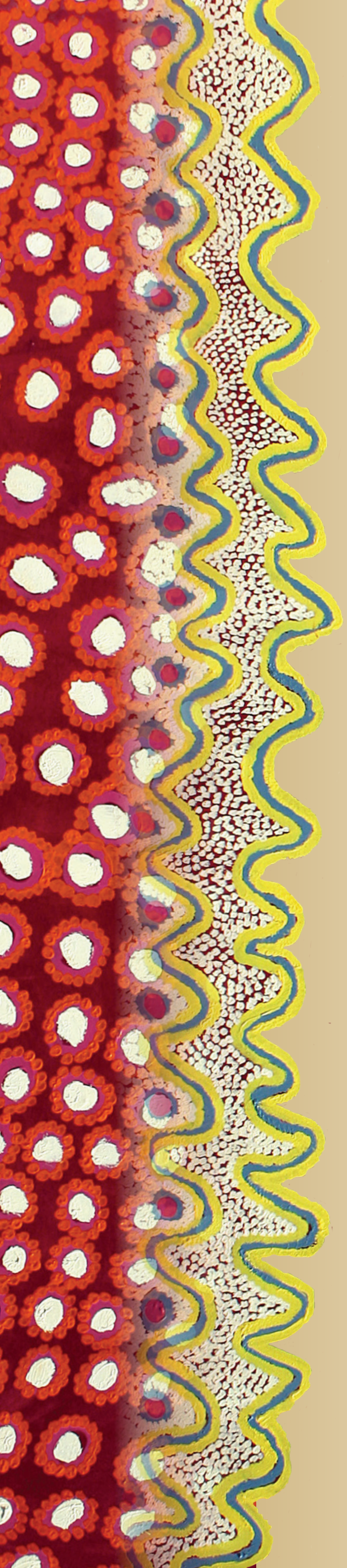
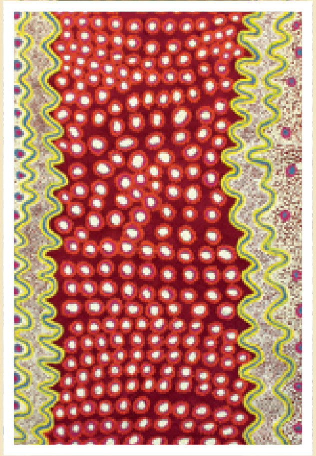


Managing Two Worlds Together

Stage 3: Improving Aboriginal Patient Journeys— **Workbook (Version 1)**

Janet Kelly
Judith Dwyer
Brita Pekarsky
Tamara Mackean
Natalie McCabe
Jacene Wiseman
Charlotte de Crespigny
Kim O’Donnell



Cover Artwork:

Kuntjanu – Mingkiri Tjuta Tjukurpa (Marsupial Mouse Dreaming)

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

Managing Two Worlds Together

Stage 3: Improving Aboriginal Patient Journeys— **Workbook (Version 1)**

Janet Kelly
Judith Dwyer
Brita Pekarsky
Tamara Mackean
Natalie McCabe
Jacene Wiseman
Charlotte de Crespigny
Kim O'Donnell

Flinders
UNIVERSITY

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

ISBN 978-1-921889-29-5

First published in April 2015

This work has been produced by Flinders University and is published as part of the activities of The Lowitja Institute, Australia's national institute for Aboriginal and Torres Strait Islander health research, incorporating the Lowitja Institute Aboriginal and Torres Strait Islander Health CRC (Lowitja Institute CRC), a collaborative partnership funded by the Cooperative Research Centre Program of the Australian Government Department of Industry.

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

Department of Health Care Management
Flinders University
Bedford Park, SA 5042 AUSTRALIA

T: +61 8 8201 7755
F: +61 8 8201 7766
E: tiffany.carlin@flinders.edu.au
W: www.flinders.edu.au

The Lowitja Institute
PO Box 650, Carlton South
Vic. 3053 AUSTRALIA

T: +61 3 8341 5555
F: +61 3 8341 5599
E: publications@lowitja.org.au
W: www.lowitja.org.au

Authors: Janet Kelly, Judith Dwyer, Brita Pekarsky, Tamara Mackean, Natalie McCabe, Jacene Wiseman, Charlotte de Crespigny and Kim O'Donnell

Managing Editor: Jane Yule @ Brevity Comms

Copy Editor: Cathy Edmonds

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

Design and Print: Inprint Design

For citation: Kelly, J., Dwyer, J., Pekarsky, B., Mackean, T., McCabe, N., Wiseman, J., de Crespigny, C. & O'Donnell, K. 2015, *Managing Two Worlds Together. Stage 3: Improving Aboriginal Patient Journeys—Workbook (Version 1)*, The Lowitja Institute, Melbourne.

Australian Government
Department of Industry and Science

Business
Cooperative Research
Centres Programme

Table of Contents

Diagrams, Figures and Tables

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 Aboriginal individual 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.

Stage 1: 2008–11

Focus: Understanding the problems

Identifying the barriers, enablers, gaps and strategies to care

MTWT reports

City Hospital Care for Country Aboriginal People—Project Report

City Hospital Care for Country Aboriginal People—Community Summary

Study 1—Report on Admissions and Costs

Study 2—Staff Perspectives on Care for Country Aboriginal Patients

Study 3—The Experiences of Patients and their Carers

Study 4—Complex Country Aboriginal Patient Journeys

Stage 2: 2012

Focus: Exploring solutions and strategies

Considering application of findings and mapping tools

MTWT reports

Stage 2: Patient Journey Mapping Tools

Stage 3: 2013–15

Focus: Improving Aboriginal patient journeys

Modifying, adapting and testing mapping tools for quality improvement and education

Knowledge exchange and translation

MTWT reports

Stage 3: Improving Aboriginal Patient Journeys—Study Report

Stage 3: Improving Aboriginal Patient Journeys—Workbook (Version 1)

Stage 3: Improving Aboriginal Patient Journeys—Case Studies

- Renal
- Cardiac
- Maternity
- Rural and Remote Sites
- City Sites

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

Acknowledgments

This Workbook is the result of mapping processes and conversations with community members, health professionals, managers, educators, students, coordinators, project officers, support workers and other researchers across Australia – we thank you for your collaboration.

The authors would like to acknowledge the following people who contributed significantly to the development of these tools and this Workbook:

Hugh Auckram, Jenny Brands, Alex Brown, Sarah Brown, Lisa Catt, Christine Connors, Carol Cooper, Wendy Corkhill, Claire Davies, Karen Dixon, Kain Donily, Toni East, Joanne Else, Amy Graham, Kylie Herman, Liz Izquierdo, Denise Karpany, Wendy Keech, Rosie King, Michael Kirkbride, Monica Lawrence, Laney Mackean, Natalie McCabe, Wendy McInnes, Laney Mackean, Jillian Marsh, Gay Martin, Lee Martinez, Sonia Mazzone, Paula Medway, Debra Miller, Jo Newham, Annapurna Nori, Sharon Perkins, Daphne Perry, Pam Pratt, Holly Prest, Mark Ramage, Damian Rigney, Christine Russell, Bronwyn Ryan, Amy Sawford, Rosalie Schultz, Tim Schultz, Kerry Taylor, Kym Thomas, Jeff Tinsley, Rachel Tipoti, Cheryl Wilden, Eileen Willis, Sarah Wyatt 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

CNC	Clinical Nurse Consultant
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

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.

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, their 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.

How to Use this Workbook and Tools

The tools contained in this Workbook are an outcome of the Improving Aboriginal Patient Journeys study, Stage 3 of the Managing Two Worlds Together project. Many Aboriginal care journeys are complex, challenging and overwhelming – not only for the person experiencing the journey but also for their family and the staff members supporting them within and across various health and support services. Thus, the aim of the IAPJ study was to develop, refine and evaluate a set of Aboriginal patient journey mapping tools for use in quality improvement and education.

This Workbook explains how to prepare for and use these PJM tools in a range of settings, and provides a writeable version of the tools for you to use. For the tools to be used effectively, and as intended, it is critical that potential users first read the guiding principles and explanations that inform the approach to, and process of, using the tools, which is as important as their format and design.

The tools were first devised for analysis and then for problem solving, quality improvement and education. They have been specifically developed to map the patient journeys of Aboriginal people – from home to hospital to home, across health services and geographical locations – particularly those from rural and remote areas of Australia needing to access hospital care. However, they can be adapted to reflect the needs of any person accessing health care.

The tools have been developed in collaboration with Aboriginal patients, their families and carers, staff in city and rural and remote hospitals, and health services over three stages of the MTWT project. As such, we anticipate they will be used to map complex patient journeys from multiple perspectives in respectful and pragmatic ways, and assist patients, families, health staff, managers, educators, students and other key stakeholders to better understand the complexities of each journey so as to make positive change. This process requires careful attention to the way in which those involved interact, and how health services and systems are structured and operate.

The main advancement in the format of the Aboriginal PJM tools from Stage 2 to Stage 3 is that they have been developed from an original set of three tables into this comprehensive Workbook with a greater emphasis on planning, comparing each patient journey to standards and quality of care, and working with the findings. The tools can now be used:

1. to understand and identify the complexity of these patient journeys
2. to make complex patient journeys visible
3. to organise the journey for analysis and response
4. to highlight the critical steps, gaps and responses, thus providing a focus for targeted action by health care providers.

They can also be used to assist staff in identifying local solutions for wider systemic problems, as well as emphasising particular patient risks that require immediate organisational, policy and procedural changes.

Six other documents accompany this **Workbook**. The first is the **Study Report** that describes the research activities of the Stage 3: Improving Aboriginal Patient Journeys study. The other five are **Case Studies** – focusing on Renal, Cardiac, Maternity, Rural and Remote Sites, and City Sites – that provide examples of how health professionals and support staff have adapted and used the tools for a diverse range of settings and patient journey types. A writeable PDF of this Workbook, along with the Study Report and all five Case Studies, are available at: www.lowitja.org.au/lowitja-publishing.

The value of the case studies is that they show practical application of the tools. It is important to note, however, that these case studies were an integral part of the development of the Aboriginal PJM tools and were undertaken at different times during the year. Therefore, they do not all reflect this final format of the tools as not all tasks within each step were developed at that time.

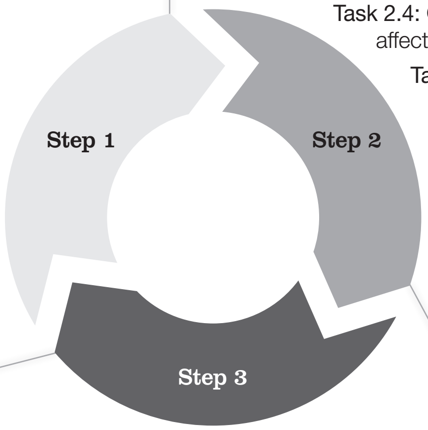
The Patient Journey Mapping Process

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 the 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.



Step 1: Preparing to map the patient journey

Focus: How to prepare adequately prior to mapping patient journeys

Considerations

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

Task 1.2: Guiding principles for respectful engagement and knowledge sharing

Step 2: Using the tools

Focus: How to map and analyse a patient journey

Data gathering

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

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

Task 2.3: Recognising the whole person experiencing the patient journey

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

Task 2.5: Bringing together multiple perspectives in chronological mapping

Task 2.6: Additional considerations for this patient journey mapping

Analysis

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

Task 2.8: Identifying key findings

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

Step 3: Taking action on the findings

Focus: How to share findings and take action towards improving practices and policies

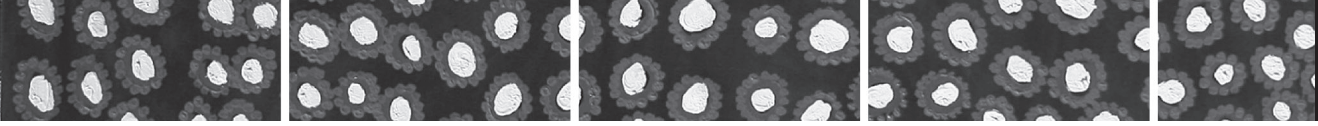
Knowledge translation

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

Planning and taking action

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

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



Key Messages

Why map patient journeys?

- To better understand what is happening for:
  - Aboriginal patients
  - their families and communities
  - staff and services at the patient’s local clinic or hospital
  - staff and services at the city hospital.
- To identify clearly what is happening at each geographic and health care site and across the entire patient journey.
- To assist local clinics and hospitals develop effective strategies for better preparation and response to these situations and events.
- To improve the quality of patient care, experiences and outcomes.

Why will these tools be useful?

- They were developed with patients and staff from the ground up, drawing on real experiences so they make sense.
- They are available at no cost.
- They use Microsoft Word, Excel or Adobe PDF, so no new programs or training are required.
- You can adapt them to suit your own needs.
- The tools can be scaled up or down and so can be used to map a relatively straightforward journey or a very complex journey.

What will mapping achieve?

Staff in both rural and remote and city hospitals and health services have found that the tools help to:

  - record and make sense of their work supporting patients on their journeys
  - document and communicate the issues, problems and strategies they know about and identify those they have not considered
  - improve planning, problem solving, patient safety and risk reduction
  - bring people (staff, managers, patients, researchers) together to work on shared understanding and solutions
  - write a case study that enables ‘practice-based evidence’ to be recognised.

- Patients and families have found that the mapping helps:
  - to make sense of what happened, is happening or may happen so they feel more in control and better able to make decisions
  - to understand the health system and its processes so they are able to be more involved in their journey of care.
- Students and researchers have found that the mapping helps:
  - to understand the whole journey from multiple perspectives
  - to tell the person’s story in the context in which it happened
  - to make sense of the complexities
  - to identify areas for systemic, operational and individual improvements.

How to Use the Tools and Why

There are many reasons why it is useful to map patient journeys, particularly complex patient journeys or the journeys of people whose needs, experiences and preferences may not be well understood by health staff, managers, policy makers, students, trainees and researchers.

Many rural and remote Aboriginal people experience complex patient journeys, particularly when accessing care in city hospitals. Their journeys may take them across multiple geographic and health care sites including:

- Aboriginal and mainstream health and support services
- primary, secondary and tertiary care
- city, rural and remote locations.

Often there is no one single person or service coordinating the journeys or follow-up, and so patients/clients may fall between the gaps in service provision. This can result in interrupted care, worsening of health conditions and significant health risks.

Mapping a patient's journey across multiple sites can assist in:

- highlighting communication, coordination and collaboration gaps and strategies
- identifying transition of care and handover points
- identifying opportunities for targeted quality improvement/auditing/service planning
- evidence-based education and training updates for staff in health and education settings.

These Aboriginal PJM tools bring together:

- the realities for the person experiencing the journey, and that of their family/community
- the perceptions and challenges of health and support staff and managers
- standards, policies and practices that are currently in use or being developed.

The tools can be used by:

- individual staff members, coordinators, educators, students, managers, researchers, policy makers, evaluators
- wards, units, services, organisations
- people undergoing health care journeys.

And result in:

- a better understanding of the complexities of the entire journey and the significant factors for patients and their families/communities, staff, managers, health services and the health system
- a comprehensive description of an individual patient journey – a 'case study'
- identification of gaps and strategies specific to the case study and in health care in general
- a snapshot of current health and support practices
- a comparison or measure of how this person's journey and experiences compare with the current or intended standards, policies or protocols (as appropriate)
- identification of personal, professional, service and systems strategies for improvements.

Outcomes can be used:

- in discussions with staff, managers, working groups and students to highlight specific points
- to identify issues and risks before they escalate, and to strengthen policies and practices so that a worst case scenario can be avoided
- to improve risk minimisation and harm prevention strategies and to provide evidence of improvements undertaken in a health service within a quality assurance framework
- by health professionals as a reflective practice exercise as part of their annual professional development.

In this section of the Workbook we introduce each step and explain what tasks are required and why.

Step 1: Preparing to map the patient journey

Step 1 focuses on how to prepare adequately prior to mapping patient journeys. Before beginning, there are a few things to consider and prepare. Spending time on planning and thinking through what you intend to do is important.

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

Ideally the person – patient, client, community member – or a family member will be involved in the mapping. If this is not possible, then involving staff or other people who worked closely with the person ensures the mapping can be more realistic and complete. It is important to avoid making assumptions about what happened for the person, how they felt, and what their priorities and concerns were.

There are a range of aspects to consider, including:

- *Whose* journey do you wish to map – which patients, locations, with what illness or injury?
- *What* is the issue, problem, need, trigger – what is the main/primary reason for mapping patient journeys?
- *What* aspects do you wish to highlight – e.g. discharge planning, cultural safety, follow-up, rehabilitation, transport costs?
- *When* will you map the journeys – before or while they are happening (planning, referral) or after they have occurred (retrospective)? Why and how will you do this?
- *How* will you conduct the mapping – face-to-face interviews with a range of people or alone as a reflective practice exercise?
- *Who* will be involved in the mapping – patients/clients/community members, carers/family members, staff, researchers, students, other key stakeholders?
- *What* do you envision doing with the results and who will you share them with – managers, peers, students, key stakeholders, community members, educators – and in what formats – reports, discussions, presentations?
- *Which* standards of care, policies, standards or key performance indicators could you compare the journey to and why – e.g. cardiac standards, cultural safety, clinical handover, timely follow-up, patient satisfaction, readmission rates?

The answers to these questions will help you to work out what permissions and ethics may be required. If this is a reflective practice exercise or course assignment, you may need no additional approvals. If this is part of a client survey or audit with information remaining within your health service, you may need organisational permissions and agreements, but not external ethics approvals.

If you are planning on publishing results, or discussing them beyond your health service, you will need ethics approvals. If you are working in Indigenous communities or health care settings you may also need additional Indigenous council, health service or community approvals.

Here are some specific aspects we found useful to consider.

1. When working directly with *patients/clients/community members*, ensure you respectfully invite them to share their stories about a recent experience and then use the prompt questions to complete each table. With permission write down or audio-tape what they say. If this is part of a research project, ensure correct informed consent processes are followed. Invite the *patients/clients/community members* to ask questions about why you are doing this and what will happen with the results.
2. When working with a *staff member*, make a time to meet or, if working across distances, arrange a teleconference, videolink or email discussions. One person takes a lead role in organising and writing up results. We found it valuable to record both the discussion about the patient journey specifically and discussions about gaps in patient journeys generally, as key issues often arose and can be recorded and then addressed at a service level.
3. When working with *case notes and electronic records*, ensure you have everything organised prior to the meeting/mapping. Check if you need permission to access records and what the required process is.

Task 1.2: Guiding principles for respectful engagement and knowledge sharing

We developed a set of underlying principles to guide the use of the tools. These are important because the way we use the tools and the way we interact with each other impact on how people – patients, carers, staff, students, educators – experience the mapping process and what our findings will be.

All collaborative activities in this project were guided by the following set of principles and agreed upon by project participants, key stakeholders and the research team.

- **Respectful engagement and knowledge sharing**. Recognising the need for joint planning and decision making and supporting Indigenous and Western knowledges to come together to generate innovations and new ways of thinking and working together (Durie 2005; Echo-Hawke 2011; The Lowitja Institute 2014).
- **A wider view of health**. A comprehensive understanding of Aboriginal health as involving psychological, social, spiritual, cultural and physical aspects for a person and community (AIDA & CHETRE 2010).
- **High standard of clinical care**. Aboriginal people should have access to a high standard of clinical, specialist and biomedical care when required.
- **Strengths based rather than deficit based**. The strengths and abilities of the person undergoing the journey, and of the staff supporting them, are acknowledged (AHRC 2010).
- **Person-/patient-centred care**. Health care that is respectful of, and responsive to, the preferences, needs and values of the person and their experiences as they journey through multiple health system sites (ACSQHC 2014; AIHW 2014; Nguyen 2008; Picker Institute Europe 2013).
- **Equity**. Not everyone begins at the same starting point with the same resources available to them. Consideration of equity assists in understanding why some patients may require additional support to ensure the same health outcomes. The starting point and level of complexity for an Aboriginal person living in a remote community may be vastly different to that of a city-based patient (AHRC 2014).
- **Cultural safety/competency**. Health care is culturally safe if it is considered so by the recipients of care. Staff can begin enacting cultural safety by being aware of their own personal and professional cultures and that of the hospital and/or health system they work within, and how this impacts and/or meets the needs of individual patients (Browne & Varcoe 2006; Taylor & Guerin 2010).
- **No blame, no shame**. The focus needs to be on continuous quality improvement and problem solving rather than blame. The aim is to better understand the complexities of current situations and challenges in order to identify issues and gaps early and enact effective strategies, thereby preventing negative outcomes (Bailie et al. 2007). The tools were described by one remote area doctor as ‘like a root cause analysis but proactive’.
- **Verify and avoid making assumptions**. Obtain correct information about both patient/client priorities and needs, and other health staff and services, by talking with people directly to build and maintain relationships and a ‘no blame, no shame’ approach.
- **Collaboration rather than competition**. The project team and staff participants actively sought to work with existing programs and emerging projects (Nirrpurranydji, Fraser & Dhunupa 2012).
- **Complexity principle**. There are often multiple complexities occurring within and along the entire patient journey for patients, their families and health care professionals. This complexity is often predictable and, once identified, appropriate strategies and supports may be established (Dwyer et al. 2011).
- **Systems-level approach**. Often individual staff and services provide good care, but this is not always supported or coordinated across the entire health system. A focus on improving communication across, as well as within, health services is needed (Lawrence et al. 2009).
- **Risk assessment and management**. Once gap points and breaks in the patient journey and care pathway are identified, they need to be addressed to reduce the risk for subsequent journeys (Standards Australia 2009).

Basically, it is important to be respectful of different people’s perceptions and not to make assumptions or judgments. This tool is designed to assist people to work together to identify and solve problems, not to cast blame or cause hurt intentionally or unintentionally. The tools can be used to highlight both gaps and barriers and examples of good practice.

We found that the *process* of bringing people together to discuss patient journeys, to adapt and use the tools, and to recognise the different perspectives is as *important as the resulting data*. The act of listening respectfully to patients, families and staff, and discussing different perspectives of health care and the challenges each person encounters, is often enlightening. These conversations build understanding between stakeholders involved in the patient journey and often lead to problems being resolved in the most effective way with meaningful benefits for patients and staff.

Step 2: Using the tools

Step 2 focuses on **how to map and analyse a patient journey**. Over the past five years we have been working with people (patients, clients), their families and staff from a wide range of health services. Together we have developed and tested a set of tools that enable patient journeys to be mapped. These tools are used for data gathering and analysis and involve thirteen tasks.

It is important to note that even though these are presented as a set of numbered tasks, you may find you move from one to another out of sequence during the mapping process.

For ease of understanding, we refer to the person undergoing the patient journey as the ‘patient’. This term can be changed if required – for example, ‘person’, ‘client’ or ‘consumer’ may be more appropriate in your setting.

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

The first task is to write the patient’s story from his or her perspective, with additional information added where required.

After talking with the patient and/or family, discussing with other staff and/or reading the case notes, write out the story/narrative account of what happened for this person.

The story or narrative may be a few paragraphs or a whole page depending on the amount of detail and your purpose for mapping. It is intended to give the reader an overview of the journey and what happened. Make sure there are no assumptions about what was important for this person and what the person did or did not understand about what was happening.

One approach is to begin with dot points and then fill in the details. You may find it useful to add to the story after completing the tables – or work between one task and another. If you are doing formal study or research, you could use Emden’s core story creation narrative analysis, which is described in the report *Managing Two Worlds Together: Stage 2 – Patient Journey Mapping Tools* (Kelly et al. 2012:3). There are also different examples of how stories have been written in the case studies. Here is one example that we wrote up and de-identified:

> *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 (Royal Flying Doctor Service or RFDS/doctor plane) for the man’s partner, so the partner was driven to the nearest town, got a lift to Alice Springs and then caught the 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 discussion and 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 Aboriginal hospital liaison 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.*

The narrative gives the reader a basic overview of the journey.

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

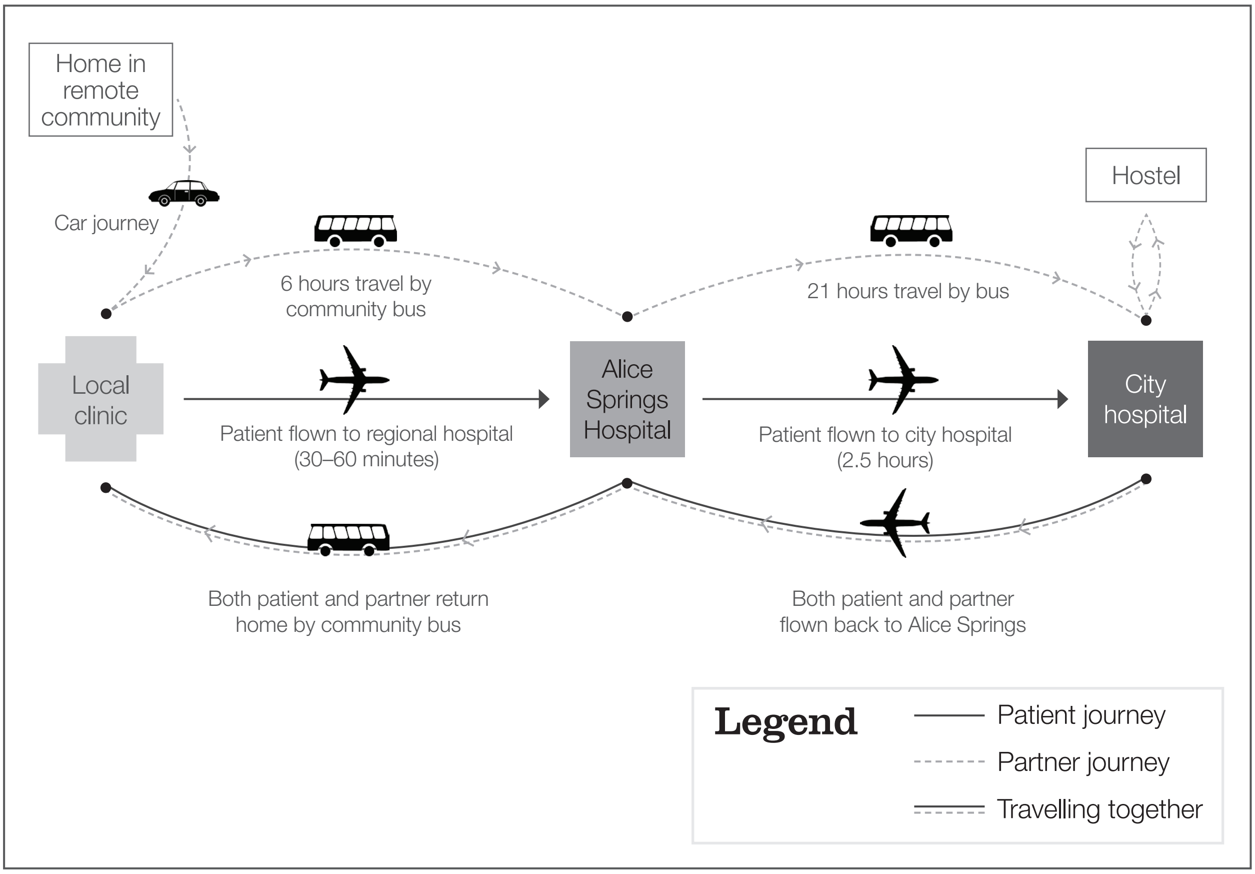
Some people understand concepts more clearly through pictures, and a good diagram is often worth a thousand words. Electronic options for drawing such diagrams include Microsoft Word 'Shapes' for simple figures, or free or user-pay versions such as 'C Maps' from the Internet for more complex ones.

On paper, whiteboard or electronically, draw/map the different geographical and health service locations of the journey and the distances involved. You can include whatever details are relevant to your focus on mapping – you may include staff and services involved at each stage, timelines, seasons or location of family members.

Patient journeys can be drawn in a variety of ways. Sometimes we found it useful to start by drawing in the key geographical locations of the journey like a travel map – home, local health service, regional health service, city hospital – and then marking in the journey (with arrows going from home to hospital and then back to home as shown in Example Figure 1, which is taken from the cardiac case studies).

At other times we represented the journey with an emphasis on the timeline, following the person's journey across the page from left to right, with home appearing on both sides of the page.

If possible, involve the patient in drawing the journey. We found it helped to clarify certain points and identify what was most significant for the patient.



Example Figure 1: Visual mapping

Task 2.3: Recognising the whole person experiencing the patient journey

This task encourages consideration of the ‘whole person’ entering the patient journey, and what is important for him/her (to the extent that the person is happy to share this information). We developed the following set of prompt questions primarily for staff, but if patients/community members are actively using this tool, the questions can be changed into first person questions: What are my family/home arrangements; I am a carer; etc.

Prompt questions

- What are the family/home arrangements – e.g. caring duties?
- Does this person have any particular concerns?
- Is the person a carer for children or family members?
- What roles does the person have in the community/workplace – e.g. cultural obligations, volunteer, health worker, interpreter or teacher?
- How is the person’s physical health usually?
- Has anything happened recently that will impact on their lives and accessing health care – e.g. care of children, land council meetings, funerals?
- Are there any other underlying or new health challenges?

This task and Example Table 1 (from the cardiac case studies) record what is important for and about the individual person entering the journey and his or her home, work or community situation. It is often useful to consider the person’s usual situation and the impact of new challenges or considerations once a health journey begins.

Example Table 1: Dimensions of health

Dimension of health	Situation	
	Local community	**City hospital**
Social and emotional wellbeing **Family and community commitments** **Personal, spiritual and cultural considerations**	Is a well-recognised and respected Elder in their community with a close extended family network Has had a recent loss of a family member, and is caring for grandchildren Is a member of the local council currently advocating with government for community improvements Brother died of cardiac complications a year ago	Patient is worried about diagnosis and feels disconnected, lonely and undervalued in city setting, although this has been alleviated by the support of some staff and the arrival of their partner Partner arrives after travelling by bus for two days Patient has had both positive and uncomfortable interactions with staff, other patients and members of the public Extended family are helping to care for the patient’s grandchildren Patient is missing major decision-making meetings Both patient and partner feel isolated and a long way from home and family
Physical and biological	Diabetes for five years New cardiac condition	Investigations have been carried out and new medications administered for patient’s acute cardiac condition

Why is this important?

The information gathered for this table enables better recognition and understanding that each person is unique and has other responsibilities and priorities to consider beyond his or her physical health. Recognition of multiple dimensions of health is needed for culturally safe and responsive care. Physical illness and injury will usually be the trigger that leads a person to engage with health care; the social, family, cultural, spiritual and emotional factors may determine how the person experiences that care, and whether they remain connected to or disengaged from the health system.

What are the consequences of not enquiring about or recording this information?

As staff become aware of these competing commitments and concerns, they can work with the person, family and community to find a workable solution, and they can plan the health care journey together to maximise the chances of good access and quality of care.

By not asking, or not knowing, staff may make assumptions about what is happening for a person or may miss opportunities to alleviate a patient's anxiety. In the worst case scenario the person may suddenly leave the health service because his or her needs and priorities are not recognised or supported.

How can this information be known?

Information can be revealed through respectful conversations with patients, their families or escorts, and/or their usual health care providers.

Findings from the MTWT study

Often this information is difficult to locate in hospital case notes but is easier to record and find in primary health care settings. In an emergency situation the focus is necessarily on physical and biomedical information, but as the person recovers, additional information is required.

Examples

These de-identified examples shared during the study highlight the importance of recognising the whole person entering the health care journey.

Mary presented to hospital in late pregnancy with complications. After being assessed, she was to be transferred to the ward. However, she left the hospital. She returned the next morning with further complications and staff were abrupt with her, having made certain assumptions about why she left the night before (drinking, didn't really care about her baby, Aboriginal people always leave). Mary's actual reason for going home was that she had left her daughter with a neighbour temporarily while she went shopping and then felt unwell and was taken to hospital. She became very worried about her young daughter, had no telephone or extended family assistance, and went back to check on her and make other arrangements.

John was admitted to a regional hospital for cardiac symptoms and was being referred to a large city hospital for an angiogram. A few weeks prior to his appointment, however, a senior Elder in John's community unexpectedly died and John needed to return to his community to be part of community sorry business. The cardiac coordinator worked with John to assist him to get home in time, rescheduled his appointments and trip to the city, and discussed what medication John needed to take and what to do if he experienced cardiac symptoms. Working together in this way, John's mental, emotional, spiritual, cultural and family wellbeing and priorities, as well as his physical health needs, were met.

Tom is an Aboriginal stockman who was suddenly evacuated for an injury requiring city hospital care. His physical recovery was relatively uncomplicated, but he became increasingly unsettled and agitated. A staff member spent time talking with Tom and learned that he was very concerned about how his family was coping with the stock and current drought conditions. There had been trouble with their main bore and he was worried whether this was fixed or not. Tom didn't have a working mobile phone (it was damaged in the accident) or enough coins or a phone card to call home, and no family member had been able to travel to the city with him in the plane. Tom had missed a recent call from family while he was having an X-ray. The staff member arranged for Tom to make a call home to discuss how things were going, and Tom's anxiety and wellbeing improved significantly.

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

A person's journey across and through the health system is often impacted by a range of factors. Not all Aboriginal people from rural and remote areas will experience all factors, but many will experience a number of them. It is the interaction of these factors that makes access to good health care and quality of care more difficult.

It is useful to map the impact of underlying factors in the different health sites or locations. It is also useful to consider the factors for the patient and for the staff and health services.

Prompt questions

1. Location
    - Where did the person go to receive care and why?
    - How easy or difficult was it for the person to get there?
    - Did the person and his or her family require/ have transport assistance (booking, Patient Assistance Transport/Travel Scheme (PATS) etc.)?
    - Did the person need accommodation – where did the person stay and with whom?
2. Impact of illness or injury
    - What was the impact of the physical health condition on the person at each stage and during travel?
    - Was the person feeling ill, was conscious/ unconscious, tired, uncomfortable, in pain?
3. Communication:
    - Did the person feel able to talk to staff and understand what was happening at each stage?
    - Is English the person's first, second, third language?
    - Is it the first or second language of health staff?
    - Was an interpreter needed, offered, arranged?
    - Was communication of concepts and ideas clear, or was confusing medical terminology used?
4. Financial resources – what is the person's personal situation and did he or she require financial assistance?
    - Can the person access money/bank/support funds?
    - How financial are the health services and support systems?
    - What has it cost the person to access health care (transport, accommodation, fees, food etc.)?
    - Have there been any changes to financial or resources provided by health or support services?
5. Cultural safety – How did this person feel about accessing services?
    - Did the person feel respected?
    - Did the person have specific needs as an Aboriginal person and were they met?

The answers to these questions can be written in note form and then summarised in Table 2, as we have done here in Example Table 2, which is taken from the cardiac case studies. We have provided an example of answers in italics.

Example Table 2: Underlying factors

Underlying factor	**Impact of location and access**	
	Local health service	**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	Manages diabetes medications and diet	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 the patient's third language Staff in local clinic speak both the patient's first language and English	No staff speak the patient's first language Particular difficulty understanding staff who also speak English as a second language Interpreter needed for informed consent
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 Additional accommodation costs for partner There may be changes to financial assistance due to change in government policies
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

If the person has a longer journey involving another health site, additional columns may be added. Exactly what is recorded in each column will depend on what impacts the person the most. Not all squares need to be completed. Follow-up may be provided by the same local health services, or may require additional visiting services.

Why is recognising underlying factors important?

Often the complexity of a person's medical condition is recognised, but the complexity of the entire journey and the underlying factors that affect a person's ability to access care and to experience continuity of care is not recognised or is not recorded and shared across the journey from one point to the next. The level of resources available in health and support services may also vary and this is important to recognise.

What are the consequences of not enquiring about or recording this information?

Although health concerns will usually lead a person to seek services, underlying factors may prevent people from becoming or remaining fully engaged with health services. If health care is provided some distance from the person's home, and if limited transport assistance is available and the person is experiencing financial concerns, it may be difficult or impossible for the person to travel. If there are additional communication challenges with health and support staff, or if the person is feeling too unwell to deal with the complexities, the person is more likely to disengage, which can be the less stressful choice.

How can this information be known?

Underlying factors can be discovered by asking the patient, family and usual health care staff about factors that may be causing concern and by considering the different resources available within each setting.

Findings from the MTWT study

Underlying factors often determine whether a person is able to undertake the patient journey and interact with multiple health services. People may be worried about travel, or simply unable to travel, due to these factors. Once aware, health and support staff can work with patients, families and communities to ensure care is as accessible and supported as possible.

Examples

> *Trevor, a retired pensioner, lives in a rural town with his wife and sees his local GP [general practitioner], with whom he has a good relationship. As his condition worsens he is referred to a specialist in Adelaide who begins monthly treatments. Trevor and his wife don't often travel to Adelaide, and they find the city busy and noisy and the traffic overwhelming. They are not comfortable driving in the city and decide to catch the Stateliner bus. They arrange to stay with family who agreed to drive them to the appointments. At each appointment, the specialist spoke very quickly, using medical jargon – they only understood about half of what he was saying.*
>
> *As the journeys continued, Trevor became increasingly unwell and his mobility decreased. He found it difficult to get up the steps of the Stateliner bus and the trips were exhausting. Trevor and his wife also worried they were expecting too much of their family driving them around. One day Trevor decided it was all too hard and that he would stop going. His wife arranged an appointment with the local health service, and over time they were able to arrange other options for care closer to home.*

In Stage 1 of the MTWT study we spoke with a group of senior Elder women about what was most important in their care, and what message they would like staff and students in city hospitals and education facilities to know. They replied, 'tell them to say hello'. They explained that a basic level of communication and human interaction is often missing, and as a result some people feel dehumanised.

Task 2.5: Bringing together multiple perspectives in chronological mapping

Many people and services play specific roles along the entire patient journey. One way to make sense of the overall patient journey is to bring together the perspectives of the patient, the family or carers, and health care staff working with health service priorities, resources and policies. The previous tasks and tables provide background information for this task.

Take a moment to review the reason for mapping the journey and see whether additional rows or columns are needed in the tables. The case studies include examples of expanded tables. For example, if you are mapping a birthing story, there may also be a row for the baby if the baby stayed in a hospital nursery or neonatal ward. If the person was required to stay in a regional centre or city, or had to return for treatment, additional columns may be added. Not all squares require completion.

Prompt questions

- What happened for this person on each step of the journey?
- What happened for the family and carers?
- What were the person's priorities, concerns and commitments and how were these impacted at various points? For example, a woman may really want to breastfeed her baby who needs to stay in the hospital, but also has other children at home to be cared for.
- What was the best and the worst thing about the journey from the patient's point of view?
- Are health service priorities different from or the same as the person's priorities? For example, a person with renal disease may need to begin dialysis three days a week to stabilise his or her condition, but the person really wants to go home to a remote area. The tables can help explain where different priorities arise.
- Is there a service gap (i.e. a gap between what a person requires and what is available)? For example, is dialysis care available in a remote area? The response to such a gap may be that the person and his or her family are supported to relocate to a regional centre. Or it could be that no cardiac rehabilitation is available in the home town, and so arrangements are made for staff to up-skill, teleconference, or make a referral to another service in another town.

Answers to these questions are then entered in Table 3, with example answers (in italics) taken from the cardiac case studies shown in Example Table 3.

Once the table is complete, specific strategies and gaps can be identified. These could be circled or numbered and discussed further.

Example 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	ECG Rapid referral to regional centre	Via RFDS to regional city for stabilisation then flight to Adelaide	Cardiac investigations and treatment	Fly back to regional city and then bus to remote community	Local clinic No local cardiac rehab
Family/carer journey	Whole family worried about the patient's health and wellbeing	No room on RFDS plane for partner	Partner followed by bus	Partner in hospital accommodation Remaining family in contact via clinic phone	Wondering whether the partner can fly back as well – who will cover costs?	Support in community
Patient priorities, concerns and commitments	Being with family and community	To maintain wellness	Needing to arrange care of grandchildren at home	Understanding what is going on and what their choices are Loneliness	Discharge information sent back to regional hospital and local clinic	Keep well
Health care/ services priorities	Management of chronic condition – diabetes	Assess new health condition	Need tertiary hospital investigations	Investigate and treat condition Need to get informed consent	Get patient and partner back home	Uncomplicated recovery
Service gaps		No GP at local clinic	No room on plane for partner so had to follow by bus	Support for partner No ALOs on weekends	Little support for partner to get home	No cardiac rehab locally
Responses to gaps	Ongoing chronic conditions support in local clinic	Good use of AHW and RAN skills and protocols	PATS assistance	Aboriginal Liaison Unit Social work assistance	Aboriginal Land Council assisted with flight costs	Outreach service Local clinic staff update skills

Specific questions may include:

- What was the most significant experience for the patient (what was the best and the worst experience in the journey)?
- What strategies are in place and working well?
- What gaps were identified and how could these be addressed?
- What standards of care exist for this kind of patient journey and how did this journey compare?

We found it useful to go back and discuss the mapping with the patient and/or carers and staff to clarify certain points and to avoid making assumptions.

Why is it important to consider multiple perspectives?

If only one perspective was considered, important aspects could be overlooked. Bringing together multiple perspectives enables a more comprehensive picture to be built.

What are the consequences of not enquiring about or recording this information?

The multiple perspectives table highlights where communication, coordination and collaboration gaps occur. It maps the 'disconnects', resourcing levels and impacts of competing demands.

Mapping a journey chronologically also makes the immediate and ongoing impact of decisions and actions, or inactions, clearer. For example, a delay in forwarding the discharge letter may be a small omission in a city hospital, but may result in a remote area nurse, doctor or worker spending four hours tracking a patient's medications.

How can this information be known?

Staff can usually locate the biomedical information relatively easily in written or electronic case notes, but it can take a while to map the actual journey from all the individual case note entries. Information about the patient and family may be missing, so staff may need to talk to patients, families or other staff who have closer relationships with the patient.

Findings from the MTWT study

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, or what was happening for family members, from the case notes (more so in tertiary than in primary care settings).

In some locations, the journey is very long and involves multiple staff, services and locations. It may be helpful to use an Excel spreadsheet if many rows and columns are added.

Examples

Reviewing the patient journey from multiple perspectives over time enables particular gaps, breakpoints and implications further along the journey to become more obvious, as in this example.

> *One midwife discovered that while Aboriginal women anticipated breastfeeding their babies, a series of events, miscommunications and transport challenges made achieving this very difficult, and none of the women were still breastfeeding when they and their babies were discharged.*
>
> *One fly-in remote area doctor spent four hours of an eight-hour remote clinic chasing up discharge notes and medications for a person who required ongoing cardiac care. The city hospital staff had no idea that a delay or omission on their part could so significantly impact on the patient, remote area doctor and other patients.*

The introduction of thrombolysis medications and clear Acute Coronary Syndrome (heart attack) protocols in remote clinics was seen to be having a positive impact on health outcomes.

Task 2.6: Additional considerations for this patient journey mapping

At the end of these tasks, information you wish to include or highlight might not have fitted within a relevant place in the existing tables (even by adding rows and columns). If this occurs, it may be useful to create a Table 4: Additional considerations, or include another model or framework.

There are examples of this in the case studies. For example, Umoona Aged Care created a table specifically to highlight the unfunded costs of supporting an Elder woman to get to Adelaide, attend all of her pre-operative tests, be supported while in hospital and return home safely. In the cardiac case studies, the group developed a model to show the benefits of working together as a multidisciplinary team to better understand cardiac patient journeys.

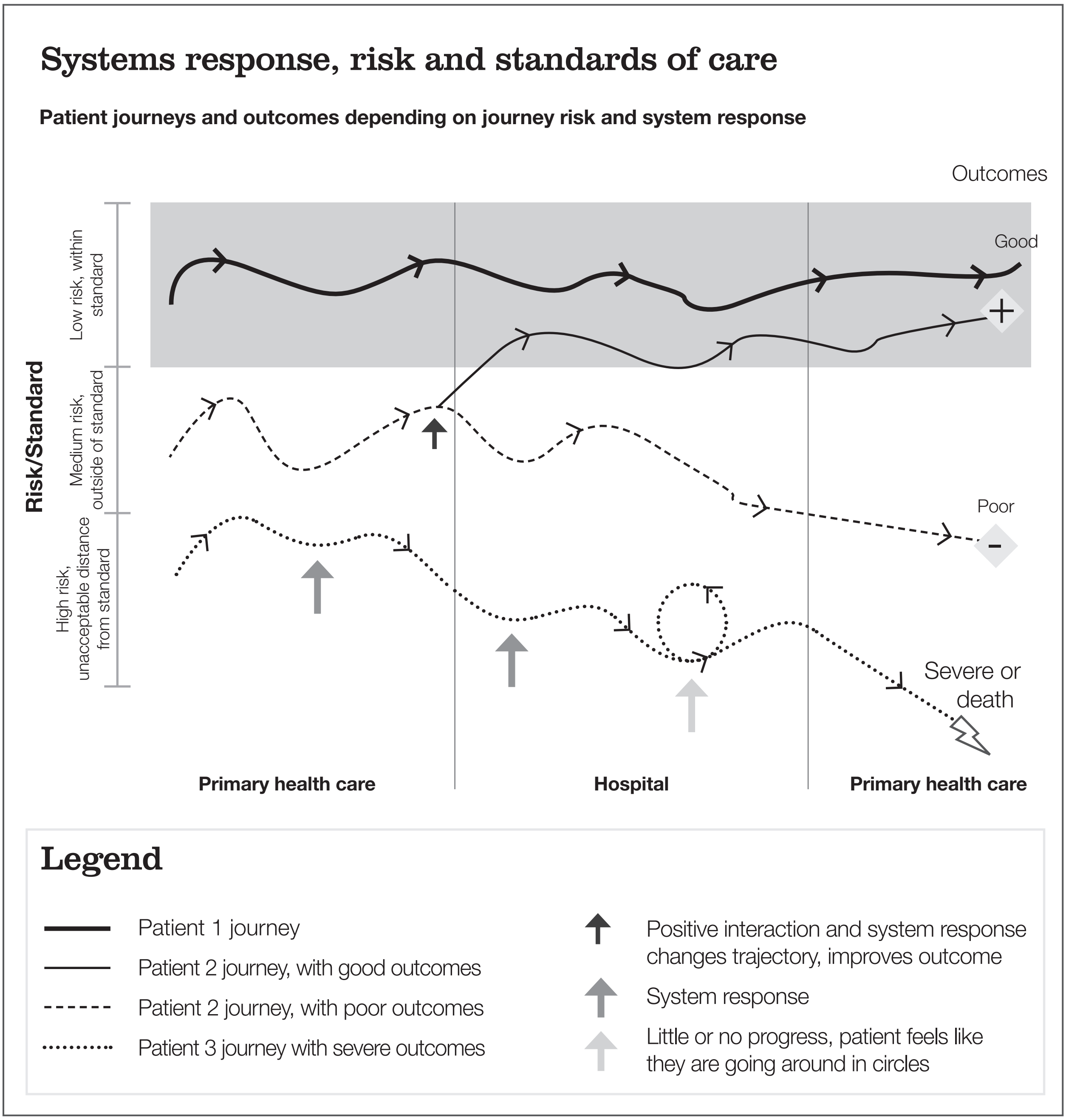
In the Renal Focus Group, one nurse mapped the discharge process to determine how a decision was made to discharge a person back to Country over the weekend. Part of this table from the renal case studies is shown below, and the whole table is available in Case Study B of the Renal Case Studies at: www.lowitja.org.au/lowitja-publishing.

Example Table 4: Additional considerations

Ward/ unit/staff involvement	Date/day	Time	Reality/complexities	Results/consequences
Renal ward **Clinical Services Coordinator**	Friday		Discharge plan is that this patient will go to Kanggawodli Aboriginal Hostel on Saturday and transfer home the following week	Coordinated transfer of care, with transport arrangements at Port Augusta available
Renal doctors	Friday		Need review by infectious diseases and cardio units prior to discharge	Probably unable to predict exact time of review and discharge
Pharmacy	Friday		Script filled, pharmacist telephoned and faxed Port Augusta late Friday re medication changes	Port Augusta Hospital was able to ensure new medications were available
Infectious diseases **Echocardiogram (ECG)**	Friday		ECG takes a while – uncertain when this was booked Review late Friday or Saturday – included the need for new antibiotics [unsure how was this communicated to Port Augusta – no documentation]	Delay in decision making and review
Cardio	Saturday		Review ECG	Delay in decision making and review
Uncertain exactly who made this decision – possibly medical	Friday/ Saturday		Arrangements made for discharge late Friday night, with return to Port Augusta on Saturday following dialysis (medical officer failed to notify all parties concerned)	Poor discharge planning, and poorly connected and supported journey home
Nurses on renal ward	Friday evening		Coordinate and manage complex discharge After-hours minimal staff and resources Multiple pressures, e.g., bed state on skeleton staff	Links in communication broken (staff unaware patient was for discharge home)
Aboriginal Liaison Officer	Friday night		Not available after hours or weekends	Support unavailable
Rural Liaison Nurse	–		Not available after hours or weekends	Support and coordination unavailable
Kanggawodli Aboriginal Hostel	–		Very brief stay – late night to early morning	Minimal opportunity for hostel to be involved in coordination and preparing for transfer

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

A useful step leading to deeper analysis is to compare this journey to the ideal standard of care. This standard may be a clinical standard, such as cardiac standards, or a systems standard, such as discharge planning and communication between services. You can choose whichever standard, policy or practice is most relevant to your setting or purpose for mapping. You can then compare how close or how far from the standard this particular journey has been, and whether the variations are minor or major. It is possible to identify specific strategies and gaps that have impacted on this journey, both positive and negative. Take into account both circumstantial/situational factors (remoteness, co-morbidities) and system responses (standing drug orders, rapid retrieval, timely referral, specialist assessment, fast track patient processes etc.).



Example Figure 2: Comparison of three different patient journeys to standards of care

Example Figure 2 shows one way that we compared individual patient journeys to a particular standard. The vertical arrows indicate where the health system has the opportunity to intervene positively and provide support and care. If this does not happen, the journey, outcomes and experiences move further away from ideal care and standards of care. Each arrow can be numbered and a detailed description of the opportunity and intervention given.

The journey of patient 1 in the above diagram is near to ideal with few complexities. This may represent the journey of a person who lives near the city hospital, and has both personal and health care resources nearby. As a result, their journey is reasonably uneventful with few variations in care are not far from the standard so only have a minor impact on their health outcomes and experience.

The journey of patient 2 reflects an experience with some unaddressed complexities. However, if specific measures are put in place (as indicated by the thick black arrow), this care journey can move from being outside of, to within, acceptable standards. If services and supports are provided at key moments, this person can experience positive health outcomes, but if there is no response, or not timely response, their experiences and outcomes will be much poorer.

The lower line journey has many unaddressed complexities and at times seems to be going in circles or backwards. It veers dangerously far from the standard, and the patient's experiences and outcomes are significantly compromised by a lack of resources, responses, or gaps in care.

In the cardiac example we have been following in this section, the patient would have the middle line journey, where he started in a remote area with inherent isolation risks, including being unable to access full specialist care immediately. However, he was given correct emergency treatment and transferred rapidly to Alice Springs and then to Adelaide, so his health care journey and outcome became within a suitable standard of care.

If you are recording a series of case studies, consider comparing those case studies that highlight the variations that may occur for patients, family and staff. There are often clear standards of care relating to the timing of assessment, medications and other treatments, and follow-up.

Consider comparing three different journeys – least complicated to very complicated. Distance and remoteness can add to complexity, but if appropriate protocols and procedures are in place, the impact of this is reduced.

Task 2.8: Identifying key findings

At the end of the mapping it is important to identify the key findings, such as the main gaps and strategies.

Prompt questions

- Did you find anything surprising?
- What was obvious, what was missing?
- What happened in the transition points between primary health care and hospital care, and between city and rural and remote services?
- Was there good communication, coordination and collaboration, or were there gaps and opportunities for change? If so, describe where these occur and why.

Examples

Examples of key findings from case studies include:

- the identification that there are few pathways in place in South Australia to assist renal nurses to support Aboriginal people to return home to remote locations for end-of-life care (Case Study A in the Renal Case Studies)
- although an Aboriginal woman may intend to breastfeed following the birth of a baby, socioeconomic, support and staff–patient communication factors can prevent this from occurring (Case Study C in the Maternity Case Studies).

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

Taking a moment to reflect on what you have learned personally and professionally is an important part of reflective practice. Was there something about the person's story that you found challenging on a personal or professional level and is there something you could do or change in the future? For example, many Aboriginal people say that they get very lonely in hospital – would this change the way you interact with patients and spend time talking with them where possible?

Are there ways that you can incorporate what you have learned through undertaking the mapping process in your work or study? For example, for some it has assisted in considering the importance of bringing together patient, carer and staff perceptions, and others are considering mapping a patient journey at least once a year for their own reflective practice and professional development.

Step 3: Taking action on the findings

Step 3 focuses on how to share findings and take action towards improving practices and policies. An important part of doing any mapping, study or research is sharing the results. Patient journey mapping provides sound, practice-based evidence that can be used by a range of staff, patients, communities and other key stakeholders to increase understanding of the issues and identify specific strategies for improvements.

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

Once the mapping is complete and the findings identified, the next step is deciding how best to share the findings, with whom and how. Findings may be shared with colleagues, integrated into training, taken to a service, unit or specific meeting, or used for reflective practice. Both strengths and gaps in care can be communicated, ensuring that good practice is recognised and that gaps are addressed.

Prompt questions

- Who do you wish to convey the results to?
- What actions or changes do you think may need to occur?
- What has become obvious to you now that wasn't obvious before, or what was confirmed for you?

Examples

Examples from the case studies include the renal nurses who incorporated their findings into the revised renal education package, and also shared findings at a Renal Society of Australasia seminar. A cardiac coordinator developed a staff education package to share findings with colleagues. An Aboriginal Patient Pathway Officer shared a case study and findings at a health care forum. Umoona Aged Care used its patient journey mapping to discuss budget implications at a board meeting.

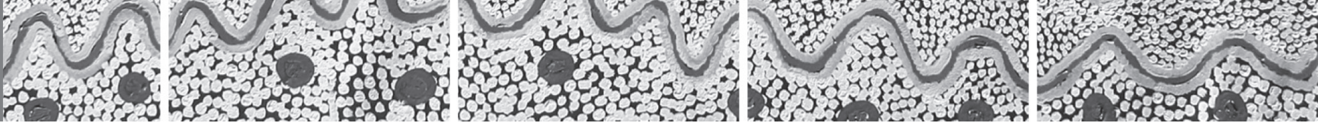
Task 3.2: Identifying actions at personal, professional, local service and systems levels to improve patient care and coordination of journeys

It is useful to make an action plan, including dates to review progress. Action planning may occur at multiple levels for increased impact.

- **Personal** – are there immediate actions for the patient, the family, or the community or health staff members involved?
- **Professional** – are there changes, education or training required for specific professional groups? For example, for renal nurses in a dialysis service, for registrars who are discharging patients to remote areas, for new Aboriginal coordinator positions?
- **Service/agency/unit** – are policy, procedural or other changes needed? For example, earlier and more comprehensive discharge planning or an increased use of interpreters?
- **System** – what needs to change or be strengthened across the health system and between agencies? For example, clinical handover between primary and tertiary care, transfer of care arrangements to provide improved continuity of care, interstate sharing of health care resources in remote areas?

It is worth considering who has the interest, influence and ability to implement change. You may wish to work with a manager, specific committee, professional group, educator and/or other key stakeholders.

A concise way to record your planning and actions is to use an action plan table. This is particularly useful for work-based and quality improvement processes, and can be continually revised and updated, with different versions and dates recorded. A, communication and cultural safety example from the renal case studies is provided in Example Table 5.



Example Table 5: Action plan

Issue	Level	Action required	By whom	When	How	Review	Action taken
Improved communication and cultural safety	Personal	Personal commitment	All staff	This year	Reflect on interactions	Nov. 2014	Individual reflection
	Professional	Reflective practice	Nurses, doctors, allied health professionals	This year	Professional development	Nov. 2014	Included in annual review process
	Local service	Cultural safety and communication training	Unit manager to arrange	Within 6 months	External facilitator	July 2014	Workshop held June 2014
	System	Evaluate effectiveness and implementation of policies	Executive representative	Within 12 months	Review complaints, patient outcomes, policy implementation	Dec. 2014	Sub committee formed

Action plan prepared by __________________________________

On / /

The Tools – A Writeable Version for You to Adapt and Change

This section of the Workbook provides the Aboriginal PJM tools in a format that you can adapt and use yourself. The prompt questions are followed by spaces for you to fill in your answers, while the tables have blank squares and blank spaces in some rows and columns for you to insert your own headings. As you become more familiar with the tools, you may find that you only use the prompt questions to trigger your thinking, and that you fill out the squares in the table to save writing information down twice.

There are various ways in which the tools can be used. You can:

- write in the blank spaces – this is a writeable PDF that allows you to type words in each space
- print off these pages and write in the answers by hand
- create your own tables using Microsoft Word or Excel.

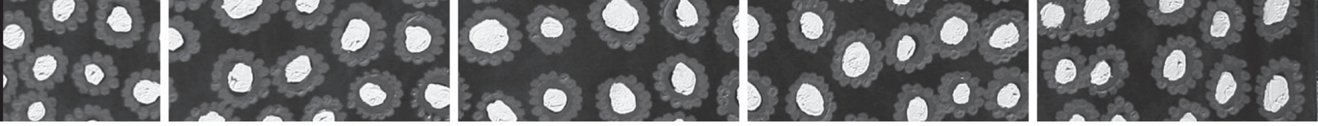
If you wish to use an expanded table, you may find it easier to create your own version using a Word document or Excel spreadsheet. This would be useful if you intend to do more in-depth mapping, particularly with the multiple perspectives matrix. (See Case Study C in the Renal Case Studies and Case Study B in the Cardiac Case Studies for examples of extended tables.)

As you become more familiar with the Aboriginal PJM tools, you may find that you only use the prompt questions to trigger your thinking, and fill out the squares in the table to save writing information down twice.

We found it really useful to have a piece of paper or Word document open to record anything we thought of while talking to patients, family members and other staff but didn't know where best to put it in the tool. Then we went back later and worked out where best to put it.

Also, when meeting and discussing patient journeys with other people, take note of the parallel discussion regarding patient journeys generally. The conversation often goes along the lines of, 'Oh yes, last week when John Smith came back we found he too had run out of discharge medication by the time he got home'. You may find it useful to note recurring themes and write a separate action plan to address them. There is an example of this in Case Study C in the Cardiac Case Studies.

If you would like further information, please contact Janet Kelly, Flinders University, at E: Janet.kelly@flinders.edu.au.



Step 1: Preparing to map the patient journey

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

Whose journey do you wish to map?

Identify the issue, problem, need, trigger – why are you interested in mapping patient journeys?

Which journeys are you interested in mapping – particular patients, specific location, particular illness/injury?

Will you be mapping before or while the journey is happening (planning) or after the journey has occurred (retrospective).

Before ☐ During ☐ After ☐

Why and how?

Is there a particular aspect you wish to highlight? For example, discharge planning, follow up, rehab, transport costs?

Who will be involved in the mapping – patients, carers/family members, other staff, researchers, students, any other key stakeholders?

What do you plan doing with the results and who will you share the results with – managers, peers, students, key stakeholders, community members, educators? In what ways – report, discussion, presentation?

Results will be used for ____________________

Results will be shared with ____________________

In the following way report ☐ meeting ☐ discussion ☐ presentation ☐

Details ____________________

Which standards of care, policies, key performance indicators could you compare the journey to? For example, cardiac standards, cultural safety, clinical handover, timely follow-up, readmission rates.

The answer to these questions will help you to work out what permissions and ethics may be required. If this is a reflective practice exercise, or a client survey or audit with information staying within your health service, you may not need ethics approval. If you are planning on publishing results, or discussing more widely, you may need ethics approval. If you are working in Indigenous communities or health care settings you may need additional approvals.

Discuss permissions, processes, approvals and ethics with your manager, community advisor and/or ethics advisor and complete below.

Manager/unit agreement

Yes ☐ No ☐ Not required ☐

Details ____

Permissions/approvals

Yes ☐ No ☐ Not required ☐

Details ____

Ethics

Yes ☐ No ☐ Not required ☐

Details ____

Arrange how the information is gained – interview with patient, case notes, electronic records, staff to be involved (via face-to-face, teleconference, email, telephone) – and write details below.

Details ____

Task 1.2: Guiding principles for respectful engagement and knowledge sharing

How will you incorporate the following guiding principles into your planning and mapping?

Respectful engagement and knowledge sharing – who are you working with and how?

A wider view of health – how will you include more than physical health?

How can you emphasise a strengths-based approach?

How will you ensure the mapping is person/patient centred and uses respectful processes?

Can you include concepts of equity – recognising that not everyone begins at the same starting point with the same resources available to them?

Which aspects of cultural safety/competency are most relevant?

How can you ensure a ‘no blame, no shame’ approach while still finding gaps in care?

How might you focus on continuous quality improvement and problem solving?

Collaboration rather than competition – who else is doing similar work or studies? Does it make sense to discuss or work with them?

Which aspects of complexity are most apparent?

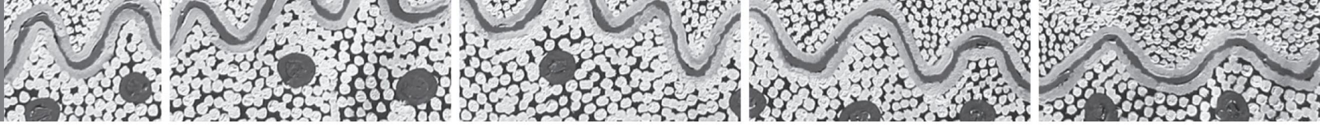
Systems level approach – how can you consider systems level issues?

Risk assessment and management – who could you discuss risks with if they are identified?

Step 2: Using the tools

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

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



Task 2.3: Recognising the whole person experiencing the patient journey

Prompt questions

What are the person’s usual family/home arrangements?

Does this person have any particular concerns?

Have there been new challenges and considerations since the journey began and in each site – if so, what are they for this person?

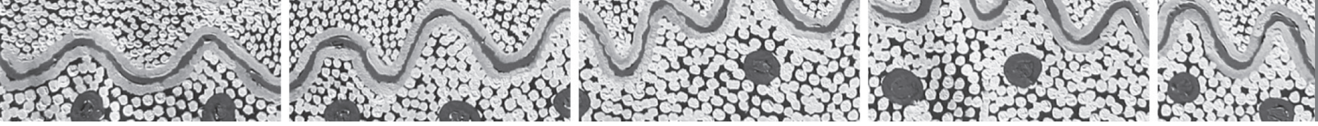
Is the person a carer for children or family members?

Has the person needed to make arrangements while unwell/away?

What roles does the person have in the community/workplace – e.g. cultural obligations, volunteer, health worker, interpreter, teacher?

How has the person’s health care journey impacted on this?

Are there particular personal, spiritual or cultural considerations for the person?



How is the person’s physical health generally? Are there any other underlying or new health challenges?

Are there new physical health issues as the journey progresses? What are they and how do they impact?

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**		
Physical and biological		

Identify the key points that the patient or carers would like communicated between home and the health service/hospital.

How will this make a difference to their care?

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

Prompt questions

Location/setting – rural and remote/city

Where did the person go to receive care and why? How easy or difficult was it to get to each location?

Impact of illness

What was the impact of the person's physical health condition at each stage and during travel?

Was the person feeling ill, conscious/unconscious, tired, uncomfortable, in pain?

Language and communication

Did the patient feel able to talk to staff and understand what was happening at each stage?

Is English the person's first, second, third language?

Is it the first or second language of health staff?

Was an interpreter needed, offered, arranged?

Was communication of concepts and ideas clear, or was confusing medical terminology used?

Was there clear communication between staff and between services?

Financial resources

What is the person’s personal situation and did he or she require financial assistance?

Can the person access money/bank/support funds?

How financial are the health services and support systems?

What has it cost the person to access health care (transport, accommodation, fees, food etc.)?

Was PATS (transport and accommodation assistance) available?

Have any budget or government policy changes impacted (positively or negatively) on the journey?

Cultural safety – the person's experience of health care

How did this person feel about accessing services?

Did the person feel safe and respected?

Did the person have specific needs and were they met?

Transfer your answers to Table 2

Note: you may not have information for every square.

If another health location was involved (e.g. rehabilitation, follow-up services, regional centre), use the third column and record what happened there, using the prompt questions.

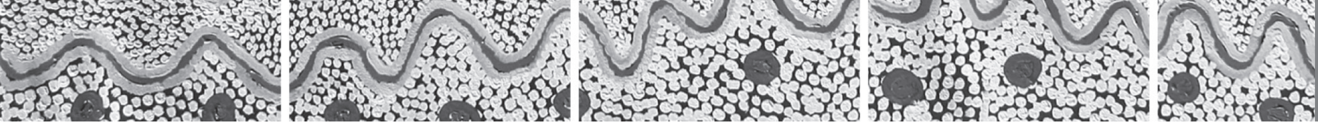


Table 2: Underlying factors

Underlying factor	Impact of location and access		
	Local health services	**City hospital**	
Rural and remote/city Travel to health care, environmental, proximity of family and support networks			
Impact of illness or injury Chronic or complex conditions, being acutely ill or injured			
Language and communication Ease or difficulty of communication between patients and staff, access to interpreters, dentures, hearing devices			
Financial resources Ability to meet costs of transport, treatment, health care, medications, inability to work, caring duties			
Cultural safety Experiences of an Aboriginal person within a health system			

Reflecting on the data you have gathered, what are the five most significant underlying factors encountered in this journey?

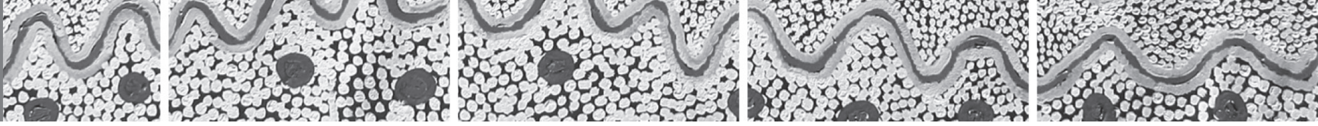
1 ____

2 ____

3 ____

4 ____

5 ____



Task 2.5: Bringing together multiple perspectives in chronological mapping

Check back to your reasons for doing the mapping and see if you need to add any rows or columns to Table 3 in this task. The information you have gathered in Tasks 2.1 to 2.4 will assist you to fill out this table. At times the process may feel repetitious, but once you finish this task, including Table 3, see if anything has become more obvious as you follow the patient's journey chronologically, and consider the different perspectives of the patient, the family and carers, and staff in the different locations.

Prompt questions

What happened for this person on each step of the journey?

What happened for the family and carer/s?

What was the best and the worst thing about the journey from the patient's and family's point of view?

What were the person's priorities, concerns and commitments and how were these affected at various points?

What were the health service priorities (these may be different or the same as the person's and can explain where different priorities arise)?

What service gaps occurred?

What responses to gaps were available or should/could be made available?

Use Table 3 to enter data. **Note:** you may not have information for every square.

An extra row and column have been added in case there is another specific aspect on which you wish to focus. If you wish to complete a more complex table, you can design your own using Microsoft Word or an Excel spreadsheet. (See Case Study C in the Renal Case Studies and Case Study B in the Cardiac Case Studies for examples of extended tables.)

Table 3: **Table 3:** Multiple perspectives

Perspective	**Patient history**	**Diagnosis/ referral**	**Travel**		**In hospital/ health care**	**Discharge or transfer**	**Follow-up**	**Comments**
Timeline								
Patient’s journey								
Family/carer journey								
Patients priorities, concerns and commitments								
Health care/ services priorities								
Another specific aspect								
Service gaps								
Responses to gaps								

Task 2.6: Additional considerations for this patient journey

If there is information you wish to include or highlight, but there is no relevant place within the other tables (even by adding rows and columns), design your own prompt questions and use Table 4 to record the results.

Table 4: Additional considerations

Health/unit/staff involvement	Date/day	Time	Reality/complexities	Results/ consequences

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

Name of standard/s used, date and where to access

Standarard: ____________________

What aspects of this journey were within standard? What was in place that assisted the standards to be met?
1 ____________________
2 ____________________
3 ____________________

What aspects deviated from the standard and why? What got in the way of ideal care?
1 ____________________
2 ____________________
3 ____________________

Were there specific circumstantial/situational factors and systems factors?

What needs changing in health care policy and practice?
1 ____________________
2 ____________________
3 ____________________

Optional – you may choose to visually represent your comparison to a standard (see Example Figure 2, p. 17) and attach it here.

Task 2.8: Identifying the key findings

What can you glean from mapping this patient journey?

Did you find anything surprising?

What was obvious, what was missing?

What happened in the transition points between primary health care and hospital care, and between city and rural and remote services?

Was there good communication, coordination and collaboration, or were there gaps and opportunities for change? If so, describe where these occurred and why.

Key findings

1 ______________________________

2 ______________________________

3 ______________________________

4 ______________________________

5 ______________________________

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

What have you learned personally and professionally as a result of mapping this patient journey?

What would you do differently now?

Step 3: Taking action on the findings

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

When you prepared to map the journey, you had some idea of what you intended to highlight in the case study. Now that you have completed the mapping, you need to decide what to do with the results.

Who do you wish to convey the results to?

What actions or changes do you think may need to occur?

What has become obvious to you now that was not obvious before, or what was confirmed for you?

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

Action plan

What main issues have you identified and what action/strategies can you take or advocate for at a personal, professional, service and/or systems level? You can enter as many as required, or create a separate Word table or Excel spreadsheet.

Table 5: Action plan

Issue	Level	Action required	By whom	When	How	Review	Action taken
	Personal						
	Professional						
	Service						
	System						

Action plan prepared by ______________________________

On / /

References

Australian Commission on Safety and Quality in Health Care (ACSQHC) 2014, *Patient and Consumer Centred Care*, ACSQHC, Canberra. Accessed 20 June 2014 at: www.safetyandquality.gov.au/our-work/patient-and-consumer-centred-care.

Australian Human Rights Commission (AHRC) 2010, *Social Justice and Aboriginal and Torres Strait Islander Peoples Access to Services*, AHRC, Canberra. Accessed 26 May 2014 at: www.humanrights.gov.au/news/speeches/social-justice-and-aboriginal-and-torres-strait-islander-peoples-access-services-2010.

Australian Human Rights Commission 2014, *Close the Gap: Indigenous Health Campaign*, AHRC, Canberra. Accessed 10 May 2014 at: www.humanrights.gov.au/close-gap-indigenous-health-campaign.

Australian Indigenous Doctors' Association (AIDA) & Centre for Health Equity Training, Research and Evaluation (CHETRE) 2010, *Health Impact Assessment of the Northern Territory Emergency Response*, AIDA and CHETRE (UNSW), Canberra.

Australian Institute of Health and Welfare (AIHW) 2014, *The Measurement of Patient Experience in non-GP Primary Health Care Settings*, Canberra.

Bailie, R., Si, D., O'Donoghue, L. & Dowden, M. 2007, 'Indigenous Health: Effective and sustainable health services through continuous quality improvement', *Medical Journal of Australia*, vol. 186, no. 10, pp. 525–7.

Browne, A. J. & Varcoe, C. 2006, 'Critical Cultural Perspectives and Health Care Involving Aboriginal Peoples', *Contemporary Nurse*, vol. 22, no. 2, pp. 155–67.

Cass, A., Lowell, A., Christie, M., Snelling, P., Flack, M., Marrngnanjin, B. & Brown, I. 2002, 'Sharing the True Stories: Improving communication between Aboriginal patients and healthcare workers', *Medical Journal of Australia*, vol. 176, May, pp. 446–70.

Durie, M. 2005,'Indigenous Knowledge within a Global Knowledge System', *Higher Education Policy*, vol. 18, pp. 301–12.

Dwyer, J., Kelly, J., Willis, E., Glover, J., Mackean, T., Pekarsky, B. & Battersby, M. 2011, *Managing Two Worlds Together: City Hospital Care for Country Aboriginal People—Project Report*, The Lowitja Institute, Melbourne.

Echo-Hawke, H. 2011, 'Indigenous Communities and Evidence Building', *Journal of Psychoactive Drugs*, vol. 43, no. 4, pp. 269–75.

Kelly, J. 2009, Moving Forward Together in Aboriginal Women's Health, unpub. PhD thesis, School of Nursing and Midwifery, Flinders University, Adelaide.

Kelly, J., Dwyer, J., Pekarsky, B., Mackean, T., Willis, E., Battersby, M. & Glover, J. 2012, *Managing Two Worlds Together: Stage 2—Patient Journey Mapping Tools*, The Lowitja Institute, Melbourne.

Lawrence, M., Dodd, Z., Mohor, S., Dunn, S., de Crespigny, C., Power, C. & Mackean, L. 2009, *Improving the Patient Journey*, Cooperative Research Centre for Aboriginal Health, Darwin.

Nirrpurranydji, S., Fraser, J. & Dhunupa, Dhwu 2012, *Enhancing Strengths, Researching with the Community*, The Lowitja Institute, Melbourne. Accessed 10 May 2014 at: www.lowitja.org.au/dhunupa-dhwu-enhancing-strengths-researching-community.

Nguyen, H. T. 2008, 'Patient Centred Care: Cultural safety in Indigenous health', *Australian Family Physician*, vol. 37, no. 12, pp. 990–4.

Picker Institute Europe 2013, *Patient & Service User Experience Surveys*, Oxford. Accessed 20 June 2014 at: www.pickereurope.org/adult-and-patient-service-user-surveys.

Standards Australia 2009, *AS/NZS ISO 31000:2009 Risk Management—Principles and Guidelines*, Council of Standards Australia. Accessed 31 May 2014 at: http://sherq.org/31000.pdf.

Taylor, K. & Guerin, P. 2010, *Health Care and Indigenous Australians: Cultural Safety in Practice*, Palgrave Macmillan, Melbourne.

The Lowitja Institute 2014, 'Knowledge Exchange'. Accessed 6 August 2014 at: www.lowitja.org.au/knowledge-exchange.

About the Authors

Janet Kelly

Study Leader, Improving Aboriginal Patient Journeys and Research Fellow, Flinders University, and Research Fellow, School of Nursing, University of Adelaide and Heart Foundation

Judith Dwyer

Project Leader, Managing Two Worlds Together Project and Professor, Health Care Management, Flinders University

Brita Pekarsky

Health Economist, Flinders University and South Australian Health and Medical Research Institute

Tamara Mackean

Senior Research Fellow, Poche Centre for Indigenous Health and Wellbeing, Flinders University

Natalie McCabe

Aboriginal Patient Pathway Officer, Queen Elizabeth Hospital

Jacene Wiseman

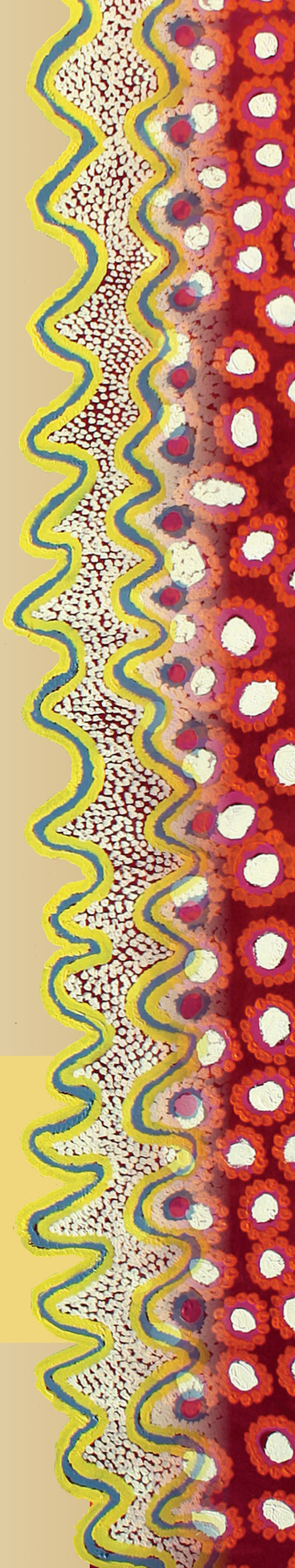
Business and Innovation Consultant, Umoona Aged Care Aboriginal Corporation

Charlotte de Crespigny

Professor of Drug and Alcohol Nursing, School of Nursing, University of Adelaide

Kim O'Donnell

Research Associate, Health Care Management, Flinders University, and Teacher, Aboriginal Health Council of South Australia



the Lowitja Institute

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

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