Interesting times —

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Abstract

Background
Treatments for kidney disease have been available in Australia for more than 50 years. Despite this, and the Northern Territory (NT) having Australia’s highest rates of kidney disease, the range of models of dialysis care in the NT has been limited until quite recently.

Objective
The paper provides a brief history of the development of dialysis services in the NT and examines the contexts in which unique models of dialysis care have emerged.

Data reviewed included published and unpublished documents and reports, relevant Departmental and ANZDATA information and interviews with past and present staff.

Discussion
The early development of renal services in the NT was characterised by a desire to limit expenditure, despite repeated disease projections that indicated rapidly escalating demand. An integrated policy response was not forthcoming to address the magnitude, persistence and growth in the burden of kidney disease. Repeated periods of capacity crisis requiring Ministerial intervention have dominated the historical landscape.

In the meantime, Aboriginal patients, communities and clinicians have advocated, with some success, for services that are closer to home and more responsive to patients’ health, social and cultural needs.

Conclusion
There has been considerable expansion of dialysis services across the NT, with several unique models of dialysis care developing over the last 15 years. While there are now some community-led services, the NT Government continues to provide the bulk of staffed services. It is yet to be seen if the new MBS item for remote dialysis services will be another game-changer.

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Background of renal services

Kidney disease is a significant and serious global health issue, with prevalence expected to double between 2010 and 2030 (Eggers, 2011). Kidney disease is considered a disease of disadvantage (Brophy et al., 2015; Cass et al., 2002; Garcia-Garcia & Jha, 2015). In Australia, there is a steep gradient in the burden of kidney disease from urban to remote areas, with people in remote areas, particularly Indigenous people, suffering much higher levels of disease (Australian Institute of Health and Welfare, 2013).

Renal treatments have been offered in Australia for more than 50 years. A key focus, however, has been on kidney transplants, a treatment that is least expensive in the long term and offers the best quality of life for most individuals (Howard et al., 2009). In the early years, maintenance dialysis was only offered to those suitable for transplantation, with the primary aim of keeping the individual alive until a kidney could be found (Petrie, 2009). Transplantation was the modality of choice. In 1979, more than 60% of people were living with a transplant, while home dialysis (peritoneal or haemodialysis) was the dominant dialysis modality (ANZDATA Registry, 1979).

Compared with other Australian patients, the characteristics of the Northern Territory’s (NT) end-stage kidney disease (ESKD) population are unique. The NT cohort is predominantly Indigenous (nearly 85%), younger, comprises more women than men and, unlike other states, the majority receives care in a staffed satellite facility. Additionally, most Indigenous Territorians receiving renal replacement therapy (RRT) live in remote or very remote, small, homeland communities and must move to urban centres to access treatments. For people already experiencing poorer health outcomes, reduced life expectancy and reduced quality of life, the impact is immense (Anderson et al., 2012; Anderson et al., 2009).

In this paper, covering the period 1980–2014, we outline how circumstances are shaping the development of unique models of dialysis care. Published material, “grey literature” including reports and reviews, and interviews with past and present staff informed the paper, as well as the lead author’s decades of experience with renal services as a clinical manager and later as senior advisor for service development.

Renal services in the NT

Renal services were comparatively slow to develop in the NT, with no services available prior to 1980. In part this was due to the relatively small population (estimated at 96,000 people in 1975) (Australian Bureau of Statistics, 1976) which remains sparsely dispersed over 1.3 million km². Most of the population congregates in two urban centres: Darwin and Alice Springs.

During the mid-1980s, NT incidence rates of kidney disease rose dramatically, reportedly doubling every three to four years (W. Hoy, 2000; Spencer et al., 1998). These high rates were almost exclusively amongst Indigenous people and likely contributing to the heavy burden of mortality estimated at 18–30 times that of the non-Indigenous population (W. E. Hoy, 2014).

The Queen Elizabeth Hospital in Adelaide provided a quarterly nephrologist visit to the NT. Patients offered replacement therapy were transferred more than 1500km south to Adelaide for assessment and treatment. Initially, maintenance haemodialysis (HD) was not available in the NT and patients were only able to return to the NT if they undertook peritoneal dialysis (PD).

The first acute HD treatment occurred in 1978 in Darwin and the first non-Indigenous home haemodialysis (HHD) patient returned to the Territory in 1976 (Gorham, 2003). By 1983 there were eight people including one Indigenous person undertaking self-care therapy in the Territory.

As few were offered HHD, and satellite HD was restricted, many people declined the offer of treatment interstate. It was thought that many Indigenous people suffered premature death (Pugsley, 1993).

In response to the growing demand for treatments in the Territory, staffed dialysis services became available, initially with a small two-station facility in Darwin in 1984 and then a larger 10-station satellite facility in Alice Springs in 1987.

Rapidly growing need

A decade later, by the mid-1990s, patient numbers had increased eight-fold, compared to a national doubling in dialysis patients (ANZDATA Registry, 1996). Service development was unable to keep up with treatment demand. The escalating incidence rate, coupled with fewer patients being transferred interstate, caught health services unaware. Services expanded and developed reactively in response to capacity crises and, due to urgency, appropriated spaces ill-designed for their purpose (Figures 1 and 2).

Additionally, the absence of a senior nephrologist for the NT program may have fostered an ad hoc approach to service expansion. Although Alice Springs had appointed a nephrologist in 1989, a visiting nephrologist continued to oversee patients in Darwin. Finally, in 1996 a full-time nephrologist was recruited. By then, a dedicated renal ward had been established at Royal Darwin Hospital (RDH). The satellite units in Darwin and Alice Springs expanded (1997) to 20 and 24 stations, respectively, becoming the largest facilities in Australia at that time (Gorham, 2003). However, HHD was no longer available as a modality choice. Natural attrition of the few patients utilising HHD, the absence of a dedicated training program, and the unplanned manner in which many patients
commenced treatment decreased the profile of this program such that by 1992 it was no longer offered.

**Acute dialysis treatment**

The lack of dedicated acute dialysis facilities in both Darwin and Alice Springs hospitals saw many unwell patients transferred daily to the respective satellite facilities for treatment. As patient numbers escalated, acute treatment areas were eventually created in the hospital by occupying any available space. In 1992 a patient waiting room in the medical ward was converted to a four-bed dialysis room at RDH. Bulky sinks, water filtration systems, dialysis equipment and treatment trolleys all added to the congestion in the room. In Alice Springs, acute dialysis was provided by the intensive care unit and later two stations were made available in the medical ward.

In 1995, RDH established a dedicated renal ward with six dialysis stations, albeit in the vacated neonatal nursery, while it was another 13 years before Alice Springs established a dedicated renal ward. The period between 1985 and 1995 was one of rapid expansion and, as described by the Chief Health Officer at that time, “dominated by crisis and ministerial interventions” (Dunjey, 1994). From early on, reactive responses to crises of capacity have characterised the development of renal services across the NT.

**Patient advocacy and community need**

By 1995, Indigenous people comprised 96% of those on dialysis. Community leaders were expressing alarm at the ever-increasing numbers of community members being lost to urban centres. The impact on the individual, their family and communities was devastatingly apparent (Devitt & McMasters, 1998; Wilson et al., 1994). The term “social price of renal disease” was coined to describe the issues of relocation and dislocation (Mahoney, 1995). That term, then and now, is patently inadequate.

The period between 1995 and 2005 was exemplified by significant advocacy and campaigning by communities, expressing their dissatisfaction and pressing for treatment options in keeping with their health, social and cultural needs.

The Tiwi Islanders, frustrated by the lack of response to recommendations in a commissioned renal report (Mahoney, 1995), negotiated directly with the Commonwealth to establish their own satellite service on Bathurst Island. The Tiwi Dialysis Centre (TDC) — opening in 1998 — was the first satellite dialysis unit in a remote community in Australia. It was the first to be managed by renal trained Aboriginal health workers (Gorham, 2000). The accredited Aboriginal Health Worker Renal Training Program, designed in the NT, was later taken up by other states and entered the national curriculum for Aboriginal health practitioners (AHP).

Initially patients at the TDC were minimal care and the single AHP was supported with fly-in fly-out nursing staff based in Darwin. Over the years, however, staffing increased as patients became more dependent and numbers increased. The training of local AHPs was not sustained.

Inspired by the Tiwi Islanders, several other communities took action on their own behalf, including exchanging land rights for a satellite HD unit (Loff & Cordner, 1998); commissioning

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*Figure 1: New NT renal patients 1986–2014*
a dialysis feasibility study (Gorham, 2003); lobbying for the re-establishment of HHD, and auctioning their own art to raise funds for services (Rivalland, 2002).

**The Purple House**

In 2000, the Kintore and Kiwikurra communities of Central Australia led a standout community action when they partnered with Papunya Tula and Sotheby’s to auction several of their own spectacular artworks. Raising over one million dollars, they then went on to establish a community-controlled and community-driven service — Western Desert Nganampa Walytja Palyantjaku Tjutaku, now incorporated as the Purple House (Rivalland, 2002) — with a number of interconnecting programs including social support in the urban area, return to country trips and respite dialysis in remote communities.

Since then, with input from a range of philanthropic organisations, the Commonwealth Government and financial and collaborative support from the NT Health Department, the Purple House has expanded incrementally to become the principal community-governed agency involved in renal services across the NT (https://www.purplehouse.org.au). More than a dialysis treatment provider, the Purple House programs strive to support patients and families in their homelands where possible. Other organisations work to emulate the Purple House model with its emphasis on maintaining connection to family and country.

**Service expansion**

At this time, Tennant Creek, five hours north of Alice Springs with a population of over 2500 people, was recording exceptionally high rates of kidney disease. Nearly a quarter of the HD population at the Flynn Drive Renal Unit, Alice Springs, came from the Barkly region. Numerous studies and plans had identified Tennant Creek (the hub for the Barkly region) as an appropriate location for the decentralisation of services (Gorham, 2003). The decision then not to proceed with a service in Tennant Creek (Cth, 6 March, 2001) drew negative media attention with Indigenous and non-Indigenous patients alike arguing equitable access to treatment was a human rights issue.

The NT was the only jurisdiction in Australia not offering HHD (Russ, 2001) and services closer to home were only available on the Tiwi Islands and Katherine region. Although there was a slight relaxation of the HHD embargo in 2001, the policy restrictions and limited funding effectively confined self-care HD to the urban area. The most contentious restriction was the so-called “client contract”, requiring a community to document how HHD would increase a patient’s productivity (Gorham et al., 2005). Due to the outcry from clinicians, this policy was never enacted.

**A policy shift — services closer to home**

In 2003, following a change in government in the NT, a

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**Figure 2: NT prevalent renal patients 1998–2014**
significant policy shift heralded a greater focus on providing dialysis services and treatments closer to home. The new direction was supported by significant funding for infrastructure ($1.8M), including for HHD in remote areas and a purpose-built dialysis facility in Tennant Creek. The change in policy was also accompanied by a commitment to implement a five-year, funded renal strategic plan. The Renal Services Strategic Plan, launched in 2005, was accompanied by $5M in recurrent funding for the development and expansion of services, including outreach, allied health and self-care therapies. The strategy was underpinned by a comprehensive implementation, monitoring and evaluation plan (NT Department of Health, 2005).

Recognising the generally poor state of most remote community housing and the likelihood of overcrowding, the NT designed the first dedicated, multi-user and relocatable treatment facility in Australia. With a two-chair capacity, it could treat up to eight people. However, training patients and installing these facilities in remote areas was a slow process (Gorham et al., 2005). The year 2004 was a busy time, with the return of the first Indigenous self-care dialysis patient to their remote community and the opening of the Tennant Creek Dialysis Unit (TCDU).

The strategy of providing services closer to home for self-care patients continued with the NT Government endorsing a policy of establishing “renal ready rooms” (RRR) in all new and refurbished remote health clinics. RRR are dedicated spaces within primary health services that are pre-configured to meet the necessary size, electrical and plumbing standards (AHIA, 2015). Operational support from the local primary health care service was crucial for the success and sustainability of the program.

However, none of the remote-based infrastructure, much of it unused at this stage, ameliorated the relentless growth in demand in the urban areas.

Many strategies were explored to decrease demand on satellite services. For instance, the acceptance of PD was comparatively low in the NT, particularly in Alice Springs, where poor community perceptions and high rates of infection significantly limited uptake. A model of supported PD was developed to counteract these issues. This program provided trained nursing staff after hours to connect and disconnect patients from automated PD machines. The PD First program was also implemented. The program involved pre-emptively inserting buried PD catheters in chronic kidney disease (CKD) patients with the aim of exteriorising the catheter when dialysis treatment was required (Sundaram et al., 2012). For a variety of reasons, neither program gained sufficient traction to impact on demand for facility dialysis.

Alice Springs Hospital (ASH) went so far as to lead a collaboration to lease and refurbish a hostel for medical accommodation — primarily to encourage the uptake of PD. Despite these efforts, the uptake of PD dwindled in Central Australia.

**Continuing pressure workforce need**

The sustained growth in the demand for renal services, driven by improved patient survival and increasing incidence rates, did not result in considered planning. Periods of forward planning, policy formation and appropriate resourcing (2003–2009) were followed by periods of abeyance in strategic direction, coupled with repeated episodes of crisis management.

Compounding demand was the difficulty of recruiting and retaining sufficiently skilled nephrology and nursing staff. Nephrologists were particularly difficult to attract. Approved staffing numbers were low and nephrologists found themselves working long hours, frequently on call. Turnover was high, with an over-reliance on advanced trainee registrars. National and international recruitment drives were facilitated by the partnership with The Queen Elizabeth Hospital. Some success was attained by encouraging Advanced trainees to return to the NT on completion of their program, more so for the Top End where there is now a relatively stable workforce of national and internationally trained nephrologists. However, in Central Australia, real stability was only achieved after 2012 through attracting internationally trained nephrologists.

In relation to the nursing workforce, the sustained demand resulted in a heavy reliance on overtime and double shifts. A number of workforce strategies were developed during this period. Some were more successful than others, while a few did not result in any benefits or increase to the workforce.

In the early years, the NT focused on establishing their own work-based training program for registered and enrolled nurses — with some success. Due to the patient population demographics, an increase in the number of Aboriginal staff in the service was desired and the Renal Aboriginal Health Worker training program was promoted — with somewhat less success. In the mid-2000s, considerable funds were allocated to an advertising and marketing campaign. It was delivered in conjunction with national and international recruitment drives for both dialysis nurses and nephrologists, with inconsistent results. The national recruitment for dialysis technicians did not result in a single application.

Other strategies included training patient care assistants to assist dialysis nurses with patient and machine preparation and treatment completion; dialysis nurse exchange programs with interstate units to facilitate knowledge exchange and skill development; a partnership arrangement with interstate
training facilities and universities to support the implementation/development of the Renal Diploma and even approaching industry to access their pool of internationally trained dialysis nurses. Despite these strategies, continuing staff shortages meant a reliance on interstate agency staff on three-month rotations—particularly in Central Australia. Unsustainably expensive, the strategy also raised quality of care issues relating to clinician–patient communication and continuity of care.

Eventually support for the development of the Renal Graduate Diploma to be delivered through the Charles Darwin University and a commitment by the Department to reimburse course fees saw a sustained program of training deliver results for the service. The program guarantees a source of renal employees during the two years of their course.

Additionally, the availability of an international nursing recruitment pathway through the 457 visa legislation, and the possibility of Permanent Residency nomination, has enabled the service to recruit from overseas and thus establish a stable nursing workforce.

Moves to coordinate — the Tristate

In Central Australia, particular issues related to the patient pathway were exacerbated by the complexity of managing patients from outer state. Alice Springs is the closest regional centre and renal services provider for many communities in the central desert area. Renal patients living in communities near the NT/WA/SA border regions were usually transferred to Alice Springs for treatments as it was the nearest tertiary service.

In 2006, 10% of patients accessing care in Alice Springs were from South Australia (SA) and Western Australia (WA). The Commonwealth Government, concerned about capacity issues, complicated by jurisdictional boundaries, convened an urgent meeting in Alice Springs. Known as the “Tristate meeting”, Health Departments from WA, SA and the NT, as well as Aboriginal Medical Services operating in the region, met to determine strategies for managing escalating demand.

Despite the evidence of services stretched beyond capacity, the Tristate meeting did not result in an agreed plan for service development, or responsibility for patients moving across borders. It did, however, result in additional support from the Commonwealth for kidney disease management programs in primary health services and capital funds for remote self-care facilities (2007).

Another policy response — deferral of dialysis

Despite the additional infrastructure and services, demand continued to outstrip service capacity. Severe capacity issues resulted in the development of a policy and procedure to clinically manage patient rescheduling, known as the ‘Deferral Policy’. The policy included strict clinical assessment and test guidelines for the deferral or rescheduling of rostered patients, although in many cases deferred patients did not present the following day. The policy had been deployed unofficially for some time before it was officially endorsed by the Department in 2007 as a last resort to manage dialysis treatment demand. The policy has repeatedly been implemented each year since that time.

During this time, dialysis services in Alice Springs were largely restricted to the Flynn Drive Renal Unit. With only one machine in the intensive care unit and no dedicated renal beds, ASH had very limited capacity to provide acute services. Although there was a small increase to two stations it was not until a major funding increase was allocated in 2007 that a dedicated renal ward providing acute dialysis was established. Treating 16 patients a day, the facility opened in 2008, but, emphasising yet again the scale and persistence of capacity issues, the new facility was immediately at capacity treating the overflow of patients from the Flynn Drive Renal Unit.

Both local and national news services highlighted capacity issues as well as the accommodation needs of people relocating from remote areas for treatment. Media reporting led to local and federal members of Parliament questioning the approach to service development in the NT.

Capacity issues continued. In 2009, Alice Springs was in such dire straits that it took the unprecedented step of redirecting patients from border communities back to their home state for assessment and treatment. The policy (publicly referred to as ‘Closed Borders’) resulted in significant community angst and public attention (Medew, 2009). Capacity of renal services in the NT was again raised in federal Parliament.

Once more a Tristate meeting was convened, this time by the NT Government. Unlike the previous meeting, agreement was reached, with SA nominating to treat all patients within the SA border and WA negotiating for patients north and east of Warburton to commence treatment in Alice Springs.

Planning for the future — or not?

The Department of Health (DoH) has rarely acknowledged and matched the sustained, escalating demand for dialysis services with a strategic plan supported by capital and recurrent funding. At only one time was a coordinated response conceded with both a five-year, DoH-funded strategy focusing on CKD management and better integration with primary health services, with a Treasury-approved, four-year rolling program of infrastructure for satellite services. The 2007 proposal would provide four satellite services over four years and the capacity to treat an additional 32 patients each year.
However, identifying suitable sites, lengthy community consultations, slow council processes and contract negotiations meant it was 2010 before the first of the new services eventually opened in Alice Springs. The new Gap Road (Nephrocare) facility was larger than required (capacity of 18 stations) to account for needs over the next 5–7 years. However, not only was establishment capacity (32 patients) exceeded before the facility opened, but subsequent growth exceeded total capacity in less than four years.

The NT DoH developed the Gap Road service as a public/private partnership — the first in the NT. Common in other states, the model's primary benefit is risk mitigation: capital and recurrent costs are known for a set period and issues with infrastructure delays, budget overruns and staffing shortages are the responsibility of the provider.

While an extension to the TCDU was nominated as the second satellite site and the contract for construction awarded in 2010, multiple delays, including insolvency of the construction company, meant completion did not occur until late 2012. Katherine township was identified as the third site, and like Gap Road, also to be a public/private partnership. Following delays and despite evidence to the contrary, in 2012, the government deferred the construction claiming it would be under-used. Speculation at the time pointed to poor advice and funding requirements elsewhere. This view was given some credence when funding for the fourth satellite dialysis unit was absorbed into general revenue. It was 2014 before the Katherine facility was opened.

In the intervening years, both Alice Springs and Darwin services implemented various measures to cope with escalating demand, including adding extra dialysis chairs and machines within already crowded facilities, using storage/office and training areas for maintenance dialysis, increasing the number of shifts per day and increasing days of operation from six to seven. Capacity at the TDC was expanded to 18 patients by increasing the rotation of fly-in fly-out staff. This change also created a highly resource-intensive service model which remains in place.

Despite these additional and organisationally time-consuming efforts, the dialysis Deferral Policy has been enacted repeatedly.

Struggling to grasp the complexity and magnitude of the problem, the Commonwealth was also reluctant to involve itself in service delivery programs that were the responsibility of state and Territory governments for fear of ‘double dipping’. Instead, in 2010, they commissioned a study to better understand disease burden, service demand, future projections and likely costs of renal services in Central Australia (Cass et al., 2011) including the Tristate region. Of the 76 recommendations made in the final draft report, only seven appeared in the final report. None were progressed.

The Commonwealth continued their (limited) interest in supporting remote renal services through funding the design and construction of Australia’s first self-contained mobile dialysis unit capable of remote area travel. The Northern Territory Government (NTG) mobile dialysis bus completed its inaugural trip in 2010, travelling to the Garma Festival in Eastern Arnhem Land and providing on-site dialysis to eight patients. The bus provided holiday and respite dialysis to remote communities in Central Australia over the next two years.

Near this time, the Purple House also built a dialysis unit (Purple Truck) funded through Medicines Australia. While the Purple Truck also provided respite dialysis, it largely used the service as temporary infrastructure in communities where services were in the throes of development.

However, by 2012 the NTG bus was struggling to maintain a regular service as resources were being drawn from already overstretched satellite services in Alice Springs. Currently the NTG bus does not operate and there are plans for Purple House to take over management.

Discussion

From early on, numerous studies and commissioned reports on the status of renal disease in the Territory have been published. All have predicted accelerated growth in demand for dialysis treatments, with many warning that the future burden on hospital resources would be enormous (Bartlett, 1997; Cass et al., 1999; Catford, 1997; W. E. Hoy et al., 1998; Krubakaran, 1998; Spencer et al., 1998; Willis, 1995; You et al., 2002). Despite these many reports, successive governments failed to respond in an integrated and proactive fashion. On only one occasion (2005) was a planned strategic direction funded sufficiently to allow significant work across both the community and hospital sectors. Many dialysis services were therefore established in an ad hoc way — usually in response to a capacity crisis.

The uniqueness of the NT patient population, including its social, cultural and linguistic diversity, has not been fully appreciated by service planners. Models of care were developed without adequate consideration regarding how these differences might affect the uptake of services. Patients had (and have) great difficulty reconciling treatment requirements with family, social and cultural obligations, to the extent that some declined treatment.

Following sustained advocacy, patients, communities and supporters came up with their own solutions. There are now several examples of community-led services in the NT. Government services have also become more responsive to the needs of their patients. Services closer to home are actively
promoted with dedicated remote infrastructure including the relocatable self-care facility, the mobile dialysis bus and renal training for Aboriginal health workers.

It is important to note that decisions not to establish services in remote areas at that time were more likely to do with curtailing budget expenditure, than a policy plan to limit patients’ involvement in service delivery. The NT is a comparatively small jurisdiction and the health budget was (and continues to be) significantly impacted by escalating renal expenditure. Many factors such as competing service priorities, poor management, the pressure of crises and isolated instances of racist behaviour, taken together, may have contributed to a perception of a discriminatory service.

By 2014, virtually all units across the NT were over capacity and struggling to meet the demand, with prevalence increasing by 150% from 2000. Staff could not remember a time when services were not at capacity. When demand so outstrips capacity, enormous pressure is placed on clinicians to make decisions on how services are allocated, who receives treatment, how this is explained to patients and families and how to deal with the negative media attention that invariably follows. Stressed patients also seek answers from clinicians about the care they are receiving. Frontline staff face immense stress.

The “rationalisation” of treatments, that is, limiting access to dialysis for people who can ill afford to miss treatment or, the triaging of patients for access to maintenance dialysis, is at cross purposes with the responsibilities of clinicians working in (peaceful) first world health systems. The perception that treatment can be deferred until there is sufficient capacity, or that patient numbers and treatment demand can be curtailed by simply withholding funds, seems to be a commonly held view by senior administrators.

Service provision was (and continues to be) possible only because of the high rate of missed treatments by patients, estimated at 20–25%. Critically, through education the nurses’ primary focus is on promoting and improving health through adherence with treatment parameters. To then defer those patients who do have good attendance and are therefore considered the best candidates to miss treatments, sends a mixed message to patients.

The development of a stable nephrology workforce has provided clinical continuity and enabled outreach programs and telehealth to be established with some consistency. Innovative models of vascular access such as interventional nephrology have been a positive outcome of the staff stability.

However, the inability to attract and retain Australian-trained renal staff has resulted in a reliance on overseas-trained staff.

The current workforce in the NT includes a high proportion (85%) of overseas-trained professionals who, primarily, speak English as a second language. At times this does present cultural and communication difficulties which are addressed through educational programs for both staff and patients.

Although recent submissions have provided additional recurrent funds for renal services development in both Darwin and Alice Springs, at the time of writing the main urban renal services were well over capacity and again being forced to implement stop-gap solutions such as the Deferral of Dialysis policy. The demand for satellite and staffed services has not diminished — 75% of renal patients receive care in a satellite facility; the government continues to provide the bulk of these services.

The successful action of the Tiwi Island community (1996) and the Kintore Community (2001) who, undeterred, advocated for funding to determine their own preferred model of care was a ‘game changer’.

Undoubtedly the next game changer will be the recently (2018) approved Medical Benefits Schedule Item for the provision of remote dialysis supported by a nurse or AHP. It represents a key initiative to improve access to culturally appropriate services across remote Australia and implementation will require whole of sector support. Along with significant remote infrastructure and financial support for the Purple House, the MBS item is expected to facilitate and support the expansion of staffed services in remote communities. This is a long-awaited outcome for patients and their families and will hopefully reduce the unrelenting escalation in demand for urban dialysis services.

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Ethics approval

Ethics approval, March 2015, Human Research Ethics Committee of NT Dept of Health and Menzies School of Health Research (HREC15-2334) and the Central Australian Human Research Ethics Committee (HREC15-283).

Acronyms

AHP Aboriginal health practitioner
ANZDATA Australian and New Zealand Dialysis and Transplant Association
ASH Alice Springs Hospital
CKD Chronic kidney disease
ESKD End-stage kidney disease
HD Haemodialysis
HHD Home haemodialysis
MBS Medical Benefits Schedule
NT Northern Territory
References


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