

MEETING THE NEEDS
OF PEOPLE
WITH CHRONIC CONDITIONS

Hāpai te whānau mo ake ake tonu

National Health
Committee

Hunga Kaititiro i te Hauora o te Tangata

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Front cover: *Chronic conditions ebb and flow throughout the lives of those who suffer from them. The cover represents walking forward within these tidal rhythms as well as portraying the sea as a place of healing. The inspiration for the theme was a person from the NHC case studies speaking about the importance of dealing with life and healing as a whole: 'The nurse came around to talk to me about my legs. All I wanted to do was stick my feet in the sea. She helped me get to the beach for the first time in nine months. After that I was happy to listen to her suggestions about my diabetes.'*

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The National Advisory Committee on Health and Disability is an independent committee appointed by, and reporting directly to, the New Zealand Minister of Health.

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Preface

Meeting the needs of people with chronic conditions is a challenge to government agencies, health providers and community groups. It is also an opportunity to continue to build effective relationships within the health sector and across sectors to address the wider determinants of health inequalities with renewed urgency.

The National Health Committee (NHC) believes that good health care is a product of the thousands of dedicated people throughout the health workforce who provide professional, heartfelt care. As a nation, New Zealand is well suited to realising that long-term health care is achieved through partnerships at every level, since it acknowledges the importance of the special relationship between Māori and the Crown established by the Treaty of Waitangi. The changes sought for effective chronic care management rest on the commitment of people to move into the new way of working in partnership with other organisations, communities, people with chronic conditions and their families/whānau.

This report sets out a comprehensive and coherent focus on meeting the needs of people with chronic conditions in New Zealand. The NHC hopes this report will provide impetus to the sector to effectively plan and implement its response to chronic conditions. The recommendations aim to help people with chronic conditions to manage their health and wellbeing in the community, to have confidence in the medical advice they receive and in the health system itself, and to access quality, well-coordinated health care.

Implementing the NHC's recommendations will require commitment from all health workers – from Primary Health Organisations (PHOs) for the NHC's proposed care and coordination model, to public health, non-government organisations (NGOs) and community providers for community and cross-sector engagement. It will also mean that District Health Boards (DHBs) and organisations in the sector will need to work to achieve integrated and aligned structures within the health system – particularly between community and specialist care, among health disciplines, and across services used by people with chronic conditions.

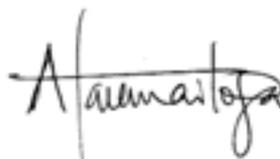
Tackling the burden of chronic conditions in New Zealand is not an issue for the health system alone. It requires a whole-of-government approach with a commitment from the health sector to work closely together as well as intersectorally with agencies such as the Ministry of Social Development and Housing New Zealand. This reinforces the close link of health with socioeconomic status.

The NHC is confident that with leadership from within government, Ministry of Health, DHBs, PHOs, NGOs and other health providers, all New Zealanders with chronic conditions can have better access to services that meet their needs. Only then can we make a step toward reducing one of the greatest sources of health inequalities in our country.

The NHC acknowledges the considerable amount of good work being done in various parts of the country for people with chronic conditions and would like to thank all those who contributed to meetings, focus groups and case studies, and who made submissions. The committee hopes the voices of the people with chronic conditions will be heard above all else as we aim to better meet their needs.



Linda Holloway
(Chair)



Api Talemaitoga
(Lead Sponsor)

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Executive Summary

'Challenge of the century'

The World Health Organization has called chronic conditions 'the health care challenge of this century'. Worldwide urgency to address chronic conditions is driven by the rapid rise in incidence and also by the associated social and financial costs for the health sector and society.

The rise in incidence can be attributed to an increase in lifestyle risk factors, the ageing population, and socioeconomic determinants of health. A majority of chronic conditions are preventable or could be better managed.

The US Institute of Medicine argued that a 'fundamental, sweeping redesign of the entire health system' is required. The organisation and delivery of health services has traditionally developed within a cure-focused model concerned with turning acute episodes into survivable events.

In response to the growing recognition of chronic conditions as a priority for strategic action, new models of care are being developed, trialled and evaluated in many countries around the world.

What are the challenges for New Zealand?

All New Zealanders are affected by chronic conditions – whether as carers for family and whānau, taxpayers, health professionals or managing their own chronic condition.

Mismanagement of chronic conditions is the leading cause of hospitalisations, accounts for 80 percent of all preventable deaths and is estimated to consume a major proportion of our health care funds. Chronic conditions are also a barrier to independence, participation in the workforce and in society – social and economic costs we are yet to calculate as a nation.

Chronic conditions account for a higher proportion of illness and deaths among Māori, people on low incomes and Pacific peoples than among the general population. The need to reduce health inequalities remains urgent. For example, by 2011, the prevalence of diabetes is predicted to increase by 148 percent among Pacific peoples and 132 percent among Māori.

Work to prevent and manage chronic conditions should ensure outcomes for groups at greatest disadvantage improve earliest and most significantly. If this approach is not taken, health inequalities are likely to grow.

The National Health Committee report

This report sets out the need for a comprehensive and focused approach to addressing the needs of people with chronic conditions in New Zealand. It is the culmination of a project carried out by the National Health Committee (NHC), involving case studies, review of international literature, a broad call for submissions and conversations with many people within and outside the health sector to answer the question: How should we meet the needs of people with chronic conditions?

The NHC consulted with a wide range of health providers and health professionals, people with chronic conditions and their families and whānau. A discussion document developed and distributed by the NHC drew thoughtful submissions from 100 people – providers, people with chronic conditions, academics and health professionals.

What are people with chronic conditions saying?

People with chronic conditions use a broad range of services repeatedly, and often frequently, throughout their lives. Living with the effects of a chronic condition gives people and their families, whānau and carers expert knowledge of their needs. Listening to them raises important questions for the health sector and beyond.

The case studies summarised in this report show that people want more time with their doctors and better explanations about their conditions. They reported unsettling failures in communication with their health providers and emphasised the need for involvement of family/whānau in their health care. They emphasised the importance of having someone to assist them with accessing and coordinating services. People with chronic conditions consistently reported difficulties with the costs of health care and associated costs for their life and that of their family and whānau. They wanted their life and culture to be recognised and asked for links between mental and physical health to be acknowledged.

A chronic care approach in New Zealand

Meeting the ongoing needs of people with chronic conditions and providing quality acute care calls for proactive primary care, as well as greater coordination of care across hospital and community-based services. It creates new demands for services that appear seamless to those using them.

The NHC sees great promise in much of the work already under way to address chronic conditions. National strategies affirm a number of features widely recognised as valuable for providing services for people with chronic conditions. The *Primary Health Care Strategy* Implementation Work Programme is undertaking directions that form a solid basis for chronic care models. District Health Boards (DHBs) have identified chronic conditions as a strategic priority. DHBs, Primary Health Organisations (PHOs), non-government organisations (NGOs) and community members throughout the country are engaging in innovative projects to respond to the needs of people with chronic conditions. These ideas and energy contribute to the momentum of system-wide change.

What needs to happen?

There are two major foci of chronic care models. The first is proactive support for people in a community setting, which emphasises the central role of primary health care. The second looks for a redesign of the health system to deliver a continuum of care across hospital and community-based services. Both areas of change are required to successfully address issues for people with chronic conditions.

The NHC seeks a way forward that is comprehensive in its approach to addressing chronic conditions. It looks to build on, and consistently implement, work under way and achieve an integrated health sector.

What is the NHC recommending?

The recommendations contained in this report fall into two broad areas: Part A addresses policy direction and outlines a comprehensive framework of areas for change, based on actions for equity. It includes planning for community collaboration. Part B focuses on service provision, presenting areas for health sector integration or alignment, as well as outlining a care and coordination model for people with chronic conditions within and across PHOs. This includes outcomes sought for information systems and workforce development to support change.

Develop District Health Board-based chronic conditions frameworks

The NHC is recommending that each DHB develop and implement a chronic conditions framework that focuses action, integrates service provision and is population specific.

The framework outlines a full range of interventions, reflecting planning for whole systems change. A generic system of chronic care management is recommended, that includes clinical pathways and programmes for people diagnosed with specific chronic diseases. The framework aims to balance the development of local responses as well as achieve areas of national consistency. The key requirements sought are based on chronic care models and best practice evidence.

Reduce health inequalities

Reducing inequalities is already a national priority. Leadership and commitment is required to remove barriers to achieving equalities of health at organisational and individual levels. The NHC believes these inequalities are resolvable and is asking that DHBs demonstrate how their approach to chronic conditions will reduce health inequalities within existing processes for accountability to the Ministry of Health.

The NHC believes that every health professional and organisation has a duty and responsibility to address racism and equity of access to health services. To support this, the NHC recommends the use of equity tools and monitoring processes by DHBs and PHOs to ensure equitable access to and through the system by populations with the highest demonstrated need.

The NHC recommends the Ministry of Health and DHBs work together to design accessible and culturally appropriate services in collaboration with high-need populations. In addition, the NHC recommends the Ministry of Health resource the development of tools capable of evaluating the separate elements of culturally appropriate services.

Plan community engagement

The NHC seeks for community engagement to take place in a planned and sustainable way. Community-based and whole-of-government collaborations can create a healthy living environment, directly affect the wider determinants of health and improve services for people with chronic conditions. There is a need to encourage cross-sectoral collaboration by identifying shared concepts and goals, sharing information on a regular basis and clarifying roles and responsibilities, including resourcing and funding. The NHC endorses this being undertaken as part of planning processes that encompass the whole district.

Integrate structures and services

The NHC is recommending the Ministry of Health work with DHBs to bring about comprehensive alignments within health and social sectors, between health providers and services and across health disciplines. It acknowledges that actions in this area will require extensive planning and implementation. However, there are considerable benefits to people with chronic conditions and some benefits to health providers in achieving integrated health systems.

Develop information and knowledge systems

Integration and alignment of services rests on data, information and knowledge. It is critical to have consistent data collection, effective communication systems, and sound processes to build knowledge. The NHC looks for outcomes congruent with chronic care models and outlines specific areas of interest.

Provide a central contact person in each District Health Board

The NHC recommends that each DHB nominate a key contact person within their current workforce structure to address problems for people with chronic conditions accessing coordinated care. It asks that this person be supported to bring to the attention of the DHB problems arising from lack of aligned or integrated services for the DHB to address.

Provide effective chronic care management and coordination

The NHC wishes to strengthen the following areas in PHOs that are evidenced to be beneficial to people with chronic conditions:

- proactive primary care: population health approaches to prevention, monitoring, and intervention
- self-management: information, skills and referrals to support the person and their family/whānau to manage their condition
- coordinated care for complex conditions: comprehensive assessment, detailed care planning, intensive support and management, and coordination of services.

To deliver these elements consistently and with accountability, the NHC is recommending that a care and coordination model is implemented. It asks that this proposed model is supported by national guidelines, and a nationally-consistent assessment and referral processes.

The need for consistent assessment and treatment of depression and pain, as well as improvements in referrals to rehabilitation and palliative care, are highlighted.

Provide a chronic care coordinator at the primary health organisation level

The NHC seeks the provision of effective coordinated care for people with chronic conditions experiencing short-term acute health/life crises or ongoing complexity of health conditions and life circumstances. It is recommending these people be allocated a care coordinator. This is strongly supported by international chronic care models as part of achieving quality care and patient safety.

Undertake workforce development

Broad workforce development recommendations include the increase of Māori and Pacific peoples in the health care workforce, as well further education and training for all health professionals. Specific recommendations include the need for resourcing and developing capability in self-management, pain management and cognitive-behavioural therapy.



Meeting the needs of people with **Chronic Conditions**

SECTION ONE



Ko koe ki tēnā,
Ko āhau ki tēnei
Kīwai o te kete

You hold that handle
And I'll lift this handle
And together we can carry the kete



1. The NHC project on chronic conditions

In 2002 the National Health Committee (NHC) met with providers in South Auckland who presented on the Counties Manukau Chronic Care Management Programme. This visit alerted the NHC to the high incidence of chronic conditions and links between this and issues of health inequalities and access for Māori and Pacific peoples. The Counties Manukau programme offered one approach to addressing the incidence and impact of chronic conditions.

The NHC made a commitment to investigate the significance of chronic conditions in New Zealand and determine what changes needed to occur to better address the needs of people with chronic conditions.

The recommendations in this report arose from research and submissions, and were grounded in the experiences of people with chronic conditions.

1.1 Project outline

The NHC project includes several strands of work, culminating in this report to the Minister; these were:

- initial meetings with a wide range of providers, non-government organisations (NGOs), government agencies, and focus groups with people with chronic conditions
- drafting and distribution of the NHC's document *People with chronic conditions: a discussion paper (2005)*, followed by receipt of submissions on the discussion paper from people with chronic conditions, academics, health professionals, and health providers
- case studies on four specific groups with chronic conditions
- meetings with Māori organisations/networks
- meetings with Pacific peoples' organisations/networks
- further consultations on aspects of the draft report.

1.1.1 Purpose of report and report audience

This document is a report to the Minister about the NHC's research on people's experiences of living with chronic conditions in New Zealand. Its purpose is to set out the need for a stronger focus on people with chronic conditions in New Zealand.

It is expected to be of relevance to the Minister of Health, Ministry of Health, District Health Boards (DHBs), Primary Health Organisations (PHOs) and NGOs. It is also likely to be of interest to advocates of people living with chronic conditions and their families/whānau.

The report:

- provides a rationale for change to meet the needs of people with chronic conditions
- presents evidence from models, systems and research that demonstrate changes required to address chronic conditions
- indicates areas of policy beneficial to addressing chronic conditions
- illustrates key concepts for providing chronic care by outlining some examples of initiatives and referring to evidence
- makes strategic recommendations based on project evidence.

Although this report focuses on people with existing chronic conditions, addressing chronic conditions requires consideration of a continuum of prevention and management. Prevention is fundamental to reducing chronic conditions and the NHC wishes to acknowledge the considerable work that has been, and is being, undertaken in the area.

1.1.2 Defining chronic conditions within the project

The NHC defines a chronic condition as any ongoing, long-term or recurring condition that can have a significant impact on people's lives¹.

This broad and inclusive definition is consistent with definitions used in other countries and by the World Health Organization.

1.2 The significance of the case studies

The case studies gave voice to people living with chronic conditions in New Zealand. Their experiences raised important systemic issues for health and other sectors, in particular the impact of culture on every aspect of service provision.

Key issues identified across case studies were confirmed by international and New Zealand evidence in a number of areas. Every area of the chronic care models put forward in Chapter three had relevance to the experience of people with chronic conditions participating in the case studies. However, the models could not show the barriers participants encountered when accessing services. This is corroborated by research on health inequalities and inequities put forward in Chapter two.

There was considerable international evidence for the need to change health systems to address chronic conditions, such as the importance of good primary health care, and the need for coordination of care and integrated systems. Within the broad areas presented in Chapter three, the experiences of people in case studies agreed with specific needs, such as involvement of family/whānau, better discharge planning or good relationships and communication with health professionals.

The experiences of pain and depression recounted by case study participants were echoed in research presented in Chapter three that explores the links between chronic conditions and depression, and chronic conditions and pain.

Submissions to the NHC added another perspective that built on case studies. Submissions endorsed a range of components of chronic care models (such as person-centred care, self-management and population health approaches), and provided insights into structural changes that would benefit people with chronic conditions. Providers argued for whole-of-government approaches, listed barriers to coordination and continuity of care, and named outcomes expected from information systems and workforce planning. These views were explored in consultations about what more could happen to meet the needs of people with chronic conditions, as presented in Chapter four.

The recommendations in this report arose from research and submissions, and were grounded in the experiences of people with chronic conditions.

-
- ▶ *The next chapter of this report describes the challenge of chronic conditions in terms of significance, increased incidence, economic and social costs, and as a driver for health inequalities.*

¹ Disabilities are not included in this definition. However, the NHC wishes to highlight that many people with a disability have one or more chronic conditions and they are sometimes causally linked.

2. The challenge of chronic conditions

This chapter considers the significance of chronic conditions and underlying reasons for their increasing incidence. It presents the relationship between chronic conditions and health inequalities and provides evidence on health inequalities for Māori, Pacific peoples and people with poor socioeconomic circumstances.

2.1 The significance of chronic conditions

Chronic conditions are ‘the health care challenge of this century’. The World Health Organization estimates that globally, 60 percent of all deaths are due to chronic conditions. In all but the least developed countries, the less well off are much more likely than the wealthy to develop, and die from, chronic conditions (WHO 2005). Over the next 10 years the number of deaths attributable to chronic diseases is projected to rise by 17 percent (WHO 2005).

Worldwide, there is growing urgency to address chronic conditions as a result of their increase in prevalence and the associated major financial and social costs for the health sector and society. For instance, in the US, the medical costs of people with chronic diseases are estimated to account for more than 75 percent of the country’s health care costs (Centers for Disease Control and Prevention 2006).

The cost to a country of chronic conditions includes direct costs (subsidising providers, pharmaceuticals, providing income support), underlying costs (capital and equipment), and indirect costs (reduced employment or social productivity). Costs borne by the person with the chronic condition and their family/whānau can include direct costs (visits to general practitioners and other health professionals/specialists, medication, aids, modifications, services such as home help, development of physical or mental co-morbidities) and indirect costs (including a loss or reduction in income, lowered participation in work and society, and the physical and emotional toll on family/whānau and other carers).

International studies show chronic conditions are the leading cause of unequal health outcomes amongst social groups (Benzeval et al 1995; Power et al 1996). In New Zealand it has been demonstrated that chronic conditions contribute the major share of inequalities in life expectancy for Māori, people with low incomes and Pacific peoples (Ajwani et al 2003).

2.1.1 Prevalence of chronic conditions in New Zealand

Chronic conditions are the leading cause of illness in New Zealand, and account for more than 80 percent of deaths. They are the leading cause of preventable morbidity, mortality and unequal health outcomes (Ministry of Health 1999).

The most common chronic conditions in New Zealand (by diagnosis) are:

- chronic neck or back problems (one in four adults)
- mental illness (one in five adults)
- asthma (one in five adults aged 15-44 yrs)
- arthritis (one in six adults)
- heart disease (one in 10 adults).

It has been estimated in the UK that 45 percent of people with chronic conditions have more than one condition (Department of Health 2004). For example, diabetes can lead to complications that are also chronic – such as kidney failure, myocardial infarction, stroke and blindness. Multiple chronic conditions are referred to as co-morbidities.

The NHC believes reducing the incidence and impact of chronic conditions among these populations is a significant way to reduce health inequalities. Responding to chronic conditions is also essential for the public health system to maintain its viability. People with chronic conditions are generating high medical costs and are vulnerable to a range of adverse outcomes.

2.1.2 Explanations for increased incidence

Current growth in the number of people living with chronic conditions is affected by:

- increase in lifestyle risk factors – in particular low levels of physical activity, poor nutrition, and tobacco use
- ageing of the general population
- social and economic determinants of health.

Increase in lifestyle risk factors

There has been a rise in lifestyle risk factors for chronic conditions internationally and in New Zealand. Lifestyle choices are made within the social, cultural and economic contexts in which people live, work, and play. Many of the modifiable factors affecting whether people develop chronic conditions and how effectively they are managed lie outside the health sector, for example in housing, income, transport, local government, education and social services (National Health Committee 1998). The social context can be influenced by the implementation of healthy public policy, such as urban design that encourages physical activity as part of everyday life, and regulation of unhealthy products such as tobacco, and foods with high fat and sugar content. Addressing these issues requires a cross-sector and whole-of-government approach, which is endorsed by the NHC. However, this report is focused primarily on ways for making changes within the means of the health sector.

Ageing population

Older people comprise a significant proportion of people with chronic conditions. Between 2002 and 2021, the proportion of the population in New Zealand aged 65 and over will increase from 11.9 percent to about 17.6 percent. By 2051 this group will comprise 25.4 percent of the total population (Ministry of Health 2004b). There are increasing levels of co-morbidity and complexity of chronic illness associated with ageing. While older people make up a large proportion of those with chronic conditions, Māori and Pacific peoples² have a disproportionately higher prevalence of chronic conditions, as well as earlier morbidity and mortality from chronic conditions (Ajwani et al 2003).

2.1.3 Costs of chronic conditions

There are major financial and social costs associated with the rising incidence of chronic conditions (WHO 2003). These costs have implications for individuals with a chronic condition, family/whānau, carers, the health sector and society as a whole. Medical care for people with chronic conditions uses a giant proportion of health resources. People with chronic conditions are significantly more likely than the general population to see their general practitioner (GP) and be admitted as inpatients, and use more inpatient days. The more chronic conditions a person has, the greater the number of avoidable hospitalisations they are likely to experience. *[For examples of international and national costs of chronic diseases, refer to Appendix 1.]*

The economic impact of chronic conditions extends well beyond direct medical expenses (WHO 2002). Chronic conditions affect mainly the productive age groups, and may contribute the largest detrimental effect to an economy of any group of disease. For instance WHO has estimated cumulative losses to Canada and the UK from 2005 to 2015 owing to labour lost from deaths due to heart disease, stroke and diabetes to be \$8.5 billion and \$32.8 billion respectively³ (WHO 2006). Labour lost due to illness as a result of chronic conditions adds even more to these figures. Recent evidence shows that chronic diseases have significantly detracted from economic growth in high-income countries (Suhrcke et al 2006).

The World Health Organization has consistently emphasised the economic imperative of preventing chronic conditions.

The cost to the world of the current and projected epidemic of chronic disease related to diet and physical inactivity dwarfs all other health costs. (World Health Organization 2003)

2 Pacific peoples are a diverse group of people from the Pacific region, including Tongan, Samoan, Fijian, Cook Island, Tokelauan and Niuean peoples who live in New Zealand, who have either migrated or identify with them because of ancestry or heritage.

3 In 1998 international dollars.

2.2 Chronic conditions: a major driver for health inequalities

There is extensive international evidence to show that social position and ethnicity affect people's health. The NHC's 1998 report *The Social, Cultural and Economic Determinants of Health in New Zealand*, the PHAC 2004 report *The Health of People and Communities*, and the *Decades of Disparity* series (2003-2006) from the Ministry of Health and University of Otago confirmed this within New Zealand. Disadvantaged groups tend to have poorer health status, greater exposure to health risks, and lower access to health services. Membership in a minority ethnic group and lower income levels are strongly associated with high rates of mortality and morbidity from chronic conditions.

In New Zealand, chronic conditions disproportionately affect Māori, people living on low incomes, and Pacific peoples. Recent research suggests these populations continue to have poor access to preventative measures, treatment for and management before chronic conditions relative to other populations. Māori are disadvantaged well beyond the disadvantages attributed to their economic status (Ministry of Health and University of Otago 2006). Unequal access to the system contributes to health inequalities between these and the general population, and unequal access through the system contributes to the widening gap in health inequalities as well as evidencing inequitable processes. *[For data on socioeconomic status and ethnicity as drivers for health inequalities, refer to Appendix 2.]*

2.2.1 Poor socioeconomic circumstances

Evidence on socioeconomic mortality trends in New Zealand (Ministry of Health and University of Otago 2006) shows that, compared with the general population, those with low incomes experience higher mortality rates from major chronic illnesses. *[For data on mortality rates for people on low incomes, refer to Appendix 2.]*

Lifestyle behaviours, psychosocial stress and health system performance all have an effect on health. These factors are influenced by socioeconomic status, which in turn has some relationship with ethnicity. The interaction among this interplay of factors is not straightforward. For example, smoking, the most influential modifiable risk behaviour, is more prevalent among those on a lower income. But recent research on contributors to health inequalities found that the contribution smoking makes to ethnic disparities in mortality is probably less than 10 percent. Socioeconomic factors contribute an additional 32 to 39 percent (Blakely et al 2006).

People on low incomes are more likely to develop chronic conditions. Furthermore, since chronic conditions have significant financial impacts that extend beyond direct medical costs, households on low incomes are likely to enter cycles of poverty and ill health. For example, living standards are lower among families with high numbers of doctor visits for child illness; families are restricted in their social and economic participation because of a child's serious health conditions (Ministry of Social Development 2004). There are also cumulative effects on health from psychosocial stressors (Seeman et al 2004).

2.2.2 Racial discrimination and ethnic disparities in health

Poor socioeconomic circumstances are not the only factor in creating health inequalities. Differences in access to and quality of health services contributes to ethnic inequalities in health. Contributions to disparities in health outcomes are made from the earliest stages of access to primary treatment and at the secondary care level in differential treatment and referral patterns. The cumulative effect of even small differences over a lifetime may have substantial effects on health outcomes (Ministry of Health and University of Otago 2006). The US Partnerships for Solutions (2004) found that non-white Americans received a greater amount of conflicting advice and incompatible medication, and had a greater number of test duplications than other Americans.

The impact of racial discrimination on ethnic inequalities in health is part of a larger picture of social structures (institutionalised racism) and individual factors (interpersonal and internalised racism) (Krieger 2000). The complex relationship between experiences of racial discrimination and health in New Zealand has been explored by the Ministry of Health (Harris et al 2006).

2.2.3 Māori

Significant differences in life expectancy exist between Māori and non-Māori. Chronic conditions contribute to this disparity. Although there has been a consistent increase in life expectancy among Māori and non-Māori since the 1950s, an 8.5 year gap in life expectancy remains. In 2002, a newborn Māori boy could expect to live 69 years, compared with 77.2 years for a non-Māori boy. At birth, a Māori girl could expect to live 73.2 years compared with 81.9 years for a non-Māori girl (Statistics New Zealand 2004).

A range of data suggests that differences in health outcomes for Māori arise, in part, from differences in health care received.

- When compared with people of European descent within the same income range, Māori were significantly less likely to have seen a doctor when sick, received recommended tests, or filled a prescription. Cost was a significant contributor (Schoen et al 2004a).
- Māori hospital patients have a higher risk of preventable, adverse effects than non-Māori, non-Pacific patients (Davis et al 2006).
- There is increasing evidence that Māori do not receive comparable health management across a range of chronic conditions. For example, Māori have significant difficulties in receiving expert help for asthma when needed, have more severe and more poorly managed asthma, and higher hospitalisation rates than non-Māori (Ministry of Health 1999).
- Māori are less likely to be referred for surgical and specialist services, and are more likely to receive lower than expected levels of quality hospital care than non-Māori (Ellison-Loschmann and Pearce 2006). For example, in both diabetes (Baxter 2002) and cardiac interventions (Westbrook et al 2001), Māori receive less intervention and treatment. The higher mortality rate for Māori (Robson et al 2006) with diagnosed cancer suggests that either diagnosis has been delayed or referral and treatment processes are inequitable.

Communication as a contributor to health outcomes

There is growing evidence that the quality of communication between Māori and health professionals affects health outcomes for Māori (Penney 2005)⁴. This evidence offers an insight into barriers to accessing health services for Māori.

- Māori feel respected in mainstream health care services when they are able to relate to and make sense of the advice from their doctor (Cram et al 2003; Jansen 2006).
- Poor communication may contribute to Māori, especially women, being less likely to visit a GP than non-Māori, which in turn increases the likelihood they will go to the doctor only when in need of urgent attention (Crengle et al 2005).
- Non-Māori doctors have reported 'lower levels of rapport' with Māori patients (Jansen 2006). This may be a reason for doctors' shorter mean consultation times for Māori (Crengle et al 2005).
- Māori receive significantly less treatment for depression and even lower payments from ACC than non-Māori (Jansen 2006).

Differential access through the health system is cumulative and contributes to earlier and higher mortality rates overall for Māori. *[For further data on Māori health status and health inequalities, refer to Appendix 2.]*

2.2.4 Pacific peoples

Pacific men and women have higher rates of avoidable mortality than the 'all New Zealand' benchmark (Ministry of Health 2004c). Pacific peoples live, on average, about eight years less than the general population. From middle age onward, chronic diseases (including ischemic heart disease, stroke, breast and lung cancer and chronic obstructive pulmonary disease) are the major causes of avoidable mortality (Ministry of Health 2004c).

Compared with the general population, Pacific peoples tend to experience higher rates of chronic conditions and disability in younger age groups (Ajwani et al 2003). Pacific children have higher hospitalisation rates (approximately 50 percent higher) for asthma than the all New Zealand average (Ministry of Health 2004c). Common conditions such as cardiovascular disease, diabetes and stroke are significantly more prevalent among Pacific peoples than among the general population (Ministry of Health 2004a, 2004c) and incidence rates are rising (Hay 2002). *[For further data on mortality and morbidity rates for Pacific peoples, refer to Appendix 2.]*

There is limited data on Pacific peoples (as a whole and by their ethnic groupings) and access to health care. This makes it difficult to make accurate comparisons with other population groups in New Zealand. There is an urgent need for richer population data on Pacific peoples to effectively manage chronic conditions within their populations. As the percentage of Pacific peoples enrolled in PHOs is higher than the national average, PHOs are ideally placed to gather this data.

⁴ This is corroborated by international studies, such as that by Towle et al (2006).

Communication is one clearly identified barrier for people for whom English is a second language. Services that wish to address this barrier for Pacific peoples must take into account their diversity of cultures and languages. Language difficulties may be compounded by cultural norms (such as hesitation in asking for help) and lead to difficulties in access through the health system (Huaku and Bray 2000).

2.3 Conclusion

In New Zealand, inequalities are not random: in all countries, socially disadvantaged and marginalised groups have poorer health, greater exposure to health hazards, and less access to high quality health care than the more privileged. (Speech at launch of Decades of Disparity III, delivered by Hon Pete Hodgson 8 May 2006)

Reducing health inequalities is integral to reducing the incidence and impact of chronic conditions. Overcoming barriers to access – both to and through the health and disability systems – is a critical prerequisite to reducing inequalities. Work to prevent and manage chronic conditions should ensure that outcomes for those with the greatest health risk improve at a faster rate than those of the population, for example by targeting populations with high need. If this approach is not taken, health inequalities are likely to grow (Graham 2004).

Developing capability within the health system to reduce inequalities will benefit all people with chronic conditions. World Health Organization recommendations and Ministry of Health directions recognise the significance of reducing health inequalities. Health policy or service delivery approaches that are not designed or delivered in a way which is culturally relevant to indigenous people or minority ethnic groups can widen the disparities between these groups and the general population. A clear understanding of the factors of culturally effective service delivery is required.

Chronic conditions cannot be prevented or managed by the health sector alone. Since the NHC's report on *The Social, Cultural and Economic Determinants of Health in New Zealand: Action to Improve Health*, the NHC has continued to recommend cross-sector and whole-of-government approaches to addressing health inequalities.

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- ▶ *The next chapter argues that despite the rise in chronic diseases, the traditional health system does not adequately meet the needs of people with chronic health conditions. In response to this, new models of care have been developed, trialled and evaluated in many countries around the world.*

3. Opportunities for change

This chapter presents the need for systemic changes to address chronic conditions and provides an overview of chronic care models. It presents evidence for the effectiveness of chronic care models and research on two aspects of chronic care models: self-management and culturally appropriate services. Finally, it provides evidence in selected areas associated with chronic disease: pain, depression, and medicine management.

3.1 The need for change

The need to change the organisation and delivery of services for people with chronic conditions is evident in international and New Zealand literature (Ministry of Health 2006b; Department of Health 2004; Counties Manukau District Health Board 2005).

The need for change was confirmed for the NHC both in submissions it received from providers and community organisations and from case studies of people with chronic conditions. It found that despite the high prevalence of chronic conditions, there is often a mismatch between the needs of people with chronic conditions and what the health system offers.

What the patient needs and wants is often not quite the same as what the health professional believes is 'best' for the patient. At the clinical intervention and diagnosis end of the spectrum, practitioner decision is essential but self-management of lifestyle behaviour needs a person-centred approach throughout. (Health professional/researcher, NHC consultation)

The NHC supports change toward more proactive and coordinated health care to better meet the needs of people with chronic conditions. Coordinated health care for people with chronic conditions requires a fundamentally different approach.

Current models focus on managing the condition, not on helping the person to manage their life in spite of the condition. (NGO, NHC consultation)

3.1.1 The Commonwealth Fund evidence

The Commonwealth Fund has undertaken a number of surveys across Australia, Canada, Germany, New Zealand, the UK and the US. The 2005 survey of 'sicker adults,' many of whom had one or more chronic conditions, provides a comprehensive overview of the failure of health systems to meet the needs of people with chronic conditions (Schoen et al 2005).

When asked to rate their country's overall health care system, the majority of adults with chronic disease (66 percent to 85 percent) in all countries said there was room for major improvement. (Schoen et al 2005)

Although New Zealand health care ranked second overall among countries surveyed, it ranked last in terms of chronic care and hospital care, coordination of services, and access to care. New Zealanders were generally more satisfied with the quality of their health care and physicians than people from any other country. However, New Zealanders ranked low in filling prescriptions, undertaking treatment or recommended tests, attending follow-up appointments or attending for care when needed. This reflects both a range of access issues and lack of support for self-management or coordinated care.

Key findings from the 2005 Commonwealth Fund survey relevant to chronic conditions include the following (Schoen et al 2005).

- Thirty-eight percent of New Zealanders reported having had problems with access to health care due to cost. This was significantly higher than for the United Kingdom, Canada or Germany.
- Patients with chronic illness often failed to receive recommended care. For example, less than half the people diagnosed with diabetes received all four recommended screening tests. Strategies known to improve or maintain health for people with chronic conditions (such as self-management or involving a nurse in the care team) were not routinely used.

- A third of New Zealanders who had been hospitalised in the previous two years experienced poor coordination of their discharge process. They did not receive information about their condition, the symptoms to watch for and/or who to contact with questions that arose after leaving. Following discharge, 15 percent attended an emergency department or were readmitted to hospital due to complications during recovery.
- A quarter of New Zealanders who had been hospitalised in the previous two years reported a failure of doctors to communicate with them or with one another.
- A quarter of New Zealanders had experienced a medical, medication or laboratory error. Errors were experienced particularly commonly among the 40 percent of respondents who had seen four or more doctors in the previous two years.

3.1.2 Shifting toward chronic care models

Health conditions facing the global western health system have changed from predominantly infectious diseases and acute illnesses to longer-term conditions. However, health systems have been slow to respond to this shift in population needs.

Medical advances improving health outcomes in acute health events have led to more specialised and fragmented care. Recognition of the need to coordinate these services for patients or to develop more effective supports for the system has been slower. Funding, education and delivery of health care have pursued a cure-focused approach concerned with turning acute episodes into survivable events. This approach views health care as a series of discrete incidents or problems to be solved. This has resulted in health systems sharing features that create barriers to meeting the needs of people with chronic conditions.

In 2001, a US report argued that a 'fundamental, sweeping redesign of the entire health system' was needed to improve quality of care and to move away from a disease focus (Institute of Medicine 2001). Different systems are needed to allow for a flow from episodic to continuous care and to provide for ongoing, regular contact between people with chronic conditions and health professionals. Different models are needed for the longer-term relationships with people who have chronic conditions; these need to be models that place a greater emphasis on communication and multi-disciplinary teamwork. There is a strong focus on patient self-management and greater attention paid to the psychosocial, emotional and spiritual wellbeing of patients. All these changes aim to provide effective care for people with chronic conditions by providing coordinated and integrated services throughout an individual patient's life course and across the health continuum of populations.

Although models for acute and chronic care can be understood as two broad approaches focused on different needs, they are not mutually exclusive. People with chronic conditions may regularly have acute needs that have to be seen within the context of their chronic condition and life situation. The central issue is how to ensure services based on both acute and chronic care models can work efficiently to achieve a continuum of care for individuals and population groups. The following table, adapted from the *Crossing the Quality Chasm Report* (Institute of Medicine 2001), presents some key differences between acute and chronic models:

Table 1: Acute and chronic care models – key differences

| Acute models | Chronic care models |
|--|---|
| Disease-centred | Person-centred |
| Doctor-centred | Team-centred |
| Focus on individuals | Population health approach |
| Secondary care emphasis | Primary care emphasis |
| Reactive, symptom-driven | Proactive, planned intervention |
| Episodic care | Ongoing care |
| Cure focus | Prevention/management focus |
| Single setting: hospital, specialist centres, general practice | Community settings, collaboration across primary and secondary care |
| 1:1 contact through visit by patient | 1:1 or group contact through visit by patient or health professional, email, phone or web contact |
| Diagnostic information provided | Support for self-management |

The following table, adapted from Kane et al (2005), provides a comparison of care processes.

Table 2: Care processes of acute and chronic care models – key differences

| Care process | Acute care | Chronic care |
|--|--|---|
| Assessment | Disease-centred | Person-centred |
| | Clinical considerations for cure | Considerations include improving functioning, prevention of complications and other diseases, quality of life |
| Treatment | Provider initiates, patient expected to comply | Patient, family/whānau, carers jointly involved in care and planning |
| | Little coordination | Coordination among multiple providers |
| | Primarily medical or pharmacological | Includes behaviour change and adaptation |
| | Little or no care planning or follow-up | Care plan with goals/objectives Clinical pathways used where possible to inform providers and patients |
| Monitoring/adjustment | Intermittent | Ongoing |
| | Contact triggered by crises or arbitrary time periods | Contact triggered by change in clinical course within ongoing care |
| | Patient untracked | Patient monitored and followed up when appointments missed |
| | Reporting of symptoms tied to encounters | Reporting of symptoms ongoing, not necessarily tied to visit |
| Acute care event (where chronic condition is exacerbated) | Focus on stabilisation | Focus on stabilisation, then identifying and rectifying cause of exacerbation |
| | Event seen as inevitable part of disease progression | Event seen as system failure or breakdown in management |
| Acute care event (where chronic condition is a co-morbidity) | Chronic condition viewed as a complication to principal problem or not focused on | Addressing chronic condition integral to treatment |
| | Resolution of principal problem seen as a success | Addressing overall functioning seen as part of definition of success |
| Post-acute care | Driven by efforts to reduce hospital stay | Most important outcomes identified and planned for |
| | Minimal patient and family/whānau support, little time for careful decision-making | Maximum patient and family/whānau involvement in decision-making. Efforts made to separate stages of decision-making. |
| | Sporadic monitoring | Continuous monitoring |
| | Limited information transfer | Person-centred record moves with patient across care providers |

3.2 Approaches compatible with chronic care models

3.2.1 Chronic care models and effective primary health care

A major component of chronic care models is effective primary health care. The NHC's report *Improving Health for New Zealanders by Investing in Primary Health Care 2000*:

- promoted a population health approach
- regarded multidisciplinary teams as essential for effective population-based health approaches
- promoted a broad primary health care approach with a focus on health promotion, early intervention and disease prevention.

Population health approach

Population health approaches are essential to effectively address the prevention and management of chronic conditions. Population health approaches identify populations for proactive care. Population groups may be identified by a range of variables, for instance age, gender, ethnicity, socioeconomic status, and being at high risk of, or diagnosed with, specific diseases, illnesses or conditions. Systematically targeting populations known to have a higher incidence of risk factors is critical to reducing health inequalities. It is also a very effective way to improve the health of the overall population. Monitoring population health makes it possible to identify trends, develop appropriate programmes and measure the results of interventions.

The outcomes sought from a population health approach are:

- effective health promotion, early intervention and disease prevention
- reduction in health inequalities among ethnic groups
- improved health of the whole population.

Multidisciplinary teams

Multidisciplinary teams have a long history in acute care delivery. In delivery of chronic care, the majority of management takes place outside the hospital; the range of disciplines and providers may be greater, patients are involved in the monitoring and management of their condition and patients may require more information and support (Kane et al 2005).

...the creation of teams may be the fundamental primary care redesign that allows other components of the Chronic Care Model to succeed. (Bodenheimer 2003)

People with chronic conditions have a wide range of medical and support needs. A team approach aims to reduce fragmentation of services and promote greater integration of care and support for the individual with a chronic condition. Interdisciplinary team care has been found to reduce the number of missed appointments, decrease hospitalisation, decrease use of specialist care, and reduce costs (Baldwin 1994).

There is evidence for the effectiveness of care delivery from multidisciplinary teams with different skill and knowledge bases (Von Korff et al 2002). Benefits of working within multidisciplinary teams include increasing individual expertise and knowledge by learning from workers in other disciplines, and increased effectiveness in clinical management (Grant and Finocchio 1995).

Health promotion, prevention and management

Broad primary health care approaches focus on health promotion, early intervention and disease prevention. The main intervention points for health promotion and prevention are:

- promoting health and wellbeing among those at risk, but not diagnosed with a chronic disease
- managing a diagnosed disease to slow the progression, prevent potential complications, and prevent other diseases developing
- preventing functional decline and disability through management
- promoting wellbeing in the face of serious illness.

Health promotion and prevention are often placed at the beginning of a linear system of care. However, there continue to be opportunities for intervention once a person is diagnosed with a chronic condition.

- A person with diabetes has an increased risk of cardiovascular disease and preventative measures can be taken to reduce their risk of developing it (New Zealand Guidelines Group 2003).
- Exercise programmes for people with cancer have been found to improve physical functioning, not just prevent decline (Segal et al 2001).
- When a condition is in its final stages, wellbeing is promoted through effective pain management, preventing emotional distress and maximising social roles (Kane et al 2005).

Proactive primary care

Within this report, reference is made to 'proactive primary care'. This term covers a range of processes or actions informing the design of care delivery and endorsed by the *Primary Health Care Strategy* including:

- establishing a system for creating, validating and updating a patient register
- identifying high-risk patients
- establishing effective recall and review processes
- using evidence-based guidelines
- achieving role clarification and establishing processes for multidisciplinary teamwork
- community partnerships to ensure effective coordination of health and social care, and collaboration on integrated services and budgets
- involving patients and carers in supporting self-management
- collaboration on areas that achieve alignment with secondary care (admissions and discharges).

Use of guidelines

Use of guidelines is promoted within chronic care models to avoid practice variations. Guidelines can be promoted within regional strategic plans, used to clarify tasks within team meetings, integrated into care practices to support evidence-based decisions, adapted for patient use to describe the patient's role in achieving guideline adherence, and within cross-disciplinary teams or community organisations to coordinate implementation.

Effectiveness studies consistently show that introducing guidelines has only a minimal impact on quality unless guidelines are integrated into the practice through education, reminders, specialist involvement or other decision-support interventions (Woolf et al 1999). In New Zealand, studies suggest that some barriers to uptake of guidelines by GPs include poor content, limited access, and lack of training sessions (Arroll 2003)⁵.

3.2.2 Chronic care management models

The British National Health Service (NHS) conceptualised chronic care management on three levels: self-management, disease management, and case management. The Australian Government's National Health Priority Action Council adapted this to: self-management, disease or care management, and care coordination.

The NHC's proposed three levels are: self-management, care management and care coordination (see Diagram 1). The names are intended to refer to a group of interventions or activities, not a theoretical approach or model. The NHC is recommending the development of guidelines in collaboration with GPs and nurses to specify these interventions.

Both disease management and case management approaches are used by organisations that have not adopted chronic care models. Variations in models of disease and case management make it difficult to determine the value of the models. In addition, the contexts and systems where these models are applied can impact on effectiveness; this is rarely accounted for.

There is some evidence that combining these approaches with chronic care models leads to greater effectiveness in managing chronic conditions (Renders et al 2001). However, this is likely to reflect the positive effect of chronic care models, not the approaches themselves. The NHC is recommending that DHBs proposing disease management programmes set these within a chronic care model, to ensure effectiveness of the approach. It also recommends that generic disease management programmes be developed in preference to single disease management programmes as one way of broadening existing approaches to disease management.

⁵ Note: Counties Manukau DHB has used sound processes for achieving guideline adherence.

Diagram 1: Levels of chronic care



Adapted from UK Department of Health. 2005.

Case management

Case management is an intensive level of management for people with complex health and life circumstances. Summary evidence on the effectiveness of case management has been mixed, due to variation of components of models and the systems they sit within. When case management involves assessing the patient's needs, developing a care plan, arranging suitable care, monitoring the quality of care, and maintaining contact with the patient and their family, case management research reviewed consistently showed positive or neutral results on a range of indicators. The research suggests that case management is more effective for those at high risk or when used in conjunction with educational measures or immediately following hospitalisation. A review of nine randomised trials, in which case management additionally included intensive education techniques, reported improved functional and clinical outcomes in the majority of the studies.

While disincentives may exist to implement case management due to cost, many studies have demonstrated that it can reduce health care expenditure (Singh 2005).

Evidence on coordinated care in Australia

The evaluation of the South Australia HealthPlus trial was primarily aimed at addressing State and Commonwealth funding issues for people with chronic conditions so that funding could move to a population health outcome-based model of care. A generic model of coordinated care was successfully implemented for people with a wide range of chronic conditions in both rural and urban settings, resulting in improved health outcomes. Service coordination was found to be a necessary additional role to their existing system. As cost savings were not sufficient to pay for coordinated care, a longitudinal study to assess the effects of service substitution on costs of non-clinical coordinator roles was suggested. The study concluded cost savings could be achieved through better targeting of patients, and selection of patients with prior hospital admissions who had potential to improve through self-management.

Disease management

Disease management is provided to people with chronic conditions categorised as high risk. There are a wide range of disease management programmes, some of which contain more elements of a chronic care model and self-management skill development than others. Since a number of effective disease management programmes combined self-management approaches, or were supported by other aspects of chronic care models, and both self-management and chronic care models are shown to be effective, it is unclear whether disease-management programmes are the contributor to positive results.

A literature review by the World Health Organization (WHO) Regional Office for Europe (Velasco-Garrido et al 2003) found widespread evidence that disease management programmes improve the management and control of (but not mortality from) chronic diseases. These programmes also improve the use of evidence-based standards of care by providers. Studies show that components of disease management and chronic care management models can be effective in improving quality of care and health outcomes (Weingarten et al 2002). No direct links were found between disease management and improvements in quality of life or cost effectiveness. WHO recommends that programme cost benefits be evaluated before introducing disease-management programmes on a wide scale and the NHC endorses this.

The National Health Service Institute for Innovation and Improvement (2006) found no single approach to disease management was superior. The key to improved care lay in team work, increased clinical knowledge, and commitment to the systematic application of change processes. This reinforces the NHC's emphasis on the significance of process and context.

Self-management

Self-management is the least intensive and most utilised level of care for people with chronic conditions. Self-management is a key element in chronic care models. It provides support for people to have greater control in managing their chronic condition through understanding their condition, being able to monitor and take appropriate action on it, and address areas of their life affected by their condition. Self-management actively involves people with chronic conditions in care planning, forming partnerships between the person, health professionals and the community. *[Further discussion and evidence on effectiveness of self-management is contained in Chapter 3.6.]*

3.3 Overview of international chronic care models

Chronic care models are a guide to improving practice and outcomes for patients and providers (Bodenheimer et al 2002a). Models and approaches for chronic care management have been extensively implemented and evaluated in many countries and have produced an evidence base to support the effectiveness of structured chronic care approaches in both improving health outcomes and reducing costs. The success of these models and approaches relies upon organisational commitment and strong leadership within the health care system.

While there is a range of models, they tend to include similar elements and principles. The two most common approaches of chronic care management models are:

- system-wide integration of services based on the chronic care model
- targeting of specific system components or populations at greatest risk of hospitalisation (Singh 2005).

An overview of major international models is provided below.

Wagner Chronic Care Model

Wagner's Chronic Care Model is a widely recognised, applied and evaluated model for chronic care. It is a versatile framework for systems reorientation with six essential components: health system culture changes, community engagement, support for self-management, delivery systems (re)design, decision support and clinical information systems. *[Further details on the Wagner model are contained in Chapter 3.3.1.]*

Innovative Care for Chronic Conditions (WHO)

The WHO Innovative Care for Chronic Conditions Framework is a set of eight essential elements for action based on the Wagner Chronic Care Model. The framework provides a guide for decision-makers in redesigning or improving a health care system's capacity to manage chronic conditions. Key components are a person-centred approach, organisation of health care, community and policy (WHO 2002).

Stepwise Framework for Preventing Chronic Illness (WHO)

The WHO Stepwise Framework is designed to provide governments with an approach to planning and implementation of policy and interventions related to the prevention and management of chronic conditions. The framework is designed to be applicable to different countries and priorities (WHO 2005).

Kaiser Permanente (US)

Kaiser Permanente is a health maintenance organisation whose system of care is focused on the needs of patients with chronic conditions using a proactive approach. Different levels of care are provided to people based on their level of risk and need. The focus is on integrating services as part of a continuum of care. Prevention, patient education and self-management are key components (Matrix Research and Consultancy 2004; Singh 2005).

Kaiser Permanente has been associated with improved quality of life, dramatically reduced use of hospital beds with chronic care programmes and greater integration between generalist and specialist care (NHS Institute for Innovation and Improvement 2006).

Evercare (US)

Evercare is a proactive case management model that uses an individualised person-centred approach for older people with chronic diseases. Integrated primary and specialist services support patients at high risk of hospital admission. The focus is on achieving outcomes that, where possible, delay or stabilise the disease. Education for the patient, family and carer on the disease, patient involvement and avoidance of unnecessary medication are some key components of the model (Matrix Research and Consultancy 2004; Singh 2005).

Use of the Evercare model in the US produced a 50 percent reduction in unplanned hospital admissions, and significantly reduced use of medications, with benefits to health. It has also had high family, carer and clinician satisfaction rates (NHS Institute for Innovation and Improvement 2006).

Chronic Disease Self-management Program (US)

Stanford University offer a range of self-management programmes facilitated by a trained person with personal experience of chronic condition(s). The focus is on support, sharing experiences, and building skills in a programme run over six weeks. Problem-solving, exercise and fatigue management are discussed. The programme has been adapted for various cultures and contexts in a number of countries, including New Zealand (Stanford University 2006).

Flinders Model of Chronic Condition Self-Management (Australia)

The Flinders self-management model is a clinician-led model that works in partnership with people with chronic conditions. Training and education of the primary health care workforce using a generic set of processes and tools to support self-management is a key feature of the model (Flinders Human Behaviour & Health Research Unit 2005).

Findings from Australian trials in a variety of clinical settings across a range of conditions show significant improvements in self-management (Flinders Human Behaviour & Health Research Unit 2005). Over 75 people in New Zealand have been trained in the model and it is being implemented in Care Plus⁶ and chronic care management programmes.

Pfizer approach (US)

The Pfizer approach uses an internet-based population and disease management application, InformaCare, and evidence-based clinical guidelines in the management of high-risk patients. The emphasis is on patient involvement in their treatment plan, self-management and coordination of care. Pfizer programmes in the US have been shown to reduce hospital admissions and improve coordination of care (Matrix Research and Consultancy 2004; Singh 2005).

3.3.1 The Wagner Chronic Care Model (US)

The Chronic Care Model developed by Wagner (Rothman and Wagner 2003; Wagner 2000) has been shown to deliver substantially better outcomes than conventional care (Wagner et al 2001b). It can be applied to any chronic condition, within different settings and for a wide range of populations (Bodenheimer et al 2002a, Wagner 1998).

6 For a brief description of the Care Plus initiative, refer to 4.3.

A meta-analysis of controlled trials of interventions for asthma, depression and diabetes found that interventions with at least one Wagner Chronic Care Model element had consistently beneficial effects on clinical outcomes and processes of care (Rothman and Wagner 2003; Wagner 2000; Tsai et al 2005). Other reviews have found that programmes based on the Wagner Chronic Care Model may also improve clinical outcomes, patient and staff satisfaction, quality of care, functional status and reduce hospital admissions (Singh 2005).

The Wagner model identifies the following themes as key elements of a health care system that promotes high quality management and care of chronic conditions.

Community resources and policies (community engagement)

Communities play an important role in bridging clinical care and everyday life. They can support a person's health care through messages of prevention, action on the wider determinants of health and wellbeing and promotion of positive attitudes to managing and living with chronic conditions. Community support groups and community providers are most effective when they have established relationships within their communities.

Some areas of community action include:

- mobilising community resources to meet the needs of people
- encouraging people to participate in effective community programmes
- forming partnerships with community organisations to support and develop interventions that fill gaps in needed services
- advocacy for policies to improve care for people with chronic conditions.

Support for self-management

Self-management supports the person with a chronic condition and their family/whānau, in the management of their condition. The support comes from both the processes used and the knowledge and information provided. The person, their family/whānau, and health providers share care planning and decision-making. Knowledge and tools are provided for managing chronic conditions. Some of the actions include:

- preparing people to manage their health and health care through education about their condition and its symptoms, purpose and use of medications, strategies for pain management, benefits of and support for lifestyle changes
- emphasising the central role of the person within their family/whānau in managing their health through collaborative decision-making
- using effective self-management support strategies that include assessment, goal-setting, action planning, problem-solving and follow-up
- organising internal and community resources to provide ongoing self-management support (including psychosocial support), links to support groups that understand the issues, and referrals to agencies that assist in a range of issues such as income support
- providing self-management resources and tools.

Delivery system design

Good systems support both acute and managed care in a coordinated process. Teams clarify roles so that some health professionals treat acute or complex chronic disease states, while others undertake support for self-management, arrange for routine and periodic testing, and ensure appropriate follow-up. Some of the actions in this area include:

- ensuring delivery of effective, efficient and quality clinical care
- using proactive and planned appointments supported by evidence-based care and population approaches
- providing self-management support
- providing care coordination with defined care management responsibilities across providers
- providing clinical case management services for people with complex conditions
- defining roles and distributing tasks among practice team members
- responding to individual needs through providing a range of services and supports (consultations for monitoring purposes, clinical interventions, phone follow-ups, support groups)
- providing accessible and culturally appropriate care.

Decision support

Providers using chronic care models ensure best practice is employed by creating ongoing learning environments, ensuring processes are in place to apply evidence-based guidelines within regular clinical practice and having specialist expertise available when issues arise in routine care. Some of the actions in this area include:

- promoting clinical care that is consistent with scientific evidence and a person's preferences
- embedding evidence-based guidelines and information in routine clinical processes
- providing a range of relevant educational opportunities for health professionals
- ensuring specialist expertise on specific chronic conditions is available on a consultative basis within primary care.

Clinical information systems (information systems)

When people with chronic conditions are effectively monitored, their potential health risks are acted upon and they have better health outcomes. This requires efficient and effective clinical information systems that support collaborative teamwork and coordinated care across providers. Such systems support integration of health records among settings and help identify relevant subpopulations for proactive care. They provide information for sound planning and treatment programmes as well as facilitate quality improvement for health care systems as a whole. They also support collaborative teamwork and coordinated care across providers. Some of the actions undertaken to improve clinical systems include:

- using software that has the capacity to (i) identify relevant subpopulations for proactive care (ii) generate timely reminders to providers to follow up individuals and (iii) alert health professionals to potential risks for those in their care
- educating teams in the use of population data for effective actions
- facilitating individual care planning
- coordinating care through systematic information-sharing with providers and the person with a chronic condition
- ensuring clarity of purpose in information-sharing across providers and community groups
- monitoring performance of practice teams.

System organisation (including organisational culture)

Leadership is significant in bringing about changes to the health care culture. Partnerships among providers and community organisations assist in promoting a collective vision to foster change. Promoting safe, high-quality health care within the community requires processes that encourage learning from experience and provide incentives for quality care. Some of the actions in this area include:

- creating a health care culture that participates in safe, high quality care
- having a coherent system for quality improvement
- implementing strategies that support comprehensive system change
- leadership that encourages open and systematic handling of errors to improve care as well as providing incentives based on quality care
- having a vision that facilitates agreements between providers to coordinate care (including clarification of funding and referral criteria).

3.3.2 People with chronic conditions and chronic care models

Models of chronic care can be correlated with the needs of people with chronic conditions. Connections between the NHC case studies and Australian research on the needs of people with chronic conditions are described below to highlight the importance of changes for people with chronic conditions.

Community

People with chronic conditions have a diverse range of needs that cannot be fully met by health and disability support services. They benefit from opportunities to increase their access to a wide range of services (such as employment, income, education, housing, and maintaining social contacts). Attitudes in the community have a large impact on the social and cultural connections experienced by a person with chronic conditions.

In relation to having a chronic illness and associated depression, I generally find it's the circumstances of living with the illness, not the illness itself that create the most problem – the financial problems, needing support in practical ways, and isolation... It's not that I think the illness would be solved if the other stressors weren't there, but the impact of the illness would be lessened if the stressors were properly addressed. (Person with multiple chronic conditions, NHC case study)

Support for self-management

People with chronic conditions and their family/whānau have a vital role in managing the condition(s). Family/whānau meet a wide range of practical and emotional needs for people with chronic conditions. When involved in care planning, family/whānau may also support behaviour and lifestyle changes. It is easier for a person to achieve a comprehensive and clear management plan when the services they deal with have established relations with one another.

Delivery system design

People with chronic conditions want continuity in their health care, regardless of how many professionals are required to assist them, or how many places they have to go to receive treatment and support. Having accessible services and knowing what each health professional contributes to their care plan helps a person to manage their condition better. This requires integrated systems and at times coordinated care. NHC case study participants particularly sought improvements in discharge from hospital to primary care.

Decision support

People with chronic conditions should be able to make informed decisions about their treatment where appropriate. They expect that advice given and decisions made by health professionals are consistent with the best available evidence. They expect health professionals to update their practices and have specialist expertise. People with chronic conditions get clear and consistent messages when all the health professionals they deal with act on the same evidence.

Clinical information systems

People with chronic conditions should be able to expect effective monitoring, and to have their potential health risks acted upon. Although it is information systems that identify them for proactive care, provide the reminder for follow-up, or create the alerts to health professionals, a person under the care of a health provider contacted for care by the health provider, has the experience is one of being 'looked after'. When a person with a chronic condition has coordinated care from a range of health professionals and organisations, and every health professional involved knows what's happening for them, they can feel more confident that their situation is understood and they are valued.

System organisation and organisational culture

People with chronic conditions have a greater chance of understanding the health care system when organisational cultures are clear about what is being provided and who is accountable. People with chronic conditions have a greater chance of understanding their condition when the system is culturally accessible and delivers consistent messages throughout the sector.

Culturally appropriate services

Culture permeates the life of individuals and the social context of communities. The culture, values, background and experiences of a person are integral to how they understand health and illness, access services and respond to health care interventions. The cultural understandings held by health professionals and provider organisations affect the services they design and offer to people. Provider and health professional understandings affect whether people with chronic conditions wish to access the services; they also affect the relationships they form with health providers, and their health outcomes.

3.4 The Counties Manukau Chronic Care Management Programme (New Zealand)

Counties Manukau DHB use a chronic care model to provide the framework for a number of chronic conditions programmes or initiatives spanning a person's life course from prevention to palliative care. The model and associated programmes were developed to consistently deliver seamless care to targeted patients with specific chronic diseases and varying levels of need (ranging from low to very high). Underlying the model are key approaches and principles of all chronic care models including: population health approaches, person-centred care, involvement of family/whānau, multidisciplinary teamwork, effective communication and information-sharing.

Initiatives within the chronic care model are determined by regional strategic priorities and plans as well as objectives from the national health and disability strategies. Individual disease projects are aligned to the model.

A significant initiative set within the framework is the Chronic Care Management programme (CCM). The CCM is the first structured chronic care management programme to be developed and evaluated in New Zealand. Key components of the CCM reflect a chronic care model, addressing system design, decision support, information systems and system organisation. The programme focuses on people with chronic conditions who have very high and complex needs. In addition to the CCM, the DHB has worked collaboratively with the community to develop 'Let's Beat Diabetes', a whole-district initiative with considerable community participation.

Selection of target groups

Chronic care models use a population approach to identify target groups, by using clinical information systems.

The selection of target groups and initiatives under the CCM is based on a set of principles and criteria, consultation with stakeholders, local and national strategic priorities, needs analysis and financial/economic analysis. The need to reduce inequalities and improve health status for Māori and Pacific peoples are two principles guiding selection. The model is designed to be generic and applicable to people with a range of chronic diseases.

Information systems

Clinical information systems are a key part of any chronic care model. The CCM put forward a number of requirements for outcomes sought from the information systems and this area continues to be one of growth and implementation. [See Diagram 2: Components of the CCM]

Practice systems that encourage proactive care

A number of practice systems support decisions for proactive care (similar to the decision support area of the Wagner model). These include: record systems that identify and flag target patients, patient registration systems, disease registers, and access to and shared knowledge of patient resources. Proactive care is seen to link back to improving cultural competency.

A flow plan of patient processes is developed in each practice, based on the guidelines and contract specifications for each disease. The patient flow plan aims to ensure information sharing, shared management goals and plans that are understood by both the patient and practice team.

Clinical guidelines and education of patients and providers

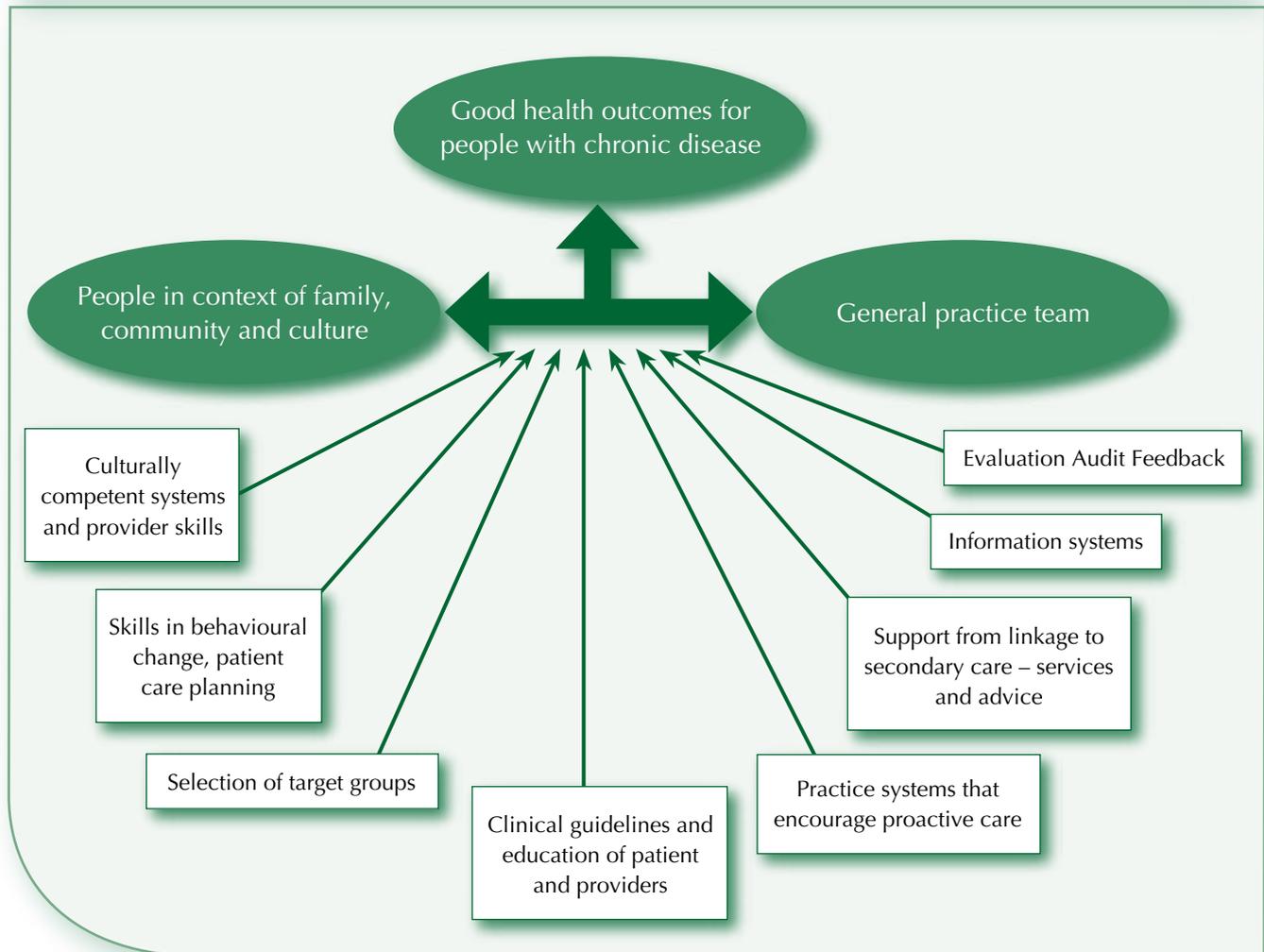
This area (which corresponds to 'decision support' in the Wagner model), embeds use of evidence-based guidelines and information in routine clinical processes. The embedding process for the CCM requires input from multidisciplinary practice teams, as well as indigenous and ethnic groups.

Guidelines aim to inform educational material (for GPs, practice nurses and patients), secondary clinical pathways, patient-held care plans and patient questionnaires.

Skills in behavioural change, patient care planning

This area uses self-management processes. Health professionals discuss the likely impacts of the condition with patients and family/whānau and jointly design a patient-held care plan to include goals, current medications, monitoring activities and action plans.

Diagram 2: Components of the Counties Manukau CCM



Patient education focuses on the patient’s total health, the physical aspects of their illness or disease and the effects and meaning of the illness in their lives using the Whānau Ora framework⁷.

Patient education is provided by the GP and practice nurse working as a team. The CCM suggests that patient education consist of four 30-minute sessions a year with the health team. A group cooperative learning model is available for Māori and Pacific patients who prefer this option. Patients have the choice of receiving their education from someone of the same culture or ethnic background or someone who speaks their first language, depending on resource availability. Community health workers and disease management nurses promote wellness and self-management for people with all chronic diseases and their family/whānau.

Support from and linkage to secondary care – services and advice

This area can be seen to correspond to the delivery system design area of the Wagner model. However, it reflects the strong need in New Zealand to focus on integration of primary and secondary care systems. Some actions in this area are: partnerships between primary and secondary care for selection of target groups, ensuring consistency of clinical guidelines; and provision of advice on chronic care management decisions by secondary care health professionals.

⁷ Whānau Ora, the centrepiece of *He Korowai Oranga*, seeks support for Māori families to achieve their maximum health and wellbeing (Ministry of Health 2002).

Care is coordinated so patients can access secondary and primary care services seamlessly. This is facilitated by established systems of communication and shared clinical information through a minimum dataset available to both primary and secondary providers.

Evaluation, audit and feedback

This component of the CCM (equivalent to the Wagner model's system organisation) is based on New Zealand quality improvement systems that evaluate team performance, patient benefits and costs as well as the processes of the programmes.

Culturally competent systems and provider skills

The CCM includes cultural competence as a core component. It is designed to meet the needs of Māori and Pacific peoples and to ensure equity in access and health outcomes for these populations district-wide. The theme of cultural competence is based on the model developed by the National Centre for Cultural Competence in the US.

The CCM model requires providers to demonstrate a willingness and ability to understand the diverse cultures of their patients and work with key people from these cultures to develop targeted interventions, communications and support (Counties Manukau 2001; Wellingham et al 2003). Achieving culturally competent systems is recognised as a developmental process for organisations, involving ongoing education and training.

The CCM outlines plans for both Māori and Pacific peoples that acknowledge their culturally specific views of health and wellbeing. Each plan focuses on systematically incorporating cultural competency into every level of the organisation: organisational values, policy, recruitment and training, community involvement, development of language and resource materials, data collection, relationships with Māori and Pacific providers and ongoing quality improvement processes.

3.5 Evidence for the use of self-management

The NHC wishes to draw attention in this chapter to two key areas of chronic care models that it wishes to see emphasised within New Zealand. Evidence on these areas is supplied where available and comment on further evidence required is noted. The key areas are:

- support for self-management
- provision of culturally appropriate services.

Both areas are referred to in New Zealand policy, either directly or indirectly, yet NHC research and case studies demonstrated a need for further development of understanding and more consistent application.

3.5.1 Defining self-management

Self-management was defined by the NHC in its 2005 discussion document as 'people with chronic conditions having greater control in looking after themselves, with the support of their families/whānau (where desired), and in partnership with health professionals and community resources'.

Self-management is a key area of chronic conditions models and has been applied in a number of countries with different emphases. Britain has adopted the Expert Patient approach which emphasises peer support in the community. Australia has adopted the Flinders model, which educates health professionals to provide support for self-management to individuals in a health context.

What are the principles of self-management?

Self-management interventions can be used at different points of the health continuum. The six principles of self-management put forward by the Flinders Human Behaviour & Health Research Unit (2006) are:

- activities that protect and promote health (healthy lifestyles)
- ability to monitor signs/symptoms of illness and take appropriate action
- knowing and understanding the health condition
- being actively involved in decision-making
- managing the social/emotional and physical impact of the condition
- following a care plan that is agreed to with health professionals.

This list does not include the spiritual impact of the condition. The NHC recommends including spiritual impact, which is an integral part of Māori models of health and many holistic approaches.

Who is self-management for?

Many people self-manage to some degree. However, these people can be supported to be more effective. There is good evidence that conditions such as the following respond to increased self-management support: diabetes, heart disease, asthma, stroke, depression, arthritis, multiple sclerosis, HIV, cancer, chronic back pain, and pain disorders (Singh 2005; Department of Health 2001).

Self-management is not appropriate for everyone. Evidence is less clear for the effectiveness of support for severe mental impairment and advanced dementia. There is evidence that people of low socio-economic or minority status groups are under-represented in self-management programmes (Singh 2005; Bury et al 2005).

Self-management initiatives

Self-management can be encouraged in group programmes or be formally implemented within a multidisciplinary approach to primary care.

Initiatives that support self-management may include:

- patient-led care plans
- self-help tools (eg self-help guides, workbooks, videos, interactive computer programmes, internet-based resources)
- telephone support (support groups, nurse-led phone support)
- group programmes and peer support groups
- self-monitoring tools (diaries, electronic records, telemonitoring).

A care plan is a written document collaboratively designed among patient and providers covering issues, aims, interventions and review processes in the patient's life. Care plans promote self-efficacy in a patient. As they often include medication lists and health histories, care plans may also reduce patient risk. Care plans are more effective when all health professionals understand their purpose and significance to the person with chronic conditions and use them as an opportunity to reinforce behaviour change.

Self-management programmes are skills-based and outcomes-based programmes that address three sets of self-management tasks: medical or behavioural management, role management and emotional management.

Programmes typically cover:

- problem-solving skills
- goal-setting, action planning, decision-making
- monitoring symptoms
- accessing and using community resources and the health system
- communicating effectively with health professionals and improving relationships with health providers.

3.5.2 Evidence on self-management

Evidence on delivery of self-management

- Group education sessions have been convincingly shown to improve patient knowledge, satisfaction and use of medication (Singh 2005). Evidence is insufficient to suggest a particular educational strategy as universally effective.
- Written care plans can improve care processes and reduce health care resource use for selected chronic diseases (Singh 2005). However, the latest review of evidence showed that care plans did not reduce hospital admissions or promote behaviour change (Singh 2006). The NHC believes enabling behaviour change involves specific skills and it is not the written plan but accompanying processes that determine behavioural changes.
- International evidence has not strongly indicated which methods work best to encourage patient involvement and there is still limited evidence on the impact of patient involvement in decision-making and planning on clinical outcomes (Singh 2005, Singh 2006).
- Although the UK Department of Health (2001) found sustained improvement in individuals' skills in self-management, more current evidence suggests that 'booster' interventions are required to sustain positive effects from such programmes (Clark 2003).

Evidence on workforce for self-management

Actions that support self-management require skills in participatory problem-solving, life management and communication. Nurse-led strategies have been shown to be effective for monitoring symptoms and disease management where appropriate (Singh 2006). Facilitation of sessions by lay people or peers can improve access to care and encourage behaviour change (Bodenheimer et al 2002b; Singh 2005). Evidence supports the value of care team members having access to health professionals with higher levels of skill than themselves (Wagner 2000).

Chronic care models emphasise team provision in primary care with clear roles and supporting information processes. Teamwork in provision of self-management within primary care settings has resulted in GPs being able to focus on less routine and more complex cases (Corben et al 2005).

Evidence on outcomes of self-management

There is now a great deal of evidence on the outcomes of self-management in terms of improved health outcomes and health system efficiencies.

Self-management has been shown to:

- improve clinical outcomes: improve physical functioning, lead to fewer and less severe symptoms, slower progress of disease and fewer complications, improve health behaviours, improve patient satisfaction (Singh 2005; Kane et al 2005; Bodenheimer et al 2002b; Department of Health 2001)
- reduce health care costs and resources (Singh 2005; Bodenheimer et al 2002b): reduce GP visits, hospitalisation and total hospital days (Lorig et al 1993; Lewin et al 1992, 1998; Kemper 1993; Bodenheimer et al 2002b); improve system efficiency and effectiveness (Bodenheimer et al 2002b)
- improve quality of life: improve emotional wellbeing and patient satisfaction (Singh 2005; Kane et al 2005); improve self-reported health outcomes: fatigue, disability, social/role activities, decrease health distress (Department of Health 2001)
- lead to improvements in healthy behaviours: exercise, cognitive symptom management, coping, and communications with physicians (Department of Health 2001)
- improve quality of care (Singh 2005): enhance communication with physicians (Lorig et al 2001); be associated with higher rates of adherence to care targets such as screening (Schoen et al 2002).

Specific examples of reduced health care costs include:

- 50 percent less hospitalisation for people with Parkinson's disease (Montgomery et al 1994)
- 40 percent reduction in GP visits for high-risk groups (Fries et al 1998)
- significant decrease in accident and emergency department visits for asthma (Choy et al 1999).

There is also growing evidence of the effectiveness of mail-delivered, computerised, or web-based interventions such as:

- an improvement in pain, disability, role function and health distress with internet education programmes for back pain (Lorig et al 2002)
- a computer-accessed intervention programme with information, decision support, and connection to other patients and health professionals for people living with AIDS (Gustafson et al 1999)
- a significant increase in perception of support by adults with type 2 diabetes accessing internet-based support interventions (Barrera et al 2002)
- a 50 percent reduction in days off work by people with arthritis on a mail-delivered programme (Fries et al 1997).

Where there is no clear evidence of effectiveness

There are some evaluations that have not found clear evidence for the effectiveness of self-management, in particular involving people in decision making and planning individual education sessions on clinical outcomes or use of health services (Singh 2005; Bury 2005). This could be the result of poor study design or inappropriate selection of patients for self-management programmes.

- Self-management does not suit all people with chronic conditions. Some patients require a higher level of support.
- Some chronic diseases are strongly associated with depression; not all studies took this into account. The mental health status of a patient can determine their ability to manage their physical chronic condition and maximise use of social supports.
- Self-management approaches need to be adapted to be culturally appropriate. Difficulties with language or cultural concepts of health for people who speak English as a second language may reduce the effectiveness of information provided.
- Self-management approaches require health professionals to have a range of non-clinical skills. Where these have not been adequate, low skill level may have contributed to poor outcomes.

3.5.1 Examples of self-management initiatives

There are a variety of initiatives in New Zealand that use different approaches to supporting self-management of chronic conditions. These initiatives are provided by NGOs, Māori providers, PHOs, and DHBs in community and hospital settings.

Four examples of different approaches to supporting self-management are profiled below. The first example, the *Living a Healthy Life* self-management programme run by Arthritis New Zealand aims to increase the effectiveness of self-management skills for any person with a chronic condition, their family/whānau and carers. The next example, the *Heart Failure Rehabilitation Programme* at Christchurch Hospital, incorporates self-management as a component of a rehabilitation programme for people with chronic heart failure. The third example, the *Strong Parents – Strong Children Programme* at Starship Hospital in Auckland, aims to help parents with chronically ill children manage illness-related stresses, and learn practical skills. The fourth example, the Māori asthma self-management programme in the Wairarapa, is an example of a collaborative community-based initiative that used a 'credit card sized' self-management plan as a tool for effective self-management of asthma.

Evidence from each of the initiatives profiled shows that support for self-management improves the health and wellbeing of people with chronic conditions and has a positive impact on their family/whānau.

Living a Healthy Life (Arthritis Foundation)

Since 1998, the New Zealand Arthritis Foundation has been licensed to provide the self-management programme Living a Healthy Life to people with chronic conditions, their family members and carers in New Zealand. The Foundation also trains leaders from other organisations such as DHBs, PHOs and NGOs to deliver the course to their client base.

Since 2000 over 100 courses have been held, with more than a thousand people with different chronic conditions participating, some of whom have more than one condition. The majority of participants have been women and are between 50-74 years old. (T Griffith, personal communication, May 2006)

HealthWest PHO (Auckland) is licensed to run the Living a Healthy Life programme for people with chronic conditions. Approximately 100 have attended programmes so far. The aim of the weekly group sessions is to increase effective self-management skills for living with chronic conditions. The course is led by health professionals, some of whom have chronic conditions, and is based on the concept of learning from the sharing of participants' experiences, problems and solutions. Some of the topics covered in the course include managing symptoms, communicating with health professionals, exercise/fitness, nutrition, managing medications, building confidence and problem-solving.

Arthritis New Zealand conducts an ongoing post-course evaluation of the Living a Healthy Life course. The evaluation has found that the course is relevant and useful to people with chronic conditions. The majority of participants reported significant benefits from the course. Participants' self-efficacy was greatly increased, and they were committed to the continual practice of positive self-management behaviours. (T Griffith, personal communication, May 2006)

The Heart Failure Rehabilitation Programme (Christchurch)

The Heart Failure Rehabilitation Programme was developed by physiotherapists and is delivered at Christchurch Hospital. It focuses on the needs of patients with chronic heart failure (CHF). The aim of the programme is to improve participants' ability to exercise and their quality of life. A key component of the programme is support for self-management – increasing the patients' understanding of treatment for CHF and their ability to identify the early signs of decompensating CHF. The programme includes an initial individual assessment with the physiotherapist, an individualised exercise programme, strategies and information regarding CHF, follow-up appointments and support for lifestyle changes. (Health Innovation Awards 2006)

Evaluation of the Heart Failure Rehabilitation Programme found significant benefits to participants in terms of improved ability to exercise, improved quality of life, lower levels of anxiety and depression. None of the participants were readmitted to hospital 12 months after completing the programme, which has many health benefits for the patient and efficiency gains for the health care system. This is a positive outcome since chronic heart failure is a progressive condition that is usually associated with decline in function over time and readmissions to hospitals account for up to 75 percent of the cost of treating heart failure. (S Fitzgerald personal communication, April 2006)

Strong Parents-Strong Children Programme (Starship Hospital, Auckland)

This programme has a behavioural intervention focus that aims to help parents with chronically ill children manage illness-related stresses, and learn advocacy and practical skills within a child development framework. The programme consists of weekly sessions over a six-week period that has input from the facilitator, group discussion, and review of 'homework' assignments. Groups discuss strategies and skills to cope with illness related stress, the importance of parents looking after themselves, getting desired information from health professionals, the role of parents in caring for their sick child, domestic organisation, and the family's way of operating after the acute phase of an illness.

Results of the evaluation of the programme show that it has significant and positive impact on the parents of chronically-ill children. (Jerram et al 2005)

Māori asthma self-management programme (Wairarapa)

The Māori asthma self-management programme was a collaborative research initiative based in rural Māori communities in the Wairarapa for six months in 1992. The programme established partnerships between the person with a chronic condition (and their family/whānau/carers) and health professionals, services and community supports. It was based around a credit card-sized asthma self-management plan which details methods for self-assessment and treatment guidelines. Each plan was tailored to the person's individual needs, including their individual therapy, medication and details for emergency help.

Initially the management plan was introduced through a series of clinics, organised by Māori community health workers, on marae and other community-based settings. The clinics focused on factors for causing asthma, recognising and responding to symptoms of unstable asthma based on the plan, reducing the frequency and severity of attacks through the use of steroids and providing relief of symptoms through the use of bronchodilators.

Community health workers had an integral role in providing support for self-management, maintaining contact with participants and encouraging them to complete their diaries. (D'Souza et al 2000)

Early evaluations found there had been significant reductions in asthma morbidity following the introduction of the self-management plan. Participants were still showing benefits in reduced asthma morbidity one year and two years after completion of the original programme.

A follow-up study six years later showed that the long-term benefits of the programme extended beyond reduced asthma morbidity, and were contingent on the partnership approach. In addition to continuing declines in asthma morbidity for participants, other long-term benefits included: cultural affirmation, improved access to other health services, a greater sense of control for participants, and positive impacts on the extended family and friends – for instance, making the home smokefree. (Te Hauora Runanga o Wairarapa et al 1999)

3.6 Evidence on culturally appropriate services⁸

Barriers to, and through, the health system for indigenous people and people in minority ethnic groups produce and perpetuate significant health inequalities. Evidence in this area provides a basis for considering the provision of culturally appropriate services. However, there are a number of research gaps regarding culturally appropriate service delivery and these are discussed later in this chapter.

The outcomes sought from the provision of culturally appropriate services are:

- increased access to quality care
- reduced inequities of service provision and reduced health inequalities in outcomes
- improved health and wellbeing.

⁸ See glossary for definition of terms including culturally appropriate, cultural safety, and cultural competence.

A person's culture, values, background and experiences influence how they understand health and illness, access services and respond to health care interventions.

There is legislative basis for achieving cultural competence of health practitioners. The Health Practitioners Competency Act 2001 requires standards of cultural competence for health practitioners. The New Zealand Public Health and Disability Act 2000 requires DHBs to reduce health disparities. The *New Zealand Health Strategy* contains a clear directive to reduce inequalities. A number of other strategies specifically refer to the provision of 'culturally appropriate services' or 'building responsive services' for particular population groups.

Culture permeates both the lives of individuals and the social context of their communities. Organisational responses to providing culturally appropriate services require thorough consideration of all aspects of service provision. Changes may be sought in design and planning of services, workforce development, evaluation and review processes. Cultural responsiveness may be a core component of provider approaches to improving access to services and health outcomes. *[For examples of initiatives see 3.7.1.]*

Some features of culturally appropriate services include:

- targeted health promotion activities
- formal partnerships and consultation with organisations or groups representing the indigenous or ethnic minority
- availability of a multilingual health workforce
- provision of information in a variety of media (both oral and printed) and languages
- provision of services in locations that are readily accessed by people of different communities, such as marae, churches, schools or shopping centres
- provision of services and facilities that welcome the participation and support of families/whānau.

3.6.1 Research gaps in evaluating culturally appropriate services

Despite the need for culturally appropriate services made apparent by poor health outcomes for indigenous and ethnic groups, there is little research on the effectiveness for improving health outcomes of incorporating cultural competence, a culturally appropriate approach or cultural safety in health and disability services. In addition, there is no evidence on what elements of these programmes are the most effective (Brach and Fraser 2000).

There are often difficulties in measurement caused by the range of other variables in a culturally appropriate programme. For example, a study in the US identified that practice-site policy promoting cultural competence was associated with higher quality of care for children with asthma. However, other variables included in the study were reporting to clinicians, initiatives to increase access and provision of continuity of care. The study therefore calls for closer examination of the relationship between cultural competence policies and specific aspects of health care quality (Lieu et al 2004).

Māori providers and evaluation needs

Although there is now evidence on gaps in service provision for Māori within the general health system, and information on what Māori providers deliver, further evaluation is needed on the impact of specific approaches or components of service provision that achieve beneficial health outcomes for Māori. *[For discussion of positive experiences from the use of culturally appropriate models, refer to the NHC Case Studies in Part Two of this report.]*

The high levels of need in Māori communities are themselves a barrier to identifying aspects or types of care management that are particularly effective for Māori. Given time and resource constraints, Māori providers are frequently more focused on project implementation than on project evaluation. In a study of iwi and Māori providers, providers agreed that external evaluations of community health service provision are more appropriately conducted by Māori evaluators. However, capacity-building in this area needs to be resourced (University of Auckland, Wellington School of Medicine, University of Otago 2002).

Further developments required

The emphasis in chronic care models and effective primary care on person-centred approaches is compatible with providing culturally appropriate services. Further research on these approaches and their health outcomes on specific populations may provide a basis for addressing barriers to access and health inequalities. Research on the outcomes of other culture-specific approaches would also be beneficial if positively evaluated

approaches are acted on in the design and delivery of general service provision. [For a summary of research on communication in relation to Māori and Pacific peoples, refer to 2.2.3 and 2.2.4.]

The NHC believes building a picture of effective culturally appropriate services requires:

- capacity-building of culturally appropriate evaluators to be resourced
- design of appropriate evaluation tools to recognise the elements of culture-specific models used in service provision
- evaluation of services that address barriers to access, to assess the impact on health outcomes for specific populations
- evaluation of services that build on person-centred approaches to be culturally inclusive for development of guidelines and models
- further research on elements of service delivery emphasised by indigenous and ethnic communities, eg communication, relationship building
- improved data collection and information systems.

3.6.1 Examples of culturally appropriate initiatives

The following examples are of approaches used by PHOs to be culturally responsive to the needs of their local populations. Profiled are the *Ngati and Healthy Prevent Diabetes Community Programme* on the East Coast, the Tongan Health Society diabetes clinics in Auckland and the clinics run by Raukura Hauora O Tainui in Auckland.

Approaches used by these organisations include: service providers speaking the same language as patients; providing transport; providing multiple services on the same site; proximity of clinics to patients' homes; having a holistic person-centred approach that addresses the diverse needs of patients and their family/whānau/community; delivering a service by Māori for Māori; the attitudes and behaviour of staff; the cost of health care services; flexible consultation time; subsidisation of medication; and partnership with iwi.

Outcomes identified as a result of these approaches include improved access to services (both to health and other support services) for Māori, Pacific peoples and other local population groups, and patient satisfaction.

The Ngati and Healthy Prevent Diabetes Community Programme

The Ngati and Healthy Prevent Diabetes Community Programme in the East Coast is a joint health and education initiative between Ngati Porou Hauora (PHO) and the University of Otago. The programme aims to reduce the prevalence of insulin resistance (diabetes type 2) through the promotion of healthy lifestyles and increased awareness of diabetes in six Ngati Porou communities.

A strong feature of the programme is a focus on the community as well as the individual. Activities such as hunting, playing touch rugby, fishing and gardening along with exercise programmes are promoted in the programme. Local runanga participate by hosting cooking demonstrations and community discussions on health and wellbeing. A mobile health service regularly travels to each community to monitor the health of those identified at high risk of diabetes. (Ministry of Health 2005b)

An evaluation of this programme is planned. A randomised survey of selected individuals preceding the programme found that type 2 diabetes mellitus is common among the population and that insulin resistance is even more prevalent, especially among younger age groups. Insulin resistance is believed to be an underlying cause of type 2 diabetes mellitus. (Tipene-Leach et al 2004)

The Tongan Health Society (PHO)

The Tongan Health Society diabetes clinic in Auckland provides an accessible environment where cultural concerns are taken into account and patients can speak in Tongan during consultations. The holistic approach includes provision of transport, the availability of podiatrists and other specialists on the same site, cooking demonstrations and exercise classes and self-management support. (Ministry of Health 2005b)

The Māori Case Management Clinic Project 2001-2003

(Raukura Hauora O Tainui, Clendon, Auckland)

The aim of the project was to improve Māori health outcomes by establishing new primary care facilities that deliver a 'by Māori for Māori' model of community health care. New clinics were established in the high deprivation areas (NZDep deciles 8-10) of Manurewa/Clendon, Papakura and Mangere in order to provide accessible health care services. Operated by Māori health providers, the facilities aim to provide a low cost, high quality and culturally appropriate service for Māori living in these communities.

Each of the clinics had to demonstrate that their model of health care incorporated tikanga (customary practice) consistent with the following Māori health paradigm:

- *Tikanga Mo Ngā Iwi Me Ngā Hapū – appropriate engagement of Māori*
- *Tino Rangatiranga – Māori control over health care*
- *Taha Whānau – involving the whānau in health care*
- *Taha Wairua – maintaining spiritual wellbeing*
- *Taha Hinengaro – maintaining emotional and mental wellbeing.*

Staff with appropriate background and experience were employed to meet the needs of the population. Since opening, the clinics have increased the number of staff in order to meet demand for services.

A key focus of each of the clinics is providing case management under Care Plus for people with chronic diseases. Each of the clinics employs a chronic disease management nurse who works with patients in developing a care plan and provides support for self-management of their disease.

The Clendon clinic opened on 1 February 2001, with a clinic opening in Papakura on 30 July 2001 and in Mangere on 8 October 2001. Results from the evaluation of the Clendon clinic showed that there was very rapid growth in registration in the initial stages, with around 50 percent of the total local Māori population registered. By November 2001 70 percent of patients registered were Māori, 12 percent were of Pacific descent. Seven percent of the enrolled population were identified with a chronic illness, with asthma and diabetes accounting for 64 percent of those with chronic conditions.

The main factors given by people for accessing the Raukura O Tainui Clendon clinic were affordability, cultural acceptability and close proximity to patients. Meeting the needs of people in the community, institutional support from Tainui and the location of the clinic in a busy shopping mall were other factors attributed to the high enrolment. Low fees, seeing the whānau as a whole, generous consultation time, the full subsidisation of medication and the approach of staff all contributed to patients' perceptions that the clinic was making an extra effort to meet their needs. Patients felt their information was secure and confidential and were assisted with accessing other support services. Patient satisfaction was reported as being very high.

The cost and value of providing a culturally appropriate service was recognised as difficult to quantify compared to other models of primary health care delivered as there is no benchmark. The average cost per visit was \$44.79, compared with an average of \$29.95 for other primary care facilities. (Maniapoto and Gribben 2003)

3.7 Relevant areas of research on chronic conditions

The NHC reviewed literature in areas associated with chronic conditions that NHC case studies and/or provider submissions suggested were relevant to service provision for people with chronic conditions. These included:

- the association of depression with chronic conditions
- pain and chronic conditions
- medicine management.

3.7.1 The association of depression with chronic conditions

Depression, and in particular untreated depression, can be seen as a chronic condition in its own right. However, it is also strongly associated with other chronic conditions.

In 2000, depression was the fourth leading cause of the global disease burden (Üstün et al 2000) and by 2020, it is predicted to be second only to heart disease globally (Chapman et al 2005). In New Zealand, the MaGPIE study found that more than a third of people consulting a GP had experienced a diagnosable mental disorder during the previous 12 months, depressive disorders being among the most common (Bushnell 2003). Studies from the US and Europe indicate that those with untreated depression attend primary care significantly more often than other patients (Herman et al 2002). The two greatest barriers to effective treatment of depression are under-treatment (50 percent) and under-recognition (30 percent). The MaGPIE study findings suggest this situation is echoed in New Zealand.

The New Zealand Mental Health Survey (Ministry of Health 2006) found mental and physical co-morbidity more than doubled the disability associated with mental or physical disorders alone. Depressive disorders may contribute to the development of a chronic disease. Depression may also adversely affect the course of the disease and limit effective treatment for the chronic condition if untreated (Chapman et al 2005). For example, depression is a predictor of poorer surgical outcomes (Jung et al 2002). There is a range of evidence on the association of depression with specific chronic diseases.

- Nearly 50 percent of asthma patients may suffer from clinically significant depressive symptoms (Mancuso et al 2000) and increased depressive symptoms have been associated with poorer asthma outcomes (Mancuso et al 2001).
- Depression and/or anxiety are among the most commonly-reported concerns of people with arthritis (Sotosky et al 1992). There are a range of beneficial treatments for depression and arthritis: (i) self-management can reduce depression and perception of pain (Barlow et al 2000) (ii) cognitive behaviour therapy (CBT) and antidepressant medication can achieve significant improvements in both the psychological and physical status (iii) aerobic activity can ameliorate depressive symptoms and pain (Chapman et al 2005).
- Approximately 30 percent of people with diabetes have depression (Anderson et al 2001). Despite this, one study found less than 25 percent of patients with diabetes were screened for depression (Rubin et al 2004). Coexisting depression and diabetes is associated with poorer glycaemic control, increased risk of complications, increased health care utilisation and costs, increased functional disability and lost work productivity (Egede 2005). Both CBT and antidepressant medication are found to decrease depression and increase glycaemic control. Total health expenditures for people with untreated depression and diabetes were found to be 4.5 times higher than for those without depression (Egede et al 2002).
- Depressive disorders are associated with risk factors for cardiovascular disease (CVD) (Davidson et al 2001) and predictive of CVD (Ruglies 2002) as well as stroke (Ramasubbu et al 2003). Patients who have had a myocardial infarction (MI) and also have depressive symptoms have more medical co-morbidities and cardiac complications, are at greater risk of mortality and are less likely to adhere to recommended lifestyle and behavioural changes (Chapman et al 2005). Treatment with serotonin uptake inhibitors is effective and most effective in combination with CBT (Guck et al 2001). Prevention of ischemic heart disease is more effective when general mental health issues are worked on in addition to diet and exercise (Elwood et al 1993).

Timely diagnosis and treatment can greatly affect chronic disease progression (Chapman et al 2005). A significant contributor to provision of timely services is coordination of both primary and secondary mental health services with other services. However, this has been found to be poor in developed countries (Blashki et al 2005).

Preventative treatment has been shown to be effective in reducing progression of depression and reducing costs. For example, self-help intervention based on CBT with minimal guidance is cost-effective in avoiding the onset of full-blown depressive disorder in primary care patients with sub-clinical depression (Smit et al 2006).

Reviews have shown that the use of chronic care management models brought substantial improvements in patient care as well as statistically-significant improvements in the symptoms of depression (Ofman et al 2004; Badamgarav et al 2003). Self-management programmes have been shown to reduce depressive symptoms (Singh 2005).

In summary, the relationship between depression and chronic conditions has important implications for:

- management of secondary depression for people with chronic diseases
- prevention of chronic diseases for people with depression
- reducing costs and increasing treatment effectiveness.

This section has focussed on depression and physical chronic conditions in response to NHC case studies. However, the New Zealand Mental Health Survey (Ministry of Health 2006) found a higher prevalence of chronic physical conditions in people with a wider range of mental disorders, which indicates possible benefits from further research.

3.7.2 Pain and chronic conditions

Providers in both Australia and New Zealand have raised the need at the primary health care level for more effective pain management (Dowrick 2006, NHC case studies).

Chronic pain affects one in five adults and is more prevalent among older people. Common chronic pain conditions include rheumatoid arthritis, back pain, neuropathy of diabetes and stroke (IASP 2004). Chronic pain is a predictor of reduced work ability (Saastamoinen et al 2005). Poor pain control can have negative effects on mobility and functioning, emotional well-being, quality of life and overall recovery (Walker et al 2006). Quality of life for people with chronic, non-malignant pain, is among the lowest observed for any condition (Kreitler and Niv 2005). Chronic pain is considered a disease in its own right (Siddall and Cousins 2004).

Inadequate pain management can lead to medical complications and is associated with increased use of health care resources and costs (Walker et al 2006). People in pain seek health care five times more frequently than others (Ospina and Harstall 2002). The MidCentral Health Emergency Department audit found 20-25 percent of admissions identified pain as the primary complaint. Severe chronic pain leads to longer hospital stays (AETMIS 2006).

Consistent and effective chronic pain management aims to: reduce emotional distress, increase functioning and independence, minimise use of drugs, promote wellbeing through balanced daily activity and prevent unnecessary acute episodes and additional consultations. Active patient self-management is necessary to evaluate the effectiveness of pain relief measures.

Pain assessment relies on tools to measure subjective perception of pain. Concepts informing perception are shaped by a range of biological, psychological and social factors. Given these factors, it is likely that culture and gender impact on perception of pain. However, more evidence is required. What is known is that racial or ethnic minority status predicts substandard access to appropriate pain assessment and treatment in the US and Western Europe (IASP 2004).

Depression is more common among people in chronic pain (Ospina and Harstall 2002; Fishbain et al 1997; Sullivan et al 1992) than the general population and pain resulting in loss of independence or mobility significantly increases depression (Williamson and Shultz 1992). Physical symptoms are common in patients with major depression (Lipowski 1990) and patients with moderate to severe depression were more likely to have developed headache and chest pain three years later (Von Korff et al 1993). Depression is not simply a co-morbid condition but interacts with chronic pain to increase morbidity and mortality (Clark 2006). Depressed chronic pain patients report greater pain intensity and less effective life management strategies (Haythornthwaite et al 1991; Weickgenant et al 1993). Chronic pain is linked with suicide and requests for assisted suicide or euthanasia (Fishbain 1999; Emanuel et al 1996).

There is evidence for the effectiveness of some common treatments for chronic pain (such as minor analgesics, massage and cognitive behavioural therapies). In addition, the use of antidepressants to effectively treat both pain and depression has been extensively examined (see review by Clarke 2006). Despite growing evidence

providing a basis for pain treatment choices for individual patients and for the development of protocols and procedures specific to each clinical setting, under-treatment of pain still occurs (ANZCA & FPM 2005; Walker et al 2006). This may be for a range of reasons including lack of assessment, lack of staff capability, lack of provider resources, or cost to the patient.

In summary, there is an under-treatment of pain in New Zealand. Under-treatment leads to unnecessary acute episodes and increased consultations. The NHC is recommending:

- more consistent assessment and management of pain
- treatment of chronic pain and depression when both are present, to reduce morbidity and mortality
- increased training and awareness of pain management, to reduce costs and increase treatment effectiveness for causal conditions of pain.

This section has focussed on depression and physical chronic conditions in response to NHC case studies. However, the New Zealand Mental Health Survey (Ministry of Health 2006) found a high prevalence of chronic physical conditions in people with a wider range of mental disorders, which indicates possible benefits from further research.

3.7.3 Medicine management

NHC case studies drew attention to the need for better understanding and management of medication. This is being addressed in some PHOs through self-management programmes and through the involvement of pharmacists with primary health care. Provider submissions for the NHC discussion document raised the need for greater coordination in medications both through effective information systems and coordinated care.

International research shows significant room for improvement in preventing iatrogenic complications, which are any adverse effects associated with medical treatment, including medication. This is of particular significance for people with chronic conditions because many use a variety of medications. One study found that 42 percent of serious, life-threatening, and fatal adverse drug events were considered preventable (Gurwitz et al 2003). Adverse drug events are caused by: insufficient research on medications, poorly coordinated systems in which different providers are prescribing for one patient, inappropriate prescription and lack of patient understanding of the use of medications (Kane et al 2005).

Prevention methods compatible with chronic care management models and effective primary care delivery include:

- coordinating patient care with an electronic information system
- including pharmacists in team care for patients with complex needs, as well as encouraging patients to use a single pharmacist
- including medication management in self-management support through provision of information and ongoing patient support systems (phone access to relevant health professionals)
- regular review of medications
- targeting high-risk patients (such as those with cognitive or physical disabilities likely to affect medication management).

Chronic care models look for medicines prescribed by specialists and community health workers to be managed through primary health care coordination. Medicine management is beneficial for all people, but especially those with complex conditions and co-morbidities.

3.8 Considerations for research implementation

Evidence from chronic care models has been shown to be good in a number of areas. However, it is not always possible to recommend best practices from research, since there are a number of factors contributing to the success of models and these components have not always been separately evaluated. For example, they have been determined for self-management, but not for culturally appropriate service delivery. Both are part of chronic care models.

Careful consideration needs to be given to applying international evidence to New Zealand where evidence is likely to have been affected by differing economic and political structures and processes. These are not always detailed in research and are rarely possible to determine from rapid reviews or other meta-analyses of research. For example, a rapid review of the most effective mix of health professionals in primary care

teams was inconclusive (Singh 2006). It listed the type of health professional, but did not provide contextual information on current relationships in the sector, population needs, and how professionals delivered services. Similarly, the same rapid review put forward no positive outcomes for a range of ways in which specialists had worked in primary care in Britain. However, NHC consultations found beneficial results from all examples provided during consultations.

Many of the areas of change outlined by chronic care models concern funding and structures. These are particularly affected by political and economic structures, and evaluations would have to be conducted in New Zealand. There are a number of areas of funding in which further exploration would be beneficial: approaches to achieving joint budgets across health and social sectors to assist flexible service packages and cross-sector projects, considering whether direct payments could benefit people with chronic conditions, and a range of issues around public/private mixes of funding. These areas are not limited to, but have relevance to, people with chronic conditions and the services delivered to them.

3.9 Conclusion

The rising incidence of chronic conditions requires changes to health services and their delivery systems. Local and international evidence and patient experience overwhelmingly support the need for a fundamental shift in the health system toward better coordinated, person-centred and proactive health care. New directions are recognised in strategies that focus on 'wellness rather than on illness, on promotion of collective responsibility for population health and on the sensible coordination of individual patient's treatment' (Brimacombe and Rowe 2003).

A major focus of chronic care models is providing support for people with chronic conditions in community settings, which emphasises the central role of primary health care. The sweeping changes put forward by the Institute of Medicine report and the Commonwealth Fund surveys indicate that chronic care models also need to focus on providing a continuum of health care. A successful model enhances the contribution of primary care as well as seeking changes to health care organisation, system design and support.

A number of models for chronic care management have been developed and tested. The resulting evidence base confirms that use of a structured chronic care approach can lead to improved health outcomes, patient satisfaction and cost reduction. However, careful consideration needs to be given to implementing research. Contextual factors, such as political or policy structures, strength of existing relationships and levels of commitment, and resourcing for changes being implemented, all affect success and are often not fully accounted for in evaluations of models.

The case studies conducted by the NHC highlighted specific issues which require particular attention in connection with chronic care delivery and systems redesign. The association of depression with chronic conditions, the need for consistent pain management and medication management are complex and interlinked features which must be considered in initial planning for any chronic care, primary health or mental health services redesign or re alignment.

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- ▶ *The next chapter outlines policy and initiatives currently underway to address chronic conditions in New Zealand and internationally.*

4. Current health policy and initiatives

Chronic care models, or aspects of them, have been implemented in a number of countries. Within New Zealand, DHBs and PHOs have undertaken initiatives that implement aspects of chronic care models or affirm underlying principles of chronic care models.

This chapter presents a summary of national policy that aims to prevent and manage chronic conditions, as well as an overview of national initiatives that contribute to reducing the incidence of chronic diseases and improving care for people with chronic conditions. The chapter concludes with themes from international approaches for comparison.

4.1 National strategies

A number of national strategies directly and indirectly relate to the prevention and management of chronic conditions, and the services provided for people with chronic conditions [refer to Table 3]. Although each strategy focuses on particular areas or populations, they have a common set of approaches and objectives.

- *Common approaches relevant to chronic conditions include:* population health initiatives, person-centred and holistic service delivery, primary prevention, health and wellbeing promotion, and cultural appropriateness.
- *Common objectives for policy implementation of value to addressing chronic conditions include:* reducing inequalities, reducing barriers to access for specific populations (Māori, Pacific peoples, people of low socio-economic status), providing a continuum of care (including coordination of care), effective monitoring, supporting data collection and information systems, development of community-based services, intersectoral collaboration and coordination, use of multidisciplinary teams supported by workforce development.

Although these strategies cover common approaches and objectives that have the potential to comprehensively address chronic conditions, they are not integrated into a common chronic conditions framework.

4.2 National initiatives

The Ministry of Health has a number of work streams that contribute to reducing the incidence of chronic diseases and improving care to people with chronic conditions [refer to Table 4]. These are detailed in the annual *Health and Independence Report and Implementing the New Zealand Health Strategy* report.

Table 3. National strategies relevant to addressing chronic conditions⁹

- The New Zealand Health Strategy *emphasises reducing inequalities within a population-based and person-centred approach. It contains broad objectives to reduce the risk factors for the incidence and/or complications of chronic conditions.*
- The Primary Health Care Strategy *has introduced wide changes to the planning, delivery and accessibility of primary services in the community that provide the basis for health promotion and the prevention and management of chronic conditions. Based on a population health approach, it recognises social, cultural and economic determinants and aims to reduce inequalities.*
- The Healthy Eating – Healthy Action: Oranga Kai – Oranga Pūmau: Strategy Framework (HEHA Strategy) *focuses on health promotion and disease prevention through improving nutrition, increasing physical activity and reducing obesity.*
- He Korowai Oranga: Māori Health Strategy, the Pacific Health and Disability Action Plan, the Health of Older People Strategy, and the New Zealand Disability Strategy *focus on particular population groups with high incidence of chronic conditions (Māori, Pacific peoples, older people and disabled people). He Korowai Oranga, has an overall aim of whānau ora and outlines the significance of family/whānau within care models. The Pacific Health and Disability Action Plan emphasises improving access to services that are culturally competent. The Health of Older People Strategy has an integrated continuum of care as a key objective, and The New Zealand Disability Strategy emphasises participation and independence.*

⁹ For further information on Ministry of Health strategies, refer to Ministry of health website. For further information on Health Information Strategy actions see www.HISAC.govt.nz

Table 3. National strategies relevant to addressing chronic conditions

- Te Kōkiri – the Mental Health and Addiction Action Plan, developed to implement Te Tāhuhu – Improving Mental Health, outlines a work programme to meet challenges relevant to a wide range of chronic conditions.
- The continuum of care outlined in the Cancer Control Strategy has relevance for managing a number of ongoing and fluctuating conditions. The Palliative Care Strategy focuses on the provision of quality palliative care to meet the needs of all New Zealanders, including people with terminal chronic diseases. Palliative care cultures are compatible with chronic care approaches.
- The Health Information Strategy for New Zealand focuses on actions to support key health and disability sector strategies, such as primary care information, e-referrals and e-discharges. A specific action zone on chronic care management covers areas of significance to chronic care models, such as decision support and coordinated care.

Table 4. National initiatives: Ministry of Health

Leading for Outcomes¹⁰

Leading for Outcomes (LfO) draws on the legislated outcomes described in the New Zealand Health and Disability Act 2000 to support a ‘whole system’ shift in the focus of health sector activities toward reducing inequalities and improving health and wellbeing for population groups in New Zealand. It identifies the logic for intervening at various points along a continuum of wellness and disease that uses chronic or long-term conditions as its basis.

An important programme deriving from LfO is Coordinated care: dependable systems for long-term conditions, whose aim is to develop a comprehensive information environment that facilitates best practice management (interventions and coordination) for long-term conditions. The work on coordinated care has been incorporated into a broader review of the Care Plus initiative to provide an enhanced and consistent approach to care coordination.

Long-term support needs of people with chronic conditions

The Ministry of Health is working with DHBs to address funding issues that are making it difficult for some people with long-term health conditions to access needed long-term support services. The aim of the work is to develop a solution that:

- *best meets the needs of people currently missing out on long-term support services*
- *best balances the risks and incentives for funders and service providers*
- *is consistent with the Government’s policy intent, in particular the New Zealand Disability Strategy.*

Diabetes/CVD Quality Improvement Plan and self-management toolkit

The Ministry of Health is commencing work on a three-year diabetes/CVD Quality Improvement Plan, as part of implementing The New Zealand Health Strategy and the Healthy Eating, Healthy Action Strategy. The plan will focus on building the capacity of DHBs to improve services for people with these conditions. The Ministry of Health plans to develop a toolkit for national diabetes/CVD self-management within the PHO context.

Knowledge and information systems

The Ministry of Health is working with key stakeholders to develop a business case to support the following key directions for systems development in the health sector: population health, targeting care to individuals, performance improvement and evidence, and care coordination and integration. Key directions contain specific action areas, such as defining communication protocols and formats to improve communication between health and social care professionals.

¹⁰ For further information refer to www.leadingforoutcomes.org.nz

4.3 Addressing chronic conditions in primary health

Primary care and chronic care models

The NHC believes chronic care models will be assisted in New Zealand through fully implementing the vision of the *Primary Health Care Strategy*. Much of the prevention and management required for chronic conditions is provided by PHOs and community-based organisations. A large proportion of primary health care consultations are spent on people with chronic conditions.¹¹

All chronic care models emphasise the central importance of delivering effective primary care. Key areas of congruence between the *Primary Health Care Strategy* and chronic care models are:

- encouraging regular attendance, and providing ongoing monitoring
- early identification of chronic diseases and timely treatment
- self-management within a family/whānau context
- multidisciplinary teams to deliver a range of care and support
- care coordination to reduce the progress of, and manage complications from, identified chronic diseases
- community settings that enable access to health care, community engagement and cross-sector collaboration.

The Primary Health Care Implementation Work Programme 2006/10¹²

The 2006/10 *Primary Health Care Implementation Work Programme* has an increased focus on chronic conditions and puts forward a number of areas for action consistent with developing a chronic care model. This is expected to address some of the issues raised by NHC case studies and provider submissions.

In the key area of reducing inequalities, greater community participation in governance, especially for Māori and Pacific peoples, has the potential to improve accessibility and cultural appropriateness of services. The use of equity tools and improved data collection for ethnic minorities is a critical step toward reducing inequalities. Greater involvement of family/whānau in care planning and management has been shown to improve health outcomes. Increasing the number of Māori and Pacific health professionals working and being trained should assist health communication and improve access.

Delivering services that appear seamless to the user are a significant part of chronic care models. Work to achieve information flow between primary and secondary services will be especially beneficial to people with chronic conditions moving across different providers and levels of care. Work planned for effective teamwork and broadening multidisciplinary teams is expected to benefit people with chronic conditions through supporting broader and more coordinated services and highlighting consistent health messages.

Primary mental health

Primary mental health is a major area of development within primary health care. Increasing capability in providing mental health care at the primary care level is one of the leading challenges outlined within Te Kōkiri. A number of PHO primary mental health initiatives target depression and chronic illness. The long-term aim of PHO mental health initiatives is to increase the capacity and capability of PHOs to deliver integrated services that respond appropriately to the mental health needs of enrolled populations.

The National Depression Initiative contains strategies to improve the capability of primary health practitioners to respond appropriately to people seeking help with depression, and to increase awareness of self-management strategies. As part of the National Depression Initiative, the New Zealand Guidelines Group (NZGG) has been contracted to develop an educational resource of simple cost-effective interventions for depression in primary health care. Part 1 of the resource will target general practice teams and Part 2 will focus on a resource for individuals and families. By June 2007, NZGG will also review and update the Guidelines for the Treatment and Management of Depression by Primary Healthcare Professionals.

11 It is estimated that people with chronic conditions account for up to 80 percent of primary health care consultations in the UK (Matrix research and consultancy for NHS Modernisation Agency 2004).

12 For further information on the Primary Health Care implementation Work Programme refer to the Ministry of Health website.

At a Ministry of Health level, mental health is being integrated into key health directions. Two examples are:

- including diagnosis of depression, anxiety and addiction as PHO Performance Management Programme indicators
- extending the scope of the LfO Coordinated Care project from diabetes and cardiovascular disease to three major diagnoses in mental health.

National initiatives: Services to Improve Access (SIA)

Increasing access to health services is an approach to reducing health inequalities and addressing chronic conditions. SIA funding enables PHOs and community groups to use innovative approaches to reaching people with high health needs. SIA initiatives include providing outreach services from a bus, transport for appointments, and services in community venues such as a marae, school or workplace.

Care Plus

Care Plus, a national Ministry of Health initiative offered through PHOs, is intended to provide coordination of care for people with chronic conditions and more complex needs. It has a number of aims congruent with chronic care models including improving care management and primary health care teamwork.

Eighty percent of PHOs were delivering Care Plus in some or all of their practices by April 2006. However, only an estimated 50 percent of eligible patients were enrolled at the end of 2006. Slow uptake was due to PHOs needing to:

- undertake training in population health approaches using electronic analysis of patient databases
- clarify roles and team processes
- provide training for nurses in management of chronic conditions.

These are all areas essential for establishing chronic care models.

A recent review indicates that Care Plus may not be appropriate for patients who need intensive interventions requiring multiple primary health care contacts over a short period of time. Work by the Ministry of Health to address issues raised by the review is taking account of the interdependencies between Get Checked, High User Health Card (HUHC) and the project *Coordinated care: dependable systems for long term conditions*.

4.4 DHB work toward chronic care models

The NHC believes that work to implement the *Primary Health Care Strategy* will be more effective for people with chronic conditions if it is focussed within a chronic care model.

DHBs are at different stages of developing and implementing a chronic care model. Aspects of chronic care models are used by DHBs to improve specific services for people with chronic conditions. Diabetes, cardiovascular disease, and cancer are the three key priorities of most DHBs. Other common priorities include respiratory conditions, stroke and severe mental illnesses.

Many DHB Strategic Plans for the next five years prioritise reducing the incidence and impact of chronic conditions, and different aspects of chronic care models are used by DHBs to improve specific services. As part of implementing national health strategies and national guidelines, DHBs have been implementing initiatives for prevention and management of chronic conditions.

Specific chronic disease plans or strategies are being developed and implemented by individual DHBs or by DHBs across regions (for example the Midland DHB's Cardiac Services plan). Some DHBs are developing and implementing generic chronic care management programmes or plans (for example, West Coast, Taranaki, and Wairarapa). Aspects of it are being implemented by other Northern DHBs.

Some DHBs are addressing the needs of people with chronic conditions through developing an integrated continuum of care (Capital & Coast) or a care framework (Bay of Plenty). The focus of these systematic approaches is on improving service delivery and coordination of care for populations of need, such as people at risk or diagnosed with chronic conditions, older people, and people with disabilities.

The NHC supports the need for a stocktake of New Zealand initiatives in chronic care as part of identifying best practice for consistent service provision. It understands this is being undertaken by DHBNZ and the Health Research Council.

Implementation of the Counties Manukau Chronic Care Management programme

In the late 1990s, South Auckland Health began working collaboratively with the local Independent Practitioners Association to address preventable acute admission. Thirty separate pilot projects were initiated as part of a broader approach to integrated care, including four disease management pilots targeting people with particular chronic diseases (diabetes, congestive heart failure, chronic obstructive pulmonary disease and asthma). Independent evaluation of these four found:

- *significant reductions in morbidity*
- *significant improvements to the efficiency of health care delivery in the Counties Manukau region.* (Wellingham et al 2003)

After reviewing evaluations, the Counties Manukau Chronic Care Working Group recommended a generic approach to chronic care for the district. This is outlined in the plan for chronic care management by Counties Manukau. Based on a population health approach, the plan provides for chronic care management and coordinated care for targeted patients across primary, community and hospital settings. A major learning from the interim evaluation of the Chronic Care Management Programme was that a significant culture change is required in general practice to make chronic care management routine. One way in which Counties Manukau is now supporting this change is by rolling out self-management training and group education programmes for PHOs.

4.5 International responses to chronic conditions

United States

Most major health organisations and regions in the US have a service delivery framework designed to improve care for people with chronic conditions. The majority are based explicitly on the Wagner Chronic Care model or focus on one component of it. Additional models outlined in the NHC report include: Kaiser Permanente, Evercare, Chronic Disease Self-management Programme and the Pfizer approach. [See Chapter 3 for an outline of these approaches, each of which has its own defined direction].

United Kingdom

Implementation of chronic care models in the UK have built on changes to primary health care policy and existing initiatives. *The NHS Improvement Plan (2004)* and *Supporting People with Long-term Conditions (2005)* set out the British Government's plan for people with chronic conditions. Some core areas for effective shifts toward primary care in communities included:

- integration of primary and secondary care processes within strategies
- changing referral and discharge planning
- targeting high-risk patients across primary and secondary care.

A number of resources to support change have been developed by the NHS Institute for Innovation and Improvement. These include literature reviews to establish evidence bases, handbooks for practical guidance, and evaluations of pilots.

Improving outcomes of people with Chronic Obstructive Pulmonary Disease – primary care

- *Establish a system for creating, validating and updating a register of people with COPD:*
 - *agree on a definition of COPD*
 - *develop a register of people with a diagnosis of COPD (confirmed by spirometry and reversibility testing) including: assessment of acute response to bronchodilators, details of other co-morbidities, and hospital admissions*
 - *develop systems to maintain valid registers.*

Improving outcomes of people with COPD – primary care

- *Be systematic and pro-active in managing the care of people with COPD:*
 - *establish a multidisciplinary team to manage the care delivery*
 - *identify a lead clinician to coordinate the care*
 - *establish practice protocols (or customise existing protocols)*
 - *establish individualised care plans for patients, maximising self-knowledge and management*
 - *embed the use of protocols through the use of computerised templates*
 - *establish proactive call and recall arrangements for people with COPD*
 - *ensure people with COPD receive optimal care, including the use of drug therapies and effective interventions for treating depression and anxiety.*
- *Involve patients in delivering and developing their care:*
 - *maximise self-management by people with COPD*
 - *develop care plans in partnership with person, family/whānau*
 - *provide appropriate and comprehensible information on COPD, medications, community supports*
 - *respond to the cultural needs of the person, their family/whānau*
 - *undertake prevention by identifying smokers and discussing cessation options.*
- *Adopt a multi-disciplinary approach to ensure effective coordination of the care of people with COPD and to offer optimal therapeutic care:*
 - *ensure patients with COPD receive pulmonary rehabilitation*
 - *assess those at high risk and offer long-term oxygen therapy to those who require it*
 - *identify a coordinator of various health and support services required*
 - *develop intersectoral arrangements and initiatives for delivering services*
 - *develop appropriate crisis intervention services.*

Developed by the NHC, based on NHS Chronic Conditions Handbook and the Australia and New Zealand COPD Guidelines

Australia

Australia has built on primary health care reform, as well as existing disease policy and public health initiatives, to develop a national chronic disease strategy to encourage coordinated action. The Strategy is based on phases of illness and is supplemented by a set of five national service improvement frameworks plus a blueprint for national monitoring of chronic diseases and associated determinants. National directions are not prescriptive and allow for practical implementation at a local level.

Underlying principles of the Australian approach are similar to New Zealand, emphasising population health and reducing inequalities. There is a strong emphasis on health promotion and prevention. Strategic areas for action include:

- recognition of chronic conditions within a range of policy areas
- the need to reduce inequalities
- achieving significant and sustainable change
- building workforce capacity
- standardising medical procedures
- developing infrastructure with national data collection and information support.

At an implementation level there is a focus on the following areas:

- setting up registers and recall systems
- optimising support for self-management through referral to self-management programmes
- facilitating coordinated and integrated multidisciplinary care across services, settings and sectors
- strengthening prevention through intersectoral and community partnerships
- adoption of evidence-based approaches and data collection.

4.6 Conclusion

National strategies affirm approaches that are pivotal to addressing chronic conditions, such as population health and providing a continuum of care. Implementation of the *Primary Health Care Strategy* has formed a solid ground upon which to build changes for chronic care.

Work is progressing within PHOs on areas essential for chronic care models, such as improved data collection and effective multidisciplinary teamwork. The Ministry of Health is working with DHBs on structural issues that require resolution to more fully support people with chronic conditions. National action on workforce and information systems will be critical to successful implementation of chronic care models.

Addressing chronic conditions is a government priority and all DHBs have identified specific chronic diseases on which they are taking action. DHBs, PHOs, NGOs and community members throughout the country are engaging in innovative projects to increase access to services that prevent and care for people with chronic conditions.

Although a number of DHBs have begun working with chronic care models or parts of them, New Zealand has yet to consistently implement chronic care models or incorporate them into comprehensive district planning.

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- ▶ *The next chapter outlines some issues underlying the development of NHC recommendations for directions to address chronic conditions within New Zealand.*

5. Building on existing change

Addressing chronic conditions is a challenge, since people with chronic conditions exist across all populations and present at varied levels of service provision throughout their life. Achieving broad and coherent actions on chronic conditions within this complex field requires steady commitment, sound planning, and solid relationships.

This chapter provides background to recommendations in the areas of planning for consistent and comprehensive action, addressing inequalities and community relationships.

5.1 Development of a chronic conditions framework

Chronic conditions policies may be more successful when they encompass prevention, promotion and control strategies, as well as making explicit the links with other government programmes and community-based organisations. (Epping-Jordan et al 2004).

Key national strategies provide sufficient direction to address chronic conditions at a national level. However, the NHC believes that implementation of strategies at a local level can be more effective for people with chronic conditions if focussed within a chronic care model.

Many DHBs have begun implementing a chronic care model, or aspects of chronic care models, to improve specific services for people with chronic conditions. The *Primary Health Care Implementation Work Programme* provides strong support for the implementation level of many areas of the model. The NHC wishes to build on this by recommending that each DHB develop and implement a chronic conditions framework within its own district. In regions where there is an existing collaborative arrangement with another DHB, DHBs may prefer to develop their plans jointly.

Chronic conditions policies are most effective when they work across diseases and emphasise management of populations (Epping-Jordan et al 2004). The proposed chronic conditions framework is intended to provide the breadth within which specific health promotion, prevention and management initiatives can be set.

The frameworks are intended to provide a consistent approach to planning and delivering services for people with chronic conditions. The NHC is asking the Ministry of Health to ensure consistency in framework development around the key components identified in Table 5. Key components should allow DHBs to respond to their districts' needs and priorities. Every DHB is at a different stage of readiness in responding to such a comprehensive plan, both in terms of relationships within the district and initiatives under way for chronic conditions.

Table 5. Key components of proposed chronic conditions frameworks

- *Addressing the needs of specific population groups (Māori, people of low socioeconomic status, Pacific peoples) based on a population health approach and a reducing health inequalities framework through implementing equity tools and monitoring processes.*
- *Integration or alignment of sectors, providers, disciplines, and initiatives relevant to chronic conditions to provide services across a health continuum.*
- *A chronic care coordinator within each DHB providing leadership and guidance to address problems that arise for people with chronic conditions and, supported by the DHB, work toward effectively aligning and integrating services.*
- *Whole-district planning processes that ensure clarity of roles and responsibilities (including resourcing and funding) within and across sectors.*
- *A PHO care and coordination model based on national guidelines.*
- *Chronic care coordinators at a PHO level.*
- *Training for new primary health care roles including self-management and effective multidisciplinary team functioning.*

The NHC is envisaging these key components being supported by:

- *national development of models, guidelines, and resources for components of national initiatives such as self-management*
- *national information support systems, including data collection and analysis, assessment and referral processes*
- *national development of tools measuring successful elements of culturally appropriate services.*

The NHC is recommending that the Ministry of Health work with all DHBs to develop chronic conditions frameworks that include key components by June 2008, with a view to implementing frameworks from July 2008. It believes this is achievable based on the prioritisation of chronic conditions for 2006/07, work programmes in primary care 2006/10, and current levels of understanding of chronic care models within the sector.

5.2 Reducing health inequalities

There is overwhelming evidence that chronic diseases disproportionately affect Māori, Pacific peoples and people on low incomes. The need to reduce health inequalities remains urgent despite being a key government priority, an aspiration in key policies and a statutory responsibility of DHBs.

Work to prevent and manage chronic conditions should ensure outcomes for groups at greatest disadvantage improve earliest and most significantly. If this approach is not taken, health inequalities are likely to grow. Health promotion directed at the general population, for instance, tends to be least successful among those already at greatest risk. At the same time, the enhanced capability being developed within the health system to reduce inequalities will benefit all people with chronic conditions.

What more needs to be done?

Leadership is required to remove barriers to achieving equalities of health at organisational levels. Within most DHBs, further support for the development of culturally appropriate services is required. The Health Equity Assessment Tool (PHAC 2004) and the Intervention Framework (NHC 1998; Ministry of Health 2002) could be used more consistently within policy and organisational processes. Some DHBs have developed and are implementing strategic inequalities plans; sharing these with other DHBs could improve quality of planning and delivery of services.

There is room for greater participation of indigenous and ethnic populations in governance. PHOs are required to involve local Māori and community groups in governance. However, there is still unrealised potential for local groups to have an impact on design and planning of services, workforce development, evaluation and review processes.

Cultural competence or cultural safety training could be undertaken more consistently across the country. Greater individual commitment is required to develop cultural competence or safety in relationships with people from indigenous and ethnic groups. The NHC believes that every health professional and organisation has a duty and responsibility to address racism and equity of access to health services. The evidence that use of objective clinical assessment tools increases access to services for Māori and Pacific peoples, shows that implicit racist attitudes need to be overcome at the health professional level.

Collaborative action is required within the health sector and with other sectors to address the wider determinants of health inequalities. There is scope for strengthened partnerships and long-term initiatives between DHBs, the Ministry of Health, the Ministry of Social Development, Te Puni Kokiri, the Ministry of Pacific Affairs and other government organisations.

Culturally accessible service provision

Culturally appropriate services aim to reduce health inequalities, increase access to quality care, and improve health and wellbeing outcomes.

New Zealand has strong legislative direction for cultural competence in the health workforce. Many of the key health and disability strategies refer to the provision of 'culturally appropriate services' or 'building responsive services' for particular populations. All providers have a responsibility to provide services that are culturally appropriate to their local populations and are accountable to local communities.

Implementation of approaches to provide culturally appropriate services is not consistent. In part this is due to lack of understanding of, and lack of evidence on, the components of culturally appropriate service provision that are effective for health outcomes. Being able to evaluate components of culturally appropriate services is a necessary step to having effective processes for assessing culturally appropriate services.

The NHC acknowledges the difficulty in designing tools to undertake this task, since any evaluation attributes judgements that are socially and culturally formed. In addition, culture, being woven into the fabric of life, cannot be separated into components easily. Particular skills, both in research and in understanding of cultural frameworks, are required and there is a need to develop capacity in this area.

NHC consultations showed funding for Māori and Pacific providers did not cover culturally appropriate aspects of service delivery. As funding for Māori providers has not been reviewed in the past five years, the NHC recommends the next review of funding take this into account.

Involving family/whānau appropriately

International research within all cultures shows the benefit for people with chronic conditions of having support from family/whānau for both practical assistance and wellbeing. Involving family/whānau in supporting self-management increases the likelihood that healthy behaviours will be adopted. Since family and whānau members are likely to have similar risk factors to the person with the chronic condition, involving family/whānau can also be an effective preventative approach.

While greater involvement of family/whānau results in significant impacts on health and wellbeing for the person with a chronic condition, it is even more critical for Māori and Pacific peoples. Participation of family/whānau is a key way in which relationships with providers can be built to increase access for Māori and Pacific peoples.

Involving family/whānau is endorsed by current strategies. However, this is still not happening consistently.

Access to services and through the health system

Ensuring all populations have access to health services is fundamental to reducing inequalities. Cost of health services, lack of suitable transport, and reduced social or employment opportunities all constitute barriers to accessing health care. For those with one or more chronic conditions, this is compounded by long-term and frequent use of health and social services. Barriers to access are prominent among population groups with poorer health status: Māori, people on a low income, Pacific peoples and migrant groups¹³.

A number of initiatives in primary health aiming to address access are promoted through chronic care models, such as placing services within community settings and providing outreach services to those who cannot get to them. Studies have also suggested increasing the range of ways in which services are delivered. For example, provision of services for groups or families has been shown to be effective and is also culturally appropriate.

In addition to the need to address access to services, there is a need to address access through the health system. Data in this area demonstrates the cumulative impact on inequitable provision of services along a disease path. Counties Manukau DHB (2006) is aiming to reduce inequalities through using tools and operating procedures that provide an objective way of assessing clinical need within clinical decision processes. A recent evaluation indicates increased provision of secondary services to Māori and Pacific populations. The NHC is recommending adoption of equity tools within all DHBs as well as monitoring of access to health services and provision of health interventions to indigenous and ethnic minority groups¹⁴.

The NHC believes the issue of access is an ongoing and complex one that could benefit from further critical analysis.

13 Although data on this is currently limited, there is some evidence that Asian health issues should be further investigated (see Appendix 2).

14 The issue of assessment criteria that exclude people of similar need is relevant to people with chronic conditions and is referred to in section 6.1.

5.3 Planning community engagement

Whole-of-government approach

Chronic conditions cannot be managed by the health sector alone. Collaboration with other sectors and partnerships between local and central government are features of chronic care models with demonstrated success (Wagner 2001b). Constructive relationships between the health sector and local government, Ministries of Social Development, Education, Housing, Transport and others are critical for achieving health improvements and reducing inequalities (PHAC 2006b). The more 'structural' (integral to our physical environment and daily habits) the intervention, the more impact is made at a population level (PHAC 2004).

The NHC strongly supports a whole-of-government approach that intervenes at:

- a structural level to reduce social and economic inequalities
- an intermediate level to influence lifestyle choice
- a service level to directly assist people with chronic conditions.

Leadership continues to be needed to engage cross-sector action within areas that promote healthy living and support intersectoral work programmes.

Chronic care models and key health directions aim to provide communities with empowering and effective roles within the health sector. When effective, PHO governance representation provides good groundwork for community engagement to address chronic conditions.

Need for planned community engagement

Chronic care models often refer to integrating policy at a community level, since this has the potential to minimise fragmentation of the health care system. (Epping-Jordan et al 2004)

The NHC looks for community engagement to take place in a planned and sustainable way. Undertaking community development in a coordinated way can assist with providing consistent messages to the community and reinforce action on health determinants. It can also increase efficiencies (Majumdar 2006). Lack of planning in community engagement is likely to result in a reduction of goodwill about community involvement in the future, duplication of resources and efforts, and fewer opportunities to share good practice.

Sustainable relationships are of particular importance for chronic conditions because of their long-term nature.

At a strategic level, sustainable relationships:

- require whole-district planning and support culture change
- allow time to embed good processes (identification of a shared language and concepts, exploration of problems and motivations, clarification of roles, determination of decision-making and evaluation processes)
- overcome administrative barriers (alignment of planning cycles, adjustment of contracts to achieve joint funding)
- are outcomes-focused (and outcomes are able to be used for assessment and implementation purposes)
- acknowledge resources involved (current priorities, additional time of joint projects).

Non-government organisations

Both the *Primary Health Care Strategy* and chronic care models put forward the need for greater interaction with, and responsiveness to, people in the community. This is reflected in moves toward redistribution of power in PHO governance arrangements, increased community consultation and adoption of self-management approaches to care. Strong community relations have historically been a strength and point of difference for NGOs. Implementation of the *Primary Health Care Strategy* has raised questions for NGOs around role and future viability. In response to local issues, DHBs and PHOs have developed a range of relationships with NGOs including: no contact, involvement in PHO boards, memorandums of understanding, formal contracts for Services to Improve Access, and NGO contracts devolved to PHOs.

The *Primary Health Care Strategy Implementation Work Programme* will be addressing clarity around NGO roles. The NHC looks for this work to provide the basis for achieving integrated service provision across the community for people with chronic conditions. It therefore encourages a focus on purchasing services that meet specific needs, rather than the needs of a service provider.

There is potential for greater innovation and collaboration between community-based groups in funded initiatives. The NHC has recommended NGOs receive joint funding with relevant local indigenous and ethnic minority groups to ensure provision of resource materials and design of services are culturally appropriate. Effective consultation (for example to develop culturally appropriate material for family/whānau) involves time. The NHC believes this should be acknowledged more tangibly for these community-based groups.

Public health action

Prevention strategies are often insufficiently connected to, and understood by, the mainstream health system. New alliances between public health, clinicians and consumers are needed. (National Public Health Partnership 2001)

New Zealand's 12 Public Health Units work with DHBs and across a number of sectors on the essential task of creating a healthy environment. Many of the modifiable factors affecting whether people develop chronic conditions lie outside the health sector. For example, although healthy lifestyle choices appear to be an individual matter, choices are made in the social, cultural and economic contexts in which people live, work, and play. These contexts are controlled by public policy, so it is crucial that policy development takes health impacts into account. Examples of healthy public policy include healthy housing, urban design that encourages physical activity as part of everyday life, and regulation of unhealthy products such as tobacco and foods with high fat and sugar content.

NHC case studies and communities

The NHC case studies highlighted the importance of cross-sector communication, and participants suggested co-location of social and health services as a potential avenue for improving both service delivery and cross-sector understanding (for instance, placing the local WINZ office in the hospital). Provider consultations and submissions asked for partnerships with the Ministry of Social Development to jointly fund initiatives that promote positive ageing and social connection.

NHC case studies consistently portrayed the impact of community attitudes on self image and experience of living with a chronic condition. Lack of understanding of people with chronic conditions led to stigma, blame and avoidance by others. Social expectations that people can be cured of a disease led to fluctuations in their health not being tolerated.

Health and other service-based organisations aiming to develop knowledge of chronic conditions have an opportunity within work programmes to promote positive support for people with chronic conditions. Health professionals consistently promoting a common district vision can effectively influence local community attitudes.

Intersectoral initiative: Providing Access to Health Solutions (PATHS)

PATHS is a joint initiative between the Ministry of Social Development (through Work and Income New Zealand) and some DHBs. The aim of the programme is to help people on the Sickness and Invalid's Benefits, many of whom have chronic conditions, to find employment. PATHS connects people with health and employment services so they can better manage their chronic condition and find work. Access to a range of health and employment interventions are provided, such as pain clinics, fitness programmes, visits to health professionals, help with CVs and preparing for job interviews. As it has become apparent that a significant proportion of people participating in the programme have one or more chronic conditions, access to physical and mental health services is offered under PATHS in some regions. (Ministry of Social Development 2005a)

Initial Ministry of Social Development evaluations show that PATHS has assisted some participants to find employment. In the Wellington region, one in three participants has found full- or part-time employment. ('Getting-off-the-benefit scheme works for some'. Dominion Post, p. 17: 3 June 2006)

Intersectoral initiative: The Healthy Housing Programme

The award-winning Healthy Housing Programme in Auckland and Northland is an example of intersectoral collaboration where preventative health measures are achieved through environmental intervention. The aim of the project is to reduce the incidence of chronic respiratory conditions (and infectious diseases) by improving the energy efficiency of homes and improving access to primary care.

The Healthy Housing Programme focuses on assisting families living in houses owned by Housing New Zealand Corporation. It targets high decile areas where there are high health needs. The DHB undertakes health assessments of families and provides referrals to health and social services as needed, as well as addressing their housing needs.

The initiative involves partnerships between Counties Manukau, Auckland and Northland DHBs, the Housing New Zealand Corporation, Auckland Regional Public Health and the Energy Efficiency and Conservation Authority (EECA) and collaboration with a wide number of other agencies, including Work and Income New Zealand. Extensive consultation has built firm community networks. (Health Innovation Awards 2005)

Similar healthy housing initiatives are occurring in other parts of New Zealand with good results.

Since its beginning in 2001-2005, nearly 3,200 families had benefited from the Healthy Housing initiative. An evaluation of the pilot programme showed that, of the families who had participated in the pilot, there was a 37 percent reduction in hospital admissions. (Housing New Zealand Corporation, Counties Manukau DHB, Auckland DHB, and Northland DHB 2005)

Preliminary results from the Housing, Insulation and Health Study by the Wellington School of Medicine found that adults and children in insulated houses reported visiting the GP less often and were admitted to hospital less often for respiratory conditions. The study also found a significant improvement in the self-reported health of adults and children living in insulated houses, compared to those that were not.

The study interviewed select households before and after half of the household homes were retrofitted with insulation. At the end of the study the remaining households were also insulated. (University of Otago 2003)

5.4 Conclusion

New Zealand has a range of national strategies that can contribute to providing direction for chronic conditions. However, implementation of these strategies needs to be more coherently focussed and actions placed within chronic care models. The NHC is recommending that a comprehensive chronic conditions framework be developed by DHBs, based on key components of chronic care models.

Overwhelming evidence that chronic diseases disproportionately affect Māori, Pacific peoples and people on low incomes, makes addressing health inequalities urgent. Further action is required to provide culturally accessible services and increase access through the health system. Since reducing health inequalities is already a national priority, the NHC is seeking leadership and commitment to remove barriers at organisational and individual levels.

A number of socioeconomic determinants of health lie outside the health sector, requiring whole-of-government interventions. Community engagement needs to take place in a planned and sustainable way. The NHC is recommending whole-district planning processes involving NGOs, public health, and other sectors as appropriate.

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- ▶ *The next chapter outlines some issues underlying the development of NHC recommendations for service provision within New Zealand. Two broad areas are focused on: integration of structures and services, and provision of effective chronic care management and coordination.*

6. Systems and service provision

People with chronic conditions use a wider range of services more frequently than the general population. Their experiences of gaps in the health system highlight the need for an integrated policy base and organisational alignment.

This chapter focuses on systems and service provision. Background to recommendations is provided in the areas of integrating structures and aligning organisations. Information systems required to support this are briefly discussed. Service provision for people with chronic conditions within PHOs is considered, workforce considerations are briefly outlined¹⁵.

6.1 Integrating structures and aligning organisations

The NHC is recommending the Ministry of Health work with DHBs to bring about comprehensive alignments within health and social sectors, between health providers and services, and across health disciplines, to benefit people with chronic conditions. The NHC is recommending that the Ministry of Health report annually on this work.

Broad areas for integration or alignment include:

- public health, primary health
- primary and secondary levels of the health system
- Māori, Pacific peoples, NGO, mental health, disability, health providers
- mental and physical health professional disciplines
- funding mechanisms and categories.

Systems redesign is a key feature of chronic care models. Aligned systems feature collaborative relationships that clarify provider roles and enable clearly-stated outcomes. Chronic care models underpin integrated care across the health continuum with effective information systems.

There are benefits to both providers and users of services in achieving integrated health systems. For providers, the gains are those of increased efficiency, improved quality, and reduced risk. These are achieved by:

- rationalising programmes across the range of providers on the basis of principles of patient need, equity, evidence of effectiveness, and provider role clarification
- reducing inefficiencies due to separate information systems, payment structures and quality measures
- reducing treatment errors through increased information sharing and effective coordination
- eliminating duplication of patient tests and assessments
- reducing risks to patients through clear roles and accountability.

Chronic care models focus on the person and their family/whānau when working toward integrated care. There are a number of benefits that flow from this for people with chronic conditions. Some of these include:

- reduced testing and assessment
- consistency of messages from all health providers
- access to a wider range of services
- comprehensive and coherent management plans
- good communication between the person with chronic conditions and their care team and among care team members.

A continuum of care underlies integrated services

The NHC seeks an integrated continuum of prevention and care¹⁶. Integrated or aligned structures and services benefit all people, especially those with chronic conditions who need to access a wide range of services, or access services more frequently.

15 Both information systems and workforce considerations are fundamental to systems and service provision. However, the NHC considered there was sufficient input from the Ministry of Health and the sector in these areas and so has limited comment to outlining key areas from chronic care models and evidence-based research.

16 A continuum of care is broadly defined by the NHC as an integrated or 'joined up' approach to the provision of health and disability services, both community and hospital based. A continuum of care incorporates a life course approach to the design and delivery of services that is holistic and person-centred in a family/whānau context.

Integrating and coordinating hospital and community-based care can increase access to care, improve patient satisfaction, lower resource use and reduce costs. Integrating care has also been shown to improve quality of care and some clinical outcomes (Singh 2005).

Considerable work is required to implement integrated approaches. Work to align or integrate primary and secondary care requires attention to broad areas such as funding allocation, workforce development, knowledge systems and service provision.

The NHC is seeking the following outcomes from a continuum of care relevant to people with chronic conditions:

- equitable and needs-based service provision
- accessible, flexible and timely services
- coordinated services with appropriate information-sharing among organisations
- collaborative partnerships between health and other sectors
- effective information systems.

The need to nominate a central contact person

The NHC is recommending that there is a chronic care coordinator within each DHB who can provide leadership on chronic conditions issues through:

- ensuring issues for people with chronic conditions are addressed
- providing guidance on training and resource needs for those working with chronic conditions
- providing an impetus to engage in proactive work to align and integrate services.

The purpose of having a contact person for chronic conditions is to ensure that one person has an overview of the breadth of areas that require progress. The NHC is not intending to make one person responsible for undertaking work that is the responsibility of, and central to, the DHB work programme and Minister's priorities.

The NHC believes high-level management support for the contact person will be required to enable this person to raise actions required to integrate or align services across the health sector. Support for this role may come from being part of a team, or from reporting lines within the DHB. However, the NHC strongly suggests that the contact person works closely at an operational level to form the type of relationships that bring about practical change. The NHC envisages the person in this position having effective working relationships with those in the DHB contributing to the chronic conditions framework, as well as with PHO coordinators who are implementing best practice guidelines, or facilitating education and training for workers in the area of chronic conditions.

Proactive work to align and integrate services is expected to begin to address issues that are indicative of larger system disjunctions including: difficulty in obtaining referrals, difficulty in coordinating care for co-morbidities, gaps in services, over-assessment, inability to form a coherent care plan, and lack of accountability when the person with chronic conditions is dealing with more than one provider. Some of these areas are already part of current work programmes. For example, the *Primary Health Care Implementation Work Programme 2006/10* plans to strengthen effective links across primary and secondary services.

Overlaps in service provision and usage

The NHC is looking for programmes to be rationalised across the district on the basis of patient need, equity, evidence of effectiveness and provider role clarification. It is recommending coordination or integration of services where there are overlaps in service provision. The process of establishing whole-district chronic conditions frameworks is expected to contribute to identifying where overlaps exist.

Planning to avoid duplication of services across DHB programmes, and community and cross-sector groups, is not intended to reduce opportunities for community groups. For example, where community programmes offer healthy lifestyle options of exercise and diet for specific diseases, the district may decide it is more efficient to offer these as a generic component for a range of programmes. As a result, a community group may offer a similar service within a wider district programme, continue to offer a culture-specific service, or develop a new service that meets both district and organisational needs.

Other forms of duplication arise from lack of flexibility in the provision and scope of some services. For example, when a person over 65 receives personal care, housework and shopping, different contracts and providers may be involved. A generic worker may simplify administration and reduce distress for a person who is not well enough to wish to interact with three different people.

Duplication of patient tests and assessments is an area of service usage overlap that costs time and money. NHC case studies showed multiple assessments were also often distressing to the patient. Direct access to diagnostic tests can reduce use of the health care system (Singh 2006). [Refer to Chapter 6.2 for electronic system support needs]

Shifting care from hospital to community-based services

In presenting the need for integration and coordination to achieve a continuum of care, the NHC is not unilaterally endorsing a shift of care from hospital to community-based services. Such a shift has been a major thrust of the UK approach. The latest report from the NHS (Singh 2006) presents a review of evidence in this area. The report found that in general, merely shifting the location of services to the community increased costs and at times reduced quality of care. Instead, good outcomes were produced by sound consideration of where care was best provided and effective processes to support care wherever it was located.

Discharge planning

Referrals and discharges, which sit at the interface of organisations or sectors, highlight systemic gaps and organisational differences. International implementation of chronic care models has increased research in this area. Some research findings from Singh (2006) include:

- use of guidelines for referrals to hospital by GPs can reduce hospital admissions
- altering staff mix in hospitals affects how long people stay in hospital and having dedicated discharge planners can reduce average length of stay
- follow-up home or telephone visits after discharge from hospital can reduce subsequent unplanned hospital admissions.

NHC case studies and submissions strongly supported the need for improvements to discharge planning from hospital. This area is within the *Primary Health Care Implementation Work Programme 2006/10*.

Some DHBs are providing good discharge planning through undertaking the following actions before the person leaves hospital.

- The GP and significant health provider (eg NGO/community organisation) is notified by fax, phone or email, that the person is being discharged.
- Hospital staff clarify any changes in medications and/or doses and highlight changes for the GP. Any tests that are pending and need to be followed up are highlighted for the GP.
- Clear instructions are given to the patient about when they need to be reviewed by their primary care provider, attend rehabilitation or attend a specialist appointment.
- Copies of community referrals are sent by mail or email from hospital nursing staff to PHOs shortly after discharge.

GPs have spoken positively about being informed of their patient's condition and being seen as part of the person's care team.

NHC submissions showed that lack of discharge planning particularly affected people in rural areas. A number of submissions from people with chronic conditions raised the need for specialist nurses (for example paediatric nurses) in rural areas to give assurance that the best care was being achieved in home care. Many of the areas of uncertainty were around symptom management. Support for self-management could have assisted these transitions.

Alignment and integration of funding

There are differing views in the sector about integration of funding for projects that sit across current funding streams. Funding already committed to services is not flexible. However, with sufficient forward planning, funding based on a population-based funding formula can be used flexibly. The NHC suggests the way forward, compatible with chronic care models, is to focus on funding becoming needs-based and moving contracting toward an outcomes focus. For example, the input focus of full-time equivalents (FTEs) is less flexible than an outcome of improving independence.

Achieving joint funding on projects between organisations may take additional time because of aligning planning cycles or having to re-write service specifications for new areas. Other barriers to overcome include inefficiencies due to separate information systems, payment structures and quality measures. The *Funding for Outcomes* pilot project (2004-2007) initiated by Cabinet is an example of 'joined-up' funding to providers in the social sector. Further work could be undertaken to review funding responsibilities and eligibility criteria to ensure consistency of funding across population groupings.

Funding criteria for people with disability and chronic conditions

International data¹⁷ shows there are significant numbers of people with both chronic conditions and disability. The NHC is recommending data be collected to establish the overlap within New Zealand.

People with chronic conditions in NHC case studies consistently asked for the same kinds of home support services that are provided for disabled people. DHBs fund personal health and the Disability Services Directorate funds disability support services for people under 65 years. In some areas, the eligibility criteria for long-term support services under either funding stream is neither clear nor consistently applied to people with chronic conditions. The Ministry of Health and DHBs are reviewing current funding criteria that make it difficult for some people with chronic conditions to access long-term support services [see Table 4 in chapter 4.2].

People with chronic conditions and disabled people require services for both medical care and social support. NHC provider submissions stated that disabled people with chronic health problems experienced difficulty accessing DHB-funded health services available to people with chronic conditions, while people with chronic conditions had difficulty accessing social supports available to disabled people. Provider submissions suggested integrating health and disability outcomes and measurements in service delivery. There is potential for stronger partnerships between Needs Assessment Service Coordinators (NASCs) and PHOs, especially in the area of intersectoral linkages.

Integration and cost savings

While it is possible to estimate cost savings within specific disease management programmes in terms of medication for particular populations (see Van Korff et al 2002; Wagner et al 2001c), it is more difficult to determine cost savings from integrating or aligning service delivery. There is some evidence that collaboration may reduce compliance and transaction costs for funders, facilitate service delivery and simplify and improve the funding of providers (Majumdar 2006). Further New Zealand-based evidence is needed on the cost savings of integration.

Alignment of mental and physical health

People with mental disorders have a higher prevalence of several chronic physical conditions (Ministry of Health 2006). However, mental and physical health have historically developed separate approaches.

Fundamental disjunctions between the academic disciplines of mental and physical health manifest in uncoordinated service structures. DHBs and providers cannot solve this issue alone. Involvement of training organisations in rethinking disciplinary alignments is required. At the DHB level, joint work programmes provide an opportunity for mental and physical health professionals to build collaborative relationships that produce clarity regarding roles, skills and services. Benefits may be gained from sharing and adapting successful approaches from other disciplines, as each discipline has particular strengths to offer. Cross-discipline supervision (usually an informal consultation over appropriate referrals) has proven valuable in a number of districts in terms of improving provision of appropriate treatment and referrals.

Cross-discipline understandings improve treatment and outcomes for a person with both a mental and physical chronic condition. NHC submissions showed that GPs required greater support to treat depression in people with chronic conditions. They also showed that mental health workers required more support to recognise when symptoms required referral for physical care. A number of submissions from pharmacists expressed concerns over potential drug interactions for people with both a physical and mental health condition when care was not coordinated across organisations.

17 An American study found that the total population of people with a chronic condition was 125 million, and the total population with a disability was 53.8 million. There were 43.2 million people with a chronic condition and a disability, 81.8 million with a chronic condition and no disability and 10.6 million with a disability and no chronic condition (Kane et al 2005).

The NHC welcomes action to ensure that the physical health needs of people with mental illness are being appropriately met. Work toward implementing *Te Tāhuhu – Improving Mental Health 2005-2015*, has formed the basis for closer relationships between mental health and primary health care. A number of the areas of *Te Tāhuhu* directly benefit people with chronic conditions (Minister of Health 2005). The mental health initiative *Knowing the People Planning* is specifically intended to bring about closer alignment of mental and physical health. Additional areas congruent with a chronic care model include continuity of care between mental health and other health services, community development, and cross-sector engagement. *Te Kōkiri – the mental health and addiction action plan*, asks DHBs and primary care providers to address the physical health needs of people most severely affected by mental illness and those suffering severe ongoing physical consequences.

6.2 Effective information and knowledge systems

Integration and alignment of services rests on effective information and knowledge from consistent data collection, effective communication systems, and sound processes to build knowledge.

Data collection is fundamental to providing information to improve the health of populations. Data gathered as part of practice management systems reduces additional administrative involvement. Without accurate population data, it is not possible to address inequalities, plan interventions, estimate costs or be accountable to an organisation's potential and actual populations. A key need in this area is the development of systems capable of providing both local and national views of populations.

Effective information flow produces health system efficiency and reduces treatment errors and omissions of care. Reviewing information flow across services provided to people with chronic conditions is a critical area, as is the implementation of systems that facilitate shared decision-making and treatment across providers.

Chronic care models rely on effective electronic information systems for:

- information capability to support population health approaches: disease registers, patient databases, risk assessment tools
- information systems to support proactive primary care over time: contact of at-risk populations, monitoring and follow-up, performance feedback
- clinical decision-making support: evidence-based guidelines, electronic reminders in practice management systems
- coordinated care systems to support timely quality treatment: accessible by the whole of a care team and the patient across providers, sharing of patient information across organisations, access to standardised information facilitates coordination
- integrated systems capability: standardised e-referral, e-assessment processes and capacity to access data across disciplines, institutions and providers; supporting electronic transaction processing, and integrated funding arrangements
- feedback and reporting to ensure quality service provision and improved patient outcomes.

These areas require substantial enabling. [See the Health Information Strategy for proposals in these areas].

Electronic tools for self-management

Electronic tools can effectively support self-management and facilitate communication between the person with the chronic condition and their care team. There are several electronic tools available to assist patients and their health care team to monitor a person's condition and assess when further intervention is needed. These tools may:

- assist a person to decide when it is time to visit the doctor (risk assessment tools)
- provide information on what to do when difficulties arise with specific conditions (decision support tools)
- allow an ongoing history to be built for use by the person and their team (monitoring tools)
- enable the person's electronic care plan (including medications for review, contacts) to be available on a secure website accessible to both them and the team (coordination tools)
- provide accurate and current information on the person's condition/s (analysis and reference tools).

The NHC understands the Ministry of Health is developing a toolkit on self-management. The NHC suggests electronic options for provision be considered including:

- community-based updatable electronic information booths accessible by people with chronic conditions who don't have web-based access
- a Ministry of Health provider website to support self-management.

Coordinated care tools and processes

Chronic care models rely on information systems designed to facilitate coordination and integration of care. Such systems enable analysis of data, have the capacity for each team member to update data and access information relevant to the care plan, and use evidence-based guidelines for decision-making.

NHC submissions agreed that sharing appropriate information across health providers and other sectors and having electronic systems to support this, is pivotal to improving coordination of care. Coordinated care requires a number of areas of work to achieve nationally standardised admission, assessment and referral processes, such as the development of a minimum data set for electronic referrals sought by the Health Information Strategy.

The *Foundation Programme* in Masterton, and the assessment and care planning tool InterRAI, are examples of systems and tools enabling effective chronic care coordination. Features compatible with chronic care models are:

- PHO-based system: systematic approach to data entry, creation and validation of disease registers, electronic tools to facilitate risk management, patient call and re-call, incorporation of evidence-based guidelines, clinical performance reporting and auditing of chronic disease management outcomes
- DHB-funded care coordination team system: systematic approach to collecting data, comprehensive assessment of health and social needs (including pain and depression assessment scales), capacity to be shared across team and providers, electronic tools to facilitate risk management, patient alerts, incorporation of evidence-based guidelines, clinical performance reporting, and capacity to analyse outcomes of interventions.

The InterRAI tool is currently being trialled in New Zealand with people over 65 years. The NHC is interested in trialling the tool for people with chronic conditions who are under 65 years, particularly where these people require services from a multidisciplinary team and/or across a range of organisations.

Access to web-based information services for coordination

Care coordination requires access to databases on community providers and resources. NHC provider submissions noted the extensive time spent in creating and maintaining a list of community resources. The NHC suggests purchasing services that are updated through the organisation providing the database. Development of community databases has the potential to contribute to whole district planning of services.

The NHC acknowledges that DHBs are entering into or have entered into business arrangements for web-based information services. Counties DHB, Waikato DHB, Lakes DHB and Taranaki DHB have purchased a service that has:

- listings of groups and resources that are updated by the organisation providing the web-based service
- a process for community input into design of the web-based service so that it meets local needs
- listings that are vetted by a local advisory group
- search functions for organisations, specific health professionals by ethnicity and service type, symptoms and health categories, maps, information to support self-management
- the capacity to be shared across all regions with the service
- the capacity to be provided using the PHO's internet access or provided as a standalone kiosk (satellite link).

Some electronic and interactive information services being provided are collecting demographic data that shows high access by young people on low incomes who would not traditionally use PHOs. These young people are using web-based information services as information 'one-stop-shops'.

This raises the question of how health services can evaluate the effect of information on health outcomes for this population. If the young person uses the information to contact a health or social service provider, this can be recorded at the point of access. If access to information does not lead to the person using a provider, it is harder to evaluate the effect of information on their health outcome. However, on the basis of demographic data collected by the website, it would be possible to set up focus groups within these populations at a local level and qualitatively explore the use made of the information.

Guidelines and pathways (decision support)

The NHC supports the development of pathways of care for specific diseases when they are placed within a chronic care model. The latest review of evidence on pathways found they may reduce hospital use by some populations (Singh 2006).

Chronic care models endorse electronic clinical decision support systems supported by evidence-based guidelines. Within New Zealand, two areas for improvement are achieving consistency of guidelines/protocols and integrating advice with electronic system. The NHC encourages practitioners to play a greater role in providing feedback on guidelines to the New Zealand Guidelines Group (NZGG). Feedback is valuable when it builds New Zealand practice-based evidence, identifies gaps, and alerts the NZGG to new areas of evidence that could be included on future programmes, subject to funding.

Privacy issues

The NHC is recommending that the Minister of Health work with the Privacy Commissioner to ensure that the legal framework to preserve patient privacy and protect health information from misuse is kept up to date with the changes in collection and use of this data. In particular, improved coordination of care for patients with chronic conditions is likely to require increased review of, and access to, patient records as part of routine treatment, and also for purposes of audit¹⁸.

Summary of work in progress

The *Primary Health Care Strategy Implementation Work Programme 2006/10* requires effective data collection and information systems. For example, improving population health approaches rests on improved data collection. Strengthening coordination between secondary services and primary care rests on implementation of electronic systems supporting standardised assessment and referral. Standardisation requires leadership from the Ministry of Health, as well as the active participation of organisations across the whole of the health sector.

In addition to current work programmes, there are opportunities for enriching data collection at existing points of collection. For example, some DHBs collecting data on disabled people for funding purposes are also collecting data on the person's chronic conditions to increase information on co-morbidities.

The *Health Information Strategy* outlines action on coordinated and integrated systems. This is expected to result in timely access to information, particularly in receiving results of tests and consultations across primary and secondary organisations. Improved access to information across health professionals is expected to reduce medical and administration errors, such as medication conflicts and lack of follow-up.

The Ministry of Health is putting forward a business case for systems development in 2007. Four key directions are: population health, targeting care to individuals, performance improvement and evidence, and care coordination and integration. Key directions contain specific action areas, such as defining communication protocols and formats to improve communication between health and social care professionals.

Systems capable of operating together to increase access to information and improve service delivery are essential for a wide range of actions critical to improving care for people with chronic conditions including: increasing coordination between health and mental health, reducing duplicate assessments by different providers, and assisting support for self-management. However, making decisions on operating systems is complex and requires leadership across the sector. Systems not only need to be agreed upon, but the use of them requires guidelines to ensure consistency of data to transfer.

6.2.1 Integration and data initiatives

A key feature of the following initiatives is provision of a single point of contact for patients either through a coordinator (the Hutt Valley DHB *Frequent Attenders Care Coordination Programme*), nurse (the *Foundation Programme* in Masterton), or care coordination centre (the Capital & Coast Care Coordination Centre) to facilitate access to health and disability support services.

¹⁸ The issues involved in access to patient records for audit purposes are discussed in depth in the report of the *Ministerial Inquiry into the Under-reporting of Cervical Smear Abnormalities in the Gisborne Region* (Duffy et al 2001) and in the subsequent report of the National Ethics Advisory Committee (Moore et al 2004).

An evidence-based assessment and care planning tool is used in each of the profiled initiatives to broadly assess a person's health and wellbeing needs. The InterRAI assessment tool being trialled by Capital & Coast DHB is also being trialled by other DHBs in different service settings. Establishing a care plan with the patient, providing support for self-management and case management for people with high needs are other key features of initiatives that aim to provide continuity of care.

Care coordination: The Hutt Valley DHB Frequent Attenders Care Coordination Programme

The Hutt Valley DHB Frequent Attenders Care Coordination Programme, for patients with chronic conditions appoints a care coordinator for each patient as a single point of contact. Care coordinators undertake home visits to discuss health issues, check that patients understand their condition and are following their medication regime, keep in contact with patients by phone, liaise between services on behalf of the person, encourage self-management, and update the person's care team to avoid any duplication and miscommunications.

The programme greatly reduced hospital admission in the first 18 months it was running. A sample of five patients showed 159 bed days were saved, 22 admissions were avoided and the number of visits to consultants was reduced by 14. (Health Innovations Awards 2005)

Assessment tools for integrated care: InterRAI

The trial of the InterRAI assessment tool in Capital & Coast DHB is part of implementing an integrated continuum of care within the Capital & Coast region. One aim is to manage the needs of people with chronic conditions and disability in the community.

An evidence-based assessment and care planning tool is used by Care Managers based within the Care Coordination Centre. Referrals are sent to the Care Coordination centre, which is the single point of entry for the majority of home and community-based referrals. Following screening of referrals, some people (generally those with chronic conditions) are appointed to a Care Manager. The Care Manager uses InterRAI, an evidence-based assessment and care planning tool, to establish a person-centred care plan for providers to deliver.

InterRAI has a wide range of triggered assessment protocols designed to capture a broad view of the person's health and wellbeing. The tool does not override clinical assessment, but provides greater validity for clinical decisions. Capital & Coast DHB will, over time, extend the use of InterRAI across a number of services.

Benefits of using the InterRAI approach across services include the client not having to repeat information or have multiple assessments, more complete assessment of clients, and sharing of care plans across services where appropriate. The tool also allows for a range of data to be gathered to evaluate effectiveness of service delivery and impact. Data can be tracked across populations, resources, conditions and providers.

Data collected between October 2005 and April 2006, shows hospitalisation rates reduced to 36 percent for people seen through Care Managers. An earlier pilot using InterRAI showed that re-assessments had reduced by up to 20 percent. (A Downes, personal communication, May 2006)

Redesign of information systems and processes in a primary care setting: The Doctors Foundation Programme Masterton, Wairarapa

The Foundation Programme was developed within a primary care setting by The Doctors Masterton, a member of the Wairarapa Community PHO, based on successful strategies from the UK. Learning from a chronic disease management pilot undertaken by the PHO for people with diabetes in 2003 also helped to develop the Foundation Programme.

The specialisation of nursing roles (including nurse-led clinics), a patient-centred approach and the use of technology are features of the Foundation Programme. The person-centred approach involves enabling the patient to be an expert at understanding the nature and implications of their illness, and the benefits and risks of treatment options. Health professionals share management options and work with the patient in developing an appropriate care plan. (Nixon et al 2006)

The pilot demonstrated that cardiovascular and diabetes risk in Māori and non-Māori populations could be significantly reduced. This was achieved through reducing financial barriers to accessing care and providing person-centred, evidence-based multidisciplinary care. The pilot highlighted the need for having conveniently designed disease registers that accurately identify patients with particular problems, disease severity or risk of complications. (Smith et al 2005)

The aim of the Foundation Programme is to deliver better chronic disease management and improved health outcomes for its population with chronic diseases through use of a pragmatic, affordable, and sustainable approach. Addressing inequalities and improving access to services is also an aim of the programme. The Foundation Programme takes general practices through the process of restructuring and reorganising on a number of system levels to enable delivery of quality chronic disease management.

The programme created and validated disease registers, and implemented:

- *a systematic approach to data entry*
- *clinical performance reporting*
- *evidence-based clinical guidelines*
- *innovative electronic tools to facilitate risk assessment, population targeting, patient call and recall, and auditing of chronic disease management outcomes (CDREvolution software developed for the practice).*

Within six months of the programme commencing, the system enabled primary prevention CVD risk-assessment for high-risk groups (helping to reduce health inequalities), improved chronic disease registration, significantly increased numbers of annual diabetes reviews, and improved quality outcome measures for patients with hypertension, diabetes, and CVD. (Nixon et al 2006)

6.3 Providing effective chronic care management

NHC case studies and consultations found that people with chronic conditions had difficulties with access to care and coordination of care. These issues were compounded when they had more than one chronic condition, requiring them to navigate an array of speciality and generic care services, at different times and in various locations.

NHC case studies were clear about the distress caused to a person when each service dealt with a different and specific health issue in isolation from other services. In an environment of fragmented and uncoordinated service delivery, people with chronic conditions are at risk of receiving less than optimal access and poorer quality services.

6.3.1 Proposed model of care and coordination

The NHC believes that improving the management and coordination of services for people with chronic conditions will optimise health outcomes. It seeks greater clarity around interventions and outcomes from providing different levels and types of care for people with chronic conditions.

The NHC is putting forward three broad levels of care for people with chronic conditions within primary care. These levels build on each other successively and inclusively and are supported by proactive primary care processes¹⁹. They are:

- *self-management*: information, skills and referrals to support the person and their family/whānau to manage their condition
- *care management*: assessment, treatment, planned review, adherence to evidence-based guidelines, referrals
- *coordinated care*: comprehensive assessment, detailed care planning, intensive support and management, coordination of services.

The NHC acknowledges that these elements are, or can be, present in current primary health care and the Care Plus initiative. However, it wishes to endorse proactive primary care processes and specifically strengthen support for self-management and coordinated care. These features are beneficial to chronic care models and could be delivered more consistently and with greater accountability. The NHC believes this can be assisted by the development of a care and coordination model supported by national guidelines on the broad levels of care.

In addition, two areas of assessment and treatment (depression and pain), and two areas of referral (rehabilitation and palliative care) are highlighted by the NHC for further development. Resource and process requirements are listed in Table 6 at the end of this chapter as they are referred to in recommendations. These are high-level and require further development in a consultative process.

6.3.2 Broad levels of care outlined

The NHC seeks the development of a chronic care management and coordination model (care and coordination model) that acts on population health approaches within the proposed chronic conditions framework and provides:

- support for self-management
- evidence-based care management
- effective coordination of care.

Provide support for self-management

There are a number of initiatives in self-management in New Zealand. However, there is no national consistency in service provision and greater support could be provided for this.

Self-management approaches are an essential component of a care and coordination model. They are an integral part of the proposed DHB chronic conditions frameworks. The benefits are well supported in the international literature [Refer to Chapter 3].

NHC case studies demonstrated the need for people with ongoing conditions to have a structure and plan for their life management of the condition. This was important for management of the physical condition. In addition, those with a sense of being able to make a difference to their life (self-efficacy) were less depressed about having the condition and less anxious about the care they received. These benefits can be achieved in primary care for people with chronic conditions, those waiting for specialist treatment, as well as older people seeking support to remain independent.

Self-management programmes and approaches enable:

- identification of symptoms
- knowledge of the condition and symptom management
- understanding of the purpose of medication and using it effectively
- support and motivation to adopt a healthy lifestyle
- connection to support groups that understand the issues
- connection to organisations that will assist in managing a range of supports (eg income).

The NHC supports the self-management approach of partnerships between health professionals, patient, family/whānau and carers. The NHC found evidence for the effectiveness of self-management approaches when:

¹⁹ This term covers a range of processes or actions that inform the design of care delivery. These are endorsed by *Primary Health Care Strategy* implementation. For further explanation see section 3.

- initiatives are set within family/whānau contexts
- information and processes are culturally appropriate
- depression has been assessed and is being managed
- approaches are appropriate for the patient's level of functioning.

Continue to provide evidence-based care management

Care management provided for people in primary care diagnosed with chronic conditions:

- covers assessment, treatment and referrals provided once a person is diagnosed with a chronic disease
- uses proactive processes, such as monitoring and planned reviews
- emphasises preventative actions to reduce the development of co-morbidities
- provides treatment based on evidence and uses evidence-based guidelines and care pathways.

Provide effective coordinated care

Care coordination delivered by a primary care team with a mix of health professionals has been shown to be effective for people with chronic conditions. The NHC seeks the provision of effective coordinated care for people with chronic conditions experiencing short-term acute health/life crises or ongoing complexity of health conditions and life circumstances.

Care coordination includes a range of key activities including:

- comprehensive assessment of medical, functional, and psychosocial needs
- detailed care planning
- coordination of specialist and community services
- intensive support for the individual (case management).

These activities need to be supported by:

- electronic information tools to ensure consistent assessment and effective service allocation
- sound processes for quality care.

Coordinated care was identified as a key requirement by participants in the NHC case studies.

- Coordinated care has been found to: increase access to care, reduce hospitalisations, and reduce costs to patients, promote person-centred care, increase access to a range of services.
- Effective electronic tools supporting coordinated care have been found to: reduce assessments, assist dependable assessment of pain and depression, facilitate access to a range of services, provide effective communication within the team and across providers, and standardise admission and referral processes.

Trial other approaches to delivering complex care

Multidisciplinary teams are essential to good chronic care management. The required team mix is not easily achieved within small or geographically isolated PHOs. Complex cases require information system support for coordination. Small numbers of complex cases or limited access to training or expertise in chronic conditions management may reduce quality of services provided.

The NHC believes complex cases requiring coordination may in some instances be more effectively managed by a multidisciplinary team operating across a number PHOs, rather than by individual PHOs. There are similar team models being trialled with older people (for example COSE), which may provide some comparison.

The need for a care coordinator

The NHC is recommending that each patient be allocated a care coordinator. Assigning a care coordinator to provide intensive support for patients at high risk (sometimes called case management) has been shown to be effective and is endorsed in chronic care models (Bodenheimer 2003).

Care coordination roles vary according to the system they sit within. Some care coordination roles are equivalent to the case management role of health professionals in specialist care. They are supported by an administrator who provides coordination of services, referrals, and follow-ups. In such cases, the administrative coordinator is the single point of contact for the person receiving care coordination.

The critical aspect of this primary care coordination role is that the locus of accountability is clarified.

- When multiple organisations and a range of specialists are involved, clarification is needed on which person is clinically accountable for the overall review and decision-making for the person with a chronic condition. This is essential to ensure good medicine management and clinical care.
- A person with chronic conditions requiring coordinated care needs to know who to call about organisational and administrative arrangements. This is essential to ensure attendance at appointments. In addition, many patients require a person they regularly speak to who can support their care plan or act as advocate in negotiating services.

The NHC suggests care coordinators be funded by PHOs and shared across small clusters of PHOs. The NHC believes this arrangement will enable smaller or isolated PHOs to provide teams for this level of complex care. In urban areas, this arrangement may be an efficient way to coordinate services. However, the NHC wishes to make clear that a PHO-level coordination structure outside of individual PHOs:

- needs to ensure effective coordination between primary and secondary services within current implementation planning
- is not intended to reduce the team interaction required within each PHO for proactive primary care and self-management
- is unworkable if there is not an effective communication system in place.

6.3.3 The need for national guidelines to support levels of care

Currently there are a number of initiatives²⁰ in chronic care management throughout the country, employing one or more of the key elements identified by the NHC. However there is no national consistency in the implementation of key elements.

The broad levels of the care and coordination model outlined earlier need to be supported by national guidelines that clarify the different types of service provision available, the criteria for accessing specific services, and processes for monitoring outcomes.

The NHC believes there is sufficient evidence for national guidelines to be developed. There are criteria, such as those used by the UK Department of Health (2005) to identify the most vulnerable patients for case management. There is evidence indicating which people most benefit from coordinated care, as well as when interventions are enhanced by combining with other interventions, such as treating depression and providing case management.

An important part of establishing levels of care within guidelines is the provision of entry and exit criteria. Good data collection on the timing and type of interventions provided will be critical to improving understanding of these criteria and interactions with other patient factors.

6.3.4 Referral areas requiring clarification

Palliative care referrals

Facilitation of a smooth transition to palliative care services should be a feature of a care and coordination model. Patients should be able to be managed within primary care for some time. For example, cancer patients can be supported to self-manage pain with a morphine pump and planning for quality of life. Palliative care fits well within primary health care when:

- self-management approaches are used
- there is effective pain management
- specialist back-up is available for advice on medication or for assessment visits to review clinical plans.

Palliative options offer an opportunity to 'plan for a good death, instead of monitoring a downward set of physical variables until death'. However, the focus on 'cure' models may contribute to GPs having difficulty in acknowledging the need to move their patient to palliative care (Murray et al 2005). The NHC would like to see further evaluation of this issue following successful implementation of self-management approaches. It may be that self-management approaches, which are compatible with a palliative care philosophy in their emphasis on quality of life, will lead to better management of pain in the community and easier transitions to palliative care.

20 Some examples of care coordination initiatives are discussed in the section on data, information and knowledge (6.2).

Referral to rehabilitation

NHC provider submissions called for improved referrals to rehabilitation. There is strong evidence for improved health outcomes from provision of rehabilitation for specific chronic conditions (CVD, stroke, COPD, cancer). For example, cardiac rehabilitation after a myocardial infarction has been shown to significantly reduce mortality, morbidity and hospital admission rates and increase quality of life (NZGG 2002). A study of referrals to cardiac rehabilitation during February 2002 revealed that only 36 percent of eligible patients were referred from hospital for rehabilitation (Doolan-Noble et al 2004).

6.3.5 Areas for improved assessment and management

Pain management

Consistent and effective chronic pain management increases functioning and independence, minimises use of drugs, and prevents unnecessary acute episodes and additional consultations.

The NHC recommends effective pain management be a component of a care and coordination model for people with chronic conditions. The NHC case studies and consultations strongly highlighted a lack of effective pain management within primary health care. Research provides evidence for the effectiveness of pain management medications (some of which alleviate both pain and depression) and for cognitive-behavioural therapy (CBT) [see Chapter 3.7].

The experience of chronic pain is widespread, and has negative health impacts. In particular, chronic pain:

- is associated with use of health care that is five times higher than average and also with longer hospital stays
- interacts with depression to increase morbidity and in some cases mortality
- affects one in five people, and is more prevalent in older people.

The NHC is recommending a national approach to pain management that incorporates increased services²¹, increased knowledge and information, and improved assessment and management processes. Increasing knowledge of pain assessment and management within primary care will require resources for both health professionals (training/supervision) and patients (information, support for self-management).

Inappropriate referrals caused by lack of access to pain management

Submissions to the NHC from providers noted that lack of access to pain management led in some cases to inappropriate referrals to palliative care teams for such services.

Providers wanted multidisciplinary pain management teams to be available to provide support, assessment and coordination of pain management for people in primary care. They proposed community palliative care coordinators working as a team with primary health care professionals in or within community pain clinics.

The NHC seeks an immediate assessment of the capacity of districts to provide pain management. This includes provision of pain management in existing hospital-based pain management units as well as primary health based initiatives.

Review of 'shared care' approaches (Singh 2006) does not support shared care between specialists and GPs for improving clinical outcomes or readmission to hospital rates. However, NHC consultations found specialist involvement in New Zealand to be beneficial for advice on medication (pain), corroboration of assessments (mental health), and making referrals (palliative care). Although wanting to ensure better provision of pain management within primary health care, the NHC is not necessarily suggesting current hospital-based pain management be shifted to community-based pain management teams. It looks to the Ministry of Health and DHBs to determine how care can most effectively be provided.

Depression

Depressive disorders may contribute to the development of chronic conditions and people with chronic conditions may develop depression as a secondary disorder. There is also evidence that the effectiveness of treatment for chronic diseases may be limited where depression is untreated [see Chapter 3.7].

21 Research undertaken by Taranaki DHB estimated that NZ should have four times the amount of pain management hours currently provided when compared to recommended figures for provision per capita from the UK.

The NHC is recommending that appropriate primary care assessment and treatment of depression be incorporated in a care and coordination model. The mental health of a patient can determine their ability to manage their chronic condition, take advantage of support, and ultimately prevent complications and secondary disease. Sufficient attention to mental health in chronic conditions management is crucial if New Zealand is to improve its success overall.

The NHC case studies made it clear that there needed to be better links between mental and physical health within primary health care. The NHC expects the work of the National Depression Initiative and the work of PHO primary mental health initiatives to contribute to addressing this [see Chapter 4].

The NHC is recommending assessment for depression be part of all primary care assessments for chronic conditions and that appropriate treatment is made available. Research supports medicine, CBT and self-management programmes incorporating CBT approaches [see Chapter 3.7]. Although there is currently limited capacity to provide CBT treatment, there is wider potential to implement self-management programmes based on CBT approaches.

Table 6. Care and coordination model: resources and processes

- *Criteria for different areas of care*
 - *outline different types of service provision for people with chronic conditions within each of the three broad areas: self-management, care management and care coordination*
 - *provide criteria to assess when a person needs to receive or stop receiving a type of service*
 - *establish processes for recording interventions and measuring outcomes.*
- *Records and performance measures*
 - *establish processes for recording interventions and measuring outcomes*
 - *promote the effective use of patient-held care plans across the sector to reinforce person-centred and coordinated care*
 - *outline a practice-level care management and coordination model with processes for assessment, review, recording and measurement.*
- *Accountability*
 - *accountability in provision of coordinated care through a single point of contact*
 - *record interventions and measure performance outcomes for all levels of care provided.*
- *Funding*
 - *provide adequate funding for the different levels of service provision*
 - *estimate the level of funding required to implement self-management approaches and chronic care management programmes nationally*
 - *estimate the level of funding required to adequately resource extended roles for coordinated care.*
- *Training*
 - *resource training to develop capability in the management or coordination of chronic conditions.*

6.4 Workforce development

NHC submissions and consultations

Submissions to the NHC and consultation on workforce issues named long-term strategic workforce planning as a priority. Submissions reinforced the direction of current policy work on the health workforce including:

- training to deliver proactive and coordinated primary health care
- multidisciplinary teamwork
- delivering comprehensive services that cross disciplines or sectors
- training to support self-management
- training in managing specific chronic conditions
- increasing specialist outreach.

Chronic care models and workforce capability

Chronic care models reinforce the need for health professionals who have the capability to:

- support partnerships with people with chronic conditions and their family/whānau
- communicate and collaborate with other professionals
- follow processes that promote quality and safety
- use communication technology competently to assist population health approaches
- respond to cultural needs.

Using a broad mix of health professionals in primary health care

Multidisciplinary teams based on population health approaches within primary health care are regarded as central in chronic conditions models, and they have consistently been shown to be effective. However, evidence is not conclusive regarding the ideal mix of staff and studies do not always include relevant factors that affect results, such as processes for role clarification or population needs. The NHC therefore suggests determination of workforce mix be evaluated within New Zealand, rather than relying on international evidence.

Submissions to the NHC endorsed a broader mix of health professionals delivering primary health care: GPs, nurses, pharmacists, social workers, mental health workers, community development workers, NASC teams, receptionists, specialist consultants, optometrists.

NHC case studies and submissions asked for greater collaboration across mental health, disability and physical health professions. It is beneficial when professional associations foster this through their association network meetings and training programmes. The process of working within a multidisciplinary team can also increase understanding of other health professional roles.

The range of professionals included in care teams is still limited, with most PHOs not expanding their care teams beyond a doctor and nurse. There are difficulties implementing team approaches in small practices and where structures are hierarchical, not collaborative. Very few PHOs have so far included social workers or community workers in care teams. Submissions to the NHC sought funded social workers to whom GPs could refer complex cases – either within the community or as part of a care team. Pharmacists and their professional bodies sought a greater role with primary health care teams, particularly in relation to medicine management, compliance monitoring and prescription review (especially on discharge from hospital)²².

The NHC believes many of these issues can be addressed within the *Primary Health Care Implementation Work Programme 2006/10*.

What health professional to use when?

The University of Birmingham found little evidence to recommend one professional group over another in most situations (National Health Service Institute for Innovation and Improvement 2006). Substituting nurses for GPs in chronic care management increased patient satisfaction, maintained the quality of care, reduced hospital admissions and reduced the length of stay in hospital. However, this could not be attributed solely to the structural change of substituting nurses, as there were supporting processes that ensured quality care.

The NHC believes achieving the best patient outcome requires determination of the roles and skills for each health practitioner and support for new work roles. Reluctance to allow health professionals to extend scopes of practice or to devolve routine tasks to other grades of health professionals hampers effective use of workforce. The NHC therefore recommends focussing on identifying particular needs and service gaps, outlining competencies before considering who best could fill these needs.

22 Support for self-management included increasing understanding of the condition, advice on symptom control, calibration of meters, dose adjustments for insulin if indicated by signs and symptoms, instruction with peak flow meters, provision of computerised lists of medications, and making up blister packs labelled in the client's language.

Role of specialists

Chronic care models and NHC submissions look for a greater involvement of medical specialists within primary care. Specialists were used in a number of approaches to delivering integrated care with primary health in the UK. This 'shared care' approach was not found to be successful in improving clinical outcomes or reducing hospital admission where this involved joint management of patients, or joint consultation and planning (Singh 2006). However, NHC submissions and consultations put forward a number of arrangements that have been found to be beneficial including:

- phone consultations between the GP and specialist to avoid unnecessary routine assessments
- more formalised arrangements between specialists and PHO-level care team to review complex cases that are not progressing²³
- supervision from specialists to ensure appropriate treatment and delay referral to specialist services.

More evaluation is needed to determine the most effective use of specialists in New Zealand.

Developing new skills

New primary care tasks (such as development of effective care plans and analysis of patient databases for proactive care) require additional time, which has to be prioritised in planning processes. Increased focus on prevention and management of chronic conditions also requires increased capability, particularly within expanded nurse roles for self-management and disease management.

Ongoing access to education and skills are required for a wide range of health professionals to fully equip them to manage chronic conditions – both in terms of how to monitor and manage care in an ongoing way and clinical knowledge of the most prevalent chronic conditions. Work is being undertaken in tertiary education agencies to respond to sector need and provide core competencies for chronic disease prevention and management. Short courses are being provided by professional bodies to update the knowledge of health professionals. Aiming to achieve efficient deployment of the workforce has provided an impetus for the sector to examine options for doctors such as earlier specialisation, or study/supervised work mixes.

The NHC endorses employer efforts to assist participation in training by staff. Some DHBs have assisted PHOs to upskill nurses in practices to take on greater management roles through providing specialist supervision and training on site. Upskilling has resulted in less referral to specialist services and specialists being referred more complex cases. Difficulties with upskilling continue to include limited time, funding, or staff relief for this to take place. Provider issues include nurses taking employment elsewhere once trained.

6.5 Conclusion

There are two major foci of chronic care model implementation. The first looks for a redesign of the health system to deliver a continuum of care across the health sector, and the second emphasises the central role of primary health care in preventing and managing chronic conditions.

Further action is required to ensure people with chronic conditions have a continuous and coordinated experience of health care. Difficulties with achieving a focus on people with chronic conditions across different systems and organisations are particularly highlighted in relation to discharges or referrals. Extensive planning is required to achieve integration and alignment, both to identify service gaps and to eliminate service duplications. Funding mechanisms do not always assist alignment or integration of services and there are complex issues around funding criteria. Needs-based funding and outcomes-focussed contracts can contribute to provide patient-centred care. In addition, change is required at tertiary levels of the sector within mental and physical health disciplines, particularly for the improvement of cross-discipline understandings such as the relationship of depression and chronic conditions.

Effective information and knowledge systems underpin successfully coordinated and integrated services. Investment in this area benefits all people, but particularly people who use a wide range of services more frequently. Electronic tools for self-management and access to web-based community databases are both areas that can support people with chronic conditions. Standardisation of electronic referral and assessment processes

²³ This has been suggested within evidence for 'stepped care' models. However, stepped care has only been shown to be effective when components of chronic care models (evaluated separately as successful) are also used. Further evaluation needs to take place on which aspects of specialist involvement are most effective.

will assist people to move between community and hospital-based care. Consistent data collection is essential to provide information for population health approaches and is one significant area of *Primary Health Care Strategy* implementation. Coordinated care tools are being trialled by DHBs and the NHC considers they have potential to be applied to people under 65 years with chronic conditions.

Although there have been major changes in primary health which provide a positive groundwork for people with chronic conditions, there is room for further improvement. The NHC is proposing a care and coordination model that has three levels of care and ensures accountability in care coordination. It seeks to progress self-management and care coordination with this model. Specific areas for improvement include palliative care and rehabilitation referrals, as well as assessment and management of pain and depression.

Increased capability is called for within the primary care workforce to respond to people with chronic conditions. Chronic care models require the use of a broad mix of health professionals, including cooperative teams of specialists and primary care health professionals. Further research and planning around this mix would be beneficial.

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- ▶ *The next chapter presents NHC recommendations based on analysis of research, consultation, submissions and case studies.*

7. Recommendations

The NHC project on chronic conditions has taken place at a time of rapid change within the health sector. Many of the changes the NHC originally sought are now being planned for or acted on. Nevertheless, the NHC believes that value can be added by presenting an overview of the breadth of change required to address chronic conditions. It is therefore endorsing actions under way in the sector alongside recommendations for new actions. For the same reason it presents actions to prevent as well as manage chronic conditions, although the project focus is on people with existing chronic conditions.

Overview of recommendations

The NHC is providing direction to the health sector for comprehensive planning that builds on existing initiatives for chronic conditions and achieves consistency of service delivery. It is recommending that each DHB implement a chronic conditions framework that focuses action, integrates service provision and is population specific. It looks for progress on implementing a framework to be reported on in DHB 2008/09 District Annual Plans.

The NHC is asking that the Ministry of Health and DHBs work together to ensure key elements of the framework are nationally consistent and appropriately funded and that each DHB develops its own local framework that includes:

- use of equity tools and monitoring processes by DHBs and PHOs to ensure equitable access to and through the system by those with the highest demonstrated need
- integration and alignment of providers and services across the health sector, supported by effective information systems and a nominated DHB-based contact person
- development and implementation of a care and coordination model by July 2008, supported by national guidelines and resources
- whole district planning to build effective relationships within the health sector and across sectors that ensure clarity of roles and responsibilities, including resourcing and funding
- effective information systems to underpin the changes sought, including nationally consistent assessment and referral processes
- training for new primary health care roles.

The NHC seeks commitment from every health sector organisation to achieve implementation of the framework, from PHOs for the proposed care and coordination model, to public health, NGOs and community providers in whole district planning for community and cross-sector engagement. It looks for all organisations to achieve integrated and aligned structures within the health system and to address access and equity issues.

These recommendations provided to the Minister of Health are intended to be acted on by the health sector. Although framed in terms of provider action, and based on both international and New Zealand research evidence, the recommendations are informed by NHC case studies and public submissions. They are also consistent with the World Health Organization's essential elements for action and contain actions common across many effective models for chronic care.

The recommendations are presented in two parts.

- **Part A** provides direction by outlining a framework of areas for change, action on equity, workforce outcomes sought and planning for community collaboration.
- **Part B** focuses on service provision, presenting areas for health sector integration or alignment, information systems sought, and services required within PHOs.

PART A: Direction

7.1 Develop DHB-based chronic conditions frameworks

Broad outcomes sought

The NHC seeks broad outcomes to address chronic conditions in New Zealand. Leadership from within the Government, Ministry of Health and DHBs is essential to:

- achieve whole-of-government responses to reducing social and economic inequalities
- provide effective cross-sector support for people with chronic conditions
- promote institutional commitment to reducing inequalities
- ensure equity of service provision is addressed
- provide a focus on chronic conditions within current policies
- achieve comprehensive strategic planning on chronic conditions
- develop community understanding of chronic conditions
- form sound and productive community partnerships
- provide direction to integrate and align structures and services
- provide effective prevention and management of chronic conditions
- develop education and training resources
- share best practice to develop national consistency
- implement efficient information systems
- develop workforce capability.

Focusing broad outcomes: Ministry of Health and DHBs

The NHC believes the most effective way to achieve these broad outcomes is through developing and implementing DHB-based chronic conditions frameworks. In regions where there are existing collaborative arrangements, DHBs may choose to involve more than one DHB to develop their plans jointly. The NHC sees the Ministry of Health having responsibility to provide leadership to ensure national consistency and baseline expectations of a chronic conditions framework.

The NHC therefore recommends that the Minister of Health request the Ministry of Health to:

- work with DHBs to ensure key elements of the framework are nationally consistent and funded and to support each DHB to develop its own local framework consistent with key elements
- require DHBs to report actions to develop and implement a chronic conditions framework in their 2008/09 District Annual Plans
- report on progress with chronic conditions framework implementation to the Minister annually
- coordinate the development of resources required by the framework using best practices from within DHBs and PHOs
- provide appropriate funding for DHBs to implement these recommendations.

Key components of framework required

The NHC seeks development of comprehensive frameworks that:

- place a full spectrum of interventions (public health initiatives, primary and secondary services) within planning for whole system change
- outline a generic system of chronic care management which encompasses clinical pathways and programmes for people diagnosed with specific chronic diseases
- are based on chronic care models and best proactive evidence.

The NHC recommends the Minister of Health request the Ministry of Health works with all DHBs to develop chronic conditions frameworks that include the following key components by June 2008, with a view to implementing frameworks from July 2008. Frameworks should:

- address the demonstrated needs of specific population groups (Māori, people of low socioeconomic status, Pacific peoples), based on a population health approach and a reducing health inequalities framework by (see 7.2):
 - implementing equity tools and monitoring processes to ensure equal access to, and through, the system by populations with the highest demonstrated need (see 7.2)
 - developing tools that measure successful elements of culturally appropriate services for the evaluation of culturally appropriate service provision (see 7.2)
- develop workforce capability and capacity to support effective multidisciplinary team functioning based on clear roles and accountabilities (see 7.7)
- build effective relationships within the health sector and across sectors as part of whole district planning processes that ensure clarity of roles and responsibilities (including resourcing and funding) (see 7.3)
- develop a continuum of chronic care responses that integrate or align sectors, providers, disciplines, and initiatives relevant to chronic conditions (see 7.4)
- appoint a chronic care coordinator within each DHB to provide leadership and guidance to address problems that arise for people with chronic conditions, and, supported by the DHB, work toward effectively aligning and integrating services (see 7.4)
- implement the proposed PHO-level care and coordination model based on a national model and guidelines (see 7.6)
- provide chronic care coordinators at a PHO level (see 7.6).

The NHC recommends the frameworks be supported by Ministry of Health actions including:

- development of a proposed national care and coordination model and national guidelines (see 7.6)
- development of supports for national initiatives (models, guidelines, resources) (see 7.6)
- development and implementation of national information systems (data collection and analysis, assessment and referral processes) (see 7.5)
- a national assessment and referral information system (see 7.5).

7.2 Reduce health inequalities

Reducing inequalities is a key government priority. Pivotal health policies refer to the Treaty of Waitangi and the aspiration to provide access to health care for all New Zealanders. DHBs have a statutory responsibility to reduce health inequalities.

Chronic conditions are a major driver of health inequalities. Any effort to limit the impact of chronic conditions should ensure that outcomes for groups at greatest disadvantage improve earliest and most significantly. This is the only approach which will both improve management and prevention of chronic conditions across the population and meet the legal and moral obligation to reduce health inequalities.

The NHC believes that racism is unacceptable and that each health professional has a duty and responsibility to provide culturally appropriate care.

The NHC seeks the following outcomes from continued work to reduce inequalities:

- government action on evidence-based solutions to reduce inequalities arising from socioeconomic determinants of health and wellbeing
- increased cultural competence and use of cultural safety approaches by the health workforce
- participation of indigenous and ethnic populations in decisions regarding governance, service design, planning, delivery and evaluation
- equity of service provision to all populations
- provision of initiatives to increase access to and affordability of health services for populations most in need
- provision of culturally responsive services and culturally appropriate information to all populations
- a workforce that takes responsibility for addressing racism at an institutional and individual level.

The NHC endorses the Ministry of Health continuing to undertake the following actions:

- target funding for populations according to best practice guidelines
- ensure provision of low cost services for people with low income
- prioritise access initiatives that reduce transport costs for people with chronic conditions
- promote intersectoral programmes that address socioeconomic determinants of health inequality
- require DHBs, through the DHB accountability framework, to reduce health inequalities.

Provide culturally accessible services

Providing culturally appropriate care is essential to improving access to health services for Māori and Pacific peoples.

The NHC recommends the Minister of Health direct the Ministry of Health to:

- make it a priority to resource the evaluation of components of culturally appropriate services
- support planning for capacity building of culturally appropriate evaluators
- develop a mechanism to receive and use feedback from service users on the cultural appropriateness of services provided by health organisations
- work with DHBs to support provision of culturally appropriate services through:
 - design of accessible, affordable and culturally appropriate services in collaboration with targeted populations (Māori, Pacific peoples, people with low income)
 - producing accessible and culturally appropriate information on chronic conditions for use in primary care
 - sharing best practice in culturally effective interventions
- ensure funding criteria for government and non-government health providers include culturally appropriate processes.

The NHC did not include Asian populations in the project scope. However, it includes evidence in Appendix 2 leading to the recommendation that the Ministry of Health:

- provide a briefing on current and future options for reducing the incidence and impact of cardiovascular disease, heart disease, diabetes and asthma among Indian New Zealanders and other Asian population groups.

Involve family/whānau appropriately

The involvement of family/whānau in the assessment, care planning and management of a person with chronic conditions can improve health outcomes, increase access to health care, and reduce health inequalities.

The NHC recommends the Minister of Health:

- request the Ministry of Health to report to the Minister on implementation of policies promoting family/whānau involvement, noting barriers to implementation
- request the Ministry of Health support DHBs and PHOs by
 - sharing evaluations of current initiatives involving family/whānau
 - collaborating on outlining options for appropriate involvement of family/whānau in both primary and secondary service levels
 - developing and providing information to support the family/whānau/carers of those with chronic conditions.

Increase access to services

The lack of affordability of health services, transport, alternative arrangements and opportunity cost is a critical barrier to access to care for low income people. For those with one or more chronic conditions, this is compounded by long-term high use of health services and by the impact that having a chronic condition can have on earning capacity. The NHC recommends the Minister of Health direct the Ministry of Health to work with DHBs to ensure equitable access to health services and provision of health interventions through:

- continued emphasis on PHO accountability for providing low-cost primary health care services
- reviewing and updating health inequality indicator reporting requirements by DHBs
- use of the *Health Equity Assessment Tool* and the *Intervention Framework* (Ministry of Health 2002b) in policy and organisational processes

- use of independent assessment tools for clinical treatment decisions
- monitoring access to health services and provision of health interventions to indigenous and ethnic minority groups in both primary (testing, treatment) and secondary settings (testing, surgery, specialist treatment)
- use of patient feedback surveys to (i) improve communication and partnerships between health providers and patients, and (ii) achieve responsiveness to culturally appropriate services
- making it a priority to include evaluation as a component of funding culturally appropriate services to build evidence of effectiveness.

7.3 Plan community engagement

Improving community engagement has the potential to address health inequalities and increase access to services, support and information that meet the needs of people with chronic conditions, their family, whānau and carers. The NHC looks for whole district planning to ensure sustainability of community engagement.

The NHC seeks the following outcomes to benefit people with chronic conditions:

- the development of community-based and whole-of-government collaborations that can (i) directly affect the wider determinants of health (ii) create a healthy living environment (iii) improve services for people with chronic conditions
- increased awareness and knowledge of chronic conditions among the public, government and NGOs working with people with chronic conditions
- improved participation of Māori, Pacific and Asian peoples in service design, delivery, monitoring and evaluation
- clarification of NGO roles
- productive and sustainable health sector and intersectoral relationships among organisations working with people with chronic conditions
- joint work programmes of benefit to people with chronic conditions within and beyond the health sector.

The NHC recommends the Minister of Health request the Ministry of Health to lead the sector by developing processes for DHBs to build successful relationships and projects that sit within whole district planning based on the following actions:

- prioritising communication: (i) identifying shared concepts and goals among cross-sector organisations across sectors (ii) regular sharing of information within and across sectors and among health professional networks and (iii) using evaluation and review cycles to build knowledge for the organisation and the sector
- clarifying roles and responsibilities at all stages of joint work programmes
- determining decision-making processes
- setting aims, objectives and timeframes
- identifying and promoting the types of joint work programmes that advance action on (i) achieving health equality (ii) addressing the wider determinants of health and (iii) increasing access to services and providing resources for them
- having sound evaluation processes including (i) specifying outcomes when setting aims (ii) building identified indicators of effectiveness into the beginning of projects
- in the area of resourcing and funding (i) recognising the need for resources to enable DHBs to establish cross-sectoral communication and initiatives (ii) overcoming barriers to funding or jointly funding cross-sector projects and (iii) aligning planning cycles across organisations
- strategically supporting culture change within health organisations to de-stigmatise people living with a chronic conditions.

In addition, the NHC recommends the Minister:

- explore cost-effective options for changing attitudes and raising awareness of chronic conditions among the public
- collaborate with the Minister of Social Development to improve the links and funding arrangements between chronic conditions and areas within the Social Development portfolio
- identify and implement the most efficient system to provide access to updated community resource information
- request the Ministry of Health to ensure NGO contracts for provision of information include the development of culturally appropriate material.

PART B: Service provision

7.4 Integrate structures and services

The NHC seeks an integrated continuum of prevention and care across primary and secondary levels. Integrated or aligned structures and services benefit all people, especially those with chronic conditions who need to access a wide range of services, or access services more frequently. A key recommendation to assist a person with chronic conditions to navigate the system and ensure access to services is that each DHB nominate a person responsible for addressing problems people with chronic conditions have accessing coordinated care.

Broad areas for integration or alignment include:

- public health, primary health
- primary and secondary levels of the health system
- Māori, Pacific, NGO, mental health, disability, health providers
- mental and physical health professional disciplines
- funding mechanisms and categories.

An integrated continuum of prevention and care is grounded in person-centred and population health approaches and delivers:

- equitable and needs-based service provision
- accessible, flexible and timely services
- coordinated services with appropriate information sharing among organisations
- collaborative partnerships between health and other sectors
- effective information systems.

The NHC recommends that the Minister of Health:

- broadly endorse alignment or integration of sectors, providers and services within the health system for the benefit of service users
- endorse the need for a key contact person within each DHB to address problems for people with chronic conditions accessing coordinated care and the requirement that this person be supported to bring to the attention of the DHB problems arising from lack of aligned or integrated services for the DHB to address
- request the Ministry of Health reports annually on work with DHBs on planning for alignment or integration within chronic conditions frameworks and achievement of the following outcomes:
 - programmes are rationalised across a range of providers on the basis of principles of patient need, equity, evidence of effectiveness and provider role clarification
 - established relationships between providers enabling referral, assessment and follow-up processes are supported by electronic information systems
 - effective information flow between primary and secondary providers produces health system efficiency and improves discharge planning for the service user
 - established relationships between providers support specialist supervision or cross-discipline supervision
 - cross-discipline understandings improve treatment and outcomes for a person with both a mental and physical chronic condition
 - alignment or integration of funding mechanisms overcomes inefficiencies due to separate information systems, payment structure and quality measures
 - funding criteria are reviewed to enable greater alignments between physical health, mental health, and disability
 - treatment errors are reduced through increased information sharing and effective coordination
 - patient risk is reduced through role clarification and accountability processes
 - service duplications (eg duplication of patient tests and assessments) are eliminated through agreed processes to share results
 - the health workforce is deployed effectively.

The NHC recommends the Minister of Health direct the Ministry of Health to work with DHBs to bring about alignment of sectors, providers and services through a range of actions including:

- reviewing current service provision to people with chronic conditions to identify areas for (i) alignment of services that need to work more closely together (ii) integration of services where there are overlaps of service provision or overlaps of service usage and (iii) identification of gaps in services for people with chronic conditions
- developing and implementing appropriate funding mechanisms (service specifications, contracts, protocols) to enable integration and alignment (i) within the health sector and (ii) across other sectors for cross-sector projects and partnerships.
- reviewing funding responsibilities and eligibility criteria to (i) ensure consistency of funding across population groupings (ii) reduce inequitable access to services and (iii) provide needs-based criteria
- reviewing information flow across services provided to people with chronic conditions to improve seamless access
- achieving long- and short-term district planning for alignment and integration of services
- building on emerging alignments between mental health, public health and primary health areas to achieve a focus on chronic conditions within existing work programmes
- clarifying roles and responsibilities of providers to support structural integration and alignment.

The NHC case studies led to the identification of further and more specific recommendations related to service integration. Some of these areas have already been identified as requiring further work by the sector. The NHC recommends the Minister of Health ensure the following outcomes are achieved:

- a specific focus on the link between depression and chronic conditions within implementation of depression initiatives in primary care
- consistent and prompt referral to rehabilitation for people with chronic conditions when this is appropriate
- provision of a seamless transition from paediatric to adult care for children with chronic conditions.

7.5 Improve information and knowledge systems

Integration and alignment of services rests on information and knowledge. It is critical to have consistent data collection, effective data communication systems and sound processes to build knowledge.

The NHC recommends that the Minister of Health:

- ensure the Ministry of Health achieve the following data collection outcomes:
 - DHBs work with PHOs, NASCs, and mental health organisations to collect data on each condition a person with a chronic condition has (disability, mental and physical health) to build national information on co-morbidities
 - the national data collection on cardiovascular disease and diabetes is extended to other chronic conditions
 - indigenous and ethnic-specific data collected at a PHO level be provided to DHBs and made accessible to the Ministry of Health to enable policy development
- endorse information systems that:
 - deliver nationally-standardised electronic admission, assessment and referral processes
 - provide consistent data collection, effective monitoring and reliable sharing of patient information across primary and secondary providers
 - assist with coordination of care between disciplines and providers
 - assist with provision of information on health and social services required for coordination of care
 - facilitate communication between a person with chronic conditions and their care team
 - provide electronic clinical decision support systems that include evidence-based guidelines and system indicators
 - ensure capacity to analyse national data sets for co-morbidities
 - ensure capacity to assess inequalities of health access for populations over time
- request the Ministry of Health evaluate electronic self-management tools for use by people with chronic conditions and their care team
- work with the Privacy Commissioner to ensure the legal framework to preserve patient privacy and protect health information from misuse is kept up to date with the changes in collection and use of this data.

7.6 Provide effective chronic care management in PHOs

People with chronic conditions often have significant difficulties with access to care and coordination of care. Greater integration and alignment of systems will assist with access and coordination. However, the NHC is also recommending that, for accountability purposes, a contact person be assigned to each person within complex health conditions.

The NHC is recommending improvements of service delivery in the area of referrals to rehabilitation and palliative care, as well as assessment and treatment of pain and depression for people with chronic conditions.

Development of a care and coordination model

The NHC recommends the development of a chronic care management and coordination model that acts on population health approaches to intervention within the proposed chronic conditions framework and provides:

- support for self-management
- evidence-based care management
- effective coordination of care.

The NHC recommends this model build on existing knowledge to specify:

- criteria for providing access to different types of care within three broad areas: self-management, care management, care coordination
- processes to record interventions and measure performance outcomes
- accountability in provision of care through a single point of contact
- funding levels appropriate to expectations.

The NHC recommends the Minister of Health request the Ministry of Health:

- develop a care and coordination model, based on the above recommendations, and have it ready for implementation by DHBs in July 2008
- develop national guidelines that:
 - outline different types of service provision for people with chronic conditions within each of the three broad areas
 - provide criteria to assess when a person needs to receive or stop receiving a type of service
 - establish processes for recording interventions and measuring outcomes
- provide adequate funding for different levels of service provision
- resource training to develop capability in the management or coordination of chronic conditions in accord with the *Primary Health Care Strategy*.

Provide support for self-management

The NHC supports the self-management approach of partnerships between health professionals, patient, family/whānau and carers. The NHC found evidence for the effectiveness of self-management approaches when:

- initiatives are set within family/whānau contexts
- information and processes are culturally appropriate
- depression has been assessed and is being managed
- approaches are appropriate for the patient's level of functioning.

The NHC recommends the Minister of Health:

- endorse self-management approaches as an essential component of DHB chronic conditions frameworks for the effective management of chronic conditions
- make it a priority to resource health professionals, community practitioners and peer supports to undertake training in self-management support
- request the Ministry of Health:
 - develop national guidelines for generic self-management programmes
 - report on progress in developing a toolkit for self-management
 - estimate the level of funding required to support and implement self-management approaches and chronic care management programmes nationally
- request the Ministry of Health to work with DHBs and PHOs to:

- record interventions and measure performance outcomes for self-management
- promote the significance of the effective use of patient-held care plans across the sector.

Provide care management

Care management is for people diagnosed with chronic conditions and:

- covers assessment, treatment and referrals provided once a person is diagnosed with a chronic disease
- uses proactive primary care processes, such as monitoring and planned reviews
- emphasises preventative actions to reduce the development of co-morbidities
- provides treatment based on evidence and uses evidence-based guidelines and care pathways.

Provide coordinated care

Coordinated care may be required in addition to self-management to provide more intensive support for people with chronic conditions when there is:

- ongoing complexity of health/life conditions
- a short-term health/life crisis.

However, coordinated care is only beneficial when people are consistently assessed and services effectively allocated. More intensive support at PHO level involves:

- coordination of appointments with health professionals and family/whānau
- advocacy and appropriate referrals to community support services
- higher levels of health care.

The NHC recommends the Minister of Health endorse the need for accountability to people with chronic conditions through identifying a person within care coordination teams to be:

- accountable for following up care planning for each person with chronic conditions (care coordinator/case manager/administrator)
- accountable for overall clinical care of each person receiving coordinated care across providers (medicine management, overall clinical direction).

Ensure appropriate referrals

Appropriate referrals reduce mortality and morbidity, increase quality of life, and reduce hospital admissions. The NHC recommends the Minister of Health request the Ministry of Health:

- work with DHBs to establish a process across community and specialist care for consistent and timely referrals to rehabilitation services for people with CVD, stroke, COPD or cancer, that increases the evidence base on referrals for chronic conditions, establishes monitoring processes, ensures appropriate funding, and optimises referrals
- undertake an economic cost-benefit analysis on timely referral to rehabilitation
- assess supports required by PHOs to provide timely and effective palliative care for people with chronic conditions.

Provide pain assessment and management

The NHC found a need for greater understanding, resourcing and provision of pain management. Research reviewed by the NHC found effective pain management could prevent unnecessary acute episodes, reduce GP consultations, assist in the prevention of secondary depression, minimise use of drugs, and increase functioning and independence.

The NHC seeks the following outcomes:

- a nationally standardised assessment tool for pain intensity
- routine assessment of pain management in primary care assessments
- provision of accessible and appropriate treatment for pain
- provision of accessible and appropriate information on pain management to health professionals and patients
- adequate resourcing of pain management initiatives, including capacity building to deliver cognitive-behavioural therapy (CBT) services.

The NHC recommends the Minister of Health:

- lead a strategic national approach to pain management
- make funding and planning of the following a resource priority within 2007/08:
 - pain management service provision
 - capacity building to provide CBT assessment and delivery
- request the Ministry of Health to:
 - update pain management guidelines and make them electronically available on the Ministry's website
 - evaluate current primary health care pain management initiatives and share best practice
- request the Ministry of Health support DHBs to:
 - develop integrated processes for pain management across secondary and primary services
 - develop accessible and culturally appropriate information on pain management for people with chronic conditions and their family/whānau.

Develop links between depression management and chronic conditions

Assessing and treating depression increases the effectiveness of self-management and pain management programmes. The NHC recommends the Minister of Health request the Ministry of Health to:

- brief the Minister on links between chronic conditions and depression within ongoing work programmes in (i) primary health care (ii) mental health
- ensure PHOs are resourced to provide appropriate assessment and treatment of depression for people with chronic conditions.

7.7 Develop workforce capability and capacity

The NHC acknowledges the workforce development within Primary Health Care Strategy implementation. This is congruent with chronic care models in emphasising the need for effective multidisciplinary team functioning. The NHC also acknowledges the Māori and Pacific peoples workforce development plans and their contribution to reducing inequalities. Work in these areas is expected to contribute to the outcomes sought by the NHC for people with chronic conditions.

The NHC is making two specific workforce recommendations. It recommends the Minister of Health ask the Ministry of Health to:

- support the development of a single contact person within multidisciplinary care teams for people with chronic conditions by assisting with role definition
- make it a priority to resource and develop capability in CBT for pain management and depression.

The NHC seeks the following broad workforce development outcomes to benefit people with chronic conditions:

- a mix of health professionals is used effectively in primary health care delivery
- numbers of Māori and Pacific peoples in the health care workforce are increased
- cross-discipline collaboration and understanding is strengthened and enabled within current work programmes
- core competencies for chronic disease prevention and management are provided in tertiary education and short courses made available locally to update health professionals in chronic care management
- training needs for new roles are identified and training is provided where required in:
 - effective multidisciplinary team functioning (including role and accountability clarification)
 - using population health approaches for proactive care
 - developing community-based cross-sector initiatives to address chronic conditions
 - supporting self-management
 - design of effective evaluation processes
 - appropriate involvement of family/whānau in care planning
 - use of Māori models of care
 - assisting Pacific peoples through pan-Pacific, or where appropriate, ethnic-specific Pacific models of care.

Summary of recommendations

- *Development and implementation of a Chronic Conditions Framework within each DHB to ensure national consistency and district flexibility on key areas evidenced to improve chronic conditions [7.1].*
- *Reducing health inequalities through the use of equity tools and addressing the evaluation needs around culturally appropriate services [7.2].*
- *Whole district planning processes for community engagement to ensure planning is sustainable [7.3].*
- *Comprehensive alignment within health and social sectors, between health providers and services, and across health disciplines to achieve continuity of care and enable coordinated care [7.4].*
- *A chronic care coordinator within each DHB providing leadership and guidance to address problems that arise for people with chronic conditions and, supported by the DHB, work toward effectively aligning and integrating services [7.4].*
- *Endorsement of consistent data collection and building of evidence for action. Effective communication systems to ensure patient safety and sector efficiency [7.5].*
- *Development of a primary health model of care and coordination for people with chronic conditions consisting of three main levels of care: self-management, care management and care coordination [7.6].*
- *A coordination team across PHOs providing a contact person for each person with complex chronic conditions [7.6].*
- *Specific recommendations for assessment and treatment of depression and pain and improvements in referrals to rehabilitation and palliative care for people with chronic conditions [7.6].*
- *Endorsement of current workforce initiatives and recommendations on specific training needs [7.7].*



NHC Case Studies

NHC discussion document submissions

SECTION TWO



Ko te tumanako, kia whakakotahi tatau ia tatou,
kia taea ai e tatou ki te hikoi whakamua.

The objective is for all of us to unite together,
so that we can move forward in unity.

NATIONAL HEALTH COMMITTEE CASE STUDIES

1. Background

1.1 Acknowledging the voice of the people

The National Health Committee (NHC) is grateful to all those who shared their lives in these case studies. Their participation has meant that any models considered to address chronic conditions have been thought through from the point of view of real people living with chronic conditions. The case studies have raised questions about how people live with chronic conditions, prompting the NHC to undertake further consultations and extend reviews of literature. As the project has unfolded, the voice of these people has emerged as central to the recommendations put forward by the NHC.

1.2 Purpose of case studies

In 2005, as part of the project on chronic conditions, the NHC contracted researchers to undertake four qualitative case studies. The case studies provide rich personal insights into the experiences of select groups of people living with a range of chronic conditions.

The purpose of the case studies was to:

- ensure the project remained relevant to the experience of people living with chronic conditions in New Zealand
- gather in-depth information on what helps and hinders people with chronic conditions and
- identify general and specific themes from identified population groups.

1.3 Selection of case studies

NHC project scoping identified a number of issues that assisted in selection of case studies including: evidence that Māori and Pacific peoples are disproportionately affected by chronic conditions; evidence that depression is a common co-morbid for people with chronic conditions and can be a chronic condition in its own right; and the limited literature on the experience of children with chronic conditions.

A number of other case studies could have been undertaken on the basis of information available at that time. The NHC was unable to undertake all of these, but recognises the need for further research on these groups. For example, certain chronic conditions have a significant impact on people from South Asia and this should be considered when meeting population needs.

The four groups selected for case studies were:

- Māori with chronic conditions
- Pacific peoples with chronic conditions
- people with chronic conditions and depression
- children with chronic conditions and their families.

1.4 Methodology

The researchers' brief was to explore the experiences of people with chronic conditions and:

- investigate what factors help and hinder them
- identify barriers to coping with and managing their conditions, and
- seek information to help identify where the gaps are in the provision of services and information.

In all instances, the proposals to undertake research and interviews were submitted to, and received approval from, the appropriate sponsoring institutions' ethics committees. All case studies used family/focus group and individual interviews to gather the information. Prospective participants were recruited from a variety of sources, including through general practitioners (GPs), primary health organisations (PHOs), non-government organisations (NGOs) and community health providers. On initial contact, potential respondents were supplied

with information sheets about the study and had the chance to ask questions. Those interested in participating had their eligibility for inclusion in the study considered, and where eligible, signed consent forms and were given interview schedule information.

The number of respondents is small, and the information provided from them is rich in detail but indicative only of issues for New Zealanders living with chronic conditions. The case studies raised issues that were corroborated by research reviewed for the report and by wider consultations, such as that for the *Primary Health Care Strategy Implementation Work Programme 2006-2010*.

Recruitment of Māori and Pacific peoples for the case studies

Relationship building was a major theme in the development of both the Māori and Pacific people case studies. Recruitment of participants rested on a relationship of trust between participants and the researchers.

For the Māori case study, participants were identified through Māori health providers and registered nurses working with Māori who have chronic conditions. Participants were contacted through Māori whānau, groups and organisations. Three hui were held with Māori consumers and two discussion groups were held with providers. These processes resulted in relationships between researchers and participants that allowed participants to feel comfortable when sharing their views and experiences.

For the Pacific case study, researchers contacted local Pacific health care providers and ensured that the way they carried out the research was appropriate for Pacific peoples. As a result, staff agreed to act as referral agents for participants if they were needed. Researchers made personal contact with prospective participants, individuals were interviewed in their homes and the caregivers' group interview was held at a participant's home. The researchers provided or organised transport, food was offered and the meetings opened with a prayer. The importance of this care in building a relationship is revealed by the depth of information provided for the case study.

1.5 Defining chronic conditions within the project

The NHC has used a definition for chronic conditions that is consistent with definitions used in other countries and by the World Health Organization.

The NHC broadly defines people with chronic conditions as people with any ongoing, long-term or recurring condition that can have a significant impact on their lives²⁴.

In determining a definition for chronic conditions, the NHC considered:

- who the definition covers
- what health conditions are, or are not, covered by the definition
- the need for a view of health that centres on the person in the context of their life
- the need to reflect changes across the life course and
- the need to consider chronic conditions as a whole grouping.

People of all ages are diagnosed with chronic conditions, including children. Generally, however, major chronic conditions emerge in middle age and most older people die from multiple chronic conditions (Bodenheimer 2002a).

Chronic conditions are often characterised by multiple risk factors and an initial period without symptoms. A wide range of physical and mental health conditions are included within the NHC definition of chronic conditions. These fall in the area of non-communicable diseases (such as asthma, arthritis, cardiovascular disease and diabetes), ongoing physical impairments (such as back injuries) and ongoing mental health conditions (such as depression).

The WHO 2002 and 2005 definitions of chronic conditions also includes communicable diseases (such as HIV/AIDS), disabilities and cancer. Although considered chronic conditions by the NHC, these conditions fell outside of the project scope.

²⁴ Disabilities are not included in this definition. However, the NHC wishes to highlight that many people with a disability have one or more chronic conditions and they are sometimes causally linked.

The NHC supports a holistic view of health and recognises that people with chronic conditions are likely to face a variety of psychological and social challenges as well as physiological issues.

The NHC recognises the changing levels of severity of chronic conditions across the life course and, therefore, the changing needs of people over time. The NHC also supports promoting positive health outcomes across the disease continuum through a range of interventions (from strategic national interventions to those that support self-management).

Policies may be more successful when they encompass prevention, promotion and control strategies, and when they make explicit links to other government programmes and community based organisations. (Epping-Jordan et al 2004)

The NHC recognises that the distinction between disease and illness is crucial for chronic care. Care that treats only the disease (relieving signs and symptoms and aiming to cure the body) cannot effectively respond to the whole experience of a chronic condition. Doing this requires addressing pain and suffering, improving functioning in daily life, and responding to other needs in a person's life.

The NHC has taken the approach of grouping chronic conditions together rather than looking at individual conditions. While specific conditions may have unique features, there are commonalities of experience across various chronic conditions – such as frequent use of health services, the need for self-management, experiences of depression or pain, and the need for ongoing use of pharmaceuticals. In addition, it is estimated that 45 percent of people with long-term conditions have more than one condition and this is likely to increase in the future (WHO 2003).

There are two areas that the NHC project scope did not specifically cover despite the clear relevance of these areas to chronic conditions: disability and health promotion.

- While recognising the considerable overlap of disability and chronic conditions²⁵, the NHC believed it could not do justice to the complexity of the issues within the scope of this report.
- Health promotion and prevention is fundamental to addressing chronic conditions. The NHC values the considerable work that has been, and is being, undertaken in this area and sees it as integral to implementing chronic care models. However, the focus of the project was on people living with diagnosed chronic conditions.

²⁵ An American study found that the total population of people with a chronic condition was 125 million, and the total population with a disability was 53.8 million. There were 43.2 million people with a chronic condition and a disability, 81.8 million with a chronic condition and no disability and 10.6 million with a disability and no chronic condition (Kane et al 2005).

2. Overview of key themes

The following key themes from NHC participants were evident in all the case studies, although they had specific and varying impacts for differing populations.

Participants spoke about how they felt about having a chronic condition, both in terms of the discrimination they met within society and the isolation they experienced because of how the discrimination made them view themselves. Understanding and acceptance of their condition, both by themselves and others, had a profound effect on their wellbeing. For Māori, their relationship to the wider community was inseparable from their experience of being Māori and attitudes toward their condition were interpreted from within their cultural experience.

The type of relationship participants had with health providers mattered greatly to people with chronic conditions. Their conditions meant they needed to see health professionals more often than other people. It was, therefore, important that the relationship was a good one, otherwise they did not want to seek help until it was absolutely necessary. For Māori and Pacific peoples, the way the relationship was formed and the type of communication that took place within it was profoundly informed by their cultural understandings.

Chronic conditions affect the whole of a person's life. Not surprisingly, people with chronic conditions did not want to be seen as a body part or a disease, but as a whole person with family connections and a life in the community. People's information needs reflect this. The importance of having the whole of their life and health seen when they interacted with the system had additional cultural meaning for Māori and Pacific peoples. However, although the impact of family/whānau involvement cannot be underestimated for Māori and Pacific peoples, they are also important for all people with chronic conditions who rely extensively on family and friends for both practical support and wellbeing.

Despite considerable support from family/whānau and friends many people with chronic conditions also need a central person to be responsible for their care. This person is needed to assist with, and advocate for, coordination of services as well as being a support in dealing with life changes. People with chronic conditions want confidence that there is someone ultimately responsible for their care who can prioritise their treatment and advise them when they receive conflicting advice or have to make important health decisions.

No matter how many health professionals assist the person with chronic conditions, or how many places they have to go to seek support, they want all the health professionals they see to know about their health history and they expect them to share this information with each other. They want services outside the health sector to recognise the effect chronic conditions have on the different areas of their lives and what is hard for them about getting care.

As people with chronic conditions use health services often, they want services to cost less and be easily accessible. Having a chronic condition affects the overall finances of a person and their family/whānau. This causes hardship and reduces chances to improve their health and living standards.

Participant recommendations have been included under sections where comment was made. The major areas of recommendation were to:

- improve relationships with health professionals
- value family/whānau
- improve coordination of services
- integrate service provision
- increase access to services and information
- acknowledge the links between mental and physical health.

3. Relationships

3.1 Relationships with the wider community

3.1.1 Discrimination and isolation

People in the case studies believed that attitudes in the community were more accepting and understanding of acute illness, but less accepting of chronic conditions. There was a societal expectation of being able to be cured and well. The fluctuations in health experienced by people with chronic illness were not easily tolerated by others.

Lack of understanding of participants' conditions led to stigma, blame and avoidance by others. This isolation was perceived differently by the different case study groups, since the way in which a person relates to the wider community and their belief in how they are seen by the community has a great deal to do with culture and interpretation. For example, Māori did not separate how their condition was perceived from how they were perceived as Māori. Case study participants with depression were more likely to state that negative attitudes in society adversely affected their image of themselves and led to isolation.

Experiences of Māori

The relationship of Māori to the wider community was inseparable from their experience of culture. Relationships with health professionals and providers were formed on the basis of a Māori view of health and wellbeing.

Māori participants experienced the shame of having a chronic condition as contributing to a loss of cultural, not just individual, identity. One participant explained that because he felt he was judged by others and there was a stigma attached to his condition, he felt unable to socialise. As he said: *'how can you socialise with a stigma hanging on to you?'* This stigma, however, was inseparable from his experience of racism or discrimination as a Māori. In this way, the judgements about his condition were not just attributed to himself but, collectively, to all Māori.

Experiences of Pacific peoples

The relationship of Pacific peoples with the wider community was not directly commented on in the case study. However, the importance placed on relationships within their own community raises questions around whether relationships with the wider community were not easy to speak of, or perhaps not easy to form because of lack of shared cultural attitudes.

Having a chronic disease was seen to be a barrier to a Pacific person's involvement in the church or other family-based activities. Attending church was seen as an integral part of participants' lives, directly impacting on their wellbeing and that of their families.

Experiences of people with chronic illness and depression

Participants with chronic illnesses and depression commented on having to cope with a range of negative attitudes from others, as well as having to deal with their own previously-held ideas about depression.

I never saw myself as the sort of person who would ever need to be on Prozac. I had a fairly jaundiced view of it and had to turn it into a joke to make it acceptable to myself. I have had to change drastically my ideas about myself which is part of why it has been hard to hold my self-esteem. Going on a benefit in my eyes has really put me at the bottom of my self-esteem. I was brought up in a family where those things were just not done.

The often-hidden nature of depression and chronic illness was highlighted, as was the fear others had of their condition once known.

Barriers remain, though, to joining in...even if others get to know me, they may not accept me... I look well to look at but they can't see the way I am affected.

People are frightened, it is one of those things people are ashamed of and don't want to talk about... There are times when people don't know how to treat me or how to approach me.

Experiences of children and families

Several families commented that a lack of understanding about their child's condition could lead to hurtful and erroneous perceptions of poor parenting. The father of a nine-year-old girl with type 1 diabetes had been on the receiving end of the attitude that *'a poor diet and lack of exercise...was why she 'got' diabetes'*, while another family, who are chronic asthma sufferers, stated that they *'felt discriminated [against] because people associated their health status with smoking'*. An even more extreme example of discrimination arising out of ignorance is related by a family whose 14-year-old daughter has a clotting disorder that manifests as bruising as a result of trauma. They said that they *'felt people were looking at them as child abusers, when the child had noticeable bruises'*.

3.1.2 Understanding and acceptance

In all case studies, the efforts of others to understand people with chronic conditions had positive consequences. However, the understanding and acceptance of having a chronic condition was again experienced differently by participants in the different groups. Those in the Māori and Pacific case studies saw understanding and acceptance resulting from being accepted as Māori or Pacific peoples and, therefore, as a cultural issue. However, those in the depression and children case studies perceived understanding and acceptance as something given to them within an individual relationship.

Experiences of people with chronic conditions and depression

What helped? People trying to understand and people asking. Not being afraid to ask and not giving up or putting it in the too-hard basket. Not acting as if diabetes and depression are contagious and not wanting to go near it.

Another way in which acceptance was welcomed was when recognition of the person's chronic condition or tiredness was accepted as *'that I am allowed to not do something and I don't have to apologise'*.

Participants recognised that a degree of self acceptance of who they were after life changes was just as important as the efforts made by others to understand them. For many, this was an adjustment process that involved grieving for who they used to be.

I have had to grieve for the person I was just like I have had to grieve for my marriage or that adjustment of letting my kids go. But I have adapted to a different life now. I have to accept being a forty-percenter in my life... Strange as it may seem, my self esteem is actually better. Before this I was a perfectionist and never felt good enough. I don't think that anymore. I look back and say 'I did have a good career, I was a good teacher,' those sort of things.

Participants provided a number of examples of how voluntary or community work, which they undertook when they felt well, helped them to feel good about themselves. It was important to them to be able to help others, be valued for what they could contribute and reciprocate support received while unwell.

I'm doing my [voluntary] job. I go to bed at night and I get up in the morning looking forward to going to work. I work with some good people and have lots of fun. I know my job. It gives me a boost and a reason to get up in the morning. ...If I didn't have a job, I'd be back in hospital years ago.

3.2 Relationships with family/whānau

3.2.1 The need to involve family/whānau

There are strong arguments for health professionals to have greater involvement with family/whānau in providing care to people with chronic conditions.

- Greater involvement is a key way in which relationships with providers can be built to increase access for Māori and Pacific peoples. It results in significant impacts on health and wellbeing for the person with a chronic condition.
- Greater involvement is culturally appropriate. However, regardless of which culture a person comes from, the support of family/whānau and friends is needed by people with chronic conditions for practical assistance and wellbeing.
- Involving family/whānau in support for self-management increases the likelihood that healthy behaviour will be adopted. Since family and whānau members are likely to have similar risk factors to the person with the chronic condition, involving family/whānau is a sound preventative approach.

All case studies made it clear that people with chronic conditions needed and valued the practical assistance given by family and friends with transport, history-taking at appointments, daily-living tasks and complex medication or monitoring routines. All participants, aware of the burden placed on their family/whānau/caregivers, emphasised the needs of a person's family and caregivers had to be considered and supported.

The health needs of the whole system needed to be assessed, not just the health needs of the person afflicted...The health needs of the caregiver are significant in addition to the immediate needs of the person.

3.2.2 Involving family/whānau

Experiences of Māori

Māori felt that health care professionals take little account of whānau as an integral part of their health and treatment process.

The Māori case study articulated the value of family/whānau involvement. This was not only reflected in whakapapa whānau but also with 'whānau' acquired through social services. An essential element of care according to the Māori case study is including the whole whānau. In this way all issues affecting the whānau are covered, not just the immediate needs of the person with the chronic conditions.

Nor is whānau restricted to family. One example was given where a rōpu rangatahi included koroua and kuia in their waka outing. The strength of this is that the koroua and kuia are able to provide wisdom that may benefit the rangatahi. This takes account of the wairua aspect of health.

Not having families/whānau present at significant health assessments led to miscommunication within families/whānau about the needs of people with chronic conditions. Additionally, not involving the family/whānau in care planning meant that someone with a chronic condition might not be able to keep an appointment if they were dependent on family/whānau for transport.

Experiences of Pacific peoples

Pacific participants spoke of the blessing of being part of a culture in which family duties were still practised and celebrated. One participant mentioned that the time when they most needed, and received, support from their family was when they were at their lowest, and found it difficult to ask for anything.

Having family members close by gave participants a sense of security. It also gave them practical support with daily activities and tasks, and fulfilling other roles such as 'advocate', 'translator', and 'errand runner'. Family support was recognised as helping participants take responsibility for their chronic conditions and health, as well as their independence. Pacific participants were clear that a willing and organised family was more important for them than any specific service.

Pacific peoples conveyed a general feeling about the lack of respect for the views and knowledge of family caregivers. Participants felt family caregivers were in the best position to explain how a family member was feeling or answer questions on behalf of their family member.

Pacific participants also spoke about the difficulties of relying on family or friends for assistance. Participants noted they found themselves faced with the dilemma of trying to minimise their needs to reduce pressure on the family, while at the same time needing to turn to them for assistance.

Pacific caregivers discussed the burden of being responsible for acting as a translator or decision maker for their loved one. Loneliness was another, less immediately obvious, stressor in caring for a family member with a chronic condition. While the caregivers were adamant they neither wanted paid caregivers to come into the home in their place, nor wished to be part of a support group, they nonetheless spoke of the need for a break from their constant caring for others. The sense of familial and cultural expectations on family members caring for their own was at times so great that they would have to find somewhere away from their family member (such as outside under the clothesline or in the backyard shed) just so they could cry in private.

Experiences of people with chronic conditions and depression

I have been very fortunate to meet [name] in the ME network as we do understand each other and can help each other. When one of us is not up to driving, the other takes us to get our groceries and vice versa. That is the best thing that has happened since moving here.

Participants found many of the tasks undertaken for people with chronic conditions were considered ‘personal’ or ones they felt they could not ask someone outside the family to do.

They particularly valued family or friends taking them to appointments. It was helpful to have someone remember what was agreed when they were in pain, tired or unwell. Respondents said they would not like to ask someone who didn’t know them well to do this for them. Participants also found it useful to have the support of family/whānau/friends attending an appointment due to the imbalance of power within the doctor-patient relationship: *‘We always go to doctors together as there is strength in numbers’*.

Partners provided necessary emotional support for participants. However, it was a strain on relationships to have to ask for many things to be done for them and it was difficult to maintain the relationship when tired and in pain. For one participant, their condition *‘meant the break-up of my first marriage because neither of us could understand what was going on and we could not cope with the other’*. Another participant said that her *‘husband did not understand or accept there was something wrong with me’* and this contributed to what she called the *‘casualty’* of her marriage.

Although there were stories of how the burden of caregiving had led to relationships breaking down, there were also stories of how facing difficulties together built strength in the partnership.

The fact that my wife and I have a wonderful relationship means we are still together, but there is a high incidence of marriage break-up with chronic fatigue as partners struggle to cope with the drastic changes and symptoms.

Experiences of children and their families

Families of children with chronic conditions found their knowledge and experience of their child’s condition was not always valued by health professionals. This was sometimes to such an extent that neither the child with the chronic condition nor their family were consulted in clinical decisions. Two families indicated just how extreme this kind of situation could become with comments such as: *‘They [doctors] don’t listen to us’* and: *‘They [doctors] don’t take any notice of her [the child]’*.

The role of the extended family, especially grandparents, was significant for children (and their immediate family). While the family was a huge source of support, it also created anxiety for families about the additional burden on older family members.

My parents [the child's grandparents] keep us [child and lead carer] out of hospital. If it wasn't for them it would cost the taxpayer to keep us in hospital or provide another support worker in our house.

For those parental caregivers who received it, counselling was helpful to adjust to issues raised by different stages in the child's condition and the impact on family life as a whole.

All families need counselling...I would never have asked for it, but it helps through difficult stages in retrospect.

3.2.3 Participant recommendations: valuing family/whānau

A key recommendation from all case studies was the requirement for service providers to listen to, acknowledge the needs and support the person with chronic conditions, their family/whānau and their caregivers.

- Participants in the Māori case study recommended that greater care be taken when matching a carer to the person needing support.
- Pacific participants emphasised the importance of connecting the family to the Pacific clinician, health worker and support worker. Pacific participants also recommended doctors assess the overall health needs of a household/family rather than the person with a chronic condition alone.
- Participants in the chronic conditions and depression case study recommended that doctors take a whole-of-life approach to people with chronic conditions to address their needs.
- Patients with chronic fatigue wanted greater knowledge and understanding from doctors about their condition. The major recommendation was for more attention to be paid to the link between physical and mental health for people with chronic conditions.
- Participants in the children's case study stated there is a need for assistance with a child's transition through life stages when they have a chronic condition. (For example, education plays a significant role in health outcomes. Educational performance can be lowered directly by absence from school for illness and indirectly through the impact of the social stigma of the illness.) Participants in the children's case study emphasised the need for active promotion and inclusion of the views of the child and family.

3.3 Relationships with health professionals

3.3.1 Poor communication and lack of understanding

All participants related stories of poor relationships with health professionals. Not being understood by health professionals, or not being able to understand them, caused participants distress and created uncertainty about how to manage their condition. Perceived lack of interest by health professionals also caused distress and frustration.

None of them are willing to see it as a challenge to solve a complex problem...the fact that what they gave the first time did not work does not prompt them to say – What else can we try?

Having a chronic condition requires a high level of communication to ensure people can effectively manage their conditions as well as having enough time to develop trusting relationships. Poor communication with health professionals made participants feel they were not cared for and destroyed trust in the health professional and, at times, in the health system.

Poor communication leading to misunderstanding was additionally interpreted by both Māori and Pacific peoples as lack of cultural affinity with health professionals or providers. All participants expressed difficulty in understanding the language and terminology used by health professionals; for Pacific peoples there was the additional barrier where English was not their first language.

When professionals rushed through appointments without giving people a clear understanding of what was happening this added to feelings of lack of care and respect. Participants felt 'talked over' by health professionals. This meant at times that participants did not take medications because they did not understand why they were needed.

Having poor relationships with health professionals also led to difficulties for participants in discussing or achieving a satisfactory prognosis for their chronic conditions. Participants found this especially stressful when there was no available treatment or management plan.

He started the interview with, 'I know nothing about your condition' [despite prior notice and the patient having seen his junior colleagues]... and proceeded to tell me I had 'women's problems' and the ending was, 'Come back when you've got a problem.' I was there for chronic constipation and the bleeding. Neither were addressed...I was just dismissed. I didn't necessarily need answers, I just needed to be treated seriously.

Experiences of Māori

Māori reported a lack of trust in providers. Building a relationship based on respect, listening and cultural understanding was essential for trust to be achieved. Māori expressed a conflict of interest and attitudes between themselves and health professionals. Māori participants felt uncomfortable with people who treated them in ways they experienced as discriminatory and did not want to use a service when this happened.

Regardless of the intention of Pākehā providers and/or health professionals, the Māori perception was that they were neither heard nor understood. Māori said health professionals *'talk in riddles – talk big words and we don't know what they are talking about'*. When a health professional did not make the effort to say things simply, Māori participants experienced a lack of respect. One participant said the *'specialist is abrupt, talks too fast, is grumpy because I hadn't taken my medications to the appointment. I felt intimidated'*. It was hard for Māori respondents to ask for explanations when they felt they were not listened to. One consequence of such interactions was that Māori were not always fully informed about medications.

Experiences of Pacific peoples

The significance of culture in the life experience of Pacific peoples is conveyed in their views of illness and responses about relationships with health professionals and providers. Some Pacific participants commented that it was *'hard to trust their doctor'*. Throughout the case study it was apparent that Pacific peoples do not usually speak openly about their own condition. None of the participants knew of, or had attended, health support groups.

Age is one area conditioned by cultural understandings, leading to Pacific peoples feeling they were not responded to in a culturally appropriate way. They found health professionals did not use the correct tone of respect when speaking with senior members of a Pacific community. On the other hand, Pacific peoples found it difficult to believe they were getting adequate care when they saw younger health professionals, as they believed they did not have the experience that would come with age.

Pacific participants spoke of the need for GPs to give patients comprehensive, easy-to-understand information about symptoms and management of their conditions, including medications. The contribution of language barriers to the situation was clear. English was a second or even third language for Pacific peoples. They found *'Palangi health workers [spoke] English too fast'*.

Pacific participants and their caregivers acknowledged traditional methods and remedies as useful to cure and/or help manage chronic conditions. Participants who regularly used traditional methods and remedies in conjunction with mainstream treatment and medicines saw them as complementary.

Experiences of people with chronic conditions and depression

Some participants in the depression case study experienced unhelpful interactions with GPs who had a disbelieving or dismissive attitude, were paternalistic, or lacked knowledge about their condition. On some occasions, physical symptoms were incorrectly attributed to mental illness, while on other occasions, the depression caused by the chronic condition was not considered.

Experiences of children and families

For children, their chronic condition may seem uncommon. Their life span may be short or uncertain. Managing uncertainty about the future was difficult for the children and their families. Often this uncertainty was not acknowledged by health professionals. Parents also had difficulty getting the child's chronic condition properly recognised and acknowledged by health professionals and support organisations.

Parents of children with chronic conditions found that not being given a clear prognosis of their child's condition prevented them from planning and making decisions. Where their child had a life-limiting condition, parents expressed frustration at health professionals being 'overprotective' and not adequately preparing them – if at all – for the child's deteriorating health and death at some point in the future. One family reported being told by a senior health professional that '*you [the parents] do not need to concern yourself with that just now*'.

3.3.2 Trust and assistance

It was the non-acceptance by the medical profession that was the hardest thing. It was a great thing to have a doctor that finally understood.

Positive relationships with health professionals were highly valued. Productive relationships with a 'good doctor' included situations where efforts were made to identify helpful nurses, doctors and specialists for participants. For instance, a doctor drawing a diagram to explain something '*was really helpful*', and made the participant feel the doctor cared and understood.

Experience of Māori

Spending time, in order to get and give all necessary information, was considered important to Māori. A good example of acceptance and understanding growing over time is where a participant spoke first of not being listened to by a health professional. When the health professional visited his home and saw his situation, there was some understanding of the participant's needs. The home visit was important in building and maintaining the relationship between the participant and the health professional.

Good relationships increased access to health services for Māori. Access was provided through those health care providers not only known by whānau, but also trusted to supply whānau with good advice about services. Common access points were through a Māori health provider, a by-Māori-for-Māori service, word of mouth, hui with kaumātua (incorporating kuia and koroua) and sharing experiences with whānau. Although there are other access points it is important that the concept of relationships is recognised as a central one for Māori. Good relationships lead to acceptance and understanding of people with chronic conditions.

Experience of Pacific peoples

Once you find the right one, kind, listens to you, then you stick with her otherwise you have to keep explaining and explaining over and over and over.

Pacific participants were especially articulate in defining that, for them, a 'good doctor' was someone you could talk to and who talked to you. They described the relief of having a '*doctor that finally understood*'. In the words of one participant:

When I go to [the Pacific Health] service, I feel comfortable and happy, although we talk about serious things, we always end up laughing, I always feel better when I have been.

Pacific peoples found sharing their experiences and humour with others managing their chronic conditions was both useful and inspiring. Perhaps most importantly, Pacific peoples spoke of the comfort and ease they felt when they were dealing with Pacific nurses and/or community support workers. For some this led to the ability to explain, without the need to translate, how they were feeling. Having services delivered by people who know you, who understand your culture as well as being able to communicate effectively with you was considered extremely important in terms of understanding and acceptance.

The following example is taken from an innovative local project using a High Needs Nurse Coordinator and Community Health Workers. It demonstrates the benefit of home-based support and having the time to listen and build trust.

Sela is a Pacific mother of two children in their late teens, living in West Auckland. Sela's GP spent years trying to help her to better manage her diabetes. Sela didn't respond to her doctor's suggestions and the doctor couldn't understand why she didn't want to get better. Eventually a home visit by a nurse was arranged. In a comprehensive discussion the nurse found out that Sela had a lump on her lower back that she was both very embarrassed about and was convinced was cancerous. Sela believed that she was going to die so she had not been concerned about managing her diabetes. Once the nurse had arranged for the lump to be removed and Sela was told that she did not have cancer, she was motivated to manage her diabetes better, with the help of her doctor. (Adapted from an account reported by a health professional, NHC consultation)

Experience of people with chronic conditions and depression

Participants also found interactions particularly helpful when health professionals had a positive attitude about their condition, were supportive of them and treated them with respect. They valued health professionals who provided information about the condition, referred them to other sources of help, and coordinated services from specialists. They also valued having medication reviewed in a timely manner.

People with chronic fatigue and depression especially valued health professionals who were knowledgeable about chronic fatigue and proactively pursued tests and treatment, while acknowledging the limits of their knowledge.

3.3.3 Participant recommendations: improving relationships with health professionals

People with chronic conditions in all the case studies expressed the need for better communication by health professionals. This included informing patients about their condition, medications and where to access available resources in the community.

- Participants in the Māori case study suggested matching Māori health professionals with Māori clients. They recommended more support for Māori health providers in training, specialist education, recruitment and retention. Participants also recommended mainstream health providers gain access to appropriate cultural awareness and training, and that this be part of the organisation's quality improvement programme.
- Participants in the Pacific case study recommended GPs and nurses spend more time with each patient, so that the health professionals involved can better understand the chronic condition and assist them to manage it.
- Participants in the depression case study recommended GPs take a more supportive attitude to mental health.
- Participants with chronic fatigue recommended GPs communicate more about possible diagnoses and inform them about what had been considered and ruled out.
- Participants in the children case study recommended that health professionals prepare children with life limiting conditions and their families for living long-term with the condition(s), as well as for deterioration and/or dying and death, in order to reduce uncertainty.

3.4 Relationships and culture in service provision

3.4.1 Lack of culturally appropriate services

Experience of Māori

Māori experienced a lack of cultural responsiveness or awareness among health professionals. Māori felt health professionals did not respond appropriately to their needs. Going to Pākeha health professionals was often daunting for Māori because they did not feel understood and felt no cultural affinity with them. At times this was experienced as a tangible form of discrimination. Māori participants reported feeling intimidated in their relationships with health professionals because of negative attitudes held by staff about their colour or ethnicity.

The general feeling expressed by participants was that Māori ‘turn off’ if they feel there is a lack of caring or understanding from professionals. This was particularly commented on by Māori participants who felt ‘whakamā’ (shy, embarrassed) when they had to speak about their bodies to health professionals they had not built a relationship of trust with. They wanted providers to understand their cultural requirements and the effects of tapu and noa (being respectful and normalising things) as routine.

Health professionals do not understand that Māori see things from a spiritual realm as well as physical and their whānau are part of their health and treatment process and these things are not considered by them enough.

Māori also experienced a lack of understanding about the way they view health and wellbeing. Māori recognise that health and wellbeing is a balancing of wairua (spirit), hinengaro (mental), tinana (physical) and whānau (family). This means treating Māori as a person in their whānau and life context, as opposed to treating the disease.

Experience of Pacific peoples

Pacific peoples experienced health professionals in general service provision as having little knowledge or understanding of their communities. For Pacific participants, health providers’ lack of cultural responsiveness included not being aware of the shame of acknowledging a chronic condition. This meant Pacific participants were reluctant to ask for assistance because it was ‘humbling’ to receive support from a service agency. The shame was worse for participants if they felt that their community negatively judged them because of their chronic condition. As one person said ‘our people are worse than judgement day’.

Although Pacific peoples were less articulate about racism as an issue, there were a few examples that imply discrimination is part of their experience. For example, one participant said they asked one of their children to phone for an appointment on their behalf as the child had a New Zealand accent and they thought this made it more likely for them to get an appointment.

Pacific participants also talked about wanting their communities to shift the focus from talking about specific health issues to managing their communities’ overall wellbeing, and to support the different roles and people involved in health care. In addition, some Pacific participants were critical of the Ministry of Health, which they felt consulted on ‘anything and everything’, and changed priorities frequently. The participants felt it might be more useful to look at how to develop family health policies than to focus on one sickness or type of chronic condition.

3.4.2 Relating to the whole person

Experiences of Māori

Māori made it clear they felt more comfortable when they met with Māori health care professionals. Māori community health workers ‘spoke the same language’ and provided an important whānau link within the community.

A number of positive examples were given of sharing a Māori view of health and wellbeing. Recognising that people need more than medication to feel better is an essential part of cultural responsiveness. The following examples were given:

- A worker took one participant to the beach because ‘just looking at it made her feel better’.
- A health professional helped to arrange ‘a kaumatua to come and say karakia with me – it’s what I wanted the most’.
- A nurse discussed with a koroua (old man) how to care for himself after a heart attack. After discussing physical aspects of his care, diet and exercise, he was asked what goals he had. He replied that he wanted to learn te reo Māori – so the nurse found information about courses he could attend.

The nurse came around to talk to me about my legs. All I wanted to do was stick my feet in the sea. She helped me get to the beach for the first time in nine months. After that I was happy to listen to her suggestions about my diabetes.

Experiences of Pacific peoples

Pacific participants also felt more 'at ease' when service providers were either culturally aware or from the same indigenous or ethnic group. They also noted that, especially for members of a numerically smaller ethnic group, one drawback could be a lack of privacy within the community.

For Pacific participants, health professionals acknowledging the importance of the participants' spiritual faith was also integral to their wellbeing. Participants in this case study emphasised the importance of prayer. One participant explained: '*you must first be well with God and then you look to the physical things*'.

One difficulty for Pacific participants was balancing cultural responsibilities and expectations against the limitations of their chronic conditions. It was difficult for them to 'learn selfishness' when living with a chronic condition.

A few years ago I nearly had asthma attacks daily; I was too tired and careless because others come first. Now I stick to the new programme plan and I have not had asthma attacks since.

4. Barriers to access

4.1 Lack of coordinated care and lack of integrated service provision

Participants in all case studies spoke about lack of coordinated care. Their experiences reflected the lack of integration between primary and secondary care; among health professionals/providers, and between health providers and government or community agencies. All participants, though expressed in different terms, felt that there was a worrying 'lack of joined-up thinking' between government-provided services and systems.

The following three areas, raised as concerns across all the case studies, highlight key barriers to a continuum of care:

- lack of coordination: assessments and appointments
- lack of coordination: care provision
- lack of integrated service provision: health sector, cross-sector.

The reality... is that patients consult multiple providers who lack coordination among themselves and across settings, resulting in care that is, at best, expensive, confusing and conflicting and, at worst, harmful to patients. (WHO 2002)

4.1.1 Lack of coordination: assessments and appointments

Participants in the case studies were frustrated by multiple assessments, which meant repeatedly giving their case history to different health professionals. They found it emotionally distressing to re-tell their story and stated they often needed another person to be present to support them to do this.

Participants would have preferred agencies to have their information ahead of time, so that consultation time focused on what new action was to be taken. This would not only have made the consultation more productive, but would also have given them confidence that the effort of being assessed would contribute to the ongoing management of their condition.

Participants found it frustrating when asked to attend appointments (sometimes at the same provider) on different days but there was no flexibility in appointment times. Relying on a family member to take time off work to transport them often meant missing an appointment.

Experiences of children and families

Despite extensive record keeping by every agency accessed by their child, parents complained that they were still often forced to repeat case histories when dealing with different agencies simply to receive the service they were entitled to; that they had to 'do the rounds'. One parent described it as 'humiliating' for her and her children to have to continually discuss their situation, financial and otherwise, with so many different agencies. This situation arose from a lack of coordinated care planning; each agency was conducting assessments for its own purposes, rather than contributing to achieving a plan for the patient's family.

4.1.2 Lack of coordination: care provision

The lack of a coordinated response across agencies with participant referrals and assessments produced what participants described as a 'lack of accountability'. Having no individual nominated to coordinate their care meant respondents were unclear about what was being provided and how this fitted into an overall plan or direction for them. There was no individual who had the whole picture when it came to decision-making and no clear idea of what changes to medication or treatment routines would achieve. This raises clear questions of risk and quality of care.

There were significant problems raised by lack of coordinated care in the transition between hospital and home. Participants talked about a 'void' in services after being discharged from hospital, including a lack of follow-up support and referral. They felt that health providers ought to be more responsible for what happened after a person left their care.

The real difficulty was there was absolutely no coordination; no-one knew what to do next... so everything was a fight.

Even when participants appeared to be receiving all the services they were entitled to and had made a successful transition from the hospital to home, the lack of coordination could still cause confusion and frustration.

What would be ideal...is for somebody to take you by the hand and look after you basically... to have somebody from the beginning for psychological support and to have some sort of advocacy service to help you find out what you need.

One Pacific participant was referred to support services within the hospital but never had this referral followed up by the appropriate support worker. She was told to contact the referrer if there was no follow-up, but did not do so. The cultural difficulties of asking for assistance and talking openly about illness were not taken into account.

On the one hand the supports are there but on the other hand you have to have the right spirit to keep asking.

4.1.3 Lack of integrated service provision

Health sector integration

It is possible that a part of the expressed need for coordinated care within the health sector was the result of health professionals not having the type of relationships with each other that would assist them to focus on a care plan for people with chronic conditions. A number of statements made by participants about not 'fitting' criteria for funding also suggest that providing more patient-focussed care would require re-thinking criteria, currently based on diagnosis, to be based on need.

So far, every time I've applied in the last two to three years I somehow don't fit, or seem to get lost in the system or fall through the gaps.

It was clear from case studies that there was a need for closer alignment of service provision in relation to mental and physical health. People with chronic conditions did not reliably have their secondary depression diagnosed and those with recognised mental illness had difficulty in getting treatment for physical symptoms (especially if the major symptoms were pain and tiredness).

Cross sector integration

The transition from being managed during an acute episode to self-managing a chronic condition is one that requires a range of social and economic supports beyond health care.

The WHO found that health providers do not make the best use of community services and resources and this was reflected by NHC case study participants. Respondents had difficulty accessing information about entitlements and supports. Trying to locate appropriate support took more time and energy than they had.

You may struggle longer than you should when you've been independent, but then get more sick from not having the support.

All participants spoke of the need for service providers to see them as a whole person in the context of their life needs. As the experience of having a chronic condition was one that affected their whole life circumstances and the lives of those around them, participants did not focus narrowly on having a specific disease, even though most health professionals did.

Every step of the way, one organisation would say, 'No, that's not us, it's someone else,' and I would spend – I had friends who started taking over for me – ages on the phone just ringing one place, ring the next place, ring the next place, no, go back to the original. And we just did that the whole time so that was frustrating.

Participants stated the need for health services to be more closely linked to NGOs or local support services. Potential support services for people with chronic conditions such as housing, social support and income support, are generally not co-located with health services. This could result in people not receiving all the benefits to which they are entitled.

I generally find it's the circumstances of living with the illness, not the illness itself, that create the most problems – the financial problems, needing support in practical ways, and isolation... It's not that I think the illness would be solved if the other stressors weren't there, but the impact of the illness would be lessened if the stressors were properly addressed.

Experiences of children with chronic conditions and their families

Lack of integrated government services was experienced by families, since parents were working across health, education and social systems for their child as well as employment and social systems for themselves as parents.

4.1.4 Participant recommendations: improving coordination of services

Participants in all case studies recommended:

- greater integration of health service provision with other government services and community support
- having one person facilitate care coordination and access to other services and support
- greater assistance in planning care and contributing to decision-making about care direction
- assessment and referral systems to share information across providers and result in better understanding the expected outcome
- services that have knowledge of a patient within their family context.

4.1.5 Participant recommendations: increasing provision of services

Participants in different case studies recommended that more support in specific areas be provided to people with chronic conditions, including:

- psychological support
- community outreach support
- home visits from nurses.

Participants also asked for:

- the Community Services Card to be extended to cover dental work, glasses and visits to specialists
- more flexibility with the disability allowance.

4.1.6 Participant recommendations: integrating service provision

All case study participants made specific recommendations about the ease of accessing services. They recommended:

- being informed about all of their entitlements (especially from Work and Income)
- support to access assistance from a range of government departments and NGOs
- providers working together on a care plan for their conditions, particularly if they had both a disability and a chronic condition or had both mental and physical health conditions
- increased funding for support groups and NGOs.

4.2 Barriers to accessing services

4.2.1 Health care costs

Despite the roll-out of subsidised primary health care, the case studies showed the financial cost of health care (including costs of consultation, prescriptions, and house calls) remains a barrier to people with chronic conditions to access services. Participants pointed out that fees were small but ongoing. This made it more likely that they would access services only when the need was urgent rather than becoming involved in population health and self-management approaches requiring ongoing contact with health professionals. Participants were also likely to cut down on medication because they simply could not afford it.

By their very nature chronic conditions need frequent visits to the health practice to ensure good control of the disease and reduce complications. This results in expense to the individual with the conditions. These payments need to be reviewed if we are to reduce the number of unnecessary hospitalisations. People should not have to choose between putting food on the table and a visit to the GP. (Health professional)

All participants spoke of the cost of health care and health-promoting lifestyles. Participants highlighted the gap between what their health professionals may consider to be the ideal eating plan for their conditions and their financial situation.

The healthy foods are really expensive. Someone needs to get real about what we can afford. It's expensive to have choice.

Participants commented that alternative health treatments were also expensive and largely unsubsidised. Paying for services not funded by the health system (such as home help, aids and home modifications) led to financial hardship. Participants felt there needed to be more government funding for specialist appointments because *'by the time you need to see a specialist, then something is definitely wrong with you'*.

Māori participants commented that while subsidised health programmes were helpful, they could not afford to continue going to the pool, gym, etc once subsidies were discontinued.

4.2.2 Transport barriers

Transport availability and transport costs were identified as a major issue by all case study participants. Participants in urban areas found that public transport did not always fit in with hospital appointment times. Some participants in rural areas had no bus service: *'Living in a rural town with no transport is not helpful'*. Participants, even in urban areas, said *'taxis are too dear'*. A provider commented that using private transport is also costly: *'There is [a] lack of money for petrol. People live day by day'*. This was particularly the case with the distances to be travelled in rural areas.

Public transport was often not suitable for tasks such as shopping, because carrying the bags was too tiring or painful and this left participants relying on others to carry out daily chores.

Transport issues sometimes caused appointments to be missed. Lack of transport was one reason given by participants for preferring outreach services and home visits.

4.2.3 The impact of financial hardship

As with all population groups, the health of people with chronic conditions is affected by a range of wider health determinants such as the type of employment, level of income and level of educational attainment.

Many participants found it hard, if not impossible, to maintain full-time employment with a chronic condition, which took a severe toll on their ability to manage the condition and their standard of living. There were some stories about employers who had tried to accommodate their illness and then terminated their employment. Most of the stories mentioned self-esteem.

I went from being a managing director of a major company and being a very busy person working from 6am to 10pm, to living on the couch, getting up at 11am and needing to go back to bed at 3pm. It took me three years to come to terms with the fact I was not the person I once was, that was the hardest thing.

Early retirement cut expected income levels. This has a greater impact on populations such as Māori, who develop chronic conditions earlier than other population groups. Additional research is required to assess whether those in manual occupations are less likely to be able to maintain employment than those in other types of employment.

Parents of children with chronic conditions used all their sick and annual leave entitlements. In addition, parents often took leave without pay, thus reducing the family income. If one parent stayed home to care for the child, the family income was further reduced.

Costs were also a barrier to forming social connections with a community or increasing life opportunities. People with chronic conditions who wanted to be involved in the community in a voluntary capacity (many noted this was good for self-esteem), found transport costs were a barrier. A number of participants wished to do further study, but found enrolment costs prohibitive.

Participants' housing options could also be limited by income. Participants spoke of the impact of location and access to transport in relation to attending health services. It was noted that damp, cold, substandard housing affected respiratory conditions. Making home modifications to assist with a chronic condition was too costly for most. Winter brought additional costs for heating. Rain and cold limited exercise options and increased the cost of drying clothing.

4.2.4 Variations in provision and eligibility of long-term support

Many participants noted there was less support for people with chronic conditions than for those eligible for disability support services or ACC.

A friend that I met through my self-management groups is on ACC. She gets her treatment quicker and she also has some home help. I don't resent her, but our conditions are really similar and it just seems unfair that she gets lots more than I do.

Parents of children with chronic conditions found inequities between the Child Disability Allowance provided at a single rate (not adjusted for needs) and ACC assistance. They also found financial assistance was inadequate, difficult to access and criteria for eligibility were applied inconsistently.

Participants in all the case studies commented on the sheer force of will and energy needed to get support.

There may be some way of getting reimbursed but you have to be well and energetic to fight your way through the system to find out the information and to take the necessary steps, so I have not pursued it.

4.2.5 Participant recommendations: increasing access to services

Improving access to services is a key recommendation by participants in all of the case studies.

Recommendations included:

- being able to access services in a timely fashion
- having some options about appointment times to coordinate other appointments and transport
- being followed up where appointments are missed
- subsidised transport
- no cost for ongoing check-ups (eg blood pressure)
- achieving greater equity in entitlements across providers (eg making Child Disability Allowance and ACC payments comparable).

Equity was also sought in provision of services. Participants wanted people with chronic conditions to have access to the same level of support as disabled people. Services recommended included:

- home support
- environmental support and equipment
- counselling services (eg for individuals to adjust to life change, or families to manage stress).

In addition to common recommendations, each case study put forward specific recommendations.

- Māori expressed a need to ensure appropriate referrals are made for Māori with chronic conditions. Having local subsidised hui for regular checking on the ongoing needs of Māori with chronic conditions was suggested by participants as an enabling strategy. Māori recommended that where services were provided to improve access to healthy activities (such as attendance at a gym or pool), permanent subsidies be provided.
- A family day clinic was suggested by Tokelauan participants in the Pacific case study where the GP, nurse and a Tokelauan-speaking health worker would be able to comprehensively assess the health needs of families and track particular chronic conditions across generations.

The need to address inequities in funding provision and care between people with chronic conditions and those with a disability was particularly emphasised in the depression and children case studies. Respondents recommended that assessment criteria for support services be based on need.

4.3 Barriers to accessing information

4.3.1 Difficulties in accessing information

Inability to access information was mentioned by all participants. Lack of information about support services and entitlements had financial and social consequences for them and their family/whānau.

Participants discussed how upsetting it was to receive incomplete information, such as:

- being told their condition was serious, but not being provided with information about what else they could do to help themselves
- being prescribed medication without being told what it would accomplish
- being asked if they wanted support, but not told what sort of support could be provided.

The manner in which information was provided was important and this had an impact on the type of relationship formed with the health professional. Participants felt there was a lack of care when 'bad news' was delivered abruptly, or relayed by telephone instead of being face-to-face with family/whānau or other support person present. One participant described being rung by the hospital and told she had cancer. She was upset and could not understand why the hospital had not first contacted her GP who could have given her the diagnosis face-to-face.

Participants spoke of a range of difficulties in accessing information.

- Medical terminology and language were a barrier to understanding information.
- Medical terminology was culturally alienating for some Māori and Pacific peoples.
- Information was often in English, whereas many Pacific peoples have English as a second or third language.
- Consultation times were too short for patients to understand their health problem.
- There was a lack of information from a caregiver's perspective.
- Patients were provided with conflicting information from different health professionals or they accessed conflicting information from other sources such as radio and internet. They did not know who to discuss the conflicting information with.

Of particular concern was the failure of many participants to understand the role of medication in their treatment. Examples included people who:

- did not take medication because they did not understand its purpose
- discontinued use of medicine when they felt well
- stockpiled medication for future use, and
- gave medication to other people they saw as having a similar condition.

One gentleman has had diabetes for years and is taking several medications for this. However he could not explain to me what diabetes was, what his medication did, or the long-term effects of his diabetes. His blood glucose was never under 10. I spent 60 minutes with this gentleman, explaining the long-term effects and how his medications worked. I then referred him to a dietician. ... He now has an excellent understanding of his condition, and his blood glucose readings are in single figures. (Pharmacist in a submission to NHC)

Pacific peoples

Tokelauan participants in the Pacific case study felt they had no rights. Participants believed that many Tokelauans still accepted anything they were told by a doctor. The participants believed that providing information and education about consumer rights should be a requirement of PHOs.

People with chronic conditions and depression

Participants spoke of a need for more awareness among health professionals and the public about accessing available resources and support groups. *'Things happen to people and the resources need to be there to support them, and people need to know those resources are there.'*

4.3.2 Beneficial provision of information

Both formal and informal information sources were mentioned by participants as helpful in terms of education and support about chronic conditions.

- Māori found information was easier to receive when there was a good relationship with health professionals.
- Pacific participants found Island-specific radio programmes especially helpful in disseminating information about chronic conditions to their communities.
- A number of participants spoke about the benefits of support groups. *'The support group, which made me realise I wasn't alone, that has been the biggest help of all.'*
- A child with diabetes commented that she had found materials produced by a diabetic support organisation a *'helpful and fun'* resource. Families found information on the internet was the most up to date.

The Diabetes Society course that I did one morning a week for a month down here at the hospital was very, very useful. It was really practical and gave us a lot of information...Information helps people understand and takes away anxiety. It helps once people understand you can largely control it by diet and exercise, rather than thinking you have to inject yourself or else you will die-type thinking.

Participants found it helpful when health professionals were knowledgeable about their condition, provided information on support available and referred people to other sources of help. Families found being given the same information as those with chronic conditions to be of great use.

4.3.3 Participant recommendations: increasing access to information

Participants in all case studies recommended the following:

- sufficient time with a health professional to understand their condition
- information in their first language with greater use made of diagrams or video presentations
- easy to understand, up-to-date and accurate information for patients and their family/whānau/carers about their condition
- more information about the purpose and effects of medications
- receiving consistent information from different providers
- providing a point of contact to discuss conflicting information
- increasing awareness among health professionals and the community about resources available to people with chronic conditions
- providing information about entitlements and support services (possibly from a social worker or advocate).

The following specific recommendations were also made.

- Participants in the Pacific case study recommended that more information about health promotion, chronic conditions and support services be disseminated to whole communities via community forums, radio and television and through provision of written material in Pacific languages. Pacific participants also recommended using an Island-specific approach to increase awareness of health and wellbeing rather than using a generic approach. They also recommended all PHOs be required to make information on patient rights available.
- A participant in the depression case study recommended providing courses or information for carers about enduring power of attorney and managing another person's financial affairs.

5. Pain and depression

5.1 Living with pain

Some participants experienced chronic pain as a fluctuating symptom of a chronic condition. Pain could be debilitating and intense. Fluctuating pain caused frustration and chronic pain often led to depression.

Sometimes I have a week or even a few days when the pain is at level 7 [on a scale of 10] nearly constantly, and by the end of that I collapse in tears of frustration because I just can't cope with it any more.

Chronic pain of uncertain origin was also thought to be worse than a defined, acute pain.

Having a source of the pain, you can concentrate on it and that makes it easier to block it out if you need to, whereas this is so nebulous and so horrendous because it is so spread out, so unconnected to anything and so internal. It is much more scary.

Chronic pain affected different areas of a person's life. It could interfere with sleep, contributing to feeling exhausted and inability to concentrate. Chronic pain reduced wellbeing when it interfered with driving, use of public transport, or otherwise limited social life. It also reduced opportunities for work or study. Chronic pain had an impact on relationships with those closest to the person with a chronic condition.

They hate seeing me in pain, struggling round. They hate the bleeding, they hate the spasms, they hate watching each new phase as it occurs. The vomiting upsets them.

Pain reduced the quality of the relationship for couples and increased the need for psychological support for the person with the pain as well as the carer. As one carer put it 'I'm his main moaning person'.

Participants found attending pain clinics beneficial. Pain-management health professionals were experienced as being supportive and responsive to participants' changing needs. Participants wanted to see information about pain management services made more widely available. However, participants also commented on the length of time taken to receive appointments and see other members of the team.

5.2 Depression and chronic conditions

Experience of people with chronic conditions and depression

Participants in the case study included people who experienced depression prior to having a chronic condition, people who developed secondary depression and people who had depression as a result of medication required for their chronic condition.

Depression and physical chronic conditions had an impact on every area of a person's life. Managing the shared symptoms and challenges of both conditions was a central concern and participants recounted in detail the difficulties they encountered in receiving care for both conditions.

Participants in the depression case study found the effect on their mental health of having a chronic physical condition was neither consistently recognised nor addressed by their GP.

Now it seems obvious that having my functions limited by my health would affect my emotions, but this wasn't even mentioned by my doctor. When it did happen, I didn't know how to cope with how I felt.

Participants with depression believed some of their physical symptoms were either incorrectly attributed to mental illness or not taken seriously. As a number of participants said '*I just wanted to be taken seriously*'. Not being believed, taken seriously, or fully informed about the results of tests, led to poor relationships with their health professional(s).

A number of participants with both depression and chronic conditions sought alternative therapies. They felt that this allowed them to be treated as a whole person and they were able to take some action about their condition. Both these positive aspects could be gained from pursuing self-management. However, the NHC case studies did not gather information on whether these participants had been offered or were engaged in self-management programmes.

6. How the case studies informed the project

People do not section off bits of their life in the way researchers or policy analysts might wish. Everything is connected and underlying values and beliefs may not be openly stated. Culture – which is really another way of speaking about life as experienced from within ourselves, our families and groups – permeates every part of our life. Whether we are in a dominant or minority culture affects our interpretation. It also affects how or whether people see themselves as individuals. For example, there were differences in the way people were affected by negative attitudes or lack of assistance. Pākeha took negative experiences personally and found these affected their self-esteem. Māori and Pacific peoples experienced discrimination and felt attacked as a people.

All people wanted their whole life expression to be taken into account for their health and wellbeing. Spiritual belief and emotional or mental states were not seen as an ‘added element’ to be considered by a service provider, but as something fundamental to understanding who they are as human beings and their place in the universe. It was part of everyday experience. When this full understanding of their life was not demonstrated by a service provider, Māori and Pacific peoples experienced a cultural alienation, while Pākeha felt their lives became more fragmented.

Where a person stands in terms of being an individual or part of a family/whānau and culture did make a difference to their experience. However, when we look at what people asked for it was very similar: All people wanted to be treated with respect. They wanted to have relationships of trust with health professionals. They wanted family and friends involved to support them when there was bad news or when they had to make decisions. At times they needed support from health professionals to work out how they could manage life circumstances and their health. They needed it to be easier and cheaper to access services and information.

People’s needs became the basis of recommendations, even though they are at times expressed in quite different language.

The recommendations arising from the case studies had much in common with what researchers, policy analysts or providers sought. The recommendations based on the experiences of people with chronic conditions are less detailed than the types of recommendations the Ministry of Health or DHBs have made, because knowing what you want from a system is different from knowing in detail how to fix it. However, the outcomes people with chronic conditions sought are just as clear as those sought by the NHC.

The value of the case studies for the recommendations is that the voice of these people lies at the heart of them and unites the breadth of vision required to have a nation in which people can live well with chronic conditions.

NATIONAL HEALTH COMMITTEE DISCUSSION DOCUMENT SUBMISSIONS

The NHC released the discussion paper *People with Chronic Conditions* in April 2005. Of the 100 submissions received, ten were from people with chronic conditions themselves, 20 from researchers and academics, 30 from NGOs and 40 from health professionals.

1.1 Key themes of submissions

Key themes raised by respondents included:

- agreement on approaches to chronic care: population health and preventative approaches; addressing the wider determinants of health; making person-centred care a reality
- agreement on the need for service provision change: coordination and continuity of care; increasing access
- broad support for workforce change
- agreement on outcomes for information systems development
- questions of access and equity
- agreement on funding priorities.

Health policies need to give priority to chronic conditions. Funding is urgently needed for locally-based research, workforce development, knowledge management, programme development and implementation, system redesign and facilitation of community and intersectoral collaboration.
(Health professional, NHC submission)

1.1.1 Agreement on approaches to chronic care

In line with international literature, respondents recognised that the health system is still oriented toward acute episodic care and requires a fundamental change in culture to support people with chronic conditions. In addition, examples were given of the dominance of the bio-medical model of care and its focus on illness, not wellness. Of particular concern was the way in which professional training that focused solely on the mind or the body was unable to recognise the interaction between the two.

There was strong support for the chronic care management models in the NHC's discussion paper.

This included support for:

- recognising the importance of environmental and social influences on health
- emphasising 'upstream' approaches, including public health initiatives, focusing on promoting wellbeing and primary prevention
- identifying people with, or at risk of developing, chronic conditions earlier using a population health approach
- providing continuous and coordinated care
- encouraging stronger community engagement and self-management.

Population health and preventative approaches

Respondents overwhelmingly supported chronic care management models taking a population-health approach that included early intervention/primary prevention and secondary prevention. Respondents noted the importance of screening and health promotion, early identification of high-risk individuals for disease prevention, as well as the need to provide follow-up for people with chronic conditions who were identified as having a high risk of complications or hospitalisation. Endorsement of prevention included social environments and interactions. Preventative measures included self-management and stronger community engagement. High-risk groups identified by providers included all patients with one chronic disease (since they have a higher likelihood of developing another) and families/whānau of people with chronic illness.

Addressing the wider determinants of health

Respondents noted the lack of understanding of determinants of health within and outside the health sector and the need for understanding population health and preventive approaches in sectors outside of health.

A significant number of comments were made on the need to promote whole-of-government approaches, including the suggestion that some services be co-located (for example, placing WINZ branches within hospitals). Some respondents were concerned that health professionals lacked knowledge about all forms of income support.

Making person-centred care a reality

In accord with international directions, respondents very strongly supported self-management. Respondents raised a number of potential concerns. These included providers off-loading their responsibilities onto patients in the name of 'self-management' and well-resourced people making better use of self-management, which would increase health disparities. Some health professionals stated that disincentives to self-management (such as lack of time for extended consultations) required national resolution. Many providers and health professionals noted the absence of national guidelines on self-management.

There was acknowledgement of the need for culturally appropriate approaches to patient management and the need for family/whānau to be integral to person-centred care models.

1.1.2 Agreement on the need for service provision changes

Improving coordination and continuity of care

There was very strong agreement regarding the need for better coordination between primary and secondary levels of care. Respondents noted that the main reason for readmission is the lack of coordinated care. Specific areas commented on the need for greater coordination between health services and family/whānau, the need for greater involvement of NGOs in discharge planning and a system to enable liaison between prescribers.

Continuity of care was seen as vital in enabling the shift toward a preventative focus. Models that assisted integrated care, such as case management and multi-agency meetings, were well supported.

Respondents noted that policy promoting a continuum of care requires full and consistent implementation. Corroborating the findings of the Commonwealth Fund Survey, the majority of respondents noted that transition from secondary to primary care continues to be inadequate. This results in lack of access to information and failure to refer to services and support, within and outside the health sector. Specific areas of transition (such as the shift from paediatric to adult services) were identified as requiring more coordination. Respondents also suggested that more thought be given to how patients could be supported between consultations, for example by information services or medicine-management programmes.

Increasing access

Access issues were noted within every area raised by respondents. The cost of transport and ancillary expenses as well as the cost of care was widely acknowledged as a common and formidable barrier to those who suffer from chronic conditions. The lack of information about High User or Community Services Cards or other benefits and services as well as disparate access to these has the potential to increase health inequalities. There was a widely-recognised need for health and mental health services to work more closely together to increase access. Lack of cultural appropriateness of services created barriers to accessing services for Māori, Pacific peoples and migrants.

Overall, comments confirmed there is a need to address access and equity issues within the health system as a whole. There was wide support for a health system that addresses mental and physical health together in order to overcome access barriers.

1.1.3 Broad support for workforce change

There was broad support for systems to be more proactive, coordinated and holistic in line with national policy. Teamwork, innovation and access to services were highly regarded. Barriers noted included patch protection, mistrust of other disciplines and gate-keeping.

Professional teamwork and multidisciplinary approaches to developing a continuum of care were positively regarded in almost all submissions. Many respondents recognised that sharing treatment information is essential to improving knowledge and relationships across the health sector and providing consistent information to patients. In particular, there was very strong support for health professionals to take the emotional and practical implications of chronic conditions into account in their assessment and treatment process. Some respondents additionally wanted to strengthen links between mainstream health professionals and complementary and alternative medicines practitioners.

Not surprisingly, given the solid support for teamwork, nearly all submissions raised the need for better use of the existing health workforce, for example, making better use of nurses, pharmacists, optometrists and social workers within PHO teams as well as in discharge planning.

A major theme of discussion groups prior to submissions was for generic community health workers in chronic conditions to have an advocacy role in connecting people to social services.

Lack of availability of specialist services and lack of timeliness in specialist services was raised by a number of respondents. There was support for specialist outreach programmes to the patient's home.

NHC submissions and consultation on workforce issues reinforced existing national policy directions. Workforce priority areas from submissions areas were:

- long-term, strategic workforce planning that addresses cross-discipline and cross-sector approaches to coordinated care
- current and future workforce training to include skills required for working in the chronic conditions area
- more effective use of health professionals within teams and across the sector.

1.1.4 Agreement on outcomes for information systems development

Respondents recognised that management of chronic conditions requires different information systems for:

- patient information to be gathered over time
- reliable and consistent information to be gathered across providers
- accessible information across primary and secondary sectors.

Information systems for patient record management and a process for sharing appropriate information across health providers and other sectors were seen by respondents as pivotal to achieving coordination of care.

Respondents particularly noted the need for:

- access to electronic decision support systems
- information technology enabling data sharing
- better utilisation of pharmacy records
- integration of information on both mental and physical health.

1.1.5 Agreement on funding priorities

There were a number of areas in which respondents commented that funding arrangements reduced effectiveness of care for people with chronic conditions.

Funding was seen as having a profound effect on coordination of care. For example, in relation to developing partnerships, respondents noted that:

- current funding systems form administrative barriers that hinder the development of partnerships within and across sectors
- inequitable access to treatment and support services arises from separate funding for different diagnostic categories, which works against a whole-of-government approach
- current funding streams perpetuate the separation of mental and physical health services.

In the area of partnerships with community organisations, a number of comments were made about capacity and resource issues. The power and funding imbalance between health and community sectors was seen as a problem for NGOs. There was some support for pooling resources and providing generic services. Some respondents suggested that NGOs could strengthen funding certainty if they operated from within PHOs.

Respondents believed there was inequitable access to funding, treatment and support of chronic conditions. Access dependent on regional prioritisation or availability of services meant that people's needs were not being met.

There were consistent difficulties with diagnosis as a criterion for funding, rather than patient need. Diagnoses either did not fit into a specific funding stream or fitted more than one funding stream and had to be coordinated. The more complex a person's condition, the more difficult it was to acquire adequate funding. Age-based criteria were also seen to create barriers.

Current funding streams were seen to perpetuate the separation of mental and physical health services. Specific examples were given of people with mental illness or an intellectual disability being denied sufficient physical health care, and drug and alcohol treatment services not accepting people with mental illness, despite it being a common co-morbidity.

Respondents were concerned about service provision for people with both a disability and a chronic condition. The difficulty accessing services because of their disability is magnified by the sheer number and range of services required for a person who has a chronic condition. Clarification is required on funding responsibilities for these people.

Lack of cultural appropriateness of services was cited as a barrier to effective access for Māori, Pacific peoples and migrants.

There were also perceived injustices stemming from variations of entitlements received by people with similar need across government agencies (for instance, ACC claimants compared with those in the public health system).

1.2 Summary of themes raised in NHC submissions

In line with international literature, respondents called for a fundamental change in the health sector culture to support people living with chronic conditions and strongly supported chronic care models and approaches. There was significant support for whole-of-government approaches entailing strong leadership to guide action on the broader health determinants. Respondents very strongly supported self-management that would 'make person-centred care a reality' and include greater family/whānau involvement. They called for leadership in support of self-management and noted the absence of national guidelines in this area. They also sought funding to enable realistic consultation times with patients for support of self-management.

There was strong agreement on the need for coordination and continuity of care. Respondents noted that the main reason for readmission to hospital is lack of coordinated care. The need for better coordination between primary and secondary levels of care was illustrated by a range of examples. Poor discharge practices were highlighted, including the need to improve referral between health providers and NGOs. Health professionals also wanted to improve their knowledge of other sectors in ways that increased appropriate referrals (for example, to WINZ). Lack of liaison between health professionals over prescribed medicines was seen as having potentially harmful consequences for patients. Continuity was also considered within primary health care, with suggestions made for increasing contact with patients between consultations (in terms of information and support).

Teamwork, innovation and access to services were highly regarded and the majority of submissions raised the need for better use of the existing health workforce. Respondents wished to see strategic workforce planning support cross-discipline and cross-sector approaches to coordinated care.

Effective information systems were seen by respondents as crucial to achieving coordination of care. Respondents wanted to share treatment information to improve knowledge and relationships across the health sector and provide consistent information to patients. Respondents also saw electronic information systems as providing valuable support for identifying those at risk and providing reminders for follow-up.

Access issues were noted within every thematic area. This points to the need to address access and equity issues within the health sector as a whole.

Respondents identified a number of areas in which funding arrangements reduced effectiveness of care for people with chronic conditions. Current funding arrangements were believed to have a profound and negative effect on coordination of care and created tensions between government and NGOs. For example, in relation to developing partnerships, respondents noted that current funding systems form administrative barriers that hinder the development of partnerships within and across sectors. Particular concerns were raised around lack of alignment of mental and physical health services creating barriers to treatment. Criteria based on diagnosis, or age, did not meet the needs of all people with chronic conditions. There were perceived injustices when ACC claimants' entitlements differed from those of the public health system.

Respondents outlined four main areas as funding priorities:

- workforce development, especially in the area of self-management
- resourcing and leadership for community and intersectoral collaboration
- knowledge management and information systems design
- local research initiatives.

APPENDIX 1: Facts on the significance of chronic conditions

1.1 Co-morbidities

- In 2001, almost one in four Americans had more than one chronic condition (Partnership for Solutions 2004).
- Obesity is closely associated with Type-2 diabetes, sleep apnoea, asthma, metabolic syndrome, arthritis, gastroenterology and cardiovascular conditions.
- Studies report a high prevalence of one or more co-morbidities among people with chronic obstructive pulmonary disease (COPD), including cancer (Yeo et al 2006).
- Depression is often a co-morbid with major chronic conditions such as diabetes and heart disease (World Health Organisation 2003).

1.2 Cost of chronic conditions

- A recent study by the Commonwealth Fund found that in each of the six countries studied, a disproportionate share of national spending was concentrated on patients with chronic diseases, especially those with multiple illnesses (Schoen et al 2005).
- In the United States total stroke costs in the next 45 years are conservatively estimated to be over \$2.2 trillion, with the highest per capita contributors being African Americans and Hispanics.
- A comprehensive American study of the direct and indirect costs of asthma concluded that asthma-related costs are substantial and driven largely by pharmaceuticals and work loss (Cisternas et al 2003).
- A British study found that the total cost of adult depression was estimated at over £9 billion in the year 2000, of which £370 million represented direct treatment costs. There were 109.7 million working days lost and 2615 deaths due to depression in 2000. The authors concluded that despite awareness campaigns and the availability of effective treatments, depression remains a considerable burden on both society and the individual, especially in terms of incapacity to work (Thomas and Morris 2003).
- Based on a US study, diabetes and its complications cost the Canadian health care system an estimated \$13.2 billion every year. By 2010, it is estimated that these costs will rise to \$15.6 billion a year (Canadian Diabetes Association).

1.3 Cost of chronic conditions in New Zealand

More economic analysis needs to be undertaken on the overall cost of chronic conditions in New Zealand. Single condition estimates do not account for the overlap of services for co-morbidities.

- The direct medical costs of strokes in New Zealand are estimated at \$150 million a year (Auckland University 2005).
- In 2005, the total financial cost of arthritis to the New Zealand health sector was estimated to be \$2.35 billion. Indirect costs (employment loss or reduced productivity, care, aids) were estimated to be three times higher than direct health costs (Access Economics Pty Ltd 2005).
- Asthma in New Zealand is conservatively estimated to cost \$825 million per year, with equivalent indirect costs. A disproportionately large part of this cost is attributable to chronic severe and/or poorly controlled asthma (Asthma and Respiratory Foundation of New Zealand).
- A person with diabetes generates hospital costs that are, on average, 2.5 times greater than someone without diabetes (Diabetes New Zealand Inc 2001).

1.4 Cost reduction in management of chronic diseases

Potential for cost reduction from improving management of chronic conditions has been well documented and provided numerous examples (Von Korff et al 2002).

- Care not delivered, or delivered wrongly, not only decreases the patient's current care but also has the potential to increase the need in the future. For example, failure to deliver a blood thinner to patients with atrial fibrillation in the United States has been estimated to account for 40,000 preventable strokes per year (Scott et al 2002).
- There is evidence of a range of healthcare cost reductions from chronic disease management methods (Department of Health 2004). For example, a five-year retrospective cohort study in the US showed that a sustained reduction in Hb1C levels among adults with diabetes was associated with cost savings within one to two years of improvement (Wagner et al 2001c).

APPENDIX 2: Facts on chronic conditions as a major driver of health inequalities

2.1 Māori mortality and morbidity

- The major chronic conditions for Māori are diabetes, cardiovascular diseases, stroke, cancer and respiratory infections.
- Māori over 35 die at almost three times the rate of non-Māori of cardiovascular disease: 569 per 100,000 compared to 205 per 100,000 (Ministry of Health 2006c).
- Diabetes is about three times more common in Māori adults than non-Māori (Hay 2002). Diabetes complications such as renal failure and lower limb amputations take place at far higher rates among Māori diabetics than among non-Māori diabetics (Ministry of Health 2006c).
- Diabetes causes as much as 20 percent of all deaths among Māori compared with four percent for non-Māori non-Pacific people (NZGG 2003).
- Māori are more than five times more likely to die from diagnosed diabetes than non-Māori, non-Pacific people. By 2011, the prevalence of diabetes is predicted to rise 132 per cent for Māori (Ministry of Health 2002).
- Māori aged 45 years and over are four times more likely to be hospitalised for a chronic obstructive pulmonary disease, and over three times more likely to die from it, than non-Māori (Ministry of Health 2006c).
- Māori are hospitalised more frequently: Hospital discharge rates are 1.4-2.5 times higher than non-Māori and hospitalisation rates are 40 percent higher for both infectious diseases and respiratory disorders, plus more than 100 percent higher for endocrine disorders (Ministry of Health 1999).
- Māori have strokes more than a decade younger than European New Zealanders (Auckland University 2005).
- Prevalence and severity of asthma are greater in Māori adults, compared with non-Māori adults. Although prevalence is similar for Māori and non-Māori children, asthma severity is greater in Māori children (Ellison-Loschmann and Pearce 2000).
- Between 1996 and 2001, the incidence of combined cancer for Māori women was 25 percent higher than for non-Māori (178.5 per 100,000). Although Māori had an 18 percent higher incidence rate overall for all cancers combined, Māori had a 93 percent higher mortality rate than non-Māori (Robson et al 2006).

2.2 Socioeconomic inequalities and mortality

- Although all income groups experienced declines in mortality throughout the 1980s and 1990s, the difference in mortality rates between low and high income groups (absolute inequality) remained static, which means that relative inequality (ratio of mortality rates in low to high income groups) increased over time (Blakely et al 2004).
- During the period 1981-1999, gaps in life expectancy overall between low and high income groups (not specific to chronic conditions) widened from 3.4-5 years for males, but remained stable for females (Ajwani et al 2003).
- Socioeconomic inequalities in mortality rates are linked to cardiovascular disease (in particular ischemic heart disease), chronic lung disease and cancer (Ministry of Health and University of Otago 2006).
- The contribution of cancer to income-related inequalities in mortality increased over the period 1981-1999, particularly for women aged 66-77 years. Lung cancer mortality rates among women on low incomes increased by 69 percent (Ajwani et al 2003).

2.3 Māori and socioeconomic inequalities

- Between 1981 and 1999, Māori were disproportionately represented in lower socioeconomic strata and consequently disproportionately affected by the health consequences of lower socioeconomic status.
- Māori to non-Māori inequalities in mortality persist within socio-economic strata and socioeconomic gradients in mortality exist within both Māori and non-Māori ethnic groups.

The different socioeconomic resources or position of Māori and non-Māori/non-Pacific groups account for at least half of the ethnic disparities in mortality for working age adults and one-third for older adults. Widening inequalities in socioeconomic resources between these groups during the 1980s and 1990s explained about one third to a half of the widening in the mortality disparity (for people of working age) (Ministry of Health and University of Otago 2006).

2.4 Increases in sickness and invalid benefit numbers

From 1992-2002, the number of sickness beneficiaries in New Zealand rose from around 30,000 to 40,000, while the number of people on the invalids benefit doubled (Ministry of Social Development 2005). Increases not attributable to population growth, population ageing and rise in age of superannuation, are associated with mental illness and musculoskeletal incapacities for the majority of New Zealand. Māori and Pacific peoples have a wider range of incapacities. For example, the conditions most affecting Māori are schizophrenia, cancer and respiratory or circulatory conditions, while for Pacific peoples, the major conditions are circulatory conditions, endocrine conditions and cancer.

2.5 Morbidity and mortality of Pacific people

- Pacific people live, on average, around eight years less than the general population (Ajwani et al 2003).
- Pacific peoples with chronic conditions experience higher rates of mental disorder (Ministry of Health 2006).
- Pacific people have higher rates of avoidable mortality than the 'all New Zealand' benchmark – approximately a 50 percent excess risk. From middle age onwards, chronic diseases (including ischemic heart disease, stroke, lung cancer and COPD) are the major causes of avoidable mortality. Pacific men have avoidable mortality rates about one and a half times those of Pacific women (Ministry of Health 2004c).
- The prevalence of diabetes among Pacific women between 25-44 years is 6.2 per 100, compared to the New Zealand average of 1.4 for females in the same age group. The prevalence of diabetes among Pacific women aged between 45-64 years is 20.1 per 100 compared to the NZ average of 6.2 per 100 for women in the same age group (Ministry of Health 2004c).
- By 2011 the prevalence of diabetes in Pacific peoples is predicted to increase by 146 percent, compared with 58 percent for European New Zealanders (Hay 2002).
- Pacific cardiovascular disease mortality rates are consistently and significantly higher than those of the total population (about twice as high in middle age, one and a half times higher than in older age). Male cardiovascular disease mortality rates are higher than the corresponding female rates for all age groups (Ministry of Health. 2004a).
- Since the 1980s, there has been a 66 percent increase in the rates of strokes for Pacific people, compared with a 19 percent decline for Europeans in the same period (Ministry of Health 1999).
- The lung cancer mortality rates for Pacific men between 25 and 64 years is twice the total New Zealand average, while Pacific men aged 65 and older have average lung cancer mortality rates (Ministry of Health 2004c).
- Pacific women have higher than average mortality rates for breast cancer (all age groups) and cervical cancer (45-64 age group) (Ministry of Health 2004c).
- Pacific children have higher hospitalisation rates (approximately 50 per cent higher) for asthma than the New Zealand average (Ministry of Health 2004c).

2.6 Morbidity of Asian New Zealanders

The term 'Asian New Zealanders' refers to people with origins in the Asian continent, from Afghanistan to Japan, and from China to Indonesia. Data for Chinese and Indian New Zealanders have been stratified because they are the two largest Asian communities in New Zealand and have significantly different health status in some areas. The following information is from the Asian Health Chart book (Ministry of Health 2006a).

- Indian New Zealanders have significantly higher cardiovascular disease (CVD) hospitalisation rates than the total population (apart from 25-44 year old females). Among older people (65 years plus) females have a higher cardiovascular disease hospitalisation rate than males for all Asian ethnic groups. This group also has higher CVD mortality rates than the total population.
- Chinese and Other Asian ethnic groups have significantly lower cardiovascular hospitalisation rates than the total population (among all age groups and for both sexes). CVD mortality is significantly lower for Chinese than the total population, in the 45-64 years and 65 plus age groups.
- Indian New Zealanders have significantly higher ischemic heart disease (IHD) hospitalisation than the New Zealand average (except for 25-44 year old females). IHD mortality rates are higher for Indian New Zealanders than for the total population.
- IHD hospitalisation rates are significantly lower for Chinese and Other Asians than for the total New Zealand population (among all ages and for both sexes). IHD mortality rates are also lower for Chinese and Other Asians than for the total New Zealand population.
- Indians have a significantly higher ambulatory sensitive hospitalisation rate than the total population.
- In the 45-64 years age group, stroke hospitalisation is significantly higher for Other Asian and Indian males than for the total population.
- In the 65 plus years age group, stroke hospitalisation is significantly higher for Indian males and females and Other Asian females than for the total population.
- Indian boys are one and a half times more likely to be hospitalised for asthma than the total population.
- Indian males and females are more likely to report having been tested for diabetes than the total population. The prevalence of self-reported (doctor-diagnosed) diabetes is over three times higher for Indian people than for the total population. Chinese and Other Asians are as likely to report having been tested for diabetes as the total population.
- Cancer registration rates are significantly lower for all Asian ethnic groups than the total population in all age groups (with the single exception of Other Asian females aged 65 plus). Stomach cancer registrations are significantly higher for Chinese females and Other Asian males than for the total population.

Glossary

acute care is treatment (usually in a hospital) for patients having a short-term or episodic illness, injury, health problem, or recovering from surgery.

Asian New Zealanders refers to people with origins in the Asian continent, from Afghanistan to Japan, and from China south to Indonesia.

care coordination refers to coordination of care at administrative and clinical levels. At the administrative level, coordination of care involves tasks such as making appointments and ensuring follow up. At the clinical level, it involves tasks equivalent to **case management**. Both are supported by effective information flows and systems.

case management includes assessment, planning, coordination, monitoring, and decision-making processes around options and services required to meet the client's health and social needs. It is characterised by collaboration, advocacy, communication, and resource management.

CBT (cognitive behavioural therapy) is a psychotherapeutic technique which assists a person to become conscious of thought and behaviour patterns and change them to act more effectively.

chronic care framework is a comprehensive action plan to meet the needs of people with chronic conditions within a DHB district. A framework includes initiatives within health promotion, prevention and management of chronic conditions and is based on a **chronic care model**.

chronic care model is a systematic approach to the planning and delivery of services for people with chronic conditions that requires broad systems change.

chronic care management refers to a range of interventions to manage or prevent a chronic condition. Management is much broader than medical management and may include information, support, treatment, family/whānau involvement, and self-management.

chronic condition is any ongoing, long-term or recurring condition that can have a significant impact on people's lives. Disabilities are not included in this definition, although many people with a disability have one or more chronic conditions and they are sometimes causally linked.

co-morbidity is the existence of more than one health condition.

continuum of care is an integrated approach to the provision of health and disability support services at all stages of a person's life and state of health. A continuum is enabled by effective data systems, good communication across the health sector, multidisciplinary teamwork and cross-sector collaboration.

coordinated care is a package of care delivered for a person with chronic conditions who is living in the community. It may include a variety of community and hospital-based services to meet their assessed health needs.

cultural competence is based on a set of experiential and interpersonal skills that allow individuals to increase their understanding and appreciation of cultural differences and similarities within and among groups.

cultural safety education and practice is a broad-based critical framework that requires a health care worker to examine his or her own attitudes, values and culture and how they affect interactions with the patient's own personal, social, historical and economic realities and culture.

culturally appropriate services aim to be responsive to, and respectful of, the history, traditions and cultural values of different people and cultures in New Zealand.

determinants of health are factors that influence health, ranging from individual biological factors and behaviours, to the social, cultural, economic and environmental contexts in which people live, work and play.

evidence-based practice is clinical decision-making based on a systematic review of the scientific evidence of the risks, benefits and costs of alternative forms of diagnosis and treatment.

health inequalities are differences in the distribution of health outcomes and status between population groups.

health inequities are avoidable, unfair or unjust differences in access to services and information, treatment, and differences in health and well-being outcomes.

health promotion is the process of enabling people to increase control over and improve their health. It is a comprehensive social and political process.

health status is a description and/or measurement of the health of an individual or population.

morbidity is illness.

mortality is death.

Pacific peoples are a diverse group of people from the Pacific region, including Tongan, Samoan, Fijian, Cook Island, Tokelauan and Niuean peoples who live in New Zealand, who have either migrated or identify with them because of ancestry or heritage.

PBFF is Population Based Funding Formula.

PHO is primary health care organisation.

population health approaches consist of organised responses to promote and protect the health and wellbeing of identified groups and to reduce health inequalities. They recognise the wider social, economic and environmental determinants of health and wellbeing that affect the development, progression and management of chronic conditions. Populations may be defined by a wide range of variables, including the level of deprivation, age, gender, ethnicity, culture, socio-economic status, locality or specific diseases, illnesses or conditions. Efficient population health approaches require accurate data collection and analysis.

person-centred care approaches focus on the diverse needs and specific circumstances of a person with a chronic condition and also their family, whānau and carers where appropriate. It requires the development of partnerships between the health professional and the person with a chronic condition, the family/whānau and carers in the prevention and management of their chronic conditions. It also involves care being provided across organisations and services in ways that appears seamless to the person.

primary health care includes a range of services designed to keep people well, from promotion of health and screening for disease to assessment, diagnosis, treatment and rehabilitation. Services provide first level contact with the health system, accessible through self-referral and have an emphasis on working with communities and individuals to improve their health.

self-management approaches enable people with chronic conditions, and their family/whānau (where appropriate) to manage their health condition and social functioning in partnership with health professionals and community resources. Self-management promotes collaborative care planning, including decision-making and design of the care plan.

tikanga is a customary practice, rule

wellbeing is the self-assessed or self-reported perception of a person with respect to their health and other aspects of their life, that may include their social, spiritual, emotional, physical needs, the degree to which these needs are met, their ability to function in daily activities, participate in their community and to make their own choices and decisions.

whānau is extended family, including kuia, koroua, pakeke, rangatahi and tamariki. The term recognizes the wide diversity of families represented within Māori communities.

whānau ora refers to Māori families being supported to achieve their maximum health and wellbeing.

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