

# NSW Chronic Care Program

Rehabilitation for Chronic Disease



Volume 1

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**NSW DEPARTMENT OF HEALTH**

73 Miller Street  
North Sydney NSW 2060  
Tel. (02) 9391 9000  
Fax. (02) 9391 9101  
TTY. (02) 9391 9900  
[www.health.nsw.gov.au](http://www.health.nsw.gov.au)

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Better Health Centre – Publications Warehouse  
Locked Mail Bag 5003  
Gladesville NSW 2111  
Tel. (02) 9816 0452  
Fax. (02) 9816 0492  
E-mail [bhc@doh.health.nsw.gov.au](mailto:bhc@doh.health.nsw.gov.au)

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# Foreword

It is estimated that chronic disease will account for up to 80 per cent of the healthcare burden by 2020 with many people having several co-morbidities. According to the Australian Institute of Health and Welfare the burden of chronic disease in 2005 is 43 per cent of all disease burden.

It is well known that rehabilitation is an integral component of the care of people with chronic disease. Comprehensive rehabilitation reduces the impact of chronic disease on health services through reduced re-hospitalisation and less reliance on other community services and treatment such as some medications. Moreover those people who have access to comprehensive rehabilitation services have an improved quality of life through increased functional capacity and a sense of control of their life through improved understanding of their disease and its management. An individual's input through self-management strategies improves adherence to their medical teams recommendations.

This guide to rehabilitation for chronic disease and its recommendations to Area Health Services have been drawn from the significant body of literature regarding best practice in gaining therapeutic outcomes for participants and best use of healthcare resources. It has also been informed through review of current services in NSW taking into consideration local needs and how services can be provided in unique circumstances. The guide also espouses the principles of the *NSW Chronic Disease Strategy 2006–2009*.

The document is published in two volumes. The first volume outlines the evidence and strategies required to have a positive impact on the participants and local communities. The second volume describes the common components of rehabilitation for chronic disease and provides some tools and links to references that support teams to provide this care.

We are pleased to endorse *Rehabilitation for Chronic Disease*. We commend the many contributors across NSW who gave of their time, knowledge and expertise to ensure this document meets the needs of the NSW Health system, collaborators and the community at large in managing the rehabilitation of people who have chronic disease.



Dr Simon Willcock  
**Chair, Chronic Care  
Implementation Advisory Group**



Professor Ron Penny AO  
**Senior Medical Advisor  
NSW Health**

# Executive summary

Chronic disease rehabilitation is an integral component in the care of people who are at high risk of developing a chronic disease, those newly diagnosed with a chronic disease, and those with significant and complex chronic conditions. There is much evidence to show that rehabilitation for chronic conditions is as effective as medical and surgical interventions.

Outcomes include:

- reduced admissions to hospital and subsequent length of stay
- reduced morbidity and mortality
- improved patient outcomes including functional and exercise capacity, and quality of life.

Goble and Worcester (1999) define rehabilitation for chronic disease as:

*'... the coordinated sum of interventions required to ensure the best physical, psychological and social conditions so that patients with chronic or post-acute disease may, by their own efforts, preserve or resume optimal functioning in society and, through improved health behaviours, slow or reverse progression of disease.'*<sup>1</sup>

Chronic disease rehabilitation ideal journey will involve the participants in:

- learning about their chronic disease process/es
- being supported to accept the disease/s
- learning about disease management according to the latest evidence
- improving functional exercise capacity and quality of life
- be supported in self-management strategies such as learning how to have input into their own care, maintaining appropriate medication regimens, and seeking follow-up surveillance over long periods of time

- being supported in behavioural modification using evidence-based approaches
- adopting healthy lifestyle behaviours that may include appropriate exercise, healthy diets, smoking cessation, and awareness of risk factors and their recommended parameters such as serum lipids, body weight, and hypertension
- being provided with strategies to improve and maintain psychosocial health
- maintaining skills and behaviours acquired in the long-term.<sup>2-4</sup>

In the NSW Health system service development priorities are:

- access to rehabilitation services for chronic disease Area-wide
- staffing – funded dedicated multidisciplinary teams who work across inpatient, outpatient and community settings and have access to clinical leadership for individual diagnostic groups
- automatic referral pathways to chronic disease rehabilitation
- acceptance of referrals from all avenues, especially general practitioners, self referral, community services such as Aboriginal Medical Services, migrant health services, nursing and allied health
- service delivery that includes multiple diagnostic groups, tailoring care to individuals with inclusion of families/carers, and integrated with medical teams
- provision of adequate venue and resources including administration support
- provision of service venue appropriate to acuity of intended participants e.g. people with cardiac disease who are assessed to be at high risk of further cardiac event will be provided with exercise sessions at a health service site where support is available in the event of an acute cardiac event

- service content that includes comprehensive assessment, psychological support and counseling, educational interventions and therapeutic individualised exercise prescription
- support for self-management strategies
- discharge from health care setting to community lead projects when the participant demonstrates and feels capable of self-management
- chronic disease rehabilitation staff involved collaboratively in the set-up, but not leadership, of community support for ongoing self-management support
- administration officers available to collect and analyse activity (recruitment and completion rates as versus potential), outcome data (functional, psychological, and quality of life status individually and collectively) and consumer satisfaction data
- review of chronic disease rehabilitation service six monthly with strategies to address service gaps
- development of collaborations with tertiary institutions and Area Health Service (AHS) research groups to support student clinical placements and research in the field of chronic disease rehabilitation.

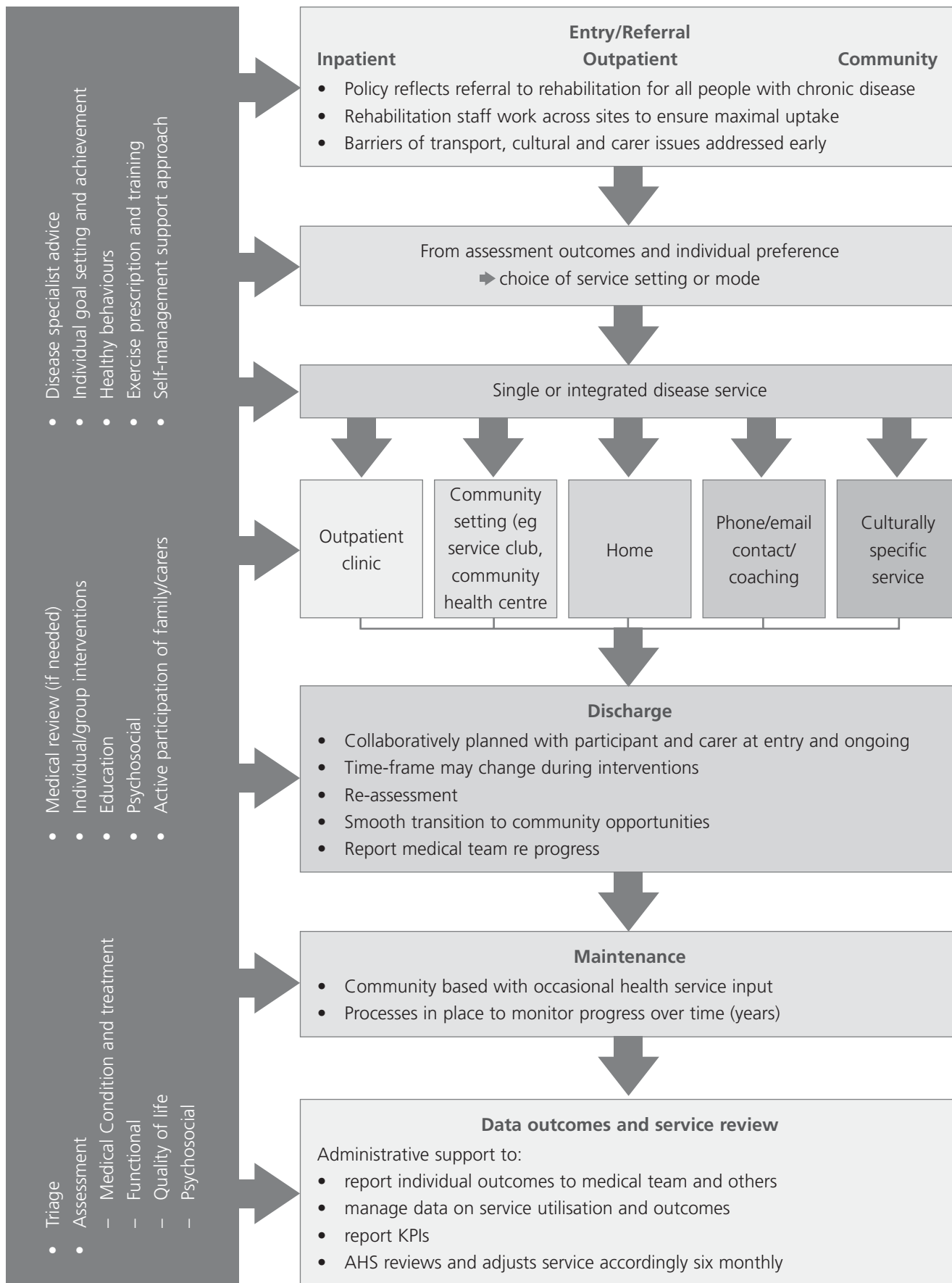
## Reporting of activities

To manage the implementation of chronic disease rehabilitation service priorities, NSW Health will do the following:

- 1 Implement key performance indicators that provide evidence of increased referral and participation rates to chronic disease rehabilitation services
- 2 Build and implant electronic point of care clinical systems for chronic disease rehabilitation service professionals. These will interface with general practice settings to allow easy exchange of assessment and information data.

**Figure 1: Model of Care for rehabilitation for chronic disease**

Aim: To provide a coordinated approach to rehabilitation care of people with (chronic disease) that ensures their best physical, psychological and social conditions are preserved or enhanced so that they may function optimally within society and, through their own improved health behaviours, slow or reverse progression of chronic disease.<sup>4</sup>



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Chronic disease will account for up to 80 per cent of the healthcare burden by 2020, and people with chronic disease will often have several co-morbidities.

Chronic disease rehabilitation is an integral component in the care of people with chronic disease including those who are at high risk of chronic disease, those newly diagnosed and those with significant and complex conditions. The key components of chronic disease rehabilitation include exercise, education (support to modify risk factors and self-management) and psychosocial support. The aim is that people achieve optimal physical and psychological function, to self-manage their disease, and to be active partners with their medical teams in decisions regarding their health care.

Chronic disease rehabilitation reduces readmissions to hospital and subsequent length of stay, and reduces morbidity and mortality. Further, chronic disease rehabilitation, for instance in the case of cardiac rehabilitation, is as effective as medications such as angiotensin converting enzyme inhibitors, beta blockers and statins. Chronic disease rehabilitation also improves patient outcomes including functional and exercise capacity and quality of life.

While it is recognised that many chronic disease rehabilitation services have been established and others re-designed across NSW since the *NSW Chronic Care Program* was funded in 2000, it is estimated that only 24 per cent of people with heart disease and one percent of people with chronic respiratory disease currently access rehabilitation services in Australia. There is much evidence that frail older people, women, people who live alone, and Aboriginal populations, commonly miss out on chronic disease rehabilitation. However, these groups have the greatest potential to gain from participation in chronic disease rehabilitation.

In addition to access considerations, there is evidence that some services are not providing consistent and evidenced-based care.

Therefore this document provides background information on the benefits of rehabilitation for chronic disease, descriptions of evidenced based requirements to achieve therapeutic outcomes, and some tools that maybe used in delivery of care.

## **Aim of ‘Rehabilitation for Chronic Disease’**

*Rehabilitation for chronic disease* aims to provide Area Health Service administrators, managers, and clinicians with an understanding of the requirements for providing evidenced-based, safe and therapeutic chronic disease rehabilitation for people with chronic disease.

This document replaces the *NSW Policy Standards for Cardiac Rehabilitation* published in 1997.<sup>5</sup> However, it could be linked in the future to a revised version of *A Policy Framework for Medical Rehabilitation* from 1995.<sup>6</sup>

*Rehabilitation for chronic disease* does not promote the replacement of current disease specific services. Rather this document aims to describe models of service delivery that will enhance access in some settings, especially where participant numbers are low and access to specialist clinicians and multidisciplinary teams are issues of concern for that locality.

An integrated model of chronic disease rehabilitation is intended to increase access to chronic disease rehabilitation for people with chronic disease and to address quality concerns. See diagram on page iv.

## Key issues

Key issues that require review and attention by Area Health Services to support this approach include:

### Access to rehabilitation services for chronic disease Area-wide

- Support access for population groups who have difficulty attending rehabilitation, such as the elderly, frail, females, Aboriginal, and people from culturally and linguistically diverse backgrounds.
- Provide flexible locations for chronic disease rehabilitation services such as outpatient, community (including local halls, service clubs, community gymnasiums) and home-based (home visits and telephone contact).
- Provide rural and remote community access through local community chronic disease rehabilitation and/or telephone linkages.
- Reduce waiting list to one week through telephone triage and counselling, and timely discharge from chronic disease rehabilitation to community services once self-management is evident.
- Access patient transport systems to meet the demand.

### Staffing

- Employ multidisciplinary teams as appropriate and available with dedicated hours for chronic disease rehabilitation including medical staff, nurses, physiotherapists, exercise physiologists, dieticians, social workers, occupational therapists, psychologists, podiatrists, and speech pathologists.
- Access local mental health professionals qualified to diagnose and manage depression/anxiety.
- Provide clinical leadership to support specialty diagnostic group interventions.
- Access professional development related to rehabilitation for chronic disease for team members.
- Review outcomes six monthly to determine if dedicated staffing hours meet population demand.

### Referral pathways to chronic disease rehabilitation

- Develop clinical pathways which include automatic referral to chronic disease rehabilitation.
- Support inpatient visits by chronic disease rehabilitation staff to introduce the concept of ongoing rehabilitation post discharge from hospital.
- Accept referrals from all avenues, especially general practitioners, self referral, community services such as Aboriginal Medical Services, migrant health services, nursing and allied health.

### Chronic disease rehabilitation service delivery

- Include multiple diagnostic groups such as people with cardiac disease (including people with heart failure), chronic pulmonary disease, diabetes, other vascular disease such as peripheral vascular disease and carotid disease, cancer and stroke (following formal stroke rehabilitation).
- Tailor to individual needs and co-morbidities.
- Encourage active participation of family/carers.
- Provide therapeutic yet safe intensity of exercise prescription.
- Integrate with and support medical care.
- Provide adequate venue and resources including administration support.

### Chronic disease rehabilitation service content should include

- Comprehensive initial assessment with ongoing assessment of parameters such as blood pressure only if indicated.
- Exercise assessment, prescription and training.
- Education including disease pathophysiology, its investigation and treatment, and recognition of risk factors and their modification.
- Psychosocial support and counselling.
- Support for self-management strategies.

### **Discharge from chronic disease rehabilitation**

- Discharge is not timed to follow completion of set sessions.
- Chronic disease rehabilitation should be a time-limited intervention within health care settings.
- Discharge is determined by evidence of an individual's understanding of their disease, it's management and demonstration of self-management as an individual feels capable.
- Discharge to community led services such as Heartmoves, Lungnet, Heart Support Australia groups and other programs set in local gymnasiums and service clubs.
- Chronic disease rehabilitation staff involved collaboratively in the set-up, but not leadership, of community support for ongoing self-management support.

### **Monitoring and data collection**

- Provide administration officers to support chronic disease rehabilitation clinicians to collect and analyse activity (recruitment and completion rates as versus potential), outcome data (functional, psychological, and quality of life status individually and collectively) and consumer satisfaction data.
- Report to NSW Chronic Care Program includes referral, participation and completion rates.
- Review chronic disease rehabilitation service six monthly with strategies to address service gaps.

### **Development of knowledge**

- Collaborate with tertiary institutions to support student clinical placements.
- Develop collaborations with AHS research groups and tertiary institutions to develop, implement and formally support research in the field of chronic disease rehabilitation.

See Figure 1 on page iv for the model of care.

Rehabilitation is an integral component of the care of people with chronic illness<sup>7</sup>. It is a process that begins at diagnosis or when an individual is identified to be at high risk of a chronic disease, and continues through the continuum of the disease.<sup>2</sup> The key components of chronic disease rehabilitation include exercise, education, self-manage support, psychosocial support and strategies to modify other risk factors. The NSW Chronic Care Program includes rehabilitation as a standard in both the Clinical Service Frameworks for Heart Failure and Chronic Respiratory Disease.<sup>8,9</sup>

This document has been developed to replace the *NSW Policy Standards for Cardiac Rehabilitation* released in 1997.<sup>5</sup> In the future it may be linked into a revised version of *A Policy Framework for Medical Rehabilitation* from 1995.<sup>6</sup>

Only about one percent of people with chronic obstructive pulmonary disease (COPD) receive pulmonary rehabilitation services in Australia and only 24 per cent of the relevant population receive cardiac rehabilitation, despite the international documentation of the benefits of chronic disease rehabilitation.<sup>10-11</sup> Access to chronic disease rehabilitation is not uniform across NSW as indicated by reporting by Area Health Services (AHS) on implementation of the Clinical Service Frameworks.

There have been many constraints on providing standardised high quality chronic disease rehabilitation services in NSW and it is recognised that existing services are variable in standard and quality. A lack of Australian evidence regarding chronic disease rehabilitation has contributed to these constraints. Additionally, there has been a lack of direction towards innovative approaches such as the incorporation of varied diagnostic groups into one service and flexibility regarding site of service and methods of service delivery. In recent years the Australian evidence surrounding the elements of chronic disease rehabilitation has grown considerably including what constitutes therapeutic exercise, self-management strategies, behaviour change and individualised, tailored service provision.<sup>2, 12-13</sup>

Consultation with many services in NSW indicates that gaps exist in the provision of high quality chronic disease rehabilitation services for all those who could benefit from chronic disease rehabilitation. These include, but are not limited to, the exclusion of some diagnostic groups such as people with diabetes and those who have had strokes, as well as population groups such as frail older people and those awaiting investigation. Some services exclude people referred from general practitioners and sources other than specialists.

Most chronic disease rehabilitation in NSW is provided through single disease specific services such as cardiac, pulmonary and stroke rehabilitation, which are supported by a strong international body of evidence. However, in areas where resources are limited an alternative option is to coordinate rehabilitation for a number of chronic diseases into one service. In this way, chronic disease rehabilitation services can provide more equitable access to those who require this care.

This paper provides an overview of rehabilitation for chronic diseases and discusses a range of issues related to the delivery of rehabilitation services in the context of chronic care in NSW. The paper does not address the needs of people following accidents, and dementia. Rehabilitation for these conditions is highly specialised, with interventions provided within specialist health professionals. Their needs cannot be effectively addressed within the services described in this document.

Additionally, the specialised rehabilitation following acute stroke is separate to that provided for people with other chronic diseases and usually occurs in the inpatient setting. Following discharge from specialised stroke services the individual may make further gains by enrolling in chronic disease rehabilitation.

The issues and barriers for effective chronic disease rehabilitation service delivery are outlined, as well as concepts of contemporary chronic disease rehabilitation. Approaches to service delivery and expected outcomes of rehabilitation for chronic diseases consistent with the published international and Australian literature are described. Issues identified through site visits and discussion with relevant AHS staff, are incorporated in the paper.

The key issues addressed include access to chronic disease rehabilitation area-wide, staffing, referral pathways to chronic disease rehabilitation, chronic disease rehabilitation service delivery and content, discharge from chronic disease rehabilitation, monitoring and data collection.

## Definition

This paper refers to rehabilitation for chronic disease. The World Health Organisation (WHO) definition of *rehabilitation* encompasses care provided for people (families and carers) who have chronic diseases such as cardiac (including heart failure), respiratory, diabetes, vascular disorders, stroke and cancer, and also rehabilitation after events such as accidents and surgical procedures. Services for frail older people also come under the scope of *rehabilitation*. The broad definition of rehabilitation as described by the WHO is:

*'... a process that assists people with disabilities to develop or strengthen their physical, mental and social skills to meet their individual/collective specific skills'.<sup>7</sup>*

Goble and Worcester (1999)<sup>1</sup> provide a definition that includes concepts from the WHO, the United States Public Health Service and the European Society of Cardiology. They describe rehabilitation as:

*'... the coordinated sum of interventions required to ensure the best physical, psychological and social conditions so that patients with chronic or post-acute (cardiovascular) disease may, by their own efforts, preserve or resume optimal functioning in society and, through improved health behaviours, slow or reverse progression of disease.'*

The American Thoracic Society (1999)<sup>14</sup> describes pulmonary rehabilitation as:

*'a multi-disciplinary program of care for patients with chronic respiratory impairment that is individually tailored and designed to optimize physical and social performance and autonomy'.*

## Changing approaches to chronic disease rehabilitation

Provision of chronic disease rehabilitation services has changed dramatically over recent years in response to the emerging Australian and international evidence.<sup>15-19</sup> Service providers have moved from the previously highly structured, didactic approach where 'classes' for exercise and education are held on a weekly basis with all participants performing the same exercise tasks and receiving pre-selected education topics. A more individualised approach has evolved. While certain educational requirements are still met, the focus now is on addressing the individual's concerns and needs, and timing the chronic disease rehabilitation service to individual requirements.

The following addresses some of the beliefs concerning chronic disease rehabilitation that have evolved through previous practice that was not evidenced based.

**Belief** – rehabilitation is for a set group of people such as those with stable coronary artery disease or those with chronic obstructive pulmonary disease who do not require continuous oxygen therapy.

**Response** – evidence supports rehabilitation being effective care for all people with chronic conditions, even if their condition is unstable. While exercise prescription is contraindicated for a few people, education and counselling is known to relieve elements of anxiety, improve mood, and can help with stabilisation of their condition.<sup>20-21</sup> Oxygen dependent people who have COPD can increase their functional capacity and quality of life with a long-term exercise program.<sup>22</sup>

**Belief** – people who are debilitated, frail or have severe/significant disease should not be involved in exercise programs.

**Response** – there are very few contra-indications to exercise prescription, both aerobic and strength training. (See Vol 2, Sections 6 and 7). Evidence-based guidelines are available from the National Stroke Foundation,<sup>23</sup> the American Heart Association,<sup>24-25</sup> the Australian Lung Foundation,<sup>10</sup> and American Diabetes Association.<sup>26</sup>

**Belief** – people who are waiting for investigations or treatment after discharge should not be involved in exercise programs.

**Response** – low intensity exercise for people awaiting further investigations or cardiac revascularization is beneficial and safe.<sup>18</sup> If medical assessment deems discharge to be safe and the individual is asymptomatic, a low intensity exercise program may proceed in a health facility in most cases. Sedentary behaviour is contraindicated as it results in physical de-conditioning and a decrease in quality of life.

**Belief** – referrals to rehabilitation can only be made by a medical specialist.

**Response** – many localities do not have medical specialists and people are successfully referred from the general practitioner or the respiratory/cardiac ward following an admission. Self-referral is also appropriate (WHO states that we all have a right to rehabilitation). A thorough assessment as outlined in Volume 2, Section 3 and 6 will identify any contraindications to the exercise component.

**Belief** – participants in rehabilitation for chronic disease are required to attend all aspects of the service.

**Response** – many participants require far more than the routinely offered aspects of rehabilitation, such as many months of attendance due to disease severity or frailty. Others require only a few sessions before it is identified that they are self-managing and may be discharged to a community support service.

**Belief** – people with heart disease should not raise their arms above their head.

**Response** – there is no evidence to suggest that this is detrimental to people with heart conditions. All activities of daily living (including hanging clothes on the line) and exercise are introduced to the individual incrementally. This is especially important for those with significant disease, and is graduated according to symptoms.

## Core components of chronic disease rehabilitation

The core components of chronic disease rehabilitation aim to assist participants to augment medical therapies through:

- 1 appropriate assessment and investigation to ensure safety yet therapeutic outcome
- 2 individualised goal setting
- 3 exercise to improve function, endurance and strength
- 4 education on topics that could include disease process, disease management and recommended therapies, and modification of risk factors
- 5 nutritional advice
- 6 mechanisms to assess and address psycho-social support
- 7 supportive measures to promote self-management in the long-term.

Stress and anxiety are often magnified with the diagnosis of a life-threatening and chronic disease.<sup>2, 18-19</sup>

Rehabilitation services aim to support participants towards self-care (function and quality of life), and enhance self-management. This involves individuals and care-givers having input to decision-making regarding participation in health promoting behaviour, behavioural modification, goal setting, and adjusting to living with a chronic disease. These strategies are implemented across all health care settings including the inpatient, outpatient and community settings.

Diabetes education, while not formally recognised as chronic disease rehabilitation, incorporates many of the concepts of rehabilitation including patient and carer health education and support to incorporate healthy behaviour change into everyday life.

It is recognised that people with a variety of co-morbidities will be involved in chronic disease rehabilitation.

The main aims and purpose of participation in chronic disease rehabilitation will be to:

- learn about their chronic disease process/s
- be supported to accept the disease
- learn about disease management according to the latest evidence
- improve functional exercise capacity and quality of life
- be supported in self-management strategies such as learning how to have input into their own care, maintaining appropriate medication regimens, and seeking follow-up surveillance over long periods of time
- be supported in behavioural modification using evidence-based approaches
- adopt healthy lifestyle behaviours that may include appropriate exercise, healthy diets, smoking cessation, and awareness of risk factors and their recommended parameters such as serum lipids, body weight, and hypertension
- be provided with strategies to improve and maintain psychosocial health
- maintain skills and behaviours acquired in the long-term.<sup>2-4</sup>

## Behaviour change theory

An understanding and application of behaviour theory is a vital underpinning of all activities within chronic disease rehabilitation. Knowledge of validated theories provides service providers with an understanding of participants' responses, actions and challenges in changing behaviour. With this understanding the service providers are better able to initiate activities and be supportive of individuals who are identified to need this aspect of care.

Some examples of behaviour theories and models of behaviour change that may be used in chronic disease rehabilitation settings are *Social Learning Theory*,<sup>27</sup> *Stages of Change*,<sup>28</sup> *Theory of Reasoned Action*,<sup>29</sup> *Self-management models of care*,<sup>12, 30</sup> the *Health Belief Model*,<sup>31</sup> *Health Locus of Control*,<sup>32</sup> and *Adult Learning Theory*.<sup>33</sup> Section 1 and 2 in Volume 2 provide a brief overview of some of these.

## Efficacy and benefit of chronic disease rehabilitation

The efficacy of chronic disease rehabilitation using established models of service delivery is well documented in the literature.<sup>2, 10, 34</sup>

Effective chronic disease rehabilitation results in improved **physical and psychological** outcomes, and better **health care utilization**, including hospital admissions and readmissions (see box below). Many studies demonstrate that chronic disease rehabilitation is as effective as some drug therapies such as angiotensin-converting enzyme inhibitors, betablockers and statins.<sup>35-36</sup> The effectiveness from each intervention (medications and chronic disease rehabilitation) is cumulative and contributes to further decrease in morbidity and mortality.

### Reduced health service utilisation

Pulmonary and cardiac rehabilitation have demonstrated economic benefits through reduced health service utilisation. It has been reported that implementing cardiac rehabilitation to all of the relevant population would actually save costs for the health care system through reduced hospital days and resource usage.<sup>35</sup> Further evidence reveals:

- persistent reductions in health care utilisation through less hospital days and visits to physicians by people who attend rehabilitation<sup>22</sup>
- people with heart failure who have received multidisciplinary management strategies in the community have a 4 per cent reduction in hospital admissions<sup>36</sup>
- rehabilitation is cost-effective when compared to other cardiology interventions such as medication, surgical and interventional procedures.<sup>35, 37</sup>

## Improved participant outcomes

- Cochrane reviews have concluded that cardiac rehabilitation reduces all cause mortality by 26–31 per cent.<sup>38</sup>
- Pulmonary rehabilitation increases functional exercise capacity, reduces dyspnoea and improves quality of life despite minimal effect on pulmonary function.<sup>39</sup>
- Patient education alone does not improve exercise tolerance or lung function. However there is strong evidence of its effect in supporting people to react to exacerbations in a more timely and appropriate manner, to medicate as requested, and to support risk factor modification e.g. smoking cessation.<sup>19, 34, 40</sup>
- Cochrane reviews have found that diabetes education, when applied in a variety of service delivery models, improves diabetes management and patient outcomes.<sup>41-44</sup>
- Stroke rehabilitation is a highly specialised service that improves function and quality of life in people following an acute stroke.<sup>23, 45</sup>
- Rehabilitation as described in this paper will improve the quality of life for people with cancer and there is also suggestion that exercise and improved nutrition will improve survival rates.<sup>46-51</sup>

## Overall outcomes of rehabilitation for people with chronic disease

Overall, participant outcomes of rehabilitation for chronic disease include:

- improved haemodynamic function
- reduced risk of further acute events
- reduction of and improved management of symptoms
- improved adherence with medical therapies
- improved self-management strategies
- improved psychological health
- reduction of identified risks for chronic disease
- increased functional exercise capacity
- improved muscle strength
- improved quality of life
- reduced dyspnea.<sup>2-4</sup>

## Under-utilisation of chronic disease rehabilitation services

Currently the potential health and economic benefits for individuals and health services from chronic disease rehabilitation are not being realised. Despite the evidence cited above there is **under utilisation of chronic disease rehabilitation services**.<sup>52-53</sup>

Factors which contribute to under-utilisation include:

- lack of medical referral
- lack of awareness by the general public of services available
- individual's not perceiving the need
- being female eg neglect of self due to carer role within the family structure
- living alone
- lack of transport and distances to service
- severity and instability of disease
- limited staff, facilities and appropriate equipment to manage participant numbers
- being a frail or older person.

To improve uptake of chronic disease rehabilitation a range of strategies have been proposed such as varying models of care, reviewing the service sites, utilising primary health care providers, advertising services, and adopting day-to-day practices which will improve utilisation of services.<sup>16, 17, 54-56</sup>

The following section provides a guide to the issues which need to be considered by Area Health Services in providing appropriate and accessible rehabilitation for people with chronic disease. These recommendations are evidence based, therapeutic and safe for participants and staff.

Area Health Services need to:

- review the available evidence relating to chronic disease rehabilitation
- review the local population demographics (including cultural issues) and particular needs
- offer a range of service delivery models
- build processes to allow flexibility to meet the needs of the local community
- review the currently available resources and those needed to allow accessible and effective chronic disease rehabilitation to be provided.<sup>17</sup>

Appropriate chronic disease rehabilitation models need to be developed by each Area Health Service through consultation with their community, potential service providers, and local health administrators. Hours of operation, such as the need for after-hour services, generic (combined) and disease specific rehabilitation models need to be considered. As individuals will have a choice of service model, it is anticipated that many of the barriers noted in section 2 will be overcome and participation rates will be enhanced. It is preferable that one team, working together and co-located, using the model of chronic disease rehabilitation will provide consistency of approach, avoid duplication of services, and maximise resource utilisation.

## Service model settings

The following settings are options for the delivery of chronic disease rehabilitation. Participant goals of their individual chronic disease rehabilitation may be defined (and re-defined) in any of these settings.

### Inpatient services

The inpatient setting is where many participants will begin their chronic disease rehabilitation. It aims to improve function/mobilisation and provide basic information to enable the individual and their family/carer to begin the process of self-management, which will continue in the outpatient and community setting. Examples include:

- mobilisation with or without aids
- discussion of activities of daily living and home assessment as necessary
- symptom recognition
- early consultation with their general practitioner
- maintenance of medicines
- quit smoking strategies and support
- basic dietary advice
- strategies to overcome social isolation.

Inpatient and chronic disease rehabilitation team members provide the interventions. Working together at this point of care is vital for supporting ongoing participation by the individual and their family/carers.

Further notations on *Strategies to enhance referral and access* are provided on page 16.

## Outpatient-based services

All participants can attend outpatient-based chronic disease rehabilitation with safety including those at high risk of further acute events.

Provision should be made for a fast-track service for the following situations:

- People returning to work early.
- People with prior understanding who are progressing well with psychological and physiological parameters.
- People requiring an update/refresher/motivation service.

Provision should also be made for a longer periods of chronic disease rehabilitation in the following situations:

- When individuals are not progressing as well as expected such as people on long term oxygen therapy.
- When frailty, disease progression, exacerbations and readmissions prevents achievement of functional gains.
- When recovery is complicated by psychological issues such as anxiety and depression.<sup>57</sup>

## Community-based services

Community based chronic disease rehabilitation allows the service to be taken to the participant and is especially useful when participants live far from a large centre.<sup>58</sup> Community settings include community halls, service clubs, day centres through the *Home and Community Care Program*, and others. A full range of services (education, self-management, exercise and psycho-social support) can be successfully delivered in these settings. The exception is the exercise component for people at high risk of further cardiac events, those waiting for further diagnostic testing (angiography) and those who have recently survived an event that involved cardiogenic shock.<sup>18</sup> See Volume 2 Section 6 and 7 for more detailed information. The venue in this instance must be a health service where support is available to manage an acute cardiac event.

## Home visiting services

Home visiting chronic disease rehabilitation is useful for frail, unwell people or those who exhibit signs of concern at leaving their homes.<sup>17</sup> They are also useful when carers are confined to the home due to their own illness or caring duties for other dependents. Home visits often result in early resolution of problems and then outpatient or community-based services can be accessed. If this is not possible the support provided

ensures correct medication schedules are being followed and provides basic education on self-management strategies and gentle exercise. The participant feels better and is more functional around their home. Further exacerbations of the disease will often be detected earlier and admission to hospital avoided.

Linkages can also be made with other community-based home services such as *Community Aged Care Packages*. These service providers can work with the rehabilitation team to support the participant to achieve rehabilitation for chronic disease goals.

## Telephone and email services

Advice by telephone and/or email is suitable for those who are unable to attend a face-to-face service for a variety of reasons such as distance, work commitments or individuals not being amenable to face-to-face service. Telephone based services are best for education and psychosocial support only as it is not possible to adequately and safely prescribe exercise over the telephone. If the participant has attended chronic disease rehabilitation for exercise assessment, including functional assessment, telephone contact may be used to provide encouragement to maintain and progress newly learnt behaviours including exercise.

It must be recognised that telephone support has been used with only moderate success as a maintenance program in respiratory patients<sup>59</sup> and has been shown to be not as effective as face-to-face services with people who have heart disease.<sup>37</sup> When used as an adjunct to 'usual care' (chronic disease rehabilitation and physician follow-up) telephone support to risk modify has been shown to be effective,<sup>60</sup> but this is only one component of chronic disease rehabilitation.

## Telehealth initiatives

Telehealth initiatives may be implemented across NSW in the future and may provide opportunities for access to chronic disease rehabilitation for some people in remote communities.

## Combination of settings

Combinations of the above service delivery settings can cater for participants who have difficulty accepting or accessing usual care and would not access services otherwise.<sup>61</sup> Examples include Aboriginal populations, other cultural groups, those living in rural and remote area, those returning to work and those people with no access to transport.

## Established model of a combination of services to meet a community need

The northern sector of North Coast Area Health Service is an example of how a combination of rehabilitation settings can work. The models of delivery for cardiac and pulmonary rehabilitation include:

- facility-based, standardised 6–8 week multidisciplinary program (available within 30 minutes drive along the more populated coast)
- education only, facility-based program with community exercise diary (when waiting times for cardiac rehabilitation are excessive)
- shortened facility-based program for those risk-stratified (low risk participants only) that enables early return to work and targets specific educational requirements
- home-based community programs which can be tailored in both content and length to suit individual requirements (ideal in areas with smaller participant numbers or where access to facility based program is limited). A complete kit for managing home-based cardiac rehabilitation was produced with an individualised, interactive patient information pack – ideal for general community health workers. Available from [kwilcox@nrdgp.org.au](mailto:kwilcox@nrdgp.org.au)
- home and clinic-based heart failure programs
- Aboriginal heart health programs [with funding and support from the Aboriginal Vascular Health Program], in addition to existing programs such as the Aboriginal Heart Care Group in Tweed Heads
- loan of equipment across sites
- support for generalist clinicians by area-based specialists
- combined heart failure and pulmonary rehabilitation programs.

## Staffing for chronic disease rehabilitation services

The following issues need to be addressed when staffing chronic disease rehabilitation services.

### Multidisciplinary care

It is important that chronic disease rehabilitation services are delivered by multidisciplinary teams.<sup>2, 4, 10, 19, 23</sup>

Team members should have equal input into the structure and any changes to delivery of the service.

This ensures expertise is provided for a range of chronic disease rehabilitation components. Team members may be drawn from, but not limited to, medical officers, nurses, physiotherapists, dieticians, occupational therapists, social workers, psychologists, podiatrists, exercise physiologists, Aboriginal health workers, multicultural health workers, pharmacists, speech therapists, and podiatrists.

### Team expertise

Health professionals involved in chronic disease rehabilitation services will vary depending on availability of staff. In many metropolitan hospitals there is greater availability of staff who specialise in disease specific areas. In the community and rural settings, staff tend to have general experience. Whatever the situation, staff need support to develop further understanding of the disease groups involved in their services. As well as disease management education, staff require education and training in behaviour change theory (including self-management), its application and in the identification and support of people with psychological needs.

### Service coordination

The chronic disease rehabilitation service will usually have a nominated coordinator with a degree or diploma or certificate of registration in a health professional field.<sup>2, 19, 23</sup>

While some team members may not have an appropriate degree, diploma or certificate in health, such as Aboriginal Health Workers, other team members can perform assessments, prescribe exercise and deliver the clinical aspects of the service.

Some rural locations may have a coordinator across sites; larger services will require a coordinator for each site.

## Administrative support and data management

Administrative support should be available to support chronic disease rehabilitation services. This ensures clinicians and other workers time is used in the most effective manner. Roles include:

- sending letters of appointments and other relevant material to participants
- registration of participants on appropriate databases
- ensuring data (discharge summaries, reports, etc) are available for the clinical team
- forwarding adequate notification of enrolment and outcomes to general practitioners, specialists and others assisting with data management
- data management (entering, analysing, reporting outcomes).

## Clinical support

It is imperative that chronic disease rehabilitation team members are given the opportunity for ongoing education and counselling. It is acknowledged that in many areas of NSW, disease specialists (medical, nursing and allied health professionals) are not available and staff may need to access information in other ways eg teleconference, videoconference. Other approaches could be introduced with memorandums of understanding with other AHSs to access appropriate clinical governance.

## Established model of specialist clinical support for multidisciplinary teams in rural communities

The northern region of Hunter New England Area Health Service provides clinical support and a multidisciplinary team approach across the Area Health Service through:

- centrally located specialist support person – cardiovascular and respiratory
- clinical manuals/tools/resources to support work with diagnostic groups
- email discussions and sharing of resources
- site attendance by specialist support person on a regular basis and as needed
- integrated cardiac, respiratory and diabetes diagnostic groups in some areas
- sessions at the various sites have a clinical leader or remote access to an expert, so that specific issues may be addressed and/or answered in a timely and accurate manner
- allied-health staff incorporated according to availability with their expertise used broadly according to need.

## Referral and access to services

Individuals have a right to chronic disease rehabilitation no matter their race, socio-economic circumstances<sup>7</sup> and also the right to decline services.<sup>62</sup>

### Area Health Services require processes that:

- increase access – through enhanced referral processes such as chronic disease rehabilitation being included on clinical pathways as a part of usual care, and decreased waiting lists to no more than a week (longer only for individual preference/needs)
- incorporate care coordination where required
- increase referral to ancillary services such as quit smoking programs
- provide opportunities for all people with chronic disease to attend a chronic disease rehabilitation service. No matter what their diagnosis, all can benefit in some way no matter how severe their disease, co-morbidities, gender or age<sup>19, 63</sup>
- include older or frail people into chronic disease rehabilitation services. Evidence indicates that the more infirm and/or elderly participants make the most gains in chronic disease rehabilitation services<sup>64</sup>
- include those who require only some of the components of chronic disease rehabilitation such as those requiring an update on disease management
- incorporate flexibility of service. This may include providing a variety of hours of operation, education and counselling only, short and long-term services, individual and group sessions
- ensure follow-up so participants are not lost to the health system such as those who are referred out of their home locality for diagnostic care and treatment which is not available locally, particularly rural and remote areas
- liaise and collaborate with other service providers, such as aged care services, to identify the most appropriate service for the individuals as well as to share knowledge regarding existing services, such as community transport.

## Strategies to enhance referral and access

### Facilitate inpatient visiting

Chronic disease rehabilitation staff can help overcome access issues by visiting people while they are in hospital. This enables:

- patient and family familiarity with chronic disease rehabilitation staff
- early identification of possible barriers to access such as transport and early return to work
- reassurance that the service can provide benefits even if the patient is very unwell or in a high risk category
- brief assessment which may identify problems that can be solved by knowledge of community care or resources
- links with some health workers to ensure entry to outpatient/community services such as psychologists and social workers (when psychological distress is identified) and Aboriginal health workers, to promote participation of Aboriginal populations
- early involvement, which increases the likelihood of ongoing participation. People who are hospitalised away from their home (people from rural areas in tertiary hospitals) can have early connection to their local services organised by chronic disease rehabilitation staff before discharge.

### Follow-up phone calls

Chronic disease rehabilitation staff should make follow-up phone calls approximately two days following discharge or have other processes in place that ensures early intervention, eg appointment made before discharge with follow-up date, time, and venue location. Phone calls provide an opportunity to recruit participants into the outpatient or community chronic disease rehabilitation service, as well as a quality improvement initiative to assess how discharge instructions are being followed.

These calls signify entry to the outpatient or community-based service as they are part of the initial assessment that supports decisions on what services are required and when. The calls provide an excellent opportunity to assess the individual's need for early psychological assessment and referral. Early intervention results in enhanced participation, an opportunity for social support and management of psychological distress.

## Established model of strategies to enhance access

### Fairfield Health Service in Sydney South

**Western Area Health Service** has high recruitment (60 per cent in 2004), participation and completion rates (81 per cent in 2004) in their cardiac rehabilitation service. Reasons for this include:

- local policy that allows recruitment without medical referral
- rehabilitation is incorporated into the clinical pathway
- inpatient visits to potential attendees are routinely conducted several times each week to address potential barriers to attendance
- phone calls made within a day or two to all people referred and/or following discharge from hospital
- telephone contact made with individuals who fail to attend over a week period – remaining in contact to discuss progress promotes participant confidence in the service.

### Home-visiting service

This allows chronic disease rehabilitation to begin in the home and results in confidence building, optimisation of medication and other therapies and referral to outpatient or community-based services.

### Referral processes

Referrals should be accepted from the following sources:

- Hospital settings.
- Other health services/hospitals.
- Specialist medical practitioners.
- General practitioners.
- Nursing.
- Allied health.
- Community services/programs/community members.
- Self/family (see notations on page 17 re need for medical team member intervention).

Referrals from the above sources are safe as services adopt a comprehensive assessment of all participants on entry to chronic disease rehabilitation, as noted in Volume 2 Sections 3, 4, 5 and 6. If the health professional has concerns about the participant's disease stability and therefore ability to exercise, they will be referred to their general practitioner or relevant specialist for thorough screening.<sup>2</sup>

#### **Established model of multiple referral sources to rehabilitation**

##### **Royal Prince Alfred Hospital in Sydney South West Area Health Service Pulmonary Rehabilitation** service has a broad referral base

- Referrals are accepted from:
  - general practitioners
  - respiratory specialists
  - respiratory nurses
  - allied health professionals
  - self-referrals.
- Participants have thorough assessment (spirometry, two 6 minute walk tests and full medical history) by experienced respiratory physiotherapists. If undiagnosed cardiac disease is suspected the patient is referred back to the general practitioner for cardiology assessment.
- If participants de-saturate excessively on exercise testing, they are referred for full arterial blood gas assessment.
- Communication is maintained with all medical staff and referring health professionals through letters, phone calls and email, as appropriate.

## **Safety**

- Participants must be individually assessed including medical history, physical examination, psychological assessment and functional exercise testing. See Volume 2 Sections 3, 4, 5, 6 and 7 for more detail.
- Safety requirements depend on the acuity of the participants, the venue of the service, and the level of training of the staff.
- Chronic disease rehabilitation services within health services require emergency plans in place and access to an emergency trolley. Community based services require as a minimum access to a telephone to call for assistance when required (000 call) and airway equipment that protects against exposure to body fluids during resuscitation procedures.

- Chronic disease rehabilitation staff should have annual training in basic life support, following protocols for clinical staff within the individual health service.
- All services must comply with standard Occupational, Health and Safety requirements.

## **Informational technology**

The NSW Chronic Care Unit will build and implant electronic point of care systems for chronic disease rehabilitation service delivery through the CHIME clinical information system. This work will be undertaken in 2006. Once established, chronic disease rehabilitation programs will use this system to access clinical information as well as record clinical encounters, including outcomes.

## **Development of further understanding of rehabilitation for chronic disease**

The evidence in Australia surrounding particular components and disease specific rehabilitation for chronic disease is building and presented at many conferences. However the published Australian evidence remains limited and well-planned research is scant.

Therefore, all chronic disease rehabilitation services where possible should contemplate incorporating:

- research activities as a part of core business by developing collaborations with the AHS research groups and local universities
- clinical placements for university students from local universities
- quality improvement projects as part of review processes.

Cardiac and pulmonary rehabilitation programs, and diabetes education services are examples of disease specific services. They are multidisciplinary, effective in most settings and successfully achieve outcomes such as improved quality of life, self-management utilisation and increase in functional exercise capacity. In metropolitan areas disease specific programs have traditionally been the service of choice. When staff, participant numbers, and equipment are limited, other options may be indicated to ensure adequate access to chronic disease rehabilitation.

## Disease integrated chronic disease rehabilitation services

NSW Health recommends an integrated approach to chronic disease rehabilitation for a range of chronic diseases. This is in contrast to the predominantly disease specific rehabilitation currently offered.

- Integrated chronic disease rehabilitation is currently the service delivery model of choice in some localities of NSW even though there is little evidence for the efficacy of this approach to date in the published literature.
- Of necessity many sites in NSW utilise the same clinicians to provide services across many diagnostic groups and share resources and facilities.
- Advantages of an integrated chronic disease rehabilitation approach include:
  - more efficient use of resources such as equipment, venues and multidisciplinary team members

- management of co-morbidities – can be addressed at one service rather than having to access separate services for each disease
- access to services may be improved when a disease-integrated model is employed especially in rural and remote areas,
- regular and viable services will be available even if numbers are small in some communities.

### Established model of a disease integrated approach

Due to low numbers of participants in each diagnostic group the **Broken Hill Health Service in Greater Western Area Health Service** provides an integrated approach in the rehabilitation for chronic disease approach. Their model includes:

- an integrated approach to providing rehabilitation services for people with cardiac and respiratory diseases
- coordination of the service in the physiotherapy department and has cardiac and respiratory nurse specialists
- participants from both diagnostic groups come on the same day with each diagnostic group attending separate exercise sessions, and a combined education session.

## Challenges

Integrated rehabilitation services may include participants who enter the service for different reasons. Some may have arthritis, coronary artery disease, chronic obstructive pulmonary disease or another chronic disease. The participants will attend many activities of the chronic disease rehabilitation service together.

The challenge for health professionals working within the services include providing access to:

- disease-specific education early in the service and following exacerbations. This will include information about reducing risk factors such as lipid target levels appropriate to that diagnostic group
- a service which is tailored to meet the needs of participants with a variety of health-related problems/goals. For instance a person with chronic obstructive pulmonary disease will most likely cite overcoming shortness of breath on exertion as their primary health related goal, whereas the person with diabetes will likely cite achieving an optimal blood glucose level as their main health related goal. Identification of the main problems and therefore goals is integral to assisting the individual through the stages of change<sup>65</sup> and adopting positive attitudes to behaviour change<sup>29</sup>
- exercise programs which are individually designed (based on thorough assessment) to achieve the optimum intensity of exercise for the individual. Assessment needs to take into consideration exercise limitations such as cardiac, respiratory, peripheral or neurological. For example, an elderly person with chronic obstructive pulmonary disease will have different limitations to a 45-year old man following his first acute coronary syndrome event.

## Assessment

- Assessment should take place at entry to chronic disease rehabilitation, at exit and at further strategic points to identify any changes (clinical, functional or psychological) impacting on the participant's progress in self-management.
- NSW Health consent procedures are to be followed at a participant's entry to the rehabilitation service. This permission is necessary to conduct assessments, collect and use data, provide interventions, and communicate with relevant service providers outside of the NSW Health system.<sup>62</sup>
- Assessment should cover personal goals, physical parameters, disease specific status, disease management, psychosocial health (particularly depression and social support), risk factors, functional exercise capacity and quality of life.
- Clinicians with understanding of particular diagnostic groups will identify contraindications (often subtle) to elements of chronic disease rehabilitation, while at the same time not restricting participation.

The aim of assessment is to:

- increase knowledge about the participant from a physical and psychosocial perspective
- identify the main problems as determined by the participant and plan goal setting (self-management)
- identify other community health and care services that may be required
- assess functional exercise capacity and from that design an individual exercise program which is safe and effective
- use results from baseline assessment as outcome measures and to measure effectiveness of the service
- communicate with and engage the participant's general practitioner.

Assessments required for each diagnostic group are detailed in Volume 2 Sections 3, 4, 5, 6 and 7.

## Education

To gain the most from health education adoption of adult learning principles and a mix of delivery modes is required. Some people respond well to group interaction, others to individual discussions, others to visual mediums.<sup>33</sup> Ideally this would involve each participant being exposed to a variety of modes. For example:

- Individual assessment includes increasing the understanding current health status, education about the individual's disease and management.
- Group work adds to this by reviewing certain diseases, their investigations, medicines, operative and interventional treatments, and need for behavioural change.
- Group work gains information from the clinical teams and also facilitates learning from others within the group.
- Other modes include pamphlets, poster, video/DVDs and audiotapes (which are effective for stress management).

## Smoking cessation

The Smoke Free Workplace Policy<sup>66</sup> provides an ideal opportunity to manage nicotine dependence during the hospital stay. Processes should be in place to ensure active smoking cessation interventions occur for all people admitted to hospital who smoke or have a history of smoking. The chronic disease rehabilitation team will be involved by providing support and access to opportunities that promote maintenance of quit smoking attempts following discharge.

While there remains some debate regarding the use of Nicotine Replacement Therapy (NRT) for people who are hospitalised for an acute cardiac event, the evidence indicates that the bolus dose of nicotine during smoking is more harmful.<sup>67-70</sup> Recently reported follow-up data from over 33,000 individuals prescribed NRT in general practice settings demonstrated no increase in mortality rates 56 days after NRT prescription.<sup>71</sup>

On entry to outpatient or community chronic disease rehabilitation, all smokers should be referred to the Quitline<sup>13, 48</sup> for telephone counselling and follow-up. The Quitline supplies consent and information forms that are faxed back resulting in early action. Some centres provide Smoking Cessation Clinics where individual support, counselling and NRT are offered. An example is the clinic at Royal Prince Alfred Hospital.

Please refer to the NSW Health guide to quit smoking interventions *'Let's take a moment' quit smoking brief intervention – a guide for all health professionals*.<sup>72</sup> Available at [http://www.health.nsw.gov.au/pubs/2005/lets\\_take\\_a\\_moment.pdf](http://www.health.nsw.gov.au/pubs/2005/lets_take_a_moment.pdf)

## Nutrition

Nutritional advice and education is a vital component for people with chronic disease.<sup>73-74</sup> Some people will require information and strategies to achieve the ideal weight, healthy diet and support to maintain this. The nutritionist will assess the participants and advice on appropriate management. Volume 2 Section 8 outlines nutritional assessment tools that may be used in chronic disease rehabilitation settings.

## Exercise

People with chronic disease commonly lose functional exercise capacity. Activities become limited by symptoms (pain, weakness, stiffness, shortness of breath) and people with chronic disease gradually do less and less. This de-conditioning process leads to problems of muscle weakness, joint stiffness, pain and decreased function. Therefore, confidence is lost in their ability to exercise or in severe cases to move far from the house or chair.

Exercise is therefore an essential part of chronic disease rehabilitation. It aims to reverse the de-conditioning spiral and restore function, while providing support and encouragement. All people with chronic disease can benefit from an individually designed program of exercise. Due to the complexities of chronic disease individuals require their own prescription of exercise with many variables needing consideration. Ideally, this aspect of rehabilitation for chronic disease will be provided by a physiotherapist or an exercise physiologist. In the absence of these team members services should seek guidance from other services where this expertise is available. Exercise assessment and prescription is discussed in detail in Volume 2 Sections 6 and 7.

## Psychological and social support

The inclusion of the recognition, assessment and management of psychological distress in clinical pathways is vital in the care of people with chronic disease. Psychological factors are still poorly recognised and treated in people with chronic disease despite the enormous clinical and public health impact.<sup>75-78</sup> For example, a range of psychosocial factors has been found to have a relationship in the development of and progression of atherosclerosis and heart disease. These include the depressive and anxiety disorders, temperament factors such as anger and hostility, and chronic life stressors including low socio-economic status, poor social support, work stress, marital stress, and caregiver strain.<sup>79-80</sup> Depression, social isolation and lack of quality social support have been affirmed by the National Heart Foundation of Australia as independent risk factors in both the development of coronary heart disease and in worsening prognosis once heart disease is established.<sup>81</sup> The risk is estimated to be of similar magnitude to that associated with other modifiable risk factors including hypertension, high cholesterol and smoking.

Depression, anxiety, social support and their assessment and management in rehabilitation for chronic disease settings are discussed in more detail in Volume 2 Section 4.

On the following page a Hunter New England Area Health Service initiative is an example of how chronic disease rehabilitation staff can be supported to provide appropriate psychological care.

## Established model of supporting teams to provide psychological care

### The northern region of Hunter New England Area Health Service

The service has been investigating and trialling ways of providing psychological support and care for people who are participating in cardiac rehabilitation services across two sites.

- 1 The cardiac rehabilitation team has built relationships with the mental health team and together they have developed a training program on Cognitive Behaviour Therapy for rehabilitation and community nurses.
- 2 Two clinical nurse consultants who work in the mental health team mentor the nurse participants in developing their skills and confidence to provide this aspect of rehabilitation care.

While clinical psychologists and psychiatrists are the appropriately trained health professionals to manage the care of people with co-morbid anxiety and depressive disorders, when they are not available, other health professionals such as social workers and nurses can be trained and supported to assist in the psychological care of people involved in the cardiac rehabilitation service in a timely manner.

## Self-management support

Self-management support is a central component of health care provision across the continuum of care. It involves support for participants (either patients or carers) to self-manage identified goals, and to improve physical, psychological health and quality of life. In conjunction with the elements of health education this supports positive behaviour change. A number of approaches to enhance self-management are being developed across Australia. Volume 2, section 2 discusses self-management support principles in more detail.

## Diagnostic groups

### Heart disease

- Many aspects of heart disease management can impact on the morbidity and mortality of the cardiac patient.
- Chronic disease rehabilitation staff can be a vital link in supporting patients and medical teams in delivering appropriate therapies demonstrated to reduce morbidity and mortality such as up-titration of medications, monitoring intended outcomes of medication, informing medical teams of ongoing yet often subtle symptoms of instability of the disease.
- Psychological distress is common following the diagnosis of a chronic disease but is heightened when the disease is of cardiac origin. Cultural expectations following diagnosis of many cardiac diseases may be that active participation in life ceases at this point and death becomes imminent. Chronic disease rehabilitation, in collaboration with the individual's general practitioner, can have a positive impact on psychological health.<sup>82-83</sup>
- Strategies known to ameliorate distress include the provision of correct information about the individual's condition, and subsequent positive messages relating to possible improvements through self-management strategies such as correct use of medical therapies and risk factor modification.<sup>84</sup>
- As has been identified by the National Heart Foundation, depression and social isolation have a strong and consistent causal relationship to cardiac disease.<sup>81</sup> Early identification and management is vital to deter potentially poor outcomes due to this distress.

### Pulmonary disease

- Early identification of disease and referral to rehabilitation services is ideal. Currently, referral to chronic disease rehabilitation happens as a last resort following failure to sustain quality of life and prevent hospital readmission through medical therapies alone.<sup>19</sup>
- Pulmonary rehabilitation should be considered for people who have dyspnoea, reduced exercise tolerance, restriction of activities or impaired health status.<sup>39</sup> Specific conditions include chronic asthma, bronchiectasis and chronic obstructive pulmonary disease.

- No person with pulmonary disease should be considered too severe to be assessed for inclusion in a chronic disease rehabilitation service.

Specific needs of people with pulmonary disease include:

- exercise prescription (including aerobic and strength training) is based on initial assessment by performing two six-minute walk tests. Exercise should be within limits of de-saturation
- muscle strengthening especially quadriceps
- use of additional oxygen when necessary
- breathing exercises and relaxation to help fear and panic associated with shortness of breath
- support and management of anxiety and depression
- provision of information on disease process and its management
- access to early chest physiotherapy to reduce repeated chest infections and hospital admissions especially for people with bronchiectasis
- identification of participants who will benefit from an extended service.

## Diabetes

- Inclusion of people with diabetes in chronic disease rehabilitation services is appropriate and has been shown to be effective and safe.<sup>85-86</sup>
- Particular needs for this patient group include specialist diabetes education which includes: support in monitoring their disease, appropriate dietary instruction, podiatry assessment and interventions and exercise services that promote appropriate monitoring behaviours such as safe blood glucose levels for exercise and regular inspection of feet.
- Daily exercise is recommended as an important component of the usual management of diabetes as it:
  - enhances the efficacy of insulin performance and consequently blood glucose levels
  - improves lipid profiles
  - supports stabilisation of arterial plaques
  - helps normalise clotting factors that can be in disarray due to high blood glucose and insulin levels
  - reduces the possibility of autonomic disorders like inappropriate cardiac function<sup>26, 87</sup>

- decreases obesity and prevents de-conditioning and loss of function.

Exercise prescription and monitoring for people with diabetes is further described in Volume 2 Section 7.

## Peripheral vascular disease

- People who have peripheral vascular disease can gain much from chronic disease rehabilitation and should be supported to attend all aspects including exercise, despite debilitating leg pain.<sup>88-89</sup>
- Benefits include improvements in the function of the vasculature and muscles, modification of health risks associated with sedentary lifestyle due to leg pain.<sup>90</sup>
- Exercise is recommended as a first-line therapeutic intervention for most people with peripheral vascular disease.<sup>89</sup>

## Cancer

- There is a growing body of evidence that people who are diagnosed with cancer will benefit from the activities of chronic disease rehabilitation.<sup>46- 51</sup>
- Exercise, nutritional advice, support to maintain healthy weight, psychosocial health and medical therapies have all been shown to improve survival and/or quality of life.

## Stroke

- Rehabilitation following an acute stroke is best provided by a specialist stroke rehabilitation team.<sup>23, 91</sup>
- Following discharge from a specialist stroke rehabilitation service, people may safely participate in chronic disease rehabilitation. However, physiotherapy advice is crucial to ensure elements of the exercise component do not cause further disability.

## Established model for safe and effective stroke rehabilitation

The physiotherapy department of **Port Kembla Hospital in South Eastern Sydney Illawarra Area Health Service** conducts an additional service for people who have recently had a stroke.

- During the inpatient stroke rehabilitation service patients are recruited for this outpatient service.
- To meet the criteria for participation in this service the participants must be medically stable, have sufficient cognition to follow verbal and visual instruction.
- The participants attend the service twice a week for six weeks and undergo exercise training that incorporates endurance and strength training.
- Outcomes are measured through six minute walk test, 10 metre walk, and 'get up and go' tests.<sup>92</sup>
- Participants are referred to community services such as Heartmoves on discharge and are encouraged to continue home walking.
- Progress is reviewed at six and twelve months following the service.

## Established model for a culturally acceptable Aboriginal rehabilitation service

**At Ballina in the northern region of North Coast Area Health Service** an Aboriginal registered nurse has taken on the role of supporting a local Aboriginal community to self-manage their heart disease in a positive manner.

- In collaboration with the local cardiac rehabilitation team, Aboriginal participants are recruited and transported to the cardiac rehabilitation service.
- To help the participants become more comfortable in the rehabilitation setting, the service is held outside the usual rehabilitation times.
- The participants all receive a multidisciplinary team approach to rehabilitation with input from the rehabilitation specialists but with the understanding that the Aboriginal nurse is standing alongside them to ease any feelings of psychological discomfort they may feel.

## Other population groups

### Aboriginal community members

- Increasing access to and uptake of chronic disease rehabilitation services is of particular importance for Aboriginal peoples as their health status is poorer than non-Aboriginal people.<sup>93</sup>
- It is known that Aboriginal peoples receive less health services despite their poorer health status.<sup>94</sup> This is also true for chronic disease rehabilitation services.<sup>95</sup>
- Ensuring access to culturally appropriate chronic disease rehabilitation services requires consultation with the local Aboriginal community and where possible the involvement of Aboriginal Health Workers. It may also include developing partnerships with services such as Aboriginal Community Controlled Health Services and ensuring the involvement of Aboriginal Hospital Liaison Officers to provide appropriate cultural links.

### Culturally and linguistically diverse community members

- Generally, with the support of multicultural health workers and health care interpreters, culturally and linguistically diverse population groups are integrated within the mainstream services successfully.
- If local data indicates exclusion of any culturally and linguistically diverse group, then consultation with the identified community should be instigated and appropriate plans for service initiated.

## Established model of providing services for Culturally and Linguistically Diverse groups

**The Western Zone of Sydney South Western Area Health Service** has a multicultural population that varies across the area.

- People from diverse cultural backgrounds attend their local health service facilities.
- Integration is provided through the teams at various sites working with different cultural health workers and the rehabilitation teams coming together in some specific cultural activities.
- One site, Liverpool, provides educational activities for Spanish speaking participants from across the area. To enhance participation, the participants attend their local service for exercise classes (closer to home).
- Another initiative is the development by the Fairfield team of a video/DVD for Assyrian speaking people, many of whom are illiterate in English as well as their own language.
- Another team, at Bankstown, works closely with the Arabic speaking community.
- All these initiatives are shared across the Area Health Service.

## Discharge

- Discharge to community-supported services should be planned from admission to the service.
- Community service providers should be supported to visit chronic disease rehabilitation services in endeavors to foster relationships between services.
- Planned discharge fosters self-ownership and management of the individual's life and ensures health services are able to provide access for more people with chronic disease.
- Length of rehabilitation services required for effective outcomes will vary with each participant. Some participants will require services for a short period (a number of weeks) and others will require several months. The period required will depend on a range of factors including:
  - the individual plan put in place by the participant, carers, family or friends and the health care providers at the commencement of chronic disease rehabilitation
  - the intervention required to achieve effective and appropriate self-management skills from a physical and psychological perspective
  - previous exposure to chronic disease rehabilitation, understanding and application of appropriate self-management skills
  - stability/instability of the individual's condition during the program eg existence of co-morbidities such as frailty and/ other disease processes
  - psychological status, particularly the presence of depression, anxiety or social isolation.

## Maintenance of skills and follow-up

- Participants and carers of chronic disease rehabilitation should be encouraged and supported to continue practice of their newly acquired skills as a life-long habit.
- Following discharge participants will need to be reviewed to determine if self-management skills and functional outcomes, acquired during chronic disease rehabilitation, have been maintained long term.
- Follow-up may occur through three or six monthly assessments (for one to two years), or through surveys, or by other means such as focus and support groups.
- Other strategies may include invitations to participants to phone into the service if a problem arises that requires counselling or return to chronic disease rehabilitation.

Chronic disease rehabilitation staff should be involved in the development of community led programs to provide ongoing support and maintain benefits from chronic disease rehabilitation over the long-term. These may include but are not limited to:

- peer-led support groups such as Heart Support Australia and Lung Net
- cultural community groups such as Aboriginal and people from Culturally and Linguistically Diverse backgrounds, led by health workers from particular cultural groups
- services in local gymnasiums. Leaders could use training from groups such as Heartmoves<sup>96</sup> to ensure their skills meet the needs of people with chronic diseases
- services provided in local service clubs
- other health service supported initiatives such as community fitness leaders trained to provide falls prevention programs, and *Active Over 50s*.

# Area Health Service review and addressing the gaps in chronic disease rehabilitation

Although there have been gains in chronic disease rehabilitation services in NSW, there remain many gaps in service delivery such as the quality of and access to chronic disease rehabilitation. To address this, Area Health Services should review their rehabilitation services and devise strategies to ensure evidenced-based, therapeutic services are available to all people within their communities. The following provides a guide for this review.

## **Access to rehabilitation services for chronic disease Area-wide**

- Services which support access for population groups known to have difficulty attending programs eg elderly, frail, females, Aboriginal, and people from culturally and linguistically diverse backgrounds.
- Flexible locations of rehabilitation services such as outpatient, community (including local halls, service clubs, community gymnasiums) and home-based (home visits and telephone contact).
- Rural and remote community access through local community rehabilitation and/or telephone linkages.
- Waiting lists eliminated (reduced to a maximum of one week) through telephone triage and counselling, and through timely discharge to community services once self-management is evident.
- Patient transport systems to meet the demand.

## **Staffing**

- Multidisciplinary teams with dedicated hours for rehabilitation to be drawn from the following professional groups: medical staff, nurses, physiotherapists, exercise physiologists, dieticians, social workers, occupational therapists, psychologists, podiatrists, and speech pathologists.
- Local access to mental health professional qualified to diagnose and manage depression/ anxiety.
- Clinical leadership to support specialty diagnostic group interventions.
- Access to training and professional development related to rehabilitation for chronic disease for team members.
- Six monthly review which includes determination that dedicated staffing hours meets population demand.

## **Referral pathways to rehabilitation**

- Clinical pathways include automatic referral to rehabilitation.
- Inpatient visits by rehabilitation staff to introduce the concept of rehabilitation post discharge from hospital.
- Referrals accepted from all avenues, especially general practitioners, self referral, community services such as Aboriginal Medical Services, migrant health services, nursing and allied health.

### **Rehabilitation service delivery**

- Multiple diagnostic groups such as people with cardiac disease (including people with heart failure), chronic pulmonary disease, diabetes, peripheral vascular disease, carotid disease and stroke (following early stroke rehabilitation).
- Tailoring to an individual's needs and co-morbidities.
- Active participation of family/carers.
- Therapeutic yet safe intensity of exercise prescription.
- Integrate with and support usual medical care.
- Adequate venue and resources including administration support.

### **Rehabilitation service content**

- Comprehensive physical, psychological and social assessment.
- Ongoing assessment of parameters such as blood pressure only if noted to be elevated or out of normal ranges.
- Exercise assessment, prescription and training.
- Education, risk factor modification including exercise prescription and training.
- Psychosocial assessment, support, management and referral as appropriate.
- Support for self-management strategies.

### **Discharge from rehabilitation**

- Rehabilitation should not be a time-limited intervention.
- Discharge is determined by evidence of an individual's understanding of their disease, it's management, demonstration of self-management and improvement in functional exercise capacity and quality of life.
- Discharge to community led services such as Heartmoves, Lungnet, Heart Support Australia groups, and others set in local gymnasiums and service clubs.
- Rehabilitation staff involved collaboratively in the set-up, but not leadership, of community opportunities for ongoing self-management support.

### **Monitoring and data collection**

- Administration officers support rehabilitation clinicians to collect and analyse outcome data (recruitment and completion rates, functional exercise, psychological, and quality of life scores and consumer satisfaction data). In the near future this will mean the use of the CHIME database from NSW Health.
- Reporting to NSW Chronic Care Program includes referral, participation and completion rates.
- Review of rehabilitation service six monthly, with strategies to address gaps in service.

### **Development of knowledge**

- Liaisons developed with tertiary institutions to support student clinical placements.
- Liaisons developed with AHS research groups and tertiary institutions to develop, implement and formally report research into the field of chronic disease rehabilitation.

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## **Review and comments received with thanks from:**

Barbara Anderson	A/Manager, Aged Care Integration Unit, Inter-Government & Funding Strategies Branch, NSW Health
Bronwyn Scott	A/Manager, Service Delivery Improvement Unit, Primary, Health & Partnerships Branch, Community Branch, NSW Health
Bronwyn Wilkinson	Manager, NSW Non-Acute Services, Health Service Performance Improvement Branch, NSW Health
Carolyn Bailey	Chronic Disease Programs Coordinator, HNEAHS
Cecily Barrack	Respiratory Coordinator, NCAHS & Northern Rivers Division of General Practice
Cheryl McCullagh	Medical Program Chair, Children's Hospital, Westmead
Clare Gardiner	A/Manager, Aged Care Integration Unit, Inter-Government & Funding Strategies Branch, NSW Health
Dale Casley	Occupational Therapist, NSCCAHS
Darryl Warrington	CNC Cardiac Rehabilitation, NSCCAHS
Dawn Mclvor	CNC Cardiology, HNEAHS
Dias Soewido	Senior Policy Analyst, Health Services Performance Improvement Branch, NSW Health
Elaine Buggy	Chronic & Complex Care Program Coordinator, SWAHS
Elizabeth Death	GP Liaison Officer, NSCCAHS
Elizabeth Huppartz	CNC Rehabilitation & Aged Care, GSAHS
Fiona Mackey	Physiotherapist, Stroke Rehabilitation, SESIAHS
Gillian Eborn	Project Officer, Health Services Performance Improvement Branch, NSW Health
Dr Gregory Bowring	Chairman NSW Branch, Australian Faculty of Rehabilitation Medicine

Jane Kerr	Area Cardiovascular Coordinator, HNEAHS
Prof Jenny Alison	Physiotherapist, University of Sydney
Jenny Sadler	Respiratory Case Manager & A/Clinical Chronic Disease Management Coordinator, Central Coast Division of General Practice
Jose Cabello	Nutrition & Dietetics Service Manager, SSWAHS
A/Pr J E Marosszeky	Director, Department of Rehabilitation Medicine, SWAHS
Kathy Meleady	Director, State-wide Services Development Branch, NSW Health
Kellie Roach	CNC Cardiac Rehabilitation, NSCCAHS
Kerri Davidson	CNC Chronic Care, Justice Health
Kerrie Goldston	Program Manager, Secondary Prevention & Cardiac Rehabilitation, National Heart Foundation of Australia
Kerry Wilcox	Cardiovascular Coordinator, NCAHS & Northern Rivers Division of General Practice
Kirsty Krieg	Senior Physiotherapist, NSCCAHS
Kym Scanlan	A/Director, NSW Chronic Care Program, Health Services Performance Improvement Branch, NSW Health
Linda Wilson	Carer Support Officer, GWAHS
Lissa Spencer	Physiotherapist, Pulmonary Rehabilitation, SSWAHS & Senior Policy Analyst, NSW Chronic Care Program, Health Services Performance Improvement Branch, NSW Health
Margaret Scott	Principle Policy Analyst, NSW Chronic Care Program, Health Services Performance Improvement Branch, NSW Health
Marjo Roshier-taks	Chronic Care Program Manager, GSAHS
Mary Dunford	CNC Pulmonary Rehabilitation, SESIAHS
Narelle Carter	NUM, Generalist Care Services, Coffs Harbour Campus, NRAHS
Nerida Campbell	CNC Heart Failure, SSWAHS
Paula Candlish	CNC Heart Failure, NSCCAHS
Dr Pesi Katrak	Rehabilitation Medicine Department, Prince of Wales Hospital, SEIAHS
Renae McNamara	Physiotherapist, Pulmonary Rehabilitation, SESIAHS
Rob Patterson	Physiotherapist, Cardiac Rehabilitation, NEAHS
Robyn Speerin	Nurse Practitioner Cardiac Rehabilitation & Heart Failure, SSWAHS & Senior Policy Analyst, NSW Chronic Care Program, Health Services Performance Improvement Branch, NSW Health
Professor Ron Penny AO	Senior Medical Advisor, NSW Health
Ros Bauer	Chronic Care Manager, GSAHS
Sara Adhami	Dietitian, SSWAHS
Selina Chaine	Secondary Prevention Project Officer, National Heart Foundation of Australia
Dr Simon Willcock	General Practitioner, Chair Chronic Care Implementation Advisory Group
Dr Stephan Lillioja	Endocrinologist, SSWAHS
Sylvia Seniuk	Chronic & Complex Care Program Manager, SESIAHS
Tod Adams	CNC Pulmonary Rehabilitation, SESIAHS
Vicki Brummell	Program Coordinator Ongoing Care, HNEAHS

Vicki Wade                    A/Manager, NSW Aboriginal Chronic Care Program, Health Services Performance  
Improvement Branch, NSW Health

Dr Wendy Harmer            Area Medical Services, SSWAHS

Zoe McKeogh                 Physiotherapist Pulmonary Rehabilitation, SSWAHS

**Collective responses from:**

Greater Southern Area Health Service  
Hunter New England Area Health Service  
South Eastern Sydney Illawarra Area Health Service  
Sydney South West Area Health Service  
Sydney West Area Health Service

