Strengthening capacity for chronic care in the NSW Health system

Report on Phase one. Executive summary

NSW CHRONIC CARE PROGRAM | **NSW Government Action Plan**

Introduction

Chronic illness can affect people at any point across the lifespan from birth to adulthood; it encompasses a broad range of disease processes and physical and emotional disorders. The incidence and burden of chronic illness is high and increasing in Australia and internationally. Chronic illness is responsible for approximately 60 per cent of the global disease burden and is increasing at a rate such that by the year 2020, developed countries such as Australia can expect that 80 per cent of their disease burden will be attributed to chronic illness.

The NSW Chronic Care Program, previously known as the NSW Chronic and Complex Care Program, is a major initiative of the Government Action Plan for Health that was developed to address the increasing burden of chronic disease. A total of $45 million was allocated to the NSW Chronic Care Program over three years from July 2000 to June 2003.

This first phase of the NSW Chronic Care Program (2000-2003) has focused on the priority health areas of respiratory disease including chronic obstructive pulmonary disease (COPD) and asthma, cardiovascular disease including heart failure, stroke, diabetes and other cardiovascular disease risk factors, and cancer. Selection of the priority health areas was based on the level of burden that these diseases place on the community and on the health system. The program has covered the course of chronic illness with particular emphasis on diagnosis, treatment, rehabilitation and self-management.

Achievements

Significant achievements in the local priority health care programs from July 2000 to June 2003 included:

- approximately 200 full-time equivalent (FTE) staff, mainly nurses and allied health staff employed in the programs across NSW
- 42,000 patients enrolled in the programs
- 56,000 inpatient bed days avoided (equivalent to 89 beds freed-up statewide)
- approximately 6,500 emergency department presentations avoided
- steady decline in unplanned admissions for heart failure, despite the increasing incidence of the disease over the period to 2003
- decline in the average length of stay in hospital for patients with COPD
- reduction in hospital admissions for patients with asthma
- reduction in avoidable emergency department presentations, hospital admissions and readmissions for cancer patients.

In addition to hospital sector savings, evaluation of local priority health care programs demonstrated improved functional capacity and quality of life for participating patients and their carers.

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Aims and principles

The aims of the NSW Chronic Care Program in phase 1 were to:

- improve the quality of life of people with chronic and complex conditions
- improve the quality of life of their carers and families
- prevent crisis situations and unplanned, avoidable admissions to hospitals.

These aims were based on the core principles of patient-centred care, timely access to services, good clinical governance, coordination and integration of care.

Statewide governance structure

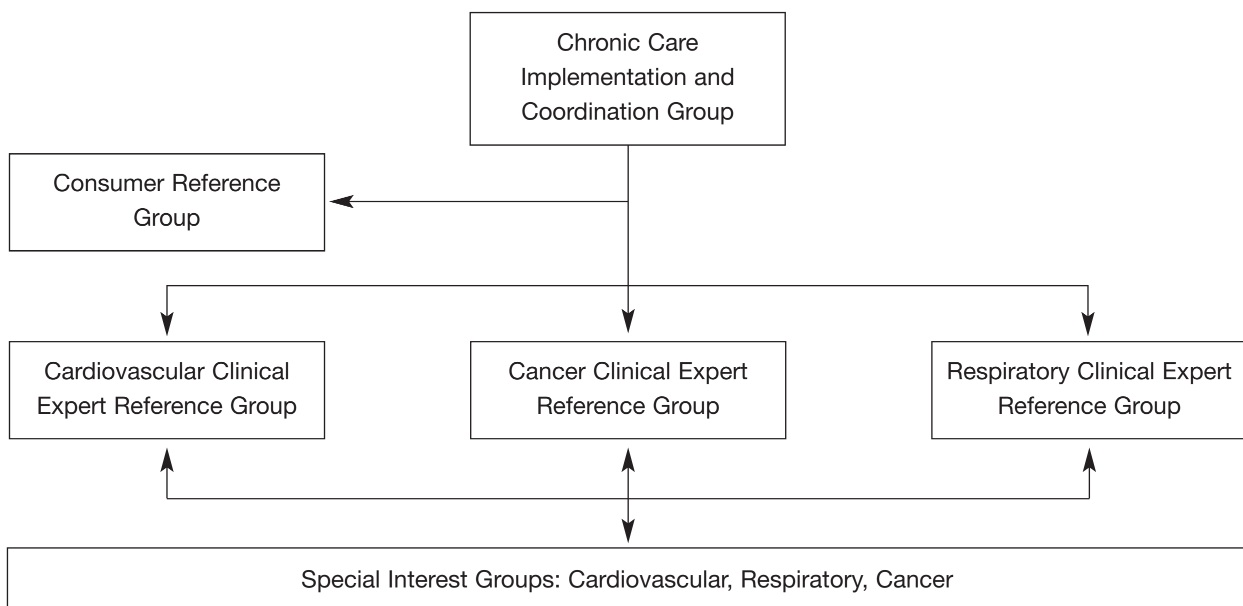
The Chronic and Complex Care Implementation and Coordination Group provided statewide leadership and direction for the NSW Chronic Care Program. The group included representation from a range of health disciplines, general practitioners, consumers, managers and external agencies. Clinical Expert Reference Groups and Special Interest Groups were established for respiratory disease, cardiovascular disease and cancer. These groups provided advice on key directions and issues relevant to the respective disease areas.

Statewide initiatives

Improving health for people with chronic illness: A blueprint for change 2001-2003 set out the goals and methodology for the NSW Chronic Care Program. Several statewide initiatives have enhanced the implementation of the NSW Chronic Care Program. These include the:

- NSW Clinical Service Frameworks for respiratory disease, heart failure and cancer, setting out standards and demonstration of compliance for implementation statewide
- *My Health Record,* a patient-held record, with over 100,000 copies distributed to February 2004
- initiation of the *NSW Aboriginal chronic disease service standards*
- forums in each of the priority health areas
- preparation for the statewide chronic care collaborative to commence in 2003-04
- coordination with Commonwealth chronic care initiatives.

Figure 1: NSW Chronic Care Program clinical governance structure, Phase one



Local priority health care programs

The cornerstone of the first phase of the NSW Chronic Care Program has been the implementation of 60 local priority health care programs in 18 Area Health Services (AHSs) across NSW. Of these programs:

- 18 focused on respiratory disease
- 25 focused on cardiovascular disease
- 13 focused on cancer
- 4 programs had a generic chronic illness focus.

Interventions primarily targeted adults. Three priority health care programs were designed specifically for children with chronic illness, focusing on cystic fibrosis, diabetes and asthma, and particularly on the transition from paediatric to adult services.

One program targeted the Aboriginal community, while other cardiovascular and diabetes programs worked closely with the NSW Health Aboriginal Vascular Health Program. Local priority health care programs also actively engaged people of cultural and linguistically diverse (CALD) backgrounds.

Example

Northern Rivers Area Health Service – 'PEAK' respiratory rehabilitation program

The PEAK respiratory program provided inpatient management and pulmonary rehabilitation to adults with COPD and asthma. The program was designed and delivered in collaboration with the local Division of General Practice. A respiratory liaison worker delivered specialised outreach services. Education and training was also provided to skill health workers in chronic respiratory care. The program was characterised by a high level of consumer involvement.

This program received a NSW Baxter Award in 2003.

Critical factors for effective health care programs

Clinical leadership and governance

Clinical leadership and governance are key drivers in improving care for people with chronic illness. Area Health Service and local clinical leadership and governance structures were central pillars to successful implementation of priority health care programs.

Clinical leadership was generally provided through medical specialists such as respiratory physicians, cardiologists and oncologists in the metropolitan areas and some rural areas. All Area Health Services identified involvement of these medical specialists as critical to the success of their programs. Rural areas relied more heavily on leadership from senior nursing and allied health staff with the support of health service managers.

Coordination of care

The appointment of designated care coordinators, facilitators or liaison officers was a feature of many of the priority health care programs and a key factor contributing to their success. The need for care coordination roles became increasingly apparent as the complex nature of chronic care was defined.

Care coordinators primarily worked to bridge the gap between service providers and to help patients with chronic and complex conditions, and to help carers navigate the health care system. It was the role of many of the care coordinators to ensure appropriate referral or access to other services or care options. The role required a diverse skill-and-knowledge base encompassing the disease process, its diagnosis and management, impact of chronic ill health on the patient and carer, and the availability of health and support services.

Multidisciplinary team approach

People with a chronic illness and their carers have a range of needs that can rarely be fully met by one health discipline, such as medicine or nursing. The psychological, social and functional impact of chronic illness necessitated the development of service models that brought together the skills and knowledge of a diverse workforce.

Multidisciplinary models of care incorporated hospital, community health and other community-based services. The key aims of multidisciplinary teams in chronic care were to:

- improve communication
- clarify roles and minimise duplication of effort
- support integrated care planning
- provide patients and carers with coordinated and high quality health care.

General practitioner links

General practitioners are key health providers for people living with chronic illness, their families and carers. Priority health care programs aimed to improve integration between the work of Area Health Services and general practice, particularly in the area of care coordination and increased use of Enhanced Primary Care (EPC) Medicare Benefit Schedule items.

Strategies of general practitioner engagement ranged from the development of communication mechanisms to the delivery of shared education and training programs. Priority health care programs that were able to engage actively with general practice reported favourable planning outcomes for managing individual patients' needs.

Self-management

Self-management is not a new concept. However the role of self-management in chronic care has gained significant support in recent years as a vital component in any effective chronic disease management model.

A major achievement of the priority health care programs has been the increased recognition of the role that people with chronic illness and their carers play in effectively managing their chronic disease. Most of the programs reported increased support for self-management skills and a greater understanding of the scope of self-management beyond basic patient education.

Example

Northern Sydney Area Health Service – 'MACARF' (Management of cardiac function) program

The MACARF program bridges hospital and community settings to improve outcomes for patients with heart failure. The heart failure nurse first contacts the patient whilst in hospital and referrals are made to a general practitioner, specialist and allied health services. Education and a follow-up home visit within seven days of discharge are provided to patients who each receive a Heart Failure Plan. A new heart failure exercise program was introduced at Ryde Hospital and the existing cardiac program at Royal North Shore Hospital was expanded to include more heart failure patients.

Example

Western Sydney and Wentworth Area Health Services – *'Cancer service without walls'*

Western Sydney and Wentworth Area Health Services worked together to develop strategies to provide a high level of coordinated care for patients with metastatic breast and lung cancer, and for surgical oncology and haematology patients. Through the development of nurse coordinators/facilitators, communication between all service providers has resulted in greater coordination of care and a smoother transitional patient care between hospital and community services.

Rehabilitation

A substantial evidence base supports the effectiveness of rehabilitation in improving clinical outcomes for people living with chronic pulmonary and cardiac disease. However rehabilitation programs for these patient groups has been available at only a few sites in NSW for some years. Improved rehabilitation access was a significant achievement of the NSW Chronic Care Program. Priority health care programs built on existing rehabilitation services to increase the number and range of programs offered statewide.

Workforce capacity

Workforce planning for chronic care has been identified as crucial for preparing the health system to meet the growing demand of chronic disease. Overall, the priority health care programs have helped to raise the profile of chronic illness as a legitimate field of practice.

All priority health care programs included education and training components to better equip health workers with the knowledge and skills to work with people with chronic illness. Many Area Health Services experienced difficulties in recruiting and retaining nursing and allied health professionals with the appropriate skills and interest in chronic care management. Rural Area Health Services reported the most significant workforce shortages.

Information management systems

People with chronic illness tend to visit multiple providers including emergency departments, hospitals, community-based services and general practitioners. It is important that appropriate and relevant information is available across care providers.

Accessing relevant patient information across the patient journey continues to be a significant challenge. The ability to track patient care across hospital and community settings and over the duration of the illness, has been problematic for local priority health care programs. In addition, the ability to use information management systems to generate reliable and relevant program-related reports has been limited. For long-term sustainability and successful planning and implementation of chronic care strategies, a uniform approach to information management systems for chronic care is needed.

Example

South Eastern Sydney Area Health Service – Chronic diseases among Aboriginal people

South Eastern Sydney Area Health Service implemented a community-supported model of health care for a defined Aboriginal population. HealthLink outreach clinics were conducted each week in a local Aboriginal community. The clinics addressed a range of health care needs including education, health promotion and clinical interventions for people with chronic illness or at risk of health breakdown. The program worked successfully to engage the local Aboriginal community.

This program received a National Baxter Award in 2003.

Example

The Children's Hospital Westmead – Diabetes day care program (DDCP)

Established in November 2000, the Diabetes Day Care Program was the first ambulatory stabilisation program to be introduced in a paediatric centre in Australia. The program has significantly improved the quality of life of children newly diagnosed with Type 1 diabetes and their families. The program helps to minimise family disruption, enables prompt resumption of school life for the child and reduces the length of hospital admissions. The model has the capacity to be adapted for other chronic childhood illnesses.

Organisational change

Establishing chronic care initiatives involves significant organisational change to establish new ways of working with people with chronic illness. Priority health care program leaders reported that staff have often been ill-prepared for the level of change required to accommodate the shift in emphasis from acute care to the longer-term care that is inherent to chronic illness. This has meant changing established and traditional boundaries between specialist services and professions, and across hospital and community settings.

Building shared responsibility between the various health providers who interact with patients with chronic and complex conditions is a challenging yet vital ingredient for improved quality of chronic care in the future.

Future directions

The groundswell of interest, support and collegiality experienced during the first phase of the NSW Chronic Care Program provides a solid foundation for the future of chronic care.

The NSW Chronic Care Program is continuing with phase two from 2003 to 2006. A total of $15 million recurrent funding has been allocated to this important initiative.

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