

# The Northern Territory Preventable Chronic Disease Strategy – promoting an integrated and life course approach to chronic disease in Australia

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## Abstract

*The need for an integrated and life course approach to the prevention and control of chronic diseases is increasingly being recognised. This paper describes the development of the Northern Territory Preventable Chronic Disease Strategy (PCDS), the strategic framework and evidence base, the design of implementation and monitoring phases, and early outcomes. The PCDS is premised on the belief that the major chronic diseases, and their common underlying risk factors, are potentially preventable. The structural challenges to larger jurisdictions taking such an integrated approach are undoubtedly larger, but the benefits are potentially great. Continuing with a series of vertical programs aimed at each single noncommunicable disease will not deliver the desired national health outcomes.*

## The burden of chronic diseases

Chronic diseases are simply defined as 'illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely' (Davis et al., 1999). They share a number of common underlying risk factors, most notably social determinants (including poverty and inequality), poor nutrition, inadequate environmental health conditions, physical inactivity, alcohol misuse and tobacco smoking (Brownson et al., 1998; Marmot & Wilkinson, 1999).

However, most health systems have been developed to respond to acute rather than chronic illnesses. In acute illness, professionals knowledgeable about the disease can offer an accurate prognosis and cure is likely.

In contrast, uncertainty pervades chronic illness management (Holman & Lorig, 2000), as the onset is often gradual (indeed the patient may be asymptomatic at time of diagnosis), the possible causes are multiple with many far in the past, and the duration is lifelong. Prognosis is uncertain, and cure impossible. Though professionals hold expert information about possible causes and treatments, only the patients or clients can provide a story of how the disease has affected their life over time (their personal disease trajectory). Patients with chronic disease are not just partners in health care, but their own principal care givers and experts in their own illness (Holman & Lorig, 2000). The challenge of creating sustainable systems that support patients regularly over long periods of time is enormous (Wagner et al, 1996).

The burden of chronic diseases constitutes a growing public health problem for the whole population in the Northern Territory (NT). Prevalence and mortality rates of ischaemic heart disease, renal disease, diabetes and chronic airways disease are all high by Australian standards (Weeramanthri & Clark, 2001). Many Indigenous people with chronic disease have one or more co-morbidities and a younger average age of onset than the non-Indigenous population.

During the 1980s, there was a demonstrable rise in the prevalence of diabetes in the NT (Markey et al., 1996), and in the 1990s, there was a rapid rise in diabetic complications (Ewald & Hall, 2000) and in the number of Indigenous people starting dialysis for end-stage renal failure (Spencer et al., 1998). Community and government concern intensified, and Northern Territory Department of Health and Community Services (NT DHCS) had to reconsider its efforts to stem the tide of renal failure and other chronic diseases. The NT Coordinated Care Trials (CCT) were one part of the response aimed at improving care for those with complex and chronic conditions (Local Evaluation Team, 2000; Weeramanthri et al, 2002). The Preventable Chronic Disease Strategy (PCDS) was another. Both the CCT and PCDS were designed in line with capacity building processes laid out in the NT Aboriginal Public Health Strategy (Public Health Strategy Unit, 1998).

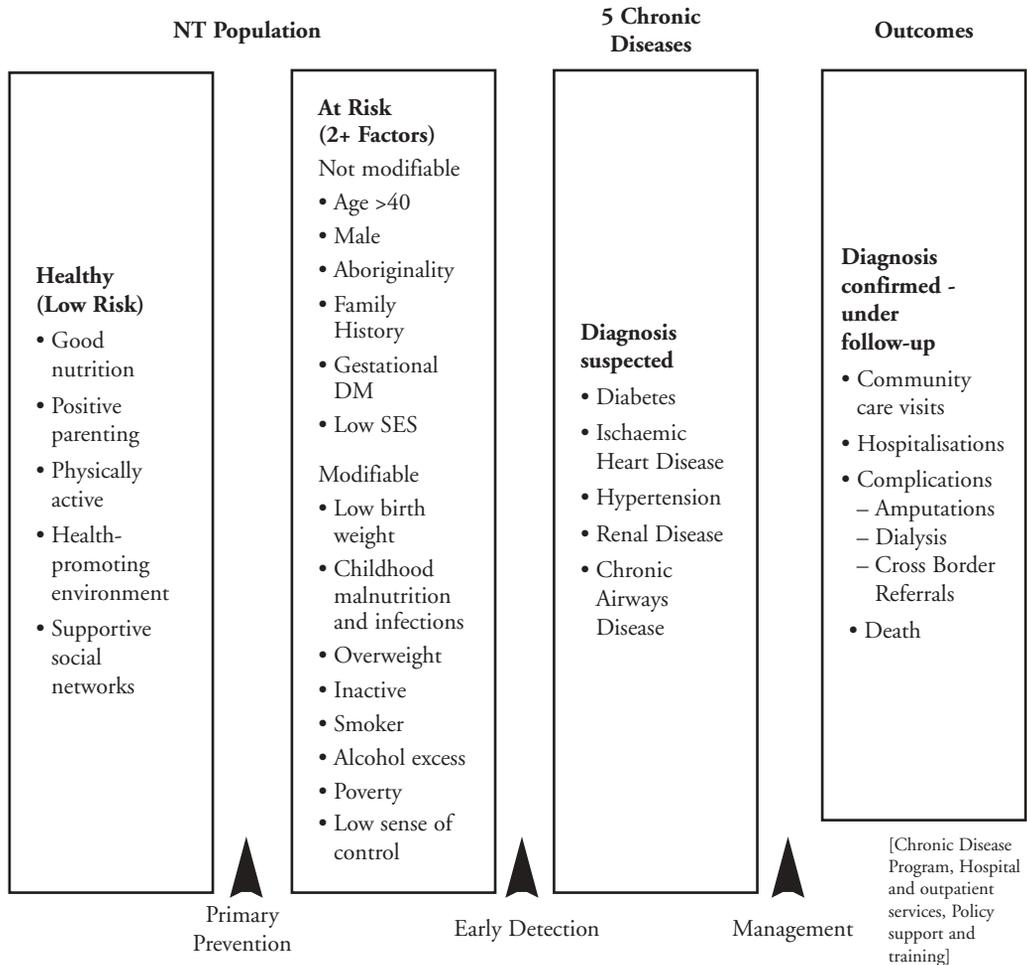
## **Development of the Preventable Chronic Disease Strategy (PCDS)**

In late 1997, the NT DHCS Chief Health Officer convened a working group drawn from operational and policy areas to develop a strategic response to renal failure and other chronic diseases. One option was to focus on a single intervention, such as the use of drugs to slow the progression of renal disease. However, since renal disease shared common underlying factors with other chronic diseases, it was felt that an integrated approach would be sensible and in line with WHO recommendations on non-communicable disease (WHO, 2000).

Having opted for an integrated approach, the limits of 'chronic disease' were then defined for the purposes of the PCDS (see Box 1). We included diabetes, hypertension, ischaemic heart disease and renal disease because of their common underlying factors and their connections through the 'metabolic syndrome' (Reaven 1988; Stern, 1996; Hoy et al, 1996). Chronic airways disease was also included because of its high impact, its inclusion in the Barker hypothesis (Barker, 1993) and high rates of smoking in the NT population. We did not feel at the time that other chronic diseases such as cancer and depression were as closely causally linked. In the end, the decision to focus on five key diseases was a pragmatic one, recognising that the boundaries of chronic disease are fluid and subject to change (Walker, 2001).

A simple three point framework was developed (see Figure 1) where the elements are displayed across the life course (Kuh & Ben-Shlomo, 1997) with prevention being preferred to cure, and early detection and good care viewed as a way to prevent complications (Ashbridge, 2000).

**Figure 1: Three point framework to guide implementation across the life course - prevention, early detection and best practice management**



**Notes on the framework**

- DM stands for diabetes mellitus and SES for socio-economic status
- ‘Aboriginality’ is a ‘proxy’ risk factor, identifying a group at high risk, most probably because of a number of associated factors linked to socio-economic disadvantage. Nevertheless, it remains a useful means of targeting interventions in the NT context.
- The boxes in the framework diagram can also be tied to a number of ‘settings’: the low risk population are mainly encountered in the community and outside the health centre (except for acute and antenatal care); the high risk population are seen in the community, but may also be targeted by screening (either based in a health centre or in the community); once the diagnosis of a chronic disease is suspected or confirmed, ongoing care becomes more health-centre based; and once complications develop, hospital care becomes more likely.

## Box 1. Definitions

### *Barker hypothesis*

Environmental factors 'program' particular body systems during critical periods of growth, in utero (leading to low birth weight) and infancy, with long term direct consequences for adult chronic disease (Barker, 1993).

### *Metabolic syndrome*

The clinical features include abdominal obesity, hypertension and perhaps albuminuria. Associated metabolic abnormalities include glucose intolerance and dyslipidemia. Genetic and environmental factors are both important in the development of the syndrome. Insulin resistance is the common underlying abnormality and may also be an intermediate link between low birth weight and adult chronic disease (Stern, 1996).

### *Life course approach*

Adult chronic disease reflects differential lifetime exposure to a broad range of physical and social factors firstly in utero and then in childhood, adolescence and adulthood. Risk accumulation does not require, nor does it preclude, a critical period of 'programming' in early life (Kuh & Ben-Shlomo, 1997).

## Specific NT issues – lifestyle, health services and culture

The population of the NT is approximately 194,000, with 28% of the population identifying as Aboriginal (ABS, 2000). The PCDS had to be relevant to the whole population, non-Indigenous as well as Indigenous, since the whole of society is affected by lifestyle change. In discussing 'lifestyle' any notion of victim-blaming was to be avoided, since in lower socio-economic groups 'lifestyle' choices are often reflective of unrelenting environmental constraints rather than personal preferences. For example, structural determinants of fresh food availability in remote settings are more important factors than personal choice in determining food intake (Lee et al, 1994).

With respect to Indigenous people in the NT, providers recognise that service delivery is complicated by issues of poverty, culture, geographical remoteness and inadequate resource allocation relative to need (Deeble et al, 1998). Two thirds of NT Aboriginal people live outside the major centres, many in small communities without a resident doctor. Though there have been recent moves to place resident general practitioners in some of the major remote communities, most community health centres are staffed by local Aboriginal health workers and resident nurses. Service arrangements at primary health care level have historically been geared to dealing with high demands for emergency and acute care services. A special audit of chronic disease activities in Top End remote area DHCS health centres in late 1997 revealed a limited use of chronic disease protocols, little use of recall systems, inconsistent follow-up after diagnosis, high levels of staff turnover, the need for staff training, and poor collation and limited analysis of local data to guide health planning (Chris Evans, personal communication). There were few materials suitable for community education. Few community health staff interviewed rated the overall quality of chronic disease management highly; most thought it at best 'poor to average'.

In addition, the special socio-cultural context of chronic disease needs to be understood. Diabetes, for example, is not simply a lifestyle disease, but rather it is seen as resulting directly from colonisation, and bound up with what is often perceived as a 'loss of culture' and a move towards Western patterns of living (Humphery et al, 1998). It has been suggested that NT DHCS has relied too heavily on visiting services and on relocating clients from their home communities to service centres, rather than building up 'presence' in communities through locally-based employment so that social relationships and cultural understanding can be developed and systematically incorporated into programs (Humphery et al, 1998).

## PCDS Objectives and Evidence Base

The 10 year objective of the strategy is to reduce the projected incidence and prevalence of the five common diseases and their underlying causes. The 3 year objective is to reduce the projected impact - hospitalisations, deaths and financial costs - of the five common diseases in the Territory.

We found that the literature on how best to organise care for chronic disease was surprisingly limited (given the importance of the subject), but relatively consistent. Key features identified included: the use of explicit plans and protocols; practice reorganisation to meet special patient needs; attention to behavioural and information needs of patients; access to specialist expertise; and supportive information systems (Wagner et al, 1996). In the NT, the importance of individual self-care, family support, community education, and community ownership were also recognised, as was the need to base the strategy on prior initiatives addressing tobacco, alcohol and nutrition (Territory Health Services, 1999; Townsend & Richards, 2000).

### **Box 2. Best buys to control chronic disease across the life course**

#### *Child and maternal health*

- Improving maternal health and infant birthweight
- Breastfeeding and promotion of child growth
- Decreasing childhood infections through better environmental health conditions
- Childhood immunisation

#### *Underlying determinants*

- Maternal and childhood education
- Alleviate poverty
- Promote 'sense of control', self care and mental well-being
- Improve food supply

#### *Lifestyle modification*

- Legislative framework governing alcohol and tobacco
- Smoking cessation and prevention programs
- Brief intervention for hazardous alcohol use
- Nutrition, weight loss and physical activity programs in high risk populations

#### *Early detection and early treatment*

- Early detection of chronic diseases and underlying risk factors
- Use of blood pressure lowering drugs to prevent progression of kidney disease

#### *Best practice management*

- Prevention of complications of diabetes
- Aggressive management of heart attacks and known cardiovascular disease
- Rehabilitation and outreach programs (cardiac, respiratory, renal)

Drawing on local, national and international literature, an evidence base was developed by a community physician and community paediatrician experienced in both medicine and public health. The evidence base encompasses a range of possible preventive and management interventions for chronic disease across the life course. Finding the right balance between these interventions requires a synthesis of evidence and experience, and consideration of local values, demographics and cost effectiveness data. Health economics analysis looking at intervention options across the care continuum has also been helpful (Beaver, 1999).

Within the evidence base, there is a list of 'best buys' relevant to the NT (see Box 2). Not all of these best buys can be actioned in full immediately, but an agenda has now been set, and will be worked on over time. The list of best buys has been seen as highly relevant by public health personnel in the Kimberley working with a predominantly Indigenous population (Garrow, 1999).

The content of the PCDS was developed through a collaborative effort. The prior establishment of the NT Chronic Diseases Network in early 1997 to link a broad range of internal and external stakeholders in chronic diseases was an important structural support (Williams & Cross, 2000). Regular updates on the PCDS consultation and development process were distributed through the Network's monthly newsletter. The written PCDS was extensively reworked over five drafts, and documents outlining the Framework and supportive evidence base were made available in 1999 and formally supported by a major Ministerial Statement.

## **PCDS Implementation and Primary Health Care**

In late 1999, the responsibility for implementing the PCDS was moved into the Primary Health Care (PHC) area of NT DHCS, in order to engage the broad PHC workforce in operational areas. A formal high-level advisory committee was created with a broad range of external stakeholders. It was understood that implementing the PCDS would necessarily involve a great deal of long term and intersectoral work. In late 2002, the NT Aboriginal Health Forum (the peak advisory body in the NT comprising representatives of NT DHCS, Office for Aboriginal and Torres Strait Islander Health within Commonwealth Department of Health and Ageing, Aboriginal Medical Services Alliance NT and Aboriginal and Torres Strait Islander Commission) established a Standing Committee on Chronic Disease and Social Determinants of Health.

The better management of chronic diseases has been named as one of the five major community health centre priorities in operational areas, and written into business plans throughout the Department, against which reporting is required. Each health centre has had to grapple with how best to implement the strategy locally, but has been able to draw on detailed chronic disease management protocols, which can be integrated into single client management plans using either a computerised information system (Weeramanthri et al, 2002), or a standardised paper based system (Maddison, 2000). Major changes have been made to orientation procedures and a special one week Advanced Skills Course in Chronic Disease Management has been developed (Peter White, DHCS Workforce Development, personal communication). A series of community based and regional workshops on chronic disease management has also been held. Early structural changes within DHCS included the setting up of a Chronic Diseases Operational Management Group in Central Australia, and employment of PCDS coordinators in both the Top End and Central Australia.

The greatest barrier to further improving the primary care management of chronic disease lies in the inadequate resourcing of the community sector. Changes to Section 100 of the PBS mean that since 2000 the Commonwealth has funded the purchasing of PBS-listed medications even in areas where there is no private pharmacy. The NT Aboriginal Health Forum has determined that the resultant savings will now be used to improve chronic disease management and promote the quality use of medicines. Such savings amount to approximately \$2.3 million per annum in the NT. As a result, six community based chronic disease coordinators and three regional coordinators have been employed in the Top End (PCDS 'Total Recall' Team) to improve the local presence and impact of chronic disease programs, and a PCDS Unit has been created in the Centre to focus on men's health, lifestyle education, well person's checks and outreach services (Annette Smith, PCDS Coordinator, personal communication). In a separate but related initiative the NT Government has funded the creation of an additional 25 child health positions across the NT, costing \$2.2 million per annum. Further

additional resourcing may become available under the Federal Primary Health Care Access Program to create new regional health delivery zones, allowing for increased access to Medicare funding.

Because responsibility for implementing the PCDS rests with operational areas, a central monitoring mechanism to track PCDS outcomes at a jurisdictional level was envisaged. The monitoring framework is based on the National Health Performance Framework (National Health Performance Committee, 2001) and utilises routinely collected information to measure trends in health outcomes (numbers going onto dialysis, hospitalisations and deaths), determinants of health (including intersectoral determinants as well as traditional risk factors), and health system performance. This framework is limited by the relative lack of good quality data on risk factor trends, social determinants and community health sector performance whereas data on hospital performance is excellent (Gollow, 2001). A baseline report containing 21 indicators was produced in early 2001, and it is planned to repeat the exercise in 2004. Preliminary analysis shows the following: a trend in improvement of birth weights; sustained high levels of immunisation; a slowing in the rate of growth of renal dialysis treatments; a decline in the number of diabetic amputations in the Top End; some improvements to the food supply; a relatively stable per capita alcohol consumption; and a continuing decline in adult smoking prevalence, though slower than in the rest of the country and with still very high levels in the Indigenous community (THS, 2001).

We are also looking to more community-level and health centre data as a more direct measure of many of the health system outputs being put into place. Audit data on patients with diabetes from rural Top End communities in 2000 has been collected by the Total Recall nurses, and compared with a similar audit from 1995. Approximately 50% of patients had an eye review in the previous 2 years (up from 20% five years previously), 70-80% of patients were on angiotensin converting enzyme inhibitors (up from 30% five years previously) and 40-80% in different communities had had a glycated haemoglobin level measured in the previous six months. To put our efforts into perspective, recent data from GPs in NSW showed that less than 15% of patients had a glycated haemoglobin level measured in the previous six months, even in those practices with a diabetes register (Harris et al, 2002).

To enhance our routine auditing capacity, we have also commenced a five year research project with the Menzies School of Health Research, funded by the State/Commonwealth Research Issues Forum, to trial an enhanced system of intensive audit and feedback of chronic disease information to 20 communities across the Top End. This project is known as ABCD (Audit and Best Practice in Chronic Disease), and includes an assessment of the quality of chronic illness care systems across six domains: community resources and policies, health system organisation, self-management support, delivery system design, decision support and clinical information systems (Bonomi et al, 2002), as well as an assessment of the process of care and health outcome measures.

## Discussion

The NT PCDS is a model for an integrated approach to chronic diseases in Australia (Bennett, 1999). Sindall (2000) has described a number of initiatives at the national level looking at such approaches, some of which, like the National Chronic Disease Prevention Framework (National Public Health Partnership, 2001) and Australian Medical Association Policy on 'Preventable Chronic Disease Strategies in Aboriginal and Torres Strait Islander Peoples' (AMA, 2001) have been directly influenced by the NT PCDS. Key players include the National Health Priority Action Council (NHPAC) which has been established 'to improve health and well-being...by identifying, advocating and facilitating actions and strategies both within and across (our emphasis) national health priorities' and the National Public Health Partnership (NPHP) which has stated that one of its main aims is to foster a more strategic approach to chronic disease prevention (Wilson, 1999). The Commonwealth Department of Health and Ageing is sponsoring a range of activities, including some important pilot projects on Indigenous chronic disease self management under the Sharing Health Care Initiative. The GP Partnership Advisory Council is working jointly with NPHP to auspice the SNAP initiative (Smoking, Nutrition, Alcohol and Physical activity) that is developing an integrated approach to these common population health risk factors in general practice. Finally the Australian Chronic Disease Prevention Alliance (comprising

the major non-government organisations) was formed in 2002 to work collaboratively on common risk factors, particularly nutrition and physical activity, and provide consistent health promotion messages.

Before the PCDS was introduced, the NT had good acute care clinical guidelines and a dominant focus within chronic disease care on individual clients and practitioners. Since the PCDS, we have much more detailed chronic disease guidelines, a focus on systems of care, expanded training opportunities with a special emphasis on the ethics of the interaction with clients, and more standardised health centre practices and dedicated staff support.

An integrated approach is particularly important for clients who have more than one disease or risk factor. The late Chairperson of NACCHO called for an 'organised rather than organ-specific' approach to Indigenous health. However, integration implies more than simply an attention to risk factors; risk factor approaches can be as 'vertical' as single disease approaches. It is important to explore the links between diseases, risk factors and underlying determinants. Integration is evident at the theoretical level in the PCDS, and translates into an integrated approach to prevention, education messages, support for self-care, screening, guideline development and data collection. Self care, in particular, is a concept central to a broad range of chronic conditions (Holman & Lorig, 2000), and can only be helped by an integrated provider approach.

Such integration also allows for maximum use of existing resources. Cooperative working relationships are vital, and in the NT, the non-government sector (Diabetes Australia, Heart Foundation, Australian Kidney Foundation and others) has been particularly supportive and collaborated actively across disease areas. The NT Chronic Diseases Network provides a structural support for such collaboration. Remarkably, Diabetes Australia NT was the successful tenderer for the provision of cardiac rehabilitation services in the NT in 2002. We believe that such a shift in organisational thinking is unprecedented, but from an integrated perspective it is quite logical.

A deliberate attempt has been made to position the PCDS within a primary health care (PHC) setting, rather than in the traditional domain of 'public health'. This has allowed greater engagement with the broad health workforce. Short term gains have been made in reskilling and restructuring at the PHC level, but longer term gains are dependent on a greater investment in health promotion and disease prevention. The broader public health workforce remains engaged, and the publication of the 'Public Health Bush Book' provides concrete examples of how primary care staff and visiting public health staff can work together in the areas of nutrition, environmental health and substance abuse (Territory Health Services, 1999).

Prevention and care are best dealt with as part of a continuum of care. The continuum approach allows health economists to model the potential cost-effectiveness of preventive interventions at a population level, and predict the flow on effects with respect to hospitalisation and other costs. It also recognises that primary, secondary and tertiary care sectors are dynamically linked. For example, the development of the new Enhanced Primary Care MBS items has provided an opportunity for DHCS to work closely with Divisions of General Practice on the development of common care planning mechanisms. Care planning for individuals at the primary care level will impact on use of secondary and tertiary care; and involving family and household members, who are often also at high risk of developing chronic disease, will strengthen preventive efforts. However, uptake of enhanced MBS items is hindered in the NT by difficulties practitioners face in setting aside time for care planning, completing paperwork and in gaining informed consent.

The evidence base demonstrated some lost (or delayed) opportunities for health gain at reasonable cost. For example, the Heart Foundation has lobbied successfully for the introduction of cardiac rehabilitation services, which commenced in 2002, the cost effectiveness of which had been noted in the PCDS. The Arthritis Foundation has also been funded to provide train-the-trainer courses for chronic disease self management programs.

The choice of the five diseases as the core group of chronic diseases was important to the initial acceptance of the PCDS. Clinicians can recognise such diseases which they treat on a daily basis, whilst people working in health promotion and disease prevention see this grouping as sufficiently broad, and inclusive of a range of social

and medical determinants, to allow non disease-specific approaches. The simplicity of the three point framework - Prevention, Early Detection and Management – was also welcomed.

We are currently considering the merits of including other chronic diseases including rheumatic heart disease, stroke and depression in a second stage of the PCDS. In May 2003, the NT Chronic Diseases Network held a conference in Darwin called ‘Uncharted Territory’ that explored the links between chronic disease, mental health and alcohol and other drugs. The most commonly discussed ‘dual diagnosis’ is the combination of mental health and drug issues, but there is a growing literature on the high prevalence of depression that clusters with and complicates chronic illness, often in socio-economically deprived populations (Palmer, 2000). Treatment of depression as a chronic illness requires exactly the same kind of systems changes we have tried to introduce through the PCDS: continuing and persisting with therapy, monitoring and watching for relapse, and establishing a good therapeutic relationship between provider and client, are more important than the initial treatment choice of medications or cognitive-behavioural therapy (Ellis & Smith, 2002).

With respect to a future prevention agenda, we need to move from ‘model’ community-based projects (e.g. Lee et al, 1994; Diabetes Project Team, 2000) to a way of funding a broad community development agenda that addresses the social determinants of health. The development of zonal health services and community controlled health boards responsible for population health outcomes (through the Primary Health Care Access Program) provides an opportunity to link increased funding to improved chronic disease outcomes via a strengthening of both preventive and management programs. An understanding of local cultures and values is central to any such local planning process.

We are also hoping to utilise the local results of the national diabetes survey (AusDiab) conducted in late 2000 (Dunstan et al, 2001) to strengthen the application of the PCDS to the non-Indigenous population of the NT, by developing a whole of government initiative to promote physical activity. The non-Indigenous population has also benefited from general practice initiatives in chronic disease management (including the Enhanced Primary Care items, and the newer diabetes Practice Improvement Program payments) and the ongoing work of government programs such as Living with Alcohol, and the activities of the non-government organisations.

Further work needs to be done on strengthening the intersectoral aspects of the PCDS. For example, improving environmental health infrastructure and maintenance will address a key underlying determinant of chronic disease, and can only be achieved through intersectoral action. We will also look at ways to combine various best buys within a settings approach (eg nutrition and physical activity programs within schools, smoking cessation and screening programs at workplaces, clinical care and family education through home visits etc).

The PCDS is now a key long term DHCS strategy. It will remain a ‘working strategy’, needing regular review as new evidence and new ideas arise. Executive and ministerial support is strong, and the strategy has attracted bipartisan political support. Following the launch of the PCDS in 1999, two further debates on the PCDS as a ‘matter of public importance’ were held in the NT Legislative Assembly in 2000, with debate centred on how best to implement the strategy. With respect to legislative levers for chronic disease, the NT Government has recently introduced welcome changes to tobacco laws including smoke free public places, public education, restrictions on sales to minors, changes to advertising regulations and a licensing system for tobacco retailing.

We should recognise that there are no perfect models of non-communicable disease control, since the person at risk or affected has ultimate control over their own behaviours and choices. Behaviour change is known to be difficult, and that should colour the empathy shown by providers to clients. Building a therapeutic partnership with clients is not an optional extra in chronic disease, but an ethical duty, and a precondition for effective and efficient care (Holman & Lorig, 2000). The aim of public policy is to put into place sustainable systems that are client-centred, support self-care, provide expert professional support, and introduce legislation where appropriate (such as in the area of tobacco control) that can make healthy choices easier.

Moving towards a more organised chronic diseases approach in Australia will require substantial reform at a jurisdictional level, strategic alliances between a range of stakeholders, and novel funding mechanisms not tied to single diseases. But there are few alternatives if we wish to achieve better population health outcomes

(Glasgow et al, 1999). A paradigm shift is needed— away from single diseases and towards a comprehensive and integrated approach.

The full version of the PCDS Evidence Base is available on the world wide web at <http://www.nt.gov.au/health/cdc/preventable/pcds.shtml>

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