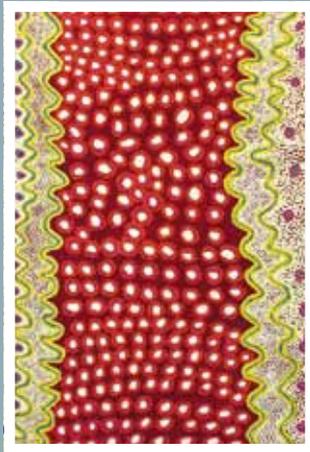


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Managing Two Worlds Together:

City Hospital Care for Country Aboriginal
People—**Project Report**



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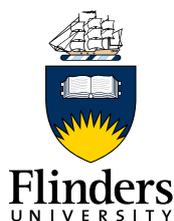
*Kuntjanu – Mingkiri
Tjuta Tjukurpa
(Marsupial Mouse
Dreaming)*

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

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Additional copies of the *Managing Two Worlds Together: City Hospital Care for Country Aboriginal People—Project Report* and *Community Summary*, along with downloadable pdfs of all six reports emanating from this project, can be obtained from:

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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 (this 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 (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/>.

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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.

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Abbreviations and Terms

AHLO Aboriginal Hospital Liaison Officer

ECG electrocardiogram

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

Project goal, scope and methods

The goal of this project is to improve knowledge of what works well and what needs improvement in the health care system 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 project is based on four separate studies:

- *Study 1—Report on Admissions and Costs* analyses the patterns of admission and length of stay of country Aboriginal patients in city public hospitals
- *Study 2—Staff Perspectives on Care for Country Aboriginal Patients* reports the views of staff who provide care for country Aboriginal patients in city and country hospitals and health services
- *Study 3—The Experiences of Patients and Their Carers* is a first-hand report of rural Aboriginal patients and their carers
- *Study 4—Complex Country Aboriginal Patient Journeys* maps four journey case studies, and analyses gaps and breakpoints in those care journeys.

Patterns of admission

Country Aboriginal patients are admitted to hospital more often than their urban and non-Aboriginal counterparts, and they often need to stay longer (hence their care is more expensive). But there is also evidence of ‘missing patients’—that is, in spite of serious health problems, some country Aboriginal patients delay seeking care, or do not get access to care in city hospitals.

Patient journeys and staff experiences

Patients and their carers spoke of many good experiences, in particular of good quality care, and of the understanding and respectful way that many staff responded to their diverse needs and priorities. They also valued the times when transport, accommodation services and the many other back-up elements of their journeys worked well, enabling reasonable access to the care they needed. The problems they spoke of occurred when these elements were not in place, or failed to connect properly, and the consequences were often serious—for their health, for them personally and for their families, and financially (for patients, families and the health system). The system of care seems highly vulnerable to breaks and gaps when tested by the circumstances of this group of patients, often in spite of the best efforts of patients, carers and staff to make it work.

The views and experiences of staff reinforced the sense of a system that functions at the edge of its capacity in seeking to meet the needs of country Aboriginal patients, so that relatively small problems (like late planes or the lack of timely interpreting services) have consequences that reverberate in cost, in lost opportunity and in poorer health. The staff interviews highlight a paradox: although some clinical units have developed very specific practical responses to patient care needs, at the health system or organisational level (and in the thinking of some staff) there seems to be a failure to acknowledge that such responses need to be reliably available. Where the system works well, responses to the complexity of the patient journey are built in.

Policy and program environment

We examined the policy and program environment in which staff and patients engage in care, and found strong, high-level policies—such as the *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009* (AHMAC 2004)—but a lack of systematic funding and programs to implement them. There are many time-limited specific initiatives (such as those funded through the Closing the Gap program), but a lack of measures to embed the results in the system of care.

Findings

1. This project found many examples of good practice, based on careful attention, creative responses to the needs and circumstances of country Aboriginal patients, and strong relationships among Aboriginal patients and their health care professionals. But these ‘best practice’ strategies and protocols are not systematically implemented.
2. This project confirms the high burden of illness experienced by country Aboriginal patients. Barriers to access mean that they are more likely to receive needed care later in the course of an illness, or not at all, as evidenced in our analysis of admissions data and in the views and experiences of patients and staff.
3. Identification and recording of Aboriginality in clinical and administrative data collections is not adequate, and the lack of reliable information impedes both understanding of health care needs and capacity to monitor improvements. Continuing attention to this problem by SA Health and all health services is needed.
4. Patients’ journeys are made harder by rigidities and gaps in the system of care, and in needed support systems. The patients (and their families/carers) undergo complex geographical and health care journeys, and this complexity is predictable due to the interaction of important underlying factors. All of these factors affect other groups of patients as well, but this group is likely to experience all or most of them. It is the interaction among the factors that makes access to good health care a complex challenge for this group of patients (and those who provide their care). The factors are summarised in Table 1.
5. The challenges of building good communication, trust and rapport in direct care interactions are significant for both staff and patients, and there are serious consequences of failure. Patients sometimes feel that their cultural values and needs are not respected, and staff sometimes struggle to communicate across differences in cultures, worldviews and experiences.
6. Coordination among care providers across geographical and sector boundaries is not reliable. When it is achieved, the benefits are real for patients, staff and organisations.
7. However, even with better coordination, support services (for travel, accommodation, coordination of physical and care journeys, interpreting and personal/family/cultural support for patients) are not adequate to need, and for some services cost is a barrier.
8. It seems that hospital systems that work reasonably well for city patients are not flexible enough for those who must travel for care. When the multiplier effect of all the barriers that impede the patient journey for country Aboriginal people is taken into account, it is clear that complexity is predictable for this group, and any attempt to improve care needs to be based on an assumption of complexity in the patient journey (as distinct from clinical complexity). Not all Aboriginal patients from the country will require tailored responses to complexity, but complexity should usually be expected.
9. Although there are many high-level statements of policy and principle to guide health care providers in caring for Aboriginal patients, there is a lack of operational policy and programs in the system of care that might support health care providers to build in reliable responses to complex patient journeys.

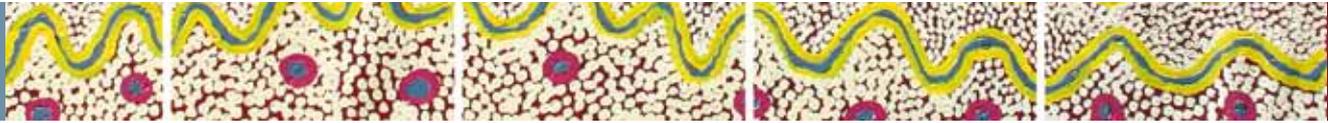
Table 1: Five factors that affect access and quality of care

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.

Conclusions

The following measures are likely to result in improvements in both the integrity of the patient journey and the effective use of health care resources.

- Approaches to improving care for this group of patients need to be based on recognition that complexity in the overall patient journey is to be expected. Responses to manage complexity should be routinely available, and ruled out only when assessment shows they are not needed. This *complexity principle* could be used as the basis for the development of operational policies, programs and protocols to enable reliable access to good care for this group of patients.
- Clinical units that regularly admit country Aboriginal patients need a dedicated coordinator role, with a focus on better pre- and post-admission preparation and follow-up. Such roles have been demonstrated to be effective elsewhere, including in relation to remote Aboriginal patients (Lawrence *et al.* 2009) and in clinical units in this project. Other clinical units need access to a coordinating resource person, a role that could be filled by Aboriginal Patient Pathway Officers or Aboriginal Hospital Liaison Officers (AHLOs), provided that a designated clinical staff member is reliably available to ensure proper communication and engagement within the clinical unit.
- Assuming that coordinating capacity is available, access and quality would be improved if the following specific measures and services were available to patients, carers/escorts and staff:
 - adequate transport and accommodation arrangements (building on the work of Country Health SA and the Community Passenger Transport network) supported by improved access to financial help with costs, including up-front Patient Assistance Transport Scheme (PATS) payments (CHSA 2011; Department of Health 2010)



- ready availability of interpreter services, and systematic implementation of the policies that require their appropriate use
 - use of pre-admission consent procedures and attention to ensuring informed consent (which may involve family and others, as well as the patient)
 - access to specialist outpatient care in regional centres, with visiting specialists working more actively with each other and with primary care providers, and backed up by use of e-health and other information technology
 - better systems to coordinate outpatient consultations wherever they occur, aimed at preventing waste and unnecessary travel.
4. The vital contribution to care made by AHLOs (and Aboriginal Patient Pathway Officers) would be further enhanced if their roles were better defined, understood and supported by both city and country staff and organisations. These workers are relied on too much to solve immediate problems in the patient journey (which should be predicted and planned for by the whole health care team) and could make a stronger contribution to ensuring quality and safety for Aboriginal patients.
 5. Support from escorts and/or family and community members is important for patients. Practical methods of incorporating family members and escorts into health care, and defining their roles properly, are needed.
 6. Attention to cultural priorities and spiritual needs should include systematic arrangements for access to *Ngangkari*, as well as making the hospital environment more friendly (through visual cues and attention to gender concerns, coldness and food preferences).
 7. Non-Aboriginal staff can and do develop skills and knowledge that help them to be effective communicators and carers across cultural and language groups. This capacity seems to require, first of all, recognition that one is ‘working in the intercultural space’ and appreciation that each of us holds cultural values and assumptions. The evidence is mounting that existing approaches to cultural awareness training are not effective. The concept and approach of cultural safety—with its focus on the essential link between culture and clinical quality and safety—may be more effective.

Next steps

This report summarises the results of Stage 1 of the project. In Stage 2 we aim to work with industry partners and stakeholders to develop further (and, where possible, test) the methods suggested in the conclusions. Success will depend on engagement by health care providers, on clinical and system leadership, and on enabling policy, programs and procedures. Health staff and units have expressed interest in being involved in work in each of the practice areas listed above. If this approach succeeds, the outcomes will be improvements in the quality of care, the integrity of the patient journey and the effective use of health care resources.

Why this Project?

The health system in South Australia is responsible for providing good care to all citizens. It is required, by legislation and policy (SA Health 2007), to respond to the particular needs and circumstances of Aboriginal people. The South Australian *Health Care Act 2008* places this obligation on the Department of Health and its health services, as the second of nine principles (Part 1:5b of the Health Care Act) states:

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 Department of Health has endorsed the *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2004–2009* (AHMAC 2004), which specifies high-level principles to guide the health system. The framework acknowledges that the health system ‘does not provide the same level and quality of care to treat illness’ for Aboriginal people, and that there is a need for greater focus on improving the performance and accountability of mainstream health services (AHMAC 2004:5). The Council of Australian Governments has reinforced the need for attention to this problem in the *National Partnership Agreement on Closing the Gap In Indigenous Health Outcomes*, which identifies ‘Fixing the gaps and improving the patient journey’ as one of six priority areas to be funded (COAG 2008:7).

This project was commissioned by the Department of Health to investigate the experiences of rural and remote Aboriginal patients who travel to Adelaide for hospital care, and the health system’s capability to respond to their needs. 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 to address the ‘symptoms’ as they manifest in so many specific ways in different clinical areas and different settings. The project aims to assist hospitals and other health services to improve their care for this patient group, based on evidence about the nature of the problems these patients experience, why these problems occur and how they might be overcome.

What is the problem?

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. The transfer of responsibility to the health portfolio in 1995 resulted in increased funding and removed some ambiguity about the role of the health system. The mainstream health system has slowly responded (Anderson *et al.* 2002), with increasing attention, to the burden of illness that Aboriginal people experience (NATSIHC 2003) and the need for effective health care.

Evidence of problems in health care

But change is patchy. Although there is evidence of increased access to primary health care in Aboriginal Community Controlled Health Services 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 (NHFA & AHHA 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 lead 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 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, Aboriginal Community Controlled Health Services 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 their 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).

Racism is a factor in marginalisation. Racism is normally defined as the belief that members of particular racial groups share characteristics that are different from (better or worse than) those of other races, and the prejudice, discrimination or differential treatment based on that belief (United Nations 1969). In Australian health care, racism can be seen in assumptions that all Aboriginal people share certain characteristics, in impaired

communication, and in failure to understand or respect the roles, beliefs, priorities and cultures of Aboriginal people—and in differential treatment based on those assumptions and patterns of behaviour (Paradies, Harris & Anderson 2008).

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 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 that recognises the knowledge of Aboriginal staff and supports them to take on this role) 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.

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.

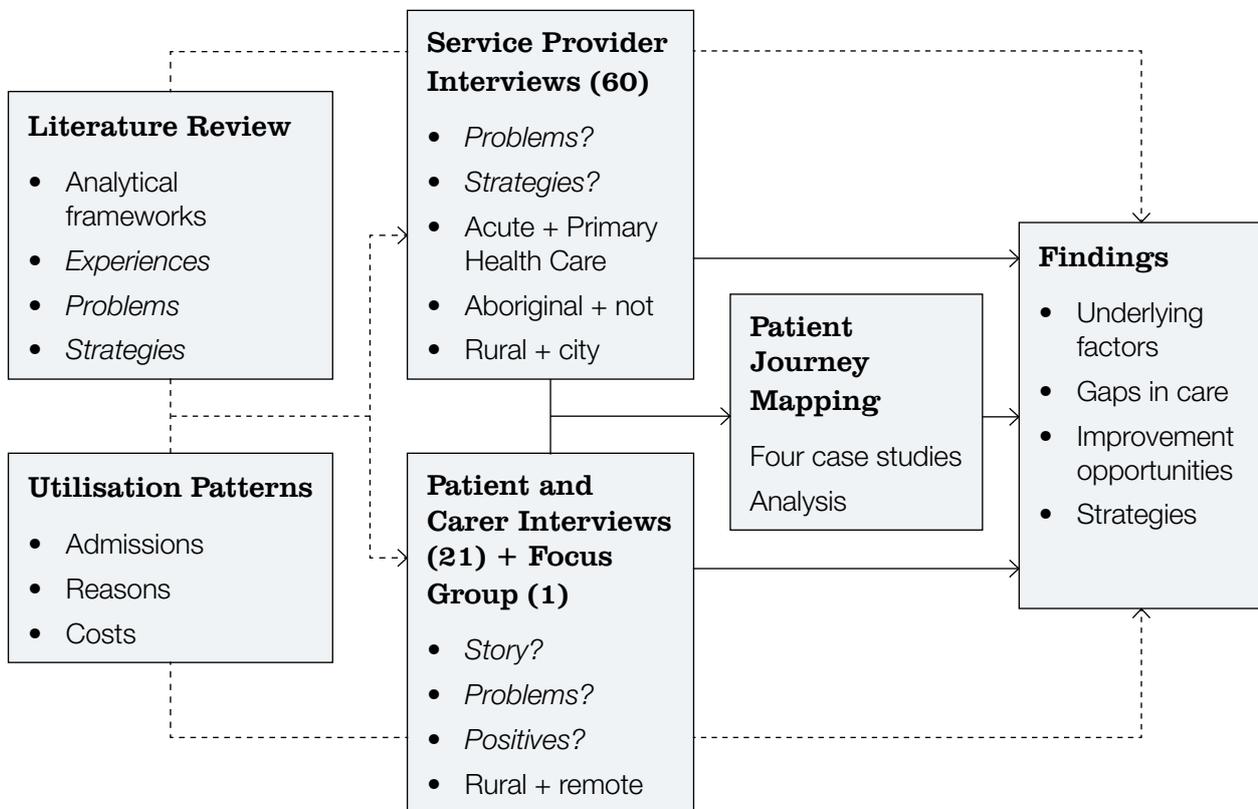
Our Approach: Project Design and Methods

The problem we set out to study is a complicated one, with many different aspects. We therefore structured the project as several linked studies using a mix of methods.

The Aboriginal Health Council of South Australia and the four major public health services at the time—Country Health SA; Central Northern Adelaide Health Service; Southern Adelaide

Health Service; and Child, Youth and Women's Health Service—agreed to participate in this project. A Project Management Group was established, with a majority of Aboriginal members, which included representatives from the health services and other stakeholders. We sought and received ethical approval from six ethics committees. The structure of the overall project is represented in Figure 1.

Figure 1: Project structure



We conducted several literature searches, the results of which are reported in the relevant sections of our reports. We examined the overall pattern of admissions of Aboriginal patients from rural and remote areas, and used this information to identify the major health problems involved. We then focused on those health problems in approaching clinical units and country health services for the staff and patient interviews.

The three qualitative studies are based on first-hand views and reported experiences of rural Aboriginal patients and their carers, and of staff who provided care for them in city and country hospitals and health services. Staff in clinical units in Adelaide public hospitals that provide care for significant numbers of rural and remote Aboriginal patients, and staff in the country and city agencies that refer patients, were asked open questions about the problems they and their patients encounter, and the strategies they use to deal with them. Patients and carers were asked about what happened when they came to Adelaide for hospital care, and about their care before and after their admissions. Based on this information, we developed a framework to analyse the sources of the difficulties experienced by patients and staff and to identify the main problems and gaps.

With the agreement of patients and carers, we chose four stories as case studies and collected other information (from health care staff involved in their care) in order to identify factors that made the patient journey more complex and those that were avoidable.

Finally, we brought together the results of all four studies to formulate our main findings and conclusions. A longer explanation of the methodology of each study is available on the project website.

Throughout the project, members of the team (primarily Dr Janet Kelly) have kept in contact with individuals and groups in the health system who are working on relevant aspects of health care, and have been learning about their work and informing them about ours. This activity, along with the involvement of the Project Management Group members, also aims to develop the working relationships that will be needed in Stage 2 of this project. Stage 2 will aim to test and/or develop some of the strategies that are suggested by our findings in Stage 1, some of which are already in development, being trialled or have been implemented.

Aboriginal Patient Admissions to City Hospitals

We analysed two years of data on admissions of Aboriginal people from country South Australia to public hospitals (2006/07 and 2007/08). Data were provided by SA Health from the Integrated South Australian Activity Collection (ISAAC). The analysis of adult admissions focused on eight health problems that are the most common reasons for admission to city hospitals (278 of 2714 admissions), while the analysis for Aboriginal children included 363 admissions for the four most common health problems (72% of all admissions).

The main findings from this analysis are presented below. A more detailed report (*Managing Two Worlds Together: Study 1 – Report on Admissions and Costs*) is available on the project website.

Data quality problems

Indigenous status is often not recorded, or not recorded accurately, by hospitals and this makes the data much less reliable. Further, the number of admissions for the conditions we focused on was quite small, which makes some analysis unreliable and reduces our ability to determine when differences between Aboriginal and non-Aboriginal people are statistically significant (i.e. when they are highly unlikely to be due to chance variations). Staff in hospitals sometimes find it difficult to ask questions about Aboriginality, and hospitals are working to address this problem.

Adult admissions

High reliance on country hospitals

Aboriginal South Australian adults (not just those living in the country) are much more likely (6.6 times higher rate) than non-Aboriginal people to be admitted to *country* hospitals for the eight conditions, and are also more likely (1.9 times higher rate) to be admitted to *city* hospitals. The relatively high reliance on country hospitals compared to the pattern for non-Aboriginal people indicates barriers to access to city hospitals (as well as problems with identification of Aboriginal status, which are likely to lead to under-counting of Aboriginal admissions, particularly in city hospitals).

Admissions to city hospitals

There were 2714 admissions of Aboriginal adults from country areas to city hospitals in the period. One-tenth (10.1%) of these admissions were for one of the eight selected health problems examined in this study (circulatory disease, digestive disease, endocrine disease, genitourinary disease, injury, kidney disease, mental health and respiratory disease). These disease groups accounted for the same proportion of non-Aboriginal admissions (10.0%).

The rate of admissions for Aboriginal adults was substantially higher (65%) than for the non-Aboriginal population. The Hills Mallee Southern SA Health region had a significantly higher than average admission rate for Aboriginal people, and the South East region had a significantly lower rate.

Admissions for particular health problems

There were 70 admissions of Aboriginal people for mental health conditions, a rate almost five times that of the non-Aboriginal population. Notably, no admissions were recorded for Aboriginal people aged 60 years and over. Rates in the Northern and Far Western region were lower than those for non-Aboriginal people.

The rate of admissions for respiratory disease (46 admissions) was twice as high for Aboriginal as non-Aboriginal people, with substantially higher rates at older ages, more than five times those in the non-Aboriginal population. People from the Eyre region had a rate of admission more than twice the average of the overall Aboriginal admission rate.

Aboriginal people from the Hills Mallee Southern region, and those from the Inner Regional remoteness category, had significantly higher admission rates for circulatory disease than non-Aboriginal people from those regions.

Cost of admissions

The *average cost per admission* was significantly higher for Aboriginal people than non-Aboriginal people overall (27% higher for the combined disease/condition groups) and for admissions for circulatory disease (54% higher).

Average length of stay

The average length of stay per admission was longer in the Aboriginal than non-Aboriginal population, both overall (23% longer) and for admissions for circulatory disease (32% longer). The actual number of days was 5.96 days compared with 4.84 days for all condition/disease groups combined, and 5.47 compared with 4.13 days for circulatory disease.

Admissions of Aboriginal children (less than 16 years old)

There were 505 admissions of Aboriginal children aged less than 16 years from country areas to city hospitals in 2006/07 and 2007/08. Almost three-quarters (71.8%) of these admissions were for one of the four selected health problems examined in this study (acute upper respiratory infections; low birth weight/short gestation; injury, poisoning and other external causes; and intestinal infectious diseases). However, these disease groups accounted for a much lower proportion of non-Aboriginal admissions (38.7%).

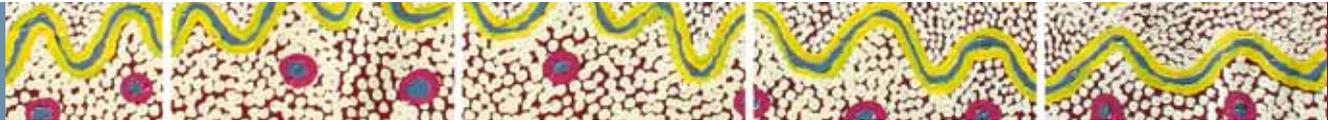
Admission rates of Aboriginal children for these health problems were 67 per cent higher than for non-Aboriginal children. But admission rates for Aboriginal children for all health problems were lower than the admission rates for non-Aboriginal children (90%). This finding suggests that either Aboriginal children do not need as many admissions for other health problems, or that they are missing out on many admissions. Again, poor identification of patients as Aboriginal is also likely to be an issue.

High admission rates for younger children

Of all admissions for these health problems, 81 per cent of Aboriginal children were aged 0 to 4 years, compared with 53.9 per cent of non-Aboriginal children.

Admissions from different regions

Admission rates varied by region, with Aboriginal children in Eyre having a 57 per cent higher rate compared with the overall Aboriginal rate. Aboriginal children in the South East and Hills Mallee Southern regions had lower rates (65% and 37%, respectively).



Admissions for particular health problems

Of admissions for the selected conditions, those due to injury, poisoning and other external causes comprised the greatest proportion of all admissions for both Aboriginal (51.5%) and non-Aboriginal children (54.0%). However, admission rates for these conditions were 59 per cent higher for Aboriginal children than for non-Aboriginal children, with a much larger differential in the 0 to 4 year age group.

The largest difference in admission rates between Aboriginal and non-Aboriginal children was for acute upper respiratory infections, with the rate for Aboriginal children just over twice that for non-Aboriginal children (mostly of children aged 0 to 4 years in both groups). Aboriginal children in the Eyre and Wakefield regions had the most elevated admission rates (more than eight times and more than six times respectively).

Admissions related to low birth weight/short gestation were 79 per cent higher for Aboriginal than non-Aboriginal children.

Admissions for intestinal infectious diseases were 50 per cent higher in Aboriginal than non-Aboriginal children. Admission rates were highest for Aboriginal children from the Eyre SA Health region (almost twice the level expected for this population, and more than seven times that for non-Aboriginal children in the region). Rates for Aboriginal children in very remote areas were more than 50 per cent higher than those for non-Aboriginal children.

Length of stay

On average, country Aboriginal children admitted for the four health problems stayed in hospital 49 per cent longer than non-Aboriginal children (6.7 days compared with 4.5 days). The greatest difference in average length of stay was for intestinal infectious diseases (more than two-and-a-half times), and the difference was 50 per cent for acute upper respiratory infection.

Patient and Staff Experiences

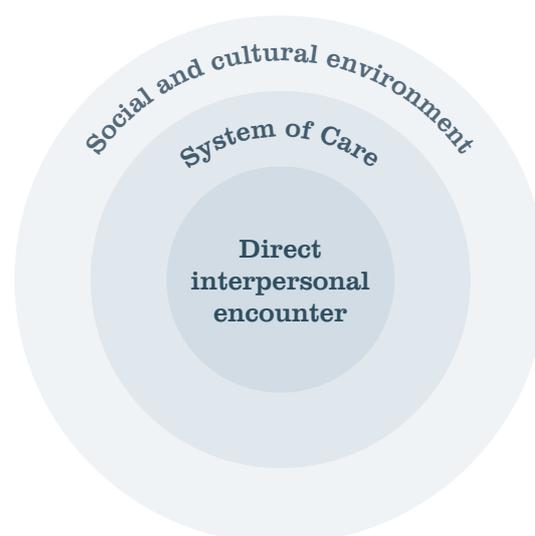
We interviewed 60 staff—about half from metropolitan hospital clinical units and about half from country health services. We asked the staff open questions about their experiences of providing care for country Aboriginal patients (description, barriers and enabling factors). We then interviewed 21 patients and carers, and conducted a focus group with eight Elder women, and asked them to tell the stories of their experiences.

The main findings are presented below: more detailed reports (*Managing Two Worlds Together: Study 2—Staff Perspectives on Care for Country Aboriginal Patients* and *Managing Two Worlds Together: Study 3—The Experiences of Patients and Their Carers*) are available on the project website.

There was a remarkable level of consistency in the main themes discussed by staff and by patients/carers, and some important differences. We analysed the two sets of interviews separately (using the software program NVivo and inductive analysis), and then compared them. Interviewees talked about issues in three domains: the direct patient–staff encounter, the care system (access and quality of care), and the social and cultural environment in which care happens. This simple structure is represented in Figure 2.

Patients and their carers spoke of many good experiences, in particular of good quality care, and of the understanding and respectful ways that many staff responded to their needs and cultural values. They also valued the times when transport, accommodation services and the many other back-up elements of their journeys worked well, enabling reasonable access to the care they needed. The problems they spoke of occurred when these elements were not in place, or failed to connect properly, and the consequences were often serious—for their health, for them personally and for their families, and financially (for patients, families and the health system). The system of care seems highly vulnerable to breaks and gaps when tested by

Figure 2: Three domains of factors affecting health care delivery



the circumstances of this group of patients, often in spite of the best efforts of patients, families, carers and staff to make it work.

Staff interviews indicated widespread recognition and energetic attention to the challenges of caring for country Aboriginal patients, as well as some lack of response and empathy. The views and experiences of staff reinforced the sense of a system that functions at the edge of its capacity in seeking to meet the needs of country Aboriginal patients, so that relatively small problems (like late planes or the lack of timely interpreting services) have consequences that reverberate in costs, in lost opportunities and in poorer health. The staff interviews highlighted a paradox: although some clinical units have developed very specific practical responses to patient care needs, at the health system and organisational level (and in the thinking of some staff) there seems to be a failure to acknowledge that such responses need to be reliably available.

The main themes in the interviews with patients/carers and with staff are summarised below in relation to each of the three domains. Codes in brackets at the end of quotes indicate the speaker.

Patients and/or carers are labelled:

- **P** (patient)
- **C** (carer)
- **PC** (patient carer) or
- **FG** (focus group)

Staff are labelled:

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

The direct clinical interaction domain

The relationship between patients and their health care providers is the foundation of care. Most participants discussed both positive experiences and the particular challenges they face when that relationship requires communication across cultures, geography and life experiences. This central challenge was summed up by one rural staff member using the concept that gave us the title for this project: 'It's like managing two worlds together, it doesn't always work' (RA2).

Patient/staff interactions

The majority of patients and carers spoke of experiencing positive interactions with most staff, but negative experiences with a minority of staff members. This difference was initially explained by patients and carers as differences in personality and approach, but they also reflected on deeper issues of basic communication skills,

respect and cultural safety. Some patients and carers had only positive experiences, while others reported being shamed, disrespected or frightened:

I had no problems while I was in there. The staff were really good. We got looked after really good, perfectly (C2).

Some might be racist or some might be good; you get things like that (P5).

The big doctor came around with his group and told me to close my mouth as I didn't need to breathe through it. Easy for him to say. He said that to me in front of all the other students (PC24).

Most staff recognised the need for skill and knowledge in intercultural communication, while some seemed not to recognise that this challenge was relevant to their clinical care role. Staff commentary focused on the importance of building trust and rapport, the challenge of communicating clinical information across cultures, and the consequences of communication failure:

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 sure you see them every day (MH6).

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).

Do they really understand in the first place, these tablets you have to keep taking forever... The ramification... if they have a stent it's reocclusion, reinfarction, possibly death... depending on their diagnosis... it has huge negative consequences (MH16).

I just have to say that I really don't... communicate very well with the women, and that is just a fact of life (M23).

Cultural safety

Patients and carers were asked how they felt staff responded to their needs as Aboriginal people. Again, their experiences were mixed:

Our experience has been very positive. We didn't encounter anything negative based on being Aboriginal. You have your radar on when you go somewhere new, and there was nothing to detect (PC23).

Every time I called the nurse, like it takes a bit long time and I notice that every time the other lady, the white woman, do the button they really come quick (P5).

Staff spoke of their discomfort in intercultural relationships, and the need for knowledge and skills:

I think you can get stuck on blame to the point where it becomes quite destructive and people... they're too scared to ask questions any more... too scared to do anything really because it's deemed as racist (MS1).

I wonder whether it's also 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 (MS10).

Strategies

Some patients and carers felt that their own knowledge and abilities were important in helping them to negotiate care, and others appreciated the practical and cultural support they received from AHLOs:

I thought I was treated better than somebody else, only because I asked questions and... when they asked me anything I was able to answer them back (P9).

Aboriginal staff work in there, they come and spend most time with us, talking to us or if we need anything give them a buzz. Makes us a bit comfortable, someone there talking to us instead of waiting for the nurses all the time (P5).

Staff focused on the importance of knowledge and relationships:

Yeah, I think having a bit of a knowledge of the things that are challenging... 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).

I think it's just really about being enquiring and polite, just as you would with anyone else, and not presume... (MH7).

Some staff expressed recognition of the importance of cultural safety, but others did not seem to recognise a particular need:

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).

... 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 [is] I think one of the most dangerous things (MS1).

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

In short, patient experiences were largely positive, but shaming, discrimination and communication failures were serious problems where they occurred. The difficulties of establishing trust and good communication across cultures, 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 staff. 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 some 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).

The care system domain

Access to care

Statistical analyses of the admission rates of Aboriginal and Torres Strait Islander 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, and yet 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). Evidence from this project regarding the much greater reliance by Aboriginal people on country hospitals reinforces concern about access to city hospitals.

Transport, accommodation and cost are major barriers

Access to affordable transport and accommodation was the most significant concern for patients and carers travelling to the city for care, and staff interviews mirrored these concerns:

I wouldn't like to see anybody else go through what I've been through with this sort of transport and worry of getting him there. At times he said, 'oh, don't worry about it, I'm not going to appointments. I can't get down, not going' (C6).

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).

Support services assist to varying degrees, but strict rules and administrative requirements create barriers. The majority of patients stayed with family or friends, with others seeking affordable options in Aboriginal hostels and Cancer Council accommodation. Many people on pensions or low wages, and those experiencing chronic conditions, struggled financially to purchase medications and make trips to Adelaide for health care:

The thing is you've got to come up with the money for the travel first and then apply for the funding afterwards and that doesn't help much, especially when you're only on a pension and we've got rent to pay, we've got bills to pay, we've got kids to look after. Putting petrol in the car, which is \$75... (P1).

The role and health of carers and escorts

Carers and escorts were supported by hospital staff to varying degrees, with some becoming part of the care team and/or strong patient advocates. Support was appreciated:

The staff were very supportive. My grandson is four years old and they brought out a bed so I could be with him. The nursing staff arranged for me to have meals when the trolley came around, help yourself they said, order what you like. I could go and get a cuppa from the kitchen (C2).

Staff recognised 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:

[Patients who have escorts or carers] 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).

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

Interpreting services are not adequate, with implications for informed consent

Interpreters were offered to some patients, but not to others, and patients' abilities to understand complex medical concepts were often overestimated. Uncertain capacity for informed consent, and lack of access to interpreters to assist with consent procedures, is a significant problem for patients and staff. Patients with a good command of English, access to written information and the ability to keep asking staff questions were best informed.

I was quite happy with all the information that I received (P12)

There's a couple of times when he had to have things done to him, we weren't told what or why that was done (C6).

Now what an x-ray on my chest has got to do with my back... He didn't explain it to me, nothing was explained to me. My wife asked why did I have to get an x-ray on my chest, he didn't answer (P3).

Care delayed or foregone

Several staff in this study expressed concern about patients with certain conditions, and those who were 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 successful strategies to address these problems were also highlighted, including the Corporate Shuttle Service (which transports outpatients between accommodation and hospitals) as an important gap-filler. But for some patients the combined effects of access barriers led to their decisions to delay seeking, or not to use, city-based health care.

Coordination and quality of care

Both metropolitan and rural staff recognised the important problem of coordination between health services—city and country, primary health care and tertiary, and Aboriginal and mainstream—for the care of country Aboriginal patients.

City staff lack needed information about patients

Problems for patients moving between hospital and community-based care predominated in concerns about coordination and continuity of

care. Lack of information about referred patients and lack of knowledge of other settings and their constraints are a problem for staff:

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).

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).

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).

Lack of coordination is expensive in human and financial terms

Patients and carers highlighted the difficulty of coordinating transport and hospital appointments and the apparent lack of understanding of most city services and staff of the need to accommodate this:

People in the city understand that you come from the country, but they don't understand exactly what that means, that you might need to catch a bus at a certain time to get back home or else have to stay another night. Sometimes you have to really push to get appointments on the same day. They say, oh, why (PC24)?

Within each setting, staff make unreliable assumptions about the roles of other care providers. Coordination among health care providers was effective in some areas, and patchy or non-existent in others. In some cases patients experienced unacceptable delays due to poor communication and lost results. The need for better use of technology, and for someone to be responsible for coordinating the overall patient journey, is clear:

There's no sort of preparation or there's no arrangements for Aboriginal people, 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).

it would also be good if we could access the electronic data manager... 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).

One woman with a broken arm travelled 500 kilometres for an x-ray and then returned home while waiting for an appointment. After some weeks, a... worker rang on her behalf and found that the x-ray had gotten lost. This required a local GP appointment and another x-ray and another round trip of 1000 kilometres. After another long delay the... worker rang again. After nine months the woman saw the specialist who said that her arm has now healed and she doesn't require surgery. However, her arm has healed with a large lump along her forearm and her functional ability has greatly reduced (FG1).

The hospital environment is sometimes cold and lonely, but good care is appreciated

Some patients found hospitals cold and lonely, with little personal or cultural support for gender and spiritual needs. Others just appreciated getting well and the environment did not matter:

Yeah, wanting another blanket and they're too frightened to ask for it (P3).

We had to use the one toilet and bath between us. I didn't like the idea of going... to the toilet and there's a man in there. It would be better if it was all women, have a women's ward or whatever. I walked in once and a man was on the toilet seat (P9).

I sort of just go along as per normal. No, I didn't have any special needs (P12).

They know me now and I have no worries about going down. This is the first time I have felt good for a while. The doctors and nurses there, they changed my life this year. I like it down there. The staff there say, 'Mrs [X], don't say you are back again', joking and welcoming me in again. Hospital is a good place to be (P4).

Discharge or transfer of care?

Some patients and carers experienced well-coordinated, collaborative and supported discharge and follow-up processes by city hospitals; others had disjointed experiences, with little consideration for home conditions or follow-up care. Local primary health care services, particularly the Aboriginal health service and/or GPs, played a major role in coordination and ensuring follow-up through a more holistic approach to case managing patients' health care journeys.

Yes, with my daughter, it is good. The doctor and specialist send all the information to the GP at the Aboriginal health service. The intern checked the GP's name and contact details before I left the other day. They also said I or she can ring them at any time to ask questions (PC23).

The Adelaide doctor sent a letter to my GP saying that I had my operation done but nothing else. There is a huge gap, not much follow-up. I have been left to my own devices a lot. I will have to go back and see the surgeon [In Adelaide] again and ask him what my options are (P7).

One staff member suggested that transfer of care might be a better approach:

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).

The distinction between transfer of care (which 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 many potential benefits—e.g. it could address the problem of inadequate access to medicines during the discharge period and the risk of serious health consequences—but would also bring additional costs for transferring agencies.

Social and cultural environment domain

The concerns of patients and carers were different from those of staff in this domain. Patients and carers focused closely on the importance of family support, and on the personal and family impacts of injury and disease. Staff spoke more of the challenges of responding to Aboriginal cultural ways and concerns in the health care setting. But both groups spoke about the impacts of racism and the realities of post-colonial Australia.

The importance of family

Patients and carers stressed the importance of having family nearby, or in contact via telephone. Family members provided patients and carers with much-needed physical, economic, social, spiritual and emotional support. Country family members travelled long distances to maintain contact. Some carers discussed extensive periods of time caring for family members:

My nieces in Adelaide came to visit. Family makes a lot of difference. If I was on my own I would be thinking, thinking. But when family and friends come and visit it is alright (P4).

I was giving him his insulin and patches for pain, the nurses taught me how to do it. I used to give him his insulin every morning, give him his shower, bath, I did all that. It was just another—like a routine for me. I feel lost now because I miss all that, really (C6).

Staff also spoke about the problems for patients of leaving the safety of their own country, and the burdens of long stays in the city:

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

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).

Responding to cultural concerns

A major concern raised by staff was the impact on Aboriginal patients of being in an environment of different cultural norms and expectations about gender:

[Some of 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).

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).

They also noted the problems some Aboriginal people experience in adhering to Western medical clinical regimes:

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 which 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).

Staff spoke of some flexibility to respond to cultural requirements, but also noted the difficulties of reconciling cultural ways with Western ethics of care:

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).

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).

Death and dying

Patients and staff spoke extensively about patients' fear of dying in hospital, and the challenges when a patient dies away from home:

She died in Adelaide and I had to bring her home then. I was looking after everybody else and calming them down and whatever else and the day they buried her I went crazy, I think it all just came out then (PC21).

When my son died, they come over and asked us to turn the machine off and everything and—but they were good. They give me a room, they let all my mob stay in one big room and they were good to talk to (PC21).

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).

Going home to die was a frequent concern (and caused some stress between staff):

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).

Aboriginal workers as cultural brokers

Staff commented on the difficult and broad roles of Aboriginal workers in the system, including the stressful nature of acting as a patient advocate and of being left with the burden of engagement with Aboriginal patients when clinical staff withdraw:

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 (RA2).

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 not many male patients with much true support really (MH16).

Post-colonial realities and systemic racism

Some patients and carers discussed how racism and colonisation impact on their approach to health care:

There's a lot of things that went on with Aboriginal people. A lot of times they just guess because you are an Aboriginal person... if you've got hepatitis or something like that they put it down as being an alcoholic... (PC22).

A number of metropolitan staff expressed concern and frustration at the lower utilisation or engagement with mainstream services by Aboriginal people, but also 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... 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).

It is not just a difference in culture that makes it difficult for Aboriginal people. Cultural and historical factors are intertwined, so that a violation of a cultural norm risks reinforcing misunderstandings that exacerbate racism and contribute to Aboriginal people experiencing hospitals and the attendant health care as culturally unsafe for them (Polascheck 1998; Ramsden 2002).

Despite these barriers, staff 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. 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, strengthen 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, a strategy can be found in the concept and approach of cultural safety. This approach to cross-cultural health care provides space for staff at all levels in the health system to explore not just cultural differences, but also those practices that reinforce cultural dominance and racism.

Case Study: A Complex Patient Journey

As Aboriginal country patients negotiate their care journeys, complexities arise, and the health system's response to these complexities is a major determinant of those journeys and their outcomes. Although clinical complexity is often present and already assumed, complexity of the country Aboriginal patient journey and the care system is often overlooked, particularly in city settings. This leads to patients, their families, communities and local country health services (as well as hospitals) bearing avoidable costs of complexity.

A detailed report (*Managing Two Worlds Together: Study 4—Complex Country Aboriginal Patient Journeys*), including information about the methods we used to map several patient and carer journeys, and the results, is available on the project website.

The following case study illustrates the complexities.

Flying blind: the patient's story

An older woman, an Elder in her community and a resident in an aged care facility, had been blind for some years. Encouraged by staff to find out if her vision could be restored, she attended a local Aboriginal health service GP in 2009 and was given a referral to see a specialist in a major regional town. After a six-month wait she travelled for six hours by road to her appointment, travelling with a carer and a driver. On arrival, she was informed that the referral was out of date, and she would not be seen until she had a new referral. She returned home for another GP visit and another referral. Finally, she saw the specialist, who said that her eye condition was beyond his ability and he referred her to an Adelaide specialist.

After much encouragement and support by aged care staff, the woman flew to Adelaide for assessment, with a companion and the aged care manager who interpreted for her. It was determined that one eye could be operated on. They returned home to wait for a surgery date. Two surgery dates were made and then cancelled in late 2010, leading to excitement and then disappointment for the woman. In January 2011, after repeated calls to the city without a positive response, the aged care registered nurse rang the local Member of Parliament and explained the situation. By that afternoon, a surgery booking was made for five weeks time.

The surgery date was set with pre-admission checks in the same week. Based on earlier experiences of problems with transport, interpretation and consent in the city hospital, the aged care staff were cautious. The patient would not be able to fly after eye surgery, so the aged care bus, with a carer and driver, was arranged. The trip took 12 hours and everyone arrived exhausted. There were three pre-admission clinic appointments the next day, which took all day. The aged care manager, anticipating that there may be difficulties, arranged for an interpreter already known to the patient to attend, but the experience was still unsettling for the patient and carers.

At one stage a repeat electrocardiogram (ECG) was ordered because the copy of the ECG sent did not have a legible date. The patient refused to have the ECG because she believed there was nothing wrong with her heart, spiritually or physically. In view of her refusal, the hospital rang the aged care facility and asked if the date was visible on the original. It was, and a copy of the ECG was faxed with the date clearly showing. The next day the woman returned for x-rays and then went back to the motel to rest. Another carer, who was more familiar to the patient,

spoke her language and knew the hospital, was called to assist the next day for surgery preparation and post-operative care.

Pre-operatively, the patient did not understand why she should take her underwear off for eye surgery and was unhappy at wearing a gown. At one stage there were four men (orderlies and nurses) around her, trying to lift her onto the trolley. She couldn't see them, but she could hear them and feel them getting closer. The only thing she knew about white men was that they were not to be trusted. She became more agitated and began to yell at them, to keep them away. The hospital staff were unable to work with her, as they saw her as uncooperative and violent, and they advised that they would cancel the surgery.

The carer intervened and said that if they would just give the two of them time and space the patient would get ready and get herself on the trolley with the carer's assistance. The woman was reassured and got changed and onto the trolley slowly and carefully. The carer covered the woman and pulled back the curtains and called the hospital staff back in—they seemed surprised at how well the two had worked together. The carer said that an anaesthetist, who had watched what was happening, came up quietly and asked the carer if everything was alright. They discussed together the need for something more than local anaesthetic and the carer assisted while a drip was put in, and promised to meet the patient in recovery.

After six hours, the patient awoke in recovery with bandaged eyes and called for the carer, who came to her bedside immediately. The carer said that she was asked by the recovery staff if she was alright being with the woman. She said, 'yes, of course', and then saw written on the case notes, 'warning—violent patient'. The patient was transferred to a ward and the carer stayed and assisted with her care until the patient fell asleep. The carer then slept in the chair until about 3 a.m., when hospital staff brought in a fold-out bed.

During discharge the next day, the city ophthalmologist requested the patient return in a week for an eye check. Ignoring the woman's refusal and the carer's explanations of the

impossibility of this arrangement, he asked the nurse to make the appointment. The patient returned home with no intention or real possibility of returning in a week's time. Fortunately, an outreach ophthalmologist happened to be visiting the remote town the following week and the local Aboriginal health service arranged for him to see this patient.

Health system response: built in or reactive?

The additional costs of complexity of the country Aboriginal patient journey are often met by patients, their families and carers, and local health services. Local Aboriginal services are not funded to send staff members as escorts, and occasionally PATS reimbursements do not occur due to confusion and communication difficulties. In this case, the saving in attending the visiting ophthalmologist locally with a staff member, rather than returning to Adelaide, was estimated to be at least \$5000. Investing in improved protocols such as timely and coordinated referrals, pre-admission consent procedures and interpreter services would further improve the efficiency of existing investments in the health system.

This case study illustrates that hospital and support service arrangements which work reasonably well for city patients are not responsive or flexible enough to respond to the complexities encountered by country Aboriginal patients. When country Aboriginal people need city hospital care, their patient journeys are highly likely to be complex, due to the impact of the five underlying factors, combined with the well-known complexities of the health system. Although *clinical* complexity is often present and already assumed, complexity of the *Aboriginal country patient journey* and the *care system* is often overlooked. This means that patients may miss out on needed care, experience poorer quality of care or face unnecessary additional stress. Patients, their families, communities, hospitals and local country health services

bear the (sometimes preventable) human and financial costs of complexity in unpredictable or unmanaged ways.

This is a difficult problem that requires both the availability of highly specific interventions and support services that can be tailored to needs, and a general method of identifying needs and planning and coordinating responses. We suggest, below, that the *complexity principle* provides the basis for general responsive capability and that a set of specific interventions and services provide the methods (noting that most of these need to be adapted for each clinical unit or stream). Finally, the question of how to fund improvements is addressed.

The complexity principle

Although not all country Aboriginal patient journeys require tailored responses to complexity, complexity should usually be expected. The results of this project indicate that complexities are currently managed in one of two ways:

- in a planned and responsive approach, in which complexity is predicted and responses are ready
- by managing problems and crises as they occur, and otherwise using ‘business as usual’ principles.

The first option is based on prediction and preparation for patient journey complexity, specifically the possibility that some patient journeys will be very complex and the certainty that, on average, country Aboriginal patient journeys to city hospitals will be more complex than other patient journeys. The outcomes (for the health system, other organisations and patients) of the planned approach to patient journey complexity tend to be better, as we observed in the results of interviews with staff. In that study, we identified three clinical units in which complexity was expected and responded to. In each, a significant number of country Aboriginal patients were cared for, and each had a specific coordinator role that was part of the clinical team. The people in these roles were responsible for working with hospital, primary health care and support services to plan for and bring together the needed responses to the complex care journeys these patients experience.

Coordination of these complex journeys is an ongoing prerequisite for good care, but not all Aboriginal patients who are admitted to city hospitals require special arrangements. What is needed is the capacity to tailor responses according to the predictable complexities. In clinical units that treat significant numbers of country Aboriginal patients, this capacity relies on a dedicated coordinator role (full- or part-time). For clinical units that admit a small number of country Aboriginal patients, coordinating capacity could reside in the hospital-based AHLO and/or Aboriginal Patient Pathway Officer team—provided that an identified member of the clinical unit team takes responsibility for communication and liaison with those workers.

Interventions and support services

Analysis of this and other case studies identified eight important interventions in the system of care and support that could have made a difference:

- access to specialist care in regional centres and arrangements in outpatient services to accommodate people who travel long distances to attend (coordinated scheduling of appointments, flexibility for unavoidable late arrivals)
- use of e-health technologies to reduce travel requirements and delays in diagnosis and care
- use of pre-admission consent procedures
- better access to interpreting services
- improved intercultural skills and knowledge among hospital staff, supported with better access to AHLOs
- better support for travel requirements, building on existing work in South Australia and learning from other jurisdictions
- better accommodation options in the city
- use of the concept (and procedures) of transfer of care rather than discharge when patients move between hospital and community care.

These priorities are consistent with those that emerged from the interviews with staff and the larger group of patients and carers.

Cost and budget implications

All Adelaide public hospitals currently have at least two strategies to manage the complexities of country Aboriginal patient care:

- additional payments to hospitals for Aboriginal patient admissions (30% case mix loading, which compensates for longer length of stay and higher cost)
- AHLOs in hospitals and access to Aboriginal Patient Pathway Officers.

The complexity of some patient journeys can be managed by these two tools alone, but for other patients these two elements are not sufficient. The case mix loading for Aboriginal patients provides for higher inpatient care costs. An equivalent budget mechanism to enable overall coordination of care, including access to necessary transport and accommodation services, may be the only effective way to improve patient journeys and could also reduce some of the costs that arise as a result of lack of coordination and adequate support services. Such a risk-bearing arrangement for outlier patients should be funded from a central pool and be available to all relevant service providers.

Main Findings: Making Sense of it All

The combined results of the four studies that make up this project provide the basis for the following main findings.

1. This project found many examples of good practice, based on careful attention, creative responses to the needs and circumstances of country Aboriginal patients, and strong relationships among Aboriginal patients and their health care professionals. But these 'best practice' strategies and protocols are not systematically implemented.
2. This project confirms the high burden of illness experienced by country Aboriginal patients. Barriers to access mean that they are more likely to receive needed care later in the course of an illness, or not at all, as evidenced in our analysis of admissions data, and in the views and experiences of patients and staff.
3. Identification and recording of Aboriginality in clinical and administrative data collections is not adequate, and the lack of reliable information impedes both an understanding of health care needs and the capacity to monitor improvements. Continuing attention to this problem by SA Health and all health services is needed.
4. Patients' journeys are made harder by rigidities and gaps in the system of care, and in needed support systems. The patients (and their families/carers) undergo complex geographical and health care journeys, and this complexity is predictable due to the interaction of important underlying factors. All of these factors affect other groups of patients as well, but this group is likely to experience all or most of them. It is the interaction among the factors that makes access to good health care a complex challenge for this group of patients (and those who provide their care). The factors are summarised in Table 1 (this table can also be found on page 3).
5. The challenges of building good communication, trust and rapport in direct care interactions are significant for both staff and patients, and there are serious consequences of failure. Patients sometimes feel that their cultural values and needs are not respected, and staff sometimes struggle to communicate across differences in cultures, worldviews and experiences.
6. Coordination among care providers across geographical and sector boundaries is not reliable. When it is achieved, the benefits are real for patients, staff and organisations.
7. However, even with better coordination, support services (for travel, accommodation, coordination of physical and care journeys, interpreting and personal/family/cultural support for patients) are not adequate to need, and for some services cost is a barrier.
8. It seems that hospital systems that work reasonably well for city patients are not flexible enough for those who must travel for care. When the multiplier effect of all the barriers that impede the patient journey for country Aboriginal people are taken into account, it is clear that complexity is predictable for this group, and any attempt to improve care needs to be based on an assumption of complexity in the patient journey (as distinct from clinical complexity). Not all Aboriginal patients from the country will require tailored responses to complexity, but complexity should usually be expected.
9. Although there are many high-level statements of policy and principle to guide health care providers in caring for Aboriginal patients, there is a lack of operational policy and programs in the system of care that might support health care providers to build in reliable responses to complex patient journeys.

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.

Conclusions and Next Steps

Based on the findings of this study, we conclude that the following measures or actions, if implemented by the health care system, are likely to result in improvements both to the integrity of the country Aboriginal patient journey and in the effective use of health care resources (and would have benefits for other country patients and for urban Aboriginal patients).

1. Approaches to improving care for this group of patients need to be based on recognition that complexity in the overall patient journey is to be expected. Responses to manage complexity should be routinely available, and ruled out only when assessment shows they are not needed. This *complexity principle* could be used as the basis for the development of operational policies, programs and protocols to enable reliable access to good care for this group of patients.
2. Clinical units that regularly admit country Aboriginal patients need a dedicated coordinator role, with a focus on better pre- and post-admission preparation and follow-up. Such roles have been demonstrated to be effective elsewhere, including in relation to remote Aboriginal patients (Lawrence *et al.* 2009) and in clinical units in this project. Other clinical units need access to a coordinating resource person, a role that could be filled by Aboriginal Patient Pathway Officers or AHLOs, provided that a designated clinical staff member is reliably available to ensure proper communication and engagement within the clinical unit.
3. Assuming that coordinating capacity is available, access and quality would be improved if the following specific measures and services were available to patients, carers/escorts and staff:
 - adequate transport and accommodation arrangements (building on the work of Country Health SA and the Community Passenger Transport network) supported by improved access to financial help with the costs, including up-front PATS payments (CHSA 2011; Department of Health 2010)
 - ready availability of interpreter services, and systematic implementation of the policies that require their appropriate use
 - use of pre-admission consent procedures and attention to ensuring informed consent (which may involve family and others, as well as the patient)
 - access to specialist outpatient care in regional centres, with visiting specialists working more actively with each other and with primary care providers, and backed up by use of e-health and other information technology
 - better systems to coordinate outpatient consultations wherever they occur, aimed at preventing waste and unnecessary travel.
4. The vital contribution to care made by AHLOs (and Aboriginal Patient Pathway Officers) would be further enhanced if their roles were better defined, understood and supported by both city and country staff and organisations. These workers are relied on too much to solve immediate problems in the patient journey, which should be predicted and planned for by the whole health care team, and could make a stronger contribution to ensuring quality and safety for Aboriginal patients.
5. Support from escorts and/or family and community members is important for patients. Practical methods of incorporating family members and escorts into health care, and defining their roles properly, are needed.
6. Attention to cultural priorities and spiritual needs should include systematic arrangements for access to *Ngangkari*s, as well as making the hospital environment more

friendly (through visual cues, and attention to gender concerns, coldness and food preferences).

7. Non-Aboriginal staff can and do develop skills and knowledge that help them to be effective communicators and carers across cultural and language groups. This capacity seems to require, first of all, recognition that one is 'working in the intercultural space' and appreciation that each of us holds cultural values and assumptions. Evidence is mounting that existing approaches to cultural awareness training are not effective. The concept and approach of cultural safety, with its focus on the essential link between culture and clinical quality and safety, may be more effective.

Next steps

This report summarises the results of Stage 1 of the project. The research team will engage in discussion with our partners in this project, with the Department of Health and with South Australia's clinical networks to seek responses to the findings of this stage of the project and to shape the next stage. In Stage 2 we aim to work with industry partners and stakeholders to develop further and, where possible, test the methods suggested in the conclusions. Success will depend on engagement by health care providers, on clinical and system leadership, and on enabling policy, programs and procedures. Health staff and units have expressed interest in being involved in the work in each of the practice areas listed above. If this approach succeeds, the outcomes will be improvements in the quality of care, the integrity of the patient journey and the effective use of health care resources.

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