) (Table 3.5.1). Almost two-thirds of these patients (65%) were driving prior to their stroke. There were significant differences in terms of age ($\chi^2 = 6.224$, $df = 1$, $p \leq .013$), with significantly more of those under 65 driving prior to stroke than those over 65. Significantly more men than women were driving prior to stroke, a finding probably related to the lower percentage of women who were able to drive ($\chi^2 = 22.514$, $df = 1$, $p \leq .0001$). Following stroke, 29% of those driving prior to stroke had stopped driving, with significant age differences (younger more than older: $\chi^2 = 10.369$, $df = 2$, $p \leq .006$) and gender differences (men more than women: $\chi^2 = 7.758$, $df = 2$, $p \leq .021$) persisting. There were significant differences in those driving prior to and post stroke ($\chi^2 = 30.343$, $df = 2$, $p \leq .001$).

Table 3.5.1 Patients' driving profile

| | 2004 | | | | 2006 | | | | Overall | |
|---------------------------------------|----------|-----|---------|-----|------|-----|--------|-----|---------|-----|
| | Under 65 | | Over 65 | | Male | | Female | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Patients who can drive | 30 | 79% | 14 | 54% | 16 | 64% | 25 | 60% | 85 | 65% |
| Driving prior to stroke | 24 | 77% | 14 | 78% | 11 | 52% | 19 | 54% | 68 | 65% |
| Driving since stroke | 23 | 79% | 8 | 42% | 11 | 58% | 11 | 37% | 53 | 55% |
| No longer driving since stroke | 3 | 13% | 3 | 30% | 4 | 29% | 9 | 47% | 19 | 29% |

Of those who were not driving prior to stroke, reasons for not driving are detailed in Table 3.5.2. For the majority, reasons were not related to stroke e.g. no longer being able to get a license. The most commonly identified reason otherwise was not driving on medical advice, followed by stroke related reasons and lack of access to a car.

Table 3.5.2 Reasons for not driving prior to stroke

| | 2004 | | | | 2006 | | | | Overall | |
|--|----------|------|---------|------|----------|------|---------|------|---------|------|
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| No access to car | 1 | 14% | 1 | 13% | 0 | 0% | 0 | 0% | 2 | 7% |
| Not driving due to cost | 1 | 14% | 0 | 0% | 0 | 0% | 0 | 0% | 1 | 4% |
| Not driving due to insurance problems | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% | 0 | 0% |
| Not driving on medical advice | 0 | 0% | 2 | 25% | 0 | 0% | 1 | 11% | 3 | 11% |
| Stroke related | 0 | 0% | 1 | 13% | 1 | 25% | 0 | 0% | 2 | 7% |
| Not stroke related | 5 | 72% | 4 | 49% | 3 | 75% | 8 | 89% | 20 | 71% |
| Overall N & % | 7 | 100% | 8 | 100% | 4 | 100% | 9 | 100% | 28 | 100% |

Of those not driving since stroke, reasons are detailed in Table 3.5.3. For a majority (48%) the reason for not driving since their stroke was described as either directly stroke stroke-related (37%) or based on medical advice (11%). Some were not driving for reasons that were described as not stroke related, such as no longer being able to get a license.

| Table 3.5.3. Reasons for not driving since stroke | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|
| | 2004 | | | | 2006 | | | | Overall | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| No access to car | 1 | 17% | 0 | 0% | 0 | 0% | 0 | 0% | 1 | 3% |
| Not driving due to cost | 1 | 17% | 0 | 0% | 0 | 0% | 0 | 0% | 1 | 3% |
| Not driving due to insurance problems | 0 | 0% | 0 | 0% | 0 | 0% | 1 | 7% | 1 | 3% |
| Not driving on medical advice | 0 | 0% | 1 | 13% | 1 | 17% | 2 | 13% | 4 | 11% |
| Stroke related | 2 | 33% | 5 | 62% | 2 | 33% | 4 | 27% | 13 | 37% |
| Not stroke related | 2 | 33% | 2 | 25% | 3 | 50% | 8 | 53% | 15 | 0% |
| Overall n & % | 6 | 100% | 8 | 100% | 6 | 100% | 15 | 100% | 35 | 100% |

The overall profile of transportation used by patients is detailed in table 3.5.4. A variety of types of transport were used, with getting a lift from family or friends the most common (71%), followed by walking (53%), using public transport (48%), and driving (41%). Overall, 30% of patients indicated that transport had become a problem since their stroke, somewhat moreso for younger patients (35%) than for older patients (26%).

| Table 3.5.4 Types of transportation used in the last 6 months | | | | | | | | | | |
|--|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|
| | 2004 | | | | 2006 | | | | Overall | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Walking (N = 121) | 20 | 56% | 15 | 58% | 15 | 68% | 14 | 37% | 64 | 53% |
| Driving myself (N = 120) | 22 | 61% | 9 | 36% | 10 | 50% | 8 | 21% | 49 | 41% |

| | | | | | | | | | | |
|--|----|-----|----|-----|----|-----|----|-----|----|-----|
| Getting lift with family or friends (N = 122) | 22 | 60% | 20 | 80% | 16 | 73% | 28 | 74% | 86 | 71% |
| Use public transport (N = 120) | 19 | 53% | 10 | 44% | 12 | 55% | 16 | 41% | 57 | 48% |
| Other (e.g. plane, taxi) (N = 100) | 7 | 25% | 5 | 28% | 4 | 19% | 7 | 21% | 23 | 23% |
| Transport problematic since stroke (N = 124) | 11 | 31% | 8 | 31% | 8 | 35% | 10 | 26% | 37 | 30% |

Finally, patients were asked about their past and current employment status, details of which are provided in Table 3.5.5.

Table 3.5.5 Employment prior to stroke

| | 2004 | | | | 2006 | | | | Overall | |
|---|----------|-----|---------|-----|----------|-----|---------|-----|---------|-----|
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | N | % | N | % | N | % | N | % | N | % |
| Full time employment prior to stroke (N = 104) | 22 | 67% | 7 | 30% | 10 | 56% | 8 | 27% | 47 | 45% |
| Part time employment prior to stroke (N = 104) | 6 | 18% | 3 | 13% | 2 | 11% | 4 | 13% | 15 | 14% |
| Employment status changed since stroke (e.g. gave up work, was off work for long period of time) (N = 102) | 20 | 63% | 7 | 30% | 8 | 44% | 7 | 24% | 42 | 41% |

Overall, almost half of the sample (46%) were employed either full- or part-time prior to stroke. As might be expected, significantly more of the younger patient cohort than the older was employed ($\chi^2= 14.429$, $df = 3$, $p\leq 0.002$). In addition, significantly more men than women were in full-time employment ($\chi^2= 14.292$, $df = 3$, $p\leq 0.003$). Following stroke, 40% of patients reported that their employment status had changed, significantly more so for younger patients ($\chi^2= 9.292$, $df = 2$, $p\leq 0.01$).

3.6. Additional patient comments:

At the end of the interview, patients were asked if they would like to make any additional comments in relation to the positive and negative aspects of stroke care received since leaving hospital. In terms of positive aspects of stroke care, a majority of patients reported being well looked after, particularly in hospital. A

majority of patients stated that they were happy/satisfied with care, especially in relation to hospital care and rehabilitation facilities, for those who had attended these facilities.

In terms of areas of stroke care in the community that could be improved, the most commonly identified issues were increased availability of services, especially physiotherapy, speech and language therapy, and emotional support/psychology. Many patients spoke about their attendance at rehab facilities post discharge from hospital. Patients reported a need for more information and help with entitlements, and more information in relation to available services. Patients highlighted a lack of information on what stroke means and what to expect after a stroke. They pointed to the need to have a 'central' person with whom they could get in contact if needed. The lack of follow-up once they came home was highlighted. Many patients reported feeling isolated once they came home and did not know how to address this. Many patients spoke about depression post-stroke and their use of anti-depressants as a result, and highlighted the lack of, and need for, emotional support.

Chapter 4: Results II: Carers

Of the 135 (patients who were RIP not included in these figures) participating in the patient survey, 53% (n = 72) of patients had a carer who also participated in the survey. Of the remaining patients for whom a carer was not involved, the primary reason for non-involvement was that the patient reported not needing a carer (45%). A further 31% did not want a carer involved in the survey, but did not provide a reason. Five patients (7%) reported that they needed a carer but did not have one. Some carers either were unavailable due to work or other demands (13%) or did not want to participate (4%).

4.1: Carer Profile

I. Carer demographic profile

Of patients for whom a carer was available (N=101; 77% of total patient sample) and who were invited to participate in the survey, 72 agreed to take part and were interviewed, a response rate of 71%. Of these, 78% were female. The majority of carers were married (80%), approximately half of whom were married to the patient. A majority (90%) of carers lived with others, 9% lived alone.

In terms of relationship of carers to the individual with stroke, 55% were the patient's spouse (35% the patient's wife, 17% the patient's husband). A further 21% of carers were a daughter of the patient, the remainder composed of the patient's son, grandchild, friend or other (e.g. daughter-in-law). A majority (69%) of carers were under 65 while 31% were in the older age category.

Table 4.1.1 outlines the carer profile subdivided by age of the patient with stroke and year of stroke.

| Table 4.1.1. Profile of stroke carer sample. | | | | | | | | | | |
|---|-----------------|----------|----------------|----------|-----------------|----------|----------------|----------|----------------|----------|
| | 2004 | | | | 2006 | | | | Overall | |
| | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| Gender | N | % | N | % | N | % | N | % | N | % |
| <i>Male</i> | 1 | 8% | 3 | 25% | 5 | 29% | 7 | 23% | 16 | 22% |
| <i>Female</i> | 11 | 92% | 9 | 75% | 12 | 71% | 24 | 77% | 56 | 78% |
| Marital Status | | | | | | | | | | |
| <i>Married</i> | 9 | 75% | 10 | 83% | 14 | 82% | 23 | 80% | 56 | 80% |
| <i>Widowed</i> | 1 | 8% | 2 | 17% | 0 | 0% | 4 | 14% | 2 | 3% |
| <i>Separated/divorced</i> | 0 | 0% | 0 | 0% | 1 | 6% | 1 | 3% | 7 | 10% |

| | | | | | | | | | | |
|--|----|------|----|------|----|-----|----|-----|----|-----|
| <i>Never married / single</i> | 2 | 17% | 0 | 0% | 2 | 12% | 1 | 3% | 5 | 7% |
| Living Arrangement | | | | | | | | | | |
| <i>Alone</i> | 1 | 11% | 0 | 0% | 2 | 13% | 3 | 12% | 6 | 10% |
| <i>Others</i> | 8 | 89% | 11 | 100% | 13 | 87% | 22 | 88% | 54 | 90% |
| Relationship to stroke patient | | | | | | | | | | |
| <i>Husband</i> | 1 | 8% | 2 | 17% | 5 | 29% | 4 | 13% | 12 | 17% |
| <i>Wife</i> | 7 | 58% | 4 | 33% | 9 | 53% | 7 | 23% | 27 | 38% |
| <i>Son</i> | 0 | 0% | 1 | 8% | 1 | 6% | 1 | 10% | 5 | 7% |
| <i>Daughter</i> | 3 | 25% | 2 | 17% | 2 | 12% | 8 | 25% | 15 | 21% |
| <i>Granddaughter</i> | 0 | 0% | 1 | 8% | 0 | 0% | 0 | 0% | 1 | 1% |
| <i>Friend</i> | 0 | 0% | 1 | 8% | 0 | 0% | 0 | 0% | 1 | 1% |
| <i>Other(e.g. mother, daughter-in-law, carer, partner)</i> | 1 | 8% | 1 | 8% | 0 | 0% | 9 | 29% | 11 | 15% |
| Age Category of Carer | | | | | | | | | | |
| <i>Under 65</i> | 11 | 100% | 5 | 46% | 14 | 88% | 16 | 55% | 46 | 69% |
| <i>Over 65</i> | 0 | 0% | 6 | 54% | 2 | 12% | 13 | 45% | 21 | 31% |

II. Current health status of carer

A majority (71%) of carers rated their current health status as excellent (26%) or good (45%). A further 22% stated that their health was average and 7% stated their health was fair. No carer reported their health as poor.

III. Patient independence

When the degree of independence of stroke patients prior to stroke was explored with carers, 76% reported that the patient with stroke was fully independent before their stroke, which reduced significantly to 31% described as fully independent post- stroke ($\chi^2 = 11.435$, $df = 4$, $p \leq .022$)(Table 4.1.2). Prior to stroke, 4% of patients needed significant levels of help. This need for help rose to 34% post-stroke. No significant differences in levels of patient dependency were found in terms of year of stroke or age category of patient.

| Table 4.1.2. Level of patient independence prior to stroke.(N =70) | | | | | | | | | | | |
|--|--|----------|-----------|----------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|
| | | 2004 | | | | 2006 | | | | Overall | |
| | | Under 65 | | Over 65 | | Under 65 | | Over 65 | | | |
| | | N | % | N | % | N | % | N | % | N | % |
| Fully Independent | | 9 | 75 | 7 | 64 | 16 | 94 | 22 | 71 | 54 | 76 |
| Little help | | 2 | 17 | 4 | 36 | 1 | 6 | 7 | 23 | 14 | 20 |
| A lot of help | | 1 | 8 | 0 | 0 | 0 | 0 | 2 | 6 | 3 | 4 |

IV. Duration of carer status

Of the 72 carers who participated in the survey, 47 (65%) reported that the person with stroke needed ongoing help and support post-stroke. Of those patients who needed ongoing help, 19 carers had already acted as the patient's primary carer prior to stroke. The 25 carers reporting that the patient with stroke did not require ongoing help had been involved in supporting the patient immediately post-stroke. However, these patients are now fully independent and do not need a carer anymore. Thirty-six carers (77%) acted as the sole or main carer after the patient's stroke, while the remaining 11 shared the caring role with others, typically other family members.

V. Carer ratings of patient cognitive function of patients with aphasia (IQCODE)

The mean score for the IQ-CODE was 3.5, with average scores between 3.3 and 3.6 for different subdivisions of the patient group (gender, year of stroke and age of patient)(Table 4.1.3). A score of 3 indicates a rating of 'no change' while a score of 4 indicates a rating of 'a bit worse'. In this group of patients with aphasia, 98% scored between 3 and 4 on the IQCODE, based on carer ratings, indicating some deterioration in cognitive function.

| Table 4.1.3 IQ Code Scores (N =50) | | | | | | |
|------------------------------------|------------------|------------------|------------------|------------------|------------------|------------------|
| | | 2004 | | 2006 | | Overall |
| | | Under 65 | Over 65 | Under 65 | Over 65 | |
| IQ Code | Mean (SD) | 3.4 (.53) | 3.5 (.70) | 3.2 (.43) | 3.7 (.66) | 3.5 (.60) |
| | Range | 3-4 | 3-5 | 2-4 | 3-5 | 2-5 |

4.2. Carer Health: Physical and Psychological status:

Table 4.2.1 presents results from the measure of vulnerability (VES) for the carer sample. On average, the carer sample fell within the normal range for this measure (overall mean score = 0.92; cut-off score = 3). Higher scores on this

measure indicate increased vulnerability, with a maximum score of 10. In this sample 11.5% (N=7) of the sample fell within the vulnerable category. No significant differences were found in terms of gender, age of patient or year of stroke. Of the 7 carers who were identified as within vulnerable range, 5 were over 65 years and 6 were female. Of the 5 vulnerable carers aged over 65, 4 were female. Of the 2 carers who were identified as vulnerable and under age 65, both were female.

| Table 4.2.1 VES Scores (N =61) | | | | | | |
|---------------------------------------|------------------|-------------------|----------------|-------------------|-------------------|-------------------|
| | | 2004 | | 2006 | | Overall |
| | | Under 65 | Over 65 | Under 65 | Over 65 | |
| VES | Mean (SD) | 0.5 (0.53) | 1 (1.3) | 0.9 (1.36) | 1.1 (1.35) | 0.9 (1.24) |
| | Range | 0-1 | 0-3 | 0-5 | 0-5 | 0-5 |

Table 4.2.2 presents results from the depression measure (HADS-D) for the carer sample. The mean score was 3.6, indicating that, on average, the carer sample was within the normal range. Average scores for different subdivisions of the patient group (year of stroke and age of patient) and gender of carer were between 2.9 and 4.1. The suggested cut-off point on the HADS depression scale indicating possible/probable clinical depression is ≥ 8 (Olsson et al. 2005). Eleven carers (15%) had scores of 8 or greater on this scale, indicating possible/probable clinical depression. Of these, 6 were under 65 and 5 over 65 years. Ten of the 11 carers with elevated depression scores were female. All six of the carers in the under 65 group who had elevated depression scores were female.

| Table 4.2.1 HADS Scores (N =61) | | | | | | |
|--|------------------|-------------------|-------------------|-------------------|-------------------|-------------------|
| | | 2004 | | 2006 | | Overall |
| | | Under 65 | Over 65 | Under 65 | Over 65 | |
| VES | Mean (SD) | 1.9 (2.56) | 3.7 (3.66) | 3.4 (3.29) | 4.1 (4.48) | 3.5 (3.81) |
| | Range | 0-8 | 1-14 | 0-11 | 0-17 | 0-17 |

In four cases (6%), carers were identified as being both in the vulnerable and depressed ranges. All four cases were female and three of the four were over age 65.

For both VES and HADS-D, no significant differences emerged in terms of gender or age group of patient, or year of patient's stroke.

4.3. Carer satisfaction with stroke services

The Carer Satisfaction Questionnaire addresses statements to carers relating to satisfaction with aspects of patient care, with which carers indicate a response on a 5-point likert scale, ranging from 'strongly agree' (assigned a score of "0") to 'strongly disagree' (assigned a score of "4"). Higher scores, therefore, indicate increased dissatisfaction with services, with a range of possible scores on this measure of 0-92. The overall mean score on this measure for this carer group was 45.7, almost exactly on the mid-point of the range (score of 46), indicating that carers were neither satisfied nor dissatisfied with stroke care, overall (Table 4.2.3). No significant differences in satisfaction were found when within group comparisons of satisfaction were conducted based on gender of carer, age category of patient, or year of stroke.

Analyses of this questionnaire were also conducted based on factors derived by Simon, Little and Birtwistle (2003). It was not possible to explore Factor 2 (amount, co-ordination and appropriateness of services), as the current study utilized a version of the questionnaire that omitted three of the five questions needed.

| Table 4.2.3 Scores of carer satisfaction by factor | | | | | | |
|--|--------------|-----------|-----------|-----------|-----------|-----------|
| | | 2004 | | 2006 | | Overall |
| | | U65 | 65+ | U65 | 65+ | |
| Factor 1: Information about community support and involving the carer | <i>Mean</i> | 11.6 | 8.2 | 11.6 | 13.9 | 11.8 |
| | <i>Range</i> | 20 (0-20) | 11 (4-15) | 14 (5-19) | 16 (4-20) | 20 (0-20) |
| Factor 3: Information about stroke | <i>Mean</i> | 5.7 | 4.8 | 4.7 | 5.6 | 5.2 |
| | <i>Range</i> | 8 (0-8) | 8 (0-8) | 8 (0-8) | 6 (2-8) | 8 (0-8) |
| Factor 4: Speed of change and concern about carer | <i>Mean</i> | 4.7 | 4.6 | 4.1 | 3.5 | 4.3 |
| | <i>Range</i> | 8 (0-8) | 6 (1-7) | 6 (2-8) | 7 (0-7) | 8 (0-8) |
| Factor 5: | <i>Mean</i> | 6.5 | 7.5 | 7.3 | 6.6 | 4.1 |

| | | | | | | |
|--|--------------|----------|-----------|----------|---------|---------|
| Listening to the carer and being heard | Range | 6 (4-10) | 4 (6-10)_ | 5 (5-10) | 3 (6-9) | 8 (0-8) |
| | | | | | | |
| Factor 6: Problem management | Mean | 4.9 | 5.5 | 4.6 | 5.9 | 5.0 |
| | Range | 8 (0-8) | 5 (3-8) | 6 (2.8) | 4 (4.8) | 8(0-8) |
| | | | | | | |
| Factor 7: Confidence in and accuracy of information | Mean | 4.4 | 3.5 | 3.6 | 4.7 | 4 |
| | Range | 8 (0-8) | 3 (2-5) | 8 (0-8) | 6 (2-8) | 8 (0-8) |

Overall, carers expressed reasonable levels of satisfaction with confidence in and accuracy of information, about being listened and heard, and concern for the carer. Thus, levels of carer satisfaction were somewhat higher for factors 4 (Speed of change and concern about carer), 5 (Listening to the carer and being heard) and 7 (Confidence in and accuracy of information), than for factors 1 (Information about community support and involving the carer), 3 (information about stroke) and 6 (problem management), although differences were not significant. No significant differences in terms of gender of carer, age group of patient, or year of stroke were found.

At the end of the interview, carers were asked if they would like to make any additional comments in relation to the positive and negative aspects of stroke care received in the community. In terms of positive aspects of care, many carers spoke of the support and reassurance they received from their GP. The availability of home help was also highlighted, as was input of physiotherapists and public health nurses, in some cases.

However, many carers felt that community stroke services required substantial improvement. Areas commonly highlighted as requiring improvement included lack of information and communication, lack of follow-up of patients once they leave hospital, and lack of a designated person with whom the carer (or patient) can make contact, even if it is just to talk to someone who understands the patient/carer situation. This lack of support was highlighted in particular for patients (and their carers) aged under 65. Lack of information was identified in relation to rehabilitation, support services, benefits to which patients and carers may be entitled, equipment that could be availed of, and details of stroke and what to expect once the patient comes home. A number of carers pointed out that there is no monitoring of carers and how they are managing the patient with stroke. The carer is expected to become “expert” in the area of stroke and stroke management, with little or no support provided. Distress and depression were identified by a number of carers as significant issues, and highlight the lack of information in relation to counselling/therapy services.

4.4. Carer satisfaction with community stroke services, where patient is deceased since leaving hospital

A total of 23 carers of patients who were deceased since leaving hospital were invited to participate in the survey, 4 of whom agreed (17%). Three of these carers were female, two the wife of the deceased and one a grand-daughter. The male carer was a nephew of the deceased. The two wives were living alone since the death of their spouse, the grand-daughter single and living alone, the nephew married and living with family. Two of the four carers described their own health as 'excellent', two as 'good'.

Prior to stroke, 3 of the 4 patients were fully independent. All four required help to varying degrees following their stroke. In 2 cases, community services had been put in place prior to the patients' discharge from hospital, in the remaining two they had not. In these two cases, no community services were received following hospital discharge. In the other two, the GP and public health nurse were most commonly involved, with a clinic nurse involved in one case.

Similar to the overall carer group, the mean score on the Carer Satisfaction Scale was 45.3 (SD: 11.7)(some questions not asked as not relevant in context of patient deceased; these items re-coded 'neither agree nor disagree' as suggested by authors). This mean score indicates that carers of patients who died after leaving hospital were reporting being neither satisfied nor dissatisfied with community stroke services.

When asked if there was anything particularly good about community stroke care received, carers reported that, overall, everyone did their best. In one case, the patient was transferred from home to a nursing home for respite, which the patient did not like and eventually returned home. Another carer reported that the patient's family were happy to provide care, but were very much on their own and did not feel they could talk to anyone; they would only call the GP if there was a significant issue, and found the GP to be very good, but many small things happened about which the family were unable to consult anyone. Lack of information about the medications prescribed was reported, with carers seeking information from the pharmacist, medication leaflets and other sources. One family experienced disjointed care between a hospital in Dublin and one outside Dublin, finding that neither hospital seemed to know who was looking after their relative with stroke.

The issue of lack of notification among health professionals of the death of a patient was also highlighted, for example one hospital sent a first dietician appointment one year after the death of the person with stroke.

Chapter 5. Discussion

This survey provides a first national overview of the experiences of patients with stroke and their carers of community stroke services, both for those with a recent stroke and for those with stroke over a longer time period. The patient cohort was identified through the HIPE scheme from four hospitals nationally, which were representative on key standard indicators of all acute hospitals across Ireland in terms of the profile of stroke and stroke care. Patients were stratified based on age, sex and time since stroke, and then selected randomly from the HIPE listing for that hospital. In some hospitals, it was not possible to fill the quota in all of the cells in the stratification matrix. This was particularly the case for younger stroke patients. For example, one of the four hospitals accounted for 50% of all young women with stroke in the HIPE dataset for the four hospitals, and 34% of young men. It was not possible to fill the quota for young women in three of the four hospitals and in one of the four hospitals for young men.

Where possible, twice as many patients were randomly selected into each cell than were needed for the survey. Thus, although 200 patients was the target sample, a total of 309 patients were contacted. A number of factors, such as transfer to nursing home, incorrect contact details and the person reporting that they did not have a stroke when contacted reduced the number of eligible patients to 251. A total of 139 interviews were completed, yielding a 55% response rate in terms of the number of eligible patients contacted and a 70% response rate when the target sample of 200 patients is the denominator. A majority of patient participants identified a carer who was also invited to participate in the survey and a majority of carers invited agreed to participate.

In terms of risk factors for stroke, a sizeable minority of patients had diabetes and were current smokers. Up to half of patients reported that they had not had their blood pressure and cholesterol checked in the past three months. Approximately one in 20 patients had not seen their GP in the past three months.

Acute Stroke Care

Two-thirds of patients had stroke diagnosed in hospital and a further quarter were diagnosed with stroke prior to hospital admission. Half of the patients surveyed reported travelling to hospital by private transport, a majority (94%) of whom were driven by someone else. However, approximately one in twenty patients with stroke drove themselves to hospital. An additional one in twenty patients with stroke travelled to hospital by public transport. Therefore, one in ten patients in the acute stage of having a stroke either drove themselves to hospital or travelled to hospital in public transport. Research evidence highlights the critical importance to patient outcome from stroke of transfer to hospital by rapid ambulance transport to maximise the potential for early radiological investigation and intervention with thrombolytic therapy (if appropriate)(Kwan 2004).

Almost half of patients reported experiencing a delay in A&E. Similar to the transport issue, this is of major concern in the context of stroke, as delays in A&E potentially further hinder timely optimal stroke assessment and intervention (Collins, 1999). Over a quarter of patients were unable to identify the type of ward to which they were admitted or in which they spent most of their stay in hospital. None of the patients were managed in a stroke unit, compared with 21% in the UK. Over half of patients were unable to identify the type of medical specialist who provided their hospital care. Where patients were able to identify the type of medical specialist, a majority were managed in hospital by a consultant geriatrician, irrespective of patient age (under or over age 65).

Over one-third of patients surveyed reported that they did not feel involved in decision-making about their care and treatment in hospital, with younger patients significantly less likely to report involvement. One in ten patients reported receiving no information in relation to stroke, while approximately another one in ten reported understanding little or none of the information provided. There was evidence from this survey of serious shortfalls in support and rehabilitation services in hospital. While a majority of patients reported receiving help with different activities of daily living in hospital, approximately one-third of patients reported not always receiving help when needed with basic activities, such as eating, washing and using the toilet. A considerable proportion of patients who needed help with swallowing and speech difficulties in hospital reported not receiving this help. Even in areas considered to be reasonably well served in the Irish context, such as provision of help and support with mobility problems, twice as many patients in this survey reported needing such help and not getting it compared with the UK survey (2005). There was a virtual absence of counselling or psychological services, with many patients raising concerns about their need to take anti-depressants in the longer term, with no other options made available to them in relation to emotional support.

Overall, discharge planning appeared to be inconsistent, with a tendency to be haphazard. Three-quarters of patients reported that there had been no family conference prior to hospital discharge, although all of these patients were returning home. This issue was found to have improved significantly across the two timeframes of the survey, such that just one in ten patients reported having had a family conference in the 2-3 year post-stroke cohort, whereas almost one-third of patients had a family conference in the more recent stroke cohort. Up to half of patients reported receiving no information in relation to lifestyle changes that might be required post-stroke. Of concern, also, was the reported lack of understanding by patients of their medicines post hospital discharge. One-third of patients reported receiving no explanation about the purpose of their medication, one-fifth reported receiving no explanation about how their medication should be taken and almost three-quarters received no explanation about potential side-effects. This finding from the patient survey was confirmed in the carer survey. Some patients and carers reported using medicine leaflets and other sources to inform themselves. The cost to patient health and well-being, and to the health

service, of medication non-compliance and iatrogenesis as a result of this lack of patient education is potentially very significant.

Community stroke services

Before they left hospital, approximately one-third of patients reported receiving a name to contact, if required, after discharge home. Most patients received no information about voluntary support groups in their area, or about national stroke organisations. While a majority of patients reported that their GP had been given all necessary information about their stroke by the hospital, one-third of patients requiring community services *de novo* post-stroke reported that the services required had not been put in place prior to hospital discharge, a further one in five patients reporting that only some services needed had been put in place. Thus, over half of the patients discharged home either had no services or only some services in place at the time that they returned home.

While over half of patients overall reported getting sufficient treatment for mobility problems after they came home, one in five patients reported that they did not receive sufficient treatment and this was more likely to be the case for patients under age 65. Almost half of patients reported not getting sufficient help with speech and language difficulties after leaving hospital, while almost three-quarters reported not getting sufficient help with emotional difficulties after leaving hospital, despite the widely acknowledged high incidence of post-stroke depression (Tharwani, 2007)). Again, where service differences were evident based on patient age, younger patients were less likely than older patients to receive the service.

Older patients were more likely to need aids and equipment after leaving hospital. For those who needed such aids, older patients were more likely than younger patients to receive the aids as soon as they needed them. Over half of patients reported needing help from social services, which they did not receive. A quarter of patients rated community services as poor or very poor.

When comparing results of this Irish survey to those of the UK (2005), there were many similarities between both survey findings. However, where services were poorer in one country than in another, Irish patients consistently reported receiving poorer care, in particular that they did not receive services that they needed. UK community stroke services have been widely criticised (Simon, 2002) and are not, therefore, a gold standard to which Irish community stroke services should be aspiring. The findings that Irish community services for patients with stroke are poorer than those in the UK is a cause for concern and indicates sub-standard service provision at community level in Ireland for patients with stroke. Where age differences were in evidence, consistently younger patients with stroke appeared to report an even greater disadvantage in relation to accessing scarce stroke services in the community than older patients, although this may also relate to reduced expectations for services among older

people (Horrocks, 2004), often involving issues of withdrawal, resignation and low expectations (Walters, 2001).

Stroke services need fundamentally to be integrated, from secondary to primary services and from acute to long-term care. There is an important liaison role to ensure communication between these two times and settings. Dedicated liaison personnel can be hugely beneficial in such a setting. One resource which may assist in this way in the coming years is the proposed Irish Heart Foundation development of a team of stroke liaison nurses who will work with the acute hospital sector. A total of 43 nurses are proposed by 2011 across all acute hospitals admitting stroke patients. Such resources can facilitate liaison and communication among patients, families and health service staff.

Service access

The services identified as most needed by patients were medical services (both GP and hospital out-patient), physiotherapy, optician and chiropody services. In a majority of cases, those reporting need for these services also reported that they had received them. No patient reported access to a community-based multi-disciplinary team, with specific service deficits, such as psychological services, notable nationally.

Younger patients with stroke were more likely than older patients to have reported paying in full for services, particularly chiropody and GP services. Other areas where people reported paying in full in order to receive the service included physiotherapy and dental services, home help and hearing services. Significantly more of the older patient population had a medical card, with older patients also more likely to have private health insurance than younger patients. Of those patients who would have liked to receive a service, but did not, the primary reasons given were that the service was unavailable or that they did not know they could avail of it. Patients did not identify cost as a barrier to accessing services. The findings on service needs and access should be considered as one source of information but not definitive in this context. It is important to remember that expressed health needs and adequacy of services provided to meet these needs reflect in part the knowledge and expectations of those assessed. They may not adequately reflect service quality or comprehensiveness. A professional needs assessment would be required to judge perceived *versus* actual needs. (see Crow et al., 2002 for a review of uses and limits of service user satisfaction measurement). IN practice, it appears that where there is a differential, it is in the direction that people are less aware and less demanding of services that assessed health and well-being would suggest appropriate.

Employment and transport

Over three-quarters of patients aged under 65 were in employment prior to stroke, a majority of whom were working full-time. Over half of this group reported a change to their employment status following stroke. The impact of stroke on the employment status of older patients was less significant, as many

older patients had retired. For those over 65 reporting being in employment at the time of stroke, approximately a quarter reported a change to employment status post-stroke.

Approximately one-third of patients who were driving prior to stroke had stopped driving post-stroke. The reasons for this were mainly but not exclusively stroke related. Patients aged over 65 were more likely to have stopped driving for stroke-related reasons, consistent with a previous Irish study (Tan, 2004).

Patient health

The physical and psychological well-being of patients was recorded using standardised measures at the time of interview to indicate patient functioning in the short- (6-12 months) and medium-term (24-36 months) post-stroke. On average, the physical and psychological health of this patient cohort was good. Ratings of health and well-being did not differ significantly for those with more recent stroke compared with those in the longer term post-stroke. However, a quarter of patients overall had moderate to severe disability and over half could be classified as vulnerable, vulnerability at a significantly higher level in the older patient cohort. This survey found almost one-third of patients with elevated depression scores which, although representing a sizeable minority of the patient group, may in fact be an under-estimate, given that a proportion of patients were taking anti-depressant medication, with resulting lower scores on the HADS-D.

Nineteen patients who participated in the survey were found to have speech and language difficulties when assessed. The option of being interviewed by a speech and language therapist was offered to all of these patients. However, only four patients indicated that they would like the interview to be conducted by a therapist, remaining patients indicating a preference to continue the interview with the interviewer. Ten patients were found to have some degree of cognitive impairment when assessed. Interviews in these cases were conducted with the patient's carer acting as proxy for the patient.

The profile of patient health and well-being in this survey may indicate that the patients who participated were at the milder end of the stroke severity spectrum. Patients were not included in the survey if they had been transferred to a nursing home from the acute hospital. Some of these patients may subsequently have been discharged home and are now living in the community. As it was not possible to identify these cases from the hospital PIMS system, these patients were not included in this survey. Overall, over one-third of patients invited to participate in the survey declined participation. Rates of refusal were higher in older patients. Reasons for refusal included lack of transportation to the hospital and unwillingness to either travel by taxi, or to have researchers call to the house. It was not possible to determine if those refusing had poorer outcome from stroke than those who participated, but this may have been the case. One in ten patients randomly selected for inclusion to the survey had incorrect contact details, or were not contactable at the address on the hospital PIMS system.

Some of these patients may have died, or may now be in long-term care, thus also representing the more severe end of the stroke severity spectrum and were not accounted for in this survey. Overall then, this study represented those who were likely to be least severely affected by stroke.

Carers of patients with stroke

The majority of carers of patients with stroke in the community were women (a finding common to studies of informal carers, although in the UK the gender ratio reverses in later life (Dahlberg, 2007)) and over half of the carer group were the spouse of the person with stroke. Survey findings indicate that carers were a neglected group, with no formal input to inform or train them for the caring role. Carers reported being provided with little or no information on what to expect after a stroke and identified an expectation that the carer could become “expert” in relation to patient care and co-ordination of community services and entitlements in the absence of support from health services or health professionals.

In terms of satisfaction with services, overall carers expressed reasonably high levels of satisfaction in some areas, but were more dissatisfied with levels of information provided, both about stroke itself and about community support services and the involvement of the carer. Carer satisfaction levels were not influenced by the age or gender of the patient, or by the length of time since stroke.

Overall, carers rated their own health as good, and on average had low levels of depression and vulnerability. However, one in six carers had elevated depression scores and one in ten carers would themselves be classified as vulnerable. These were almost exclusively women, most of whom were over age 65. The importance of supporting informal caregivers in the community, a role that enormously supports the delivery of the health service, is key to providing adequate community care to patients discharged home with stroke.

Conclusions

This survey demonstrates major deficits in the provision of information, support and services to people with stroke and their carers who are discharged to community settings. The selection of two groups at differing times since stroke and hospital discharge demonstrates the fact that considerable needs still exist some two to three years following discharge. The sample almost certainly represents those perceived as faring best post-stroke since they live relatively independently in their own homes. As such, the findings under-represent the post-acute hospital needs of stroke survivors and should be taken in conjunction with a companion report on the status of post-stroke patients who are now resident in Irish nursing homes. As a major source of disability in the community, stroke care needs to be addressed in a comprehensive and integrated way throughout the health system. Many of the problems faced for stroke care are symptoms of more generic problems with community services. Stroke itself is the

exemplar of a condition whose optimal management spans the physical, social and psychological domains and so a system which can deal well with stroke is a model for a system that can provide comprehensive care for virtually every other chronic condition.

Stroke patients and their families deserve a continuing care system that builds on the work of acute stroke care services and ensures that quality of life is optimised across the spectrum of health states that exist post-stroke.

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Appendix 1: Key Standards table

| | Key standards | N= 32 | N =4 |
|----------|--|--------------------------------------|--------------------------------------|
| Q1.9 | > 50% stay on a stroke unit | 6 | 0 |
| Q3.1 | Screened for swallow 24 hours | 26 | 21 |
| Q1.12iii | Brain scan within 24 hours | 41 | 34 |
| Q3.3 | Aspirin started by 48 hours | 43 | 48 |
| Q3.5 | Physiotherapy assessment within 72 hours of admission | 42 | 48 |
| Q4.2 | Occupational therapy assessment within 7 days of admission | 21 | 27 |
| Q5.1 | Weighed at least once during admission | 42 | 34 |
| Q5.3 | Mood assessed by discharge | 28 | 28 |
| Q6.3 | On anti-thrombotic therapy by discharge | 64 | 66 |
| Q5.5 | Rehabilitation goals agreed by MDT | 22 | 19 |
| Q7.4 | Home visit performed by discharge | 7 | 7 |
| Q1.7 | Treated on a stroke unit during their stay | 6 | 0.5 |
| | Average for 12 indicators | 29 | 28 |
| | Gender | 51% M | 51% M |
| | Age | Mean 75 (sd13) Median 78 (18-100) | Mean 74 (sd 13) Median 77 (23-97) |
| Q1.3 | Inpatient mortality | 19% | 21% |
| Q1.6 | 30 day mortality | 14% | 16% |
| Q1.4 | Length of stay to discharge alive | Mean 30.8 (sd 60) | Mean 31.6 (sd 50) |
| Q1.5 | Length of stay to death | Mean 24.2 (sd 47) | Mean 41.6 (sd121) |

Appendix 2: Patient Questionnaire.

Irish Heart Foundation National Audit of Stroke Care In association with the Department of Health
and Children

Community Audit of Stroke Care Patient/Carer Survey

Patient Questionnaire

ALL INFORMATION WILL BE RECORDED BY THE RESEARCHER :Study Number _____

Age Group : _____ **Yr Stroke:** _____

Data Collector: _____ **Date:** _____ **Duration:** _____ **Site Code** _____

Did a person in a 'carer capacity' also take part in this study Yes No

If Yes, did the carer findings differ from the patient findings? Yes No

If no, why was there no carer interviewed for this patient?;

- i. Patient did not need anyone to act as carer when discharged from hospital:
- ii. Patient needed, but did not want, anyone to act as carer when discharged from hospital
- iii. Patient needed, but did not Have anyone to act as carer
- iv. Patient carer was unavailable to take part in the study
- v. Patient carer did not want to take part in study
- vi. Patient carer was not informed / asked by patient to take part in the study.
- vii. Other _____

Section 1 Patient Profile

1.1 PATIENT INFORMATION RECORDED FROM: PATIENT PROXY

1.2 If by Proxy: Carer Partner Friend Neighbour Other _____

1.3 Study Number: _____

1.4 Gender: M F 1.5 Date of birth: _____ Age; _____

1.6 HIPE Code: _____ 1.7 Stroke Index Admission date: _____

1.8 Stroke Discharge date: _____ 1.9 Length of stay (in days): _____

1.10 Date of stroke: _____ 1.11 Number of Strokes _____

(D1 – D11 will be entered prior to interview from HIPE/PIMS)

1.12 Communication problems: Yes No

1.13. Cognitive problems: Yes No

1.14 Before we begin the rest of the questionnaire, would you like to sum up, in your own words the lead up to your stroke (e.g, any symptoms that presented in the preceding days), resulting in your admittance to hospital and your overall general health in the days following the stroke.

Section 2 – Background Information

2.1 Marital status: Married Separated Divorced Widowed Never married/Single

2.2 Do You: Live alone *Live with others If others, please specify _____

Section 3 – Health Promotion: Risk factors for stroke

3.1 Do you or did you ever smoke?

- Yes regularly now Yes occasionally now
Yes regularly in the past Yes occasionally in the past
No never (if No, please proceed to Q2.2)

3.1a Did your smoking pattern change following your stroke?:

- Yes (I quit smoking following the stroke)*
Yes (I smoked less cigarettes per day following the stroke)
Yes (I smoked more cigarettes per day following the stroke)
My smoking patterns did not change since my stroke

***If you do not currently smoke, proceed to question 3.2**

3.1(c) Are you at present:

- Trying to quit smoking Actively planning to quit
Thinking about quitting but not planning to Not thinking about quitting

3.2 a When did you last attend a GP : _____

3.2b When did you last attend the hospital doctor? _____

3.2 c When was the last time you had the following checked by either a GP or hospital doctor?

Your blood pressure? Less than 3 months ago Up to 1 year ago Up to 3 years ago
3-5 years ago Over 5 years ago Never Don't Know

Your cholesterol? Less than 3 months ago Up to 1 year ago Up to 3 years ago
3-5 years ago Over 5 years ago Never Don't Know

Your Diet? Less than 3 months ago Up to 1 year ago Up to 3 years ago
3-5 years ago Over 5 years ago Never Don't Know

3.2d Are you a diabetic? Yes No

3.3i Are you on new medication since your stroke? Yes No

3.3ii If Yes, do you take the medication as directed? Yes No

If no please specify

why? _____

Section 4 – General Health & Outlook

4.4 VES SCALE

4.4.1. Compared to others your age, how would you describe your health?

Excellent Good Fair Poor Very Poor

4.4.1. Compared to others who have had a stroke, how would you describe your health?

Excellent Good Fair Poor Very Poor

4.4.2. Are any of these activities very difficult or impossible to do?

| | Yes | No |
|---|--------------------------|--------------------------|
| (a) Reaching or extending arms above shoulder level? | <input type="checkbox"/> | <input type="checkbox"/> |
| (b) Bathing or showering? | <input type="checkbox"/> | <input type="checkbox"/> |
| (c) Walking across the room (use of walking stick or Zimmer frame is ok)? | <input type="checkbox"/> | <input type="checkbox"/> |
| (d) Stooping, crouching or kneeling? | <input type="checkbox"/> | <input type="checkbox"/> |
| (e) Doing light housework, like washing dishes, tidying up, or light cleaning? | <input type="checkbox"/> | <input type="checkbox"/> |
| (f) Walking a quarter of a mile? | <input type="checkbox"/> | <input type="checkbox"/> |
| (g) Shopping for personal items, like toilet items or medicines? | <input type="checkbox"/> | <input type="checkbox"/> |
| (h) Lifting or carrying objects as heavy as 10 pounds, like a sack of potatoes? | <input type="checkbox"/> | <input type="checkbox"/> |
| (i) Heavy housework such as scrubbing floors or washing windows? | <input type="checkbox"/> | <input type="checkbox"/> |

4.4.3. Because of your health, is it too difficult or impossible for you to perform any of these activities without help from someone else?

Yes **No**

(a) Managing money, like keeping track of expenses or paying bills?

(b) Writing, or handling and grasping small objects?

Section 5 Psychological Wellbeing, and Barthel Index

Next I want to ask about the way you have been feeling **recently**. These questions are being asked of people generally, so some questions may not apply to you, but for each statement, can you say what best describes the way you have been feeling in the past week.

5.1.1 I still enjoy the things I used to enjoy:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Definitely as much | Not quite so much | Only a little | Hardly at all |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.1.2 I can laugh and see the funny side of things:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| As much as I always could | Not quite so much now | Definitely not so much now | Not at all |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.1.3 I feel cheerful:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Not at all | Not often | Sometimes | Most of the time |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.1.4 I feel as if I am slowed down:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Nearly all the time | Very often | Sometimes | Not at all |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.1.5 I have lost interest in my appearance:

| | | | |
|---------------------------------------|--|---------------------------------------|---------------------------------------|
| Definitely | I don't take so much care as I should | I may not take quite as much care | I take just as much care as ever |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.1.6 I look forward with enjoyment to things:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| As much as ever I did | Rather less than I used to | Definitely less than I used to | Hardly at all |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.1.7 I can enjoy a good book or radio or TV programme:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Often | Sometimes | Not often | Very seldom |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.2 Barthel Index

I am now going to ask you about any difficulties that you currently experience in different areas of your life from walking to memory.

1. FEEDING

0 = unable

1 = needs help cutting, spreading butter, etc., or requires modified diet

2 = independent

2. BATHING

0 = dependent

1 = independent (or in shower)

3. GROOMING

0 = needs help with personal care

1 = independent face/hair/teeth/shaving (implements provided)

4. DRESSING

0 = dependent

1 = needs help but can do about half unaided

2 = independent (including buttons, zips, laces, etc.)

5. BOWELS

0 = incontinent (or needs to be given enemas)

1 = occasional accident

2 = continent

6. BLADDER

0 = incontinent, or catheterized and unable to manage alone

1 = occasional accident

2 = continent

7. TOILET USE

0 = dependent

1 = needs some help, but can do something alone

2 = independent (on and off, dressing, wiping)

8. TRANSFERS (BED TO CHAIR AND BACK)

0 = unable, no sitting balance

1 = major help (one or two people, physical), can sit

2 = minor help (verbal or physical)

3 = independent

9. MOBILITY (ON LEVEL SURFACES)

0 = immobile or < 50 yards

1 = wheelchair independent, including corners, > 50 yards

2 = walks with help of one person (verbal or physical) > 50 yards

3 = independent (but may use any aid; for example, stick) > 50 yards

10. STAIRS

0 = unable

1 = needs help (verbal, physical, carrying aid)

2 = independent

TOTAL (0–20): _____

Section 6 Service Access

6.0.1 Are you covered for health care by a Medical Card, either in your own name or through someone else's card?

Yes, holder of Medical Card Yes, on someone else's card Not covered

6.0.2 Do you also have private health insurance (e.g. VHI)?

Yes, in own name Yes, through family member Not medically insured

(A). In **the last year** did you need any of the services listed below?

(B). In the last year have you received or availed of each of the services listed below?

(C). If so, did you pay for the service?

(D). If no, do you feel you would like to be able to receive or avail of the service in question?

(E). If 'No' in COL B and NO in COL D: Ask, what is preventing you from receiving or availing of the service (or availing of it more often?). [Int: If nothing is preventing availing or receiving service leave blank]

| Service Type | A Did you need any of the following services ? | | B Did you receive/ avail of service? | | C If Yes, did you pay (in full or part) for service? | D If No, would you like to receive/ avail of service? | | E What prevents you from availing/receiving (more often)? |
|---|---|---|---|---|--|--|---|---|
| | Y | N | Y | N | | Y | N | |
| | | | | | Paid for in full by patient Paid for in part by patient Medical Insurance Medical Card Other | | | Never heard of Didn't know /avail Not available Transport Cost Lack of time/ reluctant On waiting list Too much hassle Not helpful Other |
| 6.1.0 GP | | | | | <input type="checkbox"/> | | | <input type="checkbox"/> |
| | | | | | | | | If other, please specify |
| 6.1.1 Respite care | | | | | | | | <input type="checkbox"/> |
| | | | | | | | | If other, please specify |
| 6.1.2 Public Health Nurse/District Nurse | | | | | | | | <input type="checkbox"/> |
| | | | | | | | | If other, please specify |
| 6.1.3 Personal care attendant | | | | | | | | <input type="checkbox"/> |
| | | | | | | | | If other, please specify |
| 6.1.4 Home Help | | | | | | | | <input type="checkbox"/> |
| | | | | | | | | If other, please specify |
| 6.1.5 Social Worker | | | | | | | | <input type="checkbox"/> |
| | | | | | | | | If other, please specify |
| 6.1.6 Meals on wheels | | | | | | | | <input type="checkbox"/> |
| | | | | | | | | If other, please specify |
| 6.1.7 Chiropody Services | | | | | | | | <input type="checkbox"/> |
| | | | | | | | | If other, please specify |

6.1.8 Physiotherapy Services

□□□□□□□□□□

If other, please specify

6.1.9 Occupational Therapy

□□□□□□□□□□

If other, please specify

6.1.10 Speech Therapy

□□□□□□□□□□

If other, please specify

6.1.11 Dietician Services

□□□□□□□□□□

If other, please specify

6.1.12 Optician Services

□□□□□□□□□□

If other, please specify

6.1.13 Dental Services

□□□□□□□□□□

If other, please specify

6.1.14 Hearing Services

□□□□□□□□□□

If other, please specify

6.1.15 Psychological Services

□□□□□□□□□□

If other, please specify

6.1.16 Counselling Services

□□□□□□□□□□

If other, please specify

6.1.17 Hospital Based Therapist, Please specify_____

□□□□□□□□□□

If other, please specify

6.1.18 Hospital Based Social Worker

□□□□□□□□□□

If other, please specify

6.1.19 Day Hospital

□□□□□□□□□□

If other, please specify

6.1.20 Day-care

□□□□□□□□□□

If other, please specify

6.1.22 Outpatient appointments. Medical

□□□□□□□□□□

If other, please specify

6.1.23 Outpatient appointments. Therapy

□□□□□□□□□□

If other, please specify

6.1.24 Other, please state

□□□□□□□□□□

If other, please specify

Section 7 Diagnosis

7.1 When were you **first** told that you had had a stroke?

- 1 Before I went into hospital
- 2 In the hospital
- 3 After I left hospital
- 4 Don't know/ Can't remember

Section 8 Admission to Hospital

8.1 How were you admitted to hospital

- By Private Transport: Self-drive Other driver
- By Public Transport
- By Ambulance

8.2 In your opinion, were you admitted to hospital quickly enough?

- 1 Yes, I was admitted as soon as I thought was necessary
- 2 I should have been admitted a bit sooner
- 3 I should have been admitted a lot sooner
- 4 I was already in hospital when I had a stroke
- 5 Don't know/ Can't say

8.3 Did you experience a delay between A & E and admission to ward? Yes No

8.4a What was the name of the ward that you were first admitted to? _____

8.4b When you were first admitted to a bed on a ward, what type of ward was it? _____

- 1 Acute assessment ward
- 2 An intensive care unit
- 3 Other type of ward/unit
- 4 Rehabilitation ward
- 5 Don't know/ Can't remember

8.5a What was the name of the ward you were on for most of your stay? _____

8.5b What type of ward were you on for most of your hospital stay? _____

- 1 Acute assessment ward
- 2 An intensive care unit
- 3 Other type of ward/unit
- 4 Don't know/ Can't remember

8.6 During your stay were you under the direct care (not a consultation only) of a:
(tick all that apply)

Consultant Geriatrician Yes No Don't know

Consultant Neurologist Yes No Don't know

Consultant in Rehabilitation Medicine (Rehabilitationist) Yes No Don't know

General Physician (non-geriatrician) Yes No Don't know

Other Yes No Don't know

NOTE: Please answer all the following questions about the hospital or unit where you spent most of your time

Section 9 Care and Treatment in Hospital

Please remember to answer the questions about the hospital or unit where you spent most of your time.

9.1 Were **you** involved as much as you wanted to be in decisions about your care and treatment in hospital?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I was not involved in decisions about my care and treatment

9.2 Were you able to understand the information you were given in hospital about your stroke?

- 1 Yes, I understood most or all of it
- 2 Yes, I understood some of it
- 3 No, I understood little or none of it
- 4 I was not given any information

9.3 Was your stroke diagnosis discussed with you?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, it was not discussed
- 4 It was not necessary to discuss it
- 5 Don't know/ Can't remember

9.4 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?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, but they wanted to talk to the staff
- 4 No, but they did not want or need to talk to the staff
- 5 I did not want family or friends to talk to the staff
- 6 Can't say

9.5 When you needed help from staff **getting to the toilet/using a bed pan** did you get it in time?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, I did not get help when I needed it
- 4 I did not need help from staff
- 5 I had a catheter

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

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, I did not get help when I needed it
- 4 I did not need help from staff
- 5 I had a nasogastric (NG) or PEG tube

9.7 When you needed help from staff with **washing**, did you get it when you needed it?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, I did not get help when I needed it
- 4 I did not need help from staff

9.8 While you were in hospital, if you needed help, did you get enough help for difficulties with **swallowing**?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get help when I needed it
- 4 I did not have any difficulties with swallowing

9.9 While you were in hospital, if you needed help did you get enough help with **speech and communication** problems?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get help when I needed it
- 4 I did not have any speech or communication problems

9.10 While you were in hospital, if you needed treatment, did you get enough treatment to help **improve your mobility**?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get help when I needed it
- 4 I did not have any mobility difficulties

9.11 While you were in hospital, if you needed it, did you get enough help and support with any **emotional issues** that might be affecting you (such as confusion, depression or crying)?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get help when I needed it
- 4 I did not have any emotional issues

9.12 Did you feel you were treated with **respect and dignity** while you were in the hospital?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, little or none of the time

Section 10 Discharge Planning

10.1 Before you left hospital, did a family conference take place or was there a family conference suggested?

Yes No Don't know/ can't remember

10.2 Before you left hospital, did staff give you information about **changes in your diet to improve your health?**

- 1 Yes
- 2 No, I did not get any information
- 3 I did not need any information
- 4 Don't know/ Can't remember

10.3 Before you left hospital, did hospital staff give you information about **physical exercise** (e.g. walking) to improve your health?

- 1 Yes
- 2 No, I did not get any information
- 3 I did not need any information
- 4 Don't know/ Can't remember

10.4 Before you left hospital, did a member of staff give you information about **stopping smoking to improve your health?**

- 1 I did not smoke
- 2 Yes
- 3 No, I did not get any information
- 4 Don't know/ Can't remember

10.5 What medications were you on when leaving the hospital ? _____

10.6 Before you left hospital, did a member of staff explain the **purpose of the medicines** you to take at home in a way you could understand?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, it was not explained
- 4 I did not need an explanation
- 5 I had no medicines to take home
- 6 Don't know/ Can't remember
- 7 Family member received information on my behalf.

10.7 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)?

- 1 Yes, enough information
- 2 Some, but not enough
- 3 No information at all, and I wanted some
- 4 I did not want any information
- 5 I had no medicines to take home
- 6 Don't know/ Can't remember
- 7 Family member received information on my behalf.

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

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No, I was not told about side effects
- 4 I did not need an explanation
- 5 I had no medicines to take home
- 6 Don't know/ Can't remember
- 7 Family member received information on my behalf.

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

- 1 Yes
- 2 No, I was not told who to contact
- 3 Don't know/ Can't remember
- 4 It was not necessary
- 5 Family member received information on my behalf.

10.10 Did hospital staff give you information about **voluntary and support groups** e.g. Voluntary Support Scheme for people who have had a stroke in your local area?

- 1 Yes
- 2 No, but I would have liked some
- 3 No, but I got information from somewhere else
- 4 Not sure/ Can't remember
- 5 Family member received information on my behalf.

10.11 Did hospital staff give you information about **national stroke organisations** or useful websites e.g. volunteer stroke scheme, stroke booklet?

- 1 Yes
- 2 No, but I would have liked some
- 3 No, but I got information from somewhere else
- 4 Not sure/ Can't remember

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

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 6 Very poor

Section 11 Care after Leaving Hospital

11.1 When were you given information on follow up services?

11.2 Were there delays experienced in commencement of services?

11.3 Do you think your own needs and wishes were taken into account / discussed with you when planning your rehabilitation with professionals?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, my wishes were not taken into account
- 4 I have not had any rehabilitation

11.4 Were the services you needed after you left hospital arranged for you? (e.g. occupational therapist, physiotherapist)

- 1 Yes, **all** the services I needed
- 2 Yes, **some** of the services needed
- 3 No, but these services were needed
- 4 It was not necessary
- 5 The services were already in place before my stroke

11.5 As far as you know, was your GP given all necessary information about the treatment or advice that you received in hospital?

- 1 Yes
- 2 No, my GP was not given all the necessary information
- 3 Don't know
- 4 I am not registered with a GP

11.6 Did you visit a GP or attend hospital for follow up appointments? _____

11.7 After you left hospital, did you need and get enough help with speaking difficulties? Specify SLT

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get enough help
- 4 I did not have any speaking difficulties

11.8 After you left hospital, did you need and get enough treatment to **help improve your mobility**? Specify physiotherapy

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get enough treatment
- 4 I did not have any mobility difficulties

11.9 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)? Specify counsellor/psychology

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No, I did not get enough help and support
- 4 I did not have any emotional issues

11.10a Did you need any aids / appliances when you came out of hospital?

Yes No

11.10b After you left hospital, did you get the **equipment and/or aids** (e.g. a wheelchair, commode or kitchen aids) you needed quickly enough?

- 1 Yes, I got it as soon as I thought was necessary
- 2 No, I would have liked it a **bit** sooner
- 3 No, I would have liked it a **lot** sooner
- 4 I did not need any equipment or aids
- 5 The equipment/aids were already in place before I had my stroke

11.10c Do you currently need any aids or equipment ? Yes No

If you need aids but do not currently have access to them, can you explain why?

11.11 Since your stroke have you received help from health and social services with getting benefits? (e.g. disability living allowance, attendance allowance, carer allowance)

- 1 Yes
- 2 No, but I would have liked help
- 3 I did not need any help
- 4 I was already receiving benefits

11.12 In the last 2 weeks did you require help from another person for everyday activities?

- 1 Yes
- 2 No

Section 12 Transport Issues /Employment

12.1 Can you drive? Yes No

12.1(a) If yes, were you driving prior to your stroke? Yes No

12.1(b) If No, why not?

No access to car

Cost

Could not get insurance

Medical Advice Stroke related Not stroke related

Other (specify) _____

12.1(c) Have you been driving since your stroke? Yes No

12.1(d) If No, why not?

No access to car

Cost

Could not get insurance

Medical Advice Stroke related Not stroke related

Other (specify) _____

12.2 Which of the following types of transportation have you used in the last 6 months? (Tick all that apply)

Walking Driving Myself Getting a lift with family or friends

Public transport such as bus or train Other (specify) _____

12.3 Overall, has transport become a problem for you because of your stroke?

Yes No

If Yes, please specify _____

12.4 Were you in full time or part time employment prior to your stroke Yes FT Yes PT No

12.4a Following your stroke, did your employment status change Yes No

If yes could you please specify _____

Frenchay Aphasia Screening Test (FAST)

GUIDELINES FOR ADMINISTRATION

The Frenchay Aphasia Screening test (FAST) has been designed to cover four major aspects of language which may be disturbed in the patient with aphasia: comprehension, expression, reading and writing. It has not been designed to test for articulatory disturbances of speech, such as dysarthria, or for speech apraxia which rarely occurs without some degree of aphasia. It has been developed for use with, and tested on, ill patients seen within days or weeks of an acute stroke (Enderby et al 1987)

Materials required

Picture card, pencil and paper.

Check

Patient is wearing spectacles, if needed. Patient can hear you adequately (raise voice if necessary).

Comprehension

Show patient card with river scene. Say 'Look at the picture. Listen carefully to what is said and point to the things I tell you to. Score 1 for each correctly performed. If instructions require repeating, score as error. Unprompted self-correction may be scored as correct. Score range 0 - 10.

Instructions

(a) River Scene.

1. Point to a boat.
2. Point to the tallest tree.
3. Point to the man and point to the dog.
4. Point to the man's left leg and then to the canoe.
5. Before pointing to a duck near the bridge, show me the middle hill.

(b) Shapes.

1. Point to the square.
2. Point to the cone.
3. Point to the oblong and the square.
4. Point to the square, the cone and the semi-circle.
5. Point to the one that looks like a pyramid and the one that looks like a segment of orange.

Frenchay Aphasia Screening Test (FAST) 'River Scene'

Frenchay Aphasia Screening Test (FAST) 'Shapes'

| <u>AMT</u> | |
|--|--------------|
| One point for each correct answer | Score |
| 1. Age | |
| 2. Time (to nearest hour) | |
| 3. An address for recall at end of test – this should be repeated by the patient to ensure it has been heard correctly: 42 West Street | |
| 4. Year | |
| 5. Name of hospital | |
| 6. Month | |
| 7. Date of birth | |
| 8. Year of first world war | |
| 9. Name of present president/monarch | |
| 10. Count backwards from 20 to 1 | |
| *11. Recognition of two persons (doctor, nurse etc) Additional item | |
| Total: / 10 / 10 (with item 11 instead of 6) | |

Other Comments

Finally there are some open ended questions

What, if anything, was particularly well done in the stroke care you received from health professionals since you left hospital?

What, if anything, needed to be specifically improved based on stroke care you received from health professionals

Any other comments?

Additional Information

Appendix 3: Carer Questionnaire.

Irish Heart Foundation National Audit of Stroke Care In association with the Department of Health
and Children

Community Audit of Stroke Care Research Protocol for Patient/Carer Survey

The Carer Questionnaire

Study Number: _____

Data Collector: _____ Date: _____ Duration: _____ Site Code _____

Section 1 – Carer Demographics

1.0 Gender: M F 1.1 Date of birth: _____

1.2 Marital status: Married Separated Divorced Widowed Never married/Single

1.3 Do You: Live alone Live with others

1.4 What is your relationship to the person who had a stroke?

Husband Wife Son Daughter Brother Sister Grandchild

Friend Neighbour Other please specify _____

1.5 How would you describe your current health status?

Excellent Good Average Fair Poor

1.6a How independent is your partner/relative since the stroke?

Fully independent Requires a little help Requires a lot of help

1.6b If he/she requires help or is fully dependent since the stroke are you the primary carer?

Yes No

1.7a How independent was your partner/relative prior to the stroke?

Fully independent Required a little help Required a lot of help

1.7b If he/she required help or was fully dependent were you the primary carer? Yes No

Section 2 Patient Cognition

Short Form of the Informant Questionnaire on Cognitive Decline in the Elderly (Short IQCODE)

(For use as cognitive screening tool with carers of patients who have aphasia)

There is no copyright on the Short IQCODE. However, the author appreciates being kept informed of research projects which make use of it. (Note: As used in published studies, the IQCODE was preceded by questions to the informant on the subject's sociodemographic characteristics and physical health.)

Now we want you to remember what your friend or relative was like 5 years ago and to compare it with what he/she is like now. 5 years ago was in 2002. Below are situations where this person has to use his/her memory or intelligence and we want you to indicate whether this has improved, stayed the same or got worse in that situation over the past 5 years. Note the importance of comparing his/her present performance **with 5 years ago**. So if 5 years ago this person always forgot where he/she had left things, and he/she still does, then this would be considered "Hasn't changed much". Please indicate the changes you have observed by **circling the appropriate answer**.

Compared with 5 years ago how is this person at:

| | 1 | 2 | 3 | 4 | 5 |
|---|---------------|----------------|-----------------|-------------|------------|
| 2.1. Remembering things about family and friends e.g. occupations, birthdays, addresses | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.2. Remembering things that have happened recently | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.3. Recalling conversations a few days later | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.4. Remembering his/her address and telephone number | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.5. Remembering what day and month it is | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.6. Remembering where things are usually kept | Much improved | A bit improved | Not much change | A bit worse | Much worse |

| | | | | | |
|---|---------------|----------------|-----------------|-------------|------------|
| 2.7. Remembering where to find things which have been put in a different place from usual | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.8. Knowing how to work familiar machines around the house | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.9. Learning to use a new gadget or machine around the house | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.10. Learning new things in general | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.11. Following a story in a book or on TV | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.12. Making decisions on everyday matters | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.13. Handling money for shopping | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.14. Handling financial matters e.g. the pension, dealing with the bank | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.15. Handling other everyday arithmetic problems e.g. knowing how much food to buy, knowing how long between visits from family or friends | Much improved | A bit improved | Not much change | A bit worse | Much worse |
| 2.16. Using his/her intelligence to understand what's going on and to reason things through | Much improved | A bit improved | Not much change | A bit worse | Much worse |

Section 3 Carer Satisfaction with Care

3.1 We are interested to know how satisfied you are with overall care you have received - where overall means care from **ALL** the people I have just listed. Please tell me how strongly you agree or disagree with these statements:

| | | Strongly Agree | Agree | Neither agree nor disagree | Disagree | Strongly Disagree |
|----|--|----------------|-------|----------------------------|----------|-------------------|
| 1. | You are satisfied with the total amount of professional help provided to you (include in this help to allow you time to do what you want to do and time off) | 0 | 1 | 2 | 3 | 4 |
| 2. | You are confident that services provided to you would adapt if your situation were to change (for example if you were ill or had an accident and were unable to do what you do now for the person you care for). | 0 | 1 | 2 | 3 | 4 |
| 3. | You are satisfied with information you have been given about help available from the community services for you.(include health and community services) | 0 | 1 | 2 | 3 | 4 |
| 4. | You are satisfied that services and equipment provided to you are usually of good quality | 0 | 1 | 2 | 3 | 4 |
| 5. | You are confident you would know whom to contact from the community services if you had a problem | 0 | 1 | 2 | 3 | 4 |
| 6. | You are satisfied with information you have been given about your role as a carer | 0 | 1 | 2 | 3 | 4 |
| 7. | You have been given enough training for the tasks (such as lifting or bathing) you need to do for the family member you look after. | 0 | 1 | 2 | 3 | 4 |
| 8. | You are satisfied with information you've been given about stroke. | 0 | 1 | 2 | 3 | 4 |

| | | | | | | |
|-----|--|---|---|---|---|---|
| 9. | You are satisfied with information you have been given about what to expect of someone who has had a stroke | 0 | 1 | 2 | 3 | 4 |
| 10. | You are confident you would know where to get information about any matter related to stroke or looking after someone who has had a stroke if you needed it. | 0 | 1 | 2 | 3 | 4 |
| 11. | You are satisfied with help you've received from the community services when you've had a problem | 0 | 1 | 2 | 3 | 4 |
| 12. | You are satisfied that the professionals involved with your care seem as concerned about you as the person you look after | 0 | 1 | 2 | 3 | 4 |
| 13. | You feel your opinion is ignored in making decisions about the person you care for | 4 | 3 | 2 | 1 | 0 |
| 14. | You are satisfied about information you have been given about financial help you might be entitled to (including benefits). | 0 | 1 | 2 | 3 | 4 |
| 15. | Given the choice, there are tasks you do now as a carer that you would rather not do | 4 | 3 | 2 | 1 | 0 |
| 16. | Services involved with your care lack co-ordination or don't work together | 4 | 3 | 2 | 1 | 0 |
| 17. | You could have been consulted more about the person you look after | 4 | 3 | 2 | 1 | 0 |
| 18. | As far as you can tell, the professionals involved with your care (doctors, nurses, social workers, physiotherapists, occupational therapists or any other professionals you see) seem to understand what being a carer is like. | 0 | 1 | 2 | 3 | 4 |
| 19. | You would have liked more assistance when applying for benefits and services | 4 | 3 | 2 | 1 | 0 |
| 20. | Essential changes to equipment, housing or services have been made too slowly | 4 | 3 | 2 | 1 | 0 |

| | | | | | | |
|-----|---|---|---|---|---|---|
| 21. | Services provided to you are at times of the day when it is convenient to have them | 0 | 1 | 2 | 3 | 4 |
| 22. | Information you have received has generally been accurate | 0 | 1 | 2 | 3 | 4 |

3.2 Overall, how satisfied are you with the help and support you have received from the community since _____ came home?

| | | | | |
|----------------|-----------|------------------------------------|--------------|-------------------|
| Very satisfied | Satisfied | Neither satisfied nor dissatisfied | Dissatisfied | Very dissatisfied |
| 0 | 1 | 2 | 3 | 4 |

Section 4 Carers Health

4.1. Compared to others your age, how would you describe your health?

Excellent or Good

Fair or Poor

4.2. Are any of these activities very difficult or impossible to do?

| | Yes | No |
|---|--------------------------|--------------------------|
| (j) Reaching or extending arms above shoulder level? | <input type="checkbox"/> | <input type="checkbox"/> |
| (k) Bathing or showering? | <input type="checkbox"/> | <input type="checkbox"/> |
| (l) Walking across the room (use of walking stick or Zimmer frame is ok)? | <input type="checkbox"/> | <input type="checkbox"/> |
| (m) Stooping, crouching or kneeling? | <input type="checkbox"/> | <input type="checkbox"/> |
| (n) Doing light housework, like washing dishes, tidying up, or light cleaning? | <input type="checkbox"/> | <input type="checkbox"/> |
| (o) Walking a quarter of a mile? | <input type="checkbox"/> | <input type="checkbox"/> |
| (p) Shopping for personal items, like toilet items or medicines? | <input type="checkbox"/> | <input type="checkbox"/> |
| (q) Lifting or carrying objects as heavy as 10 pounds, like a sack of potatoes? | <input type="checkbox"/> | <input type="checkbox"/> |
| (r) Heavy housework such as scrubbing floors or washing windows? | <input type="checkbox"/> | <input type="checkbox"/> |

4.3 Because of your health, is it too difficult or impossible for you to perform any of these activities without help from someone else?

| | Yes | No |
|---|--------------------------|--------------------------|
| (a) Managing money, like keeping track of expenses or paying bills? | <input type="checkbox"/> | <input type="checkbox"/> |
| (b) Writing, or handling and grasping small objects? | <input type="checkbox"/> | <input type="checkbox"/> |

Section 5 Carers Feelings

Next I want to ask about the way you have been **feeling recently**. These questions are being asked of people generally, so some questions may not apply to you, but for each statement, can you say what best describes the way you have been feeling in the past week.

5.1 I still enjoy the things I used to enjoy:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Definitely as much | Not quite so much | Only a little | Hardly at all |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.2 I can laugh and see the funny side of things:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| As much as I always could | Not quite so much now | Definitely not so much now | Not at all |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.3 I feel cheerful:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Not at all | Not often | Sometimes | Most of the time |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.4 I feel as if I am slowed down:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Nearly all the time | Very often | Sometimes | Not at all |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.5 I have lost interest in my appearance:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Definitely | I don't take so much care as I should | I may not take quite as much care | I take just as much care as ever |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.6 I look forward with enjoyment to things:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| As much as ever I did | Rather less than I used to | Definitely less than I used to | Hardly at all |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

5.7 I can enjoy a good book or radio or TV programme:

| | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Often | Sometimes | Not often | Very seldom |
| <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ |

Other Comments

If there is anything else you would like to tell us about your experiences of stroke care, please write it here.

Was there anything particularly good about your stroke care?

Was there anything that could be improved?

Any other comments?

Additional Information

Appendix 3: Carer Questionnaire –Patient RIP.

Irish Heart Foundation National Audit of Stroke Care In association with the Department of Health
and Children

Community Audit of Stroke Care Research Protocol for Patient/Carer Survey

The Carer Questionnaire FORM B

Study Number: _____

Data Collector: _____ Date: _____ Duration: _____ Site Code _____

Section 1 – Carer Demographics

1.0 Gender: M F 1.1 Date of birth: _____

1.2 Marital status: Married Separated Divorced Widowed Never married/Single

1.3 Do You: Live alone Live with others

1.4 What is your relationship to the person who had a stroke?

Husband Wife Son Daughter Brother Sister Grandchild

Friend Neighbour Other please specify _____

1.7 How would you describe your current health status?

Excellent Good Average Fair Poor

1.7a How independent was your partner/relative prior to the stroke?

Fully independent Required a little help Required a lot of help

1.7b If he/she required help or was fully dependent were you the primary carer? Yes No

1.7c. Did your relative with stroke come home directly from the hospital?

1.7d. If no, what happened after hospital discharge?

1.7e. If yes, were there community services organised for your family member once he/she came home? Yes No

What services were available?

For how long?

Section 3 Carer Satisfaction with Care

3.1 We are interested to know how satisfied you were with the overall care you received - where overall means care from **ALL** the following people: doctors, nurses, physiotherapists, speech & language therapists, occupational therapists, psychologists, social workers. Please tell me how strongly you agree or disagree with these statements:

| | | Strongly Agree | Agree | Neither agree nor disagree | Disagree | Strongly Disagree |
|-----|---|----------------|-------|----------------------------|----------|-------------------|
| 1. | You were satisfied with the total amount of professional help provided to you (include in this help to allow you time to do what you want to do and time off) | 0 | 1 | 2 | 3 | 4 |
| 3. | You were satisfied with information given about help available from the community services for you.(include health and community services) | 0 | 1 | 2 | 3 | 4 |
| 4. | You were satisfied that services and equipment provided were usually of good quality | 0 | 1 | 2 | 3 | 4 |
| 5. | You were confident you would know whom to contact from the community services if you had a problem | 0 | 1 | 2 | 3 | 4 |
| 6. | You were satisfied with information you were given about your role as a carer | 0 | 1 | 2 | 3 | 4 |
| 7. | You were given enough training for the tasks (such as lifting or bathing) you needed to do for your family member with stroke. | 0 | 1 | 2 | 3 | 4 |
| 8. | You were satisfied with information you were given about stroke. | 0 | 1 | 2 | 3 | 4 |
| 9. | You were satisfied with information you were given about what to expect of someone who has had a stroke | 0 | 1 | 2 | 3 | 4 |
| 11. | You were satisfied with help you received from the community services when you had a problem | 0 | 1 | 2 | 3 | 4 |

| | | | | | | |
|-----|--|---|---|---|---|---|
| 13. | You felt your opinion was ignored in making decisions about the person you cared for | 4 | 3 | 2 | 1 | 0 |
| 14. | You were satisfied about information you were given about financial help you might have been entitled to (including benefits). | 0 | 1 | 2 | 3 | 4 |
| 16. | Services involved with your care lacked co-ordination or didn't work together | 4 | 3 | 2 | 1 | 0 |
| 17. | You could have been consulted more about the person you looked after | 4 | 3 | 2 | 1 | 0 |
| 20. | Essential changes to equipment, housing or services were made too slowly | 4 | 3 | 2 | 1 | 0 |
| 21. | Services provided to you were at times of the day when it was convenient to have them | 0 | 1 | 2 | 3 | 4 |
| 22. | Information you received was generally accurate | 0 | 1 | 2 | 3 | 4 |

3.2 Overall, how satisfied were you with the help and support you have received from the community after your relative with stroke came home?

| | | | | |
|----------------|-----------|------------------------------------|--------------|-------------------|
| Very satisfied | Satisfied | Neither satisfied nor dissatisfied | Dissatisfied | Very dissatisfied |
| 0 | 1 | 2 | 3 | 4 |

Other Comments

If there is anything else you would like to tell us about your experiences of stroke care, please write it here.

Was there anything particularly good about your stroke care?

Was there anything that could be improved?

Any other comments?

Additional Information