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# Managing Two Worlds Together:

Stage 2—Patient Journey Mapping Tools



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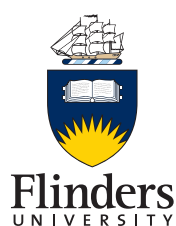
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Tjuta Tjukurpa  
(Marsupial Mouse  
Dreaming)*

**by Rama Sampson**  
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courtesy Better  
World Art

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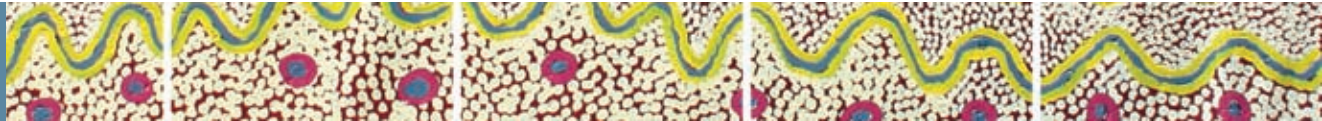
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# The Managing Two Worlds Together Project

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

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

Stage 1 of the project focused 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* (available on the website).

Stage 2 focuses on solutions and consists of a small set of action research projects. During 2012 the research team are working with partner organisations 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. The patient journey mapping tools are the first output of Stage 2.

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

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## Abbreviations and Terms

<b>ACCHS</b>	Aboriginal Community Controlled Health Service
<b>AHCSA</b>	Aboriginal Health Council of South Australia Inc.
<b>AHLO</b>	Aboriginal Hospital Liaison Officer
<b>AHS</b>	Aboriginal Health Service
<b>CHSA</b>	Country Health SA
<b>ECG</b>	electrocardiogram
<b>HACC</b>	Home and Community Care
<b>HCC</b>	Health Care Card
<b>MTWT</b>	Managing Two Worlds Together
<b>PATS</b>	Patient Assistance Transport Scheme
<b>RFDS</b>	Royal Flying Doctor Service
<b>RRMHS</b>	Rural and Remote Mental Health Service
<b>Carer</b>	Family member or friend who supports and cares for a patient
<b>Country</b>	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.
<b>Mainstream</b>	We use <i>mainstream</i> to refer to non-Aboriginal systems, institutions and practices.



# Introduction

This paper describes the patient journey mapping tools and frameworks used in the Managing Two Worlds Together (MTWT) Project. We sought to explore the barriers and enablers, gaps and strategies in relation to country Aboriginal patient journeys from rural and remote locations to city hospitals and return, from the perspective of the patient/client, their carer/family, and local health care providers.

Over the past decade, patient journey modelling and mapping have been used to highlight gaps in access, continuity and quality of care. 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, have 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). Other projects have focused on modelling within-hospital care processes to analyse patient flow (e.g., Ben-Tovim et al. 2008; Richardson, Casey &

Hider 2007) or for safety and quality purposes (ACSQHC 2010).

This paper has three sections. The first section outlines the patient journey mapping process developed in the MTWT project and the framework and tools used in this project. Section two details how these were used in each of four case studies. The third section offers guidance on using the tools in other contexts.

This project has focused on the specific needs and journeys of country Aboriginal patients in South Australia. In Stage 2 of the Managing Two Worlds Together Project, the research team is working with health staff in city and country sites to utilise and, where necessary, adapt the tools for local use. We suggest that the tools are applicable and adaptable for a wider range of patient groups, locations, journey types and health care settings. Readers are encouraged to adapt them for use in their own context.

# Section 1: Patient Journey Mapping

This section describes the process, frameworks and tools of patient journey mapping developed by the MTWT team.

## Ethics, partnership agreements and project management group

Before beginning the research, we sought agreement from 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—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 broader project

The patient journey mapping is one part of a broader project. Prior to beginning patient journey mapping we conducted several literature searches and examined the overall pattern of admissions for 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.

Qualitative studies based on the views and experiences of rural Aboriginal patients and their carers, and of staff who provided care for them in city and country hospitals and health services, were conducted. 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 patients and staff experience and to identify the main problems and gaps.

## Patient journey data collection and analysis

With the agreement of patients and carers, four individual case studies were selected from the 21 patient and carer experiences reported in interviews. The cases were 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 the reasons behind particular actions being taken. City hospitals were not contacted due to concerns about patient confidentiality, so analysis was not informed by the insights of hospital staff. Potentially identifying details were altered to protect the privacy of the people and of the health services involved.

Each case study was written and mapped as a unique patient journey, using a narrative analysis method (Emden 1998); a framework based on five dimensions of health (AIDA and CHETRE 2010); and a different framework based on five underlying factors affecting patient journeys (MTWT 2011). The priorities of patients, families and health care providers were identified, as well as health service responses and gaps. The narrative method (Bolt 2009) was designed to enable the uniqueness and context of each story to be studied in detail.

The case studies were then considered collectively, and their implications for health care providers analysed, with particular reference to preparedness, the costs of complexity, and opportunities and potential strategies for improvement. These steps are outlined below in more detail.

Interviews were arranged, recorded and transcribed. The transcriptions were checked with patients, carers and or health care providers for accuracy (verification).

## Narrative analysis— writing the story

Emden's core story creation narrative analysis approach was used to write the patient's or carer's story into a succinct one- to two-page summary. The process is done in eight steps:

- Read the full interview text several times to grasp its content.
- Delete all interviewer questions and comments from the full interview text.
- Delete all words that detract from the key idea of each sentence or group of sentences uttered by the respondent.
- Read the remaining text for sense.
- Repeat Steps 3 and 4 several times until you are satisfied that all key areas are retained and all extraneous content is eliminated. Return to full text as often as necessary to recheck.
- Identify fragments of constituent themes (subplots) from the ideas within the text.
- Move fragments of themes together to create one coherent core story.

- Return the core story to the respondent and ask, 'Does it ring true, and do you wish to correct/develop/delete any part?' (Emden 1998: 35).

The story summaries were also checked for accuracy with the patients, carers and health care providers.

## Frameworks for analysis

The story summaries were then used in a process of analysis designed to make the complexities of the patients' and carers' journeys, and the causes of that complexity, explicit and 'visible' for use in designing improvements.

### Five dimensions of health for country Aboriginal patient journeys

One of the challenges faced by all those who must 'manage two worlds together' is to be able to understand the perspectives and priorities of the other groups involved. In order to be able to 'see' the perspectives and priorities of patients and carers, the research team sought a contemporary definition of health relevant to country Aboriginal people.

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)—which build on existing definitions of Aboriginal and Torres Strait Islander health (including NAHS 1989 and Milroy 2010). The elements of the model, as used in this project, are explained in Table 1 on the next page.

This comprehensive view of health and wellbeing was used to specify the many aspects of people's health and life that were affected by their health problems and the experience of receiving health care, including city hospital care.

**Table 1:** Five dimensions of health

<b>Dimensions</b>	<b>Explanation</b>
Physical or biological	Morbidity, mortality, chronic conditions, self-reported health
Psychological or emotional	Levels of stress, transgenerational and cumulative trauma, freedom from shame, and other effects of racism and discrimination
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	Hope and despair; recognition and respect for Aboriginal people, worldviews, knowledge, values and aspirations (as experienced and as enacted in policy and programs)
Cultural integrity	Levels of community control of health; education, land rights, police and fire protection

## Five factors that affect access and quality of care

The team also needed a way to make visible the effects of several important factors in the context for patients and for the health system. The table below describes five factors that impact on access and quality of care, as identified as part of the MTWT project. Not all country Aboriginal patients will experience all factors, but many will experience a high number of them: it is the interaction among the factors that makes access to good health care more difficult.

This framework was used to specify the underlying factors and their effect on the journeys of the patients.

**Table 2:** Five factors that affect access and quality of care

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

# Chronological mapping of narrative

Once important elements in the experience of patients and the health care context were identified, the following table was used to enable the experiences and priorities of patients and carers, and of health care providers to be mapped and contrasted. It assisted us to identify more clearly the complexities, gaps and responses that arose in each journey.

**Table 3:** Chronological mapping using multiple perspectives

	Patient history	Diagnosis/referral	Trip to city	Pre-admission	In hospital	Discharge/transfer	Trip home	Follow-up
Patient journey								
Family/carer journey								
Patient priorities, concerns and commitments								
Health service priorities								
Service gaps								
Responses to gaps								



## Section 2: Case Study Examples from MTWT Project

This section describes the process and steps used for each of the four case studies in Study 4—Complex Country Aboriginal Patient Journeys. The team worked with patients, their carers and local health staff to identify the issues for each journey. When necessary, additional tools and tables were created to record specific issues or aspects.

### Case Study 1: Flying blind

This case study identifies issues for remote country Aboriginal patients seeking specialised care in the city.

#### Collection of data

1. We rang health and support services in a remote town and made a time for two researchers, one Aboriginal and one non-Aboriginal, to meet managers and staff to discuss the research. We also enquired about the best process for meeting Elders in the town to discuss the project with them. Letters/emails were sent with information about the project aims, timelines, and invitations for staff and patients and carers to be involved.
2. We met with management and staff, made arrangements and conducted staff interviews. We met the Elders and spoke about the project. Health staff and Elders shared information about the project with community members, and the invitation for them to be involved in interviews.
3. A group of senior Aboriginal Elder women requested a focus group (rather than individual interviews) to be held at the Aboriginal aged-care facility, with the aged-care bus used to pick up community members who were to be involved.
4. We returned to the remote town and met with the women and took notes rather than audio taping the focus group, as was the women's preference. Some of the community women and the manager interpreted for those for whom English was a less-used language. They were experienced interpreters, and the group's preference was for internal rather than external interpreters to be used.
5. The notes were then transcribed, checked and sent back to the aged care facility. The aged-care manager worked with the Elder women (some of whom had vision impairment) to verify the transcription was correct, provided clarification and discussed these with us by phone.
6. A few months later one of the women's stories shared in the focus group was selected by the research team as a case study for patient journey mapping. We rang the health care manager to ask if the woman involved would consent for this to occur. The manager said that unfortunately this woman had recently died, and would not be able to give consent, and she did not think her family members were involved enough in the original process to consent on her behalf. In addition, this woman had died before she had received eye care. Aged-care staff were very upset about this, and had recently supported another woman with blindness to access care. They took additional steps to ensure a successful patient journey for the second woman, but this had left them severely out of pocket. The manager invited us to return and record this recent story, with the Elder woman's permission, so that they could use it for justification and future planning, as well as for the MTWT project.

7. We returned to the remote town, and interviewed the manager and staff members/ carers who had accompanied the client, with individual informed consent. We also spoke briefly with the woman herself, as her preference was for the manager to speak on her behalf, and she was busy 'seeing' family members and visitors.
8. All recordings and notes were transcribed and written into one account that de-identified individual staff comments (to maintain privacy/ staff confidentiality). The final narrative was shared with the manager and patient for verification. Tables were used to identify the five dimensions of health, the five factors and to map the patient journey chronologically. Additional tables were created to analyse the distribution of complexity that occurred, for the client, the aged care facility, the local health service and city hospital in both the treatment and follow-up care. Another table was designed to record the expenditure for this journey.
9. A decision was made to include the first woman's story briefly, to provide reasoning for the staff actions taken in the second woman's story.

## The narrative

### 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 meet with a visiting ophthalmologist to discuss her increasing blindness. The patient was then 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 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, who had been 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 for her.

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 time.

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 12 hours. They were all exhausted when they arrived in the city, only to find that the motel was not suitable for their disability needs and they had to arrange alternative accommodation.

There were three pre-admission clinic appointments the next day, which took all day with the patient becoming 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 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 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 then drew the curtains and spoke quietly to the woman, reassuring her that she would not leave her, and reminding her of the importance of the surgery, and that she would not want to return home without her eyesight, as had 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 the recovery staff asked her 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 3am hospital staff brought in a fold-out bed for the carer.

The next day, the specialist saw the patient 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 it 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, which was a major saving in time, effort and money for all involved.

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.

## The five dimensions of health

Based on the narrative (story), we used tables to identify the specific aspects of health and care that impacted on this person and her care providers. We began by considering the 'whole person' experiencing the health journey, a person whose life is (potentially) affected in all aspects—not just physical health. All aspects are important to the person, and are likely to affect health care decision-making, planning and delivery.

For this story, we analysed the dimensions of health for both the usual situation and the new challenges involved in undertaking the health care journey, because the new challenges were so extensive in both cultural and practical terms. Some later case studies illustrate a simpler approach to the analysis.

**Table 4:** Case Study 1—Health dimensions

<b>Dimensions</b>	<b>Usual situation</b>	<b>New challenges</b>
<b>Physical/ biological</b>	Aged-care staff assist with mobility and daily needs of wheelchair for longer trips due to blindness.	Travelling to regional town stressful and tiring for no immediate gain.  Trip to Adelaide even more tiring.
<b>Psychological/ emotional</b>	Lives in a Community Controlled Aged care facility near her community.	Is frustrated by continuing blindness and is concerned about attending Adelaide hospital.
<b>Social and wellbeing</b>	Elder woman well respected in community.  Lives in supportive Aboriginal community controlled aged-care facility.  Blindness is impacting on her ability to be independent and fully active, and on her quality of life—no longer interested in being involved in community events.	Uncomfortable in other people's environments.  Traffic, noise, too many people in the city.
<b>Spirituality</b>	Lives near homelands with other Elders.  Maintains important spiritual and Christian connections.  Feels stronger and well when on homelands.	Going onto someone else's Country is like going overseas; brings sense of loss of spiritual connection to land.
<b>Cultural integrity</b>	Is recognised as senior Elder.  Failing eyesight is restricting her activities.  English is 4th language.  Speaks own language to friends, family and staff members, and Aboriginal English.  All the women residents sleep in rooms with a <i>malpa</i> (friend/companion)—they never sleep alone.	No one speaking her language.  Not being able to communicate well.  Lack of gender-specific model of care.  Lack of trusting relationships.  Experiences of being treated disrespectfully, people talking over her, and not listening to her concerns.  Knowing men are standing all around her and them wanting her to take off her underwear.  Not being accompanied by a <i>malpa</i> .  Needed aged-care worker to stay in the hospital room with her to feel safe.



## The five factors

We then considered how the five factors impacted both locally and when she travelled to the city for care. Aged-care staff helped to identify impacts.

**Table 5:** Case Study 1—Factors affecting access and quality

<b>Underlying factors</b>	<b>Local health services</b>	<b>City hospital</b>
<b>Location/setting</b>	Lives in remote aged-care facility, with family nearby to assist.	Flying home is not an option after eye surgery.  Very few close family members in Adelaide.
<b>High burden of illness and interactions with health system</b>	<b>Primary care</b> —visiting eye specialists at ACCHS.  <b>Secondary care</b> —attends hospital located near aged-care service.  Local health services/visiting specialists not able to perform complicated eye surgery.	<b>City hospital</b>  Large multi-storey building in busy city environment.  Acute-care setting is strange and difficult to understand.  Has specialised machines and skilled staff required for eye surgery.
<b>Language/communication</b>	English is fourth language.  Aged-care staff speak in a way that she understands; some staff speak her first three languages.  Staff communicate and approach her carefully and respectfully in consideration of her blindness.	City hospital staff spoke quickly and over the top of her. They approached her without explanation or adequate communication about consent to care processes  Familiar Aboriginal care provider is needed to advocate and interpret for patient
<b>Financial resources</b>	Majority of pension goes to aged-care service, which provides most daily living needs.  Cost of accessing local services negligible.	Needs assistance with travel, accommodation and additional out-of-pocket expenses such as food.  Pension continues to pay aged-care service when in city.  Patient and escorts provided with travel allowance by aged-care service.
<b>Aboriginal/ non-Aboriginal</b>	<b>Aboriginal health services</b>  Is cared for by supportive and respectful Aboriginal and non-Aboriginal staff in aged-care service and ACCHS.  <b>Hospital services</b>  Staff in local hospital respond variously; aged-care staff provide ongoing support during hospitalisation.	<b>Mainstream hospital</b>  Unknown non-Aboriginal staff, many lacking skills needed to care for country Aboriginal people.  No contact with AHLOs in outpatient appointments.  Many male staff.  Lack of understanding of her senior Elder status.  Various levels of recognition of role of aged-care workers.

## Chronological mapping of patient journey—from multiple sources

Working with the tables above enabled us to ‘pick apart’ the overall complexity of this patient’s journey, in order to identify the impacts and the aspects of the journey that could be improved. We then used the table below to map the journey chronologically from multiple perspectives, and to identify the significant gaps and strategies, barriers and enablers to good care. This highlighted problems with access, a

**Table 6:** Case Study 1—Journey mapping from multiple perspectives

<b>Case Study 1</b>	<b>Patient history</b>	<b>Diagnosis/ referral</b>	<b>Trip to city</b>	<b>Pre-admission</b>
<b>Patient journey</b>	Senior Elder woman experiencing long-term blindness.	Delayed. Repeated trips to nearest regional city.	Flight for assessment. Aged-care bus for transport.	All-day appointments very tiring.
<b>Family/local care provider journey (aged-care facility)</b>	Assisted with lifestyle impacts of long-term blindness.	Encouraged diagnosis through referral and re-referrals, advocacy to assist access to care.	Provided bus, company and advocacy.	Advocacy and interpreting.
<b>Patient priorities, concerns and commitments</b>	Isolation and daily limitations.	Raised hope, then a long wait.	Long way—2 days travel.	Long appointments, got tired.
<b>Health service priorities</b>	Treating vision impairment and co-morbidities.	Access to appropriate specialist and facility.	Specialist surgery which is located in Adelaide.	Pre-operative checks.
<b>Service gaps</b>	Poor access to vision screening in remote areas.	Lengthy and delayed referral process.	Initially no PATS payment arrangements.	No pre-admission consent arrangements. No interpreters provided by hospital.
<b>Responses to gaps</b>	Fred Hollows program.	Aged-care service arranges repeat visits.	Some travel expenses back-paid by PATS.	Pre-operative tests in same week as operation to prevent repeat trips to city. Aged-care service provide own interpreter.

delayed referral process, informed consent and interpreter availability, lost opportunities for collaboration between health services, and the patient feeling culturally and personally unsafe. Responses to these problems were mainly provided by the aged-care facility. However, the hospital provided pre-admission tests in the same week as admission, and some hospital staff responded flexibly and creatively to needs and situations as they arose.

<b>In hospital</b>	<b>Discharge/ transfer</b>	<b>Trip home</b>	<b>Follow-up</b>
Overnight stay.  Uncomfortable in hospital environment.	Discharged to aged-care service and local GP.	By aged-care bus.	Expected to return to city, but couldn't.
Advocacy and support for cultural safety.	Support and celebration.	By aged-care bus. Driver drove slowly at times so she could see scenery.	Arranged appointment with visiting ophthalmologist.
Became scared, labelled as violent.	Happy to be going home.	I can see!	Can't go back to city for check up—too far.
Surgical procedure.  Staff safety. Local GP/aged-care service.  Discharge drugs.	Local GP/aged-care service.  Discharge drugs.	Arranged by aged-care service.	Hospital specialist to review patient after 7 days in city.
Non-recognition of patients need to feel safe.  Labelling as violent by hospital staff.	Lack of collaboration for realistic follow-up options.	No involvement by health system.	No local options considered by hospital specialist.
Aged-care worker acts as advocate.  Anaesthetist's responsiveness and flexibility.  Ward staff support aged-care worker to provide direct patient care.	Timely and adequate discharge drug provision.	Aged-care service provided transport.	Visiting specialist to remote locations through AHCSA.

## Additional table

An additional table was developed specifically for this case study to assist the aged-care facility to track and justify the expenses they incurred in supporting this Elder woman to receive successful eye surgery and follow-up care. This table also highlights the differing distribution of costs when services can be provided locally rather than centrally.

Based on the costs of the trip to Adelaide for surgery, we estimated that if the woman had

returned to Adelaide for a check-up three days after returning home, the cost to the aged-care facility would have been approximately \$5000. In comparison, the cost of seeing the visiting ophthalmologist was less than \$100, leading to significant savings locally. The aged-care facility does not receive any funding to support patients attending city hospital appointments beyond PATS payments. Instead, it utilises its limited social and cultural program funds. A large commitment was made from a very small bucket of money.

**Table 7:** Case Study 1 — Distribution of costs

Distribution of costs	Amount
<b>For surgery in city</b>	
<b>Patient</b>	
Nil \$ cost but high social, emotional, spiritual and physical cost of leaving home and travelling long distances for care.	\$0
<b>Aged-care facility</b>	
Aged-care staff provided caring role, with agency staff employed to back-fill; and regular staff do overtime and night shift.	
Carers x 2 (second carer called in to assist)	\$2565
Agency back-fill x 2 (including airfare and accommodation costs)	\$3500
Driver	\$845
Bus costs, accommodation, meal allowances for patient, driver and aged-care workers	
Fuel for bus	\$360
Adelaide accommodation, 4 nights x 2 units	\$1260
Accommodation on way home x 2 rooms	\$325
Meal allowance \$355 x 1 resident, 2 carer, 1 driver	\$1420
<b>Local health agency</b>	
CHSA PATS travel reimbursement to aged-care service	(-\$300)
<b>City hospital</b>	
Usual care costs, covered from hospital budget (State and federal sources).	Not known
<b>For follow-up care—locally</b>	
<b>Patient</b>	
Care close to home—negligible time, low stress, low social, emotional, spiritual cost.	\$0
<b>Aged-care facility</b>	
1 worker and 1 driver accompany patient to appointment for 20 minutes	
Travel time 5 mins	Under \$100
<b>Local health agency/CHSA</b>	
No cost for transport and accommodation	\$0
<b>City hospital</b>	
Nil OPD appointment costs	
Specialist needs to engage with another service/practitioner to ensure follow-up.	\$0
<b>Visiting specialist costs</b>	
Met through Commonwealth extended care funding, paid directly to specialist or through employing hospital.	Not known

## How this case study was used

This patient journey case study was used in many ways, as agreed at the beginning of the research/aged-care facility partnership.

The aged-care manager used this case study:

- to support discussion at a joint meeting of the Council of Aboriginal Elders and the Aged Rights Advocacy Service,
- as a basis for discussion in a board of directors meeting to justify cost blow-out for this resident's trip to Adelaide, and
- to highlight local issues/areas for future collaboration in discussion with the local Aboriginal Health Service.

The aged-care facility also planned to work on the case study framework so that it could be used to accompany their Aged Care DVD and Learning Package (funded by HACC). It could then become a training tool for new staff, and for staff in other health services.

An aged-care and HACC consultant working with this case study anticipated its wider use:

- as a learning tool,
- for aged care staff education,
- to link patient journey preparation to existing policy documents and charts, and
- as an audit tool to follow a patient's experience in hospital.

## Case Study 2: Travelling in pain again and again

This case study highlights issues for country patients undergoing repeat trips to the city, having difficulty with coordination and follow-up care, and coping with ongoing pain and mental health concerns.

### Collection of data

1. We spoke to the Aboriginal health service manager in a rural city about the project, met with staff and interviewed interested staff members. We arranged to return for patient and carer interviews.
2. One Aboriginal worker became the main contact person and spoke to patients and carers in the region about the research and provided them with our contact details.
3. Patients chose whether they would like to be involved or not. Both the staff member and research team stressed that their decision to be involved in the research would not impact on their health care. Those interested nominated a time and place to meet for interviews.
4. This patient chose to be interviewed by phone. A call was made at a pre-appointed time and notes taken. Oral consent was given and recorded.
5. The notes were transcribed and sent to the patient for verification.
6. At a later time, this interview was chosen as a case study, which was agreed to by the patient.
7. A decision was made by the research team that this story needed to be significantly de-identified, and details have been changed to conceal the identity of the person, location, family members and sensitive aspects of illnesses and treatment.



## The narrative

### 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 partner (or their parents, if his partner 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 subsidy payments assisted with the cost of petrol, but did not cover accommodation because the man was not a health care cardholder.) 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, for which the patient returned. A follow-up MRI showed problems that needed further review.

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 become 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 one day attempted suicide, but luckily 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 (RRMHS) workers very supportive and followed their suggestion that he be admitted to the nearest hospital, with the RRMHS 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 RRMHS and he valued talking to someone whom 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 as well as by 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.

## The five dimensions of health

Based on the narrative (story), we used tables to identify the specific aspects of health and care that were impacting on this person.

**Table 8:** Case Study 2—Health dimensions

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

## The five factors

We then considered how the five factors impacted both locally and when he travelled to the city for care.

**Table 9:** Case Study 2—Factors affecting access and quality

Underlying factors	Local health services	City hospital
City/country	Short distance to local services.	Ten-hour car journeys painful and time consuming; driving in the city is a challenge.
High burden of illness	Local GP overworked, quick appointments, scripts renewed without detailed discussion, no coordination of care. Local mental health services work with both local hospital and RRMHS. Local Aboriginal Health Service provides coordinated care.	Treatment delays and failures; specialist and hospital focus on one aspect of health care needs only; remote mental health service provides specialist and coordination role.
Language & communication	Rushed communication with GP Clear communication with mental health, RRMHS and AHS staff	Finds specialist intimidating and communication about their condition, medication and treatment plan poor.
Financial resources	Low cost to access local services	High costs to patient and family of private care, travel, lost income; limited assistance from PATS.
Aboriginal/non-Aboriginal	Originally unaware they were eligible to use local Aboriginal health service. Later AHS provided coordinated and timely care.	Lack of cultural/community support in private hospital; lack of social interaction with staff.

## Chronological mapping of patient journey

Working with the tables above enabled us to ‘pick apart’ the overall complexity of this patient’s journey, in order to identify the impacts and the aspects of the journey that could be improved. We then used the table below to map the journey chronologically from multiple perspectives, and to identify the

**Table 10:** Case Study 2—Journey mapping from multiple perspectives

Case Study 2	Patient history	Diagnosis/referral	Trip to city and pre-admission
<b>Patient journey</b> Orthopaedic	Middle-aged man living in rural area. Ongoing orthopaedic problems and pain.	Saw local GP, referred to specialist in Adelaide.	Difficult day trips to and from city. 4 outpatient trips required (3 for appointments with 2 specialists; one for MRI scan).
Mental health	Became depressed, attempted suicide, family member intervened.	Rang Mental health line—admitted to local hospital with Adelaide support.	
<b>Family/carer journey</b>			Partner took day off work or, if unavailable, one of their parents went.
<b>Patient priorities, concerns and commitments</b>		Not referred to correct specialist.	City specialist prescribed strong pain relief, particularly for long trips to city, but patient became addicted—not warned of risk of addiction.
<b>Health service priorities</b>		Appropriate referral pathways.	Access to specialist care.
<b>Service gaps</b>		Local GP under-resourced, rewrote scripts without review, which contributed to addiction. No visiting orthopaedic specialist access.	Have to pay first night accommodation as not HCC holder, so don’t qualify for assistance—do day trips instead. No visiting orthopaedic specialists.
<b>Responses to gaps</b>		Mental health-line a positive experience.	PATS assistance for transport.

significant gaps and strategies, barriers and enablers to good care. This highlighted significant service gaps involving communication with and access to city hospital and GP services, and responsiveness and communication between rural and remote mental health services and the local hospital, with case management and communication provided by the Aboriginal Community Controlled Health Services.

In hospital	Discharge/transfer	Trip home	Follow-up
Multiple specialist appointments. Had 2 operations in a private hospital (to reduce waiting times) and 3 further trips for MRIs and follow-up	Unclear about what specialist was saying. GP very busy and explained very little.	From assessments and check-ups via car; from surgery via plane.	Local GP.
Admitted to local hospital for mental health problems, with local and city-based mental health support.	Ongoing mental health team support. Went to AHS which explained and coordinated all aspects of care.	From local hospital via car.	Mental health line. Was encouraged to use AHS and found it was the most coordinated care.
Partner came and stayed with family in Adelaide.	Partner did not understand specialist any more than patient did.	Patient and partner flew home together on commercial flight.	Family supportive.
Not understanding process or prognosis. Found specialist intimidating and communication lacking. No Aboriginal or rural liaison person in private hospital. Couldn't work out phone by bed. Felt unsupported.	Sometimes didn't purchase all medications prescribed as can't afford them.	Adequate pain relief for flight. Car trips very uncomfortable. Treatment did not resolve pain.	Patient seeking someone who has time to talk and listen.
Op to reduce pain and improve mobility and quality of life. Mental health.	Continuity of care.		Ongoing mental health care support.
Poor communication between specialist and local GP. Poor understanding of distances and appropriate appointment times. Little support available in city private hospital, patient got lonely.	Patient confused about treatment plan with specialist. Poor quality post-operative information sent to GP and GP too busy to explain in any detail.	Repeated day trips.	
Good networking between RRMHS and local hospital— immediate and supported admission.	Clear treatment plan with RRMHS.	PATS reimbursement for petrol costs. PATS paid for post-operation flight for patient and family. Member.	AHS doctor assisted with withdrawal, and cost and regimen of ongoing medications. Ensured patient understood treatment options, all drugs, and case management plans.

## Case Study 3: Will I ever get home again?

This case study highlights issues for patients and their carers from remote areas who need to relocate medically for health care, and specifically for renal care.

### Collection of data

1. We spoke to the renal unit manager in a rural city about the project. We met and interviewed interested staff members and arranged to return for patient and carer interviews.
2. The renal manager explained the research purpose and process to patients and invited anyone who was interested to become involved. We came to meet renal patients in the renal unit (their choice of neutral space) and then they decided if they would like to become involved in interviews.
3. Those interested chose a time and location that suited them. Some chose the renal unit, others their front porches or gardens at home. The renal manager provided safety assurances regarding individual home visits. Both the renal manager and the researcher stressed that the decision to be involved, or not, would not impact on their health care, and that interviews could be stopped at any time if the patients felt unwell or uncomfortable.
4. This particular patient chose to be interviewed in the renal dialysis unit while having dialysis, with their partner present.
5. The patient and their partner told their stories in an interview together. Notes were taken rather than a recording, as this was their preference.
6. The patient gave their consent for the renal manager to clarify any points, and explain certain procedures to us.
7. Together the renal staff and research staff ensured that the patient and carer understood that the questions were part of a research project, not part of their treatment plan. There was a high potential for confusion due to English being the patient's third language, and

that they desperately wanted to return home. The notes were transcribed and checked with the patient and renal manager for verification.

8. At a later time, this interview was chosen as a case study. We rang the renal manager to check the contact details of the patient to discuss this possibility. The renal manager said that tragically the patient's partner had died, and they had moved interstate. We spent some time considering what best to do.
9. A decision was made by the research team that this story needed to be significantly de-identified, and details have been changed to conceal the identity of the person, location, family members and sensitive aspects of illnesses and treatment.

### The narrative

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 had been surviving on one pension and were unable to pay bills. When the couple lived in their home community they ate a lot of bush tucker, and with many services supplied at low cost they could live well on one pension. However, in the regional town they had to purchase all 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 they shared their concerns with the renal nurse, who arranged social work and other assistance, including pension payments to which they were entitled.

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. On one occasion the renal nurse called the Royal Flying Doctor Service to retrieve the patient when she unexpectedly got 'rained in', and 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 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 closer 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.

### The five dimensions of health

Based on the narrative (story), and with the assistance of renal staff, we used tables to identify the specific aspects of health and care that impacted on this person and her partner.

**Table 11:** Case Study 3—Health dimensions

Dimension of health	Usual situation	New challenges
Physical or biological	Hard-working woman (self-description).	Suddenly becomes ill with renal disease.
Psychological or emotional	Strong psychological ties and important role within community.	Loss of close connection to land, family and community, finding housing, loss of partner.
Social and wellbeing	Family has own farm and home, livestock.	Has to move to live near dialysis unit, financial concerns.
Spirituality	Strong ties to homelands.	Living away from homelands.
Cultural integrity	Important family and community leader in home-lands.	Only able to return intermittently for up to 2 days at a time.

## Chronological mapping of patient journey

Working with the tables above enabled us to ‘pick apart’ the overall complexity of this patient’s journey, in order to identify the impacts and the aspects of the journey that could be improved. We then used the table below to map the journey chronologically from multiple perspectives, and to identify the significant

**Table 12:** Case Study 3—Journey mapping from multiple perspectives

<b>Case Study 3</b>	<b>Patient history</b>	<b>Diagnosis/ referral</b>	<b>Trip to city</b>	<b>Pre-admission</b>
<b>Patient journey</b>	Aboriginal Elder in their 70s—hard working. Lives with family, homes and livestock.	Sudden illness and kidney disease.	Emergency via RFDS.	Immediate admission.
<b>Family/carer journey (partner)</b>	Close-knit family and community.	Very upsetting diagnosis.  Supports patient to get help.	Followed partner to city via car then bus.	Needed to find hospital and accommodation.
<b>Patient priorities, concerns and commitments</b>	Family, land, livestock.  ‘Hard worker’ who wants to get back to working.	Acutely ill, needs help.	Wants to get well.	Very unwell.
<b>Health service priorities</b>	No obvious health issues.	Acute illness requiring immediate hospitalisation.	Acute care and stabilisation en route.	Emergency treatment.
<b>Service gaps</b>		? if renal disease could have been detected earlier, or if an acute episode?	? what level of support was available for partner’s journey?	
<b>Responses to gaps</b>				

gaps and strategies, barriers and enablers to good care. This table highlights the personal, social, cultural and financial complexities involved in medical relocation, and the crucial support and referrals provided through the regional renal unit.

In hospital/city	Discharge/ transfer	Trip home	Follow-up
Diagnosis, treatment and commence dialysis.	Transfer to outpatient dialysis appointments.	Can't go home.  Medical relocation to regional town for ongoing dialysis.	Ongoing dialysis in regional town.
Stayed in Aboriginal hostel and travelled daily via Corporate Shuttle to visit.	Husband moves to regional town.  Family still in homelands.  Stays with partner.	Only occasional visits home.  Sees remaining family only occasionally.	Is also developing kidney disease themselves.  Are living on one pension.
Renal staff provide quality clinical care and meet most patient needs.	Wants to go home, or at least be nearer to home.	Has to relocate medically to live near regional dialysis unit; can only visit home.	Wants to return home to live.  Accommodation and financial concerns.
Stabilisation, treatment.  Ongoing dialysis.	Transfer to regional renal unit.	Can only have 3 days without dialysis.	Effective dialysis.  Respond to holistic needs of patient.  Assist with arranging suitable housing.
An overestimation of patient's understanding of English and medical terms—? extent of interpreter use?	Difficulty accessing suitable accommodation and transport necessary for relocation.	No services within 700kms of home.	
Good clinical and general care by hospital staff.	Support of renal unit, community health and support services.	Nearest regional city has dialysis beds.	Renal nurse assists with arranging accommodation and social work assistance for financial concerns.  Renal unit assists patient to get home as much as possible.

## The five factors

We then considered how the five factors impacted both locally and when she travelled to the city for care.

**Table 13:** Case Study 3—Factors affecting access and quality

<b>Underlying factors</b>	<b>Home community</b>	<b>City—assessment and dialysis</b>	<b>Regional—dialysis</b>
City: country	Lives on homelands with family, has livestock and bush sites.	Long distance to city.	Closer to home in rural setting, but still a long way from home.
High burden of illness	Local AHS near home, good for PHC but unable to assess or treat new kidney disease—transferred out.	Rapid assessment and dialysis care in high-rise building in city.	Ongoing dialysis care in single-storey regional country hospital.
Language and communication	Family and local community members including remote clinic staff communicate in her first language and some English.	Speaks everyday English but finds medical terms and explanations confusing.	Other patients sometimes interpret and local staff know some words in her first language.
Financial	Community ownership of land—not an individually owned asset (like a farm).	Need to stay in hostel and buy all goods.	Need to pay all accommodation, utility and food bills.
Aboriginal/ non-Aboriginal	Aboriginal staff and visiting remote area nurses and doctors.	City hospital, with many Aboriginal patients in renal care and supportive staff.	Rural hospital—higher proportion of Aboriginal patients; staff supportive and provide wider case management.

## Case Study 4: Caring for my husband

This patient journey highlights the experiences and challenges for carers.

### Collection of data

1. We discussed the project with the local Aboriginal Health Service Manager, with a focus on staff and patient interviews. Staff interviews were conducted, then we returned for patient and carer interviews. The Aboriginal health team distributed flyers and discussed with clients the possibility of being involved.
2. We were invited to attend a local health group meeting. After introducing ourselves, we discussed the project aims and invited patients and carers to be involved in interviews.
3. Participants expressed their interest in participating and nominated a time and place to meet for an interview—at home, the health centre or in a public place.
4. The carer nominated to meet in a public venue and asked the Aboriginal Health Service Manager to accompany her for support as she had only recently become widowed.
5. The interview was conducted at the time and place agreed. Notes were taken rather than audio recording as preferred by the participant.
6. Notes were transcribed and posted to the participant for verification. We made a follow-up phone call to check for accuracy, and also to check on the participant's welfare after she had shared her experiences of caring for her husband. Counselling options were offered and the woman continued to be supported by the local Aboriginal Health Service Manager and team.
7. At a later date, this participant's story was chosen by the research team as a potential patient journey case study. We rang the Aboriginal Health Service Manager to check on the carer's wellbeing, and then

rang the carer to discuss. We raised the implications of potential public exposure of private concerns. The carer—an experienced board and committee member with a deep understanding of the implications—agreed that her story could be told.

8. The case study was written in a narrative form with health dimensions, five underlying factors, and chronological mapping tables used. We removed identifying details, including the exact location, family member details and health services involved. The final complete draft was sent to the participant for comment, changes and her approval. We removed identifying details regarding the person, location, family members and treatment.
9. We made a final telephone call and welfare check to ensure the carer was OK prior to the launch of the findings of this project. The carer said that she had made copies of the case study to share with family and friends, and found that re-reading and re-visiting her experiences had enabled her to acknowledge just how hard it had been, and to begin healing.

### The narrative

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 to a city hospital. The specialist requested that the husband be admitted by 5pm that afternoon, so they went home and packed their clothes and picked up their youngest child. The husband, being the only driver in the family, drove their car 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 in 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. One day the carer had to go back home and sort things out and asked another family member to come in and be with him. They didn’t come and the patient became very distressed, and began ringing his wife asking her to come back. Luckily other family members had flown in from interstate and were able to be with him until his wife came back to the city.

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 of the 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. 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 other nurse would not be assigned to her husband 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, and the wife alerted staff when she arrived on the ward.

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, so the wife asked to see another social worker. An older, more experienced social worker came and assisted them to arrange a will. At the wife’s request, she also arranged a meeting for the

doctors to explain the facts of the prognosis with the couple’s older children. 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 (this situation has now been remedied). 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 quickly became too unwell to transfer and he 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.



## The five dimensions of health

Based on the narrative (story), we used tables to identify the specific aspects of health and care that impacted on this person and his carer.

**Table 14:** Case Study 4—Health dimensions

Dimensions	Analysis
Physical or biological	Acute terminal illness and pain.
Psychological and emotional	Distressed by lack of privacy when receiving shocking news, adjusting to diagnosis and preparing for death, and by disrupted processes of care.
Social and 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.

## The five factors

We then considered how the five factors impacted on the patient and carer. The carer herself helped to identify these impacts.

**Table 15:** Case Study 4—Factors affecting access and quality

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.
Language and communication	Poor communication of bad news. English is first language.
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.

## Chronological mapping of patient journey

Working with the tables above enabled us to ‘pick apart’ the overall complexity of this patient’s journey, in order to identify the impacts and the aspects of the journey that could be improved. We then used the table below to map the journey chronologically from multiple perspectives, and to identify the significant

**Table 16:** Case Study 4—Journey mapping from multiple perspectives

<b>Case Study 4</b>	<b>Patient history</b>	<b>Diagnosis/referral</b>	<b>Trip to city and pre-admission</b>
<b>Patient journey</b>	Husband (non-Aboriginal) was working and felt unwell.	GP visit led to rapid blood test and CT scan locally. GP diagnosed brain tumours.  Referred to specialist—patient told to get to city hospital by 5pm Friday.	Husband drove self and family to city arriving by 4.30pm.
<b>Family/carer journey (wife)</b>	Wife pushed husband to go to GP.	Accompanied husband to all appointments.	Wife can’t drive.  Husband’s erratic driving to hospital concerning but no other option available.
<b>Patient priorities, concerns and commitments</b>		Find out what is wrong and get back to work.	Get there on time.
<b>Health service priorities</b>		Accurate diagnosis.	Get to specialist care before weekend.
<b>Service gaps</b>			No transport support to get to city safely.
<b>Response to gaps</b>		Local X-ray and investigation services.	Nil available.

gaps and strategies, barriers and enablers to good care. Again the carer assisted with this table, which identifies significant transport, communication and support gaps, as well as the various ways that hospital staff and support services responded to their needs. The carer assumed an advocacy role to ensure her husband received quality care.

In hospital	Discharge/transfer	Trip home	Follow-up
<p>Patient put into 4-bed bay.</p> <p>Terminal nature of condition communicated abruptly in public.</p> <p>Radiation therapy.</p>	<p>Discussed transfer to hospice but too ill.</p> <p>Died in hospital 5 weeks after admission.</p>	<p>Patient deceased.</p>	<p>Funeral.</p>
<p>Distress when doctor told poor prognosis and no privacy.</p> <p>Stayed with family and visited daily—stayed all day.</p> <p>AHLO support denied because patient not Aboriginal.</p> <p>Access to effective social work support delayed, second social worker very helpful.</p>	<p>Were planning transfer to hospice care, but her husband quickly became too ill to move.</p>	<p>Very sad to return home alone.</p>	<p>Family members arranged funeral.</p> <p>Local funeral home held the account until after superannuation payment.</p>
<p>Hated being in hospital, wanted wife nearby for support.</p>	<p>Get palliative needs met.</p>		
<p>Best possible treatment and care available.</p>	<p>Effective palliative care.</p>		
<p>Some staff communication and bedside skills lacking.</p> <p>Difficult for carer to access support services.</p>	<p>Palliative care provision in metro hospital medical ward.</p>		<p>Support for the carer.</p>
<p>Other staff responded to carer's requests for assistance or action.</p>	<p>Hospital was planning for transfer to more appropriate services.</p>		<p>Local Aboriginal health service providing ongoing support and services as needed.</p>

## Section 3: Using the Tools

In this section we offer suggestions about how the patient journey mapping tools may be used in other contexts, including some tips about planning, adapting the tools and utilising the results.

### Planning to use patient journey mapping

Before beginning patient journey mapping, there are points to consider.

#### 1. Check what ethics, permissions, management approval or partnerships are necessary for your setting and project

Research projects, internal audit and education processes will have different requirements.

Management and or ethics approvals may be required with/within:

- managers/health services/regions
- community groups/ community members
- reference groups
- ethics committees
- universities.

You may need or wish to seek permission or make agreements or partnerships with:

- health care organisation management
- community council or representative group
- individuals.

Consent may need to be sought at various levels including:

- verbal or written informed consent
- organisational
- community
- individual.

#### 2. Determine what kind of patient journeys you wish to record, and how you will go about it (the method). What is your main question or concern?

There are many different versions of patient journey mapping, with different options and aspects to consider, which may include one or more of the following.

Timing of actual journeys

- prospective—mapping journey of patient as it happens, from the beginning
- retrospective (past)—mapping past patient journeys.

Actual or generalised approach

- actual—following a single person's actual journey (requires greater ethical consideration but has the benefit of being a 'real' journey).

Generalised—presenting a 'typical' journey—based on participants' knowledge of 'what happens' and/or several actual journeys (removes/reduces privacy concerns but may not be as convincing).

Location

- within a specific health unit or speciality
- within a single hospital, health or support service
- across health and other sectors
- in a specific geographical location.

Focus

- a single illness—e.g., renal
- a specific approach or strategy—e.g., dialysis, chronic condition management
- a specific patient group or marginalised group—e.g., Aboriginal people, country people, young people, new arrival refugees.

### Analytical approaches

- narrative—exploring one person’s story and experience in great detail and telling their story as a whole
- thematic—drawing together themes from multiple stories.

### Methods

- interviews with patients, carers and /or staff members—individually or in groups
- participant observation—a staff member or researcher follows or accompanies a patient on their journey
- case note audit
- combination of methods above.

For actual case studies involving real patients:

### 3. Seek participants to be involved

Ensure ethics and/or other approval process is complete.

Seek participants to be involved, using whatever works best in your area—word of mouth, networking, flyers or advertisements.

Reinforce safety and privacy of participants—ensure that their decision as to whether or not to be involved will not have any impact on their health care, employment or any other aspect of their health and wellbeing. In relation to confidentiality and to prevent unintended harm, it is important to ensure that the person cannot be identified. Details that are not directly relevant to the patient story can be omitted or changed, and readers advised accordingly.

### 4. Record their story

Take notes or audio record as agreed; transcribe and verify with participant that it is correct.

### 5. Write the story/narrative

We used Emden’s core story creation narrative analysis, but a shortened or simplified version could be used by busy practitioners.

For generalised stories

Write a generalised story from a staff perspective or ward/unit experiences, based on staff knowledge, and actual patient journeys if documented journeys are available.

### 6. Use relevant tables or mapping tools

We used the five dimensions of health table to recognise the whole person entering the patient journey. These are applicable for a diverse range of patients and clients.

The five factors table highlighted the impact of underlying social and system factors on access and quality of care for country Aboriginal patients. The ‘Issues’ column could be adapted for other patient groups. For example, city/country could be deleted and the factors affecting urban Aboriginal people analysed; or ‘burden of illness’ could be deleted and ‘disability impact’ or ‘new arrival impact’ could be inserted.

The chronological mapping of the journey enabled us to see more clearly what was happening for patients, carers and health staff/services. The headings in this table could be adapted to meet other investigations, priorities and needs; for example, to identify reasons why people discharge early against medical advice, or whether a patient’s journey matches best practice standards.

When necessary we created additional tools to identify issues of complexity and financial costs. These tables are also adaptable to other issues and enquiries.

### 7. Determine what to do with the results and findings

Decide on the form and level of access to the story, in accordance with arrangements to ensure confidentiality for the patient or staff.

Use the information about issues or barriers to propose changes, and a process to implement changes, in the health care services that played a role in the journey. You may need to use other information about the health care processes to demonstrate that the barriers affect others, and to support the need for change.

## How some wards and units are using the tools in Stage 2

Some wards and units in city and country, primary health care and hospital settings have begun using the patient journey mapping tools for their specific education needs and clinical issues. These are shared here as examples and possibilities. The research team welcomes discussion and ideas about further use of the patient journey mapping tools, and encourages wards and units to adapt the tools for their own use.

### Renal health care

Renal wards and units in country and city locations are working to include the case study for in-service education. Some nurses are adapting the renal patient journey story, or writing new patient stories based on current patient and staff experiences, and working with existing and new staff members to complete the patient journey mapping tables. These stories will include details specifically relevant to these units, to ensure that the training is meaningful for staff.

### Renal education

Renal nurse educators are also looking to include the patient journey mapping tools as part of the renal training, modifying its use for novice, advanced and expert practitioners, as a way of embedding cultural awareness, sensitivity and safety into renal education.

### Cardiac and cardiothoracic units

A case manager and unit managers are working to develop a survey for staff to determine their level of knowledge and cultural safety. They are writing two generalised case studies that highlight the current issues and concerns being experienced by patients and staff in their units, with the aim of providing professional education for staff using the patient journey mapping tools. They will then survey staff again to determine the effectiveness of the education.

### Midwifery care

Midwives involved in care for country Aboriginal women are considering using the patient journey mapping tools to supplement their current training tools. One midwife is adapting the chronological table, by inserting an additional row that outlines best practice guidelines so that she can assess if these have been met in specific cases.

### Emergency department

One emergency department nurse practitioner is planning to use the tool as an internal audit and quality improvement tool. He will write up two patient journeys through the emergency department, one that went well for staff and the patient, and one that did not. He will work with other emergency department staff, using the patient journey mapping tools, to determine what is working and where the problem areas are.

### Self-discharge against medical advice

One country Aboriginal Patient Pathway Officer is working with ward staff to record the reasons why patients are self-discharging without medical advice. They are adapting the chronological table to record what is happening for the patient and family and community, as well as in the hospital and their care pathway, to determine the causes for early discharge.



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# Appendix 1: The Tools Used in this Project

## Dimensions of health

This table is useful when considering the whole person entering the journey – their situation, strengths and challenges.

### Dimensions of health—version 1

<b>Dimension of Health</b>	<b>Existing Situation and STRENGTHS</b>	<b>New CHALLENGES</b>
Physical / biological		
Psychological / emotional		
Social & wellbeing		
Spirituality		
Cultural integrity		

This second summarised version may be more useful for reports and for staff development sessions.

### Dimensions of health—version 2

<b>Dimensions</b>	<b>Analysis</b>
Physical or biological	
Psychological and emotional	
Social and wellbeing	
Spirituality	
Cultural integrity	

## Underlying factors affecting access and quality

This table describes the level of access and quality possible in different sites for this person. Additional columns can be added for regional hospitals etc.

### Factors affecting access and quality – version 1

Underlying factors	Local health services	City hospital
Location/setting		
Burden of illness and interactions with health system		
Language/		
communication		
Financial resources		
Aboriginal/non-Aboriginal		

This table can also be summarised for reports and as a staff education activity.

### Factors affecting access and quality – version 2

Underlying factors	Analysis
City/country	
High burden of illness	
Language	
Financial resources	
Aboriginal/non-Aboriginal	







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