



CENTRAL LAND COUNCIL

Submission to the Medical Benefits Schedule Review Taskforce and the Renal Clinical Committee on the proposed introduction of a *Very Remote Dialysis Medical Benefits Schedule Item*, as recommended in the Report of the Renal Clinical Committee (*recommendation 4.1*).

“My mother [now deceased] was on dialysis and she was a bush girl. She couldn’t stand Darwin and they organized for her to come back home. She refused to go back. She made a choice not to go back; she’d rather die here [Lajamanu], she said. In those days we didn’t have dialysis [here], so I can see that people are fortunate to have dialysis. If my mother would have had it, it would have made it easier for her. Dialysis was a one-way trip not to come back home. It’s not a one-way trip now.”

- Community member interview excerpt, Independent Review of the Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT) renal dialysis service at Lajamanu, Kalkarindji, Darwin and Katherine (2015)

Submitted by the Central Land Council, on behalf of Kurra Aboriginal Corporation

1st August 2017

Introduction and Submission Focus

Thank you for the opportunity to make a submission regarding the Renal Clinical Committee’s recommendation to improve access to dialysis services for patients living in very remote communities. The Central Land Council (CLC) and Kurra Aboriginal Corporation (Kurra) strongly support the Renal Clinical Committee’s recommendation to create a new MBS item to fund the provision of dialysis services in very remote areas, as outlined in *Recommendation 4.1 – Very remote dialysis item*.

Central Land Council and Kurra Aboriginal Corporation: The Tanami Dialysis Project

The CLC is a Commonwealth statutory authority established under the *Aboriginal Land Rights (Northern Territory) Act 1976* (‘ALRA’). Amongst other functions, it has statutory responsibilities for Aboriginal land acquisition and land management in the southern half of the Northern Territory. The CLC is also a Native Title Representative Body established under the *Native Title Act 1993* (‘NTA’). Pursuant to the ALRA more than 50% of the NT and more than 85% of the NT coastline is now held by Aboriginal Land Trusts on behalf of traditional owners. The CLC region covers approximately 780,000 km² of land, and 417,318 km² is Aboriginal land under the ALRA. Given existing pastoral land was not able to be claimed this Aboriginal land tends to be very arid and remote. In addition, rights have been asserted and won under the *Native Title Act 1993*, and traditional owners unable to claim land under the ALRA have succeeded in obtaining rights to small areas known as Community Living Areas, under NT legislation.



CLC Delegates

Through its elected representative Council of 90 community delegates the CLC continues to represent the aspirations and interests of approximately 17,500 traditional landowners and other Aboriginal people resident in its region, on a wide range of land-based and socio-political issues.

Central Land Council and Kurra Aboriginal Corporation – submission on the proposed introduction of a *Very Remote Dialysis Medical Benefits Schedule Item (Recommendation 4.1)*

In 2005, the CLC’s Community Development Unit (CDU) was established in order to implement community projects using rent and royalty funds from land-use agreements and affected area payments. These projects cover a range of needs as identified by communities, with one area being the provision of health services.

Since 2008, the CDU has worked with the Kurra Aboriginal Corporation (Kurra) to support the allocation of royalty income from the Granites Gold Mine to set up and deliver dialysis in Yuendumu and Lajamanu. Kurra’s members are Traditional Owners for the Granites Gold Mine Site. A committee of Kurra directors meet twice a year to monitor the program and to allocate funds for the Tanami Dialysis Project. Kurra have allocated over \$2 million to the Tanami Dialysis project since 2008, funding areas including feasibility studies and construction of remote dialysis units in Lajamanu and Yuendumu and ongoing operational costs including Aboriginal health care workers, social support workers and travel back to country. This support has made remote dialysis in the Warlpiri region possible.



Kurra Directors – Teddy Gibson, Roger Jurrah, Daniel Rockman, Sabrina Lewis, Kenneth Martin Jurrah, Freda Jurrah, Robyn Lawson, Rita Brown - 16th May 2017

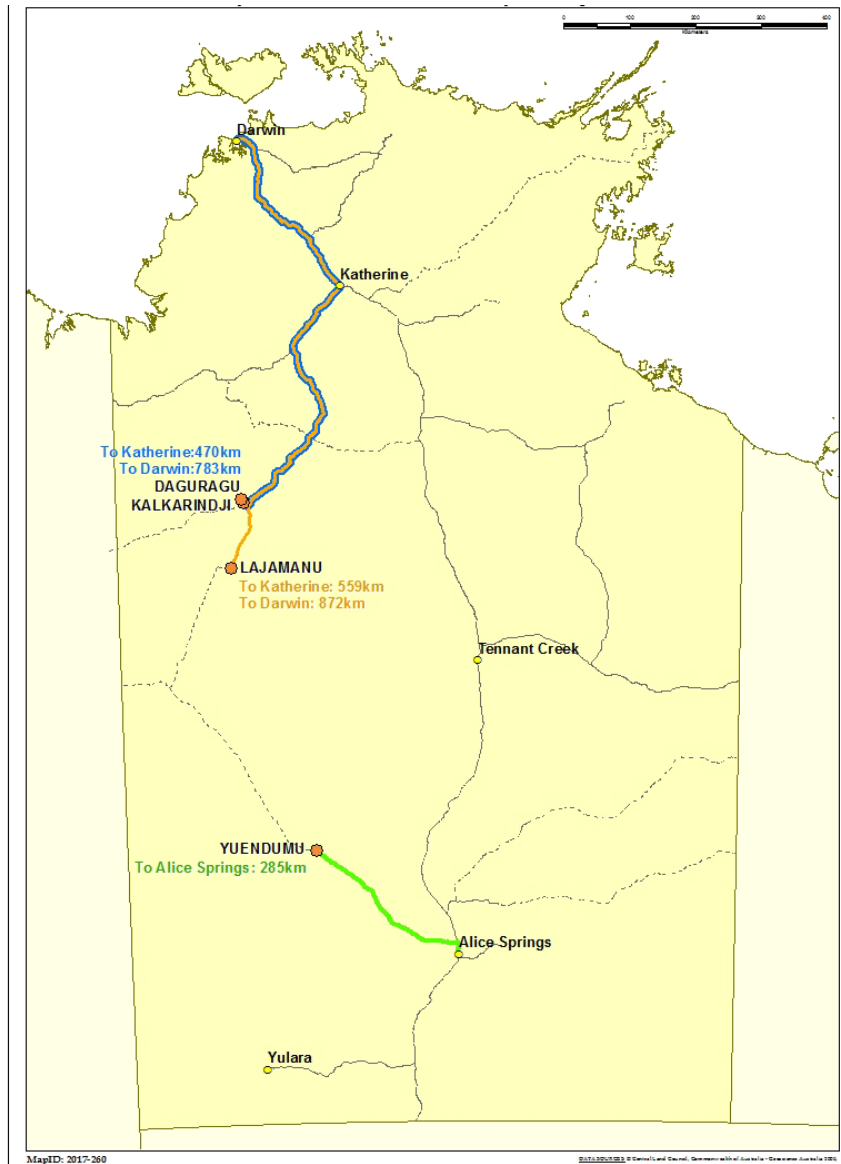


Lajamanu Dialysis Project Opening 2013

Background and Current Issues

As outlined in the Rationale for *Recommendation 4.1 Very Remote Dialysis Item*, people living in remote areas suffer higher levels of kidney disease than those living in urban areas. Furthermore, Indigenous people are also more likely to be affected. In particular, renal failure in both Lajamanu and Kalkarindji (approximately 123kms north of Lajamanu), is rising at a rapid rate (Vaarzon-Morel 2015). Before the Tanami Dialysis Project, those needing dialysis treatment from Lajamanu, Kalkarindji and Daguragu (approximately 131kms from Lajamanu) needed to travel to Katherine (approximately 560kms from Lajamanu) or Darwin (approximately 870kms from Lajamanu) for treatment. An evaluation report was prepared in 2015 for the ABA and WDNWPT that assessed the renal dialysis service at Lajamanu, Kalkarindji, Darwin and Katherine using a mixed-methods, qualitative approach. The report

indicated huge financial impacts on communities as a result of this travel, as well as significant social disadvantages such as dislocation from community, family, country and culture. For example, before the Tanami Dialysis Project, many people in Lajamanu saw dialysis treatment as a sentence which would see them disconnected from community.



Distances travelled by remote dialysis patients. Source: CLC

Commentary on Recommendation 4.1

The Independent Review of the WDNWPT renal dialysis service at Lajamanu, Kalkarindji, Darwin and Katherine (Vaarzon-Morel 2015), concluded that overall, dialysis patients expressed extensive appreciation of the service and identified many positive impacts on their lives, not only for their physical health but also for their general wellbeing and quality of life. Based on the evaluation findings of the Tanami Dialysis Project and the extremely positive outcomes that members of Kurra and their families have experienced as a result of these

services, the CLC and Kurra strongly support the Renal Clinical Committee’s recommendation to create a new MBS item to fund the provision of dialysis services in very remote areas, as outlined in *Recommendation 4.1 – Very remote dialysis item*. The introduction of the MBS item will ensure the future sustainability of the Yuendumu and Lajamanu dialysis units and ensure that the benefits from these services can be sustained beyond the life of the Granites Gold Mine, as well as provide opportunity to expand highly-valued remote dialysis treatments for renal patients from the Warlpiri lands.

Key findings from the evaluation of the WDNWPT renal dialysis service at Lajamanu, Kalkarindji, Darwin and Katherine (Vaarzon-Morel 2015) include:

- having access to dialysis services on community enabled patients to keep cultural, language and family ties:

“It’s much better here at Lajamanu. I can chat in language because a Warlpiri person is sitting next to you.... We tell them at Katherine to keep Warlpiri together but they don’t always do it.”

- The quality of care patients experienced were beyond dialysis:

“The machines are the same at Lajamanu and Darwin. Having dialysis at Lajamanu is different to Darwin hospital. They’ve got TV at Lajamanu and they give you a feed—breakfast and after the machine. They pick people up and take them back home after dialysis. The nurses at Lajamanu know you. You feel more comfortable at Lajamanu than Darwin.”

- Respite enabled participation in community life and cultural activities that were previously missed due to long periods of travel to receive dialysis in urban areas:

“It’s better to have dialysis at Lajamanu. I can’t go back to Darwin—I want to stay here. My family is here; I want to stay with family and I’ve got a job here at the Art Centre. I come here to the Art Centre every morning to paint. I’ve got an exhibition in New York that I’m painting for.... If I was in Darwin I wouldn’t have a place—an art centre—to paint.”¹

“And sometimes I do yawalyu [women’s ceremonies] here. Here I can be involved in Kurdiji [initiation] ceremony—[but] in Darwin, nothing.” [Female]

- Respite had a positive contribution to patient’s diets through access to bush food:

“Sometimes it’s hard to keep fluid down—but it’s alright, easier here [Lajamanu] when I eat bush tucker.”

“At Lajamanu a lot of people respect people who are on dialysis and bring back bush food for them—kangaroo.... They go out of their way to help sick people.”

Conclusion

In summary, the CLC and Kurra strongly support the Renal Clinical Committee's *Recommendation 4.1 – Very remote dialysis item*, to create a new MBS item to fund the provision of dialysis services in very remote areas. Enabling patients to stay connected to community, language, culture and country throughout dialysis treatment has shown to have significant impacts beyond improvements in physical well-being to influence richer quality of life. The experiences of the patients of the dialysis treatments made available by Kurra and WDNWPT are testament to the multifaceted benefits that the provision of dialysis treatment in very remote areas can bring.

References

Independent Review of the Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT) renal dialysis service at Lajamanu, Kalkarindji, Darwin and Katherine 2015, Vaarzon-Morel, P., for the Aboriginals Benefit Account (ABA) and WDNWPT.