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

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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.

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