



Final Report

Patient-led Participatory Action Research Project

Patient-led pathways to cultural understanding and better patient-nurse relationships in renal care

August 2017



Artwork

The artwork presented in the header of this report was completed by co-researchers, Margaret Heffernan, Eileen Bonney, Margaret Smith and Irene Nangala throughout the Project workshops. Drawing and colouring in the workshops were encouraged to support a relaxed environment where people could focus and learn.

Suggested citation

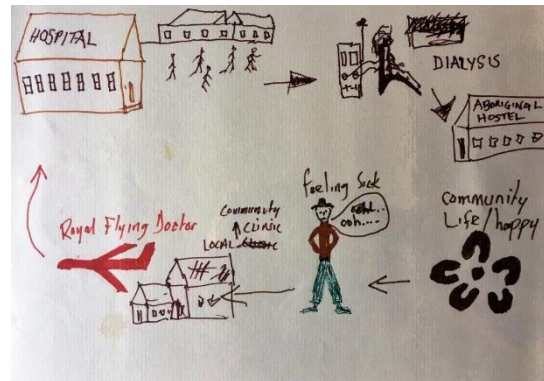
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For more information about the Project, including video interviews with some of the nurse participants, visit www.menzies.edu.au



Forward

Very sadly in March 2017, we lost our team member, Mr Nelson. We acknowledge and pay respect to his work as a co-researcher on this Patient-led Participatory Action Research Project. He was a great thinker and communicator and was very passionate about creating change to improve the lives of Aboriginal people on dialysis. He was very proud of the work of this Project in developing better relationships between Aboriginal people and renal nurses. We dedicate this Report in his honour.



**Mr Nelson's drawing of his personal story of life before and after starting dialysis, 2017.
Reproduced with the permission of his family.**

We gratefully acknowledge the vision of the Central Australian Renal Voice (CARV) consumer group who articulated their desire to have a role in teaching renal nurses about their culture and strengthening understanding and relationships between people on dialysis and the health professionals who provide their care. This Project was created from CARV's vision and led by its members.

This Project was funded by the Northern Territory Primary Health Network (NT PHN). We are grateful to NT PHN not only for funding the Project but also for their flexibility in supporting a variation to the original contract to enable us to develop a patient-led participatory action research project.

We acknowledge the support of all our partners in this Project: Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT), Fresenius Medical Care, Central Australia Health Service (CAHS) and the Poche Centre for Indigenous Health and Well-Being NT. Without the engagement and support of these partners the Project would not have been possible.

Special thanks to Kerry Taylor for her enthusiasm and contribution to the Project in participating in the workshops and in providing a friendly and welcoming environment at the Poche Centre for us to hold many of our workshops.

Finally, we want to gratefully acknowledge the leadership, generosity and teaching of the Aboriginal co-researchers – Irene Nangala, Margaret Heffernan, Eileen Bonney, Margaret Smith and Mr Nelson – and the willing participation and openness to learn of nurses who worked with us – Caroline Hombarume, Cassandra Holland, Colin Paine, Kara Page, Dean Oldfield, Wendie Hume, Mary Jane Ferrer and Ruth Queja. This Project is a testament to your desire to make a difference for Aboriginal people on dialysis in Alice Springs.

Samantha Togni on behalf of the Menzies School of Health Research Team: Gillian Gorham, Georgia Robinson and Bianca Gonos
August 2017



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Contents

1	Executive summary.....	1
2	Introduction	6
3	Project objectives	6
4	Background and context	7
4.1	The reality of kidney disease in Central Australia	7
4.2	Cultural competence and safety in health care	8
4.3	Beginnings of the Project.....	8
4.4	Emergence of the Patient-led Participatory Action Research (PAR) Project	9
5	Patient-led Participatory Action Research (PAR) Project: approach	10
5.1	The PAR approach.....	10
5.2	Key features of our approach.....	13
6	What we did	15
6.1	Project establishment.....	15
6.2	Iterative learning cycles.....	17
6.3	Key challenges in the Project	27
7	Key outcomes	28
7.1	What we achieved.....	28
7.2	Implications for improving care and better relationships in renal care	37
8	A patient-led component of cultural awareness training for clinicians	40
8.1	What we know from the literature	40
8.2	Project key learnings, enabling factors and limitations.....	42
8.3	Key features of a patient-led training initiative to increase cultural understanding and strengthen relationships in care	47
9	References.....	49
10	Appendix A: Word List	51



1 Executive summary

Project background and approach

- The Patient-led Participatory Action Research (PAR) Project to develop a patient-led component of cultural awareness training was informed by the vision of the Central Australian Renal Voice (CARV) consumer group. The CARV members wanted to have a role in teaching the renal nurses about Aboriginal culture and in building better relationships between Aboriginal people on dialysis and nurses who provide their care. Indigenous Australians experience a disproportionate burden of chronic kidney disease with end stage kidney disease rates 16 times higher for Indigenous than for non-Indigenous people.
- Menzies School of Health Research received funding for the Project from NT Primary Health Network and through CARV employed five Aboriginal co-researchers from four different language groups (Pitjantjatjara, Pintupi/Luritja, Alyawarr and Warlpiri), all with lived experience of dialysis, to lead the Project supported by a research facilitator and team from Menzies. Partners in the Project were Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT), Fresenius Medical Care, Central Australia Health Service (CAHS) and the Poche Centre for Indigenous Health and Well-Being NT. The Project was run from July 2016 to May 2017.
- A bicultural inquiry framework was adopted that brought together the PAR process and an Aboriginal approach to learning as you go along. This framework supported the Aboriginal co-researchers' input into the Project design, Aboriginal leadership of the Project and the privileging of Aboriginal ways of teaching and learning. The role of the research facilitator was to enact PAR's core working principles – relationships, communication, participation and inclusion – to guide the process, paying attention to the power dynamics and facilitating the development of harmonious relationships that engender trust between the stakeholders.
- Nurses were invited to participate in the Project through in-service presentations at each of the Alice Springs renal units and Purple House (WDNWPT). There was an enthusiastic response from the nurses and the three renal units and Purple House each supported two nurses to participate in the Project. The nurse participants were culturally diverse with countries of origin including Zimbabwe, Philippines, United Kingdom, New Zealand and Australia.

Key Project activities and outcomes

- Key activities in the Project included the establishment of the Aboriginal co-researcher team which entailed a series of workshops to build trusting relationships, develop a shared understanding of the Project and its approach, and for the Aboriginal co-researchers to articulate how they wanted to develop and lead the Project. Once the Co-researcher team was established



and the nurse participants were identified, we implemented four iterative learning cycles. Included in each cycle were four, 3-hour workshops with the nurses and in between each of these we held two, 3-hour reflective, planning workshops with the Aboriginal co-researchers.

- Language, storytelling and drawing were key features in the teaching and learning that occurred in the workshops. Key words and phrases in the four Aboriginal languages spoken by the co-researchers were shared and learning words in language was a key focus in each workshop. Information was shared via storytelling and drawing, aligning with Aboriginal ways of teaching and learning.
- Topics for each workshop with the nurses were identified by the Aboriginal co-researchers, iteratively informed by what emerged from discussions in the preceding workshop. Key topics covered in these workshops included language, living on country, bush foods and medicines, hunting, different aspects of Aboriginal culture and ways of living, how to show respect in Aboriginal culture, how to make people feel comfortable in the dialysis units, what giving care means for Aboriginal people, and kinship and family. The Aboriginal co-researchers also shared their personal stories through words and drawings of their lives before and after starting dialysis.
- There were few challenges in the Project that could not be managed by the flexible and adaptable approach to resolving issues embedded in the Project design. The co-researchers and nurses had considerable demands on their time which, at times, limited their availability to participate in the workshops. This was managed through a flexible approach to participation and maintaining communication between workshops.
- In identifying the key outcomes of the Project, we drew on the reflections shared by participants at each workshop, workshop notes, nurse participants' questionnaire responses, video interviews¹ with the nurse participants, as well as observations by the research facilitator throughout the Project. Key outcomes from the Project include:
 - The effective implementation of an Aboriginal patient-led initiative. The Aboriginal co-researchers led the process and determined the topics about which they wanted to teach the nurses at each workshop. Increasingly, the co-researchers took on the facilitation of the workshops with the nurses, relying less on the research facilitator.
 - The effective implementation of a process that engaged the nurses; there was a high level of attendance and participation from the nurses. The nurse participants reported that the workshops were an opportunity to spend time with patients outside the clinical setting and to develop relationships with the patients; they enjoyed learning through sharing together and particularly enjoyed hearing and 'seeing' the co-researchers' personal stories; and they enjoyed learning words in the Aboriginal languages. The reciprocal nature of

¹ These video interviews are available via the Menzies School of Health Research website www.menzies.edu.au



the Project enabled the nurses to share aspects of their own cultures with the Aboriginal co-researchers.

- The nurses gained a deepened level of cultural understanding and respect for Aboriginal people. In particular, the nurses gained a greater understanding of the diversity and sophistication of Aboriginal languages, increased understanding of Aboriginal culture, the importance of family as well as different aspects of Aboriginal worldview, ways of living, values and beliefs. In addition, they learned more about the experience of living in Alice Springs on dialysis away from family. The nurses' insights into the lives of Aboriginal people on dialysis prompted them to think about their practice in providing renal care for Aboriginal people and to consider how they could improve the quality of care as articulated by Aboriginal people.
- The nurses reported that their learning through the Project and the strengthened relationships with the (patient) co-researchers had begun to influence their practice. This included a greater awareness of the importance of including family in the care of people on dialysis. In their practice, the nurses reported they had become more conscious of their interactions with patients and noted a greater respect for the patient as a unique individual. Nurses also reported more "active listening" in their interactions with individual patients, taking the time to listen and understand each patient's unique circumstance despite the busyness of the workplace. This reflected the nurses' increased understanding of the importance of the relationship between them and the people on dialysis in providing effective renal care.
- There are important implications for improving care and creating better relationships in renal care based on the key Project outcomes. What has been achieved is more than cultural awareness. The achievements encompass increased cultural sensitivity, increased empathy and cultural humility. Empathy and cultural humility are two important elements in person-centred and culturally safe care. Delivering person-centred care and culturally secure and responsive health services are central to the strategic objectives of the Northern Territory Department of Health. Therefore, Project outcomes have the potential to contribute to the achievement of these strategic objectives in a practical way.

Key Project learnings, enabling factors and limitations

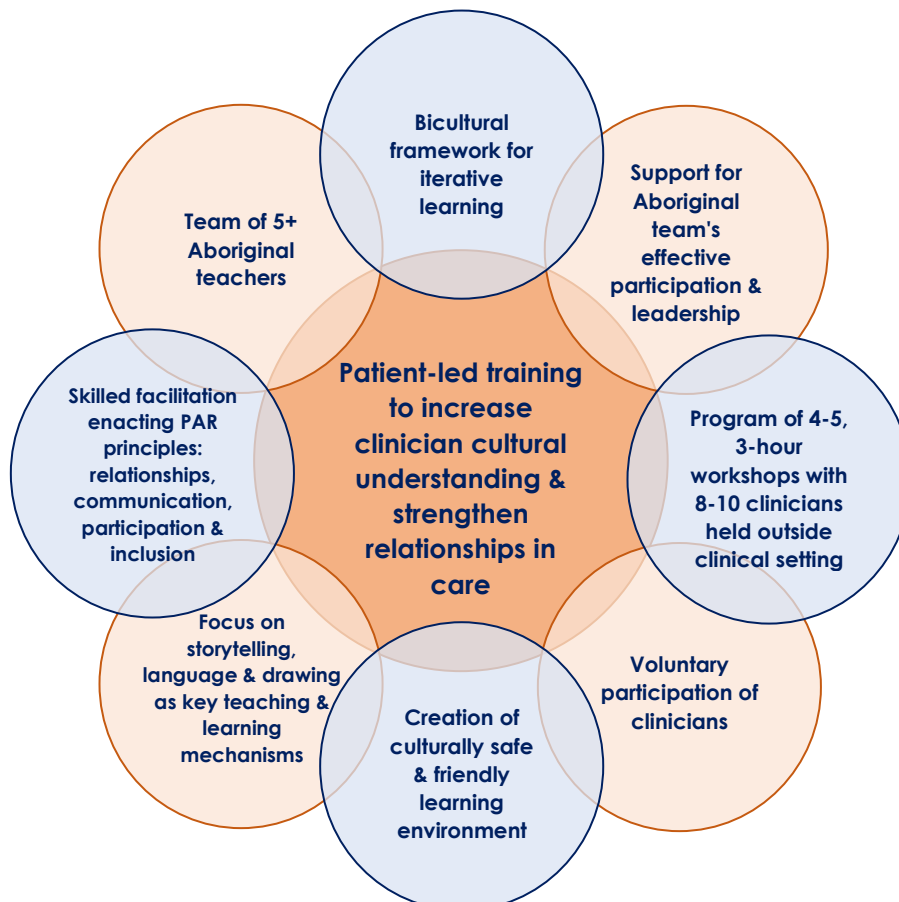
- Key learnings from implementing the Project include:
 - the patient-led initiative was feasible in terms of support from renal services and the desire and motivation of participants;
 - effective working and personal relationships at multiple levels in the Project, based on mutual trust, were important for the Project's effective implementation;



- a focus on language, storytelling and drawing were effective teaching and learning mechanisms; and
- reciprocity in relationships was fundamental to the learning that occurred.
- Important factors that contributed to the achievement of the outcomes included:
 - the bicultural inquiry framework;
 - facilitation that enacted the PAR core principles of relationships, communication, participation and inclusion;
 - flexibility and adaptability in implementing the Project;
 - voluntary participation of all participants; and
 - creating a culturally safe and friendly physical and psychological learning environment.
- While this patient-led initiative within renal services in Central Australia has been shown to be effective in deepening the nurses' cultural understanding and respect and developing better relationships between the nurses and (patient) co-researchers in the short term, it remains to be seen if these outcomes are sustained in the longer term. Further the transferability of the program to other places and settings, outside of Alice Springs and outside of renal services, is unknown.

Key features of the patient-led training initiative developed through this Project

- The diagram below presents the key features of effective patient-led training to increase clinician cultural understanding and strengthen relationships in care identified through this Project.





Conclusion

- This project demonstrated clear support from renal services and motivation by nurses and Aboriginal people on dialysis to participate in a patient-led training initiative. There is great potential to further this initiative and strengthen relationships between clinicians and patients.
- To sustain this initiative as part of the cultural awareness training program, dedicated ongoing funding for co-researchers and a facilitator is required. Importantly, the program would need to consider the burden on individual co-researchers, given the reality of the cultural, social and health context of dialysis patients living in Alice Springs. This would necessitate ongoing recruitment of patients as teachers and engaging appropriately experienced facilitators with a focus on developing the relationships critical to the success of the program.



Co-researcher Irene Nangala presenting on the Project at the AIATSIS National Indigenous Research Conference, Canberra, March 2017



2 Introduction

The Renal Research Team within Menzies School of Health Research secured funding through the Northern Territory Primary Health Network (NT PHN) for what became the Patient-led Participatory Action Research Project – a project aimed at developing a patient-led component of cultural awareness training for renal clinicians in Alice Springs. The Project was informed by the vision of the Central Australian Renal Voice (CARV) consumer group and led by its members. A team from Menzies School of Health Research facilitated the Project, led by the research facilitator (Samantha Togni).

This Final Report covers activities in the Project from July 2016 through to May 2017 when the Project was completed. The initial sections of this Report outline the Project's objectives and provide some background and context to the Project, including the Project's beginnings (Sections 3 & 4). Section 5 explores the Project's approach as well as describes who was involved. Section 6 presents a summary of key activities in the Project's establishment and development, while Section 7 outlines what has been achieved in terms of outcomes from the Project and their implications.

Key learnings and factors that have contributed to the Project's implementation and achievements as well as the Project's limitations are discussed in Section 8. Section 8 also includes the key features of a patient-led component of cultural awareness training as identified through this Project. Appendix A contains the words and phrases in Aboriginal languages shared by the co-researchers in the Project workshops.

3 Project objectives

The Project's key research questions were:

1. What would a patient-led component of the cultural awareness program for renal clinicians comprise?; and
2. How could it be feasible and sustainable?

The key aims of this Project were:

- To work collaboratively to develop the Central Australian Renal Voice (CARV) consumer group's vision for a patient-led component of cultural awareness training for renal clinicians; and
- To work with key stakeholders to consider the feasibility of a patient-led component of cultural awareness training for renal clinicians.



4 Background and context

4.1 The reality of kidney disease in Central Australia

Chronic kidney disease (CKD) is a common and serious health problem in Australia. CKD refers to all kidney conditions where a person has kidney damage and/or reduced kidney function. People with CKD suffer poor health outcomes, reduced life expectancy and reduced quality of life. The burden of CKD is considerable amongst Indigenous Australians. In the Northern Territory (NT), kidney disease rates are particularly high for Indigenous people who present for dialysis 20 years younger than non-Indigenous people [1]. In regional areas and remote communities, where 70% of NT Indigenous people live, the impact of CKD on families and communities is devastating as most people need to relocate several hundreds of kilometres from their home communities to take up treatment.

CKD is categorised into five stages according to the level of kidney function or evidence of kidney failure. People with stage 5 CKD, also known as end stage kidney disease (ESKD), require renal replacement therapy (RRT) in the form of dialysis or a kidney transplant to stay alive. In the NT, ESKD rates are 16 times higher for Indigenous than for non-Indigenous people. The demand for RRT has been growing significantly over the last ten years. In the NT the number of dialysis patients increased by 27% between 2007 and 2011 and same day RRT via haemodialysis (HD) comprises close to 50% of total NT public hospital admissions [2]. At the national level, rates of ESKD for Indigenous Australians are up to five times higher than for non-Indigenous Australians.

The need for dialysis has a major impact on health, lifestyle and social and emotional wellbeing, especially among Indigenous Australians living in rural and remote areas who are usually required to relocate for treatment. In most cases ESKD equates to permanent relocation for treatment and dislocation from their family, community and support networks. There is low uptake of self-care therapies such as home haemodialysis and peritoneal dialysis in the NT. HD in a hospital or satellite facility is the treatment modality used by the majority of NT patients. HD is an intensive and intrusive treatment that requires a significant amount of the patients' time and recurrent hospitalisation. In Australia, the majority of patients receiving HD attend a hospital or clinic for four to five hours, three times a week [3].

Within Central Australia in 2015, there were 332 people on dialysis [4] and in 2014 just over three quarters of these people (77%) relocated from their home communities to access treatment. Ninety percent of these people were on HD in a satellite facility in Alice Springs or Tennant Creek [5].

In these renal settings, Indigenous patients have expressed feelings of being misunderstood and culturally isolated, experiencing a loss of identity and a lack of understanding about their treatment [6, 7]. Contributing to these experiences are limited cultural competency within health services and cultural differences between the clinicians working in the renal health setting and the patients [8-10]. The legacy



of colonisation is also a fundamental factor not only in the health disparities between Indigenous and non-Indigenous Australians [11] but also in the way that the dominant Western culture has defined the structures and delivery of mainstream health services that incorporate embedded unequal power relations [12].

4.2 Cultural competence and safety in health care

Cultural competence is a key strategy for reducing inequities in health care access and improving the quality and effectiveness of care for Indigenous people [13]. Increasingly, health care organisations are incorporating strategies for improving cultural competence and promoting cultural safety [14]. As articulated within the National Aboriginal and Torres Strait Islander Health Plan 2013–2023 [15] developing cultural competency requires a focus on enhancing the capacity and ability of health service systems, organisations and practitioners to provide more responsive health care to diverse cultural groups. Cultural safety in health care is determined by the recipients of care [16] and requires health professionals to “reflect on their interactions and the impact of their own cultural identity on the care they provide to someone from a different cultural background” [14, p. 13].

Currently Central Australia Health Service (CAHS), provides a mandatory one-day face-to-face Aboriginal Cultural Awareness Program for staff, utilising an external provider.

The intensive, long-term dialysis treatment regime is unique within health care settings and therefore provides an opportunity for patients and clinicians to develop therapeutic relationships. These types of relationships can enable a deeper understanding of one another as people, leading to greater appreciation and respect that can increase cultural competency and safety in this health care setting. This real opportunity was evident to the CARV members in expressing their desire to work with the renal nurses to develop greater cultural understanding and better relationships in the renal care settings in Alice Springs.

4.3 Beginnings of the Project

The initial idea for the Project when funding was received in mid-2015, was to develop a series of educational video resources aimed at increasing the cultural awareness of renal clinicians in the NT. To inform the development of the Project, we began by consulting with renal nurses and Indigenous Health Practitioners from the NT's Top End and Central Australia as well as renal patients through the consumer advocacy group, the Central Australian Renal Voice (CARV). These consultations took place in late 2015 and focussed on discussions about the current issues and challenges for patients and clinicians with regard to cross-cultural communication, culturally-informed care and cultural safety. The type of educational resources that were needed to increase cultural awareness and cultural safety were also discussed in these consultations.

Nurses and Indigenous Health Practitioners consulted reported that there were a number of existing, quality educational video resources available for clinicians and



that these were not often used by time poor health professionals. In addition, it was highlighted, that if further video educational resources were to be developed they would be more effective if they were developed as part of a workshop series that included facilitated discussion and learning.

When we consulted the members of the CARV, they expressed a desire to have a role in working with renal nurses to increase the nurses' cultural understanding and to develop better relationships based on mutual respect and understanding.

4.4 Emergence of the Patient-led Participatory Action Research (PAR) Project

Responding to the outcomes of the consultations with renal nurses, Indigenous Health Practitioners and CARV members, as outlined above (Section 4.3), the Menzies School of Health Research Renal Research Team decided to propose to the Project funder, NT PHN, a change in design for the Project. The new design supported the desire of CARV members to work with renal nurses to increase the nurses' cultural understanding and to develop better relationships between renal patients and nurses through a greater appreciation and respect for each other. This change in Project design was considered by the Renal Research Team to be a better use of the funding and more likely to meet the expressed needs of patients and renal clinicians in improving cultural awareness. The revised Project scope was accepted by NT PHN in mid-2016.

The Project was then designed as a patient-led participatory action research project facilitated by a member of the Renal Research Team based in Alice Springs (Samantha Togni). The Project was developed in partnership with CARV members and in-kind support for the Project was sought and received from key stakeholders. These stakeholders – Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT), Fresenius Medical Care, Central Australia Health Service (CAHS) and the Poche Centre for Indigenous Health and Well-Being NT – subsequently became partners in the Project. The Aboriginal co-researchers, Menzies School of Health Research staff and senior staff from the partner organisations were included as Investigators for the Project.

Approval for the Project was received from the Central Australian Human Research Ethics Committee (HREC-16-413) in September 2016.



Drawing by co-researcher Margaret Heffernan in one of the Project workshops



5 Patient-led Participatory Action Research (PAR) Project: approach

5.1 The PAR approach

A participatory action research (PAR) approach was well suited to this Project and has increasingly been used in health care research and, particularly, within nursing and mental health [17, 18]. PAR is often described as a research approach that features the opinions and decision-making of those that are marginalised and voiceless in issues affecting their lives. "The primary purpose of action research is to provide the means for people to engage in systematic inquiry and investigation to design an appropriate way of accomplishing a desired goal and to evaluate its effectiveness" [17, p. 6].

PAR encompasses a systematic and cyclical process of observing, reflecting, planning, acting and sharing and is an effective approach to general problem solving at the local level [19]. PAR develops an understanding of the cultural and historical underpinnings of social structures and relationships, and how these impact people's experiences [20].

By utilising this research approach the decision makers, the actors and the people affected by these actions are able to collaborate and decide the best approach going forward to achieve mutually agreeable outcomes. As a practice, "it is empowering, enabling those who are most directly affected to make positive changes" [19, p. 1].

The PAR process is guided by four core working principles – relationships, communication, participation and inclusion [17]. These principles guide the research process to ensure that it is conducive to effective outcomes and change desired by those most affected. In practice the principles are enacted and facilitated by the research facilitator.

5.1.1 Research facilitator role

Within PAR the role of the research facilitator is not positioned as the 'expert' inquirer and analyst but rather is responsible for paying attention to process, relationships and power dynamics. The research facilitator acts as a catalyst for those leading the change, assisting them to clearly define the issue or problem and supporting them in the iterative learning process to achieve the change they desire. The process or way *things are done* defines PAR and facilitating the process is the essence of the research facilitator role. The facilitator's role "is not to push particular agendas but to neutralize [sic] power differentials in the setting so that the interests of the powerful

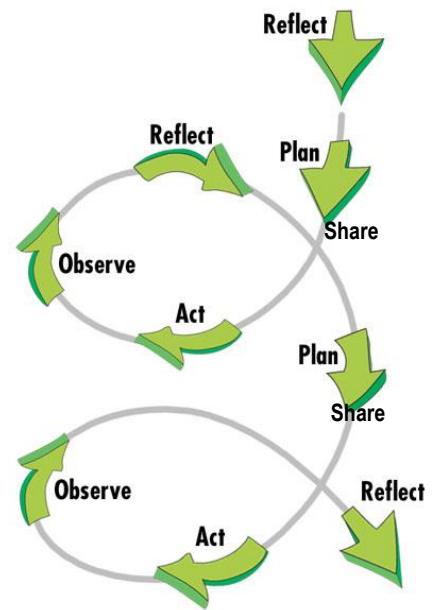


Figure 1: PAR iterative learning cycle



do not take precedence over those of other participants" [17, p. 68]. Facilitating and supporting the development of harmonious relationships that engender trust between the stakeholders is core work of the research facilitator and paramount to an effective PAR process. This is achieved through the research facilitator effectively enacting PAR's core working principles – relationships, communication, participation and inclusion – to guide the process in complex, dynamic situations.

5.1.2 Aboriginal co-researchers

Who were the Aboriginal co-researchers?

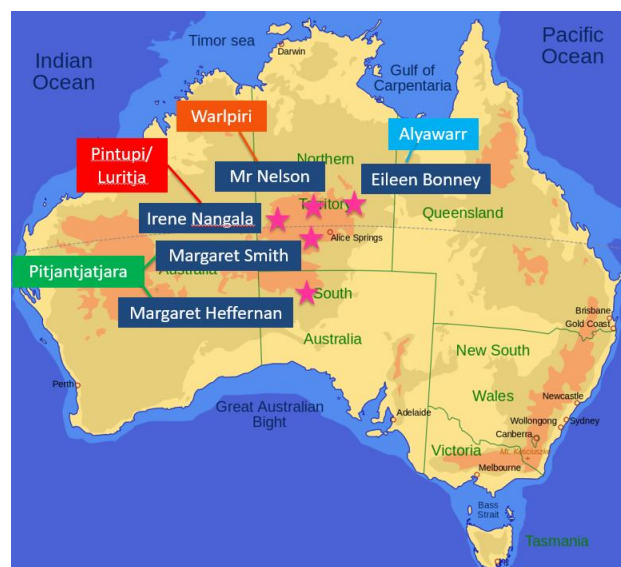
- Culturally diverse from four language groups: Pintupi/Luritja, Pitjantjatjara, Alyawarr and Warlpiri
- Recognised cultural leaders with strong cultural knowledge
- Experienced renal consumer advocates; first-hand experience of dialysis; all had relocated from home communities for dialysis treatment
- Experienced in cross-cultural work

We employed five Aboriginal co-researchers who led the Project: Irene Nangala, Margaret Heffernan, Eileen Bonney, Margaret Smith and the late Mr Nelson. All co-researchers were engaged through CARV and all have first-hand experience of dialysis. At the time of the Project, three were receiving dialysis, one was living with a kidney transplant and one co-researcher was a carer for a family member on dialysis.

All five co-researchers had relocated from their home communities across Central Australia (Kintore (NT), Imanpa (NT), Yuendumu (NT), Ampilatwatja (NT)

and Pukatja (SA)) to access dialysis in Alice Springs (see map below). Within this group of co-researchers, there were four different Aboriginal languages spoken as first languages: Pintupi/Luritja, Pitjantjatjara, Alyawarr and Warlpiri, as shown on the map below. All co-researchers were also fluent in English and had experience working in cross-cultural contexts.

Each of the co-researchers are recognised leaders with cultural standing within their communities in addition to having leadership roles as renal consumer advocates. They, therefore, brought a wealth of cultural and contextual knowledge to the Project in addition to their passion and commitment to make a difference for Aboriginal people on dialysis in Alice Springs.



Map of Australia showing the Aboriginal co-researchers' home communities (represented by pink stars) and first languages



5.1.3 Bringing together PAR and Aboriginal ways of learning as you go along

In designing this Project, we drew on work developed by Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council [21] which articulates Aboriginal concepts related to iterative action and learning. We embedded this approach within our inquiry framework that was guided by the core principles of PAR (see Section 5.1). This enabled us to bring together a bicultural framework and a shared understanding of how we would work together and embed Aboriginal ways of knowing and learning within the Project's approach and activities.

The key words and concepts in Pitjantjatjara for learning as you go along are:

<p>Kulilkatinyi Thinking, listening, understanding as you go along and over a period of time</p> <p>Nyakukatinyi Looking at or for something as you go along and over a period of time</p> <p>Palyalkatinyi Making/doing something as you go along and keeping doing something over a period of time</p>	
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Representation of the *kulilkatinyi*, *nyakukatinyi*, *palyalkatinyi* process drawn by Margaret Heffernan, 2016

As part of the process to establish the Project, the co-researchers from different language groups articulated words in their languages for these concepts (see Section 6.1).

5.1.4 Nurse participants

Through in-service presentations about the proposed Project, we invited nurses from each of the four renal dialysis units in Alice Springs to participate in the Project (see Section 6.1.2).

Each renal unit supported two nurses to participate in the Project (total of eight staff) allocating time within their shifts to participate². These nurse participants were Caroline Hombarume, Cassandra Holland, Colin Paine, Kara Page, Dean Oldfield, Wendie Hume, Mary Jane Ferrer and Ruth Queja.

Who were the nurse participants?

- Culturally diverse from Zimbabwe, Philippines, UK, NZ and Australia
- Majority had been nursing 10+ years
- Wide range of renal nursing experience from < 1 year to 15 years
- Years of experience working in renal nursing in Central Australia ranged from < 1 year to 9 years
- Diversity of roles in renal services

² Following the first workshop one of the nurses from WDNWPT resigned from her job and was replaced within the Project by an administration staff member who supports renal patients as part of her job. For ease of reading and in the interests of maintaining confidentiality, throughout this Report the group of professionals who participated will be referred to as nurses.



The eight nurses had culturally diverse backgrounds. Countries of origin included Zimbabwe, Philippines, United Kingdom, New Zealand and Australia. Additionally there was a breadth and depth of experience and qualifications within the group which included a clinical nurse manager, team leader, dialysis nurse, care coordinator, administration and client support officers. Similarly, nursing experience within the group was broad, ranging from less than four years to 30-40 years. In the area of renal nursing, experience ranged from 15 years to less than one year while renal nursing experience in Central Australia was less extensive and ranged from ten years to less than one year.

5.2 Key features of our approach

5.2.1 Relationships

The quality of relationships is important for Aboriginal people and is paramount when working cross-culturally. It was essential that the Project was established on genuine relationships of trust and respect.

Furthermore, relationships are central to the PAR process. Establishing positive working relationships are one of the core working principles of PAR as relationships have direct impacts on the quality of people's experience and subsequently the outcomes of any human enterprise [17]. Positive working relationships in any PAR project should:

- Promote feelings of equality for all people involved;
- Maintain harmony;
- Avoid conflicts, where possible;
- Resolve conflicts that arise, openly and dialogically;
- Accept people as they are, not as some people think they ought to be;
- Encourage personal, cooperative relationships, rather than impersonal, competitive, conflictual, or authoritarian relationships; and
- Be sensitive to people's feelings [17, p. 24].

Establishing and strengthening relationships was therefore essential to this Project and in establishing these relationships the research facilitator drew on the other core principles of PAR: communication, participation and inclusion (see Section 6.1).

While the quality of relationships was critical to the process, the development of better relationships between Aboriginal people on dialysis and renal nurses who provide their care was also a key aim of the Project. In this way, the quality of the relationships established through the Project's processes were integral to the Project's outcomes.



5.2.2 Storytelling, language and drawing

Story is integral to Aboriginal cultures and is a key mechanism for teaching and learning. Therefore, storytelling was central to the Project's process and used purposefully by the Aboriginal co-researchers to teach the nurse participants and convey important information and experiences meaningfully. Story is recognised as an effective tool within consumer-led initiatives to educate clinicians as story “brings the learning clinicians' attention to the experiential parts of the way they interact with consumers” [22, p. 10].

Drawing was also an important part of the process. Aboriginal people in Central Australia have a long tradition of using visual expressions in teaching and learning, whether through sand drawings, rock etchings or body painting. Drawing was used in two ways. Firstly, it was used purposefully by the Aboriginal co-researchers as part of storytelling. Secondly, we incorporated a process developed through NPY Women's Council's Uti Kulintjaku Project³ which encouraged participants to draw during the workshops as a way to relax and focus the mind [23]. Coloured paper and markers were made available at each workshop for this purpose. Many drawings were produced throughout the workshops and some of these are incorporated into the header for this Report.

As highlighted above, the Aboriginal co-researchers spoke different Aboriginal languages. The co-researchers knew that language was fundamental to the Project's teaching and learning focus aimed at increasing the cultural understanding of the nurse participants. Many words in each of the four Aboriginal languages spoken by the co-researchers were shared in the workshops. Some of these words related to common interactions between people and other words related to key topics that were discussed in the workshops (see Appendix A).

5.2.3 Reciprocity

The Aboriginal co-researchers were clear that reciprocity needed to be a feature of the way we worked together in the Project. Reciprocity meant that there was sharing and learning both ways and required engagement from all participants at a personal level. This feature of the way we worked together supported the iterative learning cycles.



Words in each of the four Aboriginal languages displayed at the workshop

³ The research facilitator, Samantha Togni and co-researcher, Margaret Smith are part of the Uti Kulintjaku Project.



6 What we did

6.1 Project establishment

There were two key components of the Project's establishment that occurred simultaneously to a certain extent: forming the team of Aboriginal co-researchers and inviting the nurses to work with us on the Project. Each of these was important in establishing strong foundations for the Project's iterative learning cycles. The PAR Project funding enabled initial workshops to establish the co-researcher team, followed by four iterative learning cycles, each comprising a workshop with the nurse participants.

6.1.1 Forming the Aboriginal co-researcher team

As highlighted above, the idea for the Project came from the CARV consumer group and through conversations with the research facilitator CARV members indicated their interest in working on the Project as paid co-researchers. Three of the co-researchers had a pre-existing working relationship with the research facilitator and the other two only knew the research facilitator through her participation in the CARV meetings. Two of the co-researchers had known each other since childhood while the others did not know each other well, each coming from different communities and language groups. In addition to the role of the research facilitator the establishment of the co-researcher team was supported by the Darwin-based project manager, Georgia Robinson, and Kerry Taylor Acting Director of the Poche Centre for Indigenous Health and Well-Being, who is experienced in educating health professionals in practice that promotes cultural safety [14].

Given that relationships are one of the core working principles of PAR [17], we needed to pay attention to the type, nature and quality of relationships within the co-researcher team in the first instance. We brought the team together for a series of five, 2-3 hour workshops to begin to build the relationships, to develop a shared understanding of the Project and the PAR approach, and for the Aboriginal co-researchers to articulate how they wanted to develop and lead the Project. Emphasis was placed on the fact that the co-researchers and the nurses would be participating as equals within the Project, sharing and learning together.

An essential element of the team establishment was to develop relationships of trust and respect between the team members and particularly with the research facilitator. The facilitation of this work was guided by the core working principles of PAR: relationships, communication, participation and inclusion [17], as outlined in the table below. It was important to have cohesion and a clarity of purpose within the team before work started with the nurse participants.



How we put the PAR core working principles into practice in the establishment of the Project

Relationships	<ul style="list-style-type: none"> • Spent time getting to know each other personally through storytelling • Respected and valued the importance of relationships for Aboriginal people • Incorporated Aboriginal knowledge and ways of knowing and learning into our inquiry framework • Reiterated that everyone would participate as equals in the Project • Always shared food at our workshops
Communication	<ul style="list-style-type: none"> • Attentive listening to the co-researchers by the research facilitator • Provided information about PAR and incorporated words in the four Aboriginal languages to increase shared understanding of concepts and how we were going to work together • Talked through the way we wanted to work with and teach the nurses and how to make them feel comfortable in working with us • Surfaced any issues that were of concern or caused frustration for the co-researchers with regard to the health system
Participation	<ul style="list-style-type: none"> • Ensured that the workshops were held at times that did not conflict with the co-researchers dialysis treatment • The flow of discussion at the workshops was directed by the Aboriginal co-researchers; the work was done at the pace that was right for the co-researchers • Provided social support and transport to support the participation of co-researchers recognising the reality of their health and social context
Inclusion	<ul style="list-style-type: none"> • Inclusion of people from a range of Aboriginal language groups in Central Australia • Flexible in our approach to participation to ensure co-researchers could continue their participation despite not being able to participate in all workshops

It was important to create an environment of care and respect to nurture the relationships in the team. The desired environment was created by remaining flexible and adaptive to the context and providing a level of social support to the co-researchers, including transport to facilitate their participation, as well as providing food at each of the workshops. The provision of this support acknowledged the co-researchers commitment but also the challenges they faced in maintaining their participation, due to the social and financial constraints stemming from living with a complex chronic condition in Alice Springs.

Over the course of the eight months of the Project, four of the five co-researchers spent time in hospital and for the other co-researcher, her brother, who was on dialysis and for whom she cared, also spent time in hospital. In addition, most of the co-researchers experienced the death of a close family member over this time, and as acknowledged at the beginning of this Report, one of our co-researchers passed away towards the end of the Project. This is the reality of life for Aboriginal person on dialysis in Central Australia and the context in which we work. Despite this, the ongoing engagement of the co-researchers reflects their dedication to wanting to



make a difference for people on dialysis in Central Australia. The support provided was essential to ensuring the co-researchers' effective participation in the Project.

6.1.2 Inviting the nurses to work with us

We sought permission to present at the regular in-services at each of the renal units and Purple House as the process of inviting the nurses to work with us on the Project. The in-services were well attended and the presentations were done by one to two Aboriginal co-researchers and the research facilitator. At these in-service presentations it was the Aboriginal co-researchers, that is, the people on dialysis, saying to the renal nurse who provide their care 'we are doing this Project, who would like to join us?' In this way, the Project was "consumer-driven and staff collaborative" [18, p. 15] reflecting the reciprocity that was central to the Project's approach.

During the Project's initial phase the Aboriginal co-researchers determined the information to be provided to the renal nurses when inviting them to come and work with us on the Project. Careful consideration was given to ensuring that the nurses knew it was a 'friendly' Project where everyone would learn. One of the key messages that the Aboriginal co-researchers shared with the nurses in the in-service presentations was "We want to work in a friendly way, sharing stories together to make things better and have good relationships." This is underpinned by reciprocity – *ngapartji ngapartji* in Pitjantjatjara.



We received a very positive response to the Project from the nurses at each renal unit and Purple House with eight nurses – two from each facility – participating. While additional nurses indicated their interest, only two nurses from each renal unit could be supported to ensure staffing numbers in the units were maintained. Limiting nurse participants to eight was effective in maintaining the balance between the numbers of Aboriginal co-researchers and nurses.

6.2 Iterative learning cycles

Four iterative learning cycles were completed. Included in each cycle were four, 3-hour workshops with the nurses and in between each of these we held two, 3-hour reflective, planning workshops with the Aboriginal co-researchers. This is presented visually in the diagram below (Figure 2). All workshops were audio-recorded with the permission of the participants, and notes of key topics discussed, reflections and learnings were captured by the project manager during the workshops. The notes from the workshops with the nurses were provided to all participants following each workshop.



In Workshops 1 and 4 with the nurses we asked the nurses to complete a one page questionnaire. The first questionnaire aimed to capture the nurses' reasons for participating in the Project, what they wanted to learn and the level of understanding they thought they had about Aboriginal people and culture in Central Australia. In the second questionnaire, the questions related to their experience of participating in the Project, what they had learned and the level of understanding they thought they had about Aboriginal people and culture in Central Australia.

Most of the reflective, planning workshops were held at the Poche Centre for Indigenous Health and Well-Being while the workshops with the nurses were held at a range of venues, depending on room availability, including the Poche Centre for Indigenous Health and Well-Being, Charles Darwin University and the Liebig Building on the Alice Springs Hospital campus. The workshops with the nurses were held mostly on Mondays from 2pm-5pm. Mondays were dialysis-free days for all the co-researchers and the afternoons from 2pm were the best time for the nurses to have time away from the renal units. A reflective, planning workshop with the Aboriginal co-researcher was usually held on the Monday morning before the workshops with the nurses to provide a focussed day for the co-researchers and enable them to settle into the space before the nurses arrived.

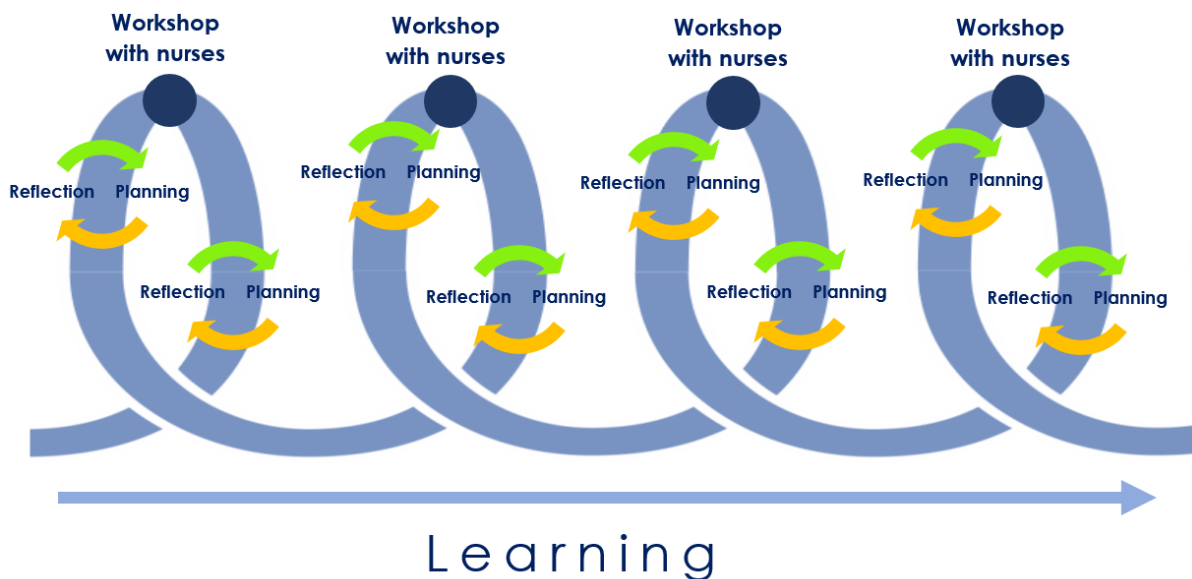


Figure 2: Our PAR iterative action learning cycle

6.2.1 Reflective, planning workshops

The purpose of the reflective, planning workshops with the co-researcher was to enhance the iterative learning process and development of the Project. These workshops provided a space for the co-researchers to come together as a team to reflect on the previous workshop with the nurses, generating shared meaning of this experience as well as insights into the nurses' understanding. The workshops were



intentionally 'lightly' facilitated, with the research facilitator asking a few key questions and then trusting the process and the relationships that were being developed to enable the conversations and discussions to flow and focus on what was important to the co-researchers.

In these workshops the co-researchers shared many stories with each other; some of these stories were about growing up in country; there were stories about hunting, family, language, health and wellbeing, Western health care, differences and similarities between Aboriginal and non-Aboriginal people as well as personal stories about being on dialysis, relocating to Alice Springs and living away from family and country. Through these stories and reflections – some of which were shared at the subsequent workshop with the nurses and some which were not – key topics emerged that the co-researchers wanted to teach the nurses at the next workshop. Throughout these workshops the key topics were captured by the research facilitator on the whiteboard. At the end of the workshops the co-researchers reviewed the topics and an outline for the next workshop with the nurses was developed.

6.2.2 Workshops with the nurses

The four workshops with the nurses held over the course of the Project, were the core mechanisms for the teaching and learning to increase the nurses' cultural understanding and develop better relationships between people on dialysis and the renal nurses. Continuing the focus on the type, nature and quality of relationships in these three hour workshops was essential to the effectiveness of the process. We needed to build trusting relationships between the Aboriginal co-researchers and the nurses. A key role of the research facilitator was to ensure the power relations between patients and health professionals, inherent in health care settings [14, 24], were neutralised in these workshops and ensure that everyone was able to participate as equals. A key strength in this Project was that all participants, in volunteering, understood that the process was intended to be patient-led.

We were also aware that this process and the associated dynamics were new to all participants. This was the first time in Central Australia that Aboriginal people on dialysis and the nurses who provided their care, were coming together as equals in a non-clinical setting to share and learn in a process led by the patients. This was a new, interactive learning experience for everyone and the iterative nature meant that there were no pre-determined learning objectives. In many ways this was a leap of faith on the part of all participants, as revealed in this quote by one of the nurse participants reflecting on the experience at the end of the Project:

When we came into this Project we were not so sure what would happen, what we would learn about but it's given us a really great opportunity and I feel even after this Project [is over] whatever we've learnt is going to make things better for us and also for the patients.

Nurse participant (N03), March 2017



Similarly, one of the co-researchers reflected in the second workshop with the nurses that initially she was feeling nervous about the workshops but once she had settled into it and knew what she was doing, especially with a focus on all the words in language, she felt comfortable and was enjoying the sharing together.

In facilitating these workshops, we continued to be guided by the PAR core working principles of relationships, communication, participation and inclusion (see the table below). By the time of the first workshop with the nurses (Workshop 1) we had the foundations of trusting relationships within the Aboriginal co-researcher team so we could build on this to develop relationships, based on trust and respect, with the nurse participants. This involved creating an environment where people felt comfortable and safe to participate and facilitating a process in which people could get to know each other encouraging “personal, cooperative relationships” [17, p. 24]. These relationships are the hallmark of PAR and also essential to Aboriginal ways of relating and learning. The development of these relationships was a major focus of the first workshop with the nurses and there were a number of key ways this was approached, as outlined below.

How we put the PAR core working principles into practice in the workshops with the nurses

Relationships	<ul style="list-style-type: none"> • Intentionally facilitated activities to enable participants to share and get to know each other on a more personal level – eg. getting to know where people were from, what languages they spoke, what they valued • Provided all participants with gift packs in the spirit of reciprocity • Reiterated that everyone would participate as equals in the Project; research facilitator paid attention to neutralising power dynamics • Always shared food at our workshops
Communication	<ul style="list-style-type: none"> • Attentive listening to all participants by the research facilitator • Provided information about PAR and how Aboriginal knowledge and ways of knowing and learning were incorporated into our inquiry framework • Collaboratively developed a set of agreements for how we wanted to work together in the workshops to ensure it was a safe place • Provided detailed notes from each workshop to all participants • Provided a list of all the words in language covered in the workshops to the nurse participants at the end of the Project. • Provided progress reports to all partners and key stakeholders following each learning cycle
Participation	<ul style="list-style-type: none"> • Ensured that the workshops were held at times that did not conflict with the co-researchers dialysis treatment and were most convenient for the nurses • Created a physical space that was relaxed and colourful with wall displays and coloured paper and markers for colouring in and drawing • The flow of discussion at the workshops was directed by the Aboriginal co-researchers; the work was done at the pace that was right for all participants • Provided social support and transport to support the participation of co-researchers recognising the reality of their health and social context



How we put the PAR core working principles into practice in the workshops with the nurses

Inclusion

- Inclusion of people from a range of Aboriginal language groups in Central Australia and from across the four renal units/services in Alice Springs
- Providing the opportunity for the nurse participants to indicate what they would like to learn from the co-researchers and what they would like to share with the co-researchers
- Flexible in our approach to participation to ensure co-researchers and nurses could continue their participation despite not being able to participate in all workshops

Mapping where we come from and the languages we speak

At the first workshop we had a detailed map of the tri-state region of Central Australia and a map of the world. As part of everyone introducing themselves we asked participants to place a sticker on the maps to indicate where they originally come from and to also share the languages they speak. The Aboriginal co-researchers indicated their country on the Central Australian map, while the nurse participants and other team members indicated where they came from on the world map. Countries of origin for the nurse participants included Zimbabwe, Philippines, United Kingdom, New Zealand and Australia. Languages spoken by participants included English, French, Shona, Filipino, Pitjantjatjara, Warlpiri, Alyawarr and Pintupi/Luritja.



Map of the world showing the nurse participants' countries of origin



Map of Central Australia showing the Aboriginal co-researchers' country

Sharing something that is important to us

We asked each of the participants to bring along to the first workshop something that was important to them that they would be happy to share with the group. This could be an object, a story, a photograph, anything that was meaningful to that person. Many of the nurses brought photographs of their families to share which made an instant connection with the Aboriginal co-researchers who asked questions about their families. Other nurse participants brought personal objects that had a special meaning that they shared. The Aboriginal co-researchers told stories about things that were important to them including aspects of Aboriginal culture and Law, and way of living. All of the objects, photographs and stories that were shared gave more insight into who each person was and what they



valued. Much of this sharing was about connecting on a human level and it generated opportunities for participants to laugh together. All participants engaged well in this process and started to get to know each other a little better. Some of these stories informed topics that were discussed at subsequent workshops.

Creating a friendly and safe environment

In creating a friendly and safe environment for the workshops there were several considerations including the venue and the physical space we created within the room as well as our commitments to how we wanted to work together and how this would be demonstrated. We intentionally made the space colourful with wall displays incorporating words in the four Aboriginal languages, and coloured paper and markers on the tables for drawing and colouring in during the workshops.

As stated above, the Aboriginal co-researchers had set the tone of the workshops at the outset by stating “We want to work in a friendly way, sharing stories to work together to make things better and have good relationships.” Building on this at the Workshop 1, we collaboratively developed a set of agreements for how we wanted to work in the workshops to make sure it was a safe space for everyone to participate. These agreements are included in the box to the right, here. At the beginning of each workshop we reiterated and reviewed these and they were visually displayed at all workshops.

At the Workshop 1 we provided gift packs to all participants. These gift packs contained a journal with local Aboriginal artwork on the cover, a colouring book – *Colouring Towards Clear Thinking* – designed and published by the Uti Kulintjaku Team of senior Anangu women (including co-researcher, Margaret Smith) from the NPY Women’s Council⁴, a packet of colouring pencils, a pen and a pot of bush balm produced by Purple House or NPY Women’s Council (for those participants from Purple House). Within the journals we included some reflective questions for the nurse participants. We also provided the nurse participants with a copy of the chapter on reflective practice from Kerry Taylor and Pauline Guerin’s book *Health care and Indigenous Australians: Cultural safety in practice* [14, pp.183-97].

Workshop agreements

- ❖ Making sure we give everyone time and space to share
- ❖ Work in a friendly way
- ❖ Aim for a better understanding
- ❖ Being open and non-judgemental
- ❖ What we talk about in the workshop stays confidential
- ❖ Don’t want to criticise or push people
- ❖ Drawing in the workshops is good!
- ❖ Show respect and not offend others
- ❖ Give people the chance to talk; don’t talk over the top of each other

⁴ See <https://www.npywc.org.au/resources/publications/>



The contents of the gift packs supported the type of environment we wanted to create in the workshops, encouraging colouring in and drawing as well as reflection. The bush balm also provided an opportunity for discussion about traditional bush medicines, health and healing.



Co-researcher Irene Nangala teaching the nurse participants some words in language in Workshop 4

6.2.3 Topics for teaching and learning

In keeping with the iterative learning process, the content of each workshop was informed by what emerged from discussions in the previous workshop. We were building on the learning over time, led by the Aboriginal co-researchers.

The outline for each workshop included a reflection on the previous workshop towards the beginning and a reflection of the current workshop at the end of the workshop. While the workshop outline guided the topics for discussion and was used by the research facilitator to move through the topics, how each topic was discussed, the direction the discussion took and the length of time dedicated to it was led by the Aboriginal co-researchers in the workshop. The workshops were also flexible to allow for other topics to emerge and be discussed as we went along. It was a very dynamic process.

As described above, through the reflective, planning workshops the Aboriginal co-researchers iteratively identified what they wanted to teach the nurses in each of the workshops (see Section 6.2.1). Key topics covered are outlined below. These are a brief summary of the detailed and interactive discussions that occurred around each of these topics in the workshops.

Language

Key words and phrases in the four Aboriginal languages spoken by the co-researchers were shared. Learning words in language was a key focus in each workshop. A list of all the words covered in all four workshops was provided to the nurse participants at the end of the Project and is included here in Appendix A.



Country

It was important for the co-researchers to teach the nurses where they come from; where their country is. This included stories and sharing Aboriginal knowledge about living on country, bush foods and hunting.

Traditional medicine

The co-researchers taught the nurses about the use of traditional medicines and shared knowledge of making these medicines from specific plants and animals. There was also some discussion about the work of traditional healers. The nurses tried some of the bush balms that were included in their gift packs. An unexpected outcome of gifting the bush balm to the participants was one of the nurses used the bush balm on her son who had a skin condition and she reported at a subsequent workshop that the balm had been effective in treating this condition.

How to show respect in Aboriginal culture

The co-researchers articulated that understanding how to show respect to Aboriginal people was one of the most important aspect of working well with Aboriginal people. Key features of showing respect in Aboriginal culture discussed were: **communication – taking the time to listen, showing patience, being friendly, happy, smiling, generous, helpful and loving, and showing kindness**. There was a discussion about the fact that there are not specific words in Central Australian Aboriginal languages for 'please' and 'thank you' as appreciation is incorporated in reciprocity and implied in the relational aspects of Aboriginal society.

Aspects of Aboriginal culture and ways of living

The co-researchers shared with the nurses the process of **birthing a baby** within Aboriginal society following Aboriginal Law and the different roles for different family members that are culturally important to ensure that the baby grows up strong and healthy. Another aspect of Aboriginal culture that was shared by the co-researchers was in relation to the relationships between men and women and particularly in the dialysis units why it is **against Aboriginal Law for men and women who are not married to be beside each other while they are on dialysis**.

How to make people feel comfortable at the dialysis units

This discussion built on the discussion about how to show respect to Aboriginal people. It focussed on relationships and communication recognising that everyone is different, so communication needs to be customised, such as the differences in talking to senior people and men and women. The importance of **showing respect**, as outlined above, using an **interpreter** to ensure people understand what is happening, and **involving family** was explained by the co-researchers. There was a discussion about **shame** as the co-researchers shared that Aboriginal people, especially when they start dialysis, can feel 'shamed' in the dialysis unit. We discussed that this meaning of shame is different to what a non-Aboriginal English speaker might understand as shame. When the co-



researchers used this word it was to mean when a person feels uncomfortable in a situation, rather than feeling ashamed, that is, feeling bad about something they have done.

Personal life stories

The co-researchers produced **drawings** in the reflective, planning workshop ahead of Workshop 3, about their personal stories of life before and after kidney disease and relocating to Alice Springs for dialysis. They used these drawings to share their personal stories with the nurses and convey the **experience of the impact of kidney disease and dialysis** has had on their lives and the lives of their families. This led to discussions about the challenges people face when living in town away from their families and how they cannot effectively maintain their roles and responsibilities within their families. This provided insight into the tensions associated with maintaining dialysis treatment and being with family, especially at important times like sorry business.



Co-researcher Eileen Bonney (left) telling her personal story to the nurse participants in Workshop 3 using her drawing (pictured right)

What giving care means for Aboriginal people

The co-researchers explained to the nurses that to give care in Aboriginal culture is about the **relationships** and **reciprocity** within families. To give care, it comes from your heart with feeling. The co-researchers shared the phrase *kurunpa mukulya* which in Pitjantjatjara and Pintupi/Luritja means to have a 'loving heart' and this is associated with caring for others. This is a similar notion to the features of showing respect in Aboriginal culture that was also discussed at the workshops and outlined above. This discussion focussed on expectations of care in the dialysis units, which the nurse participants were keen to learn about, as highlighted below.



Kinship and family

The importance of family for Aboriginal people and the different relationships people have with other family members, including what non-Aboriginal people might call extended family was explained by the co-researchers. Using drawings, the co-researchers shared their family trees to explain the relationships and teach the nurses some of the words in language for different family members. The impact of relocating for dialysis on family relationships and the role of family members in supporting people to keep up their dialysis treatment was also discussed.



Co-researcher Irene Nangala explaining her family tree to the nurse participants in Workshop 4



Co-researcher Margaret Heffernan explaining her family tree to the nurse participants in Workshop 4

In Workshop 1 we asked the nurses what they would like to learn through the Project as well as what they would like to share with the co-researchers. The nurses indicated that they would like to learn the following through participating in the Project:

- ✚ Learn about Aboriginal culture and language
- ✚ Learn about Aboriginal beliefs and way of life
- ✚ Increase understanding of Aboriginal people's expectations of care and roles of the nurses
- ✚ Increase understanding of how to provide care that respects Aboriginal people and better meets their needs
- ✚ Increase understanding of how to improve communication in care and increase understanding of Aboriginal people
- ✚ Increase understanding of how Aboriginal people feel about being on dialysis and what the nurses can do to improve their quality of life

The nurses also indicated that they would like to share their culture with Aboriginal co-researchers and also describe the different roles and responsibilities they have as



renal nurses. Throughout the workshops the nurses were able to share aspects of their cultures and describe their different roles as renal nurses.

6.3 Key challenges in the Project

There were few challenges in the Project, largely due to the flexible approach taken and the PAR process of adapting and responding to issues as they emerged in the Project. Additionally, we had a supportive and flexible funder in the NT PHN who allowed us to change the Project design considerably from the original idea, as discussed in Section 4.3, and extend the timeframe for completion of the Project once the new direction was set.

One of the key challenges in the Project was the context in which we were working. We needed to ensure that the Aboriginal co-researchers and the nurse participants could engage effectively in the Project. Both co-researchers and nurses had considerable demands on their time, which at times, limited their availability to participate in the Project workshops. The co-researchers had dialysis treatments three times a week in addition to other health appointments, social and cultural obligations and commitments. Several of the co-researchers also held key leadership roles in Aboriginal organisations and so were active in meetings and other forums. Within Alice Springs, renal services are straining to meet the current demands for dialysis treatments, and renal units are very busy places. Consequently, there were times when nurse participants were either unable to attend the workshops or were recalled to the workplace *during* the workshop due to staff shortages.

Fortunately Monday afternoons proved to be the most suitable meeting time for all participants and while the afternoon timeslot may not have been the optimum time for learning, it worked well. We ensured there was tea, coffee and afternoon tea to keep everyone going!

We responded to the challenge of the competing demands on participants' time by maintaining a flexible approach to attendance and ensured continued participation in the Project through the provision of detailed workshop notes. This enabled the co-researchers and nurses to keep up with the discussions and learning that had occurred in the workshops they were unable to attend. In addition, we provided a level of social support and transport for the co-researchers to facilitate their participation in the Project. The research facilitator maintained communication with the co-researchers between workshops as part of this support and the core focus on relationships in the Project.

Over the course of the Project only one of the four workshops with the nurses was rescheduled. This was due to ill health and sorry business for several co-researchers, leaving only one co-researcher available for the scheduled workshop. Having a team of five co-researchers worked well in terms of participant flexibility and generally between three and five co-researchers were present for each workshop.



7 Key outcomes

7.1 What we achieved

Key developments in participant learning occurred throughout the workshops and supported the strengthening of understanding, respect and stronger relationships between the Aboriginal co-researchers and the nurse participants. Of course these developments in learning were cumulative and interrelated; they occurred as part of the PAR process, not in isolated discussions.

In identifying the key achievements of the Project, we drew on the reflections shared by participants at each workshop, workshop notes, nurse participants' questionnaire responses, video interviews⁵ conducted with five nurse participants, as well as observations by the research facilitator throughout the Project.

7.1.1 An Aboriginal patient-led process

“We are putting all those words, wangka [talking], from Anangu people, the ideas that we want and we are putting it with you [research facilitator]...it's not coming from kartiya [non-Aboriginal people], wiya [no], it's coming from us, it's coming from our mouth, what we are talking to you face to face, we are telling you about what's happening [for] Anangu [Aboriginal people] with our renal, you know. We are the one[s] talking.” Irene Nangala, Aboriginal co-researcher, February 2017

As this statement by co-researcher Irene Nangala, during one of the reflective, planning workshops clearly articulates, the co-researchers were able to direct the Project and share what was important for them to teach the nurses to increase understanding of Aboriginal people and their experience of renal disease. Achieving this was critical to the effectiveness of the Project and our ability to meet our objectives. The patient-led process was also evident to the nurse participants:

The opportunity to spend time with patients outside the 'working setting.' The agenda is set by the patients and they share the things that [are] important for us to know which we can build on later on.
Nurse participant (N06), April 2017

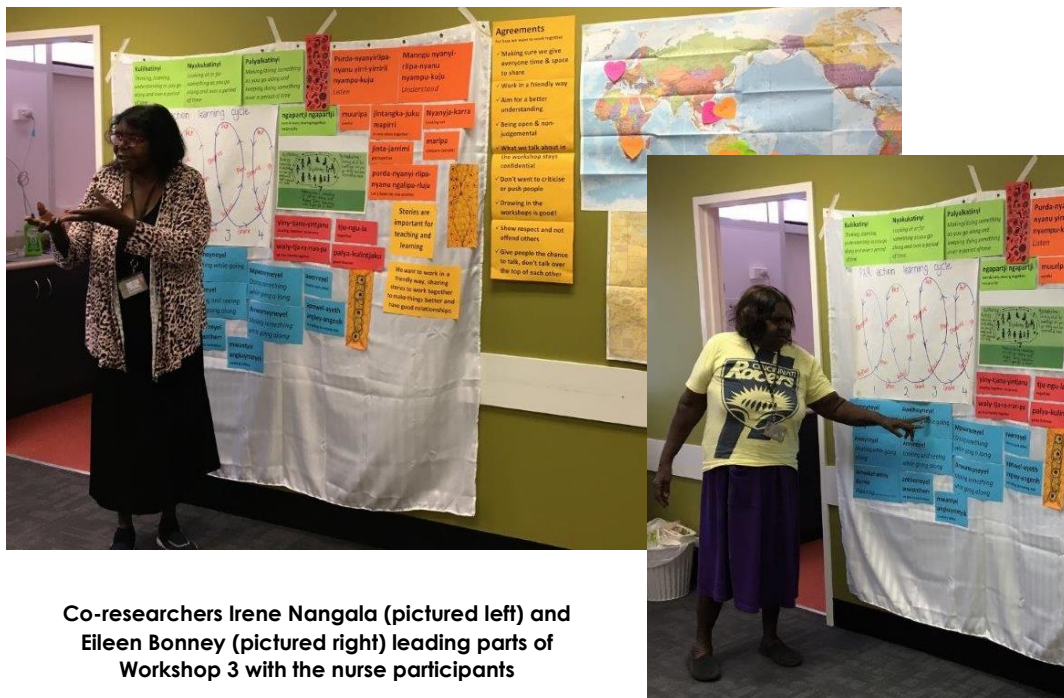
Throughout the Project, key members of the co-researcher team developed more confidence in the workshops and over time these co-researchers increasingly facilitated the workshops with the nurses with less input from the research facilitator. One of the co-researchers would regularly check in with the nurses during the workshops, asking “Are we having a good talk here? Are we working well together?”

⁵ These video interviews are available via the Menzies School of Health Research website www.menzies.edu.au



This demonstrated the co-researchers' attention to relationships and their ability to work well in a group to support learning.

The leadership by the co-researchers was enhanced by the use of language and storytelling. This enabled them to start from a place of knowledge. Co-researchers were able to share with the nurses their extensive cultural knowledge and demonstrate their skills in working cross-culturally. At each workshop there would be new words in language that the co-researchers would ask the nurses to practice saying aloud. In addition to increasing the cultural understanding of the nurses, this activity generated much laughter and built relationships.



Co-researchers Irene Nangala (pictured left) and Eileen Bonney (pictured right) leading parts of Workshop 3 with the nurse participants

Humour was used effectively by the co-researchers and a common reflection by the co-researchers following the workshops with the nurses was that they were pleased that they had been able to make the nurses laugh. It was also evident to the co-researchers that the nurses were learning from them.

The nurses are really listening to us and learning from us and our stories. Aboriginal co-researcher, March 2017

Bringing together PAR and Aboriginal concepts of learning as you go along into our inquiry framework provided a solid foundation that supported Aboriginal leadership and Aboriginal ways of teaching and learning in the Project. In the final workshop, one of the nurse participants shared that their key insight from working on the Project was



[t]he desire the patients have to have good relationships with nursing staff and willingness to share stories to support this. Nurse participant (N06), April 2017

7.1.2 A process that engaged the nurses

This Project was a new experience for the nurse participants, as highlighted above (Section 6.2.2). This fact, together with the nature of the process, meant that there was uncertainty about what to expect,

When I first said yes to participating in this Project, I did not know what to expect and I was not sure, you know. And when I learnt we would have patients with us, I thought it would be challenging thinking how would it affect us, and the information we shared. [But] I learnt during [the Project] that it was okay because there was openness and privacy [through the agreements we made of how we wanted to work together]... I am fortunate to have been a part of this Project. Nurse participant (N01), April 2017

However, as also articulated in the quote above, the process enabled the nurse participants to engage safely and effectively and at the end of the Project many expressed that they felt “fortunate” and “privileged” to be part of the Project.

I'm loving it [the Project]. This program should be out there for everyone and every nurse should do it! I've found it fantastic, I've learnt so much. Nurse participant (N04), March 2017

While the nurses were supported to attend the workshops during work time, several of the nurses attended some of the workshops that fell on their rostered days off; so they also saw the value of committing their own time to continue participating in the Project. At each of the four workshops we had six or seven of the eight nurse participants in attendance.

In the questionnaire we asked the nurses to complete in the final workshop we asked what they enjoyed most about participating the Project. Here is a summary of their responses.

- ✚ It was an opportunity to spend time with patients outside the clinical setting

It's been an interesting journey because we come here and it's outside the hospital environment and we have found that it is different because our patients...start to open up more when they are dealing with us here, [compared with] the hospital setting...out here they open up and we are learning a lot of things here that we wouldn't have



learnt in the hospital and it's making us communicate better with our patients...It's been really useful because this information we are taking it back to our clinical area and it is changing the way we do things.

Nurse participant (N03), March 2017

- ✚ It was an opportunity to develop relationships with the patients

I like that [the Project] really makes the most of opportunities to build relationships and it helps us to reflect and look for ways to use what we are learning in other contexts outside of the Project itself.

Nurse participant (N06), March 2017

- ✚ Sharing together to learn

I personally enjoyed the group sharing because it gives us so much information which branches from one topic to another topic and they are all relevant to our nurse-patient relationship.

Nurse participant (N01), April 2017

- ✚ Hearing and "seeing" the patients' stories and learning from these

Seeing the life stories from patients' pictures.

Nurse participant (N07), April 2017

Being able to understand there is more to the patient than just being a patient. Learning how to communicate with them. Respecting their stories and feelings.

Nurse participant (N04), April 2017

- ✚ Learning words in language and the laughter when the nurses were trying to pronounce these words

The laughter as we tried to pronounce the words [in Aboriginal

language]. The amazing diversity of Aboriginal culture.

Nurse participant (N07), April 2017

Members of the Project team presented the Project at the AIATSIS National Indigenous Research Conference and to the Department of Prime Minister and Cabinet in Canberra in March 2017. The presentations included the video interviews with some of the nurse participants. Audience comments and reaction to the videos indicate that the enjoyment of nurses participating in the Project was clearly evident.

The active engagement and enjoyment by nurses in the workshops highlights the safe learning environment that was created as well as an openness to learning on the part of all participants.



7.1.3 Deepened cultural understanding and respect

The learning environment that was created fundamentally achieved a deepened level of cultural understanding and, importantly, respect. This, of course, was the primary objective of the Project.

The focus on language in the workshops with the nurses (see Section 6.2.3) was instrumental to the nurses' increased cultural understanding. The Aboriginal co-researchers know that language is fundamental to culture and that learning words in Aboriginal languages would help the nurses to understand their culture. In addition, it was a comfortable and confident place to start for the co-researchers. Through this focus on language, many of the nurse participants learned for the first time that there were multiple Aboriginal languages and peoples in Central Australia. This was significant in realising a greater understanding of Aboriginal people and their culture and encouraged the nurses to focus on and understand where the co-researchers were from in Central Australia, knowing that they spoke different languages.

I think it's giving me a greater understanding and more appreciation of different language groups and different cultural identity [related to] family. So it's made me see things a little bit different in that way.

Yeah it's definitely improved my understanding. Nurse participant (N05),
April 2017

Learning words and phrases in the Aboriginal languages increased the nurses' understanding of the sophistication of the languages and cultures and of Aboriginal knowledge and way of life. Focusing on language and practicing the pronunciation of words and phrases introduced laughter as the nurses tried to wrap their tongues around the Central Australian Aboriginal words. This lightened the learning environment and provided a balance with some of the other 'heavier' content in the workshops such when the co-researchers shared their stories of life before and after end stage kidney disease.

The diverse cultures of the nurse participants and the focus on language also provided an opportunity for the Aboriginal co-researchers to ask about words and phrases in the non-English languages spoken by some of the nurse participants and for the co-researchers to learn some of these words and phrases. This further strengthened cultural understanding and relationships.

In the workshops, words and concepts in Aboriginal languages provided a great platform for the exploration of other aspects of Aboriginal culture. Discussions about how to show respect and care in Aboriginal culture, the importance of family and family relationships and ways to make people feel comfortable in the dialysis units deepened the nurses' understandings of Aboriginal culture, values and beliefs.

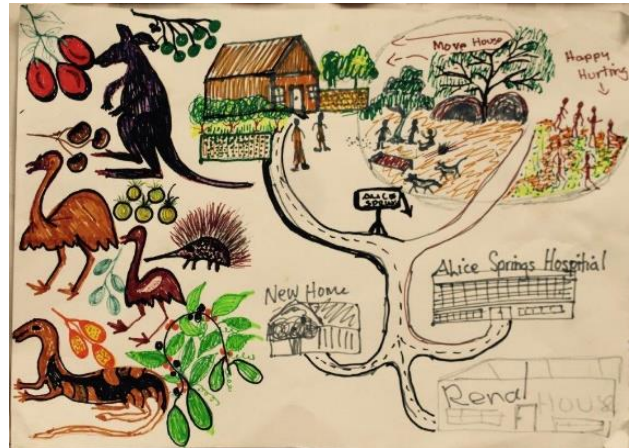
From this basis of increasing cultural understanding, a significant breakthrough in the learning occurred in Workshop 3 when the co-researchers had created drawings and told the stories of their lives. The stories shared by the co-researchers conveyed



the rich life they lived before dialysis with their families and on country, going hunting for bush foods, learning from their elders and passing on cultural knowledge to their grandchildren. What was obvious in the telling and the drawing of these stories was that the connections with family and country were not only important but life enhancing and nurturing, contributing to the co-researchers' wellbeing. Some of the co-researchers shared the traumatic experience of leaving their communities and families behind to come into Alice Springs to access dialysis treatment.

In sharp contrast to the richness of life in community, the depiction of the co-researchers' lives in Alice Springs and on dialysis were somewhat bleak and lifeless, as presented vividly in the drawing to the right here by Margaret Smith.

The sharing of these stories, both orally and through drawings, had a considerable impact on the nurses. It brought an acutely personal dimension to Central Australian Aboriginal people's experience of having to start and continue on dialysis. This provided new insight for the nurses, as illustrated in the quotes below.



Co-researcher Margaret Smith's drawing of her life before and after her brother, for whom she is carer, started dialysis in Alice Springs



Co-researcher Irene Nangala sharing her personal story using her drawing of her life before and after she started dialysis in Alice Springs

The biggest thing I have learnt is to look at my patients as people not patients. Listening to their stories [in Workshop 3] just changed everything for me. They're more than just patients on dialysis. There is more to them, there is so much more. And I think that I never stopped and thought about that [before].
Nurse participant (N04), April 2017



I really enjoyed the stories that people told us. I think that was just marvellous and also you told it with picture, as a picture story and I thought that was just a really good way of understanding where you come from and what it's like to deal with such a thing as, such a horrible disease as kidney disease. Nurse participant (N07), March 2017

I think that the key thing that I have learnt from this Project is actually hearing from the patients, about their feelings and thoughts towards their treatment. And also learning about their close family ties. It's been very helpful as you start to understand why [the patients] are doing things. Nurse participant (N01), April 2017

As revealed in these quotes from the nurses, hearing the stories of the co-researchers' lives was a turning point in deepening the nurses' understandings, not only of the richness of Aboriginal peoples' lives and culture, but also understanding of the profound impact of end stage kidney disease and relocation to Alice Springs to access dialysis.

While the Project provided an opportunity for the nurses to learn more about the culture and lives of the co-researchers, it also provided the time and space for reflection about these personal stories within their cultural context and the reality of dialysis for the people to whom the nurses regularly provide care: "hearing from the patients, about their feelings and thoughts towards their treatment". It brought a humanness to the mechanics of providing dialysis treatment. These stories were shared within the context of a deepened understanding of Aboriginal culture and ways of living supported by the Project and prompted greater reflection on the consequences of a life in Alice Springs on dialysis.

I think it's been a real privilege just learning the personal journeys that people have gone on and taken from, having to come away from their community with chronic health problems, come to a strange place.

And just how important it is to get those people back to community.

Nurse participant (N07), April 2017

The nurse participants reported an increased understanding of family and the importance of family relationships for Aboriginal people and therefore the importance of engaging family in care. Furthermore, the nurses increased their understanding of the importance of relationships between patients and nurses providing their care, if care is to better meet the needs of Aboriginal people on dialysis. For many of the nurses the insights gained through the learning in the Project brought a deeper respect for what care means for Aboriginal people within the renal care setting.



These insights about the lives of Aboriginal people on dialysis prompted the nurse participants to think about their practice in providing renal care for Aboriginal people and to consider how they could improve the quality of care as articulated by Aboriginal people.

7.1.4 Making a difference in practice: building relationships

We've built relationships with you guys [Aboriginal co-researchers]...we know about each other. Nurse participant (N02), March 2017

With regard to the sustainability of the achievements of this Project, a key strength is the fact that most of the Aboriginal co-researchers receive ongoing dialysis treatment at the renal units in Alice Springs. Therefore, the co-researchers have ongoing contact with the nurses who participated in the Project. As such, the respectful relationships that were developed through the Project between the co-researchers and the nurses have the potential to endure beyond the end of the Project. These relationships can be a resource for the co-researchers and the nurses, as recognised in the following quote by one of the nurse participants.

[The project] triggers me to reflect on my interactions and think about what I have learnt through the workshops. When I don't understand something I feel I can approach the patients who are co-researchers on the Project for guidance. Nurse participant (N06), April 2017

The reciprocal nature of the Project, meant that the nurses were also able to share aspects of their own cultures with the Aboriginal co-researchers, which helped to build the relationships. In Workshop 2 the nurses described their different roles and responsibilities in each of their positions within renal care provision. This increased the Aboriginal co-researchers' understanding of the diversity of roles and responsibilities that renal nurses held. Throughout the workshops the discussion across the various topics provided opportunities for nurses to share their experience of providing renal care and the related challenges. As a result the co-researchers came to a clearer understanding of the work of the renal nurses, including a better understanding of the concerns and priorities in providing renal care. This contributed to strengthening relationships and respect between the co-researchers and the nurse participants.

In terms of understanding how Project learnings would impact on their practice, the nurses reflected that the key differences related to their increased understanding of patients' experiences within this cultural context and consequently their care needs when receiving dialysis treatment. This included a greater awareness of the importance of including family in the care of people on dialysis and the increased understanding of the broad ranging impact of end stage kidney disease for Aboriginal people in Central Australia.



[I have learned] that everyone has a story and for each individual it is a personal journey. Chronic kidney disease not only effects individuals, it impacts on families and communities. Nurse participant (N07), April 2017

I got to share some information [with] my colleagues which can help us in giving/providing nursing care to our patients and including their family as a whole. Nurse participant (N01), April 2017

As a result, the nurse participants indicated that they had become more conscious of their interactions with patients, paying more attention to the patients as unique individuals and becoming more “active listeners” in these interactions, as reflected in the following quote.

I'm much more of an active listener with people now and I also recognise that they come from different communities and I try and interact with them about their individual communities and I think that's certainly helping me with my job. Nurse participant (N07), March 2017

For some of the nurses this meant becoming more aware of the importance to take the time to listen to each individual patient to try and understand what was happening for them despite the busyness of the workplace. This emphasised the nurses' increased understanding of the importance of the relationship between them and the people on dialysis in providing effective renal care.

Despite the busy activity it has made me take time to pause and listen. Nurse participant (N03), April 2017

I think I had the conversations [with patients before], but I don't think I stopped and thought. I think I'm remembering more now. When somebody tells me something, I think I am taking it on board more now. And making sure that I remember more, and to have that conversation with them next time, not just the basic “hello how are you?” Nurse participant (N04), April 2017

I think a lot more about every decision I make [in my job]. I think I have learnt a lot [from] these workshops in doing that. Nurse participant (N07), April 2017

These experiences of changes in their practice as a result of the learnings in the Project are demonstrated in the following nurse's reflection.

I find coming away from the workshops that I really spend a lot more time considering the interactions I have with people [at work]. And



because in the workshops it really does provide an opportunity for us to come into a space without those pressures that we're dealing with when we're in the work environment and then that allows us to actively listen and share and make those connections in a really safe environment. And when I go back to work, I can sort of take myself back to that space where we are in that environment [in the workshops] and actually use that to actually take myself back another step and even though I'm back in that busy, crazy work environment, [I think] "No, this is really important that I'm sitting down listening to people and hearing their stories and trying to understand better what's happening so that I can help in the best way that I can." Those relationships that I have been able to build with the people involved in the Project, I find really help me to improve relationships that I have with other patients that I'm spending time with. Nurse participant (N06), March 2017

What is clear from the feedback from the nurses is that the workshops not only provided a learning opportunity, they also provided an opportunity for the nurses to reflect on their practice and the implications of their learnings through the Project for their ongoing practice. The benefits of this time for reflection provided the following insight for one nurse participant:

That listening and reflection is important in our daily practice. Nurse participant (N03), April 2017

7.2 Implications for improving care and better relationships in renal care

The key Project outcomes of deepened cultural understanding and respect and strengthened relationships between the nurse participants and the (patient) co-researchers have important implications for improving care and creating better relationships in renal care. What has been achieved is more than cultural awareness. Cultural awareness is defined as "the first step in being aware that there are differences between people" [14, p. 12]. Cultural sensitivity is considered the next step where the health professional "can apply their awareness of cultural differences to their own practice" and think about how his/her own attitudes and how these might affect a person from a different culture that they are caring for [14, p.13]. There is evidence of this level of cultural sensitivity among the nurses who participated in this Project.

Furthermore, in achieving deepened cultural understanding and respect and strengthened relationships, what has emerged is increased empathy and cultural humility; two important elements in person-centred and culturally safe care [14, 25].



Providing “person-centred care across the lifespan” and “services which are accessible, appropriate, culturally secure and responsive, and effective for Aboriginal people” are central to the strategic objectives of the Northern Territory Department of Health [26, p. 10 & 11, respectively]. Therefore, outcomes from this Project have the potential to contribute to the achievement of these strategic objectives in a practical way.

7.2.1 Empathy

Empathy is a critical underpinning for person-centred care [25]. Person-centred care requires that the care provided is respectful of and responsive to a person's needs and values, and there is active engagement of the person in their care, which in turn requires a level of understanding and attunement on the part of the health professional [25, 27]. In the context of patient care, empathy is defined as:

a predominantly *cognitive* (as opposed to affective or emotional) attribute that involves *understanding* (as opposed to feeling) of the patient's experiences, concerns, and perspectives, and a capability to *communicate* this understanding [28, p. 80, emphasis in original].

In this definition of empathy in patient care, by Hojat and colleagues [28], derived from their research into factors that contribute to positive patient outcomes, they highlight three “key ingredients” of empathy in health care: cognition, understanding and communication. It can be argued that the processes adopted by this Project created a learning environment that enhanced the nurse participants' ability to think about (cognition) and come to better understand the experiences, concerns and perspectives of the co-researchers with regard to renal disease and dialysis. In the reflections from the nurses at the end of the Project it was evident that they were able to articulate these enhanced understandings and their implications for changes to their practice to improve care from a patient's perspective and strengthen relationships in the care setting.

I've always tried to have an appreciation, but I think it's having a greater understanding so I can appreciate it more and it's like when you're treating your patients as individuals and not just a patient, it's a person. And I try to do that now. It's not just a patient coming up for dialysis. It's that individual, how are they, or what sort of person are they. It's a lot more meaningful than just a patient being on dialysis. Nurse participant (N05), April 2017

The complexities of Aboriginal health can become overwhelming for health practitioners, especially as many of the issues and determinants of health are outside individual practitioners' control. As a way of coping “practitioners might just ‘do their job’ without reflecting on practice, and in the process unfortunately become desensitised to the issues” [14, p. 185]. It appears that what this Project enabled was an opportunity for the Aboriginal co-researchers who live with this



complexity, to share their experiences with the nurse participants in a way that provided insights and practical information about how the nurses could make a difference to the lives of Aboriginal people on dialysis. As a consequence this increased the nurses' empathy.

7.2.2 Cultural humility

What was evident across the course of the Project was a re-thinking of the assumptions that many of the nurse participants had with regard to the Aboriginal people on dialysis and perspectives on their treatment. New meaning or the reconstruction of existing meaning [29] emerged for the nurses through the reflection and learning from the Aboriginal co-researchers in the Project. It can be argued that this revealed increasing cultural humility on the part of the nurse participants.

In a multicultural world where power imbalances exist, cultural humility is a process of openness, self-awareness, being egoless, and incorporating self-reflection and critique after willingly interacting with diverse individuals. The results of achieving cultural humility are mutual empowerment, respect, partnerships, optimal care, and lifelong learning [30, p. 213].

Over the course of the workshops, the nurse participants demonstrated an increasing openness to listening to and learning from the Aboriginal co-researchers and this was evident to the co-researchers as well as the research facilitator. In some instances these new learnings challenged the nurses existing assumptions and required them to re-consider their understandings of issues relating to Aboriginal people and the renal care context in Central Australia. This increased cultural humility was beneficial for the nurses and co-researchers, strengthening the relationships, deepening mutual respect and redressing power imbalances, as reflected in the definition of cultural humility included above.

Cultural humility is embedded in culturally safe practice in health care settings and both are regarded as lifelong learning [14, 30]. Key principles of cultural safety include the need for practitioners to continually reflect on their practice and "talk, ask, engage with the client" [14, p. 15]. Through this patient-led project, the nurse participants were able to engage in dialogue with the Aboriginal co-researchers, who are clients of renal services, in a way that is not usually possible. The renal clinical setting is busy and not conducive to extended conversations between practitioners and patients about issues or topics broader than the immediate clinical treatment situation. The workshops provided a safe space outside of the clinical settings for rich and meaningful dialogue to occur, promoting reflection on practice and increasing cultural humility.

Cultural safety in health care requires that the care provided is "regardful of culture" as opposed to care being provided "regardless of culture". "Treating clients the same, regardless of culture, fails to acknowledge the unique needs and issues affecting people who are culturally different, either to one another, or to the healthcare provider" [14, p. 187]. The increased cultural understanding of the nurse participants achieved through the Project resulted in key insights with regard to the importance of culture and context in providing effective and culturally safe care.



One of the nurse participants, who has been working in renal services in Central Australia for several years, reflected:

I think the most important insight I'm taking away from this Project is that being a renal nurse is not all about giving dialysis treatment to our patients but also understanding in depth about their culture, which is really challenging. And this is vital to actually saying we care for them. Nurse participant (N01), April 2017

According to Taylor and Guerin [14, p. 105] “no-one need negate their own culture and cultural values in order to practice cultural safety principles and appreciate another’s culture”. To practice cultural safety is to be mindful of the way one’s own culture impacts on decisions, actions and beliefs and to “act with care, compassion and courage as you attempt to meet the healthcare needs of people in your care”.

8 A patient-led component of cultural awareness training for clinicians

8.1 What we know from the literature

Since the 1960s patients have been engaged as educators of health professionals. The rationales for the active involvement of patients as educators are well articulated and include “great potential to promote the learning of patient-centred practice, inter-professional collaboration, community involvement, shared decision making and how to support self-care” [31, p. 64].

Involvement of people who are patients, carers and service users in health professional education is diverse and patchy and given relatively low priority according to a recent literature review from the United Kingdom [32]. However, where it is happening,

[t]here is strong evidence that patient/user involvement has short-term benefits for all involved, including learners, educators, institutions and patient/users, across a wide range of domains, such as knowledge, skills, attitudes, behaviours. Longer term, there has been little evaluation to discover whether patient/user involvement has an effect on the behaviour or practice of health professionals or on health outcomes [32, p. 4].

Patient narratives involving patients sharing their stories with health professionals are commonly employed as part of medical training [33, 34] and evoke an emotional response [35]. A systematic review of patient-led teaching in medical education reported the effectiveness of patient-led teaching for health care professionals in terms of learner satisfaction and improved communication skills [34]. In addition, the positive impact of patient involvement on the patients themselves including empowerment and improvement in patient–doctor communication was highlighted in this review.



There is an increasing interest in involving patients in patient safety education for health professionals as this brings a 'patient lens' rather than the conventional 'health professional lens' to the issues and consequences of patient safety. However, there is a lack of research on the nature and impact of patient involvement or the effectiveness of these initiatives in patient safety [35].

Within the Australian Indigenous context, there is evidence that bringing together the cultures of health care organisations with Indigenous communities can improve access to health care for Indigenous Australians and that health professionals developing partnerships, eliminating bias through self-reflection, and building relationships with Indigenous people contributes to reducing health disparities for Indigenous populations [13]. Developing partnerships with Indigenous people through collaboration in the planning, implementation and evaluation of cultural competency training programs is one of the principles in culturally safe practice [13]. Working with local communities, such as a patient or consumer group, ensures that programs address the needs of those utilising the services. In considering cultural competency, clinicians working in Aboriginal health have reported the importance of "respect, engagement and knowledge of their patients' home environments and country, and their use of language and health concepts" [36, p. 548].

Increasingly, cultural immersion programs for medical and health science students through remote Aboriginal clinical placements are proving to be highly valued and deliver "profound learning experiences" for participants [37, p. 11]. Such programs involve students spending time in an Aboriginal community and/or setting. Following 'immersion', participants, valued the opportunity to connect with community members and gain cultural knowledge experientially that was relevant to their work.

The *Community as Teacher* model is one such program that involves health professional students being briefly immersed in an Aboriginal community through attendance at a camp for Aboriginal youth, run by Elders and cultural leaders in British Columbia, Canada. A study of this program involving short and longer-term follow up of participants demonstrated positive outcomes for the health professional students with regard to their capacity to practice culturally safe care [38]. This study demonstrated that culturally safe practice can be learned through brief immersion in an Aboriginal community where the community is teacher and the health professional's role is primarily as a *learner*, rather than as a health professional. Key outcomes revealed in the short-term follow up included enhanced cultural awareness and sensitivity of the students and enhanced "ability of students to conceptualize [sic] how they might overcome communication barriers in practice to build trust" [38, p. 14] – an important ability in culturally safe practice.

Over the longer-term the follow up revealed a greater appreciation of the expertise that exists in the Aboriginal community, which contributed to the students' understanding of Aboriginal health and ability to practice culturally safe care. There was also an increase in the students' self-awareness resulting in a questioning of stereotypes and assumptions and increased cultural humility [38].



Similar to our patient-led PAR project, the *Community as Teacher* program was voluntary for the health professional students, offered an opportunity for two-way learning and, importantly, took place away from the clinical setting so that the students could “interact with the community on the latter’s turf and terms” [38, p. 16]. Like our patient-led PAR Project, this program allowed “students to see the community as an authority on its members’ unique strengths, needs, and challenges” through the voices and stories of the Aboriginal people themselves [38, p. 15].

Indigenous patient-led training has the potential to increase understanding of the social determinants of health as patients share their lived experience of health and wellbeing and health care. Understanding this social view of health has been demonstrated to enable cultural respect in Indigenous health care settings, especially when service-level strategies were developed to enhance culturally respectful care [39].

Patient-led initiatives challenge the usual power imbalances inherent in health care interactions. Traditionally, these interactions in the clinical setting are almost always controlled by the service provider; “there [are] few opportunities for patients to initiate or influence the agenda” [8, p.468]. There is a growing literature on the importance and effectiveness of patient-led initiative to inform health care design and provision that is person-centred and culturally safe.

8.2 Project key learnings, enabling factors and limitations

Through our experience of implementing this Project we have identified the following key learnings together with factors that have been important in enabling the success of the Project. In this section we also articulate the Project’s limitations.

8.2.1 Key learnings

Following are the key learnings we identified through implementing the Project.

Feasibility: willingness to learn and improve relationships in care

Feasibility of the patient-led initiative was demonstrated by the support for the Project from the renal service providers and the willingness and commitment of the Aboriginal co-researchers and the nurse participants to engage effectively in the Project.

The high level of participation from the Aboriginal co-researchers and the nurses revealed their mutual desire to increase cultural understanding and improve relationships in care – despite the challenges of health conditions, family and work demands, all participants prioritised the Project workshops.

There was mutual benefit for the Aboriginal co-researchers and the nurse participants: they learned more about each other, increased respect and understanding.



Primacy of relationships

Effective working and personal relationships at multiple levels were important for the implementation of the Project. These relationships were based on trust and mutual respect and understanding.

In the workshops with nurses the Aboriginal co-researchers identified key features of showing respect in Aboriginal culture. These were communication – taking the time to listen, showing patience, being friendly, happy, smiling, generous, helpful and loving, and showing kindness (see Section 6.2.3). The relationships developed between the research team, Aboriginal co-researchers and the nurse participants incorporated these features. They were nurturing relationships and created a solid foundation for the Project.

Learning happened through sharing stories, drawings and language

Storytelling, both orally and through drawing, was an effective mechanism for teaching and learning in this Project. These ways of teaching are consistent with Aboriginal ways of teaching and learning and therefore were important for the Aboriginal co-researchers to feel comfortable and confident as teachers in the workshops. In addition, the stories shared by the Aboriginal co-researchers drew



Co-researcher Margaret Heffernan sharing her personal story using her drawing of her life before and after she started dialysis

on personal experiences and cultural knowledge providing content that was unique to the co-researchers. This provided solid ground in terms of content, further inspiring the confidence of the co-researchers.

The stories and drawings proved to be effective for the nurses to learn about the Aboriginal co-researchers, their culture and social context of their lives, health and wellbeing. The Aboriginal co-researchers' sharing of their experiences of life before and after dialysis through story and drawing evoked an emotional



response from the nurse participants. The stories shared enabled the nurses to gain greater insight into the co-researchers' experiences as well as increased their empathy and cultural understanding.

A focus on Aboriginal languages to explore words and concepts enabled learning and insight for the nurse participants about Aboriginal people, culture, worldview, values and beliefs. In this way the language brought culture to life for the nurse participants. For the Aboriginal co-researchers using words in Aboriginal languages meant that they were starting from a place of strength and knowledge and were able to demonstrate the richness and complexity of their culture through language.

Learning happened 'in relationship' – reciprocity

The learning that occurred through the Project was enabled by the relationships that were developed between the Aboriginal co-researchers, nurse participants and the research team. The trust and respect established through these relationships enabled the Aboriginal co-researchers to share personal stories and experiences, including those that were traumatic as well as those that were funny. The integrity of the stories and experiences shared by the Aboriginal co-researchers and by the nurses in response was enhanced by the nature of the relationships and the safe space that was created in the workshops. Learning through the sharing of stories and knowledge demonstrated the importance of the reciprocity enabled through these relationships.

8.2.2 Important enabling factors

We identified that the following factors that were important in enabling the success of the Project.

Bicultural inquiry framework

Drawing on Aboriginal and non-Aboriginal knowledge to bring together the PAR process and an Aboriginal approach to learning as you go along, offered a strong bicultural framework. This supported the co-researchers' input into the design of the Project. It also supported Aboriginal leadership of the Project and the privileging of Aboriginal ways of teaching and learning. In addition, the framework required a focus on relationships paying attention to the power dynamics.

Facilitation – PAR core working principles

The enacting of the core working principles of PAR – relationships, communication, participation and inclusion – was critical to the success of the Project and ensuring that it was patient-led (see Section 6). And an experienced facilitator was critical to the process of enacting the PAR principles throughout the Project. Relationships of trust were developed between the research facilitator and the co-researchers and the research facilitator was central to the provision of social support and transport indicative of the reciprocity in relationships. What we achieved in only four, 3-hour workshops was enabled by



initially focusing on the formation of the Aboriginal co-researcher team guided by the PAR core principles, focussing on relationships, and process and continuing to be guided by these principles in the workshops with the nurse participants.

Flexibility and adaptability

Flexibility and adaptability in the approach was critical to the effective implementation of the Project. All participants had differing demands on their time and as much as possible the Project activities accommodated this. Having five Aboriginal co-researchers enabled capacity and flexibility to progress the Project even when some of the co-researchers were unable to participate at certain times due to health or family reasons. Similarly, having eight nurse participants enabled this capacity and flexibility. Flexibility within the workshops also was important to facilitate the storytelling and enhance the interactive learning that occurred through the discussions in the workshops.

Voluntary participation

The co-researchers and nurse participants all voluntarily self-selected to participate in the Project. This meant that all participants were motivated and interested to participate in the Project in the first instance and were open to learning from each other.



Project participants at Workshop 1

Focus on process and space: creating a culturally safe and friendly space for learning

Based on the quality of the relationships developed, as discussed above, we were able to create a culturally safe and friendly space conducive to learning through a focus on the process as well as the venue and environment for the workshops. Importantly, this space was outside of the clinical workplaces, on more neutral ground for the co-researchers and the nurses; this was a way of enabling everyone to participate as equals, neutralising the inherent patient/health professional power



dynamic. We ensured that the rooms where we held the workshops were comfortable and welcoming and we always provided food. We also made the rooms colourful with wall displays of the words and information we were discussing. In addition, we had coloured paper and markers on the table to encourage drawing throughout the workshops. These features helped to make the participants feel relaxed and safe when they attended the workshops. In terms of process, we ensured that the Aboriginal co-researchers were supported to prepare well for the workshops with the nurses so they could increasingly lead these workshops with confidence.

The Aboriginal co-researchers were committed to working in a friendly way with the nurse participants and they were focussed on making the nurses feel comfortable, injecting the right amount of humour throughout the workshops.



Drawing by co-researcher Eileen Bonney in one of the Project workshops

8.2.3 Limitations

The Project also had limitations. The time and resources available to the Project meant that there is no medium or longer-term follow up of the nurse participants to find out if their learnings through the Project have been sustained and in what ways this has influenced their practice. Therefore, at this stage it is not clear if the outcomes achieved in the short term through this patient-led initiative continue in the longer term.

The fact that there was positive learning outcomes for the nurse participants may be partly due to the voluntary nature of participation in the Project. It is likely that the Project attracted nurses who are interested to learn more about Aboriginal people and are open to learning in different ways. However, voluntary participation in the Project is considered to be an important aspect of the PAR process, which supports people who want to actively make some change. Therefore, this is a feature of the PAR approach, rather than a limitation, as PAR is a catalyst for change where people want change.

While this patient-led initiative within renal services in Central Australia has been shown to be effective in deepening the nurses' cultural understanding and respect and developing better relationships between the nurses and (patient) co-researchers in the short term, it remains to be seen if these outcomes are sustained in the longer term. Further the transferability of the program to other places and settings, outside of Alice Springs and outside of renal services, is unknown.



8.3 Key features of a patient-led training initiative to increase cultural understanding and strengthen relationships in care

The key objective of this Project was, firstly, to understand what a patient-led component of the cultural awareness program for renal clinicians would comprise and secondly, if it could be feasible and sustainable. Based on our Project outcomes and learnings, this patient-led initiative did more than increase cultural awareness. It enhanced cultural sensitivity and understanding through which the nurse participants gained insights and increased their empathy and cultural humility. This deepened understanding and insights were beginning to inform their practice and had strengthened their relationships with the (patient) co-researchers (see Section 7).

Below we have identified key features of the patient-led training initiative developed through this Project. This training could be included in the cultural awareness program to increase cultural understanding and strengthen relationships in care.

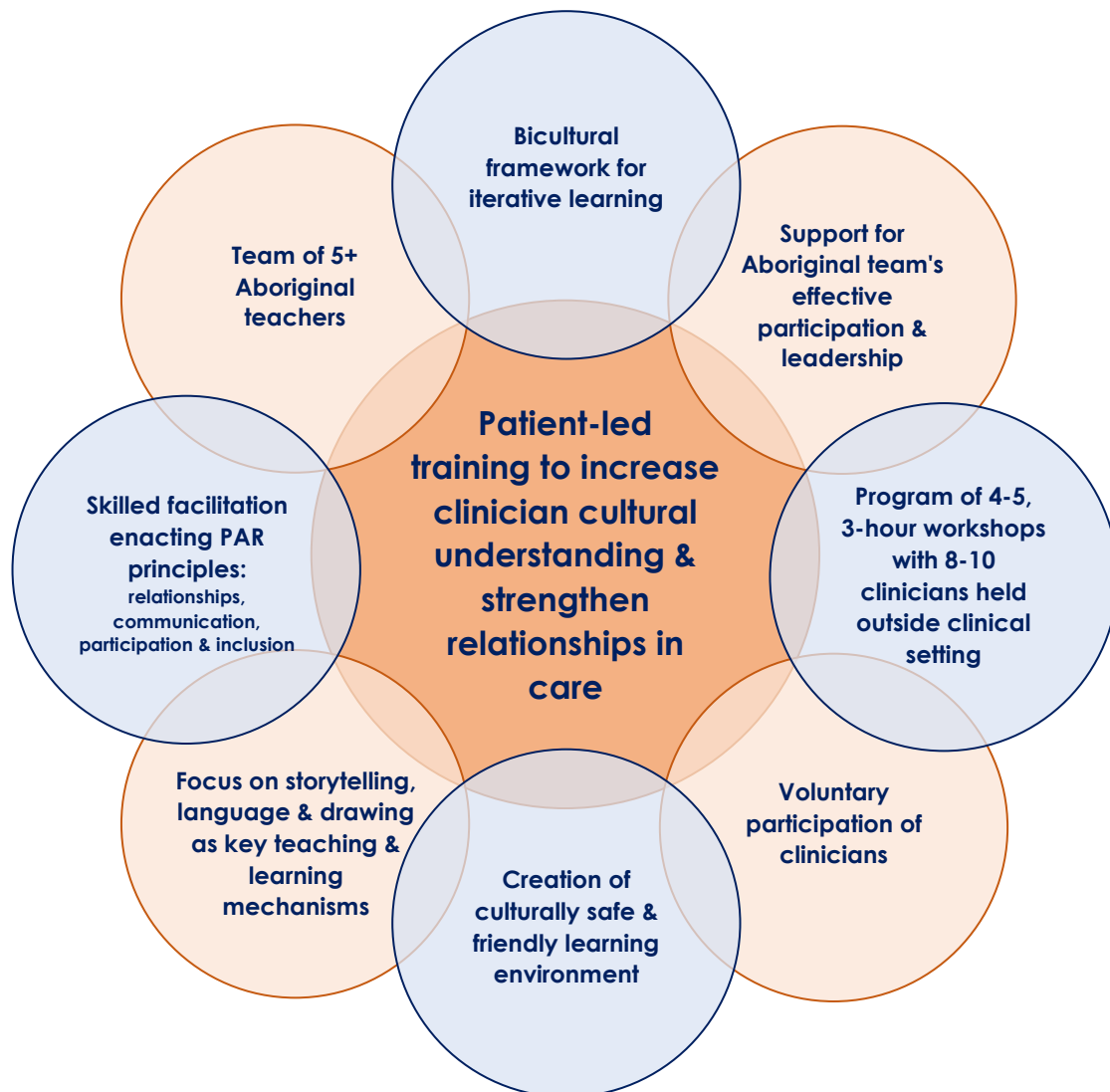


Figure 3: Key features of patient-led training to increase clinician cultural understanding & strengthen relationships in care



Through this Project we have been able to demonstrate that a patient-led training initiative for renal clinicians is feasible in terms of the level of interest and motivation to participate that was evident on the part of the co-researchers and the nurses. It is also feasible in terms of people being supported and able to attend a series of 3-hour workshops.

In terms of sustainability, there would need to be ongoing funding to support the team of Aboriginal teachers and a facilitator. In addition, there would need to be ongoing recruitment and development of the relationships between the Aboriginal people engaged as teachers to ensure their participation was manageable and did not become too burdensome given the reality of the cultural and social context of living in Alice Springs with complex chronic illness.

There is great potential for a patient-led initiative aimed at increasing cultural understanding and strengthening relationships between clinicians and patients to become part of the ongoing cultural awareness training for clinicians. Some of the nurse participants suggested that it would be beneficial to include doctors and other health professionals as well as nurses in future programs. There is also the potential for some of the workshops to be held in country close to Alice Springs which would bring different perspectives and learning mechanisms.

I just hope this can go on and all nurses can be part of this at some stage. It's a great program. It's been awesome! Nurse participant (N04), March 2017



Some of the Project participants at Workshop 4 standing L-R: Mary Jane Ferrer, Colin Paine, Kara Page, Kerry Taylor, Wendie Hume and Dean Oldfield; Seated L-R: Margaret Heffernan and Irene Nangala



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10 Appendix A: Word List

This Word List contains the words and phrases that were identified by the Aboriginal co-researchers Margaret Heffernan, Irene Nangala, Margaret Smith, Eileen Bonney and Mr Nelson during the Patient-led Participatory Action Research Project, October 2016 to April 2017.

Greetings/key words/phrases

English	Pitjantjatjara	Pintupi/Luritja	Alyawarr	Warlpiri
Yes	Uwa	Yuwa	Yew; Yaw; Yew yew	Yuwayi
No	Wiya	Wiya	Arrangkw (no, nothing) Menty (no, leave it)	Kula
Good	Palya	Palya	Mwerr	Ngurrju
Are you well/how are you?	Nyuntu palya?	Nyuntu palya?	Mwerrang ngay?	
I'm good	Ngayulu palya	Ngayulu palya		
Good-bye	Kulpai	Ngulananta nyaaku	Ingwer-ingwer areyew	
Place where people stay (home)	Ngura	Ngu-rra		
Law (traditional Aboriginal)	Tukurpa	Tju-ku-rru-pa	Iwerreny	
Shy	Kun <u>ta</u> -kun <u>ta</u>	Kun-ta	Nyerr	
Moon	Kin <u>a</u> ra	Pira	Alkent	
Name	Ini	Yini	Itna	
What's your name?	Nyumtu ini ngananya?	Yini nyuntu ngananya?		
Leave it	Wanti	Wanti		
Wait	Pa <u>t</u> ani	Patala	Alerl	

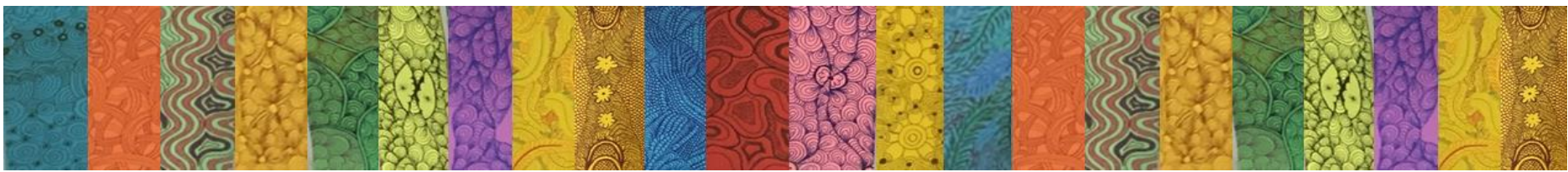


English	Pitjantjatjara	Pintupi/Luritja	Alyawarr	Warlpiri
I'm going		Ananyi-na		
One	Kutju	Kutju	Anyent	
Two	Kutjara	Kutjarra	Atherr	
Three	Maṅkurpa	Mankurpa	Arrkwenty	
Four	Kutjara-kutjara	Muti		
Five	Kutjara-maṅkurpa	Raka		
Six	Maṅkur-maṅkurpa	Katukutu		
Seven	Mankupa-mankupa-kutju	Kali		
Eight	Munti	Kuru		
Nine	Mankupa-mankupa-mankupa	Tjurukutu		
Ten	Mara mara	Kalala		
North	Alinytjara	Yalinytjarra	Ayerrer	
South	Uḷpaṛira	Uḷparirra	Antekerr	
East	Kakarara	Kakararra	Akngerrakw	
West	Wilurara	Wilurarra	Altwerl	
Monday		Man-ta-yi		
Tuesday		Tjuu-tja-yi		
Wednesday		Wii-ni-tji		
Thursday		Tju-rru-tji		
Friday		Pu-ra-ta-yi		
Butterfly		Pin-ta pin-ta		



Names for people and family

English	Pitjantjatjara	Pintupi/Luritja	Alyawarr	Warpiri
Person/people (Aboriginal)	A <u>n</u> angu	A <u>n</u> angu	Ingkerr	Yapa
Senior woman	Minyma		Arelhampwa	Yarnunjuku-parnta
Young woman	Kungka		Arelh	Milkari
Senior man	Tjilpi		Artwamp	Pariwanpa
Senior knowledgeable man				Wati riri-rirri
Man	Wati		Artwa	Wati
Old people		Yulkumanu		
Family	Walytja	Waltja	Altya	
Full or extended family	Walytjapiti			
All the family together		Waly-tja-ra-rran-pa		
Mother	Ngunytju		Amey	
Father	Mama		Akngey	
Grandmother	Kami			
Grandfather	Tjamu	Tja-mu		
Daughter	U <u>n</u> talpa	Yun-tal-pa	Ampa (of a woman) Aler (of a man)	
Son	Katja	Ka-tja	Ampa (of a woman) Aler (of a man)	
Granddaughter	Puliri	Ka-pa-li		
Grandson	Pakaji			
Cousin		Wa-tji-rra		



Health, wellbeing and care

English	Pitjantjatjara	Pintupi/Luritja	Alyawarr	Warlpiri
Sick	Pika (can also mean pain or fight dependent on context)			Nyurnu
Pain	Pika	Mikinpa	Arkweyel (to be in pain)	
Are you sick?	Nyuntu pika?	Nyuntu miinta?		
Are you feeling better?		Pa-lya lingku?		
Loving heart	Kurunpa mukulya			
Willingness to help and care	Wanganara			
To stop it before it gets worse (prevention)	Ngara tjungkutjaku pukaringku payika	Yanga-tjunkula palyala		
Prevention		Ngalkinmamkula palyanytjaku		



How we worked together

English	Pitjantjatjara	Pintupi/Luritja	Alyawarr	Warlpiri
Thinking, listening, understanding as you go along and over a period of time	Kuliḷkatinyi			
Looking at or for something as you go along and over a period of time	Nyakukatinyi			
Making/doing something as you go along and keeping doing something over a period of time	Palyaḷkatinyi			
Reciprocity; turn & turn; sharing together; we give to each other	Ngapartji ngapartji	Yinytjanu-yintjanu	Antherreyel anwantherr	
Listening while going along			Awelheyneyel	Purda-nyanyirlipa-nyanu yirri-yirriḷḷi nyampu-kuju
Listen				Purda-nyanyi
Listen to each other			Awerreyel	
Thinking while going along			Iḷterreyneyel	
Hearing while going along			Aweyneyel	
Looking and seeing while going along			Areyneyel	
Doing something while going a long			Mpwareyneyel	
Making something while going along			Arnwarneyneyel	



English	Pitjantjatjara	Pintupi/Luritja	Alyawarr	Warlpiri
Understanding as we are going along				Manngu nyanyi-rlipa-nyanu nyampu-kuju
Looking out				Nyanyja-karra
Let's listen to one another				Purda-nyanyi-rlipa-nyanu ngalipa-rluju
Planning			Arrwekel-antey iterrey	
Together	Tjungu	Tju-ngu-(la)	Iteng	
Company (people)				Marlpa
Coming together				Jinta-jarrimi
In one place together				Jintangka-juku mapirri
Careful				Muurlpa
Carefully talking				Mwentyel angkayntetyek
Not talking the wrong way				Apmwel-ayeth angkey-angenh
Good listener	Palya kulintjaku	Palya-kulintjaku		
Telling stories		Ya-ra wankanyi		

