

## Coproducing Aboriginal patient journey mapping tools for improved quality and coordination of care

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**Abstract.** This paper describes the rationale and process for developing a set of Aboriginal patient journey mapping tools with Aboriginal patients, health professionals, support workers, educators and researchers in the Managing Two Worlds Together project between 2008 and 2015. Aboriginal patients and their families from rural and remote areas, and healthcare providers in urban, rural and remote settings, shared their perceptions of the barriers and enablers to quality care in interviews and focus groups, and individual patient journey case studies were documented. Data were thematically analysed. In the absence of suitable existing tools, a new analytical framework and mapping approach was developed. The utility of the tools in other settings was then tested with health professionals, and the tools were further modified for use in quality improvement in health and education settings in South Australia and the Northern Territory. A central set of patient journey mapping tools with flexible adaptations, a workbook, and five sets of case studies describing how staff adapted and used the tools at different sites are available for wider use.

**Additional keywords:** Aboriginal health services, action research, continuity of patient care, hospitals, patient-centred care, rural health.

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### Introduction

Many Aboriginal people living in rural and remote locations of Australia experience lengthy and complex patient journeys for both emergency and planned care. Their care pathways are often clinically complex due to a higher incidence of comorbidities, and logistically complex because of the vast geographic distances, the number of healthcare locations and extensive travel required. One Aboriginal person may interact with 50 or more health professionals as they travel from home, to hospital to home, with most of these conversations occurring in English, which may be their second or third language. Access to interpreters may not be available at some sites, and they may or may not be accompanied by family members. Aboriginal people in these situations are sometimes required to make significant and life-changing decisions while alone and a long way from home (Lawrence *et al.* 2009). In addition, patients' own priorities and commitments may or may not be recognised and respected by the healthcare professionals and services they encounter (Willis *et al.* 2010; Dwyer *et al.* 2011; Australian Government 2013).

Australia has a world-class healthcare system with publicly funded primary, secondary and tertiary care, accessible to all citizens. However, this system operates in silos, with poor interservice communication and significant coordination gaps. Generally, there are no designated health professionals or support persons to coordinate the entire patient journey from home to

hospital to home (Lawrence *et al.* 2009). Staff in rural and remote healthcare settings prepare patients for journeys as best they can, but often the exact diagnosis and treatment options depend on the results of tests undertaken while in the city. Staff in urban hospitals provide required specialist care, but may experience difficulty effectively explaining the details and options to patients. Urban staff may be unaware of exactly what health care is and isn't available in the patient's home community, making discharge planning and referral challenging (Lawrence *et al.* 2009).

In response to these challenges, the Managing Two Worlds Together (MTWT) Project was undertaken at Flinders University to identify the barriers and enablers, gaps and strategies to care, funded through SA Health and Lowitja Institute grants. This project brought together the experiences of Aboriginal patients and their families, the perspectives of healthcare professionals in a range of urban, rural and remote healthcare settings, and a multidisciplinary, cross-cultural research team. The research team initially sought to use existing patient journey models and tools to analyse four Aboriginal patient journeys to better understand the entire experience for individual patients. They considered mapping real patient's journeys from diagnosis to completion, focusing on specific conditions (Lawrence *et al.* 2009; Rolley *et al.* 2009) or adapting within-hospital care processes originally used to analyse patient flow

**What is known about the topic?**

- Aboriginal patient journeys from home to hospital are often complex involving multiple care providers and settings. Patient journeys are one of seven priority areas in the Closing the Gap program.

**What does this paper add?**

- Bringing together the perspectives of patients, families and staff into a mapping framework can enable more timely and responsive care and support strategies to be developed.

(Richardson *et al.* 2007; Ben-Tovim *et al.* 2008a, 2008b). The team also considered Wagner's chronic care model (Wagner 1998) and quality and safety frameworks (Australian Commission on Safety and Quality in Health Care 2010). However, none of these models or frameworks were able to adequately record and convey the complexities and gaps in cultural care described in interviews and focus groups, or the challenges and strategies within and across healthcare and geographic sites. It was clear that the team needed to bring together the experiences and priorities of Aboriginal patients and their families, and the perspectives of primary, secondary and tertiary care providers, Aboriginal and mainstream, in urban, rural and remote locations. Over the three stages of the project, a new framework and set of mapping tools were developed, initially to assist the team to better understand patient journey stories, and then, with the encouragement and participation of health and education professionals and managers, the tools were further developed for use in clinical practice, quality improvement and education contexts. This paper outlines the processes the team engaged in, the outcomes, and further research needs.

**Methods**

A collaborative participatory action research (PAR) approach with repeated cycles of Look and Listen, Think and Discuss and Take Action guided the project. This method was co-created with Aboriginal community women in an earlier study (Kelly 2009), informed by community-based action research (Stringer 2007). It emphasises the importance of Dadirri deep listening (Atkinson 2002), Ganma-knowledge sharing (O'Donnell and Kelly 2011), and culturally safe approaches to research (Browne and Smye 2002). The project was undertaken in three stages from 2008 to 2015 in South Australia and the Northern Territory (Table 1), with the aim of better understanding and improving communication, coordination, collaboration, and cultural safety in Aboriginal patient journeys.

*Recruitment and conduct of interviews and focus groups*

Health professional participants in urban, rural and remote locations were recruited in all three stages via flyers pinned to notice boards, email invitations passed on by ward, unit and service managers, and word of mouth. Patients and their family members were told about the research and invited to be involved by health staff in rural and remote Aboriginal health services and

hospitals in Stages 1 and 2. If interested, the patients contacted the research team, or the health staff did so on their behalf. In Stage 3, interested patients were invited to work directly with their healthcare professionals to adapt and test the tools. This recruitment occurred locally within a health service as part of internal quality improvement activities. No financial payment was given to any participant; however, transport assistance was provided to patient and family participants if required. Interpreters were offered, but not required by patient and family participants. Patients and family members and carers were also offered a choice of an Aboriginal or non-Aboriginal researcher for interviews in Stage 1; all participation was voluntary. Patients and carers were adults aged 18 years to 80 years, with approximately two-thirds being female and approximately half being from remote and very remote areas. Interviews and focus groups in Stage 1 and 2 were semi-structured, using prompts related to individual journeys and practice experiences.

Aboriginal health professionals shared both work-related and personal accounts, and these accounts were analysed separately (as staff, as patients, and as family members).

**Ethics and confidentiality**

Ethical approvals were received from the Aboriginal Health Research Ethics Committee (SA), Flinders University Social and Behavioural Research Ethics Committee, and The Human Research Ethics Committee – The Queen Elizabeth Hospital. In Stage 3, additional approval was received from the Central Australian Human Research Ethics Committee and Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research as the research included Northern Territory sites. Governance agreements were negotiated with health service organisations for all three stages.

Healthcare staff provided de-identified versions of mapped journeys to the research team, to preserve confidentiality. An intellectual property agreement enabled each staff participant to keep the version of the tools that they personally developed with the assistance of the research team, and to continue using it within and beyond the MTWT project. Evaluation of the process of developing, adapting and testing the tools, and of the tools themselves occurred both within workshops and as an integral part of the PAR process in Stage 3.

**Results***Coproducting of responsive mapping tools*

The patient journey mapping results and tools in the MTWT project were informed by extensive discussion and problem solving between Aboriginal patients and their families, healthcare professionals, managers and support workers, educators, and a multidisciplinary, cross-cultural research team (Table 1). The tools were then tested within multiple sites, ensuring their wide applicability across urban, rural and remote locations. Table 2 presents the results of the coproduction process for each of the three stages. The research coordinator shared de-identified versions of tools and emerging mapping ideas between staff participants across the different study groups (with permission), enabling shared learning and a central set of mapping tools to be developed (Fig. 1).

**Table 1. Patient journey focus, method, recruitment and results across the three stages**

	Stage 1: 2008–11 Understanding the problems	Stage 2: 2012 Exploring solutions and strategies	Stage 3: 2013–15 Improving Aboriginal patient journeys
Focus	SA Health Funded <i>Look and listen</i> Identifying the barriers, enablers, gaps and strategies to care	SA Health Funded <i>Think and discuss</i> Consider application of Stage 1 findings	Lowitja Institute Funded <i>Take action</i> Modify, adapt and test mapping tools for use in quality improvement and education
Method	Identify individual patient journey experiences Semi-structured interviews and focus groups with health professionals, patients and their carers Thematic analysis, individual patient case studies Metropolitan hospital admissions data	Discuss potential for mapping framework to be developed into tools Small action projects with health and education professionals from Stage 1	Adapting, modifying and testing feasibility and effectiveness of patient journey mapping tools with health and education professionals Individual and worksite mapping Small and large workshops
Location	South Australia	South Australia	South Australia and Northern Territory
Aboriginal patients and family participants	Aboriginal patients and their family members from five rural and remote areas  • Individual interviews ( <i>n</i> = 21)  • Focus group with senior elders in remote area (participants = 9)	Aboriginal patients and family members from two rural and two remote areas  • Interviews and co-working on patient journey stories ( <i>n</i> = 8)	Aboriginal patients and family members provided formal and informal feedback to health and education professionals at multiple sites (exact numbers not recorded by staff participants)
Staff participants	Nurses, doctors, Aboriginal health workers, liaison officers, allied health staff, coordinators, managers in:  • Five Adelaide hospitals ( <i>n</i> = 26) • Five rural and remote locations ( <i>n</i> = 34)	Nurses, Aboriginal health workers and liaison officers, coordinators and managers in:  • One regional dialysis unit ( <i>n</i> = 2) • Two city hospitals ( <i>n</i> = 4) • One remote Aboriginal aged care facility ( <i>n</i> = 4)	Nurses, doctors, Aboriginal health workers and liaison officers, coordinators, managers, educators and students in:  • Three renal sites ( <i>n</i> = 6) • Five cardiac sites ( <i>n</i> = 7) • Four maternity sites ( <i>n</i> = 4)  • Four rural and remote sites ( <i>n</i> = 7) • Four city sites ( <i>n</i> = 6)
Results	1. There are many examples of good practice, but these are not systematically implemented  2. Barriers to access lead to delayed care, or no care at all 3. Identification of Aboriginality is lacking  4. Patients' journeys are made harder by rigidities and gaps in the system of care  5. The challenges of building good communication, trust and rapport in direct care interactions are significant, for staff and patients 6. Coordination among care providers across geographical and sector boundaries is not reliable, but when achieved, benefits patients, staff and organisations	The solution and strategy most popular with staff participants in Stage 1 was patient journey mapping  Two sites requested the team to return and help them map recent patient journeys Mapping assisted Aboriginal and non-Aboriginal health professionals and managers to make sense of complex patient journeys Resulting case studies were used:  • to stimulate discussion between multidisciplinary staff  • to highlight underlying issues	Existing patient journey mapping tools require modification to accurately reflect Aboriginal patient journeys across multiple geographic and healthcare settings Health professionals, managers and educators require mapping tools that: • are co-developed to ensure they meet local and specific requirements  • can be modified to suit different patient journey types - acuity, illness, location, length • require no additional training, funding or IT support  • can be easily accessed and emailed, regardless of Internet capability

(continued next page)

Table 1. (continued)

Stage 1: 2008–11 Understanding the problems	Stage 2: 2012 Exploring solutions and strategies	Stage 3: 2013–15 Improving Aboriginal patient journeys
7. Support services are not adequate to need, cost can be a barrier	• for education and training	• are immediately available for use, rather than after research results are published
8. Hospital systems are not flexible enough for country patients	• to link patient journey preparation to existing policy documents and charts	Resulting tools map journeys in a structured and organised way and enable the complexities to become manageable in three ways: 1. Makes the complexity of the entire journey visible 2. Organises the journey for analysis and response 3. Enables the critical steps, gaps and responses to be highlighted, thus providing a focus for targeted action by health professionals
9. Complexity is predictable for many patients, but not planned for	• as an audit tool to follow a patient's experience in hospital	
10. There is a lack of operational policy and programs that might support healthcare providers to build in reliable responses to complex patient journeys	• to record reasons why patients self-discharge against medical advice  • to evaluate patient care	

Table 2. Tool development in each stage

	Stage 1: 2008–11	Stage 2: 2012	Stage 3: 2013–15
	<i>Look and listen</i> Develop an analysis framework	<i>Think and discuss</i> Consider if the framework could be used for patient journey mapping	<i>Take action</i> Modify, test, adapt tools in a range of health and education sites for Continuous Quality Improvement & education Test the effectiveness of the tools:
Aim and focus	Analyse individual patient journey experiences so that they: • are told in the context in which they occur • consider the whole person entering the journey • identify the barriers and enablers that affected their journey	Map entire patient journeys:  • from home to hospital to home • across multiple geographical and healthcare sites • from the perspective of the patient and their family members, and staff in urban, rural and remote settings • identify different priorities, gaps in care, possible strategies	• for use in multiple sites • for a range of conditions, and journey types  Develop:  • a central mapping tool  • flexible adaptations • a workbook Work with each participant to identify reason for mapping, approach and use of results
Research team response and methods	Appropriate framework not found in literature search  Framework developed incorporating five dimensions of health (Australian Indigenous Doctors' Association and Centre for Health Equity Training Research and Evaluation 2010) and five factors that shape the care journey (Dwyer <i>et al.</i> 2011)	Work with Aboriginal patients and family members and health professionals in urban, rural and remote areas to map journeys	Invite Stage 1 and 2 participants plus other interested health professionals and educators to be involved in co-development of tools  Group participants into five small studies: renal, maternity, cardiac, rural and remote sites, city sites
Tool	• Narrative – summarise patient's story into a single page (Emden 1998)	• Third table incorporating chronological elements of journey and multiple perspectives (as told by patient, family and staff)	• Individual case studies explaining participants' reasons for mapping, modifications, adaptations, and presenting new version of tools
Format	• Identify critical needs and conditions of care using two tables derived from the framework	• Case study format developed (involving the narrative and all three tables)	• Central workbook that explains how to map journeys

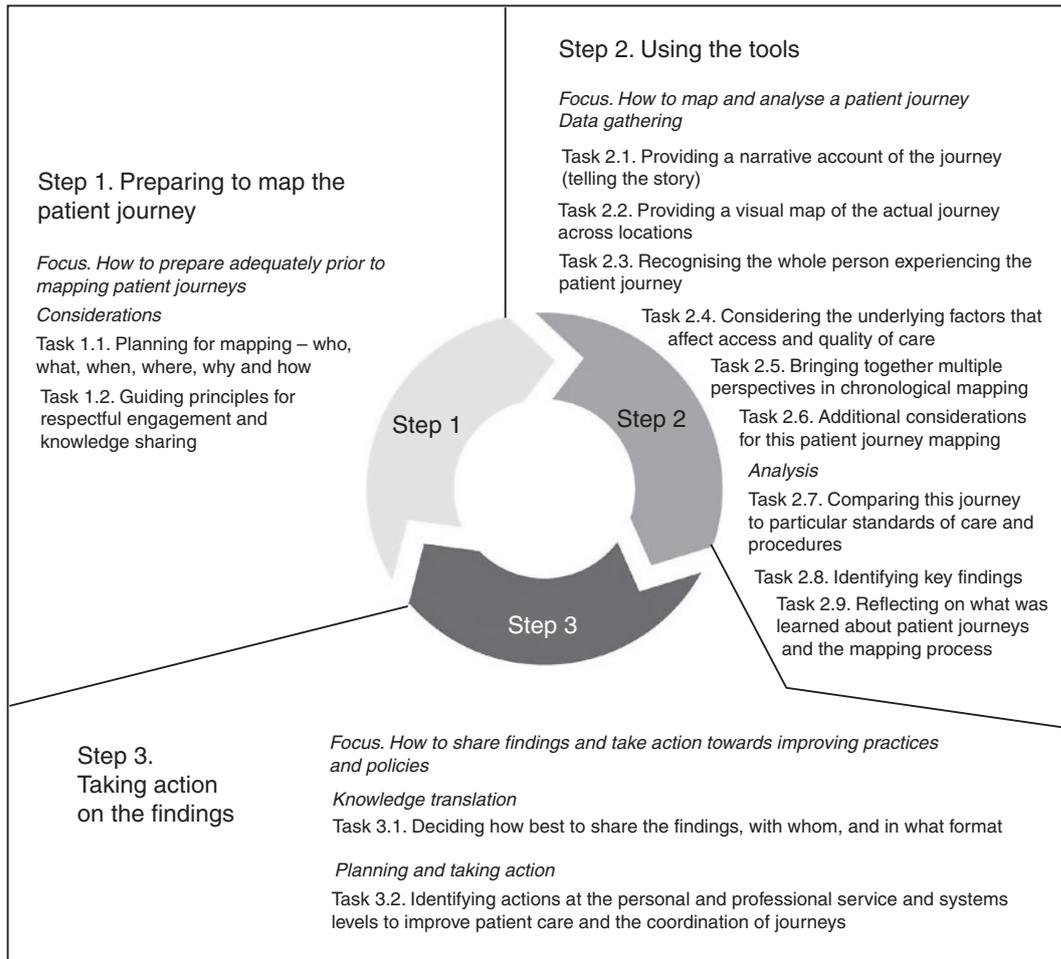


Fig. 1. Patient journey mapping tools, as described in the Managing Two Worlds Together (MTWT) workbook.

### Ease of use

Participants stressed that any tools needed to be simply formatted, accessible to a diverse range of people with different skill levels and information technology support, be easily transferable via email, and adaptable to include different journey types, levels of complexity and priorities. The tools were therefore developed in Microsoft Word and Microsoft Excel (Microsoft Corporation, Redmond, WA, USA).

### Knowledge translation

Writing the journeys into case studies enabled the issues, strategies and mapping processes to be more effectively shared with colleagues, managers, key stakeholders and a wider audience. A central workbook was developed, drawing from all case studies and mapping activities across the project. It was designed with a writable PDF section, a set of guiding principles, trigger questions, tables and diagrams. The reports and workbook remain available on Flinders University and Lowitja Institute websites at <http://www.flinders.edu.au/medicine/sites/health-care-management/research/mtwt/> and <https://www.lowitja.org.au/lowitja-publishing> (accessed 24 November 2016).

During workshops and discussions, the need to diagrammatically present the entire patient journey across primary and tertiary care, and compare individual patient journey results to standards of care was identified. A range of approaches were trialled, with the most successful included in the workbook (Fig. 2). This version is representative, and can be further refined to reflect specific illnesses and actual journeys. In this figure, the vertical axis combines two concepts: Risk and Standard (referring to variations from standard care).

### Participant reflection on the process of co-developing tools and mapping journeys

A benefit of co-producing patient journey mapping tools ‘from the ground up’ is that the tools inherently make sense, not only to those who developed them, but also to their colleagues. Staff participants, particularly nurses and Aboriginal staff, identified that previously when they noticed a gap in service delivery, they filled it themselves as best they could, or tried to raise an issue with management, but were often unsuccessful (Dwyer et al. 2014). The patient journey mapping tools have assisted them, and their colleagues, to identify practice issues, communicate them effectively, and seek strategies at personal, professional,

## Systems response, risk and standards of care

Patient journeys and outcomes depending on journey risk and system response

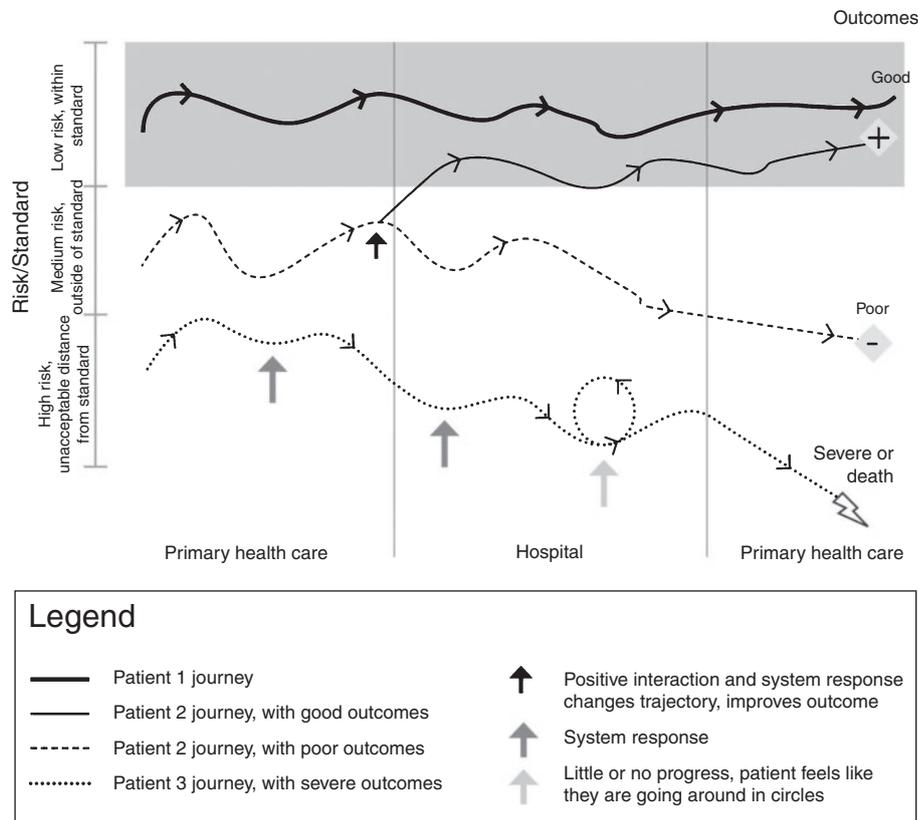


Fig. 2. Comparison of three different patient journeys to standards of care.

organisation, and system levels. The structured framework of the tools assisted them to make sense of what was happening, and to articulate this clearly to others. For example, renal nurses have used the tools to highlight issues of Friday night discharges for rural patients, and used the case study as evidence to change policy and practice. They have also mapped end-of-life journeys and strategies for assisting patients to get home in time, in a supported manner (Kelly *et al.* 2016). Midwives and Aboriginal family birthing practitioners have mapped journeys and written case studies that highlight support and coordination issues, and presented these to unit managers (Kelly *et al.* 2015a). A remote Aboriginal aged care facility used the mapping tool to highlight funding and communication issues for their board and government funders, and mental health practitioners have used the tools to plan a community-wide response to suicide (Kelly *et al.* 2015b).

The barriers to using the tools were generally two-fold: (1) finding the time within busy clinical and education schedules; and (2) initially grasping the concepts involved in patient journey mapping.

The mapping tools continue to be adapted and used in even more diverse healthcare, research and education settings. They have been adapted to map the journeys of Aboriginal patients

experiencing cancer, cardiovascular events, and burns. The outcomes of each stage are detailed in Table 2.

### Discussion

Previous patient journey mapping tools and processes have focused on healthcare redesign within an organisation (Ben-Tovim *et al.* 2008a) or on individual disease processes such as cardiac care (Lawrence *et al.* 2009). Few tools have the capacity to map a diverse range of Aboriginal patient journeys from the perspective of Aboriginal patients and their family members, and the healthcare professionals caring for them within and across several healthcare sites. It is necessary to bring all of these perspectives together to highlight the complexity of journeys and the need for quality cultural care, which includes quality clinical care. The National Aboriginal and Torres Strait Islander Health Plan 2013–2023 highlights the need for ‘coordinated, culturally appropriate services across the health system, including primary health care, hospital care and aged care’ in order to improve both patient journeys and health outcomes for Aboriginal and Torres Strait Islander people and their families (Australian Government 2013, p. 14).

The MTWT mapping tools focus centrally on Aboriginal patients, following their journey across the health system,

enabling a primary focus on the person rather than the system. This enables healthcare professionals and support staff to identify where they and their services fit in relation to the person's journey, and what they need to do to ensure continuity of care. This approach could also be applied to other patient care journeys more broadly.

The processes of development and testing in this project affirmed the applicability of the framework and tools as assessed by participants in health services; and highlighted the importance of ease of use and adaptation. Stage 3 reinforced our findings from Stages 1 and 2 regarding the need both to consider the full complexity of care journeys for this group of patients and to separate out elements and processes in a way that renders them amenable to action for quality improvement (Emden 1998; Australian Indigenous Doctors' Association and Centre for Health Equity Training Research and Evaluation 2010).

### Conflicts of interest

The authors declare that they have no conflicts of interest.

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