

# FACTORS INFLUENCING ACCESS TO URBAN GENERAL PRACTICES AND PRIMARY HEALTH CARE BY ABORIGINAL AUSTRALIANS—A QUALITATIVE STUDY

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## Abstract

This paper aims to explore the barriers and facilitators for Aboriginal and Torres Strait Islander Australians with chronic disease to access urban, mainstream general practice and primary health care. Six focus groups and five interviews were conducted with 40 participants that included Aboriginal people with diabetes, health service providers and policy makers. Using diabetes as the exemplar, participants were asked to relate their own experiences of diabetes management. Data was thematically analysed. Two overarching themes and seven other factors were identified as influencing Aboriginal people's access to health services. Cultural competence can be achieved

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within a health service when all nine factors are addressed in the context of the local community. Closing the health gap between Aboriginal and non-Aboriginal Australians requires a particular sensitivity and understanding of the facilitators and barriers for urban Aboriginal people accessing mainstream health services.

### **Keywords** (*using MeSH from Index Medicus*)

primary health care, family practice, health services, Indigenous, cultural competency, diabetes mellitus

### **Introduction**

Aboriginal Australians are disproportionately burdened with diabetes, and nationally the problem is escalating (Busfield et al., 2002; Craig, Femia, Broyda, Lloyd, & Howard, 2007; Department of Human Services, 2004; Dunstan et al., 2002; McDermott, McCulloch, Campbell, & Young, 2007; O'Dea, Rowley, & Brown, 2007; Ring & Firman, 1998). In 2004–2005, diabetes was reported by 6% of Indigenous Australians. After adjusting for age, Indigenous Australians were three to four times more likely than other Australians to report having diabetes or high blood glucose levels (Australian Bureau of Statistics, 2006). Despite this high burden of illness, uptake of health policies and clinical interventions to address the health disadvantage borne by Indigenous people is slow, and diabetes management for Indigenous Australians remains inadequate (Maple-Brown et al., 2008; Naqshbandi, Harris, Esler, & Antwi-Nsiah, 2008; Si, Bailie, Wang, & Weeramanthri, 2010).

Data from the Northern Territory indicates that the rising remote Aboriginal mortality rates from ischaemic heart disease and diabetes have been slowing since the 1990s (Thomas et al., 2006). Aboriginal community-controlled health services (ACCHS) play a crucial role in the provision of primary health care to remote communities, and it has been suggested that increasing focus on primary care services and chronic disease management and prevention in

remote communities may have contributed to this encouraging trend. However, the majority (76%) of Aboriginal Australians live in major cities and regional areas (Australian Institute of Health and Welfare, 2007), and they are more widely spread through the general population and are therefore more “hidden”. Service utilization data indicates that they often use mainstream general practice and primary health care services (PHCS) either solely or in conjunction with ACCHS and Aboriginal Medical Services (AMS). In 2006–2007 patients identified themselves as Aboriginal at 0.9% of general practice encounters across Australia (Britt et al., 2008), which equates to approximately one million encounters a year, and most likely represents significant under-reporting. The 2008 Australian Institute of Health and Welfare figures, based on responses given by 10,437 respondents to a National Aboriginal and Torres Strait Islander Health (NATSIH) 2004–05 Survey, seem to suggest that when Aboriginal people have a health problem they usually go to a doctor, most commonly a general practitioner (GP) (60%), an AMS (30%) or a hospital (7%); while in Victoria, 75% report usually attending a GP, 19% an AMS and 3% a hospital (Australian Bureau of Statistics & Australian Institute of Health & Welfare, 2008). It is noteworthy that there are currently still debates over the accuracy of these figures and criticisms in the lack of clarity in the terminology used in the survey (Australian Human Rights Commissioner, 2009; National

Aboriginal Community Controlled Health Organisation, 2009).

Although there are many similarities between the Aboriginal community and other vulnerable communities (disadvantaged due to poverty, ethnicity, age, gender, mental health problems or similar), where barriers such as language and cultural differences, low health literacy, financial constraints, unemployment and social stigma often challenge access to optimal health care (Baker, Bazargan, Bazargan-Hejazi, & Calderón, 2005; Bowie & Rocha, 2004; Murray & Skull, 2005; Shaw, Huebner, Armin, Orzech, & Vivian, 2009), there are social and cultural issues unique to Aboriginal people in Australia. A Queensland study found that up to 16% of Aboriginal Australians presenting to mainstream services reported feeling they were treated badly because they were Indigenous (Australian Bureau of Statistics & Australian Institute of Health & Welfare, 2008). A lack of local services that are culturally respectful for Aboriginal Australians has been identified in the area of palliative care (McGrath, 2007; McGrath, Holewa, & Kail-Buckley, 2007), rehabilitation services (Kendall & Marshall, 2004), and medicines information (Stoneman & Taylor, 2007). Although adaptations of mainstream chronic disease management programmes and interventions for subgroups of Indigenous communities have been attempted, our recent review of the literature found that few have been evidence-based or rigorously evaluated and none were in urban settings (Liaw et al., 2011). The inherent evidence-based nature of mainstream general practice tends to focus more on narrow biomedical and individualistic models of health than social and cultural factors (Rogers, 2004), that have far greater impact on the health of vulnerable groups such as Aboriginal people. The notion of inverse care has long been used to document the way services tend to be accessed least by those with highest need, highlighting the way health systems can perpetuate inequities in health for a range of disadvantaged and vulnerable groups

(Brett, 2011). Thus, access is a complex phenomenon, and the concept of cultural respect is an important element of wider concerns in ensuring equitable access to care.

The *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health (2004–2009)* was developed to influence the corporate health governance, organizational management and delivery of the Australian health care system to adjust policies and practices to be culturally respectful and thereby contribute to improved health care and outcomes for Aboriginal and Torres Strait Islander peoples (Australian Health Ministers' Advisory Council's Standing Committee on Aboriginal and Torres Strait Islander Health Working Party, 2004). It is in this context and in the spirit of "closing the gap" through strengthening Indigenous and non-Indigenous partnerships that we have undertaken a study to examine ways to improve the management of Aboriginal Australians with diabetes and chronic disease in urban mainstream PHCS.

An initial literature review was conducted in 2008–2009 to explore factors specific to urban Indigenous people that influence diabetes management, and to identify and assess the determinants of success and failure in chronic disease interventions (Liaw et al., 2011). We found that successful chronic disease care and interventions require Aboriginal community engagement, strong leadership, local knowledge of the community, shared responsibilities and shared care between health sectors, sustainable resources and integrated data and information systems (Liaw et al., 2011). Closing the gap in Aboriginal health care delivery and outcomes will only occur when there is a culturally competent health system that is inclusive of both Aboriginal and non-Aboriginal people, in which all patients and service providers feel culturally safe.

Our study involves a two-phased exploratory-action process. Phase 1 consisted of focus groups and one-to-one interviews with key stakeholders to explore the facilitators and

barriers to accessing mainstream services by urban Aboriginal people with diabetes; phase 2 involved developing a culturally respectful “care model” which is currently being piloted and evaluated in selected PHCS.

This paper reports the findings from the phase 1 focus groups and interviews.

## Methods

Project Agreements were negotiated with the Victorian Aboriginal Community-Controlled Health Organisation (VACCHO) and the Victorian Aboriginal Health Service (VAHS). A VACCHO representative was an associate investigator in the research team. A reference group (consisting of Aboriginal community members, representatives from Aboriginal and non-Aboriginal health services and organizations, and healthcare practitioners) provided broad advice on culturally respectful processes. While none of the six original researchers were Aboriginal, five had experience working with Aboriginal communities and three had extensive experience in Aboriginal health research. Two Aboriginal research officers with extensive experience working in Aboriginal communities were appointed after the project commenced. One in particular had experience in conducting workshops and focus groups with Aboriginal communities. Both assisted with recruiting participants and conducting the focus groups and interviews. The project was approved by the University of Melbourne’s Human Research Ethics Committee and through VACCHO’s research ethics review process.

## Setting

The number of Indigenous people living in Australia on 30 June, 2010 was estimated to be 562,681. Victoria, with 36,734 Indigenous people, had the lowest proportion of Indigenous people among its population (0.7%) (Australian Bureau of Statistics, 2009, 2010). In Victoria,

there are no remote communities. All Indigenous Victorians live in regional or urban areas; about half live in regional Victoria and half in metropolitan Melbourne (Aboriginal Affairs Taskforce, 2011). VACCHO is the peak body for Aboriginal Health representing 24 ACCHS across Victoria. VAHS is the oldest and largest ACCHS and is only one of three AMS servicing the city of Melbourne.

## *Sampling frame and recruitment strategies*

The sampling frame included Aboriginal people with diabetes, health service providers, and representatives from key government and non-government health agencies to provide insights into different aspects of effective diabetes care.

Potential patient participants were invited via service providers at various Aboriginal and non-Aboriginal community health services, as well as via the Koori liaison officers at two metropolitan teaching hospitals. Criteria for patient participants were the following:

- of Aboriginal and Torres Strait Islander descent
- diagnosed with diabetes
- over 18 years old
- able to give informed consent
- have received diabetes care in the last 12 months.

Potential health service providers and key organization representatives were identified via networks through VACCHO, VAHS, the Royal Australian College of General Practitioners and Divisions of General Practice. Personal contacts of the research team, the Aboriginal research officers and the reference group were also used to aid recruitment of participants.

## *Focus groups and interviews*

Focus groups lasted 1½ to 2 hours; interviews took 45 to 60 minutes. Participants were asked to relate their own experiences of diabetes

TABLE 1 Focus group and interview questions

<b>PATIENTS</b>
<i>Round-Robin or Introduction question</i>
Thinking of your own situation, how well is your diabetes at the moment?
<i>Transition questions</i>
Can you tell us how your health service or a healthcare provider has helped you or someone you know to better manage your/their diabetes?
Can you tell us how a health service or a healthcare provider did not help you, or someone you know, to better manage your/their diabetes?
What are the different ways Indigenous people can get diabetes care in the community? (How easy or difficult are they?)
<i>Key questions</i>
What do you look for or expect from GPs and healthcare providers when you go to them?
Do you think mainstream healthcare providers are able to help you to manage your diabetes? Why?
What do you think mainstream healthcare providers need to change or improve so they are able to help you manage your diabetes better?
<b>HEALTH SERVICE PROVIDERS AND ORGANIZATION REPRESENTATIVES</b>
<i>Round-Robin or Introduction question</i>
What is the first picture or word that comes to mind with the question: what does an Indigenous patient need to help them manage their diabetes?
<i>Transition questions</i>
Can you tell us about a good diabetes programme or intervention at a health service or a GP practice, or a good government initiative, which helped the local Indigenous community to manage diabetes? (Is that programme/intervention still currently running?)
Can you tell us about a diabetes programme or intervention or initiative that did not work for the local Indigenous community? (Is that programme/intervention still currently running?)
In your opinion, are there many health services available to Indigenous patients living in cities to help them to control diabetes? (How well are patients being served? What are the difficulties?)
<i>Key questions</i>
What should an Indigenous patient be able to expect from GPs and healthcare providers when they go to them?
Do you think mainstream healthcare providers are able to help Indigenous patients manage their diabetes? Why?
What do you think mainstream healthcare providers need to change or improve so they can help Indigenous patients to manage their diabetes?

management. The questions (Table 1), designed to provide descriptive meaning and depth to the topics, consisted of one round-robin question to introduce the topic to the participants, three transition questions and three key focus questions (Hurworth, 1996).

The two Aboriginal research officers, assisted

by a member of the research team and a student researcher, moderated all focus groups and interviews. The focus group process from participant engagement through to relationship-building and trust development, focus group organization and facilitation, reporting and feedback, was substantially adapted by the Aboriginal

research officers and the research team. This ensured cultural respect and that all participants were fully informed and totally at ease with the focus group discussions. For instance, all participants were greeted at the front entrance to make sure they did not have to navigate the unfamiliar environment of the university; food and ample time were available before and after each focus group for “yarning” and for participants to get to know one another; each focus group question was displayed on PowerPoint to help the facilitator and participants stay on track; all participants were fully reimbursed for their expenses; and each participant received a personalized report of the focus group findings. This deliberate “Aboriginalization” of the methodology that emphasizes a respect fundamental to all Aboriginal interactions has contributed significantly to the quality and richness of the data collected (Burchill et al., 2012).

### **Data collection and analysis**

Focus groups and interviews were audio-taped and recordings sent to external transcribers for transcription. Transcripts were reviewed first by the researchers present at the focus groups and interviews individually, and edited collectively until consensus was reached.

The revised transcripts were then de-identified and thematically coded and analysed in NVivo 8 by two members of the research team. Sections of transcripts were assigned multiple codes where relevant. Analysis was conducted using a template derived from our literature review findings (Liaw et al., 2011) with some themes identified *a priori* from the literature and others added as data was read and interpreted (King, 1998). This approach integrated data-driven codes with theory-driven codes. Two other members of the research team reviewed a sample of coded transcripts, and the template for analysis was discussed with the whole team and revised where necessary.

The second stage of data analysis involved organizing and grouping the codes. Based on

our literature review where a composite framework that incorporated the “Chronic Care Model” was used to assess chronic disease interventions (Liaw et al., 2011), and also work done by others who have used the Chronic Care Model as a framework (Bailie et al., 2007; Bailie, Si, O’Donoghue, & Dowden, 2007), we organized the codes in a hierarchical structure using the four key domains of the Chronic Care Model: community, patient, provider and system (Wagner, 1998; Wagner et al., 2001). Further analysis was conducted to identify barriers or facilitators for Aboriginal people with diabetes accessing urban mainstream general practice and PHCS.

### **Feedback to participants**

A short report of the preliminary findings, written in lay language, was sent with a handwritten card to each participant to express the research team’s appreciation for their contribution. The letter also informed participants about further development of the project and possible applications of the findings.

## **Results**

Six focus groups and five semi-structured interviews were conducted with 40 participants (Table 2). We identified nine major themes that influence Aboriginal people’s access to mainstream health services. Two overarching themes were identified as barriers by nearly all participants: *history* (of dispossession) and *racism and discrimination*. These may be positively transformed into facilitators if there is “recognition and acknowledgement of history”. Seven other factors were identified—*respect and trust, transport, flexibility, time, support, outreach* and *working together*. When absent, these operate as barriers (Figure 1). While there is clearly a great deal of overlap between these seven factors and the two overarching themes, *cultural competence* within a health service can

TABLE 2 Demographic characteristics of participants

Participant code	Aboriginality	Age group (years)	Gender	Diabetes status	Employment
1A	Aboriginal	40–55	F	II	gathering place manager
1B	Aboriginal	40–55	F	II	artist
1C	Aboriginal	>55	F	II	unemployed
1D	Aboriginal	40–55	F	II	NK
1E	Aboriginal	>55	F	II	NK
1F	Aboriginal	<40	F	I	works at community-controlled organization
1G	Aboriginal	>55	M	I	pastor
1H	Aboriginal	>55	F	II	housewife
2A	Aboriginal Elder	>55	M	I	retired
2B	Aboriginal Elder	>55	F	II	retired
2C	Aboriginal	>55	M	nil	works at ACCHS
2D	Aboriginal	40–55	M	II	works at ACCHS
3A	non-Aboriginal	>55	F	II	unemployed
3B	Aboriginal Elder	>55	F	II	retired
3C	Aboriginal Elder	>55	F	II	retired
3D	Aboriginal Elder	>55	F	II	works at ACCHS
3E	Aboriginal Elder	>55	F	II	retired
3F	Aboriginal Elder	>55	F	II	retired
3G	Aboriginal Elder	>55	F	II	retired
3H	Aboriginal	40–55	F	nil	nurse
3IA	Aboriginal Elder	>55	F	II	volunteer
3IB	Aboriginal	40–55	M	II	unemployed
4A	Aboriginal	40–55	F	nil	hospital liaison officer

Participant code	Aboriginality	Age group (years)	Gender	Diabetes status	Employment
4B	Aboriginal	40-55	M	nil	health worker at ACCHS
4C	Aboriginal	40-55	F	nil	nurse at ACCHS
4D	Aboriginal	<40	F	nil	liaison worker at community health service
5A	non-Aboriginal	40-55	F	NK	GP
5B	non-Aboriginal	>55	M	NK	GP
5C	non-Aboriginal	40-55	M	NK	works at community health service
5D	non-Aboriginal	40-55	F	NK	diabetes educator
5E	non-Aboriginal	<40	F	NK	dietitian
5F	non-Aboriginal	>55	M	NK	GP
5G	non-Aboriginal	40-55	F	NK	health facilitator/nurse
5IA	non-Aboriginal	>55	M	nil	GP
5IB	non-Aboriginal	40-55	F	nil	GP
6A	Aboriginal	40-55	M	II	senior researcher at an academic institute
6B	Aboriginal	40-55	M	nil	senior manager of Indigenous programmes at state-based non-government health agency
6C	non-Aboriginal	40-55	M	nil	senior manager of Indigenous unit at state-based non-government health agency
6D	non-Aboriginal	40-55	F	nil	government health agency representative
6IA	non-Aboriginal	40-55	F	nil	senior policy maker at government health agency

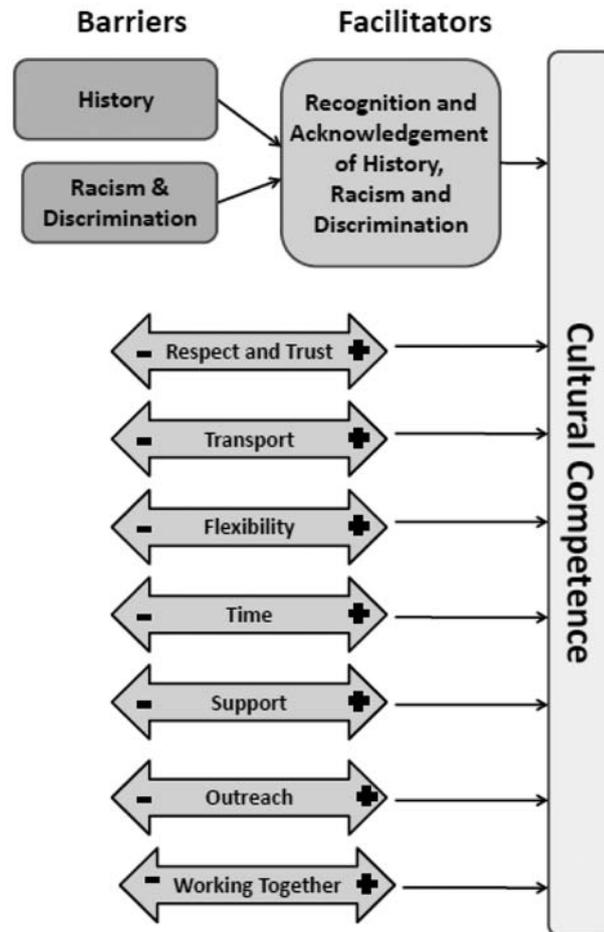


FIGURE 1 Barriers and facilitators to accessing urban mainstream general practice and health care services by Aboriginal people with chronic disease.

be achieved when all nine factors are addressed in the context of the local community.

### *History of dispossession*

Almost all participants identified history of dispossession and ongoing marginalization as major barriers to accessing care.

Aboriginal participants explained both their poor health and their reluctance to access mainstream services in terms of the painful history of Aboriginal oppression. Most notable was the way history was recalled as the recent past experienced by themselves or by their parents:

... because the loss of the land has made our people sick. There's a spiritual sickness

that—and all this stuff is like a vexation to our souls, you know, that we have to put up with. People do put up with it and have put up with it for years. 1B

... from years and years of being abused, traumatized ... as second-class citizens ... pushed out in the gutter and out of the way. 2A, 2B, 2C (in conversation, agreeing with and finishing each other's sentences)

For some Aboriginal participants, transgenerational trauma continues to go unrecognized.

Then society says "Why, why do we have this problem, what's this problem we've got, where did it come from?" And that has happened as close as one generation from me. So

the children from that generation are the ones who live it. 2D

This Aboriginal perspective was supported by non-Aboriginal participants. As one non-Aboriginal GP explained:

One of the biggest barriers [to accessing care] was just history, really, and that most of the [Aboriginal] people you were seeing had had some dealing with mainstream institutions that had been devastating on their family. I think as a group that's been made so marginal in the society it's just generally pretty hard for [Aboriginal] people to be going into [a] mainstream service where, you know, the impact of racism and classism and everything else on them just makes people feel so invisible. 5A

### ***Racism and discrimination***

Negative stereotypes and prejudices were reported in the experiences of many Aboriginal participants:

I broke my arm in the shopping centre, and I got taken into hospital. And I heard them saying "Ask her if she was drunk". 3C

General practitioners, nurses, healthcare providers and the like ... they have this perception that Aboriginal people are not really people, and we're second-rate. When we present with all these problems, we're hypochondriacs. You know, we're just out for a moan or to get something free out of the government. It's that sort of attitude. 2D

Participants were highly critical of mainstream health services that do not fulfil their duty to Aboriginal patients:

When you go to a non-Aboriginal service, a lot of them say "Oh, haven't you got your own health service?" It's "Oh you should go to your own because they understand you

better." That is still racism to me, as far as I'm concerned. 2A

The way he [the non-Aboriginal GP] was offering his service to me, he wasn't going to look after me to the standard I expected as a person. Whereas if I had gone in there and I wasn't an Aboriginal person, I daresay that it would have been a little bit different. 2D

In response to the suggestion that employing Aboriginal liaison officers could assist with Aboriginal patients, some felt that the practice in itself constituted discrimination:

What? If you've got Kooris in there okay, they'd be alright? But why can't the white treat you the same as the Koori would? It's discrimination. 3E

### ***Recognition and acknowledgement of history***

Aboriginal participants felt that recognition and acknowledgement of history was important for addressing the past and ongoing negative impacts of dispossession and other traumatic events, including racism and discrimination. They made a direct link between this and improving practice in health care delivery.

All Australians should know Aboriginal history like the land taken, the massacres that happened. The waterhole poisoned and all these bad things that have happened. Australians should know that—then they would have more respect for the original inhabitants of the land, including the doctors and nurses that look after us. Attitude has to change. 1G

### ***Respect and trust***

Respect and trust were raised by Aboriginal participants in the context of the need for equity in treatment and understanding from service providers.

To respect that we are a different people to them. That we have cultural needs. To respect that and accept it. For God's sake do that now. It's long overdue. 1C

Even in the context of transport provision by Aboriginal services, this was seen as a practice that requires respect and sensitivity. An Aboriginal Elder explained:

When I see them get picked up at this time and that time, they are like a lot of cattle, taking the cows to the shed to milk them. You know, at this time and that sort of stuff. I think our people are just treated disrespectfully quite a lot. 3IA

Non-Aboriginal participants also recognized that Aboriginal people

... need to trust the service they're going to access. 6C

### **Transport**

Provision of transport was identified by Aboriginal participants as a critical issue that would alleviate some of the pressures for Aboriginal people:

There's people that do not attend their appointments and everything because they can't get there. 1B

It is not that transport has got anything to do with culture but we care for one another. Getting people to appointments and taking them home is just part of our follow-up [at an ACCHS] with their health needs. Because we don't just look after diabetes, we look after the person, the whole person. 3IA

Aboriginal and non-Aboriginal service providers expressed frustration in dealing with transport challenges for their Aboriginal patients:

Transport, like it's so simple but oh my goodness it's such a big deal. 5E

They may be sick and you ring them up or they've rung you, how do we get them in? There's no transport.... No-one can go out and pick them up. If you're sick, who is going to want to get on a bus and come in? You just feel like lying down and being sick. 4D

### **Flexibility**

The need for flexibility—in care plans, appointment systems, payment options—apply both in non-Aboriginal and Aboriginal services. An Aboriginal Elder recalled:

I needed tablets for over the Christmas holidays. It just happened that I ran out of them. I went there [to the pharmacist at the AACHS] and he said "I can't find a prescription". 2A

An Aboriginal nurse explained that at the Aboriginal health service

... even the doctors... the nurses are more flexible. They're not going to say "The doctor said you must have it three times". My philosophy is, like everyone at the [Aboriginal] health service, there's the ideal but what's going to work for people? What are they really going to do? 3H

Non-Aboriginal service providers also recognized the value of flexibility:

I think there's a certain stiffness or formality about the average suburban general practice which can be a little bit off-putting, a bit intimidating. So I think that is a barrier, this sense of inflexibility with appointments. 5F

If people have got to wait for two months, you know, forget about it, it's too far down the track when they've got so much else going on in their lives. 5G

## **Time**

Long waiting times, regardless of whether it is at a non-Aboriginal or Aboriginal health service, is a major barrier identified by Aboriginal participants.

My appointment would be at 9:00am and he [an endocrinologist at a mainstream PHCS] wouldn't get there until 11:00am. I was always on time and I hadn't time to wait. So I missed an appointment and they never follow me up and nothing was ever done. That's why I gave up and moved on to the next one [PHCS]. It was the same thing. 1F

I took Aunty to the diabetes educator at the [hospital in Melbourne], and we waited... how long? A long time. I think we read every magazine there, got sick of each other. 3H

I actually go to appointments with some of the Elders because if I didn't go there and sit with them, it just wouldn't happen. They wouldn't wait. I went to one appointment ... it was a hospital, and we were there for five hours. 4C

Three or four hours. Even if you've made an appointment you still have to wait [at the ACCHS]. Our people are very good, you know, like punctual, very punctual and we've still got to wait. 1D

However, Aboriginal participants were more willing to tolerate waiting times in ACCHS because they feel more comfortable and better cared for:

I'm just sick of the waiting time. Plus if you've got no money you can't get a drink or anything. At least at the [Aboriginal] health service you can walk straight down and make a cup of tea or coffee. They've got a bowl of fruit sitting there, help yourself. 3D

They [at the ACCHS] are always there and they just take that time to explain everything to you. You're not pushed out the door. They really care about you. 3B

It is with my own mob [at the ACCHS] and when I ask a question it gets answered. I am not left in the dark. It is not somebody saying, do this and do that and not telling me why. 3IA

Similarly, the lack of quality time with health care practitioners, regardless of whether it is at a non-Aboriginal or Aboriginal health service, is a major barrier and source of frustration for Aboriginal patients:

When you're really sick and you go in and the doctor's talking to you and you're sort of half trying to tell them your problems, someone comes in and opens the door and says "Well are you coming out to give me a hand with this?" The doctor looked at me and said "I'll have to go. I'm sorry but I'll have to go to help them do this and that." You're sitting there with your heart out half crying telling them your problems and they just get up and go out, and you have to get up and go out too. I don't like that ... I told them that. I swore, I swore, I've never sworn in my life, I hear this big swearing word coming up, my mother was so shocked. Because I was so darn frustrated. So that's my problem with the [mainstream] health centre is they don't listen. They don't listen. 1C

When I go to the [Aboriginal] health centre sometimes the doctors haven't got spare time with you. One doctor approached me saying "I haven't got long... oh next patient". I was upset, I was crying. 1D

Service providers themselves expressed frustration at their lack of time to provide quality service, as explained by this non-Aboriginal GP:

It's great the government's got all these wonderful ideas but, you know, to write a care plan for a person so they get five physio sessions for instance, it can take an hour to do that. So you get plenty of money but where do you get the time? I know what prescription to give them and I know what to tell them what to do but having that time to integrate the whole of the information, the whole knowledge and all of that, that is something that not all GPs will be able to do. Most people who stay in general practice they do it because they really want to see people healthy but they get bogged down with so much paper work, there's so many item numbers, there's so many new programmes coming out all the time which is supposed to improve the health of people but no time to actually implement them. I mean we have four nurses in our practice and they are busy every minute of the day as well as our eight or ten doctors. There's not time to talk to each other. If you get to the toilet you're lucky. 5IB

### **Support**

Participants made it clear that support from health providers to manage health and social challenges is necessary to providing holistic care to Aboriginal people. Aboriginal participants commented:

I look for support. I expect to have help—and not just tick the box and here are some pills and see you later sort of help. 2D

They [staff at ACCHS] speak to you and let you know what's going to happen, depending on what you're going to have. They explain about your medication. You're not just shoved on this pill or that pill. They explain the reason why you've got to have them and all that. 3D

I suppose the support, you know, we [Aboriginal people] got to realize that when you get sick, it's not a Monday to Friday thing. You also get sick on weekends too. 3IB

A non-Aboriginal GP acknowledged that Aboriginal people:

... need resources that are culturally appropriate to help—they really need ongoing encouragement and coaching. Not just someone ringing them up and saying have you done your blood sugar today, but someone who can get out there and help them with that. 5IB

### **Outreach**

Participants unequivocally identified that outreach activities to promote health and raise awareness of diabetes in Aboriginal communities are necessary. An Aboriginal participant suggested:

... an Aboriginal screening day, a drop-in centre type thing where you can go and get basic screening done or just anything done. 4C

Non-Aboriginal participants also made suggestions that would improve outreach:

[Service providers should] go into where the community is comfortable rather than the community having to go where they don't know and they don't know where to go and they are not sure where to park or they are not sure what the people are like. They are in a comfortable environment where others are coming to them. 6IA

Where would the harm be for a GP to go once every month to coordinate the things that need to be coordinated in, say, just a community house? Like, I mean rather than trying to drag them to the general practice, why not have the GP go there? 5IB

### **Working together**

Health providers and organizations working together in partnership was seen by many participants as a way of providing and receiving

culturally respectful and coordinated care. An Aboriginal participant observed:

I think we need to take some responsibility ourselves as [Aboriginal] workers in organizations and go to these mainstream services. Whether it's diabetes or drug and alcohol, we need to say "Look, you get funded to look after everybody, and we want to come here and tell you how to look after our people when they come to your centres." 2C

Non-Aboriginal participants were also supportive of a partnership approach:

Maybe mainstream general practice is not going to employ Aboriginal health workers. Don't have the resources or the facilities. But if somebody like the [Aboriginal health service] had a bunch of roving health workers that could be picked up by mainstream GPs, that might be an option. 6C

Most GPs in our area would manage the majority of the medical side and the organizing of the podiatrists and all those people that you have to rush off and see. They would do that themselves but then they would use something like a community health centre or an educator. 5IB

### ***Cultural competence***

Participants identified the need for education and training to raise cultural competence in mainstream health services. An Aboriginal academic suggested:

I actually think that [cultural awareness training] should be linked to GP accreditation. Why doesn't GPET (General Practice Education and Training) ask the question "Have you done cultural safety training?" 6A

Aboriginal participants explained further:

You [health care providers] can't just say "The doors are open now for blackfellas to come into our services now". It doesn't work that way. You've got to start being culturally aware. Start speaking to people in regards to how to get the trust. 4B

Those [mainstream health care providers] that have got Aboriginal people in their area who they get visits from should go and visit the proper Aboriginal clinic service. 2A

They [health care providers] need to start talking to Aboriginal people; start getting to know people; there are a lot of white people who have never seen an Aboriginal [person] before, and they don't know the first thing about us. 2B

A non-Aboriginal government representative noted that services need to

...take into account a lot of the factors that affect Aboriginal people disproportionately. Things like resources and ability to get to appointments, those sorts of things. They offer the same standard and expect everybody to be able to step up to that and make use of that, but in fact Aboriginal people are starting from much further back. Part of the issue is that mainstream services are not culturally aware. [...] you need to treat Aboriginal people in a way that is more empowering and different. They need that additional assistance or help to access services. 6D

### **Discussion**

While many Aboriginal people prefer and are able to access ACCHS or AMS, there are some who live in areas where such services are not available or who prefer to use mainstream services because of privacy and confidentiality issues. In these cases, Aboriginal people ought to have ready access to culturally safe health

care. The findings from our literature review (Liaw et al., 2011) and the qualitative phase of our study provide insight into the factors that impact on the way Aboriginal patients in an urban setting access and use mainstream general practices and PHCS for their diabetes management, and we argue that these will be broadly relevant for other health conditions.

The primary barriers identified by participants related to the history of dispossession and marginalization which continues to contribute to the persistent health inequities that exist between Aboriginal and non-Aboriginal peoples in Australia today. This overwhelming and overarching theme was so strong that it needs to be addressed and acknowledged as a separate theme. It is a significant contributor to what makes Aboriginal people different to other vulnerable groups. Recent estimates of Aboriginal life expectancy are 11.5 years (males) and 9.7 years (females) less than non-Aboriginal Australians, with chronic diseases, particularly diabetes, contributing significantly to both morbidity and mortality (Australian Bureau of Statistics, 2004). While having come a long way from the time of European settlement in 1788, racism and prejudice are still evident in today's Australian society, and these directly contribute to the mental and physical problems and disparity experienced by many Aboriginal people (Sanson et al., 1997). Long-term consequences of the early history of the formation of the Australian nation are unfortunately a reality lived by many Aboriginal people still struggling to come to terms with the irretrievable loss of their cultures. The findings from our study suggest that Aboriginal people today do not want retribution, but they want healing. They want to be listened to; they want their stories to be told; they want their pains to be recognized and acknowledged.

As a result of this history, trust and confidence are fragile commodities for Aboriginal people, and are easily shattered by the slightest hint of insensitivity, intolerance and inability to follow up words with consistent action

or behaviour. Stories recounted in the focus groups and interviews reveal that racism and discrimination in current practice or in the recent memories of participants and their families function as strong deterrents to Aboriginal people accessing mainstream health services today. The Aboriginal participants in our study particularly indicated that they are extremely weary of the assumptions constantly made about them. They talked about the importance of respect, honesty, transparency and inclusiveness in order to gain the trust of Aboriginal people. They want equity in treatment and to be accepted for who they are. Cultural awareness leading to competence is necessary to bridge the divide between Aboriginal people and mainstream services. Mandatory cultural awareness accreditation was suggested in our focus group as having significant potential to improve health service delivery.

Poor access to transport is an issue for many Aboriginal people because of their economic circumstances (Helps et al., 2008). Our own experience with gathering participants for our focus groups and interviews certainly supports that. Our study suggests that the lack of transport often results in Aboriginal people's perceived "failure" to abide by society's "norm", such as keeping appointments or getting to appointments on time. The Aboriginal participants in our study also noted that transport provision is part of a more holistic approach to health care. The service provider participants similarly echoed this sentiment and expressed their frustrations at the system's inability to adequately address this particular need for their Aboriginal patients. Strategies and resources to support Aboriginal patients to gain transport independence is a long-term enabler to closing the health access gap between Aboriginal and non-Aboriginal people.

One consequence of the history of dispossession is that many Aboriginal people live lives of disadvantage, often shaped by factors beyond their control (for example, high rates of chronic illness, overcrowded housing, family

violence and poverty). At times this can be made more complex, even in an urban context, by traditionally extended family and community obligations. For many Aboriginal people therefore, attending to health care obligations (medication and self-management regimens, multiple appointments with different health care providers) is often a low priority. Understanding and acknowledging their significantly higher social and health needs requires being flexible in appointments, payment options and care management; potential facilitators to assist Aboriginal people to overcome the challenges their life circumstances may entail and regain control of their lives. Aboriginal participants expressed the importance of ongoing support for all aspects of their lives that impact on their health. Outreach services and follow up were identified as necessary for providing consistent health promotion and holistic care.

Long waiting time and poor quality time spent with health practitioners are further factors identified in our study that hinder Aboriginal people's management of their health. Service provider participants in our study are similarly frustrated at their own lack of time to spend with patients. Although the level of frustrations expressed about both Aboriginal and mainstream health services were similar, the Aboriginal participants alluded to the cultural aspect of Aboriginal health services which is lacking in mainstream services. Aboriginal health services also function as social gathering places for Aboriginal people and provide a more informal and less clinical environment. The staff at Aboriginal health services are also often familiar to Aboriginal people, which adds to a sense of "community".

The overwhelming sentiment expressed by all participants was the need for Aboriginal and non-Aboriginal organizations, health agencies and government and non-government bodies to work together. Pulling together resources and energies to provide comprehensive, holistic, culturally respectful care is logical but requires political will as well as the goodwill of all

involved. It also involves considered reflection by practitioners as to what constitutes culturally safe and competent health care. As our analysis shows this includes addressing a range of potential barriers as part of a holistic and culturally competent approach to diabetes health care for Aboriginal Australians.

## Conclusion

Having a choice and a voice in the types of service and health delivery available to them are important to our Aboriginal participants. Effective diabetes management needs to include access to culturally respectful and cost-effective health services, culturally and clinically competent health practitioners and culturally safe health practice environments. The strategies required are not dissimilar to those that form the basis of providing high quality care to all Australians from widely diverse backgrounds. However, because of the specific circumstances of Australian history, closing the gap requires a particular sensitivity and understanding of a people and a culture that have been suppressed and marginalized for a long time. This study has identified a number of facilitators and barriers for urban Aboriginal people accessing health care and the substantial challenges this poses for urban mainstream health services to effectively provide this care. We argue these challenges must be met by mainstream services if they are to, in partnership with ACCHS, effectively address the current gap in service delivery to Aboriginal people.

A culturally respectful care model has been developed based on the findings of this study. The model incorporates partnerships between Aboriginal and non-Aboriginal organizations, and revolves around applying practical strategies to address issues such as time, transport and outreach as well as more novel strategies to improve cultural respect. Most importantly, the model advocates a change in attitude, with basic education about the continuing effect of

history, dispossession and racism, and the need for reflective practice and listening. This model is being piloted and evaluated in selected PHCS in Melbourne, and it is hoped the model will be applicable across a broader range of settings and chronic disease conditions.

## Glossary

Aboriginal	In this paper, the terms Aboriginal and Indigenous refer to the Aboriginal and Torres Strait Islander
Aboriginal community controlled health service or ACCHS	A primary health care service initiated and operated by the local Aboriginal community through a locally elected Board of Management
Aboriginal Medical Service (AMS)	A health service funded principally to provide services to Aboriginal and Torres Strait Islander individuals; not necessarily community controlled.
Koori	Aboriginal people in south-eastern Australia use the term Koori to refer to their identity
mainstream	In this paper, refers to non-Aboriginal services

## References

- Aboriginal Affairs Taskforce. (2011). *Indigenous affairs report 2009–10*. Melbourne: Victorian Government Department of Planning and Community Development.
- Australian Bureau of Statistics. (2004). *Experimental estimates and projections, Aboriginal and Torres Strait Islander Australians, 30 June 1991 to 30 June 2009 [cat. no. 3238.0]*. Canberra, ACT: ABS.
- Australian Bureau of Statistics. (2006). *National Aboriginal and Torres Strait Islander health survey, Australia 2004–05 [cat. no. 4715.0]*. Canberra, ACT: ABS.
- Australian Bureau of Statistics. (2009). *Experimental estimates and projections, Aboriginal and Torres Strait Islander Australians, 1991 to 2021 [cat. no. 3238.0]*. Canberra, ACT: ABS.
- Australian Bureau of Statistics. (2010). *Australian demographic statistics, Dec 2009 [cat. no. 3101.0]*. Canberra, ACT: ABS.
- Australian Bureau of Statistics, & Australian Institute of Health & Welfare. (2008). *The health and welfare of Australia's Aboriginal and Torres Strait Islander Peoples [ABS cat.no. 4704.0; AIHW cat. no. IHW 21]*. Canberra, ACT: ABS & AIHW.
- Australian Health Ministers' Advisory Council's Standing Committee on Aboriginal and Torres Strait Islander Health Working Party. (2004). *AHMAC cultural respect framework for Aboriginal and Torres Strait Islander Health, 2004–2009*. Canberra, ACT.
- Australian Human Rights Commissioner. (2009). *Letter to commissioners (19 Mar 2009): Aboriginal and Torres Strait Islander Social Justice Commissioner and Race Discrimination Commissioner*.
- Australian Institute of Health and Welfare. (2007). *Aboriginal and Torres Strait Islander Health performance framework, 2006 report: Detailed analyses [cat. no. IHW 20]*. Canberra, ACT: AIHW.
- Bailie, R., Si, D., Dowden, M., O'donoghue, L., Connors, C., Robinson, G., et al. (2007). Improving organisational systems for diabetes care in Australian Indigenous communities. *BioMed Central Health Services Research* 7(1), 67.
- Bailie, R., Si, D., O'Donoghue, L., & Dowden, M. (2007). Indigenous health: Effective and sustainable health services through continuous quality improvement. *Medical Journal of Australia*, 186(10), 525–527.
- Baker, R. S., Bazargan, M., Bazargan-Hejazi, S., & Calderón, J. L. (2005). Access to vision care in

- an urban low-income multiethnic population. *Ophthalmic Epidemiology*, 12(1), 1–12.
- Bowie, S. L., & Rocha, C. J. (2004). The promise of public housing as a community-based model of health care. *Health & Social Work*, 29(4), 335–339.
- Brett, T. (2011). The inverse care law—Is Australian primary care research funding headed this way? *Australian Family Physician*, 40(8), 615.
- Britt, H., Miller, G., Charles, J., Henderson, J., Bayram, C., Harrison, C., et al. (2008). *General practice activity in Australia 2007–08 [cat. no. GEP 22]*. Canberra, ACT: AIHW.
- Burchill, M., Lau, P., Pyett, P., Kelly, S., Waples-Crowe, P., & Liaw, S. (2012). Aboriginalising our research process: ‘Hunting and gathering’ as a focus group methodology. *International Journal of Critical Indigenous Studies* (in-print).
- Busfield, F., Duffy, D., Kesting, J., Walker, S., Lovelock, P., Good, D., et al. (2002). A genomewide search for type 2 diabetes—susceptibility genes in Indigenous Australians. *American Journal of Human Genetics*, 70(2), 349–357.
- Craig, M., Femia, G., Broyda, V., Lloyd, M., & Howard, N. (2007). Type 2 diabetes in Indigenous and non-Indigenous children and adolescents in New South Wales. *Medical Journal of Australia*, 186(10), 497–499.
- Department of Human Services. (2004). Community health services—creating a healthier Victoria. Retrieved 14 September, 2007, from [www.health.vic.gov.au/communityhealth/publications/chs.htm](http://www.health.vic.gov.au/communityhealth/publications/chs.htm)
- Dunstan, D., Zimmet, P., Welborn, T., de Courten, M., Cameron, A., Sicree, R., et al. (2002). The rising prevalence of diabetes and impaired glucose tolerance: The Australian diabetes, obesity and lifestyle study. *Diabetes Care*, 25(5), 829–834.
- Helps, Y., Moller, J., Kowanko, I., Harrison, J., O’Donnell, K., & de Crespigny, C. (2008). *Aboriginal people travelling well: Issues of safety, transport and health* (Road Safety Grant Report No. 2008–01). Canberra, ACT: Department of Infrastructure, Transport, Regional Development and Local Government.
- Hurworth, R. (1996). Qualitative methodology: Common questions about running focus groups during evaluations. *Evaluation News and Comments*, 5(1), 40–52.
- Kendall, E., & Marshall, C. (2004). Factors that prevent equitable access to rehabilitation for Aboriginal Australians with disabilities: The need for culturally safe rehabilitation. *Rehabilitation Psychology*, 49(1), 5.
- King, N. (Ed.). (1998). *Template analysis*. London: Sage Publications.
- Liaw, S-T., Lau, P., Pyett, P., Furler, J., Burchill, M., Rowley, K., et al. (2011). Successful chronic disease care for Aboriginal Australians requires cultural competence. *Australian and New Zealand Journal of Public Health*, 35(3), 238–248.
- Maple-Brown, L., Cunningham, J., Dunne, K., Whitbread, C., Howard, D., Weeramanthri, T., et al. (2008). Complications of diabetes in urban Indigenous Australians: The DRUID study. *Diabetes Research and Clinical Practice*, 80(3), 455–462.
- McDermott, R., McCulloch, B., Campbell, S., & Young, D. (2007). Diabetes in the Torres Strait Islands of Australia: Better clinical systems but significant increase in weight and other risk conditions among adults, 1999–2005. *Medical Journal of Australia*, 186(10), 505–508.
- McGrath, P. (2007). ‘I don’t want to be in that big city; this is my country here’: Research findings on Aboriginal peoples’ preference to die at home. *Australian Journal of Rural Health*, 15(4), 264–268.
- McGrath, P., Holewa, H., & Kail-Buckley, S. (2007). “They should come out here...”: Research findings on lack of local palliative care services for Australian aboriginal people. *American Journal of Hospice and Palliative Medicine*, 24(2), 105.
- Murray, S. B., & Skull, S. A. (2005). Hurdles to health: Immigrant and refugee health care in Australia. *Australian Health Review*, 29(1), 25–29.
- Naqshbandi, M., Harris, S. B., Esler, J. G., & Antwi-Nsiah, F. (2008). Global complication rates of type 2 diabetes in Indigenous peoples: A comprehensive review. *Diabetes Research and Clinical Practice*, 82(1), 1–17.
- National Aboriginal Community Controlled Health Organisation. (2009). *Media Release 6 Mar 2009 : PM’s speech uses flawed “evidence” on Aboriginal health*. Available from [www.naccho.org.au/Files/Documents/09-03-06%20PM%20uses%20flawed%20evidence%20on%20Aboriginal%20health%20-NACCHO%20Media%20Release\(2\).pdf](http://www.naccho.org.au/Files/Documents/09-03-06%20PM%20uses%20flawed%20evidence%20on%20Aboriginal%20health%20-NACCHO%20Media%20Release(2).pdf)
- O’Dea, K., Rowley, K. G., & Brown, A. (2007). Diabetes in Indigenous Australians: Possible ways forward. *Medical Journal of Australia*, 186(10), 494–495.
- Ring, I., & Firman, D. (1998). Reducing Indigenous mortality in Australia: Lessons from other countries. *Medical Journal of Australia*, 169, 528–533.
- Rogers, W. (2004). Evidence based medicine and justice: A framework for looking at the impact of EBM

- upon vulnerable or disadvantaged groups. *Journal of Medical Ethics*, 30(2), 141–145.
- Sanson, A., Augoustinos, M., Gridley, H., Kyrios, M., Reser, J., & Turner, C. (1997). *Position paper on racism and prejudice: Psychological perspectives*. Melbourne: Australian Psychological Society.
- Shaw, S., Huebner, C., Armin, J., Orzech, K., & Vivian, J. (2009 Dec). The role of culture in health literacy and chronic disease screening and management. *Journal of Immigrant and Minority Health*, 11(6), 460–467.
- Si, D., Bailie, R., Wang, Z., & Weeramanthri, T. (2010). Comparison of diabetes management in five countries for general and indigenous populations: An internet-based review. *BMC Health Services Research*, 10(1), 169.
- Stoneman, J., & Taylor, S. (2007). Improving access to medicines in urban, regional and rural Aboriginal communities—Is expansion of Section 100 the answer? (Commentary). *Rural Remote Health*, 7(738 (Online)), 1–9. Retrieved from [www.rrh.org.au/publishedarticles/article\\_print\\_738.pdf](http://www.rrh.org.au/publishedarticles/article_print_738.pdf)
- Thomas, D., Condon, J., Anderson, I., Li, S., Halpin, S., Cunningham, J., et al. (2006). Long-term trends in Indigenous deaths from chronic diseases in the Northern Territory: A foot on the brake, a foot on the accelerator. *Medical Journal of Australia*, 185(3), 145–149.
- Wagner, E. (1998). Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice*, 1(1), 2–4.
- Wagner, E., Austin, B., Davis, C., Hindmarsh, M., Schaefer, J., & Bonomi, A. (2001). Improving chronic illness care: Translating evidence into action. *Health Affairs*, 20(6), 64–78.