Australian Department of Health and Ageing

Central Australia Renal Study

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Acknowledgements

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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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3.1 Introduction to the Technical Report

3.1.1 Background

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 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 CA 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 Indigenous 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.

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 Ngarluma Walaltyja Palyantjaku Tjutaku (WDNWPT) community-controlled organisation 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.

3.1.2 The Aims of the Central Australia Renal Study

The agreed purpose of the Study was to develop a range of feasible clinical service delivery models and care pathways to best meet (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.

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

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.
3.1.3 Purpose of the Technical Report

The Technical Report provides detailed methods and findings of the Study. As such, the material presented here underpins the Final Report of the Study. Further details pertaining to the program of stakeholder consultation undertaken for the Study, economic modelling and technical requirements for renal service provision in remote areas can be found in the Technical Appendices.
3.2 Methodological Approach for the Study

3.2.1 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 Appendices.

3.2.2 Evidence Review

The Study drew on a major systematic review of national and international evidence regarding issues relating to Indigenous 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 the CA region.
- Outcomes of renal disease among Aboriginal Australians.
- State of the art in Renal Replacement Therapy.
- 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.

3.2.3 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 Central Australian 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.

### 3.2.4 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 (Appendix A). 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 renal replacement therapy 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.
- Identification of the essential building blocks for provision of renal services.
- Improving governance and coordination.

### 3.2.5 Projections of the 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. The costs and benefits of continuing current models of renal service provision were modelled to 2020. The costs of alternative models for provision of renal services, with the aim of bringing renal services closer to
home, were compared in terms of both recurrent and capital expenditure required to sustain the delivery of renal services in 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 these data varies substantially between different communities, it offers a complementary approach to assessment of predicted incident numbers of people requiring renal replacement therapy.

Further detail of the modelling of costs and benefits of the provision of renal services can be found in the Technical Appendices (Appendices B, C and D).
3.3 Evidence Review

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 people 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 Indigenous people 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.

3.3.1 Methodology

Key features of the approach to the evidence review included:

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.

### 3.3.2 National and International Evidence

#### 3.3.2.1 Prevention of Chronic Kidney Disease (CKD) in the Central Australia Region

Prevention of disease or ill health is a major aim of the Australian health system. It is estimated that chronic diseases are responsible for approximately 80% of the burden of disease and injury in Australia; account for around 70% of total health expenditure; are part of 50% of GP consultations; are the leading causes of disability and death in Australia; and are associated with around 537,000 person-years loss of participation in full-time employment each year\(^1\). A small number of modifiable risk factors are responsible for the major share of the burden of preventable chronic disease. These risk factors include tobacco smoking, physical inactivity, poor nutrition, obesity and high blood pressure, which are key modifiable risk factors for chronic kidney disease. Amongst Aboriginal and Torres Strait Islander peoples, poor access to necessary preventative care and broader social determinants of health, which act across the life-course, contribute to the excess burden of chronic disease. In recognition of the need for a whole of government response aimed at Closing the Gap between Indigenous and non-Indigenous Australians, maternal and early childhood health and development, educational attainment, employment outcomes and access to safe and secure housing have been designated as necessary “building blocks” to support these national efforts.

Chronic diseases and associated risk factors are responsible for approximately two-thirds of the life expectancy gap between Indigenous and non-Indigenous Australians\(^3\). 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 Australians. This burden falls disproportionately in the ages between 35 and 65, and rates in remote areas, including those for communities across the CA cross-border region, are up to 30 times the national average\(^2,3\). 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%\(^4\). 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 Indigenous deaths, a rate seven to eleven times higher than for non-Indigenous males and females respectively\(^5\). CKD was an associated cause in a further 12% of deaths\(^5\). 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. Although beyond the scope of the terms of reference for this “Study on service planning for renal dialysis services in remote and very remote areas”, 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 this would result in an increase of almost 100% in the prevalence of ESKD, with approximately 480 Aboriginal and Torres Strait Islander peoples from across the region requiring renal services in 2020.

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. Targeted interventions across the life-course (see schematic below), bring together whole of government interventions to address social disadvantage, with health sector interventions to address early intervention and evidence-based management of risk factors for CKD and progression of disease, consistent with the current national health reform agenda, are required.
Life course approach to chronic kidney disease prevention and management
Primary prevention initiatives are required from the antenatal period with the aim of preventing the development of CKD. Although high-quality evidence of the effectiveness of interventions to prevent the development of CKD is not available, evidence indicates that the following initiatives would have a positive health impact generally and would affect intermediate outcomes known to be associated with the development of CKD:

1. Increased access to antenatal services to improve fetal and maternal health and reduce the prevalence of low birthweight.
2. Screening and intensive management of diabetes in pregnancy and encouragement of breastfeeding to prevent the development of obesity and early onset of type 2 diabetes.
3. Prevention of obesity in early childhood, particularly due to ‘catch up growth’ in those with LBW, as they are at greatest risk of developing diabetes and CKD.
4. Early childhood development initiatives to improve educational achievement and life-skills.
5. Training community members to improve housing infrastructure and to maintain improvements, thus also providing employment opportunities.
6. Installation of swimming pools in remote communities to reduce the prevalence of skin, middle ear and respiratory tract infections.
7. Food supply initiatives to improve access to affordable healthy food.
8. Community-based scabies control programs.
9. Culturally appropriate healthy nutrition, physical activity and quit smoking programs and legislative initiatives to regulate tobacco advertising.
10. Intensive nutrition and physical activity programs to delay or prevent the onset of diabetes in people with IGT.

Primary care-based screening to facilitate early detection and evidence-based management of CKD has been shown to be cost-effective in the general population. Evidence supports targeted screening of people at high risk of CKD — including Aboriginal and Torres Strait Islander peoples aged 35 years and over; people with diabetes, hypertension or cardiovascular disease; smokers; people with a family history of CKD; and people who are overweight or obese. Tests for CKD screening should include a urine test for albuminuria, preferably a first morning voided specimen, or otherwise a spot urine, and serum creatinine to estimate glomerular filtration rate (GFR). Kaninyi Vascular Collaboration (KVC) Audit Study data indicate that approximately 40% of those people attending Aboriginal primary care services, who are indicated for CKD screening, have the results of these tests entered into their medical record. The benefits of a CKD screening program should be evaluated in terms of reduction in premature cardiovascular morbidity and mortality as well as prevention of ESKD.

Modelled analyses utilising Australian evidence regarding the population burden of diabetes and hypertension, current practice patterns and RCT-based evidence regarding the effectiveness of interventions, have demonstrated that primary care-based screening for CKD and its major risk factors, followed by evidence-based management of 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, which, if closed, would improve cardiovascular and renal health outcomes.

Substantial evidence underlines the effectiveness of blood pressure lowering in reducing cardiovascular morbidity and mortality and favours the use of treatment regimens which include ACE inhibitors or Angiotensin Receptor Blockers (ARBs) in retarding the progression of CKD. Such evidence is most compelling for patients with established diabetic kidney disease. Recent large-scale RCTs suggest that ARBs are not inferior to ACEIs but conflicting evidence remains for the use of combination ACEI and ARB blockade. Diabetes is the leading cause of ESKD in many countries and is the attributed cause or a comorbid condition.
for the vast majority of Aboriginal and Torres Strait Islander peoples commencing RRT. Large trials in the
general diabetic population have provided strong evidence that intensive glycaemic therapy delays the onset
or progression of diabetic nephropathy, particularly in its early stages. Despite a lack of controlled trials
indicating benefit in the Australian Indigenous population, interventions in remote Aboriginal communities
which used historical, rather than contemporaneous controls, have suggested cardiovascular and renal
benefits from intensive management regimens.

The need for monitoring

Research undertaken for this Study has confirmed the lack of reliable, population-representative data for the
CA region regarding the burden of CKD and related chronic conditions, risk factors for the development and
progression of chronic disease, and utilisation of relevant preventative and treatment services. As concluded
in the AIHW report on prevention of cardiovascular disease, diabetes and chronic kidney disease: “There is
clearly a need for ongoing monitoring in the area of prevention. However, better data are needed, in
particular those based on measurement rather than self-reported data, as well as systematic data on
population-level initiatives.” The establishment of a CA Region CKD Registry, would enable the collection,
analysis and regular reporting of health system performance in the detection and management of CKD and
related chronic diseases. This would form one necessary part of a coordinated prevention strategy aiming to
reduce the growth in prevalence of CKD across the CA Region.

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.” Modelling undertaken for this Study will explore the
consequences of achieving this target of stabilisation of age-specific incidence of ESKD, in terms of the
projected prevalence of ESKD and costs of renal service provision until 2020.

3.3.2.2 Burden of CKD Among Aboriginal and Torres Strait Islander peoples

Premature mortality due to cardiovascular disease, diabetes and CKD contributes substantially to the gap in
life expectancy for Aboriginal and Torres Strait Islander peoples. During 2001 to 2004, Aboriginal and Torres
Strait Islander peoples were eight times more likely to die from CKD and these deaths occurred at a younger
age than amongst non-Indigenous Australians. 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.

From 2000 to 2009 the number of people from the CA region receiving dialysis treatment has tripled to more
than 200 patients. Approximately 10% of these patients are treated close to home in remote communities,
with the large majority receiving satellite haemodialysis 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.

More than 40% of adults attending Aboriginal primary care services across the CA region have either
proteinuria or reduced kidney function – the cardinal markers of earlier stages of CKD. Without coordinated
preventative initiatives, and a closing of the gap between evidence and practice in chronic disease
management, the regional demand for renal services is projected to increase markedly over the next decade.
To address the significant issues already outlined, and in response to concerns regarding the likelihood of
further increases in demand for renal services, the Department of Health and Ageing commissioned the Central Australia Renal Study.

A strong body of international literature attests to the key influences of social determinants on patterns of health and illness in populations. The health of Aboriginal people in the CA region is fundamentally shaped by their social context of severe poverty; inequitable access to a range of essential educational, housing, social and health services; marginalisation and disempowerment; and rapid social change impacting on family, kinship and community structures.

Evidence generated by the Study Team has made clear the strong association between socio-economic disadvantage and the burden of kidney disease. The Team has explored the likely pathways between key indicators – including low birth-weight, poor educational attainment, low income, unemployment and house crowding – and the onset and progression of kidney disease. Socioeconomic disadvantage leads to this heavy burden of kidney disease, which then further impacts on employment, income and quality of life for Aboriginal and Torres Strait Islander peoples in the CA region.

CKD is a complex chronic disease which requires major changes to diet, lifestyle, relocation to access necessary care for the majority of people in remote areas, and causes major disruption to families and communities. 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. In urban and rural centres, where barriers to the provision of community-based care are much less significant, success in shifting the balance of care from the hospital to community setting has not yet been demonstrated. In the context of service delivery in the CA region, the Study Team can offer no panacea or checklist for how to deliver optimal health services to comprehensively address the complex array of social, economic, educational, housing, environmental and political challenges facing Aboriginal people. We do, however, aim to explore a range of safe, effective, appropriate and sustainable options to improve health outcomes for the people and communities of the region.

3.3.2.3 Outcomes of CKD Among Torres Strait Islander peoples

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 Indigenous 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 CVD 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.

### 3.3.2.4 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.\(^9,10\) Transplantation is offered as a treatment modality to medically suitable Indigenous 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,\(^11\) Aboriginal and Torres Strait Islander peoples in the CA region experience low transplant rates. A number of additional barriers to transplant access for Indigenous 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.\(^12\) 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\(^13\) 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 Indigenous patients.\(^14\) Geographical remoteness has also been suggested as a factor associated with lower transplantation rates, but the international evidence on this point is mixed.\(^15\) Other potential barriers for Indigenous patients include delayed referral for transplant evaluation\(^16\) and delays from initial referral to transplant wait-listing.\(^16,17\)

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.\(^18\) In the remote area context of marked socioeconomic disadvantage, miscommunication\(^19\) and barriers to accessing necessary information regarding treatment options,\(^20\) 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 haemodialysis 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.\(^23\)

### 3.3.2.5 Chronic Illness Care and Prevention Services for Indigenous Peoples in Australia, New Zealand, Canada and USA

The Study methodology included a synthesis of a major review of international literature regarding Indigenous access to chronic disease services. The qualitative systematic review encompassed nearly 400 empirical and grey literature documents published between 1990 and 2007 relating to access to chronic disease services by Indigenous people in Australia, Canada, New Zealand and the United States.\(^17\) A full bibliography can be found in the Technical Appendices (Appendix I).

While there is a large body of international evidence detailing the inequities in health service access for Indigenous people in Australia and internationally, there have been few robust evaluations of interventions to improve such 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. However, the systematic review suggested that access to health services is inextricably linked to broader societal factors and the findings yielded four key approaches for improving future Indigenous access to chronic disease services. These are directly applicable to the review of renal services in the CA region and entail complex and multi-faceted interventions to:

- Challenge health system perspectives characterised by biomedicised systems of care which do not take account of social, cultural and economic contexts of health and health care delivery.

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

- Create health services that are easy to navigate with Indigenous staff, adequate resources and a focus on ongoing quality improvement.
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 set against what the review found was the broad issue 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. The methodology and findings of the review are outlined below, together with further implications for the provision of renal services in the CA region.

The review was based on the concept of candidacy, in which eligibility for medical attention and intervention is negotiated between individuals and health services. Candidacy considers the accessibility of chronic illness and prevention services for Indigenous peoples as an interplay between the users (Indigenous people) and providers (generally non-Indigenous Health providers). This enables barriers to be understood, and recognises that both parties may have explicit or implicit criteria for whether health care is sought or provided.

The following review question guided this part of the evidence review: What influences the accessibility of chronic illness care and prevention services for Indigenous peoples in Australia, New Zealand, Canada and USA? 'Access' was viewed as a broad concept and extended beyond mere service availability to include utilisation, acceptability, affordability, relevance, effectiveness and equity.

The review identified that, across the four countries, the factors influencing Indigenous access to chronic disease services could be grouped according to four broad themes affecting candidacy for health care. Each theme was pervaded by the implicit and explicit promotion of cultural difference. Documents were listed under one or more factors, depending on content.

### Table 1: Key themes identified in literature review (with number of documents*)

<table>
<thead>
<tr>
<th>Cultural Difference (119)</th>
<th>Health system factors</th>
<th>Role of governments (114)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Biomedicalisation (74)</td>
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<tr>
<td></td>
<td></td>
<td>Biomedical health information (63)</td>
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<tr>
<td>Indigenous perspectives</td>
<td></td>
<td>Self-determination (86)</td>
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<td></td>
<td></td>
<td>Social and community focus (62)</td>
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<tr>
<td></td>
<td></td>
<td>Indigenous knowledge (88)</td>
</tr>
<tr>
<td>Healthcare interactions</td>
<td>Patient-centred care (48)/patient-provider relationship (82)</td>
<td></td>
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<tr>
<td></td>
<td>Communication (73), Language and literacy (22)</td>
<td></td>
</tr>
<tr>
<td>Health services structure, function and organisation</td>
<td>Health professional relationships/roles (56)</td>
<td></td>
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<tr>
<td></td>
<td>Importance of Indigenous health staff (88)</td>
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<tr>
<td></td>
<td>Navigation and permeability of health services (71)</td>
<td></td>
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<td></td>
<td>Resource constraints (68)</td>
<td></td>
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<tr>
<td></td>
<td>Quality improvement strategies (50)</td>
<td></td>
</tr>
</tbody>
</table>

* Documents were placed in more than one category if they concerned multiple themes.
3.3.2.6 Health System Factors

**Role of governments** - Indigenous people, communities and organisations continue to perceive that governments and health systems discriminate according to Indigenous 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 and utilisation of preventative, primary care and acute care services. Of particular relevance to the delivery of renal services in the CA region is the Council of Australian Governments National Partnership Agreement on Remote Service Delivery, which commits the governments to responding to Indigenous disadvantage. 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.
- **Indigenous engagement**: Engagement with Indigenous 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 Indigenous 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.

**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. There was often an assumption that greater education and awareness relating to this biomedical information would prompt increased action on personal health issues among Indigenous people. This assumption fails to recognise the complex dimensions at play when seeking and delivering health care. When health providers displayed poor recognition of, and attention to, these 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. Such gaps directly impact on health outcomes for Indigenous renal patients in the CA region and elsewhere.

3.3.2.7 Indigenous Perspectives

**Self-determination** - The right to self-govern health services and promote alternate models of care was 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. The recent Medical Journal of Australia article outlining the achievement of equitable clinical outcomes by the Indigenous-run Kimberley Satellite Dialysis Centre (KSDC) was notable as the KSDC is the first satellite unit run by an Aboriginal Community Controlled Health Service.
Social and community focus - Indigenous family-based social structures were 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 for Indigenous people in all four countries. (This was strongly reflected in the Central Australian patient consultations conducted by the Study Team). Those health services that accommodated principles of family- and community-focused care were depicted as vibrant social spaces, while conventional health services and especially hospitals were often poorly equipped to accommodate family and social perspectives such as access to visitors, family involvement in decision-making, being able to obtain informed consent, and knowledge of whom to communicate with regarding key messages about an individual’s health care.

Indigenous knowledge - The international literature strongly voiced the importance of Indigenous knowledge 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 opinion pieces but there were few examples of health services successfully incorporating Indigenous knowledge. New Zealand’s Kaupapa Service – Whanaungatanga Model of Care23 and the Native American Patient Advocate program24 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.

### 3.3.2.8 Health Care Interactions

Patient/provider relationships - The perceived trustworthiness of the care providers, awareness of broader contextual factors affecting the acceptance and refusal of care, and adequate attention to all facets of the communication process affected service accessibility. The patient-centred care approach appeared to enable more effective Indigenous patient-carer encounters through acknowledgement of the patient’s worldview, validation of their concerns, affirmation of individuality and autonomy. Promotion of these patient-centred approaches required health professionals to dedicate a great deal of time and building of trust within the relationship.

Communication - The success or otherwise of communication played 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.

### 3.3.2.9 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 were crucial in health services. The recent article outlining the achievement of the KSDC highlighted the importance of Indigenous staff and an accessible and welcoming organisation structure:

“While there is no empirical evidence for this, the sense of ownership the patients have for the organisation, the extensive use of Aboriginal staff, including Aboriginal health workers delivering dialysis care and Aboriginal drivers to collect patients, as well as the support provided by a regional renal social worker all contribute to a unit that welcomes patients and provides culturally appropriate care.”

Demands on Indigenous staff in chronic disease services were reported, in some cases, to 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. Unrealistic expectations of improvements in health status measures were often placed on health services as a condition of funding. Research into Australian, Canadian and New Zealand Indigenous health performance measures raised concerns that disease-focused measures might take precedence over 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. The involvement of Indigenous advisory groups in the development of health system indicators, together with 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, were suggested as important steps for devising successful quality improvement initiatives.

**3.3.2.10 Culture**

The role of culture and cultural difference was a pervasive theme throughout the international literature regarding Indigenous candidacy for healthcare and therefore 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. Attempts to address these perceived differences by enhancing health professional cultural awareness and sensitivity could lead to a checklist-based approach based on assumptions of cultural difference that fails to take account of local context and issues.

The alternative 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. The key was to move beyond training of non-Indigenous staff to be culturally aware, to understanding and changing those aspects of health service delivery and the health system that exclude and marginalise Indigenous people.
3.3.2.11 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 and reflect the issues raised by stakeholders during extensive consultations undertaken for the Study. At a fundamental level, the principles for service delivery articulated in the COAG agreement – principles of priority, Indigenous engagement, sustainability, access, integration and accountability – form an appropriate basis for service planning and delivery across the region. Calls for a simple checklist-based approach to the provision of safe, appropriate, high-quality and sustainable care, belie the need for multi-faceted and complex interventions that are based on partnership and negotiated with patients and communities. 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 Indigenous staff. The Study Team however, acknowledge the inherent difficulties in attracting and retaining Indigenous staff in the CA Region. Calls to understand “non-compliance” of Indigenous renal patients focus on exploring the patient characteristics responsible for their failure to accord with the directions of service providers and health systems. Such calls shift attention from the more fundamental need for health services to deliver patient- and family-centred care and to address structural constraints including the lack of appropriately trained interpreters and lack of staff and resources to address key social issues including housing, security, transport and advocacy for patients.
3.4 Current and Future Burden of Renal Disease in the CA Region

3.4.1 Total Numbers Affected

3.4.1.1 ESKD Burden in the CA region

<table>
<thead>
<tr>
<th>Key Findings</th>
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<tr>
<td>Based on ANZDATA Registry analysis, from 1999 to 2009, the number of people receiving maintenance dialysis from Central Australia more than tripled from 62 to 209.</td>
</tr>
<tr>
<td>This increase has been driven principally by the growing number of patients commencing RRT each year.</td>
</tr>
<tr>
<td>There is a suggestion that the number of new cases may have stabilised at 35 to 40 per year. This uncertainty has been incorporated in future projections of disease burden.</td>
</tr>
<tr>
<td>The vast bulk of the ESKD disease burden falls in the ages between 35 and 65, traditionally periods of maximum family responsibilities, productivity, community contribution and leadership.</td>
</tr>
</tbody>
</table>

For Aboriginal & Torres Strait Islander patients in Central Australia, maintenance dialysis remains the predominant modality for delivery of renal replacement therapy (RRT). Based on ANZDATA Registry analysis, from 1999 to 2009, 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).
This increase 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 CA region by explicitly modelling high-and low-range scenarios.
Amongst new patients commencing RRT in the CA region, fewer than two per year are non-Aboriginal. The large majority of new Aboriginal patients are aged 45 to 64 or 25 to 44, with very few patients commencing treatment aged 0 to 24 or in the over 65 age group.

Compared to 13,404 non-Indigenous Australians commencing treatment outside the CA region from 2005 to 2009, the 174 Aboriginal patients commencing treatment in the CA region were:

- Less likely to be aged 65 and over (10.3% v. 45.9%)
- More likely to be female (56.9% v. 38.2%)
- More likely to have Type 2 diabetes (87.9% v. 38.0%)
- Less likely to have documented coronary artery disease (27.6% v. 39.6%), cerebrovascular disease (7.4% v. 15.2%) or peripheral vascular disease (13.2% v. 24.7%)*
- More likely to be a current smoker (17.8% v. 11.3%)

It should be noted that lower documented rates of comorbid vascular diseases are likely to be explained, wholly or in part, by reduced opportunities for investigation, diagnosis and documentation of these conditions.

It is important to understand 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 indigenous 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.
Figure 3: Unadjusted ESKD incidence Indigenous Australian

(2009 ANZDATA Report Ch 12)

Figure 4: Relative (age-specific) ESKD incidence Aboriginal and Torres Strait Islander peoples 2006-2008

(2009 ANZDATA Report Ch 12)
3.4.1.2  CKD Burden in the CA region

Key Findings

- 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.
- The Kanyini Vascular Collaboration Audit Study examined a random sample of 451 adult attendees at primary care services and found that 45% had micro- or macro-albuminuria and 41% CKD Stages 3 to 5, of whom 39.2% had Stage 3.
- Reduced kidney function and albuminuria are independent predictors of mortality.
- Reliable data regarding the incidence of CKD and progression to ESKD are not currently available.
- International evidence suggests that people with CKD Stage 3 are more likely to die than they are to progress to commencing RRT.
- Almost 170 people in the CA Region have been identified with advanced CKD (Stages 4 and 5).
- Data regarding the number of people with advanced CKD, by community, does not facilitate planning regarding potential sites for renal service delivery.
- Taken together these findings suggest the potential of:
  - implementation of automated electronic systems to enable de-identified data collection, reporting and feedback regarding CKD prevention and management against an agreed core set of CKD-specific performance indicators.
  - establishment of a CKD Registry for the cross-border CA region to enable the monitoring of population-level incidence and prevalence of CKD and progression to RRT.

For the purposes of the Central Australia Renal Study, data were collected and analysed from a range of sources including primary healthcare service databases, the NT Central Australia CKD database, the Kanyini Vascular Collaboration Audit Study of the detection and management of chronic disease and the NT Government 2009/10 Chronic Disease Report.

NT Central Australia CKD Database

Summary data from the NT Central Australia CKD database – which includes data from communities across the region, Nganampa Health Service – which includes data from communities across the APY Lands in South Australia, Ngaanyatjarra Health Service – which includes data from communities across the Ngaanyatjarra Lands in Western Australia are presented in Table 2.
Table 2: 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>Ngaanyatjarra 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>

This high-level review of data sources across the CA region (Table 2) identified 585 people with CKD Stages 3 to 5. More than 70% of these people had CKD Stage 3. Currently available primary care and hospital data collections do not, however, allow a comprehensive assessment of the burden of pre-dialysis CKD across the region. These data collections represent an incomplete picture of attendees at primary care services, or people who are referred to, and attend, a CKD clinic. The Study Team therefore reviewed the NT Government Chronic Disease Report\textsuperscript{4} and Kanyini Vascular Collaboration Audit\textsuperscript{5} of chronic disease detection and management, both of which aimed to describe the prevalence of CKD within the CA Region.


The Northern Territory Department of Health and Families produced a 2009/2010 Chronic Disease Report aiming to describe the prevalence of chronic diseases amongst the adults attending DHF Clinics in 26 communities across the CA region.\textsuperscript{4} A query group search was undertaken for a number of priority preventable chronic diseases (PCDs) – diabetes, hypertension, dyslipidaemia, asthma/COPD, coronary heart disease/ischaemic heart disease and CKD. The query group search was performed using Primary Care Information System (PCIS), used by the majority of DHF clinics. Amongst 6,189 community residents aged 15 years and older, 2,111 (34%) had been diagnosed with a PCD. It was estimated that 20% had diabetes, 17% hypertension and dyslipidaemia, 5% asthma/COPD, 2% CAD/IHD, and 12% CKD. The report notes difficulties in extracting data regarding renal disease as data extraction could not differentiate acute kidney injury from CKD and ACR results were not taken into consideration. The report estimated prevalence of CKD Stages 1 and 2 at 8%, CKD Stage 3 at 3% and CKD Stages 4 and 5 at 1%.

The NT Chronic Disease Report findings regarding CKD prevalence constitute an unreliable foundation for service planning. A diagnosis of CKD Stages 1 and 2 cannot be made without ACR measurement, or other evidence of renal damage, in addition to a creatinine-based estimate of eGFR. The Chronic Disease Report estimated the prevalence of CKD Stage 3, in the CA Region, to be 3%. This estimate is lower than the estimated prevalence of 5.5% from the nationally-representative sample of the adult population recruited to the Ausdiab study,\textsuperscript{26} and many times lower than the estimate from the Kanyini Vascular Collaboration Audit Study reported below.


Between October 2007 and May 2008, the Kanyini Vascular Collaboration undertook a review of primary care records, on a random selection of 1,165 people, aged 18 years and over, at eight Aboriginal medical centres in.
New South Wales, Queensland and Central Australia. 5 Within sites across the CA region, 451 patient records were reviewed. The patients whose records were reviewed had a mean age of 41.1 years and 27.1% had diabetes. Microalbuminuria was detected in 28.4% and macroalbuminuria in 16.6%. Amongst people indicated to be screened for CKD according to national preventative health guidelines, CKD screening was documented in 40%. In those with data documenting CKD stage, Stage 3 was found in 39.2% and Stages 4 and 5 in 1.8%. This rigorous study of a random sample of regular attendees at primary care services across the region revealed a heavy burden of both albuminuria and early CKD.

**Progression from Stage 3 CKD**

Before discussing a range of key issues regarding people identified as having advanced CKD (Stages 4 and 5), it is important to discuss the significance of the diagnosis of Stage 3 CKD and the availability of comprehensive longitudinal data to enable assessment of the incidence of CKD or progression of disease towards the requirement for RRT. The Study Team note, in particular, the paucity of data concerning CKD incidence and changes in prevalence over time and the inability to correlate such changes with patterns of incidence of ESKD. Nganampa Health, however, provided longitudinal measures on 65 patients with CKD Stages 3 or greater. This data was analysed and will be discussed later in this section of the Report.

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. 27 However, the likelihood that early CKD will progress to ESKD requiring renal replacement and the rate of progression remain undefined. A large-scale modelling exercise, based on prevalence estimates from the US NHANES study, predicts that approximately 11% of people who reach Stage 3 CKD will eventually progress to CKD Stage 5. 28 This analysis is based on a theoretical, not real, population and does not take into account decision making regarding whether or not to commence RRT. A prospective study of a large HMO population in the US followed CKD patients to examine progression to RRT and mortality. 28 This study found 1.3% of more than 11,000 CKD Stage 3 patients progressed to RRT over five years, but these patients were almost 20 times more likely to die than progress to RRT. A recent report from a prospective cohort study of 382 people with CKD Stages 3 to 5, who were attending a nephrology clinic in the UK, provides different estimates of risk of RRT and death. 30 In a group where the choice had already been made to refer to nephrology care, amongst 88 patients with CKD Stage 3, none required RRT within the first 4 years of follow-up. Over the complete period 1.3% progressed to RRT per year and the mortality rate was 2.5 times higher than progression to 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. For the purposes of this Study, Nganampa Health provided longitudinal eGFR measurements on 65 patients with CKD stage 3 or greater. There was a mean of 5.1 observations per patient, over a mean follow-up of 382 days. The rate of change of eGFR was variable, illustrated in Figure 5. The median change was a loss of eGFR at a rate of 2.8 ml/min/1.73m² per year (with 25th centile being a loss of eGFR of 5.6 ml/min/1.73m² per year and 75th centile a gain of 1.3 ml/min/1.73m² per year).
This variability underlies clinical uncertainty about which patients will progress. It also underlies the uncertainty in predicting the numbers of incident RRT patients from any given community. The majority of patients with CKD will in fact remain fairly stable. Even when restricting the analysis to people with more severe forms of CKD (eGFR<30 ml/min/1.73m² consistent with CKD Stages 4 and 5) there was still large inter-patient variability, although numbers are small. Renal function deteriorated rapidly amongst the 3 patients who progressed to RRT. These numbers are clearly insufficient to explore which factors might predict such rapid clinical decline. The eGFR study\textsuperscript{31} has established a cohort of 600 Indigenous adults across the Top End of the NT, Central Australia, Far North Queensland and Western Australia. The research team aims to follow this cohort to explore the factors that predict progression of CKD. As yet however, the follow-up phase of the study has not commenced.
3.4.2 Geographic Distribution

Patients with Stages 4 and 5 CKD 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. In addition, as is the case across Australia, it is not possible to accurately determine the proportion of people with advanced CKD who decide not to seek dialysis treatment. However, using data supplied from the NT Renal Services CKD database and primary healthcare services databases, the Study Team has assembled the following data regarding the number of people with advanced CKD, by community (Table 3). It should be noted that not all CA communities will be 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, currently has 16 patients with CKD Stage 3, but none with more advanced CKD.

Key findings amongst patients with Stages 4 and 5 CKD (Table 3) include:

- A large number of people identified as having advanced CKD are living in Alice Springs and Tennant Creek. However, as demonstrated in previous research by the Study Team, 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. It is not possible to discern any meaningful pattern within the CA Region, at community level, in terms of future demand for renal services.

- Small differences between global estimates provided from Nganampa and Ngaanyatjarra Health Services in September and community-level estimates provided in November-December are consistent with known patterns of mobility for community members. Data supplied by Nganampa including numbers by community, indicated that 1 in 3 of the people with advanced CKD were visitors from the Northern Territory or Western Australia.

- At the time of the Study, 35/166 patients (21%), particularly those with the most advanced or Stage 5 CKD, were waiting, with AV fistula created or PD catheter inserted, to commence RRT.
### 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>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Haasts Bluff</td>
<td>≤3</td>
<td>≤3</td>
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<tr>
<td>Harts Range</td>
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<td>≤3</td>
</tr>
<tr>
<td>Ntaria</td>
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<td>≤3</td>
</tr>
<tr>
<td>Kintore</td>
<td>5</td>
<td>≤3</td>
</tr>
<tr>
<td>Lake Nash</td>
<td>4</td>
<td>≤3</td>
</tr>
<tr>
<td>Laramba</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Mt Allen</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Nyirripi</td>
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<td>≤3</td>
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<tr>
<td>Papunya</td>
<td>≤3</td>
<td>≤3</td>
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<td>Santa Theresa</td>
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<td>≤3</td>
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<tr>
<td>Tara</td>
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<td>≤3</td>
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<tr>
<td>Ti Tree</td>
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<td>≤3</td>
</tr>
<tr>
<td>Utopia</td>
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<td>≤3</td>
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<td>Willowra</td>
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<tr>
<td>Yuendumu</td>
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</tr>
<tr>
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<tr>
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</tr>
<tr>
<td>Warburton</td>
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</tr>
<tr>
<td>Pipalyatjara</td>
<td>≤3</td>
<td>≤3</td>
</tr>
<tr>
<td>Iwantja</td>
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</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>
</tbody>
</table>
### 3.4.2.1 Changes in Geographic Distribution

Recent research has documented the very high incidence of ESKD amongst Aboriginal and Torres Strait Islander peoples living in the ATSIC regions of Warburton, Port Augusta, Aputula, Alice Springs and Tennant Creek\(^3\)\(^4\)\(^1\); which are the regions relevant to the CA Study. Current evidence regarding trends in the incidence of ESKD across the region is discussed above. With currently available data, it is not possible to predict changes in the geographical burden of disease over time *within* the CA region. Nevertheless, the small population size of the many remote communities in the region means that the number of people commencing and needing dialysis from any particular remote community, over time, will be highly variable. This has significant implications for the most effective ways to establish infrastructure required to support renal service delivery in remote communities. In particular it would be valuable for the construction of health facilities to take into account the following:

- Potential needs for dialysis provision within communities.
- Decommissioning and recommissioning of dialysis facilities.
- Implementation of a modular approach to construction of dialysis facilities, using renal ready rooms and relocatable units, to facilitate ongoing maintenance and durability of infrastructure.

During consultation, the potential benefits of modular construction of dialysis facilities, in terms of opportunities for relocation, were explored. However, several key stakeholders indicated recent quotes for movement of relocatable units had become prohibitive. In theory, a consideration of transportability of dialysis facilities would be important, and this remains a potential benefit associated with the use of relocatable units. However, given the cost for transporting facilities, relocation would appear to be a less feasible option into the future.
3.4.3 Renal Failure - Treated and Untreated

Key Findings

- Amongst people indicated by national guidelines for screening for CKD, approximately 40% are being screened.
- There is evidence of substantial evidence-practice gaps in the management of pre-dialysis CKD. If closed, this would reduce premature cardiovascular mortality and likely impact on the projected burden of ESKD to 2020.
- Late referral rates to nephrology care are similar to national rates. However, 1 in 6 patients commencing RRT are referred late, thus compromising planning and preparation for RRT.
- Home- or community-based dialysis rates, less than 10% when including patients in training, remain significantly lower than national rates.
- More than 60% of haemodialysis patients survive at least 4 years after commencing treatment.
- Peritoneal dialysis infection rates remain high and technique survival poor.
- Few Indigenous patients receive kidney transplants and survival outcomes are significantly worse than national outcomes.

Estimating treated and untreated renal failure is problematic and no methods have been validated. Nevertheless, a recent approach to estimation of the total incidence of end-stage kidney disease provides a starting point.

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-Indigenous cases receive RRT.

The age-standardised ratio of receipt of RRT, between Indigenous and non-Indigenous Australians, was 0.96, indicating that Aboriginal and Torres Strait Islander peoples had slightly lower treatment rates.

**Indicators of Access to Necessary CKD Care**

Numerous indicator frameworks could be constructed to consider access to necessary care among Aboriginal in the CA region, and consequent outcomes, across the spectrum of CKD. A range of evidence based indicators are available. For the purposes of the present Study, ten key indicators were used, based on evidence that they are markers of delivery of care to renal patients, and are strongly linked to health outcomes, or constitute key health outcomes in their own right. They are presented below, along with citation of key evidence for their inclusion (Table 4 and Table 5).
Table 4: Key health outcome indicators across the spectrum of CKD and their rationale

1. **Primary-care based screening for CKD**
   
   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.

2. **Assessment of prescribing and treatment gap in the management of elevated blood pressure in people with CKD**
   
   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.

3. **Proportion of new ESKD cases who 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.)**
   
   Evidence indicates that late referral leads to higher costs of hospitalisation, higher mortality throughout the course of RRT and lower access to kidney transplantation.

4. **Proportion of new ESKD cases that commence dialysis with functioning access**
   
   This is a measure of haemodialysis 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.

5. **Proportion of prevalent RRT patients receiving home-based therapies**
   
   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.

6. **Patient survival on haemodialysis**
   
   HD is the treatment modality being received by the majority of patients across the CA region.

7. **Peritonitis rate — episodes of peritonitis per patient year of peritoneal dialysis treatment**
   
   Peritonitis is the crucial factor affecting patient outcome and technique survival amongst renal patients.

8. **PD technique survival rate**
   
   The proportion continuing PD 1 year after initiation. This is a crucial measure of the sustainability or viability of PD.

9. **Proportion of prevalent RRT patients with a functioning kidney transplant**
   
   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.

10. **Graft survival post transplant**

    A critical measure of efficacy of kidney transplantation. Graft or transplant failure requires
recommencement of maintenance dialysis.

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 and blood pressure management of CKD in primary care do not differ greatly from that of the Australian general population. However, 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**

- Haemodialysis 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: Indicators of success in addressing clinical needs of CKD patients

<table>
<thead>
<tr>
<th>TREATMENT</th>
<th>CA region Aboriginal patients</th>
<th>National patient cohort</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screening for CKD</td>
<td>40% a</td>
<td>Direct comparison not available b</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>
</tbody>
</table>

<table>
<thead>
<tr>
<th>OUTCOMES</th>
<th>CA Aboriginal patients</th>
<th>National patient cohort</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haemodialysis patient survival (Proportion alive on HD 1 year after initiation)</td>
<td>87.5 (95% CI 81.2-91.8) f</td>
<td>84.2 (95% CI 83.3-85.0) f</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) f</td>
<td>53.4 (95% CI 51.7-55.1) f</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) f</td>
<td>0.63 (95% CI 0.59-0.66) f</td>
</tr>
<tr>
<td>PD technique survival (Proportion continuing PD 1 year after initiation)</td>
<td>50.8 (95% CI 21.4-74.2) f</td>
<td>70.5 (95% CI 68.9-72.0) f</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%) e</td>
<td>82% (95% CI 81%-84%) e</td>
</tr>
</tbody>
</table>

Table 5 – Data Sources:

aFurther unpublished analysis from the Kanyini Vascular Collaboration Audit Study. 5
bUnpublished evidence from the AusHEART study of screening and management of vascular risk indicates CKD documentation in mainstream general practice patients is poor. 38

cKanyini Vascular Collaboration Audit Study data. 5

dAusHEART Study data. 38

eSpecial 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.
†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.

*ANZDATA 2009 Annual Report.39
3.4.4 Projections of Burden of ESKD

### Key Findings

- In 2020, the number of people commencing RRT will lie between 35 and 81. An increase of up to 130% in the number of new patients commencing RRT is projected.

- The majority of this increase is driven by new Indigenous ESKD cases in the age range 45 to 64.

- In December 2020, the number of people receiving RRT in the CA region will lie between 312 (steady-state model) and 479 individuals (growth model). This represents an increase of between 30% and 100% in the number of patients receiving RRT.

3.4.4.1 Data Sources

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 end stage kidney disease 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.

3.4.4.2 Inclusion Criteria

A number of possible inclusion criteria were examined, with the aim of replicating the defined "catchment area" of Central Australia for the purposes of this Study. There is no exact overlap. The final criteria used included people who either:

- Commenced on renal replacement therapy in Alice Springs; or

- Had a residential postcode reported as 0872 or 6431 at the initiation of renal replacement therapy.

The aim of inclusion of the postcode-based criteria is to improve the capture of those patients from the relevant cross-border areas in South Australia and Western Australia. The 0872 postcode does not, however, allow distinction of residents of Western Australia from South Australia from Northern Territory (the postcode includes areas of all three jurisdictions). The postcode 6431 also covers some areas to the west of Warburton. It is not possible, on the basis of information available within ANZDATA, to distinguish which patients within this postcode region coincide exactly with the designated CA region. However, as the Study Team confirmed
during extensive consultation and verified by examination of data supplied by primary healthcare services, in particular Nganampa Health, there is extreme mobility of patients and their families both within, and in and out of, the designated area for the CA Renal Study.

The number of patient identified through the postcode route was small:

- For incident patients, in addition to the 403 identified who started RRT at Alice Springs hospital over the period 1995-2009, there were 3 people identified by the 0872 criterion, and 9 by the 6431 criterion.
- For prevalent patients, in addition to the 232 prevalent patients at the end of 2009 on the basis of the treating hospital being Alice Springs, there were an additional 3 patients identified by the 0872 criterion, and 4 by the 6431 criterion.
- However, these numbers are expected to be larger for 2010, as greater diversion of patients from SA and WA to Adelaide and Perth respectively is expected following changes in acceptance of these patients by the NT in Alice Springs.

3.4.4.3 Model Parameters

Growth model: For the growth model, the expected growth in each age group – 0 to 24, 25 to 44, 45 to 64, 65 to 74 and 75 and over – was modelled using a Poisson distribution, extrapolating the trend observed over 1995-2009 to 2020.

Lower range model: For the lower range model the arithmetic mean of the number of incident patients over 2005-9 in each age group – 0 to 24, 25 to 44, 45 to 64, 65 to 74 and 75 and over – was used as the base case and continued to 2020.

Broadly speaking this approach is similar to that used by the Study Team in recent national projections undertaken for Kidney Health Australia.16 Given the underlying catchment region is not a discrete jurisdiction, separate calculation of age-specific incidence rates per million population, and integration of projected changes in population were not possible. In each group, the actual number starting dialysis is a product of the age-specific rate together with the population in that age group. Thus, the projections for the growth scenario implicitly assume that the trends in age-specific rates and in the number of people in each age stratum observed over the period 1995 to 2009, will continue to 2020.

Another assumption is that the propensity to offer and take up the offer of RRT will not change. Data presented in the Report indicates that there are a significant, but poorly quantified number of people with advanced CKD who are either not offered, or decide not to commence RRT. Nationally this group of people with “un-treated” ESKD has not been quantified or characterised. One peer-reviewed paper has estimated that up to 50% of Australians with severe CKD might chose not to commence RRT and suggested that these are older people, predominantly over the age of 80.10 Both the Australian Institute of Health and Welfare and ANZDATA Registry are currently exploring this issue. With one key factor potentially affecting uptake of RRT being access to treatment closer to home, the expansion of provision of community-based care recommended in this Report might lead to an increase in the propensity of Aboriginal people in the CA region to undertake RRT.

3.4.4.4 Results

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. The key variable influencing burden of ESKD is likely to be that of disease incidence. 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 on this scale. This is illustrated by the 95% confidence intervals seen for each age group in Figure 6. Inspection of the recent trends suggests two possible interpretations:

- A stabilisation of the yearly number of incident patients over the last 5 years; or
- A steady long-term linear increase from 1995.

Projections of new ESKD cases, by age, were modelled under both of these scenarios.

These 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 (Figure 6). 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, bearing in mind the statistical variation inherent in analysis of numbers of this scale.

The historic age specific trends in the incidence of ESKD across the CA region were examined to determine all age likely future trends (2010 & 2020) under three possible models:

- 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.

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 6).

### Table 6: Projected prevalent ESKD cases to 2020 (239 cases in base year of 2008)

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<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>
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<td>Growth</td>
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<td>287</td>
<td>303</td>
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<td>339</td>
<td>358</td>
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<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 7).

### Figure 7: Projected prevalent ESKD cases to 2020
3.5 Current Services

3.5.1 Current Location of Services

Key Findings

- The regional centre is Alice Springs with 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.

- Current service locations do not identify where patients consider to be their home community, or where patients are likely to be located in the future.

- Including patients in training, self-care HD is currently provided to 11 patients in Ali Curung, Lake Nash, Mt Liebig, Amoonguna and Santa Teresa.

- Including patients in training, PD is currently provided to 13 patients in Tennant Creek, Alice Springs or Santa Teresa, Kintore/Kiwrirrurra and Warburton.

- Respite services are provided for up to 4 patients in Kintore, 4 in Hermannsburg and 4 in Yuendumu at any one time.

- No patients are currently receiving dialysis in the APY lands.

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 8.

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 patients. The uncertainty around progression underlies uncertainty in predicting the numbers of incident RRT patients from any given community.
Beyond the provision of satellite and in-centre HD services in Alice Springs and Tennant Creek, access to renal services is limited across the CA region. Detailed consultation with renal providers, patients and community health services indicated the following, at the time of consultation for the Study:

- Including patients in training, self-care HD is currently provided to 11 patients in Ali Curung, Lake Nash, Mt Liebig, Amoonguna and Santa Teresa.

- Including patients in training, PD is currently provided to 13 patients in Tennant Creek, Alice Springs or Santa Teresa, Kintore/Kiwirrkurra and Warburton.

- Respite services, to enable temporary return to country, are provided for up to 4 patients in Kintore, 4 in Hermannsburg and 4 in Yuendumu at any one time.

No patients are currently receiving dialysis in the APY lands. Previous attempts to establish PD in the APY Lands have been unsuccessful, due to the high rates of severe infection and technique failure. One patient had been living in a remote WA community and receiving PD for approximately six months. However, as a consequence of their support person leaving the community without warning, this patient had to relocate to another remote community to receive nurse-supported APD. This is one example of the fragility of mechanisms for ensuring the sustainability of dialysis provision in remote communities. Evidence from widespread consultation for this Study, more than 150 interviews undertaken as part of the IMPAKT study, analysis of treatment outcomes from the Kimberley Satellite Dialysis Unit and other remote community dialysis facilities indicates that lack of access to dialysis services “close to home” is a key determinant of
uptake of renal replacement therapy and adherence to treatment regimens.
3.5.2 Current Nature of Services

**Key Findings**

- There is no definitive evidence that one form of dialysis is superior to others in terms of patient mortality.
- Nationally, there is evidence that a shift from hospital-based to community- or home-based dialysis therapies would significantly reduce expenditure on renal health services.
- There is marked State- and Unit-level variation in the utilisation of home-based therapies.
- Without evidence regarding a survival benefit, or measured benefit in terms of quality of life, cost-effectiveness analyses cannot be utilised to support a shift to community-based therapies.
- The predominant modality of renal service delivery across the CA region is satellite or in-centre HD. Current facilities are located in Alice Springs and Tennant Creek, with a total of 56 machines from early 2011.
- Community-based PD and HD are available in the CA Region. However, with less than 10% of dialysis patients utilising community-based therapies, uptake has been limited.
- 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.

ESKD is inevitably fatal unless treated with maintenance dialysis or kidney transplantation. There are two principal forms of dialysis – Haemodialysis (HD) or Peritoneal Dialysis (PD). The choice of dialysis mode depends on many factors including availability of resources, age, family support, overall health and lifestyle. There is no definitive evidence that one form of dialysis, as it is currently delivered, is superior to the other in terms of patient mortality. Therefore, the decision for an individual depends on local experience and outcomes with each technique together with individual patient factors and preferences. Evidence from patient interviews undertaken through the IMPAKT study suggests that a patient’s perception of which form of treatment might enable them to “go home” strongly influences their thinking regarding desirable treatment modalities. Both HD and PD have been successfully initiated and maintained for Aboriginal and Torres Strait Islander peoples living in remote communities across Australia, however there has been significant variation in the utilisation of each home-based modality for Aboriginal and Torres Strait Islander peoples across Australia.

Nationally, there is evidence that a shift from hospital-based to community- or home-based dialysis therapies would significantly reduce expenditure on renal health services. This has been reflected in a range of State jurisdictions adopting strategies to shift treatment into the community, aiming to achieve targets of up to 50% of dialysis patients on HD and PD provided in the community. Such strategies are consistent with National Service Guidelines for the management of renal services in remote Australia, which endorse the principle of providing treatment as close to home as possible. However, nationwide there is marked State- and Unit-level variation in the utilisation of home-based therapies, emphasising the complex nature of increasing uptake of home-based therapies. Without evidence regarding a survival benefit, or measured benefit in terms of quality of life, such a shift to community-based therapies cannot be supported by cost-effectiveness analyses. In addition, it is critical to understand the current patterns, constraints and outcomes of provision of renal therapies in the CA region, to frame what might be feasible, safe and sustainable targets for treatment closer to home.
Transplantation offers people with kidney failure increased independence and freedom from the constraints of dialysis. Indigenous patients are significantly less likely to receive a transplant.44 In part this reflects much lower rates of living donor transplantation, in turn related to high rates of kidney disease among family members and other potential donors. In addition, there is evidence of poor health outcomes for donors.45 Those who do receive a transplant appear to wait longer and graft and patient survival rates are poorer than for non-Aboriginal patients. Should a transplant fail, the patient must recommence dialysis.

The predominant modality of renal service delivery across the CA region is satellite, or in-centre HD (Table 7). Current facilities are located in Alice Springs and Tennant Creek. These include the Flynn Drive satellite unit (20 machines), Gap Rd satellite unit (12 machines), Tennant Creek satellite (8 machines increasing to 16 machines in early 2011) and Alice Springs Hospital (8 machines). Peritoneal dialysis and home- or community-based HD are available in the CA region, however, uptake has been limited (Table 7). Despite dialysis, aiming to allow patients to return to country for short periods of several weeks, are located in Alice Springs (2 machines), Kintore (2 machines), Hermannsburg (2 machine) and Yuendumu (2 machine). Transplant rates remain very low for Aboriginal patients from the CA region (Table 7). Renal services are provided by NT Renal Services, Western Desert Ngalampa Walytja Palyantjaku Tjutaku Aboriginal Corporation (WDNWPT) the “Purple House”, an Aboriginal community-controlled organisation, providing the return to country service, and Nephrocare Australia, a division of Fresenius Medical Care, running the Gap Rd satellite unit under a public-private partnership arrangement with the NT Government.

**Table 7: Utilisation of RRT modalities at 31 December 2009 (ANZDATA)**

<table>
<thead>
<tr>
<th>RRT modality</th>
<th>CA region 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>

Modelling undertaken by the Study Team predicts continued rapid growth over the next decade in the number of people requiring renal services in the CA region. Capacity pressure, temporarily relieved by the opening of Gap Rd and expansion of Tennant Creek satellite units, will again rapidly build on satellite provision in Alice Springs. Current satellite and in-centre capacity across the CA region is 56 dialysis machines/ chairs. There is a need for phased expansion of dialysis chairs to 101 chairs (56 current + 45 new = 101) by 2018, providing the capacity to treat 404 dialysis patients in satellite units or hospitals. According to the high-range growth projections of ESKD prevalence, provided in Table 6 and Figure 7, 479 patients will require treatment in 2020. The expansion in dialysis would meet the projected high-range growth in demand for RRT, if only a conservative reduction in the proportion of patients relying on satellite or hospital HD from 89% (Table 7) to 84% (404/479) by 2020 were achieved.
3.5.3 Overview of Service Gap

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 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 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 8). 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 8: 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</td>
</tr>
<tr>
<td></td>
<td>Cultural skills</td>
</tr>
<tr>
<td></td>
<td>Lack of appropriately skilled interpreters</td>
</tr>
<tr>
<td></td>
<td>Inadequate Indigenous health workforce</td>
</tr>
<tr>
<td>Service provision/availability</td>
<td>Satellite dialysis facility growth not matching demand</td>
</tr>
<tr>
<td></td>
<td>Low utilisation of home/community based dialysis</td>
</tr>
<tr>
<td></td>
<td>Lack of co-ordination in service delivery</td>
</tr>
<tr>
<td>Social support</td>
<td>Lack of secure accommodation</td>
</tr>
<tr>
<td></td>
<td>Insufficient social services</td>
</tr>
<tr>
<td></td>
<td>Managing transition to town</td>
</tr>
<tr>
<td>Quality of life</td>
<td>Dislocation to receive services</td>
</tr>
<tr>
<td></td>
<td>Lack of respite services</td>
</tr>
</tbody>
</table>
3.6 Resources required to provide renal replacement treatment

3.6.1 Whole of Service Costs

3.6.1.1 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 CA region, associated with different modalities of service provision, have been estimated. Estimates of the capital costs for new satellite units, mini-satellites in communities, renal ready rooms and relocatables were included. While based on published national guidelines, these provide realistic costs, specific to the conditions in Central Australia.

3.6.1.2 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 (Appendices C and D).

### 3.6.1.3 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 Appendices (Appendix E).

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. Finding accommodation was identified by all service providers, in all jurisdictions, as the single biggest challenge for kidney patients moving to town for dialysis. Renal patients need permanent accommodation whereas the majority of available, low-cost accommodation is short term.

The absolute shortage of public housing properties is an under-resourced infrastructure need of renal patients. 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.

**Table 9: 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 early 2011</td>
</tr>
<tr>
<td>Apmere Mwerre</td>
<td>150 person -Aboriginal Hostels Managed Visitor Park – various grades of accomm including camping facilities</td>
<td>Unlikely – short term residents only - 2 weeks max</td>
<td>Not open</td>
<td>2011</td>
</tr>
</tbody>
</table>
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.

Thus social and cultural connectedness are fundamental for RRT in the CA region, along with their resource requirements. For this Study, stakeholders and patients reported that social and cultural connectedness could be maintained through being able to make regular return visits to the 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’. The first of these is respite dialysis, which will be discussed in more detail later in this Technical Report.

The second program to support social and cultural connectedness is the ‘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.
3.6.2 Technological Innovation

Key Findings

- A shared electronic health record, which enables information to follow the patient, might assist the development, implementation and sustaining of a co-ordinated, 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 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.
- The major restrictions to uptake of community-based dialysis in Aboriginal communities are not related to technical issues, so it is difficult to know how much technological innovation will enhance access to treatment closer to home.

3.6.2.1 Dialysis Innovation

Sorbent dialysis systems, which would significantly decrease the requirement for water, are not yet commercially available. Newer haemodialysis machines, such as the NxStage and Qanta machines, offer an easier user set-up and interface for self-care haemodialysis. They are not yet available in Australia and experience worldwide is limited, however they offer the possibility of increasing the uptake of self-care haemodialysis 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.

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 peritoneal dialysis 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.
3.6.2.2 **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.

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.

3.6.2.3 **‘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 Central Australia. 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.

3.6.2.4 **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.

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*Central Australia Renal Study – Technical Report*
3.6.3 Treatment Closer to Home

Key Findings

- The principle of treatment as close to home as possible has been repeatedly endorsed in renal services strategies and guidelines documents.
- Peritoneal dialysis outcomes remain a matter for concern with high infection rates and poor technique survival.
- During consultation for the Study, widespread and strongly felt reservations regarding the safety of PD in the remote community context were expressed by many community members, primary care doctors and some renal service providers.
- This “hub and spoke” model was developed within a state-based service model and has traditionally been limited to the provision of dialysis and transplantation services alone.
- In the CA context, Alice Springs was identified as the preferred hub for a regional renal service. Patients and community members indicated that permanent relocation to Adelaide, Port Augusta, Perth or Kalgoorlie was not an acceptable treatment option.
- Government, NGO and industry providers of renal services expressed readiness to collaborate in extending the provision of dialysis in remote communities in the CA region.
- Both renal ready rooms attached to local health facilities and co-located modular dialysis facilities are practical alternatives for dialysis infrastructure.

The principle of treatment as close to home as possible has been repeatedly endorsed in Australian renal services strategies and guidelines documents, however, provision of dialysis services for people living in CA is currently provided almost exclusively through satellite units in Alice Springs, Tennant Creek, Kalgoorlie, Port Augusta, Adelaide and Perth. Without valid measures of quality of life among Aboriginal and Torres Strait Islander peoples with ESKD, and with costing models for provision of nurse-supported mini-satellites in communities currently being developed, it is not possible to determine the cost-effectiveness of moving a certain proportion of patients from town-based satellite treatment to home- or community-based treatment. Nevertheless, different types of evidence gathered through this Study support expansion of care closer to home:

1. Consultation with renal patients, family members and communities across the CA region confirmed the strong desire for and commitment to support treatment on their Lands, because of the social, cultural and financial consequences for patients and families of the dislocation required to access current services.

2. The forecast growth in demand for renal services over the next decade, if met solely through expansion in satellite services provided from Alice Springs, or other major urban centres in South Australia and Western Australia, would further exacerbate the social and cultural impact of dislocation from family and community.

3. Experience elsewhere in Australia has been that uptake of renal services and adherence to treatment regimens is improved through access to care closer to home.12
The research team consulted widely regarding options for delivering renal services closer to home. Key informants included members of the Technical Reference Panel; NT Renal Services medical, nursing and allied health staff; Kimberley Renal Services medical, nursing and executive staff; WDNWPT executive, nursing and other staff; CA region primary healthcare services medical, nursing and organisational staff; industry dialysis providers (Fresenius and Baxter) nursing and executive staff; and international leaders in nephrology with direct experience in mobile dialysis delivery in Canada. Consultation with patients, their families and community members directly addressed the delivery of dialysis closer to home. (A full list of stakeholders consulted for the Study is included in the Technical Appendices.)

Before detailed discussion of the essential requirements to support community-based dialysis, the Report will provide a basic description of dialysis modalities, service delivery models and the “hub and spoke” model of renal service delivery. Dialysis services in the CA region may be provided by various combinations of dialysis modalities and service delivery models, which would be determined by the regional hub renal service provider in conjunction with the Central Australian Renal Network.

### 3.6.3.1 Dialysis Modality

Dialysis modality is defined by both location and the personnel providing dialysis. In the CA region these modalities would include:

- In-centre/satellite haemodialysis (HD) – Dialysis is performed by trained dialysis nurses. The in-centre or satellite service is generally in a metropolitan or regional centre. Dialysis is provided in a purpose built dialysis unit, generally with 4 or more dialysis chairs running on a shift basis of up to 12 shifts weekly.

- Community self-care HD – This is the equivalent of home dialysis provided elsewhere in Australia. The dialysis patient, after successfully completing self-care dialysis training, performs his or her own dialysis without nursing support. Dialysis is provided in a community-based facility such as a renal-ready room in a health facility or a dialysis demountable, as local housing provision and security is not considered suitable for home-HD.

- Community satellite/mini-satellite HD – Dialysis is performed by trained nurses in a community setting. This may be in a renal ready-area, demountable or dialysis building. Patients are resident in the community all year. Generally 4 or more patients would be dialysed in such a setting.

- (Reverse) Respite HD – Dialysis is provided by trained nurses in a community setting. Patients are not resident in the community and are dialysed for short periods of time before returning to the metropolitan satellite unit. Dialysis may be performed in renal-ready rooms, dialysis demountable or a dialysis bus. Unless dialysis is provided for 52 weeks per year, reverse respite does not add to overall dialysis capacity, as dialysis spots must be maintained for patients in the satellite unit.

- Peritoneal dialysis (PD) – Generally performed by the patient in his or her home following appropriate training.

### 3.6.3.2 Service Delivery Models

Dialysis services in Australia are generally provided by either public providers or private providers. There are also a limited number of public-private provider partnership models that have been recently developed. Unique to the NT is provision of respite dialysis by an NGO.

- Public provider – all aspects of dialysis are funded by State/Territory government and provided by state employees. Responsibility for dialysis outcomes is with the public provider.

- Public-private partnership – all aspects of dialysis are funded by State/Territory government and provided to various degrees by private haemodialysis companies. Such partnerships may include
provision of some or all of dialysis consumables, infrastructure development, technical services, nursing services and information technology. Such partnerships generally are tendered for a period of 5-7 years. Potential advantages include moving infrastructure capital cost to recurrent costs across the duration of the tender, moving the education and provision of technical and nursing staffing to the private provider and possible cost-savings. Responsibility for dialysis outcomes is with the public funder.

- NGO provider – respite dialysis is funded by a mixture of State and Federal government and private philanthropic funds. Dialysis is provided by the NGO. Responsibility for dialysis outcomes is with the State provider.
- Private provider – all aspects of dialysis are funded by private insurance and provided by a private haemodialysis company. Responsibility for dialysis outcomes is with the private company.

3.6.3.3 Dialysis Provision: Hub and Spoke Model

In Australia dialysis services began in metropolitan teaching hospitals. Expansion of dialysis provision led to the development of suburban and region satellite dialysis centres staffed by nurses, with the metropolitan renal unit providing outreach medical supervision, technical and allied health services and centralised dialysis training, surgical and transplant services. This “hub and spoke” model was developed within a state-based service model and has traditionally been limited to the provision of dialysis and transplantation services alone.
3.6.4 Community-Based Dialysis

3.6.4.1 Essential Requirements

Key Findings

- 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, it is possible to address key infrastructure requirements in most community settings.

- Committed and ongoing local support from community leadership and primary healthcare services is a mandatory pre-requisite for successful dialysis provision.

- Attracting and retaining nursing staff to provide dialysis services in remote communities is a key challenge. It is unlikely a live-in dialysis nursing workforce will be sustainable.

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

- Key stakeholders expressed interest in alternative renal workforce models which provide Indigenous people with a more central role in dialysis provision and patient support.

- The Kimberley Renal Service believe the central role for Indigenous staff in their service is one of the reasons underlying good health outcomes and high adherence to treatment regimens in the Kimberley.

- In the CA region, renal service providers, community leaders and primary healthcare services indicated profound barriers to the recruitment and retention of an Indigenous workforce.

Key Study findings regarding essential requirements to support the establishment of safe, high quality, appropriate and sustainable models of service delivery in remote communities include:

Service providers

- NT renal services, WDNWPT and Fresenius Medical Care Australia provide dialysis services in the CA region. Each of these providers expressed readiness to collaborate in extending the provision of dialysis in remote communities.

Infrastructure needs

- Patient and family housing - There is a lack of availability of safe, secure and appropriate housing to support the conduct of dialysis in the home environment. The Study Team believe that true home-based dialysis would not appear to be sustainable in CA region communities. However, if community-based dialysis is to be implemented, housing will need to be provided for returning patients and their families.
Water and Electricity Supply - Communities across the CA region, without prior experience of local dialysis provision, expressed concerns that the quality of water, poor reliability of electricity supply and inability to construct appropriate facilities might be key barriers to establishing dialysis services in communities. However, 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, it is possible to address key infrastructure requirements in most community settings. Relevant protocols are included in the Technical Appendices.

Sites for Dialysis to be performed - Marked variation in the number of people requiring dialysis in particular communities over time is predictable. These data and projections add valuable insight in shaping approaches to establishment of infrastructure for dialysis. Recommended approaches include:

- Both renal ready rooms attached to local health facilities and relocatable dialysis facilities are practical alternatives for dialysis infrastructure.
- Construction of new health facilities in remote communities to take into account potential needs for dialysis provision.
- Protocols for the commissioning, decommissioning and recommissioning of relocatable dialysis facilities established and implemented.
- An agreed modular approach to construction of dialysis facilities that addresses and facilitates transportability, ongoing maintenance and durability implemented.

Engagement with key stakeholders

- Committed and ongoing local support is a mandatory pre-requisite for successful dialysis provision requiring:
  a. Strong engagement with and support of community leadership.
  b. Strong engagement with and support of local primary healthcare services.
  c. Co-location with a key health facility such as a primary healthcare centre or aged care service to facilitate dialysis provision.

Staffing and support

- Attracting and retaining nursing staff to provide dialysis services in remote communities is a key challenge. It is unlikely a live-in dialysis nursing workforce will be sustainable, thus centralised models of fly-in, fly-out, or drive-in, drive-out nursing support from the hub unit seem appropriate to explore. A range of incentives, including the provision of appropriate housing and remote area allowances, will need to be explored to attract and retain staff.

- Key stakeholders expressed interest in alternative renal workforce models which provide Aboriginal Health Workers and community members with a more central role in dialysis provision and patient support. Such a model has been implemented by the Kimberley Renal Service, who believe it is one of the reasons underlying good health outcomes and high adherence to treatment regimens. Other remote area renal service providers have had less success in developing and sustaining a role for AHWs in dialysis provision. In the NT, despite repeated attempts to train local Indigenous people,
AHWs with a role in dialysis provision have come from other jurisdictions. This reflects the profound challenges in bridging the gap between levels of educational attainment and what is required to function as a health worker and social/cultural issues regarding providing treatment to one’s kin.

During visits to remote communities across the CA region, both community leaders and local primary healthcare staff indicated that very poor levels of educational attainment amongst young people in the communities acted as profound barriers to recruitment to AHW and other community development worker positions.

Support mechanisms for self-care dialysis in remote communities that have required a single family member to commit to being the ongoing support person have proved unreliable.

### Appropriate dialysis modality selection

- Choosing a dialysis modality that is acceptable to patients and communities is essential. There was an overwhelming concern regarding the viability of peritoneal dialysis in CA region communities
- Patients, family members and primary care services were concerned about previous poor outcomes with peritoneal dialysis in patients in their communities. They emphasised the difficulties inherent in maintaining a clean and secure environment required to support PD in homes in the community.
- Negative perceptions regarding PD will constitute a significant barrier to the expansion of this modality of care.
- Where patients were managing PD in communities there was significant social service, health care support, infrastructure and logistical support provided by the local community agencies.

### Identifying appropriate hub renal service provider

- Improved access to dialysis was a priority health issue for stakeholders from across the CA region.
- Alice Springs was identified as the preferred hub for a regional renal service as this provided much more ready access to family, community health and social support services.
- Patients and community members from the APY and Ngaanyatjarra Lands indicated that permanent relocation to Adelaide, Port Augusta, Perth or Kalgoorlie to access haemodialysis was not an acceptable treatment option.

### Identifying appropriate sites for community-based dialysis

- Coober Pedy was suggested as a possible site for a mini-satellite for people from parts of the APY Lands. Consultation with patients and community members did not reveal significant support for this proposal.
- There is a pressing need for improved access to HD on the APY and Ngaanyatjarra Lands. In the short-term, it was suggested that this need could be met through deployment of the dialysis mobile bus to provide respite dialysis for short periods in communities. Such a deployment would benefit from coordination between primary and tertiary services to ensure that patient transport, accommodation and support, as well as necessary logistic arrangements regarding the bus and nursing staff are addressed.
Through consultation with community organisations, certain facilities were identified which might provide the necessary infrastructure to move promptly to provision of dialysis on the lands. For these, and any other sites under consideration for establishment of a sustainable dialysis service, appropriate consideration is required to ensure community engagement and support, that essential infrastructure requirements are met, that there are sufficient patients capable of safely dialysing according to the proposed arrangements and issues of staff recruitment and retention can be addressed.

Facilities identified and recommended for assessment for suitability for HD were:

- The purpose-built Substance Misuse Centre in Amata, which has had very low rates of occupancy and use since being opened in August 2008. The Office of the Coordinator-General for Remote Indigenous Services, following a visit in November 2009, urged consideration of expanding the purpose and use of the centre. An appropriate area within this centre could be considered for provision of self-care or nurse-supported mini-satellite HD.

- The Ngaanyatjarra Health Service in Warburton has a renal ready room. Warburton is on the border of the CA region and it is noted that the recently finalised Western Australia Country Health Service renal plan discusses the establishment of Community Supported Haemodialysis in Warburton. From consultation undertaken during the Study, Warburton would be an appropriate site for dialysis in terms of social and family needs of patients from across the Ngaanyatjarra Lands, including areas North and East of Warburton within the CA region. Representation from Western Australia on the proposed CA Renal Network would ensure coordination of planning and support between the CA regional hub service in Alice Springs and the WA Country Health Service and renal unit in Kalgoorlie.

### 3.6.4.2 Targets for Community-based Dialysis in the CA Region

Taking account of the relatively young age of new ESKD patients in the CA region, success in establishing and maintaining a higher proportion of patients on self-care dialysis in the Top End of the NT, and growing evidence of engagement with community organisations and primary healthcare services to support dialysis in communities, the research team suggest that a greater proportion of renal patients in the CA region could be treated closer to home. The research team note there is marked variation in the proportion of dialysis patients receiving home- or community-based dialysis at the Unit level, however, national data regarding practice variability clearly indicates potential for expansion of community-based dialysis in the CA Region (Figure 9).
On the basis of rates achieved nationally, and currently sustained in some units providing care to patients from remote communities (Darwin for example), the research team suggest that renal services in the CA region aim to achieve the following:

- 10% of patients on self-care dialysis – predominantly haemodialysis – by 2015.
- 10% of patients using nurse-supported dialysis in mini-satellites in communities by 2015. This would be achieved through a phased roll-out of services, during which the cost-effectiveness of this treatment modality would be determined and key factors for sustainability explored.
- 15% of patients using nurse-supported dialysis in mini-satellites in communities by 2020.
3.6.5 Ongoing Dialysis Closer to Home: Summary of Service Options

<table>
<thead>
<tr>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Support mechanisms for self-care dialysis in remote communities reliant on a single family member have proved unreliable.</td>
</tr>
<tr>
<td>- Despite marked variation, at the Unit level, in the proportion of dialysis patients receiving home- or community-based dialysis, national data clearly indicates potential for expansion of community-based dialysis in the CA Region.</td>
</tr>
<tr>
<td>- Options for providing treatment closer to home have a range of essential requirements - at the patient-, infrastructure-, staffing- and community-level.</td>
</tr>
<tr>
<td>- Expansion of self-care HD and nurse-supported, mini-satellite HD would seem the most appropriate and sustainable options for increasing the proportion of renal patients able to return home for ongoing RRT.</td>
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</tbody>
</table>

It is appropriate to frame consideration of expansion of provision of models of care enabling more people to move back to their communities in terms of meeting patients’ health, social and cultural needs. However, provision of these services on a safe and sustainable basis in 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. Requirements for these dialysis modalities, advantages, risks and solutions are outlined below (Table 10).
Table 10: Treatment options to provide ongoing dialysis closer to home

(a) Self-care Haemodialysis

<table>
<thead>
<tr>
<th>Patient acuity and other patient-level factors required to sustain modality</th>
<th>Patient is competent in dialysis technique</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient is able to insert needles to access fistula</td>
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<tr>
<td>Patient demonstrates commitment to ongoing care – fistula management, medications, fluid control, adherence to dialysis regimen</td>
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<tr>
<td>Patient is relatively stable on dialysis – does not need medical support on a regular basis</td>
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<tr>
<td>Patient’s co-morbidities are able to be managed in the community</td>
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<tr>
<td>Patient has a reliable carer/support person and stable living situation</td>
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</table>

<table>
<thead>
<tr>
<th>Infrastructure requirements</th>
<th>Appropriate housing for patient and family</th>
</tr>
</thead>
<tbody>
<tr>
<td>Safe and secure housing, with appropriate space, design and facilities, if considering home-based dialysis</td>
<td></td>
</tr>
<tr>
<td>Renal ready room attached to community health service/other appropriate facility or relocatable dialysis facility</td>
<td></td>
</tr>
<tr>
<td>Level ground, safe and secure area</td>
<td></td>
</tr>
<tr>
<td>Reliable electricity supply – grid supplied or from a community generator (as indicated in WA and NT technical reports)</td>
<td></td>
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<tr>
<td>Reliable water and waste facilities, appropriate biohazard management (as indicated in WA and NT technical reports)</td>
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<tr>
<td>Appropriate facility, furnishing and services requirements (as indicated in WA and NT technical reports)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Staff requirements/support</th>
<th>Training and support provided from hub renal services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone hotline to staff at hub renal service</td>
<td></td>
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<tr>
<td>3 monthly staff visits to support patients in-community</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Community support requirements</th>
<th>Strong engagement with and support of community leadership</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strong engagement with and support of local primary healthcare services</td>
<td></td>
</tr>
<tr>
<td>Co-location with a key health facility such as a primary healthcare centre or aged care service</td>
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<table>
<thead>
<tr>
<th>Advantages</th>
<th>Enables patient to live at home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encourages independence and self-management</td>
<td></td>
</tr>
<tr>
<td>Least costly form of dialysis</td>
<td></td>
</tr>
<tr>
<td>Positive views expressed by patients and communities across CA region</td>
<td></td>
</tr>
<tr>
<td>Potential that patients can play a role in community education regarding kidney health and illness</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Risks</th>
<th>1. Lack of availability of safe and secure housing</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Concern regarding ability to rely on a single family member as a support person</td>
<td></td>
</tr>
<tr>
<td>3. Lack of renal service support for people performing self-care dialysis in remote sites</td>
<td></td>
</tr>
<tr>
<td>4. Potential for increasing level of acuity as course of disease progresses requiring increasing medical support</td>
<td></td>
</tr>
<tr>
<td>5. Lack of community support for people performing self-care dialysis in remote sites</td>
<td></td>
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</table>
### Solutions

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<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>Dialysis undertaken in a renal ready room or relocatable facility</td>
</tr>
<tr>
<td>2.</td>
<td>Explore potential for additional support people within community. Options might include carer support services and respite; training patients in pairs – to act as supports for each other; providing financial compensation to people already trained as support people to provide such support not only to their family member but other community members on dialysis.</td>
</tr>
<tr>
<td>3.</td>
<td>Telephone hotline to renal hub, regular contact and support visits from hub renal service</td>
</tr>
<tr>
<td>4.</td>
<td>Care plans drawn up before commencement of treatment and agreed to by all relevant stakeholders. Planning and ongoing review of patient acuity so that options for nurse-supported dialysis can be explored in a timely fashion</td>
</tr>
<tr>
<td>5.</td>
<td>Deliberate process of engagement of community leadership and local primary care services prior to commencement of training for self-care HD; close proximity to community primary care service so that assistance can be called if required</td>
</tr>
</tbody>
</table>
Table 10: Treatment options to provide ongoing dialysis closer to home

(b) Peritoneal Dialysis

| Patient acuity and other patient-level factors required to sustain modality | Patient is competent in dialysis technique  
Patient demonstrates commitment to ongoing care – catheter site management, medications, adherence to dialysis regimen  
Patient is relatively stable on dialysis – does not need medical support on a regular basis  
Patient’s co-morbidities are able to be managed in the community  
Patient has a reliable carer/support person and stable living situation  
Patient and support network have the capacity to manage the ordering, organisation and storage of dialysis fluids and other consumables |
| Infrastructure requirements | Safe and secure housing for patient and family, especially with respect to requirements for maintenance of a treatment space and appropriate hygiene |
| Staff requirements/support | Training and support provided from hub renal services  
3 monthly staff visits to support patients in-community |
| Community support requirements | Strong engagement with and support of community leadership  
Strong engagement with and support of local primary healthcare services |
| Advantages | Enables patient to live at home  
Encourages independence and self-management  
Lower cost form of dialysis  
Ease of mobility and less technically demanding form of dialysis  
Ability to provide in communities without infrastructure to support a haemodialysis facility  
Less demanding technique to learn for self-care leading to ability for rapid return to community  
Potential that patients can play a role in community education regarding kidney health and illness |
| Risks | 1. Lack of availability of safe and secure housing and particular issues with regard to maintenance of level of cleanliness required for safe dialysis within the home environment  
2. Widespread and strong negative perceptions amongst patients, community members and primary health care staff regarding viability of peritoneal dialysis in the remote community setting  
3. Concern regarding ability to rely on a single family member as a support person  
4. Lack of support for people performing self-care dialysis in remote sites such as assistance with transport and storage of supplies  
5. Potential for increasing level of acuity as course of disease progresses requiring increasing medical support  
6. Lack of uptake due to patient views of PD being a demanding and intrusive treatment modality |
| Solutions | 1. Negative perceptions of PD must be addressed for it to become a more widely accepted and feasible part of enabling more people to receive treatment close to home.  
2. Nurse-supported APD in a hostel in Alice Springs suggested as a way to demonstrate that PD can be successful and begin to address negative perceptions within CA communities.  
3. Provide funding to develop, implement and evaluate educational programs to better inform people about treatment options, including the potential role for PD as a self-care modality. |
Table 10: Treatment options to provide ongoing dialysis closer to home

(c) Nurse-supported Haemodialysis in Mini-satellites

<table>
<thead>
<tr>
<th>Patient acuity and other patient-level factors required to sustain modality</th>
<th>Patient may need support with carrying out the dialysis process</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patient may need assistance with needling his/her fistula</td>
</tr>
<tr>
<td></td>
<td>Patient is relatively stable on dialysis – does not need medical support on a regular basis</td>
</tr>
<tr>
<td></td>
<td>Patient’s co-morbidities are able to be managed in the community</td>
</tr>
<tr>
<td></td>
<td>Patient has stable housing in the community</td>
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<tr>
<td></td>
<td>A minimum of 4 patients suitable for ongoing nurse-supported HD in the community setting to achieve an acceptable cost-effectiveness of dialysis provision</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Infrastructure requirements</th>
<th>Renal ready room attached to community health service/other appropriate facility or relocatable dialysis facility</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Level ground, safe and securable area</td>
</tr>
<tr>
<td></td>
<td>Reliable electricity supply – grid supplied or from a community generator (as indicated in WA and NT technical reports)</td>
</tr>
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<td></td>
<td>Reliable water and waste facilities, appropriate biohazard management (as indicated in WA and NT technical reports)</td>
</tr>
<tr>
<td></td>
<td>Appropriate facility, furnishing and services requirements (as indicated in WA and NT technical reports)</td>
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<table>
<thead>
<tr>
<th>Staff requirements/support</th>
<th>1 nurse: 4 partial care satellite patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3-monthly senior nursing staff visits from hub renal unit</td>
</tr>
<tr>
<td></td>
<td>3-monthly physician visits to support patients and staff in mini-satellites in community, see CKD patients in the community and perform other patient reviews</td>
</tr>
<tr>
<td></td>
<td>Incentives to attract and retain skilled staff might include a remote area allowance; provision of free, secure and appropriate housing; regular travel back to Alice Springs and/or home base; exploration of options for rotation through hub and remote mini-satellite dialysis services; encouragement of career development and provision of further training opportunities; and daily telephone contact from hub renal services</td>
</tr>
<tr>
<td></td>
<td>Incentives to attract and retain an Indigenous workforce might include a remote area allowance; provision of training in the local environment; development of a career path and recognition for role in supporting dialysis patients in community; access to training in relevant aspects of care for renal patients to accredit AHWs for role in dialysis provision</td>
</tr>
<tr>
<td></td>
<td>The Study Team acknowledge the profound challenges, many of which are outside of the areas of activity and influence of the health system, which were identified by community health service stakeholders in relation to attracting and retaining AHWs in the CA region</td>
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</tbody>
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<table>
<thead>
<tr>
<th>Community support requirements</th>
<th>Strong engagement with and support of community leadership</th>
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<tbody>
<tr>
<td></td>
<td>Strong engagement with and support of local primary healthcare services</td>
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<tr>
<td></td>
<td>Co-location with a key health facility such as a primary healthcare centre or aged care service</td>
</tr>
<tr>
<td></td>
<td>Communities with 500 or more resident persons would be those more likely to have facilities and capacity to sustain a mini-satellite service</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Enables patient to return to live closer to home</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Positive views expressed by patients and communities across CA region</td>
</tr>
<tr>
<td></td>
<td>Potential that patients and staff can play a role in community education regarding kidney health and illness</td>
</tr>
<tr>
<td></td>
<td>Likelihood of increased patient adherence to treatment regimens</td>
</tr>
<tr>
<td></td>
<td>Potential for patients to take up dialysis who would have otherwise not taken it up because they had to move out of the community</td>
</tr>
<tr>
<td></td>
<td>Potential to reduce occurrence of unplanned visits home</td>
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Central Australia Renal Study – Technical Report
Reduced disruption to communities and community leadership

<table>
<thead>
<tr>
<th>Risks</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Inability to establish infrastructure for dialysis – renal ready room or relocatable dialysis facility within community</td>
<td></td>
</tr>
<tr>
<td>2. The high capital cost for the establishment of dialysis facilities in remote communities</td>
<td></td>
</tr>
<tr>
<td>3. Potential that patients who might otherwise be suitable for self-care will request nurse-supported dialysis as an alternative way to enable them to return home</td>
<td></td>
</tr>
<tr>
<td>4. Relatively expensive form of dialysis provision – as satellite service plus additional costs of accommodation for nurses, travel, car, making facility secure etc.</td>
<td></td>
</tr>
<tr>
<td>5. Potential for increasing level of acuity as course of disease progresses requiring increasing medical support</td>
<td></td>
</tr>
<tr>
<td>6. Challenges in attracting and retaining nursing staff to support service provision</td>
<td></td>
</tr>
<tr>
<td>7. Challenges in recruiting and retaining Indigenous workforce to support service provision</td>
<td></td>
</tr>
<tr>
<td>8. Patient may require accommodation close to dialysis facility</td>
<td></td>
</tr>
<tr>
<td>9. Technical problems resulting in dialysis not being able to be provided in community and patients needing to return to hub satellite unit.</td>
<td></td>
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<table>
<thead>
<tr>
<th>Solutions</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>1. Dialysis undertaken in a renal ready room or relocatable facility. Implement agreed protocols for site selection, design and to address issues with water quality, electricity etc.</td>
<td></td>
</tr>
<tr>
<td>2. Secure capital and recurrent funding to enable expansion of community-based dialysis in appropriate sites in the CA region</td>
<td></td>
</tr>
<tr>
<td>3. Phased roll-out of nurse-supported mini-satellites with formal cost-effectiveness evaluation and assessment of sustainability</td>
<td></td>
</tr>
<tr>
<td>4. Care plans drawn up before commencement of treatment and agreed to by all relevant stakeholders. Planning and ongoing review of patient acuity so that options for return to dialysis in Alice Springs or decisions for conservative therapy can be explored in a timely fashion.</td>
<td></td>
</tr>
<tr>
<td>5. Incentives to attract and retain nursing staff might include payment of a remote area allowance, provision of free accommodation, regular flights back to Alice Springs or other home base, support for further training and career development.</td>
<td></td>
</tr>
<tr>
<td>6. Multi-faceted approach to developing an Indigenous workforce including provision of training in local environment, development of a career path and recognition for role in supporting dialysis patients in community, access to training in relevant aspects of care for renal patients to accredit AHWs for role in dialysis provision.</td>
<td></td>
</tr>
<tr>
<td>7. Contingency plans developed to manage risk of technical problems requiring return of patient to the hub satellite unit.</td>
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3.6.6 Respite or Return to Country Dialysis

<table>
<thead>
<tr>
<th>Key Findings</th>
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<tbody>
<tr>
<td>Respite services are held in high regard by patients and community members.</td>
</tr>
<tr>
<td>Respite dialysis has little impact on overall demand for treatment, especially at the hub in Alice Springs.</td>
</tr>
<tr>
<td>There is no published, peer-reviewed evidence regarding the costs or cost-effectiveness of respite dialysis provision.</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>The Study estimated that the cost of provision of fixed-in-community and mobile bus respite services are significantly higher than ongoing provision of maintenance dialysis. However, respite has a key role in meeting the social and cultural needs of renal patients in the CA region and might potentially improve adherence to treatment regimens and decrease acute evacuations from communities and unplanned hospital admissions.</td>
</tr>
<tr>
<td>As with other service options, respite care has requirements at the patient-, infrastructure-, staffing- and community-level, advantages, risks and solutions.</td>
</tr>
<tr>
<td>Nurse-supported, in-community respite model would appear (albeit for greater cost) to provide access to respite for longer periods, yet to fewer patients from fewer communities, than the mobile dialysis bus.</td>
</tr>
</tbody>
</table>

Respite 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. Nevertheless, respite has little impact on overall demand for treatment, especially at the hub in Alice Springs. 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, 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. 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.

This Report seeks to provide detailed costing of alternative models for the provision of respite dialysis. We repeatedly consulted with relevant staff from NT Renal Services and WDNWPT 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. We note that this data is not published or peer-reviewed, that different providers pay for different components of service provision — dialysis consumables, staffing, capital costs etc, and the need for a formal cost-effectiveness evaluation of both models of respite care. 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. Treatment options to provide respite dialysis are considered in Table 11.
Table 11: Treatment options to provide respite dialysis

(a) Mobile Dialysis - The Dialysis Bus

<table>
<thead>
<tr>
<th>Patient acuity and other patient-level factors required to sustain modality</th>
<th>Patient may need support with carrying out the dialysis process</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patient may need assistance with needleling his/her fistula</td>
</tr>
<tr>
<td></td>
<td>Patient assessed by medical staff as stable for respite dialysis</td>
</tr>
<tr>
<td></td>
<td>Patient’s co-morbidities assessed as being unlikely to require attention during respite in community</td>
</tr>
<tr>
<td></td>
<td>Patient has stable housing in the community during visit</td>
</tr>
<tr>
<td></td>
<td>Patient has guaranteed travel arrangements for safe transport to and from the community</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Infrastructure requirements</th>
<th>Dialysis bus contains the necessary modular requirements to support dialysis including a generator</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Requires access to water, but self-contained infrastructure for water treatment</td>
</tr>
<tr>
<td></td>
<td>Satellite phone for contact with hub renal service</td>
</tr>
<tr>
<td></td>
<td>Durability and robustness of equipment to enable use on ungraded roads</td>
</tr>
<tr>
<td></td>
<td>Self-contained accommodation for staff required – otherwise this would need to be guaranteed in each community being visited by the mobile service</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Staff requirements/support</th>
<th>I nurse: 2 patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Driver with medium rigid license</td>
</tr>
<tr>
<td></td>
<td>Effective planning from renal hub to ensure mobile service meets patients’ needs to attend key community events, appropriate coordination with community leadership and health services, address transport and accommodation issues in advance</td>
</tr>
<tr>
<td></td>
<td>Incentives to attract and retain skilled staff might include a remote area allowance; provision of free, secure and appropriate housing; exploration of options for rotation through hub and mobile dialysis services; regular telephone contact from hub renal services and offer of short-term contracts to underpin mobile bus staffing</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Community support requirements</th>
<th>Strong engagement with and support of community leadership</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strong engagement with and support of local primary healthcare services</td>
</tr>
<tr>
<td></td>
<td>Ability to set up in close proximity to key health facility such as a primary healthcare centre or aged care service</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Potential to provide respite dialysis to a broad range of communities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Positive views expressed by patients and communities across CA region</td>
</tr>
<tr>
<td></td>
<td>Potential that patients and staff can play a role in community education regarding kidney health and illness</td>
</tr>
<tr>
<td></td>
<td>Infrastructure and recurrent costs are likely lower than currently provided forms of respite dialysis</td>
</tr>
<tr>
<td></td>
<td>Self-contained with minimal additional impacts on, or requirements from, community</td>
</tr>
<tr>
<td></td>
<td>Only requires access to water. Bus has a sound-proofed generator and accommodation for nursing staff.</td>
</tr>
<tr>
<td></td>
<td>Potential to reduce occurrence of unplanned visits home</td>
</tr>
<tr>
<td></td>
<td>Potential for key community and cultural leaders to increase their participation in key activities</td>
</tr>
<tr>
<td>Risks</td>
<td>Solutions</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1. Poor quality of roads and environmental conditions restrict communities which can benefit from mobile service</td>
<td>1. Formal evaluation of mobile bus dialysis service undertaken in 2011 to address cost-effectiveness, robustness and appropriateness of current design, planning and co-ordination of visits with relevant community organisations and approaches to patient selection</td>
</tr>
<tr>
<td>2. Robustness of dialysis machinery over ungraded roads unproven over long-term</td>
<td>2. Planning for mobile bus service ensures that transport services and appropriate accommodation are available.</td>
</tr>
<tr>
<td>3. Adequacy and appropriateness of dialysis, sleeping and living arrangements for patients and staff not fully evaluated</td>
<td>3. Contingency plans developed to manage risk of technical problems requiring return of patient to the hub satellite unit</td>
</tr>
<tr>
<td>4. Lack of coordination with local primary healthcare services and community organisations in planning community visits</td>
<td></td>
</tr>
<tr>
<td>5. Need to address transport and accommodation needs of patients having temporary respite using mobile bus</td>
<td></td>
</tr>
<tr>
<td>6. Patient unwilling to return to hub satellite service following period of respite dialysis</td>
<td></td>
</tr>
<tr>
<td>7. Technical problems resulting in dialysis not being able to be provided in community and patients needing to return to hub satellite unit</td>
<td></td>
</tr>
</tbody>
</table>
Table 11: Treatment options to provide respite dialysis

(b) Fixed Community Respite Haemodialysis

<table>
<thead>
<tr>
<th>Patient acuity and other patient-level factors required to sustain modality</th>
<th>Patient may need support with carrying out the dialysis process</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patient may need assistance with needling his/her fistula</td>
</tr>
<tr>
<td></td>
<td>Patient assessed by medical staff as stable for respite dialysis</td>
</tr>
<tr>
<td></td>
<td>Patient’s co-morbidities assessed as being unlikely to require attention during respite in community</td>
</tr>
<tr>
<td></td>
<td>Patient has stable housing in the community</td>
</tr>
<tr>
<td></td>
<td>Patient has guaranteed travel arrangements for safe transport to and from the community</td>
</tr>
<tr>
<td>Infrastructure requirements</td>
<td>Renal ready room attached to community health service/other appropriate facility or relocatable dialysis facility</td>
</tr>
<tr>
<td></td>
<td>Level ground, safe and secure area</td>
</tr>
<tr>
<td></td>
<td>Reliable electricity supply – grid supplied or from a community generator</td>
</tr>
<tr>
<td></td>
<td>(as indicated in WA and NT technical reports)</td>
</tr>
<tr>
<td></td>
<td>Reliable water and waste facilities, appropriate biohazard management</td>
</tr>
<tr>
<td></td>
<td>(as indicated in WA and NT technical reports)</td>
</tr>
<tr>
<td></td>
<td>Appropriate facility, furnishing and services requirements</td>
</tr>
<tr>
<td></td>
<td>(as indicated in WA and NT technical reports)</td>
</tr>
<tr>
<td>Staff requirements/support</td>
<td>I nurse: 2 respite patients</td>
</tr>
<tr>
<td></td>
<td>Incentives to attract and retain skilled staff might include a remote area allowance; provision of free, secure and appropriate housing; regular travel back to Alice Springs and/or home base; exploration of options for rotation through hub and remote mini-satellite dialysis services; encouragement of career development and provision of further training opportunities; and daily telephone contact from hub renal services</td>
</tr>
<tr>
<td></td>
<td>Incentives to attract and retain an indigenous workforce might include a remote area allowance; provision of training in the local environment; development of a career path and recognition for role in supporting dialysis patients in community; access to training in relevant aspects of care for renal patients to accredit AHWs for role in dialysis provision</td>
</tr>
<tr>
<td></td>
<td>The Study Team acknowledge the profound challenges, many of which are outside of the areas of activity and influence of the health system, which were identified by community health service stakeholders in relation to attracting and retaining AHWs in the CA region</td>
</tr>
<tr>
<td>Community support requirements</td>
<td>Strong engagement with and support of community leadership</td>
</tr>
<tr>
<td></td>
<td>Strong engagement with and support of local primary healthcare services</td>
</tr>
<tr>
<td></td>
<td>Co-location with a key health facility such as a primary healthcare centre or aged care service</td>
</tr>
<tr>
<td>Advantages</td>
<td>Potential to provide respite dialysis to a larger proportion of patients than could return home for ongoing dialysis</td>
</tr>
<tr>
<td></td>
<td>Positive views expressed by patients and communities across CA region</td>
</tr>
<tr>
<td></td>
<td>Potential that patients and staff can play a role in community education regarding kidney health and illness</td>
</tr>
<tr>
<td></td>
<td>Likelihood of increased patient adherence to treatment regimens</td>
</tr>
<tr>
<td></td>
<td>Potential to reduce occurrence of unplanned visits home</td>
</tr>
<tr>
<td></td>
<td>Reduced disruption to communities and community leadership</td>
</tr>
</tbody>
</table>
### Risks

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Inability to establish infrastructure for dialysis – renal ready room or relocatable dialysis facility within community</td>
</tr>
<tr>
<td>2</td>
<td>Relatively expensive form of dialysis provision – as satellite service plus additional costs of accommodation for nurses, travel, car, making facility secure etc</td>
</tr>
<tr>
<td>3</td>
<td>Lack of coordination with local primary healthcare services and community organisations in planning community visits</td>
</tr>
<tr>
<td>4</td>
<td>Need to address transport and accommodation needs of patients having temporary respite</td>
</tr>
<tr>
<td>5</td>
<td>Need to provide/build staff accommodation</td>
</tr>
<tr>
<td>6</td>
<td>Patient unwilling to return to hub satellite service following period of respite dialysis</td>
</tr>
<tr>
<td>7</td>
<td>Challenges in attracting and retaining nursing staff to support service provision</td>
</tr>
<tr>
<td>8</td>
<td>Challenges in recruiting and retaining Indigenous workforce to support service provision</td>
</tr>
<tr>
<td>9</td>
<td>Technical problems resulting in dialysis not being able to be provided in community and patients needing to return to hub satellite unit.</td>
</tr>
</tbody>
</table>

### Solutions

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Dialysis undertaken in a renal ready room or relocatable facility. Implement agreed protocols for site selection, design and to address issues with water quality, electricity etc.</td>
</tr>
<tr>
<td>2</td>
<td>Phased roll-out of nurse-supported mini-satellites with formal cost-effectiveness evaluation and assessment of sustainability</td>
</tr>
<tr>
<td>3</td>
<td>Planning for in-community respite ensures that transport services and appropriate accommodation are available.</td>
</tr>
<tr>
<td>4</td>
<td>Care plans drawn up before commencement of in-community respite dialysis treatment and agreed to by all relevant stakeholders.</td>
</tr>
<tr>
<td>5</td>
<td>Incentives to attract and retain nursing staff might include remote area allowance, provision of free accommodation, regular flights back to Alice Springs or other home base, support for further training and career development.</td>
</tr>
<tr>
<td>6</td>
<td>Multi-faceted approach to developing an Indigenous workforce including provision of training in local environment, development of a career path and recognition for role in supporting dialysis patients in community, access to training in relevant aspects of care for renal patients to accredit AHWs for role in dialysis provision.</td>
</tr>
<tr>
<td>7</td>
<td>Contingency plans developed to manage risk of technical problems requiring return of patient to the hub satellite unit.</td>
</tr>
</tbody>
</table>
3.6.7 Service Model Options: Summary Comparison

Haemodialysis survival has improved in the CA region, so that median survival has now extended out beyond 4 years. This accords with recently published evidence from the Kimberley Renal Service, reporting outcomes with HD for Aboriginal patients from the Kimberley region and demonstrating similar outcomes to those achieved generally for non-Indigenous Australians. The authors concluded that “HD treatment delivered closer to home can be safe and effective in remote areas”.

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. Peritoneal dialysis outcomes remain a matter of concern with high infection rates and poor technique survival. During consultation for the Study, widespread and strongly felt reservations regarding the safety of PD in the remote community context were expressed by many community members, primary care doctors and some renal service providers. Both nursing and medical staff in the ASH renal unit, however, stressed the need for re-evaluation of PD outcomes following the recent shift to the insertion of buried Tenckhoff catheters. This change in practice, with catheters subsequently brought to the skin surface at the time a patient commences dialysis, was introduced with the aim of facilitating commencement of RRT when clinically indicated and with the ancillary aim that it might reduce early infection rates.

Transplant outcomes are poorer for Aboriginal and Torres Strait Islander peoples in the CA region compared to national outcomes. Nevertheless, the most directly important comparison for the evaluation of efficacy of renal transplantation is that of transplant survival to survival for people remaining on dialysis. Key challenges include improving our ability to predict which aboriginal patients might have better outcomes; targeting our efforts to addressing health systems barriers to enabling those patients to proceed to transplant; and supporting them in the post-transplant period to obtain good health outcomes.

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.

Home- or community-based, self-care HD is a well established model of care in the Australian context. Strong evidence supports these models of care as being less costly than satellite and in-centre alternatives. Although there are examples of Aboriginal and Torres Strait Islander peoples successfully undertaking self-care HD in remote communities across the Northern Territory, Western Australia and North Queensland, separate analyses of their outcomes to assess efficacy have not been undertaken and would provide poor...
quality evidence due to small numbers and selection bias. The Kimberley analysis referred to above,22 reports outcomes for the Kimberley region cohort, the majority of whom receive nurse-supported HD in the large satellite dialysis centre in Broome.

Against the background of this evidence mix, 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.

The SWOT analysis suggests a myriad of potential 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 cross-border region of Central Australia should be provided by a regional hub service, associated satellite services and with strong linkages to community/home based dialysis. The next section describes the preferred model in detail, along with its associated resource requirements.
3.7 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. 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.

Clinical demand for dialysis services is dependent upon both the patient number requiring dialysis in a region or community and also commitment from the region or community to supporting the provision of services. There is no generally agreed number of patients that warrant provision of a regional dialysis satellite or community mini-satellite service. However, dialysis staffing ratios and economies of scale would suggest that a regional satellite would require 12 or more patients, while a community mini-satellite would require 4 or more patients to be considered viable. Decisions regarding development of such services in the CA region will require cross jurisdictional coordination processes.

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

3.7.1 The Preferred Renal Services Model: Key Characteristics

3.7.1.1 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 renal replacement therapy (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.

Tennant Creek will likely 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.

### 3.7.1.2 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.

### 3.7.1.3 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.
3.7.1.4 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.

3.7.1.5 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.

3.7.1.6 Proposed Resource Capability Matrix for the Preferred Model

Hub and Spokes services would be provided in metropolitan, regional areas and remote communities according to the principles outlined in the National Service Guidelines for the Management of Dialysis and Kidney Transplantation in Remote Australia (2006). The level of services provided in an area would be determined by clinical need and according to a resource capability matrix, which takes into account the clinical demand for dialysis services and the potential to recruit and maintain the necessary staff to provide a range of services. A proposed Resource Capability Matrix is provided in Table 12.

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*Central Australia Renal Study – Technical Report*
<table>
<thead>
<tr>
<th>Service/Staff</th>
<th>Hub</th>
<th>Regional Satellite</th>
<th>Mini-Satellite</th>
<th>Community/Self care</th>
<th>Respite Dialysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Service</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute Hospital Care</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Surgical services (access)</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Transplantation†</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>HD/PD Training</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Dialysis</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Pre-dialysis preparation</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>CKD Prevention</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Housing Support</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Psychological Support</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Interpreter Services</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Staff Education/Training</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Technical Services</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Dietician Service</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Respite Dialysis Co-ordination</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Staff requirement</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nephrologist</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Surgeon</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Dialysis Nurse/AHW</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>Dialysis Educator</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Staff Educator</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Dialysis Technician</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
## Table 12: Resource capability matrix *

<table>
<thead>
<tr>
<th>Role</th>
<th>+</th>
<th>+/-</th>
<th>-</th>
<th>-</th>
<th>-</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietician</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Social Worker</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Aboriginal Liaison Worker</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Interpreter</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Administrative Officer</td>
<td>+</td>
<td>+/-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

*Adapted from the National Service Guidelines for the Management of Dialysis and Kidney Transplantation in Remote Australia*

†The full range of transplant services are provided by a small number of quarternary metropolitan renal services

Key:  
+ Capability represents an essential requirement for that specific level of service delivery  
+/- Capability would ideally be resourced at that specific level of service delivery, however is not essential
3.7.1.7 Protocols for Dialysis Treatment Closer to Home

Provision of renal services on a safe and sustainable basis in 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.

Protocols for the establishment of dialysis treatment facilities in remote communities need to 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.

Table 13 summarises key protocol elements or criteria for options for increasing dialysis close to home in the following terms:

- **Modalities for on-going dialysis** — 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 for respite dialysis** — mobile dialysis using a “bus” and fixed community-based dialysis — that could be utilised to provide respite “return to country” dialysis.
### Table 13: 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>Housing (patient and family)</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>Staff to patient ratio (renal nurse)</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 Indigenous workforce</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Mobile staff</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Community Support</td>
<td>Engagement</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>
</tbody>
</table>
## Central Australia Renal Study – Technical Report

### Table 1: Criteria for Ongoing Dialysis and Respite Dialysis

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Ongoing Dialysis</th>
<th>Respite Dialysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Costs</td>
<td>$</td>
<td>$</td>
</tr>
<tr>
<td>Advantages</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>Risks</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>

**Cost Effectiveness**

Explore quality of life, efficacy and costs as a priority

**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
3.7.1.8 **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.
3.7.2 The Preferred Renal Services Model: Whole of Service Costs

Key Findings

- The present value cumulative cost of RRT for all current and new cases of ESKD, treated out to 2020, is estimated to be between approximately $240 and $302 million.

- The present value of the cumulative benefits of RRT in life years saved, for all new cases of ESKD out to 2020, will be between 1,319 and 1,975 by 2020.

- Implementation of a prevention strategy which was able to prevent 20% of incident ESKD cases, would result in significant savings. Under such a scenario, the present value cumulative cost of RRT for all current and new cases of ESKD, treated out to 2020, would be approximately $273 million.

- An increase in the utilisation of self-care, community-based therapies, would be likely to reduce expenditure on renal service delivery in comparison to continuation of the current heavy reliance on satellite HD.

- Community-based, nurse-supported dialysis models are relatively expensive modalities of renal service provision. However, such models potentially represent a method of service delivery which would enable more CA patients to receive treatment closer to home.

- Currently available evidence regarding the outcomes with community-based, nurse-supported dialysis models does not enable cost-effectiveness analyses to guide decision making regarding these alternative models of service delivery.

- There is a paucity of data regarding quality of life in Aboriginal Australians receiving RRT.

3.7.2.1 Overview of Methodological Approach

The approach used in this analysis follows a previously developed and reported methodology for the analysis of costs and benefits of renal replacement therapy in Australia. Many of the data limitations identified in this earlier work are also applicable in the current setting, with additional limitations due to challenges in modelling disease incidence and prevalence with relatively small numbers of patients across the CA region and a lack of published, peer-reviewed data regarding the costs and effectiveness of service provision in remote settings for Indigenous patients. Additional detail relating to the model, data sources and assumptions are reported in the Technical Appendices.

A Markov model was constructed as the basis for estimating the costs and benefits of renal replacement therapy (RRT) for Indigenous people in the CA region over 2009-2020. This model is based upon the general structure (including assumptions) of the earlier model, with cohort transition probabilities based upon an updated ANZDATA data set of patient outcomes and transitions estimated from the incident cohort of indigenous patients, from the CA region, commencing RRT during 2005-2009.

The model follows multiple cohorts of patients commencing RRT until 2020, along with existing RRT patients. The length of each ‘treatment’ cycle in the model is one year. The structure of the model is shown in detail in the Technical Appendices. The model is stratified by age.
In the absence of good-quality individual randomised control trials or large prospective observational studies conducted in Australia, this Study uses the best available Australian data to derive estimates for the model parameters. This required a substantial secondary analysis of ANZDATA to derive transition probabilities between health states and RRT modalities. Where no published evidence or registry data could be found, the opinion of clinical experts was sought.

Rates of treated ESKD for years 2009-2020 were projected based on two models of incidence in the Indigenous population: a steady-state model assuming that current annual incident patient numbers are maintained each year to 2020; and a growth model assuming that linear increases in incidence observed over the period 1995-2009 are maintained to 2020.

There are no Australian data on utility (QOL) scores for patients in dialysis and post-transplant health states. Health utility scores, derived from published international sources, were used in modelling for this Study. Given the paucity of data of health state utilities in Indigenous people, it is unclear how applicable these values might be to the Indigenous people of Central Australia, and therefore the reporting of benefits of treatment in terms of quality of life should be considered indicative only.

Cost data for provision of dialysis services were based on information provided by NT Renal Services. Given the likely differences in the resources required to deliver dialysis services by geographic region, we believe these values are the most robust estimates available for the cost of providing dialysis services in the Central Australian region. Other costs were based upon the best available published data that conform to 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 (NHDC Round 13: 2008-9) AR-DRG cost -weights have been used for relevant DRG-based costs.

As already discussed, much of the service cost data were obtained from the NT Renal Services data, and included:

- Staff costs (including nursing and allied health staff, medical).
- Direct costs associated with dialysis (including pharmacy, fluids and consumables).
- Overheads.
- Administration & communications.

Costs associated with modality initiation, such as access costs and training costs, have been costed separately and are also included. 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 takes a health care funder perspective, and does not include out of pocket costs to patients and families. Other inpatient resource use has not been included as there is no data available to inform this aspect of resource use.

NT Renal Services provides the vast bulk of ongoing RRT in the region. There is no private dialysis. The Gap Rd satellite unit has been developed as a public-private partnership, where an industry provider – NephroCare Australia – has been contracted to provide capital, equipment and staffing according to an agreed price-per-treatment (ppt) contract. The public sector remains responsible for the medical management of patients.

Stakeholders consulted for the Study suggested that opportunities for public-private partnerships, in the delivery of satellite dialysis services, should continue to be explored. Although a formal cost comparison cannot be included in this Report, as per-patient-treatment contract pricing is confidential, evidence would suggest such partnerships offer an alternative strategy to limit the growth in expenditure on RRT. The NGO sector has provided respite, not ongoing maintenance dialysis services in the region.

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 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.

### 3.7.2.2 Current Unit Costs of Dialysis

Table 14 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 14. In addition, newer pharmacological agents, which are now PBS subsidised exclusively for use in dialysis patients – cinacalcet, sevelamer and lanthanum – have been costed separately.

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 14: 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>15.2%</td>
<td>$15,382</td>
<td>20.2%</td>
<td>$15,382</td>
<td>38.8%</td>
<td>56.7%</td>
</tr>
<tr>
<td>Treatments</td>
<td>1.4%</td>
<td>$1,396</td>
<td>1.8%</td>
<td>$1,396</td>
<td>3.3%</td>
<td>1.4%</td>
</tr>
<tr>
<td>PD/APD consumables</td>
<td>1.7%</td>
<td>$1,716</td>
<td>2.3%</td>
<td>$1,716</td>
<td>3.2%</td>
<td>0.2%</td>
</tr>
<tr>
<td>Pharmaceuticals</td>
<td>0.2%</td>
<td>$160</td>
<td>0.7%</td>
<td>$562</td>
<td>0.9%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Linen/catering</td>
<td>0.9%</td>
<td>$947</td>
<td>1.2%</td>
<td>$947</td>
<td>not avail</td>
<td>not avail</td>
</tr>
<tr>
<td>Staff costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nursing (incl on costs, travel allowance etc)</td>
<td>34.4%</td>
<td>$34,847</td>
<td>36.4%</td>
<td>$27,673</td>
<td>27.4%</td>
<td>22.2%</td>
</tr>
<tr>
<td>Staff training &amp; development</td>
<td>1.7%</td>
<td>$1,674</td>
<td>4.4%</td>
<td>$3,374</td>
<td>1.2%</td>
<td>0.9%</td>
</tr>
<tr>
<td>Allied health</td>
<td>10.9%</td>
<td>$11,074</td>
<td>4.2%</td>
<td>$3,216</td>
<td>0.9%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Medical</td>
<td>24.6%</td>
<td>$24,853</td>
<td>3.2%</td>
<td>$2,465</td>
<td>4.5%</td>
<td>6.8%</td>
</tr>
<tr>
<td>PCA, Ward Clerk + Other admin staff</td>
<td>5.8%</td>
<td>$5,836</td>
<td>8.8%</td>
<td>$6,690</td>
<td>2.4%</td>
<td>3.8%</td>
</tr>
<tr>
<td>Community support/community visits</td>
<td>7.2%</td>
<td>$3,880</td>
<td>0.8%</td>
<td>$527</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>$1,049</td>
<td>2.0%</td>
<td>$1,482</td>
<td>2.1%</td>
<td>0.8%</td>
</tr>
</tbody>
</table>
### In-centre Satellite Community/Home self care HD Self care PD Community based nurse supported HD ‘mini-satellite’ Mobile dialysis dedicated rolling 6 day service

<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>Patient accommodation</td>
<td>-</td>
<td>not avail</td>
<td>-</td>
<td>not avail</td>
<td>0.0%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Transport</td>
<td>-</td>
<td>not avail</td>
<td>8.4%</td>
<td>not avail</td>
<td>11.7%</td>
<td>8.3%</td>
</tr>
<tr>
<td>Overheads</td>
<td>0.9%</td>
<td>$943</td>
<td>4.2%</td>
<td>4.9%</td>
<td>2.3%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Other costs: R&amp;M, leasing, water checking, freight</td>
<td>0.1% $89</td>
<td>0.4% $267</td>
<td>3.5% $1,906</td>
<td>- not avail</td>
<td>0.3% $308</td>
<td>0.1% $144</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>1.5% $816</td>
<td>- -</td>
<td>3.3% $3,100</td>
<td>- -</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>100.0%</td>
<td>$101,189</td>
<td>100.0% $75,980</td>
<td>100.0% $54,017</td>
<td>100.0% $65,250</td>
<td>100.0% $93,243</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>$33</td>
<td>$33</td>
<td>$33</td>
<td>$33</td>
<td>$33</td>
<td>$33</td>
</tr>
<tr>
<td><strong>Total annual costs per patient (all ongoing costs)</strong></td>
<td>$111,339</td>
<td>$86,130</td>
<td>$64,167</td>
<td>$75,400</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>$8,952</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></td>
<td></td>
<td>$5,040</td>
<td></td>
<td></td>
<td></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.
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 15.

<table>
<thead>
<tr>
<th>Resource items</th>
<th>Live donor Recipient unit cost</th>
<th>Live donor Donor unit cost</th>
<th>Deceased donor Recipient unit cost</th>
<th>Deceased donor Donor unit cost</th>
</tr>
</thead>
<tbody>
<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>$10,227</td>
<td></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>$11,770</td>
<td></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. Therefore, 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.

### 3.7.2.3 Projected Future Service Costs

As discussed, rates of treated ESKD for years 2009-2020 were projected based on three models of incidence in the Indigenous 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.

**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 pages) treated out to 2020, is estimated to be between approximately $240 and $302 million (Figure 10). 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 10: 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 11.

**Figure 11: The present value cumulative health benefit (in life years and QALYs) for all new RRT patients treated (to 2020)**

Projected future service cost: potential impact of strategies to change service need

As articulated in ‘Closing the Gap’, 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 – has 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 12).
Disease prevention strategies have significant potential to reduce service need and cost. 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 costs of treating all existing and new cases of ESKD (from 2009-2020), treated out to 2020, would be approximately $273 million (Figure 13).
Figure 13: Total present value of projected annual costs of treating all RRT patients for 2009 - 2020 assuming a prevention program can reduce the incidence of ESKD by 20%

3.7.2.4 Estimated Annual Costs for Respite Dialysis

Estimated detailed costs, on an annual basis, for respite dialysis modalities are presented below (Table 16). 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 16: 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>$393,626</td>
</tr>
<tr>
<td>Components of costs</td>
<td>%</td>
<td>$ Annual</td>
</tr>
<tr>
<td>Direct dialysis service provision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatments</td>
<td>18.2%</td>
<td>$84,115</td>
</tr>
<tr>
<td>Medical/operational sundries (incl test strips, filters, salt)</td>
<td>1.2%</td>
<td>$5,585</td>
</tr>
<tr>
<td>Dialysis paks</td>
<td>1.1%</td>
<td>$4,892</td>
</tr>
<tr>
<td>Pharmaceuticals</td>
<td>1.3%</td>
<td>$6,246</td>
</tr>
<tr>
<td>Scripts/paks</td>
<td>0.7%</td>
<td>$3,432</td>
</tr>
<tr>
<td>Linen/catering</td>
<td>1.1%</td>
<td>$4,992</td>
</tr>
<tr>
<td>Staff costs</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>$136,5641</td>
</tr>
<tr>
<td>staff training and development</td>
<td>1.2%</td>
<td>$5,716</td>
</tr>
<tr>
<td>Allied Health3</td>
<td>1.1%</td>
<td>$4,907</td>
</tr>
<tr>
<td>Medical3</td>
<td>1.3%</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>
</tr>
<tr>
<td>Vehicle costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vehicle capital (annual equivalent cost or lease)</td>
<td>2.4%</td>
<td>$11,0166</td>
</tr>
<tr>
<td>Fuel</td>
<td>2.2%</td>
<td>$10,000</td>
</tr>
<tr>
<td>Insurance/R&amp;M/registration</td>
<td>1.1%</td>
<td>$5,000</td>
</tr>
<tr>
<td>Other costs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fares (return to country)</td>
<td>3.2%</td>
<td>$14,88010</td>
</tr>
<tr>
<td>Communication/administration/support</td>
<td>2.2%</td>
<td>$10,000</td>
</tr>
<tr>
<td>Overheads (incl audit, workers comp, insurance/medical liability)</td>
<td>1.9%</td>
<td>$9,00012</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>
</tr>
<tr>
<td>Sub-Total (annual ongoing costs, excluding capital)</td>
<td>86.9%</td>
<td>$402,116</td>
</tr>
<tr>
<td>Component</td>
<td>Fixed community*</td>
<td>Mobile Dialysis Service**</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Capital costs (Annual equivalent costs)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff accommodation</td>
<td>6.4%</td>
<td>$29,525&lt;sup&gt;16&lt;/sup&gt;</td>
</tr>
<tr>
<td>Dialysis modules/relocatables</td>
<td>6.7%</td>
<td>$31,219&lt;sup&gt;18&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Total annual cost</strong></td>
<td>100.0%</td>
<td>$462,860</td>
</tr>
</tbody>
</table>

* 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 16 - 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)
2. 0.8FTE, TA for 26 days per year, including on-costs and backfill
3. Allied health staff estimated at 0.05 FTE for each service; medical staff estimated at 0.025FTE for each service
4. Based on one 1 project manager to manager 3 x 2 chair facilities
5. 0.5FTE dedicated driver and project manager (incl. on costs)
6. 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
7. Monthly lease cost of $1,500
8. 400 litres per trip X 26 trips per year X $1.70 per L
9. Based on $13,950 insurance +$4,000 R&M
10. Based on 4 return bush bus tickets per month @$155 each way (current fare to Kintore)
11. Based on 4 return bush bus tickets every 2 weeks @$155 each way
12. central admin/accounting ($2,000); insurance and audit ($7,000) from WDNWPT total divided by 3 sites
13. Pest eradication & water analysis (does not include electricity - provided by generator in truck)
14. 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
15. Satellite phone $2,500 - converted to AEC, with working life of 5 years, 5% discount rate; plus fit out, phone testing equipment
16. AEC based on quote to WDNWPT for Lajamanu proposal for $539,000, NT Govt working life of 50 years, and 5% discount rate
17. Staff accommodation in bus
18. AEC based on quote for Lajamanu proposal for $440,000, NT Govt working life of 25 years, and 5% discount rate
19. AEC based on cost of $350,000 for dialysis module, NT Govt working life of 9 years and 5% discount rate
3.7.2.5 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 17: 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 (Working life based on NT Government depreciation schedules &amp; advice; 5% discount rate)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>New 15 machine satellite unit in Alice Springs</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Bricks & mortar facility | $3,348,487 | $(3348487 - 0)/18.2559 = $183,419 per year | $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 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) |
<p>| Dialysis equipment tanks | | | |
| Generators | | | |
| Washing machines | | | |
| Burners, plus fit out | | | |
| <strong>Mini-satellite in a remote community (4 machine)</strong> | | | |
| Facility (bricks &amp; mortar), incl dialysis equipment | $500,000 | $27,388 | Working life = 50 years: annuity factor = 18.2559, no resale |
| Tank | $30,000 | $4,642 | Working life = 8 years: annuity factor = 6.4632, no resale |
| Generator | $30,000 | $4,642 | Working life = 8 years: annuity factor = 6.4632, no resale |
| Washing machines | $5,000 | $774 | Working life = 8 years: annuity factor = 6.4632, no resale |
| Turbo burner | $7,500 | $1,160 | Working life = 8 years: annuity factor = 6.4632, no resale |
| Staff accommodation (2BR house) | $539,000 | $29,525 | Lajamanu quote: Working life = 50 years: annuity factor = 18.2559, no resale |
| <strong>Total cost</strong> | $1,111,500 | $60,884 per year | |
| <strong>Renal Ready Room</strong> | | | |
| Dialysis machines | $30,000 | $4,221 | Working life = 9 years: annuity factor – 7.1078, no resale |</p>
<table>
<thead>
<tr>
<th>Strategy</th>
<th>Total cost</th>
<th>Calculated annual equivalent cost (AEC)</th>
<th>Workings/assumptions (Working life based on NT Government depreciation schedules &amp; advice; 5% discount rate)</th>
</tr>
</thead>
<tbody>
<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>Water treatment</td>
<td>$2,000</td>
<td>$309</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><strong>Total cost</strong></td>
<td><strong>$643,500</strong></td>
<td><strong>$45,272 per year</strong></td>
<td>NB other capital costs included in price per treatment</td>
</tr>
</tbody>
</table>

**Modular/relocatable facility**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th>Lajamanu quote: Working life = 25 years: annuity factor = 14.0939, no resale</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$440,000</td>
<td>$31,219</td>
<td></td>
</tr>
</tbody>
</table>

**Dialysis module for mobile service**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th>working life = 9 years: annuity factor = 7.1078; no resale (truck is leased)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$350,000</td>
<td>$49,242</td>
<td></td>
</tr>
</tbody>
</table>

3.7.3 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 and a whole-of-service model. While such requirements will evolve over time, several key issues are highlighted as characteristics of the preferred renal services model for the CA region.

3.7.3.1 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.

3.7.3.2 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 peritoneal dialysis. A small number of patients have been maintained successfully on peritoneal dialysis 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.

### 3.7.3.3 Multi-jurisdictional Funding Model

Currently, it is known that 25 ESKD patients identify cross-border communities of South Australia and Western Australia as their home. 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. On the other hand, beyond the numbers of patients, there is limited understanding about the relative resource demands of cohorts of patients originating from each jurisdiction. This information does not provide the basis for development of a funding model.

A multi-jurisdictional funding model needs to be developed, and agreed. The model will need to consider the full range of service requirements. While in principle, community-based services might be funded by the relevant jurisdictions, the significant mobility of patients within and across the cross-border region, adds complexity. Thus, the model is likely to be complex, and is likely to require remodelling and regular appropriate updating.
3.8 Workforce and Infrastructure Requirements

3.8.1 Supply

Key Findings

- Securing adequate workforce supply for renal services in Central Australia has been challenging for both clinical and support staff, with a history of high staff-turnover.
- The projected growth in ESKD cases in the CA region, combined with a shift to more community-based dialysis therapy, will necessitate the attraction and retention of an appropriately skilled, multi-disciplinary workforce.
- Partnerships between government, industry and non-government organisations will be required to expand delivery in remote communities.

The workforce supply required for a comprehensive renal service in the CA region will, by necessity, be multi-disciplinary. According to current workforce models considered for this Study, it entails input from renal specialists, general practitioners, nurses, social service providers, allied health providers and Aboriginal Health Workers among others. Across the spectrum, it will also benefit from the continuing growth of an indigenous healthcare workforce in the interests of workforce stability and cultural safety. The absolute number of renal service staff will need to increase as ESKD prevalence grows, however the composition of the workforce is likely to change with the move towards greater implementation of community-based dialysis treatment modalities.

The results of a national renal workforce survey outlined in Table 18 indicate the staff to patient ratios for the range of renal replacement therapies including the nursing, allied health and specialist roles. 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. 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. These challenges in relation to staff recruitment, retention and high turnover were voiced repeatedly to the Study Team by regional stakeholders.

In 2009, a systematic review of international evidence regarding the impact of recruitment and retention strategies for rural and remote area health workforce was undertaken for the Australian Primary Health Care Research Institute. The review 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; and strategies involving health worker obligation work for the duration of agreements, not beyond. The authors suggest an approach in which different incentives are bundled in a manner that is flexible to specific (local) contexts and call for rigorous evaluation, using pre- and post-intervention measures and with appropriate indicators for monitoring effectiveness of incentives.

**Table 18: 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>
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<td></td>
<td></td>
<td>1:125</td>
<td></td>
</tr>
<tr>
<td>Dietitian</td>
<td></td>
<td></td>
<td></td>
<td>1:150</td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
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<td></td>
<td></td>
<td>1:200</td>
<td></td>
</tr>
<tr>
<td>Pharmacist</td>
<td></td>
<td></td>
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</tr>
<tr>
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</tr>
<tr>
<td>Interpreters</td>
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<td></td>
<td></td>
<td>Difficult to quantify</td>
<td></td>
</tr>
</tbody>
</table>

Securing adequate workforce supply for renal services in the CA region has been challenging for both clinical and support staff, with a history of high staff-turnover. When compared to national figures, there are some existing shortages in staff numbers. During consultation for the Study, however, senior staff indicated that there had been greater workforce stability within the last 12 to 18 months. Nevertheless, consultation drew attention to current shortages in supply; indicating the need for an additional CKD nurse, social worker, ALO and renal pharmacist at Flynn Drive to manage current demand for services.

Future challenges relate to the projected growth in ESKD prevalence in the CA region and the need to attract and retain an appropriately skilled workforce to sustain a shift to more community-based dialysis therapy in remote communities away from the hub in Alice Springs and large satellite unit in Tennant Creek. Growth in ESKD, and potentially CKD prevalence, will require the recruitment of further nephrologists and renal nurses to maintain staff: patient ratios. Those consulted indicated the potential to further develop partnerships with industry providers, such as with Fresenius Medical Care Australia in the recently opened Gap Rd satellite unit, and with NGOs, particularly WD NWPT, in moves to expand delivery of renal services in remote communities across the CA region.

### 3.8.2 Training and Support Requirements for Different Models

#### Key Findings
To ensure the high quality of renal service delivery, ongoing training and support for renal services staff is essential, especially for those working in remote communities.

Priority areas for training include up-skilling in aspects of dialysis delivery and care for CKD patients, training addressing the socioeconomic context in which care is delivered in the CA region, and training in the appropriate use of interpreters.

Wherever possible, providing access to training within the CA region might assist in attracting and retaining a skilled workforce.

Stakeholders indicated major challenges in retaining skilled workers in remote communities. There is an increasing reliance on staff who live in urban centres and fly into remote communities several times per year.

Where models of care rely on staff to live in remote communities, well-targeted incentives are required to attract and retain appropriately skilled staff.

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.

Ongoing training and support for renal services staff working across the continuum of the disease is an important facet of ensuring that service standards remain consistently high, regardless of the models being used. In particular, because staff in rural and remote areas tend to stay for shorter periods, it can be expected that training requirements may comprise a significant amount of staff time. Stakeholders indicated the need for renal service staff to receive appropriate training in cultural awareness and safety to ensure high quality care for Aboriginal patients. Opportunities for specific training to better equip a multi-disciplinary workforce to provide sustainable renal services in remote communities, as discussed by stakeholders, included:

- Up-skilling of ENs to provide renal services.
- Further training of AHWs to develop competencies in delivering dialysis and caring for patients with CKD and/or ESKD in the community.
- Up-skilling of rural GPs in management and support of dialysis patients within the community.

Providing access to such training, preferably within the CA region, will be important to factor in to any workforce development strategy. The Study Team note the logistic constraints in attracting and retaining such a skilled workforce within remote communities. Many remote community stakeholders indicated major challenges in attracting and retaining a skilled workforce – Indigenous and non-Indigenous – and indicated an increasing reliance on staff who live in urban centres and fly into remote communities for short periods several times per year.

In addition to training, under the proposed nurse-supported community dialysis or mini-satellite model, extra support for those nurses employed in remote regions will be required to attract and retain staff. Well-targeted incentives might include the guarantee of appropriate accommodation, provision of respite and travel back to base at regular intervals, and opportunities for further career development.

Independent of necessary renal training and workforce support, there is ongoing concern that under the current system many Indigenous patients are left with an incomplete understanding of the clinical or lifestyle consequences of developing ESKD. In a region where English is not the first language for many renal patients and where interpreting is often left to friends or relatives, health providers and patients are frequently
oblivious to this misunderstanding, which can seriously affect health outcomes for renal patients.\textsuperscript{19} The availability of interpreters skilled in languages and the cultural mores of the region, to advise both the health professionals and the patients and families, was identified as a key need for renal services. Consultation for this Study identified both the need for training of renal staff in the appropriate use of interpreters and also for interpreter training to develop competencies around the complex communication issues related to ESKD.
### 3.8.3 Location Characteristics and Limitations

#### Key Findings

- The Central Australian cross-border region covers roughly one million square kilometres and is sparsely populated. By necessity, the physical characteristics of the region inform the appropriate and sustainable model for renal service delivery.

- The regional centre Alice Springs – with 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; has the necessary infrastructure to be the regional renal services hub.

- Tennant Creek, the next largest population and service centre, has the capacity to further develop a support role in the Barkley region.

- A hub and spokes model is appropriate for renal service delivery, with community-based dialysis services located in those communities with patient need, required community support and necessary infrastructure.

- Decisions regarding appropriate sites for the provision of renal services require consideration of locally-specific detail about the number of patients, community demography, location, human capital, health and community infrastructure and evidence of real engagement with and strong support of community leadership.

- 4 or more patients, a strong primary healthcare service and community leadership support would be required to sustain nurse-supported, in-community dialysis services.

- Self-care HD can be undertaken in communities with fewer than 4 patients or lacking essential health and community infrastructure to sustain nurse-supported dialysis.

The Central Australian cross-border region stretches from the entire Anangu Pitjantjatjara Yankunytjatjara (APY) Lands in South Australia, up to Tennant Creek and the Barkly Region in the Northern Territory and across to cover the land north and east of Warburton in Western Australia. It is sparsely populated, and Alice Springs with an estimated resident population of almost 28,000 has long been the regional centre for the collection of Aboriginal communities and outstations across the region. Tennant Creek is the next largest centre with an estimated resident population of approximately 3,500. The Stuart Highway connecting Tennant Creek and Alice Springs is a major thoroughfare, but otherwise there are limited bitumen sections amid vast stretches of corrugated dirt roads prone to closure due to wet weather. A ‘bush bus’ service connects many communities with Alice Springs, but when roads are closed, charter flights are the only option for transport.

By necessity, the physical characteristics of the area have informed the proposed model for renal services provision. The regional centre, Alice Springs, with the Alice Springs Hospital, transport links across the region, and a substantial renal dialysis unit has catered for cross-border patients over a long period. With similar transport advantages and a developing renal workforce, Tennant Creek could further develop a supporting role for the Barkly region.
Given the distances between these satellite centres and many of the region’s communities, and in light of the focus on providing treatment closer to home, community-based dialysis services, with one or two haemodialysis chairs for self-care and four chairs for nurse-supported haemodialysis, could be located in those communities with the patient-need, community support and necessary infrastructure. Both the Kimberley Renal Service experience and, in the CA region, the WDNWPT reverse-respite program, provide evidence that with necessary protocols in place, infrastructure and workforce challenges can be overcome to provide such services, even in very remote regions. Given the expected variation over time in the number of ESKD cases being treated from and in individual communities, stakeholders suggested that construction of health facilities will need to take account of the potential needs for dialysis provision within communities; the need for decommissioning, recommissioning and transportability of dialysis facilities; and implementing a modular approach to construction of dialysis facilities to facilitate relocation across different sites, ongoing maintenance and durability of infrastructure.

Consultations provided evidence of successful although limited Home HD and PD occurring in very remote communities, but concerns raised by patients and carers included the lack of telephone service to some patients’ homes, making assistance in times of crisis difficult to obtain. Water quality and consistent electricity supply for dialysis also remain concerns for providers and patients. Nevertheless, protocols for assessment of suitability of sites for dialysis, which take account of these key issues have been developed.
3.8.4 Alternative Workforce Options

**Key Findings**

- Stakeholders expressed strong concerns regarding the ability to attract and retain both Indigenous and non-Indigenous workers to provide sustainable health services in remote communities. Increasing reliance on “fly-in, fly-out” services was reported.

- Certain examples of innovative approaches to building a sustainable workforce were provided, including strategies to build community support for people undertaking dialysis and strategies to enhance nurse-supported models of care. The Study Team were not able to find evidence that such models have been sustainably implemented in the CA Region.

- In contrast to some success in attracting and retaining local people to develop roles as AHWs involved in the delivery of dialysis in the Kimberley region, NT renal services have tended to experience success with AHWs who have some previous health training, often from other States.

- Workforce supply for some models of care, such as the mobile bus respite model, could potentially be sourced from urban centres, on a 12-week rotational basis.

Challenges in attracting and retaining a multi-disciplinary workforce to support patients dialysing in remote communities, prompts the need to consider alternative workforce options. Spouses or other family currently provide the ongoing support for the majority of self-care dialysing patients. However this informal arrangement can and does fail and then threatens the sustainability of ongoing treatment. One approach to address this issue is to provide official recognition of the responsibility entailed in providing dialysis support, including through financial compensation, and make allowances to train dialysis support people within communities in basic requirements such as first aid. This could potentially create a group of aware and suitably qualified community members able to step in when support is required and is not otherwise available. Carer respite and support, was indicated by stakeholders as another potential mechanism of buttressing the role of dialysis buddies. During consultation for this Study, there was some evidence of the benefit of self-care haemodialysis patients working together and supporting each other in their dialysis. Where possible, it may be beneficial to provide self-care training for patients from the same community in pairs. The aim would be to provide more than one support person, so that there were options for respite for the primary dialysis support person.

The provision of nurse-supported, mini-satellite services in remote communities prompts consideration of a range of alternative workforce options. A number of alternative approaches are currently being considered in the Western Australia Country Health Service Dialysis Plan:

- Using MSOP to provide fly-in, fly-out support from specialist nephrologists and potentially dialysis nurse practitioners or other senior nursing staff.

- Up-skilling remote area GPs in the support of dialysis and CKD patients in the community, and extending the partnership between tertiary and primary healthcare services to include practical support for patients receiving care in communities.
Up-skilling AHWs to support dialysis and CKD patients in the community. The Study Team acknowledge challenges in recruiting and retaining such a workforce, especially in attracting AHWs from NT communities to take on roles in the actual delivery of dialysis services. However, potential keys to building an Indigenous workforce include: the provision of relevant training within the Lands or CA region; development of a career pathway, with appropriate financial and non-financial recognition of the importance of the role; ongoing support and training following employment; and working as part of a multi-disciplinary team, alongside nursing and other staff in providing a sustainable service.

Up-skilling ENs in the practical skills to support dialysis and CKD patients in the community.

Alternatively, with adequate training provisions, workforce supply for some models, such as the mobile dialysis bus proposal, may be able to be sourced from urban centres, on a 12-week rotational basis. Encouraging new and existing links with tertiary education providers was also discussed as a way to help build future supply for the region’s renal services workforce.
3.8.5 **Desired/Necessary Primary Health and Tertiary Services**

### Key Findings

- Engagement with and support of local primary healthcare services is a crucial factor to assure the sustainability of community-based renal service provision.

- An ideal model for service delivery should bring primary and tertiary services together in partnership to comprehensively address the full range of clinical, social and cultural needs of patients.

- An example of a model for such a partnership was seen in the Kimberley Renal Service, which offers a single fund-holding, comprehensive service across the continuum of CKD and ESKD.

Engagement with and support of local primary care services is a crucial factor to assure the sustainability of dialysis services closer to home. At a minimum, this might entail co-location of dialysis facilities with the community health service and assurance of the availability of local service staff to support self-care patients in a medical emergency. Such arrangements have been established and were reported positively in a range of communities across the region. ESKD however, is the final point on the chronic kidney disease continuum and there is potential for primary health care to make significant contribution across this spectrum. An ideal model for service delivery might bring primary and tertiary services together in partnership to comprehensively address the full range of clinical, social and cultural needs of patients. Such a partnership is the foundation for the successful Kimberley Renal Service, which offers a single fund-holding, comprehensive service across the continuum of CKD and ESKD.

The following were raised during consultation as ways to potentially improve engagement between primary and tertiary services, with the aim of building systems to enhance the quality of renal service provision:

- The implementation of an electronic health record that can be shared across the primary, tertiary, hospital and community sectors.

- Greater use of MSOP funding to enable regular visits to communities by specialist clinicians, nurses and allied health staff.

- Introduction of an Enhanced Medicare Item for renal patients to facilitate the comprehensive management of primary care needs of renal patients and provide a financial incentive for GPs to hold clinics at hub satellite units.

- Deployment of additional resources at the regional hub to provide ongoing support, up-skilling and education for primary care staff in the management of CKD in the community.

- Deployment of a web-based, automatic data collection system, compatible with primary care software systems, to enable comprehensive monitoring of the burden of CKD and to support and drive quality improvement initiatives to reduce the gap between evidence and practice in the identification and management of CKD.
3.8.6 Infrastructure Needs: Water, Power, ‘Bricks and Mortar’

**Key Findings**

- Detailed protocols have been developed in the Northern Territory and Western Australia for the provision of renal services in remote communities. Where adherence to the standards outlined in these documents can be maintained, renal services may be safely offered.

- Key technical and design requirements include the following:
  - A reliable electricity supply – grid supplied or from a community generator with 240V and >20 amp/phase
  - Water quality of acceptable or treatable standard
  - Water temperature less than 60°C
  - Adequate drainage and waste facilities
  - Appropriate management of biohazardous waste
  - Facility construction according to building, services and furnishing requirements.

The provision of self-care and nurse-supported dialysis in remote regions is a technical challenge. Some of those interviewed by the Study Team questioned the ability to ensure the necessary water quality and electricity supply, and indicated concern regarding the ability to establish the necessary structures or facilities to support delivery of renal services across the region. However protocols have been developed for the provision of dialysis in challenging conditions, both in the Northern Territory and in Western Australia. Where it is possible to maintain adherence to the standards dialysis services may be safely offered.

The outstanding technical and design requirements include the following:

- A reliable electricity supply – grid supplied or from a community generator with 240V and >20 amp/phase.
- Water quality of acceptable or treatable standard (specifications in Technical Appendices).
- Water temperature less than 60°C.
- Adequate drainage and waste facilities.
- Appropriate management of biohazardous waste.
- Facility construction according to appropriate facility, furnishing and services requirements.

Given that marked variability over time in the geographical distribution of ESKD cases is predictable, stakeholders suggested that, where possible, dialysis facilities should be relocatable units, and planning might encompass a focus on decommissioning, relocation and recommissioning of dialysis facilities. However, there
are renal ready rooms already constructed in a number of communities, in primary care facilities, for the purpose of dialysis provision. Elsewhere, existing structures might potentially be adapted for use as mini-satellites.
3.9 Social and Cultural Needs

3.9.1 Overview of Social and Cultural Impacts

Key Findings

- For Aboriginal patients in the CA region, uptake of RRT has generally necessitated moving away from kin and community. Consequences have included loss of social and cultural connectedness, loss of autonomy and control, and loss of status and authority.
- Key family and cultural leaders having to move away has profoundly affected communities.
- Patients moving to town are generally accompanied by immediate 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.
- From the patient, family and Aboriginal community point of view, the ‘cross-border’ region of this Study has meaning through the social relationships and cultural connections that extend across it. Alice Springs is 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.

For Aboriginal people in the Central Australia (CA) region, a diagnosis of kidney disease brings with it the devastating impact of having to leave home and relocate far away to undertake dialysis treatment. This triggers a cascade of social, psycho-social, cultural and physical consequences.

3.9.1.1 Particular People, Particular Experience

The consequences of kidney disease for Aboriginal people of the cross border regions are especially devastating because they differ from other Australians in ways that significantly influence their illness experience.

These differences include:

- Differences in social life and cultural heritage – in particular having a social life that is kin-based and country-focused.
- Speaking languages other than English as their first language.
- Having poor levels of educational attainment, with resulting low levels of literacy.
- Being less likely to be employed, and more likely to be living on pensions of various kinds.
- Being less likely to have secure, stable accommodation.
- Being less likely to have access to healthy and reliable food options.
- Being less likely to have access to public or private transport.
- Being unfamiliar with urban living - its landscapes, structures and accessing services.
- As a group, experiencing high rates of alcohol and drug use and of family violence.
Aboriginal kidney patients from the region are younger than non-Aboriginal patients and more likely to have dependent children. In addition, whereas approximately 75% of Aboriginal patients in the CA region need to relocate to receive treatment, 99.8% of non-Aboriginal Australians across the country do not, because they are able to access dialysis in their local area. The widespread experience of family fracture is therefore very particular to Aboriginal groups and the differences described here combines to make the treatment pathway – for Aboriginal patients – particularly arduous and challenging.

3.9.1.2 Impacts on Family

The earliest impact is the psycho-social stress on the individual who is diagnosed with chronic kidney disease at a stage where they might soon require dialysis. At that point, despite being aware of others with the disease, most know only that “it is really, really trouble” (Dialysis patient, November 2010). Fear, anxiety and stress shape the patient and family response to the diagnosis, to decisions about treatment and to planning and preparations.

The majority of CA region patients undergo haemodialysis three times each week for several hours at dialysis centres in urban centres – primarily Alice Springs. To do this the patient and (usually) some family members must leave home and move permanently to town. Their dislocation has multiple social consequences including:

- Loss of social and cultural connectedness to family and community, with a diminished capacity to be part of family and community life and to carry out family responsibilities.
- Loss of autonomy and control.
- Loss of status and authority, including cultural standing as well as loss of employment and associated financial security.
- Cultural and social loss to local communities as key family members and cultural figures leave.

*Going onto dialysis affects your spiritual, mental and physical health, it has huge impacts… I lost my car, my job, everything was falling apart.* (Dialysis patient in his 30s, October 2010)

*We don’t know where that person goes and it’s really sad… Some go to [city] and that’s a long way. The family is sitting there and they don’t know where that person goes… We are all sitting here - as the women - worried, with the worries inside our heart.* (Community member, September 2010)

Undertaking treatment and living in town is the other “side” of the experience of leaving home. The impacts of having to live in town include:

- Moving from a predominantly Aboriginal social and cultural domain into a predominantly non-Aboriginal domain.
- Establishing a coherent family life in a socially and culturally unfamiliar environment.
- Difficulties in asserting control of your life through illness, poverty, communication difficulties and lack of familiarity with the structures and services – notably social support services of urban life.
- Vulnerability within a social environment marked by high levels of alcohol and drug abuse, family violence and instability.
- Social isolation and insecurity.
Intense stress through a radical life adjustment in a context of serious illness and a demanding treatment regimen.

Whether descriptions come from Aboriginal people experiencing the trauma first hand, or carers assisting them, a clear picture emerges of the effects of end-stage kidney disease (ESKD) on patient, families and their communities.

*My life has been turned upside down. I was happy living my life in my community I was working full time as a teacher aide. Life was good. Then this [kidney failure] happened - I now have moved here ...to attend dialysis three days a week for four and a half hours... I am very homesick for my family and country. I would love to go home. My family said it is very hot at [place] for me to visit so they said they would come to visit me. But the only time I see them is school holidays and Christmas time. [I feel] Upset about this dialysis treatment and being away from my family.* (IMPAKT patient interview CP088)

*There’s stress ... [its] is a big issue. They [patients] get [here], there’s no house, no family, no money; they have no idea of this place, there’s a lot of alcohol easily available. People are in the hospital so much that they have hardly any time to do their own business, and they’re not used to living in a city environment. A stress scale done on these people would show this.* (IMPAKT interview 3-01, staff member, regional treatment centre).

### 3.9.1.3 Impacts on Community, Culture and Region

People discussed how key family and cultural figures having to move away affected their communities. Aboriginal kidney patients are younger than their non-Aboriginal counterparts – most are much younger than 65 years. These are people with social and cultural responsibilities, leaders of families and communities, holders of cultural knowledge and authority. As examples, two current APY Council Board Members are on dialysis in Alice Springs and a third Board Member’s wife is on dialysis in Adelaide. People in the home communities of these Board members feel that they have lost their active voice on the Board, since the Board members are not living in the communities to keep across the issues and needs. At the same time the Board Members themselves feel stress and pressure because they are not meeting their responsibilities to the Board or to their communities (Communication to research team, staff member, APY Council, Nov 2010).

Key community figures may be relatives of patients and, as they accompany their ailing relatives to look after them, are also lost to town. Examples given included, in the same remote community, a senior child-care worker of 19 years experience and a key schoolteacher both having to give up these positions and move to town with relatives with kidney disease. We were told of whole families affected by the disease, with members from several generations being on dialysis or having died “on the machine”. One younger woman interviewed, talked about two of her cousins in their 20s who have been told they need to start dialysis, saying “we are all renal families”.

Patients described the significant financial burden kidney disease places on them and their families. Patients and families moving to town seek help to meet their higher costs of living and patients and families look for travel and transport support to make home visits (see more below). They turn to other family members as well as their community organisations (APY, NPY Women’s Council, Nganampa, WDNWPT, Ngaanyatjarra Council, etc) for assistance. Patients sent further away for routine dialysis tend to have greater financial shortfalls. Nganampa Health Council, which administers its own PATS allocation, reported that during 2009-10, costs for renal patients rose by $20,000 when patients from the APY Lands were sent to Adelaide and Pt Augusta. (Communication to research team, Corporate Services Manager, Nganampa Health Council, Nov 2010) Ngaanyatjarra Council reported that they spend $20,000 annually to support dialysis patients and their families who are not living on the Lands (Communication to research team, Community Development Advisor, Shire of Ngaanyatjarra. Oct 2010). APY Council reported that they receive constant requests from people to support travel to visit their relatives living elsewhere on dialysis. (Communication to research team, staff member, APY Council, Nov 2010).
The outflow of people from communities represents an influx of people coming into towns – principally to Alice Springs. Community members indicated that not only immediate family carers and dependents move to town with patients, but over time other family members periodically visit. It has been estimated, for Anangu from the APY Lands, who have been sent to Adelaide to access dialysis, that as many as five people may follow a patient going for dialysis. Even taking a more conservative figure of two additional people for each patient, the projections for patient increase over the next 10 years would suggest that by 2020, the total numbers of Aboriginal people who will come to live in Alice Springs (through kidney disease), might be as high as 1,500 people. Patients and community members talked about children having to come into town from communities. There are implications for services in addition to renal dialysis, particularly accommodation, social support services and schooling. Stakeholders suggested the need for detailed study of renal patients’ and family residence and mobility patterns as the basis of planning future accommodation needs in towns and communities providing dialysis services.

These instances underscore the dramatic impact kidney disease is having in the region. 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.

Feel good now [being back in Alice Springs], it’s open for me, I can talk to anyone; not like [city]. Close to kids to come to visit and can go for funeral to the Lands. However, this man went on to say...but I need to get back to the Lands... I find it really hard because I am an Elder from [community], no good staying here [in town] for years, I’ve got a lot of kids to teach...I’m losing my spirit, culture and my Law...I don’t want to lose it. (Dialysis patient recently returned to Alice Springs from a major city, November 2010)

The NPY Women’s Council submission to this Study stated “While NPY Women’s Council understands that there may be some Anangu who would prefer to move from the Lands to Port Augusta or Kalgoorlie, it is our view, formed from extensive discussions and experience, that the majority of [Anangu] prefer to reside in Alice Springs for treatment.” This is consistent with the consultations undertaken for this Study with community people across the cross-border region.

Alice Springs is the main business base for the key agencies currently providing services into the cross-border regions. Dialysis patients living in Alice Springs consulted for the Study talked about having access to the offices of their representative organisations, which not only provided support, advocacy and some social and artistic activities but also provided telecommunications to keep in contact with communities and families.

I fought for service provision on the Lands for a very long time. I worked hard fighting for land rights, and I have worked for many years. But now I am not reaping any rewards from all my years of hard work on the Lands. Instead, I am living like an unwanted lost dog from some other place scavenging a living in this town, which is not my real home.
3.9.2 A Patient and Family Centred Focus

### Key Findings

- The evidence suggests a coherent family life supports patients to manage their health and requirements of RRT.
- Culturally safe and appropriate services can be built on a family/community focused model of care which maximises the inclusion of significant family members, healthcare and social service providers.
- Inadequate resources for social workers, support and advocacy services for patients and their families, and the lack of coordination between the relevant social service providers, are a critical barrier to comprehensively addressing renal patients’ social and cultural needs.
- Competent professional interpreters with appropriate training, adequate kidney disease knowledge and covering the range of languages relevant to the CA region are essential.
- There is a critical need for training of renal staff to work with Aboriginal interpreters.
- Significant levels of patient mobility present a complex challenge. Travelling to visit kin and community are essential parts of the social fabric for Aboriginal people across the region.

The dominant theme in patient comment, in consultation undertaken for this Study as well as previous research, was the centrality of family relationships to a meaningful life.

All we talk about is that we want to be home with families, on country (Dialysis patient living away from their home community for many years, October 2010).

Missing all the families...it’s very hard...long way from families...worrying for families...we get homesick, it’s too far...we need to sit down close to families, sit and talk and go out hunting, they can take us out to country (Dialysis patient living away from their home community for many years, October 2010).

I can see my family when they come to visit but that’s not the same as being together properly as a family all the time... and knowing what’s going on in their lives (Dialysis patient living away from their home community, September 2010).

Kidney disease, its treatments and requirements, pre-occupies patients to the extent that it severs their connections to their family, community and country. Patients draw attention to the resulting existential loneliness (“sadness” or “worry”) that they experience. Family members and some service providers observed how dislocation, in turn, undermines both patients’ motivation to continue and their health.

NPYWC ngangkari (traditional healers) report that most renal patients they see are acutely affected by loneliness, and that this exacerbates their health problems, and leads to feelings of despair and hopelessness. They say that loneliness empties and weakens the spirit, leaving Anangu feeling vulnerable and weak, a very distressing condition. They say that regular visits home to spend time with family ‘fills them up’, strengthening their spirits, building resilience and enabling them to keep on going with their treatment.57
While “patient-centred” health care is well recognised as a dimension of high quality care,\textsuperscript{59} there is increasing evidence that family/community focused models of care may be effective for Aboriginal people.\textsuperscript{60} By maximising the inclusion of significant family members, health care and other service providers might more readily develop a shared understanding of priorities and how to achieve them. Culturally safe and appropriate services can be built on this basis. Traditional healers interviewed for the Study emphasised that healing for renal patients was not about a cure but about providing some relief and taking care of a person’s spiritual wellbeing. This was linked to patients’ ability to remain linked with family and community (Communication to Study Team, Akeyulerre Healing Centre, Oct 2010). Patient and family-centred care has two dimensions: one of involving family members, to the extent practicable, in planning and decision-making around patient health requirements; and the other, involving considerations of whether and how family life and family settings are supporting or undermining patient health. As one social service provider stated “[w]e need families to do family support work” to build the capacity of the family and the support network around the dialysis patient (Communication to Study Team, Tangentyere Aged Care Services worker, Nov 2010).

### 3.9.2.1 Challenges to Patient and Family Centred-care

People consulted for the Study reported challenges to providing patient- or family-centred care for renal patients in Central Australia. These challenges include:

- The lack of resources and lack of coordination between multiple social service providers.
- Continuing poor access to interpreters.
- Patient/family mobility.

Support services for renal patients are provided across different arms of government, a range of NGOs, across jurisdictions and are poorly resourced within the health sector. The Central Australian Renal Social and Emotional Wellbeing Action Group (CARSWAG) was established in the last few years with representatives from renal services as well as social and housing service providers. While CARSWAG had defined Terms of Reference, it was a voluntary group and had no authority, nor was it accountable for the delivery of key outcomes. Over the last year, this group disbanded.

As discussed earlier, social work and Aboriginal Liaison services within the renal unit are significantly under-resourced compared to national benchmarks, and even more so considering the level of need of patients in the region. Key stakeholders identified the inadequate resources for social workers, support and advocacy services for renal patients and their families, and the lack of coordination between the relevant social service providers, as being a critical barrier to comprehensively addressing patients’ social and cultural needs.

Renal patients in Central Australia come from a diverse range of language and cultural groups and for many English is a second or third language. There are few interpreters, which presents significant challenges for effective communication. The majority of patients in the CA region have limited education and low levels of literacy. Patients have described themselves as not having adequate understanding of their illness, their treatments or their prospects.\textsuperscript{61} There is a critical need for competent professional interpreters if health and other service providers are to communicate effectively with patients and families.

Despite the need for high quality services, interpreting is not well established as a career path and interpreting work has relatively low pay rates. Available interpreter training is minimal. The Aboriginal Interpreter Service (AIS) pathway currently begins registration (at Level 1) after a three-day training course. The training does not include particular subject content; with kidney disease content being an essential grounding for interpreting in this area. While the Aboriginal Interpreter Service reported receiving few requests for interpreters for kidney patients, renal staff indicated that they rely on Aboriginal Liaison Officers, most of whom speak an Aboriginal language, but have multiple roles. In addition, renal staff reported not receiving training to work with Aboriginal interpreters. Such barriers are recognised in an explicit strategy to facilitate engagement with Indigenous people and service delivery through appropriate use of interpreters in
the Implementation Plan for the National Partnership Agreement on Remote Service Delivery between the Commonwealth of Australia and the Northern Territory.62

Aboriginal social life in the region is characterised by high levels of mobility for which kinship is the driving force. Long and Memmott63 note that:

When people visit family and friends they are not merely taking part in an enjoyable social occasion, they are also reinforcing reciprocal ties and obligations, all of which are essential parts of their social fabric. Kinship is maintained through mobility, kinship makes mobility possible, kinship supports mobility, and kinship contributes to the definition of mobility regions.

Travelling to visit kin and receiving visiting kin are, as the authors point out, essential parts of their social fabric. This movement aims to maintain social connection as much as to achieve subsidiary objectives such as accessing goods and services, or attending special occasions, including culturally significant events. Thus, despite a demanding dialysis regime, patients are also highly mobile – even to their health detriment in the view of some. The impetus to be actively socially connected motivates patients to travel and to regard kin visits to their accommodation as positive, despite the risks and the difficulties that may arise.

Significant levels of patient-initiated mobility in the cross-border region, as well as regular changes in patient health status and situation, such as changing dialysis modalities or changing accommodation, present a particularly complex challenge. Numbers of patients are on various kinds of formal and informal waiting lists – for other dialysis units (e.g. patients in Adelaide wishing to return to central Australia) or for other accommodation (43 are waiting to get into Topsy Smith hostel in Alice Springs, at least three have been in Alice Springs hospital for three or more months waiting for suitable accommodation). Planning and service delivery in such a setting requires well designed and well maintained tracking and monitoring systems that are integrated across the jurisdictions.

### 3.9.2.2 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 WNDWPT – literally meaning “Making all our families well”. WNDWPT is an Indigenous-controlled organisation representing the Yanangu people and families on dialysis. Funds to support the establishment of the organisation and its services were initially raised through the auction of significant paintings by artists from Kintore and Kiwirrkurra facilitated by Sotheby’s Australia at the Art Gallery of New South Wales.

“The significance of ‘dislocation’ for Yanangu is that it works against holding on to their identity and wellbeing. These attributes are expressed through fundamental, interconnected cultural values of family (walytja), Country (ngurrpa) and Dreaming (tjukurrpa). The impact of ‘dislocation’ on the health of dialysis patients, and upon their families and community, is so profoundly negative – and dealt with in such an inadequate manner by mainstream services – that Yanangu took the initiative of raising money to establish their own quality renal services.”64

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. WNDWPT’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, WNDWPT has renovated a building to become the Kintore “Purple House” which has allowed them to increase the amount of respite dialysis provided.
The success of these programs and the desirability expressed by Aboriginal dialysis patients to return home, even if only for visits, has prompted several other language/cultural groups to seek advice and assistance from WNDWPT about establishing their own reverse respite dialysis service on country. With the consent of its Board, WNDWPT 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.
3.9.3 Services and Supports including Accommodation, Respite and Return to Country programs

Key Findings

- Where the decision to access treatment requires people to move away from family and community, a proportion of patients will choose not to have treatment.
- Finding accommodation was identified by all service providers, in all jurisdictions, as the single biggest challenge for kidney patients moving to town for dialysis. Renal patients need permanent accommodation whereas the majority of available, low-cost accommodation is short term.
- Among renal patients living in Alice Springs, 50 to 55 patients are living in hostels, 60 in public housing, and up to 50 are living, either permanently or temporarily, in town camps. It is believed that 30 to 35 patients (15-20%) are without secure housing of any kind.

3.9.3.1 Being Diagnosed with Kidney Disease - Planning and Decision-making

The initial diagnosis of advanced chronic kidney disease, followed by preparation for and start of dialysis treatment is often accompanied by fear and anxiety. Clinicians report many patients “disengaging” at this crucial time, making planning of treatment choices and family preparations for moving to town difficult.

*It was a really big shock when my mum had to go onto dialysis, we didn’t know about her kidney problems...the family was really worried but she didn’t want to talk about it with any of the family. It was really hard. I saw her change her behaviour and go, like, into herself. She would get angry sometimes if we tried to help her and would say I’m not...sick’. The family knew not to mention it. (Daughter of a dialysis patient, November 2010)*

*When my husband went onto dialysis, he got really angry and depressed and took it out on me and the kids. It was really hard. We had to move into town. There was no support to help us cope. He lost everything...he felt useless. (Wife of a dialysis patient, October 2010)*

Stakeholders suggested that additional and appropriate psycho-social supports might be needed during this period. There could be scope for traditional healers or similar culturally acceptable supports as well as innovative approaches including possibly the systematic involvement of patient peers/mentors and Aboriginal health professionals (AHW, ALOs).

For an unknown proportion of patients a “choice” between medical treatment on the one hand, and home and family on the other, is unthinkable and they choose not to have dialysis treatment. Such families and their community organisations, including primary health care clinics and other local services, will need access to appropriate advice and palliative care services.

*I was born and bred on these lands. How on earth could I go all the way to the city, away from my family and country, knowing there was no possibility for them to come down and stay with me, no accommodation, no facilities ... There’s no way I could think about being so far away... I’d just be in total despair all the time ...*
I know that before long I will have to go on dialysis. I've already got the fistula in place. They've told me in about six months time. So I'm thinking ahead and really want there to be the funding. We've already got quite good new clinics in all of the communities but now we need the extra funding to enable [dialysis] to be provided on the Lands. Maybe it's going to be in [community], maybe in [community], or [community]. I'm not sure but somewhere so we can stay on our own country. (Senior community member, September 2010).
3.9.3.2 Living in Town on Dialysis

Key Findings

- The absolute shortage of public housing properties is a key contributing factor to accommodation problems for renal patients.

- The Salvation Army in Port Augusta described a case-management, staged approach to support people – including Aboriginal renal patients – into public housing tenancies. People move from their initial, short term accommodation into a transitional property, owned by the Salvation Army. They are provided with a range of services to support them in achieving a stable sustained tenancy including: living skills assistance, personal care, house maintenance and managing social disruption. The Salvation Army supports tenants to manage issues that threaten the tenancy.

Finding accommodation was identified by all service providers, in all jurisdictions, as the single biggest challenge for kidney patients moving to town for dialysis. 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.

The Study Team consulted widely to establish a picture of current accommodation patterns for dialysis patients in Alice Springs. A report by Homelessness Australia estimated that “approximately 40 renal dialysis patients live on Town Camp communities, often with inadequate accommodation and support. Most are originally from remote communities.”

Housing that accommodates family members, especially children and/or grandchildren, was reported as the ideal type of housing. It allows a patient to have a coherent family social life and holds the most promise for patient’s well-being and capacity to manage treatment requirements. Currently approximately 35 to 40% of patients have that option. However, having eventually been offered public housing, most patients in this region will need significant support services; first, to set up a house and establish a stable family life and second, to hold the tenancy. There are considerable costs and logistics associated with establishing and maintaining a household: getting the furniture and whitegoods, getting and keeping power supplies, keeping up with rubbish cycles, maintaining the yard, dealing with repairs and breakages and so on. With welfare level finances, often no transport and lack of familiarity with urban house maintenance routines, families need both advice and support to manage.

*So the help we need is to do with houses and living in houses. We are finding that the hardest, because we are Anangu people from the bush. We are from the bush and we are not used to paying rent and everything. It is hard for us to find enough money to pay the rent. We find that very hard. We spend all our money on rent. We are all on Centrelink money, which is not very much.*

Particular problems arise with the influx of too many additional family members, and/or involvement by household members in violence, excessive drinking/drugs or other anti-social activities. Patients have difficulties managing such situations and often end up losing the tenancy. The experience itself is stressful and humiliating.

*The trouble with our house is we had to too much trouble with drunks and fighting. All the neighbours have complained. They wrote letters to the Housing Commission and gave our house number and said we had a noisy, unruly house. So the Housing Commission has contacted me and told me that all the neighbours are
complaining, and that we would only get one more chance. One more chance and then we are to be thrown out. And where are we to go?58

Several people consulted for the Study discussed the stress for renal patients in retaining their tenancies in public housing:

*It’s very stressful for renal families to hold their houses; all the humbug every day. Some people just decide it is too hard and choose to go back home without treatment.* (Senior community member, November 2010)

The Salvation Army in Port Augusta described a case-management, staged approach to support people – including Aboriginal renal patients – into public housing tenancies. The program involves people moving from their initial short-term accommodation into one of 14 “transition” properties, which are owned by the Salvation Army. They are provided with a range of services to support them in achieving a stable sustained tenancy including: living skills assistance, personal care, house maintenance and managing disruptive families. The Salvation Army supports tenants to manage issues that threaten the tenancy. This process can take as long as needed to increase the family capabilities. When the person/family can sustain tenancy they move to public housing when it becomes available.

The manager of the program pointed out that most Aboriginal people coming in from remote communities have no understanding of the tenancy concept. The Salvation Army is producing a DVD in Pitjantjatjara to assist in the process. The effects of dislocation however may still affect outcomes, depending on family situations:

*“In the longer term the psychological and emotional impact of being where you don’t want to be, and the sadness of those people (renal patients) becomes the most difficult issue to manage. People just have to go home – then they come back late and sick, we don’t always know they’re going.”* He returned to this theme later in the conversation and emphasised how if it is not addressed the person is in danger of losing their tenancy; because they leave: *No matter how good the tenant is they give up if they get too sad.* (Manager Salvation Army Centre, Port Augusta, Nov 2010).

The new Percy Court 28-unit managed transitional housing facility in Alice Springs offers an expansion of options when it comes on line in 2011. It is unclear what residence criteria will be applied and whether its ‘transitional’ nature will limit options for renal patients. Potentially it provides a key component for establishing a scheme similar to that described for Port Augusta.

Nevertheless, across the region, the absolute shortage of public housing properties is a key limiting factor. However the review also draws attention to the potential benefits of a coordinated, case-managed approach to accommodation in conjunction with support services. This is a process that could provide the best outcomes for renal patients as well as make best use of limited resources. Several options were canvassed during consultations:

- Noting the example of the Salvation Army case-managed approach to supporting Aboriginal people to build skills and capacity to achieve stable public housing tenancy, infrastructure funding could be made available for a managed transitional housing village for renal patients and families in Alice Springs. It should include programs supporting patients and their families to maintain a tenancy.
- Resources could be allocated to monitor renal patients living in town camps, their housing situation, social and healthcare needs in collaboration with Tangentyere Housing and Aged Care Services, the Tennant Creek Interagency Taskforce, Aboriginal Hostels Limited and relevant government officers.
- A Renal Care Package similar to the EACH (Extended Assistance for Care in the Home) Package, could be established. Such packages might include care by an allied health professional; personal care; domestic assistance; transport; social support; home help and community nursing support.
- Noting the important contribution of patient assisted travel schemes (PATS) to renal patients across the CA region accessing health services that are not available close to home, the following need to be
reviewed: i) the level of reimbursement for travel and accommodation, ii) criteria for eligibility for assistance for patients required to relocate to access RRT, iii) eligibility of an escort or carer to accompany a patient seeking treatment; and iv) the lack of uniformity of schemes across jurisdictions.
3.9.3.3 Town Camps

Key Findings

- 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.

A significant proportion of renal patients – approximately 35% of Alice Springs-based patients – are currently living in the Alice Springs town camps administered by Tangentyere Council. Tangentyere Aged Care Services support five renal patients who have been assessed as eligible and received a Community Aged Care Package. Tangentyere Council do not maintain specific data on renal patients; none have been allocated a house through their usual allocation processes, nor are any on their list awaiting allocation. Neither Tangentyere nor the Renal Unit Social Worker were able to describe with any certainty the number or situation of renal patients living in town camps. Through WDNWPT, Tangentyere Housing has received a small number of requests for housing repairs and maintenance for renal patients living in Town Camps. Stakeholders reported there had been little sustained contact between Tangentyere Housing and the NT Renal Unit (through the social worker) for several years. The majority of renal patients in Tennant Creek are also living in town camps.

In a process that would appear to be both undocumented and unmonitored, renal patients go to town camps and move into the houses of relatives already living there. We were told of at least three dialysis patients living in one overcrowded house. Town camps are the focus of intense work under the Intervention and standards of living are expected to improve. Nevertheless, house-crowding remains a major issue, with occupancy estimates of between 11 and 16 people per house in the town camps. A large number of renal patients are living in town camps, primarily, because there are no alternatives. Hostels are full with long waiting lists and public housing is scarce. Town camp living conditions are problematic; drinking is more widespread and security and safety may be concerns. Patients in earlier forums expressed misgivings about being forced to live in a town camp:

“Those of us with kidney problems have serious housing concerns. Now that we have been thrown out of our Housing Commission house, we are living at (town camp), which is hard because of all the dirt and rubbish. We are really sad now that we are having to live on a town camp. It is not where we imagined ourselves living in our later years. It is not how we saw our lives working out.”

Nevertheless certain aspects of town camp living have been reported to be positive, in particular its freedom from direct regulation, the presence of other family and kin, the potential to spend time with visitors to town and the likelihood that it will be cheaper, possibly free if others have paid the rent. Patients may also see town camps as temporary arrangements while they try to find other accommodation, or try to get back home. Renal patients indicated their difficulties in getting their health needs attended to, while living in town camps. During our consultations we were told about the inability of some renal patients to receive wound dressings as there we no services responsible for providing this care in the town camps (Manager Tangentyere Aged Care Services Nov 2010).

It’s a really sad story... they [renal patients] just go to their families in the town camps, I feel really sorry for them, it’s a really bleak situation... and the numbers are increasing...But they don’t complain, they are just
happy to have a roof over their heads and to be with some family. (Tangentyere Housing Officer, November 2010)

3.9.3.4 Hostel Living

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<th>Key Findings</th>
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<tr>
<td>- Topsy Smith Hostel – the only dedicated renal hostel in Alice Springs – is currently full (40 persons) with a waiting list of 43. Ayiparinya Hostel has ten renal patients.</td>
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<tr>
<td>- Bath Street Lodge, as yet unopened, will provide long-term accommodation to up to 38 renal patients.</td>
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<tr>
<td>- Hostels do not support patients to establish a coherent family situation or address social isolation. Options canvassed by stakeholders included improved family access arrangements and specific resource allocation for patient care and social support services.</td>
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Renal patients require permanent accommodation, including ideally, the possibility of living with family members. Aboriginal Hostels’ target client group are short stay visitors and hostels are not set up to accommodate families. Around 30% of patients are currently living in hostels – almost all in Topsy Smith Hostel – the only dedicated renal hostel in Alice Springs. Topsy Smith is currently full with a waiting list of 43. The person on the top of the waiting list has been in that position for 12 months. The only other hostel with a significant number of renal patients is Ayiparinya Hostel, with ten patients. Although individual patients may be accepted periodically into other hostels (see Table 9), their requirement for permanency is ultimately an obstacle.

The as yet un-opened Bath Street Lodge will provide long-term accommodation for renal patients and a nurse-supported Automated Peritoneal Dialysis program. The opening of this hostel, as a dedicated renal patient hostel, will significantly expand accommodation capacity for renal patients in Alice Springs. Additional facilities, particularly Apmere Mwerre, will provide additional low-cost, short-term accommodation for family members visiting renal patients.

Hostel living remains a necessary option for many renal patients. It suits some – particularly older, less mobile patients as long as they are able to live independently or, if they need assistance, have a carer with them. Nevertheless hostels do not support patients to establish a coherent family situation or address social isolation. This was re-iterated by Aboriginal agencies in their comments to this review. Many patients reported hostel life as lonely or isolating:

“Yeah, Back in Alice I was lonely at that renal up there, living in the Hostel there, lonely places. No family yeah.” (IMPAKT JD164)

*But I do want to live in a house with other of my relatives, because I don’t want to live alone.*

The Study Team visited two hostels with specific additional health and medical services for clients including Kanggawodli in Adelaide and the Autumn Centre in Perth. These models offer greater support to renal patient residents. Options discussed to address the appropriateness of hostel accommodation for renal patients included improved family access arrangements and specific resource allocation for coordinated social inclusion/social connection programs and activities.
3.9.3.5 Other Concerns about Living in Town

There are a range of other important needs that patients reported regarding moving to town:

- Managing schooling and childcare arrangements for those with dependent children.
- Access to support services for patients with personal care needs (showering etc) mobility, frailty or other similar problems.
- Support services for patients (or family members) with drug/alcohol problems.
- Social and emotional well-being supports services for both patient and family.
- The accessibility of support services to renal patients living in town camps.

All of us renal patients are finding it difficult, and we want more assistance and support, and more communication between agencies and organizations. What are all of us renal patients going to do? We are all bush people from the Lands. We are new to this kind of life...
3.9.4 Maintaining Social & Cultural Connectedness

Key Findings

- Return to country and respite dialysis programs, key mechanisms for patients to retain social and cultural connectedness, have been supported by community organisations and primary healthcare services.

Patients reported maintaining social and cultural connectedness 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 has been discussed extensively in previous sections of this Report. Under the ‘Return to Country’ 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 the 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.

Return to country programs, where well coordinated with ongoing treatment needs and planned with primary healthcare and renal services, can help reinforce social and cultural connectedness for renal patients. Such programs should be considered part of comprehensive renal service delivery in the CA region and extended so that patients across the CA region can access such support.
### 3.9.5 Treatment Preferences, Uptake and Adherence

#### Key Findings

- **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.**

- **Carers reported carrying a considerable burden supporting their family and caring for a dialysis patient. Stakeholders indicated there are limited, if any, carer respite services.**

- **In the context of Aboriginal dialysis patients, the term ‘compliance’ (used only by staff) most often refers to whether or not patients actually attend dialysis. Aboriginal patients do not think of, or describe themselves, as ‘non-compliant’.**

- **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 Kimberley Renal Service, which has reported excellent adherence to dialysis prescription, has suggested the factors contributing to their success include:**
  - a sense of ownership/involvement patients have 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.

The majority of patients in the CA region currently undertake HD in satellite units in either Alice Springs or Tennant Creek. While both satellite units are within the region, they are still hundreds of kilometres from the home communities of the majority of patients. The recent decision to dialyse patients only in their home states saw some Central Australians sent even further away to satellites units in Port Augusta, Adelaide, Kalgoorlie and Perth – most of which are over a thousand kilometres from home communities.

The majority of people we consulted indicated that, given a choice between Alice Springs and locations even further afield, Alice Springs was a better option for several reasons including:

- People’s existing connections to, and familiarity with Alice Springs – Alice Springs was “town”.

- Increased opportunities for family to visits and returning home for important business.
Familiar support systems especially their representative Aboriginal organisations which were important in maintaining connections with their families and communities.

Alice Springs’ significant Aboriginal presence and connections.

From a patient’s perspective, the first consideration for both health and treatment choices is whether it will increase connectedness to family and community i.e. which is the treatment that will get me home.

But I, it can take a long time for me to keep asking “Where’s Dr T, where’s Dr T, I want to go home”. Ask them Asian nurses and all, you know, “When are you going to let me go home?” Social worker [too] and the social worker used to tell me – “Mary, you don’t ask, you just sit down and wait for when there’s a space in Kalgoorlie, you can go home” - growl, growl! (IMPARK KA008)

Existing National Service Guidelines for the management of renal services in remote Australia recognise this and endorse the principle of providing treatment as close to home as possible.9 Early in their dialysis treatment period, some patients are under the misapprehension that dialysis might “cure” their kidney problems.19 Once stabilised on dialysis, patients come to realise that regular dialysis in the satellite unit is a permanent arrangement. Stakeholders reported this can be an opportune time to address alternative treatment options, including self-care therapies with the potential to conduct treatment closer to home.

3.9.5.1 Self-care Therapies

We want to learn (the treatments) and come back and be with our families because life is to be with our families – we people want to come back to the land, we’re connected to the country. ... When we’re in hospital we don’t feel free – there’s too many houses [in the town], too many cars. But here – we go out hunting, be with our kids, our families, our people. (Home haemodialysis patient, November 2010)

Self care therapies –PD and HD – are both actively promoted to suitable patients as means to move back to their home communities. The home-based therapies teams have dedicated teaching areas within or near the satellite unit in Alice Springs. They have developed specific, culturally-appropriate programs to teach patients and have a series of patient-friendly resources to support them. Being a dialysis patient in a home community is not without challenges, but it addresses the primary concern of patients to be reconnected to family and community. Dialysis patients consulted for this Study reported that their first preference was to have their dialysis in their home community or as near as possible. They confirmed the importance of family and home connectedness as the key criteria.

However, despite active promotion, and the opportunities to return home, currently those on self-care therapies comprise less than 10% of patients in the region, well below the national levels. There are 11 patients undertaking (or training in) self-care haemodialysis and nine undertaking PD. For self-care and community-based therapies, careful consideration of the supports that can be provided by community organisations is important. Such services can determine the effectiveness and sustainability of this treatment model.

A critical issue around self-care home therapies is the need to have a carer (or carers) within the family to support the patient. Carers reported carrying a considerable burden supporting their family and caring for a dialysis patient. Stakeholders indicated there are limited, if any, carer respite services. With all self-care therapies, service providers indicated concerns regarding the growth in needs of patients over time as they age and become frailer. These patients would likely need additional supports and services if they are to remain in their communities.
3.9.5.2 Peritoneal Dialysis

Although self-care therapies fulfil the key criteria (i.e. enabling patients to return home), other considerations regarding treatment uptake were communicated to the Study Team – particularly a patient’s perception of:

- The safety of the treatment.
- Their own capacity to carry out the treatment; and related to this.
- The suitability of the treatment for their home situation as they know it.

From the trainer’s viewpoint a range of specific criteria were reported including:

- The motivation and ability of the person to learn the technique.
- A minimum level of English literacy.
- Dexterity and reasonable eyesight,
- A suitable place to undertake the treatment.
- Identified support persons.
- Capacity to manage stores associated with the treatment.

Patients talked about their own network of information, including shared stories of other patients’ experiences. While patients who are doing PD themselves were enthusiastic in pointing out its benefits, the majority of patients spoken to in the IMPAKT study, and during consultation for this Study, were not well disposed to PD. There was concern about the number of infections, the permanent placement of the tube, and particularly perceptions of hyper-cleanliness required by this modality. Many felt it was beyond them.

_I was thinking see, I had friends and family was on it - they were older than me. They died, because they probably not cleaning themselves properly you know. I’d like it -but it’s too hard for me. Mmm, cleaning and changing yeah. Yeah, it’s too hard that way and you got to have nice clean house - no kids, little kids around –_

Q: Yeah, touching everything.

_That’s what I was thinking. Yeah, see I have three grandchildren now; sometime they with me all the time._

(IMPATK Study JD161)

_You have to have everything in a good condition for that – it’s no good for desert people, we’re not hygienical, and that - it’s got to be like in a hospital (Home haemodialysis patient, Nov 2010)._  

In Warburton, where there have been several long-term successful PD patients, there is a more positive attitude to PD from patients, local nursing staff and clinicians. Patients value the speed of returning to country (compared to remaining on metropolitan HD), and the mobility and independence once home. Those patients who were successfully doing PD in the community were receiving a range of support services from the local community. The overall impression of the Study Team is that much effort will be required to overturn negative perceptions of PD in the region.
3.9.5.3 **Self-care Haemodialysis**

Currently 11 patients are doing self-care HD in the region. Interestingly the majority are in communities that are within 100km of Alice Springs. Although a more demanding, and possibly intimidating technique to learn, self-care haemodialysis avoids the need to maintain a suitable treatment space within the patient’s home. Communities where people are doing self-care haemodialysis are provided with a secure, stand-alone treatment facility which patients are asked to manage. These facilities, the treatment parameters and the role of local health clinics and other services are the subject of formal memoranda of understanding. There has been varying levels of support indicated to the Study Team among local community services, including primary health services, for renal patients doing self-care haemodialysis in communities. Such support was reported to be important in helping patients sustain their treatment in communities.

3.9.5.4 **Nurse-supported Dialysis in Communities**

Community members and dialysis patients consulted for the review spoke positively about nurse-supported dialysis in communities. This is currently offered through WDNWPT. It is perceived to be stable, safe and reliable by patients and community members. Treatment at Kintore, for example, had enabled patients to be home and with families for periods of time. This had positive flow-on effects to the whole community especially when senior cultural and community figures returned. The clearest evidence of Aboriginal community support for this model is through the requests of three other non-Pintupi communities to WDNWPT for respite dialysis services in their communities.

Currently this is a respite model only. Patients do not remain in their communities permanently. Respite care does not impact the overall numbers of patients needing dialysis services in Alice Springs. Nurse-supported respite dialysis in communities also has the potential to evolve into permanent mini-satellite care, as is being implemented in the Kimberley. Other important considerations for nurse-supported respite dialysis raised to the Study Team include:

- The possible negative impact of nurse-supported dialysis on the uptake of (unsupported) self-care therapies.
- The likelihood of an increase in patients opting to take up dialysis (offered in their own community) who would have otherwise chosen not to take up treatment at all.
- The acute shortage of staff accommodation in remote communities.

3.9.5.5 **Transplant**

Aboriginal patients are significantly less likely than non-Aboriginal patients to get a transplant. There are challenges to increasing their likelihood of transplant particularly existing high levels of co-morbidity, poorer transplant outcomes, both in terms of degree and duration of graft function, substantially higher mortality rates and difficulty in predicting the post-transplant course based upon typically available biological and demographic measures.

Nevertheless Aboriginal patients themselves have a high interest in transplant and choose to have transplants. In the IMPAKT study, over 150 Aboriginal dialysis patients – primarily remote area patients – were asked about their interest in transplant. Only ten were either not-interested or definitely against the idea. Transplant appealed because it is a treatment that can potentially return people home and give them back a ‘normal’ life:

*If I could get one, maybe, I’m happy to go back home* (IMPAKT interview 3-009)

*I’d be happy to get up and move around and do things* (IMPAKT interview 4-016)
Why do I want to get one [transplant]? *Because of my health, I don’t want to suffer the whole time. I don’t want to be in a sick state, I want to get back to normal, get a kidney and get back on with life. I don’t want to suffer too long, that’s what it’s all about, getting a new kidney, that you can move on from that and just to not to be on [it] too long.* (IMPASKT JD178)

Patients’ comments suggested some discomfort about the origin of transplanted kidneys and misgivings about taking another person’s organ. Many reported difficulties discussing the topic with family members and other non-patients. Some Aboriginal health workers expressed surprise and curiosity that Aboriginal patients were so interested in transplantation. Where patients met reservations from their family, most were prepared to negotiate acceptance of their decision.

*And I’ve talked to people from outside, like, who’s got good kidneys, and they said, Don’t go on it, don’t put yourself on the list. And they kept talking me the other way. It’s a one-way thing, they say, if you have an operation, you’re finished, that’s it. They refusing me [to do it]. They don’t like the idea, especially the family… I’m keen to have it, I’m excited to have it. They told me, Oh, you’re going to be away for a long time in hospital… I said that’s alright.* (IMPASKT 3-086)

From the patient perspective, people who are not on dialysis are unable to fully understand the position of the patient and the opportunity, rather than the danger, that transplant presents.

Currently, patients though to be suitable for transplantation by their caring nephrologist in Alice Springs are referred for assessment by a team from the SA Renal Transplant Service. A nephrologist and transplant surgeon visit Alice Springs to perform these assessments. Patients from the CA region, whether from WA, NT or SA, are treated equally in the allocation process. Considerable discussion has occurred recently about addressing the barriers to successful transplantation. However, progress in this field has been limited. From the perspective of the Central Australian region, transplantation is likely to remain an option for only a minority of people and is not likely to impact on the numbers of people requiring dialysis treatment over the next 5 years.

### 3.9.5.6 Managing Treatment Requirements

In the context of Aboriginal dialysis patients the term ‘compliance’ (used only by staff) most often refers to whether or not patients actually attend dialysis. Not surprisingly, Aboriginal patients do not think of, or describe themselves, as ‘non-compliant’, and their reported rationale for missing dialysis on any given day might include:

- The urgency of dialysis relative to the totality of issues they are grappling with.
- Negative personal social/emotional states including anger, depression, loneliness.
- Need to return home to attend to family or cultural business.
- Chaotic domestic and family life.
- Beliefs that their well-being is better served by doing something else (going home, meeting family etc).
- Alcohol and/or drug issues – their own or someone else’s.
- Disbelief that missing a treatment that is (overall) regular and continuous is risky.

One renal patient told members of the Study Team that “[it] would be worth it [to return home and miss some dialysis] because it would open my heart and spirit to get there… I’m battling to get back.”
Patient and family commentary also suggests that poor levels of understanding, including understanding of the real levels of medically assessed risk, is also a contributor. This is not to say that ultimately, some patients, with full knowledge of potential consequences, will not miss dialysis. Aboriginal patients, like any renal patients, may also make poor decisions.

Patients’ motivation to manage dialysis requirements is also strongly influenced by their experiences in the dialysis program and in the unit itself, including the quality of patient-staff relations and patients’ perception of their treatment. “Is it a unit that welcomes patients and provides culturally appropriate care?”

The experience of the Kimberley Satellite Dialysis Centre, operating since 2002 and recently reporting that patients’ adherence to care (dialysis prescription adherence and meeting clinical targets) has been excellent suggests that factors contributing to their success include:

- A sense of ownership/involvement patients have 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.

The Alice Springs renal unit Social Worker reported that a task that occupies a significant part of his time is tracking people who miss dialysis. He is available to the renal unit for 0.8 FTE and supported by an Aboriginal Liaison Officer. With over 150 renal patients in Alice Springs, of whom at least 30% are living in the most tenuous circumstance with no permanent stable accommodation, stakeholders indicated they thought it was predictable that patients will have difficulties committing to the dialysis regimes. Consultation revealed little evidence of coordination in addressing the social and cultural needs of dialysis patients either in Alice Springs or over the cross-border region.
3.10 Safety and Quality

3.10.1 Service Risk from Key Perspectives

Key Findings

- Evidence indicates that providing renal services in remote communities is not in itself dangerous.
- Key stakeholders 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 Indigenous 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.

Key decisions regarding uptake and adherence to treatment relate to whether it might increase connectedness to family and community. With growing evidence that providing renal services in remote communities is not in itself dangerous, combined with clearly expressed views regarding the need for renal services to delivered close to communities, options for how such treatment can be provided in a safe, cost-effective and sustainable manner have been discussed.

The benefits, risks and potential solutions in relation to each of the treatment modalities considered as options for bringing people closer to home – self-care haemodialysis, peritoneal dialysis, nurse-supported haemodialysis in mini-satellites and mobile dialysis – were explored in Section 3.2 and represented in Tables 10 and 11. Feedback from key stakeholders and a review of relevant policy documents indicated the need to give appropriate attention to the following key issues to underpin the safety and quality of service delivery:

- Phased implementation of new models of service delivery with rigorous evaluation of cost-effectiveness, sustainability and determination that care is being delivered in a manner that meets the clinical, social and cultural needs of patients.
- 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 Indigenous 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 Australia9 – 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 and the development of new and more central roles in renal service provision for general practitioners, Aboriginal Health Workers and Enrolled Nurses.
3.10.2 Quality/Accreditation Requirements by Jurisdiction

Key Findings

- The National Service Guidelines for the Management of Dialysis and Kidney Transplantation in Remote Australia have established a solid basis upon which to build an agreed, evidence-based set of standards against which the performance of renal services could be measured.

- Stakeholders 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.

At the request of Health Ministers, the Australian Commission on Safety and Quality in Health Care has developed a set of draft National Safety and Quality Health Service Standards to be applied across all setting of health care delivery. Accreditation, a process of regular assessment and review to determine whether a health service has met agreed standards in service provision, aims to provide a public marker of safe and high quality care and support community confidence in the healthcare system. In the area addressed by this Report, the National Service Guidelines for the Management of Dialysis and Kidney Transplantation in Remote Australia have established a solid basis upon which to build an agreed, evidence-based set of standards against which the performance of health services could be measured. This Report considered key health outcome indicators across the spectrum of CKD (Section 3.4.3) which might provide the core of a set of key indicators against which renal services could be monitored. As part of addressing the growing burden of CKD in Central Australia, the potential role for new models of service delivery and alternative workforce models has been explored. Implementation of such new models of care would need to take cognisance of these national reforms in accreditation and reforms in licensing especially as they relate to alternative workforce models.

Stakeholders consulted by the Study Team raised a number of key issues:

1. 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 renal services.

2. The need to review whether new models for renal service delivery within communities are covered by licensing requirements in each of the jurisdictions.

3. The need to build upon work already undertaken through the development of the National Service Guidelines for the Management of Dialysis and Kidney Transplantation in Remote Australia.
3.11 Sustainability

3.11.1 Stakeholder Engagement and Support for Service Models

Key Findings

- The need for collaboration in planning, resource allocation, monitoring and evaluation of the outcomes of service delivery was emphasised to the Study Team.

- In particular, engagement of local community leadership, community organisations and healthcare providers, with renal services and governments, was requested in relation to exploring and implementing short-term solutions for providing renal services closer to home.

People consulted during the Study underlined the need for broad stakeholder engagement. The need for collaboration in planning, resource allocation, monitoring and evaluation of the outcomes of service delivery was emphasised to the Study Team. In addition, engagement of local stakeholders was seen as critical to underpin the sustainability of renal services in remote communities. The Study Team note the pivotal role of the Tri-State Forum in efforts to develop a planned and strategic approach to renal patient management in the cross-border region and would suggest this forum be re-invigorated to underpin sustainable development of renal services.

The ability to sustainably implement policy regarding new models of service delivery and for patients, their families and communities to foster and benefit from these initiatives is discussed in some detail in other sections of the Report. Section 3.3 explores staffing and infrastructure requirements. On the basis of extensive consultation and case examples of innovative approaches to building workforce and community capacity, the Report makes a series of recommendations regarding how remote area renal service delivery might be sustained. Section 4 emphasises the critical need to understand and address the social, economic and cultural issues which shape how Aboriginal patients in the CA region make decisions regarding uptake and utilisation of renal services. This again fundamentally impacts sustainability of health service delivery and is reflected in a recommendation in this section of the report suggesting the Central Australian Renal Family Wellbeing Action Taskforce should report directly to the Tri-State Forum, the body proposed as having responsibility for service planning and oversight.

Communities in the APY and Ngaanyatjarra Lands argued strongly for priority to be given to addressing the needs of their renal patients, many of whom are currently required to move away to Adelaide or Perth to access care. This dislocation, stakeholders suggested, exacerbates the social and cultural problems faced by patients from the region. Engagement of local community leadership, community organisations and healthcare providers, with renal services and governments was requested in relation to possible short-term solutions, including using the mobile bus to enable respite dialysis on the Lands and also to examine the appropriateness of some already identified facilities for dialysis within communities. Here, as in all part of the CA region, engagement of all key stakeholders would seem essential for the delivery of sustainable solutions for patients and their families.
3.11.2 Reform to the Hospital and Primary Healthcare Landscape

**Key Findings**

- Stakeholders strongly supported a regional approach to renal service delivery in the cross-border areas of Central Australia, with its hub in Alice Springs.

- Current national reform processes in relation to the National Health and Hospitals Network Agreement (NHHNA) and Primary Health Care Organisations (PHCOs) are of central relevance.

- In particular, the NHHNA indicates that, noting the benefit of providing effective service models for ‘communities of interest’ that cross State borders, at the request of States, arrangements for cross-border LHNs may be agreed with the Commonwealth.

Stakeholders strongly supported a regional approach to renal service delivery in the cross-border areas of Central Australia, with its hub in Alice Springs. This is consistent with the expressed views of patients and communities, and was reported as the best way to facilitate the development of a service that could comprehensively meet the clinical, social and cultural needs of renal patients. In this context, current national reform processes in relation to the National Health and Hospitals Network Agreement (NHHNA) and Primary Health Care Organisations (PHCOs) are of crucial importance.

The Study Team note the following objectives stated within the NHHNA document, which are of particular relevance to delivery of renal services in the CA region:

- LHNs will provide an effective means of engaging with the local community and local clinicians to incorporate their views (Objective A3).

- In regional Australia, a flexible approach will be adopted to determine the regional, rural and remote network structure that best meets the needs of these communities (Objective A6 e).

- Noting the benefit of providing effective service models for ‘communities of interest’ that cross State borders, at the request of States, arrangements for cross-border LHNs may be agreed with the Commonwealth (Objective A6 f).

The NHHNA document also discusses the need to harmonise LHN boundaries with those of new PHCOs. Decisions regarding LHN structure and boundaries and harmonisation with PCO structure and boundaries will have crucial implications for planning and implementing a renal strategy in the CA region.
References


