

Data gaps and limitations

The importance of rehabilitation after coronary events or stroke and secondary prevention measures in the continuum of care for people with cardiovascular disease has long been recognised. With this recognition came the development of some indicators as a first step towards monitoring these areas. Monitoring of these areas need not be restricted to these indicators; however, they provide a useful starting point, capitalising on the experience gathered so far.

Table 1 shows the indicators developed by the National Health Priority Areas (NHPA) and the National Health Performance Committee (NHPC) for monitoring cardiovascular health that are relevant to cardiac or stroke rehabilitation, as well as those that impact on secondary prevention of cardiac and stroke events. The discussion that follows examines each of these indicators, giving details of problems, along with proposed solutions or improvements. The tasks proposed have not been assigned priorities as this is outside the scope of this paper.

Table 1: Indicators for monitoring cardiovascular health relevant to rehabilitation and secondary prevention

Indicator	Set by	Relevant to	Comments
<i>Coronary heart disease indicators</i>			
Incidence rate for myocardial infarction, age 35–69 years	NHPA	Secondary prevention	Some estimates available
Incidence rate for coronary heart disease events per 100,000 population aged 40–90 years	NHPC	Secondary prevention	Estimates available
Proportion of cardiac patients who enter and complete a rehabilitation program, all ages	NHPA	Cardiac rehabilitation	Data not available
Proportion of people with mild/moderate/severe disability at six months following diagnosis of an initial cardiac event, all ages	NHPA	Cardiac rehabilitation	Data not available
Coronary heart disease case fatality for the population aged 40–90 years	NHPA	Secondary prevention	Limited estimates available
<i>Stroke indicators</i>			
Incidence rate for stroke, all ages	NHPA	Secondary prevention	Data not available
Proportion of patients admitted to hospital with acute stroke who are managed in specialised stroke units (dedicated multidisciplinary teams), all ages	NHPA	Secondary prevention Stroke rehabilitation	Data not available
Proportion of people whose main/underlying disabling condition is stroke, age 45 years or more	NHPA	Stroke rehabilitation	Data available
Proportion of people with mild/moderate/severe disability at 6 months following diagnosis of initial stroke event, all ages	NHPA	Stroke rehabilitation	Data not available
Case fatality rate for stroke within 28 days, all ages	NHPA	Secondary prevention	Data not available

It should be noted that there are indicators for monitoring health risk factors that are not mentioned here because they relate to the population as a whole. They do not apply specifically to people with established cardiovascular disease and as such do not provide information on secondary prevention. Indicators concerning the use of appropriate medications in people with cardiovascular conditions are also lacking. It would be useful to

develop such indicators to focus directly on secondary prevention measures. This is beyond the scope of this paper but should be considered at a later stage.

Data development task

- Develop indicators concerning risk factors for heart disease and stroke in people with cardiovascular disease and their use of appropriate medications.

NHPA indicator: Incidence rate for myocardial infarction, age 35–69 years

Data issues

There are no national data sources for estimating the incidence of myocardial infarction. Monitoring the incidence of coronary heart disease is discussed in Jamrozik et al. (2000), which is reflected in the discussion of the next indicator below.

Hospital statistics are not a measure of incidence of disease because the figures represent episodes of hospitalisation rather than numbers of people. In addition, hospital admissions are affected by need, access and demand, as well as by local policies.

Presently available estimates of incidence are based on a WHO collaborative study, Monitoring Trends and Determinants of Cardiovascular Disease (MONICA), in Perth and Newcastle. Estimates are made from mortality and morbidity data adjusted by factors derived from the MONICA study.

The adjustment factors used to estimate incidence are based on data mainly collected at the MONICA centres during the late 1980s and early 1990s. However, less than half of myocardial infarctions occur in those aged 35–69 years, the age range included in the methodology devised to determine incidence (Jamrozik et al. 2000). In addition, local admission and discharge policies and practices vary between jurisdictions and at different times. These differences may limit the validity of the adjustment factors at national level. These adjustment factors have not been validated in recent times or in different jurisdictions.

Myocardial infarction events are rare below age 35 years. As stated above, most myocardial infarctions affect people aged over 69 years. For this reason, the definition of the NHPA indicator is not as useful as that of the NHPC indicator (see below), which covers a broader age range. However, for older people, diagnosis may be less reliable and comorbidity is likely to affect outcomes.

The recent introduction of troponin measurements into clinical practice has increased the sensitivity of myocardial infarction diagnosis, which may lead to higher rates of detection of minor infarcts.

Data development tasks

- Validate regularly the adjustment factors used to estimate incidence which are published in Jamrozik et al. (2000).
- Test the method developed by Jamrozik et al. (2000) in other jurisdictions and in older age groups.
- Validate adjustment factors using the ICD-10 and ICD-10-AM systems of coding.
- Broaden the age range for the NHPA indicator to include older ages (over 65 years).

NHPC indicator: Incidence rate for coronary heart disease events per 100,000 population aged 40–90 years

Data issues

There are some data available on the incidence of CHD events that can be reported for this indicator. This involves counting the number of deaths from CHD, and the number of non-fatal hospitalisations for acute myocardial infarction (AIHW: Mathur 2002). As this amounts to counting the incidence of major CHD events, it is a significant step forward in gathering information in this area. However these data can only be considered an approximation of the real incidence of all CHD events due to a number of limitations which are discussed here.

There are no national data sources for precisely measuring the incidence of CHD events. Generally, hospital statistics are not a measure of incidence of disease because the figures represent episodes of hospitalisation rather than numbers of people. There is no capacity to track individuals so any subsequent admissions to hospital related to the initial CHD event may be counted as a separate event. In addition, hospital admissions are affected by need, access and demand, as well as by local policies. Furthermore, milder CHD events which are not treated in hospital are not recorded in hospital statistics.

NHPA indicator: Proportion of cardiac patients who enter and complete a rehabilitation program, all ages

Data issues

Currently there are no national data sources for this indicator. Appendix A presents details of the data available in each state and a summary is given here:

- In Victoria, the National Heart Foundation of Australia in collaboration with the Victorian Department of Human Services determined participation rates and patient outcomes at outpatient cardiac rehabilitation programs in 1998–99.
- A similar study assessing participation in cardiac rehabilitation programs was conducted in the Hunter area of New South Wales.
- South Australia and Queensland have collected data on the use of cardiac rehabilitation programs and provided this information to the National Heart Foundation of Australia for collation. Queensland data are held by Queensland Health and are expected to be published later in 2003.
- Other studies at the local level are under way across Australia but they operate in an uncoordinated fashion, making comparisons difficult.

The studies conducted so far have highlighted problems concerning missing data and errors when the number of items collected is large.

There are concerns about the broad definition of this indicator. It could be refined to include only a subset of patients, for instance, those who have had a myocardial infarction.

A standardised data collection tool is not available at present. There is no national coordination of data collections. A national database that would collate information on cardiac rehabilitation programs has been proposed and details are provided in Appendix A.

Data development tasks

- Refine the current definition, including comments being sought from the National Heart Foundation of Australia and the Australian Cardiac Rehabilitation Association on the appropriateness of including only a subset of patients (such as those who have had a myocardial infarction).
- Consider developing a national minimum data set for cardiac rehabilitation programs, submitting it for inclusion in the National Health Data Dictionary and encouraging all cardiac rehabilitation programs to adopt it in their data collections.
- Consider establishing a national cardiac rehabilitation database (see Appendix A for details).

NHPA indicator: Proportion of people with mild/moderate/severe disability at 6 months following diagnosis of an initial cardiac event, all ages

Data issues

There are currently no national data sources for this indicator.

Information is potentially available from the assessment of patients participating in cardiac rehabilitation programs. Ideally, all patients who have had a cardiac event should undergo rehabilitation; however, in practice this is not the case and relying only on data from rehabilitation programs might provide results that are unrepresentative of the total patient population.

Studies at the local level have used the SF-36 health measure before and after the health intervention but this is not considered a measure of disability.

There are concerns about the lack of precision in the definition of this indicator. It is suggested that the definition be further refined, considering issues such as actual measures of disability, and criteria for what constitutes a cardiac event.

A standardised disability measure in the hospital data collection is not currently available.

Data development tasks

- Refine the indicator following the development of criteria for a cardiac event.
- Identify an appropriate standardised disability measure.
- All cardiac rehabilitation programs adopt the standardised disability measure in their data collections.

NHPA indicator: Coronary heart disease case fatality for the population aged 40–90 years

Data issues

There is no national data source to estimate the case fatality rate for CHD.

Complete ascertainment of CHD cases and their outcomes requires running registers that capture not only hospitalised patients but also patients managed in the community. Such registers are expensive and have been run only for limited periods in Perth and the Hunter region in New South Wales.

Hospital morbidity records provide information on outcomes, within the period of the hospital stay only, for those CHD patients who are admitted to hospital. Not all persons with CHD are admitted to hospital. About 60–70% of coronary deaths occur out of hospital. Therefore, case fatality rates based on hospital data may not be representative of all CHD patients. In addition, AIHW's National Hospital Morbidity Database holds information on individual hospitalisations, not patients, which makes it impossible to identify multiple admissions for the same patient.

The best estimates available are limited by the fact that they are partly based on acute CHD events that have been treated in hospital (AIHW: Mathur 2002). These estimates do not take into account CHD cases that do not result in an acute event or those that do not go through the hospital system.

Validation studies from the WHO MONICA project suggest that the number of deaths from CHD are underestimated, especially for younger women, if the only death certificate diagnoses used are those coded 410–414. The underestimation is largely due to CHD deaths being coded to other diagnostic categories. This difficulty can be overcome with the use of multiple cause of death codes in death certificates.

Linking patient records would allow events (hospital admission, transfers, readmissions, and death) occurring for the same person during the same clinically recognised disease episode to be identified, and provide accurate data for monitoring CHD. This would require the use of unique patient identifiers to remove the effects of multiple admissions relating to the same person and to allow linkage to death records. Although this has been done at the local level, the lack of unique patient identifiers impedes such tracking of patients at a national level.

Data development task

- Develop methods for linking data within hospitals and subsequently linking these data with mortality data.

NHPA indicator: Incidence rate for stroke, all ages

Data issues

There is no national data source for estimating stroke incidence.

Local registers of stroke cases have been run for limited periods; at 5-year intervals in areas of Perth and north-east Melbourne. These provide the best data available on the incidence of stroke in Australia, and this information has been extrapolated to give a national estimate.

It is generally considered that the incidence of stroke can be measured accurately only through stroke registers, though these are expensive to maintain.

At present, hospital morbidity data cannot be used to measure trends in rates for acute stroke due to several factors:

- Not all persons suffering from a stroke are admitted to hospital.
- Proportions of non-fatal cases admitted to hospital are changing rapidly, probably as a result of changing policy and practice relating to stroke, and changes in coding.
- The information is based on hospitalisations, not patients, making it impossible to distinguish between first and subsequent admissions for the same patient.

If the relatively large proportion of cases admitted to hospital in 1995–96 is confirmed in future studies, it should be possible to use hospital morbidity data to monitor trends in stroke from 1995 onwards because coverage of stroke cases in hospital statistics would be adequate for a reliable measure.

Data development tasks

- Test the algorithms described in Jamrozik et al. (2000) to estimate the incidence of stroke in different geographic areas.
- Develop methods to determine 'first' events, defined in terms of no previous admission for stroke within a defined period.
- Investigate the feasibility of establishing a national stroke register, or sentinel registers.

NHPA indicator: Proportion of patients admitted to hospital with acute stroke who are managed in specialised stroke units (dedicated multidisciplinary teams), all ages

Data issues

There is no national data source able to provide information on stroke patients cared for in specialised stroke units.

The SCOPES (Stroke Care Outcomes: Providing Effective Services) study, conducted by the National Stroke Foundation, aimed to compare health services for stroke patients overall, including the availability of stroke units. It covered eight metropolitan hospitals and one regional hospital, all in Victoria. The evaluation of the quality of stroke services led to the development of process indicators to examine the performance of different acute care models.

More recently, the National Stroke Foundation prepared a proposal for a National Stroke Unit Program. The program aims to identify the key elements of clinical best practice and to implement these across the diversity of clinical settings where stroke is treated in Australia. It is expected that indicators of quality will be identified as part of the process of identifying the key elements of care. The program provides a framework for describing and defining of stroke unit care in different parts of Australia. More details of the program are provided in Appendix B.

There is no agreed standard definition of what constitutes a 'specialised stroke unit'. Hospitals interpret the concept in a variety of ways, making comparisons difficult. The National Stroke Unit Program caters for this by describing a recommended model of stroke

unit care for different categories of hospitals. As the program is rolled out, facilities will develop stroke units based on the model descriptors.

Data development tasks

- Develop a standard definition of a 'specialised stroke unit'.
- Develop potential data sources to provide information on this indicator.

NHPA indicator: Proportion of people whose main/underlying disabling condition is stroke, age 45 years or more

Data issues

Data on this indicator can be derived from the Australian Bureau of Statistics Disability, Ageing and Carers Survey.

The ABS has conducted four surveys to measure the disability status of Australians – in 1981, 1988, 1993 and 1998. Only the 1998 survey allows the disabling effects of stroke to be accurately reported. Although this information was indirectly available from the 1993 survey, it was not considered an accurate measure of stroke disability in the community because stroke was identified from the underlying cause of the main disabling condition. In cases where stroke was the sudden event that caused the disability, the cause of the disabling condition was more likely to have been reported as a physical state such as paralysis. This would have caused an underestimation of the true prevalence of disability due to stroke. In the 1998, survey participants were directly asked whether they had had a stroke and the types of long-term restrictions consequently experienced.

NHPA indicator: Proportion of people with mild/moderate/severe disability at 6 months following diagnosis of initial stroke event, all ages

Data issues

There is no national data source to estimate disability 6 months after a stroke.

The Perth Community Stroke Study (1989–90) has examined levels of disability before and after stroke, with patients monitored within the first 12 months of the event. The level of disability before the stroke event was measured using the modified scaling of the Barthel Index of Activities of Daily Living (for physical function) and the Frenchay Activities Index (for social function). The Glasgow Coma Scale and the Motricity Index were used to assess disability levels after the initial stroke event.

In the absence of a national data collection, the stroke registers held every 5 years in Perth and north-east Melbourne provide the best quality data for this indicator.

The time period of 6 months specified in the indicator needs investigation as it does not reflect international practice on disability and stroke which tends to use 30 days (for short-term case fatality) and 12 months (for longer term outcomes).

A standardised disability measure in the hospital data collection is not currently available.

Data development tasks

- Identify a standardised disability measure for stroke.
- Examine the indicator definition, considering time points of 28 days and/or 12 months in keeping with international practice on disability and stroke.

NHPA indicator: Case fatality rate for stroke within 28 days, all ages

Data issues

There is no national data source to estimate the case fatality rate for stroke.

Complete ascertainment of stroke cases and their outcomes requires running registers that capture not only hospitalised patients but also patients managed in the community. Such registers are expensive and have only been run for limited periods in parts of Perth and Melbourne.

Hospital morbidity records provide information on outcomes, within the period of the hospital stay only, for those stroke patients who are admitted to hospital. This is only a subset of the data required by the indicator as defined above. In addition, AIHW's National Hospital Morbidity Database holds information on individual hospitalisations, not patients, which makes it impossible to identify multiple admissions for the same patient.

Not all persons suffering a stroke are admitted to hospital, particularly if the episode is mild or if the patient is already living in a nursing home. Therefore, case fatality rates based on hospital data may not be representative of all stroke patients. Changes in the proportion of stroke patients admitted to hospital over time have been observed too, which would pose a problem for drawing reliable trend conclusions on case fatality rates from this source. However, if the observed trend towards a rising proportion of stroke cases being managed in hospital continues, it may be possible to use this data source in future.

As the proportion of stroke patients admitted to hospital is large and appears to be increasing, it may be possible in future to use hospital morbidity records to derive information on case fatality rates. However, this would still require the use of unique patient identifiers to remove the effects of multiple admissions relating to the same person, and to allow linkage to death records. Although this has been done at the local level, the lack of unique patient identifiers impedes such tracking of patients at a national level.

Data development task

- Develop methods for linking data within hospitals and subsequently linking these data with mortality data.

Table 2: Summary of data development tasks

Indicators	Proposed tasks	Task type
Incidence rate for myocardial infarction, age 35–69 years	Validate regularly the adjustment factors used to estimate incidence which are published in Jamrozik et al. (2000).	Analysis/research
Incidence rate for coronary heart disease events per 100,000 population aged 40–90 years	Test the method developed by Jamrozik et al. (2000) in other jurisdictions and in older age groups.	Analysis/research
	Validate adjustment factors using the ICD-10 and ICD-10-AM systems of coding.	Analysis/research
	Broaden the age range for the NHPA indicator to include older ages (over 65).	Definition change
Proportion of cardiac patients who enter and complete a rehabilitation program, all ages	Refine the current definition, including comments being sought from the National Heart Foundation of Australia and the Australian Cardiac Rehabilitation Association on the appropriateness of including only a subset of patients (such as those who have had a myocardial infarction).	Consultation Definition change
	Consider developing a national minimum data set for cardiac rehabilitation programs, submitting it for inclusion in the National Health Data Dictionary and encouraging all cardiac rehabilitation programs to adopt it in their data collections.	Consultation Meta data development
	Consider establishing a national cardiac rehabilitation database (see Appendix A for details).	Consultation Data development
Proportion of people with mild/moderate/severe disability at six months following diagnosis of an initial cardiac event, all ages	Refine the indicator following the development of criteria for a cardiac event.	Data development
	Identify an appropriate standardised disability measure.	Consultation
	All cardiac rehabilitation programs adopt the standardised disability measure in their data collections.	Consultation
Coronary heart disease case fatality for the population aged 40–90 years	Develop methods for linking data within hospitals and subsequently linking these data with mortality data.	Relevant to other groups—being progressed elsewhere Consultation
Incidence rate for stroke, all ages	Test the algorithms described in Jamrozik et al. (2000) to estimate the incidence of stroke in different geographic areas.	Analysis/research
	Develop methods to determine ‘first’ events, defined in terms of no previous admission for stroke within a defined period.	Analysis/research
	Investigate the feasibility of establishing a national stroke register, or sentinel registers.	Consultation Data development
Proportion of patients admitted to hospital with acute stroke who are managed in specialised stroke units (dedicated multidisciplinary teams), all ages	Develop a standard definition of a ‘specialised stroke unit’.	Consultation Meta data development
	Develop potential data sources to provide information on this indicator.	Consultation Data development
Proportion of people with mild/moderate/severe disability at 6 months following diagnosis of initial stroke event, all ages	Identify a standardised disability measure for stroke.	Consultation
	Examine the indicator definition, considering time points of 28 days and/or 12 months in keeping with international practice on disability and stroke.	Consultation Meta data development
Case fatality rate for stroke within 28 days, all ages	Develop methods for linking data within hospitals and subsequently linking these data with mortality data.	Relevant to other groups—being progressed elsewhere Consultation
Other	Develop indicators concerning risk factors for heart disease and stroke in people with cardiovascular disease and their use of appropriate medications.	Overlaps with other groups Consultation