

**ARE PATIENTS WHO ARE NOT ADMITTED TO HOSPITAL
FOLLOWING ACUTE STROKE DISADVANTAGED?**

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“Life’s not just being alive, but being well.”

Martial (c AD 40 – c AD 104)

Roman Poet

Dedication:

I would like to dedicate this thesis to my parents Ahmed Ebrahim and Zohra Gani, and to all the kind and wonderful stroke patients and their carers who willingly participated in this study, welcomed me into their homes and gave me glimpses into their lives. This has provided me with numerous fond and many sad memories that has, and will forever, influence me.

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Preface

Stroke is a growing health burden

Each year, over 110 000 people in England and Wales will have their first ever stroke. Half of survivors at six months will be left with various degrees of disability; many of whom will be requiring assistance in everyday cares¹. Stroke is the single biggest cause of severe disability in the UK and in many developed countries².

Declining SMR for stroke in developed countries

Although stroke mortality is declining in terms of age specific rates, it is still the third commonest cause of death in the majority of developed countries^{3,4}. With the changing demographics due to ageing populations, and the increase in survival after stroke, the burden of stroke may actually be increasing⁵.

Reducing stroke incidence and improving post stroke survival

As there are at present no curative treatments for the majority of stroke patients for the acute stroke event, effective health planning needs to be aimed at both primary and secondary prevention to reduce the incidence of strokes; and at comprehensive evidence-based stroke services to reduce morbidity and improve survival after stroke. Improved acute care with reduced post stroke complications is being recognised as a means of improving stroke outcome. Effective multidisciplinary rehabilitation with the aims of increasing stroke patient independence should improve patient outcome and decrease the burden of long-term stroke care⁶.

Admission of stroke patients to hospital

There has been an increasing tendency for local policies to advise rapid admission of all stroke patients to hospital. This has been driven by two main factors, the stroke thrombolysis studies that necessitated rapid patient admission and early CT head scanning; and the stroke unit rehabilitation studies that showed improved outcomes compared to standard hospital care.

Identifying the size of the burden

There is an ongoing need for comprehensive epidemiological information to assist in detecting the actual burden of stroke, to describe current management practices and to identify areas for potential changes for effective allocation of limited resources.

The Tees Stroke Register

This thesis is based on a subset of the data collected for the Tees Stroke Register (TSR). The TSR was an epidemiological study (the largest population based study of all stroke events at the time) of the impact of new incident stroke in the northern region of England. The National Health Service Research and Development, Cardiovascular Diseases and Stroke Programme funded this study.

This thesis

At the time of the study, and to a lesser extent now, there has been considerable controversy over whether care at home could produce equivalent or better patient outcomes than conventional in-patient care for stroke patients⁷. The reason for the survival advantage of stroke unit care was still being debated. There were two randomised controlled trials and one controlled study comparing standard care (of admission to hospital) and care at home. Overall, there was no definite benefit with either model⁸. There was concern that the possible detrimental effects of hospitalisation⁹, might outweigh the impact of the small potential beneficial effects of thrombolysis and negate the benefit of stroke unit care. Studies were also being undertaken to see whether the benefits of stroke unit care could be carried over into the community^{10,11}.

In view of these controversies, this thesis was undertaken to investigate the effects of early admission to hospital (admitted) compared to community managed (not admitted) stroke patients in the Tees Stroke Register. The characteristics of the patients, the severity of the strokes, and the care received will be described. Outcomes (case fatality, handicap, disability, complications, post stroke residence and depression) and resource utilisations (investigations undertaken, medications used, rehabilitation provided, and social service assistance provided) will be the main comparisons.

CHAPTER 1

INTRODUCTION

This chapter describes the impact of stroke, whether hospitalisation may be necessary or not, potential reasons for admission and non-admission of patients, an overview of previous studies comparing hospitalised and community treatment of stroke patients, potential ways to reduce the impact of stroke, the rationale for the Tees Stroke Register and the potential advantages and limitations of community based stroke registers.

The effect of stroke: A major public and personal impact on health

Strokes affect around 140 000 people in the England and Wales every year. Of these people, 70% will be suffering from a first ever in a lifetime stroke with the remainder having a recurrent stroke². In the United Kingdom, about 5% of the national health services budget is spent on stroke management and patient care^{12,13}. Stroke accounts for 10% of all deaths in England and Wales¹⁴. It is also the single biggest cause of severe disability and the third most common cause of death in the UK and other developed countries⁴.

Stroke can results in a devastating impact on both the individual and family. Around a third of patients who survive their stroke are dependent in activities of daily living at one month and over 50% of survivors have some disability at six months including limb weakness (53%), communication problems (15%) and urinary incontinence (15%)¹⁵. Depression amongst survivors is around 11 to 25% at one month and 15%

at 4 months^{16,17,18}. Carers of disabled stroke patients are more dissatisfied with their social life and more distressed than age and sex matched controls¹⁹. In addition there may be the financial burden, social isolation and change in future outlook. Unlike most other chronic diseases and cancers, stroke is a sudden and usually unexpected event with the resultant difficulties in patients, families and carers coming to terms with their new restricted futures.

Hospital admission: Is it necessary?

At the time of our study, it was uncertain whether hospital admission was needed for the optimum care and treatment of all stroke patients^{7,20}. There now is evidence suggesting hospital stroke units, which have been shown to be better than general hospital care^{6,21,22} or stroke pathway care²³; may also be better than organised community care¹¹. However, general hospital care or stroke pathway care in hospital may have worse outcomes than domiciliary care or standard community care^{11,24}. The reasons for this still need to be determined.

Admission rates for stroke in the United Kingdom vary considerably with up to 86% of first ever stroke patients being hospitalised^{24,25}. Admission rates seem to be increasing over the last decade with many local policies now recommending early hospital admission. This is consistent with the National Service Framework (which post dates our study) recommendations published in 2001², which states:

“All patients who may have had a stroke will usually require urgent hospital admission.”

The Intercollegiate Stroke Working Party also recommends that patients should only be managed at home if appropriate assessments, investigations, care provision and supervised specialist stroke care can be provided²⁶. Care at home schemes have been tried with variable effectiveness. One trial has randomised patients to admission or home care¹¹; others to additional home care service^{10,27} early home rehabilitation²⁸ or early supported discharge^{29,30,31}.

It is uncertain whether with new developing hypo-acute stroke therapies, patients may in future require admission for treatment or may be able to be treated in the community. Pre-hospital thrombolysis for acute myocardial infarction is now being considered strongly where transfer to hospital is delayed³². New neuro-protective agents may not require pre-treatment brain imaging.

Whether acute hospital admission for all first-ever adult stroke patients (all ages, all severities, excluding subarachnoid haemorrhages) will be more beneficial overall for all outcomes than care at home from the outset, is still uncertain. The answer to this will have important potential implications in the re-organisation of stroke care services as at present, stroke accounts for about 20% of medical bed usage²⁶. Older studies on stroke trends noticed a decline in stroke case fatality that was more than expected by the reduction in age and sex related stroke incidence^{33,34}. With the progressively ageing population and higher stroke incidence with age^{2,35}, absolute numbers of stroke may start increasing in the future^{36,37,38,39}. This will result in increasing pressures for acute hospital beds. Stroke hospital admissions in the UK have on average doubled in 1978-87 to 1988-97⁴⁰.

There are now clear clinical guidelines advising the acute care arrangements (hospital or home) of all new onset stroke patients⁴¹. The evidence for this is largely derivative in that those patients in trials who accessed stroke unit care did better than those who did not^{6,41}; and for a few individual patients, thrombolysis within three hours of stroke onset may be beneficial⁴².

Potential reasons for admission and non-admission

General Practitioners would on average be expected to encounter 5-7 new incident stroke patients (2/3rds of whom would be first ever stroke patients) per year depending on their practice size. It is not feasible to expect them to maintain expertise in stroke management. Most GPs still do not have any other option apart from hospital admission for rapidly accessing multidisciplinary stroke expertise and care.

Potential reasons for admission include the need to confirm the diagnosis and prognosis, to initiate acute therapy, to minimise complications, to identify and treat complications early, to access co-ordinated multidisciplinary rehabilitation, to initiate optimal secondary prevention, and to provide for patients and carers information and social needs⁴³.

Admission patterns in the past have shown to be affected by various factors⁴⁴. The reasons for variations in admission rates are multifactorial and include stroke severity, pre-stroke dependency, patient support at home, as well as the perceptions of the patients' first medical contact. Reasons making admission more likely include severe neurological deficits, living alone, and self-referral to Accident & Emergency units^{24,44,45}.

There are numerous possible reasons as previously identified by Sudlow and Warlow⁴⁶, why patients may not be admitted to hospital. These include early death before hospital admission is possible, no perceived advantage in hospitalisation (including where death seems the likely outcome), perceived adequate care provision in the community, mild stroke deficits, refusal of patients to attend (including fear of hospitals and inconvenience for the patient and family), limited resources (hospital full or far away), and non-presentation by the patient (and family) to medical services (including late diagnosis).

Studies comparing hospital admission and community care

Previous large international population based studies that have recruited all strokes, have not analysed the possible differences in risk factors, treatment and outcome in those managed in the community and those hospitalised^{47,48,49}.

There is only one prospective randomised controlled trial (RCT) comparing care at home, and hospital care (stroke unit care and stroke team care)¹¹. Kalra *et al* concluded that stroke unit care was superior to domiciliary stroke care, which was in turn equivalent to (and possibly superior to) in-hospital stroke team care. There are few other studies comparing the outcomes of patients admitted to hospital and those not admitted to hospital. The most important of these is Bhalla's observational paper that concluded that there may be factors associated with hospitalisation which may result in certain groups of stroke patients having poorer survival and disability rates than those who stay at home²⁴.

Two small randomised control trials and one larger non-randomised trial²⁷, have looked at whether additional services at home resulted in reduced hospital admission compared to standard care (which often included admission) without any adverse outcomes. Overall, there were no differences in patient or carer outcomes. The two small RCTs (London⁸, n=43, and Northampton⁵⁰, n=21) were part of larger trials. The larger non-RCT, Wade *et al*'s²⁷ study, was not a direct comparison of admitted and not admitted patients as most patients (including those in the intervention arm) were hospitalised. It concluded that trying to prevent hospital admission was complex. There also seemed to be an apparent lack of extra benefit from additional home care services compared to standard care. Since Wade's paper, there have been numerous trials of various intensities and timings of additional physiotherapy compared to standard care that overall suggest significant benefits in some outcomes in certain patients²⁶.

The three main studies characteristics, outcomes and potential confounding factors are described next (summarised in Table 1.1).

Table 1.1: Characteristics of the main papers on admitted (hospitalised) and not admitted stroke patients.

Author , Year and Title	Baseline characteristics	Exclusions	Study size	Randomisation and Analysis	Intervention	Follow-up	Main outcomes	Conclusions
Kalra et al 2000, Alternative strategies for stroke care: a prospective randomised controlled trial	Aver age 76, Mod-severe strokes only, Clinical criteria and stroke types well matched. Lost to f/u: 3ST, 9 DSC	Severe disability pre-stroke, mild or severe strokes, institutionalised, specialist needs	979 screened, 457 randomised	Block randomisation, computer generated random no., intention to treat analysis	Stroke Unit (SU), Gen med ward/stroke team (ST), Domicil stroke care (DSC) within 72 hrs	3,6,12 months	Mortality or instit at 1 yr, without severe disability (Rankin 0-3, Barthel 18-20)	14%, 85% vs 30%,64% vs 24%,71% (similar at 3+6mo), SU>DSC>ST: 51 DSC admitted to SU within 2/52, Rankin 0-2 no diff.
Bhalla et al 2001, Does admission to hospital improve the outcome for stroke patients?	age data NOT given, community based stroke register, not matched groups	IP strokes, PIH/SAH in regression model	975 FES, 812 admitted, 163 community treated	Descriptive study, multiple regression modelling with goodness to fit checks	Hospitalisation: Observational	3 mo.	Mortality and non-dependency (BI>=18)	35%,47% vs 8%,72% Community>hospitalised: Adjusted OR (MRM) still signif diff.: Problems: subtype masking, incomplete data
Wade et al 1985, Controlled trial of a home-care service for acute stroke patients.	similar groups and stroke severity	nil	440 intervention, 417 control	controlled trial, not randomised	New home care service for 6 mo	3wk, 6 mo.	Funtional recovery, emotional adjustment, relative stress, admission rates	No differences except hospital bed days (intervention>control)
SU: Stroke Unit, ST: Stroke Team, DSC: Domiciliary Stroke Care								

The Orpington study (Kalra *et al*)¹¹

Comparison

This study compared the management of acute stroke patients at home by a multi-disciplinary stroke team with those admitted to hospital, managed by either a hospital stroke team or a multi-disciplinary stroke unit.

Methods

Randomisation was done by block randomisation with allocation codes held away from the study area.

Participants

Patients with a clinical diagnosis (WHO definition) of acute stroke up to 72 hours after stroke onset, were included in the study. Only moderate to severe strokes were enrolled. Exclusions included mild and very severe strokes, severe pre-stroke disability or institutionalised patients. A physician did the initial assessment to confirm the diagnosis and eligibility for inclusion.

Interventions

Care on the stroke unit (acute and rehabilitation) was by a specialist multidisciplinary team led by a stroke physician. The stroke team care was provided on general medical wards under the care of the admitting consultant with a specialist team undertaking assessments and collaboration with the ward based nursing and therapy staff. The domiciliary care was managed in their own home by a specialist team (who provided therapy for a maximum of three months) with district nurse and social service support.

Outcomes

There were significant differences in the primary outcome between stroke unit and stroke team, stroke unit and home care but not between stroke team and home care at three, six and twelve months. Mortality was significantly lower in stroke unit care compared to home team care at three months only. There was no significant difference between any of the groups in rates of institutionalisation at all time intervals. Modified Rankin (0-3) and Barthel 15-20 outcomes were significantly better in stroke unit care compared to home care at 12 months only. Median Rankin scores (except for stroke team care which was higher at three months) were the same, and not significantly different in comparing any of the groups at all time intervals.

Confounding factors

More than half (53%) of clinical strokes were excluded. Very few pre-stroke, baseline characteristics were reported. It is unclear whether the groups were well matched in pre-morbid case mix factors. The home care group tended to have older patients with a median age of 77.7 compared to 75 for the stroke unit group ($p=0.09$).

There was a significant crossover from the home care group to the stroke unit. One third (51/149) of home care patients were hospitalised within two weeks of their strokes. Of those, 39/51 were admitted despite no clinical deterioration.

Hospital teams tended to do worse than home care in mortality, institutionalisation and median Rankin scores, although not reaching significance (mortality $p=0.07$ at one year).

Assuming the 9/149 (6%) of home care treated patients lost to follow up were not deceased or institutionalised, there would be no significant

difference in mortality and institutionalisation between the stroke unit and home care treated patients. No patients were lost to follow up in the stroke unit care group.

Overall, more patients received therapy (and longer durations of therapy) in the stroke unit care group than the other two groups. Despite this, there were no significant differences in median Rankin scores at all intervals and using a binary Rankin category of 0-2 instead of 0-3 results in no significant differences at one year comparing any of the groups.

Common causes of death were identified as chest infection, dehydration / renal failure, and pulmonary embolism in the first three months; and recurrence or unrelated illness thereafter. The first two apparently common causes of death are unusually common as patients with very severe strokes and with any swallowing problems were excluded from the study. Dehydration with renal failure 'may cause death where basic care is lacking'⁵¹ and should be an unlikely cause of death with the apparent specialised additional to routine care, care teams provided.

The South London Stroke Register (Bhalla *et al*)²⁴

Comparison

This study compared the management of acute stroke patients at home by standard home care with those admitted to hospital.

Methods

This was a prospective, descriptive study. A community-based register of first in a lifetime stroke was established. Patients were assessed within 72 hours (examination by stroke register doctor) of stroke onset and at three months (interview). Data was confirmed with medical records and general practitioner notes.

Participants

Sudden death patients, even if due to a stroke were excluded. Of those having strokes in the community, 812 (83%) were admitted to hospital and 163 (17%) remained in the community.

Interventions

None specified. One third of admitted patients were treated on a stroke unit.

Outcomes

Significantly more hospitalised than community patients were living alone, had atrial fibrillation, had worse stroke severity indicators and overall had more investigations (except carotid dopplers) performed. At 3 months, 35% of admitted and 8% of not admitted patients had died ($p < 0.001$), and 47% of admitted and 72% of not admitted patients had Barthel ADL index scores ≥ 18 ($p < 0.001$). After adjustment for case mix variables, odds ratios were significantly higher for dependency

(Barthel <18), and tended to be higher for death at 2.21 (0.96-5.12) in admitted compared to not admitted patients.

Confounding factors

The community group was about 1/5th the size and had proportionally more missing data than the admitted group. Almost 1/5th of the community group was subtype unclassifiable. Incidence rates were low (1.04/1000 population / year) suggesting possible missed cases. CT head scans rates were significantly higher in admitted patients. It is unclear whether the study team arranged diagnostic tests, therapy or advised on patient care. It is uncertain what the median time to admission was. There were significant differences in the baseline characteristics of the groups with almost all patients with severe stroke indicators being admitted (all TACS admitted, 255/258 GCS<13 admitted and only 4/358 with paralysis not admitted). Performing multivariate analyses with very small numbers in some of the community treated patient's severity factors is prone to incorrect conclusions. Combining subtypes in the multivariate analysis may potentially mask subtype effects.

As Davenport *et al*⁵² demonstrated, comparisons may be misleading if all case mix factors are not accounted for. Bhalla *et al* acknowledged the potential non-adjustment for all case mix variables and possible subtype masking. They felt that this potential non-adjustment probably did not account for the differences as they conducted a large study over a long period of time which is required to overcome the play of chance⁵³.

The Frenchay study (Wade et al)²⁶

Comparison

This study compared the management process in one area of the city with the management process occurring in a second area that had ready access to an additional home care stroke team. The teams prime aim was to maintain patients in their own home.

Methods

It was a controlled clinical trial in which the 96 GP practices within the study health care district were subdivided into two groups, according to the two district nursing units. All stroke patients registered with 47 of the GP's formed the control group and those registered with the other 49 formed the trial group.

Participants

All patients (n= 857) with a clinical diagnosis (WHO definition) of acute stroke (all severities, first or recurrent stroke) entered on a community stroke register were included. Average dependency (mean Barthel index) at inclusion was 9.

Interventions

A multidisciplinary team provided care in the patients' homes. A neurologist with an interest in stroke care attended weekly team meetings. The GP maintained clinical responsibility. The intervention lasted up to six months after the acute stroke.

Outcomes

Patient, carer and resource outcomes at six months were analysed. There were 440 patients in the trial group and 417 in the control group. Overall, there were no differences in patient outcomes (Barthel ADL, activities

index, depression) at six months in the two groups. Comparing the not admitted patients only, there were no differences in six month Barthel scores. There were no differences in patient or carer adjustment to stroke impact. The trial group used significantly more hospital bed days.

Confounding factors

Numerous patients died before being assessed (23% in the control group and 18% in the trial group) and had missing baseline assessments (only 228/417 in the control and 250/440 in the trial group had Barthel scores assessed within seven days). Only 31% of the trial group were never admitted to hospital (21% in the control group).

Significantly more trial patients had less severe strokes (initial loss of consciousness). The trial area appeared to have a higher stroke incidence and as a consequence also higher hospital admission/population incidence rates. The extra strokes in the trial area may have used additional hospital bed days resulting in the higher bed days used.

The uptake and usage of the additional service was not able to be actively encouraged by the trial team. The non-randomisation, the non-blinding of assessments, the possible notification bias, and the insensitivity of the upper range of the Barthel index⁵⁴ may all have influenced the final outcomes.

In terms of strength of evidence, Kalra's randomised control trial has greater weight than Bhalla' descriptive study. There are several possible explanations why patients admitted may do better or why patients not admitted may do better post stroke. Both studies may be valid for their specific stroke patient cohorts, and their care provision resources in hospital and in the community.

Reducing the impact of stroke

Health policy has recently become pro-active in the quest to reduce the impact of stroke. Numerous guidelines are now available with the National Clinical Guidelines for Stroke having been published in March 2000²⁶, and updated in June 2002⁴¹, the Royal College of Edinburgh consensus document in November 2000⁵⁵, and the Scottish Intercollegiate Guidelines Network in 1997⁵⁶. Stroke forms Standard Five of the National Service Framework for Older People for England. The Standard is as follows²:

“The NHS will take action to prevent strokes, working in partnership with other agencies where appropriate.

People who are thought to have had a stroke have access to diagnostic services, are treated appropriately by a specialist stroke service, and subsequently, with their carers, participate in a multidisciplinary programme of secondary prevention and rehabilitation.”

There are four main spheres in tackling the burden of stroke death and disability:

- Primary and secondary prevention,
- Acute treatment and immediate care,
- Early and continuing rehabilitation,
- Long-term care and support

The most effective is still primary prevention, but secondary prevention and reducing disability by efficacious rehabilitation are playing a more important role than before. This is as a result of decreasing case fatality. Hypo-acute stroke treatment (such as thrombolysis) is still in its infancy and currently has a small overall impact on stroke outcome⁵⁷.

Prevention

Although the proportion of people at high risk have a higher incidence of stroke than those with moderate risk, because of the much greater numbers of people in the moderate risk group, the majority of strokes occur in the this group. Strategies thus involve targeting health resources at both those individuals at high risk and moderate risk. Population based strategies encouraging a healthier lifestyle, such as reducing smoking, increasing levels of physical activity, encouraging increased fruit and vegetable consumption and reducing salt content in processed foods will have a much greater impact than individual based strategies⁵⁸ but are difficult to implement⁵⁹. High risk patients have more to gain from specific risk reduction strategies than the general population, as fewer need to be treated to prevent one stroke⁶⁰ for example people with atrial fibrillation^{61,62}, hypertension⁶³, hypertension after stroke⁶⁴, or previous transient ischaemic attack^{65,66}. Post stroke information provision may play a factor in reducing future risks in this high risk group of patients.

Acute care

The aims of treatment are to increase survival and reduce the impact of stroke on the patient, family and carers. Successful treatments result in reduced mortality, impairment, disability and handicap. There should also be a favourable impact on quality of life. At present, experimental neuro-protective treatments and proven benefit thrombolytic treatments (for the appropriate few) are unlikely to have much overall impact due to their very restricted and selective use. Most treatments in the acute phase are supportive. Trials are needed to identify which empirical treatments and measures are of benefit⁶⁷.

Brain scanning within 48 hours in most cases is recommended²⁶ and giving aspirin early (if haemorrhage is unlikely)⁶⁸ increase survival chances⁶⁹. Vigilance and prophylaxis with regards to swallowing problems⁷⁰; immobility (deep vein thrombosis risk); infections; malnutrition⁷¹ and pressure damage risk⁷² should reduce complications.

Rehabilitation

Rehabilitation needs vary according to stroke deficits and patient needs. The current gold standard approach is multidisciplinary involvement coordinated by specialist care. Early intensive rehabilitation in a hospital stroke unit setting improves the long-term outcomes for stroke patients^{6,21}.

Long-term support

Speed of recovery after a stroke is very variable. Stroke patients need of rehabilitation vary in intensity and duration. Any patients with persistent disability at six months may benefit from further targeted rehabilitation input⁷³. The identification and treatment of depression and provision of information about facilities available to stroke patients and carers may improve their quality of life⁷⁴.

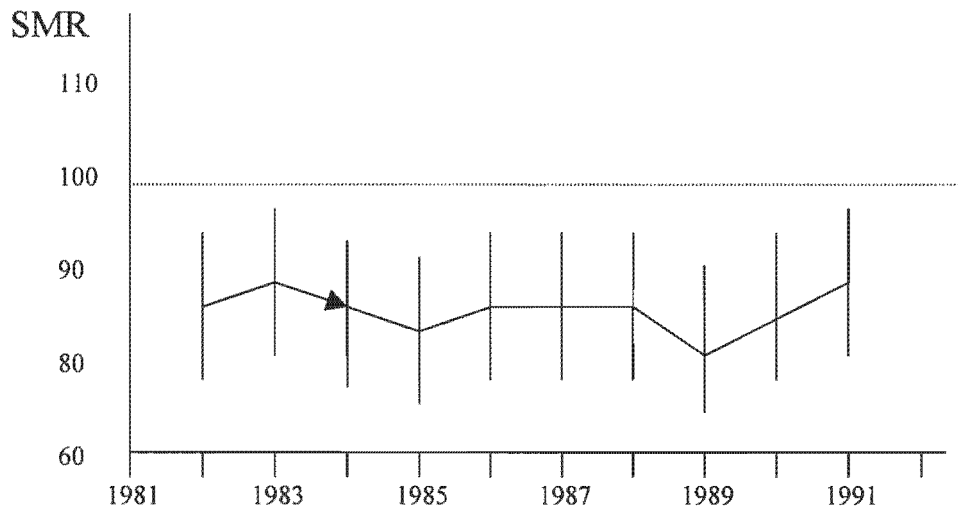
Application to our study

Our study was able to identify whether not admitted patients were disadvantaged or not following stroke, as well as taking into account that the early hospitalised patients care standards at the time may not have reached the “gold standard” recommendations above.

The Tees Stroke Register

The Tees Stroke Register project was initiated in 1994. Funding was from the United Kingdom National Health Service Research and Development Cardiovascular Disease and Stroke Programme. The reason for the project was that of consistent significant differences in standardised mortality ratios (SMRs) in two neighbouring former health authority districts (Darlington/Teesdale and North Tees). These differences were present for over ten years (Figure 1.1).

Figure 1.1: 3 year rolling SMR for stroke in North Tees using Darlington as the reference population with 95% confidence intervals.



Numerous potential reasons for the differences existed. These included differences in lifestyles, socio-economics, stroke incidence, stroke severity, co-morbidity, patterns and quality of care. In order to elucidate the potential factors resulting in the differences in SMRs between the two districts, a stroke registry was established. The main aims of the project were:

1. To establish a stroke register and stroke database in the two adjacent health districts.

2. To describe and compare stroke incidence, morbidity and mortality in the two districts.
3. To develop hypotheses to explain reasons for the difference in SMR for stroke and to identify areas requiring further exploration.
4. To compare patterns of care of stroke patients in the two districts.

As the study was population based (304,700) with all adults included (aged 18 and greater), comparisons between admitted and not admitted stroke patients could be undertaken. The register included detailed descriptions on service utilisation in addition to the extensive risk factor and pre-morbid profiling, severity assessments and outcome assessments⁷⁵. This allowed accounting for important case mix factors in the interpretation of any differences observed in admitted and not admitted patients.

The register also complied with the key criteria identified by Malmgren *et al*³⁴ and Sudlow and Warlow^{46,76} for good stroke incidence studies. The core criteria include standard definitions (WHO stroke definition, first-ever-in-a-lifetime stroke), standard methods (complete community-based case ascertainment, based on multiple overlapping sources; prospective study design, ideally with "hot pursuit" of cases; large, well-defined, stable population and a reliable method for estimating the population denominator), and standard data presentation (whole years of data collection, not >5 years of data averaged together, men and women presented separately, ages up to ≥ 85 years if possible included, standard mid-decade age bands (eg, 55 to 64 years) used in publications, unpublished 5-year age bands available for comparison with other studies, and presentation of 95% confidence intervals around incidence rates).

Potential benefits and limitation of registers

Sudlow and Warlow⁴⁶ also characterised the potential benefits of community based stroke registers. These benefits are numerous and include the following; identification of a population's stroke burden (incidence, stroke types and subtypes, prevalence, case fatality, complications, post stroke morbidity and handicap), comparisons with other registers (geographic and secular variations in incidence, process of care and outcomes), hypothesis generating and testing, deriving and testing prognostic models, assessing and improving stroke management (audit, secondary prevention measures), planning stroke services (utility of investigations, place of care and therapy provision), and enhancing education, awareness and knowledge of stroke.

There are however limitations in the interpretation of the information gathered. Registers are descriptive and allow generation of hypotheses, which should be tested with case-control studies using unbiased incident cases. Registers can also be used as a pool of patients for entry into randomised controlled trials. They are useful in providing very detailed information of stroke care in its catchments area, but this may not be able to be extrapolated more widely without standardising for all potential factors which may not all be recorded.

CHAPTER 2

AIMS, OBJECTIVES AND SETTING OF THE STUDY

This chapter describes the aims and objects of this thesis, and the setting of the Tees Stroke Register. The local epidemiology, and local services (staff and facilities) for admitted and not admitted stroke patients are described.

The Aims of the study were:

1. To compare the structure, process and outcomes of care of patients with acute stroke (first ever stroke) who were and who were not admitted to hospital.
2. To compare the demographic and clinical features of patients who were and who were not admitted to hospital.
3. To identify demographic and clinical features associated with hospital admission following acute stroke.

The Objectives of the study were:

1. To describe services available to stroke patients in the two adjacent health districts.
2. To compare the demographic and clinical features of patients with acute stroke who were and who were not admitted to hospital.
3. To compare the acute care, rehabilitation, social care and secondary prevention of patients who were and who were not admitted to hospital following acute stroke.
4. To compare the following outcomes of patients with acute stroke who were and who were not admitted to hospital: mortality, stroke recurrence, neurological impairment, disability and depression.

5. To compare the views of patients with stroke who were and who were not admitted to hospital, about stroke advice and information received.

The setting of the Tees Stroke Register (TSR)

Local epidemiology

The former Northern Region had one of the highest standardised mortality ratios (SMR) for stroke in the United Kingdom (highest of the English regions). No district within in the region had an SMR of less than 100 in 1992. The five year rolling average for the preceding five years for the region was 117 (district range 101-128)⁷⁷. Although direct comparability has been reduced by both district boundary changes within the region and region boundary changes, the three year rolling average SMR for 1994-1996 were still all above 100 for all former districts and 109 for the new region⁷⁸.

In the two adjacent former health districts, Darlington (including Teesdale) and North Tees, there has been marked difference in SMRs for stroke over several years. Despite both districts having very similar populations, Darlington has consistently had for both men and women, higher SMRs than North Tees. The unexplained identified difference in SMRs was the stimulus for the commissioning of the Tees Stroke Register.

Local services

Darlington and Teesdale

Hospitals

Darlington and Teesdale was served by a 447 bedded district general hospital, Darlington Memorial Hospital (DMH) and a 62 bed community hospital at Barnard Castle run by the general practitioners. All the main specialities were available at DMH including four intensive care and five coronary care beds. There was an age related admissions policy. Those aged >75 years old were admitted directly to acute geriatric wards. There was no stroke unit and no stroke pathway. Stroke patients were treated under the admitting geriatrician or general physician depending on the patients' age. Neurosurgery and cardiothoracic surgery services were based in the adjacent regional referral unit in Middlesbrough. Neurology services were an outreach from Middlesbrough where the inpatient beds were. A neurovascular clinic was established in Middlesbrough towards the end of the Tees Stroke Register.

Hospital Facilities

There were 138 acute medical, elderly care and rehabilitation beds. All routine investigations including CT head scanning (during normal working day), carotid dopplers and echocardiograms were available at DMH. Barnard Castle inpatients had access to blood investigations and on-site basic x-rays. Other investigations required referral to DMH. All MRI, carotid angiography and cranial angiography were undertaken in Middlesbrough.

Hospital Staff

The medical department consisted of six consultants; two with an interest in elderly care medicine. The others interests were cardiology, chest medicine, gastroenterology and diabetes & endocrinology. There were

four whole time equivalent (wte) physiotherapists and 1 wte helper associated with the medical, elderly care wards and outpatient medical services at DMH. Physiotherapy was also available at Barnard Castle. There were 1.75 wte occupational therapists and 2 wte helpers who covered all the medical and care of the elderly wards. There was funding for 1.7 wte speech and language therapists who were expected to provide only four sessions for in-patient communication problems, eleven sessions for out-patient communication problems and two sessions for dysphagia management in the community. During the period of the Tees Stroke Register, the service provision was erratic and predominantly no inpatient speech and language or dysphagia service was available. There was 1 wte dietician providing both an inpatient and outpatient service.

Community

Primary care facilities

There were 21 general practices serving the district. There were 1218 nursing home beds, 585 residential home beds and 32 long stay beds.

Primary care staff

There were during the study period around 87 general practitioners. There were 46 district nurses and 25 health visitors. Figures for practice nurses were unavailable. Physiotherapy was mainly undertaken in outpatients or in Barnard Castle for those in Teesdale. There was very limited access to any other form of therapy staff (occupational therapy, speech and language therapy, dysphagia services).

North Tees

Hospitals

North Tees was served by a 600 bedded district general hospital, North Tees General Hospital (NTGH). Overlapping the catchments area was Sedgefield community hospital run by the general practitioners with geriatric consultant input. All the main specialities were available at NTGH including three to four intensive care and six coronary care beds.

Neurosurgery and cardiothoracic surgery services were based in the adjacent regional referral unit in Middlesbrough. A weekly outpatient neurology service was provided as an outreach from Middlesbrough where the inpatient beds were. A neurovascular clinic was established in Middlesbrough towards the end of the Tees Stroke Register. Prior to this, the two consultants with an interest in stroke saw urgent TIA and minor stroke referrals in their general outpatient clinics.

Stroke patients were initially treated under the admitting geriatrician or general physician on a 30 bed acute admission ward. Patients suitable for active rehabilitation were transferred to the stroke unit or a medical rehabilitation ward if no stroke unit bed was available, under the care of one of two elderly care physicians who had an interest in stroke disease. There was also a 12 bed young disabled unit where occasionally young stroke patients would be admitted. There was a multidisciplinary approach to rehabilitation and patient care with regular audit and follow up of patients. General physicians cared for non-disabling strokes not referred for rehabilitation. Follow up and investigation of these patients were at the discretion of their consultants.

Hospital facilities

There were 122 general medical beds, 70 medical rehabilitation beds (including an 18 bed stroke unit), and 57 longer stay (continuing care, terminal care, respite and slow stream rehabilitation) beds. All routine investigations including CT head scanning (during normal working day), carotid dopplers and echocardiograms were available at NTGH. Initially 'out of hours' CT scanning was undertaken in Middlesbrough General Hospital. During the study, an acute scanning service was established in NTGH. Sedgefield hospital inpatients had access to blood investigations and on-site basic x-rays. Other investigations required referral to NTGH. All MRI, carotid angiography and cranial angiography were undertaken in Middlesbrough during the study period.

Hospital staff

The medical department consisted of 8.2 wte general medical consultants, 1.7 wte with an interest in geriatric and stroke medicine. There were 6.42 wte physiotherapists of whom 2.5 wte covered the stroke unit and the young disabled unit, 1.42 wte the day hospital and out patient rehabilitation and 2.5 wte the medical rehabilitation wards. There were 3.65 wte occupational therapists, of whom 2 wte covered the stroke unit and the young disabled unit and 1.65 wte the medical rehabilitation wards. In addition, there were 4.65 wte generic helpers, 3 wte on the stroke unit and young disabled unit and 1.65 on the medical rehabilitation wards. There were 1.5 wte speech and language therapists (0.1 wte allocated to the stroke unit), who also provided dysphagia assessment services. There were 5 wte dieticians covering all hospital and community patients. 1 wte was allocated to the stroke unit, medical rehabilitation wards and the diabetic service.

Community

Primary care facilities

There were 29 general practices serving the district. There were 932 nursing home beds, 524 residential home beds and 57 long stay beds.

Primary care staff

There were during the study period around 100 general practitioners. There were 202.5 practice nurses, 116.5 district nurses and 34 health visitors (wtes). Physiotherapy was mainly undertaken in outpatients or in Sedgefield community hospital. Although the dietetics and speech and language therapy departments at NTGH covered the community, there was limited access and facilities.

Table 2.1 compares the community staffing levels, bed facilities and consultant levels in the two districts. The rates are per 1000 residents over the age of 65 in each district. Absolute numbers and rates of consultant staffing levels were higher in North Tees General Hospital compared to Darlington Memorial Hospital. Absolute numbers and rates of acute and rehabilitation beds were also higher in NTGH. Consultant to bed ratios (6/138, 0.043) were higher in DMH than NTGH (8.2/214, 0.038). In the community, both absolute numbers and rates of all types of staff were higher in North Tees. For nursing and residential beds, absolute numbers and rates were higher in Darlington.

Table 2.1: Staff and facilities: absolute numbers and rate per 1000 residents over the age of 65 in each district and combined.

	Darlington		North Tees		Combined
	n	rate	n	rate	rate
Population > age 65	21 607	-	24 729	-	46336
Consultant medical staff	6	0.28	8.2	0.33	0.31
General practitioners	87	4.03	100	4.04	4.04
Practice nurses	-	-	202.5	8.19	-
District nurses	25	1.16	34	1.38	1.27
Health visitors	46	2.13	116.5	4.71	3.51
Nursing beds	1218	56.40	932	37.70	46.40
Residential beds	585	27.10	524	21.20	23.93
Long stay beds	32	1.48	57	2.31	1.92
Acute & rehabilitation beds	138	6.39	214	8.65	7.60

CHAPTER 3

METHODS AND POPULATION

This chapter describes the methods of the study, including study design, study population, case recruitment, categorisations of patients and strokes, and the information collected.

Overview

The population of this study is a subset of the Tees Stroke Register population. The patients were all residents of the area, had their first ever in their lifetime stroke and were not inpatients in hospital at the time of stroke onset. Patients with subarachnoid haemorrhages were excluded. The list of protocols used in the Tees Stroke Register is in table 3.1.

I have written the protocols and documented all the flowcharts. These underwent numerous drafts with reviews and input by all the study team members and supervisors.

A summary of the study methods and definitions follows. For further details on each aspect, reference will be made to the relevant section in Appendix 1.

Table 3.1: List of protocols. (please refer to Appendix 1 for more detail)
1. Definition of study cases protocol
2. Stroke inclusion criteria protocol
3. Community sources of notification protocol
4. Hospital sources of notification protocol
5. Processing of notifications protocol
6. Initial assessments protocol
7. Hospitals discharge notifications protocol
8. DHA district notifications protocol
9. DHA death notification protocol
10. CT (head) notifications protocol
11. One month assessment protocol
12. Six month assessment protocol

Study design

Type of study

This is a descriptive prospective observational epidemiological study. We did not aim to change “usual” stroke care in any way.

Study population (Appendix 1 section 1.2)

The study population comprised of all the people who lived in the study areas during the time of the study recruitment period. People were deemed resident if they had their primary residence in the study area and were ordinarily resident in the study area. The total resident population in

Darlington was 125,700 and North Tees 179,00 (1996 mid year estimates). The total over 65 years olds were 21,600 (17.2%) and 24,700 (13.8%) respectively. Table 3.2 provides further age and sex breakdown of the combined populations as recommended in good incidence studies⁴⁶.

Table 3.2: Age and sex breakdown of residents in Darlington and North Tees combined.			
Age bands	Male	Female	All
0-14	31384	29891	61275
15-19	9256	9035	18291
20-24	9073	8629	17702
25-34	23678	23318	46996
35-44	21979	21850	43829
45-54	19656	19643	39299
55-64	15282	15710	30992
65-74	12426	14646	27072
75-84	5533	9062	14595
85+	1169	3500	4669
All	149436	155284	304720

Study areas (Appendix 1 section 1.3)

The study areas were geographically defined according to the health authority boundaries into the Darlington & Teesdale and Stockton local authority areas. Post Office post-codes were used to delineate the local authority areas further.

Residents and Non-residents (Appendix 1 section 1.2 and 5.7)

Residents were included even if they may have been initially treated outside the study area. Patients seen and treated within the study areas but not ordinarily resident within the study areas were excluded.

Study duration

The recruitment period was for two consecutive years from 01 July 1995 to 30 June 1997. A six month pilot study immediately preceded the North Tees area. There was a one month pilot period in the Darlington area before the main study started. We continued to receive notifications from secondary notification sources for six months after the study period ended (31 December 1997). Mortality follow up has been ongoing via notification from the Office for National Statistics. To date, four year mortality follow up has been obtained on all patients.

Case ascertainment/Recruitment *(Appendix 1 section 5)*

Of all first ever strokes, 0.3% were expected to occur under the age of 15 years and 1% under the age of 25 years old⁴⁷. Because of the difficulties in ascertaining, obtaining consent, confirming inclusion, identifying services used (different from adults) and following up of under consent age patients, only adult patients (aged 18 years or older) were included. Less than 0.5% of all strokes in the resident populations were estimated to occur under the age of 18 years old.

Primary notification sources (Appendix 1 section 3 and 4)

Notification sources identifying suspected stroke patients soon after event onset were classified as primary notification sources. This allowed early

assessment of suspected events. Table 3.3 lists the primary identification sources used.

Resident medical officer	Other hospital doctor
Nurse	Ward clerk/secretary
General practitioner or deputy	Nursing home staff
Community rehabilitation staff	Hospital rehabilitation staff
Other	

General practitioners serving the people within the study areas were visited during the pilot phase of the study. Their co-operation, consent and assistance with notification of suspected cases were obtained. Hospital staff in both the main hospitals and selected staff in the surrounding local community, district general and tertiary referral hospitals were informed of the study prior to its start. Quarterly newsletters (most written by myself with supervisor review), explaining the progress of the study, providing preliminary results and to maintain the study profile were sent to general practitioners, hospital staff, selected nursing home and rehabilitation staff and selected local health and social service personnel. The mailing list, which was regularly updated, was around 530 people.

The study had offices in both the main hospitals, North Tees General Hospital (NTGH) and Darlington Memorial Hospital (DMH). Each had direct telephone lines, fax machines and telephone answering machines. I contacted all the on call resident medical officers (two at each of the two main hospitals) every morning everyday (weekends and public holidays

included). It was initially envisaged that a weekend phoning rota would be drawn up for all the clinicians on the study team. During periods of my leave, the research nurses deputised for me. During the weekdays, the study nurses based at each of the two main hospitals visited all the medical wards to review the ward admission lists and identify missed cases. This also maintained links with the hospital staff and encouraged direct notifications. Posters explaining how to notify suspected recent stroke cases were placed on wards, in medical outpatients, physiotherapy, radiology and accident & emergency departments. General practices were encouraged to place posters in their waiting rooms and direct referrals from patients and family members were accepted.

Secondary notification sources (Appendix 1 section 7, 8, 9 and 10)

Notification sources identifying suspected stroke patients late after stroke onset were classified as secondary notification sources. The use of multiple notification sources increased completeness of case ascertainment. Table 3.4 lists the secondary notification sources used.

Table 3.4: Secondary notification sources.	
CT/MRI head scan lists	General practice stroke registers
District death certification lists	District health authority hospital lists
Ward death certification books	Bishop Auckland hospital stroke register
Ward admission lists	South Cleveland hospital stroke unit lists
Hospital discharge lists	Regional health authority admission lists*
Other	

* later discontinued

Many of these lists generated overlapping notifications of the same suspected event. A two month trial period of telephoning the tertiary neurosurgery unit at Middlesbrough General Hospital on a weekly basis was discontinued after no new cases were solely identified by this source. The regional health authority data had considerable overlap with district health authority hospital discharge data diagnoses lists. The five main sources each solely identifying significant numbers of late identified stroke cases have been elaborated further.

Both DMH and NTGH radiology departments provided lists of all community and hospitalised patients who had a CT/MRI head scan. The scan request was included. At DMH, lists were provided monthly and scan results were immediately accessible on computer. At NTGH, lists were provided weekly but scan results were not easily accessible. I screened all the lists (preliminary screening was undertaken by the research nurse at DMH as scan results were available) for inclusion as a suspected stroke event. Where necessary, further information was obtained from the patients' medical notes before a decision was made.

Many of the surgeries kept paper or computerised stroke registers. All were asked to provide monthly lists of newly identified stroke cases including those they may have previously identified via the primary notification systems. GPs and practice managers (usually larger general practice groups) were contacted on a regular basis (four to six weekly) to remind them to forward the previous months lists and to maintain the study profile.

Darlington and North Tees Health Authorities provided regular lists of all deceased patients that were certified in any part (part I or II) of the death

certificate as having had a stroke. I reviewed all available information sources (GP records, hospital notes and nursing home nursing notes) before deciding on inclusion as a confirmed new first ever stroke event.

The district health authorities information departments provided every three months lists of all residents who had a hospital (irrespective of which hospital they were admitted to in the country) discharge diagnosis of stroke according to the International Classification of Diseases coding (ICD 10: I60-I69 and ICD 9: 410-438)^{79,80}.

Both DMH and NTGH hospital information and technology departments provided every two months lists of all patients with a discharge diagnosis of stroke (ICD10: I60-I69 and ICD 9: 410-438).

The Bishop Auckland Hospital catchment area overlapped with the study population in the Darlington area. The South Cleveland Hospital catchment area overlapped with the study population in the North Tees area. The South Cleveland Hospital stroke unit also provided rehabilitation to patients from the Middlesbrough tertiary centre neurosurgical unit to whom selected patients from Darlington and North Tees were referred for neurosurgical intervention. Both provided regular lists.

Categorisation of patients and strokes

Stroke definition (Appendix 1 section 2)

Stroke definition is derived from the World Health Organisation (WHO) *principles* as ‘rapidly developing clinical signs of focal, or at times global (for those patients in deep coma and those with subarachnoid haemorrhage), disturbance of cerebral function; with *symptoms* lasting

longer than 24 hours (unless due to an intracerebral/subarachnoid haemorrhage) or leading to death; with no apparent cause other than that of vascular origin.⁸¹ The diagnosis is based on clinical signs and symptoms at presentation. Incidental infarcts detected on brain scanning were excluded if the patients were asymptomatic. Incidental neurological deficits found on examination without supporting history or evidence of an acute injury on scanning were excluded. For the current analyses, subarachnoid haemorrhages were excluded.

First ever stroke and recurrent stroke (Appendix 1 section 2.1)

Patients with no history and no evidence in their medical records (general practitioner, hospital or nursing home) who presented with a stroke were defined as having had a first ever (in their lifetime) stroke. Patients with evidence (history or medical records) of a previous stroke, the onset of which was at least one week before their current stroke, were defined as having a recurrent stroke.

Stroke type and subtype (Appendix 1 section 2.2)

Stroke types were determined by brain imaging, lumbar puncture (LP), and post mortem (PM) results where available. Table 3.5 lists the various stroke types and how they were determined. Head scan results within both 28 days and 30 days post stroke were determined in the study.

Stroke subtypes were based on the Bamford classification⁸². These are divided into total anterior circulation syndrome (TACS), partial anterior circulatory syndrome (PACS), lacunar syndrome (LACS) and posterior circulatory syndrome (POCS) strokes. An algorithm (Appendix 2, section C part a) Establishment of Diagnosis) assisted in the consistency of determining stroke subtype.

Table 3.5: Stroke type classifications.	
Cerebral infarct (confirmed)	Infarct or normal scan (CT/MRI <=28/30 days post event onset)
Cerebral infarct (probable)	Infarct or normal scan (CT/MRI >28/30 days post event onset), PM
Cerebral infarct (with haemorrhagic transformation)	Confirmed on CT/MRI
Primary intracerebral haemorrhage	Confirmed on CT/MRI
Subarachnoid haemorrhage	Confirmed on CT/MRI/LP/PM
Unknown	No CT/MRI/LP/PM done

In uncertain clinical cases, all available brain imaging, lumbar puncture and post-mortem results were taken into account in determining stroke subtype. If limited additional information was available, myself and at least one other clinical member of the research team reviewed such cases before determining subtype. In rare cases, where there was no consensus or insufficient information, the stroke subtype was classified as uncertain. Diagnoses were reviewed, if new information was obtained at a later date.

Admitted (early hospital treated) and not admitted (community treated)

Stroke patients treated in hospital as an inpatient within seven days of stroke onset were defined as admitted (hospital treated) patients. Stroke patients who were not treated in hospital within the first seven days of stroke onset were defined as not admitted (community treated) patients. A small number of community treated patients were treated in hospital after seven days and within the first month of stroke onset. These late hospitalised cases were classified as not admitted patients.

Table 3.7: A summary of the Initial Assessment constituents.	
Administrative details	
Demographic details	Includes residence
History	Acute event
	Past medical history and stroke risk factors
	Pre-stroke handicap (Oxford Handicap Score) ⁸³
	Family history and current medication
	Social, economic and education history
Examination details	Glasgow coma scale ^{84,85}
	Abbreviated mental test score
	Neurological review and motricity index ⁸⁶
	General examination
	One week Barthel ADL Index ^{87,88,89} score

Critical information was recorded in more than one way but at different and sometimes overlapping time intervals, and in different formats. For example, incontinence information within the first week was obtained from numerous sources covering different aspects:

History proforma: as an early consequence of the stroke event

Examination proforma: Barthel Index subsection at day 7

Early supportive treatment recording: Use of catheter or sheath

The results have been reported for individual formats and as a composite variable in certain cases.

The motricity index is a composite measure of weakness of the affected side. From the weighted, summed and averaged scores (the index), comparisons between different patients and the establishment of correlations with clinical data may be performed. Six different muscle groups are assessed on the affected side and each power function is given a different weighting. Further details are in the examination section in Appendix 2.

The one month assessment (personal interview or telephone) was undertaken at 28 days or as soon as possible thereafter. The six month assessment was a postal questionnaire. For patients unable to complete the postal questionnaire, personal visits / telephone interviews and / or medical records were used to complete some of the sections. Patients alive on the 31 December 1997 were flagged with the Office for National Statistics for ongoing mortality follow up. A summary of the constituents of these assessments is in table 3.8.

The mortality assessment included the date of death, place of death and the cause of death according to the death certificate. If a new suspected stroke event was identified, the protocols for a new event notification were followed.

Table 3.8: A summary of the One and Six month assessments constituents. (The flowcharts and protocols are in appendix 1, section 11&12.)

One month assessment	Administrative and residence details
	Self reported residual deficits
	Oxford Handicap Score & Barthel Index
	Daily therapy received over the first 28 days
	Specific complications in the first 28 days
	Specific daily medications in the first 28 days
	Investigations & Operations
	New diagnoses of specific stroke risk factors
Six month assessment	Administrative and residence details
	Further events and hospital admissions
	Self reported residual deficits
	Oxford Handicap Score & Barthel Index
	Nottingham extended activities of daily living ⁹⁰
	Specific complications over the last 5 months
	Antiplatelet and hypertensive treatment
	Services utilised, Aids and Adaptations
	Wakefield depression inventory ⁹¹
	Investigations & Operations
	Stroke and health information received

Data quality and validation

All the information was collected according to study protocols, on study proformas. Accordingly, all sources of information (collateral history and patients records) where appropriate were obtained. I wrote a Manual specifically to assist in completion of the proformas by the research nurses. This was used to maintain consistency in data recording across the various sites and to highlight areas of potential and encountered problems that would influence later interpretation of data analyses. I held regular meetings with the research nurses to clarify problems encountered and to update the Manual. A summary of the various sections of the Manual is in the beginning of Appendix 1. The Manual underwent various drafts, the last of which is in Appendix 2. The latest versions of the proformas used for each of the assessments are in Appendix 3.

The information was entered onto a Paradox database designed specifically for the study. During the first few months of the project, an on-site Paradox database programmer was employed. Problems encountered were smoothed out; internal validation checks were enhanced and preset queries designed, allowing regular interim analyses of all aspects of the project to be performed. This ensured assessments were being performed at the pre-specified time intervals. Data entry personnel were trained and regular accuracy checks were undertaken. All vital information was double entered and linked (internal verification checks). During and at the end of the project, extensive data cleaning and validating was performed.

Analyses and statistical packages

The database manager assisted in and checked all analyses. Data was exported from paradox into SPSS version 11.0.0 (Copyright SPSS Inc.). For non-parametric numerical data, the Mann Whitney U test, Rank Wilcoxon and ANOVA (Analysis of Variance for smaller numbers of data) tests were used for significance testing. Comparisons of proportions used the Pearson and Chi-squared analyses, corrected for small numbers. The Log Rank test was used for comparisons of Kaplan-Meier survival analyses.

Ethics and consent

Ethical approval for the study was obtained from the local research ethics committees of both Darlington and North Tees district health authorities. All survivors and carers/family were provided with written information about the study and invited to take part. The reasons for the study and assessments required were explained. Written consent was obtained from the patient or main carer to take part in the Tees Stroke Register, to allow direct contact for the various assessments and/or allow access to their medical records. Patients were provided copies of their consent forms and their general practitioners were informed. Patients had the option to opt out at any stage during their follow up from any or all parts of their assessments. For patients who died prior to enrolment in the Tees Stroke Register, their general practitioners were asked for written consent to review their patients records (for those patients where consent was not withheld). Carers and family of deceased patients were not contacted.

CHAPTER 4

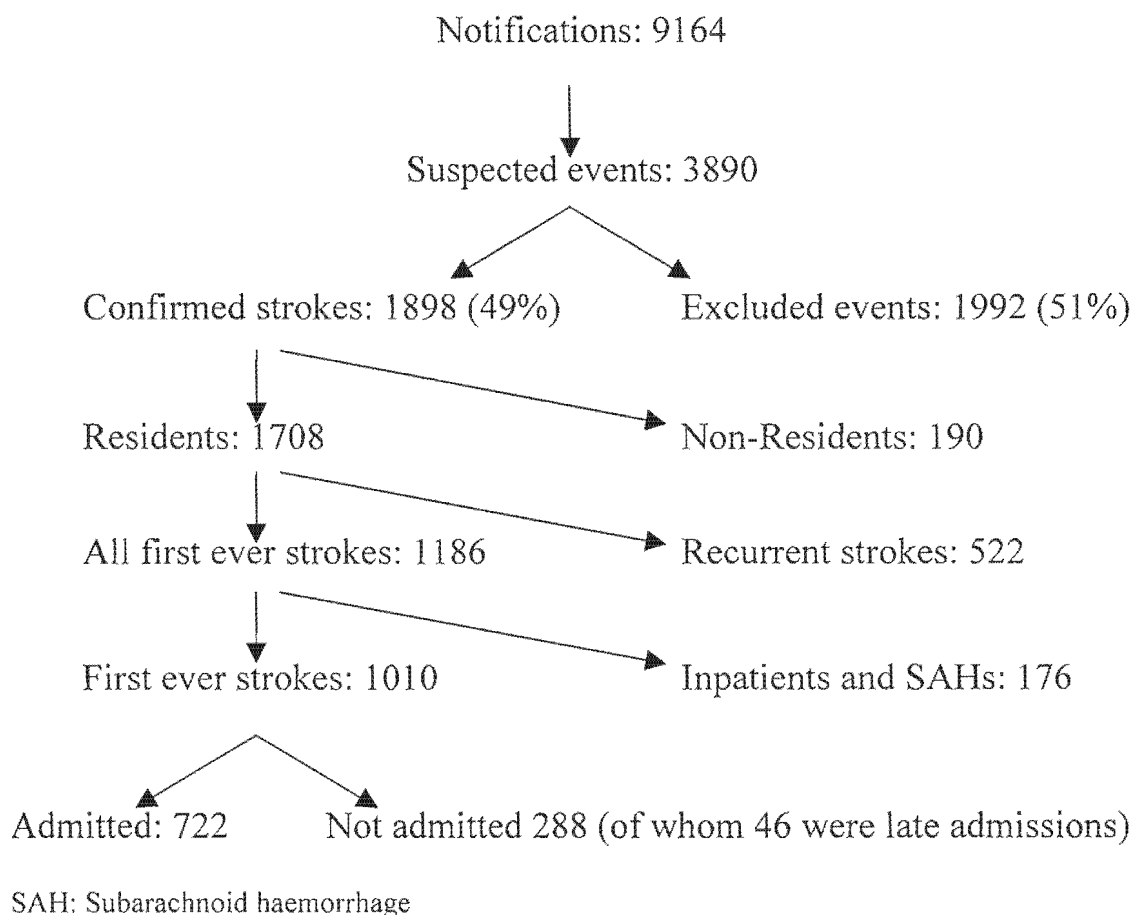
NOTIFICATIONS, DEMOGRAPHY, RISK FACTORS AND CASE MIX

This chapter describes the notification results, patient demography, pre-stroke risk factors and case mix.

Notifications and exclusions

Over the two year recruitment period of the main phase of the study, 9164 notifications were processed. The number of separate suspected events identified was 3890. Of these, 1898 were confirmed stroke events, of which 1186 were first ever resident strokes. There were 1010 first ever, resident non-inpatient, non-subarachnoid haemorrhage, strokes. Of these, 722/1010 (71.5%) were treated in hospital within seven days of stroke onset and 288/1010 (28.5%) were treated in the community (chart 4.1).

Chart 4.1: Numbers of notifications and stroke events.



First ever stroke incidence was 1.66/1000 population / year (1.31 standardised to the European Population)⁸¹. The percentages admitted in each area were 67% Darlington and 75% North Tees (p=0.01). 2/3rds (31/46) of the late admissions were in North Tees residents. 22/46 (48%) of the late admissions were admitted during day 7 and day 28 post stroke.

Of all the confirmed strokes, 21% were notified by a single source only. 17% were notified by two sources. 62% were notified by three or more separate sources. The eight most common reasons for exclusion are listed in table 4.1. In many cases, there was more than one reason for exclusion.

Table 4.1: The commonest reasons for exclusion (1992 events).		
	n	%
Previous stroke deficit	468	23
Transient Attack	341	17
Infection	223	11
Dementia/confusion	220	11
Seizure/collapse	192	10
Arrhythmia/cardiac	178	9
Intracranial neoplasm	116	6
Migraine/headache	105	5

The sources of notifications were similar in both areas. For first ever strokes, 82% of primary sources of notifications were received within two weeks of event onset compared to 21% of secondary notification sources.

For first ever strokes, 125/722 (17%) of admitted and 165/288 (57%) of not admitted patients were first notified by secondary sources. 43/288 (15%) of community cases were first identified by the DHA death notification source. Overall, community cases had fewer notifications per confirmed event, a higher proportion notified first from secondary sources, a larger proportion notified solely from secondary sources and as a consequence on average patients were notified later than hospitalised cases. See Table 4.2. Only 25 patients had recurrent strokes during the study period that on review turned out to have had an earlier stroke during the study period that had not previously been notified.

Table 4.2: Notification sources for admitted and not admitted first ever stroke patients (residents, excluding SAHs and in-patients).

	Admitted n=722 (%)	Not admitted n=288 (%)
Average number of notifications per stroke event	4.1	1.7
Single notification source per stroke event	55 (8%)	162 (56%)
First notification from secondary sources	125 (17%)	165 (57%)
Secondary sources, the only source of event of notification	113 (16%)	159 (55%)
First notification from DHA death data	7 (1%)	43 (15%)

A more detailed analysis of the value of multiple overlapping sources of case notifications in enhancing complete case ascertainment was presented (by myself), as a poster at the 1998 Spring British Geriatrics Society Meeting, published in abstract⁹².

Patient demography

The baseline demography of all the first ever stroke patients, excluding in-patients and subarachnoid haemorrhages, is in table 4.3. There were 722 patients admitted and 288 not admitted within seven days of stroke onset to hospital.

The median age in both admitted and not admitted patients was 74 years old. There were no significant differences in the median ages for males and females between the admitted and not admitted (males 72 and 72 years, females 76 and 78 years respectively). There was no significant difference in the inter quartile ranges (IQR), 65-82 in the admitted and 66-82 in the not admitted patients. Men accounted for 45.3% of admitted and 48.6% of not admitted patients, $p=0.34$.

Most admitted 586/722 (81%), and not admitted 207/288 (72%) patients were independent with little or no handicap (Oxford Handicap Scores (OHS) 0-2) prior to their stroke. 27/722 (4%) of the admitted and 44/288 (15%) of the not admitted were very handicapped (OHS 4-5) prior to their stroke. These differences were significant ($p=0.012$).

Table 4.3: Demography of first ever strokes.				
	Admitted	Not admitted	p-val	Total
	n=722 (%)	n=288 (%)		n=1010 (%)
Median age	74	74	0.835	74
IQR (range)	65-82 (31-104)	66-82 (63-86)	-	65-82 (31-104)
Male	327 (45%)	140 (49%)	0.34	467 (46%)
Pre-stroke OHS				
0-2	586 (81%)	207 (72%)	0.012	793 (79%)
3	109 (15%)	37 (13%)		146 (14%)
4-5	27 (4%)	44 (15%)		71 (7%)
Residence				
Residential or nursing care	45 (6%)	64 (22%)	<0.001	109 (11%)
Sheltered accommodation	78 (11%)	21 (7%)	<0.01	99 (10%)
Lives alone	270/638 (42%)	70/212 (33%)	0.017	340/850 (40%)

Admitted patients were less likely to be living in residential or nursing care or sheltered accommodation 123/722 (17%) versus 85/288 (30%), $p < 0.01$. The difference is more marked when comparing nursing and residential care residence in admitted 45/722 (6%) and in not admitted patients 64/288 (22%), $p < 0.001$. Of those known, excluding those living

in care, admitted patients were more likely to be living alone than not admitted patients (270/638 (42%) versus 70/212 (33%)), $p=0.017$.

Pre-stroke factors

Pre-stroke risk factors

Stroke risk factors for admitted and not admitted patients are listed in table 4.4. A history or record of current or past hypertension was more common in admitted 340/711 (48%) than not admitted 116/285 (41%) patients, $p=0.042$. Atrial fibrillation was identified in twice as many admitted 132/722 (18%) than not admitted 25/288 (9%) patients, $p<0.001$.

	Admitted (%)	Not admitted (%)	p-val
Hypertension*	340/711 (48%)	116/285 (41%)	0.042
Angina/MI	190/722 (26%)	64/288 (22%)	0.176
Previous TIA	146/722 (20%)	58/288 (20%)	0.513
AF (incl post stroke ECG**)	132/722 (18%)	25/288 (9%)	<0.001
Atrial fibrillation	128/722 (18%)	25/288 (9%)	<0.001
Peripheral vascular disease	82/697 (12%)	40/281 (14%)	0.290
Diabetes	84/713 (12%)	32/287 (11%)	0.778
Hyperlipidaemia	14/719 (2%)	6/287 (2%)	0.883
Current smoker	176/693 (25%)	79/270 (29%)	0.222
Ex-smoker	246/693 (36%)	91/270 (34%)	0.600
Family history of stroke (age <65)	206/537 (38%)	73/209 (35%)	0.384

* Current or past, ** ECG day 0-6

There were no significant differences detected in the incidence of peripheral vascular disease, TIAs, angina / previous myocardial infarctions, diabetes, hyperlipidaemia, current smokers or ex-smokers, or those with a significant family history of stroke in admitted and not admitted patients.

Selected pre-stroke medications

Table 4.5 lists selected medications patients were on prior to their stroke. More admitted patients than not admitted patients were on aspirin, warfarin or antihypertensives, but these differences were not significant. 194/722 (27%) of admitted and 65/288 (23%) of not admitted patients were on aspirin. 18/722 (2.5%) of admitted and 4/285 (1.4%) of not admitted patients were on warfarin. 255/722 (37%) of admitted and 100/288 (35%) of not admitted patients were on antihypertensive medications.

	Admitted (%)	Not admitted (%)	p-val
Aspirin	194/722 (27%)	65/288 (23%)	0.158
Warfarin	18/722 (2.5%)	4/285 (1.4%)	0.278
Antihypertensives*	268/718 (37%)	100/288 (35%)	0.475

* was not necessarily prescribed for hypertension treatment

Other potentially significant factors

Table 4.6 lists other possible confounders that may have an influence on outcomes post stroke. There were no significant differences in the rates of current and previous malignancies between admitted and not admitted patients. Where information was available, self reported personal income

was not different in the admitted 331/380 (87%) compare to not admitted 157/171 (92%) patients, $p=0.210$. Excluding patients in care, similar numbers of admitted 216/561 (39%) and not admitted patients 78/203 (38%) did not own their accommodation.

	Admitted (%)	Not admitted (%)	p-val
Malignancy	103/705 (15%)	33/285 (12%)	0.210
Income <£15k/yr	331/380 (87%)	157/171 (92%)	0.108
Rented residence	216/561 (39%)	78/203 (38%)	0.984

Case mix

The factors associated with stroke severity and stroke type are in Table 4.7, 4.8 and 4.9.

Stroke subtype

Stroke subtype is in Table 4.7. There was a higher proportion of TACS strokes in admitted 211/722 (29%) than not admitted 47/288 (16%) patients, $p=0.011$. POCS were also more common in admitted 124/722 (17%) than not admitted 33/288 (11%) patients, but this was not significant, $p=0.338$.

The proportions of PACS and LACS were higher in not admitted patients. 225/722 (31%) of admitted and 118/288 (41%) of not admitted patients were PACS, $p<0.001$. 125/722 (17%) of admitted and 77/288 (27%) of not admitted patients were LACS, $p<0.001$. Similar minor proportions were unclassifiable (5%).

Table 4.7: Stroke subtype derived from the Bamford classification.			
	Admitted (%)	Not admitted (%)	p-val: Pearson <0.001
TACS	211 (29%)	47 (16%)	0.011
PACS	225 (31%)	118 (41%)	<0.001
POCS	124 (17%)	33 (11%)	0.338
LACS	125 (17%)	77 (27%)	<0.001
Uncertain	37 (5%)	13 (5%)	0.734

Stroke severity indicators

Early death and other stroke severity indicators are in table 4.8. At 24 hours, less admitted than not admitted patients had died, $p=0.05$. By 72 hours post stroke, there were no significant differences in early mortality in admitted and not admitted patients. 73/722 (10%) of admitted and 24/288 (8%) of not admitted patients had died, $p=0.41$. At seven days, non-significantly more admitted than not admitted patients had died, $p=0.157$.

Seven day Barthel ADL Index revealed a significantly lower median value in the admitted than not admitted patients (10 versus 18, $p<0.001$). The proportion of patients with good functional recovery at one week (Barthel ADL Index ≥ 18) was significantly lower in the admitted 116/592 (20%) than not admitted 133/238 (56%) patients, $p<0.001$.

Table 4.8: Early death and stroke severity indicators.				
		Admitted (%)	Not admitted (%)	p-val
Death in 24 hrs		25/722 (3%)	18/288 (6%)	0.05
Death in 72 hrs		73/722 (10%)	24/288 (8%)	0.41
Death in 7 days		124/722 (18%)	39/288 (14%)	0.16
7 day Barthel				
	Median	10	18	<0.001
	>= 18	116/592 (20%)	133/238 (56%)	<0.001
Median motricity score		33.5	37	0.81
Dysphasia				
	by 24 hours	255/582 (44%)	64/201 (32%)	0.009
	by 7 days*	172/527 (33%)	38/201 (19%)	<0.001
Dysphagia				
	by 24 hours	346/722 (48%)	53/288 (18%)	<0.001
	by 7 days*	241/594 (41%)	34/249 (14%)	0.006
Confirmed visual field deficit				
	by 7 days*	158/722 (22%)	33/288 (12%)	<0.001
Confirmed gross sensory inattention				
	by 7 days*	81/702 (12%)	12/272 (4%)	<0.001
Urinary incontinence				
	by 24 hours	385/722 (53%)	62/287 (22%)	<0.001
	by 7 days*	276/594 (46%)	43/248 (17%)	<0.001
Glasgow coma scale (GCS)				
	Best motor score <6	42/595 (7%)	6/239 (3%)	0.009
	GCS <13/15	101/568 (18%)	4/203 (2%)	<0.001
	Best verbal score =5	415/703 (59%)	210/269 (78%)	<0.001

*Excludes early mortality, includes nasogastric tube, PEG feeding or catheter/sheath.

Paralysis assessment (motricity index) of the affected side revealed a non-significant increased overall weakness in the admitted patients compared with the not admitted patients (33.5 versus 37, $p=0.81$).

Dysphagia, dysphasia and urinary incontinence were all significantly more common in the first 24 hours and at one week in admitted than not admitted patients. At one week, 172/527 (33%) of admitted and 38/201 (19%) of not admitted patients were dysphasic, $p<0.001$. 241/594 (41%) of admitted and 34/249 (14%) of not admitted patients had impaired swallow, $p=0.006$. 158/722 (22%) of admitted and 33/288 (12%) of not admitted had documented or elicited visual field deficits, $p<0.001$ and 81/702 (12%) of admitted and 12/272 (4%) of not admitted patients had documented or elicited sensory inattention, $p<0.001$. 276/594 (46%) of admitted and 43/248 (17%) of not admitted patients had urinary incontinence, $p<0.001$.

Impaired levels of consciousness, using both best motor score on the GCS $<6/6$ or total GCS $<13/15$ revealed significantly more impairment in admitted than not admitted patients (7-18% versus 2-3%, $p<0.01$). Using the GCS speech scores with the best verbal response (5/5), the proportion of admitted patients alert and orientated (415/703-59%), were significantly less than those not admitted (210/269-78%), $p<0.001$.

Stroke type

Stroke types according to head scan results are listed in Table 4.9. Most admitted patients had head scanning within 30 days of stroke onset. For those few not admitted patients that had head scanning within 30 days, the majority 59/66 (89%) showed no bleed. In admitted patients, an

infarct or normal scan was present in 455/540 (84%) of cases. There were no significant differences in the proportions of stroke type between admitted and not admitted patients.

Table 4.9: Stroke type according to head scan and percentage of known results.

	Admitted (%)	Not admitted (%)	p-val
Infarct or normal scan	455/540 (84%)	59/66 (89%)	0.272
Intracerebral haemorrhage	85/540 (16%)	7/66 (11%)	0.272
No scan within 30 days of stroke	182	222	<0.001

CHAPTER 5

RESULTS: ACUTE CARE, INVESTIGATIONS AND REHABILITATION SERVICE USAGE

This chapter describes the acute care, investigations and rehabilitation provided to patients after their stroke. The components of the acute care were recorded for the first week (day 0-6) and first 28 days. These were supportive treatments (fluids usage, feeding, urinary incontinence management and ventilation) and drug treatments (types and timing of initiation). The investigations performed and the timings of key ones are also described. Rehabilitation services (intensity of physiotherapy, occupational therapy, dietician and speech therapy input) used in the first 28 days and in the month preceding the six month assessment are described.

ACUTE CARE

The supportive treatments utilised and the medication prescribed in the first 28 days post stroke for admitted and not admitted patients are described in this section.

Supportive treatments

Supportive treatments in the first week

Table 5.1 lists the frequencies of the various early supportive treatments in admitted and not admitted patients. During the first week post stroke, admitted patients received significantly more supportive therapy than not admitted patients. Supplementary fluid therapy (intravenous or subcutaneous) was used in 318/722 (44%) of admitted and 3/288 (1%) of not admitted patients, $p < 0.001$. Nasogastric and percutaneous

gastrostomy tube feeding were used in 63/722 (9%) of admitted and 0/288 (0%) of not admitted patients, $p < 0.001$. Catheterisation occurred in 224/722 (31%) of admitted and 12/288 (4%) of not admitted patients, $p < 0.001$. Urinary sheaths were used in 16/722 (2%) of admitted and 0/288 (0%) of not admitted patients, $p = 0.009$. Ventilation occurred in 23/722 (3%) of admitted patients.

	Admitted (%)	Not admitted (%)	p-val
Fluids (iv/sc)	318 (44%)	3 (1%)	<0.001
Nasogastric tube / PEG	63 (9%)	0 (0%)	<0.001
Catheter	224 (31%)	12 (4%)	<0.001
Sheath	16 (2%)	0 (0%)	0.009
Ventilation	23 (3%)	Not applicable	-

Supportive treatments in the first 28 days

The frequencies of the various supportive treatments in the first 28 days in admitted and not admitted patients are shown in table 5.2. During the first 28 days post stroke, admitted patients received significantly more supportive therapy than not admitted patients. Supplementary fluid therapy (intravenous or subcutaneous) was used in 349/722 (48%) of admitted and 8/288 (3%) of not admitted patients, $p < 0.001$. Nasogastric and percutaneous gastrostomy tube feeding were used in 82/722 (11%) of admitted and 1/288 (0%) of not admitted patients, $p < 0.001$. Catheterisation occurred in 257/722 (36%) of admitted and 15/288 (5%) of not admitted patients, $p < 0.001$. Urinary sheaths were used in 22/722

(2%) of admitted and 0/288 (0%) of not admitted patients, $p=0.003$.
 Ventilation occurred in 29/722 (4%) of admitted patients.

	Admitted (%)	Not admitted (%)	p-val
Fluids (iv/sc)	349 (48%)	8 (3%)	<0.001
Nasogastric tube / PEG	82 (11%)	1 (0%)	<0.001
Catheter	257 (36%)	15 (5%)	<0.001
Sheath	22 (3%)	0 (0%)	0.003
Ventilation	29 (4%)	Not applicable	-

Drug treatments

Drug treatments in the first week

Overall, medication prescribing in the first week post stroke was more common in admitted than not admitted patients (table 5.3). Aspirin was almost the sole antiplatelet (>99%) prescribed. The alternative antiplatelet prescribed was dipyridamole. For aspirin, there were significant differences in early prescribing frequencies between admitted and not admitted patients. 307/722 (42%) of admitted and 144/288 (50%) of not admitted patients were on aspirin in the first week ($p=0.005$). 270/722 (37%) of admitted and 106/288 (37%) of not admitted patients were on antihypertensives in the first week ($p=0.861$).

There was no significant difference in early opioid prescriptions in admitted 31/722 (4%), and not admitted 9/288 (3%), patients ($p=0.390$).

Early antidepressant prescription was significantly less common in admitted 29/722 (4%), than not admitted 23/288 (8%), patients ($p=0.017$).

Warfarin, heparin, antibiotics, and anticonvulsants were all significantly more frequently prescribed in the first week in admitted than not admitted patients.

	Admitted (%)	Not admitted (%)	p-val
Aspirin	307 (42%)	144 (50%)	0.005
Warfarin	38 (5%)	3 (1%)	0.002
Heparin	22 (3%)	0 (0%)	0.003
Warfarin/heparin	52 (7%)	3 (1%)	<0.001
Antihypertensives	270 (37%)	106 (37%)	0.861
Opioids	31 (4%)	9 (3%)	0.390
Antidepressants	29 (4%)	23 (8%)	0.017
Antibiotics	183 (25%)	24 (8%)	<0.001
Anticonvulsants	23 (3%)	2 (1%)	0.021

Drug treatments in the first 28 days

Overall, medication prescribing in the first 28 days was more common in the admitted than not admitted patients (table 5.4). Aspirin was significantly more commonly prescribed in not admitted than admitted patients. 381/722 (53%) admitted and 176/288 (61%) not admitted patients were treated with aspirin ($p=0.016$).

There were no significant differences in antihypertensive and antidepressant prescriptions in admitted and not admitted patients. 313/722 (43%) of admitted and 124/288 (43%) of not admitted patients were prescribed antihypertensives ($p=0.932$). 45/722 (6%) of admitted and 23/288 (8%) of not admitted patients were prescribed antidepressants ($p=0.232$).

Warfarin, heparin, opioids, antibiotics and anticonvulsants were all significantly more commonly prescribed in admitted than not admitted patients.

	Admitted (%)	Not admitted (%)	p-val
Aspirin	381 (53%)	176 (61%)	0.016
Warfarin	66 (9%)	6 (2%)	<0.001
Heparin	45 (6%)	0 (0%)	<0.001
Warfarin/heparin	90 (12%)	6 (2%)	<0.001
Antihypertensives	313 (43%)	124 (43%)	0.932
Opioids	63 (9%)	11 (4%)	0.007
Antidepressants	45 (6%)	23 (8%)	0.232
Antibiotics	257 (36%)	33 (11%)	<0.001
Anticonvulsants	31 (4%)	3 (1%)	0.010

Aspirin, anticoagulant and antihypertensive statuses

Overall, significantly less admitted than not admitted patients were initiated on aspirin by 28 days post stroke. The majority of both admitted and not admitted patients had their aspirin initiated in the first few days post event (Chart 5.1). There was a tendency for earlier initiation in not admitted patients (Charts 5.2 and 5.3). Of those patients initiated on aspirin in the first 28 days, 307/381 (81%) of admitted and 144/176 (82%) were initiated by day 6 post stroke.

Chart 5.1: Cumulative frequencies of aspirin initiation in the first 28 days in admitted and not admitted patients.

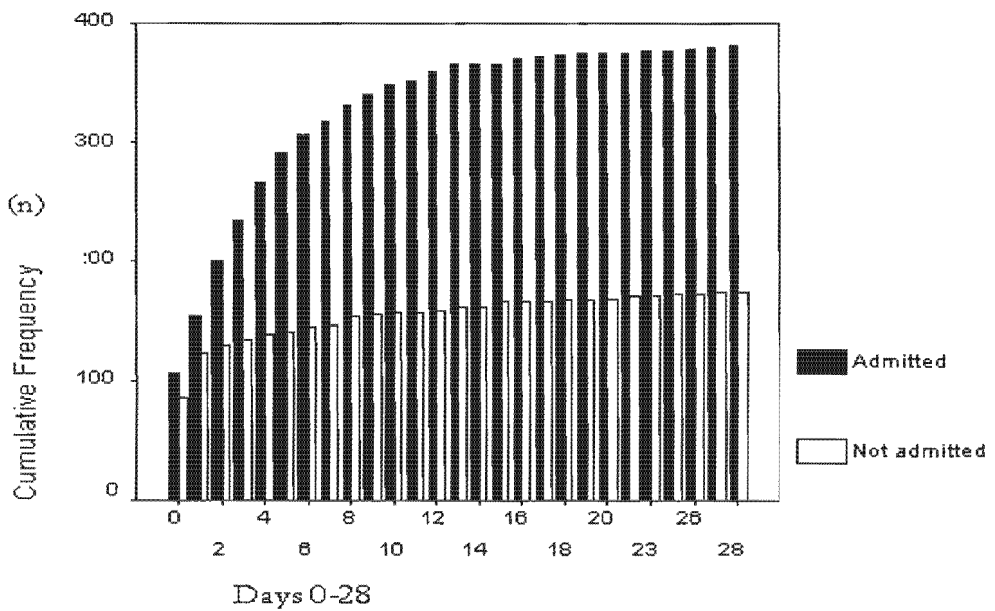
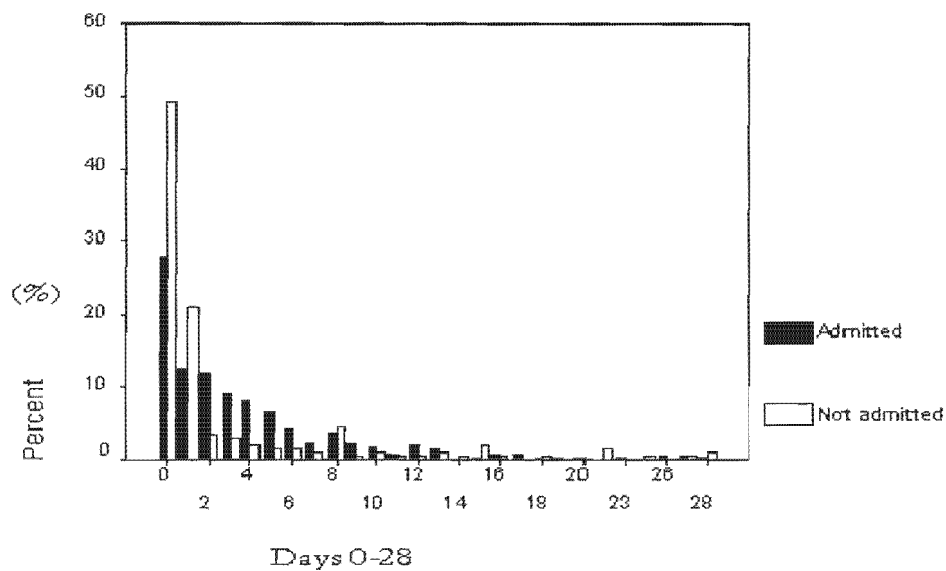
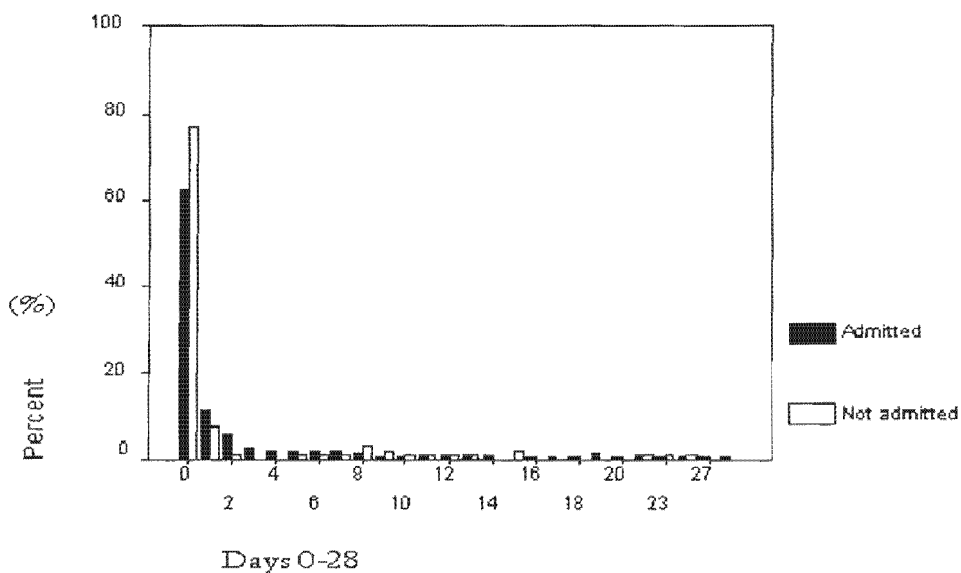


Chart 5.2: The timings of aspirin initiation in the first 28 days in admitted and not admitted patients.



The majority of both admitted and not admitted patients had their antihypertensives initiated in the first few days post event (Chart 5.3). Of those patients initiated on antihypertensives by 28 days, 270/313 (86%) of admitted and 106/124 (85%) of not admitted, were initiated by day 6.

Chart 5.3: The timings of antihypertensive treatment initiation in the first 28 days in admitted and not admitted patients.



Of those patients diagnosed as hypertensive prior to their stroke, 255/340 (75%) of admitted and 85/116 (73%) of not admitted patients were on treatment in the first 28 days post stroke. Of those on treatment for hypertension prior to stroke, 185/268 (69%) of admitted and 67/100 (67%) of not admitted patients were on treatment in the first 28 days post stroke (Table 5.5). There were no significant differences between the admitted and not admitted patients. 58 admitted patients and 39 not admitted patients were started for the first time on antihypertensive medications in the 28 days after their stroke ($p=0.017$).

Table 5.5: Pre-stroke hypertensive status and post stroke antihypertensive treatment (admitted 313/722, not admitted 124/288 treated post stroke) in the first 28 days post stroke.

	Proportion on treatment in first 28 days post stroke		
	Admitted	Not admitted	p-val
Diagnosed before stroke	255/340 (75%)	85/116 (73%)	0.713
On treatment before stroke	185/268 (69%)	67/100 (67%)	0.709
Newly diagnosed hypertensives*	58/722 (8%)	39/288 (14%)	0.007

*on antihypertensive medications in the first 28 days post stroke.

Not all patients started on aspirin or anticoagulants in the first 28 days had head scans performed in the first 28 days (Table 5.6). 260/307 (85%) of admitted and 24/144 (17%) of not admitted patients treated with aspirin in the first week had head scans performed in the first week post

stroke, $p < 0.001$. 49/52 (94%) of admitted and 1/3 (33%) of not admitted patients treated with warfarin or heparin in the first week had head scans performed during the first week, $p = 0.019$. By 28 days, 322/381 (85%) of admitted and 37/176 (21%) of not admitted patients treated with aspirin had head scans performed, $p < 0.001$. 61/66 (92%) of admitted and 4/6 (67%) of not admitted patients treated with warfarin had head scans performed, $p = 0.101$. 83/90 (92%) of admitted and 4/6 (67%) of not admitted patients treated with warfarin or heparin had head scans performed, $p = 0.097$.

Table 5.6: The proportion of patients on aspirin and/or anticoagulant treatment, having head scanning in the first 28 days post stroke.

Treatment	Admitted		Not admitted		p-val	
	d0-6	d0-28	d0-6	d0-28	d0-6	d0-28
Aspirin	260/307	322/381	24/144	37/176	<0.001	<0.001
Warfarin	36/38	61/66	1/3	4/6	0.021	0.101
Warfarin/heparin	49/52	83/90	1/3	4/6	0.019	0.097

Of those patients who survived to 28 days, the proportions on aspirin, warfarin and antihypertensives at 28 days are shown in table 5.7. 416/522 (80%) of admitted and 170/235 (72%) of not admitted patients were on aspirin or warfarin. For aspirin alone, there were no significant differences, but significantly more admitted than not admitted patients were on warfarin, $p < 0.001$. At 28 days, 280/522 (54%) of admitted and 117/235 (50%) of not admitted survivors were on antihypertensive treatment, $p = 0.374$.

Table 5.7: The proportion of 28 day survivors on aspirin, warfarin or antihypertensives.

	Admitted (%)	Not admitted (%)	p-val
Aspirin	351/522 (67%)	164/235 (70%)	0.397
Warfarin	65/522 (12%)	6/235 (3%)	<0.001
Antihypertensive	280/522 (54%)	117/235 (50%)	0.374

INVESTIGATIONS

The investigations performed and the timings thereof, in the first six months post stroke for admitted and not admitted patients, are described in this section.

Investigations performed in the first week

The frequencies of investigations performed early post stroke (day 0-6) in admitted and not admitted patients are described in table 5.8. Admitted patients had significantly more investigations performed than not admitted patients. Full blood counts were performed in 631/722 (87%) of admitted and 27/288 (9%) of not admitted patients, $p < 0.001$. Erythrocyte sedimentation rate (ESR) or plasma viscosity was performed in 270/722 (37%) of admitted and 25/288 (9%) of not admitted patients, $p < 0.001$. Blood glucose was checked in 553/722 (77%) of admitted and 26/288 (9%) of not admitted patients, $p < 0.001$.

Cholesterol levels were checked in 74/722 (10%) of admitted and 12/288 (4%) of not admitted patients, $p = 0.002$. Chest x-rays were performed in 213/722 (30%) of admitted and 2/288 (1%) of not admitted patients, $p < 0.001$. Electrocardiograms were performed in 582/722 (81%) of admitted and 10/288 (3%) of not admitted patients, $p < 0.001$.

Computerised tomography (CT) head scans were performed in 493/722 (68%) of admitted and 6/288 (2%) of not admitted patients, $p < 0.001$. Echocardiograms were performed in 73/722 (10%) of admitted patients and 1/288 (0%) of not admitted patients, $p < 0.001$.

	Admitted (%)	Not admitted (%)	p-val
Full blood count	631 (87%)	27 (9%)	<0.001
ESR/Plasma Visc.	270 (37%)	25 (9%)	<0.001
Blood glucose	553 (77%)	26 (9%)	<0.001
Cholesterol	74 (10%)	12 (4%)	0.002
Chest xray	213 (30%)	2 (1%)	<0.001
ECG	582 (81%)	10 (3%)	<0.001
CT head scan	493 (68%)	6 (2%)	<0.001
Echocardiogram	73 (10%)	1 (0%)	<0.001

Investigations performed in the 28 days

The frequencies of investigations performed in the first 28 days post stroke in admitted and not admitted patients are described in table 5.9. Admitted patients had significantly more investigations performed than not admitted patients. Full blood counts were performed in 642/722 (89%) of admitted and 83/288 (29%) of not admitted patients, $p < 0.001$. Erythrocyte sedimentation rate (ESR) or plasma viscosity was performed in 290/722 (40%) of admitted and 54/288 (19%) of not admitted patients, $p < 0.001$. Blood glucose was checked in 565/722 (78%) of admitted and 58/288 (20%) of not admitted patients, $p < 0.001$.

Cholesterol levels were checked in 81/722 (11%) of admitted and 29/288 (10%) of not admitted patients, $p=0.597$. Chest x-rays were performed in 233/722 (32%) of admitted and 20/288 (7%) of not admitted patients, $p<0.001$. Electrocardiograms were performed in 597/722 (83%) of admitted and 50/288 (17%) of not admitted patients, $p<0.001$.

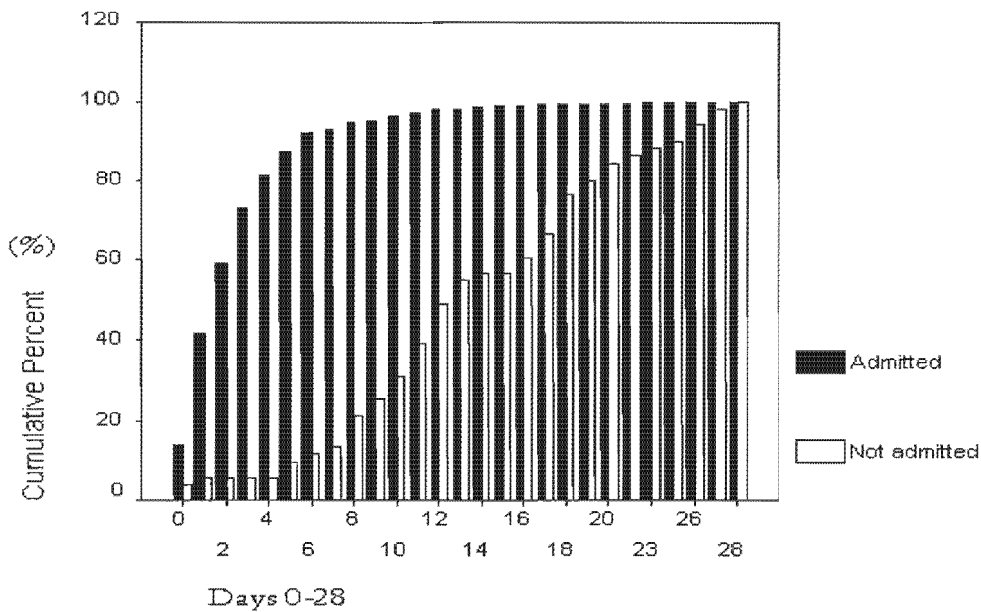
Computerised tomography head scans were performed in 536/722 (74%) of admitted and 51/288 (18%) of not admitted patients, $p<0.001$.

Echocardiograms were performed in 98/722 (13%) of admitted and 12/288 (4%) of not admitted patients, $p<0.001$. Carotid dopplers were performed in 6/722 (1%) of admitted and 0/288 (0%) not admitted patients, $p=0.191$.

	Admitted (%)	Not admitted (%)	p-val
Full blood count	642 (89%)	83 (29%)	<0.001
ESR/Plasma Visc.	290 (40%)	54 (19%)	<0.001
Blood glucose	565 (78%)	58 (20%)	<0.001
Cholesterol	81 (11%)	29 (10%)	0.597
Chest xray	233 (32%)	20 (7%)	<0.001
ECG	597 (83%)	50 (17%)	<0.001
CT head scan	536 (74%)	51 (18%)	<0.001
Echocardiogram	98 (13%)	12 (4%)	0.144
Carotid dopplers	6 (1%)	0 (0%)	0.191

The timing of CT head scans in admitted and not admitted patients are shown in more detail in chart 5.4. Head scanning was done earlier and in a greater proportion of admitted than not admitted patients. Of those patients who had a CT head scan by 28 days, 493/536 (92%) of admitted and 6/51 (12%) of not admitted patients had head scans by one week post stroke.

Chart 5.4. The cumulative percentage of all CT head scans performed in the first 28 days post stroke for admitted and not admitted patients.



Investigations performed in the first six months

The frequencies of investigations performed up to six months post stroke in admitted and not admitted patients are described in table 5.10. Overall, admitted patients had significantly more investigations performed than not admitted patients. Full blood counts were performed in 650/722 (90%) of admitted and 169/288 (59%) of not admitted patients, $p < 0.001$. Erythrocyte sedimentation rate (ESR) or plasma viscosity was performed in 298/722 (41%) of admitted and 106/288 (37%) of not admitted

patients, $p=0.191$. Blood glucose was checked in 573/722 (79%) of admitted and 123/288 (43%) of not admitted patients, $p<0.001$.

Cholesterol levels were checked in 91/722 (13%) of admitted and 54/288 (19%) of not admitted patients, $p=0.012$. Chest x-rays were performed in 244/722 (34%) of admitted and 34/288 (12%) of not admitted patients, $p<0.001$. Electrocardiograms were performed in 612/722 (85%) of admitted and 105/288 (36%) of not admitted patients, $p<0.001$. Computerised tomography head scans were performed in 543/722 (75%) of admitted and 103/288 (36%) of not admitted patients, $p<0.001$. Echocardiograms were performed in 111/722 (15%) of admitted patients and 34/288 (12%) of not admitted patients, $p=0.144$. Carotid dopplers were performed in 20/722 (3%) of admitted and 20/288 (7%) of not admitted patients, $p=0.002$.

	Admitted (%)	Not admitted (%)	p-val
Full blood count	650 (90%)	169 (59%)	<0.001
ESR/Plasma Visc.	298 (41%)	106 (37%)	0.191
Blood glucose	573 (79%)	123 (43%)	<0.001
Cholesterol	91 (13%)	54 (19%)	0.012
Chest xray	244 (34%)	34 (12%)	<0.001
ECG	612 (85%)	105 (36%)	<0.001
CT head scan	543 (75%)	103 (36%)	<0.001
Echocardiogram	111 (15%)	34 (12%)	0.144
Carotid dopplers	20 (3%)	20 (7%)	0.002

The frequencies of specialised investigations performed in the first six months post stroke in admitted and not admitted patients are described in table 5.11. Very few patients received these investigations. There were no significant differences in the frequencies of magnetic resonance imaging (MRI) head scans, MRI angiograms, conventional angiography and thrombophilia screening (one or more of the components of the thrombophilia screen) in admitted and not admitted patients.

Table 5.11: Specialised investigations performed by six months post stroke.

	Admitted (%)	Not admitted (%)	p-val*
MRI head scan	13 (2%)	8 (3%)	0.327 (0.334)
MRI angiogram	6 (1%)	6 (2%)	0.097 (0.112)
Cerebral/carotid angiogram	12 (2%)	5 (2%)	0.934 (1.000)
Thrombophilia screen	24 (3%)	8 (3%)	0.842 (0.854)

* Chi square Pearson p value (Fisher Exact test p value)

REHABILITATION AND THERAPY

Rehabilitation services used in the first 28 days post stroke and in the month preceding the six month assessment, for admitted and not admitted patients are described in this section.

Early therapy (first four weeks)

The proportion of patients receiving rehabilitation therapy and dietician input, and the median times to contact for those receiving therapy in the first 28 days post stroke, in those known, for admitted and not admitted patients are in table 5.12. Significantly more admitted than not admitted patients received rehabilitation services. Median times (days) to first contact in those receiving services were significantly shorter in admitted than not admitted patients. Physiotherapy services were utilised in 486/722 (67%) of admitted and 27/288 (9%) of not admitted patients, $p < 0.001$. Median days to first contact was 3 days in admitted and 13 days in not admitted patient, $p < 0.001$. Occupational therapy services were utilised in 261/722 (36%) of admitted and 7/288 (2%) of not admitted patients, $p < 0.001$. Median days to first contact was 7.5 days in admitted and 14 days in not admitted patient, $p < 0.001$.

Speech therapy services were utilised in 206/722 (29%) of admitted and 4/288 (1%) of not admitted patients, $p < 0.001$. Median days to first contact was 4 days in admitted and 19 days in not admitted patient, $p < 0.001$. Dietician services were utilised in 93/722 (13%) of admitted and 2/288 (1%) of not admitted patients, $p < 0.001$. Median days to first contact was 5 days in admitted and 20 days in not admitted patient, $p < 0.001$.

Table 5.12: The proportion of patients receiving therapy in the first 28 days and the median time (days) to first contact with the therapist.

Therapy		Admitted (%)	Not admitted (%)	p-val	
Physiotherapy		486 (67%)	27 (9%)	<0.001	
	1 st contact	median	3	13	<0.001
		range	0-28	5-25	
Occupational therapy		261 (36%)	7 (2%)	<0.001	
	1 st contact	median	7.5	14	<0.001
		range	0-28	11-20	
Speech therapy		206 (29%)	4 (1%)	<0.001	
	1 st contact	median	4	19	<0.001
		range	0-26	12-20	
Dietician review		93 (13%)	2 (1%)	<0.001	
	1 st contact	median	5	20	<0.001
		range	0-25	16-24	

Of those patients receiving the various therapies, the intensity of therapy (median contact days per week) received in the first 28 days is described in table 5.13. Late hospitalised patients were excluded. There was no occupational therapy during the first three weeks, speech therapy during the first week or dietician input during the first two weeks in not admitted patients.

Of those receiving physiotherapy, the intensity of therapy over the first 28 days post stroke was significantly higher in admitted (3 contacts per week) than not admitted (2 contacts per week) patients, $p < 0.001$. Of those receiving occupational therapy in the first 28 days post stroke, there was a trend for admitted patients to have more contacts (2 versus 1 contact per week, $p = 0.132$). Occupational therapy intensity during week 2 to 4 was significantly higher in admitted (2 contacts per week) than not admitted (1 contact per week) patients, $p = 0.017$.

Table 5.13: Median contact days per week with the therapists.				
		Admitted	Not admitted	p-val
Physiotherapy	week 1	2	1	0.028
	week 2-4	3	2	<0.001
	week 1-4	3	2	<0.001
Occupational	week 1	1	-	-
	week 2-4	2	1	0.017
	week 1-4	2	1	0.132
Speech therapy	week 1	1	-	-
	week 2-4	1	1	0.074
	week 1-4	1	1	0.056
Dietician	week 1	1	-	-
	week 2-4	1	1	0.478
	week 1-4	1	1	0.498

Of those receiving speech therapy, there was no significant difference in the intensity of therapy received in admitted (1 contact per week) and not admitted (1 contact per week) patients, $p=0.056$. Of those receiving dietician input, there was no significant difference in the intensity of input received in admitted (1 contact per week) and not admitted (1 contact per week) patients, $p=0.498$.

Late therapy (month 6)

Therapy usage and intensity (median contact numbers over the month) in patients using the service over month 6 is described in Table 5.14. Physiotherapy services were used in 72/446 (16%) of admitted and 8/212 (8%) of not admitted patients, $p<0.001$. In those receiving the service, there was no significant difference in the median number of contacts in admitted (3) and not admitted (2) patients, $p=0.599$. Occupational therapy services were used in 27/447 (6%) of admitted and 6/213 (3%) of not admitted patients, $p=0.081$. In those receiving the service, the median number of contacts in admitted (2) and not admitted (1) patients were significantly different, $p=0.025$.

Speech therapy services were used in 42/447 (9%) of admitted and 6/213 (3%) of not admitted patients, $p=0.003$. In those receiving the service, there was no significant difference in the median number of contacts in admitted (1) and not admitted (2) patients, $p=0.71$. Dietician services were used in 11/453 (2%) of admitted and 1/213 (0%) of not admitted patients, $p=0.076$. In those receiving the service, there was no significant difference in the median number of contacts in admitted (1) and not admitted (1) patients, $p=0.763$.

Table 5.14: Late rehabilitation: Therapy usage and median contact times over the month in those using the services, during month 6 post stroke.

	Admitted (%)	Not admitted (%)	p-val
Physiotherapy	72/446 (16%)	8/212 (8%)	<0.001
median contacts	3	2	0.599
Occupational therapy	27/447 (6%)	6/213 (3%)	0.081
median contacts	2	1	0.025
Speech therapy	42/447 (9%)	6/213 (3%)	0.003
median contacts	1	2	0.71
Dietician input	11/453 (2%)	1/213 (0%)	0.076
median contacts	1	1	0.763

CHAPTER 6

RESULTS: CASE FATALITY, SURVIVAL CURVES, HANDICAP AND DISABILITY

This chapter describes the following main outcomes of the thesis: Case fatality, Kaplan-Meier survival curves, handicap and disability; all analysed by subtype, for admitted and not admitted patients. Factors that may affect the real or apparent differences in the various outcomes are analysed further.

CASE FATALITY

The deaths in the 722 admitted and 288 not admitted stroke patients over the four years following their strokes, according to stroke subtype is described in this section.

Early case fatality (day 0-28)

Very early (24 hours post stroke) case fatalities are shown in table 6.1. Overall, 25/722 (3.5%) of admitted and 8/288 (6.3%) of not admitted patients had died, $p=0.048$. For the TACS strokes, admitted patients had significantly lower case fatality rates than not admitted patients (6/211-2.8% vs. 12/47-25.5%, $p<0.001$). For all the other subgroups, there were no significant differences.

	Admitted (%)	Not admitted (%)	p-val
TACS	6 (3%)	12 (26%)	<0.001
PACS	0 (0%)	0 (0%)	1.000
POCS	5 (4%)	3 (9%)	0.240
LACS	0 (0%)	0 (0%)	1.000
Uncertain	14 (39%)	3 (23%)	0.334
All	25 (3.5%)	18 (6.3%)	0.048

Case fatalities at seven days post stroke are shown in table 6.2. Overall, 124/722 (17.2%) of admitted and 39/288 (13.5%) of not admitted patients had died, $p=0.157$. For the TACS strokes, admitted patients had significantly lower case fatality rates than not admitted patients (65/211-31% vs. 26/47-55%, $p=0.001$). On combining the TACS and Uncertain categories, the lower rate persisted (92/248, 37% vs. 34/60, 57%). For POCS strokes, 24/124 (19%) of admitted and 3/33 (9%) of not admitted patients had died, $p=0.165$. In the less severe stroke subtypes (PACS and LACS), case fatalities were uncommon and not significantly different in admitted and not admitted patients.

	Admitted (%)	Not admitted (%)	p-val
TACS	65 (31%)	26 (55%)	<0.001
PACS	7 (3%)	2 (2%)	0.436
POCS	24 (19%)	3 (9%)	0.165
LACS	1 (1%)	0 (0%)	0.431
Uncertain	27 (73%)	8 (62%)	0.439
All	124 (17%)	39 (14%)	0.157

Case fatalities at 28 days post stroke are shown in table 6.3. Overall, 200/722 (27.7%) of admitted and 53/288 (18.4%) of not admitted patients had died, $p=0.002$. For TACS strokes, 114/211 (54%) of admitted and 33/47 (70%) of the not admitted patients had died, $p=0.043$. For POCS strokes, 36/124 (29%) of admitted and 4/33 (12%) of not admitted patients had died, $p=0.048$. For PACS and LACS strokes, there were no significant differences in the case fatality rates between admitted and not admitted patients, $p=0.334$ and 0.431 respectively.

	Admitted (%)	Not admitted (%)	p-val
TACS	114 (54%)	33 (70%)	0.043
PACS	20 (9%)	7 (6%)	0.334
POCS	36 (29%)	4 (12%)	0.048
LACS	1 (1%)	0 (0%)	0.431
Uncertain	30 (81%)	9 (69%)	0.375
All	200 (27.7%)	53 (18.4%)	0.002

Intermediate (six months) and late (year 1 and 4) case fatality

Case fatalities at six months post stroke are shown in table 6.4. Overall, 263/722 (36.4%) of admitted and 73/288 (25.3%) of not admitted patients had died, $p=0.001$. For TACS strokes, 136/211 (65%) of admitted and 40/47 (85%) of not admitted patients had died, $p=0.006$. For POCS strokes, 47/124 (38%) of admitted and 5/33 (15%) of not admitted patients had died, $p=0.014$. For PACS and LACS strokes, there were no significant differences in the case fatality rates between admitted and not admitted patients, $p=0.082$ and 0.725 respectively.

	Admitted (%)	Not admitted (%)	p-val
TACS	136 (65%)	40 (85%)	0.006
PACS	41 (18%)	13 (11%)	0.082
POCS	47 (38%)	5 (15%)	0.014
LACS	8 (6%)	4 (5%)	0.725
Uncertain	31 (84%)	11 (85%)	0.944
All	263 (36.4%)	73 (25.3%)	<0.001

Case fatalities at one year post stroke are shown in table 6.5. Overall, 295/722 (40.9%) of admitted and 81/288 (28.1%) of not admitted patients had died, $p<0.001$. The absolute difference in overall case fatality was 12.8%. There was a 46% relative increase in case fatality in admitted compared to not admitted patients at one year. For TACS strokes, 148/211 (70%) of admitted and 42/47 (89.4%) of not admitted patients had died, $p=0.007$. For PACS strokes, 52/225 (23%) of admitted and 17/118 (14%) of not admitted patients had died, $p=0.056$. For POCS

strokes, 51/124 (41%) of admitted and 6/33 (18%) of not admitted patients had died, $p=0.015$. For LACS strokes, 13/125 (10%) of admitted and 4/77 (5%) of not admitted patients had died, $p=0.196$. For the uncertain category, the difference in case fatality in admitted and not admitted patients remained not significant $p=0.446$.

Table 6.5: Case fatality by stroke subtype at one year post stroke onset.

	Admitted (%)	Not admitted (%)	p-val
TACS	148 (70%)	42 (89%)	0.007
PACS	52 (23%)	17 (14%)	0.056
POCS	51 (41%)	6 (18%)	0.015
LACS	13 (10%)	4 (5%)	0.196
Uncertain	31 (84%)	12 (92%)	0.446
All	295 (40.9%)	81 (28.1%)	<0.001

Case fatalities at four years post stroke are shown in table 6.6. Overall, the differences between admitted and not admitted patients remained significant. 436/722 (60.4%) of admitted and 135/288 (46.9%) of not admitted patients died, $p<0.001$. For TACS strokes, 171/211 (81%) of admitted and 43/47 (91%) of not admitted patients had died, $p=0.085$. For PACS strokes, 115/225 (51%) of admitted and 47/118 (40%) of not admitted patients had died, $p=0.047$. For POCS strokes, 77/124 (62%) of admitted and 14/33 (42.4%) of not admitted patients had died, $p=0.042$. For LACS strokes, 41/125 (33%) of admitted and 19/77 (25%) of not admitted patients had died, $p=0.220$. For the uncertain category, 87% of admitted and 92% of not admitted patients had died, $p=0.578$.

Table 6.6: Case fatality by stroke subtype at four years post stroke onset.

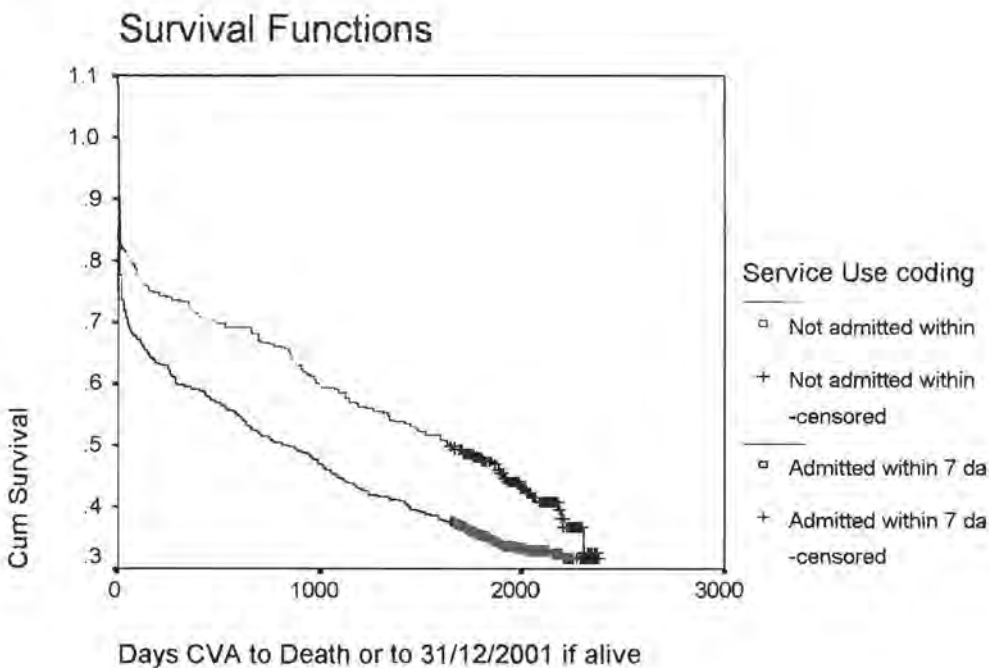
	Admitted (%)	Not admitted (%)	p-val
TACS	171 (81%)	43 (91%)	0.085
PACS	115 (51%)	47 (40%)	0.047
POCS	77 (62%)	14 (42%)	0.042
LACS	41 (33%)	19 (25%)	0.220
Uncertain	32 (87%)	12 (92%)	0.578
All	436 (60.4%)	135 (46.9%)	<0.001

KAPLAN-MEIER SURVIVAL CURVES

This section describes the survival curves of admitted and not admitted patients, according to stroke subtype and overall from stroke onset.

Chart 6.1 shows the Kaplan-Meier survival curves of all strokes for admitted and not admitted patients. There is a widening of the survival curves to 4.7% at one week post stroke - 598/722 (82.8%) of admitted and 249/288 (86.5%) of not admitted patients survived, $p=0.157$. By 28 days, the difference increased to 9.7%. 522/722 (72.3%) of admitted and 235/288 (81.6%) of not admitted patients survived, $p=0.002$. The difference initially continued to increase and by six months was 11.1% (63.6% vs. 74.7%), at one year 12.8% (59.1% vs. 71.9%) and at two years 15.3% (51.4% vs. 66.7%). By three years the curves began converging and the difference was 14.3% (44.6% vs. 58.7%) and at four years 13.5% (286/722-39.6% vs. 153/288-53.1%), $p<0.001$.

Chart 6.1: Kaplan-Meier survival curves for admitted and not admitted patients-All strokes.



Charts 6.2 and 6.3 show the Kaplan-Meier survival curves by stroke subtype for admitted and not admitted patients. For admitted patients, stroke subtype reflects survival with the increasing severity of subtypes having progressively worse survival. Lacunar strokes have the best survival with an almost linear decline in survival over time. Total anterior and uncertain category strokes have very early high fatality followed by a gradual decline in survival. For not admitted patients, the pattern of survival correlating with stroke subtype is less striking. The mildest severity subtypes (lacunar and partial anterior circulation strokes) and posterior circulation strokes all have similar survival patterns. The total anterior and uncertain categories high early fatality reflects the severity of these subtypes and is similar to that in admitted patients.

Chart 6.2: Kaplan-Meier survival curves for admitted patients, by stroke subtype.

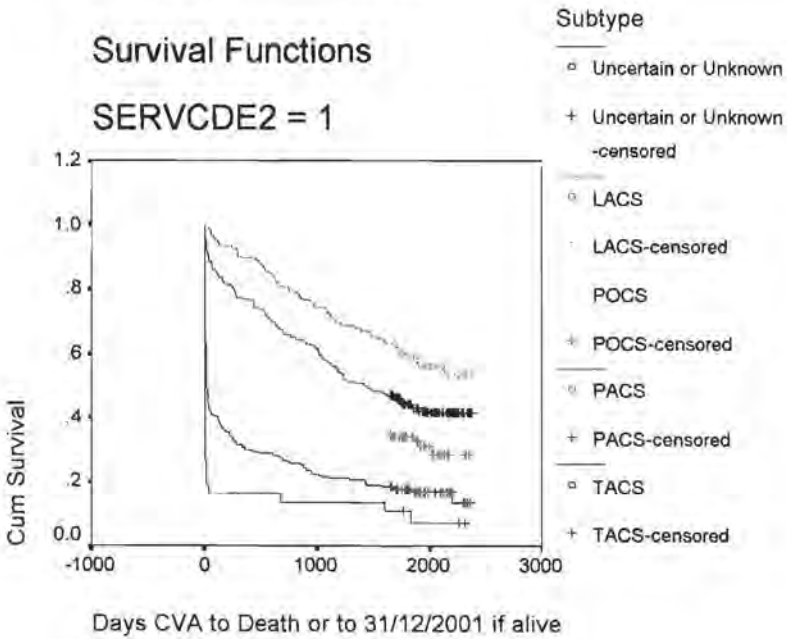
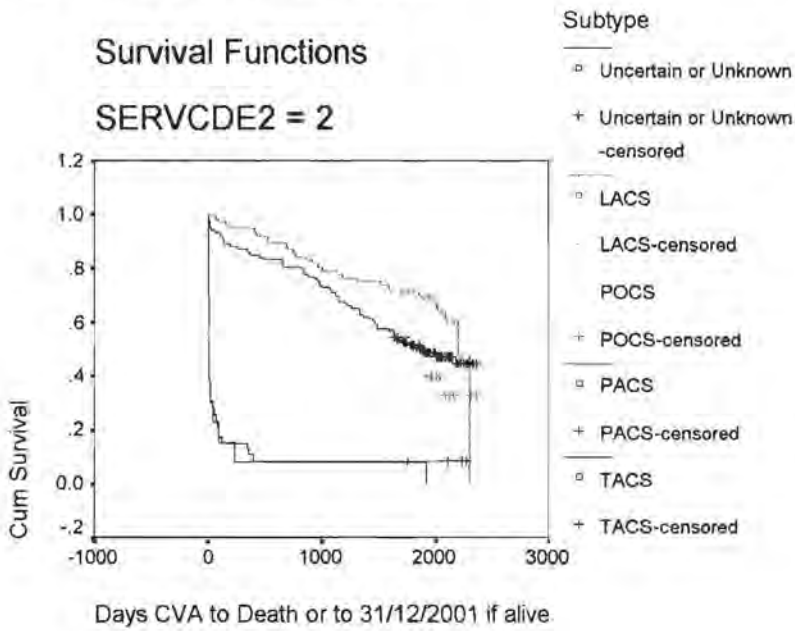
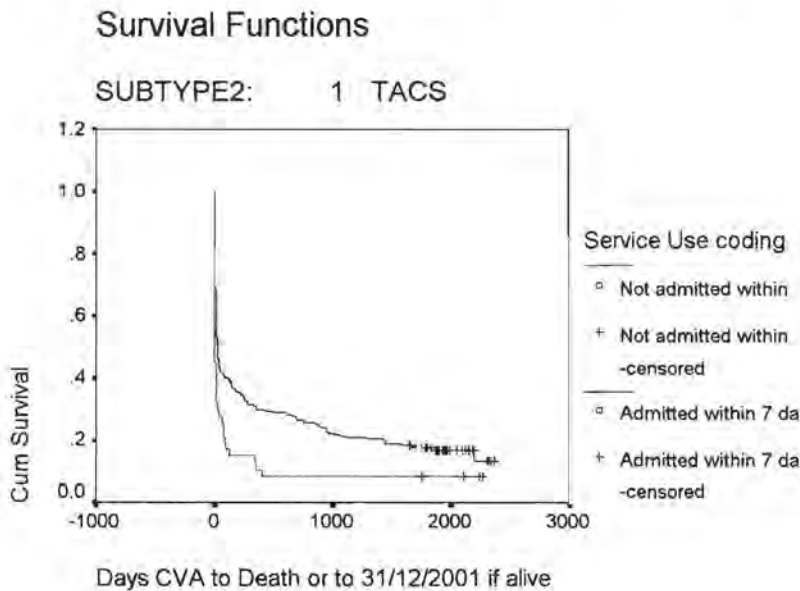


Chart 6.3: Kaplan-Meier survival curves for not admitted patients, by stroke subtype.



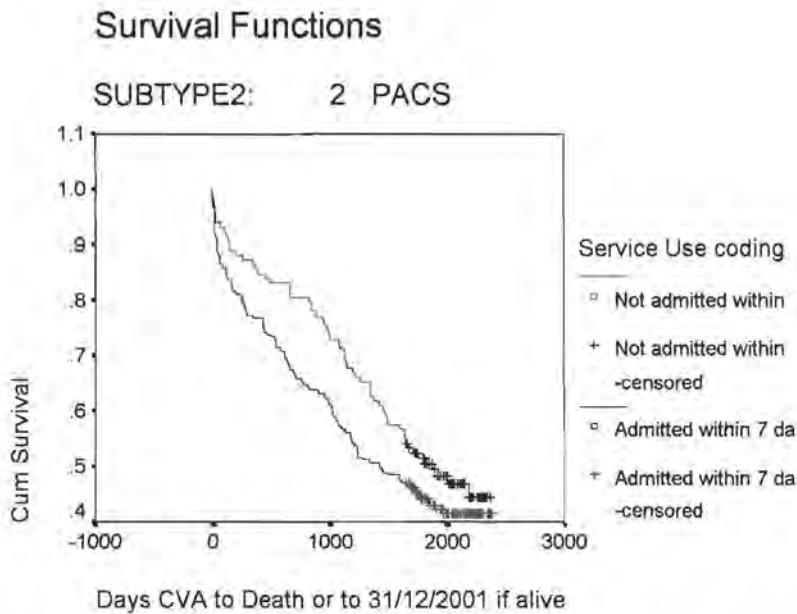
Charts 6.4 to 6.8 show the Kaplan-Meier survival curves comparing each subtype in admitted and not admitted patients.

Chart 6.4: Kaplan-Meier survival curves for total anterior circulation strokes in admitted and not admitted patients.



For total anterior strokes (chart 6.4), the general patterns of survival have similar trends in admitted and not admitted patients. Not admitted patients have higher early fatalities with the graphs gradually converging.

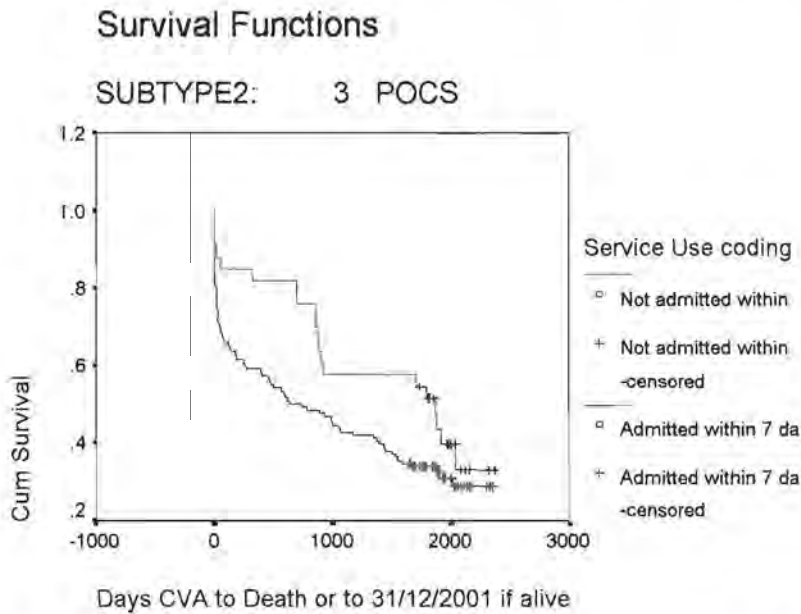
Chart 6.5: Kaplan-Meier survival curves for partial anterior circulation strokes in admitted and not admitted patients.



For partial anterior strokes (chart 6.5), the general patterns of survival are similar in admitted and not admitted patients. There is however a late divergence with this trend persisting up to four years suggesting less admitted than not admitted patients, surviving long term.

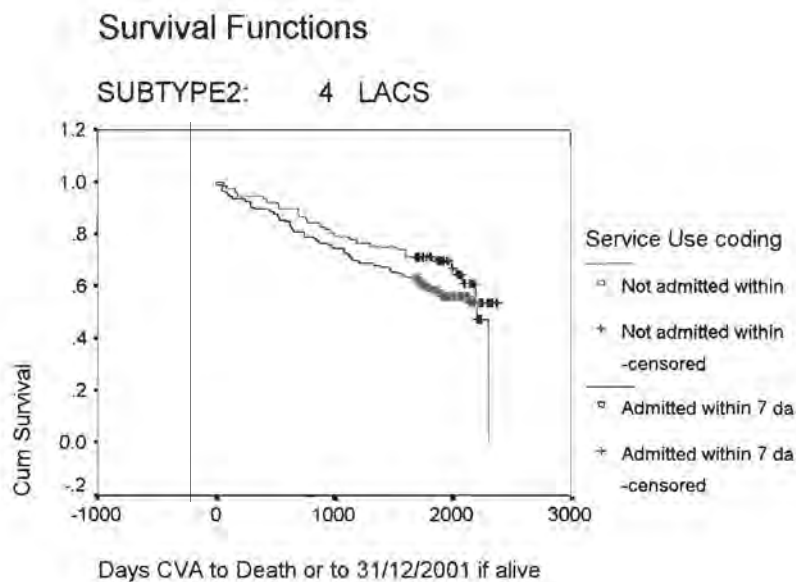
For posterior circulation strokes (chart 6.6), the general patterns of survival are less similar in admitted and not admitted patients than in the other subtypes. There is an early (by 28 days) and marked divergence in survival, the trend of which persists up to at least four years.

Chart 6.6: Kaplan-Meier survival curves for posterior circulation strokes in admitted and not admitted patients.



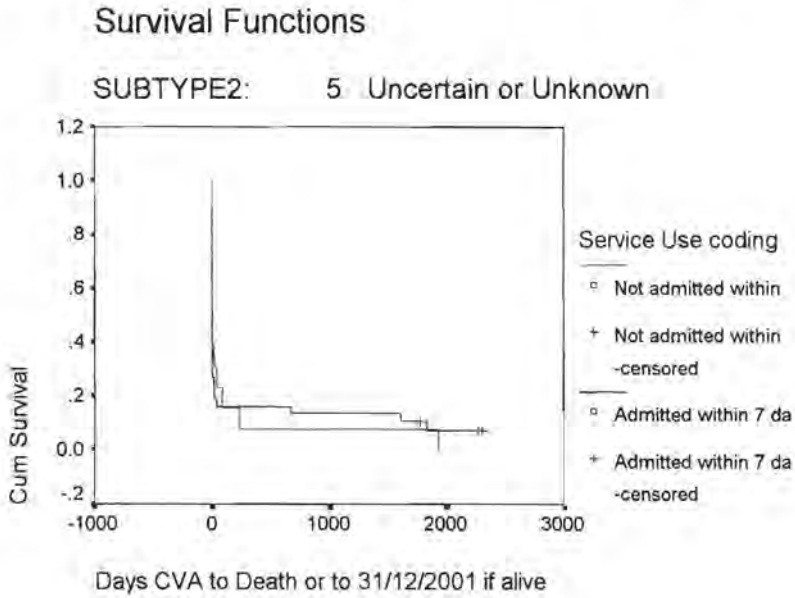
For lacunar strokes (chart 6.7), the general patterns of survival are similar in admitted and not admitted patients. There is a slight divergence with time with higher survival rates in not admitted patients. By four years this difference was not significant, $p=0.220$.

Chart 6.7: Kaplan-Meier survival curves for lacunar circulation strokes in admitted and not admitted patients.



For the uncertain category (chart 6.8), the general patterns of survival are similar in admitted and not admitted patients. In both, there are very high early fatalities with very gradual declines in survival thereafter.

Chart 6.8: Kaplan-Meier survival curves for the uncertain category strokes in admitted and not admitted patients.



HANDICAP

In this section, handicap as determined by the Oxford Handicap Scale (OHS), pre-stroke, at 28 days, and at six months, are compared in admitted and not admitted patients, by stroke subtype and overall (tables 6.7-6.9). Combined death and dependence (OHS 3-6) by stroke subtype are shown in tables 6.10 and 6.11.

Pre-stroke handicap

Table 6.7 shows the pre-stroke handicap levels for admitted and not admitted patients according to stroke subtype and overall. Overall, 586/722 (81.2%) of admitted and 207/288 (71.9%) of not admitted patients were independent prior to their stroke (OHS 0-2). 27/722 (3.7%) and 44/288 (15.3%) respectively were moderate to severely dependent prior to their stroke (OHS 4-5). Both the categorised and continuous variable analyses reveal significance (0.012 and <0.001 respectively).

For TACS strokes, 161/211 (76%) of admitted and 13/47 (28%) of not admitted patients were independent (OHS 0-2) prior to their stroke. The difference in dependence levels was significant, $p < 0.001$. Similar differences were present in the uncertain category. For PACS, POCS and LACS strokes, in both admitted and not admitted patients, there were no significant differences between the groups ($p = 0.135$ to 0.628) and most were independent (77-91%) prior to their stroke.

Within the admitted patient group, similar levels of pre-stroke dependency were present in all subtypes of stroke except lacunar strokes, where more patients were independent than any of the other subtypes. For not admitted patients, half (22/44) of all the moderate to severely

Table 6.7: Pre-stroke handicap and stroke subtype in admitted and not admitted patients.

Subtype	OHS	Admitted (%)	Not admitted (%)	p-val
TACS	0-2	161 (76%)	13 (28%)	<0.001
	3	38 (18%)	12 (26%)	
	4-5	12 (6%)	22 (47%)	
	IQR	1-2	2-4	
	median	2	3	<0.001
PACS	0-2	186 (83%)	96 (81%)	0.135
	3	32 (14%)	13 (11%)	
	4-5	7 (3%)	9 (8%)	
	IQR	1-2	1-2	
	median	1	1	0.322
POCS	0-2	96 (77%)	27 (82%)	0.628
	3	23 (19%)	4 (12%)	
	4-5	5 (4%)	2 (6%)	
	IQR	1-2	0.8-2	
	median	1	1	0.820
LACS	0-2	114 (91%)	68 (88%)	0.563
	3	10 (8%)	7 (9%)	
	4-5	1 (1%)	2 (3%)	
	IQR	1-2	1-2	
	median	1	1	0.372
Uncertain	0-2	29 (78%)	3 (23%)	<0.001
	3	6 (16%)	1 (8%)	
	4-5	2 (5%)	9 (69%)	
	IQR	0.8-2	2.8-5	
	median	2	4	<0.001
All	0-2	586 (81.2%)	207 (71.9%)	0.012
	3	109 (15.1%)	37 (12.8%)	
	4-5	27 (3.7%)	44 (15.3%)	
	IQR	0-2	0-3	
	median	1.0	1.0	<0.001

dependent not admitted patients went on to have total anterior circulation strokes. A further fifth (9/44) had strokes that were of the uncertain category. PACS and POCS subtypes had similar levels of pre-stroke dependency. As with admitted patients, not admitted LACS stroke patients were the most independent prior to their strokes.

Post stroke handicap at 28 days

Table 6.8 shows the Oxford Handicap Scores in survivors at 28 days. There were 6 missing assessments in the admitted and 4 in the not admitted patients. In 28 days survivors completing the assessment, 224/516 (43.4%) of admitted and 167/231 (72.3%) of not admitted patients were independent (OHS 0-2) post stroke. 125/516 (24.2%) and 39/231 (16.9%) respectively were mildly dependent (OHS 3). 167/516 (32.4%) and 25/231 (10.8%) respectively were moderate to severely dependent (OHS 4-5). Analysed as both categorised and continuous variables, these were significantly different ($p < 0.001$).

For TACS strokes, 5/97 (5%) of admitted and 3/14 (21%) of not admitted patients were independent (OHS 0-2). Despite the numbers being small, the difference in dependence levels was significant, $p < 0.001$. Median OHS scores however were the same (4), $p = 0.075$.

For PACS, POCS and LACS strokes, in both admitted and not admitted patients, there were no significant differences between the groups ($p = 0.308$ to 0.787) and most were independent (50-82%). Median OHS scores were the same for PACS (2) and LACS (1). For POCS the scores were 2.5 and 1 respectively for admitted and not admitted patients. Analysed as continuous variables revealed significant differences ($p = 0.02$ to < 0.001) in all three subtypes.

Table 6.8: Post stroke handicap at 28 days and stroke subtype in admitted and not admitted patients.

Subtype	OHS	Admitted (%)	Not admitted (%)	p-val
TACS	0-2	5 (5%)	3 (21%)	<0.001
	3	16 (17%)	1 (7%)	
	4-5	74 (78%)	10 (71%)	
	IQR	4-5	3-5	
	median	4	4	0.075
PACS	0-2	110 (54%)	84 (77%)	0.308
	3	44 (22%)	17 (16%)	
	4-5	50 (25%)	8 (7%)	
	IQR	2-3	1-2	
	median	2	2	<0.001
POCS	0-2	44 (50%)	23 (82%)	0.787
	3	26 (30%)	4 (14%)	
	4-5	18 (20%)	1 (4%)	
	IQR	2-3	1-2	
	median	2.5	1	0.02
LACS	0-2	63 (51%)	56 (73%)	0.578
	3	38 (31%)	17 (22%)	
	4-5	22 (18%)	4 (5%)	
	IQR	2-3	1-3	
	median	2	2	0.010
Uncertain	0-2	2 (33%)	1 (33%)	0.052
	3	1 (17%)	0 (0%)	
	4-5	3 (50%)	2 (67%)	
	IQR	1-5	2-4	
	median	3.5	4	0.306
All	0-2	224 (43.4%)	167 (72.3%)	<0.001
	3	125 (24.2%)	39 (16.9%)	
	4-5	167 (32.4%)	25 (10.8%)	
	IQR	0-3	0-2	
	median	2	1	<0.001
Missing data		5	4	

Post stroke handicap at six months

Table 6.9 shows the Oxford Handicap Scores in survivors at six months. There were 10 missing assessments in the admitted and 4 in the not admitted patients. In 6 months survivors completing the assessment, 181/449 (40.3%) of admitted and 150/211 (71.1%) of not admitted patients were independent (OHS 0-2) post stroke, 144/449 (32.1%) and 37/211 (17.5%) respectively were mildly dependent (OHS 3) post stroke, and 124/449 (27.6%) and 24/211 (11.4%) respectively were moderate to severely dependent (OHS 4-5) post stroke. These differences analysed as both categorised and continuous variables, were significantly different, $p < 0.001$.

For TACS strokes, 8/73 (11%) of admitted and 2/7 (29%) of not admitted patients were independent (OHS 0-2). The difference in dependence levels was not significant, $p = 0.278$. Median OHS scores were 5 for admitted and 3 for not admitted patients, $p = 0.408$.

For PACS, POCS and LACS strokes, in both admitted and not admitted patients, there were significant differences between the groups ($p = 0.028$ to < 0.001) with most not admitted patients being independent (71-75%). For all three subtypes, median OHS scores were higher in admitted patients. Analysed as continuous variables revealed significant differences ($p < 0.05$) in all three subtypes.

Table 6.9: Post stroke handicap at six months and stroke subtype in admitted and not admitted patients.

Subtype	OHS	Admitted (%)	Not admitted (%)	p-val
TACS	0-2	8 (11%)	2 (29%)	0.278
	3	14 (19%)	2 (29%)	
	4-5	51 (70%)	3 (43%)	
	IQR	3-5	2-5	
	median	5	3	0.408
PACS	0-2	81 (45%)	77 (73%)	<0.001
	3	63 (35%)	18 (17%)	
	4-5	36 (20%)	10 (10%)	
	IQR	1-3	1-3	
	median	3	2	<0.001
POCS	0-2	32 (43%)	21 (75%)	0.018
	3	28 (37%)	6 (21%)	
	4-5	15 (20%)	1 (4%)	
	IQR	2-3	1-2.8	
	median	3	1	0.044
LACS	0-2	58 (50%)	49 (71%)	0.028
	3	36 (31%)	11 (16%)	
	4-5	22 (19%)	9 (13%)	
	IQR	1-3	1-3	
	median	2.5	1	0.016
Uncertain	0-2	2 (40%)	1 (50%)	0.217
	3	3 (60%)	0 (0%)	
	4-5	0 (0%)	1 (50%)	
	IQR	1.8-3	1-5	
	median	3	3	0.208
All	0-2	181 (40.3%)	150 (71.1%)	<0.001
	3	144 (32.1%)	37 (17.5%)	
	4-5	124 (27.6%)	24 (11.4%)	
	IQR	0-4	0-3	
	median	3	2	<0.001
Missing data		10	4	

Combined death and dependence at 28 days

Table 6.10 shows combined death and dependence (OHS 3-6) at 28 days post stroke for admitted and not admitted patients. Overall, 493/717 (68.8%) of admitted and 117/284 (41.2%) of not admitted patients were dead or dependent at 28 days post stroke ($p < 0.001$).

For total anterior strokes, there were no significant differences in combined death and dependence between admitted 204/209 (98%) and not admitted 44/47 (94%) patients, $p = 0.155$. For each of PACS, POCS and LACS, significantly more admitted patients were dead or dependent than not admitted patients ($p = 0.002$ to < 0.001).

Table 6.10: Combined death and dependence (OHS 3-6) by stroke subtype, at 28 days post stroke for admitted and not admitted patients.

Subtype	OHS	Admitted (%)	Not admitted (%)	p-val
TACS	0-2	5 (2%)	3 (6%)	0.155
	3-6	204 (98%)	44 (94%)	
PACS	0-2	110 (49%)	84 (72%)	<0.001
	3-6	114 (51%)	32 (28%)	
POCS	0-2	44 (35%)	23 (72%)	<0.001
	3-6	80 (65%)	9 (28%)	
LACS	0-2	63 (51%)	56 (73%)	0.002
	3-6	61 (49%)	21 (27%)	
Uncertain	0-2	2 (6%)	1 (8%)	0.731
	3-6	34 (94%)	11 (92%)	
All	0-2	224 (31%)	167 (59%)	<0.001
	3-6	493 (69%)	117 (41%)	
Missing data		5	4	

Combined death and dependence at six months

Table 6.11 shows combined death and dependence (OHS 3-6) at six months post stroke for admitted and not admitted patients. Overall, 531/712 (74.6%) of admitted and 134/284 (47.2%) of not admitted patients were dead or dependent, $p < 0.001$.

For total anterior strokes, there were no significant differences in combined death and dependence between admitted 201/209 (96%) and not admitted 45/47 (96%) patients, $p = 0.891$. For each of PACS, POCS and LACS, significantly more admitted patients were dead or dependent than not admitted patients ($p = 0.006$ to < 0.001).

Table 6.11: Combined death and dependence (OHS 3-6) by stroke subtype, at six months post stroke for admitted and not admitted patients.				
Subtype	OHS	Admitted (%)	Not admitted (%)	p-val
TACS	0-2	8 (4%)	2 (4%)	0.891
	3-6	201 (96%)	45 (96%)	
PACS	0-2	81 (37%)	77 (65%)	<0.001
	3-6	140 (63%)	41 (35%)	
POCS	0-2	32 (26%)	21 (64%)	<0.001
	3-6	90 (74%)	12 (36%)	
LACS	0-2	58 (47%)	49 (67%)	0.006
	3-6	66 (53%)	24 (33%)	
Uncertain	0-2	2 (6%)	1 (8%)	0.783
	3-6	34 (94%)	12 (92%)	
All	0-2	181 (25%)	150 (53%)	<0.001
	3-6	531 (75%)	134 (47%)	
Missing data		10	4	

DISABILITY

In this section, disability as determined by the Barthel ADL Index at one week (examiner), 28 days, and six months (self reported questionnaire) is reported for each subtype in admitted and not admitted patients. Those alive and completing the assessments were analysed. In addition, results from questions concerning needing help with activities of daily living and requiring assistance in completing the six month questionnaire; and the Nottingham Extended Activities of Daily Living (EADL) at six months, are reported in the next chapter (Chapter 7).

Disability at one week

Disability at one week for admitted and not admitted patients is shown in table 6.12. In all stroke subtypes except for the uncertain category, admitted patients were more disabled than not admitted patients, $p < 0.001$. Median Barthel scores in all stroke subtypes were lower in admitted patients. Overall, 116/716 (19.6%) of admitted and 133/277 (55.9%) of not admitted patients had Barthel scores ≥ 18 , $p < 0.001$.

For TACS strokes, 2/145 (1%) of admitted and 0/16 (0%) of not admitted patients had Barthel scores ≥ 18 , $p < 0.001$. The median scores were 0 and 1 respectively. Within the admitted group of patients, stroke subtypes PACS, POCS and LACS had similar median scores (12-13). Within the not admitted group of patients, stroke subtypes PACS, POCS and LACS had similar median scores (18-19).

Table 6.12: Barthel ADL Index at one week post stroke by subtype, in admitted and not admitted patients.

Subtype	Barthel	Admitted (%)	Not admitted (%)	p-val
TACS	0-17	143 (99%)	16 (100%)	<0.001
	18-20	2 (1%)	0 (0%)	
	median	0	1	
PACS	0-17	158 (73%)	44 (39%)	<0.001
	18-20	58 (27%)	68 (61%)	
	median	13	19	
POCS	0-17	75 (77%)	7 (24%)	<0.001
	18-20	23 (23%)	22 (76%)	
	median	12	19	
LACS	0-17	94 (76%)	35 (45%)	<0.001
	18-20	30 (24%)	42 (55%)	
	median	13	18	
Uncertain	0-17	6 (67%)	3 (75%)	0.957
	18-20	3 (33%)	1 (25%)	
	median	1	12	
All	0-17	476 (80%)	105 (44%)	<0.001
	18-20	116 (20%)	133 (56%)	
	median	10	18	
Missing data		6	11	

Disability at 28 days

Disability at 28 days for admitted and not admitted patients is shown in table 6.13. Overall, at 28 days post stroke, admitted patients had lower Barthel scores than not admitted patients (median score 16 and 19 respectively), $p < 0.001$. 207/516 (40.1%) of admitted and 155/230 (67.4%) of not admitted patients had Barthel scores ≥ 18 , $p < 0.001$.

Table 6.13: Barthel ADL Index at 28 days post stroke by subtype, in admitted and not admitted patients.

Subtype	Barthel	Admitted (%)	Not admitted (%)	p-val
TACS	0-17	88 (93%)	12 (86%)	0.771
	18-20	7 (7%)	2 (14%)	
	IQR	1-10	2-14	
	median	4	4.5	0.669
PACS	0-17	103 (50%)	30 (28%)	<0.001
	18-20	101 (50%)	78 (72%)	
	IQR	11-20	17-20	
	median	17	20	<0.001
POCS	0-17	48 (55%)	5 (18%)	0.001
	18-20	40 (45%)	23 (82%)	
	IQR	11-20	18.3-20	
	median	17	20	<0.001
LACS	0-17	66 (54%)	26 (34%)	0.006
	18-20	57 (46%)	51 (66%)	
	IQR	11-20	16.8-20	
	median	17	19	
Uncertain	0-17	4 (67%)	2 (67%)	1.000
	18-20	2 (33%)	1 (33%)	
	IQR	14-18	8-20	
	median	16	10	0.714
All	0-17	309 (60%)	75 (33%)	<0.001
	18-20	207 (40%)	155 (67%)	
	IQR	9-20	16-20	
	median	16	19	<0.001
Missing data		6	5	

For TACS strokes, the proportions of patients with Barthel scores ≥ 18 were 7/95 (7%) of admitted and 2/14 (14%) of not admitted patients, $p=0.771$. Both admitted and not admitted TACS stroke patients have the lowest median Barthel scores for their groups (4 and 4.5 respectively).

For PACS, POCS and LACS strokes, admitted patients had significantly lower Barthel scores than not admitted patients ($p=0.006$ to $p<0.001$).

Disability at six months

Disability at six months for admitted and not admitted patients is shown in table 6.14. Overall, at six months post stroke, admitted patients had lower Barthel scores than not admitted patients (median score 17 and 19 respectively), $p<0.001$. 195/446 (43.7%) of admitted and 138/208 (67.0%) of not admitted patients had Barthel scores ≥ 18 , $p<0.001$.

For TACS strokes, the proportions of patients with Barthel scores ≥ 18 were 7/72 (10%) of admitted and 1/7 (14%) of not admitted patients, $p=0.702$. The median Barthel scores were 7 and 9 respectively, $p=0.672$.

For PACS and POCS strokes, admitted patients had significantly lower Barthel scores than not admitted patients ($p=0.002$ and $p=0.004$ respectively). For LACS strokes, although 59/117 (50.4%) of admitted and 42/66 (63.6%) of not admitted patients had Barthel scores ≥ 18 , median scores were similar (18 and 19 respectively). The differences in Barthel scores were not significant ($p=0.084$).

Table 6.14: Barthel ADL Index at six months post stroke by subtype, in admitted and not admitted patients.

Subtype	Barthel	Admitted (%)	Not admitted (%)	p-val
TACS	0-17	65 (90%)	6 (86%)	0.702
	18-20	7 (10%)	1 (14%)	
	IQR	2-11.8	2-14	
	median	7	9	0.672
PACS	0-17	90 (50%)	32 (31%)	0.002
	18-20	89 (50%)	71 (69%)	
	IQR	13-20	16-20	
	median	17	20	0.002
POCS	0-17	36 (49%)	5 (18%)	0.004
	18-20	37 (51%)	23 (82%)	
	IQR	14-20	18-20	
	median	18	20	0.009
LACS	0-17	58 (50%)	24 (36%)	0.084
	18-20	59 (50%)	42 (64%)	
	IQR	14-20	16-20	
	median	18	19	0.058
Uncertain	0-17	2 (40%)	1 (50%)	0.809
	18-20	3 (60%)	1 (50%)	
	IQR	13.5-18.5	0-20	
	median	18	10	0.857
All	0-17	251 (56%)	68 (33%)	<0.001
	18-20	195 (44%)	138 (67%)	
	IQR	10-20	16-20	
	median	17	19	<0.001
Missing data		13	9	

FACTORS POTENTIALLY ASSOCIATED WITH THE DIFFERENCES

Factors that may be contributing to the real or apparent differences between the subtypes in admitted and not admitted patients are explored in more detail. Stroke subtypes are further analysed according to patient's age, pre-stroke disability (OHS), residence (nursing or residential homes), and selected stroke severity factors in the first week post stroke onset.

Age and stroke subtype

The median ages and inter-quartile ranges in admitted and not admitted patients for each subtype of stroke are shown in table 6.15. For TACS strokes, the median age in admitted (79 years) was significantly lower than not admitted (85 years) patients, $p < 0.001$. For all the other subtypes, there were no significant differences in the median ages.

	Age	Admitted	Not admitted	p-val
TACS	median	79	85	<0.001
	IQR	68-83	75-90	
PACS	median	74	73	0.340
	IQR	66-81	65-79	
POCS	median	72.5	74	0.361
	IQR	62.5-81	67-81.3	
LACS	median	72	71	0.202
	IQR	64-80	59-76	
Uncertain	median	76	80	0.254
	IQR	69.3-83	71-86	
All	median	74	74	0.835
	IQR	65-82	66-82	

Pre-stroke disability and stroke subtype

The pre-stroke Oxford Handicap Score 0-2 category and median scores (for the whole subtype), for admitted and not admitted patients are shown in table 6.16. Overall, 586/722 (81.2%) of admitted patients and 207/288 (71.9%) of not admitted had scores of 0-2, $p=0.012$. Median scores were 1 and 2 respectively, $p<0.001$.

For TACS, 161/211 (76%) of admitted and 13/47 (28%) of not admitted patients were independent prior to their stroke, $p<0.001$. Median scores were 2 and 3 respectively, $p<0.001$. For PACS, POCS and LACS strokes, there were no significant differences in the proportions of patients independent prior to their stroke. Median scores for all the subtypes in admitted and not admitted patients were 1.

Table 6.16: Pre-stroke disability (OHS 0-2), median OHS (0-5) and stroke subtype in admitted and not admitted patients.

	OHS	Admitted (%)	Not admitted (%)	p-val
TACS	0-2	161 (76%)	13 (28%)	<0.001
	median	2	3	<0.001
PACS	0-2	186 (83%)	96 (81%)	0.135
	median	1	1	0.322
POCS	0-2	96 (77%)	27 (82%)	0.628
	median	1	1	0.820
LACS	0-2	114 (91%)	68 (88%)	0.563
	median	1	1	0.372
Uncertain	0-2	29 (78%)	3 (23%)	<0.001
	median	2	4	<0.001
All	0-2	586 (81%)	207 (72%)	0.012
	median	1	2	<0.001

Pre-stroke residence and stroke subtype

The proportion of patients in each stroke subtype living in residential or nursing homes for admitted and not admitted patients is shown in table 6.17. The rest of the patients were living in private residences. Overall, 45/722 (6.2%) of admitted and 64/288 (22.2%) of not admitted patients were living in residential or nursing homes, $p < 0.001$.

For TACS strokes, 22/211 (10%) of admitted and 32/47 (68%) of not admitted patients were living in residential or nursing homes prior to their stroke, $p < 0.001$. For PACS strokes, 10/225 (4%) of admitted and 12/118 (10%) of not admitted patients were living in residential or nursing homes prior to their stroke, $p = 0.040$. For LACS strokes, 2/125 (2%) of admitted and 9/77 (12%) of not admitted patients were living in residential or nursing homes prior to their stroke, $p < 0.001$. For POCS strokes, there was no significant difference in the proportions of admitted and not admitted patients living in residential and nursing homes combined.

	Admitted (%)	Not admitted (%)	p-val
TACS	22 (10%)	32 (68%)	<0.001
PACS	10 (4%)	12 (10%)	0.040
POCS	8 (6%)	2 (6%)	0.935
LACS	2 (2%)	9 (12%)	<0.001
Uncertain	3 (8%)	9 (69%)	<0.001
All	45 (6.2%)	64 (22.2%)	<0.001

Selected stroke severity factors and stroke subtype

Impairment of consciousness, speech disturbance, swallowing impairment and urinary incontinence in the various subtypes in admitted and not admitted patients are analysed further.

Impairment of consciousness

The proportions of patients with any impairment of level of consciousness (drowsiness, coma) in the first 24 hours post stroke for each subtype of stroke in admitted and not admitted patients, are shown in table 6.18. Overall, 118/704 (16.8%) of admitted and 22/258 (8.5%) of not admitted patients had impaired consciousness in the first 24 hours, $p < 0.001$.

For TACS strokes, 58/198 (29%) of admitted and 17/33 (52%) of not admitted patients had impaired consciousness level, $p = 0.012$. For POCS strokes, 32/123 (26%) of admitted and 1/30 (3%) of not admitted patients had impaired consciousness level, $p = 0.007$.

Table 6.18: Impaired consciousness in the first 24 hours post stroke, and stroke subtype in admitted and not admitted patients.			
	Admitted (%)	Not admitted (%)	p-val
TACS	58 (29%)	17 (52%)	0.012
PACS	3 (1%)	1 (1%)	0.702
POCS	32 (26%)	1 (3%)	0.007
LACS	0 (0%)	0 (0%)	1.000
Uncertain	25 (71%)	3 (60%)	0.602
All	118 (16.8%)	22 (8.5%)	<0.001
Missing data	18	30	

For PACS strokes, 3/223 (1%) of admitted and 1/115 (1%) of not admitted patients had impaired consciousness level, $p=0.702$. For LACS strokes, 0/125 (0%) of admitted and 0/75 (0%) of not admitted patients had impaired consciousness, $p=1.000$.

Speech disturbance

The proportions of patients with any speech disturbance (dysarthria, dysphasia) in the first 24 hours post stroke for each subtype of stroke in admitted and not admitted patients, are shown in table 6.19. Overall, 601/720 (83.5%) of admitted and 188/284 (66.2%) of not admitted patients had speech disturbance in the first 24 hours, $p<0.001$. For all stroke subtypes except for the uncertain category, significantly more admitted patients had speech disturbance than not admitted patients.

Table 6.19: Speech disturbance in the first 24 hours post stroke, and stroke subtype in admitted and not admitted patients.			
	Admitted (%)	Not admitted (%)	p-val
TACS	200 (96%)	34 (72%)	<0.001
PACS	196 (87%)	93 (79%)	0.045
POCS	86 (69%)	12 (38%)	<0.001
LACS	88 (70%)	43 (56%)	0.035
Uncertain	31 (84%)	6 (60%)	0.103
All	601 (83.5%)	188 (66.2%)	<0.001
Missing data	2	4	

For TACS strokes, 200/209 (96%) of admitted and 34/47 (72%) of not admitted patients had speech disturbance, $p<0.001$. For PACS strokes, 196/225 (87%) of admitted and 93/118 (79%) of not admitted patients

had speech disturbance, $p=0.045$. For POCS strokes, 86/124 (69%) of admitted and 12/32 (38%) of not admitted patients had speech disturbance, $p<0.001$. For LACS strokes, 88/125 (70%) of admitted and 43/77 (56%) of not admitted patients had speech disturbance, $p=0.035$.

Swallowing impairment

The proportions of patients with any swallowing impairment in the first 24 hours post stroke for each subtype of stroke in admitted and not admitted patients, are shown in table 6.20. Overall, 346/722 (47.9%) of admitted and 53/288 (18.4%) of not admitted patients had swallowing impairment in the first 24 hours, $p<0.001$. For all stroke subtypes, significantly more admitted patients had swallowing impairment than not admitted patients.

Table 6.20: Swallowing impairment in the first 24 hours post stroke, and stroke subtype in admitted and not admitted patients.

	Admitted (%)	Not admitted (%)	p-val
TACS	169 (80%)	29 (62%)	0.007
PACS	66 (29%)	12 (10%)	<0.001
POCS	54 (44%)	4 (12%)	<0.001
LACS	28 (22%)	4 (5%)	0.001
Uncertain	29 (78%)	4 (31%)	0.002
All	346 (47.9%)	53 (18.4%)	<0.001
Missing data	0	0	

For TACS strokes, 169/211 (80%) of admitted and 29/47 (62%) of not admitted patients had swallowing impairment, $p=0.007$. For PACS

strokes, 66/225 (29%) of admitted and 12/118 (10%) of not admitted patients had swallowing impairment, $p < 0.001$. For POCS strokes, 54/124 (44%) of admitted and 4/33 (12%) of not admitted patients had swallowing impairment, $p < 0.001$. For LACS strokes, 28/125 (22%) of admitted and 4/77 (5%) of not admitted patients had swallowing impairment, $p = 0.001$.

Urinary incontinence

The proportions of patients with urinary incontinence in the first 24 hours post stroke for each subtype of stroke in admitted and not admitted patients, are shown in table 6.21. Overall, 385/722 (53.3%) of admitted and 62/287 (21.6%) of not admitted patients had urinary incontinence in the first 24 hours, $p < 0.001$. For all stroke subtypes, significantly more admitted patients had urinary incontinence than not admitted patients.

For TACS strokes, 183/211 (87%) of admitted and 31/46 (68%) of not admitted patients had urinary incontinence, $p < 0.001$. For PACS strokes, 84/225 (37%) of admitted and 16/118 (14%) of not admitted patients had urinary incontinence, $p < 0.001$. For POCS strokes, 55/124 (44%) of admitted and 3/33 (9%) of not admitted patients had urinary incontinence, $p < 0.001$. For LACS strokes, 33/125 (26%) of admitted and 8/77 (10%) of not admitted patients had urinary incontinence, $p = 0.006$.

Table 6.21: Urinary incontinence in the first 24 hours post stroke, and stroke subtype in admitted and not admitted patients.

	Admitted (%)	Not admitted (%)	p-val
TACS	183 (87%)	31 (68%)	<0.001
PACS	84 (37%)	16 (14%)	<0.001
POCS	55 (44%)	3 (9%)	<0.001
LACS	33 (26%)	8 (10%)	0.006
Uncertain	30 (81%)	4 (31%)	<0.001
All	385 (53.3%)	62 (21.6%)	<0.001
Missing data	0	1	

CHAPTER 7

RESULTS: MEDICAL COMPLICATIONS, SIX MONTH OUTCOMES, POST STROKE RESIDENCE, STROKE INFORMATION PROVISION AND FACTORS ASSOCIATED WITH ADMISSION

This chapter describes the following main outcomes for admitted and not admitted patients: Medical complications (during the first four weeks and at six months), further six month outcomes (late post stroke complications, self reported deficits, and secondary prevention measures), post stroke residence, social service resource usage (service utilisation, and aids & adaptations provision) at six months, and stroke information provision. Factors associate with admission (demographic and clinical) are also described.

MEDICAL COMPLICATIONS

Infections, vascular complications and other complications predisposed to by stroke are shown in this section. Complications occurring within the first 28 days in all stroke patients, and from the first 28 days to six months post stroke (month 2-6) in six month survivors, are compared in admitted and not admitted patients in this section.

Early medical complications (day 0-28)

Medical complications occurring in the first 28 days post stroke in admitted and not admitted patients are shown in table 7.1. Overall, all complications were more common in admitted patients than not admitted

patients. These differences were significant for infection incidences, antibiotic usage and pressure sore incidences.

Some patients had more than one infection or types of infection in the first 28 days post stroke. 100/722 (14%) of admitted and 15/288 (5%) of not admitted patients had chest infections, $p < 0.001$. 106/722 (15%) of admitted and 12/288 (4%) of not admitted patients had urinary tract infections, $p < 0.001$. Other infections were present in 36/722 (5%) of admitted and 5/288 (2%) of not admitted patients, $p = 0.018$. Overall, antibiotics were used in 183/722 (25%) of admitted and 24/288 (8%) of not admitted patients, $p < 0.001$. Pressure sores were present in 67/722 (9%) of admitted and 3 (1%) of not admitted patients, $p < 0.001$.

Table 7.1: Early medical complications (day 0-28) in admitted and not admitted patients.

	Admitted (%)	Not admitted (%)	p-val
Infection / antibiotics	-	-	-
Chest infection	100 (14%)	15 (5%)	<0.001
Urinary infection	106 (15%)	12 (4%)	<0.001
Other infection	36 (5%)	5 (2%)	0.018
Antibiotic usage	183 (25%)	24 (8%)	<0.001
Myocardial infarction	12 (2%)	2 (1%)	0.235
Pulmonary embolus	8 (1%)	0 (0%)	0.730
Deep vein thrombosis	21 (3%)	0 (0%)	0.280
Pressure sores	67 (9%)	3 (1%)	<0.001
Stroke recurrence	11 (2%)	7 (2%)	0.161
TIAs	6 (1%)	2 (1%)	1.000

Myocardial infarctions were diagnosed in 12/722 (2%) of admitted and 2 (1%) of not admitted patients, $p=0.235$. Pulmonary emboli were diagnosed in 8/722 (1%) of admitted and 0/288 (0%) of not admitted patients, $p=0.730$. Deep vein thromboses were diagnosed in 21/722 (3%) of admitted and 0/288 (0%) of not admitted patients, $p=0.280$. Stroke recurrence (onset more than one week after the initial stroke) occurred in 11/722 (2%) admitted and 7/288 (2%) of not admitted patients, $p=0.162$. Transient Ischaemic attacks (TIAs) occurred in 6/722 (1%) of admitted and 2/288 (1%) of not admitted patients, $p=1.000$.

Late medical complications (month 2-6)

Medical complications occurring within the first six months and after the first 28 days post stroke in initially admitted and not admitted patients are shown in table 7.2. For urinary infections and pressure sores, the incidences over the last month prior to the six month assessment (month 5-6) are shown. Urinary tract infections were present in 68/459 (15%) of admitted and 28/215 (13%) of not admitted patients, $p=0.509$. Pressure sores were present in 30/456 (7%) of admitted and 4/215 (2%) of not admitted patients, $p=0.009$.

The incidences of myocardial infarctions, angina, deep vein thromboses, stroke recurrence and transient ischaemic attacks were not significantly different in admitted and not admitted patients. Diagnoses of myocardial infarctions, deep vein thromboses and pulmonary emboli were very uncommon in both admitted and not admitted patients. Angina was present in 44/457 (10%) of admitted and 28/215 (13%) of not admitted patients, $p=0.190$. Transient ischaemic attacks occurred in 36/458 (8%) of admitted and 22/215 (10%) of not admitted patients, $p=0.313$. Stroke

recurrence occurred in 8/459 (2%) of admitted and 9/215 (4%) of not admitted patients, $p=0.061$.

Table 7.2: Late medical complications (month 5-6: urinary infections and pressure sores; month 2-6: all others) in admitted and not admitted patients.

	Admitted (%)	Not admitted (%)	p-val
Urinary infections	68 (15%)	28 (13%)	0.509
Pressure sores	30 (7%)	4 (2%)	0.009
Myocardial infarction	1 (0%)	2 (1%)	0.196
Angina	44 (10%)	28 (13%)	0.190
Pulmonary embolus	0 (0%)	0 (0%)	1.000
Deep vein thrombosis	7 (2%)	0 (0%)	0.069
Stroke recurrence	8 (2%)	9 (4%)	0.061
TIA's	36 (8%)	22 (10%)	0.313

FURTHER SIX MONTH OUTCOMES

For six month survivors completing the questionnaire, late hospital admission rates, incidence of depression, self reported neurological deficits, stroke related surgical interventions, aspirin and antihypertensive treatment, smoking status and the Nottingham extended activities of daily living (EADL) score results are compared in admitted and not admitted patients in this section.

Late hospital admission and depression by six months

Of six month survivors, 71/457 (15.5%) of admitted and 21/211 (10.0%) of not admitted patients were admitted/re-admitted to hospital after the first 28 days, and by six months post stroke, $p=0.049$.

The results of the self reported Wakefield Self-Assessment Depression Inventory is shown in table 7.3. 188/354 (53%) of admitted and 106/176 (60%) of not admitted patients had scores less than 18/36, $p=0.120$. Median scores in both admitted and not admitted patients were less than 18.

	Admitted (%)	Not admitted (%)	p-val
<18/36	188/354 (53%)	106/176 (60%)	0.120
Median	17	15	-
IQR	10-23	6-22	-
Missing data	105 (22.9%)	39 (18.1%)	-

Self reported deficits at six months

The presence of self reported neurological deficits, shoulder pains, urinary incontinence, complete recovery from their stroke six months ago, and the requirement with assistance in tasks, at six months post stroke is shown in table 7.4, for admitted and not admitted patients.

Information was obtained on impairment in 667/674 (99.0%) of survivors at six months. Seven patients and/or their GPs withdrew consent for ongoing direct contact. At least 444/459 (96.9%) of all admitted and 207/215 (96.3%) of all not admitted patients six month survivors completed each part of this section of the questionnaire. 313/445 (70.3%) of admitted and 121/210 (57.6%) of not admitted patients reported requiring assistance completing the six months questionnaire, $p < 0.001$.

At six months post stroke, 112/454 (25.1%) of admitted and 61/210 (29.0%) of not admitted patients reported full recovery from their stroke, $p = 0.297$. 291/444 (65.4%) of admitted and 87/210 (41.4%) of not admitted patients reported requiring help with activities of daily living, $p < 0.001$.

Any arm weakness was reported in 271/447 (59.7%) of admitted and 93/213 (43.7%) of not admitted patients, $p < 0.001$. Any leg weakness was reported in 256/454 (56.4%) of admitted and 93/213 (43.7%) of not admitted patients, $p = 0.003$. Facial weakness was reported in 54/454 (11.9%) of admitted and 21/213 (9.9%) of not admitted patients, $p = 0.511$. Speech problems were reported in 148/454 (32.6%) of admitted and 58/213 (27.2%) of not admitted patients, $p = 0.178$. Swallowing difficulties were reported in 59/454 (13.0%) of admitted and 26/213 (12.2%) of not

admitted patients, $p=0.805$. Numbness was reported in 116/454 (25.6%) of admitted and 43/213 (20.2%) of not admitted patients, $p=0.144$. Memory impairment was reported in 220/454 (48.5%) of admitted and 102/213 (47.9%) of not admitted patients, $p=0.934$.

Table 7.4: Self-report deficits at six months post stroke in admitted and not admitted patients.*			
	Admitted (%)	Not admitted (%)	p-val
Neurological deficit			
Full recovery	112/447 (25.1%)	61/210 (29.0%)	0.297
Arm weakness	271/454 (59.7%)	93/213 (43.7%)	<0.001
Leg weakness	256/454 (56.4%)	93/213 (43.7%)	0.003
Face weakness	54/454 (11.9%)	21/213 (9.9%)	0.511
Speech affected	148/454 (32.6%)	58/213 (27.2%)	0.178
Swallowing affected	59/454 (13.0%)	26/213 (12.2%)	0.805
Numbness present	116/454 (25.6%)	43/213 (20.2%)	0.144
Memory impairment	220/454 (48.5%)	102/213 (47.9%)	0.934
Any shoulder pain	198/445 (44.5%)	59/211 (28.0%)	<0.001
Urinary continence None	300/445 (67.4%)	164/207 (79.2%)	<0.001
Occasionally	84/445 (18.9%)	17/207 (8.2%)	
Totally	61/445 (13.7%)	26/207 (12.6%)	
Assistance with ADLs	291/444 (65.4%)	87/210 (41.4%)	<0.001
Assistance with completing questionnaire	313/445 (70.3%)	121/210 (57.6%)	<0.001

*No questionnaires were returned for 5/459 admitted and 2/215 not admitted patients (withdrew from direct study contact).

Shoulder pain was reported in 198/445 (44.5%) of admitted and 59/211 (28.0%) of not admitted patients, $p < 0.001$. 22/198 (11%) of admitted and 16/59 (27%) of not admitted patients with shoulder pain reported pain in both shoulders.

Urinary continence was reported in 300/445 (67.4%) of admitted and 164/207 (79.2%) of not admitted patients. 84/445 (13.7%) of admitted and 17/207 (8.2%) of not admitted patients reported occasional urinary incontinence. The rest of the patients, 61/445 (13.7%) of admitted and 26/207 (12.6%) of not admitted patients, required pads, sheaths or catheters, as they were totally incontinent. These differences between admitted and not admitted patients in levels of continence were significant, $p < 0.001$.

Surgical interventions, secondary prevention and smoking status

Aneurysm and carotid endarterectomy surgery were uncommon in admitted and not admitted patients. No patients had aneurysm surgery by six months post stroke. 2/459 (0.4%) admitted and 2/215 (0.9%) of not admitted patients had carotid endarterectomy surgery by six month post stroke, $p = 0.438$.

Aspirin treatment, antihypertensive treatment and smoking status at six months are shown in table 7.5. 273/453 (60.3%) of admitted and 159/213 (74.6%) of not admitted patients were on aspirin treatment at six months post stroke, $p < 0.001$. 204/453 (45.0%) of admitted and 102/213 (47.9%) of not admitted patients were on drug treatment for hypertension, $p = 0.369$. 72/450 (16.0%) of admitted and 58/212 (27.4%) of not admitted

patients were regular cigarette smokers at six months post stroke, $p < 0.001$.

Table 7.5: Secondary prevention medications and smoking status at six months in admitted and not admitted patients.			
	Admitted (%)	Not admitted (%)	p-val
Aspirin	273/453 (60%)	159/213 (75%)	<0.001
Antihypertensives	204/453 (45%)	102/213 (48%)	0.369
Current smokers	72/450 (16%)	58/212 (27%)	<0.001

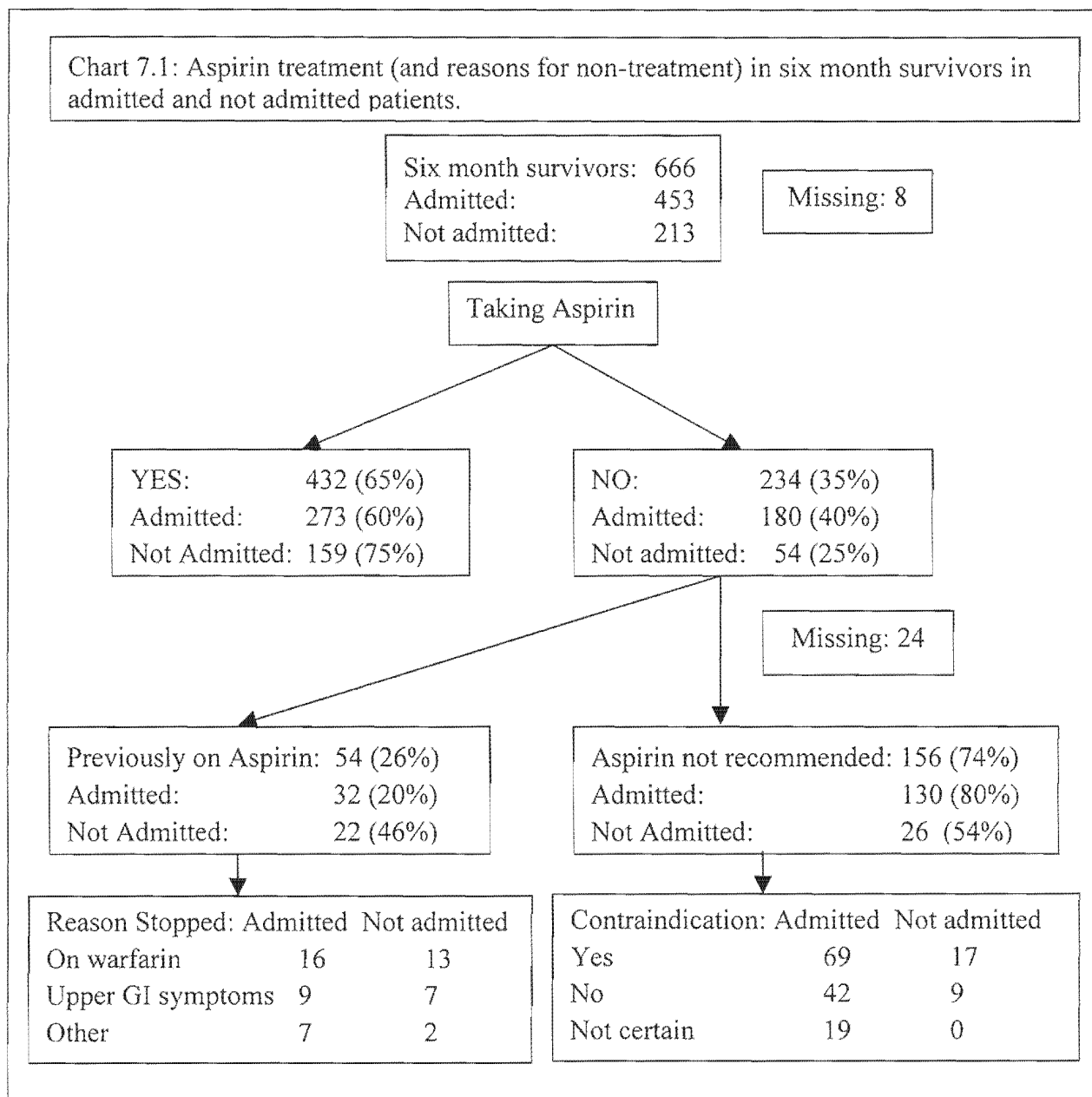
Reasons for non-treatment with aspirin are described in chart 7.1 for six month survivors in admitted and not admitted patients, completing the questionnaire. 180/453 (40%) of admitted and 54/213 (25%) of not admitted patients were not taking aspirin at six months, $p < 0.001$. Of these, 32/162 (20%) admitted and 22/48 (46%) of not admitted patients were previously recommended to or took aspirin treatment. The remaining 130/162 (80%) admitted and 26/48 (54%) not admitted patients not taking aspirin treatment, were not recommended to or were never advised to take it.

Of those previously recommended to take aspirin, the reasons for not taking aspirin included currently being on warfarin treatment (16 admitted and 13 not admitted patients) and current or previous upper gastro-intestinal symptoms (9 admitted and 7 not admitted patients).

Of those not recommended or advised to take aspirin, definite contraindications were identified in 69/130 (53%) of admitted and 17/26 (65%) of not admitted patients. Overall, 42/453 (9.3%) of all admitted and 9/213

(4.2%) of all not admitted patients at six months post stroke, had no identified reason for not being on aspirin treatment.

Chart 7.1: Aspirin treatment (and reasons for non-treatment) in six month survivors in admitted and not admitted patients.



Nottingham EADL scale results

The results of the Nottingham extended activities of daily living scale for survivors at six months are in table 7.6. The median scores for each subsection and overall, in admitted and not admitted patients are shown.

Overall, median scores were 8 for admitted and 16 for not admitted patients, $p < 0.001$.

Table 7.6: Median scores for each subsection of the Nottingham EADL at six months for admitted and not admitted patients.

Subsection (max)	Admitted	Not admitted	p-val
Mobility (6)	2	5	<0.001
Kitchen (5)	3	5	<0.001
Domestic (5)	1	2	<0.001
Leisure (6)	2	3	<0.001
Overall (22)	8	16	<0.001

Residence six months post stroke

The six month residence with pre-stroke residence, of admitted and not admitted patients is shown in this section. Overall, 346/452 (76.5%) of admitted and 190/213 (89.2%) of not admitted patients were living at home (or family home) at six months, $p < 0.001$. 22/452 (4.9%) of admitted and 10/213 (4.7%) of not admitted patients were living in residential care at six months, $p = 0.923$. 78/452 (17.3%) of admitted and 12/213 (5.6%) of not admitted patients were in nursing care at six months, $p < 0.001$. 6 admitted and 1 not admitted patients were in hospital at six months and data was missing for 7 admitted and 2 not admitted patients (9/674, 1.3% of all survivors).

For those patients living in their own or family home at the time of their stroke, their residence at six months is shown in table 7.7. Most patients,

345/675 (51%) of admitted and 190/224 (85%) of not admitted, were still living in their own or family home, $p < 0.001$. 18/675 (3%) of admitted and 4/224 (2%) of not admitted patients were living in residential care, $p = 0.192$. 71/675 (11%) of admitted and 2/224 (1%) of not admitted patients were living in nursing care, $p < 0.001$. 229/675 (34%) of admitted and 26/224 (12%) of not admitted patients had died, $p < 0.001$.

Table 7.7: Six month residence for patients who were living in their own or family homes at the time of their stroke, in admitted and not admitted patients.

	Admitted (%)	Not admitted (%)	p-val
Own/family home	345/675 (51%)	190/224 (85%)	<0.001
Residential home	18/675 (3%)	4/224 (2%)	0.192
Nursing home	71/675 (11%)	2/224 (1%)	<0.001
Dead	229/675 (34%)	26/224 (12%)	<0.001
Other or missing	12/675 (3%)*	2 (1%)	-

* 6 still hospitalised

For those patients living in residential care at the time of their stroke, their residence at six months is shown in table 7.8. No patients were living in their own or family home. 4/23 (17%) of admitted and 6/12 (50%) of not admitted patients were still living in residential care, $p = 0.059$. 2/23 (9%) of admitted and 0/12 (0%) of not admitted patients were living in nursing care. Many patients, 16/23 (70%) of admitted and 5/12 (42%) of not admitted, had died, $p = 0.135$.

Table 7.8: Six month residence for patients who were living in residential care at the time of their stroke, in admitted and not admitted patients.

	Admitted (%)	Not admitted (%)	p-val
Own/family home	-	-	-
Residential home	4/23 (17%)	6/12 (50%)	0.059
Nursing home	2/23 (9%)	-	-
Dead	16/23 (70%)	5/12 (42%)	0.135
Other or missing	1/23 (4%)	1/12 (8%)	-

For those patients living in nursing homes at the time of their stroke, their residence at six months is shown in table 7.9. 1/22 (5%) of admitted and 0/52 (0%) of not admitted patients were living in their own or family home. No patients were living in residential care. 4/22 (18%) of admitted and 10/52 (19%) of not admitted patients were still in nursing care, $p=1.00$. The majority of patients, 17/22 (77%) of admitted and 42/52 (81%) of not admitted, had died, $p=0.758$.

Table 7.9: Six month residence for patients who were living in nursing care at the time of their stroke, in admitted and not admitted patients.

	Admitted (%)	Not admitted (%)	p-val
Own/family home	1/22 (5)	-	-
Residential home	-	-	-
Nursing home	4/22 (18)	10/52 (19)	1.000
Dead	17/22 (77)	42/52 (81)	0.758
Other or missing	-	-	-

SOCIAL SERVICE RESOURCE USAGE

For those six month survivors (346 of admitted and 190 of not admitted patients) living in their own or family homes at the time of the assessment, the services received and the aids and adaptations provided are shown in this section.

Service utilisation

Services provided for those not institutionalised, at six months post stroke in admitted and not admitted patients are shown in table 7.10. Most stroke survivors did not receive any services.

Overall, 120/346 (35%) of admitted and 27/190 (14%) of not admitted stroke survivors at six months had care provision at home, and/or day centre or day hospital attendance, $p < 0.001$.

Table 7.10: Service utilisation at six months post stroke in admitted and not admitted patients, for survivors not living in care.			
	Admitted (%)	Not admitted (%)	p-val
Chiropody	48/346 (14%)	17/190 (9%)	0.099
Any of the following	120/346 (35%)	27/190 (14%)	<0.001
Home care	69/346 (20%)	14/190 (7%)	<0.001
Private home care	30/346 (9%)	6/190 (3%)	0.018
Meals on wheels	29/346 (8%)	10/190 (5%)	0.225
Day centre	19/346 (6%)	5/190 (3%)	0.189
Day hospital	28/346 (8%)	2/190 (1%)	<0.001

Aids and adaptations provision

The provision of aids and adaptations for those not institutionalised, at six months post stroke in admitted and not admitted patients are shown in table 7.11. Most six month survivors had some adaptations or aids provided by six months post stroke.

Overall, 239/346 (69%) of admitted and 90/183 (49%) of not admitted stroke survivors at six months had aids or adaptations provided, $p < 0.001$. For each adaptation or aid, more admitted than not admitted patients had it provided. Only for bed aids did this not reach significance.

Table 7.11: Aids and adaptations provision at six months post stroke in admitted and not admitted patients.			
	Admitted (%)	Not admitted (%)	p-val
House alterations	76/332 (23%)	19/183 (10%)	<0.001
Toilet	114/331 (34%)	31/183 (17%)	<0.001
Bathroom	175/330 (53%)	67/183 (37%)	<0.001
Bed	23/332 (7%)	8/183 (4%)	0.333
Feeding aids	32/335 (10%)	5/183 (3%)	0.004
Mobility aids	174/336 (52%)	66/183 (36%)	0.001
Any of the above	239/346 (69%)	90/183 (49%)	<0.001

STROKE INFORMATION PROVISION

The extent of stroke and general information, as assessed by the patient, provided to patients was recorded at the six month assessment. The results of this are shown in this section. Not all patients felt each subsection of the advice and information received part of the questionnaire was applicable to them. Not all patients were able to complete this part of the questionnaire (even with assistance) due to their deficits.

The proportions of admitted and not admitted patients who completed the questionnaire and received any information on the various stroke related topics by six months post stroke are in table 7.12. Overall, most (94% admitted and 94% not admitted) patients received some information.

Specific aspects of stroke disease included the causes of stroke, measures preventing stroke, and the rationale for their current treatment of stroke. Stroke related problems included emotional, family, mental and incontinence. Services and aids included information on health, social services and voluntary services availability; and information on appliances, aids and leisure activities for disabled people. The information on the financial aspects included how to access benefits and allowances, and advice with ones legal and financial affairs. The general health and lifestyle information incorporated advice and information on general health, giving up smoking, reducing alcohol intake, loosing weight and eating a healthier diet.

Table 7.12: The proportion that received any stroke and/or general health advice and information by six months post stroke in admitted and not admitted patients.

	Admitted (%)	Not admitted (%)	p-val
Any of below	398/425 (94%)	181/193 (94%)	0.909
Stroke disease in general	276/425 (65%)	119/192 (62%)	0.478
Specific aspects of stroke disease	341/425 (80%)	168/193 (87%)	0.040
Stroke related problems	180/425 (42%)	63/190 (33%)	0.031
Services and aids available	277/425 (65%)	89/190 (47%)	<0.001
Financial aspects and assistance	204/425 (48%)	58/190 (31%)	<0.001
General health and lifestyle	327/425 (77%)	153/192 (80%)	0.447

Of those receiving information about the specific aspects of stroke disease, the amount of information reported received in admitted and not admitted patients is shown in table 7.13. 81/423 (19%) of admitted and 41/191 (21%) of not admitted patients received enough information on the causes of stroke. 77/424 (18%) of admitted and 42/193 (22%) of not admitted patients received enough information on measures preventing stroke. 149/425 (35%) of admitted and 63/189 (33%) of not admitted patients received enough information on the rationale for their current treatment of stroke. There were no significant differences in this aspect of

reported stroke information provision to admitted and not admitted patients.

Table 7.13: Extent of information received on specific aspects of stroke disease by six months, in admitted and not admitted patients.

Information received	Admitted (%)*			Not admitted (%)*			p-val
	none	some	enough	none	some	enough	
Causes of stroke	164/423 (39%)	167/423 (39%)	81/423 (19%)	81/191 (42%)	63/191 (33%)	41/191 (21%)	0.491
Measures preventing stroke	176/424 (42%)	156/424 (37%)	77/424 (18%)	76/193 (39%)	71/193 (37%)	42/193 (22%)	0.580
Current treatment rationale	97/425 (23%)	154/425 (36%)	149/425 (35%)	34/189 (18%)	84/189 (44%)	63/189 (33%)	0.214

* the rest of those completing the questionnaires answered not applicable.

Of those receiving information about general health and lifestyle, the amount of information reported received in admitted and not admitted patients is shown in table 7.14. 54/425 (13%) of admitted and 20/191 (10%) of not admitted patients received enough information on giving up smoking. 62/425 (15%) of admitted and 21/190 (11%) of not admitted patients received enough information on reducing alcohol intake. 41/425 (10%) of admitted and 39/189 (21%) of not admitted patients received enough information on losing weight. 75/424 (18%) of admitted and 43/190 (23%) of not admitted patients received enough information on eating healthier. There were no significant differences in this aspect of

reported stroke information provision to admitted and not admitted patients.

Table 7.14: Extent of information and advice received on general health and lifestyle by six months, in admitted and not admitted patients.							
Information received	Admitted (%)*			Not admitted (%)*			p-val
	none	some	enough	none	some	enough	
Giving up smoking	87/425 (20%)	48/425 (11%)	54/425 (13%)	31/191 (16%)	34/191 (18%)	20/191 (10%)	0.113
Reducing alcohol	101/425 (24%)	38/425 (9%)	62/425 (15%)	36/190 (19%)	27/190 (14%)	21/190 (11%)	0.099
Loosing weight	136/425 (32%)	73/425 (17%)	41/425 (10%)	54/189 (29%)	34/189 (18%)	39/189 (21%)	0.205
Eating healthier	139/424 (33%)	87/424 (21%)	75/424 (18%)	52/190 (27%)	46/190 (24%)	43/190 (23%)	0.239

* the rest of those completing the questionnaires answered not applicable.

Of those answering the question and still smoking at six months, only 18/70 (26%) of admitted and 11/57 (19%) of not admitted patients reported as receiving enough information on how to give up smoking. A few (10) six month smokers reported that information on giving up smoking was not applicable to them.

FACTORS ASSOCIATED WITH HOSPITAL ADMISSION

The proportion of patients admitted to hospital within seven days of stroke onset was 722/1010 (71.5%) of all first ever stroke patients. The factors potentially associated with admission (demographic, source of referral to hospital and clinical factors) are analysed further in this section.

Demographic and first medical contact factors

Table 7.15 shows the non-clinical factors associated with early (day 0-6) hospital admission.

The proportion of all patients (excluding those in care) living alone who were admitted was 270/340 (79.4%) and not living alone who were admitted was 368/510 (72.2%), $p=0.019$. The proportion of all patients living in care who were admitted was 45/109 (41.3%) and not living in care who were admitted was 677/901 (75.1%), $p<0.001$.

Table 7.15: Non-clinical factors associated with admission (hospitalisation day 0-6).			
	Yes (%)	No (%)	p-val
Living alone	270/340 (79.4%)	368/510 (72.2%)	0.019
Living in care	45/109 (41.3%)	677/901 (75.1%)	<0.001
Male	327/467 (70.0%)	395/543 (72.7%)	0.364
Age ≥ 80	238/322 (73.9%)	484/688 (70.3%)	0.262

The proportion of male stroke patients admitted was 327/467 (70.0%) and female stroke patients admitted was 395/543 (72.7%), $p=0.364$. The

proportion of stroke patients 80+ years old admitted was 238/322 (73.9%) and under 80 years old admitted was 484/688 (70.3%), $p=0.262$.

Whether the source of first medical contact influences admission or not is shown in Table 7.16. Almost all patients seen in A&E were admitted. The proportion of patients who first consulted their General Practitioner after their stroke and were subsequently admitted was 474/729 (65%) and not seen by their GP and admitted was 228/281 (88%), $p<0.001$. The proportion of patients who first consulted the deputy General Practitioner after their stroke and were subsequently admitted was 32/43 (74%) and not seen by the deputy GP and admitted was 690/967 (71%), $p=0.663$.

Table 7.16: Source of first medical contact and proportions admitted.			
	Yes (%)	No (%)	p-val
GP	474/729 (65%)	228/281 (88%)	<0.001
Deputy GP	32/43 (74%)	690/967 (71%)	0.663

Early clinical factors

Table 7.17 shows the clinical factors associated with early (day 0-6) hospital admission. Overall, stroke patients were more likely to be admitted than treated in the community whatever their pre-morbid condition (apart from those with pre-stroke OHS 4-5), stroke subtype or stroke severity indicators were.

The proportion of patients with pre-stroke OHS of 0-2 who were admitted were 586/793 (73.9%) and without OHS 0-2, who were admitted were 136/217 (62.6%), $p=0.001$. The proportion of patients with pre-stroke OHS of 3 who were admitted was 109/146 (74.7%) and without OHS 3,

who were admitted, were 613/864 (70.9%), $p=0.359$. The proportion of patients with pre-stroke OHS of 4-5 who were admitted was 27/71 (38.0%) and without OHS 4-5, who were admitted, were 695/939 (74.0%), $p<0.001$.

Table 7.17: Clinical factors associated with admission (hospitalisation day 0-6), which occurred in 722/1010 (71.5%) of patients.

	Yes (%)	No (%)	p-val
Pre-stroke OHS 0-2	586/793 (73.9%)	136/217 (62.6%)	0.001
3	109/146 (74.7%)	613/864 (70.9%)	0.359
4-5	27/71 (38.0%)	695/939 (74.0%)	<0.001
Subtype TACS	211/258 (81.8%)	511/752 (68.0%)	<0.001
PACS	225/343 (65.6%)	497/667 (74.5%)	0.003
POCS	124/157 (79.0%)	598/853 (70.1%)	0.024
LACS	125/202 (61.9%)	597/808 (73.9%)	0.059
7 day Barthel ≥ 18	116/249 (46.6%)	606/761 (79.6%)	<0.001
Urinary incontinence	385/447 (86.1%)	337/563 (59.9%)	<0.001
Dysphagia (first 24hrs)	346/399 (86.7%)	376/611 (61.5%)	<0.001
GCS: Best verbal <5	288/347 (83.0%)	415/625 (66.4%)	<0.001

The proportion of all stroke patients with TACS strokes who were admitted was 211/258 (81.8%), and not TACS who were admitted was 511/752 (68.0%), $p<0.001$. The proportion of all stroke patients with PACS strokes who were admitted was 225/343 (65.6%), and not PACS who were admitted was 497/667 (74.5%), $p=0.003$. The proportion of all

stroke patients with POCS strokes who were admitted was 124/157 (79.0%), and not POCS who were admitted was 598/853 (70.1%), $p=0.024$. The proportion of all stroke patients with LACS strokes who were admitted was 125/202 (61.9%), and not LACS who were admitted was 597/808 (73.9%), $p=0.059$.

Urinary incontinence in the first 24 hours was present in 447/1010 (44.3%) of all stroke patients. Of these, 385/447 (86.1%) patients were admitted within one week of stroke onset, and 337/563 (59.9%) without incontinence were admitted within one week of stroke onset, $p<0.001$.

Dysphagia in the first 24 hours was present in 399/1010 (39.5%) of all stroke patients. Of these, 346/399 (86.7%) patients were admitted within one week of stroke onset, and 376/611 (61.5%) without dysphagia were admitted within one week of stroke onset, $p<0.001$.

Impaired verbal response (Glasgow Coma Scale speech score $<5/5$) in the first 24 hours was present in 347/972 (35.7%) of all stroke patients. Of these, 288/347 (83.0%) were admitted within one week of stroke onset, and 415/625 (66.4%) without impaired verbal response were admitted within one week of stroke onset, $p<0.001$.

The seven day Barthel score ≥ 18 was present in 249/830 (24.7%) of one week stroke survivors. Of these, 116/249 (46.6%) patients were admitted within one week of stroke onset, and 606/761 (79.6%) with seven day Barthel <18 were admitted within one week of stroke onset, $p<0.001$.

CHAPTER 8

DISCUSSION

This chapter describes what has been accomplished, what has been discovered and what its implications are, which of our patients tended to be admitted, what the potential problems with the study was, and the limitations of the study.

What have we accomplished?

The Tees Stroke Register (TSR) was an exceptionally large observational study of all adult first ever strokes in a population of 304,700 covering two whole districts in the United Kingdom over two years. We have prospectively followed up all 1010 stroke patients and more than 98.5% of all assessments in both admitted and not admitted patients, at all time intervals, were completed. No patients were lost to follow-up. Of those assessments not completed, the reasons were patient or GP refusal for direct patient contact. Extensive and detailed information was collected on all patients. Various factors known to potentially bias the overall outcomes (age, sex, stroke severity subtype, pre stroke dependency levels) between admitted and not admitted patients were compared and are taken into account in the interpretation of the results. Factors associated with admission were also identified. Previous descriptions of stroke care and service utilisations comparing admitted and not admitted patients are limited. There are however numerous recommendations and evidence on individual aspects of stroke care (e.g. early treatment, investigations, the potential benefits of rehabilitation therapy) which will be considered in more detail in each appropriate section of the discussion.

What have we discovered and what are its implications?

This section examines what differences between admitted and not admitted patients were observed, selective comparisons with other published work and recommendations, what the potential importance of the differences may be and what conclusions may be drawn from them.

Are there differences in case fatality, handicap or disability?

Case fatality

Overall, case fatality (apart from the first 24 hours) was higher in admitted patients. This remained significant from 28 days to 4 years post stroke.

In TACS strokes, proportionately more not admitted patients had died. This remained significant from 24 hours up to one year post stroke. By four years this no longer reached significance. In PACS strokes, there was a trend for proportionately higher case fatalities in admitted patients. This only reached significance at four years. In POCS strokes, proportionately more admitted patients had died by 28 days, and this remained significant up to four years post stroke. In LACS strokes, there was a trend for higher case fatalities in admitted patients, but this did not reach significance. For the uncertain category strokes, case fatalities were uniformly high and early in both admitted and not admitted patients, with little difference between the two groups over the four years.

The overall case fatalities are higher than other UK population based studies^{93,94}. In the Oxfordshire Community Stroke Project (OCSP) case fatalities at one year were 30% overall in all strokes combined (excluding subarachnoid haemorrhage) compared to 37.2% in the TSR.

The proportions of patients in each subtype surviving the first year followed similar patterns to previous studies with TACS having higher case fatalities than POCS. PACS and LACS had the lowest case fatalities, with LACS having very low early case fatalities. For admitted and not admitted patients combined, subtype case fatalities were higher in all categories except LACS (8.4% vs. 11%) when compared with the OCSP⁸². A proportion of the higher case fatalities in the TSR may be accounted for by the inclusion of primary intracerebral haemorrhages (PIHs). Case fatality from PIHs was 62% at one year in the OCSP.

For stroke subtypes, TSR not admitted patients had similar one year case fatality rates to the OCSP in two subtypes (PACS 14% vs. 16%, POCS 18%vs.19%), lower in LACS (5% vs. 11%), higher in TACS (89%vs.60%), and overall non-significantly better all case fatality (28.1% versus 30.0%)⁵¹.

Probable explanations for the increased early and continued significant case fatality excess in not admitted compared to admitted TACS stroke patients include not admitted patients being significantly older with more pre-stroke morbidity and increased stroke severity (impaired consciousness). In addition, the inclusion of sudden stroke deaths in the community (prior to possible hospitalisation) may also be a factor.

Handicap

For all stroke subtypes at both 28 days and six months, there was a trend for admitted patients to be more handicapped than not admitted patients. Only for TACS at six months was there no significant difference between the groups for either categorised or continuous variable analyses.

As expected, the more severe the stroke subtype, the higher the median Oxford Handicap Score (OHS) was. In both admitted and not admitted patients, LACS strokes had the lowest OHS median scores with TACS strokes the highest scores. With death and handicap combined, the trend remained unchanged. Only TACS patients showed no significant difference between admitted and not admitted patients in the combined outcome.

Overall, at six months post stroke, 331/1010 (33%) of all TSR patients were independent (OHS 0-2), compared to around 45% of OCSP patients. Not admitted TSR patients were significantly more independent than admitted patients (53% vs. 25%), and had similar levels of dependence and death at six months to OCSP patients^{82,95}.

Disability

Median Barthel Index scores were higher in not admitted than admitted patients in all stroke subtypes at all time intervals (seven days, 28 days, and six months). Only TACS stroke patients at 28 days and six months, and LACS stroke patients at six months ($p=0.058$), did not reach significance. This is consistent with the OHS results in the admitted and not admitted patients for each of the stroke subtypes.

Conclusions

Stroke case fatality at one year was higher in the TSR than similar UK population based studies. There are numerous probable explanations for the observed increased case fatality in not admitted TACS patients. Within each of the other stroke subtypes, either more severe strokes were admitted than not admitted or there were some 'factors' associated with

admission to the two district general hospitals predisposing to increased case fatality and worse functional outcomes.

Are there differences in the groups pre-stroke?

Age, sex, disability and residence

Overall, age and gender distribution were similar with no significant differences between the admitted and not admitted patients. Slightly more and slightly younger women were admitted. Age distribution by subtype however revealed significantly older patients in the not admitted TACS category of stroke patients.

Significantly more admitted than not admitted patients (96% vs. 85%) were independent with little or no handicap (OHS 0-3). Consistent with this, significantly fewer admitted patients were in residential or nursing care than not admitted patients (6% vs. 22%). Of those not in care, more admitted than not admitted patients were living alone (43% vs. 3%).

TSR patients (admitted and not admitted) were generally more dependent pre-stroke than other studies. The proportion of mild to severe dependence (OHS 3-5) was 217/1010 (21.5%) of all TSR patients, 28.1% of not admitted patients, and 17% in the OCSP⁵¹. Median Barthel scores pre-stroke in the South London Stroke Register (SLSR) were 20 (IQR 19-20) in both admitted and not admitted patients. The proportion of patients living alone in the TSR were very similar to the SLSR where 39% admitted and 31% not admitted patients were living alone. The proportion of patients institutionalised prior to their stroke in the TSR was slightly higher than in the SLSR (10.8% vs. 9%). Compared to the SLSR, a much larger proportion of the not admitted patients in the TSR, was institutionalised (22% vs. 7%)²⁴.

Risk factors, primary prevention and other factors

Significantly more admitted patients had a history of current or previous hypertension and atrial fibrillation. All other important risk factors revealed very similar incidences in admitted and not admitted patients with all p-values >0.175. More admitted patients were on aspirin, warfarin and antihypertensives, but the differences were not significant. There were no significant differences in non-stroke related factors which may have had an influence on outcomes, with similar proportions of admitted and not admitted patients having low incomes (slightly higher in not admitted patients), living in rented residences and having a history of malignancy (slightly higher in admitted patients).

Comparisons of risk factor incidence in selected population based studies are in Table 8.1. The lower incidences of hypertension, atrial fibrillation, diabetes and hyperlipidaemia in the TSR are most likely due to the observational nature of the study. Not all patients had the relevant investigations performed. This was especially so for not admitted patients. Newly (post stroke) diagnosed hypertension, hyperlipidaemia, and diabetes were not included. Newly diagnosed hypertensive patients were identified in 97/1010 (9.6%) by the first 28 days post stroke. ECGs were performed in 58.6% of patients in the first week post stroke. At most 14% of patients were on anticoagulants in the TSR. This is similar to other studies (10.6%-12.9%)^{24,96}.

Other risk factor incidences (angina, previous TIAs, peripheral vascular disease, and current smoking) in the TSR were similar to and generally higher than most previous studies. This however is not standardised as risk factor incidences are age related.

Table 8.1: A comparison of identified stroke risk factors in European population based studies of first ever strokes.

	TSR	Dijon ⁹⁷	Belluno ⁹⁶	SLSR ²⁴	OCSP ⁵¹
Hypertension (HT)	45.8%	71%	50.6%	69.3%	51.6%
Diabetes	11.6%	11%	16.6%	16.6%	9.3%
Hyperlipidaemia	2.0%	13%	5.6%	-	-
Angina/MI	25.1%	21%	19.0%	14% (MI)	17% (MI) 16% (angina)
Previous TIA	20.2%	-	11.4%	-	14.3%
Atrial fibrillation	15.5%	13%	20.2%	19.9%	17.0%
PVD	12.5%	12%	11.7%	17%	16.6%
Current smoker	26.5%	25%	19.6%	-	27.0%
On anticoagulants	2.2%	-	2.6%	2.1%	-
On HT treatment	36.6%	-	-	35.4%	-

Conclusions

Not admitted patients were slightly older, had significantly higher pre-stroke dependency levels and institutionalisation levels, and overall had similar risk factor levels to admitted patients. More admitted patients were on secondary prevention medications. The TSR had similar risk factor incidence trends to comparable UK and European studies. Under-identification of risk factors is unlikely to be significant, and if present, more likely to have occurred in not admitted patients.

Are there differences in stroke severity?

Stroke severity indicators

There are differences in stroke severity between admitted and not admitted patients. Significantly more severe strokes according to stroke subtype were admitted. In keeping with this, significantly more admitted patients had dysphasia, dysphagia and urinary incontinence in the first 24 hours of admission. By seven days, there was a trend for case fatality rates to be higher and median motricity scores in survivors to be lower in admitted patients (differences not significant). All other severity indicators were significantly more frequent in admitted patients at seven days post stroke. Seven day Barthel index median scores were considerably lower in the admitted patients. There were no significant differences in the proportions of infarcts and bleeds in admitted and not admitted patients who had head scans within 30 days of stroke onset.

There are however confounding factors. Admitted patients were more likely to be kept nil by mouth if safety of swallow was uncertain, more likely to be catheterised early, and more likely to have dysphasia documented in their hospital medical records (compared to GP or care home records). At seven days, admitted patients were less likely to be mobilised (contributed to by a fear of in-hospital falls), had more assistance with self-care tasks and more fluid replacement therapy (again restricting mobility). Catheterisation and urinary sheaths usage was higher in admitted than not admitted patients contributing further to mobility restrictions and reduced seven day Barthel scores. Whether this was a result of informal policy, nursing convenience or patient debility is uncertain. It is most likely a combination of all three.

The more objective indicators of visual field deficits, sensory inattention and reduced coma scale motor and verbal scores at one week are confirmatory of increased stroke severities in the admitted patients. On average, hospitalised patients were assessed a median of 1 day earlier (day 7 compared to day 8) post stroke, but this is unlikely to account for either the lower incidences of the above clinical severity indicators at the one week medical assessment, or the higher seven day median Barthel scores.

Comparison by stroke clinical subtype

Analysing stroke severity indicators by stroke subtype reveal significant differences. The most objective indicator is impairment of consciousness. Other indicator frequencies will be influenced by different treatment policies, deficit identification and recording practices in admitted and not admitted patients. Early (within 24 hours) impairments of consciousness were more common in not admitted TACS patients, and in admitted POCS patients. No LACS patients and only 1% of PACS patients in both the admitted and not admitted groups had impaired consciousness. Early speech disturbance, swallowing impairment and urinary incontinence were more frequently recorded in all admitted stroke subtypes.

Comparisons with other studies

Severe stroke subtypes were more frequent than other UK studies (table 8.2). This is consistent with the districts higher standardised mortality ratios for stroke and more deprived socio-economic indicators compared to the other studies areas.

Table 8.2: A comparison of stroke subtype derived from the Bamford classification, in selected UK population based studies.			
	TSR (%)	OCSP (%)	SLSR (%)*
TACS	26%	19%	20%
PACS	34%	35%	30%
POCS	16%	20%	16%
LACS	20%	26%	34%
Uncertain	5%	0%	0%

* confirmed infarcts

Overall, incidence of impaired consciousness was much lower than the WHO collaborative study⁸¹ and the SLSR, and higher than the Dijon study⁹⁷. Early dysphagia and incontinence/catheterisation rates were similar to the SLSR²⁴.

Conclusions

Objective clinical indicators confirm admitted patients had more severe stroke deficits overall. This is corroborated by the higher frequencies of the more severe stroke subtypes in admitted patients. Early hospital treatment policies confound interpretation of other stroke severity indicators in the comparison of admitted and not admitted patients. The frequencies of impairment of consciousness showed no differences in LACS and PACS patients between admitted and not admitted patients. Urinary incontinence (catheterisation), swallowing difficulties and speech disturbance were more frequently recorded in admitted patients in all stroke clinical subtypes.

Are there differences in early supportive care?

Ventilation

Ventilation, required in 29 patients, only occurred in hospital. There were no facilities for community ventilation of patients.

Fluids and nutrition

Subcutaneous or intravenous fluids were used in 44% and tube feeding in 9% of admitted patients in the first week. Almost half of admitted patients were identified as having possible dysphagia in the first 24 hours. Only 1% of not admitted patients had subcutaneous fluid therapy in the first week and none had tube feeding. Dysphagia was suspected in 18% of not admitted patients in the first 24 hours.

Overall, significantly more admitted patients had fluid therapy and tube feeding in the first 28 days post stroke. Similar proportions of admitted patients identified as having dysphagia received supplemental fluid or tube feeding therapy. Very few not admitted patients (9 in total) received any form of fluid supplementation or tube feeding in the first 28 days despite identified swallowing problems in 14% of one week survivors.

At the time of the TSR, there was considerable uncertainty as to the optimal management of post stroke feeding⁹⁸. The FOOD trial is currently underway to explore what best practice should be⁵⁷. Dehydration and malnutrition after stroke is not uncommon and is preventable⁵¹. Protein-energy malnutrition is common after stroke and increases in incidence after the first week, with a resultant increased frequency of infections, bedsores and death or dependency. Early appropriate (patients with swallowing difficulties) enteral feeding however did not prevent malnutrition⁹⁹.

Urinary care

Over one third of admitted and 5% of not admitted patients were catheterised within the first 28 days. Urinary incontinence/catheterisation is common after stroke and is as high as 58% in admitted patients²⁴. Hospital acquired infections are associated with catheterisation⁹. Wade has previously identified incontinence as a predictor of mortality¹⁰⁰. Needless catheterisation has also been identified in the past¹⁰¹. Best practice is attempted regular toileting, utilisation of pads or sheaths and avoiding use of urinary catheters. Catheters are currently advised to be used only after full assessment and as part of a planned catheter management plan using an agreed protocol^{26,102}.

Conclusions

Supportive treatments were almost exclusively limited to admitted patients. Nutritional and fluid supplementation which is expected to be beneficial on outcomes were much more common in admitted patients. Catheterisation and preventing very early feeding (keeping patients nil by mouth), may be detrimental on outcomes if used inappropriately. In admitted patients, a third were catheterised and almost half were suspected as having early swallowing problems.

Are there differences in medication usage?

Antiplatelets, anticoagulants and antihypertensives

Significantly more not admitted patients were taking aspirin within the first week post stroke. Significantly more admitted patients were started on anticoagulants in the first week post stroke. There were no significant differences in admitted and not admitted 28 day survivors on aspirin or

antihypertensives. Significantly more admitted patients were on warfarin at 28 days.

During the study, the International Stroke Trial⁶⁹ and Chinese acute stroke trial¹⁰³ were still being conducted. There was at the time no convincing evidence for or against early antiplatelet, anticoagulant or antihypertensive treatment. Current recommendations now recommend early aspirin treatment, 'appropriate control of blood pressure'² and avoidance of anticoagulation usually until day 14 post non-haemorrhagic stroke²⁶. Prophylactic anticoagulants reduce the risk of venous thromboembolism but increase the risk of cerebral haemorrhage¹⁰⁴, and by association increase mortality and morbidity, and is thus not recommended²⁶. The effect of early aspirin treatment on mortality is modest^{69,103}.

Other medications

Similar small proportions of patients were on opioids. More admitted patients were on anticonvulsants and more not admitted patients were on antidepressants. Current best practice recommendations state that centrally acting drugs should be avoided if possible²⁶.

Conclusions

Not admitted patients were being treated similarly to current best antiplatelet and anticoagulant treatment recommendations. The lower antiplatelet use and increased very early anticoagulant use in admitted compared to not admitted patients might account for some of the differences in observed outcomes. The significantly higher anticoagulant use is in keeping with the higher diagnosis rate of atrial fibrillation in admitted patients.

Are there differences in investigations performed?

Standard investigations

Admitted patients had overall significantly more investigations (apart from cholesterol levels) performed at all time intervals. Significantly more not admitted patients had cholesterol levels checked by six months post stroke. Whether performing the various investigations result in better outcomes is uncertain. What action was taken when abnormal results were found was not recorded. At the time of the study, acute maintenance of glucose levels was not standard practice or recommended, as it currently is²⁶. Most patients (and physicians) at the time of the study were unaware of the importance of cholesterol with regard to strokes and had no record of their levels being checked prior to or post stroke. Cholesterol levels were checked in less than half of admitted patients with a history of angina or myocardial infarction.

Latest recommendations suggest routine chest x-rays should not routinely be performed unless symptoms specifically indicate it²⁶. This is based on the paper by Sagar *et al* published in 1996, which should have been known at the time of the TSR study¹⁰⁵. SIGN guidelines in 1997 however suggested routine ECG, chest x-ray, full blood count, ESR, urea and electrolytes, blood glucose, and lipid measurement⁵⁶.

CT head scans were performed within the first week in 85% of admitted patients on aspirin and 94% of admitted patients on anticoagulants. Only 21% of not admitted patients on aspirin at 28 days had head scans performed by 28 days. Latest recommendations suggest head scanning within 48 hours or earlier pending clinical suspicions⁴¹.

Specialised investigations, echocardiograms and carotid dopplers

There were no differences in the frequencies of MRI scans, angiograms, echocardiograms or thrombophilia screening performed in admitted and not admitted patients by six months post stroke. Significantly more not admitted patients had carotid dopplers performed by six months post stroke.

Conclusions

The more frequent and earlier investigations performed in admitted patients suggest better identification (and by implication, treatment) of stroke risk factors and complications. Only cholesterol levels and carotid dopplers were more frequently undertaken in not admitted patients.

Are there differences in complication rates?

Early medical complications

Medical complications in the first 28 days were significantly more common in admitted patients. Infections were the most frequent complication with significantly more admitted patients on antibiotics. Urinary tract infections (UTIs) were the most common cause. This was consistent with the higher catheterisation rates in admitted patients⁹. The rate of UTIs in admitted patients in the TSR (15%) was similar to a published study at the time (16%)¹⁰⁶. Hospitals are not safe places, with acquired infection rates of 7.7-9.2 per 100 patients, the main causes of which included urinary tract infections and pneumonias^{107,108}.

Possible preventable and treatable pneumonias have been found to be present in 5.6% of patients hospitalised for acute stroke. The thirty day mortality of such patients was 26.9%. Men, patients admitted from nursing homes, those with more co-morbid illnesses, those with

diminished nutritional status, and those with more severe neurological deficits (impaired level of consciousness) had higher pneumonia rates. One death was conservatively estimated to be avoidable for every 11 pneumonia cases prevented¹⁰⁹.

Clinical deep vein thromboses and pulmonary embolisms were uncommon but were only detected in admitted patients. Rates were within expectations (<5% DVT and 1-2% PE)^{26,106}. Significantly more admitted patients developed pressure sores. This should be preventable and usually indicates poor basic care⁵¹. Early mobilisation is considered best care¹⁰² and should reduce these complications. Other complications were uncommon and not significantly different.

A recent study has also suggested the association between medical tubes (urinary catheters, nasogastric tubes and tracheostomies), increased stroke severity, increased medical complications and longer lengths of hospitalisation. The magnitude and consistency of the association was found to be 'striking'. Roth *et al* found that medical tubes remained an independent factor associated with increased medical complications, reduced function and increased resource use, even after adjustment for differences in neurological impairment. They did not attempt to determine the appropriateness of the various tube usages¹¹⁰.

Late medical complications

Medical complication rates from two to six months post stroke revealed no differences (apart from pressure sore rates which were higher in admitted patients) in admitted and not admitted patients. Most patients were no longer hospitalised by the time of this assessment. Median

hospital length of stay was 26 days. It is uncertain what if any influence earlier hospitalisation had on the incidence of late medical complications.

Conclusions

There are significant differences in early complication rates. Factors leading to the increased admitted complications are probably multiple and include increased stroke severity, reduced early mobilisation, higher catheter usage and later and lower antiplatelet usage. It is possible that not admitted patients might have had more unrecognised complications. Late complication rates were similar and most patients were being looked after in the community by this time. Two possible hypotheses for similar late complication rates are that hospitalised patients surviving to discharge were of similar severity to not admitted patients, or there were 'factors' associated with hospitalisation which reduced the post discharge complication rates of more severe hospitalised stroke patients to the level of not admitted patients.

Are there differences in rehabilitation services usage?

Rehabilitation in the first four weeks

During the first four weeks, very few not admitted patients received any form of rehabilitation therapy, whereas most admitted patients received some form of rehabilitation therapy. No not admitted patients received speech therapy, dietician input or occupational therapy in the first week post stroke. Of those that received therapy input, the intensity of therapy was less than admitted patients.

Rehabilitation during month six

Of those few patients that were receiving therapy by six months post stroke, admitted patients were receiving significantly more.

Physiotherapy was the main form of therapy received and was provided to twice as many of initially admitted patients (16%) than not admitted patients (8%). There was a large unmet need as 60% of admitted and 44% of not admitted patients were still reporting weakness. Speech and swallowing deficits were reported in 33% and 13% respectively in admitted patients, and 27% and 12% respectively in not admitted patients at six months. Very few of these patients were receiving any speech and language therapy for this.

It was known by 1996 that stroke patients may still benefit from late specialist assessment and multidisciplinary care^{73,111}, and that they should also have access to appropriate investigations, rehabilitation and emotional support¹¹². The low provision of rehabilitation and poor correspondence between impairment and services provided has not been isolated to the TSR¹¹³. The benefits of post acute domiciliary rehabilitation independent of age, gender, premorbid functional status and stroke severity have been confirmed, with patients managed at home showing a greater return to pre-morbid activity levels than those in a stroke unit, at six months and one year²⁸. The benefits of occupational therapy are still uncertain with a large recent randomised controlled trial showing no significant differences between treatment groups (including patients and their caregivers) at six months in those assigned to leisure, activities of daily living or control¹¹⁴, whereas older have indicated benefit^{115,116}.

The speech therapists role was to identify impaired swallow, optimise food and fluid consistency and effect a reduction of aspiration pneumonia^{70,117,118}; to assist in alternative appropriate communication aids and to encourage / augment spontaneous speech recovery¹¹⁹. There is still

controversy over whether there is significant benefit in therapy with DePippo showing in 1994, that explanation and advice was as effective in dysphagia management as more intensive speech and language therapist involvement¹¹⁷. Garon has subsequent to the TSR, showed no additional risk with thin fluids and possibly faster recovery in those patients with free access to normal (thin) liquids¹²⁰. Meta-analyses of dysphasia management have reached different conclusions, one showing speech and language therapy to be neither effective nor ineffective¹²¹, and another benefit¹²².

Conclusions

Admitted patients were more likely to receive rehabilitation therapy early after their stroke. Very few not admitted patients received any therapy. At six month, few patients who may have benefited from therapy were receiving it. Admitted patients were more likely to receive therapy at six months. It is unlikely that therapy in the community has played any substantial role in the observed improved outcomes in not admitted patients. It is unlikely that speech and language input has made any significant overall impact on late outcomes in admitted patients as very small numbers of affected patients potentially requiring input at six months received it.

Are there differences in six month outcomes?

Late hospital admissions

Significantly more admitted patients were re-admitted (compared to not admitted patients first admission) to hospital in the first six months post stroke. This suggests higher morbidity in the initially admitted group of patients, by six months.

Residence

Over twice as many admitted than not admitted patients were institutionalised at six months post stroke. Of those six months survivors living at home at the time of their stroke, significantly more not admitted patients were still living in their own homes. Most admitted patients living in residential care or nursing care at the time of their stroke had died by six months. Half of not admitted patients living in residential care at the time of their stroke were still living in residential care at six months.

Depression

There were no significant differences in the reporting of depression using the Wakefield Depression Inventory in those completing the self-assessment. It was expected that patients with persistent deficits, change of residence and increased dependency post stroke would be more likely to be depressed. There was a similar large non-response rate in both admitted and not admitted patients which may be masking true differences between the two groups.

Self-reported deficits and dependency

Significantly more admitted patients reported persistent weakness, urinary incontinence, shoulder pain and the need for assistance with tasks at six months post stroke. No significant differences were found in speech or swallowing deficits, numbness or memory impairment. The self-rated activities of daily living, according to the Nottingham EADL, confirmed significantly increased needs at six months in patients initially admitted.

During the first few weeks following stroke, social supports and contact are essential needs for patients and affect both depression and functional

recovery¹²³. Whether not admitted patients had better contacts and social support than admitted patients is uncertain, but may account for some of the differences found.

Secondary prevention

Not admitted patients were significantly more likely to be prescribed aspirin at six months post stroke. Of those not on aspirin, 26% of admitted and 17% of not patients had no contra-indication to treatment. More not admitted patients were on antihypertensives, but this did not reach significance. Significantly more not admitted patients were still smoking at six months.

Conclusions

Admitted patients overall had worse outcomes at six months than not admitted patients. Comparing sub-groups of pre-stroke residency also revealed significantly worse outcomes in admitted patients. As the natural history of recovery in speech deficits post stroke is spontaneous in those receiving little or no long term therapy, the similar proportions of patients with swallowing and speech problems at six months suggest similar severities of surviving stroke patients in the groups. Numbness and memory impairments were also similar. The higher incidences of persistent weakness, urinary problems and shoulder pain in initially admitted patients at six months, however suggest either more severe strokes or some 'factors' associated with hospitalisation were resulting in an increase in only these deficits at six months. Potential such factors in admitted patients were increased catheterisation rates, reduced mobility and reduced need for functional activity as hospital staff met all needs. Secondary prevention medications were provided to a greater proportion of not admitted patients at six months post stroke.

Are there differences in social service provision?

Significantly more admitted patients were receiving additional services at six months. However, special social support interventions¹²⁴, special nurse visits¹²⁵ and family care worker support¹²⁶ has not shown major benefits. Significantly more aids and adaptations were provided to admitted patients on discharge. This may be due to either more dependent patients requiring additional provision or under-recognition of not admitted patients needs, or both. As very few not admitted patients were assessed by occupational therapy either within the first 28 days (2%) or at six months (3%), under recognition of patient needs was likely.

Are there differences in information provision?

Overall, most admitted (94%) and not admitted (94%) patients assessed themselves as having received some or enough stroke related information by six months post stroke. On certain specific stroke information topics, admitted patients received significantly more information. As expected, not everyone provided with the information heeded it. The benefit of just providing information is uncertain. Education and counselling has been shown to improve patient knowledge, problem solving, and adjustment to changes in life at twelve months¹²⁷.

Who were admitted?

Age or sex did not seem to influence the decision for admission. Patients initially seen by their general practitioners were less likely to be admitted than those whose first medical contact was not their GP. Patients who were living alone, who were independent prior to their stroke and who had severe strokes, were significantly more likely to be admitted. Not all severe stroke patients were admitted, and the majority of these turned out to be resident in institutional care at the time of their stroke.

We did not canvass GPs rationale for admission or community treatment. Bamford has previously undertaken this⁴⁴. Patients in care, and with moderate to severe dependency prior to their stroke were less likely to be admitted. Patients with lacunar strokes were proportionately less likely to be admitted. Admission patterns were similar to previous studies^{44,128}.

What are the potential problems with comparing admitted and not admitted patients results in our study?

Missing cases and data quality

The main potential sources of bias in comparing the two groups would be incompleteness of case ascertainment (especially community stroke cases), and incomplete/inaccurate data recording. These potential problems have been overcome by extensive overlapping case notification sources, numerous overlapping data sources, use of protocols and a manual on how to complete the proformas, staff training and problem resolutions, double data entry of key data, regular data entry accuracy checks and final data cleaning.

Overall, there were 9164 notifications with 1898 confirmed strokes in the Tees Stroke Register (TSR). This equates to 4.8 notifications per stroke registered. There were 3450 notifications relating to the 1010 confirmed first ever strokes (on average 3.4 notifications of each confirmed stroke event). This is higher than other published studies^{47,49}. The TSR crude stroke incidence rate was 1.66 first ever strokes / 1000 population / year. This is higher than all other published UK population based stroke registers (East Lancashire Stroke Register-1.58¹²⁹, OCSP-1.29⁴⁷, South London Stroke Register (SLSR)-1.04¹³⁰). The South London Stroke Register recruited patients from January 1995 to December 1998, which incorporates the period the TSR recruited patients²⁴. They identified 163/975 (16.7%) not admitted first ever stroke patients compared to 288/1010 (28.5%) in the TSR. This may reflect a difference in informal stroke admission policies in the areas.

Missing and misreporting of information

Community cases had a larger proportion notified solely from secondary sources and as a consequence, on average, patients were notified later than hospitalised cases. In view of this, there was a potential for under recording of stroke severity, treatment given, investigations performed and services utilised in not admitted patients. Some primary care records had limited information recording. This has been minimised by as early as possible case identification and timed assessments, prospective and regular follow up of patients and a self-assessment six month questionnaire. Assessment completion rates were greater than 98.5% in both admitted and not admitted patients for all assessments. Data cleaning revealed consistency in one month assessor reported functional levels and self-reported six month functional levels.

Insensitivity of measurement techniques

There are factors apart from the effect of the stroke that may influence the results of the assessment tools used and information recorded. For example, the Barthel ADL Index measures what has actually been done and not what could be done if patients were given the opportunity to do it. Hospitalised patients may have been more likely to be confined to bed/chair, were more likely to have been catheterised and were more likely to have been treated with supplemental fluid therapy. This may account for the significantly lower one week scores in admitted patients compared to not admitted patients.

Conclusions

We have been thorough in case ascertainment and are unlikely to have missed significant numbers of not admitted cases. If any were missed, they would more likely be minor strokes that have not come to the

attention of medical care. We did not wish to affect current stroke management practices while the study was underway. As a consequence, in not admitted patients especially, there may potentially be under-recording of information with a possible under-diagnosis of stroke severity and atrial fibrillation particularly. The effect of the former would be to possibly misclassify not admitted patients to a lesser severity which in turn should result in worse not admitted compared to admitted patients, stroke subtype category outcomes.

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What are the limitations of the study?

This was an observational study. No firm conclusions can be drawn from a study of this type. The study allows the generation of hypotheses that will require testing in future. Only then can it be confirmed whether the differences observed are real or apparent. There are potential errors that may affect the interpretation of this study's findings.

Information bias in the outcomes may not have been completely eliminated. In addition, not all potential factors affecting stroke outcomes may have been assessed, recorded or taken into account in the interpretation of the results. Recording the presence of a risk factor does not quantify the risk severity. For example, classifying patients as having hypertension or not underestimates the true nature of the attributable risk as stroke risk rises progressively with increasing blood pressure¹³¹. Similarly, the recording of for example the presence or absence of pressure sores with its implied reduced mobility and resultant increased rates of post stroke adverse outcomes, does not quantify the attributable risk of adverse outcomes which probably increases with increasing pressure sore grade. Furthermore, the factors identified associated with the adverse outcomes are not all independent of each other.

Selection bias may not have been completely taken into account by the factors examined in assessing the validity of stroke subtype classification comparisons. Stroke subtypes may be insensitive and mask potential significant differences in the groups. The assessment tools used to identify masking within stroke subtypes may itself not be sensitive enough to identify differences between admitted and not admitted patients⁵⁴. Using stroke subtype classification as comparator categories

results in smaller numbers in each category. This in turn reduces the power of the study to identify significant differences.

The associations discovered are liable to confounding. The association may be real but the presumed causal hypothesised explanations may be incorrect. Adjustment for confounding factors may lead to a biased estimation of the strength of the associations. This may further be complicated by measurement imprecision and the degree of correlation between the exposure and the confounding variables.

Finally, despite the size and duration of the study, chance variation, especially in view of the much smaller not admitted group size might have arisen resulting in false associations being found.

CHAPTER 9

SUMMARY AND CONCLUSIONS

Summary

Are not admitted patients disadvantaged?

Not admitted patients had less early supportive care, less and later investigations performed, less rehabilitation provided, less aid and adaptations supplied, and less services provided at six months. Proportionally more not admitted patients had not given up smoking at six months post stroke.

There were no major differences in information provision, depression, persistent speech and swallowing deficits, memory impairment, and numbness at six months.

Not admitted patients however had better outcomes in terms of mortality, dependency, complications, self-reported six month deficits, Nottingham EADL scores, late admission to hospital and six month residence. Taking into account stroke severity differences using stroke subtype, still revealed overall improved mortality and dependency outcomes in not admitted patients.

Proportionally more not admitted patients were on antiplatelet agents and antihypertensives. Aspirin was initiated earlier in not admitted patients. Anticoagulants were generally not used in the first week post stroke in not admitted patients.

What could account for the observed better not admitted outcomes?

It is unlikely that many (if any) cases of severe not admitted stroke patients were not identified as multiple (including death certification) prospective overlapping notification sources were used for case ascertainment. There were more notification sources, and higher notification numbers per event, than any other major published population based register. Crude stroke incidences rates are the highest of any published UK stroke register. Standardised incidence rates are similar to other international population based studies.

Hypertension and atrial fibrillation were more common in admitted patients but all other risk factor incidences were similar in both groups. There were no differences in head scan results in those scanned. Impairments of consciousness by stroke subtypes were similar. More severe strokes identified by stroke subtype and objective clinical indicators were admitted. Some stroke severity indicators suggested increased stroke severity within stroke subtypes in admitted patients.

Hospital treatment practices of stroke patients confound comparisons of urinary care, early suspected swallowing deficits, reduced mobility and early dependency levels in admitted and not admitted patients. These treatment practices and hospitalisation per se, may result in increased dependency and other detrimental effects on admitted patient outcomes. Hospitals are not safe environments and the higher infection rates and complication rates identified in admitted patients may further adversely impact on admitted patients outcomes.

Early anticoagulant usage and lower secondary prevention medication usage in admitted patients may also be playing a role in the unfavourable overall outcomes.

These findings are consistent with the findings of the only other published observational population based register comparing admitted and not admitted stroke patients²⁴.

Conclusions

Not admitted patients had better outcomes despite being disadvantaged in many aspects of stroke care provision. The better outcomes are not accounted for by differences in age, sex, pre-stroke handicap, and pre-stroke residence. It is unlikely to be accounted for by differences in pre-stroke risk factors.

After taking into account the greater stroke severity in admitted patients (by using stroke subtype), not admitted patients continue to have overall better outcomes.

Certain hospital practices may be causing increased adverse outcomes in admitted patients.

Future multivariate analyses may shed more light on the various impacts of different processes of care on outcome. This may confirm whether the differences detected and the associations observed are real or apparent.

Hypotheses of the potential causes of the adverse outcomes in admitted patients need testing in randomised controlled trials.

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APPENDICES 1-3

University of Cape Town

APPENDIX 1

Appendix 1 has the list of all protocols and outline of each protocol. The outline of the Manual explaining which proformas should be used in each stroke case and how to complete follows next. Each protocol in full follows thereafter.

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THE MANUAL

The Manual explains the use of the different proformas and clarifies problems that may be encountered when completing them. Each section of the manual must be used in conjunction with the relevant protocols and proformas. It also explains which subsections are used for each patient and how to complete them. The reasons for the methods used, the type of data collected and the limitations of both in future analyses are explained in key areas. A list of the various sections in the manual is as follows.

Objective

Format

Front Sheet

Patient Check List

First Incident

Establishment of Diagnosis

Pathway through Care / Sources of Notifications

History / First Assessment

Examination

Investigations and Operations

Therapy and Complications / Therapy and Services

Recurrent Incident

One Month Assessment

Six Month Assessment

Further Mortality Assessments (12/24/36/48)

Death Assessment

Sudden Death Assessment

Excluded Assessment

The full manual and index is in Appendix 2.

1. DEFINITION OF STUDY CASES PROTOCOL

1.1 Objective

- a. To define the study population
- b. To define the criteria for inclusion in the study

1.2 The Study Population

The Register will record the population in two ways (which overlap):

Study Area Population (for comparisons between areas).

Hospital Treatment Population (for comparisons between hospitals).

The Study Area is defined geographically and is comprised of the:

- a Stockton Local Authority area, (The study was piloted in the Stockton area.)
- b Darlington and Teesdale Local Authority areas.

Postcodes obtained from the Post Office have been used to define these areas according to the local Authority Boundaries as described below.

The Hospital Treatment Populations are all new incident stroke cases treated in:

- a North Tees General Hospital
- b Darlington Memorial Hospital

The Study Population is **all incident cases of stroke** (first and recurrent) occurring in:

- i. the resident population of the study areas whilst either present in the area or absent from the area at the time of the stroke.
- ii. all non-residents who have and are hospitalised* for their stroke while in the study area

* For North Tees General Hospital and Darlington Memorial Hospital only.

1.3 Local Authority and Health Authority areas

The Local Authority areas of Stockton, Darlington and Teesdale closely follow the boundaries of the North Tees Health Authority and Darlington Health Authority areas.

These two Health Authority areas are of interest because of their markedly different Standardised Mortality Ratios for Cerebrovascular disease.

However, in the past few years the North Tees Health Authority has merged with South Tees Health Authority and Hartlepool Health Authority to form Tees Health Authority, and Darlington has merged to become part of South Durham. It is envisaged that official figures on causes of death and other demographic information may be difficult to obtain for the now defunct Health Authority areas of North Tees and Darlington. The study area has therefore been defined according to Local Authority boundaries as these are unlikely to change during the study period.

1.4 Criteria for entry into the Study

Entry into the study is dependant on the following conditions:

1. A diagnosis of stroke. (See Stroke Inclusion Criteria, Protocol 2)
2. The stroke to have occurred on or after the 1st of January 1995 for the Stockton area and on or after 1st June 1995 for the Darlington area for the pilot study.
- 3 The stroke to have occurred after the 30th of June 1995 in either areas for the main phase of the project.
4. Belonging to the study population as outlined above.
5. The stroke to have occurred before the 1st of July 1997.

2. STROKE INCLUSION CRITERIA PROTOCOL

2.0 Definition:

Stroke definition is derived from the World Health Organisation (WHO) *principles* as ‘rapidly developing clinical signs of focal, or at times global (for those patients in deep coma and those with subarachnoid haemorrhage), disturbance of cerebral function; with *symptoms* lasting longer than 24 hours (unless due to an intracerebral/subarachnoid haemorrhage) or leading to death; with no apparent cause other than that of vascular origin.’¹

2.1 Diagnosis of definite and probable stroke : See *Criteria for Diagnosis (section 2.2.3)*

As the definition of the stroke is a clinical syndrome which includes a minimum duration of symptoms (24 hours); a history from the patient, a witness, or a record of such an event being described or noted is necessary to make a diagnosis of stroke. Therefore the incidental finding of neurological deficit on examination without supporting history cannot be diagnosed as a stroke. A CT / MRI finding in a distribution consistent with the history and / or examination is not necessary for the Definite diagnosis of a Stroke but is needed to define the underlying pathology.

The diagnosis of a **probable** stroke is made when the criteria for a definite stroke are not fulfilled. This is most likely in patients with recurrent strokes and where the history is unreliable. (The category **possible** stroke is omitted as everyone referred to the register is automatically a possible stroke and without direct investigative intervention, in many cases it would be impossible to exclude the diagnosis of stroke with certainty, thus this would become a meaningless category and further increase follow-up workload for little benefit.)

Include all first ever strokes, recurrent strokes and probable strokes where the incidents are from the 01 July 1995 **and** the ages of the patients at the time of their strokes are eighteen years and older.

2.1.1 Diagnosis of first ever stroke

- notification event diagnosed as stroke
- no history compatible with previous stroke from the patient or carer
- no evidence in medical records of previous stroke

2.1.2 Diagnosis of recurrent stroke

This presents the problem of diagnosing stroke in an individual who may have residual neurological deficit from the previous stroke. There must be a definite history and /or medical record of a previous stroke (or strokes).

There must be a clear history of:

- sudden* deterioration in pre-existing neurological signs or symptoms **or**
- sudden* onset of neurological signs / symptoms in a different distribution **or**
- sudden* onset of alteration in conscious level or intellectual ability which cannot be attributed to other (non cerebrovascular) causes.

***Note:** Cases of Haemorrhage may have a more gradual onset and fluctuate.

Deterioration in pre-existing neurological signs/symptoms is commonly due to causes other than a new stroke, such as sepsis, seizure or metabolic disturbance.

Where there is a history of sudden alteration in conscious level or intellectual ability and there is evidence of an acute concurrent process e.g. infection, stroke will be diagnosed only if the intellectual / conscious level impairment persists after resolution of the acute process. The finding of **new** neurological signs in a patient suffering from another concurrent acute disorder which is not due to vascular neurological sequelae are excluded.

If history and the first medical contact examination is consistent with the diagnosis of stroke but no neurological deficit is found on the day 7* examination (i.e. there is full recovery from symptoms within 7 days, but not necessarily all signs), consider the diagnosis of a Resolving Ischaemic Neurological Deficit (**RIND**)². A haemorrhage, despite symptom duration is possible and can only be excluded with the appropriate investigations (e.g. CT/MRI/LP).

2.1.3 Exclusions

- **Stroke outside study period or age criteria.**

Defined respectively as a stroke or probable stroke where the onset has been before the 01 July 1995 **or** age of patient at time of stroke less than eighteen years old (prior to 18th birthday).

- **Transient Ischaemic Attacks**

Defined as an acute loss of focal cerebral or ocular function with symptoms lasting less than 24 hours and after adequate investigation is thought to be due to embolic or thrombotic disease.³

Note: Confirmed intracranial haemorrhages (SAHs and PIHs), irrespective of symptom duration are classified as a definite stroke *unless* excluded below.

- **Retinal Infarcts** irrespective of cause. (i.e. Even though Amaurosis fugax and Retinal emboli leading to infarction are usually labelled TIAs and Strokes respectively, for this study, they are excluded.)
- **Isolated peripheral CN lesions:** Note: Difficulty in determining Central from Peripheral lesions. All single, unilateral isolated lesions such as CN III / CN IV / CN V / CN VI / lower motor neurone VII / sudden onset sensori-neural deafness (CN VIII) / sudden onset dizziness (CN VIII) are excluded unless there is other evidence of a BS stroke, SAH or intracerebral bleed. It is possible that these lesions may be due to occlusion of terminal small perforation arteries in the POCS distribution.
- **Sudden onset dizziness without other neurological deficit.** The dizziness may be due to direct labyrinthine / utricle damage by vascular or other causes, but without additional evidence of a BS infarct or bleed (e.g. Imaging / LP), these patients are excluded. See isolated peripheral CN lesions above. If due to an intracerebral bleed without BS involvement and not due to a SAH then include under Uncertain subtype.

- **CT infarcts without neurological signs** are not stroke syndromes. (CT haemorrhages with symptoms but without neurological signs are *included*. As this is standard practice in grading SAHs, this has been extended to PIHs as well.)
- **Cerebral tumours** resulting directly in neurological signs or indirectly via haemorrhagic effects. **Note** : See below for other indirect effects of tumours.
- **Generalised cerebral anoxic events. Exclude** all patients who have had a generalised (*non-localising*) cerebral hypoxic event due to hypovolaemia (e.g. GIT bleed) **or** normovolaemic shock (e.g. ventricular arrhythmia, acute myocardial infarction, septic shock) **or** toxic inhalational gases (e.g. carbon monoxide).

Although the precipitating event resulting in the stroke is **not** due to vascular causes (e.g. emboli / lipohyalinosis / microatheroma / etc.), the resultant effect clinically and on resource requirements / utilisation is the same as having a vascular stroke, with a similar deficit.

As generalised cerebral anoxia is a terminal event in death, those patients without focal neurologic signs (other than strokes according to the included criteria), are excluded.

- **Infective aetiology.** Encephalitis. Ruptured mycotic aneurysms or vessel wall inflammation.
- **Todd's Paresis post seizure.** Symptoms always transient (but can last a few days) and history consistent with a spreading of symptoms along a limb and from one part of the body to another.
- **Intracranial venous thrombosis** unless due inflammatory non-infective vessel disease.
- **Head trauma** resulting in intracranial haemorrhages and/or haemorrhagic contusions.

- **Other:** Hypoglycaemia, Central pontine myelinolysis, electrolyte disturbances, brain abscesses due to bacterial emboli (see **Emboli** below).

Inclusions

- **Ischaemic events which may be related to tumours** resulting in a stroke syndrome. The possibility of tumour emboli, neoplastic invasion of a vessel wall, irradiation therapy or hyperviscosity resulting in the stroke are all included.
- **Dissection.** Excluding trauma (even where focal neurological signs are noted) but including congenital vascular wall pathology such as Ehlers-Danlos, pseudoxanthoma elasticum, fibromuscular dysplasia, Marfans etc.
- **Vascular Malformations.** Congenital aneurysms, arterio-venous malformations, Osler-Rendu-Weber syndrome (HHT) or Sturge-Weber syndrome.
- **Arteritis** due to TB, syphilis and meningitis. (very rare)
- **Haematological causes.** Leukaemia's, hyperviscosity, anaemias, DIC, TTP, PNH, ET etc. resulting in ischaemic or haemorrhagic strokes.
- **Inflammatory Arterial Disease.** Patients who have a stroke due to vascular wall pathology secondary to Behcets, Polyarteritis Nodosa, Giant Cell Arteritis, Takayasu's, Lupus (SLE) etc.
- **Emboli** due to fibrin (thrombus), platelet aggregates, cholesterol (ruptured atheromatous plaques), and calcium (calcified aortic valves). **Embolic events** due to bacterial vegetations (endocarditis, but exclude cerebral brain abscesses due to bacterial emboli), atrial myxomas, air (post surgery), fat (post trauma), and amniotic fluid (T3 pregnancy and delivery).
- **Iatrogenic (Procedure related)** Post surgery, angiography, post streptokinase / tPA etc. related strokes.

- **Hypovolaemia** (relative or absolute) resulting in unequivocal focal neurological signs and symptoms (e.g. post cardiac arrest, post or intra-operatively, during ACE Inhibitor trial). (10/10/96: BH, AG and HR consensus).

2.2.1 Definition of Cerebral Infarction (CI)

Definite CI if

- a) a CT scan done within 28 days of the onset of symptoms showed an area of low attenuation, no relevant abnormality, or an area of irregular high attenuation within a larger area of low attenuation (i.e. an area of haemorrhagic infarction) or if
- b) a necropsy examination showed an area of CI (pale or haemorrhagic) in a region compatible with the clinical symptoms and signs.

Patients with clinically definite stroke who had not undergone computed tomography within 28 days of onset of symptoms or those in whom an adequate necropsy examination had not been done are regarded as cases of **definite stroke**, type uncertain.

2.2.2 Definition of CI and PIH subtypes⁴

Lacunar Syndrome (LACS)

pure motor stroke, pure sensory stroke, sensori-motor stroke, or ataxic hemiparesis. Patients with faciobrachial (dysarthria / clumsy hand) and brachio-crural involvement (ataxic hemiparesis) as in the Oxford Study will be included, but those with more restricted deficits will not.

Total Anterior Circulation Syndrome (TACS): Combination of new higher cerebral dysfunction (e.g. dysphasia, dyscalculia, visuospatial disorder); homonymous visual field defect; and ipsilateral motor (and sensory) deficit of at least two areas of the face, arm and leg. If conscious level was impaired and formal testing of higher cerebral function, or the visual fields was not possible, a deficit was assumed. Note: Isolated homonymous visual field deficits are classified under POCS - see below.

Partial Anterior Circulation Syndrome (PACS): Only two of the three components of the TACS syndrome, with the higher cerebral dysfunction alone, or

with a motor/sensory deficit more restricted than those classified as LACI (e.g. confined to one limb, or to face and hand but not to the whole arm).

Posterior Circulation Syndrome (POCS)

Any of the following:

ipsilateral cranial nerve palsy with contralateral motor and/or sensory deficit; bilateral motor and/or sensory deficit; disorder of conjugate eye movement; cerebellar dysfunction without ipsilateral long-tract deficit (i.e. ataxic hemiparesis); or isolated homonymous visual field defect. Cases with quadrantanopia are classified under POCS.⁵

2.2.3 Criteria for Diagnosis

Positive Findings

- **History:** (in medical records or from patient / carer)
Reliable accurate history of focal neurological symptoms of rapid onset lasting >24 hours or still present at time of history taking.
or history suggestive of a SAH/PIH.
- **Initial Examination :** (Post event, GP **or** Hospital examination)
Examination compatible with and suggestive of a new stroke.
- **TSR Examination :**
New focal neurological signs or new brainstem signs lasting >24 hours (or dying within 24 hours of event) **or** signs suggestive of a SAH.
- **Lumbar Puncture :**
Red Blood Cells in the Cerebro-spinal fluid (CSF) compatible with a bleed in a person with a history suggestive of a SAH/PIH.
Xanthochromia in the CSF.
- **CT/MRI (or angiography) :**
Confirming recent infarct or bleed. (CTs cannot reliably distinguish either a bleed from an infarct, nor the age of it, about 10 days after the incident - from RL).
- **Autopsy :**
Compatible with *recent* cerebral infarction **or** haemorrhage.

Negative Findings

- **History:**

Reliable accurate history of either a gradual progressive onset over weeks or longer of global/bilateral/more than one vascular territory, neurological symptoms, **or** of conditions suggestive of other than stroke such as space occupying lesions (SOL), multiple sclerosis (MS), peripheral nerve or spinal cord involvement, etc.

- **Initial Examination :**

Post event, GP **or** Hospital examination finding no focal neurological signs, brainstem signs or signs suggestive of a SAH.

- **TSR Examination :**

Peripheral nerve lesions.

No focal neurological signs, brainstem signs or signs suggestive of a SAH.

- **Lumbar Puncture :**

No Red Blood Cells or xanthochromia in the CSF in a person with a history and examination suggestive of a SAH.

- **CT/MRI (or angiography) :**

Showing intracranial pathology other than vascular pathology causing the neurological signs and symptoms such as SOLs, demyelination, abscesses, subdurals, extradurals etc.

- **Autopsy :**

Not compatible with recent cerebral infarction or haemorrhage.

Uncertain Findings

- **History:**

Unreliable.

SAH **and** massive PIH with coning, are the only types of stroke which can cause 'sudden' death within an hour or so. (Large BS infarcts should cause 'instant' death.)

- **Initial Examination :**

Neurological examination not specified.

Post event, GP or Hospital examination findings of a probable cause for this event (such as myocardial infarction, infection, fracture, trauma, etc.) more likely than that of a stroke.

- **TSR Examination :**

Unsure whether new or old signs. i.e. when the degree of residual deficit in a patient with previous pathology (of any cause) before this event occurred is not known.

- **Lumbar Puncture :**

Failed/Traumatic tap in a person with a history and examination suggestive of a SAI.

Less than 50% of PIHs have positive LPs.

- **CT/MRI (or angiography) :**

Normal, showing no infarcts or bleeds. (CTs may be normal in the first 48hrs following an infarct. A 'normal' CT is common in cerebral infarction.)

Lacunar infarcts may not be detectable on CT.

MRI is more specific (technology dependent but a normal MRI excludes all but the most trivial infarct/haemorrhage.)

Old or non-compatible infarcts.

Not Available

- When a finding is not recorded/requested or unobtainable.

2.3 SUMMARY (to be used as a guide):

2.3.1 Definite Stroke

2 or more positive findings

and

either no negative findings or findings not available.

OR

Positive autopsy finding

and

1 or more uncertain findings

and

either no negative findings or findings not available.

2.3.2 Probable Stroke

1 positive finding

and

1 or more uncertain findings

and

either no negative findings or findings not available.

2.4 REFERENCES

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3. COMMUNITY SOURCES OF NOTIFICATION PROTOCOL

3.1 Objective:

To ensure complete identification of stroke cases in the community

To establish a system that is simple, reliable, flexible, and GP time efficient

To produce a system of referral that is verifiable

3.2 Background

The population size of North Tees is approximately 178 000 (1994). Of the expected 485 strokes per annum, between 150 to 290 cases will not be admitted. Of all stroke cases an estimated 40-70% will be admitted to hospital¹⁻³. This necessitates a reliable and effective system of community referrals to identify these cases.

Although Accident and Emergency, and Medical/Neurological Outpatients departments may be a source of notification, the main source will be General Practitioners(GPs). Most people, particularly the elderly, are registered with a GP and are likely to consult their doctor following a major medical event such as a stroke. GPs are also likely to receive information on their patients that may have been treated for a stroke while out of area.

3.3 Method

The Oxfordshire Community Stroke Project⁴ showed that GPs can be a reliable source of case referral. For 84.6% of this study's patients the GP was the source of first referral.

Notification of strokes and suspected strokes can be done in a number of ways:

Telephone

Fax

Postal

There are telephone answering machines and fax machines in both the Tees and Darlington Offices. All post is directed to the secretary at the Tees office.

Notification pads asking for certain basic information (see Notification Stationary) and self-addressed envelopes which are given to each GP Practice are provided by the TSR.

3.4 Study Population:

See Definition of Study Cases (Protocol 1).

3.5 Sources:

It is expected that incident stroke cases in the Community will be identified by the following sources:

- General Practitioners
- Doctor's deputising service
- Nursing Homes
- Other : District nurses
 - Accident and Emergency departments
 - Social Services
 - Therapists (Speech/Physiotherapist/Occupational Therapists)
 - Patients/Carers (especially in cases of recurrent strokes when already on the TSR)

3.6 Validation/GP Register checks:

To validate the reliability of GP/Deputising Service referrals in the study a system of checks will be incorporated.

3.6.1. A proportion of stroke cases will be admitted to hospital following assessment by the GP/Deputy, who will have notified the study team of an incident case. Hospital personnel will also notify these cases. GPs will also notify us, if not done already, if after discharge from the hospital, a patient of their practise is thought to have had a stroke according to the discharge letter. This system of double referral will ensure a high detection rate and will also act as a cross-check on referrals.

3.6.2. GP Register: This is one of the secondary notification sources.

Every month, the practice manager at each surgery in each area is contacted by the relevant research nurse and a printout of all patients with the diagnosis of stroke or suspected stroke (haemorrhages and infarctions) in that practice in the preceding month is made. This is crosschecked with the Database records to pick up possible missed cases. Such community notified cases where the source of first notification is the GP registers / records will be recorded in the notification database section for later analysis. It is expected that the smaller, non-computerised practices may have difficulty in providing this information.

3.7 Introduction to the Tees Stroke Register

a) GP practices:

GP practices will be the most important source of referral and will be contacted first. It is also a matter of courtesy to seek each GPs permission to interview his/her non-hospitalised stroke patients. In certain cases, such as cases of early stroke deaths ("sudden deaths") in the community, GP records may be the only source of background data as relatives/carers of deceased patients are not contacted. GP co-operation is thus essential.

What is necessary is to:

- Identify GP practices within the boundaries (and near the boundaries) of the Health Authority areas.
- Construct register of practices (with practice profile).
- Identify contact personnel in each practice.
- Send letter to above explaining project and requesting a meeting with the GPs and Practice Managers.
- Arrange a meeting by telephone for a mutually suitable date (15 min. for single handed practices and 30 min. for larger practices): Meeting
 - Introduce and explain the aims of the project.
 - Obtain agreement to include patients registered with the practice in the study.
 - Seek co-operation with case notification.
 - Discuss proposed method of notification.
 - Explain use of notification stationery.
 - Provide stationery and contact telephone number for further information.

Seek co-operation with data collection by requesting permission to review patients' case notes (with the patients consent).

Construct a practice profile (e.g. number of partners, size of list, use of deputising service, long-term locum / trainee employed, name of practice manager, extent of computerisation etc.)

Speak to practice manager, secretaries and reception staff where possible to ensure co-operation.

Arrange with the practice manager that new partners / locums are provided with stationery and are informed of the participation of the practice in the study.

Contact all of the practices shortly before the starting date of the notification process to remind them of the commencement of the study

b) Other Community Health Care Workers:

- Identify: Nursing and Residential Homes in the area
 - : the co-ordinators of Social services, community physiotherapy, community occupational therapy, and community speech therapy for the area
 - : the District Nursing co-ordinator
- Contact the above personnel, outline the objectives of the study and request the co-operation of their departments
- Contact the managers of the nursing and residential homes, request a visit so that the objectives of the study can be explained. (It would be emphasised that permission for visiting the patient by the TSR would need to be obtained from either the patient / relatives or main carer.)
- Ensure that a copy of the newsletter is sent to all of the above
- Ensure that a contact number is given to all of the above to allow notification, in the case of nursing homes in the form of a notification pad
- Contact all of the above shortly before the starting date of the notification process to confirm understanding and answer queries.

3.8 Community Follow-up

To ensure that the various Health Care workers continue to notify cases to the register a series of reminders need to be sent out on a regular basis.

In the case of General Practices this will take the form of:

a quarterly newsletter (GPs and Practice Managers)

a monthly telephone inquiry (Practice Manager)

In the case of other health care personnel, reminders will take the form of the quarterly newsletter.

3.9 REFERENCES

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4. HOSPITAL SOURCES OF NOTIFICATION PROTOCOL

4.0 Format

This protocol deals with primary notification procedures. For secondary sources of notifications, see protocols 7, 8 and 9.

Various methods having been instituted (in some cases only after successful trial periods) to obtain hospitalised case notifications in the two primary hospitals (North Tees General Hospital and Darlington Memorial Hospital) and the secondary hospitals.

4.1 Objective

To ensure complete identification of hospital admitted stroke cases.

To establish a system that is simple, reliable, flexible, and time efficient

To produce a system of referral that is verifiable.

4.2 Background

It is envisaged that the majority of stroke cases from the Stockton area requiring hospital admission will be admitted to North Tees General Hospital. The majority of Darlington patients will be admitted to Darlington Memorial Hospital. However a small but significant number of patients from Stockton will be admitted to South Cleveland Hospital (e.g. when there is a shortage of acute medical beds in North Tees) or to Middlesbrough General Hospital, particularly to the Neurosurgical unit in the case of subarachnoid haemorrhage or primary intracerebral haemorrhage. Middlesbrough General Hospital is also the regional Neurosurgical referral centre for Darlington Memorial Hospital.

In the Darlington area a proportion of the population live within the catchment area of Bishop Auckland General Hospital and are likely to be admitted acutely to the medical wards there in the event of stroke. Barnard Castle is served by a small GP run hospital, the Richardson Hospital which has rehabilitation facilities. A proportion of patients requiring rehabilitation rather than medical investigation, particularly elderly patients, are likely to be admitted here rather than to the General Hospital in Darlington.

As the study population includes those normally resident in the study area but who have a stroke and are treated outside the area a number of patients will be

treated in hospitals outside the local area. The Friarage Hospital, Northallerton and Hartlepool General Hospital are most likely to receive a small number of patients from the study area each year but hospitals further afield may treat a number of our study population especially if the patient was outside their residence area at the time of the stroke.

4.3 Method

To identify:

The wards most likely to treat stroke patients (i.e. acute medical wards and rehabilitation wards) in North Tees and Darlington Memorial (and South Cleveland and Middlesborough General Hospitals).

Hospital departments likely to be involved in the treatment or investigation of stroke, i.e. radiology departments, Accident and Emergency departments, pathology departments (post-mortem examinations).

To do:

Send copies of the newsletter to each department and to each consultant in the above departments.

Write to each medical consultant requesting their co-operation and permission to interview patients under their care.

Visit each ward. Explain the purpose of the study and the proposed method of notification. Leave TSR stationery/posters on each ward.

Arrange visits with other departments and discuss the aims of the study.

Notification of strokes and suspected strokes can be done in a number of ways:

The main two sources will be from the daily phoning (see 4.6 below) and from the research nurse checking the ward admission books.

Patients resident outside the Local Authority/Health Authority areas, but treated for their stroke event at Darlington Memorial Hospital or North Tees General Hospital, are included.*

*Note: If admitted due to a complication of a previous stroke which occurred while outside the area and not resident in the Local Authority/Health Authority areas, then the patient is excluded from the study for that stroke event.

4.4 Primary Sources

Resident Medical Doctors

Other Hospital Doctors

Nurse/Research Nurse (including checking the death certificate books)

Ward clerk/secretary

CT scan lists (Both a primary and secondary source : See protocol 10.)

4.5 Validation

Backup measures to pick up cases on other than medical wards (e.g. orthopaedics, outpatients, psychiatry etc.), in cases where the diagnosis is changed to a stroke / possible stroke and as a check are also used. These are CTscan registers / records, DHA lists and Hospital Discharge records. As in the methods of community referral, multiple sources of notification are present, but this is needed for completeness of case ascertainment.

4.6 Daily Phoning System

The doctors below are phoned on a daily basis every morning between 08h30 and 08h50. They were on duty for the preceding 24 hours. Information on all cases of suspected and definite strokes are obtained. Phoning is done by the TSR team on a rota basis.

4.6.1. Doctors Phoned:

Darlington Memorial Hospital

Resident Medical Officer (Usually the Senior House Officer)

- All new admissions and in-patient strokes (if asked to see in-patients).

Elderly Care Doctor - All new admissions to elderly care wards 51 and 52.

Medical Registrar - In hospital strokes not on medical/elderly care wards.

Only necessary to phone if not the resident medical officer.

North Tees General Hospital

Resident Medical Officer - Usually the Senior House Officer

- All new admissions only.

- In hospital strokes (if asked to see in-patients).

Medical House Officer-on-call - Only necessary to phone if resident medical officer is unsure of admission details (HO is first on-call between 22h00 and 09h00).

4.6.2 Information Obtained (if possible)

Hospital

Name of patient

Ward patient sent to if admitted

Date of suspected stroke

Date of birth of patient

4.6.3 Phoning By:

Weekdays - TSR registrar.

Weekends - Rota basis involving Drs Murphy / Herd / Rodgers / Gani.

Rota to be drawn up every two months taking into account the weekends the consultants are already on call and when doctors are not available. Information obtained is passed on to the TSR offices on the morning of the next working day.

Bank Holidays – The same format as weekends.

During the TSR registrar's leave, a similar rota to the weekend one will be drawn up, but including the weekdays.

4.7 Hospitals other than North Tees General and Darlington Memorial

At Bishop Auckland, Dr. Winn will inform the TSR on approximately a monthly basis of all strokes picked up in the preceding month on the BA stroke register. These patients' residential postcodes will be cross-checked to see whether eligible for inclusion and if so, whether already known to the TSR or not.

After an approx. 2 month trial period of phoning the neurosurgical wards at Middlesbrough General Hospital on a weekly basis, no new strokes (not

previously known to the TSR) were detected and this method of checking has thus been discontinued.

After an approx. 18 month period (25/04/95-01/10/96) of receiving an approximately monthly list of stroke patients in the South Cleveland Hospital rehabilitation unit, only two included stroke cases were detected (and these patients would have been picked up later; one transferred to North Tees rehabilitation unit and the other from the GP register checks). This method of checking has thus also been discontinued.

The Richardson Hospital was initially phoned on a fortnightly basis, but those patients admitted there were telephonically notified prior to the routine telephonic check, and thus this method has also been discontinued.

Initially missed cases treated at any of the district hospitals should be picked up by the secondary notification system which includes the DHA lists (see protocol 8) and GP Register lists (see protocol 3).

4.8 Hospital follow-up:

Initially it was envisaged that TSR personnel would visit other hospitals on a regular basis (quarterly), but because of the low new case ascertainment rate, it is more efficient to maintain contact and feedback via the regular (quarterly) newsletter and only visit those who request more information/details.

5. PROCESSING OF NOTIFICATIONS PROTOCOL

5.1 Introduction

A system of processing notifications was devised in order to ensure smooth running of the project. This system needs to be reliable, reproducible and efficient. The principles for processing both Primary and Secondary sources of notifications (see 5.3.1 Sources) are in general the same. This protocol deals mainly with the procedure involved in processing the Primary notifications. Refer to the individual Secondary source of notifications protocols for further details on their processing.

5.2 Objectives

- a. All notifications are recorded and are dealt with appropriately.
- b. Notifications are correctly identified as belonging to the study population
- c. All surviving notified stroke patients are contacted and arrangements made for the initial assessment.

5.3 1 Sources

Notifications are expected from numerous sources (as outlined in protocols 3,4,8,9,10). The sources may be divided into Primary and Secondary sources:

- a. Primary (early notification)
 - Resident Medical Officers
 - Nurse/Records
 - GP/Deputising Service
 - Other Hospital Doctors
 - Ward Admission Books
 - Other (Nursing Homes, Clerks/Secretaries, Other)
- b. Secondary (late notification)
 - CT Scan Records
 - DHA Death Data
 - DHA Admission Data
 - GP Registers
 - Ward Death Certificate Books
 - Other (Regional Admission Data, Dr Wynn Bishop Auckland Register, Hospital Discharge Records, Other)

In some cases, there may be an overlap between the early and late notification sources; for example, CT scan results are reviewed on a weekly basis in North Tees General Hospital. The secondary sources were initially envisaged as a check procedure to ensure as near as complete case ascertainment as is possible. It is expected that due to the late notification of included cases from the secondary sources, the initial assessments will not be able to be done within the ideal protocol time intervals for the study.

Due to the multiple sources of notifications, it is expected that each event (suspected stroke) will have more than one source of notification. All notifications for each event (in order of the receipt of each notification) are recorded as First and Further notifications for that event. Occasionally, it may be difficult to decide whether a secondary source of notification refers to a new event or whether it is a further notification of a known event. Refer to the appropriate protocol for that source of notification for clarification.

5.3.2 Method

Primary sources of notifications will be received as either (All Secondary sources of notifications are received as lists.) :

- telephone call
- postal notification slip
- fax
- direct contact with nursing staff and other hospital personnel (via daily phoning / personal contact)

On receipt of the notification the patients initial demographic details will be entered onto the register. Other details will also be recorded (on paper, and onto the database), the essential ones as follows.

- Date of receipt of notification
- Method of notification
- Appropriate to the Stockton or Darlington register
- Alive or dead at the time of notification
- Patients usual GP
- Current location of patient

The postcode should be checked against the computer record of study area postcodes to ensure that the patient belongs to the study area. "Out of area patients" i.e. patients not normally resident in the study area who have had or who are receiving treatment in the study area should be recorded as such.

"Out of area" postcodes should be processed as soon as possible for patients treated in the area as these patients may be lost to follow up in the event of early discharge from hospital, and/or may have no medical records in the area and therefore have little additional sources of data regarding first assessment history available.

A file (paper and computer) will be opened for each new patient registered. In the event of a registered patient having a recurrent stroke, no new file is opened but the date of stroke recurrence is noted and the details of the notification are taken in the usual way.

5.4 Consent

Consent is obtained from the patient or a carer at the earliest opportunity. This ensures access to medical records even if the patient is subsequently lost to follow up.

According to the Patients Charter (North Tees) and the Local Ethics Committee (NTGH), written consent is not needed from the patient to look at their records after research consent is obtained from the Ethics Committee. For patients on hospital wards the patient or where he/she is unable, the available carer is asked to sign the consent form following explanation of the study. If the patient is unable to give valid consent and a carer is not present at the time of the visit by the member of the study team to the ward the telephone number of the carer or next of kin is obtained from the nursing staff. Attempts are first made to meet the closest relative/carer on the ward to personally explain the study, answer concerns and obtain further background information. If this fails, then contact by telephone by the study team is made, the purpose of the study explained and verbal consent is sought. Where this is elicited, arrangements are made for the carer to sign both copies of the consent form at the time of their next visit to the ward. The consent forms are left with the nursing staff and the arrangements are explained. The TSR copy of the consent form is either collected from the ward or is forwarded to the study office by ward staff on

completion. A member of the study team made the initial explanation of the study and request for co-operation with the study.

5.5 Community

In the case of patients in the community at the time of notification the patient is initially contacted by telephone by a member of the study team. The study is briefly outlined and permission to visit the patient is requested. If this is given, a time and date is arranged for the initial assessment, between 5-9 days post onset of stroke ideally. If the patient does not have a contact telephone number a letter is sent inviting participation in the study. A date for the initial assessment is proposed. The patient is given the opportunity to decline or change the time or date of visit by either returning the invitation card or by phoning the TSR office. In most cases, the GP notification stipulates whether the patient has been informed briefly of the study by the GP and whether the TSR could contact the patient directly. If the patient does not contact the office before the date of visit, the visit proceeds and a member of the study team (research registrar) calls on the patient. The study is explained in more detail and if the patient agrees to participate, the patient/carer signs the consent form.

In cases where the patient has been identified as residing in a nursing home the matron will be contacted. This is to ascertain if the patient (and / or where appropriate the next-of-kin) and the patients GP has been informed of notification and to obtain their permission to visit.

5.6 Hospital

In some cases the ward will be visited and first assessment carried out at the same time. If the patient is unable to give consent because of comprehension difficulties or diminished level of consciousness, the next-of-kin will be determined from the nursing notes. Nursing staff will know if the patient is regularly visited and by whom. An interview with the appropriate relative or carer will be requested in order to obtain consent, the necessary demographic details, social history and history of the stroke if witnessed. (In the event of there being no relatives or carer available for interview, consent will be obtained by telephone from the next of kin or main carer. Further information will have to be obtained from various records.)

On completion of the first assessment, arrangements for subsequent follow-up will be explained to the patient. See First Assessment Protocol.

5.7 Outside the study area

It is envisaged that a small number of cases of stroke will occur in people who are normally resident in the study area while they are out of the and are e.g. visiting friends or relatives or while working outside the area.

These cases will come to the attention of the team:

- 1) in the case of stroke death via district health authority death data information.
- 2) if they are hospitalised outside the area via the information obtained from the district health authority hospital admission data on hospital discharges.
- 3) via the local GP when the patient is discharged from the care of the GP outside the area, or when the local GP is requested to provide information on their patient by a GP outside the area in order to facilitate care.

For cases identified as having had stroke outside the study area the local GP may be contacted to

- 1) to obtain further information on the patients circumstances e.g. the likelihood of return to the area; if the next of kin is residing in the area.
- 2) obtain permission to view the patients existing case notes.

If the patient has been hospitalised outside the study area the relevant hospital consultant will be contacted by letter/telephone and a request made that a copy of the hospital records regarding that admission be posted or faxed to the study team on the patients discharge from hospital or demise. If the patient has not been hospitalised, the relevant GP outside the area may be contacted for information if the patients own GP has insufficient details of the event.

For cases of death from stroke occurring outside the area, the local GP will be contacted for information in existing records. Further information may be sought from either the contact GP responsible for care outside the residence area (either directly or via patients local GP); or if hospitalised outside the area, the contact consultant to

arrange for copies of the relevant hospital records to be sent to study team (either directly or via the patients local GP).

5.8 Deceased notification

Patients carers or relatives are not contacted by the TSR. (Those already known to the TSR may approach the TSR themselves.). Nursing staff (especially those where patients died in Nursing Homes) may be contacted for collateral history to confirm the event and inclusion of the patient (if death due to a new stroke).

Information regarding the event resulting in the patients death and the patients background history is sought from the patients GPs records and/or Hospital records and/or Nursing Home records.

University of Cape Town

6. INITIAL ASSESSMENTS PROTOCOL

6.0 Introduction

On receipt of notification of a stroke case arrangements will be made for the initial assessment of the patient by the study research registrar. This assessment will take place either on a hospital ward or in the patient's home.

6.1 Objectives

The assessment should be

- easily carried out in the settings described
- brief (in order to minimise disturbance to the patient and to facilitate multiple assessments on one day)
- complete
- valid and reproducible.

The aim of the initial assessment is to collect the following data:

1. Demography
2. History of stroke onset (to aid diagnosis)
3. Relevant past medical history including previous strokes / TIAs, risk factors for stroke, medication
4. Social history (for Deprivation Index)
5. An assessment of premorbid health status
6. Use of medical, nursing and social services prior to stroke
7. Neurological assessment (to aid diagnosis and classification of stroke) at about one week (to allow comparisons between differing levels of neurological deficit at one week).
8. General medical examination
9. Assessment of level of function at one week

6.2 Method

The initial assessment is comprised of two parts, an interview section covering points 6.3.1-6 and an examination section covering points 6.3.7-9.

The interview section is not time dependant i.e. it does not need to be carried out at one week as all the information refers to past events. For the sake of reliability of

recall of events the interview should be carried out either before or at the time of the one week assessment. In some cases the interview section may be carried out after the one week assessment e.g. an opportunity to collect the information from the relatives of an unconscious or confused patient may not arise until after the one week assessment has been done.

However, the neurological, general and disability assessment should be done where possible between 5-9 days post stroke (ideally at day 7) to allow comparison between patients. If the initial assessment is delayed due to late notification, difficulty in setting up an appointment etc. the neurological and general examination should still be carried out as the neurological examination, even when late, may aid in confirming the diagnosis and determining the site of pathology. Similarly the general examination may support the presence of risk factors such as cardiac murmurs or "atrial fibrillation". These assessments that are performed "out of time" may require certain sections to be treated differently during the analysis of the data. It is expected that many of the community cases will not be seen within the ideal time period due to later notifications (compared with hospital cases), difficulties in arranging visits and limited resources. However, the majority are intended to be completed by day 14.

6.3 Data collected: (see Proformas: History/First Assessment, Examination, Therapy and Services, Therapy and Complications, Pathways)

6.3.1. *Collection of demographic data*

Data allowing patient identification e.g. name, address, date of birth, etc. will usually have been collected before the initial assessment at the time of notification. These details should be checked for accuracy at the initial assessment. As many of the patients in the study will have considerable disability / handicap the name address of the next of kin or main carer should be obtained to allow collection of necessary information. Where possible patients should be interviewed with a relative or close friend to improve accuracy of data. Other demographic details to be collected include ethnicity and marital status.

6.3.2. *History of stroke onset*

The history of stroke onset is of particular importance given the definition of stroke. The proforma will allow for an area of free text to briefly describe what happened at the time of stroke. Specific details to be collected include time of day, date, location, timing of first medical assessment, admission (or not) to hospital and mode of transport to hospital.

6.3.3. *Past medical history*

Only medical history of relevance indicating probable increased risk of stroke will be collected. This will include data on hypertension, previous stroke / TIA, myocardial infarction, ischaemic heart disease, atrial fibrillation, diabetes, hypercholesterolaemia, peripheral vascular disease, and in the case of female patients a history of age at menopause etc. Medication at the time of stroke will be recorded to allow a comparison with one month post stroke.

6.3.4. *Social history*

As this study is based in the north of England, an area of high social deprivation¹, information regarding the effect of deprivation on stroke risk / outcome will be of interest. Data will be collected on home ownership, domestic overcrowding, employment status and car ownership, in order to calculate a deprivation index. This information can then be compared with data on the age-matched population obtained from the national census. The comparison of income and use of benefits and allowances before and after stroke will be of interest when estimating the “cost” of stroke, of relevance not only to the individual but also to those providing funding. There is a significant level of handicap among stroke survivors, with implications for housing provision. Information regarding the type of residence required before and after stroke would be of interest, particularly when measuring the burden of stroke on local public spending. Data on specific risk factors such as cigarette smoking and alcohol usage will also be collected.

6.3.5. *Premorbid health*

A significant proportion of the stroke population will be elderly who have a higher risk of co-morbidity which may influence outcome following stroke. It is also of particular importance in this study that is comparing the mortality from stroke in two areas that may have different prevalence of co-morbid conditions in their stroke populations. The degree of premorbid handicap will be established by the Oxford Handicap Scale.

6.3.6. *Use of medical, nursing and social services prior to stroke*

Collection of this data at the outset will allow assessment of the increase in services required after a stroke, with implication for service provision and financing.

6.3.7. *Neurological assessment*

The neurological examination is primarily to establish a diagnosis, indicate the site of pathology (to allow stroke sub-type analysis), and to assess the severity of the stroke. All parts of the examination are uncomplicated in that they are possible to carry out in the patients home quickly and without disturbance to the patient. The examination should be composed of elements that have high intra and inter observer reliability. The examination will also provide a database of clinical findings in community and hospital stroke patients, allow a comparison between individual or groups of patients, and it will enable a correlation between initial findings and outcome. It will also be used in an analysis of clinical findings in different types and subtypes of strokes.

6.3.8. *General medical examination*

As before, this should be brief and relevant to the purposes of the study.

6.3.9. *Assessment of level of function*

The Barthel Index¹ (at day 5-9), an established scoring system, will be used.

Most of this information should be obtainable at the time of the initial assessment but may be supplemented by examining the medical records. Patients on whom data collection is incomplete after the initial assessment will be identified on the database

to allow completion at a later date by contacting a relative or carer of living patients. Those whose data is incomplete but where the probability of completion is very small will also be identified to ensure efficient use of time.

6.4 Arrangements for follow up

On completion of the initial assessment arrangements should be made for follow up. The patient/carer should be informed that a telephonic follow-up by a research nurse 28-32 days post onset of stroke will be undertaken. They should also be informed that a questionnaire will be sent out at about 6 months post onset of stroke, which should be completed and returned in the accompanying freepost envelope. At the first assessment, an information sheet about the project with the study team contact telephone number and address is provided in case of queries or changes of address.

The patient and carer should be thanked for their co-operation with the study.

6.5 Reference

1. Mahoney FT, Barthel DW: Functional evaluation: Barthel Index. Md Med J 1965; 14: 61-65

7. HOSPITAL DISCHARGE NOTIFICATION PROTOCOL

7.1 Introduction

This is one of the secondary sources of notifications. It enables checking the completeness of primary case ascertainment of all patients with a stroke event (resident and out side area) treated at either Darlington Memorial Hospital or North Tees General Hospital.

7.2 Objective

To obtain all patients registered as having had a stroke (including subarachnoid haemorrhages and intracerebral bleeds but excluding subdurals and extradurals) during the study period.

7.3 Method

A monthly/three monthly list as arranged with the each of the Hospital Information departments is forwarded to the Tees Stroke Registers office. The information on subsequent lists are those patients which have been entered since the last printout. This will ensure that delayed entry cases are not missed. The lists refer to patients **ICD9 Codes 430-438 OR ICD10 Codes I60-I69.**

The following information for each patient is required:

- Surname
- Forename
- Address
- Postcode (to check whether in study area or not)
- Date of Birth
- Date of Hospitalisation and Discharge
- List of Diagnoses (preferably the primary diagnosis first)

Initially it was envisaged that it would have been able to differentiate 'Stroke' as a new diagnosis from an admission with a stroke complication/previous stroke.

Unfortunately, this cannot always be determined from the Hospital lists due to their methods of recording. Thus, all patients with stroke in the diagnosis will need review unless it is clearly stated when the previous stroke occurred (and if appropriate, the patient has already been recorded on the TSR database for that event).

7.4 Notification Recording (See 7.6 Flowchart)

All patients resident and non-resident at the time of the stroke within the study period are entered onto the administrative database. This will be either as a:

- a Further Notification (of a known event)
- b New (First ever for this event) Event Notification

All patients already known to the TSR are recorded as having further notifications when the subject patient has had an assessment/review (e.g. at hospital discharge) after the suspected event. All known strokes within the study period should ideally already be recorded. The date of event in these cases will be taken as the nearest preceding notified stroke event, for the further notification recording if occurring within one month (or six months if the six month assessment has already been completed and no further stroke identified) of the known event.

All other patients are recorded as having a New Event Notification. This will either be a further event (patient already known to TSR) or first event (new to TSR).

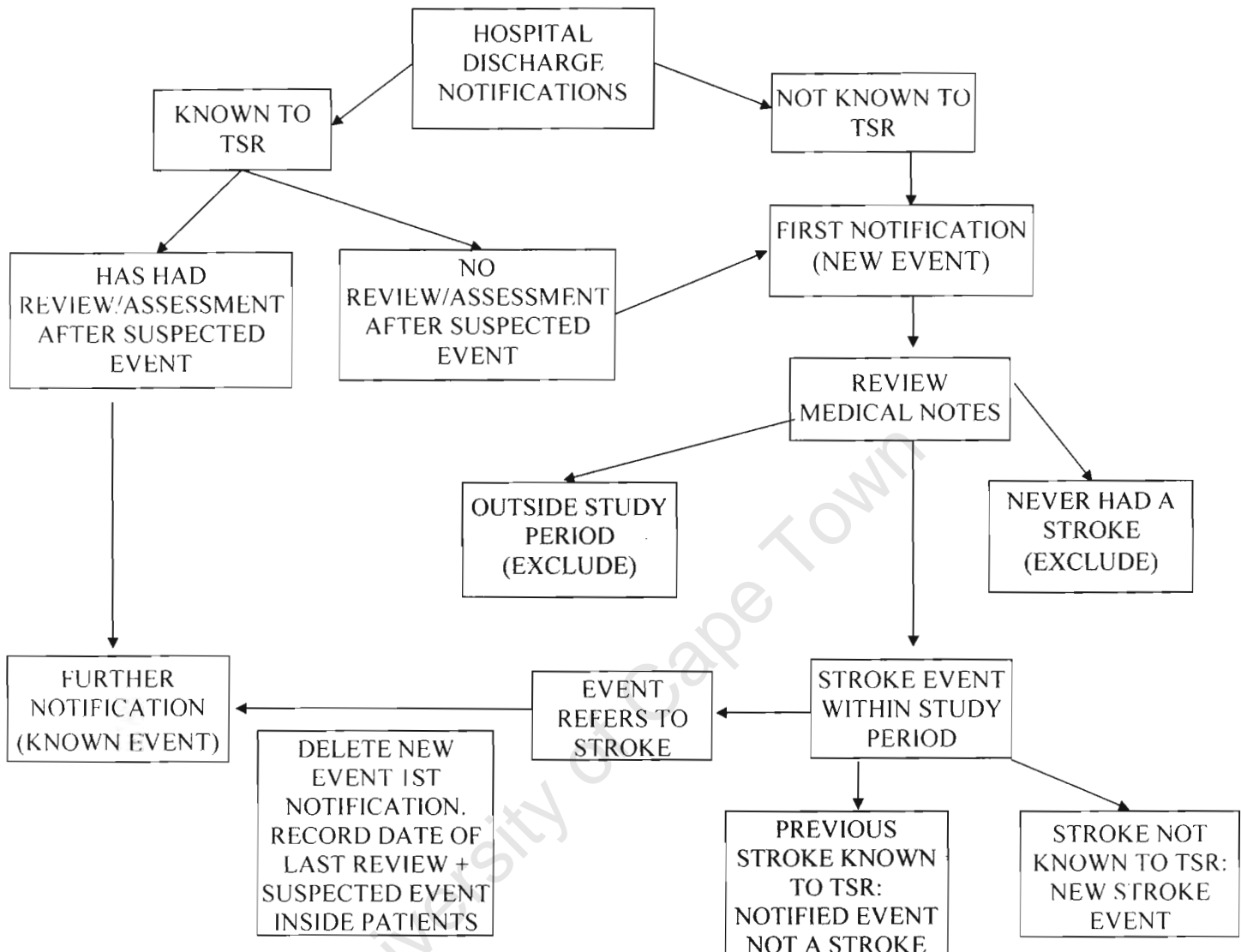
7.5 Notification Processing

All New Event Notifications will require review of the patients records to see whether they are included or excluded (and the reason for exclusion). Diagnosis sheets must be completed for all events (and the evidence for the reason for exclusion in appropriate cases).

All included patients will have the missed assessments completed retrospectively from the most reliable sources. This will usually necessitate a consultation with the patient and/or carer. It is expected that this information will not be as complete or as accurate as that obtained prospectively. This is particularly important with respect to the examination findings. All further assessments will be done prospectively as per normal.

Proformas needing completion and information on how to complete them is obtainable from the relevant sections in The Manual.

7.6 Flowchart



7.7 Problems

There have occasionally been difficulties in obtaining the lists regularly from the Hospital Information departments. The lists also seem to be incomplete.

7.8 Solutions

Darlington Information department has provided a computer program which enables the TSR to print out the lists whenever needed, without any further assistance from the information department.

The Information Technology (IT) department at North Tees General will forward an updated list on regular requests only.

8. DHA DISTRICT NOTIFICATION PROTOCOL

8.1 Introduction

This is one of the secondary sources of notifications. It enables case ascertainment of residents treated in hospitals other than those for which regular discharge lists are received. It is expected that DHA lists of residents treated in hospitals for which regular lists are being received, will be a subset of Hospital Discharge list cases.

8.2 Objective

To obtain all patients registered as having had a stroke (including subarachnoid haemorrhages and intracerebral bleeds but excluding subdurals and extradurals) during the study period in the TSR study population.

8.3 Method

A monthly/three monthly list as arranged with the District health departments in each district, is forwarded to the Tees Stroke Registers office. The information on subsequent lists are those patients which have been entered since the last printout. This will ensure that delayed entry cases are not missed. The lists refer to patients **ICD9 Codes 430-438 OR ICD10 Codes I60-I69.**

The following information for each patient is required:

- Surname
- Forename
- Address
- Postcode (to check whether in study area or not)
- Date of Birth
- Date of Hospitalisation and Discharge
- Place of Hospitalisation
- List of Diagnoses (preferably the primary diagnosis first)

Initially it was envisaged that it would have been able to differentiate 'Stroke' as a new diagnosis from an admission with a stroke complication/previous stroke.

Unfortunately, this cannot always be determined from the Tees Health lists due to their methods of recording. Thus, all patients with stroke in the diagnosis will need

review unless it is clearly stated when the previous stroke occurred (and if appropriate, the patient has already been recorded on the TSR database for that event).

8.4 Notification Recording

All patients resident at the time of the stroke within the study area and study period are entered onto the administrative database. This will be either as a:

- a Further Notification (of a known event)
- a New (First ever for this event) Event Notification

All patients already known to the TSR are recorded as having further notifications when the subject patient has had an assessment/review (e.g. at hospital discharge) after the suspected event. All known strokes within the study period should already be recorded. The date of event in these cases will be taken as the nearest preceding notified stroke event, for the further notification recording.

All other patients are recorded as having a New Event Notification. This will either be a further event (patient already known to TSR) or first event (new to TSR).

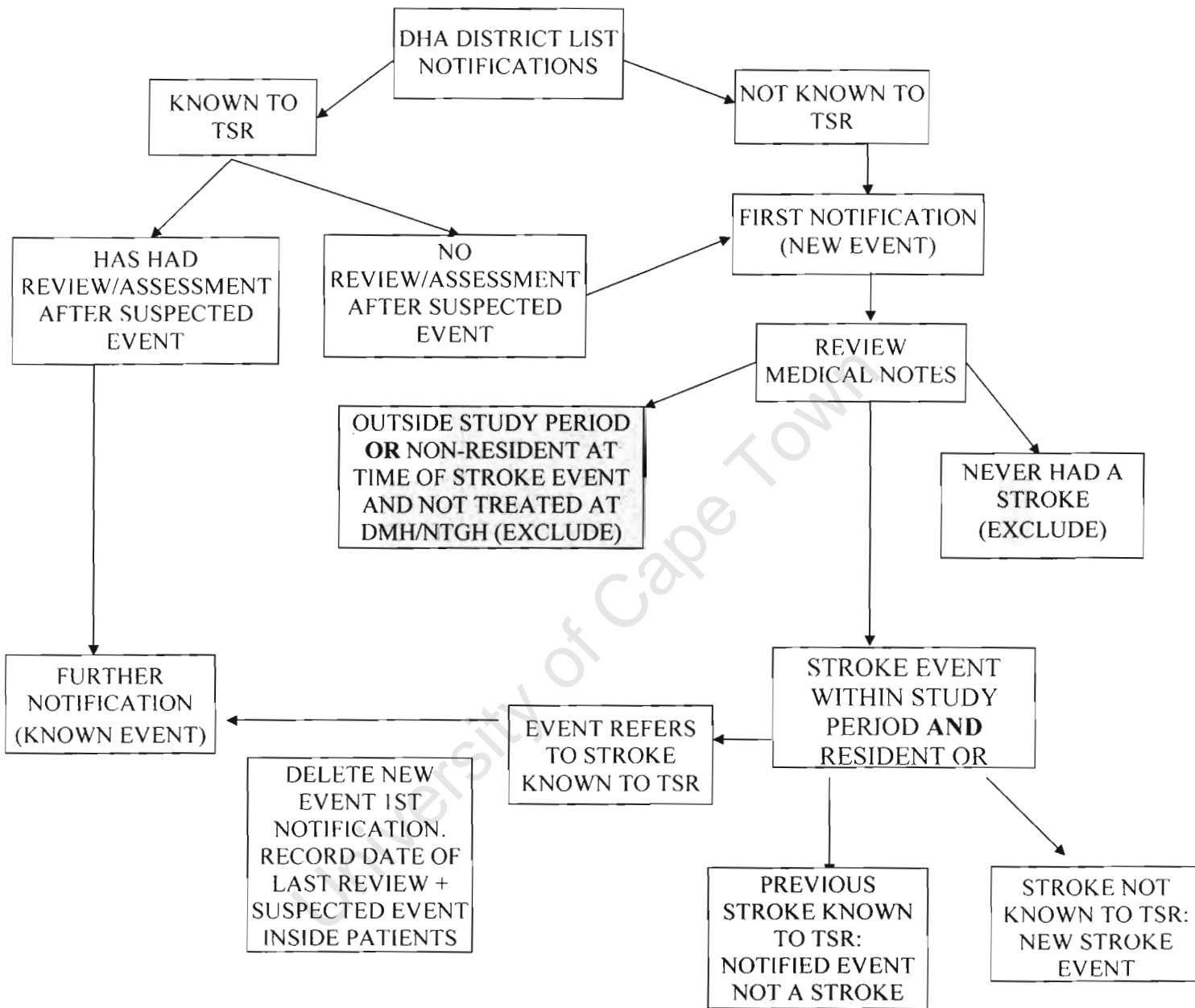
8.5 Notification Processing

All New Event Notifications will require review of the patients records to see whether they are included or excluded (and the reason for exclusion). Diagnosis sheets must be completed for all events (and the evidence for the reason for exclusion in appropriate cases).

All included patients will have the missed assessments completed retrospectively from the most reliable sources. This will usually necessitated a consultation with the patient and/or carer. It is expected that this information will not be as complete or as accurate as that obtained prospectively. This is particularly important with respect to the examination findings. All further assessments will be done prospectively as per normal.

Proformas needing completion and information on how to complete them is obtainable from the relevant sections in The Manual.

8.6 Flowchart:



8.7 Problems

There have been difficulties in obtaining the lists regularly from the District Health authorities. The lists also seem to be incomplete.

9. DHA DEATH NOTIFICATION PROTOCOL

9.1 Introduction

This is one of the secondary sources of notifications. It also allows for comparison between deaths certified as due to stroke and those due to stroke according to the TSR definition.

9.2 Objective

To obtain all patients certified as having died due to a 'Stroke' related death (including subarachnoid haemorrhages and intracerebral bleeds but excluding subdurals and extradurals) during the study period in the TSR study population.

9.3 Method

A monthly list as arranged with the District health departments in each district, is forwarded to the Tees Stroke Registers office. The information on subsequent lists are those deaths which have been entered since the last printout. This will ensure that delayed entry cases are not missed. The lists refer to **ICD9 Codes 430-438 OR ICD10 Codes I60-I69**.

The following information for each deceased is required:

Surname
Forename
Address
Postcode (to check whether in study area or not)
Date of Birth
Date of Death
Place of Death (Hospital or Place of Residence)
Causes on Death Certificate

Initially it was envisaged that it would have been able to differentiate 'Stroke' in Part I from that in Part II. Unfortunately, this cannot always be determined from the Tees Health lists due to their methods of recording. Thus, both Parts I and II stroke related deaths are noted.

9.4 Notification Recording

All patients within the study area and study period are entered onto the administrative database. This will be either as a:

- a Further Notification (of a known event)
- b New (First ever for this event) Event Notification

All patients already known to the TSR are recorded as having further notifications if either their death assessment is already completed (when all known strokes within the study period should already be recorded) or the death is within one week of the latest incident (when this is according to protocol part of the initial incident).

All other patients are recorded as having a New Event Notification. This will either be a further event (already known to TSR) or first event (new to TSR).

9.5 Notification Processing

All New Event Notifications will require review of the patients records to see whether they are included or excluded (and the reason for exclusion). Diagnosis sheets must have the Death Certificate information noted on the back and the evidence for the reason for exclusion.

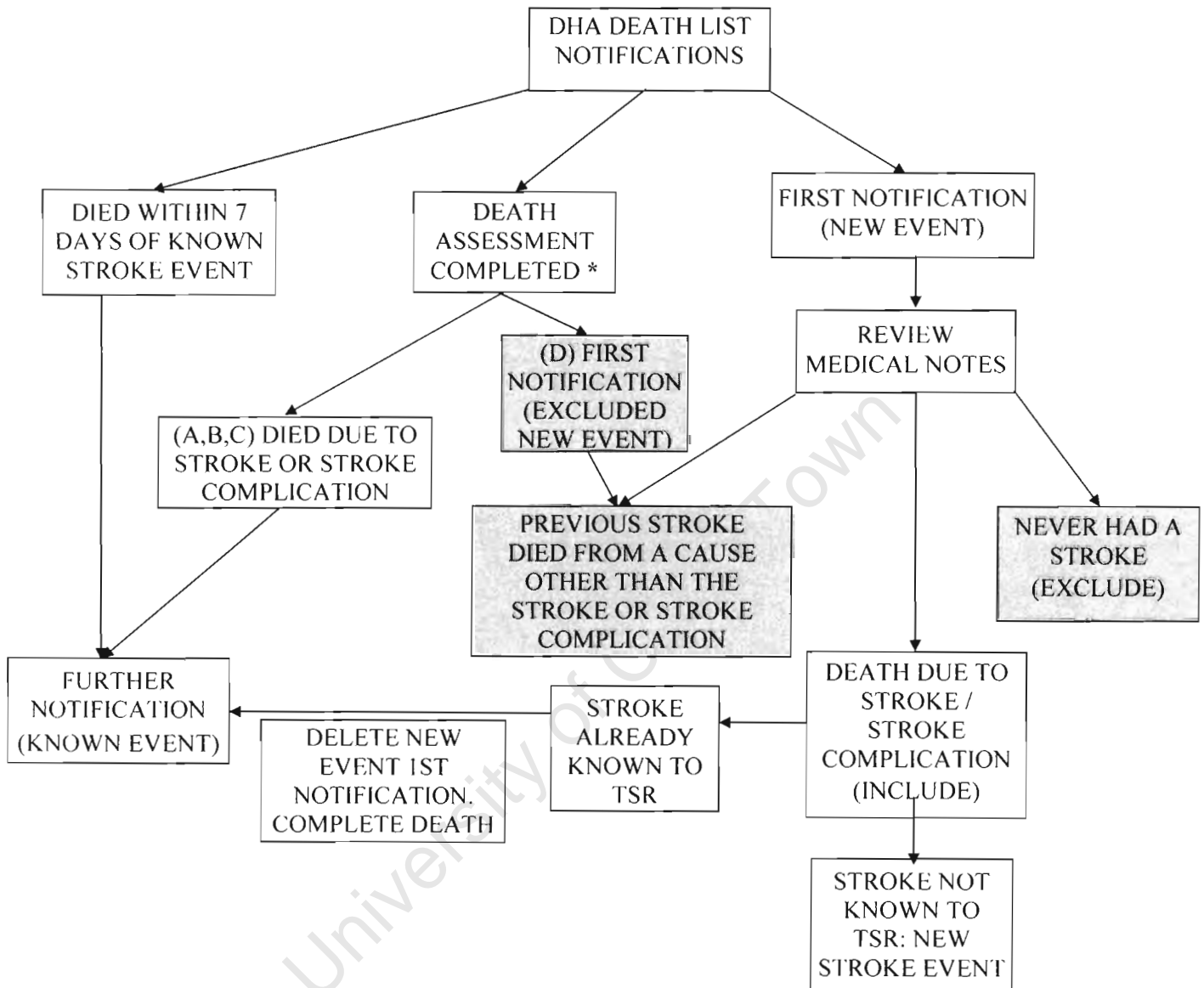
Information **not** entered onto computer on the excluded patients are:

- whether the patients are Part I or II stroke related death certifications
- the certifying doctor

All included patients will have retrospective assessments completed from the most reliable sources of record data only. It is expected that this information will not be as complete or as accurate as that obtained by contacting the family, but due to protocol, this is not allowed.

Proformas needing completion and information on how to complete them is obtainable from the relevant sections in The Manual.

9.6 Flowchart



* See Death Assessment:

- Death due to :
- A: First Ever Stroke
 - B: Recurrent Stroke
 - C: Stroke Complication
 - D: Cause not directly related to Stroke

10. CT (HEAD) PROTOCOL

10.1 Introduction:

This is one of the secondary sources of notification of potential new cases. At present, CT lists are only obtained from the two main District General Hospitals. For Darlington, it acts primarily as a secondary source whereas for North Tees it acts as both a primary and secondary source of notifications.

10.2 Format:

10.1.1. North Tees General Hospital:

CT head requests (in-patient and out-patient) and results are obtained on a weekly basis from the radiology department.

10.1.2. Darlington Memorial Hospital:

A monthly computer print out of all the patients names and hospital numbers are obtained. The requests and results are available on computer which are checked individually for each patient.

All patients already known for the event for which they are scanned, are recorded as a further notification. Those that are not previously known to the TSR for that event are further subdivided into two groups:

Initial (1st Stage) Exclusions (the reason for the requests for scans known, with or without the CT results known).

Primary (1st) CT notifications: These are all the remaining patients after the initial Exclusions are excluded. These are patients with scans (requests and results known) who require further information (usually from the medical records, but occasionally requiring consultations with the patients) before deciding whether the patients are included as a stroke or not.

This format will allow analysis of the yield of CT scans in detecting patients with new strokes and after excluding obvious non-stroke CT scan

requests/results. It will also give an indication of the accuracy in detecting patients with new strokes.

Notes: Patients already known for the event for which they are scanned and thus have a 2nd or further notification of those events, will not have the initial excluded stage identified. First Stage Exclusions are **not** included in the notification process. There is usually an interval (variable depending whether in-patient or out-patient) between the date of event and date of scanning. Clinical judgement may be needed to differentiate a new event from a late scan, although in most cases, a review of the records will clarify this. As a guide;

- all scans within 1 month of included stroke events will be regarded as referring to the initial event. (Recurrent strokes within the first month of the stroke onset should be picked up at the one month assessments if routine notification methods have failed to identify the recurrent stroke events.)
- all other included scans will need further clarification to differentiate a new event from a late scan.

10.3 1st Stage Exclusions (not needing CT result):

Requests: Age <18 years old
 Trauma (e.g.. Road Traffic Accidents (RTAs))
 Seizures (without persistent neurological deficit)
 Memory Loss/Confusion/Dementia
 Subdural/Extradural (with no localising neurological signs)
 Falls (without neurological deficit)

10.4 1st Stage Exclusions (with CT result):

Requests/Results: Tumours or Metastases on scan
 Headaches (with no subarachnoid bleed on scan)
 Falls (with Cerebral Contusions on scan)
 Subdural/Extradurals on scan

10.5 1st Notifications (requiring further information):

Stroke/CVA/Bleed (even if scan 'normal'. but exc. tumours/mets on scan)

Tumour/Mets (with a 'normal' scan or scan showing infarct/bleed)

Seizure with neurological deficit (even if 'normal', but exc. tumours/mets.)

10.6 2nd Stage Exclusions:

These are 1st notifications that, after reviewing the patients' notes and/or after direct contact with the patients, have been excluded.

10.7 Flowchart: Next Page.

10.8 CT Lists post recruitment period

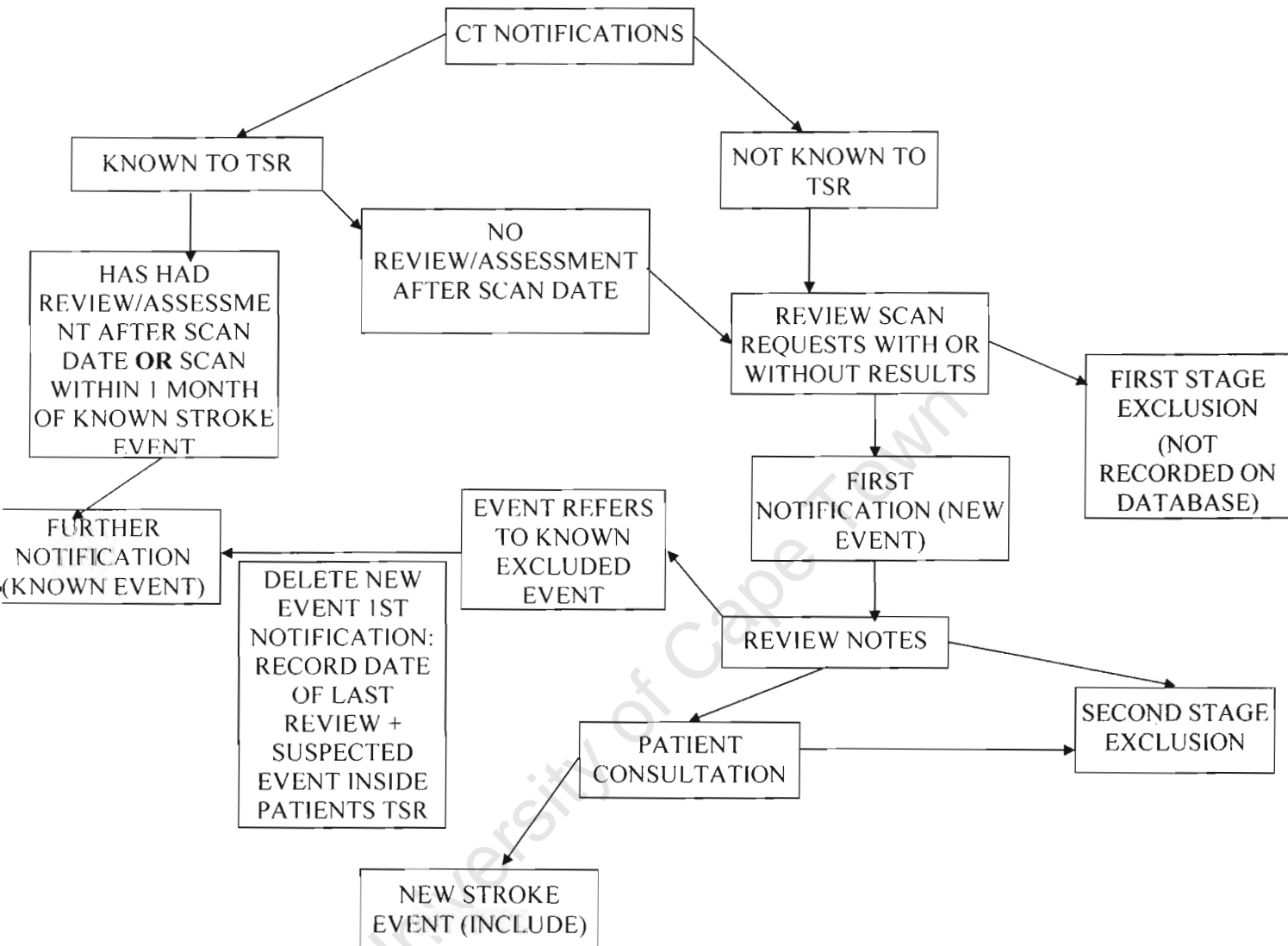
The CT lists will be reviewed in the way described above after the end of the new stroke recruitment period (30th June 1997):

for the first month (end July 1997) for in patient scans

for the first two months (end August 1997) for out patient scans

Thereafter, only patients already known to the TSR and who have a CT head scan by the 30th January 1998 will be reviewed.

10.7 Flowchart:



11. ONE MONTH ASSESSMENT PROTOCOL

11.1 Introduction

All included patients still alive, still consenting (i.e. have not withdrawn consent) and already having had their initial post-stroke assessment will be assessed at one month (time window: day 26-34 inclusive) after each included event.

Those patients for which consent is withheld for contacting them directly, checking with the patients GP and hospital records will give information with respect to mortality, subsequent medical problems, functional status and place of residence at the time of the one month assessment.

11.2 Processing

A list of all patients due an assessment the following week is printed off the computer on a weekly basis. This list shows the following information:

Name of patient and ID number of all included events.

Date of death of those known to have died.

Those refused or withdrawn consent.

Those with no initial assessment done as yet.

The files on each patient will provide the following information:

Last known location and contact telephone number.

Patients and/or carers are contacted directly, either on the hospital wards or via telephone for this assessment. Those not on the telephone (less than 5% expected) will have a monthly questionnaire posted to them.

Information for those who have changed administrative information, is updated on the database. Those who have died will have a cross placed in their one month box on the front of the file, will have the records (GP and /or Hospital) requested for the death assessment (See Death Assessment in The Manual) and any previous investigations which needs to be completed.

Those that have a suspected stroke event are notified on the TSR as a new event for that patient. Then either their records (GP and/or hospital) are reviewed prior to considering arranging a visit; or a visit by the research associate to see the patient is arranged (if there is a strong probability of a genuine recurrent stroke).

Backlog/missed cases require a retrospective interview done for those sections of the proformas for which it is appropriate.

11.3 Problems

Patients who have left the area and the forwarding address/ telephone number is not known.

Patients who have changed GPs or whose initial GP is not known.

GP practices who do not know either the current addresses or telephone numbers of the patients or relatives.

Patients and relatives/carers without telephones.

11.4 Solutions

Tees Health may provide the new GPs details if the patient has subsequently registered within the Tees District.

Darlington GPs patient registration may be available on their computerised HISS system.

11.5 Proformas Completed

The One Month Assessment proforma is completed.

The Pathways and Investigations and Operations proformas are updated.

The Therapy (Complications and Services) proformas are updated and completed.

Any gaps/queries in the History (First/Recurrent Assessment) proformas are clarified and completed.

11.6 Completion

After completing the one month assessment, *tick* the completed boxes on the front of the file. After this information is updated on the database, the file is filed away.

11.7 Queries

11.7.1 Further Stroke

Complete the initial one month assessment in the normal way. Complete all the proformas required for a further event including a repeat clinical examination.

Complete a further one month assessment for the recurrent event in the time window specified for the recurrent event.

11.7.2 Initial Assessment not completed

In some cases of late notifications, those already consented and definitely having had a stroke may have the one month assessment done by a research nurse even if the prior assessment is incomplete (e.g. awaiting examination by the study doctor etc.).

University of Cape Town

12. SIX MONTHS ASSESSMENT PROTOCOL

12.1 Introduction

All included patients still alive, still consenting (i.e. have not withdrawn consent for direct contact) and already having had their initial post-stroke assessment; will need at six months after each included event, the six months postal questionnaire sent out.

This is the final assessment after each included stroke. Those patients for which consent is withheld for contacting them directly, checking with the patients GP and hospital records will give information with respect to mortality, subsequent medical problems and place of residence at the time of the six month assessment.

12.2 Processing

A list of all patients due an assessment the following month is printed off the computer at a week before the end of each month. This list shows the following information:

Name of patient and ID number of all included events.

Those refused or withdrawn consent.

Those with no initial assessment done as yet.

Those patients known to be dead are not included in the list.

The posting date is shown as the 6 mo. due date - 17 days aiming for the patient to receive the questionnaire at the earliest 2 weeks before due.

Patients are grouped per week due and once or twice a week the patients respective GPs practice managers are contacted to confirm:

Whether the patient is alive or dead.

The present address of those alive.

Information is updated on the administration database. Those who have died will have a cross placed in their six months box on the front of the file and records (GP and /or Hospital) and the death assessment and any previous investigations will need to be completed. Those in Nursing/Residential homes will have the home contacted before posting out of the questionnaire.

SECTION G

For those in Residential or Nursing Homes, this section is omitted.

2. If a patient lives on a single level (i.e. 'Yes' to question 1), then this question is Not Applicable.

SECTION H

As in Section E, not all patients/carers will be able to complete this section. As we are not able to discern which sections/questions are completed by carers of patients who require help, during analysis, it may be more accurate to describe the Health Information as provided to the patient and/or carer.

SECTION I

For those who request further information/assistance, a Stroke Association leaflet describing information and services available is sent out to them.

G) 12/24/36 MONTH ASSESSMENT

Initially, it was envisaged that the survival of all patients would be checked at the above intervals after each of their incident strokes. Information would have been obtained from indirect sources: GP / District Death data / (Regional Death data). *If* the patient was alive then a *tick* is placed in the corresponding box on the **PATIENT CHECK LIST**. *If* the patient had died before the 12/24/36 month assessment, then a *cross* is filled in for that and all the subsequent follow-up assessments, and the Death Assessment would be completed.

Because of the administrative difficulties in tracing where surviving patients may have moved after their 6 month assessment, it was decided that notifications of the death of patients would be obtained from the central registry. For a fee, the central registry will flag patients and notify us when they die and provide us with the certified cause of death. During the study period, all patient who die will have his or her GP records and/or hospital records reviewed. (See **H) DEATH ASSESSMENT**). This will enable indefinite follow-up of mortality. It is expected that the delay in being notified of any one death will be less than 2 months after the death.

H) DEATH ASSESSMENT

The Death Assessment Sheet is completed in all cases of death due to stroke (or probable stroke) and in all previously included stroke patients who have subsequently died irrespective of the cause of death.

Those patients who have had a stroke (or recurrent stroke more than 7 days after the previous stroke, within the study period and study area at the time of the stroke), and have now died (irrespective of the duration between the onset of the latest stroke and the time of death), will need retrospective Assessments done for all stroke incidents which have not been previously recorded. A First or Recurrent Assessment should thus be completed if the Death is due to a previously unrecorded stroke incident.

Record all sources of data (*ticks*).

Date of Assessment is when the form is completed by the Assessor and is for administrative purposes only. (Unlike **d) Examination** above)

Date of Death and Time of Death:

This is when the patient died and not when the patient was certified. Certifying times may be delayed. The 24 hour clock is used.

Place of Death:

The text space is to provide further information such as name of hospital and ward etc. All assessments should have one of the six boxes *ticked*.

Certifying Doctor:

The death certificate is always completed by a doctor.

'Not Known' is *ticked* when it is unclear which one of the four boxes above it to use.

In retrospect, it is more important to record this information in all patients which have been certified as having died due to a stroke but have been excluded for failing to fulfil this study's criteria for inclusion. This is at present not been routinely recorded although it should be able to be done if there is shown to be a significant error in certifying practice in one district. Currently, only included strokes have death assessments completed where appropriate.

Cause of Death:

This is the actual certification on the death certificate (whether agreed with or not).

1 a-c are those linked factors directly leading to the patients death.

2. This is a redundant question, but aids in confirming the answers in Parts Two to Four of Section B.

3. This does not specify whether the deficit was due to the previous stroke or not.

PART TWO

4. This will allow comparison with pre-stroke, and one month Rankin (OHS) scores.

PART THREE

This is to allow comparisons with the one week and one month Barthel scores. Any queries are clarified in a compatible way to that in the first week post stroke: **Examination section f)**, page 21.

8. For those patients who answer both sections A and B, record the Wheelchair response.

PART FOUR (? Adena Linkan in Nottingham: Need contact no./address to confirm below)

This is the validated questionnaire form of the Nottingham Extended Activities of Daily Living Scale.^{NEED REF!}

Where the patient does not have a particular 'item': e.g. stairs/car/garden etc. record 'No'.

For those patients who have never done a specific chore : e.g. washing clothes/housework etc., record 'No'. Recording the answers in this will result in the 'worst case scenario' (i.e. Patients minimum function scores are recorded).

'With Help' means the assistance of a person and **not** an item or gadget such as a washing machine/magnifying glasses etc.

20 If a person has **no** difficulty (no physical or psychological support) going out, but never goes out without their partner/relative/friend, *tick* 'On my own', rather than 'With Help'.

SECTION C

1. 'If Yes,...'. It may be difficult for patients to remember when their blood pressure medication was changed and when they were last seen/contacted (for an assessment) by the study team. They may also not know which of their medication is for their blood pressure and thus whether it was changed or not. If the One Month Assessment was done late (retrospectively), and blood pressure medication was changed prior to the late assessment and after one month post stroke, this may result in false negative answers. This has implications in interpretation of the analyses.

2. The aim of this question and subquestions is to obtain a conservative number of patients eligible for aspirin and not been prescribed it. Obviously, the type of stroke (i.e. confirmed haemorrhage) and whether they were started on warfarin therapy (at the time of their stroke) prior to been recommended to take aspirin will be taken into account. It is assumed that most people will know whether they are taking aspirin (or equivalent e.g. enteric coated etc.). It is not specified when the doctor may have advised the patient to take aspirin (i.e. This may have occurred pre-stroke). Patients/carers taking both aspirin and warfarin (very few expected), may be concerned by the phrasing of the last part of the question, but usually, when such treatment is undertaken, it is explained to them that such treatment is unusual and is very specific for that individuals circumstances.

4,5,7. As most hospital medical records are reviewed at least six months post stroke, the answers to these questions may be checked.

SECTION D

1. Usually, the hospital records will need to be checked for the result of the tests/operations. Those specifying only ECGs, CXRs and/or blood tests will only need their hospital results checked if they do not have those post stroke investigations recorded on the Investigations and Operations proforma. Most other specified investigations/operations will not need to have the details recorded.

2,3. For patients living in Nursing and Residential Homes, the following are Not Applicable:

Home Care, Private Home Help, Meals on Wheels and Nurse contacts in the preceding month.

SECTION E

This is the validated questionnaire form of the Wakefield Depression Index.^{NEED REF!} Some questions may be able to be answered on behalf of the patients, by their cares. However, it is expected that most confused or dysphasic or patients with incomprehensible speech will not be able to complete the majority of the subjective mood questions. Thus, a category 'Not Answered' for each question has been added onto the computer.

8. It is expected that many patients (especially those in residential or nursing homes) may not go out on their own (or at all). Thus, for this question, a 'Not Applicable' category has been added onto the computer. Both a 'worst case scenario' or 'best case scenario' analysis is thus able to be undertaken, by either using 'Yes definitely' or 'No. not as all' for the default answers.

Note: For either scenario being applied to all the questions, the default will be different for each individual question.

In very late assessments (i.e. more than nine months of the patients stroke), this section is omitted in the retrospective assessments. This is because of the unreliability of filling in subjective mood questions retrospectively.

These are subjective questions. It is the patients (first source of information) or carers perception on the degree of remaining deficit due to the stroke. The reason for this is to enable a more accurate analysis of the degree of remaining deficit by 6 months (which is also completed on a subjective basis). It is likely that if a medical professional actively examines the patient, the completion of this table will result in more deficits being detected.

Include under numbness, any form of altered sensation due to the stroke (e.g. hyperaesthesia, parasthesia etc.). Vision is not included because of the difficulty in patients distinguishing the effects of the stroke from other causes of vision impairment. Our Pilot study and proforma review work has indicated that many patients answer in the affirmative even though they had no deficit detected on the initial examination. This may be due to an increased awareness by the patient of their previous visual impairment.

The **Barthel ADL Index** is completed as in the **Examination** section f), page 21.

Since the recent stroke, has the patient been NEWLY (post recent stroke) diagnosed as having:

	Yes	No	Not Known
Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hypertension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In retrospect, it would have been easier to ask whether the patient has diabetes/hypertension and whether this was newly diagnosed or not could have been extrapolated from the History/First assessment proforma by the computer.

Please update/complete THERAPY, OPERATIONS AND INVESTIGATIONS and PATHWAY proformas.

This may result in the need to review the patients' notes again.

b) Postal ONE MONTH ASSESSMENT

Information from the completed postal proforma will be transcribed onto a **Face-to-Face** proforma to enable data entry.

F) 6 MONTH ASSESSMENT

Refer to the SIX MONTHS ASSESSMENT PROTOCOL (Protocol 12) for when and how the various parts of this assessment is completed. The following section deals with the clarification in completing the SIX MONTHS ASSESSMENT questionnaire only. It also mentions important potential problems in analyses and the reasoning behind decisions taken.

In late assessments, complete the questionnaire retrospectively. Use all available sources of information in late cases. Correct (if there is any contradictory information) and complete any gaps in all cases.

SECTION A

1. 'Currently' refers to place of permanent residence. e.g. A person staying the weekend with a friend when the questionnaire was completed, but is currently staying permanently with his daughter (prior to the stroke, and is regarded as his own home), then tick '*Your own home*'.
2. It has been assumed that any further suspected strokes will be referred to the patients GP. Thus only GP confirmed strokes is recorded. Otherwise, if any suspected event was recorded, the false positive rate would be too high (and this would have implications on the TSR workload).
3. Not all short-lived TIAs will be reported to GPs. A potential overestimation of the number of TIAs may occur due to the patients/carers notion of what a TIA is.
- 4-7. Most will not know the dates of admission and discharge. These should be obtained from the medical records and the reason for admission confirmed.

SECTION B

PART ONE

1-3. are subjective questions. It will allow comparison with what patients were like at their one month assessment.

This question has been omitted after the yearly proforma review. It was to see whether Stroke would impact early on in a dramatic way on couples relationships (especially in the <55s).

TIA since notification event?

See page 9 a) and b) for further clarification. This must have occurred at least one week after the incident stroke. Both the Number and whether it has been recognised by a doctor as a TIA should have implications in the management of the patient.

Current cigarette smoker?	Yes	No	
If Ex-smoker or current smoker AND now stopped or cut down smoking.			
was this because of the recent stroke ?	Yes	No	Not applicable
			First Ans. Second Ans.
Options: Never smoked or Ex-smoker (stopped at least one month prior to stroke onset).	No	No	N/A
Ex-smoker (stopped smoking since stroke onset because of stroke).	No	No	Yes
Ex-smoker (stopping smoking since stroke onset unrelated to previous stroke).	No	No	No
Smoker (cut down smoking since stroke onset because of stroke).	Yes	Yes	Yes
Smoker (cutting down smoking since stroke onset unrelated to previous stroke).	Yes	No	No
No change in amount smoked since stroke onset.	Yes	No	N/A

Has appointment for OPD clinic? Yes No Date: ___/___/___

Consultant (incl. hospital): _____

This is any appointment arranged by the first month post stroke event. Inpatients at one month will be excluded in the analysis of this part as their appointments will only be arranged just prior to discharge.

Number of **GP** consultations in the first month post Stroke ? _____

Include visit at time of stroke event if done but exclude visits to practice nurse only. Include Deputy GP consultations also.

Those admitted to hospital may need to be analysed separately as the duration of hospital stay and discharge medication (e.g. warfarin) will affect the number of visits in the first month. Ideally, the number of visits in the first month post discharge would give a truer reflection on GP service utilisation, but in practical terms, this data would be very time consuming to collect.

Medication List : Only regularly taken medication is recorded.

Oxford handicap score: Complete as per **History / First Assessment** section r) page 11. (Now recorded at the end of the proforma after the Barthel ADL Index.)

Does the patient or carer feel that the patient has any residual deficit / difficulty with any of the following from the recent stroke 1 month ago? (SUBJECTIVE QUESTION)

	AREA	YES	NO	DK/NR
Weakness	Right arm			
	Left arm			
	Right leg			
	Left leg			
	Face			
Speech				
Swallowing				
Numbness (face/arms/legs)				
Memory				
Painful Shoulder	Right			
	Left			

Section 5: Medication

This section is unchanged from the initial assessment.

Section 6: Lifestyle History

The patients' lifetime history of smoking and drinking is already recorded in the initial assessment. This simplified section records only current levels of smoking and alcohol consumption.

Section 7: Social History

Most of the questions in this section of the initial assessment that have been omitted refer to socio-economic status, which is not expected to have changed in the majority of patients.

Section 8: Economic

In retrospect, this section could have been omitted from this assessment and instead been added to the Six Months Assessment. This would then have given an indication of how many previously active and employed patients (usually the under sixty-fives) have managed to get back to work.

Section 9: Benefits

This is unchanged from the initial assessment. As in *Section 8* above, it may have been more useful to include this section in the Six Months Assessment questionnaire rather than in this assessment.

E) 1 MONTH ASSESSMENT

Refer to the ONE MONTH ASSESSMENT PROTOCOL (Protocol 11) for when and how the various parts of this assessment is completed. The following section deals with the clarification in completing the ONE MONTH ASSESSMENT proforma only.

There are TWO proformas:

- a) A **face-to-face/ telephone** proforma that is completed by the research nurse/doctor.
- b) A **postal** one posted at day 25 after the incident stroke to every surviving patient which is unable to have the assessment completed by **a)** above.

It is expected that the majority of assessments will be via **a)** (direct contact with the patient or carer).

The information obtained is a subset of the First Incident (History/First Assessment and Examination) sections. This is to enable analysis of the changes effected as a result of the patients stroke.

a) Face-to-Face / Telephone ONE MONTH ASSESSMENT

As with the History/First Assessment, **Sources of data** and **Assessor** are completed (see page 8).

The **Location** is where *the patient* is at the time of the Assessment being carried out (e.g. Hospital, ward x / Nursing Home / Residential Home / HAV (Home Assessment Visit in patients home) / Outpatients etc.). It must be completed when information is obtained from a source other than from records. If information is obtained retrospectively from the records, then clearly state *records* in this space. In these cases, the location of the patient at the one month period post stroke event will be derived from the pathway and the first two sections on the ONE MONTH ASSESSMENT proforma.

The **Date of Assessment** is the date the assessment was carried out and NOT the date when it was due. This will enable analysis of reliability of data. Information relating to all the assessments whether carried out retrospectively (late) or not, refers to what the circumstances were around the one month period post stroke event.

Has the patient been (re)admitted to hospital since the recent stroke 1 month ago?

Options: NO: Never hospitalised.

Discharged from hospital after stroke onset and not readmitted by time of this assessment (d25-35).

YES: Admitted after First Assessment and after day 7 post stroke onset.

Readmitted after discharge.

Has the patient changed (permanent) address since the patients' recent stroke one month ago?

All patients discharged permanently to a residence other their permanent one prior to the stroke event answer *yes*. If the patient is only temporarily staying at the present location, and intends to go back to their previous permanent address, then the answer is *no*.

Specify reason for change in accommodation: Closer to family / Patient no longer able to cope in previous home /

Partner's illness: no longer able to cope in previous home / Financial / Other (Specify). Occasionally, it may be a combination of factors, but specify the most important one (usually: Patient's inability to cope).

New address and Telephone data are for administration purposes.

Completion for the rest of the part is as in *Section 7 : Social History* (see page 12).

Change in marital status

D) RECURRENT INCIDENT

The information obtained is almost identical to that for the FIRST INCIDENT. The only differences are in subsection c) History / First Assessment. For further information in completing the other subsections, refer to C) FIRST INCIDENT clarifications.

- a) Establishment of Diagnosis
- b) (i) Pathway through Care
 - (ii) Sources of Notifications
- c) Recurrent Stroke Assessment (see below)
- d) Examination
- e) Investigations and Operations
- f) Therapy
 - (i) Therapy and Complications
 - (ii) Therapy and Services

c) Recurrent Assessment

The reason for simplifying the proforma is to cut down duplication of recording and data entry of information.

Note: Omit *Sections 6 and onwards* if the patient has not been discharged from hospital since their previous included stroke.

Sources of data: (1:2/Tick)

Data is recorded in both the History and the Records sections until the 30th of June 1996. Tick the appropriate shaded box(es) to indicate where the source of data is obtained from for the Records section. For the History information, fill in either a '1' (if the data is reliable) or a '2' (if the data is thought to be unreliable) in the appropriate blank box(es). For the first year of data collection 01/07/95-30/06/96 information from both the records and patient/carer sources are recorded for a comparison of the quality of medical records in the two districts. In the second and final year 01/07/96-30/06/97, only the most reliable source for each question is used. Only *Tick* all the relevant boxes after 01/07/96.

Location:

This is where the Assessment is carried out (e.g. Hospital, ward x / Nursing Home / Residential Home / HAV (Home Assessment Visit in patients home) / Outpatients etc.). It must be completed when information is obtained from a source other than from records.

Assessor:

In the first year of the study, this may be more than one person as the recorder of the History and Records sources of data may be different. The initials of the person completing the form are noted.

Date of Assessment:

The date of when the Assessment is done (either History or Records completed) is recorded.

Section 1: Patients Personal Details

For the majority of patients, demographic details are expected to remain unchanged from the initial assessment. This section has thus been omitted. Although it is possible that marital status/partner may have changed, this is not been recorded.

Section 2: Acute Event

This section is unchanged.

Section 3: Past Medical History

- a) All patients have had a previous confirmed or probable stroke. The date of their last stroke and areas affected are recorded. In addition, the number of previous stroke(s) [for non-residents, not treated in either DMH or NTGH, at the time of their previous stroke(s)], are also recorded. It is expected that for the majority, this will be zero.

Occasionally, patients with previous strokes within our time period may have subsequently become resident and have a further stroke within the two year recruitment time period. Only their stroke whilst resident is followed up with further assessments.

- c) This is the summary of parts c) to p) in the initial assessment. New diagnoses and all previous valid diagnoses are recorded to enable entry in a text format onto the computer.

Section 4: Family History

The most important part is whether there is a positive family history of members by the age of sixty-five and for the vast majority of patients, this is expected to remain unchanged from the initial assessment. This section has thus been omitted.

after the first month. It is expected that services and therapy received after the first month will have a significant effect on placement but not on functional outcome or mortality (although a small effect may be expected).

Therapy:

Physiotherapy : *Tick* if unable to specify site or daily frequency.

Fill in number and site according to the explanation region.

Weekly summary refers to number of days of physiotherapy in preceding week (Not the total number of contacts). This is for comparative analysis purposes (between districts and between different therapies and services).

Occupational Therapy (OTs) : As for Speech Therapy and Dieticians, *tick* for each day therapy received / assessments done or home visits done. Further detail on the *first / main* home visit of all patients are recorded under **Home Visits** (see below).

Speech and language therapists (SALT) : They also do the swallowing assessments which are recorded in the same row. Site of therapy (as with OTs and Dieticians) is not recorded.

Dieticians : Their function in stroke patients is predominantly to advise on nutrition of parentally fed patients. They also provide advice on nutritional supplementation and on lifestyle dietary advice.

Social Worker : Record only when 'R'eferral done and when first 'S'een. The amount of work required by each referral is patient requirements dependant, but the recording of such is beyond the scope of this project. Analysis of the number of referrals and the time interval between referral and first contact between districts will be done. (When first referred is of less relevance.)

Home Visits:

Date of the first / main visit pre-discharge is recorded in all patients who have one irrespective whether this is after the first 28 days or not. This is a measure of patient service utilisation. This will obviously need to be done retrospectively via the Occupational Therapists (OTs) records for all patients alive and still in hospital who have not had a Home Visit by the 28 day assessment. It was initially envisaged that recording the number of times the OTs visited the patients residence would give a better indication of modifications needed prior to discharge (the presumption being that the more visits needed, the more aids / adaptations are needed) and thus on intensity of service utilisation. However, due to practicalities in obtaining such detailed information and the complexity of the analysis of such (the difficulty being the differentiation between a follow-up and a new home visit due to a change in patient requirements), has resulted in the omitting of the question 'How many home visits...first 4 weeks post stroke?'. It is assumed that a successful HV (patient discharged to a private residence) will have a higher service utilisation weighting to a failed HV (patient discharged to a residential or nursing home).

Services:

See the EXAMPLE above for completing the pre-incident column but fill in N/A (not applicable) if the patient was in long term hospital care / residential home care / nursing home care. While patients are hospitalised, fill in N/A. The weekly summary at the end of the discharge week will give a misleading indication of services received and this must be taken into account during the analysis.

All Day Hospital visits (even if only for physiotherapy which should be specified in the physiotherapy row) is recorded here. There is thus a potential for some duplication of data.

Include Stroke Clubs in the Day Centre row.

Fill in Bath attendant if carers other than the Home Care visit the patients at their residences for the purpose of assisting in bathing / showering only.

Health Visitors in the North Tees district only visit families of children aged 0-5 years old and it is thus expected that there will not be any such visits in this district.

'Medication'

The third cluster consists of ten rows of specific medication prescribed as oral/IV/SC/IM/PR (excluding topical) preparations. The relevant information is the onset (days post stroke, of taking the medications which is not necessarily the same as the day when first prescribed) and whether treatment continued into each of the four post stroke weeks. In all cases, record the days the medication is administered and take into account all prescribed PRN (as needed / requested). Clarification on the recording practice of some of the medication is given below.

The study does not differentiate in recording practice between IV (intravenous) and SC (subcutaneous) heparin. Topical, PV (per vaginum) and bladder installed (via catheter) antibiotics are not recorded, but PR (per rectum) antibiotics are recorded under 'Oral/PR antibiotics'.

Record 'Y' for antihypertensives if on any form of recognised antihypertensive medication irrespective if prescribed primarily for the treatment of some other medical condition (e.g. angina, prostatism, anxiety, migraine, heart failure, pedal oedema etc.). A past medical history of hypertension is recorded in **c) History / First Assessment: Section 3 c)**. Do *not* include nitrates, topical B-blockers (used in the treatment of glaucoma) or medication which may have hypotensive side-effects (e.g. antidepressants such as Lofepamine). Nimodipine is a calcium channel blocker and although its primary objective is to prevent arterial vasospasm after an intracranial bleed, it also acts as an antihypertensive.

Sometimes anticonvulsants are used as adjuvants to other forms of analgesia (e.g. carbamazepine or sodium valproate in neuralgia), but for the purposes of the study, record as 'Anticonvulsant'. Differentiating to this degree (as in the clarification of antidepressants below) in a small number of patients is not effective usage of study resources.

Pethidine / Morphine / Diamorphine and related preparations are used in stroke patients predominantly in terminal care management. Do *not* include mild opioid (e.g. codeine) containing analgesic medication such as *cocodamol*.

Occasionally antidepressants will be prescribed in anxiolytic / analgesic doses only (e.g. low dose amitryptaline for neuropathic pain), but for the study record as 'Antidepressant'.

The anxiolytics have been omitted after the yearly review. 'Anxiolytic other' refers to all others apart from that prescribed as a bed-time (nocte) dose.

(ii) Therapy and Services

This sheet records the pre-stroke and post-stroke service utilisation. There are two clusters separated by an explanation region (for filling in the Physiotherapy and Social Worker rows) and an area for recording Home Visits (HVs). The first cluster of five deals predominantly with therapists and the second cluster of eight deals predominantly with social services provided to privately (including sheltered housing) resident patients.

The pre-incident column refers to whether 'something' was received in the *four weeks* prior to the stroke or not. *Four weeks* will give a better indication than just the preceding week as some services are provided only on a monthly or fortnightly basis. Fill in either 'Y'es / 'N'o or total number of contacts (include in the total the number of daily contacts) as appropriate. Total numbers of contacts are recorded because this gives a better indication in pre and post stroke service utilisation. Thus, because this is for comparative analysis, in those cases where a patient has recently been discharged from a hospital or respite care; record the four week equivalent service contacts.

EXAMPLE: The patient admitted with a stroke on Sunday night, receives private home care (HC) 1/d over weekends and social service (SS) home care 3d/week (Tues. Thurs. and Friday). On Thursdays, the HC comes in twice to help with both the housework and shopping. The patient has been discharged from a respite care home back to a private residence on Wednesday three and a half weeks ago. Permanent SSHC only started on Tuesday 2 weeks prior to the stroke. Therefore the total number of actual HC contacts in the prior four weeks will be: $(2 \times 4) + ((3+1) \times 1) + (3) = 15$. but the four week equivalent number of contacts will be $(2 \times 4) + ((3+1) \times 4) = 24$. This latter number is more relevant for a comparison of service utilisation after the stroke event.

NOTE:

Do *not* include services provided for other people staying at the same residence unless the services (although initiated for a person other than the patient) are also being used by the patient (e.g. Dressing, bathing assistance etc.).

A limitation and thus bias of the study will be that 'late' discharged patients (those usually needing high therapy and SS support) only have their first months therapy and services recorded, whereas most of the services provided will only be in place after discharge (after the first month). The 'early' discharged group (the 'good' group usually requiring less input) will give an impression that therapy and service utilisation is low after discharge. This will have to be taken into account in analysis. Therapy and utilisation at six months will give a better reflection of the actual utilisation of services between these two groups. It is for this reason that HVs are recorded in all cases even if done

f) Therapy

This is recorded on two sheets. The first deals with medical related topics (medication, complications and interventions). The second relates to the various ancillary medical therapists and social services. It is clustered in related topics, each preceded by a pre-incident column. (baseline state) which allows for analysis of a change in 'Therapy' due to the stroke.

Day 0 is the day of the Stroke ('CVA'). The post stroke columns related to Events* (therapy / complications / services) in the first four weeks (28 days). These are summarised in the weekly columns (either a number or a 'Y'es / 'N'o indicating presence or absence) at the end of each group of seven days. Note: The summary of week one is in fact a summary of between seven and eight days depending on what time on D 0 the stroke occurred. The first four weeks post stroke is the crucial period with the highest rates of complications and mortality relative to the short time interval. Thus, interventions during this period will most likely play the biggest role in influencing outcome.

The source of information is a combination of all the available sources (patient / carer / records), the most complete and reliable one being recorded for each Event row. *Tick* all appropriate blocks (except physiotherapy and social worker rows - see below.)

* Not to be confused with Event Numbers (See **A) FRONT SHEET a)** which is completely different.

(i) Therapy and Complications

There are three clusters each with the pre-incident column referring to whether 'something' was present ('Y') in the *one week* prior to the stroke or not ('N').

'Duration'

The first cluster consists of nine rows (of which only eight are present on any form). The relevant information for each of the first eight is the onset (days post stroke) and duration (days per week for the first four weeks post stroke).

Ventilation: (best source of information is the anaesthetic/medical records):

Intravenous (IV) fluids: (best source of information for these five rows are the fluid charts)

Subcutaneous fluids:

Blood Transfusion: (omitted after the yearly review)

Nasogastric (NG) feeding:

Percutaneous Endoscopic Gastroscopy Tube (PEG) feeding: (added after yearly review, to be done retrospectively for the first year by reviewing endoscopy records in both hospitals. Onset is regarded as day of insertion.)

Catheter: (Best source of information is nursing records for in-patients for these two rows)

Penile Sheath:

Pressure sores grade: (Fill in grade prior to stroke if known and pressure sore present. Record all grades (0-5).

If more than one pressure sore of different grades are present, then record the maximum grade. Ideally, the grades (obtainable from nursing records for in-patients) at weekly intervals are needed. This will allow analysis of the presence of pressure sores and the change in severity if present.). This is able to be done retrospectively for North Tees in-patients as there is a pressure sore register.

'When Diagnosed'

The second cluster consists of seven rows (six after the yearly review). The relevant information for each is the date of the diagnosis (days post stroke) of the first and subsequent complication(s) (except for DVT where only the date of the first diagnosis is recorded). The weekly summaries refer not to the presence of a condition, but to whether a new diagnosis of that condition (relapse / recurrent event) was made in the preceding week. The presence of an ongoing infection will be extrapolated from the duration of antibiotic treatment. Duration is *not* recorded in this cluster. Diagnoses are based on clinical, investigation findings and the recording of a presumptive diagnosis with the intention to treat or not to treat. Only include events if the presumptive diagnosis is based on sufficient supportive evidence:

Chest infection: CXR, lung clinical findings, sputum results compatible with diagnosis. Requires at least one of the first three and the diagnosis/intention to treat.

Septicaemia: A combination of B/C results; clinical findings (ill, pyrexial, tachycardia, hypotension etc.), DIC results compatible with the diagnosis is needed.

Urinary infection: Clinical findings, MSU ; Urine Dipstix (nitrates / leukocytes / protein positive) and treatment intentions. Note: catheterised patients may be on prophylactic antibiotics. Still record as possible / presumed infection as the catheterised patients will be analysed as a subset.

Unspecified infection: (Omitted after yearly review as this can be inferred from antibiotic treatment if treated, and neither of the above infections are diagnosed). Used to record conditions such as cellulitis, oral candida (thrush) etc.

Deep Vein thrombosis (DVT): Venogram and/or Doppler ultrasound, clinical findings and treatment intentions.

Myocardial infarction: Refer to **c) History / First Assessment: Section 3 e)**, for criteria. (usually 2 of the following 3 needed: Clinical symptoms, ECG changes and cardiac enzymes compatible with an MI.)

Pulmonary embolus: Clinical findings, V/Q scan, ECG, Blood Gases, ECHO results.

Magnetic Resonance Angiography (MRA)

Record as for Angiography and MRI above.

CEPTIA/ TPHA / FTA (Abs) / VDRL

The majority of patients will not have tests looking for treponema pallidum (syphilis) infection. Each laboratory may use different tests. The four above are abbreviations of the more commonly used ones. In suspected cases, more than one test may be performed as some tests are non-specific (positive = present or previous infection). Clarify in the free text provided.

Specific Haematology and Immunology

Both tests which look specifically for a pro-thrombotic tendency and tests for conditions associated with an increased incidence of strokes are recorded. Results may be either positive/negative or a numerical value (with normal reference ranges).

Electro-Encephalogram

Specify whether test results are normal, non-specific, or suggestive of an underlying disorder/epilepsy.

24 Hour Electrocardiogram

Record in the same way as for ECGs.

Carotid Endarterectomy Operation

The date and side(s) operated on is recorded.

Cerebral Aneurysm 'Clip' Operation

The date and significant details of the operation are recorded (i.e. side, presence of further aneurysms, clip or packing, other complications etc.)

Other Relevant Investigations / Operations / Procedures

Record any other significant findings not coded for above, occurring by the first six months post stroke. The following are more common examples.

Relevant Investigations:

All further CT/MRI/ECHO scans.

Operations:

Ventriculo-peritoneal shunt insertion/modification.

Decompression of an intracranial haematoma.

Procedures:

Aneurysm embolisation.

Radiotherapy for an AVM.

Premature atrial contractions

Atrioventricular blocks: 1st, 2nd or 3rd degree

Other (Rhythm): Specify degree of AV block and any other rhythm abnormalities (e.g. prolonged QT interval)

Morphology: Tick all appropriate.

Borderline LVH (>3.5mV) include under LVH.

Bundle branch block (complete): include under Morphology (other) specifying RBBB or LBBB.

Prolonged QTc (>0.45ms): include under Morphology (other) and specify.

Axis deviation is not recorded.

Record the presence of q-waves even if only in one lead.

The presence of t-wave inversion in aVr and V1 is not pathological.

Note: BBB may be the cause of the ST depression, LVH and/or t-wave abnormalities.

Echocardiogram (Echo):

The latest pre-stroke and the earliest post-stroke results are recorded. The text reports are recorded.

Unless stated as transoesophageal, it is almost certainly a transthoracic echo.

Hypokinetic movement of the left ventricle/IV septum is recorded as LV dysfunction.

The presence of aortic stenosis is recorded if the gradient across the valve is greater than 10 mm Hg or the valve area is less than 0.8 cm².

The presence of mitral stenosis is recorded if the valve area is less than 2 cm².

Include under 'other', all other significant pathology (e.g. regurgitation).

Carotid Doppler Ultrasound

The latest pre-stroke and the earliest post-stroke results are recorded. The text reports are recorded.

Choose the most appropriate category for the degree of stenosis. (e.g. 15-45% record less than 30%)

? Categories used are the same as in the major Endarterectomy Trials ^{NEED REFERENCE}.

Record atheromatous plaques under other.

Computerised Tomography Head Scan (CT head scan)

The latest pre-stroke and the earliest post-stroke results are recorded. The radiologist text reports are recorded.

Unless stated as enhanced/contrast, it will normally be non-contrast/unenhanced.

More than one of the seven categories may be *ticked*.

Only for 'Infarct', specify further.

Unless stated as recent/evolving etc. (i.e. 'New') and/or chronic/mature etc. (i.e. 'Old'), leave blank.

Infarctions with haemorrhage are assumed to be haemorrhagic transformations.

If the new infarct is compatible with the new history/clinical neurological deficit, then *tick* 'Area consistent...'.
 Do not include the following under 'Infarct' (include under 'Other' and specify):

Deep White Matter ischaemia.

Periventricular ischaemic changes.

Ischaemic atrophy.

And all similar terminology.

Tick 'Structural Vascular Abnormalities' if any of the following are present:

Arterio-venous malformation(s).

Aneurysm(s)

Under 'Other' specify the following:

Previous operations/aneurysm clips/shunts.

Non-specific ischaemic changes.

Hydrocephalus.

Any other significant findings.

A degree of atrophy may be compatible with a normal scan and need not be specified.

Magnetic Resonance Imaging Head Scan (MRI head scan)

Summarise the radiologist report. Information sought is as for CT head scan results.

Carotid/Cerebral Angiography

In almost all cases, both cerebral and carotid arteries are investigated.

If the side of the aneurysm is not specified in the report, check the medical notes/discharge letter etc. to clarify.

Specify the site(s) of the aneurysm(s) in the free text.

Specify under 'Other' any other significant findings (e.g. cerebral artery thrombosis, basilar aneurysms etc.)

In retrospect, the side of the aneurysm should have been specified in the free text and just the presence of an aneurysm recorded by a *tick*.

e) Investigations and Operations

Complete the Event No. and Patient Identifier No. at the top right corner of the first page.

Investigations and operations are divided into those relevant ones done pre-stroke and those post-stroke.

In all cases, if there is no relevant result then draw a diagonal line through the relevant investigation box to indicate that this part of the form has been completed.

All results should have a *date* of when the investigation was performed, recorded.

INVESTIGATIONS

Blood count

The latest in the last six months or the latest (in cases of haematological disorders) pre-stroke are recorded. Latest Erythrocyte Sedimentation Rate (ESR) is always recorded if done. The first result within the first six months post-stroke is recorded.

High haematocrit levels are associated with stroke^{NEED REF.}. Low platelets are associated with bleeding disorders and low haemoglobins may predispose to watershed territory infarction in compromised circulatory states. An elevated White Cell Count (WCC) within the first week post stroke may be associated independently with poorer prognosis.^{NEED REF.}

Initially, plasma viscosity was also recorded, but since this is not routinely available nor requested, it has thus been omitted after the yearly proforma review.

Coagulation Screen

The latest pre-stroke and the earliest post-stroke results in the last six months are recorded. Most people will not have these tests performed. It is important to record whether the patient was taking anticoagulants at the time of the test or not.

Biochemistry

Urea, creatinine and tryglyceride results have been omitted in patients having their stroke after 30 June 1996.

Unless specifically stated as fasting levels, the glucose and cholesterol results are recorded as random levels. The latest pre-stroke and post-stroke results are recorded except for the urea and creatinine (within six months of event).

Chest X-ray.

This has been omitted in patients having their stroke after 30 June 1996.

Most results will be obtained from the radiologist reports.

Cardiomegaly: Unless it is mentioned that the heart size is normal or enlarged (increased C/T ratio, cardiomegaly etc.), leave this 'blank'. It may be appropriate in analysing to assume that in those cases where the heart size is not commented on, it is normal.

Record all degrees of cardiac failure as 'Yes'. e.g. Pulmonary oedema or congestion / Cardiac failure / Bilateral pleural effusions: (Do not include upper lobe blood diversion as a sign of heart failure.)

Infection: Focal consolidation or signs compatible with or suggestive of pneumonia/infection are recorded as 'Yes'

Other: Masses, fractures, etc.

e.g. :For reports stating "clear lung fields": record : 'blank', No, No.

Electrocardiogram (ECG):

Although the recording area has been simplified, still record all the details as per proforma Assesver7-8.xls for consistency purposes with regards to data entry. Record the latest pre-stroke and earliest post-stroke ECGs. Most are expected to be recorded by the TSR research doctor (for consistency and accuracy).

There are two parts: Rhythm (which should always have at least one *tick*) and Morphology (which in normal ECGs are left blank)

Rhythm: Only **one** of the following should always be ticked:

Sinus Rhythm (normal rate)

Sinus Bradycardia (rate <56 beats/min)

Sinus Tachycardia/Supraventricular Tachycardia (rate >100 beats/min)

Atrial Fibrillation

Pacemaker Rhythm

Other (Rhythm): Specify: Sinus arrhythmia (Brady-Tachy), Atrial Flutter etc.

In addition, one or more of the following may be ticked:

Premature ventricular contractions

Intermediate scoring is when at least 50% of the total function/effort is provided by the patient.

Specific explanations, some of which are deviations from Collins modification is listed below.:

- 1+2. Continence (of bowel and bladder) is performance over the preceding 48 hours.
Enemas are not regarded as incontinent unless the enema results in incontinence.
Faecal soiling is not regarded as incontinent.
Catheterised patients who can completely manage their own catheter care are independent.
3. Personal hygiene included brushing teeth, fitting dentures.
4. Help means that the patient can wipe self and aid in undressing.
5. Normal (not specially prepared/soft food) food eaten without help (e.g. cutting up the food/feeding), within reach of the patient is categorised as independent.
Patients that are fed via PEGs (unless the patient can completely manage the PEG feeding independently), those nil by mouth on IV fluids or those that have to be fed and are unable to drink on their own are Dependent.
6. This is the ability to transfer from bed to chair and back.
Major help means the assistance of one strong and skilled person or two (or more) normal people with or without the assistance of a hoist. The patient must be able to sit in a chair.
Minor help means the supervision or simple assistance of one person.
7. This is the indoor mobility about the residence or ward
People in wheelchairs must be able to negotiate doors and minor obstacles (e.g. corners) without assistance.
Help means the aid or supervision of **one** untrained person.
Patients who are able to walk with the assistance of two or who can take a few steps with the assistance of one are categorised as immobile.
- 8 Help means the need for assistance with buttons, zips, laces , socks, straps or clips, but the patient can put on some garments independently.
- 9 Patient must be able to carry the walking aid to be independent. The need for a stair lift categories the patient as dependent. Supervision or moral encouragement means that the patient needs help. Those that have not attempted any stairs (no stairs at home, never been out where there were stairs) are categorised as dependent, unless they actually climb a full flight off stairs at the time of this recording/examination.
- 10 The patient must be able to get in and out of the bath OR shower and wash oneself without supervision or aid, to be categorised as independent.
Patients unable to get into either a bath or a shower are dependent.

References:

1. Hodkinson, HM : Evaluation of a mental test score for assessment of mental impairment in the elderly.: Age and Ageing (1972) 1, 233.
2. Mahoney FI and Barthel DW (1965) :Functional evaluation: The Barthel Index. : Maryland State Medical Journal, 14, 61-65.
3. Teasdale G and Jennett B.: Assessment of coma and impaired consciousness.: Lancet (1974); 2, 81-84.
4. Collin C, Wade DT, Davies S, Horne V (1988).: The Barthel ADL Index: a reliability study.: International Disability Studies, 10, 61-63.
5. D H Barer : The Influence of Visual and Tactile Inattention on Predictions for Recovery from Acute Stroke: Quart. J. Med. 1990, New Series 74 Jan., No. 273, 21-32.
6. S P Stone *et al* : The assessment of visuo-spatial neglect after acute stroke: J. Neurol. Neurosurg, and Psych (1991); 54, 345-350.

Only record medical record findings if the patient has had no TSR medical assessment (deceased or having moved out of the area). Specify the date of the latest medical record findings used. It is expected that more than one medical entry date may be used as not all findings sought for may be recorded in any one assessment.

a) Body build:

This is a subjective assessment of the patient by the examiner. If known (or recorded in the notes), record the patient's weight and height. This information may be obtained from the patient and / or collateral history. Although these may not be precise for all patients, they will still give a trend of the overall Body Mass Index of stroke patients which may then be compared with the age and sex matched community figures.

b) Pulse:

i) This is the clinical assessment of the rhythm of any major pulse (usually radial).

Skipped beats or ectopics are classed as 'irregular'.

'Irregular, irregular' beats are classical of atrial fibrillation and sinus arrhythmia.

ii) This is a clinical assessment of looking for an inequality between the radial pulses which may occur in patients with extensive atherosclerotic disease.

If there is a clinical delay or a difference on pulse pressures, record the blood pressure in both arms.

c) BP (non stroke arm) phase V:

i) This is ideally the blood pressure at the day 7 (d5-9) examination, but record the blood pressure at all examinations as community cases may have no other post stroke blood pressure recordings.

The blood pressure is taken by the research doctor on one of two sphygmomanometers, ideally on the non-stroke arm, with the patient sitting in a chair (else sitting in bed, although for the unconscious, the patients will be lying in bed). The absence of audible transmitted pulse sound (Korotkov V) is taken as the diastolic pressure.

ii) The patient's blood pressure 24 hours after stroke onset is recorded. This to aid standardisation, is in preference to the first recorded blood pressure. Patients who delay seeking medical assistance longer than one day will not have a 24 hour blood pressure recorded.

d) Bruits:

Carotid bruits are known to be unreliable in detecting severe stenosis, but they should be detectable in moderate stenosis. The radiation of aortic murmurs (stenosis in particular) may be difficult to differentiate from co-existing carotid stenosis murmurs. Record the presence of any audible murmurs over each of the carotids as 'Yes' present else record 'No' not audible (Breath sounds may mask the bruit.) .

e) Cardiac murmurs:

This may also be difficult to record or analyse due to the following problems:

Isolated right sided murmurs are not commonly associated with strokes, thus only the presence of left sided cardiac murmurs is recorded.

Flow murmurs (ejection systolic murmurs at the left sternal edge or over the aortic area), common in the ill, anxious and tachycardic; may be difficult to differentiate from other significant murmurs.

Breath sounds, obesity, effusions may mask the heart sounds.

Third/fourth heart sounds in patients with a tachycardia may make the differentiation of diastolic from systolic murmurs difficult.

Record the presence of any consistent audible murmurs over the aortic and mitral areas. In patients with atrial fibrillation, intermittent flow murmurs (due to variable ventricular volumes) are not recorded as a consistent murmur as it is not present with all ventricular contractions.

f) Barthel ADL Index²

If the patient dies before day 5 then the Barthel Score at day 7* is not applicable and is left blank. Tick 'Not Known/Not Applicable'. Differentiation between the two will be done by taking d5 mortality into account.

The original Index consisted of 10 items with different scoring weights, each categorised into dependent, performs task with help or independent. Total score ranged from 0-100. Since household tasks are not assessed, patients scoring 100 may not be independent. Collin *et al* modified the scoring system and rating instructions in 1988, resulting in the 0-20 scoring scale which the TSR has decided to use. Scores for each item varies from 0-3 (1 or 2 in certain items)⁴

In general:

This is what the patient is presently doing, not what the patient may be capable of doing.

Any help (including verbal) or supervision means the patient is not independent.

Direct testing is not needed. (Use best available source of information- nurses, carers, patient etc. including direct observations and common sense)

Usually the performance over the preceding 24-48 hours is recorded.

Unconscious patients score 0 throughout.

The use of aids (walking sticks, but NOT stair lifts, etc.) to be independent is allowed.

10. Gaze paresis (CN III, IV and VI)

The full range of eye movements in each eye (Cranial nerves III, IV and VI) are tested. A new onset dysconjugate gaze noted in those where further assessment is not possible will be taken as having a gaze paresis. Strabismus (e.g. Congenital squints) are not on its own a gaze paresis. In unconscious patients, testing for 'Doll's Eye' movements may show a gaze paresis.

11. Posterior circulation

A cluster of signs suggestive of brainstem / cerebellar involvement is needed before the 'Yes' box is ticked. Not all tests can be performed in all patients (especially in the confused, dysphasic, semi-conscious, and those with Parkinson disease, debilitating arthritis or resting tremors). The most common causes of abnormal pupils are glaucoma and previous eye surgery. Only tick the 'UTA' box if no tests can be conducted, but the 'No' box if those tests performed are not suggestive of posterior circulation involvement. In the unconscious; dysconjugate gaze, abnormal pupillary response (e.g. pin-point pupils are suggestive of pontine involvement) and Cheyne-Stokes breathing are suggestive of brainstem involvement. However, the cause of brainstem ischaemia (which is a terminal event in many deaths) may not be directly due to a vascular stroke (e.g. hypotension, anoxia, hypoglycaemia, drugs etc.).

The results of tests for inco-ordination on the side of limb weakness may be difficult to interpret as limb weakness results in ataxia. Inco-ordination out of keeping with the degree of weakness may be a sign of posterior circulation involvement. Nystagmus may be a sign of labyrinthine involvement which may be due to viral infections. Co-ordination impairment may be subtle and is easily missed. A useful way is to compare the two sides. There is usually very little (if any) difference in co-ordination between the dominant and non-dominant sides on the routine tests used.

12. Facial weakness (CN VII)

A common mistake in mild facial weakness is to get the side of weakness wrong. The side of decreased skin creases, drooping corner of mouth and dribbling is the weaker side. The opposite side of the face is usually 'pulled up'. A symptom a patient may complain of is that the food seems to accumulate in the weaker cheek. Bilateral weakness may be missed unless tested actively for. Ask the patient to smile, show their teeth, 'blow-up' their cheeks and squeeze their eyes tightly closed.

Lower motor neurone CN VII weakness may be a sign of brainstem involvement (but exclude nerve trauma and Bells palsy). Upper motor neurone involvement is the expected finding in those with facial weakness.

13. Sensation

Not all modalities of sensation are tested. Only fine touch (cotton-wool), proprioception and sensory inattention are tested for alteration. In the confused or dysphasic, this may not be possible to be accurately assessed. The form of testing is based on the method documented by D.H.Barer in the *Quarterly Journal of Medicine* in 1990⁵.

i) Touch sensation

All four limbs and both halves of the face are tested. It is useful to write in whether sensation is absent, diminished or altered and whether the whole limb / half of face or only part is involved. CN V has three branches supplying sensation to each half of the face and all three should be tested.

ii) Position (Joint Position Sense-JPS or Proprioception)

Index finger and great toe position sense on both sides are tested (with the patient keeping their eyes closed). Medical records do not always specify whether the upper limb or lower limb has been tested. Assume, if JPS has been tested, and is normal, it refers to all possible limbs tested; or if abnormal, to both the finger and toe on the affected side; unless specified otherwise.

iii) Sensory Inattention

As with visual inattention, recovery by this means of testing is shown to occur rapidly. Extrapolation from D H Barer's work has shown the presence of tactile impairment decrease from 53% at day 1 to 25% at month 1⁵. If sensation is absent on any one side, then inattention cannot be tested.

Sensory inattention is not routinely tested for in general medical examinations. Unless specifically stated that there is no sensory inattention or that it is present, *tick* 'Not Recorded'. Assume positive or negative medical record findings refer to both upper limb and lower limb testing.

14 General Examination

Leg Score (total of test 4+5+6)/3

Total Motricity Score (total arm+leg)/2

The patient should ideally be sitting in a chair or on the edge of the bed, but can be tested lying down if necessary.

ARM

1. Pinch grip

Ask patient to grip a 2.5 - cm object (cube) between thumb and forefinger. Object should be on a flat surface (for example, a book). Monitor any forearm or small hand muscle.

2. Elbow Flexion

Ask patient to flex elbow to 90 degrees from a horizontal forearm position with the upper arm vertical. Examiner resists with hand on wrist and monitor biceps.

3. Shoulder abduction

Ask patient to abduct the arm with the elbow fully flexed and against the chest. Monitor contraction of deltoid; movement of shoulder girdle does not count - there must be movement of humerus in relation to scapula. Note: Supraspinatus initiates abduction of the arm.

LEG

4. Ankle dorsiflexion

Ask patient to relax the foot in a plantar flexed position and to dorsiflex foot. Monitor tibialis anterior

5. Knee extension

Ask patient to position the knee at 90 degrees with the foot unsupported, and then to extend/straighten the knee to touch the examiner's hand held level with the knee. Monitor contraction of quadriceps.

6. Hip flexion

Ask patient to sit with the hip bent at 90 degrees and to lift the knee towards the chin. Check for associated trunk movement of leaning back, by placing hand behind back and asking patient not to lean back. Monitor contraction of ilio-psoas (hip flexors).

8. Sitting Balance

Note: The phrasing of the question has changed from the pilot study proformas.

This question gives a crude measure of day 7 stability (see **14 f) Barthel ADL Index**, for other functional ratings.) and indirectly an indication of the severity of the stroke (obviously the premorbid state must be taken into account). Extrapolate the Medical / Nursing / Physio records to answer this question. Those unable to sit (with or without support, include unconscious patients in this category), or those sitting with the support of cushions or other aids (without which the patient topples to a side) record 'Yes'. Cushions / pillows are used to support a hemiplegic arm, thus unless they are also being used for the sitting balance, record 'No'. Those who do not need support should be able to sit on a chair or on the side of the bed (without the gripping onto anything for security) without falling.

9. Vision (CN II)

Direct confrontational testing of each quadrant of each eye is done. Testing for visual inattention requires the simultaneous testing of both horizontal visual field halves of one eye or different halves of each eye, where all the fields used have at least finger perception acuity. This is based on the method documented by D.H.Barer in the *Quarterly Journal of Medicine* in 1990⁵.

i) Visual fields (VF):

For those patients who have difficulty comprehending (receptive dysphasia / confused / demented), the blink or threat reflex may elicit the presence of a hemianopia. Thus in those cases where there is evidence that a hemianopia is not present but a quadrantanopia cannot be excluded, *tick* 'Unable to Assess', but write in 'no hemianopia but unsure about quadrants' and *tick* the appropriate boxes on the Diagnosis Sheet. Those with no finger perception on the tested side (e.g. cataracts, retinopathy, retinal detachment, trauma etc.) will have 'Unable to Assess' *ticked* in the corresponding boxes.

Although the absence of a blink reflex indicates a hemianopia, its presence does not absolutely exclude a hemianopia. Patients may be able to perceive rapid motion (which requires intact pathways of a reflex probably requiring functioningnuclei ?) but not be able to see items (e.g. count fingers, which requires intact pathways to and a functioning visual cortex) in the tested visual field. NEED REFERENCES.

VF defects are not routinely tested for (quadrantanopias rarely tested) in an initial medical clerk, but remember to record the following consultant ward round findings if within the 24 hour time period.

ii) Visual inattention:

This may also be assessed in patients with quadrantanopias by testing the functional visual fields. As with VF testing, not all patients can be assessed for visual inattention. Late testing may result in negative findings as extrapolation of work by D H Barer showed that by 1 month visual inattention dropped to 28% (from 63% at 1 day) in his patient group⁵, tested by this method. There are numerous other methods to augment the diagnosis if uncertain.⁶

Note: The 10 ml water swallow test is NOT carried out on patients with evidence of any of these causes of difficulty swallowing. *Tick* UTA for the second part of this assessment.

Fluids or Oral sips only (Note: This might be due to bowel obstruction, not dysphagia, and this restriction is common on surgical wards.)

Patient admitting to coughing / choking / spluttering (not dribbling) on eating or drinking.

Note: These patients (and all patients who deny any of the above symptoms) are tested with the 10 ml water swallow. This comprises of checking to see whether the patient is able to swallow 10 ml of water in one go. Any coughing / repeated clearing of the throat after the swallow is evidence of increased risk of aspiration.

Medical record findings of impaired gag reflex (CN IX and X), is suggestive of difficulty swallowing. Although the presence of a gag reflex does not necessarily imply swallowing is safe, this is assumed for recording purposes unless there is other evidence (medical or nursing notes) to the contrary (e.g. referral for swallowing assessment, NBM etc.).

7. Motor Power

i) Hand dominance

About 60% of left handed people have right brain dominance (i.e. speech centres). The other 40% and the majority (97-99%) of right handed people have left brain dominance.

"Physical" dominance. (Brain dominance can only be determined by correlating brain imaging results and physical deficit or specialised functional scanning techniques.) is determined by which side of the body is preferentially used in activities such as:

Unscrewing the lid of a jar

Kicking a ball

Writing

Leg forward first up stairs

Holding a hammer / saw / drill / gun / racquet etc.

Note: Many elderly people may have been compelled to use their right hand for writing during their formative years. If patients write with one side but use the other side for other activities, record as ambidextrous. Aiming at a target is a test of eye dominance and is only compatible if there is no visual disturbance. Patients forced to use their physical non-dominant side due to an injury or previous stroke are not recorded as ambidextrous. Record their previous dominant side prior to their disability.

ii) Power

Any movement to almost full (normal) power is recorded as 'Weakness present'. Only patients who score 1/6 on the GCS Motor response will have 'No movement' in all four limbs tested *ticked*. For those who have limbs (or part of limbs) missing, *tick* UTA (or fill in UTA **iii**) below) in the appropriate places. In unco-operative patients, it may be difficult to distinguish (esp. in the legs) 'Normal power' from slight weakness. Power will usually be recorded as 'Weakness present' rather than UTA and make a note on the side that this may be an underestimate.

Note: 'Normal' power for elderly frail people is not equal to maximum power in the assessor. This is a clinical judgement. However, patients who have weakness due to causes other than the assessed incident (previous stroke / arthritis etc.) are recorded as having that weakness but take this into account when filling in the subtype table on the Establishment of Diagnosis sheet.

iii) Motricity Index

This Index was statistically formulated by Demeurisse *et al* in 1980 to correlate the examination of a limited number of movements in patients with vascular hemiplegia with initial severity. From the weighted, summed and averaged scores (the index), comparisons between different patients and the establishment of correlations with clinical data may be performed. Six different muscle groups are assessed on the affected side and each power function is given a different weighting.

Arm 1. Pinch grip (2.5cm cube between thumb and index finger)

Leg 4. Ankle dorsiflexion

2. Elbow flexion

5. Knee extension

3. Shoulder abduction

6. Hip flexion

Scoring :

Test 1	Score	Criterion	Tests 2-6	Score	Criterion
	00	no movement.		00	no movement.
	33	beginnings of prehension.		28	palpable contraction, but no movement.
	56	grips cube. without gravity.		42	movement without gravity.
	65	holds cube against gravity, full range of movement.		56	movement against gravity, full range of movement.
	77	grips against pull, but weaker than other side.		74	movement against resistance, but weaker than other side
	100	normal.		100	normal.

Obviously the score of 74 and 77 refer to a 'Normal power' 'other side'. Thus, patients who have a disability on the non-tested side may score 74 or 77 on the tested side even though the tested side power may be stronger than the non-tested side. Clinical judgement and experience is needed. A flicker of movement (e.g. fingers / toes) should be recorded as 33 and 28 respectively. There are no in-between numbers. Score the highest power response in all cases but be aware that this may be an underestimate in unco-operative patients.

Totals (The range in all cases is 0-100)

Arm Score (total of test 1+2+3)/3

3. Visuospatial disorder /inattention

For those patients who have incapacitating arthritis of their hands, weakness of their dominant hand, poor vision, receptive dysphasia or marked confusion, this assessment may not be possible. *Tick* UTA for 1) or 2) or both. Occasionally, the patient may use their non-dominant hand for the drawings, in which case be aware that the assessment is of visuospatial orientation and not whether there is a tremor or absolute accuracy. Either *tick* or *cross* the appropriate *boxes* on the right side of the page for correct or incorrect drawings respectively.

1) Ask the patient to fill in all the numbers on the clock face. If necessary, ask the patient to draw a bigger clock face. Correctly drawn clocks will have all the numbers placed in their correct positions within the clock face circle. Should numbers be absent / duplicated / filled in incorrectly (wrong order / position / number), then place a *cross* in the box.

Note: The clock face must vaguely resemble a circle. Patients who squeeze in the last number(s) due to a small circle but place them in the correct position / region, without any other errors should be *ticked* as correct (e.g. '12' written below or above '11' and '1' as the space between was too small).

2) All three faces of the box and all nine lines joining at the appropriate corners must be present. This is a test of 'depth' perception. Those with two dimensional drawings are incorrect. Absolute proportions and orientation of the box are not intended to be assessed with this drawing test.

Note: It may be possible to test the drawing of the box but not the clock, as writing the numbers may be too difficult for patients either using their non-dominant side or with only some function of their dominant hand.

4. Dysphasia

See the Note at the end of d) 1. above.

If the patient is aphasic (or GCS Verbal response 1) then *tick* Yes, and for the second of the following two questions UTA, i.e. leaving 4 ii) blank. Unless the patient is unconscious GCS 3 or 4, (then leave 4 i) blank also), it may be possible to test for a receptive deficit. ** In theory a patient has to be conscious before being able to be classified as aphasic -Need to D/W HR/BH for consistency in recording**

If the patient is dysphasic then *tick* Yes, and specify for the following two questions what type of dysphasia. 4 i) and 4 ii) will aid in classification of the dysphasia, but it is not sensitive nor specific and thus, even if the patient answers all the questions correctly, but there is clear evidence of mild receptive/expressive dysphasia (Usually admitted by both the patient and carer/partner), then specify appropriately. In Expressive Dysphasia, the patient may admit to knowing what wants to be said but being unable to 'get the words out'. The carer / partner and patient may admit to noticing inappropriate words (word substitution, neologisms and/or phrases in place of words). The failure to remember the names of people may not be expressive dysphasia, but anomia (the failure to name items correctly) is a sign of expressive dysphasia.

If the patient has visual problems or incomprehensible speech due to severe dysarthria, it may not be possible to test for expressive dysphasia, in which case *tick* UTA for both the 4.ii) question and in specifying whether expressive dysphasia is present or not.

Cortical Dysphasia (Receptive and Expressive) may be impossible to differentiate from Confusion in a Stroke patient, and some confused patients will probably be recorded as having dysphasia. Comparison of d7 and first 24hr examinations with the History, will help deciding which box is ticked in the Establishment of Diagnosis sheet under recording the deficits due to the stroke.

Note: Some patients (esp. if elderly and anxious) may answer 4.i) 'Does a stone sink in water' incorrectly, but this on its own is insufficient evidence to classify the patient as having receptive dysphasia.

5. Dysarthria

If the degree of dysarthria is not recorded, then leave the column of three boxes specifying severity blank. It is useful to have collateral history in patients who may have been dysarthric prior to this incident and in patients with slight dysarthria, where this may be usual for them or where they may be missing their dentures. Record dysarthria is present even if unchanged from previously or if 'normal' for the patient, but it useful to make a note whether the assessor is of the opinion that this is unchanged from previously or not as this may help in the diagnosis of uncertain cases.

Note: Occasionally, in the GCS, the verbal response is recorded as 2. In these cases the degree of dysarthria should be incomprehensible (although possibly difficult to understand if some words are understood). If most words are understood then the GCS verbal response should not be 2.

6. Dysphagia

The following constitute evidence of difficulty swallowing :

Nasogastric tube (NGT)

'Percutaneous Endoscopic Gastrostomy Tube' (PEG)

Thickened fluids

Nil by mouth (NPM/NBM) sign for that patient.

Unconscious patients

There is No Movement (see 7 ii) Motor Power assessment) in all limbs.

The patient needs support to sit.

Note: In mild cases of dysphasia, the Verbal response may be 5 (or possibly 4, however, confusion may be difficult to distinguish from expressive dysphasia). Confused patients may answer appropriately, but incorrectly whereas those with dysphasia may answer either inappropriately (esp. receptive/mixed) or with neologisms (esp. expressive/mixed). There is however overlap both between the confused and the dysphasic and between the different types of dysphasic patients. What may be helpful is that those with just expressive dysphasia, unlike confused patients, may be able to point out or recognise correct answers.

2. Abbreviated Mental Test Score (AMTS out of 10)

Those who are markedly dysphasic (esp. if receptive) / comatose or have incomprehensible speech cannot be assessed properly with this test, thus *tick* the UTA (unable to assess) box. As a guide, any patient who scores less than 2 of the 3 receptive questions or both of the expressive questions incorrect cannot be assessed adequately with this version of the MTS.

Our Modified MTS is still compatible with previous versions. It is slightly modified from Hodkinson¹ The test comprises of 10x1 mark questions, three of which are divided into 2 parts. Score 1 for each question completely correct (2x1/2 for each of the three divided questions) and 1/2 a mark for an almost correct answer except for the divided questions which score 1/2 for each correct part answer (allowed to be out by 1 on either side of WW1 and WW2 years).

WW1 start 04/08/1914 WW2 start 03/09/1939: Only YEARS wars started tested!
 -Occasionally, patients give the END of the war dates (1918/9 and 1944/5). Repeat the question asking for the START of the wars.
 Half Marks for:
 -out by one on age/year questions.
 -getting the time wrong by 1/2-1 hr instead of within 1/2 hr.
 -getting 2 out of the 3 parts (day/month/year) in DOB correct (Need all three correct for full point).
 -getting only the number '42' or the name 'West Street' correct. Note: '42 West' scores only 1/2.
 -two or three mistakes in counting down from twenty. (One mistake in counting down from twenty is allowed and scores the full point.

It is best to write in the patient's answers to these questions : Age, 'Time' (i.e. How many minutes out from the correct time), Year, WWI/II dates, DOB, and '20-1' (i.e. How many incorrect/missing numbers) if the answer is incorrect or partially correct.

1. Age: Present age.
2. Time: According to the original test by Roth and Hopkins (1953), this is the time to the nearest hour. It has been modified in the above test.
3. Address (5 min. recall- i.e. end of test): Original 37 item test scored 1 mark for '42' and 1 mark for 'West Street' but the AMTS scored 1 or 0 if completely correct or not. This is the rationale for using 1/2 marks.
4. Name of place only in AMTS. Name of town added in the modified version and each now scores 1/2.
5. Year :getting the year wrong by ten **and** then getting the question correct on repetition of the question later, (e.g. in mildly dysphasic patients who may say 1966 and later correct to 1996.) scores the full point.
6. AMTS tested date of WWI only. Year sufficient. Initial test allowed for an error of 3?. The modified version asks for start of both wars and allows for an error of one only, and each now scores 1/2.
7. Date of Birth.: In the AMTS, day and month was sufficient. The modified version requires year as well, and as previously the year can be out by one.
- 8 AMTS scored 0 or 1 for 2 person recognition. The modified version scores 1/2 for each correct answer. (e.g. doctor/nurse/patient/cleaner etc.).
9. Queen Elizabeth or Elizabeth or Elizabeth II scores 1. Note Queen Elizabeth the 1st scores 1/2 only.
10. AMTS scores 0 or 1, but in the original 37 item test, the scoring was 0/1/2. See above for scoring. Occasionally the patients continue from the request, saying 19 18 17 16 etc. (missing out 20) but score the full point for these patients.

In general,

if it seems that a patient does not understand, the question may be repeated.

e.g. Ensure the patient knows the 5 min. recall address accurately by asking it to be repeated straight after saying the address.

if a patient corrects a wrong answer after repetition of the same question, the patient scores the full point.

e.g. In giving the start date of WWII in answer to WWI start date and correcting when asked WWII start date.

d) Examination

Location : Place of patient at last recorded assessment.

Date : Date of last recorded assessment (usually the d7* TSR assessment) used for completing the form. (This is not when the proforma is filled in from the records.)

Assessor : This must be recorded by those doing the d7* TSR assessment.

(*Ideally day 7 findings but with a range from d5-9 post stroke for In-patients, and up to day 14 for Out-patients.)

Only one of each set of *boxes* (shaded and blank) are *ticked* to explain the source of information which is filled in, in the respective areas of the proforma. If the patient has died before the d7* TSR assessment, then fill in the last noted medical assessment in records (incl. GP notes) between d5 and d7. Not available (N/A) is *ticked* if the patient has died before an assessment was done or the patient has had a further stroke prior to the assessment being done. It may still be possible to do a late assessment if the new stroke involves the opposite side to the previous one.

For patients admitted to hospital within 24 hours of their stroke, *tick* '...findings... First 24 hours post stroke.' If not admitted to hospital, record the GP findings when first seen and *tick* either '...findings... First 24 hours post stroke.' or '...Admission...(..GP notes..)' if first seen after 24 hours from the stroke onset. The date the GP / Deputising service first sees the patient post stroke is recorded under the Pathways through Care proforma (see section **b**) (i)).

Any other examination information (e.g. OPD notes) which will aid in the subtyping of the stroke should be written at the back of the diagnosis sheet.

Neurological Examination

1. Conscious level (Glasgow Coma Scale out of 15)³

Circle appropriate scores

If not recorded in medical records then print **NR** as score /15.

It is a useful measure of overall severity of stroke and is a reflection of the *level of consciousness* of a patient.

Although particularly for head injury patients, it has been described to potentially include vascular causes of changing states of altered consciousness. Each response is evaluated independently of the other as one or more components of this scale may not be testable. A crucial criterion for predicting outcome, which is not being assessed is the duration of the different levels of responsiveness.

For consistency, both in recording the Medical Records and the 7d* Examination, Score as follows:

Eyes:

Patients who are drowsy and need verbal prompting to keep their eyes open score 3.

Patients who are asleep/dozing and initially require a verbal stimulus to awake score 4 unless they fulfil the explanation for scoring 3.

Patients who initially have their eyes open but after having them closed (by the examiner) do not open their eyes irrespective of the stimulus score 1. (This is to prevent scoring 4 for unconscious patients with their eyes open.)

Painful stimuli should be applied to the limbs as grimacing with supra-orbital or jaw-angle pressure may cause eye closure.

Movement:

For the purpose of assessing the degree of altered consciousness it is the best response from the best limb that is recorded.

Should the patient have normal purposeful movements of the limbs (e.g. rubbing the eyes, picking up a cup etc.), then the Motor response on the GCS will be 6. This will give a more accurate movement assessment (than scoring it as 5) in confused and receptive dysphasic patients who may not understand to obey commands. This is at variance with the original description as the authors believed that 'purposeful' and 'voluntary' movement could not be judged objectively.

? A flicker of movement still scores 2 (rather than 1) as the response must fulfil the previous categories criteria to be scored as the lower category.

Verbal:

The patient with incomprehensible dysarthria (moans and groans) scores 2.

The patient with dysphasia scores at least 3, but may score 5 depending on the degree of dysphasia (see note below).

The original description describes 'Inappropriate speech', as "intelligible articulation...speech only used in an exclamation or random way (shouting, swearing) and no sustained conversational exchange is possible."

Should the GCS be 3 or the patient noted to be unconscious and unresponsive, then :

? The patient is Aphasic.

Dysarthria cannot be assessed.

The patient has evidence of difficulty swallowing.

- d) Most people will need prompting in listing their various benefits. These are benefits the patient may be receiving for themselves (2,3,4,5) and benefits which the patient and partner (where applicable) may receive together (1). Do not include pensions (old-age/ war/ deceased spouses pension ..etc.). Do not include benefits due to the partner only (where applicable). Do not include 'Free NHS dental, sight tests, prescriptions, glasses, wigs and fabric supports' as this is free for all pensioners, unless the patient is not a pensioner (then record it under :5) Other and specify). The Mobility and Community Care components of the Independent living fund payments are usually combined in the Disability Living Allowance.
- e) It is expected that some people may be reluctant to disclose accurate information. It is useful to explain this information is required to give us an indication whether the patient/couple may be eligible for further benefits as well as allowing a comparison with other stroke patients. As a guide, a combined income (interest, benefits, all pensions) for a couple of over £120-150 per week, depending on savings (including property) probably disqualifies them from further benefits, but in *all* cases explain that they may need to speak to a social worker and social security for confirmation (as DLA, AA and others may be available independent of income and savings).

Please also check Barthel details (if the stroke occurred more than nine days ago : to be filled in retrospectively) and hand dominance (which may need collateral history) are completed in the appropriate sections in the Examination proforma.

1. Oxford Handbook of Clinical Medicine, 2nd edit.(1990): R A Hope, J M Longmore, P A H Moss and A N Warrens: Angina Pectoris and Myocardial Infarction, pp. 278-280.
2. Oxford Handbook of Clinical Medicine, 2nd edit.(1990): R A Hope, J M Longmore, P A H Moss and A N Warrens: Migraine: pp. 416.
3. Krailo M D, Pike M C: Estimation of the distribution of age at natural menopause from prevalence data.: American J. of Epidemiology, 1983: 117, 3: 356-361.

b) Cigars and pipe-smokers are excluded. The evidence linking pipe-smoking and atherosclerosis is less clear-cut than cigarettes. It is not expected that many people will be able to afford to smoke the quantity of cigars necessary to be of significance in atherosclerosis.

(i) *Tick* appropriate boxes for all positive responses.

Regard people who in the past tried cigarettes, disliked them and thus did not continue smoking (<20 cig./d for <1 year) as 'never smoked'. 'Non-smoker' refers to whether the person at the time of the stroke was **not** regarded as a current cigarette smoker (i.e. Ex-smoker or Never smoked).

A 'Current Smoker' is defined as a person who was smoking regularly within 30 days of the onset of the stroke. It will not be possible to analyse how many people consciously stopped smoking in the 30 day periods prior to the onset of their strokes.

(ii) The number of years smoking is derived from when started, when ended and whether there were any long periods of abstinence (usually during pregnancy). Most smokers admitted to hospital usually do not smoke until discharged. thus the majority of hospitalised patients at day 7* will answer 'No' to "Still smoking since this stroke?". The one month questions will be a truer reflection on changing patterns of smoking post stroke.

c) Remember to ask about nightcaps or small amounts used to help people going to sleep at night.

(i) 'Non-drinker' refers to people who have never drank/stopped drinking alcohol. As in **a) (i)** above, those who have tried alcohol transiently only, are recorded as '.never.'. The terms 'regularly' and 'occasionally' are to give an indication only and refer to most days/every day and less than 2-3 times a week respectively. Use the same approximations in **(ii)** if these terms are used in the medical records.

(ii) Take the average / week over the last month.. For those that drink less regularly than once a week will usually have the <=2 units box *ticked*. Approximate relative units of alcohol are as follows (but be aware of different concentrations of alcohol in various drinks):

1 pint of beer	2 units
1 glass of wine	1 unit
1 tot of whiskey	1 unit

Section 7: Social History

a) For patients in Residential homes / Nursing homes or Continuing Care Hospital beds, parts **b) to h)** of this section are omitted. Note: For in-patient strokes, the patients place of usual residence is recorded i.e. Unless they are in continuing care, the usual residence prior to admission is recorded. Rented residences/self-contained flats are recorded under 'own home..' rather than 'Other' (e.g. Bedsits).

b) 'owned outright..' means that there is no longer any mortgage outstanding.

c) 'upper levels' is defined as a change in level (either up or down, with a flight of stairs) from the ground floor (entrance level).

d) Do not count small kitchens, bathrooms, toilets or hallways. Do count living rooms, bedrooms, the kitchen (if two people can sit down to eat in it), and all other main rooms in the residence.

f)+g) Include patient in totals.

Section 8: Economic and Education History

This section is to obtain information, which when used in combination will give an indication of the persons social class. Thus, as the social class structure is known in the two districts, a comparison of stroke age related incidence and mortality rates in different social classes may be made.

a) Do not include part-time education. Most elderly people left full-time education at the ages of 13-15. It is expected that few will have attended full-time further education.

b) Those unemployed and not looking for a job are still placed under 'Unemployed looking for a job'.

Those who have incapacity (disability) benefit and are of working age (<65 for males and <60 for females) should have 'Unable to work ...' *ticked* irrespective of their pre-stroke OHS. In theory, the OHS should be at least 2.

c) Fill in the husbands occupation in all cases even though in some instances it may seem inappropriate (e.g. early divorce or death) to use for social class extrapolation. It is expected that the numbers of these cases will be small and the time which would be taken trying to filter them out not worthwhile. As many people may have had a variety of jobs, record the main occupational class which should enable the following categorisation:

Occupational class	Class I (Professional)	(*Need list of examples for each category*)
	II (Senior administrative and managerial)	
	IIIa (Skilled non-manual)	
	IIIb (Skilled manual)	
	IV (Partly skilled manual)	
	V (Unskilled manual)	

- r) A patient who answers 'Yes' to '..limit their daily activities..' must score at least 2 on the OHS/Rankin Score. If 'No' is answered, then the score must be 0, 1 or 2. As soon as some assistance (by one other person) is needed in daily activities (e.g. going to toilet/bathing/dressing, but not needing assistance to drink) then the score is 3. Patients who need the assistance of at least two other people or need help with mobility and transferring would score 4. Patients who are bed-bound or totally dependent score 5. (See 6 Month Questionnaire, Section B, Part 2, p.4: Rankin Score categories).

Section 4: Family History

a)+b) Genetic related relatives only.

(angina/TIA is excluded: ask specifically for brain haemorrhages and brain thromboses as well as 'strokes')

Record the 'most positive' result: e.g.

- Aware of one close relative with a MI/Stroke, but lost track of other family members - *tick* "one 1st degree relative" rather than "Not Known".
- Lost track of some family members, but those known have not had a MI/Stroke - *tick* "none" rather than "Not Known".
- If the patient has no siblings and is unsure whether the parents causes of death are MIs/Strokes, *tick* "none" unless the parents had a MIs/Strokes; however, if unsure whether the parents had MIs/Strokes, then record "Not Known".
- Similar principles apply to age cut-off. Those > or = 65 are excluded.

? Why 65 yr. for MI (+ve FH for MI >50-60 yr. depending on the study).

In the records, if Family History (FH) is recorded as 'nil' or only positive findings with no mention of MI or Stroke, then assume no positive Family History for both a)+b) and *tick* "none".

Section 5: Medication

a) According to the most reliable information, this is whether the patient was taking aspirin regularly, with the last dose within 48 hours of the stroke onset. This will allow an analysis of compliance for those not taking, but prescribed aspirin.

"When commenced" refers to the beginning of the last unbroken stretch of aspirin taken.

Should the patient not be on aspirin (e.g. never prescribed or not compliant) and there are no contra-indications to it, then *tick* 'No' to the question asking whether there are any contra-indications. A list of relative and definitive contra-indications to aspirin is given. *Tick* all that apply. Include Hiatus Hernia under 'Gastritis/Heartburn'.

This part was added after the yearly proforma review.

b) This part is self-explanatory. "When commenced" is as in a) above, but if not known, fill in 'NK' in space provided. Do similarly for c) below.

c) Examples are:

- Ticlopidine, Phenindione (*Dindevan*), Dipyridamole (*Persantin*) and Heparin.
- Cinnarizine (*Sturgeron*), Nicotinic Acid Derivatives (*Hexopal*, *Ronicol*), Naftidrofuryl oxalate (*Praxilene*), Oxpentifylline (*Trental*), Thymoxamine (*Opilon*) may all be used in PVD and function primarily as vasodilators with limited/no anti-platelet/anti-thrombotic effects.

d) List all medication PRESCRIBED to be taken regularly AND in addition, any other medications which were taken regularly at the time of the stroke. Remember to ask about oral contraceptives and HRT where appropriate. The reason for specifying as above is because compliance of medication can only be elicited after careful, direct questioning of the patient and/or carer/relative. Most patients admitted to hospital via GPs have a list of the prescribed medication (pharmacy note or GP letter) accompanying. Even on asking patients to list their medication, unless specifically asked, patients usually will not admit to not taking their medication.

This format will also allow analysis of patients prescribed hypertensive / anti-thrombotic medication, but were not compliant (i.e. answered 'No' for Section 3 c) 2nd qu. and Section 5 a), b), c)). This will **not** elicit non-compliance of medication for all the other medical conditions.

Dosages of medication are not recorded. (except for Aspirin in Section 5 a))

Section 6: Lifestyle History

a) Answers to this is a function of patients/carers memories rather than whether they were or weren't actually provided any advice on the listed topics. The source of the advice is sought, thus if a patient for example cut down smoking/salt intake without a doctor/dietician/nurse having actually given the advice then record 'No'. If a patient had consulted for example a dietician in the recent past, what advice they can remember being given is recorded. If a patient was given advice but was unable to carry out the recommendations (e.g. arthritis limiting exercise) still record that advice was provided.

- f) In theory, two of the three criteria¹ are needed for the diagnosis. In practice, patients/carers are unlikely to be able to provide this information. A history of an admission to hospital where the diagnosis of Myocardial Infarction / Heart Attack is made and told to the patient/carer is sufficient. Changes on the ECG (suggestive of old MIs) on its own are not enough to make the diagnosis of a history of MIs.
- g) *Tick* all boxes that apply and date the latest event for each category. If it is uncertain which procedure was performed then *tick* the 'not known' box. Valvoplasty (open or closed) is recorded under 'valvular surgery-other'.
- h) As in g) above. Specify ASD (Atrioseptal Defect) or VSD (Ventriculoseptal Defect) under 'other'. Asking whether it was previously known whether the patient had a murmur over the heart may be helpful.
- i) As far as the patient/carer was aware, was there any history of hyperlipidaemia (high or excess fats / cholesterol in the blood) ? Few patients/carers are aware of the term 'triglycerides' and it is expected that most of those with hyperlipidaemia will answer DK/NK for this question. This question has thus been subsequently eliminated in the yearly proforma review. Some of the more common groups of drug therapy are as follows: anion-exchange resins, clofibrate group, nicotinic acid group, fish oil, HMG CoA reductase inhibitor, but preferably record the trade name. It is not specified whether patients are presently compliant on lipid lowering treatment. It will be known whether they should be taking such prescribed treatment as this is recorded in *Section 5 d*).
- j) A previous diagnosis of Peripheral Vascular Disease (PVD) is not essential. Suggestive terms used by doctors to explain PVD are 'hardening of the arteries', and 'poor circulation'. Present or previous symptoms compatible with Intermittent Claudication are needed. e.g.. pain in the back of the lower legs (calves), worse on walking or climbing stairs, relief on resting and in severe cases rest pain. Varicose veins, pedal oedema, night cramps and poor mobility due to arthritis or trauma; without evidence of co-existing arterial symptoms are excluded. Peripheral neuropathy without signs of ischaemia (e.g.. ulcers or gangrene) are usually also excluded. As in g) and h) *tick* all boxes that apply and date the latest event for each category.
- k) Rather than trying to explain what 'Carotid endarterectomy' is, ask first whether the patient has had any neck operations and if the answer is *Yes* then further clarification will be necessary (to exclude thyroid surgery etc.).
- l) A headache on its own is insufficient. The patient must explain what actually occurs and what they do when it happens. Symptoms and associations suggestive of migraine include a positive family history, aura, precipitant factors, nausea and vomiting, needing to go and rest in a quiet, darkened area etc.². Other common causes of headache (which may occur in addition to the migraine) may be excluded by the history alone. If the history is uncertain or atypical, *tick* the DK box but fill in the rest of the details. This will allow analysis of both cases of probable migraine 'Yes' ('History compatible with...') and all cases of possible/probable migraine 'Yes/No/DK' ('attack within last year'). If the history is not available *tick* DK and leave the rest of the question blank.
- m) Synonyms include 'cancers/growths/tumour' although not all growths are malignant. Whether operated on or not does not always correspond to 'whether still present' or not. 'Primary site' is usually the name of the type of tumour or organ of origin and 'extent' is both size and/or degree of spread.
- n) Epilepsy is defined as more than one episode of seizures due to abnormal brain electrical activity. In retrospect, it is more relevant to obtain how long ago the last seizure was (or age at last seizure), but for database consistency, date of last seizure will continue to be recorded. The relevant information may be derived. Because there are various subtypes of epilepsy, a previous diagnosis of epilepsy is more reliable than fulfilling various clinical questions.
- o) It is unlikely that confirmed diabetics will be left untreated as all should at least be given dietary advice. Record their prescribed treatment at the time of the stroke. (Treatment information is further detailed in *Section 5 d*.)
- p) It may be assumed that all woman over the age of 60 are post-menopausal unless there is evidence to the contrary. Data extrapolated from Krailo and Pike showed 3 responders aged 55 and over out of 195 were still menstruating and none of the three were over 58 years of age (sample size 46). They showed that after taking corrective factors into account, 0.75% of women aged 58 would be expected to be still menstruating.³
- (i) At least one full course (1 month) must have been used. Depo preparations (injectable), oral and patches are included. Patients who have not tolerated hormone contraception and stopped after a one month trial are excluded. duration of use and how long ago stopped is in years and months.
- (ii) A hysterectomy without oophorectomy will not result in anovulation. but many patients within the first four years post hysterectomy will start developing menopausal symptoms^{Need reference!}. HRT is hormone replacement therapy which is used to treat menopausal symptoms and osteoporosis.
- q) Specify ALL current long term illnesses/health problems/handicaps even if already recorded elsewhere.
- Included examples : Hypothyroidism, gout, hypertension (HT), angina, PVD, arthritis, back pain, epilepsy (if last seizure within the last 2 years), peptic ulcers, crohns, ulcerative colitis, asthma . psoriasis, COPD (chronic obstructive pulmonary disease) etc.
- Excluded examples : Previous curative operations for ulcer disease/ trauma' tumours; Previous infective diseases (pneumonia/diarrhoea/urinary tract infection etc.) etc.
- Not all Included conditions may affect a persons daily activities (e.g.. HT, psoriasis etc.). Note that each patients daily activities may be unique and thus this a slightly subjective question.

ii) It has not been specified whether swallowing was worse if present prior to the stroke. Differentiate difficulty swallowing tablets (which is NOT included in isolation) from dysphagia (difficulty swallowing solids/liquids resulting in coughing/spluttering/regurgitation/choking sensation).

- d) Tick all boxes that are applicable. For the Table, tick the box indicating the side of the body with NEW onset weakness (and if Bilateral, then the side predominantly affected). For cases of crossed and bilateral paresis (Brain Stem strokes), fill in Y (yes) in '11. Other deficit'.
Sensory deficit includes parasthesia / numbness. Differentiate from unilateral or bilateral parasthesia / numbness of just the fingertips and other conditions such as peripheral nerve lesions / syringomyelia / carpal tunnel syndrome / vasculitides and hyperventilation etc.
Remember in 7 and 8 to fill in the general rows and if known the specific rows. Only fill in the general rows if one cannot sub-specify the Speech or Visual Problems.
Dysarthria is indistinct/slurred speech that is sensible (if there is no dysphasia).
Dysphasia is muddled/jumbled speech that is distinct (if there is no dysarthria).
(See Examination Section d) part 4 and 5 for more details.)
A history of difficulty seeing on one side is suggestive of a Homonymous hemianopia. Blurred vision and diplopia is filled in under '8. Other'.
A positive history of a Visiospatial disorder is seldom obtained but suggestive history is that of suddenly getting lost/disorientated while walking/driving in a familiar environment and/or the partner/carer noticing the patient neglecting one half of his/her body.

Brain stem/Cerebellar signs are suggested by a history of sudden/rapid onset ataxia (truncal/limb/gait), vertigo, diplopia, inco-ordination and drowsiness. The most important complaints are that of failure to co-ordinate hand movements and/or falling over to one side when sitting/standing/walking; out of keeping with the degree of weakness present.

Always attempt to fill in the Negatives 'N' (no) rather than leaving boxes blanks (not known/unsure).

Section 3: Past Medical History

Questions a) to r) 'History' refers to whether prior to this event (Pre-Stroke) the relevant medical information was known. It is NOT what is discovered at this event or subsequent to it.

Note: When completing the records/medical notes (all sources in patients folder: incl. physio, nursing, etc.):

- FH (family history), if recorded as Nil or a list of positive findings: Assume 'No' unless stated otherwise (Section 4: a) +b)).
- No previous operations or a list of all previous operations: Assume no cardiac/peripheral vascular or endarterectomy operations unless stated otherwise (Section 3: g)+j)+k)).
- PMH (past medical history), if No (other) previous medical history of note, assume 'No' for relevant questions (Section 3: c)+d)+e)+f)+m)+n)+o)) **only** if there are a list of definite negatives recorded as well. Questions in Section 3: h)+i)+j)+l) are not routinely asked and unless there is evidence (e.g.. under previous investigations for cholesterol or under examinations for heart murmurs) of its presence/absence, record as not known / not recorded (NR).

- a) and b) A history of definite neurological deficit must be obtained. This must have lasted for at least 24 hours before complete recovery to be classified as a stroke. A previous diagnosis of a slight stroke/mini stroke could be either a TIA or a Stroke (incl. RINDs). Episodes of solitary dizziness or acute confusion without other confirmatory neurological signs/symptoms are excluded. (See Protocol No. 2 Stroke Inclusion Criteria). A history of TIAs should be sought for. Previous transient episodes of parasthesia / slurring / dysphasia / weakness / inco-ordination is suggestive of a TIA.
- c) A patient must have been diagnosed as having hypertension resulting in either advice given and/or therapy initiated. A single high blood pressure reading is not compatible with a history of hypertension. A patient may deny having hypertension if on treatment and the blood pressure is well controlled. Asking if the patient is on any treatment for blood pressure may clarify the problem. A patient who is not compliant on treatment should have the 'No' ('current treatment') ticked, although all the prescribed medication should be recorded under *Medication* Section 5 d).
- d) Do not include tachycardia or palpitations (rapid regular beats) which can be precipitated by anxiety/fear/exercise etc.
- e) As in c) above. A single episode of chest pain is not suggestive of Angina. Suggestive features may be found in most standard Medical Text Books eg.¹. Not all patients who have had Myocardial Infarctions (MIs) have angina. Patients who may no longer have angina post Coronary Artery Bypass Grafts (CABGs), are still be recorded as 'Yes' as they still have a history of angina.

c) History / First Assessment

Filling in the History form is relatively self-explanatory. This section is to augment the explanations on the proforma and to resolve possible difficulties that may be encountered. This section should be read in conjunction with the above proforma. After the yearly proforma review, a scaled down version (omitting certain parts) of the proforma has been used (from 01/07/96) for the final year.

Sources of data: (1/2/Tick)

Data is recorded in both the History and the Records sections until the 30th of June 1996. Tick the appropriate shaded box(es) to indicate where the source of data is obtained from for the Records section. For the History information, fill in either a '1' (if the data is reliable) or a '2' (if the data is thought to be unreliable) in the appropriate blank box(es). For the first year of data collection 01/07/95-30/06/96 information from both the records and patient/carer sources are recorded for a comparison of the quality of medical records in the two districts. In the second and final year 01/07/96-30/06/97, only the most reliable source for each question is used. Only *Tick* all the relevant boxes after 01/07/96.

Location:

This is where the Assessment is carried out (e.g. Hospital, ward x / Nursing Home / Residential Home / HAV (Home Assessment Visit in patients home) / Outpatients etc.). It must be completed when information is obtained from a source other than from records.

Assessor:

In the first year of the study, this may be more than one person as the recorder of the History and Records sources of data may be different. The initials of the person completing the form are noted.

Date of Assessment:

The date of when the Assessment is done (either History or Records completed) is recorded.

Section 1: Patients Personal Details

If a person is of mixed Ethnic group then tick 'e) Other ethnic group'

Only one box should be ticked for the left sided column and if b/c/d is ticked then one further box should be ticked in the right sided column.

One box must be ticked in the left sided column for the Marital Status.

Section 2: Acute Event

a) Part a) should only necessary to be filled in if the diagnosis of stroke is not certain. This is to help subsequent decision making in classifying when reviewing the patient.

The 'Symptom Table' is also useful in decision making, especially in SAHs (and in Migraine).

'Before' refers to the preceding 24 hours from the onset of focal neurological symptoms.

'After' refers to up to six hours from the time around the onset of neurology.

As in subsequent Tables, if the information is not certain or not available then leave the boxes blank.

b) The date refers to the onset of persistent neurological deficit and NOT to episodes of preceding TIAs (if any have occurred).

The location is usually one of the following: At Home (Place of residence: Including Nursing and Residential Homes); Relatives Home; Shopping; Overseas; At a Function or Club; In the Bar; Outside (In the Garden, Walking); In Hospital; Other (Specify).

c) '* or on completion of evolving stroke' refers to patients who may have had bleeds, fluctuate during the course of the event and may gradually develop neurological deficit. This must be distinguished from; Intracranial Neoplasms where the onset of symptoms is usually over a longer period and is progressive (although they do sometimes present indistinguishably clinically from a stroke); from Hemiplegic Migraine (see section 3 I)) and from Todds Paresis post seizure.

i) Tick all boxes that are applicable.

i) Incontinence is defined as loss of awareness of wanting to urinate or loss of control of bladder function

A person who knows when needing to urinate, is unable to get to the toilet and is aware of the inevitability of the pending 'incontinence' and eventually loses control should not be labelled as incontinent. (Differentiate from Bladder Instability, Frequency and Stress Incontinence)

b) (ii) Sources of Notifications

Initially, it was envisaged that after creating a high profile for the TSR, patients with suspected/confirmed strokes would be notified without needing to actively seek for such cases. Thus both sensitivity and specificity for each form of notification could be analysed. In practice, the Pilot study showed that; due to ongoing rotation in junior hospital staff and inevitable changes in other staff and GPs; an active check for stroke cases on a regular basis is needed (see Setting up a Stroke Register: Methods for a description of the active role by the TSR in case ascertainment and resultant bias in analysis of Notification source.)

In theory, every source of notification, both primary sources and secondary (back-up) methods should be recorded. This will allow analysis of the yield of each source and specificity of most, but not the specificity in all cases (e.g.. not all CT head results are registered - only probable and possible ones are reviewed and registered). The date of each notification allows analysis of duration between notification and stroke event and is thus recorded. The date of notification for secondary sources is taken as the day the list (of patients and dates) is received by the TSR personnel. This is for standardisation of CT lists, DHA lists (death and admission data) and Hospital discharge lists.

A potential source or error in yield / specificity in secondary sources of information, is that the date of events (e.g. only dates of when the CTs are done are known) are not always available or correct. Thus in those lists where there is an element of doubt as to whether the list dates (not the date the list is received, e.g. if the list dates are after the one month assessment) refers to a new event or to a further notification of a known event, notification entry will be as for a new event. There is the potential that late (more than one month after the event) CT scan lists or GP register lists (some of which commonly and mistakenly list the date of stroke event as they date they are informed about it) will result in increased excluded (as an 'old stroke') notifications of new events when in fact they are just further notifications of a previous known event (either late or due to a mistake in the date). Those that refer to dates within the month period of a known event are classified as a further notification unless there is evidence of a recurrent stroke within the first 28 days of the known event. This is because early recurrent strokes will be picked up at the one month assessment and duplication of workload will also be minimised.

For certain sources, specify in more detail by circling the appropriate block.

- OPD - Out Patients Department
- A/E - Accident and Emergency
- GP - General Practitioner(s) Surgery

The methods of notification are : Fax / 'Phone (internal or external) / Post / Direct (any face to face contact) / Sheet/Records (ward / hospital patient lists / nursing records)

Examples: TSR nurse obtained notification from reviewing ward Nursing records: Notify as Nurse: Ward: Sheet.
TSR informed from ward nurse personally/telephonically: Notify as Nurse: Ward: Direct/'Phone respectively.

TSR doctor finds out about previous stroke after reviewing patient (history/examination): Notify as Other (specifying TSR Doc.) : Hospital/Home/OPD (Location pt. seen) : Direct.

b) (i) Pathway through Care

The Patient Identifier number is entered in the top right hand corner.

The dates of the onset of the stroke, first contacts and transfers(for those admitted to hospital) are filled in the appropriate boxes.

If the patient was a patient in a hospital at the time of the stroke then **IP** (In-patient) is filled in else **OP** (Out-patient) is filled in.

The **Location** is where the patient was at the time of the contact (e.g. Nursing Home) or the ward and hospital the patient was in on that date. This allows for sub-analysis of the two different areas with regards the influence of Nursing homes on both the incident and mortality rates.

Contact requires actual physical presence of the professional and **not** just telephonic advice. The **1st professional contact EXCLUDES** medical doctors which are filled in under **1st medical contact** (SHO, Deputising GP etc.). The **Profession** rather than the name should be filled in for this category(e.g.. District Nurse, Paramedic, Ambulance Personnel etc.). If a patient arrives at A/E without first being seen by a professional or doctor then **A/E contact** is filled and not the above two categories (which are left blank). For In-patient strokes, one of the ward nurses are usually the 1st professional contact and the House Officer (H.O.) or Senior House Officer (S.H.O.) are the usual 1st medical contacts. As the patient is already on a ward, this is recorded under **Location**. The first OP contact row (and usually the A/E row also) is left blank for IPs, unless the stroke actually occurred in the Out Patients department or in A/E.

Admission ward is the date and location of the patient on initial admission to hospital (IPs and OPs). For IPs, this is before the stroke onset which will allow analysis of duration of hospital stay prior to stroke onset. For OPs, this is always after the stroke onset.

Occasionally, a patient on a non-medical ward (e.g. psychiatry/orthopaedics) may be asked to be reviewed by a medical consultant with regards to the patients stroke and unless the patients management is taken over by the consultant, this contact is not analysed in the care of the patient.

The **Transfers** include both internal (between different wards in the same hospital) and external (between different hospitals) movements. For IPs, analysis of transfers post stroke event will take into account that the first transfer is from the ward where the first professional/medical contact occurred which is not always the same as the admission ward.

When a patient is discharged from hospital, then the placement section of the form is filled in. *Tick* the appropriate box. **N**-represents Nursing, **Res**-Residential and **Other**, Other than hospital (e.g.. relatives home / re-housed home). **Home** is *ticked* if the patients private residence prior to the stroke and after discharge are the same.

Should a patient be readmitted to hospital for a reason other than a new stroke within the first **6 months** of each **incident**, then the date(s) of admission , hospital(s) and date(s) of discharge are completed.

For OPs, if admitted to hospital within the first 7 days of the incident stroke, then a box in each of the three sections at the bottom of the page should be *ticked*. **except** if the transport to hospital is Not known, when the **1st Ambulance contact** should be left blank.

Always *Tick* one of the three boxes specifying whether the patient has been hospitalised within the 7d time interval. *Tick yes* in all IP cases. This will allow analysis of those stroke cases with in-patient hospital management within the first week.

NOTE: Patients who call the ambulance and are admitted without prior contact with their GP/Deputy, have to be seen in A/E and are usually transported by Paramedics.

ALGORITHM to derive the subtype classification (Based on the OCSF computer classification, modified by the addition of the Quadrantanopia category). Data derived from the Establishment of Diagnosis sheet 'Area Affected' table.

Subtype	1	2	3	4	5	6	7	8	9
TACS	Y	Y	-	Y	Y	-	-	NY	-
	-	Y	Y	Y	Y	-	-	NY	-
	-	Y	Y	-	Y	-	Y	NY	-
	Y	Y	-	-	Y	-	Y	NY	-
	Y	Y	-	Y	NC	NY	-	NY	-
	-	Y	Y	Y	NC	NY	-	NY	-
	Y	Y	-	-	NC	NY	Y	NY	-
	-	Y	Y	-	NC	NY	Y	NY	-
	Y	Y	-	-	Y	-	NC	NY	-
	-	Y	Y	-	Y	-	NC	NY	-
	Y	Y	-	NC	Y	-	-	NY	-
-	Y	Y	NC	Y	-	-	NY	-	
LACS	Y	Y	-	N	N	N	N	N	N
	-	Y	Y	N	N	N	N	N	N
POCS	-	-	-	-	-	-	-	Y	-
	-	-	-	-	NY	Y	-	-	-
	N	N	N	N	Y	-	N	-	N
OTHER	N	N	N	N	N	N	N	N	Y

Patients NOT CODED by TACS, LACS, POCS, OTHER are coded as PACS.

Patients classified as LACS have to be alert i.e. minimum GCS = E4, M6, V2 in first 24 hours after event.

Y = Yes

NC = Not Certain

N = No

NY = Not Yes (at any examination)

- = Yes / No / Not Certain

Note: Patients which may fulfil the algorithm for LACS may occasionally be classified as PACS if there are restricted/patchy deficits in the limb(s).

1 Hunt WE, Hess RM. :Surgical risk as related to time of intervention in the repair of intracranial aneurysms. J. Neurosurg 1968; 28: 14-20.

2 Botterell EH, Lougheed WM. Scott JW, Vanderwater SL.: Hypothermia, and interruption of carotid, or carotid and vertebral circulation, in the surgical management of intracranial aneurysms. : J Neurosurg. 1956: 13: 1-42.

3 Drake CG (Chairman). Report of World Federation of Neurological Surgeons Committee on a Universal Subarachnoid Haemorrhage Grading Scale (Letter).: J Neurosurg. 1988; 68: 985-986.

4 Myer FB, Morita A et al : Medical and Surgical Management of Intracranial Aneurysms.: Mayo Clin Proc 1995; 70:153-172.

5 Hankey GJ, Warlow CP : Lacunar transient ischaemic attacks: a clinically useful concept? : Lancet 1991; 337 Feb 9: 335-338.

6 Bamford J, Sandercock P, Dennis M, Burn J, Warlow W.: Classification and natural history of clinically identifiable subtypes of cerebral infarction.: Lancet 1991; 337 June 22: 1521-1526.

SAHs. Note: At present in the analysis, a patient is presumed to be Imaged if the 'Stroke, but known whether infarct or haemorrhage' box is **not ticked**. It is possible, but unlikely that a patient has had an LP without Imaging resulting in classification under SAH. This theoretical discrepancy will be overcome when analysing the Imaging results directly from the Investigation Proforma. Occasionally, there will be difficulty in distinguishing PIHs from SAHs on Imaging alone as one may extend into the other. Clinical findings and history will be the deciding factors, but in general, SAHs seldom extend into the brain parenchyma, thus PIHs are more likely if scanning shows both subarachnoid and parenchymal involvement.

Over 80% of non-traumatic SAH is caused by aneurysmal rupture. 40-50% re-rupture within 6 months and the mortality of re-rupture is around 78%⁴. Despite the high incidence of aneurysms, detection on CT scanning of aneurysms are not as frequent as expected after a haemorrhage so many haemorrhages will be sub-classified as None identified / Not known. Occasionally, patients may have cerebral angiography (recorded in Investigations and Operations) that may help in sub-classification.

The *Hunt and Hess*¹ Clinical Grading system of SAH has been used. Alternatives are the *Modified Botterell*² and *World Federation of Neurological Surgeons*³ clinical systems. All three have correlated well with outcome. The clinical assessment is done at admission.

The final table is used to subtype all the infarcts^{5,6} and primary intracerebral haemorrhages. Sometimes more than one subtype may be fulfilled, in which case *tick* the uncertain box. Sometimes the clinical subtype does not correspond with the imaging expected subtype. In these cases *tick* both the uncertain and clinical subtypes and make a note of the expected imaging subtype. Record the presence of all deficits due to **this** incident even if there is resolution of some symptoms/signs by the time of assessment/within the first 24 hours, as this more accurately indicates the areas involved and thus the more likely subtype.

Clarification:

Deciding whether a deficit is present and whether if present, it is due to this incident stroke may be very difficult. Refer to the Examination section (**d**) for more detail on problems which may be encountered. Thereafter, subtyping the stroke may also be tricky. Refer to the subtype information cross-table ^{Still needs to be typed onto computer (already on paper)} but take into account detail of the various subtypes in Protocol 2 Stroke Inclusion Criteria: Definition of CI and PIH subtypes section. e.g. deficit confined to face and hand but not whole arm is a PACS (not a LACS).

If hemianopia is NO only then is it **possible** for quadrantanopia to be YES. If hemianopia is YES then quadrantanopia is NO and if hemianopia is uncertain, then both must be uncertain. Occasionally, it may be possible to be certain about the absence of a hemianopia but not the absence of a quadrantanopia.

If either Visual Inattention OR Sensory Inattention (Lower Limbs and/or Upper Limbs) is present then *tick* YES. If one is NOT present and the other is uncertain then *tick* NO. Only if both are uncertain, is UNCERTAIN *ticked*.

If there is dysarthria **without** Brainstem or Facial involvement, then *tick* YES 'Other deficit' and specify Dysarthria. (Note: Difficulty in classifying slight dysarthria: See Examination section D part 5) With dysarthria alone, it is not possible to classify the subtype as both PACS, extended LACS or POCS are possible.

NOTE:

All TACS will have hemianopias, but not all hemianopias will be TACS. All quadrantanopias will be POCS but not all POCS will have quadrantanopias.

In recurrent cases of stroke where extension on the same side has occurred, *tick* all present deficits but be aware that the subtype may not correspond to the boxes ticked. The subtype is dependent on the degree of NEW deficit which is inferred from a combination of residual weakness from previous stroke(s) and present total deficit. It is expected that in many of these cases the UNCERTAIN subtype will be *ticked*. These cases will have to be reviewed later for the most likely subtype to be allocated.

POTENTIAL ANALYSES (Not previously noted in the literature):

PIH classification and natural history using a modified Bamford et al Cerebral Infarct classification system.
Recurrent Stroke (either using total deficit or new deficit) classification and natural history.

C) FIRST INCIDENT (since 01 July 1995 inclusive)**a) Establishment of Diagnosis (Diagnosis Sheet)
(Includes Event Number, Incident Number is One)**

For Events which are Not Strokes, see subsection J) Excluded Assessment Sheet.

To be completed after the HISTORY, EXAMINATION and LP/CT/MRI RESULTS for all included cases.

The First Table is to aid in confirming diagnosis of a **new** stroke. (*tick* ONE box in EACH row).

- History (at initial TSR assessment or in medical notes) - If either History is compatible with a **new** stroke then *tick* YES. Note: Despite *tick*ing YES, the patient may still be excluded. See subsection J) Excluded Assessment Sheet.
- Initial medical examination - Obtained from the records (GP e.g. Community notifications, Hospital or Nursing Home). If the examination is compatible with a **stroke** (a new stroke cannot be reliably differentiated from an old stroke on examination alone), then *tick* YES.
- TSR "One week" examination - d7* findings by the TSR doctor / Medical Records. Occasionally, it may not be possible to determine whether after Examination, focal or localising neurological signs are present. *Tick* NOT CERTAIN. In these cases the History obtained is crucial in making the diagnosis. Note: Despite *tick*ing YES, the patient may still be excluded. See subsection J) Excluded Assessment Sheet.
- CT/MRI brain scan* - *tick* NO if Normal Scan or if no infarction / haemorrhage noted, NOT CERTAIN if scan equivocal/non-specific, YES if haemorrhage or Infarction noted, and NOT AVAILABLE if result not available or scan not requested. Note: Despite *tick*ing YES, the patient may still be excluded. See subsection J) Excluded Assessment Sheet.
- Lumber puncture - *tick* YES if blood in CSF, NO if no blood in CSF and NOT CERTAIN if 'bloody' LP tap.

Note: *tick* NOT AVAILABLE if information not known.

*Examples of confirmatory evidence of Stroke Disease (Old or Recent):

- Areas of low density
- Regions of low attenuation

(Note: Haemorrhages Enhance but Infarcts do not. MRI is more specific, picks up infarcts earlier but is less specific in identifying haemorrhages if done very early compared with CT)

*Non-specific results:

- Deep White Matter infarction/ischaemia
- Periventricular ischaemic changes
- Patchy involvement

In retrospect, the filling in of the above table should have been done according to the criteria in Protocol 2: **STROKE INCLUSION CRITERIA**, which would aid in the making of the Final diagnosis for each event, but as this table is not going to be analysed separately, the Final diagnosis is all that is important. At present, continue to complete the above table according to the previous format, but be aware that in itself, the table is not important.

The Final diagnosis should either be Stroke (Cerebrovascular Accident) / SAH (Subarachnoid Haemorrhage) / PIH (Primary Intracerebral Haemorrhage) or RIND (Resolving Ischaemic Neurological Deficit). Those patients that die within 1 week due to their Stroke are classified under Stroke / SAH / PIH. Those patients whose symptoms resolve within 1 week, but have CT/MRI/LP evidence of haemorrhage are classified under Stroke / SAH / PIH. Infrequently, even after completing the Diagnosis table, because of a lack of sufficient information, the diagnosis is suggestive of a stroke but one cannot be certain. In these cases, the Probable stroke box should be *ticked*. (**See Protocol No.2 Stroke Inclusion Criteria**. Note: Positive, Negative and Uncertain findings do not correspond with the boxes ticked in the first table.) Probable stroke cases should be treated as a Stroke as far as further assessments go, but we intend to go back to them later and if possible, decide which definite categories they are most compatible with.

All strokes are further classified according to their CT/MRI/LP results. If all these are NOT AVAILABLE, then *tick* 'Stroke, but not known whether infarct or haemorrhage'. A non-compatible infarct on CT means that the territory (on CT or MR scanning) involved does not correspond to the territory expected (from History and Examination information) to be involved. Patients with a classical history of SAH, if not imaged or LPed are also classified under 'Stroke, but not known whether infarct or haemorrhage' but then the SAH grading is used in preference to the PIH/Infarct Table. This will allow analysis of both confirmed SAHs and presumed (clinical and confirmed combined)

B) PATIENT CHECK LIST

To be placed (stapled/glued) onto the front of folder at the time of the First Event. This is used to keep track of each patient's (and each event of each patient) data acquisition and data entry onto the computer. At a glance, it should show what information is still outstanding, what data entry is awaiting and what assessments may be needed in the future for each patients incidents.

The patient's Name and Identification number are filled in initially. Date of each Event entered under corresponding event number. Note: Dates may not necessarily be chronological. Recurrent Events are filled in chronologically (according to dates of notification) in subsequent columns.

As each group of proformas are completed, the relevant block on the check list is *ticked*. As the data is entered onto the computer, its relevant block is *ticked*. Should certain assessments not be applicable, a *cross* should be placed in the box (e.g. If a patient dies 3 months after the First Incident, then *crosses* should placed in all subsequent assessment boxes).

Should a patient subsequently die due to causes other than a suspected new stroke then a large *cross* is placed in the subsequent Event column. Should a patient be excluded for a specific Event then a single *diagonal line* is drawn through that excluded event column only.

Each patient will be followed up at regular intervals as specified on the check lists **and** every incident stroke will also be followed up at 6 months with a modified (limited/functional) assessment *if* the new incident stroke has been before the 6 month assessment. There is obviously a potential for a certain degree of overlap in when concurrent assessments may be due, but this will be outweighed by the benefit of a fixed time interval follow-up of all cases. A Recurrent Assessment must be completed on all confirmed strokes after the first incident stroke (i.e. first stroke after 31-06-95), irrespective when we are notified about the recurrent stroke. This has the advantage of gathering as much information about each stroke even though some of the assessments (e.g. Examination) may be incomplete.

Note: Occasionally, the stroke notified may not be the first incident stroke. In these cases, a First Assessment should be completed for the first incident stroke **and** a Recurrent Stroke Assessment should also be completed for the notified stroke event. This is a large amount of initial work/information, but for accuracy and completeness of data, is the only feasible method. A very small proportion of patients (approx. <5%) should fall into this category. In these cases, the Event No. 1 refers to the Recurrent Stroke Assessment and the First Assessment will be Event No. 2.

Note: For the Event Number, it is not relevant whether a patient if not previously known to the Tees Stroke Register, has had a stroke prior to 01-07-1995.

A) FRONT SHEET (incl. Consent Form and Information Sheet)

All patients have a front sheet completed. Only included patients require consent forms completing but it is preferable to have consents on all patients seen.

Data is entered onto computer and a print out of the front sheet is done after the initial notification of each Event received. A unique identification number for each patient is allocated at the time of the first Event.

a) Event Numbers :

These are NOT allocated according to chronological stroke incidents but according to chronological referrals of suspected stroke incidents.

Event No. 1 is the first referred and recorded event whether included or excluded.

Even if subsequently it is found that the patient has had a previous stroke in the study period, the first referred event retains the original number, and the newly identified incident becomes Event No. 2.

The reason for this is because of database functioning of linking data to patient identifier and event numbers.

b) Incident Numbers :

These are chronological according to time of included confirmed strokes irrespective when those strokes are identified. This is for analysis purposes, where the 'order' of strokes are needed.

Incident Numbers are obtained by the chronological ordering of included Events according to dates of stroke and are thus not entered specifically on either proformas or onto the computer.

c) Initial Data :

Patient Identification number and Study Area (Residential district takes preference to treatment district).

Name of patient (prefixed by Mr./Mrs./etc.)

Date of Birth (DOB), Date of each Event (suspected stroke), Date of Death.

Address (include. Town, Postcode and Telephone number) for all Events.

Contact Name, Address and details.

Registered GP Name and Practise details for all Events.

Whether hospitalised at each Events initial notification.

The hospital(s) and record number(s).

Whether each Event was a confirmed Stroke (i.e. included) else patient is excluded from further assessments for that specific Event. Initially, all notifications are presumed strokes until excluded.

List of when routine assessments due, whether appointments have been made and when / by whom completed.

Whether patient is dead at time of notification or not.

Whether initial consent was received: See Copies of Consent Forms, Study Information and Hospital Local Ethical Guidelines on the use of patient information and confidentiality.

- Completed consent forms

initially 3 copies - for GP/Patient/own records (copy for GP subsequently omitted).

- Study information given to patient at time of receiving consent.

d) Recording Consent :

Consent may be : (Y)es : Full signed consent.

(N)o : Unable to contact relative/carer and patient unable to give consent . (e.g. confused/ receptive dysphasia/ drowsy/ comatose etc.)

(V)erbal : Patient mentally fit but unable to sign the consent form.

(R)efused : Patient/Carer denied consent.

(W)ithdrawn : Patient/Carer, after initially giving consent, subsequently withdraws it.

(M)edical Notes : Consent for contact with the patient or carer is denied, but access to GP/Hospital notes is allowed. (This form of refusal may be due to either the GP advising against contacting the patient/carer or the Patient/Carer not wishing to be directly involved.)

Certain details are filled in on the notification proformas and pathways proformas at this time. These are, source and date of notification and where the patient is at the time of notification.

APPENDIX 2

THE MANUAL

OBJECTIVE

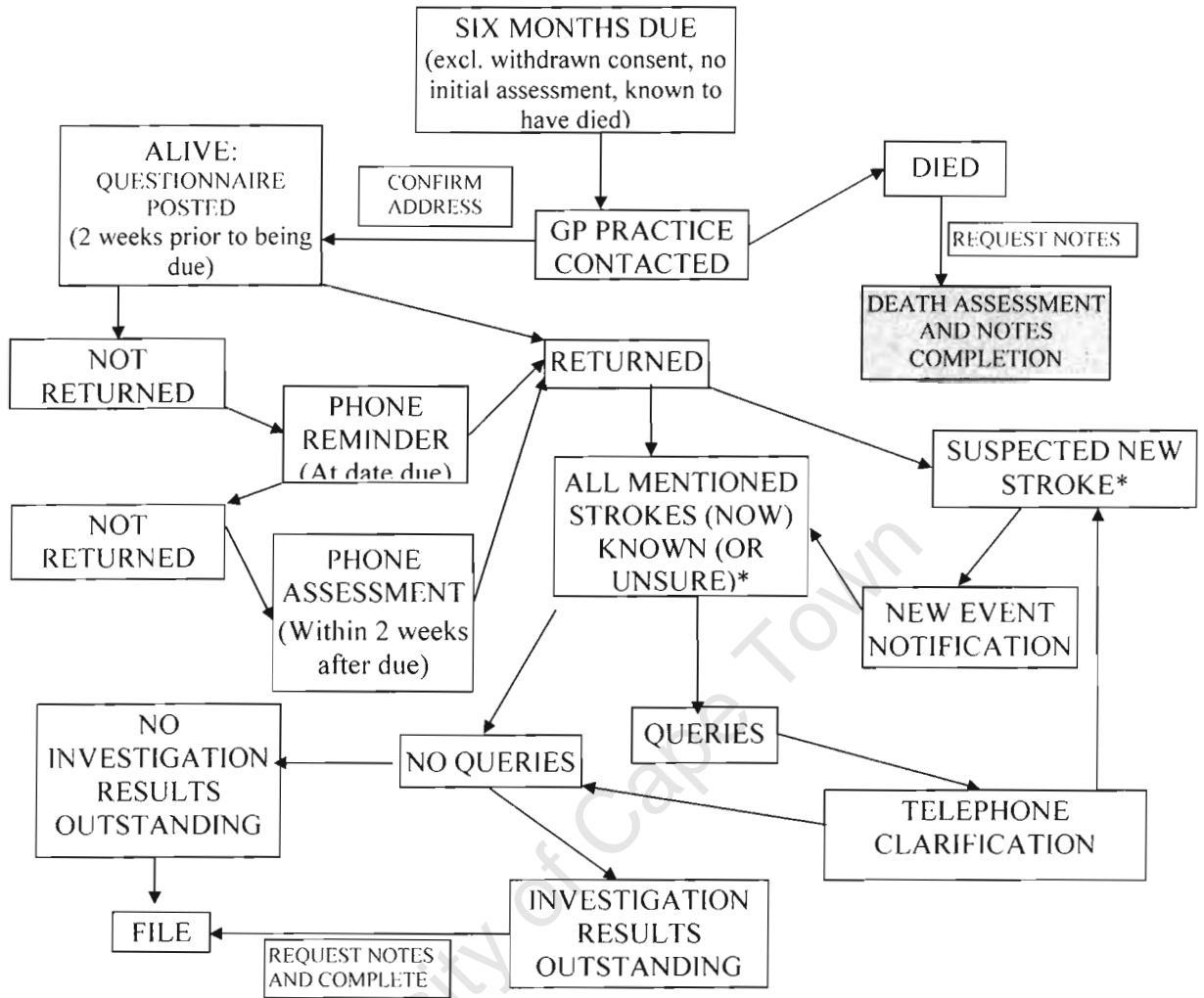
The Manual explains the use of the different proformas and to clarify problems that may be encountered when completing them. Each section of the manual must be used in conjunction with the relevant protocols and proformas. It also explains which subsections are filled in for each patient and how to fill them in. The reasons for the methods used, the type of data collected and the limitations of both in future analyses are explained in key areas.

FORMAT

The Manual is set out in various sections. Each section covers a specific area of patient information. There is overlap in some sections. The sections comprise of background to and explanations of the specific proformas. The sections and subsections are as follows:

	Page
A) FRONT SHEET (incl. Consent Form and Information Sheet)	2
a) Event Numbers	
b) Incident Numbers	
c) Initial Data	
d) Recording Consent	
B) PATIENT CHECK LIST (incl. Recurrent Stroke and Data Entry Check Lists)	3
C) FIRST INCIDENT (since 01 July 1995 inclusive)	4
a) Establishment of Diagnosis	4
b) (i) Pathway through Care	7
(ii) Sources of Notifications	8
c) History/ First Assessment	9
d) Examination	15
e) Investigations and Operations	23
f) Therapy	
(i) Therapy and Complications	26
(ii) Therapy and Services	28
D) RECURRENT INCIDENT	29
a) Establishment of Diagnosis	
b) (i) Pathway through Care	
(ii) Sources of Notifications	
c) Recurrent Stroke Assessment	
d) Examination	
e) Investigations and Operations	
f) Therapy	
(i) Therapy and Complications	
(ii) Therapy and Services	
E) 1 MONTH ASSESSMENT	30
F) 6 MONTH ASSESSMENT	32
G) 12/24/36 MONTH ASSESSMENTS	34
H) DEATH ASSESSMENT	34
I) SUDDEN DEATH ASSESSMENTS	35
J) EXCLUDED ASSESSMENT	36
Establishment of Diagnosis	

12.7 Flowchart



:*Section A, page 1, Question 2 of six months assessment questionnaire.

12.4 Withdrawn consent for direct contact

All patients who have not refused consent (or who have only refused consent for direct contact) and survive at least six months after their incident stroke, must have a six month assessment completed.

For those deemed to have withdrawn consent for direct contact, the GP (and/or hospital) records will need reviewing to derive as much information as is possible. Obviously, not all questions will be able to be completed, but the following minimum information should be available:

Current residence.

Recurrent Stroke/TIA in preceding six months.

Current medication (any change, complications, contraindications etc.).

New medical problems diagnosed.

Investigations/Appointments arranged/undertaken.

Services organised (and no. of GP visits in month 5-6 post stroke).

Hospital admission(s)

12.5 Problems

Patients who have left the area and the forwarding address/ telephone number is not known.

Patients who have changed GPs or whose initial GP is not known.

GP practices who do not know either the current addresses or telephone numbers of the patients or relatives.

Patients and relatives/carers without telephones.

12.6 Solutions

Tees Health may provide the new GPs details if the patient has subsequently registered within the Tees District.

Darlington GPs patient registration may be available on their computerised HISS system.

12.3 Backlog

Backlog/missed cases are forwarded to the TSR person dealing with the six month queries. The GPs practice managers are to be contacted first to confirm whether the patients are alive or not and then a telephonic retrospective interview is done for those sections of the questionnaire for which it is appropriate. The section omitted is:

Section E - Mood

Those not on the telephone (or not able to do it over the phone) will require the research nurse/doctor to visit the patient for completion of the form. In those patients who have not returned the questionnaire, reminder questionnaire, are not on the telephone and the assessment is now more than three months overdue will be deemed as withdrawn consent for direct contact. In these cases, no further action will be taken in attempting to contact them directly. It is thus important to try and prioritise visits to catch as many cases before the 9 month cut off as is possible. This has been implemented since April 1997.

All cases of initially consenting patients should have at least 1 questionnaire and a reminder questionnaire sent out **and/or** an attempted/failed visit before being deemed as withdrawn consent for direct contact.

Late notified (>6 months) and seen stroke cases will either have the six month questionnaire completed at the same time of the initial assessment (if the patient/carer is thought to probably encounter difficulties in doing the assessment retrospectively on their own) or the questionnaire and freepost envelope is left with the patient/carer to complete after explanation how to complete it retrospectively. Even late cases should have at least one further reminder/follow-up (if the questionnaire left with them is not returned) before being abandoned (withdrawn consent for direct contact).

Individualised computer printed address labels and letters for each six month questionnaire pack is produced. Packs each including an addressed freepost envelope enclosed are posted once or twice a week, about 2 weeks before the due date.

Returned questionnaires are registered and updated on the computer. Those not received by the due date are phoned by the secretary to confirm that they have received the questionnaire and that they intend to or have returned it. Should the patient/carer decide to withdraw from the study at this point, this is recorded as withdrawal prior to the six months questionnaire and dealt with as described in 12.4: Withdrawn consent for direct contact.

If not received within 1 week of the reminder telephone call, the patients details are forwarded to the delegated TSR person dealing with the six month queries and a telephonic interview is undertaken to obtain the information. Thus, ideally, all assessments will be completed within 2 weeks of the due date.

Returned questionnaires are reviewed by the secretary to check completeness (but not accuracy), any queries being noted on the front cover of the questionnaire.

Those with no queries, further suspected stroke events or investigation results outstanding are filed with the folders. The appropriate pending results boxes on the front covers of the folders are crossed.

Those that have queries (including unanswered questions), are sent on a weekly basis to the TSR person dealing with them. These are clarified and completed by telephone before being returned to the TSR office, where it is checked whether the notes may be required or not.

Those that require review of the patients records (investigation results), are filed with the patients folder and the notes requested.

Those that have a suspected stroke event are notified on the TSR as a new event for that patient. Then either their records (GP and/or hospital) are reviewed prior to considering arranging a visit; or a visit by the research associate to see the patient is arranged (after the patient is contacted by telephone, there is a strong probability of a recurrent stroke). The questionnaire is processed in the usual way as described above.

2. are those factors contributing but not directly resulting in the persons demise.

This will be able to be converted to ICD codes for aiding analysis.

Death due to:

This is what is assessed by the TSR team as the most likely cause of the persons death. This may not necessarily correspond to what has been written on the death certification (It should correspond in most cases). This will allow analysis of the cause of death by means of; the death certification, the 'actual' (most probable cause: TSR assessment) cause and by time cut-offs (e.g. Such as assuming all deaths within first week or two are due to the stroke while those in the remainder of the first month are due to a stroke complication.). This last suggestion is the one most fraught with potential errors.

If a patient died directly due to their stroke (i.e. Never recovered consciousness or progressively deteriorated without other complications) then one of the first two boxes are *ticked*.

Recurrent stroke (as recorded in the 'Establishment of Diagnosis Sheet') refers to whether the patient has had more than one stroke incident (irrespective whether prior to the start of the study or not).

A stroke complication is *ticked* when the stroke predisposes the patient to a condition which resulted in the patients death. There is no fixed time interval for this to occur. Examples are (list not comprehensive):

Septicaemia due to UTI due to incontinence / catheter as a result of the stroke.

Respiratory failure due to pneumonia due to poor cough / aspiration as a result of the stroke.

Septicaemia due to pressure sores due to immobility as a result of the stroke.

Pulmonary embolus due to a DVT due to immobility as a result of the stroke.

Other conditions apart from the stroke may precipitate any of the above and it may become difficult to differentiate stroke from being the cause of, contributing factor to or not directly associated with; the death.

Examples of causes which may not be directly related to stroke are (list not comprehensive):

Myocardial Infarction or Arrhythmia

Toxin or Electrolyte abnormality

Death due to Malignancy or its complications (unless a stroke)

Haemorrhage (Apart from ICH/SAH)

Liver failure

Renal failure

Trauma (unless predisposed by the stroke)

Bowel perforation

Chronic Obstructive Pulmonary Disease

Heart Failure

Stroke prior to this assessment:

It is a check as explained above to ensure that previous incidents which fulfil study criteria are not missed. This information is not recorded on the computer. *Tick* the 'No' box if all previous strokes (if any) are known and the relevant assessments are recorded. (Requires First or Recurrent Assessments for all previously unrecorded strokes.)

Autopsy held:

The summary and any other relevant information is noted in the free text area. This is to aid in decision making as to the cause of death which is *ticked* below. Both the autopsy cause of death and the free text is entered onto the database, but the text is not intended to be separately analysed.

I) SUDDEN DEATH ASSESSMENTS

These are patients notified as having died due to a stroke where the time between the onset of the event and the death is less than 12 hours (most cases less than a few hours or found dead). These are usually certified as 1a Stroke (or synonym).

This may be their first or recurrent notified stroke event.

IS IT A STROKE ?

10-20% of known stroke patients will die suddenly due to a myocardial infarction. ^{NEED REF!} This figure will be higher in those known to have angina and previous MIs.

Few stroke syndromes cause 'Sudden Death'.

Clues that the death is less likely to be due to a stroke are:

No noted new focal neurological deficits or brain stem signs.

Hypotension

Pyrexia

Heart failure (resulting in respiratory distress)

A preceding infective course (i.e. non-settling chest infection, ischaemic peripheries)

Marked dyspnoea (to be differentiated from cheyne-stokes respiration)

A blood picture of markedly deteriorating renal function.

The final decision will be based on the **TSR STROKE INCLUSION CRITERIA PROTOCOL 2**.

The majority of events will be excluded or included under probable stroke. The majority of these probable strokes will be community cases. It is thus expected that there will be scant information with regards to the initial signs and symptoms. Simplified Proformas extracted from the History and Examination proformas will be used. The assessment undertaken and other proformas completed are otherwise the same as before.

J) EXCLUDED ASSESSMENT

Establishment of Diagnosis Proforma (Includes Event Number and Patient Identifier Number)

See **Stroke Inclusion Criteria (Protocol No.2)**. Note: Positive, Negative and Uncertain findings *do not* correspond with the boxes ticked in the first table.

Criteria for Diagnosis

Positive Findings

- **History:** (in medical records or from patient / carer)
Reliable accurate history of focal neurological symptoms of rapid onset lasting >24 hours or still present at time of history taking.
or history suggestive of a SAH/PIH.
- **Initial Examination :** (Post event, GP or Hospital examination)
Examination compatible with and suggestive of a new stroke.
- **TSR Examination :**
New focal neurological signs or new brainstem signs lasting >24 hours or signs suggestive of a SAH.
- **Lumbar Puncture :**
Red Blood Cells in the Cerebro-spinal fluid (CSF) compatible with a bleed in a person with a history suggestive of a SAH/PIH.
Xanthochromia in the CSF.
- **CT/MRI (or angiography) :**
Confirming recent infarct or bleed. (CTs cannot reliably distinguish either a bleed from an infarct, nor the age of it, about 10 days after the incident -from RL).
- **Autopsy :**
Compatible with recent cerebral infarction or haemorrhage.

Negative Findings

- **History:**
Reliable accurate history of either a gradual progressive onset over weeks or longer of global/bilateral/more than one vascular territory, neurological symptoms, or of conditions suggestive of other than stroke such as space occupying lesions (SOL), multiple sclerosis (MS), peripheral nerve or spinal cord involvement, etc. (NB. Be aware of multiple embolic events, more than one vascular territory may be involved but each will have rapid onset of symptoms).
or
Reliable accurate history of a non-stroke event resulting in neurological signs/symptoms (e.g. infection resulting in septicaemia).
- **Initial Examination :**
Post event, GP or Hospital examination finding no focal neurological signs, brainstem signs or signs suggestive of a SAH.
or
Initial examination and investigations confirming a non-stroke event resulting in neurological signs/symptoms (e.g. electrolyte disturbance).
- **TSR Examination :**
Peripheral nerve lesions.
No focal neurological signs, brainstem signs or signs suggestive of a SAH.
- **Lumbar Puncture :**
No Red Blood Cells or xanthochromia in the CSF in a person with a history and examination suggestive of a SAH.
- **CT/MRI (or angiography) :**
Showing intracranial pathology other than vascular pathology causing the neurological signs and symptoms such as SOLs, demyelination, abscesses, subdurals, extradurals etc.
- **Autopsy :**

Not compatible with recent cerebral infarction or haemorrhage.

Uncertain Findings

- **History:**
Unreliable.
SAH and massive PIH with coning, are the only types of stroke which can cause 'sudden' death within an hour or so.
- **Initial Examination :**
Neurological examination not detailed.
Post event, GP or Hospital examination findings of a probable cause for this event (such as myocardial infarction, infection, fracture, trauma, etc.) more likely than that of a stroke.
- **TSR Examination :**
Unsure whether new or old signs. i.e. when the degree of residual deficit in a patient with previous pathology (of any cause) before this event occurred is not known.
- **Lumbar Puncture :**
Failed/Traumatic tap in a person with a history and examination suggestive of a SAH.
Less than 50% of PIHs have positive LPs.
- **CT/MRI (or angiography) :**
Normal, showing no infarcts or bleeds. (CTs may be normal in the first 48hrs following an infarct. A normal CT is common in cerebral infarction.).
Lacunar infarcts may not be detectable on CT.
MRI is more specific (technology dependent but normal MRI excludes all but the most trivial infarct/haemorrhage)
Old or non-compatible infarcts.

Not Available

- When a finding is not recorded/requested or unobtainable.

The First Table is completed. In most cases, a TSR examination will not be necessary for excluding the patient (i.e. the patient has **Negative findings**). If the Criteria for a Definite or Probable Stroke are not fulfilled then the patient is excluded.

Definite Stroke

2 or more positive findings
and
either no negative findings or findings not available.

OR

Positive autopsy finding

Probable Stroke

1 positive finding
and
1 or more uncertain findings
and
either no negative findings or findings not available.

Tick the box which best corresponds to the reason of exclusion.

Note: Transient Ischaemic Attacks are when *symptoms* resolve within 24 hours. *Signs* may still be elicited but the patient and carer are not aware of the deficit/sign.

Primary Brain Tumours are recorded under 'intracranial neoplasm', but metastases are recorded under 'other'.

In all cases where the Other box is ticked, a reason for the exclusion must be stated with further details noted below or on the back of the Establishment of Diagnosis Sheet. In cases where a definite TIA occurs in addition to an 'Other' cause (e.g. Seizure / Hypoglycaemia / Arrhythmia etc.) *tick* both relevant boxes. In those cases, in addition to the 'Other' cause for exclusion, the TIA is uncertain, *tick* only the 'Other' box, but specify '?TIA' as well.

Reason for change in Data Collection: (up dated : Last 06/96)

Present staffing levels are unable to cope with obtaining the detailed amount of information which was initially envisaged would be essential.

After One Year of comparison data collection:

1. Histories (First Assessment from both the Medical Records and from the Patient/Relative)

This is a duplication of data and a large proportion of the excess workload.

The proposal is to obtain a single set of data from the single most reliable source (but if necessary in uncertain cases, more than one source) starting from the 01 July 1996.

There should be little or no need for alterations in either the Proformas or the Database structure (although possibly the Database Proforma may need slight modifications).

2. Examination

The 24hour Examination is an unreliable way of recording the full assessments carried out by the Medical Team as more detailed examinations are usually carried out on the day following admission or (in NTGH) on transfer to the Stroke Unit.

There seems to be 3 important items to record in the first 24 hours:

- GCS

- BP at 24hrs

- Whether there was difficulty with swallowing (Any Source: Medical or Nursing Records)

There is scope for inferring of information: e.g. If a patient was kept NBM and on IVT then it is acceptable to assume that there was concern with the safety of swallowing.

Again, there should be no need to change Proformas or the Database (although modifying/deleting certain sections may make data entry easier).

The 7day Neurological Examination may have one of two purposes:

- Subtyping the Stroke

- Analysis of finding in different Subtypes of strokes.

If both are wanted, then this should be unchanged, although certain parts could be done by the Research Nurse: (the following are examples only)

GCS : This can be difficult at times.

AMTS : There is a protocol explaining how to do the test and score the results.

Drawings

BP : Standardisation may be a problem.

If it is to subtype the stroke only, then once the Subtype is clear, not all sections of the Neurological Examination is necessary.

There has been no agreement as yet whether an examination is appropriate (for analysis purposes) after a certain interval after the stroke, although in some cases it provides confirmatory evidence of the stroke. (Some patients are notified more than 3 months after their strokes and at least one has not been assessed by the TSR team 6 months after their incident stroke). Perhaps a 2 month/new stroke cut-off, with Research Nurses obtaining First Assessment History/Pathways and Therapy information for delayed notifications (possibly doing the HAVs - No extra transport costs) ?

Late examinations are also unreliable in subtyping as it would underestimate deficit. Previous studies have shown a majority recover from inattention within one month of their stroke.¹ Power recovery is also variable which may result in difficulty in deciding between LACS and PACS. Late studies are also NOT reliable in some data (e.g. AMTS/GCS) collected (although the GCS and other findings could in certain circumstances be extrapolated from the History and Present findings).

Retrospective Examinations, where a patient being seen for a stroke is found to have had a previous stroke within the study period, is almost impossible to do meaningfully (Should NOT be included in analysis), but is occasionally useful in confirming the previous incident and the subtype (esp. in cases when a different side is affected).

1. D H Barer: QJofM, NS 74, No. 273, pp21-32, Jan 1990:

Extrapolated: Inattention in Incontinent and Non-incontinent strokes combined.

Tactile	D1	%	M1	%	Visual	D1	%	M1	%
Impaired	136	53	63	25		210	63	76	28
Normal	122	47	193	75		125	37	193	72

3. Investigations (After review with BH): First Incident (subsequent Incidents: record only Post incident results)

It may be more appropriate to record whether certain investigations were performed only:

The following is a possible future Investigation record:

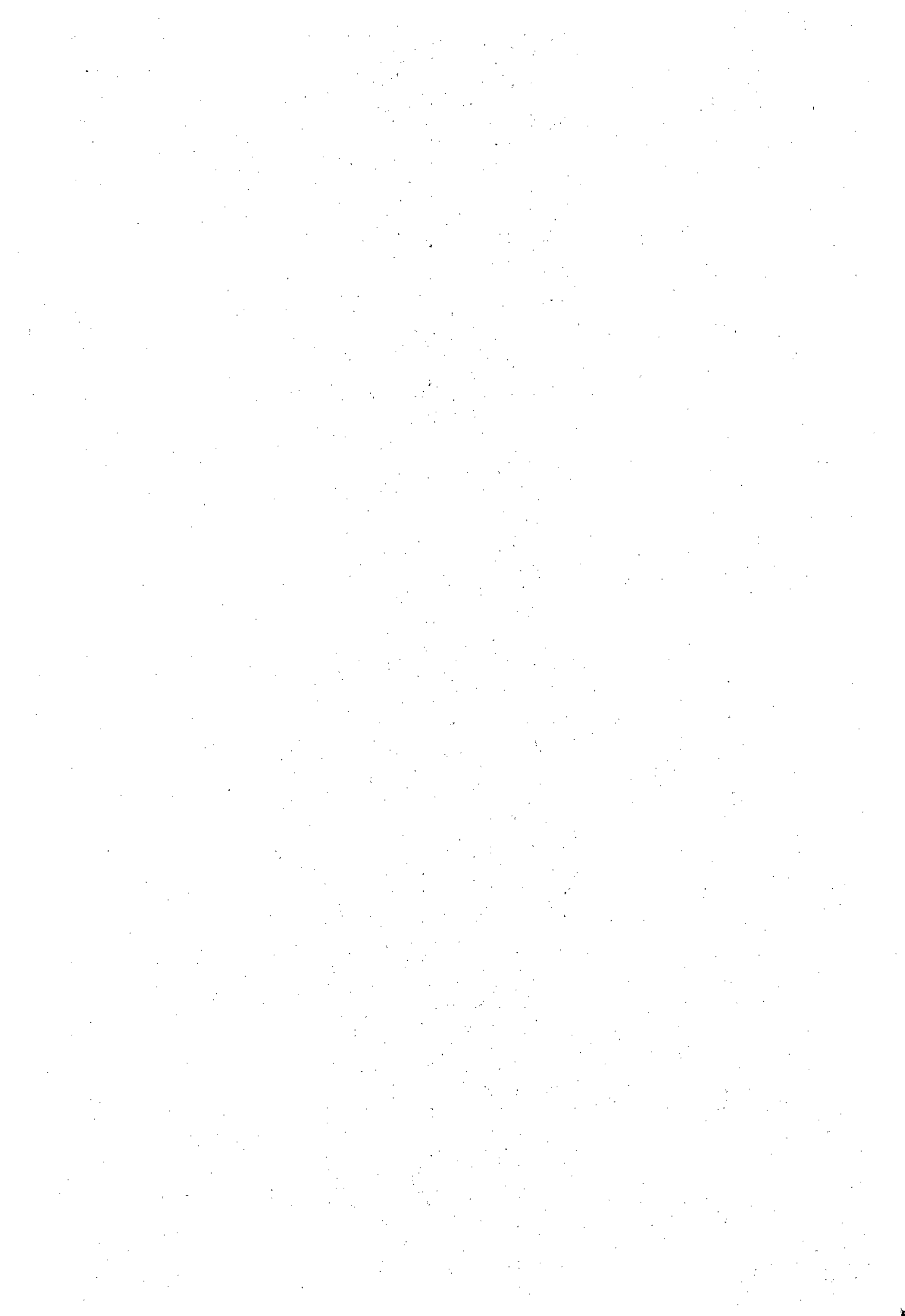
- 1st Coagulation Screen result after incident **if** patient has bleeding disorder or on anticoagulants.
- Glucose (random) during admission/week prior to stroke.
- ?whether tested in past (year/six months). :Excl. Date
- Cholesterol (random) whether tested in past (year/six months). :Excl. Date
- ECG unchanged.
- ?whether SR/AFib/Isch. Changes/LVH only
- Echo unchanged.
- ?whether done or not within six months of event (pre or post) :Excl. Date
- Carotid dopplers unchanged.
- ? whether done or not within six months of event (pre or post) :Excl. Date
- CT head unchanged.
- MRI unchanged.
- ?whether done or not within six months of event (pre or post) :Excl. Date
- Carotid Angiography: whether done or not within six months of event (pre or post) :Excl. Date
- MRA: whether done or not within six months of event (pre or post) :Excl. Date
- Immunology/Specific Haematology: whether done or not within six months (post)/unlimited time period (pre) of event :Excl. Date
- Carotid Endarterectomy Operation unchanged.
- Cerebral Aneurysm 'Clip' Operation unchanged.

This would result in no longer recording whether the following investigations were carried out:

- FBC
- U&E
- Fructosamine/HbA1c
- VDRL/TPHA/CEPTIA etc.
- CXR
- EEG
- 24 HR ECG tape
- 24 HR BP tape

4. Notifications:

To only record the first ever notification from July 01 1996.



APPENDIX 3

RELEVANT TSR PROFORMAS

Front Page – Patient assessments check list

Patient consent form

Patient information sheet

Establishment of Diagnosis

Pathway and Notifications

History/First Assessment

Examination

Therapy and Complications

Therapy and Services

Investigations and Operations

One Month Assessment

Six Month Review

Death Assessment

Patient Check List

Patient Name : _____

Patient Id : _____

Enter a cross if not available or inappropriate

	1		2		3	
	Completed	Entered	Completed	Entered	Completed	Entered
Consent	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Diagnosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
History/Recurrent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Examination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pathways	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Investigations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pending Results	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1 Month	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 Months / Limited	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Notes :

H + E NTGH or DMH	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other Hospital _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other Hospital _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GP Notes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Missing Data :

Incident	Incident	Incident

Patient Id: _____

Event No. : _____

	Diagnosis of STROKE compatible with:	Yes	No	Not certain	Not available
1	History (at initial TSR assessment or medical notes)				
2	Initial medical examination				
3	TSR "One week" examination				
4	CT / MRI brain scan				
5	Lumbar puncture				
6	Autopsy findings				

Final diagnosis:

Stroke (deficit persisting for >1 week) / SAH (Subarachnoid Haemorrhage) / PIH

RIND (resolving ischaemic neurological deficit; <1 week, >24 hrs)

Probable Stroke, but not certain.

TIA (deficit lasting <24 hrs)

Intracranial neoplasm

Other (Specify _____)

Inclusion in Register:

Yes (incl. Probable Strokes)

No

If No, reason for exclusion:

If Included:

First ever stroke.

Recurrent stroke.

If Included:

Cerebral infarct - Assumed (CT Normal / Non-compatible infarct).

Cerebral infarct - Confirmed (CT Infarct in territory of new deficit).

Cerebral infarct with secondary haemorrhagic transformation (CT / MR).

Primary intracerebral haemorrhage (CT / PM / MR confirmation).

Subarachnoid haemorrhage (CT / MR / LP confirmation).

Stroke, but not known whether infarct or haemorrhage.

If Primary intracerebral haemorrhage or S.A.H., cause ?

Berry aneurysm

Arterio-venous malformation

Blood disorder eg. bleeding diathesis

Other (Specify _____)

None identified / Not known

If Subarachnoid Haemorrhage, *Hunt and Hess*¹ Grade ?

Grade I+II : Asympt. / Severe headache, no neuro. deficit other than CN palsy.

Grade III : Drowsiness and mild deficit.

Grade IV : Stupor, mod. to severe hemiparesis / early rigidity / vegetat. disturb.

Grade V : Deep coma, decerebrate rigidity and moribund appearance.

Not Known

If diagnosis is Stroke, RIND or Probable Stroke, determine subtype (excl. SAHs) :

	Area affected	Yes	No	Not certain
1	Unilateral weakness (and/or sensory deficit) affecting face			
2	Unilateral weakness (and/or sensory deficit) affecting arm/hand			
3	Unilateral weakness (and/or sensory deficit) affecting leg/foot			
4	Dysphasia / Aphasia			
5	Homonymous hemianopia			
6	Quadrantanopia (if No hemianopia)			
7	Visuospatial disorder eg. sensory or visual inattention			
8	Brainstem / cerebellar signs.			
9	Other deficit			

Subtype:

Total anterior circulation syndrome

Partial anterior circulation syndrome

Posterior circulation syndrome

Lacunar syndrome

Not certain (eg. if more than one subtype fulfilled or asymmetrical bilateral involvement.)



CONSENT FOR PATIENTS WITH STROKE
AND THEIR CARERS TO REGISTER WITH THE
TEES STROKE REGISTER

NAME OF PARTICIPANT

NAME OF CARER/ RELATIVE*

I consent to take part in the Tees Stroke Register **
and

I consent to the TSR research staff looking at my medical records.

(**delete if only medical records looked at.)

I understand the research is designed to increase medical knowledge to try to improve care of people with stroke.

I have read the note of explanation and have had time to think about it.

I have also had the study explained to me by the research doctor/nurse.

Consent can be withdrawn at any stage without reason and without prejudice to treatment in any way.

All information is entirely confidential.

I have a copy of the information sheet and this consent form and I am happy to be part of this study.

Signed Date
(Participant)

I am the main carer/closest relative* and I agree that we (carer/relative and participant) would be happy to be part of this study.

Signed Date
(Carer/Relative)

If either party is dissatisfied in any way as a result of taking part in this project, you can speak or write to the Local Research Ethics Committee. Enquiries to Dr M. J. Smith, Department of Mental Health, North Tees General Hospital, Tel.: (01642) 617617 ext. 4320.

I confirm that I have explained the nature of the Tees Stroke Register to the above, and have given time for any queries to be answered.

Signed Date/...../.....

Name Post Research Nurse / Doctor*

*delete as appropriate



Information for patients and relatives

Stroke is a very important illness, particularly in the Northeast. We have been funded by the Department of Health to look at all the people with strokes or suspected strokes, how individuals and their families are affected by stroke and what help they receive. We also hope to find out more about the causes of stroke, the speed of recovery and especially why stroke is particularly common in the north.

The study is headed by Dr Barbara Herd and Dr Jeremy Murphy, both of whom are consultant physicians in the area, with support from Dr Richard Thomson and Dr Helen Rodgers from the University of Newcastle upon Tyne. Dr Akif Gani is the research doctor who will be helped by research nurses.

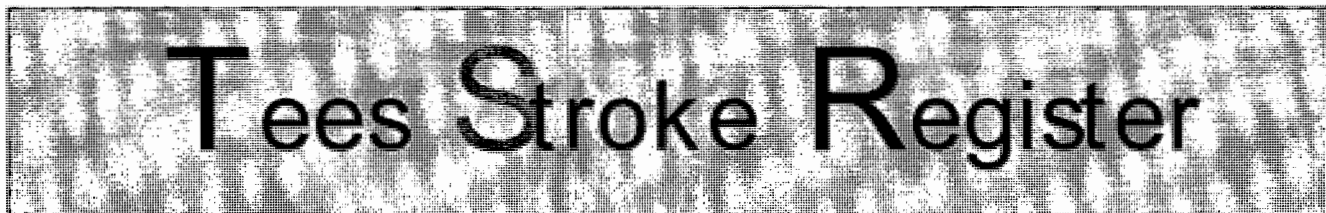
We would like to invite you to take part in this study. You will be contacted by telephone or personally by a member of the research team. If you agree to participate, we will ask you and your relatives a few questions about the stroke, your health and present circumstances. This will be followed by a short examination. No extra tests or tablets are involved. Thereafter, we will either write to you or find out via the telephone about your progress after one month and six months. In addition, we would like your permission to obtain information about your stroke and medical background from your medical records.

If the stroke has made it difficult for you to understand or give your consent, a close relative or carer will be asked.

If at any stage, you or your relatives/carers require further information, please do not hesitate to ask us. The study team can be contacted on : 01642-624896 (24 hour number with answer-phone).

All information is entirely confidential. Participation in the study will not affect your care in any way and you are entirely free to refuse to take part at any stage.

As a result of this study we hope to be able to improve the services provided for stroke patients and their families in the future.



Thank you for your help in this important study.

Pathway through Care

Event	Date	Time	Name/Profession	IP OP	Location
Onset					
1st professional contact					
1st medical contact					
A/E contact					
1st OP contact			Consultant		Outpatients Dept. Domiciliary Visit
Admission Ward			Consultant		
Transfer 1			Consultant		
Transfer 2			Consultant		
Transfer 3			Consultant		
Transfer 4			Consultant		
Transfer 5					
Transfer 6					
Placement					Home N-Home Res:Home Other
Discharge A					
Re-admission 1			Consultant		
Discharge B					
Re-admission 2			Consultant		
Discharge C					
Death			certifying doctor		

*In Hospital within 7d of Stroke Event (beginning) : YES NO Not Known

admitted* to hospital: 1st Admission requested by:

- GP
- Deputising service
- Self/Carer/Neighbour/Relative referral to A/E
- Hospital doctor (DV, OP clinic)
- Other (specify) _____
- Not known

1st Ambulance contact:

- Paramedic
- Non-paramedic
- Not able to specify
- Not applicable

Sources of Notifications

Patient Identifier : _____

Source (may be more than one source)	Specification (Circle Appropriate)	Date (for each notification)	Method (D/F/Ph/P/S or L)
GP / Deputising Service			
Nursing Home	North Tees	Darlington	
Resident Medical Officer	North Tees	Darlington	direct
Other Hospital doctor	Medical Surgical	OPD A/E	
Nurse	Ward	District / Community	OPD A/E
Clerk / Secretary	Ward	GP	OPD A/E
Ward admission book	North Tees	Darlington	direct
Ward death certificate book	North Tees	Darlington	direct
CT scan register / records	North Tees	Darlington	list/sheet
GP registers / records			list/sheet
Dr Winn / BA register	Bishop Auckland		list/sheet
DHA admission data	Tees Health	Durham	list/sheet
DHA death data	Tees Health	Durham	list/sheet
Hospital discharge records	North Tees	Darlington	list/sheet
Regional admission data	Northern & Yorkshire RHA		list/sheet
Other (specify _____)			

First admission : Transport to hospital by:

-
-
-
-
-
-

- Ambulance (request unknown)
- Ambulance (requested by doctor)
- Ambulance (999 call by patient/carer/relative/neighbour)
- Own transport
- Taxi
- Other (specify) _____
- Not known

History/First Assessment



- Patient
- Patient's spouse / partner
- Relative (relationship) _____
- Friend / neighbour
- Nursing Home Staff / records
- Hospital records / GP referral letter
- GP records
- Ward staff

Patient Identifier: _____

Assessor : _____

Location (incl.Hosp.): _____

Date of Assessment: ___/___/___

Sources of data :
(tick)

Section 1: Patients Personal Details

Sex: M F Age: ___ yrs

- Ethnic group:
- a) White
 - b) Black
 - c) Asian
 - d) Oriental
 - e) Other ethnic group
 - f) Unsure

*If Known:
(Specify for b/c/d)*

- Black Caribbean
- Black African
- Bangladesh
- Indian
- Pakistani
- Chinese
- Other

- Marital status:
- Single never married
 - Married (Present/Prev.)
 - Not known

- If previously married*
- Widowed
 - Divorced / separated

Cohabiting

Section 2: Acute Event

a) Narrative history / examination:

Symptom	Before	After	No
Headache			
Nausea			
Vomiting			
Blurred vision			
Palpitations			

b) History of event

Date: ___/___/___

Time of Stroke (or time of waking): ___ h ___

Location: _____

Awake or Asleep : _____

c) Early features (within the first 24 hours post stroke *or on completion of evolving stroke)

Yes No DK

i) History of global impairment of level of consciousness ?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

- If yes* - Loss of consciousness / coma
- Drowsiness

- Confusion
- Not specified

ii) Urinary incontinence -Incontinence within the first 24*hrs ?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

If yes -Present prior to this stroke ?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

iii) Difficulty with swallowing within first 24*hours of stroke ?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

If yes -Present prior to this stroke ?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------

Yes No NK

c) Is there a past history of hypertension ?

--	--	--

if yes, on treatment at time of stroke?

--	--	--

Is there a history compatible with:

d) Irregular pulse / heart beat

--	--	--

if yes: Atrial fibrillation (told to patient/recorded in notes)

--	--	--

e) Angina?

--	--	--

f) Previous MI? (Date of last MI if 'Yes' : ___ / ___ / ___)

--	--	--

g) Cardiac surgery / Invasive investigation ?

--	--	--

if yes, (tick and date latest)

angiography	<input type="checkbox"/>	_____	valvular surgery- replacement	<input type="checkbox"/>	_____
angioplasty	<input type="checkbox"/>	_____	- other	<input type="checkbox"/>	_____
CABG	<input type="checkbox"/>	_____	pacemaker insertion (permanent)	<input type="checkbox"/>	_____
not known	<input type="checkbox"/>	_____			

h) Valvular heart disease / Septal defects ?

--	--	--

if yes,

mitral stenosis	<input type="checkbox"/>	aortic regurgitation	<input type="checkbox"/>
mitral regurgitation	<input type="checkbox"/>	other _____	<input type="checkbox"/>
aortic stenosis	<input type="checkbox"/>	not known	<input type="checkbox"/>

i) Hyperlipidaemia

History of raised lipids?

--	--	--

Presently or previously treated?

--	--	--

if yes, diet? drug treatment?

if drug treatment known, name of drug ? _____

j) Peripheral vascular disease

History compatible with claudication / diagnosis of P.V.D. made ?

--	--	--

Peripheral artery surgery / Invasive investigation?

--	--	--

if yes, (tick and date latest)

angiography	<input type="checkbox"/>	_____	lower limb bypass graft	<input type="checkbox"/>	_____
angioplasty	<input type="checkbox"/>	_____	amputation	<input type="checkbox"/>	_____
aortic aneurysm repair	<input type="checkbox"/>	_____	not known	<input type="checkbox"/>	_____

k) Carotid endarterectomy

History / record of carotid endarterectomy

--	--	--

if yes, (tick and date) left _____ right _____

m) Malignancy

Has the patient got or ever had a malignant tumour?

--	--	--

if yes, describe - year of diagnosis _____
 - whether still present _____
 - primary site/extent _____

--	--	--

n) Epilepsy diagnosed before current stroke ?

--	--	--

if yes, age of onset _____
 date of last seizure _____

Section 5: Medication

a) Taking **ASPIRIN** at the time of the stroke ?

if yes, dose _____ mg
 when commenced _____
 why? (Tick all boxes that apply)
 previous stroke / TIA
 previous MI / angina
 atrial fibrillation

Not known
 Not known

P.V.D.
 other (specify) _____
 not known

--	--	--

if no, any contra-indications to aspirin* ?

if yes, (tick) Prev. Intolerance/Allergy
 Previous Ulcer(s)
 Prev. Lower GI bleeding
 Bleeding Disorder**

Present Gastritis/Heartburn
 Present Ulcer(s)
 Present Lower GI bleeding
 Other _____

--	--	--

(*Exclude Warfarin as a contra-indication. **Haematological Disorder predisposing to Bleeding)

b) Taking **WARFARIN** at the time of the stroke ?

if yes, when commenced _____
 why? (Tick all boxes that apply)
 previous stroke / TIA
 previous MI
 irregular pulse / atrial fibrillation
 pulmonary embolus

P.V.D.
 D.V.T.
 valvular heart disease
 other (specify) _____
 not known

--	--	--

d) List medication taken regularly at the time of current stroke:

Not known

Section 6 : Lifestyle History

b) Smoking (Cigarettes only)

(i). Which best described the patient at the time prior to this stroke ?

Non-smoker

-Never smoked ?

Current or Ex-smoker

If yes- Within the last month(30 days) of present stroke ?
 (ie. If yes, then - Current Smoker)

Not known

(ii) If current or ex-smoker,

Number of years smoking ? _____ yrs

If current, -Number of cigarettes/week on average within the last year ? _____

-If previously different, - number of cigarettes/week then ? _____

-Still smoking since this stroke ?

--	--	--

If ex-smoker, -Number of cigarettes/week on average when patient was smoking ? _____

-How long has the patient not been smoking ?

<6 months
 6mo.-1year
 >1year-18mo.
 >18mo.-2years

>2-5 years
 >5-10 years
 >10 years
 not known

c) Alcohol

(i) How often at the time prior to this stroke, did the patient drink alcohol, including home-brew ?

(tick one box only)

Non-drinker	-Has never drunk alcohol		<input type="checkbox"/>
	-Used to drink alcohol, but none for at least 1 month(30 days) prior to this stroke	-occasionally	<input type="checkbox"/>
		-regularly	<input type="checkbox"/>
Current	-Drinks alcohol once or twice a month or less		<input type="checkbox"/>
	about once a week		<input type="checkbox"/>
	2 or 3 times a week		<input type="checkbox"/>
	on most days		<input type="checkbox"/>
	every day		<input type="checkbox"/>
Not known			<input type="checkbox"/>

(ii) *If current*; record average no. of units of alcohol per week (before this stroke) _____ u

Not known

<=2 units

Section 7: Social History

a) Place of usual residence at the time of this stroke *(tick one box only)*

own home/family home or other private residence	<input type="checkbox"/>	(Registered) Nursing home	<input type="checkbox"/>
sheltered housing (warden controlled)	<input type="checkbox"/>	Hospital / Continuing care	<input type="checkbox"/>
Residential Care Home	<input type="checkbox"/>	Not known	<input type="checkbox"/>
Other (specify) _____	<input type="checkbox"/>		

(If patient lives in "Residential/Nursing home/Hospital", then proceed to section 8 else proceed to section 7 b)

b) The accommodation in which the patient lives is: *(Please tick one box only)*

- owned outright by the patient or his/her family	<input type="checkbox"/>
being bought with a mortgage or loan by the patient or his/her family	<input type="checkbox"/>
rented from a private landlord	<input type="checkbox"/>
rented from a council	<input type="checkbox"/>
- rented from a housing association or charitable trust	<input type="checkbox"/>
rented or rent free with a job, farm, shop or other business	<input type="checkbox"/>
other (specify) _____	<input type="checkbox"/>
Not known	<input type="checkbox"/>

c) The accommodation in which the patient lives is: *(Tick one box only)*

on ground floor level only	<input type="checkbox"/>
on ground floor and upper levels	<input type="checkbox"/>
on upper level(s) only, with lift access	<input type="checkbox"/>
on upper level(s) only, with no lift access	<input type="checkbox"/>
Not known	<input type="checkbox"/>

d) How many rooms does the household have for its own use? Total no. _____ * Not known

e) Who lives with the patient? *(Please tick all boxes that apply)*

no one	<input type="checkbox"/>	daughter-in-law(s)	<input type="checkbox"/>	parent(s)	<input type="checkbox"/>
husband / wife / partner	<input type="checkbox"/>	son-in-law(s)	<input type="checkbox"/>	other relative*	<input type="checkbox"/>
daughter(s)	<input type="checkbox"/>	sister(s)/brother(s)	<input type="checkbox"/>	other**	<input type="checkbox"/>
son(s)	<input type="checkbox"/>	grandchild(ren)	<input type="checkbox"/>	not known	<input type="checkbox"/>

(*specify relationship _____ **specify relationship _____)

f) How many adults (over 16 years at last birthday) are there living in the home ?* _____ Not known

g) How many of these adults are aged over 65 ?* _____ Not known

h) How many children (aged 0 to 15 years) are there living in the home ?* _____ Not known

i) Driving/Vehicles

Yes No DK

(i) Does the patient currently have a valid driving licence ?

If yes, does the patient have a HGV (Heavy Goods Vehicle) licence ?

(ii) Has the patient been driving in the month (30 days) prior to this stroke ?

(iii) Does the patient or any other members of his/her household normally have the use of a car or van ?

If yes, does the patient or any other members of his/her household own a car or van ?

Section 8: Economic and Education History

b) Employment status

- Retired
- Working for an employer full-time(more than 30 hrs / week)
- Working for an employer part-time(less than 30 hrs / week)

- Self-employed or employing other people
- On a government employment or training scheme
- Waiting to start a job already accepted

- Unemployed and looking for a job
- Unable to work because of long term illness or disability
- Looking after the home or family

- In full-time education
- Other (specify) _____
- Not known

c) Occupation (current or previous)

Male (or husband of married or widowed women)
 _____ Not known

Female (regardless of marital status)
 _____ Not known

d) Benefits (Excluding ALL pensions)

Does the patient receive benefits ?

Yes	No	DK
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If yes, type(s) of benefit(s) ?

1) For people on low incomes

- Income Support
- Housing Benefit
- Council Tax Benefit

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

2) Unemployment Benefit (only available upto age 65-F and 70-M)

<input type="checkbox"/>

3) For sick, injured or disabled people

- Statutory Sick Pay
- Incapacity Benefit (prev.Sickness/Invalidity benefit)
- Severe Disablement Allowance (<65 for init. claim)
- Attendance Allowance (only if >65yrs old)
- Disability Living Allowance (<65 for initial claim)
- Disability Working Allowance.(must still be working)

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

4) Independent Living Fund Payments

- Mobility Supplement
- Community Care Grant
- Invalid Care Allowance (For people of working age caring for a severely disabled person)

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

5) Other _____

<input type="checkbox"/>
<input type="checkbox"/>

6) Not known which (other) benefit(s) received

e) Income (before stroke; post tax; includes the whole households income preferably)Whole Household Not wishing to disclose Patient and Spouse/Partner Not Known

per annum

which is the same as

per week

£0 - £2,499

up to £47

£2,500 - £4,999

£48 - £96

£5,000 - £9,999

£97 - £192

£10,000 - £14,999

£193 - £288

£15,000 - £19,999

£289 - £384

£20,000 - £24,999

£385 - £481

£25,000 - £29,999

£482 - £577

£30,000 - £34,999

£578 - £673

£35,000 - £39,999

£674 - £769

£40,000 - £44,999

£770 - £865

£45,000 - £49,999

£866 - £961

over £50,000

over £962

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

Please check whether patients' handedness is recorded in the examination, else record here: _____
 whether Barthel has to be inferred from the history and has been completed.

Examination

T R
tees stroke register

Patient identifier: _____

Assessor: _____

Location (incl. Hosp.): _____

Date of Assessment: ___ / ___ / ___

All Clinical findings are those at First Assessment Examination

(tick)

OR medical records on day 7*-else d8/d6/d9/d5

All Medical Record findings are of those in the First 24hrs post stroke

(tick)

OR at Admission if available (or GP notes if not admitted).

N/A N/A

NEUROLOGICAL EXAMINATION

1. Conscious level (On day 7*-else d8/d6/d9/d5-circle appropriate day; and in first 24 hrs)-Circle Number:

<u>Eye opening</u>	<input type="checkbox"/>	<u>Best motor response</u>	<input type="checkbox"/>	<u>Best verbal</u>	<input type="checkbox"/>
Never	1 1	None	1 1	none	1 1
To pain	2 2	Extension to pain	2 2	Incomprehensible	2 2
To sound	3 3	Flexion to pain (abn)	3 3	Inappropriate	3 3
Spontaneously	4 4	Flexion to pain (n)	4 4	Confused	4 4
		Localises pain	5 5	Orientated	5 5
		Normal	6 6		

Total - At First Assessment (Now) / First 24hrs

___ / ___ /

2. Mental Test Score (now-Score 1 for correct response - tick or write in each individual score)

UTA

Age	_____	WWI / WW2	_____
Time to nearest hour	_____	DOB	_____
Address for recall at end	_____ 42 West St.	Recognise 2 persons at bedside	_____
Name of hosp / town	_____	Name of Monarch	_____
Year	_____	Countdown (20 - 1)	_____

Score: ___ / 10

3. Visuospatial disorder / inattention

1) Patient to draw a clock face here (including numbers).

UTA

clock

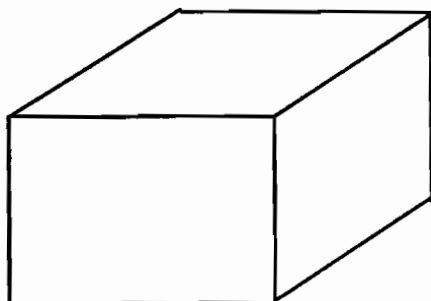
box

tick if correctly drawn

cross if incorrect

clock

2) Patient to copy a 3D box here.



3D box

		Day7* Assessment			First 24hr Exam.		
		Yes	No	UTA	Yes	No	NR
4. Dysphasia	Is the patient dysphasic/aphasic?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>If yes,</i>						
	Receptive dysphasia ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Expressive dysphasia ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	i) <u>Receptive language</u>						
	"Close your eyes"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
	"Does a stone sink in water"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
	"Point to the ceiling"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
	ii) <u>Expressive language</u>						
	Able to name 3 objects*?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
<i>If yes,</i> correctly name function of objects?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				

*eg. Pen-write/Watch-time/Spectacles-looking.

5. Dysarthria	Is the patient dysarthric?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>If yes,</i>						
	slight slurring	<input type="checkbox"/>	<input type="checkbox"/>				
	difficult to understand	<input type="checkbox"/>	<input type="checkbox"/>				
	incomprehensible	<input type="checkbox"/>	<input type="checkbox"/>				

6. Dysphagia	Is there evidence of difficulty swallowing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Is there evidence of dysphagia on 10ml (water) swallow standardised assessment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Motor power

Day7* Assessment

First 24*hr Exam.

(tick all appropriate boxes)

i) Is the patient normally	Right-handed	<input type="checkbox"/>	<input type="checkbox"/>	Left-handed	<input type="checkbox"/>	<input type="checkbox"/>
	Ambidextrous	<input type="checkbox"/>	<input type="checkbox"/>	Not Known	<input type="checkbox"/>	<input type="checkbox"/>
	RIGHT	ARM	LEG	LEFT	ARM	LEG
ii) Power	No movement	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Weakness present	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Normal power	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	UTA/Not Recorded	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

iii) *If no unilateral signs then tick Not Applicable and proceed to part 8, else assess side of new onset weakness*

Motricity Index (each scored as below) Side Tested Right Left Not Applicable

- | | | | |
|-----------------------|-------|-----------------------|-------|
| 1. Pinch grip | _____ | 4. Ankle dorsiflexion | _____ |
| 2. Elbow Flexion | _____ | 5. Knee extension | _____ |
| 3. Shoulder abduction | _____ | 6. Hip flexion | _____ |

The 'Motricity Index' after Demeurisse *et al*, 1980.

Test 1	Score	Criterion	Tests 2-6	Score	Criterion
	00	no movement.		00	no movement.
	33	beginnings of prehension.		28	palpable contraction, but no movement.
	56	grips cube, without gravity.		42	movement without gravity.
	65	holds cube against gravity.		56	movement against gravity.
	77	grips against pull, but weaker than other side.		74	movement against resistance, but weaker than other side
	100	normal.		100	normal.

8. Sitting balance	Does the patient require support to sit ?	Yes	No	Yes	No	NR
	(If patient is able to sit without support then tick <i>no</i> else <i>yes</i> .)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14 General Examination

(Record Medical Notes findings (most recent complete entry) if patient deceased or out of area- tick box)

If medical notes used, most recent date of Medical findings: ___/___/___

a) Body build: Lean
 Normal
 Overweight
 Obese
 NR

If known: Wgt _____
 Height _____

b) Pulse:

i) regular
 irregular
 irregularly irregular
 Not Recorded

ii) radial inequality? Yes UTA/NR
 No
 If yes, record BP in both arms R ___/___
 L ___/___

c) BP (non-stroke arm) phase V

i) Day post CVA ? ___ systolic ___
 diastolic ___

ii) 24 hours Post CVA systolic ___
 diastolic ___
 Not Known

d) Bruits

	Yes	No	NR
Carotid Left	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Right	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

e) Cardiac murmurs (Left-sided heart murmurs only)

Yes <input type="checkbox"/>	No <input type="checkbox"/>	NR <input type="checkbox"/>	If yes, specify	systolic <input type="checkbox"/>	diastolic <input type="checkbox"/>	Not Recorded <input type="checkbox"/>
				aortic systolic <input type="checkbox"/>	aortic diastolic <input type="checkbox"/>	
				mitral systolic <input type="checkbox"/>	mitral diastolic <input type="checkbox"/>	

f) Barthel ADL Index Day 7* Assessment **Inferred from History** **Not Known /**
 (what patient is presently doing, not what patient may be capable of doing.) **Records** **Not Applicable**

- | | | | |
|--------------------------------|---|--|-------|
| 1. Bowel | 0 = incontinent
2 = continent | 1 = occasional accident (<=1/week) | _____ |
| 2. Bladder | 0 = incontinent (or catheter)
2 = continent | 1 = occasional accident (<=1/day) | _____ |
| 3. Grooming | 0 = needs help | 1 = independent (for face/hair/shaving) | _____ |
| 4. Toilet | 0 = dependent
2 = independent in all actions | 1 = need some help | _____ |
| 5. Feeding | 0 = dependent
2 = independent in all actions | 1 = need some help, e.g. cutting | _____ |
| 6. Transfers from bed to chair | 0 = unable to sit out of bed
2 = needs help of 1 or supervision | 1 = needs major help (2 people) but can sit out
3 = independent | _____ |
| 7. Mobility | 0 = immobile
2 = walks 50m* with help
(*or indoors from room to room) | 1 = propel self in wheelchair
3 = walks 50m* independently | _____ |
| 8. Dressing | 0 = dependent
2 = independent (includes buttons, zips, laces) | 1 = need help, does half | _____ |
| 9. Stairs | 0 = unable to manage
2 = independent | 1 = needs help | _____ |
| 10. Bathing | 0 = unable to manage | 1 = independent (bath or shower) | _____ |

Score ___/20

THERAPY and SERVICES

Date of stroke: / /

Event	Services received before stroke* Date	C V A	Days post stroke Wk 1							Week 1 Summary	Days post stroke Wk 2							Week 2 Summary	Days post stroke Wk 3							Week 3 Summary	Days post stroke Wk 4							Week 4 Summary	Fill in if pre-discharge Weeks 5 6 7			
			1	2	3	4	5	6	7	frequency (number)	1	2	3	4	5	6	7	frequency (number)	1	2	3	4	5	6	7	frequency (number)	1	2	3	4	5	6	7	frequency (number)				
*prior 4 weeks		0	1	2	3	4	5	6	7	frequency (number)	1	2	3	4	5	6	7	frequency (number)	1	2	3	4	5	6	7	frequency (number)	1	2	3	4	5	6	7	frequency (number)	5	6	7	
Physiotherapy																																						
Occ. Therapy																																						
Speech therapy																																						
Dietitian																																						
Social worker																																						

For Social worker, only fill in the letters R and S representing the day of referral (R) and the day first seen (S).

If physiotherapy received, specify where received : In-patient**
 (fill in appropriate letters on form above) Out patient department O
 **and how often/day received Community/Domiciliary C
 Day Hospital H

If Home Visit(s) done by occupational therapist, specify: Date of visit: / / (for first / main visit in all cases)

Which people attended?
 (tick / number)

Patient	<input type="checkbox"/>	Number of Family Members	<input type="checkbox"/>
Occupational Therapist	<input type="checkbox"/>	Community Occupational Therapist	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	Community Physiotherapist	<input type="checkbox"/>
Social Worker	<input type="checkbox"/>	District Nurse	<input type="checkbox"/>
General Practitioner	<input type="checkbox"/>	Other (specify) _____	<input type="checkbox"/>
Occupat. Therapist Helper	<input type="checkbox"/>		<input type="checkbox"/>

Omit while patient in : Hospital Res-Home N-home	Total number contacts before stroke*	(tick/number)	(number)	(tick/number)	(number)	(tick/number)	(number)	(tick/number)	(number)	(tick/number)	(number)	(tick/number)	(number)	(tick/number)	(number)	(tick/number)	(number)
Meals on wheels																	
Home care**																	
Day Hospital																	
Day Centre																	
District Nurse																	
Practice Nurse																	
Bath Attendant																	
Health Visitor																	

** Private or Social Service provided
 Please check BP within 24 hrs and whether weight / height has been recorded in general examination.



INVESTIGATIONS AND OPERATIONS

Event No.: _____

Patient Identifier : _____

Pre-Stroke (incident stroke)	Post-Stroke (incident stroke)																																										
<p>Blood Count Latest within last 6 months: <i>if</i> haematological disorder present / ESR in all cases.</p> <table style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 60%;"></th> <th style="width: 20%; text-align: center;">Result</th> <th style="width: 20%; text-align: center;">Date</th> </tr> </thead> <tbody> <tr> <td>Haemoglobin</td> <td style="border-bottom: 1px solid black;"></td> <td style="border-bottom: 1px solid black;"></td> </tr> <tr> <td>White Cell Count</td> <td style="border-bottom: 1px solid black;">Void</td> <td style="border-bottom: 1px solid black;"></td> </tr> <tr> <td>Haematocrit to 2 decimal points</td> <td style="border-bottom: 1px solid black;"></td> <td style="border-bottom: 1px solid black;"></td> </tr> <tr> <td>Platelet count</td> <td style="border-bottom: 1px solid black;"></td> <td style="border-bottom: 1px solid black;"></td> </tr> <tr> <td>Erythrocyte Sedimentation Rate</td> <td style="border-bottom: 1px solid black;"></td> <td style="border-bottom: 1px solid black;">/ /</td> </tr> </tbody> </table>		Result	Date	Haemoglobin			White Cell Count	Void		Haematocrit to 2 decimal points			Platelet count			Erythrocyte Sedimentation Rate		/ /	<p>First result Post Stroke (Leave Blank <i>if</i> Not Available)</p> <table style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 60%;"></th> <th style="width: 20%; text-align: center;">Result</th> <th style="width: 20%; text-align: center;">Date</th> </tr> </thead> <tbody> <tr> <td>Hb</td> <td style="border-bottom: 1px solid black;"></td> <td style="border-bottom: 1px solid black;">/ /</td> </tr> <tr> <td>WCC</td> <td style="border-bottom: 1px solid black;"></td> <td style="border-bottom: 1px solid black;">/ /</td> </tr> <tr> <td>Hct</td> <td style="border-bottom: 1px solid black;"></td> <td style="border-bottom: 1px solid black;">/ /</td> </tr> <tr> <td>Plts</td> <td style="border-bottom: 1px solid black;"></td> <td style="border-bottom: 1px solid black;">/ /</td> </tr> <tr> <td>ESR</td> <td style="border-bottom: 1px solid black;"></td> <td style="border-bottom: 1px solid black;">/ /</td> </tr> </tbody> </table>		Result	Date	Hb		/ /	WCC		/ /	Hct		/ /	Plts		/ /	ESR		/ /						
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OTHER RESULTS									
CEPTIA / TPHA / FTA(abs) / VDRL (in order of preference)									
Not Known / Available _____					Latest test date : _____ / / .				
Result : _____ Positive _____					Negative _____				
If positive, patient treated? Yes _____					No / NK / NAvail. _____				
diagnosis and further investigations? _____									
Specific Haematology / Immunology Tests									
If Done (At any time) :									
				Date		Result			Reference Values
				/ /		_____			_____
				/ /		_____			_____
				/ /		_____			_____
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Carotid Endarterectomy Operation									
Performed	Pre-CVA	Yes	No	Date	Post-CVA	Yes	No	Date	
	Right	_____	_____	/ /	Right	_____	_____	/ /	
	Left	_____	_____	/ /	Left	_____	_____	/ /	
Cerebral Aneurysm 'Clip' Operation									
Performed	Pre-CVA	Yes	No	Date	Post-CVA	Yes	No	Date	
		_____	_____	/ /		_____	_____	/ /	
	Details	_____			Details	_____			
	(eg. side)	_____				_____			
Other Relevant Results (eg. Further CT scans / Further ECHO results / Further MRI results / etc.)									
Other Relevant Procedures / Operations (eg. Radiotherapy for AVM / etc.)									
Tests Pending (place on separate list, to be reviewed at 6/12 assessment)									



ONE MONTH ASSESSMENT

- Patient
- Patient's spouse / partner
- Relative (relationship) _____
- Friend / neighbour
- Nursing Home Staff
- Hospital records / GP referral letter
- GP records
- Ward staff

Patient Identifier: _____

Assessor : _____

Location (incl.Hosp.): _____

Date of Assessment: ___/___/___

Sources of data :
(tick)

Has the patient been (re)admitted to hospital since the recent stroke 1 month ago ?

Yes No

If Yes, Complete Pathway Proforma

Has the patient changed to a **new permanent residence** since the patients recent stroke one month ago ?

(If never discharged since initial stroke one month ago, then tick No:

Do not include temporary residence in relatives home or respite care, tick No)

Yes No

If No, go to next section

If Yes, Reason for change of accommodation: _____

Arrangements for rehousing commenced before stroke: Yes No Not known

New address: _____

Telephone: _____

Type of accommodation (see manual) _____

Ownership of accomodation (see manual) _____

Levels of accomodation (see manual) _____

How many rooms does the household have for its own use ? Total no. _____ Not known

Who lives with the patient? *(Please tick all boxes which apply)*

no one
 husband / wife / partner
 daughter(s)
 son(s)

daughter-in-law(s)
 son-in-law(s)
 sister(s)/brother(s)
 grandchild(ren)

parent(s)
 other relative*
 other**
 not known

(*specify relationship _____ **specify relationship _____)

How many adults (over 16 years at last birthday) are there living in the home ? _____ Not known

How many of these adults are aged over 65 ? _____ Not known

How many children (aged 0 to 15 years) are there living in the home? _____ Not known

Does the patient or any other members of his/her household normally have the use of a car or van ? Yes No DK

Does the patient or any other members of his/her household own a car or van ? Yes No DK

Stroke since notification event ? Yes No

If Yes, and after 1 week since incident stroke, then will need **Recurrent Stroke Assessment** done.

TIA since notification event ? Yes No

If Yes, number _____

Was a TIA diagnosed by a doctor ? Yes No

Current **cigarette** smoker ? Yes No

If Ex-smoker or current smoker **AND** now stopped or cut down smoking,
was this because of the recent stroke ?

Yes No

Not applicable

Driving since stroke ? Yes No

Has appointment for OPD clinic ? Yes No Date: ___ / ___ / ___

Consultant (incl. hospital): _____

Number of **GP** consultations/visits in the first month post Stroke ? _____

(Include visit at time of stroke event if done but exclude visits to practice nurse only)

Medication List : _____

Does the patient or carer feel that the patient has any residual deficit / difficulty with any of the following from the recent stroke 1 month ago ? (SUBJECTIVE QUESTION)

	AREA	YES	NO	DK/NR
Weakness	Right arm			
	Left arm			
	Right leg			
	Left leg			
	Face			
Speech				
Swallowing				
Numbness* (face/arms/legs)				
Memory				
Painful Shoulder	Right			
	Left			

(*including parasthesia/altered sensation)

Day 30 Barthel ADL Index (presently) :

- | | | | |
|--------------------------------|---|---|-------|
| 1. Bowel | 0 = incontinent
2 = continent | 1 = occasional accident (<=1/week) | _____ |
| 2. Bladder | 0 = incontinent (or catheter)
2 = continent | 1 = occasional accident (<=1/day) | _____ |
| 3. Grooming | 0 = needs help | 1 = independent (for face/hair/shaving) | _____ |
| 4. Toilet | 0 = dependent
2 = independent in all actions | 1 = need some help | _____ |
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3 = walks 50m* independently | _____ |
| 8. Dressing | 0 = dependent
2 = independent (includes buttons, zips, laces) | 1 = need help, does half | _____ |
| 9. Stairs | 0 = unable to manage
2 = independent | 1 = needs help | _____ |
| 10. Bathing | 0 = dependent | 1 = independent (<i>bath or shower</i>) | _____ |

Score: _____ / 20

Oxford handicap score (presently) : _____ / 5

(OHS: 0 No symptoms 1 Minor symptoms-No interference with lifestyle 2 Handicap-Able to look after themselves
3 Not totally independent 4 Not needing constant attention 5 Constant attention required.)

(AWAIT RL VALIDATION QUESTIONNAIRE)

Since the recent stroke, has the patient been NEWLY (post recent stroke) diagnosed as having :

	Yes	No	Not Known
Diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hypertension	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please update/complete THERAPY, OPERATIONS AND INVESTIGATIONS and PATHWAY proformas. (Don't forget to ask about whether patient has had any further operations and investigations including blood tests)

TSR

tees stroke register

SIX MONTHS REVIEW

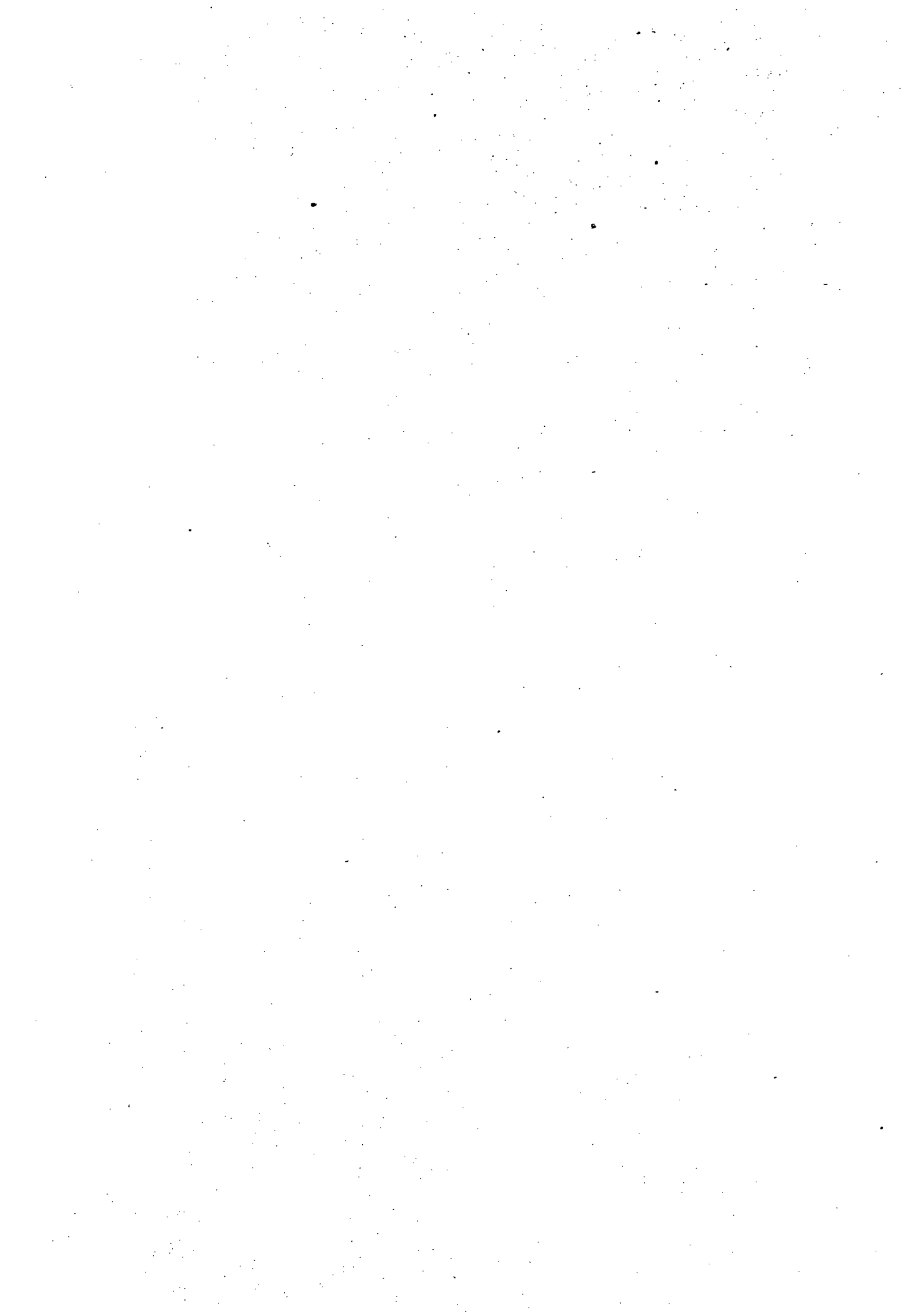
Patient ID :

Patient Name :

Date sent out :

Date returned :

Tees Stroke Register



How to Answer the Questions

Thank you for filling in this questionnaire. It may help to complete the questionnaire in several stages. All of your answers will be treated as confidential. Please try to answer every question even if you do not think it applies to you, or if it seems repetitive. By answering every question you will give us information which will help to improve services for stroke patients locally.

There are several types of questions in this booklet. Most of them can be answered by ticking a box for either YES or NO.

For example :

Do You Live in Teesside

YES

NO

Some of these questions have several boxes and you may be asked to tick one only, or to tick as many boxes as apply to you.

For example :

How Long Have You Lived on Teesside?

(please tick one box only)

Less than 3 years

3 to 5 years

5 to 10 years

More than 10 years

A small number of questions ask you to write in your answer on a line.

For example :

In What Area of Teesside Do You Live?

I live in Stockton

If you need help with the questions, please ask a friend or relative to assist you.

If you are unsure how to answer any of the questions, please contact us on the telephone number below.

If you find a question too difficult to answer or if you do not wish to answer it, please move on to the next question.

If you have any queries or concerns, please contact :

Dr Akif Gani
Tees Stroke Register
North Tees General Hospital
Stockton
Cleveland
TS19 8PE

Tel : (01642) 624 896

Six Months Review

SECTION A - General Update:

The questions in this section ask for information about your current residence and whether you have been readmitted to hospital following your stroke (suspected stroke or brain haemorrhage) SIX months ago.

1. Where are you currently staying ?

- Your own home*
- A relatives home*
- A friends/neighbours home*
- A residential home*
- A nursing home*
- Hospital*

Other, please specify.....

2 Have you had a further stroke since we last saw or contacted you, which has been diagnosed by a doctor ?

- Yes*
- No*

3 Have you had a transient ischaemic attack (TIA - a mini stroke where symptoms resolved within 24 hours) since we last saw or contacted you with regards to your stroke (*suspected stroke or brain haemorrhage*) SIX months ago.?

- Yes*
- No*

If Yes, was a TIA diagnosed by a doctor ?

- Yes*
- No*

4 Have you been admitted to hospital since we last saw or contacted you ?

- Yes*
- No*

If Yes, when were you admitted to hospital ?

Day	Month	Year
+	+	

If No, please go to Section B, Page 3

5. Why were you admitted to hospital ?

.....

.....

6 Which hospital were you admitted to ?

North Tees General Hospital

Darlington Memorial Hospital

Middlesbrough General Hospital

Bishop Auckland General Hospital

South Cleveland Hospital

Other, please specify.....

7. ***If*** you were discharged after this admission, when did you leave the hospital ?

Day	Month	Year
+	+	

SECTION B - Everyday Activities:

The questions in this section ask for details about your stroke and problems with everyday activities. The questions may not all seem to apply to you but please try to answer every question.

PART ONE

1. Do you feel that you have made a complete recovery from your stroke six months ago ?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

2. Do you require help from another person for everyday activities ?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

3. Do you currently have any of the following problems ?
 (*Please tick ANY boxes which apply*)

Weakness/paralysis of your <u>right</u> arm	<input type="checkbox"/>
Weakness/paralysis of your <u>left</u> arm	<input type="checkbox"/>
Weakness/paralysis of your <u>right</u> leg	<input type="checkbox"/>
Weakness/paralysis of your <u>left</u> leg.....	<input type="checkbox"/>
Weakness/paralysis of your face	<input type="checkbox"/>
Difficulty with your speech.....	<input type="checkbox"/>
Difficulty with your swallowing	<input type="checkbox"/>
Numbness affecting your face, arms or legs	<input type="checkbox"/>
Difficulty with your memory.....	<input type="checkbox"/>

PART TWO

4. For this question, please tick **ONE** box next to the sentence which best describes your present health:
(Please tick ONE box only)

I have no symptoms at all and cope well with life.

I have a few symptoms but these do not interfere with my everyday life.

I have symptoms which have caused some changes in my life but I am still able to look after myself.

I have symptoms which have significantly changed my life, prevent me from coping fully on my own, and I need some help in looking after myself.

I have quite severe symptoms which mean I need to have help from other people but I am not so bad as to need attention day and night.

I have major symptoms which severely handicap me and I need constant attention day and night.

PART THREE

For this part, please tick only ONE box for every question.

5. **In the last TWO WEEKS, have you managed to get in and out of the bath or shower and wash yourself ?**

without any help or supervision from someone else

only with help or supervision

or have you not managed to have a bath or shower at all

6. **In the last TWO WEEKS, have you managed to go up and down the stairs ?**

without any help or supervision from someone else

with the help of a walking aid (stick or frame) and/or with someone helping you in any way (e.g. supervising you, physically assisting you or carrying your walking aid)

or have you not managed to go up and down the stairs at all

7. **In the last TWO WEEKS, have you managed to get your clothes out, put them on and fasten them ?**

without any help or supervision from someone else

with someone helping you to do fastenings only (e.g. zips, buttons, laces)

or have you needed more help than this

8. In the last **TWO WEEKS**, have you managed to walk around inside your home/ward ?

If you normally use a wheelchair to get around indoors, please answer SECTION B else answer SECTION A only.

8.1.SECTION A:

without any help or supervision from someone else,
or with the help of a walking aid only (e.g. stick, frame,
trolley)

with one person helping or supervising you

with more than one person helping you

or have you not managed to walk around inside your
home at all

8.2.SECTION B: (for wheelchair users only)

**In the last TWO WEEKS, have you managed to use a
wheelchair to get around indoors ?**

without any help or supervision from someone else

or do you use a wheelchair to get around indoors with
someone helping you

9. **In the last TWO WEEKS, have you managed to get from your bed to a chair and back again ?**

without any help or supervision from someone else

with a little help from one person only (i.e. either to supervise you for safety or give you a little assistance only)

with a lot more help from one or more people

or have you not managed to move from your bed to a chair and back again at all

10. **In the last TWO WEEKS, once your meals are prepared (by yourself or someone else) and placed in front of you, have you managed to feed yourself ?**

without any help or supervision from someone else

with someone helping you to cut the food (or spread butter/margarine) only

or have you needed more help than this

11. **In the last TWO WEEKS, when you used the toilet or commode, have you managed to get to the toilet or commode, get on and off, undress and dress, and clean yourself ?**

without any help or supervision from someone else

with someone helping you to undress/dress or get on or off the toilet/commode only (you need to be able to clean yourself without help)

or have you needed more help than this

12. In the last **TWO DAYS**, have you managed to do all of the following tasks (even if someone has handed you the things you need): clean your teeth, wash your face, brush your hair, fit your false teeth (if you have them), and shave (men only) ?

without any help or supervision from someone else

with someone helping you do one or more of the tasks

13. In the last **WEEK**, have you been unable to make it to the toilet or commode in time to pass water ?

no

occasionally (not more than once a day)

more often (more than once a day)

or do you have a catheter (tube) which a nurse, relative or other person looks after for you (i.e. empties the bag when necessary)

or do you look after your catheter entirely by yourself

14. In the last **WEEK** have you been unable to make it to the toilet or commode in time to open your bowels ?

no

not more than once

more often (i.e. more than once)

or have you needed enemas or suppositories to help you open your bowels

PART FOUR

The questions in this part ask you more about your activities around and outside your home.

PLEASE RECORD ONLY WHAT YOU HAVE ACTUALLY DONE IN THE LAST WEEK OR SO AND NOT WHAT YOU THINK YOU COULD DO, OUGHT TO DO OR WOULD LIKE TO DO.

(Please tick only ONE box for each question in this section)

1. Do you walk around outside ?On my own On my own with difficulty With help No **2. Do you climb stairs ?**On my own On my own with difficulty With help No **3. Do you get in and out of the car ?**On my own On my own with difficulty With help No

4. Do you walk over uneven ground ?On my own On my own with difficulty With help No **5. Do you cross roads ?**On my own On my own with difficulty With help No **6. Do you travel on public transport ?**On my own On my own with difficulty With help No **7. Do you manage to feed yourself ?**On my own On my own with difficulty With help No

8. Do you manage to make yourself a hot drink ?

- On my own
- On my own with difficulty
- With help
- No

9. Do you take hot drinks from one room to another ?

- On my own
- On my own with difficulty
- With help
- No

10. Do you do the washing up ?

- On my own
- On my own with difficulty
- With help
- No

11. Do you make yourself a hot snack ?

- On my own
- On my own with difficulty
- With help
- No

12. Do you manage your own money when you are out ?

- On my own
- On my own with difficulty
- With help
- No

13. Do you wash small items of clothing ?

- On my own
- On my own with difficulty
- With help
- No

14. Do you do your own housework ?

- On my own
- On my own with difficulty
- With help
- No

15. Do you do your own shopping ?

- On my own
- On my own with difficulty
- With help
- No

16. Do you do a full clothes wash ?

- On my own
- On my own with difficulty
- With help
- No

17. Do you read newspapers or books ?

- On my own
- On my own with difficulty
- With help
- No

18. Do you use a telephone ?

- On my own
- On my own with difficulty
- With help
- No

19. Do you write letters ?

- On my own
- On my own with difficulty
- With help
- No

20. Do you go out socially ?On my own On my own with difficulty With help No **21. Do you manage your own garden ?**On my own On my own with difficulty With help No **22. Do you drive a car ?**On my own On my own with difficulty With help No **23. Have you driven a car, van, lorry or motorbike in the last TWO weeks ?***Yes* *No*

SECTION C - Health:

The questions in this section ask about you health and medication.

1. Do you have high blood pressure or are you on treatment for high blood pressure ?

Yes
 No
 Not sure

If Yes, have you had your blood pressure medication altered since we last saw you or contacted you ?

Yes
 No

2. Are you presently taking Aspirin regularly (every day or every second day) ?

Yes
 No

If No, have you previously been recommended to take Aspirin regularly by a doctor ?

Yes
 No

If Yes, why was it stopped ?

.....

If No, was there some reason (e.g. bleeding problems, ulcers, heartburn, on warfarin or other medical problem) why you could not take Aspirin ?

Yes
 No

3. Have you smoked any cigarettes in the last TWO weeks ?

Yes
No

4. Do you have **OR** have you had any of the following health problems in the last month ?

	YES	NO
Urinary (waterworks/bladder) infection.	<input type="checkbox"/>	<input type="checkbox"/>
Pressure sore(s).	<input type="checkbox"/>	<input type="checkbox"/>

5. Have you had any of the following health problems since we last saw or contacted you ?

	YES	NO
Angina	<input type="checkbox"/>	<input type="checkbox"/>
Heart attack	<input type="checkbox"/>	<input type="checkbox"/>
Deep venous thrombosis (blood clot in leg)	<input type="checkbox"/>	<input type="checkbox"/>
Pulmonary embolism (blood clot in lung)	<input type="checkbox"/>	<input type="checkbox"/>

6. Do you have **OR** have you had a painful shoulder in the last month ?

Yes, right shoulder

Yes, left shoulder

Yes, both shoulders

No

7. Have you had any other new health problem since we last saw or contacted you ?

Yes

No

If Yes, please specify and give details :

.....

.....

.....

.....

SECTION D - Services and Investigations:

The questions in this section ask about the services and investigations you may have received since your stroke SIX months ago. All of the questions may not apply to you but please try and answer every question.

1. Have you had any investigations, operations or tests carried out at a hospital since we last saw you or contacted you ?

Yes

No

If Yes, have you had any of the following ?

Investigation / Operation	YES	Hospital
Carotid Endarterectomy	<input type="checkbox"/>	
MRI	<input type="checkbox"/>	
Carotid Doppler	<input type="checkbox"/>	
CT Head Scan	<input type="checkbox"/>	
Carotid/Cerebral Angiography	<input type="checkbox"/>	

Other, please specify.....

2. Have you had any of the following services in the last week

Yes

No

If yes, how many times in the last week ? (If seen more than once a day, please remember to include total number of times in the last week.)

Services Received	YES	How many times in the last ONE week ?
Home Care	<input type="checkbox"/>	
Private Home Help	<input type="checkbox"/>	
Meals on Wheels	<input type="checkbox"/>	
Day Centre	<input type="checkbox"/>	
Day Hospital	<input type="checkbox"/>	

3. Have you been seen by any of the following people (see table below) in the last month ?

Yes

No

If Yes, how many times in the last one month ?

Person	YES	How many times in the last ONE month ?
GP	<input type="checkbox"/>	
Nurse		
District Nurse	<input type="checkbox"/>	
Practice Nurse	<input type="checkbox"/>	
Health Visitor	<input type="checkbox"/>	
Not sure which	<input type="checkbox"/>	
Physiotherapist	<input type="checkbox"/>	
Occupational Therapist	<input type="checkbox"/>	
Speech Therapist	<input type="checkbox"/>	
Dietician	<input type="checkbox"/>	
Social Worker	<input type="checkbox"/>	
Chiropodist	<input type="checkbox"/>	

Note: For people living in Nursing Homes , in the above questions no.s :

2. Home Care and Private Home Help : NOT APPLICABLE

3. Nurse : NOT APPLICABLE

SECTION E - Mood:

The questions in this section ask you about your present mood and feelings.

PLEASE READ THE STATEMENTS CAREFULLY, ONE AT A TIME, AND TICK THE BOX NEXT TO THE ANSWER WHICH BEST INDICATES HOW YOU ARE FEELING. IT IS IMPORTANT TO INDICATE HOW YOU ARE NOW, NOT HOW YOU WERE OR HOW YOU WOULD HOPE TO BE.

PLEASE ANSWER EVERY QUESTION.

(Please tick only ONE box for each question in this section)

1. I feel miserable and sad

- Yes, definitely
- Yes, sometimes
- No, not much
- No, not at all

2. I find it easy to do the things I used to

- Yes, definitely
- Yes, sometimes
- No, not much
- No, not at all

3. I get very frightened or panic feelings for apparently no reason at all

- Yes, definitely
- Yes, sometimes
- No, not much
- No, not at all

4. I have weeping spells or feel like it

- Yes, definitely
- Yes, sometimes
- No, not much
- No, not at all

5. I still enjoy the things I used to

- Yes, definitely
- Yes, sometimes
- No, not much
- No, not at all

6. I am restless and can't keep still

- Yes, definitely
- Yes, sometimes
- No, not much
- No, not at all

7. I get off to sleep easily without sleeping tablets

- Yes, definitely
- Yes, sometimes
- No, not much
- No, not at all

8. I feel anxious when I go out of the house on my own

- Yes, definitely
- Yes, sometimes
- No, not much
- No, not at all

9. I have lost interest in things

- Yes, definitely
- Yes, sometimes
- No, not much
- No, not at all

10. I get tired for no reason

- Yes, definitely
- Yes, sometimes
- No, not much
- No, not at all

11. I am more irritable than usual

- Yes, definitely
- Yes, sometimes
- No, not much
- No, not at all

12. I wake early and then sleep badly for the rest of the night

- Yes, definitely
- Yes, sometimes
- No, not much
- No, not at all

SECTION G - Aids and Adaptations:

The questions in this section ask about your home and any aids and adaptations you may have. For those in Residential or Nursing homes, please OMIT this section, and go to section H, page 28.

1. Are all the rooms in your home on one level ?

Yes

No

2. *If No*, are you confined to one floor of your home because of your health ?

Yes

No

3. Do you have any aids, or have any alterations been made in the bathroom to make things easier ? For example, rails or a bath board ?

Yes (or waiting for)

No

If Yes, did you have the alteration/aid to help with bathing before your stroke six months ago, after your stroke six months ago, or are you waiting for the alteration/aid ?

<i>Alteration / aid</i>	<i>Provided before stroke</i>	<i>Provided after stroke</i>	<i>Waiting for</i>
<i>a. Bath or Grab rails</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>b. Shower</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>c. Bath hoist</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>d. Bath seat/board</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Do you have any aids to help with toileting ? For example, a commode, a raised toilet seat or incontinence aids ?

Yes (or waiting for)

No

If Yes, did you have the aid to help with toileting before your stroke six months ago, after your stroke six months ago, or are you waiting for the alteration/aid ?

<i>Aid</i>	<i>Provided before stroke</i>	<i>Provided after stroke</i>	<i>Waiting for</i>
<i>a. Grab rails</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>b. Commode</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>c. Bedpan/urinal/bottle</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>d. Catheter</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>e. Raised toilet seat</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>f. Incontinence pads</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Do you have any aids in the bedroom to make things easier for you to get in and out of bed ? For example, a bed hoist, a bed raise or a special bed ?

Yes (or waiting for)

No

If Yes, did you have the aid in the bedroom before your stroke six months ago, after your stroke six months ago, or are you waiting for the alteration/aid ?

<i>Aid</i>	<i>Provided before stroke</i>	<i>Provided after stroke</i>	<i>Waiting for</i>
<i>a. Bed hoist</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>b. Bed raise / Bed blocks</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>c. Special bed / mattress</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Do you have any of the following aids for your chair or your bed? For example special cushions to prevent pressure sores?

Yes (or waiting for)

No

If Yes, did you have the aid before your stroke six months ago, after your stroke six months ago, or are you waiting for the item?

<i>Aid</i>	<i>Provided before stroke</i>	<i>Provided after stroke</i>	<i>Waiting for</i>
<i>a. Sheepskin</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>b. Special cushions</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>c. Special chair / Chair raise.</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Have any alterations been made to the house to make things easier for you to get around?

Yes (or waiting for)

No

If Yes, did you have the alteration made before your stroke six months ago, after your stroke six months ago, or are you waiting for the alteration?

<i>Alteration</i>	<i>Provided before stroke</i>	<i>Provided after stroke</i>	<i>Waiting for</i>
<i>a. Widened doorways</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>b. Stair rails</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>c. Stair lift / Vertical lift</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>d. Ramp at front or rear</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Do you use any aids for getting about ? For example, a wheelchair or sticks ?

Yes (or waiting for)

No

If Yes, did you have the aid before your stroke six months ago, after your stroke six months ago, or are you waiting for the item ?

<i>Aid</i>	<i>Provided before stroke</i>	<i>Provided after stroke</i>	<i>Waiting for</i>
<i>a. Manual wheelchair</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>b. Electric wheelchair</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>c. Walking frame (Zimmer)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>d. Walking stick(s)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>e. Walking trolley</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>f. Crutches</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. Do you have any aids for helping you with meals ? For example, kitchen gadgets or special cutlery ?

Yes (or waiting for)

No

If Yes, did you have the aid before your stroke six months ago, after your stroke six months ago, or are you waiting for the item ?

<i>Aid</i>	<i>Provided before stroke</i>	<i>Provided after stroke</i>	<i>Waiting for</i>
<i>a. Kitchen gadgets</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>b. Special cutlery / crockery</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>c. Feeding tubes</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Do you have any other aids or adaptations ?

Yes (or waiting for)

No

If Yes, did you have the aid before your stroke six months ago, after your stroke six months ago, or are you waiting for the alteration/aid/item ?

Please specify:

<i>Aid / Adaptation</i>	<i>Provided before stroke</i>	<i>Provided after stroke</i>	<i>Waiting for</i>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION H - Health Information:

How much advice and information do you think you have received on the following ? *(Please tick only one box on each line)*

	Topic	None	Some	Enough	Not Applicable
a	Stroke disease in general	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b	Causes of stroke	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c	Measures for preventing stroke	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d	Your current treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e	Emotional problems related to stroke	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f	Family / Marital problems related to stroke	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g	Health and Social services available for stroke patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h	Voluntary services available for stroke patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i	Appliances / Aids available for disabled people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j	Leisure activities for disabled people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k	Dealing with legal and financial affairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l	Benefits and allowances for disabled people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m	Your general health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n	Incontinence problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o	Giving up smoking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p	Cutting down alcohol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q	Losing weight	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r	Eating a healthier diet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION I - The Final Section:

This section asks whether you have needed help to fill in the questions. If you have any comments about the questionnaire, please write them below.

1. Have you needed help from someone else to fill in this questionnaire ?

- Yes
- No

If Yes, who helped you complete the questionnaire ?

- Wife/Husband/Partner*
- Daughter*
- Son*
- Daughter-in-law*
- Son-in-law*
- Brother/Sister*
- Friend/Neighbour*
- Nurse*
- Home Help*

Other relative, please specify

Other, please specify

Your telephone number or contact number of person who helped fill in this questionnaire: (.....).....

2. Please let us know if you have any other comments on this questionnaire:


.....

.....

Thank you for completing this questionnaire, please return it as soon as possible in the freepost envelope provided.


Stockton on Tees
Tees Stroke Register

Stroke Unit
North Tees General Hospital
Stockton on Tees
Cleveland
TS19 8PE

 (01642) 624896
Fax (01642) 624927

Darlington
Tees Stroke Register

Department of Medicine
Darlington Health Services Unit
Hollyhurst Road
Darlington
DL3 6HX

 (01325) 743084
Fax (01325) 743084

T R
tees stroke register

Death Assessment

Sources of data :

- Nursing Home Staff
- Hospital records / GP referral letter
- GP records
- Ward staff
- Other (specify): _____

Patient Identifier: _____

Assessor : _____

Date of Assessment: ___ / ___ / ___

Date of death: ___ / ___ / ___

Time of death: ___ h

Place of Death: _____

- | | | | |
|----------------|--------------------------|------------------|--------------------------------|
| Hospital | <input type="checkbox"/> | Nursing Home | <input type="checkbox"/> |
| Own home | <input type="checkbox"/> | Residential Home | <input type="checkbox"/> |
| Relatives home | <input type="checkbox"/> | Other (specify) | <input type="checkbox"/> _____ |

- Certifying Doctor:**
- | | | | |
|------------------|--------------------------|----------------------|--------------------------|
| GP/Deputising GP | <input type="checkbox"/> | Senior House Officer | <input type="checkbox"/> |
| House Officer | <input type="checkbox"/> | Other Doctor | <input type="checkbox"/> |
| Not Known | <input type="checkbox"/> | | |

Cause of death: Actual Certification

1a) _____

1b) _____

1c) _____

2) _____

- Death due to*:**
- First ever stroke
 - Recurrent stroke (even if first TSR incident stroke)
 - Stroke complication
 - Other cause not directly related to stroke

(*According to TSR Assessment)

If death due to First ever / Recurrent Stroke then will need appropriate assessments completed for this event.

Stroke prior* to this assessment ? Yes No Not Known

(*after last assessment if done, within study period and study area at time of stroke)

If Yes, will need completion of appropriate retrospective assessments.

Autopsy held? Yes No / Not Known

If Yes; Results of autopsy:

- Cause of Death** (according to autopsy report)
- | | | | |
|-----------------------------------|--------------------------|------------------------|--------------------------|
| Subarachnoid haemorrhage | <input type="checkbox"/> | Intracranial neoplasm | <input type="checkbox"/> |
| Primary intracerebral haemorrhage | <input type="checkbox"/> | Infection | <input type="checkbox"/> |
| Cerebral infarct | <input type="checkbox"/> | Cardiac (MI/CCF/other) | <input type="checkbox"/> |
| Haemorrhagic infarct | <input type="checkbox"/> | Other | <input type="checkbox"/> |

Not Known

