Managing Two Worlds Together

Stage 3: Improving Aboriginal Patient Journeys— **Cardiac Case Studies**

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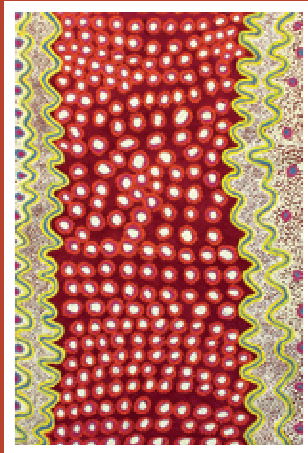

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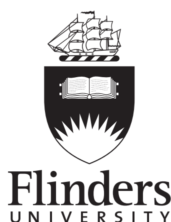

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Downloadable pdfs of the *Managing Two Worlds Together. Stage 3: Improving Aboriginal Patient Journeys—Cardiac Case Studies* and the other four Case Studies, along with printed copies and a pdf of the Study Report and a writeable pdf of the Workbook, can be obtained from:

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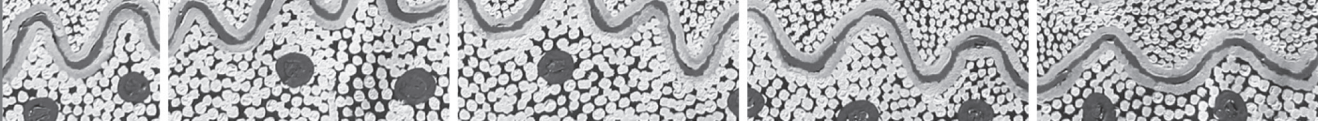

The Managing Two Worlds Together Project

The Improving Aboriginal Patient Journeys (IAPJ) study is the third stage of the Managing Two Worlds Together (MTWT) project. The MTWT project investigated what works well and what needs improvement in the health system for Aboriginal people who travel for hospital and specialist care from rural and remote areas of South Australia and the Northern Territory to city hospitals.

Stage 1 (2008–11) focused on understanding the problems that occur within and across patient journeys, and the barriers and enablers to access, quality and continuity of care. Challenges and strategies from the perspectives of individual Aboriginal patients, their families, and health and support staff and managers were examined using interviews, focus groups and patient journey mapping. Complex patient journeys were analysed and a patient journey analysis tool was developed collaboratively with staff, patients and carers.

Stage 2 (2012) focused on possible solutions and strategies. As the research team shared findings with health care providers, case managers and educators in a range of different health and education settings, the potential and scope of the Aboriginal patient journey mapping (PJM) tools for quality improvement, training and education emerged. The resulting tools consist of a set of tables that enable an entire patient journey to be mapped across multiple health and geographic sites, from the perspective of the patient, their family and health staff in each location.

Stage 3 (2013–15) involved an expanded research team and staff participants working together in a range of health care and education settings in South Australia and the Northern Territory. The aim was to modify, adapt and test the Aboriginal PJM tools developed in Stages 1 and 2. As the project progressed the basic set of tools was further developed with flexible adaptations for each site. This involved three steps – Preparing to map the patient journey, Using the tools and Taking action on the findings – organised into 13 tasks with prompt questions. Careful consideration was given as to how the information that emerged from the use of the tools could best highlight communication, coordination and collaboration gaps within and between different health care providers (staff, services and organisations) so as to inform the design of effective strategies for improvement. These were compared and combined with existing policies, practice and protocols.

Diagram 1 (below) sets out these three stages, along with the focus and outcomes of each stage.

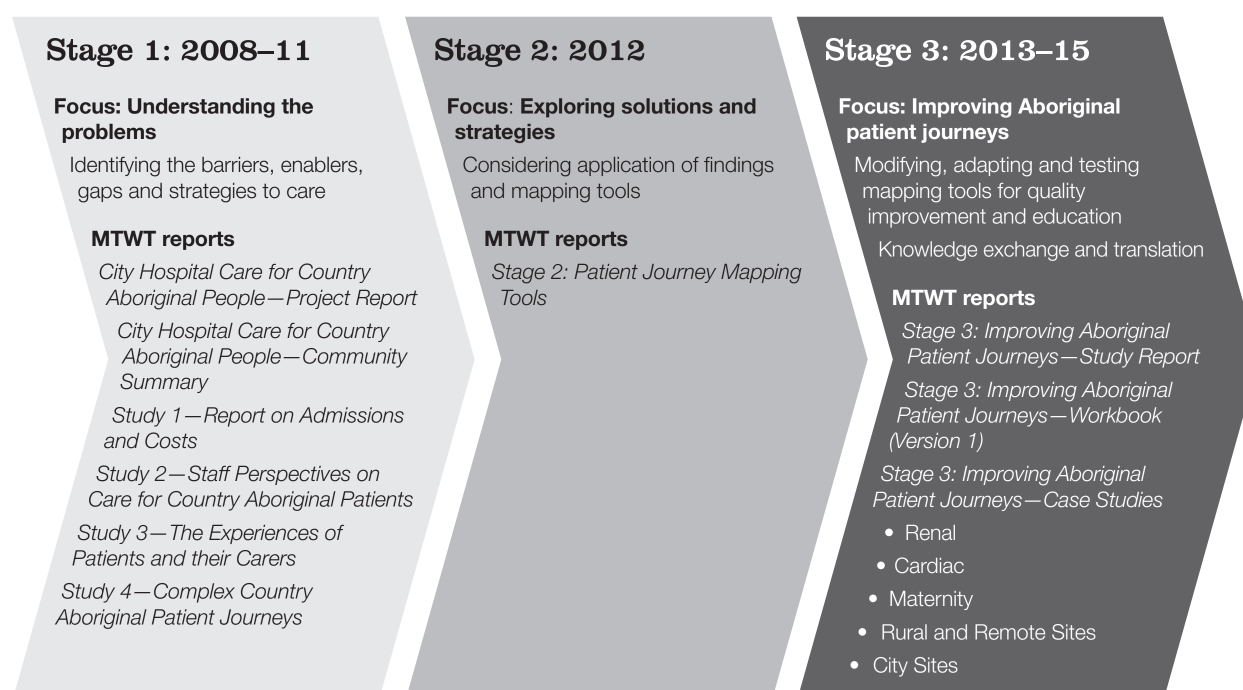

Diagram 1: The three stages, focus and outcomes of the Managing Two Worlds Together project

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Alex Brown, Sarah Brown, Lisa Catt, Christine Connors, Charlotte de Crespigny, Karen Dixon, Judith Dwyer, Toni East, Amy Graham, Kylie Herman, Liz Izquierdo, Wendy Keech, Rosie King, Michael Kirkbride, Monica Lawrence, Wendy McInnes, Gay Martin, Lee Martinez, Sonia Mazzone, Laney Mackean, Tamara Mackean, Paula Medway, Debra Miller, Jo Newham, Annapurna Nori, Kim O'Donnell, Brita Pekarsky, Sharon Perkins, Pam Pratt, Damian Rigney, Christine Russell, Bronwyn Ryan, Kerry Taylor, Kym Thomas, Cheryl Wilden, Eileen Willis, Jacene Wiseman and Chris Zeitz.

We would also like to acknowledge the editorial assistance of Jane Yule and Cathy Edmonds, the design work of Rachel Tortorella at Inprint Design, and the Lowitja Institute CRC for providing ongoing support for this study and publishing its outcomes.

Abbreviations and Terms

AHW	Aboriginal Health Worker
ALO	Aboriginal Liaison Officer
APPO	Aboriginal Patient Pathway Officer
CNC	Clinical Nurse Consultant
CTSU	Cardiothoracic Surgical Unit
ECG	Electrocardiogram (recording of heart's electrical activity)
Echo	Echocardiogram (a sonogram that creates images of the heart)
GP	General Practitioner
IAPJ	Improving Aboriginal Patient Journeys
MTWT	Managing Two Worlds Together
PATS	Patient Assistance Transport/ Travel Scheme – South Australia/ Northern Territory
PJM	Patient Journey Mapping
RFDS	Royal Flying Doctor Service
RHD	Rheumatic Heart Disease

Terminology

The use of the terms 'Aboriginal', 'Aboriginal and Torres Strait Islander', 'Indigenous' and 'Elder' reflect the preference of the people with whom we worked.

Aboriginal Patient Pathway Officer or APPO – A patient coordination role funded through the Council of Australian Governments; most of these positions are no longer funded.

Key stakeholders – People who are impacted by, or may affect, the patient journey and the mapping exercise.

Patient journey – The health care journey as experienced and perceived by a person, his or her family, and staff.

Case study – The use of the term 'case study' refers to specific problem-solving activities undertaken by participating health staff to better understand and improve care for their patients. We also recognise individual patients as 'people' rather than 'cases'.

Patient – We have used the word 'patient' to identify the person undergoing a health care journey. In some services other terms may be used, such as 'client'. At all times we recognise that 'patients' are individual people with unique personal, family and/or cultural needs and priorities.

About the Cardiac Case Studies

This report on Cardiac Case Studies is complemented by reports on four others – dealing with Renal, Maternity, Rural and Remote Sites, and City Sites – published as part of the Improving Aboriginal Patient Journeys Study, Stage 3 of the Managing Two Worlds Together project.

Three cardiac case studies are presented in this report:

- **Case Study A:** Hospital Education and Reflective Practice
- **Case Study B:** Adapting the Tools to Highlight Significant Gaps and Delays in Care
- **Case Study C:** Northern Territory Cardiac Coordination.

These case studies describe the ways in which four groups of cardiac staff in Adelaide, Alice Springs and Darwin adapted and used the Aboriginal PJM tools. During 2013 the Improving Aboriginal Patient Journeys Study Leader, Dr Janet Kelly, worked with each group separately, bringing together the ideas from each group to build a detailed cardiac mapping tool. This was the preferred option (rather than a single focus group) due to vast geographic distances and busy workloads.

The tools were then developed and adapted further by each group to meet their exact needs. Work with the mapping tools continued in most sites beyond the study timeframe. In the Top End and central areas of the Northern Territory, the Aboriginal PJM tools continue to be adapted and used by cardiac clinical nurse consultants and cardiologists in an 18-month Heart Foundation Focus Grant. More detailed cardiac case studies will soon be available through this project.

The cardiac staff in this study centred their work on the following question and task:

- How can these tools be adapted to map complex cardiac health care journeys within and across health services and state/territory boundaries?

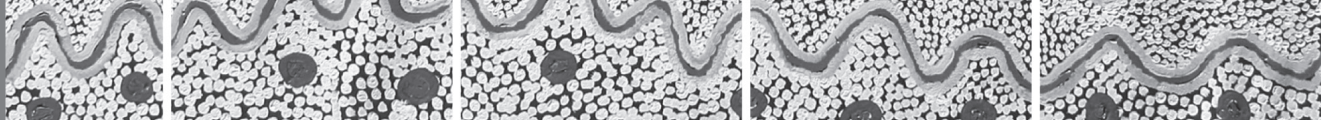
The purpose of these three case studies is to:

- provide cardiac-specific examples of complex patient journeys and the approaches used to better understand the underlying factors, and possible strategies for improved care
- illustrate how the MTWT patient journey mapping tools can be adapted and used for quality improvement and education, and to improve communication, coordination and collaboration within and across health services.

Case Study A presents an Education Package developed by a cardiac coordinator for cardiac staff. Case Study B introduces an expanded version of the tools that enable very complex patient journeys across health services and state/territory boundaries to be mapped, highlighting the different staff and services involved. Case Study C describes how this was further adapted and developed in the Northern Territory. All three took place before the Workbook was finalised, and the experiences, insights and feedback from cardiac staff was integral to developing final versions of the tools.

Key identifying factors in patient journey accounts have been changed to protect the privacy of individuals and their families. Ethics approval was given by Flinders University, the Aboriginal Health and Research Ethics Committee, The Queen Elizabeth Hospital Human Research Ethics Committee, the Central Australian Human Research Ethics Committee, and Menzies School of Health Research. Required governance arrangements (Site Specific Assessments) were also completed with each SA Health site involved.

Health professionals are invited to use the tools in their own settings, and to adapt and adopt them by adding columns or rows to focus on specific issues and concerns. Information on how to use the tools can be found in the *Stage 3 Improving Aboriginal Patient Journeys—Workbook.* The Workbook, Study Report and the four other Case Studies are available at: www.lowitja.org.au/lowitja-publishing.



Contact details

For further information on the Improving Aboriginal Patient Journeys study, contact Dr Janet Kelly, IAPJ Study Leader, at E: Janet.kelly@flinders.edu.au or T: +61 8 8201 7765.

To discuss case study details with the cardiac nurse leaders involved, please contact them directly:

- **Case Study A:** Mark Ramage Case Manager, D'Arcy Sutherland Cardiothoracic Surgical Unit, Royal Adelaide Hospital at E: mark.ramage@health.sa.gov.au
- **Case Study B:** Daphne Perry, Aboriginal and Torres Strait Islander Remote Area Clinical Liaison Nurse for Cardiac Surgery, Flinders Medical Centre at E: daphne.perry@health.sa.gov.au
- **Case Study C – Top End:** Jeff Tinsley, Nursing Unit Manager, Chronic Disease Coordination Unit, Royal Darwin Hospital at E: jeffrey.tinsley@nt.gov.au or Hugh Auckram, Cardiac Clinical Nurse Consultant, Darwin Hospital at E: cardiaccoord.ths@nt.gov.au
- **Case Study C – Central Australia:** Wendy Corkhill and Sarah Wyatt, Cardiac Clinical Nurse Consultant, Central Australian Hospital Network at E: cardiacnursecoordcentral.ths@nt.gov.au.

The Patient Journey Mapping Process

By the end of the study the process of mapping Aboriginal patient journeys consists of three main steps:

- Step 1: Preparing to map the patient journey
- Step 2: Using the tools
- Step 3: Taking action on the findings

Each step involves a number of tasks that were developed throughout the project by pulling together the experiences of staff participants involved in testing and using the Aboriginal PJM tools. Diagram 2 (below) provides an overview of these tasks.

It is important to note that in this and other Case Studies not all of the tasks described here are carried out fully in every case study. This is because the case study activities occurred before the final version of the tools and tasks were developed.

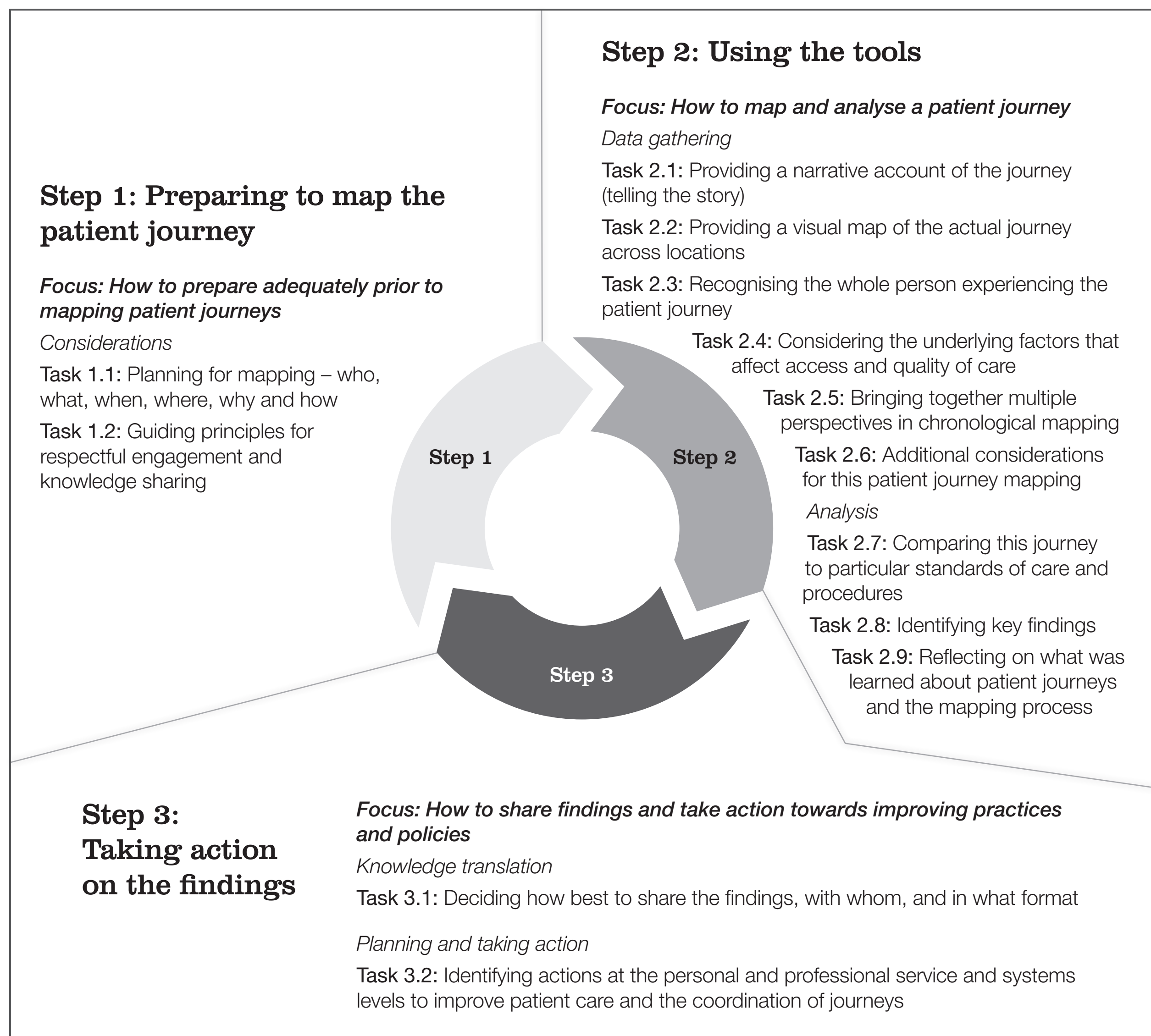


Diagram 2: The process of using the Aboriginal PJM tools – an overview

Case Study A: Hospital Education and Reflective Practice

Authors: Mark Ramage and Janet Kelly

Who was involved in the mapping?

Mark Ramage has worked in cardiac care in The Royal Adelaide Hospital for many years, and became involved in earlier stages of the Managing Two Worlds Together (MTWT) project. He currently works as Case Manager, D'Arcy Sutherland, Cardiothoracic Surgical Unit.

The Royal Adelaide Hospital Cardiothoracic Surgical Unit is a separate surgical suite maintaining a preoperative ward and Intensive Care Unit devoted solely to adult heart and chest surgery. This unit provides care predominantly for people from South Australia and the Northern Territory.

Mark has been involved in Stages 1–3 of the MTWT project. Michelle Munro, Ward A6 Clinical Service Coordinator, was also involved in the earlier work before taking leave.

Focus of this case study

This case study demonstrates how a 'typical' cardiac patient journey can be mapped by combining two or more actual patient journeys to highlight specific issues that have occurred for patients recently, without identifying any one patient. Using three of the mapping tools, a case study was created as part of an education package that invites staff to consider the actions they could take to improve patient care. Mark is also designing a pre- and post-education survey to measure the effectiveness of the education session.

Step 1: Preparing to map the patient journey

Task 1.1: Planning for mapping – who, what, when, where, why and how

A major finding of the MTWT project, particularly relevant to cardiac units, is that although clinical complexity is often well recognised and responded to, the complexity of the entire patient journey, and the specific personal and cultural needs of rural and remote Aboriginal patients, may be overlooked. While discussing these findings, Mark recalled recent interactions with rural and remote Aboriginal patients in which he found that some of their specific needs had been overlooked. In his cardiac coordination role, the impact of such oversights was more obvious. In order to protect the privacy of individual patients, Mark brought together experiences of a few recent patients, changed key identifying aspects and wrote a case study to use for staff training.

Mark and Janet met and discussed the recent interactions. This combination of real patient stories ensured confidentiality, while maintaining relevance for staff. Mark was also studying a leadership course and wished to incorporate his new learning with the education process to devise a pre- and post-education survey for staff to determine if this education intervention had been successful in changing staff perception and knowledge.

The aim of writing the case study and staff education package was to:

- utilise the insights of the cardiac coordinator to highlight current issues and initiate appropriate responses
- improve the reflective practice of cardiac staff
- help improve the cultural competency and responsiveness of staff through a tailored education session.

Task 1.2: Guiding principles for respectful engagement and knowledge sharing

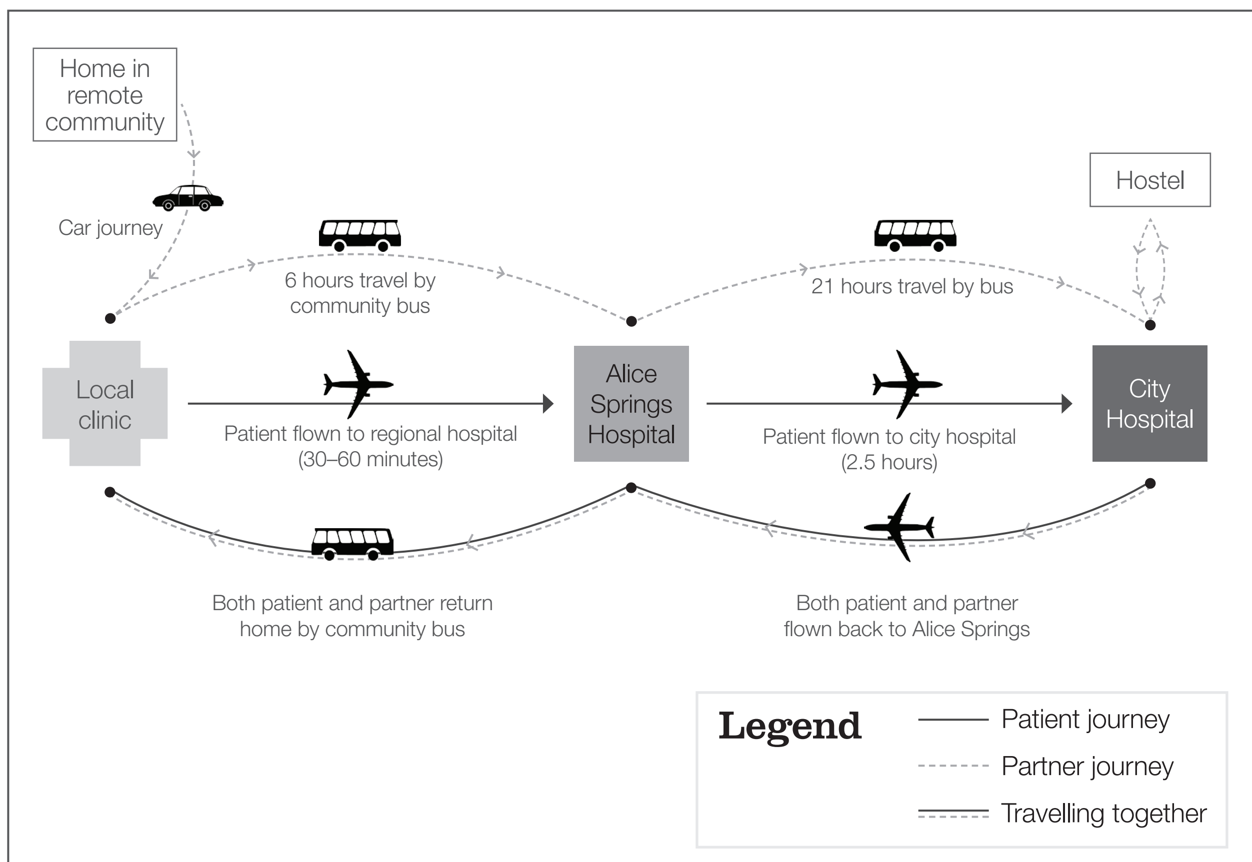
Mark recognised the need to focus on a wider view of health and patient-centred care. He was interested in highlighting current gaps in care, both cardiac specific and social, cultural, spiritual and interpersonal aspects. In order to protect the privacy of patients, he combined the experiences of different patients into one case study. He was then able to share this case study with staff and to discuss particular aspects and the need for improved responsiveness.

Step 2: Using the tools

Task 2.1: Providing a narrative account of the journey (telling the story)

The following provides and overview of the journey.

> *An Aboriginal Elder man living in a remote community experienced increasing shortness of breath and a heavy chest on a Friday afternoon. His family encouraged him to attend the local clinic and he was found to be having a myocardial infarction (heart attack) and was rapidly sent to Alice Springs and then Adelaide. Initial urgent treatment occurred at both hospitals, and then he had surgery. There was no room on the retrieval plane (RFDS/doctor plane) for the man's partner, so the partner was driven to the nearest town and then caught a lift to Alice Springs and then a bus to Adelaide. On arrival in Adelaide the partner stayed in the hostel, visiting the hospital every day.*
>
> *There was no interpreter service for their first language available in Adelaide, and English was both the patient and partner's third language. A telephone interpreter who spoke their second language was located for informed consent. Ongoing explanations were given in English, but some staff were too busy and spoke quickly, and the patient and his partner also had difficulty understanding the doctor's accent. There was no AHLO or social work support available until the Monday. The social worker assisted in arranging financial assistance so that the partner could afford to stay in Adelaide. The patient had a relatively uncomplicated recovery and was flown back to Alice Springs Hospital, where he was reassessed, and then two days later the patient and his partner returned to their own community on the bush bus. Their local health service provided follow-up care in collaboration with the cardiac clinical nurse consultant in Alice Springs.*



Case Study A – Figure 1: Visual mapping

Task 2.2: Providing a visual map of the actual journey across locations

Figure 1 (see p.5) illustrates the patient and his wife's journey from home to Alice Springs to the city hospital and return. The patient had a straightforward emergency transfer, whereas his wife spent many hours travelling by bus. Once in Adelaide she travelled to and from the hospital to visit him.

Task 2.3: Recognising the whole person experiencing the patient journey

Mark and Janet discussed the benefits of highlighting the strength and usual situation for this patient before his patient journey began, and the challenges that occurred for him and his partner when they were transferred to a city hospital. Table 1 incorporates these aspects. The delay in seeing a chaplain was a real issue experienced recently by a cardiac patient.

Case Study A – Table 1: Dimensions of health

Dimension of health	Situation	
	Local community	**City/regional hospital**
Social and emotional wellbeing	Lived in a remote community and station for all his life; never travelled to a city larger than Alice Springs Raised on a Christian mission	No time to see family and say goodbye Has never flown before; wife accompanies as escort Anxiety over pain; urgent procedure i.e. IV medications, ECGs, heart monitors On arrival in Adelaide, ambulance ride to hospital Urgent angiogram; some difficulty understanding procedure as English is not first language
Family and community committments	Older member of the community; lives with wife and extended family Active member of the community and church Occasionally travels to Alice Springs on pay day to catch-up with family members	Worried about family Never been to a big city but excited about seeing one Worried about where wife will stay and how she will eat and get about
Personal, spiritual and cultural considerations	Lives near homelands with family Maintains important spiritual and Christian connections Feels connected and stronger when on own land	Nervous, anxious and excited at the same time Wanted to see a chaplain but unsure how to ask; no one asked about religion and he really wanted to pray with a chaplain Not being able to communicate effectively, no one taking the time to speak slowly and to take time to listen Not gender-specific model; shaved in the groin area by a female
Physical and biological	Lives with wife in remote community Usually independent, is a retired jackaroo on a pension	Retrieved by plane from local community health centre to Alice Springs hospital then to Adelaide Experienced chest pain with shortness of breath and feeling of impending doom

Task 2.4: Considering the underlying factors that affect access and quality of care

The underlying factors that impacted on this patient were then identified, with an emphasis on the factors that impacted most when he accessed city health services versus services closer to home, as shown in the two columns of Table 2.

Case Study A – Table 2: Underlying factors

Underlying factor	Impact of location and access	
	Local health services	**City/regional hospital**
Rural and remote/city Travel to health care, environmental, proximity of family and support networks	Local health clinic and community centre within walking distance	Long distance to city – flight or extended bus trip
Impact of illness or injury Chronic or complex conditions, being acutely ill or injured	Self manages diabetes and diet, medications from local clinic	Cardiac surgery, pain and stiffness New medications and heart conditions require adjustments
Language and communication Ease or difficulty of communication between patients and staff, access to interpreters, dentures, hearing devices	English is third language Staff in local clinic speak both first language and English	No staff speak first language Difficulty understanding staff who also speak English as second language Interpreter needed for informed consent Can understand and speak English if it is spoken slowly and given time, but staff very busy and communication rushed
Financial resources Ability to meet costs of transport, treatment, health care, medications, inability to work, caring duties	Some costs covered by community arrangements	Financial stress of being in city, unable to access bank accounts easily Need to purchase warm clothes and cover accommodation costs for partner
Cultural safety Experiences of an Aboriginal person within a health system	Combines Traditional and Western understanding of health and diabetes	New cardiac condition and Western interventions

Task 2.5: Bringing together multiple perspectives in chronological mapping

Bringing together the perspectives of the patient, the family and staff along the entire journey enables specific gaps and strategies to be identified, as shown in Case Study A – Table 3. Specific time and financial challenges occurred for the patient's wife travelling behind via road. The patient's physical condition was responded to well, but there were gaps in social and cultural support for both the patient and his wife during the weekend. On discharge he was given only three days of discharge medication, so it was very important that there was involvement of the nurse at Alice Springs to review his care and ensure that the correct medication was available, otherwise he would have run out on his return home. Similarly, cardiac coordination was provided as an outreach service by the local remote clinic in collaboration with Alice Springs. When the staff at the Royal Adelaide Hospital are aware of the entire journey, they can more clearly understand the reasons for meeting individual patient needs and completing the required paperwork and processes to ensure improved continuity of care.

Case Study A – Table 3: Multiple perspectives

Perspective	Patient history	Diagnosis/ referral	Trip to city	In hospital	Discharge/ transfer	Follow-up
Patient's journey	Shortness of breath and heavy chest Friday afternoon	ECG Rapid referral to regional centre	Via RFDS to regional city for stabilisation then flight to Adelaide	Cardiac investigations and treatment	Fly back to Alice Springs, stay overnight and then bus to remote community	Local clinic Outreach cardiac rehab
Family/carer journey	Worried for grandparent/ family member	No room on RFDS plane for wife, she has to follow by car and then bus	Wife followed by bus	Wife in hospital accommodation maintaining phone contact with family via clinic and Aboriginal liaison on weekdays	Concerns over how the wife will get home – who will cover costs?	Support in community
Patient priorities, concerns and commitments	Family and community	To maintain wellness	Care of grandchildren at home	Understanding what is going on and what the choices are Loneliness	Information back to regional hospital and local clinic Only three days' discharge medication given	Keep well
Health care/ services priorities	Management of chronic condition – diabetes	Assess new health condition	Need tertiary hospital investigations	Investigate, treat condition with surgery Informed consent	Assist patient and partner back home	Uncomplicated recovery
Service gaps		No GP at local clinic	No local specialist facility	Support for partner No Aboriginal Liaison Officers on weekends	Financial support for wife to fly home Only three days' discharge medication given	No cardiac rehabilitation locally
Responses to gaps	Ongoing chronic conditions support in local clinic	Good use of remote area nurse skills and protocols	PATS assistance for flights	Aboriginal Liaison Unit Social work assistance Aboriginal clinic in home community	Aboriginal land council assisted with travel costs. Cardiac CNC arranged further medications before returning home	Outreach service Local clinic staff update skills

Task 2.6: Additional considerations for this patient journey mapping

A worksheet for staff education

Mark devised a worksheet to use in the cardiac unit for staff education (Case Study A – Figure 2). There was an opportunity to work with staff for about an hour, so he focused on a brief intervention that would be possible in this timeframe and that would be meaningful for staff.

Dimension of health	Important aspects for this patient	How you could respond to this?
Social and emotional wellbeing **Family and community commitments** **Personal, spiritual and cultural considerations**		
Physical and biological		

Underlying factor	Issues that arose for this patient	How you could respond to this?
Rural and remote/city		
Impact of illness or injury		
Language and communication		
Financial resources		
Cultural safety		

What are 5 things that you could consider and do or initiate to improve care for country Aboriginal patients?

1 ____________________

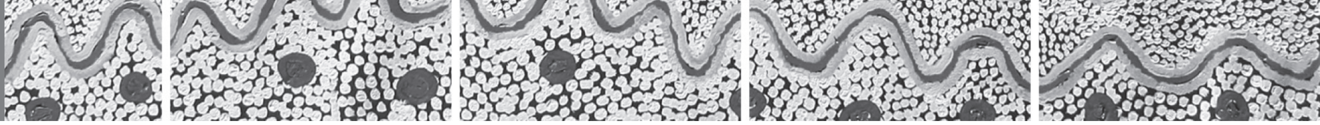
2 ____________________

3 ____________________

4 ____________________

5 ____________________

Case Study A – Figure 2: Staff education worksheet



Task 2.7: Comparing this journey to particular standards of care and procedures

Part of preparing this case study and worksheet involved discussions with Aboriginal liaison staff. They identified that usual hospital admission questions regarding religious preferences and support were overlooked in this case study, and that there were at least three opportunities in the admission process where this information could have been recorded. This was fed back to the cardiac team.

Mark is also interested in designing a pre- and post-education survey to see whether staff have benefited from the education package. He has not yet been able to run this education session.

Task 2.8: Identifying key findings

Specific Royal Adelaide Hospital findings related to the cardiac patient journey include:

- the admission process was disrupted due to the emergency nature of the admission and the missing information was not sought closer to surgery, leading to communication, support and religious needs going unrecognised; the intervention of the cardiac manager enabled this gap to be identified and overcome at the last minute
- a preference for a same-gender practitioner to conduct the groin shave was either not recognised or unable to be accommodated
- access to cultural and social support services remains restricted in city hospitals on weekends
- the provision of only three days' discharge medication may lead to difficulties on discharge if the primary care services are not alerted.

Wider patient journey findings include:

- good outcomes for patients in remote areas are achievable when appropriate emergency care, coordination and follow-up is provided
- family members may need to make extensive travel arrangements to reach city hospitals, and may need financial assistance and support to stay in the city and return home
- Aboriginal liaison and clinics play a vital role in enabling patients and carers to remain connected to their families during city hospitalisation
- the role of the cardiac clinical nurse consultants is important for continuity of care, medication access and follow-up.

Task 2.9: Reflecting on what was learned about patient journeys and the mapping process

What worked with the mapping?

The mapping enabled Mark to highlight the issues that he had identified and to share them in a structured yet non-threatening way with other staff. Mark had both the time and role to identify and act on specific gaps in care.

Adapting the tools

Only Table 2 was changed:

- Table 2: Underlying factors – a column was added to consider how each underlying factor was experienced by the person in both the local clinic and the city hospital.

What didn't work/what would we do differently next time?

Ideally, patients themselves would be involved in the mapping, but this mapping was done retrospectively long after the patients had returned home.

Step 3: Taking action on the findings

Task 3.1: Deciding how to share the findings, with whom, and in what format

Mark has not yet been able to conduct the education sessions with staff in the cardiac unit. However, this case study has been used by other student groups, and was shared with the Heart Foundation Lighthouse project as a way to create cardiac case studies and involve staff in identifying strategies for improved care.

Task 3.2: Identifying actions at personal, professional, local service and systems levels to improve patient care and coordination of journeys

Mark spoke to staff about the importance of following-up on admissions information after emergency admissions. He is working on a pre- and post-education staff survey to enable the effectiveness of the cardiac education package to be measured.

Case Study B: Adapting the Tools to Highlight Significant Gaps and Delays in Care

Authors: Daphne Perry and Janet Kelly

Who was involved in the mapping?

Daphne Perry works as an Aboriginal and Torres Strait Islander Remote Area Clinical Liaison Nurse for Cardiac Surgery and as the Cardiac Surgery preadmission coordinator at the Flinders Medical Centre in Adelaide. The Flinders Medical Centre provides cardiac care for people predominantly from South Australia and the Northern Territory. Daphne became actively involved in testing the mapping tools during Stage 3 of the MTWT study.

Focus of this case study

This case study involved adapting the tools to enable very complex cardiac patient journeys to be mapped across and through a range of health services. We did this in two stages – first, in a one-hour session we mapped a journey within South Australia visually and adapted a table to see whether it could accommodate the complexity involved. Then we met again and adapted the tools to map a more complex journey involving both the Northern Territory and South Australia. Unfortunately, we were unable to map an actual entire patient journey as Daphne needed to take leave. However, this case study, and the work Daphne contributed, was crucial to the development of more detailed version of mapping tools and led to further work with cardiac staff in the Northern Territory. This mapping continues within a 2014 Heart Foundation Focus Grant project.

Step 1: Preparing to map the patient journey

Task 1.1: Planning for mapping – who, what, when, where, why and how

During a meeting with Daphne, her colleague Sue Treadwell and Flinders Medical Centre cardiac managers, one manager observed that it seemed counterintuitive to provide a solution (the mapping tools) before we knew what the problem was. This observation led to recognition of the importance of identifying an issue or problem or the specific reason for mapping. Daphne identified that her major current concern was the very significant time it was taking for patients requiring valve surgery to access and receive the required dental care prior to surgery. (Patients need to be 'dentally fit' – i.e. have no gum disease or tooth decay prior to some cardiac surgery – because there is a risk of severe cardiac complications due to oral bacterial infections travelling through the blood stream.) Therefore, we agreed that the aims of mapping were to:

- identify exactly where the significant time delays were occurring between assessment for cardiac intervention and getting access to appropriate dental care to enable surgery
- identify specific barriers to effective and timely care for cardiac patients within South Australia and those travelling from the Northern Territory.

Task 1.2: Guiding principles for respectful engagement and knowledge sharing

During this case study no specific individual patient journey was recorded; rather, the mapping sought to reflect a range of recent cardiac patient journeys. Care was taken to discuss and identify issues for patients, families and staff in respectful and non-identifying ways.

Step 2: Using the tools

Task 2.1: Providing a narrative account of the journey (telling the story)

At this stage of the project we were not working directly with patients. Our intention was to map an entire patient journey, but Daphne's workload increased when other support staff (Aboriginal Patient Pathway Officers and a specific Aboriginal-focused nurse position) left as their contracts and funding ended. She then also needed to take leave. Instead, we talked about a typical patient journey, reflecting recent patient journeys and conversations Daphne had had with a range of patients regarding their journeys.

Task 2.2: Providing a visual map of the actual journey across locations

Case Study B – Figure 1: Visual mapping – a typical interstate cardiac journey

Task 2.3: Recognising the whole person experiencing the patient journey

We then discussed recognising the unique background and situation for each patient and the challenges and considerations regarding each journey. In the original version, physical health was listed first, but we decided to list psychological, social, spiritual, cultural and family first so that they were not overlooked (this is the way the dimensions now appear in the Workbook). Daphne completed Table 1.

Case Study B – Table 1: Dimensions of health

Dimension of health	Situation	
	Local community	**City/regional hospital**
Social and emotional wellbeing **Family and community commitments** **Personal, spiritual and cultural considerations**	Person lives in a remote area with family members including young children Works in local mine	Long distance to the city Difficult for partner and children to travel to city
Physical and biological	Past history rheumatic heart failure and rheumatic heart disease	Decreased health and energy levels, some chest pain while at work, evacuated to nearest regional centre then to Adelaide Needs valve surgery

Task 2.4: Considering the underlying factors that affect access and quality of care

Daphne identified the need to consider what happened for people when they accessed local health services, the major regional hospital in South Australia or the Northern Territory, the Adelaide hospitals, and follow-up and rehabilitation. She was finding that follow-up and rehabilitation needs and processes were overlooked or under-reported, and so it was important to capture this. We therefore considered the underlying factors in four settings and stages of the journey as shown in Table 2.

Case Study B – Table 2: Underlying factors

Underlying factor	Impact of location and access			
	Local health services	**Darwin/Alice Springs/regional hospital**	**Adelaide Hospital**	**Follow-up – rehab**
Rural and remote/city What care is available and how this is experienced	Visits local Aboriginal health service or health service at the mine	Transferred to regional hospital from work with chest pain	Specialised care only available in Adelaide. Appreciated receiving the treatment, but anxious about heart surgery	Rehab via regional centre Is not working or attending work health services
Impact of illness or injury Chronic or complex conditions, being acutely ill or injured	Usually fit and healthy. Occasional visit to local health services with family members	Seek assessment and stabilisation of health problem	Investigations and prepared for surgery Need for surgery explained and informed consent obtained	City-based rehabilitation program
Language and communication Patient interactions with staff	Proficient in everyday English which is second language	Staff explained what was happening. In pain and anxious, but understood basic information	Difficulty understanding health practitioners for whom English is their second language	City-based program, but staff adapted it so that it made more sense
Financial resources Impacts of financial costs/ constraints	Minimal cost to attend	Emergency flight, no cost to patient. Family unable to travel the long distance easily	Has minimal cash with him. No access to ATM, no family members to assist. Social worker visit	Ongoing services and medications provided by local health service at minimal cost
Cultural safety Experiences of an Aboriginal person within a health system	Has long-term relationship with both health services	Stabilised at regional centre, then flown out. Staff very efficient and explained things well. No connection with Aboriginal staff – was in emergency for a short time	Cardiac staff notified Aboriginal liaison unit who provided cultural and social support, and link to family and community via phone	At first did not understand the need for follow-up and rehab until explained by visiting local clinic doctor

This table enabled us to highlight how the patient's needs may change in different sites and stages of the journey. The requirement for additional support to understand what is happening, to maintain links to home, culture and family, and for financial and social assistance became more obvious. Being transferred to the other end of the country for urgent health care, crossing state borders and encountering differing support systems, sometimes with no personal identification or credit cards, poses specific difficulties.

Task 2.5: Bringing together multiple perspectives in chronological mapping

We then started mapping the entire cardiac patient journey across the Northern Territory and South Australia and all the different people, health units and support services involved.

We decided to create two tables – Table 3 (Part a) from first diagnosis and referral to surgery, and Table 3 (Part b) from immediate post-operative to follow-up and rehabilitation. The process we used

was that Daphne described the major steps in a 'typical' journey and we wrote these as column headings. She then identified all the people involved in a person's cardiac journey and we included these as row headings. We discussed the benefits of changing these tables from two Word documents to a single Excel spreadsheet. The cardiac nurses work with Excel and are familiar with its functions. As discussed previously, we did not get to finish using these tables together. However, these tables were pivotal to discussions in the Northern Territory (see Case Study C).

Case Study B – Table 3 (Part a): Multiple perspectives – first diagnosis to surgery

Perspective	Patient history	Diagnosis	Referral	Meeting date	Referral date	Pre-surgical screening	Dental	Recovery time	Travel to hospital	Surgery	Comments
Timeline											
Patient's journey											
Family/carer journey											
Patient priorities, concerns and commitments											
Health care/ service priorities											
Best practice/ standards											
Services/staff involved											
Dental/oral											
RHD registry											
Remote clinic staff – AHW, Registered Nurse, Doctor											
PATS											
NT hospital											
ALO NT											
ALO SA											
APPO											
Cardiac Coordinator SA											

Case Study B – Table 3 cont...

Perspectives	Patient history	Diagnosis	Referral	Meeting date	Referral date	Pre-surgical screening	Dental	Recovery time	Travel to hospital	Surgery	Comments
Cardiac Coordinator NT											
Cardiologist											
Hostel/ accommodation											
Transport											
Social worker											
Rehab services											
CTSU secretary											
CTSU research											
Other											
Service gaps											
Responses to gaps											

Case Study B – Table 3 (Part b): Multiple perspectives – discharge to follow-up

Perspectives	Discharge	Transfer	Post -discharge clinic	30-day check	60-day check	Follow-up	Comment
Timeline							
Patient's journey							
Family/carer journey							
Patient priorities, concerns and commitments							
Health care/ service priorities							
Best practice/ standards							
Services/staff involved:							
Dental/oral							
RHD registry							
Remote clinic staff – AHW, Registered Nurse, Doctor							
PATS							
NT hospital							
AHO NT							
AHO SA							
APPO							
Cardiac Coordinator SA							
Cardiac Coordinator NT							
Cardiologist							
Hostel/ accommodation							
Transport							

Case Study B – Table 3 cont...

Perspectives	Discharge	Transfer	Post -discharge clinic	30-day check	60-day check	Follow-up	Comment
Social Worker							
Rehab services							
CTSU secretary							
CTSU research							
Other							
Service gaps							
Responses to gaps							

Task 2.6: Additional considerations for this patient journey mapping

There were no additional considerations for this patient journey mapping.

Task 2.7: Comparing this journey to particular standards of care and procedures

During our conversations and in preparation of these tables, we considered what ideal practice would look like, which is why we included the row heading 'Health care & Best practice/standards' in Table 3 (Parts a and b).

Task 2.8: Identifying key findings

Although we did not complete mapping a specific patient journey, we discussed the need to identify key findings and appropriate strategies to address these. Daphne identified that some of the issues regarding pre-surgery arrangements and timing of discharge would require service or systems-level interventions.

Task 2.9: Reflecting on what was learned about patient journeys and the mapping process

During the mapping and conversations the complexity of these cardiac patient journeys and the numerous people, health units, health services and support services involved were highlighted. The significant role Daphne played in keeping track of patients across the health care landscape and juggling timelines, schedules and appointments became obvious. The significant beneficial role of other coordination and support staff such as Aboriginal Patient Pathway Officers, Aboriginal liaison staff and cardiac nurse positions funded by the Council of Australian Governments was clear to see. At the time of mapping there were also major changes taking place within SA Health and NT Health. The Aboriginal Patient Pathway Officer positions came to the end of their contracts and were not renewed. New cardiac coordinator positions and protocols in the Northern Territory were developed, changing Daphne's cardiac coordination role in South Australia. Daphne strongly suggested that the project also needed to work with Northern Territory cardiac coordinators to enable mapping to continue in the changing environment.

What worked? Reflections on the mapping process

The tools highlighted the detail and complexity of cardiac patient journeys and the many different people and processes involved.

Adapting the tools

In order to map the level of detail required, and to see whether these tools could actually meet Daphne's need, we began by visually drawing a patient journey and adapting the multiple perspective matrix. Daphne had a very limited amount of time allocated to this research activity, and we maximised the usefulness of our time together. In a one-hour session Daphne described a typical cardiac patient journey within South Australia and Janet drew the journey and mapped from multiple perspectives, adjusting the headings of rows and columns in Table 3: Multiple Perspectives, with input from Daphne. In a second meeting, Daphne and her manager decided that the tools could be useful, and we then set about further adapting the tools to map patient journeys across state/territory borders. There were additional complexities in these journeys that Daphne wished to examine.

What didn't work/what would we do differently next time?

Daphne was very busy in her position, and she was allocated little time to spend on mapping actual patient journeys. She then was on reduced hours and needed to take leave. Ideally the patients themselves would be involved in telling their story from their perspective and this information would be included in the tables.

Step 3: Taking action on the findings

Task 3.1: Deciding how best to share the findings, with whom, and in what format

Daphne suggested that Janet should work with the cardiac coordinators in the Northern Territory to map journeys from the beginning of their journeys and at the end. She herself needed to take leave and was unable to continue with the mapping at the time.

Task 3.2: Identifying actions at personal, professional, local service and systems levels to improve patient care and coordination of journeys

Janet met with Northern Territory cardiac coordinators in Darwin and Alice Springs, introducing Daphne's adapted mapping tool as a starting point. The tools were well received in the Northern Territory and the next stage of development of the tools is shown in Case Study C.

Case Study C: Northern Territory Cardiac Coordination

Authors: Janet Kelly, Natalie McCabe, Jeff Tinsley, Hugh Auckram, Wendy Corkhill and Sarah Wyatt

Who was involved in the mapping?

Dr Christine Connors, Associate Director Health Development Branch, Northern Territory Department of Health; Dr Pupalan Iyngkaran (Balan), Cardiologist, Royal Darwin Hospital; Jeff Tinsley, Cardiac Nurse Manager; and Wendy Corkhill, Cardiac Coordinator, helped to arrange workshops in Darwin and Alice Springs to explore whether the tools could be useful and appropriate to map cardiac patient journeys. There was interest in their use for quality improvement and education.

In Darwin, Jeff Tinsley and Hugh Auckram, Cardiac Coordinator, brought together a diverse group of cardiac nurses and medical and Aboriginal health staff to attend the workshop, with one remote area nurse participating via teleconference. Participants were from:

- remote health: staff included Dr Paul Burgess, Remote Area Physician; Heather Keighley, Regional Manager Top End; and Robyn Jones, Tracey Sheehan and Jennifer Wyllie, Preventable Chronic Disease Educators
- acute care: staff included Jeff Tinsley, Unit Manager Coronary Care/Chronic Disease Unit; Hugh Auckram, Cardiac Coordinator; Laizza Baby, Assistant Unit Manager Coronary Care/ Chronic Disease Unit ; and Marcus Ilton, Director of Cardiology
- NT Health: Christine Connors, Associate Director, Health Development, NT Health, and Bernie Shields, Health Worker.

In Alice Springs, Wendy Corkhill and Sarah Wyatt, Cardiac Coordinators, and Jade Eaton, administration, attended a half-day workshop. Other staff who could have been involved in the mapping were unavailable on the day.

Natalie McCabe, Aboriginal Patient Pathway Officer with the Queen Elizabeth Hospital, Adelaide, travelled with Janet Kelly and assisted with the workshops. Natalie had been working with the Aboriginal patient journey mapping tools and working out how best to adapt and use them within a hospital system (see Case Studies A and B in the City Sites Case Studies).

Focus of this case study

The focus of this case study was to determine if the patient journey mapping tools could be adapted and used to map a range of cardiac patient journeys both within the Northern Territory and between the Northern Territory and South Australia. Rather than following an individual patient journey, this case study highlights what was learned about each step of the mapping process in Darwin and Alice Springs. Individual cardiac patient journeys are now being mapped using these tools in the Northern Territory as part of a 2014 Heart Foundation Focus Grant.

Step 1: Preparing to map the patient journey

Task 1.1: Planning for mapping – who, what, when, where, why and how

The two cardiac workshops were flexible in design, meeting the needs, resources and availability of local staff. In both locations the cardiac coordinator had chosen three recent cardiac patient journeys and had case notes and electronic notes ready for the workshop.

The mapping tool version developed with Daphne Perry (Case Study B) was used as the basic mapping tool, with Table 3 columns and row headings changed as required to meet the Northern Territory patient journey situation. There were planned changes in the Northern Territory for cardiac care and coordination, and NT Health saw that the mapping process and resulting case studies had the potential to assist with continuous quality improvement, service planning and education.

Task 1.2: Guiding principles for respectful engagement and knowledge sharing

It was agreed that existing health service confidentiality arrangements would be upheld during discussion of patient details within the workshop (see Diagram 2: Involvement of staff participants, patients and communities in Stage 3, Project Report, p. 5). Both workshops were based on strong respect of Aboriginal patients' needs and priorities.

It was established early in the workshops that the aim was to use the tools for quality improvement and education rather than to cast blame. Dr Paul Burgess suggested that mapping patient journeys using the tools was 'like doing a root cause analysis but proactive', enabling issues to be highlighted and strategies designed before worse case scenarios occurred.

Step 2: Using the tools

Task 2.1: Providing a narrative account of the journey (telling the story)

In Darwin the workshop group chose a recent patient journey to map. Only one of the doctors and one of the cardiac coordinators had cared for this patient but neither was directly involved in the recent cardiac journey. Relying solely on the case notes, it soon became obvious how difficult it was to map a person's journey through episodes of care without a consistent narrative. As we pieced together the story, some inconsistencies became apparent. For example, early in the journey one patient was labelled 'non-compliant' but in fact this person had a very strong history of managing his/her medications and complex chronic conditions very well.

In Alice Springs two different patient journeys were mapped. Both patients were well known to Wendy, and so she provided the central narrative, checking details in the case notes.

Task 2.2: Providing a visual map of the actual journey across locations

Visual maps are not yet developed, but the need for mapping was raised, particularly to explain the distances and challenges in travel involved in journeying from the person's home to regional health service and to Darwin. At times hand-drawn maps or Google Maps were used to assist in greater understanding.

Task 2.3: Recognising the whole person experiencing the patient journey

The need for Table 1 to highlight, remind and inform staff of the person entering the journey became apparent. It was very easy for staff to focus predominantly on physical health rather than the social, emotional, spiritual, cultural and family aspects. When relying on case notes alone, we found that this information is usually not recorded. It is only through speaking to the patient or perhaps staff from the local health service that these aspects can be known. A question that arose was that if personal aspects and preferences are not known, then how can they be included in patient-centred care? Together the group came up with a range of dimensions that may be important to map.

Case Study C – Table 1: Dimensions of health

Dimension of health	Situation	
	Local community	**City/regional hospital**
Social and emotional wellbeing **Family and community commitments** **Personal, spiritual and cultural considerations**	Family arrangements and supports, caring role, community and home situation, living conditions, employment/education, role in community, funerals, grief, trust, celebration e.g. Mother of three young children, part-time Aboriginal support worker at school	Being unwell or needing to travel may prevent the person from meeting obligations or participating e.g. care of children, land council meetings, funerals e.g. needs to arrange care of children and sick leave while having cardiac investigations. Is concerned about her job.
Physical and biological	Any comorbidities, chronic conditions, self-reported health e.g. diabetes Add cardiac-specific risk factors	New illness and impact on the person and family e.g. diagnosed with cardiac illness – requires further investigation in city and new medications

Task 2.4: Considering the underlying factors that affect access and quality of care

There was deep discussion about underlying factors that impacted different patients and about how these are recognised to greater or lesser degrees. Staff who work in a range of settings across the Northern Territory and also accompany patients to Adelaide highlighted how an Elder person might communicate freely and interact effectively and comfortably within the local clinic, and perhaps less so in Darwin Hospital depending on the extent to which he/she has built a relationship and has positive experiences with staff, but in Adelaide might be immobilised verbally and physically by the illness, the change in environment, by not knowing anybody, and by having no one who readily understands the patient, the language and the culture. Prompts and possible factors for Table 2 were developed (these later became prompt questions as shown in the final workbook).

Case Study C – Table 2: Underlying factors

Underlying factor	Impact of location and access		
	Local health services	**City/regional hospital**	**Follow-up**
Rural and remote/city Travel to health care, environmental factors, proximity of family and support networks	What is available locally in primary health care, permanent or long-term staff – high turnover of staff	Distance from home to hospital or specialist care	What services are available and where are they
Impact of illness or injury	Shock, worry, tiredness, increasingly unwell	Impact of investigations, new medications, treatments	What difficulties arise, what do they need, how are they supported after discharge
Language and communication Patient interactions with staff, and communication between staff and between health services	Is English first, second, third language of person and staff, interpreter access Do staff communicate well with the patient and other health staff/services – difficulties/strategies	Is English first, second, third language of person and staff, interpreter access Do staff communicate well with the patient and other health staff/services – difficulties/strategies	Is English first, second, third language of person and staff, interpreter access Do staff communicate well with the patient and other health staff/services – difficulties/strategies
Financial resources Of the person, other funding, resources Support services available	Person's financial situation Cost to person of accessing local services	Person's financial situation Access to banking Cost to person of accessing hospital or specialist services	Person's financial situation Cost to person of accessing services
Cultural safety Experiences of an Aboriginal person within a health system	Previous and current experiences of health care and government services Culturally safe and respectful options, continuity of care, choice	Previous and current experiences of health care and government services Culturally safe and respectful options, continuity of care, choice	Previous and current experiences of health care and government services Culturally safe and respectful options, continuity of care, choice

Task 2.5: Bringing together multiple perspectives in chronological mapping

Bringing together multiple perspectives was found to be a really important aspect of the mapping. Due to the vast distances and different services involved in many cardiac patient journeys, a timeline was added to the multiple perspectives matrix. In addition, in acute cardiac events, receiving timely care is crucial for improved health outcomes. The group considered the standards of care (cardiac, culture, hospital discharge, transfer of care) that they could use to analyse each patient journey. There was also discussion about how detailed to make Table 3 in order to reflect the many people and services that play specific roles along the entire patient journey. Daphne's Table 3 in Case Study B was introduced and used as a guide for further work. During the half-day workshops, the following Table 3 was used as a starting point.

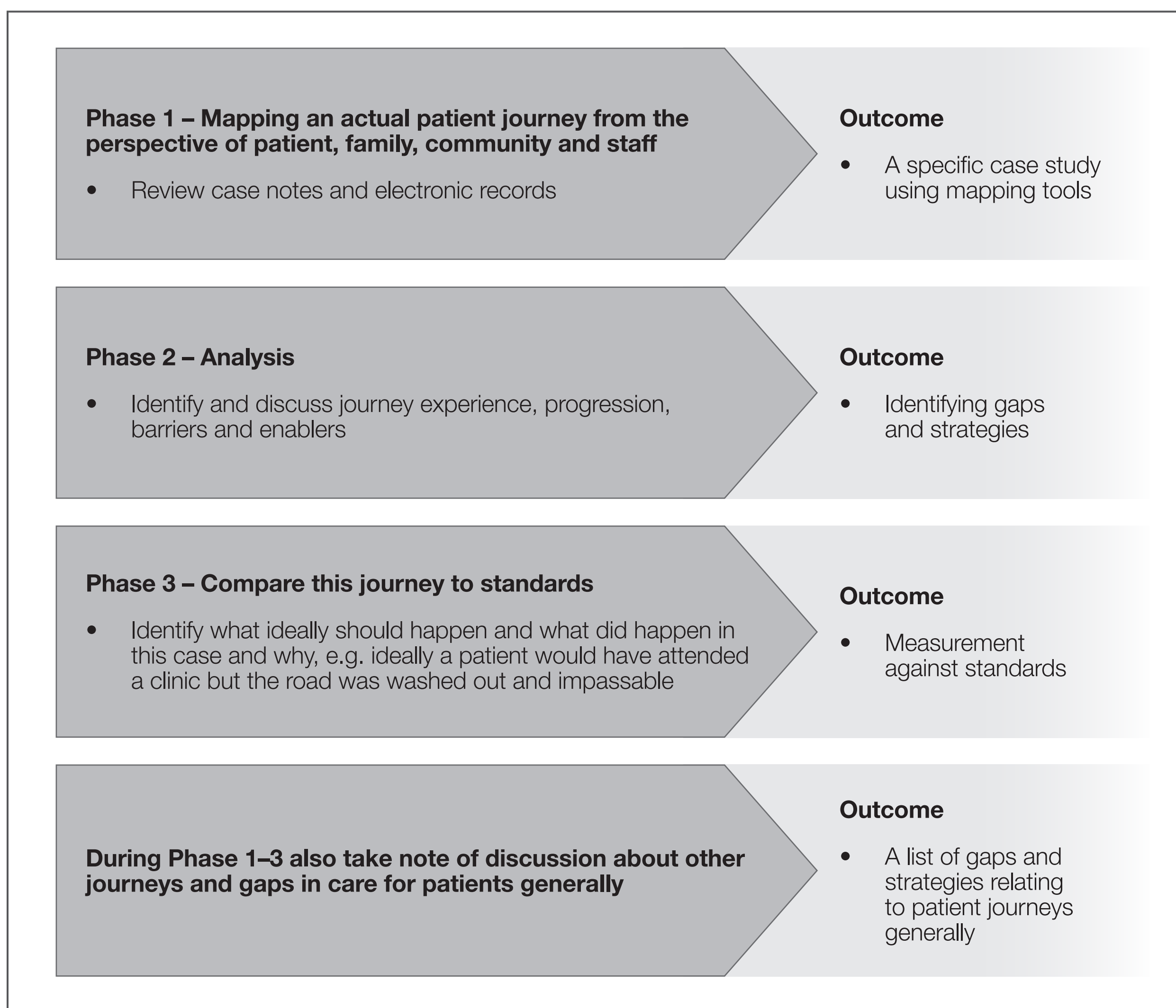
Case Study C – Table 3: Multiple perspectives

Perspective	Patient history	Diagnosis/ referral	Trip to city	Patient transfer /Pre-admission	In hospital	Discharge/ transfer	Trip home	Follow-up
Timeline								
Patient's journey								
Family/carer journey								
Patient priorities, concerns and commitments								
Health services priorities/ standards								
Service/health care gaps								
Responses to gaps (actual and potential)								

Task 2.6: Additional considerations for this patient journey mapping

What became clear during the workshops was that the process of mapping, analysing and comparing the journeys to standards was as important as the outcome (the completed mapping and case study). The discussions with patients and their families, between different staff members, and between staff and patients and families, identified and clarified many points, leading to a new understanding of each other's experiences and challenges.

In addition, there arose conversations about patient journeys generally, relating both to this specific patient journey, and to a broader range of journey experiences. Significant issues were often raised regarding patient journeys generally, and it was important to record these, which is illustrated in Figure 1 (below).



Case Study C – Figure 1: Mapping patient journeys, specifically and generally, and working with the results

Task 2.7: Comparing this journey to particular standards of care and procedures

The staff in both workshops discussed which cardiac standards and protocols would be most useful. There had recently been a review and the tools could assist in measuring how effective the proposed changes were as part of a quality improvement process.

Task 2.8: Identifying key findings

One patient was labelled as non-compliant early in his/her journey due to a single event when they were feeling very unwell. This had the potential to have a negative influence on the rest of their health care interactions in both Northern Territory and South Australia.

It was also difficult to determine how patients felt about travelling to Adelaide for heart surgery, whether a companion travelled with them and if there were any significant underling factors impacting on their journey.

Task 2.9: Reflecting on what was learned about patient journeys and the mapping process

What worked? Reflections on the mapping process

Bringing together a range of staff members in the Darwin workshop led to more informed discussions about patient journeys from multiple perspectives. Staff left the workshop having learned a lot from each other. Visual mapping, including geographical locations and distances to hospitals, was found to be important. Getting to the point where everyone agreed on what the journey 'looked like' was a critical step in ensuring each key aspect was included.

Adapting the tools

It was easy for clinical staff to 'zone in' automatically on the physical and clinical issues. After these workshops the order of how the dimensions of health were initially listed in Table 1 were changed, so that physical aspects were considered only after the social, emotional, spiritual, cultural and family factors. In some locations, the journey was very long and involved many steps, and staff added multiple columns and rows to the table. It may be useful to switch to an Excel spreadsheet if this occurs.

What didn't work/what would we do differently next time?

We found that case notes are good for recording single episodes of care, but not the entire journey. Often it is difficult to identify patient concerns or priorities from the case notes (more so in tertiary than in primary care settings) or what was happening for family members. It became obvious that mapping is so much more accurate with the direct involvement of patients and families, otherwise staff may guess or surmise the facts.

Step 3: Taking action on the findings

Task 3.1: Deciding how best to share the findings, with whom, and in what format

Staff participants in both workshops identified multiple ways to share the findings using the resulting case studies for quality improvement, service planning and education. They planned to share findings with staff peers in a range of hospital and primary care settings and cardiac clinical groups, and with policy makers and managers.

Task 3.2: Identifying actions at personal, professional, local service and systems levels to improve patient care and coordination of journeys

A decision was made to apply for a Heart Foundation Focus Grant to enable the work to continue in a structured way. This was successful and work involving cardiac coordinators, cardiologists, NT Health managers and services is continuing over 18 months.

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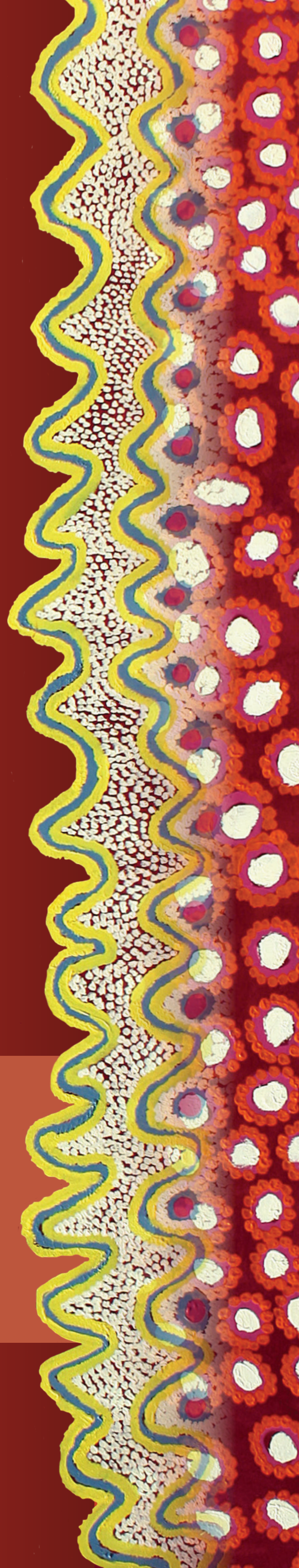

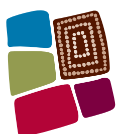

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