

Secondary prevention and rehabilitation after coronary events or stroke

A review of monitoring issues

September 2003

Australian Institute of Health and Welfare
Canberra
AIHW Cat. No. CVD 25

© Australian Institute of Health and Welfare 2003

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, no part may be reproduced without prior written permission from the Australian Institute of Health and Welfare. Requests and enquiries concerning reproduction and rights should be directed to the Head, Media and Publishing, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601.

A complete list of the Institute's publications is available from the Publications Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601, or via the Institute's web site (<http://www.aihw.gov.au>).

ISBN 1 74024 318 8

Suggested citation

Australian Institute of Health and Welfare 2003. Secondary prevention and rehabilitation after coronary events or stroke: a review of monitoring issues. AIHW Cat. No. CVD 25. Canberra: Australian Institute of Health and Welfare.

Australian Institute of Health and Welfare

Board Chair
Dr Sandra Hacker

Director
Dr Richard Madden

Any enquiries about or comments on this publication should be directed to:

Susana Senes
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Phone: (02) 6244 1171
Email: susana.senes@aihw.gov.au

Published by Australian Institute of Health and Welfare

Printed by Pirion

Contents

- Acknowledgments v
- Introduction.....1
 - Coronary heart disease in a nutshell1
 - Stroke in a nutshell.....2
 - Definitions2
- Data gaps and limitations3
 - NHPA indicator: Incidence rate for myocardial infarction, age 35–69 years.4
 - NHPC indicator: Incidence rate for coronary heart disease events per 100,000 population aged 40–90 years.5
 - NHPA indicator: Proportion of cardiac patients who enter and complete a rehabilitation program, all ages.5
 - NHPA indicator: Proportion of people with mild/moderate/severe disability at 6 months following diagnosis of an initial cardiac event, all ages.....6
 - NHPA indicator: Coronary heart disease case fatality for the population aged 40–90 years.....7
 - NHPA indicator: Incidence rate for stroke, all ages.....7
 - NHPA indicator: Proportion of patients admitted to hospital with acute stroke who are managed in specialised stroke units (dedicated multidisciplinary teams), all ages.8
 - NHPA indicator: Proportion of people whose main/underlying disabling condition is stroke, age 45 years or more.....9
 - NHPA indicator: Proportion of people with mild/moderate/severe disability at 6 months following diagnosis of initial stroke event, all ages.....9
 - NHPA indicator: Case fatality rate for stroke within 28 days, all ages.10
- Current knowledge on coronary heart disease12
 - Incidence of coronary heart disease12
 - Survival, disability and quality of life after a CHD event.....12
 - Cost of coronary heart disease12
 - Risk factors for coronary heart disease13
 - Strategies for reducing the recurrence of CHD events13
 - Cardiac rehabilitation14
- Current knowledge on stroke.....16
 - Incidence of stroke16
 - Survival, disability and quality of life after stroke16
 - Cost of stroke17

Risk factors for stroke	17
Strategies for reducing stroke recurrence	18
Stroke rehabilitation.....	19
Conclusion.....	21
References.....	22
Appendix A: Establishment of a minimum database for outpatient cardiac rehabilitation in Australia	25
Appendix B: The National Stroke Unit Program.....	29

Acknowledgments

This report was prepared by Susana Senes from the Australian Institute of Health and Welfare, with financial assistance from the Australian Government Department of Health and Ageing.

Thanks are due to Steve Bunker, Erin Lalor, Paul Magnus, Lynelle Moon, Louis Young, Krissa O'Neil, Geoff Donnan, Helen Dewey, Amanda Trift, Ian Ring and Garry Jennings for reviewing the paper and providing helpful comments.

Introduction

An estimated 3.2 million Australians (17% of the population) reported having a cardiovascular condition in 2001 (ABS 2002). For those with established cardiovascular disease (heart, stroke and vascular disease), it is important to try to prevent the occurrence of further cardiovascular events such as acute myocardial infarction (heart attack) or stroke. This is known as secondary prevention. Rehabilitation programs can help heart and stroke patients reduce their risk of recurrence of such events and return to an active life.

Deaths from cardiovascular disease have fallen at an average age-adjusted rate of 3.8% per year over the period 1987–98, a faster fall than that for deaths overall. Secondary prevention and rehabilitation programs are both likely to have contributed to this decline. However, there are currently limitations on our ability to assess their contribution. Our estimates are made mainly from death and hospital statistics or from self-reports from surveys. There is no national system for directly measuring the incidence of coronary heart disease or stroke; nor do we have routine national information on some of the major cardiovascular risk factors such as high blood pressure and high blood cholesterol. There is also no similar information on cardiac or stroke rehabilitation programs and who uses them. These systems need to be developed to contribute to the national monitoring of cardiovascular disease.

This paper firstly highlights gaps and deficiencies in the monitoring of rehabilitation after coronary events or stroke and prevention of further events, and proposes ways to overcome them. It also suggests actions for advancing our capacity to establish a baseline and later assess the impact of policies and measures directed at cardiac and stroke rehabilitation and secondary prevention of cardiovascular events. It finally reviews current knowledge on cardiac and stroke rehabilitation and secondary prevention. This publication is intended to inform discussion in relation to monitoring among the National Heart, Stroke and Vascular Health Strategies Group, National Health Performance Committee, National Health Priority Action Council and other interested groups.

Coronary heart disease in a nutshell

Coronary heart disease (CHD) is caused by poor oxygen supply to the heart muscle. This results from atherosclerosis (a thickening or hardening of the walls of a blood vessel) of the coronary arteries which supply the heart with blood. The manifestations of CHD can include episodic chest pain (angina), acute myocardial infarction (heart attack), heart failure and sudden cardiac death. In some cases, there may not be any manifestations of symptoms. It is the commonest form of heart disease and the single most important cause of death in Australia, representing 21% of all deaths. Modifiable risk factors for CHD include tobacco smoking, high blood pressure, high blood cholesterol, diabetes, a sedentary lifestyle and being overweight. Men are at considerably greater risk of the disease than women. Also at much greater risk are older people, those with a family history of the condition and Aboriginal and Torres Strait Islander people. The excess risk increases greatly with the number of risk factors present. Effective strategies to manage patients with CHD include reduction of risk factors, surgery, angioplasty and use of medications, including aspirin, beta blockers, calcium channel blockers, ACE-inhibitors and cholesterol-lowering agents (Edwards et al. 1998, AIHW 2001, DHAC & AIHW 1999).

Stroke in a nutshell

Stroke is the most important manifestation of cerebrovascular disease. A stroke occurs when an artery supplying the brain suddenly becomes blocked (ischaemic stroke) or bleeds (haemorrhagic stroke). This causes loss of function of part of the brain and impairment in any or all of a range of functions including movement of body parts, vision, planning, communication and swallowing. The risk of stroke increases markedly with age. Aboriginal and Torres Strait Islander people are also at greater risk than other Australians. Major modifiable risk factors for stroke include high blood pressure, tobacco smoking, diabetes, atrial fibrillation and other cardiac disease, and narrowing of the carotid arteries. Each year, there are about 40,000 to 46,000 stroke events among Australians, and the number of people who have had a stroke at some time in their lives is estimated at 120,000–220,000. Each year about 12,000 of these patients suffer another stroke. The condition is the leading cause of long-term disability in adults, representing 25% of all chronic disability, and is Australia's second biggest single killer, accounting for around 10% of all deaths. To maximise functional outcome and minimise disability, many patients need rehabilitation after a stroke (AIHW 2001, Hankey 2000, Thrift et al. 2000).

Definitions

Disability can be an impairment of body structure or function, a limitation in activities or a restriction in participation (see below).

Rehabilitation is a process aimed at enabling persons with disabilities to reach and maintain their optimal functional levels. With the introduction of the International Classification of Functioning, Disability and Health (see below), the definition of rehabilitation can be seen as a coordinated process that enhances 'activity' and 'participation' (Disler et al. 2002). Although there has traditionally been a focus on physical medicine, rehabilitation is now acknowledging the patient's social context.

The following definitions are based on the International Classification of Functioning, Disability and Health (ICF) (WHO 2001). Terms are defined in the context of health.

Impairments are problems in body function or structure such as significant deviation or loss.

Activity is the execution of a task or action by an individual.

Participation is the involvement in a life situation.

Activity limitations are difficulties an individual may have executing activities.

Participation restrictions are problems an individual may experience in involvement in life situations.

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

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

Current knowledge on coronary heart disease

Incidence of coronary heart disease

There are no directly measured national data on the incidence of CHD in Australia. However, there are estimates available of major coronary events that warrant admission to hospital or cause death. It is estimated that there were 18,817 CHD events (mainly heart attacks) among people aged 35–69 years in 1997–98 (AIHW 2002). Non-fatal heart attacks accounted for two-thirds of such cases. However, these estimates do not include cases of CHD that present without any symptoms or cases of angina that do not require management in hospital.

Survival, disability and quality of life after a CHD event

Of those people aged 35–69 years having a coronary event during 1991–93, 36% of men and 40% of women died (AIHW: McElduff et al. 2000). Men with a previous coronary event accounted for 30–40% of male coronary deaths, compared with 20–30% in women. This confirms the very high death rate that still occurs among those having a coronary event. However, given the large number of events occurring each year, it is also evident that there are many Australians needing rehabilitation and secondary prevention.

Physical problems associated with myocardial infarction include unexpected weakness caused by deconditioning, breathlessness on exercise, and angina.

About one in six people with acute myocardial infarction become depressed at the time. This can cause fatigue, reduced concentration, irritability and disturbed sleep (Hare & Bunker 1999). Depression is associated with increased mortality, recurrent coronary events, angina, heart rhythm disturbances, rehospitalisation, emotional instability, prolonged disability, impaired quality of life and continued smoking in cardiac patients (Creed 1999). It is therefore important to attend to psychological factors in these patients.

Most people with myocardial infarction have anxiety problems on admission to hospital and again just before discharge (Thompson & Lewin 2000). Although in most cases anxiety and depression slowly ease over the following weeks, about one in four people remain distressed 1 year after the event.

Cost of coronary heart disease

There are no up-to-date figures on the current cost of CHD in Australia. The latest estimates available are now 10 years old. According to these estimates, CHD accounted for \$894 million in 1993–94 and was the most expensive cardiovascular condition to treat (23% of total cost of cardiovascular disease and 2.7% of total recurrent health expenditure) (AIHW: Mathers & Penm 1999). This included hospital services, medical services, pharmaceuticals, allied health services, nursing homes and research. The majority of resources were spent on hospital services (64%) and drugs (12%). As the incidence of CHD is unknown, it is not possible to estimate lifetime health system costs for a person with CHD.

The total cost of acute myocardial infarction (heart attack) in 1993–94 was estimated at \$164 million (18% of CHD cost). The average total cost per hospital admission for acute myocardial infarction was \$5,898 in 1998–99 (AIHW 2001).

Risk factors for coronary heart disease

The major modifiable risk factors for CHD are:

- tobacco smoking
- high blood pressure
- high blood cholesterol
- overweight and obesity
- insufficient physical activity
- diabetes.

People who are depressed, socially isolated or without quality social support may also have a greater risk of developing CHD.

Strategies for reducing the recurrence of CHD events

The following measures are effective in reducing the risk of further coronary events in people with established CHD:

- lowering of high blood pressure
- smoking cessation
- weight control, if appropriate
- healthy diet
- regular exercise
- antiplatelet drugs (aspirin) used long-term
- lowering of blood cholesterol with drugs (statins), even when in the 'normal' range in patients with acute myocardial infarction or unstable angina
- beta blockers for patients with acute myocardial infarction or heart failure
- angiotensin-converting enzyme (ACE) inhibitors for patients with acute myocardial infarction or heart failure
- tight control of diabetes.

There is evidence that starting these therapies in the hospital can lead to better long-term use and better clinical outcomes (Fonarow et al. 2001). Table 3 lists goals for reducing particular risk factors.

Table 3: Goals for prevention of CHD events for people with known CHD

Risk factor	Goal
Total cholesterol	<4.0 mmol/L
LDL cholesterol	<2.5 mmol/L
HDL cholesterol	>1.0 mmol/L
Triglycerides	<2.0 mmol/L
Smoking	Cessation
Blood pressure	<140/90 mmHg
Body mass index (BMI)	<25 kg/m ²
Waist circumference	Male: <94 cm; Female: <80 cm
Physical activity	Establish/maintain at least 30 minutes of moderate intensity physical activity on 5 or more days of the week.

Source: National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand 2003

Cardiac rehabilitation

What is cardiac rehabilitation and who provides it?

Cardiac rehabilitation encompasses all measures used to help heart patients. It aims to:

- maximise physical, psychological and social functioning to enable patients to live productively and with confidence
- assist and encourage behaviours that are likely to reduce the risk of further cardiovascular events and conditions, such as identifying and modifying risk factors and encouraging adherence to recommended medical therapies.

Cardiac rehabilitation services should include physical activity, health education and counselling programs tailored to the individual needs of the patient and family (Goble & Worcester 1999, NSW Health Department 1997).

The World Health Organization recommends that cardiac rehabilitation services be available, and routinely offered, to everyone with cardiovascular disease and be delivered by trained health professionals. Most programs in Australia provide services for patients following heart attack, heart surgery and coronary angioplasty. Some programs also cater for patients with stable angina or chronic heart failure (AIHW 2001).

Cardiac rehabilitation should begin in hospital as soon as possible after admission. With the trend toward shorter hospital admissions, there is a greater need for patients to continue rehabilitation services on an outpatient or community basis. These programs provide the link between inpatient hospital care and ongoing care.

Group outpatient programs, conducted in hospitals and community health centres, are the main models operating throughout Australia, but programs vary across the country. A few Divisions of General Practice run programs as well. Programs generally consist of weekly or twice-weekly sessions of group education and discussion in addition to light to moderate exercise. They are conducted by multidisciplinary groups of health professionals. Patients attend as soon as possible after leaving hospital. Partners and other family members are encouraged to attend too. Home-based and outreach programs are also being developed in rural and remote areas of Australia.

Use of programs

There are no national data systems to monitor the proportion of patients who enter and complete a cardiac rehabilitation program. Details of the data available in each state are shown in Appendix A and a summary is presented here.

Where programs exist, only a minority of eligible patients are enrolled in, or attend, a structured outpatient cardiac rehabilitation program. In Victoria, 53% of patients discharged from hospital following coronary artery bypass surgery participated in a cardiac rehabilitation program, compared with 27% of patients with heart attack and 10% of patients after angioplasty (Bunker et al. 1999). Overall, only one in three eligible patients joined a cardiac rehabilitation program.

In Western Australia less than one in five patients admitted to hospital for a cardiac condition were likely to receive rehabilitation. In the Hunter region of New South Wales, 43% of eligible patients reported being invited to attend outpatient cardiac rehabilitation. Overall, 19% of eligible patients completed a program following discharge from a public hospital.

There is little information on participation rates among Aboriginal and Torres Strait Islander people. A study of patients who presented to Townsville General Hospital during or after a cardiac event in 1997–98 showed that Aboriginal and Torres Strait Islander patients were significantly less likely to enter cardiac rehabilitation programs than other Australians (5% versus 31%) (Traven Lea, personal communication).

Overseas there is evidence that women, older patients, those living in more deprived areas, those living in rural areas and those who are unemployed are less likely to undergo cardiac rehabilitation (King et al. 2001).

Health outcomes of patients attending outpatient cardiac rehabilitation

There is good evidence that cardiac rehabilitation confers beneficial effects, above usual medical care, on exercise capacity, blood lipid levels, smoking, exercise habits, use of medications, social adjustment, use of health-care services, and on the risk of recurrence of cardiac events or deaths (O'Connor et al. 1989, Goble & Worcester 1999).

There are no national data on outcomes for patients who undergo cardiac rehabilitation. A study involving 1,567 patients from 15 cardiac rehabilitation programs in Victoria showed significant improvements in physical and mental health-related quality of life scales. On completion of a cardiac rehabilitation program, the participants' average scores on all physical and mental scales considerably exceeded those at entry and those reported by persons with heart disease in the 1995 National Health Survey.

Current knowledge on stroke

Incidence of stroke

There are no directly measured national data on the incidence of stroke in Australia. The best estimates available come from local registers that have been run for limited periods only. First-ever stroke incidence rates (age- and sex-adjusted to the world population) range from 76 per 100,000 population in Perth during 1995–96 to 100 per 100,000 population in Melbourne during 1996–97 (Jamrozik et al. 1999, Thrift et al. 2000).

Survival, disability and quality of life after stroke

Of those having a first-ever stroke, 80% are alive at 28 days and 63% are alive 1 year after their stroke (Thrift et al. 2000). About one in six survivors of a first-ever stroke have a recurrent stroke over the next 5 years (Hankey et al. 1998). Recurrent strokes have a similar 28-day survival rate to that of first-ever strokes.

Nearly all patients are disabled at the time of the stroke. There may be permanent paralysis of one side of the body, speech or swallowing difficulties, problems with memory, personality changes or a range of other difficulties. Depression and anxiety are common after stroke and many survivors have difficulty returning to their previous leisure activities (Burvill et al. 1995a, Burvill et al. 1995b). Recovery is most rapid in the early weeks and nearly complete, if it is to be so, within 6 months of the stroke. By the end of the first year, about half of all survivors of stroke remain dependent on others for activities of daily living (Hankey et al. 2002).

Among 30-day survivors of first-ever stroke, about half survive 5 years (Hankey et al. 2002). Of those who survive to 5 years, one-third have a disability and one in seven are in ongoing institutional care.

The majority of survivors are disabled at 3 and 12 months after stroke (Sturm et al. 2002). Although physical independence and occupation are most severely affected, stroke survivors are disabled over a wide range of areas. These include mobility, social functioning, orientation and economic self-sufficiency. Stroke also carries emotional and behavioural consequences that can influence the effectiveness of rehabilitation, and have a severe impact on life satisfaction (Hochstenbach 2000). These psychological problems need to be treated too (White & Johnstone 2000).

Although problems in orientation are unlikely to be modifiable in most cases, much of post-stroke disability may be improved. Care in a stroke unit for acute stroke will reduce impairment and disability. Rehabilitation services may reduce disability in the areas of mobility, physical independence and social relationships by providing mobility and communication aids and modifying the environment. Occupational therapy can reduce limitations to occupational participation.

Stroke has a marked impact on quality of life. When assessing outcomes, it is important to measure quality of life in addition to death and disability, as people who have had a stroke may rate their quality of life as low even when they are able to perform activities of daily living (Teasell 2003).

Cost of stroke

Stroke has been estimated to account for about 4% of the total costs of disease in Australia (AIHW & CHPE 1995).

The total first-year costs of all first-ever strokes in Australia during 1997 were estimated at \$555 million and the lifetime costs at \$1.3 billion (Dewey et al. 2001). This included direct service use, care-giver time, out-of-pocket payments, and production losses. The definition of stroke used does not include subarachnoid haemorrhage or transient ischaemic attack. The average cost per case in the first year of a first-ever stroke was \$18,956; over a lifetime it was \$44,428. In contrast, the average cost per case during the first year after recurrent stroke was \$21,786. The average cost per rehabilitation admission was estimated to be \$13,627.

Rehabilitation (inpatient and outpatient) was the largest component of total cost during the first year after a first-ever stroke, amounting to \$156 million (28%). In addition, community rehabilitation cost a further \$10 million. Acute hospitalisation cost almost as much (\$154 million, 28%), followed by nursing home care (\$63 million, 11%).

Risk factors for stroke

The risk of stroke increases with:

- age
- previous transient ischaemic attack or stroke
- high blood pressure
- tobacco smoking
- diabetes
- high blood cholesterol
- atrial fibrillation
- narrowing of the carotid arteries (carotid stenosis).

How common are risk factors for heart disease and stroke?

- 43% of Australians aged 18–75 years (around 5.7 million) did not undertake sufficient physical activity to achieve health benefits in 2000 (AIHW 2002).
- 19% of Australians aged 14 years and over (about 3.1 million) smoked regularly in 2001 (AIHW 2002). A further 3.6% smoked occasionally.
- 29% of Australians aged 25 years and over (about 3.6 million) had high blood pressure or were on blood-pressure-lowering medication in 1999–00 (AIHW 2002).
- 50% of Australians aged 25 years and over (over 6 million) had high blood cholesterol levels in 1999–00 (AIHW 2002).
- 60% of Australians aged 25 years and over (about 7.5 million) were overweight or obese in 1999–00 (AIHW 2002). Of these, 21% (2.6 million) were obese.
- 7.5% of Australians aged 25 years and over (an estimated 938,700) had diabetes in 1999–00 (AIHW 2002).

The high prevalence of risk factors suggests that many patients could benefit from interventions to prevent stroke and coronary events.

Strategies for reducing stroke recurrence

There is wide variation in the care given to people with stroke. This is due to resource availability, cost, access to services, preferences of patients and differences in medical practitioners, hospitals and governments, as well as poor evidence on the effectiveness of many aspects of stroke care (Hankey & Warlow 1999).

Effective interventions to treat stroke in the acute phase and to prevent the occurrence of subsequent stroke events are summarised below. There are some components of stroke care, such as physiotherapy, occupational therapy and other forms of rehabilitation, for which there is limited conclusive evidence; however, this does not mean they are ineffective.

Treatments to manage acute stroke include:

- organised care in a stroke unit by a multidisciplinary team (level 1 evidence)
- aspirin for acute ischaemic stroke (level 1 evidence)
- tissue plasminogen activator (tPA) given within 3 hours of onset of acute ischaemic stroke (level 1 evidence).

Measures for preventing recurrent stroke in patients with transient ischaemic attack (TIA) or stroke include:

- lowering of blood pressure (level 1 evidence)
- smoking cessation
- regular exercise
- antiplatelet drugs (aspirin, aspirin + dipyridamole, or clopidogrel) long-term for patients with normal heart rhythm (level 1 evidence)
- anticoagulation (warfarin) long-term for patients with atrial fibrillation (level 1 evidence)
- lowering of blood cholesterol with drugs (statins) in patients with established CHD (level 1 evidence)
- carotid endarterectomy for patients with severe narrowing of the internal carotid artery on the symptomatic side and who are fit for surgery
- tight control of diabetes
- weight control, if appropriate
- a healthy diet.

Effective prevention is the most powerful strategy to reduce the burden of stroke.

Rehabilitation and secondary prevention of recurrent stroke should begin on day 1 after stroke, as the risk of recurrent stroke is highest in the first 6 months after the event (Hankey et al. 1998, Hankey 2000).

The most important modifiable predictors of poor long-term outcomes (death, institutionalisation or disability) are low levels of physical activity before the stroke and subsequent recurrent stroke (Hankey et al. 2002).

Although the effectiveness of certain measures is well established, they are currently underused. Stroke units provide organised care with a multidisciplinary team including professionals such as neurologists, other doctors, nurses, physiotherapists, occupational therapists, speech pathologists, dietitians and social workers. This care is appropriate for all patients, but it is not currently widely available in Australia. Similarly, only about 1 in 4 patients with transient ischaemic attack or stroke in whom long-term anticoagulant drugs

are indicated actually receive this treatment (Hankey & Warlow 1999). Aspirin is likewise underused for secondary prevention of vascular disease (Mollison et al. 1999).

However, there is evidence that the care of people with heart disease and stroke problems improved during the 1990s, with more effort being directed to prevention (AIHW: Henderson et al. 2002). There have been significant rises in the prescription of blood-pressure-lowering drugs, aspirin, anticoagulants and blood-cholesterol-lowering drugs. General practitioners are also more likely than in the past to do check-ups and to provide counselling and advice to their patients with a history of heart disease or stroke. It is reasonable to assume that this involved discussions about the patients' lifestyle and suggestions to change risk behaviours if indicated.

Stroke rehabilitation

What is stroke rehabilitation and who provides it?

Rehabilitation is an integral part of the acute and long-term care of those who have had a stroke. It has a role in:

- helping stroke survivors maximise their potential for recovery and providing practical ways of dealing with ongoing disability
- supporting and training family members and friends to assist with the ongoing care of stroke survivors in the community
- preventing recurrent stroke through medication and behavioural modification.

Most people who have suffered a stroke can benefit from rehabilitation, from the most mildly affected people to those severely disabled. Rehabilitation begins in the acute hospital environment as soon as possible after the stroke and, depending on each individual's needs, may continue in a specialised inpatient rehabilitation unit or be provided through hospital outpatient services, in the patient's home or at a community rehabilitation facility.

Rehabilitation services may also be provided in hostels and nursing homes. The nature of rehabilitation services available for stroke patients varies across Australia (AIHW 2001).

Rehabilitation includes setting mutually agreed goals tailored to the individual. Progress is monitored regularly. Retraining and practice in performing everyday tasks are important activities. Specialised equipment and aids may be used. Medications may also be prescribed. Rehabilitation also involves providing psychological support, education and advice on a healthy lifestyle to stroke survivors and to their family and friends. A successful return home and resumption of previous activities may require the support of community services, e.g. Meals on Wheels or home-nursing services. The duration of formal rehabilitation varies according to individual needs, from 1 or 2 weeks to several months (Pollack & Disler 2002).

A multidisciplinary team approach is used, involving doctors, nurses, physiotherapists, occupational therapists, speech pathologists, social workers, neuropsychologists, orthotists and leisure therapists. Informal carers (family members, neighbours, friends and volunteers) play an important part in the lives of disabled stroke survivors. Carers provide assistance with a wide range of daily activities including mobility outside the home, managing money, organising appointments and services, housekeeping and house maintenance. Some carers help with personal-care tasks such as bathing and dressing. Carers themselves face considerable psychological strain and require both emotional and practical support.

Use of programs

It is not known what proportion of stroke patients in Australia participate in a rehabilitation program (inpatient or outpatient).

It has been estimated that in Perth during 1989–90, about 25% of hospitalised stroke patients underwent a period of inpatient rehabilitation in a specialised rehabilitation unit. In north-east Melbourne during 1996–97, it is estimated that about 39% of hospitalised stroke patients were admitted for a period of inpatient rehabilitation. This latter estimate excludes cases of subarachnoid haemorrhage.

Health outcomes of patients attending stroke rehabilitation

Most of the evidence in favour of rehabilitation after stroke is based on evaluation of a multidisciplinary program as a whole, or a particular discipline (such as speech therapy), rather than on the individual components of rehabilitation (Pollack & Disler 2002).

Patients treated in a stroke unit, which can offer prolonged rehabilitation if needed, are more likely to survive, regain independence, and return home than those receiving conventional care in a general hospital ward. These improved outcomes are also seen for those units that admit patients more than 1 week after the stroke event. The benefits of stroke units are not restricted to patients of any particular sex, age or stroke severity, or to a specific model of stroke unit care. The important factors of stroke unit care are the provision of coordinated multidisciplinary rehabilitation, staff specialisation in stroke or rehabilitation, and improved education and training of staff, patients and carers (Stroke Unit Trialists' Collaboration 1997, Stroke Unit Trialists' Collaboration Cochrane Review 2003).

Outpatient rehabilitation, whether provided in a community rehabilitation centre (day hospital), a hospital outpatient clinic or in the patient's home, is also effective in reducing the risk of death, dependency, institutionalisation or deterioration (Outpatient Service Trialists. Cochrane Review 2003). Providing home rehabilitation services for stroke patients can reduce the total length of hospital stay and produce similar outcomes for death and disability, compared with continuing inpatient rehabilitation (Early Supported Discharge Trialists. Cochrane Review 2003). Home rehabilitation has also been shown to be cost-effective when compared with continued inpatient rehabilitation (Anderson et al. 2002).

Assessment of specific techniques used in rehabilitation therapy is under way in some areas but in many cases good quality research is not available. Greater intensity speech therapy produces better outcomes than less intense therapy, which appears to give little or no benefit (Teasell 2003). Combining different motor recovery treatments improves motor outcomes after stroke. Physiotherapy can still improve mobility and reduce disability years after a stroke (Wade et al. 1992). There is also strong evidence that good social support improves outcomes (Teasell 2003).

Conclusion

Cardiovascular disease poses a heavy burden on the health of Australians. Coronary heart disease and stroke are its most costly manifestations, both in terms of suffering for patients and their carers and of the financial burden for the community as a whole.

Risk factors for heart disease and stroke remain very common among Australians, including those with established cardiovascular disease. It is imperative that efforts are made to prevent further cardiovascular events among the latter and to reduce the overall level of risk within the population as a whole. Although effective measures and behaviours that reduce this risk are well established, there is evidence that they are not being adopted to the extent that they should.

This paper has identified gaps and deficiencies in our knowledge of CHD and stroke incidence, interventions and outcomes at a national level and suggested possible solutions. Introducing the measures proposed here would help to improve our capacity to monitor the impact of strategies and programs directed at prevention and recovery. Follow-up work to improve data availability as suggested in this report will continue through available mechanisms.

References

- Anderson C et al. 2002. Stroke rehabilitation services to accelerate hospital discharge and provide home-based care. An overview and cost analysis. *Pharmacoeconomics* 20:537-552.
- ABS (Australian Bureau of Statistics) 2002. National Health Survey 2001: summary of results. Cat. No. 4364.0. Canberra: ABS.
- AIHW (Australian Institute of Health and Welfare) & CHPE (Centre for Health Program Evaluation) 1995. Preliminary estimates: disease costs and impact study (DCIS). Canberra: AIHW & Centre for Health Program Evaluation.
- AIHW (Australian Institute of Health and Welfare) 2001. Heart, stroke and vascular diseases – Australian facts 2001. AIHW Cat. No. CVD 13. Canberra: AIHW (Cardiovascular Disease Series No. 14).
- AIHW (Australian Institute of Health and Welfare) 2002. Australia's health 2002. Canberra: AIHW.
- AIHW (Australian Institute of Health and Welfare): Henderson J, Pan Y, Britt H, Charles J et al. 2002. Cardiovascular problems and risk behaviours among patients at general practice encounters in Australia 1998-00. AIHW Cat. No. GEP 9. Canberra: AIHW (General Practice Series No. 9).
- AIHW (Australian Institute of Health and Welfare): Mathers C & Penm R 1999. Health system costs of cardiovascular diseases and diabetes in Australia 1993-94. AIHW Cat. No. HWE 11. Canberra: AIHW (Health and Welfare Expenditure Series No. 5).
- AIHW (Australian Institute of Health and Welfare): Mathur S 2002. Epidemic of coronary heart disease and its treatment in Australia. AIHW Cat. No. CVD 21. Canberra: AIHW (Cardiovascular Disease Series No. 20).
- AIHW (Australian Institute of Health and Welfare): McElduff P, Dobson A, Jamrozik K & Hobbs M 2000. The WHO MONICA Study, Australia 1984-93: a summary of the Newcastle and Perth MONICA Projects. AIHW Cat. No. CVD 11. Canberra: AIHW (Cardiovascular Disease Series No. 13).
- Bunker S, McBurney H, Cox H & Jelinek M 1999. Identifying participation rates at outpatient cardiac rehabilitation programs in Victoria, Australia. *J Cardiopulm Rehabil* 19:334-338.
- Burvill PW, Johnson GA, Jamrozik KD, Anderson CS et al. 1995 a. Anxiety disorders after stroke: the Perth Community Stroke Study. *British Journal Psychiatry* 166:328-332.
- Burvill PW, Johnson GA, Jamrozik KD, Anderson CS et al. 1995 b. Prevalence of depression after stroke: the Perth Community Stroke Study. *British Journal Psychiatry* 166:320-327.
- Creed F 1999. The importance of depression following myocardial infarction. *Heart* 82:406-408.
- DHAC (Department of Health and Aged Care) & AIHW (Australian Institute of Health and Welfare) 1999. National health priority areas report: cardiovascular health 1998. AIHW Cat. No. PHE 9. Canberra: DHAC and AIHW.
- Dewey HM, Thrift AG, Mihalopoulos C, Carter R et al. 2001. Cost of stroke in Australia from a societal perspective. *Stroke* 32:2409-2416.
- Disler PB, Cameron ID & Wilson SF 2002. Rehabilitation medicine. *MJA* 177:385-386.
- Early Supported Discharge Trialists 2003. Services for reducing duration of hospital care for acute stroke patients (Cochrane Review). In: *The Cochrane Library*, Issue 2, 2003. Oxford: Update Software.

- Edwards CRW, Bouchier IAD, Haslett C & Chilvers ER (eds.) 1998. Davidson's principles and practice of medicine, 7th edition. Edinburgh: Churchill Livingstone.
- Fonarow GC, Gawlinski A, Moughrabi S & Tillisch 2001. Improved treatment of coronary heart disease by implementation of a cardiac hospitalization atherosclerosis management program (CHAMP). *Am J Cardiol* 87:819-822.
- Goble AJ & Worcester MUC 1999. Best practice guidelines for cardiac rehabilitation and secondary prevention. Melbourne: Heart Research Centre.
- Hankey GJ 2000. Transient ischaemic attacks and stroke. *Med J Aust* 172(8):394-400.
- Hankey GJ & Warlow CP 1999. Treatment and secondary prevention of stroke: evidence, costs and effects on individuals and populations. *Lancet* 354:1457-1463.
- Hankey GJ, Jamrozik K, Broadhurst RJ, Forbes S et al. 1998. Long-term risk of first recurrent stroke in the Perth Community Stroke Study. *Stroke* 29(12):2491-2500.
- Hankey GJ, Jamrozik K, Broadhurst RJ, Forbes S et al. 2002. Long-term disability after first-ever stroke and related prognostic factors in the Perth Community Stroke Study, 1989-1990. *Stroke* 33:1034-1040.
- Hare DL & Bunker SJ 1999. Cardiac rehabilitation and secondary prevention. *Med J Aust* 171:433-439.
- Hochstenbach J 2000. Rehabilitation is more than functional recovery. *Disabil Rehabil* 22(4):201-204.
- Jamrozik K, Broadhurst RJ, Lai N, Hankey GJ et al. 1999. Trends in the incidence, severity and short-term outcome of stroke in Perth, Western Australia. *Stroke* 30: 2105-2111
- Jamrozik K et al. 2000. Monitoring the incidence of cardiovascular disease in Australia. AIHW Cat. No. CVD 16. Canberra: AIHW (Cardiovascular Disease Series No. 17).
- King KM, Humen DP, Smith HL, Phan CL et al. 2001. Predicting and explaining cardiac rehabilitation attendance. *Can J Cardiol* 17(3):291-296.
- Mollison LC, James-Wallace MJ, Kirke AB, Stein GR et al. 1999. Underuse of aspirin for secondary prevention of vascular disease. *Med J Aust* 170(7):339-341.
- National Heart Foundation of Australia & Cardiac Society of Australia and New Zealand 2003. Guideline for the prevention of cardiovascular events in those with known coronary heart disease. Accessed April 2003 (www.heartfoundation.com.au).
- NSW (New South Wales) Health Department 1997. New South Wales policy standards for cardiac rehabilitation. NSW Health Department.
- O'Connor GT, Buring JE, Yusuf S et al. 1989. An overview of randomized trials of rehabilitation with exercise after myocardial infarction. *Circulation* 80:234-244.
- Outpatient Service Trialists 2003. Therapy-based rehabilitation services for stroke patients at home (Cochrane Review). In: *The Cochrane Library, Issue 2, 2003*. Oxford: Update Software.
- Pollack MRP & Disler P 2002. Rehabilitation of patients after stroke. *Med J Aust* 177:452-456.
- Stroke Unit Trialists' Collaboration 1997. Collaborative systematic review of the randomised trials of organised inpatient (stroke unit) care after stroke. *BMJ* 314:1151-1159.
- Stroke Unit Trialists' Collaboration 2003. Organised inpatient (stroke unit) care for stroke (Cochrane Review). In: *The Cochrane Library, Issue 1*. Oxford: Update Software.
- Sturm JW, Dewey HM, Donnan GA, Macdonnell RAL et al. 2002. Handicap after stroke: how does it relate to disability, perception of recovery and stroke subtype? *Stroke* 33:762-768.

- Teasell R 2003. Stroke recovery and rehabilitation. *Stroke* 34:365–366.
- Thompson RT & Lewin RJP 2000. Management of the post-myocardial infarction patient: rehabilitation and cardiac neurosis. *Heart* 84:101–105.
- Thrift AG, Dewey HM, Macdonell RAL, McNeil JJ et al. 2000. Stroke incidence on the east coast of Australia. *Stroke* 31:2087–2092.
- Wade DT, Collen FM, Robb GF & Warlow CP 1992. Physiotherapy intervention late after stroke and mobility. *BMJ* 304:609–613.
- White MA & Johnstone AS 2000. Recovery from stroke: does counselling have a role to play? *Disabil Rehabil* 22(3):140–143.
- World Health Organization 2001. *International Classification of Functioning, Disability and Health*. Geneva: WHO.

Appendix A: Establishment of a minimum database for outpatient cardiac rehabilitation in Australia

This appendix was prepared by Steve Bunker, National Heart Foundation of Australia.

Why is cardiac rehabilitation important?

Cardiac rehabilitation programs minimise the risk of further cardiac events and help people return to an active and satisfying life. Cardiac rehabilitation attenders have been shown to have improved outcomes compared with non-attenders, including a reduction in mortality and better psychosocial functioning.

Lack of routine data collection and monitoring

The number of structured outpatient cardiac rehabilitation programs throughout Australia has grown considerably during the last 15 years. In 2001 there were 265 individual sites conducting outpatient programs.

Although much has been achieved in establishing these programs there is no routine data on:

- the nature of cardiac rehabilitation programs
- the numbers and characteristics of those who: a) are referred, b) attend, c) drop out
- health outcomes of attenders.

The following joint recommendation was made recently by the Australian Cardiac Rehabilitation Association and National Heart Foundation:

Each cardiac rehabilitation program should, at a minimum, collect the numbers of cardiac patients who are referred, as well as the proportion who enter and complete a rehabilitation program, including the basic demographic information of age, gender and diagnosis.

So far, progress in this area has been confined to ad hoc state and program-level initiatives as outlined below.

South Australia

In 2000 the National Heart Foundation (SA Division), the South Australian Cardiac Rehabilitation Association and South Australian Cardiac Rehabilitation Program Coordinators collaborated to develop a minimum data set for cardiac rehabilitation in South Australia and engaged all cardiac rehabilitation programs in data collection. The data provide information on:

- numbers of clients attending cardiac rehabilitation
- patient demographics
- who is referring patients to cardiac rehabilitation services
- the length of time between discharge and attendance at cardiac rehabilitation programs.

Data from the Department of Human Services can be accessed to identify the total number of patients eligible for cardiac rehabilitation and to make statewide estimates.

Victoria

In 1996 a pilot project involving 20% of programs in Victoria collected standardised data on basic demographics from cardiac rehabilitation attenders during a specified period. The data for program attenders were compared with data for all patients eligible to participate, identified from the Victorian Inpatient Minimum Database. Overall only 22% of eligible patients participated in cardiac rehabilitation following a cardiac event, with rates varying according to diagnosis (CABG 39%, AMI 14%, PTCA 20%).

During 1998–99 a more extensive study was undertaken in Victoria. Rates of participation in cardiac rehabilitation were 43% for CABG, 25% for AMI, and 26% for PTCA. Men were more likely to participate than women (27% versus 19%).

Queensland

To develop a statewide, strategic approach to cardiac rehabilitation services, and in response to a lack of data on program use, a centralised database for a minimum data set on cardiac rehabilitation was established in 2000. The majority of cardiac rehabilitation coordinators in Queensland agreed to participate in the pilot. The aim was to determine the basic demographics of cardiac rehabilitation participants to compare these with demographic data from Queensland Health. The results of the data collection were to be used to evaluate cardiac rehabilitation services and to improve the delivery of cardiac rehabilitation and secondary prevention programs. The data are held by Queensland Health but their release is embargoed until publication later in 2003.

Western Australia

An audit of outpatient cardiac rehabilitation programs in 2000 commissioned by the Western Australian Department of Health revealed fewer than 1 in 5 patients admitted to hospital for a cardiac condition were likely to receive rehabilitation. It was recommended that the department develop and implement an agreed data set for systematic monitoring and evaluation of service participation, adherence, quality, effectiveness and cost as part of a statewide strategy. Funding for the Western Australian Heartcare Strategy is being considered by the Western Australian Department of Health for 2003–04.

New South Wales

In New South Wales there is no statewide database or minimum data set for cardiac rehabilitation. However, several initiatives have been undertaken within individual Area Health Services, such as the one in the Hunter Area Health Service detailed below.

In the Hunter region a collaborative initiative including the University of Newcastle, the Hunter Area Health Service and the National Heart Foundation has established the Hunter Heart and Stroke Register. It monitors the incidence, prevalence and health outcomes of heart disease in the Hunter region and the data are used to improve and monitor quality of services.

In 1998, data were collected from all patients discharged from public hospitals in the Hunter region who were eligible for cardiac rehabilitation. Of all eligible patients, 43% reported being invited/referred, 28% reported attending and 19% reported completing a cardiac rehabilitation program. Of all those eligible for rehabilitation who did not attend or complete a program, 74% were not invited or referred to the program, suggesting that an important barrier to the use of rehabilitation services might be lack of routine triggers and referral systems.

Member of the Register project are now working with cardiac and stroke rehabilitation coordinators in the region to develop a minimum database for all participants in rehabilitation programs in the Hunter. The Register is exploring linkage of data to provide information on hospital readmissions and treatment and mortality data.

What is needed to establish routine data collection and monitoring?

It is proposed that:

- an advisory committee be established, with representatives from the National Heart Foundation of Australia; Commonwealth, state and territory health departments; the Australian Cardiac Rehabilitation Association; and other key stakeholders
- the advisory committee oversee a project to map current activities and investigate the feasibility of establishing a national cardiac rehabilitation database (Issues that require further investigation include the development of a national cardiac rehabilitation data set based on nationally agreed definitions; and linkages to other initiatives such as the proposed National Cardiac Procedures Registry.)
- the advisory committee report and make recommendations on the procedure, structure and management of a national cardiac rehabilitation database
- all cardiac rehabilitation programs be encouraged and supported to collect standardised routine data.

Expected outcomes of the database

Outcomes of a national cardiac rehabilitation database would include:

- baseline regional, statewide and national rates of use for cardiac rehabilitation programs
- identification of differences between program attenders and non-attenders
- development and evaluation of strategies to increase utilisation rates
- baseline data for ongoing monitoring and benchmarking of cardiac rehabilitation practice and service delivery
- data to support the further development and resourcing of programs
- information and data support to those who work in cardiac rehabilitation and secondary prevention.

Bibliography

Goble AJ & Worcester MUC 1999. Best practice guidelines for cardiac rehabilitation and secondary prevention. Melbourne: Heart Research Centre on behalf of Department of Human Services, Victoria.

McBurney H, Morrow L, Briffa T & Norton K on behalf of the Australian Cardiac Rehabilitation (ACRA) & the National Heart Foundation 2000. Performance indicators for cardiac rehabilitation programs.

Morris J & Bunker S 1998. Report on the development of a minimum database to identify participation rates and patient outcomes at outpatient cardiac rehabilitation programs in Victoria, Australia. Melbourne: National Heart Foundation of Australia.

Wenger NK et al. 1995. Cardiac rehabilitation: clinical practice guideline number 17.
Rockville, MD: US Department of Health & Human Services, Public Health Service, Agency
for Health Care Policy and Research and the National Heart, Lung and Blood Institute.

Appendix B: The National Stroke Unit Program

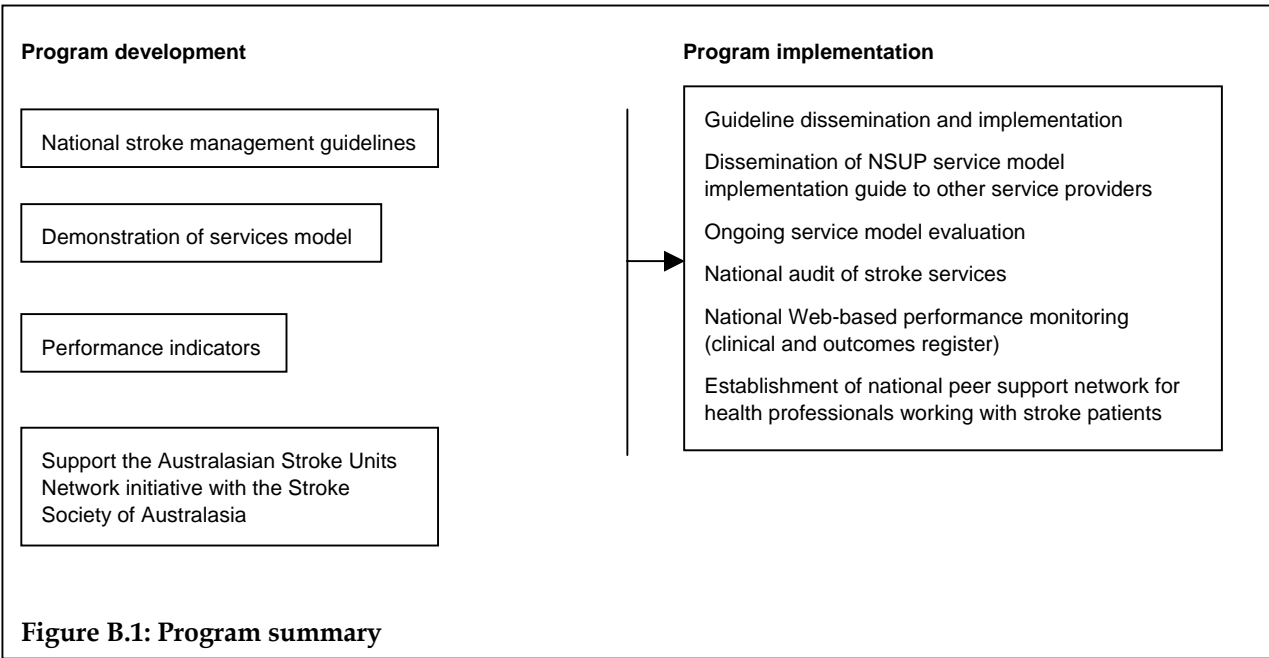
This appendix was prepared by the National Stroke Foundation.

The objective of the National Stroke Unit Program is to develop a cohesive stroke policy that identifies the key elements of clinical best practice. Such a policy will help to ensure that clinical best practice is implemented across a diverse range of clinical settings, resulting in coordinated stroke services throughout Australia. The policy will also support continual improvement of these services by establishing performance measures for the provision and monitoring of care for stroke patients (Table B.1).

The National Stroke Unit Program can be described in three distinct phases:

- Phase 1 includes a policy analysis and the development of a model. It also includes initial work on the development of a national set of guidelines for stroke management and validation of clinical performance indicators, as well as some formative evaluation of the model.
- Phase 2 entails further detailed evaluation of the program, a national health services audit and completion of the guidelines.
- Phase 3 involves the implementation of accreditation systems for stroke programs, program evaluation and program roll-out to other jurisdictions.

Figure B.1 summarises the major aspects of the program and shows how program development relates to program implementation.

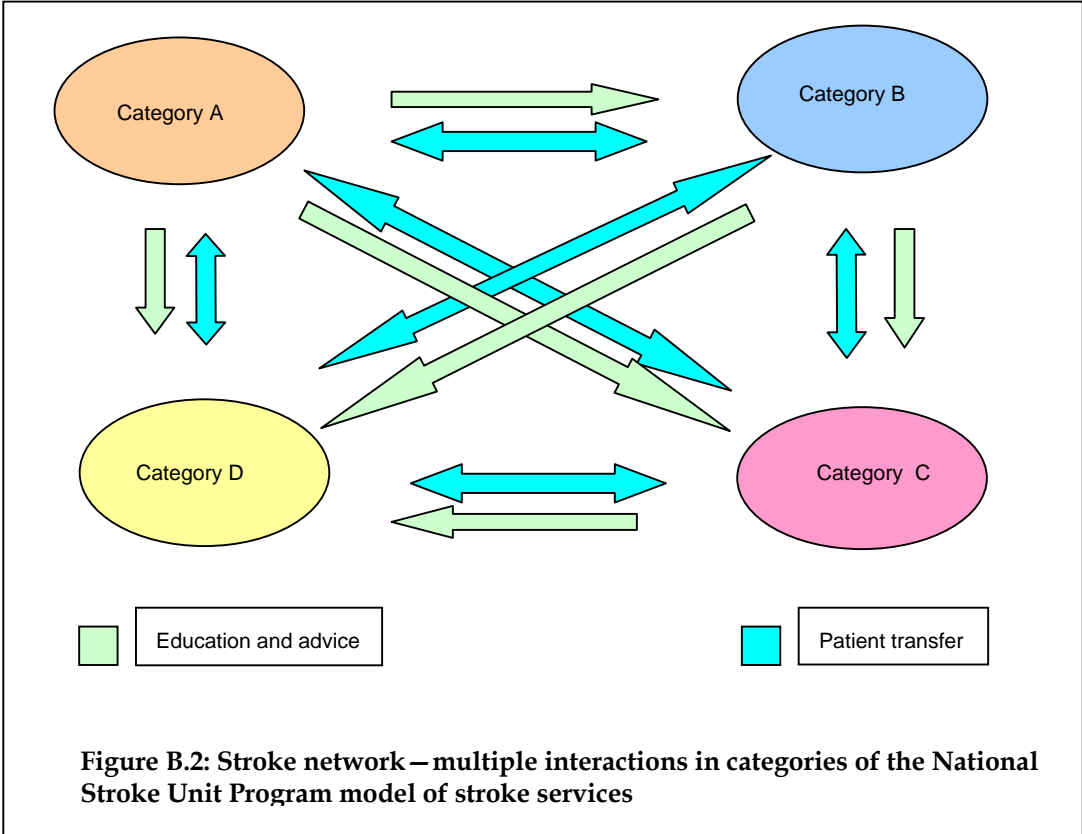


Work to date

The initial phase of the program has produced a policy document based on available literature, stakeholder meetings and expert consultation (NSF 2002). A set of process indicators has been identified for monitoring clinical practice at the local level and a model for delivering optimal stroke care across Australia has been conceptualised.

In developing a model of stroke care that aims to ensure equity for all Australians, it is acknowledged that it is inappropriate for similar levels of stroke unit care to be provided in all settings. It is also unlikely that all patients will require the same level of care. The model has therefore been graded across four categories of care defined by the structure and specialist resources available. An outline of the core or fundamental components of stroke care that should be provided in all settings is presented in Table B.1).

The model anticipates that, in organising care across different sites or within area health regions, clinical centres will work together to achieve optimal service delivery using the same protocols and care plans as part of an overall strategy to deliver best practice. The term 'stroke network' has been used to describe the process of communication and patient transfer that supports the development of 'virtual stroke units', ensuring optimal stroke care in facilities that do not necessarily admit enough stroke patients to warrant the dedication of a specialised unit (see Figure B.2). The network facilitates optimal stroke care via communication between hospitals of varying categories and provides access to education, stroke expertise and support. Protocols for identifying and transferring appropriate patients would also exist within the network.



The model proposes that stroke teams in less specialised centres (Categories B to D) are supported by health care teams in more specialised centres. This necessitates the development of a network among stroke service providers. Such a network would enable hospitals with limited access to resources for managing complex stroke patients to develop protocols for transferring patients and provide access to specialist advice from a more experienced stroke team. The network of stroke services may operate on the basis of administrative regions or clinical service networks. Depending on local needs and systems, support may be provided to all other categories by a primary 'Category A' facility, or a

system of flow-on support may be provided with each category supporting the team in the next category facility (see Table B.1).

The model aims to delineate how the implementation of clinical processes could permit smaller hospital sites to cooperate more closely with already established stroke units, and to provide a framework that guides the establishment of stroke units in larger hospitals. In this way, capacity is built within the health service system, within regions or networks of hospitals, permitting access to expertise and potentially other resources that may have previously been unavailable to patients and staff.

Table B.1: Stroke service model – summary

Component of care		Category A	Category B	Category C	Category D
STRUCTURE	Immediate access to computerised tomography (CT)	✓	✓	✓ (within 24 hours)	✗ Transfer to facility with CT with patient consent
	Access to high dependency unit ¹	✓	✓	✗	✗
	On-site access to neurosurgery ²	✓	✗	✗	✗
	Geographically located stroke unit	✓	✓	✓ (or a mobile stroke team with care plan)	✗ Recommend transfer Provide care required on-site via protocols
PROCESSES	Specialised, dedicated, multidisciplinary team	✓	✓	Multidisciplinary team supported by specialist team at Category A/B	Multidisciplinary team supported by specialist team at Category A/B
	Emergency department protocols for rapid triage	✓	✓(or transfer)	✓(or transfer)	Protocols for transfer
	Access to regular professional development and education relating to stroke	✓	✓	Access to professional development relating to stroke and support from Categories A & B	Access to professional development relating to stroke as required and support from Categories A & B
CLINICAL PROFILE	Management of all strokes including complex strokes	✓	✗	✗	✗
	Stable stroke	✓	✓	✓	✓
	Elected deviation from model Patient/physician informed decision not to adhere to model transfer recommendation in particular cases such as:	—	—	✓	✓
					<ul style="list-style-type: none"> • palliative care • low complexity care

1 High Dependency Unit (HDU): The recommendation for access to high dependency units at category A and B hospitals is made so patients who deteriorate may be appropriately managed. Access to a HDU may become a priority if tPA is licensed for use in Australia.

2 Neurosurgery: Access to neurosurgery is recommended for Category A model of care. This recommendation is made so that neurosurgical opinions and intervention regarding complex patients can be accessed (e.g. those diagnosed with hydrocephalus). In the event that tPA becomes licensed for use in Australia, the need for access to neurosurgery may become a consideration for authorisation to administer the drug.

Table B.2: Performance indicators identified for the National Stroke Unit Program for appropriate inpatients

Indicator	SCOPES	UK process domain	Readiness to implement
Documentation of swallowing ability within 24 hours of arrival at hospital	Yes	Initial assessment	Yes
Brain imaging with CT or MRI scan within 12 hours of arrival at hospital	Yes	Clinical diagnosis	Yes
Allied health assessment within 1 day of admission: physiotherapy assessment occupational therapy assessment speech pathology assessment	Yes	Multidisciplinary assessment and screening and functional assessment	Yes
A clinical care plan exists to avoid complications and promote urinary continence	Yes	Management and care planning	Trial
A multidisciplinary team meets with the patients and their carer within 7 days of admission	No	Communication with patients and carers	Trial
Appropriate discharge strategy: a timely and informative provision of a discharge summary	Yes	Primary/secondary interface	Yes
Commencement of aspirin for patients with a thrombotic or thrombo-embolic stroke within 24 hours of admission	Yes	—	Yes
Commencement of an anti-platelet or anti-thrombotic agent for patients with a thrombotic or thrombo-embolic stroke at time of separation	Yes	6-month follow-up and review	Yes
A self-management (consumer) care plan	No	Communication with patients and carers	Under development

The performance indicators are intended for all acute stroke services as well as being a tool to monitor and improve current practice. In addition, they must be viewed in the broader context of initiatives to improve quality and safety for patients.