Submission from NZORD on the National Health Committee discussion paper on people with chronic conditions.

A fundamental culture change is required to shift our health sector from an acute focus to one that better meets the needs of people with chronic conditions. The health sector has traditionally focused primarily on medical needs, whereas a complex range of social, cultural and economic factors affect people's health status, many of which lie outside the health sector.

This statement needs clarification. If it is intended to mean a fundamental shift of the whole health delivery system, then it is wrong. For those with acute problems the acute focus needs to remain and not be diminished.
If the intention is to talk about how the system deals with chronic conditions, then it is right to emphasise a focus on the holistic needs of the person. Those with chronic conditions are frequently frustrated by piecemeal and uncoordinated approaches to their health care and disability support needs, including income support and other social supports.

People with chronic conditions – a definition

The National Health Committee is using a broad definition of people with chronic conditions – including people with any ongoing, long term or recurring condition that can have a significant impact on a person's life.

A wide range of physical and mental health conditions comes under this definition, including asthma, arthritis, diabetes, chronic neck or back problems, depression, HIV and cardiovascular disease. It is common for people to have more than one chronic condition, and for others to live with multiple conditions.

The NHC's work focuses on people in the context of their whole life, rather than taking a disease-based approach. It is appropriate to take a holistic view, as people often live with more than one chronic condition and people's experiences with chronic conditions are intertwined with their social and economic contexts. People with long-term conditions are often expert at managing their condition/s.

Chronic conditions can affect people's mental, emotional and spiritual wellbeing as well as their physical health. Depression is a common ongoing condition in itself, and can be associated with many other chronic conditions such as diabetes or cardiovascular disease. For instance, depression is a risk factor for cardiovascular disease, and people with cardiovascular disease have a higher likelihood of experiencing depression than those without cardiovascular disease. In addition, people with mental illness experience relatively high levels of physical illness.[2]

The NHC believes that spiritual wellbeing should be an integral part of the concept of health and has a role in the support of people with

chronic conditions. Our human nature is comprised of both body and soul, and our physical, emotional, and spiritual health are closely intertwined. Times of injury, disease, acute or long-term illness, and their accompanying suffering, often raise profound questions of human meaning, affecting whänau, families and individuals.

In the context of long-term conditions, it is important to address individuals' spiritual health. An individual's spiritual state, as expressed through relationships with their Creator, God, ancestors, environment or other people, can support or undermine efforts at maintaining or restoring physical and mental health.

This work by the NHC concerns people with chronic health conditions, rather than people experiencing disability. However, some chronic conditions may result in impairments and some people with chronic conditions may identify as having a disability. There is a need to avoid perpetuating the myth that disabled people are unwell, while recognising that disabled people with chronic health conditions may face similar challenges to others, and must have access to health services without discrimination.

Question for respondents

Do you agree with the NHC's definition of people with chronic conditions?

Yes, in general, but we express concern about the narrow range of examples given here and throughout the document, which may imply that the needs of some groups have not been well thought through. There is little reference at all to Neurological conditions which as a group make up a very significant number of people with chronic conditions. Nor are references made to metabolic diseases, for example, which although individually rare, together make up a significant number of people with chronic conditions, and often more severe and complex ones.

More significantly, many chronic conditions often lead to disability e.g. Alzheimers, Parkinson's disease, Multiple Sclerosis, Stroke, Motor Neurone Disease, Arthritis, and a significant number of metabolic diseases as well. This shows the statement about the "myth that disabled people are unwell" to be a narrow and simplistic view of disability and its relationship to health. While some disabled people have stable impairments and simply need adaptive equipment or removal of barriers to participate in society, this is not true for the majority of disabled people.

For the majority of disabled people, disability results directly from their health condition, is exacerbated by decline in health status, and is diminished by improved diagnosis and treatment. For the majority, health and disability are directly linked and intertwined. Head injury and mental health, chronic heart and respiratory diseases, and such things as kidney disease and serious joint disease, are further examples where the level of disability is directly related to treatment access and outcomes for the health condition they have. Outcomes for those affected by stroke are also significantly influenced by speed of diagnosis intervention with treatment.

Reliance on the social model of disability is entirely valid for the employment, social and educational interests of the "more able disabled" but is an unhelpful model to rely on in assessing matters in relation to chronic conditions, or in suggesting that disability and disability supports should not be considered in this discussion. Such an approach will miss the interconnectedness of health and disability for most with chronic conditions, and the emphasis that is needed on primary prevention, diagnosis, treatment and holistic care, to improve health status and reduce disability for the majority who have disease driven disability resulting from a chronic health condition.

The National Health Committee's report on the lives of adults with intellectual disability, and work by the Mental Health Commision on the physical health status of those with mental health disability, are also clear pointers to the strong links between disability, chronic conditions and health status.

Prevention and management of chronic illness

Key elements of better supporting people with chronic illness are to ensure early identification of chronic illness, prevent complications where possible, slow the progression of disease and prevent other conditions from developing. Chronic conditions are largely preventable and share a range of common risk factors – such as inactivity, unhealthy diets, obesity, depression, stress, tobacco use and alcohol misuse.[3] Prevention is, therefore, a critical issue in the management of chronic conditions. The World Health Organization promotes a 'common risk factor' approach to the prevention of chronic conditions, where a cluster of such factors contributes to chronic conditions.[3] The 13 population health objectives in the New Zealand Health Strategy reflect a focus on prevention.

As chronic conditions share common features both in terms of prevention and management, the NHC believes primary prevention must be considered as an integral aspect of supporting people with chronic conditions. There are still important opportunities for primary prevention once people have been diagnosed with a chronic condition/s. For example, if a person has diabetes, they will be at an increased risk of cardiovascular disease. Support for that person should include preventative measures to reduce their risk of developing cardiovascular disease. Chronic care management programmes present opportunities to encourage primary prevention of a range of related chronic conditions, as well as preventing complications of diagnosed illness. Different conditions will progress along the life course in different ways, with a number of potential intervention points for both prevention and management across the progression of illness.

This paper focuses on supporting people with chronic conditions rather than on prevention, but it incorporates aspects of prevention where relevant to effectively support people with chronic conditions.

An emphasis on prevention should not be excluded. Long term solutions to the growing numbers with chronic conditions will only be partly solved by being simply more efficient in dealing with the person. There needs to be a coherent and comprehensive strategy that aims at primary prevention (e.g. as there already is for Newborn Metabolic screening, head injury

prevention, reducing obesity, falls prevention, etc). Some areas of prevention also need to be enhanced, such as pre-natal screening for preventable conditions, widening newborn screening for metabolic conditions, and incorporating more genetic knowledge into managing risks of chronic conditions.

This is also the point at which pharmaceutical treatment for some neurological and metabolic conditions need to be factored in and seen not simply as a Pharmac issue for managing the drugs budget, but chronic conditions for which drug therapy can delay the onset of neurological deterioration, or significantly improve the health and quality of life of someone affected by a metabolic condition.

Waiting lists are another example of chronic conditions and resulting disability being compounded by rationing mechanisms. The National health Committee should investigate the impact that waiting lists, restricted drug expenditure and Pharmac's policies, lead to the continuation of poor health, or the early decline into poor health, for some people with chronic conditions, and the extent to which this leads to disparity of health status and disparity of access to health care, for these populations. There must also be answerable questions about ethics and public law obligations in such an approach.

What does support mean?

Supporting people with chronic conditions (i.e., management) more effectively does not just mean better services or treatment. The NHC sees 'management' or support as encompassing everything that people do to live a full life with a chronic condition/s. This may include:

- *formal and informal social/community support*
- *family/whänau support and involvement in living with chronic conditions*
- *self-management of chronic conditions*
- *prevention of complications*
- *primary prevention of other conditions*
- *access to better information on chronic conditions*
- *access to culturally appropriate services and treatment (including complementary and alternative health services).*

The term 'support' is primarily used in this paper to reflect a broader understanding than the traditional medical term 'management'. It should not be confused with support services such as disability support.

This section is correct but for the last sentence. As stated above, for most with chronic conditions disability support services can be an integral part of their total needs and ability to function on a personal, domestic, employment and social level. If a new model is to be developed for health care of those with chronic conditions, it will fail in its objective to be holistic if disability supports are left out. They cannot be excluded any more than the income, housing, social and emotional/spiritual side of the person could be excluded.

Inequalities in health

Internationally, it is established that social position and ethnicity affect people's health outcomes, with socially disadvantaged groups tending to have poorer health status, greater exposure to health risks, and less access to health services. In addition, indigenous peoples tend to experience worse health than other groups. Inequalities in health outcomes are well documented in New Zealand, between ethnic and socio-economic groups, as well as geographic, gender and age disparities. For instance, gaps in life expectancy between Mäori and Pacific peoples, and the rest of the population increased markedly during the 1980s and 1990s.[8]

The NHC argues for a strong focus on people with chronic conditions due to the large contribution of such conditions to health disparities.

In noting the problems of disparities for ethnic and socio-economic groups, we urge the National Health Committee to recognise other areas of growing disparity, and particularly within chronic conditions:

People with rare disorders collectively make up 8% of the whole population, the same size as the pacific population in NZ. If there is simply continued emphasis on the list of top 10 health priorities, and the sort of examples given in this document seem to follow that theme, then there will be a growing disparity of health status for many thousands of people affected by rare conditions (most of them chronic) whose interests will suffer relative neglect.

It is important to note that such people are already disadvantaged by a lack of expertise to diagnose, prevent and treat their disorders. It is not as though they have already quality care available to them, and should thus accept the priority for the top 10 on the list as a reasonable exercise in whole population health gains. Their interests will fall behind and over time this will exacerbate the disparity in the community. There are enough disparities already, without adding more.

Chronic conditions and disparities in health

- Chronic diseases contribute the major share of the growing disparity in life

expectancy between Mäori and Pacific, and non-Mäori non-Pacific people.[8]

- In comparison with other groups, Mäori and Pacific peoples tend to get chronic disease at a younger age, and to experience more severe illness. In the Decades of Disparity study cited above, the Mäori and Pacific 45–64 and 65+ age groups were found to contribute substantially and about equally to the ethnic disparity in life expectancy at birth.[8]
- Diabetes is about three times more common in Mäori adults than non-Mäori.[9] Mäori and Pacific people are more than five times more likely to die from diagnosed diabetes than non-Mäori, non-Pacific people.[10]
- Mäori and Pacific people tend to be diagnosed with diabetes at a younger age than non-Mäori, non-Pacific people. The average age of diagnosis is 47-48 years for Pacific peoples compared with 54 years for New Zealand Europeans.[10]
- Some children have been diagnosed with type 2 diabetes; almost all of these have been Mäori or Pacific children.[6]

As there are significant inequalities in severity and onset of chronic illness, improving how people with chronic conditions are supported is an efficient way to reduce health inequalities. As Barbara Starfield, Professor at John Hopkins University School of Public Health, has stated:

"Personal health services have a relatively greater impact on severity…than on incidence. As inequities in severity of health problems…are even greater than inequities in incidence of health problems, appropriate health services have a major role to play in reducing inequities in health." [11]

Preventing chronic illness (and risk factors such as inactivity and obesity) through a range of primary prevention initiatives and diagnosing people earlier will also play a major part in reducing inequalities in health.

The comments by Professor Starfield seem to confirm our submission that primary intervention, early diagnosis and best treatments, are key factors in reducing the impact of chronic conditions, and reducing the resulting disability burden as well.

Why it is important to improve support for people with chronic conditions

Chronic conditions affect the lives and wellbeing of many New Zealanders. Living with a chronic condition, or with several conditions, can have a significant impact on peoples' lives, including family wellbeing and capacity to undertake fulfilling work and other activities.

Even though the majority of people using the health sector have chronic conditions, our health system is still largely based on an acute model of care. The traditional model of health care is cure-focused, and treats people using a problem-solving approach. This approach is not well suited to people with chronic conditions.

Instead, a focus on supporting people with chronic conditions emphasises:

- a 'people-centred', holistic approach with a focus on self-management
- attention to psychosocial, emotional and spiritual wellbeing
- a greater emphasis on communication, teamwork and integration across services
- ongoing, regular contact between people with chronic conditions and health care services – moving from episodic to continuous care.

As raised earlier, improving how people with chronic conditions are supported is also an efficient way to reduce inequalities in health.

Again we emphasise that there needs to be a "horses for courses" approach. The acute focus should be retained where it is appropriate (and it is very appropriate in many situations) and the holistic approach further developed where needed. But it would be wrong to assume that a holistic approach is relevant to all chronic conditions, despite it being relevant for most. For many chronic conditions it is possible for patients to develop enough skill to self manage, with the support of a GP or other health professional on an occasional (acute) basic. Epilepsy, asthma and in some cases diabetes can be considered in this category. It can even be true for some with mental illness. Emphasis should in fact go onto the idea of strengthening the capacity of patients to become experts in self management of their condition, so it is more feasible for them to stay in the part of the system that needs "acute" support only, from time to time. The holistic approach to chronic conditions should be the fallback position when the expert patient/expert family, connected to their health professional when required, falls short of a suitable method of managing their health condition.

Who needs to be involved in supporting people with

chronic conditions?

People with chronic conditions, and their families, have often lived with the effects of their illness for many years, and have expert knowledge of their own experiences and needs. Efforts to improve how chronic conditions are dealt with must involve people with chronic conditions and family members, and interventions must be planned and coordinated in partnership with the person with chronic illness.

Chronic conditions cannot be prevented or managed by the health sector alone. Many of the factors affecting whether people develop chronic conditions, their risk of developing complications and how effectively they manage lie outside the health sector – for instance, housing, income, transport, local government, education and social services.[12] The issue of chronic conditions should be high on the agenda of the whole community. Tackling chronic illness demands an intersectoral approach and strong community engagement.

Agree. There are many intersectoral issues that make a significant difference, but the response seems slow to drive coordination of them. Accessible transport and housing are a couple of examples that would have significant impacts on holistic health and quality of life, and improve independence, rather than see a continuation of significant barriers presented in those two areas. The impact of these factors on health status and quality of life could be as significant for many people with chronic conditions, as socioeconomic determinants are for others.

The best place for regular, proactive support of people with chronic conditions is the community setting, which includes primary health care.[vi] In the UK, people with chronic conditions account for up to 80 percent of primary health care consultations and it is likely that New Zealand would have a similar proportion.[15] It has been suggested that up to 30 percent of hospital admissions in New Zealand could be prevented with timelier primary care intervention.[13]

Primary health care is an appropriate setting for chronic conditions management because it is based in the community, there is regular contact between people and health professionals (often over many years) and most people with chronic conditions can be supported well in primary health care with some specialist input. In addition, many conditions have a spectrum of severity, with most people being at the less severe end. Primary health providers have generalist skills, experience and networks that are useful in supporting people with chronic conditions.

It is important to realise that for many chronic conditions (this may apply especially to metabolic diseases) there is often no expertise in primary care to give competent medical care. Specialist services are often needed and primary care may only be relevant for their "other typical" health problems. This poses problems for the holistic model as well as being an ongoing problem for such people under present arrangements. Issues include:

1. **How to get access to clinical services when expertise in limited and located in one or two centres only,**
2. **How to manage the transition from (generally quite good) multidisciplinary case management in paediatric services, to the silo issues and generally poorly coordinated system in adult medicine. Having a GP as case coordinator who referes to specialists does not always work well or efficiently for many, especially with rarer conditions.**

The Primary Health Care Strategy, released in 2001, highlights the central role of primary health care in improving population health. The approach includes:

- a greater emphasis on population health[vii], health promotion and preventative care
- community involvement
- involving a range of professionals and encouraging multidisciplinary approaches to decision making
- improving accessibility, affordability and appropriateness of services
- improving co-ordination and continuity of care
- providing and funding services according to the population's needs as opposed to fee for services when people are unwell.[viii]

The Primary Health Care Strategy supports the broadening of primary health teams to include allied health professionals such as social workers, pharmacists, physiotherapists, occupational therapists and podiatrists.

Another example of an innovative programme is Capital and Coast Health's programme to improve the health management of high users of hospital services. Invariably these will be people with chronic conditions, and though the programme is driven firstly by the impact on hospital bed usage (or blockage) the programme looks to provide a comprehensive holistic response to their many and complex needs. A very good programme is being implemented. A pity it took the health economics and health services delivery problem of bed blocking as the trigger to take a serious look at the significant needs of this small but very high demand patient group.

Other countries

There are significant moves in many countries to improve how care for people with chronic illness is structured and delivered. At the global level, the World Health Organization has advocated for an innovative approach to chronic conditions based on the 'Chronic Care

Model', developed by Edward Wagner and used extensively in the United States and increasingly around the world[ix].[1]

The World Health Organization set out eight essential elements for taking action, which build on the Wagner model for chronic care:

1. support a paradigm shift (from an acute to a chronic care model)
2. manage the political environment (to build political commitment for change)
3. build integrated health care
4. align sectoral policies for health
5. use health care personnel more effectively (eg, team models, new training, changing roles)
6. centre care on the patient and family (self-management, patient-centred care)
7. support patients in their communities
8. emphasize prevention

"As its ultimate goal, the chronic care model envisions an informed, activated patient interacting with a prepared, proactive practice team, resulting in high-quality, satisfying encounters and improved outcomes." [14]

The core features of chronic conditions models are similar, but terminology varies slightly across different contexts. Common elements of chronic care models include: changing the patient and carer role, process and system redesign, workforce planning and development, knowledge management, and partnerships between health and the community.[15] Some examples of these five elements are given in the following table.

Questions for respondents

- **What are your views on the best way/s to approach chronic conditions in New Zealand?**
- **What lessons can we learn from existing models to improve how people with chronic conditions are supported?**
- **What other key initiatives are going on around New Zealand (that are not**

included in Appendix 2)?[xiv]

The model use in the UK seems a sensible approach. Rather than a paradigm shift for the whole system, make the shift only in the areas of need, and to the extent needed. There is no doubt that more comprehensive and holistic care is needed for many, but avoid the mistake of overdoing it in areas where it is not needed.
Building the concept of the expert patient/expert family is one that is likely to reduce the need to over-provide with more detailed holistic care for those who cannot attain this goal, and the self-management inherent in it.
But it is most important to be able to provide more coordinated and comprehensive care and treatment where the needs are greater and the consequences more complex.

Support for self-managing chronic conditions

Self-management support is a core element of a chronic conditions approach, and is a way to encourage a more patient-centred model. In the New Zealand context, family/whānau involvement in managing chronic conditions is crucial. Some people may prefer the terms 'shared management' or 'shared care' to avoid implying that it is an individualistic approach.

Definition of self-management

The NHC defines self-management 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."

It is important to recognise that many people already self-manage to some degree – for instance, in taking a range of medications, obtaining support from family/whānau members and friends or community resources, or by playing a key role in developing a care plan in partnership with health providers.

It should also be emphasised that self-management may not be appropriate for some people, or in some circumstances. For example, some children or people with illnesses such as dementia may not be in a position to self-manage.

Self-management programmes

While people's experiences of their chronic condition/s differ according to their symptoms and the treatment they receive, there are commonalities in the day-to-day challenges that people with chronic conditions face. Self-management programmes aim to equip people with the knowledge, skills and support to cope with these challenges and feel confident in managing their own lives with a chronic condition/s.

Increasing individuals' self-efficacy in managing the effects of their chronic condition/s is a key aspect of self-management programmes. Course participants are introduced to specific self-management techniques to this end. Programmes focus on how people manage both the medical aspects of living with chronic condition/s (eg, taking medications), as well as the lifestyle aspects (eg, fatigue, pain management, relaxation, exercise, and healthy eating).

There is a large body of overseas evidence to show that self-management programmes can provide important benefits for participants. For example, in a number of evaluations of the Chronic Disease Self Management Programmes developed in the US, sustained improvements were obtained in individuals' skills in self-management and in disease outcomes.[20] In a five-year research project, the programme was evaluated in a randomized study involving more than 1000 subjects. This study found that people who took the programme, when compared to people who did not, improved healthy behaviours (exercise, cognitive symptom management, coping, and communications with physicians), improved their health status (self-reported health, fatigue, disability, social/role activities, and health distress), and decreased their days in hospital.[20]

The UK has implemented the Expert Patient Programme, based on the Lorig model, as a key plank in their approach to supporting people with chronic disease. This programme has had some success in working with traditionally 'hard to reach' groups such as people from deprived areas and people with mental health issues. Participation rates in the Expert Patient Programme for people from black and ethnic groups are almost as high as their proportion of the total population (6.9 percent of those in the Expert Patient Programme are from black and ethnic groups, compared with a national percentage in England of 8 percent).[18]

Arthritis New Zealand has conducted two post-course evaluations for the "Living a Healthy Life" courses that they have delivered in New Zealand since 1998.[21]

These both concluded that the courses were relevant and useful to people with chronic conditions, and that the majority of participants felt they had benefited greatly from the course. The post-course evaluation of the courses delivered from 2000 to 2002 also concluded that participants' self-efficacy was greatly increased, and they were committed to the continual practice of positive self-management behaviours.

It should be recognised that a self-management programme is only one way to encourage self-management, and that not everyone wants to be part of a group programme. Other self-management interventions that are provided to individuals include patient-led care plans, patient-held records, and asthma self-management plans.

Questions for respondents

- **Do you agree with the NHC's definition of self-management?**
- **What role do you think self-management has in living with chronic conditions?**
- **Do you think self-management should be better encouraged and supported in New Zealand, and if so, how?**

Role of complementary and alternative care

A significant proportion of New Zealanders use complementary and alternative health practitioners to help manage chronic conditions.

The complementary and alternative health paradigm is well suited to people with chronic conditions, as it tends to involve longer, more holistic consultations and is more 'people-centred' than the disease-based biomedical approach. The complementary and alternative paradigm has tended to encourage self-management and acknowledge people's spirituality and religious beliefs as part of holistic care. However, in reality most health practitioners, whether operating within complementary and alternative medicine (CAM) or mainstream health contexts, do not operate solely using one model. Many practitioners use other models as well as the biomedical, such as Mäori or Pacific health models, behavioural science or psychological models.

Some practitioners have trained in biomedical and CAM approaches and offer both interventions. A survey of Auckland GPs showed that a third of respondents practised one or more forms of alternative medicine, and two thirds referred patients for CAM therapies.[23] Anecdotal evidence suggests a growing number of referrals by GPs to homeopaths for conditions such as glandular fever, chronic fatigue syndrome and recurrent ear/nose/throat infections.[xvi] However, in many contexts CAM therapies do not have the same status as biomedical interventions in terms of funding or support.

People with chronic conditions may use a combination of CAM products and biomedical pharmaceuticals, without practitioners from either approach being aware of what they are using. New Zealand research has identified occasions where interactions between pharmaceuticals and CAM products have occurred.[xvii] Presenters to a symposium on the integration of CAM and mainstream medicine, held by the NHC in November 2004, highlighted the need for an adverse events reporting structure, and one presenter suggested doctors need to expand their patient drug histories to include questions on CAM products.

In addition, improving the relationship between the CAM and biomedical sectors may have the downstream effect of improving patients' confidence for revealing their use of CAM products to mainstream practitioners.

The development of PHOs with a population health and community focus is an opportunity for allied health professionals (such as physiotherapists, occupational therapists, podiatrists and social workers) to be integrated with primary health care, and ultimately for CAM practitioners to become part of the team.

Questions for respondents

- **What role do you think complementary and alternative medicine has in living with chronic conditions?**
- **Do you think complementary and alternative medicine should be better encouraged and supported in New Zealand, and if so, how?**

There is no doubt that CAM can be of benefit to people, whether through the satisfaction of having explored all other options for their condition, finding a treatment that works for them, having more time spent on listening to their needs, or even as a placebo effect. Religion and spirituality would fit into this category too. As noted in the introduction in this paper, these factors can enable people to feel better and more at ease with life, and if they feel better they will be better. We note for example that chaplaincy services are provided as part of public hospital services.

However there needs to be some caution about how free CAM practitioners are to offer untested and unproven remedies, and we express particular concern at reports of CAM practitioners advising patients to reject the advice of registered medical practitioners. There is potential for considerable risk in such cases, and there needs to be improved oversight and regulation of how CAM practitioners operate.

There is probably little consequence in a CAM practitioner suggesting a different topical ointment for treatment of an itchy skin condition, for which there is uncertain cause and limited treatment options, but we have significant concerns about the apparent enthusiasm of some CAM practitioners to advise patients to change other prescribed medications. This could be very dangerous in some cases and we feel continued anxiety about the tendency for some to campaign against vaccinations, or offer alternatives for cancer treatment, for example.

xvii CAM symposium, November 2004

SECTION 3: SUMMARY OF ISSUES – PEOPLE WITH CHRONIC CONDITIONS

The NHC believes it is crucial to canvas the views and experiences of people with chronic conditions to help provide relevant advice to the Minister of Health. People with chronic conditions have extensive experience in living with their conditions and in interacting with health and other services.

The NHC has held four preliminary focus groups with people with chronic conditions in the Wairarapa and Christchurch. More than seventy people were involved. Three groups were associated with Arthritis New Zealand and the Stroke Foundation, and the other was a support and exercise group for Pacific people.

People were asked to highlight the main factors that helped and hindered them in living with chronic conditions. The following information is an initial starting point in identifying the key issues for people with chronic conditions. Further information will be gained from this consultation and from case studies with people with chronic conditions that the NHC will carry out shortly. The views expressed here are reported as they were stated in the focus group context, and are not necessarily views held by the NHC.

NZORD thinks that the importance of support groups and the information, support, advice, practical tips, and experience they can impart to people with chronic conditions (or other health issues for that matter) have not been adequately factored into the discussion document. Some support groups provide support and information services (such as field officers) that are publicly funded health and disability support services. Others do similar functions without the benefit of public fundsing. Overall they fill a very important role but the "formal" health system often leaves them out of key considerations. e.g.

1. **many policy discussion documents fail to note their roles or discuss their functions and place in the system,**
2. **many health professionals still fail to even inform patients about them as a source of information, advice and support**
3. **most support groups are very poorly funded and rely on charitable grants for survival**
4. **they are even under pressure not to take money from the pharmaceutical industry because Pharmac believes it might compromise their independence in relation to treatment issues**

Support groups need to be recognised more explicity as an important part of holistic care and improved information. In the case of many rare disorders it is now likely that a motivated patient or support group will become more expert on practical day to day management of a condition, and in sources of information and expertise about it, than any registered medical practitioner or CAM practitioner they are likely to meet. This sets the scene for a responsive health professional to work in partnership with them to optimize health management.

Final summary.

This submission is hurried and late, so may not be as carefully reasoned or worded as it should be. But we'd like to emphasise:

Yes - do aim to build comprehensive and coordinated models of care for those with chronic conditions.
But - do not aim to do this for all of them. Take a case by case approach to building categories of people for whom it would be desirable - where complexity is associated with chronicity would be a good guide to a starting point.
Aim to build the expertise of individuals and their families so they become experts in the condition, and can work towards self-management as a goal, in associated with their health professional.
Design the coordination system for those who need it, to take note of their total needs and work to meet them.
Ensure that families and support groups are included in the design of systems, whether to support the expert patient who is self managing, or to be a part of the holistic supports for those with more complex needs.
Don't make the mistake of trying to distinguish disability and disability support from the health care of those with chronic conditions - for the majority they are integrated.