

ACT Chronic Conditions Strategy — Improving Care and Support

2013 - 2018

Foreword by Katy Gallagher

The ACT Chronic Conditions Strategy 2013 - 18 sets a direction for the care and support of those living with chronic conditions in the ACT over the next 5 years. Although the ACT enjoys good health compared to the rest of Australia, the prevalence of chronic conditions is increasing significantly and currently accounts for nearly 80% of the total burden of disease and injury in the ACT.

In recent years approximately half the potentially preventable hospital presentations in the ACT were due to chronic conditions. Furthermore, people aged 45 years and over are currently more likely to be hospitalised for chronic conditions compared to other health problems. Ongoing improvements in the management of chronic conditions will be able to prevent unnecessary hospital presentations and have significant follow on benefits for the health system as a whole. This can only be achieved through close collaboration between ACT and federal governments, hospital and primary health services as well as non government organisations and the broader community.

I recognise that good health management is of central importance to the wellbeing and quality of life of all residents of the ACT. The ACT Chronic Conditions Strategy - Improving Care and Support sets out a basis for improving the quality of support and management of chronic conditions in the ACT through a person centred approach.

The development of this strategy involved wide consultation with the community and stakeholders including service providers, consumers, carers, advocacy groups and clinicians. I sincerely thank all contributors for the feedback that is such a critical component in the development of policy that accurately reflects the views of the ACT community. I would also like to express my gratitude to the members of the ACT Primary Health and Chronic Disease Steering Committee for their valuable expertise and guidance during the development of the strategy.

I believe the ACT Chronic Conditions Strategy - Improving Care and Support 2013 - 18 will provide excellent direction for the delivery of chronic disease initiatives and services in the ACT.



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Executive Summary

The increasing prevalence of chronic conditions is one of the biggest burdens facing the Australian health system and has significant ramifications for the Australian economy and the lives of those living with one or more chronic conditions.

This Strategy for Improving Care and Support for those Living with Chronic Conditions has been developed in conjunction with those living with chronic conditions and the many health and support services focused on improving their quality of life. The development of this Strategy builds on the successes and outcomes arising from the ACT Chronic Disease Strategy 2008 - 2011 which saw significant achievements in the advancement of health promotion and prevention strategies as well as specialist services for those with chronic conditions including the introduction of home – tele monitoring, telephone coaching, the introduction of a Parkinson’s and Other Movement Disorders Specialist Nurse, and the continuation of the successful courses in chronic disease self management.

This new Strategy has a more focused scope than the previous one, prioritising integrated service provision and support for those living with chronic conditions. It has not taken a disease focus nor has it focused on those areas which have their own specific strategy or service plan such as primary health, mental health, cancer, health promotion and palliative care. It does appreciate the complex, dynamic nature of chronic conditions and highlights that many now live with more than one condition adding complexity to their care and support needs. It also recognises that the responsibility for care and support for those living with chronic conditions is not confined to a few specialist roles and services but rather is one of the mainstays of primary health care, and is the responsibility of all those who work across the health and community sector.

This Strategy promotes a patient centred approach to planning, implementation and evaluation of all aspects of support and care for those living with a chronic condition. It supports system level changes to the way services are delivered.

This Strategy pledges the ACT to the following commitment.

In the ACT we are all working together to ensure our health system is patient and carer centred, evidence informed, and that any person living with a chronic condition:

1. Receives appropriate screening and early detection.
2. Receives the right care, in the right place, at the right time from the right team.
3. Has a plan which supports active participation in their care.
4. Is aware of relevant support options and how to access them.
5. Is provided with the information and support to stay healthy and/or minimise the risk of other conditions.
6. Does not have to repeat their story unnecessarily.

To achieve this is going to take commitment and effort on the part of many. The provision of care and support to those living with chronic conditions occurs through the dynamic interplay of ACT Health services, primary health care services, complementary therapists, support and advocacy groups, other government services, non-government providers, family, friends and carers. To provide appropriate, effective and efficient services requires focus, communication, integration, resources and collaboration.

The key priority action areas identified in the development of this Strategy to promote attainment of the Commitment are to:

- Optimise existing services through enhanced integration.
- Improve access.
- Better support those in the community.
- Improve person centredness.
- Enhance early detection and secondary prevention.
- Enhance governance and system enablers.

All services are encouraged to adopt the Commitment and Priority Action Areas relevant to their services so that together the ACT can provide significantly improved care and support to those living with chronic conditions.

Development of this Strategy

ACT Health's broad policy document "Your health – our priority: Ready for the Future" demonstrates the ACT Government's commitment to further improving the health of people living in the Canberra region. It is a key document that sets the future direction for health services by ensuring that people have access to the right type of health care. Essential to the success of that plan is that health services are provided in partnership with consumers, government agencies, GPs and other private health care providers and non-government organisations. Chronic disease management is highlighted as a priority area for attention.

The ACT Chronic Disease Strategy 2008 - 2011 set the previous direction for chronic disease prevention, detection and management in the ACT. ACT Health wants to build on the successes obtained as a result of the ACT Chronic Disease Strategy 2008 - 2011 including the Chronic Disease Management Unit and other outcomes outlined in Attachment 1 and develop a document that outlines the principles and strategies for improving chronic disease care in the ACT community into the future.

This Strategy was developed following extensive consultation with clinicians, people living with chronic conditions, carers, support and advocacy groups and policy makers. Representative comments from those consultations with consumers, providers and clinicians have been included in this document (Attachment 2).

Scope of this Strategy

Chronic conditions are many and varied as evidenced by those listed in Box 1. Many people with a chronic condition have more than one disease (co-morbidity). There are conditions which affect many (eg cardiovascular disease and diabetes) and many which are less prevalent. Chronic conditions affect people of all ages.

This Strategy aims to be inclusive, but not duplicative in its approach. Consequently this Strategy does not intend to focus on specific diseases but rather on the way all services within the ACT can better respond to meet the needs of people in the ACT and surrounding region living with chronic conditions. It is intended that this Strategy provides guidance and linkages in the development and implementation of disease and/or service specific plans for the ACT including diabetes and other chronic diseases.

This Strategy has a five year time span in recognition that system wide change does not occur quickly and that many of the existing evidence informed activities implemented under the previous Strategy require time for consolidation for their benefits to be realised.

Implementation of the Strategy will be overseen by the ACT Primary Health and Chronic Condition Steering Committee to ensure that implementation occurs, is monitored and adjusted as appropriate over the life of the Strategy.

Exclusions to this Strategy

Primary health care providers have an important role and responsibility for the high quality management and care of those living with chronic conditions. This is addressed in the ACT Primary Health Care Strategy and is not specifically duplicated in this Strategy.

Readers should note that preventive health and health promotion activities for the general population are also not included in this Strategy. These are addressed in Towards a Healthier Australian Capital Territory - A Strategic Framework for the Population Health Division 2010 - 2015.

Likewise readers are referred to the ACT Palliative Care Strategy and Service Plan and specific disease service plans where they exist which address issues related to specific disease, end stage disease management and palliative care.

The impact of chronic conditions on mental health is recognised as important. Mental Health conditions can also be chronic conditions. Mental health services for the ACT are addressed in the Mental Health Service Plan 2009 - 2014, and therefore are outside the scope of the strategy. Likewise, while cancer can be a chronic condition, cancer services are addressed in the draft ACT Cancer Services Plan and therefore will not be specifically addressed in this document. However, there will be much within this Strategy that will be relevant for these groups. As this is a Strategy, specific guidelines on the treatment and care of specific disorders is not included.

How to use this Strategy

Whilst implementation of this Strategy will be overseen by a dedicated committee who will develop a specific work plan which will drive specific initiatives, improvements to care and services for those living with a chronic condition is going to require the contribution from all across the service sector. All Services and business units must consider integrating the Commitment Goals and Key Action Areas outlined in this Strategy with any planned enhancements to current activities that can be articulated and incorporated into relevant strategies and plans.

The Chronic Condition Context

The ACT population is ageing. This shift, along with an increase in life expectancy and changes to lifestyle, will result in an increase in the number of people living with one or more chronic conditions.

A condition is defined as chronic if it has been, or is likely to be, present for at least six months. Examples of chronic conditions include asthma, cancer, cardiovascular disease, diabetes mellitus, musculoskeletal conditions and stroke.¹ An indicative list of chronic conditions is included in Box 1.

Arthritis	Glaucoma
Asthma	Heart failure
Autoimmune disorders	Hepatitis
Blood disorders	HIV / AIDS
Cancer	Hypertension
Chronic Fatigue Syndrome	Macular degeneration
Chronic Respiratory Disease / Lung Conditions	Mental illnesses
Chronic Pain	Muscular Dystrophy
Chronic pancreatitis	Multiple Sclerosis
Coronary heart disease	Oral disease
Crohn's Disease	Osteoporosis
Cystic Fibrosis	Parkinson's Disease
Diabetes	Peripheral vascular disease
Endometriosis	Chronic kidney failure (at all stages)
Epilepsy	Severe Obesity
Gastro-intestinal disorders	Sleep disorders
	Stroke

Please note this is not an exhaustive list, but rather examples to demonstrate the range of chronic conditions.

Box 1: Indicative list of chronic conditions

Chronic conditions can be characterised as:²

- Having complex and multiple causes.
- Frequently having a gradual onset and at times a protracted diagnostic phase, although they can have a sudden onset and be preceded by acute illness.
- Occurring across all ages, although they become more prevalent with older age.
- Impacting quality of life variously through physical limitations, pain, disability and psychosocial consequences.
- Usually long term and persistent, and may lead to a gradual deterioration of health.
- While usually not immediately life threatening, they are the most common and leading cause of premature death.

¹ Australian Government. Department of Health and Ageing Fact Sheet: *Chronic Disease Management Medicare Items*. August 2011

² Adapted from: National Health Priority Action Council. *National Chronic Disease Strategy*. Canberra: Australian Government Department of Health and Ageing, 2006.

In the ACT chronic conditions:³

- account for approximately 80% of the total burden of disease and injury in both the ACT and Australia. The three leading contributors to the total burden of disease and injury in the ACT were cancers (19%), mental disorders (15%), and cardiovascular disease (15%).
- were the most likely cause of hospitalisation of people over the age of 45 in 2008 - 09. Persons 45 years and over were most likely to be hospitalised as a result of chronic obstructive pulmonary disease (COPD); osteoporosis and osteoarthritis; cardiovascular disease; lung and colorectal cancer; chronic kidney disease and diabetes. Those under 45 years were more likely to be hospitalised as a result of asthma (0-14 years), oral disease (15-24 years) and depression (25-44 years).
- contributed to the underlying cause of death for ACT residents (31% cardiovascular disease, 7% respiratory disease, 5% degenerative disorders and 4% diabetes) with over 80% of deaths in the ACT attributable to chronic disease.

Many chronic conditions are preventable, particularly through lifestyle modification. Despite this approximately a third (34%) of all ACT resident deaths in 2007 and half of the total potentially preventable hospitalisations were theoretically avoidable indicating that there are further significant opportunities for improvement⁴. People from vulnerable population groups are more likely to experience chronic conditions because of many factors including lower socio-economic status, social isolation, high rates of tobacco and alcohol usage, physical inactivity and poor nutrition. In Australia, population groups particularly vulnerable to chronic conditions include Aboriginal and Torres Strait Islander people, people with disabilities, people with mental health issues, migrants and refugees, people held in the criminal justice system, long-term unemployed, young people from low socioeconomic or disadvantaged backgrounds and homeless people. Chronic disease contributes to two-thirds of the health gap between Aboriginal and Torres Strait Islander peoples and other Australians. Fifty eight per cent of excess deaths are due to chronic diseases (ie circulatory disease as well as cancer, diabetes, respiratory disease and kidney disease). For kidney disease the mortality gap has widened in recent years because the rate of increase in deaths is faster for Aboriginal and Torres Strait Islander Australians. There has been no improvement in deaths due to diabetes and the incidence of end stage renal disease has more than tripled over the last decade.⁵

People with chronic disease were also found to be less likely to be employed full-time, and more likely to be unemployed, than those without chronic disease.⁶ Chronic conditions are often associated with disability, which for some can be significant such as severely restricted mobility.

Most of the care and support for people with chronic conditions occurs outside acute health facilities. Carers are those people who provide unpaid care for family members or friends who need assistance to live in the community because of a disability or a chronic condition. Families and carers of people living

³ ACT Health. 2012 *Australian Capital Territory Chief Health Officer's Report 2012*.

⁴ *ibid*

⁵ Australian Health Ministers' Advisory Council, 2011, *Aboriginal and Torres Strait Islander Health Performance Framework Report 2010*, AHMAC,

⁶ <http://www.aihw.gov.au/chronic-diseases/> accessed 22/02/2012

with chronic disease are more likely to develop a chronic disease themselves.⁷ Carers need support in their own right because providing care can involve significant daily physical, emotional and mental demands that place them at increased risk of chronic conditions, particularly anxiety and depression.

The reasons for the increasing prevalence of these conditions are complex. Care must be taken to ensure individuals do not feel blamed for their condition. The idea that a condition is potentially preventable can contribute significantly to the stigma felt by people with such conditions. This can perpetuate their disadvantage and result in accessing services late, if at all.

ACT Health is responding to the increasing rate of chronic conditions in the community and the resultant burden on the health system, by focusing on health promotion initiatives that support a preventive health agenda. The agenda focuses on initiatives that will tackle those risk factors that contribute to poor health such as; smoking, physical inactivity, poor nutrition, alcohol and other drug use. Health promotion strategies which promote collaboration with partners and address the social determinants of health to enable people to make healthy choices along with early detection and treatment of chronic conditions are key to improving the health of the ACT population. The 'Towards a Healthier Australian Capital Territory - A Strategic Framework for the Population Health Division 2010 - 2015' outlines the ACT's approach in this regard. In addition the ACT Primary Health Care Strategy has as one of its six guiding principles a focus on disease prevention and promotion of a holistic understanding of health as wellbeing rather than the absence of disease. As a consequence, while the importance of preventive health and health promotion strategies in the management of chronic conditions is acknowledged, they are not the focus of this Strategy document.

Readers are encouraged to review the Chief Health Officer's Reports for details of other actions being implemented across government agencies to also improve the social determinants of health status.

The ACT is fortunate to have a dynamic support and advocacy sector for people living with chronic conditions. There are a number of groups who have a wider remit than just chronic conditions but who provide necessary support and advocacy services such as the Health Care Consumers Association, Council of the Ageing, Carers ACT and others which are condition specific such as the Heart Foundation, Asthma Foundation, Pain Support ACT, the Epilepsy Association, the AIDS Action Council, Parkinsons ACT, Diabetes ACT and Kidney Support Group. The support and contribution of these groups is vital to the integrated nature of services for those living with chronic conditions.

The extent to which people with chronic conditions need active care and management depends on many factors and varies across time and may even vary for each condition at different times. Whilst the condition may be always present, most people living with chronic conditions only consider themselves 'sick' when their condition flares. It is important then to consider the management of chronic conditions as a dynamic state as people move up and down the Chronic Condition Management Triangle (Figure 1) over time. This Triangle depicts the three levels of care that the health system must have the capacity to provide which corresponds to these different levels of disease complexity.

⁷ Government of South Australia. Department of Health. 2007. The health and wellbeing of adult carers in South Australia – an epidemiological study 1994 – 2004.

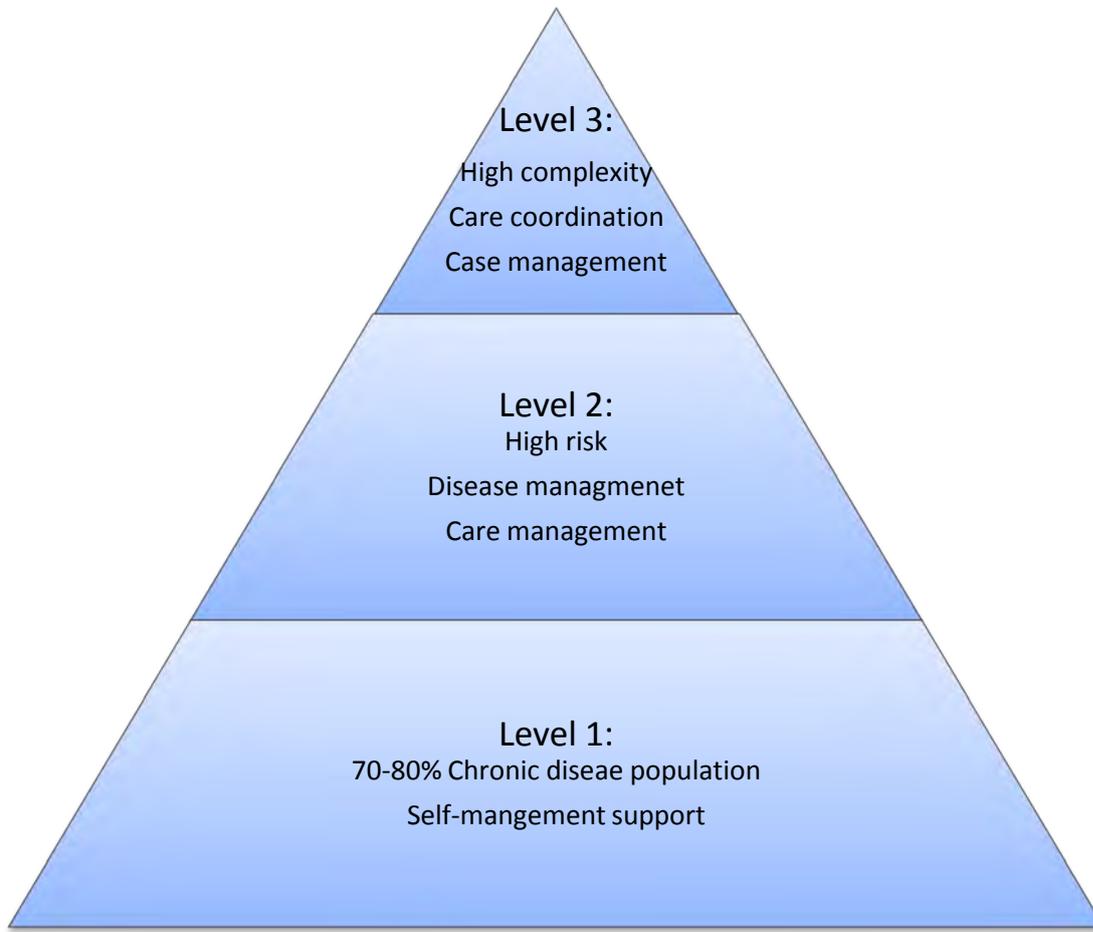


Figure 1: Chronic Conditions Management Triangle⁸

Good management of chronic conditions includes:

- improved early detection and intervention.
 - limiting the numbers of people progressing up the pyramid through integrated support and evidence based care.
 - recognising that people will regularly move from one level to another in both directions
 - limiting the impact of the condition on quality of life.
- provision of timely information about the condition, and appropriate services and support.

⁸ National Health Priority Action Council. 2006. National Chronic Disease Strategy. Department of Health and Ageing, Canberra.

Linkages with Other ACT Plans and Strategies

The ACT Strategy for Improved Care and Support of those living with Chronic Conditions 2013 - 2018 is influenced by, and contains linkages with, a number of other planning and strategy documents in the ACT. Figure 2 sets out the ACT Planning Framework within which this Strategy has been developed. However, it is important to note that many other strategic plans and policy documents from other ACT Government services, peak bodies, community groups, non-government and private organisations have been developed which identify priorities and strategies for improved care and support of people with chronic conditions. Some of these plans include:

- Chief Minister and Cabinet:
 - *The Canberra Plan: Towards our Second Century* builds on the original Canberra Plan and prepares for the city's future. It has a strong focus on health, education, municipal services, climate change, water security, housing affordability and skills shortages.
 - *Building Our Community — the Canberra Social Plan* identifies the changes in Canberra's social environment and the determinants of disadvantage and exclusion. It highlights the opportunities and challenges ahead, and the means of achieving sustained improvement in access, equity and participation for the people of the ACT.
- Community Services:
 - *They've gotta listen – Aboriginal & Torres Strait Islander Young People in Out of Home Care.*
 - *Finding their way home: Children's experiences of homelessness.*
 - *ACT Children's Plan 2010 - 2014.*
 - *Young People's Plan 2009 - 2014.*
 - *ACT Strategic Plan for Positive Ageing 2010 - 2014.*
 - *Australian Early Development Index (AEDI).*
- Territory and Municipal Services:
 - *Accessible Public Transport in the ACT Action Plan 2009 - 2012.*
- Environment and Sustainable Development: *Sustainable Future Program.*
- Non Government Organisations and peak bodies strategic plans relevant to the ACT eg Council of the Ageing, Carers ACT, Health Care Consumers Association of the ACT, Diabetes ACT, Heart Foundation, Pharmacy Guild of Australia's Roadmap, Self Help Organisations United Together (SHOUT), Mental Health Community Coalition of the ACT and Carers ACT.

The Strategy acknowledges that the challenge is to develop linkages with these strategies and plans to provide an inclusive and comprehensive, patient-centred approach to improved care and support for those with chronic conditions.

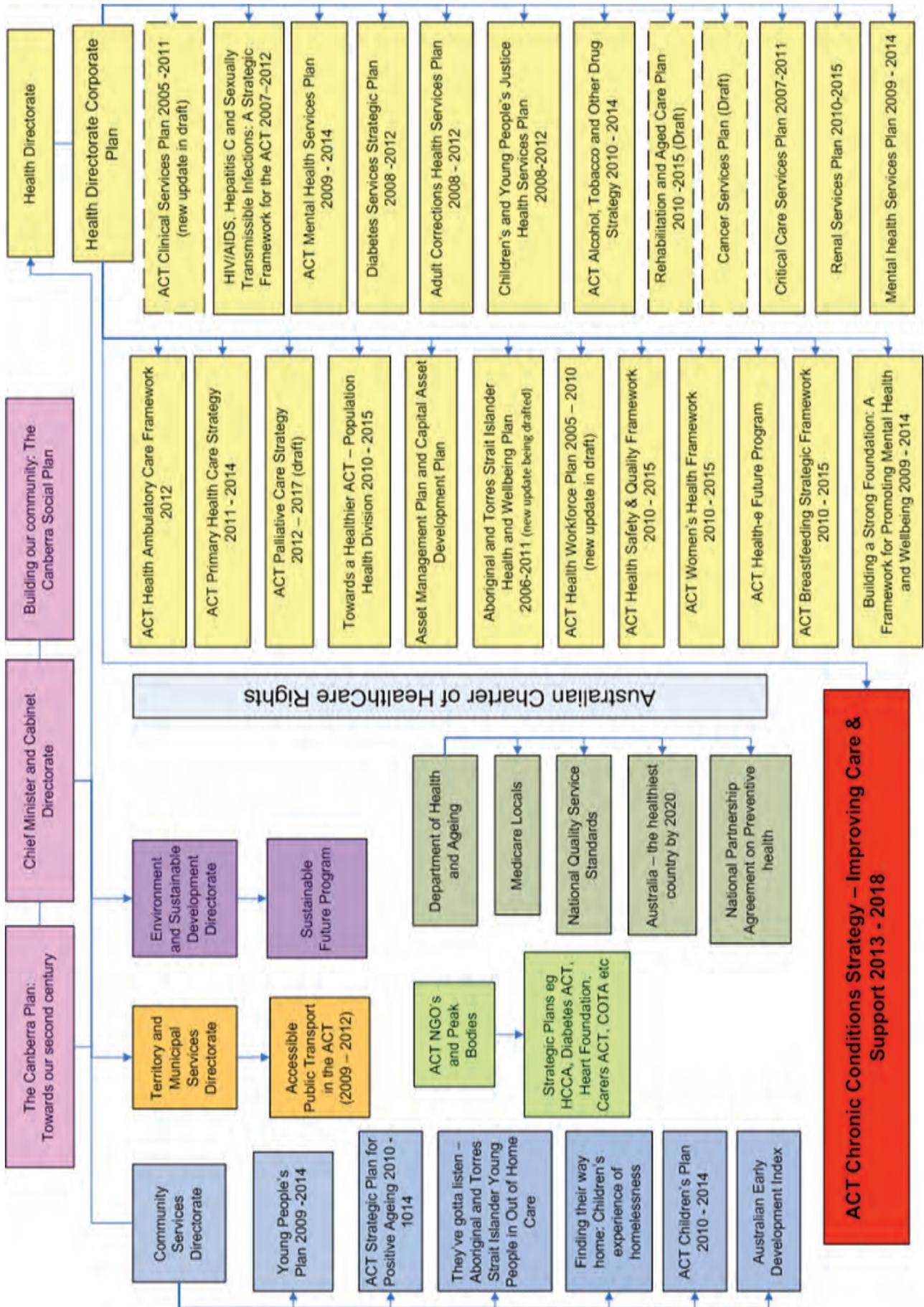


Figure 2: ACT Planning Framework

ACT Health Role

ACT Health has a leadership role in the development of ACT strategic and planning documents for the provision of health care related services in the ACT. In doing so, it is acknowledged that such documents will extend to cover people beyond the geographic boundaries of the ACT and beyond the direct “control” of ACT Health. As part of this leadership role, ACT Health develops such documents in cooperation and collaboration with a wide range of individuals, communities, community-based non-government organisations, service providers in the public and private sector as well as NSW Health and the Australian Government Department of Health and Ageing.

More specifically, this leadership role is exercised by ensuring that this Strategy meets the needs of people living with chronic conditions and their carers and is undertaken within a framework of services and in partnership with people with chronic conditions, their carers, support networks and service providers.

Commitment

For many people with a chronic condition, living with their condition is a part of their life, for the rest of their life. The health system must be responsive to the needs of these people in such a way that empowers them to live their lives to their fullest potential and with a focus on living well. As such, this Strategy is based on the following commitment.

In the ACT we are all working together to ensure our health system is patient and carer centred, evidence informed, and that any person living with a chronic condition:

1. Receives appropriate screening and early detection.
2. Receives the right care, in the right place, at the right time from the right team.
3. Has a plan which supports active participation in their care.
4. Is aware of relevant support options and how to access them.
5. Is provided with the information and support to stay healthy and/or minimise the risk of other conditions.
6. Does not have to repeat their story unnecessarily.

Box 2: ACT Commitment

This Commitment is applicable to all people with chronic conditions regardless of age, severity, stage of condition or their treating team. This Strategy outlines key priorities to contribute to attainment of this Commitment.

Each of the goals contained in the Commitment is further explained as follows.

GOAL 1: EVERY PERSON AT RISK OF A CHRONIC CONDITION RECEIVES APPROPRIATE SCREENING AND EARLY DETECTION

In many cases early detection can delay the development or progression of chronic conditions and their complications and can improve a person's quality of life and their ability to self-manage, thus potentially avoiding unnecessary hospital admissions thereby reducing the cost of complex care and reducing premature death. Early detection can even halt or reverse the development of chronic conditions for some people. Supporting people to modify their lifestyle and reduce their health risks is a key strategy to prevent or slow the progression of chronic conditions. The high prevalence of co-morbidities in people with chronic conditions makes it important to also screen these people for other likely conditions.

Effective early detection involves:⁹

- Evidence informed screening strategies for specific population groups including tailored strategies for particular 'at risk' groups such as the Aboriginal and Torres Strait Islander population and people who inject drugs.
- A broad range of activities including:
 - risk factor screening - eg overweight, lack of physical activity, poor nutrition.
 - screening for disease markers for eg High blood pressure, high cholesterol, raised blood sugars, sexually transmissible infections.
 - screening for mental health conditions including depression and anxiety.
 - recognition that not all chronic conditions are obvious for example chronic kidney disease where it is possible to lose up to 90% of kidney function before experiencing any symptoms.
 - detection of complications of chronic conditions.
- Significant involvement of primary and community health providers (general practice, pharmacists, fitness professionals, community health workers) in undertaking:
 - screening.
 - arranging further investigations as required.
 - appropriate treatment with medications.
 - self-management and psychosocial support.
 - referral to lifestyle interventions eg smoking cessation, exercise programs.
 - appropriate specialist referral.
- Appropriate linkages and referral pathways between primary/community health providers and supportive community and hospital based services.
- Ensuring screening is accessible, opportunistic and affordable.

⁹ Adapted from the NSW Department of Health. 2006. NSW Chronic Care Program Phase Three: 2006 - 2009, NSW Chronic Disease Strategy.

GOAL 2: EVERY PERSON WITH A CHRONIC CONDITION RECEIVES THE RIGHT CARE, IN THE RIGHT PLACE, AT THE RIGHT TIME FROM THE RIGHT TEAM

People living with chronic conditions need appropriate support and clinical care to reduce the progression of their condition, its symptoms and complications, to maximise their quality of life and to reduce unnecessary hospital admissions and acute care. The focus of the management of chronic conditions should be on providing appropriate care at the appropriate time and in the appropriate setting provided by an appropriate team of health professionals and community based supports. This will often mean the right care is provided in the home or community based settings. The right care is often not hospital or specialist care, but spans community and primary health care settings.

Team based care is critical to providing comprehensive support. The composition of the 'team' will be varied according to the needs of the person, their condition/s, their social circumstances and current health status. Team members can be drawn from many services. The central team member is the person with the chronic condition, and where appropriate their carer or significant other as shown in Figure 3.

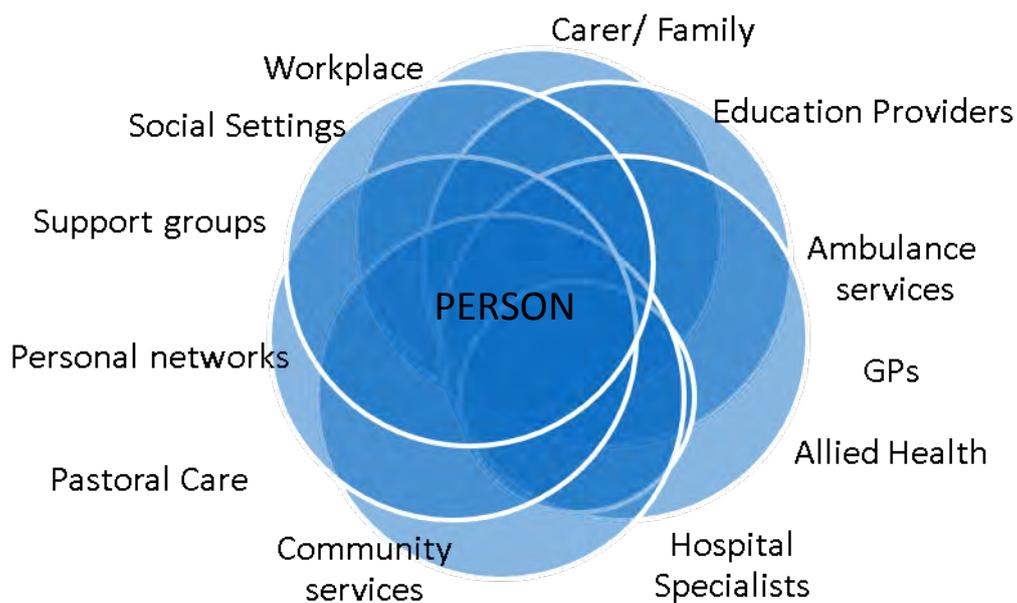


Figure 3: The Potential Chronic Care Team

GOAL 3: EVERY PERSON WITH A CHRONIC CONDITION HAS A PLAN WHICH SUPPORTS ACTIVE PARTICIPATION IN THEIR CARE

The presence of a current plan is central to achieving optimal, coordinated, comprehensive chronic care and support. Each person with a chronic condition should have a plan. For some, the plan may be an informal understanding between themselves and their primary care giver regarding their goals, monitoring their condition and knowing how to best manage their symptoms. For others it will be a comprehensive document with contributions from all in their care and support team. In many cases this will be a care plan developed and monitored by the person's GP who will coordinate access to services and ensure a holistic view is taken. For others it will be a plan that has been developed and coordinated by a health professional with expertise in chronic conditions.

The extent to which an individual will participate in their own care will be determined by their ability, the extent and complexity of their health needs, availability of services, and many other individualised factors. The extent to which each person can contribute to both their own care and planning of that care in large part will be determined by their level of health literacy. It is important for all those working with people living with chronic conditions to foster greater health literacy and optimise each person's involvement in their care planning and care. Having a plan enables:

- A comprehensive, integrated approach which acknowledges all conditions and health issues and does not give undue focus to a single disease process.
- The identification of short and long term goals, acknowledging the chronic nature of the person's condition/s.
- Identification of each team member's role and responsibility including the primary care giver, primary clinician, care coordinator and clinicians and services most likely to assist and in which situations.
- A planned approach to nutrition, physical activity, symptom management and a reduction in exposure to triggers.
- Clear pathways to follow if the condition flares or deteriorates.
- An effective communication tool between all care providers and support services.
- Acknowledgement of the individual's capacity to access treatment and services based on affordability, access and support and document strategies to address shortfalls.
- Details of specific psychosocial support options to address for financial, employment, education, housing, and other social, economical and environmental issues.
- Current and accurate advice regarding medications, including over the counter and complementary therapies.

There is strong evidence to support a model of empowered self management of, or active participation in, chronic conditions. It firmly places the person at the centre of their care and care decisions. Active participation does not occur in isolation, but rather forms an integral part of the broader care planning and management process. Having a plan can help empower, define the extent of, and legitimise the role of the person's own contribution to their ongoing care and recognises their expertise in their condition and care requirements.

GOAL 4: EVERY PERSON WITH A CHRONIC CONDITION IS AWARE OF RELEVANT SUPPORT OPTIONS AND HOW TO ACCESS THEM

Coping with the impact of a chronic condition can be hard and often relentless. It is often not only clinical care that is required to help people better adjust to their lives with a condition. Tapping into others who have the same condition or have an in-depth knowledge of the success factors, tips and 'tricks' of managing a chronic condition and an understanding of how to get the most out of life and the supports available can be very beneficial.

There are many services available to support people with chronic conditions in the ACT. These include allied health providers, support groups, advocacy groups, complementary therapists, suppliers of equipment and aids, education providers, community and social groups, transport providers, financial advisors and counsellors.

It can be complex and confusing to navigate the options that are available and appropriate. Plans developed with the person living with a chronic condition should detail the support options that are appropriate and how best to access them.

GOAL 5: EVERY PERSON WITH A CHRONIC CONDITION IS PROVIDED THE NECESSARY INFORMATION AND SUPPORT TO STAY HEALTHY AND/OR MINIMISE THE RISK OF OTHER CONDITIONS

Many chronic conditions result from risk factors that are amenable to change. Health promotion and risk reduction should not stop when a person is diagnosed with a chronic condition. Ways to stay healthy will vary according to the individual's situation. Understanding and responding to this can have a significant impact on limiting the progression of certain diseases and improving the quality of life.

There are a range of physical activity and nutrition programs available that specifically address the needs of people with or at risk of certain chronic conditions. Evidence based complementary therapies that promote wellbeing, stress management and relaxation can also play an important role.

Addressing factors such as income, employment, education, health literacy and social inclusion are critical in promoting health and reducing risk, and require collaborative and concerted whole-of-government and whole-of-community action. The ACT Government is actively involved in a number of initiatives aimed at addressing the social determinants of health, equity, partnerships, action across the continuum, cultural change, supportive settings and community participation.

There are a range of factors that are known to reduce the risk of deterioration and potential hospitalisation for many with chronic conditions where the person can take an active role if they are provided the necessary information and support to do so. These include for example:

- Management of medications in collaboration with medical practitioners and pharmacists.
- Personal hygiene, particularly in regards to preventing transmission of viruses.
- Immunisation programs as recommended.
- Good nutrition and physical activity.

GOAL 6: EVERY PERSON WITH A CHRONIC CONDITION DOES NOT HAVE TO REPEAT THEIR STORY UNNECESSARILY

A person centred system is one where communication is strong and seamless. People with chronic conditions don't want to have to always repeat their medical history, medications, and other details and are often not in the best place to accurately remember their medical history as they can often be rightly focused on their current symptoms and issues.

Advances in eHealth including secure electronic messaging, electronic medical records (eMR) within the health system and the national Person Controlled Electronic Health Record (PCEHR) provide promising mechanisms to assist with timely, accurate transfer of information between services and providers at the direction of the patient.

The patient story though is also a very powerful tool. Stories can assist in identifying weaknesses in services and processes. They can also be very useful in educating health professionals. The telling and hearing of patient stories can also be a strong validating process for individuals.

Key Priorities

This Strategy focuses on the way services work, and more particularly, how they work together to support people living with a chronic condition in the ACT. In recognition of this complexity, a matrix approach to action is required.

The following key priorities have been identified to match the Pyramid Of Chronic Conditions (Figure 1), Our Commitment and known service gaps. Each priority is accompanied by a list of suggested action areas. These are intended as a guide only and the implementation of specific actions to meet each action area will be determined by relevant services and by the Improved Care for Persons with Chronic Conditions Steering Committee which will have broad representation and will develop a specific work plan.

Key Priority Action Areas for Improving Care and Services for People with Chronic Conditions:

1. Optimise existing services through enhanced integration.
2. Improve access.
3. Better support those in the community.
4. Improve person centredness.
5. Enhance early detection and secondary prevention.
6. Enhance governance and system enablers.

Box 3: Key Priority Action Areas for Improving Care and Services for People with Chronic Conditions

The following table shows the interdependent nature of both the commitment goals and the key priorities.

Commitment Goals

	Receives appropriate screening and early detection	Receives the best care, in the best place at the best time from the right team	Is provided with the information and support to stay healthy and/or minimise the risk of other conditions	Has a plan which supports active participation in care	Is aware of relevant support options and how to access them	Does not have to repeat their story unnecessarily
Key Priorities						
Optimise existing services through enhanced integration		✓		✓	✓	✓
Improve Access	✓	✓		✓	✓	
Better support those in the community		✓	✓	✓	✓	
Improve Patient Centredness	✓	✓	✓	✓	✓	✓
Early Detection and Illness Prevention	✓	✓	✓	✓	✓	
Enhance governance and system enablers	✓	✓	✓	✓	✓	✓

Figure 4: Matrix of Goals and Key Priorities

PRIORITY 1: OPTIMISE EXISTING SERVICES THROUGH ENHANCED INTEGRATION

There are a range of excellent services and programs addressing the needs of people with chronic conditions in existence in the ACT. Over the last five years in particular there has been a growth in focused services addressing the particular needs of some chronic conditions. Throughout the consultation period in developing this Strategy it became apparent that improved awareness of, communication between, and integration of these services and recognition and respect for various roles and responsibilities is a priority if they are to better meet the needs of people with chronic conditions.

Integrated care is the provision of person centred care in which health services work with each other and with the person (and/or their carer) with a chronic condition to ensure coordination, consistency and continuity of care over time and through the different stages of the person's condition.¹⁰

Given the often complex nature of the needs of people with chronic conditions their need for integrated care is perhaps the greatest. At present many services have grown historically to best meet the needs of the service, and the need to be efficient. Services should however be designed and targeted so that clients receive the right care at the right time and in the right setting. This requires them to still be efficient, but also responsive to the needs of individual patients. This type of service delivery requires a partnership approach, greater communication and collaboration and a preparedness to refer appropriately across all service providers and sectors. There also needs to be a greater focus on the needs of each patient as often those living with one or more chronic conditions have needs that don't neatly fit into program or service eligibility criteria. It is particularly important in these instances that services and providers address the identified needs rather than leave a person not receiving adequate care.

In progressing this priority there also needs to be a stronger recognition of the value of informal communication networks through both consumers and clinician's social and professional networks. Using these networks to influence behaviour will be an effective change strategy.

Standard 6 of the new National Safety and Quality Health Service Standards program is focussed on clinical handover with a focus on the inclusion of patients and carers and the handover or transition of patients within and between various services. Increased focus in this area will provide welcome improvements for those living with chronic conditions.

1. Optimise existing services through enhanced integration. Areas of action could include:
 - 1.1. Development of integrated pathways of care across all relevant services with referral and discharge criteria and timely processes, where possible based on care needs rather than age or diagnosis.
 - 1.2. Promote cross-specialist care coordination through the better use of care plans and tele-health for case conferences.

¹⁰ Department of Human Services. Primary Health Branch. 2008. *Revised Chronic Disease Management Program Guidelines for Primary Care Partnerships and Primary Health Care Services.*

- 1.3. Build on the Chronic Disease Registers to optimise coordinated, proactive care and extend the capture to a greater range of conditions.
- 1.4. Develop specific transition guidelines and management plans for those moving from paediatric to adolescent services, and those moving from adolescent to adult services to ensure appropriate continuation of support and care.
- 1.5. Build on the concept of Shared Care Guidelines to enhance integration between GPs and specialist chronic care teams / specialists for specific chronic conditions.
- 1.6. Use existing social and professional networks to improve the sharing of information.
- 1.7. Enhancement of support for GPs through for example:
 - 1.7.1. Supported access to community health services.
 - 1.7.2. Improved phone access to specialist support for GPs.
 - 1.7.3. Joint presentation at Grand Rounds between GPs and specialists.
- 1.8. Continued promotion of Advance Care Plans and uptake in their use in care decisions.
- 1.9. Assist the development of integrated models of service provision across non-government providers, complementary therapists, support groups and advocacy groups to achieve better economies of scale.

PRIORITY 2: IMPROVE ACCESS

People with chronic conditions often require access to multiple service providers (eg. Nurses, allied health professionals, Aboriginal Health Workers, GPs, medical specialists, community supports) across multiple settings (hospital, emergency department, community health, clinics and home) over periods of time, often decades.

Access to these services in the ACT at present is variable. Depending on the person's location, their condition, their age and other factors including financial status, access to the right services may be relatively rapid. However there is room for improvement in access to outpatient, outreach and community based services and the need to reduce waiting times for particular clinics and services.

There is also evidence to suggest that financial constraints can have a significant impact on people accessing appropriate services, support, medications and aid.¹¹ Particular strategies are therefore required to address access issues associated with cost. Targeted actions are also required to improve access for those from disadvantaged groups such as Aboriginal and Torres Strait Islanders, refugees and those without transport.

¹¹ Bayliss et al, 2003. 'Descriptions of Barriers to Self-Care by Persons with Comorbid Chronic Diseases' in *Annals of Family Medicine*, 1(1): 15-21 and anecdotal information provided through the consultation process

2. Improve Access. Areas of action could include:
 - 2.1. Recognition by all services that chronic conditions are often associated with some degree of disability and options for access to services must address flexibility and ease of access for clients.
 - 2.2. Continued development and enhancement of the on-line directories to improve access to timely, accurate and relevant information about services, eligibility criteria, referral processes and cost.
 - 2.3. Continued opportunistic and targeted enhancement of health literacy across the community through for example community forums, expos, newsletters.
 - 2.4. Further options for ambulatory care and outpatient clinics in community based settings, as detailed in the Ambulatory Care Framework 2012. This is timely given the development of the new enhanced community health centres which can be designed to improve models of care for people with chronic conditions.
 - 2.5. Engagement in the planning for the new sub-acute hospital to promote integrated service provision for those with chronic conditions.
 - 2.6. Expanded use of telehealth in the home for people with chronic conditions for example home monitoring, coaching, video consultation appointments and home medication management for a range of conditions including chronic pain
 - 2.7. Continued enhancement of services to vulnerable groups:
 - 2.7.1. Expanded outreach services through Winnunga Nimmityjah Aboriginal Health Service
 - 2.7.2. An expanded role for Companion House to include ongoing care coordination for migrants and refugees with complex needs
 - 2.7.3. Improve access to and uptake of interpreter services
 - 2.7.4. Integrated chronic care programs with other service providers such as:
 - Aged care
 - Disability services
 - Transport / housing
 - Education
 - Ambulance
 - Carers
 - CALD support workers
 - Alcohol and other drug services.
 - 2.7.5. Outreach workers and case management models for people with complex needs and those accessing services from various government agencies, particularly those not eligible for paediatric or aged care support.
 - 2.8. Enhancements to equipment and aid services.

PRIORITY 3: BETTER SUPPORT THOSE IN THE COMMUNITY

Focusing on supporting those living with chronic conditions in the community is a shift from the reactive, often hospital based and episodic system. This revised focus requires stronger partnerships and enhanced communication with the person themselves, primary health care providers, community based services and specialist services. The evolution of the roles of chronic care coordinator and case manager for those with complex needs have arisen based on the evidence of success of such coordination and partnership approach.

Supporting people with a chronic condition and their carers to live well in the community further enhances an active participation approach. Providing better, more timely access to support and services may prevent deterioration in the person's condition, reduce exacerbation of symptoms and may decrease the need for the more expensive acute hospital services. Building self efficacy and resilience is important in long term wellbeing. It will also contribute to reducing carer burden and fatigue.

For self-management and active participation in care to become better integrated into the health and human service system, it is important that there is support for health professionals, people living with chronic conditions and for their families and carers. Health professionals need to be supported to provide care in partnership with people living with chronic conditions, rather than the traditional care giving role for which many were trained. Enhanced supports that enable people to implement their chronic condition plans are also required.

3. Better support those in the community. Action areas to could include:
 - 3.1. Expanding self management and active participation support.
 - 3.2. Target self management courses for special groups eg. Young people, adolescents, new parents.
 - 3.3. Provide self management clinics to offer follow up support and encouragement to graduates of self management courses.
 - 3.4. Consider expanded use of on-line and social media technologies to support those in the community.
 - 3.5. Provide refresher courses to update information and provide ongoing encouragement.
 - 3.6. Enhance specific training options for carers of those with chronic conditions.
 - 3.7. Work with the National Health Call Centre Network to ensure:
 - 3.7.1. Appropriate use and uptake of telehealth services such as the After hours GP Helpline
 - 3.7.2. Support for those with known conditions at home who need advice on changes in their condition, coaching, self management and medication advice.
 - 3.8. Incorporate self management principles and support into all health care practices, as appropriate.
 - 3.9. Explore relevant opportunities to integrate care of chronic conditions into the National Disability Insurance Scheme pilot.
 - 3.10. Respite – Identify and pilot cost effective models of respite for chronic conditions particularly for those whose age makes them ineligible for existing programs eg children, teenagers and those under 65.

PRIORITY 4: IMPROVE PERSON CENTREDNESS

Person or patient centredness is a broad concept that covers many strategies and approaches, many of which are covered in other actions mentioned in this document. The evidence is still emerging but what has been studied to date shows a strong positive correlation between person centredness, quality and safety, patient and carers perceptions of care and organisational effectiveness.¹²

Achieving a person centred approach requires not only placing the person at the centre of all care and care decisions but also involving their carers, significant others and the broader community. Further, research demonstrates that achieving person centred care also requires a focus on the staff delivering that care – ensuring that they feel cared for, are appropriately educated, and that they are fully supported in providing person centred care.¹³

Person centredness can also foster a greater focus on personal strengths, capacity and function. This will assist in limiting the person being viewed only through a chronic condition label.

4. Improve person centredness. Action areas to could include:
 - 4.1. The use of patient journeys and process mapping of high volume chronic conditions and for those with multiple chronic conditions to identify improvements to patient satisfaction and organisational effectiveness, particularly in the acute setting.
 - 4.2. Patient centred chronic condition management plans which incorporate the medical, psychological and social aspects for the person with the chronic condition.
 - 4.3. Engagement of persons living with chronic conditions on clinical governance and clinical network committees.
 - 4.4. The use of patient stories:
 - 4.4.1. At governance committees to give voice to system issues.
 - 4.4.2. For education of all health professionals – undergraduate and continuing education.
 - 4.5. Encourage consumers and service providers to be actively involved in the progression of the eMR, PCEHR and secure messaging to ensure they meet the needs of people with chronic conditions.
 - 4.6. Implement processes and education (including health coaching) to support staff to make patient centred decisions.

¹² Australian Commission on Safety and Quality in Health Care. 2011. Patient-centred care: Improving quality and safety through partnerships with patients and consumers.

¹³ *ibid*

PRIORITY 5: ENHANCE EARLY DETECTION AND ILLNESS PREVENTION

The earlier a condition is detected the earlier management to limit its progression and impact can begin. Illness prevention refers to improving function and includes minimisation of the impact of established conditions, prevention of complications and the development of some conditions.¹⁴ There are some known co-morbidities that are prevalent in certain chronic conditions and these should be particularly screened for. Examples include kidney disease and diabetes, depression and many chronic conditions, obesity and sleep disorders, chronic pain and many chronic conditions. Equally there are known population groups at risk for high prevalence of chronic conditions including Aboriginal and Torres Strait Islanders and carers where opportunistic screening should occur.

5. Enhance early detection and illness prevention. Action areas in collaboration with the implementation of the ACT Primary Health Care Strategy could include:
 - 5.1. Development of a culture of evidence based opportunistic screening and risk identification across all services, particularly those working with high risk and vulnerable groups.
 - 5.2. Collaboration with local and national public awareness campaigns through local targeted activities to promote awareness for example through national days/weeks
 - 5.3. Integration with the Healthier Work Service to:
 - 5.3.1. Improve health of ACT Health staff to be better role models and deliver consistent messages.
 - 5.3.2. Provide supportive workplaces for people with chronic conditions and their carers.
 - 5.3.3. Explore opportunities for screening programs.
 - 5.4. Work to enhance the uptake of the Get Healthy Information and Coaching Service[®] including for those with known conditions.
 - 5.5. Encouragement of the inclusion of physical activity and nutrition requirements in chronic condition management plans, including referral to specific programs, recognising specific limitations and focus areas.
 - 5.6. Further partnerships and collaborations with community pharmacists, the Medicare Local, GPs and practice staff and community sector organisations to enhance opportunities for lifestyle and risk factor modification, screening and early detection.
 - 5.7. Development of guidelines for familial risk identification and genetic counselling for appropriate conditions.

¹⁴ Australian Health Minister's Conference. *National Chronic Disease Strategy*. Canberra: Australian Government, 2006.

PRIORITY 6: ENHANCE GOVERNANCE AND SYSTEM ENABLERS

The health system is a complex, dynamic collection of services, providers and individuals. Providing the right care, at the right time, in the right place by the right team requires careful attention to system design, workforce and the policies and processes under which they work. This Strategy on its own will achieve little. It needs to be accompanied by the focused intent to improve, the allocation or re-allocation of resources and the engagement and commitment of management to become a reality.

6. Enhance governance and strengthen system enablers. Action areas to that will provide better support and care for those with chronic conditions could include:
 - 6.1. Establishment of a discrete Chronic Care Steering Committee¹⁵ which would oversee the implementation of the Strategy and Evaluation Framework, develop a specific work plan,¹⁶ facilitate improved integration between sectors and facilitate appropriate resourcing for enhanced chronic care.
 - 6.2. The expansion of interprofessional learning opportunities including:
 - 6.2.1. Patients as teachers / professionals.
 - 6.2.2. Integrated Grand Rounds.
 - 6.2.3. Health coaching.
 - 6.3. Continued support for integrated research and academic opportunities.
 - 6.4. Exploration of opportunities to pilot new workforce models, particularly with respect to care coordination and system navigation.
 - 6.5. Facilitation of better community and primary health care incident reporting to identify weaknesses in systems and processes.
 - 6.6. Identification of opportunities to build on the introduction of the new National Safety and Quality Health Service Standards¹⁷ to improve care for people with chronic conditions.
 - 6.7. Improved data analysis capacity to be able to better monitor and evaluate services, processes and outcomes.
 - 6.8. The opportunistic piloting / adoption of alternative models of funding to enhance integrated service models rather than episodic care.
 - 6.9. Fostering genuine commitment to collaboration and cross referral in a climate of mutual professional respect.
 - 6.10. Implementation/ enhancement of cross-directorate processes to remove barriers to improved care for those living with chronic conditions including access to housing, supported accommodation, employment opportunities, financial support and transport.

¹⁵ Membership to include the following representatives: General practitioner, carer, Aboriginal and Torres Strait Islander, Aboriginal and Torres Strait Islander Service provider, person with a chronic condition, consumer advocate

¹⁶ In the development of such a work plan the feedback received during the consultation should be further reviewed to assist in setting priorities

¹⁷ Australian Commission on Safety and Quality in Health Care. 2011. *National Safety and Quality Service Standards*.

Conclusion

This Strategy builds on the great work already being undertaken in the ACT to address the often complex needs of those living with chronic conditions. The Strategy supports a comprehensive approach to achieve the Commitment to people living with chronic conditions, which while ambitious and aspirational is harmonising and galvanising. The success of this Strategy will rely heavily on all parts of the service sector improving the way they work together to provide integrated, comprehensive and seamless services and support to those living with chronic conditions and their carers.

Attachment 1: Achievements under the ACT Chronic Disease Strategy

The ACT Chronic Disease Strategy 2008-2011 (the Strategy) was developed following extensive consultation over 2007 - 2008. The Strategy is aligned with the National Chronic Disease Strategy, which was agreed by the Australian Government and all state and territory governments in November 2005. Implementation of the Strategy was overseen by the ACT Primary Health and Chronic Disease Strategy Committee (the Committee). The Strategy has made considerable progress in ensuring chronic disease prevention, detection and management is coordinated, collaborative and interprofessional, and addresses the needs of specific groups. Specific achievements over the lifetime of the Strategy are as follows:

- ACT Health undertook a range of initiatives aimed at increasing the number of infants being exclusively breastfed from birth to six months, and encouraging ongoing breastfeeding with complementary foods until at least 12 months of age in line with National Health and Medical Research Council recommendations.
- The *Get Healthy Information and Coaching Service* was implemented from 1 July 2010. *Get Healthy* is a free and confidential telephone based service that provides information and ongoing coaching support to ACT adults who would like to eat healthier, be more active, or achieve and maintain a healthy weight.
- The *Aboriginal and Torres Strait Islander Tobacco Control Strategy* was finalised, and an Advisory Group established to guide its implementation. Smoking cessation programs are being delivered by Winnunga Nimmityjah Aboriginal Health Service and Gugan Gulwan Youth Aboriginal Corporation through three year service funding agreements from 2010 - 2013. The Strategy will be evaluated by the University of Canberra.
- Health Promotion Branch began implementation of the ACT Government's three year \$11 million *Healthy Future: Preventive Health Program* (from 2009/10 - 2011/12). This program is aligned with the National Partnership Agreement for Preventive Health and consists of a range of health promotion campaigns under the *Healthy Kids, Healthy Future* program (early childhood and school settings) and the *Healthy at Work* program (workplace settings).
- ACT Health continued to deliver the *Self-Management of Chronic Conditions* program, which aims to enhance the capacity of individuals to self manage their chronic disease. "Living a Healthy Life with Long-Term Conditions" courses are conducted in partnership with Arthritis ACT and SHOUT Inc.
- A *Home Tele-monitoring Service* was established by the Chronic Disease Management Unit to provide remote monitoring of patients where daily monitoring at home can assist with stabilisation of their condition. Eligible patients include those with chronic heart failure, chronic obstructive pulmonary disease (COPD) or diabetes.

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- The *Improving Care for People with Chronic Conditions (Chronic Care) Program* was expanded over the life of the Strategy. This program provides care coordination for people with chronic obstructive pulmonary disease, diabetes and heart failure.
 - The Chronic Disease Management Unit established a register of people who have chronic health conditions. The *Register*, tracks the care coordination and preventative health care of patients with chronic heart failure, chronic obstructive pulmonary disease and diabetes as well as the patients of a number of chronic disease care units.
 - The *Chronic Disease Telephone Coaching Service* was implemented. This service aims to assist people with less complex chronic diseases by providing them with regular contact for health and lifestyle advice and support. People enrolled in the program receive regular phone calls from a registered nurse to discuss their condition and work towards achieving their personal health goals. The service is operated by Medibank Health Solutions with funding provided by ACT Health.
 - The Committee received updates and collaborated where necessary on a number of initiatives relating to chronic disease being progressed by other ACT Government Directorates, including the Sustainable Futures Program (Environment and Sustainable Development); the ACT Affordable Housing Action Plan (Chief Minister and Cabinet); and the Australian Early Development Index (Community Services/Education and Training).
 - Policy and Government Relations worked on two shared care arrangements projects – a Standard Operating Procedure for the development of shared care arrangements with General Practice; and Haematology Shared Care Guidelines.
 - ACT Health worked in partnership with the Australian Government to implement the national *Measure Up* social marketing campaign. ACT residents aged from 45 to 49 years were sent *Measure Up* resources along with an invitation to visit their GP for the 45 to 49-year-old MBS health check if they have risk factors. The mail out has been supplemented by advertisements in TV, radio, print media and a range of other modalities including bus shelters and shopping trolleys.
 - ACT Health's Interprofessional Learning Program (IPL) offered a variety of teaching and learning opportunities in IPL for health professionals, educators and support staff. Three IPL research projects ran concurrently in the ACT:
 - An action research project to strengthen inter-professional learning and practice across the ACT health system (originally Australian Research Council linkage grant funded, 2006 - 10).
 - Interprofessional learning in primary health care to encourage active patient self-management of chronic disease (Commonwealth funding, 2009 - 10).

Evaluating the impact of the patient-as-professional within a network to self-manage chronic disease (Commonwealth funding 2009 - 11).

Attachment 2: Comments received during the consultation phases

Throughout the initial consultation for this Strategy we were privileged to hear many stories. Some of the comments received from consumers, clients, carers and providers are repeated here.

Conditions don't shut down – why are services only provided 9 – 5.

I had to wait 6 months to see a specialist here after being diagnosed with my condition in Sydney.

I was admitted to hospital for six weeks so that I didn't have to pay for a course of medications.

The Epilepsy Association is very good at going into workplaces to help them understand their co-workers who have epilepsy.

I had to admit a client to a nursing home because I couldn't get any service to administer her insulin at home.

You are not looking at this from the perspective of the people who are sick. Information needs to be tailored to consumer understanding. Doctors are not listening.

Parents often fear their child's 18th birthday knowing that they are no longer eligible for paediatric services and that there are no like services for young adults.

We have no outpatient service for some conditions and then we have to keep people in hospital until they are fully stabilised. This could happen in their home if we had the right service.

When you're not well, trying to navigate poorly designed transport systems is almost impossible. You then can't get to appointments or access aids. You can be seen as being 'non-compliant'.

My clients often won't get their recommended medications because they can't afford them. The health care card only covers prescription medications – so they won't buy the more expensive over the counter medications which can really help manage their symptoms.

If you don't have anyone looking after you, it makes it hard to abide by the rules. You also can't plan for anything when the services are so secretive and you don't know what time surgery or discharge will be.

Specialists are great but they so often have such a narrow focus of just one disease. I have seven. I would love all my specialists to get together in one room and discuss my plan.

My oxygen machine broke on a Friday night – the only person I could get on to who could help was in Sydney and said that the part should get to me by Tuesday.

We need boundary breakers.

We must not forget that many patients like to tell their story. This is different from telling you about their treatment regime.

We need a re-emergence of the general medical specialist to be able to manage chronic conditions and their com-morbidities.

Raising awareness about chronic conditions is a challenge – they are not very ‘sexy’.

We need a Paediatric Care and Assessment Team – a PCAT like the ACAT model.

People are often given a disease label and thrown into the mix to find their own way.

We need to retrain health professionals to help them become involved in decision making, providing options and choices for people, and not just communicate and impose a decision already made.

Glossary

Advanced Care Plans (ACP)	ACP is a process of reflection, discussion and communication that enables a person to plan for their future medical treatment and other care, for a time when they are not competent to make, or communicate, decisions for themselves. ACP is about person-centred care and is based on fundamental principles of self-determination, dignity and the avoidance of suffering. ¹⁸ In the ACT Respecting Patient Choices is a program implementing ACP.
Allied Health	Health professional who work alongside doctors and nurses in the delivery of health care. A variety of professions are listed as allied health professions by various government authorities and departments, health service providers, health funds and tertiary institutions. ¹⁹
CALD	Culturally and Linguistically Diverse
Condition	Used in this document to refer to diseases and those conditions for which there may not be a specific diagnoses or where there are multiple diagnoses. People living with chronic conditions have identified a strong desire to be viewed as more than just a single diagnoses and are more comfortable with the term condition than disease. This document has used condition where appropriate. The term disease is still used when referring to specific diseases, referenced material or in the historical context.
COPD	Chronic Obstructive Pulmonary Disease
Disease	An abnormal condition usually defined by a specific diagnoses.
Grand Rounds	A teaching tool used predominantly by the medical profession to present cases and new treatments.
Pastoral Care	Pastoral care is a person-centred, holistic approach to care that complements the care offered by other helping disciplines while paying particular attention to spiritual care. The focus of pastoral care is upon the healing, guiding, supporting, reconciling, nurturing, liberating, and empowering of people in whatever situation they find themselves. ²⁰
National Health Call Centre Network	NHCCN through its contracted services provides nationwide access 24 hours a day, seven days a week to healthcare triage, health advice and health information. Its trading name is <i>healthdirect</i> . ²¹
Shared Care Guidelines	A set of guiding principles based upon best practice which aims to optimise patient care for certain conditions that were once mainly managed by hospital based specialists and are now best managed in a shared arrangement between a medical specialist and a GP.
Get Healthy Information and Coaching Service®	The Get Healthy Information and Coaching Service® is a government funded telephone service available to NSW and ACT residents aimed at providing information and ongoing support for adults in relation to healthy eating, physical activity, and achieving and maintaining a healthy weight. Ph. 1300 806 258 ²²

¹⁸ Australian Health Ministers' Advisory Council (AHMAC). A National Framework for Advance Care Directives. Consultation Companion Guide for the Draft Framework. Draft ed. Canberra: AHMAC; 2010

¹⁹ Allied Health Professional Australia. <http://www.ahpa.com.au/Home/AboutAlliedHealth.aspx>

²⁰ The Pastoral Care Council of the ACT

²¹ <http://www.healthdirect.org.au/>

²² www.gethealthynsw.com.au

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