

NSW GOVERNMENT ACTION PLAN

Improving health
care for people
with chronic illness

A blueprint for change 2001-2003

*'reconfiguring
the way health
services are
provided'*

NSW HEALTH DEPARTMENT

This work is copyright. It may be reproduced in whole or part for study or training purposes, subject to the inclusion of an acknowledgement of the source. Commercial usage or sale is not permitted.

SHPN: (HPA) 010153
ISBN: 0 7347 3345 3

© NSW Health Department 2001

*Improving health care for people with chronic illness –
a blueprint for change 2001-2003*
NSW Government Action Plan, Sydney.

Further copies of this draft report can be downloaded from
the NSW Health Web site www.health.nsw.gov.au

Copies of this draft report will be made available in large print
and alternate formats upon request.

For more copies contact:

Better Health Centre – Publications Warehouse
Locked Mail Bag 5003 Gladesville, NSW 2111
Tel. (02) 9816 0452
Fax. (02) 9816 0492
TTY. (02) 9391 9900

September 2001

Contents

Letter to the Minister.....	2	Opportunities for improved care	15
1. Members of the Chronic and Complex Care Implementation and Coordination group (CCCICG)	3	Key deliverables.....	15
2. Members of the Clinical Expert Reference Groups.....	4	9. Drivers for change.....	16
3. Executive summary	5	Leadership.....	16
A. Personal Health Records for all patients with chronic and complex conditions within six months	6	Bringing together clinical expertise	16
B. Better coordination of care through care planning for all patients.....	6	Clinical champions – collaboration on care models.....	16
C. Agreed standards for all patients by agreement on clinical service frameworks.....	6	Clinical governance.....	17
D. Enabling of clinical leadership and consumer participation.....	7	10. Special interest groups (SIGs) – workshop forums.....	18
E. Closer collaboration with general practice....	7	Cardiovascular SIG Workshop	18
4. Recommendations	8	Cancer SIG Workshop.....	19
A. Personal Health Records for all patients with chronic and complex conditions within six months	8	Respiratory SIG Workshop.....	19
B. Better coordination of care through care planning for all patients.....	8	11. Personal Health Record	21
C. Agreed standards for all patients by agreement on clinical service frameworks.....	8	12. Clinical service frameworks	22
D. Enabling of clinical leadership and consumer participation.....	8	13. Connecting links in the chain of care	23
E. Closer collaboration with general practice....	9	14. Evaluation.....	24
5. Background	10	Proposed approach to evaluation of the NSW Priority Health Care Programs.....	24
6. The current situation	11	Level 1: Area Program	25
The problems faced by people with chronic and complex medical conditions	11	Level 2: Area Collaboration	25
7. Building a better health system for people with chronic illness	13	Level 3: State.....	25
Guiding principles.....	13	Appendices A-E	26-60
8. The way forward – priority health care programs	14	A Program specifics.....	26
Priority health care programs	14	B Data analysis of performance measures ..	52
Goals and specific objectives.....	14	C Terms of reference for the CCCICG.....	56
		D Terms of reference for Clinical Expert Reference Groups	58
		E Terms of reference for special interest groups	60
		Glossary of acronyms.....	62
		Endnotes.....	63

Letter to the Minister

The Hon Craig Knowles MP

Minister for Health
Parliament House
Sydney NSW 2000

Dear Minister,

On behalf of the Members of the *Chronic and Complex Care Implementation and Coordination Group*, we submit the Report for Year 1 of the *Chronic and Complex Care Program*.

Over the past year we have met with hundreds of clinicians and health care professionals and consulted widely throughout metropolitan and rural New South Wales. People working in our health system and consumers have also participated in our Working Groups and helped to form the recommendations outlined in this Report. These recommendations have been endorsed by the Clinical Council.

This process has created teams of clinicians, consumers and managers across hospitals, community and general practice. These teams, through the priority health programs, will deliver a higher standard of care and improve the quality of life and health outcomes for patients and carers. This has been a remarkably successful journey through our first year.

The achievements reported here are an international first and are delivering a major improvement in health care for people with chronic illness. This is a coordinated systemic effort to reconfigure the way health services are provided for people with chronic and complex conditions.

As Co-Chairs, we wish to thank all members of the *Chronic and Complex Care Implementation and Coordination Group*, Clinical Expert and Consumer Reference Groups and Special Interest Groups for their enthusiasm and commitment.

In particular, we commend the convenors of the Cardiovascular, Cancer, Respiratory and Consumer Working Parties who encouraged open and stimulating debate towards achieving consensus on a number of difficult system and patient care issues.

We would also like to thank the NSW Health Department Chronic and Complex Care Secretariat, comprising Dr Janine Stennett, Gary Mulheron, Evelyn Agar, Simon Johnston, John Slater, Meryl Edwards and Dr Isabella Smith for their continuing support and hard work.



Associate Professor Steven Boyages
Co-Chair



Professor Ronald Penny AO
Co-Chair



Chronic and Complex Care Implementation and Coordination Group

1

Co-Chairs		
A/Prof. Steven Boyages	Director, Centre for Research & Clinical Policy, NSW Health Department	
Prof Ronald Penny AO	Director, Centre for Immunology, St Vincent's Hospital	
Members	Title	Area
Acheson, Dr Thomas	GP Director	Hornsby-Kuringai-Ryde Division of General Practice
Baker, Adj.Prof. Kathy	Director, Community and Extended Care Services/Nursing Services and Organisational Development	Royal North Shore Hospital
Becker, Ms Jenny	Area Director, Nursing Services	Central Coast AHS
Bragg, Ms Ros	Policy Officer	Council of Social Services of New South Wales (NCOSS)
Broe, Prof Tony	Director, Geriatric Medicine	Prince of Wales Hospital
Burton, Ms Louise	Chair, Chronic Illness Alliance and Manager, Program Development, Cancer Services	NSW Cancer Council
Caplan, Dr Gideon	Director, Post Acute Care Services	Prince of Wales Hospital
Cullen, Dr John	Clinical Director General, Geriatric and Rehabilitation Medicine	Concord Repatriation General Hospital
Crossing, Ms Sally	Consumer Representative	Breast Cancer Action Group
Harnett, A/Prof Paul	Director and Staff Specialist, Medical Oncology & Palliative Care	Westmead Hospital
Harlum, Ms Janeane	Clinical Nurse Consultant	Braeside Hospital
Harris, Ms Sue	Director, Allied Health	South Western Sydney AHS
Hensley, Prof Michael	Professor of Medicine and Head of the School of Medical Practice	University of Newcastle
Hodgkinson, Dr Suzanne	Director, Department of Neurology	Liverpool Health Service
Johnson, AO Ms Betty	Convenor	Consumer, Community and Interagency Issues Working Party
Johnstone, Ms Kim	Director, Community Health Services	Western Sydney AHS
Kearsley, Prof John	Professor, Cancer Services	St George Hospital
Kibble, Mrs Gabrielle	Chair of External Review and Evaluation Committee	
Kollios, Ms Moira	Clinical Nurse Consultant	Parramatta Community Health Centre
Lillioja, A/Prof Stephen	Director of Endocrinology	Liverpool Hospital
May, Dr Stephen	Visiting Medical Officer and Nephrologist	New England AHS
McGrath, Prof Katherine	Chief Executive Officer	Hunter AHS
Onley, Ms Julienne	Manager Policy and Professional Services	Australian Nursing Homes and Extended Care Association (NSW)
Oates, Prof Kim	Chief Executive Officer	Children's Hospital, Westmead
Pratt, Ms Heather	Manager, Diabetes Centre	Blacktown-Mt Druitt Health
Raphael, Prof Beverley	Director, Centre for Mental Health	NSW Health Department
Smerdley, Dr Peter	Director Continuing & Community Services	St George Hospital
Spigelman, Prof Allan	Director Clinical Governance Unit	Hunter Area Health Service
Stewart, A/Prof Graeme	Director, Clinical Immunology and Allergy	Westmead Hospital
Tofler, Prof Geoffrey	Professor of Cardiology	Royal North Shore Hospital
Torzillo, Dr Paul	Clinical Director, Respiratory & Critical Care	Royal Prince Alfred Hospital
Vandercroft, Ms Dawn	Manager, Nutrition Department	Central Coast AHS
Ward, Ms Denise	Project Officer Strategic Policy & Planning	Department Ageing, Disability and Home Care
Webster, Prof Ian	Chair, Health Care in the Community Working Group	
White, Prof Les	Executive Director	Sydney Children's Hospital
Wilson, Dr Andrew	Deputy Director-General, Public Health and Chief Health Officer	NSW Health Department

3

CERGS

Clinical Expert Reference Group

2

Cardiovascular CERG		
Prof Geoffrey Tofler (Co-Chair) Dr Ana Singer (Co-Chair)	Professor of Cardiology, Royal North Shore Hospital GP Director, South Eastern Division of General Practice	
Colagiuri, A/Prof Stephen Cullen, Dr John Davidson, Ms Trish Doughty, Ms Shannon Duggan, A/Prof Karen Edwards, Mr Peter Goldston, Ms Kerrie Hodgkinson, Dr Suzanne Morton, Dr Brian Sindone, Prof Andrew Swinburn, Dr Elizabeth	Director, Endocrinology Department Clinical Director General, Geriatric and Rehabilitation Medicine Clinical Nurse Consultant Physiotherapy Adviser Hypertension Diagnostic Service Cardiovascular Disease Expert Advisory Group and Illawarra Stroke Unit Project Cardiac Rehabilitation and Secondary Prevention Director, Department of Neurology General Practitioner Cardiologist Director, Emergency	Prince of Wales Hospital Concord Repatriation General Hospital St George Hospital Moruya Hospital Bankstown-Lidcombe Hospital Primbee NSW National Heart Foundation Liverpool Hospital Willoughby NSW Concord Repatriation General Hospital Mona Vale Hospital
Cancer CERG		
A/Prof Paul Harnett (Co-Chair) Dr Tom Acheson (Co-Chair)	Director and Staff Specialist, Medical Oncology and Palliative Care, Westmead Hospital GP Director, Hornsby-Kuringai-Ryde Division of General Practice	
Cahill, Ms Philippa Crossing, Ms Sally Davidson, Dr Peter Hicks, Ms Mary Iosifidis, Ms Aspasia Kanagarajah, Dr Shanthi Kearsley, Prof John Nagiello, Ms Halina Penman, Dr Andrew Luxford, Dr Karen Smith, Dr Michael	Nursing and Patient Services Manager, Divisions of Cancer Services and Clinical Support Services Consumer Representative General Practitioner Clinical Nurse Consultant Social Worker in Charge Head, Geriatric Medicine Professor Cancer Services Senior Planner Chief Executive Officer Evidence Based Medicine Manager Palliative Care Unit	Cancer Care Centre St George Hospital Breast Cancer Action Group Cowra NSW Tamworth Base Hospital Wollongong Hospital Port Kembla Hospital St George Hospital Royal North Shore Hospital NSW Cancer Council National Breast Cancer Centre Mt Druitt Hospital
Respiratory CERG		
Prof Michael Hensley (Co-Chair) A/Prof David McKenzie (Co-Chair) Dr Peter Clyne (Co-Chair)	Professor of Medicine and Head, School of Medical Practice, University of Newcastle Director of Respiratory Medicine, Prince of Wales Hospital Chief Executive Officer, Western Sydney Division of General Practice Inc	
Berend, Prof Norbert Cane, Ms Lindsay Chan, A/Prof Daniel Hodges, Ms Barbara Lillystone, Mr David Marks, Dr Guy Peters, Dr Matthew Laurie, Ms Kate Strachan, Ms Patricia	Chairman of Research Chief Executive Officer Geriatrician Aged Care and Rehabilitation Physiotherapy Adviser Community Paediatrician Respiratory Medicine Respiratory Unit Clinical Nurse Consultant, Chest Clinic A/Director Health Service Development	Royal North Shore Hospital Asthma NSW Bankstown Hospital Wollongong Hospital Hornsby Child Health Centre Liverpool Hospital Concord Repatriation General Hospital Tamworth Base Hospital Bathurst Base Hospital
Consumer Reference Group		
Johnson, AO, Ms Betty (Chair)	Consumer, Community and Interagency Working Party	
Broe, Prof Tony Bragg, Ms Ros Burton, Ms Louise Byatt, Ms Karen Crossing, Ms Sally Kibble, Mrs Gabrielle Johnstone, Ms Kim Stennett, Dr Janine Webster, Prof Ian	Director, Geriatric Medicine Policy Officer Chair, Chronic Illness Alliance and Manager, Program Development, Cancer Services Home and Community Care Program Consumer Representative Chair of External Review and Evaluation Committee Director, Community Health Services Secretariat Chair, Health Care in the Community Working Group	Prince of Wales Hospital Council of Social Services of New South Wales (NCOSS) NSW Cancer Council Department of Ageing, Disability and Home Care Western Sydney Area Health Service Chronic and Complex Care Implementation and Coordination Group

4

Executive summary

This Report of the NSW Chronic and Complex Care Program highlights the first year's activities of the *Chronic and Complex Care Implementation and Coordination Group* (CCCICG) established under the Government's Action Plan for Health to improve service provision for people with chronic health care needs.

The NSW Chronic and Complex Care Program has three broad aims:

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

Health systems in NSW and most other developed countries are built around hospitals, and yet hospital admissions are isolated and very brief events in a person's health care.

Most people receive care from a number of doctors and other health professionals outside hospital walls.

Currently, people with chronic and complex medical conditions have to function as their own 'patient record', repeating their medical history every time they see a new clinician.

This can be especially problematic for people with complicated medical histories who need to see multiple service providers and who worry that clinicians are not receiving appropriate information. Gaps or duplication in services can occur.

The elderly, in particular, are especially disadvantaged by having to coordinate their own care.

In 1999/2000, 17% of total public hospital admissions were attributed to 73,800 people who have the chronic and complex conditions of Cardiovascular Disease (CVD), Diabetes, Cancer and Respiratory Disease. These admissions equate to 36% of total public hospital bed days and an approximate public hospital cost of \$1.1 billion.

In order to address these concerns, the NSW Government has provided \$45 million over three years (2000-2003) to address the three priority health areas identified at both a State and National level as areas where there is significant potential to achieve better health outcomes for people with chronic disease. These areas include Cardiovascular Disease (and its risk factors, such as Diabetes), Cancer and Respiratory Disease.

A total of sixty Priority Health Care Programs have been introduced throughout New South Wales under the Chronic and Complex Care Program (Appendix A1). The programs are being rolled out across the seventeen Area Health Services and the Children's Hospital, and include twenty-four programs in the area of Cardiovascular Disease, thirteen programs in the area of Cancer, eighteen in Respiratory Disease and five Generic Programs.

Problems faced by Norma Smith now

Norma Smith was diagnosed with heart failure three years ago. She lives in Western Sydney and has required urgent admission to hospital four times in the last six months.

Norma and her family are becoming increasingly anxious and concerned. They have seen lots of doctors but have not received an agreed plan of what they should do and what their general practitioner needs to do.

On every occasion she visits the hospital Norma spends five hours in the Emergency Department and repeats the same history to a different doctor.

Norma's GP is unaware of her hospital admissions and receives conflicting information.

3

5

3

Leadership in implementation of the Priority Health Care Programs is being provided by the Co-Chairs of the *Chronic and Complex Care Implementation and Coordination Group (CCCICG)*, Professors Steven Boyages and Ronald Penny and the Co-Chairs of Clinical Expert Reference Groups and Special Interest Groups: Associate Professor Paul Harnett, Dr Thomas Acheson, Professor Michael Hensley, Associate Professor David McKenzie, Dr Peter Clyne, Professor Geoffrey Tofler, Dr Ana Singer and Chair of the Consumer, Community and Interagency Issues Working Party, Ms Betty Johnson AO.

The Membership of each of these Groups is drawn from a wide range of consumers and clinical staff, including general practitioners, specialists and clinical nurse consultants.

There are a number of clear benefits to consumers from the NSW Chronic and Complex Care Program. These include:

A. Personal Health Records for all patients with chronic and complex conditions within twelve months

Accurate summary records which can be carried by patients when visiting clinicians can improve communication and care. A personal health record contains key items of information regularly updated. Such records act as a source of information for patients, carers and health service providers.

Benefits to patients

- Better informed patients and carers about their illness and what to expect from health services
- Information and knowledge shared between patients, doctors and other health team members
- Reduced stress for patient (and carer) in having to repeat/remember previous diagnostic tests and results, so no gaps or duplication
- Immediate access to personal information such as diagnostic test results, medication, allergies, emergency contact numbers.

B. Better coordination of care through care planning for all patients

Patients, specialists, hospital and community pharmacists, general practitioners and other health professionals will participate in developing a documented care plan, which sets out clearly an individual course of care. This might include diet, exercise, emergency procedures and a range of other information to assist the patient in managing their own condition and to provide clear communication between health providers.

Benefits to patients

- Each patient will have a single contact point in hospital, either telephone triage or a care manager.
- Improved Admission and Discharge Planning
- Multidisciplinary team approach to health care needs
- Care managers for each patient where needed
- Less duplication of diagnostic tests
- Improved health outcomes and quality of life for patients
- Reduced crises, unnecessary hospital admissions and length of stay in hospital

C. Agreed standards of care across the State for all patients by agreement on clinical service frameworks

Clinical Service Frameworks currently being developed for cardiovascular disease, cancer and respiratory disease, will provide Statewide standards of care. They will provide health professionals with clear guidance on key components of care and include clear roles and responsibilities.

Benefits to patients

- Evidence-based blueprints for tackling all aspects of chronic and complex disease, from prevention and early diagnosis, to emergency services and palliative care
- Consistency in standards of care for everyone, no matter where in NSW they live
- 'Living' documents that will grow and change over time according to changing health needs

6

D. Enabling of clinical leadership and consumer participation

Clinicians will be fully involved in management decision-making in hospitals and Area Health Services to ensure resource allocation and service delivery address all local health priorities.

Consumers will be routinely included as members of service planning groups.

Benefits to patients

- Better-informed clinicians with a more detailed understanding of patients' service experiences and needs
- More appropriate services which address all aspects of patients' and carers' requirements
- Allocation of resources to areas of local health need

E. Closer collaboration with general practice

General practitioners and specialists will be routinely engaged for case conferencing and care planning through use of Enhanced Primary Care Medicare Benefit Schedule items.

Benefits to patients

- Multidisciplinary care incorporating team and patient case conferencing provides a more effective structure for chronic and complex care.
- When admissions are necessary, they will be planned between general practitioners, specialists and hospital staff through better use of patient data to bypass Emergency Departments where possible.

The achievements presented in this Report reflect a major change in health care for people with chronic illness. For the first time, probably anywhere in the world, a coordinated systemic effort is being undertaken to reconfigure the way health services are provided for people with chronic and complex conditions.

How service provision will make a difference for Norma Smith now

- Norma Smith was diagnosed with heart failure following her attendance at hospital on two occasions.
- She was given a clear plan put together by heart experts on what she should do and what her general practitioner needed to do on a regular basis.
- Because of the severity of Norma's problem, a care manager was provided to liaise with her general practitioner about her care.
- If Norma needs to attend an Emergency Department in the future she will be given a care plan summary to present to the doctors
- Norma can also ring her general practitioner or her care manager if she becomes concerned and needs advice concerning her condition.

Recommendations

4

A. Personal health records for all patients with chronic and complex conditions within twelve months

1. Within twelve months patients with chronic and complex care needs in cardiovascular disease, cancer or respiratory disease will be provided with a personal health record when first receiving services from the public health system.
2. The personal health record will be held by the patient and will contain key items of information on the patient's diagnosis and care.
3. Health service providers will use the personal health record at each visit by the patient, and they will add key items of information as needed.
4. This record will act as a source of information for patients, carers and health service providers.

B. Better Coordination of Care Through Care Planning

5. All patients receiving services from the public system and their carers will participate with clinicians in developing documented care plans, and will receive a copy of the plan to keep in their personal health record.
6. Members of the multidisciplinary care team will contribute to the care plans as required.
7. Clinicians within the public health system will communicate with other providers, especially general practitioners, to develop a care plan.

B. Agreed standards of care across the state by agreement on clinical service frameworks

8. Clinical Service Frameworks will be developed for cardiovascular disease, cancer and respiratory disease to provide Statewide standards of care based on evidence for better practices and health outcomes.
9. Clinical Service Frameworks will incorporate guidelines and standards already developed at state, national and international levels.
10. Clinical Service Frameworks will provide health professionals with clear guidance on key components of care required across the State for each of the priority disease areas.
11. Clinical Service Frameworks will continue to evolve to incorporate new practices and data to guarantee community access to continuously improving practice.
12. Clinical Service Frameworks will include clear roles and responsibilities for health and other professionals involved in chronic and complex care.

D. Enabling of clinical leadership and consumer participation

13. Clinicians will be fully involved in management decision making to ensure resource allocation and service delivery address health priorities.
14. Consumers will be routinely included as members of service planning groups.

E. Closer collaboration with general practice

15. General practitioners and specialists will be routinely engaged for case conferencing and care planning through use of Enhanced Primary Care Medicare Benefit Schedule items.
16. Information systems will be identified and developed to assist in clinical decision making and better provide continuity of care, including the use of a unique patient identifier with the privacy, confidentiality and security of patient information to be protected in compliance with Commonwealth and New South Wales privacy requirements.
17. Training infrastructure will be developed to provide continual re-skilling for health professionals to ensure effective implementation of better practices.
18. Multidisciplinary care incorporating team and patient case conferencing will provide the structure for chronic and complex care.
19. When admissions to hospital are necessary, they should be planned between general practitioners, specialists and hospital staff through better use of patient data to bypass Emergency Departments where possible.

Background

5 New and advancing medical technologies, improved longevity and an aging population have dramatically changed the way health services are delivered in developed countries,

A few statistics illustrate the extent of this need. Worldwide, an estimated 691 million people have high blood pressure; the number of people with diabetes is predicted to increase from 135 million now to 300 million by 2025; and about 25 million people currently suffer from dementia^{1 2}.

At the same time, the culture and structure of health service delivery systems in Australia have evolved to focus primarily on people with temporary or acute health needs and acute episodes of care.

This acute-care orientation is reflected in the current emphasis on illness diagnosis, patient-initiated consultations, and curative and/or symptom relieving treatments.

Further, funding arrangements that support one-to-one service provision and divide responsibility for health care between the different levels of government and different program areas perpetuate a lack of health service integration in this country.

In the absence of any coordinating entity, people who rely on multiple health services for ongoing care and their quality of life must themselves coordinate their own care, organising and linking the services they require in the primary, community health and acute care settings.

This situation has led chronic illness to be described as 'a need in search of a system'³.

This Report outlines how NSW Health is implementing a more effective and efficient system to improve health care for the chronically ill.

Current situation

The passage through the health system for people with ongoing chronic and complex health care needs is represented schematically in Figure 1 which shows that below a certain degree of severity a person's medical condition may be predominantly self-managed (eg. through exercise and diet). Beyond this threshold, continuing and coordinated community-based care, including general practice, community nursing, allied health services and/or ambulatory care may be required. As severity and length of illness progresses, hospitalisation may be required.

Within the current health system, there is insufficient linkage (including responsibilities and communication processes) within and between services provided in the primary and community health and acute care sectors. From the perspective of consumers, this compromises the continuity, convenience and cost-effectiveness of patient care, and overall quality of life.

The problems faced by people with chronic and complex medical conditions

6

Some of the problems experienced by people with chronic and complex health problems include:

- Having to function as their own 'patient record', repeating their medical history every time they see a new clinician. This is especially problematic for people with complicated medical histories who worry that they may provide inaccurate or insufficient information to clinicians, and also for people who are unable to provide information on demand such as in crisis admissions to Emergency Departments, or people suffering from dementia.
- Having to undergo the same diagnostic test more than once, because their current service provider is unable to access previous test results performed by other service providers.

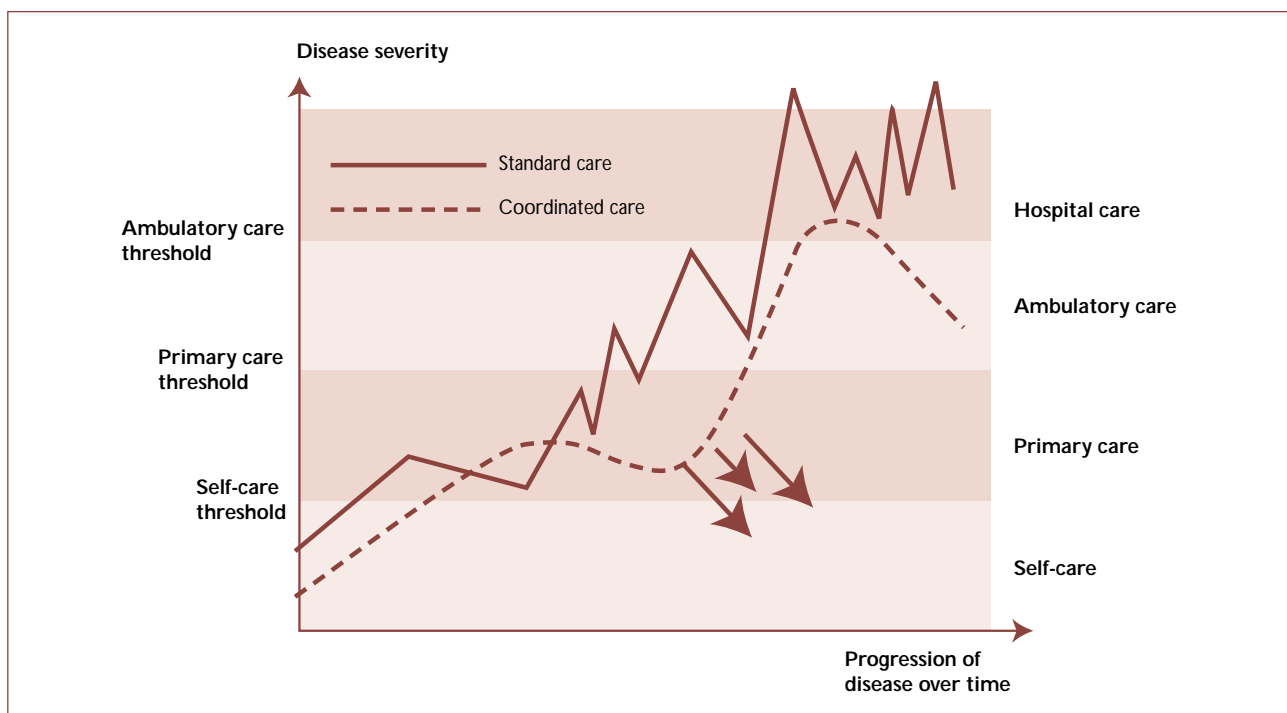


Figure 1. A person's interaction with health services as a function of disease progression and severity (adapted from Edwards & Hensher)⁴.

11

6

- Having to wait lengthy periods to see the clinician of their choice. Over time, this results in people seeing multiple service providers for similar services and an ultimate breakdown in continuity of care.
- The inconvenient location of service providers, which requires them to travel long distances to access the services they require. For example, people with diabetes may need to access services provided by endocrinologists; general practitioners; ophthalmologists and optometrists; vascular surgeons, cardiologists and nephrologists; podiatrists and physical therapists; dermatologists; psychologists; nurses; nutritionists; and community health workers.
- The lack of assistance in contacting and reaching the services required which means that people have to take considerable time off work, school, and so on, in order to schedule appointments and access care.
- The tendency for clinicians to focus on the presenting problem rather than the patient's overall health care needs.

The problems faced by Health Services

Acute hospital admissions and readmissions for people with chronic and complex health care needs account for a disproportionate number of hospitalisations and health care expenditure.

At a State level, 17% of public hospital inpatient admissions (excluding psychiatric) for the year 1999/2000 were provided for chronic and complex medical conditions. Categorised into the three priority health care areas of Cardiovascular Disease (including its risk factor Diabetes), Cancer and Respiratory Disease, this represents 36% of total Public Hospital bed days.

Impact of Chronic and Complex Care Service Delivery on the NSW Health System

- In NSW 23,000 people are admitted to hospital with heart failure each year.
- This accounts for 58,000 hospital admissions.
- 30,000 of these hospital admissions are through Emergency Departments
- 4,000 people with heart failure are admitted four or more times in a year
- 85% of admissions of people with congestive heart failure, renal failure, diabetes, chronic obstructive airways disease, stroke and HIV/AIDS are to public hospitals.
- 30% of these admissions are through Emergency Departments

Report of the NSW Health Council ^{5 6}

Building a better health system for people with chronic illness

The particular needs of people with chronic and complex medical conditions present a significant challenge to the way that health care is currently organised, requiring patients to communicate and interact with a number of health care providers at any given time. This can include general practitioners, specialists, hospital and community pharmacists, community health workers, mental health workers, allied health and community care services in order to avoid duplicating tests and procedures.

“We recognise that the implementation of a State-wide approach will be complex and that change must take place at both a State-wide and local level. We don’t want to prescribe a formula. We want to stimulate debate and provide incentives for change.”

Report of the NSW Health Council⁷

Patients with chronic care needs are entitled to a health system that provides easy transition through the various settings or interfaces of health.

Inappropriate hospitalisation for many people with chronic illness requires health services to be developed which provide more appropriate care.

Considerable opportunity exists to improve the health and quality of life of people with chronic and complex conditions, through the prevention of crisis situations that result in frequent unnecessary admissions and re-admissions to hospital.

Many complex and ongoing health problems, such as asthma, diabetes, hypertension and mental health problems can be managed with timely and effective treatment in an outpatient setting, thereby preventing and/or reducing unplanned and unnecessary hospital admissions^{8,9}.

The achievements presented in this report reflect a major change in health care for people with chronic and complex medical conditions. For the first time, probably anywhere in the world, a coordinated systemic effort is being undertaken to reconfigure the way health services are provided for people with chronic illness.

Guiding principles

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

- Supporting consumers at the centre of the health system with services designed around their unique health needs.
- Developing the capacity of consumers to participate fully in their own health care and more effectively navigate their way through the health system.
- Ensuring easier and more timely access to appropriate community-based services.
- Facilitating continuity of relationships between health providers at various levels of the health system and between health providers and consumers.
- Developing organisational and governance systems and structures to support long-term orientation of care within the health system.

7

13

8 Priority health care programs

In 2000, the NSW Government provided a \$45 million three-year package to fund new models of care to address the needs of patients suffering from chronic illness, their carers and their families, as well as the structural problems that health service providers face in caring for the chronically ill. This constitutes one of the major reforms currently being implemented by the NSW Government's Action Plan for Health.

A total of sixty Priority Health Care Programs have been introduced throughout New South Wales under the Chronic and Complex Care Program. In line with State and National health care priorities, these include twenty-four programs in the area of Cardiovascular Disease, thirteen programs in the area of Cancer, eighteen programs in the area of respiratory disease and five generic programs. Specific details of each of these programs are listed by Area Health Service at Appendix A1

Funding was allocated to Area Health Services according to the NSW Health population based Resource Distribution Formula. Access to funding was dependent on an open and transparent Expression of Interest and formal assessment process, as well as provision of detailed Implementation and Evaluation Plans.

Broad goals of the Priority Health Care Programs

The broad goals of the Priority Health Care Program are to:

- Improve the quality of life of people with chronic and complex care needs.
- Improve the quality of life of their carers and their families
- Prevent crisis situations and unplanned and unnecessary admissions to hospital.

Goals and specific objectives

The Government's Plan aims to achieve three broad outcomes:

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

Specific objectives of the NSW Priority Health Care Programs, include:

- Promoting greater coordination and continuity of care between hospitals, general practice and community care providers.
- Establishing links with relevant Commonwealth initiatives, in particular, strategies under the Federal Government's Enhanced Primary Care Package (eg. new MBS items and Sharing Health Care and Coordinated Care Trial initiatives).
- Establishing links with relevant State initiatives, including other NSW Health (Government Action Plan strategies and mental health and drug and alcohol initiatives) and NSW Ageing and Disability strategies.
- Developing and implementing strategies to address the needs of special needs groups, including Indigenous groups, people from culturally diverse and non-English speaking backgrounds and socioeconomically disadvantaged groups.

Opportunities for improved care

This initiative is providing a number of opportunities to improve the care and quality of life of people with chronic and complex care needs in New South Wales. These include:

- Development of Clinical Service Frameworks in the key priority areas of Cardiovascular Disease, Cancer and Respiratory Disease. The frameworks will ensure consistent and high standard health care, and evidence-based best practice across all health services, regardless of geographical locations.
- Improved coordination between acute care services, general practitioners, and primary and community health care services.
- Strong clinical governance to enable clinicians to be more fully involved in management decision-making.
- A consumer-focused health system that is responsive to the needs of consumers, eg, improved coordination of care to better meet the needs of people with chronic and complex health care needs.
- Increased use of Enhanced Primary Care Medicare Benefit Schedule (EPC MBS) items such as Health Assessments, Case Conferencing and Care Planning for people with complex multidisciplinary care needs and chronic conditions.
- Health care provided in ways that reduce excessive dependence on hospital inpatient care.
- Improved State and Commonwealth infrastructure initiatives such as Information Management, Information Technology and development of a Unique Patient Identifier to complement chronic care program initiatives.

Key deliverables

Key deliverables of the Priority Health Care Programs include:

- Development of standards and principles setting out broadly what people with chronic and complex health care needs can expect from a high quality service.
- Development of clinical guidelines and protocols, covering the nature of care to be provided, by whom, where and when.
- Identification, development and implementation of information systems to assist in clinical decision making, promotion of continuity of care and supporting consumers in making their own decisions regarding their health.
- Development of education and training infrastructure for health care professionals.
- Development and monitoring of agreed performance indicators and targets to assess the efficacy of the Priority Health Care Programs in improving care for people with chronic and complex medical conditions.
- Specification of health service research and development activity.

Relevant documentation concerning NSW Area Health Service Proposals, Implementation and Evaluation Plans and Background Working Papers can be obtained from the NSW HealthWeb site at: <http://www.health.nsw.gov.au>

Drivers for change

9 Leadership

The *Chronic and Complex Care Implementation and Coordination Group* (CCCICG), the Membership of which is listed at the front of this Report, was established to oversee the implementation of the Priority Health Care Programs in chronic and complex care.

Associate Professor Steven Boyages and Professor Ronald Penny Co-Chair the CCCICG. The CCCICG has brought together leading clinicians, general practitioners, specialists, consumers, nursing and allied health workers, senior Area Health Service managers and other NSW Government Agencies to work with the Department and Area Health Services as a team to improve clinical practice and health service delivery at the point-of-care.

The broad objective of the CCCICG is to implement the vision for improving health service provision to people with chronic and complex health needs.

Through its membership it has specified and directed the development and implementation of strategies, tools and interventions necessary to turn this vision into practice.

“Clinicians with proven success in innovation must drive and lead this process alongside senior health managers, many of whom have supported clinical innovations in these areas.”

Report of the NSW Health Council¹⁰.

Bringing together clinical expertise

Clinical Expert Reference Groups (CERGs) have been established across each of the three priority health care areas (Cardiovascular Disease, Cancer and Respiratory Disease) to oversight and monitor the implementation of the Priority Health Care Programs. Each CERG is chaired by two doctors – a specialist and a general practitioner.

Members of the CERGs include doctors, nurses, allied health professionals, health administrators, consumers and representatives from key consumer organisations.

The involvement of general practitioners in implementation of the Priority Health Care Programs is crucial to the processes involved in improving care for the chronically ill and many opportunities exist for improving coordination of care through Divisions of General Practice across NSW.

The CERGs provided invaluable support in assessing the initial Expressions of Interest from Area Health Services and in providing guidance to program leaders in their development of detailed Implementation and Evaluation Plans.

Clinical champions – collaboration on care models

Special Interest Groups (SIGs) for Area Health Service program leaders were convened in June 2001 under the CERG umbrella to focus on congestive heart failure (CHF), cancer and chronic obstructive pulmonary (lung) disease (COPD) and cancer services. Terms of Reference for the SIGs are available at Appendix A7.

The Special Interest Groups will:

- Establish collaboration between Areas on chronic and complex care
- Exchange information and views on Chronic and Complex Care programs
- Focus on the patient's experiences, needs and holistic outcomes
- Address primary and community-based service issues for continuum of care
- Examine implementation and evaluation (eg. Quality of Life measures)
- Agree on key clinical processes, performance indicators and deliverables
- Agree on areas of collaboration and development mechanisms (eg. effective models of care)
- Agree on the nature and content of draft clinical service frameworks

Area Health Service program leaders agreed on strategies in a number of vital areas at the workshops – quality of life instruments; performance indicators; data collection and sharing; case conferencing; and implementing discharge plans. Ongoing collaboration is being fostered through electronic communications and sharing of data and tools.

Clinical governance

The need for clinical leadership and greater networking of services was a key theme raised in the NSW Health Council Report.

Clinical governance of the Priority Health Care Programs is ensuring clinical engagement and leadership, clinical involvement in the planning, operation, monitoring and evaluation of the programs, as well as ensuring the provision of quality clinical care to people with chronic and complex medical conditions.

“We have noted the new directions of ‘clinical governance’ in the UK National Health Service and the comprehensive attempts to involve health professionals in the development of clinical practice guidelines (with doctors leading the way...”

Report of the NSW Health Council¹¹.

Special interest groups (SIGs)

10 Workshop forums

In June/July 2001 the three Special Interest Groups conducted workshops to share information and set targets for measuring future progress.

Cardiovascular SIG Workshop

Area Health Service programs in Cardiovascular Disease are spread across three main clinical areas: Heart Failure, Stroke and Diabetes.

The Special Interest Group Workshop Forum focused on Heart Failure and considered in detail the different challenges for urban and rural service delivery.

Individual Care Plans are a major feature of the programs, integrating all service providers, including general practitioners, hospital and community pharmacists, community nurses, allied health workers and home and community care agencies.

Indicators

General consensus on the following Process Indicators was reached at the Special Interest Group Workshop Forum for Heart Failure:

- ACE Inhibitor usage (unless contraindicated)
- Pre-Discharge Review
- Echocardiogram usage
- EPC MBS Item usage for Discharge Conferences and Heart Failure Care Plans

Health outcome indicators

The following Health Outcome Indicators were also agreed at the Special Interest Group Workshop Forum on Heart Failure:

- Quality of Life – Minnesota Living with Heart Failure Tool
- Unplanned readmissions
- Length of Stay
- Patient compliance with Care Plan and associated requirements

How will services be different for heart failure patients?

A typical Heart Failure Program within Northern Sydney Area Health Service

This Northern Sydney Area Health Service cardiovascular program aims to improve patient discharge procedures, and implement patient and carer education programs prior to discharge.

Coordinated care between patients, carers, clinicians, general practitioners and other health service providers will also enable early identification of symptoms able to be treated on an outpatient basis before they reach crisis stage and require admission to hospital.

Cardiovascular disease facts

- Macro-vascular diseases include diabetes and cardiovascular diseases (CVD) such as hypertension, coronary heart disease, stroke, heart failure, peripheral vascular disease, and rheumatic fever.
- CVD affects 2.8 million Australians aged over 18 (16% population).
- Diabetes Type 1 affects 0.2% of the population and Type 2, 3.3%. Prevalence increases with age, and for every case diagnosed it is estimated that there is another undiagnosed.
- A third of stroke patients suffer permanent disability, and numbers of stroke patients are increasing with improved survival rates and increasing longevity.
- Aboriginal people have a disproportionately high burden of chronic disease. They have the 4th highest prevalence of type 2 diabetes in the world.¹²

Cancer SIG Workshop

The Cancer Workshop Forum focused on the concept of 'Avoidable Admissions' and possibilities for reducing unplanned and unnecessary admissions to hospital. Strategies currently under consideration include:

- Single contact point in hospital – telephone triage for patients and general practitioners to advise on issues relating to their disease, such as new symptoms or possible adverse reaction to medication.
- Improved systems of hospital-based care – better structured clinics and clearly delineated clinical management protocols.
- Better patient education – understanding of disease and treatment.
- Better community support – better access and more appropriate referral to nursing and other support services.
- Acute Referral Service – better resourced assessments and procedures in non-Emergency Department ambulatory setting.
- Technology – improved drug delivery, symptom control, eg. antiemetics, outpatient infusion treatments, oral chemotherapy.

The Special Interest Group Workshop Forum for Cancer also registered interest in the concept of a Personal Health Record for Cancer patients as a large number of specialised services are usually simultaneously involved in providing care. The Group agreed to work collaboratively to explore different models of Personal Health Records currently in use.

Indicators

The Workshop reached agreement on an appropriate Quality of Life scale, the Symptom Distress Scale to assess the impact on patients, and the FAMCARE Scale to assess the impact on Carers.

How will services be different for cancer patients?

A typical Cancer Program in Western Sydney and Wentworth Area Health Services

This joint initiative between Western Sydney and Wentworth Area Health Services is providing new cancer service arrangements that will increase community support to patients with advanced malignancy.

Redesigned oncology record systems will improve patient care and provide a focus for quality assessment, outcome evaluation and clinical research.

Patients who formerly carried the burden of coordinating their own care will be monitored and systems will be adjusted to improve care.

These two Area Health Services are collaborating to strengthen clinical linkages with general practitioners and other community based health service providers.

Strategies are also in place to improve existing services and pathways to enable resources to be targeted more effectively.

Cancer facts

- On average one in three men and one in four women in Australia are likely to develop cancer before the age of 75.
- Four cancers account for 55% of new cancers in men – prostate (24%) and lung (12%), melanoma of skin (10%) and colon cancer (9%).
- For women the top four cancers are breast (29%) and colon (10%), melanoma of skin (9%) and lung cancer (7%).
- The median age of cancer diagnosis is 69 for males and 66 for females¹³.

10 Respiratory SIG Workshop

A Special Interest Group Workshop Forum for Respiratory Disease identified Chronic Obstructive Pulmonary Disease (COPD) as the major area of interest, in particular the extension of rehabilitation programs.

The Global Obstructive Lung Disease (GOLD) Program and Guidelines currently under development by the Thoracic Society of Australia and New Zealand are effective interventions currently being considered by the Group.

A Discharge Summary and Data Base developed by South Eastern Sydney Area Health Service has also gained wide support.

How will services be different for patients with chronic respiratory disease?

A typical Respiratory Program within Macquarie Area Health Service

Macquarie Area Health Service is using a multidisciplinary approach to manage episodes of chronic respiratory disease before hospital admission is required.

The Area Health Service is establishing a comprehensive multidisciplinary outpatient program and education package for the rehabilitation of chronic respiratory disease patients who experience repeated and unnecessary admissions to hospital.

All appropriate patients will be offered an adaptable, efficient and effective 'Bigger Fitter Better' (BFB) program tailored to their needs. The program will be available in all towns within Macquarie Area Health Service.

Respiratory disease facts

- Respiratory disease is the third largest cause of death in NSW, accounting for 7.6% of all deaths.
- High risk/high burden population subgroups include indigenous people, low socio-economic status groups, and people in rural and remote areas.
- Smoking is the major factor in several of the respiratory diseases, especially in COPD and lung cancer.
- Asthma affects an estimated 14-20% of children and 10% of adults in NSW.
- NSW total asthma deaths have fallen, but the cost of asthma to the Australian community has been estimated at between \$585-720 million annually. (Report on the costs of Asthma in Australia from the National Asthma Council, 1992)
- The genetic disease cystic fibrosis generated 8,424 bed days in 1997-98.
- COPD reduces mobility and independence, and patients have particular needs for coordinated care, rehabilitation and palliation¹⁴.

Record

Personal Health Record

A major finding of activities to date is the need for development of a Personal Health Record to improve communication and facilitate continuity of care for people with ongoing chronic health care needs.

A draft framework for a NSW Personal Health Record has been developed for consideration by the CCICG and Special Interest Groups. Steps are also being taken to ensure the document complies with NSW Privacy legislation.

The Personal Health Record for people with chronic and complex medical conditions will include important information relating to the patient's illness and treatment, and will be provided in a folder which can be updated throughout periods of care.

Content of the Personal Health Record will include sections for recording such information as:

- Personal and demographic details
- Key health contacts, including General Practitioner
- Types of personal assistance the patient is currently receiving
- Emergency information concerning allergies and sensitivities, known adverse reactions to drugs and blood type
- Appointment schedules

- Past and present health problems
- Information about what the patient needs to do, and what the patient's general practitioner needs to do
- Key measures such as weight
- Current medication, including when, how and how often to take prescribed drugs
- Care Plan tailored to the patient's health needs
- Case Conference reports
- Hospital Discharge Summaries

The introduction of a Personal Health Record will significantly reduce the number of problems currently faced by people with chronic and complex medical conditions.

11

21

Clinical service frameworks

12

A major outcome of the work of the Special Interest Groups will be the development of Clinical Service Frameworks incorporating best-practice standards of care that patients with chronic and complex medical conditions can expect from a high quality health service, whether they live in Bourke or Bondi.

The Clinical Service Frameworks will incorporate recognised standards developed to date, such as those outlined in the UK NHS '*Coronary Heart Disease and Cancer Frameworks*'¹⁵, the '*National Heart Foundation Guidelines for Management of Patients with Chronic Heart Failure in Australia*'¹⁶, the NSW '*Optimising Cancer Management*' model¹⁷, and the '*Evidence Based Review of the Australian Six Step Asthma Management Plan*'¹⁸.

The frameworks will identify priorities, summarise the way to make progress, and outline State and National tools to support implementation. They will also set out the milestones, goals and performance indicators for health services, and identify future areas of work. Draft frameworks will be disseminated for consultation by December 2001.

The frameworks will be new blueprints for tackling chronic disease in the NSW Health system. Initially, they will focus on the State and National health priority areas of Cardiovascular Disease, Cancer and Chronic Obstructive Pulmonary Disease (COPD). All of the frameworks will incorporate service integration strategies to ensure patients receive seamless care.

People in all parts of the State are entitled to quality care which is consistent with best practice everywhere. Delivery of this care may involve not only local doctors, community services or hospitals, but also services from specialist regional or metropolitan centres.

The frameworks will be consistent with the NSW Quality Framework and will set out the standards for services which are required for patients with chronic illness, no matter where they live throughout NSW. They will be living documents which will grow and change over time. They will deal progressively with the many different aspects of care from prevention and early diagnosis, to emergency services and palliative care.

They are intended to assist health care professionals in delivering better, fairer and more accessible health care across the State. If, for example, best practice demands rehabilitation programs, then all patients will have access to rehabilitation delivered through care packages tailored to their own individual needs.

The structure of the frameworks will be based on the evidence of better practices and similar to that adopted in other developed countries such as the UK, with sections covering effective interventions and service models which provide systemic approaches to identifying people at high risk, investigation and treatment, and clinical audit. Immediate priorities will be identified, with milestones and goals.

The frameworks will ensure that we have a health system in New South Wales characterised by:

- Clear points of entry and exit
- Agreed standards and principles of care, setting out broadly what people can expect from a high quality health service
- Clear roles and responsibilities for Clinicians.

For further information on existing standards and guidelines, please see 'Background Documents' at: <http://www.health.nsw.gov.au>

22

Connecting links in the chain of care

The Priority Health Care Programs have been endorsed by the Divisions of General Practice across New South Wales and are engaging consumers, clinicians, managers, general practitioners and community care agencies in ways that encourage all health service providers to work together to provide an appropriate, effective and well coordinated response to the health care needs of people with ongoing chronic and complex health care needs.

The CCCICG has ensured that programs approved for funding incorporate multidisciplinary care planning as an essential component of strategies to support the role of general practitioners as care planners for the chronically ill. Also, as indicated earlier, general practitioners are Co-Chairs of the CERGs.

Care managers are increasingly liaising with general practitioners and consumers in the preparation of individualised care plans for people with ongoing chronic health care needs.

Individual Care Plans provide a method for ensuring that information and knowledge is shared between patients, their general practitioner and health care providers in different health settings.

Financial incentives offered by the new Commonwealth Enhanced Primary Care Medicare Benefit Schedule Items (EPC MBS) are assisting in encouraging general practice involvement in the care planning process.

Expected benefits from linking primary and acute care services with general practitioners in the chain of care, and in developing care plans for people with chronic and complex medical conditions, include:

- Consumers at the centre of the NSW Health system with services designed around their unique health needs
- Health services designed with consumer input
- Linkage of general practice with primary and acute care, and community services
- Prevention of crisis situations and stressful and unnecessary readmissions to hospital
- Reduced lengths of stay in hospital through supported early discharge
- Introduction of rehabilitation programs
- Education programs for consumers on self management techniques.

Strategies to improve links in the chain of care are also being strengthened by ongoing collaboration with other Implementation Working Groups, such as the Models of Care Implementation Working Group, the Consumer and Community Participation Implementation Working Group and the Working Party implementing the Health Care in the Community Reinvestment Strategy.

A wide range of best-practice models of care are currently being implemented across New South Wales in order to ensure that people with chronic and complex medical conditions can access the health care they need in a more efficient and coordinated way.

Although the programs are still in the early stages of development, a number of Area Health Services are already reporting improvements in the way that services are provided for people with chronic and complex health care needs.

13

23

Evaluation

14 Proposed approach to evaluation of the NSW Priority Health Care Programs

Underlying principles

The basic principles underlying the proposed approach to evaluation of the NSW Priority Health Care Programs are as follows:

- Data to be sourced from existing collections as a by-product of administrative and care delivery processes.
- Any new systemic data collection should avoid onerous or resource-intensive demands.
- Data should be capable of informing administrative and clinical decision-making.

Considerations in the development of an approach to evaluation

The NSW Priority Health Care Programs represent only one component of the broader Government's Action Plan (GAP) for Health. In addition to chronic care, emergency care, acute care and intensive care services are also undergoing substantial reform with a view to improving the delivery of quality health services, better managing costs and improving health outcomes for people in metropolitan, regional and rural NSW.

Specific objectives of the evaluation will be to determine, among other things, the extent to which implementation of the GAP has:

- Improved the quality of health care.
- Improved access to health services.
- Increased value for money of expenditure on health care.
- Increased involvement of clinicians in determining health care priorities and setting and monitoring standards of clinical practice.
- Empowered individuals and communities.

- Increased effectiveness and efficiency of decision making.
- Encouraged promotion and maintenance of good health.
- Produced sustainable models of care.

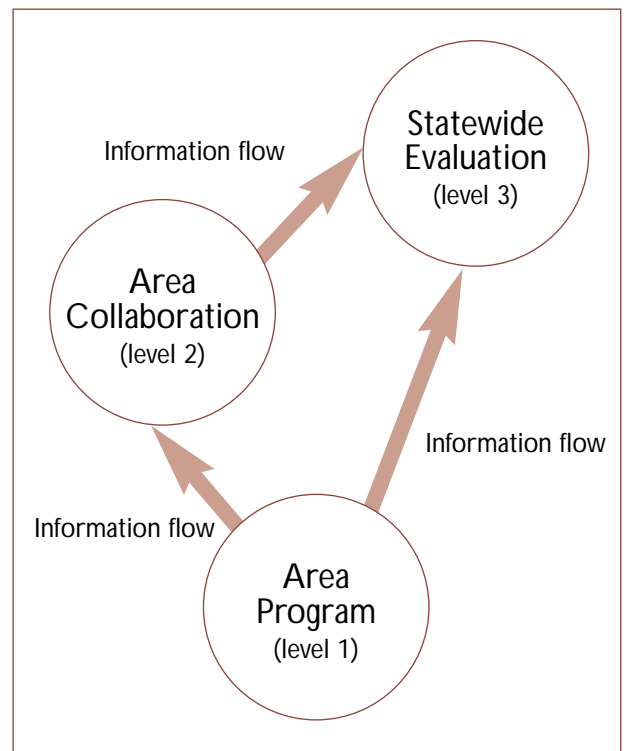


Figure 2

A hierarchical approach to Evaluation

A hierarchical approach is proposed for evaluation of the NSW Priority Health Care Programs, with evaluation occurring at three levels:

- L1: Area Program or local level
- L2: Area Collaboration level
- L3: State level

The flow of information between the three levels is indicated in Figure 2. This shows that evaluation activities at the Area Program and Area Collaboration levels will support the Statewide evaluation.

Level 1: Area Program

Evaluation at this level will be used to monitor what is happening against expectations and local program objectives, to understand how and why it is happening and to help managers and clinicians involved in the program to make policy, planning and clinical decisions.

Primary responsibility for evaluation at the Area Program level will rest with key Program administrative and clinical personnel. The six areas for suggested local evaluation are:

- patients
- service provision and processes
- resources
- health outcomes
- quality of health care
- system change.

Level 2: Area Collaboration

Primary responsibility for evaluation at this level and the development of the clinical service frameworks will rest with the Chronic and Complex Care Implementation Coordination Group and the Cardiovascular, Respiratory and Cancer Clinical Expert Reference Groups and Special Interest Groups who will target such areas as:

- effective interventions and clinical care processes for people with specific chronic conditions (eg., congestive cardiac failure and chronic obstructive pulmonary disease);
- tools, resources and strategies to assist implementation of these interventions, audit tools and performance indicators to ensure appropriate standards of service; and
- progress milestones and goals within an agreed timescale which can be measured, and subsequently, the development and implementation of Statewide agreed clinical service frameworks to guide the provision of services for people with specific chronic conditions across NSW.

Level 3: State

The state evaluation will explore the outcomes of the NSW Priority Health Care Programs at the highest level. Information gathered at a state level will inform on what the Programs established for cardiovascular disease, respiratory diseases and cancer are achieving or have achieved across NSW.

The state level evaluation will also satisfy a higher level of accountability (eg. the NSW External Review and Evaluation Reference Group, Treasury and Government).

For further information on Monitoring and Evaluation, please see 'Background Documents' at: <http://www.health.nsw.gov.au>

Appendix A

Program specifics

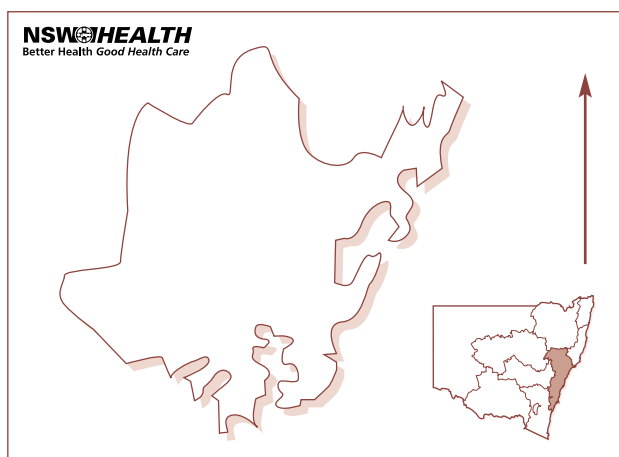
The following Area Health Service summaries provide a brief description of each of the Priority Health Care Programs and their projected benefits for people with chronic and complex medical conditions.

The Programs demonstrate a concerted commitment on the part of clinicians, general practitioners, consumers and allied health staff towards improving service provision across the spectrum of care from acute to primary and community care settings.

Further information on each of the programs can be obtained by contacting the Program coordinators listed next to the summaries, or by visiting the Chronic and Complex Care website at **www.health.nsw.gov.au**

Central Coast Area Health Service

A



Program Manager/Contact

Dr Peter Lewis

(Heart Disease Risk Factor Management)
 Director, Public Health Unit
 Tel. (02) 4349 4845
 Plewis@doh.health.nsw.gov.au

Ms Pam Woolfe

(Respiratory Services for Patients with COPD)
 Director of Community Nursing
 Tel. (02) 4320 3311
 pwoolfe@doh.health.nsw.gov.au

Dr Peter Gale

(Community Stroke Support Service)
 Director Rehabilitation
 Tel. (02) 4320 2002
 pgale@doh.health.nsw.gov.au

Ms Jenny Becker

(Community Cancer Services)
 Area Director of Nursing
 Tel. (02) 4320 3489
 jbecker@doh.health.nsw.gov.au

Programs

Heart Disease Risk Factor Management – improving awareness of risk factors

The program aims to improve the management of risk factors for cardiovascular disease in hospital and the community. Interventions to address risk factors identified in hospital (such as lifestyle modification and medication as appropriate) will be commenced in the hospital, highlighted in an electronic discharge report and continued in the community setting. General practitioners will be supported in

their management of the risk factors by Area wide risk factor management guidelines consistent with peak national bodies.

Integration of Respiratory Services for Patients with Chronic Obstructive Pulmonary Disease (COPD)

The main purposes of the program are to enhance the patient's ability to manage their illness and to facilitate early interventions in exacerbations of the illness through a case management approach. A care plan will be developed by a multi-disciplinary team, including the patient and carer, with elements of the model including post-discharge home education, increased access to a community based respiratory rehabilitation program, and support for the patient's self-management program.

Community Stroke Support Service (CSSS)

The program will provide a community based therapy service for patients following a cerebrovascular accident (CVA). The service will assist patients in improving and maintaining quality of life.

The Stroke Support Service will provide a program for patients consisting of 6-week blocks of weekly or twice weekly education/exercise/assessment sessions. Assessment and follow up will occur after each program, and at 6 months.

This service has not previously been available outside the acute health system and will complete the continuum of care for patients from acute to community.

Community Cancer Services

The primary aim of the program is to optimise the management of the patient's illness in the most appropriate setting to ensure quality of life is maintained for the patient, carer and family.

A highly specialised service, currently only available to patients in the acute hospital setting, will be taken into the community and the homes of cancer patients, providing a more comfortable alternative environment for the delivery of specialised care.

The delivery of care in the home will also allow for the education and training of patients and their carers concerning treatment, management and the implications of their illness, and will also enhance linkages between existing acute and community settings.

27

A Children's Hospital at Westmead



the
children's
hospital at Westmead

Program Manager/Contact

A/Prof Peter Van Asperen

(Cystic Fibrosis)

Head Department of Respiratory Medicine

Tel. (02) 9845 3444

Peterv@chw.edu.au

Prof. Martin Silink

(Diabetes)

Professor and Director, Institute of Paediatric

Endocrinology

Tel. (02) 9845 3172

martins@chw.edu.au

Programs

Transitional Care Model for Children with Cystic Fibrosis

The aim of this program is to establish a day treatment centre for the 350 children with Cystic Fibrosis (CF) who attend the hospital, and to progress the transitional service which has been established to facilitate transfer of the children to adult care.

The treatment centre will provide the basis for a home intravenous (IV) antibiotic service (which has already been piloted), as well as a convenient assessment centre for early identification and treatment of respiratory exacerbations in these patients. It will also maintain the other benefits of hospitalisation by including nutrition, physiotherapy and social work interventions.

This day treatment centre will reduce hospitalisation rates and length of stay, improve quality of life and has the potential to improve long term outcomes, including preservation of lung function and survival by slowing the progression of lung disease. The centre will also complement the transitional clinic for adolescents, already established for the last 2 years, which fosters their transition from dependent care in childhood to independent care in adult life. This will further improve quality of life as well as slow disease progression by ensuring children continue to receive optimal treatment as young adults.

Ambulatory Stabilisation program for newly diagnosed children and adolescents with diabetes

Type 1 Diabetes is a chronic disorder reducing the quality of life for people with the disease, as well as their families and carers. The acute and chronic complications of diabetes can lead to crises often resulting in unplanned admissions to hospital. A 'good start' at the onset of this chronic disease has been shown to improve quality of life and reduce the number of subsequent re-admissions to hospital for acute complications of the disease. In NSW the current stabilisation of newly diagnosed diabetes in children and adolescence is based on in-patient care with an average length of stay (ALOS) of 5-7 days.

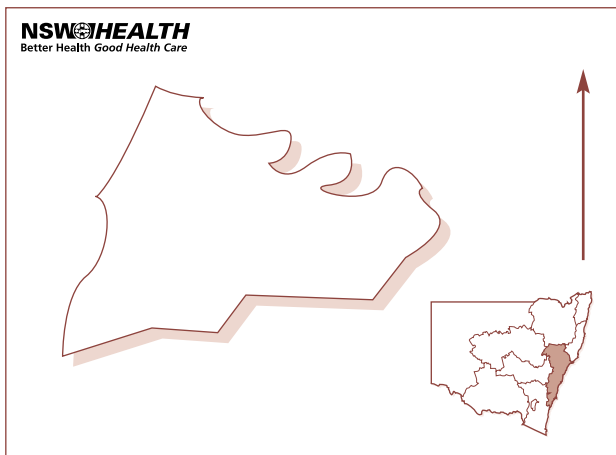
The purpose of the Diabetes Ambulatory program is to introduce a multi-disciplinary ambulatory stabilisation program for children and adolescents with newly diagnosed diabetes. The program aims to improve quality of life and either reduce, or maintain, levels of unplanned hospital admissions.

The outcomes of the program in the first 6 months have demonstrated that the program improves quality of life, is safe and cost-effective, and effective in preventing crisis situations (hypoglycaemia and diabetic ketoacidosis) and unplanned hospital admissions.

The ambulatory program has provided an exciting new model for the initial management and education of children and adolescents diagnosed with type 1 diabetes in Western Sydney.

Central Sydney Area Health Service

A



Program Manager/Contact

Dr Christine Jenkins

(COPD)

Tel. (02) 9957 2344

Crj@med.usyd.edu.au

A/Prof Iven Young

(COPD)

Tel. (02) 9515 7041

iveny@mail.med.usyd.edu.au

Ms Margaret McGill

(Diabetic Footcare Services)

Tel. (02) 9515 3737

Marg@email.cs.nsw.gov.au

Professor Dennis Yue

(Diabetic Footcare Services)

Director of Diabetes Services

Tel. (02) 95153737

dennis@email.cs.nsw.gov.au

Dr Alastair Corbett

(Stroke)

Tel. (02) 9767 6416

Alastair@med.usyd.edu.au

Prof. Phil Harris

(Cardiac Failure)

Tel. (02) 9515 7609

philh@card.rpa.cs.nsw.gov.au

Programs

Coordinated Care of patients with Chronic Obstructive Pulmonary Disease (COPD)

The program will identify patients admitted to the Emergency Department but who may be able to be discharged home where care will be managed by a multidisciplinary team across community and hospital services.

The program will improve home care and outpatient rehabilitation services and will provide smoking cessation counselling services to support patients in the community. It will also promote better communication with general practitioners, home and community nursing services, and hospital-based services.

Developing Diabetes Footcare Services across CSAHS: a coordinated and integrated approach

The program aims to develop an integrated model of care for the treatment of diabetic foot disease. It will service patients in hospital and in the community. A re-organisation of existing services and use of an information management and technology infrastructure underpin the program. The program incorporates contemporary treatment, management pathways and the development of an integrated information/communication system in consultation with GPs.

Enhancing Quality of Care for Patients with Stroke and mobilising effective community support for their carers

Multidisciplinary management of inpatient care for stroke in all acute care and rehabilitation facilities will be improved as a result of this program, which will ensure that health providers in hospitals and the community have access to care plans and appropriate information to effectively manage stroke patients.

Stroke coordinators will facilitate the patient's smooth transition from the acute stroke unit to rehabilitation and on to the community. They will case manage patients with particular attention being placed on compliance with management plans and treatments, coordination of rehabilitation and support services and liaison with general practitioners, including organising case conferences.

29

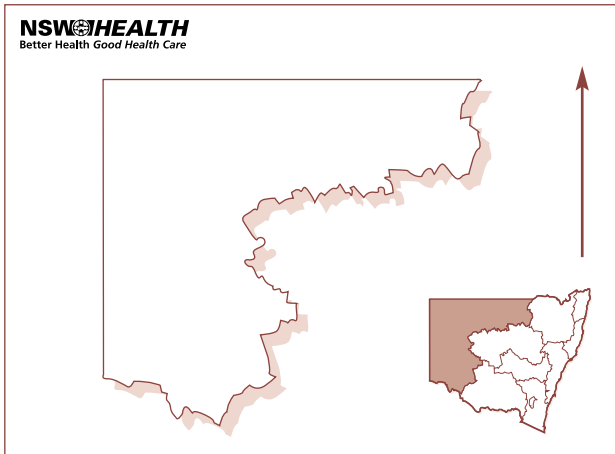
A

Better Transitions of Care from hospital to the community for patients with cardiac failure

The program will coordinate inpatient and community based services, initially involving nursing coordinators, to improve transition of care to the community. A nursing coordinator will organise the patient's discharge documentation, notify the patient's general practitioners and arrange continuity of medication and home visits.

The program incorporates a home visit by the nursing coordinator one week after discharge to focus on medication review, social needs, dietary and lifestyle reinforcement, patient education and carer support. Telephone contact arrangements will be put in place to address patient concerns regarding changes in symptoms. Collaboration with general practitioners in discharge planning and development of ongoing care plans is an essential component of the program.

Far West Area Health Service



Program Manager/Contact

Ms Lyn Hamilton

Director Primary Health Care

Tel. (08) 8080 1478

lhamiltonfwhs@doh.health.gov.au

Programs

Chronic Disease Coordination and Continuity of Care

The program is focusing on cardiovascular issues, in particular diabetes. The proposed model of care has three layers of intervention.

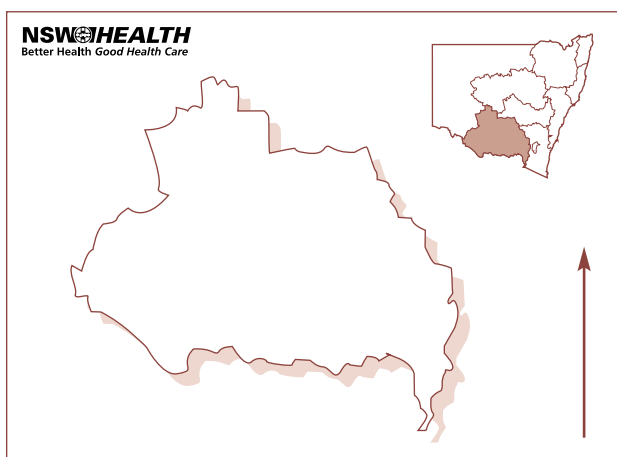
The first layer involves setting up coordination mechanisms to embed primary health care structural pathways of care for people with chronic and complex care needs. This includes forming partnerships with all health service providers, as well as setting up information collection and management systems to monitor progress.

The second layer involves forming a Chronic Disease Network of clinical service providers that will act as a forum for planning and reviewing service development and delivery and providing professional development and peer support.

The third layer involves forming a joint metropolitan/rural partnership for the delivery of medical, allied health and other relevant expertise to clients and staff around cardiovascular issues.

It is hoped that this model will improve levels of service delivery and management for clients and their carers through a more coordinated approach to case management. It will result in better communication between service providers leading to service integration and reduction in service duplication. Clients will develop skills around self management and an early intervention approach will lead to improved access to community based services, as opposed to crisis management.

A Greater Murray Area Health Service



Program Manager/Contact

Ms Chris Packer

Priority Health Care Coordinator

Tel. (02) 6023 7110

chris.packer@swsahs.nsw.gov.au

chris.packer@gmahs.nsw.gov.au

Programs

Respiratory Disease – Asthma Project

The program focuses on written Asthma Action Plans developed by the general practitioner case manager in consultation with the client. This will involve employment of asthma care coordinators to facilitate a team approach to asthma management forming linkages with the acute health system, supporting the general practitioner case manager role, and assisting in the coordination process involving other health service providers.

Patients will be at the forefront of decision making with regard to their care and self management. They will receive education on their medical condition and treatment/care options from their general practitioner and/or asthma educators. The care coordinator will ensure that all appropriate referrals and follow up reviews are made in consultation with the client to ensure optimum continuum of care.

Cardiovascular Disease: Aboriginal Diabetes Project

The project focuses on the establishment of a network of trained, community-based Aboriginal diabetes health care workers to develop and implement local early detection and intervention projects, including the introduction of a community based 'Well Person's Health Check' program aimed at the Aboriginal/Torres Strait Islander population over 15 years of age.

The program includes referral to general practitioners, an integrated case management approach to those at risk, development of partnerships, and care coordination with Divisions of General Practice and service providers to implement chronic disease self management strategies.

The program aims to integrate the services provided by a range of community and hospital based organisations with particular focus on Aboriginal community based care strategies which can draw upon culturally acceptable practices and priorities.

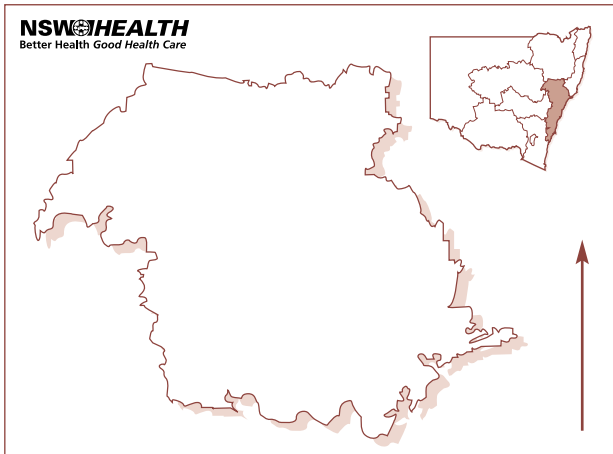
Palliative Care Project

The program aims to increase access to integrated palliative care services for the terminally ill, their carers and families, within the Griffith and Carathool Shires.

Expected outcomes include the availability of Case Managers for the terminally ill and managed care in the home.

Implementation of this program will provide for a flexible model of care, a consistent palliative care policy framework, a palliative care medical consultancy service and development of an ongoing education program across the Greater Murray Area Health Service.

Hunter Area Health Service



Program Manager/Contact

For further information on the HAHS Chronic Disease Management Model
 Tel. (02) 49257838
 Fax. (02) 49257803
chronicdisease@hunter.health.nsw.gov.au

Programs

An integrated clinical management model for people with Chronic Respiratory Disease

The aim of the program is to improve or maintain the health of people with Chronic Obstructive Airways Disease (COAD) and Asthma through better coordination and linkage between hospitals, community care providers and consumers.

Elements of the program include the use of Asthma Action Plans, guidelines for general practitioners in referral of patients to appropriate exercise programs, pulmonary rehabilitation programs, and general practitioner involvement in the planning of patient care.

An integrated clinical management model for people with chronic cardiac disease

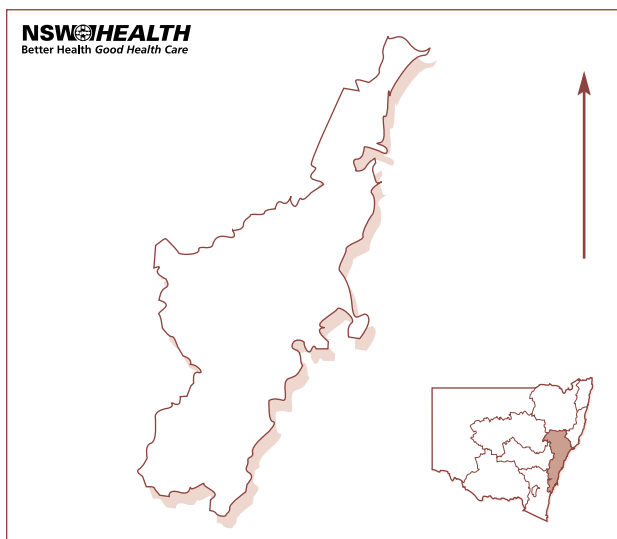
The aim of the program is to improve or maintain the health of people living with chronic heart failure through better coordination and linkage between hospitals, community care providers and consumers of health care.

Elements of the program include the development of self management plans to enable patients and carers to monitor their own health; and heart failure rehabilitation programs in local communities incorporating exercise and education.

An integrated clinical management model for people with Cancer as a chronic disease

The program aims to improve or maintain the health and well being of people with cancer through the application of best practice in cancer management, improved coordination of services, promoting health, independence and optimal patient functioning.

A Illawarra Area Health Service



Program Manager/Contact

Ms Sylvia Seniuk

Chronic and Complex Care Program

Tel. (02) 4275 5112

seniuks@iahs.nsw.gov.au

Programs

The Best of Life with Heart Failure

This project is focusing on an individually tailored, multidisciplinary heart failure rehabilitation program. The rehabilitation program includes education sessions and supervised exercise programs held once a week, over a six week period. An individualised program is developed for each patient based on a needs assessment conducted by a multidisciplinary team. The program ensures that the patient has access to all integrated services across the continuum of care. The program is addressing the need for a specific heart failure rehabilitation program in the Illawarra and Shoalhaven areas.

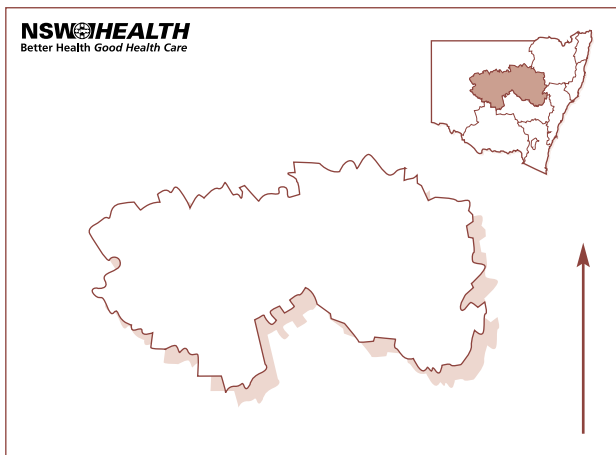
Improved management for people with chronic airflow limitation

The program will develop, implement and monitor a multidisciplinary pulmonary rehabilitation program for patients with Chronic Airflow Limitation (CAL). Education and support for patients and their carers, the development of crisis management plans and case conferencing across the continuum of care are all elements of the program. Clinical pathways will be developed and implemented across the Northern Illawarra and Shoalhaven regions.

Development of A Coordinated Delivery System for Stroke Care

The program is focusing on case management of all stroke patients by a dedicated stroke nurse, who coordinates care, supports and educates patients and carers, and monitors adherence to the clinical pathway. Following discharge from hospital, the patient will have access to individualised task-related circuit training, and the stroke nurse will be available for home visits.

Macquarie Area Health Service



Program Manager/Contact

Ms Robyn Gunter

Chronic & Complex Care Coordinator
Tel. (02) 6841 2330
rgunt@doh.health.nsw.gov.au

Programs

Cardiac and Stroke Prevention and Rehabilitation and Breathe Up Respiratory Rehabilitation Program. (CASPAR & BU RRP).

These programs involve evidence based therapies that aim to improve health care for persons with cardiovascular disease and chronic respiratory disease, provide greater coordination of care between hospitals, general practitioners and other community-based health care practitioners, and provide support for carers.

CASPAR and BU RRP are comprehensive, long-term programs involving medical evaluation, prescribed exercise, risk factor modification, education and counselling.

The Chronic & Complex Care Coordinator will ensure the implementation of integrated cardiac/respiratory program management and expansion of the rehabilitation programs to include home based and individual approaches.

The Coordinator will also ensure that clients have access to professional intervention and support for primary and secondary prevention of cardiovascular disease and chronic respiratory disease.

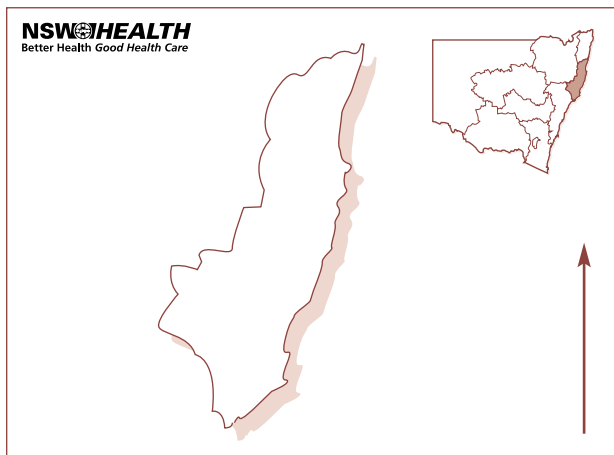
A feature of the programs will be increased and improved communication incorporating a computerised referral system developing strong links with the Division of General Practice.

Improving access to cardiac and respiratory rehabilitation services and primary prevention programs to address risk factors such as tobacco smoking, physical inactivity, poor diet, heavy alcohol consumption, hypertension, elevated blood lipids, diabetes mellitus and obesity, will help to improve the cardiovascular and respiratory health of the community and decrease pressure on acute hospital services.

(The age distribution of the population within the Macquarie Area Health Service incorporates an increasing number of elderly people. This will place increasing demands on hospital and rehabilitation services).

A

Mid North Coast Area Health Service



Program Manager/Contact

Ms Beth Fuller
Chronic and Complex Care Program Manager
Tel. (02) 6592 9958
bfuller@doh.health.nsw.gov.au

Programs

Integrated Chronic Care Model for people with Cancer

The program will better coordinate care for patients accessing cancer or palliative care services through the use of Self Management Action Plans and multidisciplinary Primary Care Plans. A skilled and educated workforce will be supported by the establishment of a Chronic Care Clinical Network, that will provide a range of flexible service delivery options and provide a forum for service planning, monitoring and evaluation.

Options for extending palliative care across the area will be identified via a coordinated network of service providers. The service options might include web-based information, after hours call centres, volunteer seminars and bereavement seminars.

Integrated Chronic Care Model for people with Chronic Respiratory disease

The program will establish and coordinate an area wide evidence-based system of care for the management of asthma and an area-wide evidence-based system of care for Chronic Airways Limitation (CAL).

Components of the model include:

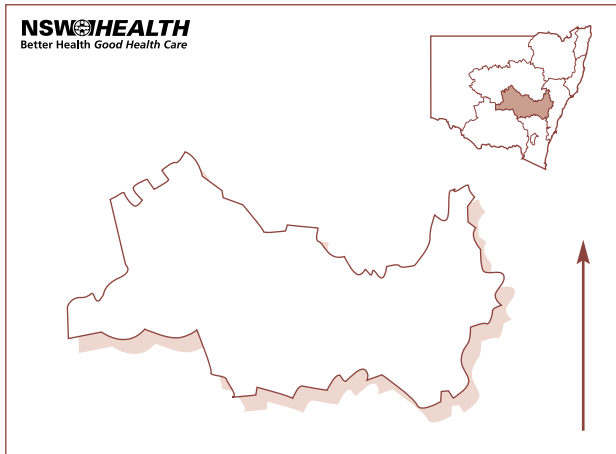
- Self Management Action Plans. The integrated model will allow for greater linkage to health promotion strategies eg. physical activity and smoking cessation.
- Primary Health Care Environment, involving the use of Multidisciplinary Primary Care Plans utilising a coordinated network of clinical health workers who will provide a range of flexible service delivery options as well as a forum for service planning, monitoring and evaluation.
- Flexible Rehabilitation Delivery Options tailored to individual needs.

Integrated Chronic Care Model for people with cardiac disease

The program will establish and coordinate an evidence based system of care to foster a coordinated multidisciplinary approach to improve post-acute care. Components of the program include:

- A self management action plan developed for cardiac rehabilitation linked with the Commonwealth's Enhanced Primary Care package and consistent with best practice guidelines.
- The development of multidisciplinary Primary Care Plans will effect a more coordinated model of care. A skilled and educated workforce will be supported by the establishment of a Chronic Care Clinical Network that will provide a range of flexible service delivery options and provide a forum for service planning, monitoring and evaluation.
- Flexible Delivery Options for Rehabilitation, to extend cardiac rehabilitation across the Area via a coordinated network of service providers.
- An essential element of the program is the strengthening of links to existing community based rehabilitation programs such as walking programs or smoking cessation programs.

Mid Western Area Health Service



Program Manager/Contact

Ms Michelle Davies

(Palliative Care and Oncology)
 Coordinator Palliative Care and Oncology Services
 Tel. (02) 6886 11205
 michelld@doh.health.nsw.gov.au

Ms Anne Lea

(Respiratory Disease)
 Coordinator Clinical Services Development
 Tel. (02) 6360 7882
 annel@doh.health.nsw.gov.au

Ms Trish Strachan

(Cardiovascular Disease)
 Director Health Service Development
 Tel. (02) 6339 5564
 trishst@doh.health.nsw.gov.au

Programs

Integration of Palliative Care and Oncology Services

The program is developing a model of care that will integrate the coordinated processes and services for a range of palliative care and oncology activities and will develop links with a range of activities and services along the continuum of care, acknowledging the role of general practitioners as gatekeepers to a range of services.

Elements of the model include:

- Population based activities
- Partnerships between Mid Western Area Health Service cancer services and the private sector
- Partnerships with local communities
- Networked multidisciplinary services provision on an outreach basis
- Specialist Palliative Care/Oncology Services
- Intersectorial linkages

The service model will be context specific, changing according to specific population characteristics.

Coordinated Care Program for People with Respiratory Disease

The Chronic Care Respiratory Program aims to achieve a coordinated 'continuum of care' pathway for clients with Chronic Obstructive Pulmonary Disease (COPD). This flexible model will accommodate the different services and resources available throughout the Area, and promote where appropriate, locally accessible, community based services

Core components of the model will include:

- The early identification and tracking of clients
- Case management processes with emphasis on early intervention, rehabilitation and health maintenance
- The active involvement of clients and their carers in management
- Quality management review processes.

A The program will result in improved continuity of care for patients, increased participation in their own management, increased access to rehabilitation services and improved quality of life.

Coordinated Care Program for People With Cardiovascular Disease

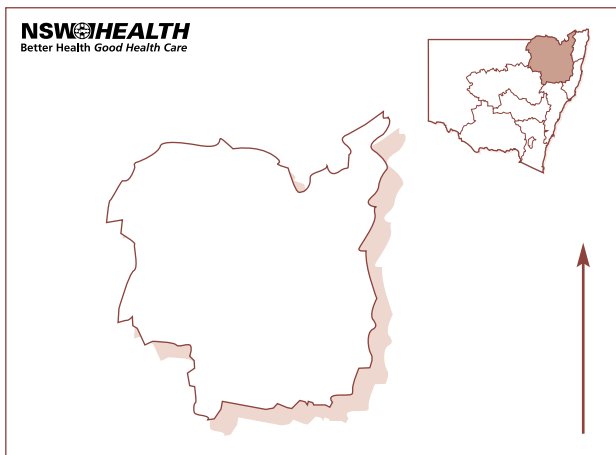
The Chronic Care Cardiovascular Program aims to achieve a coordinated 'continuum of care' pathway for clients with coronary artery disease and heart failure. A model of care accommodating the different services and resources available throughout the Area and promoting locally accessible, community based services will be developed.

Core components of the model will include:

- The early identification and tracking of clients
- Case management processes with emphasis on early intervention, rehabilitation and health maintenance
- The development and implementation of better practice guidelines for each management phase
- The active involvement of clients and their carers in management
- Quality management review processes.

For the patient, the program will result in improved continuity of care, increased participation in the management of their own health, increased access to rehabilitation services and improved quality of life.

New England Area Health Service



Program Manager/Contact

Ms Karen Edwards
(Cardiovascular, Respiratory and Cancer)
Director of Community and Mental Health Services
Tel. (02) 6776 4874
KLEdwards@doh.health.nsw.gov.au

Programs

Clinical Networking Model of Care for Chronic Illness – Cardiovascular

The program will help people with cardiovascular disease manage their illness better by offering a coordinated approach to their health care needs. A major part of coordinated care is teaching people with cardiovascular disease and their carers how best to manage the effects of the disease, eg. through attendance at cardiac rehabilitation programs.

It is envisaged that quality of life for people with cardiovascular disease, and their carers, will improve with less stressful hospital admissions and the availability of local support networks.

Clinical Networking Model of Care for Chronic Illness – Cancer

The program aims to help people with cancer manage their illness better by offering a coordinated approach to their health care needs. This will involve teaching people with cancer and their carers how best to manage the effects of the disease, eg. through information about signs and symptoms of complications and what to do if these occur.

The Chronic Care Program means that people with cancer are less likely to have unexpected or inappropriate admissions to hospital and are more likely to feel confident that they can manage certain aspects of their disease themselves. It is envisaged that quality of life for people with cancer and their carers, will improve with less stressful hospital admissions and the availability of local support networks.

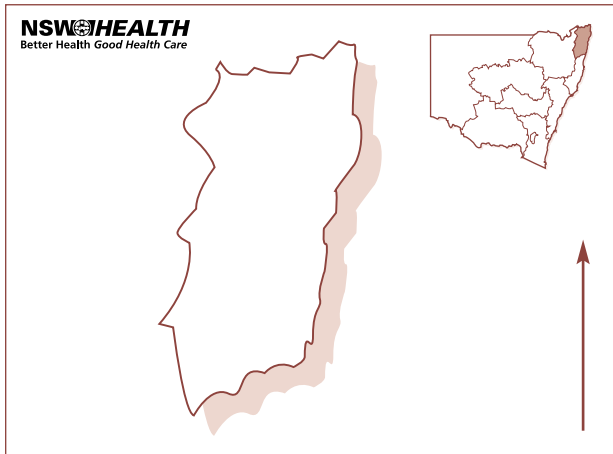
Clinical Networking Model of Care for Chronic Illness – Respiratory

The program aims to help people with chronic respiratory disease manage their disease better by offering a coordinated approach to their health care needs. This will involve teaching people with chronic disease and their carers how best to manage the effects of the disease, eg. through attending pulmonary rehabilitation programs.

The Chronic Care Program means that people with chronic disease are less likely to have unexpected admissions to hospital and are more likely to feel confident that they can manage certain aspects of their disease themselves. The quality of life for people with chronic disease and their carers will improve with less stressful hospital admissions and the availability of local support networks.

A

Northern Rivers Area Health Service



Program Manager/Contact

Vicki Rose

(Cardiovascular, Respiratory and Cancer)
Operational Support Manager
Tel. (02) 6620 2143
Vickir@nrhs.health.nsw.gov.au

Programs

Cardiovascular Disease Proposal

The purpose of the Heart Failure program is to facilitate the discharge planning process through a liaison worker, who has specific knowledge and skills in Heart Failure Management. This will involve linking the patient and their carer, the patient's general practitioner, Specialist, hospital and Community Health staff, to formulate a personalised care plan including self management strategies to promote health for the patient at home, and reduce stress for the carer.

The liaison worker will then support the patient in the community with other home and community services as indicated in the care plan. Teaching the patient and their carer to recognise and report early signs and symptoms of deterioration will help to prevent crisis situations that may require readmission to hospital.

Wherever possible the patient will be linked to existing cardiac rehabilitation services to provide a forum for commencement of safe exercise and support from other patients. Until now Heart Failure Patients have not previously been included in cardiac rehabilitation programs and it is envisaged that support groups will develop.

Heart Failure patients will now have a comprehensive community and self-management plan that provides information and ongoing support to implement the lifestyle changes required to prevent deterioration of health.

Cancer Program

The three components of the Cancer Program are:

- A data base or register to provide quality information concerning diagnosis, treatment outcomes, and future service planning.
- A paper Patient Held Record, or diary, aims to promote user friendly communication and coordination with other care providers, including cross-border services. The paper held record would aim at providing information on medications, diagnostic results, pathology, care provider information, eg. general practitioner, patient and carer questions and answers, schedule times and appointments. Cancer Liaison Workers will have an important role in the coordination of discharge planning to community care. Education programs and cancer literature will be provided, and the relevant Patient Held Record sections completed prior to discharge.
- The program will establish a way to standardise how cancer support groups are formed, funded, and maintained. Assessing the needs of each community is an important component in this project. The service content of Cancer Support Groups will be reviewed to include self-management practices, eg. symptom management, and resources required to ensure sustainability.

Respiratory Illness Program

The program is implementing an Area wide 'PEAK' respiratory model which will incorporate the following evidence based interventions to improve health care and outcomes for adults with chronic respiratory disease.

- P** Patient Empowerment
- E** Exercise
- A** Activities of daily living
- K** Knowledge

Respiratory liaison workers have been appointed to the three major centres.

Liaison workers will be responsible for the provision of site based and home pulmonary rehabilitation programs, patient and family education programs concerning their disease. and self management strategies during acute admission.

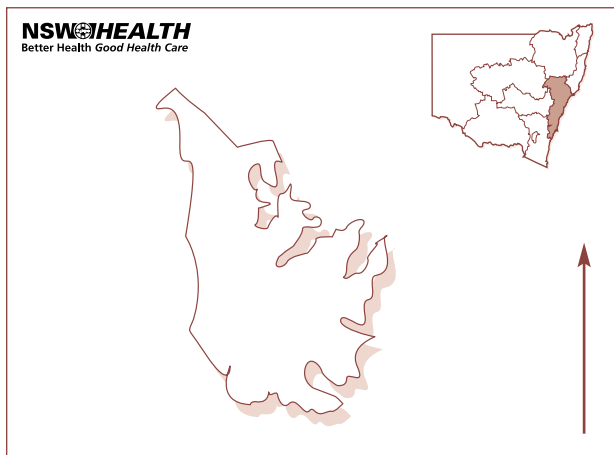
Other features of the model are improved discharge planning by facilitating general practitioner and multidisciplinary team involvement in the formulation of discharge care plans for chronic respiratory patients, and improved uptake of evidence based guidelines for specific respiratory disease management at individual sites.

Two fully equipped pulmonary rehabilitation kits, with multidisciplinary training components have already been provided across the Area Health Service. The kits will enable smaller health sites to conduct intermittent pulmonary rehabilitation programs from August 20th 2001.

(An Infrastructure Proposal has established infrastructure common to all three programs)

A

Northern Sydney Area Health Service



Program Manager/Contact

Ms. Gayle Mortimer

Chronic and Complex Care Program Coordinator,
Tel. (02) 9926 6764
gmortime@doh.health.nsw.gov.au

Programs

Management of Cardiac Failure (MACARF)

The program involves a MACARF Nurse, in collaboration with a General Practitioner, visiting the patient within the first week after discharge. They assess dietary and medication understanding, educating and emphasising the need for daily weighing and exercise. The patient keeps a diary of these activities and together they identify any barriers and alternate strategies. The nurse stays in regular phone contact with the patient, with changes in condition reported to the general practitioner who directs patient care. Consumers are encouraged to participate in self-care decisions and services delivery development and evaluation. Improved communication with general practitioners and opportunities to further develop collaborative relationships with community services, are being explored.

Respiratory Medicine

An Acute/Post Acute Care (APAC) service provides an acute substitution community model of care. Patients with Chronic Obstructive Airflow Disease (COAD) may have all or the lesser severity of their

hospital care at home. Acute interventions and a self-management care plan will be developed, with particular attention paid to precipitating factors for hospital presentation. The plan includes strategies to activate if particular signs and symptoms arise and, in collaboration with the general practitioner, ongoing prevention and maintenance planning is undertaken.

A Pulmonary Rehabilitation program will provide patients with COAD the opportunity to develop self-management strategies, exercise tolerance and support networks in an accessible location and supportive environment. Consumers are encouraged to participate in self-care decisions and services delivery development and evaluation.

Diabetes

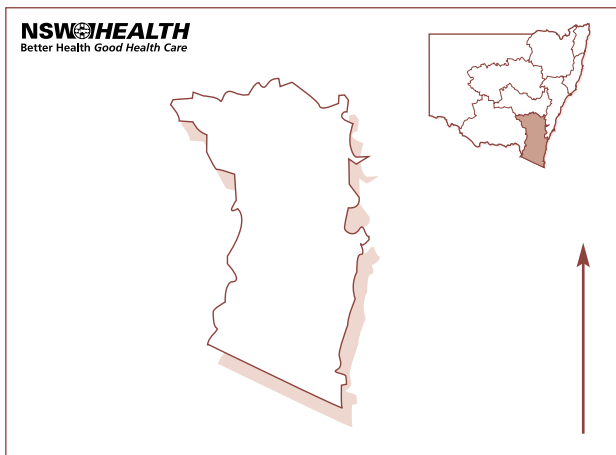
Patients at risk will be referred to the High Risk Foot Clinic (HRFC) from a wide range of settings. The patient is assessed, required interventions initiated, and a care plan recommended on referral back to local services. A Diabetes complications screening service (DCSS) will provide complications screening for patients with diabetes from the community.

Consumers are encouraged to participate in self-care decisions and services delivery development and evaluation. Improved communication with GPs and opportunities to further develop collaborative relationships with community services are being explored.

Cancer Services

The program is based around a 'Virtual Cancer Centre' linking public, private, hospital, clinic and community settings to provide high quality cancer care. Patients will be classified as having complex or less complex cancers. Complex cancer cases will be urgently referred to a major centre while less complex cases will be treated in the appropriate setting. Consumers are encouraged to participate in self-care decisions, and opportunities to consult with the community will be undertaken.

Southern Area Health Service



Program Manager/Contact

Ms. Carole Wallace

Health Improvement

Tel. (02) 6218 7641

carole.wallace@sahs.nsw.gov.au

Programs

Cancer Recovery Enhancement Program (CaRE)

The CaRE program will identify and address issues impacting on the quality of life of cancer patients and will reduce the need for hospital presentations and/or admissions in crisis situations.

A centrally located coordinator and a local facilitator in each of the six planning divisions will coordinate and monitor the proposed intervention, including establishing regional cancer teams, development of care plans and patient held records, mapping of cancer services and educating patients, carers and relevant Area staff.

The program interventions will increase access and knowledge of local services for both consumers and staff, and increase patient/carer quality of life. They will also promote self-management and independence.

Stroke Management Program (StAR)

The StAR Program is a care coordination model involving a centrally located coordinator and a local facilitator for each of six planning divisions. They will provide the interface and support the implementation and evaluation of the model of care which includes education and heightened community awareness of 'Brain Attack' and the importance of early presentation, development and application of best practice' acute and post-acute management plans, weekly case-conferencing with all involved practitioners and care-providers to support goal setting and re-evaluation and client /carer education to support involvement and informed decision making.

It is anticipated that earlier presentation, implementation of Best Practice management in acute care and rehabilitation, and coordinated and effective community links will decrease disability and complications, reduce length of stay and improve quality of life for both client and carers.

Respiratory Program (LungSmart)

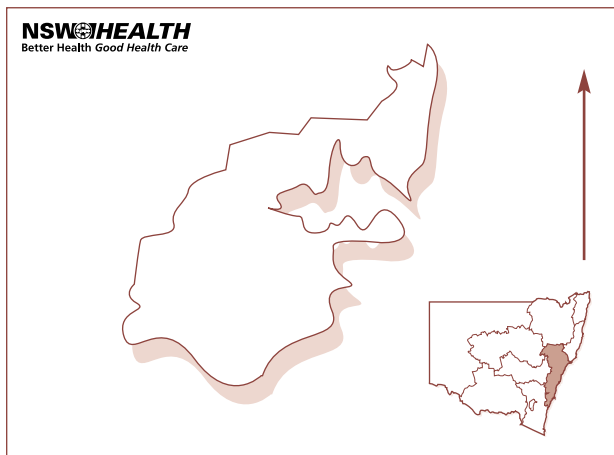
Lungsmart will develop, implement and evaluate an integrated respiratory care program for chronic lung disease in SAHS.

A centrally located coordinator and six local facilitators in each of the six planning divisions will implement the model of care, which includes the development of a pulmonary rehabilitation program in each planning division, provision of information to patients and carers regarding appropriate support services, improved discharge planning and automatic referral to rehabilitation programs, well documented care coordination and planning by multidisciplinary team and case managers, and the establishment of mechanisms to support and care for patients at home.

Expected outcomes from the Lungsmart program include improved quality of life, encompassing life satisfaction, confidence, health perception, motivation and functionality.

A

South Eastern Sydney Area Health Service



Program Manager/Contact

Dr Lucy Chen

(COPD, Aiming for Asthma Improvement,
Congestive Cardiac Failure)
Planning and Evaluation Officer
Tel. (02) 9947 9853
Chenl@sesahs.nsw.gov.au

Ms Meg Bassar

(Chronic Diseases Among Aboriginal People,
Nursing Homes)
Planning and Evaluation Officer
Tel. (02) 9382 8177
Bassem@sesahs.nsw.gov.au

Ms Colleen Leathley

(Connecting Cancer Care)
Planning and Evaluation Officer
Tel. (02) 9947 9845
Leathleyc@sesahs.nsw.gov.au

Nicole Cockayne

(Diabetes)
Research Officer
Tel. (02) 8382 2021
qumedu@stvincents.com.au

Programs

Coping with Chronic Obstructive Pulmonary Disease (COPD) in South East Health

The COPD program aims to provide cardio-pulmonary rehabilitation and patient education as key strategies in the prevention, detection, treatment and rehabilitation of patients with COPD.

Another key element is enhanced coordination of patient care in the community.

A written treatment plan will be provided instructing patients on medication changes, indications requiring consultation with their general practitioner, and how to notify their case manager, PAROS nurse or community health nurse. Participation in ongoing community exercise rehabilitation programs will make it possible for health workers to identify patients in difficulty. Access to a multidisciplinary management team will allow early detection of deterioration, and exposure to smoking cessation messages. Community based nurse and physiotherapist involvement will promote linkages to other community services, such as Home Care Packages, as many COPD patients are housebound and severely disabled by their illness.

Chronic Diseases Among Aboriginal People

This program seeks to improve the quality of life of Aboriginal and Torres Strait Islanders residing within the South Eastern Area Health Service through a local community-based coordinated model of health care that will engage a range of strategies including risk factor management and health care intervention to reduce the burden of chronic disease.

(Over 5,000 residents identify as being of Aboriginal or Torres Strait Islander descent within the South Eastern Sydney Area Health Service. Of these, just under 2,000 reside in the Randwick and Botany local government areas).

Consultations have been held with community members and general practitioners, Aboriginal community members, local Aboriginal service providers and local medical practitioners have been invited to join the Implementation Committee. Refurbishment of the Arrunga Centre at La Perouse has commenced and clinics will be held there.

An Aboriginal Health Education Officer will run the clinic, provide chronic disease management education to clients and carers, and facilitate access to other chronic disease initiatives.

Congestive Cardiac Failure (CCF)

This program aims to improve the quality of life of CCF patients, their carers, and families, and improve disease management, which will lead to reductions in crisis presentations to hospitals. Main elements include coordinating cardiac rehabilitation, enhancing education to patients and general practitioners, and developing and adapting relevant guidelines and pathways to improve the quality and standard of service delivery.

The model incorporates a multidisciplinary approach with congestive cardiac failure patients primarily managed by their general practitioner with support from a Nurse Liaison Officer, who reinforces medication education to the patient and their family, reviews diet and makes referral for psychosocial and therapeutic involvement from Community Health peers. A congestive cardiac failure team of specialist medical officers and clinical nurse consultants can be contacted in emergencies to organise treatment at home by post acute services, or to smooth the patient's transition through hospital care back into the community.

Connecting Cancer Care Program

Consistent with the aims of the Chronic and Complex Care framework, this program is largely a 'bridging' and educational program, linking hospital and community services to facilitate coordinated care for cancer patients. Main elements include community based care for cancer management linking patients, carers, cancer services, community health services and general practitioners; education about disease management and service access to patients and carers; quick response support for unplanned presentations of palliative care patients to Emergency Departments; clinical education and information sharing; case conferencing and clinical protocol development; and databases and care guidelines to inform care provision and enhance care continuity.

Aiming for Asthma Improvement

Educational in nature, the program focuses on asthma prevention in children.

The program will engage asthma educators to extend the asthma management program to schools, and to follow up Emergency Department presentations, admissions and discharges from hospital concerning the quality use of medications and asthma management. It will also introduce standardised clinical practice guidelines across the Area, and strengthen links between hospital and community based services.

A written Asthma Management Plan has been shown to improve asthma control, and the program aims to ensure that each child has a plan which has been negotiated with their doctor. This will enable self-management at the onset of asthma problems and help avoid unnecessary Emergency Department attendances and stressful hospital admissions.



Diabetes Footcare – a Comprehensive Diabetes Complication Reduction Strategy

The main aim of this project is to better manage podiatry services in the Area, so as to deter development and exacerbation of foot-related problems that often lead to amputations and long bed-stays in hospital. An Area Coordinator will link existing services, educate clinical staff and carers about foot care, and collect relevant data.

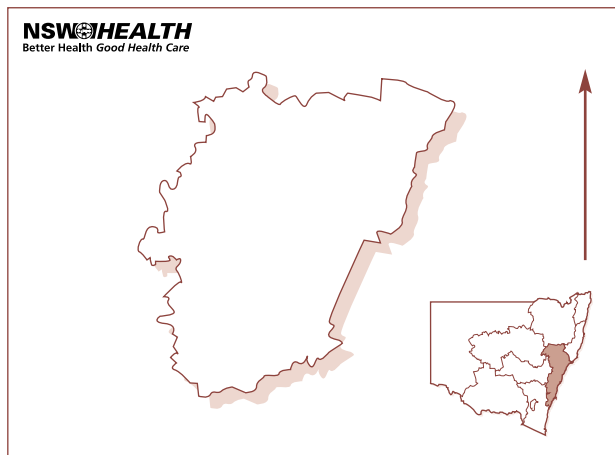
Podiatry assessment forms have been developed for the screening of patients 'at risk' and this process has commenced in two sectors. Staff at each sector have been equipped and trained in the use of updated podiatry tools and there has been an increase in the number of podiatry sessions available each week. Sectors have also established a network for liaison with other service providers within and outside of the South Eastern Sydney Area Health Service, and contact has been initiated with the Divisions of General Practice.

Chronic Disease Management in Nursing Homes: A Collaborative Approach

The program aims to provide specialist aged care medical support to general practitioners, nursing home staff and families to manage residents within nursing homes and hostels, and to reduce inappropriate presentations to Emergency Departments and admissions to hospital. The program will provide standardised, health practitioner supported care to allow appropriate residents to remain in their usual place of residence for episodic chronic disease exacerbation, and terminal phase care of chronic diseases. The development of Advanced Care Directives and treatment algorithms to allow consenting patients with end-stage illness to be managed at home are key components of the program, as are comprehensive clinical assessment, multidisciplinary case-conferencing and involvement and education of key stakeholders.

South Western Sydney Area Health Service

A



Program Manager/Contact

Mr Rene Pennock

Chronic and Complex Care Program Manager
Tel. (02) 9828 5964
rene.pennock@swhs.nsw.gov.au

Programs

Integrated Vascular Care

The program involves establishing multidisciplinary teams and Specialist Liaison Nurse (SLN) positions. SLNs will provide the primary coordinating role and will principally operate in the community, sharing knowledge with other members of the multidisciplinary team, including the patient and their carers, the patient's general practitioner, specialist and primary health nurse.

The premise upon which this intervention is based is that patient care will be improved by a nurse with condition-based specialist knowledge, who provides advice to the patient and other members of the multidisciplinary team regarding the best management of the condition.

The SLN positions will provide optimum coordinated care to patients with chronic and complex conditions in the area of cardiovascular disease. This position will also enhance liaison between general practitioners and other health service providers and will result in improved and more appropriate access to services.

Extended Hours Palliative Care Service and 24 hour access to Palliative Care Advice

The purpose of the program is to provide coordinated 24 hour/7 days a week palliative care advice to registered palliative care patients, and to provide extended hours of service and coordinated support to cancer patients in need of palliative care. The program will implement and maintain an IT based networked clinical register of cancer palliative care patients. General practitioners will be engaged and trained to promote a shared care approach. Individual care plans will be developed in conjunction with the general practitioner, patient, family and/or carer and the palliative care team.

The program will enhance current service delivery by making available 24 hour access to specialist palliative care advice. A new networked palliative care register will prevent duplication of data collection procedures and provide the capacity to respond to patient concerns. Extended hours of service and coordinated support will be made available in all Sectors for patients with cancer in need of palliative care.

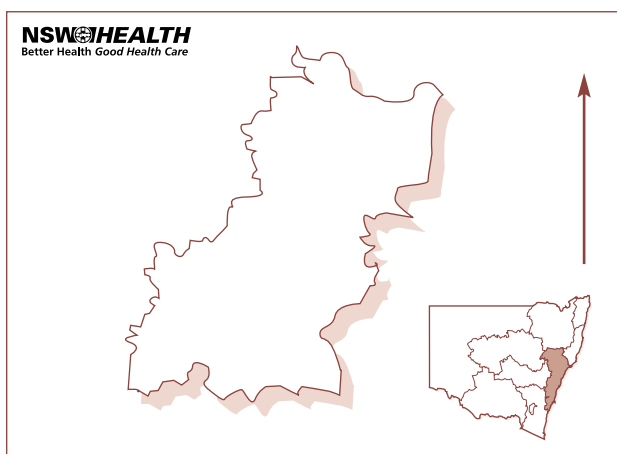
Integrated Respiratory Care

Patients referred to various Respiratory Assessment Services will receive a comprehensive assessment, including diagnostic tests to decide whether they require hospital or community-based treatment. If a patient is to be discharged a care plan will be developed with the patient, patient's family and carers, the patient's general practitioner and other community service providers

The respiratory specialist liaison nurse position is based on a shared funding arrangement between the Fairfield Division of General Practice and the South Western Sydney Area Health Service (through the Priority Health Care Programs to work with COPD and asthma patients. This important initiative provides an opportunity to improve health outcomes for patients with COPD and poorly controlled asthma. A nurse educator will supplement care provided by general practitioners and the respiratory specialist. The position will also enhance liaison between general practitioners and health professionals involved in the care process.

47

A Wentworth Area Health Service



Program Manager/Contact

Ms Gail Boyle

Chronic and Complex Care Program Manager

Tel. (02) 4734 2615

boyleg@wahs.nsw.gov.au

Programs

Chronic Airflow Limitation Management Program (CALM)

The overall aim of the CALM Program is to assist patients with chronic and relapsing illness to better understand their condition, to improve quality of life by maximising respiratory fitness and to better coordinate care in hospital and after discharge.

The specific aims of the CALM program are:

- To help patients and their families to better understand and cope with their chronic symptoms by provision of a 12 week education and exercise program conducted at the hospital for the first 6 weeks, and in the community for the second 6 weeks.
- To improve access to care for these patients by provision of a mobile clinical team who can visit patients in their homes.
- To improve in-hospital treatment of exacerbations of CAL with an evidence-based managed care plan.
- To improve coordination of ongoing care following discharge from hospital by maximising communication between all health care providers. The CALM Program coordinator will provide a central point of contact to facilitate this.

Cancer Service Without Walls

The *Cancer Service Without Walls* program is a joint collaborative project linked with Western Sydney Area Health Service. The program aims to improve clinical linkages with General Practice and other community based health providers, increase community support to patients with far advanced malignancy and redesign oncology record keeping and systems to improve patient care and provide a focus for quality assessment, outcome evaluation and clinical research.

The model of care involves the appointment of nurses, based in the hospital sector, with a liaison, coordination and education role across sectors, and the development of a single cancer record available to the Emergency Department after hours, together with a patient held summary.

The program will also foster linkages with General Practice and initiate a clinical review of all cases to identify unplanned admissions, avoidable admissions and system changes required to prevent repetition.

Diabetes Project

The Diabetes program aims to improve coordination of screening for diabetes complications in the community and establish an after hours emergency contact number for people with Type 1 diabetes in order to reduce unplanned admissions to hospital.

The model of care consists of patient education, the development of Managed Care Plans initiated by General Practitioners, and education and up skilling of GP surgery staff through collaboration in the development of managed care plans.

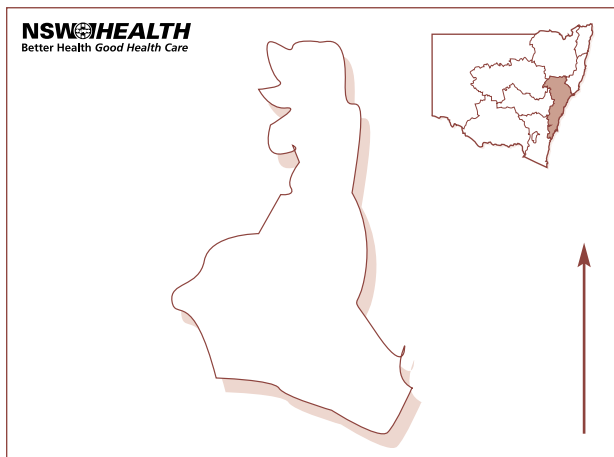
A 24hr telephone help line aimed at crisis calls for people with Type 1 diabetes will be implemented to support the overall program and offer constant patient support. Progress will be monitored by a computerised diabetes data-base system ('Cardiab')

Collaborative Community Approach – Chronic and Complex Care

This Community Health program will develop coordinated strategies and a community focused infrastructure to support patients and their carers in management of their illness. The program incorporates a community-based approach and is designed to complement local programs targeting specific chronic and complex conditions.

A

Western Sydney Area Health Service



Program Manager/Contact

Ms Alison Tidbury

(Chronic Lung Disease, Vascular Risk Assessment and Management)

Health Services Planner

Tel. (02) 9845 7010

alison.tidbury@wsahs.nsw.gov.au

A/Prof. Paul Harnett

(Cancer 'Without Walls')

Director and Staff Specialist

Tel. (02) 9845 6432

paul.harnett@westgate.wh.usyd.edu.au

Dr Jane Holmes-Walker

(Young Adults with Diabetes)

Staff Specialist

Tel. (02) 9845 6796

jane.holmes-walker@westgate.wh.usyd.edu.au

Improved Ambulatory Care for People with Chronic Lung Disease

The Respiratory Ambulatory Care Service has been developed with the aim of improving quality of life and providing extended support in the community for people with chronic lung disease.

The service has established a Comprehensive Pulmonary Rehabilitation Program with a multidisciplinary team of health professionals. Based at three sites, the program will provide education to patients and carers, exercise conditioning, smoking cessation counselling, psychological support, nutritional support and occupational therapy reviews.

The service also provides a 24 hour telephone support service and extended specialist nursing support service in the community for patients with severe chronic lung disease.

Coordinated Vascular Risk Assessment and Management Program

The program will include the development of Area evidence-based vascular risk management guidelines and protocols; a patient register that facilitates communication between health service providers and patients; development of a system of care planning that facilitates communication between providers, patients and carers; a training strategy for health providers; and an education strategy for patients and carers.

The expected outcomes include an improved system of coordinated and integrated primary and secondary care for people with (and at risk of) vascular disease. Health service providers, patients and their carers and families will have a greater understanding of chronic care self-management. These outcomes will assist patients with chronic and complex health care needs in developing control over their condition and improving their quality of life.

Transitional Services – Young Adults with diabetes

The program aims to ensure all young adults with diabetes are receiving appropriate long-term preventative care by facilitating a transition of care from diabetes services provided by the Children's Hospital at Westmead to services based in Wentworth, Western Sydney and South Western Sydney Area Health Services.

The primary purpose of the program is to track patients transferred to adult care (public and private) and ensure that regular review occurs over a two year period following transfer. The program will also identify problems in maintaining regular review. Patients admitted to hospital within the Western Sydney Area Health Service will be monitored under the tracking system to ensure regular review over a two year interval in order to prevent unnecessary readmissions to hospital.

Cancer Service Without Walls

The 'Cancer Service Without Walls' program is a joint collaborative project linked with Wentworth Area Health Service. The program aims to improve clinical linkages with General Practice and other community based health service providers, increase community support to patients with far advanced malignancy and redesign oncology record keeping and systems to improve patient care and provide a focus for quality assessment, outcome evaluation and clinical research.

The model of care involves the appointment of nurses, based in the hospital sector, with a liaison, coordination and education role across sectors, the development of a single cancer record available to the Emergency Department after hours, together with a patient held summary.

The program will also foster linkages with General Practice and initiate a clinical review of all cases to identify unplanned admissions, avoidable admissions and system changes required to prevent repetition.

Data analysis of performance measures

B Data analysis

As at the time of writing, analysis has been conducted for the baseline year of 1999/2000. This financial year is a complete data set containing all activity of both public and private hospitals. It is a reasonable indicator of the state of play of Chronic and Complex Care activity in an environment pre implementation. This data set was selected due to its known completeness. Data since July 2001 has been less reliable and not as complete.

Work has commenced on assessing the quarters September-December 2000 and January-March 2001. These quarters were selected for comparison as they represent the last quarter before

commencement of the Chronic and Complex Care Priority Health Care Programs and the first quarter with these programs. Significant data problems have occurred with assessing this data as Area Health Services make the transition to new patient management systems and face delays on supplying inpatient data to NSW Health. It is anticipated that the first report comparing these two quarters will be available in September 2001.

Baseline Data 1999/2000.

Source: Inpatient Statistics Collection (ISC) 1999/2000.

Respiratory Disease

(excludes same day admissions)

Respiratory Disease Baseline Public Hospital	Separations	% Total Seps	Length of Stay	% Total LOS
Planned Admissions	8,394	17.65%	119,692	23.34%
All Unplanned	39,162	82.35%	393,073	76.66%
Total	47,556	100.00%	512,765	100.00%
Unplanned Admissions	6,597	16.85%	96,592	25.08%
Unplanned Readmissions	2,683	6.85%	36,120	9.19%
Unplanned Emergency Admissions	25,656	65.61%	220,286	56.04%
Unplanned Emergency Readmissions	4,226	10.79%	38,075	9.69%
Total	39,162	100.00%	393,073	100.00%

Respiratory Disease Baseline Private Hospital	Separations	% Total Seps	Length of Stay	% Total LOS
Planned Admissions	5,714	67.11%	60,699	67.47%
All Unplanned	2,801	32.89%	29,270	32.53%
Total	8,515	100.00%	89,969	100.00%
Unplanned Admissions	868	30.99%	10,262	35.06%
Unplanned Readmissions	199	7.10%	2,282	7.80%
Unplanned Emergency Admissions	1,534	54.77%	14,884	50.85%
Unplanned Emergency Readmissions	200	7.14%	1,842	6.29%
Total	2,801	100.00%	29,270	100.00%

Respiratory Disease is defined as – Emphysema, Other COPD, and Asthma (ICD10 Codes J43, J44, J45).

CVD / Diabetes (excludes same day admissions)

CVD/Diabetes Baseline Public Hospital	Separations	% Total Seps	Length of Stay	% Total LOS
Planned Admissions	12,934	17.02%	220,627	23.82%
All Unplanned	63,049	82.98%	705,675	76.18%
Total	75,983	100.00%	926,302	100.00%
Unplanned Admissions	12,387	19.65%	217,554	30.83%
Unplanned Readmissions	4,743	7.52%	64,384	9.12%
Unplanned Emergency Admissions	39,521	62.68%	363,451	51.50%
Unplanned Emergency Readmissions	6,398	10.715%	60,286	8.54%
Total	63,049	100.00%	705,675	100.00%

CVD/Diabetes Baseline Private Hospital	Separations	% Total Seps	Length of Stay	% Total LOS
Planned Admissions	10,064	69.32%	107,654	68.58%
All Unplanned	4,455	30.68%	49,327	31.42%
Total	14,519	100.00%	156,981	100.00%
Unplanned Admissions	1,408	31.60%	117,789	36.06%
Unplanned Readmissions	318	7.14%	4,280	8.68%
Unplanned Emergency Admissions	2,436	54.68%	24,675	50.02%
Unplanned Emergency Readmissions	293	6.58%	2,583	5.24%
Total	4,455	100.00%	49,327	100.00%

CVD/Diabetes is defined by Heart Failure and Complications (ICD10 codes I50 and I51); Diabetes (ICD10 codes E10 and E11 and all sub categories).

Cancer (excludes same day admissions)

Cancer Baseline Public Hospital	Separations	% Total Seps	Length of Stay	% Total LOS
Planned Admissions	13,860	34.44%	167,595	36.36%
All Unplanned	26,379	65.56%	293,306	63.64%
Total	40,239	100.00%	406,901	100.00%
Unplanned Admissions	6,243	23.67%	89,170	30.40%
Unplanned Readmissions	2,824	10.71%	35,665	12.16%
Unplanned Emergency Admissions	13,255	50.25%	132,403	45.14%
Unplanned Emergency Readmissions	4,057	15.38%	36,068	12.30%
Total	26,379	100.00%	293,306	100.00%

B

Cancer Baseline Private Hospital	Separations	% Total Seps	Length of Stay	% Total LOS
Planned Admissions	7347	74.57%	74983	72.25%
All Unplanned	2505	25.43%	28806	27.75%
Total	9852	100.00%	103789	100.00%
Unplanned Admissions	1078	43.03%	13924	48.34%
Unplanned Readmissions	274	10.94%	3203	11.12
Unplanned Emergency Admissions	989	39.48%	10254	35.60%
Unplanned Emergency Readmissions	164	6.55%	1425	4.95%
Total	2505	100.00%	28806	100.00%

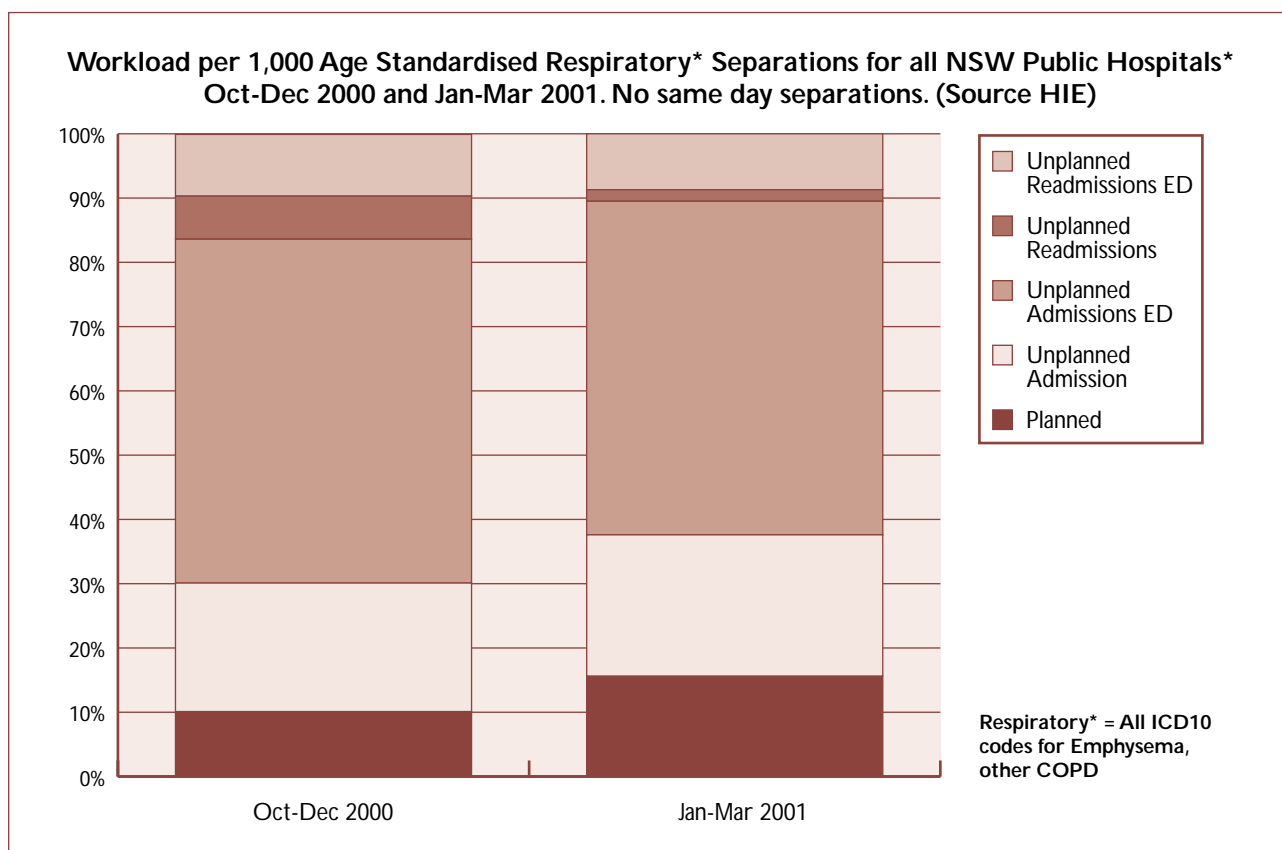
Cancer is defined by all ICD 10 codes associated with Cancer of the: Oesophagus; Stomach; Colon; Pancreas; Larynx; Trachea, bronchus and lung; Melanoma of the skin; Other neoplasm of the skin; Female breast; Cervix; Uterus; Testes; Prostate; Bladder; Brain; Ill defined sites; Lymph nodes; Respiratory and digestive systems; Secondary Malignant neoplasm; Lymphosarcoma and reticulosarcoma; Hodgkin's disease; Other malignant neoplasms of lymphoid and histiocytic tissue; Multiple myeloma and immunoproliferative neoplasms; Lymphoid Leukaemia; Myeloid leukaemia; Monocytic Leukaemia; Other specified leukaemia; Leukaemia of unspecified cell type.

Expected outcomes

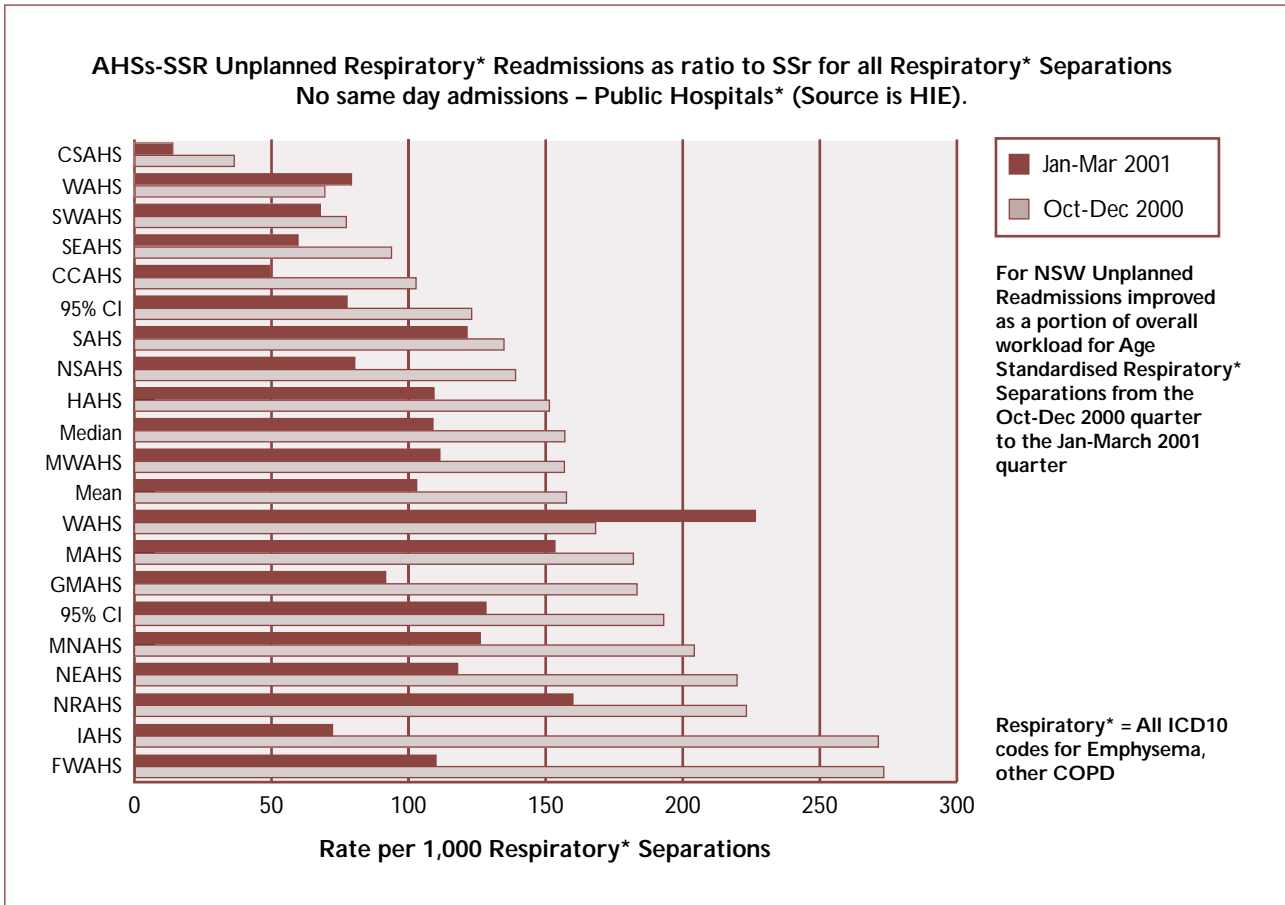
Outcomes are expected to show improvements in the performance indicators graphical examples are shown herein.

Example of a comparison of activity across successive quarters.

NB. Graphical analysis shown below was conducted on an incomplete data set. The graph should be used for illustrative purposes only.



Example of AHS performance across successive quarters



Chronic and Complex Care Implementation Group

C Terms of reference

Aim

To define, develop, and oversee the implementation of strategies to promote a coordinated statewide approach to achieving best-practice standards of health care for people of all ages with chronic and complex needs in NSW.

Roles and responsibilities

1. Operational/administrative

- a) To develop a work plan for the Statewide Chronic and Complex Care Implementation Group (SCCCIG), specifying milestones, deliverables and a process to guide Area Health Service use of the enhanced funding for chronic disease care in NSW.
- b) To establish and oversee the operation of Priority Health Care Programs to develop and guide implementation of best-practice approaches to providing health care to people with the chronic conditions nominated in the workplan.
- c) To monitor, evaluate and report on progress and achievement of the Group's key deliverables and objectives.

2. Health service delivery

- a) To agree on a set of values and principles to govern the delivery of health services to people with chronic and complex conditions in NSW.
- b) Consistent with the values and principles identified in 2(a), to identify systemic issues affecting the delivery of care to people with chronic illness in the following broad areas:
 - Consumer and community participation
 - Dissemination of information to and sharing of knowledge between consumers, community groups and professionals at all levels of the health system

- Funding models and strategies
- Information technology (IT) infrastructure
- Education and training needs of health professionals
- Monitoring and evaluating the quality of health care
- Corporate and clinical governance structures
- Inter-agency issues.

- c) To develop a framework for chronic disease care that specifies interventions and strategies to address the issues identified in 2(b).
- d) To develop clinical service standards and/or models of care for people with cardiovascular disease, respiratory illness and cancer.

3. Education and training

- a) To work with the Teaching and Research Implementation Group to identify and develop the strategies needed to address the training, workforce and professional development issues affecting statewide implementation of best-practice in chronic disease care.

4. Health services research

- a) To work with the Teaching and Research Implementation Group to evaluate and commission, where necessary, health services research to measure the impact of different service delivery models on health outcomes and the quality of life of people with chronic and complex health conditions and their carers.
- b) To develop a continuous improvement framework for monitoring the progress and outcomes of initiatives undertaken through the Priority Health Care Programs.

5. Consumer and community participation

- a) To develop and put in place a strategy to ensure that consumers, carers and community organisations are informed of and able to participate in the deliberations of the SCCCIG.
- b) To ensure that the strategy developed in 5(a) provides indigenous groups, people from culturally diverse and Non-English speaking backgrounds and socioeconomically disadvantaged groups the opportunity to input into the Group's deliberations.

6. Communication and marketing

- a) To develop methods for disseminating/receiving information about the activities, progress and outcomes of the SCCCIG to consumers, carers and community organisations, relevant government agencies and health professionals in all sectors of the health system.

7. Information technology infrastructure

- a) To work with the Information Management Implementation Group and other key stakeholders to develop and recommend a process for implementing the IT systems and structures articulated in 2(c).

8. Governance

- a) To make recommendations to Area Health Services on appropriate methods for establishing the clinical and corporate governance strategies identified in 2(c).

Other functions

- To work with the Models of Care, Acute Care, Emergency Services and Intensive Care Implementation Working Groups to determine workplans, milestones and methods of evaluating achievement of the Government's Action Plan.
- To provide advice to the Director-General, through the Models of Care Implementation Working Group and the Clinical Council, on progress and achievement of milestones.

Reporting and accountability:

The SCCCIG will report directly to the Models of Care Implementation Working Group and, through this Group, to the Director-General for Health. The SCCCIG will report to the Models of Care Implementation Working Group on a monthly basis.

Day-to-day accountability of the SCCCIG will be to the Public Health Division of the NSW Health Department through the Centre for Research and Clinical Policy.

Appendix D

Clinical Expert Reference Groups

D Terms of reference

Aim

To oversee a systematic approach to achieving the objectives of the NSW Priority Health CARE Program for people with cardiovascular disease, cancer and respiratory disease, including:

- Prevention of crisis situations and reduction of unplanned admissions to hospitals;
- Improvement in the quality of life of people with these conditions; and
- Improvement in the quality of life of their carers and families.

Roles and responsibilities

- To define the scope of the Cardiovascular, Cancer and Respiratory Clinical Expert Reference Groups.
- To provide expert advice to the Statewide Chronic and Complex Care Implementation Group (SCCCIG) on:
 - (a) proposed Area Health Service (AHS) programs in cardiovascular disease, respiratory disease and cancer.
 - (b) Area program implementation and evaluation plans; and
 - (c) progress of AHSs towards achievement of key program milestones and deliverables; consistent with the SCCCIG guidelines for Area Programs.
- To identify evidence-based interventions and clinical care processes for management of the nominated conditions;
- To identify, where possible, models of care that deliver these interventions;
- To identify practical tools, resources and strategies to assist AHS implementation of improved models of care;
- To identify audit tools and performance indicators to help ensure services are being delivered to an acceptable standard;

- To establish milestones and goals against which progress within agreed time-scales will be measured.
- To establish the NSW Networks across the nominated conditions to make recommendations to the SCCCIG regarding:
 - strategies to promote increased communication between clinicians working in the nominated areas across NSW, in particular, to foster greater sharing of expertise, information and evidence
 - mechanisms for ongoing monitoring and evaluation of health services for people with these conditions across NSW
 - strategies to facilitate consumer and community participation in the design and planning of services for people with these conditions
 - management of the interface between public and private service providers
 - strategies to support appropriate linkage between clinical groups and the NSW Health Department
- To produce Clinical Service Frameworks across the nominated conditions, to promote a standardised, evidence-based approach to achieving best-practice standards of care across NSW.

Other functions

- To participate in information sessions and workshops hosted by the SCCCIG for groups developing Area Programs in the nominated conditions.
- To act as a resource for groups developing and implementing Area Programs in cardiovascular disease, cancer and respiratory disease.

Key outputs

The key output of the CERGs will be the Clinical Service Frameworks in each of three priority health areas. These documents will evolve progressively to:

- specify standards and define service models for people with these conditions in NSW
- specify initial milestones, goals and performance indicators against which progress towards the achievement of these standards, within agreed time-scales, can be measured
- identify practical tools and resources to support implementation of best-practice models of care
- outline a system for reviewing and updating the contents of the document in line with new medical and policy developments.

Reporting and accountability:

The Clinical Expert Reference Groups will report to the Co-Chairs of the SCCCIG through the SCCCIG Secretariat. Reporting will be on a monthly basis.

The SCCCIG Co-Chairs and Secretariat will be invited to attend all meetings of the CERG.

Minutes of the meetings will be distributed to SCCCIG members via the SCCCIG Co-Chairs in a timely manner.

Appendix E

Special Interest Groups

E Special Interest Groups for the Chronic and Complex Care Program were drawn from the combined membership of the CCCICG and Clinical Expert Reference Groups for Cardiovascular Disease, Cancer and Respiratory Disease.

Terms of reference

Aims

- To collaborate in a systematic approach to achieving the objectives of the NSW Priority Health Care Program for people with heart failure, cancer and respiratory disease.
 - To drive cultural changes within the NSW health system
 - To share learning
 - To provide guidance in the development of models of service delivery
 - To contribute to the creation and implementation of Heart Failure, Cancer and Respiratory Disease Clinical Service Frameworks
- #### *Roles and Responsibilities*
- To participate in a NSW Heart Failure, Cancer and Respiratory Disease Networks to:
 - communicate with heart failure, cancer and respiratory teams across NSW to share expertise, information, data and evidence
 - facilitate consumer and community participation in the design and planning of services for people with heart failure, cancer and respiratory disease
 - share strategies to improve the interface between public and private service providers
 - improve linkages between clinical groups and the NSW Health Department
 - To contribute to the development of Clinical Service Frameworks for heart failure, cancer and respiratory disease, incorporating a standardised, evidence-based approach to achieving best-practice standards of chronic care for people throughout NSW
 - To develop targets for performance measurement in heart failure, cancer and respiratory disease – quantitative, qualitative, fixed and/or variable – which relate to specific program outcomes or goals
 - To provide advice to the Heart Failure, Cancer and Respiratory Disease Clinical Expert Reference Groups and the Chronic and Complex Care Implementation Coordination Group (CCCICG) on implementation and evaluation of Area Health Service programs in heart failure
 - To identify evidence-based interventions and clinical care processes for management of the nominated conditions.
 - To identify models of care that consistently deliver these interventions
 - To identify practical tools, resources and strategies to assist AHS in implementation and evaluation
 - To participate in information sessions and workshops on heart failure, cancer and respiratory disease.

Key output

The key output of the CERGs during 2001-2002 will be the development of Clinical Service Frameworks for Heart Failure, Cancer and Respiratory Disease. The Special Interest Groups will contribute to the development of the Clinical Service Frameworks, which will evolve progressively to:

- specify standards and service models for people with heart failure, cancer and respiratory disease
- identify milestones and performance indicators against which progress towards these standards can be measured
- outline mechanisms for reviewing and updating the document in line with new clinical and policy developments.

Membership of the Special Interest Groups***Co-Chairs of the Heart Failure Clinical Expert Reference Group***

- Professor Geoffrey Tofler
- Dr Ana Singer

Co-Chairs of the Cancer Clinical Expert Reference Group

- Associate Professor Paul Harnett
- Dr Thomas Acheson

Co-Chairs of the Respiratory Disease Clinical Expert Reference Group

- Associate Professor David McKenzie
- Dr Peter Clyne

Executive support

- Centre for Research and Clinical Policy
- NSW Health Department

Members

- AHS heart failure, cancer and respiratory disease CCC program leaders
- Other relevant program leaders
- Interested members of CCCICG and CERGs
- Centre for Research and Clinical Policy managers

Membership may also include

- Nursing, allied health and health promotion professionals
- Specialist clinicians
- General practitioners
- Community care agency representatives
- Consumer representatives

Chairs of the Special Interest Groups may from time to time invite participation and/or seek advice from others to ensure appropriate representation – such as people from indigenous or non-English speaking background.

Reporting and Accountability

The Special Interest Groups are subcommittees of the respective Clinical Expert Reference Groups. The Chairs will report through the Department's Centre for Research and Clinical Policy to the CCCICG, from March 2001.

Endnotes

1. Farrell, M. (1998). *Trends in the global health care environment: The developed countries*. Contemporary Nurse, 7, 180-189.
2. Public Health Division (1997). *The health of the people of NSW: Report of the Chief Health Officer*. Sydney: NSW Health Department.
3. Etwiler, D. (1997). *Chronic care: A need in search of a system*. The Diabetes Educator, 23, 569-573.
4. Edwards, N. & Henscher, M. (1998). *Managing demand for secondary care services: the changing context*. British Medical Journal, 317, 135-138.
5. Report of the NSW Health Council – *A Better Health System for NSW*, NSW Health Department, Sydney, 2000.
6. *ibid*
8. Bindman, A.B., Grumbach, K., Osmond, D., Komaromy, M., Vranizan, K., Lurie, N., Billings, J. & Stewart, A. (1995). *Preventable hospitalisation and access to health care*. The Journal of the American Medical Association, 274, 305-311.
9. Rich, M., Beckham, V., Wittenberg, C. et al. (1995). *A multidisciplinary intervention to prevent the readmission of elderly patients with congestive heart failure*. The New England Journal of Medicine, 333, 1190-1195.
10. Report of the NSW Health Council, *op. cit.*
11. *ibid*.
12. *Current Situational Analysis: Macro-Vascular Diseases*, NSW Health, 2000.
13. *Current Situational Analysis: Cancer*, NSW Health, Sydney, 2000.
14. *Current Situational Analysis: Respiratory Disease*, NSW Health, Sydney, 2000.
15. *Coronary Heart Disease and Cancer Frameworks*, UK NHS www.doh.gov.uk/nsf/nsf/home.htm
16. *National Heart Foundation Guidelines for Management of Patients with Chronic Heart Failure in Australia* (http://www.heartfoundation.com.au/prof/index_fr.html)
17. *Optimising Cancer Management*, NSW Health, Sydney, 1999.
18. *Evidence Based Review of the Australian Six Step Asthma Management Plan*, National Asthma Campaign, NSW Health, Sydney, 2000.

Glossary

Glossary of acronyms

Commonly used acronyms	
AHS	Area Health Service
ALOS	Average Length of Stay
CAL	Chronic Airflow Limitation
CCCICG	Chronic and Complex Care Implementation Coordination Group
CDMS	Chronic Disease Management System
CERG	Clinical Expert Reference Group
CF	Cystic Fibrosis
CHF	Congestive Heart Failure
COAD	Chronic Obstructive Airways/Airflow Disease
COPD	Chronic Obstructive Pulmonary Disease
CRD	Chronic Respiratory Disease
CSF	Clinical Service Framework
CVA	Cerebrovascular Accident
CVD	Cardiovascular Disease
ED	Emergency Department
EHR	Electronic Health Record
EPC	Enhanced Primary Care
GAP	Government's Action Plan
GOLD	Global Obstructive Lung Disease
GP	General Practitioner
HIC	Health Insurance Commission
HIE	Health Information Exchange
ICD-10AM	International Classification of Diseases – 10th revision, Australian Modification
ISC	Inpatient Statistics Collection
IT	Information Technology
IV	Intravenous
MBS	Medicare Benefit Schedule
PHCP	Priority Health Care Program
PWD	People With Diabetes
RSI	Relative Stay Index
SIG	Special Interest Group
TLOS	Total Length of Stay
UPI	Unique Patient Identifier

