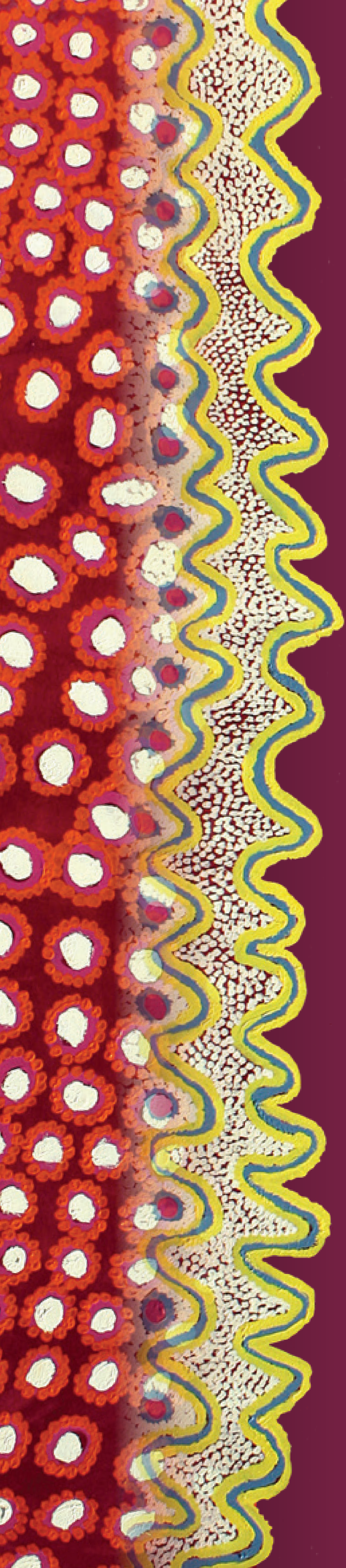

Managing Two Worlds Together

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

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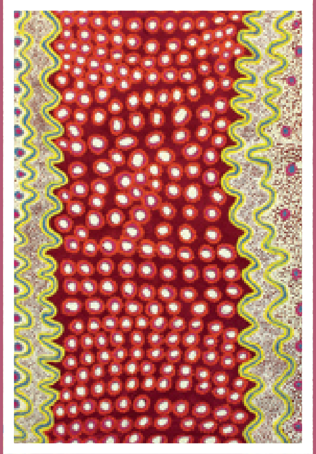

Cover Artwork:

Kuntjanu – Mingkiri Tjuta Tjukurpa (Marsupial Mouse Dreaming)

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Flinders University

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

ISBN 978-1-921889-30-1

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.

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

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Managing Editor: Jane Yule @ Brevity Comms

Copy Editor: Cathy Edmonds

Design and Print: Inprint Design

For citation: Kelly, J., Herman, K., Martin, G., Wilden, C., East, T., Russell, C. & Brown, S. 2015, *Managing Two Worlds Together. Stage 3: Improving Aboriginal Patient Journeys—Renal Case Studies*, The Lowitja Institute, Melbourne.

Australian Government
Department of Industry and Science

Business
Cooperative Research
Centres Programme

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Diagram, 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 (2013–14) 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

The authors would like to acknowledge the following people who were indirectly involved as participants or indirectly as advisors or key stakeholders of this study:

Hugh Auckram, Alex Brown, Lisa Catt, Wendy Corkhill, Charlotte de Crespigny, Karen Dixon, Judith Dwyer, Amy Graham, Liz Izquierdo, Rosie King, Michael Kirkbride, Monica Lawrence, Natalie McCabe, Wendy McInnes, Lee Martinez, Sonia Mazzone, Laney Mackean, Tamara Mackean, Paula Medway, Debra Miller, Jo Newham, Annapurna Nori, Kim O'Donnell, Brita Pekarsky, Sharon Perkins, Daphne Perry, Pam Pratt, Mark Ramage, Damian Rigney, Bronwyn Ryan, Kerry, Taylor, Kym Thomas, Jeff Tinsley, Eileen Willis, Jacene Wiseman and Sarah Wyatt.

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

APPO	Aboriginal Patient Pathway Officer
CNARTS	Central Northern Adelaide Renal and Transplantation Service
CSC	Clinical Services Coordinator (a nursing ward or unit leader position)
CKD	Chronic Kidney Disease
ECG	Electrocardiograph (recording of heart's electrical activity)
IAPJ	Improving Aboriginal Patient Journeys
MTWT	Managing Two Worlds Together
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.

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

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'.

End of Life – The point in a person's life where doctors identify that a person's health is deteriorating and they don't have long to live, and they move to a conservative health care pathway.

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

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.

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

About the Renal Case Studies

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

Four renal case studies are presented in this report:

- **Case Study A:** Coordinating an End-of-life Journey
- **Case Study B:** Friday Night Discharge
- **Case Study C:** Transplant Continuity of Care
- **Case Study D:** Culturally Safe Renal Education.

All four describe the ways in which six renal nurse leaders in Adelaide, Port Augusta and Alice Springs formed the Renal Focus Group and adapted and used the MTWT patient journey mapping tools in South Australia and the Northern Territory. During 2013 they held regular teleconferences to discuss and highlight issues and strategies in providing continuity of care for patients accessing renal care, particularly when patients transition between renal services.

Four of the nurses mapped specific patient journeys that occurred for patients/clients within and across their clinical and geographic areas. The Improving Aboriginal Patient Journeys Study Leader, Dr Janet Kelly, worked with each of these nurses individually and the Renal Focus Group as a whole to adapt the tools to meet specific needs, map the patient journey, explore the intricacies of each care pathway, and identify key findings and actions for improved care.

The focus group centred its work on the following question and task:

- How can we best provide patient-centred care and improved continuity of care across our health system with our current resources and health care structures?

The purpose of these four case studies is to:

- provide examples of how the MTWT patient journey mapping tools can be adapted and used in health care settings for quality improvement and education
- identify communication, coordination and collaboration gaps and strategies
- provide renal-specific examples of complex patient journeys.

Case Studies A and B follow a similar format to that described in the IAPJ Workbook and in Diagram 2. Case Study C introduces an adaptation that has not yet been trialled and Case Study D introduces an Education Package for renal nurses. All four took place before the Workbook was finalised, and the experiences of, and feedback from, the renal nurses was integral to developing the final version of the IAPJ tools.

Key identifying factors in each of these patient journeys, and of those in the other case studies, have been omitted or changed to protect the privacy of people and their families. Ethics approval for the study was given by Flinders University, the Aboriginal Health Research and Ethics Committee, The Queen Elizabeth Hospital Human Research Ethics Committee, the Central Australian Human Research Ethics Committee, and Menzies School of Health Research. Required governance arrangements (Site Specific Assessments) were also completed with each SA Health site involved.

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

Contact details

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

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

- Case Study A: Kylie Herman, Clinical Services Coordinator, Port Augusta Dialysis Unit at E: Kylie.herman@health.sa.gov.au
- Case Study B: Gay Martin, Clinical Services Coordinator, C8 Renal and Transplant Unit, Royal Adelaide Hospital at E: gay.martin@health.sa.gov.au
- Case Study C: Toni East, Clinical Practice Consultant Renal Transplantation, Central Northern Adelaide Renal and Transplantation Service
- Case Study D: Cheryl Wilden, Nurse Education Facilitator (Renal), Royal Adelaide Hospital/Central Adelaide Local Health Network at E: cheryl.wilden@health.sa.gov.au.

Other Renal Focus Group members include:

- Christine Russell, Manager, SA Health Mobile Dialysis Truck at E: ChristineE.Russell@health.sa.gov.au
- Sarah Brown, Chief Executive Officer, Western Desert Nganampa Walytja Palyantjaku Tjutaku, Alice Springs (Remote Dialysis Units) at E: Sarah.Brown@wdnwpt.com.au.

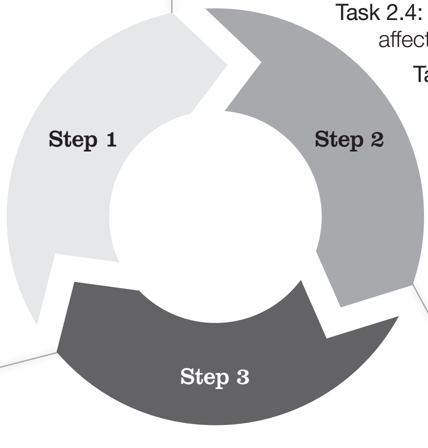
The Patient Journey Mapping Process

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

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

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

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



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

Case Study A: Coordinating an End-of-life Journey

Authors: Kylie Herman and Janet Kelly

Who was involved in the mapping?

Kylie Herman is a Clinical Services Coordinator (CSC) who has worked in renal care and remote area nursing for more than 12 years. Her role includes management of the Port Augusta Dialysis Unit in which 80–90 per cent of patients are Aboriginal.

Nicole McLauchlan is an Aboriginal Patient Pathway Officer (APPO) at Port Augusta. Her role was to coordinate patient journeys and she and Kylie worked closely together

Port Augusta Dialysis Unit provides the most northern dialysis service in South Australia and therefore attracts a high proportion of patients who have relocated from remote areas of northern and western South Australia for ongoing dialysis. Remote area patients face particular challenges, including dislocation from family and home community, long-distance travel (which prevents short visits), and a total change in living and financial conditions.

Kylie and Nicole were involved in co-designing the very first versions of the mapping tools in Stages 1 and 2 of the MTWT study. Their work has been integral to the development of the tools.

Focus of this case study

This case study records the priorities for a long-term dialysis patient to return to her remote home community for end-of-life care, and the efforts of a dialysis manager and APPO to ensure this could occur. It highlights the behind-the-scenes work required when clear pathways and resources are not already in place. This case study is presented using the mapping tools outlined in the Workbook. However, not all tasks were developed at the time this case study took place, and so some tasks are not completed. This is clearly shown. Also, Step 3 is long because the renal nurses wished to consider deeply the implications of this case study, and are continuing to focus on improving end-of-life care.

Step 1: Preparing to map the patient journey

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

During a Renal Focus Group teleconference, Kylie spoke about a recent patient journey that had been challenging for both the client and staff. Kylie and Nicole undertook to coordinate and support a woman's return back home for end-of-life care and to connect with family and Country prior to passing. Kylie described how the difficulties they experienced were due to the following factors:

- the woman became unwell very rapidly
- her home was a long distance away and had minimal transport options
- there were no clear processes and pathways in place
- given the limited health care resources available in her home community, clinical opinions were divided about whether the woman should remain in the regional city or return home.

Kylie and Nicole could find very little information available in South Australia to guide them in arranging and coordinating this journey and they scrambled to create a safe pathway for this woman to return home in time. They spent a lot of time seeking suitable transport and palliative care options, and negotiating with family members, staff at the remote clinic, the remote area doctor, Port Augusta staff and city-based specialists.

The Renal Focus Group recognised that this situation raised serious questions about the options and choices available for people in South Australia who have been on dialysis for many years and who have become increasingly unwell as a result of their co-morbidities (diabetes, liver disease and/or cardiovascular disease) and are making end-of-life decisions. Although some options and resources are available, the agreements, pathways and coordination activities required to enable timely and supported return-to-home journeys are not yet in place (compared to recent developments in the Northern Territory).

The Renal Focus Group decided that the aims of mapping this journey were to:

- highlight the complexities and challenges for Aboriginal people, their families and staff in rural, remote and Adelaide specialist services in relation to supporting end-of-life journeys
- identify key strategies to improve future journeys.

Task 1.2: Guiding principles for respectful engagement and knowledge sharing

Respectful engagement was needed, including discussion with the woman's family about writing the case study. The family chose not to be involved in the writing of this case study (they were still grieving), but the family had a close relationship with Kylie and had already discussed many of the factors, issues and strategies with her.

Step 2: Using the tools

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

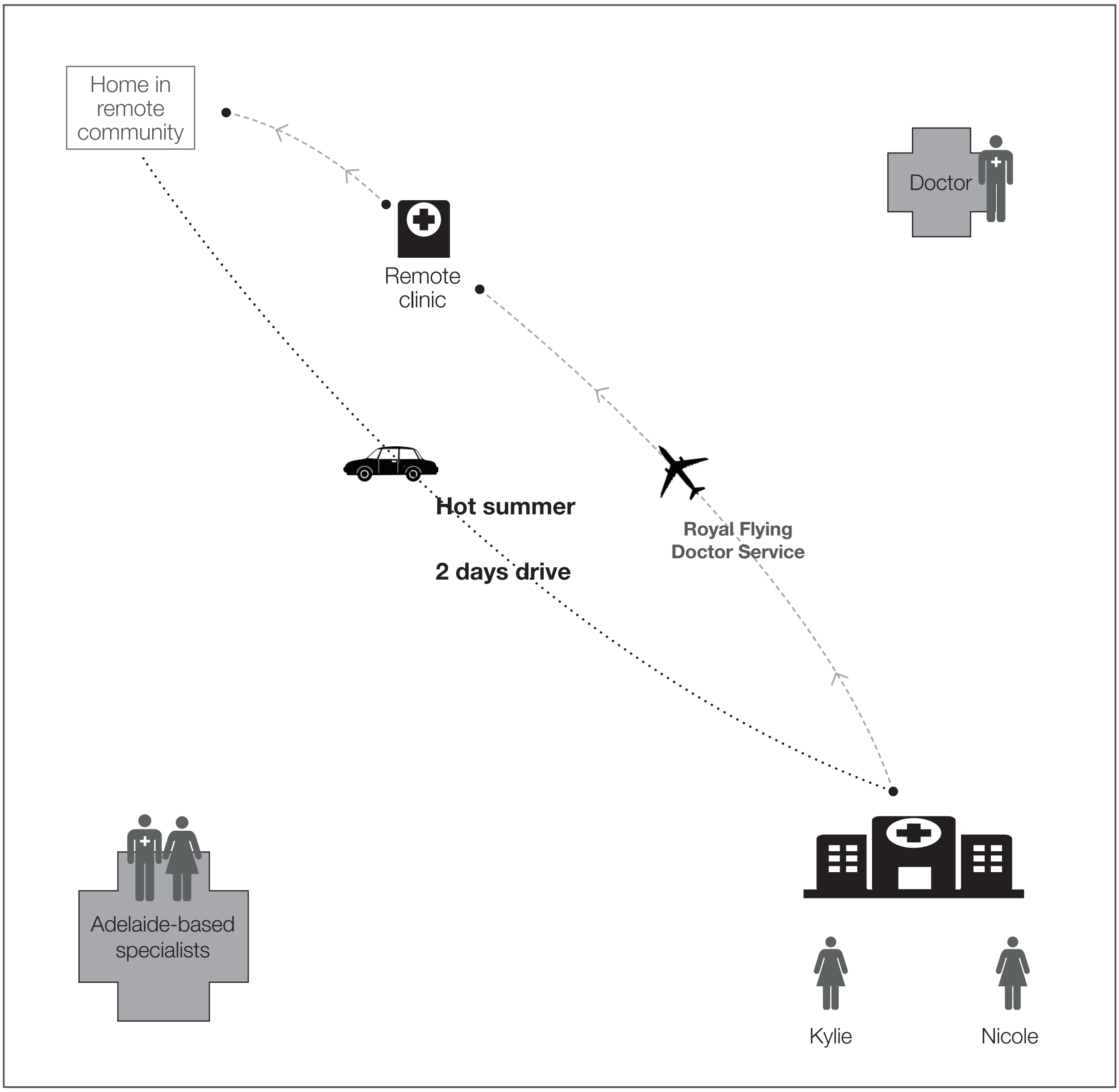
This patient, an Aboriginal woman, originally lived in a remote area of South Australia. She developed renal disease in her thirties and began renal dialysis. Health carers advised her to have dialysis three times a week, but dialysis was unavailable near her home (the nearest involved a drive of two days) and she often needed to return home for connection to community and family, thereby missing dialysis sessions. She transferred her dialysis care to Port Augusta and attended dialysis when she was able. She experienced difficulties juggling financial arrangements in Port Augusta and often stayed with extended family. Her preference was to be home, but when she stayed there she became unwell and needed to be flown out by the Royal Flying Doctor Service (RFDS) for emergency care. After receiving this care, she felt better and continued living and travelling, juggling her dialysis and other personal, family and cultural needs.

In 2013 she became increasingly unwell, and then very unwell, and was admitted to a nursing home in Port Augusta. The doctor said that some of her organs were shutting down and that she had only a few months to live. Kylie visited her and asked what she wanted to do, who she wanted with her and where she wished to be when she died. The woman wanted to go home and say goodbye to family and friends. Arrangements were made and re-made as she became increasingly unwell, but eventually she returned home in time to reconnect with family and share stories before she died.

Very few resources were available in the small, remote community clinic to which this woman was returning. It was staffed by Aboriginal workers and a visiting doctor, but having no nurses made the provision of services, medications and care challenging. Also, this patient had often returned home in the past, and at times had become unwell and required evacuation via the RFDS. The remote doctor and clinic held some concern that this journey could also end in a RFDS flight if the patient or her family became overwhelmed. However, this patient and her family were very clear that bringing her home was their best option, and they worked with Kylie to make arrangements. Family members were the primary care givers and provided end-of-life care, in their home, in the remote community.

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

Kylie developed Figure 1 to highlight the services and staff available in each setting, and the vast distance between Port Augusta and their home community. Other important aspects were the season and the length of time it would take to drive on the bush roads. Of note is the positioning of the doctors – one in Port Augusta, the specialist in Adelaide, and the remote area doctor (not in the remote community) who provided consultation via phone.



Case Study A – Figure 1: Visual mapping

Task 2.3: Recognising the whole person experiencing the patient journey

Kylie began the process of mapping the journey by considering the person as an individual with specific personal, family and cultural needs and priorities. Table 1 shows the patient's situation at the beginning of her illness and during her stay in Port Augusta for dialysis.

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

Kylie considered the underlying factors that were impacting this person's access and quality of care both in Port Augusta and in her remote community (Table 2).

Case Study A – Table 1: Dimensions of health

Dimension of health	Situation	
	Last 8 years	**Port Augusta – current**
Social and emotional wellbeing **Family and community commitments** **Personal, spiritual and cultural considerations**	Feels very strongly the need to be involved in family and cultural happenings, and in funerals, family caring arrangements Doesn't really feel comfortable in a town like Port Augusta, which has a different social structure to her home community. Experiences difficulty sustaining housing and paying bills, and is often homeless or stays with extended family when she can Town lifestyle is not her priority or preference Returns home to her remote community regularly	Wants to return home to family for end of life
Physical and biological	An Aboriginal woman in her late forties who has been on dialysis for 7–8 years Has several co-morbidities (not listed as de-identified for confidentiality) Has not been able to attend dialysis regularly as feels the need to return to her home community Unable to keep her daily fluid intake to within the narrow limits advised by renal health carers	Renal function is deteriorating, other organ function also deteriorating

Case Study A – Table 2: Underlying factors

Underlying factor	Impact of location and access	
	Port Augusta – regional centre	**Remote – homelands**
Rural and remote/city	Has extended family, but not immediate family, living in Port Augusta	Homelands
Impact of illness or injury	Understood the diagnosis and need for dialysis, but did not fully understand or was unable to incorporate this information into lifestyle changes to maintain daily fluids in narrow limits and attend regular dialysis As she felt immediately better following evacuation and dialysis, perhaps she was not able to fully appreciate the significant impact each episode was having on the overall health of her kidneys, heart and liver, or perhaps the other aspects, priorities and needs in her life overrode this knowledge As she became increasingly unwell and went into the aged-care facility, the doctor spoke to her and said she might only have a few months to live Kylie spoke to the woman about her end-of-life options and the woman decided she would rather go home and die than stay in Port Augusta and slowly deteriorate – once she made that decision, her health deteriorated rapidly A series of plans was made to accommodate the woman's wishes and get her home as soon as possible	The remote clinic had limited facilities, a visiting doctor and Aboriginal Health Workers, but no Registered Nurses When this person had become unwell in the past she had been evacuated via the RFDS – this occurred on numerous occasions Due to this history, and the limited resources in this isolated community, the remote clinic was reluctant for this person to be transferred back home for end-of-life care Staff expressed concern that this person would need to be evacuated again, or that family would have unrealistic expectations of what they could provide – no palliative care services were available in this community.
Language and communication	English is second language but has a good command of English Reasonable understanding of dialysis process and reasons but couldn't understand why she was not a high priority for a kidney transplant	Community members mostly speak language
Financial resources	Difficulty paying bills and living in rental accommodation	Family and community are closer – more options for accommodation and food than in a regional centre
Cultural safety	This person was well travelled and knew the health system and how to access services – in many ways she was more comfortable in the setting of Port Augusta than many other renal patients She had relatives who were both very traditional and more regional – she, herself, had a mix of upbringing in both areas	Closer to home and family who provided most of the end-of-life care

Task 2.5: Bringing together multiple perspectives in chronological mapping

Kylie mapped the entire journey, from the woman's perspective, as well as that of her family and staff. Table 3 shows Kylie's accounts from her conversations with the woman and her family members. At a later time (to allow time for grieving), the family could be invited to add to this journey mapping account. The final column has been added to show what was happening behind the scenes and the questions that arose for staff.

Case Study A – Table 3: Multiple perspectives

Perspectives	Patient history	Worsening condition	In aged-care facility	Supporting patient choices – end-of-life decisions	Discharge/ transfer	At home	Comments
Patient's journey	Person in her forties who had had dialysis for seven to eight years	Organ failure, incontinence	Deterioration Life decisions		Wants to get home	Very unwell but happy to be home	
Patient priorities, concerns and commitments	Wishes to be with family and community as much as possible	When becomes unwell, seeks dialysis, feels okay for a while, and then doesn't feel okay anymore	Can't travel Doesn't want to stay here	Wishes to connect with particular family members in Port Augusta to say goodbye and then go home to see family before dying	Travel home to see family and be back on her home Country	To be with her family and share stories	Perhaps realised too late the long-term effects of missing dialysis, or felt she had no choice – she needed to live life as best as possible
Family/carers priorities	Woman has lived between remote community and Port Augusta for seven years	Family would like her to come home	Very few family members can visit Port Augusta	Family work closely with Kylie to make arrangements Are very worried about how best to provide care	Limited options Assistance with car hire, flights	Family gather and provide support and caring duties	Family spent much time talking with Kylie about what would happen and debriefing when she died
Health services priorities	Dialysis three times a week	Doctor explained that her underlying health had deteriorated and she had only months to live – focus on palliative care	End-of-life care	Providing optimal medical care in regional city versus supporting the choice to return home	Availability, timeliness, cost, options, comfort, ability to travel	Comfort, pain relief, skin care Support family who are main carers	Service-based care versus patient-focused care – how to provide best level of care – what is best practice?

Case Study A – Table 3 cont...

Perspectives	Patient history	Worsening condition	In aged-care facility	Supporting patient choices – end-of-life decisions	Discharge/ transfer	At home	Comments
Service gaps	No dialysis near home	No palliative care options in remote area	No aged-care facilities at home	No palliative care in home community	Few options available	No palliative care services	What if Kylie and the APPO were not involved?
Health service response	Staff explain cumulative effect but person's other needs outweigh her ability to attend for regular dialysis	End-of-life care	Dialysis CSC visited to discuss end-of-life choices Using the Respecting Patient Choices guide to determine and support person's priorities and wishes	Remote clinic not resourced for palliative care Port Augusta sent as many resources as possible Community social worker arranged home and yard clean up	Negotiate with RFDS – fly direct due to worsening condition	Local clinic supplied pads, sheets. Renal clinic provided phone support Port Augusta palliative services sent items Social worker filmed stories	Renal CSC and APPO arranged multiple aspects of transport, care, discussions with staff, family
Family response	Family in home community and extended family in Port Augusta	No immediate family in Port Augusta. Extended family could only offer limited support	Very few family members could visit	Family apprehensive, wanted remote clinic to help, then took on role	Will the person die on the way home? Pick up in car	Care and pain relief for the patient's last few days	Family member rang renal unit to say the woman passed peacefully

Task 2.6: Additional considerations for this patient journey mapping

Not required for this case study.

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

Not (yet) completed for this case study.

Task 2.8: Identifying key findings

This case study highlights a range of issues and strategies. Kylie worked closely with the woman's family and Port Augusta and remote-based services to make arrangements and fill any gaps left in service provision.

Upholding end-of-life choices

The nephrologist identified and explained to the woman that she had severe complications from renal failure, and it was expected that she only had a few months to live. Kylie visited the person at the aged-care facility on the same day. She felt comfortable discussing end-of-life decisions with this woman because they had built a good rapport over the years, and the woman was at the point where she knew the end of her life was imminent.

Kylie followed a step-by-step Respecting Patient Choices/Advance Care Directive plan using the precursor to the current Advance Care Directives (2014) and found it a good process to follow. Together they discussed where the woman wanted to die and what she would like around her. The woman was very clear that she wanted to go back home to be with family, and to die and be buried there. Prior to going home, she wanted to meet up with a family member at Port Augusta and say goodbye. She wanted Kylie to tell certain family members that she loved them if she could not return home in time.

Together Kylie and the woman wrote up a statement of choices and these were put in the front of the case notes. This statement included a clear description of the current health condition, and the patient's decision that she didn't want resuscitation or dialysis if she was unable to speak or became unconscious. She wanted medication to remain relaxed and pain free. She wanted all her family to know she loved them, and that she didn't want to let them down but she just got sick. This message was to be given to them if she was unable to see them face-to-face before she died. She nominated enduring guardians.

Key people involved in this woman's care

Multiple people and services assisted in the woman's return to her home community.

- The family: Kylie spoke to a family member (often by telephone) who became the main carer. They discussed that the person returning home would require a lot of family support and involvement. The remote area clinic did not have the capacity to provide palliative services and there was no option for the person to die in the clinic – all care would need to take place in the family home.

Kylie also had extensive discussions with the remote area clinic, the doctors involved in the woman's care, the local palliative care team, the pharmacist and the social workers.

- The nephrologist: the nephrologist was concerned that there were few services available in the remote area and that this woman's care needs would not be adequately met. A discussion about the benefits and concerns regarding patient-centred care and service-based care followed.
- The remote area clinic doctor: the doctor in the remote area was familiar with this patient, who had been quite demanding at times in the past and had needed numerous evacuations. The doctor was concerned that the person would need to be evacuated again, or that the family would become scared or overwhelmed. There was also concern about what the end-of-life experience would be like and whether the clinic had adequate resources to support the woman and her family (there was no registered nurse to assist with strong pain relief).
- The remote area social worker: the family home was not set up for an ill person, and so the remote area community social worker coordinated house preparations and additional resources. They also organised that, once the woman arrived home, there would be a video camera available to record her telling stories to family, which they could keep to view later.
- The social worker in Port Augusta: the social worker in Port Augusta arranged a meeting with particular family members and photographs were taken to share with family back home. This visit was very important to the person, as she wanted to see these family members, check that they were safe and well, and to say goodbye. This opportunity gave her great peace of mind.

- Port Augusta Palliative care services: Kylie sought assistance from the Port Augusta palliative care team, and it was decided that the team would provide supplies and liaise directly with the family about how they would care for her. The Port Augusta palliative care team helped pack many comfort items that were taken to the remote community by a family member in a hired vehicle. These included an egg carton mattress to prevent pressure sores, pads, dressings and skin creams.
- Pharmacist/palliative care team/doctor: Kylie also worked with the local pharmacist, the palliative care team and the doctor in the remote clinic to arrange the appropriate medications so that the woman could have adequate pain management. The remote clinic had little capacity to be involved in palliative care and there was no registered nurse on site to give injections, so strong pain relief patches that the family could apply were supplied. The family originally assumed that the local clinic would become more involved, but this was not going to be possible. Kylie spoke to the family members about how they could cope at home and what would happen in the last few days, and she explained that the medications should make their family member comfortable and that she would not be in pain.
- Aboriginal Patient Pathways Officer: the APPO made a lot of behind-the-scenes arrangements and held in-depth discussions about each possible transport option, including the RFDS.

Transport dilemmas

There were many obstacles to getting this woman home, and various plans were made and discarded rapidly over a period of time as the woman's condition quickly deteriorated.

- Plan 1 – the family would come and pick her up: in some ways this may have been the easiest option, but there were many obstacles. It was a two-day drive home in summer and the family did not have a suitable car. Also, the woman had become quite incontinent and immobile and managing this on a long journey with few facilities would be difficult. The family was understandably concerned that something could happen on the way home and about the implications of this. Financial assistance for a hire car (that was reliable and had air conditioning) was sought. A young family member living in Adelaide was to pick the woman up and drive her home. This person was very concerned about what might happen and asked Kylie to give reassurance that the woman would make it home alive. Kylie was unable to give total reassurance because the woman's condition was deteriorating rapidly. The implications for this family member if the woman died in his/her care were significant.
- Plan 2 – chartered flight: the doctors felt unable to sign approval for her to fly on a chartered flight because she was deteriorating rapidly. Also, there would have been difficulty physically getting her into the plane.
- Plan 3 – Angel Flight: the woman was unable to take this charity option because she needed to be fit enough to walk onto the wing of the plane to get inside; by this stage she was bound to either a wheelchair or stretcher.
- Plan 4 – RFDS: after extensive discussions and the fact that there were no other options to get this woman home, a flight with RFDS was arranged. RFDS had a scheduled flight to a nearby community with a spare seat and agreed to transport the woman there, where the family member with the hire car would meet them and drive the woman to her home community. However, once RFDS picked the woman up and saw how unwell she was, they diverted and took her straight to her home community.

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

Although Kylie has worked in remote areas, she has never been to this particular community, which is at least a two-day drive from Port Augusta and has limited health care services. Alice Springs services were unable to provide palliative care; although Alice Springs is located closer geographically, there are issues regarding cross state/territory border care arrangements.

This patient journey was a big undertaking for Kylie, who had not organised anything like this before. Her reflections on supporting the patient's journey follow.

- Kylie sought advice from the doctors involved in this woman's care but they indicated that their health service has no responsibility to get people back home in these situations. They were also concerned that there was little capacity for the woman to be cared for by the remote clinic and the doctors felt that they could provide better care if she stayed in Port Augusta. Kylie, Nicole and others could also have said to the woman, 'No, you have to stay here in Port Augusta', but they just couldn't do that. Instead, they tried every avenue possible to meet her wishes.

- It became very clear to Kylie that she was the only person in a position to provide help and direction to assist this woman to return home. The woman and her family didn't have the capacity to organise at this level – and there was a real concern that she would die on the way home.
- Without the Respecting Patient Choices discussion and documentation, it would have been difficult to justify the costs, time and effort involved in arranging to send this person from a regional clinic to a remote clinic.
- With the arrangements with the RFDS, the timing was lucky. RFDS was flying to a nearby community that week, with no one else booked to be on board, so it could take an extra passenger. However, when RFDS staff members saw how sick she was, they made the decision to fly direct to her home. She may not have survived the car trip from the original destination to home, or not easily.
- This woman was home for a few days only – originally, we thought she had several weeks, but she was rapidly deteriorating. We asked her family to let us know once she did pass. They rang us a few days after she got home to say she had passed very peacefully.
- The doctor in the remote clinic also gave good feedback. He said that although initially he was not comfortable to have the person back, he was impressed with the way it had turned out and would be happy for that to occur again in any area he was working in.
- This woman was always going to be buried in her home community, so how much better for her family and community members that she was able to travel home alive and say her goodbyes first? This also has wider implications for other existing and potential renal patients, their families and communities. If they know such options are available, travelling to Port Augusta and Adelaide do not seem to be a one-way trip.

Factors that helped in the patient journey included:

- respecting patient choices – being clear about what her wishes were at a quite simple/basic level; once staff knew what the goal was, they could work to that
- working out what support the family and others could or could not provide
- working out what was needed each step of the way
- determining what Port Augusta staff and services could provide in the way of advice, medication, aids, etc.
- liaising with other health professionals – for example, the nephrologist, remote doctor and pharmacist – to determine the most appropriate pain relief in last few days (the most convenient ended up being strong pain relief patches; determining the right dosage and how often to apply them; ensuring that the clinic could get the patches stocked because a supply of this level of drug could not be sent up with family members); this woman's usual medications were sent with her (although in the end she was unable to swallow)
- having the APPO assisting with transport and other arrangements.

Complicating factors

A few health staff members struggled with the amount of time, resources and money being spent on someone who they felt had already used (and at times abused) staff and the system for many years. This suggests perceptions of the deserving patient and issues of compliance. It also perhaps reflects an emphasis on physical and medical health processes without a deeper consideration of the other four factors of health – social, emotional, cultural and spiritual.

What worked? Reflections on the mapping process

Using the MTWT tools to map the journey enabled Kylie to see the entire journey and the gaps more clearly. It set out the coordination very clearly and was easy to use. While actually involved in assisting the client with the journey planning, it seemed really messy and difficult to explain, but using these tools to map the journey and all the people involved made the process clearer.

Clearly setting the journey out enabled a range of other people to identify each stage and complexity and their own roles and strategies for improvement.

The main result of this mapping is the case study and Kylie's reflections, which the Renal Focus Group intends to use for education and care planning.

Adapting the tools

Minimal changes were made to the tables to enable the case study to be recorded adequately. These included:

- Table 1: Dimensions of health – combining the non-physical dimensions (psychosocial, social, spiritual, cultural and family) into one row
- Table 2: Underlying factors – consideration of how each underlying factor was experienced in both Port Augusta and in the person's home community
- Table 3: Multiple perspectives – column headings were changed to reflect the specific aspects and locations of this journey, beginning from the time the person's condition deteriorated.

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

Ideally, the person and the family would be involved in writing this case study to enable a more complete picture. However, this was not possible at the time of writing (after the woman had passed) as the family needed time to grieve.

Step 3: Taking action on the findings

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

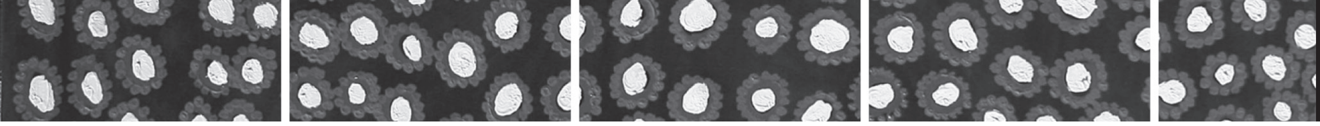
Kylie will provide a five- to ten-minute video interview about this case study and her involvement, and this will be used as the introduction of the case study in future education sessions. The case study can then be used to trigger discussion with colleagues and students.

One education session that is planned involves each attendee taking on the role of the patient, the family in a remote community, dialysis nurse, remote area doctor, Aboriginal Health Worker, pharmacist, palliative care worker, city-based renal specialist, local registrar etc. After reading or hearing the case study, each person will consider the information or resources they need, and who they need to talk to. This will encourage health professionals to identify more clearly the entire patient journey, their role within it, and the importance of communication and collaboration for effective coordination.

The education package could also be used for discussion and pre-planning at Port Augusta and other city and rural dialysis units. The MTWT study (Stage 1) found that wards and units that prepare for journey and care complexity, and put resources and systems in place, are best able to meet patient needs.

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

- Design a template for complex journey planning: the case study and mapping tools could be used as prompts to design a template to use for planning other end-of-life journeys or return-to-Country journeys. Rather than relying on an email trail, the journey could be planned and mapped using the MTWT tools format, with the gaps and issues highlighted and made more obvious. This could then be shared between the many different people involved.
- Work with palliative care/Aboriginal/rural and remote services: this case study could also be used as a basis for discussion with a range of palliative, Aboriginal and rural/remote services about how best to work collaboratively to meet patient and community needs.



Case Study B: Friday Night Discharge

Authors: Gay Martin, Kylie Herman and Janet Kelly

Who was involved in the mapping?

Gay Martin works as a Clinical Services Coordinator in the Renal Transplant Unit at the Royal Adelaide Hospital, and has worked in renal clinics, home dialysis and education across a range of hospitals over the last 38 years. The Renal Transplant Unit provides specialist care for all patients with acute and chronic renal failure and transplantation for South Australian and Northern Territory patients.

Kylie Herman is a CSC who has worked in renal care and remote area nursing for more than 12 years, including management of the Port Augusta Dialysis Unit in which 80–90 per cent of patients are Aboriginal.

The Port Augusta Dialysis Unit provides the most northern dialysis service in South Australia and therefore attracts a high proportion of patients who have relocated from remote areas of northern and western South Australia for ongoing dialysis. Remote area patients face particular challenges, including dislocation from family and home community, long-distance travel (which prevents short visits), and a total change in living and financial conditions.

Both Gay and Kylie became involved in the MTWT in Stages 1 and 2, sharing detailed information about the barriers and enablers to providing quality and continuity of care for rural and remote Aboriginal people requiring renal care. During 2013 Gay and Kylie suggested the tools could be used to help identify and address communication, coordination and collaboration gaps and strategies in renal patient journeys within and between Port Augusta Hospital and the Royal Adelaide Hospital.

Focus of this case study

This case study highlights the need for communication and collaboration both within, and between health services to ensure continuity of care. Written from a nursing perspective, it follows the mapping process shown in the Workbook, and therefore provides another example of a complete case study. Ideally in patient journey mapping both the patient and family would be involved, and future mapping would include this.

Step 1: Preparing to map the patient journey

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

During a Renal Focus Group teleconference Gay and Kylie discussed a recent patient journey that could have had negative outcomes due to miscommunication and coordination challenges. Fortunately, the dialysis nurses had ensured the gaps in care were filled, but the group was concerned that the experience could be repeated.

An Aboriginal woman had been transferred from Port Augusta to Adelaide due to infection, had stayed in hospital for ten days and then returned to Port Augusta. The emergency trip to Adelaide and the care within the hospital had been well coordinated and were relatively uncomplicated, but the communication, coordination and collaboration for her trip home were less than ideal. The renal nurses were very concerned about what happened for this woman and about the high potential that existed for serious negative outcomes.

The aim of mapping this journey was to track back through the decision-making and coordination process to determine where the gaps occurred and the strategies and policies that could be put in place to prevent this happening again. Gay, as a senior nurse, was in a position to use this case study as a form of practice-based evidence and to advocate for policy and practice changes.

The mapping process

Although Gay had intended to write this case study herself, competing challenges and schedules made this difficult. After a few months, Janet and Gay decided to meet and do the mapping together. Together they tracked and mapped the patient journey and the decision points, and considered other factors that had impacted on this journey (such as bed state and bed pressures).

Task 1.2: Guiding principles for respectful engagement and knowledge sharing

As they were unable to include the woman's own perspectives at this time, this case study is told from the nurses' perspective. However, it was recognised that including the woman and her families' perspective would have made this mapping more accurate and rich. Gay began this case study by reading the case notes and speaking to Kylie to gain additional information from Port Augusta.

Step 2: Using the tools

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

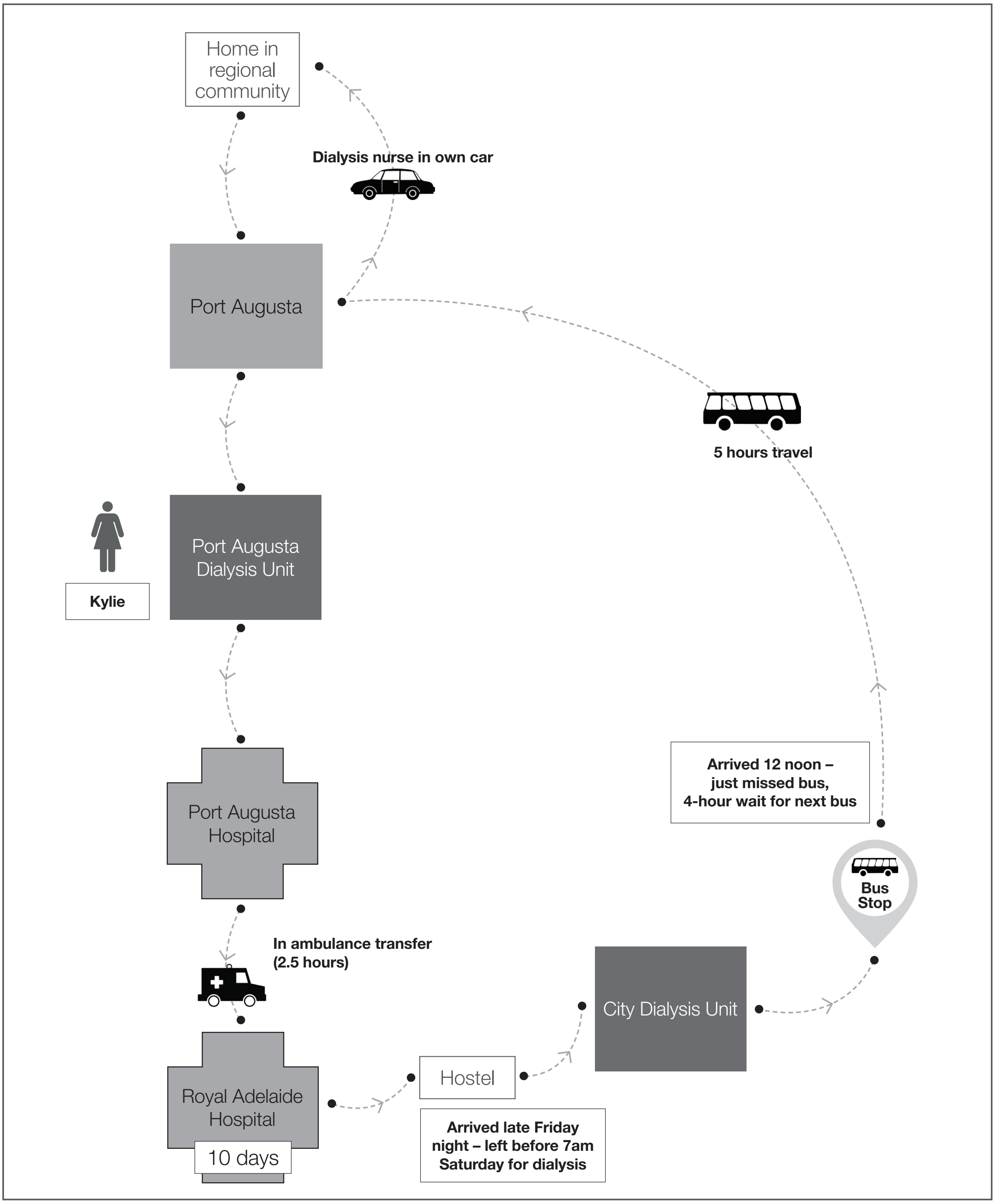
This Aboriginal woman is aged in her fifties and lives near Port Augusta with another family member. She has a history of diabetes, began dialysis in late 2012 and has had repeated infections. English is her second language, and she is very shy and quiet in the city hospital setting. In 2013 she suffered an infection and was transferred from Port Augusta Hospital to the Royal Adelaide Hospital. She was an inpatient for 10 days and plans were made for her to be discharged to the Kanggawodli Aboriginal hostel in Adelaide. She was to attend dialysis locally until the following week when she would return home. However, a change of plans (due to patient review and possibly bed pressures) led to a rapid discharge late on Friday evening, an overnight stay at Kanggawodli, dialysis at 7.30 am on Saturday morning, and then transfer to the bus depot for transport back to Port Augusta by public bus.

Staff at the dialysis unit rang Port Augusta Hospital Saturday lunchtime and said that the woman was on her way home on the 4.00 pm bus and could they arrange her transport home to Port Augusta via taxi. Kanggawodli staff also rang the Port Augusta dialysis unit to express concern because they thought the woman had not seemed very lucid when she had left them after a short overnight stay. When the Port Augusta staff again rang the Adelaide dialysis unit to check how the patient had been when she was there, the nurse said, 'she is mature enough to know what she is doing'. When asked if the patient had eaten or drunk sufficiently, the nurse was unable to say. This woman was also diabetic and did not have a mobile phone, nor did her family have a phone at home, and there was no information about whether she had money or food with her. Realising that there was no other weekend support available, and being very concerned, a dialysis nurse went to meet the 4.00 pm bus in her own car, in her own time. The woman was not on it, and so the nurse returned and met the 9.00 pm bus – which the woman was on.

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

Gay and Janet developed their version of Figure 1 to visually represent the patient's journey over time from home to hospital to home (described in Task 2.1). The emphasis in this figure is on the timeframes, locations, distances, and health and support services in each place. This figure highlights what happened for the woman when she was discharged late on a Friday night, with a subsequent short overnight stay at the Aboriginal hostel, and then early morning dialysis, a lengthy four hour wait at the bus depot, a long five-hour trip to the town near her home, and then a 20-minute drive home. The dialysis staff had no idea that it would take nine-and-a-half hours for her to get home, and they had not checked that she had eaten adequately, or had food and drink or money to buy them on the way home.

For a patient with diabetes, post dialysis, this was potentially very serious. This figure highlights the significant ramifications for rural/remote patients of a late Friday night change of plans and discharge without additional supports being put in place. If it was not for the Port Augusta dialysis nurse meeting each bus in her own car, the patient would not have gotten home that night. Neither she nor her family have phones, and the family did not know she was being discharged.



Case Study B – Figure 1: Visual mapping

Task 2.3: Recognising the whole person experiencing the patient journey

Gay gathered the information needed to consider the dimensions of health (Table 1). The inclusion of the women's own perspective would make this case study much stronger, but this option was not immediately possible. However, the possibility of adding her perspective will be considered, both for this and for future case studies.

Case Study B – Table 1: Dimensions of health

Dimension of health	Situation	
	Port Augusta dialysis	**City/regional hospital**
Social and emotional wellbeing **Family and community commitments** **Personal, spiritual and cultural considerations**	Lives independently near Port Augusta with another family member	Alone in city, no escort, no family
Physical and biological	Renal disease Diabetic Repeated infections	Treatment of infection

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

Gay identified that for this mapping it was important to consider the underlying factors when this woman accesses services in Port Augusta, Royal Adelaide Hospital and the hostel (Table 2).

Task 2.5: Bringing together multiple perspectives in chronological mapping

Table 3 shows the patient journey from multiple perspectives. It focuses specifically on the return journey, which is where the issues arose.

Case Study B – Table 2: Underlying factors

Underlying factor	Impact of location and access		
	Port Augusta Dialysis Unit	**City hospital dialysis**	**Hostel**
Rural and remote/city	The woman usually gets to dialysis on the health bus Admitted to hospital	Inpatient – infection No family nearby to visit	Discharge to Kanggawodli hostel with nursing care available Transport provided by Corporate Shuttle
Burden of illness	Relatively new to dialysis, repeated vascular infections	Infection requiring specialist care	Access to nursing supervision overnight
Language and communication	English is second language	Very shy – speaks only to people she has built a relationship with, or who take time to connect with her	More people with same/similar cultural background as staff and residents
Financial resources	Health care card	Emergency transfer – may not have financial resources	No time for hostel to enquire or organise financial assistance – 7.30 pm Friday to 7.00 am Saturday only
Cultural safety	Dialysis unit has predominantly Aboriginal patients and staff and patients know each other well	The ratio of Aboriginal to non-Aboriginal patients No Aboriginal staff on ward ALO visited	Comfortable and culturally safe place to stay, supportive of diabetic and dialysis patient needs Understand distance and travel impacts

Case Study B – Table 3: Multiple perspectives

Perspective	Patient history	Usual dialysis care	Trip to city	Admission	Discharge/ transfer	Accom-modation – hostel	Dialysis care	Discharge/ transfer	Trip home	Questions
Patient's journey	Recently commenced dialysis (end of 2012)	Royal Adelaide Hospital/ Port Augusta	Emergency	Sepsis	Planned discharge but discharged 7.00 pm on Friday ? due to bed pressures Discharged, drugs organised	Kanggawodli, overnight briefly	Outpatients dialysis x 1 Saturday morning	Taxi to bus depot Call to Port Augusta Saturday am	Via public bus	Is there a mechanism to check patients get home okay?
Timeline	Late 2012				Friday pm late	Overnight	7.30 am dialysis	? discharge early pm, 1.00–2.00 pm	4.00 pm bus – 9.00 pm arrival Met by dialysis nurse	How long was she without food and water while travelling?
Service gaps					After hours discharge – lack of time for proper discharge planning		? food provided	Change of plans, inadequate communication and handover discharge after hours ? if food or money	Poor communication regarding transport plans No after-hours service in region	Late change of plans Poor communication and lack of coordination between medical and nursing staff and different sites
Responses to gaps		Transport provided		Uncomplicated transfer and admission	Discharge drugs provided + script sent to Port Augusta	Supported medical hostel	Saturday am dialysis session	Port Augusta staff met shortfall	Port Augusta staff met bus in own time, in own car ? why not a taxi voucher given? ? rural and remote/city vouchers not interchangeable	Improved handover and documentation has been introduced

Task 2.6: Additional considerations for this patient journey mapping

In order to track what actually happened, how the decisions were made and the implications of these decisions, we created Table 4. Gay tracked through the case notes to find the relevant information for this table.

Case Study B – Table 4: Additional considerations – discharge planning and processes, the problems with late Friday discharges

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 (Echo)**	Friday		Echo 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 Echo	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

Case Study B – Table 4 cont...

Ward/unit/staff involvement	Date/day	Time	Reality/complexities	Results/ consequences
Kanggawodli Aboriginal Hostel	–		Very brief stay – late night to early morning	Minimal opportunity for hostel to be involved in coordination and preparing for transfer
City-based dialysis unit: Nurse and Registrar	Friday night		Provide dialysis and transfer to bus station Telephone Port Augusta Hospital and say she is on the 4.00pm bus	Miscommunication of travel time and assumptions made on how the woman could get from the bus to home
Port Augusta dialysis staff	Saturday morning		Dialysis staff working morning clinic received the call from city based dialysis unit that the woman was on her way to Port Augusta and could they arrange a taxi for her to get home Dialysis chair arranged for Tuesday	No Aboriginal Health Service support staff available after Saturday morning Port Augusta staff unable to contact the woman or her family, and so could not arrange to leave a taxi voucher for her
Kanggawodli Aboriginal Hostel	Saturday morning		Hostel staff phone Port Augusta dialysis expressing concern as the woman did not seem lucid when she left them early in the morning	Port Augusta staff alerted of potential for disconnected journey and the woman being unwell
Port Augusta dialysis staff	Saturday morning		Port Augusta dialysis nurses telephone city dialysis unit to enquire if the woman's blood sugar levels were stable, if she had eaten pre- and post-dialysis, and if she had money with her Unable to elicit this information and the woman had already been taken to the bus depot Port Augusta nurses decide they would meet the bus themselves in their own car to ensure the woman got home safely They were unable to contact the woman or her family as they have no telephone number Nurses met the 4.00pm and 9.00pm bus	Staff have no option but to meet each bus in their own car on Saturday afternoon and evening Poor communication between sites Underestimation of impact of the journey home for the woman, who possibly had no food, drink, money or escort for 9.5 hours while travelling Having diabetes, being post-dialysis and post-infection, and on new medications – significant risk of hypoglycaemia or other complications
Renal CSC			Plans for review regarding discharge of rural and remote patients	Changes in policy and practice to be strongly advised

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

This case study highlighted that additional procedures and policies were needed for coordination of care and discharge processes.

Task 2.8: Identifying key issues

This case study highlights the potential for serious complications when many people are involved in a patient's journey and late changes are made to discharge plans.

The main concerns regarding communication and coordination for this journey included:

- that it was unclear who was accountable for supporting the woman on each part of the journey, and across the entire journey
- that this woman attended the city outpatient dialysis unit as a non-regular visitor – there were no established relationships and communication between the woman and the dialysis staff (unlike in Port Augusta, where there were longstanding relationships and arrangements)
- the non-recognition by city dialysis staff of the length of time and distance this woman would be travelling, without a companion, and with little or no personal resources (telephone, money, food, water)
- the negative impact on this women's health and wellbeing of the hospital admission + a very brief overnight stay at the hostel + possibly a lack of food + dialysis + diabetes + a long wait at the bus depot + a lengthy bus trip + being unsure if anyone would be there to pick her up in Port Augusta
- that receiving staff at Port Augusta were unable to determine whether this woman had food or money for food/drinks and were concerned because she has diabetes and requires dialysis.

The dangers of the late Friday afternoon transfer/discharge included the fact that:

- the CSC had already left the ward having put a discharge plan in place
- there was a minimal skeleton staff after hours
- no support staff were available
- there were short timeframes
- there was a late arrival at the hostel
- minimal or no transport was available to pick up the woman from Port Augusta bus depot.

In relation to discharge planning:

- it was difficult to determine from the case notes why the discharge plans were changed
- there appears to be an underestimation of the time it takes to book and have an echo, then get it reviewed by both cardio and infectious diseases staff.

Limitations of case notes include that:

- they record single episodes of care, not journeys
- it can be difficult to track decision points and determine how or why certain decisions are made.

In summary, it is not appropriate to discharge rural Indigenous patients on their own, after hours or at the weekend unless all the aspects of a safe journey are in place and there is an agreement regarding accountability and a full handover and transfer of care from one service to another.

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

What worked? Reflections on the mapping process

The MTWT tools enabled Gay to write up the case study in an organised way and highlight the very real potential for harm when patient journeys do not involve adequate levels of communication, collaboration and coordination.

Going through the mapping process helped Gay to identify, dissect and investigate exactly what happened.

Adapting the tools

Changes were made to the tables to enable the case study to be recorded adequately. These included:

- Table 1: Dimensions of health – combining the non-physical dimensions (psychosocial, social, spiritual, cultural and family) into one row
- Table 2: Underlying factors – consideration of how each underlying factor was experienced in Port Augusta, the city hospital and the hostel in Adelaide
- Table 3: Multiple perspectives – dialysis care was added to the columns, and timelines to the rows
- Table 4: Additional considerations – as we mapped the journey, it became obvious that Table 4 could be used to outline the exact sequence and events leading up to the discharge.

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

Ideally, the perspectives of the patient and her family would be included in this case study.

The woman’s own perspective would have been very valuable. Without this, a level of assumption and guess work occurred and some questions remained unanswered. For example, we did not know if this woman requested to go home earlier or if there were other aspects of her journey that were significant to her and the decisions made. Such points are often not recorded in case notes. Also, inclusion of perspectives from the Aboriginal hostel and the city dialysis unit would have ensured a more comprehensive representation.

Step 3: Taking action on the findings

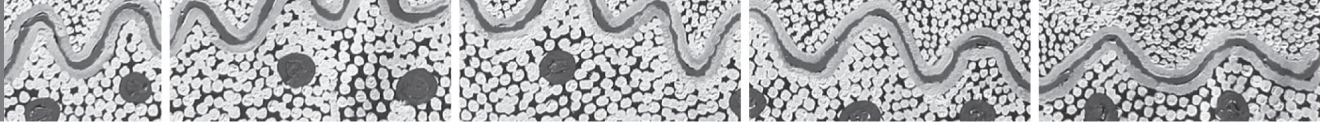
Task 3.1: Deciding how best to share the findings, with whom, and in what format

This case study will be used to highlight the significant risks and negative impacts for patients of poorly planned, unaccompanied late Friday night or weekend discharge and transport home, particularly for patients from rural and remote locations. This will be discussed in renal forums to inform policy and practice.

This case study will be used to help create a journey map template to complement existing paperwork and include additional specific information and details for transition between services.

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

This case study was used to highlight gaps and identify how existing discharge standards are implemented and what needs to be changed or strengthened (Table 5). There are now improved handover and documentation procedures in place at the Royal Adelaide Hospital Renal and Transplant Unit.

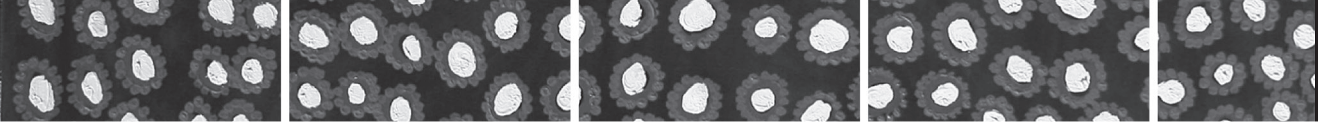


Case Study B – Table 5: Action plan

Issue	Level	Action required	By whom	When	Review date	Action taken
Rural/ remote patients report feeling lonely while in hospital	Personal	Each staff member and volunteer to engage in conversation with patients more often	All staff and volunteers	From now	30 May 2014	Review patient satisfaction feedback Meeting between Renal Unit and Aboriginal Liaison Unit Manager
Variable patient involvement in discharge planning	Professional	Enact patient-centred care policy	All staff, nursing, medical, support	Within 1 month	30 May 2014	Case study review by unit leader
Improved coordination and handover	Service	Ensure adequate planning and handover / transfer of information. Update policies and procedures	Nursing staff in each renal and dialysis unit. Teleconference to finalise details	Within 2 months	30 June 2014	Discussed in June teleconference. Draft
Responding to bed state pressures while also ensuring safe discharge	System	Review which patients are discharged and in what circumstances	Unit managers, administration	Within 3 months	30 July 2014	Draft proposal to be discussed at next ** meeting

Action plan prepared by ______________________________

On / /



Case Study C: Transplant Continuity of Care

Authors: Toni East and Janet Kelly

Who was involved in the mapping?

Toni East has worked in renal and transplantation services for nearly 30 years and is currently a Clinical Practice Consultant Renal Transplantation at the Royal Adelaide Hospital as part of the Central Northern Adelaide Renal and Transplantation Service (CNARTS). Late in 2012, Toni read an article by Cheryl Wilden and Janet Kelly in the Renal Society of Australasia Newsletter and asked to be involved in this study.

Focus of this case study

This case study shows how the tools – particularly Table 2: Underlying factors and Table 3: Multiple perspectives – can be expanded to record in detail each person and health unit involved in patient care. Only blank tables are shown because Toni needed to take extended leave and was unable to complete mapping individual case studies. However, the tool format is useful and may be adapted for other sites and situations requiring in-depth mapping.

The case study introduces an adaptation of the tools that has not yet been trialled. It took place before the Workbook was finalised, so it does not follow the same layout and guidelines as suggested in the Workbook.

Choosing which patient journeys to map

Toni was concerned there may be a significant disconnect in nursing care pre- and post-transplant, and that this impacts patient experiences, as well as communication, across the entire journey.

The aims of mapping these patient journeys are to:

- map the transplant journey from the perspective of the patient and the patient's family to communicate patient needs and priorities and highlight gaps and strategies in care
- use the tools for critical reflection
- build practice-based evidence and advocate for any needed changes.

The mapping process

Toni found it difficult to find time to work with the tools within her busy work schedule, and also had difficulty making sense of how to use the tools (in their early format). Being new to the study, Toni's feedback was invaluable in helping to develop the prompt questions for the Workbook.

Janet and Toni met and discussed the mapping process and how Toni would like to use the tools, and then adapted and expanded the tools to suit. At the time of writing, Toni has not yet been able to finish using the tools due to unexpected leave. However, the renal group decided it was useful to include this case study because it provides another example of how the mapping process and tools can be adapted for a specific purpose.

Adapting the tools

Changes were made to the tables to suit the needs of the case study:

- Table 1: Dimensions of health – Toni highlighted that a person's pervious health care experiences can impact significantly on the experience of the transplant journey; therefore, 'previous health care experiences' was added as another row
- Table 2: Underlying factors – Toni saw the benefit of considering the underlying factors that impact primary and transplant care, and follow-up; the underlying factors of both the person undergoing the transplant journey and of the services involved were considered
- Table 3: Multiple perspectives – Toni wished to highlight the need for coordination between the pre-transplant and post-transplant nurses and each of the hospital staff members and how this may impact continuity of care. The many different health care providers involved in transplant care are included in this table, as is the timeline over which the journey occurred. In addition, the optimal pathway (standard of care) was included to provide a comparison, with inclusion of complicating factors to explain variation to the standard. With so much detail, it was necessary to split this table into two parts.

Mapping the journey

Toni is in the process of mapping journeys with patients and is using the templates shown in Tables 1, 2 and 3 (Parts a and b) to record their journeys.

Case Study C – Table 1: Dimensions of health

Dimension of health	Situation	
	Background	**New and existing challenges**
Social and emotional wellbeing **Family and community commitments** **Personal, spiritual and cultural considerations**		
Physical and biological		
Previous health care experiences		

Case Study C – Table 2: Underlying factors

Underlying factor	**Impact of location and access**			
	Local health service	**CNARTS transplant service**	**Local health service**	**Follow-up post-transplant**
Rural and remote/ city				
Impact of illness or injury				
Language and communication				
Financial resources				
Cultural safety				

Toni envisions that using the tools will enable her and other staff to receive patient feedback about the barriers and enablers to a connected and supported patient journey. They will then be able to develop appropriate strategies to address these.

Case Study C – Table 3 (Part a): Multiple perspectives

Perspective	Patient history	Pre-transplant work-up	Assessment and education	Active list	Call in for transplant	Travel to hospital	Transplant	Comments
Timeline								
Patient's journey								
Patient priorities, expectations, hopes								
Health care **Optimal pathway (standard)**								
Complications/ aspects **(i.e. carer needs)**								
Services/staff involved								
Pre-transplant nurse								
Post-transplant nurse								

Case Study C – Table 3 (Part a) cont...

Remote clinic staff – Aboriginal Health Worker, Registered Nurse, Doctor	
Transport	
Transplant secretary	
Doctors – Registrar	
Doctor – Consultant	
Aboriginal Health Liaison Officer	
Pharmacist	
Dietitian	

Case Study C – Table 3 (Part a) cont...

Perspective	Patient history	Pre-transplant work-up	Assessment and education	Active list	Call in for transplant	Travel to hospital	Transplant	Comments
Social worker								
Referrals to other units **(Dermatology, gastric)**								
Hostel/ accommodation								
Transport								
Health service connection								
Other								
Service gaps								
Responses to gaps								

Case Study C – Table 3 (Part b): Multiple perspectives

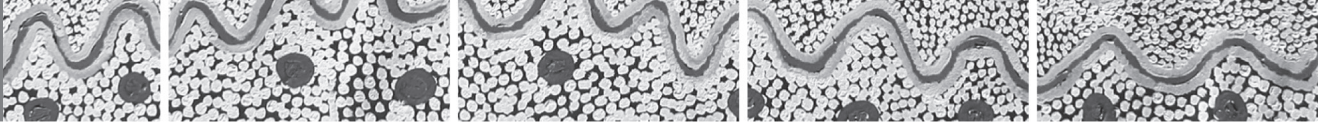
Perspective	Education	Discharge to home or hostel	Transfer	Hand-over of care	Post-discharge clinic	Re-admission	Follow-up	Comments
Timeline								
Patient's journey								
Patient priorities, expectations, hopes								
Health care **Optimal pathway**								
Complications/ aspects **(i.e. carer needs)**								
Services/ staff involved								
Pre-transplant nurse								

Case Study C – Table 3 (Part b) cont...

Perspective	Education	Discharge to home or hostel	Transfer	Hand-over of care	Post-discharge clinic	Re-admission	Follow-up	Comments
Post-transplant nurse								
Remote clinic staff – Aboriginal Health Worker, Registered Nurse, Doctor								
Transport								
Transplant secretary								
Doctors – Registrar								
Doctor – Consultant								
Aboriginal Health Liaison Officer								
Pharmacist								

Case Study C – Table 3 (Part b) cont...

Dietitian	
Social worker	
Referrals to other units **(Dermatology, gastric)**	
Hostel/ accommodation	
Transport	
Health service connection	
Other	
Service gaps	
Responses to gaps	



Prompt questions to determine findings

Toni has developed a list of prompt questions to help analyse the patient journey.

- How did this journey compare to transplant standards (identify what these are)?
- What was learned from recording the patient's perspective?
- What is working well?
- Main issues: gaps identified?
- What protocols/procedures are already in place? What needs reviewing/updating?
- Any recommendations from recent studies/reports and how does this patient journey compare to others?

Reflection on the mapping tools

This would be a useful tool not just for Aboriginal patients, but also other rural and remote patients.

Case Study D: Culturally Safe Renal Education

Authors: Cheryl Wilden and Janet Kelly

Who was involved in the mapping and education?

Cheryl Wilden works as a renal Nurse Education Facilitator based at the Royal Adelaide Hospital. Her role involves training new and existing staff in renal care, and she has worked in the area of renal care for more than 20 years. Cheryl first became involved in the study in 2012 when the renal nurses invited her to join conversations about how to improve patient journeys. Cheryl and Janet began discussing how the mapping tools could be used in renal education programs.

Focus of this case study

This case study presents a Renal Education Package developed in collaboration with the renal nurses in the focus group to ensure current issues are incorporated into ongoing training. Concepts of nursing knowledge development and cultural safety underpin this education package.

This case study took place before the Workbook was finalised, so rather than following the exact format shown in the Workbook, it presents three session modules:

- Session 1: Introduction to patient journey mapping
- Session 2: Using the tools for reflective practice
- Session 3: Using the tools to develop your own case study.

This education package will be revised following feedback of the Renal Case Studies and the Workbook.

Using the patient journey mapping tools for renal education

In 2013 Cheryl was rewriting the renal education curriculum and began incorporating patient journey mapping and cultural safety into the training. The aims of using patient journey mapping concepts and tools in the renal education curriculum were to:

- assist students in critical reflection regarding meeting care needs of particular patients
- combine concepts of quality renal care with cultural safety
- enable the learning and findings of the Renal Focus Group to be incorporated into renal education; this transmission of shared knowledge is an effective way to capture the wealth of experience in this area from senior renal nurses
- encourage students to continue using the tools to provide a rich source of ongoing information about how to help our patients and improve their journeys.

The mapping process

Cheryl and Janet met every few months to discuss how the tools could best be used in renal education to communicate the findings of the renal group and to promote culturally safe care.

Adapting the tools to fit an education package

Cheryl adapted the tools to reflect renal settings and used them with students in face-to-face classes and distance education modules. She then reviewed the education unit and process and, as a result, Version 3 (following) includes the following adaptations.

Renal Education Package (Version 3) for renal nursing students

Session 1: Introduction to patient journey mapping

We currently work within a culturally diverse health system and, as such, it is important that we ensure that all patients receive effective, understandable and respectful care that is provided in a manner compatible with their cultural health beliefs, practices and preferred languages (Lubkin & Larsen 2012:355).

Effective communication is the crux to providing culturally appropriate care, not only for the patient and the patient's family but for all care providers who may become involved with the patient throughout the health care journey.

Aboriginal and Torres Strait Islanders are one of the most at-risk groups in Australia for developing Chronic Kidney Disease (CKD) (Kidney Health Australia 2012) due to a complex mixture of decreased access to quality health care and social determinants of health. If we are to improve the health outcomes for this group of patients, we need to ensure that we look beyond the physical and immediately obvious aspects of care of the patient and consider how his or her emotional, social and spiritual wellbeing, as well as cultural integrity, may also be affected. These considerations are even more important if the patient lives in a remote or rural area.

The aim of this education package is to help renal nurses gain insight into the complex issues along the CKD continuum, as well as the challenges for individuals with CKD who live in remote or rural areas as their health deteriorates. There will be some challenges that are unique to Aboriginal people and others that are shared by all in a rural or remote location.

This education package is part of a much wider study called Managing Two Worlds Together. The MTWT project aims to improve knowledge of what works well and what needs improvement in the system of care for Aboriginal patients from rural and remote areas of South Australia who need to attend city hospitals.

Funded through SA Health, Stage 1, involved studying admissions data over two years and interviewing staff in city and rural/remote locations about the barriers and enablers, gaps and strategies of care (n = 60). The focus was on the six main reasons Aboriginal people are admitted to city hospitals, which are renal, cardiac, mental health, birthing, injury and respiratory.

The team then spoke to 29 rural/remote patients and their immediate carers about their experiences from first diagnosis, the referral and trip to the city and home again, or medical relocation. Of these, five patients were involved with dialysis care. The next phase of the research involved choosing four patient journey experiences to study in more depth. Patient journey mapping tools that could follow the journey across Aboriginal community-controlled, general practice, rural/remote hospital and city hospital care were developed.

Results of MTWT study

Both staff and patients identified *communication* between health units and between staff and patients and their family members as an important aspect of care. Staff spoke of their varying levels of experience and comfort in intercultural interactions, and patients shared stories of how this was perceived and received.

Access issues, particularly transport and accommodation, were repeatedly raised by both staff and patients, as were concerns about informed consent. The availability and use of interpreters, and clarity in the role and support of family and carers, were described as variable.

Coordination and quality of care often depended on how well information was exchanged between health services across the State, or even within a single hospital. Improved patient journeys occurred when patients were transferred to another health service rather than discharged from a hospital with no planned contact or exchange of information with the next health care facility.

Both patients and staff spoke about the importance of trying to meet specific *cultural and individual needs of patients*, such as same-gender health carers for intimate care and working closely with patients, their families and communities in relation to death and dying. Some staff raised concerns about the approach of colleagues, and some patients shared stories of racism they had experienced. More often, patients spoke about a staff member's personality and whether they felt respected as a person. A group of senior Elder women stressed the importance of saying hello and that they felt like a non-person when staff attended their physical needs but did not acknowledge them as a person. Each patient also spoke strongly of the importance of maintaining contact with family, either face-to-face or via the telephone. Staff discussed specific challenges in providing support for rural/remote family members, particularly if an escort was unwell or overwhelmed, or family arrived on a Friday evening needing accommodation support.

Key themes regarding complexity emerged. Overall, while clinical complexity was often recognised and responded to, complexity of the entire patient journey was often overlooked. Wards or units that provided the most coordinated and responsive care were those that had been able to predict complexity and build in appropriate responses and services. Other wards or units that were less aware or prepared for journey complexities reacted to problems as they arose, often relying on the Aboriginal Liaison Officer unit for immediate problem solving. Many staff members engage in good practice and creative solutions, tailoring responses to predictable complexities, but the hospital and health system do not adequately support them. This results in pockets of well-coordinated care, but not across the health system as a whole. Everyone – patients, their families, rural/remote and city health services – risk extra costs when patient journey complexity is overlooked.

Patient journey mapping tools

Patient journey mapping tools were developed as part of the MTWT project, originally for analysis, but many more uses are emerging. While developed specifically for rural/remote Aboriginal patients, the tools can easily be adapted for other patient groups.

The tools in this Renal Education Package consist of three tables. Table 1 recognises the needs of the whole person entering the journey, and uses five dimension of health; Table 2 considers the five underlying factors that complicate patient journeys, and Table 3 brings together the perspectives and experiences of patients, family and staff and follows the patient journey from first diagnosis to follow-up.

Case Study D – Table 1: Dimensions of health

Dimension of health	Situation	
	Local community	**City/regional hospital**
Social and emotional wellbeing	Strong psychological ties and important role within community	Loss of close connection to land, family and community, needs to find new housing, loss of partner
Family and community commitments	Family has own farm and home, livestock Is important leader in community	Has to move to live near dialysis unit, financial concerns
Personal, spiritual and cultural considerations	Important family and community ties to homelands	Living away from homelands Only able to return intermittently for up to two days at a time
Physical and biological	Hard-working woman (self-description)	Suddenly becomes ill with renal disease

Case Study D – Table 2: Underlying factors

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

Case Study D – Table 3: Multiple perspectives

Perspective	Patient history	Diagnosis/ referral	Trip to city	Pre-admission	In hospital/ city	Discharge/ transfer	Trip home	Follow-up
Patient's journey	Aboriginal Elder, lives with family	Sudden illness and kidney disease	Emergency via RFDS	Immediate admission	Diagnosis, treatment, commence dialysis	Transfer to outpatient dialysis appointments	Medical relocation	Ongoing dialysis in regional town
Family/carer journey (partner)	Close-knit family and community	Very upsetting diagnosis Supports patient to get help	Followed partner to city via car then bus	Needed to find hospital and accommodation	Stayed in Aboriginal hostel and travelled in daily	Husband moves to regional town Family in homelands	Only occasional visits home	Partner also developing kidney disease Are living on one pension
Patient priorities, concerns	Family, land, livestock	Acutely ill, needs help	Wants to get well	Very unwell	Most patient needs met	Wants to go home, or at least be nearer to home	Medical relocation	Wants to go home Financial concerns
Health service priorities	No obvious health issues	Acute illness requiring immediate hospitalisation	Acute care and stabilisation en route	Emergency treatment	Stabilisation, treatment Ongoing dialysis	Transfer to regional renal unit	Can only have three days without dialysis	Effective dialysis Social and emotional wellbeing Safe housing
Service gaps		? earlier detection, or acute episode	support for partner's journey		Overestimation of patient's understanding of English	Access to accommodation and transport	No services within 700 kilometres of home	
Response to gaps					Good clinical and general care interpreter	Support by renal unit, community health and support services	Nearest regional city has dialysis beds	Assist with accommodation and social work referral and planning visits home

Session 2: Using the tools for reflective practice

Part 1 – Sharing a patient's story

Objectives: The aim of this session is to introduce the complexity of the renal patient journey and begin to identify issues related to the patient journey. It is instructive to read 'Case Study 3: Will I ever get home again?' in *Managing Two Worlds Together: Study 4—Complex Country Aboriginal Patient Journeys* (Kelly et al. 2011:10–12), which is available on the MTWT website at: www.flinders.edu.au/medicine/fms/sites/health_care_management/mtwt/documents/Study%204_WEB.pdf.

Reflection: What aspects of the patient journey do you think were planned well? What challenges do you think would have been most difficult to help the patient overcome?

Identify where your role would fit in this patient's journey. Do you work in a city hospital or in a local community or regional hospital?

How could a nurse in your role improve the journey and communication with the different care providers and health services?

Rationale: Encourage nurses to think from within a single unit and follow a patient journey across many units/sites – give different perspectives.

Part 2 – Introduction to the tools

Objectives: Plan strategies for meeting different patient needs along the journey. This session is designed to introduce the renal patient assessment tool and how to use it to assess Aboriginal renal patients.

Activity: Online discussion or face-to-face forum looking at challenges and barriers across the journey of accessing renal care. Highlight the complexity of the renal patient care and of the whole patient journey, including the decision-making process for this patient and the education they would require.

The information provided in Renal Education Package (REP) Figure 1 is often the only information that is 'handed over' regarding a patient. Brian (a pseudonym) is a 50-year-old Aboriginal male who has presented in a busy city dialysis unit for his first week of dialysis. He is married with four young children, and he owns and runs a farming property 450 kilometres from the nearest town on the border of South Australia and the Northern Territory. He was diagnosed with CKD secondary to IgA (Immunoglobulin A) nephropathy in June 2009.

For this activity, review the information provided in REP Figure 1 and then try to fill in what you can in REP Tables 1 and 2.

Past medical history	Physical assessment 6/7/2011
Former smoker	**BP 220/142**
HT	**HR 110**
complicated appendectomy several years ago	**Resp 24**
No family history of CKD	**Bilateral crackles**
	Urine dipstick – protein ++++ and Blood ++++

Mr Brian X UR 123456	June 09	June 10	July 11	July 11
	27	1	6	6
	06:30	10:00	8:05	12:10
Sodium	141	142	140	140
Potassium	4.3	4.4	6.2	3.2
Bicarbonate	26	32	18	26
Urea	10	33.7	20.5	7.3
Creatinine	206	350	702	351
Albumin	28	24	24	26
Calcium	2.08	2.03	2.46	2.3
Phosphate	1.14	1.47	1.82	.95
Intact PTH			23	
Haemoglobin	120	90	122	124
Iron Saturation		12	28	
Ferritin			921	
E – GFR	43	22	5	
Kt/V				1.21
URR				65

Case Study D – REP Figure 1: Hand-over and case note information

Review the information in REP Figure 1 and, combined with what you have learned about CKD and the impact it may have on a patient, complete REP Table 1.

Case Study D – REP Table 1: Dimensions of health over three years

Dimensions of health		**Challenges**	
	2009	**2010**	**2011**
Social and emotional wellbeing			
Family and community commitments			
Personal, spiritual and cultural considerations			
Physical/biological			

Reflection: What challenges might Brian have faced in 2009, 2010 and 2011? Would his health necessarily impact on these different dimensions of health? Why?

In conjunction with the information presented in Brian's case study and the guidelines outlined for general practice by Kidney Health Australia (2012) in *Chronic Kidney Disease (CKD) Management in General Practice* (available on the Kidney Health Australia website at: www.kidney.org.au/HealthProfessionals/CKDManagementinGeneralPractice/tabid/789/Default.aspx), complete REP Table 2.

Case Study D – REP Table 2: Renal care and management of condition over three years

Management	**2009**	**2010**	**2011**
Lifestyle changes			
Fluids			
Diet			
Medications			
Education			

Reflection:

- What dimensions of health were you familiar or comfortable with? What was more difficult? Why?
- Which table did you feel more comfortable filling in?
- What information did you find was missing about Brian and made completing the table difficult?
- What other information would you now consider asking Brian?

Rationale for this reflection is that it highlights both clinical complexity + whole of journey complexity.

Session 3: Using the tools to develop your own case study

Objectives: Identify needs and gaps from patient and health care perspectives. Develop strategies to help improve the patient journey.

Activity: Use the patient journey mapping tool provided as part of your patient assessment for your case study presentation at the end of semester. (Note: version 4 of this education package will use the Improving Aboriginal Patient Journeys Workbook – but this education package pre-dates the release of the Workbook.)

Outline what you could do to help improve the patient journey both now and in the future.

Case Study D – REP Table 3: Dimensions of health

Dimensions of health	Current challenges	Future challenges
Social and emotional wellbeing		
Family and community commitments		
Personal, spiritual and cultural considerations		
Physical/biological		

Case Study D – REP Table 4: Renal care and management of condition over one year

Management	Current issues	Future issues
Lifestyle changes		
Fluids		
Diet		
Medications		
Education		

Case Study D – REP Table 5: Underlying factors

Underlying factor	Impact of location and access	
	Home/local community	City/regional hospital
Rural and remote/city		
Impact of illness or injury		
Language and communication		
Financial resources		
Cultural safety		

Reflection: What challenges may the patient be facing, and what other challenges may be ahead? What additional information or insights about the patient, the journey and the health system did you gain from using this tool? What did you learn about this patient that you did not know before?

Rationale: assists nurses to reflect on their role in improving the patient journey.

End of education session.

Reflections on students using the mapping tools

Cheryl reported that students found it difficult to engage with early versions of the mapping tools. She found she needed to explain the tools and prompt students on how to fill out the tables. This feedback helped to structure the format of the Workbook and prompt questions.

Reflections of the Renal Focus Group

At the end of 2013 the Renal Focus Group reflected on the group activities, the benefits, what made the group work, and what they had all brought to the group.

The Renal Focus Group meetings and connections provided a safe space and place for knowledge exchange to take place regarding:

- the challenges and strategies of being a nurse working in renal health and Aboriginal health
- how to provide patient-centred care in such an inflexible and disconnected health system, particularly for more vulnerable patients
- how clinical and education leaders could work together to ensure nurses provide best practice
- relationship building, leading to improved communication and interconnection between clinical wards and units and dialysis, and education
- debriefing opportunities
- the knowledge Janet was able to bring from across the IAPJ study, other disciplines and sectors
- the acknowledgment and inclusion of each nurse's needs and interests individually, as well as collectively.

The Renal Focus Group considered the issues that made the group work:

- the group developed as interested and passionate nurses came together
- it was highly flexible – there was recognition that each nurse was really busy, and teleconferences were held monthly or bi-monthly when everyone was available
- space was created for the nurses to discuss a range of issues most important to them; if they needed to talk about clinical issues, Janet stopped taking minutes
- Janet was an external person who asked questions about the things that the renal nurses forgot they knew or assumed everyone else knew
- Janet wrote up minutes and sent them back to the group for confirmation
- the group discussion content was confidential; only the themes were shared, with permission
- Janet met each person individually (face-to-face, phone, email), as well as collectively, which enabled each person's individual needs and challenges to be explored and then discussed at a focus group level when appropriate; therefore, critical reflection occurred at the individual and the collective level
- trust that Janet would treat conversations and case studies as confidential until it was agreed they were suitable for wider distribution
- previous work and dissemination of case studies with focus group members in earlier stages of the MTWT project provided a platform upon which the group could expand.

The renal nurses brought different skills to the group, including:

- knowledge about the issues and priorities for people when they go home
- staff experiences and awareness from going out on the renal bus as well as working in city sites
- an awareness and reminder that renal care can be provided in a range of creative patient-centred ways – Sarah Brown would remind us that 'these people are travellers, and care facilities need to complement their needs'
- how to use research to support improvements in practice
- networks and networking.

The renal participants were the only group of participants that were positioned and functioned as a defined focus group in this study. Diagram 3 illustrates how all seven nurse leaders came together and shared knowledge, leading to improved practices, revised policies, updated renal education, and new partnerships and networks. The participants felt that their involvement in the group and resulting actions improved the ability of themselves and their colleagues to respond to Aboriginal renal patients' care needs in a more comprehensive way.

Diagram 3: How the Renal Focus Group functioned

Postscript

The Renal Focus Group membership has broadened in 2014 to include palliative care staff, and the work continues on improving Aboriginal patient journeys, particularly those focused on end of life care.

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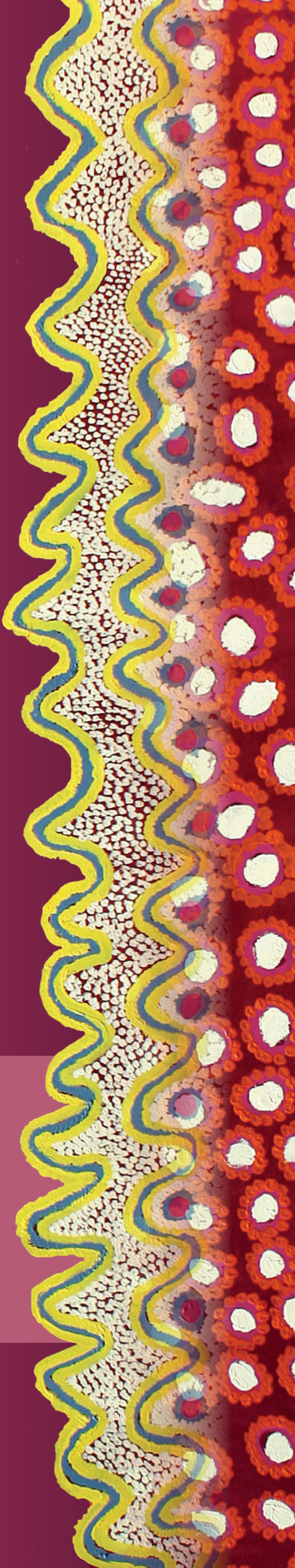

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