

health

Outcome

indicators

STROKE

Report of a working group
to the Department of Health



FOREWORD

The Government consultation document "A First Class Service - Quality in the new NHS", published in 1998, emphasised three essential aspects of ensuring delivery of high quality of care by the National Health Service: setting, delivering and monitoring standards. It also discussed the importance of partnership between the Government and the clinical professions and patients in achieving such quality.

This series of 10 reports concerns the third aspect - monitoring standards. It represents the culmination of work that was started several years ago under the auspices of the Clinical Outcomes Group, chaired jointly by the then Chief Medical Officer, Sir Kenneth Calman, and the Chief Nursing Officer, Dame Yvonne Moores. The work was commissioned by the former Central Health Outcomes Unit of the Department of Health. The Unit has since moved and is now called the National Centre for Health Outcomes Development (NCHOD), based jointly at the Institute of Health Sciences, University of Oxford and the London School of Hygiene and Tropical Medicine, University of London.

The background to the work was the need to ensure that the NHS is driven by considerations of quality and outcome. The Department wanted to build on an earlier set of Population Health Outcome indicators, which had been limited by the constraints of existing routine data. It therefore commissioned systematic work on ten clinical topics, to be undertaken by a Working Group on each, tasked to make recommendations on 'ideal indicators' for each condition. 'Ideal indicators' were defined as statistical measures of what should be known, and realistically could be known, about the outcomes of the condition in routine clinical practice. The Groups were asked to consider a wide spectrum of possible uses of outcome indicators, from national monitoring of NHS performance by government to the periodic assessment of local services by clinicians and users.

The work of the Working Groups was coordinated by Michael Goldacre, University of Oxford. A particular feature of the work is that the Groups have recommended definitions and technical specifications for each indicator. It is hoped that people interested in monitoring the topic covered by each indicator will use the same definitions so that comparisons can be facilitated. Moreover, the methodology adopted by the Working Groups is applicable to developing health outcome indicators for many other conditions.

The publication of these reports, however, is only one further step on a long road of quality assessment in health care. The reports present 'menus' of suggestions for ways in which outcomes might be monitored in a variety of settings, by a variety of organisations and people. It goes without saying that NCHOD will welcome feedback on the reports and on the development and use of outcome indicators.

I believe that the work described here shows the value and potential of partnerships between various parties. Each working group had members who brought together perspectives of all the relevant clinical professions plus patients, NHS managers, policy makers, researchers and others as appropriate. The recommendations of the Working groups show quite clearly how these various perspectives may contribute to a broader and more balanced monitoring of standards. I would personally like to congratulate and thank everyone who has worked so hard and well to bring this initiative to fruition.

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OUTCOME INDICATORS FOR STROKE

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SUMMARY OF RECOMMENDATIONS

Using a variety of check lists including a health outcome model, the Group identified outcome indicators which were fully specified in a standard format and are included in this Report. Outcome indicators, whose numbers correspond to the specifications in Section 4, were grouped under four headings relating to the aim of the intervention.

Recommendations for implementation were made for each indicator using the following categories:

- A.** To be implemented generally on a routine basis.
- B.** To be implemented generally by periodic survey.
- C.** To be implemented where local circumstances allow on a routine basis.
- D.** To be implemented where local circumstances allow by periodic survey.
- E.** To be further developed either because the link with effectiveness is not clear or the indicator specification is incomplete.

Category	Page	
<i>Indicators related to reduction/avoidance of risk of first/subsequent stroke</i>		
A	18	1A. Incidence of hospitalised stroke.
C	20	1B. Population-based incidence of stroke.
A	22	2. Percentage of general practice patients who have had their blood pressure recorded in the previous five years.
B	24	3. Median and inter-quartile range of systolic blood pressure within a general practice population.
C	26	4. Percentage of general practice patients, identified as hypertensive, whose most recent systolic blood pressure measurement is less than 160 mm Hg.
B	28	5. Percentage of patients within a general practice population who have a prescription for aspirin therapy at six months after stroke (without proven haemorrhage).
D	30	6. Percentage of general practice patients with a diagnosis of atrial fibrillation who have a prescription for anticoagulant therapy.
<i>Indicators related to reduction of death from stroke</i>		
A	32	7A. Case-fatality rate within 30 days of a hospital admission for stroke.
C	34	7B. Case-fatality rate within 30 days of stroke (in-patient or community-based treatment).
A	37	8. Population-based mortality rates.
<i>Indicators related to reduction/avoidance of complications from stroke</i>		
E	38	9. Percentage of patients within a provider unit population for whom a formal swallowing assessment was undertaken within 24 hours of a stroke.

A	40	10. Incidence of pressure sores during the in-patient stay within a hospital provider unit population with a primary diagnosis of stroke.
D	43	11A. Percentage of patients within a community provider population who, six months following a stroke, have one or more pressure sores.
B	45	11B. Percentage of patients in a nursing home population who, six months following a stroke, have one or more pressure sores.
D	48	12. Rate of emergency re-admissions (for any reason) within 30 days of discharge, per provider unit population with a primary diagnosis of stroke.

Indicators relating to improving function and well-being after stroke

B	50	13. Multi-professional involvement in the week following admission within a provider unit population admitted with a primary diagnosis of stroke.
A	52	14. Distribution of the Barthel Index of Activities of Daily Living (ADL), at discharge from hospital, within a provider unit population with a primary diagnosis of stroke.
B	55	15. Distribution of the Barthel Index of Activities of Daily Living (ADL), within a population of patients six months following stroke.
E	58	16. Assessment of aphasia within a population of patients six months following stroke.
E	61	17. Assessment of outdoor mobility within a population of patients six months following stroke.
E	63	18. Assessment of social functioning within a population of patients six months following stroke.
E	65	19. Assessment of depression within a population of patients six months following stroke.
D	68	20. Summary of changes in the Barthel Index measured at discharge from hospital and at six months post-stroke, within a provider unit population admitted for stroke.
A	70	21A. Percentage of people admitted with a primary diagnosis of stroke who return to their pre-admission category of accommodation on discharge from hospital.
B	72	21B. Percentage of people admitted with a primary diagnosis of stroke who are living in their pre-admission category of accommodation six months following admission to hospital.
D	74	21C. Percentage of people with a diagnosis of stroke who were not hospitalised and are living at their pre-stroke category of accommodation six months after the stroke.
E	76	22. Summary of a measure of patients' or carers' knowledge of available health and social services, six months after stroke.
E	78	23. Summary of a measure of patient satisfaction within a population, six months after stroke.
E	80	24. Assessment of carer burden, six months after stroke.

1. INTRODUCTION TO THE REPORT

Health outcome indicators

- 1.1** This Report is one of a series containing the recommendations of working groups set up to develop 'ideal' indicators of the health outcomes of specific conditions. The background to the work, commissioned by the Department of Health, is summarised in Appendix A.
- 1.2** Health outcomes have been defined as changes in health, health related status or risk factors affecting health, or lack of change when change is expected. They may be the result of the natural history of the condition or may be the effect of interventions to prevent or treat it. The particular concern of the working groups has been to make recommendations about outcomes which may be attributable to interventions or the lack of them.
- 1.3** The term indicator has been defined as an aggregated statistical measure, describing a group of patients or a whole population, compiled from measures or assessments made on people in the group or the population. An indicator may not necessarily provide answers to whether care has been 'good' or 'bad'; but well chosen indicators, as the term implies, should at least provide pointers to circumstances which may be worth further investigation.
- 1.4** An 'ideal' indicator has been taken to mean what should be known, and realistically could be known, about the outcomes of the prevention and care of specific conditions. The development of the recommendations has, of course, been tempered by considerations of the likely cost and availability of information. However, the working groups have tried to be reasonably far-sighted in their views about future advances in information systems.
- 1.5** For each condition the working group has developed a menu of indicators which can be used by different groups of people for a variety of purposes. In particular, an attempt has been made to recommend, within each set, indicators which reflect a population, clinical, patient, and in relevant cases, a carer perspective.

Stroke Working Group

- 1.6** The terms of reference and membership of the Group are shown in Appendix B. The Group included representatives of professional, managerial and patient groups involved with the prevention and treatment of stroke.

1.7 The work of the Group had three main components:

- development of check lists, including a health outcome model for stroke, to assist members choose candidate indicators, by which is meant potential indicators worth detailed consideration
- specification of candidate indicators
- recommendations about implementation and further development.

1.8 In this Report:

- the health outcome model is described in Section 2
- work commissioned to support the model is included in Appendix C
- check lists for choosing candidate indicators are outlined in Appendix D
- guidelines for specifying candidate indicators are described in Appendix E
- a review of indicators developed previously is in Appendix F
- candidate indicators chosen for specification are listed in Section 3
- candidate indicator specifications are included in Section 4
- recommendations about implementation and development are made in Section 5
- references to all sections and appendices are in Appendix G.

Recommendations

1.9 The recommendations made by the Group were categorised as those which:

- can be implemented generally throughout the NHS as there are systems available which can provide the requisite data
- could be implemented now where local circumstances allow, and more generally in the near future once expected developments are in place
- will not be possible to implement in the near future but, because of their desirability, they should be considered in the future development of clinical and management information systems
- require further work before a recommendation can be made.

1.10 The recommendations have been further categorised as to whether the requisite indicators should be available:

- routinely on a universal and continuous basis
- from periodic surveys and/or sampling, either at different points in time nationally or in geographical areas when there is a particular need or interest.

2. HEALTH OUTCOME MODEL FOR STROKE

Definition and scope of the work

- 2.1** Stroke is commonly defined as 'a clinical syndrome typified by rapidly developing signs of focal or global disturbance of cerebral functions, lasting more than 24 hours or leading to death, with no apparent causes other than of vascular origin'.
- 2.2** It is a clinical diagnosis, usually applied to cerebral infarction or haemorrhage and includes posterior fossa strokes which may present without hemiplegia.
- 2.3** The Group decided that, for the purpose of its work, the definition of stroke should not include:
- subarachnoid haemorrhage without focal signs which has a very different clinical presentation, cause and natural history
 - transient ischaemic attacks which are similar in terms of cause to stroke but lead to rapid full recovery of function, although these attacks suggest a liability to a full-blown stroke.
- 2.4** The Group decided that the scope of the work should exclude the very small number of strokes in children and adults aged under 20. Where possible, first strokes should be distinguished from second or subsequent strokes.

Developing a health outcome model

- 2.5** Although some original work was commissioned by the Group, the greater part of the input to the development of the stroke outcomes model came from already published national work including:
- *Stroke*, an epidemiological overview published in 1994 by the Central Health Monitoring Unit (Department of Health 1994).
 - *Health care needs assessment for stroke*, one of the 19 reviews commissioned by the Department of Health (Wade 1994).
- 2.6** The health outcome model was developed as an aid to help Group members to identify potential indicators. The model contains four elements:
- an overview of the epidemiology of the disease
 - a review of causes and risk factors
 - a review of the course, complications and consequences
 - a review of relevant interventions.

Overview of epidemiology

2.7 On the basis of data obtained from population surveys in England and research studies (Wade 1994) it has been estimated that the overall incidence of stroke is 2.4 per 1000 population per year with the incidence of first stroke being 2.0 per 1000 per annum. The incidence varies markedly with age between 2 per 1000 for ages 55 to 64 and 20 per 1000 in people over 85 years of age. In all except the young the risk of stroke is higher in men than women.

2.8 The prevalence of people who have survived a stroke is 5 to 7 per 1000 population with at least 50% left with physical disability and many suffering memory impairment. In certain settings such as Part III accommodation and nursing homes, patients with stroke form a major proportion of the residents.

2.9 In 1990 stroke accounted for 9% of male and 15% of female deaths (Department of Health 1994). More than 90% of these deaths were in people aged over 65 years. It should be noted that:

- mortality from stroke is higher in the winter and lower in the summer months
- mortality rates from stroke are higher in social classes IV and V than in social class I
- mortality rates are higher in the North of England than in the South
- for several decades the mortality rates have been declining in Western countries but recently this fall may have slowed
- age standardised death rates in England have fallen by about 20% between 1984 and 1992 but because of the increased number of elderly, total stroke deaths only fell by 7% during the same period.

2.10 Prescriptions used in the treatment and prevention of heart disease and stroke doubled between 1987 and 1992, whilst total NHS prescriptions rose by one third (Department of Health 1994).

Causes and risk factors

2.11 Strokes occur when the blood supply to a focal part of the brain is interrupted permanently. This may occur through local thrombosis, embolism or haemorrhage from an artery. Cerebral infarction may occur without symptoms and evidence of previous infarction may often be found in elderly patients developing epileptic seizures and in patients presenting with their first stroke. Intracerebral haemorrhage accounts for 11% to 12% of strokes, the remainder being due to infarction. Increasing age is the strongest risk factor and most strokes occur in people over 65. The relative risk associated with the most important risk factors is shown in Exhibit 1 (Wade 1994), expressed as how many more times likely it is that someone with a risk factor will have a stroke compared to an individual without it.

EXHIBIT 1: SUMMARY OF STROKE RISK FACTORS (Wade 1994)

Risk factors	Relative risk
Mild hypertension over 160/95	7
Atrial fibrillation	3-7
Past transient ischaemic attack	5
Heart failure	5
Age 55 to 64 versus 75 and over	5
Smoking	2-5
Alcohol acute intoxication	5
Epilepsy	4
Ischaemic heart disease	3
Snoring	3
Physical inactivity	2.5
Diabetes	2.2
Obesity	1.8
FEV-1 < 3.01	1.8
Social class (I versus V)	1.6

2.12 Since stroke is a complication of cerebrovascular disease it is possible to classify risk factors into four groups:

- evidence of existing cerebrovascular disease
- evidence of generalised vascular disease
- risk factors for vascular disease where the link is understood
- associations with vascular disease where the mechanism is unclear.

2.13 In one study (Sandercock et al. 1989) 14% of stroke patients had suffered a previous transient ischaemic attack (TIA) and 14% had a carotid bruit. The relative risk of stroke associated with a TIA is 5.2. A past history of stroke also carries an increased risk at about 7% per annum. However, the prevalence of carotid stenosis (which gives rise to the bruit) is quite high (23% of men age 69 years were found to have it in one study) but the absolute risk associated with it may be quite low. Even if there were a safe 100% effective treatment for carotid stenosis, it would only prevent 1.3% of all strokes (Wade 1994). Consequently identifying these risk factors may be important for individual patients but will not greatly influence overall stroke incidence.

2.14 Stroke and other vascular disease are often seen together. Of those people with a diagnosis of stroke 38% have ischaemic heart disease, 25% have peripheral vascular disease and 13% are in atrial fibrillation (Sandercock et al. 1989).

- 2.15** Raised arterial blood pressure is the most important avoidable risk factor for stroke and accounts for a third to a half of the population attributable risk. Diabetes mellitus carries a relative risk of 2.2. Smoking, obesity and physical inactivity also carry a slightly increased risk (Wade 1994).
- 2.16** Other factors may increase the risk of stroke (Wade 1994). Snoring may be associated with a doubling of the risk of stroke but it is unclear how to interpret this. There is evidence that maternal health and early fetal and neonatal nutrition may influence the risk of vascular disease, including stroke, in later adult life. Social and economic factors may be of importance. Severe life events are more common in the year preceding a stroke than in controls. A study of social deprivation in London demonstrated an association between increased unemployment in an area and increased stroke mortality. Alcohol taken to excess by either binge drinking or consistent heavy drinking increases the risk of stroke independently from its association with hypertension. Lastly there is an association between a low FEV-1 (indicating chest disease) and the risk of stroke.

Course, complications and consequences

- 2.17** About 30% of patients with a stroke will die, most of them in the first three weeks and most as a direct result of the stroke itself. A few die unexpectedly from other causes such as pulmonary embolism. Patients who survive are at increased risk of death, another stroke, or a heart attack, at around 10%, 7% and 10% per annum respectively (Wade 1994).
- 2.18** Disability from stroke fluctuates markedly over the first week: up to 25% deteriorate and 25% improve dramatically. Hence early measures of severity may be of limited use in predicting future outcome. One week after a stroke it is easier to predict recovery over the next six months. The more severe the disability at one week the more severe will be the long term disability (Wade 1994).
- 2.19** Neurological recovery is fastest in the first month although useful recovery may continue for much longer. Care is still required after the first six months, particularly to treat hypertension and depression. The best predictor of long term disability is the presence or absence of urinary incontinence, which can identify about half of those who will need long term care (Wade 1994). Exhibit 2 summarises the proportion of people with a stroke who will experience certain levels of functional deficit.
- 2.20** In common with other patients with poor mobility, stroke patients are at increased risk of pressure sores, all or most of which should be preventable. If there is prolonged limb immobility patients may develop contractures which further impair function.

**EXHIBIT 2: FREQUENCY OF COMMON PROBLEMS AFTER A STROKE
(Summarised from Wade 1994)**

Problem	Percentage at six months
Loss of power in a limb (partial or complete)	53%
Not physically independent	53%
Needs help feeding	33%
Needs help dressing	31%
Not oriented	27%
Unable to walk independently indoors	15%
Marked communication problems	15%
Incontinent of urine	11%
Incontinent of faeces	7%

Relevant interventions

2.21 The Group reviewed the relevant interventions for stroke using the following classification of types of interventions aimed to:

- reduce or avoid risk of first stroke:
 - in low risk population
 - in high risk population
- reduce death from stroke
- reduce or avoid complications from stroke
- reduce or avoid risk of subsequent stroke
- improve function and well-being after stroke:
 - reduce impairment from stroke
 - reduce disability from stroke
 - reduce handicap from stroke
 - support carers.

2.22 The main interventions that may reduce the risk of both first and subsequent strokes are:

- detection and treatment of hypertension
- long term aspirin therapy for selected patients
- anticoagulant therapy for selected patients
- carotid endarterectomy for selected patients
- population health promotion programmes.

- 2.23** Raised arterial blood pressure is a major avoidable risk factor for stroke. There is good evidence from randomised controlled trials that reducing blood pressure, even from mildly elevated levels, reduces the risk of stroke. The relative risk reduction is of the order of 30% to 50% (Collins et al. 1990) though the absolute risk reduction will depend on the pre-existing risk of a particular patient or group of people. As stroke incidence is ten times higher in people aged 65 to 74 than in people aged 45 to 54 this similarly alters the number of people who would need to be treated to prevent one stroke. It has been estimated that 850 man years of treatment for people aged 35 to 64 with mild hypertension are required to prevent one stroke.
- 2.24** Treatment with aspirin in a dose of 300 mg per day has been demonstrated to reduce the risk of vascular death, including stroke, by 15% to 30% in patients who have had a transient ischaemic attack (Wade 1994). The addition or substitution of other medications including anticoagulants has not been shown to be any more effective in this condition except when there is co-existing mitral valve disease or a trial fibrillation. Patients who have had an ischaemic stroke should be treated long term with aspirin.
- 2.25** Anticoagulants in the presence of cardiac disease, especially atrial fibrillation may reduce the risk of stroke by 50% (Wade 1994). The difficulties of controlling anticoagulation therapy, its costs and the modest population benefit make this an area where clinicians still differ as to best policy.
- 2.26** Carotid arterial surgery is of undoubted benefit for patients with severe carotid stenosis. However, these patients form a small portion of the whole.
- 2.27** Population programmes aimed at reducing blood pressure by altering the national diet to include less salt could theoretically reduce stroke incidence by 20%, but in practice are likely to prove disappointing in their impact (Wade 1994).
- 2.28** Adequate research has not been completed to identify effective interventions which modify the early course of stroke although heparin and thrombolytic agents show some potential.
- 2.29** Special investigations and scanning may add to the confidence of the diagnosis but it remains controversial whether the measures influence the final outcome for the patient. The NHS Centre for Reviews and Dissemination at University of York carried out a short review of the literature about the use of computer tomography scanning in stroke. This is at Appendix C and the main findings are that there is as yet little research which evaluates the use of CT scans in stroke and none of the current clinical criteria for carrying out routine CT scans are supported by evidence that this procedure leads to benefits that outweigh the costs. It was decided not to develop a proxy outcome indicator related to CT scanning.

2.30 The level of impairment of a patient may vary widely in the first few days after a stroke. There has been considerable discussion over the setting in which immediate care should be carried out and the York Centre were commissioned to complete a short literature review. This is at Appendix C and the main findings are:

- early and co-ordinated rehabilitation appears to provide benefit without necessarily increasing the amount of therapy given in total
- there is insufficient evidence to support the superior effectiveness of any one particular setting, such as a hospital stroke unit, for the provision of care in the acute phase of the illness
- there is no agreed definition of a stroke unit or what it should entail thus it is difficult to compare studies
- evidence from trials suggest that 'stroke units' may lead to more rapid recovery in the short term but there is conflicting evidence about sustained improvement in the long term.

2.31 The available evidence points towards the improved effectiveness of rehabilitation achieved by a co-ordinated multidisciplinary team and it is also likely that the process of setting up such co-ordinated approaches will generate the participation of enthusiastic professionals. The presence of such individuals may well impact beneficially on the effectiveness of any given method of organisation.

2.32 Similarly for the long term reduction of impairment from stroke, treatments are provided by several professional groups working for different agencies. There is evidence that rehabilitation is more effective when it is part of a co-ordinated specialist service but at present there is little support to favour any particular techniques or interventions over another.

2.33 Many patients are left with long term impairment after a stroke which can have profound consequences for their physical functioning, social and emotional well-being. Although impairment may be fixed, the degree of disability and handicap suffered can be influenced by the patient and the care received. To receive adequate support there must be:

- community support services that are available to people after a stroke
- an assessment process to match individual needs to particular services
- a review mechanism to ensure that a patient is gaining benefit or improved outcomes from the services provided.

2.34 Much of the long term care will take place in the home and involve family and carers as well as the statutory and voluntary organisations. Carers need:

- recognition of the consequences to them and support in carrying out their onerous role
- information about the disease, care techniques and the resources available to them.

3. CHOICE OF CANDIDATE INDICATORS

- 3.1** To assist the Group choose the candidate indicators, literature reviews were commissioned and a matrix was developed to ensure the coverage of all relevant aspects of health outcomes.
- 3.2** The Group commissioned three short literature reviews, which are shown in Appendix F, from the UK Clearing House on Health Outcomes covering:
- overview of stroke outcome measures
 - measurement of long term outcomes of stroke
 - measurement of impact of stroke on carers.
- 3.3** To ensure that all potentially useful aspects of outcomes were considered the matrix in Exhibit 3 was drawn up using the following dimensions:
- aims of interventions (see paragraph 2.21)
 - perspectives of measurement (see paragraph D6).
- 3.4** For each part of the matrix, consideration was given to possible indicators. Using the information in the health outcome model, candidate indicators were identified as shown in the paragraphs which follow. The numbers in the text relate to the Exhibit and indicator specifications in the next section.

EXHIBIT 3: MATRIX FOR STROKE OUTCOME INDICATORS

Aim of health intervention	Primary measurement perspective			
	Population	Clinical	Patient	Carer
* Reduce or avoid risk of first stroke/subsequent stroke	1A,1B,2,3	4,5,6		
* Reduce death from stroke	8	7A,7B		
* Reduce or avoid complications from stroke		9,10,11A,11B,12		
* Improve function and well-being after stroke		13,14,15,20	16,17,18,19,21A-C,22,23	22,24

- 3.5** Factors related to the reduction or avoidance of **risk from first or subsequent stroke** were considered to be the detection and treatment of hypertension, the appropriate use of aspirin and anticoagulant therapy. The occurrence of stroke can be used to measure the success of risk reduction. The following candidate indicators were specified:
- Incidence of stroke:
 - 1A:** incidence of hospitalised stroke
 - 1B:** population-based incidence of stroke.
 - Detection and treatment of hypertension as a risk factor for stroke:
 - 2:** percentage of general practice patients who have had their blood pressure recorded in the previous five years
 - 3:** median and inter-quartile range of systolic blood pressure within a general practice population
 - 4:** percentage of general practice patients, identified as hypertensive, whose most recent systolic blood pressure measurement is less than 160 mm Hg.
 - Use of aspirin therapy to reduce risk of subsequent stroke:
 - 5:** percentage of patients within a general practice population who have a prescription for aspirin therapy at six months after stroke (without proven haemorrhage).
 - Use of anticoagulant therapy to reduce risk of subsequent stroke:
 - 6:** percentage of general practice patients with a diagnosis of atrial fibrillation who have a prescription for anticoagulant therapy.
- 3.6** The following indicators which relate to the monitoring of **death from stroke** were specified:
- 7A:** case-fatality rate within 30 days of a hospital admission for stroke
 - 7B:** case-fatality rate within 30 days of stroke (inpatient or community-based treatment)
 - 8:** population-based mortality rates.
- 3.7** Key **complications following stroke** were considered to be difficulty in swallowing, pressure sores and unplanned re-admission to hospital. The following indicators were specified:
- 9:** percentage of patients within a provider unit population for whom a formal swallowing assessment was undertaken within 24 hours of a stroke

- 10:** incidence of pressure sores during the in-patient stay within a hospital provider unit population with a primary diagnosis of stroke
- 11A:** percentage of patients within a community provider population who, six months following a stroke, have one or more pressure sores
- 11B:** percentage of patients in a nursing home population who, six months following a stroke, have one or more pressure sores
- 12:** rate of emergency re-admissions (for any reason) within 30 days of discharge, per provider unit population with a primary diagnosis of stroke.

3.8 The **improvement of function and well-being after stroke** can be assessed by measures of the patient's impairment, disability, handicap, awareness of the condition and satisfaction. Two indicators related to carers have been included. The following indicators were specified:

- 13:** multi-professional involvement in the week following admission within a provider unit population admitted with a primary diagnosis of stroke
- 14:** distribution of the Barthel Index of Activities of Daily Living (ADL), at discharge from hospital, within a provider unit population with a primary diagnosis of stroke
- 15:** distribution of the Barthel Index of Activities of Daily Living (ADL), within a population of patients six months following stroke
- 16:** assessment of aphasia within a population of patients six months following stroke
- 17:** assessment of outdoor mobility within a population of patients six months following stroke
- 18:** assessment of social functioning within a population of patients six months following stroke
- 19:** assessment of depression within a population of patients six months following stroke
- 20:** summary of changes in the Barthel Index as measured at discharge from hospital and at six months post-stroke, within a provider unit population admitted for stroke
- 21A:** percentage of people admitted with a primary diagnosis of stroke who return to their pre-admission category of accommodation on discharge from hospital
- 21B:** percentage of people admitted with a primary diagnosis of stroke who are living in their pre-admission category of accommodation six months following admission to hospital
- 21C:** percentage of people with a diagnosis of stroke who were not hospitalised and are living at their pre-stroke category of accommodation six months after the stroke
- 22:** summary of a measure of patients' or carers' knowledge of available health and social services, six months after stroke
- 23:** summary of a measure of patient satisfaction within a population, six months after stroke
- 24:** assessment of carer burden, six months after stroke.

4. CANDIDATE INDICATOR SPECIFICATIONS

- 4.1** This section contains the detailed specifications of the candidate indicators chosen by the Group. They have been grouped together by the types of health intervention as shown in Exhibit 3.
- 4.2** Guidance notes which explain the attributes used in the specifications are included in Appendix E.
- 4.3** The detailed work of the specifications was carried out by Moyra Amess, James Coles and Robert Cleary of CASPE Research.

Candidate indicator 1A

Characteristics

Specificity: Generic
Perspective: Population
Timeframe: Cross-sectional
Outcome relationship: Direct

Title	Incidence of hospitalised stroke
Intervention aim	Reduce or avoid risk of first or subsequent stroke.
Definition	For a given resident population, age-group, sex and year: <i>the number of provider spells containing one or more consultant episodes with stroke as a primary diagnosis where the episode start date is in the relevant year, divided by the size of the population of interest.</i> The resulting fraction should be expressed per 10,000 population, and its numerator also reported.
Rationale	Hospitalised incidence of stroke serves as an indicator for failure to prevent, based on the assumption that many who suffer a stroke, particularly the more serious cases, are admitted to hospital. However, in the UK the Oxford Community Stroke Project (1983), suggests some 40-90% of stroke episodes are managed at home. This indicator is therefore more useful if considered alongside Indicator 1B (Population-based incidence of stroke).
Potential uses	National and regional trends over time; geographical comparisons.
Potential users	Policy makers, clinicians and commissioners.
Possible confounders	When making inter-district or regional comparisons the interpretation of this indicator may be complicated by variable service provision within these areas. This is particularly relevant as regards the balance of stroke services between primary and secondary care. It is likely that effective primary and community services would lead to a reduced number of hospital admissions for stroke. Without specific knowledge of the services available in any particular area under comparison, interpretation will be difficult and the value of the indicator limited.
Data sources	The numerator may be obtained from CMDS data with a primary diagnosis of stroke (ICD-10 codes I61 (intracerebral haemorrhage), I62 (other non-traumatic intracranial haemorrhage), I63 (cerebral infarction), I64 (stroke, not specified as haemorrhage or infarction)), which are held by the relevant commissioner(s) for the relevant year. The denominator may be obtained from population estimates held by health authorities and other agencies.
Data quality	The validity of the indicator will depend on the quality of the CMDS diagnoses which is unlikely to be uniformly high. It is also possible that some of the hospital spells identified will be re-admissions for patients who have deteriorated since their first discharge. Such episodes may be coded with stroke as a primary diagnosis, and therefore this indicator may over estimate the incidence of stroke. Linkage of hospital stroke episodes by the NHS number would identify multiple admissions and allow further scrutiny as to whether the episode should be counted as an additional stroke incident for that year. Variation will reflect differing levels of aetiological factors for stroke, as yet largely unknown, as well as reflecting the

result of programmes to reduce known risk factors. Quantified information about hospitalised incidence should help decision-making about the local provision and development of services.

Comments

No specific points.

Further work required

Studies to investigate the diagnostic coding of re-admissions following stroke would provide some assessment of the reliability of the data source for this indicator.

Conclusions & priority

A - To be implemented generally on a routine basis.

References

Oxfordshire Community Stroke Project (1983). Incidence of stroke in Oxfordshire: first year's experience of a Community Stroke Register. *British Medical Journal*, **287**, 713-717.

Candidate indicator 1B

Characteristics

Specificity: Generic

Perspective: Population

Timeframe: Cross-sectional

Outcome relationship: Direct

Title	Population-based incidence of stroke
Intervention aim	Reduce or avoid risk of first or subsequent stroke.
Definition	For a given resident population, age-group, sex and year: <i>the number of cases of stroke recognised as occurring within the given year, divided by the size of the population of interest.</i> The resulting fraction should be expressed per 10,000 population, and the numerator should be reported.
Rationale	Stroke is thought to be potentially avoidable. The incidence could be decreased by reducing the prevalence of modifiable risk factors, the main treatable risk factor being hypertension (Havas 1987). Population-based stroke incidence therefore serves as an indicator of the success or failure to prevent stroke in the population.
Potential uses	National and regional trends over time; geographical comparisons.
Potential users	Policy makers, clinicians and commissioners.
Possible confounders	Risk factors for stroke in the populations being compared are potentially confounding variables. Some control may be obtained if the results are stratified by age, sex and recognised risk factors such as smoking.
Data sources	The numerator may be obtained from GP records. Such records should register both hospital and community managed episodes of stroke for patients. In general practices which have computerised patient records, stroke may be identified through use of Read coding of, for example, stroke (XOOD1) or cerebral infarction, unspecified (XaOkZ) (NHS Centre for Coding and Classification 1996). The denominator may be obtained from population estimates held by health authorities and other agencies.
Data quality	The validity of the indicator will depend on the quality of the GP practice data which is unlikely to be uniformly high. The data source relies on correspondence between primary and secondary care through discharge letters or summaries. There may, therefore, be patients who were hospitalised as a result of stroke, but without an identified GP, who would be missed through this approach. Similarly, patients who die suddenly as a result of stroke and do not present to health services will also be missed. A pilot study comparing incidence of chronic diseases as recorded in GP paper records and that recorded on computer records suggests under-reporting in the latter (Murphy and Jenkins 1995).
Comments	It would be useful to undertake validation studies, comparing the recording of stroke in GP records with that in community stroke registers and that recorded periodically in the national morbidity surveys. We suggest that the greatest value in monitoring the community-based incidence of stroke would be in places where there is a commitment to the establishment and maintenance of stroke registers

based on multiple sources including hospital and GP records. These could act as 'marker populations', to be used as proxies for the population as a whole. Elsewhere, the community-based incidence of stroke could be monitored through GP records by periodic survey.

Further work required

Further investigation of the quality of computerised records within general practices, particularly in the light of the recent more relaxed data collection requirements for chronic disease management programmes (NHS Executive 1995).

Conclusions & priority

C - To be implemented where local circumstances allow on a routine basis.

References

Havas, S. (1987). Prevention of heart disease, cancer and stroke: The scientific basis. *World Health Forum*, **8**, 344-351.

NHS Executive (1995). *GPs' out of hours services. FHSL (95)68*. NHS Executive, Leeds.

NHS Centre for Coding and Classification (1996). *The Read Codes October 1996 Demonstrators*. NHS Executive, Leeds.

Murphy, P., and Jenkins A. (1995). *Medics: practice feedback report*. Northumberland Health.

Candidate indicator 2

Characteristics

Specificity: Condition-specific

Perspective: Population

Timeframe: Cross-sectional

Outcome relationship: Indirect

Title	Percentage of general practice patients who have had their blood pressure recorded in the previous five years
Intervention aim	Reduce or avoid risk of first or subsequent stroke.
Definition	For a given general practice and on a specific day: <i>the number of patients who have had their blood pressure recorded within the last five years divided by the number of patients currently registered</i> . The resulting fraction should be expressed as a percentage and reported by patient age-group and sex.
Rationale	Raised arterial blood pressure is the most important avoidable risk factor for stroke and accounts for a third to a half of the population attributable risk (Wade 1994). Raised blood pressure may be present for many years without causing symptoms and such asymptomatic hypertension could be detected (and subsequently treated) early by routine measurement of blood pressure in general practice.
Potential uses	Local management of practice; GP provider based comparisons; monitoring of national targets.
Potential users	Clinicians, provider management, commissioners.
Possible confounders	Comparisons between general practices may be affected by the frequency with which patients visit their general practitioner. This is determined by a number of variables other than an episode of illness such as access, appointment times and availability, transport, and the doctor-patient relationships. Substantial changes in list size over time may affect the indicator and its interpretation.
Data sources	<p>Prior to October 1st 1996, the GMS health promotion programme package (bands II and III) required the recording of blood pressure of the practice population. Targets of 90% coverage were achieved after five years of running the programme (General Medical Services Committee 1993). Although this data collection is no longer compulsory (NHS Executive 1996), the inclusion of monitoring of this nature is encouraged within the locally specified programmes which have now replaced it.</p> <p>Health of the Nation targets include an aim to reduce systolic blood pressures by 5 mm Hg by the year 2005 (Department of Health 1995). For computerised practices, Read codes exist for BP screening for example, first call (90D1), abnormal BP on first call (90D9) and check done (901A) (NHS Centre for Coding and Classification 1996). Ninety-five percent of general practitioners in England were providing full GMS programmes for primary prevention of stroke in 1995 (Department of Health 1996).</p>
Data quality	Accuracy of data will depend on the quality of data yielded by the new health promotion programmes. Although there are no requirements to monitor the quality of these data, some individual HAs are considering the introduction of local checks to assess the accuracy and validity of the data.

Comments	There should be local encouragement for general practices to continue to monitor blood pressure as part of their health promotion programme.
Further work required	None recommended.
Conclusions & priority	A - To be implemented generally on a routine basis (by an annual priority audit).
References	<p>Department of Health (1995). <i>Public Health Common Data Set 1994</i>. Institute of Public Health, University of Surrey.</p> <p>Department of Health (1996). <i>Statistical Bulletin: statistics for general medical practitioners in England: 1985-1995</i>. Department of Health, London.</p> <p>General Medical Services Committee (1993). <i>The new health promotion package</i>. BMA, London.</p> <p>NHS Executive (1996). <i>GP health promotion. FHSL (96) 35</i>. NHS Executive, Leeds.</p> <p>NHS Centre for Coding and Classification (1996). <i>The Read Codes October 1996 Demonstrators</i>. NHS Executive, Leeds.</p> <p>Wade, D.T. (1994). Stroke (acute cerebrovascular disease). In <i>Health care needs assessment</i>. Vol.1, (ed. A. Stevens and J. Rafferty), pp. 111-255. Radcliffe Medical Press, Oxford.</p>

Candidate indicator 3

Characteristics
<i>Specificity:</i> Condition-specific
<i>Perspective:</i> Population
<i>Timeframe:</i> Cross-sectional
<i>Outcome relationship:</i> Direct

Title	Median and inter-quartile range of systolic blood pressure within a general practice population
Intervention aim	Reduce or avoid risk of first or subsequent stroke.
Definition	For a given general practice and year: <i>the median and interquartile range of systolic blood pressure, measured within the given year.</i> These statistics, with the associated number of cases, should be reported by patient age-band and sex. To facilitate comparisons with the Public Health Common Data Set (Department of Health 1995), corresponding means should also be reported.
Rationale	Significant public health gains would be expected from reducing the average blood pressure level of the whole population, and from the detection and appropriate treatment of raised blood pressure in individuals (Department of Health 1992). For the majority of individuals, whether conventionally ‘normotensive’ or ‘hypertensive’, it has been concluded that a lower blood pressure should confer a lower risk of vascular disease (Department of Health 1992). As well as screening for patients with raised blood pressure in the local practice populations, this indicator will facilitate local annual monitoring of, and action towards the Health of the Nation target which is ‘to reduce mean systolic blood pressure in the adult population by at least 5 mm Hg by the year 2005’ (Department of Health 1995).
Potential uses	National monitoring; GP provider based comparisons; HA comparisons.
Potential users	Policy makers, clinicians, commissioners.
Possible confounders	Because the denominator for this indicator is the whole general practice population, the indicator will be influenced by the proportion of patients for whom relevant blood pressure data are available. Indicator 2 may to some extent assist interpretation of low scores.
Data sources	Although no longer required by the General Medical Services Committee health promotion programme package, general practitioners should be encouraged to undertake regular checks on the blood pressure of their local population (see data sources, Indicator 2).
Data quality	Accuracy of data will depend on the quality of records yielded within the health promotion programmes and GP systems in general. Currently there are no requirements to monitor the quality of these data, but some individual HAs are considering the introduction of checks for accuracy and validity.
Comments	As well as monitoring change at a population level, data underlying the indicator could be used to look at changes in blood pressure within individuals.

Further work required None recommended.

Conclusion & priority **B - To be implemented generally by periodic survey.**

References

Department of Health (1992). *The Health of the Nation: a strategy for health in England*. HMSO, London.

Department of Health (1995). *Public Health Common Data Set 1994*. Institute of Public Health, University of Surrey.

Candidate indicator 4

Characteristics

Specificity: Condition-specific

Perspective: Clinical

Timeframe: Longitudinal

Outcome relationship: Direct

Title	Percentage of general practice patients, identified as hypertensive, whose most recent systolic blood pressure measurement, is less than 160 mm Hg
Intervention aim	Reduce or avoid risk of first or subsequent stroke.
Definition	For a given general practice and year: <i>the number of patients previously diagnosed as hypertensive, whose most recent systolic blood pressure measurement in the given year is less than 160 mm Hg, divided by the number of patients previously diagnosed as hypertensive.</i> The resulting fraction should be expressed as a percentage and reported together with its denominator, by patient age-group and sex.
Rationale	Significant public health gains would be expected from reducing the average blood pressure level of the whole population and from the detection and appropriate treatment of raised blood pressure in individuals (Department of Health 1992). It has been estimated that anti-hypertensive treatment could reduce the incidence of stroke by 40% (Collins et al. 1990; MacMahon et al. 1990). For the majority of individuals, whether conventionally 'normotensive' or 'hypertensive', it has been concluded that a lower blood pressure should confer a lower risk of vascular disease (Collins et al. 1990; MacMahon et al. 1990). The indicator is defined as all patients previously identified (within their GP records) as hypertensive, because continued blood pressure monitoring is considered appropriate in such cases.
Potential uses	GP audit; national monitoring; GP provider based comparisons; HA comparisons.
Potential users	Policy makers, clinicians, commissioners.
Possible confounders	Compliance with treatment/advice. Hypertension which is intractable to treatment. Variation in recording blood pressure within individuals. Potential variability in the definition of hypertension should be considered when interpreting comparisons across practices.
Data sources	Denominator data should be obtainable from GP information systems by identifying patients with a diagnosis of hypertension. For computerised systems, Read codes are available to identify such patients (G2.. - BP+ hypertension) (NHS Centre for Coding and Classification 1996). Although no longer required by the General Medical Services Committee health promotion programme package, general practitioners should be encouraged to undertake regular checks on the blood pressure of their local population (see data sources, Indicator 2).
Data quality	Accuracy of data will depend on the quality of data yielded by the new health promotion programmes and GP information systems in general.
Comments	No specific points.

Further work required None recommended.

Conclusion & priority **C - To be implemented where local circumstances allow on a routine basis.**

References

Collins, R., Peto, R., MacMahon, S., Hebert, P., Fiebach, N.H., Eberlein, K.A., Godwin, J., Qizilbash, M., Taylor, J.O., and Hennekens, C.H. (1990). Blood pressure, stroke and coronary heart disease. II: short-term reductions in blood pressure: overview of randomised drug trials in their epidemiological context. *Lancet*, **335**, 827-838.

Department of Health (1992). *The Health of the Nation: a strategy for health in England*. HMSO, London.

MacMahon, S., Peto, R., Cutler, J., Collins, R., Sorlie, P., Neaton, J., Abbott, R., Godwin, J., Dyer, A., and Stamler, J. (1990). Blood pressure, stroke and coronary heart disease. I: prolonged differences in blood pressure: prospective observational studies corrected for the regression dilution bias. *Lancet*, **335**, 765-774.

NHS Centre for Coding and Classification (1996). *The Read Codes October 1996 Demonstrators*, NHS Executive, Leeds.

Candidate indicator 5

Characteristics
<i>Specificity:</i> Condition-specific
<i>Perspective:</i> Clinical
<i>Timeframe:</i> Cross-sectional
<i>Outcome relationship:</i> Indirect

Title	Percentage of patients within a general practice population who have a prescription for aspirin therapy at six months after a stroke (without proven haemorrhage)
Intervention aim	Reduce or avoid risk of subsequent stroke.
Definition	<p>For a given general practice and year: <i>the number of patients who had a stroke (without proven haemorrhage) in the given year and who, six months later, had a current prescription for aspirin, divided by the number of patients who had a stroke (without proven haemorrhage) in that year.</i> The resulting fraction should be expressed as a percentage and reported by patient age-group and sex.</p> <p>For the purposes of this indicator, the patients referred to are those currently under the care of their general practitioner.</p>
Rationale	Aspirin is well established as secondary prophylaxis in patients with arterial thrombotic disorders (British Medical Journal 1988). It has been shown that regular aspirin reduces the risk of subsequent stroke, myocardial infarction, or vascular death (Antiplatelet Trialists' Collaboration 1988). The prescription of aspirin on a long-term basis following most cases of ischaemic stroke is therefore recommended and most patients would therefore have a prescription six months after the incident.
Potential uses	Local audit; management of patient groups; GP based comparisons of the effectiveness of primary care provision in reducing the incidence of subsequent strokes.
Potential users	Clinicians, commissioners.
Possible confounders	It is possible, due to the costs involved, that rather than using a doctor's prescription, patients will obtain their aspirin 'over-the-counter'. This is likely to vary with socio-economic and demographic factors associated with eligibility for free prescriptions.
Data sources	<p>Denominator data should be obtainable from GP information systems by identifying cases of stroke in a given year. For computerised systems the required Read codes to identify strokes without proven haemorrhage are cerebral infarction (XaOKZ) and stroke of unknown pathology (X00DR). Each of these cases should then be followed up to six months for a current prescription for aspirin (Read code xO2LX) (NHS Centre for Coding and Classification 1996).</p> <p>The maintenance of a stroke register would provide the denominator data for this indicator (see data sources, Indicator 2).</p>

Data quality	The quality of the data relies on the reliability of GP information systems for identifying diagnoses of stroke and patients' current prescriptions as well as the ability to link these. The existence of a stroke register may enhance the access to, and quality of, this information.
Comments	An alternative indicator, addressing the primary prevention of stroke, could look at the use of aspirin in patients who have had transient ischaemic attacks. However, difficulties with establishing this diagnosis accurately may cause problems in case ascertainment.
Further work required	None recommended.
Conclusion & priority	B - To be implemented generally by periodic survey.
References	<p>Antiplatelet Trialists' Collaboration (1988). Secondary prevention of vascular disease by prolonged anti-platelet therapy. <i>British Medical Journal</i>, 296, 320-31.</p> <p>British Medical Journal (Editorial) (1988). Aspirin all round. <i>British Medical Journal</i>, 296, 307-308.</p> <p>NHS Centre for Coding and Classification (1996). <i>The Read Codes October 1996 Demonstrators</i>. NHS Executive, Leeds.</p>

Candidate indicator 6

Characteristics
<i>Specificity:</i> Condition-specific
<i>Perspective:</i> Clinical
<i>Timeframe:</i> Cross-sectional
<i>Outcome relationship:</i> Indirect

Title	Percentage of general practice patients with a diagnosis of atrial fibrillation, who have a prescription for anticoagulant therapy
Intervention aim	Reduce or avoid risk of first stroke.
Definition	For a given general practice population: <i>the number of patients with a diagnosis of atrial fibrillation, who have a prescription for anticoagulants, divided by the number of patients with a diagnosis of atrial fibrillation.</i> The resulting fraction should be expressed as a percentage, and reported, along with the numerator by age-group and sex.
Rationale	Anticoagulants have been described as highly effective for preventing cardioembolic strokes (Albers 1995). Cardioembolism accounts for approximately 20% of ischaemic strokes and is the most likely cause of a stroke in patients with atrial fibrillation, who have suffered a recent anterior myocardial infarction or have prosthetic valves (Cerebral Embolism Task Force 1989). Atrial fibrillation affects 2% of individuals in their 60s and 10% of those over 80 (Batstone 1996). The average practice will have approximately seven patients per 1,000 on warfarin, of which almost half are receiving their anticoagulation care directly from their local practice (EQUIP Project 1996). An important factor is the availability of anticoagulation monitoring facilities and the benefit of anticoagulation depends crucially upon the quality of control. Monitoring may help identify non-availability of such facilities.
Potential uses	Identification of significant variation in the use of anticoagulation therapy for the prevention of stroke within GP populations with atrial fibrillation.
Potential users	Clinicians, commissioners, policy makers.
Possible confounders	No specific ones identified.
Data sources	Denominator data should be obtainable from GP information systems identifying patients with a diagnosis of atrial fibrillation. For computerised systems Read codes are available to identify such patients (atrial fibrillation - G5730) (NHS Centre for Coding and Classification 1996). The numerator will be the number of patients identified with a diagnosis of atrial fibrillation who have a prescription for anticoagulants (Read code- x01Nx) at the time of survey.
Data quality	The quality of the data depends on the reliability of GP information systems for diagnoses and prescriptions. The data source also relies on a correspondence between primary and secondary care through discharge letters or summaries. A pilot study comparing incidence of chronic diseases as recorded in GP paper records and incidence recorded on computer records suggests under reporting and the need for improvement in data quality (Murphy and Jenkins 1995).

Comments	No specific points.
Further work required	None recommended.
Conclusion & priority	D - To be implemented where local circumstances allow by periodic survey.
References	<p>Albers, G.W. (1995). Antithrombotic agents in cerebral ischaemia. <i>The American Journal of Cardiology</i>, 75, 34B-38B.</p> <p>Batstone, G. (1996). Digest of evidence: stroke prevention. <i>Journal of Clinical Effectiveness</i>, 1, 75-76.</p> <p>Cerebral Embolism Task Force (1989). Cardiogenic brain embolism. <i>Archives of Neurology</i>, 46, 727-743.</p> <p>EQUIP (Evaluating Quality in Practice) Project and the FACTS Project (Framework for Appropriate Care Throughout Sheffield) (1996). <i>Anticoagulation: a city-wide perspective</i>. Evaluating Quality in Practice Project, University of Sheffield.</p> <p>NHS Centre for Coding and Classification (1996). <i>The Read Codes October 1996 Demonstrators</i>. NHS Executive, London.</p> <p>Murphy, P., and Jenkins, A. (1995). <i>Medics: practice feedback report</i>. Northumberland Health.</p>

Candidate indicator 7A

Characteristics
<i>Specificity:</i> Generic
<i>Perspective:</i> Clinical
<i>Timeframe:</i> Longitudinal
<i>Outcome relationship:</i> Direct

Title	Case-fatality rate within 30 days of a hospital admission for stroke
Intervention aim	Reduce death from stroke.
Definition	For a given provider unit population, and year: <i>the number of patients registered as having died (regardless of certified underlying cause) within 30 days of an admission (to the given unit in the given year) containing one or more episodes with a primary diagnosis of stroke, divided by the total number of admissions (to the given unit in the given year) containing one or more episodes with a primary diagnosis of stroke.</i> The resulting fraction should be expressed as a percentage and should be reported with associated numerators as an overall figure and by age-group and sex.
Rationale	<p>Mortality following a stroke may in part represent an adverse outcome of antecedent health care. Comparisons of mortality rates, across local populations will reflect both the effectiveness of care within individual provider units (both hospitals and general practices) and the presenting characteristics of patients. Although social and environmental factors are thought to have a strong influence on the distribution of stroke mortality in England and Wales, the documentation of such inequalities provides a strong argument for the strengthening of local health services (both primary and secondary) in areas of high stroke incidence.</p> <p>Due to the uncertain quality of diagnosis coding on death certificates, for the purpose of this indicator, deaths for any reason are used for the numerator.</p>
Potential uses	Changes over time in fatality rates, nationally; clinical audit within provider units.
Potential users	Commissioners and clinicians.
Possible confounders	Comparisons should be made in the context of case-mix information confounders covering co-morbidities and the severity of patient populations. Secondary diagnoses on the current admission record provide one source, although completeness of these data may be variable. Alternatively, with general linkage of hospital activity and death certificate data, previous admissions for defined groups of relevant morbidities could be used as a basis for standardisation. This method was used by the Scottish Clinical Outcomes Group in their report on Clinical Outcome Indicators (Clinical Outcomes Group 1995). Another possibly relevant descriptor for the in-patient population would be the discharge Barthel score provided by Indicator 14.
Data sources	The numerator would be obtained from death certificates linked by a patient identifier to previous admissions for stroke (ICD-10 codes I61-4 as listed in Indicator 1A) with an admission date within the previous 30 days. The denominator may be obtained from CMDS data with a primary diagnosis of stroke.

Data quality	Potential problems lie with the accuracy of data with respect to diagnostic information (especially co-morbidity and severity), and those fields shared with death certificates and which are required for linkage with them. Linkage of hospital records to death certificates is feasible (Acheson 1967; Henderson et al. 1992).
Comments	No specific points.
Further work required	None recommended.
Conclusion & priority	A - To be implemented generally on a routine basis.
References	<p>Acheson, E.D. (1967). <i>Medical Record Linkage</i>. Oxford University Press.</p> <p>Clinical Outcomes Working Group of the Clinical Resource and Audit Group (1995). <i>Clinical Outcome Indicators</i>. The Scottish Office, Edinburgh.</p> <p>Henderson, J., Goldacre, M.J., Griffith, M., and Simmons, H. (1992). Recording of deaths in hospital information systems: implications for audit and outcome studies. <i>Journal of Epidemiology and Community Health</i>, 46, 297-299.</p>

Candidate indicator 7B

Characteristics
<i>Specificity:</i> Generic
<i>Perspective:</i> Clinical
<i>Timeframe:</i> Cross-sectional
<i>Outcome relationship:</i> Direct

Title	Case-fatality rate within 30 days of stroke (in-patient or community-based treatment)
Intervention aim	Reduce death from stroke.
Definition	<p>For a given residential population and year: <i>the number of patients who having had a stroke, are then registered as having died (regardless of certified underlying cause) within 30 days of that stroke, divided by the total number of patients who had a stroke in the given year.</i> The resulting fraction should be expressed as a percentage and reported by age-group and sex.</p> <p>The date from which a 30 day period is determined should be the date of the earliest documentation which refers to the stroke incident (see data sources).</p>
Rationale	<p>Mortality following a stroke may in part represent an adverse outcome of antecedent health care. Comparisons of mortality rates, across local populations will reflect both the effectiveness of care within individual provider units (both hospitals and general practices) and the presenting characteristics of patients. Although social and environmental influences are thought to have a strong influence on the distribution of stroke mortality in England and Wales, the documentation of such inequalities provides a strong argument for the strengthening of local health services (both primary and secondary) in areas of high stroke incidence. Indicator 7B intends to provide a more complete picture of mortality from stroke, in that hospital data alone (Indicator 7A) are less reliable as they typically only identify stroke cases which were admitted to hospital and not people who died in accident and emergency departments or who were certified dead on arrival.</p> <p>Due to the uncertain quality of diagnosis coding on death certificates, for the purpose of this indicator, deaths for any reason are used for the numerator.</p>
Potential uses	Changes over time in fatality rates, nationally; clinical audit within provider units.
Potential users	Commissioners and clinicians.
Possible confounders	Comparisons should be made in the context of case-mix information covering co-morbidities and the severity of patient populations. Secondary diagnoses on the current admission record provide one source although completeness of these data may be variable. Alternatively, with general linkage of hospital activity and death certificate data, previous admissions for defined groups of relevant morbidities could be used as a basis for standardisation. This method was used by the Scottish Clinical Outcomes Group in their report on Clinical Outcome Indicators (Clinical Outcomes Group 1995). Another possibly relevant descriptor for the in-patient population would be the discharge Barthel score provided by Indicator 14.

Data sources

The denominator data should be obtained from GP records and cases may be identified by the date the patient presented to the GP or, in the case of immediate admission to hospital following the stroke, the date of admission, both of which should be recorded on the GP patient record. Ideally, another source would be a stroke register. Stroke events on GP information systems could be identified using Read codes (for example stroke - XOOD1 or cerebral infarction - XaOkZ) (NHS Centre for Coding and Classification 1996). Such systems also identify any relevant co-morbidities. Numerator data may be obtained from linked death certificates.

Keeping the indicator as counting all strokes and not solely those which were only cared for in the community, will reduce the need to ascertain from GP notes a hospital episode, which may not be reliably recorded.

Data quality

Potential problems lie with the accuracy of data with respect to diagnostic information (especially co-morbidity and severity), and those fields shared with death certificates and which are required for linkage with them. Linkage of hospital records to death certificates is feasible (Acheson 1967; Henderson et al. 1992). However, similar general practice record linking has not been attempted to date on a large scale. There are studies commencing which intend to link death certificate data with GP records (Oxford Record Linkage System, personal communication). The indicator can make use of Read codes in general practice which makes it more difficult in those practices which are non-computerised. The only other method of yielding these data would be by survey and manual searching through notes. This would be both time-consuming and also assumes complete documentation of such events.

If feasible, to compare with hospital figures from Indicator 7A, it may be helpful to report deaths by whether the patient had a hospital admission or not.

Comments

The problems with linking data from general practice should be reduced when there is a unique identifier such as the new NHS number recorded on the death certificate. The problems with capturing these data as specified may mean this indicator needs more information system development before its routine use. Limiting the indicator to focus on deaths following admission to hospital (Indicator 7A) may be more realistic while relying on current data or data which are likely to be available in the near future.

Further work required

Examination of hospital records relating to stroke could be used to check that general practice records are up-to-date with hospital related deaths.

Conclusion & priority

C - To be implemented where local circumstances allow on a routine basis.

References

Acheson, E.D. (1967). *Medical record linkage*. Oxford University Press.

Clinical Outcomes Working Group of the Clinical Resource and Audit Group. (1995). *Clinical Outcome Indicators*. The Scottish Office, Edinburgh.

Henderson, J., Goldacre, M.J., Griffith, M., and Simmons, H. (1992). Recording of deaths in hospital information systems: implications for audit and outcome studies. *Journal of Epidemiology and Community Health*, **46**, 297-299.

NHS Centre for Coding and Classification (1996). *The Read Codes October 1996 Demonstrators*. NHS Executive, Leeds.

Candidate indicator 8

Characteristics

Specificity: Generic

Perspective: Population

Timeframe: Cross-sectional

Outcome relationship: Direct

Title	Population-based mortality rates
Intervention aim	Reduce death from stroke.
Definition	Adapted from Public Health Common Data Set indicator CDS-C3B (DoH 1993b). For a given population, age-group and sex: <i>deaths from stroke (ICD-10 codes I61-164) per 100,000 resident population.</i>
Rationale	Mortality following a stroke may in part represent an adverse outcome of antecedent health care, both in relation to primary prevention health care as well as effectiveness of treatment and rehabilitation services. Comparisons of mortality rates across local populations will reflect the effectiveness of care within individual provider units, the presenting characteristics of patients and the underlying causes of stroke which are in part unknown. Although social and environmental influences are thought to have a strong influence on the distribution of stroke mortality in England and Wales, the documentation of such inequalities provides a strong argument for the strengthening of local health services (both primary and secondary) in areas of high stroke incidence.
Potential uses	Population based comparisons.
Potential users	Local and national policy makers.
Possible confounders	The Public Health Common Data Set reports this indicator by age and sex. A wide range of other patient variables have a potential influence on the indicator.
Data sources	Office for National Statistics.
Data quality	The indicator relies on the accuracy of recording the underlying cause of death by the death certificate.
Comments	No specific points.
Further work required	None recommended.
Conclusion & priority	A - To be implemented generally on a routine basis.
References	Department of Health (1993b). <i>Public Health Common Data Set 1993. Part 1: indicator definitions.</i> Institute of Public Health, University of Surrey.

Candidate indicator 9

Characteristics
<i>Specificity:</i> Condition-specific
<i>Perspective:</i> Clinical
<i>Timeframe:</i> Cross-sectional
<i>Outcome relationship:</i> Indirect

Title	Percentage of patients within a provider unit population for whom a formal swallowing assessment was undertaken within 24 hours of a stroke
Intervention aim	Reduce or avoid complications of stroke.
Definition	For a given provider unit population and year: <i>the number of patients for whom a formal swallowing assessment was undertaken and documented, within 24 hours of admission for a stroke in the given year, divided by the number of patients admitted for stroke within the relevant year.</i> The resulting fraction should be expressed as a percentage and reported in patient age-groups.
Rationale	Dysphagia has been reported to occur in 28-45% of patients with acute stroke (Odderson and McKenna 1993). Aspiration has been found in 32-51% of patients with stroke and dysphagia (Barer 1984 and 1989, Gordon et al. 1987). Pneumonia is a complication of aspiration (Gordon et al. 1987) and is also the second most frequent cause of death within the first month after cerebral infarction, accounting for nearly one third of stroke deaths (Bounds et al. 1981). An immediate assessment of swallowing is important in treating patients with acute stroke. Careful assessment and management of dysphagia may dramatically reduce aspiration complications and the associated increased length of stay (Odderson et al. 1995).
Potential uses	Clinical audit and management of patients.
Potential users	Clinicians, provider managers, commissioners.
Possible confounders	No specific ones identified.
Data sources	Currently, collection of numerator data would require a survey of patient notes to identify whether an assessment has been made, i.e. a note of such or by the presence of an assessment form such as the standardised bedside swallowing assessment (SSA). Alternatively, where more sophisticated clinical information systems including multi-professional patient records are available, the data may be more accessible and their analysis more feasible on a routine basis.
Data quality	The quality of the data would rely on the legibility and completeness of patient documentation which will vary. A dedicated field within a computerised system would increase the reliability and completeness of such data.
Comments	The relationship between the assessment and treatment of dysphagia has not been fully investigated in terms of outcomes of death or avoidable chest infections. It is recognised that dysphagia is common and associated with a worse outcome (Gordon et al. 1987), but this may simply be that dysphagia accompanies severe strokes and therefore interventions to reduce swallowing problems may not effect morbidity or mortality. In the future measuring of the occurrence of chest infections alongside this indicator may be valuable.

Further work required	Investigation of the reliability of surveys to collect swallowing assessment data from patient notes and further research to establish whether the identification of dysphagia leads to a reduction in mortality and morbidity.
Conclusion & priority	E - To be further developed because link with effectiveness is not clear.
References	<p>Barer, D.H. (1984). Lower cranial motor function in unilateral vascular lesions of the cerebral hemisphere. <i>British Medical Journal</i>, 289, 1621-1622.</p> <p>Barer, D.H. (1989). The natural history and functional consequences of dysphagia after hemispheric stroke. <i>Journal of Neurological and Neurosurgical Psychiatry</i>, 52, 236-241.</p> <p>Bounds, J.V., Wiebers, D.O., Whisnant, J.P., and Okazaki, H. (1981). Mechanisms and timing of deaths from cerebral infarction. <i>Stroke</i>, 12, 474-477.</p> <p>Gordon, C., Hower, R.L., and Wade, D.T. (1987). Dysphagia in acute stroke. <i>British Medical Journal</i>, 295, 411-414.</p> <p>Odderson, I.R., and McKenna, B.S. (1993). A model for management of patients with stroke during the acute phase, outcome and economic implications. <i>Stroke</i>, 24, 1823-1827.</p> <p>Odderson, I.R., Keaton, J.C., and McKenna, B.S. (1995). Swallow management in patients on an acute stroke pathway: quality is cost effective. <i>Archives of Physical Medicine and Rehabilitation</i>, 76, 1130-1133.</p>

Candidate indicator 10

Characteristics
<i>Specificity:</i> Generic
<i>Perspective:</i> Clinical
<i>Timeframe:</i> Cross-sectional
<i>Outcome relationship:</i> Direct

Title	Incidence of pressure sores during the in-patient stay within a hospital provider unit population with a primary diagnosis of stroke
Intervention aim	Reduce or avoid complications from stroke.
Definition	For a given provider unit population and year: <i>the number of patients admitted with a stroke who acquire one or more pressure sores during a hospital provider spell which ends in the given year, divided by the total number of patients admitted with a stroke who were discharged in the given year.</i> For the purposes of this indicator, only pressure sores of grade two or above should be counted. The resulting fraction should be expressed as a percentage and reported as an overall figure and by age-group and sex.
Rationale	<p>Pressure sores are common in hospital settings, represent a significant burden of suffering for patients and their carers and are costly to the NHS (Effective Health Care 1995). New pressure sores occurred in 4-10% of patients admitted to a UK district general hospital, depending on the case-mix (Clark and Watts 1994). Health authorities received guidance from the NHS Management Executive encouraging them to set targets for an overall reduction in prevalence of at least 5% (NHS Executive 1993). Evidence and experience suggest that prevalence rates, because they are affected by incidence rates, healing rates, admission and discharge policies, are very difficult to interpret (Effective Health Care 1995). Comparison of incidence rates are therefore proposed but will only reflect the effect of prevention policies if suitable adjustment is made for differences in the risk status of patients admitted (Effective Health Care 1995).</p> <p>The indicator is specified as the incidence of acquired pressure sores of grade two and above so as to avoid the difficulties of reliable assessment of grade one pressure sores, consisting of non-blanchable erythema with intact skin.</p>
Potential uses	Clinical management of patients and clinical audit. Provider comparisons.
Potential users	Clinicians, commissioners, provider management.
Possible confounders	To control for relevant patient risk factors, the indicator data should ideally be analysed per 'at risk' group.
Data sources	Many provider units are monitoring pressure sore rates. Most do it by weekly data collection of assessment proforma completed by ward staff. Where facilities are in place, some are entering data onto a ward nursing system alongside other patient details. Whether a paper or computerised data collection system is in place, the minimum information required would be patient's identification details, patient diagnosis, and an assessment of pressure sore status on admission (to identify pressure sores acquired during the in-patient stay). Several pressure sore grading systems are in use (Healey 1996) although four ulcer gradings are generally used (Smith 1995).

To allow data comparison, grading systems which define a grade/stage two pressure sore as 'partial thickness skin loss or damage involving epidermis and/or dermis' (Smith 1995) should be used. This staging is from a ulcer scale developed and generally used for reporting the prevalence of pressure sores, and guiding therapy (National Pressure Ulcer Advisory Panel 1989).

Currently, retrospective monitoring of CMDS data, would allow identification of pressure sores (decubitus ulcer, ICD-10 code L89) within patients who also had a primary diagnosis of stroke (ICD-10 codes I61-I64 as listed in indicator 1A) for any episode within any hospital spell. This would allow calculation of prevalence rates. ICD-10 coding does not identify acquired sores or the grading of sores. The introduction of an additional sub-division of L89 would allow this discrimination. Optional use of Read codes would allow some additional information to be recorded in relation to grade of sore.

Data quality

The quality of the data would depend on the system in place and the existence of quality control checks on data entry. The data quality may also be affected by poor inter-rater reliability. This may be addressed by suitable training for all ward staff in the use of both risk and pressure sore assessment tools.

Comments

The *prevalence* of pressures sores can be recorded now in line with the NHSME targets. An adjustment to current clinical coding would allow *newly acquired* pressure sores to be recorded. Supporting information on the risk factors of individuals with pressure sores would require more sophisticated systems.

Further work required

An additional code to distinguish acquired pressure sores within the ICD-10 coding structure is recommended. To aid interpretation, the development of 'at risk' assessment tools should be undertaken, such as the Waterlow or Norton scales (Smith 1989).

Conclusion & priority

A - To be implemented generally on a routine basis.

References

Clark, M., and Watts, S. (1994). The incidence of pressure sores with a National Health Service trust hospital during 1991. *Journal of Advanced Nursing*, **20**, 33-36.

Effective Health Care (1995). *The prevention and treatment of pressure sores*. University of Leeds, University of York.

Healey, F. (1996). Using incidence data to improve risk assessment. *Journal of Tissue Viability*, **6**, 3-9.

NHS Management Executive (1993). *Priorities and planning guidance 1994-95 EL(93)54*. Department of Health, Leeds.

National Pressure Ulcer Advisory Panel (1989). Pressure ulcer prevalence, cost and risk assessment: consensus statement. *Decubitus*, **2**, 24-28.

Smith, D.M. (1995). Pressure ulcers in the nursing home. *Annals of Internal Medicine*, **123**, 433-442.

Smith, I. (1989). Waterlow/Norton scoring system: a ward view. *CARE - Science and Practice*, **7**, 93-95.

Candidate indicator 11A

Characteristics

Specificity: Generic
Perspective: Clinical
Timeframe: Cross-sectional
Outcome relationship: Direct

Title	Percentage of patients within a community provider population who, six months following a stroke, have one or more pressure sores
Intervention aim	Reduce or avoid complications from stroke.
Definition	For a given community provider population, and year: <i>the number of patients who have had a stroke in the given year, and who six months (± 21 days) later have one or more pressure sores, divided by the number of patients who have had a stroke in the given population and year.</i> For the purposes of this indicator, only pressure sores of grade two or above should be counted (see data sources). The resulting fraction should be expressed as a percentage and reported as an overall figure and by age-group and sex.
Rationale	<p>Pressure sores which occur in hospital and community settings, represent a significant burden of suffering for patients and their carers, and are costly to the NHS (Effective Health Care 1995). Health authorities received guidance from the NHS Management Executive encouraging them to set targets for an overall reduction in prevalence of at least 5% (NHS Executive 1993). This indicator will offer a reflection on the quality of care for stroke patients. The prevalence of pressure sores should be relatively small and variations should be examined in light of case-mix factors. Interpretation of the indicator with respect to the quality of care will require additional information about the length of time each patient has been under the current care arrangements.</p> <p>The indicator specifies the prevalence of pressure sores of grade two and above so as to avoid the difficulties of reliable assessment of stage one pressure sores, consisting of non-blanchable erythema with intact skin.</p>
Potential uses	Clinical management of patients and clinical audit.
Potential users	Clinicians, commissioners.
Possible confounders	To control for severity of stroke and other risk factors for pressure sore development, the indicator data would ideally be analysed per 'at risk' group.
Data sources	As a result of the NHSME guidance, commissioners are required to collect prevalence data on pressures sores. There appear to be few specified standards as to how these data are reported, so the value of using commissioner data to obtain this indicator is unclear. The primary data on individual sores may be collected by district nurses employed by a community trust or GP practice. Ideally, community providers would operate a central stroke register allowing easy identification of patients who have a stroke in the given year. These data could then be used to identify patients due for a six months follow-up after their stroke, to assess if any have developed any pressure sores. Alternatively, if a central register is not in use,

individual district nurses could be responsible for collecting this information, knowing from their patient records who had a stroke and when, and following them up at six months.

To collect the numerator data a proforma for the identification of pressure sores should, at the least, provide information on the number of pressure sores above grade two as well as the patients' history, the equipment in use, and an 'at risk' score. To allow data comparison, grading systems which define a grade/stage two pressure sore as 'partial thickness skin loss or damage involving epidermis and/or dermis' (Smith 1995) should be used. This staging is from a ulcer scale developed and generally used for reporting the prevalence of pressure sores and guiding therapy (National Pressure Ulcer Advisory Panel 1989).

Data quality

The quality of the data would depend on the system in place and the existence of quality control checks on data entry. The data quality may also be affected by poor inter-rater reliability. This may be addressed by suitable training for staff in the use of both risk and pressure sores assessment tools. Completeness of the stroke register if in use will also affect the validity of the denominator.

Comments

The occurrence of pressure sores could also be regarded as a 'sentinel event' and a topic for audit of the circumstances of care of the individual patient.

Further work required

To aid interpretation, the development of 'at risk' assessment tools should be undertaken, such as the Waterlow or Norton scales (Smith 1989).

Conclusion & priority

D - To be implemented where local circumstances allow by periodic survey.

References

Effective Health Care (1995). *The prevention and treatment of pressure sores*. University of Leeds, University of York.

NHS Management Executive (1993). *Priorities and planning guidance 1994-95*. EL(93)54. Department of Health, Leeds

National Pressure Ulcer Advisory Panel (1989). Pressure ulcer prevalence, cost and risk assessment: consensus statement. *Decubitus*, **2**, 24-28.

Smith, D.M. (1995). Pressure ulcers in the nursing home. *Annals of Internal Medicine*, **123**, 433-442.

Smith, I. (1989). Waterlow/Norton scoring system: a ward view. *CARE - Science and Practice*, **7**, 93-95.

Candidate indicator 11B

Characteristics

Specificity: Generic

Perspective: Clinical

Timeframe: Cross-sectional

Outcome relationship: Direct

Title	Percentage of patients in a nursing home population who, six months following a stroke, have one or more pressure sores
Intervention aim	Reduce or avoid complications from stroke.
Definition	For a given nursing home population and year: <i>the number of patients who have had a stroke in the given year, and who six months (\pm 21 days) later have one or more pressure sores, divided by the number of patients who have had a stroke in the given population and year.</i> For the purposes of this indicator, only pressure sores of grade two or above should be counted. If possible, pressure sores should be reported as acquired or present on admission. The resulting fraction should be expressed as a percentage and reported as an overall figure and by age-group and sex.
Rationale	<p>Indicator 11A assesses the number of pressure sores suffered by those cared for by district nurses, and thus does not consider residents of nursing homes. The indicator specified here focuses on pressure sores among people in local authority and private nursing homes. The NHS Executive set a target in 1994 for all service purchasers and providers, to reduce pressure sores by 5% from existing pressure sores prevalence levels (NHS Executive 1993). Studies have estimated pressure sore prevalence rates in general within nursing homes of 7% (Department of Health Care for Elderly People 1996) to 23% (Smith 1995). This indicator, by measuring the number of patients who have had a stroke and who have one or more pressure sores six months later, will in part reflect the quality of care delivered to this vulnerable group. The prevalence of pressure sores should be relatively small and variations should be examined in light of case-mix factors. Interpretation of the indicator with respect to the quality of care will require additional information about the length of time each patient had had a stroke before admission to the nursing home.</p> <p>The indicator is specified as the prevalence of pressure sores of grade two and above so as to avoid the difficulties of reliable assessment of stage one pressure sores, consisting of non-blanchable erythema with intact skin.</p>
Potential uses	Clinical management of patients and clinical audit.
Potential users	Clinicians, commissioners.
Possible confounders	To control for the severity of stroke and other risk factors for pressure sore development, the indicator data would ideally be analysed per 'at risk' group.
Data sources	The quality of information systems within nursing homes is likely to vary from the use of basic manual patient records containing administrative, medical and nursing information to more sophisticated computerised systems. Ideally, to facilitate use of this indicator, a centralised stroke register is required to identify patients in the

home who have had a stroke. When using the register, a system which identifies patients who are six months post-stroke could then be used to prompt when an assessment of their pressure sore status was due. The register would also easily identify the patients who had had a stroke in the given year to provide the denominator.

The Royal College of Physicians Continuous Assessment Review and Evaluation (CARE) scheme is an audit tool devised to enable staff to undertake clinical audit in long-term care. Such a scheme provides a structured data collection system on various aspects of long-term care including pressure sores. The survey tool guides collection of data regarding the presence of pressure sores, their grade(s), patient's 'at risk' status, equipment in use and whether the information is documented. Information is also collected on whether the sore was acquired before or since admission to the facility. This information would require an assessment of pressure sore status 'on admission' which is likely to be common practice. Use of such an instrument would provide a formal structure for the regular collection and review of pressure sore rates within the indicator.

Nursing homes are required to have twice yearly inspections, but currently this does not include a requirement to capture information such as pressure sore data. Commissioners may wish to consider augmenting these inspections to include aspects of pressure area care such as monitoring of pressure sores.

To allow data comparison, grading systems which describe a grade/stage two pressure sore as 'partial thickness skin loss or damage involving epidermis and/or dermis' (Smith 1995) should be used. This staging is from a ulcer scale developed and generally used for reporting the prevalence of pressure sores and guiding therapy (National Pressure Ulcer Advisory Panel 1989).

Data quality

The quality of the data would depend on the system in place and the existence of quality control checks on data entry. The data quality may also be affected by poor inter-rater reliability. This may be addressed by suitable training for staff in the use of both risk and pressure sores assessment tools. Inclusion of pressure sore data as a requirement for nursing home inspections may improve the availability and quality of data.

Comments

The occurrence of pressure sores could also be regarded as a 'sentinel event' and a topic for audit of the circumstances of care of the individual patient.

Further work required

To aid interpretation, the development of 'at risk' assessment tools should be undertaken, such as the Waterlow or Norton scales (Smith 1989).

Conclusion & priority

B - To be implemented generally by periodic survey.

References

Department of Health Care for Elderly People (1996). *Nature and extent of pressure sores and their prevention in nursing homes in Sheffield*. University of Sheffield.

NHS Management Executive (1993). *Priorities and planning guidance 1994-95. EL(93)54*. Department of Health, Leeds.

National Pressure Ulcer Advisory Panel (1989). Pressure ulcer prevalence, cost and risk assessment: consensus statement. *Decubitus*, **2**, 24-28.

Smith, D.M. (1995). Pressure ulcers in the nursing home. *Annals of Internal Medicine*, **123**, 433-442.

Smith, I. (1989). Waterlow/Norton scoring system: a ward view. *CARE - Science and Practice*, **7**, 93-95.

Candidate indicator 12

Characteristics
<i>Specificity:</i> Generic
<i>Perspective:</i> Clinical
<i>Timeframe:</i> Longitudinal
<i>Outcome relationship:</i> Direct

Title	Rate of emergency re-admissions (for any reason) within 30 days of discharge, per provider unit population with a primary diagnosis of stroke
Intervention aim	Reduce or avoid complications from stroke.
Definition	For a given provider unit and year: <i>the number of emergency in-patient admissions (to any unit and for any reason) not more than 30 days after discharge from hospital following admission for stroke to the given unit in the given year, divided by the total number of admissions for stroke to the given unit, in the given year.</i> This fraction, expressed as a percentage, should be reported with its numerator both as an overall figure and by patient age-group and sex.
Rationale	Unplanned re-admissions may reflect an adverse outcome of antecedent health care, and failures in post-stroke care in both hospital and community settings, have been documented (Smith et al. 1981, Ebrahim et al. 1987). With appropriate consideration of patient risk factors, re-admission rates may draw attention to aspects of the planning, organisation and delivery of care which may require review.
Potential uses	Clinical audit; provider based comparisons.
Potential users	Clinicians, provider management, commissioners.
Possible confounders	Comparisons should be made in the context of case-mix information covering the severity and co-morbidity of the patient populations. In this context, Indicator 14, giving discharge Barthel scores may also be useful as a case-mix descriptor.
Data sources	Within a given unit, CMDS data on emergency admissions could be used to identify re-admissions by matching episodes with the same local patient identifiers that occur within the reference period. Capture of re-admissions to other hospitals would rely on routine use of the new NHS number.
Data quality	The validity of the indicator would rely on the quality of the CMDS diagnoses which are unlikely to be uniformly high. Interpretation of the results of this indicator should be undertaken with some consideration of the potential perverse incentives to score well on this indicator (Milne and Clarke 1990). Key methodological issues relating to re-admission rates are discussed in Henderson et al. (1989).
Comments	As specified, this indicator does not exclude in-patient deaths or those patients who died within the 30 day follow-up period. In view of this, the indicator should be considered alongside the 30 day case fatality rate supplied by Indicator 7A. At best, it should be compiled excluding the deaths within 30 days. This could be done with systems linking hospital and death records.

Further work required	None recommended.
Conclusion & priority	D - To be implemented where local circumstances allow by periodic survey.
References	<p>Ebrahim, S., Barer, D., and Nouri, F. (1987). An audit of follow up services for stroke patients after discharge from hospital. <i>International Disability Studies</i>, 9, 103-105.</p> <p>Henderson, J., Goldacre, M.J., Graveney, M.J., and Simmons, H.M. (1989). Use of medical record linkage to study re-admission rates. <i>British Medical Journal</i>, 299, 709-713.</p> <p>Milne, R., and Clarke, A. (1990). Can re-admission rates be used as an outcome indicator? <i>British Medical Journal</i>, 301, 1139-1140.</p> <p>Smith, M.E., Walton, M.S., and Garraway, W.M. (1981). The use of aids and adaptations in a study of stroke rehabilitation. <i>Health Bulletin</i>, 39, 98-106.</p>

Candidate indicator 13

Characteristics
<i>Specificity:</i> Condition-specific
<i>Perspective:</i> Clinical
<i>Timeframe:</i> Cross-sectional
<i>Outcome relationship:</i> Direct

Title	Multi-professional involvement in the week following admission within a provider unit population admitted with a primary diagnosis of stroke										
Intervention aim	Improve function and well-being after stroke.										
Definition	<p>For a given provider unit and year: <i>the proportions of patients admitted for stroke in the given year who are assessed within one week of admission by each of a set of potentially relevant professions.</i> The categorisation of professions (shown below) is taken from the Royal College of Physicians stroke minimum data set proforma. Use of this categorisation would be used to present nine percentage scores.</p> <p><i>Which professionals assessed the patient during the first week of admission?</i></p> <table> <tr> <td>1. Doctor</td> <td>6. Speech and language therapist</td> </tr> <tr> <td>2. Nurse</td> <td>7. Clinical psychologist</td> </tr> <tr> <td>3. Physiotherapist</td> <td>8. Social worker</td> </tr> <tr> <td>4. Occupational therapist</td> <td>9. Other</td> </tr> <tr> <td>5. Dietician</td> <td></td> </tr> </table>	1. Doctor	6. Speech and language therapist	2. Nurse	7. Clinical psychologist	3. Physiotherapist	8. Social worker	4. Occupational therapist	9. Other	5. Dietician	
1. Doctor	6. Speech and language therapist										
2. Nurse	7. Clinical psychologist										
3. Physiotherapist	8. Social worker										
4. Occupational therapist	9. Other										
5. Dietician											
Rationale	Well organised multi-disciplinary rehabilitation increases the rate of improvement in stroke patients, although the long term effectiveness is unclear (Effective Health Care 1995). Stroke patients managed within specialist units (where a key characteristic was specialist multi-disciplinary team care) compared to general medical wards were more likely to be alive and living at home a year after stroke (Stroke Unit Trialists' Collaboration 1995). This indicator will measure the level of multi-professional input within stroke care. It is recognised however, that this may reflect the availability of necessary resources as much as it reflects on the organisation of the care.										
Potential uses	Clinical audit; management of patients.										
Potential users	Clinicians, commissioners.										
Possible confounders	No specific ones identified.										
Data sources	The numerator information may be obtained from a survey of the notes (probably nursing notes in combination with medical notes) to identify a documented reference to an assessment made by each profession, using the list as the survey tool. Alternatively, this information will be available if used routinely within the Royal College of Physicians stroke minimum data set. This is a two-sided proforma designed to collect a set of information on each patient admitted with a stroke. Question 12 asks the health care staff to tick which of nine types of professionals have assessed the patient during the first week of the admission. Use of this indicator could advance data collection standards. The denominator data may be										

obtained from CMDS data with a primary diagnosis of stroke for an admission episode (ICD-10 codes I61, I62, I63, I64 as listed in Indicator 1A)

Data quality	The quality of the data may rely on the patient notes or the quality of CMDS data which are not uniformly reliable.
Comments	As well as presenting the scores as nine separate percentages, other, composite, scores could be used, e.g. 'percentage of patients assessed by three or more professional groups'. As specified, the indicator captures the range of professional involvement in a given case. Ideally, multi-professional care additionally implies co-operation between the professionals. An indicator reflecting the extent to which the individuals work as a multi-professional team would be valuable. However, the difficulty of defining an operational measure of this co-operation has led to the more limited approach as specified here.
Further work required	None recommended.
Conclusion & priority	B - To be implemented generally by periodic survey.
References	<p>Effective Health Care (1995). <i>The prevention and treatment of pressure sores</i>. University of Leeds.</p> <p>Stroke Unit Trialists' Collaboration (1995). A systematic review of specialist multi-disciplinary team (stroke unit) care for stroke in patients. In <i>The Cochrane Database of Systematic Reviews - Stroke Module</i>, (ed. C. Warlow, J. Van Gijn, P. Sandercock). BMJ Publishing Group.</p>

Candidate indicator 14

Characteristics
<i>Specificity:</i> Condition-specific
<i>Perspective:</i> Clinical
<i>Timeframe:</i> Cross-sectional
<i>Outcome relationship:</i> Direct

Title	Distribution of the Barthel Index of Activities of Daily Living (ADL), at discharge from hospital, within a provider unit population with a primary diagnosis of stroke
Intervention aim	Improve function and well-being after stroke.
Definition	<p>For a given provider unit and year: <i>a summary of the distribution of Barthel ADL scores, as assessed at discharge, for patients who, having been admitted for stroke, were discharged in the given year.</i> The indicator should be reported by patient age-band and sex as well for the whole population. The size of the relevant population together with the number of cases for which an assessment was available should also be reported.</p> <p>A suitable summary of the distribution would include a measure of both central tendency and dispersion. Both means (and standard deviations) and medians (and interquartiles ranges) are used widely in the literature. Alternatively, the distribution could be summarised by using categories such as those suggested by Stone et al. (1994):</p> <ul style="list-style-type: none"> - independent (Barthel 20) - mild dependence (Barthel 15-19) - moderate dependence (Barthel 10-14) - severe dependence (Barthel 5-9) - very severe dependence (Barthel 0-4). <p>While the total Barthel score provides an assessment of overall disability, it would also be valuable to know about the underlying pattern of specific disabilities. In view of this, the distribution of scores for the individual component items of the Barthel should also be reported.</p>
Rationale	Stroke is a major cause of functional impairment. Rehabilitation following stroke aims to minimise disability and handicap. Assessment of functional ability to evaluate the resulting impact of rehabilitation services may be a useful indicator of successful care. Measurement of the functional status of patients at discharge will in part reflect the effectiveness of stroke management and rehabilitation. In addition, this indicator provides a baseline for longitudinal follow-up of patients' functioning (see Indicator 20).
Potential uses	Clinical audit; provider based comparisons.
Potential users	Clinicians, commissioners, provider management.
Possible confounders	Comparisons between populations should be made in the context of case-mix information covering severity, co-morbidity and length of stay.

Data sources	The assessment could be made by ward staff and documented in patient notes. To facilitate aggregation of individual assessments, the information could form part of a stroke data base. The Royal College of Physicians stroke minimum data set includes the Barthel Index. When there are practical difficulties in performing a full Barthel assessment at the time of discharge, it has been shown that the total Barthel score can be accurately predicted from the scores on three easily remembered items: mobility, bed transfers and urinary continence (Ellul et al. 1997).
Data quality	The Barthel Index has been shown to be reliable with different observers in a wide variety of situations (Gompertz et al. 1993), and it is a valid measure of physical disability (Wade and Hewer 1987). The value of the indicator would be compromised by low rates of completion - a danger where the data are not derived from information systems which support operational activities.
Comments	<p>The Working Group suggested that additional useful information may be obtained if the dimensions assessing 'bowels' and 'bladder' are augmented. If the assessment score is 0 in terms of their dependency within these two sections, an additional question as to whether 'faecal soiling' is present could be added for the bowels sub-section, and an additional question to identify those who are 'catheterised' and those who are 'incontinent' for the bladder section. Inclusion of this additional information does not affect the calculation of the total Barthel score.</p> <p>A pre-morbid assessment of function is essential to assess the true benefits of the care received. Information currently recorded is often unreliable (Benbow et al. 1994) and could be improved by using standardised assessments such as the Barthel, though this information may be difficult to verify. Where only limited information is available, a hierarchical version of the Barthel Index may be used to estimate the total score (Barer and Murphy 1993).</p>
Further work required	Further refinements to augment the Index as noted above.
Conclusion & priority	A - To be implemented generally on a routine basis.
References	<p>Barer, D., and Murphy, J. (1993). Scaling the Barthel: a 10-point hierarchical version of the activities of daily living index for use with stroke patients. <i>Clinical Rehabilitation</i>, 7, 221-277.</p> <p>Benbow, S., J, Watkins, C., Sangster, G., Ellul, J., and Barer, D. (1994). The availability and reliability of information on the pre-morbid functional status of stroke patients in hospital. <i>Clinical Rehabilitation</i>, 8, 281-285.</p> <p>Ellul, J., Watkins, C., and Barer, D. (1996). Estimating total Barthel scores from just three items: The European Stroke Database minimum dataset for assessing functional status at discharge from hospital. <i>In press</i>.</p>

Gompertz, P., Pound, P., and Ebrahim, S. (1993). The reliability of stroke outcome measures. *Clinical Rehabilitation*, **7**, 290-296.

Stone, S.P., Ali, B., Auberleek, I., Thompsell, A., and Young, A. (1994). The Barthel Index in clinical practice: use on a rehabilitation ward for elderly people. *Journal of the Royal College of Physicians of London*, **28**, 419-423.

Wade, D.T., and Hewer, R.L. (1987). Functional abilities after stroke: measurement, natural history and prognosis. *Journal of Neurological and Neurosurgical Psychiatry*, **50**, 177-182.

Candidate indicator 15

Characteristics

Specificity: Condition-specific

Perspective: Clinical

Timeframe: Cross-sectional

Outcome relationship: Direct

Title	Distribution of the Barthel Index of Activities of Daily Living (ADL), within a population of patients six months following stroke
Intervention aim	Improve function and well-being after stroke.
Definition	<p>For a population of patients suffering a stroke occurring within a given period of time: <i>a summary of the distribution of Barthel ADL scores for patients, as assessed at six months (\pm 21 days) post-stroke.</i> The indicator should be reported by patient age-band and sex as well for the whole population. The size of the relevant patient population together with the number of cases for which an assessment was available should also be reported.</p> <p>A suitable summary of the distribution would include a measure of both central tendency and dispersion. Both means (with standard deviations) and medians (with interquartiles ranges) are used widely in the literature. Alternatively, the distribution could be summarised by using categories such as those suggested by Stone et al. (1994):</p> <ul style="list-style-type: none"> - independent (Barthel 20) - mild dependence (Barthel 15-19) - moderate dependence (Barthel 10-14) - severe dependence (Barthel 5-9) - very severe dependence (Barthel 0-4). <p>While the total Barthel score provides an assessment of overall disability, it would also be valuable to know about the underlying pattern of specific disabilities. In view of this, the distribution of scores for the individual component items of the Barthel should also be reported.</p>
Rationale	<p>Indicators 15 to 19 are designed to capture various aspects of physical and psychosocial functioning, six months following a stroke. This indicator uses the same instrument as described in Indicator 14, but administered six months after stroke. While ADL at six months post-stroke will in part be determined by levels of pre-morbid functioning, it is also likely to be influenced by the effectiveness of the care received. Given the difficulty of measuring pre-stroke functioning (see comments below) the cross-sectional approach proposed here is suggested as a basis for comparing the outcome of care for different populations where assumptions about their underlying similarity can be made (e.g. within time-trend comparisons).</p> <p>The indicator might be used to follow-up a group of patients who were admitted to a given unit's hospital as a result of their stroke, or to assess the disability in a resident or GP population of stroke patients.</p>
Potential uses	Clinical audit; monitoring trends over time.

Potential users	Clinicians, commissioners, and provider management.
Possible confounders	As noted above comparisons between populations should be made in the context of case-mix information covering severity and co-morbidity, although some adjustment is being made by reporting the results by age and sex.
Data sources	<p>The identification and follow-up of stroke patients is best achieved through the use of a stroke register. Such a register may be general practice based - allowing GPs to follow-up their patients, through either a postal survey or during a consultation. Patients who have had a stroke in the given year (and who are still living) could be identified, and forms generated for an assessment of their Barthel Index score at six months after the date of their stroke. Alternatively, a register might be based at a hospital stroke unit so allowing follow-up of patients admitted for stroke within a given year, although particular consideration would need to be given as to whether patients have died since their discharge from hospital. To avoid duplicate assessments by both a GP and a hospital following up their population of patients, the use of a resident population-based stroke register to identify and follow-up all stroke patients would be desirable.</p>
Data quality	<p>The Barthel index has been shown to be reliable with different observers in a wide variety of situations (Gompertz et al. 1993), and it is a valid measure of physical disability (Wade and Hewer 1987). The Barthel Index has been successfully used within a postal survey, achieving good response rates (Gompertz et al. 1995; Harwood et al. 1994b). The value of the indicator would be compromised by low rates of completion - a danger where the data are not derived from information systems which support operational activities. Identification of who completed the form, i.e. patient or carer, should also be obtained to assist interpretation of comparisons.</p> <p>The reliability of a stroke register relies on ensuring it is maintained and updated by the various sources, e.g. GPs and hospital consultants. The quality of the data may also be affected by variation in diagnostic tendencies.</p>
Comments	<p>Efforts have been made to collect data about the patients' pre-stroke health state. The TyPE (Technology of Patient Experience) specification for stroke developed by the Health Outcomes Institute, includes a Health Status Questionnaire to be administered during the acute hospitalisation period which asks the patients about their function and disability in the time frame 'during the four weeks immediately prior to the stroke (Matchar et al. 1994). Pre-stroke residence is also collected as an indicator of pre-stroke function and health status.</p>
Further work required	None recommended.

Conclusion & priority

B - To be implemented generally by periodic survey.

References

- Gompertz, P., Pound, P., and Ebrahim, S. (1993). The reliability of stroke outcome measures. *Clinical Rehabilitation*, **7**, 290-296.
- Gompertz, P., Pound, P., Briffa, J., and Ebrahim, S. (1995). How useful are non-random comparisons of outcomes and quality of care in purchasing hospital stroke services? *Age and Ageing*, **24**, 137-141.
- Harwood, R.H., Gompertz, P., and Ebrahim, S. (1994). Handicap one year after a stroke: validity of a new scale. *Journal of Neurology, Neurosurgery and Psychiatry*, **57**, 825-829.
- Matchar, D.B., Goldstein, L.B., and Heyman, A. (1994). *The Stroke Type Specification*. Health Outcomes Institute, Bloomington, US.
- Stone, S.P., Ali, B., Auberleek, I., Thompsell, A., and Young, A. (1994). The Barthel Index in clinical practice: use on a rehabilitation ward for elderly people. *Journal of the Royal College of Physicians of London*, **28**, 419-423.
- Wade, D.T., and Hewer, R.L. (1987). Functional abilities after stroke: measurement, natural history and prognosis. *Journal of Neurological and Neurosurgical Psychiatry*, **50**, 177-182.

Candidate indicator 16

Characteristics

Specificity: Condition-specific

Perspective: Patient

Timeframe: Cross-sectional

Outcome relationship: Direct

Title	Assessment of aphasia within a population of patients six months following stroke
Intervention aim	Improve function and well-being after stroke.
Definition	For a population of patients suffering a stroke occurring within a given period of time: <i>a summary of patients' responses to an assessment of aphasia (to be specified), as administered six months (± 21 days) post-stroke.</i> The summary statistics will describe the distribution of scores, broken down by patient age-band and sex. The size of the relevant patient population together with the number of cases for which an assessment was available should also be reported.
Rationale	<p>As referred to in Indicator 15, this indicator is one of a series of indicators which intend to capture various aspects of physical and psycho-social functioning six months after stroke. Assessment of aphasia at six months after the stroke incident, will reflect in part the quality of rehabilitation and community service provision.</p> <p>The ability to communicate is an important component of everyday activities. A recent review concluded that speech and language therapy is effective if targeted to patients with specific deficits and needs and is provided intensively (Enderby and Emerson 1996). It is important to identify patients with a speech and language problem so the appropriate therapy is provided.</p> <p>For the purposes of this indicator, the required instrument to assess aphasia should meet practical considerations relating to its administration. Secondly, the metrical properties of the instrument (in terms of validity, reliability and sensitivity to clinical intervention) should have been demonstrated in the population of interest. The selection of a single standard instrument to measure aphasia would be helpful to facilitate comparisons across provider units or districts. However, further work is required to determine an appropriate tool.</p> <p>One example of such an instrument is the Frenchay Aphasia Screening Test (FAST) (Enderby and Crow 1996). This is a short, simple and standardised method of identifying and gauging language deficit so identifying those who require further assessment and therapy. An alternative approach is to ask a simple question to either the carer or patient as to whether they (following the stroke) can make themselves understood to people outside the family. This was used in the OPCS survey of disability in GB (Martin et al. 1988).</p>
Potential uses	Clinical audit; monitoring trends over time.
Potential users	Clinicians, and provider management.

Possible confounders	Comparisons between populations should be made in the context of case-mix information covering severity and co-morbidity.
Data sources	The identification and follow-up of stroke patients is best achieved through the use of a stroke register. Such a register may be general practice based - allowing a GP to follow-up their patients, through either a postal survey or during a consultation. Patients who have had a stroke in the given year (and who are still living) could be identified, and forms generated for an assessment of their aphasia at six months after the date of their stroke. Alternatively, a register might be based at a hospital stroke unit so allowing follow-up of patients admitted for stroke within a given year, although particular consideration would need to be given as to whether patients have died since their discharge from hospital. To avoid duplicate assessments by both a GP and a hospital following up their population of patients, the use of a resident population-based stroke register to identify and follow-up all stroke patients would be desirable.
Data quality	<p>The FAST tool has reliability and validity in the relevant population and is usable by non-specialists as a screening instrument (Enderby et al. 1987; Enderby and Crow 1996). The FAST has been used successfully at a six month follow-up and considered appropriate for community use. The quality of the data will also depend on the methods of data collection employed. Further investigation and study would be required. The value of the indicator would be compromised by low rates of completion - a danger where the data are not derived from information systems which support operational activities.</p> <p>The reliability of a stroke register relies on ensuring it is maintained and updated by the various sources, e.g. GPs and hospital consultants. The quality of the data may also be affected by variation in diagnostic tendencies.</p>
Comments	<p>This indicator is also relevant to the follow-up of groups of stroke patients in long term care populations, e.g. those in long-stay wards, residential care and nursing homes.</p> <p>In the case of those in residential care, systematic data collection may be particularly difficult to establish. Local authority owned homes may be more readily influenced by commissioners with respect to quality initiatives, but private homes are under no obligation to undertake this type of activity.</p>
Further work required	The Working Group considered that this assessment should be by periodic survey, but were unable to make definitive recommendations about which measure to use. This should be left to local decisions, pending results of further investigation of measurement instruments. Further work is also required to determine the appropriateness of six months after stroke as a time interval for such assessments.

Conclusion & priority **E - To be further developed because the indicator specification is incomplete in that further work is needed to identify a measurement tool. Once completed, the resulting indicator would be implemented by means of periodic survey where local circumstances allowed.**

References

Enderby, P., and Crow, E. (1996). Frenchay Aphasia Screening Test: validity and comparability. *Disability and Rehabilitation*, **18**, 238-240.

Enderby, P., and Emerson, J. (1996). Speech and language therapy: does it work? *British Medical Journal*, **312**, 1655-58.

Enderby, P., Wood, V., Wade, D., and Langton-Hewer, R. (1987). Aphasia after stroke: a detailed study of recovery in the first three months. *International Journal of Rehabilitation Medicine*, **8**, 166-170.

Martin, J., Meltzer, H., and Elliot, D. (1988). *The prevalence of disability among adults. OPCS surveys of disability in GB, Report 1*. HMSO, London.

Candidate indicator 17

Characteristics

Specificity: Condition-specific

Perspective: Patient

Timeframe: Cross-sectional

Outcome relationship: Direct

Title	Assessment of outdoor mobility within a population of patients six months following stroke
Intervention aim	Improve function and well-being after stroke.
Definition	For a population of patients suffering a stroke occurring within a given period of time: <i>a summary of patients' responses to an assessment of outdoor mobility (to be specified), as administered six months (\pm 21 days) post-stroke.</i> The summary statistics will describe the distribution of scores, broken down by patient age-band and sex. The size of the relevant patient population together with the number of cases for which an assessment was available should also be reported.
Rationale	<p>Indicators 15 to 19 are a series of indicators which, used either independently or together, will capture various aspects of physical and psycho-social functioning, six months after stroke (see rationale in Indicator 15 for more comment).</p> <p>Assessment of outdoor mobility at six months after the stroke incident, will reflect the extent of recovery, and in part the effectiveness of a rehabilitation process. Mobility questions have also been found helpful especially for assessment among patients discharged to the community. Such an assessment complements the indicators (15 to 19) developed to assess outcome from a patient's perspective. The type of measure should meet both practical, and measurement criteria outlined in the rationale of Indicator 15.</p> <p>An example of an outdoor mobility assessment is the mobility section from the Extended ADL scale (Nouri et al. 1987). The extended ADL is a 22-item postal self-report questionnaire which is designed to measure the more complex tasks required to live in the community, i.e. those beyond basic care. One sub-scale includes six questions assessing mobility over uneven ground, on stairs, in and out of the car, walking outside and travelling on public transport. Patients are asked to score whether they can do any of these 'with help', 'on their own with difficulty' or 'on their own'. The scale is suggested as appropriate for studies evaluating rehabilitation outcome after stroke and is suitable for postal surveys (Lincoln and Gladman 1992).</p> <p>An alternative option is to use a single question from EASY (Elderly Assessment System) (Philp 1997). The question asked 'are you able to walk outside?' would allow the proportion of patients responding a) as much as fifty yards or more without help; b) a few yards or more, but not as far as fifty yards and c) unable to walk outside house to be reported.</p>
Potential uses	Clinical audit; monitoring trends over time.
Potential users	Clinicians, commissioners, and provider management.

Possible confounders	Comparisons between populations should be made in the context of case-mix information covering severity and co-morbidity.
Data sources	See Indicator 15.
Data quality	The Extended Activities of Daily Living scale has been tested for validity as both a total index score as well as independent reporting of the four subsections (Lincoln and Gladman 1992). The quality of the data will also depend on the methods of data collection employed. Further investigation and study would be required. The value of the indicator would be compromised by low rates of completion - a danger where the data are not derived from information systems which support operational activities.
Comments	See Indicator 15.
Further work required	The Working Group considered that this assessment should be by periodic survey, but were unable to make definitive recommendations about which measure to use. This should be left to local decisions, pending results of further investigation of measurement instruments. Further work is also required to determine the appropriateness of six months after stroke as a time interval for such assessments.
Conclusion & priority	E - To be further developed because the indicator specification is incomplete, in that further work is needed to identify a measurement tool. Once completed, the resulting indicator would be implemented by means of periodic survey where local circumstances allowed.
References	<p>Lincoln, N.B., and Gladman, J.R. (1992). The extended Activities of Daily Living scale: a further validation. <i>Disability and Rehabilitation</i>, 14, 41-43.</p> <p>Nouri, F.M., and Lincoln, N.B. (1987). An extended activities of daily living scale for stroke patients. <i>Clinical Rehabilitation</i>, 1, 301-305.</p> <p>Philp, I. (1997). Can a medical and social assessment be combined? <i>Journal of Royal Society of Medicine</i>, 90, S11-13.</p>

Candidate indicator 18

Characteristics

Specificity: Condition-specific

Perspective: Patient

Timeframe: Cross-sectional

Outcome relationship: Direct

Title	Assessment of social functioning within a population of patients six months following stroke
Intervention aim	Improve function and well-being after stroke.
Definition	For a population of patients suffering a stroke occurring within a given period of time: <i>a summary of patients' responses to an assessment of social functioning (to be specified), as administered six months (\pm 21 days) post-stroke.</i> The summary statistics will describe the distribution of scores, broken down by patient age-band and sex. The size of the relevant patient population together with the number of cases for which an assessment was available should also be reported.
Rationale	<p>Indicators 15 to 19 are a series of indicators which, used either independently or together, will capture various aspects of physical and psycho-social functioning six months after stroke (see rationale in Indicator 15 for more comment).</p> <p>As well as a return to full physical functioning, an important outcome following a stroke is the extent to which patients are able to participate in social activities as before. Assessment of social functioning at six months after the stroke incident complements the indicators (15 to 19) developed to assess outcome from a patient's perspective. The type of measure chosen should meet both the practical and measurement criteria outlined in the rationale of Indicator 15.</p> <p>The Frenchay Activities Index (FAI) questionnaire assesses the frequency of a variety of domestic, leisure, work and outdoor activities (Bowling 1995). It was developed as an objective measure of actual activities undertaken by a person with a stroke in the recent past (Holbrook and Skilbeck 1983), and has been used as an outcome assessment in one year survivors of stroke (Dijkerman et al. 1996). The scale was developed using a UK population and the activities require more decision making and organisation on the part of the subject than most of the activities in the ADL scales. The scale is a 15-item questionnaire designed for interviewer-administration and asks about time periods of three or six months. The index can be assessed by questionnaire rather than observation and therefore it is possible to use it in a survey (Cockburn et al. 1990). Further work to investigate its use as a self-completion postal questionnaire would be required.</p>
Potential uses	Clinical audit; monitoring trends over time.
Potential users	Clinicians, commissioners, and provider management.
Possible confounders	Comparisons between populations should be made in the context of case-mix information covering severity and co-morbidity.
Data sources	See Indicator 15.

Data quality	The Frenchay Activities Index (FAI) has been tested on patients with acute stroke and has acceptable construct validity and reliability (Bowling 1995). It has also been found to be a valid measure for stroke survivors over 70 years of age (Cockburn et al. 1990). The value of the indicator would be compromised by low rates of completion - a danger where the data are not derived from information systems which support operational activities.
Comments	See Indicator 15.
Further work required	Further studies investigating the use of the Frenchay Index as a postal questionnaire tool and in stroke patients who have not necessarily received care in a hospital setting. Further work is also required to determine the appropriateness of six months after stroke as a time interval for such assessments.
Conclusion & priority	E - To be further developed because the indicator specification is incomplete, in that further work is needed to identify a measurement tool. Once completed, the resulting indicator would be implemented by means of periodic survey where local circumstances allowed.
References	<p>Bowling, A. (1995). <i>Measuring disease</i>. Open University Press, Buckingham.</p> <p>Cockburn, J., Wade, D., and Smith, P. (1990). The influence of cognitive function on social, domestic and leisure activities of community-dwelling old people. <i>International Journal of Disability Studies</i>, 12, 169-172.</p> <p>Dijkerman, H.C., Wood, V.A., and Langton-Hewer, R. (1996). Long-term outcome after discharge from a stroke rehabilitation unit. <i>Journal of the Royal College of Physicians of London</i>, 30, 538-546.</p> <p>Holbrook, M., and Skilbeck, C.E. (1983). An activities index for use with stroke patients. <i>Age and Ageing</i>, 12, 166-70.</p>

Candidate indicator 19

Characteristics

Specificity: Condition-specific

Perspective: Patient

Timeframe: Cross-sectional

Outcome relationship: Direct

Title	Assessment of depression within a population of patients six months following stroke
Intervention aim	Improve function and well-being after stroke.
Definition	For a population of patients suffering a stroke occurring within a given period of time: <i>a summary of patients' responses to a single item well-being measure (to be specified), as administered six months (\pm 21 days) post-stroke.</i> The summary statistics (to be specified) will describe the distribution of scores broken down by age-group and sex. The size of the relevant patient population together with the number of cases for which an assessment was available should also be reported.
Rationale	<p>Indicators 15 to 19 are a series of indicators which, used either independently or together, will capture various aspects of physical and psycho-social functioning, six months after stroke (see rationale in Indicator 15 for more comment).</p> <p>Emotional consequences of stroke are well documented (Robinson and Price 1982; Angeleri et al. 1992). Depression is associated with decreased physical functional ability in stroke patients and depression in old age carries a poor prognosis, with increased use of health and social services facilities (D'Ath et al. 1994).</p> <p>Several brief measures of general well-being or quality of life are available. One such single question is in the Psychological General Well-being Schedule (Bowling 1991), which asks:</p> <p><i>How happy, satisfied, or pleased have you been with your personal life (during the past month)?</i> The permitted responses to this question are:</p> <ul style="list-style-type: none"> - very dissatisfied or unhappy most or all of the time - generally dissatisfied, unhappy - sometimes fairly happy, sometimes fairly unhappy - generally satisfied - very happy most of the time - extremely happy - could not have been more satisfied or pleased. <p>This single item well-being question is currently being tested as a screen for depression among the elderly aged 75 and over (Philp, personal communication). Alternatively, the 15-item Geriatric Depression Scale (GDS15) (Sheikh and Yesavage 1986) has been tested as a reduced scale of four questions and been found to provide an encouraging combination of brevity, sensitivity and specificity among elderly patients (D'Ath et al. 1994). The 'COOP chart - feelings' question also provides another single item example (Scholten and Weel 1992) providing visual cues of happy/sad faces and has been tested in a number of settings (Bruusgaard et al. 1993; McHorney et al. 1992).</p>

While this is of necessity a cross-sectional measure, it is suggested that comparisons between populations and over time may yield useful information about the effectiveness of support and rehabilitation offered to stroke sufferers.

Potential uses	Clinical audit.
Potential users	Clinicians; commissioners; provider management.
Possible confounders	Population-based comparisons may be effected by other socio-economic factors which predispose patients to depression.
Data sources	The screening could take place as part of the annual over 75 check for those in that age-group or opportunistically when the patient attends surgery. Alternatively, it is suggested that the question may be attached to a series of other questions being put to the patient at a six month review of the long term impact of stroke (Indicators 15 to 19). The value of the indicator would be compromised by low rates of completion - a danger where the data are not derived from information systems which support operational activities.
Data quality	The quality of the data yielded through this type of assessment is currently being investigated (Philp, unpublished).
Comments	See Indicator 15.
Further work required	The Working Group considered that this assessment should be by periodic survey, but were unable to make definitive recommendations about which measure to use. This should be left to local decisions, pending results of further investigation of measurement instruments. Further work is also required to determine the appropriateness of six months after stroke as a time interval for such assessments.
Conclusion & priority	E - To be further developed because the indicator specification is incomplete, in that further work is needed to identify a measurement tool. Once completed, the resulting indicator would be implemented by means of periodic survey where local circumstances allowed.
References	<p>Angeleri, F., Angeleri, V.A., Foschi, N., Giaquinto, S., and Nolte, G. (1993). The influence of depression, social activity, and family stress on functional outcome after stroke. <i>Stroke</i>, 24, 1468-1483.</p> <p>Bowling, A. (1991). <i>Measuring health</i>. Open University Press, Buckingham.</p> <p>Bruusgaard, D., Nessioy, I., Rutle, O., Furuseth, K., and Natvig, B. (1993). Measuring functional status in a population survey. The Dartmouth COOP functional health assessment charts/WONCA used in an epidemiology study. <i>Family Practice</i>, 10, 212-218.</p>

- D'Ath, P., Katona, P., Mullan, E., Evans, S., and Katona, C. (1994). Screening, detection and management of depression in elderly primary care attenders. I: the acceptability and performance of the 15 item Geriatric Depression Scale (GDS15) and the development of short versions. *Family Practice*, **11**, 260-266.
- McHorney, A.C., Ware, J.E., Rogers, W., Raczek, A.E., and Lu, T.F. (1992). The validity and relative precision of MOS short form and long form health status scales and Dartmouth COOP charts: results from medical outcomes study. *Medical Care*, **30 Suppl**, 253-265
- Robinson, R.G., and Price, T.R.(1982). Post-stroke depressive disorders: a follow-up study of 103 patients. *Stroke*, **13**, 635-641.
- Scholten, J.H.G., and Van Weel, C. (1992). *The Dartmouth COOP Functional Health Assessment Charts/WONCA*. MEDITekst, Lelystad.
- Sheikh, J.A., and Yesavage, J.A. (1986). Geriatric Depression Scale (GDS): recent findings and development of a shorter version. In *Clinical Gerontology: a guide to assessment and intervention* (ed. T. Brink). Howarth Press, New York.

Candidate indicator 20

Characteristics

Specificity: Condition-specific

Perspective: Clinical

Timeframe: Longitudinal

Outcome relationship: Direct

Title	Summary of changes in the Barthel Index as measured at discharge from hospital and at six months post-stroke, within a provider unit population admitted for stroke
Intervention aim	Improve function and well-being after stroke.
Definition	For a population of patients having been admitted for stroke at a given provider unit in a given year: <i>a summary of the changes observed in individual patients, from a baseline at discharge to a follow-up at six months (\pm 21 days) post-stroke, with respect to the Barthel Index score.</i> The summary statistics, broken down by age and sex, should describe the distribution of the observed changes in terms of the proportion of scores which ‘go up’, i.e. improve, go down or remain the same. The size of the relevant population together with the number of cases for which an assessment was available should also be reported.
Rationale	<p>While the total Barthel score provides an assessment of overall disability, it would also be valuable to know about the changes in the underlying pattern of specific disabilities. In view of this, the observed changes for the individual component items of the Barthel should also be reported.</p> <p>While cross-sectional indicators can provide some indication of rehabilitative success, longitudinal measures allow a better assessment of the benefits of rehabilitation as they take into account the severity of disability at the outset of rehabilitation. The comments on the selection of the Barthel Index, given in the rationale of Indicator 14, apply here also.</p>
Potential uses	Comparisons between different rehabilitation programmes; evaluation of rehabilitation programmes.
Potential users	Clinicians, commissioners, and provider management.
Possible confounders	Comparisons between populations should be made in the context of case-mix information covering severity and co-morbidity.
Data sources	<p>The indicator relies on the assessment of the Barthel Index score at discharge (see Indicator 14) and a further assessment at six months after discharge. Denominator data to identify your patient group would be available from the CMDS for the relevant year (ICD-10 codes I61, I62, I63, I64 as listed in Indicator 1A).</p> <p>This indicator requires follow-up at six months after discharge, which is feasible using similar methods to those described for Indicators 15-19. An alternative to additional data collection may be to use data from Indicator 15, identifying from the stroke patient population those who had been admitted to hospital as a result of their stroke.</p>

Data quality	The Barthel Index has been shown to be reliable with different observers in a wide variety of situations (Gompertz et al. 1993), and it is a valid measure of physical disability (Wade and Hewer 1987). The Barthel Index has been successfully used within a postal survey, achieving good response rates (Gompertz et al. 1995; Harwood et al. 1994b). The value of the indicator would be compromised by low rates of completion - a danger where the data are not derived from information systems which support operational activities.
Comments	Such a longitudinal indicator may also be used for those patients who were not admitted as a result of their stroke if it is possible to record the Barthel scores at an appropriate time in the community setting.
Further work required	None recommended.
Conclusion & priority	D - To be implemented where local circumstances allow by periodic survey.
References	<p>Gompertz, P., Pound, P., and Ebrahim, S. (1993). The reliability of stroke outcome measures. <i>Clinical Rehabilitation</i>, 7, 290-296.</p> <p>Gompertz, P., Pound, P., Briffa, J., and Ebrahim, S. (1995). How useful are non-random comparisons of outcomes and quality of care in purchasing hospital stroke services? <i>Age and Ageing</i>, 24, 137-141.</p> <p>Harwood, R.H., Gompertz, P., and Ebrahim, S. (1994b). Handicap one year after a stroke: validity of a new scale. <i>Journal of Neurology, Neurosurgery and Psychiatry</i>, 57, 825-829.</p> <p>Wade, D.T., and Hewer, R.L. (1987). Functional abilities after stroke: measurement, natural history and prognosis. <i>Journal of Neurological and Neurosurgical Psychiatry</i>, 50, 177-182.</p>

Candidate indicator 21A

Characteristics
<i>Specificity:</i> Condition-specific
<i>Perspective:</i> Patient
<i>Timeframe:</i> Cross-sectional
<i>Outcome relationship:</i> Direct

Title	Percentage of people admitted with a primary diagnosis of stroke who return to their pre-admission category of accommodation on discharge from hospital
Intervention aim	Improve function and well-being after stroke.
Definition	For a hospital provider unit, and year: <i>the number of patients admitted with a primary diagnosis of stroke in the given year, who are discharged to their pre-admission category of accommodation, divided by the total number of admissions with a primary diagnosis of stroke within the given unit and year.</i> This fraction, expressed as a percentage, should be reported with its numerator both as an overall figure and by patient age-group and sex. The indicator should also be accompanied by the frequency distribution of both the admission source and the discharge destination.
Rationale	A return home following stroke is assumed to be a successful outcome of rehabilitation, that reflects the level of dependency following rehabilitation (Indredavik et al. 1991). This indicator focuses on those patients who were admitted to hospital as a result of their stroke and are well enough to return to similar accommodation following their hospital care.
Potential uses	Clinical audit; provider based comparisons.
Potential users	Clinicians, provider management, commissioners.
Possible confounders	Comparisons should be made in the context of information on the relative severities of the patient populations. A Barthel Index score may be useful in this role. It is recognised that some changes of address will not reflect an increased dependency following stroke. The occurrence of irrelevant moves may vary between populations as a function of, for example, socio-economic factors.
Data sources	The denominator may be obtained from CMDS in-patient episode data with a primary diagnosis of stroke (ICD-10 codes I61, I62, I63, I64 as listed in Indicator 1A) and an admission date in the given year. The numerator, also available from the provider unit CMDS, will be those cases whose 'source of admission' and 'discharge destination' match. Possible categories of accommodation coded by the CMDS are for example, 19 - usual place of residence, 54 - NHS run nursing home, residential home or group home, 65 - local authority Part 3 residential care home, 85 - non-NHS (other than local authority) run residential care.
Data quality	The validity of the indicator will depend on the quality of the CMDS diagnoses which are unlikely to be uniformly high.
Comments	A limitation of this indicator is that it does not distinguish between warded and unwarded accommodation.

Further work required	None recommended.
Conclusion & priority	A - To be implemented generally on a routine basis.
References	Indredavik, B., Bakke, F., Solberg, R., Rokseth, R., Haaheim, L., and Hilme I. (1991). Benefit of a stroke unit: a randomised controlled trial. <i>Stroke</i> , 10 , 5-8.

Candidate indicator 21B

Characteristics

Specificity: Condition-specific

Perspective: Patient

Timeframe: Cross-sectional

Outcome relationship: Direct

Title	Percentage of people admitted with a primary diagnosis of stroke who are living in their pre-admission category of accommodation six months following admission to hospital
Intervention aim	Improve function and well-being after stroke.
Definition	For a provider unit, and year: <i>the number of patients admitted with a primary diagnosis of stroke who six months following their admission are in their pre-admission category of accommodation divided by the total number of admissions with a primary diagnosis of stroke within the given unit and year.</i> This fraction, expressed as a percentage, should be reported with its numerator both as an overall figure and by patient age-group and sex.
Rationale	A return home following stroke is assumed to be a successful outcome of rehabilitation, that reflects the level of dependency following rehabilitation (Indredavik et al. 1991). This indicator focuses on those patients who were admitted to hospital as a result of their stroke. Indicator 21C provides comparable figures for those strokes which were not hospitalised.
Potential uses	Clinical audit; provider based comparisons.
Potential users	Clinicians, provider management, commissioners.
Possible confounders	Comparisons should be made in the context of information on the relative severities of the patient populations. A Barthel Index score may be useful in this role. It is recognised that some changes of address will not reflect an increased dependency following stroke. The occurrence of irrelevant moves may vary between populations, as a function of, for example, socio-economic factors.
Data sources	The denominator may be obtained from CMDS data with a primary diagnosis of stroke (ICD-10 codes I61, I62, I63, I64 as listed in indicator 1A), admission source data, e.g. 19 - usual place of residence, 54 - NHS run nursing home, residential home or group home, 65 - local authority Part 3 residential care home, 85 - non-NHS (other than local authority) run residential care, and the admission date. The numerator would need to be obtained from GP records indicating the residential category six months after the stroke to identify if it is different to the pre-admission category. A range of Read codes exist to code such categories of accommodation, e.g. lives in a nursing home (13F61), lives in an old peoples home (13F72) (NHS Centre for Coding and Classification 1996). Where a GP register is capable of identifying admissions to hospital with a diagnosis of stroke, it could act as an alternative source for denominator data. The availability of such records is more likely if the GP holds a stroke register. Prior to October 1st 1996, a stroke register was required as part of the GMS health promotion programme (GMS 1993). In

1995, 95% of doctors were running this programme (Department of Health 1996). For computerised systems and if using denominator data obtained from CMDS data, record linkage via the NHS number would be required.

Data quality

The validity of the indicator will depend on the quality of the CMDS diagnoses which are unlikely to be uniformly high. Deriving the denominator from GP data may be hampered by incomplete recording of admissions for stroke, although a dedicated stroke register may reduce this likelihood. The value of the indicator would be compromised by low rates of completion - a danger where the data are not derived from information systems which support operational activities.

Comments

A limitation of this indicator is that it does not distinguish between warded and unwarded accommodation. Lengths of stay may be useful additional information in the interpretation of this indicator.

Further work required

None recommended.

Conclusion & priority

B - To be implemented generally by periodic survey.

References

Department of Health (1996). *Statistical Bulletin: statistics for general medical practitioners in England: 1985-1995*. Department of Health, London.

General Medical Services Committee (GMS) (1993). *The new health promotion package*. BMA, London.

Indredavik, B., Bakke, F., Solberg, R., Rokseth, R., Haaheim, L., and Hilme I. (1991). Benefit of a stroke unit: a randomised controlled trial. *Stroke*, **10**, 5-8

NHS Centre for Coding and Classification (1996). *The Read Codes October 1996 Demonstrators*. NHS Executive, Leeds.

Candidate indicator 21C

Characteristics

Specificity: Condition-specific

Perspective: Patient

Timeframe: Cross-sectional

Outcome relationship: Direct

Title	Percentage of people with a diagnosis of stroke who were not hospitalised and are living at their pre-stroke category of accommodation six months after the stroke
Intervention aim	Improve function and well-being after stroke.
Definition	For a given GP and year: <i>the number of patients registered as having had a non-hospitalised stroke in the given year who are living at their pre-stroke category of accommodation six months after their stroke, divided by the total number of patients registered as having had a non-hospitalised stroke within the given year.</i> This fraction, expressed as a percentage, should be reported with its numerator both as an overall figure and by patient age-group and sex.
Rationale	See Indicator 21B. Unlike 21B, this indicator looks at only those cases of stroke which did not involve an admission to hospital.
Potential uses	Local audit; comparisons between different rehabilitation programmes; evaluation of rehabilitation programmes.
Potential users	Clinicians, provider management, commissioners.
Possible confounders	Comparisons should be made in the context of information on the relative severities of the patient populations. It is recognised that some changes of address will not reflect an increased dependency following stroke. The occurrence of irrelevant moves may vary between populations, as a function of, for example, socio-economic factors.
Data sources	Both numerator and denominator data would be obtained from GP records identifying any change in category of accommodation since the stroke incident. The availability of such records is more likely if the GP holds a stroke register. Prior to October 1st 1996, a stroke register was required as part of the GMSC health promotion programme (GMSC 1993). In 1995, 95% of doctors were running this programme (Department of Health 1996). A range of Read codes exist to identify both stroke diagnoses, accommodation status (see indicator 20B) and discharged from hospital (8HE.) (NHS Centre for Coding and Classification 1996).
Data quality	The validity of the indicator will depend on the quality of the GP records which is unlikely to be uniformly high. A dedicated stroke register may provide better data and 95% of practices were running the GMSC programme in October 1995 (Department of Health 1996). The value of the indicator would be compromised by low rates of completion - a danger where the data are not derived from information systems which support operational activities.
Comments	No specific points.

Further work required	None recommended.
Conclusion & priority	D - To be implemented where local circumstances allow by a periodic survey.
References	<p>Department of Health (1996). <i>Statistical Bulletin: statistics for general medical practitioners in England: 1985-1995</i>. Department of Health, London.</p> <p>General Services Medical Committee (GMS). (1993). <i>The new health promotion package</i>. BMA, London.</p> <p>NHS Centre for Coding and Classification (1996). <i>The Read Codes October 1996 Demonstrators</i>. NHS Executive, Leeds.</p>

Candidate indicator 22

Characteristics

Specificity: Condition-specific

Perspective: Patient/carer

Timeframe: Cross-sectional

Outcome relationship: Indirect

Title	Summary of a measure of patients' or carers' knowledge of available health and social services, six months after stroke
Intervention aim	Improve function and well-being after stroke.
Definition	For a GP population of patients having had a stroke in a given year: <i>a summary of patients' (or carers') responses to a questionnaire measuring patient knowledge/awareness of available health and social services for stroke (to be specified), administered six months after the stroke.</i> The summary statistics (which have not been specified), will describe the distribution of scores from the instrument, broken down by patient age-group and sex.
Rationale	Following a stroke, patients are likely to need significant input from health and social services during the immediate rehabilitation period. However, a significant number will also need continued support over a much longer period, and often for the rest of their lives. A range of services may be available, for example home help, social worker, a continence service, a laundry service, and financial support. The level of awareness of different stroke services among individuals who had a stroke six months previously, will in part, reflect whether the range of services were offered and an appropriate needs assessments for individual care packages undertaken.
Potential uses	Clinical audit; trends over time.
Potential users	Clinicians; provider management, commissioners.
Possible confounders	It is recognised that different configurations of services are available in different places and it is therefore recommended that any data collection methods should reflect local service provision (see for example, Philp and Young 1988).
Data sources	No existing measures to support this indicator were identified. Specification of a suitable data collection method will have to consider the role of carers as informants, in those cases where direct data collection is impractical.
Data quality	No particular points.
Comments	No specific points.
Further work required	Development and testing of appropriate data collection methods.
Conclusion & priority	E - To be further developed because the indicator specification is incomplete, in that further work is needed to identify a measurement tool.

References

Philp, I., and Young, J. (1988). Audit of support given to lay carers of the demented elderly by a primary care team. *Journal of the Royal College of General Practitioners*, **38**, 153-155.

Candidate indicator 23

Characteristics

Specificity: Condition-specific

Perspective: Patient

Timeframe: Cross-sectional

Outcome relationship: Direct

Title	Summary of a measure of patient satisfaction within a population six months after stroke
Intervention aim	Improve function and well-being after stroke.
Definition	For a GP population of patients having had a stroke in a given year: <i>a summary of patients' responses to a questionnaire measuring satisfaction with in-patient care and/or community care (to be specified) administered six months after the stroke.</i> The summary statistics (which have not been specified), will describe the distribution of scores from the instrument, broken down by patient age-group and sex.
Rationale	While satisfaction is itself a desirable outcome, there is also evidence that care which is less satisfactory to the patient is also less effective (Kaplan et al. 1989). It has also been shown that patients' reported levels of satisfaction can reflect doctor's technical competence as judged by independent, professional assessors (Dimmatteo and Hays 1980). In 1988, the King's Fund Consensus Statement (1988) on the treatment of stroke recommended the involvement of stroke patients and their carers in the setting and subsequent monitoring of standards with a view to improving stroke care.
Potential uses	Clinical audit; trends over time.
Potential users	Clinicians, provider management, commissioners, public.
Possible confounders	A range of social and demographic variables have been shown to be confounders which influence patient satisfaction (Fitzpatrick 1990). As a minimum, comparative analyses of satisfaction would be informed by knowledge of the age/sex of patients at different units.
Data sources	Two promising instruments were identified which are validated specifically for the evaluation of patient satisfaction in patients following a stroke (Wellwood et al. 1995b; Pound et al. 1994). The London Stroke Satisfaction Score (Pound et al. 1994) has also been used as part of a postal survey at six months (Gompertz et al. 1995). Both the instruments were developed specifically for in-patient hospital care. Further work is needed to develop an appropriate assessment tool for the community aspects of stroke care.
Data quality	There is a potential for bias resulting from the selecting out of patients unable to participate in the survey, the influence of the presence of carers or patients at the time of participation and the lack of a well established, valid and reliable measure of satisfaction (Wellwood et al. 1995b).
Comments	Needs validation against objective measures of quality.

Further work required	Selection of a generic measure, or development of condition specific questionnaire, on the basis of pilot data collection experience with stroke patients.
Conclusion & priority	E - To be further developed because the indicator specification is incomplete, in that further work is needed to identify a measurement tool.
References	<p>Dimatteo, M.R., and Hays, R. (1980). The significance of patients' perceptions of physician conduct: a study of patient satisfaction in a family practice centre. <i>Journal of Community Health</i>, 6, 18-34.</p> <p>Fitzpatrick, R. (1990). Measurement of patient satisfaction. In <i>Measuring the outcomes of medical care</i>, (ed. A. Hopkins, D. Costain). Royal College of Physicians, London.</p> <p>Gompertz, P., Pound, P., Briffa, J., and Ebrahim, E. (1995). How useful are non-random comparisons of outcomes and quality of care in purchasing hospital stroke services. <i>Age and Ageing</i>, 24, 137-141.</p> <p>Kaplan, S., Greenfield, S., and Ware, J. (1989). Assessing the effects of physician-patient interactions on the outcomes of chronic disease. <i>Medical Care</i>, 27, S110-S127.</p> <p>King's Fund Consensus Statement (1988). Treatment of stroke. <i>British Medical Journal</i>, 297, 126-128.</p> <p>Pound, P., Gompertz, P., and Ebrahim, S. (1994). Patient satisfaction with stroke services. <i>Clinical Rehabilitation</i>, 8, 7-17.</p> <p>Wellwood, I., Dennis, M.S., and Warlow, C.P. (1995b). Patients' and carers' satisfaction with acute stroke management. <i>Age and Ageing</i>, 24, 519-524.</p>

Candidate indicator 24

<p>Characteristics <i>Specificity:</i> Condition-specific <i>Perspective:</i> Carer <i>Timeframe:</i> Cross-sectional <i>Outcome relationship:</i> Direct</p>
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Title	Assessment of carer burden, six months after stroke
Intervention aim	Support carers.
Definition	<p>Three alternative approaches to the assessment of carer burden were considered.</p> <p>1. One approach is to undertake an assessment across the various causative factors thought to underlie carer burden; see Appendix F (F35-59) of this report. The seven dimensions of carer burden identified are:</p> <ul style="list-style-type: none"> - information and skills - depression, anxiety and stress - satisfaction with care and with caring - social support and networks - services - financial outcome - physical health status. <p>2. A second method is to undertake a more direct assessment of the burden or stress of caring by using a questionnaire based index. A number of such measures exist, such as the Care-Giver Strain Index (Robinson 1983) and the Relatives' Stress Score (Greene et al. 1982). These instruments are also discussed in Appendix F. Other simpler tools exist which assess carer burden, such as the Critical Interval method of assessing need, where the carer indicates the length of time a person can be left without needing attention (Issacs and Neville 1976).</p> <p>3. Thirdly, an alternative option would be to augment the postal assessment of disability (see Indicator 15). Each item of the functional ability assessment would be extended with an additional question. For example, for "Do you climb stairs?" the additional question "If you cannot, who is there to help you?" would be added. In order to get the carer's perspective, this may be used in addition to a carer burden assessment tool.</p> <p>Whichever method or approach is used, it will be necessary to define the carer population. Some definitions of carers are available from the literature, for example, a 'carer' may be defined as either:</p> <p>Anyone who looks after or cares for a handicapped person to any extent in their own home or elsewhere (Equal Opportunities Commission 1982).</p> <p>OR</p> <p>A person looking after or providing some form of regular service for a sick, handicapped or elderly person living in their own or another household (Green 1988).</p> <p>However, such definitions may be difficult to operationalise.</p>

Rationale	<p>Carer burden is multidimensional incorporating issues of support, help, protection, and social dynamics as well as the physical and behavioural aspects (Quereshi 1986, Pearlin et al. 1990). More recently the burden upon carers has to some extent been acknowledged with the introduction of the Carers Act 1996. A population of 250,000 people will have about 1,500 survivors of stroke living in the community with over half being dependent in at least one activity of daily living (Langton-Hewer 1990). Substantial numbers of people care for stroke patients nationally. Assessments of burden may provide useful information to identify the needs of the carer and the person being cared for, assess the adequacy of existing services or the impact of specific interventions which aim to reduce carer burden.</p>
Potential uses	<p>Clinical audit; trends over time.</p>
Potential users	<p>Providers, clinicians, commissioners, public.</p>
Possible confounders	<p>Carers' perception of burden may be related to their own physical, social and mental state as well as other factors. It is suggested that a more general assessment using a multi-factorial assessment instrument such as the General Health Questionnaire (Goldberg 1972) may be appropriate in addition to a specific assessment of burden (Philp 1994).</p>
Data sources	<p>Currently, little information is documented about carers on a routine basis. New data sources would be required to collect relevant data. If the carer were to be the source of the information, a self-administered questionnaire may be suitable. Personal or telephone interviews may be a preferred alternative. It is unlikely that information is readily available in a standard form and direct communication with the carer may be the more reliable source, despite the inherent bias and interpretation issues.</p> <p>If postal questionnaires are used these could be distributed six months after a stroke from the general practice. Such a task would be facilitated if the practice maintained a stroke register. However, even where stroke sufferers have been identified, identification of an associated carer may not be straightforward and an incomplete survey may be inevitable.</p> <p>While some of the practical difficulties of data collection can be addressed, it must be recognised that carer burden is a particularly sensitive issue. Individuals receiving questionnaires may not identify themselves as a carer or may feel uncomfortable about the care of a loved one being addressed in terms of burden or strain. Equally some carers may not be in sympathy with the person for whom they are caring, as they are often forced into the role. Additionally, routine measurement of burden may raise expectations of additional assistance under circumstances that may not be met.</p>

Data quality	<p>The quality of the data would depend on the source. Any questionnaires designed and developed to be completed by the carer would need field testing for validity and reliability. Alternative systems for capturing this information either within a hospital or general practice would also need evaluation to determine the nature of the data and the likely availability.</p> <p>Both the Care-Giver Strain Index and Relatives' Stress Score have been used in several research studies and are brief, and found to be practical. The Care-Giver Strain Index has been used and was developed to detect strain among carers of physically-impaired elderly people living at home in the United States. Encouraging results with respect to validity and reliability have been obtained in this population. The Relatives' Stress Score was developed to assess the amount of stress and upset experienced by relatives as a result of caring for an elderly mentally impaired person living at home. Both scales, although requiring further testing in stroke populations with higher physical needs, are judged as valuable instruments which could be incorporated into clinical practice (Philp 1994).</p>
Comments	<p>In some cases where a carer's perception of burden is influenced by her own physical health, mental health and morale a more general assessment has been suggested as appropriate, using a multi-factorial assessment instrument such as the General Health Questionnaire (Goldberg 1972).</p>
Further work required	<p>Further research is required before any recommendations can be made regarding the capture of information about carer burden in relation to stroke. In particular, further consideration should be given to the possibility of augmenting the disability assessment as noted above.</p>
Conclusion & priority	<p>E - To be further developed because the indicator specification is incomplete in that further work is needed to identify a measurement tool.</p>
References	<p>Equal Opportunities Commission (1982). <i>Who cares for the carers: opportunities for those caring for the elderly and handicapped</i>. Equal Opportunities Commission, Manchester.</p> <p>Green, H. (1988). Informal Carers. <i>General Household Survey 1985 series. GHS No15, Supplement 16</i>. HMSO, London.</p> <p>Greene, J.G., Smith, R., Gardiner, M., and Timbury G.C. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: a factor analytic study. <i>Age and Ageing</i>, 11, 121-126.</p> <p>Goldberg, D.P. (1972). <i>The detection of psychiatric illness by questionnaire</i>. Oxford University Press.</p>

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5. RECOMMENDATIONS

To be implemented generally on a routine basis

- 5.1** It is **recommended** that the following indicators be implemented generally on a routine basis (the numbers for the indicators refer to those used in Section 4):
- 1A: incidence of hospitalised stroke**
 - 2: percentage of general practice patients who have had their blood pressure recorded in the previous five years**
 - 7A: case-fatality rate within 30 days of a hospital admission for stroke**
 - 8: population-based mortality rates**
 - 10: incidence of pressure sores during the in-patient stay within a provider unit population with a primary diagnosis of stroke**
 - 14: distribution of the Barthel Index of Activities of Daily Living, at discharge from hospital, within a provider unit population with a primary diagnosis of stroke**
 - 21A: percentage of people admitted with a primary diagnosis of stroke who return to their pre-admission category of accommodation on discharge from hospital.**
- 5.2** Data on **hospitalised stroke** are routinely collected and can be used now to calculate incidence rates of strokes requiring hospital admission. They can be used within a district or region to show trends over time and provide information for service planning.
- 5.3** The percentage of patients in a general practice who have had their **blood pressure recorded in the previous five years** will indicate the extent to which general practitioners use opportunities for prevention of stroke in their patients by measuring blood pressure. Where the percentage is low, the indicator would show geographical areas where more attention could be given to stroke prevention.
- 5.4** The **case-fatality rate** of hospitalised patients within 30 days of a stroke may reflect the quality of care given to patients but will also be influenced by case mix. The proposed measure is that of 30 day case-fatality including patients who die after discharge from the first admission episode. This would require linkage to death certificates. Without linkage, case-fatality rates could be calculated using currently available data for those deaths which occur in the hospital admission for the stroke.
- 5.5** The population based **mortality rate** reflects in part the failure to prevent stroke and in part the adverse outcome of the occurrence of stroke. It can be used to study the trends nationally and locally. This rate is already being monitored as part of the Health of the Nation targets. Its reliability depends on the accuracy of death certification for stroke.

- 5.6** The acquisition of **pressure sores in hospital** is an indicator of care although it may be influenced by factors preceding admission. Length of stay (the period of time at risk) may need to be considered when looking at hospital-acquired pressure sores, but they should be avoidable even in long-stay patients. The ICD-10 code does not allow pressure sores present on admission to be distinguished from those acquired in hospital. The Group recommend that the diagnostic code be subdivided to distinguish pressure sores present on admission to hospital from those acquired in hospital. The Read code does distinguish these and could be used. For pressure sores present on admission it would be helpful to code whether they improved, deteriorated or remained the same while in hospital.
- 5.7** The distribution of the **Barthel Index of Activities of Daily Living at discharge** from hospital is useful in clinical audit. We also recommend its use for monitoring trends over time and geographical variation on a large population level. It is a reflection both of case-mix and of the effectiveness of the hospital care and it should be used with caution, if at all, as an outcome indicator for comparison of provider units. However, it would be a valuable measure of case-mix to use in interpreting other indicators and as a baseline measurement to compare with the Barthel Index at six months.
- 5.8** **Discharge of patients to their previous accommodation** is an indication of successful rehabilitation but is also dependent on case-mix. Destination at discharge is more easily collected than that several months after discharge as it does not require linking of records. This information is available and could be analysed at little additional expense. The percentage of patients returned to their pre-admission category of accommodation at six months is a more useful figure as some patients are discharged to another unit for rehabilitation but it is less readily collected.

To be implemented generally by periodic survey.

- 5.9** It is **recommended** that the following indicators be implemented generally by periodic survey:
- 3: median and inter-quartile range of systolic blood pressure within a general practice population**
 - 5: percentage of patients within a general practice population who have a prescription for aspirin therapy at six months after stroke (without proven haemorrhage)**
 - 11B: percentage of patients in a nursing home population who, six months following a stroke, have one or more pressure sores**

- 13: multi-professional involvement in the week following admission within a provider unit population admitted with a primary diagnosis of stroke**
- 15: distribution of the Barthel Index of Activities of Daily Living (ADL), within a population of patients six months following stroke**
- 21B: percentage of people admitted with a primary diagnosis of stroke who are living in their pre-admission category of accommodation six months following admission to hospital.**

5.10 A measure of the **distribution of systolic blood pressure** in a general practice population is useful for monitoring changes over time. This indicator relates to the Health of the Nation target of reducing the population blood pressure.

5.11 The percentage of patients receiving a **prescription for aspirin therapy** at six months after a stroke (without proven haemorrhage) is a process indicator of the quality of care they are receiving. It may reflect either hospital or GP care as GPs may be reluctant to initiate aspirin therapy if a patient is discharged without it. We acknowledge that there is no way of readily assessing if the patients are complying with the therapy.

5.12 Patients with reduced mobility are at increased risk of **pressure sores**. Preventing the development of pressure sores in patients following a stroke, in long-term care, is in part a reflection of the standard of care they are receiving. This information could be collected as part of the annual inspection of nursing homes and residential homes and used to monitor different providers of such care.

5.13 Co-ordinated care of patients with stroke should be started soon after admission to hospital so as to obtain the best outcome. **Multi-professional involvement** is a proxy measure of co-ordinated care and is taken to reflect the standard of care patients receive. It may be useful locally to validate the measure on a sample basis to ensure that recorded involvement reflects true co-ordination.

5.14 The distribution of the **Barthel Index Activities of Daily Living (ADL) scores at six months after a stroke** shows the range of outcomes in the population. The population in our recommended indicator includes both those admitted to hospital and those cared for in the community and is therefore not directly comparable with the ADL scores at discharge from hospital.

5.15 For many patients successful rehabilitation should result in their living in their **pre-admission category of accommodation six months following admission**. This aim may be influenced by the availability of home support and/or lack of preferred alternative accommodation. It should be considered with other indicators assessing avoidance of complications and of improved function following stroke.

To be implemented where local circumstances allow on a routine basis

5.16 It is **recommended** that the following indicators be implemented where local circumstances allow on a routine basis:

1B: population-based incidence of stroke

4: percentage of general practice patients, identified as hypertensive, whose most recent systolic blood pressure measurement is less than 160 mm Hg

7B: case-fatality rate within 30 days of a stroke (in-patient or community-based treatment).

5.17 The **population-based incidence of stroke** is important in measuring the true incidence of the condition, to assess trends, review the effects of interventions and plan services. However, the data are not readily available. They could be collected from GP computer systems or from a well maintained community based stroke register. The latter requires resources and local commitment. It would be preferable to focus resources on a few well organised stroke registers, as example populations, rather than to seek population based data more widely if data are of doubtful quality in the absence of stroke registers.

5.18 The proportion of patients with diagnosed hypertension with a current **systolic blood pressure less than 160 mm Hg** gives an indication of the control of their hypertension. This can be used to assess the effectiveness of the local treatment of hypertension.

5.19 The **case-fatality rate within 30 days** for all patients with stroke gives a more reliable picture of the mortality associated with stroke than that for only those admitted to hospital. It can only be compiled where all strokes are accurately recorded and it needs identification of all deaths (e.g. by linkage of death certification medical records).

To be implemented by periodic survey where local circumstances allow

5.20 It is **recommended** that the following indicators be implemented where local circumstances allow by periodic survey:

- 6: percentage of general practice patients with a diagnosis of atrial fibrillation who have a prescription for anticoagulant therapy**
- 11A: percentage of patients within a community provider population who, six months following a stroke, have one or more pressure sores**
- 12: rate of emergency re-admissions (for any reason) within 30 days of discharge, per provider unit population with a primary diagnosis of stroke**
- 20: summary of changes in Barthel Index as measured at discharge from hospital and at six months post-stroke, within a provider unit population admitted for stroke**
- 21C: percentage of people with a diagnosis of stroke who were not hospitalised and are living at their pre-stroke category of accommodation six months after the stroke.**

5.21 Anticoagulation therapy is not of proven benefit in everyone with atrial fibrillation. Benefit depends on age and other risk factors, but the indicator would allow comparisons to be made between practices and districts, and trends over time could be monitored.

5.22 Preventing the development of **pressure sores** in patients with reduced mobility is in part a reflection of the standard of care they receive. It may also be affected by case-mix.

5.23 The rate of **emergency re-admissions within 30 days of discharge** reflects to some extent the adequacy of discharge planning and community support. Some admissions will be unavoidable but the indicator can be used to determine whether local rates are in line with those found generally. Comparisons could be made between different provider units and trends over time could be monitored.

5.24 A summary of **changes in Barthel dependency between discharge and six months after a stroke** would be an appropriate time frame for assessment of recovery. It will reflect both the quality of care received and the natural history of recovery.

5.25 The percentage of **patients who were not hospitalised and are living in their pre-stroke category of accommodation six months following admission** should indicate successful rehabilitation. It may be influenced by the availability of home support and/or lack of preferred alternative accommodation. It should be considered with other indicators assessing avoidance of complications and of improved function following stroke.

To be further developed

5.26 It is **recommended** that the following indicators require further work on the methods of measurement. If development is successful the following indicators should be implemented by periodic surveys where local circumstances allow:

- 16: assessment of aphasia within a population of patients six months following stroke**
- 17: assessment of outdoor mobility within a population of patients six months following stroke**
- 18: assessment of social functioning within a population of patients six months following stroke**
- 19: assessment of depression within a population of patients six months after a stroke.**

5.27 It is **recommended** that the following indicators require further development before implementation is considered either because the link with effectiveness is not clear, the indicator specification is incomplete, or the practical value of the indicator is uncertain:

- 9: percentage of patients within a provider unit population for whom a formal swallowing assessment was undertaken within 24 hours of a stroke**
- 22: summary of a measure of patients' or carers' knowledge of available health and social services, six months after stroke**
- 23: summary of a measure of patient satisfaction within a population, six months after a stroke**
- 24: assessment of carer burden, six months after stroke.**

5.28 Aphasia following stroke is a devastating condition. At present there is no one short, widely accepted instrument for assessing it. The extent to which this outcome can be influenced by care is uncertain.

5.29 Outdoor mobility is particularly important to those living in the community following a stroke but no instrument has been validated in stroke patients. The extent to which this outcome can be influenced by care is uncertain.

- 5.30 Social functioning** is of importance to patients who have had a stroke and would reflect the outcome of rehabilitation. No measure has been validated in this group of patients and so further work is required.
- 5.31 Depression** in patients with stroke may decrease their functional ability and may be related to their rehabilitation and social support. Further work is require to validate a measure in this group of patients.
- 5.32 Assessment of swallowing** following a stroke is important to reduce the risk of aspiration and its assessment is part of quality hospital care. This could be collected by systematic prospective recording and computerisation or by an audit of patient notes and therefore may require some additional resources to collect. The relationship between the results of the assessment and eventual outcome is not yet clear.
- 5.33** Patients and their carers need to have **knowledge of the health and social services available** if they are to gain maximum benefit from them. There are no existing measures to assess this but, if one was developed and shown to be useful, it could be used for clinical audit and the comparison of provider units.
- 5.34 Patient satisfaction with services** is important but there is no brief measure for use in day-to-day practice which has been shown to be valid and sensitive to variation in service provision.
- 5.35 Impact of care on carers** is recognised as an important problem and work on ways of measuring this for the carers of people with stroke has been the subject of research. Further work is required to develop a brief valid instrument for use in routine service settings.

Conclusions

- 5.36** As described in the indicator specifications, indicators collected routinely may be used to highlight differences:
- over time
 - between providers
 - between groups of patients.
- 5.37** The main use of such indicators is to make broad comparisons to identify significant differences or anomalies that require further detailed examination. Small differences in routine indicators may be attributable to a wide range of factors, many of which will probably not reflect differences in health outcomes which can be attributed to the process of care.

5.38 Some indicators may best be used in combination to gain additional information. For example:

- if the case-fatality rate following stroke is high the indicators relating to the 'process proxy indicators for outcome' should be examined
- if pressure sore rates are high other indicators of adverse outcome should be examined
- if the population based incidence of stroke in a particular population is high the indicators relating to prevention of first or subsequent strokes should be examined in more detail.

5.39 There are a number of indicators which are suggested based on data collection at six months after a stroke. These could be collected at a single contact at this time and would enable a fairly comprehensive assessment of the outcome of a stroke to be made. This would probably be most appropriately carried out in general practice but could be done at an out-patient visit.

APPENDIX A: BACKGROUND TO THE WORK

Summary

A1. Over the last few years a major component of the Department of Health's and NHS Executive's strategy has been to promote the development and use of measures of health outcome. In July 1993 the Central Health Outcome Unit (CHOU) was set up within the Department of Health (DoH). Commissioned by the DoH, in 1993 a feasibility study of potential outcome indicators was published by the Faculty of Public Health Medicine and a package of indicators was published by the University of Surrey for consultation. Following these two phases of development, a third phase of work was initiated by the CHOU. Its remit is to report on 'ideal' health outcome indicators.

Central Health Outcome Unit

A2. The CHOU is an internal DoH unit whose goal is 'to help secure continuing improvement in the health of the people of England through cost-effective and efficient use of resources' (Lakhani 1994). The objectives of the Unit are to:

- encourage and co-ordinate the development of health outcome assessment, particularly in respect of the development of appropriate methods, appropriate data collection systems, expertise, analytical skills, and interpretation
- encourage and support the use of health outcome assessment and information in making policy about health interventions and in the planning, delivery and monitoring of services.

A3. Several national committees have a special interest in outcomes and are kept informed of progress:

- Clinical Outcomes Group
- Public Health Network
- CMO Working Group on Information Management and Technology.

Phases 1 and 2

A4. The Faculty of Public Health Medicine was commissioned to undertake a feasibility study of potential indicators which reflect health end-points for health services and which cover topics in which health care has an important contribution to make. This work, (McColl and Gulliford 1993) was constrained in that the set of indicators were to:

- be based on reliable routinely collected data
- reflect health service interventions rather than the wider influences on health.

A5. The University of Surrey was commissioned to produce a package of comparative statistics based on the outcome measures recommended in the feasibility study. Forty indicators were chosen, 18 for maternal and child health, three for mental health and the rest for other topics in adult health. The publication (Department of Health 1993a) contained indicator definitions, maps and scatter plots showing geographical variations, and tables presenting the rates, with corresponding observed numbers and confidence intervals when appropriate.

The Phase 3 work: ideal indicators of health outcome

A6. In the third and current phase of the work on health outcomes a number of research institutions were commissioned to assist in developing a structured approach to identify indicators to cover a number of clinical topics. The prime contractor is the Unit of Health-Care Epidemiology, Department of Public Health and Primary Care, University of Oxford.

A7. The respective roles of the supporting organisations are as follows:

- Unit of Health-Care Epidemiology, University of Oxford, to provide epidemiological and managerial support to the Group and co-ordinate the input of the other agencies.
- CASPE Research, in London, to provide technical advice with regard to the indicators and their data sources, and prepare the detailed indicator specifications.
- NHS Centre for Reviews and Dissemination, University of York, to produce reviews of the literature on the effectiveness and cost-effectiveness of relevant interventions.
- UK Clearing House on Health Outcomes, Nuffield Institute of Health, University of Leeds, to provide support in identifying measures and instruments to be used for assessing outcomes.
- Royal College of Physicians' Research Unit, in London, to co-ordinate the clinical input.

- A8.** In the previous work a key criterion for selection of indicators was the requirement for the work to be based on routinely available data. This practical constraint has meant that the recommended indicators were selected and opportunistic rather than an ideal set. This inevitably led, as the DoH acknowledged, to a bias towards outcomes which may be measurable now but which may not necessarily be those which are most appropriate and most needed. The aim of the third phase is to advise on and develop 'ideal' outcome indicators without confining recommendations to data which have been routinely available in the past.
- A9.** The initial task of the third phase of the work was to select clinical topics for detailed study. In order to ensure that the work would be manageable, and that the NHS would have the capacity to absorb the output, the CHOU decided to limit the activity to five clinical topics a year.
- A10.** A workshop to initiate the work which was attended by over 70 individuals representing a wide range of interests was held in January 1995. A report of the proceedings has been published (Goldacre and Ferguson 1995). The main aims of the workshop were:
- to identify the criteria which should be used to choose clinical topics for the Phase 3 work
 - to suggest a list of potential clinical topics which workshop participants would like to be included in the Phase 3 work.

Stroke scored highly against all the criteria and appeared on all the shortlists of topics to be addressed which were developed at the workshop.

- A11.** Following further consultation within and outside the DoH, the CHOU decided in June 1995 to include the following topics in the first two years of Phase 3 work:
- Asthma
 - Breast cancer
 - Cataract
 - Diabetes mellitus
 - Fracture of neck of femur
 - Myocardial infarction
 - Pregnancy and childbirth
 - Severe mental illness
 - Stroke.

Health outcome information

A12. The Group was influenced in its work by considering the potential uses of outcome information, as follows:

- for clinical decision-making and audit of clinical work, including:
 - audit and management of health professionals' practice
 - research
- for informing decisions about the strategic and operational development of services
- for comparisons of organisations in the delivery of services which may be:
 - provider based
 - population based
- for assessing progress towards standards or targets for health outcomes, agreed nationally or locally, which may be:
 - identified from the research literature
 - set by clinical and managerial decisions.

A13. Current managerial interests which are relevant to the use of health outcome information include:

- The NHS goal 'to secure, through the resources available, the greatest improvement in the physical and mental health of people in England'
- clinical audit
- evidence-based commissioning.

A14. An important purpose of this work has been to recommend indicators which, if possible, would allow 'health gain' to be assessed alongside information used to measure health service input. Our particular focus has been to make recommendations about aggregated statistical information about people with stroke which can be used to:

- enable providers of care to review outcomes of the care of their patients
- make comparisons, where appropriate, of health outcomes against locally agreed targets and/or between different places and/or over time.

A15. The information may be obtained from continuous data collection systems but, when having continuously collected information is unnecessary, or when the cost or complexity of this is high, use should be made of sample survey techniques or periodic surveys.

A16. Health indicators are more likely to be successful if they fit naturally into the everyday work of health care professionals than when they have to be collected as a separate activity. The aim is to have indicators that are:

- *Relevant* because professionals use them everyday in treating their patients and will record them accurately.
- *Reliable* because they can be validated or cross checked from other sources.
- *Responsive* because they readily identify changes in the patient's state of health.
- *Research-based* because there is a plausible link between processes of care and outcome.

A17. In common with the approach taken to other types of indicators by the NHS, the Group recognise that useful outcome indicators should be capable of identifying circumstances worthy of investigation but that, in themselves, they may not necessarily provide answers to whether care has been 'good' or 'bad'. In particular it is recognised that there may be difficulties in drawing causal conclusions - say, that a particular aspect of care caused a particular outcome - from indicators derived from non-experimental clinical settings. Nonetheless the vast majority of clinical care is delivered in routine than experimental practice. The assessment of its outcomes entails, by definition, the use of observational rather than experimental data.

A18. To be useful, work on 'ideal' outcome aspects needs to incorporate considerations of practicability. It is a time of rapid change in information technology. What may be feasible now in some places may not be feasible everywhere. What may not be practical today may become so in a year or two.

APPENDIX B: STROKE WORKING GROUP

The Stroke Working Group

B1. The Stroke Working Group was formally constituted in December 1995 and met three times, completing its work in September 1996. The Report was completed in May 1997. The terms of reference were:

- To advise on indicators of health outcomes for the prevention, treatment and care of stroke including its effect on carers.
- To make recommendations about the practicalities of the compilation and interpretation of the indicators, and to advise if further work is needed to refine the indicators and/or make them more useful.

B2. The membership of the Working Group and the staff of the supporting organisations are shown below. The composition of the Group included the major professional and managerial groups and representatives of patients and carers involved with the care of stroke.

Chairman and members

Physicians	Anthony Rudd, St. Thomas's Hospital (Chairman) Martin Dennis, Edinburgh David Barer, Newcastle Derick Wade, Oxford
GP	Colin Waive, Durham
Nurse	Karen Waters, Manchester
Psychologist	Nadina Lincoln, Nottingham
Social worker	Bridgit Penhale, Hull
Physiotherapist	Margaret Hastings, Dumbartonshire
Occupational therapist	Caroline Hill, Southampton
Speech/language therapist	Pam Enderby, Sheffield
Researchers	Shah Ebrahim, Royal Free Hospital Ian Philp, Sheffield Wolfgang Schady, Manchester
CEOs	Neil Goodwin, Manchester Suzanne Cosgrave, Worthing
DoH	Vivien Press
Stroke Association	Sylvia McClachlan
College of Health	Marcia Kelson

Academic support and secretariat

Michael Goldacre, Alastair Mason, John Fletcher, University of Oxford
Moyra Amess, James Coles & Robert Cleary, CASPE Research, London
Anthony Hopkins & Penny Irwin, Royal College of Physicians, London
Alison Eastwood, NHS Centre for Reviews and Dissemination, University of York
Andrew Long & Gillian Fairfield, UK Clearing House on Health Outcomes,
Nuffield Institute of Health, University of Leeds.

APPENDIX C: WORK COMMISSIONED FROM NHS CENTRE FOR REVIEWS AND DISSEMINATION

Alison Eastwood, November 1995

SCOPE

C1. The Working Group commissioned two short literature reviews related to stroke effectiveness issues:

- use of computed tomography scanning in stroke
- organisation of stroke services.

COMPUTED TOMOGRAPHY SCANNING

C2. Computed tomography (CT) is of potential benefit for stroke patients in a number of different situations as shown in Exhibit C1.

EXHIBIT C1: INDICATIONS FOR CT SCANS (Sandercock et al. 1985)

To establish diagnosis:

- Differentiate 'stroke' from 'non-stroke' in patients with a poor history (dysphasia, confusion, coma) or a progressive deficit
- Identify the pathological type of stroke (intracranial haemorrhage or cerebral infarction).

To identify surgically treatable type of stroke:

- Supratentorial haematomas suitable for evacuation
- Cerebellar haematomas or infarcts, with or without obstructive hydrocephalus
- Arteriovenous malformations or aneurysms.

To exclude intracranial haemorrhage:

- Already receiving or before anti-coagulant or anti-platelet treatment
- Before angiography (for presumed ischaemic minor stroke, etc).

In spontaneous subarachnoid haemorrhage:

- Confirm presence of blood
- Localise any intracerebral haematoma
- Identify site of bleeding
- Identify source of bleeding - for example, aneurysm or arteriovenous malformation
- Identify cause of deterioration: hydrocephalus, recurrent haemorrhage, cerebral infarction secondary to vasospasm.

- C3.** It has been argued that for CT scanning to be useful, it needs to take place about 7-10 days after the onset of acute stroke (Donnan 1992; Wardlaw 1994). Subtle differences are observable within four hours but are difficult to interpret, and some infarcts pass through a period of iso-density around day three hindering CT detection (Donnan 1992). On the other hand, after longer periods haemorrhages may have resolved, thus appearing identical to infarcts (Wardlaw 1994). Scans carried out at a later stage may rarely change management of stroke (Blais 1994).
- C4.** There are some arguments as to the accuracy of CT scans, regarding false-negative readings, lesion size, timing of scan and variations in interpretation (Ebrahim 1990), but the main issue appears to be whether the routine use of CT scans in stroke is warranted. It is considered to be a safe, straightforward, repeatable, non-invasive procedure for patients (Blais 1994), with only a small radiation risk to patients (Wessex Institute of Public Health Medicine 1994). Estimates of the cost of a CT scan range from £80 (Allison 1994) to £100 (Wardlaw 1994) up to £250 (Ebrahim 1990), excluding capital investment.

Effectiveness

- C5.** Unfortunately, there is little evidence evaluating the use of CT scans in stroke. As Ebrahim (1990) noted about the possible indications: 'The currently recommended criteria for performing a CT scan are for patients with an atypical clinical course, young patients, where there is diagnostic doubt, and when anti-platelet or anti-coagulant therapy is to be started. None of these criteria are supported by evidence that they lead to benefits that outweigh costs.'
- C6.** In her review of stroke, Blais (1994) examined the literature on the use of CT scanning to confirm diagnosis and found contradictory evidence. Although some reports emphasised the importance of scanning, others questioned the cost of acquiring and maintaining equipment to give detailed images when differentiation between broad stroke causes to define appropriate therapies has not been shown to influence outcome. Studies which evaluated the benefit of CT scanning also report varying results. Sandercock and colleagues (1985) estimated that only in up to 28% of patients with a first stroke did a CT scan provide useful information. Blais also identified two studies, one of which (the SEPIVAC Project) reported a high reliability for clinical diagnosis of stroke with about 1% of cases clinically diagnosed as first-ever strokes having some other lesion on CT (Ricci et al. 1991). The second study showed no significant difference in mortality between patients given heparin with CT, confirmed cerebral infarction, and those given heparin without CT (Sandercock and Lindley 1993). She concludes that 'the proportion of stroke patients for which CT scanning may be required is unclear, the exact proportion depending to a large extent on whether clinicians plan to use anti-haemostatic agents for either acute treatment or long-term secondary prevention' (Blais 1994).

Cost-effectiveness

- C7.** The arguments for the cost-effectiveness of routine CT scanning rests on the belief that by scanning, bed days and mortality will be avoided. However, there is conflicting evidence as to whether any such beneficial effects outweigh the additional costs of introducing routine scanning.
- C8.** Ebrahim (1990) evaluated the costs and benefits of two policies. One policy involved CT scanning every patient with a stroke in the United Kingdom, the other involved giving aspirin to every stroke patient surviving the first month without using CT scanning. The second policy proves to be more attractive, both in terms of standard cost appraisal and cost per utility, as the large scanning costs are avoided and despite the increase in misdiagnosis, a proportion of the misdiagnosed patients with tumours and subdural haematomas will be diagnosed eventually without CT. He emphasises the need to evaluate the impact of CT scanning on the number of lives saved or disability prevented, as well as the proportion of altered diagnoses or patients whose management is changed. 'As a major emphasis in medicine is the art of diagnosis, it is easy to over-value the importance of altered diagnoses. CT scanning makes only a small contribution to the diagnosis of stroke from other conditions that mimic it.'
- C9.** Lees (1993) estimates that if aspirin were given indiscriminately without CT scanning, then 15% of patients would receive aspirin following haemorrhagic stroke. If aspirin increases the risk of recurrent haemorrhage by 25% in these patients, this would result in 11 unnecessary strokes per 100,000 population per year, with an average cost of 30 bed days. This would cover the cost of performing a CT scan in all patients. However, no references to the source of his estimates are given. A similar argument is provided elsewhere (Wardlaw 1994). In contrast, Allison (1994) suggests that the costs of CT scanning outweigh the benefits and advocates the continued use of selective rather than routine CT scanning in stroke patients.
- C10.** In a recent costing study (Wessex Institute of Public Health Medicine 1994), the authors concluded that there was no proof to recommend the routine use of CT scans in the management of stroke. They attempted to model different scenarios for scanning patients, and identified the need for further research to determine the effect of a number of different factors. In particular these include the increase in risk of cerebral haemorrhage from anti-platelet therapy in those patients who have had haemorrhagic stroke, and the difference in benefit of anti-platelet therapy in patients with haemorrhagic or ischaemic strokes. Until more evidence is available, they suggest the vague recommendation that CT scans should only be undertaken in patients 'in whom the diagnosis of stroke is not certain and in those patients who would benefit most from intervention with anti-platelet therapy.'

C11. Blais (1994) concludes that: 'Clinical history and examination are the most cost-effective investigations of all. Data on the cost-effectiveness of investigations, including CT scanning and its impact on management of stroke patients, are scarce.'

ORGANISATION OF STROKE SERVICES

C12. Stroke patients may be treated either in the community or in hospital. Based on studies throughout the UK from 1970 to 1990, hospital admission rates for stroke patients vary between 40% and 78% (Blais 1994). There is continued discussion about the need to admit stroke patients to hospital, but little evidence exists to aid this debate. The decision to admit will be dependent on a number of factors, including the severity of the stroke, diagnostic uncertainty, the need for acute medical treatment and the availability of home care and domiciliary rehabilitation services. The aim of this section is to assess the availability of research on the effectiveness and cost-effectiveness of differing methods of organising stroke services, both in hospital and in the community.

Hospital based stroke services

C13. In recent years, attention has been focused on the delivery of hospital based stroke services through a 'stroke unit'. In a paper describing the development of stroke units, O'Connor (1994) distinguishes between stroke intensive care units (SICUs), rehabilitation stroke units (RSUs), and comprehensive stroke units (CSUs). SICUs 'were modelled on the existing intensive care and coronary care units; therefore, as many stroke patients as possible are either admitted directly or quickly transferred to such units depending on the availability of beds'. CSUs are aimed towards rehabilitation rather than the intensive care of a SICU, although patients would be directly admitted to such units provided their condition was stable. RSUs are units where patients are transferred after the acute phase. Only those patients likely to benefit from rehabilitation will be admitted to RSUs thus excluding patients with mild stroke likely to recover without treatment and those with severe stroke. SICUs were established in the US, but have not been repeated in this country. When the first survey of stroke units was undertaken in 1984, 11 units were identified. In a survey undertaken in 1991, 42 operational stroke units were identified (excluding five in planning stage and four which were day units only) and seven units had closed. All of the 34 units that responded to the survey were RSUs and 16 units were part of another ward or unit while 18 were administratively separate discrete units.

- C14.** Ebrahim (1990) notes that plans to develop stroke units were proposed in 1974 by the Royal College of Physicians, but that stroke units have not been universally established and provide only a fraction of stroke care. However, they have become a main thrust of research, although their 'contribution to improved standards of care for stroke patients is not assessed in any of the trials established to measure their effects.'
- C15.** Wade (1994) considered the organisation of services, identifying the difficulty in disentangling "...the effects of a different organisation from the effects of different types or amounts of treatment. A further problem is the absence of any agreement about the meanings of words such as 'stroke unit', 'stroke ward', and 'stroke team'."
- C16.** In evaluations of stroke services, there is no clear definition of a stroke unit as Blais (1994) noted : 'The definition of a stroke unit ranges from a specialised multidisciplinary team who provide services wherever a patient is situated to a geographically defined ward of variable size (10-20 beds) on which care is provided by a mobile stroke team. Some stroke units care only for patients in the early stage after a stroke whereas others only accept patients for rehabilitation. Such models neglect patients who are not admitted to hospital. A multidisciplinary approach and a well-organised mode of delivery of services are common features of stroke units.'
- C17.** In the Cochrane Collaboration systematic review of stroke units (Stroke Unit Trialists' Collaboration 1995), the definition developed by Garraway (1985) is used: 'a multidisciplinary team of specialists who are knowledgeable about the care of the stroke patient and provide care for such patients'. These criteria are applied to either a mobile stroke team or a geographically defined stroke ward.
- C18.** Six reviews have looked at stroke unit evaluations. Ebrahim (1990) identified four trials evaluating stroke units in comparison with usual medical ward care. He combined the studies and found that stroke unit care produced a 1.6 times better early outcome than medical unit care. Late outcomes were also improved in stroke units, but the result was not statistically significant, probably due to the small sample size of most trials. The author notes that 'stroke units may have only a limited impact on motor impairment and disability, the bulk of improvement being due to spontaneous recovery, but might be expected to have a major effect on handicap, quality of life of partner and family, and adjustment to disability. No recent studies have examined such possibilities'. Ebrahim (1990) also noted that 'the educational and research benefits of stroke units have not received any formal evaluation'.

- C19.** Langhorne et al. (1993) undertook a meta-analysis of 10 randomised controlled trials (1586 patients) treated in stroke units or general wards. They found a 28% reduction in mortality within the first four months which persisted to 12 months, and concluded that the management of patients in a stroke unit is associated with a reduction in mortality. This was not accompanied by an increase in morbidity, but analysis of functional outcomes was limited by the lack of consistent data between studies.
- C20.** This review has subsequently been expanded by a systematic review of specialist multidisciplinary team care for stroke inpatients (Stroke Unit Trialists' Collaboration 1995). Twelve published and six unpublished randomised controlled trials were identified which compared a treatment group receiving specialist care compared with controls receiving routine care in general wards. Specialist in-patient care was associated with a reduction in both the odds of death and of poor outcome at final review compared with routine care. The authors concluded that stroke patients managed within specialist units compared to general medical wards are more likely to be alive and living at home a year after stroke. There is no evidence that stroke unit care increases the time spent in hospital.
- C21.** As part of the Stroke Unit Trialists' Collaboration, Langhorne (1995) surveyed the characteristics of the stroke units in the randomised controlled trials identified in the meta-analysis. A number of characteristics were found which were significantly more frequent in stroke units compared to general wards:
- multidisciplinary team care with regular team meetings
 - nursing expertise in rehabilitation
 - the routine participation of carers in the rehabilitation process
 - regular stroke education for both staff and carers.
- C22.** As part of an overview of stroke for Northamptonshire Health Authority, Blais (1994) evaluated models of health care for delivering stroke services. She concluded that '...Stroke units could achieve an earlier start to rehabilitation therapy, a more rapid recovery, and in some cases improve function and survival, but there is conflicting evidence about the long-term effects. No firm conclusions can be made at this stage as it is still unclear whether it is the overall organisation or certain components that improve patients' outcomes.'
- C23.** In a systematic review of the literature on stroke rehabilitation (Effective Health Care 1992), studies evaluating stroke units of various descriptions were examined. Conflicting results were found, although some studies were less reliable than others. They concluded that well organised multidisciplinary rehabilitation yields a more rapid rate of recovery, but the evidence of long-term effects is unclear.

- C24.** Wade (1994) reports on studies evaluating stroke units and wards, identifying the problems of comparability of studies and the conflicting evidence. He also examined the US literature on stroke intensive care units (SICUs), but found no evidence to justify their introduction. O'Connor (1994) describing the development of stroke units in the UK found that SICUs which evolved in the US have not been developed in this country.
- C25.** Ottenbacher and Jannell (1993) carried out a meta-analysis of 36 trials of various design (3,717 patients) evaluating the effectiveness of stroke rehabilitation programmes. They found that the average patient receiving focused stroke rehabilitation performed better than about two thirds of comparison group patients. Importantly, they also found that there was a significant interaction between research design and the blinding of outcome measures, and identified the need to ensure blind reporting of outcome measures, particularly for non-randomised comparisons. They conclude that the improvement in functional performance appeared to be related to early initiation of treatment, but not to the duration of intervention. Improvement was also associated with patient's age (with younger patients doing better than older), as well as study design (with less rigorous studies reporting greater improvement). This study highlights the need to ensure good quality research design, including blinding and outcome measurement. However, it is now problematic to consider the use of a randomised controlled trial to evaluate the effectiveness of a stroke unit against standard care, due to ethical considerations. Although there is insufficient evidence to support the widespread introduction of stroke units, there would appear to be a general consensus that an organised multidisciplinary approach to care is beneficial.
- C26.** There is little evidence on the costs of stroke units and Blais (1994) concluded that 'cost-benefit analyses of stroke units are not easy to perform and have not been done. At present, we are unable to compare the relative benefits of stroke units with other forms of care because we lack a useful common measure of health and an adequate knowledge of the costs of the services.' In his overview, Wade (1994) identifies a randomised controlled trial of a Norwegian stroke ward which was cost-effective in comparison with general medical ward care. There is also evidence that rehabilitation costs may not differ significantly for a stroke unit compared to a general medical ward (Effective Health Care 1992).

Community based services

- C27.** There are two aspects to community services, firstly the care of stroke patients in the acute phase and secondly the provision of community based rehabilitation services. For both aspects there is limited evidence on effectiveness. Blais (1994) was unable to discover any studies assessing the effectiveness of acute home care for stroke patients and their families. She

identified two randomised trials looking at domiciliary and hospital-based rehabilitation for stroke patients, which found domiciliary-based care to be as effective or lead to better functional outcome than hospital-based care. There is some evidence that community provision of rehabilitation is effective, although such provision is not necessarily associated with a reduction in hospital use, and can be an emotional burden on carers (Effective Health Care 1992). Observational studies have reported equivalent or improved physical independence for patients treated at home. However, a controlled trial evaluating additional home care services found no reduction in hospital admission rates, length of stay, or increased independence. A comparison of domiciliary care and out-patient attendance found domiciliary therapy more effective at improving mobility (Wade 1994).

C28. Blais (1994) identified two Scottish schemes co-ordinating services for discharged patients through a member of the hospital stroke team working in the community. These schemes are currently being evaluated. There are a couple of on-going randomised trials which will provide evidence on the comparison of stroke units, hospital and community stroke teams, and also on the effectiveness of normal discharge compared to community team or hospital outreach (Langhorne, personal communication).

Conclusion

C29. There is insufficient evidence to support the effectiveness of any one specific organisational method of stroke care. There is no agreed definition of a stroke unit, or what it should entail, and consequently studies evaluating specific interventions are difficult to compare in detail as the components of the interventions vary. Despite these limitations, evidence from trials suggests that 'stroke units' lead to more rapid recovery in the short-term. However, there is conflicting evidence for sustained improvement in the long-term. Early and co-ordinated rehabilitation appears to provide benefit, without necessarily increasing the amount of therapy given in total.

C30. In summary, the available evidence points towards the improved effectiveness of a co-ordinated multidisciplinary team to deliver stroke care. It is also likely that the process of setting up such co-ordinated approaches to care will require the participation of enthusiastic professionals with expertise in the area, and it may well be the presence of such individuals which will produce the greatest impact on the effectiveness of any given method of organisation.

APPENDIX D: METHODS FOR CHOOSING CANDIDATE INDICATORS

- D1.** Candidate outcome indicators were identified by the Group with the help of the following:
- the health outcome model for stroke (see Section 2)
 - various classifications of the characteristics of outcome indicators.
- D2.** The Group noted that indicators may be related to:
- i. environmental factors in the general population or relating to the individual
 - ii. knowledge, attitudes, behaviour in the general population
 - iii. knowledge, attitudes including satisfaction with service delivery, behaviour of individual patients with stroke
 - iv. patients' symptoms, function, health status, well-being
 - v. patients' clinical state
 - vi. patients' pathological/physiological state
 - vii. events occurring to patients as the endpoints of earlier occurrence of disease and/or interventions such as contacts with general practitioners, issuing of prescriptions, out-patient visits, in-patient admissions and death
 - viii. knowledge, satisfaction with services delivery, emotional and physical well-being of carers.
- D3.** The data sources for the indicator entities noted in paragraph D2 will differ. It is likely that:
- indicators for (i) and (ii) would come from population surveys
 - indicators for (iii), (iv) and (viii) would come from patients and carers either opportunistically or when specifically called
 - indicators for (v) and (vi) would come from doctors and other health professionals
 - indicators for (vii) would come from administrative information systems.
- D4.** The Group recognised the high cost and complexity of obtaining information from continuous data collection systems. Particular consideration was given to obtaining outcome indicator data from sample survey techniques such as a periodic survey when it is not essential to have continuously collected information.
- D5.** Four characteristics of an outcome indicator have been identified and each has been classified. They are:
- measurement perspective, relating to whose perspective the indicator is most relevant (see paragraph D6)
 - specificity (see paragraph D7)
 - measurement timeframe (see paragraph D8)
 - outcome relationship, in that the indicator is either a direct or an indirect, proxy measurement of outcome (see paragraph D9).

- D6.** For the Group's purposes measurement perspective was classified as that from the patient's, the carer's, the clinical, or the population's viewpoint. In the treatment of stroke, for example, a measure of quality of life may be most relevant to the patient's perspective while clinical concerns may properly focus on measures of urodynamics. The population perspective has a broader view, best addressed by measures able to assess the burden of the condition as a whole. Of course, these perspectives are not necessarily in opposition and will often be associated with shared goals. Where possible, a set of indicators should be developed which satisfies all of these measurement perspectives.
- D7.** The specificity of an indicator relates to whether it is specific or generic in application. For example, mapping of neurological impairment is specific to neurological function. The measurement of blood pressure is much less specific and would be influenced by a number of conditions. Condition-specific indicators have the advantage that their relative insensitivity to other conditions is likely to increase their sensitivity to changes in the condition of interest. Generic measures provide outcomes relevant to a wide range of conditions. A comprehensive indicator set might contain examples of both generic and specific indicators.
- D8.** The measurement timeframe relates to whether the indicator is:
- cross-sectional and thus an indicator at a single point in time for any one individual
 - a longitudinal measure of progression over time for any one individual.
- D9.** The Group's main task has been to develop direct indicators of health outcome although in many areas it may be difficult to identify or obtain such information. However, it is recognised that some care processes are so closely related to the production of benefits that the successful completion of the intervention might be used as a proxy measure of the actual outcome. In the absence of direct outcomes, proxy indicators have therefore been developed.
- D10.** There is increasing recognition of the importance of outcome measures derived from data generated by patients and carers. For the purposes of our work, three main areas of interest have been identified:
- impact of the condition on the patient and/or carer
 - satisfaction of the patient and/or carer with the care provided and/or outcomes achieved
 - awareness of the patient and/or carer of the management of the condition.

D11. The condition may impact on the patient in terms of:

- general health
- specific impairments associated with the condition
- disabilities
- handicaps.

D12. The condition may impact on carers in terms of their:

- physical health
- psychological health
- social functioning.

D13. With the assistance of the check-lists and a knowledge of the disease supplemented by commissioned work, the Group addressed the following key questions:

- What are health professionals trying to achieve for each patient?
- What can each patient realistically expect will be achieved for him/herself?
- What should be achieved for the population as a whole in respect of the prevention, care or cure of the disease?

APPENDIX E: GUIDANCE NOTES FOR INDICATOR SPECIFICATIONS

Indicator title	A short title to identify the indicator
Intervention aim	<p>Distinguishes the level of intervention for which the indicator is primarily developed. It is assumed that, for a given condition, an ideal set of indicators would be reasonably balanced across the spectrum of health intervention stages. For stroke these stages are:</p> <ul style="list-style-type: none">- reduce or avoid risk of first stroke- reduce death from stroke- reduce/avoid complications from stroke- reduce or avoid risk of subsequent stroke- improve function and well-being after stroke:<ul style="list-style-type: none">• reduce impairment• reduce disability• reduce handicap• support carers.
Characteristics	<p>Classifies the indicator on four dimensions:</p> <ul style="list-style-type: none">- Specificity: <i>condition specific or generic</i>.- Perspective: <i>population, clinical or patient</i>.- Timeframe: <i>cross-sectional</i> measure or <i>longitudinal</i> assessment of change.- Outcome relationship: whether it is a <i>direct</i> measure of outcome or an <i>indirect</i> measure of structure or process, used as a proxy for outcome.
Indicator definition	<p>In addition to a definition of the variable of interest, the description specifies:</p> <ul style="list-style-type: none">- how the variable is to be aggregated across cases, e.g. definitions of both a numerator and a denominator- if a variable is to be reported with respect to a set of denominators, e.g. mortality broken down by age and sex- if appropriate, how longitudinal change in the variable is to be represented, e.g. over what time interval and whether absolute difference or proportional change.
Rationale	<p>A brief statement of the reasons and objectives behind the indicator, both in terms of the issues it addresses and its selection from a range of potential alternatives.</p>
Stroke definition	<p>A single definition of stroke has been used as identified in paragraphs 2.1 to 2.4. Its application is affected by the rationale, location of incidence and data sources used and these factors are addressed in each indicator definition.</p>
Potential uses	<p>The following classification has been used:</p> <ul style="list-style-type: none">- local management of practice- local audit

- provider based comparisons
- population based comparisons
- assessment of regional/national trends or progress towards targets.

It is recognised that a given indicator may serve several purposes. Indicators that are valuable for the management of individual patients are likely to have practical advantages with respect to data collection in a clinical setting. However, in order for such indicators to be useful for other purposes, a method of aggregation across cases must be specified for the variable of interest.

Potential users

The following classification has been used:

- national/regional policy makers
- provider management
- commissioners
- clinicians
- consumers/public.

Possible confounders

This section has attempted to identify the population risk factors likely to influence the outcome indicator, and therefore useful in its interpretation. Where such factors are well defined and have a clear or potential association with the outcome of interest, they may be used to specify denominators to be included in the indicator definition itself.

Data sources

Where possible, existing sources of data have been identified for deriving the indicator and the degree to which complete coverage of the population of interest would be obtained has been noted. Where data are not widely available from existing systems, suggestions for new methods of data collection, capable of wide implementation have been made.

Data quality

While the theoretical capabilities of existing and proposed information systems are outlined above, the actual or expected limitations of those systems - in terms of their completeness and accuracy etc. - are noted in this section.

Comments

General comments regarding the indicator's definition, validity, practicality etc.

Further work required

Suggestions about the additional research and development work required to complete the indicator's specification to a level appropriate for large scale piloting.

Conclusions & priority

A statement indicating the Working Group's assessment of the priority for implementation.

References

Appropriate references used in the construction of the indicators.

APPENDIX F: WORK COMMISSIONED FROM UK CLEARING HOUSE ON HEALTH OUTCOMES

Gillian Fairfield and Andrew Long, May 1996

SCOPE

F1. The Working Group commissioned three short literature reviews related to stroke health outcome measures:

- overview of stroke outcome measures
- measurement of longer term outcomes of stroke
- measurement of impact of stroke on carers.

OVERVIEW OF STROKE OUTCOME MEASURES

Introduction

F2. The range of outcome measures available were identified from three main sources:

- Measurement in Neurological Rehabilitation (Wade 1992)
- Literature from UK Clearing House on Health Outcomes
- Literature searches of the Medline (1991-5) and Cinahl (1982-95) data bases searching for key words, CEREBROVASCULAR DISEASE, OUTCOMES, MEASURES, INSTRUMENTS, QUALITY OF LIFE. The search was confined to abstracts only in the English language.

F3. The review covered published literature only. It did not include measures:

- used in routine practice
- under development
- not mentioned in abstracts.

F4. The outcome measures identified were classified primarily according to the WHO model of impairment (ICIDH model) as related to:

- impairment
- disability
- handicap
- multidimensional.

F5. In addition outcomes were included which are related to:

- prognosis
- adverse reactions or complications
- patient/carer satisfaction and expectations
- clinical processes.

Available measures

- F6.** A summary of available outcome measures is shown in Exhibit F1.
- F7.** The main outcome measures used in published controlled trials of rehabilitation effectiveness are shown in Exhibit F2.
- F8.** The most commonly noted outcome measures used in research are summarised in Exhibit F3.

Summary of main points

- F9.** In reviewing the types of measures available it should be noted that:
 - measures of impairment and disability predominate as they are relatively easy to measure
 - handicap is a complex concept relevant to individuals with no absolute against which to measure
 - although disability and handicap are more relevant to outcome, measures of impairment which are usually disease specific, such as the severity of a stroke, may be required to interpret them
 - some measures of disability also measure handicap
 - proxy measures of outcome are often used but more work is needed to determine the link between process and outcome.

EXHIBIT F1 : AVAILABLE OUTCOME MEASURES

Outcome	Classification	Examples
IMPAIRMENT	Arousal	Glasgow Coma Scale
	Motor	Ashworth scale, MRC grades, Motricity Index, Motor club assessment, Fugl-Myer assessment
	Sensory	Clinical
	Cranial nerves	Swallowing, visual acuity, hemianopia
	Cognition	PASAT (attention and information processing), BIT (neglect), FAST (aphasia), PICA (communication), RPAB, RBMT (new memory), MMSE (orientation language), CAPE (orientation and learning), BDEA (communication), Weschler Adult Intelligence scale.
	Psychological	GHQ, HAD, Wakefield self assessment depression inventory, Beck inventory, Hamilton inventory
	Severity	NIH, Canadian, Orgogozo, Scandinavian stroke scales, Hemispheric scale
DISABILITY	Physical interaction (mobility and personal care)	ADL Activities of daily living (in excess of 40 identified), Barthel ADL Index, Gait speed, Functional Ambulation Categories, FAT (proximal control and dexterity), NHPT (manual dexterity)
	Psychological interaction	Hodgkinson Mental test, RBMT, FAST
	Global disability	Extended ADL e.g. Nottingham. ADL, Rivermead ADL (RMI), Frenchay Activities Index, OPCS disability scales, FIM
HANDICAP	Orientation, mobility, dependence, self sufficiency, occupation, social integration	NHP, Rankin Score, Life Satisfaction Index, FAI, Nottingham EADL, Jeffrey's measurement, Edinburgh Rehabilitation Status Scale, Functional Autonomy Measurement, London Handicap Scale, Oxford Handicap Scale, WHO handicap scales
MULTI-DIMENSIONAL	Global outcome Quality of life	NHP, Quality of life well being scale, SF-36, Life satisfaction index, HOI-Type Stroke scale, SIP
OTHER	Prognostic outcomes	Incontinence, conscious level, Allen Score
	Negative outcomes	Mortality, complications
	Patient carer satisfaction, expectations etc.	Pound questionnaire, Caregiver strain index, CHIPS, Kellner's Questionnaire
	Process (proxy) outcomes	Key worker, stroke register, re-admissions, Discharge destination, number of patients on aspirin

BDEA Boston Diagnostic Aphasia Examination
 CAPE Clifton Assessment Procedures for Elderly
 EADL Extended Activities of Daily Living
 FAST Frenchay Aphasia Screening Test
 FIM Functional Independence Measure
 HAD Hospital Anxiety and Depression Scale
 NHP Nottingham Health Profile
 PASAT Paced Auditory Serial Addition Test
 RBMT Rivermead Behavioural Memory Test
 SIP Sickness Impact Profile

BIT Behavioural Inattention Test
 CHIPS Cohen, Hoberman Inventory
 FAI Frenchay Activities Index
 FAT Frenchay Arm Test
 GHQ General Health Questionnaire
 MMSE Mini Mental State Examination
 NHPT Nine Hole Peg Test
 PICA Porch Index or Communicative Ability
 RPAB Rivermead Perceptual Assessment Battery

EXHIBIT F2 : MAIN OUTCOME MEASURES USED IN RANDOMISED CONTROLLED TRIALS OF ACUTE STROKE AND REHABILITATION UNITS (n=18).

Impairment	Disability	Handicap	Generic multi-dimensional health profiles	Other
Neuromuscular deficit (n=2) Neurological deficit score n=1 Motor function n=1 Wakefield depression inventory n=1 GHQ for carers n=2 Sensory loss n=1 Depression n=1 Dysphagia n=1 Gait speed n=1 HAD scale n=1 Functional communication profile n=2 PICA porch index of communicative ability n=3 BDEA n=1 Hodgkinsons Mental test n=1	ADL n=6 Barthel ADL n=9 Rankin disability scale n=1 FAI n=3 FAC n=2 Motor club assessment n=1 Motricity index n=2 FAT n=1 NHPT n=2 Rivermead motor assessment n=1 Rivermead mobility index n=1	NHP n=1 Rankin disability n=1 FAI n=3	NHP n=1	Discharge destination n=5 Mortality =5 Onset of therapy n=1 Complications n=1 Length of stay n=4 Follow up appointment given n=1 Use of hospital services n=1

With the exception of the BDEA and PICA the outcome measures were only used up to one year.

EXHIBIT F3 : COMMONLY USED OUTCOME MEASURES IN RESEARCH

- | | |
|---------------------------------|------------------------------|
| Mortality | Geriatric Depression Scale |
| Barthel index | Mental Test Score |
| Other ADL | Motricity Index |
| Functional Independence Measure | NIH stroke scale |
| Nottingham Health Profile | Hamilton Depression Scale |
| Rankin Scale | General Health Questionnaire |
| Frenchay Activities Index | Sickness Impact Profile |
| Scandinavian Stroke Scale | Discharge destination |

MEASUREMENT OF LONGER TERM OUTCOMES OF STROKE

F10. Stroke illustrates well the complexity of monitoring outcomes for a condition that runs a chronic course. For many patients stroke is a permanent feature of their life from which they cannot escape. 'For a patient, the most important aspect of his disease is not the grade of hemiparesis as such but his ability to perform daily activities and to fulfil social roles' (Haan et al. 1993b). Long-term outcomes of psychological well-being, quality of life and handicap must be considered. Yet there is no consensus on the best way to do this. In addition, the longer term effects of multidisciplinary rehabilitation versus medical care have not been demonstrated. Evans et al. (1995) in their meta-analysis of the long-term benefit of short term rehabilitation on survival or functional ability showed that without continuation of therapy the initial benefits of rehabilitation were not sustained.

F11. The aims of this section are to:

- clarify the nature of quality of life, long-term disability and handicap in relation to stroke
- suggest which of these areas are most relevant to measure
- outline and review the available measures
- suggest a range of possible outcome indicators for the long term outcomes of stroke.

Defining terms

F12. Within the WHO ICIDH classification, *disability* is defined as a restriction or limitation in the ability to perform a normal activity, and *handicap* as a disadvantage resulting from impairment or a disability that limits or prevents the fulfilment of a social role that is normal for that individual. Long-term disability may or may not result in handicap, depending on the formal (health and social care) and informal (carer) support available to the individual. It is not only the presence or absence of disability and/or handicap that matters, but also its magnitude and perceived significance. The latter depends on the physical, social and economic setting and available resources (Cole et al. 1995).

F13. While the notion of *health related quality of life* (HRQL) has emerged as a key concern for policy makers, health professionals and researchers, confusion remains over its definition, dimensions, ways to arrive at an overall quality of life, and its relationship with other health and life experiences (Ebrahim 1995). Patrick and Erickson's (1993) definition illustrates its possible scope: 'Health related quality of life is the value assigned to duration of life as modified by the impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy.'

F14. In this way, HRQL can be perceived as the final effect of impairment, disability and handicap, with health perceived three dimensionally as physical, social and mental well-being. Common dimensions explored include: physical functioning, psychological functioning, social interaction, sexual functioning and spiritual and economic aspects.

Deciding what to measure

F15. In considering the long-term outcomes of stroke, or indeed for any chronic condition, the question to be addressed is: is it more appropriate to measure quality of life, or handicap, or both? In addition, long-term disability, in terms of its consequences and impact on the user, can usefully be perceived as inextricably intertwined with handicap, and a necessary part of the measurement of handicap.

F16. Six basic 'survival roles' are outlined in the ICDH classification in its handicap section (Harwood et al. 1994a). These define disadvantage in terms of:

- orientation including sight, hearing and cognition
- physical independence
- mobility, the distance one can move from one's bed
- occupation including employment, house work and recreation
- social integration and economic self-sufficiency including the ability to earn an income and the possession of resources to enable problems to be overcome.

F17. These roles complement the seven dimensions for the assessment of elderly people (Royal College of Physicians and British Geriatric Society 1992), namely:

- activities of daily living
- mental health functioning
- psychological functioning
- physical health functioning
- social resources
- economic resources
- environmental resources.

All are important, related to handicap and are constituents of quality of life.

F18. There are three possible approaches to measuring long-term outcomes of stroke relating to:

- overall quality of life
- global handicap
- the individual components of handicap.

Measuring quality of life

F19. In a recent review, Gill and Feinstein (1994) identified 159 different instruments of quality of life. Despite recognition of the subjective and personal nature of quality of life, the measures had varying bases in a user's perspective. As the authors comment, quality of life can be suitably measured only by determining the opinions of users, and "supplementing or replacing the authoritative opinions contained in statistically 'approved' instruments." The schedule for the evaluation of individual quality of life (SEIQoL) (McGee et al. 1991) and the patient generated index (PGI) (Ruta et al. 1994) are examples of such an approach. An alternative, although somewhat crude and simplistic, is to ask the question: 'how would you rate your present quality of life?' (Haan et al. 1993b).

F20. Much recent interest has lain in the potential of multi-dimensional health profiles (MDHPs) such as the SF-36, the Nottingham Health Profile or the EuroQol. They are properly described as profiles in that they:

- collect information on several aspects or dimensions of health status and health related behaviour in a single instrument
- are intended to cover a range of topics which is not specific to any one patient or population group
- present the results for each aspect separately, not as some overall index of health.

F21. A list of those in common use are shown in Exhibit F4. MDHPs differ in both the dimensions they cover and the way these are defined. For example, the NHP asks people whether they have any of 38 problems, irrespective of whether or not these are due to ill-health. The SF-36 takes different approaches to different topics. While self-reported general health and mental health are measured directly, the bulk of the questionnaire is concerned with the impact of health and illness on physical function, mobility and social activities. The EuroQol is predominantly designed to return a single value for health, but can be used as a six-dimensional profile.

F22. In the context of stroke, Haan et al. (1993a) reviewed 10 'quality of life' instruments (in fact, MDHPs). They note the wide range of domains explored (a valued aspect) and the length of the instruments (a problem, raising the question of their impracticality for use within routine practice, and even within clinical trials). Furthermore, more information is needed on the responsiveness of the instruments to patient and clinically significant change over time.

**EXHIBIT F4 : MULTI-DIMENSIONAL HEALTH PROFILES:
ITEMS AND DIMENSIONS**

Name of instrument	No. of items	No. of scored dimensions
Duke - UNC Health Profile	63	4
Duke Health Profile (17 item selection from Duke-UNC Profile)	17	4 (6)
Nottingham Health Profile Part I	38	6
Sickness Impact Profile and Functional Limitations Profile (UK version of SIP)	136	12 (2)
Dartmouth Co-op Function Charts	9	9
McMaster Health Index Questionnaire	68	3
Medical Outcomes Survey (MOS) Full 149 item "Functioning and well being profile"(FWBP)	149	35 (8)
MOS FWBP - C (Condensed version of full instrument)	113	20 (4)
MOS Short Form - 36 item instrument	36	8/9
MOS Short Form - 20 item instrument	20	6
MOS Short Form - 6 item instrument	6	6
EuroQol (6 item profile)	6	5/6

Measuring global handicap

F23. Five measurement scales are available and they are shown in Exhibit F5. As Harwood et al. (1994a) comment, the SMAF approach, identifying disabilities which are not compensated for by aids or assistance, is attractive. Care must however be taken in interpreting its results across settings and populations to allow for variations in the availability, acceptability and accessibility of services to alleviate disabilities. In general, it is important to describe individuals' own situation, as they or their carers perceive it, and assess their satisfaction with this state of affairs (thus, for example, the London Handicap scale).

EXHIBIT F5 : MEASURES OF HANDICAP (Harwood et al. 1994a)

Measures	Key features
Modified Rankin scale	Derived from the Rankin disability scale; many descriptors are still of disability rather than handicap; focus on physical independence
Jeffreys measure	Used in community surveys
Functional Autonomy Measurement System (SMAF)	Estimates handicap by identifying disabilities which are not compensated for by aids or assistance
Edinburgh Rehabilitation Status scale	A measure of medico-social dysfunction; focus on dependency, activity, social integration, and effect of symptoms on lifestyle
London Handicap scale	Based on the 6 ICIDH survival roles; weightings derived from a sample and applied to the six dimensions to obtain an overall value

Measuring the individual components of handicap

F24. The individual components of handicap include:

- long-term disability
- mental health and psychological functioning
- physical functioning
- social functioning
- economic functioning and environmental support.

- F25.** Measures of disability emphasise the functional dimension of health. The Index of Independence in Activities of Daily Living (ADL), the full name of what is now commonly called Activities of Daily Living scales, and functional assessments are primary criteria used to determine eligibility for services whilst bearing little relationship to actual need.
- F26.** ADL scales have been widely reviewed and are in common use, the most frequent being the Barthel Index or derivatives. Wade and Collin (1988) found the Barthel Index to be valid, reliable, responsive to change and as good as any other single index as a measure of physical disability. However, Wellwood et al. (1995a) found that it may underestimate patient and carer problems by up to 30%. For measuring long-term disability, it is important to address not only the personal activities of daily living (washing, dressing etc.) but also the more complex activities required to live in the community (walk outdoors, cook, manage a household, do the shopping). This suggests the need to use an extended ADL scale (Gladman et al. 1993).
- F27.** Mood disorder, in particular depression, may be a specific complication of stroke (Folstein and Maiberger 1977). In the early weeks following a stroke depression may be as high as 22-27% (Robinson et al. 1983). The prevalence falls only slightly over the next six months (Robinson and Price 1982). Problems in defining depression make it difficult to identify who is depressed and depression is also under-diagnosed. Carers' mental and psychological function is related to stroke patients' mental health. Depression is also related to the patient's perception of support from key relationships.
- F28.** There are many available measures for mental health and psychological functioning. In the Perth community stroke study, the General Health Questionnaire (GHQ) was found to be the best screening instrument (Johnson and Buevill 1995). However, use of the GHQ as part of routine practice for stroke patients may be too time consuming. An alternative is to ask a single question such as 'have you felt depressed over the last two weeks?' This may provide a simple initial indicator, followed up as appropriate by use of a standardised measure.
- F29.** In addition to measuring long-term disability, it may be appropriate to assess physical functioning, building on the approach adopted in the health checks for people over 75 (Williams and Wallace 1993).
- F30.** It is well recognised that social networks have beneficial effects (Wenger 1992). There are available measures but it is unclear which parts of the network are important for the user. Access to support and services is an essential element.

F31. Receiving services and benefits that patients require and are entitled to is essential to reduce handicap and improve quality of life. No measures are available. A process measure - assessment of need for and receipt of information and services - may be used.

Case-mix confounders

F32. Care must be taken in interpreting measures and indicators on long-term disability and handicap. Possible case-mix variables include:

- initial severity following the stroke
- initial incontinence
- patient and carer attitudes and beliefs about the condition, disabilities and recovery potential
- other co-morbidities.

Conclusion

F33. Measuring the long-term outcomes of stroke in terms of quality of life, disability and handicap is a complex issue. Use of the ICIDH classification provides an appropriate way to explore and measure quality of life rather than the use of available MDHPs. Global measures of handicap may be difficult to interpret, confusing the relative importance of their individual components. Measuring each separately has the advantage of clarity. It is essential to uncover the users' and carers' perceptions and assess their satisfaction with the processes of care, information provision, services and support.

F34. Measuring long-term disability and handicap provides an indication of genuine attention to the patients' experience of illness and on how it affects their everyday activities and social role. A service focused on preventing and caring for those with long-term disability and handicap represents a service focused on long-term patient/carers outcomes.

MEASUREMENT OF IMPACT OF STROKE ON CARERS

Introduction

F35. The role of the informal carers of stroke patients is poorly recognised. At present there is no framework to assess the outcomes of caring for carers in a way that is sensitive, systematic and effective. Most importantly there is no framework in place to do anything with the information if and when it is obtained.

F36. The aims of this section are to:

- explore the nature of caring and carers
- summarise the literature on the impact on carers of caring for someone with a chronic illness, with particular reference to stroke
- suggest areas of carer outcome for closer consideration
- outline available outcome measures for assessing the impact of caring
- suggest a range of possible outcome indicators for the carers of stroke patients.

What is a carer?

F37. There are several definitions of a carer:

- 'Anyone who looks after or cares for a handicapped person to any extent in their own home or elsewhere' (Equal Opportunities Commission 1982).
- 'A person looking after or providing some form of regular service for a sick, handicapped or elderly person living in their own or another household' (Green 1988).

F38. Both the quoted definitions belie the complexity of caring. In their valuable paper Nolan et al. (1995) outline multiple definitions and models for the meaning of caring. These try to separate out the different components of caring such as issues of support, help, protection, social dynamics, the complex emotional/affective components and the physical and behavioural aspects (Quereshi 1986; Pearlin et al. 1990). What emerges is that caring comprises all of these dimensions as well as the practical day to day care giving. Attention in any measurement process should not be given solely to the physical aspects of caring at the expense of these other aspects.

F39. Bowers (1987) has proposed that caring should be purpose orientated rather than task orientated and suggested that there are five types of care:

- anticipatory care, based on anticipated future need
- preventive care, monitoring at a distance
- supervisory care, direct help with activities
- instrumental care, doing activities for the cared for
- protective care, maintaining the self esteem of the cared for person by minimising their awareness of failing abilities and maximising the extent to which they perceive themselves independent.

F40. Nolan et al. (1995) add three further types:

- preservative care, preserving the cared for persons sense of 'self'
- (re)constructive care, developing new and valued roles
- reciprocal care, receiving help from the cared for at the financial, material and psychological levels and including the satisfaction of caring.

F41. Much of a carer's role is invisible, which has implications for the latent needs and outcomes of carers. Anticipatory and preventive care do not involve direct help and as such may not come to the attention of the health and social services. However, both have a considerable effect on the carer's life. Recent research on carer stress (Nolan et al. 1994) has shown that physical caring tasks are poor predictors of carer stress, and that relationship and social issues are more important. Instrumental and supervisory care are also perceived by carers as the least stressful aspects of caring with protective care being most stressful. Any examination of the carer's perspective on outcome must therefore, recognise the different types of caring role, its (in)visibility and associated impact on the carers.

F42. The manner in which someone becomes a carer is of importance and depends on the type of illness the patient suffers. Some carers, for example those caring for the terminally ill, become carers slowly while others, as in the case of stroke, may become carers overnight with no time for preparation. With the tendency to early discharge or home care a carer may have little or no time to prepare for their new role. They may have little understanding or knowledge of the illness and their ability to assimilate information at a time of crisis is likely to be diminished. Both the ability and willingness of a carer to care is important to establish at an early stage. Carers may have to make important decisions while learning new skills and must be supported both psychologically and practically. It has been noted that professional consultation with carers is very often lacking and that the carers often lack knowledge about both the illness and services available (Norman 1987).

F43. Carers need (sufficient) information about the illness, its progress and prognosis, together with information about appropriate services and voluntary agencies. They may also need practical skills training. For example, the carer of a stroke patient may need instruction on lifting techniques, ways to communicate with the stroke patient and exercises to do with the patient. As Nolan et al. (1994) point out, establishing the ground rules from the outset should be seen as an investment in the future and adopted as minimal good practice. It must be remembered that carers needs are ongoing and continually evolving, hence their information and skill requirement must be reviewed. Whilst the emphasis of community care is on sustaining carers rather than relieving them of the caring role (Silvey 1991) carers have a right *not* to care if they so wish.

Caring for patients with stroke

- F44.** A population of 250,000 people will have about 1,500 survivors of stroke living in the community with over half being dependent in at least one activity of daily living (Langton-Hewer 1990). There are therefore substantial numbers of people caring for stroke patients nationally. These carers are likely to be elderly and have needs of their own.
- F45.** The majority of those providing care are likely to be close family. One study has shown that 66% of carers are spouses and 20% children of the stroke patient (Greveson and James 1990). A Northern Ireland study (Evason and Whittington 1993) of carers and elderly patients revealed that 91% of carers estimated their input as in excess of 50 hours per week and that the majority of care was provided by one person. In general an array of social networks and support were lacking. This study found that only 26% of carers received advice on caring while 77% received advice on services and 64% on benefits. Carers cared at the cost of loss of employment, relationships and reduced financial opportunities.
- F46.** A survey of patients and carers three years after stroke revealed that few patients and carers were in contact with hospital services (Greveson and James 1990). Thirty per cent of these carers were under strain and 50% had problems with social adjustment. Many patients were unaware of available sources of help or how to obtain advice. Few patients received advice regarding financial help. Most patients felt they were unable to assimilate information early on and many felt abandoned and would have liked a named person to provide ongoing support. Suggestions by the patients and carers involved in this survey for improved services and support after stroke included better post-discharge support (22%), more information about stroke and resources (21%), more practical help (21%), access to stroke clubs (8%) and more rehabilitation (5%).
- F47.** Similar results regarding carers' lack of awareness of services and voluntary agencies for stroke have been found in other studies (Anderson 1988). A pilot study in Birmingham showed a requirement for more information on stroke (McLean and Roper-Hall 1991). However, there is little real evidence that increasing information or input will increase the overall well-being or social functioning of carers. Provision of information in booklets has been reported to be useful but there was no measurable effect on physical or social outcome (Pain and McLellan 1990). Attendance at a day hospital or home physiotherapy in Bradford still left patients and carers emotionally distressed and socially restricted (Young and Forster 1992).
- F48.** Many carers suffer emotional stress, frustration and depression (Wade et al. 1986; Carnwath and Johnson 1987). A study of carers of stroke patients showed that increased anxiety in carers was the most commonly reported

symptom six months after stroke and significant depression was seen in 11 to 13% of carers over the first two years after stroke (Pain and McLellan 1990). This depression was only partly related to the extent of physical disability of the patient; as a carer's level of depression was related to the patient's level of depression and general activities. These findings have been confirmed by a recent study in Perth where 55% of carers showed emotional distress at one year, unrelated to patient's physical illness, but related to social functioning (Anderson et al. 1995). Increased physical illness and health problems have also been noted in carers (Williams 1993).

F49. Studies of carers' satisfaction with services have found that carers while satisfied with care in hospital were dissatisfied with services after hospital discharge (Pound et al. 1993). It has been suggested that those carers able to identify satisfactions of caring are likely to have a greater well-being (Nolan et al. 1994).

The impact of caring

F50. When considering the impact of caring for carers it is essential that all the aspects of caring are considered and that a wide definition of carer is assumed. Since caring has physical, psychological, social and economic aspects, the consequences of caring must be considered in these terms. Although the majority of work on the impact and consequence of caring on the carer has focused on negative outcomes it must be remembered that there are also positive, rewarding and satisfying outcomes to caring.

F51. There has been much work on carer burden and stress. Carer burden refers to the load or responsibilities carried, or to the time and effort required for one person to attend to the needs of another (Montgomery et al. 1985). Much of the research has taken place in the context of psychiatric illness, with increasing interest in recent years in those caring for people with physical disabilities.

F52. Burden can be thought of as encompassing the health related status and behaviour of the patient, the tasks required of the carer and the impact of these tasks on the carer's life (Poulshock and Deimling 1984). Carer burden can be divided into objective (external) burden and subjective (as experienced by the carer) burden. Additionally, burden can be directly attributable to the patient or to other sources. Increasing burden may affect the carer's subjective well-being leading to 'stress'. Precipitating factors (Nolan et al. 1994) include:

- carers feeling out of control of events
- caring for a person who is unappreciative, demanding and manipulative
- not receiving sufficient support from the family and lack of adequate finances.

F53. Although burden and stress are useful concepts they rely on a simple cause and effect model suggesting that exposure to certain situations caused stress. Individuals react to events in different ways. All events are not necessarily stressful all of the time and not all events are equally stress provoking to all people. Stress and burden are multidimensional concepts with social, psychological, physical and economic components. It may be valuable to consider these various dimensions separately.

F54. The literature on caring for a person with stroke, combined with the more general literature on carers and carer burden, highlights a number of areas of relevance in considering the outcomes for carers:

- Information and skills (see paragraph F55).
- Depression, anxiety and stress which can be features of caring and may have a considerable impact on the carer.
- Satisfaction with care and with caring as there is growing evidence that satisfaction of caring can be used as a risk assessment tool and that in the absence of satisfaction even small tasks become a burden (Nolan, personal communication).
- Social support and networks are valuable to carers but it is not certain which components are most valuable although they are likely to be:
 - provision of information about support agencies
 - named contact person.
- Receipt of appropriate services by patient and carer is essential to maintaining patient and carer in their home.
- Financial outcome as many carers are not aware of financial benefits or do not receive them.
- Physical health status as maintenance of physical health is an essential to the carer.

F55. Carers need prompt advice and information on stroke, what it means to be a carer, on services and benefits available and voluntary agencies. Provision of this information should occur prior to discharge. The usefulness of the information depends on the perspective adopted. Therefore carers should be asked what they think they need to know. Carers also need training in skills required for caring (e.g. lifting, help with transfers). It should be noted that carers needs are ongoing and will change. Even an experienced carer should not be assumed to have up to date knowledge and skills. In addition it is recognised that carers may not be able to assimilate information early in the

caring process. The information and skill requirements of carers should be re-assessed in the medium and long term. A good outcome for carers could be having their informational and skill needs assessed and being in receipt of appropriate information and training.

Outcome measures

F56. A number of specific measures have been developed to measure the impact of caring. These and other measures that have been used in the context of stroke are listed in Exhibit F6.

EXHIBIT F6 : MEASURES OF CARER OUTCOME

Type of measure	Examples
Burden	The Care Giver Strain Index Relatives Stress Score The Burden Interview Carers Assessment of Difficulties Index (CADI) *Carers Assessment of Managing Index (CAMI)
Stress	Relatives Stress Score General Health Questionnaire (GHQ)
Depression, anxiety	GHQ Wakefield Depression Scale
Satisfaction	Carers Assessment of Satisfaction Index (CASI) Carers Satisfaction Questionnaire (Homesat, Hopsat)
Multidimensional	Nottingham Health Profile (NHP) GHQ SF-36
Social networks and support	Interview Schedule for Social Interaction (ISSI)

* A measure of coping rather than burden.

F57. Challis et al. (1994) reviewed measures of carer burden and suggested that either the Relatives Stress Score or Care Giver Strain Index could be incorporated into routine clinical practice although both measures would require further testing of their psychometric properties in particular construct validity. They further suggested that either of these measures could be used in conjunction with a more general measure of stress such as the General Health Questionnaire. However, Nolan et al. (1995) felt that the use of such measures was too simplistic and have developed their own range of measures (CADI, CAMI, CASI). These measures require further testing of their psychometric properties.

F58. It should be noted:

- There are two approaches to measuring the impact of caring on carers; the use of a global measure such as the Care Giver Strain Index, or the measurement of the individual components of burden and stress. Some of the measures in the latter approach will be relevant to patient outcomes, namely depression, anxiety and satisfaction and could form the basis of an assessment of both patient and carer.
- Carers' perception of burden may be related to their own physical, social and mental state and other factors. An assessment of these dimensions may be more appropriate than measures of burden or stress.
- There are several measures of social support available. Carers do not live in isolation they have a range of social networks. Although it is accepted that informal social networks are highly valuable there is no consensus on which dimensions of social support networks are essential to the well-being of carers. In addition not all support is useful (Rook 1992). Measuring outcome in terms of social support alone will therefore not be sufficient.
- Measures of finance, receipt of services, information and training are lacking.
- The measures listed are largely those used in research as opposed to everyday practice. Some measures may be impractical and costly to use in routine practice.

Conclusion

F59. Exploring the impact of caring on informal carers is important. In view of the complexity of caring and its impact on carers it may be more meaningful to adopt the approach of measuring the individual components of burden and stress rather than the global approach. However, whichever approach is ultimately adopted it is important to recognise that the outcomes of carers and

those that they care for are interdependent. The outcomes for carers must therefore form an integral part of assessing and monitoring outcomes for stroke patients. Carers' outcomes should be assessed at the same stages that patient outcomes are assessed i.e. at discharge, at six months and in the longer term.

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