# Rapid review of stroke registers and outcomes

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To undertake a rapid review of the literature on stroke registers and their effect on outcomes.  
There is a lack of evidence to support or refute a contribution of stroke registers to improved stroke outcomes.

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Key Messages

- Stroke is a major health problem in the United Kingdom (UK), being the third most common cause of death and the single most cause of ongoing disability. It is now widely recognised that stroke is preventable and treatable.

- Stroke is the leading cause of disability and death in Wales and is one of the Welsh Assembly Government’s top priorities for the NHS and social services in Wales.

- There is a lack of evidence to support or refute that stroke registers improve health outcomes.

- Considerable stroke/transient ischaemic attack data and information is already routinely collected by primary and secondary care in hospital discharge records and GP registers.

- Further development of primary and secondary care records and registers encompassing the stroke pathway has the potential to improve service integration, planning and surveillance across Wales and to improve participation in audit and research. Access to stroke information held in GP registers and hospital discharge records may not be readily available to all disciplines and across organisational boundaries. Anonymised linkage of GP and hospital data reflecting the content of the Welsh stroke pathway could form the basis of an efficient stroke register.

1 Introduction

Historically, the diagnosis of stroke was seen as a consequence of ageing and treatment was conservative rather than pro-active. However, early medical management has now been shown to have an impact on patient outcome. Stroke is a major health problem in the United Kingdom (UK), being the third most common cause of death and the single most cause of ongoing disability. Each year 150,000 people have a stroke and whilst the majority of these are in the over 65 age group, 1,000 will be under 30 years of age. Therefore, annually in the UK there may be 250,000 people living with disabilities caused by stroke. Although stroke remains the third most common cause of death in developed countries and in Wales stroke is the leading cause of disability and one of the leading causes of death, it is now widely recognised that stroke is preventable and treatable.¹

The Royal College of Physicians first carried out a National sentinel audit in 1998 which it has continued to undertake on a bi-annual basis ¹. The objective of the audit is to assess the quality of care for people who have had a stroke and to help hospitals use audit as a means of quality improvement. The audit uses 13 organisational indicators and 12 process...
indicators, along with a number of primary and secondary outcome measures relating to death, disability and length of stay.

In August 2007, the Minister for Health and Social Services Wales issued *Implementation of national standards for stroke services in Wales-action for commissioners and providers.* The circular confirmed that tackling stroke was one of the Welsh Assembly Government’s top priorities for the NHS and social services in Wales and announced a formal programme of work to guide and direct the progressive implementation of the standards for stroke care set out in the *National service framework (NSF) for older people in Wales.* One of these standards was the establishment of stroke registers.

In December 2007, *Improving stroke services: a programme of work,* was issued to build on the requirements of *Implementation of national standards for stroke services in Wales-action for commissioners and providers* by setting out a formal programme of work to improve services for patients who are at risk of, or who have had a stroke. It highlighted work that had been taken forward and set out a formal programme of work for the Welsh Assembly Government, the stroke partnership project, the NHS, social services and the voluntary sector.

The stroke work programme is ongoing and has continued to make progress, with the development of driver diagrams, care bundles and intelligent targets for stroke that will be incorporated in the Annual Operating Framework (AOF) from April 2010.

A recommendation of the *National clinical guidelines for stroke* was that in addition to GP practice-based stroke registers, clinical services should also have registers of all patients admitted to their organisation. Considerable work in Wales has been undertaken to improve the management of chronic diseases such as stroke and consideration is being given to the feasibility of setting up a stroke register.

Ironically given the range of registers in place there is a dearth of definitions on what a disease register is. For the purpose of this paper a disease register is: Linkage of data covering the process of care (if any care has been provided), outcomes and demography. This personal data is systematically maintained for all individuals with a diagnosis. Theoretically for stroke this could relate to those with a diagnosis of stroke or those diagnosed as being at risk of stroke.

## 2 Aims

The aim of this document is to undertake a rapid review of literature and information related specifically to stroke registers and outcomes.
3 Research question

The research question used for the purpose of this rapid review of the literature was whether stroke registers influence outcomes.

4 Identifying existing and ongoing research

4.1 Literature searching

A scoping search was initially undertaken on stroke registers and stroke registries to identify published evidence and refine the final search strategy. Search terms were kept broad to maximise retrieval of references and included the following search terms; stroke, stroke registries, registries, registers, disease registers, data collection, outcomes, influence, effectiveness, general practitioner, dependency, mortality, morbidity, quality of health, independence, local health boards, primary care trusts, regional and national.

Databases accessed: Medline, Embase, British Nursing Index, Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials; British Nursing Index and the Health Management Information Consortium databases.

In order to achieve production of the review within the short timescale for delivery a pragmatic approach was necessary to search the vast amount of literature and evidence available on stroke.

Other resources were used to identify grey literature on this topic.

As resources were limited, the literature review and appraisal was not subject to additional interrogation by separate reviewers.

Search period January 1996 – January 2010

Key policy documents and guidelines

Randomised controlled trials

Systematic reviews

Observational studies

Papers in English or English translation only.

5 Results

The scoping search revealed several good quality reports that included relevant reviews of information and literature on the use of stroke
registers. Due to time constraints these secondary source documents were used extensively to inform the present document, supplemented by appropriate evidence identified through the searches.

5.1 Registers

Registers have been used in many differing forms and variations across the global healthcare arena for many years. A hospital-based register usually contains data of patients with a specific type of disease diagnosed and treated at the hospital. The *National clinical guidelines for stroke* published in 2000, noted that a stroke register is necessary because routine hospital statistics do not accurately count stroke patients. A population-based register is a collection of data of patients who reside within a particular area and share a common characteristic, for example a GP practice register for a specific chronic disease i.e. stroke, diabetes, asthma, hypertension and coronary heart disease.

Recognition of the importance of stroke registers is again highlighted in the 2008 *National clinical guidelines for stroke*. The aim of the guidelines is to improve the quality of care to everyone who has a stroke in the UK regardless of their age, gender, type of stroke, location or any other feature. Within the quality improvement section governance/audit, one of the recommendations they put forward is that clinical services should take responsibility for all aspects of data collection: keeping a stroke register of all patients admitted to their organisation with stroke and providing leadership in clinical audit.

Warlow et al in an expert commentary believe that organised services are vital to reduce the burden of stroke, and stroke registers are recognised as an invaluable tool in planning and monitoring the performance of stroke services.

In one study it was found that the benefits of setting up a stroke register included a co-ordinated stroke service and improved participation in research and audit.

Stroke registers are a valuable tool in secondary prevention of potential strokes for people who have already had episodes of transient ischaemic attack (TIA)/stroke. An additional benefit suggested in the English *National service framework (NSF) for older people* is that their usefulness could be further developed to support primary prevention of stroke. It is well recognised that many risk factors have a role in increasing the risk of a stroke, including a previous stroke or episode of TIA, hypertension, history of heart attack, diabetes, high blood cholesterol and atrial fibrillation. Primary intervention and data collection may assist in preventing the initial episode of stroke and not just the complication of post-stroke consequences i.e. preventing obesity, lowering alcohol intake.
and smoking cessation campaigns. This area of research whilst supported is outside the scope of this document.

Proposed support functions of stroke registers include:

- Improve the quality of care
- Improving the outcome of care
- Audit
- Research
- Planning services
- Monitoring services
- Secondary prevention
- Primary prevention
- Understanding socio-demographic issues
- Understanding the burden of disease
- Supporting practitioners

### 5.2 Hospital-based stroke registers

Suggested benefits of hospital based stroke registers include:

- Less costly to operate than population registers
- Fewer human/financial resources required to run register

Hospital based stroke registers only contain data on those patients who have been hospitalised and diagnosed with a stroke and do not capture the same data as that held at GP practice level.

In Northern Ireland, for example, the *Improving stroke service in Northern Ireland*\(^\text{10}\) guidelines, published in 2008 included the recommendation that a regionally agreed hospital-based stroke register be in use by March 2010 to support service development, research and audit. This is in addition to the GP stroke/TIA registers that are maintained as part of the GMS contract.

In Scotland, in 2002, a *Coronary heart disease and stroke strategy*\(^\text{11}\) were published and in 2009 a *Scottish stroke care audit*\(^\text{12}\) was established that includes all hospitals managing acute stroke in Scotland. The NHS Quality Improvement Scotland (NHSQIS) also published the *Clinical standards for*
stroke services: care of the patient in the acute setting\textsuperscript{13} against which stroke services monitor their progress.

Using a stepwise approach to stroke surveillance, the World Health Organisation (WHO) STEPS Stroke feasibility study\textsuperscript{14} offered an entry point to countries to register stroke patients in health-information systems. The feasibility study was used to test methods which focused on hospitalised stroke patients in nine different surveillance sites located in five low-income and middle-income countries. The aim of the study was to ascertain whether stroke registers could be set up in geographically diverse populations in low-income and middle-income countries, using standardised data-collection manuals and methods. The study concluded that STEPS Stroke could be used in diverse populations to provide data in a standardised manner in countries with little or no previous records of stroke.

Another longstanding stroke register is the Swedish Riks Stroke Register\textsuperscript{15}. This is a hospital-based stroke register additional to that of the routine hospital discharge register. The Riks Stroke Register includes 79 hospitals with a participation rate of approximately 84%. Quality monitoring of the healthcare system is required by law in Sweden, although individual patients can choose to opt out of being included. The register was set up with the aim of supporting high and consistent quality of care for stroke patients across Sweden and includes the following data sources; primary prevention, acute management, rehabilitation and secondary prevention and family and community support. Data is collected from case records, during hospital stay, at discharge and 3 months post-discharge by the means of a questionnaire.

An American based study by Hills et al\textsuperscript{16} looked at three quality of care methods with a large cohort of stroke and TIA patients to define deficiencies and improve care. All initially indicated sub-optimal care but showed improvement after implementation of a web-based registry. The study suggests that in addition to hospital-wide interventions, participation in a registry may improve care in stroke patients. Other studies such as the 17 year long study by the Barcelona Stroke Registry\textsuperscript{17} identified the need to establish stroke registers and stroke units.

Outcomes data collected by hospital based stroke registers include:

- Mortality
- Disability
- Length of hospital stay

Resourcing hospital based stroke registers will require:

- Agreement on a data set
Collecting outcome data

### 5.3 Population-based registers

Suggested benefits of population based stroke registers include:

- Population disease registers allow rapid analysis of population-based data and are therefore able to provide real time patient information.
- Population based registers utilise more than one data source thereby enabling surveillance of stroke incidence/prevalence across a population and not just those patients hospitalised or attending GP.
- Understanding the difference and dynamics between sexes, age groups, social class and ethnic groups.
- It has been shown that population-based coronary heart disease (CHD) registers offer the potential to provide support to practitioners, facilitate improvements in patient care and allow real time efficient monitoring of care provision and patient outcomes.
- Identification of vulnerable groups.

The WHO stroke register\(^\text{18}\) was the first attempt to collect data on stroke from a community in a uniform manner from countries with different social, cultural, and environmental background. The project lasted from May 1971 to September 1974 and was a joint undertaking of WHO and 15 collaborating centres in 10 countries from Asia, Africa and Europe. About 2 million people were under surveillance and data was obtained from 6,395 new cases of stroke (3,270 men and 3,125 women).

The WHO MONICA project\(^\text{19}\) commenced in the first half of the 1980s and lasted until the first half of 1990s. Stroke registers were established in 17 centres in 10 countries. Study populations were residents in geographically defined areas and included men and women ages 35 to 64 years, with an optional inclusion of the 65 to 74 years decade. All stroke events in defined populations were ascertained and validated according to a common protocol and uniform criteria. Almost 25,000 stroke events in more than 15 million person-years were analysed.

The EUROCISS project\(^\text{20}\) was set up to provide a general guide and updated methods for the surveillance of stroke to those European Union countries which lack appropriate surveillance systems and therefore wish to implement a population-based register in order to produce comparable and reliable indicators. Taking into account developments in new diagnostic criteria, treatment and information technologies in recent years, the Manual of Operations developed by EUROCISS provides a standardised and simple model for the implementation of a population-based register. The EUROCISS Project recommends starting from a minimum data set and...
following a step-wise procedure based on standardised data collection, appropriate record linkage and validation methods. The Manual of Operations for Stroke is intended for investigators, health professionals, policy makers and data collection staff interested in the surveillance of stroke.

Problems with the use of different case ascertainment and study methods mean that comparable data on stroke incidence across European countries are lacking. The European Register Of Stroke (EROS)\textsuperscript{21} was a 4 year prospective study across Europe aimed at estimating the impact of stroke, understanding the factors underlying variation in the quality of care and outcome after stroke, and answering unresolved issues with regard to the influence of socio-demographic, case-mix and stroke healthcare, quality factors on the variations in health or stroke patients around Europe. The self-selected cities of London, Helsinki, Glasgow, Edinburgh, St Petersburg, Kaunas, Warsaw, Dijon, Menora, Florence, and Stockholm participated in EROS. The study developed and used a tool to assess the impact of the quality of care on the outcome of care. Health outcomes including mortality, disability and health related quality of life were assessed within the first week post stroke, then at three months and a year after the initial stroke. This was the first multi-population study without age restriction using identical study criteria and identified considerable differences in total stroke incidence across Europe.

Of particular relevance to the UK is a prospective, single-blind, randomised controlled trial undertaken by Kalra et al\textsuperscript{22} in patients recruited from a population-based stroke register. The two-year study was conducted in Bromley, an outer London borough. Bromley is a mainly middle class suburban district that has a large proportion of people aged over 75 years of age and although comparatively healthy and affluent, it does have areas of deprivation. The study included all strokes in patients over 16 years of age with the population-based register providing collected key demographic, clinical and outcome data in keeping with the core data set of major stroke registries. Outcome measures of the study included primary measure; death or institutionalisation, secondary measure; dependence, functional abilities, mood, quality of life, resource use, length of hospital stay and patient, carer and professional satisfaction. The study concluded that stroke units were found to be more effective than a specialist stroke team domiciliary care in reducing mortality, institutionalisation and dependence after stroke.

In England, as in Wales and Northern Ireland, GP stroke/TIA registers are maintained as part of the GMS contract and they also participate in the National sentinel audit\textsuperscript{1}. In March 2001, the Department of Health further recognised the importance of developing better stroke services including the development of stroke registers in the NSF for older people\textsuperscript{9} which was followed in 2007 by the issue of the National stroke strategy\textsuperscript{23}. The strategy provided a quality framework to improve stroke services across
England and proposed the establishment of stroke networks to improve the co-ordination and improvement of stroke care which is being accomplished by inclusion of stroke within the existing cardiac networks.

Many registers or registries have been widely used for CHD, asthma and diabetes prior to the introduction of the Quality and Outcomes framework (QOF) in 2004. An example of this is the Have a heart project in Paisley, Scotland, which used CHD registers that included information from a number of national and local databases within the region, from both primary and secondary care settings. Clark and Findlay conclude that population-based CHD registers offer the potential to provide support to practitioners, facilitate improvements in patient care and allow real time efficient monitoring of care provision and patient outcomes.

The FINMONICA stroke register (1983-1992) was a population-based register that covered three areas of Finland that linked hospital discharge and cause of death data. The main objective of the study was to investigate the association of socioeconomic status with morbidity and mortality of stroke and the prognosis, treatment and diagnostic pattern of stroke events. The strength of the study was in its large population-based design, standardised protocols and rigorous quality control.

Population disease registers also allow rapid analysis of population-based data. Giampaoli et al suggests that a stroke register provides the means to understand the characteristics, the burden, and the consequences of the disease in the population, and can provide information to plan healthcare services. Wolfe et al also used population-based registers in a study to measure the incidence of stroke in a defined population with outcome information measured at specific periods post-stroke.

The literature indicated that the outcomes that can be assessed using population based stroke registers include:

- Mortality
- Disability
- Quality of life
- Place of residence i.e. whether returned to pre-stroke home or place of abode
- Dependence
- Functional abilities
- Mood
- Resource use
• Length of hospital stay
• Pharmacological support
• Patient/carer satisfaction.

This list is just representative of some of the outcomes that could be incorporated into a population based register. The information and data held provides a broad picture of the stroke patient’s journey and will provide information useful not just to the individual planning of care but also on a much wider scale to assist and develop service planning.

Resourcing population based stroke registers will require:

• Agreement on dataset and co-ordinating body i.e. network or host co-ordinator
• Collection of outcome data
• Financial and human contribution
• Technological expertise, collaboration and linkage
• Agreement on use of data e.g. additional long term use could be for data to be part of a longitudinal study

5.4 General practice registers

General practice (GP) disease registers are used to evaluate outcome and survival of patients with a chronic and or limiting illness. Disease registers form an important component of the General Medical Services (GMS) Contract. The QOF was introduced across the UK as part of the GMS contract in April 2004 and has four main domains, namely clinical, organisational, patient experience and additional services with each domain containing a set of measures known as indicators. Practices are able to score on the basis of achievement against each of the 129 indicators up to a maximum of 1000 points.

Within the QOF, general practices are remunerated for many chronic diseases that have a disease register including coronary heart disease, cancer, diabetes, asthma, hypertension, hypothyroidism, mental illness and stroke.

Within the QOF targets for 2009/2010 (see appendices 1 for full list of stroke indicators for this period) the first indicator is that a GP practice can produce a register of patients with stroke or TIA. The GP practice reports the number of patients on its stroke/TIA register and also as a proportion to its total list size. Although the GP registers may not be completely accurate for those diagnosed pre-2003 (due to the variation in diagnostic
criteria that were used then) they have an important role in providing valuable information and data to be used for service planning and healthcare development.

5.5 Quality

Measuring quality of outcomes in the NHS is not a new concept. Donabedian developed guidelines for assessing quality of care that included structure, process and outcomes in the 1980’s. The Department for Health document *High quality care for all* defined quality in the NHS in the terms of patient safety, clinical effectiveness and the experiences of patients.

The quality of a register is particularly important to ensure valid continuous monitoring and comparison of data and information. In their 2006 study, Hare et al suggest that stroke registers present an opportunity to not only focus on secondary prevention, but also the long term needs of patients and their families.

Quality control of registers is also important to allow valid monitoring and comparison. The quality of the register depends on its completeness of coverage, completeness of information and internal/external validation.

The quality improvement, governance and audit section of the *National Clinical guidelines for stroke* notes that stroke services require quality improvement and attention to governance is essential. It also notes that the primary needs are to collect appropriate data in a timely manner, to analyse the data and then to act upon the findings.

In Germany regional hospital-based stroke registers have been in use for many years. The German Stroke Registers Study Group is a voluntary network of the ongoing registers which has developed and implemented a set of twenty-four evidence based quality indicators for assessing the quality of stroke care within regional stroke registers.

5.6 Outcomes

Very little detailed literature was found to support or refute the hypothesis that having a stroke register actually improves outcomes for stroke patients. Bejot et al note that the development of stroke registries has allowed the accumulation of a wealth of data on the epidemiology of stroke and its evolution in space and time.

Registers are important as public health tools. Access to reliable population-based data on incidence, prevalence and outcome is essential to public health practice. It also noted that registers are useful to assess outcomes as part of audit and are good for monitoring the outcome of interventions aimed at the whole population.
The usefulness of registers is however, dependent on the quality of their design and the data they contain. Registers should only be set up to study important health problems and should have clearly established objectives.33

Simpson et al34 supported using a clinical computer system to record disease register data and suggest that maintenance of accurate and complete disease registers assist audit, quality assurance and improvement of the quality of patient care.

As previously discussed it is difficult to measure outcomes without having a quality standard or framework to measure against. Individual patient and or carer bias may also influence any self reported outcome success. Whilst many studies support stroke registers, it is difficult to prove that the stroke registers themselves specifically have an effect on improvements in stroke care as there may be other initiatives that have also taken place at the same time i.e. improved access to preventative and acute stroke care pathways, prompt imaging and thrombolysis making it difficult to separate out for analysis and evaluation that it is specifically the stroke register that was the beneficial influence.

6 Conclusions

- Current information systems are fragmented. The development of clinical networks using the stroke pathway has the potential to improve service delivery, planning and surveillance across Wales, whilst facilitating integration and collaboration across disciplines and organisations involved in stroke care services.

- Considerable stroke/TIA data and information is already routinely collected by primary and secondary care in hospital discharge records and GP registers. For example, in Wales, since the introduction of the GMS Contract QOF in 2004 all GP practices have a stroke/TIA register.

- Further development of primary and secondary care records and registers encompassing the stroke pathway has the potential to improve service integration, planning and surveillance across Wales and to improve participation in audit and research. Access to stroke information held in GP registers and hospital discharge records may not be readily available to all disciplines and across organisational boundaries. Anonymised linkage of GP and hospital data reflecting the content of the Welsh stroke pathway could form the basis of an efficient stroke register.
7 References


8 Appendices

8.1 Quality and Outcomes Framework indicators for Stroke 2009/2010

- STROKE 1. The practice can produce a register of patients with stroke or TIA
- STROKE 13. The percentage of new patients with a stroke or TIA who have been referred for further investigation.
- STROKE 5. The percentage of patients with TIA or stroke who have a record of blood pressure in the notes in the preceding 15 months
- STROKE 6. The percentage of patients with a history of TIA or stroke in whom the last blood pressure reading (measured in the previous 15 months) is 150/90 or less
- STROKE 7. The percentage of patients with TIA or stroke who have a record of total cholesterol in the last 15 months
- STROKE 89. The percentage of patients with TIA or stroke whose last measured total cholesterol (measured in the previous 15 months) is 5mmol/l or less
- STROKE 12. The percentage of patients with a stroke shown to be non-haemorrhagic, or a history of TIA, who have a record that an anti-platelet agent (aspirin, clopidogrel, dipyridamole or a combination), or an anti-coagulant is being taken (unless a contraindication or side effects are recorded)
- STROKE 10. The percentage of patients with TIA or stroke who have had influenza immunisation in the preceding 1 September to 31 March