Australian Department of Health and Ageing

Central Australia Renal Study

June 2011

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**Part 1: Key Findings and Recommendations**

**Part 2: Final Report**

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[Logo of The George Institute for Global Health]
Acknowledgements

The Study Team acknowledges the input of the members of the Technical Reference Panel who provided critical input based on their expertise relevant to the Study. We thank the many stakeholders we consulted for their genuine engagement and the patients and community members for recounting their experiences.

Disclaimer

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

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Part 1: Key Findings and Recommendations
Key Findings and Recommendations

1.1 Purpose of the Study

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

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

The Study was undertaken to inform the governments in the cross-jurisdictional region to make evidence based policy decisions, in order to better meet the health and service needs of Aboriginal dialysis patients in the region, in affordable and sustainable ways.
1.2 Key Findings of the Study

Current and future burden: Numbers needing treatment

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

Location of people needing treatment

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

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

Treatment options

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

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

Estimated costs associated with providing treatment

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

1. A stabilisation and a growth scenario of incident cases, with a continuation of current service provision methods.
Whole-of-service costs (2009 to 2020) were estimated as $240 million for continuation of current services assuming a stabilisation of prevalence (predicting 312 patients in 2020), or $302 million assuming a linear growth in prevalence (predicting 479 patients in 2020).

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

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

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

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

Capital costs (including housing) and respite dialysis were costed separately to service delivery.
1.3 Preferred Renal Services Model for Central Australia

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

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

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

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

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

- The spokes will not allow patients from all communities to obtain treatment closer to home: Mobile dialysis and respite dialysis is recommended to provide supplementary service to allow more people to be closer to home.
1.4 Overarching Considerations: Pre-requisites of Implementation

The primary recommendation of the Study focused on the preferred service model for Central Australia. However, the implementation of the service model will occur against the background of a several key overarching factors. Accordingly, a supplementary recommendation of the Study is the need to consider seven overarching considerations. These are central to enabling the primary recommendation, and must underpin the implementation plan. Further details can be found in the body of this Report. The key considerations are:

1. **Prevention effort must be part of the suite of activities** - Noting the identification, by primary care and renal services, of almost 600 people with CKD Stages 3 to 5, and evidence suggesting these cases represent a fraction of the actual number with CKD in the cross-border region, an integrated approach to CKD prevention should be implemented. The approach to prevention should include interventions across the life course, including primary prevention, early intervention and evidence-based management of risk factors for CKD and progression of disease. Further details of an evidence-based approach to prevention across the life course can be found in the Technical Report (Section 3.3.2.1).

2. **Services need to be shaped in ways which recognise social and cultural determinants of treatment uptake, adherence and outcome** - In accordance with principles enunciated in the COAG National Partnership Agreement on Remote Service Delivery and the National Service Guidelines for the Management of Dialysis and Kidney Transplant in Remote Australia, dialysis should be provided as close to home as possible.

   Practical approaches to developing appropriate health service structures and modes of delivery are crucial for implementation. Considerable evidence attests to the significance of proximity to care, availability of transport, welcoming physical spaces and meaningful roles for Aboriginal and Torres Strait Islander people.

   Treatment close to home will not always be possible in the CA region. Accordingly, respite dialysis services and return to country programs should be provided as part of an integrated, coordinated regional renal service and priority should be given to addressing accommodation and social support issues for patients and their families. It has been estimated that up to five people may follow a patient moving to an urban centre to access RRT.

3. **Jurisdictional drivers must be accommodated within a Tri-State service model** - As discussed in this report, the CA region is a multi-jurisdictional region, which presents governance challenges. Any recommendations and/or implementation plans will hinge on a united response from all jurisdictional governments. This clearly implies the need for accommodation of the separate needs of the jurisdictions, and agreement of an appropriate mechanism for governance and coordination across the region.

   At the same time, as repeatedly emphasised in consultations, the cross-jurisdictional setting mandates the need for collaboration in planning, resource allocation, monitoring and evaluation of the outcomes of service delivery. Formulating and implementing cohesive, effective and equitable patient care, needs to occur across governments, and within a Tri-State Agreement. This may be within the framework of existing Tri-State mechanisms/agreements, or it may require the development of specific new ones. In this regard, it would be worthwhile exploring an independent brokerage role for the DoHA, with their ongoing and formalised commitment to be agreed with the States and Territories.

   Specifically however, whether through existing mechanisms or the establishment of new ones,
4. Protocols for dialysis treatment closer to home in the particular circumstances of CA must be agreed and formalised - Provision of renal services on a safe and sustainable basis in remote communities requires a number of enabling factors and entails certain risks.

A broad range of well-documented environmental factors require specification, including location, services, design, construction, water, electricity, drainage and management of bio-hazardous waste. Access to safe and secure housing for patients returning to remote communities for ongoing dialysis was also articulated.

Based on evidence-based practice and treatment, key criteria were outlined in this report for establishment of dialysis treatment facilities in remote communities. It is not possible to supply a checklist of community characteristics required to sustain the provision of dialysis services. Decisions regarding sites for services will require consideration of locally-specific detail about the community.

As part of coordinated regional implementation, the criteria will need to be formalised and agreed, in order to ratify them as protocols.

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

Stakeholders, and a review of relevant policy documents, indicated the following as an ideal suite of elements for maintaining safety and quality:

- Phased implementation of new models of service delivery with rigorous evaluation of cost-effectiveness, sustainability and appropriateness of care.
- Adherence to protocols for assessment of site selection, construction, design and equipping of dialysis facilities.
- Workforce strategies that build, up-skill, support and retain a multi-disciplinary workforce with strong Aboriginal and Torres Strait Islander involvement.
- Engagement of community leadership and primary healthcare services in a partnership to sustain community-based service delivery.
- Adherence of all service providers to relevant standards.
- National approaches to training and accreditation, especially as they impact on alternative workforce models.
- Development of a core set of key indicators against which renal services could be monitored.

6. Addressing workforce requirements of the service delivery model must be a priority - When compared to national figures, the evidence shows that currently, there are shortfalls in staff numbers. Recruitment, retention and high turnover for the remote area health workforce is well documented. Renal services require multi-disciplinary teams and they require
highly skilled staff. Quite apart from clinical and specialist skills, English is not the first language for many renal patients in the CA region. These problems are not specific to renal services.

Renal service delivery in remote communities across the CA region shares common challenges with other rural and remote health services in building and maintaining an appropriately skilled multi-disciplinary workforce.

A combination of recruitment/retention, up-skilling and alternative workforce strategies will need to be pursued:

i) **Recruitment and retention strategies:** While evidence-based strategies are limited, several documented candidate strategies need to be actively pursued for recruitment and retention of rural and remote area health workforce.

- Most incentives focus on remuneration. However non-financial incentives, such as housing and improved working conditions, as part of remuneration packages, have the potential to improve retention.
- Innovative approaches to housing were particularly emphasised as a key driver of recruitment and retention, acknowledging that this is likely to include a range of approaches such as building, renovating and rent subsidisation.
- An approach in which different incentives are bundled in a manner that is flexible to specific (local) contexts is also required.

ii) **Alternative renal workforce models which provide Aboriginal and Torres Strait Islander people with a more central role in dialysis provision and patient support:** There was strong endorsement from stakeholders for further training of Aboriginal Health Workers to develop competencies in delivering dialysis and caring for patients with CKD and/or ESKD in the community.

iii) **Alternative workforce models based on specific training:** The provision of renal services, by its nature, requires a multi-disciplinary workforce. As a ‘gold standard’ multi-disciplinary teams in the CA region should include: Nephrologists, nursing staff, educators, social workers, dieticians, pharmacists, Aboriginal Liaison Officers, Aboriginal Health Workers and have access to professional interpreters. (See Section 9 of the Final Report for further details.)

To better equip the existing multi-disciplinary workforce to provide sustainable renal services in remote communities, several examples of better utilising existing skill mix were proposed:

- Up-skilling of ENs to provide renal services.
- Up-skilling of rural GPs in management and support of dialysis patients within the community.

As a co-requisite of this strategy, alternative multi-disciplinary workforce models need to flourish collaboratively, alongside existing primary care services.

iv) **Innovative provider partnerships:** The provision of renal services in the CA region will be best served by a collaborative and inclusive approach across public, private and non-government sectors. A number of examples were documented where industry providers are contracted to provide capital, equipment and staffing according to an agreed price-per-treatment contract. Such collaborative approaches provide one model for funding expansion in dialysis service provision. Such arrangements might enable capital expenditure to be amortised over the period of a contract and provide an alternative strategy for recruiting and maintaining the remote area renal workforce through increasing the potential pool of skilled staff.

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

1. Priorities for health service data collection to inform renal service planning in the CA region were identified as part of the Study (see Section 9 of the Final Report for further details). These data collections need to be established if service need projections are to be updated regularly, as recommended by this Study.

2. New models of care for the CA region are being canvassed – respite care and remote mini-satellite care, with expansion of self-care. In the first instance, careful evaluation of the efficacy, cost-effectiveness and sustainability of renal service provision in remote communities with these new models will be essential.

3. The implications for transition from facility-based service provision to community-based provision then need to be incorporated into service planning cycles.

As an Appendix to Part 2, the Final Report, the key evidence from this Study has been used to develop a potential implementation scenario for the preferred service model (Appendix 1 to the Final Report).
Part 2: Final Report
2 Background

2.1 Introduction

Premature mortality due to cardiovascular disease, diabetes and chronic kidney disease (CKD) contributes substantially to the gap in life expectancy for Aboriginal and Torres Strait Islander Australians. In 2004 to 2006, Aboriginal and Torres Strait Islander Australians in the Northern Territory, South Australia, Western Australia and Queensland were seven and eleven times more likely, for males and females respectively, to die from CKD and these deaths occurred at a younger age than amongst non-Indigenous Australians. End-stage kidney disease (ESKD), requiring dialysis or a transplant to maintain life, has a major impact on quality of life for all patients. The excess burden of disease in remote areas, both in terms of disease incidence and prevalence, and the social and cultural impact of dislocation from family and community to access necessary care, vastly amplifies this impact on Aboriginal and Torres Strait Islander peoples. More than 40% of adults attending Aboriginal primary care services across the Central Australia (CA) region have either proteinuria or reduced kidney function – the cardinal markers of earlier stages of CKD.

The risk factors for CKD can be categorised as fixed and modifiable. Fixed risk factors include family history, a genetic predisposition and increasing age. Modifiable risk factors include low birthweight, socioeconomic disadvantage, diabetes, high blood pressure, overweight and obesity, tobacco smoking, physical inactivity and poor nutrition. Amongst Aboriginal and Torres Strait Islander peoples, factors that arise early in the life-course, including poor maternal health and low birthweight and the burden of childhood infection and chronic inflammation, have been associated with increased risk of developing CKD. The association between markers of socioeconomic disadvantage, including leaving school early, unemployment, low household income and house crowding, and age- and sex-standardised incidence of ESKD are particularly strong for Aboriginal and Torres Strait Islander peoples.

The need for, and benefits of, coordinated preventative initiatives for future generations are undisputed. (See Technical Report Section 3.3.2.1 for more detailed consideration of prevention of CKD over the life course.) CKD is a complex chronic disease which requires major changes to diet, lifestyle and access to and utilisation of medical services. Accordingly, the National Indigenous Health Equality Summit, held in Canberra in March 2008, proposed a set of key targets to achieve the COAG commitment of closing the Aboriginal and Torres Strait Islander life expectancy gap within a generation. The secondary prevention target relevant to CKD was: “Stabilize all-cause incidence of end-stage kidney disease within 5–10 years.”

At the same time, demand for renal services among Aboriginal Australians is projected to increase markedly over the next decade. While all Australian jurisdictions are faced by a growing burden of CKD and are attempting to meet the profound challenges of provision of renal services in the community setting, the issues posed by the likelihood of further increases in demand for renal services among Aboriginal Australians in the CA region are particularly pressing. It is against this background that the Central Australia Renal Study was undertaken.
2.2 The Central Australia Renal Study

From 2000 to 2009 the number of people from the CA region receiving dialysis treatment has tripled to more than 200 patients. Fewer than 10% of these patients are treated close to home in remote communities, with the large majority receiving satellite haemodialysis (HD) in Alice Springs or Tennant Creek. This rapid growth in demand has placed renal services under intense capacity pressure. In response to these pressures, decisions were made to restrict access to dialysis in Alice Springs for patients from the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands in South Australia and Ngaanyatjarra Lands in Western Australia, further compounding dislocation from family and community.

The region of Australia considered in this Study is a cross border region. The Central Australian cross-border region includes the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands in South Australia and extends up through the Northern Territory to the Barkly region and Tennant Creek. It crosses the Western Australian border to the land north and east of Warburton and reaches to the Queensland border in the east. This area encompasses three State/Territory jurisdictions.

The roughly one million square kilometres is sparsely populated and includes some of the most disadvantaged regions in Australia. The Aboriginal and Torres Strait Islander peoples proportion of the population is high, ranging from 18.8% in Alice Springs to 84.5% in the APY Lands. It is a much younger population, with a median age that in some areas is more than ten years below the national average. As the Key Findings of this Study explain, these characteristics significantly affect patterns of health and illness, how CKD presents, is treated, and how services can be provided.

In the CA region, CKD management and RRT are currently provided by a range of primary, secondary and tertiary providers, which are linked to varying degrees. The specialist renal unit is based at Alice Springs Hospital and provides the bulk of renal services. The Western Desert Ngaanyatjarra Pitjantjara Tjutaku (WDNWPT) Aboriginal Corporation focuses on respite dialysis in communities and return to country programs. Fresenius Medical Care Australia manages a satellite dialysis service in Alice Springs, under a public-private partnership with NT Health. Primary health care services across the region manage populations with a heavy burden of CKD and associated chronic diseases. There are a number of community-based, social welfare advocacy groups which are heavily involved in catering for and promoting the social and cultural needs of people with CKD. These groups include the NPY Women’s Council and the NT Council of Social Services. The groups listed above, and others, were valuable participants in the Study consultations and stakeholder workshops.
2.3 The Aims of the Study

The agreed purpose of the Study is to develop a range of feasible clinical service delivery models and care pathways to best meet the current and projected needs for Aboriginal and Torres Strait Islander patients from remote communities requiring dialysis in the CA region. The Study aimed to be underpinned by robust modelling of demand for and costs of renal service provision, and forward planning and service delivery options that appropriately address the service needs of Aboriginal people across the CA region.

The Study will build on the body of work already undertaken by the Australian Health Ministers’ Advisory Council in the development of the National Services Guidelines for the Management of Dialysis and Kidney Transplantation in Remote Australia 2006.

The Study will inform communities, policy makers and service providers about future renal needs and workable and sustainable service options that take into account quality requirements, patients and staff safety, technical and economical feasibility and workforce needs.
2.4 Terms of Reference for the Study

The Australian, Northern Territory, South Australian and Western Australian Governments agreed the Terms of Reference for a Central Australia Renal Study. These were as follows:

- Map the current and future clinical, social and cultural needs of renal patients in remote and very remote locations, with a focus on establishing trends in the need for renal services in remote Australia.
- Make projections (with high and low range) of these needs for the next 5-10 years based on the best available data of chronic disease and chronic kidney disease in communities and the incidence and prevalence of end stage renal disease.
- Identify service models, their availability and efficacy, including treatment modalities and the known and potential uptake of these treatment modalities over the last 1-2 years.
- Consult with Aboriginal and Torres Strait Islander peoples in the context of viable service delivery options on various treatment modalities and the associated training and support needs.
- Make recommendations on the feasible clinical service delivery solutions considering:
  - Avenues to increase the uptake of self-care and other appropriate modalities cost-effectiveness (including but not limited to volume, sustainability, whole of service costs, etc).
  - Patient safety – including quality and accreditation requirements in each State or Territory jurisdiction.
  - Social aspects including but not limited to dislocation, provision of housing (for patient and family dislocated from community and also ensuring housing on their return) and community disruption (i.e. elders having to leave community to seek treatment).
  - Return to country programs – including better ways to deliver these services.
  - Viability, given the requirements for specific infrastructure, location characteristics and limitations.
  - Sustainability of service delivery including workforce issues.
  - Cultural needs of patients; as well as their referred treatment pathways.
  - Patient compliance and mechanisms to improve compliance rates taking account of the multitude of reasons for non-compliance i.e. cultural, service delivery quality etc.
  - Alternative workforce options and consequent training needs.
  - Desired/necessary primary health and tertiary service interface to monitor.
  - Effective management of patients along the chronic disease/chronic kidney disease pathway.
2.5 This Report

This Report describes the Study, a review of previous evidence, key findings of the Study and the recommendations to emerge from the findings. Full details regarding Study methodology, analysis and findings can be found in the Technical Report (Part 3) and Technical Appendices (Part 4).

The Study Team wish to thank CA regional stakeholders from primary healthcare services, renal service providers and government agencies and departments who have provided data or information incorporated into the Report. Wherever possible, the Study Team has cross-verified data between sources, for example primary care, renal unit, NT Government Chronic Disease Report and Kanyini Vascular Collaboration data regarding the burden of CKD in the CA region. However, we can only vouch for the accuracy and completeness of data collected through high quality, peer-reviewed, research studies including the Kanyini Vascular Collaboration Audit, Kanyini Qualitative Study and IMPAKT Study and through analyses conducted using the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA).
3 Methodology

3.1 Approach

The methodology consisted of four key streams to understand the complexities of the situation including the enablers and barriers to renal services in the CA region as seen from key perspectives. Each component is briefly described below with full details to be found in the Technical Report and Technical Appendices.

3.1.1 Evidence Review

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

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

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

3.1.2 Data Analysis

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

- Australia and New Zealand Dialysis and Transplant Registry (ANZDATA).
- CKD prevalence data obtained from primary care services in the CA region.
- Findings reported in the Chronic Disease Report 2009/2010 from the NT Department of Health & Families.
- Kanyini Vascular Collaboration Audit Study data.
- CKD clinic data from the Alice Springs Hospital renal unit.
- NVIVO databases from the IMPAKT and Kanyini qualitative studies.

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

The Study Team conducted extensive consultation across the CA region, with a diverse range of patient, community, service provider and government stakeholders. A full list of stakeholders consulted is included in the Technical Appendices. A detailed stakeholder engagement plan was developed in consultation with the Renal Study Steering Committee.

Consultations – predominantly face to face – were undertaken with more than 220 people, including more than 80 Aboriginal renal patients, family and community members across the CA region. A number of patient forums were also held across the region which gave patients and family members further opportunity to share their experiences of accessing and utilising renal services.

The following themes were covered in community consultations:

- The local health care system and its context.
- Current priority concerns in relation to kidney patients/kidney disease.
- What is currently working and what is not working in renal services.
- Outlining examples of good practice in renal services.
- Outlining enablers and barriers to seeking, accessing and providing renal services.
- Defining both met and un-met needs with regards to renal services from the perspective of patients, communities and health services.
- Identification of required services, support, training, infrastructure to ensure sustainable and safe RRT for the CA region.
- Factors that contribute to effective and sustainable services.
- Identification of the essential building blocks for provision of renal services.
- Improving governance and coordination.

3.1.4 Projections of Burden of ESKD

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

In addition, available data on the prevalence of various stages of chronic kidney disease were examined. Although the framework and collection of this data varies substantially between difference communities, it offers a complementary approach to assessment of predicted incident numbers of people requiring renal replacement therapy.
4 Evidence review

4.1 Purpose of this Section

This section presents a synthesis of the evidence review undertaken. It included empirical and grey literature documents, published over the last two decades relating to chronic disease in general, CKD in particular, and development of appropriate services for Indigenous peoples in Australia, Canada, New Zealand and the United States.

A more detailed account of the approach to, and findings of, the synthesis of the literature appears in the Technical Report, and a complete bibliography appears in the Technical Appendices. An overview of the methodology and key findings of the review are outlined below, together with further implications for the provision of renal services in the CA region.

There is a large body of international evidence detailing the disproportionate burden of disease and inequities in health service access for Aboriginal and Torres Strait Islander peoples in Australia and internationally. However, there have been few robust evaluations of interventions to improve access, and only limited reviews of the literature to understand why inequities occur. As such, there is still limited evidence to favour one intervention to improve access above another.
4.2 Methodology

Key features of the approach to the evidence review include:

A broad and inclusive search strategy was taken in the initial stages using the three core elements as search terms:

(1) Indigenous peoples from Australia, New Zealand, Canada and USA.

(2) Health care services.

(3) Chronic illness care and prevention.

The international databases examined included:

- Medline
- EMBASE
- The Cochrane Library
- PsycINFO
- ERIC
- Science Citation and Social Science Citation Indexes via the Web of Science
- CINAHL
- BiblioMap
- HealthPromise.

The electronic database search was augmented by purposive sampling with a specific focus on capturing grey literature sources. The grey literature was considered key in determining perspectives that are not traditionally represented in academic journals - especially Indigenous perspectives.

To access this grey literature the following searches were conducted:

- Government and non-government websites.
- General searches using ‘Google’ and ‘Google Scholar’.
- Australasian databases (AMI, APAIS-Health, ATSIhealth, Health and Society, RURAL, Meditext) via Informit.
- Australian Indigenous Health Infonet.
4.3 National and International Evidence: Overview

4.3.1 Burden of CKD Among Aboriginal Australians

Chronic diseases and associated risk factors are responsible for approximately two-thirds of the life expectancy gap between Aboriginal and Torres Strait Islander and non-Indigenous Australians. It is well established that Aboriginal and Torres Strait Islander peoples have an incidence rate of ESKD, the irreversible and most severe form of CKD in which dialysis or a transplant is required to maintain life, which is significantly higher than non-Indigenous. This burden falls disproportionately in the ages between 35 and 65, and rates in remote areas, including those for communities across the CA region, are up to 30 times the national average. The burden of earlier stages of CKD amongst Aboriginal and Torres Strait Islander peoples is less well characterised.

Based on data from the AusDiab study, the prevalence of CKD amongst Australians aged 25 years and over is estimated at 11.5%. However, comprehensive population-based data regarding CKD prevalence and incidence for Aboriginal and Torres Strait Islander peoples, either nationally or specifically pertaining to the CA region are not available. Between 2004 and 2006 in Queensland, South Australia, Western Australia and the Northern Territory, CKD was recorded as the underlying cause of death in nearly 4% of all Aboriginal and Torres Strait Islander deaths, a rate seven to eleven times higher than for non-Indigenous males and females respectively. CKD was an associated cause in a further 12% of deaths.

Surveys in individual remote Aboriginal communities have documented high rates of early stages of CKD and its cardinal markers of reduced kidney function and proteinuria. An audit of screening and management of chronic disease in Aboriginal primary care, undertaken through the Kanyini Vascular Collaboration, has confirmed that more than 40% of regular adult attendees at Aboriginal primary care services across the CA region have reduced kidney function or proteinuria. This health service, rather than population-based data, underscores the burden of CKD which needs to be addressed across the CA region.

The terms of reference for this Study focused on service planning for renal dialysis services in remote and very remote areas. However, the key role for prevention must be acknowledged. Without coordinated preventative initiatives, and a closing of the gap between evidence and practice in chronic disease management, modelling undertaken for this Study predicts a continued linear growth in demand for renal replacement therapy. Without effective prevention, an increase of almost 100% in the prevalence of ESKD is predicted over the next decade.

4.3.2 Outcomes of CKD Among Aboriginal Australians

Chronic diseases account for 70% of total health expenditure in Australia. Analysis of hospitalisations in 2004-5, indicates that 1 in 4 hospitalisations were complicated by the comorbidities of cardiovascular disease and/or diabetes and/or CKD. Across the spectrum of disease severity, from early CKD to ESKD, kidney disease has been shown to be associated with an increased risk of death and disability, and to be inextricably linked with cardiovascular disease and diabetes.

Both reduced kidney function – eGFR <60mls/min consistent with CKD Stage 3 – and albuminuria have been shown to be independent predictors of mortality in the general population. In addition, early CKD is strongly associated with risk of major vascular events – both acute myocardial infarction (AMI) and stroke. With progression of CKD, these risks become more pronounced. Amongst people receiving dialysis for ESKD, almost 10% die each year due to cardiovascular disease, at rates many times higher than healthy people of the same age and sex. Amongst people hospitalised for AMI, CKD is a strong predictor of mortality. A review of the 2001-2 cohort with acute coronary syndromes who presented at Alice
Springs and Royal Darwin Hospitals, found that CKD complicated 39% of Aboriginal and Torres Strait Islander cases and it was the strongest predictor of long-term survival.

Diabetes is the leading attributed cause of ESKD amongst Aboriginal and Torres Strait Islander peoples and is present as a comorbidity amongst the vast majority of patients. In terms of prevention of ESKD, the management of blood pressure and glycaemic control amongst people with diabetes are critical targets for secondary prevention. This complex inter-relationship of CKD, diabetes and cardiovascular disease underlines the need to address prevention and management of CKD within a coordinated chronic disease strategy. A comprehensive renal hub service will need to have access to specialised diabetes and cardiovascular services. However, it should be noted that the full spectrum of cardiology services, including for example cardiovascular surgical services, are not available in the range of Australian rural locations where significant renal hub services have been successfully established.

4.3.3 Renal Replacement Therapy: State of the Art

Opportunities exist to reduce the impact of the health burden associated with ESKD through disease prevention and informed planning of renal service delivery. Existing international evidence and local costings indicate that home- or community-based dialysis is less expensive than hospital or satellite HD, while for those patients who are suitable candidates, kidney transplantation is more cost-effective than any form of dialysis.

Kidney transplantation is considered the optimal treatment for most non-elderly patients with ESKD, conferring a significant survival advantage and improvement in quality of life over dialysis therapy. Transplantation is offered as a treatment modality to medically suitable Aboriginal and Torres Strait Islander patients across the country, including from the CA region. South Australia and the Northern Territory share common waiting lists and transplant organ allocation protocols. South Australia consistently has the highest organ donation rate of any Australian jurisdiction and the Central Northern Adelaide Renal and Transplantation Service partners with NT Renal Services to provide a comprehensive transplant service to patients from the CA region. Renal transplantation in Western Australia is coordinated through a state-wide service, using agreed protocols for transplant work-up, assessment for suitability, approaches to acute transplantation and ongoing management. Aboriginal patients in rural and remote areas, including the area relevant to this Study, have been successfully transplanted. Nevertheless, consistent with poor access nationally, Aboriginal and Torres Strait Islander peoples in the CA region experience low transplant rates. A number of additional barriers to transplant access for Aboriginal and Torres Strait Islander patients from remote areas should also be acknowledged.

When adjusting for age, sex, cause of renal disease, comorbidities and region, Aboriginal and Torres Strait Islander peoples on dialysis undergo transplantation at approximately one-quarter the rate of the majority Caucasian population. This disparity is evident for access to deceased and living donor transplantation. A number of potential mediators may contribute, including language barriers, health practitioners’ attitudes and the lack of culturally appropriate patient education programs. The IMPAKT study documented the lack of culturally appropriate educational materials regarding kidney transplantation, specifically targeted to preferred ways of communicating and levels of health literacy of Aboriginal and Torres Strait Islander patients. Geographical remoteness has also been suggested as a factor associated with lower transplantation rates, but the international evidence on this point is mixed. Other potential barriers for Aboriginal and Torres Strait Islander patients include delayed referral for transplant evaluation and delays from initial referral to transplant wait-listing.

Recent national discussion regarding how best to assess benefit for recipients post transplant, and regarding giving priority to recipients according to their likelihood of long-term survival, will potentially further impact on Aboriginal and Torres Strait Islander peoples’ access to transplantation. People with complex, chronic diseases, such as kidney disease, must negotiate often fragmented health care systems to access necessary care. In the remote area context of marked socioeconomic disadvantage, miscommunication and barriers to accessing necessary information regarding treatment options, health system barriers become a particular challenge.
There is no definitive evidence that one form of dialysis is superior to others in terms of patient mortality. Marked State- and Unit-level variation in the utilisation of home-based therapies is evident in Australia. Substantial variability between countries, jurisdictions and renal centres in dialysis utilisation patterns suggests a strong influence of non-medical factors\(^{21}\) including physician bias, the local health services delivery context – for example inability to expand satellite HD capacity has led to development of a PD first treatment strategy in various centres and regions, models for physician reimbursement and health service funding. Recent renal strategies developed by State jurisdictions have generally set targets to encourage a shift of dialysis provision into the community setting. However, such strategies suggest increase in uptake of community-based dialysis using both HD and PD in a complementary not competitive fashion.\(^{22}\)

A number of key issues to be taken into account include:

- The treatment pathway for each patient across the ‘life-course’ of ESKD is likely to include transition from one modality of treatment to other modalities. (Modelling undertaken for the Study has been based on actual treatment pathways and transitions for the CA region patient cohort.)

- These transitions are from PD to HD, dialysis to transplant, hospital to community and, less frequently, each of these in reverse.

- Randomised controlled trial evidence does not exist confirming that one form of dialysis is superior to other forms in terms of mortality or quality of life.

- For a minority of ESKD patients there are some contraindications to particular dialysis modalities – for HD, the inability to maintain vascular access; and for PD, abdominal adhesions from previous surgery or presence of an abdominal hernia. However, where prospective evaluation of ESKD cohorts has been undertaken, the majority of patients are deemed medically and psychologically suitable for both HD and PD.\(^{21}\)

- Patient-centred models of care give priority to early and ongoing patient education and emphasise the ability to make an informed choice between dialysis modalities.

- Evidence suggests that patients might choose between therapies based on their perception regarding which therapy will have the least impact on how they wish to lead their lives, thus enhancing their freedom and autonomy.\(^{23}\)

### 4.3.4 Chronic Illness Care and Prevention Services for Indigenous Peoples in Australia, New Zealand, Canada and USA: Key Influences

The systematic review confirmed that access to health services is inextricably linked to broader societal factors. Full details of the systematic review can be found in the Technical Report (Section 3.3.2.5). A full bibliography can be found in the Technical Appendices (Appendix I).

In summary, four inter-related approaches for improving future Indigenous access to chronic disease services were suggested by the literature. The successful approaches are ones that:

1. Challenge *health system perspectives* which do not take account of social, cultural and economic contexts of health and health care delivery.

2. Promote *indigenous perspectives* and understandings characterised by the right to self-govern health services and promote alternative models of care.

3. Create *health services* that are easy to navigate with Indigenous staff, adequate resources and a focus on ongoing quality improvement.
4. Enable health care encounters that are built on the trustworthiness of care providers, awareness of broader contextual factors affecting the acceptance and refusal of care, and give appropriate attention to communication processes.

These approaches are directly applicable to the review of renal services in the CA region and entail complex and multi-faceted interventions. They need to be considered against the background of a predominantly non-Indigenous health system managing the provision of care through institutions that Indigenous communities and organisations seek to have a greater role in shaping.

From the distillation of the literature review, the factors influencing accessibility of chronic illness care and prevention services for Indigenous peoples can be summarised under five main headings:

- Health system factors.
- Health care interactions.
- Health services structure, function and organisation.
- Cultural perspectives.
- Indigenous perspectives.

The key findings under each heading are described below.

Health system factors

Biomedicalisation and biomedical information - There was substantial documentation of the lack of awareness among many Indigenous people regarding the biomedical information that predominated in all health services. This included particular diseases, risk factors and clinical effects. The literature underscored the flaws in the assumption that greater education and awareness relating to this biomedical information would prompt increased action on personal health issues among Indigenous people. When health providers displayed poor recognition of, and attention to, social, cultural and economic dimensions (beyond biomedical concepts), this served to create unbridgeable gaps in clinical encounters. Similar gaps were reflected in literature relating to communication during health interactions, and have previously been explicitly documented in relation to access to, and the provision of, renal services in Australia.  

Health care interactions

Patient/provider relationships - The perceived trustworthiness of care providers, awareness of broader contextual factors affecting the acceptance and refusal of care, and adequate attention to all facets of the communication process affect service accessibility. Patient-centred care within this context enables more effective Indigenous patient-carer encounters through acknowledgement of the patient’s worldview, validation of their concerns, affirmation of individuality and autonomy. It is widely acknowledged, however, that promotion of patient-centred approaches are labour and time intensive, and require building of trust within the patient/provider relationship.

Communication - The success or otherwise of communication has been reported to play a powerful role in the accessibility of chronic health care services for Indigenous people in all four countries. Poor understanding of written or spoken health professional advice; too much, too little, or too rapidly delivered information; language difficulties; and poor provision and use of interpreter services, were often raised in the literature. There was little rigorous evaluation of interventions to address communication gaps. The literature highlighted that important health messages needed to be communicated to social and family networks to allow for effective decision-making processes. Strategies such as talking with family or community groups, and moving away from the traditional one-to-one education encounters to introduce information, were particularly useful in engaging family and social networks as well as individuals.
Health services structure, function and organisation

Navigation and permeability - The accessibility of chronic disease services for Indigenous people in all four countries was directly dependent on the practical features of the health service and the healthcare provided. Those factors raised in the literature included:

- Proximity of health services.
- Availability of transport.
- Minimal or no out-of-pocket costs for attendance and treatments.
- After-hours access.
- Outreach services and mobile clinics.
- Welcoming physical spaces.
- Indigenous staff as a critical point of contact.

Indigenous health staff - Indigenous staff roles have been shown to be crucial in health services. The recent article outlining the achievement of the Kimberley Satellite Dialysis Centre (KSDC) highlighted the importance of Indigenous staff and an accessible and welcoming organisational structure.

However, consistent anecdotal reports indicate that demands on Indigenous staff in chronic disease services can overwhelm training opportunities and professional support, thus affecting the sustainability of service provision.

Quality improvement and resource constraints - Quality improvement in chronic disease health services for Indigenous patients was often challenged by resource constraints, the competing demands of the need for acute care services, and the lack of clear delineation of staff roles. At the same time, expectations of improvements in health status measures are high. Research into Australian, Canadian and New Zealand Indigenous health performance measures has suggested that disease-focused measures can overshadow the development of locally-specific health indicators that may reflect differing values and be less amenable for use as performance measures in the classical sense.24

At a practical level, a suite of processes have been canvassed in the international literature, to drive successful quality improvement. The involvement of Indigenous advisory groups in the development of health system indicators, the setting of clear goals that have meaning for local people and communities, and the key role for Indigenous health workers in quality improvement programs, have all been suggested as important steps for devising successful quality improvement initiatives.

Cultural perspectives

The role of culture and cultural difference was a pervasive theme throughout the international literature regarding Indigenous access. Different attitudes to food, the role of shame, different clothes, different gender and avoidance protocols, different social obligations, different spiritual and healing beliefs, different use of time, and different levels of passivity and shyness, were frequently perceived by health professionals and mainly non-Indigenous organisations to be potential barriers to accessing care.

The approach of ‘cultural safety’ was extensively described in the literature. This Maori-developed movement shifted the role of culture away from a check-list approach based on a person’s ethnic background toward a critical examination of health care encounters. In doing so it built on a realisation that sensitivity and awareness alone have done little to improve Indigenous peoples’ access to better health care. Examples include developing tools that critically examine notions of culture and the avoidance of stereotyping; and making explicit the differences between cultural phenomena and those related to socio-economic disadvantage.
Indigenous perspectives

**Self-determination** - The right to self-govern health services and promote alternate models of care has been well documented as being central in Indigenous perspectives on access. Evidence showed that where Indigenous-governed services were recognised as the sole provider of care, the administrative and financial barriers they faced were lower, and services appeared to be more comprehensive. At the same time, a quantitative study of New Zealand community-governed, not-for-profit organisations indicated they were more likely to charge lower fees, employ a higher number of Indigenous staff, and provide more community services such as health promotion, thereby improving access. In Australia, the recent publication of the achievement of equitable clinical outcomes by the Indigenous-run KSDC, confirms the New Zealand experience. The KSDC is the first satellite unit run by an Aboriginal Community Controlled Health Service.

**Social and community focus** - Indigenous family-based social structures are well documented as a source of practical and emotional support for health care needs, while dislocation from family and land emerged as a particularly difficult aspect of accessing chronic disease health care, and consequently determinant of poor health outcomes, for Indigenous people in all four countries.

**Indigenous knowledge** - The international literature strongly voiced the importance of Indigenous knowledge underpinning better access and outcomes. Such knowledge was reported as stemming from connection to land and natural environments; ceremony, stories and spiritual practice; access to traditional foods; and the role of elders in knowledge formation. The importance of traditional healing and healers featured in a range of studies, articles, reviews and the like. On the other hand, there were few examples of health services successfully incorporating Indigenous knowledge. New Zealand’s Kaupapa Service – Whanaungatanga Model of Care and the Native American Patient Advocate program are two notable exceptions. Disregard for Indigenous knowledge may form a barrier to engagement of Indigenous people, their family and community in the provision of necessary chronic disease care.

Implications for renal service delivery in the CA Region

The key themes identified in this international literature review are directly relevant to the delivery of renal services in the CA Region.

**First** - Aboriginal and Torres Strait Islander people, communities and organisations continue to perceive that governments and health systems discriminate according to Aboriginal and Torres Strait Islander status. Key policy responses in Australia to address this perception of discrimination have been made through commitment to the Close the Gap campaign and a range of initiatives to address inequitable access to and utilisation of preventative, primary care and acute care services. The Council of Australian Governments National Partnership Agreement on Remote Service Delivery has articulated principles that form an appropriate basis for service planning and delivery across the region. Schedule C of this Agreement indicates the following principles for delivery of programs and services for Aboriginal and Torres Strait Islander peoples:

- **Priority:** Programs and services should contribute to Closing the Gap.
- **Aboriginal and Torres Strait Islander engagement:** Engagement with Aboriginal and Torres Strait Islander people and communities should be central to the design and delivery of programs and services.
- **Sustainability:** Programs and services should be resourced over an adequate period of time.
- **Access:** Programs and services should be physically and culturally accessible to Aboriginal and Torres Strait Islander people.
- **Integration:** There should be collaboration between and within governments at all levels and their agencies.
**Accountability**: Programs and services should have regular and transparent performance monitoring, review and evaluation.

The provision of safe, appropriate, high-quality and sustainable care has been shown to need multi-faceted and complex interventions that are based on partnership and negotiated with patients and communities.

**Second** - Practical approaches to developing appropriate health service structures and modes of delivery will be crucial to improving the delivery of renal services: proximity to care, availability of transport, mobile clinics, welcoming physical spaces and meaningful roles for Aboriginal and Torres Strait Islander staff.

**Third** - In light of the international evidence, strategies to address poor adherence to treatment regimens amongst Aboriginal and Torres Strait Islander renal patients will be best served if they focus on transforming health services to deliver patient- and family-centred care. Addressing structural constraints, for example the lack of appropriately trained interpreters, lack of staff and lack of social resources such as housing, security and transport, will be fundamental to providing patient-centred care.
5 Current and Future Burden of Renal Disease in the CA Region

5.1 Total Numbers Affected

ESKD burden in the CA region

For Aboriginal and Torres Strait Islander patients in the CA region, maintenance dialysis remains the predominant modality for delivery of RRT. Analysis of ANZDATA Registry data, from 1999 to 2009, shows that the number of Aboriginal and Torres Strait Islander peoples receiving maintenance dialysis from the CA region more than tripled from 62 to 209 (Figure 1).

Figure 1: Prevalent ESKD patient

![Bar chart showing prevalent dialysis patients in CA region, by Aboriginality](image)

The increase in prevalence has been driven principally by the growing number of patients commencing RRT each year. However, there is a suggestion that the number of new cases per year may have stabilised, in the 35 to 40 range (Figure 2). Similar uncertainty about the direction of current incident rates exists for whole-of-Australia predictions of the burden of ESKD, and adds a degree of uncertainty which is incorporated in the forward projections for the Central Australia region by explicitly modelling high-range and low-range scenarios.
It is important to consider trends in renal services requirements in the CA region in the context of national trends. Overall, unadjusted ESKD incidence for Aboriginal and Torres Strait Islander peoples remains approximately four times higher than the national average. This rate varies by state, with disease incidence in South Australia, Western Australia and the Northern Territory ranging from approximately 1.5 to 3 times higher than national Aboriginal and Torres Strait Islander rates (Figure 3). The vast bulk of this burden falls in the ages between 35 and 65 (Figure 4), traditionally periods of maximum productivity, family and community contribution and leadership.
Accurate and detailed representations of the geographic distribution of prevalent Aboriginal and Torres Strait Islander dialysis patients are problematic. Most are acknowledged to be an inaccurate reflection of health need because the majority of patients in remote regions must relocate to access renal care. Research effort has been directed to providing accurate detailed representation of the community of origin for Aboriginal and Torres Strait Islander ESKD patients. However, the acquisition of these data has
required painstaking manual collection and collation. Such an approach therefore is labour intensive and lacks timeliness, and cannot be considered adequate to underpin service development.

**CKD burden in the CA region**

Data were collected and analysed from a range of sources, with full details available in the Technical Report. Based on primary care and renal unit data, 585 people in the CA Region were identified with CKD Stages 3 to 5. More than 70% had CKD Stage 3. These data are presented in Table 1.

As outlined in the methodology, these data represent people identified by service providers, in individual patient records, as being diagnosed with CKD. While service provider data are a reliable indicator, they do not represent complete capture of cases of disease. As such these data are likely to represent an improvement on previous data sources, but still likely represent a significant undercount. Accordingly, the total numbers for the region should be treated with caution.

**Table 1: People with CKD in CA Region**

<table>
<thead>
<tr>
<th>Database</th>
<th>CKD Stage 3 (eGFR 30 to 59)</th>
<th>CKD Stage 4 (eGFR 15 to 29)</th>
<th>CKD Stage 5 (eGFR &lt;15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NT Health CA dataset</td>
<td>300</td>
<td>104</td>
<td>29</td>
</tr>
<tr>
<td>Nganampa Health Service</td>
<td>51</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Ngaantyajarra Health Service</td>
<td>65</td>
<td>18</td>
<td>4</td>
</tr>
<tr>
<td>Total across CA region</td>
<td>416</td>
<td>132</td>
<td>37</td>
</tr>
</tbody>
</table>

On balance, international evidence suggests that people with CKD Stage 3 are more likely to die than they are to progress to commencing RRT. Concerns have been raised that Aboriginal patients might progress more quickly through stages of CKD and that there might be a different balance between the excess risk of premature mortality and progression to ESKD. Nevertheless, there is a paucity of evidence to substantiate or refute such concerns. The variability in progression, reinforced by data provided by Nganampa Health Service which followed known CKD patients over time, underlies the uncertainty in predicting the numbers of incident RRT patients from any given community. A better understanding is required regarding which factors are associated with rapid progression of CKD, and which with preservation of renal function.

Even when restricting consideration to people with more severe forms of CKD (CKD Stages 4 and 5), progression to ESKD is not assured. Patients with Stages 4 and 5 CKD, however, have more advanced disease and are likely to have been referred to renal services to discuss treatment options, initiate planning for and track progression towards RRT.

Nevertheless, almost 20% of patients in the CA Region commence RRT as ‘late-referred’ patients – first seen by a renal service within three months of commencing renal replacement therapy. In this situation, patients are unable to receive timely education regarding treatment options and have little ability to achieve planned commencement of renal replacement. Late referral has been shown to be associated with higher costs of hospitalisation, reduced access to transplantation and poor health outcomes.

**Projections of burden of ESKD**

The data used for analysis was obtained as a de-identified extract from the ANZDATA Registry. This Registry contains details of all patients in Australia (and New Zealand) who have received renal replacement therapy (dialysis or transplantation). It does not include patients with ESKD who did not
receive renal replacement therapy. Data are supplied to the registry by all renal units throughout Australia and New Zealand on a regular basis.

The demographic data supplied for individual patients includes the residential postcode at initiation of renal replacement therapy, together with the treating renal unit. It does not include individual identification of the particular aboriginal community people came from, or consider their home, nor does it include details of residential postcodes six or 12 months prior to commencement of renal replacement therapy. Nevertheless, it represents an accurate estimate of the demand placed upon renal services to provide treatment for people with ESKD.

Historic age-specific trends in the incidence of treated ESKD across the CA region were examined to determine likely future trends for the years 2010-2020. Three possible scenarios have been modelled:

- The Steady State Model, with a stabilisation of the yearly number of incident patients.
- The Growth Model, with a steady long-term linear increase in the yearly number of incident patients, consistent with growth seen since 1995.
- The Prevention Model, where a coordinated program might prevent 20% of incident ESKD cases.

Projections were modelled under each of these scenarios. Full details of the analyses, and their assumptions are provided in the Technical Report and Technical Appendices.

The projections indicate that, in 2020, the number of people in the CA region of all ages commencing RRT will lie between 35 and 81. On the basis of these models, an increase of up to 130% in the number of new patients commencing RRT above 2009 figures is projected. The majority of this increase is driven by new Aboriginal ESKD cases in the population aged 45 to 64 years. Changes in the transplant rate or dialysis survival in the next ten years will have some effect, but such effects are likely to be numerically much less important and historically have been much more stable. A further issue is the statistical variation inherent in analysis of numbers of this scale.

These projections indicate that, on 31 December 2020, when combined with current survival probabilities for ESKD patients receiving treatment in the CA region, the number of people receiving RRT in the CA region will lie between 312 (steady state model) and 479 individuals (growth model) (Table 2).

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Steady State</td>
<td>250</td>
<td>260</td>
<td>268</td>
<td>275</td>
<td>281</td>
<td>286</td>
<td>291</td>
<td>296</td>
<td>301</td>
<td>305</td>
<td>309</td>
<td>312</td>
</tr>
<tr>
<td>Prevention</td>
<td>255</td>
<td>271</td>
<td>279</td>
<td>287</td>
<td>298</td>
<td>310</td>
<td>322</td>
<td>337</td>
<td>352</td>
<td>370</td>
<td>389</td>
<td>409</td>
</tr>
<tr>
<td>Growth</td>
<td>255</td>
<td>271</td>
<td>287</td>
<td>303</td>
<td>321</td>
<td>339</td>
<td>358</td>
<td>380</td>
<td>402</td>
<td>427</td>
<td>453</td>
<td>479</td>
</tr>
</tbody>
</table>

On the basis of these models, an increase of between 30% and 100% in the number of patients receiving RRT above 2008 figures is projected (Figure 5).
Figure 5: Projected prevalent ESKD cases to 2020
5.2 Geographic Distribution

Accurate data describing population prevalence of CKD by community are not available. Data were obtained specifically for this Study, from the NT Renal Services CKD database and primary healthcare services databases to describe the number of people with advanced CKD, by community.

The distribution of people with advanced CKD presented in Table 3. For communities with 3 or fewer individuals with advanced CKD, the exact number has been omitted to protect privacy.

Several caveats should be acknowledged when considering Table 3:

- Not all CA region communities are represented in this Table, which presents data regarding advanced CKD only. For example, according to recent data supplied by Nganampa Health Service, Amata, a community in the APY Lands with a population count of 288 at the 2006 Census, currently has 16 patients with CKD Stage 3, but none with more advanced CKD.

- A large number of people identified as having advanced CKD are living in Alice Springs and Tennant Creek. Previous research\(^2\) has confirmed that a significant number of these patients will have relocated to regional centres to access necessary specialist care and are likely to consider a remote community, not the regional centre, their home.

- Many remote communities have a small number of people identified with advanced CKD. This means that the number of people commencing and needing dialysis from any particular remote community, over time, will be highly variable. It is not possible to discern any meaningful pattern within the CA Region, at community level, in terms of future demand for renal services.

- The data below do not reflect known patterns of mobility for community members. For example, data supplied by Nganampa including numbers of people with CKD by community, indicated that more than 1 in 3 of the people with advanced CKD were visitors from the Northern Territory or Western Australia.

- These data are a one-off collection, undertaken for this Study, and as such they only present a snapshot at a point in time. On the other hand, these data provide a starting point for understanding the geographic distribution of people affected by advanced CKD in the region.
Table 3: People with advanced CKD by community

<table>
<thead>
<tr>
<th>Community</th>
<th>CKD Stage 4 (eGFR 15 to 29)</th>
<th>CKD Stage 5 (eGFR &lt; 15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alice Springs</td>
<td>18</td>
<td>≤3</td>
</tr>
<tr>
<td>Alice Springs CAAC</td>
<td>25</td>
<td>7</td>
</tr>
<tr>
<td>Tennant Creek</td>
<td>20</td>
<td>4</td>
</tr>
<tr>
<td>Ali Curung</td>
<td>6</td>
<td>≤3</td>
</tr>
<tr>
<td>Amooguna</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Ampilatwatja</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Canteen Creek</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Docker River</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Elliott</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Epenarra</td>
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<td>≤3</td>
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<tr>
<td>Haasts Bluff</td>
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<td>≤3</td>
</tr>
<tr>
<td>Harts Range</td>
<td>≤3</td>
<td>≤3</td>
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<tr>
<td>Ntaria</td>
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<td>≤3</td>
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<tr>
<td>Kintore</td>
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<td>Lake Nash</td>
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</tr>
<tr>
<td>Laramba</td>
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<td>≤3</td>
</tr>
<tr>
<td>Mt Allen</td>
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<td>≤3</td>
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<tr>
<td>Nyirripi</td>
<td>≤3</td>
<td>≤3</td>
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<tr>
<td>Papunya</td>
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<td>≤3</td>
</tr>
<tr>
<td>Santa Theresa</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Tara</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Ti Tree</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Utopia</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Willowra</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Yuendumu</td>
<td>4</td>
<td>≤3</td>
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<tr>
<td>Blackstone</td>
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<td>≤3</td>
</tr>
<tr>
<td>Jamieson</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Kiwirrkurra</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Wanarn</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Warburton</td>
<td>8</td>
<td>≤3</td>
</tr>
<tr>
<td>Pipalyatjara</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Iwantja</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Pukatja</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Fregon</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Mimili</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Nyapari</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>127</strong></td>
<td><strong>39</strong></td>
</tr>
</tbody>
</table>

At the time of the Study, approximately one in five patients - particularly those with the most advanced or Stage 5 CKD - were waiting, with an AV fistula created or PD catheter inserted, to commence RRT.
5.3 Renal Failure: Treated and Untreated

Estimating the burden of treated and untreated renal failure is problematic and no methods have been validated. Reliable data regarding the proportion of people in the CA region who choose not to take up RRT are not available. Nevertheless, a recent approach to estimation of the total incidence of end-stage kidney disease at the national level might prove helpful.

Data extracted from the ANZDATA 2007 Report indicate that 8,599 Australians commenced RRT during 2003 to 2006. For the same period, combining these ANZDATA cases with people who died with end-stage kidney disease indicated as a cause of death on their death certificate, but who did not receive RRT, there were 16,610 total cases of end-stage kidney disease. (National Healthcare Agreement: Baseline performance report for 2008-09).

Thus, it is estimated that the treated proportion of patients is approximately half of those with ESKD (8,599/16,610 = 52%).

A recent presentation by the Australian Institute of Health and Welfare, of a soon to be published report ("Total incidence of end-stage kidney disease KRT-treated and other cases, 2003-2007"), identified the following key points:

- Nationally, the ratio of treated: non-treated ESKD is approximately 1:1.
- Untreated cases are predominantly amongst those aged 70 and over.
- Among Aboriginal and Torres Strait Islander peoples, who are affected by ESKD at a younger age, 84% of cases receive RRT, while only 51% of non-Aboriginal and Torres Strait Islander cases receive RRT.
- The age-standardised ratio of receipt of RRT, between Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander peoples, was 0.96, indicating that Aboriginal and Torres Strait Islander peoples had slightly lower treatment rates.

Indicators of access to necessary CKD care

To consider access to necessary care among Aboriginal people with CKD in the CA region, a range of indicators are available. For the present Study, ten key indicators were used, based on evidence that they are markers of delivery of care to renal patients across the spectrum of CKD and are strongly linked to health outcomes, or constitute key health outcomes in their own right (Table 4). This table is not intended to be prescriptive with respect to jurisdictional reporting requirements. Rather, it harnesses the evidence for the purposes of this Study, to provide a framework for describing the extent to which clinical needs of CKD patient are addressed. References are provided for each indicator in the table.
Table 4: Key indicators across the spectrum of CKD and their rationale

<table>
<thead>
<tr>
<th>1. Primary-care based screening for CKD</th>
<th>Documented evidence of measurement of blood pressure, estimated GFR (marker of kidney function) and Albumin to Creatinine Ratio amongst people indicated to be screened according to national preventative guidelines. Evidence indicates that opportunistic screening for CKD amongst high-risk patients in primary care is likely to be highly cost-effective.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Assessment of prescribing and treatment gap in the management of elevated blood pressure in people with CKD</td>
<td>Assessment in people with CKD, using relevant national management guidelines, of the proportion of people in whom blood-pressure lowering therapy is indicated that are not receiving such therapy. In addition, the proportion of people receiving blood-pressure lowering therapy who are failing to meet suggested blood pressure targets. Evidence indicates that evidence-based management of elevated blood pressure would reduce premature mortality and progression to ESKD.</td>
</tr>
<tr>
<td>3. Proportion of new ESKD cases that are referred late to nephrology care (Patients are characterised as having been referred late when they are first seen by nephrology services within 3 months of commencing RRT.)</td>
<td>Evidence indicates that late referral leads to higher costs of hospitalisation, higher mortality throughout the course of RRT and lower access to kidney transplantation.</td>
</tr>
<tr>
<td>4. Proportion of new ESKD cases that commence dialysis with functioning access</td>
<td>This is a measure of HD commencement in a planned fashion with a functioning fistula (or graft). Evidence indicates that commencing dialysis without functioning vascular access is causally associated with higher mortality.</td>
</tr>
<tr>
<td>5. Proportion of prevalent RRT patients receiving home-based therapies</td>
<td>Evidence indicates that a shift to home-based therapies would reduce healthcare costs and that receipt of dialysis treatment close to home in remote areas is associated with higher rates of adherence to complex renal treatment regimens and better treatment outcomes.</td>
</tr>
<tr>
<td>6. Patient survival on HD</td>
<td>HD is the treatment modality being received by the majority of patients across the CA region.</td>
</tr>
<tr>
<td>7. Peritonitis rate — episodes of peritonitis per patient year of peritoneal dialysis treatment</td>
<td>Peritonitis is the crucial factor affecting patient outcome and technique survival amongst renal patients.</td>
</tr>
<tr>
<td>8. PD technique survival rate</td>
<td>The proportion continuing PD 1 year after initiation. This is a crucial measure of the sustainability or viability of PD.</td>
</tr>
<tr>
<td>9. Proportion of prevalent RRT patients with a functioning kidney transplant</td>
<td>Evidence indicates that kidney transplantation is more cost-effective and associated with better quality of life and improved treatment outcomes for most patient groups. There is ongoing debate regarding transplant outcomes amongst Aboriginal and Torres Strait Islander peoples.</td>
</tr>
</tbody>
</table>
Data from a range of primary care surveys, renal unit level and national registry reports can be considered, to assess success in addressing CKD treatment needs. Where data are available, both published and unpublished, results from the CA region can be compared to representative national findings (Table 5). Key points to note from Table 5 are as follows:

**Treatment**

- Screening rates appear low, however national representative rates are not available. With the heavy burden of disease in the CA region, this shortfall is likely to have a large impact.
- Blood pressure management in people with CKD in Aboriginal Health Services in the CA region does not differ greatly from that of the Australian general population. Again, with a much heavier burden of disease in the CA region, the quality shortfall is likely to have a much larger impact.
- The proportion of patients with late referral among CA region patients is consistent with national rates.
- The proportion of CA region patients commencing dialysis in a planned fashion is approaching national rates.
- Access to home- or community-based renal services remains a significant service delivery challenge.

**Outcomes**

- HD survival among CA region patients, with median survival beyond 4 years after initiation on dialysis, appears consistent with national rates. However, comparison to national survival should be interpreted cautiously, as the CA region cohort is younger than the national cohort.
- PD and transplantation among suitable patients are areas that are a priority for monitoring and evaluation to improve health outcomes.
### Table 5: Addressing clinical needs of CKD Patients: Treatment and Outcomes

<table>
<thead>
<tr>
<th>Clinical Indicator</th>
<th>CA region Aboriginal patients</th>
<th>National patient cohort</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TREATMENT</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screening for CKD</td>
<td>40% a</td>
<td>Direct comparison not available d</td>
</tr>
<tr>
<td>BP evidence-practice management gap</td>
<td>50% c</td>
<td>58% d</td>
</tr>
<tr>
<td>Late referral (2005-2009 patient cohort)</td>
<td>17% e</td>
<td>22% e</td>
</tr>
<tr>
<td>Dialysis initiation with functioning access (New patients 2008)</td>
<td>40% f</td>
<td>54% f</td>
</tr>
<tr>
<td>Access to home-based dialysis (Proportion of 2009 prevalent cohort)</td>
<td>5% e</td>
<td>17% e</td>
</tr>
<tr>
<td><strong>OUTCOMES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Haemodialysis patient survival (Proportion alive on HD 1 year after initiation)</td>
<td>87.5 (95% CI 81.2-91.8) i</td>
<td>84.2 (95% CI 83.3-85.0) i</td>
</tr>
<tr>
<td>Haemodialysis patient survival (Proportion alive on HD 4 years after initiation)</td>
<td>61.5 (95% CI 50.9-70.5) i</td>
<td>53.4 (95% CI 51.7-55.1) i</td>
</tr>
<tr>
<td>Peritonitis rate (Infections per patient-year of PD treatment in 2008)</td>
<td>1.35 (95% CI 0.58-2.67) t</td>
<td>0.63 (95% CI 0.59-0.66) t</td>
</tr>
<tr>
<td>PD technique survival (Proportion continuing PD 1 year after initiation)</td>
<td>50.8 (95% CI 21.4-74.2) t</td>
<td>70.5 (95% CI 68.9-72.0) t</td>
</tr>
<tr>
<td>Transplant (Proportion of 2009 prevalent cohort)</td>
<td>6% e</td>
<td>46% e</td>
</tr>
<tr>
<td>5-year functioning kidney transplant survival</td>
<td>25% (95% CI 7%-49%) o</td>
<td>82% (95% CI 81%-84%) o</td>
</tr>
</tbody>
</table>

**Table 5 - Data Sources:**

- ^a^ Unpublished analysis from the Kanyini Vascular Collaboration Audit Study.
- ^b^ Unpublished evidence from the AushEART study of screening and management of vascular risk indicates CKD documentation in mainstream general practice patients is poor.
- ^c^ Kanyini Vascular Collaboration Audit Study data.
- ^d^ AushEART Study data.
- ^e^ Special data request ANZDATA Registry November 2011. For the purposes of these analyses, the CA region included patients who commenced dialysis treatment in Alice Springs, plus those whose postcode (0872 and 6431) indicated geographic origin within the Alice Springs area, APY lands or Warburton areas.
- ^f^ ANZDATA Registry 2009. Alice Springs Renal Unit Individual Hospital Report 2003-8. Alice Springs Renal Unit patients were substantially younger than the Australian average, which is likely to account for some or all of the difference in haemodialysis survival.
6 Current Services

Service capacity in the CA region is dynamic, evolving and growing. The snapshot description provided here serves to inform service development. Full details of the data collected for the Study to obtain a summary of current services can be found in the Technical Report (Section 3.5) and Technical Appendices (Appendix A).

6.1 Current Location of Dialysis Facilities

The Central Australian cross-border region covers roughly one million square kilometres and is sparsely populated. The current location of services is illustrated in Figure 6.

The regional centre Alice Springs has a tertiary hospital; transport links; government, social services and community organisation offices; and a renal unit with capacity for comprehensive renal service delivery across the continuum of CKD. Tennant Creek is the next largest population and service centre.

It should be noted that this map presents where facilities are currently located only, as background to the Study and its recommendations for service development. It does not identify where patients consider to be their home community, or where patients are likely to be located in the future.

As discussed previously, predicting future patient location patterns is particularly problematic because the number of people over time from any particular remote community commencing or needing dialysis is highly variable. Moreover, the variability in progression of CKD is well documented. Specific data provided by Nganampa Health Service, which followed known CKD patients over time, attests to this among CA region patients. The uncertainty around progression underlies uncertainty in predicting the numbers of incident RRT patients from any given community.

Figure 6: Renal Services in NT and Central Australian region catchment

Source: DoHA, Australian Govt.
6.2 Current Nature of Services

The predominant modality of renal service delivery across the CA region is satellite or in-centre HD (Table 6). Current facilities are located in Alice Springs and Tennant Creek, with a total of 56 machines from early 2011.

<table>
<thead>
<tr>
<th>RRT modality</th>
<th>CA Aboriginal patients % (n = 223)</th>
<th>National non-Aboriginal patients % (n = 17,195)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PD</td>
<td>2%</td>
<td>13%</td>
</tr>
<tr>
<td>Home HD</td>
<td>2%</td>
<td>5%</td>
</tr>
<tr>
<td>Satellite or hospital HD</td>
<td>89%</td>
<td>36%</td>
</tr>
<tr>
<td>Transplant</td>
<td>6%</td>
<td>46%</td>
</tr>
</tbody>
</table>

* As indicated previously, analysis undertaken for this Study enabled identification of a specific cohort of patients whose first treatment was undertaken at a post code in the CA region. In line with previous work, non-Aboriginal patients were able to be reliably identified from the ANZDATA.

Community-based PD and HD are available in the CA Region. However, uptake has been limited, with less than 10% of dialysis patients utilising community-based therapies. Data sought by and provided for this Study from stakeholders indicated a sparse distribution of self care. Including patients in training, self-care HD is currently provided to 11 patients across CA in Ali Curung, Lake Nash, Mt Liebig, Amoonguna and in Santa Teresa.

Uptake of peritoneal dialysis in CA region communities is much lower than the national average. Currently, negative perceptions regarding PD are a significant barrier to the expansion of this modality of care. Including patients in training, PD is currently provided to 13 patients across the CA region in Tennant Creek, Alice Springs or Santa Teresa, Kintore/Kiwiirkurra and in Warburton.

No patients are currently receiving dialysis in the APY lands. This likely reflects lack of access to dialysis services closer to home, which is well demonstrated as a determinant of uptake of RRT and adherence to treatment regimens.

Respite dialysis services, aiming to allow patients to return to their home communities for periods of several weeks, are located in Alice Springs, Kintore, Hermannsburg and Yuendumu. However, the services are currently limited: Respite services are provided for up to 4 patients in Kintore, 4 patients in Hermannsburg and 4 patients in Yuendumu at any one time.
6.3 Gap Analysis

Access for CA region Aboriginal patients to necessary health services to slow progression of CKD, prepare for dialysis if and when it is required, and build capacity to self-manage and thus access treatment as close to home as possible, is limited by a combination of remoteness, poverty, lower educational attainment and cultural and language differences. Enhancement in outreach services to remote communities by CA region Renal Services and facilitation of CKD management through enhanced engagement and partnership with local health providers has the potential to reduce disease progression, improve the acute transition to dialysis therapy and thus health outcomes.

Language and cultural barriers between Aboriginal patients and health service providers have been well documented and result in frequent if not pervasive miscommunication. Such miscommunication may further decrease the ability of patients to access appropriate care. Previous research has documented the lack of appropriately trained interpreters and health service staff have expressed concern regarding their own capacity to appropriately utilise interpreter services. An Aboriginal interpreter training program addressing renal and related chronic diseases for interpreters for the cross-border language communities, and short courses for renal health professionals in working with Aboriginal interpreters, would potentially address these important gaps in service provision.

Provision of renal replacement therapy in the CA region has been characterised in particular by continuous increases in demand for satellite dialysis services. However expansion of satellite dialysis service facilities has been episodic and generally driven by crises when demand exceeds supply. Limited uptake of home or community based dialysis options further exacerbates this problem. Processes that plan for appropriate expansion of satellite dialysis in a timely manner and encourage a greater proportion of patients to utilise home or community-based dialysis have the potential to reduce this problem.

The vast majority of patients who require renal replacement therapies have to date had to relocate to Alice Springs. There they face significant barriers to obtaining secure accommodation and managing the transition to an urban environment including such activities as accessing social services and financial assistance. Opportunities exist to improve accommodation provision and social work services that would diminish the burden of relocation on patients and their families.

Patients, their families and communities face considerable distress with forced relocation to the urban area for dialysis. There has been a limited ability for some groups to access return-to-community respite dialysis through the Western Desert Ngarluma Walytja Palyantjaku Tjutaku Aboriginal Corporation (WDNWPT). In 2011, both NT Renal Services and WDNWPT aim to commence mobile dialysis services, which will increase return to community dialysis options. Enhancement of such a service, to a greater number of communities in a number of modes, offers an improved quality of life for patients and their respective communities.

Thus, gaps in current service provision cross a range of dimensions, including geographic, cultural, clinical and social dimensions (Table 7). Some of these are specific to renal services while others relate more generally to health services in remote central Australia. In making recommendations on a preferred renal services model for the CA region, the full spectrum of challenges needs to be kept in mind in order to assess sustainability of expansion of services.
### Table 7: Challenges for service delivery models in CA region renal services

<table>
<thead>
<tr>
<th>Area of Challenge</th>
<th>Contributors to Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Culturally appropriate services</td>
<td>Language, Cultural skills, Lack of appropriately skilled interpreters, Inadequate Aboriginal and Torres Strait Islander health workforce</td>
</tr>
<tr>
<td>Service provision/availability</td>
<td>Satellite dialysis facility growth not matching demand, Low utilisation of home/community based dialysis, Lack of co-ordination in service delivery</td>
</tr>
<tr>
<td>Social support</td>
<td>Lack of secure accommodation, Insufficient social services, Managing transition to town</td>
</tr>
<tr>
<td>Quality of life</td>
<td>Dislocation to receive services, Lack of respite services</td>
</tr>
</tbody>
</table>
7 Resources Required to Provide Renal Replacement Treatment

7.1 Whole of Service Costs

Full details of assumptions, inclusions and exclusions, and modelling of whole of service costs can be found in the Technical Appendices (Appendices B, C and D).

Dialysis

Cost data for provision of dialysis services were based on information provided by NT Renal Services. As NT Renal Services have been the providers of renal services in the CA region to people from the cross-border region, these were considered to be the relevant costs to be used in the present analyses.

Given the likely differences in the resources required to deliver dialysis services by geographic region, these are likely the most robust estimates available for the cost of providing dialysis services in the Central Australian region. These data included:

- Staff costs (including nursing and allied health staff, medical).
- Direct costs associated with dialysis (including pharmacy, fluids and consumables).
- Overheads.
- Administration & 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 (NHCDC Round 13: 2008-9) AR-DRG cost-weights have been used for relevant DRG-based costs.

There are currently no published estimates of costs for respite dialysis, either using the mobile bus or nurse-supported in community models. For each respite model, the annual cost of service provision, to provide access to how many communities, for how many people, for what period, have been estimated using known cost components derived from NT sources (noting that respite dialysis to provide return to country is specific to the Region).

Capital costs, as relevant to conditions in the Central Australia 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 included. While based on published national guidelines, these provide realistic costs, specific to the conditions in Central Australia.

Transplant

For residents of the CA region, surgery, initial hospitalisation and the immediate and intensive post-transplantation monitoring occurs in Adelaide. Accordingly, the unit costing from the recently completed national report for Kidney Health Australia has been used. 31

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. Data sources are discussed in more detail in the Technical Appendices.
Supporting infrastructure

Comprehensive protocols exist, and are used, in Western Australia and the Northern Territory which set out the requirements for the establishment of dialysis treatment facilities in remote communities. These clearly address issues of minimum standards with regard to water quality, electricity supply, location and design. In general, the evidence indicates that it is possible to address key infrastructure requirements in most community settings. Full and detailed consideration of these requirements can be found in the Technical Report (Section 3.8, Section 3.10), and the Technical Appendices (Appendix E).

Patient housing

Finding accommodation was identified by all service providers, in all jurisdictions, as the single biggest challenge for kidney patients moving to town for dialysis. Alongside the fundamental challenge of finding accommodation, challenges in maintaining tenancies were also highlighted. The Study Team consulted widely to establish a picture of current accommodation patterns for dialysis patients in Alice Springs. Full details of these consultations and their findings can be found in the Technical Report (Section 3.9).

Public housing waiting lists in all jurisdictions are two years or longer, rising to three years in the Northern Territory and four years in some localities such as Tennant Creek. Renal patients need permanent accommodation whereas the majority of available, low-cost accommodation is short term.

Among renal patients living in Alice Springs, 50-55 patients are living in hostels, 60 in public housing, and a high proportion of the remainder are living, either permanently or temporarily, in town camps. The Renal Unit Social Worker suggested that 30-35 patients (15-20%) were without secure housing of any type. This is consistent with a report from Homelessness Australia which estimated that “approximately 40 renal dialysis patients live on Town Camp communities, often with inadequate accommodation and support. Most are originally from remote communities.”

Moreover, patients moving to town are generally accompanied by family, carers and dependents. Research has estimated that as many as five people may follow a person going for dialysis. This has implications for accommodation, social support services, employment and education. Renal patients need permanent accommodation whereas the majority of available, low-cost accommodation is short term.

The Study found that approximately 35% of Alice Springs-based patients are living in town camps administered by Tangentyere Council. Concerns were expressed regarding these patients’ access to necessary health and social services. The majority of renal patients in Tennant Creek are living in town camps.

The absolute shortage of public housing properties is an under-resourced infrastructure need of renal patients. As a case in point, Table 8 provides a snapshot of current hostel based accommodation of patients who have relocated to town. As the snapshot highlights, most hostel accommodation is stop gap in nature, rather than dedicated, or even focused on renal patient needs.
Table 8: Summary of hostel and visitor accommodation in Alice Springs *

<table>
<thead>
<tr>
<th>Name</th>
<th>Type</th>
<th>Renal patients?</th>
<th>Renal residents</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Topsy Smith</td>
<td>40 bed Aboriginal hostel for renal patients</td>
<td>Yes – no children; independent</td>
<td>40</td>
<td>permanent places; Full; waiting list of 43 renal patients;</td>
</tr>
<tr>
<td>Ayiparinya</td>
<td>94 bed Aboriginal hostel Short term transients</td>
<td>Yes –only if on public housing waiting list; no priority given; can accommodate family</td>
<td>10</td>
<td>No permanent residents; waiting list of renal patients</td>
</tr>
<tr>
<td>Akangkentye</td>
<td>65 bed Aboriginal hostel</td>
<td>Yes –only if on public housing waiting list; no priority given;</td>
<td>2</td>
<td>No permanent residents</td>
</tr>
<tr>
<td>Sid Ross</td>
<td>40 bed Aboriginal hostel – medical transients</td>
<td>No (except for hospital procedures)</td>
<td>0</td>
<td>No permanent residents</td>
</tr>
<tr>
<td>Lodge, Bath St</td>
<td>38 bed Managed Accommodation – medical support facility for PD</td>
<td>Yes - does not cater for families</td>
<td>Not open</td>
<td>Open 2011</td>
</tr>
<tr>
<td>Percy Court</td>
<td>28 unit Housing Village – Managed transitional housing</td>
<td>probably</td>
<td>Not open</td>
<td>Open 2011</td>
</tr>
<tr>
<td>Apmere Mwerre</td>
<td>150 person Aboriginal Hostels Managed Visitor Park – various grades of accommodation including camping facilities</td>
<td>Unlikely – short term residents only – 2 weeks max</td>
<td>Not open</td>
<td>Open 2011</td>
</tr>
</tbody>
</table>

Estimating patient housing costs

The current housing shortage for patients is highlighted by the qualitative data obtained for the Study. The forecast increase in prevalence suggests the number of houses that would need to be built each year to 2020, for facility based dialysis alone.

Cost estimates for housing provision were obtained from the WDNWPT Lajamanu submission and a quotation for housing construction provided by WDNWPT[TM]. The NT Department of Construction and Infrastructure also provided advice regarding the cost of housing and depreciation schedules relating to housing and other renal service infrastructure.

Staff housing

While acknowledging that building housing for patients and families, rather than staff, is the main driver of cost for renal services, the needs of staff accommodation cannot be ignored. In estimating resources required for renal services delivery, the Study formally included the cost of accommodation for Staff as part of the whole of service costs for models of community-based, mini satellite and respite dialysis.

The role of accommodation in the recruitment and retention of staff also needs to be borne in mind. Innovative remuneration packages are likely to include the provision of housing – either through existing housing stock or through new building. These costs are difficult to predict, and as such they have not been included in the modelling undertaken for the Study. The need to keep them in mind as part of the suite of workforce strategies is explored however (see Section 9 of this report).
Innovative supporting “infrastructure” to better address social and cultural needs.

As part of the Study extensive consultation was undertaken to fully describe social and cultural needs of renal patients. Details can be found in the Technical Report (Section 3.9).

Dialysis patients consulted for this Study reported that their first preference was to have their dialysis in their home community or as close to home as possible. This view reflects the well-documented impact of retaining social and cultural connectedness as fundamental to well being, treatment adherence and health outcomes. In the context of Aboriginal dialysis patients, treatment adherence needs to be considered from a range of perspectives. From a staff perspective adherence most often refers to whether or not patients actually attend dialysis. Aboriginal patients do not think of, or describe themselves, as non-adherent. Patients discussed attendance at, or missing dialysis in terms of the totality of social, emotional, family and cultural issues they were grappling with. Poor levels of understanding of the potential consequences, and/or disbelief about risks of missing dialysis sessions, would also appear to contribute.

The impact of kidney disease and its management for Aboriginal patients needs to be understood within this social and cultural context. The maintenance of social and cultural connectedness is fundamental for RRT in the CA region. For this Study, stakeholders and patients reported that social and cultural connectedness could be maintained through being able to make regular return visits to their home community and by having a stable, if diminished, family life in town. There are two programs that currently support this: respite dialysis and ‘Return to Country’.

Respite dialysis

Respite dialysis services, enabling temporary return to country, are provided by WDNWPT in the CA region. Consultation undertaken during the Study underscored the high positive regard patients and community members have for respite dialysis provision. Several communities and community organisations across the Region expressed strong interest in exploring options for respite dialysis care in their community. Patients who are provided short-term treatment in communities for periods of several weeks will require ongoing maintenance dialysis, predominantly in a satellite centre, throughout the rest of the year.

Current capacity supports respite dialysis for up to 4 patients in Kintore, 4 in Hermannsburg and 4 in Yuendumu at any one time, using the nurse-supported in-community model. In the last 12 months, both NT Renal Services and WDNWPT have developed proposals to commence mobile dialysis provision using a bus, with the potential of providing respite to a larger number of renal patients from more communities. There is no published, peer-reviewed data regarding the costs or cost-effectiveness of respite dialysis provision, using either model.

Since January 2008, in Canada the North Alberta Renal Program has provided a mobile bus dialysis program to improve access for patients in the rural communities of Whitecourt and Hinton, 180 and 280kms respectively from Edmonton. This service provides 6-days per week maintenance dialysis and is not a respite service. The dialysis bus staff include a driver, also trained to help with the dialysis machines, one registered nurse and one enrolled nurse. The staff work 12-hour shifts and return each day, following the patient dialysis runs, to their home base. Alberta Health Services, in a 2009 Annual Report, estimated the cost per run using the mobile bus to be approximately 2.5 times the average cost per run for satellite units across North Alberta.39 The Annual Report did not provide detail regarding what components were included in the costings of mobile dialysis provision. However, the potential benefit of such a model, in comparison to investing in local infrastructure in small communities with variation over time in the number of patients requiring treatment, underlines its potential role in the CA region.

Detailed costing of alternative models for the provision of respite dialysis were undertaken for the Study. The NT Renal Services and WDNWPT provided information regarding the number of patients and communities such care might reach, factors required to sustain such models of care and the costs of mobile bus and in-community respite. Cost data for provision of respite dialysis services were based on information provided by NT Renal Services, WDNWPT and the NT Department of Construction and Infrastructure.
‘Return to Country’ program

In this program patients from the western desert region are able to travel to their home communities for short visits for family and other business. WDNWPT, with a program budget of approximately $50,000 per year, has provided opportunities for 70 patients from its communities to return home up to 6 times per year. This has enabled approximately 200 community visits per year, with a designated ‘Return to Country’ car and a casual driver. Without this program, or other funding, patients would be unable to afford the costs of travel to communities several hundred kilometres way. The Return to Country program supports patients to persist with their treatments and to establish a pattern of planned, short visits with reliable returns for dialysis. WDNWPT and NPY Women’s Council have explicit policies and funds for this and Nganampa provides some funding on a case by case basis. However, NPY Women’s Council were unable to meet the much higher costs of patient travel from/to major capital cities (Adelaide and Perth) and dialysis patients sent to those centres were further disadvantaged.
7.2 Technological Innovation

Dialysis innovation

Sorbent dialysis systems, which would significantly decrease the requirement for water, are not yet commercially available. Newer HD machines, such as the NxStage and Qanta machines, offer an easier user set-up and interface for self-care HD. They are not yet available in Australia and experience worldwide is limited, however they offer the possibility of increasing the uptake of self-care HD by making the technical aspects of dialysis easier for the patient. The major restrictions to uptake of home/community-based dialysis in Aboriginal communities are not related to technical issues, so it is difficult to know how much technological innovation will enhance the utilisation of this treatment modality. (See Technical Report Section 3.9.5 for factors associated with treatment preferences and uptake).

A recent review of peritoneal dialysis outcomes in Australia confirmed poor results in terms of overall mortality, peritonitis-related mortality, peritonitis rates and technique survival amongst Aboriginal and Torres Strait Islander peoples in remote areas. The history of poor outcomes with PD in the CA region has shaped the dominant negative attitudes of patients, communities, primary care and renal service providers to this treatment modality. Innovations in PD primarily revolve around more bio-compatible solutions to prolong technique survival. It is unlikely such innovation will enhance the uptake of PD, however it may decrease the rate of technique failure in those who undertake PD.

Major improvements in decreasing infectious complications of transplantation might lead to improved graft and patient survival, which would potentially directly benefit Aboriginal patients from the CA region. With concern regarding achieving a balance between adequate immunosuppression to protect graft function and the risk of infection, innovation leading to an ability to reduce the burden of immunosuppression might be of particular relevance to improving outcomes for patients from remote areas.

Mobile dialysis

Mobile dialysis is now possible with current technology for provision of dialysis. There is no published, peer-reviewed evidence regarding the costs or cost-effectiveness of respite dialysis provision. Estimates suggest that the cost of provision of fixed-in-community and mobile bus respite services are significantly higher than ongoing provision of maintenance dialysis. For instance, Alberta Health Services estimated the cost per treatment using a mobile bus to be approximately 2.5 times the average cost per treatment for satellite units across North Alberta.39

Stakeholder consultation in the present Study indicated that respite services are held in high regard by patients and community members, although respite dialysis is reported to have little impact on overall demand for treatment, especially at the hub in Alice Springs. On the other hand, respite is seen to have a key role in meeting the social and cultural needs of renal patients in the CA region.

‘Fly-in fly-out’ services

In general, fly-in fly-out services have been established in coastal and island communities. Such services tend to depend on threshold levels of infrastructure, population and activity to support regular air services. A service is being considered for the Kimberley region, for example.
These circumstances are not the case in the CA region. Virtually no communities have regular air services to and from Alice Springs. Regular travel between urban areas and communities is via road and subject to seasonal accessibility.

On the other hand, models of fly/drive-in, fly/drive-out nursing support from the parent/hub renal unit/service provider seem appropriate to explore. A range of incentives, including the provision of appropriate housing and remote area allowances, will likely need to be explored to attract and retain staff.

**Information and communication technology**

Recent decades have seen crucial technological advancements in the development of dialysis technologies, transplantation and the use of information and communication technology throughout the health sector. Across the course of CKD, there are a range of new technological advancements that could significantly impact on renal service delivery in the CA region. Three are notable in this regard:

- A shared electronic health record, which enables information to follow the patient, will assist the development, implementation and sustaining of a coordinated, comprehensive strategy for renal services.

- Electronic decisions support (EDS) systems have significant potential to improve uptake of guideline-based recommendations in clinical practice, especially in the management of complex chronic disease.

- Current and future developments in Information and communication technology (ICT) will have significant potential to improve the ability for remote consultation and general communication with self-care patients and renal staff providing care in remote communities.
7.3 Service Model Options: Summary Comparison

As already reported, there is no definitive evidence that one form of dialysis is superior to others in terms of patient mortality. On the other hand, community negative perceptions regarding PD are well documented and reported, and present a significant barrier to the expansion of this modality of care.

Apart from clinical efficacy, key additional parameters for comparative analysis of service model options need to be considered. There is strong evidence that, for people in remote communities, lack of access to dialysis services closer to home is a determinant of uptake of RRT and adherence to treatment regimens. In line with this finding, specific parameters for considerations of service models are provided by a successful case example, the Kimberley Renal Service. This service has reported excellent adherence to dialysis prescription, and excellent health outcomes. The factors reported to contribute to their success include:

- A sense of ownership/involvement by patients, for the organisation providing the service.
- Extensive involvement of Aboriginal staff.
- A regional renal social worker.
- A dialysis patient transport service run by an AHW who, as a community member, has close knowledge of family networks and movements.
- On-site primary health care.
- Provision of dialysis closer to home.

Against the background of this successful case example, a detailed SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis of RRT service options was undertaken for this Study. It included consideration of:

- Current modalities of renal replacement – in-centre HD, satellite HD, self-care HD and PD.
- New modalities of maintenance dialysis – nurse-supported, community-based HD or ‘mini-satellite’ service provision; mobile dialysis utilising a dedicated rolling six day per week service between two communities.
- Respite dialysis using the mobile bus or nurse-supported in community models.

Full details of the SWOT analysis can be found in the Technical Report (Sections 3.6.3 to 3.6.7).

The SWOT analysis suggests a myriad of options for service delivery improvement in the CA region. The purpose here is to identify an evidence-based approach to the development of services, and an approach which provides structure and strategy, rather than a menu. The evidence suggests that expansion of models of care, and underlying resource requirements, can be framed in terms of three intersecting dimensions:

- Enabling more people to obtain treatment closer to home.
- Meeting patients’ health, social and cultural needs.
- Consideration of sustainable resourcing models.

The primary recommendation of this Study is that renal services for people in the CA region should be provided by a regional hub service, associated satellite services and with strong linkages to community based primary health services. This preferred model represents an ideal model, with aspiration to comprehensively address the current gaps in service for Aboriginal and Torres Strait Islander renal patients. A range of practical considerations may constrain or reshape the ultimate implementation of the service model against this gold standard.
The fundamental premise of the preferred model is that it represents a structured and sustainable transition from the current urban facility model, to expansion of community based care. The next section describes the preferred model in detail, along with its associated resource requirements.
8 Characteristics of the Preferred Renal Services Model for the CA Region

To achieve a structured and sustainable transition to expansion of community based care, a ‘hub and spoke’ model is the preferred model. As indicated, ‘preferred’ in this context represents the ideal model with aspiration to comprehensively address the current gaps in service. It is acknowledged that, ultimately, practical considerations may constrain or reshape the service model against this gold standard.

The Hub renal unit would coordinate the provision of comprehensive renal services across the continuum of CKD, with spokes being the sites where community and self-care options are expanded in communities. Based on current evidence, expansion of self-care HD and nurse-supported, mini-satellite HD are the most appropriate and sustainable options for increasing the proportion of renal patients able to return home for ongoing RRT.

Below, the key characteristics of the preferred model, and whole of service cost components for it, are considered.

8.1 The Preferred Renal Services Model: Key Characteristics

8.1.1 Location of a Hub and its Services

Renal services for people in the CA region should be provided by a regional hub service in Alice Springs. From the patient, family and Aboriginal community point of the view, the cross-border region of this Study has meaning through the social relationships and cultural connections that extend across it. Alice Springs is the most familiar urban centre. With the exception of locations closer to home, Alice Springs was indicated to be the preferred location for routine dialysis for the vast majority of Aboriginal people interviewed during this Study.

In line with its regional role, the hub is characterised in terms of the service it will provide, rather than as an aggregation of facilities. It will provide integrated services across the spectrum of CKD:

- Support primary care services to implement evidence-based screening and management of early CKD.
- Provide community-based education regarding treatment options to patients and families early in the CKD course.
- Prepare patients for RRT to ensure a planned commencement to treatment.
- Train patients for self-care maintenance dialysis.
- Provide maintenance dialysis in the community, satellite and hospital setting.
- Provide respite dialysis and return to country programs.
- Capitalising on existing relationships and transplant capacity, collaborate with Adelaide-based renal transplant services to coordinate work-up for transplantation, ensure appropriate communication and organisation around the time of transplantation, and provide post-transplant follow-up.
- Be delivered by a multi-disciplinary team with sufficient resources and capacity to maintain accepted benchmark levels for nursing, medical, allied health and Aboriginal Health Worker AHW staff.
Ideally, Tennant Creek would function as a mini hub – able to provide a limited array of support services to communities across the Barkley region, but reliant upon overall strategic support and planning from Alice Springs.

Housing

Based on the projected numbers of people requiring treatment in the coming decade, appropriate housing infrastructure development is a priority. In the first instance this will need to consist of suitable housing in the centres, to provide appropriate support for access to facilities. Ongoing construction in communities, with the transition to community models of care, will become more critical as remote community facilities are established.

Specifically, construction of suitable public housing for renal patients and their families should be prioritised in Alice Springs and Tennant Creek. A key – although not sole – driver of housing need will be the access to treatment at the hub provided to patients from other jurisdictions. The evidence suggests a current shortfall of at least 30 houses in Alice Springs and 20 houses in Tennant Creek.

An ongoing schedule of public housing construction, adding a minimum of a further 10 houses per year will be required, to support the transition from urban facility based care to community based care. This reflects that establishment of community based care – both mini satellite and supported self care will have housing requirements.

Noting the planned opening of the Bath Street Lodge in 2011, which will provide hostel accommodation for a further 38 renal patients, the waiting list for hostel accommodation and forecast growth in demand for RRT, work should begin in 2011 to plan further expansion in dedicated renal hostel accommodation in Alice Springs.

8.1.2 Satellite Dialysis Capacity

The preferred service model is based on expansion of both hub and spoke capacity, based on current patient numbers and location.

Taking the high-range projection as a starting point, planning will need to take into account growth in prevalent ESKD numbers to 480 patients by 2020. In line with the disease projections, satellite dialysis capacity should be increased to bring online 15 new HD chairs in 2012, 2015 and 2018. The recommended increases in capacity in 2015 and 2018 should be contingent on the results of repeat projections of disease burden. Additional capital and recurrent funding will need to be provided, to meet the projected growth in demand for renal services in the CA region (based on the unit costs provided below).

Location of the first satellite development is likely to be in Alice Springs, to capitalise on the existing infrastructure already in place there. Subsequent locations will depend on updated repeat projections of disease burden, and patterns of patient location.

8.1.3 Community Dialysis

Community dialysis capacity is a key component of the preferred renal services model. As a starting point, stakeholders identified potentially suitable infrastructure within communities. These provide the starting point for establishing community dialysis capacity. The following sites should be assessed for conversion to facilities for maintenance dialysis: the purpose-built substance misuse centre in Amata and the Ngaanyatjarra Health Service renal ready room in Warburton.
8.1.4 Home Dialysis/Self Care

As discussed previously, state-of-the-art in renal services, in Australia and internationally, suggests that both PD and HD should be part of the suite of services available to patients. As also discussed, PD is associated with poor outcomes and very negative perceptions in the CA region. The expectation from this Study is that PD safety and quality should be improved and its uptake encouraged where appropriate. However, in considering increased uptake of self care and supported self care, it needs to be acknowledged that the predominant preferred modality in the CA region will remain HD. Accordingly, the preferred service model assumes a predominantly HD modality as follows:

- Renal services in the CA region should aim to increase the proportion of patients receiving self-care, maintenance dialysis – predominantly HD – to 10% by 2015 and 15% by 2020.
- Renal services in the CA region should aim to provide nurse-supported, maintenance dialysis in communities to 10% of patients by 2015 and 15% by 2020.
- HD provision in remote communities should use renal ready rooms or modular facilities, not in-home models of care.

8.1.5 Protocols for Dialysis Treatment Closer to Home

The risks, and their solutions, in the provision of renal services on a safe and sustainable basis in communities encompass a broad range of factors. They include the usual suite of safety and quality requirements of renal replacement treatment. However risk assessment and management also need to include the complex and much broader context of community and home environments.

At the broadest level, it is not possible to supply a checklist of community characteristics required to sustain the provision of dialysis services. Decisions regarding sites for services will require consideration of locally-specific detail about community demography, location, human capital, health and community infrastructure and, most importantly, evidence of real engagement with community leadership.

On the other hand, standard protocols for the establishment of dialysis treatment facilities in remote communities must be agreed. They should outline minimum standards with regard to location, services, design, construction, water, electricity, drainage and management of bio-hazardous waste. Access to safe and secure housing for patients returning to remote communities for ongoing dialysis will need to be part of the protocol. The requirements are known: they need to be agreed and ratified. Minimum dialysis service standards consistent with the National Service Guidelines for the Management of Dialysis and Kidney Transplant in Remote Australia should be developed and implemented across the cross-border region, as part of a Tri-State Agreement.

Table 9 summarises key protocol elements or criteria for options for increasing dialysis close to home in the following terms:

- Modalities — including self-care HD, PD and nurse-supported HD in mini-satellites — that could be utilised to provide ongoing dialysis close to home; and second.
- Modalities — mobile dialysis using a “bus” and fixed community-based dialysis — that could be utilised to provide respite “return to country” dialysis.

More detailed consideration of the requirements at the patient, infrastructure, staffing and community level is provided in the Technical Report. Alongside the requirements, detailed consideration is also provided of advantages, risks and suggested solutions in relation to mobile bus and fixed, in-community models of respite dialysis. Details can be found in Sections 3.6.3 to 3.6.7 and Section 3.10 of the Technical Report and Appendix E of the Technical Appendices.
### Table 9: Summary of key criteria for treatment options to provide dialysis closer to home

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Ongoing Dialysis</th>
<th>Respite Dialysis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Self Care HD</td>
<td>PD</td>
</tr>
<tr>
<td>Acuity and Patient Level factors</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Patient technique competence</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Self-cannulation</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Medically stable</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Carer/social support</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Patient numbers within community</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Travel arrangements/safe transport</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infrastructure</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Housing (patient and family)</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Secure and appropriate facilities at home</td>
<td>++</td>
<td></td>
</tr>
<tr>
<td>Renal ready room or HD module</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Reliable electricity supply</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Reliable water supply and waste facilities</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Home hygiene</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Robust mobile infrastructure</td>
<td>++</td>
<td></td>
</tr>
<tr>
<td>Staff Requirements</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Staff to patient ratio (renal nurse)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support from hub service</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Telephone hotline to hub</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>3-monthly support visits to patients</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Outreach specialist visit</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Staff incentives</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Role for Aboriginal and Torres Strait Islander workforce</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Mobile staff</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Community Support</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Engagement</td>
<td>+</td>
<td>++</td>
</tr>
<tr>
<td>Leadership</td>
<td>+</td>
<td>++</td>
</tr>
<tr>
<td>Primary care support</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Co-location with existing health infrastructure</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Criteria</td>
<td>Ongoing Dialysis</td>
<td>Respite Dialysis</td>
</tr>
<tr>
<td>-------------------</td>
<td>------------------</td>
<td>------------------</td>
</tr>
<tr>
<td><strong>Costs</strong></td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td><strong>Advantages</strong></td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>In community</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Independence</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Stakeholder support</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Allows mobility</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Self-care training</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Enhanced adherence</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Enhanced uptake of RRT</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Reduced unplanned evacuations</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Broad reach, enhanced access</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td><strong>Risks</strong></td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Lack of housing</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Overburden carer</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Need for renal service support</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Increasing patient care needs over time</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Negative perceptions</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Disincentive to self-care</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Staff recruitment and retention</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Technical equipment failure</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Lack of coordination with PHC</td>
<td>+</td>
<td>+</td>
</tr>
</tbody>
</table>

Key:  
++ Criterion represents a crucial requirement, or highly significant advantage or risk  
+ Criterion is important yet less critical than ++, or represents a less significant advantage or risk  
+/- With regard to patient-level factors, criterion would be beneficial, yet not a definite requirement  
Explore quality of life, efficacy and costs as a priority
8.1.6 Linkages of Renal Services with Primary Care Services

Engagement of the regional renal hub service with primary healthcare services is essential to establish a sustainable, integrated renal service addressing the needs of patients across the continuum of CKD. Three broad issues for which engagement is essential are:

1. Support of primary care services in the management of early CKD.
3. Provision of holistic primary care services to dialysis patients, especially for patients receiving maintenance dialysis in satellite units attached to the regional hub.

Partnership between renal services and primary care services will be essential to close the evidence-practice gap in the detection and management of CKD. This partnership could bring together specialised nursing, medical and allied health staff from the renal service, with primary care-based chronic disease and CKD staff. Strategies that were supported by stakeholders, and for which there is supporting evidence, for example from the Kimberley Region Renal Service model, could include:

- Regular outreach clinics within community-based primary care services.
- Provision of appropriate and targeted community-based CKD education to patients and families, early in the course of CKD, incorporating discussion of strategies to maintain health and prevent progression of CKD, and treatment options for advanced CKD, including the range of RRT modalities and conservative management.
- Regular video- or teleconferencing support for primary care-based chronic disease staff in case management of CKD patients.
- Development and implementation of appropriate, locally-specific programs to build capacity and further develop primary care skills in the management of CKD.

Engagement with primary healthcare services, in the provision of self-care and nurse-supported dialysis in communities, will need to be formalised. This could occur in the form of a service delivery agreement which addresses issues of co-location and defines roles and responsibilities in supporting dialysis patients to remain within the community. Such service delivery agreements would be able to outline the commitment, roles and responsibilities of community organisations, patients and their families in delivering dialysis within communities.

This Study found critical gaps in the provision of primary healthcare services to dialysis patients. Multi-disciplinary primary healthcare, providing holistic primary health services – a ‘one stop shop’ for dialysis patients – is the gold standard for renal services. In the preferred model for the CA region, development of a primary health care clinic in/near to the satellite units in Alice Springs and Tennant Creek is envisaged.
8.2 The Preferred Renal Services Model: Whole of Service Costs

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

- Introduction of new modalities of maintenance dialysis – nurse-supported, community-based HD or ‘mini-satellite’ service provision and mobile dialysis with a dedicated rolling six day per week service between two communities.
- Expansion of respite dialysis using the mobile bus or nurse-supported in community models.
- Capital costs, as relevant to conditions in the Central Australia region, associated with different modalities of service provision.
- The Technical Appendices (Appendix B, C and D) fully detail the methods used in costings for the Study. The methods used have been extensively peer-reviewed for a series of government and NGO reports, have been published in the scientific literature and form the basis of recent State-wide Renal Service Plans for Queensland and Tasmania.

8.2.1 Current Unit Costs of Dialysis

Table 10 presents the unit costs of dialysis per patient per annum, by treatment modality. Costs associated with modality initiation, such as access costs and training costs, have been costed separately and are also included in Table 10. In addition, newer pharmacological agents, which are now PBS subsidised exclusively for use in dialysis patients – cinacalcet, sevelamer and lanthanum – have been costed separately.

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. This analysis therefore does not include out of pocket costs to patients and families. Other inpatient resource use, 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.
Table 10: Annual cost of each dialysis modality per patient (NT Renal Services, 2009 dollars)

<table>
<thead>
<tr>
<th></th>
<th>In-centre</th>
<th>Satellite</th>
<th>Community/Home self care HD</th>
<th>Self care PD</th>
<th>Community based nurse supported HD ‘mini-satellite’</th>
<th>Mobile dialysis dedicated rolling 6 day service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimated health system expenditure per patient year (AUD 2009)</td>
<td>$101,189</td>
<td>$75,980</td>
<td>$54,017</td>
<td>$65,250</td>
<td>$93,243</td>
<td>$119,800</td>
</tr>
<tr>
<td>Components of costs</td>
<td>%</td>
<td>$</td>
<td>%</td>
<td>$</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Direct dialysis service provision</td>
<td></td>
<td>$15,382</td>
<td>20.2%</td>
<td>$15,382</td>
<td>38.8%</td>
<td>$20,945</td>
</tr>
<tr>
<td>Treatments</td>
<td>15.2%</td>
<td>$1,223</td>
<td>1.6%</td>
<td>$1,223</td>
<td>2.3%</td>
<td>$1,223</td>
</tr>
<tr>
<td>Medical/operational sundries (incl test strips, filters, salt)</td>
<td>1.4%</td>
<td>$1,223</td>
<td>1.6%</td>
<td>$1,223</td>
<td>2.3%</td>
<td>$1,223</td>
</tr>
<tr>
<td>Dialysis packs</td>
<td>1.2%</td>
<td>$1,223</td>
<td>1.6%</td>
<td>$1,223</td>
<td>2.3%</td>
<td>$1,223</td>
</tr>
<tr>
<td>Medicals</td>
<td>1.7%</td>
<td>$1,223</td>
<td>1.6%</td>
<td>$1,223</td>
<td>2.3%</td>
<td>$1,223</td>
</tr>
<tr>
<td>Scripts/packs</td>
<td>0.2%</td>
<td>$1,223</td>
<td>0.3%</td>
<td>$1,223</td>
<td>0.6%</td>
<td>$1,223</td>
</tr>
<tr>
<td>Linen/catering</td>
<td>0.9%</td>
<td>$1,223</td>
<td>0.3%</td>
<td>$1,223</td>
<td>0.6%</td>
<td>$1,223</td>
</tr>
<tr>
<td>Staff costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing (incl costs, travel allowance etc)</td>
<td>34.4%</td>
<td>$34,847</td>
<td>36.4%</td>
<td>$27,673</td>
<td>37.4%</td>
<td>$14,791</td>
</tr>
<tr>
<td>Staff training &amp; development</td>
<td>1.7%</td>
<td>$1,223</td>
<td>1.6%</td>
<td>$1,223</td>
<td>2.3%</td>
<td>$1,223</td>
</tr>
<tr>
<td>Allied health</td>
<td>10.9%</td>
<td>$1,223</td>
<td>1.6%</td>
<td>$1,223</td>
<td>2.3%</td>
<td>$1,223</td>
</tr>
<tr>
<td>Medical</td>
<td>24.6%</td>
<td>$1,223</td>
<td>1.6%</td>
<td>$1,223</td>
<td>2.3%</td>
<td>$1,223</td>
</tr>
<tr>
<td>PCA, Ward Clerk + Other admin staff</td>
<td>5.8%</td>
<td>$1,223</td>
<td>1.6%</td>
<td>$1,223</td>
<td>2.3%</td>
<td>$1,223</td>
</tr>
<tr>
<td>Community support/community visits</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communications</td>
<td>1.0%</td>
<td>$1,223</td>
<td>0.3%</td>
<td>$1,223</td>
<td>0.6%</td>
<td>$1,223</td>
</tr>
<tr>
<td>Patient accommodation</td>
<td>-</td>
<td>not avail</td>
<td>-</td>
<td>not avail</td>
<td>-</td>
<td>not avail</td>
</tr>
<tr>
<td>Transport</td>
<td>-</td>
<td>not avail</td>
<td>-</td>
<td>not avail</td>
<td>-</td>
<td>not avail</td>
</tr>
<tr>
<td>Overheads</td>
<td>0.9%</td>
<td>$1,223</td>
<td>0.3%</td>
<td>$1,223</td>
<td>0.6%</td>
<td>$1,223</td>
</tr>
<tr>
<td>Other costs: R&amp;M, leasing, water checking, freight</td>
<td>0.1%</td>
<td>$1,223</td>
<td>0.3%</td>
<td>$1,223</td>
<td>0.6%</td>
<td>$1,223</td>
</tr>
<tr>
<td>Other ongoing costs (community based HD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>incl admin, site visits, nurse accommodation in community</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>3.3%</td>
</tr>
<tr>
<td>Total</td>
<td>100.0%</td>
<td>$101,189</td>
<td>100.0%</td>
<td>$75,980</td>
<td>100.0%</td>
<td>$54,017</td>
</tr>
<tr>
<td>Price per treatment (assuming 3 treatments/week for HD, and price per day for PD*)</td>
<td>$649</td>
<td>$487*</td>
<td>$346</td>
<td>$179**</td>
<td>$598**</td>
<td>$768</td>
</tr>
<tr>
<td>Other drugs (cinacalcet, sevelamer, lanthanum + EPO)</td>
<td>$10,117</td>
<td>$10,117</td>
<td>$10,117</td>
<td>$10,117</td>
<td>$10,117</td>
<td>$10,117</td>
</tr>
<tr>
<td>Transplant work up costs for those on waiting list (2%)</td>
<td>$200</td>
<td>$200</td>
<td>$200</td>
<td>$200</td>
<td>$200</td>
<td>$200</td>
</tr>
<tr>
<td>Total annual costs per patient (all ongoing costs)</td>
<td>$111,339</td>
<td>$86,130</td>
<td>$64,167</td>
<td>$75,409</td>
<td>$103,393</td>
<td>$129,950</td>
</tr>
<tr>
<td>One off costs - Access costs</td>
<td>$9,934</td>
<td>$9,934</td>
<td>$9,934</td>
<td>$9,934</td>
<td>$9,934</td>
<td>$9,934</td>
</tr>
<tr>
<td>One off costs – Additional costs for Home HD patient training (initiation year only)</td>
<td>$5,040</td>
<td>$5,040</td>
<td>$5,040</td>
<td>$5,040</td>
<td>$5,040</td>
<td>$5,040</td>
</tr>
</tbody>
</table>

*Data supplied by Fresenius suggest that under existing contracts, a comparable price per treatment, excluding capital related costs, would be $388.

**Price per day for PD.

Central Australia Renal Study – Final Report
Current unit cost of transplant

As already discussed, the rate of transplant among patients in the CA region is low. The barriers to transplantation have also been explored in the evidence review. Nevertheless, for completeness of whole of service cost, the unit cost of transplant has been considered. The results of the analysis are presented in Table 11.

<table>
<thead>
<tr>
<th>Resource items</th>
<th>Live donor</th>
<th>Live donor</th>
<th>Deceased donor</th>
<th>Deceased donor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Recipient unit cost</td>
<td>Donor unit cost</td>
<td>Recipient unit cost</td>
<td>Donor unit cost</td>
</tr>
<tr>
<td><strong>Year 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery and hospitalisation</td>
<td>$37,362</td>
<td>$15,832</td>
<td>$37,362</td>
<td>$3,000</td>
</tr>
<tr>
<td>Regular Immunosuppressive therapy (PBS)</td>
<td>$21,694</td>
<td></td>
<td>$21,694</td>
<td></td>
</tr>
<tr>
<td>Additional Immunosuppression (induction and acute rejection)</td>
<td>$7,648</td>
<td></td>
<td>$7,648</td>
<td></td>
</tr>
<tr>
<td>Other drugs</td>
<td>$8,619</td>
<td></td>
<td>$8,619</td>
<td></td>
</tr>
<tr>
<td>Non drug follow-up costs</td>
<td>$6,227</td>
<td></td>
<td>$6,227</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL YEAR 1 COST</strong></td>
<td>$81,549</td>
<td>$15,832</td>
<td>$81,549</td>
<td>$3,000</td>
</tr>
<tr>
<td><strong>Year 2 onwards</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular Immunosuppressive therapy</td>
<td>$10,227</td>
<td></td>
<td></td>
<td>$10,227</td>
</tr>
<tr>
<td>Other drugs</td>
<td>$724</td>
<td></td>
<td>$724</td>
<td></td>
</tr>
<tr>
<td>Non drug follow-up costs</td>
<td>$819</td>
<td></td>
<td>$819</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL YEAR 2 -ONWARDS COST</strong></td>
<td>$11,770</td>
<td></td>
<td></td>
<td>$11,770</td>
</tr>
</tbody>
</table>

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

8.2.2 Projected Future Service Costs

As discussed, rates of treated ESKD for years 2009-2020 were projected based on three models of incidence in the Aboriginal and Torres Strait Islander population:

- **The Steady State Model**, with a stabilisation of the yearly number of incident patients.
- **The Prevention Model**, where a coordinated program might prevent 20% of incident ESKD cases.
- **The Growth Model**, with a steady long-term linear increase, consistent with growth seen since 1995.

For the purposes of estimating future cost trends, the upper and lower limit of these scenarios (Growth and Steady State) were modelled.
As a starting point, present value costs and benefits were calculated, assuming provision of current service methods. The impact on future service costs of significant changes in treatment innovation uptake, were also estimated.

### 8.2.3 Projected Future Service Costs: Continuation of Current Service Provision Methods

The present value of costs of treating all existing and new cases of ESKD (from 2009-2020), assuming continuation of current service provision methods (in approximately similar proportions of patients) treated out to 2020, is estimated to be between approximately $240 and $302 million (Figure 7). This model includes whole of service costs as described previously, but does not include capital expenditure or respite care cost. These are considered separately below. The trends reflect the Growth Model and the Steady State Model of projected rates of ESKD.

**Figure 7:** The cumulative present value treatment cost of all new and existing RRT patients treated out to 2020

The present value of the cumulative benefits of RRT in life years (LYs), for all new cases of ESKD out to 2020, will be between 1,319 and 1,975 by 2020. The present value of the benefits of RRT in quality-adjusted life years (QALYs), for all new cases of ESKD to 2020, will be between 725 and 1,087 QALYS. The annual and cumulative total health benefits (present values) of providing RRT to all new cases of ESKD out to 2020 are summarised in Figure 8.
8.2.4 Projected Future Service Cost: Potential Impact of Strategies to Change Service Need

Ambitious targets for health and service gains for Aboriginal CKD patients have been agreed by all governments. The potential impact on future service costs for RRT of two key exemplars – increased self care and improved prevention efforts – have been estimated.

A gradual shift to more self-care over the next decade is likely to achieve more people being dialysed closer to home without any increase in expenditure, or marginal reduction in expenditure. This is in contrast to the increased expenditure that would be required if there were a significant expansion of mini-satellites to get people closer to home. For the purposes of modelling, targets of 10% self care by 2015 and 15% self care by 2020 for all prevalent and incident patients have been considered.

The present value of costs of treating all existing and new cases of ESKD (from 2009-2020), with uptake of self care as outlined above, treated out to 2020 (assuming 80% HD, 20% PD), is estimated to be between approximately $236 million and $296 million (Figure 9).
Disease prevention strategies have significant potential to reduce service need and cost. Development of a prevention strategy alongside the development of the renal replacement treatment services is beyond the scope of the present Study. Nevertheless the key components of effective prevention across the life course were reviewed as part of the background to the Study (Section 3.3.2.1 of the Technical Report).

For the purposes of exposition and modelling in the Study, a 20% reduction in ESKD incidence consequent to prevention efforts was selected. A 20% reduction in incident ESKD cases in response to a coordinated prevention program, from 2011 onwards would have significant impact on prevalent numbers and costs. Under such a prevention scenario, the present value of costs of treating all existing and new cases of ESKD (from 2009-2020), treated out to 2020, would be approximately $273 million (Figure 10).
8.2.5 Estimated Annual Costs for Respite Dialysis

Estimated detailed costs, on an annual basis, for respite dialysis modalities are presented below (Table 12). The total cost for the fixed, community-based respite model, based on 16 patients being treated for up to three months each per year is $463,087. The total cost of the bus, based on 26 trips of 1 week duration, providing dialysis for 4 patients on each trip (utilisation of the bus for 26 weeks each year) is $331,086. The fixed, community model would appear, for greater cost, to provide access to respite for longer periods, to fewer patients from fewer communities than the mobile bus.
Table 12: Annual cost of respite dialysis (2009/10 dollars)

<table>
<thead>
<tr>
<th>Component</th>
<th>Fixed community*</th>
<th>Mobile Dialysis Service**</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(2 chair unit)</td>
<td>(intermittent, 2 weeks in 4)</td>
</tr>
<tr>
<td>Estimated health system expenditure per year (2009/2010 dollars)</td>
<td>$462,860</td>
<td>$393,626</td>
</tr>
</tbody>
</table>

Components of costs

<table>
<thead>
<tr>
<th>Component</th>
<th>%</th>
<th>$ Annual</th>
<th>%</th>
<th>$ Annual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct dialysis service provision</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatments</td>
<td>18.2%</td>
<td>$84,115</td>
<td>10.7%</td>
<td>$42,058</td>
</tr>
<tr>
<td>Medical/operational sundries (incl test strips, filters, salt)</td>
<td>1.2%</td>
<td>$5,585</td>
<td>0.9%</td>
<td>$3,403</td>
</tr>
<tr>
<td>Dialysis paks</td>
<td>1.1%</td>
<td>$4,892</td>
<td>0.6%</td>
<td>$2,446</td>
</tr>
<tr>
<td>Pharmaceuticals</td>
<td>1.3%</td>
<td>$6,246</td>
<td>0.8%</td>
<td>$3,123</td>
</tr>
<tr>
<td>Scripts/paks</td>
<td>0.7%</td>
<td>$3,432</td>
<td>0.4%</td>
<td>$1,716</td>
</tr>
<tr>
<td>Linen/catering</td>
<td>1.1%</td>
<td>$4,992</td>
<td>0.2%</td>
<td>$780</td>
</tr>
<tr>
<td>Staff costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing (incl travel/remote allowance for both &amp; on-costs for mobile service)</td>
<td>29.5%</td>
<td>$136,564*</td>
<td>26.9%</td>
<td>$105,9552*</td>
</tr>
<tr>
<td>staff training and development</td>
<td>1.2%</td>
<td>$5,716</td>
<td>0.9%</td>
<td>$3,318</td>
</tr>
<tr>
<td>Allied Health³</td>
<td>1.1%</td>
<td>$4,907</td>
<td>1.2%</td>
<td>$4,907</td>
</tr>
<tr>
<td>Medical³</td>
<td>1.3%</td>
<td>$6,074</td>
<td>1.5%</td>
<td>$6,074</td>
</tr>
<tr>
<td>Driver/Project Manager/officer (incl travel allowance and on costs for mobile unit)</td>
<td>5.8%</td>
<td>$27,0564</td>
<td>20.0%</td>
<td>$78,8385</td>
</tr>
<tr>
<td>Vehicle costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vehicle capital (annual equivalent cost or lease)</td>
<td>2.4%</td>
<td>$11,0166</td>
<td>4.6%</td>
<td>$18,0007</td>
</tr>
<tr>
<td>Fuel</td>
<td>2.2%</td>
<td>$10,000</td>
<td>4.5%</td>
<td>$17,6808</td>
</tr>
<tr>
<td>Insurance/R&amp;M/registration</td>
<td>1.1%</td>
<td>$5,000</td>
<td>4.6%</td>
<td>$17,9509</td>
</tr>
<tr>
<td>Other costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fares (return to country)</td>
<td>3.2%</td>
<td>$14,88010</td>
<td>8.2%</td>
<td>$32,24011</td>
</tr>
<tr>
<td>Communication/administration/support</td>
<td>2.2%</td>
<td>$10,000</td>
<td>0.7%</td>
<td>$2,797</td>
</tr>
<tr>
<td>Overheads (incl audit, workers comp, insurance/medical liability)</td>
<td>1.9%</td>
<td>$9,00012</td>
<td>0.3%</td>
<td>$1,36813</td>
</tr>
<tr>
<td>Other costs: furniture/fittings; evaluation; project expenses; small medical capital; oxygen; food; freight; satellite phone</td>
<td>11.4%</td>
<td>$52,64014</td>
<td>0.4%</td>
<td>$1,73215</td>
</tr>
<tr>
<td>Sub-Total (annual ongoing costs, excluding capital)</td>
<td>86.9%</td>
<td>$402,116</td>
<td>87.5%</td>
<td>$344,385</td>
</tr>
</tbody>
</table>

Capital costs (Annual equivalent costs)

| Staff accommodation | 6.4% | $29,52516 | 0.0% | $017 |
| Dialysis modules/relocatables | 6.7% | $31,21918 | 12.5% | $49,24219 |
| Total annual cost | 100.0% | $462,860 | 100.0% | $393,626 |

* It is estimated that this respite option could treat up to 16 patients, from several communities, for up to 3 months each per year

** It is estimated that this respite option could treat up to 50 patients, from 12 or more communities, for up to 2 weeks each per year (4 patients on each trip, 2 trips each per year, utilising bus 26 weeks each year)

The fixed, community-based model, compared to the mobile bus, would appear, for greater cost, to provide access to respite for longer periods, to fewer patients from fewer communities.

Table 12 - Footnotes

1 Based on 1.5FTE to cover annual, remote and sick leave, PD and travel days + 1.5FTE * $10,000 remote allowance (on costs included in overheads)
0.8FTE, TA for 26 days per year, including on-costs and backfill

Allied health staff estimated at 0.05 FTE for each service; medical staff estimated at 0.025FTE for each service

Based on one 1 project manager to manager 3 x 2 chair facilities

0.5FTE dedicated driver and project manager (incl. on costs)

Annual equivalent cost (AEC) based on capital outlay of $40,000 (Toyota Hilux), traded in every 3 years for $10,000 using 5% discount rate

Monthly lease cost of $1,500

400 litres per trip X 26 trips per year X $1.70 per L

Based on $1,3950 insurance +$4,000 R&M

Based on 4 return bush bus tickets per month @$155 each way (current fare to Kintore)

Based on 4 return bush bus tickets every 2 weeks @$155 each way

central admin/accounting ($2,000); insurance and audit ($7,000) from WDNWPT total divided by 3 sites

Pest eradication & water analysis (does not include electricity - provided by generator in truck)

Based on AEC for $20,000 furniture & fittings for dialysis unit and accommodation, with working life of 4 years & discount rate 5%, + $15,000/year evaluation costs + $10,000/year project expenses + $10,000/year small medical equipment + $12,000/year other expenses

Satellite phone $2,500– converted to AEC, with working life of 5 years, 5% discount rate; plus fit out, phone testing equipment

AEC based on quote to WDNWPT for Lajamanu proposal for $539,000, NT Govt working life of 50 years, and 5% discount rate

Staff accommodation in bus

AEC based on quote for Lajamanu proposal for $440,000, NT Govt working life of 25 years, and 5% discount rate

AEC based on cost of $350,000 for dialysis module, NT Govt working life of 9 years and 5% discount rate
8.2.6 Estimated Capital Costs

Capital costs for the establishment of the preferred renal services model are presented below. These are indications of the costs for each example of the necessary bricks and mortar. Multiples of the capital costs would depend on the nature of the phased roll out strategy of the preferred service model.

Taking satellite services, as a case in point, three 15-station satellites over the next ten years have been suggested as the likely service need, based on disease projections. The cost for establishment of a satellite is estimated below as being $3.35 million (at 2009/10 dollars). Each satellite established will then be a multiple of this base cost. The funding arrangement is not specified. This might involve a scenario where the NT Government and other governments partner with industry – as has been the case in Gap Rd – to amortise such capital costs over the period of a contract which also factors in the costs of providing dialysis and often of providing nursing staff.

As another case in point, expansion of services to achieve more people being dialysed closer to home can be considered. Increases in self-care to 10% (2015) and to 15% (2020), as modelled above, would translate to such dialysis services being provided for up to 70 patients, based on current disease projections. In turn the successful implementation of service need changes would require the establishment of renal ready rooms or “relocatables”, with their associated capital costs. Similarly, the anticipated expansion of mini-satellites as a complementary means to achieve treatment for up to 70 patients closer to home would have multiples of the attendant costs detailed below.
### Table 13: Capital costs (2009/10 dollars)

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Total cost</th>
<th>Calculated annual equivalent cost (AEC)</th>
<th>Workings/assumptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>New 15 machine satellite unit in Alice Springs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bricks &amp; mortar facility dialysis equipment tanks generators washing machines burners, plus fit out</td>
<td>$3,348,487</td>
<td>($3,348,487 - 0)/18.2559 $183,419 per year</td>
<td>600m² – based on 15 stations at 9m² per dialysis station plus floor space for storeroom, meeting rooms, nursing station, administration, toilets, laundry etc and existing specifications of Gap Rd satellite facility $5,000/m² ($ 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 components, cannot apply differential annuity factors to various components)</td>
</tr>
<tr>
<td>Mini-satellite in a remote community (4 machine)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Facility (bricks &amp; mortar), incl dialysis equipment</td>
<td>$500,000</td>
<td>$27,388</td>
<td>Working life = 50 years: annuity factor = 18.2559, no resale</td>
</tr>
<tr>
<td>Tank</td>
<td>$30,000</td>
<td>$4,642</td>
<td>Working life = 8 years: annuity factor = 6.4632, no resale</td>
</tr>
<tr>
<td>Generator</td>
<td>$30,000</td>
<td>$4,642</td>
<td>Working life = 8 years: annuity factor = 6.4632, no resale</td>
</tr>
<tr>
<td>Washing machines</td>
<td>$5,000</td>
<td>$774</td>
<td>Working life = 8 years: annuity factor = 6.4632, no resale</td>
</tr>
<tr>
<td>Turbo burner</td>
<td>$7,500</td>
<td>$1,160</td>
<td>Working life = 8 years: annuity factor = 6.4632, no resale</td>
</tr>
<tr>
<td>Staff accommodation (2BR house)</td>
<td>$539,000</td>
<td>$29,525</td>
<td>Lajamanu quote: Working life = 50 years: annuity factor = 18.2559, no resale</td>
</tr>
<tr>
<td>Total cost</td>
<td>$1,111,500</td>
<td>$60,884 per year</td>
<td></td>
</tr>
<tr>
<td>Renal Ready Room</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Dialysis machines</td>
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<td>$4,221</td>
<td>Working life = 9 years: annuity factor = 7.1078, no resale</td>
</tr>
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<td>Tank</td>
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<td>$4,642</td>
<td>Working life = 8 years: annuity factor = 6.4632, no resale</td>
</tr>
<tr>
<td>Generator</td>
<td>$30,000</td>
<td>$4,642</td>
<td>Working life = 8 years: annuity factor = 6.4632, no resale</td>
</tr>
<tr>
<td>Washing machines</td>
<td>$5,000</td>
<td>$774</td>
<td>Working life = 8 years: annuity factor = 6.4632, no resale</td>
</tr>
<tr>
<td>Turbo burner</td>
<td>$7,500</td>
<td>$1,160</td>
<td>Working life = 8 years: annuity factor = 6.4632, no resale</td>
</tr>
<tr>
<td>Water treatment</td>
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<td>$309</td>
<td>Working life = 8 years: annuity factor = 6.4632, no resale</td>
</tr>
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<td>Lajamanu quote: Working life = 50 years: annuity factor = 18.2559, no resale</td>
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<tr>
<td>Total cost</td>
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<td>$45,272 per year</td>
<td>NB other capital costs included in price per treatment</td>
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<td>Modular/relocatable facility</td>
<td>$440,000</td>
<td>$31,219</td>
<td>Lajamanu quote: Working life = 25 years: annuity factor = 14.0939, no resale</td>
</tr>
<tr>
<td>Dialysis module for mobile service</td>
<td>$350,000</td>
<td>$49,242</td>
<td>Working life = 9 years: annuity factor = 7.1078; no resale (truck is leased)</td>
</tr>
</tbody>
</table>

8.3 Specific Jurisdictional Requirements

An overarching consideration for the preferred renal services model for the CA region is the need to accommodate jurisdictional drivers within both a whole-of-region, whole-of-service model. Any recommendations and/or implementation plans will hinge on a united response from all jurisdictional governments. This clearly implies the need for accommodation of the separate needs of the jurisdictions, and agreement of an appropriate mechanism for governance and coordination across the region.

At the same time, as repeatedly emphasised in consultations, the cross-jurisdictional setting mandates the need for collaboration in planning, resource allocation, monitoring and evaluation of the outcomes of service delivery. Formulating and implementing cohesive, effective and equitable patient care needs to occur across governments, and within a Tri-State Agreement.

While requirements will evolve over time, several key issues are highlighted as characteristics of the preferred renal services model for the CA region.

The location of the hub at Alice Springs

The hub is envisaged as a regional provider, not a jurisdictional one. Accordingly, people from other jurisdictions within the region will have clear rights of access. Specifically, people from the APY Lands and Ngaanyatjarra Lands will have clear rights of access to the renal services hub in Alice Springs. While partly this represents a renal service capacity issue which needs to be addressed, it equally represents a critical issue in the near future with respect to availability of housing/accommodation.

The Western Australia Country Health Service (WACHS) is in the process of finalising its renal dialysis plan for 2010 to 2021 during the period of consultation for the Central Australia Renal Study. Several of the patients from the CA region are currently receiving treatment in Kalgoorlie and Perth. In general, patients from communities to the North and East of Warburton indicated that family and cultural links tended to point towards Alice Springs. Warburton, a larger community with a population count of 568 at the 2006 Census, is at the border of the CA region and figures clearly within WACHS strategic planning. The development of the renal ready room within the Ngaanyatjarra Health Service building in Warburton has the potential to provide ongoing and/or respite dialysis to patients from the CA region. It would seem appropriate for the renal hub service in Alice Springs to liaise with renal service providers in Kalgoorlie, local health services and community organisations to devise the optimal models for collaboration to meet the service needs of patients from the WA cross-border communities.

Status of renal services on the lands/communities

As the preferred services model is implemented it will be important to consider existing community approaches, perceptions and preferences.

For example, there are no current visits or services from nephrologists or specialised renal nurses to communities of the APY Lands. Currently, there are about 25 people from the APY Lands receiving treatment for ESKD. The majority of patients are receiving dialysis in Alice Springs, four in Port Augusta and one patient is in Adelaide, having recently received a transplant. No patients are currently receiving dialysis on the APY Lands. The implementation of the preferred model might see regular respite services (or “reverse respite services”) provided on the APY Lands by the “mobile dialysis bus”, provided by the NT. It would be anticipated that, in collaboration with the SA Department of Health and the Lands, a trial with the “mobile dialysis bus” in the early stages of implementation, might provide the best opportunity to gain experience of various service approaches for this particular setting, and work towards long term solutions.
In the Ngaanyatjarra Lands of Western Australia, plans for regular nephrology visits from Kalgoorlie and Alice Springs are being put into place. Currently there are around 25 people from the CA region cross-border communities of the Lands receiving treatment for ESKD. Three are receiving dialysis in Perth, six in Kalgoorlie, one is receiving peritoneal dialysis in Warburton and one in Kintore. The remainder are receiving dialysis in Alice Springs. It should be noted that it is in Western Australian communities of the cross-border region that there are some positive experiences of PD. A small number of patients have been maintained successfully on PD in communities for several years and this modality of care is one option that could be explored as part of a strategy to provide treatment as close to home as possible for suitable patients. The implementation of the preferred model of service delivery might see the development of the renal ready room in Warburton as a model for ongoing, within community dialysis and the extension of respite services using the mobile bus. As for the APY Lands, these might represent the best options for short-term initiatives to serve as models for long-term and sustainable approaches.

Resourcing within a multi-jurisdictional region

The multi-jurisdictional region is differentially represented in the total burden of renal disease. The current jurisdictional proportion of the total demand for renal services across the CA region is: Northern Territory 80%, South Australia 10% and Western Australia 10%. There is no evidence that the incidence or prevalence of ESKD is growing at different rates in different jurisdictions or communities within the cross-border CA region.

A key plank of the cross-jurisdictional service model will be an appropriate resource allocation formula. Resource allocation and all its funding implications across the spectrum of whole of service costs estimated in the present Study will need to be developed and agreed within the context of a Tri-State Agreement. While it is beyond the scope of the present Study to pre-empt the nature of the resourcing model, the necessity of having such a model is emphasised.
9 Implementation of the Preferred Renal Services Model: Key Influences

The key influence of seven overarching considerations underpin the implementation plan:

- The role of prevention.
- The role of social and cultural determinants of treatment uptake, adherence and outcome.
- Recognition/incorporation of jurisdictional drivers.
- Safety and quality requirements.
- Protocols for dialysis treatment closer to home.
- Workforce requirements.
- Strategic monitoring and evaluation.

Key role for prevention

Noting the identification, by primary care and renal services, of almost 600 people with CKD Stages 3 to 5, and evidence suggesting these cases represent a fraction of the actual number with CKD in the CA region, an integrated approach to CKD prevention should be implemented. Full details are provided in the Technical Report (Section 3.3.2.1). In brief, prevention should include:

- Primary prevention initiatives from the antenatal period with the aim of preventing the development of CKD.
- Primary care-based screening to facilitate early detection and evidence-based management of CKD; which has been shown to be cost-effective in the general population.
- Evidence-based management of modifiable risk factors for the progression of CKD – hypertension, diabetes and proteinuria – is likely to be highly cost-effective. The KVC Audit Study has revealed evidence-practice gaps in the management of blood pressure and cholesterol in Aboriginal primary care, similar to gaps in mainstream primary care. Intensive management of blood pressure and intensive glycaemic control in people with type 2 diabetes is likely to reduce premature cardiovascular morbidity and mortality, in addition to slowing the progression of CKD.

Key role for cultural and social determinants of treatment uptake, adherence and outcome

Extensive consideration of cultural and social needs of renal patients in CA was undertaken for the Study, and full details can be found in the Technical Appendices (Appendix A). The key role of maintaining social and cultural connectedness has clear practical implications for service implementation.

In accordance with principles enunciated in the COAG National Partnership Agreement on Remote Service Delivery and the National Service Guidelines for the Management of Dialysis and Kidney Transplant in Remote Australia, dialysis should be provided as close to home as possible.

Although provision of ongoing maintenance therapy is essential to maintain life, respite dialysis services and return to country programs should be provided as part of an integrated, coordinated regional renal service. A key case study is provided by the WNDWPT endeavours over the last decade:

Case Study: Western Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (WNDWPT)

In 2001, driven by a desire to overcome some the challenges of providing patient and family-centred care to dialysis patients, and reduce the impact of dislocation by establishing trips back home to country to improve wellbeing, Yanangu from the Western Desert established Western
Desert Nganampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (WNDWPT) – literally meaning “Making all our families well”. WDNWPT is an Aboriginal and Torres Strait Islander controlled organisation representing the Yanyuwa people and families on dialysis.

In 2004 WDNWPT began operating a reverse respite dialysis program with one machine in the Kintore Health Centre. This offered planned, short-term visits home to maintain family and community life and be on country. WDNWPT’s services have grown to provide holistic care to meet the needs of dialysis patients and families from the Western Desert. These include supporting patients whose wish is to return to their communities to pass away, providing support for preparing to return home for visits, access to healers and bush medicine at the ‘Purple House’ in Alice Springs, and a weekly GP clinic held at the ‘Purple House’. Recently, in Kintore, WDNWPT has renovated a building to become the Kintore “Purple House” which has allowed them to increase the amount of respite dialysis provided.

With the consent of its Board, WDNWPT has undertaken feasibility studies at Ntaria, Yuendumu and Lajamanu on the provision of onsite, nurse-assisted dialysis and has established reverse respite services at Ntaria and Yuendumu with funding coming from government agencies as well as mining royalty money available to some community members.

Noting the challenge identified by all service providers, of finding suitable accommodation for renal patients across the CA region, and with the projected growth in demand for RRT and estimate that up to five people may follow a patient moving to an urban centre to access RRT, priority should be given to addressing accommodation and social support issues for patients and their families.

Recognition of jurisdictional drivers

As discussed in this report, the CA region is a multi-jurisdictional region, which presents governance challenges. Any recommendations and/or implementation plans will hinge on a united response from all jurisdictional governments. This clearly implies the need for accommodation of the separate needs of the jurisdictions, and agreement of an appropriate mechanism for governance and coordination across the region.

At the same time, as repeatedly emphasised in consultations, the cross-jurisdictional setting mandates the need for collaboration in planning, resource allocation, monitoring and evaluation of the outcomes of service delivery. Formulating and implementing cohesive, effective and equitable patient care needs to occur across governments, and within a Tri-State Agreement. There may potentially be a pivotal role for the Tri-State Forum in efforts to develop a planned and strategic approach to renal patient management in the cross-border region, if this forum was re-invigorated to underpin sustainable development of renal services. In this regard, it would be worthwhile exploring the role for the DoHA to provide an independent brokerage role, with their ongoing and formalised commitment to be agreed with the States and Territories.

Specifically, however, whether through existing mechanisms or the establishment of new ones, seamless service delivery across the region will require, as a minimum, a Tri-State Agreement and process for:

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

Safety and quality requirements

Service risk from a range of key perspectives requires consideration. Stakeholders consulted for this Study, and a review of relevant policy documents, indicated appropriate attention is needed for the following:

- Phased implementation of new models of service delivery with rigorous evaluation of cost-effectiveness, sustainability and appropriateness of care.
- Adherence to protocols for assessment of site selection, construction, design and equipping of dialysis facilities.
Workforce strategies that build, up-skill, support and retain a multi-disciplinary workforce with strong Aboriginal and Torres Strait Islander involvement.

Engagement of community leadership and primary healthcare services in a partnership to sustain community-based service delivery.

Adherence of all service providers to relevant standards including the National Service Guidelines for the Management of Dialysis and Kidney Transplantation in Remote Australia – which include discussion of the required capabilities and resource profiles for dialysis units in remote areas.

National approaches to training and accreditation, especially as they impact on alternative workforce models.

A list of key health outcome indicators across the spectrum of CKD was identified for the purposes of this Study. These might provide the basis of a core set of key indicators against which renal services could be monitored.

The National Service Guidelines for the Management of Dialysis and Kidney Transplantation in Remote Australia can be utilised to develop an agreed, evidence-based set of standards to measure the performance of renal services. Stakeholders also discussed the need for all service providers to commit to deliver care according to agreed standards, in line with the relevant jurisdictional and national standards for safety and quality in delivery of healthcare services.

More detailed consideration of safety and quality considerations can be found in the Technical Report (Section 3.10) and the Technical Appendices (Appendix E).

Protocols for dialysis treatment closer to home

Provision of renal services on a safe and sustainable basis in remote communities requires a number of enabling factors and entails certain risks. It is not possible to supply a checklist of community characteristics required to sustain the provision of dialysis services. Decisions regarding sites for services will require consideration of locally-specific detail about community demography, location, human capital, health and community infrastructure and, most importantly, evidence of real engagement with community leadership.

Based on evidence based practice and treatment, key criteria were outlined in this report for establishment of dialysis treatment facilities in remote communities. A range of well-documented factors require specification, including location, services, design, construction, water, electricity, drainage and management of bio-hazardous waste. Access to safe and secure housing for patients returning to remote communities for ongoing dialysis were also articulated. These criteria will need to be formalised and agreed as protocols, across the region. Further details can be found in the Technical Report (Sections 3.6.3 to 3.6.7).

Workforce requirements

Recruitment, retention and high turnover for the remote area health workforce is well documented. Renal services require multi-disciplinary teams and they require highly skilled staff. Quite apart from clinical and specialist skills, English is not the first language for many renal patients in the CA region. Further details of the nature of the capabilities, the workforce needs and approaches are considered in the Technical Report (Section 3.8).

Renal service delivery in remote communities across the CA region shares common challenges with other rural and remote health services in building and maintaining an appropriately-skilled multi-disciplinary workforce. A recent systematic review of international evidence regarding the impact of recruitment and retention strategies for rural and remote area health workforce found that:

- A wide range of individual, organisational and contextual factors impact on workforce retention.
- There is a lack of rigorous evaluations measuring effectiveness of retention strategies.
Most incentives focus on remuneration

- Non-financial incentives, such as housing and improved working conditions, have the potential to improve retention.
- Strategies involving health worker obligation work for the duration of agreements, not beyond.
- An approach in which different incentives are bundled in a manner that is flexible to specific (local) contexts is required.
- Rigorous evaluation, using pre- and post-intervention measures and with appropriate indicators for monitoring effectiveness of incentives is essential.

Considering renal services specifically, the evidence shows that there are some existing shortfalls in staff numbers, when compared to national figures. The results of a national renal workforce survey outlined in Table 14 indicate the ‘gold standard’ staff to patient ratios for the range of renal replacement therapies including the nursing, allied health and specialist roles. It should be noted that interpreters are included. These should be professionals in the relevant languages, not family, and with training and knowledge of kidney disease.

### Table 14: Renal workforce

<table>
<thead>
<tr>
<th></th>
<th>In-Centre HD</th>
<th>Home HD</th>
<th>PD</th>
<th>Partial Care (Satellite)</th>
<th>Self-Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing</td>
<td>1:3</td>
<td>1:12</td>
<td>1:20</td>
<td>1:4</td>
<td>1:5</td>
</tr>
<tr>
<td>Nursing</td>
<td></td>
<td></td>
<td></td>
<td>1:100 CKD</td>
<td></td>
</tr>
<tr>
<td>Nephrologist</td>
<td></td>
<td></td>
<td></td>
<td>1:60 ESKD, 1:100 CKD</td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
<td></td>
<td>1:125</td>
<td></td>
</tr>
<tr>
<td>Dietician</td>
<td></td>
<td></td>
<td></td>
<td>1:150</td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td></td>
<td></td>
<td></td>
<td>1:200</td>
<td></td>
</tr>
<tr>
<td>Pharmacist</td>
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<td></td>
<td></td>
<td>1:125</td>
<td></td>
</tr>
<tr>
<td>ALO</td>
<td></td>
<td></td>
<td></td>
<td>Difficult to quantify</td>
<td></td>
</tr>
<tr>
<td>AHW</td>
<td></td>
<td></td>
<td></td>
<td>Difficult to quantify</td>
<td></td>
</tr>
<tr>
<td>Interpreters</td>
<td></td>
<td></td>
<td></td>
<td>WACHS and Kimberley Renal Service currently defining requirements for AHWs within alternative workforce structures for remote satellites</td>
<td>Difficult to quantify</td>
</tr>
</tbody>
</table>

It should be noted that the predominantly satellite and in-centre dialysis that is currently provided in the CA region is resource intensive. Those modalities requiring partial self-care, such as community-based dialysis, have lower RN to patient ratios, but the broader involvement of social services and other support remains the same.

Key stakeholders expressed interest in alternative renal workforce models which provide Aboriginal and Torres Strait Islander people with a more central role in dialysis provision and patient support. Anecdotally, the Kimberley Renal Service reported that the central role for Aboriginal and Torres Strait Islander staff in their service underpins their achievements in terms of health outcomes and adherence to treatment regimens in the Kimberley. There was strong endorsement from stakeholders for further training of Aboriginal Health Workers to develop competencies in delivering dialysis and caring for patients with CKD and/or ESKD in the community.

At the same time, opportunities for specific training to better equip a multi-disciplinary workforce to provide sustainable renal services in remote communities, were also supported and included:
- Up-skilling of ENs to provide renal services.
- Up-skilling of rural GPs in management and support of dialysis patients within the community.

The availability of interpreters, skilled in the appropriate languages and with competencies around communication issues related to kidney disease, is a key need for renal services.

It is worth noting that public-private partnerships, where industry providers are contracted to provide capital, equipment and staffing according to an agreed price-per-treatment contract, were also canvassed in discussions with stakeholders, as a model of funding expansion in dialysis service provision, rather than being related to PD or HD. Such arrangements were seen as enabling capital expenditure to be amortised over the period of a contract and provide an alternative strategy for recruiting and maintaining the remote area renal workforce through increasing the potential pool of skilled staff.

**Strategic monitoring and evaluation: a core component of implementation**

With the expansion of service delivery, and the establishment of new models of care, ongoing monitoring and evaluation are essential to ensure that implementation is sustainable, and that transitions in service options are appropriate. Three areas are highlighted in this regard:

Identified priorities for health service data collection to inform renal service planning in the CA region will need to be addressed, if service need projections are to be updated regularly, as recommended by this Study. These data should include:

- Establishment of the population-level burden of CKD.
- Rates of disease progression.
- Factors associated with the progression of CKD to ESKD.
- Factors associated with uptake of treatment.
- Factors influencing patient and transplant organ outcomes for Aboriginal kidney transplant recipients.

New models of care for the CA are being canvassed – respite care and remote mini-satellite care, with expansion of self-care. In the first instance, careful evaluation of the efficacy, cost-effectiveness and sustainability of renal service provision in remote communities with these new models will be essential. The implications for transition from facility-based service provision to community-based provision then need to be incorporated into service planning cycles.

The key evidence from this Study has been used to develop a potential implementation scenario for the preferred service model. It is presented as an Appendix to this Report (Appendix 1 to the Final Report).
Appendix 1 to the Final Report: Options for Implementation of the Recommended Service Model

i. Introduction

Development of a detailed implementation plan is beyond the scope of this report. However, as a starting point, it is possible to distil the evidence from the Study to describe a scenario of how a structured approach to the establishment of sustainable service delivery, with a transition from urban facility-based service provision, to community based care, might progress. The possible scenario is described in the schematic below.

ii. Key Assumptions Underpinning an Evidence-based Structured Approach

The following should be read as one potential scenario over the coming decade, reflecting:

- A ‘gold standard’ approach to service planning based on current estimates of service need.
- A Growth Model of ESKD prevalence (492 patients by 2020), one of several potential projections identified in this Study, and its associated costs.
- An aspirational view of the transition from urban facility based service provision to community based care.

Given that this is one potential scenario, the estimates contained within it are not immutable: both their absolute levels and their apportioning may change. For instance, prevalence may decrease or increase, changing service need. Transition to community based care may occur at a different pace, incurring different costs in different categories – more community based housing infrastructure for instance, rather than more facility associated infrastructure. Respite care overall may be more or less successful than anticipated, or its different forms (fixed versus mobile and so forth) might be more or less successful than anticipated in this scenario. Each of these outcomes has implications for cost estimates. For this reason, the scenario outlined below includes cycles of monitoring and evaluation of the impact of the introduction of new models of care. These evaluation cycles are reflected in the plan, un-costed, but are considered a fundamental plank of establishing sustainable models, and sustainable transition to them.

Quite apart from the assumptions that underlie the implementation scenario outlined here, practical considerations will also impact implementation.

iii. Reading the Schematic

The elements of the implementation scenario, and their costs, are derived from the prevalence and cost estimates developed as part of the Study, more specifically the Growth Model, and a continuation of
current service provision. The plan considers all of the intersecting service components associated with this model and their development over the decade – taking 2012 (FY 2012/2013) as the immediate term, 2015 (FY 2015/2016) as the medium term and 2020 (FY 2019/2020) as the longer term.

The scenario is divided into 4 main slices, horizontally: capital requirements (in green), facility based care (in blue), new models of care (in red) and cycles of monitoring and evaluation (in black). Dollar values are plotted on each of the trend lines for service costs. Cost estimates have been extrapolated to Financial Years (as indicated along the horizontal axis), from the modelling undertaken for the Study. (See Section 8.2 of the Final Report for further details)

In the immediate term - July 2012-June 2013:

- Working up from the horizontal axis, capital investment is likely to include housing in Alice Springs and Tennant Creek, the establishment of a new 15-station satellite unit (Alice Springs in the first instance) and a mini-satellite (possibly Amata). In addition, the establishment of community-based care through a renal ready room (possibly Warburton) is included. Capital costs for satellite, mini-satellite and ready room establishment are estimated at approximately $5.2 million, and housing at $10.5 million.
- The total cost of patient housing provision over the decade is estimated at $40 million to 2020, the costs reflect projected prevalence, existing housing shortfalls, and unit costs based on estimates provided by WDNWPT and NT Department of Housing and Infrastructure. Prevalence projections and current housing shortfall suggest the need to construct 20 houses initially and 10 houses per year at an approximate cost of $0.5 million per house. The expenditure in the immediate term reflects the first tranche of construction.
- Housing estimates do not reflect costs of including housing in recruitment/retention of renal staff. Estimates of staff accommodation costs are included in cumulative whole-of-service costs.
- Cumulative service costs, including facility based treatment, supported community based treatment and supported self care are estimated at approximately $110 million, including $85 million already spent from 2009 to end June 2012 across the region, with FY 2012/2013 costs approximately $25 million.
- Respite dialysis is costed as commencing in FY 2012/2013, at a cost of $1 million.

In the medium and long term - July 2013 to June 2020:

- Again working up from the horizontal Axis, capital costs are less certain because the nature of the expenditure will to a great extent reflect the results of the impact analysis of the new community based models. Irrespective, based on prevalence alone, a satellite will need to be equipped, and appropriate housing supplied. Their growth is assumed to be a fairly flat function, however, while the capital infrastructure to support more community-based care (mini-satellites and ready

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1 Details of the model and its cost estimates can be found in Section 8.2
2 Details of capital costs estimates can be found in Section 8.2.6
3 Details of patient housing costs can be found in Sections 7.1 and 8.1
4 Details for staff accommodation costs included in the modelling can be found in Table 10
5 Details of projected service costs can be found in Sections 8.2.1 – 8.2.4
6 Details of respite care costs can be found in Section 8.2.5
rooms) are estimated to gradually increase. The location will depend on current patient dispersion and service capability at the time.7

- Cost of patient housing provision is based on the need for 10 houses per year at an approximate cost of $0.5 million per house, with estimated housing need reflecting prevalence projections.

- Overall, service costs are estimated in the Study to continue in linear fashion from December 2009 to December 2020, to a cumulative total of approximately $302 million, in line with modelled whole-of-service costs per patient.8 The diagram shows the cumulative costs extrapolated to Financial Years, from FY 2012/2013 to FY 2019/2020, and are estimated to be approximately $205 million.

- Service cost estimates are driven by the predictions of ESKD prevalence in the Growth model. However, there is an assumption that there may be a transition in cost from facility-based care (and cost) to more community based care (and cost) over the decade. The extent of the transition will determine the precise nature of the cost pattern. The extent of the transition will also influence capital expenditure. This transition is reflected in the growing share of the total service cost by new models of care (red line) and decreasing share of the total by facility based care (blue line).

- Respite care is assumed to grow gradually beyond establishment in the immediate term with additional respite care established by 2015.9

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7 For details of projected prevalence estimates see Section 5.1, and for capital cost estimates see Section 7.1 and 8.2.6
8 For details of projected service costs see Section 8.2.1 – 8.2.4
9 For details of respite care cost estimates see 8.2.5
Central Australian Renal Services: A potential implementation scenario for the recommended service model

Sustainable and structure transition from urban facility-based care to home & community-based care

Cycles of monitoring & evaluation

New models of community based care
- Respite (fixed & mobile)
- Nurse-supported mini-satellite

Current models of care
- In-centre
- Satellite
- Self-care dialysis
- Transplant

Infrastructure Capital
- Satellite
- Mini-Satellite
- Ready-room
- Patient Housing

Financial Year

2012

2015

2018

2020

Immediate

Mid-term

Longer-term

* Cumulative service costs for facility and community care include staff costs, direct costs, overheads, administration and communications, and are extrapolated from Total Cumulative Present Value Cost (Jan 2009-Dec 2020) estimated at $302M
* Estimates for respite models were derived from NT data sources, and include all known cost components, and adjusted for numbers of patients and communities to be served
* Estimates for capital costs of new satellites, mini satellites, ready rooms, relocatables were based on published guidelines adapted for CA
* Patient housing construction costs estimates were based WDNWPT and NT Government estimates, and reflect prevalence projections
References


25. Lavoie JG. Indigenous Primary Health Care Services in Australia, Canada and New Zealand. Winnipeg: Centre for Aboriginal Health Research; 2003.


38. de Vries D, Sweet M. Scoping Study for Lajamanu Dialysis Project. Invisible Disease-Silent Voices. Western Desert Ngarampa Walytja Palyantjaki Tjutaku Aboriginal Corporation WDNWPT; 2010. Quote for housing construction received by WDNWT November 2010 and provided to Study Team.
