

**National Service Standards
for Remote Area Access to
Dialysis and Transplantation Services**

DRAFT

National Standards for Remote Area Access to Dialysis and Transplantation Services

AIM: To improve access to and choice of services, reduce inequalities and enhance the quality of dialysis and transplantation services available for Aboriginal and Torres Strait Islander Australians residing in remote and rural areas.

Background

Remote area renal services for Aboriginal and Torres Strait Islander Australians were identified as an important area for reform by clinicians, bureaucrats and non-government representatives in the Health Reform Agenda discussions in 2002 associated with the renewal of the Australian Health Care Agreements. This issue was subsequently included as one of the items in the National Health Reform Agenda. The national importance of this work, with its specific focus on Aboriginal and Torres Strait Islander people requiring remote area renal services continues to be recognised.

Kidney disease is a significant health burden for Aboriginal and Torres Strait Islander Australians, and particularly for those who live in remote areas. While recognising that prevention of chronic diseases such as kidney disease is of critical importance to reducing this burden, this project has focused on the development of strategies which will facilitate the holistic care of Aboriginal and Torres Strait Islander people living in remote areas of Australia who require renal replacement services.

Principles and strategies

In 2004, a comprehensive review of the current status of access to renal services for Aboriginal and Torres Strait Islander Australians with end stage kidney disease living in remote areas was undertaken. This included consultation with a broad range of stakeholders, including service providers of remote area renal services. This work informed the development of a range of principles and strategies to improve access to renal services for Aboriginal and Torres Strait Islander Australians living in remote areas.

Governments endorsed the principles and approved the strategies listed below to improve access to renal services for Aboriginal and Torres Strait Islander Australians living in remote areas in July 2005. Feedback to date has indicated that the principles and strategies are relevant and meaningful to clinicians and administrators.

The strategies are consistent with the principles proposed to guide the development and operation of remote area renal services for Aboriginal and Torres Strait Islander Australians living in remote areas. These principles are:

- Prevention and management of chronic kidney disease requires the provision of effective primary health care services;

- Planning for remote renal services requires recognition of the unique needs and disadvantaged circumstances of remote communities and their impact on service delivery;
- Planning for remote renal services requires a focus on local needs, workforce, flexibility, accountability and whole of government collaboration at the regional level;
- All jurisdictions will work towards improving access to all modalities of renal replacement therapies for people living in remote areas;
- Renal dialysis treatments should be available as close to home as possible;
- Transplantation is the optimal treatment for appropriate patients; and
- Aboriginal and Torres Strait Island consumers and communities should participate in the planning for remote renal service provision.

The strategies are:

- A national consensus document on service standards for remote area renal dialysis and transplant services should be developed for consideration by jurisdictions. Existing performance frameworks should incorporate performance measures that reflect these service standards;
- Jurisdictions through their Aboriginal and Torres Strait Islander Health forums and advisory mechanisms should ensure that there are increased levels of local community engagement, decision making capacity and advocacy opportunities for communities and consumers in remote renal service development;
- Jurisdictions take into account current and anticipated need for independent, in-community dialysis in the planning, design and establishment of new (and refurbished) health facilities in remote communities;
- Jurisdictions will endeavour to ensure that the primary health care workforce has sufficient expertise to provide a supportive, local clinical environment for patients on renal replacement therapy;
- Specific mechanisms to develop and sustain the specialised multidisciplinary renal workforce should include:
 - Relevant Aboriginal Health Worker competency development and implementation is progressed and consistent with the service standards;
 - Referral of the need for a non-medical renal workforce outreach support program (similar to the Medical Specialist Outreach Assistance Program) to the AHMC National Rural Health Policy Sub-committee for their consideration;
 - Ensuring that the outcomes of the review of access to specialist services being conducted by the AHMC National Rural Health Policy Sub-committee provide for improved access to general physicians with particular expertise in diabetes, cardiovascular disease and kidney disease;
 - Increasing the number of Aboriginal and Torres Strait Islander people working across all the health professions which form part of a renal services team; and
- The work of Australians Donate to maximise the kidney donation rate should be supported, particularly initiatives which will increase the availability of donor kidneys for Aboriginal and Torres Strait Islander clients.

It is recognised that some of the strategies have a practical focus, while others address broad issues. The strategies can broadly be considered in three categories, and Health Ministers have agreed that the strategies may be progressed according to these categories:

- those which are a matter for individual jurisdictions. These include the strategies proposing engagement with and employment of Aboriginal and Torres Strait

Islander people, planning of facilities and nurturing an effective Primary Health Care workforce.

- those which are pertinent to current deliberations of other AHMAC subcommittees and related organisations. These include the strategies regarding the specialised multidisciplinary workforce and kidney donation.
- those which require national collaboration to develop consensus on a specific issue. This is best exemplified in the strategy proposing the development of Remote Area Renal Service Standards (which is the focus of this paper). These standards will facilitate national consistency while still enabling jurisdictional flexibility in their implementation.

The Standards

Development and Refinement

A consensus document for remote area renal service standards, encompassing not just clinical care, but other features of a holistic approach to managing end stage kidney disease, including client and family education and support is being developed. A small cross-jurisdictional Government Technical Working Group (TWG) has prepared a preliminary draft of these standards. Membership of the TWG is on the basis of expertise in remote area renal services, and experience of working with Aboriginal people; it includes both clinicians and administrators.

The intent of the standards is to improve communication and consistency, and through the promotion of best practice and a strategic approach to developing integrated services, to minimise risk, improve patient outcomes, and increase efficiencies. This will be evaluated through the inclusion of indicators and performance measures within the standards.

The TWG is consulting with a wide range of remote health and renal service providers, including relevant government health service providers, the Aboriginal Health Community Controlled sector and relevant professional groups about the development of these standards. This draft service standards document is being distributed by the TWG widely within their jurisdictions, the feedback collated and further refinement of the document undertaken.

A workshop will be held in early 2006 to work through the issues raised, and to finalise the proposed standards (it is anticipated that the service standards will be submitted for approval to Health Ministers mid 2006). Stakeholders identified through the preliminary consultations for both the service standards and the broader project, and from both the government and non-government sector will be invited to this workshop. A briefing on the progress of the overall project will also be included on the agenda of this workshop.

Format

The format of the standards is based on a hybrid of publicly available national and international Standard and Guideline documents. Its intent is to be a document that is clear, concise and readily accessible for service providers, clinicians and the public. It incorporates a Resource Capability Matrix to separate levels of service providers dependent on available resources.

The Standards cover the four areas of clinical services

1. Chronic Disease Management
2. Access to haemodialysis treatments
3. Access to peritoneal dialysis treatments
4. Optimise access to and outcomes for Renal Transplants

Within each area “markers of good practice” identify practices that address the issues of access, education, clinical process, infrastructure, workforce capability and sustainability, cultural safety and client and family support.

The markers of good practice are aligned with the resource capabilities of service delivery areas and are guided by the Resource Capability Matrix. This matrix provides a guide for the infrastructure necessary to deliver and support renal services in rural and remote locations. The term “Levels” are used for ease of identification of service delivery areas rather than to denote role delineation within hospitals or their service capability levels.

In addition, in order to provide a number of formatting options for how the standards can be presented, the “markers of good practice” have been reallocated to one of the four service delivery areas

- Primary Health Care
- Rural and Remote Dialysis Units
- Regional Dialysis Units
- Tertiary Renal and Transplantation Units

The intention of this format is to provide a ready guide for service delivery areas on the necessary activities and infrastructure required for their facility in order to meet the standards.

Other options for the standards have been suggested and include reorganising markers under the following headings

1. infrastructure,
2. workforce,
3. resources,
4. partnerships,
5. practices

Feedback is necessary to determine which format is the most useful and instructive.

Further information

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Glossary

Access: refers to the creation of a fistula, insertion of a Tenckhoff catheter or subclavian catheter to enable dialysis to take place.

ALO: Aboriginal Liaison Officer whose role is to provide the cultural bridge between Aboriginal and Torres Strait Islander Australians and the largely non-Aboriginal and Torres Strait Islander health care workforce.

Buddy: Person who provides assistance to the client in delivering their dialysis treatment. Usually spouse or family member but can be anyone committed to the client.

Centre: interchangeable with Facility or Unit and refers to the building the service is run from.

Chronic Kidney Disease (CKD): a condition involving deterioration of renal function, which may develop over short or long time frames

Community-based Dialysis: refers to self-care haemodialysis undertaken in any space within a remote/rural community, including home, clinic, dedicated facility or other allocated space. It usually refers to single client set-ups but may include a group of people undertaking self-care dialysis and sharing machines.

Dialysis: the process of removing the body's metabolic wastes and excess fluid that would normally be carried out by the kidneys. The two forms of dialysis are haemodialysis and peritoneal dialysis.

District Medical Officer/General Practitioners (DMO/GP): interchangeable terms referring to the medical support being provided in the area

Donor: Refers to the person donating an organ. Cadaver donor is from someone who has died but had consented previously to donating his or her organs. Live or living related donor is from someone with a compatible blood group to the receiver who has consented to donating a kidney. Although it is usually a family member, live donors are no longer restricted to blood relations.

End Stage Kidney Disease (ESKD): the final stage of renal disease where remaining kidney function is less than 5% of normal kidney function and renal replacement therapy is required to sustain life.

Fistula: the surgical joining of an artery and a vein usually in the lower arm, to increase circulation through the superficial venous veins to make them larger and stronger. This allows easier access for needles in order to perform haemodialysis.

Haemodialysis (HD): involves pumping the blood through an external circuit and artificial kidney in order to filter out the waste products before the blood is returned to the body. People on dialysis usually attend treatment three times a week for a minimum of four hours per treatment.

Home-based Dialysis: refers to a client undertaking dialysis in their home with the partial or complete assistance of a buddy or carer. Home based dialysis can be either peritoneal (PD) or home haemo-dialysis (HHD).

Home Training Unit: refers to hub, facility or point of contact for staff responsible for the training of patients wishing to undertake home therapies and also the ongoing management of the same patients once they are at home or in their communities.

In-centre Dialysis: Refers to a unit within a hospital and implies greater input from the renal team and access to tertiary referral services.

Peritoneal Dialysis (PD): a form of dialysis that uses the peritoneal membrane in the abdomen as the filter to remove the wastes and excess fluid that would normally be removed by healthy kidneys.

Continuous Ambulatory Peritoneal Dialysis (CAPD): involves the regular exchange of 2-3L of fluid via a surgically inserted abdominal tube four to five times a day.

Automated Peritoneal Dialysis (APD): the use of an automated machine to warm, deliver and drain the necessary fluid volume over a set number of hours.

Primary health care (PHC): refers to the first point of continuing health care, usually provided by nursing and health worker staff in community health clinics supported by visiting medical staff.

Relocation: refers to a patient transferring from their normal place of residence to a regional centre for an indefinite period in order to access treatment.

Renal Unit: refers to a facility, which offers a range of renal services other than dialysis. These may include investigations and management of renal disease, surgical intervention and preparation for treatment and transplantation.

Renal Replacement Therapy (RRT): a form of treatment that replaces the functions of the kidneys and can be haemodialysis, peritoneal dialysis or transplantation.

Satellite Service/Centre/Unit/Facility: refers to a facility managed by a parent hospital where people come as outpatients to access dialysis services. Satellite services usually accommodate more than 4 clients and are staffed. A satellite facility can either stand-alone or be within an established facility.

Self-care: refers to the ability of a client to attend to his or her own dialysis treatment without specialist supervision or intervention and includes PD, APD and HHD.

Transplantation (Tx): the process of removing a functioning kidney from a donor and placing it in the abdomen of an appropriate recipient. Transplantation is a treatment and not a cure and involves taking medications for the rest of the recipient's life.

Pre-emptive Transplantation: refers to providing a functioning kidney transplant for someone who has renal disease but has not yet started dialysis therapy.

Telemedicine: phone, video or computer communications for the purpose of facilitating patient care.

Resource Capability Matrix

Level	Capability	Resource profile
Primary Health Care Service	<ul style="list-style-type: none"> • Early CKD identification and evidenced based best practice management for patients in remote and rural areas with systems for timely referral to Nephrologist, • Able to meet the primary health needs and oversee the delivery of renal medications for community members undertaking RRT in conjunction with main referral centre. • Awareness, understanding and ability to support dialysis patients in attaining and retaining transplant waiting list status. 	<ol style="list-style-type: none"> 1. DMO, RN, AHW, 2. Visiting Nephrologist, CKD, HDD, PD and Tx nurses 3. Sound and reliable communication pathways, including phone/fax, Internet and telemedicine, 4. Access to patient travel for completion of tests and access creation
Rural/remote Dialysis Units (Level 1)	<ul style="list-style-type: none"> • Provide maintenance haemodialysis services. • In conjunction with main referral centre offer support to patients living in area who are undertaking RRT • Assist with organisation and completion of transplant work up for patients dialysing in area. • Facilitate regular patient reviews by multidisciplinary renal team 	<ol style="list-style-type: none"> 1. Renal trained RN, EN, AHW plus VET accredited locals 2. As per 2 under PHCS plus visits/input from SW/ALO, dietitian and access nurse 3. As per 3 and 4 under PHCS, 4. Access to renal training and ongoing educational support, onsite visits by Educator and rotation to level 2 & 3 unit 5. Culturally appropriate educational resources
Regional Dialysis Units (Level 2)	<ul style="list-style-type: none"> • As for Level 1 plus • CKD monitoring and intervention through multidisciplinary management care plans and community education • Patient and family education and training in modalities of choice • Patient relocation and support on home therapies • Facilitate transfer to tertiary centres for those requiring higher levels of service support in consultation with multidisciplinary team 	<ol style="list-style-type: none"> 1. As for Level 1 plus 2. Access to qualified Interpreters 3. Access to Allied Health - SW/ALO, Dietitian, psychologist 4. Access to CKD, PD, Tx and HDD educators 5. Adequate and appropriate space for home training units 6. Systems and staff to support remote home therapies - funding for regular community visits, accommodation and TA
Tertiary Renal Units Level 3	<ul style="list-style-type: none"> • As for Level 2 plus • Access to pre-emptive and vascular surgery • Access to imaging and interventional radiology • Transplant work up and post transplant care • 24hr Acute Dialysis and Nephrologist on call • Accreditation for Advanced Nephrologist trainee • Renal staff training 	<ol style="list-style-type: none"> 1. As for Level 2 plus 2. Nephrologists at recommended level - 1:50 /dialysis patient 3. Theatre time and surgeons experienced in access creation 4. Access to accredited renal courses 5. Allied health staff at benchmarked ratios – CKD 1:80 (Canada), SW/ALO 1:50 (CNSW), Dietitians 1:150 (NKF), Psychologist 1:3000 (WA) OT 1:600 (WA/NT),

		<p>Pharmacist 1:500 (W/A/NT) Adjusted for ethnicity, social disadvantage and increased co morbidities – awaiting further data</p>
<p>Transplantation Services</p>	<ul style="list-style-type: none"> • All of above plus • Transplantation services 	<ul style="list-style-type: none"> • As for level 3 plus • Full transplantation team (Nephrologist, Tx Surgeon, Tx Nurse, Donor Coordinator, Psychologist, Immunologist)

Standard One **Chronic Disease Management**

<p>Aim</p>	<p>To ensure people receive timely and appropriate education, nephrology referral, medical and surgical management to minimise disease progression and complications and allow the patient and their families to make informed and supported decisions regarding renal replacement therapy.</p>
<p>Rationale</p>	<ul style="list-style-type: none"> ○ The burden of chronic diseases is greater in Aboriginal and Torres Strait Islander Australians but there is also a significant difference between urban and remote populations – the latter suffering excessive rates of kidney disease. The cost of managing chronic diseases is high not only for health services but also for family and communities in terms of decreased education, disrupted employment opportunities and social engagement and an increase in the need for carers. Kunitz et al 1995, Weeramanthri et al 1999, WA DoH 2001, ACDDPA 2004, Access Economics 2003, NRHP report to AHMAC 2002, McDonald et al 2003, Cass et al 2004, Begley et al 2005. ○ Earlier identification and management reduces morbidity and mortality and promotes treatment choice and resource utilisation. Renal Outreach programs that support the primary health care area in identification and management of renal disease have significant benefit. Levin 2000, Hays 2002, Crawford et al 2002, Pogue et al 2002, KHA 2004, O'Sullivan et al 2004, Hoy et al 2005, Thomas 2005. ○ Multidisciplinary management for Aboriginal and Torres Strait Islander Australians relocating for treatment is necessary to improve outcomes through the promotion and improvement of psychosocial preparedness for treatment. Wilson et al 1994, Levin et al 1997, Gruen et al 2002, Goldstein et al 2004, Curtis et al 2005. ○ Undetected mis-communication between health professionals and Aboriginal and Torres Strait Islander people occurs frequently. Poor understanding is linked to reduced uptake of services and sub-optimal disease management and therefore poor outcomes. Bennett et al 1995, Hoffman 1997, Devitt et al 1998, Lawrie 1999, Williams 1999, Trudgeon 2000, Cass et al 2002, Lowell et al 2005, Coulehan et al 2005. ○ Under-served and vulnerable populations such as Aboriginal and Torres Strait Islander Australians living in remote areas, are at greater risk of adverse health outcomes. Effective information and communication technology can improve outcomes through increased access to health services, cost-effective care, educational opportunities and enhanced social support. Hovenga et al 1998, Mun et al 1999, Chang et al 2004, Jennett et al 2003.

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Level	Markers of good practice
PHCS	<ul style="list-style-type: none"> • Screening and recall system in place for chronic diseases • Guidelines for renal disease screening of at risk people available in unit • All known chronic kidney disease patients are referred to nephrologist at GFR of less than 30mls or at current minimum standards. • 12 monthly staff kidney disease education attended through chronic disease educational programs or similar (GP /KCAT programs/Chronic Disease Nurse) • Established links to renal units and Nephrologists for support and development of CKD management plans. • Algorithms developed locally in conjunction with renal units, support management plans. • Primary health staff (PHS) are able to coordinate patient care utilising a number of communication methods – telemedicine: video, phone, fax and computer. • Interpreter services are available to assist with patient consultations • Refurbished or newly designed community clinics include designated dialysis areas with appropriate plumbing and electrical services in anticipation of future dialysis needs. • Surgical intervention for access creation in pending patients on site is supported.
Rural/remote dialysis units Level 1	N/A
Regional Dialysis Units Level 2	<ul style="list-style-type: none"> • Renal staff are able to offer education to local community health centres on CKD management and treatment modalities. • Renal unit staff provide link between nephrologists and PHC in CKD management of patients and implementation of multidisciplinary care plans. • Aboriginal Liaison Officer (ALO) positions are in place to facilitate the transfer of pending patients to urban area. • Management plans utilised include actions related to housing needs, support services, schooling and finances in urban area. • Culturally appropriate and locally designed educational material is developed to cover pre-dialysis management, modalities and treatment preparation including education on pre-emptive transplant therapy. • Interpreter services are used to assist with education and preparation for treatment through telemedicine (phone or video)

	<ul style="list-style-type: none"> Where it is not available locally, regular visits by multidisciplinary team occur and include Nephrologist, Dietitian, Social worker, nurse educator, PD, Tx and CKD nurse to update, educate staff and review pending patients.
<p>Tertiary Renal Units Level 3</p>	<ul style="list-style-type: none"> Established multidisciplinary renal outreach team including nephrologist, CKD nurse, Dietitian, social worker and ALO. Access to further Allied Health Services as needed eg psychologist, occupational therapist and physiotherapists Culturally appropriate educational material around CKD management, treatment options and requirements developed in formats and languages to suit local needs. Management plans implemented include surgical review, access planning, assessing and establishing social supports and access to Interpreters. Working relationships with surgical teams and primary health services support creation of uncomplicated vascular access in remote/rural areas. Telemedicine is available to improve and increase support of the PHC area in management of patients with CKD. 100% of all known CKD patients have dialysis access created prior to commencement of dialysis. Pre-emptive transplantation should be investigated and encouraged for all known CKD patients. Travel costs for patient and escort and hostel accommodation is organised to cover investigations, access creation and preparation for relocation to urban area. Appropriate imaging is available for assessment and planning of access. Databases are maintained for pending patients with stage of disease, management plan and actions.
<p>Transplantation Services</p>	<p>As for Level 3</p>

Standard Two	Access to Haemodialysis Treatments
Aim	Renal Services will offer haemodialysis treatment in environments that have been designed around patients' clinical, social and cultural needs, at home or as close as possible to people's homes.
Rationale	<ul style="list-style-type: none"> ○ Providing access to home dialysis or treatments closer to home has been shown to improve health and quality of life outcomes. Patients are more likely to return to work, engage in social and community activities utilising the flexibility to attend treatments at a day and time of their choosing. De Vecchi et al 1999, Gorham 2000, Kneipp et al 2004, Lynn et al 2005, Blagg 2005, ○ People required to relocate hundreds of miles for treatment suffer social and emotional dislocation, are financially disadvantaged and lack the family and community supports necessary to engage in disease management and treatment uptake. Wilson 1994, Devitt et al 1998, Gorham 2001, Villarba et al 2004. ○ Home based therapies regardless of location are less expensive than satellite or incentre dialysis but patients, families and community members require appropriate education and ongoing support. Goeree et al 1995, De Vecchi et al 1999, Griffin 1999, Lee 2002, Blagg 2005 ○ Community consultation, negotiation and education (clinic, council and traditional owners), prior to establishing home and/or community based therapies, is necessary to engender appropriate levels of support for the patients. Wakerman et al 1998, Arthur et al 2000, Reath et al 2002, Villarba et al 2004, Kneipp et al 2004, Gorham et al 2005. ○ Culturally appropriate education is necessary to improve understanding, uptake of services and outcomes. Bartlett 1995, Assal et al 1995, Devitt 1998, Coulehan 2005. ○ Access to effective information and communication technology can reduce isolation and improve support for both patients and local service providers through increased access to specialist and linguistic services, improved educational opportunities and cost-effective patient management. Hovenga et al 1998, Mun et al 1999, Chang et al 2004, Jennett et al 2003.

Level	Markers of Good Practice
PHCS	<ul style="list-style-type: none"> PHC staff are aware of patients undertaking home-based therapies in the community, have access to specific and appropriate protocols and in conjunction with renal services are able to assist the patient manage their treatment (including primary health care, medication dispensing, preparation and delivery of blood samples). PHC staff have access to an established educational program on RRT – choices, consequences and patient support required. PHC staff maintain good communication links (telephone, email, video conferencing) with Home Training Unit nurses for the monitoring and support of HD patients in the community
Rural/remote dialysis units Level 1	<ul style="list-style-type: none"> Units provide high quality maintenance haemodialysis services including regular reporting against CARI guideline's clinical indicators (adequacy, access evaluation, clinical parameters) as part of quality improvement process. All staff delivering haemodialysis treatments will have completed at least one unit of theory in an accredited renal course as well as a practical placement in a regional or urban renal unit. All staff will have access to and receive ongoing renal education at least three monthly (Journal club, Industry developed educational packages, inservices and demonstrations). Staff will be assessed yearly by a qualified Renal Nurse Culturally appropriate and locally produced educational resources are available around disease and treatment management Local Aboriginal and Torres Strait Islander people are employed in the unit in a variety of positions. Local Aboriginal and Torres Strait Islander people are offered and supported to complete specialised renal training through VET or higher education courses. Renal staff are aware of patients receiving home based therapies in community and have access to protocols after hours in order to assist with trouble shooting. Respite for home and community based haemodialysis patients is offered in unit. Centrifuge is available to spin bloods Staff and patients have access to appropriate electronic and internet facilities as well as to suitably trained interpreters to facilitate patient reviews, consultation and education. Staff facilitate regular patient reviews by multidisciplinary renal team either onsite or via telemedicine.
Regional Dialysis Units	<ul style="list-style-type: none"> As for Level 1 plus Regional dialysis units are established in areas where the need for local people to relocate to the urban area for treatment is significant. These units should be promoted for stable patients and staffed by trained

Level 2	<p>local people who are supervised by a minimum of renal trained registered nurses.</p> <ul style="list-style-type: none"> • Larger regional units may have access to staff and patient training and development programs that include: <ul style="list-style-type: none"> • Space available for staff teaching sessions, inservices and practical demonstrations. • Home and self-care training programs designed to meet the needs of the local people in terms of numeracy, literacy and cultural appropriateness. • A dedicated self-care trainer with appropriate qualifications and experience in training and cultural awareness. • Adequate and appropriate space allocated for patient training away from main treatment area. • Qualified interpreters with medical terminology facilitate education and development of educational material. • Access to travel and accommodation for the buddy to undertake training. • Community consultation and onsite visits carried out in preparation for home and community-based dialysis. • Memorandum of Understanding developed with community councils, clinics and landowners to determine and agree on treatment site, support and services provided to patients returning to community. • Local guidelines for space, infrastructure and operational issues for home and community-based haemodialysis which cover criteria for storage space, deliveries, tanks, pumps, chillers and phone lines. • The provision of a minimum of 6 monthly home visits for patients on home based therapies to evaluate environment, and provide patient, family and PHC staff education.
Tertiary Renal Units Level 3	<ul style="list-style-type: none"> • As for Level 2 and Standard One Level 3. • Home and Community-based dialysis is promoted and supported for all people able to either independently or with assistance, undertake their dialysis treatment without clinical supervision. • Communication protocols are established with PHC to regularly discuss patient assessment, medication and management issues including discharge summaries. • Telemedicine is utilised extensively to communicate with smaller and regional units for patient consultations and staff education.
Transplantation Services	As for Level 3

Standard Three	Access to Peritoneal Dialysis Treatments
Aim	Renal Services will promote peritoneal dialysis including automated peritoneal dialysis to patients deemed clinically and socially suitable by offering appropriate levels of training and ongoing support in the remote regions.
Rationale	<ul style="list-style-type: none"> ○ Peritoneal dialysis (PD) offers the best opportunity for people to return to their communities with minimal infrastructure, cost and supports. Carruthers et al 2004, Lim 2004, ○ PD is often not the treatment of choice for the majority of Aboriginal and Torres Strait Islander Australians with renal disease from remote or rural Australia. McDonald et al 2003, Tonelli et al 2005, ○ Regular onsite visits to assess patient technique, review procedures and provide family, community and health staff education are necessary to provide adequate and appropriate support for isolated patients. Griffin 1999, Carruthers et al 2004, Lim 2004. ○ Culturally appropriate education is necessary to improve understanding, uptake of services and outcomes. Coulehan 2005, Devitt 1998, Bartlett 1995, Assal et al 1995 ○ Access to effective information and communication technology can reduce isolation and improve support for both patients and local service providers through increased access to specialist and linguistic services, improved educational opportunities and cost-effective patient management. Hovenga et al 1998, Mun et al 1999, Chang et al 2004, Jennett et al 2003.
Level	Markers of Good Practice
PHCS	<ul style="list-style-type: none"> • As for Standard Two • PHC staff are aware of protocols for peritonitis, line change and exit site infection and in consultation with renal services administer appropriate care. • PHC staff maintain good communication links (telephone, email, video conferencing) with peritoneal dialysis (PD) nurses for the management of PD patients in the community
Rural/remote Dialysis units Level 1	<ul style="list-style-type: none"> • As for Standard Two Level 1
Regional Dialysis	<ul style="list-style-type: none"> • As for Standard Two, Level Two for larger Regional Units

<p>Units Level 2</p>	<ul style="list-style-type: none"> • PD training is offered to all patients deemed physically suitable or who have appropriate family and community support. • Respite is planned in conjunction with local Aged Care facilities where appropriate to provide additional support for patients and family. • Training and support is offered to facilities undertaking respite care for PD patients. • High quality peritoneal dialysis care is provided and monitored through regular reporting against CARL guideline's clinical indicators (adequacy, infection rates, membrane function) as part of quality improvement process.
<p>Tertiary Renal Units Level 3</p>	<ul style="list-style-type: none"> • As per Level 2 above and Level 3 in Standards One and Two
<p>Transplantation Services</p>	<p>As per Level 3</p>

Standard Four	Optimise Access to and Outcomes of Renal Transplants
Aim	To increase remote area Aboriginal and Torres Strait Islander Australians' access to the kidney transplant waiting list and ultimately to transplantation, and to provide a high quality support service that enables recipients to achieve the best quality of life.
Rationale	<ul style="list-style-type: none"> ○ Transplantation offers the best outcomes in terms of clinical indicators, patient quality of life and cost benefits. Gordon 2001, Cass et al 2004, ○ Aboriginal and Torres Strait Islander Australians have the lowest rate of kidney transplants in the ESKD population and have greater difficulty in getting on the transplant waiting list. Bennett et al 1995, Narva et al 1996, Ayanian et al 1999, Epstein et al 2000, McDonald et al 2003, Cass et al 2004, ○ Aboriginal and Torres Strait Islander Australians on the transplant waiting list living in remote regions should not be disadvantaged by distance in terms of completing regular tests to maintain active transplant status and extended cold ischaemic times as a result of travel arrangements. ○ Culturally appropriate education is necessary to improve understanding, uptake of services and outcomes. Colehan 2005, Devitt 1998, Bartlett 1995, Assal et al 1995, Gordon 2001. ○ Access to effective information and communication technology can reduce isolation and improve support for both patients and local service providers through increased access to specialist and linguistic services, improved educational opportunities and cost-effective patient management. Hovenaga et al 1998, Mun et al 1999, Murray et al 1999, Chang et al 2004, Jennett et al 2003.
Level	Markers of Good Practice
PHCS	<ul style="list-style-type: none"> ● PHC staff in consultation with renal staff have prepared procedures for urgently locating and evacuating patients and their pre-identified buddies in the event of notification of an available kidney. ● PHC staff are aware of patients in the community on active transplant waiting list and of the recurrent tests and procedures necessary to maintain active status and facilitate the completion of these tests. ● PHC staff liaise with transplant nurse and Nephrologist to ensure transplanted patients living in community are adequately and appropriately monitored and managed including medication requirements and available stock levels.
Rural/remote	<ul style="list-style-type: none"> ● Renal unit staff are aware of all patients on active transplant waiting list in area and have access to

<p>Dialysis Units Level 1</p>	<p>procedure for transfer of patient in the event of notification of available kidney</p> <ul style="list-style-type: none"> Renal unit staff are aware of recurrent tests and procedures necessary to maintain patient on active transplant list and facilitate the completion of these tests. Renal Unit staff liaise closely with transplant nurse and nephrologist regarding medical or surgical issues that could jeopardise 'active' status of patients.
<p>Regional Dialysis Units Level 2</p>	<p>As for Level One</p>
<p>Tertiary Renal Units Level 3</p>	<ul style="list-style-type: none"> Dedicated Tx nurse reviews and assesses all new patients in conjunction with Nephrologists for appropriateness for future transplantation. Pre-emptive transplantation is offered, investigated and encouraged for eligible patients. Transplantation education has been designed to meet the needs of the local people in terms of literacy and cultural acceptability and is provided in a culturally appropriate format such as video interviews. Workup and tests are commenced and completed prior to patients transferring to home-based therapies or rural/remote satellite facilities to minimise logistical difficulties of completing tests at a later stage. Access to services to complete transplant workup and recurrent tests necessary to stay active are available. <ul style="list-style-type: none"> Agreements established with Cardiology departments to undertake timely investigations and corrective procedures necessary for admission to pre-transplant list. Develop procedure between PHC, dialysis units and dental services to ensure patients living in remote/rural areas are reviewed regularly. Establish procedures with PHC, dialysis units and radiology department to plan for the transport, booking and completion of recurrent tests. Dialysis patients are interviewed, educated and assessed yearly to provide ongoing opportunities to commence work-up for the active transplant waiting list. Agreements with transplant hospital and regional and urban renal units cover on site patient assessment for "Active transplant list". Unit develops and disseminates robust policies and procedures for the maintenance of patients on the active transplant waiting list including timely retrieval from remote areas that addresses travel arrangements for both patient and escort to hospital and airport. Post transplantation care is formally instituted and shared between the local primary health care service and the transplantation hospital mediated through mechanisms such as videoconferencing. Unit provides high quality education, monitoring and management of transplanted patients through regular reporting against acceptable guidelines for clinical indicators as part of quality improvement process.

	<ul style="list-style-type: none"> • Transplantation Nurse outreach service is available to provide additional monitoring and ongoing support for transplanted patients and PHC staff in remote areas. • Facility has the ability to perform and interpret renal biopsies and immunosuppressive levels • Maximise efforts to increase organ donations amongst Aboriginal and Torres Strait Islander Australians through educational campaigns.
<p>Transplantation Services</p>	<ul style="list-style-type: none"> • Establish procedures for cadaver transplants to reduce cold ischaemic time for patients living in remote or rural areas, which addresses patient location, available transport and flight schedules. • Cultural assistance is provided for patients travelling to urban areas – meeting at airport, escorting to hospital and ward and ensuring escort accommodation is in close proximity to hospital. • Access to videoconferencing for patients undertaking transplantation distant from their family and community supports is provided to lessen the impact of isolation and loneliness.

Quick Reference for Service Areas

Standard	Primary Health Care
Aim	Primary health care staff are aware of and support the conditions, activities and services necessary to improve access and care for people with renal disease residing in rural and remote areas.
Rationale	
Level	Markers of Good Practice
Minimum standards expected of all PHCS	<ul style="list-style-type: none"> Guidelines for renal disease screening and recall system are in place for chronic diseases All known chronic kidney disease patients (CKD) are referred to nephrologist at GFR of less than 30mls or at current minimum standards. Established communication links to renal units and Nephrologists to facilitate shared care of CKD patients including implementation and monitoring of management plans. PHC staff are aware of patients undertaking home therapies in community, have access to specific and appropriate protocols and in conjunction with renal services are able to assist the patient manage their treatment (eg primary health, medication dispensing, preparation and delivery of blood samples). 12 monthly staff kidney disease education on RRT including modalities, consequences and patient support required, attended through chronic disease educational programs or similar (GP /KCAT programs/Chronic Disease Nurse/Chronic Kidney Disease Nurse) Primary health staff (PHS) have access to reliable communication methods to effectively manage renal patients including telemedicine: video, phone, fax, email and internet. All community clinics being established or undergoing refurbishment have areas designated for dialysis with appropriate plumbing and wiring.
Standards expected of PHCS in rural and remote areas servicing Aboriginal and Torres Strait Islander Australians	<ul style="list-style-type: none"> Interpreter services are available to assist with patient consultations. Algorithms for the management of renal patients across the care continuum are developed locally in conjunction with referring renal services. Surgical intervention for access creation in pending patients on site is supported PHC staff aware of patients in community on active transplant waiting list and of the recurrent tests and procedures necessary to maintain active status and facilitate the completion of these tests. PHC staff, in consultation with renal staff, have prepared procedures for urgently locating and evacuating patients and their pre-identified buddies in the event of notification of an available kidney. PHC staff liaise with transplant nurse and Nephrologist to ensure transplanted patients living in community are appropriately monitored and managed including dispensing medications and maintaining adequate

	stock levels.
Standard	Rural Remote Dialysis Units
Aim	Dialysis facilities in rural and remote locations embrace the activities and functions necessary for the provision of high quality dialysis treatments including the support and monitoring of patients undertaking home-based therapies.
Rationale	
Level	Markers of Good Practice
Minimum standards expected of all small stand alone dialysis units.	<ul style="list-style-type: none"> • Provide high quality maintenance haemodialysis services including regular reporting against CARI guideline's clinical indicators (adequacy, access evaluation, clinical parameters) as part of quality improvement process. • All staff delivering haemodialysis treatments will have completed at least one unit of theory in an accredited renal course as well as a practical placement in a regional or urban renal unit. • All staff will have access to and receive ongoing renal education at least three monthly (Journal club, Industry developed educational packages, inservices and demonstrations). • Staff will be assessed yearly by a qualified Renal Nurse • Staff and patients have access to appropriate electronic and internet facilities to facilitate patient reviews, consultation and education. • Renal staff are aware of patients receiving home based therapies in community and have access to protocols after hours in order to assist with trouble shooting • Respite for home and community based haemodialysis patients is offered in unit. • Centrifuge available to spin bloods
Standards expected of small rural and remote dialysis units.	<ul style="list-style-type: none"> • Culturally appropriate and locally produced educational resources are available around disease and treatment management. • Staff, assisted by interpreter services, facilitate regular patient reviews by multidisciplinary renal team either onsite or via telemedicine. • Renal unit staff are aware of all patients on active transplant waiting list in area and have access to procedure for transfer of patient in the event of notification of available kidney • Renal unit staff are aware of recurrent tests and procedures necessary to maintain patient on active transplant list and facilitate the completion of these tests. • Renal Unit staff liaise closely with transplant nurse and nephrologist regarding medical or surgical issues that could jeopardise active status of patients.

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| | <ul style="list-style-type: none">• Local Aboriginal and Torres Strait Islander people are employed in unit in a variety of positions.• Local Aboriginal and Torres Strait Islander people are offered and supported to complete specialised training through VET or higher education courses. |
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Standard	Regional Dialysis Units
Aim	Regional dialysis units are aware of and strive to develop the activities and infrastructure necessary to offer a more comprehensive service to the local community that moves beyond maintenance dialysis and includes chronic kidney disease management and renal replacement therapy education and training.
Rationale	
Level	Markers of good practice
Minimum standards expected of all regional dialysis units	<ul style="list-style-type: none"> • As per minimum standards in rural and remote dialysis units. • Renal staff are able to offer education to local community health centres on CKD management and treatment modalities. • Renal unit staff provide link between nephrologists and PHC in CKD management of patients and implementation of multidisciplinary care plans. • Respite is planned in conjunction with local Aged Care facilities where appropriate to provide additional support for patients and family. • Training and support is offered to non-dialysis facilities undertaking respite care for PD patients.
Standards expected of regional dialysis units in rural and remote areas.	<ul style="list-style-type: none"> • Larger regional units may have access to staff and patient training and development programs that include: <ul style="list-style-type: none"> • Space available for staff teaching sessions, in-services and practical demonstrations • Home and self-care training programs offered to all patients deemed physically suitable or who have appropriate family and community support. • Programs designed to meet the needs of the local people in terms of numeracy, literacy and cultural appropriateness. • a dedicated self-care trainer with appropriate qualifications and experience in training and cultural awareness • Adequate and appropriate space allocated for patient training away from main treatment area. • Qualified interpreters with medical terminology trained to facilitate education and development of educational material • Access to travel and accommodation for the buddy to undertake training. • Community consultation and onsite visits carried out in preparation for home and community-based dialysis • Memorandum of Understanding developed with community councils, clinics and landowners to determine and agree on treatment site if necessary, support and services provided to patients

	<p>returning to community.</p> <ul style="list-style-type: none"> • Local guidelines for space, infrastructure and operational issues for home and community-based haemodialysis which cover criteria for storage space, deliveries, tanks, pumps, chillers and phone lines as applicable. • The provision of minimum 6 monthly home visits to evaluate environment, and provide patient, family and PHC staff education. • Aboriginal Liaison Officer (ALO) positions to facilitate the transfer of pending patients to urban area. • Management plans utilised related to housing needs, support services, schooling and finances in urban area. • The development of culturally appropriate and locally designed educational material to cover pre-dialysis management, modalities and treatment preparation including education on pre-emptive transplant therapy. • Interpreter services to assist with education and preparation for treatment through telemedicine (phone or video) • Where it is not available locally, regular visits by multidisciplinary team and include Nephrologist, Dietitian, Social worker, nurse educator, PD, Tx and CKD nurse to update, educate staff and review pending patients
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Standard	Tertiary Renal Units and Transplantation Units
Aim	Tertiary renal units identify and aim to develop the services and infrastructure necessary to provide a high quality, comprehensive renal service for remote areas. This includes chronic kidney disease management, education, surgical and psychosocial preparation for renal replacement therapy, home therapies training and transplantation services.
Rationale	
Level	Markers of Good Practice
Minimum standards expected of all tertiary renal units.	<ul style="list-style-type: none"> • Established multidisciplinary renal team including nephrologist, CKD nurse, Dietitian, social worker and ALO. • Access to further Allied Health Services as needed eg psychologist, occupational therapist and physiotherapists • Culturally appropriate educational material around CKD management, treatment options and requirements developed in formats and languages to suit local needs. • Management plans implemented include surgical review, access planning, assessing and establishing social supports and access to Interpreters. • Databases are maintained for pending patients with stage of disease, management plan and actions. • Telemedicine (video/phone) is available between PHC area and satellite units to increase support and improve patient consultations and staff education. • Appropriate imaging is available for assessment and planning of access. • 100% of all known CKD patients have dialysis access created prior to commencement of dialysis. • Dedicated Transplant (Tx) nurse reviews and assesses all new patients in conjunction with Nephrologists for appropriateness for future transplantation. • Pre-emptive transplantation is investigated and encouraged for all known CKD patients. • Unit provides high quality education, monitoring and management of transplanted patients through regular reporting against acceptable guidelines for clinical indicators as part of quality improvement process. • Dialysis patients are interviewed, educated and assessed yearly to provide ongoing opportunities to commence work-up for the active transplant waiting list. • Facility has the ability to perform and interpret renal biopsies and immunosuppressive levels.
Standards expected of tertiary renal units supporting	<ul style="list-style-type: none"> • As for Regional dialysis Units • Travel and accommodation costs for patient and escort are organised to cover investigations, access creation and preparation for relocation to urban area

<p>Aboriginal and Torres Strait Islander Australians and services in rural and remote areas.</p>	<ul style="list-style-type: none"> • Transplantation education has been designed to meet the needs of the local people in terms of literacy and cultural acceptability and is provided in a culturally appropriate format such as video interviews. • Workup and tests are commenced and completed prior to patients transferring to home-based therapies or rural/remote satellite facilities to minimise logistical difficulties of completing tests at a later stage. • Access to specialist services to complete transplant workup and recurrent tests necessary to stay active is available. <ul style="list-style-type: none"> • Agreements established with Cardiology departments to undertake timely investigations and corrective procedures necessary for admission to pre-transplant list. • Develop procedure between PHC, dialysis units and dental services to ensure patients living in remote/rural areas are reviewed regularly. • Establish procedures with PHC, dialysis units and radiology department to plan for the transport, booking and completion of recurrent tests. • Agreements with transplant hospital and regional and urban renal units, cover on site patient assessment for “Active transplant list”. • Unit develops and disseminates robust policies and procedures for the maintenance of patients on the active transplant waiting list including timely retrieval from remote areas that addresses travel arrangements for both patient and escort to hospital and airport. • Procedures established for cadaver transplants to reduce cold ischaemic time for patients living in remote or rural areas, which addresses patient location, available transport and flight schedules. • Cultural assistance is provided for patients travelling to urban areas – meeting at airport, escorting to hospital and ward and ensuring escort accommodation is in close proximity to hospital. • Access to videoconferencing is provided for patient to lessen impact of distance from family and community support. • Shared management for post transplantation care of returning patients is instituted with transplantation hospital through mechanisms such as video conferencing • Transplantation Nurse outreach service is available to provide additional monitoring and ongoing support for transplanted patients and PHC staff in remote areas. • Maximise efforts to increase organ donations amongst Aboriginal and Torres Strait Islander Australians through educational campaigns.
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