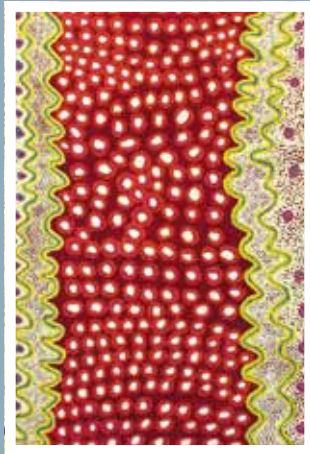


Janet Kelly
Brita Pekarsky
Judith Dwyer
Tamara Mackean
Eileen Willis
John Glover
Malcolm Battersby



Managing Two Worlds Together:

Study 4—Complex Country Aboriginal Patient Journeys



Cover Artwork:

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

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

Janet Kelly
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Judith Dwyer
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Eileen Willis
John Glover
Malcolm Battersby

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Additional copies of the *Managing Two Worlds Together: Study 4—Complex Country Aboriginal Patient Journeys*, along with downloadable pdfs of all six reports emanating from this project, can be obtained from:

Department of Health Care Management

Flinders University
Bedford Park, SA 5042 AUSTRALIA
T: +61 8 8201 7755
F: +61 8 8201 7766
E: tiffany.carlin@flinders.edu.au
W: www.flinders.edu.au

The Lowitja Institute

PO Box 650, Carlton South
Vic. 3053 AUSTRALIA
T: +61 3 8341 5555
F: +61 3 8341 5599
E: admin@lowitja.org.au
W: www.lowitja.org.au

Authors: Janet Kelly, Brita Pekarsky, Judith Dwyer, Tamara Mackean, Eileen Willis, John Glover and Malcolm Battersby

Managing Editor: Jane Yule

Copy Editor: Cathy Edmonds

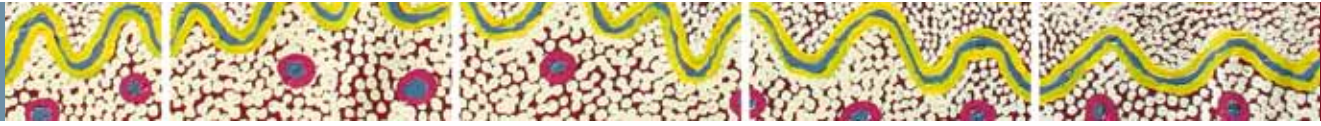
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The Managing Two Worlds Together Project

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

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

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

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

- *Managing Two Worlds Together: Study 1— Report on Admissions and Costs* (available on the website)
- *Managing Two Worlds Together: Study 2— Staff Perspectives on Care for Country Aboriginal Patients* (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* (**this report**—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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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
MRI	magnetic resonance imaging
PATS	Patient Assistance Transport Scheme
R&RMHS	Rural and Remote Mental Health Service
Carer	Family member or friend who supports and cares for a patient
Country	In describing where people live, we use the terms <i>country</i> and <i>rural</i> to include all non-metropolitan areas. We use the more specific terms <i>regional</i> , <i>remote</i> and <i>very remote</i> 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. <i>Country</i> 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 <i>mainstream</i> to refer to non-Aboriginal systems, institutions and practices.

Introduction

This report presents four case studies that map the patient journeys of country Aboriginal patients and carers who travelled from rural or remote South Australia to Adelaide for hospital care. It analyses the common elements in these journeys and their implications for health care providers. This study is part of the Managing Two Worlds Together project, and its goal is to illustrate the complexities involved in these real patient journeys, and how city and country health services prepare for and respond to these complexities.

Australian States have responded to the needs of country Aboriginal patients in a variety of ways. Within South Australia, country Aboriginal patients journeying to metropolitan hospitals may be supported to varying degrees by a wide range of health and support staff, including Aboriginal Health Workers, nurses and doctors in Aboriginal Community Controlled Health Services, community health services and/or general practices; visiting or hospital-based medical specialists; metropolitan and country hospital staff; Aboriginal Hospital Liaison Officers (AHLOs); Aboriginal Patient Pathway Officers; and rural liaison nurses. Support can also be provided through transport and accommodation services.

Methods

The Aboriginal Health Council of South Australia and the four major public health services at that time (Country Health SA, Central Northern, Southern Adelaide, and Women's and Children's Health Services) all agreed to participate in the Managing Two Worlds Together project. A

Project Management Group was established, with a majority of Aboriginal members, and including representatives of the health services and other stakeholders. We sought and received ethical approval from six ethics committees.

Over the past decade, patient journey modelling and mapping have been used to highlight gaps in access, continuity and quality of care, to analyse patient flow (Curry, McGregor & Tracy 2007) and for accreditation purposes (ACSQHC 2010). There are two broad approaches. The first focuses on modelling within-hospital care processes (for example, Ben-Tovim et al. 2008; Richardson, Casey & Hider 2007). The second type maps whole patient journeys, through different settings of care. This approach uses a range of methods including interviews, focus groups, review of health service care plans and observation of a patient's actual journey from diagnosis to completion. This method has been used for specific conditions such as cardiac care (Lawrence et al. 2009; Rolley et al. 2009), Parkinson's disease (Baker & Graham 2004) and diabetes (Wiebe 2011).

The particular difficulties of care journeys for rural and remote patients, including Aboriginal patients, have been identified (Department of Health 2010; Dixon 2010; AHCSA 2011; DHS 2010; Lawrence et al. 2009). Based on this work, and the results of our broader project, we developed a framework to analyse the journeys of the patients in this study. The framework focuses on the experiences of country Aboriginal patients, their carers and health professionals, in both city and country sites, as the patient navigates the health system for a range of health concerns. It brings together the country Aboriginal patient's own health and life priorities, the experiences and challenges of the journey, and the health system's capacity for response.

Defining health for country Aboriginal patient journeys

The Australian Indigenous Doctors' Association has developed a comprehensive model of health in five dimensions, for the purposes of assessing positive and negative health impacts (AIDA & CHETRE 2010), building on existing definitions of Aboriginal and Torres Strait Islander health (including NAHS 1989 and Milroy 2010). The following dot points illustrate how this model has been used for the current research project:

- **physical or biological**—morbidity, mortality, chronic conditions, self-reported health
- **psychological or emotional**—levels of stress, transgenerational and cumulative trauma, freedom from shame, discrimination, racism
- **social wellbeing**—family and kinship systems, community cohesion; access to quality housing, education, employment, living conditions, support services; self-determination, participation, trust, social inclusion
- **spiritual**—recognition and respect for Aboriginal people, worldviews, knowledge, values and aspirations (enacted in policy and programs); hope and despair
- **cultural integrity**—levels of community control of health, education, land rights, police and fire protection (AIDA & CHETRE 2010).

This comprehensive view of health and wellbeing highlights the many aspects of people's health and life that can be affected when they require city hospital care.

Five underlying factors that affect Aboriginal patient journeys

This study also uses a framework of five factors derived from analysis of staff and patient interviews. This framework identifies five underlying factors that affect the needs and experiences of Aboriginal patients from the country who come to Adelaide for care (Table 1).

It is the *interaction* of all these underlying factors—being a country person in a city setting, experiencing a high burden of illness (and needing care across the hospital/non-hospital divide), perhaps not having English as a first language, perhaps being poor, and being Aboriginal in a mainstream system—that makes city hospital care for country Aboriginal patients a unique challenge for the patients themselves and for their carers and staff. It is important to note that not all Aboriginal country patients experience all of these factors equally or uniformly.

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.

Data collection and analysis

Four individual case studies were selected from the 21 patient and carer experiences reported in interviews. The cases are broadly representative of the breadth of experiences, ages, locations and health conditions of the larger interview sample. With each patient's permission, their local health care providers were contacted and asked more specific questions about their care, local health service arrangements and reasons behind particular actions being taken. Hospitals were not contacted, due to concerns about patient confidentiality, so this analysis is not informed by the insights of hospital staff.

Potentially identifying details in these case studies have been altered to protect the privacy of the people and health services involved.

Each case study was written and mapped as a unique patient journey, using a narrative analysis method (Emden 1998) and the five dimensions of health (AIDA & CHETRE 2010). The priorities of patients, families and health carers were identified, as well as health service responses and gaps. This method enabled the uniqueness and context of each story to be studied in detail (Bolt 2009).

The case studies were then considered collectively, and their implications for health care providers were analysed, with particular reference to preparedness, the costs of complexity, and opportunities and potential strategies for improvement.

Four Patient Journeys

The four case studies are summarised and analysed below.

Case Study 1: flying blind

Background

This case study involves two patients who sought eye care. The experiences of the first patient impacted on the experiences of the second patient, and on the approach taken by the management and staff in the aged care facility where both patients lived.

The first patient, an Aboriginal Elder for whom English was the second language, was supported by the Aboriginal aged care facility to see a visiting ophthalmologist for increasing blindness. The patient was referred to a city hospital for further investigation and eye surgery. While consenting for further treatment, it became apparent that the patient was highly apprehensive about flying and about the need to attend an Adelaide hospital. The staff arranged two escorts, one companion and one person who was able to interpret and assist with communication) and disability-friendly transport and accommodation (the patient used a wheelchair). When the patient and escorts arrived at the hospital, the staff raised concerns about consent, saying that without an accredited interpreter, the patient could not give informed consent. The hospital staff cancelled the surgery and prepared a booking for a flight back home for all three people. One escort rang the aged care manager, who tried to talk directly with the ophthalmologist. However, by the time the manager could speak to the doctor and explain that an interpreter had been sent and that the patient was, in fact, consenting, the doctor had moved on in the surgical list and said it was too late—the surgery was booked out. So the patient and escorts flew back without the operation being done. The patient was very frustrated and angry and when interviewed for this project had very poor vision. The aged care manager planned to act as an escort on the next

trip to ensure the procedure occurred, and to be on hand to solve any problems that arose. The patient refused to fly again and died before regaining sight.

Patient's story

A second resident, a senior Elder woman who had been blind for some years, also needed eye surgery. In 2009 an enrolled nurse involved in the Fred Hollows program began the process. First, a referral was arranged with a doctor in the local Aboriginal health service and an appointment made to see a specialist in the major regional town. After six months, an appointment was available and the woman travelled six hours by road with a carer and driver. When they arrived, they were informed that the referral was out of date and they would need to get another referral. They returned home and saw the general practitioner (GP) for a second referral, and waited months for their appointment. Finally, they saw the specialist, who said that her eye condition was beyond his ability and referred her to an Adelaide specialist. After much encouragement and support by aged care staff, the woman flew to Adelaide for assessment with a *mulpa* (friend/companion) and the aged care manager, who interpreted. It was determined that one eye could be operated on. They returned home to wait for the surgery date. Two surgery dates were made and then cancelled by the hospital in late 2010. The woman was very excited, then very upset, both times. No further surgery date was set. In January 2011, after repeated calls to the city and no positive response, a staff nurse rang the local Member of Parliament and explained the situation. By that afternoon, an appointment was made for five weeks hence.

A surgery date was set with pre-admission checks in the same week. The patient would not be able to fly after surgery, and so it was decided to take the aged care bus with a carer and

driver. A second resident, requiring high levels of disability care, also required surgery the same week. The two patients were related, and could provide family support to each other. The three staff and two patients travelled to Adelaide in one day—a trip that took twelve hours. They were all exhausted when they arrived in the city and found that the motel was not suitable and they had to arrange alternative accommodation.

There were three pre-admission clinic appointments the next day, which took all day and the patient became quite upset. The carer was only able to interpret some of the information provided. The aged care facility, anticipating difficulties, had arranged for an interpreter already known to the patient to join her and the carer at the hospital. This assisted the process, but it was still a long day. At one stage a repeat ECG (electrocardiogram) was ordered because the copy of the ECG sent did not have a legible date. The patient refused to have the ECG, saying, 'I am a Christian woman, I've got Jesus in my heart, there is nothing wrong with my heart'. 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 second copy of the ECG was faxed with the date clearly showing. The next day the patient returned for x-rays and then went back to the motel to rest. Another carer, with whom the patient was more familiar, and who spoke the same language and was more familiar with the hospital, was called to assist the next day with surgery preparation and post-operative care. This carer had just completed a training course in Adelaide and was about to fly home, but cancelled her flight and moved into the motel with the others.

Having a carer familiar with the hospital was very reassuring for the patient, but when it came time to get ready for surgery things became difficult. The patient did not understand why she should take her underwear off for eye surgery and was unhappy 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 approaching her. 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 carer had never seen her like this before (she had never been

so frightened in aged care). The hospital staff were unable to work with her as they saw her as uncooperative and violent and said that they would have to cancel the surgery. The aged 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 carer drew the curtains and spoke quietly to the woman, reassuring her that she would not leave her, and reminding her of the importance of her surgery, and that she would not want to return home without her eye sight, as happened to the other resident. The woman was reassured and got changed and onto the trolley slowly and carefully, with only the carer helping. The carer covered the woman and pulled back the curtains and called the hospital staff back in. 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. The carer held the woman's *murras* (hands) while the anaesthetist put a drip in and the procedure went ahead, with the carer promising to meet the woman 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 carer was shocked. The woman was transferred to a ward and the carer stayed with her. She gave the woman her tablets, with hospital staff recording in the case notes that this had occurred. The carer held the woman's hands and sang and said evening prayers until she fell asleep. The carer then sat in the chair in the room, having promised to stay all night. This Elder woman was a widow and never slept in a room alone, but always with another woman, as is culturally appropriate. At about 3 a.m. hospital staff brought in a fold-out bed for the carer.

The next day the patient was seen by the specialist prior to discharge. He took off the bandages and said he wanted to see her again in a week. Ignoring the patient's refusal, he asked the nurse to make the appointment. The carer explained that they came from a remote town

and would take two days to drive home. They could not return so soon; the patient would be exhausted. The doctor shrugged and said he wanted to see her in a week. The patient and her carer collected the discharge drugs and met the aged care van at the door and began the two-day trip home. The patient enjoyed being able to see the countryside on the long trip home, and when the van arrived she was happy to be able to see the aged care staff members clearly for the first time.

The hospital appointment card arrived the next week. Fortunately, an outreach ophthalmologist clinic, federally funded and organised through the Aboriginal Health Council of South Australia, happened to be visiting the remote town the following week and the local Aboriginal health service arranged an appointment. This involved a two-minute drive and carer support for half an hour. This woman's life has changed with the surgery and she now has vision in one eye (the other was too badly damaged). She is very social and independent, greeting extended family members who come to visit, and is more involved in cultural and aged care events.

Analysis: health system planning for and response to complexity

Analysis using the five dimensions of health and the five underlying factors that affect access and quality of care is summarised in Tables 2 and 3 (only major factors are included).

The analysis of this case study highlights the contrasting approaches of the aged care service and the hospital to the possible complexity of this country Aboriginal patient's journey. Based on experience and their intimate knowledge of this patient, the Aboriginal aged care staff case managed complex needs and carefully engineered solutions to ensure successful outcomes.

The hospital had not anticipated the need for an interpreter or considered pre-admission consent processes. However, staff sought solutions such as contacting the aged care service to get a usable ECG and involving the carer. Other aspects illustrate a lack of flexibility to respond to follow up and continuity of care requirements. A lack of preparedness and skill to manage this patient's care resulted in her becoming distressed and labelled as violent.

Further discussion with the aged care manager highlighted that Patient Assistance Transport Scheme (PATS) assistance was not fully utilised due to lack of communication between health and aged care services.

Who bears the costs of complexity?

This patient's journey was substantially more complex compared to that of most patients receiving eye surgery, whether they are from country or city South Australia. The additional costs of complexity of this patient's journey were largely met by the aged care service, which is not funded for the extensive support role it played. Those costs (including staff wages and backfilling) are estimated to be approximately \$7000. The savings in attending the visiting ophthalmologist locally with a staff member, rather than returning to Adelaide for the short appointment, was estimated by the Aboriginal health service to be at least \$5000.

Opportunities for improvement

Investing in improved procedures such as timely and coordinated referrals, pre-admission consent processes and better interpreter services could improve care and reduce unnecessary costs. The problem in this case, as for many patients with complex care needs, is that costs and savings accrue to different budgets, thus reducing or removing the financial incentive to improve coordination.

Strategies and action: PATS and pre-admission consent

Following the documentation of this case study, and with the permission of the patient and Aboriginal aged care manager, the case was shared with the manager of PATS. The Aboriginal aged care service became one of the first sites to trial a new approach to PATS forms and procedures, and reimbursement for this and other patient journeys has been negotiated.

The consent process for another resident requiring surgery at a different hospital involved significant discussions and communication

Table 2: Case Study 1 health dimensions

Dimensions	Analysis
Physical or biological	Blindness leads to a decreased quality of life and is a risk factor for falls and other injuries.
Psychological or emotional	Frustrated by blindness, concerned about flying, fearful of unknown situations and people.
Social wellbeing	Elder who is well respected and supported by local community and aged care to maintain kinship and culturally appropriate arrangements; prefers Elder and family companions when travelling.
Spirituality	Lives near homelands with other Elders and maintains important spiritual connections; feels uncomfortable away from homelands.
Cultural integrity	Involved in cultural meetings, activities and decision making, but failing eye sight restricts involvement; gender needs and Elder status unrecognised in city settings.

Table 3: Case Study 1 journey analysis

Underlying factors	Analysis
City/country	Eye surgery requires two days' travel by road each way; city environment very unfamiliar (e.g. multi-storey buildings).
High burden of illness	Patient's blindness meant she needed a carer to guide and advocate for her, and couldn't see the staff, adding to her distress and leading to being labelled as violent.
Language	No hospital staff spoke her language; major preventable problems with interpretation; carer role as interpreter not recognised or well utilised.
Financial resources	Costs for aged care service high; patient's money tied up in residential care fees.
Aboriginal/non-Aboriginal	With some exceptions, hospital staff generally seemed to lack knowledge and skill in intercultural relationships; no contact with AHLOs.

between the aged care facility and the hospital prior to admission. The result was a smooth final consent process on the day of admission and surgery. Further work by SA Health and metropolitan hospitals on pre-admission consent processes is needed.

Case Study 2: travelling in pain again and again

Patient's story

A middle-aged Aboriginal man, employed but on a low income, had two chronic conditions requiring ongoing care. He was referred by the local GP to see a specialist in Adelaide for worsening orthopaedic problems. When he attended the first appointment (a painful five-hour journey each way), the specialist advised that he needed a different specialist, and referred him on. After a few months he returned to Adelaide and the second specialist suggested he have an MRI (magnetic resonance imaging) scan (another trip) then return for a second consultation (another trip). On each occasion the man and his wife (or their parents, if she could not get time off work) travelled to Adelaide and back on the same day. They did not stay overnight because they had no family in town, could not afford to pay for accommodation and could not afford more than one day off work. PATS assisted with the cost of petrol, but did not cover accommodation because the man was not a health care card holder. The patient negotiated mid-afternoon appointments to allow time to drive to Adelaide and back on the same day.

Even though finances were tight, at one stage this patient decided to use the private health system in order to receive health care and relief from the pain more quickly. He had an operation and was flown home. A month later he returned by car for a follow-up MRI scan and specialist visit. The specialist determined that he needed a second operation, which the patient returned for. A follow-up MRI showed problems that needed further review. It was at this stage that the project interview took place.

The patient described the 'really bad' pain he experienced on these repeated trips. The surgeon gave him a script for pain-relief

medication and told him to take it as needed. The man did not realise he could get addicted to this medication and saw the local GP for repeat prescriptions as the trips and pain continued. The local GP did not have a lot of time to spend on each consultation (there was a GP shortage in his region; the patient said, 'you just go in and out, not a lot of checking up') and these prescriptions continued for some months.

The man felt that the specialist doctors did not explain or discuss his condition, treatment or medications clearly and he found the visits to specialists intimidating. During admission to the private hospital he became very lonely. Staff provided physical care immediately after the operation, but reduced their interaction once the patient was more mobile. There were no AHLOs or Aboriginal staff in the private system. A family member stayed with a cousin in the northern suburbs and visited during the day.

The repeated trips to Adelaide were time consuming and pain filled. The additional chronic condition required expensive medications. The patient became increasingly depressed and attempted suicide, but a family member happened to be nearby and intervened. Together they returned home and rang the mental health line. The patient found the Rural and Remote Mental Health Service (R&RMHS) workers very supportive and followed their suggestion that he be admitted to the nearest hospital, with the R&RMHS team working with the local mental health team to facilitate this. The admission process was very smooth; the patient reflected that without this assistance he may have been waiting in emergency for hours. A teleconference was organised with an Adelaide psychologist at R&RMHS and he valued talking to someone who he did not know and who was not a family member.

This patient is now attending the local Aboriginal health service, where he is cared for by a GP and Aboriginal nurses and health workers. He had not used this service previously, believing that it was for health care card holders only. The Aboriginal health service GP coordinates his total health care, and explains in depth about drugs and treatment. The patient has successfully withdrawn from the narcotics and values the coordinated health care he receives for all his health concerns.

Table 4: Case Study 2 health dimensions

Dimensions	Analysis
Physical or biological	Ongoing back pain and additional chronic condition and drug dependence; travelling long distances very painful.
Psychological or emotional	Ongoing pain and increased medication usage lead to isolation, depression and suicide attempt.
Social wellbeing	Supportive partner and grown children, and works full-time for low pay; social wellbeing reduced by pain and isolation.
Spirituality	Struggling to remain connected.
Cultural integrity	Identifies as part of the local Aboriginal community, but pain limits participation.

Table 5: Case Study 2 journey analysis

Underlying factors	Analysis
City/country	Ten-hour car journeys painful and time consuming; driving in the city a challenge.
High burden of illness	Treatment delays and failures; specialist and hospital focus on one aspect of health care needs only; local GP not coordinating care; Aboriginal health service and remote mental health service ultimately take these roles.
Financial resources	High costs to patient and family of private care, travel, lost income, limited assistance from PATS.
Aboriginal/non-Aboriginal	Lack of cultural/community support in private hospital; lack of social interaction with staff.

Analysis: health system planning for and response to complexity

Analysis of this case study highlights the problem of lack of overall coordination of care and poor access to specialist care. The major dimensions of health and underlying factors that impacted on this patient journey are summarised in Tables 4 and 5.

The local mainstream GP provided initial referral and short follow-up visits, but would have expected definitive treatment to be provided by a specialist. The private hospital provided technical care, but few support services, and lacked the capacity to provide AHLO support or companionship. The patient's suicide attempt was the catalyst for an improvement in his care, through the supportive response of the local Aboriginal health service, the R&RMHS and the

local mental health team. These services have assisted this patient to re-establish some sense of control over his health and care, even though his health concerns continue.

Who bears the costs of complexity?

The additional personal and financial costs of complexity in this case were borne by the patient and his family in the repeated trips to Adelaide. PATS assisted with transport costs, but not accommodation (because the person was not entitled to a health care card). The shortage of GPs in this patient's home town, combined with the apparent implicit 'handover' of care when referral was made, led to short visits and unresolved problems, adding to the consequences for this patient. A potentially preventable mental health crisis added to personal and health system costs.

Opportunities for improvement

A more effective approach to accessing specialist care could be achieved using tele-health and regional specialist visits. The recent changes to the Medicare Benefits Schedule that allow for tele-health items, including those provided by an Aboriginal Medical Service with a GP or Aboriginal Health Worker assisting the patient, will improve the capacity to provide such services. However, the success of these items will depend upon the capacity for Aboriginal health services to develop networks with suitable specialists in Adelaide. Repeated trips for appointments, arranged regardless of personal and financial costs of attendance, are a significant burden for regional people on low income. Greater collaboration between city specialist services and local practitioners in the management of complex consultations would also improve care and reduce overall costs.

PATS is moving to the use of electronic funds transfer and fuel vouchers to prevent extensive out-of-pocket travel expenses.

Case Study 3: will I ever get home again?

Patient's story

An Aboriginal woman in her seventies from a remote area of South Australia had an acute episode of renal disease and was flown to Adelaide. She was stabilised and began renal treatment, and then had ongoing dialysis care as an outpatient. Her partner followed her to Adelaide and they lived in a hostel during this time. This patient had worked in many places across South Australia. She could discuss everyday concepts in English, but technical and health-related language was more difficult. This communication difficulty was often underestimated by staff in the city hospital. After some months, the patient asked to be transferred to another renal unit nearer to her home and family. Another Aboriginal patient helped the patient and her partner to talk this through with the doctor. First, suitable long-term accommodation needed to be arranged, and the country and city dialysis units, social workers and hostels collaborated to arrange the move.

At the time of the project interview, this patient was attending dialysis three times a week in a country location. Because she could only be off dialysis for two days, three at the most, travelling to her home and family, hundreds of kilometres away in a remote location, became more and more financially difficult, and impossible in wet conditions. The patient and her partner both spoke of missing their home, livestock, bush tucker and family, and wanted to talk to the doctor again about going home to live.

The couple were surviving on one pension and were unable to pay bills. They shared their concerns with the renal nurse, who arranged social work and other assistance. When the couple lived in their home community, they could live well on one pension; they ate a lot of bush tucker and many services were supplied at low cost. However, in the regional town they had to purchase food and services. In addition, many family members came to stay, which increased their costs. It was no longer possible to live on one pension and the renal nurse coordinator and social worker arranged for them to access payments to which they were entitled.

In order to coordinate effective dialysis care, the renal nurse worked closely with the couple, taking a wider case management role and coordinating dialysis sessions around the couple's trips home, and on occasion calling the Royal Flying Doctor Service to retrieve the patient if she got rained in. The renal nurse also ensured access to the social worker for assistance with the challenges of town living as necessary.

Postscript

When we rang to discuss this case study further, the renal nurse told us that the patient's partner had suddenly become ill and died. The renal nurse negotiated for her to have renal dialysis closer to home on a temporary basis during the funeral and sorry business. She returned for dialysis but did not wish to go back to the accommodation that she had shared with her partner. She was given temporary supported accommodation, but then became very ill, was hospitalised for a week and lost the accommodation placement. She expressed a desire to return home and have dialysis in another town, nearer to home and family, and

to where her partner was buried. The renal unit assisted her to save her pension to buy a bus ticket home (she was sharing most of her pension with extended family members at this stage). The Aboriginal Patient Pathway Officer tried to find accommodation with the help of a social worker in the other town, but nothing suitable was available. The woman returned home and then went to stay with family in the nearer town and presented for dialysis there, saying that she would not be returning to the original dialysis unit. She is now living with family and having dialysis in this new location.

Analysis: health system planning for and response to complexity

Analysis of this case study highlights the comprehensive approach to care management taken by the regional centre renal unit. In this case, the renal unit staff were responsive to all five dimensions of health, and supported this patient in relation to accommodation, transport, finances and arranging dialysis care around cultural events. The relevant factors are summarised in Tables 6 and 7.

Table 6: Case Study 3 health dimensions

Dimensions	Analysis
Physical or biological	Acute and then chronic illness, physiological effects of stress and change in diet.
Psychological or emotional	Adjustment to major life changes and stressors such as moving house, changing lifestyle and activities, separation from family, loss of partner.
Social wellbeing	Accommodation challenges, kinship obligations and family responsibilities, as well as costs of living in regional centre contributing to financial pressure, support and advocacy of other Aboriginal patients, travel problems that change over time.
Spirituality	Disconnection with home and country through physical separation.
Cultural integrity	Language barriers and chronic illness limit participation in cultural life; is only able to return intermittently for up to two days at a time.

Table 7: Case Study 3 journey analysis

Underlying factors	Analysis
City/country	Regional renal unit remote from home; medical relocation difficulties.
High burden of illness	Renal disease a major impact on home life and livelihood.
Language	Difficulty with medical terms and understanding explanations; no interpreting provided.
Financial resources	High out-of-pocket costs with relocation to regional centre while costs of maintaining home remain; limited financial resources in spite of a lifetime of work (community rather than individually owned assets not able to be sold).

Who bears the costs of complexity?

For this family, the costs of kidney disease were severe in disruption to their cultural and family life, their finances, housing and support structures. They made decisions among reduced options. The health services showed a sense of responsibility to support the family's decisions, and there was significant investment by staff in assisting with all aspects of care and living conditions. The significant contribution by the staff was possible because the unit was prepared for complexity and had the infrastructure, experience and networks to identify and address the issues. One critical financial problem arose from differences in the cost of living in town rather than at home. A second critical financial issue arose because even though this woman had worked all her life, she did not have superannuation and the land she had lived on and developed with her husband did not have a commercial value.

Strategies

The methods, skills and cultural competency of the renal nurse and other staff were important in this patient's experience, as were the support services they were able to mobilise. A method of capturing and sharing this knowledge is needed. The recently established Aboriginal Patient Pathway Officer role provides assistance with arranging transport between country and city and home locations, which was a significant factor for this family.

Case Study 4: caring for my husband

Carer's story

This Aboriginal woman and her non-Aboriginal husband lived in a regional town. The husband suddenly became unwell and thought he might have 'had a stroke or something'. The GP conducted an initial assessment and tests. He advised the couple that the husband had 'tumours in his brain', and arranged an urgent admission. The specialist asked that the husband be admitted by 5 p.m. that afternoon, so they went home and packed their clothes and their youngest child into the car. The husband, being the only driver in the family, drove to Adelaide. The woman said, 'they didn't tell him he couldn't drive', and no one thought of an alternative; they

were just focused on getting to the city on time. On the way there the husband became confused and drove erratically, with their child reminding his father to keep to the right speed and to keep to the left lane. They made it to the hospital in time and the husband was admitted into a four-bed bay.

That evening they were approached in the open four-bed bay by a junior doctor who said, 'sorry, you are going to die. It could be six weeks, six months or six years.' The woman and her husband burst into tears, and she recalled, 'I looked up at all these white faces looking at us stunned and us crying. There was no privacy.'

The woman stayed with family in the suburbs and visited every day. She became her husband's main carer, and he became distressed when she was not around. Family members visited in the evenings after work. The man was moved often from ward to ward and bed to bed, and his wife took his belongings home every night in case they got lost. She related that most nursing and medical care was good except for four specific events. The first involved her husband being left in tight, wet clothes until she arrived in the morning and demanded they be changed. The second was when a nurse refused him pain relief even though it was prescribed. This nurse said he needed to 'ask for it', but he was no longer able to speak for himself. A junior nurse tried to intervene, but was ineffectual. The woman did not know who else to speak to and went home distressed. The next morning a new senior nurse spoke about arranging pain relief and when the woman reported what had happened the previous day, the matter was quickly addressed, with pain relief given and an assurance that the nurse would not work there again. The third event occurred when a new doctor came in and started moving her husband's head around, making her husband flinch, without explaining why he was doing so. She found this very upsetting. The fourth was when her husband slipped undetected into a diabetic coma.

The couple made two attempts to get help from a social worker to write a will while her husband was still able to do so. The first social worker said she did not think she could help. The wife asked for another social worker and an older, more experienced social worker came

and assisted them to arrange a will. She also arranged a meeting for the doctors to explain the facts of the prognosis with the couple's older children at the wife's request. The wife also asked for AHLO support during this difficult time, but was told that the AHLOs could not help her because the patient (her husband) was not Aboriginal. Family, friends, workmates and employers of both the man and his wife came to visit, or called to offer support.

The husband began receiving radiation treatment, but his condition quickly deteriorated. The hospital offered a transfer to a hospice, and began to make arrangements, but the patient became too unwell to transfer and died in the city hospital five weeks after admission. His wife and her family arranged for his body to be taken home for the funeral.

Analysis: health system planning for and response to complexity

In this case study, some vital services were overlooked and others were delayed or denied. The most relevant factors are summarised in Tables 8 and 9.

The lack of transport services for the initial (urgent but not emergency) travel to Adelaide placed the family at risk. Social work assistance was delayed, and AHLO support was denied. Ward-based care was compromised by moves from ward to ward and by several incidents of poor care. It is not possible to determine if the failure to arrange palliative care in a timely way was preventable. This story illustrates the difficulty for carers when overall coordination or case management by the hospital is lacking, or not made clear to the carer.

Who bears the costs of complexity?

The family in this case bore the financial and health costs and potential risks of the trip to Adelaide. The carer seems to have incurred significant personal cost, and financial costs of the long stay in Adelaide. The hospital incurred the financial costs of care, which are likely to have been greater than the funding provided.

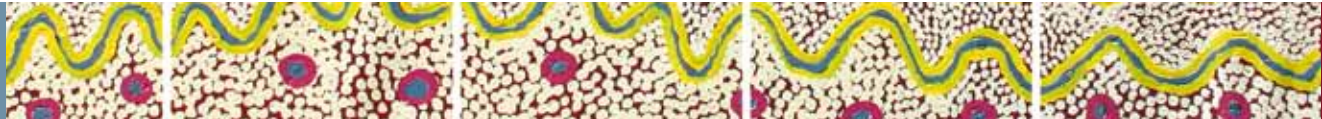


Table 8: Case Study 4 health dimensions

Dimensions	Analysis
Physical or biological	Acute terminal illness and pain.
Psychological or emotional	Distressed by lack of privacy when receiving shocking news, adjusting to diagnosis and preparing for death, and by disrupted processes of care.
Social wellbeing	Supportive family and friends; wife took advocacy and caring role; rapid financial and legal arrangements a priority.
Spirituality	Separated from usual spiritual supports by distance.
Cultural integrity	Aboriginal carer needed cultural support.

Table 9: Case Study 4 journey analysis

Underlying factors	Analysis
City/country	Journey to city on initial diagnosis dangerous and stressful, very limited transport options for urgent but not emergency care.
High burden of illness	Problems with case management of inpatient care.
Financial resources	Sudden loss of income, financial and legal assistance needed urgently.
Aboriginal/non-Aboriginal	Access to AHLOs denied to carer because patient was not Aboriginal, suggestion that medical staff lacked comfort with intercultural communication.

Strategies

This case study highlights significant transport and support issues relating to immediate but not emergency transfer to city hospitals. Work is progressing in this area through the Community Passenger Networks (convened by the Department for Families and Communities and involving the Red Cross and local government authorities). These networks aim to provide

transport brokerage and information, and offer last resort transport for medical, specialist and social appointments. Aboriginal Patient Pathway Officers are also involved in addressing this problem.

The question of access to AHLOs requires clarification in general. The hospital involved advised us that their policy now covers Aboriginal carers of non-Aboriginal patients.

Discussion and Conclusions

These case studies illustrate both the strengths and the weaknesses of the health system. Universal access means that hospital care is provided free of charge, often at a high standard of technical quality. However, the case studies also highlight the fact that hospital and support service arrangements that work reasonably well for city patients are not responsive or flexible enough to respond consistently to the complexities encountered by country Aboriginal patients. When country Aboriginal patients 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, may experience poorer quality of care or may 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, which requires both the availability of highly specific interventions and support services tailored to needs and a general method of identifying, planning and coordinating responses. We suggest that the *complexity principle* could provide the basis for general responsive capability and that a set of specific interventions and services could provide the methods for implementing responses (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 case studies indicate that complexities are currently managed in 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 the average patient journey. 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 (see *Study 2—Staff Perspectives on Care for Country Aboriginal Patients*, available on the website). The study found that clinical units with established protocols for preparing for and responding to admissions of country and Northern Territory Aboriginal patients reported better experiences than those that lacked this capacity. 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. 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.

Country health services involved in these case studies were more likely than city services to pay attention to addressing complexities in order to ensure access to the required care for their patients.

Coordination of these complex journeys is an ongoing prerequisite for good care. Not all Aboriginal patients who are admitted to city hospitals have significant additional costs associated with their pre-admission and post-discharge journeys. Therefore, a system that responds to complexity by assuming high costs and complexities for all patients is likely to be inefficient. Instead, the capacity to tailor responses according to the predictable complexities is needed. In clinical units that treat significant numbers of country Aboriginal patients, a dedicated coordinator role (full- or part-time) is needed. 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.

These roles should also be supported with protocols for admission, coordination, discharge and transfer of care that include identification of and access to needed support services (for accommodation, travel and follow-up care).

Interventions and support services

Analysis of these 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 emerging from the interviews with staff and the larger group of patients and carers.

Cost and budget implications

From a health economic perspective, there is a failure to adequately fund the higher than average complexity of country Aboriginal patient care and support needs (a shift of the curve of distribution of complexity) and a failure to fund outliers (individual cases with extraordinarily complex care needs and high costs). When patients such as those whose experiences are reported here need to be admitted to a metropolitan hospital, the complexity of their care may or may not be anticipated and managed. All Adelaide public hospitals have at least two strategies in place:

- additional payments to hospitals for Aboriginal patient admissions (30 per cent case mix loading)
- AHLOs in hospitals and access to Aboriginal Patient Pathway Officers.

The complexity of some patient journeys can be managed by these two tools alone. However, for other patients these two elements are not sufficient. For a patient and/or referring agencies (often small budget holders) in a system that has only these two elements in place, the consequences include the possibility that:

- the requirement for an admission is not identified in a timely manner, leading to more costly admissions or possibly no admission and worse health outcomes
- a referral is made but the patient does not choose to travel due to previous bad experiences (or the bad experiences of other people in the community)
- a patient travels to the hospital but the admission does not occur due to breakdowns in communication around key points such as the consent process
- a small budget holder bears significant costs that have not been planned for in the budget, which is intended to fund routine and predictable local care.

Some financial costs resulting from patient journey complexity are avoidable through better responses (such as pre-admission protocols for informed consent). Some of these financial costs can be incorporated in routine payments for costs of care while in hospital, as is the case with the additional cost-weight paid to hospitals for admissions of patients who identify as Aboriginal

(intended to cover the costs of the predictably higher than average length of stay). But some costs are incurred elsewhere, by small budget holders. Other financial costs are borne by patients. Sometimes, patient journey complexity (and its cost) is overwhelming, and needed health care may not be received, with significant consequences for the patient (and family and community) in poor health outcomes.

The diagnosis related groups (DRG)-based payment system for hospitals includes a loading (of approximately 30 per cent) for Aboriginal patient admissions, which compensates for the additional costs associated with longer than average length of stay (caused by several factors). An equivalent budget mechanism to enable overall coordination of care, including necessary transport and accommodation services, may be the only effective way to improve patient journeys and 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.

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Lowitja
INSTITUTE

Australia's National Institute
for Aboriginal and Torres Strait
Islander Health Research

The Lowitja Institute

PO Box 650, Carlton South
Vic. 3053 AUSTRALIA

T: +61 3 8341 5555

F: +61 3 8341 5599

E: admin@lowitja.org.au

W: www.lowitja.org.au

