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CENTRAL AUSTRALIA RENAL STUDY TECHNICAL REPORT UPDATE

Final Report for the Australian Government | 2016

Acknowledgements

The Study Team acknowledges the input and assistance of the Northern Territory Department of Health and the Aboriginal Community Controlled Health Services in Central Australia.

We acknowledge the input of Professor Stephen McDonald, Dr Paul Lawton and Dr Jeannie Devitt and thank the many staff who gave their time and assistance in the compilation of this Report.

Disclaimer

This Report was commissioned by the Australian Government Department of Health, Indigenous and Rural Health Division with the intention of updating components of the *Central Australia Renal Stud*y also commissioned by the Australian Government in 2010.

The Study comprised four discrete components including a *Part III Technical Report* based on data current to 2009. In 2014, the Australian Government engaged the Menzies School of Health Research to update the information in the *Part III Technical Report* to:

- Provide information relating to changes (since 2009) in the burden of chronic kidney disease (CKD).
- Provide financial and service demand modeling of projected future need.

Research, analysis and writing of the Report was undertaken by Gillian Gorham[1], Alan Cass[1], Kirsten Howard[2] and Katherine Evans[1].

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

Suggested citation

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Note: The term ‘Aboriginal’ is used in this Report to represent both Aboriginal and Torres Strait Islander people.

Introduction

In 2010, the Australian Department of Health and Ageing contracted The George Institute for Global Health to conduct the *Central Australia Renal Study*. The objective of this study was to develop a range of feasible clinical dialysis service delivery models to meet the current and projected needs of Aboriginal and Torres Strait Islander kidney disease patients in the Central Australia (CA) region. The process involved extensive stakeholder engagement, collection and analysis of local data and an evidence synthesis based on national and international literature.

In June 2011, the final report of the *Central Australia Renal Study* was provided to the Department and consisted of four parts:

Part 1: *Key Findings and Recommendations*

Part 2*: Final Report*

Part 3: *Technical Report*

Part 4: *Technical Appendices.*

The *Technical Report* contained specific information and data relating to:

- Activity and projections for future demand.
- Availability and location of renal services.
- Costs related to infrastructure and recurrent expenditure of the alternative models of care.

The *Technical Report* also provided an analysis of the cost of renal service provision in the CA region.

The Australian Department of Health has a requirement to maintain relevant and current information on the burden of renal disease and the requirement for renal replacement therapies in the CA region, particularly in relation to emerging trends.

The Department of Health engaged the Menzies School of Health Research (Menzies) to update certain components of the *Technical Report* and asked service providers operating in the CA region to work with Menzies to provide the relevant data required to update tables, figures, graphs and accompanying commentary.

The updated information contained in this Report follows on from the data provided in the 2011 report, which was current to the year 2009.

Scope of Report

This Report provides current and relevant information pertaining to certain sections of the original *2011 Central Australia Renal Study Technical Report* (The Study).

Further qualitative research was not requested, nor undertaken, for the purposes of this Report.

Information is provided in two separate sections.

The first of these titled, "Renal disease and services", focuses on the known burden of CKD:

- Incidence and prevalence of end stage kidney disease (ESKD).
- Current service location and capacity.
- Models of care and evident service gaps.
- Workforce issues.

The second component is entitled, *"Projected demand and costs", and includes:*

- Projections of ESKD prevalence.
- Likely future demand for renal services in the Central Australian (CA) region.
- Whole-of-service costs associated with providing renal replacement therapy (RRT) including:
    - Recurrent expenditure for dialysis treatments and transplants.
    - Supporting infrastructure and additional resources.

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Executive Summary

Part One: Renal disease and services

The purposes of this section are to build on the previous study to outline changes in Central Australia (CA) in relation to the known burden of kidney disease and the location and accessibility of services:

- Identify the current burden of chronic kidney disease (CKD) in the CA region utilising information from the primary and tertiary health services in the region;
- Compile and analyse data from the primary and tertiary service providers to gain a better understanding of the burden of comorbid conditions amongst CKD patients and assess whether rates of progression to end stage kidney disease (ESKD) can be determined;
- Identify changes/improvements in CKD management since 2009;
- Describe the current incidence and prevalence of ESKD in the CA region and how this compares to projections in The Study;
- Describe the location and capacity of current service provision and how this has changed since 2009;
- Describe the available models of care for treatment, the ability of these models to meet the needs of patients, and identify evident gaps in service provision;
- Describe the current workforce availability and issues for service provision.

Methodology

This section consists largely of quantitative analysis of several data sets.

Data on the burden of kidney disease and service provision in the CA region was compiled from a number of sources. Analysis consisted of both aggregation of primary and tertiary care data sets and relevant survival analyses using longitudinal cohort data from the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). The relevant data sets and how the information was utilised are outlined below.

1. ANZDATA provided ESKD data for the Northern Territory (NT) by year, and in comparison to, other jurisdictions for:
    a) incidence and prevalence of ESKD
    b) trends in incident and prevalent rates of ESKD
    c) treatment uptake, modality, location and trends
    d) demographics of incident renal patients
    e) comorbidities of incident renal patients
    f) integrated and survival rates by treatment modality
    g) transplant graft survival rates
    h) cause of death for prevalent dialysis patients.
2. NT Department of Health (DoH) Alice Springs Hospital Renal Service (ASRS) and Aboriginal primary health services in the NT in central Australia provided:
    a) CKD prevalence data
    b) geographic distribution of CKD patients in CA.
3. Datasets held by ANZDATA, ASRS and Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT) enabled an assessment of current service provision, and comparison to 2009, for:
    a) some basic analysis relating to rates of progression and outcomes for CKD patients in stages 3, 4 and 5
    b) treatment modality uptake and location
    c) dialysis models of care, location, capacity and utilisation
    d) demand and service gaps.
4. An assessment of workforce requirements for renal services, including current availability, workforce models and training programs is also provided.
5. This report referred to the findings in a number of key local documents and reports including:
    a) Annual Report 2011 for the Chronic Conditions Prevention and Management Strategy (CCPMS) 2010-2020, NT DoH.
    b) Northern Territory Department of Health (2012). *Renal Services Framework 2012-2017.*

c) Ernst and Young (2014). *Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation: Service Delivery Model.*

d) Ridoutt R, Pilbeam V, Lee K (2010). *Final Report Aboriginal Health Worker Profession Review.* Darwin: Northern Territory Department of Health and Families.

Findings

Overall

- Data collection has improved across all services.
- Patient management appears to have improved with primary health services playing a greater role in the ongoing care and management of patients with CKD and patients with ESKD who are receiving renal replacement therapy (RRT).
- Demand for RRT has been sustained. Incidence rates have not plateaued and the number of people receiving RRT is in-line with projections made in the 2011 Study.
- Dialysis services in Alice Springs remain stretched despite the expansion of two satellite services in the region and growth in community-based dialysis since 2009.
- More patients are accessing treatment within their community, both in terms of long-term dialysis management and utilisation of palliative services.
- Workforce issues related to adequate dialysis nursing staff and nephrologists have improved since 2009. The number of Aboriginal people employed in renal services remains low as does the availability of allied health staff.

Chronic kidney disease

Data on the prevalence of CKD in CA was collated from service providers in the NT. Given that no data was available from health services that straddle the border regions of South Australia and Western Australia, the number of people known to have CKD, in comparison to the findings of the 2011 Study, has increased considerably. In particular, there are a far greater number of patients managed by the Aboriginal Medical Services serving the CA population. It is not known whether this reflects an increasing incidence and population prevalence of CKD, or whether this indicates improved primary care screening and identification of people at high risk of CKD. Key findings include:

- More than 640 people are known to have CKD stages 3, 4 or 5 in the CA region of the NT compared to 433 in 2009.

The number of patients with CKD stage 5 has more than doubled from 29 to 61.

Aboriginal primary health services in CA have identified, and currently manage, 347 patients with stages 3 to 5 CKD.

145 (41.8%) of primary care-managed CKD patients are known to, and managed in collaboration, with the Alice Springs Renal Services (ASRS).

- Amongst patients who do not die and remain in the care of ASRS, more than 50% of people with CKD stage 4 will commence dialysis within two and a half years.
- Over nine years of follow-up, more than one-third (36%) of all patients with CKD referred to ASRS commenced dialysis in CA.

From 2009-2014, data collection on the number of people with CKD in the CA region and their management has improved.

Renal replacement therapy

Incidence

- Since 2010, there has been an increasing trend in the number of patients commencing RRT in CA.
- The overwhelming majority of people requiring RRT are Aboriginal Australians.
- People commencing treatment in the NT are, on average, approximately 20 years younger than in other jurisdictions.
- In the 18 months to June 2014, more than three-quarters of all new patients were required to relocate from a remote community to commence dialysis.

Prevalence

- Prevalent dialysis patients have continued to increase in-line with the 'Preventative' projection model developed for the 2011 Study.
- More than 90% of patients in CA receive haemodialysis as a treatment modality, which is unchanged since 2009.
- Fewer patients are choosing peritoneal dialysis now compared to 2009.
- CA has the highest proportion of satellite dialysis patients in Australia.
- The higher demand for satellite services has significant resource implications.

Service models and locations

- There has been a 42% increase in dialysis treatments delivered in CA since 2009.
- 90% of patients receive care in a satellite unit.
- Approximately 25% of people are receiving services closer to home. However, fewer than 10% of people are receiving care in their own community.
- The NT Department of Health (DoH) has invested considerable funding and resources to support community-based self-care dialysis:
    - Uptake of self-care has not met expectations and the use of sites fluctuates according to patient health and personal preference for treatment.
    - At the time of this Report, seven patients at four sites were undertaking self-care haemodialysis – the same as in 2009.
    - Consequently a significant amount of community infrastructure for self-care dialysis is under-utilized.
- The Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT) has increased services in CA and now provides:
    - Treatments at one urban and six remote sites with two additional sites planned in 2015.
    - 8% of all treatments delivered in CA.
    - More than 70% of all dialysis treatments delivered in remote parts of the Alice Springs Hospital catchment area.
- In 2013/2014, the DoH and WDNWPT mobile dialysis services delivered over 200 treatments to a variety of communities.
- In 2014, there are more opportunities for people to receive care in their home community when compared to 2009.

Capabilities for service provision

- Alternative models of dialysis care are sustainable in the CA region.
- Dialysis services in remote communities require a significant level of support:

  - Few communities have the infrastructure and services necessary to support staffed dialysis services.
  - Provision of staff accommodation is usually necessary.
  - Staff work in isolation and staff 'burn-out' and turnover can impact on the sustainability of services.

- Without support for transport to remote communities, mobile dialysis services and respite services are expensive options for patients.
- The WDNWPT model of service delivery supports patients with transport and accommodation assistance.
- Collaboration and co-ordination across departments and organisations is necessary for the successful and sustainable delivery of remote services.

Workforce issues

- Compared to 2009, the renal workforce in CA is more stable.
- In 2014, there are more nephrologists working in Alice Springs when compared to 2009.
- Access to specific Allied Health Services (dietetics and podiatry) has improved since 2009.
- Access to social support services – particularly relating to the availability of Aboriginal Liaison Officers, interpreters and social workers – has not improved since 2009 and may be poorer for the majority of patients attending ASRS.
- Registered nurses make up the majority of renal trained staff in the NT. There are few enrolled nurses and no dialysis professionals.
- The majority of renal nursing staff in Alice Springs and Tennant Creek have been trained overseas. A substantial proportion speaks English as a second language.
- There are no renal-trained Aboriginal Health Workers (AHWs) in the NT. Possible causes for this include:
  - Indications from the Batchelor Institute of Indigenous Tertiary Education suggest a lack of demand from registered AHWs to learn dialysis treatments.

  - There has been no demand from industry or community for registered AHWs to undertake the available post-graduate units in renal care.
  - Registered AHWs make up only a small percentage of the health workforce in CA and are considered a rare resource.
  - Completion rates for registered AHWs cannot keep up with current demand in the NT.

- Other options to train Aboriginal people to assist with dialysis treatments, such as Dialysis Assistant and Dialysis Technician courses, have been investigated.
- The viability of a Vocational Education and Training (VET) course in dialysis treatments for Aboriginal people is uncertain, given historically low certificate completion rates, unknown course development costs and unclear demand.

Part Two: Projected demand and costs

The purpose of this section is to provide an analysis of future costs of renal service provision in the CA region based on future projections of ESKD modeled on alternative scenarios of incidence rates.

This section covers:

- Projections of ESKD prevalence and future demand for renal services in the Central Australian (CA) region.
- Whole-of-service costs associated with providing renal replacement therapy (RRT) including dialysis treatments, transplants, supporting infrastructure and required resources.

Scope and Limitations

The approach used in this analysis follows a previously developed and reported methodology for the analysis of costs and benefits of renal replacement therapy (RRT) in Australia (1, 2). Many of the data limitations identified in this earlier work are also applicable in the current setting, with additional limitations due to challenges in modeling disease incidence and prevalence with relatively small numbers of patients across the CA region. A lack of published, peer-reviewed data regarding the costs and effectiveness of service provision in remote settings for Aboriginal and Torres Strait Islander patients was another notable limitation.

As up-to-date financial data were unavailable for this Report, cost data for provision of dialysis services were based on information provided by the Northern Territory (NT) Department of Health (DoH) for the 2011 CA Renal Study. This data was reflective of costs expended to deliver dialysis services in CA in 2010. As NT Renal Services, under the DoH, have been the main providers of renal services in the CA region, these were considered to be the most relevant costs to be used.

Detailed total-cost-of-service analyses were undertaken for the Report, with cost projections till 2025. Estimates of prevalence of ESKD were modeled based on incident and prevalent rates from 2000-2013.

Findings

Demand and Cost Models

Three scenarios for future projected demand were modeled. In each scenario, whole-of-service costs were estimated for the period 2014-2025 (in 2013 dollars). These included the following scenarios:

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

In this scenario, new patients commencing treatment are approximately equivalent to the attrition rate from death with a prediction of 299 prevalent patients in 2025.

Whole-of-service costs (2014-2025) were estimated at $264 million for continuation of current services assuming a stabilisation of prevalence.

2. A growth scenario of incident cases, with a continuation of current service provision methods.

Based on past incidence rates and improvement in survival rates, this scenario modeled a linear growth of prevalent numbers of ESKD patients, predicting 485 patients in 2025.

Whole-of-service costs (2014 to 2025) were estimated at $342 million assuming a linear growth in prevalence.

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

This scenario suggested that incident numbers would increase at a lower rate than in the growth scenario and predicted 406 patients in 2025.

Under such a prevention scenario, the present value of costs of treating all existing and new cases of ESKD (from 2014-2025), treated out to 2025, would be approximately $302 million.

Additional Findings

- The present value cumulative cost of RRT for all current and new cases of ESKD, treated out to 2025, is estimated to be between approximately $264-342 million.
- The present value of the cumulative benefits of RRT in life years saved, for all new cases of ESKD out to 2025, will be between 1,293 and 2,108 by 2025.
- Implementation of a prevention strategy, which was able to prevent 20% of

incident ESKD cases, would result in significant savings. Under such a scenario, the present value cumulative cost of RRT for all current and new cases of ESKD, treated out to 2025, would be approximately $302 million.

- Community-based, nurse-supported dialysis models are relatively expensive modalities of renal service provision. However, such models potentially represent a method of service delivery which would enable more CA patients to receive treatment closer to home thus better meeting the social and cultural needs of Aboriginal patients within this region.
- Evidence currently available regarding the comparative outcomes of the various dialysis models (urban, regional and remote satellite services, nurse-supported and self-care community-based dialysis) does not enable cost-effectiveness analyses to guide decision making regarding these alternative models of service delivery.
- Although there is a wealth of qualitative data describing life for Aboriginal kidney patients, there is an absence of the customarily used “quality of life” (QoL) data, particularly utility-based quality of life estimates for calculating quality adjusted life years (QALYs). Evidence suggests that standard tools and/or instruments for systematically assessing quality of life are unlikely to adequately capture aspects of QoL important for Aboriginal Australians and certainly have not yet been validated for use with Aboriginal Australians receiving RRT. Therefore this important component of health economic modeling has not been adequately addressed to date.

Part 1: Renal Disease and Services

Chronic kidney disease

MAIN FINDINGS

- More than 640 people are known to have chronic kidney disease (CKD) stages 3, 4 or 5 in the CA region of the NT compared to 433 in 2009.
- The number of patients with CKD stage 5 has more than doubled from 29 to 61.
- Aboriginal primary health services in CA have identified, and currently manage, 347 patients with stages 3 to 5 CKD.
- 145 (41.8%) of primary care-managed CKD patients are known to, and managed in collaboration, with the Alice Springs Renal Services (ASRS).
- Amongst those patients who do not die and remain in the care of Alice Springs Renal Services (ASRS), more than 50% of people with CKD stage 4 will commence dialysis within two and a half years.
- Over 9 years of follow-up, more than one-third (36%) of all patients with CKD referred to Alice Springs Renal Services commenced dialysis in CA.
- Data collection on the number of people with CKD in the CA region, and their management, has improved from 2009 to 2014.

The Northern Territory (NT) has a population of approximately 250,000 people sparsely spread over a land mass of 1.3 million square kilometres. Aboriginal Australians make up almost 30% of the population with more than 70% living in remote or very remote communities (1). Territorians, like most Australians, suffer high rates of chronic diseases which are responsible for approximately 80% of the burden of disease and injury in Australia (2). The related and linked chronic diseases of diabetes, heart disease and kidney disease are more prevalent in the Aboriginal population who also suffer high rates of premature death. Chronic diseases contribute to two-thirds of all Aboriginal deaths, and metabolic disorders such as diabetes and kidney disease, are seven times more likely to be the cause of death of an Aboriginal Australian in the NT (3). There is a steep gradient in the burden of kidney disease from urban to remote areas, with people in remote areas suffering much higher levels of disease (4).

In the absence of an agreed nationally consistent method for data collection, the exact number of people with CKD across Australia is unknown. However, based on

data from the Ausdiab study, one in nine Australians aged 25 years and over have early CKD (5). People with earlier stages of CKD are at high risk of death due to heart disease. Similarly, the burden of CKD amongst Aboriginal Australians is not well documented, although kidney disease is known to occur frequently and the burden to be higher in remote areas (6).

The 2011 *Annual Report: NT Chronic Conditions Prevention and Management Strategy 2010-2020* (3) noted that adult health checks, which would assist in the early identification of chronic conditions, that are precursors to renal disease, were only undertaken with 7.6% of eligible Aboriginal adults across the NT. Scheduled monitoring of known diabetics in the community varied between 40 and 80%.

Similar results were found following recent work undertaken by a group of general practitioners (GPs) in Queensland and New South Wales. Using an extraction tool for the Communicare system (PenCat), a set of key indicators for the management of chronic disease and CKD by primary health services has been developed. The indicators identify patients who are at risk of developing kidney disease because they have risk factors such as smoking, heart disease, hypertension and diabetes. Such indicators can be used to prompt a GP to test the 'at risk' population of their service for early stages of kidney disease, thereby identifying and potentially commencing CKD management earlier in the disease process, with greater potential for preventive treatment (7).

Data on the prevalence of CKD in CA was collated from service providers in the NT. Information from the health services that straddle the border areas of South Australia, Western Australia and the NT was unavailable for this Report. The data were produced from the combined Communicare systems of Central Australian Aboriginal Congress (CAAC), Anyingini Health Services and the CKD database maintained by Alice Springs Renal Services (ASRS). Duplicate cases across data systems have been identified and removed from analyses.

Table 1 identifies the number of known patients with CKD in the CA region and the managing service. Those patients managed by the Aboriginal Medical Services, and referred to ASRS, are identified as a subset. These data do not include patients in CKD stages 1 and 2 (with an eGFR of more than 60mL/min). The data do not account for patients who have kidney disease but have not been diagnosed; nor those who are at high-risk of kidney disease (people with diabetes, hypertension, and heart disease) but have not been screened.

No data was available from health services in the border regions of South Australia and Western Australia for this Report. Such data was made available for the 2011

CA Renal Study. For the 2011 Study, the number of duplicate records that may have been included in the provided numbers from the various health services is unknown. The 2011 Study identified 433 patients in CKD stages 3, 4 and 5. While the numbers known to, and managed by, ASRS in 2014 (446) are relatively similar to the findings in the 2011 Study, there are a far greater number of patients (347) identified and managed by the Aboriginal Medical Services (Table 1). Of these patients, 202 are not identified as patients of the ASRS. Additionally, the number of patients in CKD stage 5 (but not receiving dialysis) is double that noted in the previous study (29 to 61).

Table 1: Known CKD patients in the CA region, Sept 2014

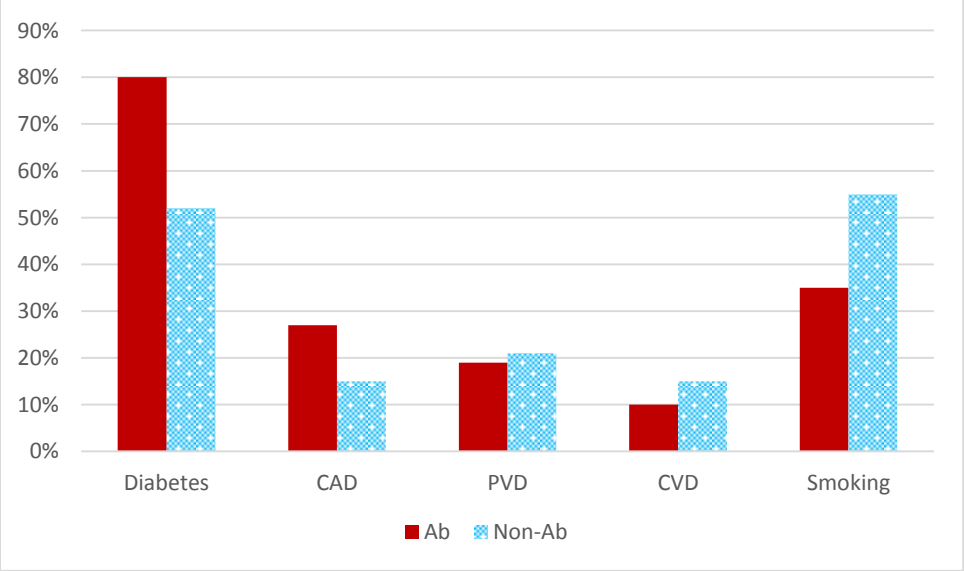
	Stage of CKD				
Health service	3a	3b	4	5	Total numbers
CAAC Alice Springs	81	52	25	16	174
Also known to NTG	16	29	15	12	72
Anyinginyi Health Service	93	50	23	7	173
Also known to NTG	32	21	15	5	73
NT Renal Services	132	143	116	55	446
TOTALS	**258**	**195**	**134**	**61**	**648**

While all services aim to maintain information on the care and management of the CKD cohort, including blood results, medication regimes, the latest clinical indicators and data on the prevalence and management of comorbidities such as diabetes, hypertension and cardiac disease, this information was not readily extractable. In many cases the data were incomplete and it was difficult to determine the proportion of CKD patients with comorbidities.

However, ANZDATA (8) maintains information on the comorbidities (either suspected or diagnosed) of new patients commencing renal replacement therapy. In the absence of robust data on the CKD cohort in Alice Springs, an analysis of the comorbidities of incident renal patients commencing at ASRS between 1988 and 2012 was undertaken. This analysis identified a high proportion of patients with diabetes and coronary artery disease (CAD); known risk factors for kidney disease. Data collected on other co-morbidities include peripheral vascular disease (PVD), cerebro-vascular disease (CVD) and smoking.

Aboriginal Australians commencing renal replacement therapy (RRT) were more likely to present with diabetes that required some form of medication treatment (80%) than non-Aboriginal Australians (50%), and were more likely to be diagnosed or have a suspected diagnosis of CAD. Non-Aboriginal Australians were more likely to suffer from CVD, PVD and be a current or former smoker than Aboriginal Australians. As non-Aboriginal Australians make up a small proportion of the dialysis population in Alice Springs, these numbers should be treated with caution (Figure 1).

Figure 1: Comorbidities of presenting incident patients, Alice Springs, 1988-2012



Source: ANZDATA

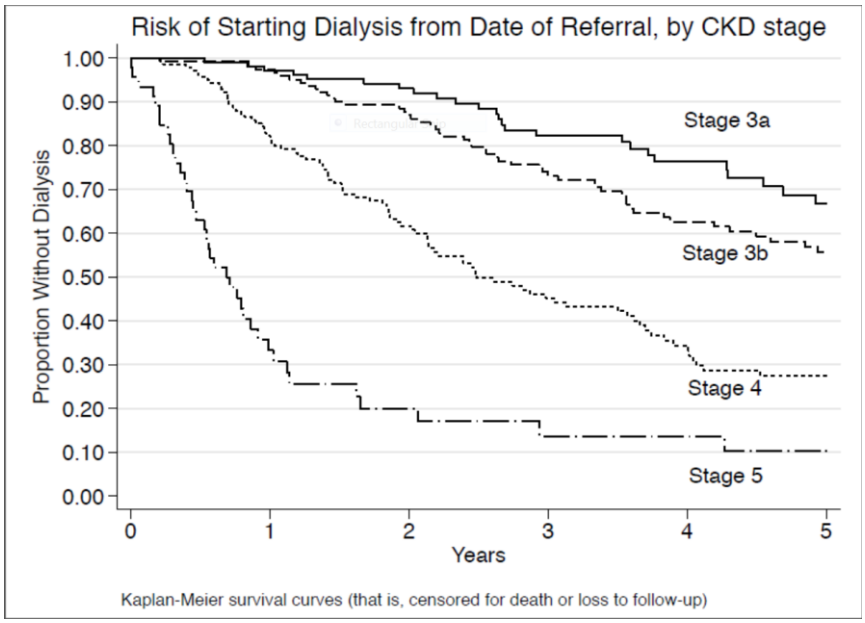
As noted, there is little consistency within the NT or across Australia in relation to the collection of information regarding CKD incidence, prevalence and management. ASRS should be commended for their attempts to improve the data collection for patients with CKD and their diligence in backdating information where records were available. Since 2009, they have made efforts to maintain comprehensive data sets of referred CKD patients. Although there are 865 records that detail patient pathways and treatment modalities between 2005 and 2014, the majority are from 2009 onwards.

These data have enabled analyses to be undertaken regarding the rates of progression to ESKD, and the requirement for dialysis (Figure 2), and the outcomes of the known CKD cohort (Figure 3). Of those referred to the renal service in CKD stage 4 (eGFR 15-29mL/min), amongst those patients who do not die and remain in

the care of ASRS, nearly 50% commenced dialysis within two and a half years (Figure 2). For people referred in CKD stage 5 (eGFR <15mL/min), nearly 75% commence dialysis within 12 months.

However, these analyses only refer to those patients known to have CKD who were referred to the ASRS and cannot be used to infer rates of disease progression for patients managed solely by the primary health services. Furthermore, these data are incomplete, particularly for patients referred to the service prior to 2009. Despite concerns regarding data completeness, these analyses provide the best indication to date of the outcomes for patients with CKD managed by ASRS.

Figure 2: Rate of progression to end stage kidney disease

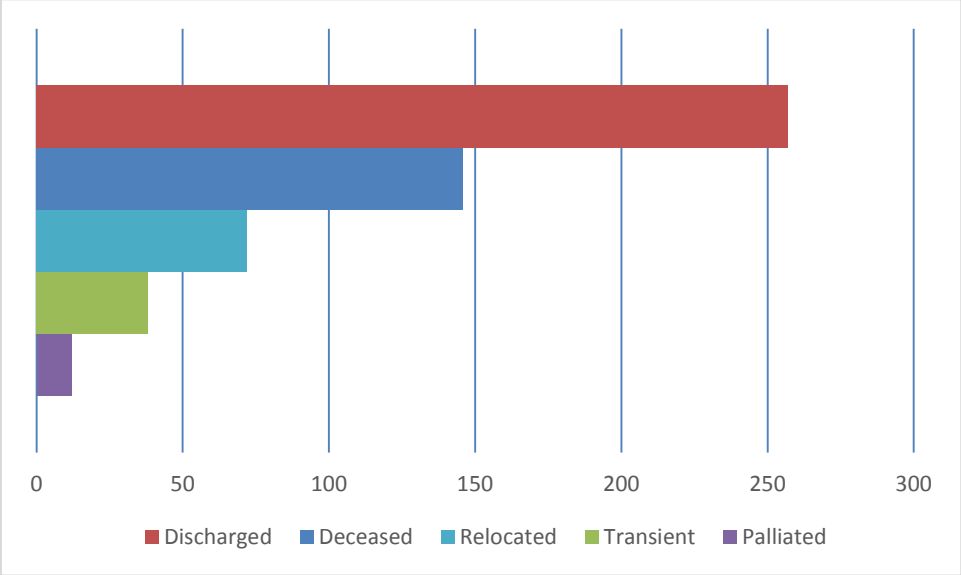


Source: Alice Springs Renal Services CKD data, 2005-2014

Of the 865 patients with CKD managed from 2005-2014, 36% commenced dialysis and 64% left the care of the ASRS. Reasons for people leaving the care of the ASRS were discharge, death, relocation, palliation and a category termed 'transient' (Figure 3). 'Transient' includes people who were under the care of another service or who did not return. 'Palliated' includes patients who declined therapy, those with malignancy, and those whose management was taken over by the palliative care service. 'Discharged' was less clear, but covered reasons such as 'regained [kidney] function' or 'not requiring the ongoing care of a nephrologist'. A significant proportion did not require ongoing care, and in most cases, this appeared to be related to the

age of the patient and the likelihood that the patient might die of other causes before requiring dialysis. These causes include heart disease, stroke and cancer.

Figure 3: Outcomes of known CKD cohort (excluding ongoing RRT patients in CA)



Source: Alice Springs Renal Services CKD data, 2005-2014

Renal replacement therapy

MAIN FINDINGS

Overall the rates of new and established patients with end stage kidney disease (ESKD), including their general demographics and original geographic distribution, are consistent with the findings of the 2011 CA Renal Study.

Incidence

- Since 2010, there has been an increasing trend in the number of patients commencing renal replacement therapy (RRT) in Central Australia (CA).
- The overwhelming majority of people requiring RRT in the CA region are Aboriginal Australians.
- People commencing treatment in the Northern Territory (NT) are at least 20 years younger than in other jurisdictions.
- More than three-quarters of all new patients in the 18 months to June 2014 were required to relocate from a remote community to commence dialysis.

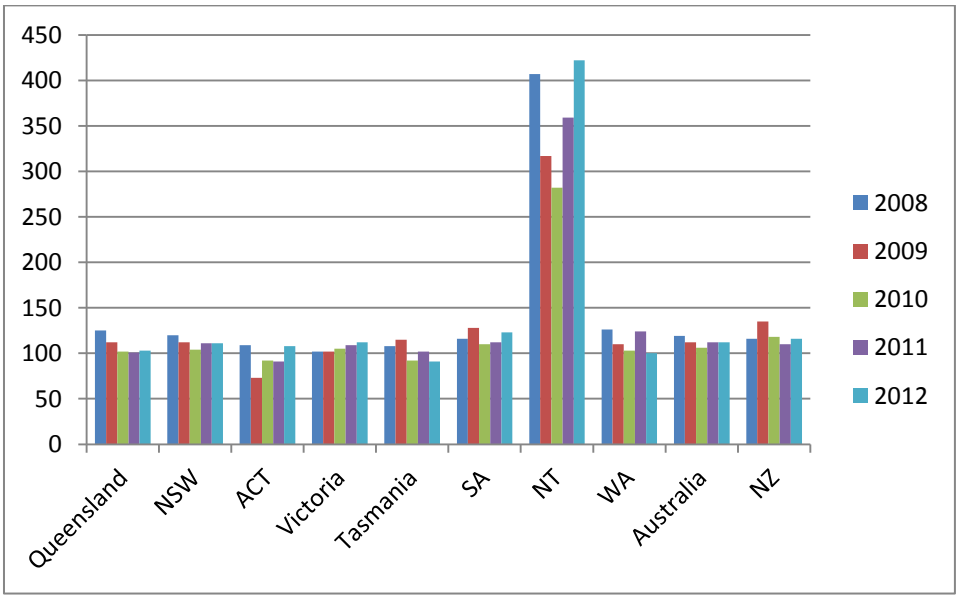
Prevalence

- Prevalent dialysis patients have continued to increase in-line with the 'Preventative' projection model developed for The CA Renal Study.
- More than 90% of patients in CA receive haemodialysis as a treatment modality. This is unchanged since 2009.
- Fewer patients are choosing peritoneal dialysis now compared to 2009.
- CA has the highest proportion of satellite dialysis patients in Australia.
- The higher demand for satellite services has significant resource implications.

Incidence

In Australia, ESKD incidence, measured in terms of the numbers of people per million population commencing RRT, has remained steady over the last five years. In the NT, with its smaller population, incidence rates are expected to vary more from year-to-year compared to other jurisdictions. Nevertheless, from 2010 the NT has experienced the greatest increase in incidence, with a year-on-year increase of approximately 22% in 2011 and 15% in 2012 (Figure 4).

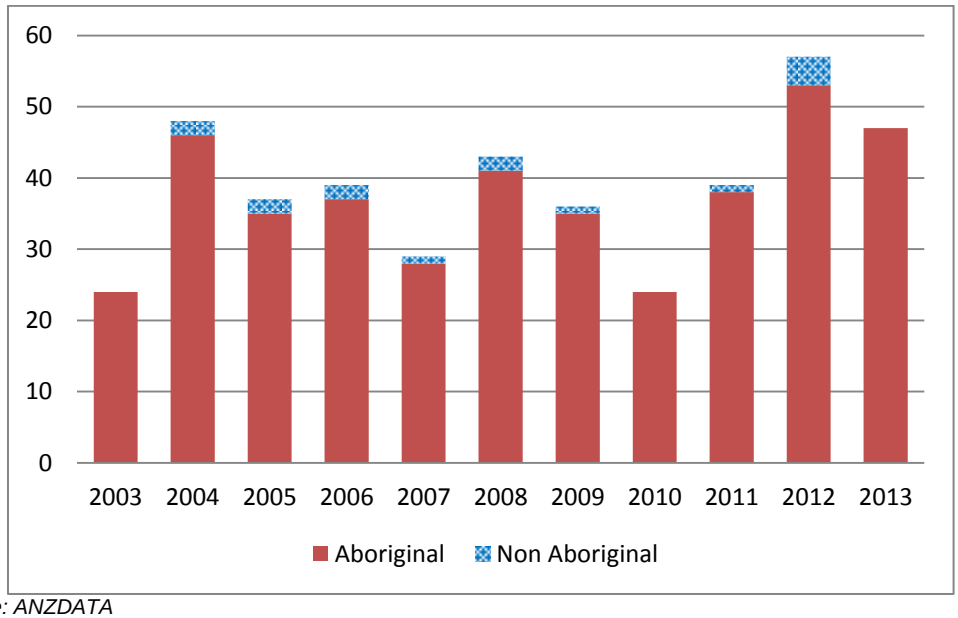
Figure 4: Incidence of ESKD per million population by state and country, 2008-2012



Source: ANZDATA

The large majority of new patients requiring RRT in the CA region are Aboriginal Australians, with very few non-Aboriginal people (including Torres Strait Islanders or Pacific Islanders) or other ethnic minorities. While there was a slight increase in 2012 of non-Aboriginal Australians commencing RRT in Alice Springs, the overall numbers of non-Aboriginal people have stayed relatively stable over the last 10 years (Figure 5).

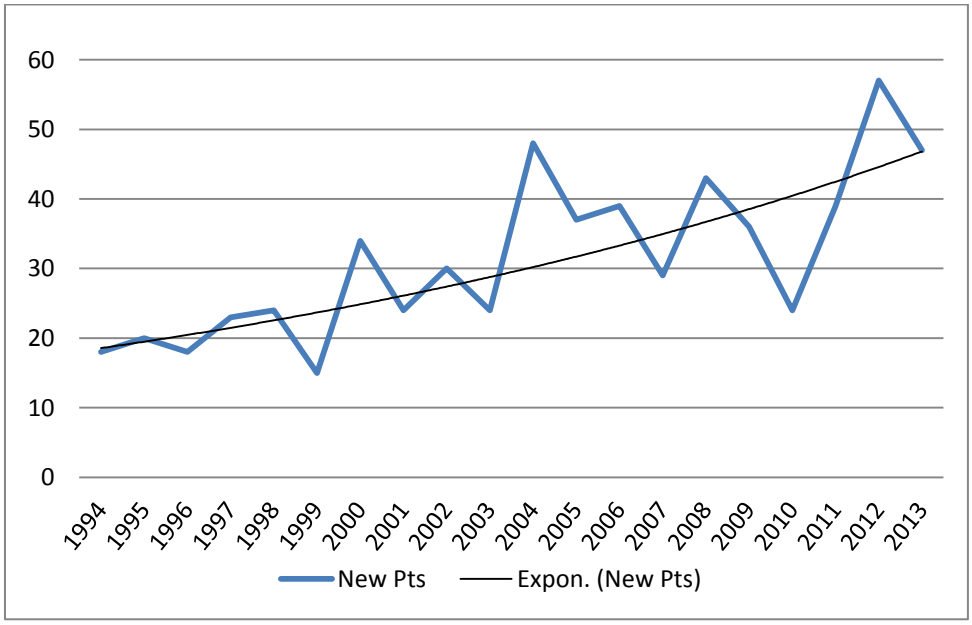
Figure 5: New patients commencing dialysis at Alice Springs by Aboriginality, 2003-2013



Source: ANZDATA

As noted (Figure 4), the NT is one of the few jurisdictions in Australia that has recorded increasing incident rates of ESKD over the last three years. In 2012, the actual number of new dialysis starts in CA was the highest number of incident patients recorded since data collection commenced. The 2011 Study suggested a possible plateauing of new cases per year of 35–40. However, the trend line (Figure 6) indicates a continued rise in new patients, with absolute numbers of 40 and above for the last three years.

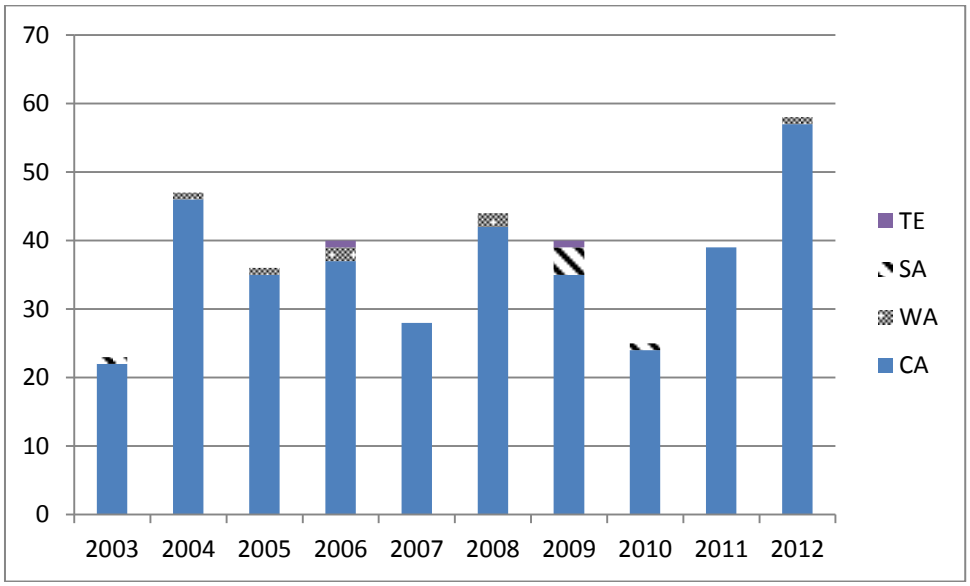
Figure 6: Trend in new renal patient numbers for Alice Springs, 1994-2013



Source: ANZDATA

Incident rates reported by ANZDATA are based on data provided by individual units. New patients commencing in other cities such as Perth or Adelaide, who transfer to Alice Springs shortly after commencement, are often not included in the incident numbers for CA. Patients primarily transfer in order to dialyse closer to family and their community. However, due to capacity issues in the ASRS, the number of patients transferring from interstate units, particularly from South Australia, has decreased since 2010 (Figure 7).

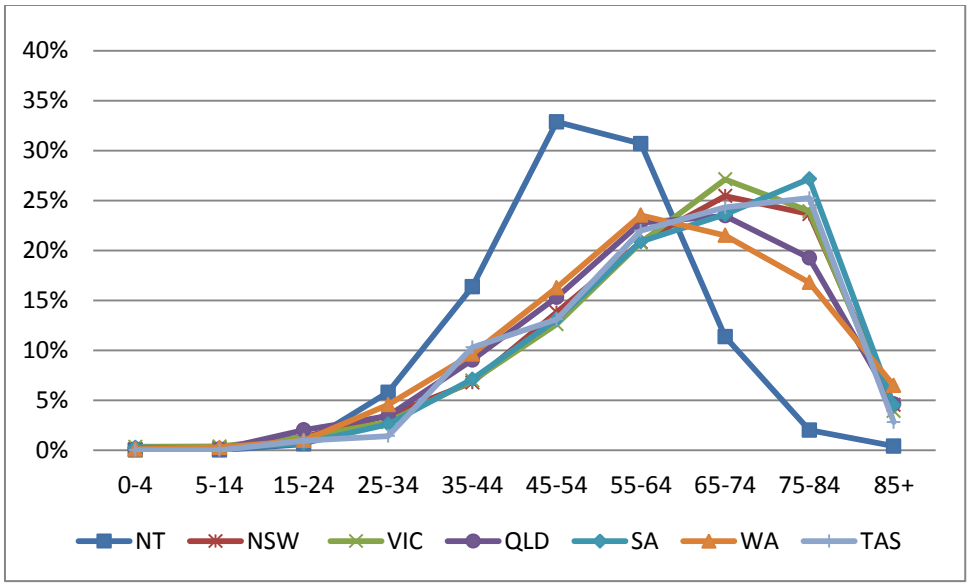
Figure 7: New renal patients in CA by commencing state or region, 2003-2012



Source: ANZDATA (TE: Top End; SA: South Australia; WA: Western Australia; CA: Central Australia).

ESKD patients in the NT are considerably younger than patients in the rest of Australia. Notwithstanding the younger age of ESKD patients, the proportion of patients with a transplant or receiving self-care therapies, particularly in CA, is considerably lower than other states. More than 85% of Northern Territory dialysis patients are 65 years of age or younger in contrast to other states where the majority (60%) of dialysis patients are over 65 years (Figure 8).

Figure 8: Age at commencement of dialysis by state, 2012



Source: ANZDATA

From January 2013 to June 2014, 86 patients from communities across CA commenced dialysis at ASRS. Almost one-quarter of these patients were living in Alice Springs, however the large majority (77%) were required to relocate to Alice Springs in order to commence treatment. These data suggest that many communities are losing young to middle-aged people, many of whom will have significant family and community responsibilities. This is unchanged since 2009.

The long-standing attrition of key decision makers and community leaders from remote communities has been described frequently in government and non-government reports alike for a number of decades (9-12). However as the true impact is difficult to quantify, change to service delivery models have been slow.

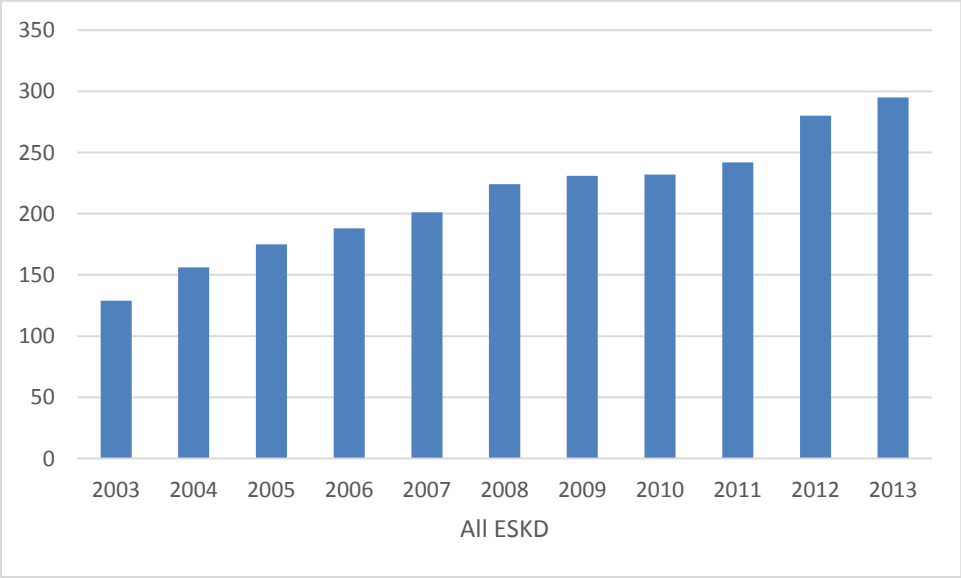
The issue will be investigated as part of a broader and comprehensive research study into the cost-effectiveness of difference models of dialysis care.

Prevalence

The number of patients commencing treatment in CA has been greater than the number of people exiting the service either through death or relocation. Thus, prevalent patient numbers have increased.

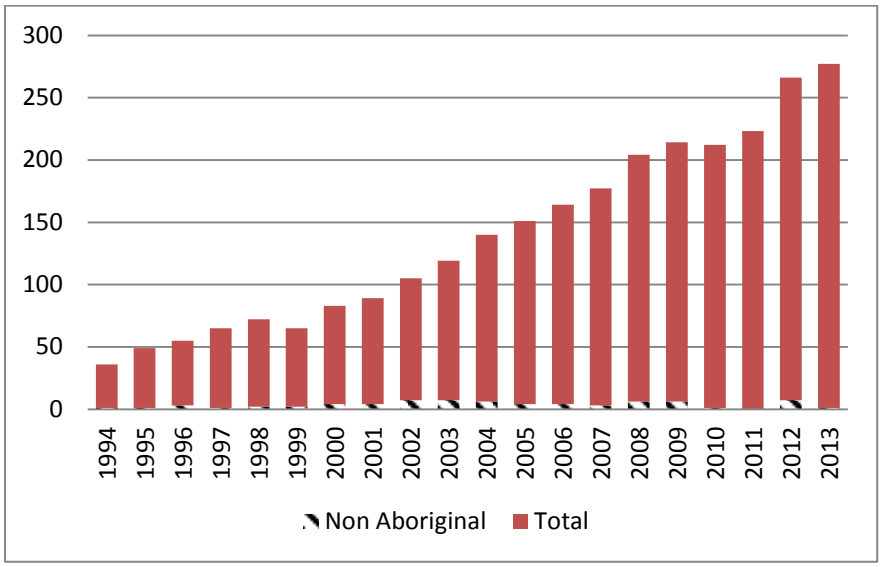
In 2012, prevalent ESKD patient numbers at ASRS increased by 16%. This was followed by a 6% increase in 2013 (Figure 9). This growth has been in patients receiving haemodialysis (HD), who are almost exclusively Aboriginal people (Figure 10).

Figure 9: All ESKD Patients in CA 2003 - 2013



Source: ANZDATA

Figure 10: Prevalent dialysis patients in CA region by Aboriginality, 1994-2013

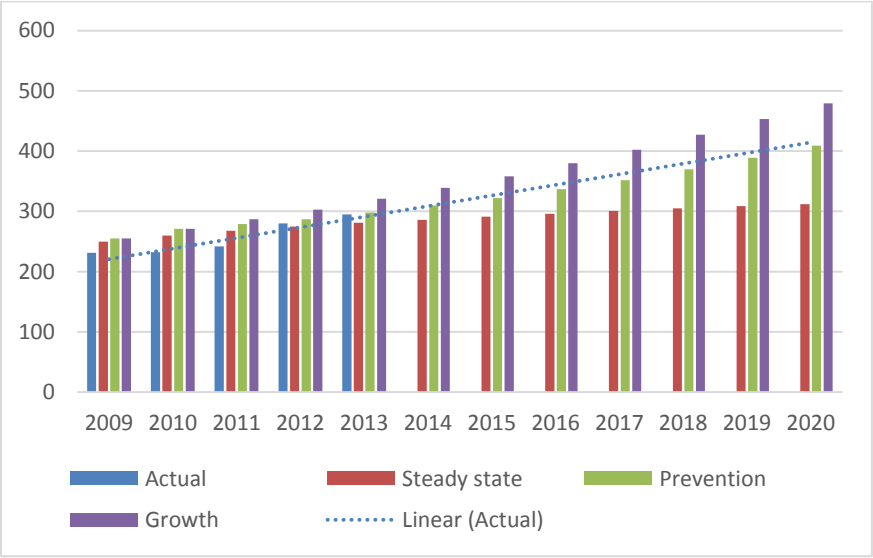


Source: ANZDATA

The 2011 Study suggested that while incident numbers of ESKD patients might plateau, a sustained increase in the prevalent number of patients was expected. The Report provided three models – 'Steady State', 'Preventative' and 'Growth' and projections were made out to 2020. (Updated projection models are provided in the Projected Demand and Costs Section.).

The following graph (Figure 11) illustrates the actual numbers of ESKD patients against the three projection models. The 'Preventative' projection model has proven to be the closest model to reflecting the number of patients recorded by ANZDATA in 2012 and 2013. 'Preventative' suggested ASRS would be managing 287 patients in 2012 and 298 in 2013, with actual numbers of 280 and 295 respectively. A trend line for actual numbers has been added which further emphasises how closely the number predicted in the 'Preventative model reflect actual numbers of dialysis patients.

Figure 11: Actual ESKD patients compared with 2011 CA Renal Study projections

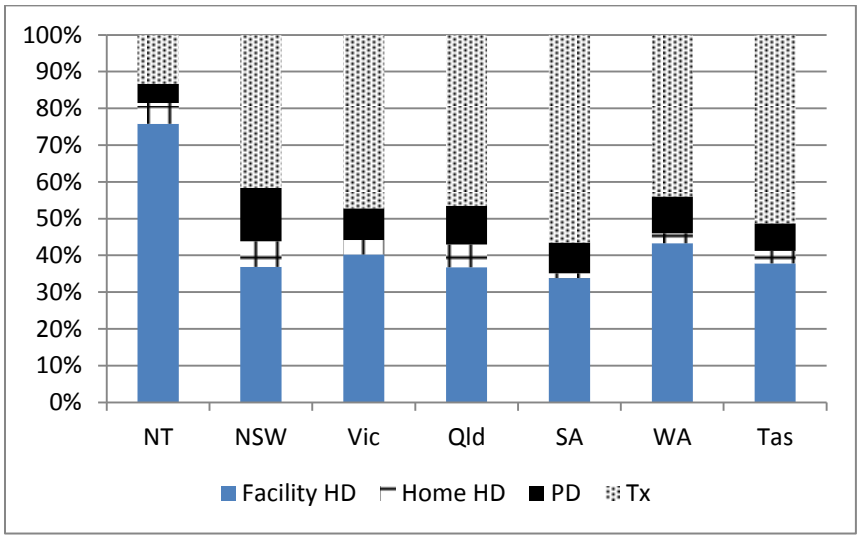


Source ANZDATA and 2011 CA Renal Study

Modality uptake

There is a marked difference in treatment modality uptake in the NT compared with other jurisdictions, where transplantation and peritoneal dialysis (PD) make up a greater proportion of the treatment modalities (Figure 12). Nationally, less than 50% of people receive care in a satellite facility compared to 75% in the NT. While the proportion of people undertaking self-care haemodialysis (HD) is relatively similar across all jurisdictions, the disparity between the NT and other states lies in the number of people with a functioning transplant. This figure is as high as 55% in some states.

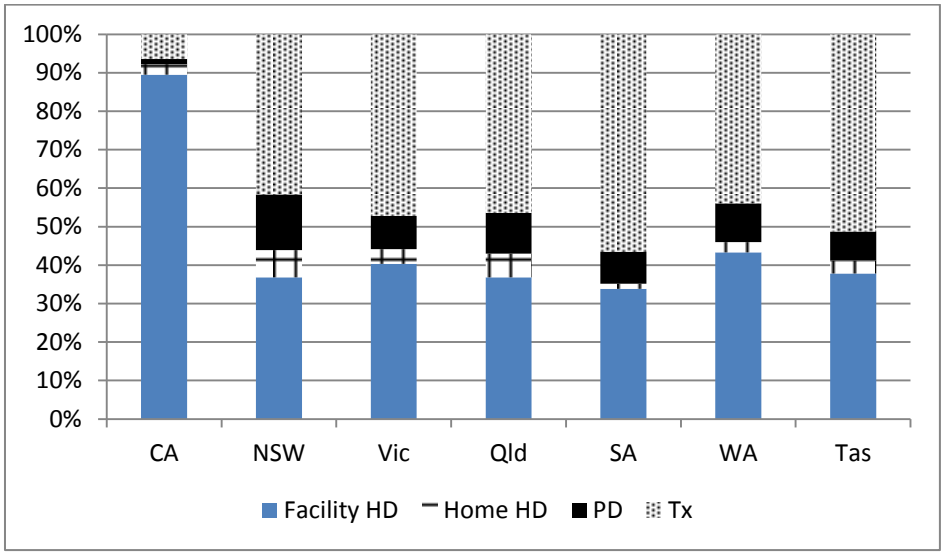
Figure 12: Proportion of patients receiving RRT by modality and state, 2013



Source: ANZDATA (HD: haemodialysis; PD: peritoneal dialysis; Tx: transplant).

When the comparison is narrowed to the CA region (Figure 13), the disparity is even more marked with nearly 90% of patients receiving care in a satellite facility. Unlike other jurisdictions, less than 10% of patients in CA have a functioning transplant. The differences in uptake of modalities also point to differences in resource requirements including infrastructure, staffing and recurrent expenditure.

Figure 13: Comparison of RRT uptake in CA with other jurisdictions 2013



Source: ANZDATA (HD: haemodialysis; PD: peritoneal dialysis; Tx: transplant).

Treatment uptake and modalities have changed little since 2009 (Table 2) despite a number of strategies to support self-care therapies in the NT. The vast majority of patients continue to receive care in a staffed HD facility.

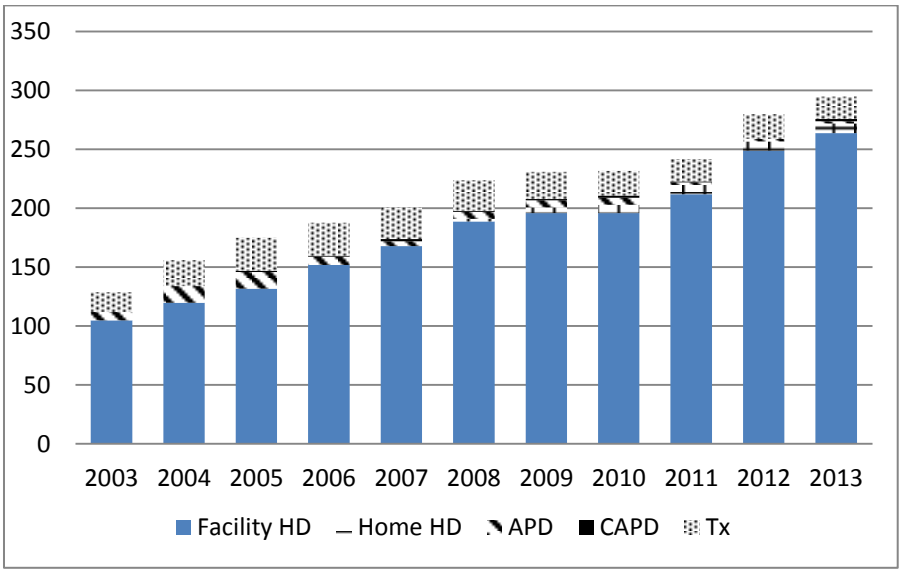
Table 2: Comparison of treatment uptake; 2009 with 2013

RRT Modality	2009	2013
Peritoneal dialysis (PD)	2%	1%
Home haemodialysis (HD)	2%	3%
Satellite or Hospital HD	89%	89%
Transplant	6%	6%

Source: ANZDATA and 2011 CA Renal Study

However, there has been a slight change in the configuration of the self-care therapies since 2009, with fewer people undertaking automated peritoneal dialysis (APD) and more people taking up home HD (Figure 14).

Figure 14: All ESKD patients in CA region; 2003-2013



Source: ANZDATA (HD: haemodialysis; APD: automated peritoneal dialysis; CAPD: continuous ambulatory peritoneal dialysis; Tx: transplant).

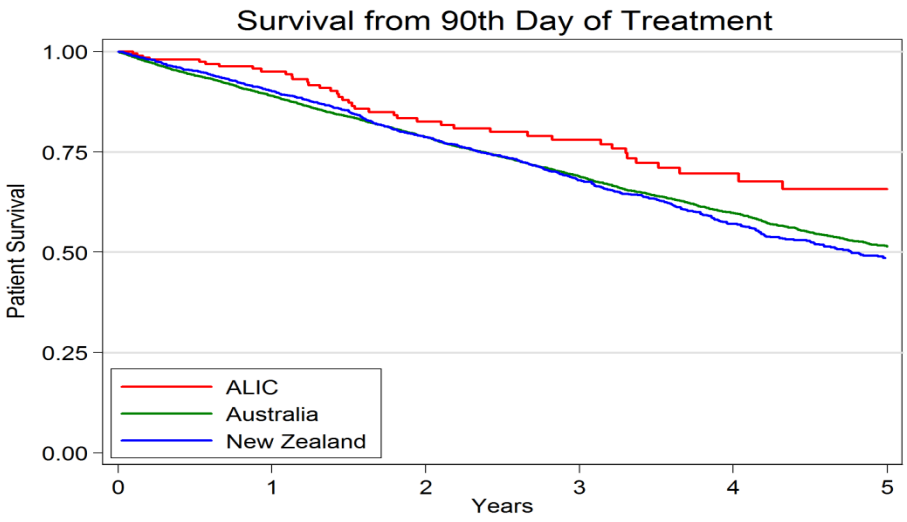
Transplantation

Transplantation rates for Aboriginal Australians are low Australia-wide. The 2013 *Australian and New Zealand Dialysis and Transplant Registry Report* recorded that 20 Aboriginal Australians received a transplant in 2012 compared to 801 non-Aboriginal Australians (13). Pre-emptive transplants (i.e. prior to commencing dialysis) are even rarer for Aboriginal Australians with only two having occurred in the last six years compared to over 500 in the same period for non-Aboriginal people. Ten dialysis patients in Alice Springs received a transplant between 2007 and 2012. Of the 10 transplant recipients, two were non-Aboriginal, one of whom received a kidney from a living donor.

Survival rates

Survival rates for all dialysis patients under the care of the Alice Springs Renal Services (ASRS) have improved significantly over the last 15 years and are now higher than for the rest of Australia (Figure 15). The age discrepancy between patients in the NT and the rest of Australia will have a significant impact on any comparison of survival rates. However, this is unlikely to be the sole reason for differences in survival for patients in CA. Furthermore, it does not account for improvements in survival over time that have been seen within the CA dialysis patient population.

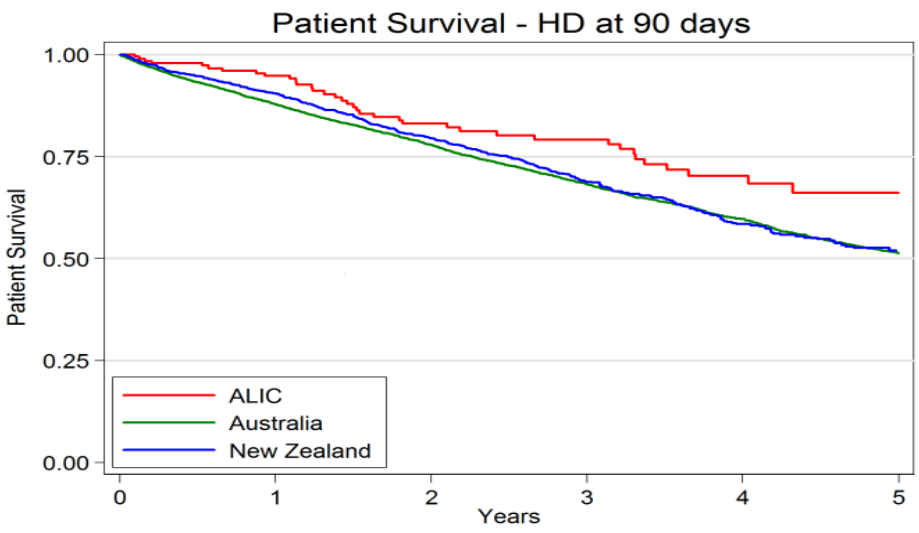
Figure 15: All dialysis patient survival in CA region; 2007-2012



Source: ANZDATA (ALIC: Alice Springs Renal Service).

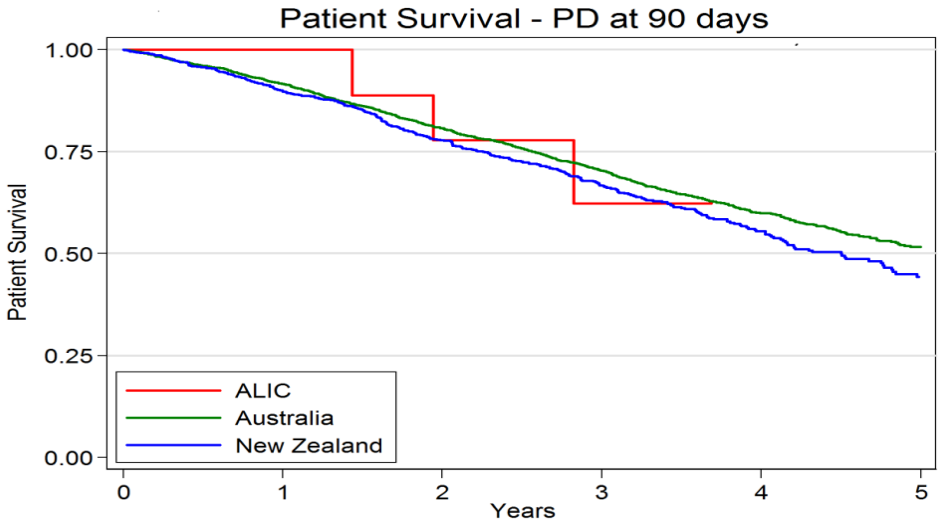
Figures 16 and 17 provide the breakdown in survival rates between HD and PD patients. The numbers of people on PD in the CA region are very low, and as such, these data (Figure 15) are unreliable as an indicator of survival outcomes.

Figure 16: Haemodialysis patient survival in CA region, 2007-2012



Source: ANZDATA (ALIC: Alice Springs Renal Service).

Figure 17: Peritoneal dialysis patient survival in CA region; 2007-2012



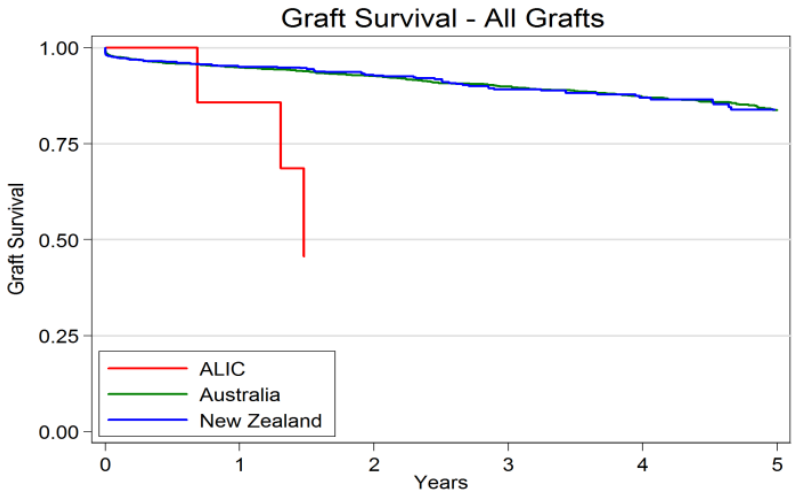
Source: ANZDATA (ALIC: Alice Springs Renal Service).

Between 2007 and 2012, there were three kidney graft losses in Alice Springs due to death or graft failure – all for Aboriginal recipients. Two patients died from overwhelming infection within the first year and one suffered an acute rejection. Kidneys are allocated according to an algorithm that includes blood type, human leukocyte antigen (HLA) matching and waiting time on dialysis. While blood type incompatible transplantation remains experimental, the advent of newer combinations of immunosuppressive drug therapy means exact HLA matching is less critical. Data relating to the matching of the HLA between donor and recipient are maintained for each transplant.

Aboriginal transplant recipients are more likely to have a significantly higher number of HLA mismatches than non-Aboriginal Australians. This seems particularly evident in Alice Springs, where in the last six years, more than 90% of all transplantations for Aboriginal people had five or more HLA mismatches.

Aboriginal Australians are more likely to suffer graft loss or death, primarily from infection, in the first year post transplant compared to their non-Aboriginal counterparts (14). Although transplant numbers are low, outcomes for transplantation in Alice Springs have been poor (Figure 18). Increasing focus is being given in research to achieving a better understanding of the reasons for poor transplant outcomes amongst Aboriginal Australians. Research is exploring the relationships between the number of HLA mismatches, dosing of immuno-suppressive medications, burden of infectious complications, health service access, patient and provider factors and transplant outcomes.

Figure 18: Graft Survival in transplanted patients in CA region; 2007-2012

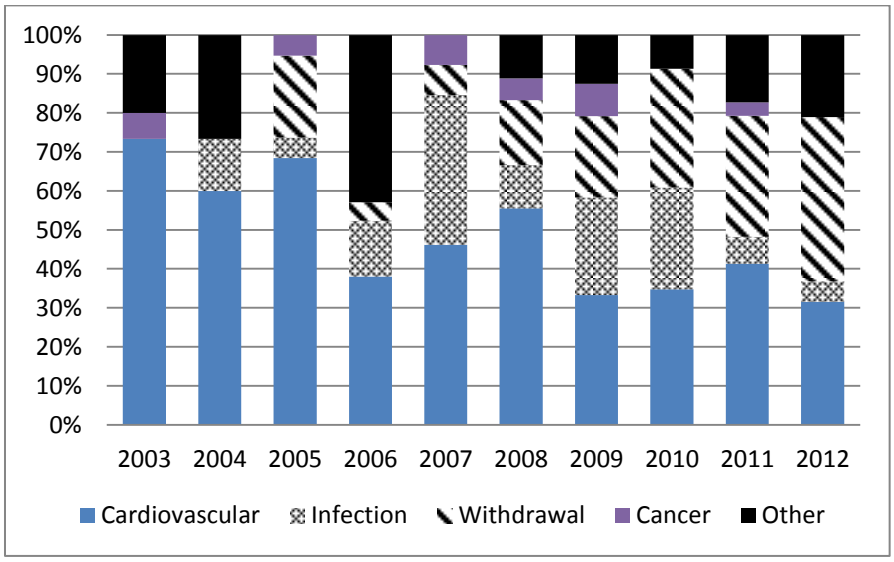


Source: ANZDATA (ALIC: Alice Springs Renal Service).

ANZDATA maintains information on causes of death for all patients receiving maintenance RRT. This information (Figure 19) should be interpreted with some caution. 'Cause of death' codes used in the ANZDATA registry are not World Health Organization ICD-10-based and are influenced by the interpretation of renal service staff entering data. Results are therefore challenging to compare with national death data. However, there has been a substantial decrease in the number of people identified as dying from an infective cause while the number of people identified as withdrawing from treatment has increased.

The growing proportion of patients choosing to withdraw from treatment in CA may be a result of the renal-palliative care program that commenced in the NT in 2008-2009, which focused on supporting people to return to their community for end-of-life care. The reduction in cardiovascular causes of death may be due to a number of factors including earlier referral leading to better pre-dialysis care and management of comorbidities, improved post-dialysis care including fluid management, and improved rates of dialysis attendance. The relationships between these factors are the subject of current research projects.

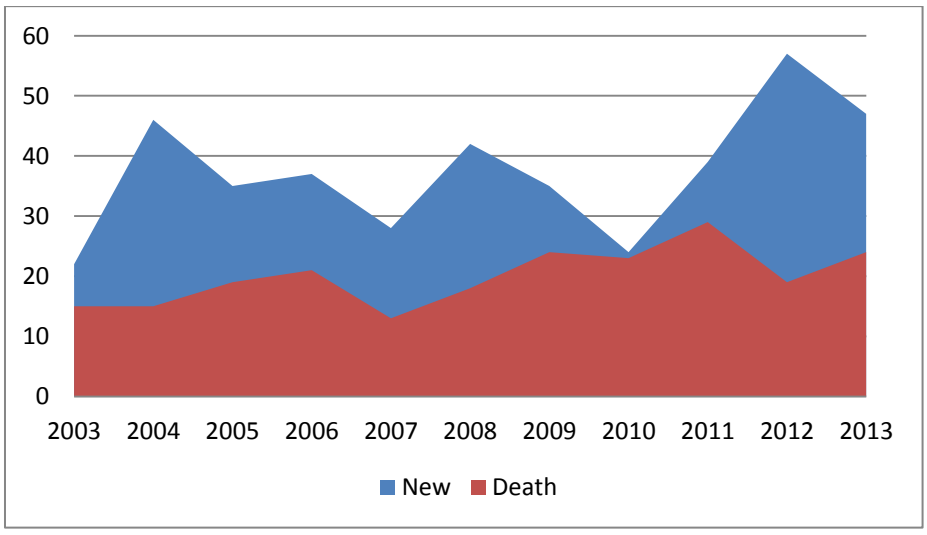
Figure 19: Cause of death for all renal patients in Alice Springs; 2003-2012



Source: ANZDATA

The contribution of high patient numbers commencing RRT to the growth in demand for services is clearly evident. However, other factors, including fewer people transferring out of the CA area in comparison to those transferring in, the younger age at commencement of RRT, and the improved survival rate, will also contribute to the net gain and growth in the demand for renal services in the region (Figure 20).

Figure 20: Net gain per year, new patients and deaths in CA region; 2003-2013



Source: ANZDATA

Service models, capacity and location

MAIN FINDINGS

- There has been a 42% increase in dialysis treatments delivered in Central Australia (CA) since 2009.
- 90% of patients receive care in a satellite unit.
- Approximately 25% of people are receiving services closer to home. However, fewer than 10% of people are receiving care in their own community.
- The Department of Health (DoH) has invested considerable funding and resources to supporting community-based self-care dialysis:
    - Uptake of self-care has not met expectations and the use of sites fluctuates according to patient health and personal preference for treatment.
    - At the time of this Report, seven patients at four sites were undertaking self-care haemodialysis – the same as in 2009.
    - Consequently, a significant amount of community infrastructure for self-care dialysis is under-utilised.
- The Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT) has increased services in CA now providing:
    - Treatments at one urban and six remote sites with two additional sites planned in 2015.
    - 8% of all treatments delivered in CA.
    - More than 70% of all dialysis treatments delivered in remote parts of the Alice Springs Hospital catchment area.
- In 2013/2014, the DoH and WDNWPT mobile dialysis services delivered over 200 treatments to a variety of communities.
- In 2014, there are more opportunities for people to receive care in their home community when compared to 2009.

Dialysis models of care

There are a range of dialysis models of care (MOC) in the Northern Territory (NT) (Table 3). Traditional models of care include satellite dialysis, home haemodialysis and peritoneal dialysis. There are a number of possible variations and alternative configurations to these treatment options in the NT, with location of service a critical component to the models of care.

Table 3: Dialysis treatment options and models of care in the NT

Modality	Model type	Model description
Haemodialysis (HD) is a treatment for kidney failure through the removal of wastes and excess water from the body using a dialysis machine to pass the blood through an artificial kidney. The procedure requires a surgical intervention to create a vascular access. Treatment is usually three times a week for 4-6 hours, but patients have notably improved outcomes with more frequent (daily) or longer, slower dialysis (nocturnal). There are several models of care for HD in the NT. In this context a 'station' refers to a dialysis machine and chair which can theoretically treat up to four people over a week.		
Haemodialysis	In-centre 6-10 stations	In-centre refers to dialysis services within the hospital that are reserved for acute or clinically complex patients who need a higher staff-to-patient-ratio for supervision and care. Dialysis treatment is usually co-located with a renal ward where care can be provided within a specialist framework that includes access to allied and support services such as social workers, dietitians, educators etc. In-centre facilities are usually part of a hub service. In the NT facilities are based at Alice Springs Hospital and Royal Darwin Hospital.
	Urban satellite unit 8-26 stations	Based in the urban community these provide services to the majority of dialysis patients and may also include home dialysis self-care training. Most patients attend three times a week for 4–6 hours and facilities usually offer four shifts, i.e. one machine can treat four patients. Alice Springs has two facilities: the main public service at Flynn Drive, which also hosts the self-care training programs, and the Gap Rd facility, which is a public/private partnership. In the Top End, facilities are available in Nightcliff and Palmerston.
	WDNWPT Purple House 2 stations	The Purple House facility based in urban Alice Springs has been added as an additional model because it provides periods of dialysis treatment for public patients attending the Flynn Drive facility. The service is the hub for the remote facilities managed by WDNWPT in the CA region including the cross border regions in Western Australia (WA). Although only consisting of two stations, the facility is operated in a similar fashion to a satellite service, with social supports, general practice visits and dietary education. WDNWPT's mission is to provide more than dialysis services, and promote a holistic program of respite, social support, community engagement and empowerment.
	Regional satellite unit 8–12 stations	Based in regional centres where there is sufficient demand and population. Facilities are available at Tennant Creek and Katherine in the Top End.
	Rural/remote unit 4–6 stations	There is only one remote dialysis unit in the NT comprising more than two machines. It is based on the Tiwi Islands and is managed by the NT Renal Service (NTRS). The patients are a combination of semi-independent and dependent. It operates on a fly-in fly-out weekly staff roster with accommodation for staff on the island.

Modality	Model type	Model description
	Community-based self-care 1–2 stations	These facilities, of usually two dialysis stations, provide a safe place for self-care patients who may not have appropriate space in their homes to undertake HD treatment. The facilities are designed for multi-users and were established in remote communities where there was a projected demand. Users are responsible for maintaining their equipment, stores and a clean environment. Usually patients prefer not to dialyse at night so capacity is limited to a 1:2 ratio, i.e. one machine to two patients. The home training manager visits on a regular basis. There are six facilities in CA (although not all are occupied), and a further 17 in the Top End. Additionally, a 'drop-in centre' in each region is co-located with the HD training units. These facilities enable urban self-care patients to have some autonomy with their treatment times. Currently there are no self-care patients residing in Alice Springs.
Haemodialysis	Home self-care	A number of self-care patients have been able to install the dialysis equipment in their residences (private and rented), providing them with autonomy with their treatment times and lengths. This is attractive for patients wishing to do daily or nocturnal dialysis. There are no self-care patients dialysing in their own homes in CA.
	Supported community-based dialysis 2–4 stations	This model is currently being provided by non-government organisations (WDNWPT and Miwatj Health), with some assistance from NTRS for machines, consumables and technical support. WDNWPT provides services in six communities in the NT and patients are a combination of permanent residents and those having respite from urban centres. Rotations are usually periods of two months to give people adequate time and assistance is provided for transport to and from the community. As the facilities have permanent staff living in the community, evening and weekend shifts are offered, and most of the facilities treat six patients in three shifts. Miwatj has commenced services in one community in East Arnhem and is offering a combination of permanent and respite treatments.
	Mobile dialysis services 2 stations	This service, originally established by NTRS, was intended to provide short periods of community dialysis for special occasions, such as sporting, cultural events and sorry business. The NTRS bus has two dialysis stations and is fully independent with generator, air-conditioning, staff quarters and storage sufficient for 3-5 days. It does not have wheelchair access. The bus is based in Alice Springs but has provided services to many communities across the NT and into South Australia. Visit lengths are usually 3-5 days not including travel time. WDNWPT also has a mobile service. The 'Purple Truck' has two dialysis stations and wheelchair access but no staff quarters. Unlike the NTRS service, the WDNWPT truck does not routinely return to Alice Springs, but provides services for extended

Modality	Model type	Model description
		periods (weeks to months) in communities. Staff travel to the vehicle when rotating, taking the necessary consumables with them. The truck has visited numerous communities primarily in the western desert region of CA. Both services are based in the CA region.

Peritoneal dialysis (PD) is a treatment for kidney failure through the removal of wastes and excess water from the body by instilling fluid into the peritoneal cavity via a catheter, where it dwells for several hours. Wastes travel across the peritoneal membrane into the fluid which is exchanged periodically for fresh fluid. A surgical procedure is necessary to insert the peritoneal catheter through the abdominal wall into the peritoneal cavity where it stays permanently.		
Peritoneal dialysis	Continuous ambulatory peritoneal dialysis (CAPD)	CAPD is considered a home-based therapy carried out by either the patient or a carer. It involves exchanging several litres of dialysis fluid a number of times a day (usually 4–5 times), with each session taking about 40–60 minutes. Treatment can be done virtually anywhere with no infrastructure required, although sufficient dry storage for the consumables is necessary.
	Automated peritoneal dialysis (APD)	APD follows the same concept as CAPD, although a small machine assists with the instillation and removal of the fluid. This is also a home based therapy undertaken by the patient or family member. The fluid exchange is continuous and usually overnight. It has the benefit of providing freedom during the day, but requires the patient to be connected to the machine for 10 or more hours overnight to get adequate clearances. Power is required for this modality as well as sufficient dry storage space.
	Supported automated peritoneal dialysis	This service has been offered in the past, both in the Top End and CA. It involves a salaried support person assisting several APD patients to set up, connect and disconnect from the machine. Patients need to be within the same location, if not within the same accommodation, such as a hostel, for efficiency. The support officer attends each evening to connect the patients and will then return in the morning to disconnect them. This service is useful for patients unable to undertake their own treatment who are also unable to have haemodialysis for clinical or personal reasons.

As noted, haemodialysis (HD) is the therapeutic modality for more than 90% of the ESKD population in CA. Few patients choose self-care HD and there is a greater demand for staffed satellite dialysis services in CA than in any other jurisdiction.

Currently the majority of dialysis treatments are delivered from the two satellite facilities based in Alice Springs and a regional satellite HD service in Tennant Creek. The NT Department of Health (DoH) is the main provider of renal services in CA. Alice Springs Hospital (ASH) has an in-centre facility that is dedicated to providing acute and overflow services but usually operates at capacity due to patient numbers attending the large satellite facility based at Flynn Drive - ostensibly considered the home unit for the majority of patients in Alice Springs. The DoH also has a partnership with Fresenius Medical Care, a company manufacturing and providing dialysis products, therapies and services, to provide a satellite service in Gap Rd Alice Springs under their subsidiary Nephrocare.

A number of patients (both intermittently and permanently) are also able to access staffed HD services in remote communities courtesy of the mobile dialysis services and through a non-government organisation – Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT) Aboriginal Corporation.

WDNWPT, a community-controlled organisation, provides staffed dialysis services in small facilities in remote communities, primarily in the CA region. The organisation is funded through a number of financial mechanisms, including government (local and national), philanthropy and fundraising. At the time of this Report, these services were not identified nor reported as separate facilities by ANZDATA.

Location of services

In the 2013/2014 financial year, Alice Springs urban renal services (including Nephrocare) delivered 27,192 treatments and Tennant Creek Dialysis Unit (TCDU) 6,564 treatments. WDNWPT provided another 590 treatments at the Purple House also based in Flynn Drive. Together this represents more than 90% of all dialysis treatments delivered in CA. Tennant Creek provides almost 20% of all dialysis treatments and offers services closer to home, if not at home, for a significant proportion of the patients from the Barkly region. These numbers include all treatments delivered in staffed facilities in urban (and regional in the case of TCDU) areas, including the training facility.

This represents a 33% increase in treatments since 2009 in urban and regional satellite facilities alone. There has also been a substantial increase (360%) in treatments delivered in remote settings (Table 4) although this only comprises 9% of all treatments in CA.

WDNWPT provided a number of treatments in their staffed facilities (two-four stations) largely based in remote communities. During 2013/2014, WDNWPT provided 2,978 treatments in one urban and four remote facilities, making up approximately 8% of all treatments delivered in CA.

Overall there has been an increase of 42% in dialysis treatments in CA.

Table 4: Dialysis treatments delivered in CA; 2009/10 and 2013/14

Facility	2009/2010	2013/2014
ASRS (ASH and Flynn Drive)	19,813	18,058
Nephrocare	823	9,134
TCDU	4,635	6,564
WDNWPT (Purple House)	528	590
Urban and regional staffed facilities	**25,799**	**34,346**
NTG Remote (includes MB to SA)	591	939
WDNWPT Remote (includes MB to WA)	132	2,388
Total treatments	**26,522**	**37,673**

Source: ASRS {MB: mobile bus}

Capacity of services

The 2011 Study indicated that demand for dialysis treatments was projected to grow at such a rate that an increase in dialysis capacity by an additional 15 positions in 2012, 2015 and 2018 (total of 45 extra positions) would be necessary to keep pace. At that time expansions of services were already underway with the construction of the new Nephrocare eight-station dialysis facility in Alice Springs nearing completion (capacity 32 patients) and the expansion of an additional eight stations in Tennant Creek planned for completion in 2011.

However, ASRS was under extreme pressure in managing dialysis patient numbers and explored additional measures to increase capacity including implementing a roster that created an additional shift utilising Sundays, and offering a middle shift to patients who only required short hours. This did not provide a substantial increase in capacity, but assisted with the safe management of patients until additional services came on-line.

Towards the end of the 2009/2010 financial year, Nephrocare became operational in Alice Springs. Nephrocare had designed the Gap Rd facility to cater for future expansion and accommodate up to 20 chairs if necessary. As a result Nephrocare commenced operation with 12 rather than eight dialysis stations and quickly expanded to 48 patients within two months.

The TCDU expansion was opened in 2012 and a staged increase in patient numbers has occurred since that time. At the end of 2013/14, there were 48 patients dialysing at TCDU (Table 5). The facility was not at capacity and there were patients from Tennant Creek dialysing in Alice Springs.

Table 5: Comparison of CA satellite dialysis capacity 2009/10 with 2013/14

Facility Location (stations)	2009/2010 Patients	2013/2014 Patients	Potential Patient Capacity (1 station to 4 patients)
ASH (8)	(Acute and overflow dialysis)	(Acute and overflow dialysis)	32
Flynn Drive (26)	112	147	104
Nephrocare (20)	48	72	80 (Limited by funded contracted treatments)
Tennant Creek (16)	32	48	64 (Currently limited by funding)
Total Patients	**192**	**267**	**280**

Source: ASRS

Current location and capacity of services

The current location of services and patient numbers consistently accessing each service at the end of September 2014 is reported below (Table 6). For each site, the number of patients treated, and total number of treatments delivered in September 2014 (in brackets), is indicated. Some patients who are registered with ASRS will occasionally dialyse at facilities managed by WDNWPT, and vice versa.

Table 6: Current service locations in CA region; patient numbers (treatments); Sept 2014

Location and provider	Urban satellite	Regional satellite	Self-care HD	Remote CBD	PD
NTG					
Flynn Drive	147 (1654)		1 (14) [Tr]	0 (18) [MB]	3
Nephrocare	72 (730)				
Amoonguna			2 (16)		
Elliot					1
Ali Curung			1 (7)		1
Ti Tree			1 (11)		
Lake Nash			3 (28)		
Tennant Creek		48 (566)			
WDNWPT					
Purple House	4 (55)			0 (5) [MB]	
Hermannsburg				4 (50)	
Yuendemu				5 (68)	1
Kintore				4 (55)	
Warburton				1 (13)	
Kiwirrkurra				4 (48)	
Total Pts (treatments)	**223 (2439)**	**48 (566)**	**8 (76)**	**18 (257)**	**6**

Source: ASRS (CBD: community based dialysis; Tr: Training; MB: mobile bus)

On average, and if fully adherent with HD treatments, each patient should have approximately 13 dialysis sessions per month. However, these numbers fluctuate from month-to-month for a variety of reasons. Variation in attendance is particularly evident at satellite units where some patients will regularly omit several treatments a

month. The reasons for poor attendance rates at urban satellite units have been the focus of several studies as well as future research.

Additionally, Warburton and Kiwirrkurra are relatively new services funded under a contract with the Western Australian Department of Health. The number of treatments delivered in September 2014 will not be indicative of yearly activity.

At the end of September 2014, there were seven people undertaking self-care HD in their home communities in CA. The actual number of treatments completed in the remote area fluctuates as patients are more mobile and move between Alice Springs and their home communities for various reasons. There are no patients dialysing in their own home either in Alice Springs or a remote community. Six patients were on PD at the end of September 2014, of which three were in their home community.

Community-based services

The two station dialysis facilities in the NT were originally established in remote areas as part of a program to increase access to treatment closer to home. The facilities were designed for independent use and are a combination of rooms in primary health facilities and specifically designed facilities dedicated for use by self-care patients. They were designed to be unstaffed facilities.

The availability of renal services in remote locations, specifically the type of infrastructure, capacity, and use, is indicated below (Table 7).

The calculation of the capacity of a community-based facility was originally based on self-care multi-user usage, with patients sharing the management of the facility. Most patients prefer not to dialyse in the facilities at night and therefore use is limited to daylight hours.

The capacity of these facilities potentially increases significantly when staffed, although this does increase the cost of delivering each treatment. Theoretically, a two station facility with three staff, can care for up to eight patients over four shifts or provide up to 1,248 treatments a year. However, this is far more difficult to deliver in practice.

Facilities based in remote areas are isolated and staffing is often limited. Operating a facility at capacity, and with a tight roster, is not always possible due to the need to maintain good work practices as well as the organisation’s specific work guidelines. Issues affecting staffing rosters and staff numbers include: meal breaks away from the work environment, regular consecutive days off rather than split days,

adequate time between shifts, allocated travel time, and satisfactory accommodation. Additionally, staff rosters rarely cater for adequate time for administrative tasks such as ordering stores, reviewing clinical charts, and other managerial responsibilities. 'Burnout' is a known occupational hazard for nursing staff in remote areas where staff turnover can be high.

Terminology

The following definitions apply to Table 7.

Renal ready rooms (RRR) are specific dedicated spaces for HD patients to undertake (usually) their own HD treatment. The room is usually within a healthcare facility or other public facility where separate access is provided so that patients/users may come and go outside normal working hours. Many health facilities in the NT now have a specifically designed room allocated to self-care HD patients. If the facility is new, then it is likely the room will be of adequate space to accommodate two machines and storage of consumables for up to four patients. As home and community-based self-care dialysis only became available in 2004 in the NT, many RRRs were established within older facilities and therefore were limited in space particularly for storage. Most of these are only suitable for a single machine.

Dongas were originally designed as a relocatable facility that could be moved to areas of demand. However, as circumstances changed in the NT and cost of construction, infrastructure and availability of the required workforce was impacted upon by a number of remotely-based government programs, the cost of relocation escalated by a phenomenal 900%. Consequently, the design of the relocatable changed to be suitable as a more permanent structure, since it was no longer essential to retain the narrow width necessary for loading onto a truck.

Table 7: Location, capacity and usage of community-based infrastructure; Sept 2014

Location	Type of facility	Capacity	Current numbers
NTG (not staffed)			
Mt Liebig	1 station RRR	2	0
Santa Teresa	2 station RRR	4	0
Amoonguna	2 station donga	4	2
Ti Tree	2 station donga	4	1
Ali Curung	2 station donga	4	1
Lake Nash	2 station donga	4	3

Laramba	1 station RRR	2	0
WDNWPT (staffed)			
Hermannsburg	2 station donga	8	4
Yuendemu	2 station donga	8	6
Kintore	2 station RRR	8	6
Warburton	2 station RRR	8	4
Kiwirrkurra	2 station donga	8	4
**Lajamanu*	2 station donga	8	4
TOTALS		**62**	**31 +**

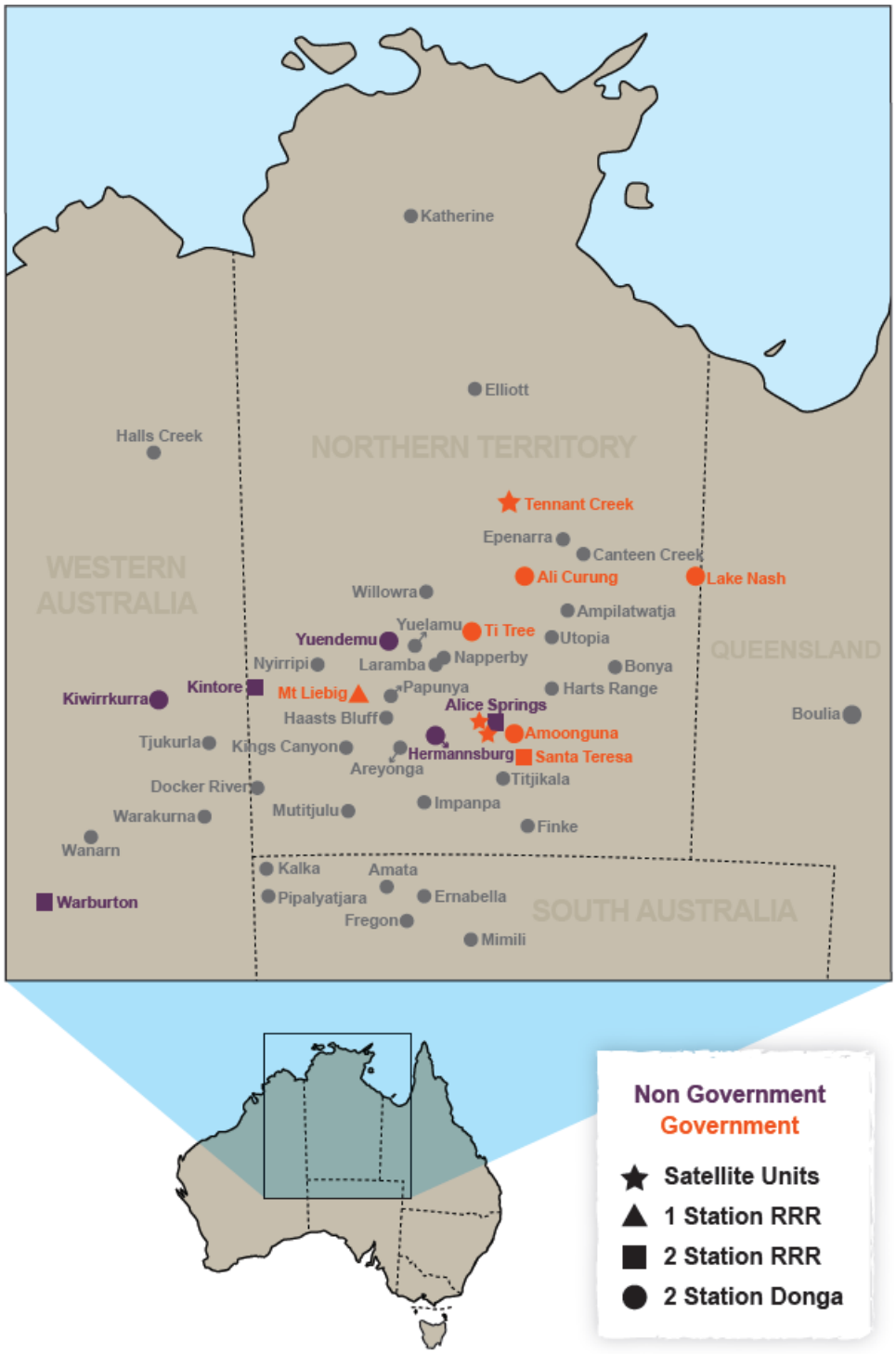
*Source: ASRS and WDNWPT * Technically Lajamanu is in the Top End catchment area*

Service demand and access

The majority of people on dialysis in the CA region relocate to access treatment. Their home communities are spread over the entire CA region and include the eastern border of Western Australia (WA), the northern lands of South Australia (SA) and parts of Queensland (Qld). Figure 19 identifies the majority, but not all, of these communities. Only communities with two or more renal patients are noted. It provides some indication of the breadth of the catchment area for the Alice Springs Renal Services. The map also indicates the locations of current services, types of service and providers. When compared to 2009, both the DoH and WDNWPT have increased service locations and treatments in remote areas.

This map clearly illustrates the insignificance of jurisdictional borders and service catchment areas in terms of patient preference for access to care.

Figure 21: Map of home communities of patients attending ASRU and service locations; 2014



Strategies to increase access

DoH home and community-based program

The NT Department of Health *Renal Services Framework 2012-2017* (15) supports a strategy to develop models of care that provide treatments at home or closer to home, based on the principle of affordable and sustainable services. The rollout of significant infrastructure to remote areas and well-funded, self-care training and support programs, support this strategy. Self-care dialysis as a treatment option is the least expensive therapy model and is known to have improved quality of life and health outcomes (16-18). However, nationally the number of patients able or willing to undertake self-care training and independent dialysis is a small proportion of those who require treatment, or wish to be treated at home or closer to home (8).

Established in the NT in 2004, the self-care home and community-based HD program provided dedicated training programs not restrained by time limits and included considerable on-site support for community-based patients. Additionally, significant funding was allocated to establishing the necessary infrastructure to enable people to dialyse safely in their communities.

Since 2009, the number of sites in CA set up to accept self-care patients has expanded with an additional two sites. However, the program has failed to attain the anticipated numbers of self-care patients. Furthermore, the use of sites fluctuates according to patient health and personal preference for treatment. While there has been an increase in self-care patients supported by the ASRS, the number of sites utilised has not significantly expanded. At the time of writing there were seven patients dialysing independently at four sites.

The uptake, which is not dissimilar to other jurisdictions on a population basis, has meant that the vast majority of patients in CA, are dialysing far from their home communities, family and support networks. Further, there is a significant amount of infrastructure set up for community dialysis that is currently vacant or under-utilised.

WDNWPT community-based supported care

WDNWPT Aboriginal Corporation was established in response to community calls for services closer to home (10). The corporation represents the people of the Western Desert region, which encompasses communities in the NT and WA. In 2004, WDNWPT delivered their first supported dialysis treatment in the remote community of Kintore. The organisation prides itself on delivering more than dialysis treatments. Services provided include: return to country program (travel and

accommodation support to home communities), social support in the urban area, assistance with travel and accommodation costs, service navigation, social activities, advocacy, wellbeing including podiatry, bush medicine and bush tucker, health promotion and education and primary health care (19).

In 2009/2010, WDNWPT delivered dialysis treatments in one urban and one remote community site. Patients primarily received respite treatments at these locations rotating back to the DoH service in Alice Springs after several weeks. A further two sites commenced in late 2010. Since then, two established sites expanded to accommodate additional chairs and treatments, the mobile bus was established, and three additional sites have commenced – one in the Top End (Lajamanu) and two in WA (Warburton and Kiwirrkurra). There are currently plans to expand to two additional sites in early 2015.

Overall increase in services in remote communities

Since 2009, there has been a substantial increase in opportunities for people to receive care in their home communities (Table 8).

In 2009/2010, ASRS delivered 310 treatments in training and 591 in remote areas. While the number of people in training decreased in 2013/2014 (157 treatments), the number of treatments in the remote area increased by 59% (939).

WDNWPT delivered 528 treatments at the Purple House in Alice Springs, and 132 treatments at the remote community of Kintore in 2009/2010. In 2013/2014, the number of treatments delivered at the Purple House was similar (590), but the number of remote sites had expanded and treatments had increased by 1700% (does not include mobile bus).

WDNWPT currently delivers 70% of all treatments within remote communities in the catchment area of ASRS.

Table 8: Comparison of patient access to community-based services 2009/10 with 2013/14

Location	2009/2010	2013/2014
NTG (not staffed)		
Training	310	157
Santa Teresa	138	115
Amoonguna	150	314
Ali Curung	143	134
Ti Tree	82	77
Mt Liebig	78	
Lake Nash		197
Laramba		
WDNWPT (staffed)		
Purple House AS	528	590
Kintore	132	846
Hermannsburg		678
Yuendemu		591
Warburton		165
TOTAL	**1561**	**3865**

Source: ASRU

Mobile dialysis services

There are two mobile dialysis services operating from Alice Springs.

Department of Health Mobile Dialysis Bus

The NT DoH Mobile Dialysis Bus Service was established in 2010 with the intention of providing renal patients, unable to undertake their own treatment, opportunities to visit their home communities. Visits would be on a rotating basis and could be coordinated to coincide with community events such as festivals, sporting carnivals and sorry business.

A report of the Mobile Dialysis Bus Service was provided to the Australian Government by the NT DoH in 2011 (20). The Report noted that the mobile bus service achieved its objectives of:

- Providing increased access to home communities. In the first year the service completed 12 trips and provided treatments to 50 patients across the NT.
- Providing a focal point for education. The bus was present in Alice Springs town for Kidney Health Week and also at the Tennant Creek and Alice Springs Royal Show offering kidney health checks and educational material.
- Raising the profile of renal disease in communities. When in remote communities, staff engaged with the community encouraging visits to the bus to watch educational DVDs, observe treatment and receive education.

An assessment of attendance rates, hospitalisations and emergency evacuations for the patients using the facility for the 12 months before implementation, compared to the 12 months after implementation, noted a number of improvements including a:

- significant decrease in hospitalisations
- no emergency evacuations
- slight increase in treatment attendance.

While these data were promising, the Report indicated that it was incomplete and ongoing evaluation should take place regarding the impact of the program.

The Report concluded with an evaluation of expenditure over the first year, and noted that while costs were high, a substantial proportion was expended on set up costs and that second and ongoing years were likely to be more cost-effective. Additionally, the considerable expense to patients accessing the service, who were responsible for their own transport to and from communities, was highlighted. The Report listed a number of recommendations and suggestions to improve utilisation, efficiency and access.

In 2013/2014, the mobile service delivered 101 treatments, 26 of which were delivered in the Anangu Pitjantjatjara Yankunytjatjara (APY) lands by the SA Government who leased the vehicle for the visit. The service suffered significant downtime due to repairs, maintenance and poor weather. Additional constraints included:

- A part-time project officer who was the sole person with a medium rigid license, limiting the number of community visits and the time the bus could be away

- Lack of dedicated funding for the service ensuring that it was linked to, and limited by, staffing availability and activity of the satellite service
- A higher nursing staff requirement per trip than initially anticipated.

At the time of this Report, plans to change the service model to provide a regular service between a number of communities were being considered. However, the project officer recently resigned and the status of the service is currently unknown. An evaluation of the costs of maintaining and delivering the service is provided in section two of this Report.

WDNWPT Mobile Dialysis Service

The WDNWPT Mobile Dialysis Service (Purple Truck) was established in 2011 with the intention of providing respite services in communities without dialysis services and supporting access in other communities during times of increased demand. It was initially built as a one station facility, but a second station was inserted in 2013. The refurbishment limited the activity of the Purple Truck during this time. In 2013/2014, the truck provided 108 treatments to seven communities, with additional treatments to the community of Warburton (contracted to the WA Country Health Service). The Purple Truck was used as a temporary facility while the Warburton Renal Clinic was being established.

The service now operates as temporary infrastructure providing treatments in communities for extended periods rather than a few days. Supplies are brought to the Purple Truck by rotating staff.

An evaluation of the service has not been undertaken, although the model was briefly covered in the Report prepared by Ernst and Young of the WDNWPT Aboriginal Corporation Service Delivery Model (19).

The Purple Truck service model differs from that of the DoH mobile dialysis service in a number of ways. Specifically the Purple Truck provides:

- A dedicated full-time coordinator and support officer.
- More than one staff member able to drive the vehicle.
- Community visits for weeks rather than days.
- A service that does not come ‘back to base’ between community visits.
- Staff rotations of several weeks with exchanges occurring in the community.

- Patients with transport and assistance with accommodation in the community.

An evaluation of the cost of managing the service and a comparison of expenditure between the two mobile services is provided in section two of this Report.

Capabilities for service provision

Main Findings

- Alternative models of dialysis care are sustainable in the Central Australia (CA) region.
- Dialysis services in remote communities require a significant level of support
  - Few communities have the infrastructure and services necessary to support staffed dialysis services.
  - Provision of staff accommodation is usually necessary.
  - Staff work in isolation and staff 'burnout' and turn-over can impact on the sustainability of services.
- Without support for transport to remote communities, mobile dialysis services and respite services are expensive options for patients.
- The WDNWPT model of service delivery supports patients with transport and accommodation assistance.
- Collaboration and co-ordination across departments and organisations is necessary for the successful and sustainable delivery of remote services.

There are few communities in the Northern Territory (NT) that are not touched by kidney disease. In the larger communities, there are clan groups and families with kidney disease running through generations. The majority of these communities have limited infrastructure and resources available including accommodation, reliable essential services, and qualified essential service maintenance staff.

Providing staffed dialysis services where it is needed, even in the larger communities, is a highly resource intensive strategy that would need to demonstrate improved outcomes for it to be deemed cost-effective. This struggle to find the balance between accessible services and cost-effective care is not specific to either the NT or Australia. Other countries, particularly Canada and New Zealand, have also struggled with providing accessible services to their remote and rural populations (21, 22). As a result, and despite demonstrated demand from remote communities, satellite services are more likely to be considered in rural centres with populations, industry or infrastructure that would support sustainability of the service, including the ability to attract and retain trained renal staff.

In addition, satellite services, distant from the main referral centres of Darwin and Alice Springs, function with the minimum level of clinical renal support. These units usually have basic renal staffing levels, and while some have access to onsite medical staff, the expert renal advice from nephrologists and the broader renal multidisciplinary team is via telephone or on a visiting basis.

Patients admitted to these units need to be effectively managed and supported within the available resources. Patient clinical stability and physical ability are important factors, as is the mental state of the patient. 'Burnout' in remote communities is an occupational hazard and inexperienced staff, or staff unaccustomed to working in isolated conditions, will more acutely feel the stress of managing patients who are clinically or physically difficult. Staff turnover and retention are important considerations for the sustainability and quality of a service and it is critical that patients, families and potential service providers have realistic expectations and understand some of the limitations of a service in rural and remote areas.

The development of agreements and arrangements with local health service providers, regional hospitals and non-government primary health services, are important for the safety, quality and sustainability of units in rural and remote areas.

Since 2009, the NT Department of Health (DoH) has increased access to treatments in the Barkly Region with the expansion of the Tennant Creek Dialysis Unit (TCDU). There has been no other expansion or establishment by the NT DoH of staffed services in rural or remote locations.

The 2006 National Service Guidelines for the Management of Dialysis and Kidney Transplantation in Remote Australia describe a resource capability matrix that is applicable to the physical structures that are the focus of various services along the renal continuum of care (23); from the primary health care clinic, remote, rural and regional satellite facilities, to tertiary renal centres. The matrix outlines the capabilities of each facility and the necessary human resources, infrastructure and support services necessary to provide the identified level of care.

A similar matrix has been developed to describe the various dialysis models of care that might be applicable in the NT. The matrix describes the infrastructure, resources and support services required to maintain and sustain a service in the NT environment and also comments on the clinical and demographic characteristics of clients suitable for each model of care.

The term ‘satellite’ is used in this context to describe a facility’s relationship to the main service. Most services run on a ‘hub and spoke’ model where the hub is the facility from which the resources are directed, which is normally a tertiary hospital. Spokes, or satellites, are usually supported by the hub with visiting services and may be of any size and location. For convenience, many satellites in regional and rural areas are located in hospitals where either:

1. Space is already conveniently configured for the essential electrical and water standards or;
2. Co-location provides the necessary level of resource support required by dialysis units.

Due to the cost of infrastructure establishment and refurbishment in remote areas, units in these locations often ‘make do’ with the space and facilities at hand. Consequently, remote units are rarely designed to standard or have the necessary space for storage, waiting areas, offices or interview rooms that are required to manage the service. This cramped and inappropriate work environment is an additional stress for staff and future developments should aim to avoid the mistakes of the past.

An additional consideration for remote area service delivery is the requirement to provide suitable accommodation for staff. It is unlikely that remote area residents, with the required clinical skill set (competencies in dialysis treatment), will be found and there are limited numbers of renal trained staff in Australia. Attracting and retaining staff will be dependent on a number of factors including capacity to provide suitable accommodation. Accommodation is limited across the NT, but more so in remote areas. The experience of service providers on the Tiwi Islands, and in Kintore, Yuendumu and Lajamanu, is that the establishment of the service is contingent on the provision of staff housing.

A matrix of each dialysis model of care, identifying the desired resources and capabilities required for service delivery (Table 9), along with the strengths and weaknesses of models that have the potential to provide services closer to home (Table 10), follow below.

Table 9: Dialysis service provision capability matrix for the NT

Service Description	Infrastructure	Resources/Support Services required	Client requirements
In-centre hospital dialysis Provision of acute dialysis, interventional and investigational renal services and pre and post transplantation care.	Usually within a large teaching hospital and co-located with a renal ward. 6-10 dialysis stations.	• Renal multidisciplinary team including: nephrologists, skilled renal nursing staff, pre-dialysis education, dietitian, social worker, renal pharmacist, physio, psychologist, renal educator and access to accredited courses • Access to medical engineering and dialysis equipment technician • Onsite tertiary level surgery, radiology, pathology and nuclear medicine.	Accepts all levels of patients.
Urban satellite unit Primary function is to deliver maintenance HD. Usually co-located with support and ancillary renal services such as pre-dialysis education, training in self-care therapies and home therapies support.	Due to their 'stand-alone' nature the facilities are large with adequate parking, storage, offices, meeting rooms, kitchens and waiting areas to meet the needs of the patients and staff. Additionally, separate areas are designated for home training. The Australasian Health Facility Planning Guidelines (24) provide detailed descriptions of the essential criteria for dialysis units. In the NT, back-up power (generator) and water supply (storage tanks) are essential criteria. 8 or more stations.	• Renal multidisciplinary team either on site or visiting as needed • Human resources including experienced renal trained staff, administration support, patient care assistants, cleaners, technician support • Services including: catering, laundry, waste management (general and medical waste removal), oxygen delivery and safe storage • Patient transport to and from treatment • IT systems that interface with DoH • Vehicles for clinical and support staff movement including home therapy visits. Desired • Visiting GP service.	Accepts all level of patients except: • Require a bed for treatment • Systemic infection • Suppurating wounds • Carrying drain • Regularly physically aggressive or threatening.
Regional satellite unit Primary function is the delivery of maintenance HD. May provide some support for patients undertaking home therapies and	Often co-located with other health services for ease of access to support services such as pathology, pharmacy, waste management, stores delivery. Refer to Australasian Health Facility Planning	• Human resources including experienced renal trained staff, administration support, patient care assistants and cleaners • Regular visits by renal multidisciplinary team • Immediate technician support by phone and on site within 48 hrs	Accepts most patients who are deemed by medical staff to be clinically stable and mobile with

Service Description	Infrastructure	Resources/Support Services required	Client requirements
oversight of transplanted patients living in the region. Coordination of dialysis clinics for visiting nephrologist. Site may also be used for clinics for visiting multidisciplinary team.	Guidelines for infrastructure requirements. Reasonable level of community infrastructure and access to government services is desirable. 8–16 stations.	• Services including: catering, laundry, waste management (general and medical waste removal), oxygen delivery and safe storage • Contracted services for facility repairs and maintenance, ground maintenance • IT systems that interface with DoH • Minibus or contract for patient transport to and from treatment • Vehicle for clinical and support staff movement around town. Desired • Visiting GP service.	aids, except: • Confused, agitated or verbally noisy • Regularly miss treatments of 4 or more/month • Suppurating wounds • Interdialytic fluid gains of more than 8% of body weight.
Rural/remote satellite unit Primary function is the delivery of maintenance HD. May provide some oversight of patients undertaking home therapies and transplanted patients living in the region. Coordination of dialysis clinics for visiting nephrologist. Coordination of clinics for visiting multidisciplinary team.	May be co-located with other health services for ease of access to support services and clinical staff. Facilities should be designed with reference to Australasian Health Facility Planning Guidelines for infrastructure and space requirements. In addition, remote area facilities require sufficient storage to enable continuous service during wet season interruptions. Other infrastructure requirements include: • Generator • Water holding tank of sufficient capacity • Consideration of requirements for staff accommodation. 4-8 stations.	• Human resources including: experienced renal trained staff, administration support and patient care assistants who multi-task as cleaners/transport officers • Renal multidisciplinary team visiting at regular intervals • Immediate technician support by phone and on site within 48 hrs • Contracted services (possibly with shire or council) for waste removal, repairs and maintenance and ground maintenance • Agreement with primary health care to manage all general health conditions, acceptance of biohazard waste, pathology samples and delivery of medications • Local contracts for catering and laundry or facilities within unit to undertake these tasks • Processes for the freight and delivery of	Accepts most patients who are deemed by medical staff to be clinically stable and compliant with treatment. Exception criteria as above plus: • Patients with permanent central lines that require frequent re-wiring or replacement • Requires two

Service Description	Infrastructure	Resources/Support Services required	Client requirements
		consumables to the site – this may involve a number of contracts for barge and road transport • IT systems that interface with DoH • 4WD vehicle for clinical and support staff movement and patient transport. Assumptions • Patients accessing the service (either those returning to the community or from surrounding areas) have their own accommodation • Staff are local or accommodation is available. Fly-in, fly-out service of short rotations is less cost effective.	people to transfer (negotiated).
Self-care HD Patients are trained to be independent in their dialysis and access treatment either in their home or an established multi-user facility (RRR or donga) in their remote community. Patients are monitored during the transition and orientation to the new environment. Phone contact with the training unit is encouraged at each dialysis treatment and the home training manager visits on a regular basis to check technique, environment and provide moral support.	Accessing self-care treatment in the home requires no additional infrastructure other than a phone line. Multi-user facilities are also available in RRR or donga. • Facility should meet space criteria for dialysis stations and storage • 1,000L tank and pump if reliability of community water an issue • Phone-in unit connected to training facility • May require fencing if not co-located with other services. 1 -2 stations.	• Regular visits by home training manager • Immediate technician support by phone and on site within 48 hours • In the case of dongas, contracted services (possibly with shire or council) for facility repairs and maintenance, ground maintenance • Agreement with primary health care to manage all general health conditions, acceptance of biohazard waste, pathology samples and delivery of medications • Processes for the freight and delivery of consumables to the site – this may involve a number of contracts for barge and road transport. Assumptions • Patients accessing the service (either those returning to the community or from surrounding areas) have their own accommodation.	Patients are clinically stable and they or their carer, have been trained and deemed competent and safe with the dialysis treatment.

Service Description	Infrastructure	Resources/Support Services required	Client requirements
Community-based supported care This model of care has expanded in recent times and is provided by Aboriginal controlled organisations supported through a range of funding sources including Territory and Australian Government departments. The model offers dialysis in remote communities to a combination of permanently remote-based patients and those seeking respite from the urban area. Care is provided by trained staff in small facilities. Volume of patients is required to be cost effective and most facilities are running three shifts – equivalent to six patients. Patients are given extended periods in the community of up to two months before rotating back to urban area - depending on demand. The delivering organisation may also offer additional support such as patient transport between the urban and remote area and even accommodation.	Service is provided in small facilities – mostly 2 station RRR or donga. • Facility should meet space criteria for dialysis stations and storage • 1,000L tank and pump if reliability of community water an issue • Phone-in unit connected to training facility • May require fencing if not co-located with other services. 2-4 stations	• Experienced renal trained staff • Depending on patient numbers, may also require patient support officer who provides store management, cleaning, transport and administration support • Immediate technician support by phone and on-site within 48 hrs • Contracted services (possibly with Shire or Council) for waste removal, repairs and maintenance, ground maintenance • Agreement with primary health care to manage all general health conditions, acceptance of biohazard waste, pathology samples and delivery of medications and provide assistance when needed • Processes for the freight and delivery of consumables to the site – this may involve a number of contracts for barge and road transport • IT systems that interface with DoH • 4WD vehicle for clinical and support staff movement and patient transport • Funding or mechanisms to support patient transport to and from communities. Assumptions • Patients accessing the service (either those returning to the community or from surrounding areas) have their own accommodation • Staff live in the community for extended periods.	Patients have been deemed clinically suitable by medical staff and acceptance criteria are similar to that for a rural/remote unit.

Service Description	Infrastructure	Resources/Support Services required	Client requirements
Mobile dialysis service There are two mobile dialysis services in the NT, one managed by the NTG and the other by an Aboriginal controlled organisation. Each service operates differently with the NTG service providing short-term holiday service of 3-5 days in remote areas. The Aboriginal controlled organisation tends to use the bus to provide temporary infrastructure and community stays can be several months at a time.	There are two services in the NT, both provided from a purpose built module fitted to a truck. Each module has slightly different facilities but essentials include: • Wiring specific for medical facilities • Sufficient space to safely accommodate machines and filtration systems • Sufficient storage for consumables • Robustness to deal with remote area conditions • Satellite and UHF phones • Generator of sufficient size to run air-conditioning, dialysis machines and water filtration • Water tanks and method of connecting to external water source and three phase access for connection to external power • Wheelchair access.	• Renal trained staff • Staff with medium rigid licenses • Project officer to coordinate community visits, resources and patient transfer • Funding or mechanisms to support patient transport to and from community. Assumptions • Potable water available in community • Community approves parking spot for vehicle • Patients have accommodation in community • Technical support is not provided while on the road.	Patients have been deemed clinically suitable by medical staff and acceptance criteria are similar to that for a rural/remote unit.
Continuous ambulatory peritoneal dialysis A home-based therapy carried out by either the patient or a carer. It involves several fluid exchanges a day and treatment can be done virtually anywhere.	No specific infrastructure is required other than: • Sufficient dry storage for the consumables • A clean safe environment to carry out the treatment that can be accessed at regular intervals during the day.	• Regular visits by PD training manager • Agreement with primary health care to manage all general health conditions and assist with storage of medications and transfer of pathology • Processes for the freight and delivery of consumables to the site – this may involve a number of contracts for barge and road transport. Assumptions • Patients have their own accommodation with suitable space for treatment and storage of consumables.	Patients have been trained in treatment, and they or their carer, have been deemed competent and safe with the dialysis treatment.

Service Description	Infrastructure	Resources/Support Services required	Client requirements
Automated peritoneal dialysis A home-based therapy carried out by either the patient or a carer involving the exchange of fluid overnight with the assistance of a machine. As such, it only involves one connection and disconnection in 24 hrs.	No specific infrastructure is required other than: • Reliable power supply • Sufficient dry storage for the consumables • Sufficient room in the bedroom for the machine trolley.	• As above	Patients have been trained in treatment, and they or their carer, have been deemed competent and safe with the dialysis treatment.

Alternate models possible in the NT			
Supervised self-care As above. In some states with an elderly population, self-care HD patients are supported in maintaining their independence by a 'roaming nurse'. The nurse visits the patients at home on the day of dialysis to offer support and check calculations and machine parameters if required. The nurse does not set up the machine or do the dialysis treatment but may assist with needling if required.	As above	As above • Renal trained clinician to visit each dialysis treatment.	Patients are clinically stable and have been trained and deemed competent and safe with the dialysis treatment. May not be able to needle or are dialysing alone.
Supported automated peritoneal dialysis (APD) A home-based therapy delivered by a salaried support person who assists a number of patients having the same therapy. It involves the support officer setting up the APD machine, and attending the connection and disconnection for the patient.	No specific infrastructure is required other than: • Reliable power supply • Sufficient dry storage for the consumables • A clean safe environment to carry out the treatment.	• Salaried officer trained in the APD connection and disconnection technique • Sufficient volume of patients requiring service to make employment of support person viable • Proximity of patients to each other, in terms of their night accommodation, to make the program practical • Regular visits by PD training manager. Assumptions • Patients have their accommodation with suitable space for treatment and storage of consumables • The number of patients requiring service is manageable by the support officer.	Patients are suitable for PD.

Table 10: SWOT analysis of dialysis models of care that provide services closer to home

Model	Strengths	Weaknesses	Opportunities	Threats
Regional satellite unit	• Increases access to services for regional and rural population • Enables people to be treated closer to their communities • Decreases requirements for patient accommodation and social supports in urban area • Likely to have positive impact in urban area with decreased 'urban drift' and opportunities for 'mischief' from accompanying family and community members • Increases dialysis capacity in urban area.	• Requires renal trained staff experienced in working autonomously • Requires a community of sufficient population base to attract and retain staff • Requires a volume of patients to ensure quality and cost-effective service • Requires community infrastructure and services of sufficient level to support facility • Requires outreach services from hub for dialysis clinics and staff education • Would still require accommodation for many patients.	• Increase local business and employment through service contracts • Increase local employment for nurses, administration and support staff • Increase awareness of renal disease and encourage CKD screening in community • Reduced requirement for patients to visit urban area for review as outreach team seeing pre-dialysis patients in region can also see dialysis patients • Staff rotations from hub unit provide opportunities for up-skilling and relief.	• Main industry of region based on transient workforce (e.g. defence force) leading to constant program of recruitment and training • Recruitment and retention hindered by availability of accommodation in area • Difficult and costly for staff to rotate to hub unit for sufficient time to up skill and undertake refresher courses.
Rural/remote satellite unit	As above Plus • Enables more people to be treated in, or close to, their community • Likely to have benefits for patients in terms of disposable income, employment and retaining role in community • Likely to have benefits for remote communities able to retain elders and key community figures.	• Requires sufficient renal patient numbers to ensure service remains viable and cost-effective • Requires certain level of community infrastructure and services to support facility • May require a higher staff to patient ratio due to isolation from medical assistance • Requires experienced renal trained staff used to working independently and autonomously	As above but on a smaller scale Plus • A partnership with primary health care (PHC) where staff are up-skilled in CKD management and dialysis treatments to provide opportunities for rotation and cross relieving for more efficient use of staff in community.	As above, plus • Difficulty in finding renal trained staff wishing to remain permanently in community, or be part of rotating team • Service has to be delivered with fly-in, fly-out (FIFO) staffing roster – decreasing engagement with community and increasing costs • FIFO transport is restricted to road increasing costs by increasing travel time

Model	Strengths	Weaknesses	Opportunities	Threats
		• Likely to require renal staff accommodation • May require additional housing for non-community member patients.		• FIFO or drive-in, drive-out service may be halted by seasonal access • Staff unable to travel unaccompanied in remote areas increasing resource requirements • Possible community disharmony from non-community member accessing service. Will require prior agreements.
Community-based supported HD - permanent	As above, plus • Enables some people to be treated in their community • Likely to have improved clinical and quality of outcomes for patients.	• Requires experienced renal trained staff as patients are more likely to be dependent and frail • Less cost–efficient unless all shifts utilised • Requires staff accommodation.	• Staff have opportunities to be involved in other community and social support activities • Staff have time to provide education • Increase awareness of renal disease and encourage CKD screening in community • May reduce requirement for patients to visit urban area for review if sufficient numbers of CKD and dialysis patients in community warrant visit by renal outreach team • May be able to develop partnerships with other units for staff rotations • A partnership with PHC where staff are up-skilled in CKD management and dialysis treatments to	All of the above, plus: • Unable to reach agreement with shire/council for R&M and support services and are required to manage from hub.

Model	Strengths	Weaknesses	Opportunities	Threats
			provide opportunities for rotation and cross relieving for more efficient use of staff • Provides opportunities for local employment and contracts with shire/council and local services for R&M and support.	
Community-based supported HD - respite	• Provides opportunities for people to have treatment in their communities for short periods • Likely to have a psychological benefit for patient and families that is hard to quantify • Continuous service increases dialysis capacity in urban area.	As above, plus: • Does not decrease requirements for patient accommodation and social supports in urban area • May need visiting patient accommodation in community • Patients will need financial and organisational assistance with travel arrangements • Require staff accommodation in community • Requires additional staff to oversee operations and provide link between units.	As above.	All of the above, plus: • Tracking of patients and treatments completed may be more difficult as patients move between sites.
Self-care HD	As above, plus: • Does not require staff • Does not require staff accommodation • Least expensive dialysis model.	• Only small percentage of dialysis population will be able to attain independence • Takes much longer to train most Aboriginal people to safe and confident level due to language barriers and unfamiliarity with technology.	• Provides opportunities for local employment and contracts with shire/council and local services for R&M and support of multi-user facilities • Multi-user facilities enable patients to support each other.	• Lack of community support to assist with stores deliveries, removal of waste etc. adds to patient stress • Insufficient hub renal staff resources to undertake regular community visits and review.

Model	Strengths	Weaknesses	Opportunities	Threats
		• Requires significant coordination and support from urban area • Carers find delivering treatment personally burdensome.		
Self-care PD (CAPD or APD)	As per self-care HD.	• Low uptake due to poor perception of treatment option • Can be a personally resource intense treatment for patient and carer • Requires significant coordination and support from urban area • High infection rates and technique failure in the Aboriginal population.		• Lack of community support to assist with stores deliveries, removal of waste etc. adds to patient stress. • Insufficient hub of renal staff resources to undertake regular community visits and review.
Mobile bus – visiting	• Can offer respite dialysis services to a broader area and greater number of communities • Likely to have a psychological benefit for patient and families that is hard to quantify • Does not require capital infrastructure for dialysis in community • Does not require permanent staff accommodation • Can be run completely independently with own power • Can deliver services on short	• Requires experienced renal trained staff due to isolation of service • Requires driver with medium rigid license • Can only deliver services for limited time if unplanned • Patients will require support to make their own way to and from community • Requires staff willing to 'rough it' (cramped quarters or tent) if community accommodation unavailable • Inability to store spare dialysis equipment for back up.	• Staff have opportunities to be involved in other community and social support activities • Staff have time to provide community education • Bus can be used for other educational or health service activities.	• Difficulty in finding renal trained staff wishing to be part of rotating team • Some communities will be seasonally inaccessible • Vehicle breakdown can halt service.

Model	Strengths	Weaknesses	Opportunities	Threats
	notice.	• Does not decrease requirements for patient accommodation and social supports in urban area • Requires access to potable water • Truck size and set up requirements can be daunting for uninitiated • High R&M due to environment.		
Mobile bus – dedicated	As per community-based supported HD, plus: • Does not require capital infrastructure for dialysis in community • Establishes service quickly in a community • Can provide service to two communities with same infrastructure • Dedicated service incurs less wear and tear • Rotating staff can bring stores and supplies to vehicle • Consumables and spare dialysis equipment can be stored in one community (base) rather than both Base community is closer than hub service.	• Requires driver with medium rigid license • Requires experienced renal trained staff due to isolation of service • Requires accommodation in one or both communities for staff • Requires site where access to potable water and power is available • Truck size and set up requirements can be daunting for uninitiated.	• Staff have opportunities to be involved in other community and social support activities • Staff have time to provide community education.	As above

Alternate models possible in the NT				
Supervised self-care HD	As above, plus: • Enables people to be treated in their own home • Requires no infrastructure • Known to have improved clinical outcomes for patients • Less expensive dialysis model • Roaming staff can assist with coordination of services and provide support.	• Only small percentage of dialysis population will be able to attain independence • Takes much longer to train most Aboriginal people to safe and confident level due to language barriers and unfamiliarity with technology • Patient numbers limited by distance between residences.	• Provides opportunities for people who may be reluctant to dialyse by themselves or unable to self-needle to have treatment at home • Roaming nurse does not need to be registered nurse (RN).	• Patient may become dependent on visits and monopolise roaming nurses' time, limiting ability to see other patients • May increase the requests for assistance, reducing their ability to dialyse independently.
Supported APD	• Support officer does not require health qualifications • Training is quick – few days to weeks • Reduces demand for satellite dialysis positions • Reduces likelihood of repeat infection • Provides freedom for patients during the day • No special electrical or plumbing requirements required.	• Restricted to room for 10-12 hours each evening • Need reliable power • Need volume of patients to be financially viable • Need patients to live in close proximity to each other to be practical.	• Gain confidence through observation and ultimately self- manage procedure • Patients able to support each other when in same environment • Support officer position hours are ideal for people with families or day jobs.	• Patients may become impatient in morning and disconnect themselves risking contamination • Alarms from lines kinking overnight might result in treatment being halted by patient rather than problem solved and treatment recommenced.

Workforce issues

Main Findings

Workforce issues related to adequate numbers of dialysis nursing staff and nephrologists appear to have improved since 2009. However, the number of Aboriginal people employed in renal services, and availability of allied health staff remain low. In 2014 and compared to 2009:

- The renal workforce in Central Australia (CA) is more stable
- There are more nephrologists working in Alice Springs
- Access to specific Allied Health Services (dietetics and podiatry) has improved
- Access to social support services – particularly relating to the availability of Aboriginal Liaison Officers, interpreters and social workers – has not improved and may be poorer for the majority of patients attending Alice Springs Renal Service (ASRS)
- Registered nurses make up the majority of renal trained staff in the Northern Territory (NT). There are few enrolled nurses and no dialysis professionals.
- The majority of renal nursing staff in Alice Springs and Tennant Creek have been trained overseas. A substantial proportion speak English as a second language.
- There are no renal trained Aboriginal Health Workers (AHWs) in the NT. Possible causes for this include:
    - Indications from the Batchelor Institute of Indigenous Tertiary Education suggest a lack of demand from registered AHWs to learn dialysis treatments.
    - There has been no demand from industry or community for registered AHWs to undertake the available post-graduate units in renal care.
    - Registered AHWs make up only a small percentage of the health workforce in CA and are considered a rare resource.
    - Completion rates for registered AHWs cannot keep up with current demand in the NT.
- Other options to train Aboriginal people to assist with dialysis treatments, such as Dialysis Assistant and Dialysis Technician courses, have been investigated.
- The viability of a Vocational Education and Training (VET) course in dialysis treatments for Aboriginal people is uncertain, given historically low certificate completion rates, unknown course development costs and unclear demand.

Renal workforce

The renal workforce consists of a multidisciplinary team with a broad range of skills and experience. The team of professionals is directly supported by a range of trained and untrained health workers including: patient care assistants, dialysis assistants and technicians. Professionals required in the area of Indigenous health include: Indigenous Liaison Officers, interpreters and cultural brokers.

Staff quotas and configurations of staffing compliments vary widely across Australia and identifying ratios for each profession/discipline is problematic with an absence of current benchmarks. Australia lacks a nationally agreed standard for staff to patient ratios for each discipline involved in renal services. Health services within each jurisdiction generally establish their own benchmarks according to available resources. In contrast, societies for nephrologists, nurses and allied health will undertake surveys and make recommendations based on work patterns, workloads and available international benchmarks (25-27). Workforce benchmarks established by international societies are often used as a guide, although these standards generally underestimate the requirements of a group of people with high levels of comorbidities, poor access to health services due to remoteness and geographic distribution and reduced uptake due to cultural and language barriers.

However, it is generally accepted that ratios should exist for the number of patients receiving renal replacement therapy (RRT) and individual specialists including: nephrologists, nursing staff, dietitians, social worker and pharmacists. Additionally, access to specialist services such as podiatry, physiotherapy, occupational therapists and psychology/counseling, should be readily available for patients with kidney disease (28).

A comparison of benchmarks for the main disciplines found in the literature, are noted below (Table 11). The Queensland benchmarks, while based on the 2002 British National Renal Workforce Planning Group recommendations, made adjustments for cultural and access barriers and the higher levels of comorbidities in Aboriginal patients.

Table 11: Renal workforce staff benchmarks

Source	Nephrologist	Dialysis Staff	Dietitian	Social Worker	Pharmacist
BRSMT	1:75	1:4	1:135	1:140	1:250
SRCN		1:3	1:100	1:70	1:125
CA Renal Study	1:60	1:4	1:150	1:125	1:125

BRSMT: British Renal Society Multidisciplinary Team; SRCN: Statewide Renal Clinical Network;

Nephrologists

Attracting and retaining skilled and qualified staff in the NT is an ongoing issue with geographic location, environment, cost of transport and isolation playing a significant role in the high rates of staff turnover. Specialist staff (nephrologists) in particular have been difficult to attract and retain with a strong perception that there are better opportunities interstate for career advancement, exposure to acute services including transplantation, and greater potential for remuneration through private practice.

In 2009, there was one full-time nephrologist based in Alice Springs, although funding for four full-time equivalents was available. A second nephrologist was employed towards the end of the year, but for extended periods Central Australia (CA) was critically understaffed and unable to fill vacant positions despite national and international recruitment campaigns.

By 2014, this had improved with four full-time nephrologists employed by ASRS.

Allied Health Staff

Alice Springs Hospital (ASH) manages all allied health staff to ASRS. Like many other busy services, available resources are coordinated and mobilised to where the need is perceived as greatest. Due to their physical separation from the main

centres or hubs, satellite services will often have access to specialist staff on an outreach or rotational basis.

ASRS has access to dietetics, social work and pharmacy support from Alice Springs Hospital (ASH). In 2009, an Aboriginal Liaison Officer (ALO) was attached to the satellite dialysis service at Flynn Drive on a full-time basis. However, due to an inability to maintain sufficient levels of ALOs within ASH, access to ALO services are now on a referral basis, with a full-time social worker coordinating requirements for the majority of renal patients.

Two full-time dietitians provided services to all renal patients in the CA region including those with CKD; an increase of one full-time position since 2009.

Additionally, ASRS has entered a collaborative arrangement with Central Australian Aboriginal Congress (CAAC) to deliver regular general practice clinics from the Flynn Drive service. A regular podiatry clinic is also delivered by CAAC, a service that is considered essential due to the high prevalence rate of diabetes amongst Aboriginal kidney patients.

WDNWPT also provides similar services through the Purple House in Flynn Drive. Actual full-time equivalents are unknown but a podiatry clinic, GP clinic, and social support, are also offered to all patients who visit the facility, regardless of where they are receiving dialysis.

Dialysis Trained Staff

The high number of patients choosing haemodialysis as a treatment option in the NT requires a substantial number of dialysis trained staff. The historical shortages in this area have necessitated consideration of workforce options and configurations that do not rely solely on registered nurses and moreover, appropriately address the cultural needs of Aboriginal people who make up over 95% of the patient population in Alice Springs.

Exploration of these options has been undertaken on a number of occasions, over many years and therefore makes up the greater part of this section.

Dialysis staffing across Australia

The majority of care delivered by a renal service occurs in satellite units or facilities and involves provision of dialysis. The delivery of a dialysis treatment is, at a minimum, a competency-based skill that is not taught as part of the basic nursing

and midwifery training program. Renal care is a post-graduate education and training program provided either on-the-job or as a tertiary institution-based qualification. It is a specialised field, and as such, shortfalls in renal staff rosters, due to sick leave or inadequate staff levels, are more difficult to fill from the general nursing staff pool.

In 2009, the Renal Society of Australasia (RSA) surveyed 228 Australian units and 25 New Zealand units to understand and describe the renal nursing workforce in Australia and New Zealand (27). The Report found that in all states and territories except for the NT, staff were older than the general nursing workforce and tended to be employed in a part-time capacity. Most satellite units do not operate a night shift or operate on Sundays. This work roster is attractive to certain staff - mainly older staff or who have growing children and would prefer to work fewer hours in less demanding circumstances. Although the catalyst for the survey was the belief of members that there was a significant skill shortage in renal services, managers who responded to the survey indicated that they were always able to fill shortfalls on the roster. Anecdotally, it appears that the large number of part-time staff maintained by most units assist with the cover of roster shortfalls by undertaking the extra shifts required.

This Report uses the following definitions of renal professional staff.

Registered nurses (RNs) – The Report does not differentiate between the many different roles RNs hold in renal care. These roles can be as autonomous as the nurse practitioner or as broad as the nurse manager. However, it is accepted that the RN referred to in the Report has had some on-the-job training or a post-graduate qualification in renal care. RN post-graduate qualifications are nationally recognised diplomas delivered by tertiary institutions.

Enrolled nurses (ENs) – Level 1 nurses with training or post-graduate qualifications in renal care. The Industry Skills Council has an approved VET package in renal care for ENs.

Dialysis professionals – A dialysis professional (in this Report) is a person with a science rather than health background who has been trained in the dialysis treatment. A nationally accredited training package for this discipline could not be found (although there are USA packages), and it is unclear if training for dialysis professionals still occurs in Australia. Dialysis professionals are often referred to as ‘dialysis technicians’ because of their base qualifications. However, ‘dialysis

equipment technicians', who service, maintain and repair dialysis machines, but do not deliver dialysis treatments, are also referred to as 'dialysis technicians'.

The *RSA Australian and New Zealand Dialysis Workforce Survey 2009* also commented on the professions working within renal services, but not the number of staff with post-graduate qualifications or where they received their training, i.e. within Australia or overseas.

The survey identified that nationally:

- 2,433 RNs, 188 ENs and 295 dialysis professionals were working in the field but made no mention of AHWs.
- The ACT and Tasmania only employed RNs.
- Victoria had the highest percentage of dialysis professionals comprising 9.3% of the workforce.
- South Australia had the greatest heterogeneity within its workforce with 25% made up of both ENs and dialysis professionals.
- The NT was noted as having 1.1% of the renal workforce made up by dialysis professionals. This may have referred to the one or two AHWs who were employed in the service at that time. Similarly, Western Australia has several AHWs working in the Kimberley but this was not discussed or noted as a separate discipline.

Dialysis workforce in NT

In comparison to other states, the NT's renal service was more recently established (13). Dedicated renal services in the NT commenced in the early 1990s. This was followed shortly after by the development of recognised and locally offered renal training programs for nursing staff (12). Consequently, well-established staff training programs and stable staff complements are a comparatively recent development in the NT.

The NT renal trained workforce is fairly homogenous with RNs making up 99% of the workforce and only three ENs. There are no AHWs and no dialysis professionals in the NT renal workforce.

Nationally, while nursing and midwifery have been identified as skill shortage areas, dialysis nursing has not been specifically identified as such. Similarly, the NT does not currently identify dialysis nursing as a skill shortage. Although historical data for

the NT are not available, many staff can recall the numerous strategies to build the dialysis workforce, including overseas recruitment drives, expanding the disciplines endorsed to provide dialysis care and developing locally delivered renal care programs. While the 'grow your own strategy' has been the preferred option, it has taken many years for the renal post-graduate program to become established and deliver results. Currently more than 65% of the RNs employed in renal services have, or are working towards, a post-graduate qualification in renal care.

Additional strategies attempted in the past, with the aim of delivering a more sustainable workforce, have included:

- In 1997, a renal AHW training program was developed and several training courses were delivered in the ensuing years including a course for AHWs from the Kimberley. Ten AHWs from the NT and four AHWs from the Kimberley commenced training - only two from the NT and three from the Kimberley successfully completed the courses.
- At the same time, a training program for ENs was also established. Six ENs completed the course – only one is still in the workforce.
- A concerted recruitment drive for trained dialysis professionals in 1997 was unsuccessful.
- Attempts to identify an established, accredited dialysis professional course in 2007, so that it could be delivered in the NT, were unsuccessful.
- Training patient care assistants as dialysis assistants – several were successfully trained and employed across NT – tend to be used more in regional and remote units.
- Offering short contracts of three months for dialysis trained RNs from an interstate relief dialysis agency. While this strategy was expensive, it did result in a number of staff choosing to return on their own accord for extended employment with NTRS.
- Employment of overseas trained staff on 457 visas.

The constant recruitment, training and replacement of staff on short term contracts has financial implications, but it also has repercussions for staff developing a rapport

with patients, for maintaining consistency of practice, and ultimately, for the quality of care delivered.

In Central Australia (CA), the most effective strategy has been the employment of nurses under the 457 visa option. Many of these nurses are now permanent residents. This strategy has provided a stable and consistent workforce. However, it has also changed the culture of the dialysis environment substantially, with more than 85% of the workforce speaking a language other than English (or Aboriginal dialect) as a first language.

This significant change in the renal workforce has added new dimensions to the well-described cross-cultural communication challenges in providing renal services to Aboriginal patients in the NT, and added complexity to personal interactions between patients and staff.

Aboriginal health workers/practitioners

The lack of AHWs working in renal services in the NT has been raised at every forum on renal services for Aboriginal people for the last 20 years. Registered AHWs, trained and qualified to deliver dialysis treatment, would seem a reasonable and appropriate solution to the cross-cultural and workforce issues faced by renal services in the Territory. Registered AHWs in the NT have a similar scope of practice to RNs, and are able to work unsupervised and administer medications, unlike ENs and dialysis professionals.

Aboriginal workforce availability

Registered AHWs have completed coursework and clinical practice to a Certificate IV level. Although there are three entry level training courses/qualifications for AHWs identified in the Health Training Package (HLT07), only one provides entry as a registered AHW in the NT:

- HLT43907 Certificate IV in Aboriginal and/or Torres Strait Islander Primary Health Care (Practice).

The course takes a minimum of 3.5 years to complete, although most AHWs ‘staircase’ their way through the qualifications and may take considerably longer.

Many students decide to stop at Certificate II or III and work in support areas such as Family Wellbeing or Health Support Services. These positions are generally

known as Aboriginal community workers (ACWs), although in the field, the nomenclature may be less well defined.

The NT Department of Health advised that in the CA region there are 22 registered AHWs working in 13 remote communities, with a further four based in Alice Springs. These numbers do not include AHWs based at the Alice Springs Hospital. There are also 13 ACWs in the remote region. Of 18 remote CA communities with Aboriginal health staff, fewer than eight have more than one employee; only five communities have three or more Aboriginal health staff.

Anyinginyi Health Aboriginal Corporation has advised they have three AHWs.

The Central Australian Aboriginal Congress reported a 45% employment rate of Aboriginal health staff in their five remote and four urban clinics. Less than 20% of all health staff are AHWs.

Overall the CA region does not have a large pool of registered AHWs.

Aboriginal health worker training

The training of AHWs is unable to keep pace with the need in the NT. Data provided from the Batchelor Institute of Indigenous Tertiary Education (BIITE) regarding training and people in training in the CA region identified the following:

- 121 qualifications were awarded between 2008 and 2014. The majority (110) were Cert II or Cert III.
- Of the 29 current enrollments, two-thirds are for Cert II in Family Wellbeing.
- Ten students are enrolled in Certificate IV in Aboriginal and/or Torres Strait Islander Primary Health Care (Practice).

However, the majority of these enrollments are for one or two units in the certificate; students may not necessarily enroll in further units required to complete the certificates. This pattern of non-completion is reflected in the findings from the recent *National Report on Social Equity in VET 2013* (29), and suggests that Aboriginal Australians and people from remote and very remote locations, had lower educational qualifications upon entering VET study, higher rates of non-completion of secondary school, and study at much lower qualification levels. Pass rates for Aboriginal VET students were lower than the national average. Additionally, there is some evidence that Aboriginal Australians from remote areas will take substantially longer to complete a course in VET in the NT.

Factors may include:

- The course format - block studies on campus versus reverse block delivery, e.g. the trainer travels to the community.
- Whether the student made their own decision to study and had chosen the subject or has there been direction from the community or family member. Examples include:
    - A need/skill shortage has been identified and the community have determined who will fill the gap.
    - Sufficient enrolments are required to make a particular course viable for delivery.
- Relevant employment opportunities at the end of training appearing uncertain.
- Current employment status, i.e. whether a student is increasing their skill set or hoping to get employment as a result of the qualification.

These factors are relevant to any proposed new courses or efforts to drive an increase in numbers of Aboriginal Australians in particular fields of study.

The statistics provided by BIITE and the DoH indicate a potential disconnect between training and employment. The *Forrest Review: Creating Parity*[1]*,* noted that Aboriginal Australians accumulate Certificate I and II qualifications that are not valued by employers and rarely translate into jobs (30). Job seekers need to be assured that there is real employment at the end of the pathway and that training is not being promoted for the sake of training.

Aboriginal health worker renal training program

While the NT led the way in AHW renal training, it has not been able to sustain either the training program or the numbers within the workforce. Over a four-year period between 1997 and 2001, the NT enrolled 10 AHWs in a renal training program. Only two people successfully completed the program and were able to take a full patient load and work with minimal supervision. Another AHW continued to work in the service under supervision and with a reduced patient load. The training time for all the AHW was in excess of six months. The training time for RNs

[1] Source: Licensed from the Commonwealth of Australia under a Creative Commons Attribution 3.0 Australia License. The Commonwealth of Australia does not necessarily endorse the content of this publication.

undertaking a similar competency-based program is approximately six weeks. AHW staff were paid at their nominal level during training and were therefore not financially disadvantaged by the length of the training period. The two AHWs who successfully completed the program were non-Territorians with EN qualifications.

There are currently no renal trained AHWs employed in the NT either within NTRS or non-government organisations.

Although there are developed units for renal AHW training (HLTAHW054 and HLTAHW055), these have not been utilised to date. BIITE advise that there has been neither a request from industry nor students to access the units.

The only other jurisdiction to support and employ AHWs in the dialysis setting in Australia is the Kimberley Aboriginal Medical Services Council. They have continued to train and maintain AHW numbers within their dialysis and kidney health programs.

During the NT Renal AHW training program, it became apparent that there were a number of cultural, historical and organisational factors which made training and work very challenging for the AHWs. These same factors and barriers were also identified in the recent (2010) *Final Report Aboriginal Health Worker Profession Review* undertaken for the NT Department of Health and Families (31). The Report, which assessed the AHW profession across all organisations in the NT, reiterated the following points as barriers to successfully training, supporting and employing AHWs in general in the workforce.

- *A relatively low base of clinical knowledge*: the key role of the majority of AHWs from remote communities at that time (of the earlier training program) was brokerage between community members and non-Aboriginal primary health staff. The AHW training program was originally designed to provide AHWs with skills to assist primary health staff to manage non-acute conditions in remote communities and was not designed to provide a high level of clinical assessment and management skills.
- *The length of the training program in the urban area:* largely due to the above, the training time for AHWs was six months or more. This exerted pressure on both the AHW and their families. The extended periods away from the community resulted in additional personal costs to the student in terms of support for urban accommodation, transport and living expenses, return visits to community, and organising carers for children. Not

surprisingly, students took unplanned leave which disrupted the training schedule and extended their training time.

- *Too much sorry business*: renal disease is prevalent amongst the Aboriginal population in the NT and the AHWs in-training experienced constant sorry business and sadness. They found the closeness to a group of people with reduced life expectancy both confronting and distressing.
- *Culture and occupational health and safety*: the following set of circumstances has been coined 'occupational health and safety' by the authors of the aforementioned Report into the AHW profession. They state that these issues led to experiences of 'burnout' and the way AHWs dealt with it was to 'walk away' from their positions, often temporarily or sometimes permanently. ***All of these issues were evident for some if not all of the AHWs in the renal training program.***
    - *Avoidance relationships*: dialysis treatment requires close personal contact. Needling, taking blood pressure measurements and handling another person's blood are activities that cause concern for many AHWs, particularly if the person is in a relationship of avoidance with the AHW. Interactions were particularly difficult for the female AHWs and it was noted that they were more likely to have demands placed on them by dialysing elders or community leaders to adjust clinical parameters or provide treatments outside of the organisation's procedures.
    - *Fear of blame or payback*: being held responsible for adverse patient events was raised by several AHWs. Missed treatments, large fluid shifts, and poor blood pressure control often led to collapse in a dialysis patient. Additionally, renal patients are at high-risk of experiencing a sudden cardiac event leading to death. These events can occur during a dialysis treatment, although they are unlikely to be related to the actions of the carer.
    - *Emotional or community responsibility*: AHWs often have close or extended family members with kidney disease. The obligation, whether it be real or perceived, to take on the responsibility of carer for these patients is often very strong.
    - *Health problems of AHWs themselves* e.g. diabetes, high blood pressure and hearing problems.

- *Living in crowded housing: often* with other family members who are not working and therefore interrupting the sleep of AHWs.
- *Humbug from family and community members*: in the case of AHWs working in their own community, this can be significant and contribute to considerable occupational stress.

The Report stated that these issues were persistent across all organisations and had been noted in previous reviews. The fact that AHW numbers had remained static in the previous 10 years and had not grown at similar rates to other clinical workforces, indicated that the issues were significant and remained unaddressed.

From a service provider perspective, with an expectation that a renal trained AHW will be able to replace a registered nurse in terms of scope of practice and autonomy, the training time might be considered money well spent if longevity in the role could be assured. However, given the OH&S factors noted above and rates of burnout among AHWs in general, a renal AHW role may not be an attractive career path for many AHWs.

In looking to other regions that have been successful with AHW programs, it appears the cultural OH&S issues might be more significant in the NT than in other regions. Discussions with Aboriginal people from the Kimberley and Far North Queensland suggest that payback, avoidance relationships and emotional obligation/labour may not be accorded the same prominence. The two successful renal trained AHWs in the NT were from interstate, already had EN qualifications and, by their own account, did not experience the cultural impediments as intensely as local AHW trainees.

Unregulated workers

Both the Australian Nursing Federation (ANF) and the Australian Nursing and Midwifery Council (ANMC) recognise that there are a growing number of unregulated workers in the Australian Health Care industry and that regulation and credentialing will be difficult to achieve (32).

In their 2008 Report, the ANF made several recommendations about registering these workers so that consistency of standard and practice can be maintained for patient safety. The possibility of service providers training people with minimal

health knowledge in complicated health practices remains an issue for the service responsible for the delivery of care (33).

Dialysis professionals are unregulated workers and are employed in several states in Australia. They do not have a health background and qualifications are usually a Certificate III in Science Technology. Dialysis professionals/technicians have been discussed for several years in the NT as a possible solution to workforce shortages. An accredited course dedicated to the training of technicians has not been identified in Australia and it appears that units provide their own training and credentialing under their health department's registered training organisation (RTO) status. The limitations for most units lie in the responsibility of the supervising unit to determine the scope of practice and whether limitations are placed on areas of patient care, including the administration of medications such as heparin, lignocaine and IV fluids.

Proposal for an Indigenous dialysis professional/technician training package

In 2013, the Northern Territory Renal Services was asked to provide a report and submission to the Australian Government for the development of a dialysis technician (professional) training package, suitable for Aboriginal people from remote communities. The request arose from the Renal Planning meeting held in the East Arnhem region in May 2013. The proposed training is based on a VET qualification (HLT32512 Cert III in Health Services Assistance) and would require 6–12 months of training. Additional requirements include: an RTO authorised and willing to do the training, funding for course development and delivery, preceptors and student placements within facilities where they can practice their skills.

The training program will enable the person to assist with the set up and strip down of the dialysis machine and monitor the dialysis treatment such as taking and recording BP readings. This training program will not allow the dialysis technician (professional) to insert or remove the fistula needles or initiate or conclude the dialysis treatment.

Once successfully completed, it offers a study path towards the HLT33207 Certificate III in Aboriginal and/or Torres Strait Islander Primary Health Care.

Dialysis assistant

A support officer to assist the dialysis nurse with the dialysis treatment is also possible and can be taught on-site. This role, like the dialysis

technician/professional, is also an unregulated health worker and would perform duties related to preparing equipment before and after the dialysis treatment. The main duties would not involve clinical work with the patient such as needling, entering dialysis parameters, removing needles, commencing or concluding treatment. Activities may involve weighing the patient, recording blood pressures and preparing dialysis equipment.

The difference in the role and function of the Indigenous dialysis technician/professional and the dialysis assistant is minimal, but the assistant will not receive a qualification or undergo any formal education. While this strategy provides employment opportunities for local people it does not provide a career pathway. However, it does allow employees to experience some of the role and function of a dialysis carer without a commitment to study. Additionally, it may demystify the work role sufficiently to encourage people to explore education in the area.

An overview of the strengths and weaknesses associated with each category of renal staffing (Table 12) follows.

Table 12: Dialysis workforce options

Discipline	Strength	Weakness
Registered nurse	• Able to provide care autonomously and independently • Can give IV medications and certain other medications without supervision • Has clinical training to provide care to more acute and unstable patients • There is an accredited post-grad course in renal care in NT.	• Shortage of renal trained and experienced RNs in NT • Wages are high compared to other disciplines • National shortage of full-time renal trained staff.
Enrolled nurse	• Can work with remote supervision of RN • Is a cost-effective alternative to an all RN staff complement • Training time is relatively short • There is a nationally accredited VET renal course for ENs.	• There are certain limitations to scope of practice including administration of IV medications • No EN renal training programs have been run for some time in the NT • There is a limited number of renal trained ENs in Australia.
Renal trained AHW	• They are culturally the most appropriate discipline to deliver renal care in NT • Can work autonomously and independently • Can give IV medications and certain other medications without supervision.	• There are currently no renal trained AHWs working in the field in the NT • Only registered AHWs (Cert IV) can do the training • There are a limited number of AHWs working in remote and urban primary health services in CA and drawing from this pool might be counter productive • Training is likely to take up to six months with the majority spent away from their communities • Cultural OH&S may impact on longevity of the workforce.
Dialysis professional	• There are more dialysis professionals then renal trained ENs in Australia • It is a cost-effective alternative to an all RN staff model.	• There is no nationally accredited course • They require Cert III qualifications in a science field • They do not have a health qualification or background • They are considered an

Discipline	Strength	Weakness
		unregulated worker and their scope of practice in the NT would have to be determined • They may not be able to work independently • Does not alleviate need for RN or AHW • Previous recruitment drives in the NT have been unsuccessful.
Cert III health care assistant dialysis	• Provides a culturally appropriate complement to a renal staffing model • Is likely to provide a career pathway in health • Provides employment for local Aboriginal people.	• Cannot provide any of the dialysis treatment • Would need to be more than a two chair facility to appreciate the benefit of their role • Course is yet to be written and RTO deliverer determined • Does not alleviate the need for RN or AHW.
Dialysis assistant	• Provides a culturally appropriate complement to a renal staffing model • Can be taught the role on site • Do not need entry qualifications or formal training • Provides employment for local Aboriginal people.	• Cannot provide any of the dialysis treatment • Would need to be more than a two chair facility to appreciate the benefit of their role • Does not provide a career pathway • Does not alleviate the need for RN or AHW.

Part 2: Projected demand and costs

Part Two: Projected demand and costs

The purpose of this section is to provide an analysis of future costs of renal service provision in the CA region based on future projections of ESKD modeled on alternative scenarios of incidence rates.

This section covers:

- Projections of ESKD prevalence and future demand for renal services in the Central Australian (CA) region.
- Whole-of-service costs associated with providing renal replacement therapy (RRT) including dialysis treatments, transplants, supporting infrastructure and required resources.

Scope and Limitations

The approach used in this analysis follows a previously developed and reported methodology for the analysis of costs and benefits of renal replacement therapy (RRT) in Australia (1, 2). Many of the data limitations identified in this earlier work are also applicable in the current setting, with additional limitations due to challenges in modeling disease incidence and prevalence with relatively small numbers of patients across the CA region. A lack of published, peer-reviewed data regarding the costs and effectiveness of service provision in remote settings for Aboriginal and Torres Strait Islander patients was another notable limitation.

As up-to-date financial data were unavailable for this Report, cost data for provision of dialysis services were based on information provided by the Northern Territory (NT) Department of Health for the 2011 CA Renal Study. This data was reflective of costs expended to deliver dialysis services in CA in 2010. As NT Renal Services, under the Department of Health, have been the main providers of renal services in the CA region, these were considered to be the most relevant costs to be used.

Detailed total-cost-of-service analyses were undertaken for the Report, with cost projections till 2025. Estimates of prevalence of ESKD, were modeled based on incident and prevalent rates from 2000-2013.

Summary of Findings

Demand and Cost Models

Three scenarios for future projected demand were modeled. In each scenario, whole-of-service costs were estimated for the period 2014-2025 (in 2013 dollars). These included the following scenarios:

- A stabilisation scenario of incident cases, with a continuation of current service provision methods.

In this scenario, new patients commencing treatment are approximately equivalent to the attrition rate from death with a prediction of 299 prevalent patients in 2025.

Whole-of-service costs (2014-2025) were estimated at $264 million for continuation of current services assuming a stabilisation of prevalence.

- A growth scenario of incident cases, with a continuation of current service provision methods.

Based on past incidence rates and improvement in survival rates, this scenario modeled a linear growth of prevalent numbers of ESKD patients, predicting 485 patients in 2025.

Whole-of-service costs (2014 to 2025) were estimated at $342 million assuming a linear growth in prevalence.

- A prevention scenario, where prevention efforts achieved a 20% reduction of ESKD from the growth model.

This scenario suggested that incident numbers would increase at a lower rate than in the growth scenario and predicted 406 patients in 2025.

Under such a prevention scenario, the present value of costs of treating all existing and new cases of ESKD (from 2014-2025), treated out to 2025, would be approximately $302 million.

Additional Findings

- The present value cumulative cost of RRT for all current and new cases of ESKD, treated out to 2025, is estimated to be between approximately $264 and $342 million.
- The present value of the cumulative benefits of RRT in life years saved, for

all new cases of ESKD out to 2025, will be between 1,293 and 2,108 by 2025.

- Implementation of a prevention strategy which was able to prevent 20% of incident ESKD cases, would result in significant savings. Under such a scenario, the present value cumulative cost of RRT for all current and new cases of ESKD, treated out to 2025, would be approximately $302 million.
- Community-based, nurse-supported dialysis models are relatively expensive modalities of renal service provision. However, such models potentially represent a method of service delivery which would enable more CA patients to receive treatment closer to home thus better meeting the social and cultural needs of Aboriginal patients within the CA region.
- Evidence currently available regarding the comparative outcomes of the various dialysis models (urban, regional and remote satellite services, nurse-supported and self-care community-based dialysis) does not enable cost-effectiveness analyses to guide decision making regarding these alternative models of service delivery.
- Although there is a wealth of *qualitative* data describing life for Aboriginal kidney patients, there is an absence of the customarily used "quality of life" (QoL) data, particularly utility-based quality of life estimates for calculating quality adjusted life years (QALYs). Evidence suggests that standard tools and/or instruments for systematically assessing quality of life are unlikely to adequately capture aspects of QoL important for Aboriginal Australians and certainly have not yet been validated for use with Aboriginal Australians receiving RRT. Therefore this important component of health economic modeling has not been adequately addressed to date.

Overview of Methodology

Approach to Projection Modelling

Rates of treated ESKD for years 2014-2025 were projected based on three models of incidence in the Aboriginal population in Central Australia (CA):

1. Steady state model, assuming that current annual incident patient numbers are maintained each year to 2025.
2. Growth model, assuming that increases in incidence observed over the

period 2000-2013 are maintained to 2025.

3. Prevention model, where a coordinated disease management program might prevent 20% of incident ESKD cases.

A Markov Model was constructed as the basis for estimating the costs and benefits of renal replacement therapy (RRT) for Indigenous people in the CA region over 2014-2025. This model is based upon the general structure (including assumptions and cohort transition probabilities) of the earlier model utilised in the 2011 CA Renal Study Report. The updated ANZDATA data set of projected patient numbers is estimated from the incident cohort of Indigenous patients, commencing RRT during 2000-2013 in the CA region.

The Model follows multiple cohorts of patients commencing RRT until 2025, along with existing RRT patients. The length of each 'treatment cycle' in the Model is one year. The structure of the Model is shown in detail in Appendices A and B. The Model is stratified by age.

In the absence of good-quality individual randomised control trials or large prospective observational studies conducted in Australia, this Report used the best available Australian data to derive estimates for the model parameters. This required a substantial secondary analysis of data from ANZDATA to derive transition probabilities between health states and RRT modalities.

Approach to Economic Modelling

As noted, much of the service cost data has been based on information provided by Department of Health for the 2011 CA Renal Study. This data was reflective of costs expended to deliver dialysis services in CA in 2010, and as the Department of Health continues to be the main providers of renal services in the CA region, these were considered to be the relevant costs to be utilised.

These values have been indexed to 2013 dollars as more up-to-date financial data was unavailable for this Report. Again, we believe these values are the most robust estimates available for the cost of providing dialysis services in the CA region, given the likely variances in the resource requirements for the delivery of dialysis services between differing geographic locations – State/Territory, urban and remote.

These data sets included:

- staff costs (including nursing and allied health staff, medical)
- direct costs associated with dialysis (including pharmacy, fluids and

consumables)

- overheads
- administration and communications.

Where possible, other costs have been based upon the best available published data. These included:

- Australian Government guidelines for the application of economic evaluation to funding submissions to the Pharmaceutical Benefits Advisory Committee (PBAC) and the Medical Services Advisory Committee (MSAC).
- The most recent (National Hospital Cost Data Collection (NHCDC) Round 16: 2011-12) Australian Refined Diagnosis Related Groups (AR-DRG) cost-weights have been used for relevant diagnosis related groups-based costs. These have been indexed to 2013 dollars using the Australian Institute of Health and Welfare (AIHW) health price indexes specific for government expenditure on hospital services.

The methods used in costings for this Report have been extensively peer-reviewed for a series of government and non-government (NGO) reports, have been published in scientific literature (3, 4) and form the basis of statewide Renal Service Plans for Queensland and Tasmania (5).

Other Costs and Considerations

Some cost considerations, which are critically important in the understanding of the economic impact of RRT on service providers and the individual, were not included in this report due to a lack of available and applicable evidence.

- *Out-of-pocket costs to patients and families*. There is a paucity of data regarding the level of out of pocket costs experienced by RRT patients in Australia, and there is no data that is applicable to this setting.
- *Provision of respite dialysis*. The 2011 CA Renal Study included cost data for provision of respite dialysis services based on information provided by NT Department of Health (NT Renal Services), Western Desert Nganampa Walytja Palyantjaku Tjutaku (WDNWPT) and the NT Department of Construction and Infrastructure. However, respite dialysis was not included in the modeling of the costs over 2014-2025 for the following reasons:
    - Provision of respite dialysis has little overall impact on the need for

ongoing maintenance dialysis provision.

  - The data upon which the respite costings were estimated is not published or peer-reviewed.
  - A formal cost-effectiveness evaluation of models of respite care has not been undertaken.

- *Other inpatient resource use*. Health expenditure not directly related to the provision of dialysis and transplant services, has not been included as there is no data available to inform this aspect of resource use.
- *A cost comparison of public/private service delivery models versus public service delivery models*. The NGO sector in CA has provided both respite and ongoing maintenance dialysis services in the region. The funding arrangement may vary and involve a scenario where the government partners with industry to amortise capital costs over the period of a contract (as has been the case for the Gap Rd satellite facility), or fund the costs of providing treatments and/or nursing staff (as has occurred with the WDNWPT Purple House). This form of partnership has benefits in terms of risk management for a number of financial areas including limiting potential capital over-expenditure and determining recurrent costs (in the form of a price per treatment - PPT). Evidence would suggest such partnerships offer an alternative strategy to limit the growth in expenditure on RRT; a formal cost comparison was beyond the scope of this Report.
- *Staff accommodation*. The role of accommodation in the recruitment and retention of staff is an important factor in establishing sustainable services, and thus is a resource requirement for renal service delivery, particularly in remote areas. Service providers have explored innovative remuneration packages that include the provision of accommodation from new or existing housing stock. These costs are difficult to predict, and as such, they have not been included in the projection modeling. However, capital costs have been included in the establishment costs for staffed remote community-based facilities.
- *Quality of Life impacts*. Explicit considerations of the quality of life impacts of different dialysis modalities for Indigenous kidney patients has not been considered in this Report as no estimates are available. The quality adjusted life years (QALY) calculations are based upon the utility values used in the 2011 CA modeling report.

Future Work

The identified evidence gaps noted above are not restricted to the CA region. The absence of rigorously evaluated data to inform policy and assist with effective strategy development is an ongoing issue for service providers and funders across jurisdictions, both nationally and internationally. A recently funded National Health and Medical Research Council Partnership grant, to be led by the Menzies School of Health Research, aims to address many of these evidence gaps. The partnership will evaluate the cost-effectiveness of each dialysis model of care when costs beyond the delivery of dialysis services alone are considered. The scope of the project will include quantitative as well as qualitative components including an exploration of quality of life aspects important to Aboriginal people.

Whole of Service Costs

As an approximation of whole of service costs, the following costs were considered in the modeling

- Transplantation.
- Current modalities of dialysis treatment – in-centre haemodialysis (HD), satellite HD, self-care HD and peritoneal dialysis (PD) - at current rates of use.
- Nurse-supported, community-based HD or 'mini-satellite' service provision - at current rates of use.
- Capital costs, as relevant to conditions in the Central Australia region, associated with different modalities of service provision.

As noted previously, other costs that would conceivably be considered appropriate for inclusion in an economic model such as loss of productivity, out of pocket costs and quality of life impacts have not been included in this analysis.

Transplant

The rate of transplantation among patients in the CA region is low (6). The reasons for this, and the difficulties in increasing transplantation numbers, are complex and beyond this Report. Nevertheless, for completeness of whole of service cost, the unit cost of transplant has been considered.

The annual cost of transplant includes surgery and hospitalisation, immunosuppressive therapy, specialist review and consultations and other drugs, as well as donor costs for a transplant.

For transplant patients living in the CA region, surgery, initial hospitalisation and the immediate and intensive post-transplantation monitoring occurs in Adelaide. Accordingly, we have used costings from the relevant public hospital AR-DRG costs from the NHCDC (Round 16, 2011-12). This figure is presented in 2013 dollars[2]. As there is no specific AR-DRG code for donor-associated costs of kidney transplantation, an assumption was made based upon expert opinion to base the cost incurred for a living kidney donor on the cost weight for a kidney procedure[3].

[2] Updated to reflect 2013 PBS and MBS costs and the indexed values of the NHCDC Round 16 AR-DRG costs (AIHW health price indexes specific for government expenditure on hospital services).
[3] Australian NHCDC Round 16 public sector cost weights for AR- DRG codes L04A and L04C for kidney procedures (with costs indexed to $2103 using AIHW health Price Indexes)

No ongoing costs have been included for living donors. The cost of organ procurement from a deceased donor was unavailable from published sources, and has been estimated at $3,000 based on expert opinion. This is likely to be an under-estimate and does not include costs associated with the coordination of organ procurement and allocation. As with dialysis, there is little available data on renal and non-renal inpatient resource use in patients with a functioning transplant. As such these costs have not been estimated. The unit costs of transplantation per patient per annum, by treatment modality, are summarised in Table 13.

It should be noted that some evidence suggests that the ongoing costs of transplantation amongst Aboriginal recipients in the NT in the second, and subsequent years following transplantation, are significantly higher than amongst non-Aboriginal NT recipients (7, 8).

However, with the very low transplant rate and low prevalence of patients with a functioning transplant in the CA region, modeling of the costs of renal service provision in the CA region is driven more by the costs of dialysis provision.

Table 13: Unit cost kidney transplant per patient per year (AUD 2013)

Resource Item	Live Donor Recipient Unit Cost	Live Donor Donor Unit Cost	Deceased Donor Recipient Unit Cost	Deceased Donor Donor Unit Cost
Year 1				
Surgery and hospitalisation	$42,096	$20,527	$42,096	$3,000
Regular Immunosuppressive therapy (PBS)	$17,117		$17,117	
Additional immunosuppression (induction and acute rejection)	$7,648		$7,648	
Other drugs	$9,053		$9,053	
Non-drug follow-up costs	$6,540		$6,540	
TOTAL YEAR 1 COST	**$82,456**	**$20,527**	**$82,456**	**$3,000**
Year 2 onwards				
Regular Immunosuppressive therapy (PBS)	$8,032		$8,032	
Other drugs	$761		$761	
Non-drug follow-up costs	$860		$860	
TOTAL YEAR 2 ONWARDS COST	**$9,653**		**$9,653**	

Dialysis

The Department of Health provides the vast bulk of ongoing RRT in the region. There are no private dialysis services in Central Australia or the Northern Territory. The Gap Rd satellite unit has been developed as a public/private partnership, where an industry provider (NephroCare Australia) has been contracted to provide capital, equipment and staffing according to an agreed price-per-treatment (PPT) contract. The public sector remains responsible for the medical management of patients.

The unit costs of dialysis per patient per annum by treatment modality, is presented in Table 14. Costs associated with modality initiation, such as access costs and training costs, have been costed separately and are also included in Table 14. In addition, newer pharmacological agents, which are now PBS subsidised exclusively for use in dialysis patients – cinacalcet, sevelamer and lanthanum – have been costed separately. These additional drug costs are somewhat uncertain, as cinacalcet will be removed from the PBS in August 2015, and the number of dialysis patients continuing cinacalcet under a range of industry schemes or using private prescriptions is not known. However, of the total additional PBS drug costs, cinacalcet currently comprises $1,185 of the $10,035 average cost per patient per year. EPO costs have also been included.

Table 14: Annual cost of each dialysis modality per patient (2011 CA Renal Study, 2013 dollars)

	In-centre		Satellite		Community / home self-care HD		Self-care PD		Community based nurse supported HD	
Estimated health system expenditure/pt/yr (AUD 2013)	**$112,183**		**$81,699**		**$58,083**		**$70,161**		**$100,262**	
Components of costs	%	$(AU 2013)	%	$(AU 2013)	%	$(AU 2013)	%	$(AU 2013)	%	$(AU 2013)
Direct dialysis service provision										
Treatments	15.2%	$17,052	20.2%	$16,503	38.8%	$22,536	56.7%	$39,781	22.6%	$22,659
PD/APD consumables										
Medical/operational sundries	1.4%	$1,571	1.8%	$1,471	3.3%	$1,917	1.4%	$982	2.2%	$2,206
Dialysis consumables	1.2%	$1,346	1.6%	$1,307	2.3%	$1,336	0.0%	$0	1.3%	$1,303
Pharmaceuticals	1.7%	$1,907	2.3%	$1,879	3.2%	$1,859	0.2%	$140	1.7%	$1,704
Scripts/packs	0.2%	$224	0.7%	$572	0.9%	$523	0.1%	$70	0.9%	$902
Linen/catering	0.9%	$1,010	1.2%	$980	-	not avail	-	not avail	1.3%	$1,303
Staff costs										
Nursing	34.4%	$38,591	36.4%	$29,738	27.4%	$15,915	22.2%	$15,576	38.6%	$38,701
Staff training and development	1.7%	$1,907	4.4%	$3,595	1.2%	$697	0.9%	$631	1.1%	$1,103
Allied health	10.9%	$12,228	4.2%	$3,431	0.9%	$523	1.4%	$982	1.4%	$1,404

	In-centre		Satellite		Community / home self-care HD		Self-care PD		Community based nurse supported HD	
Medical	24.6%	27597	3.2%	$2,614	4.5%	$2,614	6.8%	$4,771	1.7%	$1,704
PCA, ward clerk and other admin staff	5.8%	$6,507	8.8%	$7,190	2.4%	$1,394	3.8%	$2,666	8.5%	$8,522
Community support / community visits					7.2%	$4,182	0.8%	$561		
Other costs										
Communication	1.0%	$1,122	2.2%	$1,797	2.1%	$1,220	0.8%	$561	1.0%	$1,003
Patient accommodation	-	not avail			-	not avail	-	not avail	0.0%	$0
Transport	-	not avail	8.4%	$6,863	-	not avail	-	not avail	11.7%	$11,731
Overheads	0.9%	$1,010	4.2%	$3,431	0.9%	$523	4.9%	$3,438	2.3%	$2,306
Other costs: R&M, leasing, water checking, freight	0.1%	$112	0.4%	$327	3.5%	$2,033	-	not avail	0.4%	$401
Other ongoing costs (community based HD)										
incl admin, site visits, nurse accommodation	-	-	-	-	1.4%	$813	-	-	3.3%	$3,309
Total	**100.0 %**	**$112,183**	**100.0%**	**$81,699**	**100.0%**	**$58,083**	**100.0%**	**$70,161**	**100.0%**	**$100,262**
Price per treatment (assuming 3 treatments per week for HD and price per day for PD*)		**$719**		**$524**		**$372**		**$192***		**$643**
Other drugs (cinacalcet, sevelamer,		$10,035		$10,035		$10,035		$10,035		$10,035

	In-centre		Satellite		Community / home self-care HD		Self-care PD		Community based nurse supported HD	
lanthanum + EPO)										
Transplant work up costs for those on waiting list (2%)		$19		$19		$19		$19		$19
Total annual costs per patient (all ongoing costs)		**$122,237**		**$91,753**		**$68,137**		**$80,216**		**$110,316**
One-off costs - Access costs		$11,013		$11,013		$11,013		$9,925		$11,013
One-off costs - Additional costs for Home HD patient training (initiation year only)						$5,419				

** Price per day for PD.*

PD: Peritoneal Dialysis
APD: Automated Peritoneal Dialysis
PCA: Patient Care Assistant
R&M: Repairs and maintenance

Capital Costs

Capital costs, as relevant to conditions in the Central Australia (CA) region, associated with different modalities of service provision, have been estimated. Estimates of the capital costs for new satellite units, mini-satellites in communities, renal ready rooms and relocatables were based on information provided by the NT Department of Health, NT Department of Construction and Infrastructure and WDNWPT. These costs, provided in 2010 for the 2011 CA Renal Study, have been updated to 2013 dollars. While inclusions of the capital requirements are based on published national guidelines, these provide realistic costs, specific to the conditions in CA.

Capital costs are indications of the costs for each example of the necessary 'bricks and mortar'. Multiples of the capital costs depend on the nature of an implementation strategy and of the preferred service model.

Based on disease projections, the 2011 CA Renal Study suggested that three 15-station satellite facilities would be required over a 10 year period to meet service need. Since 2010, there has been a physical expansion in current sites of up to 20 stations, enabling an additional 80 patients to be treated dependent on available recurrent funding. The cost for establishment of a satellite facility is estimated as being $3.39 million (at 2013 dollars) (Table 15). Each satellite established will then be a multiple of this base cost.

Supporting Infrastructure

Comprehensive protocols exist, and are used, in the Northern Territory and Western Australia which set out the requirements for the establishment of dialysis facilities in remote communities. These clearly address issues of minimum standards with regard to water quality, electricity supply, location and design. Dialysis services have been established in several remote and very remote communities where the levels of support services and existing infrastructure have varied. The evidence indicates that key infrastructure requirements for dialysis services can be provided if funding is available. The additional resource requirements for these services have been included in the costings in Table 15.

Respite Dialysis

Respite dialysis services, enabling temporary return to country, are provided by WDNWPT in the CA region. However, short-term treatment in communities, which may be for periods of several weeks, does not negate the requirement for ongoing maintenance dialysis, predominantly in a satellite centre, throughout the rest of the year.

Current capacity supports respite dialysis for a number of patients in Alice Springs (Purple House), Kintore, Ntaria and Yuendumu, using the nurse-supported in-community model. Additional services have also commenced at Warburton, Kiwirrkurra and Lajamanu with further services planned for Santa Teresa.

The NT Department of Health and WDNWPT commenced mobile dialysis services in 2011. Both organisations have noted the high 'down time' of the services due to repairs, maintenance and weather conditions. The NT Department of Health provided a comprehensive report of the mobile dialysis service's first 12 months to the Australian Government - *Final Report of the Mobile Dialysis Service 2011* (9). The Report noted the high cost of delivering the service to remote communities (estimated at over $4,600 per person per trip) but suggested that much of the costs would be offset by the significant reduction in emergency evacuations and hospitalisations for patients who had utilised the facility. The Report proposed that costs were likely to reduce in the second and subsequent years.

WDNWPT has not undertaken a formal cost-effectiveness evaluation of their service and there is no published, peer-reviewed data regarding the costs or cost-effectiveness of respite dialysis provision using either model.

Other Costs

Productivity changes have not been included in this analysis. There are no reliable Australian data that can be used to estimate the opportunity cost of lost productivity due to ESKD, therefore the present analysis has not included productivity changes. In addition, there is a paucity of data on out-of-pocket costs incurred by patients and thus, these costs have also not been included.

Quality of life (QoL) and quality adjusted life years (QALYs) were not incorporated into the funding model. QoL is a significant factor in assessing outcomes of treatments from the patient's perspective and QALYs can be measured using a

preference-based measurement of disease management and treatment impacts. This economic index of outcome combines patient survival with an adjustment for QoL. QALYs can be factored into the cost-effectiveness analyses of renal services by assessing how one treatment modality may offer greater independence or better physical, social and emotional well-being over another treatment. There are no Australian data on utility (QoL) scores for patients in dialysis and post-transplant health states.

Moreover, the availability of culturally appropriate and validated quality of life tools, designed specifically for Aboriginal Australians receiving RRT, are not available. Notwithstanding that QoL was an area that was specifically omitted from this Report, comment should be made on the difficulties of attaining reliable QoL data in this population. For instance, current QoL assessment tools, with a focus on mobility, physical functioning, pain and anxiety, may have little relevance to Aboriginal Australians who have expressed the importance of connections to family, community and land over physical health (10, 11). This important area is the subject of future work led by Menzies.

However, health utility scores, derived from published international sources, were used in modeling for this Report (12). They would be standard practice for economic evaluation when directly measured utilities are not available. Given the dearth of data of Health State utilities in Aboriginal Australians, it is unclear how applicable these values might be in the Central Australian context, and therefore the reporting of benefits of treatment in terms of QoL should be considered indicative only. These Health State utilities are presented in Table 23 under ‘Cost and Health Outcomes of Treatment’.

Table 15: Capital costs ($2013 based on indexing of $2009/10) using AIHW Health Price Index (state, territory, local government gross fixed capital formation)

Facility type	Total Cost (indexed to $2013)	Calculated annual equivalent cost (AEC)	Working/assumptions (Working life based on NT Government depreciation schedules and advice, 5% discount rate)
New 15 machine satellite unit in Alice Springs			
Bricks and mortar facility dialysis equipment, water tanks, generator, fit out	$3,389,157	=($3,389,157 - 0)/18.2559 $185,647 per year	600m^2 – based on 15 stations at 9m^2 per dialysis station plus floor space for storeroom, meeting rooms, nurses' station, administration, toilets, laundry etc. and existing specifications of Gap Rd Satellite facility $5,000/m^2 ($ 2007) = $5,580/m2 in $ 2009 (AIHW deflators for state, territory, local govt gross fixed capital formation) Assume a working life of 50 years, no resale: annuity factor = 18.2559. NB: as fixed price for all factors cannot apply differential annuity factors to various components.
Mini Satellite in a remote community (4 machines)			
Facility (bricks and mortar) including dialysis equip	$506,073	$27,722	Working life = 50 years: annuity factor = 18.2559, no resale
Tank	$30,364	$4,698	Working life = 8 years: annuity factor = 6.4632, no resale
Generator	$30,364	$4,698	Working life = 8 years: annuity factor = 6.4632, no resale
Washing machines	$5,061	$783	Working life = 8 years: annuity factor = 6.4632, no resale
Incinerators	$7,591	$1,175	Working life = 8 years: annuity factor = 6.4632, no resale
Staff accommodation (2bdr house)	$545,547	$29,883	Based on Lajamanu quote Working life = 50 years: annuity factor = 18.2559, no resale
Total Cost	**$1,125,000**	**$68,958 per year**	
Renal Ready Rooms			
Facility refurbishment	$26,073	=($26073-0)/7.7217 = $3,376	Working life = 10 years: annuity factor = 7.7217, no resale
Dialysis equipment	$36,364	$6,284	Working life = 7 years: annuity factor = 5.7864, no resale

Facility type	Total Cost (indexed to $2013)	Calculated annual equivalent cost (AEC)	Working/assumptions (Working life based on NT Government depreciation schedules and advice, 5% discount rate)
Tank	$30,364	$4,698	Working life = 8 years: annuity factor = 6.4632, no resale
Generator	$30,364	$4,698	Working life = 8 years: annuity factor = 6.4632, no resale
Washing machines	$5,061	$783	Working life = 8 years: annuity factor = 6.4632, no resale
Incinerators	$7,591	$1,175	Working life = 8 years: annuity factor = 6.4632, no resale
Staff accommodation (2bdr house)	$545,547	$29,883	Based on Lajamanu quote Working life = 50 years: annuity factor = 18.2559, no resale
Total Cost	**$681,364**	**$50,897**	
Modular/relocatable facility (Donga)			
Facility including dialysis equipment	$445,344	$31,598	Lajamanu quote Working life = 25years: annuity factor = 14.0939, no resale
Tank	$30,364	$4,698	Working life = 8 years: annuity factor = 6.4632, no resale
Generator	$30,364	$4,698	Working life = 8 years: annuity factor = 6.4632, no resale
Incinerator	$7,591	$1,175	Working life = 8 years: annuity factor = 6.4632, no resale
Total cost	**$513,663**	**$37,969**	
Mobile Service			
Dialysis module for truck	**$354,251**	**$49,840**	Working life = 9 years: annuity factor = 7.1078, no resale

Projected Future Service Demand

Potential Impact of Strategies to Change Service Need

Economic modeling of renal replacement therapies has revealed the lower costs associated with self-care therapies such as home haemodialysis, peritoneal dialysis and transplantation over satellite dialysis (3, 13, 14).

Additionally, a focus on prevention strategies with increased uptake of screening and monitoring guidelines and adherence to protocol driven care has also proven to be effective in delaying progression to ESKD and the requirement for dialysis (4, 15-17).

Thus modeling of future demand invariably considers the cost and benefits of strategies that reduce the requirement for staffed dialysis services.

The 2011 CA Renal Study incorporated cost projections based on an increase in self-care therapies to 10% by 2015 and 15% by 2020, as well as a preventative growth model that factored in a 20% reduction in the projected incident rates from 2011 onwards.

In the last 10 years concerted efforts have been made in the Northern Territory in both these areas, with particular emphasis on increasing the number of people choosing self-care dialysis. While there have been small increases in patients undertaking home haemodialysis, and the number of transplant patients, these are not proportional to the increase in prevalent numbers of people requiring renal replacement therapy (RRT) (6).

The uptake of self-care therapies, particularly in Central Australia, has remained consistently low despite the considerable levels of funding and onsite support. The combined number of patients undertaking a self-care therapy, and patients with a functioning transplant, remains below 10%. By far the greater majority of people requiring RRT in CA receive dialysis in a satellite facility.

The projection of future costs based on a strategy of increased uptake of self-care therapies may not be a useful demand or cost modeling strategy or a realistic expectation in the CA context.

On the other hand, the uptake of prevention strategies with improved monitoring and management of chronic conditions may have more impact on RRT service demand and economic requirements. The 2011 CA Renal Study proposed a projection model that incorporated a 20% discount on the projected incident rates as a result of improved primary and secondary care interventions and management. This model has proven to be

the closest to actual prevalence rates as outlined in the preceding *Renal disease and services section.*

Continuation of Current Service Provision Methods

Calculation Methods

We have calculated the present value of costs and benefits of treating all existing and new cases of ESKD (from 2014-2025), assuming continuation of current modality usage and current service provision methods. Details regarding the projection and costing methodology are provided in the Appendices.

As discussed, rates of treated ESKD for years 2014-2025 were projected based on three models of incidence in the Aboriginal population in Central Australia:

- *The Steady State Model*, with a stabilisation of the yearly number of incident patients.
- *The Growth Model*, with a steady long-term increase in incident patients, consistent with growth seen since 2000.
- *The Prevention Model*, where a coordinated program might prevent 20% of incident ESKD cases.

The projected numbers for each scenario are represented in Figure 22. The number of new patients projected to commence treatment each year for each scenario to 2025, are based on historical activity of new patients commencing treatment between 2000 and 2013.

Figure 22: Projected incident patient numbers for Steady, Growth and Prevention Models

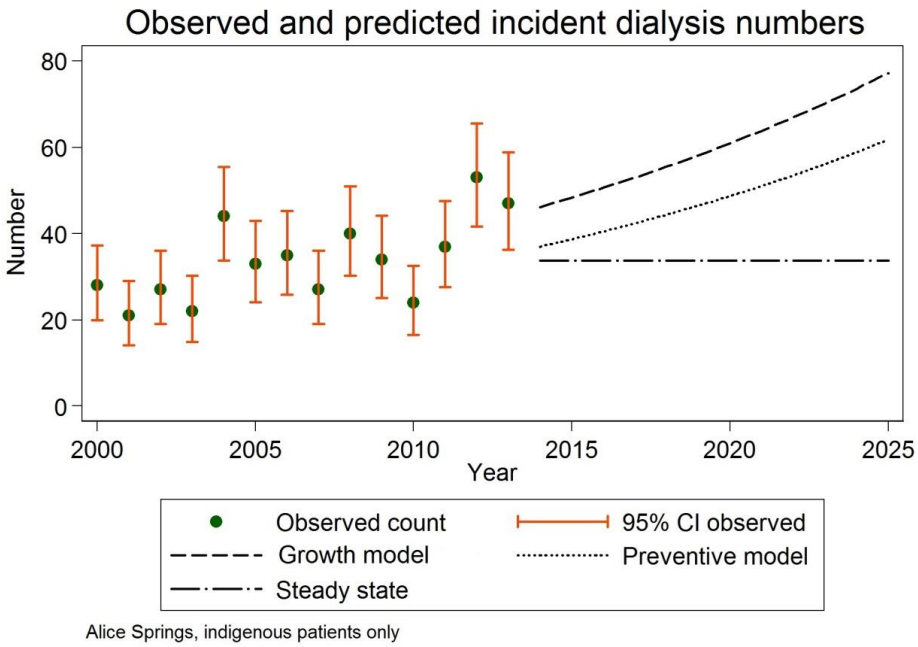
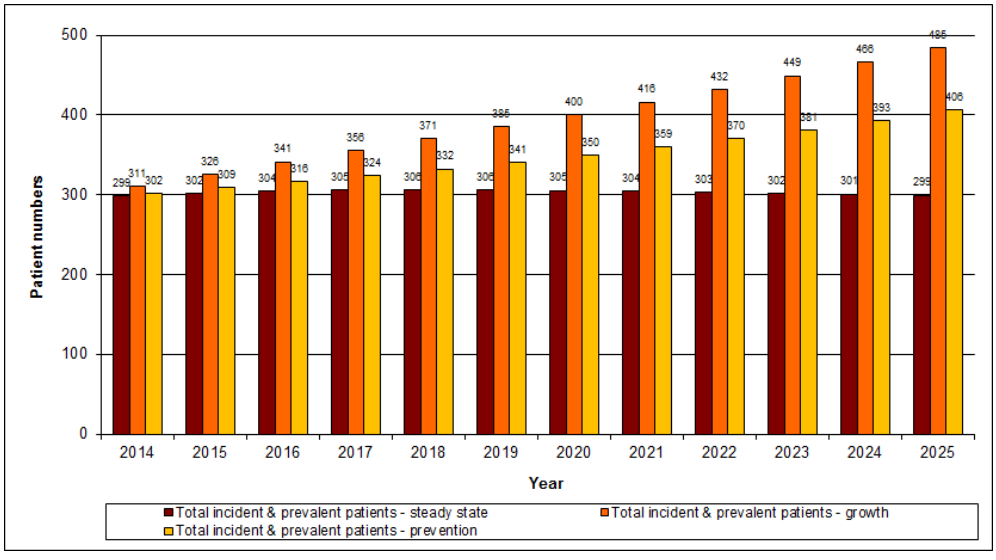


Figure 23 presents the trends for all three modeled scenarios (Steady State, Growth and Prevention) for total prevalent patient numbers.

Under the Prevention model, which has demonstrated the closest alignment to the actual increases in prevalent patient numbers in CA since 2009, it is estimated that an additional 121 patients will require RRT by 2025.

Figure 23: Total estimated patient numbers out to 2025



Tables 16-18 illustrate both the projected incident and prevalent numbers according to each modeled scenario (Steady state, Growth and Prevention models).

Table 16: Total incident and prevalent patient numbers for Steady State

Year	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Total incident patients each year	33.14	33.14	33.14	33.14	33.14	33.14	33.14	33.14	33.14	33.14	33.14	33.14
Total patient numbers	298.9	302.0	304.2	305.4	305.9	305.8	305.3	304.4	303.3	302.0	300.6	299.2

Table 17: Total incident and prevalent patient numbers for Growth Scenario

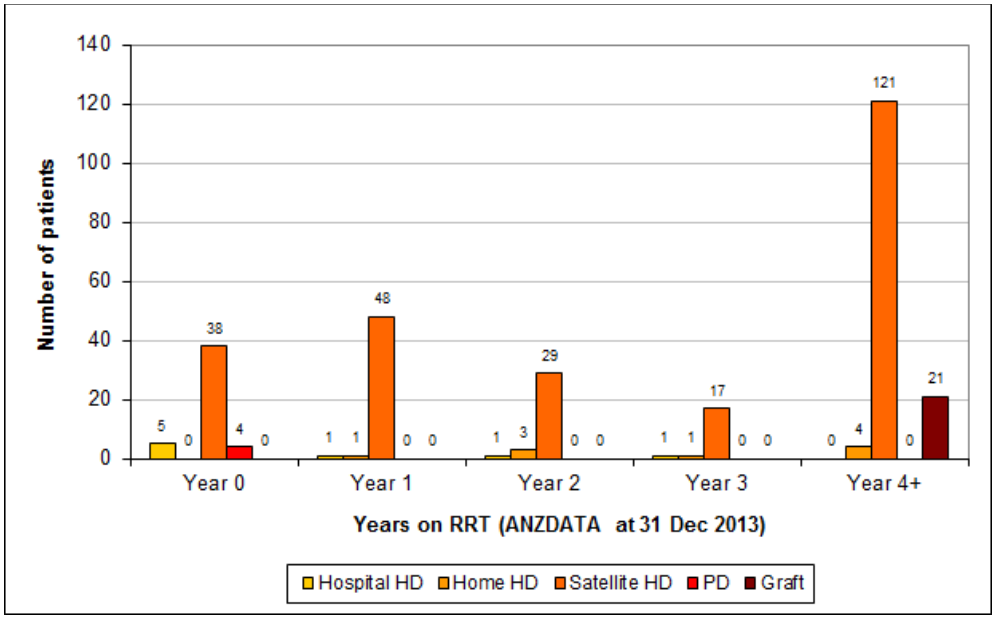
Year	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Total incident patients each year	44.95	46.94	49.02	51.19	53.47	55.86	58.36	60.98	63.72	66.60	69.62	72.63
Total patient numbers	310.5	326.0	341.1	355.9	370.5	385.3	400.4	415.9	432.0	448.8	466.3	484.6

Table 18: Total incident and prevalent patient numbers for Prevention model

Year	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Total incident patients each year	35.96	37.55	39.21	40.95	42.78	44.69	46.69	48.78	50.98	53.28	55.69	58.10
Total patient numbers	301.7	308.9	316.4	324.1	332.1	340.6	349.6	359.3	369.8	381.0	393.0	405.9

Figure 24 shows current (31 December 2013) NT patterns of RRT modality usage by number of years on RRT, as recorded by ANZDATA. The patterns confirm the low up-take of home therapies and the relatively minimal transitioning between modalities. The patterns form the basis of the transition probabilities.

Figure 24: Pattern of modality usage by years on RRT in existing NT patients (December 2013)



Source: ANZDATA

For the purposes of the cost modeling, prevalent patient numbers were allocated across the different modalities according to historical uptake and transition probabilities. The methodology utilised is described in greater detail in Appendices A and B.

The proportion of RRT in Central Australia per modality are identified in Table 19.

No transplants had been received amongst the cohort commencing RRT from 2009-2013. Amongst all prevalent patients treated for four or more years, 14% have a functioning transplant. Amongst all prevalent patients in CA, 13 of the 285 (4.6%) Indigenous patients have a functioning transplant, compared to 8 of the 10 (80%) non-Indigenous patients.

Table 19: Proportion of RRT patients receiving each treatment modality in each year

Modality	All Current Patients				
	0	1	2	3	4+
APD/CAPD	0.09	0.00	0.00	0.00	0.00
Hospital HD	0.11	0.02	0.03	0.05	0.00
Satellite HD	0.81	0.96	0.88	0.89	0.83
Home HD	0.00	0.02	0.09	0.05	0.03
Graft	0.00	0.00	0.00	0.00	0.14

As illustrated in Table 19, approximately 8% of patients categorised in ANZDATA as receiving Satellite HD treatment receive the model of care referred to as “Community based nurse supported HD” this has been incorporated into projections of cost estimates (6).

Cost and Health Outcomes of Treatment to 2025

Cost of Treatment

The unit costs of dialysis per patient per annum, by treatment modality, have been summarised previously in Table 15. These costs have been utilised in determining the future costs of service delivery in Central Australia.

Annual Costs of Treating Projected Cases of ESKD out to 2025

Annual costs are provided for each projected scenario in Tables 20-22 using both discounted and undiscounted rates. Present value of all future costs are discounted at 5% - which is standard discounting for the application of economic evaluation to funding submissions to the Pharmaceutical Benefits Advisory Committee (PBAC).

The present value annual cost of RRT of both new and prevalent patients is estimated to remain at around $27-29 million over 2014-2025 in 2013 dollars.

As of 31 December 2025, this would represent an annual cost of RRT service provision of between $28-$47 million in 2025 dollars.

Annual and Cumulative Costs – Discounted and Undiscounted

Table 20: Total projected annual costs of treating all RRT patients for 2014-2025 ($ millions; Steady State)

Year	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Total patient numbers at year end - prevalent cohort	266.33	240.64	217.61	196.93	178.34	161.63	146.58	133.03	120.80	109.78	99.82	90.82
Total cost prevalent cohort	$23.62	$20.29	$17.43	$14.98	$12.89	$11.09	$9.55	$8.22	$7.08	$6.11	$5.26	$4.54
Total incident patients each year	33.14	33.14	33.14	33.14	33.14	33.14	33.14	33.14	33.14	33.14	33.14	33.14
Total incident patients (new & continuing at year end)	32.60	61.42	86.63	108.53	127.60	144.23	158.75	171.45	182.57	192.31	200.87	208.38
Total costs incident cohort	$3.82	$6.43	$8.38	$9.77	$10.74	$11.41	$11.86	$12.11	$12.21	$12.20	$12.09	$11.91
Total patient numbers	298.93	302.06	304.23	305.46	305.95	305.86	305.34	304.48	303.37	302.09	300.68	299.20
Total discounted annual costs (all patients)	**$27.45**	**$26.71**	**$25.81**	**$24.75**	**$23.62**	**$22.50**	**$21.40**	**$20.33**	**$19.30**	**$18.31**	**$17.36**	**$16.46**
Cumulative present value costs	**$27.45**	**$54.16**	**$79.97**	**$104.73**	**$128.35**	**$150.85**	**$172.25**	**$192.58**	**$211.88**	**$230.19**	**$247.55**	**$264.00**
Total undiscounted annual costs (all patients)	**$27.45**	**$28.05**	**$28.46**	**$28.66**	**$28.72**	**$28.72**	**$28.68**	**$28.61**	**$28.51**	**$28.40**	**$28.28**	**$28.15**
Cumulative undiscounted total costs	**$27.45**	**$55.49**	**$83.95**	**$112.61**	**$141.32**	**$170.04**	**$198.72**	**$227.33**	**$255.84**	**$284.24**	**$312.52**	**$340.66**

Table 21: Total projected annual costs of treating all RRT patients for 2014-2025 ($ millions; Growth)

Year	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Total patient numbers at year end - prevalent cohort	266.33	240.64	217.61	196.93	178.34	161.63	146.58	133.03	120.80	109.78	99.82	90.82
Total cost prevalent cohort	$23.62	$20.29	$17.43	$14.98	$12.89	$11.09	$9.55	$8.22	$7.08	$6.11	$5.26	$4.54
Total incident patients each year	44.95	46.94	49.02	51.19	53.47	55.86	58.36	60.98	63.72	66.60	69.62	72.63
Total incident patients (new & continuing at year end)	44.24	85.39	123.53	158.98	192.24	223.74	253.87	282.94	311.25	339.05	366.57	393.86
Total costs incident cohort	$5.19	$8.94	$11.97	$14.34	$16.22	$17.77	$19.04	$20.07	$20.93	$21.62	$22.19	$22.64
Total patient numbers	310.56	326.03	341.14	355.90	370.58	385.37	400.45	415.97	432.06	448.83	466.38	484.68
Total discounted annual costs (all patients)	**$28.81**	**$29.23**	**$29.40**	**$29.32**	**$29.11**	**$28.86**	**$28.58**	**$28.30**	**$28.01**	**$27.73**	**$27.46**	**$27.19**
Cumulative present value costs	**$28.81**	**$58.04**	**$87.44**	**$116.77**	**$145.88**	**$174.73**	**$203.31**	**$231.61**	**$259.62**	**$287.34**	**$314.80**	**$341.99**
Total undiscounted annual costs (all patients)	**$28.81**	**$30.69**	**$32.41**	**$33.95**	**$35.38**	**$36.83**	**$38.30**	**$39.81**	**$41.38**	**$43.01**	**$44.72**	**$46.50**
Cumulative undiscounted total costs	**$28.81**	**$59.50**	**$91.92**	**$125.86**	**$161.25**	**$198.08**	**$236.38**	**$276.19**	**$317.57**	**$360.59**	**$405.31**	**$451.81**

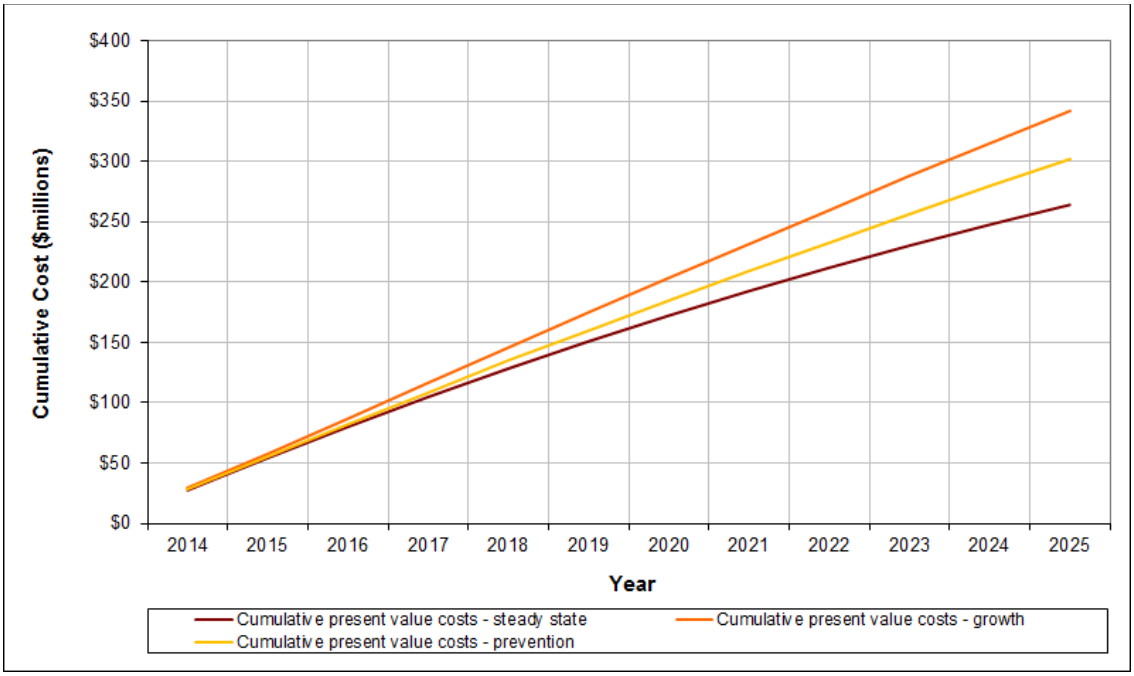
Table 22: Total projected annual costs of treating all RRT patients for 2014-2025 ($ millions; Prevention)

Year	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Total patient numbers at year end - prevalent cohort	266.33	240.64	217.61	196.93	178.34	161.63	146.58	133.03	120.80	109.78	99.82	90.82
Total cost prevalent cohort	$23.62	$20.29	$17.43	$14.98	$12.89	$11.09	$9.55	$8.22	$7.08	$6.11	$5.26	$4.54
Total incident patients each year	35.96	37.55	39.21	40.95	42.78	44.69	46.69	48.78	50.98	53.28	55.69	58.10
Total incident patients (new + continuing at year end)	35.39	68.31	98.83	127.18	153.79	178.99	203.09	226.35	249.00	271.24	293.25	315.09
Total costs incident cohort	$4.15	$7.15	$9.58	$11.47	$12.98	$14.21	$15.23	$16.06	$16.74	$17.30	$17.75	$18.12
Total patient numbers	301.72	308.96	316.43	324.11	332.13	340.62	349.68	359.38	369.81	381.02	393.07	405.91
Total discounted annual costs (all patients)	**$27.77**	**$27.44**	**$27.01**	**$26.46**	**$25.87**	**$25.30**	**$24.77**	**$24.28**	**$23.82**	**$23.40**	**$23.02**	**$22.66**
Cumulative present value costs	**$27.77**	**$55.21**	**$82.22**	**$108.68**	**$134.54**	**$159.84**	**$184.62**	**$208.90**	**$232.72**	**$256.13**	**$279.14**	**$301.80**
Total undiscounted annual costs (all patients)	**$27.77**	**$28.81**	**$29.78**	**$30.63**	**$31.44**	**$32.29**	**$33.20**	**$34.16**	**$35.20**	**$36.31**	**$37.49**	**$38.75**
Cumulative undiscounted total costs	**$27.77**	**$56.59**	**$86.36**	**$116.99**	**$148.43**	**$180.72**	**$213.92**	**$248.08**	**$283.28**	**$319.59**	**$357.08**	**$395.83**

Cumulative Cost of Treating ESKD

The cumulative present value of costs of treating all existing and new cases of RRT (from 2014-2025), assumes continuation of current service provision methods (in approximately similar proportions of patients) and treatment out to 2025. Costs are estimated to be between approximately $264-$342 million (Figure 25 and Tables 20-22). This model includes whole of service costs as previously described, but does not include capital expenditure or respite care cost. Capital expenditure has been considered separately in Table 15.

Figure 25: The cumulative present value treatment cost of all new and existing RRT patients treated out to 2025



Under the prevention scenario (Table 22), the present value of costs of treating all existing and new cases of ESKD (from 2014-2025), treated out to 2025, would be approximately $302 million. A continuation of this model from 2014 onwards, with an ongoing 20% reduction in predicted incident ESKD cases in response to a coordinated prevention program, would have significant impact on prevalent numbers and costs. Cost projections from the prevention model are presented in Figure 25 above.

Health State Utilities (Quality of Life Weights)

There are no Australian data on utility quality of life (QoL) scores for patients in pre (i.e. dialysis) and post-transplant health states. The health utility scores for dialysis and post-transplant states, derived from published international sources, are summarised in Table 23. Given the scarcity of data of health state utilities in Aboriginal Australians, it is unclear how applicable these values might be to the Aboriginal kidney patients in Central Australia, and therefore, the reporting of benefits of treatment in terms of quality adjusted life years (QALYs) should be considered indicative only.

Table 23: Health utility scores for dialysis and post-transplant states

Assumptions	Value	Source	Justification for Source
Renal Transplant		Laupacis et al (1996)	Pre and post-transplant time trade-off (TTO) utility valuation study conducted on transplant patients and on dialysis patients (pre-transplant)
Time after transplant			
1 month	0.68		
3 months	0.71		
6 months	0.75		
12 months	0.74		
Time weighted average 0 - 12 months	0.7325		
18 months	0.7		
24 months	0.7		
Time weighted average 12-24 months	0.7		
Dialysis (pre-transplant)	**0.55**	Laupacis et al (1996)	
Death	**0**	Convention	

Health Outcomes (in Life Years and Quality-adjusted Life Years)

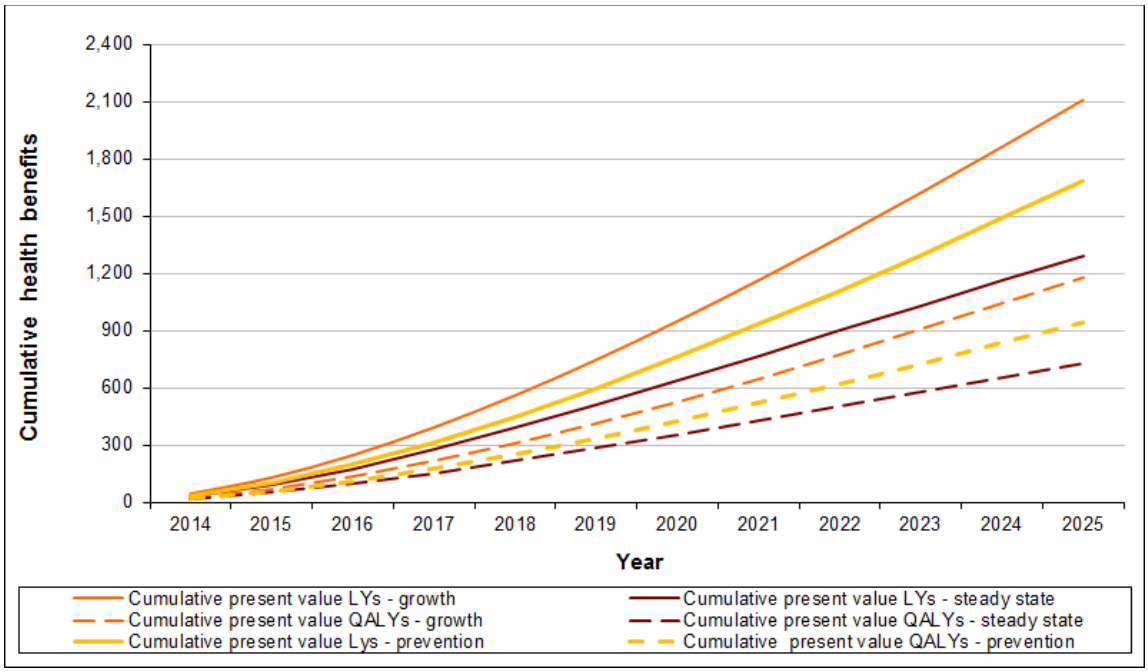
Consistent with previous reports, we have continued to model both survival (life years, LYs) and quality adjusted survival (quality adjusted life years, QALYs). Whilst data on the true quality of life implications of various dialysis modalities for Aboriginal Australians is unavailable, we have continued to use this estimate of dialysis utility in a non-Aboriginal population (0.55), to indicate that the effect on QoL of being on dialysis (and therefore on QALY calculations) is significant. Simply

relying on health outcomes expressed as survival estimates (in LYs), does not adequately capture the significant detrimental impacts on QoL resulting from dialysis.

The present value of the cumulative benefits of RRT in LYs, for all new cases of ESKD out to 2025, will be between 1,293-2,108 by 2025. The present value of the benefits of RRT in QALYs, for all new cases of ESKD to 2025, will be between 724-1,181 QALYs.

The annual and cumulative total health benefits (present values) of providing RRT to all new cases of ESKD out to 2025 are summarised in Figure 26. (Undiscounted health benefits are reported in Table 29-31 in Appendix D).

Figure 26: The present value cumulative health benefit (in life years and QALYs) for all new RRT patients treated (to 2025)



Summary and Analysis of Findings

Limitations

The approach used in this analysis follows a previously developed and reported methodology for the analysis of costs and benefits of renal replacement therapy (RRT) in Australia (1, 2). Many of the data limitations identified in this earlier work are also applicable in the current setting. Additional limitations include: challenges in modeling disease incidence and prevalence with relatively small numbers of patients across the Central Australia (CA) region and a lack of published, peer-reviewed data regarding the costs and effectiveness of service provision in remote settings for Aboriginal and Torres Strait Islander patients.

As up-to-date financial data were unavailable for this Report, cost data for provision of dialysis services were based on information provided by the NT Department of Health for the 2011 CA Renal Study. This data was reflective of costs expended to deliver dialysis services in CA in 2010. As NT Renal Services under the Department of Health have been the main providers of renal services in the CA region, these were considered to be the most relevant costs to be used.

Detailed total-cost-of-service analyses were undertaken for the Report, with cost projections up to 2025. Estimates of prevalence of end stage kidney disease (ESKD), were modeled based on incident and prevalent rates from 2000 to 2013.

Demand and Cost Models

A Markov Model for treated ESKD patients was constructed, to which the existing patterns of RRT utilisation in the CA region were applied in order to predict the future health care costs and health outcomes associated with treating new and existing ESKD patients for each year, up-to and including, 2025.

Three scenarios for future projected demand were modeled. In each scenario, whole-of-service costs were estimated for the period 2014-2025 (in 2013 dollars). These included the following scenarios:

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

In this scenario, new patients commencing treatment are approximately equivalent to the attrition rate from death with a prediction of 299 prevalent patients in 2025.

Whole-of-service costs (2014-2025) were estimated as $264 million for continuation of current services assuming a stabilisation of prevalence.

2. A growth scenario of incident cases, with a continuation of current service provision methods.

Based on past incidence rates and improvement in survival rates, this scenario modeled a linear growth of prevalent numbers of ESKD patients, predicting 485 patients in 2025.

Whole-of-service costs (2014-2025) were estimated as $342 million assuming a linear growth in prevalence.

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

This scenario suggested that incident numbers would increase at a lower rate when compared to the growth scenario and predicted 406 patients in 2025.

Under such a prevention scenario, the present value of costs of treating all existing and new cases of ESKD (from 2014-2025), treated out to 2025, would be approximately $302 million.

Additional Findings

- The present value cumulative cost of RRT for all current and new cases of ESKD, treated out to 2025, is estimated to be between approximately $264 and $342 million.
- The present value of the cumulative benefits of RRT in life years saved, for all new cases of ESKD out to 2025, will be between 1,293 and 2,108 by 2025.
- Implementation of a prevention strategy which was able to prevent 20% of incident ESKD cases, would result in significant savings. Under such a scenario, the present value cumulative cost of RRT for all current and new cases of ESKD, treated out to 2025, would be approximately $302 million.
- Community-based, nurse-supported dialysis models are relatively expensive modalities of renal service provision. However, such models potentially represent a method of service delivery which would enable more CA patients to receive treatment closer to home thus better meeting the social and cultural needs of Aboriginal patients within the CA region.

- Evidence currently available regarding the comparative outcomes of the various dialysis models (urban, regional and remote satellite services, nurse-supported and self-care community-based dialysis) does not enable cost-effectiveness analyses to guide decision making regarding these alternative models of service delivery.
- Although there is a wealth of *qualitative* data describing life for Aboriginal kidney patients, there is an absence of the customarily used quality of life (QoL) data, particularly utility-based QoL estimates for calculating quality adjusted life years. Evidence suggests that standard tools and/or instruments for systematically assessing QoL are unlikely to adequately capture aspects of QoL important for Aboriginal Australians and certainly have not yet been validated for use with Aboriginal Australians receiving RRT. Therefore this important component of health economic modeling has not been adequately addressed to date.

Appendices

Appendix A: The Projection Model Structure and Assumptions

A Markov Model was constructed as the basis for estimating the costs and benefits of RRT in Australia. This model is based upon the general structure (including some assumptions) of an earlier model used to estimate costs and health outcomes of RRT. Transition probabilities were based upon detailed analysis of the patient cohort from 2005-2009, as modality uptake has changed little in the intervening years.

The model follows a cohort of men and women newly treated for ESKD, along with existing RRT patients. The length of each 'treatment cycle' in the model is one year. The structure of the model is shown in detail in Figures 27 and 28. The first diagram represents the pathway for patients undergoing their first year of any type of RRT. The second diagram represents the pathway for patients undergoing any type of RRT in the second and subsequent years. Treatment and outcomes are shown in the elliptical shapes and arrows show the transitions that can occur. The model is stratified by the following age groups:

- 25-44 years
- 45-64 years
- 65-74 years
- 75 years and older.

Main Assumptions

The health states and pathways are the same for all types of ESKD. The treatment and outcome states in the ESKD model are as follows:

- Dialysis: includes hospital haemodialysis (HD), home HD, satellite HD and peritoneal dialysis.
- Functioning kidney transplant: patients may undergo a pre-emptive transplant from a live donor after diagnosis of ESKD, or receive a first transplant following dialysis.
- Transplant outcomes: graft success or failure. A graft failure may result in a re-graft, a return to dialysis or death.
- Death: may occur whilst on dialysis or after transplant.
- Transition probabilities for year 0 to year 4 are based on the actual treatment and outcome probabilities derived from a cohort of incident

Aboriginal RRT patients (2005-2009) from ANZDATA.

- Transition probabilities from year 4 onwards are based on the application of constant year 4 transition probabilities.
- Total resource utilisation and benefits are calculated based on probability transitions at 6 months in each treatment cycle.

Other parameters included in the model are:

- Costs of each treatment modality.
- Utility weights (QoL assessments) associated with the outcomes of each treatment modality (based on Laupacis et al, 1996).
- The present value of all future costs and benefits was used (discounted at 5% per annum).

Projected incidence patients by age for each modeled scenario

Table 24: Projected Incident patients 2014-2025, steady state model (aged 25+)

Age group	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
25-44	9.93	9.93	9.93	9.93	9.93	9.93	9.93	9.93	9.93	9.93	9.93	9.93
45-64	20.50	20.50	20.50	20.50	20.50	20.50	20.50	20.50	20.50	20.50	20.50	20.50
65-74	2.64	2.64	2.64	2.64	2.64	2.64	2.64	2.64	2.64	2.64	2.64	2.64
75+	0.07	0.07	0.07	0.07	0.07	0.07	0.07	0.07	0.07	0.07	0.07	0.07
Total	**33.14**	**33.14**	**33.14**	**33.14**	**33.14**	**33.14**	**33.14**	**33.14**	**33.14**	**33.14**	**33.14**	**33.14**

Table 25: Projected Incident patients 2014-2025, growth model (aged 25+)

Age group	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
25-44	14.92	15.81	16.76	17.76	18.82	19.94	21.13	22.39	23.73	25.14	26.65	28.15
45-64	26.71	27.71	28.74	29.82	30.93	32.09	33.29	34.53	35.83	37.17	38.56	39.95
65-74	3.27	3.36	3.46	3.57	3.67	3.78	3.89	4.01	4.13	4.25	4.37	4.50
75+	0.06	0.05	0.05	0.05	0.05	0.05	0.05	0.05	0.04	0.04	0.04	0.04
Total	**44.95**	**46.94**	**49.02**	**51.19**	**53.47**	**55.86**	**58.36**	**60.98**	**63.72**	**66.60**	**69.62**	**72.63**

Table 26: Projected Incident patients 2014-2025, prevention model (aged 25+)

Age group	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
25-44	11.94	12.65	13.41	14.21	15.05	15.95	16.91	17.91	18.98	20.12	21.32	22.52
45-64	21.36	22.16	22.99	23.85	24.75	25.67	26.63	27.63	28.66	29.73	30.84	31.96
65-74	2.61	2.69	2.77	2.85	2.94	3.02	3.11	3.21	3.30	3.40	3.50	3.60
75+	0.04	0.04	0.04	0.04	0.04	0.04	0.04	0.04	0.04	0.03	0.03	0.03
Total	**35.96**	**37.55**	**39.21**	**40.95**	**42.78**	**44.69**	**46.69**	**48.78**	**50.98**	**53.28**	**55.69**	**58.10**

Transition Probabilities

Transition probabilities between health states and modalities remain as previously modeled for the 2011 CA Report. Published Australian data on the probability of an ESKD patient undergoing a particular type of RRT, of switching between treatment modalities, and on the outcomes of this transition were not available. For that reason a dedicated secondary data analysis was conducted, assessing data on the RRT modality received and treatment outcomes for the cohort of ESKD patients commencing RRT in the NT in the period 2005-2009, as recorded in the ANZDATA Registry. The data were grouped by age (25-44 years, 45-64 years, 65-74 years, and 75 years and older) and Aboriginality. An annual transition probability was estimated for each of the first four years of treatment, with the year 4 rate applied as a constant transition probability from year 5 onwards. All transitions between states occur at 6 months (that is, midway through the yearly cycle).

Appendix B: Markov modelling of incident patient transition possibilities

Figure 27: Markov Model for ESKD patients in the first year of RRT (Year 0)

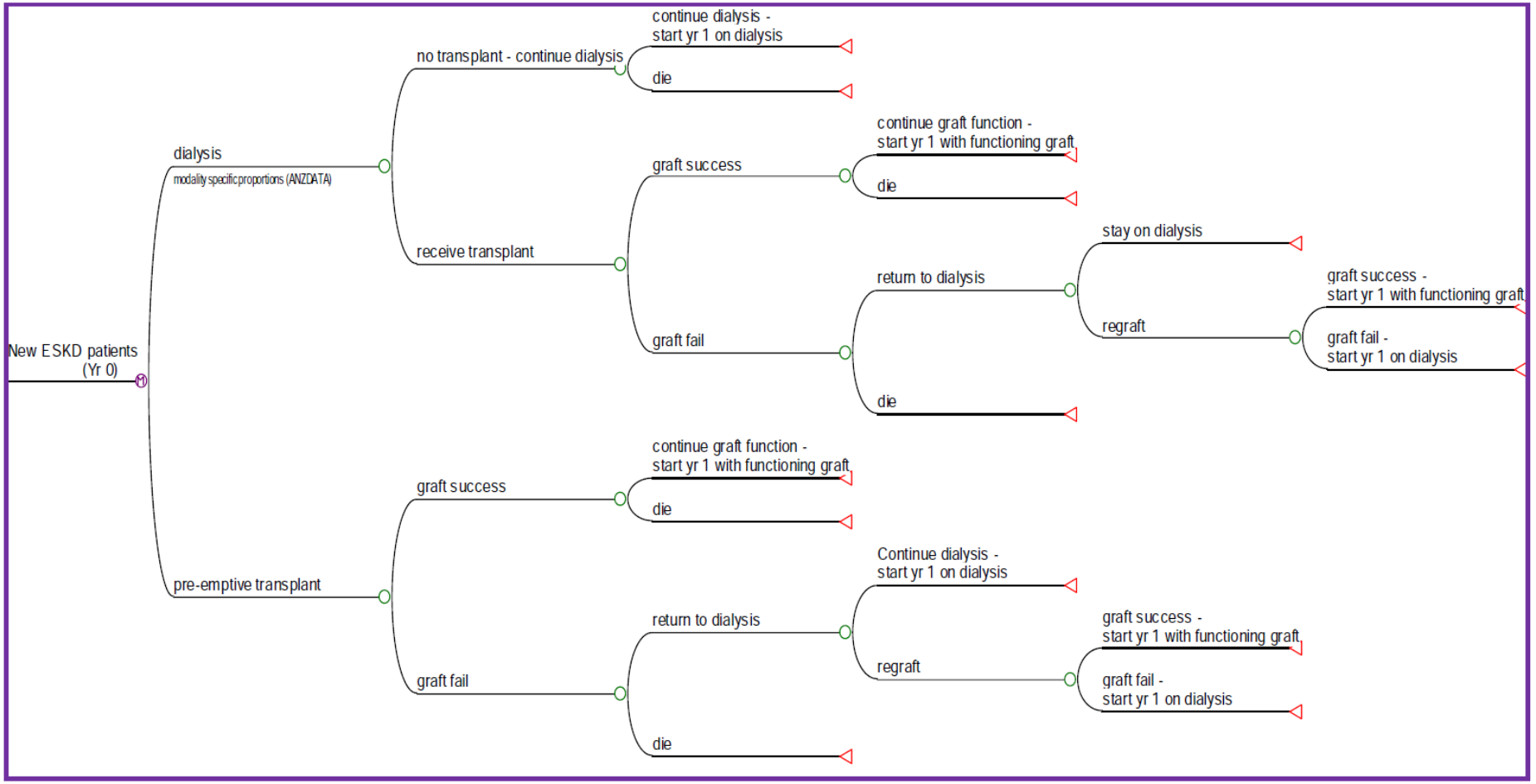
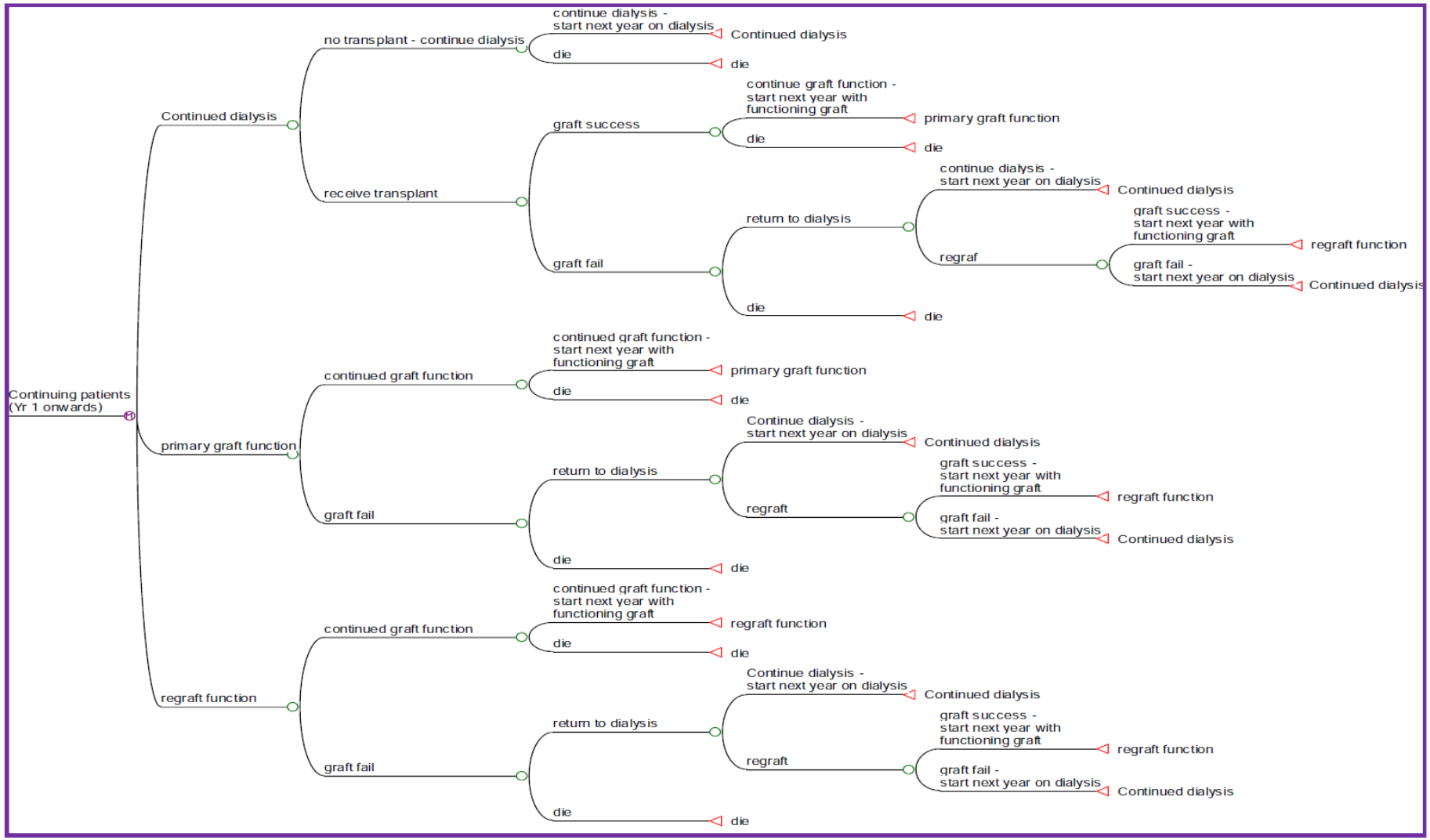


Figure 28: Markov Model for ESKD patients in the second and subsequent years of treatment (Years 1+)



Appendix C: Undiscounted Costs

Table 27: Total undiscounted projected annual costs of treating all RRT patients for 2014 – 2025 ($ millions) (Steady state)

Year	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Total cost prevalent cohort	$23.62	$21.30	$19.22	$17.34	$15.66	$14.15	$12.79	$11.57	$10.47	$9.47	$8.58	$7.77
Total costs incident cohort	$3.82	$6.75	$9.24	$11.31	$13.05	$14.57	$15.89	$17.04	$18.05	$18.93	$19.70	$20.38
Total annual costs (all patients)	$27.45	$28.05	$28.46	$28.66	$28.72	$28.72	$28.68	$28.61	$28.51	$28.40	$28.28	$28.15
Cumulative total costs	$27.45	$55.49	$83.95	$112.61	$141.32	$170.04	$198.72	$227.33	$255.84	$284.24	$312.52	$340.66

Table 28: Total undiscounted projected annual costs of treating all RRT patients for 2014 – 2025 ($ millions) (Growth)

Year	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Total cost prevalent cohort	$23.62	$21.30	$19.22	$17.34	$15.66	$14.15	$12.79	$11.57	$10.47	$9.47	$8.58	$7.77
Total costs incident cohort	$5.19	$9.39	$13.20	$16.60	$19.72	$22.68	$25.51	$28.25	$30.92	$33.54	$36.15	$38.73
Total annual costs (all patients)	$28.81	$30.69	$32.41	$33.95	$35.38	$36.83	$38.30	$39.81	$41.38	$43.01	$44.72	$46.50
Cumulative total costs	$28.81	$59.50	$91.92	$125.86	$161.25	$198.08	$236.38	$276.19	$317.57	$360.59	$405.31	$451.81

Table 29: Total undiscounted projected annual costs of treating all RRT patients for 2014 – 2025 ($ millions) (Prevention)

Year	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Total cost prevalent cohort	$23.62	$21.30	$19.22	$17.34	$15.66	$14.15	$12.79	$11.57	$10.47	$9.47	$8.58	$7.77
Total costs incident cohort	$4.15	$7.51	$10.56	$13.28	$15.78	$18.14	$20.41	$22.60	$24.73	$26.83	$28.92	$30.98
Total annual costs (all patients)	$27.77	$28.81	$29.78	$30.63	$31.44	$32.29	$33.20	$34.16	$35.20	$36.31	$37.49	$38.75
Cumulative total costs	$27.77	$56.59	$86.36	$116.99	$148.43	$180.72	$213.92	$248.08	$283.28	$319.59	$357.08	$395.83

Appendix D: Health Outcomes

Table30: Total undiscounted health benefit (life years and quality adjusted life years) for all new RRT patients out to 2025 (Steady state)

Year	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Total cumulative life years	32.87	96.64	187.69	302.72	438.51	592.39	762.05	945.51	1,141.05	1,347.17	1,562.57	1,786.13
Total cumulative QALYs	18.09	53.27	103.64	167.61	243.44	329.59	424.77	527.84	637.81	753.85	875.20	1,001.22

Table 31: Total undiscounted health benefit (life years and quality adjusted life years) for all new RRT patients out to 2025 (Growth)

Year	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Total cumulative life years	44.59	133.15	262.77	430.90	634.97	873.03	1,143.58	1,445.44	1,777.75	2,139.95	2,531.70	2,952.75
Total cumulative QALYs	24.54	73.40	145.12	238.63	352.56	485.82	637.54	807.06	993.89	1,197.71	1,418.31	1,655.57

Table 32: Total undiscounted health benefit (life years and quality adjusted life years) for all new RRT patients out to 2025 (Prevention)

Year	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	2025
Total cumulative life years	35.68	106.52	210.22	344.72	507.97	698.43	914.86	1,156.35	1,422.20	1,711.96	2,025.36	2,362.20
Total cumulative QALYs	19.64	58.72	116.10	190.90	282.05	388.65	510.03	645.65	795.11	958.16	1,134.65	1,324.45

Appendix E: Calculation of Present Value of Costs and Benefits

Costs and Health Outcomes of Prevalent and Incident Patients

The formula for calculating the present value of the cost of treating current ESKD patients is summarised in Equation 1. The prevalent cohort is based on the number of ESKD patients in Central Australia, by modality of treatment, as recorded on the ANZDATA Registry to the end of December 2013. Patients are followed up until the end of 2025.

Prevalent patients

Equation 1: Prevalent Patients

$$PVTC_p = \sum_{t=1}^{n=12} \sum_{2013\ prevalent\ cohort} (P_{1tp}) [(P_{2tp}) (C_{2p}) + (P_{3tp}) (C_{3p})]$$

$PVTC_p$ = present value of the total cost of treatment for the ESKD prevalent cohort as at 2013 out to end 2025

$P1_{tp}$ = probability of being alive in year *t*

$P2_{tp}$ = probability of having dialysis in that year

$C2_p$ = present value of the annual cost of dialysis (by modality)

$P3_{tp}$ = probability of having a kidney transplant in that year

$C3_p$ = present value of the annual cost of transplant (by type of transplant)

Incident patients

The formula for calculating the present value of the cost of treating new ESKD patients (2014 to 2025) is summarised in Equation 2.

Equation 2: Incident Patients

$$PVTCi = \sum_{t=1}^{n=12} (P1ti)\,[(P2tI)\,(C2i) + (P3tI)\,(C3i)]$$

$\int t \int$ 2014-2025 Incident cohort

$PVTC_i$ = present value of the total cost of treatment for the ESKD incident cases out to end 2025

$P1_{ti}$ = probability of being alive in year *t*

$P2_{ti}$ = probability of having dialysis in that year

$C2_i$ = present value of the annual cost of dialysis (by modality)

$P3_{ti}$ = probability of having a kidney transplant in that year

$C3_i$ = present value of the annual cost of transplant (by type of transplant)

Benefits are calculated using a similar formula, where the present value of annual cost of dialysis and transplant in Equation 1 is replaced by the present value of the health outcomes (life years and quality adjusted life years) generated by dialysis and transplant. The total present value of cost and benefits of treating existing and new cases of ESKD projected out to the end of 2025, is the sum of Equation 1 and 2 ($PVTC_p + PVCT_i$).

Appendix G: Glossary and Acronyms

Table 33: Table of terms and definitions

Aboriginal Community Worker	An Aboriginal person working in the health field who is not registered but has a certificate level qualification.
Aboriginal Health Worker	An Aborignal Health Worker has completed a Diploma in Primary Health Care Practice and is registered to practise in the primary health care setting.
Aboriginal Liaison Officer	An Aboriginal person employed to assist Aboriginal Australians navigate organisations and systems and provide cultural brokerage.
Aboriginal and Medical Services Alliance Northern Territory	Peak Indigenous body representing Aboriginal medical services in the NT.
Australian and New Zealand Dialysis and Transplant Registry	A disease specific registry that collects data on people with end stage renal disease in Australia and New Zealand.
Automated Peritoneal Dialysis	A form of peritoneal dialysis that utilises a machine to carry out fluid exchanges overnight while the patient sleeps.
Coronary Artery Disease	One of a group of diseases that affects the heart and blood vessels and most commonly responsible for heart attacks.
Continuous Ambulatory Peritoneal Dialysis	A form of dialysis that uses the peritoneal membrane as a filter and requires the exchange of fluid – via a permanently situated tube – into the peritoneal cavity a number of times a day.
Community-based dialysis	Haemodialysis delivered or undertaken in remote communities.
Chronic Kidney Disease	The slow, progressive and irreversible loss of kidney function.
Cardio Vascular Disease	A group of diseases that affect the heart and blood vessels and includes coronary artery disease (heart attacks), cerbrovascualr disease (strokes) and hypertension.
Dialysis	Refers to a form of treatment for end stage kidney disease that removes the waste products from the blood through a process of filtration. There are two types of dialysis - peritoneal dialysis and haemodialysis.
Donga	A dedicated facility for dialysis treatments in remote communities - originally designed to be

	relocatable.
Enrolled Nurse	A health practitioner that has completed certificate level qualification in nursing and must work under the supervision of a Registered Nurse.
End Stage Kidney Disease	Irreversible and permanent loss of kidney function requiring dialysis or transplantation to sustain life.
Estimated Glomerular Filtration Rate	A measurement of kidney function.
Haemodialysis	The process of dialysis that removes waste products and excess water from the body by pumping the body's blood through an artificial kidney.
Human Leukocyte Antigen	HLA is a protein or marker found on most cells in the body which is responsible for the regulation of the immune system in the body. The body recognises the HLA markers as either belonging or foreign and acts to destroy foreign cells.
Hub	Centre within a statewide or regional service that provides specialist care such as nephrologist, social work, dietitan and outreach services to regional services. Hub is usually a parent facility for satellite serices.
In-centre	A facility within a hospital or teritary service reserved for acute treatments
Incidence	The number of new cases of a certain condition occuring within a given population over a certain period.
Models of Care	Clinical treatments that may be offered according to clinical need, patient circumstances and availability of services.
Mobile Bus	Self-contained and self-sufficient dialysis service set up in a vehicle to enable treatments to be delivered in a variety of settings.
Peritoneal Dialysis	A form of dialysis treatment that utilises the peritoneal membrane as a filter to clean wastes from the body. It involves exchanging fluid through a permanently situated tube in the abdominal cavity.
Peripheral Vascular Disease	Disease that affects the periperal vessells furtherest from the body.
Prevalence	The number of people with a certain condition in a given population over a known period.
Renal Ready Room	A room ususally set up in a primary health facility dedicated for kidney patients to have dialysis

	treatments.
Renal Replacement Therapy	Refers to the different treatment modalities for end stage renal disease: transplantation, haemodialysis and peritoneal dialysis
Spoke	Services supported by specialised Hubs that provide satellite dialysis services, patient education and support.
Transplantation	A surgical procedure where a healthy organ from a deceased or living donor is placed in another person to replace the function of a damaged organ.
Vocational Education and Training	Education which directly develops expertise in techniques related to technology, skill or scientific technique. Vocational education is classified as using procedural knowledge.

Table 34: Table of abbreviations

ACW	Aboriginal Community Worker
AIHW	Australian Institute of Health and Welfare
AHW	Aboriginal Health Worker
ALO	Aboriginal Liaison Officer
AMSANT	Aborignal and Medical Services Alliance Northern Territory
ANZDATA	Australian and New Zealand Dialysis and Transplant Registry
APD	Automated Peritoneal Dialysis
AR-DRG	Australian Refined – Diagnostic Related Group
ASRS	Alice Springs Renal Services
ASH	Alice Springs Hospital
CA	Central Australia
CAD	Coronary Artery Disease
CAPD	Continuous Ambulatory Peritoneal Dialysis
CBD	Community-based dialysis
CKD	Chronic Kidney Disease
CVD	Cardio Vascular Disease
DoH	Department of Health
EN	Enrolled Nurse
EPO	Erythropoietin
ESKD	End Stage Kidney Disease
eGFR	Estimated Glomerular Filtration Rate
FIFO	Fly-in-Fly-out
HD	Haemodialysis
HLA	Human Leukocyte Antigen
MOC	Models of Care
MB	Mobile Bus
MBS	Medical Benefits Schedule
MSAC	Medical Services Advisory Committee
NGO	Non Government Organsiastion
NHCDC	National Hospital Cost Data Collection
NHMRC	National Health and Medical Research Council

NT	Northern Territory
NTRS	Northern Territory Renal Services
PBS	Pharmaceutical Benefits Scheme
PD	Peritoneal Dialysis
PHC	Primary Health Care
PPT	Price Per Treatment
PVD	Peripheral Vascular Disease
QALYs	Quality Adjusted Life Years
QoL	Quality of Life
R&M	Repairs and Maintenance
RN	Registered Nurse
RRR	Renal Ready Room
RRT	Renal Replacement Therapy
TCDU	Tennant Creek Dialysis Unit
VET	Vocational Education and Training
WDNWPT	Western Desert Nganampa Walytja Palyantjaku Tjutaku

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