Ms. Kathy Bell

Is NACCHO’s Health Financing Policy Officer, and has worked with NACCHO since June 1997. One aspect of Kathy’s work with them has been to consult with the members and draft NACCHO position papers on various general practice issues, and to provide support to their representatives on several general practice advisory bodies. She has previously worked in health policy in the Commonwealth Health Department, and as a lecturer at Edith Cowan University.

Dr. Sophia Couzos BAppSc MBBS
DipRACOG MPH&TM FRACGP FACRRM FAFPHM

Is Public Health Officer for the National Aboriginal Community Controlled Health Organisation in Canberra. She is a public health physician with seven years experience as a primary health care practitioner within Aboriginal Community Controlled Health Services, in the remote Kimberley region of Western Australia. She has used systematic review methodology to provide the evidence-base required for progress in Aboriginal health, and applies it to primary health care within the framework of Aboriginal community control.

Dr. John Daniels MBBS FACRRM

Is the medical director at the Aboriginal Medical Service Co-operative, where he has worked for 12 years. He has previously worked as a senior public servant, and has served on government committees, hospital boards and tribunals.

Mr. Puggy Hunter

Is Chairperson of the NACCHO. He is also vice-chairperson of the Aboriginal and Torres Strait Islander Health Council, the Australian Health Ministers’ policy advisory body on Aboriginal health established in 1996. He is a member of many ministerially-appointed bodies which advise on issues that impact on the health of Aboriginal people, and is chairperson of the Kimberley Aboriginal Medical Services Council. He is known for his colourful language, his generosity and his perceptive insights into Aboriginal affairs. He has a passionate commitment to Aboriginal community control, and often says that it is no longer acceptable to ‘do’ Aboriginal health without Aboriginals. He has a strong voice of commonsense, moderation and consensus in the Aboriginal political movement.

Dr. Naomi Mayers OAM

Is recognised in Australia and internationally for her outstanding contribution to Aboriginal health over many years. She has been the Chief Executive Officer of the Aboriginal Medical Co-operative since 1972, and is currently the Deputy Chair of NACCHo. She was Chair of the National Aboriginal Health Strategy Working Party, and has served on numerous government committees, boards and international reference groups. She was recently awarded a doctorate in Aboriginal Affairs from Tranby Aboriginal College in NSW.

Dr. Richard Murray MBBS DipRACOG FRACGP

Has been Medical Director of the Kimberley Aboriginal Medical Services Council for 7 years. He is an experienced remote area medical practitioner, with extensive operational experience in clinical service delivery and management of Aboriginal community controlled health services in the Kimberley region, public health programs, Aboriginal Health Worker training, and health promotion. He is a medical adviser to a number of national and WA-based policy bodies on Aboriginal health.
Aboriginal community controlled health services

3.1 Introduction

Aboriginal Community Controlled Health Services (ACCHSs) are culturally appropriate, autonomous primary health services initiated, planned and governed by local Aboriginal communities through their elected Aboriginal board of directors.

ACCHSs are the practical expression of Aboriginal self-determination in Aboriginal health. By definition, they are not government run. Aboriginal communities around Australia have been establishing community controlled services since 1971.

There are now over 100 ACCHSs operating across Australia in all States and Territories. All Aboriginal communities have unmet primary health care needs and in many ACCHSs primary health care is not available.

At the national level all ACCHSs are members of their umbrella body, the National Aboriginal Community Controlled Health Organisation. There are similar umbrella structures at the State/Territory level.

This chapter summarises the structure and function of ACCHSs in their delivery of comprehensive primary health care to Aboriginal people.

It contextualises many of the current developments in Australian general practice within the preferred model of care to Aboriginal people. The ACCHS model of care pre-dates and exemplifies the application of the Alma Ata Declaration on primary health care endorsed by the World Health Organization (WHO 1978).
3.2 National and state/territory Aboriginal Community Controlled Health Organisations

At a national level, the National Aboriginal Community Controlled Health Organisation (NACCHO) is the umbrella organisation representing Aboriginal community controlled health services on matters relating to Aboriginal health and well-being. In keeping with its major objective of delivering holistic and culturally appropriate health and health related services to the Aboriginal community, some of NACCHO’s major activities include:

- representing and advocating for constituent Aboriginal communities in matters relating to health services, health research, health programs et cetera;
- promoting, increasing, developing, and expanding the provision of culturally appropriate health care through local Aboriginal community controlled primary health care services;
- assisting member organisations to provide their communities with health and health-related services;
- assessing the health needs of Aboriginal communities (through research, data analysis, surveys etc.), and taking steps to meet these needs; and
- liaising with governments, departments, and organisations within both the Aboriginal and non-Aboriginal communities on matters relating to the well-being of Aboriginal communities.

NACCHO was previously known as the National Aboriginal and Islander Health Organisation (NAIHO).

In 1974, during a national meeting on Aboriginal health, ACCHSs met separately and decided that there should be a separate national umbrella organisation of ACCHSs. The organisation was established in 1976 after a meeting of all ACCHSs at Sydney University. The Redfern Aboriginal Medical Service funded the organisation’s first national meeting where it was officially named NAIHO.

During this time State health departments were setting up their own Aboriginal Health Units and there was opposition to the establishment of an Aboriginal community controlled body as well as the establishment of further ACCHSs. There was minimal government funding support for the first ten ACCHSs which were largely financed through donations.

In 1985, NAIHO established its own secretariat, with an office in Melbourne, and accepted government funds for the first time, having previously relied entirely on donated monies. In 1992, NAIHO changed its name to NACCHO. The change in the organisational title reflected Torres Strait Islanders’ pursuit of self-determination and the associated establishment of their own culturally appropriate structures.

NACCHO is governed by an elected Board of Directors, and administration and coordination is carried out by NACCHO’s National Secretariat, which was established in Canberra in 1997 and works under the direction of the Board.

At the State and Territory level, there are similar umbrella organisations which are members of NACCHO and represent the Aboriginal Community Controlled Health Services in that State/Territory. They function under a similar structure to NACCHO with a State/Territory-based secretariat (Box 3.01).
The State/Territory Aboriginal Community Controlled Health Organisations are participants, with governments and with the Aboriginal and Torres Strait Islander Commission (ATSIC), in health planning under the Framework Agreements on Aboriginal health.

3.3 Primary health care and community control

The definition of primary health care adopted by the National Aboriginal Health Strategy (NAHS) Working Party in 1989 was derived from the 1978 World Health Organization Alma Ata definition. Primary health care is:

Essential health care based on practical, scientifically sound, socially and culturally acceptable methods and technology made universally accessible to individuals and families in their communities in which they live through their full participation at every stage of development in the spirit of self-reliance and self-determination.

Further to this, community controlled health was defined in the following terms:

Community control is the local community having control of issues that directly affect their community. Aboriginal people must determine and control the pace, shape and manner of change and decision-making at local, regional, state and national levels.

Community control in matters of health, particularly in the delivery of primary health care, is an entrenched international principle that provides the foundation for the delivery of appropriate and acceptable health care.

Australia is a signatory to the 1975 International Convention on the Elimination of All Forms of Racial Discrimination that ‘guarantees’ the right of everyone to social and cultural rights. In 1978, the WHO Primary Health Care Conference at Alma Ata declared that ‘the people have the right and duty to participate individually and collectively in the planning and implementation of their health care’.
The Convention concerning Indigenous and Tribal People in Independent Countries (1989) also made the following affirmation:

Governments shall ensure that adequate health services are made available to the [indigenous and tribal] peoples concerned or shall provide them with resources to allow them to design and deliver such services under their own responsibility and control so that they may enjoy the highest attainable standard of physical and mental health. Health services shall, to the extent possible, be community-based. These services shall be planned and administered in cooperation with the peoples concerned and take account of their economic, geographic, social and cultural conditions as well as their traditional preventive care, healing practices and medicines. The health care system shall give preference to the training and employment of local community health workers and focus on primary health care while maintaining strong links with other levels of health care services (International Labour Organisation Convention 1989).

Box 3.02 Definition of an Aboriginal Community Controlled Health Service (NACCHO Memorandum of Association 1997)

Aboriginal Community Controlled Health Services must be:
- Incorporated Aboriginal organisations.
- Initiated by a local Aboriginal community.
- Based in a local Aboriginal community.
- Governed by an Aboriginal board of directors that is elected by the local Aboriginal community.
- Delivering holistic and culturally appropriate health services to the community, by which it is controlled.

3.4 Background to the development of ACCHSs

All of the indicators of socioeconomic and health status (eg education, income and employment levels, infant mortality, life expectancy, adult morbidity and mortality rates) clearly show Aboriginal people to be by far the most disadvantaged group in Australia.

Over the past 20 to 30 years there have been several major inquiries into the health of Aboriginal people (National Aboriginal Health Strategy, Royal Commission into Aboriginal Deaths in Custody etc.), the most recent being the House of Representatives Standing Committee Inquiry into Indigenous Health (1999). It has become clear that the appalling, and in some respects worsening, state of Aboriginal health is embedded in the history of dispossession and alienation experienced by Aboriginal people, and in ongoing poverty and disadvantage.

Improving Aboriginal health is not just about improving the physical well-being of an individual. It is about working towards the social, emotional, and cultural well-being of the whole community in which each individual is able to achieve their full potential as a human being. It is also based on the need to acknowledge the reality that Aboriginal people have never ceded sovereignty of their land.
Box 3.03 The benefits of community control in health (NAHS Working Party 1989)

- Significantly improved access—because the local community has ownership and control of the service, and because service delivery is flexible and responsive (for example, outreach services are often a feature), Aboriginal people are more likely to access the care they need.

- The full range of primary health care services is available in one place—service delivery is integrated and holistic, rather than being built around different specialties or ‘body parts’.

- Public-health or population activities are implemented at a primary care level.

- The care provided is culturally appropriate and caters for the social and cultural needs of those it serves—the organisation is run by Aboriginal people, employs Aboriginal or culturally aware non-Aboriginal people, and delivers care in a sensitive and inclusive way.

- The sector is both cost-effective and cost-efficient; it delivers value for money—based on local knowledge, services are targeted at areas of local need.

- The sector represents a major source of education, training, achievement, and pride, for Aboriginal people and promotes community responsibility.

- Community control in health builds Aboriginal community capacity and social capital.

- The promotion of horizontal cross-agency/cross-strategy approaches to address the socioeconomic underpinnings of poor health in Aboriginal communities (which individual organisations are unable to address in isolation).

- Prevention of covert and overt racism from non-Aboriginal staff working in Aboriginal health and prevention of unethical behaviour and presumptions about lifeways and illnesses that may lead to inaccurate diagnosis.

- Provision of relevant training and culturally appropriate information for the non-Aboriginal community.

- The sector represents a significant intellectual resource on Aboriginal health matters. Knowledge required to improve Aboriginal health status is not innate; it must be acquired. The community controlled sector has developed a large pool of knowledge and expertise about Aboriginal health issues, which enables it not only to deliver appropriate care, but also to advocate effectively for Aboriginal people in health.

- In practical terms, the Aboriginal community controlled health service sector provides leadership in primary health care in Australia in areas such as evidence-based medicine (with the development of clinical care guidelines based on systematic reviews of available evidence) (Couzos & Murray 1999; Couzos et al 1998) and use of information technology for purposes such as patient recall.

- Provision of a resource for culturally appropriate research.

There is no simple, quick-fix medical solution to Aboriginal health—the solutions lie in Aboriginal people being able to enjoy their right to self-determination. All relevant inquiries and studies have shown conclusively that culturally appropriate, comprehensive primary health care, based on maximum community participation, is the best way of addressing Aboriginal health.
From a beginning at Redfern in Sydney in 1971, ACCHSs have been established around the country as the practical expression of Aboriginal self-determination in Aboriginal health. The ACCHS model of participatory holistic primary health care integrates illness care with disease prevention, intersectoral collaboration and advocacy for social justice.

Many ACCHSs provide comprehensive primary health care services and employ general practitioners as part of a multidisciplinary team. Smaller services provide remote nurse or Aboriginal health worker outposts.

Many Aboriginal people access some primary health care services through mainstream private general practice, but, by definition, this model cannot provide culturally appropriate primary health care because such services are not controlled by Aboriginal communities according to the principles of Aboriginal society.

In some States and the Northern Territory, government controlled clinics have been established to deliver primary care services to Aboriginal people. Again, such services are not culturally appropriate because they are government controlled, not Aboriginal community controlled.

Many individuals and communities have no adequate access either to culturally appropriate services or to other arrangements and where culturally appropriate services exist they are often severely under-resourced and unable to fully meet community needs.

The cultural, locational, financial, and other barriers to access by Aboriginal people to mainstream services have been comprehensively described, and it is clear that for many Aboriginal people these barriers are very significant.

Aboriginal people have low levels of access to private GPs. While the average Australian sees a GP five times per year (Government’s Response to the Reviews of General Practice 1998), Aboriginal and Torres Strait Islander people average fewer than two GP consultations a year (Deeble et al 1998; p.20, Table 2.11). Cultural, educational, linguistic and lifestyle factors mean that some Aboriginal people are not comfortable attending a private general practice, and will do so only where there is no alternative or their health problem has become extreme. Some private practices do not bulk bill, and this creates a financial barrier for Aboriginal people, a large proportion of whom experience extreme and lifelong poverty. Distance and lack of transport also represent physical access barriers, particularly (but not only) for Aboriginal people in remote areas.

Some of the benefits that properly resourced Aboriginal community controlled health services can deliver are shown in Box 3.03.

In practical terms, the benefits of a strong Aboriginal community controlled health sector are already being demonstrated through health gains such as measurable improvements in immunisation rates and reductions in sexually transmitted disease (STD) rates in several areas with Aboriginal community controlled health services (ANCARD 1997; Miller et al 1999). Valuable partnerships are also being developed in a number of jurisdictions between the Aboriginal community controlled health sector and other players such as hospitals, GPs, specialists, other health and community organisations, and academic institutions.
3.5 **Access to primary health care-funding and medical benefits schedule issues**

Contrary to popular belief, Commonwealth Government expenditure on Aboriginal health is not high. Taking the Medical Benefits Schedule or ‘Medicare’, the Pharmaceutical Benefits Schedule, Aboriginal health funding through OATSIH and other Commonwealth programs into account, the Commonwealth currently spends significantly less per head on the health of each Aboriginal person than on the health of each non-Aboriginal person.

Approximately 63 cents per head is spent by the Commonwealth on health services to Aboriginal and Torres Strait Islander people, for each dollar spent per head on the health of other Australians (Deeble et al 1998; p.11, Table 2.2). Only a portion of the 63 cents is spent on culturally acceptable and effective services to Aboriginal people.

The current low level of accessibility to appropriate primary health care for Aboriginal people contributes to poor health status. Lack of meaningful access to primary care is also contributing to a higher dependence by Aboriginal people on hospital-based care (Deeble et al 1998; p.16, Table 2.7), a result of failed prevention and the immediate burden of disease. This is expensive to the health care system and less than optimal for the individuals concerned.

Equitable access to appropriate primary health care, complemented by other reforms, has the potential to bring about real long-term improvements to Aboriginal health outcomes.

Organised and comprehensive preventive health care delivered by primary health care services is potentially very cost effective. This is particularly true in delivering comprehensive programs to the Aboriginal population, who suffer a greater burden and risk for disease.

When the risk is high, the benefit from an intervention (that is, the reduction in absolute risk for the disease) will be greater. This is true when the relative risk reduction of the intervention remains constant (and is independent of risk status), which is usually the case (Glasziou & Irwig 1995).

For example, screening 20,000 people with a low risk for renal disease will prevent one case of end-stage renal failure (ESRF) (Barratt et al 1999), but the same screening applied to high-risk Aboriginal clients could prevent at least 40 cases of ESRF. This translates to a considerable reduction in cost relativities.

Furthermore, in overseas studies health checks have been shown to be cost-effective in the elderly. One nursing home admission can be avoided for every 17 elderly people receiving a health check over three years (Stuck et al 1995).

The Medicare Benefits Schedule now remunerates GPs to undertake health checks in the elderly Aboriginal and non-Aboriginal population and develop chronic disease care plans that encourage regular review and early therapeutic interventions. However, unless processes for organised delivery of such health checks are in place, optimal population health outcomes will not be sustainable and the costs of prevention will no longer be offset by reductions in the cost of acute or rehabilitative care.
In May 1996, Minister Wooldridge agreed to give Aboriginal Community Controlled Health Services the legal ability to bulk bill under Medicare. The limited Aboriginal-specific health funding provided by the Commonwealth Government is insufficient to meet the high level of unmet need in Aboriginal primary health care, and is a complementary and ‘gap-closing’ measure. Like other Australians, Aboriginal people are entitled to equitable access to Medicare as a citizenship right, and measures to improve Aboriginal access to Medicare are priorities.

The House of Representatives Standing Committee Inquiry into Indigenous Health (1999) reported that the:

> level of expenditure on Aboriginal and Torres Strait Islander health …is not excessive and would generally seem to be insufficient to meet the present level of need for health and related services (House of Representatives Standing Committee Inquiry in to Indigenous Health [HRSCIIH] 1999; p.8, 2.11).

A Health Insurance Commission review of Aboriginal and Torres Strait Islander access to Medicare and the Pharmaceutical Benefits Scheme (PBS) in 1997 (Keys Young 1997) suggested a range of reforms to Medicare enrolment and claiming procedures to overcome the inequity in Medicare access. The Health Insurance Commission is trialing some options to assist services to overcome administrative difficulties in effectively claiming for all consultations.

### 3.6 Access to medications

The above mentioned Keys Young Review of Aboriginal access to the Pharmaceutical Benefits Scheme in 1997 found major barriers in access to medicines—not only in remote areas where distance and lack of health services are obvious problems, but also in urban and rural areas. Barriers identified include poverty, transport problems, cultural factors and educational disadvantage. In particular, the impact of patient co-payments, administrative difficulties around concessional status, the separation of clinical and pharmaceutical services and issues of cultural safety were highlighted.

These barriers translate to low levels of spending by government on medicines for Aboriginal people.

Through NACCHO involvement in the Australian Pharmaceutical Advisory Council, government and a range of peak health and consumer bodies have been working to address the problem. The new Section 100 arrangements for supply of medicines through Aboriginal health services in remote areas is an important first step.

For the first time, government and non-government Aboriginal health services in remote areas are now able to be supplied PBS medicines on a bulk supply basis through community pharmacy. The community pharmacy is then reimbursed directly by the Health Insurance Commission.

This means that medicines are more accessible to the community and medicine management can be more closely integrated with primary health care. By November 1999, 37 ACCHSs serving a combined population of 58,000 people had been approved for Section 100 supply of PBS medication.

This scheme has also provided an opportunity to build local partnerships between Aboriginal health services and community pharmacy in quality use of medicines.

An information booklet for services considering setting up Section 100 supply arrangements has been prepared by NACCHO and is available from the NACCHO office.
The medication needs of Aboriginal people in urban and rural areas must also be addressed and this remains a priority for NACCHO. Aboriginal Community Controlled Health Services need well-resourced community pharmacy support roles and NACCHO and the Pharmacy Guild are currently undertaking a project on this with the Commonwealth Department of Health and Aged Care.

Legislative restrictions in the use of medications can impose further barriers for Aboriginal people to access timely medications. The supply of Schedule 4 or ‘prescription only’ medicines by Aboriginal health workers and nurses in Aboriginal health services is very common, particularly, but not exclusively, in remote areas. These medicines are provided for the standard treatment of common acute conditions (eg antibiotics for STD, skin infections, ear disease, trachoma, rheumatic fever prophylaxis) or the filling of compliance aids in those taking long-term medication. However, much of this activity is technically illegal in most jurisdictions, thus posing a barrier to the delivery of best practice. As vaccines are classified as Schedule 4 medications, the administration of important public health interventions such as childhood and adult vaccines by Aboriginal health workers is also restricted. The role that these Aboriginal health workers play in performing this function is of critical importance in improving Aboriginal health.

A useful model for Aboriginal primary health care services would be a statutory mechanism for approval of problem-orientated ‘standing orders’ which set out the clinical circumstances in which medicines can be used by professionals other than medical practitioners. A problem-orientated standing order incorporating clinical assessment and decision points as well as medical therapeutics provides a rational ‘quality use of medicine’ framework for use of prescription medicines in proscribed clinical circumstances. Such standing orders are in reasonably widespread use but mostly lack the support of a statutory framework.

Mechanisms also need to be developed that encourage and maintain PBS listing of medications for public health benefit of high-risk populations such as the Aboriginal and Torres Strait Islander population. Examples include antifungal agents.

3.7 The framework agreements

A major impediment to reform in Aboriginal health has been a lack of coordination between Federal and State governments, with consequent ‘buck-passing’; and difficulties in the relationship between governments and Aboriginal organisations.

In order to overcome these obstacles, Framework Agreements on Aboriginal and Torres Strait Islander health were signed in each State and Territory between July 1996 and February 1999. The signatories to the agreements are the State/Territory Health Minister; the Commonwealth Health Minister; the Chairperson of the Aboriginal and Torres Strait Islander Commission (ATSIC); and the Chairperson of the State/Territory peak body for Aboriginal community controlled health services (ie the State/Territory NACCHO affiliate).

The Framework Agreements aim to improve health outcomes for Aboriginal and Torres Strait Islander peoples through:

1. improving access to both mainstream and Aboriginal and Torres Strait Islander-specific health and health related programs which reflect the level of need;
2. increasing the level of resources allocated to reflect the higher level of need of Aboriginal and Torres Strait Islander peoples, including within mainstream services, and transparent and regular reporting for all services and programs; and
3. joint planning processes which will inform the allocation of resources and allow for:
   • full and formal Aboriginal and Torres Strait Islander participation in decision making and determination of priorities;
   • improved cooperation and coordination of current service delivery, both Aboriginal and Torres Strait Islander specific services and mainstream services, by all spheres of government; and
   • increased clarity with respect to the roles and responsibilities of the key stakeholders.

While no Agreement between the partners has yet been developed at the national level, agreements have now been signed for each State and Territory.

The philosophy underlying the Framework Agreements is based on recognition that intersectoral collaboration and a partnership approach are critical to achieving improved health outcomes. The interdependence between the different sectors, with each bringing different expertise, skills, and resources to the table, means that together the players can work towards long-term health goals which would not be achievable by any one player alone.

Successful collaborative relationships are based on several core principles:
   • the relationship is formalised, with clear roles and responsibilities;
   • the partners are well chosen, and the expertise, skills, and resources of each are acknowledged and utilised;
   • commitment is demonstrated through the application of resources to the partnership;
   • the partners share information; and
   • the partners demonstrate integrity.

While the Framework Agreements fulfil the first of these criteria by setting out the roles and responsibilities of the signatories, there are still difficulties in many areas with achieving the other criteria. In some cases, the Aboriginal community controlled health sector finds that its expertise, skills and resources are not recognised and valued by the other partners. The resources committed to Aboriginal health by both Federal and State governments remain far from adequate and there are power inequalities based on the Aboriginal community controlled health sector’s dependence on government for funding, which affect the collaborative relationship.

On the other hand, Aboriginal community control and ownership is very powerful but is not always recognised as such. Recognition of this power is an enabling factor for collaboration, and is underpinned by the recommendations of the major relevant national reports such as the National Aboriginal Health Strategy and the Report of the Royal Commission Into Aboriginal Deaths in Custody.

NACCHO’s view is that the content of the Framework Agreements on Aboriginal and Torres Strait Islander health is basically sound and several positive outcomes have been recognised:
   • The planning mechanisms established under the agreements have led to improved intersectoral communication and collaboration in several States/Territories and regions.
   • Joint regional Aboriginal health plans are under way or completed in several areas.
   • NACCHO and most of its State/Territory affiliates have accessed some resourcing since the signing of the agreements.

However, the implementation of the agreements is lacking in several areas:
   • The national and State/Territory forums are frequently being presented with policy and program decisions after the event rather than being active participants in these decisions, and in some cases their advice is not acted upon by governments. In many cases, funding decisions continue to be made without reference to the agreed planning structures.
The Aboriginal community controlled health sector is not an equal partner in the partnerships and planning processes, due to resource and information inequalities.

There has been an inability to enforce the accountability requirements implicit in the Framework Agreements.

The agreements have not (to date) led to the provision of adequate, needs-based resourcing for Aboriginal health. Increases in funding have been incremental.

The Australian National Audit Office noted in 1998 (and reported in the House of Representatives Standing Committee Inquiry into Indigenous Health, 1999) that:

... the Framework Agreements are ‘in-principle’ agreements without any detail committing the parties to undertake specific action, provide a level of funding or achieve quantifiable outcomes within an agreed timeframe. Furthermore there is no recourse for [Department of Health and Aged Care] where States and Territories do not comply with the requirements of the Agreements.

Whether the Agreements work depends on the ‘level of commitment by State and Territory staff to the process’ (HRSCIIH 1999; p.10, 2.18).

These issues need to be addressed in the implementation of the next round of Framework Agreements (which will cover the period from July 2000) so that improved resourcing can increase Aboriginal access to appropriate primary health care services and offer greater health gains in the future.

Box 3.04 The unique roles and experiences of General Practitioners within Aboriginal Community Controlled Health Services.

- In keeping with the philosophy of Aboriginal community control and the holistic view of health that this entails, GPs in ACCHSs deliver services within an integrated primary health care model. This is not always the case for GP services in other sectors, where less attention may be given to whole person care, and a disease oriented approach may instead be adopted.

- Because ACCHSs are managed by boards from the local community, who set overall direction for the service, GPs in these settings are ultimately responsible to the community. This relationship with the outside community, from which the service’s clients are also drawn, is very different from that experienced by GPs working in private practice.

- The need to deliver culturally appropriate services in a sensitive way means that the GP needs to acquire knowledge and skills that would not be required in other contexts.

- There is an emphasis on a multidisciplinary team-based approach to health care delivery, with Aboriginal health workers often playing a pivotal role. GPs in ACCHSs generally work closely with other health care providers, particularly Aboriginal health workers and nurses, and are often involved in clinical training.

- Because of the context of poverty and disadvantage, and the complex mix of chronic and acute conditions often experienced by Aboriginal people, some of which (particularly some infectious diseases) are rarely seen in the mainstream community, GPs in ACCHSs are in a position to gain an unusually broad range and depth of clinical experience.

- Doctors in the ACCHS sector are more likely to be working on a salaried rather than a fee-for-service basis.
3.8 The role of general practitioners in aboriginal health

General practitioners, along with other health care workers, have an important role to play in breaking the cycle of Aboriginal disadvantage, by providing appropriate, high quality health care to Aboriginal communities.

GPs, particularly those working in an Aboriginal community controlled context, have the opportunity to go beyond ‘band-aid’ approaches. They can help to implement population-based approaches to public health problems, as well as evidence-based approaches to the management of chronic conditions; support Aboriginal community development; support skills transfer by becoming involved in Aboriginal health worker training; and advocate for improvements in environmental conditions. Such actions can help to effect real and lasting improvements in the health of Aboriginal communities.

NACCHO is of the view that to be effective in Aboriginal primary health care, general practitioners must have a positive approach and excellent interpersonal skills, along with an understanding of the Aboriginal view of health, culture and history. General practitioners in this setting must also be able to provide high quality clinical care within a culturally appropriate framework, and be able to work effectively with peers in a team work environment.

GPs in Aboriginal community controlled health services work in a unique environment, and their role and experiences differ from the role and experiences of mainstream GPs. Some of these differences are shown in Box 3.04.

In terms of the integrated and holistic approach to primary care, utilising multidisciplinary teams and operating within a socially and culturally aware context, ACCHSs can be seen as a positive role model for the reform of primary health care.

3.9 Recruitment of general practitioners

It is well known that Aboriginal health services generally have difficulty attracting doctors, and this difficulty is compounded for rural and remote area Aboriginal health services. This is illustrated by the following statistics drawn from the Australian Institute of Health and Welfare’s publication, Medical Labour Force 1995. This report showed that in 1995, of nearly 49,000 practising doctors in Australia, only 512 worked in Aboriginal health services, and only 193 of these worked in Aboriginal health services as their primary job.

The same report demonstrated inequity in the distribution of general practitioners within Aboriginal Community Controlled Health Services indicative of under-resourced and insufficient numbers of services.

- While there were 269 employed medical practitioners per 100,000 head of population in Australia overall, there were only 148 Aboriginal health service clinicians per 100,000 Aboriginal population.
- The distribution of Aboriginal health service clinicians differed significantly from the distribution of the Aboriginal and Torres Strait Islander population. The ratio of Aboriginal health service clinicians to Aboriginal population was lower in the States/Territories with larger Aboriginal populations, with NSW, WA, and the NT having lower than average ratios and Queensland having only 44.2 doctors per 100,000 Aboriginal and Torres Strait Islander population.
There are several explanations for the difficulty Aboriginal health services, in urban and well as rural and remote areas, have experienced in attracting and retaining medical practitioners:

- Remuneration issues—Salaried GPs working in ACCHSs need to be remunerated at a level at least equal to salaried GPs in other sectors, and financial incentives need to be in place to attract GPs to ACCHSs in areas of hardship, particularly remote and rural areas. Currently, the chronic under-resourcing of the ACCHS sector presents a barrier to reasonable and equitable remuneration of salaried GPs.
- Lack of information for medical practitioners about working in Aboriginal health—Measures need to be undertaken to address this, for example, exposure of medical students to comprehensive education and training in Aboriginal health issues (both clinical and socio-cultural aspects). Information could also be provided for GPs through a range of media (eg professional journals) about Aboriginal health issues and the positive aspects of a career in Aboriginal health.
- Limited exposure of medical practitioners and students to Aboriginal health services via short-term placements—The increased availability of short-term placements for students and graduates would promote employment in the ACCHS sector as a positive experience.
- The challenges of working in an unfamiliar social, cultural, and professional context.
- The demands and challenges of working in a context where many clients suffer extreme social, economic, and educational disadvantage—This disadvantage impacts heavily on health status generally, and may affect adherence to or success of medical treatment.
- The frustration of working in an under-resourced environment—Appropriate treatments may be too costly for the client, and a significant part of a doctor’s time may be taken up ‘chasing’ resources. In addition, the shortage of medical practitioners working in the sector can mean that the available doctors work unreasonably long hours, may be constantly on-call, and have little or no access to locum relief.
- The demands and challenges related to working in rural and remote areas—When combined with other factors affecting recruitment and retention of doctors in Aboriginal health, there is a ‘multiplier effect’ which makes it exceptionally difficult for some remote services to attract and keep medical practitioners.
- The relatively poorer access to professional development and support services—including the perceived loss of social and professional networks and the relatively low professional status of such employment.

### Location of Aboriginal Community Controlled Health Services

As of 1997, there were 110 Aboriginal Community Controlled Health Services around Australia. According to the GP Accessibility Remoteness Index of Australia (ARIA), 54 per cent of services are located in highly accessible or accessible locations, and 35 per cent in remote or very remote locations (Figure 3.01).

ACCHSs vary greatly in size and function but they all operate in an environment of significant under-resourcing which places major constraints on service delivery. Larger ACCHSs provide a range of clinical services and other health-related programs. These services typically employ several doctors (generally around three to eight or more full time equivalent positions), as well as significant numbers of Aboriginal health workers (often in a ratio to doctors of around 3:1 or 4:1), and other staff including management and administrative staff.

In smaller ACCHSs, Aboriginal health workers play a lead role in clinical and other work. Such services usually do not have access to on-site medical, dental or nursing care.
Larger services account for approximately half of the total, and they typically cater to an Aboriginal population of approximately 4,000 to 8,000 people, though this varies considerably. The other half of the services are smaller in terms of budgets and staffing, and in terms of the populations they serve, typically under 3,000 people and sometimes significantly fewer.

A significant proportion of the Aboriginal population attend ACCHS services. In 1997, an average of 89.5 per cent of the clients attending ACCHSs were Aboriginal (NACCHO 1999). In contrast, a national survey of general practice activity during 1998–99 (BEACH—Bettering the Evaluation and Care of Health) revealed that out of 96,901 GP consultations from 1000 randomly selected GPs, only 1.1 per cent of encounters were with Aboriginal clients (Britt 1999). The bulk of Aboriginal people prefer to access their health care through ACCHSs. By virtue of the high proportionate load of Aboriginal clientele, the ACCHSs have developed significant expertise in Aboriginal health matters.

In 1997, as a national aggregate, most of the Aboriginal clients attending ACCHSs were female as 39 per cent of attendances were male. This is consistent with the pattern of male GP attendances in the population as a whole.

A significant proportion of ACCH services negotiate for specialist medical consultations to take place on-site to improve Aboriginal client access to specialist care. In 1987, 47 per cent of all ACCH services reported that specialists regularly consulted from their clinics.

The geographic locations of ACCH services are shown in the map section at the back of this text.
### 3.11 Structure and function of service delivery within ACCHSs

In accordance with the *National Aboriginal Health Strategy* (1989) and commitments made in the Framework Agreements in each State and Territory, Aboriginal primary health care services should be Aboriginal community controlled in structure. Aboriginal employment is a key feature of ACCHSs.

Good information about service delivery in the ACCHS sector has recently become available through the introduction of new annual service activity reporting arrangements for Commonwealth-funded Aboriginal primary health care services. This is a joint initiative undertaken by NACCHO and the Commonwealth Department of Health and Aged Care, through its Office for Aboriginal and Torres Strait Islander Health.

Under the new arrangements, all funded services have completed a detailed report covering their activities for the 1997–98 financial year. Although the information gathered through this process is not comprehensive, it does profile the work of services and provides a sound basis not only for service accountability but also for identifying and addressing resource gaps, identifying areas of strategic importance, and supporting continuing quality enhancement.

The findings of the first round of service activity reporting illustrate the distinctions between the care delivered by Aboriginal primary health care services and the care delivered through other providers such as private general practitioners.

The 106 services that participated in service activity reporting covered an estimated total health service population of 410,000 Aboriginal and Torres Strait Islander people. This figure exceeds the ABS 1996 Census estimate of the total Aboriginal and Torres Strait Islander population. While undercounting of the Aboriginal population at Census time is well recognised, ACCH services are likely to have reported overlapping population boundaries to define their activity. It should not be concluded that the majority of Aboriginal and Torres Strait Islander people have access to ACCHSs.

The total staffing for all the services funded through the Department of Health and Aged Care and State/Territory governments was less than 1,500. This does not count some staff funded from elsewhere, such as Medicare-funded doctors, but the numbers of these are small. Available data indicates that there are fewer than 200 doctors working in ACCHSs across Australia. In view of the vastly greater health care needs of Aboriginal people, whose morbidity rates are generally two to three times that of the population as a whole, it is clear that 1,500 health care staff, including 200 doctors, cannot meet the comprehensive primary health care needs of all Aboriginal people.

In fact, many areas with significant Aboriginal populations do not have ACCHSs, and even where there are services they are not currently resourced at a level to enable them to provide comprehensive care to the whole Aboriginal community in their catchment areas. For example, the whole of the greater Sydney area has only three ACCHSs—in Redfern, Mt Druitt and Campbelltown. Many Aboriginal people in the greater Sydney area cannot physically access these three services, nor is there capacity to provide for this need.

In 1997–98, 106 ACCH services provided 860,000 episodes of health care to their clients. Acute and chronic disease care was supplemented with coordinated preventive health care interventions, health promotion, mass screening, advocacy and transport services.

Recall and reminder functions feature as a prominent activity of ACCHS services. Ninety-three percent of all services offered clinical reminders to Aboriginal and Torres Strait Islander clients.
The vast majority of Commonwealth-funded Aboriginal primary health care services provided transport services to Aboriginal clients. Nearly all provided Aboriginal staff to act as advocates and/or interpreters, and most services arranged for referred Aboriginal clients who were being transported long distances by air or bus to be picked up on outward and return journeys if required.

The majority of services also provided letters of support for clients who needed public housing or who faced eviction; emergency food aid for families in need; accommodation at a safe house or women’s shelter for victims of family violence; free medications and/or meeting the patient co-payment at the local pharmacy; and retrieval of the bodies of those who died away from their communities.

The vast majority of employees within ACCHSs are Aboriginal. In 1997–98, ACCHSs reported that around 71 per cent of employees in ACCHSs were Aboriginal or Torres Strait Islanders. Nearly all of these were non-medical staff. They included managers and administrative staff, large numbers of Aboriginal health workers, some nursing staff, a small number of other allied health workers, and support staff such as drivers and cleaners.

An independent survey in 1995 reported that 63.5 per cent of state health services did not employ Aboriginal people. ACCHSs also offered significantly more in-house training to their Indigenous staff, who were also more likely to be enrolled in formal training than State health Indigenous staff (Sibthorpe et al 1998). Higher levels of Aboriginal employment in the government health sector may lead to improvements in the expression of cultural sensitivity.

Ultimately, discrete service level descriptors do not capture the complexities of holistic service delivery in ACCHSs. This can be explained by the fact that services are provided within the framework of Aboriginal culture and, while Aboriginal languages do accommodate the complex inter-related constructs involved, Western languages cannot and nor can the relevant Aboriginal constructs be translated.

### 3.12 Health priorities and population health

Mainstream general practice has not fully explored the ‘exceptional potential’ in every GP consultation for significant population health outcomes. GPs require a structure that will encourage a shift in the clinical paradigm so that they are encouraged, remunerated and supported to put all levels of prevention and health promotion into practice. Health promotion is not merely a process of client enabling. The health sector has a responsibility to implement an integrated approach that reorients service delivery beyond the mere provision of curative care (Ottawa Charter for Health Promotion 1986).

Many GPs working in ACCHSs and other Aboriginal health services are already undertaking considerable population health work but current remuneration structures on the Medicare Benefits Schedule (MBS) do not reward such work, though the new items introduced into the MBS in November 1999 for Enhanced Primary Care should go some way to addressing this. Insufficient training, human resources, clinic infrastructure, adequate time as well as remuneration are all issues that need to be addressed to enhance the GP role in population health. Remuneration of GP population health activities must be seen to strengthen the primary health care sector, not to reward efforts away from this activity.
Priority health problems were canvassed with Aboriginal Community Controlled Health Services when the National Aboriginal Health Strategy was being reviewed in 1994 (National Aboriginal Health Strategy Evaluation Committee 1994). Two broad areas were identified as priority health problems—medical and socioeconomic problems. These are shown in Box 3.05 in no particular order.

Often underestimated is the effect of diseases that are characteristically seen in underdeveloped nations, such as endemic skin infections, rheumatic fever, leprosy and trachoma. These diseases still occur in Australia and almost exclusively affect Aboriginal people and Torres Strait Islanders.

The findings of the first round of ACCH service activity reporting indicated that most large services had an organised approach that maximised clinic contacts for the delivery of preventive health care during the period 1998–99. Most ACCH services had opportunistic systems operating to deliver preventive checks to clients with diabetes; monitor follow-up for children highlighted as being at-risk; monitor antenatal care; and offer opportunistic Pap smears and follow-up those who were overdue. This was despite only 42 per cent of larger and 12 per cent of smaller services having a commercial computer-based system for prompting opportunistic health checks.

Organised approaches depend on locally and internally developed protocols for preventive health care. Around 50 per cent of larger ACCH services reported that they used internally developed standard treatment guidelines or protocols.
Around 92 per cent of larger ACCH services indicated that they distributed condoms to their Aboriginal communities. Nearly 70 per cent of large ACCH services reported that expanded STD contact-tracing was routinely undertaken (eg involving negotiating who will approach contacts, obtaining contact sexual histories, offering screening tests and treatment, education and further tracing if the contact is positive).

Immunisation activity was a key priority for ACCH services. Of larger services, 67 per cent operated their own childhood immunisation register, whilst 50 per cent of smaller services also operated a local register.

In contrast, regional State health units could not report the immunisation status of Aboriginal children in 1996 prior to the Australian Childhood Immunisation Register. When ACCH services were also surveyed in 1996, 69 per cent could provide immunisation data on children 0–2 years and could define Aboriginality (Wronski et al 1996).

In order to coordinate the immunisation coverage of Aboriginal children, 72 per cent of smaller and 61 per cent of larger ACCH services reported a cooperative arrangement for childhood immunisation with other health care providers. Eighty-four per cent of larger ACCH services reported a cooperative relationship for other public health activity with regional State/Territory public health units.

In 1998–99, 86 per cent of larger ACCH services and 62 per cent of smaller services reported that pneumococcal vaccine was routinely organised for the at-risk Aboriginal and Torres Strait Islander population. Influenza vaccine was routinely organised by 92 per cent of larger services and 74 per cent of smaller services.

The extent of GP participation in national public health strategies or ability and willingness to participate is currently unknown. General practitioner involvement in such vertical population programs and in the horizontal integration of population programs into the clinical context needs to be made more transparent for health planning purposes.

Improving the transparency of this core activity will influence standards, benchmarks, funding formulas and assessment of infrastructure needs as they relate to public health activities provided by primary health care services and GPs. This is particularly important in ensuring that population health activity will be relevant to the health of Aboriginal people.

National population strategies are often vertical and disease-focused and the challenge for primary health care is to refocus the body-part programs towards implementation in a comprehensive and primary health care context. This is not possible to do if the funding structures of national strategies, for example, are linked to specific disease or body-part programs. The manner in which funding programs are/have been targeted undermines the horizontal integration that is necessary to ensure program relevance, particularly to Aboriginal and Torres Strait Islander communities.

However, national strategy development is now under review. National top-level approaches have been increasingly focused on a health promotion approach which brings the range of strategy issues together, possibly using a primary prevention strategy as a way of clustering strategy issues. This emphasises the importance of a primary health care approach to population control programs.

One of the many recommendations arising from a Commonwealth meeting on 23 March 1999 as part of the National Public Health Partnership (NPHP) effort to improve coordination of national public health strategies was that ‘where national strategies are funded, their funding arrangements
and frameworks need to be sufficiently flexible to enable horizontal integration at the service delivery level’. Furthermore, ‘individual strategies cannot make a health impact unless the core issue of an adequate, basic and sustained local service delivery infrastructure and capacity is in place’ (DHAC 1999).

Population health activities must be evidence-based. Health care decisions, programs and interventions should be made explicit to ensure that processes are recognized as best practice. This ensures that:

- health professional decision-making will lead to better health outcomes; and
- preferred health investments are made (because the direction of effort to one alternative means that another is denied).

Explicit decision-making requires that there be links to the research evidence and use of systematic review methodology in searching, appraising and synthesising the evidence. Cogent decision-making is required to define optimal population-based interventions. This avoids the alternative of ‘opinion-based’ decisions influenced by historical, political or ideological values and/or resources.

Interventions in the Aboriginal population need to be defined by considering the application of the research evidence in circumstances where there is an increased absolute risk for disease. The design and delivery of programs needs to be culturally appropriate and be part of a community development process.

“Generalists have tended to take a back-seat role while the health dollars went to the ‘body-part’ with the best argument. In Aboriginal health particularly, the ‘organized’ approach, not the ‘organ’ approach to health care is needed.”

Puggy Hunter

Systematic Review of existing evidence and primary care guidelines in the management of NIDDM in Aboriginal and Torres Strait Islander Populations1998. AGPS.

### 3.13 Education and training

In the context of a holistic concept of health, education is an important health issue for Aboriginal communities. In Aboriginal communities, as in the wider community, educational status is strongly linked to employment status, income, and health status. Secondary and tertiary education are particularly important in maximising opportunities in life.

Low levels of secondary and tertiary education are a major contributing factor to the poor health status of many Aboriginal people. Those with a higher level of education are likely to have better employment chances and higher incomes. They are also generally able to make better life choices, have a better understanding of their basic rights, and have the confidence to access services.

The 1996 Census illustrated the importance of enhancing training opportunities for Aboriginal children. Compared with 1986, fewer Aboriginal children left school under the age of 14 years or at 15 years of age. However, in 1996, in every State except South Australia, the proportion of Aboriginal children leaving school at 14 years of age and under was higher than that for the total population.
In addition, more Aboriginal children left school in 1996 at 16 years and over than in the 10 years previously. This reflected trends in the total population, but the rate of change for the Indigenous population was higher (McLennan 1999). Whilst this is an encouraging trend there remains much work to be done before Aboriginal educational needs are fully addressed and the gap between Aboriginal and non-Aboriginal educational standards is eliminated.

The failures of the past are well documented. In 1986, in the NT, nearly 20 per cent of Aboriginal people had never attended school. In 1996, in the NT, 8.2 per cent of Aboriginal people had never attended school, compared with 0.73 per cent of the total Australian population.

The legacy of poor educational opportunities for Aboriginal people has required the development of pathways to link whatever training Aboriginal people have with a means for further education. Such bridging courses are important in enhancing educational improvement, and this is well exemplified by certificate level training for Aboriginal health workers being linked to a route for tertiary level qualifications. Promoting such bridging courses will overcome a key obstacle for Aboriginal people—the lack of linkage to progress their skills.

It is critical that efforts are concentrated on increasing the proportion of Aboriginal children that firstly complete primary and secondary schooling but also that clearly meet the standards of literacy and numeracy associated with achieving those education levels.

Clearly, this will require a concerted effort to prevent and treat the chronic deafness currently affecting thousands of Aboriginal children due to chronic suppurative otitis media (Couzos et al 1998).

**Aboriginal health workers**

The National Aboriginal Health Strategy (1989) has recognised the central role of the Aboriginal Health Worker (AHW) program in achieving better health outcomes for Aboriginal communities (Box 3.06).

The roles of AHWs vary, but may include health education, liaison, referrals, training, and clinical work. In remote and rural areas in particular, there are frequently no other health care professionals available on a regular ongoing basis, and AHWs have an important clinical care role.

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Puggy Hunter, Chair, NACCHO, National Rural Health Conference, Adelaide, March 1999

We have university courses …[offering] bridging courses to make education look good and I don’t say that you should discredit this process but the reality is the universities need to say to the high schools—hey, hold on a minute, these kids you’re sending me are not up to scratch. Then the high schools need to get up and say to the primary schools that these kids you’re sending me are not up to scratch. And the primary schools needs to break up and make the point that these kids that they’re producing are not up to scratch.

The sad part for me is that I went through a system that, just because I was big, I went up to the next class—never because I could read or write properly and I think today how sad it is that they’re still producing kids like me after all those years and I think where’s all this going? So as far as I’m concerned, the education system is a key element of actually picking up Aboriginal health and non-Aboriginal health I can tell you and it’s just not happening.

Puggy Hunter, Chair, NACCHO, National Rural Health Conference, Adelaide, March 1999

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aboriginal community controlled health services
Aboriginal doctors

Aboriginal participation in the medical workforce is currently very limited. This is largely due to the social, economic, geographical and educational disadvantage that many Aboriginal people experience, which pose barriers to their entry into, and success in, medical training courses. There are now around 30 Aboriginal doctors in Australia with another 60 currently in training.

There are enormous potential advantages in increasing the numbers of Aboriginal doctors to work in Aboriginal health service delivery. Where Aboriginal doctors have grown up in Aboriginal communities, they have had first-hand experience of the social, cultural and economic factors involved in Aboriginal health, which helps to equip them to provide appropriate treatment in a sensitive way.

Aboriginal doctors are also often role models for younger Aboriginal people. Strong positive measures need to be undertaken to increase the number of Aboriginal students entering and graduating from medical schools—as recommended by the Report of the Ministerial Review of General Practice Training in 1998. Adequate income support, through Abstudy, is a vital prerequisite to increasing the number of Aboriginal doctors in Australia.

Training curricula

Aboriginal Community Controlled Health Services have contributed greatly towards the development of appropriate and relevant training curricula and training opportunities for students across the whole education continuum for the improvement of Aboriginal health.

In particular, there has been a focus on cultural safety and organised and integrated population approaches within a primary health care context. The Royal Australian College of General Practitioners (RACGP) Training Program includes an Aboriginal health curriculum (basic and advanced skills) with a population focus that has been developed in partnership with NACCHO. This is a positive model of the value of collaborative endeavours, and similar collaboration needs to be developed for educating GPs at all levels in Aboriginal health matters. Such activities are in progress as NACCHO chairs the Indigenous Health Subgroup of the General Practice Partnership Advisory Council and the General Practice Education and Training Council (GPETC).

The Australian College of Rural and Remote Medicine (ACRRM) has also developed a curriculum for GP training in Indigenous Health, derived from the RACGP program.

Through the GPETC, NACCHO has recommended that medical education and training must foster a primary health care approach to professional practice. It should adopt the principles of the periodic health examination, community control and participation, health awareness, health promotion and health education, and a focus on the well-being of the whole community rather than the medical management of the individual patient’s presenting problems.

Box 3.06 Importance of Aboriginal health workers

The National Aboriginal Health Strategy (1989) states that: The AHW program is recognised throughout Aboriginal communities as one of the most important factors in efforts to improve Aboriginal health status. One of the major factors in the success enjoyed by the AHWs is the fact that they have a close association with and an intimate knowledge of the communities they serve. This knowledge and association arises from the fact that they are generally members of that community who have been selected by their peers to undertake the training program and ultimately to work as an AHW in that community.
NACCHO is also part of the national consortium to develop the Postgraduate Public Health Program for Clinicians (led by the Mt Isa Centre et al). This important initiative will aim to enhance GP training in population health.

**Divisions**

There are many opportunities for existing divisions of general practice to make a contribution to Aboriginal population health. Divisions which receive weighted funding for the Aboriginal and Torres Strait Islander population in their area should use this funding effectively, and it is also important that specific projects in Aboriginal health undertaken by Divisions are well targeted.

While many divisional proposals may be well intentioned, a sound basis in the health issues and needs of Aboriginal communities will ensure programs are well targeted and do more good than harm. Given the limited resources available to address the enormous problems in Aboriginal health, it is vital that the available funding is properly targeted to population programs and projects that will be most effective.

For many reasons, including the already advanced population role of staff within ACCHSs, all proposals for programs and projects in Aboriginal health must be developed in consultation and collaboration with the Aboriginal community and their health organisations.

**Workforce issues**

In July 1998 the Commonwealth Government, through the Office for Aboriginal and Torres Strait Islander Health, commissioned a consortium headed by NACCHO to undertake a study of the requirements for and supply of the health workforce for Aboriginal and Torres Strait Islanders. It is expected that education and training will be one of the major issues to be identified, particularly in relation to increasing Indigenous participation in the health workforce. The study is expected to be completed in June/July 2000.

### 3.14 Research and data issues

Ten years ago, the National Aboriginal Health Strategy (NAHS 1989) described issues still relevant to health research involving Aboriginal people.

> Concern has always been expressed by Aboriginal people at the way researchers, be they anthropologists or medical scientists, are continuing to invade the privacy of Aboriginal communities in order to conduct research which appears largely designed to serve their own academic, political or professional needs... This research is most often undertaken with little or no proper consultation with communities... [they] have little or no control … and rarely provides any benefit to Aboriginal participants and is in fact often used in a detrimental manner by the media and governments.

The central issue of Aboriginal self-determination and partnership in matters of health applies strongly to the conception and conduct of Aboriginal health research. The National Health and Medical Research Council (NHMRC), since the release in 1991 of the interim *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*, has promoted the ethical conduct of research involving Aboriginal populations. Much of the foundation for these ethical guidelines was informed by NAIHO (the precursor to NACCHO) as a result of a national workshop in 1986.

Whilst these guidelines will be revised in 2000, researchers continue to be ignorant of the historical context of research conducted involving Aboriginal people and the need to adhere to ethical recommendations.
Unlike research involving animals, there is no legislative requirement that these research guidelines be adhered to. Researchers are expected to adhere to NHMRC guidelines and are under penalty of the withdrawal of NHMRC funding if researchers breach them. However, ‘There are no other penalties for researchers who breach ethical guidelines, unless a subject of research who suffers damage brings a civil action’ (Kerridge et al 1998).

The prospect of a civil action is not enough to ensure that guidelines are adhered to when the research adversely impacts on the population as a whole when compared with a single client. Poorly researched aggregated and unidentified data can still have an adverse effect on the Aboriginal population. Furthermore, ‘it is not and is unlikely to be known how many private organisations do not comply with the NHMRC guidelines’ (Kerridge et al 1998; p.369).

Clearly, unless these issues are addressed through a process of legislative reform, there will be serious barriers to the confidence with which Aboriginal people can participate in research as well as Commonwealth public health programs such as health registers when there is no certainty that privacy guidelines on the use of data pertaining to them will be adhered to.

The Aboriginal Health and Medical Research Council (AHMRC) Ethics Committee in NSW, has explained how:

... the harms which have been perpetrated upon Aboriginal people in the name of research have not yet evaporated and numerous research topics still reflect absolute indifference to the needs of the Aboriginal community and betray that certain applicants are oblivious of indispensable ethical requirements so necessary for positive outcomes in research into Aboriginal health (AHRC 1998; Submission p.2).

Institutional Ethics Committees (IECs) need to be cognisant of the significance of Aboriginal community approval for research.

The Aboriginal community itself…is the determining body in matters relating to Aboriginal health information rather than any national, State or Territory, or IEC…The underlying principle… is the inviolate and unfettered nature of the Aboriginal community itself to ultimately consider research into Aboriginal health (AHRC 1998; Guidelines p.10).

**Strategic research priority setting**

Whilst investigator-driven research is important, strategic and priority-driven research are particularly important in Aboriginal health. Strategic research has the potential to improve population health and the effectiveness, efficiency and equity of health care delivery, according to the *Health and Medical Research Strategic Review* (Wills 1999).

Although the ‘conception’ of research questions was highlighted by the NAHS in 1989, it is only in the last few years that emphasis has turned to who asks the research questions.

Every approach to inquiry research is based on a set of assumptions. The framework, the cultural, and philosophical value system within which the research is conceived, designed and conducted... reflects the values of the dominant culture...Aboriginal research, rather than reflecting the fancy of the individual researcher, needs to become problem oriented and Aboriginal people should be defining the problems ... The community should be involved in framing the questions so that the research is relevant to their needs.

That is why recent strategic research approaches have examined ways in which the Aboriginal community can define research priorities in conjunction with a comprehensive analysis of relevant information.
A priority setting process for strategic Aboriginal health research is supported by the NHMRC with input from NACCHO, through a subgroup of the Strategic Research Development Committee—the Research Agenda Working Group (RAWG).

In meeting the objective of delivering holistic and culturally appropriate health and related services to the Aboriginal community, NACCHO supports:

- the development of research into specific diseases affecting Aboriginal people;
- the development of research in epidemiology and bio-statistics to equip Aboriginal communities to evaluate, monitor and address specific diseases and health procedures directly affecting Aboriginal people;
- assessment of the particular and overall health needs of the Aboriginal community by means of research, data analysis, surveys, performance indicators and other appropriate ways; and
- the representation and advocacy for constituent Aboriginal communities in health research and data analyses and related socioeconomic factors and ethical matters which affect the well-being of Aboriginal people.

A summary of principles to guide priority setting in research affecting the health of Aboriginal people is shown in Box 3.07.

**Box 3.07 A guide to priority-setting research in Aboriginal health**

- Aboriginal health research should focus on improving Aboriginal health outcomes.
- Research should lead to sustainable health outcomes and be transferable.
- Aboriginal health research should involve a partnership with the Aboriginal community and their peak organisations.
- Research should focus on areas of public health importance for Aboriginal people.
- Interventional rather than observational studies should be emphasised.
- Research should be directed to identified gaps in knowledge in relation to the disease, treatment and structural impediments to treatment (health system issues).
- Research should assist with evidence-based decision making at all levels of health care delivery.
- ‘Primary health care’ relevance should be a major influence on research questions.
- Commercial interests should not be the driving force for Aboriginal health research as this may redirect important research resources towards inappropriate health interventions.
- Appropriate health interventions are those that are relevant to the Aboriginal community and to primary health care, are sustainable, address socioeconomic antecedents to disease, and consider the impact of co-morbidity, compliance and family or cultural issues that may affect choices in optimal health strategies.

**Community-driven research**

Aboriginal communities and their health services need to be enabled to conduct research relevant to their health needs. This was recommended by the NAHS in 1989 so that health services were provided with the financial resources to undertake specific priority research projects (NAHS Working Party 1998; p.210).
This highlights an often-held misconception that Aboriginal communities oppose all forms of research. A major shift in thinking for many researchers who currently and in the future wish to partake in research involving Aboriginal people is needed. The view that Aboriginal community groups have of research is not the problem. The major challenge is to alter the way researchers view the role of Aboriginal community groups.

NACCHO has responded to many research guidelines that have emerged from a range of sectors, including the NHMRC (NACCHO 20 Nov 1998; NACCHO 28 Jul 1998). NACCHO has also developed its own research guidelines (NACCHO Data Protocols) as a product of the Framework Agreements (AHRC Ltd 1997).

NACCHO affiliates have also developed State-based guidelines that relate to information sharing with State health departments (AHRC Ltd & NSW Health 1998). Others have guidelines in relation to specific projects (Qld Aboriginal and Islander Health Forum 1994).

NACCHO affiliates have official relations with a number of research institutions. NACCHO has a Memorandum of Understanding with James Cook University in Townsville, North Queensland. AMSANT is a member of the Cooperative Research Centre in the NT. WAACCHO is a part of the Indigenous Maternal and Child Health Collaborative Research Network in WA.

### Collection of Aboriginal data

The concept of ‘one’s ownership over one’s body or information of one’s self’ (privacy) (Kerridge et al 1998) is particularly important to Aboriginal people. Self-determination includes the right to maintain control over health matters and what personal information others have about them.

The use of Aboriginal health data is regulated by a number of instruments and documents. The NACCHO position is documented in the *National Aboriginal and Torres Strait Islander Health Protocols for the Routine Collection of Standardised Data on Aboriginal and Torres Strait Islander Health (1997)* [Protocols].

The partners to the Aboriginal and Torres Strait Islander Framework Agreements in each State and Territory agreed to the national development of the above mentioned data protocols for the routine collection of standardised data on Aboriginal and Torres Strait Islander health.

These protocols recognised Aboriginal and Torres Strait Islander ownership of Aboriginal data and clarified the use and potential use of all data. In particular, they were developed to clarify the use of de-identified data as such data may readily become ‘identified data’ when Aboriginality is revealed in conjunction with other data that identifies location.

Whilst the protocols provide all necessary information for use of Aboriginal health data, some States have entered into agreements, or have jointly developed health information guidelines, to ensure that correct procedures are carried out when dealing with Aboriginal health data. In most cases this refers to data collected within the respective mainstream health sector, which also needs to reflect the NACCHO data protocols.

For example, in one such State document the obtaining of consent is essential where:

- Aboriginality is a key determinant;
- data collection is explicitly directed at Aboriginal peoples;
- Aboriginal peoples as a group are to be examined in the results;
- the information has an impact on one or more Aboriginal communities; and
- Aboriginal health funds are a source of funding.
It is recommended that mechanisms be established (if they have not already been established), through the existing Framework Agreement partnership process at the State/Territory Forums, for dealing with State/Territory health department (and other agencies) requests for de-identified Aboriginal data from any State or Commonwealth register. The mechanisms are to comply with the NACCHO data protocols.

All parties recognised the importance of Aboriginal ownership of health data and the need to:

... establish culturally sensitive and ethical privacy and confidentiality protocols for the routine collection of standardised data on Aboriginal and Torres Strait Islander health. These protocols are to recognise Aboriginal and Torres Strait Islander ownership of the data including clarity about the use of and potential use of the data (Framework Agreements 1996).
3.15 References

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