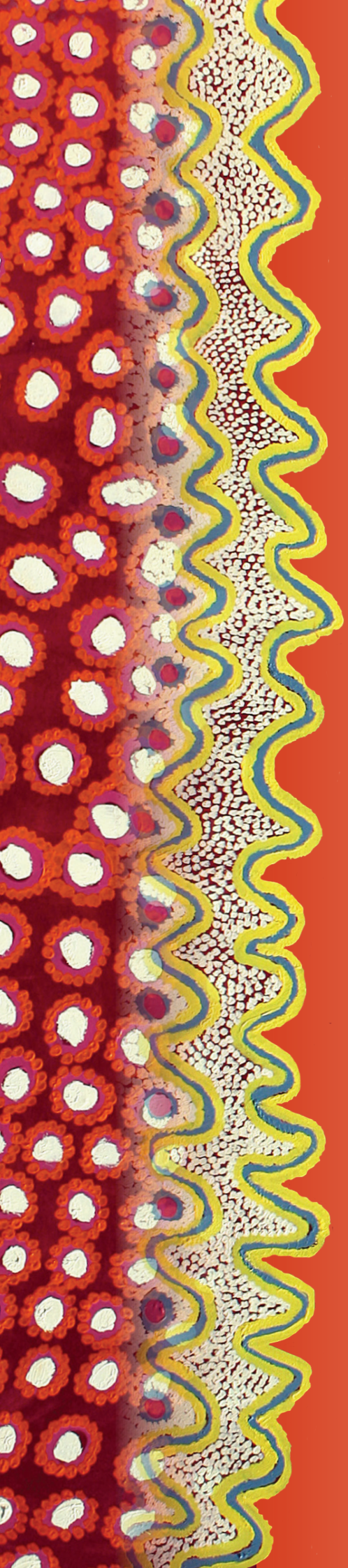

Managing Two Worlds Together

Stage 3: Improving Aboriginal Patient Journeys—
Rural and Remote Sites Case Studies

Janet Kelly
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Debra Miller
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Kym Thomas
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Cover Artwork:

Kuntjanu – Mingkiri Tjuta Tjukurpa (Marsupial Mouse Dreaming)

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

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Flinders UNIVERSITY

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

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

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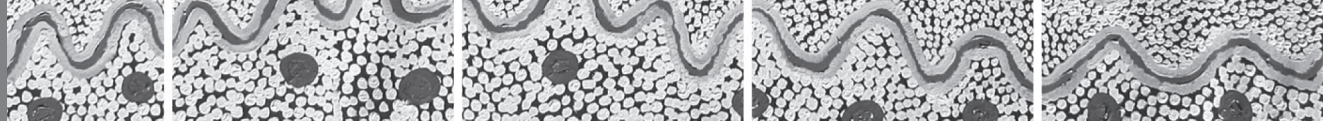


The Managing Two Worlds Together Project

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

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

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

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

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

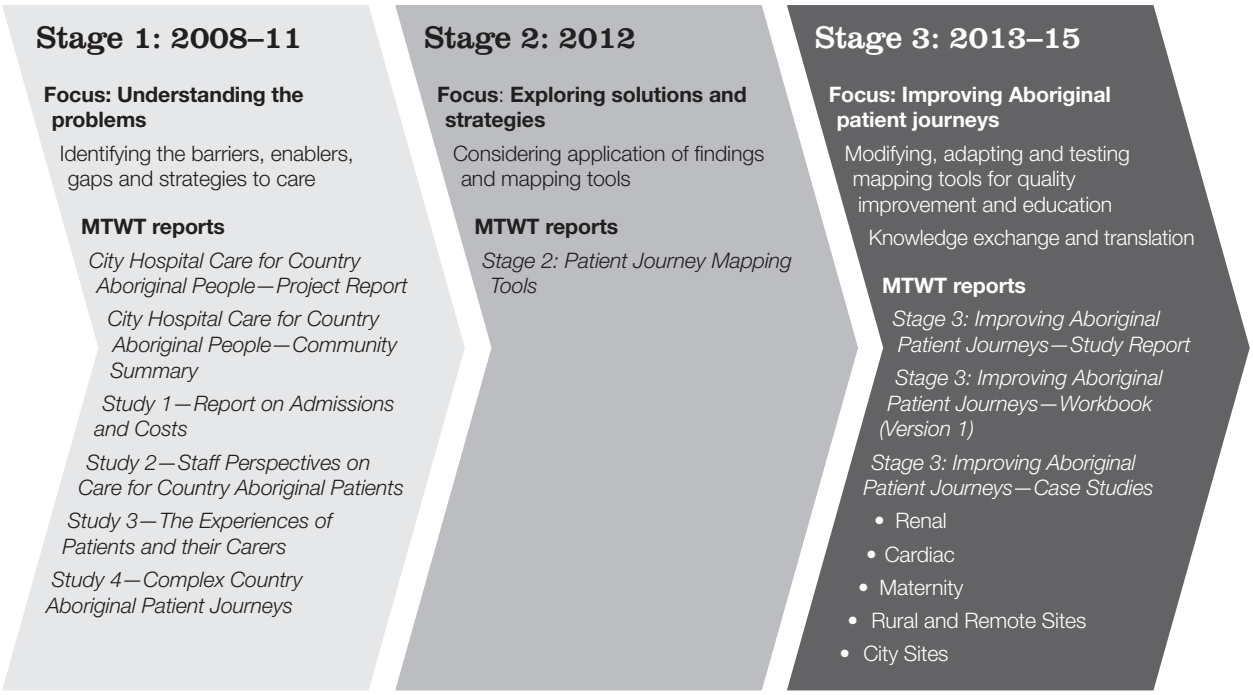
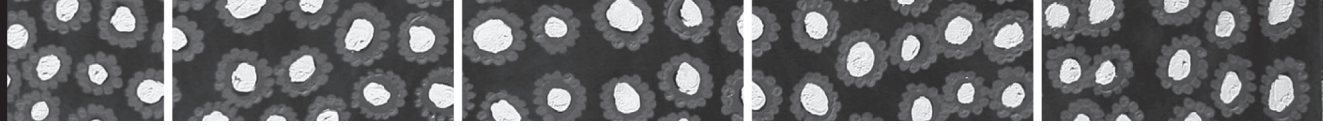


Diagram 1: The three stages, focus and outcomes of the Managing Two Worlds Together project



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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
IAPJ	Improving Aboriginal Patient Journeys
MTWT	Managing Two Worlds Together
PJM	Patient Journey Mapping
UAC	Umoona Aged Care

Terminology

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

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

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

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

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

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

About the Rural and Remote Sites Case Studies

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

Three case studies from rural and remote sites are presented in this report:

- **Case Study A:** Umoona Aged Care
- **Case Study B:** Oak Valley
- **Case Study C:** Mental Health Mapping, Port Augusta.

All three describe the ways in which rural and remote area staff adapted and used the MTWT patient journey mapping tools for use with and for local Aboriginal people and communities.

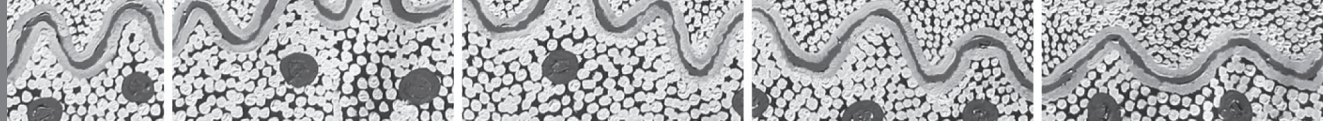
The purpose of this report is to:

- provide examples of how a set of patient journey mapping tools can be adapted and used in aged care and in Aboriginal community-controlled health services
- illustrate how the tools can be used for continuous quality improvement and education to improve communication, coordination and collaboration within and across aged care and health services
- highlight the cultural needs of Aboriginal Elder residents who need to attend specialist health services.

Case Study A provides details of how a remote aged care facility used the tools to map an unsuccessful patient journey and identify strategies to improve future resident journeys. This case study follows the format described in the Workbook and in Diagram 2. Case Study B illustrates that sometimes mapping new journeys is not the most appropriate approach; instead, adapting existing electronic case notes and forms based on staff experiences of gaps in communication may be more suitable. Case Study C discusses how the tools were adapted to support service mapping and the development of a task force for suicide prevention.

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*. The Workbook, Study Report and the four other Case Studies are available at: www.lowitja.org.au/lowitja-publishing.



Contact details

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

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- **Case Study A:** Sonia Mazzone, Executive Officer, Umoona Aged Care Aboriginal Corporation, at E: eo@uacac.com.au / PO Box 347, Coober Pedy SA 5723 or T: +61 8 8672 5605
- **Case Study B:** Debra Miller, Aboriginal Patient Pathway Officer/Aboriginal Liaison Officer, Ceduna District Health Service, at E: debra.miller@health.sa.gov.au
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- **Case Study C:** Bronwyn Ryan, Early Intervention Mental Health Project Office, Country Health SA, at E: Bronwyn.Ryan@health.sa.gov.au
- **Case Study C:** Kym Thomas, Manager, North West Regional Residential Rehabilitation at E: kym@adac.org.au
- **Case Study C:** Lee Martinez, Mental Health Academic, Centre For Regional Engagement University Of South Australia at E: Lee.martinez@unisa.edu.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.

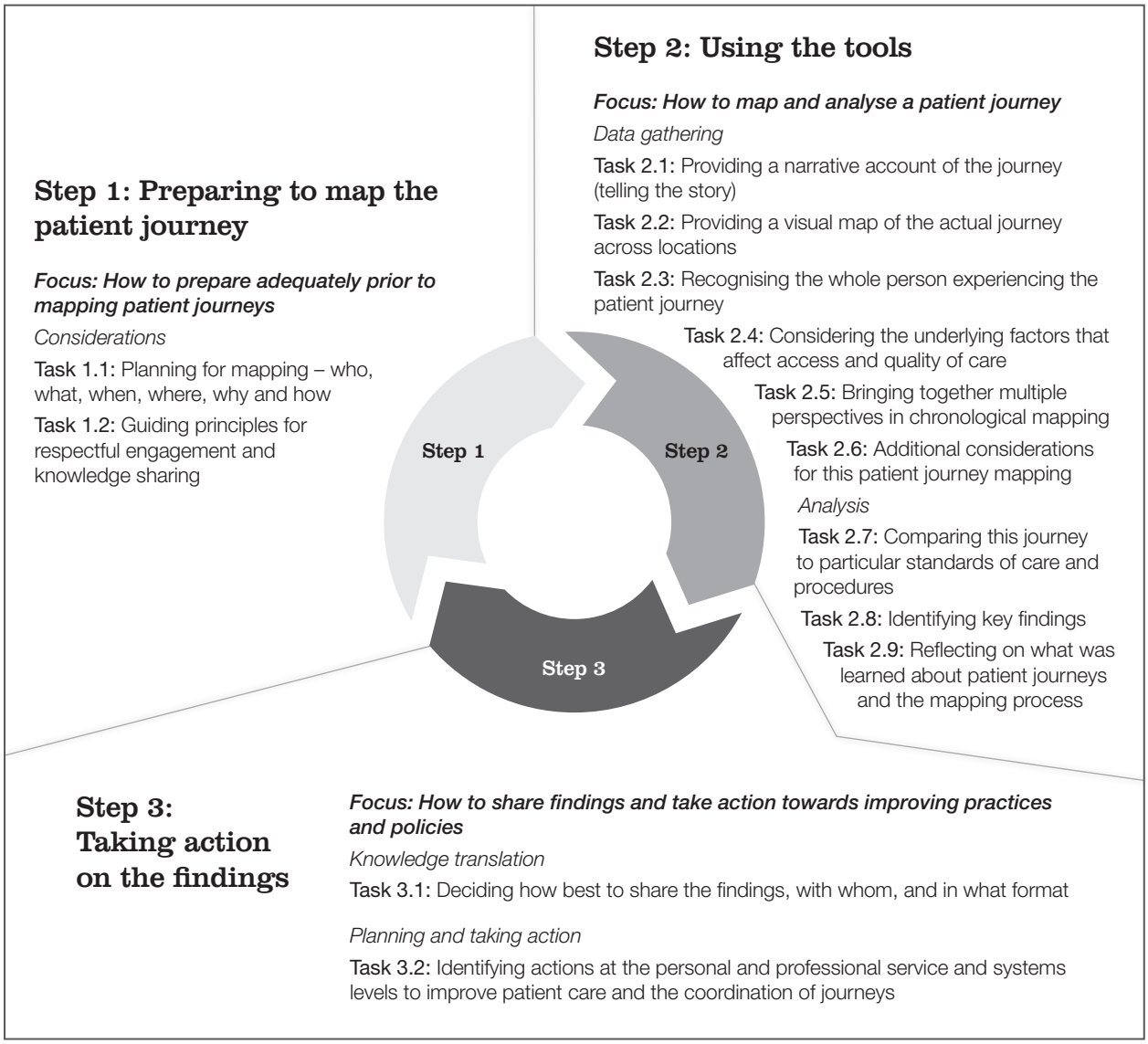


Diagram 2: The process of using the Aboriginal PJM tools – an overview

Case Study A: Umoona Aged Care

Authors: Jacene Wiseman, Sonia Mazzone and Janet Kelly

Who was involved in the mapping?

Jacene Wiseman is a Business and Innovation Consultant who works with not-for-profit organisations including Aboriginal, CALD (culturally and linguistically diverse) and mainstream providers to build their capacity through corporate governance training, mentoring and support, strategic and business planning, continuous quality improvement, workforce development and service model evaluation, in addition to operational and organisational systems development, performance and reporting.

Jacene has worked with Umoona Aged Care (UAC) Corporation since 2008, is based in Adelaide and was able to meet the research team regularly during planning and writing up of the Case Studies. She also liaised with UAC management, board, family, staff and residents about the mapping, what focus it should take and how it should be written up for a wider audience.

Sonia Mazzone is the Executive Officer of UAC and has extensive experience in business and facility and service delivery management. Her focus is on culturally safe, responsive and person-centred service delivery for Aboriginal people from Coober Pedy and surrounding areas. Sonia works closely with the Directors and Elders of UAC and the community and is therefore a key conduit in not only implementing but also identifying appropriate sources for accurate information on cultural safety practices and family engagement within the Aboriginal community.

The Elder women involved in this study were residents of UAC, and one was also a director of the organisation. They met as a focus group in Stages 1 and 2 of the Managing Two Worlds Together project and gave personal and cultural approval for the study to take place in Coober Pedy.

The staff of UAC became involved in the mapping process and the testing of the tools. Kim O'Donnell is an Aboriginal researcher at Flinders University and research team member of the IAPJ study. Kim and Janet Kelly visited UAC together three times to meet with the Elder women and staff, to discuss the Managing Two Worlds Project and to identify the level of involvement that they would like to have. Kim brought specific cultural and Aboriginal health research knowledge to the study and enriched the relationship building process.

Jacene, Sonia and the Elder women invited Janet to return and help map a patient journey in response to the complexities that occurred and the extensive effort UAC needed to ensure that residents did actually receive the health care they required in Adelaide city hospitals. This resulted in the 'Case Study 1 – Flying blind' in the MTWT Stage 2 report[1] that outlined two patient journeys. Over time, the Elders asked that the first journey, that of Mrs Riley, be re-written in more detail naming Umoona Aged Care as key participants and naming Mrs Riley who requested, as did her family, that she be identified.

Focus of this case study

This case study discusses the experiences of an Elder woman seeking eye care for blindness and travelling to Adelaide for surgery, which was then cancelled due to an issue with informed consent. Tragically, this woman never received the needed surgery and died without ever regaining her sight. The impact of this experience and outcome for the woman, other residents and staff of the aged care facility was significant, and led to future health care journeys being significantly planned and resourced by UAC, despite the fact that it did not receive additional funding to provide this support.

1 J. Kelly, J. Dwyer, B. Pekarsky, T. Mackean, E. Willis, M. Battersby & J. Glover 2012, *Managing Two Worlds Together: Stage 2—Patient Journey Mapping Tools*, The Lowitja Institute, Melbourne, pp. 6–15.

Step 1: Preparing to map the patient journey

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

Known as Tjilpi Tjuta Kanyini, (translated as 'Caring for our Elders'), UAC is an Aboriginal-controlled organisation managed by a Board of Directors elected by the members of the organisation from the local community. It is located in the remote desert town of Coober Pedy (574 kilometres and approximately six hours by road from the nearest regional specialist services in Port Augusta and 852 kilometres and approximately 10 hours by road or two and a half by air from emergency and specialist surgical services in Adelaide). Elders, staff and family have extensive experience of the challenges faced when coordinating and undertaking any trip to attend appointments or emergency transfers to these facilities.

Tjilpi Tjuta Kanyini clients and residents are part of the unique Aboriginal cultural community of Central Australia. Throughout the Elders' lives, their ancestors have taught them how to survive on the land through traditional practices of hunting and gathering of native wildlife and bush tucker. Today they continue to share this knowledge with the next generation by travelling to Country and teaching these skills and amazing stories.

As contemporary Elders with a nomadic past they represent the strongest connection to these traditions including connection to Country. This connection is vital in ensuring they maintain their responsibility to family and communities across a number of areas surrounding Coober Pedy, including Oodnadatta, Anangu Pitjantjatjara Yankunytjatjara Lands, Alice Springs, Kingoonya, Port Augusta and some surrounding stations.

The Elder involved in this patient journey mapping was a senior Elder resident and had also worked at UAC. This Elder had not experienced planned care episodes in city hospitals and was positioned to share both the cultural context and systemic challenges encountered in the journey as she navigated the health system. The Board of Directors is proud of its service and has endorsed the sharing of knowledge and the lessons learned based on a snapshot of these experiences. The Board believes it may help other health care providers better understand the needs of Aboriginal people when receiving care and contribute to increased cultural understanding, respectful engagement, improved health outcomes and more positive experiences for Aboriginal people.

Task 1.2: Guiding principles for respectful engagement and knowledge sharing

All activities in discussing, preparing, mapping and reporting on this case study were based on respectful collaboration between the research team and UAC residents, board members, family members and staff. Joint decision making and approval regarding draft and final versions of the journey mapping and case study descriptions were key elements of this trust-based activity.

Step 2: Using the tools

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

Mrs Riley's journey

> *Umoona Aged Care Aboriginal Corporation is an Aboriginal-specific, purpose-built residential facility located in the desert town of Coober Pedy. Port Augusta is the closest regional health service and is the point of referral for specialist diagnostic and treatment requirements. Adelaide is approximately 10 hours away by road or two and a half hours by air and is the point of referral or on-referral for more complex needs, specialised services or surgical interventions.*
>
> *UAC is co-located with the Coober Pedy Hospital and Health Service and at the time of this study UAC provided daily care for high- and low-care residents and overnight care for low-care residents only. Residents with high-care needs were cared for overnight by the hospital. As such, residents resided at the hospital but were UAC clients. The care models and approaches differed significantly, with inherent tensions between mainstream and culturally specific approaches evident.*
>
> *Mrs Riley was a recipient of this sometimes convoluted (complex or interdependent) service model. UAC staff cared for her during the day and settled her at night, and the hospital responded to her overnight care needs. UAC*

also provided meals, outings, coordination and attendance at medical and visiting specialist appointments at the local Aboriginal Health Clinic, and provided support to maintain her independence and wellbeing, including trips to Country to reconnect with land and culture.

As a 78-year-old traditional Aboriginal woman, originally from the Western Desert area, she understood basic English but spoke little as it was her second language. As a senior Elder, hers was a respected voice within community with a significant role in passing on stories, teaching and healing. Due to her deteriorating eyesight, she was referred to a visiting ophthalmologist. An Aboriginal Aged Care Worker, who spoke language, accompanied her to this appointment along with her daughter who was also her carer. Following discussions, she was referred to a city hospital for further investigation and possible eye surgery.

While waiting to attend the appointment it became increasingly apparent that she was extremely apprehensive about taking her first trip by air, staying in unfamiliar surroundings and being in the hospital where other people went but – in her experience – never returned. Her fears of the procedure were compounded by her decreasing independence, loss of confidence and her need to use a wheelchair to board and disembark the plane. The community and Elders gathered around, with lengthy conversations centred on encouragement and support for Mrs Riley and the significant changes that her increased sight would bring in retaining her independence and enhancing her cultural and spiritual wellbeing.

Knowing that understanding medical terminology and speaking English with enough fluency to attest to understanding and providing informed consent was vital, the UAC Executive Officer consulted with the ophthalmologist to determine the most appropriate way to provide the required documentation while also meeting systemic and cultural requirements. Additionally, while UAC was the cultural pivot, the hospital was ultimately the primary health care provider and needed to be informed and to approve all strategies and stages of implementation. This required significant communication between the service providers to enable a culturally appropriate response to occur.

The Executive Officer, Sonia Mazzone, also worked closely with the Registered Nurse at the local Aboriginal Health Clinic to explain the procedure to Mrs Riley, satisfy medical requirements and complete the required documentation, including written consent to the procedure prior to transfer. Sonia had also spoken to staff at the city hospital, informing them of the language barrier and Mrs Reilly's fears. It was arranged that Mrs Riley's daughter Jeannie, who had been involved in the original planning an would travel with, care for and support her during her stay, interpreting where necessary to attest to the consent already obtained. As further preparation, Sonia had consulted with and talked through the process and explained the documentation and the purpose of these documents with Jeannie. Transport to the city hospital was coordinated through the Aboriginal Step Down Service and the Aboriginal Health Clinic, with Sonia acting as liaison. (These services provide non-medical services for Aboriginal people from rural and remote communities who travel to Adelaide for acute services care, including transport and accommodation coordination.)

With much trepidation, Mrs Riley completed the flight and the two wheelchair transfers required and was met by the Step Down bus. Unfortunately, another passenger requiring transport was a wadi (an older male Aboriginal person) from another part of Country. Under culture, it was inappropriate for Mrs Riley to travel in the same vehicle with this person but there was no other option due to the timeframes involved. Both Mrs Riley and her daughter were extremely distressed at this breach of cultural protocol and on arrival had difficulty explaining to staff why they were upset.

Following admission, the assigned anaesthetist conducted a pre-operative consult with Mrs Riley. Jeannie translated during this consult, including affirming Mrs Riley's consent to the surgery. However, concerns were raised about the validity of the consent, saying that without an accredited interpreter, the patient could not give informed consent. On this basis, permission to proceed was refused and the planned surgery was cancelled.

Very distressed, Jeannie contacted Sonia, who then tried to contact the ophthalmologist to explain that an interpreter had been used, full consent was obtained prior to travel, and that Jeannie was next of kin and had the legal capacity to sign, with her mother's permission, on her mother's behalf. Before this contact could be made, Mrs Riley's scheduled surgery had been cancelled, she was removed from the operating list, her place was allocated to another person and she was informed she would be placed on the waiting list for surgery at a later date. Mrs

Riley and Jeannie remained at the hospital until transport and flights could be arranged for their return home to Coober Pedy and UAC.

They flew back without the operation being done. Mrs Riley was very frustrated and angry and when interviewed for this project had very poor vision. To identify and redress any potential barriers or miscommunication, the Executive Officer made a commitment to Mrs Riley to personally escort her when the time came for her to have the re-scheduled operation. Mrs Riley refused to fly or repeat the experience for fear of the same outcome and died before regaining her sight.

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

[Optional]

Task 2.3: Recognising the whole person experiencing the patient journey

We began by identifying what was important for Mrs Riley.

Case Study A – Table 1: Dimensions of health

Dimension of health	Situation	
	Local community	**City hospital**
Family and community commitments	Respected and acknowledged as a Senior Elder in community Involved in community decision making and consultation with a high degree of interaction	Separated from family
Social and emotional wellbeing	Used to a lot of talking, sharing and interaction with other Elders and staff	Isolated, doesn't know, and can't communicate effectively with staff
Personal, spiritual and cultural considerations	Is a very traditional woman with a strong commitment to spirituality and religious practice Performs Nunkgari (spiritual healing)	Away from family, culture and country Feels displaced
Physical and biological	An Aboriginal Elder woman in her late seventies, who uses a wheelchair	Limited mobility

We then considered the underlying factors that significantly impacted on her access to and quality of care. Language and communication barriers and geographic distance were two major factors that were not overcome by the health system in this journey story.

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

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

Case Study A – Table 2: Underlying factors

Underlying factor	Impact of location and access		
	Umoona Aged Care	**Coober Pedy Hospital**	**City hospital**
Rural and remote/ city	Lives near homelands	Adjacent to Umoona Aged Care Facility	Long distance by road or air. Has never flown before
Impact of illness or injury Chronic or complex conditions, being acutely ill or injured	Had underlying cardiac condition	Hospital staff able to support and provide interventions where necessary	Condition may be exacerbated by underpinning fears and lack of familiarity with setting and processes
Language and communication	English is her second language and reads very little English Prefers to talk in language	Understands basic English, which is her second language. Can read some English with assistance from family/carer	Needs interpreter for informed consent
Financial resources	Limited resources	N/A	Daughter would need financial assistance during planned episode and inability to provide this will further increase potential for negative health episodes and outcomes
Cultural safety Experiences of being an Aboriginal person within a health system	Cared for by Aboriginal and non-Aboriginal staff, some of whom speak first language and share cultural background	Cared for by non-Aboriginal hospital staff and UAC staff	Staff predominantly non-Aboriginal

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 A – Table 3: Multiple perspectives

Perspective	Patient history	Usual care	Diagnosis/ referral	Trip to city hospital	In hospital	Discharge/ transfer	Trip home	Comments
Patient's journey	Deteriorating eyesight	Routine oriented – used to environment, carers and family	Visits to specialists often at short notice so limited opportunity to fully explain or prepare her for appointments and tests	Fly to city Picked up by Step Down bus	Pre-surgical decision that informed consent was not adequate and surgery cancelled	Hospital made return flight bookings	Returned without surgery	Patient returned very frustrated and angry
Timeline								
UAC involvement	Liaising with specialists, Aboriginal Health Service, collating accurate medical records, hospital ward staff, family, Step Down provider, motel accommodation, airline, financial assistance and coordinating UAC staff	Transport, carer and language support provided at medical appointments	Work with ophthalmologist to arrange informed consent process	Arrange for her daughter to accompany her and coordinate accommodation, financial assistance, transport and personal support	Jeannie rang UAC UAC tried to talk to surgeon	Jeannie felt excluded and unable to ask questions – Executive Officer became key conduit, advocate and contact person Coordination of discharge timeline and requirements provided by Executive Officer due to a lack of knowledge of available services in this remote community	Independent verification of all arrangements with Executive Officer as carer no longer confident about the information being provided	Carer felt powerless in city hospital

Case Study A – Table 3 cont...

Perspective	Patient history	Usual care	Work up	Trip to city hospital	In hospital	Discharge/ transfer	Trip home	Comments
Patient priorities, concerns and commitments	Used to travelling on land but not to cities, unfamiliar environment, difficulty moving around safely	Senior Elder, active, involved and consulted about all facets of choice, care and lifestyle	Fear of flying but also increasing loss of independence	Fear of flying Unfamiliar environment Having to travel close to older man in bus (culturally inappropriate)	Safety and respect – different care model that did not fully acknowledge cultural imperatives, safety and respect	Responsibility for coordinating and keeping everyone informed fell to Executive Officer to ensure the same message was received and understood by all persons involved	Never really settled back into independent lifestyle – loss of confidence and motivation was evident	Patient refused to travel to the city again after her previous experience
Health service priorities	Surgery	Regain eyesight and improve quality of life and wellbeing	Discussions and support from other Elders, Executive Officer explaining procedure and support needs with resident and family	Transport priority but did not factor cultural protocols and safety	Risk of litigation/ adverse outcome/ liability	Meet predetermined mainstream discharge requirements and schedules	Disappointment further compounded by fear of flying	
Service gaps	New consent to be arranged	Needed orientation to new environment as unfamiliar			Daughter not always acknowledged as carer, support person	Coordinated communication Cultural awareness and safety		Informed consent processes

Case Study A – Table 3 cont...

Responses to gaps	Resident refused any further treatment	Sharing experience with other Elders raised their concerns and fears about accessing any primary health services	Communication strategy to reinforce positive outcomes implemented Complex care and risk plans developed to identify and address issues prior to transfer	Risk assessments and planning to make the transfer as smooth as possible	Executive Officer became advocate/ carer by default Carer support provided by family or UAC staff for all trips to city appointments and procedures Family/ carers briefing now provided, access to Executive Officer and clear lines of priority of contact, communication and support now included in trip plans	Increased communication and education regarding discharge planning and remote considerations May refuse to accept transfer if discharge documentation, medication and appropriate handover not provided. Research undertaken to source a range of transfer packs that will provide a foundation for most appropriate and user-friendly format to trigger identification of information and responses to individual, cultural and service needs	Constant reassurance and contact to support the journey and provide a more positive experience	Need for improved, agreed and binding pre-admission informed consent processes Need for improved discharge planning to address remote service, resources and availability of pharmacy, aids, resources and planning for appropriately skilled staff to be available on admission

Task 2.6: Additional considerations for this patient journey mapping

Additional support needed for carer who was not used to staying alone and was not familiar or comfortable with being in the city.

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

This case study highlights that additional procedures and policies are required for informed consent to take place, even though it was organised prior to admission in this case.

Task 2.8: Identifying key issues

- The patient journey was highly stressful and of no benefit to the resident.
- Resulted in a refusal to travel for specialist care again.
- Difficult to encourage/convince next patient to travel.

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

What worked?

Building trust and working relationships – as the relationship continues, and we work together, joint decision making enables us to do further work. The case study was jointly written as shared intellectual property.

Adapting the tools

This case study identifies participants, rather than de-identifying them, at the express request of the Elders, UAC Board and the family members involved.

Reflections on patient's journey and UAC role

For a client undertaking a planned journey to access medical or health services, considerable preparation, liaison and details need to be consolidated prior to the trip. UAC implements a risk management approach by using a documented trip plan. This provides the prompts for planning and coordination including:

- method of transport fares, accommodation (and prepayment for accommodation as staff do not carry money or have access to money), fuel orders, air fares, address, map, after hours contact numbers for reception
- number of carers, travel allowance, overtime, emergency contact numbers
- resident's needs – alerts, medication, diet, clothing, toiletries, money, Medicare card, bush medicine
- family contact details approved by Executive Officer
- cultural profile, cultural safety and security.

There is a need to set up paperwork so that it works both as a care plan for UAC staff to capture health and welling needs, and as a quick 'tick and flick' sheet with identified triggers for response for wellbeing.

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 in the following ways:

- as a case study for staff education – to be used in conjunction with the Tjilpi Tjuta Kanyini 'Keeping our Culture, Caring for our Elders' DVD
- to inform the development of a transfer form that could accompany residents when they need to travel to the city for specialist care
- to assist in future journey planning.

It will be used with other services to:

- highlight the complexities of rural and remote patient journeys, and the need for improved communication, coordination and collaboration

- highlight the need for improved pre-admission and discharge planning that leads to secure and agreed pathways.

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

Jacene worked with Janet and Sonia to write a patient journey planning document/pro forma that could be used to prompt planning for known complexities. This is something that either Jacene or Sonia can often do themselves, but is difficult for new staff. Using prompts from the tools and previous journey experiences of residents and staff, and researching other forms that are currently being used by general practitioners, the Royal Flying Doctor Service etc., a new form and process is being developed.

Case Study B: Oak Valley

Authors: Debra Miller, Jo Newham 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 worked as an Aboriginal Patient Pathway Officer (APPO) from July 2009 and then as a Senior Aboriginal Health Worker in Oak Valley Health Service for nine months from December 2012 to September 2013. 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.

Jo Newham is the South Australian research officer for the ABCD project (2010–14), which aims to improve the quality of primary health care available to Indigenous people. Jo worked closely with the Aboriginal Health Council of South Australia to support its member services to implement a continuous quality improvement program. Jo also conducted research around these implementation activities to investigate the local barriers and enablers to these activities, which were then used to identify strategies to strengthen its effectiveness in South Australia.

Focus of this case study

This case study highlights that sometimes mapping journeys using the tools is not the priority or the greatest need. Instead, the experiences and findings from other patient journeys can be used to inform future journey planning, including the possibility of adapting existing electronic systems and paperwork to enable particular client information to be communicated effectively to city staff.

Step 1: Preparing to map the patient journey

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

Debra and Janet had worked together early in Stage 3 and planned to meet again to continue mapping. Debra moved from her APPO role to a Senior Aboriginal Health Worker role in the remote community of Oak Valley, and invited Janet to visit. Janet joined another colleague, Jo Newham, who was visiting Oak Valley at the same time and doing case note audits.

Task 1.2: Guiding principles for respectful engagement and knowledge sharing

Janet worked with Debra and the community to determine the most suitable time to visit, avoiding the men's ceremonies when the community and roads were closed to women.

Step 2: Using the tools

A few weeks before the planned trip, there was a change of nursing staff, and a new nurse travelled out in convoy with Janet and Jo. He was new to remote area nursing and to Oak Valley, and there were two days of intense handover by the relieving Remote Area Nurse. At the same time, many members of the community returned to Oak Valley and the clinic was very busy with adult and child health check-ups. It was impossible for Debra to be involved in the mapping, or in the case note audits, as she was helping the new nurse to get to know the clinic and the community members.

Taking a pragmatic approach, Janet and Jo pitched in and helped with the clinic activities, and in between discussed the recent barriers and enablers in patient journeys and communication between remote areas, regional centres and city hospitals that Debra had noted. One aspect highlighted was the difficulty in ensuring information about people's personal and cultural preferences was communicated clearly (for same gender care or interpreters for informed consent, for example). This may be written by the remote area clinic if there is time prior to transfer, but may or may not be read by the receiving hospital. It was not unheard of for this information to return with the patient still sealed in the envelope it was sent in.

Jo and Janet looked at the electronic case note system to see whether this could be addressed. We realised that if information about the need for interpreters and same gender care for intimate care were written into the 'Alerts and other information' section it was automatically transferred onto the front page of the patient summary and transfer information. Nursing and medical staff automatically look in this section for information about allergies and other important medical information.

Another benefit was that Debra could write this information in a case record of each local community member for the benefit of the new nurse, thus it would have an immediate positive impact.

Findings

Sometimes staff are too busy to engage with patient journey mapping, but their experiences and knowledge can be used to adapt existing paperwork and electronic health records to ensure important information is communicated between remote and city sites.

Step 3: Taking action on the findings

On return to Adelaide, Jo and Janet discussed this finding with the records manager at the Aboriginal Health Council of South Australia and explored the possibility of implementing this strategy more widely.

Case Study C: Mental Health and Suicide Prevention Mapping, Port Augusta

Authors: Bronwyn Ryan, Kym Thomas, Lee Martinez and Janet Kelly

Who was involved in the mapping?

Bronwyn, Kym and Lee all worked in the area of mental health in Port Augusta and Whyalla in regional South Australia. They attended a presentation where Janet shared findings from the Stage 2 mapping, and made a time to explore how the mapping could be used for suicide prevention and support. The local health services were looking to respond to a recent increase in suicides and concerns expressed by Aboriginal community members.

The focus of this case study

This case study discusses how a suicide case study example and service mapping were combined for discussion in health, support and community meetings to inform the development of an action plan and task force.

Background

Tragically, there were a large number of suicides in the Spencer Gulf area over December and January 2011/12. This led to widespread concern among community members, service providers, managers and policy makers.

Service providers in Port Augusta and surrounding areas wished to review the services that were available in their area, determine to the extent to which these were utilised, and develop a plan regarding prevention, crisis response and post-crisis care. They requested the assistance of the MTWT project leader (Janet Kelly) to plan and begin patient journey and service provision mapping.

There was a range of government and non-government services in Port Augusta, Whyalla and Port Pirie, as well as State-wide and Commonwealth programs, and these were coordinated to a greater or lesser extent. A draft State-wide Mental Health Care Plan had been released for comment but was not going to be in place until the end of the year. It was acknowledged there was local need for a local action plan before then.

Step 1: Preparing to map the patient journey

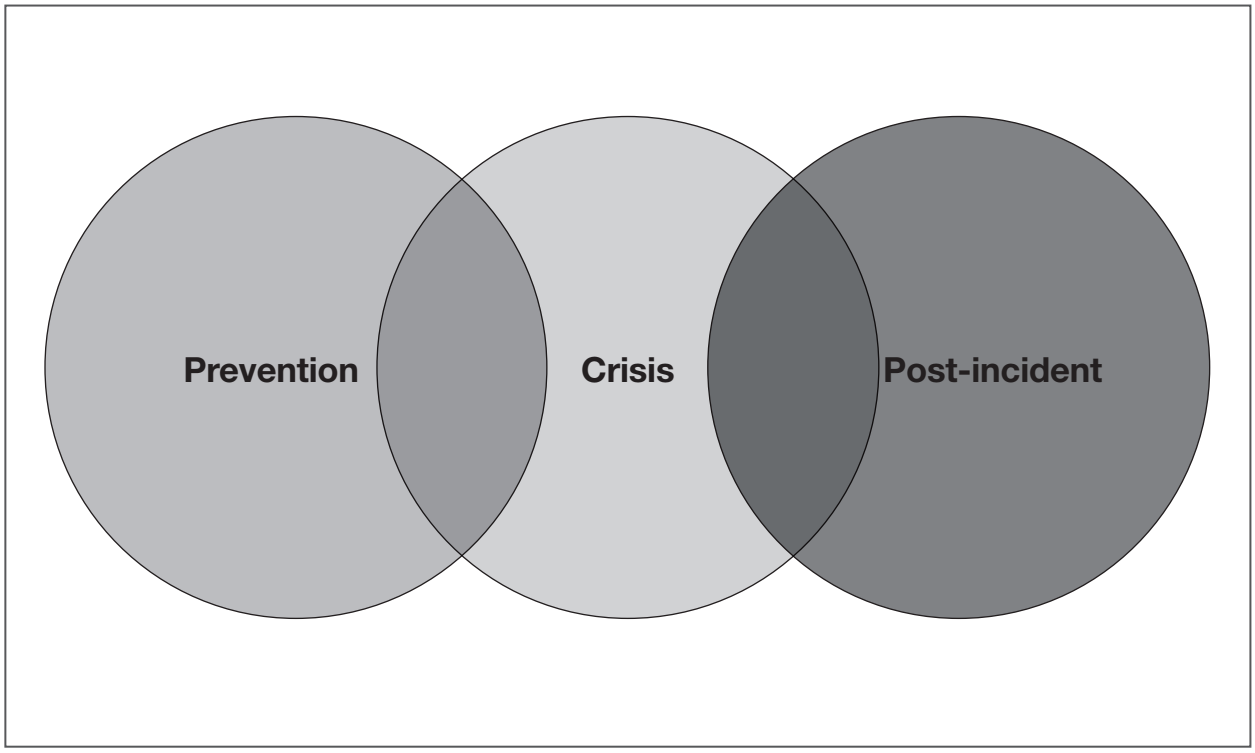
Task 1.1: Planning for mapping – who, what, when, where, why and how

Bronwyn, Kym, Lee and Janet met to discuss what form of mapping would be most responsive to the immediate need. Together we considered the benefits and limitations of mapping an actual patient journey of suicide or attempted suicide using the tools, and decided that the tools alone could not meet the need.

We decided that there was benefit in providing a ‘suicide patient journey scenario’ to centre discussion, and also to map the services and community support and resources that were available for an individual, his or her family and staff in the prevention, crisis and post-incident phases of a suicide or attempted suicide. The scenario was very carefully written with local Aboriginal people using the three tables available at the time (dimension of health, underlying factors, multiple perspectives), recognising and respecting local Aboriginal peoples’ recent experiences and tragedies.

This specific patient journey map is not shown here due to the very personal and sensitive nature of the stories of those associated with it. Rather, what we did with the case study results is discussed.

Using the findings we identified the three main areas where community services and groups could intervene. We developed a simple three-circle Venn diagram shown in Figure 3. We thought broadly about the groups and services that might be included, such as service groups, Aboriginal Elders, church groups, hospital, schools, police, health services, non-government agencies, sports clubs and social services.



Case Study C – Figure 1: A service mapping tool

Task 2.2: Guiding principles for respectful engagement and knowledge sharing

There were two main guiding principles. First, whatever was developed had to be accessible and understandable for all participants in the meetings, including community members for whom English may not be a first language. Second, this could not just be another talkfest – it had to lead to real and responsive action.

Step 2: Using the tools

We developed a strategy to progress the mapping and action plan:

1. consult with stakeholders re possible mapping and actions plan (currently in progress)
2. form a core working group
3. agree on a common goal/vision and specific tasks
4. map service availability in local areas and beyond, the extent to which they are being utilised and by whom, referral pathways and networking, and identify the gaps; include services not immediately obvious; consider prevention, crisis and post-incident services and support
5. consider mapping individual or generalised patient journeys – one where suicide prevention/ intervention worked and one where the person suicided (this may occur alongside step 4)
6. use relevant literature, policies and programs.

Step 3: Taking action on the findings

Bronwyn facilitated health service and community meetings and used the scenario and three-circle Figure 1 to map what was available locally and to focus the discussion.

Bronwyn sent an email following the meetings to share what happened. An excerpt follows:

- Yes went really well! We had representation from police/hospital/community mental health/major NGOs [non-government organisations] both Aboriginal and non-Aboriginal and community members so an excellent range.
- We mapped what people are currently doing/ where their agency does most of their work/and what the gaps are.
- We then went through the scenario and discussed in the groups who would do what in the specific situation then identified the gaps and recorded those.
- The outcome was that once everything was collated we would forward this information back to the group and meet again as a task group for further discussion on how to address and prioritise the gaps.

Next steps

This task force became very active and effective and continues to function in Port Augusta as the Suicide Intervention and Life Promotion Action Group (SILPAG), in which there is strong community ownership.

Kym, through his involvement with SILPAG and local Aboriginal men's group Males in Black Inc., was successful in a funding application to produce a DVD entitled 'Speaking the Unspeakable'. This short movie features families, friends, relatives and community service providers talking about the effect that suicide has had on them personally. Its primary role is to educate people about suicide, and it is planned for release in May 2015.

About the Authors

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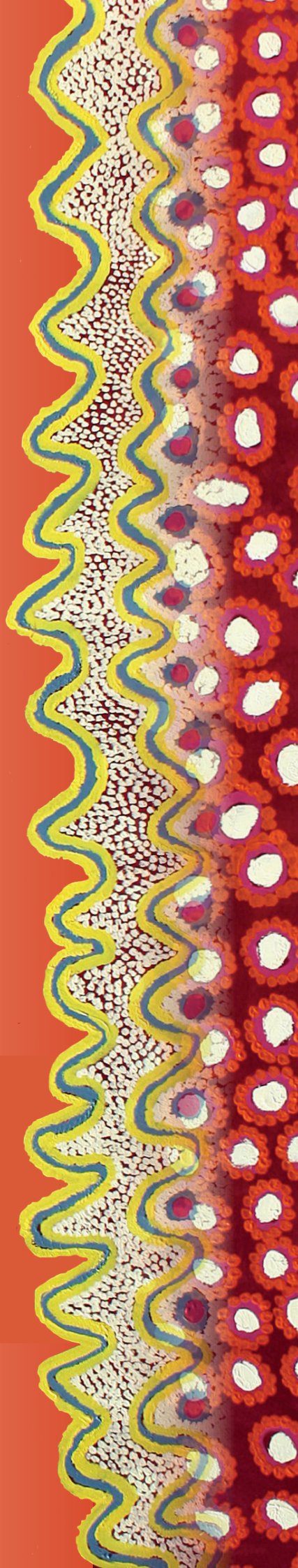

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