

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.^{30, 48} 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*⁴⁹ 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.

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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.



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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 2021.⁵⁰ 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.⁶² 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.⁵⁰ 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.⁵¹ 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.⁵² 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

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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.⁵³ 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.⁵⁴ 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.⁵⁵

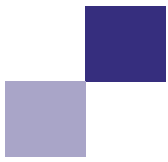
Initiatives in the first phase of the NSW Chronic Care Program for people from culturally and linguistically diverse backgrounds included information about chronic illness and its management being made available in various community languages, such as for COPD and heart failure. In seeking to enhance 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



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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.⁵⁵ Many factors contribute to this including geographic isolation, socioeconomic disadvantage, shortage of health care providers, greater exposure to injury risks and Aboriginal health needs.⁵⁶

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.⁵⁵ 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 2001.⁵⁷ 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.⁵⁸

- 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.⁸ The purpose of the record is to improve



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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.⁹

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.^{59, 60, 61} 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.⁶² 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.⁶³

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

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health overall, and over half have experienced major negative effects on life opportunities such as travel, paid work and pastimes.⁶⁴ 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.⁶⁵

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.”⁶⁶*

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.^{67,68} Despite this, several organisations have not fully introduced self-management

support, with many limiting its introduction to patient education only.^{69,70} 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.⁷¹ 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,⁷² 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,⁷³ 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..."*⁷⁴

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.⁷⁵ 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.⁷⁶

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 Service⁷⁷ 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.⁷⁸ 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)

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.⁷⁹

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.⁸⁰

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.¹

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.⁸¹

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:

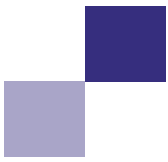
- Type 1, or insulin-dependent diabetes mellitus (IDDM), characterised by a complete deficiency of insulin and affecting approximately 10-15 per cent of people with diabetes. The onset of type 1 diabetes is generally during childhood
- Type 2, or non-insulin-dependent diabetes mellitus (NIDDM), the most 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



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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).⁸² 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.⁸³

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.⁸² 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.⁸⁴ 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.⁸⁴

Self-efficacy

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

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.⁸⁵ 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.⁸⁶
- 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.¹¹



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 2003.⁸⁷
- 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.³⁰
- 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.⁸⁸ 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).¹¹
- 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.¹¹

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.⁸⁹
- 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.¹¹

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.⁹⁰
- 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.⁹⁰
- Aboriginal death rates for COPD were 3-4 times the total Australian rate in 1999–2001.¹¹

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.⁹⁰
- 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).⁹¹

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.⁹¹
- 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.⁹²
- Depression alone has been identified as the fourth leading cause of disease burden in Australia after heart disease, stroke and pulmonary disease.⁹⁰ 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.⁹³
- 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.¹¹
- 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.⁹⁴ This includes 14-20 per cent of children and adolescents.^{95,96}
- 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).⁹⁷
- In Australia mental illnesses are also a major cause of chronic disability, accounting for 27 per cent of years lost due to disability.⁹² 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.⁹⁸

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.⁹⁹
- 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.¹⁰⁰

Hospitalisations

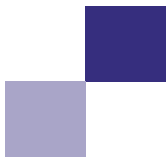
- There were 48,731 hospitalisations for males for musculoskeletal diseases and 47,590 hospitalisations for females in NSW in the financial year 2002–03. This represents 5 per cent of all male hospitalizations and 4 per cent of all female hospitalisations for this period.

Dementia

Disease burden

- Approximately 1 in 20 people over 65 and 1 in 5 over the age of 80 have some form of dementia.⁹⁰ 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 2001.¹⁰¹ 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 2016.¹⁰²
- 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*.¹⁰³

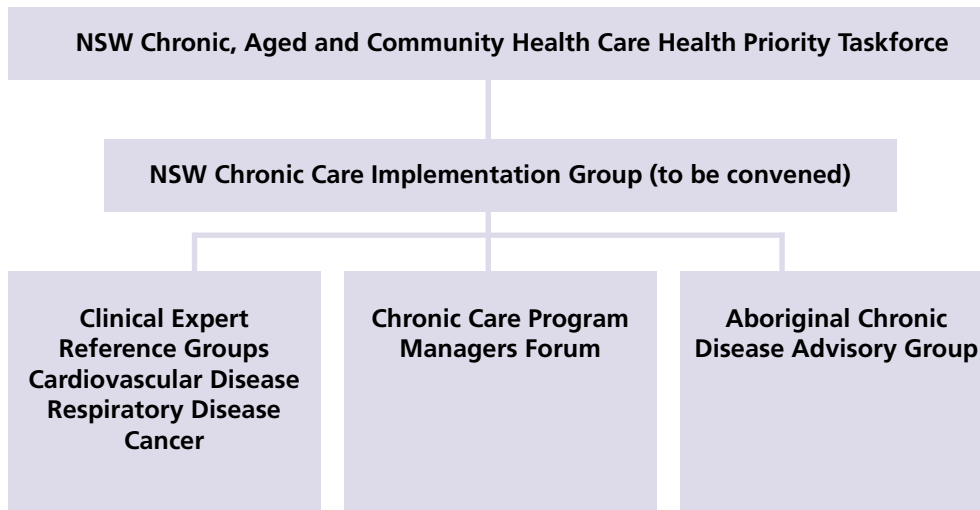


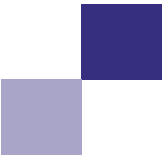
Appendix 2: Community based services for people with chronic illness

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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