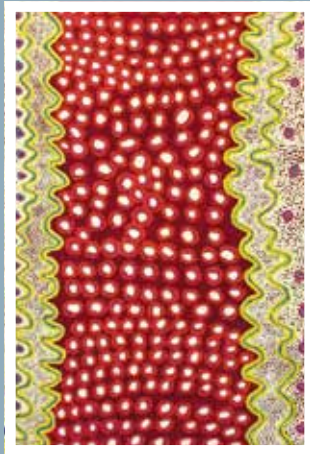


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# Managing Two Worlds Together:

**Study 2**—Staff Perspectives on Care for  
Country Aboriginal Patients



## Cover Artwork:

*Kuntjanu – Mingkiri  
Tjuta Tjukurpa  
(Marsupial Mouse  
Dreaming)*

**by Rama Sampson**  
painting (no.74),  
courtesy Better  
World Art

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ISBN 978-1-921889-14-1

This work has been produced by Flinders University and is published as part of the activities of The Lowitja Institute – Australia’s National Institute for Aboriginal and Torres Strait Islander Health Research, which incorporates the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health (CRCATSIH). The CRCATSIH is a collaborative partnership funded by the Cooperative Research Centre Program of the Australian Government Department of Innovation, Industry, Science and Research.



This work has been funded by the South Australian Department of Health. The views expressed herein are solely those of the authors and do not reflect the views of the SA Department of Health or its Minister.

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Additional copies of the *Managing Two Worlds Together: Study 2—Staff Perspectives on Care for Country Aboriginal Patients*, along with downloadable pdfs of all six reports emanating from this project, can be obtained from:

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**Cover Artwork:** *Kuntjanu – Mingkiri Tjuta Tjukurpa (Marsupial Mouse Dreaming)* by Rama Sampson painting (no.74), courtesy Better World Arts

**Design and Print:** Andrea Gill and InPrint Design

**For citation:** Dwyer, J., Kelly, J., Willis, E., Mackean, T., Battersby, M., Pekarsky, B. & Glover, J. 2011, *Managing Two Worlds Together: Study 2—Staff Perspectives on Care for Country Aboriginal Patients*, The Lowitja Institute, Melbourne.

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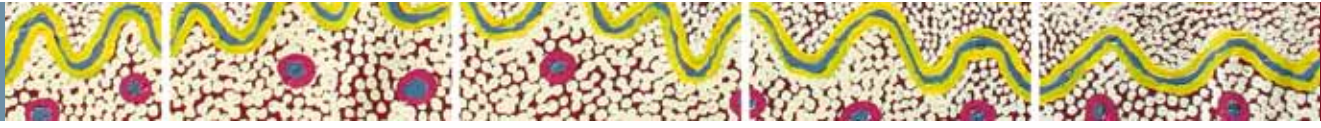
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# The Managing Two Worlds Together Project

The Managing Two Worlds Together project aims to add to existing knowledge of what works well and what needs improvement in the system of care for Aboriginal patients from rural and remote areas of South Australia (and parts of the Northern Territory). It explores their complex patient journeys and what happens when they come to Adelaide for hospital care

The relationship between patients and health care providers is the foundation of care and requires communication across cultures, geography and life experiences. As a staff member in one rural Aboriginal Community Controlled Health Service put it: 'It's like managing two worlds together, it doesn't always work'.

Stage 1 of the project focuses on the problems. Four studies were conducted and are reported in six documents:

- *Managing Two Worlds Together: City Hospital Care for Country Aboriginal People Project Report* (available on the website and as a printed document)
- *Managing Two Worlds Together: City Hospital Care for Country Aboriginal People Community Summary* (available on the website and as a printed document)

- *Managing Two Worlds Together: Study 1— Report on Admissions and Costs* (available on the website)
- *Managing Two Worlds Together: Study 2— Staff Perspectives on Care for Country Aboriginal Patients* (**this report**— available on the website)
- *Managing Two Worlds Together: Study 3— The Experiences of Patients and Their Carers* (available on the website)
- *Managing Two Worlds Together: Study 4— Complex Country Aboriginal Patient Journeys* (available on the website).

Stage 2 will focus on solutions and will consist of a small set of action research projects. During 2012 the research team will work with partner organisations in this study to develop and/or document the implementation of strategies to improve the health care journeys for country Aboriginal patients, based on existing good practice and on the findings of Stage 1.

Full details about the project are available at the Managing Two Worlds Together website, which is hosted by Flinders University at: <[www.flinders.edu.au/medicine/sites/health-care-management/research/MTWT/](http://www.flinders.edu.au/medicine/sites/health-care-management/research/MTWT/)>.

## Acknowledgments

We thank the participants in this project—the patients, carers and staff in hospitals, support services, primary health care and aged care settings throughout South Australia—who have generously contributed their insights and experiences.

The research team is also grateful to our industry partners, and to members of the Project Management Group, which has functioned as a true sounding board for our emerging ideas and as a dynamic source of advice about the ‘two worlds’ we have explored.

We acknowledge the support of the Department of Health in South Australia, which funded this study through the Strategic Health Research Program.

We thank Paul Basso, Phillip Battista, Tiffany Carlin, Alwin Chong, Charlotte de Crespigny, Karen Dixon, Zell Dodd, Cathy Edmonds, Grant Emmerson, Mitchell Fitzgerald, Ruth Harris, Kylie Hermann, Rosie King, Monica Lawrence, Laney Mackean, Pam Maslin, Nicole McLachlan, Sonia Mazzone, Azi Mian, Debra Miller, Dave Moodie, Kim O’Donnell, Sharon Perkins, Mark Ramage, Roland Ruff, Emily Tinning, Catherine Turnbull, Tez Williams, Gai Wilson, John Willis, Rae Winter, Chris Zeitz and Rob Zadow who contributed in various capacities.

## Abbreviations and Terms

**ACCHS** Aboriginal Community Controlled Health Service

**AHLO** Aboriginal Hospital Liaison Officer

**APY** Anangu Pitjantjatjara Yankunytjatjara

**GP** general practitioner

**PATS** Patient Assistance Transport Scheme

**Country** In describing where people live, we use the terms *country* and *rural* to include all non-metropolitan areas. We use the more specific terms *regional*, *remote* and *very remote* in accordance with Australian Bureau of Statistics Accessibility/Remoteness Index for Australia (ARIA) definitions to indicate remoteness in terms of access along the road network.

*Country* is used by Aboriginal people with a larger meaning of belonging and as a spiritual, as well as a geographic, home. The context of usage is a guide to interpretation of meaning.

**Mainstream** We use *mainstream* to refer to non-Aboriginal systems, institutions and practices.

# Summary

This report presents the results of a qualitative study of the perspectives of health care staff on the challenges of providing health care for country Aboriginal patients, with a focus on Adelaide's public hospitals. This study is part of a larger project that aims to add to existing knowledge of what works well and what needs improvement in the system of care for Aboriginal patients from rural and remote areas of South Australia. More information about the Managing Two Worlds Together project, and the other studies that are part of it, is available at [www.flinders.edu.au/medicine/sites/health-care-management/research/MTWT/](http://www.flinders.edu.au/medicine/sites/health-care-management/research/MTWT/).

## Methods

We interviewed 60 staff working in public hospitals, Aboriginal Health Services, community health services, and aged care and support services in Adelaide and four regions of South Australia. We recorded in-depth interviews, asking questions about their experiences and the barriers and enablers to good care, then transcribed and analysed the results using computer software.

## Good practice and creative approaches

Staff spoke about challenges and strategies in three domains: the direct interpersonal encounter between staff and patients; the system of care; and the broader social and cultural environment. Many staff in metropolitan hospitals and country health services spoke about actively seeking ways to provide good quality care for country Aboriginal patients, and gave examples of creative solutions to problems. But there were also many difficulties.

## The direct interpersonal encounter

Most participants discussed the difficulties of establishing trust and good communication across cultures and among people with very different life experiences and worldviews, and the importance of making it work if clinical care is to be safe and effective. The data highlight the complexity of the challenge, as well as the importance of the skills and competence of staff, and some of the ways in which they succeed, struggle or fail. Recognition of the fact of working in the intercultural space seems to be a necessary foundation for giving attention to the skills and methods that work. Staff emphasised the importance of respect, engagement and knowledge of their patients' home environments and their use of health concepts. Cultural awareness training did not emerge as a major enabler.

## Access barriers

Transport and accommodation are major practical barriers to access, but access problems are made more difficult by a frequent lack of financial resources and the strict rules, allowances and paperwork requirements in public subsidy schemes (such as PATS, the Patient Assistance Transport Scheme). The corporate shuttle service was seen as an important gap-filler.

Interpreting services are often needed, but are not reliably available. Uncertain capacity for informed consent is one serious consequence of the combination of difficulties with interpreting services and cultural differences in thinking about health and health care. Staff recognise the vital role of carers, but also the limitations arising from the carers' own health status, their lack of preparedness in many ways for the demands of

the role, limited funding to support them, and the lack of formal recognition of carers as part of the health care team.

For some patients, the combination of barriers results in decisions not to use city-based health care, or in receiving care late in the course of illness or injury. This perception by staff is supported by data on admission rates (adjusted for burden of illness) and strong reliance on country hospitals.

## Coordination and quality of care

Problems for patients moving between hospital and community-based care predominate in concerns about coordination and continuity. The question of quality (i.e. the extent to which health care achieves its purpose) was seen primarily in relation to the impact of problems in the direct interpersonal encounter, and of coordination problems and patient comfort concerns.

Staff lack of knowledge of other health care settings is a recognised problem, which persists in spite of many years of attention to the need for better communication between health care providers. This seems to be another case of ‘two worlds’ that don’t work together. Within each setting, unreliable assumptions are made about the roles of other care providers, and the need for someone to be responsible for coordinating the overall patient journey seems clear. The distinction between transfer of care (which currently applies only between hospitals/inpatient settings) and discharge from care (when patients are returning home or to residential care) may be a useful focus for thinking about this problem and seeking to address it. There are three important differences: agreement to transfer is negotiated in advance; information accompanies rather than follows the patient; and costs are borne by the transferring agency. A shift to ‘transfer’ has implications for both primary and hospital care providers. Recognition of the value of care coordinators may be seen as evidence that supports this approach; it could also address the problem of inadequate access to medicines during the discharge period.

## Social and cultural environment

Cultural differences and stereotyping can be major impediments to Aboriginal people accessing appropriate health care. Barriers include the difficulties they may have regarding mixed-sex wards or receiving care from health professionals of the opposite sex; the anxiety and loneliness they face leaving their country for treatment (with the possibility they may die away from home); and the boredom and coldness of the urban hospital environment.

Despite these barriers, respondents reported the willingness of many Aboriginal patients and their families to comply with hospital regimes, or to adapt their practices to Western biomedical processes (although this sometimes met with unintended and unforeseen negative consequences). We found examples of hospital staff attempting to adapt routines and procedures to Aboriginal preferences.

Two clear ways forward were identified—first, strengthening the role of the Aboriginal Health Workers, Aboriginal Hospital Liaison Officers (AHLOs) and Aboriginal Patient Pathway Officers as key personnel in building bridges between the two worlds; and, second, embracing the concept of cultural safety. This approach to cross-cultural health care provides space for staff at all levels in the health system to explore cultural differences, as well as practices that reinforce cultural dominance and racism.

## Five underlying factors

Access to good quality care for this group of patients is undermined by the interacting effects of five underlying factors (Table 1). Most are experienced by other groups of patients as well, but this group is affected by more of them, more often—it is the combined interactive effects of each factor that makes good care difficult.

**Table 1:** Five factors that affect access and quality of care

<b>Issue</b>	<b>Explanation</b>
<b>City/country</b>	Some of the problems facing country Aboriginal patients and their health care providers are common to all country patients.
<b>High burden of illness</b>	People with chronic or complex conditions are affected more by systemic health care problems, especially across hospital/non-hospital sectors, although any patient may experience care problems.
<b>Language</b>	Some communication challenges that patients and staff encounter are common to all population groups for whom English is not a first language.
<b>Financial resources</b>	It is harder for all people who have little or no extra money to meet the costs of transport, treatment, being admitted for health care, and time off work or away from home and family.
<b>Aboriginal/non-Aboriginal</b>	There are ways in which Aboriginal people experience unique disadvantage in their interactions with the mainstream health system (and other social systems); and mainstream worldviews and beliefs about health and health care are often different from those held by Aboriginal people.

## Five gaps or breakpoints in the system of care

Five gaps or breakpoints in the current system of care impede reliably good access and continuity of care for this group of patients. The strategies (many of which are already in use but not systematically available) summarised in Table 2 were identified as opportunities for action.

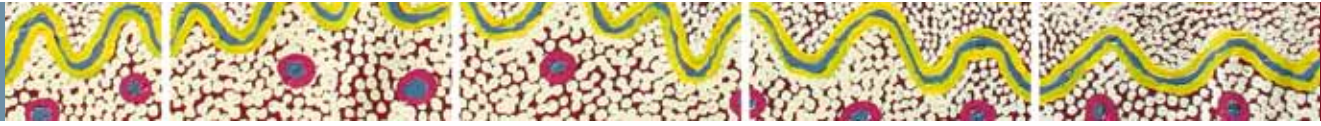
## The policy challenge

The ‘gap-filling’ approach outlined above will only work if it is undertaken in a supportive policy and program environment. To address the serious health and health care problems facing country Aboriginal people, it is essential that the high-level legislative and policy statements that

acknowledge the need for particular attention to Aboriginal health and health care are elaborated into operational policies, procedures and programs.

Although policies provide high-level statements of goals and a mandate for improvement, they do not provide detailed guidance for hospitals, health services or their staff. The *SA Health Aboriginal Health Care Plan 2010–2016* acknowledges the need for systemic implementation of relevant policies and mandates action and reporting by regional health services to this end (SA Health 2010:21, 34).

The staff we interviewed knew the problems, and had identified and often implemented strategies in response. What is needed at policy level is a program for implementation of better access, coordination and cultural safety in hospitals and health services, in governance, management and operations.



**Table 2:** Summary of opportunities to bridge the five divides in the system of care

<b>System gap or breakpoint</b>	<b>Opportunities for action</b>
<b>City/country</b>	<p>Provide more specialised care in the country (outreach clinics)</p> <p>Improve transport options.</p> <p>Improve accommodation services, including Step Down Units and a 'bed state' service in Adelaide.</p> <p>Streamline PATS procedures and consider escort needs for long-term admissions.</p>
<b>Acute/non-acute</b>	<p>Establish dedicated care coordinators in clinical units.</p> <p>Consider routine use of transfer rather than discharge procedures.</p> <p>Improve staff access to information about other agencies, using information and communication technology.</p> <p>Apply S100 rules to discharge drugs; manage Medicare numbers.</p>
<b>Language</b>	<p>Ensure policy on access to interpreters is applied.</p> <p>Adapt informed consent procedures, including pre-admission consents.</p>
<b>Financial resources</b>	<p>Patient journey requirements should be met using a purpose-designed funding mechanism.</p>
<b>Social and cultural</b>	<p>Bring high-level policy on cultural respect to the operational level</p> <p>Clarify and strengthen the roles of AHLOs and units in hospitals</p> <p>Formalise and support the roles of escorts and carers.</p>

# Introduction

This report presents the results—from the perspectives of staff in various settings—of a qualitative study of the experience of providing care for country Aboriginal patients who travel to Adelaide’s public hospitals.

This report is part of the Managing Two Worlds Together project, which aims to add to existing knowledge of what works well and what needs improvement in the system of care for Aboriginal patients from rural and remote areas of South Australia (and parts of the Northern Territory). It explores their complex patient journeys and what happens when they come to Adelaide for hospital care.

## What is already known about this topic?

Until 1995 responsibility for Aboriginal and Torres Strait Islander health was shared between the health portfolio, the Department of Aboriginal Affairs, and the Aboriginal and Torres Strait Islander Commission. Since the transfer of responsibility to the health portfolio in 1995, the mainstream health system has slowly responded (Anderson et al. 2002) with increasing attention to the burden of illness Aboriginal people experience (NATSIHC 2003) and the need for effective health care.

But change is patchy. Although there is evidence of increased access to primary health care in Aboriginal Community Controlled Health Services (ACCHSs) and mainstream general practice, screening rates and prevention of complications for Aboriginal patients are still lower than for the general population (AIHW 2011:95–8). Aboriginal people do not have equitable access to necessary primary health care services for several reasons and this is reflected in

high numbers of potentially preventable hospitalisations (DoHA 2009; AIHW 2011:95–8). Although emergency department visits and hospitalisation rates for Aboriginal people are relatively higher, procedure rates are lower. Waiting times for surgery are longer than for non-Aboriginal patients, and nearly double for some cardiac and cataract surgery (AIHW 2011:100).

Aboriginal people are often sicker or clinically more complex at an earlier age and have some different care needs related to their life circumstances and positions in society. Experiences of shaming, misunderstanding and stereotyping make engagement with the health system less effective than it can and should be (National Heart Foundation of Australia & Australian Healthcare and Hospitals Association 2010; Purdie, Dudgeon & Walker 2010).

Aboriginal patients sometimes receive care that is ineffective, insensitive or inappropriate (Eckermann et al. 2006). Language and interpersonal communication breakdown across the cultural divide leads to difficulty in assessing symptoms, reaching an accurate diagnosis and providing effective care (Kowanko et al. 2003; Taylor & Guerin 2010; Purdie, Dudgeon & Walker 2010).

There is also evidence that access for Aboriginal patients and families, including rural and remote people, is compromised by barriers to care that affect them differentially (AIHW 2011). These include resources for travel and accommodation, availability of supportive or rehabilitation care, such as cardiac rehabilitation (NHMRC 2005; Cass et al. 2002), and continuity of care across different health and support services (Lawrence et al. 2009). The poorer health status of carers, the need for escorts and difficulties in fully understanding medical information for some patients, carers and interpreters (Stamp et al. 2006) further impede access and quality of care.

## Schools of thought on these problems

Some studies of access and quality problems have concluded that the reasons for the disparities are not clearly understood (e.g. Fisher & Weeramanthri 2002), while other authors highlight the importance of recognising and addressing institutional racism (e.g. Henry, Houston & Mooney 2004). There are three important schools of thought—marginalisation, post-colonial theory and systems theory—about the underlying reasons why Aboriginal people and other marginalised groups experience differential access and quality of care, even in public health systems (like Australia's) that aim to provide universal access to quality care.

### Marginalisation

There is evidence that patients from marginalised groups in society inherently mistrust mainstream health services and carers, based on previous experiences of poor communication, judgment, stereotyping, victim blaming and refusal of service (Alford 2005; Rogers et al. 2005). Socio-political issues impact directly on care delivery for these groups, making health care places personally unsafe or unresponsive for some. A lack of choice of service providers, or of staff from their own population group, deepens marginalised people's discomfort (Stamp et al. 2006).

Mainstream services often lack the flexibility, understanding or capacity to meet individual needs, and disconnections between health and support services add further complications (Harris et al. 2009; Taylor & Guerin 2010). In the primary health care setting, ACCHSs and/or choice of general practitioners (GPs) are available for many. But all Australian hospitals are mainstream institutions based on strong Western medical models of care, and choice of provider is not normally available. Non-inclusion of family and carers in health care planning and poor consideration of a patient's own priorities lead to limited health outcomes (Lowell et al. 2001) and unsafe care. Although many public health systems have responded to these problems with cultural awareness training for staff, these programs have not delivered the anticipated

benefits (Westwood & Westwood 2010) and other approaches are being sought and tried (AIDA & RACP 2004; Nygen 2008; Dudgeon & Walker 2011).

### Post-colonial theory

Post-colonial theoretical frameworks provide critical cultural perspectives that question the thinking behind cultural policies and the extent to which they address historical and ongoing impacts of colonisation, disadvantage, marginalisation and 'othering' (Browne & Varcoe 2006; Sherwood & Edwards 2006; Taylor 2010). Closer examination of unequal power relations inherent in health care encounters, particularly when members of the dominant group provide health care, enable new understandings about how systems and even deeply committed individuals can unknowingly and unwittingly contribute to racial inequality. Questions are raised about how some behaviours get defined as normal and others as cultural, and about what creates an unspoken norm that marginalises people (Browne & Varcoe 2006). A reconsideration of culture as both dynamic and negotiated, with enduring elements, recognises Aboriginal people's individual relationships to, and expression of, culture, and the fact that people may enact their cultures differently depending on the situation or context (Lynam et al. 2007).

### Systems theory

Systems theory offers insights into the problems of gaps and breakpoints in health care, and the difficulties for specialised agencies in seeking to meet the broad health needs of people with complex health problems. Complexity theory (e.g. Plsek & Greenhalgh 2001) is particularly relevant here. Staff and managers in hospitals report that although small improvement projects are often successful, it is hard to sustain changes designed to improve care. The recent Improving the Culture of Hospitals project (Willis et al. 2010) and work on cardiac care reported by Lawrence et al. (2009) have documented successful changes and indicate the requirements for sustaining them. They conclude that good methods (based on a quality assurance



approach) are crucial, but not enough, and that sustainable change requires attention at all levels, from respectful ways of working with Aboriginal communities to system policy and leadership.

## Previous Australian research on staff perspectives

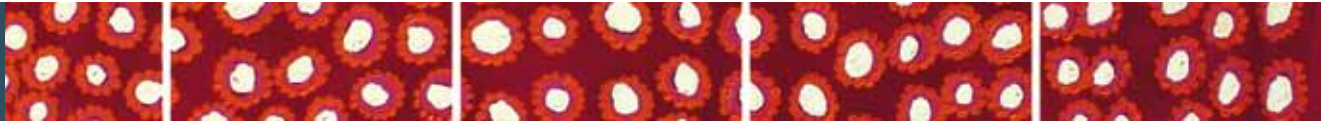
The only Australian study we found that addresses health care providers' perspectives on care for country Aboriginal people in city hospitals was conducted by Stamp et al. (2006), who report on the perspectives of three Aboriginal Health Workers and their families. They identified problems with fear of dying in hospital, the rigours of travel, financial concerns, lack of privacy and family space, communication problems between providers of health care and under-resourcing of AHLOs. But the study did not examine the perspectives of the hospital staff, and was limited in its exploration of the perspectives of primary care and support service providers.

In short, the poor health status of Aboriginal and Torres Strait Islander people has been well described, and there is some evidence about the underlying reasons for the differences. There is also some understanding of the problems Aboriginal people experience in getting access to health care, and why. But there is a comparative lack of knowledge about the factors in the health care system itself that enable the known problems to continue, or of the feasible means of changing them to remove or reduce those problems. This project seeks to contribute to addressing this gap in knowledge.

## Research questions

This study is based on the proposition that an understanding of the experiences and insights of staff in both acute hospitals and referring primary care agencies is a necessary basis for sustainable efforts to achieve improvement. If health care providers knew with confidence what to do to improve care for country Aboriginal patients, they would be more likely to act effectively to do so. Such actionable knowledge needs to encompass both an understanding of the causes of enduring problems, as well as a set of methods or strategies for addressing the 'symptoms' as they manifest in so many specific ways in different clinical areas and different organisations. This study therefore addresses two research questions.

- What are the main problems that affect the provision of good health care in city public hospitals for Aboriginal patients from the country, as experienced by staff in Adelaide public hospitals and in referring or support services?
- What are the sources of these problems, inside the health system and externally, that need to be addressed in order for access and quality to be improved?



## Methods

We set out to explore the ways staff think about the challenges they face, and how to overcome them, through in-depth interviews rather than surveys or other ways of ‘counting’ the contributing factors. We did not seek to quantify the problems, because such examination needs to be based on a better understanding of their nature and sources than we currently have.

The project team negotiated partnership agreements with the Aboriginal Health Council of South Australia and all the regional public health services in South Australia, and received ethical approval from six ethics committees. The project has been guided by the advice of a Project Management Group comprising industry partners and ‘end users’ of the research.

We interviewed (singly or in small focus groups) 60 staff, about half of whom work in relevant clinical units (i.e. those that admit a significant number of country Aboriginal patients) in Adelaide hospitals and one Adelaide support

service. The other staff we interviewed were working in regional hospitals, ACCHSs, aged care, and community health in four regions of the state. About one-quarter of the staff were Aboriginal. The interview questions were open-ended and asked participants about their experiences of barriers and the underlying causes of difficulties, and about enabling factors and strategies for improving care or overcoming barriers. With this approach we sought to generate unguided commentary, as well as to assess the relevance of existing explanations and understandings. The interview schedule is provided in the attachment to this report.

We recorded, transcribed and analysed the interviews. We read the text, and grouped like comments and ideas together to generate an overall picture of what the staff were telling us, and the implications for the health system and for health care delivery. A more detailed explanation of the methods is given in the attachment.

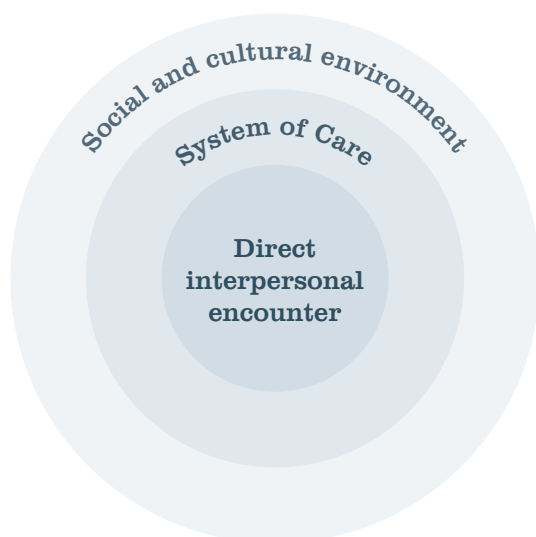
## Results: Analytical Framework

The interviews addressed three concerns:

- the challenge of the direct interpersonal encounter in care delivery
- aspects of the system of care and the necessary support services (problems with access, coordination and quality)
- factors in the broader social environment that are relevant to health care.

Thus in presenting the results, we move from the core of direct clinical and care interactions to the care system and to the broader social and cultural environment (Figure 1).

**Figure 1:** Three domains of factors affecting health care delivery



There were several major themes in each domain. It is important to note that many of the problems encountered by country Aboriginal patients and their care providers also affect other people (such as the problems inherent in travelling long distances for care, or not having English as a first language). We revisit this commonality in the 'Discussion and conclusions' section.

Representative quotes from interviews are included throughout the results. Codes in brackets at the end of quotes signify characteristics of the participants.

The first letter is either:

- **M** (metro) or
- **R** (rural or remote)

followed by:

- **H** (hospital)
- **G** (general practice)
- **A** (Aboriginal Community Controlled Health Service)
- **C** (community health service)
- **S** (support or other service, such as aged care, accommodation).

# Challenges in the Direct Interpersonal Encounter

The relationship between patients and their health care providers is the foundation of care, and most staff recognised the particular challenges they and their patients face when that relationship requires communication across cultures, geography and life experiences. This central challenge was summed up by one rural staff member: 'It's like managing two worlds together, it doesn't always work' (RA2).

The major themes in this domain are summarised in Table 3.

## Problems with trust and rapport

### Building trust and rapport across cultural and other divides

The central theme was the importance of building trust and rapport between rural Aboriginal patients and their health care providers, and the difficulties of doing so across cultures, communication styles, worldviews and life circumstances.

The impact on rural Aboriginal people of being transferred for care is exacerbated by lack of information and communication difficulties, as two rural staff explained:

You can see how nervous they are; they don't know where they're going, they don't know what's at the other end and they don't know who's going to be standing there for them (RA2).

They get homesick straight away because there's no-one—if they're actually in hospital there's no-one that they can talk to, you know, or no-one's speaking the language or they don't know how to talk to somebody else and it's the shyness that comes out (RH7).

Most metropolitan hospital staff explicitly recognised that they were communicating 'across cultures', and about half spoke of the need to take this into account in order to establish workable rapport, while others acknowledged some enduring difficulties:

People just tend to sort of—I don't know, keep to themselves... so you really need to communicate, really have to stress that communication, go in there and make them feel—you know a lot of those basic things, so make them feel welcome and make sure you see them every day (MH6).

A really difficult thing for me, being a white male in a foreign environment, is having any possibility of communicating with a shy woman with poor English, possibly, who comes from a totally different cultural background... I just have to say that I really don't... communicate very well with the women and that just is a fact of life (MH23).

It can be a little bit hard as a health professional, to gauge how much information the patient or the care giver is taking on board because our culture is usually to make eye contact with someone and the nodding and knowing that 'yes, I'm with you, I'm understanding what you're doing', whereas you don't often get that kind of body language feedback from Aboriginal patients so you're hard pressed, sometimes, to know that they're understanding and whether they feel like they can ask you a question (MH 20).

**Table 3:** Summary of themes in the direct interpersonal encounter

Issue/aspect	Major themes
<b>Problems</b>	Building trust and rapport across cultural and other divides. Communicating clinical information and health literacy. Consequences of communication failure.
<b>Causes</b>	Discomfort in intercultural relationships. Lack of knowledge and skills.
<b>Strategies</b>	Establishing connections and knowledge of life circumstances. Building relationships reliably. Cultural awareness, cultural respect, cultural safety.

About half of the metropolitan hospital staff commented on their experiences of rural Aboriginal patients as being 'shy':

... [they are] very withdrawn and quiet (MH11).

... they get shy, nervous, they don't talk to you, they don't know the way we speak to them (MH16).

The behaviour experienced as 'shyness' by staff may have other meanings for patients. Metropolitan and rural staff recognised the tendency for some Aboriginal people's expressions of agreement or assent to signify other meanings:

They tend to agree with most of the things you suggest... because they're trying to be helpful and good, but of course it's not really very fruitful if they don't really understand what you're saying. So it is harder to sense you've really connected (MH1).

Generally speaking, these women don't ask for anything, and much to their detriment at times I think (MH18).

... that confusion about what people's responses actually mean [is] I think one of the most dangerous things (MH1).

... and you have to build up a trust relationship where they can tell you what they don't understand, and so that you can ask them to tell you what they think it all means. Otherwise they just nod and say yes—that does not mean they understand, it means they are being respectful, or giving a response they think is right (RC1).

Several hospital staff expressed concern about their own lack of cultural knowledge, and the potential to make mistakes:

I would have absolutely no idea who I was offending by saying the wrong thing... (MH1).

One rural staff member noted the need to observe expected forms of respect and the emotional impact of not doing so:

This particular lady... constantly said 'don't call me miss or girl, call me Mrs Such and Such... I don't want to be called by my first name, I'm a married woman, I'm a widow, that's my title, please do that'. And I watched her do that over three different shifts of staff and there was nothing ever documented and put on her preferred name, you know? So I began to sort of—kind of doing the caring role. I was doing the bed baths with her and keeping her calm and every time I left or went away for something to eat and come back I'd have to go through the whole process again of calming her down. She's a very senior

woman within her Aboriginal cultural network and she's not to be addressed by her first name, so don't call her 'good girl' for eating or drinking her tea (RA2).

## Communicating clinical information and health literacy

Concern about an observed tendency of Aboriginal patients not to disagree or not to ask for help even when they needed assistance (e.g. pain relief) has been noted above. However, patients can lack even the most basic information about their care, such as the purpose of their visit to Adelaide, as one rural staff member noted:

People don't understand exactly what they're going to Adelaide for. Sometimes they think it's just a visit, but it is actually an admission (RC1).

Staff noted other basic problems that may not be unique to Aboriginal people, such as patients being sent to Adelaide without medical history information:

So we know they've come for an angiogram but we don't have any other history (MH16).

Another issue common to all groups of patients is that for those whose problems are clinically complex (e.g. maternity patients who also have cardiac problems), communication is complicated because:

they probably hear slightly different things from everybody and that would confuse them even more (MH5).

A rural staff member explained that treatment often makes you feel worse before it makes you better:

If you go into hospital—quite often if I have, I've actually not felt that bad when I went in. Then if I've had an operation or whatever's happened and you feel like crap—so if you haven't got that understanding to start—and I find that a problem. Like, after five days I'm saying, 'why do I still feel so sick, I'm supposed to be getting better?' So all of that has to compound that for people (RS4).

Metropolitan staff also spoke of the difficulties of getting clinical and social information:

Information exchange... just doesn't happen very well at all (MH16).

You'd love to see a real summary of all their home situation, that would give us an idea... being traditional and their language is not equal to ours so you really have to dig for information that's relevant for them... (MH6).

One rural staff member spoke of failure to explain clinical information effectively, using an example of a person who thought his cancer had gone away:

Sometimes doctors and nurses don't explain things so that Aboriginal people can understand them... You have to tell it to people straight, in ways they understand (RC1).

Several metropolitan hospital staff noted the importance of using the right ideas and language for clinical purposes, and checking for understanding:

From my experience the ways that we explain things makes the difference between whether patients understand us or not. If we say, 'do you feel short of breath?', they will say 'no', or look questioning or just stare at us. But if we ask, 'are you short of wind, have no wind?', they understand and say, 'yes, short of wind' (MH16).

Checking with people if you're... understanding this correctly is an enabler. I don't know why people would tend to do that more with African communities and other communities but not so much with Indigenous communities (MS1).

A rural staff member commented on the need to engage the patient actively to be sure of understanding:

... they have to trust you enough to explain it back to you (RC1).

Rural staff also commented on Aboriginal people being asked the same questions over and over:

When people have been out of the hospital I might ask them sometimes, 'how was it?' 'Oh, the nurses are nice but everyone keeps asking the same questions over and over and over again' and it's virtually like an interrogation and that's overwhelming too... this is what we use notes for, ask the question once. But if you go in there, have a look and

see what the person's said, don't go in that repetitive thing because Anangu do... react to that (RA1).

One rural Aboriginal staff member explained the importance of communication for healing:

A lot of healing goes on around talk, around communication, and a lot of health information, like their health literacy, comes through talking not through people giving them papers or me talking to them, it's through conversational stuff. So when the doctor comes in and sees the client and discusses whatever with one or two, it's better if it's more like a communal thing. It's impossible, I know, to marry the two but maybe there's some sort of meeting ground (RA2).

## Consequences of communication failure

Both metropolitan and rural staff noted the potential consequences when communication fails, including serious adverse outcomes:

White people say they are non-compliant, but do they really understand, in the first place, these tablets you have to keep taking forever? You have to go and get more tablets, do they actually understand that? I don't know... The ramification... if they have a stent it's reocclusion, reinfarction, possibly death... depending on their diagnosis... it has huge negative consequences (MH16).

A participant, speaking of patients from the Top End of the Northern Territory for whom communication had been a sustained problem, commented:

They then become a flight risk because they don't know why they're here, no-one's actually communicating with them—so 'what am I here for?'—and so we've had some women abscond (MH8).

A rural staff member reflected on the emotional and communication consequences of misunderstanding for a man who was normally able to speak English:

I went in to see him and I've never seen him so angry. He just sat there and he spoke complete [Aboriginal] language (RA2).

## Causes of problems

### Discomfort in intercultural relationships

Aboriginal patients bring with them to hospital the experience of discrimination in the broader community, and this affects their expectations—as indicated above in relation to some of the difficulties of establishing rapport. Some staff bring unhelpful attitudes to their approach, and some inadvertently shame patients. 'Aversive racism' (Gaertner & Dovidio 2005) refers to the effects of discomfort on interactions among people of different races, and was described by one member of a remote area focus group:

And I'd feel really uncomfortable if somebody walked in and walked past me and had a big conversation over there with [a non-Aboriginal patient]—and I'd been here longer, like I'd sit down and think 'what's wrong with me?'... it does happen and that doesn't help their recovery, like it's a setback again, so... they're behind the eight ball before they even get there because it just compounds and it just delays and makes things last longer (RS4).

One staff member acknowledged that previous experiences with health staff may make people reluctant to engage:

The various professional people that they meet who, knowingly or without intent, might say things or do things which might offend or frighten the person. We had, just the other day, an Aboriginal patient on the ward here who we'd managed, through I think some luck, we were able to get him a dental appointment really quickly, and we had an agency nurse... who made the comment, 'wow, that was really lucky that you got an appointment. Gee'—made some sort of comment, I can't remember, saying how it was a fluke that this guy managed to get an appointment and then walked off. Now this Aboriginal patient was quite shamed by that... and so then refused to go to the appointment and this is after months and months of waiting for something. He felt shamed by that. I think people often don't do it on purpose but they might make comments (MH3).

Racism in a hospital was also reported by a nurse currently working in the community:

It's very, very patronising to start with. Even as an observer there's a lot of absolute racism, absolute racism, in your face... when people are spoken to, referred to. And I think also as a colleague it's hard to listen to how people are being spoken about. I go back and work there a little while and then over lunch I can't cope with the way clients are spoken about (MS1).

One metropolitan hospital staff member, when asked about seeking feedback about communication from Aboriginal patients, was frank about reluctance to engage:

I haven't asked them, and I really don't know if I'd want to (MH9).

Another noted the response of Aboriginal patients to the arrival of a non-Aboriginal person:

There's a lot of chatter you can hear as you go into a room but it just stops when you go in (MH18).

## Lack of knowledge and skills

Some metropolitan staff recognised that their concerns about perceptions or accusations of racism got in the way of good communication:

I think you can get stuck on blame to the point where it becomes quite destructive and people don't want to—they're too scared to ask questions any more for fear of it being racist, too scared to ask any questions, too scared to do anything really because it's deemed as racist (MS1).

One metropolitan-based support service member who had opportunities to observe hospital staff interacting with Aboriginal patients noted:

They stand over people, they yell at you, they talk... very fast. Like, I wonder whether it's also experience. And I and the staff have been around a bit and we've got some training and education behind us but we've also got life experience and cultural experience. Some of the staff I'm talking about are actually young, and not necessarily—haven't had those experiences, so sometimes there is overt

racism. Sometimes it's ignorance, sometimes there's prejudice... those things are real when you go on the client pathway, sitting with someone, just to observe their story or what's going on to them... on a couple of occasions I've sat with them and I haven't said anything and I'm just looking at them and we're just sort of having a non-verbal dialogue and it's clear that this is something that they experience all the time (MSA10).

One rural staff member with extensive experience in Aboriginal health commented on the questions of a friend he visited while she was in hospital:

She said, 'why is it just because you're black everyone thinks you're deaf and a baby as well?... they talk to you loudly... and then talk in baby talk—oh, have we had our din dins and all that', and this is someone that had a mind like a steel trap... (RA1).

One hospital staff member noted the importance of feedback and follow up when inappropriate communication happens:

Often with agency nurses it's happened, that they've been quite inappropriate, and when it's been like that our team leader of the nurses... has actually gone back and pulled them aside and said, 'look, no' (MH3).

Several metropolitan and rural staff commented on the importance of taking time and the apparent lack of it:

But that caring thing is just not as it used to be. We need more of that... I suppose they haven't got time to be as caring as they'd like to be. I don't know, but it just doesn't seem to be the same (RA2).



## ‘You’ve got to be willing to be good at it’: strategies for effective care

### Establishing connections and knowledge of life circumstances

Staff noted some strategies for establishing a sense of connection, including asking about the patient’s home base, using a map to enable patients to show staff where they are from, and acknowledging the strangeness of the situation:

I think it’s also about sharing those stories... making people feel comfortable so they know it’s not unique to them... that everybody feels anxiety about coming into hospital (MH4).

Others articulated the social and clinical importance of first-hand knowledge of the life circumstances of their patients:

Once you’ve worked out in the bush and gone and visited the people in simple little dwellings out from the sort of outstations I think you’re better able to understand how they might feel away from that. Also if you’re treating them in a big hospital you kind of—you’ve got some idea of what they’re going back to and the challenges that that might pose to their management. So in terms of thinking about treatment and what you’re going to put them on, you’re obviously going to try and simplify the treatment as much as you can so you can get the most bang for your buck and not have it too complicated because each level of complexity in the treatment is going to reduce the chance it’s going to work (MH11).

Yeah, I think having a bit of a knowledge of the things that are challenging for these people, or a bit of an insight, is helpful... there is capacity to moderate what you do a bit, we can be a little bit flexible and that can be helpful (MH11).

### Building relationships reliably

The importance of building relationships, and the benefits when they are established (e.g. with patients who experience many or long admissions), were explained by one metropolitan staff member:

I think it’s just really about being enquiring and polite, just as you would with anyone else, and not presume—and they’re often traps in a busy setting... We have a lot of regular patients... and it’s just like part of our family coming in (MH7).

They were supported because of their loneliness but we also gained so much information from them. I feel very lucky to be in this role, that I had the opportunity to do that (MH7).

One experienced metropolitan staff member discussed the impact on patients when health staff who visit communities are short term or unreliable (making people very slow to engage and trust), and the importance of developing relationships over time:

One thing that we’ve found to be really important is developing relationships with Aboriginal communities—for example, when I started going out to Aboriginal communities to set up a service, setting up a service just wasn’t an easy thing. It took six to twelve months to set up a service because I would go there, you would meet with community members, you would meet with patients, you would meet with the Elders and just sit with the Elders and talk about what you do and who you are and it was a really lengthy process until they were comfortable with you going up and setting up a service. The one thing that we were very, very firm about was we were not going to promise anything that wasn’t sustainable because we thought we’ve been down that path too many times... What I’ve found is it’s taken—you know, I’ve been going to most places now for about three years and it’s now—in probably the last year—that things are really meshing and that community members—I’m really being accepted... (MH3).

## Cultural awareness, cultural respect, cultural safety

Advocates, policy workers and researchers have developed several frameworks to improve the capacity of mainstream staff to communicate with and care for Aboriginal patients. Cultural awareness training aims to give staff an understanding of cultural beliefs, practices and values of the 'other' population group, as well as an awareness of the participants' own cultural assumptions, and has been used for more than two decades. But this approach has been challenged in evaluations of its effectiveness (Browne & Varcoe 2006; Coffin 2007) and by more recent thinking.

The *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009* (AHMAC 2004) emphasises eight high-level principles, but does not deal with the practical questions of how to implement cultural respect. Cultural safety is a concept developed originally in New Zealand (Nursing Council of New Zealand—Te Kaunihera Tapuhi o Aotearoa 2002; Ramsden 2002) and proponents argue that it provides a more effective way of thinking about and responding to the kinds of problems documented in this report. In this thinking, cultural awareness is seen as reinforcing rather than changing the assumption that the problem lies in the 'other' culture or the 'other' group. Conversely, cultural safety calls for an understanding of the ways in which the thinking and assumptions of the dominant culture may be unhelpful or unhealthy, and may impede patient safety and good clinical care. The reflections of some staff seem to fit better with this latter concept:

You know, it's not a one-way street—it's a two-way journey and it's about the health sector being willing to meet Aboriginal people halfway (MH3).

It's not just that Aboriginal people need to adapt to a hospital; we need to adapt to at least make it as friendly as possible (RA1).

Supporting them having their own voice in there, and supporting them to be listened to and to be heard and just checking, constantly, that somebody's okay with that and not just being polite and just saying 'yes'... that

confusion about what people's responses actually mean. I think [that is] one of the most dangerous things (MS1).

While staff in three hospital units spoke of recent cultural awareness training that had been useful, about half of metropolitan hospital staff were unaware of any cultural awareness programs being provided in their hospitals, and some questioned why this had not been part of the induction.

Metropolitan staff spoke of learning from colleagues and peers who had worked closely with Aboriginal people in specific urban, rural and remote areas and shared their skills and knowledge, and some sought training with a more practical orientation. One hospital staff member summed up experiential knowledge:

You need someone who is educated and is interested and respects them, that's what you need... Just be yourself, just be open and relaxed and not too stiff and starchy... I don't know how you sort of get everybody up to speed, it's a really tricky one. I said to the young junior nurses that are on... 'if you get any time tonight go and talk to this man and you'll learn more than you ever will out of a textbook'. So you've got to be willing to be good at it (MH7).

## Conclusion

The difficulties of establishing trust and good communication across cultures and among people with very different life experiences and worldviews, and the importance of making it work if clinical care is to be safe and effective, were discussed by most participants. These results highlight the complexity of the challenge, as well as the importance of the skills and competence of staff, and some of the ways in which they succeed, struggle or fail. Recognition of the fact of working in the intercultural space seems to be a necessary foundation for giving attention to the skills and methods that work. Staff who felt some level of confidence in this endeavour emphasised the importance of respect, engagement and knowledge of their patients' home environments, and of their use of language and health concepts. Cultural

awareness training did not emerge as a major enabler, a result that is consistent with other recent findings (Willis et al. 2010; Westwood & Westwood 2010) and with the critique of cultural awareness (RACGP 2010).

Racism is a hard word, with several meanings, and both Aboriginal and non-Aboriginal people tended to avoid using it. The problem for staff, as several comments above illustrate, is that it isn't necessary for the individual to *intend* to discriminate against a person for their actions or communication style to have a negative impact. 'Systemic' or 'institutional racism' refers to the subtle ways in which policies and practices affect one racial group more than or differently from others with or without the intention of doing so (Henry, Houston & Mooney 2004). 'Aversive racism' refers to the ways in which people struggle or fail to communicate and relate well across cultures (Gaertner & Dovidio 2005).

Recently, scholars and practitioners have described the challenge more positively as 'working in the intercultural space' (Taylor 2002; Mignone et al. 2007). Aboriginal people in city hospitals have to do this all the time; non-Aboriginal staff, particularly if they lack experience, may be unaware of the need for skills and knowledge in order to be effective in intercultural communication. Doing so successfully requires all participants to attend to this challenge, and to develop practice skills and knowledge about the life circumstances of their patients. Such knowledge may be tacit or explicit, and may be developed consciously or simply because of the person's attention to courtesy and respect. Recognition of the importance of this challenge for health and health care (clearly evident in many of the staff we interviewed) is the starting point for better practice.

# System of Care: Access

Statistical analyses of the admission rates of Aboriginal people by the Public Health Information Development Unit (PHIDU 2010) note an apparent paradox: on average Aboriginal people are admitted to hospital more often than other Australians, but there are indications that some groups of Aboriginal people are not getting to hospital as often (or as soon) as would be expected given their health status (AIHW 2011; Shahid et al. 2011). This project has also identified a relative over-reliance on country hospitals by Aboriginal people, which may indicate the impact of barriers to access to city hospitals (see xxxx). Several staff in this study expressed concern about patients with certain conditions, and those who are older and living in more remote areas, not getting treatment when they should:

We're seeing people here who actually haven't accessed the system so their cancers are very, very advanced. We've seen [Aboriginal people] who have got... major carcinoma that's disfiguring, just distorting their body shape... so they've obviously been in pain... for a long time and that suggests to me that... they're reluctant or reticent or unable to access systems for whatever reason (MS10).

Some metropolitan staff expressed concern that Aboriginal people don't engage with mainstream services:

We're in the ivory tower, so to speak. We've got all the latest and greatest equipment here. We can prescribe almost anything that's ever been invented (if it's useful) from here, but if people aren't actually coming to us then they're not going to get the benefit... (MH1).

We report on the major barriers to access identified by staff. The major themes are summarised in Table 4.

## Travelling for health care

About two-thirds of staff discussed the problems of patients travelling long distances for health care. Travelling while unwell or in pain is difficult in any case, but for this group there are also concerns about patient safety, the high costs of missed connections, the challenges of negotiating unfamiliar systems and the lack of public transport within country regions. The relative inflexibility of both the available transport methods and the hospital system interact, and it is not surprising that some people are reluctant to take on these challenges.

## Consequences for health and health care of travelling while unwell

Many country staff expressed concern about Aboriginal patients being required to travel long distances while unwell, with negative consequences for their health and health care:

Sometimes the people from the communities in the Territory may have to be away from community for three days to get here and... people have been exhausted, falling asleep. Assumptions have been made about their health status but in fact they've just been travelling... (MS10).

Someone comes out of hospital with a leg in plaster and a broken leg, what are you afraid of? DVT [deep vein thrombosis]. You're going to bus them out and you've got a 13- or 14-hour [journey]—and you can't [tell] the bus driver... 'every two hours pull up I want to stretch my legs' or 'I want to step outside' (RA1).

**Table 4:** Summary of themes in the access to care domain

<b>Issue/aspect</b>	<b>Major themes</b>
<b>Travelling for health care</b>	<p>Consequences for health and health care of travelling while unwell.</p> <p>Patient safety on the journey.</p> <p>Lack of preparation in emergency transfers.</p> <p>Risk of missed connections, late arrivals and cancellations.</p> <p>Lack of familiarity with city transport.</p> <p>Finding your own way home: challenges, costs and delays.</p> <p>Transport within country regions is lacking.</p> <p>Support that works: step down/corporate shuttle service.</p> <p>PATS: help and limitations.</p>
<b>Accommodation</b>	<p>Shortage of hostel and hospital-based accommodation, and booking problems.</p> <p>Importance of detailed knowledge of resources, especially for arrivals out of hours.</p> <p>Long-stay accommodation is hard to find and costly.</p>
<b>Carers and escorts</b>	<p>Contribution to care and recovery.</p> <p>Carers and escorts may be unwell, or inappropriate to the role.</p> <p>Need for 'escort swaps' for long-stay patients.</p> <p>Need to define role and expectations more clearly.</p>
<b>Access to spiritual carers (Ngangkari)</b>	<p>Role is increasingly recognised.</p> <p>Problems with availability and payment.</p>
<b>Language and interpreters</b>	<p>Cultural differences in use of language.</p> <p>Availability of interpreters.</p> <p>Using family members.</p> <p>Failure to recognise the need.</p> <p>Tensions for workers who are community members.</p>
<b>Informed consent</b>	<p>Consent and the telephone interpreter service.</p> <p>Role of trusted interpreters.</p>
<b>Financial resources</b>	<p>Costs of staying away from home.</p> <p>Concern about limitations of PATS arrangements.</p> <p>Northern Territory patients and problems with the Basics Card.</p> <p>Costs as a barrier to city care.</p>

A staff member at an Adelaide support service raised concerns about patients who are unfamiliar with the city and arrive early in the morning for clinic appointments after an overnight bus trip:

They just want to have a sleep for three hours before their appointment and have some breakfast, which isn't that much to ask really (MSA10).

## Patient safety on the journey

Country staff also raised concerns about the safety of Aboriginal patients who use public transport to travel long distances for health care. Risks arise, for example, when, in some regional towns, the bus arrives late at night when hotels are just closing, leaving escorts and patients, particularly women, frightened of 'drunk men' (RA4).

In another community an Aboriginal Health Worker meets the five o'clock morning bus at the highway in her own car when patients return. She reported recently seeing a newly discharged Elder get off the bus and go around to lie under a bench to wait until morning light when she planned to walk into the town to seek a ride to her own home community. The worker reported that the woman felt it was unsafe to get off at the next stop due to racism, vulnerability and being unsure whether anyone was planning to meet her (RA4).

Flying can also present difficulties. Flights may be arranged, particularly for hospital transfers and for people with serious conditions, depending on availability and funding. For some older remote Aboriginal people, past experiences of harsh treatment associated with flying (in the case cited below, with police) make them unwilling to travel by air:

If that's how you were treated in a plane, that's your first experience, that's what's going to stick in your mind. Of course they'd be terrified, you would refuse the plane. So we couldn't even get him on the Flying Doctor plane (RA1).

## Lack of preparation in emergency transfers

In emergency situations, getting patients to Adelaide is fairly straightforward once they reach the road or air ambulance. However, patients often arrive in Adelaide without basic items:

They may go down with the helicopter or ambulance—often it happens in a hurry. Patients may have no paperwork, cards, money, clothes etc. Usually no one is able to travel with them due to lack of room (RC1).

## Risk of missed connections, late arrivals and cancellations

A planned trip (for elective admission or outpatient care) from a remote area can be difficult for patients and those supporting them on their journey, potentially involving several different modes of transport or connections and stretching from very early mornings through long days and overnight on a bus. The risk of missed connections and late arrivals is high. Many country staff discussed the long hours they spend trying to arrange transport and accommodation for planned admissions or outpatient appointments, for patients and for carers or escorts. Two inflexible systems—the hospital appointment system and the transport system—collide, and a clinic running late can have major consequences:

People in Adelaide don't realise if you miss the bus then you have to wait another 24 to 48 hours to catch the next one, find accommodation and all. And some people don't have money or family down there (RC1).

Metropolitan staff also raised concerns about cancellation of appointments and admissions after patients had already begun their journeys and were unable to be contacted.

## Lack of familiarity with city transport

Both country and city staff recognised that many country Aboriginal people are unfamiliar with metropolitan transport systems (driving in the city, catching buses, trains, trams or

taxis) and patients can ‘get lost’ between the hostel/accommodation and admissions or appointments:

There have been cases where people have turned up and the taxi hasn’t been there or... the person doesn’t speak very much English and they’re trying to explain where they’re going and half the time they don’t really know where they’re going... I’ve heard a lot of disasters of people just freaking, just panicking or not getting in the taxi (RA2).

### Finding your own way home: challenges, costs and delays

Country patients transported to Adelaide for health care may be expected to find their own way home. While Aboriginal health services generally assist patients on both journeys, this does not always occur. City-based staff may not appreciate the extent of travel and arrangements involved. One respondent spoke about a teenager with a mental illness who was transferred involuntarily to Adelaide from a very remote area. This metropolitan staff member reported that the emergency department to which the young person was taken revoked the detention, and a hospital staff member handed over a taxi voucher, saying ‘catch this, go to the bus station and catch a bus back to [home community]’ (MH3). This young person did not speak English, did not know how to catch a taxi or a bus in Adelaide, and lived a long way from the nearest bus service.

Both country and city staff discussed the fact that patients and carers often faced long trips home without money for food and drinks, and noted that there is little or no capacity within the system to provide money for this. Staff in a range of settings reported that they bought food for patients from their own money.

While the Royal Flying Doctor Service was seen as being very efficient in getting patients to hospital, there were often unavoidable delays in getting patients back home due to emergency priority and availability of planes:

They are usually exceptionally good... Usually they’ll pick up a patient within three or four days... we had a patient in the last couple of months who—it just worked out that it was two weeks of waiting and the poor old family was chewing the bit to get back... Sometimes it happens but most of the time they’re pretty great (MH6).

Interstate patients who live beyond the Royal Flying Doctor Service flight limits face particular problems:

It is difficult to get [spinal patients] back to Darwin. They can’t sit upright so we can only use the plane with a stretcher—the Medi-jet—we had to wait until it happened to come down and if they don’t have anyone more urgent to get back then he could possibly get the patient back, but it may take months (MH19).

### Transport within country regions is lacking

Country staff identified a lack of public transport in regional and remote areas as a major issue for patients accessing emergency care, outpatient and specialist appointments, or follow up. Metropolitan staff highlighted instances where lack of access or availability of transport has led to delays in treatment and follow up, with adverse health outcomes.

Long distances and extreme weather conditions in many regions make walking to health care impossible and lack of public transport means that clinic transport assistance is essential. Access to the nearest hospital is also often problematic. An outpatient appointment for patients from one community can mean two nights away from home, due to the infrequency and time of day of bus services. One rural staff member in a regional town explained:

You know, Adelaide to here is fine but [a regional centre] to here is problematic and from here to [a remote community] is a huge problem, a massive problem. So people get to here and then they get stuck here because there’s no regular transport between [the remote community] and here (RA6).

## Support that works: step down/corporate shuttle services

Rural staff emphasised the need for help with the journey to the city and in negotiating city transport systems. One-third of all participants mentioned the step down/corporate shuttle service, which picks patients up from the airport, bus, train station or accommodation and transports them to a hostel or hospital, which they regarded as very helpful for many patients and carers:

... especially if they're remote and they've come into a big city and they think 'this is scary' and those sorts of things, knowing that they can be picked up from this spot here and transported to home, or temporary home for the time being down here, it's a big help (MH13).

## PATS: help and limitations

The Patient Assistance Transport Scheme (PATS) provides limited financial support for travel and accommodation costs for the patient and, if needed, a single carer or escort, and has strict documentation requirements and limitations. Some Aboriginal health services provide up-front payment to patients and carers, but are 'out of pocket' if the trip does not take place, or the paperwork is not completed and returned appropriately. Other services require patients to pay up front, but if they lose track of receipts and paperwork they may not be reimbursed. PATS has been trialling clearer guidelines and prepaid petrol vouchers and bus tickets in some areas.

## Accommodation

Most country Aboriginal people rely on hostels, hospital-based accommodation, or homes of family and friends when they need accommodation in Adelaide. PATS funding is generally available, but within strict limits (in 2011, \$30 per night per funded person for accommodation but the first night is not covered except for health care card holders). In this study

most metropolitan and all country staff identified accommodation as a major issue for Aboriginal patients, for several reasons.

## Shortage of hostel or hospital-based accommodation, and booking problems

There's not enough beds... we're turning away numerous people every day and all the hostels are at 100 per cent capacity (MSA10).

We had a woman who came down from the Territory and she needed to stay in town for three or four weeks... but she was at [the other side of the city] so it wasn't terribly easy for her, in a completely foreign environment, and in a town that she wasn't familiar with, to organise transport and all that sort of stuff... (MH8).

There is no single telephone booking arrangement across the hostels in Adelaide and country staff spoke of being on the telephone for hours trying to arrange hostel accommodation. Hospital-based accommodation is often cheaper but even harder to get. One-third of country and metropolitan staff reported that accommodation at or near the hospital is preferred by many country patients and their families. The lack of accommodation near Flinders Medical Centre, which forces patients and carers to travel hours each day, was raised by several metropolitan and country staff.

## Importance of detailed knowledge of resources, especially for arrival out of hours

AHLOs, Aboriginal Health Workers, Step Down Unit staff and social workers are usually involved in arranging accommodation, and they need detailed knowledge of the system and services:

It is also important that we know the system so we know who to call to help the clients, who will do pick-ups from homes or hostels, and what is provided at hostels and other accommodation. If people stay with relatives they won't get picked up which is really difficult... (RS1).



City hospital ward staff highlighted the difficulty when patients and carers arrive late or on weekends, or in emergency situations when these support services are not available. Staff from one ward discussed the necessity of keeping a spare mattress to drag into the tea room so that late arrival escorts could sleep there overnight.

## Long-stay accommodation is hard to find and costly

Country staff and social workers discussed the increased difficulty in finding long-stay accommodation for patients needing to stay in Adelaide for extended periods, particularly for renal or cancer treatments and pregnancy/neonatal complications. In the past Aboriginal housing could arrange a house for three to twelve months where families could stay together, 'like a home away from home' (RA6), but staff perceive that this has become less likely with the new mainstreamed housing system. Metropolitan and country staff commented on the difficulties experienced by mothers of newborns and families trying to pay for accommodation in Adelaide while also covering the costs of their usual accommodation at home.

While any solutions to these travel and accommodation problems are likely to increase costs to the system, the consequences of missed appointments are also costly. The challenge is to find ways of making travel, transfer and accommodation arrangements more reliable, while also ensuring that the coordination of appointments and other access requirements (such as interpreters and arrangements for informed consent) within hospitals is better aligned with travel arrangements.

## Support for and role of carers and escorts

Almost all metropolitan staff recognised the importance of family or community carers for rural and remote Aboriginal patients, with many highlighting the loneliness and isolation they see for patients without an escort:

The patient is just so isolated and sad, being in here by themselves (MH10).

All country staff stressed the importance of Aboriginal patients having a companion for company and support if they choose, particularly remote, traditional and very ill people, for similar reasons to those mentioned by city hospital staff:

... loneliness, homesickness and the need to come back home earlier (RA2).

It alleviates a lot of the fears that that person has, knowing that they've got somebody with them that can help them through this time... everybody should go with an escort because it's support, it's company, it's everything. It's really important (RS4).

## Contribution to care and recovery

Both city hospital and country staff expressed appreciation for the contribution of carers and escorts, including for better recovery, support to complete treatment, assistance with communication and mobility:

They have less muscle tension and therefore less pain... Sometimes with... surgery there is some post-op delirium and having an escort helps to settle that so you want somebody they can identify with (MH15).

With an escort they might be able to go outside safely... if they have a chair and there is an escort who can take them out and back again (MH19).

What we rely on is perhaps the often more mature support person, like an aunty or someone like that, who comes down to help... they're more interactive with me... making sure there's a support person always would be a big help (MH23).

## Carers and escorts may be unwell, or inappropriate to the role

There can be limitations to the assistance escorts can provide, especially if they are themselves very ill or are otherwise seen as inappropriate:

The aunt's usually an older person... and they're even quieter than the patient, because they're an extra generation on, generally speaking (MH18).

We have had escorts that have been sent down with quite severe illnesses... they have spent more time in hospital than the patient (MH19).

People are not prepared for the size of the hospital and what is going to happen to them there... The carer can be just as confused and overwhelmed (RS1).

Even in sickness if there are decisions of any consequence to be made it's got to be the right person that helps an Aboriginal through it (RA1).

In reality, the ideal escort may not be available in emergency or... when the plane's idling they're not going to find, at all times, an appropriate escort. It's whoever is available at the time or whoever has got the less commitments (MH10).

## Need for escort swaps for long-stay patients

Financial support for transport for a single escort is provided by the PATS scheme, but this causes difficulty with long-term stays (e.g. six months for cancer care):

We would love for the Patient Assistance Transport Scheme to allow an escort swap for long-term patients. At the moment they only allow for one escort but even if we could have one or two extra escorts... (MH10).

## Need to define role and expectations more clearly

Currently the role of the escort or carer is not clearly defined, or negotiated. Interviewees advised that AHLO units are generally relied upon to support carers in many practical and social ways, a role which may be appropriate but doesn't of itself address the role of the carer in the clinical unit. There was support among

some of those we interviewed for addressing this gap. One country Aboriginal health staff member summarised the opportunity:

The health providers have to figure out what they want from that escort, be very clear about that and then marry that with the expectations of the client (RA3).

## Access to spiritual healers—*Ngangkaris*

### Role is increasingly recognised

*Ngangkaris* are traditional healers, and their role is increasingly recognised in city hospitals for traditional ceremonies and patient support, particularly in the area of mental health:

Initially there was a terrible lack of understanding—the clients wouldn't go into some of the rooms at all but now we smoke the rooms... some people have a very real sense of what's in that room... maybe there is a sense that that hasn't been properly handled because there was something that occurred there they had a connection with or something... then they'll just leave (MH3).

We emphasise the importance of utilising not just whitefella medicine but also blackfella way and the importance of working together... people are more willing to engage with our service because of that (MH3).

One remote area nurse was clear about the role of *Ngangkaris* for healing:

I think I've found out, especially with the more traditional people, we actually aren't the healers, that's still their *Ngangkaris*, that's still their traditional healers (RA1).

Another country hospital staff member reflected on a patient whose symptoms were serious but no cause could be identified, despite extensive investigation in a city hospital:

... it turned out she'd been sung or cursed... and an Aboriginal Health Worker down in Adelaide picked it up and sent her back here and we got the *Ngangkari* to come and cure her. And we'd spent—I don't know, tens of thousands of dollars on every treatment

known to man and it was something as simple as recognising that there was a cultural cause rather than a physical cause (RH6).

## Problems with availability and payment

*Ngangkari*s may not be readily available and there are administrative difficulties in paying them:

When we first wanted to get *Ngangkari*s down going through admin was a nightmare because they basically wanted ABN numbers [Australian Business Numbers] and all that sort of stuff and then ‘what are the qualifications of these people?’ and it was an absolute nightmare (MH3).

One solution was to include administration staff on trips to the Anangu Pitjantjatjara Yankunytjatjara Lands so that they could:

recognise the importance of a *Ngangkari* and can see that it’s the community that determines if a person is a good *Ngangkari* or not and that you don’t need the ABN (MH3).

Although *Ngangkari*s are salaried for the work they do on the Lands, this does not cover trips to Adelaide. Individual health services, the Aboriginal Health Council of South Australia and families cover the cost of *Ngangkari* services, transport and accommodation, and interpreters and companions. However, in mental health, particularly, the cost has been seen as justified:

It’s quite an expensive process. We’ve done it probably about three times now and each of those three times we’ve had fantastic outcomes (MH3).

## Language and interpreters

The obligation to respond to the interpreting needs of all non-English speakers is explicitly recognised in the health system (Policy and Intergovernment Relations Division 2001). However, problems related to language and access to interpreting were raised by most staff we interviewed, particularly in relation to

remote Aboriginal patients. This problem can be profound, especially for people from outside South Australia:

It’s often hard to find out what language they speak because there’s often no level of communication because they’re totally overawed by the whole thing and withdraw into themselves, as Aboriginal women tend to do under those circumstances (MH8).

## Cultural differences in use of language

Illness can exacerbate problems with speaking and understanding English, especially for some older people who tend to revert to their first language. There are also differences in ways of using and expressing language, and this takes time to navigate by all involved:

I think Anangu say with... a couple of words and a couple of gestures what takes us paragraphs to say. We’re the verbose people. The other thing I think to remember too is... if you’re talking to someone with language, that they try to understand as much as anybody... but they’ve got to translate the English into Pitjantjatjara, form a response in Pitjantjatjara then translate that response into English to come out with it and that takes seconds and what are us Europeans uncomfortable with? Silence. Yet to Anangu I don’t think they have a problem with a 25-second silence (RA1).

Rural staff noted the need to put things simply and unambiguously:

The fact is that when you give choices, you’ve got to be very careful how you do it (RA1).

In addition, there may be differences in the way younger and older speakers use language, and some Western and medical concepts may lack equivalence in Aboriginal languages:

The interpreters say, ‘look we haven’t got a word for skin grafts’, and it’s really not knowing about their treatment (MH10).

## Availability of interpreters

About one-third of all participants raised the problem of availability of interpreting services. We were advised that there was only one accredited Anangu Pitjantjatjara Yankunytjatjara (APY) interpreter in Adelaide in 2010, with two older people retiring from this work. The telephone interpreter service can help (by providing access to interpreters elsewhere), but as one rural staff member put it:

Over the phone is hard (RA2).

One rural staff member explained his/her own role as an informal and cultural interpreter:

Sometimes we'll get a phone call and—they'll ring up and they'll want to talk to me so I'll talk to the clients and then I'll explain to the liaison officer what the client was talking about (RH7).

## Using family members

About one-quarter of all staff expressed their recognition that it is not appropriate to rely on family members for interpreting sensitive or medical information, for good reasons:

OK, if we've got a sensitive topic and the patient may want the procedure but the family member won't, we've found that... we've been caught out before (MH10).

I think often if they have family there one of them can speak reasonable English and can understand enough to explain it to a family member, but it's not always ideal having a family member doing all the explaining so it would be better to have really good interpreting services that they can utilise (MH5).

We sometimes use family in everyday conversation but when it comes to informed consent we always make sure it's done properly (MH10).

## Failure to recognise the need for interpreters

Two rural staff members commented on metropolitan staff not recognising the need for interpreters, for example:

Just because someone can say 'hello', 'good morning' to you in English [don't assume] that they're going to have the ability to understand sophisticated concepts of the surgical intervention or whatever else you need but you do really need a person with good interpreting skills (RA1).

A metropolitan staff member agreed:

A lot of people are fooled by the English [that people from the APY Lands] speak and think that, okay, because they can speak a bit they actually are able to understand a lot (MH3).

A small number of metropolitan staff indicated reluctance to recognise the problem and make use of the services that are available:

Language can be a barrier. We tend to be able to get around that. It's not so much of an issue... hopefully they have an escort that we can get translation off but by and large we're sort of—it's a barrier but it's not a steep one that we've had overly big issues with (MH15).

## Tensions for workers who are community members

Interpreters who are community members can be reluctant to be involved when major treatment or consent decisions are made, and confidentiality is a concern within small communities:

It's also taking on the responsibility of interpreting things to the Elders or to other community members effectively. It's a huge responsibility. I think that's where [X] got away with it a lot longer because he's non-Indigenous and he doesn't have any factors of payback or blame for getting it wrong, he's neutral. So it's all good and well for family to interpret but if an Elder comes back and says 'you didn't say it the right way; what you said happened differently' and you're doing it over the phone or you're doing in that context, that'd be challenging (RA2).

Rural staff spoke of the need to understand Aboriginal protocols, gender and seniority concerns in the interpretation task. An Aboriginal care provider talked about men who need catheterisation, and require a male interpreter with high-level skills:

I'll do anything else but that, yeah. The men, they would get really offended, that's why I'd say, 'no, I won't talk to you, you'll have to get one of my male workers to go and talk to him'. Sometimes they open up or... if that man hasn't been through the traditional way but they'd still rather talk to him than talk to me (RH7).

That gentleman in particular trusted that person and had a connection with him and probably went, 'yeah, okay, I'll consent'. He was probably a bit frightened about what it was all about and maybe didn't understand 100 per cent but trusted the interpreters and trusted the system (RA2).

This comment raises an ethical and professional issue about the boundaries of the role of interpreters. Should they just interpret language, or also act as brokers, cultural interpreters or advisers to the patient (Lester, Vaarzon-Morel & Carter 1982)?

## Informed consent

Problems with ensuring informed consent to investigations and procedures were a common concern, with more than a third of all metropolitan hospital staff speaking of language and communication problems compromising consent:

Sometimes they're absolutely not sure what they're consenting to (MH11).

### Consent and the telephone interpreter service

Two people expressed concern about the quality of consent when telephone interpreters are used, or when interpreters are not available:

I would organise a lot of phone consents. Again, not ideal, but better than not consenting properly (MH19).

I don't believe anybody can honestly say they have got consent if they have not really been able to through lack of interpreters—it's ludicrous (MS1).

### Role of trusted interpreters

The role of known interpreters was noted by one rural staff member:

## Financial resources

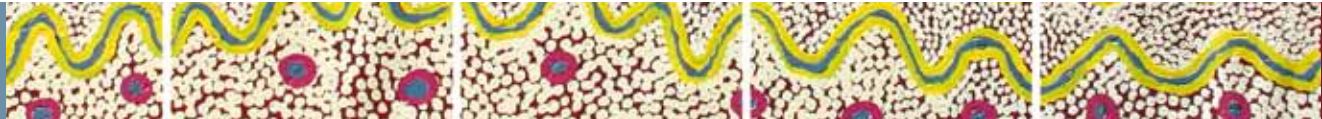
The impact of illness and the costs of treatment for people who lack financial reserves is a major underlying factor in many of the problems staff spoke about. They also addressed it directly.

### Costs of staying away from home

For Aboriginal people and families the additional costs of staying away from home for health care can tip families or Elders who are coping into financial stress:

... that means they've got to stay for two weeks in [a regional centre] and being away from home... is not the easiest for them and then there's the financial component, they can't support themselves financially because most of the community clients are paying, you know, high electricity accounts, rent and the majority of their pension goes to that (RA2).

Finances are always, I think, a big thing, especially people that have their money managed by, like, an agency or through the public trustee. Finances are a big issue for everyone at the moment and you know the costs of travelling down here and still having bills to pay at home, trying to survive down here as well, accommodation, food, all that sort of stuff, you know, and trying to help out other family members and then leaving themselves short (MH13).



Country staff spoke clearly about the poverty of many patients in their areas and the problems of cash flow when additional expenses are incurred:

There is an assumption by many people that patients have jobs and can pay themselves and get reimbursed, but most Aboriginal patients do not have jobs or spare money. There is no emergency fund within their family. With accommodation they need money up front, but most people haven't got it (RC1).

### Concern about limitations of PATS arrangements

Nearly half of the city and all country staff identified that the current PATS arrangements do not adequately assist patients from remote areas or those experiencing financial difficulty.

### Northern Territory patients and problems with the Basics Card

Support staff and social workers discussed spending long periods of time supporting Aboriginal patients and their carers to access financial assistance and services. Income management has caused additional difficulties:

The Basics Card is a real pain... It's that fine line, too, between—the Aboriginal Liaison Department are really trying not to support that strong welfare mentality now but it's a fine line between not—trying to empower, or re-empower, patients or escorts to come down and take ownership of their health and wellbeing to—where some people just haven't got the capacity, in terms of they can't read road signs to make their way to Woolworths to buy their shopping. Yeah, so it's a touchy one, too; it's a hard one (MH10).

### Cost as a barrier to city care

Some country staff noted that some Aboriginal patients ultimately choose not to travel to Adelaide because the financial, personal and family costs are too high.

## Conclusion

Access problems are only partly the direct result of the distance people have to travel. Problems with transport and accommodation are made more difficult by a frequent lack of financial resources to purchase alternatives, and the strict rules, allowances and paperwork requirements in public subsidy schemes. Uncertain capacity for informed consent is a serious consequence of the combination of difficulties with interpreting services and cultural differences in thinking about health and health care. Staff recognise the vital role of carers, but also the limitations arising from the carers' own health status, their unpreparedness in many ways for the demands of the role, limited funding to support them, and the lack of formal recognition of carers as part of the health care team. Some successful strategies to address these problems were also highlighted, including the corporate shuttle service as an important gap-filler. But for some patients the combination of barriers to access results in decisions not to use city-based health care.

# System of Care: Coordination and Quality

Both city and country staff recognised the important problem of coordination between city and country, primary and tertiary health care, and Aboriginal and mainstream health services for the care of country Aboriginal patients. They also raised several problems affecting quality of care. The major themes that emerged from discussions about coordination and quality of care are summarised in Table 5.

## Coordination across settings

Staff spoke of many problems with coordination and continuity of care (across different settings and locations) in relation to the logistics of admissions/appointments and the transfer back to regional hospitals or to home.

**Table 5:** Summary of themes in coordination and quality of care

Issue/aspect	Major themes
<b>Coordination across settings</b>	<ul style="list-style-type: none"> <li>Confusion about who to talk to when and where.</li> <li>Hospital staff need information about social and cultural situations.</li> <li>Information transfer back to country staff: delays and denials.</li> <li>Role of AHLO units.</li> <li>Potential contribution of information and communication technology.</li> </ul>
<b>Logistics and the hospital environment</b>	<ul style="list-style-type: none"> <li>Inflexible appointment systems collide with stretched logistics.</li> <li>Patient preparation is often inadequate.</li> <li>Environment—feeling cold.</li> </ul>
<b>Discharge and follow up</b>	<ul style="list-style-type: none"> <li>Discharge or transfer of care?</li> <li>Discharge planning problems.</li> <li>Timeliness of discharge.</li> <li>End-of-week discharges/transfers.</li> <li>Discharge drugs: too little, too expensive.</li> <li>Follow-up care is a critical problem.</li> </ul>

## Confusion about who to talk to when and where

In each setting the majority of staff expressed confusion about how to contact staff from other settings to discuss patient transfer, health care, discharge planning or follow up. Staff in some wards and services had developed networks that crossed organisation boundaries; others had not. Those who had included staff working in care for chronic conditions (notably mental health and renal care), those working in coordination roles (burns and cardiac units) or simply those with long-term experience.

## Hospital staff need information about social and cultural situations

Metropolitan staff indicated that although they usually receive adequate clinical and medical information about patients referred or transferred to an Adelaide hospital from country South Australia or interstate, they often need to know more about patients' home, cultural and social situations:

Occasionally we need to chase up investigations and that sort of stuff but in general the medical documentation is good. But in terms of understanding their cultural background and that sort of stuff, that is not communicated down to us (MH8).

We do find that admission information usually is poor for everybody across the board... usually you're starting from scratch and you have nothing to start with... you don't really know what they're about or who's at home, what their living conditions are like, any support services, you don't have anything (MH6).

Some metropolitan staff members, particularly those in specialty areas, specifically ask if patients are Aboriginal so that they can let the Aboriginal Hospital Liaison Unit know:

If I get a phone call [and find the patient is Aboriginal], I always let our Aboriginal liaison know of an ETA [estimated time of arrival] so they're one of the first people who see them when they hit ET [Emergency Theatre] (MH12).

Country staff also identified this problem:

There's no sort of preparation or there's no arrangements for Aboriginal people so if you're a non-Aboriginal person or Aboriginal person it's the same arrangement so there's no—we don't ring someone and say, 'look, so and so is coming and they're going to have some special needs because of their Aboriginality' or whatever, we just send them down. It's purely a clinical-based decision. There's no consideration of the sort of social, family or cultural aspects of the transfer, which, to me, always seems like it's missing in some ways (RH6).

A lack of patient social history can impact negatively on clinical decisions, such as on deciding the surgery or treatment that is most appropriate for a particular patient depending on his or her ability and tendency to access health care in or near the home community.

One of the things that we face is lack of information... So we know they have come for an angiogram but we don't have any other history... So all of that is an instant barrier (MH16).

One hospital staff member explained the benefits of direct communication across settings:

Often the health care centre in the community knows a lot more about the patient than you would expect because they know all about the family background and about why they make certain decisions and so on. If you're in a situation where you don't understand why a patient is making a decision, often just ringing the GPs and the health care workers there, they can explain quite a lot (MH5).

Staff members in a rural Aboriginal service reported on an information pack they had developed to accompany patients living in aged care when they are transferred to Adelaide:

Just a brief summary on her current situation, so '[her Elder status], cared for exclusively by female staff', so what she's used to... 'Assisted with her activities of daily living to attain maximum quality of life and cultural considerations'. Then some of her function capacities, like hearing, sight, reading, just little things... We were very conscious when we put that together to not make it so big... the thing is of about six pages and highlight the things that we think they're not aware of.



Well, they can put it on the front of their folder or anything, you know, at the end of the bed, but the information might be that little bit extra to make their stay in that hospital a little more comfortable (RA2).

As one city doctor summed up:

Improving communication would be helpful and getting people to—for us to understand what's going on up there and for them to understand what we need down here, what our limitations are (MH8).

## Information transfer back to country staff: delays and denials

Aboriginal health staff and Remote Area Nurses highlighted difficulties in accessing patient and discharge information from hospitals. Unlike hospital-to-hospital transfers, where patient information is 'automatically transferred', discharge papers are often delayed or sent to another agency, such as the nearest hospital or GP. Some Remote Area Nurses and Aboriginal staff reported that when they rang hospitals for information about patients who they, themselves, had transferred to metropolitan hospitals, hospitals refused to give the information because they were neither doctors nor hospital staff.

In small country towns there may be three or four different health agencies supporting an Aboriginal person's health care (local hospital, GP, community health service, ACCHS). Country primary health care staff commented on how discharge information was often sent to hospitals or GPs, but not to other primary health care agencies. If they didn't have a good relationship with the local hospital or GP, then they did not get information:

However, in terms of the discharge from here, though, that's a bit different. We're fortunate enough to have a shared care model that we can go over and say, 'give us the notes, we need to know', but that probably wouldn't work for other people from our community (RA2).

Some city staff acknowledged this problem; one reported:

We have an information folder which we give interns when they start—they're here for three months—and we're making a new section there for isolated patients in that not only will their discharge information be faxed but a copy will be given to the patient, and certainly we can also fax a copy to the clinic if the fax number is made available to us; that'd be good (MH15).

## Role of AHLO units

Staff commented on the significant amount of time required to 'chase' information and make appointments, arrangements and contacts, and the difficulty for staff within clinical units to fulfil this role without support or dedicated resources. The AHLOs often became a pivotal connecting point and many hospital staff acknowledged their important contribution in the care arrangements for country patients.

Sometimes when I'm sending someone down I'll actually write down in the notes or give them a call and I say, 'this person needs help so if you could take him to the liaison officer when he gets there and just explain to the liaison officer they need help to get around the hospital, and their English is not very good'. Cross my fingers that it works (RH7).

## Potential contribution of information and communication technology

Both metropolitan and country staff saw the potential benefits of improved information and communication technology networks between rural and remote areas, citing ease of sharing discharge information and results:

They could put it straight through electronically, straight through to the system to the computer... As soon as that discharge letter—you could look at it and it automatically goes to the person's file, it's been noted, so when the person comes in it's always sitting in there. And that's the quickest, most efficient way to do it... nothing should get lost in the system (RA6).

It was suggested that visiting specialists could have all of the information 'at their fingertips' and thereby reduce the number of repeated tests

(which could mean two to four days' travel to the nearest major city). One specialist who visits remote areas explained:

In theory I'll be able to access the radiology that they had done in Alice Springs on the internet from the Pitjantjatjara Lands which will be good... and it would also be good if we could access the electronic data manager... then that would be very helpful, too, because we could look at all the blood results... the radiology results and even discharge summary... it would save a lot of mucking around and would benefit the patients a lot too. Sometimes patients end up getting tests repeated because you don't know what was done because the patient wasn't quite able to tell you (MH11).

A staff member in one clinical unit described a process for patients who require significant follow-up care (which works sometimes). Staff document verbal consent to talk to the community-based services the patient or family uses, and then arrange a virtual case conference with staff in those agencies using whatever medium is available:

So if they've got a computer and internet we'd be online where they can see a PowerPoint presentation of their patient's journey and then they'll get faxed or emailed or sent a discharge summary and follow-up requirements. Included in that pack will be what they've had, their treatment, some of the issues we've had, including psychosocial, and their follow-up requirements, exercise, things like that, and points of contact for help, mental health, psychology, physiotherapy, OT [occupational therapy], nursing, medical, they've got a whole list of contacts they can call (MH10).

## Logistics and the hospital environment

### Inflexible appointment systems collide with stretched logistics

Several country staff related instances of country patients being refused service when they arrived late for an outpatient appointment. In some

cases patients and their carers or escorts had travelled vast distances and were told to come back for another appointment in a week or a month. Unfortunately, some patients were so upset by their experiences that they refused to travel to the city again.

### Patient preparation is often inadequate

Both metropolitan and country staff emphasised the need for more patient education in the home community prior to admission, particularly for planned and elective surgery. They suggested that it could include peers who have experienced similar procedures, and explanations given in local language and conversational style. This strategy has been effectively used for cardiac care (Lawrence et al. 2009). It was also acknowledged that this is not possible for emergency admissions, unless general community education programs have been in place.

It would be good if there was somebody up there with good understanding of what the procedures were and could explain it before they come (MH16).

If there had been some capacity to actually have some teleconferencing or video linkages to communicate—to talk things through and to be able to do things like virtual tours, to be able to show people... That's a way of at least being able to bridge some of that narrative (MSA10).

### Environment—feeling cold

A quarter of all staff described the hospital physical environment as off-putting for Aboriginal people. Both country and metropolitan staff highlighted that country patients, particularly those north and west of the state, find hospitals very cold. They often need additional blankets, beyond what may be deemed 'necessary' by Adelaide staff members:

A lot of times I've tried to explain to people that they come from a hot country, they're not used to being cold (RH7).

## Discharge and follow up

The period after discharge from acute care is important for patient safety, with real potential for complications (Kripalani et al. 2007), but lack of continuity of care is a persistent problem in general, and potentially worse for country patients. Staff spoke about the need for new ways of handling these problems, of planning and coordinating transfers or discharges, including the problem of discharge drugs. They also expressed concern about fragile or non-existent ways of ensuring follow-up care.

### Discharge or transfer of care?

The notion of transferring the care of patients with ongoing care needs, rather than discharging them, has arisen in various areas of care in Australia, including mental health care (Crawford et al. 2004) and has been taken up in Country Health SA. The important distinction is that effective transfer of care is only achieved when the receiving agency or care provider has affirmed acceptance of the transfer of that patient's care and has the necessary information. Several staff discussed the use of transfer rather than discharge as a helpful way to ensure patients do not fall into gaps between city and country, tertiary and primary health care services, and follow up. Both city and country staff identified the need for improved transfer and discharge planning between city and country.

Some city staff were very clear about the need to transfer rather than discharge care:

If you focus on discharge, that's where people fall through the nets and you get the bad outcomes. You need to be able to transfer, you need to have identified people following on so that not only the patient, but the family, everyone, knows exactly what's happening and it's going to—I mean, you'll still get people falling through the nets but it's going to minimise that (MH3).

Staff in specialised units spoke of transferring patients back to the local country hospital rather than discharging them to home, primarily to ensure that a health professional was checking the patient at the end of the journey. This also

ensured the best form of transportation for the patient's condition (usually flights) could be arranged:

... they always fly back. It's too big a surgery and too painful for them to prolong and it's too risky (MH15).

Early transfer back to country hospitals was arranged where possible:

If we can get them back to their local—or at least to a regional—hospital that's somewhere near them, at least family can visit (MH6).

There was a significant difference between wards and units that had long-term relationships and contacts with country and interstate health services, including Aboriginal and community health services, and those that did not:

The CNC [Clinical Nurse Consultant] will know about the nursing counterparts and allied health counterparts, what hospital they have come to, and do the handover and make the call and the social worker can back that up as well, as can the physio. So they'll make their links to their counterparts in remote settings as required (MH1).

### Discharge planning problems

There is evidence that discharge summaries are not reaching the right recipients in a timely manner, and are in effect not used (Wilson et al. 2001). For staff in this study, the impact of discharge information not arriving with patients was significant in time wasted and care continuity lost:

Discharge planning is not really happening... Very few teams do it well... We have clients discharged here to us without medications, without just—well, I think, I've never had a client actually come with a discharge summary, it's always me ringing, and then it's five days after the fact. Imagine if that person goes back to a community and they've got a dressing that needs to be done and it's left for five days until the discharge summary comes through; the patient ends up back in hospital (MS10).

Putting a system in place would help. We've done the discharge summary now... who do I need to send this discharge summary to? It's all well and good that you've written a discharge summary but if it goes to a place where it is irrelevant to the patient, well, that's not a good outcome for the patient... What's the point of a discharge summary going back to Alice Springs Hospital [when the patient comes from a community 500 kilometres away]? What are they going to do with that? But you can take it back to a community, then at least there's a clinic nurse there and they can go, 'oh, yeah, I know such and such, yeah, I can chase him up' (MH14).

The need for coordination of discharge preparation by a multidisciplinary team was recognised by some hospital staff. The problems when such preparation is not done were noted:

Sometimes decisions are just made unilaterally by various members and then you just have to run with it... sometimes you think you've got a couple of weeks... before they leave and then the doctor will make a decision on the round whether they can go at the end of the week and suddenly we don't have [everything ready in time] (MH20).

Other metropolitan staff highlighted early multidisciplinary discharge planning:

So we have a discharge planning session where we talk about everything from how the patient's going, what's going to happen when they get home, who's going to be following them up, to how they're going to get home... we have doctor, patient, nursing staff, allied health people who have been involved in the care plus the Aboriginal Health Workers at this end, and at that end we have the GP, care givers, family, whoever is involved in the care (MH3).

## Timeliness of discharge

Country staff stressed the imperative of getting people with strong links to country back on their land as quickly as possible. Metropolitan staff spoke of reasons that discharge may be delayed, including trying to access Royal Flying Doctor Service flights, access to beds in the

local hospital, patient readiness (clinical), and availability and skills of country staff and health services.

Some metropolitan staff also expressed concerns about home conditions being unfavourable for healing (for example, for patients with skin grafts returning to non-air-conditioned buildings with little access to clean water and surrounded by gritty sand):

And it's that fine line between discharging early to try and reduce that length of stay [or] we might hold onto the patient a lot longer than we would another patient who was local because we just want to really make sure that patient is 100 per cent ready to go home (MH10).

One metropolitan nurse identified the importance of clear, consistent information for patients, which can be difficult when a patient's condition changes. For example, changes in predicted dates of discharge can be perceived by patients as dishonest, and they then may think:

'Well, you're no good, you lied to me', so I tell the doctors, 'don't give them a set date until you're absolutely sure because you will lose their respect' (MH7).

## End-of-week discharges/transfers

Both metropolitan and country staff members identified the difficulties that occur with end-of-week transfers and discharges. Metropolitan staff highlighted the challenges of meeting patient and carer needs when patients are transferred late on a Friday afternoon:

People tend to look after people and then think it's Thursday and this person's not getting better, we'd better transfer them to Adelaide... the transfer's organised on Thursday, they get a plane down on Friday, they lob here at four o'clock in the afternoon and everyone's gone home. The Aboriginal Hospital Liaison Officers have gone home, all our [home ward] people... so it's very difficult and the lack of good support... on weekends is actually quite an issue... If they come from Gove or somewhere like that via Darwin and then they lob in a level-six intensive care unit, it's pretty powerful (MH8).

Similar issues occurred for country staff members when patients were transferred back to the home community late in the week without prior discharge planning between city and country services. One rural nurse explained:

discharges that happen from metro... on a Friday afternoon or a late Thursday with no prior contact with the local services to see what may be available to meet that person's needs... services for this region don't operate on the weekend, generally speaking, unless its pre-approved... It's not a 24-hour service or an on-call service so we can't initiate services after hours... if that's not pre-arranged then it severely affects the patient's experience... then potentially puts them at risk of not wanting to go back and access services when they actually really need to the next time... we try and avoid Friday discharges... at all costs but it's still happening for metro (RH9).

## Discharge drugs: too little, too expensive

During the time that we were conducting the interviews, new rules regarding discharge medications came into place. Under the new rules patients receive one instead of two weeks of medications, no discharge scripts are given and patients are billed for medications on discharge. This new arrangement was causing concern for both city and country staff:

If their GP is booked out for two weeks, right there you've got a major problem already. So the system isn't really being all that helpful. There's sort of a lack of cooperation between the hospital—which is mindful of its own pharmacy budget problems—and then getting in to see GPs through the federally funded Medicare system and so... there's not a shared fiscal responsibility across the two funders, the people fall in that gap. So if someone gets home and after four or five days they think, 'oh, I've only got two days of pills left, I'll ring up and see my GP' and the GP's secretary says, 'that's fine, I'll get you in two-and-a-half-weeks time', then they're left in no-man's land, which is really quite unfair (MH1).

For Aboriginal people from remote areas who are usually eligible for free medication under the S100 scheme, this arrangement is very difficult if they need to stay in Adelaide rather than return home immediately:

When you discharge a client from a hospital they are given three days' worth of medications and if they're put into a hostel they're then expected to make a GP appointment, get to that GP appointment, get to a pharmacy to get the scripts filled, have the money for those scripts and know how to take the medication. That is unrealistic; that's not going to happen (MS10).

... we have the pharmacist speak to them, we sometimes organise dosettes if we think that is what is necessary. But we don't know if they go back and fill their scripts after they run out. And the hospital now charges for discharge medications, so I don't know whether they recoup their cost for discharge medications (MH16).

Rural and remote areas nurses spoke of the unique issues of providing medication for patients who have returned from Adelaide with minimal amounts of medication and an unpaid bill:

We have had the odd bill from the hospitals... for medication dispensed—what can you do?... my co-worker, he just wrote a note on the bottom and said that Indigenous people are exempt and sent it back; there's nothing much else you can do (RA12).

## Follow-up care is a critical problem

Follow-up care is seen as a critical problem. Many metropolitan staff expressed concerns about what happens for patients after they leave hospital:

One of the big things I'm racking my head about is follow up. It doesn't matter what we do, we're still having big problems with follow up, especially if they're over the border (MH10).

Part of the reason that we fail is because... we don't know what happens and really that's not good care, we should be able to assess where the patient's going to afterwards. We have a duty of care to the people to ensure

that they're safe and that they don't bounce back really... knowing what's going to happen to the patient within the first week of discharge is where my main interest is... I've got to ensure that those patients are going to a safe environment, that there's somebody with them for that seven days and that they have access to adequate health care or at least some health professional, a nurse or whatever (MH15).

Our follow-up success rate, in terms of getting information on the outcome of babies, Aboriginal babies, is appalling. Maybe 20 or 30 per cent... of Aboriginal pre-term babies, we have the information about that outcome, which is absolutely abysmal, compared with, like, 70 to 80 per cent for the white, urban, prem baby. Why is that happening? (MH23).

Sometimes follow up is difficult because services are not available in people's local areas. For example, patient's teeth sometimes need to be removed prior to cardiac surgery to prevent infection, but getting dentures afterwards is an unreliable process:

Many of them go back to places that don't actually have a place to fit dentures. Six months later they still don't have them. I don't know how the system lets them slip through. I saw one man who was chewing on kangaroo for months now without any dentures. The plan was that he was to get new dentures and I was pretty upset that he never did get them (MH19).

... in some areas people are waiting six to twelve months to get an appointment with the visiting specialist (RS4).

... follow up—they probably don't get followed up as well as white people... due to distance, isolation, which consultants goes, where, when (MH16).

Follow up was also difficult if patients were very mobile:

We also rely a lot on our patients contacting us in between appointments if there are problems with their pressure garments or if they're too big or too small or they need—they've run out of supplies and I find that the Aboriginal population generally doesn't initiate asking for things. Especially when they're

at a distance or if they're travelling between different remote communities it can be really hard to track people down and they won't have asked for more supplies so they may go for some months (MH20).

One doctor spoke of an awareness of the need for the right people to coordinate follow up. This might involve an Aboriginal person:

So that was a big lesson for me, that just because you're in a tertiary centre doesn't mean you know best, that understanding how to best utilise the expertise in the country is probably one of the most important things I think... I can't coordinate it really... I can't pick up the phone and talk to the Aboriginal Health Worker at Coober Pedy and expect, really, much joy from that, but they [an Aboriginal-focused coordinator] could or their Aboriginal health care workers could (MH23).

However, country staff indicated that even with their connections and skills, follow up—particularly in remote areas—can be difficult:

Someone will come back, 'oh, didn't you do this or do that?' They don't realise that there's 119,000 square kilometres that people are wandering around here, that the nurses actually think that we're exactly like a hospital except our corridors are a little bit longer, yeah, about 750 kilometres... But that—actually I don't think that some of the nurses who have only ever been in the city can actually picture what a remote area clinic is like or the wide open spaces that people do wander, that you can't always follow on (RA1).

We get phone calls like, 'okay, we're going to discharge someone back to [location] can you tell us the closest hospital', and we go, 'it's us', and then they go, 'oh, well, can you just do this and this', and you go, 'well, it's eight hours' drive to get them home', you know, like, 'you're better off getting all the appointments all done in one hit instead of thinking they can come backwards and forwards all the time' (RH6).

Even closer to towns, there are issues of how to contact patients for follow up:

Addresses could be another problem, you know, some don't have post boxes or letterboxes or anything... (RS4).

## Conclusion

Problems for patients moving between hospital and community-based care predominate in concerns about coordination and continuity. The question of quality (i.e. the extent to which health care achieves its purpose) was seen primarily in relation to the impact of problems in the direct interpersonal encounter, and of coordination problems and patient comfort concerns.

Staff lack of knowledge of other settings and their constraints and requirements is a recognised problem that persists in spite of many years of attention to the need for better communication between health care providers. This seems to be another case of 'two worlds' that don't work together. Within each setting, unreliable assumptions are made about the

roles of other care providers, and the need for someone to be responsible for coordinating the overall patient journey seems clear. The distinction between transfer of care (which applies only between hospital/inpatient settings) and discharge from care (when patients are returning home or to residential care) may be a useful focus for thinking about this problem and seeking to address it. There are three important differences: agreement to transfer is negotiated in advance; information accompanies rather than follows the patient; and costs are borne by the transferring agency. A shift to transfer has implications for both primary and hospital care providers. Recognition of the value of care coordinators may be seen as evidence that supports this approach; it could also address the problem of inadequate access to medicines during the discharge period.

## Social and Cultural Environment

Many unique cultural issues, which are different for Aboriginal people compared to other country patients, were raised by both Indigenous and non-Indigenous health professionals. A number of metropolitan staff expressed concern and frustration at the lower utilisation or engagement with mainstream services by Aboriginal people:

OK, they're not oriented to the Aboriginal people and maybe that's half the problem, but you know that there's services there, they're meant to be generic, for everybody, that can help but they're not utilised by the Aboriginal community for whatever reason that may be. I suppose the most I've learned over the last twelve months is that maybe that's more—I don't know—more a culture thing or the way they're brought up, I don't know. I don't know a lot about the Aboriginal community and what they believe and what they don't believe... But, yeah, I don't know if it's a culture thing or of what history's played in Australia, I don't know (MH9).

The same person recognised that failure to acknowledge and respond to the different needs of Aboriginal patients did not work:

Even when I say from my experience on the wards, what I did there, it was like you treated them like any other Tom, Dick or Harry that came through the ward. We did our normal treatment, did what we had to do and when it came to discharge, yeah... you just did the normal protocol for everybody and that's been my experience for 20 years... that's what my experience has been, that's what I've been doing, so it's only been in, like, the last year with [a chronic disease project], okay, maybe things have to change a little bit, so I guess I recognised that it wasn't working (MH9).

As the above respondent ponders, it is not just a difference in culture that makes it difficult for Aboriginal people, it is also the past history of colonisation that explains why current health services may not meet their needs. These cultural and historical factors are intertwined, so

that a violation of a cultural norm risks reinforcing misunderstandings that exacerbate racism, contributing to Aboriginal people experiencing hospitals and the attendant health care as culturally unsafe for them (Polascheck 1998; Ramsden 2002).

This section analyses the ways in which staff experience or observe the impact of cultural differences and experiences of discrimination on health and health care. The major themes raised in the interviews are summarised in Table 6.

### Men's and women's business: gender and hospital wards

#### Mixed-gender wards are difficult for many patients

The difficulties of mixed-gender wards were noted by both city and rural staff:

[Our wards] are mixed gender, which is a huge issue. We try to avoid it but... last week we got an admission [of an Aboriginal woman] and she was put in a bay with three men. Of course she was just freaking out and terrified the whole time. So as soon as the sun came up, we moved her into a bay with women and she was okay (MH16).

She was also in an ICU [intensive care] unit with three other older men that she found quite disturbing so—and she was right in the corner of the room and the nurse's station was—they watch the rooms quite intensively and I kept sort of just pulling the curtain a little bit over to give her—just to block her vision of the guys next door, and they kept coming in and pushing it open and saying, 'we need to be able to see her the whole time' and I said, 'I am sitting here with her'. So that was



**Table 6:** Summary of themes in social and cultural environment

<b>Issue/aspect</b>	<b>Major themes</b>
<b>Men's and women's business: gender and hospitals</b>	Mixed-gender wards are difficult for many patients. Gender of care provider: respecting patient autonomy. Gender and the role of escorts, carers.
<b>Leaving Country</b>	Leaving the safety of home Country, especially for long city stays.
<b>Adherence to clinical regimes</b>	Lack of compliance or lack of resources? Perceived cultural barriers to compliance. Reasserting autonomy in long-term admissions.
<b>Death and dying: resistance to hospital</b>	Fear of dying in hospital. Implications for carers/escorts when a patient dies. Delayed notifications and compromised consents. Going home to die.
<b>Aboriginal workers as cultural brokers</b>	Aboriginal workers fulfil broad roles. Advocacy is stressful. Being left with the burden of engagement.
<b>Capacity to accommodate cultural care</b>	Some cultural accommodation is happening. Cultural accommodation in tension with Western ethics of care.
<b>Systemic racism, post-colonial realities</b>	Stereotyping reinforces discomfort. Responding with aggression.

challenging, that she—and I said, 'look, it's not—she's never been in a room with men her whole life, let alone three white fellahs', and they said there was nothing they could do, the beds were full, once she was cleared to be moved out of ICU she'll go to her own room on the ward, and I just kept telling and telling and telling her that (RA2).

### Gender of care provider: respecting patient autonomy

Concerns about the gender of care providers have been well documented (e.g. Fisher & Weeramanthri 2002), and participants confirmed this:

If there's, say, a female patient who has issues with male nurses then generally we wouldn't allocate a male nurse to look after them and certainly wouldn't have a male nurse treating that person without a female nurse present. With the men it's a bit more difficult because obviously nurses are—highly female (MH15).

... a lot of female staff can be a problem, with the very traditional males. We try to find a male staff member, which is very important... And you can tell pretty quickly, because they are hanging on to those sheets for dear life and there is no way that any woman is going to be involved in that way... If we have someone who just won't let the [female] nurses near them we just have to get one of the doctors to do it (MH19).

However, one rural support service manager suggested that Aboriginal people sometimes make pragmatic decisions where they can see their gender preferences cannot be met. The quotes below reveal this pragmatism, but also point to possible culturally sensitive ways to deal with the difficulties of ensuring patients are treated by same-gender health professionals:

We [an aged care service] have a very culturally sensitive care model—males will shower males, females will shower females—and there's been times when we haven't been able to get a male worker—not very often but sometimes. If they're in that hospital ward they'll let a nurse do it but they wouldn't accept one of our workers going over and doing it, so it's quite strange. So as soon as they walk into the doors of a hospital they appreciate and they relinquish some of their cultural wishes and directions that they would normally demand and they were a little bit more 'okay' (RA2).

This pragmatic viewpoint was reinforced by a remote area male nurse:

You could say below the belt is men or women's business. It'd be nice if you could keep that but you've got to remember that Anangu are as pragmatic as anybody else. Now I've been involved in women's business, I've been involved in birthing and I've said to the women, 'but you know'—and they've said, 'no, we asked you, you do what you have to' because they recognise that they were getting into trouble and that. So virtually it's the person that gives you the mandate to act; if they don't give you the mandate, don't act (RA1).

He went on to explain that health professionals need to be receptive and open to patient preferences, and not make cultural decisions on patients' behalf:

... and I think one of the things is, too, as Europeans, that we don't set ourselves up to be the keeper of sacred Anangu law. It is still very much—we're aware of it, we respect it but we still listen to what the individual says, 'yes, you can help, please help me', but if they say 'no go zone', let's have a look at any alternative to make it comfortable for them. And I've got no—if someone says, 'no, I don't want you to do that for me', I don't mind finding someone else to do it... that's important, observe those cultural things as much as possible but don't ever forget that someone's also there wanting pain relief or something like that. If they say, 'look, please fix me', don't hold back and say, 'oh, no', because it's—like I said, Anangu keep their own law (RA1).

## Gender and the role of escorts and carers

At times it is difficult for Aboriginal people to take responsibility for decision making that is outside their scope of authority. The quote below illustrates the difficulties for women or men when they are asked to make decisions for family members where the issue is clearly men's or women's business. A hospital staff member recounted an example where there was the need for a graft in the genital area and the mother was present with her son:

... so she wasn't able to give consent so we had to find a male member of the community who was able to have the discussion. She didn't want to hear any of the conversation about what the procedure was going to be or didn't want to know anything about it at all because that was just not allowed to be discussed with women and that made things a little bit difficult (MH20).

## Leaving Country

### Leaving the safety of home Country, especially for a long city stay

Some health professionals recognised that leaving the safety of one's home to travel to another area, outside of one's own Country, was a fearful experience for many remote Aboriginal people, even when they were not ill, and fear is an additional barrier for Aboriginal people when they are evacuated to a city hospital during illness. Coupled with this, a long-term stay in the city is a considerable burden both to them and families left at home:

Coming onto land... that may not be your land for Aboriginal people is another great barrier. If you're from one particular tribal group it might not actually be appropriate for you to come to Adelaide according to traditional culture. You may be on somebody else's land where you have no business being and you may not have their consent to be there. I don't think that in big hospital systems we think about the small, intimate details (MH4).

Just being such a long way from their family, their culture, their community (MH10).

For the country mob to leave their Country where they are, where they live, to go to Adelaide first—for any—you know, just going for an appointment, that's fine, they can get in and out, but anything that needs treatment, needs an operation, needs long-term, looking at two weeks to months or whatever, it takes a lot out of them financially, emotionally, no stability, health, family thing, all that stuff (RA6).

## Adherence to clinical regimes

### Lack of compliance or lack of resources?

One consistent issue raised by the health professionals about the care they provide for Indigenous patients is the apparent lack of adherence to medical regimes.<sup>1</sup> Interviews with health professionals on this topic revealed a nuanced interpretation of what 'lack of compliance' might be. It ranged from grappling with understanding the motives and behaviour of the Aboriginal patients and families to a clear understanding that the non-compliant behaviour arose from a lack of resources. Our data illustrate 'lack of compliance' in many instances is better interpreted as a lack of a key resource for health, such as access to appropriate health care, transport or housing. We found that in some instances clinicians modify the clinical care they provide to accommodate such structural determinants of Indigenous health. The two quotes below provide an insight into this thinking:

It's difficult for us to determine whether they would be able to monitor their INRs [International Normalised Ratios] and Warfarin levels appropriately in their community. We have done mechanical valves and we try and avoid them; however, it would make it a lot easier if we actually were aware of—if we had a history of whether they were compliant with medication and whether they do front up at their clinics and so on (MH15).

Aboriginal children... they'll sweat from the areas that are not burnt but the other areas are difficult so it's really hard for overheating, so again we're expecting them to wear garments or gels and so on, so it's difficult. Or they need to be in air-conditioning and a lot of them don't have that sort of facility either... And the garments are supposed to be hand washed every day and looked after fairly carefully. Also the gels that we use are also needed to be washed every day (MH20).

<sup>1</sup> One hospital participant suggested that the term *adherence* is less loaded than *compliance*.

## Perceived cultural barriers to compliance

Health professionals also provided a range of cultural explanations for why Aboriginal people from remote communities appear not to comply with medical regimes. They were divided between those who assumed 'traditional culture' explained behaviour and those who saw cross-cultural interactions as problematic. For example, many clinicians acknowledged that some Aboriginal people had different views about illness causation and treatment, and that this impacted on compliance, such as through lower expectations of outcomes or a lack of comprehension of the way medications work:

Aboriginal people have a very different idea... of what causes someone to not be well and the way that they've treated things in the past is very different as well. They get the Ngangkari that comes, does what they have to do and they get better straight away... you've started them on medication [and] it's going to be 14 days before there's any effect, that doesn't quite fit in with the way that they work, so you can understand that perhaps if there's not that understanding of the way that whitefella medicine works, they might not be willing to pursue it (MH3).

Non-compliance was also defined as a response to hospital structures, Western timetables and routines. This particularly applied to children, who were presumed to spend less time in the structured environment of school and as a result to be less cooperative in hospital and to adult instructions. This was particularly distressing for staff caring for children with burns, where significant restrictions are required for optimal outcomes:

... and they're coming into a hospital environment which is extremely structured and we're expecting them to be very consistent with routines and the structure and it's often very long term with a burn injury, it's not just an injury that you can treat in five minutes, it may take months, if not years, to actually complete the process of bigger burns (MH20).

Some metropolitan staff also explained Aboriginal non-compliance by suggesting that they had different understandings of time, timeframes and accounting for the passage of time:

One thing I noticed about particularly remote Aboriginal people is they don't have a number system like we have. If you ask an Aboriginal person 'how old is your child?', they don't say, 'oh, three-and-a-half'; they'll say to you, 'well, that's a drinking child' or 'that's an eating child' or 'that's a walking child' and a drinking child is a baby breastfeeding and an eating child is an older baby who is now on solids and a walking child is a toddler. I think that when we talk about 'you must take 100 milligrams of this three times a day at seven o'clock and five o'clock and midnight'... I don't think that a lot of Western people understand that unless you've grown up being educated in big cities and Western cultures you may actually not even be able to identify with that numbering system. You often say to Aboriginal people in Alice Springs, 'okay, I'll see you at one o'clock on Thursday', so you turn up two days later on the Thursday and one o'clock and they're not there and you're 'where are you?' Well, you didn't say which Thursday and one o'clock is kind of middle of the day time so that's actually for them anywhere between about 11 and 2.30 (MH4).

## Reasserting autonomy in long-term admissions

Not all behaviour was seen as a response to fear of the unknown. Nurses suggested that some facets of non-compliance were the result of being in hospital for extended periods of time. These patients are in need of rehabilitative care, but are no longer critically ill. In such cases, patients express their frustrations through refusal to cooperate with care. Such behaviour was not confined to Aboriginal patients, and was also viewed as an act of empowerment, a way for patients to reassert control over their lives in the face of pain and strict routines:

Now that's not necessarily just Aboriginal patients, it seems to be a bit of a factor with a patient who is here for a long term with a big burn injury and again it's sort of that sense of control, they don't have any other way of controlling what's happening to them so they tend to lash out and start to refuse cooperating with treatment and we do see

quite a lot that actually get a bit aggressive as well, in terms of verbally aggressive, spitting, punching out (MH20).

## Death and dying: resistance to hospital

A number of participants, especially Aboriginal Health Workers, illustrated the ways in which large tertiary hospitals in Adelaide were seen as places where people ostensibly went for care but died away from country and kin. Resistance to hospitalisation or failure to comply with hospital routines, slowness in agreeing to procedures and family resistance were easily explained in light of these insights.

### Fear of dying in hospital

These quotes from rural staff illustrate the basis for the fear of dying in hospital:

It depends what you're down the hospital for, due to the hospital is the last place you go to, that's how most people would think, hospital's the place where you go to die and that's why most people will put off operations and all that kind of thing, due to 'okay, I'm going to have my operation, I might end up dying so I might as well stay here and die' (RS4).

One of the issues is often that the relatives don't want them to go because they've seen other people die in hospital. They see the plane go up and think they're never going to see that person again. There's an awful lot of distress with that one. Then you have also the fact that sometimes the family are not notified as well and all of a sudden all hell breaks loose (RA2).

The realities of peoples' experiences make it difficult for rural and remote health staff to recommend very ill patients be transferred to Adelaide:

If someone dies down there alone it is terrible. You have to get the body back up here and everyone is really upset... It is generally better to have sick people up here—for cancer or something (RC1).

## Implications for carers/escorts when a patient dies

Some metropolitan staff members recognised that many Aboriginal patients have specific beliefs and needs regarding death and dying and tried to accommodate these:

We have had a couple of deaths here of Aboriginals and they require certain things from the body. I think in a few cases we've managed to get Elders or somebody—I think one of the people that died, their escort was actually an Elder or somebody of high standing and gave advice on stuff that needed to be done (MH15).

Hospitals are not only seen as unsafe for the Aboriginal patients, they are also unsafe for the Aboriginal escort who may well take the brunt of the patient's death. Escorts are faced with a dilemma—one of their kin has died away from country, and they have failed in their role of caring/protecting the person from the malevolent spirits that may inhabit hospitals. Should they stay or flee the negative environment when traditionally the most appropriate action is to avoid places of evil? These quotes illustrate the problem:

The escort may run away before the person dies, we have had some who have done that, because they might not be the right person to be there and they will get the blame. And again everyone sees it different... All you can do then is notify the community and say, look this happened and they packed their bags and left, and we don't know where they are. Somehow they make their way back to the community. I don't know how (MH19).

... you get payback and all of that sort of stuff—sometimes there is, sometimes there's not, but, yeah, that's probably one of my really real concerns and what happens to the person who goes with that person and when that other person dies how are they dealt with (RS6).

## Delayed notifications and compromised consents

Aversion to hospitals can be compounded by administrative glitches whereby families are not notified of the death of their kin, or the protocols for seeking consent for resuscitation or the procedures for handling the body may not be done in a timely or respectful manner or according to protocol. This exacerbates Aboriginal people's fear of city-based hospitals as places of death and danger:

Well, there was no sort of reason, he just went and that was it. The saddest part was it took two weeks for the hospital to actually inform relatives. I know I found out two weeks later but it was a week—because I had been travelling with work and I came back here to see him and he was gone. It was like nobody actually had informed our service and I think the service reported back to me that it took four days for them to find out that he'd died. That's a significant time for an Aboriginal family group of people as well as his connections with [place] and his involvement over the years as a very vocal, strong community member who assisted in getting the funding for our building and the services—he was a board member (RA2).

## Going home to die

Rural staff also highlighted how they assisted people to return home. As the first quote below demonstrates, this is not always achieved without some recriminations directed to other staff who intervene on behalf of the patient:

I then started to discuss those issues with the doctor and the doctor wasn't happy; he said, 'no, there's no way we can let her go home. We still need to do further investigation'... Eventually he took me aside and he said, 'look, you take her home; you sign all the paperwork', and it was quite intense (RA2).

We had this Aboriginal man who was transferred out and he had terminal cancer and he had to return to us and they were concerned because he wouldn't interact with them and they didn't know what to do because his partner started wailing and they thought that she was severely depressed

and needed to be put on antidepressants... and I said, 'first of all, obviously wailing is part of all the process that's happening and the grief and the whatever and the best thing for you is to actually transfer them back sooner rather than later and let us then work with the family'. And we saw them the other day out camping, happy being back home, you know, their needs being addressed, what they want, being out in the bush—even though they've got a house in town—but just still having that part of Country with them (RH6).

## Aboriginal workers as cultural brokers

An abiding theme in this research project was the work of AHLOs in large tertiary hospitals and Aboriginal Health Workers in regional health services. Their work straddles knowledge of the administrative procedures of the health care system and the cultural tensions facing Aboriginal people. They anticipate the problems, act as advocates, and generally attempt to 'soften up' the bureaucratic system in order to humanise it for Aboriginal patients.

## Aboriginal workers fulfil broad roles

The quotes below give some insight into the breadth of their roles:

I actually went to the [hospital] myself, on my own time, and sat with her for the weekend and observed what they were actually doing for her, what benefit it was having for her health and her psychological and physical and spiritual wellbeing, and acted as an advocate for her to the nurses. So I was sort of spending maybe ten or twelve hours on the Saturday and the Sunday and what eventuated was she just continually said, 'I want to go home; I want to go home. I don't want to die here, I don't want to die away from my country'... In the meantime we're going into six weeks that she'd been away and I explained that it was—that her care, I saw, was culturally inappropriate (RA2).

... and often when family members come down one of the things that happens all the time is that the family member usually takes the opportunity to tell us, 'hey, I've got really sore teeth and I need to see a dentist' and our Aboriginal Health Workers [in a city support service] help them with that as well, so we help the family, and we might take them to Centrelink or we'll do that sort of stuff. I mean, by helping the family member you're helping the patient as well, so we do that. We work closely with Metro Home Link, who are great and will often give us money for food vouchers. We've got fantastic social workers that really know about all this sort of stuff now (MH3).

## Advocacy is stressful

The advocacy role is not without its tensions for Aboriginal workers. As Williams, Thorpe and Chapman (2003) show, the emotional labour performed by Aboriginal staff brings a high level of stress. The quote below illustrates the burden placed upon Aboriginal health staff in attempts to mediate optimum health care:

It was if something happened to her on the Flying Doctor's I was responsible and I had to explain to the family. I had to do all the waivers basically and I had to sign her out of hospital; so I did that and I sat down with the lady again and said 'are you sure this is what you want to do?' (RA2).

## Being left with the burden of engagement

Similarly, experienced non-Aboriginal health professionals can act as cultural brokers to alleviate fear and anxiety in patients. However, this requires trust and taking time to explain the procedures and their relative seriousness. Significantly, this study found that some health professionals leave all cultural matters to the AHLOs, abrogating any responsibility to engage with Aboriginal patients on their cultural terms. The burden on AHLOs was noted:

We have two AHLOs and one Aboriginal health nurse and they are just overrun, too busy to do anything except accommodation,

flights, bookings, help get money from the bank or showing them around or organising food, accommodation. They try to look after the carers as well that come down, they have to find them accommodation and all that sort of stuff as well. So they are limited in their resources and they don't really supply... many male patients with much true support really. Occasionally, if we have someone who is homesick and they are alone, and are really struggling, they [AHLOs] will go out and buy some paints and little canvas and stuff and they will do things like that occasionally but that is very sporadic (MH16).

## Capacity to accommodate cultural care

None of the participants we interviewed underestimated the difficulties of providing culturally appropriate and safe care for Aboriginal people. There was a ready recognition that it required close communication with the patient and the family, complex administrative processes, close liaison between the home community and city hospital, and funding. The quote below reveals the dilemma facing health professionals and family members at times of severe illness:

And if someone has gone down there and gets sicker and dies suddenly you have 20 people to bring back for the funeral. It is generally better to have sick people up here—for cancer or something. But some family think 'if they are really sick they should be in Adelaide'. It gets hard to know when to send them to Adelaide and when to keep them here, and what family think of it all (RS1).

## Some cultural accommodation is happening

The work of Aboriginal health and liaison workers, along with other staff, has resulted in some accommodation of Aboriginal beliefs to allay fear and anxiety. In some instances this has resulted in the incorporation of healing or smoking ceremonies to rid the environment of evil forces and restore harmony. In some

hospitals that work closely with communities, the *Ngangkari*s come in when someone has died and do a smoking to move the spirits on:

We've had cleansing in this service a few years ago where they did a whole—throughout the cardiac area, including medical as well as surgical, and it was last year or the year before they did the whole hospital (MH15).

## Cultural accommodation in tension with Western ethics of care

Despite the cultural accommodation illustrated above, particularly the work done by AHLOs, the gap between Western biomedical ethics of care and Indigenous perspectives creates a rift that at times is difficult to cross. This is not only a matter of lack of understanding on either side, but also one of ambivalence built into both cultures over the issues of patient consent. This is most obvious in the area of 'not for resuscitation' orders. Although there is a desire by all parties for people to receive palliative care in their own homes or communities, and that care not be unduly extended where it is uncomfortable, the capacity for families to sign 'not for resuscitation' orders, or for health professionals to adequately explain the outcomes, remains a complex area with no clear directions for action:

A lot of family will not—it's funny because in the mainstream world all this paperwork is sort of done when you're—on your admission process to residential care. You talk to any Aboriginal person about end of life stuff and they just back off and go 'no, no'. They don't do death well at all (RA2).

[quoting policy] 'Cultural limitations also apply as the not for resuscitation consent can invoke a blame factor resulting in pay back issues particular to Aboriginal people. The factors that place the Elder in disadvantaged situations require an advocate who is both culturally neutral and understanding these issues. The designated advocate may also act—be their next of kin for these and other reasons and to this end the following signatories will endorse a declaration in lieu of a not for resuscitation consent form.' So that's what I actually did—well, something similar, but we worked on it when I got back—for the

lady in the QEH [Queen Elizabeth Hospital] to make sure the doctor was happy that I was signing it (RA2).

Some participants noted the dilemma they faced in dealing with the differences between Indigenous and non-Indigenous beliefs around death. The solutions are not necessarily obvious and the quote below conveys some of the complexity. In this case it was impossible to allow cultural considerations to take precedence over more contemporary approaches:

She was diagnosed with cancer and she just got it in her head she was going to die—and she was, she was going to die but she might have lived longer but she probably would have been in a lot of pain—she made us take her to family for a weekly trip and said, 'drop me off on Monday and come back and get me on Saturday', and we took her to the outskirts of... a homestead. We then get a phone call from the Alice Springs Hospital, she'd been flown out—she took herself out to the bush, sat down and just wanted to die, dehydrated—but someone actually found her and had her resuscitated and sent to hospital and she got transferred back to us and she was so angry. She was a very, very angry woman. She said, 'that person—it was a white person—'had no right. I was doing something that I wanted to do. I don't want to die in hospital, I don't want to die in a bed and I don't want to be sick. It's my time. This is my culture. My grandparents did it and that's what I'm going to do'... She got herself back up there again and did it and the second time... she died out in the bush (RA2).

Although the establishment of aged care homes is a positive step in the care of the elderly in Indigenous communities, the following quote highlights new dilemmas that have emerged for Indigenous care providers, particularly when caring for those with dementia:

We're providing a really good health service and aged care service and people are living longer than they would have if they were still living in the community or out bush... but then you look at the cultural conflicts when things like dementia, high dementia, kicks in, and what conflict that causes in the cultural world. We've had experience with one resident who has been doing and saying things the wrong way but it's not him, it's just the dementia, he's not knowing what he's



doing and saying. So you kind of think about the history of people going out to die in the bush, well that would have avoided some of that too, wouldn't it, their mental capacity to know what they're doing, especially with such strong powers—and he did, he had very, very strong powers (RA2).

What is clear from the above account is that culturally sensitive care can be provided when careful attention is paid to the individual's wishes. The quote below illustrates the successful resolution of a 'good death' organised by a health professional for an Indigenous woman:

And she actually instigated it, she said to me, 'when we get home... I want you to write down everything I want so there's no arguments. I don't want to be a piece of rope, I don't want them pulling and tugging me and I want to be laid to rest where I want to be laid to rest.' And she did it, she was amazing, and it actually snowballed into—the other Elders are doing the same thing now. She wrote a stat dec [statutory declaration]—I stayed out of it totally because I didn't want to be seen as—because obviously I'd spent so much time with her—and she sat down with her pastor and an independent Justice of the Peace and she said 'I want to be buried at [place]' (RA2).

## Systemic racism, post-colonial realities

When country Aboriginal staff were invited to comment on racism in metropolitan hospitals, they indicated that the racism in these hospitals was no better or worse than is experienced in their own regions. They then spoke of Aboriginal-only sections of the local motel where rooms are not air-conditioned (RA4), of councils using dogs to move Aboriginal people from one camp ground to another (RA7), or Elders spoken to as if they were children (RA2).

[Racism] is a hard word. I feel a bit sensitive towards that word. Certainly, yes, judgments play—you hear lots of judgment or whatever. I mean, you don't hear that as much and yet they seem to generalise patients regardless of whether it's race or general judgment (MH14).

## Stereotyping reinforces discomfort

At a more subtle level, some staff noted that the labelling of Aboriginal people is pervasive and extends beyond the hospitals to welfare services and to assumptions that they all engage in excessive gambling, smoking and drinking. One support service staff member said:

there have been other occasions where... clients have those Basic Cards—and you ring up and you say, 'we want to purchase some clothing', and they say, 'yep, but there's no alcohol allowed', and there's just an assumption made that because someone's Indigenous they're going to want to buy alcohol or they're going to want cigarettes. Well, that is overt racism but luckily it's not been directed at our clients. We have, I guess, been in the firing line so we've been able to stop it and take the person down another path (MA10).

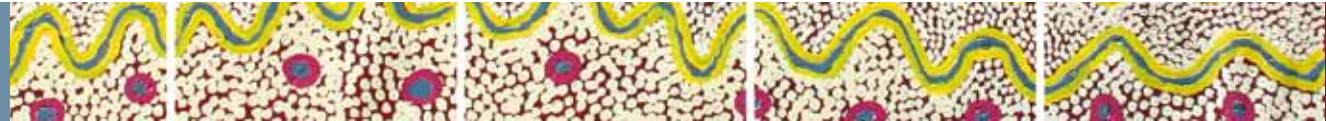
One non-Indigenous health professional noted that racist comments were sometimes exacerbated by media reports that result in all Aboriginal people being stigmatised:

And sometimes those conversations are sparked from something that's happened in the media. It could spark off someone that's on the ward. They might not necessarily be talking about Mr X on the ward. But talking about Aboriginal people or Aboriginals, they're—like they are all like that. You know... we're not... no one race is perfect so Aboriginal patients should not get generalised as much... should they (MH14)?

## Responding with aggression

Some staff also felt that there were probably cases where Aboriginal people responded to racism with aggression and as a consequence were labelled as violent. In such cases there needs to be more critical examination of the behaviour of non-Aboriginal staff:

I think other issues that perhaps Aboriginal people and staff face are—I think unfortunately there is a lot of inherent racism still alive in Australia and I think that as staff we're inclined to support our colleagues, perhaps without necessarily looking at some of the underlying motives behind why we



behave the way that we do. Staff in hospitals are very protective of people who may present to be aggressive or violent but I think it's important for staff to question—you know, is my colleague suggesting the person's being aggressive because they're being aggressive or are they just a person in distress who doesn't understand and who is frustrated and it is being perceived as aggression because of my colleague's own personal views and values about that person's race or ethnicity and I've seen situations where that's occurred (MH4).

## Conclusion

As the opening quote in this section notes, cultural differences and racism can be major impediments to Aboriginal people accessing appropriate health care. Barriers include the difficulties Aboriginal people may experience in mixed-sex wards or in receiving care from

health professionals of the opposite sex; the immense anxiety, sorrow and loneliness they face leaving their country for treatment with the possibility they may die away from home; and the boredom and coldness of the urban hospital environment. Despite these barriers, respondents reported the willingness of many Aboriginal patients and their families to comply with hospital regimes, or to adapt their practices to Western or biomedical processes, mindful that this sometimes met with unintended and unforeseen negative consequences. Similarly, we were alerted to examples of hospital staff attempting to adapt routines and procedures to Aboriginal preferences. Two clear ways forward were identified: first, strengthening the role of the Aboriginal Health Workers, AHLOs and Aboriginal Patient Pathway Officers as key personnel in building bridges between the two worlds and, second, embracing the concept of cultural safety. This approach to cross-cultural health care provides space for staff at all levels in the health bureaucracy to explore not just cultural differences but also those practices that reinforce cultural dominance and racism.

## Discussion and Conclusions

This study has shown that many staff members in both metropolitan hospitals and country health services are actively seeking ways to provide good quality care for country Aboriginal patients. The accounts of the experiences and thinking of health care staff give insight into important challenges for the health care system. This section presents a framework for the underlying causative factors of the problems staff identified, and discusses five kinds of gaps or (interacting and overlapping) breakpoints in the current system of care that impede reliably good access and continuity of care for this group of patients, with a focus on the implications and opportunities for action. It also considers the policy challenge implicit in the results of this study.

### Analytical framework: five underlying factors

Aboriginal patients from the country who come to Adelaide for care experience several difficulties in common with other groups of patients because of the impact of five underlying factors. Table 1 (from the 'Summary' section of this report, and repeated here) summarises the major interacting factors that affect this group of patients (and others), and that underlie many of the problems patients and staff encounter.

**Table 1:** Five factors that affect access and quality of care

Issue	Explanation
City/country	Some of the problems facing country Aboriginal patients and their health care providers are common to all country patients.
High burden of illness	People with chronic or complex conditions are affected more by systemic health care problems, especially across hospital/non-hospital sectors, although any patient may experience care problems.
Language	Some communication challenges that patients and staff encounter are common to all population groups for whom English is not a first language.
Financial resources	It is harder for all people who have little or no extra money to meet the costs of transport, treatment, being admitted for health care, and time off work or away from home and family.
Aboriginal/non-Aboriginal	There are ways in which Aboriginal people experience unique disadvantage in their interactions with the mainstream health system (and other social systems); and mainstream worldviews and beliefs about health and health care are often different from those held by Aboriginal people.

It is the interaction of all these underlying factors—being a country person in a city setting, having a high burden of illness and needing care across the acute/community divide, perhaps not having English as a first language, perhaps being poor, and being Aboriginal in a mainstream system—that makes city hospital care for country Aboriginal patients a unique challenge for the patients themselves and for their carers and staff. Each factor, and the interactions among them, has important implications for this group and, taken together, argue the need for explicit attention to the needs of country Aboriginal people. The commonality of some of these factors for country people, patients with chronic or complex illness, and those of non-English speaking backgrounds also underlines their importance for the health system. As one of our advisers succinctly put it, ‘if we could fix health care for Aboriginal people, we could fix it for everyone’.

## Five gaps and breakpoints, and potential solutions

### The city/country divide

All country patients are affected by distance, lack of local services, the need for appropriate transport and accommodation, and lack of coordination of care. Some Aboriginal patients experience these problems more acutely because of remoteness, financial hardship, and difficulties using metropolitan transport systems and accommodation services (SA Health 2010:20). There are two major gaps that could be addressed, and both are included as priority requirements in the SA Health (2010) *Aboriginal Health Care Plan 2010–2016*.

### Specialised care in the country

The first major gap is the lack of specialised care in the country (e.g. respiratory and renal care and cardiac rehabilitation), which leaves serious gaps in the quality and continuity of care for rural patients, including rural Aboriginal

patients. Some clinical units, and some primary care services, have found ways to ameliorate this problem, including mental health care, burns care and cardiac care providers, but it remains a major gap. This matter is on the agenda for Country Health SA (SA Health 2007) and is highlighted in the *Aboriginal Health Care Plan 2010–2016* (SA Health 2010:18).

### Transport

Transport within regions, across Adelaide, and to and from the city arose as a major access barrier for Aboriginal country patients. With fewer specialist services available in regional and remote areas, patients are required to travel further for care and investigations. Public transport schedules and clinical appointment times often conflict, with patients needing to stay overnight, increasing the cost and time away from home. This is reported to be a serious deterrent for Aboriginal patients, discouraging them from attending city appointments (Helps *et al.* 2008; Stamp *et al.* 2006), and our data support this concern.

### Accommodation

There is currently no central service to locate vacancies at Aboriginal hostels or hospital accommodation across Adelaide. This means that country providers and AHLO units spend extended periods of time ringing each hostel individually to find accommodation for patients and carers, and at times appointments are cancelled when accommodation cannot be found. These problems bring hidden costs in staff time and cancellations, which could be readily reduced through a central ‘bed state’ register.

The Step Down Units in Adelaide, Port Augusta and Ceduna have been a very positive step towards bridging the hospital–home gap, particularly for remote patients, and their value is endorsed in the *Aboriginal Health Care Plan 2010–2016* (SA Health 2010:21). Further expansion of these units in other areas, particularly Coober Pedy, the Mallee and the South East region, could be considered.

## Patient Assistance Transport Scheme

The current PATS has been interpreted differently across the state by health staff and users. Recent review has led to changes including use of prepaid bus tickets, electronic funds transfer services and improved electronic tracking of paperwork. These are positive strategies towards increased standardisation and ultimately cost savings for patients and health services. Ongoing work in this area is needed, including consideration of funding 'escort swaps' for patients who stay in the city for extended periods and of procedures to authorise additional escorts in exceptional circumstances.

## The acute/non-acute divide

The problem of lack of continuity of care between acute and primary or follow-up care providers is known to contribute to significant rates of complications after discharge (AMA 2006; Forster et al. 2003; Jorm, White & Kaneen 2009; O'leary et al. 2006). It emerges in this study as a critical breakpoint in the system, particularly affecting those who carry a high burden of chronic or complex illness, with four potential strategies for action.

## Dedicated care coordinators in clinical units

The first strategy is the role of dedicated care coordinators within clinical units that treat significant numbers of country Aboriginal patients. In the hospital clinical units involved in this study, those that reported more positively on their capacity to care for country Aboriginal patients had dedicated resources in place—a clinical coordinator and/or an AHLO to coordinate arrangements for admission, care and discharge with patients and carers and with rural staff and services. They also were more likely to have staff who go out from Adelaide to rural sites to see staff and patients.

There is evidence and policy to support this initiative. Lawrence et al. (2009) report on the introduction of dedicated liaison officers who

can actively network and communicate across service and state boundaries to ensure a smooth and complete transition of care with adequate preparation and follow up for country Aboriginal patients of the Flinders Medical Centre cardiac service. The value of such roles is recognised in the *Aboriginal Health Care Plan 2010–2016* (SA Health 2010). The data from this study also suggest that this approach works best when the coordinator is within the clinical unit.

## Transfer rather than discharge

The second strategy is a shift from the procedures of discharge to the procedures of transfer of care. *Discharge* implies the end of the responsibility of the acute sector. *Transfer* is used when patients are transferring between inpatient settings, and brings with it obligations for active handover of information, active consent by the receiving care provider (and thus mutually acceptable timing and transport arrangements) and allocation of costs. For country Aboriginal patients, the strategy of requiring effective transfer of care regardless of destination (i.e. to primary care providers if patients are going home) may be a useful one. The concept is under active consideration in Country Health SA as part of its work on the patient journey (CHSA 2009), and this concept is supported by current thinking about effective clinical handover (e.g. AMA 2006; Botti et al. 2009; Jeffcott et al. 2009) and by our results.

## Mutual knowledge of roles, resources and constraints

The third strategy is a set of suggested or actual methods to ensure better understanding of relative roles, resources and constraints between city and country services. This is one of the many roles of dedicated coordinators (e.g. Lawrence et al. 2009), and can also be assisted through improved use of information and communication technology for information sharing among city and country staff. A user-driven service directory (capable of being updated directly by staff in the relevant units rather than relying on a central resource) is one approach. Several rural staff suggested, for example, that photographs of their clinics, and the roads leading to them,

might help city staff to understand the limitations on their ability to receive discharged patients at certain times of the week or year.

## Discharge drugs and Medicare numbers

The final strategy concerns discharge drugs and Medicare numbers. Aboriginal patients living in remote areas of South Australia are provided with free medications through the S100 scheme (DoHA 2011a) and new arrangements enable GPs across the state to assist patients with chronic conditions to access low-cost medication (DoHA 2011b). However, wait times to get a GP appointment in country areas can be one to three weeks for non-urgent care (RDAA & NRHA 2010). Adelaide and regional public hospitals now charge patients for discharge medications, and some hospitals supply requirements for one week (rather than two or three weeks). Patients who do not produce their Medicare cards when they collect their discharge medications are billed for the full cost (rather than the Pharmaceutical Benefits Scheme cost), which may well be more than 100 dollars. These requirements cause additional work for staff (chasing Medicare numbers and paperwork), create worry and hardship for patients and families, and make a negligible difference to hospital budgets. A procedural solution to ensure the availability of Medicare numbers, and/or to make S100 arrangements available based on eligibility at home, could entirely resolve the cost problem. Arrangements to increase the time period covered by discharge drugs for people who face long distances and travel times (travelling home or to access GPs and community pharmacies) could solve some continuity of treatment problems.

## The language divide

A high proportion of Aboriginal patients from remote areas (80–90 per cent of those living in the APY Lands) do not speak English as their first, or possibly second or third, language (ABS 2006), and use concepts of health and illness that differ in important ways from mainstream thinking. There are two major gaps in this domain that should be addressed.

## Availability of interpreting services

One important solution to this problem, already mandated in policy (Department of Health 2006) and recognised in plans (SA Health 2010:34) but not enacted reliably, is to ensure adequate availability of interpreting services. This will cost additional money (to meet established standards), and also requires attention to recruitment and training strategies.

## Adapting informed consent procedures

The second priority problem relates to the effectiveness of informed consent procedures. This is not simply a language problem, but language and literacy difficulties compromise the capacity of Aboriginal patients to give informed consent to treatment. This problem is one that hospital and other health staff work to overcome, but it remains a concern for them. Attention to this matter, in consultation with experienced staff and community representatives, would enable the development of better approaches and better guidance for health care staff and patients in this critically important area. Protocols for pre-admission consent may be a solution.

## The financial divide

The factors that make access to good health care difficult for country Aboriginal patients also affect other groups. Difficulties are not simply the additive effect of each of the five underlying factors but, rather, a multiplier effect of their interaction, creating a vicious circle of barriers and problems, all made harder by the lack of ready cash to buy solutions and by the inflexibility of stretched public systems. The heavy total burden for this group of patients arising from their complex patient journeys argues for special funding measures designed to make the system of care more robust and reliable. This question is further addressed in the related study of complex patient journeys (see xx).

## The Aboriginal/ mainstream divide

Staff recognised the particular impact of some aspects of the hospital environment on country Aboriginal patients, particularly the need for attention to gender concerns and the problem of feeling cold. These practical concerns, along with difficulties in the direct interpersonal encounter between staff and patients, highlight the fundamental task for all participants to work in the 'intercultural space'. Staff commentary indicates this task is not systematically recognised and addressed in a practical way (although there are some inspiring examples of skill and success in this endeavour). The problems of establishing the necessary rapport and trust for good clinical care were well understood by staff. In many different ways, they acknowledged that as health care providers they can only work well in the intercultural space if they first recognise this reality, and recognise that it requires particular approaches, skills and forms of respectful acknowledgment and inclusion. Some also articulated the converse: if you don't acknowledge the reality, and therefore don't even recognise the need for skill and knowledge, you will be neither comfortable nor effective in providing care for this group of patients. There are three main opportunities to bridge this divide within health care.

### Bringing high-level policy to the operational level

The staff interviewed for this study described a wide array of responses to the needs of rural Aboriginal patients, but absent from their accounts was a sense of supportive policy and procedures to mandate and guide their work and ensure reasonable resourcing. The effective measures they reported were often supported by project funding or other 'soft' money, and were not properly embedded in the system of care. Staff reported struggling to find ways to respond to a special group of patients with particular needs, but also sensed that special treatment is not justified or supported—that everyone should be treated the same.

But the situation of country Aboriginal patients cannot be reasonably understood without acknowledgment of how it came to be what it is, and the continuing impact of the broad social determinants of health and access to health care. In the health care enterprise, the previous experiences of country Aboriginal people continue to shape their current interactions with the system, and current relationships between Aboriginal and non-Aboriginal people in society shape the way staff and patients interact within health care, with implications for the quality of the care provided. The parlous economic situation of some communities also has many implications for health care access and quality.

What seems to be lacking is an effective, systematic and sustained response. High-level statements of principle, like the *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009* (AHMAC 2004), are helpful guides, but only make a difference if the implications for policy and practice are identified and responses are systematically operationalised in health care delivery.

The release of the *Aboriginal Health Care Plan 2010–2016* (SA Health 2010) is an important step towards a systemic response for Aboriginal patients. It identifies 'establishing cultural security policy, protocols and standards in hospital and health services' as part of a priority initiative in quality and safety (SA Health 2010:34). There are two immediate practical strategies that we would add to this approach.

### The role of Aboriginal Hospital Liaison Units and AHLOs: clarification is needed

First, the contribution of Aboriginal Hospital Liaison Units in metropolitan hospitals, and the AHLOs who staff them, could be enhanced. Aboriginal Hospital Liaison Units and/or AHLOs exist in all major hospitals, often in a separate department or team located within allied health divisions. They provide support and assistance to Aboriginal patients in all areas of the hospitals. Aboriginal Patient Pathway Officers, located physically within hospitals but with reporting lines to Country Health SA, are a new addition to the workforce. Their role is to assist in improving the

coordination of the Aboriginal country patient journey. Their exact role in each location may vary.

There is wide variation across metropolitan hospitals in the structure, location, relationships, staffing and resourcing of Aboriginal Hospital Liaison Units, and this alone tends to argue for attention to the most effective arrangements. Staff generally appreciate the contribution of AHLOs, but expressed some misunderstanding of or frustration with their roles. Sometimes, it seems that AHLOs are expected to fulfil functions that are best done by staff within the clinical units. Resources from the Improving the Culture of Hospitals project give some guidance to develop the role of AHLOs in relation to quality of care.<sup>2</sup>

### The role of escorts and carers: formalise and support

Second, carers and escorts who accompany Aboriginal patients to city hospitals are a source of both help and concern for city hospital staff. There is little formal recognition of the role, resources to support it are strictly rationed in ways that can be counterproductive, and sometimes escorts are themselves too ill or otherwise not equipped for the role. However, there are ways in which carers and escorts could contribute to effective care that are helpful to staff and also respectful of the needs and limitations of the carers. Attention to this issue could include making the nature of the role and its support more explicit for all concerned, and collaboratively identifying the demands on and requirements of effective escorts (from the point of view of patients, escorts, and both city and country staff).

## The policy challenge

Potential ways to address identified gaps and breakpoints in the system of care have been discussed above, including the pervasive challenge for staff and patients of working across cultures. But the 'gap-filling' approach will only work if it is undertaken in a supportive policy and program environment. To address the serious health and health care problems facing rural Aboriginal people, it is essential that the high-level legislative and policy statements that acknowledge the need for particular attention to Aboriginal health and health care are elaborated into operational policies, procedures and programs. The mandate to do so is explicit in both the *National Indigenous Reform Agreement (Closing the Gap)* (COAG 2008) and the *South Australian Health Care Act 2008*. The *National Indigenous Reform Agreement* identifies 'fixing the gaps and improving the patient journey' (COAG 2008:B63) as one of five priority areas. Part 1:5 of the Health Care Act specifies cultural respect as the second of nine principles that should guide the operation of the health system:

Aboriginal people and Torres Strait Islanders should be recognised as having a special heritage and the health system should, in interacting with Aboriginal people and Torres Strait Islanders, support values that respect their historical and contemporary cultures.

The *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009* (AHMAC 2004:5), a national framework published in South Australia, acknowledges the need for 'improving the performance and accountability of mainstream services'. It defines cultural respect as the 'recognition, protection and continued advancement of the inherent rights, cultures and traditions of Aboriginal and Torres Strait Islander people' (AHMAC 2004:7).

<sup>2</sup> The resources are available on the Quality Improvement Toolkit page of the St Vincent's Hospital website ([www.svhm.org.au/aboutus/community/ICHPToolkit/Pages/toolkit.aspx](http://www.svhm.org.au/aboutus/community/ICHPToolkit/Pages/toolkit.aspx)) and are referenced by the Australian Council on Healthcare Standards.



While the Act and the Cultural Respect Framework, along with other policy agreements (NATSIHC 2003), provide high-level statements of goals and a mandate for improvement, they do not provide detailed guidance for hospitals, health services or their staff. Further, the documents seem to lack credible attention to the nature of the links between cultural respect and clinical care concerns. The concept of cultural safety (Ramsden 2002) may be more helpful in acute and other care settings, with its emphasis on ensuring the safety of patient care and the care environment, including the ways in which mainstream cultural practices and concepts contribute to problems for the care of Aboriginal patients. However, any such principles and policies will only work if systematically applied.

The SA Health Aboriginal Health Care Plan 2010–2016 acknowledges the need for systemic implementation of relevant policies and mandates action and reporting by regional health services to this end (SA Health 2010:21, 34). The need for systemic attention to implement policies has long been identified (see Anderson et al. 2002). More recently, the Improving the Culture of Hospitals project (Willis et al. 2010) has demonstrated a model to link efforts to improve hospital care for Aboriginal people with quality frameworks, and has contributed to the inclusion of a small number of relevant standards in the Australian Council on Healthcare Standards accreditation program (ACHS 2011).

It may be helpful to think about other major challenges for safe and effective care, such as that posed by blood-borne viruses (including HIV). While there is no equivalence in the content of these two areas, the pathway from policy to implementation may be a relevant comparison. In the case of blood-borne viruses, identification of the significance of the problem led fairly swiftly to the development of policies, programs and procedures, like the articulation of specific arrangements and requirements for universal precautions across the range of health care settings. Serious attention was also given in several operational areas—from the establishment of dedicated clinical units through to occupational health and safety to protocols for enacting privacy principles. If such an approach was pursued in relation to access coordination and quality of care for (rural) Aboriginal patients, guided by cultural respect principles, many of the practical problems for patient care that staff discussed in this study might be addressed. Examples would include arrangements for informed consent, allocation of liaison responsibilities at the right levels (including clinical units), procedures for the availability of Medicare numbers and S100 prescriptions, and protocols for the safe transfer of care.

The staff we interviewed knew the problems, and had identified and often implemented strategies in response (the perspectives of patients and carers from a parallel study are reported separately). What is needed at policy level is a program for implementation of better access, coordination and cultural safety in hospitals and health services, in governance, management and operations.

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## Attachment: Methods

This study received ethical approval from Flinders University and the Southern Adelaide Health Service Social and Behavioural Research Ethics Committee, the Aboriginal Health Council of South Australia's Aboriginal Health Research Ethics Committee, The Queen Elizabeth Hospital Ethics of Human Research Committee, Child Youth and Women's Health Services Human Research Ethics Committee, Royal Adelaide Hospital Research Ethics Committee and Department of Health Human Research Ethics Committee. Formal partnership agreements were negotiated with the Aboriginal Health Council of South Australia and all four major public health services in South Australia at the time the project commenced: Central Northern Adelaide Health Service; Child, Youth and Women's Health Service; Country Health SA; and Southern Adelaide Health Service. These agencies incorporate the public hospitals and primary and secondary health and aged care services owned and operated by the state government.

A Project Management Group made up of representatives of each of the partners and others with Aboriginal health and research expertise was convened prior to commencement of the project. The Project Management Group provided a vital source of information about issues of concern and the pattern of service delivery to Aboriginal people from the country, as well as advice to support the research team's thinking and the research design throughout this project.

We sought to interview staff who provide care for country Aboriginal patients in a range of settings (city hospitals and support services; country ACCHSs, community health, aged care and hospitals). Interviews were designed to elicit staff views and opinions about the experience of providing city hospital care to country Aboriginal patients, or referring and/or supporting or sharing care for these patients. Questions were open ended and asked participants about their experiences of barriers and the underlying causes of difficulties, and about enabling factors and strategies for improving care or overcoming barriers.

An initial literature search focused on evidence about the provision of care to Aboriginal people and other marginalised groups, models of care, standards and best practice. This existing evidence about barriers and enablers for effective care in mainstream health organisations was used as the basis for probing questions, which were used to prompt further discussion of matters raised by the interviewees. With this approach we sought to generate unguided commentary, as well as to assess the relevance of existing explanations and understandings. The interview schedule is at the end of this section.

Six clinical conditions that are the most common causes of admission (based on principal diagnoses) of country Aboriginal people to metropolitan hospitals were identified from hospital admissions data for Adelaide public hospitals—they were cardiac, respiratory, renal, birthing, injury and mental health conditions. In consultation with our industry partners, six clinical units in metropolitan hospitals that were known to admit country Aboriginal patients with these health problems, and that included all five major metropolitan hospitals, were identified and approached, along with one city support service for Aboriginal patients. In consultation with the Aboriginal Health Council of South Australia and Country Health SA, four country regions were selected on the basis of geographic spread and different degrees of remoteness, and primary health care or aged care providers in those regions were approached for interview.

All the metropolitan units we approached, and all but one of the country organisations, agreed to participate and gave good access to consenting staff for interviews or focus groups (one agency declined due to unsuitable timing). Individual staff within the hospital clinical units were identified in consultation with unit leaders, with the aim of involving staff from a range of disciplines who were experienced in providing or supporting care for country Aboriginal patients. Twenty-eight staff within the clinical units were invited to participate and all agreed to do so (22 as individuals; six in pairs). In the country, with the assistance of regional mainstream and ACCHS managers, we purposefully selected staff who were involved in planning and arranging Aboriginal patient care

and transfer to metropolitan hospitals. Of the 32 who were approached for individual interviews, six agreed to participate as individuals, six participated in pairs, and 20 elected to participate with others in four focus group discussions.

Of all those who participated (60 in total), just over one-quarter (16) are of Aboriginal background (mainly in the rural group), and one-quarter are male (mainly in the urban group). Just over 60 per cent (37) work in hospitals, just under a quarter (14) work in ACCHSs, and 15 per cent (nine) work in other services (e.g. support, aged care).

This sample reflects the relevant workforce, but may not be representative. First, no hospital-based AHLOs were interviewed, for several reasons (including not having time available). In order to compensate for this absence, JK attended several AHLO meetings, asked for comments on the issues of concern to this study and took notes of the discussions. The comments of AHLOs are discussed separately where relevant in the text.

Second, it is likely that staff with an interest in the area agreed to participate. While we deliberately sought to engage with some staff who were not overtly sympathetic to the position of Aboriginal patients, it is logical to think that unsympathetic staff would have been less likely to be nominated to participate in this study. Third, the total sample over-represents Aboriginal health care workers, a decision based on the need to incorporate their expertise and perspectives on the care received by Aboriginal patients referred by or from their services.

Staff were assured of confidentiality regarding their individual responses to the interview questions, and that the clinical units or country

locations and agencies would not be identified. However, interviewers also alerted staff to the fact that effective protection of the anonymity of their clinical units or locations may not be possible, given the specialised nature of the care they provide. All staff were offered the option of choosing to be interviewed by an Aboriginal or non-Aboriginal interviewer, in order to remove the self-censoring that often occurs in inter-cultural communication (NHMRC 2003). All non-Aboriginal staff were interviewed by non-Aboriginal interviewers (JK and EW); some of the interviews and focus groups with mixed or mainly Aboriginal participants were conducted jointly by an Aboriginal researcher (Kim O'Donnell) and a non-Aboriginal member of the research team (JK).

Interviews were audio recorded and transcribed, and coded using NVivo8 software. Preliminary data were analysed after two interviews had been conducted to identify emerging explanations. Midpoint in the interview process the research team reviewed and interpreted the data to ensure questions and the participant sample remained relevant. When all data were collected, inductive thematic analysis (Gerber and Moyle 2004) was used to explore themes, models and care practices described by country and city health professionals, and to generate deeper understanding of current personal, cultural, organisational, political and structural factors that impact on health care.

Although our focus was on care for South Australian patients, Adelaide public hospitals also provide significant levels of care for Aboriginal people from the Northern Territory, and to a lesser extent from border areas of New South Wales and Victoria. Staff included their experiences of providing care for these patients in their interview responses.

## Interview/focus group outline

Role—please explain what you do in your job.

General discussion of barriers—Can you talk about your experiences of providing care to Aboriginal people from remote regions and what gets in your way in your efforts to provide effective care?

Probe questions (to enquire further about issues on which there is research evidence, such as fear, shame, lack of resources, gender and language differences)—for example: you mentioned xx, could you talk some more about that?

Discussion of perceived causes and picking up on underlying issues—Why do you think this happens?

Probe questions regarding causes as above—some of the literature suggests that causes and underlying issues such as institutional racism, cultural differences and distance impact on health care. Can you comment on this? Also if an issue is raised—when you identify an issue, do you have any way of raising it for resolution?

Discussion of enablers—Thinking about your experience of these problems or barriers, what are the factors in your working environment that have helped to make things better?

Probe questions relating to enablers as above—some of the literature suggests that the use of interpreters, Aboriginal Hospital Liaison Officers and Aboriginal Health Workers, cultural respect policies and linking more closely with Primary Health Care makes a big difference. Can you comment on this?

Discussion of strategies—Thinking back on your experiences, if you had the power what are the important changes, in hospital care, that need to be achieved to improve the care for Aboriginal people from remote areas?

Probe questions on changes needed, or examples of good practice—some of the literature suggests that Aboriginal Community Controlled Health Services, Rural Liaison Nurses in Metro Hospitals and Step Down Units make a positive difference. Can you comment on this?







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