



Progress Report

Project Name	PAR Project: Developing a patient-led component of cultural awareness training
Report compiled by	Samantha Togni & Georgia Robinson
Project aims	
<p>This project's genesis is the Central Australian Renal Voice – a renal consumer advocacy group's – desire to work with renal clinicians to increase clinicians' cultural understanding and to develop better clinician-patient relationships based on mutual respect and understanding. Adopting a participatory action research approach the project engaged Aboriginal people on dialysis and renal clinicians who work with researcher facilitators through iterative action and learning cycles. The aim is to explore how a consumer-led training component of cultural awareness training could work.</p>	
Overview of project's achievements to date	
<p>The project is funded through Menzies School of Health Research by the Primary Health Network. It has received great enthusiasm and engagement from senior management to staff and patients involved in renal services in Alice Springs. This consumer-led project involving people from four Aboriginal language groups in Central Australia, is offering a transformative experience for Aboriginal people and the mainly non-Aboriginal renal workforce involved in their care.</p>	
Summary of activities	
<ul style="list-style-type: none"> ▪ <i>High level stakeholder engagement</i> ▪ <i>Central Australian Human Research Ethics Committee approval</i> ▪ <i>Establishing the project and training with Aboriginal co-researchers</i> ▪ <i>In-service presentations at Alice Springs renal units and ASH renal ward</i> ▪ <i>Workshop One</i> ▪ <i>Workshop Two</i> ▪ <i>Workshop Three</i> ▪ <i>Next Steps</i> 	
Stakeholder engagement	
<p>Support for the project was sought from the following:</p> <ul style="list-style-type: none"> - <i>Central Australia Health Service (CAHS)</i> - <i>Fresenius Medical Care</i> - <i>Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT) Aboriginal Corporation</i> - <i>Central Australia Renal Voice (CARV)</i> <p>Engaging these stakeholders was a critical step in progressing with the project and the ethics application. The above stakeholders are responsible for providing dialysis care in the Central Australia region. For us to engage participants in the project, we required the approval and support from them to proceed.</p> <p>In engaging these stakeholders the project team was mindful of the various demands and challenges faced by these stakeholders. Health services in Central Australia and particularly renal health services are under significant pressure from increasing patient numbers combined with funding and staffing challenges. Indigenous renal patients and the carers of patients are experiencing a multitude of difficulties with housing, income, relocation, transport, social isolation and other worries for family and country.</p> <p>To effectively engage the stakeholders under these circumstances, the project team took a flexible approach, maintaining communication, including face to face meetings to share information about the project at times that were most convenient to the stakeholders. Social and logistical support was provided to the Aboriginal co-researchers and it was important to identify an appropriate physical space to meet and create a safe space for</p>	



the Aboriginal co-researchers to establish and develop their leadership of the project. The Poche Centre in Alice Springs has provided access to its meeting room and facilities for our workshops. This space works well and we have all been made to feel very welcome and provided with great support.

To have the level of engagement and stakeholder ‘buy in’ that we do is exceptional and highlights the desire of both clinicians and consumers to engage and strengthen relationships and to learn from each other.

Investigators were identified to ensure a range of skills and knowledge in the area of qualitative research, lived experience of dialysis and cultural knowledge and renal health care in Central Australia. The following people were invited and accepted positions as project Investigators:

- *Samantha Togni (Senior Qualitative Researcher, Menzies)*
- *Kerry Taylor (Deputy Director of the Poche Centre, Flinders NT)*
- *Gillian Gorham (Renal Research Program Manager, Menzies)*
- *Sarah Brown (CEO, WDNWPT)*
- *Tara Conlon (Clinical Nurse Manager, Flynn Drive Renal Unit)*
- *Bigani Dube (Clinical Nurse Manager, Fresenius Renal Unit)*
- *Adrian Nelson (Co-Chair, Central Australian Renal Voice (CARV), Community Researcher)*
- *Margaret Heffernan (Community Researcher)*
- *Margaret Smith (Director, NPY Women’s Council, Community Researcher)*
- *Eileen Bonney (Director, Ampilatwatja Health Centre, Community Researcher)*
- *Irene Nangala (Co-Chair, Central Australian Renal Voice (CARV) & Director, WDNWPT)*
- *Georgia Robinson (Renal Research Project Manager, Menzies)*

Project Team:

<i>Project Director & Facilitator</i>	<i>Samantha Togni (Menzies)</i>
<i>Project Facilitator</i>	<i>Kerry Taylor (The Poche Centre NT)</i>
<i>Project Manager</i>	<i>Georgia Robinson (Menzies)</i>

Patient co-researchers: *Five Aboriginal co-researchers have been engaged. Co-researchers are either on dialysis, have received a kidney transplant or are the carer of a person on dialysis.*

Nurse participants: *Nine nurse participants from Fresenius Gap Road, Flynn Drive Renal Unit, WDNWPT & ASH Renal Ward took up the opportunity to participate in the project.*

Ethics

Approval was received from the Central Australia Human Research Ethics Committee on September 9, 2016.

Letters of support for the project were provided by:

Margot Hurwitz, Vice President and Managing Director of Fresenius Medical Care
Naomi Heinrich, General Manager of Alice Springs Hospital
Irene Nangala, Chairperson of the Board of WDNWPT and CARV

Establishing the project & in-service presentations

In the lead up to the first workshop, as part of ‘cycle one’ the project facilitator and project team worked with the co-researchers in intensive face-to-face sessions. These sessions involved increasing our joint understanding of the PAR process as well as Indigenous theories and ways of working together; learning, sharing, doing and planning. This included exploring these concepts using words in the four Aboriginal languages spoken by the Aboriginal co-researchers.

The co-researchers, with support from the project facilitator, presented the project plan and information during in-services at each of the dialysis units in Alice Springs (Gap Road, Flynn Drive, Purple House and ASH renal ward). The preparation for and presentation at the in-services were an essential component of establishing the



project and the leadership of the Aboriginal co-researchers. The in-services were an opportunity to inform the renal nurses about the project and invite them to participate in this process of learning together. The project was really well received with enthusiastic engagement and commitment from the nurses. The project actions and meetings so far have been aimed at building the confidence of the Aboriginal co-researchers to develop their leadership of the project and working in this PAR way of planning, doing, reflecting and learning, in a cross cultural space. Much of the work has been conceptual work around language and culture in planning for the workshop with the nurses. Learning together and sharing the language is an important foundation of cultural awareness.

Following each in-service presentation, the project facilitator met with the Aboriginal co-researchers to reflect on the presentations; how they went and the feedback and response from the nurses. These reflections and learnings informed the subsequent in-service presentations and continued to inform and develop the focus the project.

The project team and co-researchers met on the following occasions, for 2 – 3 hours at a time as part of the process to develop and prepare for the in-service presentations and then reflect on and learn from each in-service presentation in establishing the project:

- | | | |
|----------------------|-------------------------|---------------------------|
| - Thursday 21st July | - Tuesday 16th August | - Wednesday 7th September |
| - Friday 22nd July | - Wednesday 17th August | - Friday 30th September |
| - Monday 15th August | - Tuesday 6th September | - Wednesday 19th October |

The co-researchers provided a project progress update to the Central Australia Renal Voice quarterly meeting on the 15th and 16th of September as an important step in feeding back to the wider stakeholder group.

Workshop One

The first workshop, bringing together both the co-researchers and the renal dialysis nurses was held at the Poche Centre in Alice Springs on the 21st October 2016. The workshop began with some activities for everyone to get to know one another; where we all come from, the languages we speak and how long we have been living in Alice Springs. Discussion moved on to how we will all work together over the course of the project and the theories of PAR, as well as how this process of working and learning together aligns with Aboriginal ways of being and doing. There was a focus on language and the concepts and words in language and any words in the three Aboriginal languages spoken by the Aboriginal co-researchers were displayed on the wall and discussed.

Gift packs were provided to all participants. These gift packs contained gifts which were purposefully selected to prompt the sharing of knowledge, telling of stories and discussion. They contained:

- Western Desert Dialysis Bush Balm *or* NPY Women's Council Bush Balm
- A journal for attendees to take notes during the workshops and to write down thoughts, comments or ideas in between workshops. The journals included the following questions as a guide for the nurses reflections in between workshops:
 - How are you applying or using what you learned in the PAR workshop?
 - What difference is this making to you and/or your work with renal patients?
 - What are you noticing in your work with renal patients?
 - What are you are you puzzled or uncertain about?
 - What are your questions to bring to the next workshop?
- A Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council Uti Kulintjaku 'colouring towards clear thinking' colouring in book + coloured pencils

Traditional medicines, the plants used in these medicines and how they are made and used were discussed as well as how Aboriginal Australian traditional healing and medicines are used in conjunction with Western medicine, within the renal units. Several of the nurses also shared the use of traditional medicines and healing in their home countries.

We discussed different ways of working in workshops, including using drawing and colouring to help concentration. One of the Aboriginal co-researchers described using drawing and colouring as ways to free the



mind, leaving worries behind to focus on the workshop.

Together, we talked about why we want to work on this project, what it means to each of us and what we hope to learn from and share with each other. We made agreements together on the ways we will work, ensuring that it is a safe space for all involved. We identified what we wanted to learn from each other and what we wanted to teach each other, as well as things we would think about in the time until our next workshop together.

The project facilitator works with the co-researchers both before and after each workshop to plan for and debrief on each workshop.

Workshop Two

The second workshop was held on the 28th November, 2016 at The Poche Centre in Alice Springs. Engagement in the project after the initial workshop was strong with good attendance by both co-researchers and nurse participants. The workshop recapped the previous workshop briefly followed by reflecting on how each participant felt about the workshop, what they learned or how it has impacted their practice since. We then learned some basic phrases in Aboriginal languages: Pitjantjatjara, Warlpiri, Pintupi Luritja and Alyawarr.

Discussion about cultural norms in healthcare for different cultures and how these intersect with the expectations of both Aboriginal patients and healthcare staff. We discussed some of the issues faced by the patients and nurses here in Alice Springs and worked to help each other understand the background to some of these issues, such as dialysis prioritisation and the importance of respecting Aboriginal customary practice, particularly kinship avoidance.

Sharing stories and experiences with one another has been a focus of these workshops so far, with participants and co-researchers sharing personal stories, photos and memories. This has been a really powerful tool in creating a meaningful understanding of one another. An important aspect of building relationships is showing respect, we looked at what respect means in our respective cultures and how it is shown.

We concluded the workshop by discussing ideas and actions for the next workshop as well as final reflections; what each of us will be taking away from the day.

Workshop Three

The third workshop was held on the 13th February, 2017 in the Library Seminar Room at Charles Darwin University in Alice Springs. Again, attendance by both co-researchers and nurse participants was strong, indicating a maintained interest and engagement in the project.

The workshop began with reflections since the last workshop, feedback from both the Aboriginal co-researchers and the nurse participants on how they have felt about the last workshop and if this has had any impact on their interactions or practices.

We further discussed the importance of language, practicing some words and phrases in Pitjantjatjara, Alyawarr, Pintupi Luritja as well as Filipino. The co-researchers shared their dialysis experience with the participants, including drawings of their journey from living in their home communities to being diagnosed and eventually relocating to town for treatment. The impact of these stories was really powerful and evoked emotional responses from the nurse participants.

The co-researchers and nurse participants spoke about what it takes for people to feel comfortable in the dialysis unit as well as the method and manner in which people's blood test results are communicated to them.

Some of the co-researchers along with Samantha and Kerry will be presenting the project at the AIATSIS conference in Canberra next month, further discussion ensued regarding other methods of sharing the information and processes of the project back to stakeholders and interested parties.

Again, the workshop concluded with some final thoughts and reflections of the day.



Next steps:

- The final workshop for this project to be scheduled for early April
- Presenting the project at the AIATSIS Conference in Canberra in March 2017
- Presenting at the Poche Centre (NT) seminar series, April 2017
- Feedback project progress to each of the dialysis units (during in-service) and the Central Australia Renal Voice quarterly meeting

The artwork in the page header is a combination of drawings by Eileen Bonney, Irene Nangala and Margaret Heffernan.