



Final Report – Executive Summary

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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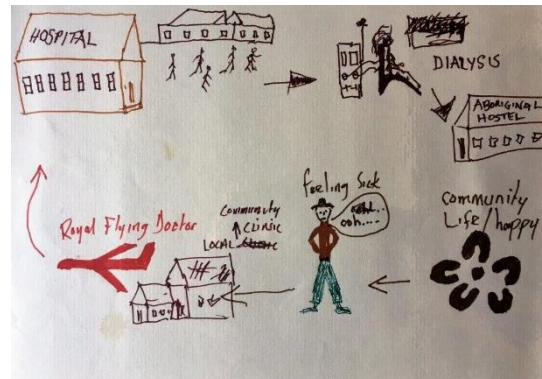
This is the Executive Summary of the Project's Final Report which can be accessed at www.menzies.edu.au

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
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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

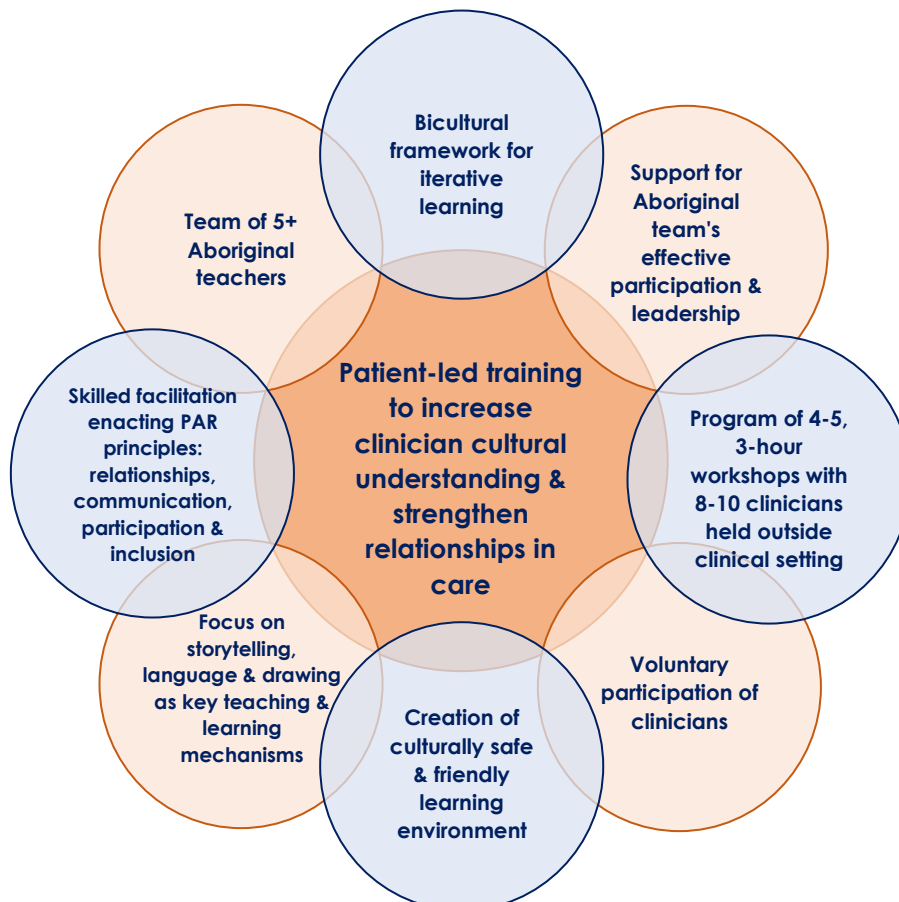
- Key learnings from implementing the Project include:
 - the patient-led initiative was feasible in terms of support from renal services and the desire and motivation of participants;
 - effective working and personal relationships at multiple levels in the Project, based on mutual trust, were important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

Visit www.menzies.edu.au to access a copy of the Project's Final Report