

Managing Two Worlds Together

Stage 3: Improving Aboriginal
Patient Journeys—
Maternity Case Studies

Janet Kelly
Paula Medway
Debra Miller
Lisa Catt
Monica Lawrence



Cover Artwork:

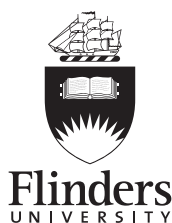
Kuntjanu – Mingkiri
Tjuta Tjukurpa
(Marsupial Mouse
Dreaming)

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

Managing Two Worlds Together

Stage 3: Improving Aboriginal
Patient Journeys—
Maternity Case Studies

Janet Kelly
Paula Medway
Debra Miller
Lisa Catt
Monica Lawrence



© Flinders University, 2015

ISBN 978-1-921889-32-5

First published in April 2015

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

This work is the copyright of Flinders University. It may be reproduced in whole or in part for study or training purposes, or by Aboriginal and Torres Strait Islander community organisations subject to an acknowledgment of the source and no commercial use or sale. Reproduction for other purposes or by other organisations requires the written permission of the copyright holder(s).

Downloadable pdfs of the *Managing Two Worlds Together. Stage 3: Improving Aboriginal Patient Journeys—Maternity 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:

Department of Health Care Management

Flinders University
Bedford Park, SA 5042 AUSTRALIA

T: +61 8 8201 7755

F: +61 8 8201 7766

E: tiffany.carlin@flinders.edu.au

W: www.flinders.edu.au

The Lowitja Institute

PO Box 650, Carlton South
Vic. 3053 AUSTRALIA

T: +61 3 8341 5555

F: +61 3 8341 5599

E: publications@lowitja.org.au

W: www.lowitja.org.au

Authors: Janet Kelly, Paula Medway, Debra Miller, Lisa Catt and Monica Lawrence

Managing Editor: Jane Yule @ Brevity Comms

Copy Editor: Cathy Edmonds

Design and Print: Inprint Design

For citation: Kelly, J., Medway, P., Miller, D., Catt, L. & Lawrence, M. 2015, *Managing Two Worlds Together. Stage 3: Improving Aboriginal Patient Journeys—Maternity Case Studies*, The Lowitja Institute, Melbourne.

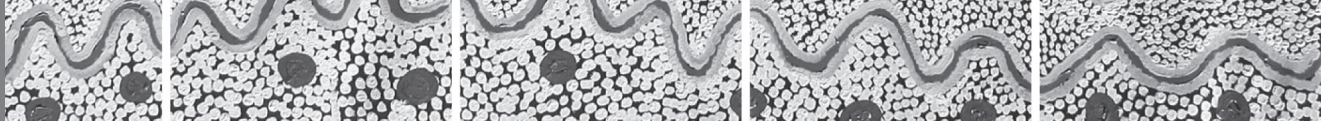


Australian Government
Department of Industry and Science

Business
Cooperative Research
Centres Programme

Table of Contents

| | |
|---|----|
| The Managing Two Worlds Together Project | v |
| Acknowledgments | vi |
| Abbreviations and Terms | vi |
| About the Maternity Case Studies | 1 |
| The Patient Journey Mapping Process | 3 |
| Case Study A: Debriefing by the Aboriginal Maternal Infant Care Team | 4 |
| Case Study B: Improving Cultural Communication in the Nursery | 9 |
| Case Study C: Long-distance Baby | 12 |
| Case Study D: Developing Midwifery Education Sessions | 17 |
| Case Study E: Using the Tools as a Methodology for Honours Study | 20 |
| | |
| Diagrams, Figures and Tables | |
| Diagram 1: The three stages, focus and outcomes of the Managing Two Worlds Together project | v |
| Diagram 2: The process of using the Aboriginal PJM tools – an overview | 3 |
| | |
| Case Study A – Table 1: Dimensions of health | 5 |
| Case Study A – Table 2: Underlying factors | 6 |
| Case Study A – Table 3: Multiple perspectives | 7 |
| | |
| Case Study B – Table 2: Underlying factors | 10 |
| | |
| Case Study C – Table 1: Dimensions of health | 14 |
| Case Study C – Table 2: Underlying factors | 15 |
| Case Study C – Table 3: Multiple perspectives | 16 |
| | |
| Case Study D – Figure 1: Role examples | 18 |



The Managing Two Worlds Together Project

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

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

Stage 2 (2012) focused on possible solutions and strategies. As the research team shared findings with health care providers, case managers and educators in a range of different health and education settings, the potential and scope of the Aboriginal patient journey mapping (PJM) tools for quality improvement, training and education emerged. The resulting tools

consist of a set of tables that enable an entire patient journey to be mapped across multiple health and geographic sites, from the perspective of the patient, their family and health staff in each location.

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

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

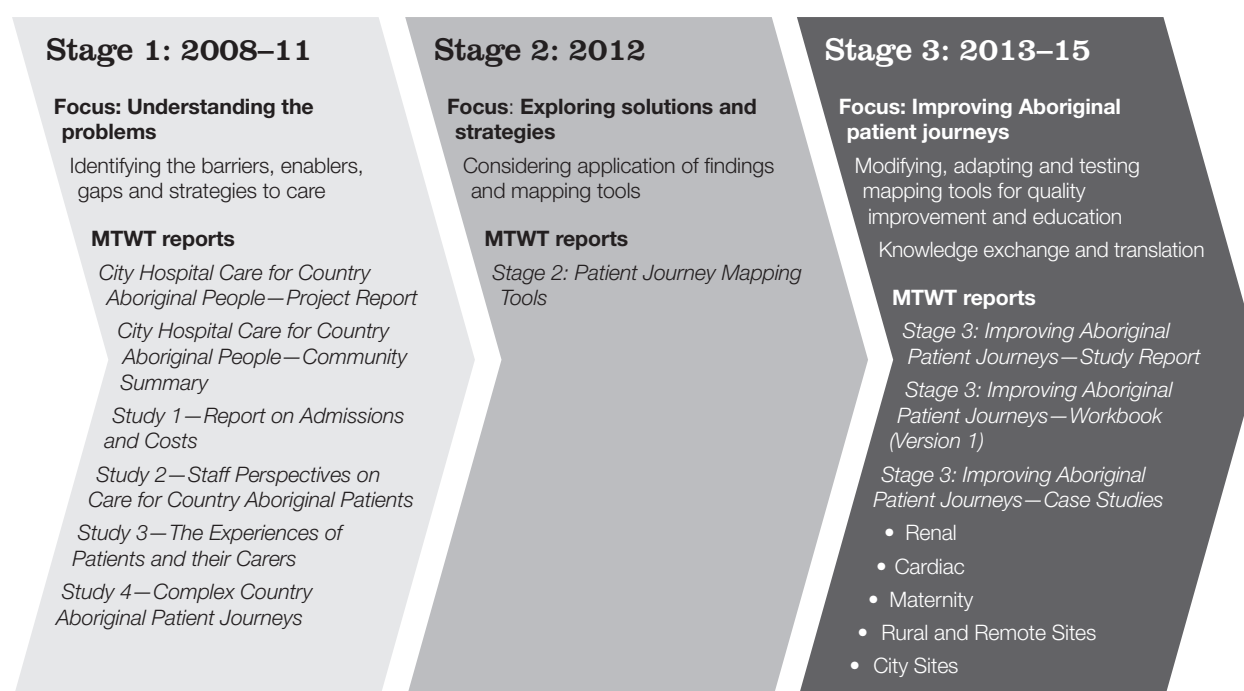


Diagram 1: The three stages, focus and outcomes of the Managing Two Worlds Together project

Acknowledgments

The authors would like to acknowledge the following people who were involved in, or assisted with, the development of the tools and these case studies:

Hugh Auckram, Alex Brown, Sarah Brown, Wendy Corkhill, Charlotte de Crespigny, Karen Dixon, Judith Dwyer, Toni East, Amy Graham, Kylie Herman, Liz Izquierdo, Rosie King, Michael Kirkbride, Natalie McCabe, Wendy McInnes, Gay Martin, Lee Martinez, Sonia Mazzone, Laney Mackean, Tamara Mackean, Jo Newham, Annapurna Nori, Kim O'Donnell, Brita

Pekarsky, Sharon Perkins, Daphne Perry, Pam Pratt, Mark Ramage, Damian Rigney, Christine Russell, Bronwyn Ryan, Kym Thomas, Jeff Tinsley, Cheryl Wilden, 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

| | |
|--------------|--|
| ACCHS | Aboriginal Community Controlled Health Service |
| AFBP | Aboriginal Family Birthing Project |
| ALO | Aboriginal Liaison Officer |
| AMIC | Aboriginal Maternal and Infant Care |
| APPO | Aboriginal Patient Pathway Officer |
| COAG | Council of Australian Government |

| | |
|-------------|---|
| FMC | Flinders Medical Centre |
| IAPJ | Improving Aboriginal Patient Journeys |
| MTWT | Managing Two Worlds Together |
| PATS | Patient Assistance Transport/Travel Scheme – South Australia/Northern Territory |
| PJM | Patient Journey Mapping |

Terminology

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

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

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

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

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

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

About the Maternity Case Studies

This report on Maternity Case Studies is complemented by reports on four others – dealing with Renal, Cardiac, 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.

Five maternity case studies are presented in this report:

- **Case Study A:** Debriefing by the Aboriginal Maternal Infant Care Team
- **Case Study B:** Improving Cultural Communication in the Nursery
- **Case Study C:** Long-distance Baby
- **Case Study D:** Developing Midwifery Education Sessions
- **Case Study E:** Using the Tools as a Methodology for Honours Study

All five describe the ways in which midwives in Adelaide and rural areas adapted and used the MTWT patient journey mapping tools in South Australia. The Improving Aboriginal Patient Journeys Study Leader, Dr Janet Kelly, worked with each midwife individually 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. She also adapted a previous case study into an education package.

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

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

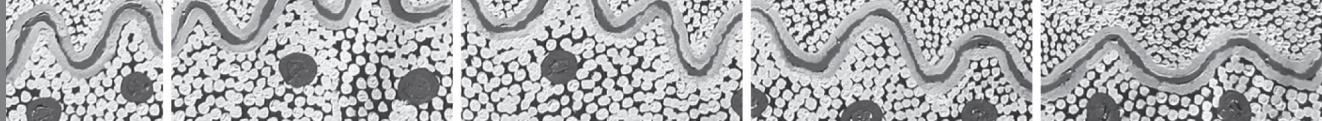
The purpose of these case studies is to:

- provide examples of how the patient journey mapping tools can be adapted and used to highlight gaps and strategies in care for Aboriginal mothers, their babies and families.

Case Study A describes how an Aboriginal Family Birthing Program team involving a midwife and Aboriginal Maternal and Infant Care (AMIC) workers used the tools to map a woman's recent maternity journey in order to reflect on what happened for her and to debrief together. Case Study B shows how the tools were adapted to produce a one-page communication brief for nursery staff. Case Study C presents the journey of a woman from a remote area before AMIC workers were available in that location, and Case Study D explains how the tools can be used for education sessions. Case Study E discusses how a midwife from a regional location used the tools in her honours study for analysis and to develop evidence for change.

Key identifying factors in each patient journey 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 *Stage 3 Improving Aboriginal Patient Journeys—Workbook (Version 1)*. 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 midwives involved, please contact them directly:

- **Case Studies A and B:** Paula Medway, Midwife, SA Health, at E: Paula.Medway@health.sa.gov.au
- **Case Study C:** Debra Miller, Aboriginal Patient Pathways Officer/Aboriginal Liaison Officer, Ceduna District Health Service, at E: debra.miller@health.sa.gov.au
- **Case Study D:** Monica Lawrence, Senior Lecturer, Indigenous Health (Nursing, Midwifery, Medicine, Allied Health, Public Health), Poche Centre for Indigenous Health and Wellbeing, Flinders University, at E: Monica.lawrence@flinders.edu.au
- **Case Study E:** Lisa Catt, Midwife/Educator, Women's and Children's Hospital, at E: lisa.catt@health.sa.gov.au.

The Patient Journey Mapping Process

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

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

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

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

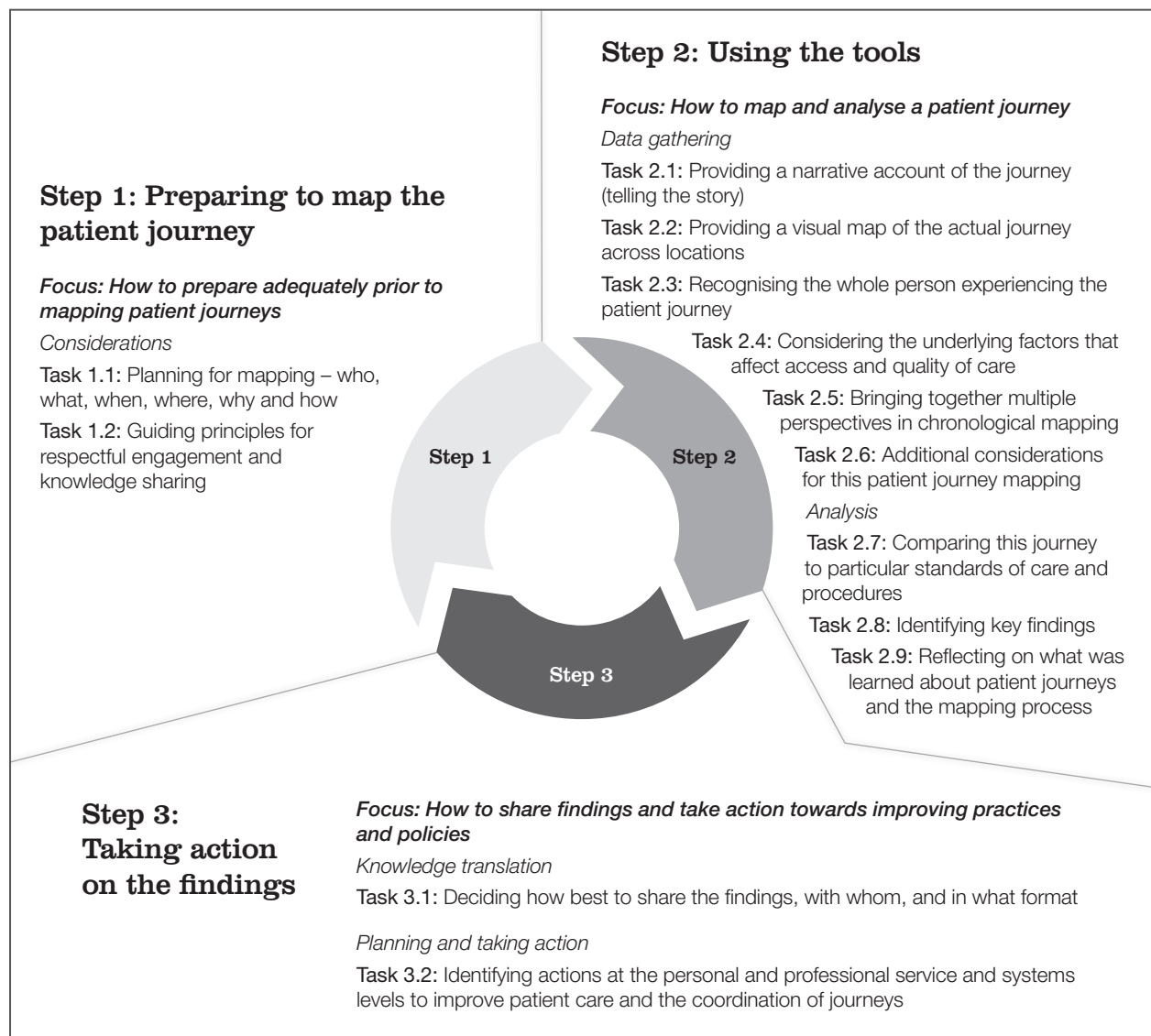


Diagram 2: The process of using the Aboriginal PJM tools – an overview

Case Study A: Debriefing by the Aboriginal Maternal Infant Care Team

Authors: Paula Medway and Janet Kelly

Who was involved in the mapping?

Paula Medway has worked as a midwife in South Australia and the Northern Territory in hospitals and remote locations. In 2013 Paula was working with the Aboriginal Family Birthing Project (AFBP) at the Flinders Medical Centre (FMC). Her role involved supporting Aboriginal women and their families, and working in partnership with Aboriginal maternal infant care workers. The FMC provides maternity, nursery and neonatal intensive care for women and their babies predominantly from South Australia and the Northern Territory. Women with threatened miscarriage, premature labour or other health complications may travel from rural and remote areas to the FMC and remain in Adelaide for days, weeks or months.

Paula became involved in Stage 3 of the MTWT project and was interested in exploring how the mapping tools could assist with improved communication and cultural safety.

The focus of this case study

This case study describes the use of the patient journey mapping tools for debriefing, and for then communicating concerns regarding patient care and support from one staff group to another. This use of the tools was developed by the midwifery and Aboriginal maternal infant care group at a major city hospital.

Step 1: Preparing to map the patient journey

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

Paula and the AMIC workers had been considering how best to use the tools. Soon after, they supported a woman and her baby who came to their unit from a rural location with an emergency admission and an extended stay for the baby in the nursery. During this time, many things happened in their physical, personal, family, social and cultural lives. Fortunately, both the mother and baby survived, but the mother experienced very difficult times both within the hospital, with her own health, birthing and healing, and with family and social circumstances. The AFBP staff were aware of the myriad of complexities and supported the woman as much as possible. However, at the same time, some of the other hospital staff made assumptions and judgments about the mother's situation and actions without knowing or considering the exact circumstances and what was happening for her. Following these events, Paula and the Aboriginal workers sat together and wrote the woman's journey using the first three tables of the mapping tools that were developed at the time. They did this as a way to make sense of what had happened, both for the woman and between the woman and various staff members.

This case study has been heavily de-identified to protect the privacy of the mother and baby involved.

Task 1.2: Guiding principles for respectful engagement and knowledge sharing

The AFBP was embedded in Aboriginal preferred ways of engaging during pregnancy, birthing and postnatal care. These guiding principles were incorporated into the mapping processes. Paula worked closely with Aboriginal women and their families, and Aboriginal and non-Aboriginal staff, bringing together different perspectives and increasing cross-cultural understanding.

Step 2: Using the tools

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

A narrative account was written as the midwife and AMIC workers came together and shared their knowledge of the woman and baby's journey. Each staff member had worked closely with them at different times, attending to different circumstances, including other staff responses to the woman and her baby. The journeys are not told in detail here to protect the privacy of the woman and her baby. The focus here is ways of using the tools for debriefing, rather than focusing on the woman and baby's detailed journeys.

A young pregnant Aboriginal woman from a rural location was flown to Adelaide for emergency admission. During her pregnancy she had experienced some health complications that were attended to by her regional health centre, but now she was experiencing early labour and needed an emergency caesarean section. The mother experienced some postnatal complications and the baby was in the nursery for some weeks. The young woman had difficulty securing accommodation; there are no hostels near the FMC, and other hostels across Adelaide were full. She was uncomfortable living in a nearby caravan park by herself, and had little personal funds for transport. Walking was

difficult for her due to her physical complications. She arranged to stay with extended family some distance across the city, but events occurred that made this option unsuitable and another option was unavailable. It was often difficult for her to get to the nursery in time to meet the specialists.

At the same time a family member at home became very unwell, and she felt acutely the distance between them. The AMIC and Aboriginal liaison staff supported the young woman through these complexities as best they could with the few resources available to them. Some other nursery and midwifery staff were less aware and less understanding and at times made judgments about why the young woman was not with her baby in the nursery.

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

No visual map was used at this time

Task 2.3: Recognising the whole person experiencing the patient journey

The AMIC team began by considering the young woman and what was happening for her in all aspects of her health and life, and recorded these in Table 1. The staff knew these details from working closely with the young woman. Together they were able to provide a comprehensive account of what was important for this person.

Case Study A – Table 1: Dimensions of health

| Dimension of health | Situation | |
|--|---|--|
| | Local community | City/regional hospital |
| Social and emotional wellbeing | | Very stressful hospitalisation |
| Family and community commitments | Family in regional area | Death in the family – cannot return home for funeral No hospital or hostel accommodation available Was to stay with extended family but unable to at the last moment due to social reasons Has to travel vast distances every day to visit baby |
| Personal, spiritual and cultural considerations | Strongly connected to family and community | Feels a long way from home Separated from family and community by distance |
| Physical and biological | Uneventful first pregnancy until early labour | Antenatal complications with labour, and postnatal complications Emergency caesarean section Baby in nursery – mother staying in Adelaide with family and in hostel Walking long distances uncomfortable |

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

The underlying factors that impacted on this woman and her baby were identified. Table 2 was adapted to add planned actions, and who took the actions, so that this table could more clearly identify staff responses.

Case Study A – Table 2: Underlying factors

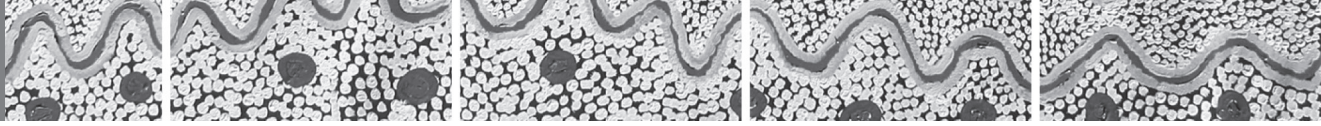
| Underlying factor | Impact of location and access | | |
|------------------------------------|--|--|---|
| | Issues/factors | Planned actions | By whom |
| Rural and remote/city | From regional area Staying in Aboriginal hostel – travel by bus or with family | Support mother and baby | Antenatal, labour ward and nursery staff, AMIC and ALOs |
| Impact of illness or injury | Underlying health concern (diabetes, cardiac, renal) | Good coordination of care | AMIC midwife |
| Language and communication | English second language | Consider phone interpreter for consent | Nursery staff, AMIC and ALOs |
| Financial resources | No card, no money Fill out form for Centrelink | Centrelink | AMIC worker arranged |
| Cultural safety | Uncomfortable in nursery | Additional support by Aboriginal staff | AMIC and ALOs |

Task 2.5: Bringing together multiple perspectives in chronological mapping

The AMIC team mapped the mother and baby's journey, adapting the column headings in Table 3 to reflect this maternity journey and adding a row for the baby.

Case Study A – Table 3: Multiple perspectives

| Perspective | Antenatal care | Trip to city | Delivery surgery | Postnatal and nursery | Discharge/transfer | Trip home | Follow-up |
|---|--|------------------------|--------------------------------|--|--|------------------------------|------------------|
| Mother's journey | Some health complications, cared for at regional health centre | Threatened miscarriage | Emergency caesarean section | Postnatal complications Baby in nursery, need to stay in city | To home community | Via bus | AMIC program |
| Baby's journey | | | Delivered by caesarean section | Prematurity requiring nursery care | | | |
| Family/carer journey | Supportive in local community | Unable to accompany | | Contact by phone City family able to support in only limited way due to other factors | | | |
| Patient priorities, concerns and commitments | Healthy pregnancy | Safety | Safe delivery of baby | To heal For baby to be healthy Staff/service support To have somewhere safe to stay and be able to visit baby often | To get home safely | Long trip Baby care needs | Supportive care |
| Health services and priorities | Local health service | Good emergency care | Successful delivery | Physical care of mother and baby | | | |
| Service gaps | | | | Responding to other health, social, financial, emotional needs | | | |
| Responses to gaps | | | | AMIC ALO Social workers Some staff need communication and cultural safety skills update | Transfer of information from city to country | | AMIC |



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

The AMIC team considered what had happened for this woman in view of the support and understanding offered by staff for the many complexities in her journey and her life at the time. They then compared the AMIC and ALO responses and general staff responses, using the AMIC program guidelines as standards of good care. Of concern was the lack of cultural and personal safety this young woman experienced in staff interactions.

Task 2.8: Identifying key findings

The AMIC team summarised five key findings.

1. This woman had a very complicated health care journey – many complexities (other than physical) were not recognised by many (non-Aboriginal) staff.
2. Opportunities for support and relationship building were overlooked.
3. The young woman felt judged by many staff members and was very uncomfortable in the nursery.
4. There was no suitable accommodation near to the hospital.
5. Staff need to become more aware of what is happening for patients, and the impact of their own interactions.

Again, these have been de-identified to protect the privacy of the woman and baby involved.

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

The AMIC team found that using the tools was a useful way of bringing together all of their experiences in supporting this woman and baby. It enabled them to make sense of what had happened, and to identify the most concerning key aspects. They decided it was a useful debriefing tool. It was also a communication tool, enabling them to record the aspects and gaps of this woman's care that they wished to convey to other staff.

Step 3: Taking action on the findings

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

The group decided that Paula would take this case study to the unit manager to highlight the situation for this woman and baby, and to highlight the missed opportunities for staff to support her better.

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

At a unit level, Paula and the Unit Manager planned to implement changes in staff awareness and training, and to focus on providing higher levels of culturally safe care.

The issues related to accommodation and transport were relayed to the hospital and regional administration to add to the existing body of knowledge about the shortage of appropriate accommodation in the southern area of Adelaide.

Case Study B: Improving Cultural Communication in the Nursery

Authors: Paula Medway and Janet Kelly

Who was involved in the mapping?

Paula Medway has worked as a midwife in South Australia and the Northern Territory, in both hospitals and remote locations. In 2013 Paula was working with the Aboriginal Family Birthing Project (AFBP) at the Flinders Medical Centre (FMC). Her role involved supporting Aboriginal women and their families, and working in partnership with Aboriginal maternal infant care workers. The FMC provides maternity, nursery and neonatal intensive care for women and their babies predominantly from South Australia and the Northern Territory. Women with threatened miscarriage, premature labour or other health complications may travel from rural and remote areas to the FMC and remain in Adelaide for days, weeks or months.

specifically by staff in the neonatal ward to provide background to one baby's home situation, family and community. The baby's mother was from a remote area in the Northern Territory and was transferred to this Adelaide metropolitan hospital for a premature birth, with a family member as an escort. Both mother and escort had returned to their remote community, but the baby remained in the nursery, under the care of the nursery staff.

Paula needed a succinct summary that could be placed at the end of the baby's cot for nursery staff to read during shift changes.

The AFBP was embedded in Aboriginal preferred ways of engaging during pregnancy, birthing and postnatal care. These guiding principles were incorporated into the mapping processes. Paula worked closely with Aboriginal women and their families, and Aboriginal and non-Aboriginal staff, bringing together different perspectives and increasing cross-cultural understanding.

The focus of this case study

This case study shows how the Aboriginal PJM tools were adapted for a specific purpose – to provide a single-page information sheet for staff in the nursery about a baby's family and culture and how best to contact the baby's family if required. This case study does not follow each of the steps of the Workbook. Rather, it demonstrates how the tools can be used for other purposes.

Step 2: Using the tools

Paula and Janet considered the information that Paula needed to convey, and which of the tools would best provide this information in a succinct way in a single page that could be placed at the end of the cot or in the front of the case notes.

An adapted version of Table 2, with an added action/strategy column, was devised. Case Study B – Table 1 is heavily de-identified to protect the privacy of the mother and baby. Asterisks denote where identifying information has been removed.

Step 1: Preparing to map the patient journey

Paula was interested in adapting and using the mapping tools to assist nursery staff in Adelaide to better understand the personal and cultural context of some of the patients. She was asked

Case Study B – Table 2: Underlying factors

| Underlying factor | Impact of location and access | | |
|------------------------------------|--|--|--|
| | Issues/factors | Actions and strategies | Who |
| Rural and remote/city | <p>Baby is from *, one of the homelands near *, Northern Territory, approximately *km * of Darwin and *km west of *</p> <p>These are very remote places that are isolated and accessible only by air in the wet season</p> <p>The baby's parents are [names] and they are very traditional Yolgnu people who prefer to stay at their outstation rather than in the bigger community of *</p> | <p>Paula can source a map and some pictures of the home community if staff would find this helpful</p> | <p>* (CSC Aboriginal Maternity Models of Care) is happy to help in any way, ph (office) or m * for assistance</p> |
| Impact of illness or injury | <p>Baby was born at * weeks gestation and his * health issues stem from his prematurity</p> | <p>Ongoing care from specialist Doctors, Midwives and nurses</p> <p>Transfer to Darwin Special Care Nursery at Royal Darwin Hospital (Ward 6B) when appropriate</p> | <p>Neonatal Unit</p> |
| Language and communication | <p>The primary language spoken at * is *, a dialect of *</p> <p>* is widely spoken in the * area, but there are many different dialects</p> <p>Both parents speak limited English</p> | <p>* clinic can assist in finding the appropriate person to give consent if required</p> <p>They will also be responsible for ensuring the consent is informed i.e. interpreted correctly</p> <p>Consider phone interpreter to assist with consent process</p> | <p>* clinic number: (08) *</p> <p>* outstation phone box: (08) (Keep in mind that sometimes you might get someone picking up the phone here that doesn't speak English well)</p> <p>* Primary School: (08) * – sometimes this is the only phone that works in this community</p> |
| Financial resources | <p>Registration and Centrelink papers</p> | <p>Ensuring paperwork is complete</p> | <p>Aboriginal maternal Infant Care worker * arranged Centrelink form and Birth Registration papers when * (mother) and * (escort) were still in Adelaide</p> |
| Cultural safety | <p>Baby will be separated from its family until discharged from FMC</p> | <p>* (Mother) has given consent for staff or volunteers to give cuddles where possible</p> | <p>* Aboriginal Family Birthing Program and some of the Aboriginal Health/Liaison Workers happy to help out with this</p> |

Please note – there is no Table 1: Dimensions of health in this Case Study.

Staff from the nursery reported back to Paula that they found the information sheet very useful and referred to it often. There were a lot of midwives from overseas working in the nursery who did not have an understanding of the community, culture or extremely remote location that this baby came from.

Paula reflected that adapting and using the tool for this specific task was a relatively easy process because she had already used the tool for another purpose and was familiar with it. She found it was a useful way to 'package' the knowledge she had about remote communities and provide the information the baby's mother had shared with her in conversation over the previous week.

Paula reflected that it would not have been as culturally appropriate to sit down and ask these questions directly; rather, it was more culturally respectful and safe for the information to be exchanged in conversation once a relationship had been built and/or through conversation with escorts (family members) and Aboriginal staff members if the mother felt uncomfortable talking with staff directly. It was also important that the information was written in a culturally respectful manner to avoid assumptions and stereotyping.

This tool became an effective way for experienced practitioners or those who had worked closely with the mother to communicate information to other staff.

Step 3: Taking action on the findings

Paula worked with the AMIC team, other midwives and the unit manager to find ways to improve cultural safety and communication between staff, mothers, babies and their families.

Case Study C: Long-distance Baby

Authors: Debra Miller and Janet Kelly

Who was involved in the mapping?

Debra Miller is an Aboriginal woman from the Kokotha/Mirning tribal groups from the Far West Coast of South Australia. She has worked as an Aboriginal Patient Pathway Officer (APPO) since July 2009, then as a Senior Aboriginal Health Worker in Oak Valley Health Service for nine months and since October 2013 has returned back to Ceduna District Health Service in the APPO/ Aboriginal Liaison Officer (ALO) position that has just received further funding until June 2016.

A lot of Debra's work has been around patient journeys and supporting patients to travel away for medical treatment in metropolitan and other hospitals. Finding funding to support patient travel, accommodation, transport etc. has been quite difficult at times, especially for pregnant women and children as there are not a lot of funding and support services available for them to access.

Aboriginal Patient Pathway Officers were created as part of the Council of Australian Government's (COAG) Close the Gap funding to provide support for rural and remote patients who need to travel for health care. Unfortunately, most APPO positions in both metropolitan and rural and remote locations are no longer funded, meaning that a network of APPOs no longer exists.

Debra has been involved in the MTWT project from the beginning of Stage 1, sharing the challenges and barriers for remote area patients and strategies used by the staff to support them.

The focus of this case study

This case study follows the journey of a woman who lives in a remote area, and travelled to a regional town and then a regional city for the birth of her baby. She was confused about why she had to travel to a regional city to birth, and was concerned about the health of her baby who had low birth weight. The importance of Aboriginal services and staff to support her in her journey is highlighted.

Step 1: Preparing to map the patient journey

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

During Stage 1 of the MTWT project, Janet travelled to rural and remote areas to talk to patients about their journeys. One woman who had recently had a baby agreed to be interviewed and for her story to be mapped in more detail to highlight the complexity. This story was considered for the *Study 4 – Complex Country Aboriginal Patient Journeys report*¹ in Stage 1, but was unable to be completed in time. During Stage 2 and 3 midwives have been asking for a case study example and this case study was used.

¹ J. Kelly, B. Pekarsky, J. Dwyer, T. Mackean, E. Willis, J. Glover & M. Battersby 2011, *Managing Two Worlds Together: Study 4—Complex Country Aboriginal Patient Journeys*, The Lowitja Institute, Melbourne.

Task 1.2: Guiding principles for respectful engagement and knowledge sharing

Care was taken that patients had informed consent whether to be interviewed. Local Aboriginal health and support staff told patients about the project and if people were interested in being involved they told Janet and she then met the patient at a time and place of their choice, and ensured informed consent was obtained prior to the interview. Janet also sought permission from this woman to speak to the local community midwife to clarify certain aspects of her care. This case study has been purposefully de-identified to protect the woman's identity. The community numbers in many remote areas are small, and to name her community and details of her journey would identify her.

Step 2: Using the tools

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

An Aboriginal woman in her thirties lives in a very remote homeland and ended up birthing her baby in a different regional hospital to the one she originally intended. Her two daughters were being cared for by other family members in South Australia and she had been visiting them and making her way back to the same hospital that she had birthed her last baby, when her car broke down. She stayed nearby with extended family and then went to the local clinic for an antenatal appointment. Another appointment was made but she did not, or could not, attend.

When she was near the end of her pregnancy, she went to the hospital thinking she would birth there, but was told she could not, and she was unclear about the reasons for this. (Staff in separate interviews explained that they were a low care facility and without three antenatal visits, women cannot birth there.) The woman was booked onto the public transport bus and transferred to a larger regional town and a Step Down Unit some hours away. She describes sneaking onto the bus and hiding her pregnancy as she did not think they would accept such a heavily pregnant woman travelling.

She stayed in the Step Down Unit for a few days until she went into labour, when she transferred to

the hospital. During her labour she was attended by a midwife and student nurse who were supportive. She asked to be able to sleep the rest of the night and for staff to give the baby a bottle, which occurred, and an Aboriginal worker brought her baby to her in the morning. She was very happy with this arrangement.

The woman describes sharing a room with a white woman who she found 'a bit racist' and she made complaints to staff and the white woman was moved to another room. She said most staff were 'OK' but some staff, both Aboriginal and non-Aboriginal, she found 'a bit off putting'. She felt that it took staff longer to respond to her bell than to the bell of non-Aboriginal patients, and so she 'didn't bother ringing the bell anymore'. After two days she was discharged and moved back to the Step Down Unit and a midwife visited her the next day. Her baby was underweight and she was very concerned about this; her last two babies had been much bigger. Her main concerns were not being able to birth nearer to home, having an underweight baby and feeling that she was not being well supported or given enough information, and being discharged two days after the birth.

A week later she travelled back by public bus and stayed in the Step Down Unit in a remote town, waiting until the baby put on more weight. Her discharge information had been sent directly to her remote home community, and so she and the local midwife were initially relying on her Blue Book for information. She was planning to wait until the baby put on weight, then make her way back to her car that was a couple of hundred kilometres along the highway, and to drive home over a day or two depending on the weather. Her family wanted her to fly back earlier, but she preferred to stay and make sure the baby was OK and then drive home. She said she liked staying in the Step Down Unit, saying that it was a safe place for her and her baby, that it was clean and warm, with good meals and there were extended family members also staying in the unit at the same time. She felt supported and safe there. She worried that 'the baby might get sick' if she had to stay out in town camp.

Postscript. This region has since had an AMIC worker begin who helps encourage and support Aboriginal women to have adequate antenatal care to birth locally (if low risk). This is working very well and more women are having first trimester antenatal checks and gestational diabetes checks and are birthing locally.

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

Not done in this case study.

Task 2.3: Recognising the whole person experiencing the patient journey

The women's personal and cultural priorities and needs were recorded using Table 1.

Case Study C – Table 1: Dimensions of health

| Dimension of health | Situation | |
|--|--|---|
| | Local community | City/regional hospital |
| Social and emotional wellbeing | Support of extended family and community | Is a long way from home with no escort to accompany her |
| Family and community commitments | Travelling to visit children who are staying with different relatives and then driving nearer home for birth Extended family members also staying in Step Down Unit | Transferred further away from family for birth |
| Personal, spiritual and cultural considerations | Lives with extended family and community in homelands | Disconnected from family, community and Country |
| Physical and biological | Fit and healthy pregnant woman, pregnant | Healthy pregnancy and labour |

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

There were significant underlying factors impacting at different stages of the journey. Table 2 was

adapted to enable these to be highlighted when the woman is at home, in the regional city and the regional town where she stayed on her way to and from the regional city.

Case Study C – Table 2: Underlying factors

| Underlying factor | Impact of location and access | | |
|--|--|--|--|
| | Local community | Regional city | Regional town |
| Five divides | | | |
| Rural and remote/city | Lives in very remote setting with local ACCHS services | Nearest rural hospital 1–2 days travel Nearest SA major regional hospital 3 days travel | Regional and rural town 3 days travel from home |
| Interactions with the health system | Local ACCHS with minimal services Staff speak first Aboriginal language | Local rural hospital requires antenatal contact which patient did not have/participate in, and so she was transferred to nearest regional hospital Birthed in two different regional hospitals in two states previously | A good halfway point to recover before driving home – warm, good food, safe, supported |
| Language and communication | Speaks Aboriginal English and Aboriginal language | Some communication/ language style difficulties | Can speak with family and staff easily |
| Financial resources | No or low cost to access | Has to travel vast distances with associated costs | No cost to patient |
| Cultural safety | Aboriginal specific | Mainstream services | Aboriginal specific Other extended family members staying there |

Task 2.5: Bringing together multiple perspectives in chronological mapping

The perspectives of the woman and staff in various locations along her journey were brought together in Table 3, in which negative aspects are shown in italics. Following the entire journey in this way provides a clearer explanation of the whole journey and the woman's experiences in each location.

The baby had an uncomplicated delivery and postnatal period, and so a separate row was not required. If he had stayed in the nursery longer or was transferred to a metropolitan hospital, a separate row would have been included.

Case Study C – Table 3: Multiple perspectives

| Perspective | Diagnosis/ referred to local health service | Trip to regional city | In hospital/regional centre | Discharge/transfer | Trip home | Follow-up |
|--|---|--|---|---|---|--|
| Patient's journey | Pregnant ? level of antenatal care | Private car to remote clinic Clinic car to local hospital Public bus to regional hospital | Stay in Step Down Unit until labour Transfer to hospital, birth, postnatal ward for 3 days, discharged with baby back to regional Step Down Unit | Transferred to local town Step Down Unit Staying there until baby gains weight Discharge letter sent direct to remote community | Patient will travel to her car that is being repaired and then drive 1–2 days home on remote roads alone No buses go to her home area | At local remote community with Remote Area Nurse |
| Family/carer | | | Says she didn't need carer but liked connecting with extended family staying in Step Down Unit | Daughters and family want her to go home | Family want her to fly home – but she prefers to drive | |
| Patient priorities and concerns | | Seeking birthing in local town but is transferred on | This baby underweight compared to her other babies, so wanted more information, reassurance and support from midwives Kept in contact with family by phone Staff responded quicker to the white woman's bell, so she didn't ring the bell any more Some staff alright – yell out 'I will be there soon' Aboriginal staff good Staff put baby in nursery as asked so mum could have a good sleep – felt better then | Wants to be nearer home and family | Wants to pick up car from repair garage on way home | Does not know why she was transferred out to regional town for birthing |
| Health care priorities and concerns | | Low-care facility and lack of antenatal care locally – cannot provide birthing service | Care for mother and child | No transfer or discharge letter – just Child and Youth Health blue book Local midwives helping with feeding and weight gain Step Down Unit a safe halfway point | Safe transfer of mother and baby | See Remote Area Nurse for checks |
| Service gaps and responses | Not adequate antenatal care to birth at local hospital, referred to regional hospital 7 hours away by bus | Had to catch a bus for 7 hours when 7 months pregnant and ? early labour risk | Non-recognition or response to this woman's anxiety regarding her baby It is her third baby but the other two were 'normal' body weight | ? who will track her trip home May/be APPOs | Step Down Unit is good, clean, and can keep baby free from infection, drugs, flu until he is stronger Good food and showers | |

Case Study D: Developing Midwifery Education Sessions

Authors: Monica Lawrence and Janet Kelly

Who was involved in the mapping and education?

Monica Lawrence is a Registered Nurse who has worked clinically with Aboriginal people, predominantly in cardiac care, and is now involved in teaching a core Indigenous health topic to nursing and midwifery students, allied health and Master of Public Health students at Flinders University in South Australia. Monica invited Janet to present sessions with a focus on patient journeys to student midwives.

Janet Kelly, MTWT study leader, was involved in the original interview and mapping the journey, and in providing midwifery education at Flinders University. Janet is also a Registered Midwife who has worked closely with Aboriginal women in rural and remote and city women's health services for 20 years.

Monica was involved in the first version of the mapping tools in Stages 1 and 2 of the MTWT study as a member of the Project Management Group, and in Stage 3 as a research team member. Monica's earlier work on Aboriginal people's cardiac patient journeys was integral to the MTWT project.²

The focus of this case study

This case study presents two versions of midwifery education sessions that can be easily modified to include new or localised patient journeys. Considering patient journeys and care pathways from multiple perspectives and engaging in reflective practice and cultural safety underpins this education approach.

Session 1

Preparation

Prepare/map/obtain a case study to discuss. This could be a recent local case study or one from the MTWT project.

Prepare and bring the following items to the session: copies of the patient journey story, whiteboard markers, coloured sticky labels, butchers paper (if no whiteboard), and the roles of the different people involved in the patient journey written on badges, sticky labels or slips of paper.

An example of the various roles in different sites is listed in Case Study D – Figure 1.

² M. Lawrence, Z. Dodd, S. Mohor, S. Dunn, C. de Crespigny, C. Power & L. MacKean 2009, *Improving the Patient Journey: Achieving Positive Outcomes for Remote Aboriginal Cardiac Patients*, Cooperative Research Centre for Aboriginal Health, Darwin.

| Family | Home community | Regional city | Rural town |
|--------------------------|-----------------------------------|-----------------------------|-------------------|
| Woman | Aboriginal Health Worker | Midwife – antenatal | Community midwife |
| Baby | Registered Nurse in remote clinic | Student nurse | Doctor |
| Partner | | Midwife – labour ward | Step Down worker |
| Other children | | Midwife – postnatal ward | PATS officer |
| Grandmother, etc. | | Nursery staff | Hostel staff |
| | | Midwife preparing discharge | |
| | | Doctor | |
| | | Other mum sharing room | |
| | | Hostel staff | |
| | | Bus driver | |

Case Study D – Figure 1: Role examples

Education session plan

1. Introduce the session and explain that it will involve following a patient journey and considering the journey, communication and care implications from multiple perspectives.
2. Hand out role labels and three sets of coloured sticky notes to each participant.
3. Explain that while the exercise is taking place, people are to consider three things from the perspective of the role they have been given (mother, grandmother, doctor, midwife, bus driver etc.):
 - a. What are you thinking?
 - b. What do you need to know?
 - c. Who do you need to talk to?
4. Hand out copies of the patient journey story.
5. Invite participants to read the story aloud, one person and one paragraph at a time.
6. While this is being read, the facilitator draws the journey on a whiteboard (or butchers paper), showing clearly the different locations, services available and the person's journey between and through each of these.
7. At the end of the story, look at and discuss the visual mapping.
8. Invite participants to finish writing their sticky notes.
9. Invite each participant to come up to the board and put their sticky notes in the location in which they belong and speak about the three aspects – what they are thinking, what they need to know, and who they need to talk to.
10. Facilitator then brings the discussion together, inviting participants to reflect on the key findings and what they have learned personally and professionally through the exercise.
11. Each participant is then invited to consider how they can incorporate that new learning into their practice.

Session 2

Use either the narrative in Case Study C or a local narrative (from the local region or a recent patient journey). Extract Tasks 2.3, 2.4 and 2.5 (prompt questions and tables) from 'Section 2: How to Use the Tools and Why' of the Workbook to create a small education package.

Consider or discuss with the person organising or hosting the education session if there is a specific focus you/they would like to bring to the session. For example, there may be an emphasis on communication, cultural safety, discharge planning etc. Weave this focus into the education session. Provide copies of the relevant standards and invite participants to compare what happened in this journey with care standards and procedures. Identify key findings and strategies for action to address these.

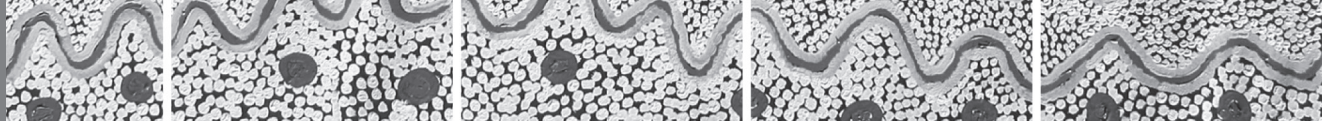
Reflections on using these education packages

The first education session is very interactive, and each time we have used it students have become very engaged in the process. Identifying the different perspectives, experiences and needs enables participants to step out of their usual

positioning within the health system and consider how each individual interacts, the importance of clear communication, and the impact of clear or unclear communication for others along the health care journey. Many participants had 'light bulb moments' during this session. Identifying distances between locations and encouraging sharing of stories between participants assists in creating a greater understanding of the complexity and challenges within some of these health care journeys.

The second education session could be a follow-on session, or individual learning, focusing on a specific standard or procedure and enabling a more detailed analysis or recognition of important aspects. In one session cultural safety standards were used in response to a recent incident that had occurred.

Another option to develop education is to encourage students to work with a mother in the clinical practice and map her patient journey (with appropriate permissions).



Case Study E: Using the Tools as a Methodology for Honours Study

Authors: Lisa Catt and Janet Kelly

Who was involved in the mapping?

Lisa Catt is a midwife who has been working in a regional setting and recently conducted honours research about the experiences of Aboriginal women being transferred from a rural midwifery-led collaborative care model to a metropolitan tertiary obstetric model. Lisa works closely with Aboriginal Maternal Infant Care (AMIC) workers as part of the Aboriginal Family Birthing Project (AFBP) at the Murray Bridge hospital. She also works part-time in the Women's and Children's Hospital midwifery education team as an education facilitator for metropolitan AMIC students.

Lisa became involved in Stage 3 of the MTWT project when she was seeking to map the women's journey for her study.

The focus of this case study

This case study explored whether the mapping tools could be effectively used as a research methodology for an Honours study. Possible benefits of using patient journey mapping to create and analyse a person's journey story (narrative), as well as drawing themes from interview discussions generally (thematic analysis), were considered. Examples of the mapping and journey stories are not detailed here; rather, we suggest people obtain Lisa's honours thesis "*The experience of Aboriginal women transferred from rural midwifery-led collaborative care model to metropolitan tertiary obstetric model – A Case Study*" and/or contact Lisa directly to discuss.

Step 1: Preparing to map the patient journey

Lisa and Janet met to discuss patient journey mapping and whether the tools could be used for honours-level study, and how best to approach this. Careful consideration was given to ethics and to the extent to which each woman's story would be presented. Identifying or private aspects of stories were not included in the narrative or the tools, and each woman approved the final version of her journey mapping before the thesis was completed (member checking). Lisa was the midwife caring for the women, as well as the researcher. Only retrospective journeys were mapped (and therefore Lisa was no longer a significant care provider), and the invitations to participate were given via the AMIC workers, with assurances that participation or non-participation would not impact on present or future care.

The exact location of the study and each woman's home community are not identified. Any potentially identifying aspect was discussed in thematic analysis (which brought together all three women's experiences) rather than in individual journey stories. Lisa was very aware of the trust the women gave in becoming involved in this study and sought to honour this. Lisa also decided not to name the city hospitals; rather, the focus was on identifying gaps and working with staff and management to address them.

Step 2: Using the tools

Lisa conducted three interviews and analysed them for themes. She then used the mapping tools to map each journey story separately. The tools at the time consisted of the first three tables in the Workbook – Table 1: Dimensions of health, Table 2: Underlying factors, and Table 3: Multiple perspectives. Lisa used each table and

identified the need for prompt questions in order to understand what each table signified. She found that it worked best for her to use each interview to fill out the three tables and then write the narrative. The next step was to compare the findings of the thematic analysis and the mapping tools/narrative.

Lisa found that using both thematic analysis and journey mapping enabled different and similar issues to be identified. There is something very powerful about telling a person's journey story in the context in which it happened. The mapping tools also provide a succinct summary of the key aspects and gaps, providing a unique way of packaging and sharing the information with busy clinicians and support staff. Lisa drew the significant factors that occurred in each journey and identified possible actions for improved quality and continuity of care.

Four key themes arose.

1. Experiences – safety, disappointment, depersonalisation, anxiety, loneliness and stress.
2. Support systems – distance, transport, accommodation, finances and kinship.
3. Health systems – cultural safety, clinical competency, biomedical care, institutional processes and coordination of services.
4. Communication – reliability, respect and confidence.

Step 3: Taking action on the findings

Lisa listed seven key recommendations for action involving hospital staff, the AFBP, metropolitan hospital policies and procedures, and state health support of patient journeys and improved transfer of care.

On the final day of writing her thesis, Lisa attended a meeting in which the South Australian Women's and Children's Health Network committed to embed the AFBP within its health service irrespective of COAG funding. The network proposes to provide services to women who come from rural and remote areas so that they can be included in and supported by AFBP with an allocated AMIC worker as the primary care giver in a collaborative model.

Lisa's research was an effective means of developing evidence-based research regarding key issues and possible solutions. It also provides key journey stories that can be used for education of staff and students. It could have implications for quality improvement; if women's maternity journeys were mapped again in six and 12 months' time, the introduction of new policies and practices could be evaluated.

About the Authors

Janet Kelly

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

Paula Medway

Midwife, Flinders Medical Centre, SA Health

Debra Miller

Aboriginal Patient Pathways Officer/
Aboriginal Liaison Officer, Ceduna District
Health Service

Lisa Catt

Midwife/Educator, Women's and Children's
Hospital

Monica Lawrence

Senior Lecturer Indigenous Health, Poche
Centre, Flinders University, previously Acting
Regional Manager, Aboriginal Family Clinic,
Southern Adelaide Local Health Network



the
Lowitja
Institute

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

The Lowitja Institute

PO Box 650, Carlton South
Vic. 3053 AUSTRALIA

T: +61 3 8341 5555

F: +61 3 8341 5599

E: publications@lowitja.org.au

W: www.lowitja.org.au

