

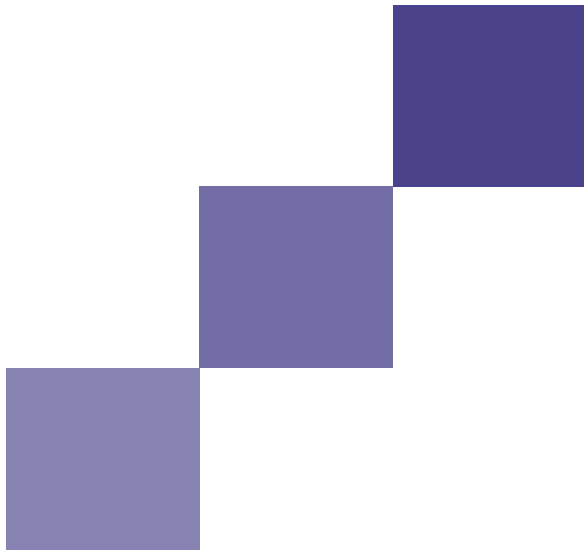
# NSW Chronic Care Program: Phase Two 2003–2006

Strengthening health care for people with chronic illness



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October 2004



# Foreword

Chronic diseases cause significant distress and burden for people with the illness and their family and carers. Chronic diseases also account for a significant number of potentially avoidable emergency department presentations, hospital admissions and readmissions. With the ageing of the population, this burden will increase.

Phase one of the NSW Chronic Care Program (2000–2003) was an innovative period for NSW. The Program was responsible for facilitating 60 priority health care programs statewide that aimed to enhance the care provided for people with chronic illness, improve their quality of life and that of their carers and reduce hospital presentations. The focus was on the priority areas of cardiovascular and respiratory disease and cancer.

The first phase of the NSW Chronic Care Program was notable for its many achievements and successes, with over 56,000 bed days avoided. The Program also highlighted barriers to implementation of chronic care and began to identify solutions to overcome these.

We are delighted to announce phase two of the NSW Chronic Care Program (2003–2006), which will provide the opportunity to build on the initiatives and lessons learned during phase one. Key components of phase two include establishing new governance arrangements including the overarching Chronic Care Implementation Committee, new Clinical Expert Reference Groups and continuing the Chronic Care Program Managers Forum. Implementing the Clinical Service Frameworks, a major initiative from phase one, will comprise a significant component during phase two, with the Chronic Care Collaborative supporting their implementation during 2004.

Developing robust and sustainable models for chronic care, with strengthened links with primary health care including general practitioners and community organisations will be a strong feature during phase two. Enhancing care coordination, care planning and review and multidisciplinary care for people with chronic illness will be key features throughout phase two. Developing the chronic care funding model and addressing workforce issues to support and enhance chronic care will also be addressed. Working with the Commonwealth to develop the National Chronic Disease Strategy, and other significant national chronic care initiatives will provide valuable policy frameworks to guide chronic care nationally.

We are excited to be involved in the NSW Chronic Care Program, phase two, and look forward to tackling the many issues and challenges to improve the care provided for and quality of life of people with chronic illness in NSW.

Professor Ron Penny

**Chair, NSW Chronic Care Program**



# Executive summary

## This document

The purpose of this document is to outline the key issues in gearing the NSW health system to meet the challenge of improving the care provided to people with chronic illness in phase two of the NSW Chronic Care Program.

The document is aimed at senior managers, policy makers, clinicians involved in providing care for people with chronic illness, and organisations working with and representing people with chronic illness and their carers.

## Background

Chronic disease is defined for the purposes of the NSW Chronic Care Program, consistent with definitions used in national and other initiatives, as being:

*“characterised by complex causality, multiple risk factors, a long latency period, a prolonged course of illness, functional impairment or disability, and in most cases, the unlikelihood of cure.”<sup>1</sup>*

The incidence of chronic illness is increasing worldwide, with chronic disease accounting for nearly 80 per cent of the disease burden worldwide by 2020. Chronic disease has a significant impact on hospital admissions and readmissions. The ageing of the population will also impact on the increasing burden experienced due to chronic disease.

The NSW Chronic Care Program was established in 2000 for a three-year period under the Government Action Plan to enhance the care provided for people with chronic illness. The focus was on the priority diseases of cardiovascular and respiratory disease and cancer.

This activity reflected initiatives being undertaken at a national level through the National Health Priorities Action Council (NHPAC). NHPAC was established as a sub-committee of the Australian Health Ministers' Advisory Council (AHMAC) in June 2000 and charged with the responsibility of driving improvements in health services to achieve better health outcomes in the national health priority areas. The national health priority

areas include cardiovascular disease, diabetes, cancer, asthma, mental health, arthritis and musculoskeletal conditions and injury prevention.<sup>2</sup>

There were many significant achievements during phase one of the NSW Chronic Care Program. These included:

- Key policy frameworks developed and disseminated including:
  - Blueprint document outlining policy directions for chronic care in NSW
  - Clinical Service Frameworks for heart failure, respiratory disease and cancer
  - *My Health Record*, the patient held health record.
- Sixty priority health care programs established across NSW focusing on the priority health areas. Through these programs:
  - Over 200 staff were employed to work with people with chronic illness across NSW
  - Over 42,000 patients were enrolled
  - Over 56,000 bed days were avoided, equating to a saving of 89 hospital beds throughout NSW during the approximate 2 years of operation of these programs.

In view of the successes of phase one of the NSW Chronic Care Program, \$15M recurrent was allocated to support its continuation to phase two (2003–2006).

This funding has been allocated to:

- Area Health Services (AHSs) for local implementation of the Clinical Service Frameworks and successful elements of the priority health care programs from phase one, many of which are continuing into phase two
- NSW Chronic Care Collaborative, including \$26,000 for each participating Area Health Service for project support and GP involvement
- Review, revision and ongoing distribution of *My Health Record*.



# Executive summary

## NSW Chronic Care Program: Phase Two

NSW faces significant challenges in dealing effectively with the increasing burden of chronic illness. To meet these challenges successfully, policies and strategies need to be effected:

- across chronic disease groups
- across the health service system
- across the spectrum of care
- across age and population groups.

Development and implementation of these initiatives must actively involve patients and their carers, community and hospital based clinicians, general practitioners and other health care providers. There is recognition that improved health outcomes for people with chronic disease will only be achieved if there is integration and coordination between a patient centred approach, a positive policy environment, initiatives for enhanced health system organisation and community resources and services.

The **aims** for phase two of the NSW Chronic Care Program are to:

- improve the quality of care provided for people with chronic and complex conditions
- improve the quality and quantity of life of people with chronic and complex conditions
- improve the quality of life of their carers and families
- reduce crisis situations and unplanned and avoidable admissions to hospitals.

The **principles** for phase two incorporate:

- patient-centred care
- empowerment of patients to participate in their own health care
- equitable, easy and timely access to appropriate and optimal care
- coordinated and integrated care
- supportive organisational, governance and leadership structures
- enhancement of workforce capacity to improve the general and specialised care provided for people with chronic illness
- promotion of a quality and safety framework
- monitoring and evaluation

The **nine strategic directions** during phase two are to:

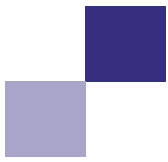
- provide governance and leadership
- develop and integrate chronic care policy
- strengthen the focus on patients and carers
- establish a comprehensive self-management approach
- strengthen workforce capacity for chronic care
- develop and refine chronic care information systems
- develop the chronic care funding model
- communicate the successes and lessons learned from the NSW Chronic Care Program
- evaluate and monitor the NSW Chronic Care Program phase two.



# Executive summary

The following table provides a summary of the key proposed activities to be undertaken for each of the strategic directions for phase two.

<b>Strategic directions and key proposed activities for Phase Two</b>
<b>1. Provide governance and leadership</b>
<ul style="list-style-type: none"><li>■ Establish the Chronic, Aged and Community Health Care Health Priority Taskforce.</li><li>■ Establish the revised NSW Chronic Care Implementation Group.</li><li>■ Establish Clinical Expert Reference Groups for cardiovascular disease, respiratory disease, cancer and diabetes.</li><li>■ Establish the Aboriginal Chronic Disease Advisory Group.</li><li>■ Continue the Chronic Care Program Managers Forum.</li><li>■ Facilitate annual Forums in the priority disease areas of cardiovascular disease, respiratory disease and cancer.</li><li>■ Facilitate the Aboriginal Chronic Disease State Conference (2005) and regular Aboriginal Vascular Health Workers' Forums through the Aboriginal Vascular Health Program.</li><li>■ Establish mechanisms to support chronic care champions in NSW.</li></ul>
<b>2. Develop and integrate chronic care policy</b>
<p><b>At a broader level</b></p> <ul style="list-style-type: none"><li>■ Develop the NSW Chronic Care Model that defines the key players, elements and interrelationships for optimal chronic care.</li><li>■ Participate in the development of key national initiatives influencing chronic care in NSW, including the National Chronic Disease Strategy and National Service Improvement Frameworks.</li></ul> <p><b>Across chronic disease groups</b></p> <ul style="list-style-type: none"><li>■ Continue implementation of the Clinical Service Frameworks for the initial priority health areas of respiratory disease, heart failure and cancer across NSW.</li><li>■ Monitor progress against the agreed standards and demonstrations of compliance from July 2003, incorporating effective elements of the local priority health care programs.</li><li>■ Implement the NSW Chronic Care Collaborative in conjunction with the Clinical Excellence Commission to enhance implementation of the Clinical Service Frameworks for chronic obstructive pulmonary disease (COPD) and heart failure across NSW.</li><li>■ Develop the NSW Clinical Service Framework for Chronic Disease.</li></ul>



# Executive summary

## Across the health service system

- Develop the model of care for people with chronic illness with an emphasis on community-based care, involving general practitioners and private health providers and working with aged care services. The model should also address the needs of carers and health workers.
- Strengthen links with general practitioners through the NSW General Practice Council, NSW Alliance of Divisions of General Practice, Divisions of General Practice and other general practitioner organisations and bodies.
- Establish strong links with NSW Health Department initiatives such as the new NSW General Practice Council and the after hours general practice initiative.
- Identify and disseminate successful strategies for engaging GPs from Phase one.
- Strengthen links across the health system to support care provided for people with chronic illness including primary health care and acute post-acute care in the community.
- Identify effective elements of psychosocial care and incorporate these as part of chronic care service delivery.
- Strengthen links with mental health services.
- Participate in the development of key national initiatives influencing chronic care in NSW, including the National Chronic Disease Strategy and National Service Improvement Frameworks.

## Across the spectrum of care

- Support implementation of the NSW Chronic Disease Prevention Strategy 2003–2007 in collaboration with NSW Centre for Chronic Disease Prevention and Health Advancement.
- Explore initiatives for intervening at earlier stages of the chronic disease trajectory.
- Strengthen the role of care coordinators, care planning and review, multidisciplinary care and rehabilitation in providing enhanced care for people with chronic illness.
- Strengthen links with palliative care services to support care provided to people with chronic illness.



# Executive summary

## Across age and population groups

- Strengthen systems of care for children and young people with chronic illness.
- Support the implementation of primary prevention initiatives aimed at children and young people in particular to prevent the later onset of chronic disease.
- Support the implementation of initiatives for children and young people with parents with chronic illness.
- Continue to strengthen care provided to adults with chronic illness.
- Strengthen systems of care for older people with chronic illness to ensure effective, coordinated and integrated care.
- Finalise, launch, implement and monitor the *NSW Aboriginal Chronic Disease Service Standards for Area Health Services* across NSW.
- Strengthen links with the NSW Aboriginal Vascular Health Program.
- Strengthen links with Aboriginal community controlled health services.
- Encourage provision of information on chronic illness and care in community languages.
- Ensure that chronic care initiatives are responsive to the special needs of culturally and linguistically diverse population groups.
- Strengthen initiatives to enhance health care provided to rural and remote populations with chronic illness.
- Establish initiatives to enhance chronic care among prison populations.

## 3. Strengthen the focus on patients and carers

- Ensure that patients and their carers are placed at the centre of care.
- Review and disseminate the next edition of *My Health Record*, the patient held record, specifically for people with chronic illness to better manage their illness.
- Ensure that people with chronic illness and their carers have access to quality information about the illness and its diagnosis and management.
- Explore options for promoting the health and quality of life of carers of people with chronic illness, including young carers.

## 4. Establish a comprehensive approach to self-management support

- Develop the NSW approach for self-management support for people with chronic illness.



# Executive summary

<b>5. Strengthen workforce capacity for chronic care</b>
<ul style="list-style-type: none"><li>■ Enhance the workforce capacity in providing care for people with chronic illness through education and training and enhancing organisational capacity.</li></ul>
<b>6. Develop and refine chronic care information systems</b>
<ul style="list-style-type: none"><li>■ Develop a chronic care information template for inclusion in community-based information systems such as the Community Health Information Management Enterprise, that also captures hospital based patient information.</li><li>■ Participate in the development of the Electronic Health Record as relevant for people with chronic illness.</li></ul>
<b>7. Develop the chronic care funding model</b>
<ul style="list-style-type: none"><li>■ Develop the chronic care funding model that is relevant for the NSW context and comprising NSW health service system components and appropriate links with Commonwealth, local and community based organisations.</li></ul>
<b>8. Communicate the successes and lessons of the NSW Chronic Care Program</b>
<ul style="list-style-type: none"><li>■ Disseminate the NSW Chronic Care Program Report <i>Strengthening capacity for chronic care in the NSW health system: Report on Phase One</i> and associated resources list.</li><li>■ Communicate the lessons of the <i>Evaluation of the Aboriginal Vascular Health Program 2000–2003</i>.</li><li>■ Continue to develop and disseminate the <i>NSW Aboriginal Vascular Health Matters</i> newsletter.</li><li>■ Continue forums in priority disease areas.</li></ul>
<b>9. Evaluate and monitor the NSW Chronic Care Program Phase Two</b>
<ul style="list-style-type: none"><li>■ Continue regular reporting on progress in meeting the standards outlined in the Clinical Service Frameworks for heart failure, respiratory disease, cancer and Aboriginal chronic disease.</li><li>■ Review the impact of the NSW Chronic Care Collaborative.</li><li>■ Establish a process for evaluation of phase two.</li></ul>

# Executive summary

Implementation of the Clinical Service Frameworks and priority health care programs highlighted several key areas in which further focused efforts are required to achieve best practice in chronic care. The following table outlines the key areas identified and the activities undertaken or started by July 2004 to address them.

Key areas for activity	Activity undertaken/started by July 2004
Improving access to spirometry for the diagnosis of COPD and asthma	<ul style="list-style-type: none"> <li>■ \$285,000 allocated to AHSs to purchase and maintain spirometers.</li> <li>■ Spirometry training conducted.</li> </ul>
Improving access to echocardiography for the diagnosis of heart failure	<ul style="list-style-type: none"> <li>■ NSW Chronic Care Collaborative.</li> <li>■ Survey of Area Health Services in July 2004.</li> </ul>
Improving uptake of angiotensin converting enzyme (ACE) inhibitors and beta blockers for people with heart failure	<ul style="list-style-type: none"> <li>■ NSW Chronic Care Collaborative.</li> </ul>
Increasing access to and participation in rehabilitation for people with chronic illness	<ul style="list-style-type: none"> <li>■ Collation of rehabilitation manuals and associated resources from phase one.</li> </ul>
Increasing the focus on self-management	<ul style="list-style-type: none"> <li>■ Consultancy to develop NSW approach to self-management.</li> <li>■ Three statewide workshops using the Flinders self-management model.</li> </ul>
Establishing cancer service management structures	<ul style="list-style-type: none"> <li>■ Work underway through NSW Cancer Institute.</li> </ul>
Enhancing the appointment of care coordinators for people with chronic conditions	<ul style="list-style-type: none"> <li>■ NSW Chronic Care Collaborative</li> <li>■ NSW Cancer Institute.</li> </ul>
Ensuring a multi-disciplinary approach in providing care for people with chronic illness	<ul style="list-style-type: none"> <li>■ NSW Chronic Care Collaborative</li> <li>■ NSW Cancer Institute.</li> </ul>
Ensuring continuity of care across health services	<ul style="list-style-type: none"> <li>■ NSW Chronic Care Collaborative</li> <li>■ NSW Chronic Care Model consultancy.</li> </ul>
Engaging general practitioners (GPs)	<ul style="list-style-type: none"> <li>■ Consultancy to identify successful GP engagement initiatives, phase one.</li> <li>■ \$81,000 allocated to participating Area Health Services for GP involvement in the NSW Chronic Care Collaborative.</li> </ul>
<i>My Health Record</i>	<ul style="list-style-type: none"> <li>■ Review of <i>My Health Record</i> commissioned July 2004.</li> </ul>
Promoting advance care planning and use of advance care directives	<ul style="list-style-type: none"> <li>■ NSW Chronic Care Collaborative – workshop undertaken to promote advance care planning.</li> </ul>



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# Background

## Introduction

The rising incidence of chronic illness poses a continuing challenge for the NSW health system. By the year 2020 approximately 80 per cent of the disease burden in the developed world will be attributable to chronic illness.<sup>3</sup> In NSW chronic illness accounts for a significant number of hospital admissions, many of which have been increasing over the past decade. The ageing of the population will contribute significantly to the increase in the burden of chronic disease. The Aboriginal population experiences significantly higher rates of morbidity and mortality due to chronic diseases than non-Aboriginal people.

The evidence suggests that chronic conditions can be managed effectively at a largely primary health care level, with appropriate treatment, access to specialists, self-management support and extended, regular and ongoing follow-up. Yet, the current health system is geared towards focusing on acute episodes of care. This acute care focus does not adequately meet the needs of people with chronic diseases. Establishing systems of care that are geared towards the needs of people with chronic conditions is essential to ensure that the health system can address the rising burden of chronic care in the future.

The implementation of the NSW Chronic Care Program was a landmark initiative aimed at establishing and enhancing care for people with chronic illness. The first phase of the program from 2000–2003 reported many successes and lessons learned about how to provide better care for people with chronic illness. These covered issues such as governance and leadership, care coordination, self-management and rehabilitation, strengthening links with general practitioners, workforce capacity, information systems and organisational change. This first phase contributed significantly to a reduction in hospital admissions and lengths of stay for the priority areas of cardiovascular and respiratory disease and cancer.

Phase two of the NSW Chronic Care Program (2003–2006) provides the opportunity to build on the successes from phase one, disseminate these across Areas and statewide and embed these as part of mainstream health care.

Recurrent funding of \$15 million per annum has been allocated to phase two of the NSW Chronic Care Program. From this, funding has been allocated to Area Health Services to June 2006 to support the continued implementation of this important program, together with statewide initiatives.

## This document

The purpose of this document is to outline the key issues in gearing the NSW health system to meet the challenge of improving the care provided to people with chronic illness in phase two of the NSW Chronic Care Program.

The document is aimed at senior managers, policy makers, clinicians involved in providing care for people with chronic illness, organisations working with and representing people with chronic illness and their carers.

# Achievements and challenges in Phase One (2000–2003)

Phase one of the NSW Chronic Care Program, occurring over the period 2000 to 2003, resulted in many significant achievements at statewide and local levels. Challenges to the enhancement of chronic care were also identified.

## Statewide level

At the state level, governance and leadership structures were established to support the implementation of the NSW Chronic Care Program. These structures have contributed to the groundswell of support for chronic care that was generated during the first phase of this program and included:

- Chronic and Complex Care Implementation Coordination Group – to provide overall guidance and direction
- Clinical Expert Reference Groups—to provide specific clinical advice
- Special Interest Groups – to disseminate information on specific clinical areas amongst a wider forum of interested clinicians
- Forums for the chronic care program managers and in each of the disease specific priority areas of respiratory disease, cardiovascular disease and cancer.

Clarifying the health priorities for the first phase of the NSW Chronic Care Program was critical and resulted in a focus on respiratory disease, comprising asthma and chronic obstructive pulmonary disease (COPD), cancer, and cardiovascular disease and its associated risk factors including diabetes.

Several significant NSW chronic care policy documents were developed outlining the directions for the NSW Chronic Care Program. These included:

- *Improving health for people with chronic illness: A blueprint for change 2001–2003* was an important policy setting document, outlining the goals and methodology for the NSW Chronic Care Program.<sup>4</sup>
- The Clinical Service Frameworks for respiratory disease, heart failure and cancer set out standards and demonstrations of compliance for statewide implementation.<sup>5,6,7</sup>

- *My Health Record*, a patient held record, was developed with over 120,000 copies distributed.<sup>8</sup>
- The development of the *Aboriginal Chronic Disease Area Health Service Standards* was important in recognising the high level of need amongst this population group.
- The early planning phases of the NSW Chronic Care Collaborative were initiated, to support statewide implementation of the Clinical Service Frameworks.

## Area Health Service level

The cornerstone of the first phase of the NSW Chronic Care Program at an Area Health Service level was the implementation of 60 local priority health care programs focusing on the nominated priority health areas of respiratory disease, cardiovascular disease and cancer.

Of the 60 priority health care programs:

- 18 focused on respiratory disease
- 25 focused on cardiovascular disease
- 13 focused on cancer
- Four were generic chronic disease programs.

There were numerous achievements of the local priority health care programs over the period July 2000–June 2003:

- Over 200 full time equivalent (FTE) staff, mainly nurses and allied health, were employed in the programs across NSW.
- Over 42,000 patients were enrolled in the programs.
- Over 56,000 bed days were avoided through the implementation of the local priority health care programs.
- Over 6,500 emergency department presentations were avoided.
- For heart failure, there was a steady decline in unplanned admissions. This was commendable given the increasing incidence of heart failure over this period.
- For COPD, the average length of stay in hospital declined.
- For asthma, there was a reduction in hospital admissions.



# Achievements and challenges in Phase One (2000–2003)

- For cancer, there was a reduction in avoidable emergency department presentations, hospital admissions and readmissions.

The savings of 56,000 bed days through the 60 local priority health care programs in phase one equates to saving 89 hospital beds throughout NSW during the approximate two years of operation of these programs.

In addition to hospital sector savings there are many other reports that the programs were successful in achieving improved functioning and quality of life for patients and their carers. These benefits cannot be measured simply in dollar savings alone.

## Critical factors for success

Critical factors and associated challenges for the effective implementation of the priority health care programs were identified during phase one. These factors were constant across disease categories and rural and metropolitan programs and included:

- clinical leadership and governance
- coordination of care
- multidisciplinary team approach
- links with general practitioners
- self-management and rehabilitation
- workforce capacity
- information systems
- organisational change.

The incorporation of these factors into the 60 programs contributed to their success, as well as providing challenges to be addressed and overcome.

The success of the majority of these programs is evident in their continuation into phase two of the NSW Chronic Care Program (2003–2006). A more detailed discussion of the findings of the first phase of the NSW Chronic Care Program is reported in *NSW Chronic Care Program 2000–2003: Strengthening capacity for chronic care in the NSW health system – Report on Phase One*.<sup>9</sup>

## Definition of chronic disease

Defining the term 'chronic disease' is important. NSW has adopted the definition provided by the National Public Health Partnership (2001) that,

*Chronic diseases are usually characterised by complex causality, multiple risk factors, a long latency period, a prolonged course of illness, functional impairment or disability, and in most cases, the unlikelihood of cure.*<sup>1</sup>

In addition to these features, chronic disease is often episodic, having periods where exacerbation of the illness is possible, with return to previous functioning or to reduced or improved functioning. Further, episodes may occur and recur over several years or decades, with varying lengths of duration.

Chronic disease can alternatively be categorised as either:

- non-fatal, non-communicable chronic disease (eg arthritis and musculoskeletal disease)
- serious, eventually fatal, non-communicable chronic disease (eg heart failure or cancer)
- persistent communicable diseases (eg HIV/AIDS).

A clear understanding of the features that define and delineate chronic disease is important for planning for future services for chronic care, as these features impact directly on the patterns and types of service need with regard to both hospital based and primary health care services.

The term 'chronic conditions' is also used in the literature. This broader term refers to health problems, including diseases and ongoing impairments, such as amputations and blindness that require ongoing management over a period of years or decades. The emphasis in the NSW Chronic Care Program phase two will be on chronic disease, with a focus on serious, eventually fatal chronic disease.

# Models of care for chronic disease

## Background

During the past three years there has been an emergence of literature concerning models of care for chronic disease. This has comprised a significant new body of work that was not available at the initiation of phase one of the NSW Chronic Care Program. The emergence of these models and their increasing prominence in the literature indicates general recognition of the forecasted significant impact of chronic illness on health systems worldwide, and the need to embrace systems of care that are better suited to dealing with chronic care needs.

Two international models have been identified as being particularly comprehensive, containing elements and concepts that are helpful in guiding preliminary thinking about a NSW Chronic Care Model. These are:

### 1. Improving Chronic Illness Care (ICIC) Chronic Care Model

The model was developed in the United States.<sup>10</sup> ICIC is a national program supported by The Robert Wood Johnson Foundation with direction and technical assistance provided by the MacColl Institute for Healthcare Innovation, the latter represented by Professor Edward Wagner and his colleagues.

This model defines the key elements of a health system fostering optimal chronic care as being to:

- mobilise community resources to meet needs of patients (*The Community – resources and policies*)
- create a culture, organisation and mechanisms that promote safe, high quality care (*Health System – Organisation of Health Care*)
- empower and prepare patients to manage their health and health care (*Self-management Support*)
- assure the delivery of effective, efficient clinical care and self-management support (*Delivery System Design*)
- promote clinical care that is consistent with scientific evidence and patient preferences (*Decision Support*)
- organise patient and population data to facilitate efficient and effective care (*Clinical Information Systems*).

### 2. World Health Organisation (WHO) Innovative Care for Chronic Conditions (ICCC) Framework<sup>3</sup>

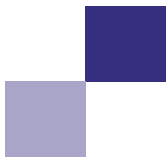
This model was developed by the WHO Observatory on Health Care for Chronic Conditions (CCH) following a review of health care models and best practices from around the world. The WHO Framework provides a comprehensive guide for decision-makers who want to improve their health system's capacity to manage chronic conditions. It is an expansion of the ICIC model outlined above.

The WHO framework proposes that optimal care occurs when a health care triad of patients/families, health care teams and community supporters communicates and collaborates at all levels of care, with support from the larger health care organisation, the broader community and the policy environment. Key elements for taking action to improve chronic care are to:

- support a paradigm shift for services to encompass care for chronic conditions
- manage the political environment through bidirectional information sharing and building consensus and political commitment among stakeholders at each stage
- build integrated health care to ensure shared information across settings and providers and across time
- align sectoral policies for health
- use health care personnel more effectively by providing training in the skills required for chronic care
- centre care on the patient and family
- support patients in their communities
- emphasise prevention.

## Towards a NSW Chronic Care Model

Key elements of the two models above reflect many of the principles and strategies of the NSW Chronic Care Program, as well as the critical factors for success that were identified in the Program's first phase. In doing so, they provide support for development of a chronic care model that is applicable to the local context. Work is being undertaken during phase two to define key elements and their inter-relationships for incorporation into a NSW chronic care model.



# Burden of chronic disease in NSW

The significant achievements of phase one of the NSW Chronic Care Program were demonstrated in reductions in the number of hospital admissions and length of stay and enhanced quality of life of people with chronic illness and their carers. Over 40,000 people with chronic conditions (including respiratory disease, cardiovascular disease and cancer) benefited through participation in the 60 priority health care programs operating in phase one.

Although these achievements are significant, there is still much to be attained. For example, it has been estimated that the 40,000 people with chronic illnesses of respiratory disease, cardiovascular disease and cancer who participated in phase one represent only around 10 per cent of the total number of people with chronic care needs in NSW.

## High priority chronic diseases

The incidence of chronic disease is increasing, with several studies reporting this trend internationally. As mentioned earlier in this document, approximately 80 per cent of the disease burden in the developed world will be attributed to chronic illness by the year 2020<sup>3</sup>, with the ageing of population adding significantly to this increase.

A range of chronic diseases is identified as contributing to this trend, with the highest priority diseases noted to be cardiovascular disease (including diabetes), respiratory disease (chronic obstructive pulmonary disease and asthma), cancer, dementia and mental illnesses. Updated information regarding burden of chronic disease for these high priority chronic conditions is detailed in Appendix 1.

There are several other chronic diseases affecting people in NSW. These diseases have lower incidences and prevalences within the population than the high priority diseases listed above. However, these other chronic diseases can cause distress and impact on quality of life for those with these illnesses as well as impacting on carers and family. These other chronic diseases also contribute to presentations to emergency departments, hospital admissions, hospital readmissions and mortality in this state. Systems of care established for the chronic

diseases contributing to the greatest degree of burden are also likely to impact on systems of care for these other illnesses.

## Disease burden for specific population groups

NSW faces challenges in dealing with the chronic care needs of specific population groups. Aboriginal people are one such group who suffer disproportionately from chronic diseases and have higher rates of chronic diseases at younger ages than the rest of the population. A range of socioeconomic factors and health risks are determinants of poor health among Aboriginal people, and need to be addressed in a culturally appropriate way in developing strategies to improve chronic care.<sup>11</sup>

Prison populations are also reported to suffer disproportionately from chronic disease, with high self-reported levels of asthma, back conditions, hepatitis C and presence of co-morbidities.<sup>12</sup> A survey of NSW offenders in 2001 indicated that 40 per cent reported a disabling illness or condition, most commonly musculoskeletal in nature.<sup>12</sup> Mental health problems were the most common cause for hospitalisation, accounting for 28 per cent of hospitalisations.

## Comorbidity of chronic disease

Comorbidity of chronic illness (that is having more than one chronic disease) is high. There is significant evidence supporting the link between comorbid physical and mental illnesses, such as a person with heart failure also having depression at the same time, as well as comorbid physical illnesses, such as a person with COPD also having diabetes.

- Comorbidity of physical and mental illnesses is high. Approximately 43 per cent of people with a mental disorder had one or more physical conditions in a 12-month period such as a heart problem, diabetes or cancer in comparison with about 39 per cent of Australian adults generally.<sup>13</sup>



# Burden of chronic disease in NSW

- People treated for depression have a higher risk (2.3 times) of having a heart attack than those without it. Approximately 50 per cent of people who have an affective or depressive disorder also have a related physical health problem.<sup>13</sup>
- In an examination of the links between 'stress' and coronary heart disease, the National Heart Foundation of Australia reported that depression, social isolation and lack of social support are significant risk factors for coronary heart disease, along with the better known physical risk factors such as smoking and hypertension.<sup>15</sup> Depression is also associated with an increased risk of developing diabetes and poorer diabetic control.<sup>16,17</sup> Additionally, approximately half the people being treated for cancer have a psychiatric disorder, usually with depressive symptoms. It has also been reported that those with asthma symptoms are more likely to experience higher rates of major depression and a lower quality of life.<sup>18</sup>
- People with depression may also indulge in more risky health behaviours. There is evidence that 35 per cent of people with mental disorders smoke tobacco. The effects are age specific, being more prevalent in younger adults.<sup>19</sup>
- The extent of co-morbidity increases with age, as does the prevalence of chronic illness. People 60 years of age and above have been estimated to have a mean of more than two chronic conditions.
- Co-morbidity usually results in a significant reduction in quality of life, including social isolation. For example, health surveys such as SF-36, a 36-item short-form survey that assesses limitations in activities, pain, mental health and general health perceptions indicates that scores for people with two or more serious conditions decrease dramatically.
- Comorbidity is likely to become an increasing problem with the ageing of the population.<sup>20,21</sup>

Providing care for people with multiple conditions has implications for service delivery in providing the best possible care whilst ensuring coordination of care across generalist and specialist health care providers. As the current health system is generally better oriented toward treating single, acute diseases, rather than multiple illnesses, comorbid conditions can often be untreated or undertreated. For example, patients with pulmonary emphysema were less likely to receive lipid lowering medications.<sup>22</sup> Further, prominent physical illnesses can overshadow a comorbid mental disorder, resulting in under-diagnosis and a lack of effective intervention.



# NSW Chronic Care Program Phase Two 2003-2006

The NSW Chronic Care Program phase two provides the opportunity to build on and ensure continuity of the aims and principles set out in phase one of the program. The aims and principles of phase two listed below are largely a continuation of those established at the outset of the program. Additions and modifications reflect emerging literature and refinements to chronic care practice over the three years of the first phase.

## Aims

The aims of the NSW Chronic Care Program phase two include those of phase one, as well as building on these. The aims for phase two are to:

- improve the quality of care provided for people with chronic and complex conditions
- improve the quality and quantity of life of people with chronic and complex conditions
- improve the quality of life of their carers and families
- reduce crisis situations and unplanned and avoidable admissions to hospitals.

## Principles

Strengthening the capacity of the NSW health system to improve service delivery for people with chronic health care needs requires development and implementation of strategies aimed at:

- supporting people with chronic illness at the centre of the health system with services designed around their unique health needs
- developing the capacity of people with chronic illness to participate fully in their own health care and more effectively navigate their way through the health system
- ensuring equitable, easier and more timely access to appropriate health and related services
- facilitating continuity of care between health and related providers at various levels of the system and between providers and people with chronic illness

- facilitating the uptake of evidence based care by health providers for people with chronic illness
- developing organisational and governance systems, structures and leadership to support continuity of care within the health and related systems
- enhancing workforce capacity to improve the general and specialised care provided for people with chronic illness.
- promoting the provision of care for people with chronic illness within a quality and safety framework.
- supporting the monitoring and evaluation of chronic care initiatives.

## Strategic directions

This second phase of the NSW Chronic Care Program addresses several strategic directions. These are summarised below and addressed in more detail in the following pages.

- Provide governance and leadership.
- Develop and integrate chronic care policy:
  - across chronic disease groups
  - across health service system
  - across the spectrum of care
  - across age and population groups.
- Strengthen the focus on patients and carers.
- Establish a comprehensive approach to self-management support.
- Strengthen workforce capacity for chronic care.
- Develop and refine chronic care information systems.
- Develop the chronic care funding model.
- Communicate the successes and lessons learnt from the NSW Chronic Care Program.
- Evaluate and monitor the NSW Chronic Care Program phase two.

# 1. Provide governance and leadership

Driving change through the NSW health system to develop better systems of care for people with chronic illness requires the establishment of quality governance and leadership structures. Through phase one of the NSW Chronic Care Program there was a groundswell of support, interest and collegiality in striving to provide better systems of care for people with chronic illness. Phase two will build on these increased levels of support.

## Chronic, Aged and Community Health Care Health Priority Taskforce

### ■ Establish the Chronic, Aged and Community Health Care Health Priority Taskforce

The establishment of the Chronic, Aged and Community Health Care Health Priority Taskforce (covering primary and community health care, chronic care, community acute-post acute care and aged care) was recommended by the Independent Pricing and Regulatory Tribunal (IPART) report to the NSW Health Department, as one of several taskforces to be established.

The taskforce's role will be to:

- provide advice on overall directions and major initiatives for primary and community health, community acute-post acute, chronic care and aged care
- facilitate collaborations, links and a strategic integrated approach across these areas of care.

## NSW Chronic Care Implementation Group

### ■ Establish the revised NSW Chronic Care Implementation Group

The NSW Chronic Care Implementation Group will be the overarching chronic care advisory group in the state providing strategic direction and guidance on the key issues confronting the effective implementation of the NSW Chronic Care Program. The group will bring together leading clinicians, specialists, general practitioners, nursing and allied health staff, senior

management and people with chronic illness and their carers to work in collaboration with the NSW Health Department to improve care provided for people with chronic illness.

The group's role will be to provide high-level advice on:

- issues relating to the implementation of the Clinical Service Frameworks for respiratory disease, heart failure and cancer
- the development of enhanced models of care for people with chronic illness.

## Clinical Expert Reference Groups

### ■ Establish Clinical Expert Reference Groups for cardiovascular disease, respiratory disease, cancer and diabetes

The Clinical Expert Reference Groups (CERGs) will continue to provide valued clinical expertise in the priority health areas of respiratory disease, cardiovascular disease and cancer. A new CERG will be established to focus on diabetes.

Membership of the CERGs will include doctors (specialists and general practitioners), nurses, allied health, senior management and people with chronic illness and their carers. Representation will be drawn from across NSW, including rural and remote communities. In the area of cancer, ensuring links with Area Directors/ Coordinators of Cancer Services Forum and the NSW Cancer Institute and its associated committees will be critical.

The role of the CERGs will be to:

- provide specialist clinical and community expertise in enhancing systems of care for people with the specific priority diseases
- provide specialist advice across the course of illness from prevention through to diagnosis, rehabilitation and palliation.



# 1. Provide governance and leadership

## Aboriginal Chronic Disease Advisory Group

### ■ Establish the Aboriginal Chronic Disease Advisory Group

Aboriginal populations experience higher levels of chronic disease at an earlier age than the rest of the Australian population. Strategies to improve chronic care among Aboriginal people must be culturally appropriate and must be tailored to the specific needs and determinants of Aboriginal health.

The role of the Aboriginal Chronic Disease Advisory Group will be to:

- oversee the finalisation of the *NSW Aboriginal Chronic Disease Area Health Service Standards*
- provide expertise to drive the implementation of this important framework and other strategies to enhance the health care provided to Aboriginal people with chronic illness.

## Forums

- **Continue the Chronic Care Program Managers Forum**
- **Facilitate annual Forums in the priority disease areas of cardiovascular disease, respiratory disease and cancer**
- **Facilitate the Aboriginal Chronic Disease State Conference (2005) and regular Aboriginal Vascular Health Workers' Forums through the Aboriginal Vascular Health Program**

The Chronic Care Program Managers Forum will continue as a valuable mechanism to facilitate implementation of statewide policy directions in chronic care. The Chronic Care Program Managers have been integral in facilitating the reorientation of health systems in providing better care for people with chronic illness and their carers.

Priority Health Forums will continue to provide advice and a forum for discussion among the broader group of clinicians working in specific disease areas of chronic care. The forums will continue to be convened under the umbrella of the CERGs and will focus on cardiovascular disease, respiratory disease, cancer and diabetes.

An inaugural statewide conference on Aboriginal Chronic Disease is planned for 2005. This conference and six-monthly Aboriginal Vascular Health Worker Forums will be convened by the Aboriginal Vascular Health Program.

## Supporting chronic care champions

### ■ Establish mechanisms to support chronic care champions in NSW

The first phase of the NSW Chronic Care Program witnessed strengthening support for chronic care amongst a diversity of health workers – medical, nursing and allied health staff, from hospital and community based services drawn from rural and metropolitan areas. It is critical to harness this support into the future, to ensure that the NSW Health system has the leadership needed to equip its services to manage chronic disease appropriately.

## 2. Develop and integrate chronic care policy

Further development and integration of chronic care policy to provide a framework for chronic care activity statewide is a crucial part of the second phase of the program. Critical factors to optimal chronic care were identified during phase one. These included clinical leadership and governance, coordination of care, a multidisciplinary team approach, links with GPs, self management, strengthening workforce capacity and information systems. Phase two of the NSW Chronic Care Program will enable the facilitation and implementation more broadly of these effective elements across NSW and across the priority disease categories.

During the second phase of the NSW Chronic Care Program more emphasis will be placed on community based care for people with chronic illness, with effective links to the hospital sector, given that most people with chronic illness require only relatively short episodes of care in acute health settings throughout the course of their illness. This emphasis acknowledges that most ongoing chronic care is or should be delivered in the community with links to specialists, including primary health care, general practice and community based services. For example, patients with ovarian cancer from Western Sydney Area Health Service spent only three per cent of their total care in hospital.<sup>23</sup> People with asthma and diabetes similarly manage their conditions largely in a community setting.

### At a broader level

At a broader level, chronic care policy development during phase two will include:

- Development of a NSW Chronic Care Model
- Participation in developing national chronic disease policy.

### Develop the NSW Chronic Care Model

- **Develop the NSW Chronic Care Model that defines the key players, elements and interrelationships for optimal chronic care**

At a general level, a key first step in the process of further developing and integrating chronic care policy will be the development of a NSW Chronic Care Model. By incorporating key elements identified in phase one as well as those drawn from international models<sup>3, 10</sup> into a dynamic and integrated framework, the model will demonstrate the ways in which key elements and players can interact to improve health outcomes for people with chronic disease. In doing so, the model would be applicable to a range of chronic conditions, health care settings and populations.

### Participate in developing national chronic disease policy

- **Participate in the development of key national initiatives influencing chronic care in NSW, including the National Chronic Disease Strategy and National Service Improvement Frameworks**

The National Health Priorities Action Council (NHPAC) is the key national body, including NSW representation, with the responsibility of driving improvements in health services to achieve better outcomes in the national health priority areas. This aligns with the aims of the NSW Chronic Care Program. NHPAC was established as a sub-committee of the Australian Health Ministers' Advisory Council (AHMAC) in June 2000. The national health priority areas include cardiovascular disease, diabetes, asthma, cancer, mental health, arthritis and musculoskeletal conditions and injury prevention.<sup>2</sup>

NHPAC has been given the responsibility by AMHAC of developing the National Chronic Disease Strategy as part of the national reform agenda of the Australian Health Care Agreement. This strategy has the potential to be an important overarching strategy for the country to progress chronic care. NHPAC also has carriage of the development of National Service Improvement Frameworks for the health priority areas (with the



## 2. Develop and integrate chronic care policy

cancer framework the first to be developed) and also undertakes initiatives and projects to progress care for people with national health priority illnesses and prevent the development of these illnesses. NSW Health also works with other national committees on the development of chronic disease related initiatives, such as the AHMAC Care of Older People Working Group, which is developing clinical pathways for stroke.

### Across chronic disease groups

**Phase one of the NSW Chronic Care Program focused on the priority diseases of cardiovascular disease, respiratory disease and cancer.**

**Phase two will explore opportunities for the transfer of models of care developed for these diseases to other chronic diseases and will review newer models of chronic care that are more broadly applicable across multiple diseases.**

The focus on management of selected chronic diseases in phase one was based on the high degree of burden they represented in terms of hospital admissions and readmissions and presentations to emergency departments.

The second phase of the NSW Chronic Care Program will continue to build on the work established in phase one on these priority diseases, but will also move to consideration of the broader applicability of strategies and models of care developed for these diseases to other chronic diseases.

### Clinical Service Frameworks for respiratory disease, cancer and heart failure

- **Continue implementation of the Clinical Service Frameworks for respiratory disease, heart failure and cancer across NSW**
- **Monitor progress against the agreed standards and demonstrations of compliance from July 2003. This will incorporate the effective elements of the local priority health care programs**

The Clinical Service Frameworks in the three health priority areas of respiratory disease, heart failure and cancer will continue as a major platform of the NSW Chronic Care Program into phase two.<sup>4,5,6</sup> These important frameworks draw on evidence based practice to set standards for optimal care for people with chronic conditions. They also outline targets and demonstrations of compliance for achievement within agreed timeframes over the three year period to 2006.

Area Health Services are reporting regularly on progress against the relevant standards and demonstrations of compliance of the Clinical Service Frameworks for each six monthly reporting period. Baseline measures against all of the standards were collated by Area Health Services (AHSs) in July 2003 and the December 2003 reports indicate that progress is being made. It is acknowledged that each Area Health Service faces different challenges in ensuring that key standards are met.

Recurrent funding of \$15 million has been allocated to support the ongoing implementation of the NSW Chronic Care Program, with most of this funding allocated to Area Health Services to support the implementation of the Clinical Service Frameworks locally. This will involve drawing on the successful elements of the priority health care programs in phase one and spreading these elements more widely within the Area Health Service and across the state. It should be noted that many of the 60 priority health care programs that commenced in the first phase of the NSW Chronic Care Program are continuing into the second phase to 2006, with many tackling broader dissemination across their respective Area Health Services.

Several key areas for activity to improve chronic care have been raised in the Clinical Service Frameworks. Further focused efforts are required during phase two to ensure their successful implementation, and activity is already underway to do so. These include:

## 2. Develop and integrate chronic care policy

Key areas for activity	Activity undertaken/started by July 2004
Improving access to spirometry for the diagnosis of COPD and asthma	<ul style="list-style-type: none"> <li>■ \$285,000 allocated to AHSs to purchase and maintain spirometers</li> <li>■ Spirometry training conducted.</li> </ul>
Improving access to echocardiography for the diagnosis of heart failure	<ul style="list-style-type: none"> <li>■ NSW Chronic Care Collaborative</li> <li>■ Survey of Area Health Services in July 2004.</li> </ul>
Improving uptake of angiotensin converting enzyme (ACE) inhibitors and beta blockers for people with heart failure	<ul style="list-style-type: none"> <li>■ NSW Chronic Care Collaborative.</li> </ul>
Increasing access to and participation in rehabilitation for people with chronic illness	<ul style="list-style-type: none"> <li>■ Collation of rehabilitation manuals and associated resources from phase one.</li> </ul>
Increasing the focus on self-management	<ul style="list-style-type: none"> <li>■ Consultancy to develop NSW approach to self-management.</li> <li>■ Three statewide workshops using the Flinders self-management model.</li> </ul>
Establishing cancer service management structures	<ul style="list-style-type: none"> <li>■ Work underway through NSW Cancer Institute.</li> </ul>
Enhancing the appointment of care coordinators for people with chronic conditions	<ul style="list-style-type: none"> <li>■ NSW Chronic Care Collaborative.</li> <li>■ NSW Cancer Institute.</li> </ul>
Ensuring a multi-disciplinary approach in providing care for people with chronic illness	<ul style="list-style-type: none"> <li>■ NSW Chronic Care Collaborative.</li> <li>■ NSW Cancer Institute.</li> </ul>
Ensuring continuity of care across health services	<ul style="list-style-type: none"> <li>■ NSW Chronic Care Collaborative.</li> <li>■ NSW Chronic Care Model consultancy.</li> </ul>
Engaging general practitioners (GPs)	<ul style="list-style-type: none"> <li>■ Consultancy to identify successful GP engagement initiatives, phase one.</li> <li>■ \$81,000 allocated to participating Area Health Services for GP involvement in the NSW Chronic Care Collaborative.</li> </ul>
<i>My Health Record</i>	<ul style="list-style-type: none"> <li>■ Review of <i>My Health Record</i> commissioned July 2004.</li> </ul>
Promoting advance care planning and use of advance care directives	<ul style="list-style-type: none"> <li>■ NSW Chronic Care Collaborative – workshop undertaken to promote advance care planning.</li> </ul>



## 2. Develop and integrate chronic care policy

### Develop the NSW Clinical Service Framework for Chronic Disease

#### ■ Develop the NSW Clinical Service Framework for Chronic Disease

Phase one saw the development of three disease specific Clinical Service Frameworks. It is now proposed that the successful strategies and initiatives of phase one be synthesised to develop a generic NSW Clinical Service Framework for Chronic Disease. This is in line with activities occurring at a national level to develop a National Chronic Disease Strategy. The NSW Clinical Service Framework for Chronic Disease would contain elements relating to the prevention and management of specific priority chronic diseases, such as heart failure and diabetes.

Diabetes continues to be a major burden on the NSW community in terms of disability, quality of life, and hospital service use for those people with diabetes, as well as affecting those providing care for them. Poor glucose control leads to more diabetes complications, with an attendant increase in costs.<sup>24, 25</sup> Literature indicates that sustained improvements in diabetes management as measured by hemoglobin A<sub>1c</sub> (HbA<sub>1c</sub>) levels lead to reductions in health care utilisation and costs.<sup>26</sup> NSW Health developed a framework for improving the management of diabetes in 1996, which, in light of the many subsequent developments and refinements in diabetes management and chronic care, now requires review and updating.<sup>27</sup>

### NSW Chronic Care Collaborative

#### ■ Implement the NSW Chronic Care Collaborative in conjunction with the Clinical Excellence Commission to enhance implementation of the Clinical Service Frameworks for COPD and heart failure across NSW

The NSW Chronic Care Collaborative is a key initiative for 2004 to assist with widespread implementation of the Clinical Service Frameworks for COPD and heart failure.<sup>28</sup> The collaborative is a joint initiative between the Clinical Excellence Commission and NSW Health. The NSW Chronic Care Collaborative draws on collaborative methodology developed by the Institute for Health Improvement in the US to spread evidence based knowledge, skills and proven good practice across multiple sites over a defined period of time.<sup>29</sup>

Twenty two teams from across NSW are participating in the NSW Chronic Care Collaborative to achieve core aims around the diagnosis and management of COPD and heart failure, which are drawn from the Clinical Service Frameworks. The strategies disseminated through the collaborative will draw on the successes of the local priority health care programs and other evidence-based strategies and assist in their dissemination throughout AHSs and across the state.

The methodology employed by the NSW Chronic Care Collaborative is designed to promote a learning environment in which cultural change can be facilitated and encouraged. During 2004 the statewide and Area-based planning teams associated with the NSW Chronic Care Collaborative will have a key role in gearing the NSW health system for chronic care. The collaborative learning sessions will bring together clinicians and managers, sharing their experiences and exchanging information about resource materials, tools and knowledge gained from conducting local priority health care programs and provide opportunities to consider new roles and new ways of delivering quality health services for people with chronic illness.

## 2. Develop and integrate chronic care policy

### Across the health service system

**The first phase of the NSW Chronic Care Program has largely focused on establishing enhanced systems of care for people with chronic illness across the acute sector (emergency departments and hospital based services) with links to the community sector.**

**The challenge for the second phase will be establishing systems of care with a community-based emphasis and strengthening the links with the acute based health care sector.**

Providing care for people with chronic illness involves working with many services that comprise the NSW health system. Developing policy frameworks and strategies for chronic care that embrace the diversity of the health service system components and establish clear linkages between these components is essential for progressing chronic care in NSW. People with chronic illness generally have their health care provided in the community. The emphasis on community-based care provides a challenge in establishing good models of care with links to the acute health care sector.

Key players in the provision of community-based care are:

- general practitioners
- community based nursing and allied health staff, including those in community health services, acute-post acute care and outreach health care services
- private providers who are also important, with up to 60 per cent of care for people with chronic illness being provided by private providers.

### Strengthen links with general practice

- **Strengthen links with general practitioners through the NSW General Practice Council, NSW Alliance of Divisions of General Practice, Divisions of General Practice and other general practitioner organisations and bodies**
- **Establish strong links with NSW Health**

**Department initiatives such as the new NSW General Practice Council and the after hours general practice initiative**

- **Identify and disseminate successful strategies for engaging GPs from phase one**

General practitioners are key health providers for people with chronic illness, their families and carers. Engaging general practitioners is an ongoing and important task in enhancing the care provided to people with chronic illness. It is known that approximately 50 per cent of chronic care consultations in general practice in Australia are currently not receiving best practice management.<sup>30,31,32</sup>

Barriers to GP engagement in chronic care initiatives have been identified as including:

- general practice being a predominantly encounter-based system geared towards management of acute presentations
- the perceived complex and time consuming nature of chronic disease management
- lack of knowledge of multidisciplinary services available or how to access them
- inadequate use of tools such as computerised patient recall systems and the use of practice nurses and other general practice staff to enhance care
- issues of patient compliance and motivation
- complexity of government incentives (eg EPC items), paperwork involved or changes to criteria leading to their low uptake.<sup>33</sup>

Priority health care programs in phase one of the NSW Chronic Care Program aimed to improve integration between the AHSs and general practice, particularly in the area of care coordination and increased use of MBS items. Strategies ranged from the development of communication mechanisms between health services and general practices, to the delivery of shared education and training programs with health service staff, general practitioners and general practice staff, particularly practice nurses. Area Health Services that were able to engage actively with general practice reported favourable outcomes in terms of planning for



## 2. Develop and integrate chronic care policy

the management of individual patient needs over the care continuum. However, the results were variable across NSW, indicating the need for a continued emphasis on engaging and working with general practice in phase two.

As a first step to progressing this aim, the NSW Chronic Care Unit has commissioned a review and report titled *GP Integration in the Management of Patients with Chronic Diseases*. The review sought input from GPs, Divisions of General Practice and Area Health Service staff to identify both barriers and effective strategies for integration and effective partnerships between general practice and Area Health Service providers of chronic care services. The report identifies key strategic approaches that will be further promoted during phase two. These include:

- development of formal agreements between Area Health Services and Divisions of General Practice
- joint funding for projects to advance integrated care activities
- practicing GPs being employed in liaison roles
- co-location of Area Health Service staff in Divisions of General Practice in a liaison position to facilitate integrated care planning.

Both NSW and Commonwealth governments have been supportive of the development of service models to improve community access to after hours primary care services, and work is continuing to progress this initiative.

### Strengthen links across community health, community acute post-acute care and community based services

- **Strengthen links across the health system to support care provided for people with chronic illness including primary health care and acute post-acute care in the community**

As stated above, people with chronic illness largely rely on health services provided in the community. Community based care for people with chronic illness can comprise primary health care, community acute-

post acute care and other community based services (provided through non-government organisations, private industry or other government departments). The focus of community based care is to maintain good health for people with chronic illness in their home environment, enhancing and supporting self-management of the illness and reducing hospital admissions and readmissions linked to disease exacerbations or recurrences.

There is further potential within the NSW Chronic Care Program to improve linkages with community based services to ensure that people with chronic illnesses receive the support they need in a well-planned and coordinated manner while ensuring their ongoing appropriate access to clinical specialist services. Another goal for the second phase of the program is to achieve better integration of chronic care initiatives into mainstream health services. This will be initiated by scoping the potential for strengthening links with community based services.

A range of community based services are available for people with chronic illness, including:

- primary health care services provided in the community setting through both public and private sectors
- Primary Health Care Networks<sup>34</sup>
- Community Acute Post-Acute Care (CAPAC), which includes programs such as Hospital in the Home, Post Acute Care and community Ambulatory Care Programs<sup>35</sup>
- Community service packages (ComPacks).<sup>36</sup>

Links between these services and chronic care will be strengthened during phase two. A detailed description of these community services is provided in Appendix 2.

Discharge planning is an important component of the transition between hospital and community based services. Implementation of the *Effective Discharge Planning Framework* will assist with the ease of these transitions, which are particularly important for people with chronic illness to prevent further readmissions.<sup>37</sup>

## 2. Develop and integrate chronic care policy

### Incorporate psychosocial care

- **Identify effective elements of psychosocial care and incorporate these as part of chronic care service delivery**
- **Strengthen links with mental health services**

A characteristic of many chronic illnesses is the co-occurrence of psychosocial problems or mental disorders, such as depression and anxiety. This largely relates to the chronic nature of these conditions, their detrimental impact on quality of life and functioning and the impact on psychosocial wellbeing of certain symptoms of these illnesses such as the increase in anxiety levels caused by breathlessness for people with COPD. Further, psychosocial distress may also be a precursor to the development of chronic illness. For example, one significant study highlighted that depression, social isolation, lack of quality social support and catastrophic life events are significant independent risk factors for coronary heart disease, and are of similar magnitude to other known risk factors, such as smoking.<sup>15</sup> Mental health problems and disorders where they occur as co-morbidities with chronic physical conditions may go undetected and hence untreated.

The co-occurrence of psychosocial problems or mental disorders with chronic illness has implications for chronic care, requiring the inclusion of psychosocial components in routine assessment and interventions provided. The inclusion of these components in care has been shown to reduce psychosocial distress among patients with chronic illness, with these improvements being maintained over time.<sup>38</sup>

In phase one of the NSW Chronic Care Program there was increasing recognition of the importance of incorporating psychosocial components within the care provided to the respective patient groups. This included the incorporation of psychosocial components in assessments and interventions provided, the provision of resources about mental health issues, provision of a psychologist for routine assessment and intervention and links with mental health services including psychiatric consultation and liaison services in major hospitals.

Several resources are available for addressing comorbid chronic physical health disorders and depression and anxiety, such as those available through beyondblue the national depression initiative and the NSW Association for Mental Health. The cancer area, particularly breast cancer, is probably the most advanced in the chronic care area in incorporating psychosocial elements. Collaboration with the range of mental health services and professionals is also recommended. Guidelines have been developed for psychosocial care provided to people with breast cancer.<sup>39</sup> NHPAC has also auspiced a review of the psychosocial impact of the national priority health conditions and appropriate intervention points.<sup>40</sup>

### Across the spectrum of care

**Phase one of the NSW Chronic Care Program focused on strengthening the components of treatment and ongoing care.**

**Phase two will, in collaboration with others, also explore aspects of prevention, earlier intervention in the chronic disease trajectory and palliative care.**

Chronic care covers the spectrum of interventions from prevention through to palliative care. Diagnosis, treatment and ongoing care were the main focus of phase one. Working collaboratively with health promotion, primary health management care and palliative care services, phase two will seek to include aspects of prevention, earlier intervention and palliative care.

### Prevent chronic disease

- **Support implementation of the *NSW Chronic Disease Prevention Strategy 2003–2007* in collaboration with NSW Centre for Chronic Disease Prevention and Health Advancement**

There is now overwhelming evidence that major contributing factors to chronic disease – smoking, physical inactivity, poor nutrition and obesity – are preventable in the general population.<sup>41, 42</sup> Addressing these factors in an effective and systematic manner can lead to a reduction in the incidence of chronic illness



## 2. Develop and integrate chronic care policy

for chronic respiratory disease, cardiovascular disease, diabetes (Type 2) and cancer.

The focus of the NSW Chronic Care Program has largely been on developing and enhancing models of care for people who already have one or more chronic conditions. While the local chronic care programs are not generally directed toward the primary prevention of disease, they do include a range of secondary prevention strategies aimed at reducing severity and frequency of acute episodes or disease progression rather than at reducing incidence or prevalence. Further, the Clinical Service Frameworks for respiratory disease and heart failure include primary prevention standards and demonstrations of compliance for statewide achievement.

The second phase of the NSW Chronic Care Program will be complemented by the implementation of the *NSW Chronic Disease Prevention Strategy 2003–2007*, which has a clear focus on primary prevention.<sup>43</sup> An integrated approach, using both primary and secondary prevention strategies, is likely to be the most effective way to relieve the burden of chronic illness on the health service system and on the community.

### Intervene earlier in the chronic disease trajectory

#### ■ Explore initiatives for intervening at earlier stages of the chronic disease trajectory

There is a high rate of mortality among populations with chronic illness. For example, 50 per cent of people with heart failure will die within a five-year period.<sup>44</sup> Also, many chronic illnesses, once established, are not reversible, such as diabetes type 2 or COPD. This has prompted questions about where best to focus efforts and interventions in the chronic disease progression pathway to gain the greatest health and related outcomes. It would seem that focusing attention earlier in this disease pathway would be of benefit.

Intervening earlier in the chronic disease pathway requires focus on:

- the known cluster of risk factors that contribute to chronic illness eg tobacco smoking, physical inactivity, poor nutrition, obesity and psychosocial distress<sup>42,43</sup>

- earlier disease states that may progress to chronic disease eg hypertension and ischaemic heart disease progressing to heart failure.

Scoping the most effective points for intervening earlier in the chronic disease trajectory will be an important initial step.

### Strengthen management of chronic disease

#### ■ Strengthen the role of care coordinators, care planning and review, multidisciplinary care and rehabilitation in providing enhanced care for people with chronic illness

Phase one of the NSW Chronic Care Program identified key components in providing and enhancing care for people with chronic illness. These included care coordination, care planning and ongoing review, multidisciplinary care and rehabilitation. These components are also supported widely in the chronic care literature as effective components of chronic care.<sup>4,5,6</sup>

A range of different models of care coordination, care planning, multidisciplinary care and rehabilitation emerged through the local health priority programs during phase one of the NSW Chronic Care Program. For example, some Area Health Services undertook priority health care programs where care coordinators were based in either hospital or community settings, were drawn from a diversity of disciplines and undertook a range of tasks in these roles.<sup>9</sup> Similarly models of multidisciplinary care are emerging in NSW involving different health professionals, differing processes, varying roles among those involved in the care and across diverse settings. Models for rehabilitation for patients with heart failure and COPD also emerged during phase one. The models offer rehabilitation to patients in groups (either with patients with the same illness or grouped with others with various illnesses) or individually and in either clinical or community based settings or at home. Most delivery is by physiotherapists, nurses and other health professionals who have undertaken specific training supported by physiotherapists, in order to improve the availability of and access to rehabilitation across large geographic areas.



## 2. Develop and integrate chronic care policy

The second phase of the NSW Chronic Care Program will seek to strengthen management of chronic disease by building on the achievements of phase one and the lessons learned, and further refining the effective mechanisms needed to implement these core components of chronic care and embed these as part of routine care. This will be undertaken through:

- ongoing support for the implementation of the Clinical Service Frameworks for heart failure, respiratory disease and cancer. Area Health Services in phase two have been allocated funds to support the implementation of these frameworks with progress to be monitored regularly based on the standards and demonstrations of compliance outlined.
- the NSW Chronic Care Collaborative, which will assist in enhancing diagnostic and management processes, as well as the processes of care coordination, care planning and review, multidisciplinary care and rehabilitation across NSW for patients with heart failure and COPD. Many of the processes of care established for people with these illnesses will also be transferable to patients with other chronic illness.

### Strengthen links with palliative care

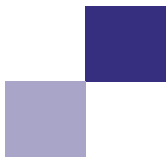
- **Strengthen links with palliative care services to support care provided to people with chronic illness**

Approximately 50 per cent of people with heart failure will die within a five-year period and a majority of people with COPD will die from this illness or related complications<sup>44, 45</sup> Palliative care services are available throughout NSW and provide a range of health services for people at the end stage of their life. Palliative care services in NSW primarily care for people with cancer, which constitutes approximately 85-90 per cent of adult palliative care referrals, with the other 10-15 per cent including other progressive diseases such as advanced organ failure, HIV/AIDS and degenerative neurological diseases.<sup>46</sup>

Palliative care in NSW is provided by specialist medical, nursing and allied health staff, generalist clinicians and support services operating in a range of settings including the person's home, community facility and hospital. There are many models of palliative care service delivery operating across NSW. These range from dedicated specialist palliative care services providing direct care to patients, to palliative care consultancy services to provide community based specialist support for referring health professionals such as GPs and community nursing services, to programs providing palliative care skills training to staff so they can provide this care. *The NSW Palliative Care Framework: A guide for the provision of palliative care in NSW* outlines principles of palliative care service delivery, key elements, models of care and future directions for NSW.<sup>46</sup> This framework acknowledges the palliative care needs of people with chronic illness.

In the first phase of the NSW Chronic Care Program, the need to strengthen links with palliative care services was identified, particularly for patients who are dying with chronic illnesses other than cancer. This requires establishing and strengthening links between specialist health service areas and palliative care services.

Advance care planning and advance care directives are being increasingly recognised as a useful mechanism for having a person's preferences for end of life care known after they have become incompetent to decide on that care themselves. The NSW Health Department has released a document titled *Using Advance Care Directives (NSW)* to provide advice to health professionals on the best practice use of advance care directives within an advance care planning process.<sup>47</sup> With the high mortality and loss of functioning experienced by people with chronic illness, advance care planning is of interest for people with chronic illness and their carers. Phase two of the program will aim to incorporate their uptake, primarily through the NSW Chronic Care Collaborative. An Advance Care Planning Workshop has already been undertaken and further activities are planned to promote and support this initiative.



## 2. Develop and integrate chronic care policy

### Across age and population groups

**The first phase of the NSW Chronic Care Program focused strongly on systems of care for adults and older people with chronic illness.**

**The second phase of the NSW Chronic Care Program will additionally seek to strengthen systems of care for other population groups including children and young people, Aboriginal people, people from culturally and linguistically diverse backgrounds, people living in rural and remote locations and those in correctional facilities.**

Chronic disease affects people of all ages and from differing population groups. During the first phase there was some initial work undertaken with children with chronic illness and with Aboriginal populations. The second phase of the NSW Chronic Care Program will strengthen these components, and will provide opportunities to enhance care for other population groups.

#### Strengthen systems of care for children and young people with chronic illness

- **Strengthen systems of care for children and young people with chronic illness**
- **Support the implementation of primary prevention initiatives aimed at children and young people in particular to prevent the later onset of chronic disease**
- **Support the implementation of initiatives for children and young people with parents with chronic illness**

Chronic illness also affects children and young people, with several chronic illnesses having their onset during this time. The prevalence of asthma in Australian children is among the highest in the world and is increasing.<sup>30, 48</sup> Diabetes Type 1, though less common than Type 2 diabetes, has its onset mainly during childhood. Cystic fibrosis affects approximately one

in 2,500 babies born in NSW. Health care for children and young people with chronic illness is mainly provided by general practitioners, general and specialist paediatricians, hospital based paediatric services and three specialist children's hospitals, including medical, nursing and allied health staff.

The main focus of the NSW Chronic Care Program in phase one has been on adults and older people. Some initiatives in phase one focused on children and young people with chronic illness, with some notable achievements. Building on these achievements in phase two will be important.

The key issues to be addressed for children and young people with chronic disease in phase two of the Chronic Care Program are:

- provision of developmentally appropriate health care and support for children and young people. This includes care and support that is multidisciplinary, addresses physical, psychosocial and emotional domains and is family focused
- ensuring early detection and management of chronic illness, particularly diabetes and asthma
- provision of appropriate specialist medical care for the chronic illness that is linked to primary health care (including general practitioners) and the range of support services that may be needed for the child or young person and their family
- supported transition from child to adolescent to adult health care services, as consistent with the Greater Metropolitan Transitional Taskforce framework *Transition care for young people with chronic childhood illnesses*<sup>49</sup> and its associated activities.

Models of care such as that developed for children with cystic fibrosis through the Children's Hospital may be of benefit in providing models of specialist care for children with other chronic illnesses.

## 2. Develop and integrate chronic care policy

### Model of care for children with cystic fibrosis

The Children's Hospital has developed a model of care for children with cystic fibrosis including:

- early detection of cystic fibrosis
- the establishment of a centre that provides ambulatory care for children with cystic fibrosis
- an adolescent clinic, which provides education, extended hours access, outreach services and transition services to ensure smooth transitions of care to adult services.

#### The centre provides:

- initial comprehensive assessment by a cystic fibrosis clinical nurse consultant
- follow-up by others from the multidisciplinary team
- education for families with children newly diagnosed
- assessment and management of acute episodes
- a home intravenous antibiotic service.

#### Outcomes from the clinic include:

- a reduction in presentations to emergency departments (on average 1.5 less presentations per month)
- a reduction in home visits by 40 per cent
- reduced length of stay in hospital through the introduction of home intravenous antibiotics
- attendance at the adolescent has increased from 30 per cent to 90 per cent of adolescent patients.

Children and young people are also affected by chronic illness through having parents with a chronic illness. This can impact on the children's own health, create disruption in their lives and can often involve assuming a carer role from a young age. Reviewing initiatives underway in the area of mental health and elsewhere can provide direction for initiatives for children with parents with other chronic illnesses.

Prevention initiatives targeted at children and young people can be effective in preventing and reducing later onset of chronic disease. Supporting the implementation of the *NSW Chronic Disease Prevention Strategy 2003–2007* (referred to earlier) outlining primary prevention initiatives that can prevent later onset of chronic disease will be beneficial.

### Support and enhance care provided to adults with chronic illness

#### ■ Continue to strengthen care provided to adults with chronic illness

Many of the local programs in phase one of the NSW Chronic Care Program aimed to enhance the diagnosis and management of adults with chronic illness, specifically cardiovascular disease, respiratory disease and cancer. Many lessons were learnt during this initial phase. Building on these and strengthening their implementation will be important in phase two.

Factors that enhance care for adults with chronic illness are similar to those for other population groups including care coordination, care planning and review, smooth transitions between hospital and community based services, multi-disciplinary care, self-management approaches and rehabilitation. The implementation of the Clinical Service Frameworks for heart failure, respiratory disease and cancer will provide impetus for strengthening care provided to adults with these chronic illnesses, as will participation in the NSW Chronic Care Collaborative.

Chronic illness during adulthood can impair functioning, which in turn can have an impact on employment, financial status and other lifestyle issues. Chronic illness also impacts on family members. Many community-based organisations provide support for people with disabilities and their carers and families. These include non-government organisations and government-based services that provide diverse services such as those focusing on vocational issues, financial issues, providing support groups and a range of disability related services. Strengthening links with community-based services that can provide support for people with chronic illness is important for this population group. Lessons can be learnt from the areas of mental health and HIV/AIDS and initiatives such as ComPacks (referred to earlier) in strengthening service linkages and enhancing care provided to people with other chronic illness.



## 2. Develop and integrate chronic care policy

### Strengthen systems of care for older people with chronic illness

#### ■ Strengthen systems of care for older people with chronic illness to ensure effective, coordinated and integrated care

The ageing of the population is being experienced throughout the developed world internationally, including Australia. It has been estimated that the number of people aged 65 years and over will increase by 22 per cent between 2002 and 2011, and by 65 per cent between 2002 and 2021. In 2011 this age group will comprise 15 per cent of the total NSW population, increasing to 19 per cent in 2021.<sup>50</sup> Many, if not most of this older age group, will experience at least one chronic condition. The prevalence of chronic illness increases within this age cohort. For example, approximately 1 in 20 people over 65 years have some form of dementia compared to 1 in 5 for those aged over 80 years.<sup>62</sup> The increasing proportion of the population aged 80 years and over therefore has significant implications for health care delivery for chronic illness into the future.

The *Framework for integrated support and management of older people in the NSW health care system 2004–2006* clearly acknowledges the importance of integrating and coordinating care for older people with chronic illness.<sup>50</sup> The emphasis throughout the framework is on coordination and integration of the range of health and related services supporting older people with health care needs. This range of services includes general health services such as emergency departments, hospital wards, community health as well as specific aged care services.

Specific aged care services span hospital and community based services, and include medical, nursing and allied health staff. They may provide care directly to patients as well as providing a consultancy service to others providing care for older patients. They focus on older people with special needs such as those with:

- multiple co-morbidities and problems involving several body systems and medical specialities
- chronic diseases that impair cognitive and physical functioning, especially the neurodegenerative diseases of older people and

- informal networks that are stressed and compromised by the burden of care required.

In the first phase of the NSW Chronic Care Program initial links were established between chronic care programs and aged care services, with some innovative models of care emerging. This was reflected in initiatives with hospital and community based aged care services and with residential care services for older people with chronic illness. These models will be strengthened during phase two. The new models of care will need to consider how best to incorporate chronic care for an increasing number of older patients across the broader health system.

### Strengthen systems of care for Aboriginal people with chronic illness

- Finalise, launch, implement and monitor the *NSW Aboriginal Chronic Disease Area Health Service Standards across NSW*
- Strengthen links with the NSW Aboriginal Vascular Health Program
- Strengthen links with Aboriginal community controlled health services

Aboriginal populations experience higher mortality and morbidity from chronic illness than the general population. For example, Aboriginal populations experience double the rate of mortality from cardiovascular disease than non-Aboriginal people in NSW, with the premature mortality rate five times the rate for non-Aboriginal people.<sup>51</sup> For respiratory diseases, the hospital separation rate for Aboriginal people was four times the rate of non-Aboriginal people and for diabetes it was over five times the rate.

The NSW Aboriginal Vascular Health Program, established in July 2000, supports implementation of the components of the *NSW Aboriginal Health Strategic Plan (1999)* which relate to diabetes, diseases of the circulatory system and renal disease.<sup>52</sup> Program initiatives including the *NSW Aboriginal Chronic Disease Area Health Service Standards* seek to enhance Area Health Service programs in chronic care to ensure responsiveness to the needs

## 2. Develop and integrate chronic care policy

of the Aboriginal population. Current initiatives of the Aboriginal Vascular Health Program include demonstration site projects located at 20 sites across NSW, development of the Aboriginal Vascular Health Network which disseminates information via the bulletin *Vascular Health Matters*, health worker education, training and support, and development of the *Aboriginal Vascular Health Resource Catalogue*.

Finalising and implementing the *NSW Aboriginal Chronic Disease Service Standards* for Area Health Services will be an important new component in phase two of the NSW Chronic Care Program.<sup>53</sup> This framework sets evidence-based standards to guide Area Health Services in the provision of appropriate and accessible services for Aboriginal people. It covers the range of chronic diseases affecting Aboriginal populations including diabetes, cardiovascular disease, renal disease, respiratory disease and cancer and outlines demonstrations of compliance for achievement within agreed timeframes (as in the Clinical Service Frameworks).

Extensive consultation with Aboriginal communities and health workers and other health providers has informed the development of the standards to date. The standards document is due for release in 2004, with implementation statewide to follow. Implementation of the standards can be usefully informed by the lessons learned and models of care developed through the Aboriginal Vascular Health Program demonstration site projects in operation since 2000 in selected sites across NSW. Reporting will be undertaken in the same manner outlined for the Clinical Service Frameworks above.

### Address the chronic care needs of culturally and linguistically diverse populations

- Encourage provision of information on chronic illness and care in community languages
- Ensure that chronic care initiatives are responsive to the special needs of culturally and linguistically diverse population groups

More than 25 per cent of NSW residents were born overseas and around 20 per cent speak a language other than English at home. The composition and age

structure of the overseas-born population reflects patterns of migration. Following World War II large numbers of migrants came from Europe to NSW, including Eastern Europe, United Kingdom, Northern Europe, Greece, Italy and Yugoslavia. This was followed by migrants from the Middle East. More recently migrants have come in large numbers from Asian countries, particularly China, Vietnam and the Philippines.

In general, overseas-born residents have better health than Australian-born residents reflecting the 'healthy migrant effect'. However, some diseases are more prevalent among some country-of-birth groups. For example, people born in Southern Europe and the Middle East reported a higher prevalence of current diabetes than NSW residents generally.<sup>54</sup> People born in South Asia, the Middle East, Melanesia, Micronesia and Polynesia had high hospitalisation rates for diabetes complications and coronary heart disease compared to NSW residents generally.<sup>55</sup>

Initiatives in the first phase of the NSW Chronic Care Program for people from culturally and linguistically diverse backgrounds included information about chronic illness and its management being made available in various community languages, such as for COPD and heart failure. In seeking to enhance the cultural sensitivity of chronic care initiatives in phase two, it is recognised that it will be beneficial to involve Area Multicultural Health Directors/Managers as well as individuals, relevant community agencies and representatives from particularly identified communities to:

- identify the particularly affected communities and how they may be appropriately targeted
- address service delivery issues
- develop appropriate initiatives.

### Address the needs of rural and remote populations

- Strengthen initiatives to enhance health care provided to rural and remote populations with chronic illness

People living in rural and remote areas across Australia have worse health generally than those living in metropolitan areas. In NSW in the financial year



## 2. Develop and integrate chronic care policy

1999–2000 hospitalisation rates for ambulatory care sensitive conditions (which particularly includes chronic conditions) increased dramatically with remoteness and were almost seven times higher among residents of ‘very remote’ areas compared with residents of ‘highly accessible’ areas.<sup>55</sup> Many factors contribute to this including geographic isolation, socioeconomic disadvantage, shortage of health care providers, greater exposure to injury risks and Aboriginal health needs.<sup>56</sup>

During the first phase of the NSW Chronic Care Program several innovative and effective strategies and models of care emerged for people with chronic illness in rural and remote communities. These included:

- establishment of specialist health care positions within Area Health Services providing direct patient care and consultancy services across the Area
- strategies to enhance the skills of the workforce in identifying and managing specific chronic illness
- establishment of new models of care involving care coordination and links between hospital and community health services including general practitioners
- development and implementation of protocols reflecting new ways of working based on evidence
- introduction of cardiac and pulmonary rehabilitation services across multiple sites.

The NSW Chronic Care Collaborative will assist with the dissemination of these newly developed models of care across rural NSW populations. Also working with the NSW Rural Health Taskforce and other initiatives aimed at enhancing the quantity and quality of the health workforce in rural NSW will help disseminate chronic care initiatives to populations with chronic illness across NSW.

### Address the needs of prison populations with chronic illness

- **Establish initiatives to enhance chronic care among prison populations**

Prison populations tend to experience poorer health than the NSW population generally. Offenders are largely males, from disadvantaged backgrounds, with low levels of educational attainment, over representation of Aboriginal and Torres Strait Islander people and

people with mental illnesses and drug dependencies.<sup>55</sup> It is important that the health needs of offenders are addressed while they are in prison and that their health does not deteriorate further during incarceration.

Justice Health is a statutory health corporation under the *NSW Area Health Services Act, 1997* that provides health services to more than 24,000 people annually in:

- 28 correctional centres (2 to open in 04/05)
- 11 periodic detention centres
- two transitional centres
- eight police cell complexes
- 14 local court complexes
- nine Juvenile Justice centres
- Adult Drug Court
- Correctional Centre Release Treatment Scheme
- Youth Drug Court.

The opportunity for Justice Health to provide chronic care services is generally short given that:

- 27 per cent of offenders are incarcerated for less than eight days
- 17 per cent of offenders are incarcerated for between eight and 30 days
- 56 per cent remain longer than 30 days
- Only 10 per cent are incarcerated for longer than six months.

This increases the importance of coordination of the discharge planning process and good linkages with community based services. This will ensure that individuals in custody who are diagnosed with or provided with treatment and care for a chronic disease while incarcerated are linked with community services on discharge for a smooth transition of care and ongoing management and support in the community. This is particularly relevant for Aboriginal offenders for whom Aboriginal controlled community health services play this role on their release into the community.

In phase two of the Chronic Care Program, initiatives will be established to enhance chronic care provided to prisoner populations. Participation of Justice Health in the NSW Chronic Care Collaborative during 2004 will be a key mechanism for enhancing chronic care.

### 3. Strengthen the focus on patients and carers

Patients and carers will continue to be the focal point of the NSW Chronic Care Program in phase two. Providing services that are centred around the patient and their needs is a key principle of the NSW Chronic Care Program and is fundamental to providing effective and appropriate care.

*My Health Record*, a patient held record of their health and related care was well received by patients and their carers. Revising this record to incorporate ideas for improvement will be undertaken.

Carers of patients with chronic illness, although acknowledged in phase one, were the focus of limited attention at the statewide level. Increasing their profile will be a focus in phase two.

#### Place patients at the centre of care

##### ■ Ensure that patients and their carers are placed at the centre of care

Ensuring that patients and their carers are placed at the centre of care is a key principle of the NSW Chronic Care Program, initiated in phase one of the Program and continuing through to phase two. Placing patients at the centre of care has implications for what, how, where and when care is delivered.

A range of initiatives are in operation at various levels to promote a patient centred approach, such as:

- The NSW Health Partners in Health initiative which was launched in 2001.<sup>57</sup> This key document provides the overarching framework for ensuring that all people in NSW, no matter where they live, what language they speak or other needs they have, can have equal access to participate in health decision making and to obtain information they need to improve their own and their community's health.
- At the state level the NSW Health Participation Council (HPC) was established to support the implementation of *Partners in Health*. Priorities identified at an HPC meeting in June 2004 include:
  - developing a better 'dashboard indicator' for patient satisfaction

- sponsoring the Annual Consumer Forum
- encouraging a statewide rollout of the Health Care Consumer Advocacy training
- promoting the Your Health Rights and Responsibilities brochure
- providing advice about what communities are saying about the NSW health system and ways that they can assist in rebuilding trust within the health system.<sup>58</sup>

- At the local level structures have been established for the involvement and participation of the community and consumers in AHSs across NSW, with the aim to impact on the health services delivered locally being more responsive to local and individual patient needs.
- Through the Perfecting Health Care Delivery initiative, the Hunter Area Health Service has assembled a description of patient centred care in community-based services as viewed by local patients and their carers.

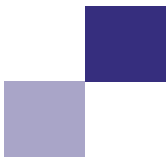
Initiatives were also put in place through the NSW Chronic Care Program to respond to the needs of people with chronic illness in terms of service delivery and information needs. This will be continued and strengthened during phase two. For example:

- The Area Health Services participating in the NSW Chronic Care Collaborative have all engaged in mapping patient journeys and consultation with patients and their carers to better inform the delivery of chronic care services locally.
- At the state level patient and carer involvement in governance structures will continue, including in the NSW Chronic Care Implementation Group, to ensure that patient and carer issues are raised and addressed.

#### *My Health Record*

- **Review and disseminate the next edition of *My Health Record*, the patient held record, specifically for people with chronic illness to better manage their illness.**

*My Health Record*, is a patient-held folder in which a patient's health information can be organised and available in one place.<sup>8</sup> The purpose of the record is to improve



## 3. Strengthen the focus on patients and carers

communication and enhance continuity of care for people with ongoing health care needs who interact with multiple health service providers. *My Health Record* is an innovative tool to assist patients and their carers to be more informed partners in the management of their illness.

*My Health Record* allows for updating of information during care, such as medications, details of health care provider contacts including general practitioner, appointments and information about what the patient needs to do. The record includes plastic sleeves for the easy insertion of the patient's information, including discharge summaries, care plans and case conference reports.

Over 120,000 copies of *My Health Record* have been distributed across NSW since the record's launch in December 2002.

An initial review of *My Health Record* in early 2003 highlighted some potential changes to enhance the use of the record. A more comprehensive review of *My Health Record* will be undertaken and improvements incorporated into future editions. Making the record more easily accessible for culturally and linguistically diverse groups will also be explored.

### Ensure access to information on chronic illness and its management

- **Ensure that people with chronic illness and their carers have access to quality information about the illness and its diagnosis and management**

People with a chronic illness and their carers require quality information about their illness and its diagnosis and management so that they can make informed decisions about their care. Information on chronic illness is available through a diversity of organisations, such as AHSs, Heart Foundation, NSW Cancer Council, Asthma Foundation or Diabetes Australia and in a diversity of formats (hard copy, electronic through the internet and verbally in consultation with professionals or others). Local priority health care programs during phase one of the NSW Chronic Care Program developed information on chronic illnesses, including in community languages. These are listed in the NSW Chronic Care Program

resource list which provides an overview of materials developed during phase one and can be accessed through the NSW Health website.<sup>9</sup>

Ensuring that health workers are aware of quality information on chronic illness and its management and disseminate this information to patients and their carers, as part of their overall care will be a core component during phase two. Information for people with a chronic illness also incorporates skills of behaviour management, problem solving and goal setting that can be of benefit for patients in managing their illness. Self-management programs for people with chronic illness provide a valuable source of information about the illness and its management, and other skills required to live with a chronic illness. Supporting health professionals to develop skills to provide quality self-management programs for patients and their carers to maximise their benefits will be strengthened during phase two of the program.

### Enhance the role of carers

- **Explore options for promoting the health and quality of life of carers of people with chronic illness, including young carers**

Chronic illness not only affects people with the illness, but also impacts on those providing care for people with the illness. In addition to the time and logistical restraints, physical burdens and financial costs that carers may bear, care giving also poses mental and physical health risks.<sup>59, 60, 61</sup> In Australia it is has been estimated that there are currently 2.3 million carers, of which most are female, 21 per cent are aged over 65 years and 40 per cent have been providing care for 10 years or more.<sup>62</sup> There is also a growing group of children and young people with caring responsibilities, with approximately 17 per cent of carers under the age of 26 in Australia.<sup>63</sup>

A national survey of carer health and wellbeing in 1999 indicated that as a result of providing care, over half of all carers have suffered a decline in physical health, a third of all carers have been physically injured, over half believe they have worse mental and emotional



### 3. Strengthen the focus on patients and carers

health overall, and over half have experienced major negative effects on life opportunities such as travel, paid work and pastimes.<sup>64</sup> For young carers, the negative impacts of care giving on physical and mental wellbeing, life choices and future opportunities may be lifelong.

Including carers in the care of people with chronic illness is an integral component of quality chronic care. Options will be explored for enhancing the health and quality of life of carers during the second phase of the Chronic Care Program.

Strategies to enhance the health and quality of life of carers in phase two will include:

- Strengthening links with the NSW Carers Program. The NSW Chronic Care Program will seek opportunities to promote synergistic initiatives with the NSW Carers Program during phase two. The NSW Carers Program, managed by the NSW Department of Health working in partnership with the Department of Ageing, Disability and Home Care, has as its priorities the provision of:
  - more practical support and training for carers
  - greater access by carers to counselling and emotional support
  - improved responsiveness of service systems (both health and community services) to the needs of carers.
- Consideration of young carers. Australian and international literature indicate that a range of policies and programs should be utilised to meet young carers' needs. Young carer specific programs are crucial. Adapting current programs that already work to suit the needs of young carers is also required, and will be a focus of activity during phase two
- Enhancing recognition and engagement of carers throughout the continuum of care. Carers identify key areas where improvement is required as including:
  - early recognition and engagement of carers in the patient care process
  - meaningful involvement of carers in assessment, care planning and discharge planning processes
  - meaningful discussions involving carers regarding options for future care and preparation for discharge
  - provision of written information for patients and carers
  - ongoing post-discharge support for patients and carers.<sup>65</sup>

Some of these issues are being addressed at a local level across NSW through the NSW Chronic Care Collaborative. At a statewide level, policy documents for the NSW Chronic Care Program will continue to promote a patient and carer centred approach through phase two.



## 4. Establish a comprehensive approach to self-management support

- **Develop the NSW approach for self-management support for people with chronic illness**

### Self-management support

Self-management is a process whereby patients can engage in activities that protect and promote their health, manage their symptoms and signs of illness, monitor behaviours and manage the impact of their illness.

Self-management support has been described as working in partnership in:

*“... empowering and preparing for patients to manage their health and health care through:*

- *Emphasizing the patient’s central role in managing their health*
- *Use of effective self-management support strategies that include assessment, goal setting, action planning, problem solving and follow up*
- *Organising internal and community resources to provide ongoing self-management support to patients.”<sup>66</sup>*

The introduction of self-management support represents a change in the roles of the health care provider and the patient and their carer, with the health care provider becoming more of a partner in providing advice on symptoms, treatment and providing referral and the patient and their carer becoming more proactive and increasingly responsible for their care in partnership with health providers. Self-management acknowledges the central role of patients themselves (and their carers) as the principal care givers, since people with chronic illness live many years with that illness and many aspects of treatment are under their direct control, such as diet, exercise, self-measurement and medication use.

The effectiveness of including approaches to self-management support in chronic care can have positive impacts on patient behaviour, health status, health care service use, social functioning, life satisfaction and patient-carer provider communication.<sup>67,68</sup> Despite this, several organisations have not fully introduced self-management

support, with many limiting its introduction to patient education only.<sup>69,70</sup> It should be noted that chronic care programs that have not included self-management support approaches have been limited in their effectiveness.

Self-efficacy is a core component of effective self-management. Self-efficacy has been defined as a person’s belief in his or her ability to perform a desired task or behaviour.<sup>71</sup> When applied to a person with chronic illness, self-efficacy means the person’s belief that they can manage their life despite their illness. The link between self-management approaches and improvements in a person’s self-efficacy are important in contributing to these changes.

### Establishing a comprehensive approach to self-management support

In the first phase of the NSW Chronic Care Program, two specific self-management support models were introduced into several of the priority health care programs. These were the:

- South Australian Flinders University’s Partners in Health program,<sup>72</sup> which has a strong emphasis on health care providers working in partnership with patients to identify their level of self-efficacy, self-determine health goals and plan actions to attain those goals
- Stanford University programs: Living With Chronic Disease,<sup>73</sup> a group based and peer led model that facilitates problem-solving skills and other self-management techniques.

These models have been used in various settings. For example, the Aboriginal Vascular Health Program has helped to provide training for Aboriginal Health Workers to implement self-management support within their communities, using both the Flinders and Stanford models.

During the second phase of the NSW Chronic Care Program, establishing self-management support as a core component of chronic care will be facilitated. The NSW Chronic Care Collaborative provides a solid foundation to achieve this statewide. The development of a document outlining the NSW approach to self-management support will provide a valuable resource to assist statewide implementation.

## 5. Strengthen workforce capacity for chronic care

### ■ Enhance workforce capacity to provide care for people with chronic illness through education, training and enhancement of organisational capacity

*"...effective support of patients is more likely to occur when the providers of care themselves have the information, training, resources and time to deliver effective interventions..."*<sup>74</sup>

Enhancing workforce capacity is a process initiated within organisations and communities in response to their strategic priorities, to ensure that the people working within these systems have the abilities and commitment to contribute to organisational and community goals.<sup>75</sup> Addressing workforce capacity involves enhancing the knowledge and skills base of staff, as well as building the organisational system around the workforce to enhance their efficiency, effectiveness, career progression and satisfaction. Workforce development from an organisational perspective also involves skill distribution, leadership, role delineation, functional specialty and other support structures such as information technology and human resource management.<sup>76</sup>

Addressing workforce capacity at an organisational and management level involves supporting organisational change to provide a work environment supportive of providing care for people with chronic illness. This involves establishing clear policy directions, attention to resourcing, staff recruitment, training and retention and establishing and maintaining information systems. Managing change is a core component of chronic care health service delivery, often involving realigning work roles and functions and organisational systems to support chronic, rather than acute care needs.

The knowledge and skills required by staff in working with people with chronic illness are different to those required for working with people with acute health care needs, largely due to the nature of the illness. Key requirements for working with people with chronic illness include:

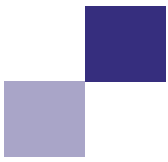
- specific knowledge of the illnesses, their diagnosis and management

- increased emphasis on coordination of care across multiple providers
- working as part of a multidisciplinary team
- fostering and supporting behavioural change approaches and self-management approaches for patients and their carers, as well as approaches for enhancing adherence to treatment regimes.

A comprehensive study of education and training needs of community health staff for chronic disease management in the Hunter Area Health Service<sup>77</sup> indicated that:

- it is important to provide management with skills and strategies to lead and support change
- 65 per cent of community health staff surveyed spend more than 50 per cent of their time with patients with chronic illness
- 75 per cent reported the work as rewarding
- 75 per cent agreed that non-compliance with treatment is a major issue for patients with chronic illness
- 82 per cent of respondents thought that helping patients manage their chronic condition is what the future of health care is about
- almost half of community health staff respondents reported being more confident dealing with, and therefore more likely to respond to day-to-day needs than to be proactive with patients with chronic illness.

Studies such as this one highlight the issues to be dealt with in developing appropriate training and education strategies for chronic disease management. The development of a workforce strategy for chronic care for NSW will be valuable in progressing this area, with clear articulation of the competencies for staff and management in working with people with chronic illness. Progressing specific strategies to enhance workforce capacity will also be important.



## 6. Develop and refine chronic care information systems

- **Develop a chronic care information template for inclusion in community based information systems such as the Community Health Information Management Enterprise, that also captures hospital based patient information**
- **Participate in the development of the Electronic Health Record as relevant for people with chronic illness**

Timely, useful data about individual patients with chronic illness and populations of people with chronic illness from clinical information systems is a critical feature of chronic care. People with chronic illness are likely to visit multiple providers across numerous settings – hospital and community based, in public and private facilities – over the many years of their care. Each of the multiple health care providers will generate information regarding the patient's demographics, illness, its diagnosis and management including a care plan and any health outcomes achieved and record this information either electronically or in paper form. The ability to share this information across the multiple health care providers, within privacy legislation requirements, is critical to ensure continuity of care.

Registries for people with chronic illness have been reported as beneficial in enhancing their care, particularly through their ability to enhance recall and feedback systems, necessary for planning chronic care.

Management of health services requires information on health organisation goals and indicators to achieve these, budgets including expenditure and monitoring patient care (such as hospitalisations or community presentations) and health and related outcomes of patient care. Current information systems in NSW Health are geared towards inpatient care, having limitations for chronic care, where the majority of chronic care occurs in community based settings.

During the first phase of the Chronic Care Program many programs identified clinical information needs as important. Some programs developed quality information systems for their chronic care patients, including the use of hand held computers for storing and retrieving patient records in Western Sydney Area Health Service, the incorporation of chronic care information into the Community Health Information Management Enterprise (CHIME) in New England Area Health Service and the hospital based respiratory information system developed in South Eastern Sydney. Several others developed programs in Excel or Access databases that although, being valuable for specific chronic care program staff, encountered problems in limited access by health providers across the Area Health Service or limited capacity for storing patient information.

Progressing clinical information needs for chronic care in NSW involves identifying a consistent statewide chronic care minimum data set for collection that is supported by a chronic care data dictionary. Progressing this area also involves working with the current and newly proposed information systems, such as CHIME and the Electronic Health Record (EHR) to ensure incorporation of appropriate chronic care information.



## 7. Develop the NSW chronic care funding model

- **Develop a chronic care funding model that is relevant to the NSW context and comprises NSW health service system components and appropriate links with Commonwealth, local and community based organisations.**

Another key area for activity in phase two is to develop a chronic care funding model, the objectives of which are to:

- create opportunities to better plan and manage services for people with chronic illness within and across acute care and community health settings
- improve accessibility of services, particularly for those people with multiple or complex needs
- support the implementation of Clinical Service Frameworks to enable services to be tailored to meet the needs of individual patients and their carers
- leverage Commonwealth initiatives in funding general practitioners and others in providing care for people with chronic illness
- address episode funding for people with chronic illness that has generally focused on acute inpatient care.

It is proposed that a funding model be developed for the management of chronic diseases, starting with a number of selected conditions defined by the Clinical Service Frameworks in the priority areas. Given the absence of clear separation of the costs of managing these conditions it will be necessary to implement some transitional arrangements. A starting point will be the clear identification of people with chronic illness within existing funding streams (including episode funding).

Eventually the funding model will be developed to focus on the cost of providing a package of care to patients at different stages of chronic illnesses, based on agreed clinical management plans, derived from the Clinical Service Frameworks. These could, for example, provide incentives to reduce the level of acute care admissions.



## 8. Communicate the NSW Chronic Care Program's successes

- **Disseminate the NSW Chronic Care Program Review of phase one and resources list**
- **Continue to develop and disseminate the NSW Aboriginal Vascular Health Matters newsletter**
- **Continue forums in priority disease areas**

Many successes and innovative models of care and resources to support these have evolved in phase one of the NSW Chronic Care Program. Forums for the NSW Chronic Care Program phase one final review, chronic care program managers and in the priority health areas of cardiovascular disease, respiratory disease and cancer have been valuable in disseminating findings and lessons learned among clinicians working in this field across NSW.

Other means of disseminating findings of the NSW Chronic Care Program will also be explored. The NSW Chronic Care Collaborative will provide a valuable mechanism for disseminating effective models of care for people with chronic illness during 2004. The list of resources developed through the local priority health care programs during the first phase of the NSW Chronic Care Program will also provide a valuable resource.

Effective models of care have also been developed in working with Aboriginal populations through the Aboriginal Vascular Health Program. The Aboriginal Vascular *Health Matters* newsletter will continue to be disseminated highlighting the challenges faced by and successes of this program.<sup>78</sup> The websites for the NSW Chronic Care Program and the NSW Aboriginal Vascular Health Program will continue to provide an important mechanism for dissemination of information. Forums for chronic care program managers and priority disease areas will continue.



## 9. Evaluation and monitoring

- **Conduct and disseminate findings of the review of the first and second phases of the NSW Chronic Care Program**
- **Continue six monthly reporting on progress in meeting the standards outlined in the Clinical Service Frameworks for heart failure, respiratory disease, cancer and Aboriginal chronic disease**
- **Review the impact of the NSW Chronic Care Collaborative**

Evaluation and monitoring are core components of the NSW Chronic Care Program to inform progress in NSW, program achievements and highlight areas requiring further attention.

The review of the first phase of the NSW Chronic Care Program has provided useful information on achievements attained and flagged issues for attention to enhance progress in chronic care initiatives statewide. The report will be widely disseminated.

Implementation of the Clinical Service Frameworks for heart failure, respiratory disease, cancer and Aboriginal chronic disease are a core component of the second phase of the Chronic Care Program. Monitoring of progress towards meeting the standards outlined in these documents will occur on a six-monthly basis. Monitoring of progress at the Area Health Service level will incorporate a quality improvement approach, involving selected patient samples at selected health service sites.

A review of the NSW Chronic Care Collaborative will provide information on the process of implementation of the Collaborative and achievements attained, particularly in meeting the Collaborative aims.

A review of phase two of the Chronic Care Program will be undertaken in 2006 to inform the directions of phase three of the Chronic Care Program.



# Glossary

## Aboriginal Community Controlled Health Services (ACCHSs)

An Aboriginal community controlled health service is defined as

*“a primary health care service initiated by local Aboriginal communities to deliver holistic and culturally appropriate care to people within their communities. Their board members are elected from the local Aboriginal community.” (NACCHO website [www.naccho.org.au](http://www.naccho.org.au))*

## Arthritis and musculoskeletal conditions

‘Arthritis’ describes a disorder of one or more joints. Arthritis disorders are part of a broader group of disorders of the muscles and bones called musculoskeletal disorders. Three of the most commonly occurring musculoskeletal conditions are osteoarthritis, rheumatoid arthritis and osteoporosis.

Osteoarthritis, one of the most common types of arthritis, is a degenerative condition of the cartilage in joints. Osteoarthritis is most commonly found in the knees, neck, lower back, hip and fingers and generally develops between the ages of 45 to 90 years, but is a common feature with increasing age.

Rheumatoid arthritis is the most common form of inflammatory arthritis, and is characterised by joint swelling and destruction, as a result of the immune system attacking the tissues lining the joints. The resulting inflammation causes pain, heat and swelling. The disease can also cause inflammation of connective tissue, blood vessels and organs. Rheumatoid arthritis most commonly develops between the ages of 25 and 50 but can begin at any age.

Osteoporosis is not a form of arthritis but is another type musculoskeletal disorder. Osteoporosis is a disease where bone density and structural quality deteriorate, leading to an increased risk of fracture, most commonly involving the bones of the spine, the hip and the wrist. Other bones are commonly affected, including the shoulder, ribs and the pelvis. Osteoporosis is more common in women because for five to ten years following menopause there is a sharp decline in the female hormone oestrogen, which plays a central role in maintaining bone mass balance.

## Asthma

A chronic inflammatory disorder of the airways in which many cells and cellular elements play a role, in particular, mast cells, eosinophils, T lymphocytes, macrophages, neutrophils and epithelial cells. In susceptible individuals, this inflammation causes recurrent episodes of wheezing, breathlessness, chest tightness, and coughing, particularly at night or in the early morning. These episodes are usually associated with widespread but variable airflow obstruction that is often reversible either spontaneously or with treatment. The inflammation also causes an associated increase in the existing bronchial hyper-responsiveness to a variety of stimuli.<sup>79</sup>

## Chronic obstructive pulmonary disease (COPD)

A respiratory disease state characterised by airflow limitation that is not fully reversible. The airflow limitation is usually both progressive and associated with an abnormal inflammatory response of the lungs to noxious particles or gases.<sup>80</sup>

## Cancer

Cancer is a group of diseases in which abnormal cells proliferate and spread out of control after being affected by a carcinogen or random gene mutation and form a mass called a tumour or neoplasm. Tumours may be benign (non-invasive) or malignant (invasive) and spread to other parts of the body (metastasis). Cancer can develop from most types of cells in different parts of the body, each with its own pattern of growth and spread. Some invade and spread quickly, while others may remain in the body for years without showing any symptoms. A number of cancers share risk factors, but most have a unique set of factors responsible for their onset. These include smoking, dietary influences, infectious agents, radiation (including ultraviolet radiation), as well as genetic factors. Causal factors for many cancers remain unknown. Some cancers can be prevented through the avoidance of known risk factors. Risk of death for many cancers can be reduced by screening, early detection and treatment and appropriate management and follow-up.

## Cardiovascular disease

Cardiovascular (or circulatory) diseases comprise all diseases of the heart and blood vessels, including

# Glossary

coronary heart disease (or ischaemic heart disease), stroke (or cerebrovascular disease), heart failure and peripheral vascular disease.

## Care coordinator

A nominated professional who facilitates patient-centred and integrated care and continuity of care across the continuum of care. The care coordinator may be a treating clinician or general practitioner in standard cases or a specialised coordinator (where available) in more complex cases. The care coordinator liaises with and coordinates service providers, provides patient and carer education and acts as a point of contact for all. Care coordinator roles may be filled by nurses (specialist or general) or other health professionals.

## Care plan

In relation to chronic care, 'care plan' refers to an individualised management plan developed for a patient with chronic illness. The plan should state the diagnosis, interventions (pharmaceutical and others) being undertaken to manage the illness, goals being strived for by the patient, have a multidisciplinary care focus and incorporate a self-management approach (including patient and carer education).

## Chronic condition

Chronic condition is a broader term than chronic disease and refers to health problems, including diseases and ongoing impairments, such as amputations and blindness that require ongoing management over a period of years or decades.

## Chronic disease

Chronic diseases are usually characterised by complex causality, multiple risk factors, a long latency period, a prolonged course of illness, functional impairment or disability, and in most cases, the unlikelihood of cure.<sup>1</sup>

## Cystic fibrosis

Cystic fibrosis is a genetic disorder, affecting glands secreting mucus and sweat throughout the body. Abnormally behaving mucus causes obstruction of organ passages, which leads to, among other complications, chronic obstructive pulmonary disease, abnormal functioning of the pancreas and liver, and

bowel obstruction, resulting in malnutrition. These manifestations may appear at any point in life from before birth to much later in childhood or even in adolescence. The disease is frequently fatal in childhood and young adult life. Median survival is 31 years.<sup>81</sup>

## Diabetes

Diabetes or 'diabetes mellitus' (the medical term) is a chronic condition characterised by high blood sugar levels, caused by a deficiency of insulin or resistance to its action. Insulin is produced by the pancreas and helps sugar enter the body's cells to be converted into energy. In uncontrolled diabetes, the sugar builds up in the bloodstream and can lead to a range of short- and long-term problems, including damage to vital organs.

There are three main forms of diabetes:

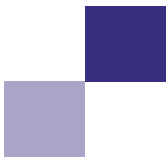
- Type 1, or insulin-dependent diabetes mellitus (IDDM), characterised by a complete deficiency of insulin and affecting approximately 10-15 per cent of people with diabetes. The onset of type 1 diabetes is generally during childhood
- Type 2, or non-insulin-dependent diabetes mellitus (NIDDM), the most common form of diabetes, affecting mainly people aged 40 years and over. Risk factors include heredity, pregnancy, low birthweight, age and lifestyle factors such as poor diet and physical inactivity and particularly obesity
- Gestational diabetes occurs during pregnancy in about 4-6 per cent of women not previously known to have diabetes. Such women are at increased risk of developing diabetes mellitus later in life.

## Heart failure

Heart failure occurs when the heart loses its ability to pump enough blood through the body. Usually, the loss in pumping action is a symptom of an underlying heart problem, such as coronary artery disease. Heart failure usually develops slowly, often over years, as the heart gradually loses its pumping ability and works less efficiently. Some people may not become aware of their condition until symptoms appear years after their heart began its decline.

There are two types of heart failure:

- Systolic heart failure – when the heart's ability to contract decreases. The heart cannot pump with



# Glossary

enough force to push a sufficient amount of blood into the circulation. Blood coming into the heart from the lungs may back up and cause fluid to leak into the lungs, a condition known as pulmonary congestion

- Diastolic heart failure – when the heart has a problem relaxing. The heart cannot properly fill with blood because the muscle has become stiff, losing its ability to relax. This form may lead to fluid accumulation, especially in the feet, ankles and legs. Some patients may have lung congestion.

## Mental health and illness

Mental health is not simply the absence of mental illness but describes the capacity of individuals and groups to interact with one another and their environment in ways that promote subjective wellbeing, optimal development and use of mental abilities (cognitive, affective and relational).<sup>82</sup> Mental health is a state of emotional and social wellbeing in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively or fruitfully, and is able to make a contribution to his or her community.<sup>83</sup>

Poor mental health has been associated with risk factors such as genetic history, poor diet/nutrition, and adverse life events such as abuse and violence, lower socio-economic status, relationship dysfunction, and unemployment. It affects children, adolescents and adults and can have a significant impact on family functioning, parenting, and work capacities.

Mental health problems and mental disorders refer to the spectrum of cognitive, emotional and behavioural disorders that interfere with the lives and productivity of people. A mental disorder is a diagnosable illness that significantly interferes with an individual's cognitive, emotional or social abilities.<sup>82</sup> Mental disorders differ in type and degree of severity. Some of the major mental disorders perceived to be public health issues are depression, anxiety, substance use disorders, psychosis and dementia.

## Multidisciplinary care

Comprehensive care provided by a team of various health professionals (medical – general and specialist, nursing and allied health), using a care team approach and tailored to decision-making regarding diagnosis, treatment planning and other aspects of care for individual patients.

## Prevention

Interventions that occur before the initial onset of a disorder.<sup>84</sup> In the context of chronic disease, prevention refers to identifying and intervening in the risk factors that are in the causative chain in the development of chronic disease in order to stop the onset of chronic disease. For example, minimising smoking uptake among teenagers to prevent later onset of lung cancer, or the identification and management of hypertension in an adults to prevent development of cardiovascular disease.

## Respiratory disease

Respiratory disease includes a range of diseases affecting the respiratory system that includes the airways, lungs, respiratory centre of the central nervous system, chest wall and pulmonary circulation. In terms of the burden of chronic disease the two main respiratory diseases include asthma and chronic obstructive pulmonary disease.

## Risk factors

Those characteristics, variables, or hazards that, if present for a given individual, make it more likely that this individual, rather than someone else selected at random from the general population, will develop a disorder.<sup>84</sup>

## Self-efficacy

A person's belief in his or her ability to perform a desired task or behaviour.<sup>71</sup>

## Self-management

A process whereby patients can engage in activities that protect and promote their health, manage their symptoms and signs of illness, monitor behaviours and manage the impact of their illness.

## Self-management support

Empowering and preparing patients to manage their health and health care through:

- emphasising the patient's central role in managing their health
- use of effective self-management support strategies that include assessment, goal setting, action planning, problem solving and follow up
- organising internal and community resources to provide ongoing self-management support to patients.

# Appendix 1: Information on burden of chronic disease

The following information on the burden of chronic disease relates to Australia and NSW data. Information is presented regarding cardiovascular disease, diabetes, asthma and COPD, cystic fibrosis, cancer, mental illnesses, arthritis and musculoskeletal conditions, and dementia. It has been derived from the NSW Chief Health Officers Report, unless otherwise stated.<sup>85</sup> Definitions of the following diseases are included in the Glossary.

## Cardiovascular disease

### Disease burden

- In NSW, cardiovascular diseases (CVD) are the leading cause of disease burden in both males and females.

### Deaths

- In 2002, cardiovascular diseases accounted for 17,895 deaths (39 per cent of all deaths) in NSW, or around 50 deaths each day.
- CVD caused more than one-third of years of life lost due to premature death. This included coronary heart disease that caused half (50.1 per cent) and stroke that caused more than one-quarter (26.3 per cent) of cardiovascular disease deaths. The next most common causes were heart failure and peripheral vascular disease.
- More males than females die from cardiovascular disease, with overall male death rate from cardiovascular disease being almost 1.5 times the female rate.
- Death rates from cardiovascular disease have more than halved since 1980. This decline has been steeper in males than in females. The declining death rate can be attributed to both reduced incidence of cardiovascular disease, reductions in some risk factors, such as smoking and improved survival of people with disease.

### Hospitalisations

- Hospitalisation rates for cardiovascular disease in Australia are higher for males (around 1.6 times the female rate) and increase with age, with people aged 60 years and over contributing about 60 per cent of hospitalisations.<sup>86</sup>
- Cardiovascular diseases were the principal reason for 149,560 hospitalisations of NSW residents (7.1 per cent of all hospitalisations) in the financial year 2002–03. More than one-third of these hospitalisations (35 per cent) were for coronary heart disease and 12 per cent were for stroke. The next most common causes were heart failure and peripheral vascular disease.
- Hospital separation rates of Aboriginal people with cardiovascular disease are almost double that of non-Aboriginal people.
- Hospital separation rates of Aboriginal people for rheumatic heart disease, hypertension and ischaemic heart disease are significantly higher than rates for non-Aboriginal people.<sup>11</sup>



# Appendix 1: Information on burden of chronic disease

## Diabetes

### Disease burden

- Of the three main forms of diabetes (Type 1, Type 2 and gestational diabetes), Type 2 diabetes is the most common (98-99 per cent of people with diabetes in the Aboriginal population and 80-85 per cent of people with diabetes in the total population), affecting mainly people aged 40 and over.
- Around 6.7 per cent of males and 5.6 per cent of females aged 16 years or more reported having diabetes or high blood sugar in the NSW Health Survey in 2002 and 2003.<sup>87</sup>
- Diabetes and its associated complications including cardiovascular, kidney, foot and eye diseases, contribute significantly to mortality, morbidity, poor quality of life and loss of potential years of life. Of all people in Australia with diabetes in 1999–2000:
  - 19 per cent were hospitalised with coronary heart disease
  - 15.4 per cent had retinopathy
  - 12 per cent over the age of 25 had a heart attack
  - 22.6 per cent died from kidney disease.

### Deaths

- Diabetes is the sixth highest cause of death by disease in Australia and has been identified as a priority area at state, national and international levels.
- In 2000–2001, death rates from diabetes among the Aboriginal population were almost 15 times higher than other Australians.
- Diabetes is the main cause of around two per cent of all deaths in NSW, and is a contributing cause in 8.6 per cent of all deaths, with cardiovascular disease being the most common cause of death among people with diabetes.

### Hospitalisations

- Hospitalisations due to diabetes in NSW have declined over the past 10 years. This may indicate improved management of diabetes in primary health care settings. However, there is increasing evidence that half of the people with Type 2 diabetes are not aware they have the condition. Early diagnosis is recognised as being important as careful diabetes management can reduce morbidity from long-term complications.
- Age-adjusted hospital separation rates for a primary diagnosis of diabetes mellitus among Aboriginal people are over five times higher than the rates for non-Aboriginal people.
- Aboriginal people living in rural areas are five times more likely to be hospitalised for diabetes than Aboriginal people living in urban areas. This may be due to improved reporting of Aboriginality in rural areas, and poorer access to health services resulting in higher rates of complications such as infections, kidney disease and cardiovascular disease.

# Appendix 1: Information on burden of chronic disease

## Asthma

### Disease burden

- About 40 per cent of all Australians will have respiratory symptoms consistent with asthma at some time in their lives.
- The prevalence of current asthma is estimated at 11 per cent. The prevalence of asthma is higher among children than adults, with the prevalence of asthma in Australian children being among the highest in the world.<sup>30</sup>
- Approximately 15 per cent of children aged 2–12 years were reported to have current asthma in NSW in 2002, with many experiencing high levels of severity.<sup>88</sup> There is evidence of increasing asthma prevalence and severity in children.
- Asthma is more prevalent in Aboriginal populations than in non-Aboriginal Australians (17 per cent compared to 12 per cent in 2001).<sup>11</sup>
- The prevalence of asthma in Aboriginal people generally increases as age increases, with peaks at ages 5–24 years and 55 years and over. In comparison, asthma prevalence peaks in the 5–24 year group in the rest of the Australian population.<sup>11</sup>

### Deaths

- In 2002, there were 139 deaths from asthma, with an ongoing decline in deaths from 242 in 1998 and 181 in 2000. Many asthma deaths are preventable.<sup>89</sup>
- In NSW in 2002, deaths from asthma constituted a much smaller proportion of all deaths (0.2 per cent in males and 0.4 per cent in females) than COPD.
- In 1999–2001, asthma death rates for the Aboriginal population were more than twice that of the total Australian population.<sup>11</sup>

### Hospitalisations

- NSW hospital separation rates for asthma substantially decreased between 1989–90 and 2002–03. The age-adjusted separation rate for asthma decreased by 45 per cent for all age groups and by 51 per cent in people aged from 5–34 years. This decrease may reflect the continuing improvements in asthma management outside of hospitals, as well as gradual changes in coding practices.
- Asthma is responsible for a smaller proportion of all hospital separations than COPD (around 1 per cent in both males and females) in NSW.



# Appendix 1: Information on burden of chronic disease

## Chronic obstructive pulmonary disease

### Deaths

- In Australia in 1998, COPD was the fourth cause of death in males and the sixth cause of death in females. COPD is also a major contributor to death from other causes.<sup>90</sup>
- COPD was the main contributor to respiratory deaths in NSW in the years 1998–2002, which alone accounted for 6.5 per cent of all deaths (7 per cent of all deaths in males and 6 per cent of all deaths in females).
- In NSW between 1983 and 2002, the male death rate from COPD decreased by 49 per cent, while, the female death rate increased by 24 per cent. Reductions in male mortality from COPD follow the decline in smoking rates among males and better management of the disease. The increase in the female death rate could be due to the delayed effect of increases in the proportion of female smokers from the late 1970s to mid-1980s.<sup>90</sup>
- Aboriginal death rates for COPD were 3-4 times the total Australian rate in 1999–2001.<sup>11</sup>

### Hospitalisations

- In Australia, in 1997–98, there were almost 40,000 hospital separations with the principal diagnosis of chronic obstructive pulmonary disease, with an average length of stay of 5.3 days.<sup>90</sup>
- In NSW between 1989–90 and 2001–02, the rate of hospital separations for COPD increased by 15 per cent for all ages and by 28 per cent in people over 65 years old, with trends differing significantly between males and females. Between 1989–90 and 2001–02 COPD hospital separation rates increased by 7 per cent in males aged over 65 years and by 62 per cent in females in the same age group. The rates also decreased by 0.3 per cent in males and increased by 39 per cent in females of all ages. Consequently, the difference between male and female hospital separation rates for COPD has narrowed over this period.

## Cystic fibrosis

- Cystic fibrosis is a genetic disorder affecting approximately one in 2,500 babies born in NSW. The disease affects many bodily organs with the most serious manifestations in the lungs, where a disease like COPD develops. Cystic fibrosis is frequently fatal in childhood. However, improvements in effectiveness of treatment for cystic fibrosis have contributed to increased survival. Recently introduced screening of infants may also impact on this.



## Appendix 1: Information on burden of chronic disease

### Cancer

#### Disease burden

- In NSW, cancers were the second most common cause of disease burden for males and females (after cardiovascular diseases) in 1999–01, accounting for just under one-third of years of life lost due to premature death.
- In NSW in 2002, there were 30,448 new cases of cancer (54 per cent in males) and 12,338 deaths from cancer (56 per cent in males). In males four cancers accounted for 59 per cent of new cancers including prostate cancer, colorectal, melanoma of skin and lung cancer. In females, four cancers accounted for 58 per cent of new cancers including breast cancer, colorectal, melanoma of the skin and lung cancer.
- There has been an increase in incidence rates for all cancers in NSW over the last thirty years. This is due to earlier diagnosis of some cancers from screening initiatives, such as breast and prostate cancer, a real rise in new cases of some cancers, such as melanoma of the skin and lung cancer in females and improved notification of cancer cases.
- Cancer incidence rates to 2010 are predicted to fall from 2000 levels in males but increase in females. However, the number of cancer cases is projected to rise from 2000 levels (by 19 per cent in males and 20 per cent in females).<sup>91</sup>

#### Deaths

- In NSW in 2002, three cancers accounted for 47 per cent of cancer deaths in males including lung cancer, colorectal cancer and prostate cancer. In females, three cancers accounted for 43 per cent of cancer deaths including breast cancer, lung cancer and colorectal cancer.<sup>91</sup>
- Reduced death rates for all cancers over the last decade reflect effective treatment of some cancers (such as childhood leukaemias) and the cumulative effect of small decreases in deaths for other cancers (including cancers of the testes and colon in young males and cancers of the breast and melanoma in females).



# Appendix 1: Information on burden of chronic disease

## Mental illnesses

### Disease burden

- Mental illness accounts for 13 per cent of the total disease burden and about 30 per cent of the non-fatal disease burden in Australia.<sup>92</sup>
- Depression alone has been identified as the fourth leading cause of disease burden in Australia after heart disease, stroke and pulmonary disease.<sup>90</sup> Depression is the leading cause of death by suicide (also an increasing issue in child and adolescent age groups) and was the most common reported mental illness by adults.<sup>93</sup>
- The large discrepancies in mental health and emotional wellbeing of Aboriginal people compared with non-Aboriginal people are well recognized, and result in higher hospital separation and mortality rates for mental and behavioural disorders, and higher rates of self-harm, suicide and incarceration.<sup>11</sup>
- At least one in five adults in Australia will be affected by a mental health problem at some stage in their lives, with 50 per cent of these affected long-term.<sup>94</sup> This includes 14-20 per cent of children and adolescents.<sup>95,96</sup>
- In Australia in 2002, 63 per cent of adults were classified as having low levels of psychological distress, 25 per cent as having moderate levels, 9 per cent as having high levels and 3 per cent as having very high levels. Females reported higher levels of distress than males. Reported rates of high and very high psychological distress have risen significantly from 1998 (10.5 per cent) to 2002 (12.2 per cent).<sup>97</sup>
- In Australia mental illnesses are also a major cause of chronic disability, accounting for 27 per cent of years lost due to disability.<sup>92</sup> Affective disorders account for 33 per cent of the burden of mental disorders, followed by substance abuse disorders (24 per cent) and then anxiety disorders (23 per cent). In young adults aged 15-24, depression, bipolar affective disorder and suicide and self-inflicted injuries together accounted for 22 per cent of the total disease burden for this age group. For adults, aged between 25-64 years, depression is the second leading cause (6 per cent) accounting for almost as much of the disease burden as ischaemic heart disease.
- In NSW the burden of psychological distress in terms of total inability to perform usual functions, accounted for more than 2 million days in a four-week period or 26 million days per year for people aged 16 years and over. Further a large proportion of people with mental illness have life expectancies more appropriate to parts of Africa (that is in their 50s), rather than the rest of the population with a life expectancy to late 70s or early 80s.<sup>98</sup>

Further information on specific initiatives underway in NSW for mental health is outlined in the Centre for Mental Health, NSW Health Department website.

# Appendix 1: Information on burden of chronic disease

## Arthritis and other musculoskeletal conditions

### Disease burden

- Arthritis and other musculoskeletal conditions also contribute significantly to disability burden experienced and have recently been identified as a national health priority.<sup>99</sup>
- In NSW in 1996 osteoarthritis was the third main cause of years of life lived with a disability after depression and dementia, with a higher prevalence among females. For new cases contributing to years of life lived with a disability, musculoskeletal diseases comprised the third major category for females in NSW in 1996.
- Chronic disability associated with juvenile chronic arthritis and osteoporosis also occurs in young people and is associated with high morbidity, frequent hospitalisation and reduced quality of life. New therapies are being made available to improve the quality of life of young people with osteoporosis and chronic arthritis.<sup>100</sup>

### Hospitalisations

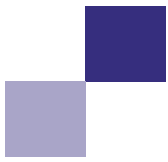
- There were 48,731 hospitalisations for males for musculoskeletal diseases and 47,590 hospitalisations for females in NSW in the financial year 2002–03. This represents 5 per cent of all male hospitalizations and 4 per cent of all female hospitalisations for this period.

## Dementia

### Disease burden

- Approximately 1 in 20 people over 65 and 1 in 5 over the age of 80 have some form of dementia.<sup>90</sup> With the ageing of the population over the next two decades, the burden from dementia will also rise significantly, especially in the oldest age groups.
- The current number of NSW residents with dementia was estimated to be 54,720 in 2001.<sup>101</sup> Projections for Australia indicate these figures will double to 91,200 in 2020. Dementia is expected to overtake depression as the largest cause of disability burden in Australia by 2016.<sup>102</sup>
- The increasing prevalence of dementia is part of a rising pattern of neurodegenerative diseases that particularly affect older people. The growth in such diseases, which are chronic and disabling, presents a considerable challenge to the health and community care service systems.

Further information on initiatives underway in NSW for dementia are available through the Primary Health and Community Participation Branch, NSW Health and are outlined in the *Future Directions for Dementia Care and Support in NSW 2001–2006*.<sup>103</sup>

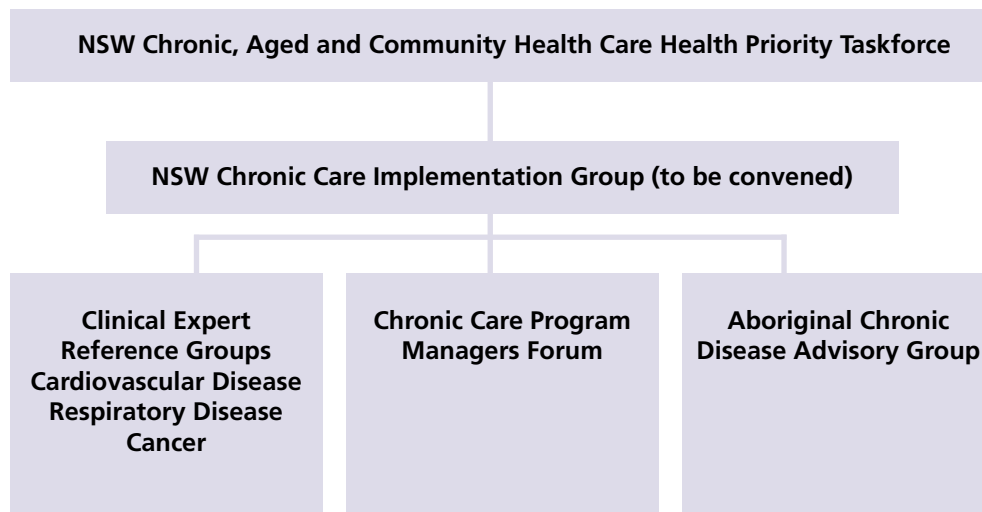


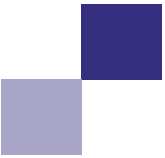
## Appendix 2: Community based services for people with chronic illness

The following community based services are available for people with chronic illness. During phase two of the NSW Chronic Care Program, a focus of activity will be the strengthening of links with these services.

- **Primary and community health care** services are provided through public and private health services and comprise a broad range of community based health services. Services may be provided from a community health centre or other community based locality or provided in the person's home.
- **Primary Health Care Networks** are an innovative approach to strategically bring together a range of community based workers such as health, local government, other government departments and non-government organisations providing community based care, to ensure a more strategic and coordinated approach to the provision of primary health care services.
- **Community Acute Post-Acute Care (CAPAC)** services are a substitute for acute hospital care. The CAPAC team comprises a range of health professionals providing acute care to patients in accordance with a clinical assessment of the patient's needs and specific treatment protocols. CAPAC services provide the patient with personal and clinical support and effective coordinated management of an acute, acute on chronic or post acute condition for a defined period. Patients considered for inclusion in these programs are medically stable and do not require high levels of clinical support. This may include patients with multiple morbidities and complex needs. The care setting is often the patient's place of residence, and can include an outpatient clinic or day only treatment clinic. CAPAC includes programs such as Hospital in the Home, Post Acute Care and community Ambulatory Care programs that are a substitute for acute or post acute care in hospitals.
- **Community service packages (ComPacks)**  
Access to a range of community-based support services is an important component in the overall care for people with chronic illness. Increasing complexity, both in the hospital system and the community sector can make it more difficult for people with chronic disease to access suitable care and support at home. There are multiple service providers and range of community service types and greater options for care at home. A range of service types include community nursing, home care and domestic assistance, meal services, day centre care, respite care, transport, gardening aid and disability services. ComPacks provide care and support to help older people return home from hospital. These individualised community care packages are designed to meet each patient's assessed clinical and support needs for a defined period, minimising the need for readmission in the first six weeks after discharge. Services provided include home care and support, community nursing, personal care, housekeeping, meals and transport.

# Appendix 3: NSW Chronic Care governance structure, Phase Two





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