Australian Department of Health and Ageing

Central Australia Renal Study

June 2011

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Executive Summary
Disclaimer

The Central Australia Renal Study (the Study) was commissioned by the Office for Aboriginal and Torres Strait Islander Health (OATSIH) within the Department of Health and Ageing (DoHA) in August 2010. It was instigated in order to develop a range of feasible clinical services delivery models to meet the current and projected needs for Aboriginal and Torres Strait Islander patients from remote communities in the Central Australia (CA) region requiring dialysis.

The analysis and conclusions presented here are those of the authors.
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Purpose of the Study

The Central Australia Renal Study was undertaken against the following background:

- Increasing numbers of Aboriginal people in the Central Australia (CA) region requiring renal replacement therapy (RRT), predominantly in Alice Springs.
- Recognition of the lack of culturally appropriate service options and, in particular, service options allowing treatment as close to home as possible.
- Recognition that treatment may require relocation and, where it does, support needs to be provided for patients and families.
- Concerns about the negative impact of a lack of culturally appropriate service options on treatment uptake.

The Study was undertaken to inform the governments in the cross-jurisdictional region to make evidence based policy decisions, in order to better meet the health and service needs of Aboriginal dialysis patients in the region, in affordable and sustainable ways. It builds on the body of work already undertaken by the Australian Health Ministers’ Advisory Council in the development of the National Services Guidelines for the Management of Dialysis and Kidney Transplantation in Remote Australia 2006.

The Australian, Northern Territory, South Australian and Western Australian Governments agreed the Terms of Reference for the Study.
The Approach

The methodology consisted of four key streams:

ii.i Evidence Review

The Study included a major systematic review of national and international evidence regarding issues relating to Aboriginal and Torres Strait Islander chronic disease in general, chronic kidney disease (CKD) in particular and development of appropriate services. The review sought to describe the:

- Burden of renal disease among Aboriginal and Torres Strait Islander people overall, and in the CA region.
- Outcomes of renal disease among Aboriginal and Torres Strait Islander people.
- State of the art in RRT.
- Influences on chronic illness care and prevention services for Indigenous peoples in Australia, New Zealand, Canada and USA.

The review entailed synthesis and analysis of documents from the United States, Canada, New Zealand and Australia published over the last two decades. The publications included both empirical and grey literature to allow for perspectives not traditionally represented in academic literature, particularly Indigenous perspectives.

ii.ii Data Analysis

The Study Team analysed the best available qualitative and quantitative data on patterns and outcomes for renal service delivery, alternative models of service delivery and patient and community experiences of health, illness and negotiating care.

Work undertaken also included comprehensive economic analysis to estimate the costs and benefits of provision of RRT for Aboriginal and Torres Strait Islander peoples across the CA region from 2009 to 2020. This model was built on the actual health outcomes and care transitions of the cohort of patients commencing RRT in the CA region between 2005 and 2009.

ii.iii Consultation

The Study Team conducted extensive consultation across the CA region, with a diverse range of patient, community, service provider and government stakeholders. A number of patient forums were also held across the region which gave patients and family members further opportunity to share their experiences of accessing and utilising renal services.

A detailed stakeholder engagement plan was developed in consultation with the Study’s Steering Committee.
Projections of Burden of End Stage Kidney Disease (ESKD)

Using ANZDATA, historic age-specific trends in the incidence of treated ESKD were examined to determine likely future trends for the years 2010-2020 in the incidence and prevalence of ESKD across the CA region.

In addition, available data on the prevalence of various stages of CKD were examined. Although the framework and collection of this data varies substantially between difference communities, it offers a complementary approach to assessment of predicted incident numbers of people requiring RRT.
iii Key Findings of the Study

iii.i Current and Future Burden: Numbers Needing Treatment

Based on analysis undertaken for this Study using Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) data, the prevalence of ESKD cases to 2020, on a year by year basis, were estimated. A number of scenarios were modelled, indicating that the number of people receiving treatment in the CA region will lie between 312 (based on a stabilisation of the yearly number of incident patients) and 479 (assuming a steady long-term linear growth consistent with the trend since 1995) individuals.

iii.ii Location of People Needing Treatment

The Study sought and obtained data from key stakeholders which described the current distribution of patients with advanced kidney disease by community in the CA region. A large number of people identified as having advanced kidney disease are living in Alice Springs or Tennant Creek, who, based on previous research, are likely to have relocated from a remote community. Data collected for this Study indicates that many remote communities have a small number of people identified with advanced kidney disease. The small numbers commencing and needing dialysis in individual communities at any point in time is highly variable, making it difficult to predict future demand for services.

Data provided for the Study allowed capture of important information about community resources, alongside disease prevalence. These data were able to inform the preferred renal services model and, in particular, where service expansion might most sustainably and affordably be commenced.

iii.iii Treatment Options

Available treatment options were reviewed against a set of criteria specific to the location and population of the CA region. These included three core dimensions: being able to provide treatment closer to home in the remote parts of the region; provision of services which meet health, social and cultural needs; and sustainability of required resourcing models.

The Study identified a suite of appropriate treatment options which would improve service delivery overall on these dimensions, and would address the diverse needs and characteristics of the region. The suite includes satellite dialysis, community based nurse supported dialysis, mobile dialysis and respite dialysis. Alongside these treatment options, support for increased self-care was also seen as a key part of the service delivery environment.

iii.iv Estimated Costs Associated with Providing Treatment

Detailed total-cost-of-service analyses were undertaken in the Study (Section 8 of the Final Report), with cost projections till 2020. In line with the estimates of prevalence of ESKD, several scenarios for treatment costs were explored. In each scenario, whole-of-service costs were estimated for the period 2009 to 2020 (based on 2009 dollars), with approximately $45 million estimated to have been already spent during 2009 and 2010.
These included the following scenarios:

1. **A stabilisation and a growth scenario of incident cases, with a continuation of current service provision methods.**

   Whole-of-service costs (2009 to 2020) were estimated as $240 million for continuation of current services assuming a stabilisation of prevalence (predicting 312 patients in 2020), or $302 million assuming a linear growth in prevalence (predicting 479 patients in 2020).

2. **A stabilisation and a growth scenario of incident cases, with increased uptake of self care (10% of patients by 2015, and 15% of patients by 2020).**

   Whole-of-service-costs of treating all existing and new cases of ESKD (from 2009-2020), with uptake of self care as outlined above, treated out to 2020 (assuming 80% Haemodialysis (HD), 20% Peritoneal Dialysis (PD)), were estimated to be between approximately $236 (stabilisation model) and $296 million (growth model)

3. **A prevention scenario, where prevention efforts achieved a 20% reduction of ESKD from the growth model by 2020.**

   Under such a prevention scenario, the present value of costs of treating all existing and new cases of ESKD (from 2009-2020), treated out to 2020, would be approximately $273 million.

Capital costs (including housing) and respite dialysis were costed separately to service delivery.
iv  **Key Recommendations of the Study**

iv.i  **Preferred Renal Services Model for the CA Region**

The primary recommendation of this Study is that renal services for people in the cross-border CA region should be provided by a regional hub service, associated satellite services and with strong linkages to community based primary health services. This preferred model represents an ideal model, with aspiration to comprehensively address the current gaps in service for Aboriginal and Torres Strait Islander renal patients. A range of practical considerations may constrain or reshape the ultimate implementation of the service model against this gold standard.

The fundamental premise of the preferred model is that it represents a structured and sustainable transition from the current urban facility model, to expansion of community based care.

Broadly, a ‘hub and spoke’ model, which has three broad arms, is recommended:

- The Hub renal unit would coordinate the provision of comprehensive renal services across the continuum of CKD. Alice Springs is recommended to be the Hub, given its serviced capacity, with Tennant Creek functioning as a mini hub.

- The spokes will be the sites where nurse-supported and self-care options are expanded in communities, to allow patients to be closer to home. Expansion of self-care HD and nurse-supported, mini-satellite HD are the most appropriate and sustainable options for increasing the proportion of renal patients able to return home for ongoing RRT. Several sites, based on consultation for the Study, were identified as suitable for the first wave of community care expansion.

- The spokes will not allow patients from all communities to obtain treatment closer to home; Mobile dialysis and respite dialysis is recommended to provide supplementary service to allow more people to be closer to home.

iv.ii  **Overarching Considerations: Pre-requisites of Implementation**

The primary recommendation of the Study focused on the preferred service model for the CA region. However, the implementation of the service model will occur against the background of a several key overarching factors. Accordingly, a supplementary recommendation of the Study is the need to take into account seven overarching considerations that are central to enabling the primary recommendation, and must underpin the implementation plan.

1. **Prevention effort must be part of the suite of activities** - Noting the identification, by primary care and renal services, of almost 600 people with CKD Stages 3 to 5, and evidence suggesting these cases represent a fraction of the actual number with CKD in the cross-border region, an integrated approach to CKD prevention should be implemented. The approach to prevention should include interventions across the life course, including primary prevention, early intervention and evidence based management of risk factors for CKD and progression of disease.
2. Services need to be shaped in ways which recognise social and cultural determinants of treatment uptake, adherence and outcome - Practical approaches to developing appropriate health service structures and modes of delivery are crucial for implementation. Considerable evidence attests to the significance of proximity to care, availability of transport, welcoming physical spaces and meaningful roles for Aboriginal and Torres Strait Islander people.

Given that treatment close to home will not always be possible in the CA region, respite dialysis services and return to country programs should be provided as part of an integrated, coordinated regional renal service and priority should be given to addressing accommodation and social support issues for patients and their families.

3. Jurisdictional drivers must be accommodated within a Tri-State service model -

The CA region is a multi-jurisdictional region, which presents governance challenges. Any recommendations and/or implementation plans will hinge on a united response from all jurisdictional governments. This clearly implies the need for accommodation of the separate needs of the jurisdictions, and agreement of an appropriate mechanism for governance and coordination across the region. As a minimum, a Tri State Agreement and process addressing:

- Coordinated regional planning in harmony with jurisdictional service planning.
- Development of the funding model as a basis for resource allocation.
- Agreed status of renal services on the lands/communities.

4. Protocols for dialysis treatment closer to home in the particular circumstances of the CA region must be agreed and formalised – Safe and sustainable renal service provision in remote communities requires specification of a broad range of well-documented environmental factors, including location, services, design, construction, water, electricity, drainage and management of bio-hazardous waste. Access to safe and secure housing for patients returning to remote communities for ongoing dialysis were also articulated. It is not possible to supply a checklist of community characteristics required to sustain the provision of dialysis services, and decisions regarding sites for services will require consideration of locally-specific detail about community. However, as part of coordinated regional implementation, the criteria will need to be formalised and agreed, in order to ratify them as protocols.

5. The full suite of safety and quality requirements must be built in, although they will require customisation – The National Service Guidelines for the Management of Dialysis and Kidney Transplantation in Remote Australia can be utilised to develop an agreed, evidence-based set of standards to measure the performance of renal services. As a threshold issue, harmonised treatment protocols should be developed and agreed across jurisdictions. The process will be challenging, given that it will require the engagement of clinicians, governments and communities. Implementation of a workable cross-jurisdictional service model requires consistency in assessment and treatment.

6. Addressing workforce requirements of the service delivery model must be a priority - Renal services require multidisciplinary teams with highly skilled staff. Quite apart from clinical and specialist skills, English is not the first language for many renal patients in the CA region. Recruitment, retention and high turnover for the remote area health workforce is well documented. These problems are not specific to renal services. Renal service delivery in remote communities across the CA region shares common challenges with other rural and remote health services in building and maintaining an appropriately skilled multidisciplinary workforce. A combination of recruitment/retention, up-skilling and alternative workforce strategies will need
to be pursued. In addition, the provision of renal services in the CA region will be best served by a collaborative and inclusive approach across public, private and non-government sectors.

7. **Strategic monitoring and evaluation should be a core component of implementation** - With the expansion of service delivery and the establishment of new models of care, ongoing monitoring and evaluation are essential to ensure that implementation is sustainable, and that transitions in service options are appropriate.
Road Map to the Report

To fully report findings of the Study, the final report consists of 4 distinct parts:

- **Part 1 Key Findings and Recommendations** – Describes the key findings of the Study which form the basis of the major recommendations. An implementation scenario, encapsulating the recommendations, is described at Appendix 1 to the Final Report.

- **Part 2 Final Report** - Provides a distillation of the complex technical basis and findings of the Study. Specific cross-referencing to more detailed technical information is provided.

- **Part 3 Technical Report** – Describes the methods and findings of the Study in technical depth.

- **Part 4 Technical Appendices** – Provides additional technical information around the data collection, data analysis, modeling and literature searches undertaken for the Study.