



Yuendumu
Dialysis Support Service Feasibility Study

Final Report

May 2008

Western Desert Nganampa Walytja Palyantjaku
Tjuṯaku Aboriginal Corporation

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1. The Yuendumu Dialysis Services Feasibility Study

The existence of the Western Desert Nganampa Walytja Palyantjaku Tjuṭaku Aboriginal Corporation's (WDNWPT) Kintore renal facility is well known to dialysis patients and their families across Central Australia. The success of this model is something that other remote communities are keen to understand in order to explore options for renal dialysis services for their own community members. To this end the Kurra Aboriginal Corporation agreed in early 2007, to set aside \$30,000 for the Central Land Council to appoint a consultant to conduct a feasibility study on the provision of dialysis support services for Warlpiri patients from Lajamanu, Yuendumu and surrounding Warlpiri communities. WDNWPT was appointed to carry out the study drawing on its relevant expertise and experience.

The feasibility study required that WDNWPT form a 'kidney committee' of patients and key community members and, with the help of this committee, provide information to patients and community members about current services provided by the Alice Springs Renal Dialysis Unit and WDNWPT, listen to their ideas and priorities with regard to dialysis services, consult government and non-government agencies and then develop dialysis support options and provide costings for those options. The study team with the kidney committee was required to prioritise up to five dialysis service options to be presented to the Kurra Aboriginal Corporation in March, 2008.



Yuendumu Meeting, February 2008

2. Executive Summary

The Yuendumu Feasibility Study commenced in October 2007 and was completed prior to the Kurra Aboriginal Corporation meeting in Lajamanu on the 11th of March 2008. The study was conducted by Megan Hoy and Georgia Stewart as employees of Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation.

Early in the work it became obvious that it would be difficult to provide services for both Yuendumu and Lajamanu communities and patients through the same model. It was decided to provide two separate processes and reports. Whilst Yuendumu Dialysis patients and their families move to Alice Springs to receive treatment, Lajamanu patients dislocate to both Katherine and Darwin.

This report addresses issues and priorities for the Yuendumu region only. We aim to have the Lajamanu Feasibility report available by the 30th June 2008.

In accordance with the Study contract, detailed consultations were conducted with Warlpiri dialysis patients, family members and other community members both in Alice Springs and Yuendumu. These consultations were facilitated by the development of a Yapa Kidney Committee early in the project. This committee supported the study team and provided advice on meetings and consultations.

2.1 Key Findings

From the commencement of this study it was apparent that dialysis patients and their families from Yuendumu, Nyirripi, Yuelamu and Willowra shared a clear priority which was to access dialysis treatment in Yuendumu. This shared vision formed the backbone of a final, more holistic service model, incorporating management, Yapa governance through a 'Kidney Committee', expert advice through an external advisory committee, Alice-Springs based support for patients, funding for shorter, non-dialysis Return to Country visits as well as brokerage funding. All of these components were added to the basic community-based dialysis model during the process of detailed discussions and consultations. As a result a single model evolved and was supported through the process rather than a range of different options as had been anticipated at the start of the study.

Throughout consultations there was much discussion about the model that is currently presented to renal dialysis patients by the Northern Territory Government. Under this model 1-2 Warlpiri renal patients would undertake self-care training and return home permanently with the skills to do their own haemodialysis. Under this model patients are provided with a dialysis machine, filtration system, dedicated phone line and consumables as well as technical backup and over the phone support from the Renal Unit. As this model would only enable the return of a small number of dialysis patients, it did not meet the priority of the yapa committee to enable all dialysis patients access to a regional dialysis service. Importantly, this option is also less likely to be accessed by senior custodians because of their comorbidities. Yuendumu Dialysis Service would provide the most equitable access possible for all dialysis patients, enabling them all to return home for extended dialysis holidays if they are well enough. It was also apparent that most patients did not have an adequate understanding or awareness of what is

involved in self-care training and were anxious about committing to it. However the committee recognized the need to develop awareness and interest in self dialysis plus the potential of self care to lift awareness of CKD in the community.

As a result the proposed model does not incorporate self-care training however it also does not exclude it. The option of patients from Yuendumu and surrounding communities undertaking Self Care training some time in the future and utilizing one of the two dialysis machines in the agreed model was considered possible and appropriate.

The proposed model, endorsed at the final community meeting in Yuendumu on the 4th of February, 2008, was then presented to Kurra Aboriginal Corporation at its Lajamanu meeting (March 11, 2008). The resolution proposed a 4-stage funding process which would support the project's development, implementation and review from March 2008 to March 2012.

Kurra Aboriginal Corporation endorsed the resolution making a one year funding commitment for Stage 1 (development phase) of the project and an in-principle agreement to fund stage 2 and stage 3 (an additional three years of establishment and operational funding) contingent on satisfactory progress of Stage 1.

3. Background

3.1 The WDNWPT Story

In the 1990's community members from Kiwirrkurra, Mt Liebig and Kintore were already talking about the difficulties for communities and families of an increasing number of *Yanangu* being forced to move to Alice Springs for renal dialysis treatment. They were concerned about these people missing country and family, not being able to do what they should be doing out in their communities and on country-teaching their children and grandchildren.

Senior Kintore community leader Mr Zimran, had started dialysis and understood, through first hand experience, the challenges and sadness facing renal dialysis patients as a result of dislocation and the consequent loss of cultural engagement and connection to family and country. He understood the enormous implications of this phenomenon for cultural continuity and well-being. Although kidney disease is now expanding to affect younger community members, the largest proportion of those with end-stage renal failure tend to be in their late forties and beyond. This group possesses the richest understanding and knowledge of language and traditional culture and is responsible for transferring that knowledge to younger generations, those "coming up behind". Their permanent removal from their communities fractures this process and creates significant stress for individuals who are unable to meet their cultural obligations and feel a tremendous sense of loneliness and despair.

Apart from the severe dislocation suffered by individuals who face homelessness, loneliness and the shame of living on other people's traditional country, this group recognized the terrible loss to their own community's pool of knowledge of family (*walytja*), country (*ngura*), stories (*tjukurrpa*) and ceremonies (*tuḷku*). These elements are the determinants of *Yanangu* well-being and the obligation to know (*kulintjaku*) and learn (*nintintjaku*) is the very basis of *Yanangu* Law.

Mr Zimran and other senior community members started talking to Papunya Tula and Sothebys and NT politicians like Peter Toyne about getting dialysis machines out in Kintore. In order to raise funds, a unique partnership was formed between *Yanangu*, sympathetic members of the Aboriginal Art industry and local politics, and community controlled health services. Papunya Tula Artists Pty Ltd. then commissioned four remarkable collaborative paintings by senior Pintupi men and women in Kintore and Kiwirrkura. These were auctioned by Sothebys along with a range of donated works at the Art Gallery of NSW in Sydney, November 2000.

The auction raised over AUS\$1 million and was used to establish our organisation, The Western Desert Nganampa Walytja Palyantjaku Tjuḷaku Aboriginal Corp Inc. (WDNWPT). This name loosely translates as "*Making all our families well*", in recognition of *Yanangu* desire to mitigate the extent to which kidney disease threatens the preservation of *Walytja* or extended familial relatedness at a fundamental level.

After the auction, WDNWPT started its 'Return to Country' program, getting people home for overnight visits between dialysis treatments. Shortly after, the patient support program commenced to help improve the quality of life for patients in Alice Springs through advocacy, activities to relieve boredom like picnics and the renal choir, assistance with negotiating town-based services and case management support for patients with complex needs.

3.2 WDNWPT Services for *Yanangu* Families

In April 2004, the organisation opened the first remote renal dialysis clinic in Central Australia at Kintore. Since then we have been returning people home for dialysis holidays each year of between two and six weeks, and providing alternative dialysis facilities and patient support in Alice Springs from a converted suburban house. Patient support includes advocacy, housing, linking clients with other services, case management for high needs clients, strong partnerships with organisations and agencies eg. Palliative care, NT Shelter, Tangentyere, Red Cross, Centrelink, Aboriginal Hostels etc. as well as recreational activities such as the renal choir and bush medicine workshops.



The WDNWPT Purple House, Alice Springs

As the project has grown we have added more services. We currently have a GP clinic two mornings each week and are looking to add a podiatry and Occupational Therapy Service in the coming months. We have two workers enrolled in the Aboriginal Health Worker training courses based in Alice Springs and Kintore.

The main goal of WDNWPT is hence to significantly improve the quality of life of *Yanangu* on dialysis by supporting them holistically in Alice Springs through our Patient Support Program and by providing them with the opportunity to return home as frequently as possible, for short as well as extended stays.

When WDNWPT started we were supporting just seven renal patients and their families. In seven years that number has grown to 35 and, according to recent data on kidney disease in the region, will continue to grow dramatically.

The benefit of establishing WDNWPT early on is that new renal patients are able to gain immediate benefit from the project and have some support and relief during the early period of dislocation and loneliness after arriving in Alice Springs. They are also able to look forward to organised visits home for short stays between dialysis as well as extended periods on dialysis in Kintore.

A thorough and detailed evaluation of this program released in 2006, demonstrated its success and cost-effectiveness and has enabled WDNWPT to negotiate successfully for Government funding for nurses' wages, three dialysis machines and some capital infrastructure, including our small dialysis house in Alice Springs and two vehicles.

3.3 WDNWPT Structure

Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (WDNWPT) is an Aboriginal Corporation under the Aboriginal Councils and Associations Act 1976 and is a registered not-for-profit organisation. The membership of the organisation is open to all adult Aboriginal people (*Yanangu*) living permanently in the Haasts Bluff Land Trust and Kiwirrkurra Community in the Western Desert Region of Central Australia.

The WDNWPT Governing Committee is made up of 12 *Yanangu* members who are drawn evenly from the area of its membership. The Committee members are elected annually at an Annual General Meeting. Despite being geographically dispersed, *Yanangu* maintain strong links through kin, language and extended family networks, alongside shared rights in country.

Currently WDNWPT patients are drawn from a diverse range of Western Desert communities including Mt Liebig, Hermannsburg, Haasts Bluff, Papunya, Mt Liebig, Walungurru (Kintore), Docker River and Nyirripi in the Northern Territory and Kiwirrkurra, Tjukuḷa, Blackstone and Warakurna in Western Australia. The membership of this WDNWPT client group is determined by the *Yanangu* Governing Committee and is based on family relationships.

The aims of WDNWPT are consistent with the Commonwealth Renal Plan and the N.T Renal Strategy. In these plans, both Federal and Territory governments strongly recognise dislocation as a major contributor to poor health outcomes for renal patients.

3.4 WDNWPT Dialysis Service Model

Alice Springs

Purple House (owned by WDNWPT) with two dialysis machines and 1.2 nursing positions

Manager (fulltime)

Patient Support Program- fulltime position

Admin worker (part-time)

Trainee Aboriginal Healthworker

Trainee admin worker (part-time)

GP Clinic-2 mornings per week

Return to Country Program

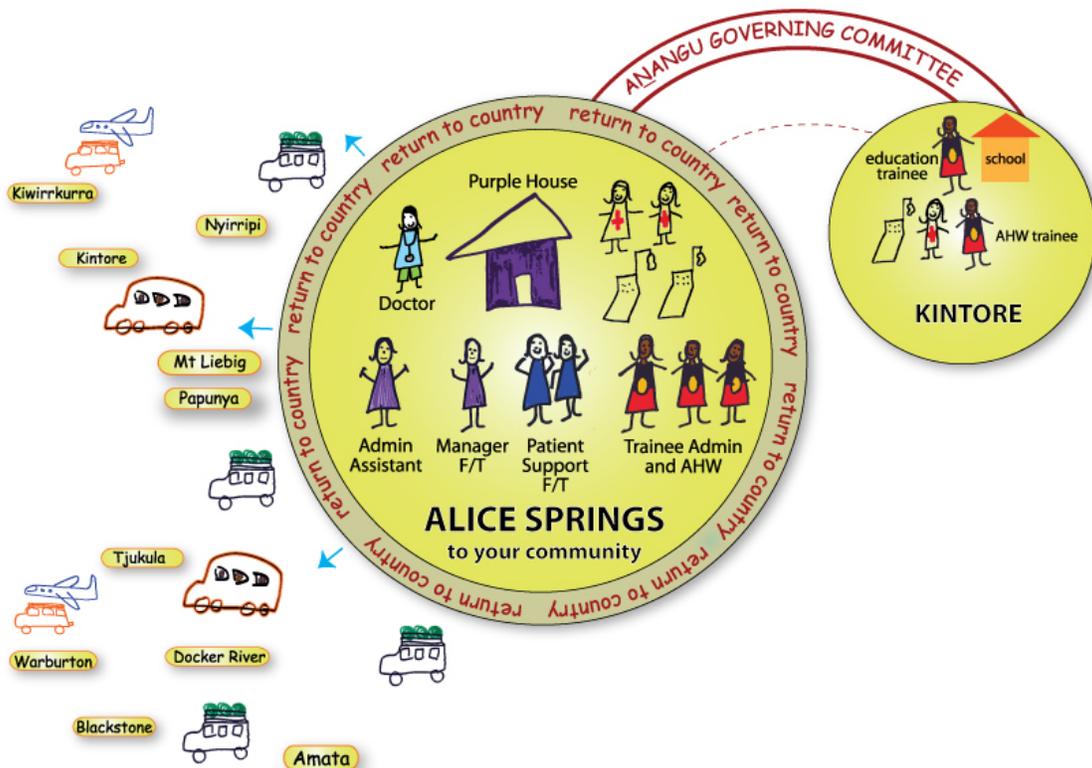
Kintore

Dialysis room with one machine

Nurse's accommodation

Nurse (fulltime)

4WD



3. 5 Membership of Current Governing Committee

Marlene Spencer Nampitjinpa (Chairperson), Bobby West Tjuparrula (Vice Chair), Marilyn Nangala (Public Officer), Irene Nangala, Pilita Napurrula, Desma Napaltjarri, Audrey Turner Nampitjinpa, Warren Eddy and Kai Kai (Barbara) Reid, Bundi Rowe Tjupurrula



Marlene Spencer Nampitjinpa, WDNWPT Chairperson

4. Renal Patient Data for Yuendumu and Surrounding Communities

4.1 Current Renal Patient Numbers for Yuendumu, Nyirripi, Willowra and Yuelamu

At the time we commenced the study there were six renal patients from Yuendumu, three from Willowra, three from Nyirripi and one from Yuelamu. Unfortunately while undertaking this study one of the Yuendumu renal patients passed away adding a sense of immediacy and importance to the outcomes of this study. One Yuendumu patient is receiving dialysis in Adelaide and another moved interstate with his family but has since returned.

In addition to the seven patients described above, another six patients from Alice Springs were added to our list. The Renal Unit identifies this group as longer term residents of Alice Springs (ie. they were living in town when they started dialysis treatment), but were originally either from Yuendumu, Nyirripi, Willowra or Yuelamu. Community and family members wanted them included in a future service and believed they would wish to access patient support, return to country trips and/or Yuendumu dialysis services if they were to start.

4.2 Chronic Kidney Disease (CKD) Figures for Yuendumu, Willowra, Nyirripi and Yuelamu

As with most remote Central Australian communities, the chronic kidney disease (CKD) figures for Yuendumu and the surrounding communities of Nyirripi, Willowra and Yuelamu show a strong upward trend over the next few years.

Anecdotal figures for the growth of renal disease provided by one of the Yuendumu WYN Health doctors, predict that 6 people from Yuendumu, Willowra and Nyirripi (2 from each community) are likely to require dialysis in the next 5 years. They also predict that up to 40 people are at significant risk of requiring dialysis in the next 5 years (20 from Yuendumu, 15 from Nyirripi and 5 from Willowra). CKD data provided by the Alice Springs Renal Dialysis Unit shows that the overall number of people starting dialysis within five years is slightly lower at 37, with 13 of those likely to commence dialysis within two years.

4.3 Interpreting CKD Data

The Renal Dialysis Unit CKD table below represents the most current information available on chronic kidney disease for individuals from Yuendumu and surrounding communities. The data depends on blood tests taken in remote communities which are indicated by dates in column four. Some community members may not attend clinic regularly so the dates of their last blood test may be quite old. Obviously the most recent blood tests will provide the most reliable information.

Gender	Community	Referred	Cr (umol/L)	Date	GFR (ml/min)
F	Nyirripi		142	17-Oct-07	33
F	Nyirripi	2-Nov-05	98	18-Sep-06	53
F	Nyirripi	1-Jan-99	209	18-Oct-07	22
F	Nyirripi	3-Apr-04	107	12-Oct-06	47
F	Nyirripi	28-Feb-06	120	22-Mar-07	41
F	Nyirripi	7-Jan-04	121	14-Nov-07	41
F	Nyirripi	31-May-04	128	12-Dec-07	38
M	Nyirripi	14-Jan-08	251	10-Jan-08	25
F	Nyirripi	10-Mar-04	139	3-May-04	39
M	Nyirripi	10-Mar-04	138	16-Feb-07	35
M	Nyirripi	10-Nov-05	388	11-Dec-07	15
Gender	Community	Referred	Cr (umol/L)	Date	GFR (ml/min)
F	Yuelamu	10-May-04	153	1-Feb-08	31
F	Yuelamu	27-Oct-03	284	12-Dec-07	15
M	Mt Allen	25-Feb-08	143	1-Feb-08	49
F	Yuendumu	1-May-07	111	21-Jan-08	51
F	Yuendumu	20-Feb-07	0	20-Feb-07	53
F	Yuendumu	18-Apr-07	129	1-Aug-07	38
F	Yuendumu/Nyirripi	8-Apr-02	183	22-Mar-07	25
F	Yuendumu/Willowra	7-Sep-06	212	8-Feb-08	22
F	Yuendumu	31-Jan-00	169	20-Jun-05	28
F	Yuendumu	13-Feb-07	93	26-May-05	0
F	Yuendumu		260	27-Dec-07	17
F	Yuendumu	9-Dec-02	299	30-Oct-07	13
M	Yuendumu	9-Mar-04	204	30-Aug-07	34
M	Yuendumu	24-Sep-07	363	2-Oct-07	17
F	Yuendumu	24-Jun-04	123	8-Oct-07	44
M	Yuendumu	24-Sep-07	138	20-Sep-07	54
F	Yuendumu	14-Apr-03	127	24-Jan-07	38
M	Yuendumu	21-Sep-07	169	28-Jan-08	42
M	Yuendumu		197	20-Nov-07	34
Gender	Community	Referred	Cr (umol/L)	Date	GFR (ml/min)
M	Willowra	10-Feb-62	204	6-Mar-07	33
F	Willowra	12-Oct-05	140	21-Sep-07	35
F	Willowra	27-Oct-03	102	25-Apr-07	48
M	Willowra	4-Dec-03	301	29-Jan-08	18
F	Willowra		103	27-Jun-07	51
F	Willowra	23-Nov-06	167	4-Sep-07	29
Gender	Community	Referred	Cr (umol/L)	Date	GFR (ml/min)
M	Mt Allen	25-Feb-08	143	1-Feb-08	49

CKD Data supplied by Alice Springs RDU, February 2008

All individuals referred to in the table have a GFR of less than 60. GFR (ml/min) refers to glomerular filtration rate or the amount of urine being processed by a single cell in the kidney. People with a GFR below 60 are considered to have chronic kidney disease. There are many factors that can influence how soon or whether a person with a low GFR will end up on dialysis.

These include;

- What type of kidney disease the person suffers
- How actively they are being managed for high blood pressure, diabetes, medication and diet.

Generally speaking, those with a GFR below 30 are at a high risk of starting dialysis within two years, while those with a GFR between 30 and 60 are at a high risk of starting dialysis between two and five years.

It is hoped that the development of renal dialysis support services for Warlpiri renal patients and their families will ensure a demonstrable improvement in the quality of life of existing and future Warlpiri renal dialysis patients and will have the added benefit of providing opportunities for focusing greater attention on preventative options for kidney disease within these communities.

Our experience in Kintore has shown that the presence of the dialysis unit in the community provides an educational function in the alleviation of future kidney disease through an earlier awareness of symptoms and preventative measures, and in the demystification of options for patient care. As we have learned from our experience the most powerful way to communicate information about renal disease and treatment is through the presence of the patients themselves. The presence of the dialysis machine also enables people to see the reality of life on dialysis treatment and provides opportunities for building awareness about kidney disease and preventative options.

5. Consultations

A range of consultations were undertaken in a variety of settings throughout the Feasibility Study. The following timeline provides a summary of the key consultations and other meetings, presentations and events.

5.1 Feasibility Study Consultation, Milestone and Meeting Timeline

15 October	Feasibility Study Commences
16-19 October	Study team visit individual patients and family members in Alice Springs to explain the study
22 October	Patient Meeting at the Purple House
29 October	Meeting with local member, Karl Hampton, at the Purple House
9 November	Visit to the Nightcliff Renal Unit
11-12 November	Yuendumu visit – consultations with families, clinic, WYN Health, Warlukurlangu Artist Association, Community Council, Women’s Centre, Aged Care Facility etc.
21 November	Presentation to GMAAC meeting
26 November	Yuendumu Family and Patient visit to the Alice Springs Renal Unit and Meeting at the Purple House. 20 Yapa attend meeting and form a Steering Committee of 10 (8 community and family members and 2 dialysis patients)
29 November	Meeting with Warlukurlangu Artist Association Coordinator Cecilia regarding \$20,000 contribution for patient support in Alice Springs
12 November	Meeting with Jill Gorham Senior Renal Nurse Advisor, NT Renal Services and Linda McKelvie, Manager Alice Springs Renal Dialysis Unit at the Purple House
10 December	\$22,000 contribution received from Warlukurlangu Artist Association for patient support and Return to Country trips.

4 February	Final Community Consultation –Yuendumu Community Council & Community members meeting, Yapa Kidney Committee Meeting
11 March	Progress report presented to Kurra and resolution to fund first phase passed in Lajamanu.
31 March	WDNWPT employs Phynea Maher as the Warlpiri Patient Support Worker (20 hrs per week)
18 April	WDNWPT meets with Karl Hampton to up date him on progress and ask for his support.
24 April	Warlpiri Dialysis Project Manager position advertised in the Advocate.
14 May	Interviews held for Manager’s position. Michael Harries is offered and accepts the job.
16 May	Funding agreement for phase 1 signed by WDNWPT governing committee.

5.2 Process for Consulting Renal Patients, Family and Community Members

This feasibility study was undertaken with the aim of developing a range of options (up to 5) for Warlpiri dialysis patients, then investigating the logistical and financial aspects of each option. At the start of all consultations with family, renal patients and relevant services we presented the WDNWPT model as a simple, colourful diagram and explained the long process of developing the organisation, from early discussions about the impacts of kidney disease that started in the Western Desert during the 1990's, through to the establishment of the Kintore dialysis clinic in 2004.

Throughout consultations we were careful to explain that the process of developing WDNWPT was a slow and sometimes difficult one which had met with significant opposition in the early days. We hope that, in prioritising a basic model, the Warlpiri patients and families that we spoke to were doing so with a realistic and informed understanding of what might be possible and the level of energy and passion that would be required for the outcomes of the feasibility study to bear fruit.

To aid our consultations we used simple pictorial diagrams throughout to assist people to visualize their future dialysis service. Interpreters were utilised at all formal gatherings with the exception of the final Yuendumu meeting where two interpreters agreed but were unable to attend on the day because of a sick child and the third organised on the day was unable to attend at the last minute.

5.3 Development of a Yuendumu Dialysis Services Model

5.3.1 Community Based Dialysis

Initial consultations involved approaching dialysis patients from Yuendumu and surrounding communities in their homes in Alice Springs or at the Alice Springs Renal Dialysis Unit (RDU). A small meeting of four patients was also held at the WDNWPT Purple House. The feasibility study was introduced and patients were asked what assistance or services would make their life easier while living in Alice Springs on dialysis and what was particularly hard about their lives on dialysis now. For the most part, this involved patients listening to the outline of the feasibility study and learning more about the WDNWPT model, then providing us with information about their situation and any problems. This approach was also taken with the first round of consultations in Yuendumu where the study team approached small family groups, asked a pre-determined set of questions (see Attachment E, Consultation Questionnaire) and showed people a colourful set of drawings that describe the WDNWPT model, its staff and the services it offers.

This information was also provided to the members of the Granites Mine Affected Areas (GMAAC) Corporation at their meeting in November, 2007.

Early on in consultations with renal patients and their families it became clear that there were key components of a service model that were unanimously supported and not open for negotiation. The main component described was the capacity for renal dialysis patients to be dialysed in or near their home community. It was agreed that access to this service would be shared between Warlpiri patients from Yuendumu, Willowra, Yuelamu and Nyirripi including homeland centres located near those communities. At all stages of the consultation it was made clear that through this model no patients would

return home permanently, rather they would share the facility on an extended holiday basis. The only option for permanent return to their home community was for renal patients to successfully complete self-care training.

As with the Kintore model the community-based dialysis service would require:

- A dialysis unit of some description. Options for renovating existing buildings including the old clinic and women's centre were explored in consultations but were considered too time-consuming and costly. It was agreed that the best option was a stand alone, 2-chair dialysis unit of similar design to the unit that has been purpose-built for self-care training behind the RDU in Alice Springs. It was unanimously agreed that the unit should be located between the Council offices and the new Yuendumu clinic. The Yuendumu Community Council gave in principle support to allocating one of the two land lots for this purpose but this process will need to be finalized during Stage 1 of the project.
- Funding for a full-time renal nurse with a 3 bedroom house and 4WD vehicle. Again we explored options for existing accommodation in Yuendumu but there is none. It was agreed during consultations with Yapa and community administrators that new accommodation would need to be provided and a new land lot allocated during Stage 1 of the project.

5.3.2 Social and Community Support

As talks progressed and people asked more questions about the services provided by WDNWPT, they began to express growing support for the addition of a 'footprint' in Alice Springs. This footprint would need to include the following:

- A Project Manager. The project manager would be needed to work alongside the Yapa Kidney committee to implement the funding agreement with Kurra Aboriginal Corporation including driving the establishment and eventually the operation of the project including, creation of a separate organisation, development of MOU's with Government and non-Government agencies, infrastructure planning and development, land allocation, fundraising and submission writing etc. Staff supervision, budget management and on going liaison with the Renal Dialysis Unit would be vital for the project's success and sustainability.
- A Patient Support Worker. Through our talks it became apparent that a small number of Warlpiri patients had some immediate and pressing health or related issues that we could address with comparatively minor effort. Our experience at WDNWPT led us to believe that providing practical support to people (within limits) was an appropriate response and would begin to demonstrate the potential tangible benefits of Alice Springs-based 'patient support' as part of a future dialysis support service. To this end we were able to arrange an ACAT assessment for one patient followed by physiotherapist consultations, visits to the GP clinic by 4 Yuendumu patients at the Purple House, negotiate appropriate accommodation for another patient with Topsy Smith Hostel, provide assistance with Centrelink forms and coordinate at least 4 patients returned to Yuendumu for short visits through the WDNWPT Return to Country program.

These actions helped demonstrate the future tangible benefits of patient support in Alice Springs which would include day to day assistance for renal

dialysis patients, particularly those with complex needs, as well as planning return to country visits and liaising with Renal Unit staff and the Yuendumu-based renal nurse. It was agreed that, as has been the experience of WDNWPT, the success of a dialysis service in Yuendumu would be largely dependent on this type of social and community support in Alice Springs.

- In addition to these two positions it was agreed that the town-based support would require a vehicle, funding to establish an office space, flexible brokerage funding to assist patients through difficult times and funding for return to country visits.

5.4 Key Meetings

(see also Attachment C for a more detailed description of meetings)

5.4.1 Patient and Family Meeting, Purple House Alice Springs, 26 November, 2007

A more formal meeting of Warlpiri Dialysis patients and their families was held in Alice Springs at the WDNWPT Purple House on the 26th of November 2007. The aims of this meeting included to:

- a) Provide family members with information about kidney disease, dialysis and safety issues around community-based dialysis and self-care training. This need for information became apparent when the study team attended the GMAAC meeting and were asked a large number of questions about all of the above. We agreed to organise an information session with our nurse at the Alice Springs meeting.
- b) Show family members the Renal Dialysis Unit in Alice Springs
- c) Start to consolidate a model for a Yuendumu dialysis service based on earlier consultations.

The group started by touring the Renal Dialysis Unit in Flynn Drive. Most family members had never visited the unit before and were confronted by the large number of patients and the general lack of privacy.

An information session followed on kidney disease, dialysis and safety issues related to community-based dialysis.

The large diagram of the WDNWPT model was again used to recall the separate parts of the service. Then a blank sheet of cardboard was used with “stick-on” components: machines, return to country, accommodation, nurses, manager, patient support workers, vehicles etc. As family and patients discussed what was needed the study team stuck the pieces on under the headings of Yuendumu and Alice Springs.

Initially it was clear that the desire of families was to have their family members on dialysis back in the community all of the time but they also wanted the service to be shared equally amongst all patients from Yuendumu, Nyirripi, Yuelamu and Willowra. They agreed that the only possible option was for patients to return home for holidays of 1-3 weeks on an equitable basis a few times each year.

The meeting agreed that the essential components of the model in Yuendumu would include:

- 1 x 2 chair dialysis unit
- 1x fulltime nurse and oncosts
- 1 4WD vehicle
- Nurse's accommodation
- Office and household furniture
-

The essential components of the model in Alice Springs would include:

- 1 x part-time project manager and oncosts

The aim of this position would be to implement the outcomes of the Feasibility study: This might include implementation of incorporation of a new organisation, employment of staff, supervision of staff, organizing office space, pursuing future funding options, etc.

- 1 x part-time patient support worker and oncosts

The aim of this position would be to improve the quality of life of Warlpiri renal patients in Alice Springs by regularly visiting patients with higher needs and making sure they attend dialysis, liaising with RDU staff and families over Return to Country trips, ensuring patients are well enough to return home, assisting with town-based services and provide some recreational opportunities.

- 1 x small town-based vehicle
- Return to country funding
- Brokerage
- Funding for office equipment
- Office rental
- Admin costs

There was wide spread support for the proposed model as it was presented.

The meeting agreed to form a 'Kidney Committee' to work with the study team in further developing funding options for the Kurra Aboriginal Corporation and to assist with future consultations in Yuendumu.

Kidney Committee Members

Lottie Napangardi Robertson
James Japangardi Marshall (renal patient)
Belle Nakamarra Dickson (renal patient)
Alan Jungarrayi Dickson
Jean Napanangka Brown
Freda Napaljarri Jurra
Doris Napaljarri Jurra
Monica Napurrurla White
Ruth Napaljarri Stewart
Eddie Jampijinpa Robertson

The majority of the committee members have direct family currently on dialysis. There are also representatives from the Yuendumu Community Council, WYN Health Board, Kurra Aboriginal Corporation and GMAAC.

The study team explained to those attending the meeting that the prospect of realising the model was contingent upon the following:

1. The extent to which the Kurra Aboriginal Corporation and possibly GMAAC agree to fund some or all of the model and for what period of time;
2. The extent to which the Northern Territory Government agrees to support the project and what that support is contingent upon.

The study team informed the meeting that the cost of the model agreed to so far was likely to be close to \$1 million in infrastructure costs and more than \$300,000 in annual running costs.

The study team agreed to discuss the model with NT and Federal members of Parliament as well as NT Renal services and to discuss possible funding contributions.

5.4.2 Family and Community Meeting, Yuendumu, 4th February, 2008

The aims of this meeting included:

- a) Providing family and community members with a progress report on the feasibility study;
- b) Gaining in principle support from family and community members for a Yuendumu Dialysis Service model

Two dialysis service models were presented to the meeting as well as three funding options.

The first model was based on a self-care training model combined with patient support in Alice Springs and Return to Country funding. This model was presented as a means for a small number of Warlpiri patients to learn to do their own dialysis in order to return permanently to their home community with the added benefit of extra support for other dialysis patients including patient support and more regular short visits home to family. The study team explained that this option could enable the community to receive a demountable dialysis unit from the NT Government with technical and consumable support and a phone-line.

This model was rejected by the meeting because it did not offer community based dialysis to all dialysis patients from Yuendumu, Willowra, Nyirripi and Yuelamu. It was accepted however that some time in the future one or two patients might agree to do self-care training with the aim of returning home permanently, but at this stage there was not a strong enough understanding of what it entails, a high level of anxiety over individuals doing their own dialysis as well as concern that this model would exclude the majority of dialysis patients from community-based dialysis.

The second model (see diagram attached) was based on an equitable community based dialysis model with a two chair demountable unit supported by a full-time nurse. It was clearly explained that the equitable nature of this model would mean that no patients would return home permanently, instead they would each have access to 1-3 week holidays a few times each year.

The study team explained that there would be no additional community housing attached to this proposal and that all visits home to communities whether they be short or longer trips with dialysis would need to be based upon a clear set of rules set up by the Yapa Kidney Committee. These rules would be established to make sure that people are well enough when they go home, are having regular dialysis and taking their medication and return home at the agreed time. Families were informed that it would be their responsibility to house and care for their family member when they returned home and not the responsibility of the nurse.

Three funding options were presented to the community which include full funding by the Kurra Aboriginal Corporation with agreed annual outcomes and an independent evaluation after three years, partial funding by the Kurra Aboriginal Foundation and the NT Government based on a commitment to self-care training by 1-2 Warlpiri dialysis patients and a transitional funding arrangement whereby Kurra Aboriginal Corporation commences with full-funding of the project but on the basis of annual outcomes negotiated with the NT Government which, if fulfilled, would lead to an agreed amount of funding from the NT Government commencing after three years (based on a full, independent evaluation). No clear funding preference was agreed to at the meeting.

The meeting agreed that a final approved model and funding option would be implemented by a Project Manager with the Yapa Kidney Committee and overseen by an Advisory Committee made up of individuals with specialised skills from particular agencies (eg. WYN Health, NT Renal Services, WDNWPT, CLC Community Development Unit etc).

5.4.3 Yapa Kidney Committee Meeting, 4th February, 2008

Immediately after the Yuendumu community meeting a smaller meeting of the Yapa Kidney Committee was held. The committee endorsed the model supported in the larger community meeting.

The committee discussed a list of agreements that underpin the agreed model and discussed then endorsed each agreement individually. The agreements are as follows:

Agreements from Consultations

Yuendumu

The Yuendumu dialysis service recommended through this feasibility study must include a dialysis unit in Yuendumu.

The dialysis unit should have 2 stations and would be available equally to all renal dialysis patients from Yuendumu, Willowra Nyirripi and Yuelamu.

All renal dialysis patients would be able to spend two to three weeks on dialysis in Yuendumu a number of times each year but would not be able to return home permanently unless they complete self care training.

If a Warlpiri renal patient learns to do his/her own dialysis through self-care training then one of the two dialysis stations could be dedicated to their use but also used by visiting renal patients.

The renal unit must be supported by a full-time nurse to ensure that all patients are able to return home for two to three weeks on dialysis each year regardless of whether they have completed self-care training.

A funding package for a dialysis unit in Yuendumu must include a nurse's wages and on-costs, accommodation and related costs and a 4WD vehicle.

In addition to a project manager (see below) the success of the project will also depend on the employment of a part-time patient support worker in Alice Springs to ensure that Warlpiri patients are well and healthy enough to return home for dialysis and to have some support with housing, Centrelink etc while living in Alice Springs.

The Alice Springs funding package would include a Project Manager and oncosts, Patient Support Worker and oncosts, Office space and related costs, Return to Country funding, Brokerage and a town-based vehicle

Governance and Management

The Yuendumu dialysis service will operate as a separately incorporated body and will be governed by a Yapa Governing Committee.

The Yuendumu dialysis service will be managed on a day to day basis by a Project Manager.

The Yuendumu dialysis service will work cooperatively with but independently to WYN Health on the basis of a negotiated Memorandum of Understanding.

The Yuendumu dialysis service will work cooperatively with the NT Department of Health's NT Renal Services and Alice Springs Renal Dialysis Unit on the basis of a negotiated Memorandum of Understanding

Proposed Yuendumu Dialysis Service Model

The key components of the proposed model developed through consultations described above include:

Yuendumu

- 1 x 2 chair dialysis unit
- 1x fulltime nurse and oncosts
- 1 4WD vehicle
- Nurse's accommodation
- Office and household furniture
- 1 casual Yapa liaison position

Alice Springs

- 1 x part-time project manager and oncosts

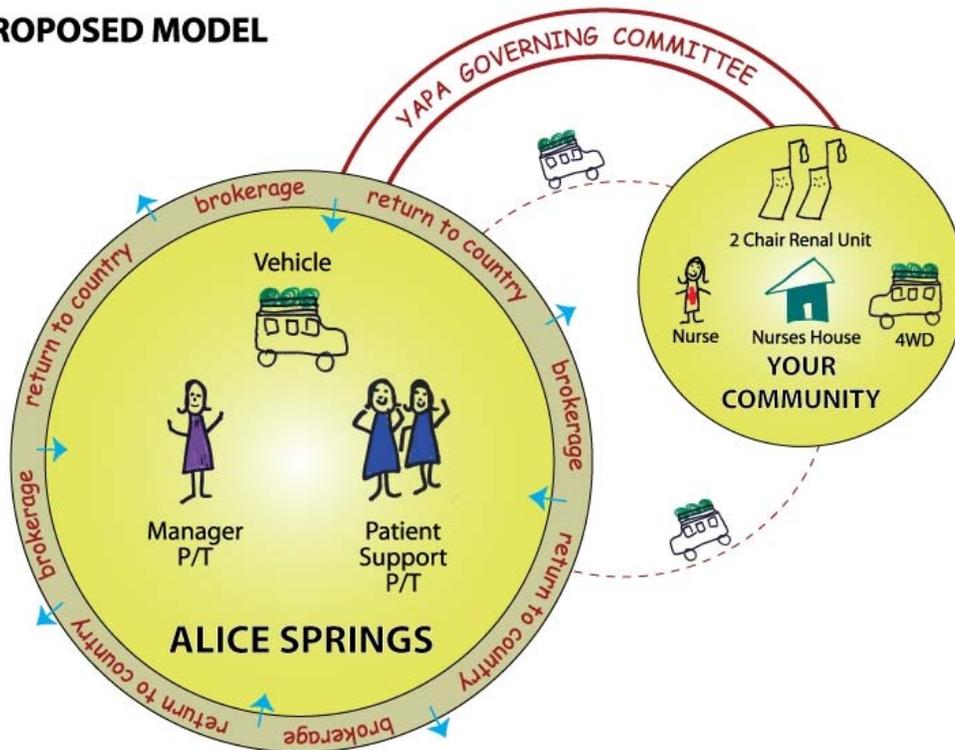
The aim of this position would be to implement the outcomes of the Feasibility study: This might include implementation of incorporation of a new organisation, employment of staff, supervision of staff, organizing office space, pursuing future funding options, etc.

- 1 x part-time patient support worker and oncosts

The aim of this position would be to improve the quality of life of Warlpiri renal patients in Alice Springs by regularly visiting patients with higher needs and making sure they attend dialysis, liaising with RDU staff and families over Return to Country trips, ensuring patients are well enough to return home, assisting with town-based services and provide some recreational opportunities.

- 1 x small town-based vehicle
- Return to country funding
- Brokerage
- Funding for office equipment
- Office rental
- Admin costs

PROPOSED MODEL



Total Budget

Total Capital Infrastructure:	\$1,010,000
Total Annual Recurrent:	\$358,680
One off costs	\$30,000
GST	

6. Resolution to Kurra Aboriginal Corporation March, 2008

The draft model described above was presented to a final meeting of family and community members in Yuendumu in February, 2008. The draft model was ratified by the larger meeting and a series of agreements (see 5.4.3 Yapa Kidney Committee Meeting, 4th February, 2008) were endorsed by the Yapa Kidney Committee at a meeting immediately following the community meeting. The Kidney Committee agreements represent a summary of the key principles drawn from consultations that underpin the proposed Yuendumu Dialysis Service model described above. Endorsement of these principles by the Committee ensured that the proposed model did not reflect any inaccurate assumptions made by the Study team and provided an opportunity for the Committee to go over all key aspects of the model and endorse them prior to the model being presented to Kurra Aboriginal Corporation for funding

Following the final consultation meeting in Yuendumu, the study team drafted a resolution for the Kurra Aboriginal Corporation's meeting in Lajamanu in March, 2008. This resolution outlined a four stage approach to developing, funding and implementing the project.

6.1 The Resolution

Stage 1

Kurra Aboriginal Corporation agrees to provide funding to employ a Project manager for an initial 12 month period. It is proposed that The Project Manager will initially be employed by the Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (WDNWPT) to enable the following preliminary work to be undertaken:

- a) Induction into the project by WDNWPT staff including familiarisation with the agreed project model, introduction to the community-based dialysis model at Kintore as well as meeting patients and families, RDU staff etc
- b) Progress towards the Incorporation of the Yuendumu Dialysis Service as an independent organisation under the Aboriginal Corporations Act.
- c) Establishment of an expert advisory committee to assist the project manager with strategic, financial, technical and health related planning and decision-making in accordance with the broad guidance of the Yapa Kidney Committee. This advisory committee should include representation from bodies such as NT Renal Services, WYN Health, WDNWPT, CLC Community Development and the existing Yapa Kidney Committee.
- d) Maintenance of the existing Yapa Kidney Committee to provide community, family and patient input to project development and to establish rules and broad guidelines for the running of the project.
- e) Development of Memoranda of Understanding between the Yuendumu Dialysis Service and the NT Health Department and WYN Health to

ensure cooperative working relationships and access to client information and records.

- f) Development of a clear and realistic set of annual outcomes for each of the first three years of the Yuendumu Dialysis Service (commencing March 2009 to March 2010). These outcomes will vary for each year eg. there may be no remote dialysis until year 2. The goals of the first year will relate more to infrastructure development, short return to country trips to country, establishment of office space etc. Progress on annual outcomes will be presented to Kurra Aboriginal Corporation at each March Meeting.
- g) Consultation with Territory and Federal Governments over potential funding contributions towards the development and implementation of this project. The project Manager, with the assistance of the Kidney Committee and Expert Advisory Committee should explore possible alternative funding options including Shared Responsibility style agreements.
- h) Application for leases within Yuendumu Community for the proposed Dialysis Unit and Nurse's accommodation

Stage 1 Budget

March 2008-March 2009

Patient Support (20hrs)	plus oncosts	$35 \times 20 \times 26 =$	18,200
Project Manager (32hrs)	plus oncosts	$45 \times 32 \times 52 =$	74,880
Recruitment and orientation			4,000
Staff development			3,000
Staff travel			5,000
Brokerage			12,000
Return to Country			13,000
Office rental (\$300 per wk x 52)			15,000
Phone/fax/internet			5,000
Office Supplies			2,000
Accounting			8,000
Audit			2,000
Fuel/maintenance			6,000
Patient Support Worker mileage			3,000
Governance: traveling & meeting costs			20,000
Insurance:			
Medical liability (\$10 million dollars)			8,000
Assoc Liability			4,000
Contents			1,000
Vehicle			1,300

Yapa liaison position (casual) 4hrs/week @ \$30/hr	6,240
	\$211,620
	GST \$21,162
	Total \$232,782

Capital Infrastructure

4WD vehicle	45,000
Office furniture	3,000
Computer/fax/printer	4,000
	\$52,000
	GST \$5,200
	Total \$57,200

Stage 1 Budget Total \$289,982

*includes 6 month funding for Patient Support Worker to supplement 6 month funding provided by Warlukurlangu Arts Centre until August 2008

Stage 2 (March 2009- March 2010)

The Project Manager will be required to present a progress report to the March 2009 meeting of Kurra Aboriginal Corporation against the outcomes set out in the Agreement proposed in Resolution 3 (above). If the Corporation is satisfied with progress towards the completion of key tasks outlined above then a proposal will be made for the provision of infrastructure and other recurrent funding as outlined in the Extended Project Budget below.

This budget will take into account any funding contributions negotiated by the Project Manager and Kidney Committee with Northern Territory and Federal governments and other potential funding agencies.

Stage 3 (March 2010- March 2012)

Once full project funding is achieved the Project Manager will report annually to Kurra Aboriginal Corporation against agreed annual outcomes. These outcomes will reflect realistic targets for project development, patient support, return to country trips and community based dialysis outcomes. Where Federal and Territory funding contributions are made towards the project then separate outcomes will need to be negotiated with these funding bodies.

Stage 4 (August 2011-March 2012)

Kurra Aboriginal Corporation will provide funding for a detailed and independent external evaluation of the project. The criteria for this evaluation will be negotiated with all funding bodies.

Extended Project Budget

This budget reflects a combination of the total infrastructure costs for the project in addition to 12 months recurrent funding for all aspects of the proposed project.

Alice Springs

Capital infrastructure

Patient support vehicle	30,000
Office furniture	3,000
Computer/fax/printer	4,000
	\$37,000

Recurrent Annual Costs

Patient Support (20hrs)	(incl. oncosts) 35 x 20 x 52 =	36,400
Project Manager (32hrs)	(incl. oncosts) 45 x 32 x 52 =	74,880
Recruitment and orientation		4,000
Staff development		3,000
Staff travel		5,000
Brokerage		15,000
Return to Country		20,000
Office rental (\$300 per wk x 52)		15,000
Phone/fax/internet		5,000
Office Supplies		2,000
Accounting		8,000
Audit		2,000
Fuel/maintenance		6,000
Governance: Traveling & meeting costs		20,000
Governance training		10,000
Insurance:		
Medical liability (\$10 million dollars)		8,000
Assoc Liability		4,000
Contents		1,000
Vehicle		1,300
		\$230,580

Yuendumu

Capital Infrastructure

Two station renal facility*	350,000
Nurse's accommodation*	550,000
Fencing and garden supplies	10,000
Office equipment and household furniture	10,000
4WD Vehicle	75,000

Lot service fees x 2 (Department of Primary Industries)*	28,000
	\$1,023,000

Recurrent Annual Costs

Nurse's wages and oncosts	100,000
Nurse's Accom electricity	2,000
Staff development	3,000
Food supplies for pts on dialysis	5,000
Housing works and maintenance (\$50 x 52)	2,100
Vehicle maintenance and fuel	10,000
Vehicle insurance and registration	2,000
Telephone/fax/internet	4,000
Yapa liaison position (casual) 4hrs/week @ \$30/hr	6,240
	\$134,340

One-off Expenditure

Three Year Evaluation	\$30,000
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Total Capital Infrastructure:	\$1,023,000
Total Recurrent:	\$364,920
Total one-off expenditure:	\$30,000
	Total \$1,417,920
	GST \$141,792
Extended Project Budget Total	\$1,559,712

* Add CPI Index x 3.5% to overall project budget each year to cover inflation

* Add 12% per annum to all building costs

* The \$14K is an estimated amount that the DPI indicates is the cost of servicing a lot on a community that is not being used for community purposes. The Yuendumu Community Council may be approached to waive this fee but DPI may still recommend that the costs be recovered by the Council

Feasibility Study Conclusion

In conclusion, dislocation due to ESKD is having an ongoing serious impact on these regional communities, including patient families, individual patients and community strength. As a health model, centralised dialysis is recognised as a problematic and expensive treatment option with poor, or at best fair, outcomes for remote indigenous patients. There is therefore a case for funding a regional dialysis program based on the second model. Our assessment is that there is very little likelihood that either the Territory or Federal government will offer nurse assisted dialysis at community level in the foreseeable future and while the self care model may attract government funding, it would only work for a very small number of renal patients. Extrapolating data also strongly indicates a steady increase in ESKD numbers within the region over the next five years, further depleting communities of their cultural mentors. Given the positive

outcomes from the WDNWPT program operating at Kintore, the willingness of WDNWPT to cradle a new separate program and not least, the enthusiasm of Tanami regional communities to 'bring their people home', this project could, if managed and implemented well, deliver substantial measurable benefits for individuals and communities. It is an opportunity to significantly improve community services for the region and this could be considered as 'value adding' because further economic, social and cultural benefits would flow from community development. CKD has been a wound sapping the strength and viability of many communities for many years. Model two is likely to have the most far reaching benefits and also presents a strong argument for government assistance with service delivery. Probably most importantly of all, the study has found that there is a powerful cross community will to address the damage caused by CKD / dislocation.

Following a detailed presentation by Sarah Brown and Georgia Stewart at the March 2008, Kurra Aboriginal Corporation meeting in Lajamanu, an agreement was made by Kurra Aboriginal Corporation members to fund the proposed Stage 1 of the Yuendumu project, allocating \$289,982 to employ a project manager and complete one year of establishment for the project. In addition, the members agreed in principle to fund the remaining three stages of the project pending successful progress towards the preliminary tasks outlined for the project manager and Yapa Kidney Committee in Stage 1. This progress is to be evaluated by the Corporation members at their March meeting in 2009.

7. Glossary

Community-based dialysis - Any dialysis option occurring within the community. Emphasizes general location anywhere outside of an institution dedicated to dialysis delivery.

Chronic Kidney Disease (CKD) – the situation of kidney disease deterioration prior to dialysis (previously known as chronic failure; Chronic Renal Insufficiency).

End Stage Kidney Disease (ESKD) – when kidney function deteriorates to a level where the patient can only survive with the assistance of artificial dialysis.

Haemodialysis (HD) – a machine pumps blood from the body via needles, through a filtration system and back. Institutional treatment cycles usually last 4-5hrs, 3 times weekly.

Renal Dialysis Unit (RDU) – the regional institution ‘responsible’ for the full range of dialysis-associated services, located in Flynn Drive, Alice Springs. In fact RDU is properly termed a satellite unit (see below), but the close relationship with the hospital (ASH), the broad range of dependent dialysis clients, and the housing of the Outreach and Self-Care training teams make it more than this.

Attachment A

Patient List

Maudie Nelson	Alice Springs
Mavis Wayne	Alice Springs
Ruby Wayne	Alice Springs
Norah Nelson	Nyirripi
Samuel Nelson	Nyirripi
Gregory Williams	Nyirripi/Tennant Creek
Kenny Gorey	Willowra
Tommy Martin	Willowra
Serena Robinson	Willowra
Dorothy Forrest	Yuendumu
James Jabanardi Marshall	Yuendumu
Paddy Stewart	Yuendumu
Belle Dickson	Yuendumu
Lenny Davis (aka Leonard Walker)	Alice Springs
Flora Scott McDonald	Alice Springs
Howard Wayne	Alice Springs

Attachment B

Kidney Committee Members

James Japangardi Marshall (renal patient)

Belle Nakamarra Dickson (renal patient)

Alan Jungarrayi Dickson (key contact)

Jean Napanangka Brown (key contact)

Freda Napaljarri Jurra

Doris Napaljarri Jurra

Monica Napurrurla White

Ruth Napaljarri Stewart

Eddie Jampijinpa Robertson

Lottie Napangardi Robertson

Stephen Marshall

Dennis Williams

Attachment C

Consultations (detail)

Warlpiri Patient Meeting (22 October, 2007)

Four Yuendumu renal patients attended, as well as an interpreter, the two study team and the WDNWPT Manager, Sarah Brown. Sarah detailed the seven year history of WDNWPT. She used a large diagrammatic interpretation of the model to illustrate the current services and plans for expanding Kintore dialysis services in the near future. The scope of the Dialysis Support Feasibility Study was also discussed and the plan to travel to Yuendumu, invite family members to come to Alice Springs, develop a committee, including patients and together develop a model for dialysis services for Yuendumu renal patients. Renal patients were asked for names of family members they wished us to consult with in Yuendumu. Two patients expressed interest in coming out to Yuendumu to visit family.

Warlpiri renal patient: "It's hard to find money to get fuel to come in for dialysis. I get stuck out there and get sick".

One patient expressed concern for her elder sister, also on dialysis. He said that she has been in poor health for some time and he thinks she would benefit from some more help in town and isn't able to see her husband much, because he works out at Mt Theo (an outstation 170km from Yuendumu).

Karl Hampton (MLA) visits Purple House (29 October, 2007)

Karl Hampton, the current member for Stuart in the Northern Territory Legislative Assembly was invited to the Purple House to discuss the future of dialysis for Yuendumu and Lajamanu. He spoke with the WDNWPT Manager, Sarah Brown at length about the WDNWPT model, looked in on the WDNWPT members dialysing at the Purple House and observed a WDNWPT committee meeting. Mr Hampton said that the issue of dialysis in Yuendumu has been raised numerous times by renal patients, and he would like to assist the process by liaising with the NT Health Minister, the Hon Dr Chris Burns. He said that he has already told Dr Burns about the feasibility study and would like to be kept up to date with the study.

Visit to the Nightcliff Renal Unit (9 November, 2007)

While in Darwin one of the study team visited the Nightcliff Renal Unit to learn about self-care training and to meet Lajamanu patients. The Self-Care Training Unit offers training to those interested in learning to dialyse at home – all self-care clients receive telephone support from the self-care unit and general health care from their community clinics. At the time of the visit the Manager, Dorothy was supporting 11 people doing haemodialysis outside of a medical facility and training 4 more. All but one of these 11 clients were living in top-end Aboriginal communities; most of these on islands. The facility within which the self-care training operates is a purpose built demountable with wiring and plumbing for 2 chairs. It also has suitable storage, toilet facilities, secure storage for waste, and disabled access. NT Department of Health and Community Services currently provide these relocatable units for self-care clients. The relocatable dialysis units were proposed as an option for dialysis in Yuendumu and Lajamanu.

Other Outcomes from this Consultation

Dorothy recommended that a 2-machine unit be shared by 4 self-care clients. She also raised the issue of waste; it is her biggest problem as there are strict guidelines about the disposal of clinical waste and the remote locations make transporting waste difficult. Dorothy also suggested that in terms of location of a unit, traditional owners and family groups should be consulted about potential locations, if it is to be shared by more than one client it should be centrally located and it is best if it is separate from other organisations and facilities, but close to supportive organisations.

Dorothy said it is very important that the client and the community understands that each person is responsible for their own dialysis so as to avoid blame and anxiety in the event that a person does not attend dialysis, becomes ill or dies.

At the Nightcliff Renal Unit, one Lajamanu renal patient was dialysing at the time of the visit. This woman said she would like to get home more often to see family and would like to dialyse at Lajamanu if there was a facility there. She asked us to speak to her sister in Lajamanu.

Yuendumu Community Consultation (11-12 November, 2007)

Prior to traveling to Yuendumu, relevant organisations were identified and contacted regarding potential dialysis and support services. During these initial conversations many indigenous and non-indigenous staff members expressed interest and enthusiasm regarding the development of dialysis services. One renal patient traveled with the study team and spent a night with her family.

Several family meetings were held focusing on the circumstances and concerns regarding specific renal patients. Following are some of the contributions family members made:

- One woman said: *"It is hard for my nephew because he doesn't have enough money and can't look after his kids properly in town"*
- Concern was expressed for elderly or frail clients: *"They need someone to check on them and look after them in Alice Springs – take them on a picnic, cook up some meat."*
- A sister of a renal patient expressed her concern: *"My sister is sometimes in (a town camp) on her own. She is missing renal and getting sick"*.
- The family of a renal patient was upset about the impact of having this elderly man in Alice Springs all the time. He used to spend all his time with his brother. They are both elderly and frail and are senior men in the community. *"They are both lonely for each other – he needs to be here". "Because my brother is stuck in town for dialysis, he gets bored and goes drinking". "Sometimes that old man (renal patient) moves to a town camp for the weekend because he's lonely. The renal bus can't find him and he misses dialysis. When he's in the town camp, he drinks too much grog"*.
- Housing is a problem. One man, a renal patient, wanted to rent a house. His brother discouraged him as not only would he struggle to find money for rent, he would have family from out bush coming to stay, drinking and taking him away from dialysis.
- Some patients are lonely living in hostels, some find it too expensive and say the food is no good.

- The son of a dialysis patient said, *“I don’t know who to contact about how my mother is going at dialysis. I visit her, but I need to know if she’s okay, and if she’s going to dialysis regularly.”*

Key organisations were identified as they would potentially be involved in establishing and or delivering renal services in Yuendumu.

Yuendumu Clinic

The study team had a joint meeting with staff from WYN Health and the Clinic Manager. Both organisations said that from their experience suitable and attractive housing was crucial in recruiting and retaining staff and adequate funding needs to be allocated for this purpose. The Clinic Manager was supportive and enthusiastic about having dialysis services in Yuendumu. It was explained that in Kintore the involvement of the clinic with dialysis services was to provide general health care, allow the use of some diagnostic equipment and store some medications. This is a similar level of support given to self-care dialysis clients in the top-end remote communities. The WDNWPT patient rules and governing committee were also discussed. Some of the beneficial outcomes of WDNWPT services were discussed, specifically that there were fewer evacuations from communities of WDNWPT members and higher levels of compliance with renal dialysis in Alice Springs.

WYN Health

The WYN Health doctors, manager and public health nurse made valuable contributions. They pointed out that WYN Health is a regional organisation working across Willowra, Yuendumu and Nyirripi. They would like to see dialysis services including all of these communities. They supported the use of a purpose-built relocatable unit and recommended that the dialysis services become an independently incorporated organisation. WYN Health was particularly interested in the Alice Springs based patient support for WDNWPT members. They see this as critical to the success of remote health service delivery. WYN Health Manager, Scott Campbell Smith informed us of WYN Health’s plans to establish a liaison office in Alice Springs to provide support to Warlpiri receiving health treatment in town. He is very supportive of the proposed Patient Support and Project Manager’s positions created from the Yuendumu dialysis service being housed in one office complex in Alice Springs as part of creating a Warlpiri ‘footprint’ in Alice Springs.

As a public health body, WYN Health is concerned about prevention of kidney disease. They were pleased to hear about WDNWPT’s prevention strategies and involvement of Aboriginal Health Workers in community education and dialysis.

WYN Health plan to provide regular transport for patient travel between Alice Springs and Yuendumu, Willowra and Nyirripi in the near future. They are keen to coordinate this travel with Warlpiri renal patients; in the short term for return to country trips, and for dialysis in the future. If this eventuates they see a dialysis support organisation as covering the cost of transport for renal patients. One of the medical doctors has a background in renal medicine and expressed interest in supporting a renal facility in Yuendumu. Two members of the WYN Health Board were recommended to be involved in the development of renal services for Yuendumu. One of these people is a Kidney Committee member.

Warlukurlangu Artists Association Inc.

The Warlukurlangu manager, initiated contact with WDNWPT early in 2007 after one of the senior artists moved to Alice Springs for dialysis. The manager is very concerned about this one particular artist and would like to organise for him to get home to Yuendumu regularly. Following further discussion about how WDNWPT supports renal patients in Alice Springs and coordinates return to country trips, she offered to contribute funds for a part-time patient support/return to country coordinator for 6-months. Since this initial conversation, \$20 000 has been committed by Warlukurlangu Artists for this purpose. WDNWPT have offered to oversee recruitment and employ this worker until Warlpiri renal services get underway. Cecelia also offered accommodation of such worker in Yuendumu for overnight trips. The manager said Warlurkurlangu Artists are able to fundraise for dialysis through art auctions. They have held art auctions over the past 2 years and raised funds for eye surgery and a specialist ear clinic in Yuendumu.

Yuendumu Community Council

At the time of our first visit the CEO was a temporary appointee. The issues of housing and location of a renal facility were discussed. The acting CEO advised that remote community management would be regionalized in mid-2008, and that imminent changes from the Commonwealth Government Emergency Intervention and an impending Federal election will have implications for the negotiation of land tenure. At the moment there will need to be consultation with the Community Council members, Traditional Owners and the Department of Planning and Infrastructure in obtaining use of land for renal nurse housing and for dialysis purposes.

The anticipated involvement of the Yuendumu Community Council in the running of dialysis services in Yuendumu was also discussed. Such involvement may include general waste disposal, and provision of electrical and plumbing services. It was agreed that an MOU will need to be drawn up to formalise any arrangements.

Essential Services Officer (ESO)

The Yuendumu Essential Services Officer was consulted about the power and water supply in Yuendumu. The power supply for Yuendumu is from a diesel generator. The supply is stable with occasional outages for 12-15 minutes. The ESO said it is possible to prioritise an electrical circuit so that in the event of reduced power supply, or an increase in demand, the power supply for the dialysis facility will be continuous and non-essential areas, such as residential, will be temporarily ceased. The ESO was interested to hear about how the Kintore water supply fared in the development of the dialysis clinic there. He said that water samples are collected regularly. The results of which are available through Power and Water Authority. He also said that sufficient water pressure will need to be ensured for the dialysis facility through a designated water tank and pump attached to the facility, as is the case in Kintore.

Noel Mason, Government Business Manager Yuendumu

Noel provided us with advice on the process for allocating land lots in Yuendumu for the purposes of a renal dialysis facility and nurse's accommodation and the cost of servicing lots that are to be utilized for non-community purposes. According to Noel this fee (approximately \$14,000 per lot) may be waived by the community and DPI but this will need to be followed up if the project progresses further.

Prior to Christmas the study team wrote to the Community Council who provided in principle support for the allocation of a lot between the Community Council and clinic for the purpose of a demountable renal unit. There are currently no lots available for staff accommodation but the Council agreed in principle to allocate one for nurse's accommodation further down the track (see attachment H, Correspondence). Final allocation of lots cannot be made until all relevant parties including the CLC are consulted. Under the new 5 year lease arrangements a request will be made to Margaret Clark in the NTER office in Darwin. According to Noel if DPI is happy with the lot allocation then there will be no problems with NTER but a formal application process will need to be made.

Yuendumu Women's Centre

The Yuendumu Women's Centre coordinator was aware of WDNWPT and had been to the Purple House. She has been involved in supporting a Yuendumu woman who required dialysis and assisted her to dialyse at home on peritoneal dialysis. This woman is now a haemodialysis client at the RDU. The coordinator is interested in promoting dialysis in Yuendumu as she has seen how the dislocation from home affects the individual and their families. The Women's Centre was a valuable place to call and send faxes when organizing meetings and getting in contact with committee members.

The location of a dialysis facility was discussed. The women's centre has obtained approval for taking of the premises of the old clinic, which will leave the current site vacant. It was suggested that this be considered for dialysis. Measurements and photographs were taken with a view to obtaining quotes for renovation for dialysis. The building, a renovated house, was quite run down but appeared structurally sound. The use of a relocatable unit was also discussed. In follow up conversations with Simon Murphy, for Centre for Appropriate Technology it was determined that renovation of this site would be costly and time-consuming given the current shortage of trades people as a result of the Intervention. The facility is also very large and the study team considered it too big for one staff member to maintain.

Granites Mine Affected Areas Corporation (GMAAC) meeting (21 November, 2007)

The study team was invited to a GMAAC meeting in Alice Springs to present an outline of the Kurra Dialysis Feasibility Study and report on progress so far. The purpose of the meeting was to use the Kurra Dialysis Feasibility Study as an illustration of how royalty money can be used to benefit communities. At the meeting were delegates from Yuendumu, Nyirripi, Willowra, and Lajamanu. The WDNWPT model was explained through diagrams, photographs and discussion. There was much interest generated and many questions asked. Discussion ranged from explanations of dialysis, kidney function and kidney failure to safety aspects of dialysis, particularly power outages. At the end of the discussion it was agreed that a copy of the findings of the Kurra Dialysis Feasibility Study would be provided to GMAAC for their consideration.

Department of Planning and Infrastructure (DPI)

The Department of Lands and Infrastructure (DPI) was contacted to discuss possible locations for accommodation of a renal nurse and dialysis facility. Peter Seibert, Manager Indigenous Community Land Use Planning advised that there were two available lots for staff accommodation and that there was an available lot between the Clinic and the current CDEP office. A letter was written to the Yuendumu Community Council to consider allocation of these lots for the purpose of accommodation and a dialysis facility.

The Council wrote back giving in principal support (see Attachment H, Correspondence) for the location of a future dialysis unit on a lot behind the Council offices, between the Council and the new clinic. This site was also approved in principle by all community members spoken to during both visits to Yuendumu and is considered a neutral location with respect to family groups. The location of a housing lot for nurse's accommodation was supported but was deferred until the project is further developed and a potential site can be identified.

Power and Water Authority

The Power and Water Authority are responsible for collecting, testing and collating results of water quality in Yuendumu and Lajamanu. They provided extensive documentation of water quality, which was then forwarded to Fresenius technicians and management for their advice regarding water quality and treatment requirements for haemodialysis.

Power and Water Authority were also consulted regarding the cost of plumbing in a demountable Dialysis Unit and connecting the unit to Power. They reported that the location of the proposed unit between the Council Offices and the new clinic means that the power and water infrastructure would be in place and that a small fee would be required to install power and water meters at the site (approximately \$56 and \$55 respectively).

Yuendumu Family and Patient Meeting, Purple House (26 November, 2007)

20 people attended a meeting at the WDNWPT Purple house to learn about dialysis options and develop a model for dialysis in Yuendumu. Four Alice Springs based dialysis patients attended, the rest traveled from Yuendumu and Nyirripi. While the renal patients were being picked up, the others visited the Alice Springs Renal Dialysis Unit. Many had never seen a dialysis machine before. Comments were made regarding the lack of privacy and the sheer number of beds at the unit. Following this everyone met at the Purple House, first to walk through the dialysis room where two WDNWPT members were dialysing and then a meeting was held. The key purposes of this meeting were to form a committee and develop a model for dialysis support services. However, before this the WDNWPT manager, Sarah Brown explained the WDNWPT model in detail using a large diagram to illustrate the parts of the WDNWPT model, the numbers of machines, nurses, vehicles AHW and other staff, where they are located and how they all work together.

Following this, Sarah, who is also a registered nurse talked about the function of the kidneys, kidney disease and kidney failure. The next passage is a story that was used to describe a common way that kidney failure can develop:

A teenager is pregnant, she is young to be a mum, she's not fully grown herself. That baby gets born too early and it is very small. The baby's kidneys are also too small and don't have enough filters, and won't grow more as the child grows. As this person grows, their kidneys will be like a tiny filter for a goldfish bowl trying to clean a great big swimming pool. The kidneys get wrecked because there's not enough filters to do the job.

Every time you get an infection – scabies, school sores, runny nose or glue ear – your body tries to fight that off and your kidneys have to work hard to clean the infection out of your blood. If you get high blood pressure or diabetes, this also harms your kidneys.

The WDNWPT renal nurse, Deb Lillis talked about what dialysis is and how haemodialysis works:

Dialysis is replacing kidneys that don't work. The machine cleans the rubbish and extra water out of the blood. The kidneys also make hormones that make blood and bones strong and give you energy. The tablets replace this. We have trouble with this because renal patients don't realise dialysis isn't enough, they need to take their tablets as well. The machine looks really complicated, but those machines are really just safety mechanisms. The machines are big safety mechanisms and just shut down if there is a problem and the alarm goes off. If the power goes down the machines have battery back up – dialysis machine goes for half an hour if there is a power outage. If the power goes out or the water pressure drops, if there is any big problem the best thing to do is to push the machine away – they'll be fine, they just lose a little bit of blood.

There were many questions asked, including if dialysis is okay when people are sick? Is the water quality in Yuendumu okay and what about power outages? The need for AHW on communities to be involved with dialysis was expressed, as well as the need for a community nutrition worker. There was discussion about what causes kidney failure, how to prevent it and the relationship of diabetes and high blood pressure to kidney disease and failure. There were questions about how to care for renal patients, including appropriate diets, fluid restrictions and the need for good housing if people are at Yuendumu on dialysis.

Community Meeting, Yuendumu (February 4, 2008)

The study team traveled to Yuendumu on Sunday, February 3rd to conduct a final round of consultations with Yuendumu community members. Two dialysis patients also drove out with the study team to attend the meeting and spend time with family.

Posters were sent to the community 2 weeks prior to the meeting and placed in public venues by local health workers. Faxes were sent to Nyirripi, Willowra and Yuelamu notifying those communities of the meeting. Faxes were also sent to staff at the Yuendumu Community Council, Women's Centre, WYN Health, Warlukurlangu Arts Centre and Old People's facility.

The meeting was attended by 30 community members. (see Attachment D Meeting Attendance Lists)

Yapa Kidney Committee Meeting (February 4, 2008)

Immediately after the Yuendumu community meeting a smaller meeting of the Yapa Kidney Committee was held. The committee endorsed the model supported in the larger community meeting. Some general concerns about individual renal patients were

discussed. The budget was gone over in some detail with Alan Dickson who is a member of the Kurra Aboriginal Corporation and is keen to support the project at the Lajamanu meeting.

Jean Brown said she would be interested in supporting her mother in law Belle Dickson to learn self-care training.

The committee discussed a list of agreements that underpin the agreed model and discussed then endorsed each agreement individually.

WYN Health

A follow-up meeting was held with the WYN Health Manager, Scott Campbell Smith. Scott reiterated his support for the project and reinforced his concern that preventative kidney health programs should somehow be linked to the project. Scott felt that it might be difficult for WYN Health to employ the Project Manager for the Yuendumu dialysis project as an interim measure as their employer body is Congress. Scott advised us to speak to Steve Putz, Congress Remote Services Manager.

We discussed the potential for a Yuendumu dialysis service Project Manager and Patient Support Worker to be housed together but independently in office space in Alice Springs sometime in the future –a move which would be supported by WYN Health. Scott expressed support for the provision of community and social services through employment of a patient support worker in Alice Springs as part of a proposed Warlpiri Dialysis support service.

(see Attachment H, Correspondence- WYN Health Support Letter)

Attachment D

Meeting Attendance Lists

Patient Meeting Purple House 22/10/07

Wilfred Nelson Jupurrula
Belle Dickson Nakamara
Megan Hoy
Sarah Brown

Samuel Nelson Jupurrula
Dorothy Forrest Napurrula
Georgia Stewart
Deb Lillis

Yuendumu Family and Patient Meeting, Purple House (26 November, 2007)

Jean Brown
Nancy Napurrurla Oldfield
Biddy Napaljarri White
Belle Nakamarra Dickson
Nellie Wayne
Monica Napurrurla White
Eddie Roberston
Samuel Nelson
Violet Marshall
Dorothy White
Megan Hoy

Lottie Williams Robertson
Ruth Napaljarri Stewart
Freda Napaljarri Jurra
Doris Jurra
Pamela Napurrurla Sampson
Alan Dickson
James Marshall
Sarah Brown
Janet Collins
Georgia Stewart
Deb Lillis

Community Meeting, Yuendumu (3-5 February 2008)

Jean Brown
Stephen Marshall
Ruth Stewart
Dennis Williams
Reva Dickson
Johnny Miller
Ama Robertson
Amos Egan
Lyn Simms
Wendy Brown
Kathleen Martin
Nellie Wayne
Amos Egan
Laurence Karpa
Eddie Robertson
Megan Hoy
Scott Campbell Smith (Manager, WYN Health)
Cecilia Alfonso (Manager, Warlukurlangu Arts Centre)

Simon Fisher
Peggy Brown
Monica White
Glenys Brown
Alan Dickson
Peggy Lockman
Maisie Wayne
Peggy Brown
Bessie Simms
Wilfred Nelson
Maria Brown
Rosie Fleming
Malcolm Fry
Dadu Gorey
Georgia Stewart

Yapa Kidney Committee Meeting (4 February, 2008)

Jean Brown
Alan Dickson
Ruth Stewart
Eddie Robertson

Dennis Williams
Stephen Marshall
Monica White
Georgia Stewart & Megan Hoy

Attachment E

Initial Consultation Questionnaire

Warlpiri Dialysis Feasibility Study

Questionnaire

Date

Name
Community
Address in town
Family/carers in town
Family on community
Dialysis days

Introductions & Outline of study

WDNWPT asked by CLC to

- Look into options for dialysis patients and their families from Yuendumu and Lajamanu
- Develop kidney committee to talk to community members and services about which options best suit them
- Liaise with organisations on communities about resources available to support options
- Present report to CLC by June 2008

Options for Western Desert members:

- 1 Machines in communities
- 2 Return to country
- 3 Patient support in town
- 4 Purple house

Questions

1 What do you find hard about living in Alice Springs on dialysis?
2 What would make your life easier or better?
3 Would you like to be involved talking about dialysis services for your community?

Any other comments??

Attachment F

Support for Warlpiri Dialysis Patients during the Feasibility Study

As we came into contact with Warlpiri renal dialysis patients and their families through this study, it became apparent that a small number had some immediate and pressing health or related issues that we could address with comparatively minor effort. Our experience at WDNWPT led us to believe that providing practical support to people (within limits) was an appropriate response and would begin to demonstrate the potential tangible benefits of a future dialysis support services. As such we have documented the assistance that we managed to provide throughout the period of the feasibility study.

- Secured accommodation for one female renal patient at the new Topsy Smith hostel and helped her to move her belongings. We also referred this patient to the Adult Health physiotherapist and organised two appointments at the WDNWPT GP clinic. We assisted this patient to attend the grog rally in town and a bush medicine workshop at the Purple House and took her home to Yuendumu to visit family on our consultation trips.
- Referred one male renal patient to the Renal Unit social worker for assistance with Centrelink Carer Payment and involved him in consultations with GMAAC in November.
- Arranged two appointments at the WDNWPT GP clinic for a patient living on a town camp. We later referred this person to the Adult Health physiotherapist resulting in improved access to her house through construction of an earth slope and provision of a wheelie walker.
- Organised a return to country trip for one male patient through the Jimmy Little Foundation and made a referral for the same man to Topsy Smith Hostel.
- Took three patients on Return to Country trips when we visited Yuendumu for meetings.
- Purchased a bed for a female patient living on a town camp who was struggling to get up from a low bed. Referred same person to Allied Health for a shower chair and replacement wheelie walker.

Following our first consultation in Yuendumu, the Warlukurlangu Arts Centre Coordinator agreed to provide WDNWPT with \$20,000 to employ a part-time support worker to assist Warlpiri renal patients in Alice Springs and to organise Return to Country visits. Some of this funding was used to provide material supports to patients prior to the employment of a support worker.

Attachment G

Job Descriptions

1. Warlpiri Renal Dialysis Patient Support and Return to Country Worker

This position is on a trial basis for 6 months subject to ongoing funding by Mining Royalty Bodies, GMAAC and Kurra Foundation in 2008. The person will be employed by the Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation for the initial 6 months with future employment arrangements to be negotiated through the Yuendumu/Lajamanu Renal Dialysis Feasibility Study.

The position will commence as a part-time position 12 hrs per week (preferably three mornings per week) on a rate of \$25 per hour.

Desired qualities

- Experience working with Aboriginal people residing in remote area Central Australia
- Capacity to work flexibly and with a high degree of autonomy
- Empathy for and understanding of the needs of remote area renal dialysis patients

Duties

- Provide social and advocacy support for Warlpiri renal dialysis patients from Yuendumu, Nyirripi, Mt Allan, Willowra and Yuelamu and identified longterm Warlpiri Renal patients from Alice Springs. Prioritise support for high needs patients.
- Organise Return to Country visits on an equitable basis
- In consultation with patient group develop guidelines for Return to Country visits to ensure patients are well before they leave and return at agreed time.

2. Yuendumu Dialysis Service Project Development Manager

Duty Statement

32 hrs per week

Salary: \$66,560 (full-time \$79,040)

Salary Sacrifice through CBB

Six weeks annual leave

Project Description

Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (WDNWPT) is a not for profit, community based organisation providing town-based and remote dialysis services for Western Desert Dialysis patients. In March 2008, WDNWPT completed a feasibility study into options for establishing similar services for Warlpiri

Dialysis patients on behalf of Kurra Aboriginal Corporation (a body established to facilitate royalty disbursements for specific Warlpiri families and communities).

In March 2008, Kurra Aboriginal Corporation allocated \$257,380 to WDNWPT to auspice the one year development phase of the Yuendumu Dialysis Service. An in principle commitment was also made to fund a further three years of the project, including capital infrastructure, if sufficient progress is made at the end of the establishment year of the project. An option therefore exists for this position to transition to an operational manager after one year.

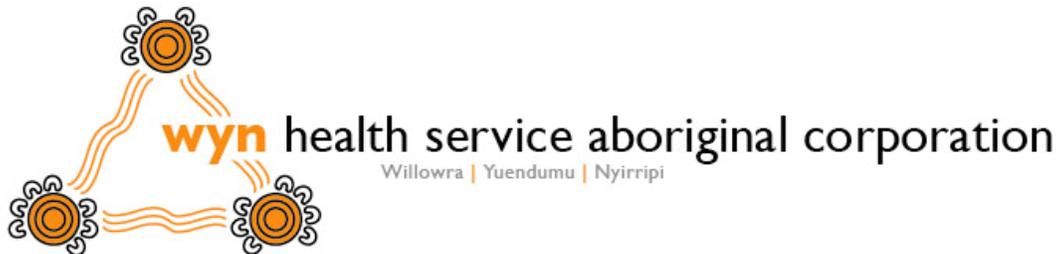
Duties

The project manager will be responsible for implementing the development phase of the project and making significant and demonstrable progress towards each of the following outcomes:

- i) Induction into the project by WDNWPT staff including familiarisation with the agreed project model, introduction to the community-based dialysis model at Kintore as well as meeting Yapa (Warlpiri people) patients and families, RDU staff etc.
- j) Progress towards the Incorporation of the Yuendumu Dialysis Service as an independent organisation under the Aboriginal Corporations Act.
- k) Establishment of an Expert Advisory Committee to assist the project manager with strategic, financial, technical and health related planning and decision-making in accordance with the broad guidance of the Yapa Kidney Committee. It is recommended that this Advisory Committee include representation from bodies such as Territory Department of Health (NT Renal Services), Federal Department of Health, WYN Health, WDNWPT, CLC Community Development and the existing Yapa Kidney Committee.
- l) Liaison with WYN (Willowra, Yuendumu, Nyirripi) Health over the establishment of a joint office facility in Alice Springs.
- m) Maintenance and capacity building of the existing Yapa Kidney Committee to provide community, family and patient input to project development and to establish rules and broad guidelines for the running of the project.
- n) Development of Memoranda of Understanding between the Yuendumu Dialysis Service and the NT Health Department and WYN Health to ensure cooperative working relationships and access to client information and records.
- o) Development of a clear and realistic set of annual outcomes for the first operational year of the Yuendumu Dialysis Service (March 2009 to March 2010) to be presented to the Kurra Aboriginal Corporation meeting in March 2009.

- p) Consultation with Territory and Federal Governments over potential funding contributions towards the development and implementation of this project. The Project Manager, with the assistance of the Kidney Committee and Expert Advisory Committee should explore possible alternative funding options including Shared Responsibility style agreements.
- q) Application for leases within Yuendumu Community for the proposed Dialysis Unit and Nurse's accommodation.
- r) Reporting consistent with the WDNWPT and Kurra Aboriginal Corporation Agreement (attached)

H. Correspondence



18/2/08

RE: Dialysis Project for Yuendumu.

To Whom it May Concern,

This letter is written in support of the proposed dialysis project for Yuendumu and to outline some of the various possibilities for WYN health involvement in the future. This letter also notes some of our concerns and aspirations for the project.

There is no doubt that the proposed dialysis project enjoys strong community support in Yuendumu and the WYN Board likewise endorses the proposal. We hope and expect that it will allow Warlpiri elders on dialysis to have stronger contact with their Yuendumu based family and community.

The WYN Board also endorses the 'Kintore model' for the project, featuring a strong organisational presence in Alice Springs and strong social support for people on dialysis. In this connection we would like to note that it is possible that WYN, along with Western Arrernte Health Service, Pintupi Homelands and perhaps Santa Teresa and Mutitjulu Health services will be establishing a shared administrative support office in Alice Springs in the very near future. This is in response to a strong push from the Federal Government towards the regionalization of remote health services. Should this occur, we anticipate that we would be in a good position to house and support the emerging dialysis project within the same office and administrative structure, with a view to it becoming independent at a later stage.

WYN Health Service would also like to offer the participation of its staff and or Board members on any steering committee that may be formed to guide and develop the project

further. We feel that a close working relationship with the Drs, nurses, health workers and other clinic based staff will be necessary for the project to succeed and we look forward to contributing what we can towards achieving good working relationships. On a related point, although it appears that a basically independent organisation is at present the most likely administrative arrangement for the project, it is also possible that the project and WYN Health will need to consider sharing administrative and allied support staff either as an interim arrangement, in the short term or perhaps as a long term arrangement that will give us work-force flexibility and achieve economies of scale. We note that regionalization and amalgamation is a strong trend currently in the health field and that it does seem that organisations are more viable in the long term when they are larger. It is important too to have strong community control and WYN Health has an existing Board structure of that nature which the dialysis project could be a part of, either within WYN or in a 'federated' system. WYN is also open to considering all or any of these options.

WYN undertakes a great deal of patient transport to and from Alice Springs and it is likely that we would be able to provide this service for dialysis patients in the future. Indeed, this could commence immediately as a way to facilitate short visits to the Yuendumu, Willowra and Nyirripi communities.

Finally, we would also like to flag some concerns and requests we have for the project. First and foremost, we feel that dialysis is a last and desperate resort in the struggle to have healthy community members. We would like to see this project have an equal emphasis on preventing kidney disease, that is, on community education, nutrition and active lifestyles. We urge you to consider working these preventative measures into the project in some way. Secondly we are very concerned that the community's perceptions and expectations of the project might be unrealistic. We feel it is of the upmost importance that in your consultations you make certain that community members are absolutely clear that the project will only be able to bring a small number of patients home at any one time and only for short periods.

Overall, however, we wish you every success and offer any support we may be able to give.

Yours Sincerely,

Scott Campbell-Smith
WYN Health Manager



ABN: 29 524 300 320

Monday, 17 August 2009

Megan Hoy
NT Renal Service Study

Dear Megan,

Ref: Feasibility Study – Yuendumu

At the meeting on 11th December 2007, Council agreed to allocate in principle an area adjacent to Lot 612 for a Renal Unit in Yuendumu. This area was considered appropriate due to its close proximity to the Clinic. The area will need to be surveyed and this approval does not imply tenure.

Unfortunately at this stage there are no available lots for a Renal Nurse but Council has supported this application and when the Renal Unit Proposal is closer to fruition a Lot will be identified.

All allocation of Lots will need to be approved by the other interested parties.

Council is supportive of this Proposal for a Renal Unit in Yuendumu and look forward to further discussions.

Regards,

Janis Frost

**Janis Frost
CEO**