

**Health Care Access for Aboriginal and Torres Strait
Islander People Living in Urban Areas, and Related
Research Issues: A Review of the Literature**

Margaret Scrimgeour • David Scrimgeour

Cooperative Research Centre for
Aboriginal Health

Discussion Paper Series: No. 5

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Commissioned by the Cooperative Research Centre for Aboriginal Health

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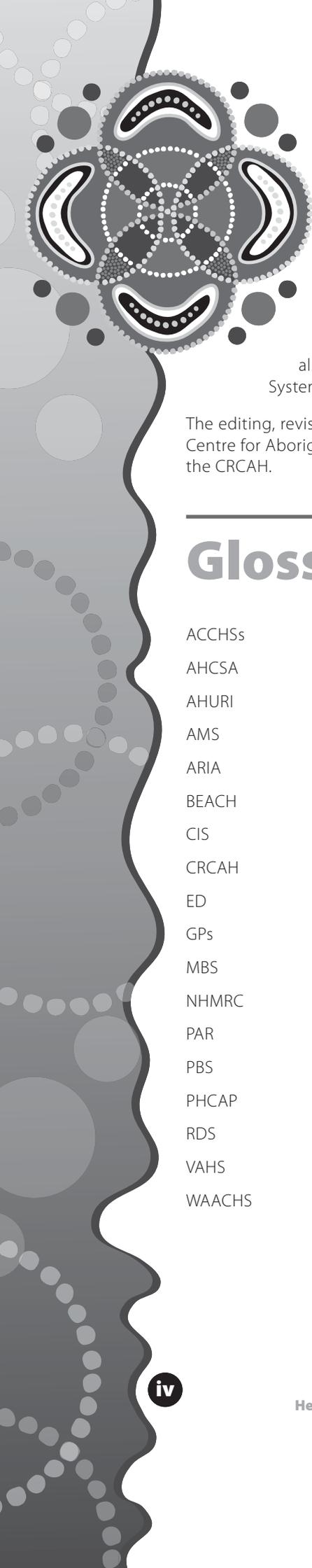
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Glossary

ACCHSs	Aboriginal Community Controlled Health Services
AHCSA	Aboriginal Health Council of South Australia
AHURI	Australian Housing and Urban Research Institute
AMS	Aboriginal Medical Service
ARIA	Accessibility/Remoteness Index of Australia
BEACH	Bettering the Evaluation and Care of Health
CIS	Centre for Independent Studies
CRCAH	Cooperative Research Centre for Aboriginal Health
ED	Emergency Department
GPs	General Practitioners
MBS	Medicare Benefits Scheme
NHMRC	National Health and Medical Research Council
PAR	Participatory Action Research
PBS	Pharmaceutical Benefits Scheme
PHCAP	Primary Health Care Access Program
RDS	Respondent-driven Sampling
VAHS	Victorian Aboriginal Health Service
WAACHS	Western Australian Aboriginal Child Health Survey

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Executive Summary

It is well recognised that the health status of Australia's Aboriginal and Torres Strait Islander population is much worse than the rest of the Australian population, and it is generally accepted that barriers to health care access contribute to this poor health status. There is only limited information on the specific health status and health needs of Aboriginal and Torres Strait Islander people living in urban areas, and the extent to which barriers to health care are a significant problem in this population remains largely unresolved.

In the statistical and demographic literature there are different definitions of 'urban', which can lead to contradictory data on the number of Aboriginal and Torres Strait Islander people living in urban areas. For the purpose of this review, we define 'Aboriginal and Torres Strait Islander people living in urban areas' as *Aboriginal and Torres Strait Islander people residing in major towns and cities, where the Aboriginal and Torres Strait Islander population is a minority within a larger total population, and where 'mainstream' (i.e. not Indigenous-specific) health services exist either as the only available health services, or as an alternative to Indigenous-specific services such as Aboriginal Community Controlled Health Services (ACCHSs)*. Using this definition, it is clear that (despite the fact that a higher proportion of Aboriginal and Torres Strait Islander people live in remote areas than non-Indigenous people) a significant majority of the total population of Aboriginal and Torres Strait Islander people live in urban areas.

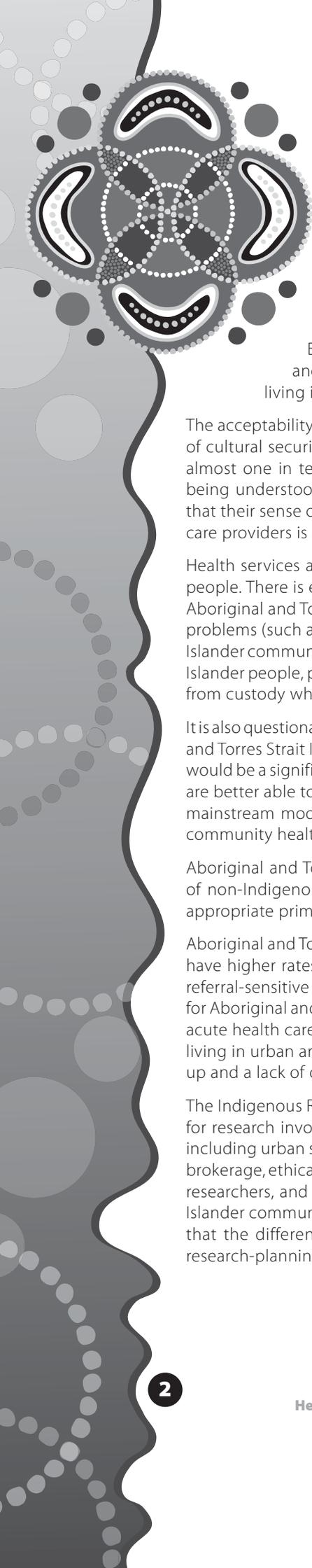
Aboriginal and Torres Strait Islander people living in urban areas are a heterogeneous and mobile population, with frequent movement between urban and other areas, and within urban areas. Aboriginal and Torres Strait Islander people within urban areas have been described as an 'invisible minority' and are exposed to discrimination and to an attitude that they are not 'real Aborigines'. Aboriginal and Torres Strait Islander people living in urban areas have identified strengths deriving from family and community networks and community organisations (including ACCHSs).

Mortality rates for Aboriginal and Torres Strait Islander people are much worse than for non-Indigenous people; this applies across all residential zones. For non-Indigenous people, there is a steady gradient in mortality rates from lower mortality rates in the most urbanised areas to higher mortality rates in the most remote areas. For Aboriginal and Torres Strait Islander people, while there is a similar overall trend, mortality rates are higher in metropolitan urban areas than in 'inner regional' areas, and mortality rates are lower in 'very remote' areas compared to 'remote' areas. This suggests that there are factors affecting Aboriginal and Torres Strait Islander people in the most urban areas that are detrimental to life expectancy, and there are factors affecting Aboriginal and Torres Strait Islander people in the most remote areas that are beneficial to life expectancy.

Morbidity rates for Aboriginal and Torres Strait Islander people are also much worse than for non-Indigenous people across all residential zones. There is insufficient data to enable direct comparisons of morbidity for Aboriginal and Torres Strait Islander people living in different locations in Australia. However, there is some evidence to suggest that morbidity may be worse in remote communities, but that there are differences in disease patterns between remote and urban areas, with some diseases being more common in the urban Aboriginal and Torres Strait Islander population. It is likely that the mortality pattern reflects an underlying morbidity pattern, with some factors in the most urbanised areas that are detrimental to health, and some factors in the most remote communities that are beneficial to health.

Recent government policies are likely to accelerate a trend of migration to urban areas. This trend is being encouraged by market-fundamentalist think tanks and organisations. Recent government policies have shifted from support for self-determination and the establishment of Indigenous-specific services to an expectation that Aboriginal and Torres Strait Islander people, especially in urban areas, will access mainstream services (including health services).

ACCHSs were established initially in urban areas to overcome the failure of mainstream services to address Aboriginal and Torres Strait Islander health needs. Despite evidence of an increasing urban Aboriginal and Torres Strait Islander population, there has not been an expansion in the number of urban ACCHSs in recent years.



Recent government initiatives to improve the access of urban Aboriginal and Torres Strait Islander people to health care include reforms to the Medicare Benefits Scheme to make it accessible to Aboriginal and Torres Strait Islander people; reforms to the Primary Health Care Access Program; and the recently announced Urban Brokerage Program. However, expenditure on health services for these people is not only less than for their rural and remote counterparts, but also less than for urban non-Indigenous people. There is evidence that urban Aboriginal and Torres Strait Islander people are less satisfied than remote Aboriginal and Torres Strait Islander people with their access to health care.

Barriers to health care can be classified as problems of availability, affordability, acceptability and appropriateness. All these barriers are relevant for Aboriginal and Torres Strait Islander people living in urban areas, but the acceptability and appropriateness of services are particularly relevant.

The acceptability of health services to urban Aboriginal and Torres Strait Islander people is related to the notion of cultural security. The fact that health services are not always culturally secure is borne out by the fact that almost one in ten urban Aboriginal and Torres Strait Islander people report difficulties in understanding or being understood by service providers. Also, older urban Aboriginal and Torres Strait Islander people report that their sense of shame about their health problems and the lack of success in following the advice of health care providers is a major barrier to accessing health services.

Health services also should be appropriate to the health needs of urban Aboriginal and Torres Strait Islander people. There is evidence that mainstream health services do not adequately address the complexity of many Aboriginal and Torres Strait Islander people's health problems, and do not adequately address particular health problems (such as mental health and addiction problems) that are common within Aboriginal and Torres Strait Islander communities. There are also particular sub-populations, including: 'homeless' Aboriginal and Torres Strait Islander people, people visiting from remote communities, youth, and people currently in or recently discharged from custody who have particular problems of health care access.

It is also questionable whether fee-for-service general practice that is reliant on income from bulk-billing Aboriginal and Torres Strait Islander people would be financially sustainable. Introducing co-payments, on the other hand, would be a significant financial barrier to accessing health care. ACCHSs, with salaried general practitioners (GPs), are better able to address the health care needs of urban Aboriginal and Torres Strait Islander people. Another mainstream model of health care provision suitable for urban Aboriginal and Torres Strait Islander people is community health services employing salaried GPs and Aboriginal Health Workers.

Aboriginal and Torres Strait Islander people attend hospital emergency departments at about twice the rate of non-Indigenous people, but it is not clear whether these attendances are used as a substitute for more appropriate primary care.

Aboriginal and Torres Strait Islander people have higher hospitalisation rates than non-Indigenous people. They have higher rates of hospitalisation for ambulatory-sensitive conditions and lower rates of hospitalisation for referral-sensitive procedures. This suggests that there continues to be problems in access to primary health care for Aboriginal and Torres Strait Islander people. There are problems related to the interface between primary and acute health care sectors; in particular, there can be difficulties for Aboriginal and Torres Strait Islander people living in urban areas (perhaps temporarily) on discharge from hospital, when there may be inadequate follow-up and a lack of continuity in medications.

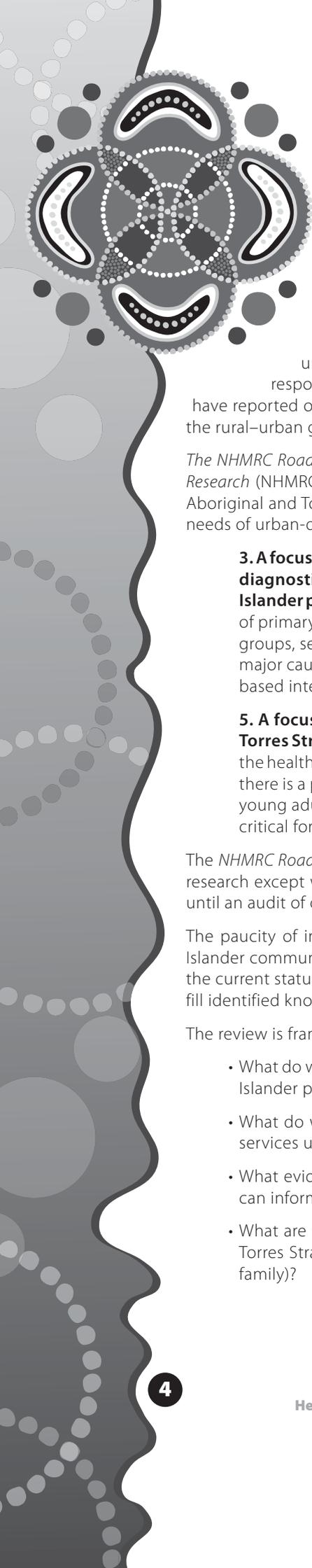
The Indigenous Research Reform Agenda provides a general framework for identifying 'best practice' principles for research involving the health needs of Aboriginal and Torres Strait Islander people in a range of settings, including urban settings. This framework provides a focus on issues including research priority setting, research brokerage, ethical research, collaborative and participatory research methodologies, involvement by Indigenous researchers, and reporting and dissemination. The heterogeneous profile of urban Aboriginal and Torres Strait Islander communities demands that negotiations over research are locally based. This is necessary for ensuring that the different needs and perspectives of urban-based populations are taken into account during the research-planning phase.

ACCHSs are identified in the literature as being well positioned to determine local health research needs and to assist in the brokerage and conduct of related research activity. Research brokerage should be framed by national and local Indigenous research guidelines and protocols, and where it is deemed appropriate research agreements should be developed in consultation between researchers and representatives of local community interests.

Cultural identity issues are likely to arise within urban-based Aboriginal and Torres Strait Islander research, and these issues should be mediated within the context of culturally safe research practices and through the direct involvement of local community representatives and Aboriginal and Torres Strait Islander organisations. The 2003 National Health and Medical Research Council (NHMRC) document *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* provides a comprehensive overview of fundamental Indigenous cultural traditions to guide the development of culturally safe research.

The literature indicates that in urban and remote contexts Aboriginal and Torres Strait Islander researchers have a proven capacity to engender trust, communicate in culturally appropriate ways and make contact with otherwise 'hidden' sub-populations for research purposes. This should provide the necessary impetus for research projects to include planned approaches for the training and inclusion of Indigenous people as necessary members of research teams.

As a 'hidden' and frequently mobile population, Aboriginal and Torres Strait Islander people living in urban areas represent a challenge when it comes to sampling and recruitment for research projects such as those that may shed more light on issues of health care access. Most sampling methods have problems with sampling bias. However, forms of chain-referral sampling, and particularly respondent-driven sampling, are potentially useful methodologies that may overcome some of the difficulties. If the research is conducted in a culturally secure manner, involving Aboriginal and Torres Strait Islander community organisations and researchers, these sampling methodologies have the potential to reach into the various urban Aboriginal and Torres Strait Islander communities.



Introduction

There are identified information gaps about the health status and health service needs of urban-dwelling Aboriginal and Torres Strait Islander people in Australia (Lake 1992; NHMRC RAWG 2002; Craig *et al.* 2005). In an analysis of a decade of Aboriginal health research, Lake (1992) found a predominance of large-scale, descriptive studies and research focusing on remote communities and on children. He noted that few research reports focused on adults, urban populations, common causes of death or disease, or developing or evaluating appropriate responses to the observed differences in health status. Craig *et al.* (2005) observed that few studies have reported on differences in health status between Indigenous people in urban and rural areas, although the rural–urban gradient has been assumed to be similar to that occurring in the non-Indigenous population.

The NHMRC Road Map: A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health through Research (NHMRC RAWG 2002) identified six research themes critical to achieving substantial health gain for Aboriginal and Torres Strait Islander people. Two priority themes (themes 3 and 5) relate directly to the health needs of urban-dwelling Aboriginal and Torres Strait Islander people:

3. A focus on health services research which describes the optimum means of delivering preventive, diagnostic and treatment based health services and interventions to Aboriginal and Torres Strait Islander peoples. This priority theme encompasses research that examines the effectiveness and efficiency of primary health care and related services recognising factors such as geographic location, community groups, service infrastructure, governance and service mix. This theme also involves a focus on specific major causes of death, illness and disability and the application of preventive, diagnostic and treatment based interventions and health services (NHMRC RAWG 2002:9).

5. A focus on engaging with research and action in previously under-researched Aboriginal and Torres Strait Islander populations and communities. Gaps remain in knowledge and understanding of the health issues of some Aboriginal and Torres Strait Islander populations and communities. For example, there is a paucity of information on the needs of urban communities; Torres Strait Islander communities; young adults and the elderly. Priority needs to be given to research that produces data and knowledge critical for health gain in these populations or communities (NHMRC RAWG 2002:12).

The *NHMRC Road Map* adopts the position that descriptive research is less important than intervention-based research except where there are information gaps to be filled, and that it is premature to identify these gaps until an audit of current research has occurred.

The paucity of information about the health status and health needs of urban Aboriginal and Torres Strait Islander communities in Australia has been established. This review of the literature is positioned to report on the current status of research and to provide an information base for the development of targeted research to fill identified knowledge gaps.

The review is framed by four key questions:

- What do we know (and not know) about the patterns of health service use by Aboriginal and Torres Strait Islander people living in urban areas?
- What do we know (and not know) about the pathways into and out of secondary and tertiary health services use by Aboriginal and Torres Strait Islander people living in urban areas?
- What evidence is currently available about methods and approaches to research into these areas that can inform discussions and the design of an effective and culturally safe research project?
- What are some of the methods or approaches that would be appropriate for sampling Aboriginal and Torres Strait Islander people living in urban areas (for example, respondent-driven, network, extended family)?

The review is organised into four main chapters conforming closely to the questions listed above. Each chapter includes a brief conclusion and list of main points.

Chapter 1 helps set the context for consideration of the substantive review questions. Various ways of defining the term 'Aboriginal and Torres Strait Islander people living in urban areas' are investigated and a working definition of the term is suggested. The extent of heterogeneity represented by often-dispersed urban Aboriginal and Torres Strait Islander populations is then investigated. This is followed by an overview of current knowledge about the health of Aboriginal and Torres Strait Islander people living in urban areas.

Chapter 2 considers identified barriers to different levels of health care access by Aboriginal and Torres Strait Islander people living in urban areas. These barriers are broadly classified as problems of availability, affordability, acceptability and appropriateness. We consider the history of access to health services by Aboriginal and Torres Strait Islander people living in urban areas that has led to the contemporary policy environment. We then examine the available literature on access to primary, secondary and tertiary health care for Aboriginal and Torres Strait Islander people living in urban areas. Based on the available knowledge, some areas for further research are also suggested.

Chapter 3 sets out to identify methods and approaches that are consistent with current best practice principles for Indigenous research, particularly for research involving the interests of Indigenous people dwelling in urban areas. Appropriate approaches to research with Aboriginal and Torres Strait Islander people in urban contexts are identified under the main headings of: Cultural safety, cultural competence and cultural respect; Indigenous research reform; Research priority setting; Research brokerage; Diversity and identity; Ethical research guidelines and protocols; Research agreements; Collaborative and participatory research; Indigenous researchers; and Reporting and dissemination.

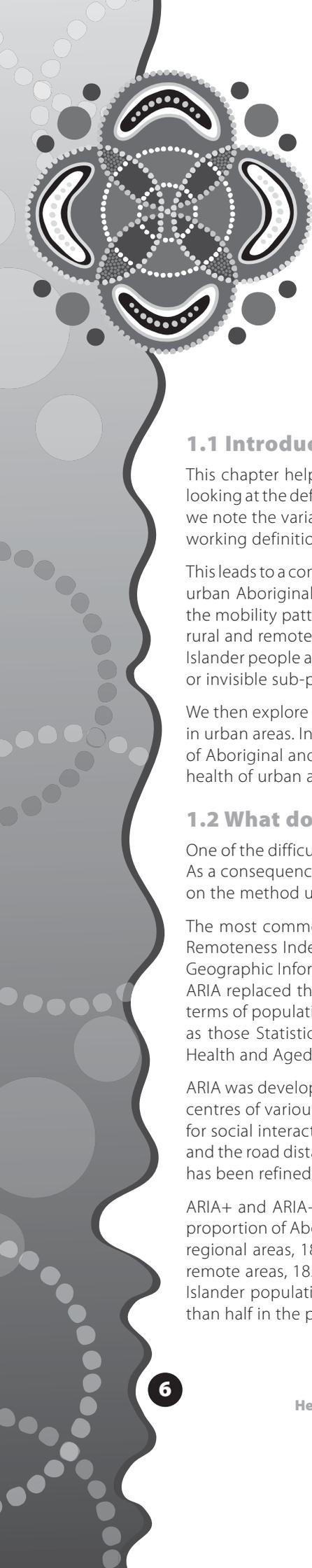
Chapter 4 considers the acknowledged problems associated with identifying a 'community' for the purpose of research involving Aboriginal and Torres Strait Islander people living in large urban areas. It is noted that Aboriginal and Torres Strait Islander communities living in urban contexts are commonly characterised by a heterogeneous network of family relations and organisational memberships geographically dispersed and intermixed; by a constant inflow and outflow between urban areas and other sites, and by frequent changes of address for many who stay within the urban area. The implications of this profile for the identification of appropriate research sampling methods are explored. Some examples of sampling procedures are identified from published literature on the health of urban Aboriginal and Torres Strait Islander people.

Literature search strategy

Published literature was accessed through the following databases: PubMed; Australian Indigenous HealthInfoNet; ATSIROM; AustHealth; Meditext; APAIS-Health; ATSIhealth; Web of Science; and Sociological abstracts. A typical search strategy was: (oceanic ancestry group[mh] OR aborigin* OR indigenous OR native) AND (australia* OR australia[mh]) AND (urban) AND (health OR medic*) AND (access OR utilization). Other key word searches included research, ethics, sampling, cultural safety and cultural security. References in relevant literature led to sourcing of full-text articles. A 'snowballing' technique was often used, with articles being located as 'related articles' from online articles, or as referenced articles.

A second strategy involved a search of available internet resources that yielded approximately forty relevant websites including international and Australian Government departments of health, Aboriginal and Torres Strait Islander research clearinghouses, special university library Aboriginal and Torres Strait Island health bibliographies, national health research organisations, Indigenous research centres, public policy centres and think tanks.

A third strategy involved a survey of unpublished literature including workshop reports, community organisation reports, research protocols or guidelines, and media reports. Useful information was also accessed through informal interviews with health service delivery professionals, librarians, statisticians and public health academics.



1. The Health of Aboriginal and Torres Strait Islander People Living in Urban Areas

1.1 Introduction

This chapter helps set the context for the substantive issues that are the subject of this review. We begin by looking at the definition of the term 'Aboriginal and Torres Strait Islander people living in urban areas'. In particular, we note the variations in methods used for defining 'urban' in statistical and descriptive studies and propose a working definition of the term for application within this current review.

This leads to a consideration of the literature detailing the extent of heterogeneity represented by often-dispersed urban Aboriginal and Torres Strait Islander populations. In particular we detail (1) current literature outlining the mobility patterns of Aboriginal and Torres Strait Islander people within urban settings and between urban, rural and remote settings; (2) the problematic notion of identity as it is applied by Aboriginal and Torres Strait Islander people and by government agencies; and (3) the difficulty in identifying the needs of largely uncounted or invisible sub-populations such as public-place dwellers.

We then explore what is currently known about the health of Aboriginal and Torres Strait Islander people living in urban areas. In particular, we note that although there is much information available about the health status of Aboriginal and Torres Strait Islander people as a whole, this information is not often disaggregated into the health of urban and non-urban Aboriginal and Torres Strait Islander people.

1.2 What do we mean by 'urban'?

One of the difficulties with definitions is that there are different methods for classifying spatial regions as 'urban'. As a consequence, there are sometimes inconsistencies in available statistical and descriptive data, depending on the method used.

The most commonly used classification of area across Australia by remoteness is based on the Accessibility/Remoteness Index of Australia (ARIA), which was developed by the National Centre for Social Applications in Geographic Information Systems (GISCA) as the underlying methodology for the determination of remoteness. ARIA replaced the earlier Rural, Remote and Metropolitan Areas classification, which defined 'metropolitan' in terms of population, 'remote' in terms of both distance to population centres and population density, and 'rural' as those Statistical Local Areas that were neither metropolitan nor remote (Commonwealth Department of Health and Aged Care 2001).

ARIA was developed as an index based on the road distance people must travel from a given location to service centres of various sizes. A service centre is an area where people can access goods, services and opportunities for social interaction. The population size of the service centre serves as a proxy for the availability of services, and the road distance is used as a proxy for the degrees of remoteness from these services (ABS 2006a:120). ARIA has been refined and extended to develop ARIA+ (or ARIA plus) and ARIA++ (or ARIA double-plus).

ARIA+ and ARIA++ have five levels: major cities, inner regional, outer regional, remote and very remote. The proportion of Aboriginal and Torres Strait Islander people living in major cities in 1996 was 30.1 per cent; in inner regional areas, 18.7 per cent; in outer regional areas, 23.2 per cent; in remote areas, 9.1 per cent; and in very remote areas, 18.9 per cent (Glover *et al.* 2004:19). In other words, almost half the Aboriginal and Torres Strait Islander population in 1996 lived in major cities or inner regional areas; this is likely to have become greater than half in the past ten years.

For the extensive Western Australian Aboriginal Child Health Survey (WAACHS) conducted by the Telethon Institute for Child Health Research and Curtin University, a new classification of remoteness, called the Level of Relative Isolation, was designed (Zubrick *et al.* 2004; Zubrick *et al.* 2005). This new classification is based on ARIA++, but has been specifically designed to describe the circumstances of Aboriginal people living in more remote areas of Western Australia. The five Levels of Relative Isolation range from none (the Perth metropolitan area) to low, moderate, high and extreme. In the WAACHS in 2001, one-third (34 per cent) of Western Australian Aboriginal children lived in the Perth metropolitan area; 24 per cent lived in areas of low isolation, 21 per cent lived in areas of moderate isolation, 11 per cent lived in areas of high isolation and 10 per cent lived in areas of extreme isolation.

Another classification applied is the Australian Bureau of Statistics Section of State classification, which reflects the concentration of population. This has four levels: major urban (urban areas with a population of 100,000 or more); other urban (with a population of 1000 to 99,999); bounded locality (rural localities with a population of 200 to 999); and rural balance (the remainder). The proportion of Aboriginal and Torres Strait Islander people in major urban areas in 1996 was 30.3 per cent; in other urban areas, 42.3 per cent; in bounded locality areas, 10.8 per cent; and in rural balance areas, 16.6 per cent (Glover *et al.* 2004:11). In other words, 72.6 per cent of Aboriginal and Torres Strait Islander people lived in urban areas (major or other) in 1996, and this is likely to have increased over the past ten years. The problem with this classification is that large Aboriginal communities in remote areas with over 1000 inhabitants, such as Wadeye in the Northern Territory, get classified as 'other urban'.

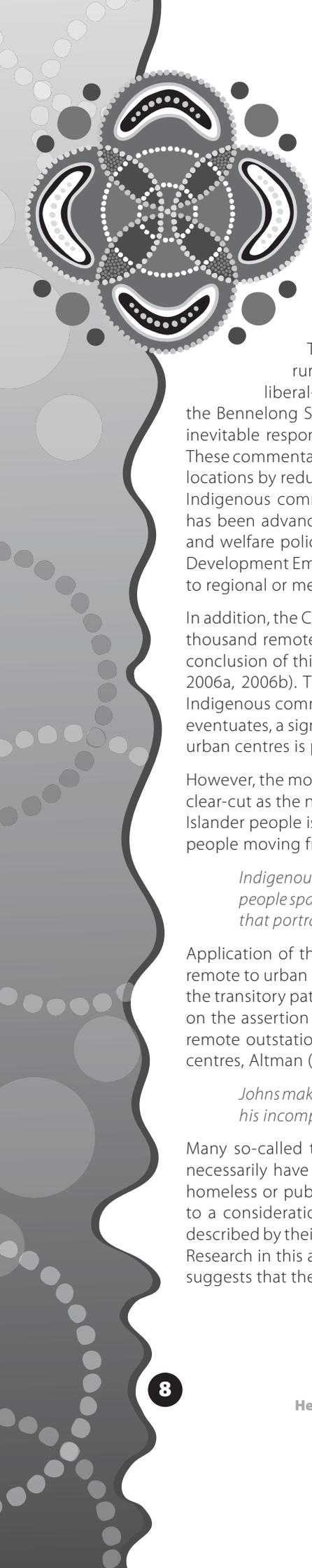
For the purpose of this review, 'Aboriginal and Torres Strait Islander people living in urban areas' refers to Aboriginal and Torres Strait Islander people residing in major towns and cities, where the Aboriginal and Torres Strait Islander population is a minority within a larger total population, and where 'mainstream' (i.e. not Indigenous-specific) health services exist either as the only available health services or as an alternative to Indigenous-specific services such as ACCHSs. This definition is a broad one, as it includes people living in rural towns, but for people living in these situations there are definitely common issues that differ in some ways from the situation of Aboriginal and Torres Strait Islander people living in discrete Aboriginal and Torres Strait Islander communities. As such, we suggest that it is an appropriate definition for a review of the available data on health care access issues for Aboriginal and Torres Strait Islander people living in these situations.

1.3 Who are 'Aboriginal and Torres Strait Islander people living in urban areas'?

A consideration of what is meant by 'Aboriginal and Torres Strait Islander people living in urban areas' raises significant issues such as:

- What constitutes an Aboriginal and Torres Strait Islander urban population for the purpose of research?
- Who should be counted in or out of consideration when considering the health needs of urban-dwelling Aboriginal and Torres Strait Islander people?
- What does it mean to 'dwell' in an urban area?
- How can researchers take account of the largely uncounted but significant Indigenous population that moves between arbitrarily designated demographic and geographic zones?

'Aboriginal and Torres Strait Islander people living in urban areas' does not describe a homogeneous entity. Paul (1998:68) criticises an Australian Medical Association guide on Aboriginal health for medical practitioners that refers to 'the Aboriginal community' rather than communities, suggesting that readers of the guide 'may have an already problematic view of Aboriginal homogeneity reinforced'. Aboriginal and Torres Strait Islander people living in any major urban area include people whose ancestors lived on the land that is now built upon, people whose families moved to the urban centre generations ago (either forcibly or voluntarily), people from rural and remote areas who now spend most of their time in the urban area, and people from rural and remote areas who are visiting the urban area for various reasons and for various lengths of times. Bronwyn Fredericks, an Aboriginal woman who grew up in Brisbane, has stated: 'There is no single urban Aboriginal experience or identity. The experiences are as diverse as the population and include a diversity of experience, need, prospects shaped by gender, education, religion, age and level of human security' (Fredericks 2004:30).



Ross (1996) reported that over the previous thirty years the count of urban Aboriginal and Torres Strait Islander people increased by almost a factor of twelve, in contrast to those living in non-urban areas, which increased by just over one-and-a-half times (a similar magnitude to the increase in both urban and non-urban areas for the total population). This dramatic increase in the population of urban Aboriginal and Torres Strait Islander people is likely to be due to an increase in identification by people of mixed ancestry, but the author suggests that there is likely to have been a contribution from a drift to urban areas by Aboriginal and Torres Strait Islander people from non-urban areas.

The trend involving increased movement by Aboriginal and Torres Strait Islander people from rural and remote areas to urban areas has recently been hailed by commentators from neo-liberal-oriented think tanks and organisations (such as the Centre for Independent Studies (CIS), the Bennelong Society and the Murdoch press) as a desirable shift from an unsustainable lifestyle and as an inevitable response to labour market forces (e.g. Howson 2005; Hughes & Warin 2005; Johns 2006a, 2006b). These commentators have encouraged governments to facilitate the movement of people from remote to urban locations by reducing funding to remote communities. This strategy is recommended on the basis that remote Indigenous communities represent 'policy failures' and are not deserving of ongoing support. This position has been advanced in conjunction with announcements of substantial changes to Indigenous employment and welfare policies. A number of recent federal government initiatives, such as changes to the Community Development Employment Program, are likely to have the effect of forcing people to relocate from remote areas to regional or metropolitan urban areas in search of work.

In addition, the Commonwealth Government has recently ordered an Australia-wide audit of approximately one thousand remote Indigenous communities where there are fewer than one hundred people residing. At the conclusion of this audit, specific communities will be targeted for resettlement or service reduction (Karvelas 2006a, 2006b). This situation represents a potential for driving large-scale outward migration from remote Indigenous communities to urban centres (Howson 2005; Hughes and Warin 2005; Johns 2006a, 2006b). If this eventuates, a significant increase in the number of homeless and itinerant Indigenous people dwelling in major urban centres is predicted.

However, the movement of Aboriginal and Torres Strait Islander people from remote to urban locations is not as clear-cut as the neo-liberal advocates like to present it. Migration to urban areas by Aboriginal and Torres Strait Islander people is accompanied by a high population turnover, with many Aboriginal and Torres Strait Islander people moving from urban areas back to more remote settlements. Taylor (2006:63) has noted that

Indigenous people in the city are not just similar to those in country areas—to a large extent they are the same people spatially displaced at different stages of their lives. This tends to undermine classical models of migration that portray migrants as income maximisers in undifferentiated labour markets.

Application of the term 'out-migration', when applied to the movement of Aboriginal people from rural and remote to urban locations, is disputed by Altman (2006). He argues that 'circular migration' more aptly describes the transitory pattern of Aboriginal migration in and out of rural and remote locations in Australia. Commenting on the assertion by Johns (2006a) that reduced income support payments to Indigenous people residing on remote outstations will force a massive out-migration of Indigenous people from rural and remote to urban centres, Altman (2006:15) responded that:

Johns makes the fundamental mistake of confusing circular migration with labour migration, thus demonstrating his incomprehension of cultural difference and the strength of Indigenous ties to the land that they own.

Many so-called transient Aboriginal people with ongoing links to remote Aboriginal communities do not necessarily have access to accommodation in urban areas, so become classified by government agencies as homeless or public-place dwellers. The issue of Aboriginal and Torres Strait Islander homelessness is relevant to a consideration of the health care needs of Indigenous people residing in urban areas because people described by their status as either homeless or as public-place dweller are most likely to reside in urban locations. Research in this area regularly fails to capture specific population data. However, emerging evidence of trends suggests that the number of homeless Aboriginal and Torres Strait Islander people in urban areas is increasing.

Another factor of significance is that Aboriginal and Torres Strait Islander public-place dwellers often report the motivation to reside in urban areas as being related to accessing services to meet their own health care needs or the need to support family members in hospital for extended periods of time (Maypilama *et al.* 2004; Memmott *et al.* 2004).

Aboriginal and Torres Strait Islander homelessness is considered to be a problem because, in comparison to their mainstream counterparts, a higher proportion of Aboriginal and Torres Strait Islander people are affected (Commonwealth Advisory Committee on Homelessness 2001). Aboriginal and Torres Strait Islander homelessness is experienced not only by individuals, but also commonly by families. The underlying causes and factors are reportedly compounded by Aboriginal and Torres Strait Islander people's poor health and by their financial and social status (Commonwealth Advisory Committee on Homelessness 2001).

Mobility into and out of urban areas by Aboriginal and Torres Strait Islander people is also accompanied by mobility (with frequent changes of address) within urban areas. According to Taylor (2006:64):

Very little is known in a comprehensive way about the scale, direction and pattern of such mobility, or about the characteristics of those involved. The fact is, policy makers who contemplate the effects of temporary mobility on the spatial pattern of demand do so in an information vacuum. The basic policy issue at stake is how to most effectively plan for a population that is frequently mobile. How is the need for services best defined and provided for when individuals often shift their place of residence, even within the same locality? Which population should be employed as the base when considering such issues as ... [the] need for health services?

It is clear that Aboriginal and Torres Strait Islander people living in urban areas represent both a heterogeneous and a mobile population. It is also a population that (compared to Aboriginal and Torres Strait Islander people living in remote areas who are easy to identify) is more dispersed and difficult to identify. This reality presents problems for both service delivery and research in urban contexts. A report of the House of Representatives Standing Committee on Aboriginal Affairs on the needs of urban-dwelling Aboriginal and Torres Strait Islander people recognised these difficulties (House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs 2001:18):

[In urban areas] there may not be a 'community' at all, but a loose network of geographically dispersed family and organisational affiliations not at all obvious to non Aboriginal observers. The needs of those without networks at all often go unnoticed and unmet. The disadvantages of cultural isolation can be just as acute as those of geographic location (Para 2.28).

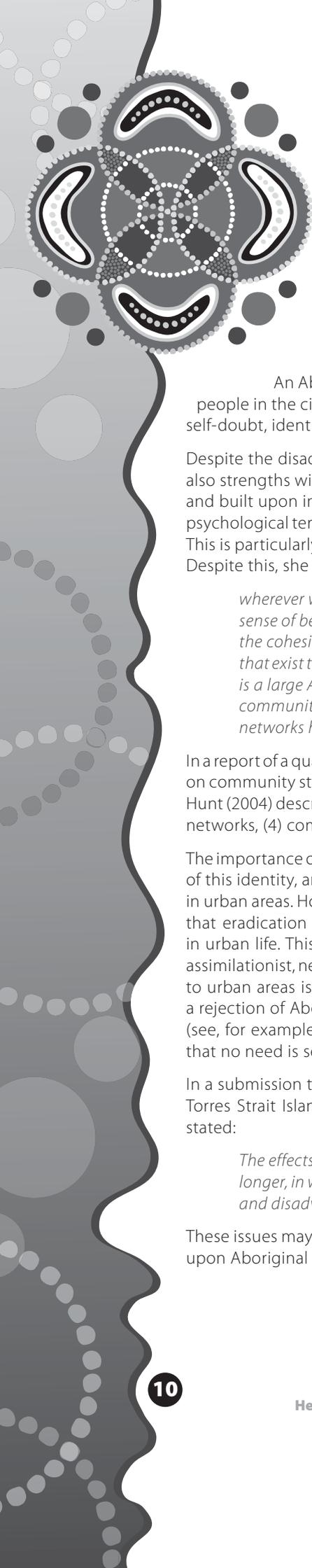
In urban areas with a dispersed Indigenous population, it may be more difficult for service providers and planners to know whether they are reaching the Indigenous people most in need of assistance or involving all sectors of the community in decision making. Indigenous people, when only a small proportion of the community, may have 'a very quiet voice' in local decision making forums (Para 2.29).

The same report also noted that Aboriginal and Torres Strait Islander people suffer a particular form of discrimination as a result of perceptions from the wider Australian community about their identity (House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs 2001:18–19):

Urban dwelling Indigenous people may also suffer from having their Aboriginality denied and be assumed to be assimilated. The stereotypes of 'real' Aboriginals being those living 'out bush' or in 'traditional' settings may lead to the denial of the possibility of a dynamic, contemporary Indigenous culture in urban areas (Para 2.30).

In urban areas, the social barriers faced by Indigenous people may be less apparent and, thus, generate less political pressure to be addressed (Para 2.31).

Mainly Urban, a previous report prepared by the same committee in 1992, also observed that urban Aboriginal people are often not viewed as 'real' Aboriginal people and have become the 'forgotten people of Australia' (House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs 1992). It is pertinent to note that in the United States of America, although more than half of American Indigenous people (American Indians/Alaska Natives) live in towns and cities, urban Indigenous people have been called the 'invisible minority' because their needs often go unrecognised (Duffy, Goldberg & Buchwald 2006).



In a study of social capital among urban Aboriginal and Torres Strait Islander people, Brough *et al.* (2006:407–08) stated:

It is clear that Australia lacks a social environment conducive to trust-building between Aboriginal and non-Aboriginal Australians. It is in this context that the social and economic linkages necessary for Aboriginal and Torres Strait Islander empowerment are ill-formed. Mostly we witness a failure to acknowledge the diversity of Aboriginal identities, along with a failure to imagine ways in which strong Aboriginal identities can be allowed to mingle in multicultural landscapes without being assimilated, hybridized or otherwise de-legitimated. Stereotypical, racist and other exclusionary practices and ideas are the drivers of inequality.

An Aboriginal woman from Queensland, Bronwyn Fredericks, has stated: 'It is not easy for Aboriginal people in the city. Life in big cities presents Indigenous people with many factors and interactions that create self-doubt, identity confusion and anguish' (Fredericks 2004:31).

Despite the disadvantages that urban Aboriginal and Torres Strait Islander people have to deal with, there are also strengths within the urban Aboriginal and Torres Strait Islander communities, which should be recognised and built upon in any initiatives to address the disadvantages. Aboriginal lawyer Larissa Behrendt refers to the psychological terra nullius, where even though Aboriginal people are present, they are not seen (Behrendt 2006). This is particularly a feature of the urban areas in Australia, she says, where the Aboriginal presence is pervasive. Despite this, she makes the point that

wherever we have lived in urban areas, there is a newer imprint and history, that is meaningful and creates a sense of belonging within Aboriginal communities that have formed in urban areas ... Another dimension to the cohesiveness of Aboriginal communities in the Sydney area is the tight-knit kinship and family networks that exist there, reinforcing traditional ties. Once a network of clans within the Eora nation, in Sydney now there is a large Aboriginal population (second only to the Northern Territory) that consists of clusters of Aboriginal communities in La Perouse, Redfern, Marrickville, Mount Druitt, Penrith and Cabramatta. Family and kinship networks help tie these separate enclaves together (Behrendt 2006:7).

In a report of a qualitative study that attempted to identify urban Aboriginal and Torres Strait Islander perspectives on community strengths in order to develop a strength-based approach to health promotion, Brough, Bond and Hunt (2004) described five key strengths: (1) extended family, (2) commitment to community, (3) neighbourhood networks, (4) community organisations and (5) community events.

The importance of Aboriginal and Torres Strait Islander identity, and the family and community bonds that are part of this identity, are crucial to efforts to improve the health of Aboriginal and Torres Strait Islander people living in urban areas. However, there has been a long history in Australian Government Indigenous policy of assuming that eradication of Aboriginal or Torres Strait Islander culture and identity is a prerequisite for participation in urban life. This attitude, which was openly espoused when the official government Indigenous policy was assimilationist, never completely disappeared and is now enjoying a re-emergence. In this perspective, migration to urban areas is meant to be permanent, motivated by a lack of employment opportunities, and represents a rejection of Aboriginal or Torres Strait Islander culture, which is increasingly portrayed as being dysfunctional (see, for example, Johns 2006a). With these attitudes becoming more prominent, it should not be surprising that no need is seen for culturally secure services in urban areas.

In a submission to the Commonwealth Parliamentary Inquiry into the needs of urban-dwelling Aboriginal and Torres Strait Islander people, the National Aboriginal Community Controlled Health Organisation (NACCHO) stated:

The effects of invasion and colonization on Aboriginal peoples impacted earlier and have been impacting for longer, in what are now urban areas. It is therefore hardly surprising that dispossession and alienation, poverty and disadvantage are felt as keenly by Aboriginal people in urban areas as elsewhere. (NACCHO 2001)

These issues may contribute to the significant health problems, which, as will we see in the next section, impact upon Aboriginal and Torres Strait Islander people living in urban areas.

1.4 Health status of Aboriginal and Torres Strait Islander people living in urban areas

There is often a misconception among policy makers, and indeed, the general public, that efforts should be directed to Aboriginal people in remote areas only, as Aboriginal people in urban areas are not seen as having the same level of need. This myth needs to be overcome. Aboriginal people in all areas—urban, rural, and remote—experience similarly poor health status (NACCHO 2001).

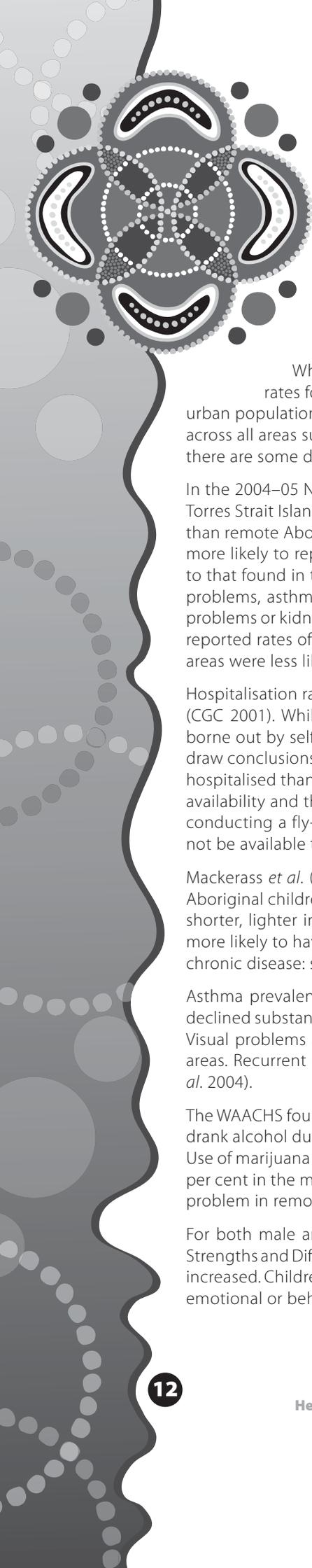
Much of the data on Aboriginal and Torres Strait Islander mortality and morbidity come from jurisdictions that include both urban and non-urban Aboriginal and Torres Strait Islander people (either national data, or data from individual States or Territories). Specific data on the health status of Aboriginal and Torres Strait Islander people living in urban areas are limited. Recently, organisations such as CIS and the Bennelong Society have suggested that it is poor health in remote areas that is responsible for the poor national statistics, implying that if Aboriginal and Torres Strait Islander people left remote areas and settled in urban areas, the consequent access to mainstream health services would resolve the health crisis. For example, in a CIS monograph, Hughes and Warin (2005:11) stated that ‘the gap of 18 years in life expectancy is an average for Aborigines and Torres Strait Islanders and so underestimates the seriousness of ill-health in remote communities’. They go on to say:

Health data from remote Australia have become less available as the many barriers created by separatism and bureaucracy (masquerading behind so-called ‘ethical’ considerations) have driven out mainstream medical researchers and clinicians. Tragically, the limited data available suggest that the Coombs experiment has resulted in much worse health, and hence lower life expectancy, for remote than for other Aborigines and Torres Strait Islanders, let alone than for non-Indigenous Australians (Hughes & Warin 2005:13).

Hughes and Warin do not specify what these ‘limited data’ are. As with many other allegations in this monograph, this is an unsubstantiated statement; the evidence shows a more complex picture. This would not be such a concern if CIS did not have undue influence with the previous Coalition federal government. (In his speech calling for a ‘new paternalism’ in Aboriginal and Torres Strait Islander health in 2005, the then Minister for Health and Ageing, Tony Abbott, extensively quoted Hughes and Warin as though he was citing authoritative research.)

It is true that, as with non-Indigenous mortality, the mortality rates for Aboriginal and Torres Strait Islander people appears to be higher in rural and remote areas than in urban areas. Using data from Queensland, South Australia, Western Australia and the Northern Territory (the jurisdictions with the most accurate identification of Aboriginal and Torres Strait Islander status), it has been calculated that the death rate in all these jurisdictions of Aboriginal and Torres Strait Islander people (both male and female) outside the capital cities and the ‘other major urban areas’ of the Gold Coast and Townsville is about one-and-a-half times the rate of these metropolitan areas (a rate ratio of 1.48). This calculation needs to be treated with a degree of caution, as the incomplete and inconsistent quality of data across regions may make the calculation unreliable. Cunningham (2002a) believes that ‘the apparent difference in Indigenous mortality in remote compared with urban areas is of a magnitude that could be explained by relative modest regional differences in data quality’. Glover *et al.* (2004), however, point out that even where death registrations are understated, population data are also likely to be understated, so they suggest that this cancelling-out effect supports the data analysis that mortality is higher in remote areas than in urban areas. What is not debatable is the established fact that for both urban and non-urban Aboriginal and Torres Strait Islander people the mortality rates remain much worse than for non-Indigenous people. It also should be noted that mortality rates for the total population are higher for people living in rural areas compared to those living in urban areas, and that this inequality is not explained by the higher proportion of Aboriginal and Torres Strait Islander people living in rural areas (Hayes, Quine & Taylor 2005).

Using ARIA+ as a measure of area of residence, the death rates for the total Australian population show a distinct gradient from lower rates in the major cities to higher rates in very remote areas. Aboriginal and Torres Strait Islander death rates are substantially higher than non-Indigenous rates across the ARIA+ classes. However, they do not show the same continuous gradient as the total population. The death rate for Aboriginal and Torres Strait Islander people in the inner regional areas is lower than in the major cities, and increases steadily over the next two ARIA+ classes (outer regional and remote), before declining in very remote areas.



This finding is significant. Instead of the expected gradient in mortality rates from the most urban populations to the most remote, there are anomalies at both ends of the curve. It appears that compared to the total Australian population, Aboriginal and Torres Strait Islander people living in major cities are exposed to factors that have an adverse effect on life expectancy, and that in very remote areas there are factors predisposing them to better life expectancy. Both influences need further exploration. For the purpose of this review, it is the fact that there are adverse effects on life expectancy in metropolitan areas that is most significant. It can certainly be hypothesised that problems of access to health care may play a role.

While it is well recognised that Aboriginal and Torres Strait Islander people suffer higher morbidity rates for many conditions, these statistics are not often disaggregated into rates for urban and non-urban populations. The information that is available suggests that Aboriginal and Torres Strait Islander people across all areas suffer rates of morbidity that are much worse than in the non-Indigenous population, but that there are some differences in the morbidity patterns in different locations.

In the 2004–05 National Aboriginal and Torres Strait Islander Health Survey (ABS 2006a), urban Aboriginal and Torres Strait Islander people were slightly more likely to have excellent or very good self-reported health status than remote Aboriginal and Torres Strait Islander people (44 per cent as opposed to 41 per cent) but were also more likely to report fair or poor health status (23 per cent as opposed to 19 per cent). This trend was similar to that found in the earlier survey in 2001. More urban people reported that they suffered from arthritis, back problems, asthma or eyesight problems, while more remote people reported that they suffered from heart problems or kidney disease. Rates of self-reported diabetes were not significantly different across locations. Self-reported rates of smoking and excessive alcohol consumption were similar across locations. People in remote areas were less likely to have daily fruit or vegetable intake (ABS 2006a).

Hospitalisation rates appear to be higher for Aboriginal and Torres Strait Islander people living in remote areas (CGC 2001). While the trend may be affected by lower Indigenous ascertainment rates in urban areas, it is borne out by self-reported hospitalisation rates (ABS 2006a), which are higher in remote areas. It is difficult to draw conclusions from this trend because, for various reasons, people in remote areas may be more likely to be hospitalised than those in urban areas for similar health conditions (e.g. country hospitals may have better bed availability and there may be pressure to keep bed-occupancy rates high to avoid closure; and a flying doctor conducting a fly-in clinic in a remote community may be more likely to arrange hospitalisation if he/she will not be available the next day to monitor progress).

Mackerass *et al.* (2003) described the prevalence of markers of growth and chronic and infectious disease in Aboriginal children living in urban and remote areas in the Northern Territory. Children from remote areas were shorter, lighter in body weight and had lower body-mass index (all markers of chronic infections) and were more likely to have visible infections. Urban children were more likely to have some potential markers of adult chronic disease: systolic blood pressure and total cholesterol and insulin levels.

Asthma prevalence in Aboriginal children is higher in urban areas. The WAACHS found that the prevalence declined substantially from 30 per cent in the Perth metropolitan area to 7 per cent in areas of extreme isolation. Visual problems also showed a gradient across levels of relative isolation from a higher prevalence in urban areas. Recurrent ear infections were more common in remote areas and started at a younger age (Zubrick *et al.* 2004).

The WAACHS found that 49 per cent of mothers of Aboriginal infants smoked during pregnancy and 23 per cent drank alcohol during pregnancy, and that these prevalences were uniform across all levels of relative isolation. Use of marijuana during pregnancy, however, was higher in urban areas, declining from 11 per cent in Perth to 2 per cent in the most remote areas (Zubrick *et al.* 2004). Inhalant abuse occurs across all areas, but is a particular problem in remote communities, while intravenous drug abuse is much more of an urban phenomenon.

For both male and female children, the risk of emotional or behavioural difficulties (using a version of the Strengths and Difficulties Questionnaire) was highest in the Perth metropolitan area, with a decline as remoteness increased. Children living in the most remote areas were one-fifth as likely to be at high risk of clinically significant emotional or behavioural difficulties compared to children in the Perth metropolitan area (Zubrick *et al.* 2005).

An extensive review of diabetes in Aboriginal and Torres Strait Islander populations in 1998 identified a lack of information on the burden of disease among Aboriginal and Torres Strait Islander people in urban areas (de Courten *et al.* 1998). This is still the case; an attempt to provide information on the prevalence of diabetes in Aboriginal and Torres Strait Islander people in the Darwin area ran into difficulties with recruitment (see below) but should still yield useful information (Cunningham *et al.* 2006).

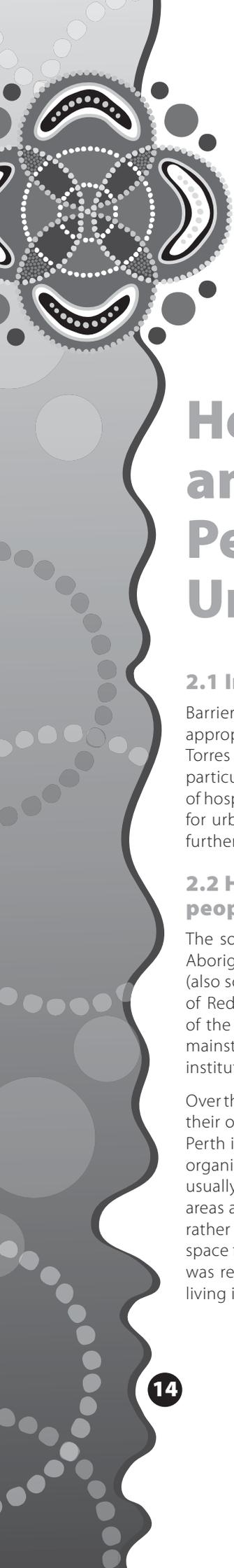
To summarise the evidence from the rather patchy data on morbidity patterns across the urban–remote continuum for Aboriginal and Torres Strait Islander people, on average it appears that morbidity levels for Aboriginal and Torres Strait Islander people in all environments is much worse than for non-Indigenous people, and the overall levels of morbidity are probably much the same whether Aboriginal and Torres Strait Islander people live in urban, rural or remote environments. There are, however, some differences in the morbidity patterns. In remote areas there are higher rates of infectious diseases, while there is evidence that rates of some chronic diseases are higher in urban areas. Mental health problems appear to be more common in urban areas. Rates of smoking and alcohol use are constant across environments, but patterns of some drug use differ: petrol sniffing is more of a remote phenomenon, while opiate and amphetamine use is more common in urban areas

1.5 Conclusion

A significant majority of the total population of Australian Aboriginal and Torres Strait Islander people live in urban areas. They represent a heterogeneous and mobile population, with frequent movement between urban and other areas, and within urban areas. Aboriginal and Torres Strait Islander people within urban areas have been described as an ‘invisible minority’ and are exposed to discrimination and to an attitude that they are not ‘real Aborigines’. This situation contributes to the poor health status of Aboriginal and Torres Strait Islander people living in urban areas that emerges from the limited data, despite claims by some commentators that the overall poor health of Aboriginal and Torres Strait Islander people is largely a result of the remoteness and failed policies of remote communities. The assumption is sometimes made that the availability of mainstream health services in urban areas means that access to health care is not a major problem for urban-dwelling Aboriginal and Torres Strait Islander people. The issue of whether or not this is the case will be explored in the next chapter.

1.6 Main points

- A significant majority of the total population of Aboriginal and Torres Strait Islander people lives in urban areas.
- Aboriginal and Torres Strait Islander people living in urban areas are a heterogeneous and mobile population, with frequent movement between urban and other areas, and within urban areas. Members of this population have been described as an ‘invisible minority’ and are exposed to discrimination and to an attitude that they are not ‘real Aborigines’.
- The discrepancies in health status between Aboriginal and Torres Strait Islander people and the non-Indigenous population occur in all residential areas within Australia. There is evidence that there are factors affecting Aboriginal and Torres Strait Islander people in most urban areas that are detrimental to life expectancy, and there are factors affecting Aboriginal and Torres Strait Islander people in the most remote areas that are beneficial to life expectancy. There are some health conditions, including mental health disorders, that appear to be more prevalent in Aboriginal and Torres Strait Islander people living in urban areas.
- Recent government policies are likely to accelerate a trend involving migration by Aboriginal and Torres Strait Islander people to urban areas from remote areas. At the same time government policies have shifted from self-determination and the establishment of Indigenous-specific services, to an expectation that Aboriginal and Torres Strait Islander people, especially in urban areas, will access mainstream services. This is despite the fact that ACCHSs were established initially in urban areas to overcome the failure of mainstream services to address Aboriginal and Torres Strait Islander health needs.



2. The Patterns of Health Service Use, and the Pathways into and out of Secondary and Tertiary Health Services, by Aboriginal and Torres Strait Islander People Living in Urban Areas

2.1 Introduction

Barriers to health care access can be classified as problems of availability, affordability, acceptability and appropriateness. In this chapter we look at the available data about access to health care by Aboriginal and Torres Strait Islander people living in urban areas, and demonstrate that all these barriers are significant, but particularly the latter two. There are problems with access at all levels of the health care system, but the pattern of hospital use suggests that better access to primary care in particular is likely to lead to better health outcomes for urban Aboriginal and Torres Strait Islander people. At the end of the chapter we suggest some areas for further research.

2.2 History of health services for Aboriginal and Torres Strait Islander people in urban areas

The social movement that emerged in the early 1970s among Aboriginal activists and their supporters for Aboriginal community control of health services was initially very much an urban phenomenon. The first ACCHS (also sometimes referred to as AMS, or Aboriginal Medical Service) was established in the inner Sydney suburb of Redfern. At that time Redfern had the largest Aboriginal community in Australia, and the establishment of the health service was a response to the difficulties experienced by urban Aboriginal people in accessing mainstream health care (difficulties related both to financial reasons and to discriminatory practices in medical institutions) (Foley 1982).

Over the following few years many other Aboriginal communities in metropolitan and provincial cities established their own health services. For example, a service was established in Fitzroy in inner Melbourne in 1973, and in Perth in 1974 (Lavoie 2004). In the early years many ACCHSs relied on voluntary work and donations from aid organisations, but eventually funding from the federal Department of Aboriginal Affairs (established in 1972) was usually forthcoming. The establishment of ACCHSs in remote areas came later, starting in the late 1970s; in these areas an ACCHS generally took over a health service previously provided by the State or Territory government rather than setting up an alternative to ongoing mainstream health services. In urban areas ACCHSs provided a space for Aboriginal and Torres Strait Islander people to receive health care in an area in which cultural security was respected. This was not such an imperative in remote areas, where people have the cultural security of living in communities where they are the majority population (Scrimgeour 1997).

The development of ACCHSs and other Aboriginal and Torres Strait Islander community-controlled organisations, referred to by Rowse (2002) as the 'Indigenous sector', has been the most significant manifestation of the policy of self-determination, which became official federal government policy in 1972. The important role of ACCHSs in providing comprehensive primary health care to Aboriginal and Torres Strait Islander people in urban and non-urban environments has been widely acknowledged, despite the fact that difficulties with funding, especially the short-term fragmented nature of contracts from multiple funding sources, has limited the effectiveness of the services provided (NACCHO 2001; Lavoie 2004). Henry, Houston and Mooney (2004) point out the different performance criteria for ACCHSs compared to mainstream services:

In Perth, Derbal Yerrigan AMS funding was cut when an 'overspend' arose because of success in attracting clients; at the same time the teaching hospitals' overspend was 120 times as great as Derbal Yerrigan. The teaching hospitals were given an extra \$100 million to cover their overspend (Henry, Houston & Mooney 2004:517).

Over the past decade, while the policy of self-determination has not been officially repudiated, some commentators have suggested that the self-determination policy has failed, and the previous Coalition federal government introduced policies that place less emphasis on self-determination.

In recent years, while ACCHSs have continued to receive funding from the Commonwealth Government, the emphasis has been more on 'mainstreaming' of health services, particularly in urban areas. *We Can Do It!*, the 2001 report of the House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs, stated that 'In urban areas at least, the urgent priority should be on meeting the needs of Indigenous people through better access to mainstream services'; further, 'It may be necessary to invest in parallel Indigenous specific structures or services where mainstream services are inadequate or non-existent' (House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs 2001:9, Para 1.39). The report did not outline, however, how mainstream services might be evaluated to be 'inadequate', and there is little evidence of increased investment in 'parallel Indigenous specific structures or services'.

In a speech in December 2006, the then federal Minister for Families, Community Services and Indigenous Affairs, Mal Brough (2006), made the following statements:

The needs of the Indigenous community are not all the same. It is indisputable that access and opportunities is much greater in urban areas than in remote areas. However, it is also indisputable that service delivery for Indigenous Australians in urban areas needs to improve. The majority of Indigenous Australians live in cities and towns, where good services, education and employment are available. Too often, Indigenous Australians for a variety of reasons do not access these services and feel unable to take advantage of employment and other opportunities. Setting up parallel services in these places, often with lower standards and expectations, has not produced the results that organisations like [the Aboriginal and Torres Strait Islander Commission] sought to deliver. Indeed sometimes these parallel services have alienated people from the broader community and from opportunities. Our approach will be to facilitate access to all services, rather than establish alternatives. Mainstream providers will no longer be allowed to shirk their responsibilities to the first Australians. This means that they will have to step up to the mark. They will have to adapt their services to suit Indigenous Australians in the same way that they have done for other groups in Australian society.

In urban areas where most Indigenous Australians live, the aim is to improve the functioning of mainstream services for Indigenous Australians and improve access to jobs in the mainstream economy. Simply put, I expect all Federal government departments and anyone else delivering on behalf of the government to ensure equitable access for every Australian for those services ... Indigenous specific programmes will continue to focus on assisting Indigenous people to make the full use of mainstream services.

Mainstreaming is not assimilation. I don't want Indigenous people to be invisible in these services, I want those services to cater appropriately for the needs of Indigenous people—so they get the same opportunities as others.



This speech de-emphasised the role of urban Indigenous organisations, including ACCHSs, in favour of mainstreaming despite the evidence of the effectiveness of ACCHSs and also despite evidence of the limitations of mainstreaming provided by government agencies themselves. During the second term of the Howard government from 1998–2001, the Commonwealth Grants Commission undertook a significant inquiry into Indigenous funding (CGC 2001). This important report has never received the attention it deserved (Altman 2004). Altman highlighted just some of its main findings:

- *It is clear from all available evidence that mainstream services do not meet the needs of Indigenous people to the same extent that they meet the needs of non-Indigenous people;*
- *Indigenous Australians in all regions access mainstream services at a very much lower rate than non-Indigenous people;*
- *The mainstream programs provided by the Commonwealth do not adequately meet the needs of Indigenous people because of barriers to access; and*
- *Commonwealth Indigenous-specific programs are intended to provide targeted assistance to Indigenous people to supplement the delivery of services through mainstream programs ... the failure of mainstream programs to effectively address the needs of Indigenous people means that Indigenous-specific programs are expected to do more than they were designed for ... (CGC 2001:xvi–xvii, cited in Altman 2004:40).*

Evidence from other countries supports the importance of separate Indigenous-specific services. In New Zealand, Canada and the USA—countries with Indigenous minorities that have been able to achieve better Indigenous health outcomes compared to Australia—there has been a recognition that separate Indigenous services have a place; this has often been seen as a way of governments fulfilling their obligations under the conditions of treaties. The USA, for example, has had a federally funded Indian Health Service for decades, providing an integrated system of health care, which has been a major factor in the reduction of health inequalities between Indigenous and non-Indigenous Americans (Kunitz & Brady 1995; Kunitz 2004).

Separate Indigenous services do not absolve mainstream providers of the responsibility for providing high quality and culturally appropriate services for Indigenous people. Indigenous-specific services should be seen as additional services to help overcome identified inequalities. Indigenous-specific services also provide Indigenous people with a greater choice. Commenting on the situation in New Zealand, Crengle, Crampton and Woodward (2004:354) make the point that:

the development of Māori providers has afforded Māori... the choice between 'mainstream' providers and Māori providers... (there are signs that Māori providers deliver services that are more accessible, appropriate, affordable and acceptable to the Māori community and that Māori take advantage of Māori providers when there is one available in their area.

Rowse (2002) also emphasises the fact that Indigenous people are given greater choices by having both Indigenous-specific services and the opportunities offered by mainstream services. In his view:

the best feature of a policy of Indigenous self-determination is ... that it maintains the real possibility of choice by Indigenous Australians. 'Assimilationism', as practised in the past, was often coercive in its methods and patronising in its assumptions (Rowse 2002:6).

From this perspective, the emergence, over the past decade, of a neo-assimilationist ideology in think tanks and government should be a cause for concern.

Another well-publicised component of the previous Coalition federal government's Indigenous affairs policy is the concept of mutual obligation, or Shared Responsibility Agreements. These are agreements between the government and discrete Aboriginal and Torres Strait Islander communities, which only exist in rural and remote areas. As Morrissey (2006:354) says:

By constantly focusing on discrete 'Aboriginal communities', there is a continual reinforcement of the notion that the primary cause of Aboriginal impoverishment is their remote location. Urban Aboriginal people (the large majority) are sponged off the picture and a reified notion of culture and the 'facts' of geography swamp out history and the socio-economic relations as the causes of Aboriginal misery.

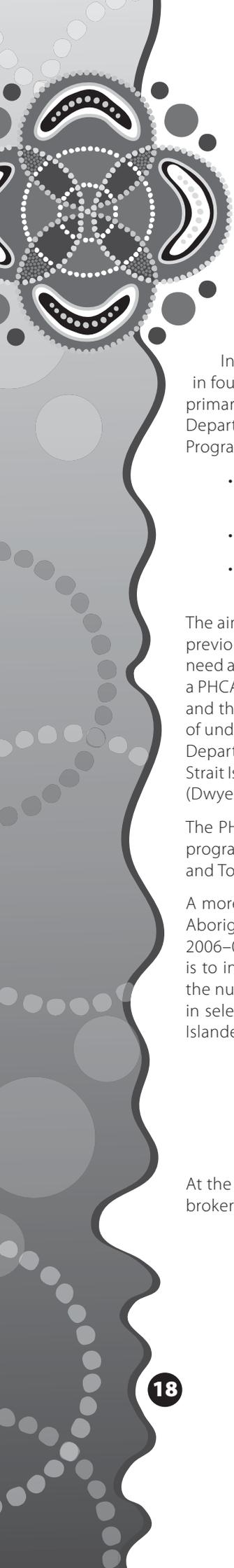
Thomas and Anderson (2006:74) commented on the current policy environment thus:

The Federal Government's 'new' approach to Indigenous affairs emphasizes terms such as 'shared responsibility', 'accountability' and 'outcomes'. The special rights of Aboriginal and Torres Strait Islander peoples as the Indigenous owners of Australia are not acknowledged as clearly as before; however, the need for 'partnerships' and 'collaboration' are still acknowledged. For a long time, research and debate about health care services for Indigenous Australians has concentrated on Aboriginal community-controlled health services and their responsibility and accountability for the health care and health of their communities. (However, this might change as the Federal Government Minister has recently claimed that such Indigenous organizations are not sufficiently accountable to their communities, and that the government plans to reduce their role while increasing their accountability to government.) Indigenous people use many other health services... which should also be accountable to the special needs of Indigenous patients if governments are to accept their shared responsibilities to improve Indigenous health outcomes and care.

Recent Commonwealth Government initiatives to improve access to health care for Aboriginal and Torres Strait Islander people has concentrated on improving access to the Medicare Benefits Scheme (MBS) and the Pharmaceutical Benefits Scheme (PBS), which are considered to be key pillars of the national system of health care from which all Australians are entitled to benefit. A report by Keys Young (1997) prepared for the Health Insurance Commission (since renamed Medicare Australia) demonstrated significant deficits in Aboriginal and Torres Strait Islander people's access to the MBS and the PBS. The report noted that many Aboriginal and Torres Strait Islander people were not enrolled in Medicare, ACCHS claims on Medicare were low, and there were significant limitations on Aboriginal and Torres Strait Islander access to the PBS. Various recommendations were made, and changes and new initiatives that have followed in subsequent years include the following:

- more systematic use of an exemption under subsection 19(2) of the *Health Insurance Act 1973* that enables Indigenous-specific health services to bulk-bill Medicare for services provided, regardless of the fact that their GPs are salaried;
- introduction of certain Enhanced Primary Care items designed to meet the particular needs of Aboriginal and Torres Strait Islander people;
- development of a new Indigenous enrolment form for Medicare to allow relevant community members to vouch for an individual's identity;
- introduction of a voluntary Indigenous identifier for people enrolling in Medicare;
- establishment within Medicare Australia of a network of Medicare Liaison Officers for Indigenous Access with a range of responsibilities such as promoting Medicare enrolment, facilitating the processing of Medicare claims, and training and support for health service providers and communities;
- introduction of an Aboriginal and Torres Strait Islander access line for Medicare enquiries, staffed by Medicare Liaison Officers and their support staff;
- development by Medicare Australia of an Indigenous communications strategy, including such initiatives as an Indigenous Medicare Toolkit and production of *Well and Good* magazine;
- use of S100 of the *National Health Act 1953* to enable supply of PBS medicines to clients of eligible and approved Aboriginal and Torres Strait Islander health services in remote areas; and
- provision of pharmacists, where necessary, to dispense medications to Indigenous customers who are unable to present a Medicare card (Urbis Keys Young 2006).

Urbis Keys Young was commissioned by Medicare Australia and the Commonwealth Department of Health and Ageing in 2005 to examine the effectiveness of these changes and initiatives (Urbis Keys Young 2006). The study confirmed the value of initiatives to increase Aboriginal and Torres Strait Islander enrolment in Medicare and to support the claiming of Medicare rebates on behalf of Aboriginal and Torres Strait Islander people. The report noted that most ACCHSs now receive some Medicare income under the subsection 19(2) exemption, but



the total value of such income is relatively modest by comparison with Indigenous Health Program funding. A number of ACCHS representatives and other stakeholders told the researchers that the most desirable approach to funding of Aboriginal and Torres Strait Islander services would be to provide a single grant that included the 'cashing out' of Medicare on the basis of an appropriate formula.

In relation to access to the PBS, it was found that arrangements under S100 of the *National Health Act 1953* have greatly improved access to PBS medications for Aboriginal and Torres Strait Islander people living in remote areas, but that access to medications remains a major problem for Aboriginal and Torres Strait Islander people living in urban areas (with cost being the greatest single barrier).

In the mid-1990s the Council of Australian Governments implemented Aboriginal Co-ordinated Care Trials in four sites to test the impact of pooling Commonwealth and State/Territory funding on the development of primary health care services, including fund-holding for secondary and tertiary care services (Commonwealth Department of Health and Aged Care & KPMG 2001). Building on these trials, the Primary Health Care Access Program (PHCAP) was announced in 1999–2000, with the following objectives:

- to increase the availability of appropriate primary health care services where they are currently inadequate;
- to reform the local health system to better meet the needs of Aboriginal people; and
- to empower individuals and communities to take greater responsibility for their own health (OATSIHS 2002).

The aim of PHCAP is to set up regional Aboriginal and Torres Strait Islander health boards, which will hold funds previously spent by States or Territories; MBS funding will be calculated on a per capita basis and adapted for need and remoteness. PHCAP initiatives have been rolled out in various locations across Australia. An example of a PHCAP project in an urban area is Nunkuwarni Yunti, the ACCHS in metropolitan Adelaide. Nunkuwarni Yunti and the Aboriginal Sobriety Group (a community-controlled substance-abuse program) have a memorandum of understanding with the Central Northern Adelaide Health Service (a regional division of the South Australian Department of Health). The memorandum of understanding identified service gaps for Aboriginal and Torres Strait Islander people, and proposed integrated mainstream and Indigenous-specific strategies to close the gaps (Dwyer, Silburn & Wilson 2004; Nunkuwarni Yunti 2006).

The PHCAP process has been slow and complex, and only a few urban sites have seen any benefits from the program. The future of this program, and its long-term impact on health care access and outcomes for Aboriginal and Torres Strait Islander people living in urban areas, remains unclear.

A more recent Commonwealth Government initiative to address problems of access to health care for urban Aboriginal and Torres Strait Islander people is the 'urban brokerage' concept. The initiative was announced in the 2006–07 federal Budget, with an allocation of \$12.63 million over the next four years. The aim of this initiative is to increase the range of health services that urban Aboriginal and Torres Strait Islander people access, and the number of times they access these services; Indigenous-specific brokerage services have been established in selected urban and regional areas to meet this aim. According to the Office of Aboriginal and Torres Strait Islander Health website (OATSIHS 2006):

A brokerage service provides an identifiable and accessible entry point into the health care system for Indigenous clients, and a focal point for mainstream health professionals who wish to extend their health practice to meet Indigenous health needs effectively. A brokerage service links Indigenous Australians to a range of mainstream primary health care providers. Its main role is to assist Aboriginal and Torres Strait Islander people to choose the providers appropriate for them from a register maintained by the service.

At the time of writing this review, a competitive process is underway to select organisations to become urban brokerage services in selected urban sites in New South Wales, Queensland, Victoria and Western Australia.

Despite these initiatives, and despite the fact that urban Aboriginal and Torres Strait Islander people suffer significant health problems, it appears that expenditure on health services for these people has been not only less than for their rural and remote counterparts, but also less than for urban non-Indigenous people. Total health expenditure per capita for Aboriginal and Torres Strait Islander people in urban areas is \$1145, lower than for non-Indigenous people in urban areas (\$1375) and lower than that for Aboriginal and Torres Strait Islander people in remote areas (\$2259) (AIHW 2001:13). In 1998–99 the ratio of Indigenous/non-Indigenous Medicare expenditure was 0.43 in urban areas, 0.53 in rural areas and 0.43 in remote areas; the ratio of Indigenous/non-Indigenous PBS expenditure was 0.36 in urban areas, 0.48 in rural areas and 0.25 in remote areas (AIHW 2001). This shortfall in spending is remarkable; Henry, Houston and Mooney (2004) estimate that the provision of culturally secure services might increase costs for Aboriginal patients by more than 50 per cent.

2.3 Access to primary care

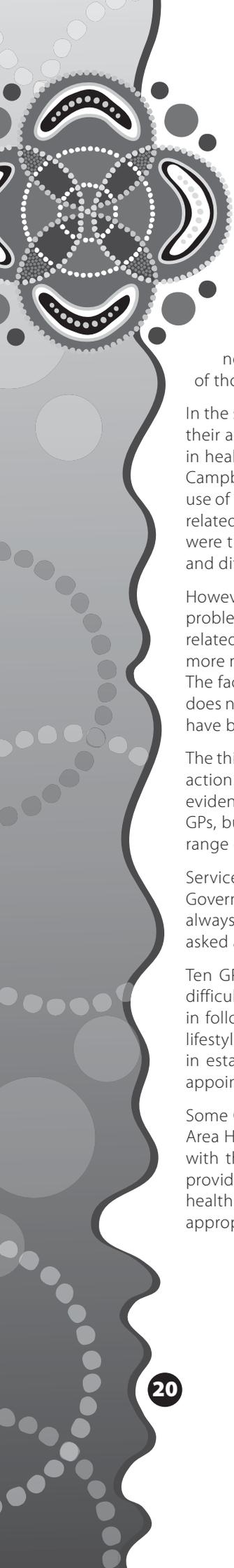
Health services include primary care services such as those provided by GPs, nurses and allied health professionals. These services may be provided in a range of settings including community health centres and clinics, doctors' rooms and hospitals (ABS & AIHW 2005:179). The Australian Primary Health Care Research Institute has defined primary health care as:

socially appropriate, universally accessible, scientifically sound first level care provided by a suitably trained workforce supported by integrated referral systems and in a way that gives priority to those most in need, maximises community and individual self-reliance and participation and involves collaboration with other sectors. It includes health promotion, illness prevention, care of the sick, advocacy and community development (Sibthorpe, Glasgow & Wells 2006:552).

There is evidence that it is access to the primary care component of the overall health system that has the biggest impact on health outcomes. In a review of the literature on the effectiveness of primary care in a range of countries (but with particular emphasis on the USA), Starfield *et al.* (2005) showed that the supply of primary care physicians was significantly associated with lower all-cause mortality, whereas, interestingly, a greater supply of specialty physicians was associated with a higher mortality. However, some USA studies show that in urban areas the supply of primary care physicians is less closely related to the health of urban African–Americans than it is for urban whites or for African–Americans in rural areas. This demonstrates that the mere availability of primary care physicians may not ensure access to primary care, particularly for more deprived populations in urban areas. This problem of access is likely to be at least a part of the explanation for the fact that the mortality of Aboriginal and Torres Strait Islander people in metropolitan areas is less than expected when compared to the mortality trend for non-Indigenous Australians along the urban–remote axis.

There is evidence that Aboriginal and Torres Strait Islander people are less satisfied with their access to primary health care than non-Indigenous Australians, and that (despite the fact that the assumption is often made that availability of health services in urban areas means better access), urban Aboriginal and Torres Strait Islander people are less satisfied than non-urban Aboriginal and Torres Strait Islander people with access issues. In the WAACHS (Silburn *et al.* 2006) the proportion of primary carers of Aboriginal children in Western Australia who reported being happy with access to community services and facilities was significantly below that reported by carers of non-Aboriginal children in a previous survey. However, as the level of relative isolation increased, there was an increase in the proportion of carers of Aboriginal children who were satisfied with access to a community or child health clinic (i.e. carers in urban areas reported less satisfaction with access). This trend was not evident in rates of reported satisfaction among carers of non-Aboriginal children. There was also an increase in satisfaction with access to ACCHSs as the level of remote isolation increased.

One of the few studies that has specifically investigated access of Aboriginal people to urban primary health care services was a two-year project conducted on behalf of the Macarthur Division of General Practice in the south-western Sydney region (Craig 2002). The project was undertaken in three phases: the first phase investigated the role of GP receptionists in ensuring access of Aboriginal people to GP services; the second phase investigated the views of Aboriginal people on their access to health care; and the third phase described the range of services that are provided to the Aboriginal people in the area and what action could be taken in the future to increase access of Aboriginal people to primary health care.



In the first phase, twenty receptionists working in GP surgeries in the Macarthur Division area were interviewed about their usual practices in dealing with Aboriginal people face-to-face or over the telephone. It is appropriate to ascertain the attitudes and practices of receptionists, as they are the first contact personnel in GP surgeries and can have a significant effect on access. As may be expected from interviews with the receptionists themselves, there was little direct evidence of receptionists treating Aboriginal people in a discriminatory way, but according to the report the majority of receptionists acted in an indirectly discriminatory way, unintentionally disadvantaging Aboriginal patients by treating them the same as other patients instead of recognising their special needs. The majority of the receptionists had little cultural awareness of the differences between Aboriginal and non-Aboriginal people, but while the report suggested they would benefit from some training, only half of those interviewed expressed interest in attending training.

In the second phase, fifty-five Aboriginal people were interviewed to determine their views on their health and their access to local health services. The majority of those interviewed did not feel intimidated or out of place in health services, but some did feel discriminated against in GP surgeries and preferred to use the ACCHS in Campbelltown. Most people were happy with the care they received from their GPs. Four major barriers to the use of health services were identified: financial barriers, transport, communication and shame. Financial barriers related mainly to co-payments for services and prescriptions and the cost of transport. Other problems mentioned were the lack of telephones to make appointments, low literacy levels (making it difficult to read information) and difficulties in understanding what doctors or receptionist were asking them to do.

However, the greatest barrier that older Aboriginal people mentioned was the shame they felt about the health problems they had and the lack of success in following the advice given to them by GPs. This was seen to be related to poor self-esteem resulting from the past experiences of Aboriginal people, and it was suggested that more needs to be done to empower local Aboriginal people to take more positive actions on their own behalf. The fact that 'older Aboriginal people' raised this issue does not necessarily mean that the younger generation does not have the same problem. It may be a reflection of the fact that older Aboriginal people are more likely to have been diagnosed with so-called 'lifestyle diseases' with connotations of failure of personal responsibility.

The third phase, describing the range of services that are provided to the Aboriginal people in the area and what action could be taken in the future to increase access of Aboriginal people to primary health care, grew from evidence in the earlier phases that Aboriginal people were generally happy with the care they received from GPs, but often the care they received did not adequately address in a proactive or ongoing way the complex range of problems they experienced (Craig 2002).

Service utilisation data were collected as part of the project. Utilisation data from the New South Wales State Government-funded Area Health Service suggested that information on identification of Aboriginal status was not always collected or that Aboriginal use of the services was very low. Staff members at ten general practices were asked about usage, but since questions about Aboriginal status were rarely asked, the figures were unreliable.

Ten GPs who saw a significant number of Aboriginal patients were interviewed to identify any particular difficulties or issues they encountered. A common concern was 'losing track of Aboriginal clients', with difficulties in following-up treatments and ensuring compliance given irregular attendance. The difficulty in promoting lifestyle changes such as regular exercise or dietary improvements was also mentioned, as was the difficulty in establishing confidentiality and trust. The report's author suggested that developing trust required long appointments, but that 'the system was against it' (Craig 2002:25).

Some GPs specifically stated that they do not get involved in mental health or drug and alcohol services. The Area Health Services for both of these had long waiting lists; apparently the GPs did not want to be burdened with the ongoing care of difficult cases while waiting for services, which ideally should have been able to provide an immediate response. As mental health and addiction services are crucial aspects of the primary health care needs of urban Aboriginal and Torres Strait Islander people, this finding raises questions about the appropriateness of mainstream GP services in meeting these needs.

GP services to the Aboriginal community in this area were used more often by women and children than by men, despite the preponderance of many conditions among men. The study concluded that links between the Aboriginal Health Service, the Area Health Service and GPs were not good with respect to services provided for the Aboriginal community, and recommendations were made to try and improve the links.

The Urbis Keys Young report, which was commissioned by Medicare Australia and the Commonwealth Department of Health and Ageing in 2005 to examine the effectiveness of MBS and PBS changes and initiatives (Urbis Keys Young 2006), noted that some Aboriginal and Torres Strait Islander people, particularly in urban areas, are in a position to choose between the use of private GPs and ACCHSs, or to use one or the other as they prefer. Reasons for choosing private GPs included greater privacy or anonymity, maintaining long-term doctor–patient relationships or simple convenience. It was suggested that the quality of care Aboriginal and Torres Strait Islander people receive from mainstream services is very variable, and recommendations were made to enhance the role of private GPs in providing health care to Aboriginal and Torres Strait Islander people.

As part of the Urbis Keys Young study, a telephone survey of a sample of GPs from postcode areas with relatively high numbers of Aboriginal and Torres Strait Islander residents was conducted in each State and Territory. Of the 407 GPs in the survey, approximately half were based in metropolitan areas.

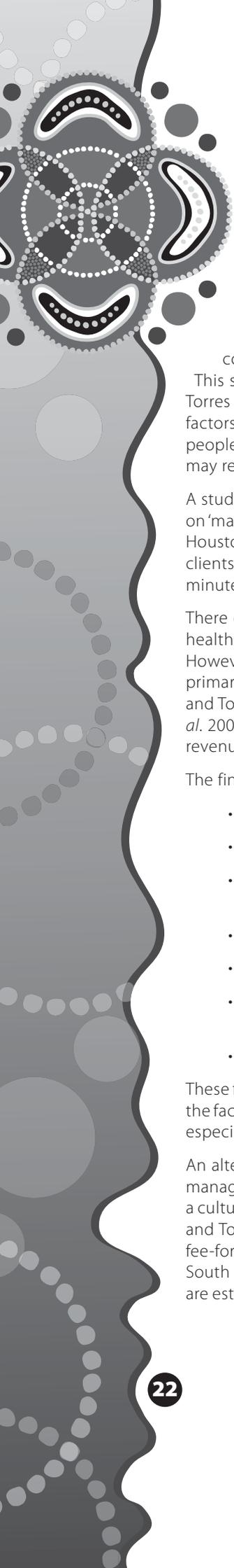
The GPs were asked for their opinions on factors that might limit the number of Indigenous people using a general practice. Answers included the following:

- availability of an ACCHS nearby (37 per cent);
- availability of another local practice or hospital that most Aboriginal and Torres Strait Islander people use (32 per cent);
- Indigenous people may not feel comfortable in a mainstream practice (27 per cent);
- cost—may not be able to afford the charges (26 per cent);
- location/transport difficulties (18 per cent);
- no Aboriginal and Torres Strait Islander people on staff (16 per cent);
- language barriers (13 per cent); and
- practice does not bulk-bill (12 per cent).

Other barriers mentioned were the practices' lack of skills or experience in Aboriginal and Torres Strait Islander health, and differing attitudes (to health and related matters) between Aboriginal and Torres Strait Islander and non-Indigenous Australians.

Although only 24 per cent of the GP respondents said that for a given illness or problem consultations with Aboriginal and Torres Strait Islander patients generally took longer than those with non-Indigenous patients, qualitative research as part of the same study indicated that consultations with Indigenous patients often took longer than average. The authors of the report suggested that this might be because Aboriginal and Torres Strait Islander patients are less likely to go to the GP regularly, and thus are more likely to have more problems, or more serious problems, by the time they present. While this might be one of the reasons for the more complex health problems experienced by Aboriginal and Torres Strait Islander patients, the authors seem to have overlooked the socioeconomic determinants of health. Aboriginal and Torres Strait Islander people who regularly attend a GP, in an ACCHS or elsewhere, also are more likely to have complex health issues compared to non-Indigenous Australians (Thomas *et al.* 1998; Larkins, Geia & Panaretto 2006). The fact that only one-quarter of GPs reported that consultations with Aboriginal and Torres Strait Islander people took longer suggests that the more complex needs of Aboriginal and Torres Strait Islander patients are often not met by mainstream GP services.

Evidence for this is also provided by other studies. The ongoing *Bettering the Evaluation and Care of Health* (BEACH) study provides an insight into the patient demographics, reasons for encounter, problems managed, treatment and referrals in mainstream general practice across Australia. The 2003 BEACH report (Britt *et al.* 2003) showed that 1.4 per cent of consultations involved Aboriginal and Torres Strait Islander people. This is significantly less than the proportion of Aboriginal and Torres Strait Islander people within the Australian community (2.2 per cent) but may be an underestimate due to under-ascertainment of Aboriginal and Torres Strait Islander status in general



practice records. The nature of problems managed for Aboriginal and Torres Strait Islander patients differed somewhat from the non-Indigenous consultations, but the number of problems managed per encounter was almost identical (147.7 per 100 Aboriginal and Torres Strait Islander encounters, compared with 148.1 per 100 total encounters). Two studies have used similar methodology to the BEACH study to investigate consultations in urban ACCHSs: Thomas *et al.* (1998) analysed data from all consultations at Danila Dilba Aboriginal Medical Service in Darwin for two separate weeks, six months apart, in 1994; and Larkins, Geia and Panaretto (2006) analysed data collected from consultations at the Townsville Aboriginal and Islander Health Service over two fortnightly periods in 2000–01. Both these studies showed that significantly more problems were managed in ACCHSs for each consultation compared to consultations with Aboriginal and Torres Strait Islander patients in mainstream general practice.

This suggests that ACCHSs are better able to manage the more complex health problems in Aboriginal and Torres Strait Islander patients; whether this is due to different fee structures, greater cultural sensitivity, other factors or a combination of factors requires further investigation. Ivanitz (2000:53) says that 'when Aboriginal people attempt to access mainstream biomedical health care, power imbalances between the doctor and patient may result in the needs of patients being unmet'.

A study of the activities of the staff of Derbal Yerrigan, the Perth ACCHS, suggested that for every dollar spent on 'mainstream equivalent services', 75 cents are spent on 'culturally secure aspects of care' (Houston 2004:172). Houston also reported on a small study by the East Perth Public Health Unit of Aboriginal and non-Aboriginal clients with sexually transmitted infections; staff time involved in finding contacts was on average over 220 minutes for Aboriginal clients and under 40 minutes for non-Aboriginal clients (Houston 2004:174).

There do not appear to be studies that have specifically investigated the financial sustainability of providing health care to urban Aboriginal and Torres Strait Islander people using the MBS as the source of funding. However, a financial analysis has been conducted of the Care and Prevention Programme, a comprehensive primary health care program for homosexual and HIV-positive men in inner-city Adelaide, who, like Aboriginal and Torres Strait Islander people, can be considered a marginalised population with complex needs (Rogers *et al.* 2005). It concluded that the program would not be sustainable with the current MBS as the only source of revenue. According to the authors:

The financing gap arose from an interacting array of factors, including:

- the proportion of patients who are bulk-billed;
- the complexity of patients needs;
- the GPs not compromising best practice, leading to longer consultations and hence a lower MBS rebate per hour;
- the need for support from a trained nurse;
- the effect of a culture that accepts 'long consultations' on the duration of consultations practice-wide;
- the strategy of some patients to see GPs only when they have more complex requirements, rather than for shorter consultations that would (paradoxically) increase the practice's MBS income per hour; and
- the additional costs of training staff (Rogers *et al.* 2005:561).

These factors are also applicable to primary care services for urban Aboriginal and Torres Strait Islander people. In the face of an MBS financing structure that limits the capacity for a comprehensive primary health care approach, especially for people with complex needs, alternative models for financing health care need to be considered.

An alternative model exists—the model provided by ACCHSs, which has been shown to be more effective at managing the complex health issues of many Aboriginal and Torres Strait Islander patients, as well as providing a culturally secure environment for the provision of health care. In the literature on health services for Aboriginal and Torres Strait Islander people in urban areas, the discussion is usually limited to two models: ACCHSs and fee-for-service general practice. A third alternative, which exists in a few major urban areas (in Victoria and South Australia) and deserves more consideration, is government-funded community health centres. As these are established in areas of low socioeconomic status, they often have a significant role in the provision of health

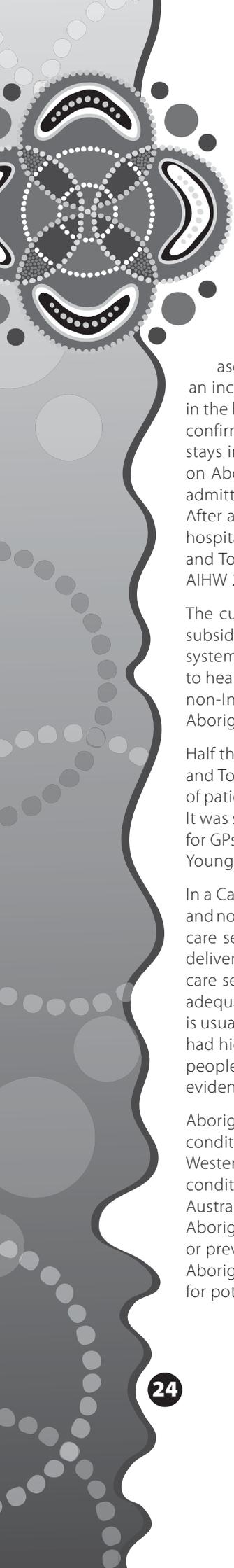
care to Aboriginal and Torres Strait Islander people. The GPs are salaried, so they are more able to provide the care needed for people with complex health needs, and in many cases the health staff members have extensive experience working in Aboriginal and Torres Strait Islander health so are more likely to provide a culturally secure environment. Community health services, with salaried GPs and often Aboriginal Health Workers, are 'mainstream' in that they are not Indigenous-specific, and provide a model that can potentially address the health care needs of urban Aboriginal and Torres Strait Islander people and other disadvantaged groups in more deprived urban areas.

Firebrace *et al.* (2001) describe the role of a Koori health worker in a mainstream community health service in Melbourne. The Koori worker was able to establish a strong relationship with the local Koori community and to build effective working relationships with, and referral pathways to, health care providers, including GPs.

A report on community perspectives on community health services in South Australia found that in that state there were two models of primary health care: fee-for-service general practice and publicly funded community health services (Warin *et al.* 1998). (The role of ACCHSs was not mentioned, but these could be considered Indigenous-specific publicly funded community health services.) Eighty per cent of community members interviewed confirmed that there are differences between each model, with 95 per cent of these preferring the community health service model. The main positive features were having more time with the doctor; being treated as a 'whole person'; more choice and control; focus on health promotion and disease prevention; access to other services; and greater opportunities for community participation.

Despite the potential for these alternative models to provide better primary health care for Aboriginal and Torres Strait Islander people, the emphasis in recent years has been on reforming the MBS, which is based on the fee-for-service model. The MBS reforms that were introduced after the 1997 Keys Young review (outlined in Urbis Keys Young 2006) had three components: (1) allowing salaried ACCHS doctors (and Aboriginal Health Workers in some situations) to claim Medicare rebates, which effectively only saves money for one part of the Department of Health and Ageing by getting funds from another part; (2) making it easier for Aboriginal and Torres Strait Islander people to get Medicare cards, and for their health providers to access their Medicare details; and (3) introducing a Medicare item to allow GPs to be reimbursed for a comprehensive health check on Aboriginal and Torres Strait Islander patients. The Urbis Keys Young report (2006) showed that these reforms had the effect of increasing Aboriginal and Torres Strait Islander enrolment in Medicare and the claiming of Medicare rebates on behalf of Aboriginal and Torres Strait Islander people. The report did not produce any evidence that these improvements have had any effect on Aboriginal and Torres Strait Islander morbidity, disability and mortality. Given the limitations of the fee-for-service model of health care for Aboriginal and Torres Strait Islander people (with their complex health issues and cultural need), and that claiming of Medicare reimbursement by health professionals is based on the fee-for-service model, MBS reforms alone may not be sufficient to address Aboriginal and Torres Strait Islander health care needs in urban areas.

The PBS reforms that were introduced after the 1997 Keys Young report (Urbis Keys Young 2007) have had the effect of improving access for Aboriginal and Torres Strait Islander people to essential medications, but only in remote areas. The use of S100 of the National Health Act has enabled supply of PBS medicines to clients of eligible and approved Aboriginal and Torres Strait Islander health services in remote areas. This means that in remote communities Aboriginal and Torres Strait Islander people can have their medications dispensed from their health centres without any co-payment. In urban areas Aboriginal and Torres Strait Islander people still need to present a prescription to a pharmacist and pay the required co-payment for their medications. Given the fact that many Aboriginal and Torres Strait Islander people are poor, and often have complex health problems requiring several medications, this continues to present a significant barrier to optimal health care for many urban Aboriginal and Torres Strait Islander people (Couzos 2005). The National Aboriginal Community Controlled Health Organisation has been active in lobbying the federal government to address this problem. It appears that some limited reforms to improve access to medications for urban Aboriginal and Torres Strait Islander people may be announced soon (Couzos 2006).



2.4 The pathways into and out of secondary and tertiary health services use by Aboriginal and Torres Strait Islander people living in urban areas

Secondary health services are specialist health services and are usually provided in the hospital setting. Tertiary health services are the more specialised hospital services, which are located in metropolitan centres, to which people with serious medical conditions are referred from other hospitals without the same facilities.

Data on utilisation of hospitals by Aboriginal and Torres Strait Islander people are limited by inaccurate ascertainment of Aboriginal and Torres Strait Islander status in many jurisdictions. However, there has been an increasing focus on the implementation of strategies to improve the quality of health information systems in the hospital sector (ABS & AIHW 1997; Anderson *et al.* 2002). As the quality of data has improved, research has confirmed that Aboriginal and Torres Strait Islander people are more likely to be admitted to hospital, have longer stays in hospital and have more complex problems (Ishak 2001; Anderson *et al.* 2002). Per capita expenditure on Aboriginal and Torres Strait Islander people (compared to non-Indigenous people) is 1.6 times higher for admitted hospital patients and 1.9 times higher for non-admitted hospital patients (ABS & AIHW 2005:180). After adjusting for age, Aboriginal and Torres Strait Islander people are about twice as likely to be admitted to hospitals as other Australians (ABS & AIHW 2005:198). About 94 per cent of hospitalisations involving Aboriginal and Torres Strait Islander people are in public hospitals, compared to 60 per cent for other Australians (ABS & AIHW 2005:198).

The current government spends a significant amount of the health budget on the private health insurance subsidy to encourage people to take out private health insurance. With an increasingly privatised health care system, people without private health insurance are becoming more and more disadvantaged in their access to health care, particularly to specialist care and hospital procedures. In the 2001 National Health Survey urban non-Indigenous adults were three times more likely to report having private health insurance than urban Aboriginal and Torres Strait Islander adults (AIHW 2005).

Half the GP respondents in the Urbis Keys Young report identified problems with regard to referring Aboriginal and Torres Strait Islander people to specialist services (including imaging and pathology), particularly because of patient discomfort and lack of culturally appropriate services, or for cost reasons (e.g. services not bulk-billed). It was said that referral of Aboriginal and Torres Strait Islander patients to specialists tend to be time-consuming for GPs because patients may have limited recall or understanding of their previous medical history (Urbis Keys Young 2006).

In a Canadian study Shah, Gunraj and Hux (2003) examined the discharge diagnoses for hospitalised Aboriginal and non-Aboriginal patients in Ontario, Canada. The authors developed three categories of diagnoses: ambulatory-care sensitive (ACS) conditions (those conditions for which high-quality appropriate primary health services deliverable under ideal circumstances are thought to potentially eliminate the need for hospitalisation), referral-care sensitive (RCS) procedures (which require access to specialists and tertiary care centres and also require adequate primary care to identify the need for referral) and insensitive conditions (those for which hospitalisation is usually considered obligatory and not directly preventable with outpatient care). Canadian Aboriginal people had higher rates of hospitalisation for ACS conditions and lower rates of RCS procedures, than non-Aboriginal people; this persisted even after controlling for remoteness and socio-economic status. There is increasing evidence that a similar situation exists for Australian Aboriginal and Torres Strait Islander people.

Aboriginal and Torres Strait Islander people have higher rates of admission to hospitals for 'ambulatory-sensitive' conditions. In study of 1993–94 hospital separation data from New South Wales, Queensland, South Australia, Western Australia and the Northern Territory, age-specific acute hospital separation rates for ambulatory-sensitive conditions were 1.7 to 11 times higher for Aboriginal and Torres Strait Islander populations than for other Australians (Stamp *et al.* 1998). Ishak (2001), using New South Wales data from 1989 to 1995, also found that Aboriginal and Torres Strait Islander people were more likely than other Australians to be admitted for primary or preventable conditions. In 2003–04 the Australian Institute of Health and Welfare (2005:200) estimated that Aboriginal and Torres Strait Islander people were seven times as likely as other Australians to be hospitalised for potentially preventable chronic conditions.

A study of Aboriginal and Torres Strait Islander perinatal mortality, which is double that of the rest of the community, also provided support for the need for greater investment in primary health care. The authors found that the excess perinatal mortality is because Aboriginal and Torres Strait Islander babies are born too early and too small, rather than because of factors related to inadequate hospital care (Johnston & Coory 2005). They conclude that to reduce the mortality rate, priority should be given to primary health care interventions (e.g. interventions to reduce mortality smoking or genitourinary infections) rather than improving access to high-quality hospital care.

While the age-adjusted rate of medical admissions for Aboriginal and Torres Strait Islander people to hospitals in New South Wales from 1989 to 1995 was approximately double that of non-Indigenous people, the non-Indigenous rate for surgical procedures was approximately 1.3 times the Aboriginal and Torres Strait Islander surgical admission rate. Aboriginal and Torres Strait Islander people were more likely to be admitted for emergency surgery rather than for planned surgery, and while approximately 25 per cent of surgical admissions for Aboriginal and Torres Strait Islander people was through emergency departments, the proportion was only 14 per cent in the non-Indigenous population (Ishak 2002). An analysis of the National Hospital Morbidity database 1997–98 showed that Aboriginal and Torres Strait Islander public hospital patients were significantly less likely than other patients to have a principal procedure recorded, even after adjusting for patient, episode and hospital characteristics (Cunningham 2002b). In 2003–04 the Australian Institute of Health and Welfare (2005:202) reported that 72 per cent of hospitalisation episodes involving Aboriginal and Torres Strait Islander patients included the performance of a procedure, compared with 81 per cent of hospitalisation episodes for other Australians. When care involving renal dialysis was excluded, 54 per cent of Aboriginal and Torres Strait Islander hospitalisation procedures included a procedure being performed compared with 79 per cent of non-Indigenous hospitalisation episodes.

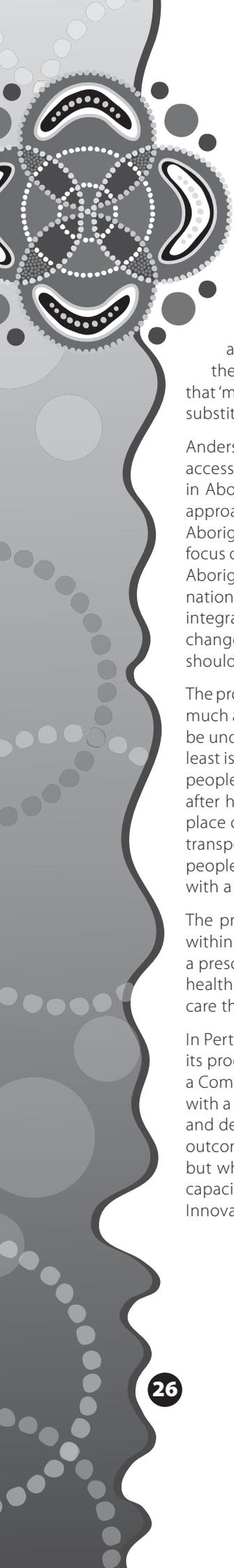
A cohort study of public sector patients with heart attacks admitted to Queensland hospitals between 1998 and 2002 found that Aboriginal and Torres Strait Islander patients were 22 per cent less likely to have a coronary revascularisation procedure (angioplasty or bypass surgery) following heart attack than non-Indigenous patients (Coory & Walsh 2005). The authors suggested that there were at least four possible reasons why Aboriginal and Torres Strait Islander patients have relatively low rates of coronary procedures.

First, relative contraindications such as co-morbidities, smoking and obesity may be more common. Second, Aboriginal and Torres Strait Islander people may prefer not to have the procedure. Third, Aboriginal and Torres Strait Islander people may have less access to procedures because they are more likely to live in remote areas and be admitted to small hospitals. Fourth there may be discrimination, albeit subtle, in the public hospital system (Coory & Walsh 2005:509).

The authors suggested that the high rate of co-morbidities was probably a significant factor, and they advised investment in primary care to reduce the prevalence and severity of co-morbidities.

A recent review by the Australian Institute of Health and Welfare (Mathur, Moon & Leigh 2006) found that compared with other Australians, Aboriginal and Torres Strait Islander people are more likely to suffer a heart attack, to die from it before being admitted to hospital, and to die from it if admitted to hospital. In hospital they were less likely to receive key medical investigations or common procedures such as bypass surgery or angioplasty. They also found that Aboriginal and Torres Strait Islander people admitted to hospital for coronary heart diseases have more co-morbidities than other Australians, but this did not appear to account for differences in procedure rates.

While these findings suggest a range of barriers to Aboriginal and Torres Strait Islander people receiving the same level of health care as other Australians, delays in actually accessing hospital care (which are suggestive of problems with the interface between primary care and the acute sector) may be a significant factor. Urban and non-urban Aboriginal people in the Northern Territory (as well as non-urban non-Aboriginal people) were found to experience significant delays in management of acute myocardial infarction (Ong & Weeramanthri 2002).



A review of published Australian literature about emergency department (ED) care of Aboriginal and Torres Strait Islander people showed that Aboriginal and Torres Strait Islander people attend EDs about twice as often as other Australians. The waiting times of Aboriginal and Torres Strait Islander patients are similar to, or slightly shorter than, those of non-Indigenous patients. However, more Aboriginal and Torres Strait Islander patients choose to walk out before being seen, which the authors of the review suggest may reflect greater Aboriginal and Torres Strait Islander dissatisfaction with ED care (Thomas & Anderson 2006).

Thomas and Anderson (2006) found no clear picture from the literature about how many Aboriginal and Torres Strait Islander people use the ED as a substitute for primary care provided by ACCHSs or GPs; they suggest that it is the task of future researchers to assess whether such a pattern exists. They also note that 'more important than questions about whether substitution is occurring are questions about whether this substitution leads to better or worse medical care for Indigenous patients' (Thomas & Anderson 2006:73).

Anderson *et al.* (2002) examine the extent to which strategies to improve Aboriginal and Torres Strait Islander access to acute care and related hospital services have been integrated with the current national strategy in Aboriginal and Torres Strait Islander health. They note that at a local level many hospitals have developed approaches to improve Aboriginal and Torres Strait Islander access to hospitals through the employment of Aboriginal advocates, liaison officers and interpreters. However, they argue that there has been insufficient focus on the interface between the primary and acute sectors. They further suggest that if strategies to improve Aboriginal and Torres Strait Islander access to the secondary and tertiary health care sector are to integrate with national strategies in Aboriginal and Torres Strait Islander health, implementation mechanisms are required to integrate hospital-based quality assurance processes with existing reform initiatives. To ensure organisational change, they recommend that standards and guidelines developed as part of such quality assurance processes should be linked with hospital accreditation.

The problems faced by Aboriginal and Torres Strait Islander people after discharge from hospital have not received much attention by researchers. The assumption is made that once people are discharged from hospital they will be under the care of their 'usual GP'. The fact that some people may not have a usual GP is not attended to, or at least is not seen as being the problem of the hospital. The result is that many Aboriginal and Torres Strait Islander people, who have higher rates of hospitalisation than non-Indigenous people, do not get adequate follow-up after hospitalisation. This is obviously a problem for Aboriginal and Torres Strait Islander people whose usual place of residence is outside the urban area in which the hospital is situated, and who do not have immediate transport arranged back to their home community (and so are temporarily 'Aboriginal and Torres Strait Islander people living in urban areas'). However it can also be a problem for Aboriginal and Torres Strait Islander people with a more permanent connection to the urban area.

The problem of inadequate follow-up after discharge particularly relates to medications. The usual practice within hospitals is to provide only a few days of ongoing medication; it is the responsibility of the patient to get a prescription from a GP to ensure continuity. Many Aboriginal and Torres Strait Islander people, with complex health problems, are discharged with a number of medications, but due to lack of access to appropriate primary care the medications are soon discontinued.

In Perth the Canning Division of General Practice established an Aboriginal Primary Health Care Team to ensure its programs and activities acknowledge and provide for these people in the community. The team developed a Community GP Links project that links Aboriginal and Islander patients discharged from Royal Perth Hospital with a local GP of their choice within the Canning region. Liaison officers worked with the patient to encourage and develop relationships with their GP and with other organisations and services within the community. The outcomes, according to a previous posting on the Canning Division's website <www.canningdivision.com.au> but which is no longer accessible, were improved continuity of care, access to local health service providers, capacity building and development of self-esteem, reduced re-admission rates and better health outcomes. Innovations such as this deserve wider dissemination and appropriate evaluation and emulation.

2.5 Particular health issues with problems of access

2.5.1 Dental care

Oral health is an important but often neglected aspect of primary health care, and Aboriginal and Torres Strait Islander people have higher rates of dental caries in children (Roberts-Thomson 2004) and higher rates of periodontal disease than other Australians (Commonwealth Department of Health and Ageing 2003). There appears to be little published data on access of urban Aboriginal and Torres Strait Islander people to dental care, but there seems little doubt that the long waiting lists for public dental services and the financial barriers to private dental services would significantly reduce access. In some areas ACCHSs have been able to overcome some of the problems in accessing dental services by providing such services as part of comprehensive primary care (see, for example, Parker *et al.* 2005).

2.5.2 Addictions

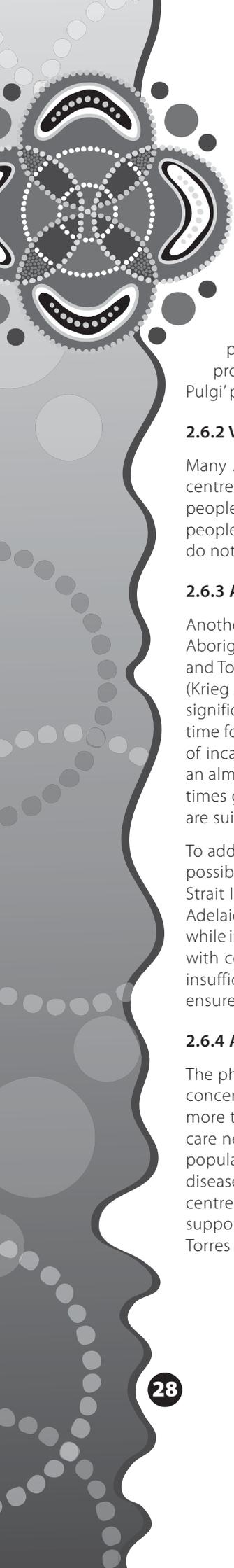
The urban Aboriginal and Torres Strait Islander population is significantly affected by alcohol abuse and the abuse of illicit drugs, and prevention, treatment and rehabilitation services in urban areas are an essential element of their health care needs (NACCHO 2001). In a review of substance abuse and primary care among Aboriginal and Torres Strait Islander people, Gray *et al.* (2004:ix) make the following points:

- specific alcohol and drug services only reach a small proportion of Indigenous people;
- primary health care services reach most of the Indigenous population and have the potential to have significant impacts on Indigenous alcohol and substance misuse;
- programs to reduce alcohol and misuse harm that appear to be useful are run within ACCHSs in a number of areas;
- programs within primary health care services to address alcohol and substance abuse and harm currently have very little resources and are unable to address the need for them;
- general practice-based primary care currently only provides reactive services for substance misuse harm and private GP involvement in broader services is ad hoc and based on the goodwill of individual practitioners;
- primary health care services (ACCHSs, GPs, and State and Territory government services) have the potential to do much more to prevent and ameliorate alcohol and substance misuse harm if allocated appropriate resources; and
- programs to address substance misuse and related harms should be based within primary health care services that reach the broader Indigenous community and need to focus on working collaboratively with the many other agencies attempting to address these problems.

In 2003 the Canadian Population Health Initiative convened a meeting in Winnipeg, Manitoba, of Aboriginal leaders on the health of urban Canadian Aboriginal people. The participants' vision for the future was that 'accessible, spiritually based treatment would be available for addictions and other health problems, and care would be provided by qualified Aboriginal professionals working out of community multipurpose health centres where holistic, "one-stop shopping" care would be available' (Canadian Population Health Initiative 2003:3). What is notable about this statement is the prominence given to the need for addiction treatment services.

2.5.3 Mental health care

Despite the fact that Aboriginal and Torres Strait Islander people are disproportionately affected by mental health disorders, and are twice as likely to be hospitalised for mental and emotional conditions than non-Aboriginal people, community mental health services do not adequately meet the needs of Aboriginal and Torres Strait Islander people living in urban areas (NACCHO 2001). Although cautions were expressed about the quality of the data, the Australian Bureau of Statistics and Australian Institute of Health and Welfare (2005) estimated that after adjusting for age, the rate at which community mental health services are accessed by Aboriginal and Torres Strait Islander people is 1.4 times that of other Australians.



2.6 Aboriginal and Torres Strait Islander urban sub-populations with particular access needs

2.6.1 'Homeless' Aboriginal and Torres Strait Islander people

The significant number of Aboriginal and Torres Strait Islander people who are homeless or public-place dwellers within urban areas represents a sub-population that presents particular problems with regard to health care access, and concerns have been expressed that current government policies are likely to lead to an increase in the number of people in this category (Memmott *et al.* 2004). Mainstream general practices are not well equipped to provide the kind of services required. Some ACCHSs have developed programs to extend services to homeless Aboriginal and Torres Strait Islander people; an example is the 'No Pulgi' program run by Nunkuwarrin Yunti in Adelaide (Nunkuwarrin Yunti 2006).

2.6.2 Visitors from remote communities

Many Aboriginal and Torres Strait Islander people from rural and remote communities spend time in urban centres for varying periods of time and for various reasons. As such they are 'Aboriginal and Torres Strait Islander people living in urban areas' if only temporarily. Some of these people fit into the above category of homeless people but some have a residence, often boarding with relatives. They have particular health needs but often do not have a regular primary care provider within the urban area.

2.6.3 Aboriginal and Torres Strait Islander people in custody

Another reflection of Aboriginal and Torres Strait Islander disadvantage is the disproportionately high numbers of Aboriginal and Torres Strait Islander people in prisons. National age-standardised incarceration rates for Aboriginal and Torres Strait Islander people is around ten times the rate for non-Indigenous people, and the figure is rising (Krieg 2006). Most prisons are in urban areas, and incarcerated Aboriginal and Torres Strait Islander people have significant health care needs while in prison and after discharge. The post-release period, in particular, is a crucial time for the provision of integrated health and social services to address these priorities and to break the cycle of incarceration (Krieg 2006; Binswanger *et al.* 2007). Released Aboriginal prisoners in Western Australia have an almost ten-times greater risk of death than the general Western Australian population and an almost three-times greater risk of death compared with their Aboriginal peers in the community. The main causes of death are suicide, drug- and alcohol-related events, and motor vehicle accidents (Stewart *et al.* 2004).

To address these needs, according to Krieg (2006:535), 'dedicated services are required. Mainstreaming cannot possibly address the complexity of needs for Aboriginal families'. Krieg's experience with Aboriginal and Torres Strait Islander prison health services came from working on a program established by Nunkuwarrin Yunti, the Adelaide ACCHS. Nunkuwarrin Yunti's Prisoner Health Team provides primary care services for Aboriginal people while in prison and when returning to the community, and integrated discharge planning for Aboriginal prisoners with complex needs. In the 2004–05 Nunkuwarrin Yunti annual report it was noted that 'current services are insufficient to meet demand due to limited resources available and the barriers and hurdles to be crossed to ensure effective outcomes are met' (Nunkuwarrin Yunti 2006:12).

2.6.4 Aboriginal and Torres Strait Islander youth

The physical and mental health of Aboriginal and Torres Strait Islander young people in urban areas is a major concern (NACCHO 2001). Aboriginal and Torres Strait Islander youth aged between ten and twenty-four constitute more than one-third of the urban Aboriginal and Torres Strait Islander population, and have important health care needs, particularly in relation to sexual health, mental health and substance abuse. They also represent a population that should be targeted for preventive health care to help ameliorate the epidemic of adult chronic disease in the Aboriginal and Torres Strait Islander population. Young people are often reticent to attend health centres; in a 1991 report on the health of young Aboriginal and Torres Strait Islander people, Brady recommended support for locally run, low-profile drop-in centres, youth groups and youth health services for Aboriginal and Torres Strait Islander people in country towns and urban centres (Brady 1991:42).

2.6.5 Torres Strait Islanders

Today 85 per cent of all Torres Strait Islanders are resident on mainland Australia, mainly in urban centres of north Queensland, as well as in Brisbane and Sydney, rather than on the islands of the Torres Strait (Taylor 2006). A study of issues of access and attitudes to health care by Torres Strait Islanders living in urban centres on mainland Australia (Ban 2004) found that in general they were not comfortable seeking medical treatment and delayed accessing any health service. Most used ACCHSs, followed by private medical services and hospital outpatient services. The most common reason given for the choice of type of service was convenience and access and quality of the relationship and trust with the medical staff. Respondents expressed a high level of satisfaction with the private medical services they used; concerns were expressed about long waiting times in ACCHSs and as hospital outpatients, and there were confidentiality concerns at ACCHSs.

2.7 Barriers to access to health care

The evidence presented in previous sections of this chapter suggests that Aboriginal and Torres Strait Islander people living in urban areas have significant problems with access to health care. Tom Calma, the Aboriginal and Torres Strait Islander Social Justice Commissioner (HREOC 2005), positions the problem of access to health services experienced by Aboriginal and Torres Strait Islander people as being related to systemic discrimination. The Commission argues that, historically, Aboriginal and Torres Strait Islander people have not had the same opportunity to be as healthy as non-Indigenous people:

This occurs through the inaccessibility of mainstream services and lower access to health services, including primary health care, and inadequate provision of health infrastructure in some Aboriginal and Torres Strait Islander communities. The Royal Australasian College of Physicians describes these health inequities as 'both avoidable and systematic'. This legacy remains to be fully addressed and is a significant barrier to the full enjoyment of the right to health for Aboriginal and Torres Strait Islander peoples (HREOC 2005:13).

Otim (2001) suggests that it is necessary to explore the nature of barriers faced by Indigenous Australian communities and individuals in their attempts to access and consume mainstream primary health care services. In addition, he suggests that subsequent research is required to establish why those barriers exist and what can be done to reduce them. Barriers to primary health care access by Aboriginal and Torres Strait Islander people are framed by Otim (2001) as being related to factors that are locational, economic and/or sociocultural. In other words, the barriers relate to availability, affordability and acceptability. To these three barriers, another barrier related to the appropriateness of health services for the health needs of urban Aboriginal and Torres Strait Islander people could be added. These will be considered in turn.

2.7.1 Availability

While locational barriers are generally associated with Aboriginal and Torres Strait Islander people living in rural and remote areas rather than in urban areas, Aboriginal and Torres Strait Islander people living in urban areas are disproportionately represented within the lower socioeconomic strata, and are disproportionately concentrated within low socioeconomic suburban areas with relatively poor access to health services (but usually not the services that contribute to poor health such as fast-food outlets, illicit drugs, poker machines and alcohol).

2.7.2 Affordability

The close connection between poverty and poor health is one of the most robust findings of social epidemiology (Baum 1998). The fact that poverty also limits access to health-promoting information, services, medications and technologies compounds the problem. The mean equivalent household income of Aboriginal and Torres Strait Islander people in 2003 was only 59 per cent of the corresponding income of non-Indigenous people (ABS & AIHW 2005).

Since the Keating Labor government introduced a co-payment for PBS-subsidised medications (which has been increased by the Howard Coalition government), the cost of medications, particularly for the many middle-aged and older Aboriginal and Torres Strait Islander people with multiple chronic diseases, has become a significant barrier to effective health care.



The impact of poverty on accessibility of health care is not limited to the direct costs of health care. For example, the National Aboriginal and Torres Strait Islander Health Survey showed that 18 per cent of urban Aboriginal and Torres Strait Islander people do not have a working telephone, which has implications for health emergencies when hospitals, ambulances and doctors need to be contacted quickly (AIHW 2005).

2.7.3 Acceptability

There are a number of barriers that continue to restrict the access of Aboriginal and Torres Strait Islander peoples to quality health care in Australia. Some of these barriers are structural in terms of poor linkages and co-ordination across the system, some are socio-economic, some are about the availability and distribution of services and some are clearly cultural. These include health service provider attitudes and practice, communication issues, mistrust of the system, poor cultural understanding and racism. The availability of health services including mainstream health services that are culturally equipped to provide services to Aboriginal and Torres Strait Islander peoples is one of the key factors that will contribute to improved health outcomes (AHMAC 2004)

While locational and economic barriers to health care access are clearly significant for urban Aboriginal and Torres Strait Islander people, it is arguable that sociocultural issues are more significant. Heggenhougan (1991) has argued that acceptability is more important than availability or affordability as a determinant of utilisation of health care services.

The report of the Western Australian Health Reform Committee, *A Healthy Future for Western Australians*, points out that in addition to considering access issues in geographical/distance terms, 'it is also important to recognise that access should be seen more broadly as being about barriers to use, as perceived by the potential patient' (Western Australian Department of Health 2004:41). Further:

This wider definition then allows issues of cultural barriers to be included which are especially important for Aboriginal people. Services which are 'culturally secure' for Aboriginal people are ones where the cultural barriers for them are no greater than for non-Aboriginal people. Too often in Western Australia (and the rest of Australia) services fall well short of being culturally secure. The committee has identified this as one of the most important sources of inequity in the Western Australian Health System. If progress is to be made in improving Aboriginal health then improved access for Aboriginal people to hospital care must be a priority (WA Department of Health 2004:41).

Houston (2004) provides an account of the notion of cultural security as this relates to the provision of health care services for Aboriginal and Torres Strait Islander peoples in Australia. He asserts that mainstream health services are based on non-Aboriginal culture and that this situation represents a barrier to access because of the insufficient consideration given to the cultural security of Aboriginal and Torres Strait Islander people. In a discussion of the experiences of Aboriginal and Torres Strait Islander people living in urban metropolitan areas, he explains that people commonly demonstrate a preference for accessing community-controlled health services because services are delivered by these services in ways that are considered culturally secure. In this situation, it is the quality (or cultural appropriateness) of service and not geographic proximity that is most important to consider. Houston (2004:169) explains:

In metropolitan Australia ... mainstream health services may be located 'just around the corner' but Aboriginal people often travel long distances to get AMS's such as Derbal Yerrigan in Perth and the Victorian AMS in Melbourne.

Similarly, Paul (1998:69) quoted a statement by Aboriginal leader Ted Wilkes that for Perth Aboriginal people accessing health care 'there is a psychological distance which is as great in its effect as geographical distance experienced by Aborigines in the north of the state'.

Houston questions the assumption that if you live in geographic proximity to a service, then access is considered equal. He makes the point that:

Such problems can also apply, perhaps in varying ways, to Aboriginal and Torres Strait Islander communities in urban, rural and remote settings, a point often overlooked, particularly in respect of urban communities. The assumption there is generally that, if you live in close geographic proximity to a service, then access is often considered equal. Such simplistic thinking overlooks the substantial unfreedoms suffered by Aboriginal and Torres Strait Islander communities especially in settings where they are a minority either as a proportion of the total population or as a proportion of the service users (Houston 2004:166).

Recognition of difference both between and within so-called 'communities' of Aboriginal and Torres Strait Islander peoples in Australia is positioned as a key to the development of health service delivery that is culturally secure and respectful. Houston (2004) points out that in considering the role of cultural security it is important to remember that there is not a single homogeneous Aboriginal culture and that important regional variations exist. He explains the importance of this recognition as follows:

The movement towards culturally secure health services must proceed with a strong appreciation of the fact that the cultural life of Aboriginal Peoples, be they Ngaanyatjarra, Nyoongars, Pintubiu or Badi, is not the same. There is not a single homogeneous Aboriginal culture; there are important regional variations. There is a wholeness in Aboriginal life but it is within the context of being peoples (Houston 2004:120).

The National Strategic Framework for Aboriginal and Torres Strait Islander Health Strategy states that one of the barriers to health care is 'a workforce that is largely non-Indigenous and not trained in the issues relevant to Aboriginal and Torres Strait Islander individuals, families and communities' (NATSIHC 2004:20). In the Urbis Keys Young report, only 21 per cent of the GPs in the sample said they had any specific training related to Indigenous health; 42 per cent said that apart from their current practice they had other experience with Aboriginal and Torres Strait Islander patients; and 44 per cent said that their Division of General Practice provided some assistance, advice or training to GPs working with Aboriginal and Torres Strait Islander patients (Urbis Keys Young 2006).

As well as ensuring better training in Aboriginal and Torres Strait Islander health for the non-Indigenous health workforce, increasing the number of Aboriginal and Torres Strait Islander health care providers is another obvious way of improving cultural security in health care for Aboriginal and Torres Strait Islander people.

About one in twelve (8 per cent) urban Aboriginal and Torres Strait Islander people reported more difficulty than remote Aboriginal and Torres Strait Islander people in understanding and/or being understood by service providers (AIHW 2005). This is not as high as in remote areas (where it is 19 per cent) but it indicates a problem of acceptability of health services.

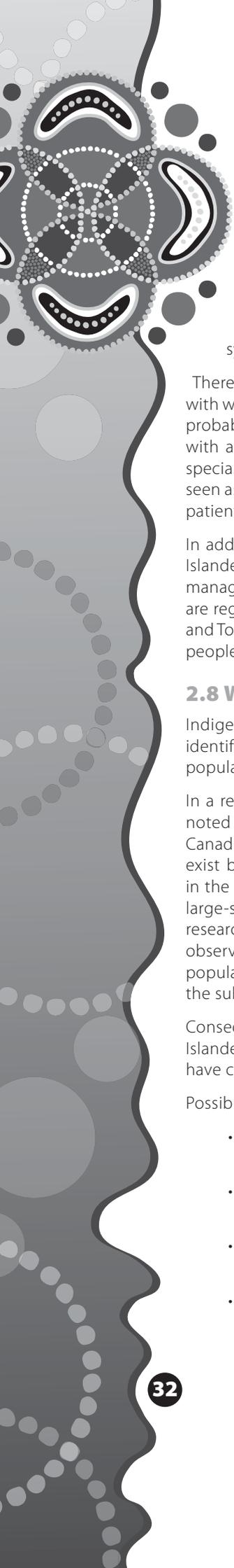
The notions of cultural security and cultural respect in health service delivery for Aboriginal and Torres Strait Islander people have only started to appear in the Australian literature in the past decade or so. There is an international literature, particularly from North America, that has led to an increased currency for the notion of cultural security for minority groups, particularly Indigenous peoples, in service delivery and research (see next chapter). Shane Houston's PhD thesis (Houston 2004) explores the issue in depth, and the Australian Health Ministers' Advisory Council Standing Committee on Aboriginal and Torres Strait Islander Health's *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health* (AHMAC 2004) is another key document. In this document, cultural respect is described as follows:

Recognition, protection and continued advancement of the inherent rights, cultures and traditions of Aboriginal and Torres Strait Islander Peoples.

Cultural Respect is achieved when the health system is a safe environment for Aboriginal and Torres Strait Islander peoples and where cultural differences are respected.

The goal of Cultural Respect is to uphold the rights of Aboriginal and Torres Strait Islander peoples to maintain, protect and develop their culture and achieve equitable health outcomes (AHMAC 2004:7).

The literature on access to all levels of health care for Aboriginal and Torres Strait Islander people living in urban areas suggests that cultural security and cultural respect remain fundamental principles for ACCHSs, but are often not achieved in other health services.



2.7.4 Appropriateness

One of the barriers to health care access for Aboriginal and Torres Strait Islander people living in urban areas that emerges from the literature discussed above is the poor performance of the health system in meeting the needs of those with complex and multiple health conditions. Whether this issue comes under the rubric of 'cultural security' is debatable. Houston (2004) appears to suggest that it could be considered as a component of cultural security, but it is a problem that is not just confined to Aboriginal and Torres Strait Islander people; newly arrived refugees and people living with HIV are other examples of groups with complex health problems who present challenges for the health care system.

There is evidence that fee-for-service primary medical care does not deal well with the complex health problems with which many Aboriginal and Torres Strait Islander people present, and this failure of the primary care system probably contributes to the higher rate of admission for Aboriginal and Torres Strait Islander people to hospital with ambulatory-sensitive conditions. Once in hospital, individuals are usually admitted under a particular speciality that deals with the presenting problem, but not necessarily with related conditions, which may be seen as the responsibility of other specialties. After discharge from hospital, Aboriginal and Torres Strait Islander patients do not always receive the follow-up that is required.

In addition, there are particular health issues that are more common within the Aboriginal and Torres Strait Islander population (particularly mental health problems and alcohol and other drug misuse) that are not well managed within the present health care system. Mainstream mental health care and alcohol and drug programs are regularly portrayed as being in 'crisis', but even within this crisis situation there is evidence that Aboriginal and Torres Strait Islander people do not utilise the services that are available at the same rate as non-Indigenous people.

2.8 What we do not know

Indigenous health research in Australia has focused more on the 'size of the problem' rather than on the identification of ways to respond to observed differences in health status between Indigenous and mainstream populations (Hunt 2005).

In a review of 254 research papers on Aboriginal populations in Canada cited in Medline, Kue Young (2003) noted that only five provided data on urban Aboriginal people, despite the fact that over 40 per cent of Canadian Aboriginal people live in urban areas. This, he suggested, was an example of the discrepancies that exist between published research and the actual health needs of Canada's Aboriginal population. Similarly in the Australian context, a 1991 analysis of a decade of Aboriginal health research found a predominance of large-scale, descriptive studies, and research focusing on remote communities and on children (Lake 1992). Few research reports focused on urban populations, or on developing or evaluating appropriate responses to the observed differences in health status. Despite constituting over half of the Aboriginal and Torres Strait Islander population in Australia, the health situation and health needs of people living in urban situations have been the subjects of only limited research.

Consequently, there is the potential for research into aspects of health care access for Aboriginal and Torres Strait Islander people living in urban areas, which could have benefits on health outcomes. The literature review we have conducted identifies some deficits in the available information that need to be addressed.

Possible research questions include:

- What is the connection between the health status of Aboriginal and Torres Strait Islander people living in urban areas and the barriers to health care access?
- Within the Australian health care system, what is an appropriate level of expenditure for primary health care for Aboriginal and Torres Strait Islander people living in urban areas, given the level of need?
- What are the health-seeking behaviours of Aboriginal and Torres Strait Islander people living in urban areas?
- What are the financial barriers to health care access for Aboriginal and Torres Strait Islander people living in urban areas?

- What makes a primary, secondary or tertiary health service culturally secure?
- What are the components of primary care services that make it acceptable and appropriate for Aboriginal and Torres Strait Islander people living in urban areas?
- What are the most appropriate models of primary health care delivery for Aboriginal and Torres Strait Islander people living in urban areas?
- What should be the role of mainstream health services in improving health outcomes for Aboriginal and Torres Strait Islander people living in urban areas?
- How can mainstream health care services become more acceptable and appropriate for Aboriginal and Torres Strait Islander people living in urban areas?
- How can the interface between the primary care sector and the acute sector be improved to ensure better health outcomes for Aboriginal and Torres Strait Islander people living in urban areas?
- What can be done to improve the management of mental health addiction problems for Aboriginal and Torres Strait Islander people living in urban areas within primary health care?
- How can access to health care be improved for particular groups of Aboriginal and Torres Strait Islander people living in urban areas (e.g. homeless Aboriginal and Torres Strait Islander people, Aboriginal and Torres Strait Islander people visiting from remote areas, Aboriginal and Torres Strait Islander people in or recently discharged from prison, youth, Torres Strait Islanders)?

2.9 Conclusion

There has been only a limited amount of research into issues of health care access for Aboriginal and Torres Strait Islander people living in urban areas, and culturally safe research that addresses some of the outstanding issues is needed. However, the literature agrees that there are significant barriers to accessing health care for Aboriginal and Torres Strait Islander people living in urban areas. This was the case thirty-five years ago, when Aboriginal activists in Sydney founded the Redfern Aboriginal Medical Service. The ACCHS movement has probably been the most significant development that has improved access to health care for Aboriginal and Torres Strait Islander people living in urban areas by providing culturally secure medical care for people with complex health needs, and providing special services for particular groups and to meet particular health needs. Despite the development of ACCHSs over the past thirty-five years, barriers to health care access persist. The current emphasis on increasing Aboriginal and Torres Strait Islander access to mainstream services in urban areas is obviously important, but unless it is complemented by strategies that recognise the unique needs (and strengths) of the Aboriginal and Torres Strait Islander communities, the limited evidence from the literature suggests the problems will continue.

2.10 Main points

- Despite the fact that urban Aboriginal and Torres Strait Islander people suffer significant health problems, expenditure on health services for this population is not only less than for their rural and remote counterparts, but also less than for urban non-Indigenous people.
- The literature identifies a broad range of potential barriers to health service access by Aboriginal and Torres Strait Islander people. Specific factors impacting on Aboriginal and Torres Strait Islander people defined by their urban status are not often differentiated.
- There is evidence that urban Aboriginal and Torres Strait Islander people are less satisfied than remote Aboriginal and Torres Strait Islander people with their access to health care.
- Fee-for-service general practice has limitations when it comes to addressing the complex health needs of urban Aboriginal and Torres Strait Islander people. It is also questionable whether fee-for-service general practice reliant on income from bulk-billing Aboriginal and Torres Strait Islander people would be financially sustainable. Introducing co-payments, on the other hand, would be a significant financial barrier to accessing health care.



- ACCHSs, with salaried GPs, are better able to address the health care needs of urban Aboriginal and Torres Strait Islander people. Another mainstream model of health care provision suitable for urban Aboriginal and Torres Strait Islander people is community health services employing salaried GPs and Aboriginal Health Workers.
- Aboriginal and Torres Strait Islander people have higher hospitalisation rates than non-Indigenous people. They have higher rates of hospitalisation for ambulatory-sensitive conditions and lower rates of hospitalisation for referral-sensitive procedures. This suggests that there continues to be problems in access to primary health care for Aboriginal and Torres Strait Islander people.
- Aboriginal and Torres Strait Islander people attend hospital emergency departments at about twice the rate of non-Indigenous people, but it is not clear whether these attendances are used as a substitute for more appropriate primary care.
- There are problems related to the interface between primary and acute health care sectors. There are particular difficulties for Aboriginal and Torres Strait Islander people living in urban areas (perhaps temporarily) on discharge from hospital, when there may be inadequate follow-up and often a lack of continuity in medications.
- Barriers to health care can be classified as problems of availability, affordability, acceptability and appropriateness. All these barriers are relevant for Aboriginal and Torres Strait Islander people living in urban areas, but the acceptability and appropriateness of services are particularly relevant.

3. What Evidence Is Currently Available about Methods and Approaches to Research into these Areas that Can Inform Discussions about the Design of an Effective and Culturally Safe Research Project?

3.1 Introduction

This chapter sets out to identify methods and approaches consistent with current best practice principles for research involving the interests of Indigenous people dwelling in urban areas. Emerging frameworks for enacting these principles are of interest when considering ways of improving current Indigenous research approaches across the spectrum. The discussion will be referenced, therefore, by two main frameworks identified from the literature as representing a potential for informing the design and conduct of effective and culturally safe Indigenous health research. These frameworks include (a) the Indigenous Research Reform Agenda and (b) cultural safety and cultural respect in health service delivery and research contexts.

The Indigenous Research Reform Agenda represents a general paradigm for articulating proposals for change to Indigenous research processes in Australia. However, it should be noted that proposals for change are not exclusively represented in the Australian literature under this banner. In addition, the notions of cultural safety and cultural respect in research and health service delivery provide relatively new ways of looking at the sometimes conflicting or competing interests of minority and/or marginalised populations and mainstream representatives.

Appropriate approaches to research with Aboriginal and Torres Strait Islander people in urban contexts are identified in this chapter under the following key headings:

- Cultural safety, cultural competence and cultural respect;
- Indigenous research reform;
- Research priority setting;
- Research brokerage;
- Diversity and identity;
- Ethical research guidelines and protocols;
- Research agreements;
- Collaborative and participatory research;
- Research capacity building; and
- Reporting and dissemination.



3.2 Cultural safety, cultural competence and cultural respect

Literature detailing the concepts of cultural safety, cultural competence and cultural respect in Indigenous research contexts is limited mainly to accounts emanating from Canada, the USA and New Zealand. In Australia, although the concept of cultural safety in research has apparent links to the more general concerns raised by advocates for Indigenous research reform and culturally appropriate Aboriginal and Torres Strait Islander service provision, the extent of alignment between these frameworks has not been subject to analysis. The international literature identifies the notion of cultural safety mainly as a process involving the prior education of researchers and service providers, whereas the Australian literature provides a main focus on organisational systems for ensuring the cultural safety of Indigenous people.

Kirkham *et al.* (2002) (a group of Canadian researchers) applied the notion of cultural safety as the basis for interrogating the interplay among culture, health and health care provision in a study of the hospitalisation and help-seeking experiences of diverse ethnocultural populations. In particular, the authors were concerned to underscore the methodological implications for practising 'culturally safe' research. They proposed that the notion of cultural safety could provide a useful conceptual apparatus to address methodological issues associated with research involving participation by Indigenous and other minority groups in countries such as Canada. A key aspect of their proposed research approach was the initial attention given to developing researcher understanding that the historical experiences of marginalised and minority group members impacts on their current situations in respect to their health status.

Stubben (2001) suggests that development of so-called 'cultural competence' derives from the efforts of American Indians to protect the cultural integrity of both service delivery programs and research. He nominates a range of cultural, historical, social and spiritual issues that must be learned prior to and when conducting service or program delivery or research among American Indian communities. Cultural competence in service delivery and research is described by Stubben (2001:1466) as 'a process in which the service provider or researcher must acknowledge cultural differences, develop awareness of personal cultural values, understand cross-cultural interactions, learn the family's culture, and adapt the program or research project to fit the culture'.

The notion of cultural safety in research is clearly relevant to a consideration of Aboriginal and Torres Strait Islander health research practice in Australia. A cultural respect framework has been developed by the Australian Health Ministers' Advisory Council's Standing Committee on Aboriginal and Torres Strait Islander Health Working Party (AHMAC 2004). The proposed framework aims to strengthen relationships between the health care system and Aboriginal and Torres Strait Islander people. The authors state that, from the outset, there was recognition that the framework should link with other key documents such as the 2003 *National Strategic Framework for Aboriginal and Torres Strait Islander Health* and the 2002 *Aboriginal and Torres Strait Islander Health Workforce National Strategic Framework*. At the systems level the framework notes the importance of ensuring that proposed research has relevance across all health modalities. At the organisational level the framework emphasises the importance of cultural competence in design and implementation of research. At the care delivery level the framework notes the importance of research that recognises the importance of privacy, ethics and safety aspects that are culturally secure (AHMAC 2004:15).

The NHMRC *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC 2003) provides a comprehensive overview of fundamental Indigenous cultural traditions to guide the development of research. As such, this document represents a significant educative tool and provides a solid basis for the development of a culturally safe research framework in Australia.

A comprehensive consideration of cultural security/safety as this applies to the provision of Aboriginal and Torres Strait Islander health care in Australia is provided in a PhD thesis by Shane Houston (2004) entitled 'The Past, the Present, the Future of Aboriginal Health Policy'. The concept of cultural safety/security in health care delivery is relatively new in the health care literature and originated in the early 1990s in New Zealand. Application of the cultural safety concept in New Zealand health care contexts has carried a strong emphasis on recognition of the historical and social processes that have subordinated the Māori people and have negatively influenced their health outcomes (Kirkham *et al.* 2002:226). In New Zealand the overall goal of the notion of cultural safety in health care has been described as the impetus to 'take remedial action against the very conditions that prompted its formulation: deep seated disadvantage and inadequate understandings of Māori models of

health' (Kearns & Dyck 1996:372). According to Ramsden (1993), one goal of the notion of cultural safety is to challenge stereotypical notions of cultural groups in ways that require providers from the majority culture to challenge their own stereotyped views of a minority culture. Cultural safety promotes positive recognition of diversity. Recognition of cultural safety requires that Indigenous worth is recognised and reflected in health care provision. Central components of a cultural safety framework developed for application in nursing contexts (as presented by Ramsden 1993) include the following:

(a) Recognition that all interactions are bi-cultural. (b) The need for nurses as bearers of 'culture' to examine their own cultural realities, attitudes and behaviours, the impact these have on others; and, (c) the necessity for practice initiatives to be undertaken only with input from the care recipient (Kirkham et al. 2002:226).

3.3 Indigenous research reform

Over the past three decades a critique of research involving Indigenous issues (including health research) has gained momentum in Australia and in other countries such as the USA, New Zealand and Canada. This critique includes concerns raised about the apparent lack of progress towards delivery of promised benefits to Indigenous peoples deriving from their participation in research activity. It is commonly argued, for example, that it is the interests of researchers and not the interests of Indigenous people that drives much research activity and that past and continuing processes of colonisation still shape the way research is framed (Rigney 1999; Tuhiwai Smith 1999; Dodson 2000; Humphery 2000; Thomas 2004). Recently in Australia this advocacy has been represented mainly (but not exclusively) within a broad framework commonly referred to in the literature as the Indigenous Research Reform Agenda.

The movement to reform Indigenous health research activity has foreshadowed the formalisation of a broad-based and cross-disciplinary agenda for reform of Indigenous research across a range of social science disciplines. This evolving and cross-disciplinary reform agenda has developed in response to the well documented and ongoing poor track record of Indigenous health research when its value is measured in terms of improved health outcomes (Henry, J. et al. 2004). Reform proposals are underpinned by a commitment to the principles of Indigenous self-determination and an argument for due recognition of Indigenous cultural authority and knowledge, and diverse cultural protocols, priorities and values within the construction of research (Rigney 1999; Humphery 2000; Anderson et al. 2003; Henry, J. et al. 2004). In Australia Indigenous participation in every aspect of health research is increasingly recognised as an important element of any research project that aims to improve Indigenous health (Kowal, Anderson & Baillie 2005).

In a detailed account of the history of Indigenous health research in Australia entitled *Indigenous Health and Western Research*, Humphery (2000) identifies a range of unresolved issues linked directly to increasing the benefits from health research to Indigenous peoples. These unresolved issues include:

- Indigenous control of the research agenda (research priority setting);
- Indigenous control of the research process (building Indigenous research capacity);
- improved processes for quality control (monitoring of research);
- improved processes for consultation and negotiation of research (research brokerage); and
- improved processes for transferring research findings into policy and practice (appropriate dissemination of research findings).

In a review of the literature entitled *The Indigenous Research Reform Agenda in Australia*, J. Henry et al. (2004) drew on the available literature to identify key elements of the Indigenous Research Reform Agenda as follows:

- involvement of Aboriginal communities in the design, execution and evaluation of research;
- defining a coordinating role for Aboriginal community-controlled organisations associated with the research;
- consultation and negotiation with Indigenous organisations as ongoing throughout the life of a research project;
- mechanisms for ongoing surveillance of research projects by Indigenous partner organisations;



- ownership and control of research findings by participating Aboriginal community-controlled organisations;
 - processes to determine research priorities and benefit to the Indigenous communities involved;
 - transformation of research practices from 'investigator-driven' to an adoption of a needs-based approach to research;
 - determination of ethical processes for the conduct of research;
 - linkage between research and community development and social change;
 - the training of Indigenous researchers; and
- the adoption of effective mechanisms for the dissemination and transfer of research findings.

3.4 Research priority setting

The question of who should initiate Aboriginal and Torres Strait Islander health research remains unresolved. Historically, Western institutions and their representatives have taken a leading role in identifying and determining the cause of a wide range of Indigenous 'problems' in Australia, including health problems (Henry, J. *et al.* 2004). According to some commentators, Investigator-driven research that proceeds with scant reference to Indigenous priorities and Indigenous values remains the main paradigm for research involving Indigenous domains of interest in Australia (Dodson 2000; Dunbar *et al.* 2004). This situation has been challenged on a number of fronts, most formally through the nomination of Indigenous health research priorities in documents including the *National Aboriginal and Torres Strait Islander Health Strategy* (NATSIHC 2002) and *The NHMRC Road Map: A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health through Research* (NHMRC RAWG 2002).

Various commentators in Australia suggest that the establishment of Indigenous health research priorities should be located within the control of the community-based Indigenous health sector (Houston & Legge 1992; Anderson 1996; Humphery 2000). It is argued that ACCHSs, through their role as health service providers at the community level, are well positioned to determine local health research needs and to assist in the brokerage and conduct of related research activity (Anderson 1996). Anderson (1996) argues that if ACCHSs become involved in research priority setting, a closer alignment between the interests of researchers and the interests of Indigenous people may be achieved.

The importance of establishing Indigenous priorities for research into Aboriginal and Torres Strait Islander health service delivery in Australia is emphasised by Houston (2004). Houston points out that a careful analysis of pathways in health areas that are considered important by Aboriginal people is necessary because such an examination will reveal areas where change is required. Further, Houston suggests that:

Progress in these areas will build Aboriginal and Torres Strait Islander trust and acceptance in health services and facilities and the quality of services they offer. This can lead to improved health gain (Houston 2004:120).

According to the *NHMRC Road Map*, many mainstream health programs have an Aboriginal and Torres Strait Islander focus yet, at present, there is little reliable data on the uptake of these programs by Aboriginal and Torres Strait Islander people or of their effectiveness. The *NHMRC Road Map* also notes that 'there is little to no information on the history of Aboriginal and Torres Strait Islander health and health care services in Australia' (NHMRC RAWG 2002:12). The *NHMRC Road Map* outlines six research themes critical to achieving substantial health gain for Aboriginal and Torres Strait Islander people. Two themes directly relevant to issues under consideration in this review include theme areas three and five as follows:

3. A focus on health services research which describes the optimum means of delivering preventive, diagnostic and treatment based health services and interventions to Aboriginal and Torres Strait Islander peoples (NHMRC RAWG 2002:9). 5. A focus on engaging with research and action in previously under-researched Aboriginal and Torres Strait Islander populations and communities (NHMRC RAWG 2002:12).

The authors of the *NHMRC Road Map* adopt the position that descriptive research is less important than intervention-based research except where there are information gaps to be filled, and that it is premature to identify these gaps until an audit of current research has occurred. In a summary of issues arising from community consultations over priorities for Aboriginal and Torres Strait Islander health research, the *NHMRC Road Map* makes substantial reference to the importance of further investigating issues of health service provision, utilisation, access and impact. This summary provides the basis for positioning research involving health service delivery for urban-dwelling Aboriginal and Torres Strait Islander people within the context of a research agenda involving the interests of a combined Aboriginal and Torres Strait Islander population in Australia.

Under each nominated research theme area (see above), the *NHMRC Road Map* indicates specific areas of research requiring urgent action. For the purpose of this review we have selected identified areas that address the central review questions relating to health research issues involving urban Aboriginal and Torres Strait Islander populations. These identified priority areas and draft research questions are outlined in the Appendix of this review.

3.5 Research brokerage

The importance of brokering research in conjunction with appropriate representatives of Indigenous interests is positioned as central to the achievement of sustainable and community-based solutions to a range of identified Indigenous issues (Anderson & Saunders 1996; Dunne 2000; Dunbar *et al.* 2004). According to Anderson and Saunders (1996), it is crucial that institutional reform in the area of Indigenous health research is framed on the basis of widespread responsibility sharing and that this process respects Indigenous people and organisations as full partners. The available literature in this area focuses mainly on the experience of brokering research with Aboriginal and Torres Strait Islander people in rural and remote settings. Only a limited number of commentaries detail research brokerage issues in urban community contexts in Australia (see Henderson *et al.* 2002; Holmes *et al.* 2002; Hurley 2003; Hunt 2005).

Indigenous community-based organisations are identified as important sites for identifying research priorities and for facilitating research brokerage (Anderson & Saunders 1996; Dunne 2000; Dunbar *et al.* 2004). These organisations are well placed to fulfil a research brokerage role because the individuals employed by these organisations 'have knowledge of local communities, experience in mediating competing interests in research and experience dealing with outside agents' (Dunbar & Scrimgeour 2006a). There is evidence to suggest, however, that members of the research community (including those responsible for the funding, ethical assessment and conduct of research) do not routinely consult with appropriate community-based organisational representatives over proposals for research until long after funding for research has been granted (AIATSIS 1999; Hurley 2003; Dunbar *et al.* 2004). As long as this situation persists, it is argued that individual and collective Indigenous community interests in research are not likely to be adequately represented or protected (Dunbar & Scrimgeour 2006b). Hurley (2003) advocates for consultations over research with urban Indigenous populations to take place at an early stage. She outlines this position as follows:

Indigenous communities have been intensively researched, written about and consulted with in the past, and as a result of negative experiences may be sceptical about the consultation process. Consultation needs to be undertaken prior to the commencement of projects, not as an afterthought. Consultations should begin at the development and concept stage to allow time for feedback and should continue through every stage of the project, through to evaluation (Hurley 2003:7).

In negotiating research issues with community-based organisations it is important to be aware that in some circumstances the authority of Indigenous-controlled organisations to represent broader group interests may be contested at the local level (Henderson *et al.* 2002). Commentators also advise that it may be necessary to negotiate over proposals for research with more than one representative Indigenous organisation at the local community level (AIATSIS 1999; Henderson *et al.* 2002). Navigating a way through different organisational and individual interests for the purpose of brokering research is recognised as being a potentially complex undertaking. In particular, it is noted that negotiations over research may be complicated by different organisations in a community having varying expectations of research outcomes and different levels of interest and commitment to proposed research (AIATSIS 1999; Henderson *et al.* 2002).



Based on their experiences conducting health-related research in urban settings in Victoria, Henderson *et al.* reported that it is possible for researchers and their local Indigenous partners to:

find themselves between conflicting family groups or perceived to favour some families or organisations over others. The challenge for outsiders is to understand and address this, and for insiders to work between them while living in communities ... (Henderson et al. 2002:485).

In a commentary on consultation processes involving a range of Indigenous policy areas, the House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs (2001) suggests that an acknowledged problem in large urban areas is the difficulty associated with identifying a 'community' for the purpose of consultation and decision-making.

Indigenous communities in an urban context may be a network of family relations and organisational memberships geographically dispersed and intermixed. This in turn makes it difficult for agencies to know who to consult when seeking to extend the involvement of Urban Indigenous people in decision-making (House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs 2001:54).

Reference is also made to difficulties sometimes experienced in regional urban areas where there is a reportedly higher likelihood that negotiations over policy issues will be complex:

clan allegiances and loyalties, coupled with a history of unresolved family disputes, is a recipe for disaster and causes great disruption and distrust today within mixed Aboriginal communities, especially in regional urban areas (House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs 2001:56).

Further, the committee noted that:

The dysfunction seems most pronounced where families or individuals move into existing communities or are forced together over time, creating distinctions between locals and 'outsiders'. The results can be two fold:

—services that are monopolised by particular family groups; and

—nepotism where family loyalties lead to the appointment of untrained and unsuitable people to positions of power (House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs 2001:56).

In an example of the problems associated with negotiations over delivery of Aboriginal and Torres Strait Islander services in urban settings (cited from a submission to the committee), the report noted:

One of the problems we have in Perth—and you will find that it is probably the same issue in all the major cities—is that it is really hard to define the Aboriginal community ... Is it Armadale? Is It North Bridge? Is it Balga? It is very hard to get that sense of community in Perth because the level of dispossession in the metropolitan area is far higher than anywhere else in the state (House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs 2001:54).

The identified complexity of negotiations with Indigenous representatives over policy and service delivery issues is of relevance to researchers intending to broker the terms of research with Indigenous peoples in urban settings. The literature offers no ready solutions except the often-repeated advice to 'negotiate locally' and to recognise the potential for multiple Indigenous community perspectives and competing interests to emerge during negotiations over research. Recognition of the heterogenous profile of Aboriginal and Torres Strait Islander communities is also cited as important. This issue is overviewed in more detail in the following section of this review.

3.6 Diversity and identity

There is a recognised and problematic tendency for researchers in Australia to assume that Indigenous communities are made up of homogenous groupings of people with shared goals (Brady 1980; Sullivan 1996; AIATSIS 1999; Hurley 2003). Brady (1990:20) warned researchers against the application of Western-centred notions of 'community' to groupings of Aboriginal people because the Aboriginal need for independence of

action results in a 'so-called community... composed of small, labile, autonomous collections of people who rarely come together for a shared purpose'. Sullivan (1996:11) also noted that most development proposals involving Indigenous peoples in Australia have been predicated on 'an unreasonable assumption of "community" that assumes homogeneity and harmonious interaction'.

In a statement on diversity in Aboriginal and Torres Strait Islander populations residing in the Western Sydney area, Hurley (2003:6) advises researchers as follows:

Aboriginal and Torres Strait Islander communities are as diverse as any other community. We are not all one cultural group and not all the same. Every community will have common ground and similarities, but also very different issues. Too often it is assumed that one Indigenous person is the knowledge holder and the sole voice for the whole community in which they live. There are different traditions and customs, different ways of communicating, different understandings, different sensitive issues, different Elders.

The application of criteria for inclusion or exclusion of individuals in minority group research design is positioned by Kirkham *et al.* (2002) as a cultural safety issue. In their view, the imposition of arbitrary inclusion criteria for research cohorts increases the potential for researchers to 'do harm' to both fragile communities and individuals who are identified as potential research participants. Kirkham and her colleagues argue that if researchers proceed without reference to local community advice over inclusion criteria, then the risk of breaching the cultural safety of individuals is necessarily increased. In Australia AIATSIS (1999) advises researchers that in Aboriginal community contexts, the 'community' should be considered to include 'anyone who sees themselves as part of that community and is accepted by other members as having some rights of inclusion' (AIATSIS 1999:120).

Hurley (2003) suggests that the identity of Aboriginal and Torres Strait Islander people should be determined only by Aboriginal and Torres Strait Islander people. For the purpose of negotiating inclusion criteria for proposed research in the Western Sydney region, she recommended an Aboriginal and Torres Strait Islander Commission test of identification as follows: (1) a person must be of Aboriginal and/or Torres Strait Islander descent, (2) a person must identify as an Aboriginal and/or Torres Strait Islander person, and (3) a person must be accepted as an Aboriginal and/or Torres Strait Islander person by the community in which they live (Hurley 2003:5). According to Hurley, this identification test is acceptable to most Indigenous groups in the Western Sydney region but the extent to which it is accepted by other urban Indigenous communities remains unclear.

3.7 Ethical research guidelines and protocols

Institutions engaging in research of interest to Indigenous people in Australia have developed a range of formal guidelines and protocols to guide the research community. In a published review of the literature entitled *Ethical Assessment of Indigenous Health Research*, Dunbar and Scrimgeour (2005) identified significant evidence of Indigenous community impatience with the proposition that the formalisation of guidelines for the ethical conduct of Indigenous health research has been enough to ensure that the rights and interests of Indigenous participants in research activity are adequately represented. Commentators have reportedly argued that Indigenous research guidelines and protocols do not mandate for substantial changes to the way researchers operate and that, currently, inadequate institutional mechanisms are in place to monitor the activity of researchers once formal ethics committee approval has been granted.

Following is a brief overview of some documents identified from the literature as resources with potential application to the development of ethical and culturally safe research in urban Aboriginal and Torres Strait Islander contexts.

The *National Statement on the Ethical Conduct of Research Involving Humans and Supplementary Notes* (hereafter referred to as the *National Statement*) (NHMRC 1999) represents the overarching guide to the conduct of health research involving human subjects and is endorsed by many other academic and research bodies whose interests extend beyond medical research. When proposals for research include substantial Indigenous participation, human research ethics committees are guided in the first instance by the *National Statement*, and also by the document: *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (NHMRC 2003). The *Human Research Ethics Handbook: Commentary on the National Statement on Ethical Conduct in Research Involving Humans* (NHMRC 2001) provides additional guidance to human research ethics committees in the assessment of Indigenous health research proposals.



The NHMRC's *Values and Ethics* guidelines are framed around six core values underpinning Indigenous cultural life. These values include reciprocity, respect, equality, responsibility, survival and protection, and spirit and integrity (NHMRC 2003). The background section of the document articulates the reasoning behind the incorporation of these core values as the basis for designing research and each nominated value is supported by a series of 'Points to Consider'. These points are intended to provide a reference for researchers and human research ethics committee members when framing and ethically assessing proposals for health research.

Keeping Research on Track: A Guide for Aboriginal and Torres Strait Islander Peoples about Health Research Ethics (NHMRC 2006) is designed to support Indigenous organisations and individuals when negotiating the terms of research. In particular, the document provides questions for community members to ask of intending researchers, as well as resources that community organisations may find useful when negotiating the terms of proposed research. The document also includes a focus on ensuring appropriate recognition of Indigenous cultural diversity across Australia and the importance of providing opportunities for interpretation of distinct local Indigenous cultural values and protocols through research.

AIATSIS (1999) provides a range of sample ethics guidelines, protocols and contracts to guide intending researchers (AIATSIS 1999:155, Appendix 3). These documents are drawn from research institutions and organisations involved in Indigenous research in Australia and may provide a potential source of guidance to researchers aiming to negotiate the terms of agreement over research in ways that are consistent with reform initiatives in the Indigenous health research field.

A recent collection of potentially useful Aboriginal research guidelines and protocols is provided by Hurley (2003) in a document entitled *Respect, Acknowledge, Listen: Practical Protocols for Working with the Indigenous Community of Western Sydney*. This comprehensive collection was selected to guide researchers involved in a broad range of social research with urban Aboriginal populations in New South Wales. The collection is situated in the document under the heading of 'Other protocol resource documents' (p.18).

The Australian Housing and Urban Research Institute (AHURI) *Ethical Principles and Guidelines for Indigenous Research* (AHURI 2002) is a document developed by the institute to guide researchers involved in research of interests to Indigenous peoples. Given that the work of the institute involves significant interaction with urban Aboriginal and Torres Strait Islander populations, the guidelines represent a potentially useful resource for those intending to engage in similarly focused social, infrastructure and health services research.

The development of research agreements between professional researchers and representatives of Indigenous community interests is considered in more detail in the following section of this chapter. However, it is important to note that research agreements should refer directly to national and local research guidelines and protocols for Aboriginal and Torres Strait Islander research such as those indicated above.

3.8 Research agreements

The negotiation of research agreements is promoted as a way to ensure that special issues of concern to local Indigenous community members are not overlooked in the design and ethical review of research. It is suggested that the establishment of research agreements helps to (a) ensure that all parties understand and agree to abide by the focus and boundaries of research, and (b) provide scope for local Indigenous community members to impose specific conditions to govern proposed research (WHO 2004). According to WHO, research agreements inform Indigenous peoples about what they can legitimately expect and require in the context of collaborative research.

Commentators in Australia have suggested that research agreements represent a potential for providing a sharp focus on the rights and responsibilities of all research stakeholders and a practical framework for monitoring the progress of research (Dunbar & Scrimgeour 2006b). In a commentary on brokering the terms of research with Aboriginal people in the urban area of Western Sydney, Hurley (2003) recommends the development of legally binding contracts to protect ownership of Aboriginal cultural knowledge. Under the heading of 'Ownership' she explains:

The knowledge and expertise of Indigenous culture is owned by its Indigenous peoples. Any access to this information must have cleared permission from the relevant individuals and the Indigenous community. Permission can be individual or communal. An agreement outlining the conditions of consent must be obtained from the owner/s of the knowledge prior to commencing the project. It is advised that contracts be drawn up between Indigenous and Non-Indigenous parties. Proper legal representation and advice for the Indigenous community members should be offered so that they may have proper understanding and knowledge of what they are signing for (Hurley 2003:9).

A research agreement is not intended to replace obligatory national or institutional procedures for reviewing and authorising Indigenous health research. The establishment of effective research agreements between Indigenous peoples and researchers relies substantially on reference to national and local research guidelines (WHO 2004). These guidelines are intended to articulate the positioning of Indigenous people on key cultural, protocol and methodological issues (WHO 2004). (A sample World Health Organization Indigenous research agreement proforma is listed in the bibliography of this review at WHO 2004).

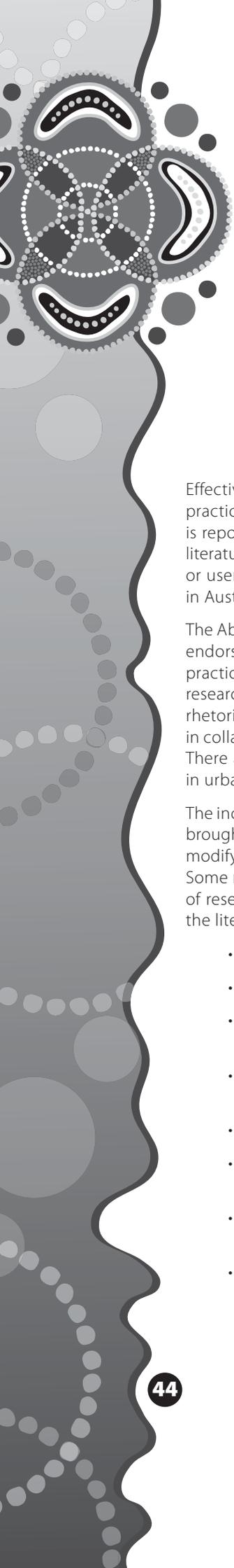
The Aboriginal Health Council of South Australia (AHCSA) Research Ethics Committee requires intending researchers to complete a standard application form asking for details about proposed health research in key areas such as consultative processes with Aboriginal communities; the identified need for the research; the proposed benefits of the research to Aboriginal people; and the nomination of methods for reporting back to Aboriginal community members (AHCSA 2003). Dunbar and Scrimgeour (2006b) noted that questions posed in the AHCSA document align with (a) issues included in the World Health Organization Indigenous research agreement proforma, and (b) issues previously identified in Australia as being crucial to the achievement of Indigenous research reform. As such, the AHCSA application form may provide useful guidance to researchers intending to develop research agreements in negotiation with Indigenous peoples.

3.9 Collaborative and participatory research

There is generalised support for the application of approaches to Indigenous research that include collaborative and participatory processes. The literature suggests that participatory and collaborative research processes support a change in the positioning of Indigenous peoples from 'researched' to 'researcher' and provide possibilities for Indigenous people to derive greater benefit from research activity (Henry, J. *et al.* 2002). Commentators point to the suspicion and lack of trust many Indigenous people feel towards research, and the related need for development of collaborative research partnerships as a way of building trust (e.g. between government and community-controlled health service providers and between Indigenous and non-Indigenous researchers) Tuhiwai Smith 1999; Hurley 2003). The importance of developing collaborative research partnerships was underlined by Anderson (2000) when he suggested that even the highest priority Indigenous health research will have limited outcomes if the communication and collaboration processes used in the research are underdeveloped.

Evidence of Indigenous participation in research projects is increasingly required by funding bodies and ethics committees in Australia, but there is an identified lack of clarity about the required nature of this participation (Kowal, Anderson & Baillie 2005). Given this situation, Kowal, Anderson and Baillie (2005:469) suggest that researchers may 'pragmatically seek Indigenous participation not only for logistical purposes, but also for political and administrative purposes'. With this in mind, the authors attempted to clarify the variety of meanings given to the concept of 'Indigenous participation in research'. They identified so-called empowerment research as the means by which Indigenous participation in health research will directly lead to health benefits for those involved in the project, and perhaps the community in general. When a community development or empowerment research approach is adopted, the rationale is that 'participation' in its own right is viewed as the intervention. The causal chain is that Indigenous participation in research leads to participation of community members, which leads to empowerment, increased control over one's life and eventually improved health (Baum 1998). According to Kowal and her colleagues:

More debate will contribute to a refined understanding of the potential benefits of and reasons for Indigenous participation in health research. When involving Indigenous people in health research, good intentions should not preclude clear and honest thinking about the nature of their participation (Kowal, Anderson & Baillie 2005:469).



It is proposed that diverse Indigenous interests and cultural protocols should drive research problem identification and the selection of appropriate methodological approaches. It is also proposed that the expertise of outsider researchers (including both Indigenous and non-Indigenous researchers from outside a community) should not outweigh the cultural authority and knowledge of Indigenous people (Hurley 2003). Commentary from the literature about the role of research methodology in the achievement of these objectives is outlined by J. Henry *et al.* (2002:3) as follows:

Historically, tensions between Indigenous peoples and the broader research community have related to issues of power and control of the research process, and to control over the outputs of research. Research methodology has been significantly implicated in the playing out of these tensions. The work of Tuhiwai Smith has contributed importantly to the elevation of research methodology as an important site of struggle between the interests of researchers and the interests of Indigenous community members. In her book 'Decolonizing Methodologies: Research and Indigenous peoples', she advocated for the identification of methodologies that have the potential to ensure that research with Indigenous peoples can be 'more respectful, ethical, sympathetic and useful'...

Effective collaboration with potential 'users' of research is likely to improve the uptake of research into policy and practice and yet the development of partnerships between researchers and prospective research participants is reportedly difficult and time consuming (Baum 1998; Fleisher *et al.* 1998). The international health research literature identifies a barrier to the uptake of mainstream health research as a lack of 'buy-in' by research participants or users (Lomas 1997). Similar observations have been made in regard to Indigenous health research activity in Australia (Tsey 2001).

The Aboriginal and Torres Strait Islander health research literature in Australia includes numerous commentaries endorsing a collaborative research approach, but few accounts of how such approaches might operate in practice (Hunt 2005). This observation underlines the need for more reflexive accounts of so-called collaborative research in Indigenous community settings and points to a significant gap in the literature at the point where the rhetoric of research reform is translated into practice. Most available reflexive accounts of research conducted in collaboration with Aboriginal and Torres Strait Islander people describe research in rural and remote settings. There are relatively few accounts relating specifically to the experience of conducting collaborative research in urban settings.

The increasing incorporation of Participatory Action Research (PAR) approaches by public health researchers has brought with it increased attention to the fundamental importance of ongoing critical reflection on practice, while modifying practice in response to newly acquired ways of thinking about the research in question (Baum 1998). Some reflexive accounts of participatory and collaborative research that may usefully inform the development of research with Aboriginal and Torres Strait Islander people in urban settings in Australia are identified from the literature as follows:

- *Trying to Make a Difference; A Whitefella PhD Story* (Hunt 2005)
- *How Children Grow: Indigenous and Health Professional Perceptions* (Smith *et al.* 2003)
- *Sharing the True Stories: Improving Communication between Aboriginal Patients and Healthcare Workers* (Cass *et al.* 2002)
- *Development of Guidelines for Non-Indigenous People Undertaking Research among the Indigenous Population of North-east Victoria* (Henderson *et al.* 2002)
- *Yolgnu Longgrassers on Larrakia Land* (Maypilama *et al.* 2004)
- *Popular Education, Capacity-building and Action Research. Increasing Aboriginal Community Control over Education and Health Research* (Boughton 2001)
- *The Yarning Report: Research Partnerships: Yarning about Research with Indigenous Peoples* (Franks *et al.* 2001)
- *Consultation, Rapport, and Collaboration: Essential Preliminary Stages in Research with Urban Aboriginal Groups* (Dunne 2000)

- *Researching Aboriginal Health: Experience from a Study of Urban Young People's Health and Well Being* (Holmes et al. 2002)
- *Access of Urban Indigenous Populations into Local Primary Health Care Services* (Craig 2002; Craig et al. 2005)
- *Strong in the City: Towards a Strength-based Approach in Indigenous Health Promotion* (Brough, Bond & Hunt 2004).

Within the broad public health research field, the incorporation of new methods and methodologies has emphasised the importance of reflecting on research practice and involving people more actively in research endeavours (Baum 1998). Baum, MacDougall and Smith (2006) outline some fundamental aspects of PAR as follows:

Participatory action research ... differs from most other approaches to public health research because it is based on reflection, data collection, and action that aims to improve health and reduce health inequities through involving the people who, in turn, take actions to improve their own health (Baum, MacDougall & Smith 2006:855).

Participatory research is promoted as a way of addressing issues of immediate concern and interest at the local community level. Participatory research methodologies are promoted for application within Indigenous community contexts on the basis that these methodologies 'emphasize respect for the individual and a commitment to social change' (St Dennis 1992:51).

Some relevant commentaries on the application of PAR approaches in Indigenous community contexts in Australia include (among others) Stringer and Genat (2004), Stringer (1996), Henry and McTaggart (1996) and Boughton (2001).

Three common PAR attributes are proposed by Henry and McTaggart (1996) as follows:

- shared ownership of research projects;
- community-based analysis of social problems; and
- an orientation towards community action.

PAR principles (as outlined by Stringer 1996) are operationalised by the terms 'look, think and act':

- *looking* means gathering information, defining and describing the situation;
- *thinking* refers to exploring, analysing, interpreting and explaining; and
- *acting* is the development, implementation and evaluation of plans of action devised by participants.

In a description of a PAR initiative in a Native Canadian community, Chrisman et al. (1999) emphasised the importance of ensuring that research initiatives can be sustained by the community in the absence of professional researchers. The university researchers involved in this PAR project defined community capacity as 'the (community's) ability to effectively develop, mobilize, and use resources to manage change' (Chrisman et al. 1999:135). The researchers therefore concentrated on research capability as the first step in achieving this broader aim. In their view, 'Establishing the tribe's ability to gather, analyze and present data is a significant step toward more general community capacity' (Chrisman et al. 1999:135). Chrisman and his colleagues also point out that the success of their project was attributable to the 'community development' or 'community organisation' components. The principles of community organisation that guided the project strategy included:

- a clear definition of the relevant community;
- the involvement of community members and community resources in defining the problems, proposing solutions and making changes happen, using methods with which they are familiar; and
- sustainability of the project in the absence of the organiser.



Despite broad support for the application of PAR methodologies in the Indigenous health research field, applying participatory research principles in practice is reportedly not easy. Dunbar *et al.* (2004) noted that in applying PAR principles, some problematic issues still confront the research community. In particular, they noted that researchers continue to report problems in areas including:

*Identifying key and appropriate research stakeholders; identifying a 'community' for the purpose of conducting research; engendering Indigenous community ownership of the research problem; negotiating the identification of shared concerns; competing time demands on health professionals and Indigenous community members; under-developed research skills base at the institutional and Indigenous community levels (Dunbar *et al.* 2004:40).*

3.10 Indigenous researchers

The development of Indigenous research capability is positioned in the international and Australian literature as a central component of reformed and collaborative research efforts (Tuhiwai Smith 1999; Boughton 2001; Tsey 2001; Walker, Taylor & Ballard 2002; McNaughton & Rock 2003). Research reform proponents argue for the adoption of methodological approaches with a demonstrated capacity for incorporating Indigenous community members as key participants in the research process (including the role of researcher). Commentaries in the literature reference this issue by terms including Aboriginal research methodologies, capacity building, skills and knowledge exchange, knowledge traditions and strengths perspective.

Commenting on the situation in Canada, McNaughton and Rock (2003:4) observed that the Royal Commission on Aboriginal Peoples and other studies:

agree that a significant element of the solution [to the costs of social problems facing Indigenous peoples] is the need to shift the research paradigm from one in which outsiders seek solutions to 'the Indian problem' to one in which Indigenous people conduct research and facilitate solutions themselves. The Dialogue on Research and Aboriginal Peoples reflects a clear shift away from the ways in which research has been understood and organized in relation to Aboriginal peoples. Once understood more as intriguing or pertinent research objects, Aboriginal peoples are increasingly seen as researchers and research partners conducting research within Aboriginal knowledge traditions, using Aboriginal methodologies as well as methodologies drawn from interaction with non-Aboriginal intellectual traditions.

At the same time, non-Aboriginal researchers are seen less as the conventional 'external experts' and increasingly as equal partners involved in developing new understandings of Aboriginal knowledge and ensuring that research and research training directly benefit Aboriginal nations and communities. In this context Aboriginal research is more a method of study than an area of study. In its emerging conception, 'Aboriginal research' is research that derives its dynamic from traditions of thought and experience developed among and in partnership with Aboriginal nations in Canada and other parts of the world.

Tuhiwai Smith (1999:193) (a Māori advocate for more direct involvement by Māori in research activity in New Zealand) points out that when Indigenous people become researchers and not merely the researched, the activity of research is transformed in the following ways:

*Questions are framed differently;
Priorities are ranked differently;
Problems are defined differently; and
People participate on different terms.*

In Australia involvement by Aboriginal and Torres Strait Islander researchers is proposed as an important way of achieving useful research outcomes at the same time as achieving ethical and culturally safe research objectives. Tsey (2001) represents capacity building as an essential aspect of developing partnerships between researchers and Indigenous communities and he emphasises the need to identify and prioritise research capacity building through training, mentoring and other support. Based on their experiences of fostering Indigenous research capacity at AHURI, Walker, Taylor and Ballard (2002:27) identified the most problematic element as 'trying to juggle community time frames and funding body deadlines and the need to undertake activities that fall outside the normal research process'.

Reflexive research accounts from the Australian literature describe attempts to access Aboriginal viewpoints on health and other social issues through the intervention of local Aboriginal researchers (Holmes *et al.* 2002; Brough, Bond & Hunt 2004; Maypilama *et al.* 2004). Within these research projects, Indigenous researchers were directly involved in interviewing participants and analysing data. Brough, Bond and Hunt (2004) describe in detail the conduct of open-ended interviews and focus groups by Aboriginal researchers. The purpose for this research was to access viewpoints about the nature of Aboriginal community strengths in an urban setting. This research identified five key strengths although the authors stressed that these strengths should not be considered a complete list, but instead a starting point for the community development phase of their project. These identified strengths included extended family, commitment to community, neighbourhood networks, community organisations and community events (Brough, Bond & Hunt 2004:218). These findings may provide useful insights for research into the health care needs of Indigenous people in urban settings. By building on identified urban community strengths, a pathway to accessing the viewpoints and experiences of otherwise 'invisible' Aboriginal and Torres Strait Islander cohorts may be found.

3.11 Reporting and dissemination

Commentaries from the international mainstream health research literature indicate that since the 1980s there has been a failure to provide research findings in 'user-friendly' formats. This situation is positioned as a significant impediment to research transfer (Rothman 1980; Stocking 1995; Lomas 1997). Matthews *et al.* (2002:vii) reported that:

the health literature overwhelmingly acknowledges that processes associated with the transfer of research findings into health policy, clinical practice, service delivery systems and changed human behaviour, are ad hoc, unpredictable, difficult, and subject to a range of complex and multi-dimensional barriers. Indigenous health research literature strongly supports this notion.

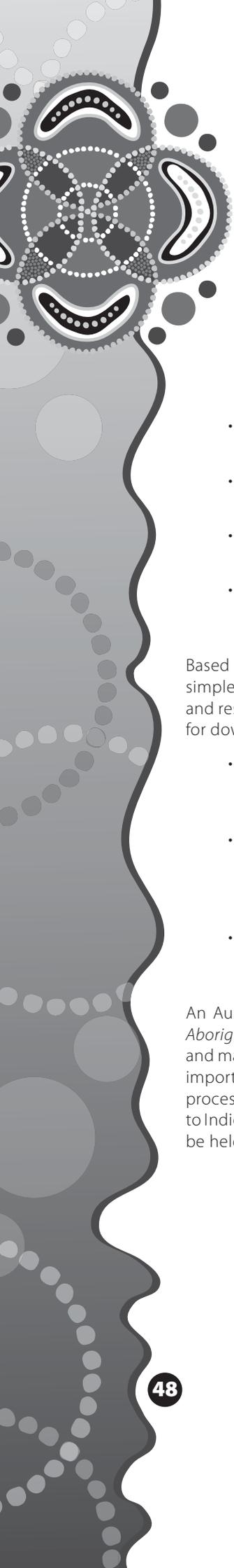
In Australia improved processes for transfer and dissemination of Indigenous health research findings are identified as a priority area for action. A frequently expressed concern is that Indigenous research findings are not usually presented to Indigenous communities in an accessible form and that, even when this does occur, feedback is often delayed (Kimberley Aboriginal Health Workers 1992; Miller & Rainow 1997; AIATSIS 1999). This situation reduces the potential for research findings to impact positively on the health behaviours of Indigenous people, and reinforces the perception that the main beneficiaries of research are researchers themselves (Jenkin *et al.* 2001; Matthews *et al.* 2002).

Commentators in Australia position Indigenous people experiencing health problems as key potential beneficiaries (and therefore key 'users') of research (Anderson 1996; Winch & Hayward 1999; Anderson 2000; Hunter 1992). Anderson (1996) suggests that the Indigenous subjects of research have the greatest potential stake in research outcomes, but most researchers do not identify the Indigenous 'researched' as major users of research findings. To address this problem, Anderson (2000) encourages Indigenous health researchers to 'think beyond the project' by considering their work within the context of broader policy and uptake systems. He explains his position as follows:

Most of our thinking around better ways to do Aboriginal health research has focused on the project. It has tended to focus on participatory action research and models for working effectively with Indigenous communities. I argue that we need to think about the broader environment in which we do the research. It is the policy process and issues around uptake of the research that are important. We need to move beyond good ways of doing projects to thinking about research within broader systems... (Anderson 2000).

Matthews *et al.* (2002) nominated a range of approaches to guide the promotion and uptake of health research into health services policy, practice, delivery and people's behaviour. These approaches are drawn from a select review of the Australian and international health research literature and provide a particular focus on ways that institutions can support the uptake of Indigenous health research findings. In summary, recommended approaches include:

- institutional support for the broadly-based Indigenous Research Reform Agenda;
- institutional support for stakeholder 'buy-in' to research through developing and supporting strong collaborative partnerships between researchers and potential research users;



- institutional focus on facilitating the involvement by potential *users* of research in the development and implementation of research proposals. In the Indigenous health context, major potential *users* of research include Aboriginal communities and community-controlled organisations, politicians, health policy makers, planners and managers, health care service providers and practitioners, the general public, and other researchers and academics;
- catering for the preferred/most effective information formats for each identified audience when preparing information about the research. Possible formats include ministerial briefings, academic papers and reports, media launches/releases/ interviews, plain English reports, local language materials, workshops, inclusion in academic courses, electronic dissemination, flip charts, newsletters, opportunistic promotion and so on;
- the inclusion of a realistic budget to support effective transfer and dissemination activities *during* and after the research project;
- provision of specialist communications support (editing, summarising, resource preparation, media and political promotion) within the research institution;
- adopting pro-active approaches to ensuring that research findings are considered by policy makers and key opinion-leaders; and
- institutional support for the development of appropriate processes for cross-cultural communication between Indigenous and non-Indigenous researchers and research participants (Matthews *et al.* 2002:v).

Based on the work of Matthews *et al.* (2002) and Jenkin *et al.* (2001), the CRCAH in Darwin produced a set of simple guidelines aimed at helping researchers think about how to effectively communicate new knowledge and research findings to a variety of audiences. These guidelines were produced as brochures and are available for download from the CRCAH website (CRCAH 2002). The brochures include:

- 'Promoting the use of research' (2002)—helps researchers plan dissemination by looking at potential user groups and their needs. It encourages researchers to think about getting their message across from the time they plan their research, throughout the project and after the research has been completed.
- 'Budgeting for research transfer and dissemination' (2002)—proceeds from the Cooperative Research Centre for Aboriginal and Tropical Health's experience that 'researchers routinely underestimate the costs and time involved in the active promotion of their research'. It outlines the costs involved in the different formats used to disseminate research findings.
- 'Writing for health policy makers, planners and managers' (2002)—reproduces guidelines for report writing developed by the Canadian Health Services Research Foundation, which proposes a highly focused approach to writing about research for this particular user group.

An Australian Institute of Aboriginal and Torres Strait Islander Studies review entitled *Research of Interest to Aboriginal and Torres Strait Islander Peoples* (AIATSIS 1999) recommended a range of principles to guide research and management practices involving research of interest to Indigenous peoples. These principles recognise the importance of disseminating research findings through a process of ongoing communication during the research process, and through the dissemination of plain English and other non-academically oriented research products to Indigenous people with an interest in the research. The AIATSIS review argued strongly that researchers should be held accountable for returning research results to Indigenous communities involved in the research:

Initial negotiations with the community should determine who receives the results, how many copies, and in what format. In addition to formal results which are usually in written form, it may be appropriate to return results in more accessible forms which may include a Plain English Report, audio-visual material and possibly using the internet. It is often appropriate to run a workshop for the community to explain the results (AIATSIS 1999:86).

Ethical Principles and Guidelines for Indigenous Research (AHURI 2002) includes a section relating specifically to dissemination processes and protocols for Indigenous research. The AHURI guidelines state:

AHURI gives high priority to effective dissemination of research findings and works closely with research teams to ensure that findings are of value to policy makers and practitioners. With respect to research with Indigenous people, AHURI is committed to ensure that the (Indigenous people) from the relevant community or group receive the results of the research delivered in a form which can be understood by them. This may require the use of alternative reporting formats including poster presentations, focus groups, meetings with individuals or small groups or community forums. Publishing research findings in Indigenous newspapers, newsletters, or through Koorinet or Indigenous Online Networks (ION) at the University of South Australia, will ensure a broader coverage within the Indigenous academic and community arena (AHURI 2002:6).

AHURI requires that research proposals involving Indigenous participation include a costed dissemination strategy.

3.12 Conclusion

The Indigenous Research Reform Agenda provides a general framework for identifying best practice principles for research involving the health needs of Aboriginal and Torres Strait Islander people in a range of settings, including urban settings. This framework provides a focus on issues including research priority setting, research brokerage, ethical research, collaborative and participatory research methodologies, involvement by Indigenous researchers, and reporting and dissemination. Within research in urban settings, the literature identifies some issues that are likely to require special attention. In particular, local research brokerage and involvement by Indigenous researchers are identified as being especially important.

The literature offers no ready solutions to overcoming the identified complexities of negotiating and conducting research with heterogeneous Indigenous populations in urban settings. Researchers are advised to 'negotiate locally' and recognise the potential for multiple perspectives and competing interests to emerge. They are also strongly advised to be aware that identity issues are at the core of concerns about 'cultural safety' in Aboriginal and Torres Strait Islander research, especially in urban contexts. If cultural safety is breached, harm may be done to individuals and communities. In urban contexts the literature also suggests that local Aboriginal and Torres Strait Islander community representatives should be the arbiters of questions surrounding identity and research inclusion and exclusion criteria. Collaborative and participatory research processes are recommended on the basis that they help ensure Aboriginal voices inform and direct research activity.

3.13 Main points

- The Indigenous Research Reform Agenda provides a general framework for identifying best practice principles for research involving the health needs of Aboriginal and Torres Strait Islander people in a range of settings, including urban settings. This framework provides a focus on issues including research priority setting, research brokerage, ethical research, collaborative and participatory research methodologies, involvement by Indigenous researchers, and reporting and dissemination.
- Aboriginal and Torres Strait Islander communities have a heterogeneous profile. Local negotiations over research are recommended as a way of mediating the different needs and perspectives of urban-based populations.
- Negotiating the terms of research with Indigenous populations in urban settings is likely to be complicated by difficulties in identifying a 'community' for the purpose of research and the necessity to mediate sometimes-competing interests and different levels of commitment to the identified research question.
- Through their role as health service providers at the community level, ACCHSs are identified as being well positioned to determine local health research needs and to assist in the brokerage and conduct of related research activity.
- Establishing local priorities for research into Aboriginal and Torres Strait Islander health will reveal areas where change is required.



- There is an extensive range of national and local Indigenous research guidelines and protocols to guide the construction of ethical and culturally safe research in urban Aboriginal and Torres Strait Islander contexts. Some commentators recommend the development of research agreements and/or binding contracts as a practical intervention to guide negotiations over research and to protect the interests of Indigenous participants. Research agreements also represent a potential for providing a research monitoring and evaluation framework.
- The notion of 'cultural safety' is identified in the international literature mainly as a process involving the prior education of researchers and service providers about Indigenous cultural traditions. The Australian literature provides a main focus on organisational systems for ensuring the cultural safety of Indigenous people in service delivery and, to a lesser extent, in research contexts. The NHMRC (2003) document *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* provides a comprehensive overview of fundamental Indigenous cultural traditions to guide the development of culturally safe research.
- Cultural identity issues are likely to arise within urban-based Aboriginal and Torres Strait Islander research. These sensitive issues should be mediated within the context of culturally safe research practices and through direct involvement by local community representatives and Aboriginal and Torres Strait Islander organisations.
- Collaborative and participatory research processes are recommended on the basis that they help ensure Aboriginal voices inform and direct research. It is essential, however, that researchers are explicit about the actual nature of Aboriginal participation in research.
- Aboriginal and Torres Strait Islander researchers add value to research that involves their interests. The literature indicates that in urban and remote contexts, Aboriginal and Torres Strait Islander researchers have a proven capacity to: engender trust, to communicate in culturally appropriate ways and to make contact with otherwise 'hidden' sub-populations for research purposes.

4. What Are Some of the Methods or Approaches that Would Be Appropriate for Sampling Aboriginal and Torres Strait Islander People Living in Urban Areas?

4.1 Introduction

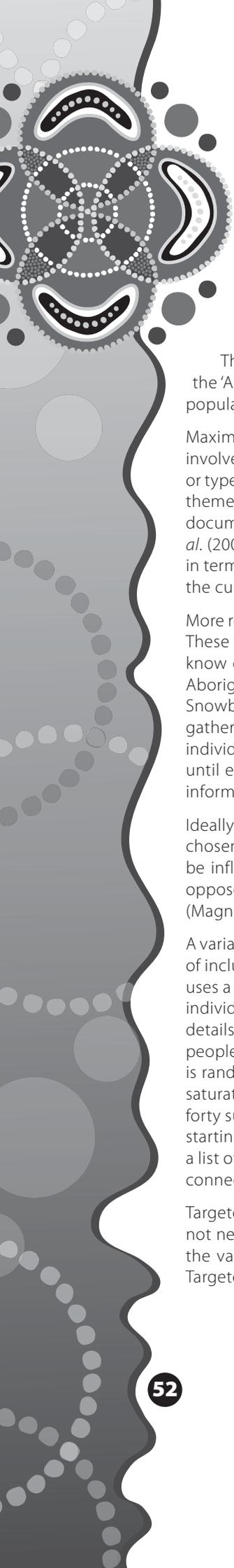
An acknowledged problem in large urban areas is the difficulty associated with identifying a 'community' for the purpose of Aboriginal and Torres Strait Islander research. Aboriginal and Torres Strait Islander communities in urban contexts constitute a heterogeneous network of family relations and organisational memberships geographically dispersed and intermixed within a much larger non-Indigenous population, with a constant inflow and outflow between the urban area and other sites, and frequent changes of address for many who stay within the urban area. For research to produce valid findings in these contexts, appropriate sampling methods will be required.

This chapter explores sampling methods that may be appropriate for researching issues of health care access for urban Aboriginal and Torres Strait Islander people. Some examples of sampling procedures that have been described in the published literature on the health of urban Aboriginal and Torres Strait Islander people are outlined.

4.2 Sampling methods

In general, the preferred approach to sampling is probability sampling, defined as a sample in which sample elements are chosen randomly in such a way that each element has a non-zero probability of selection that may be calculated (Magnani *et al.* 2005). However, researchers who wish to study urban Aboriginal and Torres Strait Islander people find that such sampling methods are inapplicable due to the lack of a sampling frame (i.e. there is no available list of urban Aboriginal and Torres Strait Islander people), the mobility of the people and the fact that they constitute a small proportion of the total urban population. The literature on the sampling of such hidden and hard-to-reach populations is largely a result of the emergence of the HIV epidemic, and the need for researchers to identify appropriate samples of groups who are at risk of HIV infection (such as intravenous drug users, men who have sex with men, prostitutes and homeless people), who for various reasons are not easily 'captured' by standard sampling methods (Faugier & Sargeant 1997).

Various non-probability sampling methods are used by researchers to access such hidden populations. Examples include types of convenience sampling such as cluster sampling and facility-based sampling. Such sampling methods are prone to significant sampling bias (i.e. the sample chosen may not be representative of the whole population being studied). However, for many purposes these sampling methods may be appropriate for studies involving urban Aboriginal and Torres Strait Islander people, at least for initial studies. Examples in the literature include a qualitative study of social capital within an urban Aboriginal and Torres Strait Islander context with a research team of three Aboriginal and three non-Aboriginal researchers (Brough *et al.* 2006). They used a purposive recruitment method to recruit participants for focus group discussions or individual in-depth interviews. The



participants were mostly clients of a cross-section of Aboriginal and Torres Strait Islander community organisations, which had been identified through an initial community-engagement phase of a larger research project. In another example, de Crespigny *et al.* (1998) interviewed twelve older urban Aboriginal and Torres Strait Islander women about medication use. The authors state that:

we located and reached the 'hard-to-reach' group with the assistance and ethics approval of the wider Aboriginal community in Adelaide. Once we had the support of this community we worked with particular Aboriginal home care workers who were in touch with older Aboriginal women (de Crespigny et al. 1998:9).

The actual sampling method was not stated, but was presumably a convenience sample. The reference to the 'Aboriginal community in Adelaide' suggests a lack of appreciation of the heterogeneity of the Aboriginal population.

Maximum variation sampling is a sampling method that addresses the heterogeneity of a population and involves selecting a small sample with maximum variation in defined attributes, such as age, education, gender or type of illness (Higginbotham, Albrecht & Connor 2001). It can be used to highlight the common experiences, themes and outcomes that the members of the sample have in common despite their variations, as well as to document unique experiences. In a study of the experiences of patients with end-stage kidney disease, Cass *et al.* (2002) used a maximum variation sampling approach. The participants covered as wide a range as possible in terms of age, sex, duration of kidney experience (receiving or providing treatment), degree of familiarity with the culture and language of the other group, and experience in cross-cultural communication.

More refined sampling methods, which are variations of chain-referral sampling, are less prone to sampling bias. These forms have been used in hidden populations, and are suitable when members of the target populations know one another or are densely interconnected (Heckathorn 2002), which is generally the case with urban Aboriginal and Torres Strait Islander people. The best known form of chain-referral sampling is snowball sampling. Snowball sampling entails identifying an initial number of subgroup members from whom the desired data is gathered, who then act as 'seeds' to help identify other subgroup members to be included in the sample. These individuals in turn are asked to provide information on other subgroup members, and the process continues until either a target sample size has been reached, or the sample has become 'saturated' (i.e. no more useful information is being provided) (Magnani *et al.* 2005).

Ideally, initial seeds should be randomly chosen, but in practice this may not be possible, so the seeds are often chosen by convenience sampling. This raises the potential problems of sampling bias, as the total sample will be influenced by the choice of initial seeds, and tends to be biased towards favouring more cooperative as opposed to randomly chosen subjects (volunteerism bias), and those who are part of larger personal networks (Magnani *et al.* 2005).

A variation that allows a degree of randomisation is to take a random selection of each recruitment wave instead of including all the named subgroup members. An example of this is Klovdahl's random-walk procedure, which uses a random selection of only one individual from each wave (Klovdahl 1989). In this procedure, one or more individuals are selected randomly from a population, and are then asked to provide the names and contact details of those with whom a specified type of relationship exists (e.g. other Aboriginal and Torres Strait Islander people known to the individual who are currently residing in the urban area). From this list, a further individual is randomly selected, and the process continues until the required number of subjects has been obtained (or saturation has occurred). If forty subjects are required, the procedure might consist of one 'random walk' through forty subjects starting from one individual, or it might consist of four random-walks through ten subjects each, starting from four individuals in the first wave. With each wave consisting of one subject randomly chosen from a list of potential subjects identified by the previous subject, its results reveal structural features of the network connecting members of the target population (Klovdahl 1989; Heckathorn 1997).

Targeted sampling has been described as an extension of snowball sampling (Magnani *et al.* 2005), but it does not necessarily involve snowball sampling. It involves an initial ethnographic assessment aimed at identifying the various subgroups that exist within a given population (Watters & Biernacki 1989; Magnani *et al.* 2005). Targeted sampling aims to avoid the problem of sampling bias that may occur in pure snowball sampling if the

seeds belong to a particular network or subgroup. After an initial assessment of the various subgroups within the target population, the initial seeds are chosen to try and ensure that each subgroup is represented. However, there is still the possibility of sampling bias, as the choice of the initial sample will be limited by the quality of the ethnographic assessment.

There are possible sources of bias in chain-referral methods of sampling (Heckathorn 2002). These include:

- sampling bias (discussed above);
- volunteerism bias: both initial and subsequent subjects may be more likely to be cooperative subjects;
- homophily bias: if one group recruits more peers than other groups, its recruitment pattern will be over-represented in the sample; and
- the sample over-represents those with large personal networks, and the more socially isolated members of the target population are neglected.

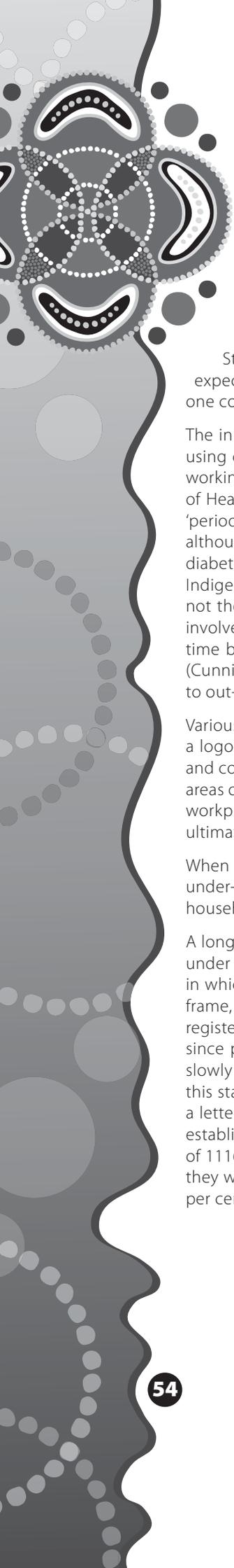
A form of chain-referral sampling that is said to minimise these biases of chain is respondent-driven sampling (RDS). In particular, RDS can be shown to produce samples that are independent of the initial subjects from whom sampling begins. It also reduces the bias from volunteerism, and can control for biases resulting from differences in the size of personal networks (Heckathorn 1997, 2002). RDS differs from traditional sampling in that it involves a dual incentive system—the reward for being interviewed plus a reward for recruiting others into the study. Each subject is paid a small reward for being involved in the research (such as completing an interview), and is also given a fixed number of recruitment coupons and told that if they pass the coupons onto peers who present for interview, the recruiter will be paid a further small reward for each recruited peer. The number of coupons given to each recruiter is usually limited to three; a greater number is not advised to prevent the emergence of ‘semi-professional recruiters’, and the limited number also minimises the influence of any one recruiter on the final sample composition. If there are particular subgroups the researchers wish to access, a small extra bonus may be paid to recruiters for recruiting people from these subgroups. Data collection proceeds through successive ‘waves’ or recruitment cycles until the sample reaches ‘equilibrium’ with respect to the variable being measured. Equilibrium is achieved when estimates do not change during subsequent cycles of recruitment; in theory, this is reached within six waves or less regardless of the characteristics of the initial seeds (Heckathorn 1997, 2002; Magnani *et al.* 2005).

Another feature of RDS is that the relationship between recruiters and recruits, and the personal network size, is documented so that recruitment biases can be assessed and adjusted for in the analysis. According to Magnani *et al.* (2005:571):

The RDS sampling method includes four essential elements. If one or more of these are not present, the sampling method is not RDS. These are: (i) documentation of who recruited whom must be tracked; generally through a coupon system; (ii) recruitment must be rationed with generally no more than three coupons allotted per ‘seed’; (iii) information on personal network size must be gathered and recorded; and (iv) recruiters and recruits must know one another (i.e. have a pre-existing relationship).

The fact that RDS involves small incentive payments may bias such studies to include a higher proportion of less financially well-off subjects who would have a greater incentive to receive the payment. However, Heckathorn (1997, 2002) claims that the dual incentive system, which means that each respondent has the incentive of not just receiving the payment themselves but also enabling payment to their recruiter, helps to overcome this bias.

RDS appears to be a flexible and robust method that can produce a sample having good coverage of the heterogeneity of the targeted hidden population. Although it is potentially applicable to the urban Australian Aboriginal and Torres Strait Islander population, there do not appear to be any examples of RDS in this population. An example of snowball sampling from the literature on urban Aboriginal and Torres Strait Islander people is the study by Craig *et al.* (2005) investigating access to primary health care services in south-western Sydney. However, the snowball sampling technique was not used to provide a sample of Aboriginal and Torres Strait Islander people; it was used to identify services and programs in addition to the main health services in the area.



Cunningham *et al.* (2006) provide an informative account of the problems with recruitment of Aboriginal and Torres Strait Islander people living in urban areas to a large epidemiological study; in this case a study of diabetes in Aboriginal and Torres Strait Islander people living in the Darwin area (the DRUID study), which involved a variety of recruitment strategies including snowball sampling (although it was not named as such). Darwin was considered by the study planners to have a number of characteristics that would facilitate recruitment: perceived community support for the study; strong stable family networks; excellent identification of Aboriginal and Torres Strait Islander status; a relatively high Aboriginal and Torres Strait Islander population within a relatively small urban area; existing partnerships between researchers and practitioners; and a pool of local Aboriginal and Torres Strait Islander people with research experience. Despite these advantages, recruitment was slower than expected, and the ultimate number of participants was lower than expected, leading to the abandonment of one component of the follow-up study due to lack of statistical power.

The initial recruitment strategy involved three main components: (1) recruiting through the local ACCHS; (2) using community and family networks starting with members of the study's Indigenous Steering Group and working outward (i.e. snowball sampling); and (3) contacting people through the Northern Territory Department of Health and Community Services. Each of these methods had difficulties. The ACCHS was going through a 'period of instability' and, as recruitment to the study was not core business, it did not get much attention, although recruitment improved after a study staff member was seconded to the ACCHS to provide part-time diabetes education at no cost while recruiting participants. In the snowball sampling component, in which the Indigenous Steering Group members were the seeds, the enthusiasm of the group members varied. Some did not themselves participate, while others referred 'scores of participants', although it is not clear whether this involved chain-referral or whether all were referred by the initial seeds. The authors speculate that 'a long lead time between applying for and receiving funding led to a diminution in the momentum among the group' (Cunningham 2006:5). Contacting people through the health department database had problems, mainly due to out-of-date or incorrect addresses.

Various other recruitment methods were subsequently used. Efforts to increase awareness included designing a logo and a slogan; a community launch; distribution of information packages; booths at shopping centres and community events; newspaper, radio and television advertisements; and media releases. Doorknocking in areas of high Aboriginal and Torres Strait Islander concentration was abandoned due to lack of success. Visits to workplaces (primarily government agencies and community service organisations) were more successful and ultimately provided 40 per cent of the participants.

When the final study population was compared with census data for the same region, there was a marked under-representation of males, but no substantial differences in age, place of residence, Indigenous group or household income.

A longitudinal study of the health and wellbeing of young urban Aboriginal people in Melbourne, conducted under the auspices of the Victorian Aboriginal Health Service (VAHS), the local ACCHS, used a sampling strategy in which the plan was to develop a list of young Aboriginal people aged fifteen to twenty-five as a sampling frame, and then to take a random sample from the list (Holmes *et al.* 2002). Initially the plan was to use people registered as patients with VAHS to obtain the list, but the VAHS institutional ethics committee rejected this, since people on the register had given their names only for the purposes of patient care. Instead a list was slowly developed using a range of contacts, but after several months there were only 400 names on the list. At this stage the VAHS institutional ethics committee re-considered, and agreed that the researchers could send a letter to those on the VAHS patient register, advising them of a new after-hours youth clinic that had been established and advising them that their name would be added to the list unless they objected. From a final list of 1116 young people, a random sample of 425 was selected, but 27 per cent of these were rejected because they were known to have left Melbourne, to be non-Aboriginal or to have died. Of the 312 remaining, 104 (33 per cent) were unable to be contacted, and 29 (9 per cent) decline to participate, leaving 176 in the study.

The problem with contacting people from a health department or health service database, as was found in both the Darwin DRUID and the VAHS young people's study, is that the study is likely to run into difficulty due to frequent address changes. A similar problem was found in a study that used mail to reach patients seen at an urban American Indian health facility in Washington State (60 per cent of whom were Indigenous); it was estimated that only 61 per cent of patients actually received the mail. Patients who were Indigenous, and patients who were seen more than three months before the study, were significantly less likely to have working mail addresses (Duffy, Goldberg & Buchwald 2006).

In some cases it may be important to obtain information on a particular subpopulation that is a small proportion of the overall study population. This could be Aboriginal and Torres Strait Islander people within a larger mainstream study, or a particular subpopulation within a specific Aboriginal and Torres Strait Islander study. In these cases, oversampling can be used. In New Zealand, through the Waitangi Treaty, researchers are required to demonstrate sufficient statistical power to analyse Māori and non-Māori health data. Consequently, a body of knowledge has emerged regarding statistical methods for oversampling (Adams, Nickson & Saunders 2006).

Aboriginal and Torres Strait Islander people living in urban areas usually have strong, and often large, family networks. It is possible that these family networks could be used as a form of cluster sample, which would allow a range of some variables such as age, but would still be likely to lead to problems with sampling bias. It may be possible to have a small sample of extended families (e.g. from different language groups) to provide the seeds for chain-referral sampling, although this could still lead to sampling and volunteerism biases.

Although extended families usually include respected elders, it would be a mistake to expect that if an elder gives approval for involvement in a research project, other family members would necessarily agree to participate. Respect for individual autonomy is a feature of Aboriginal and Torres Strait Islander culture in all settings, and suspicion about research remains strong.

4.3 Conclusion

As a 'hidden', and frequently mobile population, Aboriginal and Torres Strait Islander people living in urban areas represent a challenge when it comes to sampling and recruitment for research projects aimed at shedding light on issues of health care access. Most sampling methods have problems with sampling bias, but forms of chain-referral sampling, and particularly respondent-driven sampling, are potentially useful methodologies that may overcome some of the difficulties.

4.4 Main points

- Aboriginal and Torres Strait Islander people living in urban areas are a 'hidden' population and present challenges for research that requires sampling. The experience of research involving Aboriginal and Torres Strait Islander people within urban areas also reveals significant problems with recruitment.
- Convenience sampling (including using extended families for cluster samples) may be appropriate for some purposes, but has problems with sampling bias.
- Variations of chain-referral sampling are often used for accessing hidden populations. Snowball sampling is the best-known form. Other variations include the random-walk procedure and targeted sampling.
- Respondent-driven sampling is a form of chain-referral sampling that has theoretical benefits and overcomes some of the biases in other methods of sampling. There do not appear to be any examples of this sampling methodology being used in research involving the Aboriginal and Torres Strait Islander population.
- Oversampling can be useful to obtain data about Aboriginal and Torres Strait Islander people within a wider mainstream study, or about a particular subpopulation within a study involving Aboriginal and Torres Strait Islander people.



References

Adams, K., Nickson, C. & Saunders, M. 2006, 'Indigenous Health: Is it every researcher's business?', *Australasian Epidemiologist*, vol. 13, no. 1, pp. 2–5.

Aboriginal Health Council of South Australia (AHCSA) 2003, application form. Accessed on 20 December 2006 at: <http://www.ahcsa.org.au/media/docs/ahrec_app3.pdf>.

Altman, J. 2004, 'Practical Reconciliation and the New Mainstreaming: Will it make a difference to Indigenous Australians', *Academy of Social Sciences: Dialogue*, vol. 23, no. 2, pp. 35–46.

Altman, J. 2006, '[Letter to Editor:] Land Ties Are Strong', *The Australian*, 8 February, p. 15.

Anderson, I. 1996, 'Ethics and Health Research in Aboriginal Communities', in J. Daly (ed.), *Ethical Intersections: Health Research, Methods and Researcher Responsibility*, Allen & Unwin, Sydney, pp. 153–65.

Anderson, I. 2000, 'Building Collaboration in Aboriginal and Torres Strait Islander Research' (video transcript), Cooperative Research Centre for Aboriginal and Tropical Health (CRCATH) Learning Conference, August 2000, Darwin.

Anderson, I. & Saunders, W. 1996, *Aboriginal Health and Institutional Reform within Australian Federalism*, Discussion Paper No. 17, Centre for Aboriginal Economic Policy Research, Australian National University, Canberra.

Anderson, I., Clarke, A., Renhard, R., Otim, M. & Andrews, S. 2002, 'Linking Acute Care to a Strategy for Improving Aboriginal Health', *Australian Health Review*, vol. 25, no. 5, pp. 118–29.

Anderson, I., Griew, R. & McAullay, D. 2003, 'Ethics Guidelines, Health Research and Indigenous Australians', *New Zealand Bioethics Journal*, vol. 4, no. 1, pp. 20–9.

Australian Bureau of Statistics (ABS) 2006a, *National Aboriginal and Torres Strait Islander Health Survey, 2004–05*, cat. no. 4715.01, ABS, Canberra.

ABS 2006b, 'Synthesising Estimates of Indigenous Child Health Based on the WA Child Health Survey', Research Paper, ABS, Canberra.

ABS & Australian Institute of Health and Welfare (AIHW) 1997, *The Aboriginal and Torres Strait Islander Health Information Plan*, Australian Health Ministers' Advisory Council, Canberra.

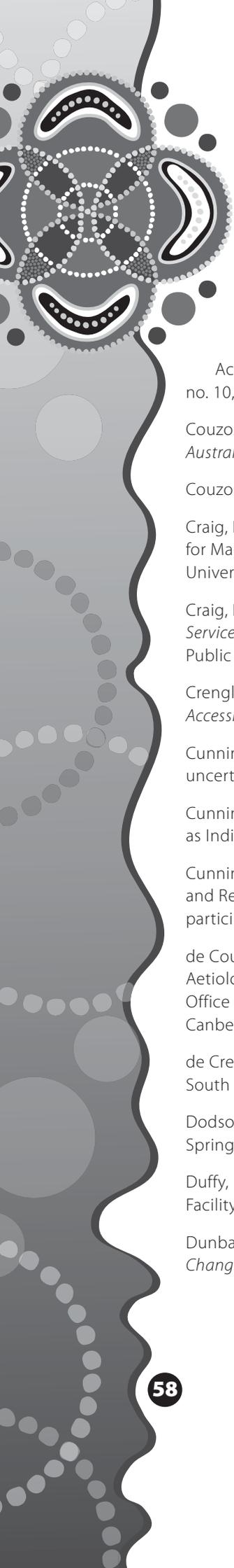
ABS & AIHW 2005, *The Health and Welfare of Australia's Aboriginal and Torres Strait Islander People 2005*, ABC cat. no. 4704.0, AIHW cat. no. IHW14, Australian Government Publishing Service (AGPS), Canberra.

Australian Health Ministers' Advisory Council (AHMAC): Standing Committee on Aboriginal and Torres Strait Islander Health Working Party 2004, *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009*, Department of Health South Australia. Accessed on 15 December 2006 at: <<http://www.health.vic.gov.au/koori/cultural-respect-framework.pdf>>.

Australian Housing and Urban Research Institute (AHURI) 2002, *Ethical Principles and Guidelines for Indigenous Research*. Accessed on 15 December 2006 at: <http://www.ahuri.edu.au/research_agenda_funding/about_funding/>.

Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) 1999, *Research of Interest to Aboriginal and Torres Strait Islander Peoples*, Commissioned Report No. 59, Australian Research Council. Accessed on 23 December 2006 at: <http://www.arc.gov.au/pdf/99_05.pdf>.

- AIHW 2001, *Expenditures on Health Services for Aboriginal and Torres Strait Islander People 1998–99*, AIHW cat. no. AIHW7, AIHW, Canberra.
- AIHW 2005, *National Aboriginal and Torres Strait Islander Health Survey*, AIHW, Canberra.
- Ban, P. 2004, 'Access and Attitudes to Health Care of Torres Strait Islanders Living in Mainland Australia', *Australian Journal of Primary Health*, vol. 10, no. 2, pp. 29–35.
- Baum, F. 1998, *The New Public Health: An Australian Perspective*, Oxford University Press, Melbourne.
- Baum, F., MacDougall, C. & Smith, D. 2006, 'Participatory Action Research (Glossary)', *Journal of Epidemiology and Community Health*, vol. 60, no. 10, pp. 854–7.
- Behrendt, L. 2006, 'What Lies Beneath', *Meanjin*, vol. 65, no. 1, pp. 4–12.
- Binswanger, I., Stern, M., Deyo, R., Heagerty, P., Cheadle, A., Elmore, J. & Koepsell, T. 2007, 'Release from Prison: A high risk of death for former inmates', *New England Journal of Medicine*, vol. 356, no. 2, pp. 157–65.
- Boughton, B. 2001, *Popular Education, Capacity-building and Action Research. Increasing Aboriginal Community Control over Education and Health Research*, CRCATH Occasional Paper Series No. 5, CRCATH, Darwin.
- Brady, M. 1980, 'The Problem with Problematising Research', *Australian Aboriginal Studies*, no. 1, pp. 18–20.
- Brady, M. 1991, *The Health of Young Aborigines: A Report on the Health of Aborigines Aged 12 to 25 Years Prepared for the National Youth Affairs Research Scheme*, AIATIS, Canberra.
- Britt, H., Miller, G., Knox, S., Charles, J., Valenti, L., Henderson, J., Pan, Y., Bayram, C. & Harrison, C. 2003, *General Practice Activity in Australia 2002–2003*, AIHW cat. no. GEP 14 (General Practice Series No. 14), AIHW, Canberra.
- Brough, M. 2006, 'Blueprint for Action in Indigenous Affairs', speech delivered to National Institute of Governance—Indigenous Affairs, Canberra, 5 December 2006. Accessed on 16 January 2007 at: <http://www.atsia.gov.au/Media/speeches06/05_12_06.aspx>.
- Brough, M., Bond, C. & Hunt, J. 2004, 'Strong in the City: Towards a strength-based approach in Indigenous health promotion', *Health Promotion Journal of Australia*; vol. 15, no. 3, pp. 215–20.
- Brough, M., Bond, C., Hunt, J., Jenkins, D., Shannon, C. & Schubert, L. 2006, 'Social Capital Meets Identity: Aboriginality in an urban setting', *Journal of Sociology*, vol. 42, no. 4, pp. 396–411.
- Canadian Population Health Initiative 2003, *Urban Aboriginal Communities: Proceedings of a Round table on the Health of Urban Aboriginal People March 21 2003*, Canadian Institute for Health Information, Ontario.
- Cass, A., Lowell, A., Christie, M., Snelling, P., Flack, M., Marrnganyin, B. & Brown, I. 2002, 'Sharing the True Stories: Improving communication between Aboriginal patients and healthcare workers', *Medical Journal of Australia*, vol. 176, no. 10, pp. 466–70.
- Chrisman, N., Strickland, C., Powell, K., Squeochs, D. & Yallup, M. 1999, 'Community Partnership Research with the Yakama Indian Nation', *Human Organization*, vol. 58, no. 2, pp. 134–41.
- Commonwealth Advisory Committee on Homelessness 2001, *Working Towards a National Homelessness Strategy*, Department of Families and Community Services, AGPS, Canberra.
- Commonwealth Department of Health and Aged Care 2001, *Health Services in the City and the Bush: Measures of Access and Use Derived from Linked Administrative Data*, AGPS, Canberra.
- Commonwealth Department of Health and Aged Care & KPMG 2001, *The Aboriginal and Torres Strait Islander Co-ordinated Care Trials, National Evaluation Report, Volume 1, Main Report*, AGPS, Canberra.



Commonwealth Department of Health and Ageing 2003, *National Aboriginal and Torres Strait Islander Oral Health Workshop Report*, AGPS, Canberra.

Commonwealth Grants Commission (CGC) 2001, *The Indigenous Funding Inquiry*, CGC, Canberra.

Cooperative Research Centre for Aboriginal and Tropical Health 2002, *Thinking Beyond the Project Brochures*. Accessed on 5 December 2006 at: <<http://www.crcah.org.au/research/downloads/Thinkingbeyondtheproject1.pdf>>.

Coory, M. & Walsh, W. 2005, 'Rates of Percutaneous Coronary Interventions and Bypass Surgery after Acute Myocardial Infarction in Indigenous Patients', *Medical Journal of Australia*, vol. 182, no. 10, pp. 507–12.

Couzos, S. 2005, 'PBS Medications: Improving access for Aboriginal and Torres Strait Islander peoples', *Australian Family Physician*, vol. 34, no. 10, pp. 841–4.

Couzos, S. 2006, personal communication.

Craig, P. 2002, *Access of Urban Indigenous Populations into Local Primary Health Care Services*, report prepared for Macarthur Division of General Practice, Centre for Health Equity Training Research and Evaluation, University of New South Wales, Sydney.

Craig, P., Harris, E., Ruscoe, W. & Nicholson, S. 2005, *Access of Indigenous Populations into Primary Health Care Services in Macarthur, Southwest Sydney*, Revised Monograph Muru Marri, Indigenous Health Unit, School of Public Health & University of New South Wales, Sydney, pp 23–34.

Crengle S., Crampton, P. & Woodward, A. 2004, 'Māori in Aotearoa/New Zealand', in J. Healey & M. McKee (eds), *Accessing Health Care: Responding to Diversity*, Oxford University Press, Oxford, pp. 281–302.

Cunningham, J. 2002a, 'Comparing Indigenous Health Status across Regions: A numerical example of uncertainty', *Australian and New Zealand Journal of Public Health*, vol. 26, no. 6, pp. 497–9.

Cunningham, J. 2002b, 'Diagnostic and Therapeutic Procedures among Australian Hospital Patients Identified as Indigenous', *Medical Journal of Australia*, vol. 176, no. 2, pp. 58–62.

Cunningham, J., O'Dea, K., Dunbar, T., Weeramanthri, T., Zimmet, P. & Shaw, J. 2006, 'Study Protocol—Diabetes and Related Conditions in Urban Indigenous People in the Darwin, Australia Region: Aims, methods and participation in the DRUID Study', *BMC Public Health*, vol. 6, no. 8, pp. 1–23.

de Courten, M., Hodge, A., Dowse, G., King, I., Vickery, J. & Zimmet, P. 1998, 'Review of the Epidemiology, Aetiology, Pathogenesis and Preventability of Diabetes in Aboriginal and Torres Strait Islander Populations', Office for Aboriginal and Torres Strait Islander Health Services, Department of Health and Family Services, Canberra.

de Crespigny, C., Grbich, C. & Watson, J. 1998, 'Older Aboriginal Women's Experience of Medication in Urban South Australia', *Australian Journal of Primary Health Interchange*, vol. 4, no. 4, pp. 6–15.

Dodson, M. 2000, 'Human Genetics: Control of research and sharing of benefits', *Australian Aboriginal Studies*, Spring–Fall, pp. 56–71.

Duffy, D., Goldberg, J. & Buchwald, D. 2006, 'Using Mail to Reach Patients Seen at an Urban Health Care Facility', *Journal of Health Care for the Poor and Underserved*, vol. 17, no. 3, pp. 522–31.

Dunbar, T., Arnott, A., Scrimgeour, M., Henry J. & Murakami-Gold, L. 2004, *CRCATH 1997–2002; Working towards Change in Indigenous Health Research: LINKS Project Research Report*, CRCAT, Darwin.

- Dunbar, T. & Scrimgeour, M. 2005, *Ethical Assessment of Indigenous Health Research, A Review of the Literature*, Discussion Paper No. 14, Onemda VicHealth Koori Health Unit, The University of Melbourne, Melbourne.
- Dunbar, T. & Scrimgeour, M. 2006a, 'Indigenous Research: Connecting with communities', *Journal of Bioethical Inquiry*, vol. 3, no. 3, pp. 179–85.
- Dunbar, T. & Scrimgeour, M. 2006b, 'Ethical Governance of Indigenous Health Research in Australia: Implementation of NHMRC research guidelines into practice', *Monash Bioethics Review*, vol. 25, no. 2, pp. 53–62.
- Dunne, E. 2000, 'Consultation, Rapport, and Collaboration: Essential preliminary stages in research with urban Aboriginal groups', *Australian Journal of Primary Health—Interchange*, vol. 6, no. 1, pp. 6–14.
- Dwyer, J., Silburn, K. & Wilson G. 2004, 'National Strategies for Improving Indigenous Health and Health Care', *Aboriginal and Torres Strait Islander Primary Health Care Review, Consultant Report No. 1*, Department of Health and Ageing, Canberra. Available at: <[http://www.healthconnect.gov.au/internet/wcms/publishing.nsf/Content/health-oatsih-pubs-reviewphc.htm/\\$FILE/1national.pdf](http://www.healthconnect.gov.au/internet/wcms/publishing.nsf/Content/health-oatsih-pubs-reviewphc.htm/$FILE/1national.pdf)>.
- Faugier, J. & Sargeant, M. 1997, 'Sampling Hard-to-Reach Populations', *Journal of Advanced Nursing*, vol. 26, pp. 790–7.
- Firebrace, S., Hammond, M., Bell, B., Mathison, P., Watson, A. & Hurley, B. 2001, 'Improving Koori Access to Darebin Community Health Service', *Australian Journal of Primary Health*, vol. 7, no. 1, pp. 120–3.
- Fleisher, L., Woodworth, M., Morra, M., Baum, S., Darrow, S., Davis, S., Slevin-Perocchia, R., Stengle, W. & Ward, J. 1998, 'Balancing Research and Service: The experience of the Cancer Information Service', *Preventive Medicine*, vol. 27, pp.584–92.
- Foley, G. 1982, 'Aboriginal Community Controlled Health Services: A short history', *Aboriginal Health Project Information Bulletin*, no. 2, pp. 13–15.
- Franks, C., Brown, A., Brands, J., White, E., Ragg, L., Duffy, M., Walton, S. & Dunbar, T. 2001, *The Yarning Report: Research Partnerships: Yarning about Research with Indigenous Peoples*, CRCATH, Darwin.
- Fredericks, B. 2004, 'Urban Identity', *Eureka Street*, no. 10, pp. 30–1.
- Glover, J., Tennant, S. & Page, A. 2004, *The Impact of Socioeconomic Status and Geographic Location on Indigenous Mortality in Australia 1997–99*, Occasional Paper Series 1, Public Health Information Development Unit, Adelaide.
- Gray, D., Siggers, S., Atkinson, D. & Stempel, P. 2004, *Substance Abuse and Primary Health Care among Indigenous Australians*, Aboriginal and Torres Strait Islander Primary Health Care Review, Consultant Report No. 7, Commonwealth of Australia, Canberra.
- Hayes, L., Quine, S. & Taylor, R. 2005, 'New South Wales Trends in Mortality Differentials between Small Rural and Urban Communities over a 25-year Period, 1970–1994', *Australian Journal of Rural Health*, vol. 13, pp. 71–6.
- Heckathorn, D. 1997, 'Respondent-driven Sampling: A new approach to the study of hidden populations', *Social Problems*, vol. 44, no. 2, pp. 174–99.
- Heckathorn, D. 2002, 'Respondent-driven Sampling II: Deriving valid population estimates from chain-referral samples of hidden populations', *Social Problems*, vol. 49, no. 1, pp 11–34.
- Henderson, R., Simmons, D., Bourke, L. & Muir, J. 2002, 'Development of Guidelines for Non-Indigenous People Undertaking Research among the Indigenous Population of North-east Victoria', *Medical Journal of Australia*, vol. 176, no. 20, pp. 482–5.



Henry, B., Houston, S. & Mooney, G. 2004, 'Institutional Racism in Australian Healthcare: A plea for decency', *Medical Journal of Australia*, vol. 180, no. 10, pp. 517–20.

Henry, C. & McTaggart, R. 1996, 'Action Research', *Changing Education. A Journal for Teachers and Administrators*, vol. 3, no. 2, pp. 6–11.

Henry, J., Dunbar, T., Arnott, A., Scrimgeour, M., Matthews, S., Murakami-Gold, L. & Chamberlain, A. 2002, *Indigenous Research Reform Agenda: Rethinking Research Methodologies*, CRCATH, Darwin, pp. 1–17.

Henry, J., Dunbar, T., Arnott, A., Scrimgeour, M. & Murakami-Gold, I. 2004, *Indigenous Research Reform Agenda—A Review of the Literature*, Links Monograph Series 5, CRCAH, Darwin.

Higginbotham, N., Albrecht, G. & Connor, L. (eds) 2001, *Health Social Science: A Transdisciplinary and Complexity Perspective*, Oxford University Press, Melbourne.

Holmes, W., Stewart, P., Garrow, A., Anderson, I. & Thorpe, L. 2002, 'Researching Aboriginal Health: Experience from a study of urban young people's health and wellbeing', *Social Science and Medicine*, vol. 54, pp. 1267–79.

House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs 1992, *Mainly Urban: Report of the Inquiry into the Needs of Urban Dwelling Aboriginal and Torres Strait Islander People*, AGPS, Canberra.

House of Representatives Standing Committee on Aboriginal and Torres Strait Islander Affairs 2001, *We Can Do It! The Needs of Urban Dwelling Aboriginal and Torres Strait Islander Peoples*, AGPS, Canberra.

Houston, S. 2004, 'The Past, the Present, the Future of Aboriginal Health Policy', PhD thesis, Curtin University, Perth.

Houston, S. & Legge, D. 1992, '[Editorial:] Aboriginal Health Research and the National Aboriginal Health Strategy', *Australian Journal of Public Health*, vol. 16, no. 2, pp. 114–15.

Howson, J. 2005, 'Aboriginal Land Rights: The next battleground', *Quadrant*, vol. 49, no. 6, pp. 24–9.

Hughes, H. & Warin, J. 2005, 'A New Deal for Aborigines and Torres Strait Islanders in Remote Communities', *Issue Analysis*, no. 54, Centre for Independent Studies, Sydney.

Human Rights and Equal Opportunity Commission (HREOC) 2005, *Aboriginal and Torres Strait Islander Social Justice Report*, Commonwealth of Australia, Canberra. Accessed on 24 December 2006 at: <http://www.hreoc.gov.au/social_justice/sj_report/sjreport05/>.

Humphery, K. 2000, *Indigenous Health and Western Research*, Discussion Paper No. 2, VicHealth Koori Health Research & Community Development Unit, The University of Melbourne, Melbourne.

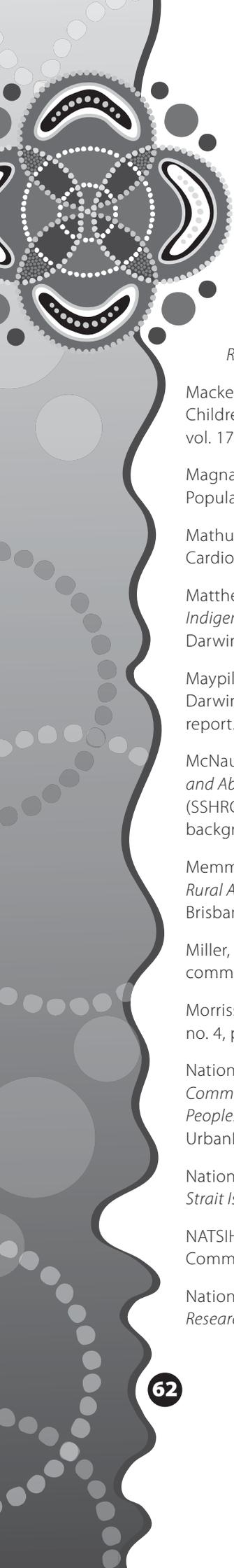
Hunt, J. 2005, *Trying to Make a Difference; A Whitefella PhD Story*, revised monograph of Inaugural Indigenous Health Unit Research Day 2004 Muru Marri, Indigenous Health Unit, School of Public Health & University of New South Wales, Sydney, pp. 45–6.

Hunter, E. 1992, 'Feedback: Towards the effective and responsible dissemination of Aboriginal health research findings', *Aboriginal Health Information Bulletin*, No. 17, May.

Hurley, A. 2003, *Respect, Acknowledge, Listen: Practical Protocols for Working with the Indigenous Community of Western Sydney*, Community Cultural Development, Liverpool, NSW.

Ishak, M. 2001, 'Hospitalisation Patterns of Australia's Aboriginal Population and their Implications', *Aboriginal and Islander Health Worker Journal*, vol. 25, no. 5, pp. 20–5.

- Ishak, M. 2002, 'Differences in the Surgical Admissions to Hospital between the Indigenous and Non-Indigenous Populations of Australia', *Australian and New Zealand Journal of Surgery*, vol. 73, pp. 200–04.
- Ivanitz, M. 2000, 'Achieving Improved Health Outcomes for Urban Aboriginal People: Biomedical and ethnomedical models of health', *Australian Journal of Public Administration*, vol. 59, no. 3, pp. 49–57.
- Jenkin, R., Frommer, M., Tjhin, M. & Rubin, G. 2001, 'Report on Links between Aboriginal Health Research, Policy and Practice', *Part Two: When Research Reports and Academic Journals Are Clearly not Enough; Strengthening the Links between Aboriginal Health Research and Health Outcomes*, Occasional Paper Series Issue 4, CRCATH, Darwin.
- Johns, G. 2006a, 'Social Stability and Structural Adjustment', paper presented at Bennelong Society Sixth Annual Conference: Leaving Remote Communities, 2 September, Melbourne.
- Johns, G. 2006b, '[Opinion:] The Land Rights Initiative Has Failed', *The Australian*, 7 February, p. 12.
- Johnston, T. & Coory, M. 2005, 'Reducing Perinatal Mortality among Indigenous Babies in Queensland: Should the first priority be better primary care or better access to hospital care during confinement?', *Australia and New Zealand Health Policy*, vol. 2, no. 11, pp. 1–5.
- Karvelas, P. 2006a, 'Aborigines to Lose "Sit-down" Welfare', *The Australian*, 29 March, p. 6.
- Karvelas, P. 2006b, 'Push to Break up Remote Camps', *The Weekend Australian*, 27 May, p. 1.
- Kearns, R. & Dyck, I. 1996, 'Cultural Safety, Biculturalism and Nursing Education in Aotearoa/New Zealand', *Health and Social Care in Community*, vol. 4, pp. 371–4.
- Keys Young 1997, *Market Research into Aboriginal and Torres Strait Islander Access to Medicare and the Pharmaceutical Benefits Scheme*, Report for Health Insurance Commission, Canberra.
- Kimberley Aboriginal Health Workers 1992, 'The Importance of Aboriginal Research Feedback: Why and how it should be given back', *Aboriginal and Islander Health Worker Journal*, vol. 16, no. 2, pp. 4–6.
- Kirkham, S., Smye, V., Tang, S., Anderson, J., Blue, C., Browne, A., Coles, R., Dyck, I., Henderson, A., Lynam, M. J., Perry, J., Semeniuk, P. & Shapera, L. 2002, 'Rethinking Cultural Safety while Waiting to Do Fieldwork: Methodological implications for nursing research', *Research in Nursing and Health*, vol. 25, no. 3, pp. 222–32.
- Klov Dahl, A. 1989, 'Urban Social Networks: Some methodological problems and possibilities', in M. Kocen (ed.), *The Small World*, Ablex Publishing, New Jersey, pp. 176–210.
- Kowal, E., Anderson, I. & Baillie, R. 2005, 'Moving Beyond Good Intentions: Indigenous participation in Aboriginal and Torres Strait Islander health research', *Australian and New Zealand Journal of Public Health*, vol. 29, no. 5, pp. 468–70.
- Krieg, A. 2006, 'Aboriginal Incarceration: Health and social impacts', *Medical Journal of Australia*, vol. 184, no. 10, pp. 534–6.
- Kue Young, T. 2003, 'Review of Research on Aboriginal Populations on Canada: Relevance to their health needs', *British Medical Journal*, vol. 327, pp. 419–22.
- Kunitz, S. 2004, 'The History and Politics of Health Care for Native Americans', in J. Healey & M. McKee (eds), *Accessing Health Care: Responding to Diversity*, Oxford University Press, Oxford, pp. 303–23.
- Kunitz, S. & Brady, M. 1995, 'Health Care Policy for Aboriginal Australians: The relevance of the American experience', *Australian Journal of Public Health*, vol. 19, no. 6, pp. 549–58.
- Lake, P. 1992, 'A Decade of Aboriginal Health Research', *Aboriginal Health Information Bulletin*, no. 17, pp. 12–16.



Larkins, S., Geia, L. & Panaretto, K. S. 2006, 'Consultations in General Practice and at an Aboriginal Community Controlled Health Service: Do they differ?', *Rural and Remote Health*, vol. 6, p. 560. Accessed on 6 January 2006 at: <<http://www.rrh.org.au/articles/subviewnew.asp?ArticleID=560>>.

Lavoie, J. 2004, 'Governed by Contracts: The development of Indigenous primary health services in Canada, Australia and New Zealand', *Journal of Aboriginal Health*, vol. 1, pp. 6–24.

Lomas, J. 1997, *Beyond the Sound of One Hand Clapping: A Discussion Document on Improving Health Research Dissemination and Uptake*, Centre for Effective Health-care, The University of Sydney, Sydney.

Mackerras, D. E. M., Reid, A., Sayers, S. M., Singh, G. R., Bucens, I. K. & Flynn, K. A. 2003, 'Growth and Morbidity in Children in the Aboriginal Birth Cohort Study: The urban–remote differential', *Medical Journal of Australia*, vol. 178, no. 2, pp. 56–60.

Magnani, R., Sabin, K., Saidel, T. & Heckathorn D. 2005, 'Review of Sampling Hard-to-Reach and Hidden Populations for HIV Surveillance', *AIDS*, vol. 19 (suppl. 2), pp. S67–S72.

Mathur, S., Moon, L. & Leigh, S. 2006, *Aboriginal and Torres Strait Islander People with Coronary Heart Disease*, Cardiovascular Diseases Series, AIHW, Canberra.

Matthews, S., Scrimgeour, M., Dunbar, T., Arnott, A., Chamberlain, A., Murakami-Gold, L. & Henry, J. 2002, *Indigenous Research Reform Agenda: Promoting the Use of Health Research*, Links Monograph Series 4, CRCATH, Darwin, pp. 1–35.

Maypilama, E., Garngulkpuy, C., Greatorex, J. & Grace, J. 2004, 'Yolngu Longgrassers on Larrakia Land', August, Darwin. Accessed on 18 December 2007 at: <http://learnline.cdu.edu.au/yolngustudies/docs/Longgrass_report.pdf>.

McNaughton, C. & Rock, D. 2003, *Opportunities in Aboriginal Research Results of SSHRC's Dialogue on Research and Aboriginal Peoples*, prepared by Craig Social Sciences & Humanities Research Council of Canada (SSHRC). Accessed on 20 December 2006 at: <http://www.sshrc.ca/web/apply/background/aboriginal_backgrounder_e.pdf>.

Memmott, P., Long, S., Bell, M., Taylor, J. & Brown, D. 2004, *Between Places: Indigenous Mobility in Remote and Rural Australia*, Position Paper: Australian Housing and Urban Research Institute, Queensland Research Centre, Brisbane.

Miller, P. & Rainow, S. 1997, '[Commentary:] Don't Forget the Plumber: Research in remote Aboriginal communities', *Australian and New Zealand Journal of Public Health*, vol. 21, no. 1, pp. 96–9.

Morrissey, M. 2006, 'The Australian State and Indigenous People: 1990–2006', *Journal of Sociology*, vol. 42, no. 4, pp. 347–54.

National Aboriginal Community Controlled Health Organisation (NACCHO) 2001, *Submission to the Commonwealth Parliamentary Inquiry into the Needs of Urban Dwelling Aboriginal and Torres Strait Islander Peoples*, 2 March. Accessed on 2 January 2006 at: <<http://www.naccho.org.au/PolicyReports/Reports/UrbanDwelling.html>>.

National Aboriginal and Torres Strait Islander Health Council (NATSIHC) 2002, *National Aboriginal and Torres Strait Islander Health Strategy*, Commonwealth of Australia, Canberra.

NATSIHC 2004, *National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003–2013*, Commonwealth of Australia, Canberra.

National Health and Medical Research Council (NHMRC) 1999, *National Statement on the Ethical Conduct of Research Involving Humans and Supplementary Notes*, NHMRC, Canberra.

NHMRC 2001, *Human Research Ethics Handbook: Commentary on the National Statement on Ethical Conduct in Research Involving Humans*, NHMRC, Canberra.

NHMRC Aboriginal and Torres Strait Islander Research Agenda Working Group (RAWG) 2002, *The NHMRC Road Map: A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health through Research*, NHMRC, Canberra.

NHMRC 2003, *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*, NHMRC, Canberra.

NHMRC 2006, *Keeping Research on Track: A Guide for Aboriginal and Torres Strait Islander Peoples about Health Research Ethics*, NHMRC, Canberra. Accessed on 4 January 2006 at: <<http://www.nhmrc.gov.au/publications/synopses/e65syn.htm>>.

Nunukwarrin Yunti 2006, *Annual Report 2004–2005*. Accessed on 18 December 2006 at: <http://www.nunku.org.au/index.php?option=com_docman&task=cat_view&gid=60&Itemid=176>.

Office of Aboriginal and Torres Strait Islander Health Services (OATSIHS) 2002, *Primary Health Care Access Program*, Commonwealth Department of Health and Aged Care, Canberra.

OATSIHS 2006, 'Urban Brokerage Services'. Accessed on 28 December 2006 at: <<http://www.health.gov.au/internet/wcms/publishing.nsf/content/health-oatsih-programs-brokerage>>.

Ong, M. & Weeramanthri, T. 2002, 'Delay Times and Management of Acute Myocardial Infarction in Indigenous and Non-Indigenous People in the Northern Territory', *Medical Journal of Australia*, vol. 173, no. 4, pp. 201–04.

Otim, M. 2001, *Indigenous Health Economics and Policy Research*, Discussion Paper No. 4, VicHealth Koori Health Research & Community Development Unit, The University of Melbourne, Melbourne.

Parker, E. J., Misan, G., Richards, L. C. & Russell, A. 2005, 'Planning and Implementing the First Stage of an Oral Health Program for the Pika Wiya Health Service Incorporated Aboriginal Community in Port Augusta, South Australia', *Rural and Remote Health*, vol. 5, p. 254. Accessed at: <<http://www.rrh.org.au/articles/showarticlenew.asp?ArticleID=254>>.

Paul, D. 1998, "'It's not as Easy as Just Walking in the Door": Interpretations of Indigenous people's access to care', *Australian Journal of Primary Health—Interchange*, vol. 4, no. 1, pp. 66–71.

Ramsden, I. 1993, 'Kawa Whakaruruhau. Cultural safety in nursing education in Aotearoa (New Zealand)', *Nursing Praxis in New Zealand*, vol. 8, no. 3, pp. 4–10.

Rigney, L. 1999, 'Internalization of an Indigenous Anticolonialist Cultural Critique of Research Methodologies: A guide to Indigenist Research Methodology and its principles', *Wicazo Sa Review*, Fall, vol. 14, no. 12, pp. 109–13.

Roberts-Thomson, K. 2004, 'Oral Health of Aboriginal Australians', *Australian Dental Journal*, vol. 49, no. 3, pp. 151–3.

Rogers, G., Barton, C., Pekarsky, B. A., Lawless, A. C., Oddy, J. M., Hepworth, R. & Beilby, J. J. 2005, 'Caring for a Marginalised Community: The costs of engaging with culture and complexity', *Medical Journal of Australia*, vol. 183, no. 10, pp. S59–S63.

Ross, K. 1996, *Population Issues, Indigenous Australians*, AIHW Occasional Paper, ABS cat. no. 4708.0, ABS, Canberra.

Rothman, J. 1980, *Using Research in Organizations: A Guide to Successful Application*, Sage Publications, Beverly Hills, CA.



Rowse, T. 2002, *Indigenous Futures: Choice and Development for Aboriginal and Islander Australia*, University of New South Wales Press, Sydney.

St Denis, V. 1992, 'Community-Based Participatory Research: Aspects of the concept relevant for practice', *Native Studies Review*, vol. 8, no. 2. pp 51–74.

Scrimgeour, D. 1997, *Community Control of Aboriginal Health Services in the Northern Territory*, Menzies Occasional Paper Issue No. 2/97, Menzies School of Health Research, Darwin.

Shah, B., Gunraj, N. & Hux, J. 2003, 'Markers of Access to and Quality of Primary Care for Aboriginal People in Ontario, Canada', *American Journal of Public Health*, vol. 93, no. 5, pp. 798–802.

Sibthorpe, B., Glasgow, N. & Wells, R. W. 2006, 'Emergent Themes in the Sustainability of Primary Health Care Innovation', *Medical Journal of Australia*, vol. 183, no. 10, pp. S77–S80.

Silburn, S., Zubrick, S., De Maio, J. A., Shepherd, C., Griffin, J. A., Mitrou, F. G., Dalby, R. B., Hayward, C. & Pearson, G. 2006, *The Western Australian Child Health Survey: Volume 4, Strengthening the Capacity of Aboriginal Children, Families and Communities*, Curtin University of Technology & Telethon Institute for Child Health Research, Perth.

Smith, D., Mununggurr, L., Bamundurruwuy, D. & Edmond, K. 2003, *How Children Grow: Indigenous and Health Professional Perceptions*, CRCATH, Darwin.

Stamp, K., Duckett, S. & Fisher, D. 1998, 'Hospital Use for Potentially Preventable Conditions in Aboriginal and Torres Strait Islander and other Australian Populations', *Australian and New Zealand Journal of Public Health*, vol. 22, no. 6, pp. 673–8.

Starfield, B., Shi, L. & Macinko, J. 2005, 'Contributions of Primary Care to Health Systems and Health', *Milbank Quarterly*, vol. 83, no. 3, pp. 457–502.

Stewart, L., Henderson, C., Hobbs M., Ridout, S. & Knuiman, M. 2004, 'Risk of Death after Release from Jail', *Australian and New Zealand Journal of Public Health*, vol. 28, no. 1, pp. 32–6.

Stocking, B. 1995, 'Why Research Findings Are not Used by Commissions—And what can be done about it', *Journal of Public Health Medicine*, vol. 17, issue 4, pp. 380–2.

Stringer, E. 1996, *Action Research: A Handbook for Practitioners*, Sage Publications, Thousand Oaks, CA.

Stringer, E. & Genat, W. J. 2004, *Action Research in Health*, Pearson Prentice-Hall, Upper Saddle River, NJ.

Stubben, J. 2001, 'Working with and Conducting Research among American Indian Families', *American Behavioral Scientist*, vol. 44, no. 9, pp. 1466–81.

Sullivan, P. 1996, *All Free Man Now: Culture, Community and Politics in the Kimberley Region, North-Western Australia*, Australian Institute of Aboriginal and Torres Strait Islander Studies, Canberra.

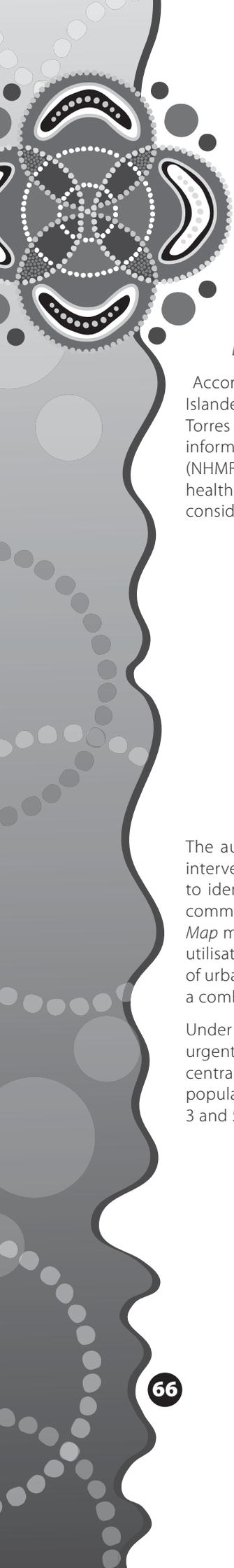
Taylor, J. 2006, *Population and Diversity: Policy Implications of Emerging Indigenous Demographic Trends*, Centre for Aboriginal Economic Policy Research, Australian National University, Canberra.

Thomas, D. 2004, *Reading Doctors' Writing: Race, Politics and Power in Indigenous Health Research, 1870–1969*, Aboriginal Studies Press, Canberra.

Thomas, D. & Anderson, I. 2006, 'Use of Emergency Departments by Aboriginal and Torres Strait Islander People', *Emergency Medicine Australasia*, vol. 18, pp. 68–76.

Thomas, D., Heller, R. & Hunt J. 1998, 'Clinical Consultations in an Aboriginal Community Controlled Health Service: How are they different to consultations with Australian general practice', *Australian and New Zealand Journal of Public Health*, vol. 22, pp. 86–91.

- Tsey, K. 2001, 'Making Research More Relevant to the Needs and Aspirations of Indigenous Australians: The importance of research capacity development', *Aboriginal and Islander Health Worker Journal*, vol. 5, no. 1.
- Tuhiwai Smith, L. 1999, *Decolonizing Methodologies: Research and Indigenous Peoples*, Zed Books Ltd, London and New York.
- Urbis Keys Young 2006, *Aboriginal and Torres Strait Islander Access to Major Health Programs*, report prepared for Medicare Australia & Department of Health and Ageing, Canberra.
- Walker, R., Taylor, C. & Ballard, J. 2002, *Developing Paradigms and Discourses to Establish More Appropriate Frameworks and Indicators for Housing Programs*, AHURI, Western Australia Research Centre, Perth.
- Warin, M., Baum, F., Kalucy, L., Murray, C. & Veale, B. 1998, 'Not just a Doctor: Community perspectives on medical services in women's and community health services', South Australian Community Health Research Unit, Flinders University, Adelaide.
- Watters, J. & Biernacki, P. 1989, 'Targeted Sampling: Options for the study of hidden populations', *Social Problems*, vol. 36, no. 4, pp. 416–30.
- Western Australian Department of Health 2004, *A Healthy Future for Western Australians: Report of the Health Reform Committee*, Western Australian Department of Health, Perth.
- Winch, J. & Hayward, K. 1999, 'Doing it Our Way: Can cultural traditions survive in universities?', *New Doctor*, Summer, pp. 25–7.
- World Health Organization 2004, 'Indigenous Peoples and Participatory Health Research: Planning and management: Preparing research agreements', (Annexe B). Accessed on 27 December 2006 at: <http://www.who.int/ethics/indigenous_peoples/en/index.html>.
- Zubrick, S., Lawrence, D., Silburn, S. R., Blair, E., Milroy, H., Wilkes, T., Eades, S., D'Antoine, H., Read, A., Ishiguchi, P. & Doyle, S. 2004, *The Western Australian Aboriginal Child Health Survey: Volume 1, The Health of Aboriginal Children and Young People*, Telethon Institute for Child Health Research, Perth.
- Zubrick, S., Silburn, S., Lawrence, D. M., Mitrou, F. G., Dalby, R. B., Blair, E. M., Griffin, J., Milroy, H., De Maio, J. A., Cox, A. & Li, J. 2005, *The Western Australian Child Health Survey: Volume 2, The Social and Emotional Wellbeing of Aboriginal Children and Young People*, Curtin University of Technology & Telethon Institute for Child Health Research, Perth.



Appendix

National Health and Medical Research Council, Aboriginal and Torres Strait Islander Research Agenda Working Group (NHMRC RAWG) 2002, *The NHMRC Road Map: A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health through Research*, NHMRC, Canberra.

According to *The NHMRC Road Map*, many mainstream health programs have an Aboriginal and Torres Strait Islander focus yet, at present, there is little reliable data on the uptake of these programs by Aboriginal and Torres Strait Islander people or of their effectiveness. The *NHMRC Road Map* also notes that 'there is little to no information on the history of Aboriginal and Torres Strait Islander health and health care services in Australia' (NHMRC RAWG 2002:12). The *NHMRC Road Map* outlines six research themes critical to achieving substantial health gain for Aboriginal and Torres Strait Islander peoples. Two themes directly relevant to issues under consideration in this review include:

3. A focus on health services research which describes the optimum means of delivering preventive, diagnostic and treatment based health services and interventions to Aboriginal and Torres Strait Islander peoples. This priority theme encompasses research that examines the effectiveness and efficiency of primary health care and related services recognising factors such as geographic location, community groups, service infrastructure, governance and service mix. This theme also involves a focus on specific major causes of death, illness and disability and the application of preventive, diagnostic and treatment based interventions and health services (NHMRC RAWG 2002:9).

5. A focus on engaging with research and action in previously under-researched Aboriginal and Torres Strait Islander populations and communities. Gaps remain in knowledge and understanding of the health issues of some Aboriginal and Torres Strait Islander populations and communities. For example, there is a paucity of information on the needs of urban communities; Torres Strait Islander communities; young adults and the elderly. Priority needs to be given to research that produces data and knowledge critical for health gain in these populations or communities (NHMRC RAWG 2002:12).

The authors of the *NHMRC Road Map* adopt the position that descriptive research is less important than intervention-based research except where there are information gaps to be filled, and that it is premature to identify these gaps until an audit of current research has occurred. In a summary of issues arising from community consultations over priorities for Aboriginal and Torres Strait Islander health research, the *NHMRC Road Map* makes substantial reference to the importance of further investigating issues of health service provision, utilisation, access and impact. This summary provides the basis for positioning research involving the interests of urban-dwelling Aboriginal people within the context of a broader research agenda involving the interests of a combined Aboriginal and Torres Strait Islander population in Australia.

Under each nominated research theme area, the *NHMRC Road Map* indicates specific areas of research requiring urgent action. For the purpose of this review we have drawn from the Road Map-identified areas that address the central review questions as these relate to the interests of urban-dwelling Aboriginal and Torres Strait Islander populations. These selected identified priority areas and draft research questions are listed under theme areas 3 and 5 as follows:

3. A focus on health services research which describes the optimum means of delivering preventive, diagnostic and treatment based health services and interventions to Aboriginal and Torres Strait Islander peoples.

- the way that political decisions and inter-governmental relations impact on health. Financing decisions, including allocation of funds, priority setting, and the relationship between investment, need and utilisation require understanding and action. The question was asked: 'why is it that Aboriginal and Torres Strait Islander peoples' receive significantly fewer health interventions than non-Aboriginal and Torres Strait Islander peoples when they are significantly sicker?';
- generating evidence about the efficiency and effectiveness of health spending and how that relates to risk factors: 'what are the best buys in Aboriginal and Torres Strait Islander health?' This should provide a strong justification for increased investment in prevention and integrated primary care initiatives, rather than in the acute care sector;
- a broader framing of health services to encompass and complement programs in housing, education and justice in a primary care setting. Integrated approaches that cross agencies and programs are essential. To work, these need to sit in a community controlled setting. Research can provide information about what works and why;
- barriers to accessing health services: the reality of living in poverty, having a poor sense of identity, lacking emotional support, living with racism, experiencing incarceration and living with violence all operate as barriers to access; and
- health services themselves may pose risks to Aboriginal and Torres Strait Islander health. For many Aboriginal and Torres Strait Islander peoples, there are low levels of trust, particularly in interactions with mainstream health services. There needs to be understanding of what makes services effective and accessible, and the reasons why mainstream services often fail Aboriginal and Torres Strait Islander people. The focus should be on evaluating and improving health systems. A system of accrediting services as culturally safe should be considered.

Draft research questions

- What are the critical success factors in the delivery of health services for Aboriginal and Torres Strait Islander peoples?
- What makes mainstream services work for Aboriginal and Torres Strait Islander peoples? Why do mainstream institutions (hospitals, universities, research agencies) often fail Aboriginal and Torres Strait Islander peoples?
- How can services be designed and delivered that support core cultural values; what are the long term health benefits of delivering services in culturally appropriate ways and how does this compare to the cost of such delivery systems?
- Does the current system of allocating funding correspond to need?
- What factors shape the utilisation of primary health care services by Aboriginal and Torres Strait Islander peoples?
- What is the impact of Aboriginal Medical/Health Services and other community based service provision systems on health outcomes for communities: in an historical and contemporary context? (NHMRC RAWG 2002:10–11)



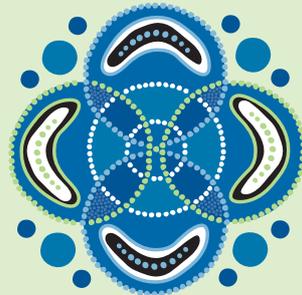
5. A focus on engaging with research and action in previously under-researched Aboriginal and Torres Strait Islander populations and communities.

- a focus on certain geographic populations: while it was accepted that some Aboriginal and Torres Strait Islander populations had been the subject of significant amounts of research, there were many others who had experienced none at all, and had identified their circumstances as requiring research attention. These populations could be located in rural or remote settings, but more often were Aboriginal and Torres Strait Islander peoples living in major cities and the urban periphery. The situations of these urban and urban fringe populations were identified as a significant research gap, especially considering that the largest concentrations of Aboriginal and Torres Strait Islander populations are located in urban settings.

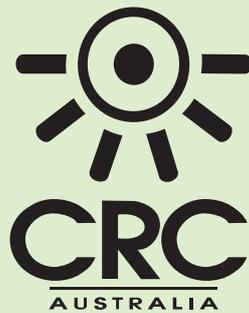
Draft research questions

- What are the coping strategies in an urban Aboriginal identity and urban Torres Strait Islander identity?
- What are the regional specific barriers to accessing health services? What are the specific issues in accessing health services in peri-urban areas, and what is the ability of those services to change in response to rapid changes in demographics?
- What is the prevalence and incidence of specific health conditions across various settings, geographic areas, age gaps etc? (NHMRC RAWG 2002:13–14)





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