

Irish Heart Foundation National Audit of Stroke Care

AUTHOR(S)

Frances Horgan, Anne Hickey, Hannah McGee, Desmond O'Neill

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Irish Heart Foundation
National Audit of Stroke Care

A stroke is an interruption of the blood supply to part of the brain. The term “stroke” comes from the fact that it usually happens without any warning, “striking” the person from out of the blue.

A stroke is caused by a blockage of an artery supplying blood to the brain (cerebral thrombosis) or a bleed into the brain from a burst blood vessel (cerebral haemorrhage).

Irish Heart Foundation Council on Stroke



“Stroke is the third most common cause of death and the most common cause of acquired major physical disability in Ireland.”

Irish National Audit of Stroke Care



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Irish National Audit of Stroke Care (INASC)

Report prepared on behalf of the Irish Heart Foundation National Stroke Review Group by the Irish National Audit of Stroke Care (INASC) Research Team, Royal College of Surgeons in Ireland (RCSI) and Trinity College Dublin (TCD).

INASC Research Management Team

Dr Frances Horgan - School of Physiotherapy, RCSI

Dr Anne Hickey - Division of Population Health Sciences (Psychology), RCSI

Professor Hannah McGee - Division of Population Health Sciences (Psychology), RCSI

Professor Desmond O'Neill - Department of Medical Gerontology, TCD

INASC Research Steering Group

Professor David Whitford - Division of Population Health Sciences (General Practice), RCSI

Professor Seamus Cowman - Faculty of Nursing and Midwifery, RCSI

Ms Maeve Royston - Division of Population Health Sciences (General Practice), RCSI

Dr Séan Murphy - Department of Geriatric Medicine, Midland Regional Hospital, Mullingar

Dr Emer Shelley - Division of Population Health Sciences (Epidemiology & Public Health Medicine), RCSI

Professor Miriam Wiley - Economic and Social Research Institute, Dublin

Professor Ronán Conroy - Division of Population Health Sciences (Epidemiology & Public Health Medicine), RCSI

INASC Project Research Staff

Research Staff at the Division of Population Health Sciences (Psychology), RCSI: Ms Karen Galligan, Ms Helen Corrigan, Ms Maeve Proctor, Ms Oonagh Mullan, Ms Abigail Henderick, Ms Anna-May Fitzgerald, Ms Philippa Coughlan, Dr Bernadette O'Sullivan, Dr Maja Barker and Ms Claire Donnellan

Irish Heart Foundation National Stroke Review Group

Dr John Bowman - Chair

Ms Ciara Breen - Association of Occupational Therapists of Ireland

Ms Breda Cleary - Institute of Community Health Nurses

Dr Mary Codd - Irish Heart Foundation Board of Directors

Mr James Conway - Health Service Executive (Chronic Care)

Ms Anne Copeland - Volunteer Stroke Scheme

Dr Tim Counihan - University College Hospital Galway

Ms Audrey Craven - Neurological Alliance of Ireland

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Dr Morgan Crowe - Royal College of Physicians of Ireland

Ms Caroline Cullen - Irish Heart Foundation

Dr Mark Delargy - Irish Association of Rehabilitation Medicine

Dr John Devlin - Chief Medical Officer's Office

Ms Fionnuala Duffy - Health Service Executive (National Hospitals Office)

Ms Mary Durkin - An Bord Altranais (Nursing Board)

Ms Tracy Egan - Irish Heart Foundation

Dr Siobhan Jennings - Health Service Executive (Population Health Directorate)

Professor Peter Kelly - Irish Consultant Neurologists Association

Mr Kieran Loughran - Headway

Ms Julie Lynch - Health Service Executive (Primary, Community and Continuing Care)

Dr Brian Maurer - Irish Heart Foundation

Dr Bob McDonnell - Health Service Executive (Health Information Unit)

Dr Riona Mulcahy - Irish Society of Physicians in Geriatric Medicine

Ms Patricia Munnelly - Irish Nutrition and Dietetic Institute

Professor Eoin O'Brien - Irish Heart Foundation

Ms Fionnuala O'Brien - Health Service Executive West (Population Health)

Ms Anne O'Farrell - Health Service Executive North East

Ms Mary O'Mahoney - Irish Society of Chartered Physiotherapists

Dr Denis O'Mahony - Cork University Hospital

Mr Michael O'Shea - Irish Heart Foundation

Dr Emer Shelley - Health Service Executive (National Plan for Stroke)

Ms Tracy Swanton - Association of Occupational Therapists of Ireland

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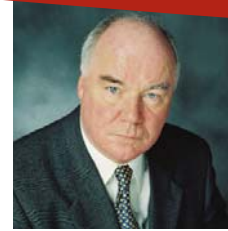
Finally, as a research team, we thank the Irish Heart Foundation and Department of Health and Children for the opportunity to conduct this first national study in a comprehensive manner - from organisational aspects through to community and nursing home settings. The support of the National Stroke Review Group was much appreciated over the course of the project. Many professionals, patients and families made the project possible. We hope that the combined efforts of our sponsors, contributors and research team will stimulate, drive and guide much-needed improvements in stroke care in Ireland.

Irish National Audit of Stroke Care (INASC) Research Team

Foreword

Message from the Irish Heart Foundation

Stroke is the third most common cause of death and the most common cause of acquired major physical disability in Ireland. A failure to recognise effective therapies has led to a fatalistic approach to treatment and an often nihilistic approach to coping with the survivors.



Dr. Brian Maurer,
Medical Director,
Irish Heart Foundation

The Council on Stroke of the Irish Heart Foundation was formed in 1997 and is composed of representatives of 15 medical and associated disciplines. Concerned by the apparent failure of the Irish health system to provide services conforming to an international standard for victims of stroke, the Council asked the Irish Heart Foundation to commission an audit of the services which are available. The Irish Heart Foundation agreed to fund this audit mindful of the fact that the Government had failed to address the problem of stroke as suggested in Building Healthier Hearts (1999). A working party was established in 2004 under the Chairmanship of Dr John Bowman to establish the audit. It sought tenders, nationally and internationally, and following assessment of these by a panel of three international experts, the Irish Heart Foundation commissioned a team from the Royal College of Surgeons in Ireland and Trinity College Dublin to produce a report on the situation.

The work presented in this report - The Irish Heart Foundation National Audit of Stroke Care - confirmed the impression of professionals working in the field that stroke services in Ireland are so poorly organised that they are largely ineffective.

- Stroke units are virtually non existent - only one hospital has such a unit.
- A tiny fraction of patients who might benefit from acute interventions such as thrombolysis are assessed for this therapy.
- Acute rehabilitation is only available to one in four patients or is delayed beyond the point at which it is most effective.
- Continuing care and long-term recovery programmes are haphazardly organised or do not exist.
- The patient journey is not a steady progression through a seamless and properly organised unitary service.
- The quality of care is determined by chance, location and a haphazard combination of circumstances.
- The results are predictable.
- Too many people die from stroke because they cannot access optimal treatment sufficiently rapidly.
- Too many survivors are left with avoidable and unduly prolonged disability.

The report shows that these problems can only be solved by the establishment of a coordinated clinical service centred on providing services in all hospitals treating people with acute stroke; the continuing improvement of pre-hospital emergency services; the provision of expert advice on the management of the stricken individual; smooth and timely transit through the stroke unit to recovery; rehabilitation and continuing care and the presence at all stages of the necessary professional expertise. This requires refocusing of the present unfocused and uncoordinated structures, adoption of treatment protocols which conform to international best practices and major investment in proper facilities.

Rehabilitation services must be integrated into acute care and geared toward producing optimal outcomes for the individual. Aftercare and long-term support for those who remain disabled must be recognised as an integrated part of the service. All this should be continued with an aggressive approach to prevention which works as effectively in stroke as in other forms of cardiovascular disease.

The Irish Heart Foundation began the process which eventually developed the Cardiovascular Strategy. It now asks Government and the HSE to implement the promise given in Building Healthier Hearts to develop a strategy for the Management of Stroke. This audit identifies the needs of those who suffer a stroke and points the way towards a solution which would reduce its burden. The success of the Cardiovascular Strategy shows what can be achieved.

Finally I would like to thank all those who contributed to the funding of this report through donations made to the Irish Heart Foundation. Special thanks goes to the Association of Irish Floral Artists for their generous donation.

Dr Brian Maurer Medical Director, Irish Heart Foundation

Executive Summary

Stroke is the third leading cause of death and disability worldwide. It constitutes a formidable burden of disability for patients, their families, health professionals and the wider community. It combines aspects of both acute and chronic disease, and there is increasing evidence that those affected by stroke can benefit to a very significant extent from organised stroke care throughout the course of the illness. Delivering this care requires a unique combination of skills, drawing on neurosciences, cardiovascular medicine, general medicine, the science of ageing, rehabilitation, vascular surgery, and public health. Local and timely evidence on the service performance is essential to assess quality of care and to improve services. This has not been available to date in Ireland.



The aim of this project was to conduct a national audit of stroke care in hospital and the community in the Republic of Ireland. This was achieved by completing six separate surveys and by drawing conclusions based on complementary information across the studies. The six surveys are described next. Where possible, audit systems used in the UK's Sentinel audit were used to provide an opportunity for comparison of relative, as well as absolute, levels of achievement of recommended standards of care.

Methods

Organisational Study - All public hospitals providing acute stroke services participated in senior team executive interviews (n=37 hospitals: interviews with chief executive and senior nursing, medical and therapy representatives).

Clinical Audit - All public hospitals providing acute stroke services and participating in the Hospital In-Patient Enquiry (HIPE) scheme provided access to medical charts (n=36 hospitals).

General Practitioner (GP) Survey - A national survey of randomly selected GPs was completed (n= 204 GPs participated; response rate 46%).

Public Health Nurse (PHN) and Allied Health Professional (AHP) Survey - Senior Local Health Office (LHO) managers for services for people with disabilities and for older people for the four HSE regions were interviewed (N=7). They nominated AHP and PHN managers for more discipline-specific, semi-structured interviews (N=25). Managers then nominated frontline staff to provide a profile of stroke care (N=43 survey responses).

Nursing Home Survey - A national interview survey investigated experiences of nursing home proprietors, staff and patients in randomly selected nursing homes, stratified by geographic location (N=60; 20 in Dublin and 40 outside the Dublin area).

Patient/Carer Survey - This survey investigated current health status and experiences of stroke services by patients with stroke and their carers following discharge from hospital. The sample was identified through four representative hospitals. Patients who were discharged to home and were either 6-12 months or 24-36 months post-discharge were contacted. They were stratified by age and gender to ensure coverage of those with potentially different service needs and experiences. A total of 139 patients and 72 nominated carers (55% and 71% response rate respectively) participated in home interviews.

Main findings

Primary Care and Primary Prevention of Stroke

- There was little or no organised system of care for the prevention and management of stroke in primary care in Ireland. GPs in practices involved in Heartwatch (the coronary heart disease chronic disease management programme) and those with access to practice nurses were more likely to engage in evidence-based prevention and risk assessment activities relating to stroke.

Emergency and Acute Hospital Care: facilities and diagnostics

- Stroke units reduce mortality and disability and are the recommended standard to deliver optimal care for acute stroke patients. Only one Irish hospital (of 37) had a fully resourced stroke unit. One in 37 hospitals in Ireland (3%) compares with 91% of similar UK hospitals having a stroke unit (Sentinel audit 2006).

- Optimal stroke care requires protected beds. There were only 12 designated stroke unit beds nationally. These figures indicate a ratio of 0.03 beds per stroke patient (the UK comparison is 0.82 beds) (Sentinel audit 2006).
- Delivering thrombolysis requires rapid access to diagnostic facilities. Many Irish hospitals did not have access to facilities for brain scanning, MRI or carotid endarterectomy. For instance, 30% of hospitals did not have routine access to CT scanning within 48 hours of the stroke and only 41% had access to emergency MR scanning. Provision of thrombolysis was almost nonexistent (1% of Irish stroke patients received thrombolysis).
- People having a Transient Ischaemic Attack (TIA or 'mini stroke') should have timely referral to, and assessment at hospital clinics to reduce the risk of stroke. Only 16% of Irish hospitals had TIA services compared with 78% in the UK (Sentinel 2006).
- Stroke is a medical emergency. Three in four patients (78%) believed they attended hospital as soon as necessary but almost half (44%) reported delays in processing through Emergency Departments.
- The majority of, but by no means all, patients (71%) were admitted to an acute hospital on the day of their stroke. This was similar to UK figures (72%). However, the proportion getting to hospital within two hours of the stroke was substantially lower in Ireland: 5% admitted within two hours of the onset of the stroke (compared with 39% in the UK (Sentinel 2006)).

Emergency and Acute Hospital Care: staffing and multidisciplinary care

- Optimal stroke care requires adequate specialist treatment. Only one-third of hospitals could identify a lead consultant physician with responsibility for stroke care. Furthermore, only five hospitals had protected consultant physician time for stroke care by having committed consultant sessions.
- There were only five clinical nurse specialists and two clinical specialist therapists working in stroke care nationally.
- Acute stroke has wide-ranging effects on physical function but also potentially on the individual's mobility, cognitive and emotional function and ability to communicate. A multidisciplinary team is needed to assess and meet these challenges. The availability of a multidisciplinary team was very limited, with services from some disciplines relatively more frequently available (e.g. occupational therapy, physiotherapy) and others almost non-existent (e.g. clinical psychology, social work).
- This meant considerable deficiencies in timely access to assessment and intervention. The gap was particularly notable for speech and language therapy (SLT) services. A formal SLT swallow assessment within 72 hours of admission is best practice. This happened for only 25% of Irish patients (compared with 67% in the UK (Sentinel 2006)). A formal SLT communication assessment within 7 days is advised. This occurred for 29% of Irish patients (compared with 69% in the UK (Sentinel 2006)).
- Access to physiotherapy and occupational therapy was also lower than in the UK, with 43% of patients assessed by a physiotherapist within 72 hours of admission (compared with 71% in the UK (Sentinel 2006) and 22% assessed by an occupational therapist within 7 days of admission (compared with 68% in the UK (Sentinel 2006)).

Discharge from Hospital, Access to Rehabilitation and Community Services

- Optimal acute care improves patient status at time of discharge. Irish patients were more disabled at discharge than those in the UK. For instance, only 28% were assessed as independent in activities of daily living when discharged from hospital (compared to 39% in the UK (Sentinel 2006)).
- Clear communication with patients and families about diagnosis, prognosis and post-hospital care is essential before patients are discharged. Documented hospital chart evidence of staff discussion of stroke diagnosis and prognosis with patients and/or families was low, at 22% and 18% respectively. In the UK, 69% had a documented discussion about diagnosis and 59% about prognosis before discharge (Sentinel 2006). Staff highlighted the need for improved communication to facilitate a seamless transition from hospital to community.
- Family carers are an essential resource in enabling satisfactory hospital discharge. However, hospital-initiated assessment of carers' needs post-discharge was evident from hospital charts for only a quarter of Irish patients (24%). Similarly, there was little documented evidence that the skills required to manage stroke patients at home were taught to carers (12% in Ireland, compared with 71% in the UK (Sentinel 2006)). In the UK, 63% of patients had a home visit linked to discharge to identify needs and to support patients and carers (Sentinel 2006). This was the case for only 7% of Irish patients.
- Patients and carers also identified major deficits in the provision of information, support and services during and following the patients' discharge from hospital. Carers reported receiving little information about what to expect when the patient came home and little or no information about the services or entitlements that might be available to them.
- Rehabilitation services are needed in the community to enable continued recovery of this very vulnerable group of patients after their discharge from hospital. Professionals across the spectrum of services agreed that community-based rehabilitation was seriously inadequate. They described a range of barriers to the development of multidisciplinary team services, including the absence of a strategic plan, funding and staff employment ceilings. Barriers to service provision based on age were also notable. There was limited access to rehabilitation for younger patients, with only five hospitals routinely accepting stroke patients under age 65 years to their rehabilitation unit.
- In this situation of limited community services, carers reported that they needed to become 'expert' in managing the patient at home. One in ten of these carers could themselves be classified as at risk of health problems. These were almost exclusively women, most of whom were more than 65 years old.

Clear communication with patients and families about diagnosis, prognosis and post-hospital care is essential before patients are discharged.

- Nursing homes provide post-hospital care for those patients who are most disabled or vulnerable following a stroke. Nursing home managers described lack of coordination and communication between health professionals in the acute services, the community and nursing homes. They reported a dearth of physiotherapy, occupational therapy and speech and language therapy for residents with stroke. There was a concern that nursing home residents were particularly 'invisible' in terms of rehabilitation needs. In relation to service provision very little distinction could be seen between public and private nursing homes. Overall, it was felt that those surviving stroke and living in the community, including those residing in a nursing home, needed access to rehabilitation based on need, regardless of their place of residence.

Secondary Prevention and Risk Factor Management

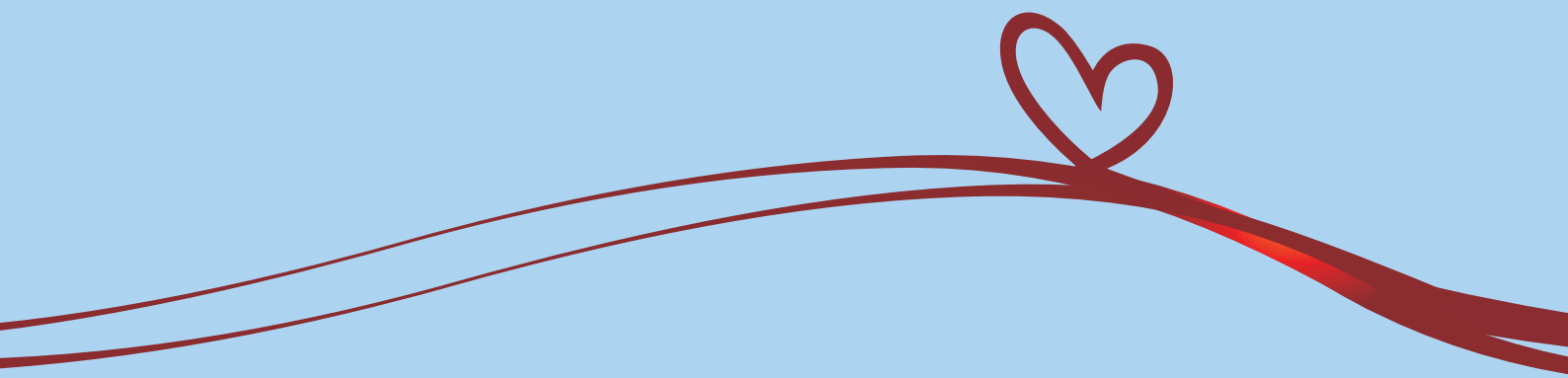
- The most common risk factors for stroke in the hospital chart audit were hypertension (51%), followed by atrial fibrillation (22%). A similar profile was evident in the UK (Sentinel 2006).
- Generic lifestyle factors to promote secondary prevention following stroke, i.e. stopping smoking, physical activity, diet and alcohol management, were documented as having been discussed with the patient in only a small proportion of cases. Two-thirds of patients had blood cholesterol levels documented in hospital charts. Of these, 39% had elevated cholesterol. Only 29% of patients with elevated cholesterol received dietary advice on reducing their cholesterol level.

Plans for Stroke Services

- Service planning: It was clear from the various components of the project that front-line staff throughout Ireland, without specific national investment in stroke care, had improvised and set up services in an ad hoc way in order to best overcome the daily challenges of stroke care. While neither a satisfactory or comprehensive solution, these activities can form the basis of a more strategic and clearly resourced service in the future. Most encouraging was the finding that 23 of 37 hospitals had already submitted service plans for stroke service development.
- Staff training and development: Evidence on staff training and information provision made clear that much work has to be done to provide training opportunities for staff to meet the complex needs of the person with stroke and their families, both in hospital and in community settings.
- The focus of INASC was on service delivery for those who had experienced stroke. The other essential element in the management of stroke is population awareness of both risk factors for stroke (and how to address them) and warning signs for stroke (and how to respond). Evidence from other Irish and international studies signals the need for substantial education on both these issues. A public awareness campaign is needed to promote cardiovascular health and rapid recognition and response when a stroke is suspected.

Conclusions

- INASC has identified substantial deficits in primary prevention; emergency assessment, investigation and treatment in hospital; discharge planning; rehabilitation and ongoing secondary prevention, and through all this, communication with patients and families.
- Availability of services of proven efficacy for those admitted to hospital with stroke in Ireland was very poor and in marked contrast to the current situation in the UK. There was also considerable variation in access to services. In particular, lack of access to acute stroke units, to early CT scanning, and to identifiable local lead physicians with responsibility for developing stroke care should be addressed as a matter of urgency.
- Performance across a broad range of indicators of quality of stroke care was much poorer in Ireland than in the UK. Of twelve key indicators of quality of care, Ireland fared more poorly on all than the UK. The UK audit system has been operating for almost a decade. Evidence from successive audit cycles is that improved practice can be demonstrated. Thus this Irish audit should be seen as a first step in a cycle of continual planning, intervention for improvement and outcome evaluation.
- Stroke services in the community were found to be ad hoc and varying greatly from one community area to another. There was a lack of coherence to services in the community for persons with stroke both nationally and regionally. Access to services critical to ongoing rehabilitation post-stroke were scarce or non-existent in many areas. These services were seldom available in nursing home settings.
- These findings will be a major cause of concern for people who have suffered a stroke and their families, and for health professionals and the community more widely. They point to the need for urgent investment in stroke services in Ireland. Commitment and resources need to be galvanised through an over-arching policy, with designated funding and an urgent timeframe for the development of stroke services.



Chapter 1

Introduction



Background

Stroke is the third leading cause of death and disability worldwide and constitutes a formidable burden of disability for patients, their carers and the wider community. Approximately 10,000 people are admitted to hospital in the Republic of Ireland each year with stroke disease as a primary diagnosis (HIPE data, ESRI 2007). It is estimated that over 30,000 people in Ireland are survivors of stroke, many of whom have significant residual disability including hemiparesis (48%), the inability to walk (22%), need for help with activities of daily living (24-53%), clinical depression (32%) and cognitive impairment (33%) (IHF Council on Stroke, 2001).

It is an illness that requires a unique breadth of skills in its prevention and management, combining elements of neurosciences, cardiovascular medicine, general medicine, science of ageing, rehabilitation, and public health, while fusing chronic disease management with the treatment of potentially devastating acute events. This complexity is reflected in the membership of the IHF Council on Stroke, which represents 15 medical and associated disciplines.

Many strokes are preventable, and research has shown that fast and effective treatment can rescue brain tissue from damage and significantly reduce further damage and residual disability. However, stroke is relatively neglected. Recent UK statistics highlight differences in status and resourcing of coronary heart disease (CHD) compared to stroke (National Audit Office 2006). Services for coronary heart disease are relatively well established in Ireland (Coughlan 2004; Health Services Executive 2007). This is not the case for stroke.

Organised Stroke Care

The profile of stroke care in the UK is increasing. Several factors have contributed to this change, including the National Clinical Guidelines for Stroke (2000, updated in 2004). The stimulus for these guidelines was the findings of the first round of the National Sentinel audit of stroke (Intercollegiate Working Party for Stroke 2001-02), which confirmed suboptimal stroke care. The Royal College of Physicians, Clinical Effectiveness and Evaluation Unit (CEEU) conducted the first round of the National Sentinel Stroke Audit in the United Kingdom in 1998 and further rounds in 2002, 2004 and 2006. The aims of the Sentinel audit are to benchmark the quality of local stroke services compared to national standards; to identify changes in stroke service organisation and quality of care for those who have been affected by stroke since previous audits; and to evaluate the extent to which National Clinical Guidelines for Stroke have been implemented.

It is recognised that the organisation of services can have an important effect on patient outcome (Langhorne and Dennis 1998). Primary prevention measures considerably reduce the risk of stroke (Elkind 2005). Comprehensive stroke units provide reductions in mortality, length of stay and improved patient outcomes (Slot et al 2008, Stroke Unit Trialist's Collaboration 2005). There is also evidence for the effectiveness of rehabilitation units (Kalra et al 2000). The early supported discharge team model has been tested in a small number of randomised studies. Early results indicate a reduced length of hospital stay and better long-term patient functional outcomes (Early Supported Discharge Trialist's 2002, Fjaertoft et al 2005, Langhorne et al 2005). In view of the evidence on organised stroke unit care, many lives can be saved: extrapolating from UK data, it is likely that 350-500 deaths a year could be saved if stroke unit care is introduced in Ireland. Many reports have articulated the unmet service and information needs of stroke patients and their families after discharge from hospital (Martin et al 2002). What is clear from experience elsewhere, particularly from the three rounds to date of the UK Sentinel audit, is that improvement can be achieved in a reasonable timeframe through continuous investment, evaluation and planning.

Stroke and Primary Care

Stroke is a preventable disease. The development of primary care services, so that they become the cornerstone of care and preventive services for communities across the country, is consistent with best international practice. The UK's Royal College of Physicians (2004) recognises that much of the responsibility for delivering effective secondary prevention and managing longer-term problems associated with stroke lies with the primary care team. According to Ireland's Primary Care Strategy (Department of Health and Children 2001), a shift in the balance from secondary specialist care to primary generalist care is required.

Of all health care providers, GPs typically have the most frequent contact with their patients. For instance, over 90% of those aged 65 years and over in Ireland have seen their GP in the previous year (McGee et al 2005). Thus, GPs have ready access to individuals most at risk of stroke disease and are well placed to implement prevention and screening programmes. For example, Noone et al (2001), in their study of 195 discharged stroke patients in Ireland, found that the majority of patients (87%) had seen their GP since their hospital discharge, whereas just less than half (48%) had been reviewed in medical out-patient clinics.

Rehabilitation after Stroke

On their discharge, patients who have suffered a stroke frequently have persisting clinical problems including impaired upper and lower limb function, communication difficulties and cognitive problems, difficulties mobilising indoors, outdoors and on stairs, and limited independence in self-care, depression and social inactivity (Andersen et al 2002). Stroke rehabilitation can be delivered in a hospital and community setting. The structure necessary to deliver comprehensive rehabilitation, whether in hospital or in the community, is the multidisciplinary team. Evaluation of the benefits of community rehabilitation following a stroke is limited and has been attributed to the lack of a clear definition on what constitutes the service, how it is organised, the level of specialisation versus generic rehabilitation, and over how long a period the service is delivered (Geddes and Chamberlain 2001).

Return to the community after acute hospitalisation for stroke can be difficult for the person with stroke, their primary carer and the extended family. At this time the person has to assume increased responsibility for independent functioning, in the absence of the supportive environment of the acute phase in-patient hospital setting. Continuity of services is important during this period (Bhogal et al 2003). Unfortunately, many reports document the unmet service and information needs of the person with stroke, their carers and families following hospital discharge (Martin et al 2002).

Stroke and Nursing Home / Long-Term Care

In Ireland there are approximately 9,500 long-stay nursing home beds in the public sector and 18,000 in the private sector. There is a dearth of research in Ireland regarding issues directly relating to care and services offered in nursing homes. Based on UK studies, it is estimated that about 75% of residents in nursing homes are moderately or severely disabled (Bajekal 2000). In a recent Irish census-based national study comparing elderly disabled people in the community and in nursing homes, Falconer and O'Neill (2007) identified the presence of high levels of disability among nursing home residents, with over 85% of residents having at least one recorded disability. The authors concluded that nursing homes are populated by a very frail group of older people in society and there is a need for appropriate health and care resources for older people in nursing homes.

Whereas no figures are available for Ireland, in the UK and US it is estimated that about 25% of stroke patients move from acute care directly to institutionalised care (Rudd et al 2005; Browne et al 1999). It is now accepted that stroke is one of the leading causes of disability in nursing home residents (Lee and Choi 2002).

Fahey et al (2003), in a large controlled observational UK study, identified that older people living in nursing homes receive poorer care than those living at home. In particular there was under use of beneficial drugs, poor monitoring of chronic disease, and overuse of inappropriate or unnecessary drugs. Noone et al (2001) found that therapy or activity staff were not available in many Irish nursing homes. Eighty per cent of nursing homes had less than 6 minutes of 'activity staff' time per occupied bed per day, while 47% of nursing homes surveyed had none.

The Person with Stroke and His/Her Family

The high level of physical and psychological morbidity associated with stroke results in a significant burden for both patients and their carers. On their discharge from hospital, stroke patients frequently have persisting clinical deficits including impaired upper and lower limb function, communication difficulties, cognitive problems, limited mobility and independence in self-care, social inactivity and depression (Andersen et al 2002). At least three-quarters of people having a stroke are managed in the community, meaning that optimisation of stroke care in the community setting is central to minimising disability from stroke (Russman and Katzan 2005).

There is considerable evidence that patients and carers experience generally positive reports of their time in hospital, but rising levels of dissatisfaction once patients are discharged home (Healthcare Commission 2005; 2006). Dissatisfaction is focused particularly on poor communication with patients in relation to stroke, lack of involvement in decisions about their care, inadequate rehabilitation and insufficient support with emotional problems (Healthcare Commission 2005).

Other findings indicated an overly narrow focus of rehabilitation in hospital, directed at achieving discharge rather than dealing with issues of importance to the individual with stroke (Tyson and Turner 2000). A poor level of service has been identified in the community, with shortcomings in particular in relation to limited communication from hospital to community services and frequently poor liaison across community services (Tyson and Turner 2000). Hare et al (2005) found that the major issues that patients and carers in the community had to face were information needs. Many were unclear about the specific roles of different health professionals. There was a lack of contact with services; for example, little or no hospital contact. Carers felt they had to become "experts" in dealing with the problems that arose. Ongoing psychological and emotional problems (for example, fear of another stroke, generalised anxiety) were not being addressed. The care received appeared to be reactive rather than proactive, with patients and carers reporting persistent difficulties that were not being attended to by health professionals.

Background to INASC

Despite the fact that there is robust international evidence that stroke units reduce death and disability by 25% (Langhorne et al 1993; Rudd et al 2005), existing Irish evidence suggests that hospital services are poorly prepared for this major advance in stroke care (Coughlan 2004). Community services appear to be under-resourced and not focussed to the needs of people with stroke (Noone et al 2001; Swanton et al 2004). This is against a background of no national or regional policy on stroke within the Irish health services. The Council on Stroke of the Irish Heart Foundation made four principal recommendations to the Irish government in 2000. These have yet to be adopted.

The report recommended the following:

1. Prevention and health promotion: develop active programmes for the primary, secondary and tertiary prevention of stroke. Primary prevention could most usefully be undertaken in conjunction with the National Cardiovascular Health Strategy. Secondary and tertiary prevention should be based in Stroke Services.
2. Acute treatment and rehabilitation: that in every general hospital admitting patients with acute stroke, people with stroke should be admitted to a Stroke Service under the care of a dedicated specialist(s) in stroke care, associated interdisciplinary team, appropriate diagnostic technology (for example, CT/MRI) and a clearly defined continuum of care. Access to tertiary services (for example, carotid endarterectomy) should also be available. Rehabilitation strategies should start from admission and should be continued during the hospital stay.
3. Community rehabilitation: out-patient rehabilitation should be made available for all patients of all ages in each Health Board area, on the basis of 250-300 patients discharged to the community/year per 250,000 population. These should encompass the full interdisciplinary team, with either a domiciliary focus or adequate transportation if provided as out-patient care. Services should be available at any age and the model of the stroke services at Baggot Street Hospital (Dublin) should be considered. The activities of the Volunteer Stroke Scheme should be developed and supported.
4. Stroke Register: since stroke is such a devastating and costly illness, and because little data is available on stroke in Ireland, a register of people with acute stroke should be established as a priority, similar to that of the cardiac surgery, coronary care and cancer registries.

Aim and Objectives of the Irish National Audit of Stroke Care (INASC)

There is a dearth of reliable data on the provision of services for stroke in Ireland. The aim of the project was to conduct a national audit of hospital and community stroke care for the Republic of Ireland - the first Irish National Audit of Stroke Care (INASC).

The objective of the audit of hospital-based stroke services was to establish the current level and functioning of services for the care of stroke patients in acute hospitals in the Republic of Ireland. The audit of hospital-based services had two components:

- i) An audit of the organisational aspects of stroke care in acute hospitals with regard to their resources for organised stroke care; and
- ii) A clinical audit of stroke care involving the review of clinical case notes for a selected national sample of patients with stroke.

The objective of the audit of community-based stroke services was to establish the current level and functioning of services for the ongoing care of stroke patients in community settings in the Republic of Ireland. The community component of this audit involved surveys of:

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

This report integrates the findings of the six detailed INASC reports, as listed above.



Chapter 2

Methodology



General Practitioner Survey

The aim of this survey was to document the availability of evidence-based structures for supporting stroke care and prevention in general practice and to profile the views, experiences, and needs of Irish GPs in this context. This was a cross-sectional study of randomly selected GPs practising in the Republic of Ireland. Participation was invited by postal survey. A telephone reminder followed at two weeks. GPs could return the questionnaire or complete it by telephone interview. A final reminder questionnaire was sent to non-responders within the following two weeks. Of the target sample of 484 GPs, 36 were ineligible and 204 responded (a response rate of 46%).

Hospital Organisational Audit

The aim of the organisational audit of hospital-based stroke services was to establish the current level and functioning of services for the care of stroke patients in acute hospitals in the Republic of Ireland, with regard to their resources for organised stroke care. The audit was conducted in all 37 relevant public acute hospitals. Findings represent the organisation of services in mid-2006. The audit of organisational aspects of stroke care involved structured face-to-face group interviews by two research team members with relevant senior personnel in each hospital. This included a senior member of the management team (usually the Chief Executive Officer, Hospital Manager), a lead medical clinician in stroke care, the director of nursing and a senior therapist manager involved in stroke care using the Royal College of Physicians London (United Kingdom) (RCPUK) National Sentinel Stroke Audit 2004 Organisational Audit Proforma, with modifications for the Irish setting.

Hospital Clinical Audit

The aim of the clinical audit was to conduct a review of clinical case notes for a selected sample of patients with stroke. The final sample was the 36 hospitals that participated in the Hospital In-Patient Enquiry (HIPE) scheme. The audit of clinical aspects of stroke care involved a retrospective review of approximately 2,500 clinical case notes for a selected sample of patients in 36 public acute hospitals. The audit sample included consecutive discharged cases with a primary diagnosis of stroke (ICD 10 codes: I61, I63 and I64, including subcategories) during the specified six month period: January, February and March; July, August and September 2005. The number of patients discharged over the six month period was 2,570.

Inclusion criteria were as follows: Intracerebral Haemorrhage (I61), Cerebral Infarction (I63), Stroke, not specified as haemorrhage or infarction (I64).

Exclusion criteria were as follows: Cases with subarachnoid haemorrhage (I60), subdural and extradural haematoma (I62). Local chart auditors were identified through the stroke physician and by means of contact with relevant hospital departments. Seventy-six chart auditors underwent training. The audit proforma used was the Royal College of Physicians London (United Kingdom) (RCPUK) National Sentinel Stroke Audit 2006 Clinical Audit Proforma.

Survey of Public Health Nurses (PHNs) and Allied Health Professionals (AHPs)

The aim of this survey was to document the availability of evidence-based structures for supporting stroke care in the community and to profile the views, experiences, and needs of Irish AHPs and PHNs in this context. This study involved a cascade approach to the selection of AHPs and PHNs. Regional Local Health Office (LHO) managers for services for people with disabilities and for services for older people for each of the four HSE regions were contacted and interviewed. The LHO managers then nominated AHP and PHN managers for further discipline-specific interviews. Following semi-structured interviews, managers nominated frontline staff to provide a profile of the experience of stroke care in urban and rural settings. Frontline staff were surveyed by a postal questionnaire developed on the basis of interviews with LHO and discipline-specific managers.

Nursing Home Survey

The aim of this report was to document the current status of community stroke provision in the nursing home context. The specific focus was nursing home service provision, as perceived by key nursing home staff and residents with stroke. A cross-sectional survey design was used to investigate the experiences of nursing home proprietors, staff and patients. Five hundred and seventy-two public and private nursing homes were identified in the Republic of Ireland. A random selection was made to recruit 60 nursing homes nationally, stratified by geographic location (20 nursing homes in Dublin and 40 selected from outside the Dublin area). All of the invited residents who had had a stroke, agreed to participate. The selection resulted in 35 private nursing homes and 25 public nursing homes participating. All 60 nursing homes were visited and the proprietor or nominee was interviewed. The view of service users is an integral part of any service quality evaluation. In half of the 60 randomly selected nursing homes (10 in Dublin and 20 outside Dublin), a brief interview survey was conducted with nursing home residents with a history of stroke.

Patient and Carer Survey

A sample of 200 patients with a primary diagnosis of stroke, discharged from hospital across the Republic of Ireland was the focus of this study, along with their primary carer. Patients were stratified by age (younger versus older (65+)), gender, geographic location (urban versus rural) and time since stroke (early: 6-12 months versus intermediate term: 24-36 months). Geographic location was stratified by selecting patients post-stroke discharged from specific hospitals in Ireland.

In order to take account of hospital size and geographic location, the hospitals selected for inclusion were the Adelaide and Meath Hospital Incorporating the National Children's Hospital, Dublin, the Midland Regional Hospital at Mullingar, Mallow General Hospital, Cork, and Mayo General Hospital, Castlebar. These hospitals were comparable on key standards to all other public acute hospitals (N=32) in the Republic of Ireland involved in the INASC Clinical Audit.

Patients whose acute stroke care took place in these four hospitals were included in the survey if they had been discharged from hospital within the required study time periods, namely, 6-12 months prior to interview (timeframe slightly different for each hospital, depending on interview start date timeframe was relevant 6-month period between January - October 2006), and 24-36 months prior to interview (relevant 12-month period between January 2004 and April 2005).

Identification of patients discharged from these hospitals was through the Hospital In-Patient Enquiry (HIPE) scheme office at the Economic and Social Research Institute (ESRI), using the same ICD10 codes as were used for the INASC Clinical Audit (codes I61, I63, and I64 for the 2006 cohort; equivalent ICD9 codes 431, 434, and 436 for the 2004 cohort).

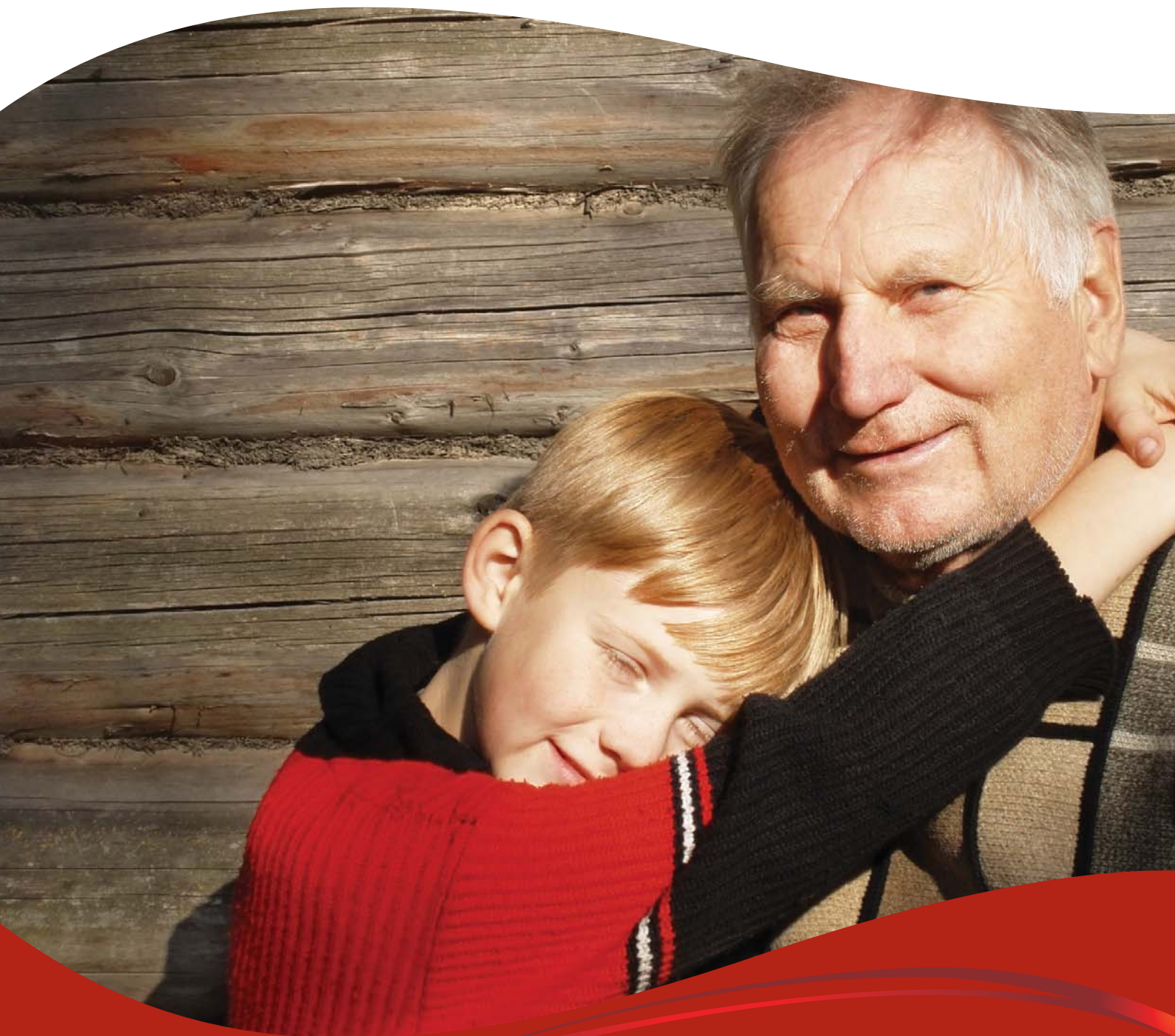
Four questionnaires were developed for this survey: a patient questionnaire; a carer questionnaire; a proxy questionnaire, for use where a patient was unable/unwilling to take part but was happy for a relative to take part on his/her behalf; and a carer questionnaire, for use where the person with stroke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

Ethical Approval

Ethical approval for all projects was provided by the Royal College of Surgeons in Ireland's Research Ethics Committee. In advance of hospital components of the audit, the National Hospitals Office of the Health Service Executive and the Chief Executive Officers of the relevant hospitals granted permission. In a small number of cases, the chart audit component was also reviewed by the local hospital research ethics committee.



Summary of Results



3.1 General Practitioner Survey

Primary Prevention

GPs reported little systematic or organised primary prevention of stroke. Results indicated an absence of regular clinics for primary prevention activities. GP activity in relation to the primary prevention of stroke by targeting hypertension, atrial fibrillation (AF), warfarin anti-coagulation and diabetes is presented in Table 3.1.

Table 3.1 Percentage of GPs carrying out activities recommended in primary stroke prevention guidelines (N=201)

	Hypertension %	Atrial fibrillation %	Warfarin anti-coagulation %	Diabetes %
Screening	46	17	-	58
Diagnosis	63	37	-	69
Management	60	37	-	62
Initiation	-	-	28	-
Monitoring	-	-	61	-
Referral	44	37	38	59
Comprehensive guidelines covering all of the above	24	12*	12*	29

*Refers to a comprehensive guideline/protocol covering all the areas relevant to AF and warfarin anti-coagulation.

Most GPs (86%) reported that there were barriers to implementing primary prevention strategies for stroke in their practices, including staffing, time, funding and lack of screening protocols and risk-factor management protocols. Almost half of GPs (46%) stated that additional nurses, in particular practice nurses, would help to overcome these barriers, and 15% stated that dedicated clinics would enable stroke primary prevention strategies to be implemented.

Heartwatch Scheme

Just over one-third of GPs (35%) indicated that their practice was part of the Heartwatch scheme. With two exceptions, preventive services were significantly better for GPs involved in Heartwatch (structured heart-related chronic disease management programme). These exceptions were screening for atrial fibrillation and having referral guidelines for warfarin anti-coagulation, both of which occurred significantly more frequently in non-Heartwatch practices. Both relate to atrial fibrillation, which is not included as one of the Heartwatch risk factors, since it is a risk factor for stroke (see Table 3.2).

Table 3.2 Relationships between being part of Heartwatch and stroke service related variables (N=210)

	Heartwatch %	Non-Heartwatch %	χ^2	df	p
Has a register of patients with hypertension	46%	22%	10.6	1	.001
Has conducted audit of patients with HTN* within last 2 years	17%	2%	12.5	1	<.001
Routinely screens for AF^	44%	66%	7.5	1	<.01
Has register AF patients	30%	10%	10.9	1	.001
Has referral guidelines for warfarin anti-coagulation	23%	43%	6.5	1	<.05
Runs a warfarin clinic	47%	31%	4.3	1	<.05
Register of patients with diabetes	73%	41%	15.7	1	<.001
Runs a diabetes clinic	38%	18%	7.6	1	<.01
Has conducted audit of patients with diabetes in the last two years	30%	17%	3.9	1	<.05
Runs general healthy lifestyle clinics	20%	7%	5.2	1	<.05
Runs smoking cessation clinics	14%	4%	4.3	1	<.05
Has a stroke register	23%	8%	6.5	1	<.05
(Computerised stroke register)	(88%)	(48%)	4.7	1	<.05

Note: The continuity correction value is reported, this compensates for any overestimate of the chi-square value when used with a 2 x 2 table.

*HTN: Hypertension

^AF: Atrial fibrillation

The availability of a practice nurse is a necessary pre-requisite for participation in the Heartwatch scheme. Relationships between GP ratings of stroke service related variables indicated significantly better results for GPs, who rated their access to a practice nurse as good or excellent (Table 3.3).

Table 3.3 Relationships between GP ratings of access to practice nurse and stroke service related variables (N=210)

	% Good access	% Poor access	χ^2	df	p
Has a register of patients with hypertension	35%	16%	5.4	1	<.05
Routinely screens for AF	55%	74%	4.4	1	<.05
Has register of patients AF patients	21%	6%	4.7	1	<.05
Has initiation of warfarin anti-coagulation guidelines	33%	12%	6.9	1	<.01
Runs a warfarin clinic	45%	17%	11.1	1	.001
Has register of patients with diabetes	61%	24%	19.8	1	<.001
Runs a diabetes clinic	30%	10%	7.4	1	<.01
Stroke register computerised	80%	22%	7.9	1	<.01
Hospital medical team routinely liaise prior to hospital discharge	6%	21%	7.0	1	<.01

Stroke Register and Communication at Hospital Discharge

A minority of GPs (14%) reported that they had a stroke register. A majority of GPs (86%) reported that they were not sent information in relation to stroke patients immediately before their discharge from hospital. Information provided by the hospital following the patient's discharge typically concerned medications and diagnostic test results, stroke type and severity. Less than two-thirds of GPs (64%) reported that they received notification from the hospital indicating the point at which the patient was fully discharged from hospital, namely that the patient had no further out-patient visits.

Secondary Prevention

The use of guidelines in relation to key secondary prevention issues was typically poor. GPs most frequently provided information to stroke patients on smoking cessation and adherence to medication. Approximately three-quarters of GPs reported that they always provided information on these lifestyle modifications. Considerably fewer GPs reported always giving information on physical activity, alcohol consumption, weight management, diet/healthy eating, and reducing salt intake. Three-quarters of GPs believed there were barriers to implementing secondary prevention strategies in their practice, including time (60%), staffing issues (57%), funding issues (33%), lack of protocols/guidelines (17%) and lack of space (almost 10%).

Stroke Rehabilitation and Long-Term Care

GPs reported very limited access to a range of allied health professionals, including occupational therapist, speech and language therapist, dietitian, psychologist, counsellor, social worker, or vascular surgeon. Nearly two-thirds of GPs (62%) responded that they did not receive communication regarding rehabilitation services that had been organised for the person with stroke following discharge from hospital. Most GPs (87%) believed that the availability of existing rehabilitation services was inadequate for their stroke patient population. Just over two-thirds of GPs (68%) had stroke patients who were residing in nursing homes.

3.2 Hospital Organisational Audit

Presentation to Hospital and Organisation of Care

Only one of 37 hospitals had arrangements with the local ambulance service for emergency, rapid transfer to hospital for patients with acute stroke. Three-quarters of hospitals (78%) had on-site emergency access to computerised tomography (CT), while just under half had on-site access to MRI scanning (49%). None of the 37 hospitals had a routine thrombolysis service in the accident and emergency department.

Very few hospitals provided therapy assessment in the emergency department. Five sites reported that swallow assessment was available. In the majority of hospitals (84%), patients with acute stroke were admitted to a general medical ward.

Only one Irish hospital (3%) had a stroke unit. Five hospitals described models for stroke care at their hospital which did not fulfil the full definition of a Stroke Unit, but seemed to represent an intermediate stage in organised stroke care. Even if the other five hospitals with organised stroke care are included, the total count of 16% is in marked contrast to the UK 2004 Sentinel audit, which identified 79% of centres as having a stroke unit. Figures were 91% in the most recent 2006 UK Sentinel audit.

Access to In-hospital Rehabilitation

Only 35% of hospitals had access to an on-site rehabilitation unit, although the majority of hospitals (n=30, 81%) had access to a generic rehabilitation unit, usually under the direction of a geriatrician (Table 3.4). The median number of rehabilitation beds was 19 (range 6-80, IQR 13-34). The total available was 685 (inclusive of on-site and off-site rehabilitation units).

Table 3.4 Access to a generic in-patient rehabilitation unit (37 sites)

	N	%	UK 2004	UK 2006
Yes	30	81	63%	Not available
Yes onsite	10	35*		
Yes offsite	21	72		
No	7	19		

A mixed rehabilitation unit (generic rehabilitation unit) was defined as follows: a multidisciplinary team (including specialist nursing staff) in a ward providing a generic rehabilitation service but not exclusively caring for stroke patients.

* One site had access to both an on-site and an off-site generic rehabilitation unit.

In general, there was limited access to rehabilitation for younger stroke patients. None of the hospitals had access to a specialist community stroke team for continuing longer-term management of stroke patients after their discharge from hospital.

Medical Management

Thirty per cent of hospitals did not have routine access to CT scanning within 48 hours of stroke, and the level of access to emergency MR scanning was 41%. There was low access to carotid doppler scanning within 2 weeks after a TIA, with no availability in 14% of sites admitting patients with stroke.

Six of the 37 (16%) hospitals had a neurovascular clinic, with an average of four clinics in a 4-week period. Three of these 6 shared the same service, while the other three had individual services. Carotid endarterectomy was performed on-site in about a third of hospitals (30%). The remaining hospitals referred patients to other hospitals for this procedure. In many cases, detailed information regarding the number of procedures and patients referred was not available. Over 90% of the hospitals did not have agreed stroke or TIA protocols between acute and primary care services. This compared poorly with UK figures (49% in Sentinel 2004).

Specialist Roles

About one-third of hospitals (12 sites, 32%) stated that there was a consultant physician with specialist knowledge of stroke who was formally recognised as having principal responsibility for stroke services at the hospital. However, only 5 of these were recognised with a formal sessional commitment in their contract. None of the hospitals had a stroke co-ordinator. Five of the 37 hospitals had a clinical nurse specialist in stroke care. One hospital had two clinical specialist therapists (one was a physiotherapist and the other an occupational therapist).

Interdisciplinary Services - Continuing Education in Stroke and Team-working

Although an interdisciplinary service was available in all hospitals, there was limited use of a single central set of patient records. Only three hospitals (8%) indicated that they had an interdisciplinary care pathway for stroke. Stroke-specific team meetings only occurred in a minority of cases (22%).

Communication with Patients and Carers

The majority of hospitals were not organised to allow patients and/or family to have ready access to their stroke management plan. Patient literature was routinely displayed in the stroke unit. There was limited availability of patient versions of local or national guidelines, and on standards of stroke care, carer allowances or voluntary agencies.

Discharge Planning and Ongoing Rehabilitation

Four hospitals (11%) had a hospital or community liaison person. In general, access by the hospital to public health nursing and liaison psychiatric nursing was rated as good to excellent. The majority of hospitals, 30 of the 33 for whom replies were available (91%), described community stroke services as very limited for stroke patients under 65 years of age. In particular, there was very little access in the community to medical social work and psychology services (Table 3.5).

Table 3.5 Access to community services (37 sites) (N sites)

	No access	Very limited	Quite limited	Good	Excellent
Medical social worker	28	8	0	0	1
Psychology	27	9	0	0	1
Dietician	16	17	1	2	1
Speech and language therapy	13	19	3	0	2
Liaison psychiatric service	4	6	4	19	3
Liaison psychiatric nurse	2	5	3	22	4
Occupational therapy	1	21	9	4	2
Public health nurse	0	1	4	19	13
Physiotherapy	0	14	12	8	3

Stroke Service Plans and Some Comparisons with UK Sentinel Data

Nearly two-thirds of hospitals (23 sites, 62%) had submitted a plan for stroke services in their annual service plans for 2007. Comparative results in a number of key areas for the last three rounds of the UK audits (UK Sentinel audit 2006) clearly demonstrates that with investment from the UK government, progress has followed in key aspects of service provision and specialisation (Table 3.6).

Table 3.6 Comparison of key areas between Ireland and Sentinel audit

	Ireland 2006	UK 2002	UK 2004	UK 2006
Stroke unit	3%	73%	79%	91%
Rapid transfer to hospital	3%	NA	4%	12%
Routine thrombolysis	0%*	NA	NA	18%
Neurovascular clinic	16%	NA	65%	78%
Mobile stroke team	14%	NA	23%	29%
Early support discharge team	0%	NA	14%	22%
Specialised community team	0%	NA	25%	32%
Consultant with responsibility for stroke care	32%	80%	90%	98%

NA = Not Available

* Hospital organisational audit (37 hospitals)

3.3 Hospital Clinical Audit

Chart Sample and Demographic Profile

Clinical audit data relating to the process of care was returned from the 36 participating acute hospitals. There were 2,570 cases identified through HIPE for the specified six-month period in 2005. There were 170 (7%) missing charts, with 227 (9%) charts identified as miscoded. The final number of cases identified as stroke was 2173. Half the cases were men (52%; n=1124) and 47% were women (n=1021). Gender data was missing in 28 cases (1%). (In Sentinel 2006, 48% of cases were men and 52% women.) The mean age was 75 years (S.D. 13; median 78 years; range 18-100). Approximately 19% of patients were aged younger than 65 years. The UK and Irish gender and age profiles were notably similar.

Stroke Onset and Hospital Stay

The mean time from stroke to hospital admission was 1.1 days (SD 4, range 0-53). In Sentinel 2006, 39% of cases were admitted within 2 hours of stroke onset, while in INASC 5% (85/1737) were admitted within 2 hours. Nineteen percent (n=408) of stroke patients died as an in-patient. The confirmed mortality rate within 30 days of the stroke was 15% (n=317) (Table 3.7).

Table 3.7 In-patient and 30-day mortality

	INASC	Sentinel 2006	Sentinel 1998
Died in hospital	19% (408)	26%	NA
Unknown	4%	1%	
30-day mortality*	15% (317)	22%	29%
Unknown	13%	5%	

NA not available.

* Deaths within 30 days of stroke

The mean length of stay in hospital was 29.8 days (SD 47.2; median 14 days; range 0-388 days) (Table 3.8).

Table 3.8 Hospital length of stay

	INASC	Sentinel 2006	Sentinel 1998
Length of stay to discharge alive	Mean 29.8 sd 47.2 Median 14 IQR 7-30	Mean 27.7 Median 15	Mean 36
Length of stay to death	Mean 26 days sd 59 Median 9 IQR 3-24	Mean 18.6 Median 10	Mean 17

IQR Interquartile range
sd standard deviation

While in hospital, the majority of patients (69% n=1496) spent more than 50% of their stay on a general ward with 1% in a stroke unit. The majority of stroke patients (61%) were under the care of a general physician, followed by 31% consultant geriatrician, 7% consultant neurologist and 1% consultant in rehabilitation medicine.

CT Scanning Following Stroke

In total, 93% of patients had a scan after their stroke, with 40% having the scan within 24 hours of the stroke. This figure is somewhat lower than the recent UK Sentinel audit (42%). The mean time from onset of stroke to scan was 2.6 days (SD = 7, median = 1). In Sentinel 2006, the average time from stroke to scan was median 1 day (IQR 1-3). Only 4% of INASC cases were scanned within three hours of admission, 5% at 6 hours and 9% scanned within 12 hours of stroke. This is low compared with the 9% scanned within 3 hours of admission in the Sentinel 2006 audit.

Case-mix and Co-morbidities

The majority of presenting stroke patients (83%) had a medical co-morbidity (Table 3.9). The most common co-morbidities were hypertension (51%), previous stroke or TIA (25%), followed by atrial fibrillation (22%).

Table 3.9 Known co-morbidities prior to admission with stroke (N=2173)

Co-morbidity	INASC % (N)	Sentinel UK 2006
Atrial fibrillation	22% (469)	20%
Previous stroke/TIA	25% (541)	29%
Impaired glucose tolerance	1% (22)	NA
Diabetes mellitus	12% (260)	16%
Hyperlipidaemia*	17% (372)	19%
Hypertension^	51% (1108)	53%
MI or angina	14% (307)	20%
Valvular heart disease	4% (92)	3%
Other+	18% (388)	5%
None apply/detected	17% (362)	21%
None of the above	22% (479)	21%
1 of the above	29% (626)	29%
2 of the above	24% (524)	27%
3 of the above	25% (544)	23%

* Hyperlipidaemia = total cholesterol >5 or LDL >3.0mmol/L (UK 2006 Clinical Audit Proforma)
 ^ Hypertension = systolic > 140 or diastolic > 85 (UK 2006 Clinical Audit Proforma)
 + Other = Congestive cardiac failure (CCF) and Polymyalgia Rheumatica

Nearly half of all stroke patients (49%) had newly detected co-morbidities after their admission with stroke (Table 3.10), the most common being hyperlipidaemia (12%) and hypertension (11%).

Table 3.10 Newly detected co-morbidities since admission (N=2173)

Co-morbidity	INASC % (N)
Atrial fibrillation	7% (155)
Previous stroke/TIA	1% (28)
Diabetes mellitus	4% (85)
Hyperlipidaemia*	12% (251)
Hypertension^	11% (229)
MI or angina	1% (28)
Valvular heart disease	12% (255)
Other	12% (267)
None apply/detected	49% (1063)

* Hyperlipidaemia = total cholesterol >5 or LDL >3.0mmol/L
 ^ Hypertension = systolic > 140 or diastolic > 85
 This question was not asked in the 2006, 2004 and 1998 Sentinel audits.

Thrombolysis and Aspirin

Only 29 of 2,173 patients (1%, 14 of 36 sites) were documented as receiving thrombolysis. Just under half of INASC patients (45%) had commenced aspirin by 48 hours after their stroke. This compares with 71% on aspirin in the most recent Sentinel data (2006).

Pre-admission Medication

Over half the patients were on antihypertensives and antiplatelet/thrombotic therapy before their admission, while a quarter were on lipid lowering treatment (Table 3.11).

Table 3.11 Cardiovascular medication profile pre-admission

	INASC % (N)	Sentinel 2006
Anti-hypertensives	56% (1219)	57%
Anti-platelet/anti-thrombotic	52% (1133)	51%
Lipid lowering treatment	25% (546)	33%

Accommodation Pre-Stroke and at Discharge

While similar proportions lived at home pre-stroke in Ireland and Sentinel 1998 (the only UK comparable date), more were discharged home in the UK (67% and 77% Sentinel 1998 and 2006 respectively versus 56% in INASC). In the Irish sample, 15% were newly institutionalised (13% Sentinel 2006).

Level of Independence: Functional Level pre-Stroke and Dependency at Discharge

The majority of patients (73%) were independent in their daily activities prior to their stroke, while 13% were dependent. Sentinel 2006 found that 77% of patients were independent in everyday activities before their stroke. The average Barthel Index score at discharge was 13.5 (SD 7.1; median 17; range 0-20) (Table 3.12), indicating, on average, a moderate level of disability.

Table 3.12 Level of Independence (N=1563)

Barthel Score	INASC % (N)	Sentinel 2006	Sentinel 2004	Sentinel 1998
Independent (20)	28% (445)	39%	37%	35%
Mild disability (15-19)	26% (410)	24%	29%	28%
Moderate disability (10-14)	15% (238)	15%	14%	17%
Severe disability (5-9)	14% (221)	8%	8%	9%
Very severe disability (0-4)	16% (249)	13%	12%	11%

Multidisciplinary Assessment and Standards within 24 hours, 72 hours and 7 days

Levels of multidisciplinary assessment were substantially lower when compared with UK Sentinel 2006 audit figures. While 26% of patients were screened by staff for swallow problems within 24 hours, only 25% had a formal swallow assessment by a speech and language therapist in the first 72 hours since their admission for stroke (67% UK 2006). Less than half were assessed by a physiotherapist (43%) within this time (71% UK 2006). The majority of patients were receiving nutrition (81%; 93% UK 2006); most of these (82%) were on oral nutrition. Only a fifth of patients were assessed by an occupational therapist within 7 days (Table 3.13), with 13% assessed by a social worker within 7 days of referral.

Table 3.13 Patient assessment within 7 days of admission after stroke (N=2173)

Standards	INASC % (N)	Sentinel UK 2006	Sentinel UK 1998
Communication assessment SLT			
Yes	29% (637)	69%	61%
No	30% (658)		
No but*	37% (804)		
Missing	3% (74)		
Occupational therapy assessment			
Yes	22% (476)	68%	43%
No	45% (977)		
No but**	30% (646)		
Missing	3% (74)		

* Answer 'No but' = if patient died within 7 days; patient was still unconscious; it is documented that the patient had no communication problems; patient is receiving palliative care.

**Answer 'No but' = if patient died within 7 days; patient was still unconscious; it is documented that the patient had no difficulties performing everyday activities; patient is receiving palliative care.

Forty-one percent of stroke patients had documented evidence in their charts that they had been weighed during hospital admission. The mood of patients was assessed in 28% of cases, while 41% had been given a cognitive assessment.

Management and Care Planning

In relation to care planning, there was written evidence of rehabilitation goals agreed by the multidisciplinary team in 22% of cases. This compares to 76% in the 2006 Sentinel audit.

Risk Factor Management and Secondary Prevention

In just over half of cases (51%), the probable underlying cause for the stroke had been identified. In the 2006 Sentinel audit, the underlying causes for the stroke were identified in 73% of cases. The causes identified most commonly in INASC were hypertension (56%), followed by atrial fibrillation (28%). A similar profile was evident in Sentinel 2006 (Table 3.14).

Table 3.14 Probable causes for stroke recorded at discharge (N=1114)

Cause of stroke	INASC % (N)	Sentinel UK 2006
Carotid stenosis	11% (118)	9%
Current smoker	14% (156)	17%
Alcohol abuse*	6% (67)	6%
Atrial fibrillation	28% (317)	27%
Myocardial infarction in last month	4% (48)	4%
Hypertension	56% (623)	62%
Diabetes mellitus	14% (154)	NA
Missing	46% (516)	NA

*Alcohol abuse number of units per week > 21 female and > 28 male

NA not asked in Sentinel 2006 or 1998

Percentages sum to > 100% as more than one cause for stroke was given

Generic lifestyle factors to promote secondary prevention following stroke were documented as having been discussed with the patient and his/her carer in only a small proportion of cases. Factors discussed included smoking cessation (9%, UK 2006 79%), alcohol management (7%, UK 80%), physical activity (8%, UK 41%) and diet (14%, UK 42%). Two-thirds had blood cholesterol levels documented; 39% of these had elevated cholesterol, and 29% of those with elevated cholesterol received dietary advice on reducing their cholesterol through dietary management.

Nearly half of all cases (47%) had elevated blood pressure in the acute phase after stroke. The majority of patients were discharged on cardiovascular medications. This profile is similar or higher, particularly concerning antihypertensive medications, to Sentinel 2006 (Table 3.15).

Table 3.15 Cardiovascular medication profile at discharge

	INASC % (N)	Sentinel 2006
Anti-hypertensives	78% (1306)	57%
Anti-platelet/anti-thrombotic	85% (1423)	86%
Lipid lowering treatment	70% (1177)	79%

Communication with Patients and Carers

A formal discussion in relation to stroke diagnosis (22%) and prognosis (18%) was recorded as taking place in approximately a fifth of cases. In the United Kingdom (Sentinel 2006), 69% had a documented discussion about diagnosis and 59% about prognosis before discharge. The carer's needs were assessed in 24% of cases (68% Sentinel 2006), while there was evidence that the skills required to care for the patient at home were taught in 12% of cases (compared with 71% in the UK (Sentinel 2006)).

Discharge Planning from Hospital and Onward Referral

In 56% of cases there was evidence that the general practitioner was notified of the patient's details by the day of discharge from hospital. In the UK in 2004, the patient's discharge was notified to the GP in 65% of cases. The average notification delay from discharge was on average 18 days (SD 35). The median was 5 days (IQR 0-22 days). Thus half of those GPs notified after discharge were contacted within a working week. The GP summary letter included a description of the patient's functional ability in approximately a quarter of cases (24%), in contrast to over half (57%) in the 2004 UK Sentinel audit. A home visit took place in a very small number of cases (7%), in contrast to over 63% of patients in the 2006 Sentinel audit. Thirty-five percent of patients had carotid imaging within three months of their stroke. In the 2004 UK Sentinel audit, 50% of cases had carotid imaging performed within 3 months to check for carotid stenosis.

Clinical Audit: 12 Key Indicators

The Irish and UK results on the 12 key indicators from INASC and the 2004 and 2006 Sentinel audits are presented to give an overview of quality of hospital care (Table 3.16).

Table 3.16 12 Key standards and indicators of stroke care INASC versus Sentinel

	Key standards % Compliance with indicator <i>Patients</i>	INASC (<i>N</i> = 2,173) %	Sentinel 2004 (<i>N</i> = 8,697) %	Sentinel 2006 (<i>N</i> = 13,625) %
Q1.2iii	Brain scan within 24 hours	40	59	42
Q1.7	Treated on a stroke unit during their stay	2	46	62
Q1.9	>50% stay on a stroke unit	1	40	54
Q3.1	Screened for swallow within 24 hours	26	63	66
Q3.3	Aspirin started by 48 hours	45	68	71
Q3.5	Physiotherapy assessment within 72 hours of admission	43	63	71
Q4.2	Occupational therapy assessment within 7 days of admission	22	57	68
Q5.1	Weighed at least once during admission	41	52	57
Q5.3	Mood assessed by discharge	28	47	55
Q6.3	On anti-thrombotic therapy by discharge	85	95	100
Q5.5	Rehabilitation goals agreed by MDT	22	68	76
Q7.4	Home visit performed by discharge	7	69	63
	Average for 12 indicators	30	61	65

The Irish audit reported lower coverage on all 12 key indicators than both the 2004 and 2006 UK Sentinel audits. Particularly notable was the virtual absence of stroke unit care in Ireland, while over half were treated in such units by 2006 in the UK. While the initiation of appropriate medication, technological assessment, physiotherapy and patient body weight assessment were conducted for over 40% of Irish patients, services requiring other members of a multidisciplinary team (swallow, occupational therapy needs, mood assessment and multidisciplinary discharge goals for rehabilitation) were available to only about one in four stroke patients. Home assessment was also a service for a minority in Ireland (7%) and the majority (>60%) in the UK.

3.4 Public Health Nurse and Allied Health Professional Survey

Local Health Office Managers (LHOM) Interviews

The LHOMs raised a number of concerns in relation to service planning and service provision.

Service Planning

'There is historical under-funding and under-development of services, with no overall cohesive plan. Demand exceeds supply of rehabilitation opportunities.'
(Physiotherapist)

Across the four HSE regions, there is no designated coordinator or formal structured system for stroke service provision in Ireland. Stroke is managed as part of a generic workload; responsibility for those aged 65 and over is with Services for Older People and for those under 65 years with Disability Services. Business plans for stroke had not been sanctioned for implementation. All managers welcomed the development of a national strategy for stroke.

Local Service Provision

'Patients and carers will eventually receive the necessary equipment and training, but there are severe delays with equipment provision due to budgetary constraints.'
(Physiotherapist)

'Lack of staffing in SLT means that reviews are constantly behind as the waiting list is prioritised over review of existing clients.' (Speech and language therapist)

'There's not enough manpower to provide an efficient, quality, evidence-based service. Due to work pressures, there's often not enough time to discuss clients' needs and concerns with other health professionals.' (Occupational therapist)

A recurring issue across the four HSE regions was that of inadequate staff resources and of significant variation in the availability of specialist staff both between and within regions, resulting in considerable inequity in relation to service access. Special attention was also drawn to the lack of age-appropriate services for stroke. A shortage of rehabilitation services for those under 65 years was noted and, in some parts of regions, it was described as non-existent. Access to national services, such as the National Rehabilitation Hospital (NRH), for patients under age 65 was described as limited owing to long waiting lists. The discrepancy between acute care and continuing care was also highlighted nationally, with resources to ensure adequate transition from acute to community care identified as a distinct unmet need.

Need for Care Pathways and a Common Patient Record

There were no clear care pathways in place for stroke care nationally. The need for hospitals to work with primary care teams to develop a more coordinated approach was emphasised. A common record system was deemed to be very helpful to prevent undue delays in processing referrals, setting up treatments, communicating with others on the team and dealing with patient/family queries. Most community-based disciplines recorded information in files that were not common to other disciplines, resulting in duplication of information gathered by different disciplines, thus highlighting the need for multidisciplinary team record-keeping.

Barriers/Solutions for Stroke Management

'There is no 'stroke team' in place. There is a patchiness of resources/services - not standardised across areas/HSE nationally'. (Public health nurse)

Managers reported that current barriers to comprehensive stroke management in the community were, primarily, lack of funding and existing whole-time equivalent (WTE) staff ceilings. An additional barrier identified was the hospital/community interface, which was described as 'problematic'. There was a general need identified to raise the profile of stroke nationally and to gather evidence in relation to the numbers of individuals with stroke and the needs of those with stroke in the community, in order to facilitate appropriate service planning for the future.

The Ideal Stroke Service

Finally, LHO managers highlighted the characteristics of an ideal stroke service in Ireland as one that would be comprehensive, fully integrated, seamless between hospital and community care, amply resourced, and with a clear national structure for responsibility.

Allied Health Professional and Public Health Nurse Manager Interviews

The managers highlighted concerns in relation to community stroke care and access to a full range of community rehabilitation services.

Communication from Hospital to Community

'There is poor communication between hospital and community, and poor communication between community health professionals.' (Occupational therapist)

Communication from hospitals to community health professionals before stroke patients are discharged was described as very variable and generally very poor. A liaison person was in place in some areas to manage discharge for some patients (this was a general, not stroke-specific service). A stroke register or discipline-specific register did not exist in any HSE region. Enhanced information technology was identified as a means of greatly improving communication. Early contact with community services prior to hospital discharge, to allow time for appropriate services to be organised, was identified as a priority. Lack of designated stroke coordinators and dedicated stroke teams were seen as major impediments to appropriate levels of rehabilitation for persons with stroke discharged to the community.

'There is lack of communication with AHPs due to the location of the various clinics. It would be easier if all AHPs were located in a central area to improve communication.' (Dietitian)

Inequitable Access to Rehabilitation

In many areas there was no rehabilitation programme for patients with stroke and the treatment that was available was described as fragmented. The duration of input from physiotherapy was between 6 and 12 weeks for most areas. Across HSE regions, it was reported that there were better dedicated services for persons with stroke aged 65 and over, with no - or very little - funding for those under 65 years of age. Thus, for example, situations arose where people in their 50s with stroke were not entitled to rehabilitation or home care packages and, as a result, were placed in nursing homes indefinitely.

Ongoing Rehabilitation and Long-Term Management

Where community rehabilitation was provided, ongoing support for patients with stroke was variable when it finished, both across and within HSE regions. Patients might be referred to voluntary organisations, such as Headway, or to a day hospital, day centre, or might be maintained at home with or without respite. There was a noted lack of day services nationally for stroke patients under the age of 65. Access to specialist rehabilitation units, such as those in Baggot Street community stroke rehabilitation unit, Dublin and National Rehabilitation Hospital (NRH) in Dun Laoghaire, was very limited, frequently involving long waiting times.

Where patients with stroke required long-term management, the follow-up of patients was described as sporadic. Resources and workload were cited as the primary reasons for being unable to guarantee this long-term management, in addition to limited interdisciplinary services and short-term respite care. The review of younger patients under 65 years with stroke was particularly difficult for occupational therapy (OT) owing to low numbers of community OTs, insufficient budgets for aids and appliances, and the limited availability of home help. There was no formalised system of review for all disciplines, in particular for dietetics and in psychology, where review was seen to be impossible in some regions because of lack of staff. Out-of-hours support was not available, routinely, for any of the therapies. Public health nurses (PHNs) could organise weekend essential services, but this was limited to priority patients, some of whom may have a stroke, but the service was generic and not specific to community stroke care. In some areas,

ongoing support might be in the form of a stroke group, or out-of-hours support may be available in the form of providing respite for a number of hours to facilitate a family member's doctor's appointment or a family commitment. For patients with stroke in community hospitals and nursing homes, a limited service from allied health professionals was available, but was typically very intermittent.

'Only stroke patients who can attend the dietetic clinic or who have a Percutaneous Endoscopic Gastrostomy (PEG) tube in place are reviewed by the community dietitian.'
(Dietitian)

Support for the Person with Stroke and their Carer

The availability of a key worker was identified as important in the provision of a streamlined service and it was considered that developing a stroke service in this way could redress some of the poor communication practices that were felt to exist in relation to patients with stroke being discharged from the acute sector to the community. The support of carers was identified as a key component of rehabilitation post-stroke. In that regard, enhancing home help and respite services was seen to be very important. Attention to transport issues for patients and the barrier to accessing rehabilitation that this presents was identified. The need to provide more education and training in relation to stroke was highlighted.

Future Developments in Stroke Care

The development of a National Stroke Strategy was considered important. Particular attention to the urban/rural divide and the very different challenges to service provision in these areas (for example, access to transport in isolated rural areas; literacy rates in some groups, particularly among older men) were emphasised. The need to create greater public and professional awareness of stroke, and of the particular skills that different professional groups can bring to stroke management and rehabilitation was highlighted. The development of a 'services directory' for each local health area was suggested.

Frontline Staff Survey

Frontline staff delivering the service highlighted concerns in relation to community rehabilitation services for persons with stroke.

Stroke Management and Service Provision

In a majority of cases, the management of stroke for all disciplines was general and not stroke-specific. The majority of allied health professionals (AHPs) (physiotherapy, occupational therapy (OT), speech and language therapy (SLT)) and all PHN respondents did not meet as a team to discuss referrals. Communication between hospital and community was predominantly reported as 'limited'. Treatment typically took place in health centres, clinics and, where necessary, in the home setting, although a domiciliary service was not available in some areas. Public health nurses primarily saw patients in their home setting. Challenges experienced working in the home setting included limited space, limited access to resources, difficulty installing appliances in challenging physical environments, very time-consuming, very difficult to carry out standardised assessments, lack of assistance, lack of patient adherence, and poor social circumstances of patients.

Waiting lists to avail of services varied considerably both between and within disciplines, depending on the HSE area. In some areas, a waiting list of up to a year was reported for SLT services; assessment waiting lists were typically shorter - up to three months post-referral. OT waiting lists varied from days up to three months. Waiting lists for physiotherapy were typically 2-4 weeks, while PHNs reported no waiting lists; patients were typically seen 24-48 hours after their discharge from hospital.

'There is no designated service for under-65 year olds for treatment. Waiting list is prioritised based on such things as functional disability, pressure care issues. Progressive neurological conditions are awarded higher priority. Waiting lists are stagnant at present due to staff shortages, so living alone/history of falls or clients with stroke are most likely to receive our service.' (Occupational therapist)

Duration of Rehabilitation Programme

The average duration of treatment for patients with stroke varied. SLT (depending on individual patient needs) ranged from 8 sessions (under-resourced service) to blocks of six weeks followed by review. The remaining areas varied from 3 to 12 months. For OT, the duration of treatment varied depending on severity and client needs. For dietitians, the treatment duration varied depending on the patient and the location of treatment, e.g. dysphagia versus PEG feed, and hospital versus clinic. Treatment could range from 2-3 months to indefinitely. A similar situation pertained for physiotherapy: the duration of treatment varied depending on client need and the location of service. For district care units (DCU), it was usually 12 weeks, but for a generic caseload it might be less or more than this, depending on the patient's need. Public health nurses reported that the duration of treatment depended entirely on the patient's need and would continue for as long as was needed.

Onward Referral and Opportunity to Review

Age was identified as a key factor in determining services to which AHPs could refer, since those under age 65 could be referred to some services, if appropriate, such as the NRH, whereas day hospitals are not generally available to those under age 65. Almost half of SLT respondents reported providing onward referral to stroke patients, such as day hospitals and the NRH, Dun Laoghaire. The majority of OTs also provided onward referral to day hospitals, if transport was available, and to Baggot Street (Dublin) community stroke rehabilitation unit. Onward referral from PHNs was primarily to day-care and respite centres, and to stroke care support groups, where available. Physiotherapists referred patients to the Volunteer Stroke Scheme and day hospitals. The majority of dietitians did not provide this service, but also suggested that they did not need to do so.

A majority of respondents from SLT, OT, dietetics and physiotherapy provided reassessment for patients with reduced activity for six months or longer after stroke, with a view to providing a period of further targeted rehabilitation. PHNs reported a limited, non-standardised, review of patients with stroke and highlighted the urgent need for clinical nurse specialists/advanced nurse practitioners in stroke care at community care level.

'There is essentially no psychological service for people with stroke in the community. Acute brain injury services may see people with stroke, but only those aged under 65.' (Psychologist)

Role in Nursing Homes

Approximately half of SLTs and physiotherapists provided services in private nursing homes, slightly more providing services in public nursing homes. PHNs did not provide any services to nursing homes, public or private.

'There are limited rehabilitation services in private nursing homes, unless the client pays for the service - no equity in access. There is no specialist focus for stroke care in the community, and no standardised follow-up.' (Public health nurse)

3.5 Nursing Home Survey

Proprietor/Nursing Home Manager Interviews:

Nursing home proprietors raised a number of concerns in relation to care after discharge to the community.

Accessing Health Services

Access to most health professionals was reported as low, with the exception of access to a GP (91%), which was said to be very good. Access to a public health nurse (PHN) was rated by the majority as 'none' or 'limited'. Some public nursing homes employed a physiotherapist either full-time or part-time. Access to occupational and speech and language therapists (OT and SLT) was reported as being poor in both public and private nursing homes. Access to a dietitian was very limited, while psychological and counselling services in public nursing homes were almost non-existent. Access to a community psychiatric nurse was somewhat better in public nursing homes (61%) than in the private sector (55%). Poor access to a social worker was reported by 83% of public nursing homes. A majority of managers reported that access to chiropody services was of great importance in the care of older people but typically was a service that was paid for by the nursing home resident.

Residents' Profile

The sixty nursing homes surveyed had over 3,000 (3,239) residents, with a median of 41 and range from 18-174. Almost 600 of the residents (18% of the total) had previously had a stroke. Less than 1% (N=22) had suffered a stroke since admission to the nursing home. The overall nursing home age profile included 80% of residents aged 75 years or more, with 4% aged less than 65 years. This pattern was reasonably similar in public and private nursing homes. Dublin nursing homes had a somewhat younger resident profile than those outside Dublin (22% versus 13% aged less than 75 years). Of those resident in nursing homes aged 65-74 years, approximately one in four (23%) are resident in a nursing home as a result of a stroke.

In the 30 nursing homes selected for resident interview, there were 1,479 residents, 257 (17%) of whom were reported as having had a stroke in the past. Of these, eighteen residents were able to be interviewed, representing 7% of the total population of patients affected by stroke in this group of nursing homes, all of whom consented to take part. Seven men and eleven women participated. The mean age was 82.3yrs (SD = 7.2; median 82; range 69-100 years). Sixteen residents interviewed had a functional capacity of 75 (Barthel) or less. Thus, all were moderately to severely physically dependent.

Communication Between Nursing Homes, Primary Care and Acute Services

Approximately half the nursing homes reported informal contact with the GP. However, there was minimal contact with allied health professionals. Approximately 35% of nursing homes described communication with hospitals as poor and 65% as good or excellent. Nursing home managers initiated most communication. Almost all nursing homes reported receiving information about the resident before his or her admission to the nursing home, and a letter accompanied the patient on transfer. However, in about half of cases, some vital clinical information was omitted and the nursing home had to follow up on this information following transfer.

Much of the information that was lacking related to a comprehensive risk assessment in relation to falls, cognitive impairment, psychological well-being, pressure ulcer risk assessment, or activities of daily living (ADL) as measured by an OT. The lack of initial information frequently led to delays in sourcing suitable equipment, such as mattresses, wheelchairs and armchairs, and chair alarms after the patient has been admitted. There was a concern that psychiatric or cognitive problems experienced by the patient were

often not reported. A number of suggestions were made to improve communication with the acute services, including the provision of designated personnel to liaise between the nursing homes and the hospital, the presence of managers of long-stay units at case conferences in the acute setting, and an improved understanding of the role of long-term care.

Payment for Healthcare Services for Nursing Homes with Residents Affected by Stroke

Few public nursing homes had residents who paid for services (e.g. physiotherapy, occupational therapy, speech and language therapy, dietitian and chiropody). However, over half of the private nursing home managers reported that residents paid for physiotherapy (61% of homes, compared with 5% paying for physiotherapy sessions in public nursing homes) and counselling (67%), and over a quarter paid for occupational therapy (27%). Managers reported that access to these services would be better if these residents were living at home in the community and emphasised that, based on need, appropriate health services should be available regardless of address.

Overall Health and Well-Being of Residents with Stroke

Almost all managers reported that there were no specific guidelines for stroke rehabilitation in their nursing home. Most of their stroke residents had been discharged from all active rehabilitation and were admitted some time after the stroke, with no instructions relating to maintenance therapy required. Most nursing homes described rehabilitation services as being very limited, typically shared between community and day-care services, with services to nursing homes coming third in line. Managers agreed that continuing assessment was integral to the rehabilitation process.

Balance and mobility problems were the most common disability, with over 80% of nursing home residents with stroke being affected. Most (87%) were deemed at risk of falls. Over 60% were deemed to have some level of cognitive impairment while over half had problems with swallow or communication.

Levels of cardiovascular medication prescribing for this post-stroke group appeared low, with just under half of the group being prescribed anti-platelet (42%) or anti-hypertensive medication. Use of cholesterol-lowering medication and anti-coagulants was lower (36%). One in two residents was prescribed anti-depressant (53%) or sedative medication (56%). The medication profile was similar across nursing homes (public/private; Dublin/Outside Dublin homes).

National Census questions were used to characterise the profile of nursing home residents with stroke for this INASC nursing home survey, allowing comparison with a profile analysis of dependency in Irish nursing homes by Falconer and O'Neill (2007). Managers reported that 41% of stroke residents had one of the following conditions: blindness, deafness or a severe vision or hearing impairment, compared to 26% in the Census nursing home sample. Almost all INASC nursing home residents had a condition that substantially limited one or more of their basic physical activities, such as walking, climbing the stairs, reaching, lifting or carrying (96% versus 68% in Census). Similarly, a majority of residents in INASC were reported to have difficulties in learning, memory and concentration (83% versus 58% Census). None of the residents with stroke were considered to be easily able to go outside the home alone to a shop or to visit a doctor's surgery or to be able to work (versus 71% Census). Thus, the INASC findings indicate significantly poorer functioning than was found in the overall nursing home resident profile described by Falconer and O'Neill (2007).

Service User Perspective, Service Planning and Strategy Development

Of the 18 residents interviewed, the greatest gap reported between service need and provision was for physiotherapy and occupational therapy in each case, five residents reported needs that were not met. Notably all residents highlighted a need for chiropody.

Managers reported that the allocation of resources was focused on acute services and active rehabilitation, with little attention directed towards long-term care, where it was felt that the focus for health funding should be on ability rather than on disability and on optimising quality of life. There was a need for more integration between nursing homes and acute, community and social services to provide optimal services for the older person. Improved communication between the hospital and nursing home and a greater availability of appropriate health professionals would facilitate a seamless transfer of patients. The nursing home, as part of the wider community, played a key role in the secondary prevention of stroke and in the provision of support services to families affected by stroke.

Education and Training

None of the nursing homes had an identified member of staff with a specific responsibility for stroke care. There were no specific training courses for staff looking after the person with stroke in long-term care. Generic courses for care of older people are provided by the Further Education and Training Awards Council (FETAC) (for care staff) and the HSE for nursing staff. Managers considered that specialist nurses were required on multidisciplinary teams to deliver comprehensive care to persons with stroke in long-term care. Many managers reported that nursing homes have a poor public image and therefore recruitment of staff into long-term care services is a challenge.

3.6 Patient and Carer Survey

Patient Demographic Profile

One hundred and thirty-nine patients participated in this study, of whom 76 (57%) were men. The mean age was 67 years (S.D. 12.5; range 28 to 96 years). Fifty-two percent of the sample were aged 65 and over (reflecting the survey stratification procedure). Over half (55%) of the sample interviewed were married, the remainder were widowed (25%), never married (14%) or separated/divorced (6%). Twenty-four percent of those interviewed lived alone. A majority of patients (82%) reported attending a GP in the last three months, and half the patients reported attending a hospital doctor within the last three months.

Early Management and Hospital Care

'When I asked why he had the stroke, I got no answers, my questions fell on deaf ears'. (Carer)

'On the whole everyone did their best'. (Carer)

'She was looked after well; the nurses stopped to talk to me'. (Carer)

'I saw lots of doctors I couldn't fault the medical care'. (Patient)

'I was waiting on a trolley for four days and nights before being admitted to a ward'. (Patient)

'I couldn't get a doctor to see my wife the night of her stroke; there should be a doctor on call'. (Carer)

A majority (78%) reported that they were admitted to hospital as soon as they thought it was necessary, with almost half of the patients (44%) experiencing a delay between Accident and Emergency and admission to a ward. Almost one-third (29%) of patients stated that their stroke diagnosis was not discussed with them. A majority of patients (87%) reported always being treated with respect and dignity while in hospital. Over two-thirds (69%) of patients rated their stay in hospital as either very good or excellent, and only 2% reported it as poor or very poor.

Communication and Information

'It was very difficult to get information on what she was entitled to'. (Carer)
'They kept my wife and kids up to date with information'. (Carer)
'My wife was scared after her stroke; you need someone to explain the illness'. (Carer)
'I found it difficult to meet and talk with doctors'. (Carer)

Less than half the patients (45%) reported involvement in decisions about their care and treatment while in hospital, older patients reporting significantly more involvement in decision-making than younger patients. Over half the patients interviewed (52%) understood most or all the information provided to them in hospital, a quarter understood some information, the remainder either understood little or none (12%), or were given no information (11%). Almost three-quarters of patients reported that their family/person close to them was given the opportunity to talk to staff if required (71%). Of the remaining 29% of patients, one quarter (7%) reported that their family wanted to speak with staff, but were not afforded the opportunity.

A majority of patients reported needing help with daily activities. While in hospital, support needed by patients was not always available (for example, of those who had difficulty swallowing (27% of total) 33% did not get help when they needed it; while 64% of patients had no speech and communication difficulties, 35% of those who did reported not getting help when they needed it). Of those who reported having mobility difficulties (59%), a majority (70%) always received help when needed and 14% received some degree of help.

Discharge Planning

'My wife was a nurse, so she knew what to expect, but she wasn't consulted about my care'. (Patient)
'She was just discharged and forgotten about'. (Carer)
'She was on a load of tablets; no one ever told us what they were'. (Carer)
'He needed a wheelchair but was sent home without one; it took two weeks and had to be collected'. (Carer)

Almost three-quarters (74%) of the patients interviewed reported that no family conference was suggested or took place before patients left hospital. In relation to secondary prevention, almost half (44%) reported receiving information relating to diet prior to discharge. Over half (58%) received information about physical exercise to improve their health. However, one-third of patients reported not getting any information. Of those who were smokers, 65% received information about stopping smoking, but 28% received no information.

In relation to discharge medications, 34% of patients reported that the purpose of their prescribed medication was not explained to them. Seventy percent of patients were not informed before leaving hospital about potential medication side-effects.

Less than one-third of patients reported receiving a contact name from the hospital if they were worried about their condition after they left hospital (31% versus 53% in the UK). One in two patients said they would have liked some information in relation to voluntary stroke support groups in their area, stroke organisations and websites, but did not receive any (52%).

Care after Discharge from Hospital

'The hospital sent on all the results but the GP insisted he did not receive them'.

(Patient)

'No one seemed to know who was looking after him; there was no follow-up, and very little support was available'. *(Carer)*

'The GP monitors my blood pressure'. *(Patient)*

'After I got home, there should have been someone to help from the start'. *(Patient)*

The majority (81%) of patients stated that their GP had been given all necessary information about their stroke, while 14% reported being unsure whether or not their GP had been informed. On discharge from hospital, over one-third (34%) reported that they were never given any information in relation to follow-up services. Where follow-up services were organised, some patients (39%) reported receiving services immediately, others (10%) reported a delay of 1-6 months in receiving services, and some (24%) received no services at all.

Very few patients (44%) were consulted about their needs or wishes for rehabilitation on discharge. Of those with speech and language difficulties, nearly one-third (31%) reported getting sufficient help, with a further one-fifth (21%) reporting getting some help. However, almost half of those who needed help with speech and language difficulties (48%) reported that they did not get enough help once they left hospital. Of those reporting mobility problems, 22% felt that they did not get enough treatment after leaving hospital. One in three (36%) stated that they had emotional difficulties after leaving hospital, almost three-quarters (70%) of whom reported not getting enough help and support.

General Health: Physical and Psychological Status

'He gets very frustrated with his speech and balance'. *(Carer)*

'The psychiatrist came but he wouldn't speak to him'. *(Carer)*

'He panics in crowds, I wasn't prepared for the memory and personality change; it creates tension and arguments in the house'. *(Carer)*

'I hated people saying "you're so lucky"'. (Patient)

'I felt completely empty'. *(Patient)*

A majority of patients (62%) in this sample had no significant disability as assessed using the Barthel Index (Table 3.17). However, just over a quarter of the population had moderate (14%) or severe (12%) levels of disability.

Table 3.17 Barthel Index Scores: Category Membership (n for each category)

Range of Barthel Index scores	Modified Rankin Scale Category (cut off)	2004 Under 65 N (%)	2004 Over 65 N (%)	2006 Under 65 N (%)	2006 Over 65 N (%)	Overall N (%)
0 - 75	Incorporates moderately severe and severe	3 (8%)	5 (21%)	1 (4%)	6 (16%)	15 (12%)
76 - 90	Moderate disability	4 (11%)	5 (21%)	4 (17%)	4 (10%)	17 (14%)
91 - 95	Slight disability	4 (11%)	4 (17%)	3 (13%)	4 (10%)	51 (12%)
96+	No significant disability	26 (70%)	10 (41%)	16 (66%)	25 (64%)	77 (62%)
Total		37 (100%)	24 (100%)	24 (100%)	39 (100%)	124 (100%)

The Vulnerable Elders Survey (VES) is a 13-item screening tool for assessing at risk older people in the community. On the VES scale the mean score was 3.5. Based on a cut-off score of 3, above which a person is deemed to be vulnerable, over half (57%) the patient population were in the vulnerable range (Table 3.18). Levels of vulnerability were significantly higher in women ($X^2 = 5,927$, $df = 1$, $p \leq .015$), with 65% of women in the vulnerable category, compared to 41% of men (Table 3.18).

The Hospital Anxiety and Depression Scale - Depression subscale (HADS-D) was used to assess psychological distress. The mean score for the depression scale of the HADS was 5.6 (sd 3.8). Patient scores ranged between 0 and 17, with higher scores indicating increased depression (Table 3.18). The cut-off point on the HADS depression scale indicates that the probable depression is 8 (Olsson et al 2005). In this survey, a majority of patients (70%) were not depressed, with 30% of respondents scoring in the depressed range. No differences in depression were found based on age, gender or year of stroke.

Table 3.18 Vulnerability (VES) and depression (HADS) profiles: Category Membership (n for each category) (N = 111)

	2004 Under 65 (N = 33) N (%)	2004 Over 65 (N = 25) N (%)	2006 Under 65 (N = 20) N (%)	2006 Over 65 (N = 33) N (%)	Overall (N = 111) N (%)
Non-vulnerable category	20 (61%)	9 (36%)	9 (45%)	16 (48%)	54 (49%)
Vulnerable category	13 (39%)	16 (64%)	11 (55%)	17 (52%)	57 (51%)
	Mean (sd)	Mean (sd)	Mean (sd)	Mean (sd)	Mean (sd)
HADS	5.9 (4.2)	4.1 (3.2)	6.7 (4.6)	5.6 (3.2)	5.6 (3.8)

Access to Community Services

'I was on a waiting list for physiotherapy. It was a terrible limbo situation. Would I slip back?' (Patient)

'We were assured by the medical team that services were available but they never materialised; the hospital and community weren't working together'. (Carer)

'We had to make the changes to the bathroom ourselves; otherwise it would have taken three years.' (Carer)

'I didn't want to leave Baggot Street'. (Carer)

'A contact person would have been nice, someone to talk to'. (Patient)

'Going to the Volunteer Stroke Scheme helped. Meeting other people who had suffered a stroke helped'. (Patient)

'She was on three hours' home help a day, then it was cut to one hour/day, then stopped without any notification. After appeal, she was given one and a half hours per week'. (Carer)

The most commonly needed services identified by patients were GP (96%), out-patient medical appointments (66%), optician (57%) and physiotherapy (53%). Of those patients who needed a particular service, the proportion of those who received it ranged between 75% and 100% for most services. However, of those who needed hearing services, only 50% received them. Similarly only 40% of those who needed counselling and 56% of those who needed psychology services received these services.

In many cases, those under 65 years and those between 65 and 70 themselves paid for services, either in full or in part. The most common reasons reported for not being able to avail of services were that the service was not available or that the patient didn't know about it. A majority of patients in the over 65 age-group (91%) had a medical card, significantly more than in the younger patient group ($X^2=18.817$, $df = 3$, $p \leq .001$), reflecting entitlement to a medical card over age 70. Similarly, a higher percentage of patients over 65 had medical insurance cover (42%) compared with patients under 65 years (34%). Eight people in the overall sample had neither medical card nor private health insurance. All these were in the under 65 age-group.

Transport Issues / Employment

'The worst thing is his independence is gone; he can't drive now'. (Carer)
'Transport is a big problem; he gets day care but it's two bus rides away'. (Carer)
'I was only 52 and had my own business. I miss the contact with work colleagues and can go for weeks without seeing anyone'. (Patient)
'My wife can't get a bus pass - she is under 65 - and my earnings are slightly over the threshold. It seems unfair that my wife can't go out during the day; she feels it's too expensive as we have to pay for taxis and I don't have my own transport'. (Carer)

Almost two-thirds of these patients (65%) were driving before their stroke with significantly more men than women indicating that they could drive ($X^2 = 40.417$, $df = 1$, $p \leq .001$). There were significant differences in age ($X^2 = 6.224$, $df = 1$, $p \leq .013$), with considerably more of those under 65 driving prior to stroke than those over 65. Following stroke, 29% of those driving before their stroke had stopped driving. For a majority of those not driving since their stroke, the reason for not driving was described as either directly stroke-related (37%) or based on medical advice (11%).

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



Additional Patient Comments

'I had great family support. Without that, it would have been awful'. (Patient)

'Family and friends were left to pick up the pieces'. (Patient)

'My energy levels are zapped after my stroke'. (Patient)

'It would help to talk to someone to get ready emotionally to fight the stroke'. (Patient)

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

In terms of stroke care in the community, the most commonly identified issues for improvement were increased availability of services, especially physiotherapy, speech and language therapy, and emotional support/psychology.

Patients reported a need for more information and help with entitlements, and more information in relation to available services. Patients highlighted a lack of information on what stroke means and what to expect after a stroke.

Patients and their carers highlighted the need to have a 'central' person with whom they could get in contact if needed. The lack of follow-up once they came home was highlighted and many patients reported feeling isolated once they came home and did not know how to overcome this. Many patients spoke about depression post-stroke and their use of anti-depressants as a result, and highlighted the lack of, and need for, emotional support.



Chapter 4

Discussion



Introduction

These findings present the first national overview of the processes of hospital and community-based stroke care in the Republic of Ireland. Availability of services of proven efficacy for those admitted to hospital with stroke is deeply inadequate and is in marked contrast to the situation in the UK. In particular, the lack of access to acute stroke units, CT scanning within 48 hours and identifiable local lead persons with responsibility for developing stroke care need to be addressed as a matter of some urgency.

Primary Prevention

Primary prevention of stroke requires significant development, an example of missed opportunity in this regard being the low level of anti-coagulation pre-stroke (6%) in a population where nearly 22% were known to have atrial fibrillation.

Stroke Unit Provision and Stroke Care

The organisational audit revealed shortcomings in stroke unit care in Ireland. With one exception, stroke units were notable by their absence in the Republic of Ireland. The one hospital with a stroke unit in accordance with the definition set out in the UK organisational audit represents 3% of Irish hospitals, in contrast to 91% of hospitals in the United Kingdom (Sentinel 2006) which have a stroke unit.

The inadequate provision of stroke unit care in Ireland is contrary to the considerable international evidence of the benefits of organised stroke unit care. The Stroke Unit Trialist's Collaboration demonstrated that, within clinical trials, there were fewer deaths and less morbidity for those patients admitted to stroke units (Stroke Unit Trialist's Collaboration 2002). Based on incidence data, the authors estimated that patients managed on non-specialist wards had a 14% - 25% higher mortality rate than those managed in stroke units.

The reorganisation of acute stroke care provision in Ireland would greatly increase the potential to save lives. Despite the overwhelming evidence supporting the benefits of stroke unit care, and the recommendations of the Irish Heart Foundation Stroke Report (2000), the Republic of Ireland is at present very underdeveloped with regard to the provision of specialised stroke units in the acute hospital setting.

Primary prevention of stroke requires significant development, an example of missed opportunity in this regard being the low level of anti-coagulation pre-stroke (6%) in a population where nearly 22% were known to have atrial fibrillation.

Brain Imaging

The majority of patients (93%) had CT imaging after stroke. The National Clinical Guidelines for Stroke (2004) recommend scanning within 24 hours of stroke. However, only 40% achieved this standard in INASC. The lack of access to rapid neuro-imaging has implications for the introduction of thrombolysis in Ireland. Thrombolysis is not available routinely in any Irish hospital, in comparison to 18% of UK hospitals that now offer thrombolysis (Intercollegiate Working Party for Stroke 2006). One percent of INASC patients were thrombolysed - a similar percentage as in Sentinel 2004.

In leading international centres, between 5-30% of patients are treated with emergency thrombolytic stroke therapy. This treatment reduces mortality and disability, with an efficacy equivalent to the impact of acute stroke unit care itself. Expert international bodies recommend it and it is rapidly becoming best

practice internationally. As such, availability of thrombolysis therapy is an important component of acute stroke management, and ought to be accessible nationally to all patients with stroke, fulfilling the criteria for administration of thrombolytic stroke therapy.

While these processes were not directly assessed in INASC, deficiencies in neurovascular imaging capability were confirmed and need to be addressed to ensure equitable and accessible care. Attention to in-hospital system delays, alongside public education in relation to stroke as a medical emergency and the role of trained paramedical staff will all need to be examined if thrombolysis is to be administered to stroke patients efficiently and equitably. Lessons learned in Ireland and elsewhere regarding promoting more rapid and comprehensive thrombolysis delivery to acute coronary syndrome patients now need to be transferred to stroke care.

Emergency Care

The majority (71%) were admitted to hospital on the same day as their stroke and this was comparable to Sentinel 2006 (72%). However, the proportion getting to hospital within two hours of the stroke was substantially lower in Ireland, with only 5% being admitted within two hours, compared with 39% in Sentinel 2006.

Multidisciplinary Assessment

The INASC data demonstrates considerable deficiencies in timely access to allied health professionals. The gap was particularly notable for speech and language therapy (SLT), with formal SLT swallow assessment within 72 hours in just one in four cases and formal SLT communication assessment within 7 days occurred in one in three cases. Access to physiotherapy, occupational therapy and social work was also low. The high proportions of patients not seen within 72 hours and 7 days is of concern since early intervention by a multidisciplinary team can lead to considerable functional benefits. The absence of an early consultation with rehabilitation therapists, and subsequent delays in initiating rehabilitation, impacts on patients' later functional recovery and is an issue which requires urgent attention.

Communication with Patients and Carers

The provision of accurate, timely information and advice is a recommended component of service provision for those affected by stroke. The proportion of patients in INASC with documented evidence of a discussion in relation to stroke diagnosis and prognosis was low. There were further major deficits in the provision of information, support and services to people with stroke and their carers discharged to community settings. Integral to the provision of information is effective communication with the person with stroke and his or her family/carer to ensure that they have a good understanding of their illness, possible problems and realistic goals (Smith et al 2004).

Secondary Prevention and Medication

In line with the deficiencies in assessment, diagnosis and management of stroke outlined above, stark differences were noticed between the INASC and the UK Sentinel audits. Secondary prevention is effective in stroke (Sacco 2006). Key targets are lifestyle (smoking, exercise, diet and alcohol), blood pressure treatment, diabetes treatment, hypercholesterolaemia treatment, and in thromboembolic stroke (the most common form), anti-platelet agents and anti-coagulation for atrial fibrillation.

The performance on medications was more reassuring for the use of anti-thrombotic agents and anti-hypertensive agents, with discharge rates similar to the UK Sentinel audit. Less impressive were the low rates of prescribing statins, and given a prevalence of 22% for atrial fibrillation, also a low rate for anti-coagulation, and are a cause of concern for education and training.

Patient Outcomes

Mortality levels in Irish hospitals appeared to be lower than in Sentinel. This may be because of the different method of identifying cases in the two studies (i.e., retrospectively in INASC, prospectively in Sentinel), so that direct comparisons may not be valid. Furthermore, mortality status at 30 days was unknown in a significant proportion of cases in INASC (13%) compared to the UK audit (5%).

The patient profile for INASC was similar to the Sentinel profiles in several aspects. However, Irish patients were more disabled at discharge, with 28% independent in activities of daily living when discharged, in contrast to 39% in the UK (Sentinel 2006).

Access to appropriate health professionals following a standardised needs assessment is lacking at hospital and, more particularly, at community levels and is a cause for significant concern in terms of achieving maximum recovery following stroke. An estimate of levels of disability at time of discharge to the community should form the basis of planning specialised stroke services. Standardised care plans and ongoing education for relevant health professionals were also highlighted as matters requiring attention. Gaps in services and limited resources were reported across all HSE areas, as well as lack of a uniform system for recording patient information, such as levels of disability and clinical/functional status.

Nursing home residents with stroke were found to be considerably more disabled than other nursing home residents and community dwelling older people (O'Hanlon et al 2005). The particular needs from the community multidisciplinary team of patients with stroke residing in nursing homes is an important issue for consideration which has, up to now, been relatively neglected.

Discharge Planning from Hospital and Onward Referral

The general practitioner (GP) was notified on the day of discharge in half (56%) of cases and only 24% of discharge summaries had functional ability noted. Phase 1 of INASC found that all the 37 acute hospitals sent a discharge summary to the GP as standard practice. However, the GP INASC report identified problems with the receipt and/or timeliness of these reports.

Where community services for persons with stroke existed, they were generic in nature, rarely multidisciplinary in function, and either deficient in (or completely deprived of) certain disciplines, notably occupational therapy, speech and language therapy, clinical nutrition, social work and clinical psychology.

The Stroke Transfer of Care (ToC) form was developed by the Royal College of Physicians UK (RCPUK 2005) in response to earlier Sentinel audit findings (2004) to bridge a communication gap and to meet the needs of both the patient and primary care practitioners in the UK. The Stroke ToC form captures in a concise and accessible format the information essential to the seamless transfer of stroke patients to primary care, including key information regarding: initial diagnosis, investigations undertaken, assessments on transfer, medications (including secondary prevention), lifestyle advice, rehabilitation, and follow-up appointments and home care arrangements. Development of a similar standardised discharge proforma that links from the MDT in the hospital setting to the primary care team in the community setting would ensure an appropriate and timely communication across the medical, nursing and allied health professionals involved in stroke care in both hospital and community contexts.

Community Rehabilitation - Allied Health Professionals and Public Health Nurses

INASC findings indicated major gaps in the community in the provision of multidisciplinary team services for people with stroke. All managers and disciplines indicated a significant need for further development in multidisciplinary team services for people with stroke, but highlighted a range of barriers to achieving this goal. These included absence of a strategic plan (akin to the National Cardiovascular Health Strategy), lack of funding, employment ceilings, as well as barriers to service provision in the structure of health services, where entitlement to services are determined in many instances by age (over or under age 65).

These are some of the significant challenges that must be overcome in order to have in place a system of comprehensive, integrated, community-based stroke rehabilitation and long-term management. What is available currently is fragmented and 'ad hoc', despite the best efforts of individual members of nursing home staff and health professionals in community settings.

Concern was expressed that residents with stroke in nursing homes did not always have the same access to support services, such as transportation or therapy services, as those affected by stroke who are living in their own homes. Everyone outside the hospital sector is in the community setting and deserving of equal treatment, based on need, regardless of whether their address is a private residence or an institution such as a nursing home. Nursing home residents with stroke thus should feature as community residents in any planning or service provision. Issues relating to service access must be redressed by enhanced partnerships between the appropriate service-providers and health professionals, and this collaboration must include those affected by stroke and their families.

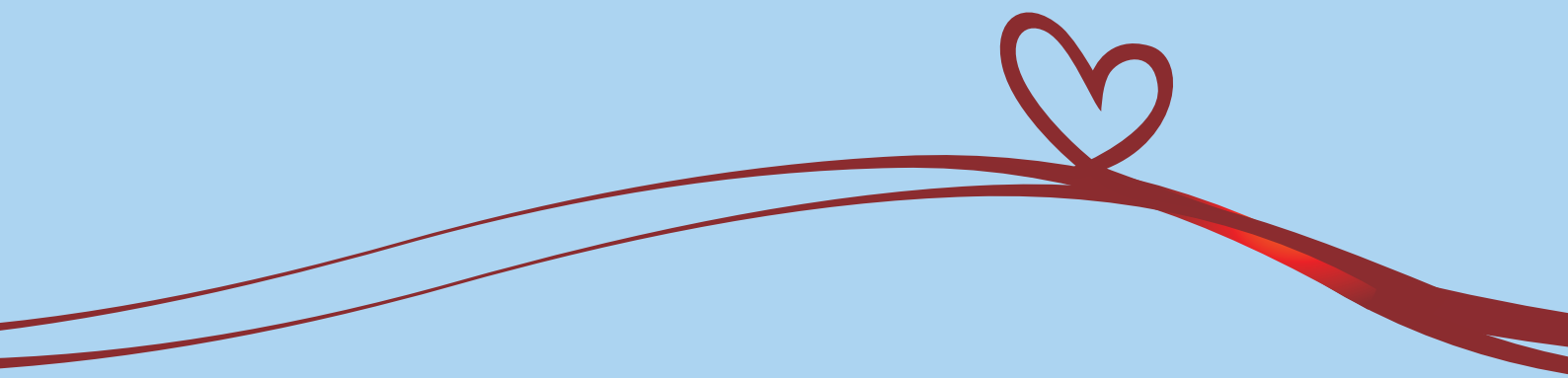
Comparing Irish Audit Findings with UK Sentinel Data

The INASC hospital data was compared to the UK Sentinel audit data to facilitate comparison with a neighbouring country and to allow observation of the potential improvements that can occur with appropriate funding. Caution, however, must be exercised in directly comparing the two audits owing to the different methods of identification of stroke patients (prospectively in the UK study and retrospectively in the INASC study).

While comparison of process of care indicators are likely to be valid, direct comparison of outcome (which is dependent on stroke severity as well as treatment received) should be used very cautiously. One of the likely effects of regular audit is of a more complete awareness of the needs for documentation of actions taken. Results, from the INASC hospital clinical audit, discussed here are based on the assumption that actions recorded are actions confirmed as having been delivered. Similarly, where actions (e.g. related to secondary prevention) have not been recorded, they have to be assumed as not completed.

Another core component to address if a national audit is to be maximally useful is the quality of the key criteria such as diagnostic categories in hospital charts. While this was possible as part of the current hospital chart audit, there is parallel Irish evidence to indicate cause for concern both in terms of false positives (cases incorrectly designated as stroke) that could be included in an audit and false negatives (stroke cases incorrectly designated with another diagnostic label) that could not be included in an audit (Harbison 2007). A system to increase completeness and accuracy of the diagnostic system, such as specifically collected stroke register data, needs to be established as an ongoing quality assurance mechanism.

In summary, the findings of the most recent round of the UK Sentinel audit (Intercollegiate Working Party for Stroke 2006) provides comparative UK results over four rounds of Sentinel audits (1998, 2002, 2004, 2006) in a number of key areas. The findings from these consecutive UK audits demonstrate clearly that with investment from government, progress has followed in key aspects of service provision and specialisation. As was evident from direct comparisons of Irish and UK results, Ireland fared worse on all 12 key markers of quality of care.



Conclusion



Using mid-1990s costs, Ashburn (1997) estimated that an unrehabilitated stroke patient cost the UK health services £64,000 more than a rehabilitated patient over their lifetime. Given these findings and the more general international literature documenting improved patient outcomes and lower mortality, the lack of stroke units in Ireland is particularly striking. Irish stroke care as documented here, is inadequate, poorly organised and does not come close to best practice by international standards. The extremely poor access to rapid neuro-imaging is striking (4% scanned within 3 hours of admission). This deficit needs to be addressed as a matter of urgency and in an equitable way throughout the country.

The high percentages of co-morbidities among patients suggest significant potential for primary stroke prevention. Primary care has a significant role to play in this regard. As companion reports on nursing home resident and community residents and carers after stroke affirm, facilities currently appear to be even more incomplete in the community. Initiatives such as Heartwatch could be expanded from its current secondary prevention post acute coronary syndrome focus, to a more expansive cardiovascular prevention role, giving equal emphasis to cardiac and cerebrovascular conditions.

Until now, stroke has been a 'poor relation' when compared with coronary heart disease. In the UK, the OXVASC study demonstrated that acute cerebrovascular disease was in fact more common

than acute cardiac ischaemia at population level. Similarly, the NAO report (2005) showed the major disparity between funding and resources given over to heart disease compared with stroke. Audit can be the start of a process of more focused care for those with stroke, as is evident in the UK with successive cycles of the Sentinel audit. Serial national audits for stroke and other high profile medical conditions in Ireland would be a helpful driver for change and for improved services. Performance across a broad range of indicators of quality of stroke care was much poorer in Ireland than in the UK.

This report indicates substantial deficits in primary prevention, timely and thorough assessment, investigation and treatment, rehabilitation, secondary prevention, discharge planning, preparation of patients and family for discharge, and ongoing community rehabilitation and support for patients and their families in the community, both for patients living at home and for those residing in nursing homes. These findings are consistent with, and amplify, the nature and extent of the deficits in the systems for stroke care outlined in the six INASC surveys, and must be considered to represent a major cause of concern for people with stroke, their families, as well as for healthcare professionals and the Irish government. The findings point to the need for a radical and urgent review of stroke services in Ireland to provide appropriate care for those suffering from stroke in Ireland.

Implications

1. The major deficits in structures, staffing and expertise in services at all stages of the journey of those affected by a stroke calls for a coordinated response between the many agencies involved. A **national strategy for stroke** is required for the development of preventive, treatment and supportive services for those who have suffered a stroke.
2. This national strategy for stroke further requires **regional governance and coordination of implementation of stroke care** to the highest international standards (akin to the regional directors of cancer services in each Health Service Executive Administrative Area), with particular consideration given to ensuring that stroke expertise supports both hospital and community services, and to combining acute and chronic disease management approaches.
3. Planning, delivery of care and quality assurance of the complex care needed for those affected by stroke requires the availability of real-time data to support patient care. Urgent consideration should be given to a **stroke register** to enable timely communication between services, to support needs estimation, and to facilitate audit and quality assurance.
4. **Supportive structures are needed for the detection and management of primary and secondary risk factors for stroke in primary care.** While such structures would have much in common with approaches to risk factors for heart disease, particular importance should be given to facilitating the proactive management of atrial fibrillation as a major risk factor for stroke which is not shared with heart disease.
5. **Reconfiguration of pre-hospital emergency services** to recognise and prioritise the urgent transfer of patients with stroke to those hospitals that have stroke units.
6. The national strategy for stroke needs to clarify the **urgent development of geographically defined stroke units**, with access to adequate expertise and physical and staffing resources. On the basis of the Clinical Audit, at least 5,000 acute stroke cases, with a mean length of stay of 26 days, can be expected in one year: this translates to a minimum 365 stroke unit beds in general hospitals and is a conservative estimate, given the potential cases missed by the Hospital In-Patient Enquiry (HIPE) scheme, the likelihood of sub-arachnoid haemorrhages being managed in stroke units, and the numbers of patients referred on for further rehabilitation.
7. Such stroke units need to be configured regionally to ensure that **basic services are available on site**:
 - Acute stroke unit with expertise in stroke medicine, general medicine, specialist nursing and therapy, rehabilitation, psychological medicine/psychiatry, as well as physiological monitoring
 - 24-hour availability of neuro-imaging
 - 24-hour availability of stroke specialists trained in thrombolysis (on-site or via tele-medicine)
 - Doppler ultra-sound
 - Neurovascular clinic / transient ischaemic attack (TIA) services
 - Care management pathways to ensure an effective liaison with other rehabilitation and community services and appropriate chronic disease management programmes.There should be formal pathways to ensure rapid and smooth access to:
 - Vascular surgery
 - Neuroradiology, including interventional neuroradiology
 - Neurosurgery.
8. Implementation of stroke units needs to incorporate recognition that **rehabilitation starts from the day of admission and continues within the general hospital, dedicated rehabilitation units, supported home discharge and into the community (including nursing homes).** The planning of stroke rehabilitation should recognise the complexity of the process, including:
 - Stroke-specific expertise
 - The management of the frequently-occurring acute and chronic co-morbidities and complications of stroke
 - The interactions with other age-related diseases and disabilities, and psychological complications (particularly depression, cognitive impairment(s) and dementia)

- Access to rehabilitation should be needs-based, not influenced by location, and equitable, and be provided by a full rehabilitation team with adequate governance and leadership.
- 9. **Systems for the sharing of information** and clinical data must be improved, with improved communication and transfer of information to facilitate a seamless transition for the person with stroke from hospital to community-allied health professionals, public health nurses and general practitioners.
- 10. **Systems for follow-up between stroke specialists and the primary care need** to be developed and resourced for long-term follow-up, given the complexity and inter-individual heterogeneity of post-stroke complications, risk of further stroke, and the potential for continuing longer term recovery. These systems should give a high priority to systematic secondary prevention, rehabilitation and support.
- 11. **Ongoing support and rehabilitation from community teams** which have the full complement of disciplines is required for those affected by stroke who are discharged to community and nursing homes. This should be coordinated, and consideration should be given to care management with an identified care manager. These teams will need support and liaison with secondary stroke care services and psychiatry services.
- 12. **The provision of information on stroke for those affected by stroke needs to be dramatically improved**, and while some improvement can be expected from the establishment and universal application of stroke units for all admitted with stroke, the role of clinical nurse specialists in stroke is likely to be an important development in this regard, and this role should be developed for each stroke unit. Improved information and communication is needed throughout the patient journey with stroke, including admission, discharge planning, and follow-up care in the community.
- 13. **Major developments in staffing numbers and training will be required for stroke units, intensive rehabilitation (hospital or community), early supported discharge, and long-term rehabilitation, including nursing home care.** While forecasting staff requirements can be a difficult science, compounded by both emerging new assessments and treatments, as well as other responsibilities for the physicians most usually involved in stroke medicine (geriatricians, neurologists and rehabilitationists), it is important nonetheless to give some guidance in view of the deficiencies in staff numbers and service at all levels of the patient's journey shown in this series of audits.
As a guideline, we recommend the following staffing recommendations from the UK Workforce Planning Guidelines for Stroke (2008), with additional calculations (social work and psychology) from Towards Excellence in Stroke Care (2000). Additional consideration should be given to developments in radiology, vascular surgery, vascular-imaging technicians and psychiatry.
- 14. **Specialist training in stroke is required for all disciplines**, including higher diplomas in gerontological, stroke and rehabilitation nursing, the provision of clinical nurse specialists in stroke, and advanced practitioner therapist posts developed across all stroke services nationally.
- 15. **Equitable, needs-based access should be monitored to ensure that age, location, race and health-insurance status do not diminish access to required services**, with due consideration for specific risk factor profiles in certain ethnic groups; indications for gerontologically attuned services for those requiring them; and the particular complexity of needs of those of all ages requiring nursing home care.
- 16. **Public awareness programmes should be developed** to promote an awareness of stroke symptoms and signs, as well as the need to seek urgent attention for stroke and TIA.
- 17. **Provision of transportation choices for those who can no longer drive or use public transport with ease as a result of stroke** is critical to social inclusion and health, and should be developed as a part of a national stroke strategy.
- 18. **This audit cycle should be repeated in three years across all stages in the journey of patients who have suffered a stroke**, to monitor developments towards excellence in stroke care.

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Appendix

Submissions received by the Irish Heart Foundation July 2005

A number of individuals who had had a stroke, or cared for a family member who had experienced a stroke provided information in advance of the commencement of this National Stroke Audit. These were considered in the development of the proposed methodology for the project. These individuals are not named individually to protect confidentiality.

In addition, a number of professional organisations made submissions as follows:

- Cavan and Monaghan Occupational Therapy Services
- Irish Association of Social Workers
- Irish Society of Chartered Physiotherapists
- Naas General Hospital Physiotherapy Department
- National Council for the Professional Development of Nursing and Midwifery
- North Western Stroke Group
- Royal Hospital Donnybrook
- St Camillus Hospital Limerick Clinical Therapies
- St James's Hospital Dublin Physiotherapy Department
- St Vincent's University Hospital Dublin Occupational Therapy Department.

The contribution of all these submissions is acknowledged.



Helpline: 1890 432 787
www.irishheart.ie

Irish Heart Foundation
4 Clyde Road, Ballsbridge, Dublin 4
Tel: (01) 668 5001
Fax: (01) 668 5896