

The Big Red Kidney Bus Project
Providing access to holiday dialysis: a literature review

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Background

One in three adults is at increased risk of developing chronic kidney disease (CKD). The risk factors for CKD include: age (60 plus years), diabetes, high blood pressure, a family history of kidney failure, established heart problems (heart failure or heart attack) and/or having had a stroke, obesity, smoking, and being of Aboriginal and Torres Strait Islander origin. Almost one in ten adults presenting to general practice have CKD and many more (an estimated 80%) have a least one CKD risk factor. This means that CKD is an important public health issue, both in Australia and internationally. The condition is asymptomatic in its early stages, so the condition requires active management to optimise prognosis and to minimise progression to later stages of the condition, where kidney failure means that dialysis and transplantation must be considered. CKD often occurs in conjunction with cardiovascular disease (CVD) and/or diabetes. CKD can significantly increase the mortality and morbidity associated with CVD and diabetes. Indeed, kidney and urinary diseases are the ninth commonest cause of death, accounting for more deaths than breast cancer, prostate cancer and road deaths ([Kidney Health Australia](#)). There are a range of evidence based clinical guidelines, recommendations and clinical consensus resources to support the management of CKD ([CKD management in general practice](#)).

End stage kidney disease (ESKD), where there is significant kidney damage and reduction in kidney function, is a growing problem. Currently each day, six Australians commence dialysis or transplantation ([Kidney Health Australia](#)). The majority (71%) of dialysis in Australia is conducted in hospitals or satellite centres. Almost a fifth (19.5%) of patients have peritoneal dialysis of some sort (continuous ambulatory peritoneal dialysis, CAPD, or automated peritoneal dialysis, APD) (Agar, 2011). The remaining patients have home haemodialysis, although numbers are increasing, particularly in Victoria and Queensland, due to strong advocacy for this treatment mode (Agar, 2011).

The issue of travel is important for people needing haemodialysis (HD). The need to travel to receive treatment means that dialysis has a substantial impact on people's daily lives. The impact on quality of life has previously been reported (Ekelund & Andersson, 2007; Welch & Austin, 1999). The Dialysis Outcomes and Practice Patterns Study (DOPPS), a large cohort study that surveyed almost 21,000

patients, is one of several that has demonstrated that longer travel time is associated with increased mortality and reduced quality of life (Moist et al., 2008). Compared to those with travel time of 15 minutes or less, quality of life was significantly lower with longer travel time. Not only is access an issue when people are in their usual environment. People often need to travel for work and require access to treatment whilst away from home. Given the demands of work, domestic life and treatment, people may also seek to take a holiday: accessing suitable dialysis services becomes an additional consideration when planning such a break.

People requiring dialyses may have concerns about accessing services they are not familiar with. The regular service provider offers safety and engenders trust. Although the incidence is low, there are concerns about adverse impacts when accessing a different provider, such as contracting hepatitis C. Such concerns need to be addressed if people requiring dialyses are going to be able to take holidays. This review discusses the evidence base surrounding options for so-called 'transient' patients, that is, people receiving dialyses away from their usual provider.

The aim of the literature review was to assess what evidence there was for service arrangements to enable people requiring haemodialysis to access dialysis services when away from home, particularly when on holiday.

Method

A preliminary on-line search was conducted using the search terms 'dialysis, travel, vacation and holidays'. This provided access to the 'grey literature', including agency reports, press releases and government, non-government organisations and commercial websites. Conference proceedings, poster abstracts, theses, books and review articles were excluded. Searches were then conducted of several scientific electronic databases, covering health and social sciences literature. The MEDLINE, EBSCO, PsycINFO, ProQuest and CINAHL databases were searched using similar search terms to those above. The Medical Subject Heading (MeSH) thesaurus was used to determine appropriate MeSH terms. MeSH and non-MeSH terms were used, according to the respective search engines. The search was conducted during January-February 2014 and was not time limited (that is, no historical cut-off date was set). Only English language material was accessed.

The evidence was assessed according to the NHMRC rating system that refers to the design of reviewed studies.

Level I	A systematic review of all relevant Randomised Controlled Trials (RCT)
Level II	At least one properly designed RCT
Level III-1	Well-designed pseudo-RCTs
Level III-2	Comparative studies with concurrent controls and allocation not randomised, case-control studies or interrupted time series with a control group
Level III-3	Comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group
Level IV	Case series, either post-test or pre-test and post-test.

Beyond research studies, evidence can be obtained from what is referred to as 'Level 5' sources. These include what the UK's Oxford Evidence Based Medicine group refer to as 'expert opinion without explicit critical appraisal, or based on physiology, bench research or 'first principles' ([Centre for Evidence Based Medicine](#)).

Results

There was limited evidence, either scientific or otherwise, on the topic of haemodialysis services outside traditional units. The Cochrane Library systematic reviews, the source of Level 1 evidence, focused on clinical and technical management of kidney disease. The search did not identify any research studies that directly explored the topic, so there was no opportunity to rate the quality of the evidence. Most of the materials obtained were purely descriptive, rather than evaluative. A possible explanation is that services may have been evaluated but the findings are not available in the public domain. In the course of the overall project, the search for such information will continue, via contacting key stakeholders directly.

The chief areas considered in the evidence base can be placed into three categories: mobile or satellite services, services for 'transient' patients and specialised vacation booking brokering systems. An overview of the evidence for each of these is provided below.

Mobile and satellite dialysis services

There are several mobile dialysis services in Australia. Given the vast distances to be travelled in Australia, most of these services operate for rural and remote communities. The services usually operate as satellite services, from the nearest health service. They are not necessarily 'mobile' therefore: rather, an 'offsite' or satellite unit is made available to a community where there a cluster of patients. Case examples are given below.

The aged-standardised incidence of ESKD is greater for Aboriginal and Torres Strait Islander (ATSI) communities. The greater prevalence of CKD in some ATSI communities is due to the high incidence of risk factors, plus increased likelihood of poor living conditions, malnutrition, alcohol abuse and streptococcal throat and skin infection. Since many ATSI communities live in rural and remote communities, the majority of services illustrated have been established to meet the needs of this sub-population.

Many of the initiatives highlighted arose from the findings of the Central Australia Renal Study (CAR), commissioned in 2010 by the Office for Aboriginal and Torres Strait Islander Health (OATSIH), part of the Commonwealth Department of Health and Ageing (DoHA). Much lobbying and advocacy work preceded the CAR study, the aim of which was to conduct cross-jurisdictional research in order to develop a range of feasible clinical services delivery models to meet current and projected needs for ATSI people from remote communities in the Central Australia (CA) region requiring dialysis.

Kimberley Renal Support Service

KAMSC (Kimberley Aboriginal Medical Services Council), a regional Aboriginal Community Controlled Health Service (ACCHS), is an umbrella agency for a network of member ACCHS representing towns and remote communities across Western Australia's Kimberley region. A satellite dialysis centre was established in Broome in 2002. However, by 2004 it had reached capacity (40 haemodialysis patients) due to the increased incidence of ESKD in the region. A review showed that dialysis prevalence had more than tripled in 10 years and was growing faster than elsewhere in Western Australia (WA). Renal services needed to expand so that people needing haemodialysis didn't need to move to Perth. In 2008 the Kimberley Renal Support Service (KRSS) was set up, to provide dialysis services and ESKD prevention programs. These incorporate 'early detection, tracking / monitoring, management of CKD and its risk factors, timely and coordinated pre-dialysis education and care, and improved support for clients on home therapies'. Subsequent Commonwealth government funding led to the creation of dialysis units in Derby, Fitzroy Station and Kununurra. These services treat patients in a satellite service. As of October 2013, they had capacity for 36 patients. A similar number are on a waiting list and continue to use services in Perth and Broome.

Northern Territory Renal Services

The Northern Territory Renal Services mobile dialysis bus has been fully operational since March 2011. The bus enables patients to be less dependent on regional hospital facilities. However, this service is not an outreach service. Its aim is to provide short-term dialysis, by allowing patients to attend events such as festivals and sorry business, which necessitate patients being away from home and from usual treatment centres in Alice Springs and Darwin. The service recognises patients' cultural needs and provides greater flexibility of service delivery, tailored to their community lifestyle.

Purple House Dialysis Centres

The Western Desert Nganampa Walytja Palyantjaku Tjutaku - Aboriginal Corporation (WDNWPT) manages a number of so-called 'Purple House' Dialysis Centres which provide haemodialysis in Alice Springs, Walungurru (Kintore), Yuendumu and Ntaria (Hermannsburg). In 2011, they launched a mobile dialysis unit, the 'Purple Dialysis Truck' to serve areas across the Central Desert Region in the Northern Territory, South Australia and Western Australia. The project was developed by the Pintupi people with the financial support of the NT government, Fresenius Medical Care Australia, Medicines Australia and a grant from the Jimmy Little Foundation's 'Thumbs Up' health promotion program. The partners hope to demonstrate the robustness and effectiveness of the program in order to obtain re-current funding. The 'Purple Dialysis Truck' project not only provides an outreach dialysis service, allowing dialysis patients to spend some time at home with family/community; it also has awareness raising and educational objectives. Communities are encouraged to promote healthy eating, particularly amongst young children, to prevent chronic diseases such as diabetes and kidney disease. Adults with diabetes and kidney disease receive education about self-management and be encouraged to regularly attend medical check-ups. The aim is to prevent the need for dialysis.

Country Health South Australia Local Health

In January 2014, Country Health South Australia Local Health launched their renal dialysis truck. Funded by the Commonwealth and South Australian governments, the service enables outback patients, chiefly from Anangu Pitjantjatjara Yankunytjatjara (APY) lands and Coober Pedy to access dialysis without having to travel to Port Augusta or Adelaide for treatment.

International models

Elsewhere, such as in the US and Canada, similar mobile and satellite services operate for rural and remote communities. For example, Alberta Health Services use a 'Greyhound' type bus to provide a dialysis service to rural patients. Commonly, a large truck or trailer takes the necessary equipment to such locations. There are clear benefits for patients, as travel time is much reduced, making access easier, cheaper and more convenient.

Alberta Health Services

Alberta Health Services has operated a mobile dialysis service since 2008. In 2010, the service was extended to Lac La Biche for three days per week. The bus is equipped with six renal dialysis stations, two renal health nurses and a nephrologist. Telehealth videoconferencing equipment links patients to allied health and specialist staff based in Edmonton. It is located adjacent to the local hospital. It saves patients travelling several hours to Edmonton or St. Paul to receive treatment.

New Zealand, in particular Christchurch, pioneered home haemodialysis (HHD) training in the 1970's. By 2009, the proportion on HHD was 25%. Whilst still representing a greater proportion of the population than in Australia, the majority are still treated at hospitals. This is due to a number of factors, including a diminishing interest in HHD amongst clinicians and the rise in comorbidities in the population, making HHD less attractive. So, whilst the North and South islands have satellite sites, by and large there are limited opportunities for holiday dialysis arrangements. As will be seen below, these are chiefly available for those who have HHD training and can self-manage their condition.

Vacation models

With regard to programs enabling people on dialysis to take holidays, there is much less evidence available. Researchers have commented upon the small proportion of those on HD who take holidays: a US study of quality of life in patients receiving HD reported that only 13% had been on holiday since beginning dialysis (Rocco, Mercieri, & Yavuzer, 2006). The people receiving HD had significantly low scores on the SF-36 (a measure of quality of life) than the general population. This finding suggests that whilst holidays can benefit a person's health, people on dialysis may find it too

difficult to contemplate arranging a holiday. The anecdotal evidence provided by consumer feedback on the websites access suggests that the challenges can be addressed. Most resources recommend the person on dialysis discuss the situation with their usual healthcare provider, so that all the factors can be considered (Black, 2009). Practical factors such as service and insurance costs need to be determined. Researchers have also highlighted the need for good nutritional advice to be given to patients, since eating habits can alter on holidays (Ohlrich, 2006).

The following sections provide a brief overview to illustrate the facilities currently available in Australia and overseas. Specific financial arrangements are not outlined, since these can alter over time. There are often inter-state and inter-country reciprocal health cover arrangements. For actual holiday costs, some agencies operate funding schemes to support those on low and fixed incomes. For example, in the Netherlands, a person can apply to the [Netherlands Kidney Foundation](#) for support.

Australia

Across Australia, a number of permanent sites offer services to those travelling, but places are limited and need to be booked. Payment is often required from interstate visitors. For example, Lorne Dialysis Unit operates as a satellite unit of Geelong Hospital (Barwon Health): this means there isn't a renal physician on site.

The New South Wales (NSW) government operates an 'Away from home haemodialysis' (AFHH) program. The AFHH Program aims to increase flexibility for NSW residents requiring haemodialysis. The service, run by EnableNSW, facilitates access to dialysis services when travelling away from home for work, holiday and educational purposes. Eligible patients can access up to three sessions per year, at no cost, at a participating private renal unit elsewhere in Australia or Auckland, New Zealand (subject to availability and program funding).

In Victoria, the consumer-led Dialysis and Transplant Association (DATA) have two holiday homes in Rosebud and Yarrowonga both equipped with dialysis machines and RO water filtration systems. More details can be found at: [Victorian Holiday Homes](#).

Kidney Health Australia host a 5-day Kids Kidney recreational camp annually. The program has operated for over a decade for children (aged 7 to 17) from across Australia. Camps have been held in Queensland, Victoria and South Australia. These camps are open to children, their siblings and parents. The camps have onsite paediatric renal nurses. There is scope for family members to learn more about kidney disease as well as for the kids to have fun. Kidney Health Australia are also currently developing a [Kidney Campervans](#) program, to provide important respite or holiday dialysis

options for those on dialysis. This program will be available to those who have received training in home haemodialysis. The campervans will be specially fitted out with dialysis machines and available initially on the Gold Coast in Queensland. The goal is for this program to be expanded to key cities nationally as funds are available. The Wade Family has generously pledged \$50,000 to get this program started and Mr Wade is raising funds through various adventure motoring trips.

New Zealand

New Zealand offers a range of holiday options. It is not clear whether they are for NZ residents only. Funded by Lions Clubs, the Otago and Southland Caravan accommodates six people and has a Fresenius 4008b machine in a private area. The caravan can be hired for a week for a small fee, for use during specified periods at various resorts and locations throughout Otago and Southland. The Hawkes Bay Mobile Holiday Camper Van provides accommodation for six and space for a haemodialysis machine. The Wellington Regional Kidney Society offers a three bedroom home in a suburban street on the outskirts of Taupo. One room houses a Gambro AK 90 'bicarb' machine. The Christchurch Kidney Society has a mobile unit for direct hire to NZ and overseas patients, with the potential of reduced or waived fees for those under the care of Christchurch Hospital. These services are only available to those with HHD training, as the equipment is not supported by healthcare staff.

United States and Canada

The US 'summer camp model' is available to children and adults. The National Kidney Foundation (NKF) produces a comprehensive directory listing camps throughout the United States that accommodate kids with CKD and their families ([National Kidney Foundation](#)). Some camps cater also for adults with CKD. One example is Camp Chimer, sponsored by the Children's Mercy Hospital, Kansas, the Dream Factory and the National Kidney Foundation of Kansas and Western Missouri. Children between 9 and 17 years old who have a kidney transplant, or who need HD or PD can attend. Another, Camp Reynal, has been operating in Texas since 1992, catering for over 1,200 children. It aims to provide an 'exciting, challenging, encouraging, supportive, safe and healthy environment for children with renal and urology disease, and to foster fun, growth, exploration, discovery, friendship, self-esteem and independence. Through support from corporate, individual, and foundation donors, Camp Reynal is one of the few US camps providing on-site dialysis. The [YMCA](#) has a ranch in the Colorado Rockies with an on-site dialysis center. Other options can be found via the [Dialysis finder service](#).

The Canadian Association of Nephrology Nurses and Technologists (CANNT) Journal published an account of a couple fitting out a campervan with HD equipment and touring around Canada and the US (Payumo, 2006). A letter to the journal commented on the increase in cruises equipped with support for people needing dialysis (Pengelly, 2006).

Europe

People on dialysis in the European Community (EC) have the benefit of reciprocal healthcare agreements when travelling within the EC on holiday. A number of agencies will assist people with holiday bookings, either by telephone or online. Several of the organisations' websites, such as that of the UK's [National Kidney Federation](#), provide consumer feedback on the arrangements at a wide range of overseas dialysis services. In Scotland, three nurses established Holiday Dialysis Scotland Ltd in 2003, to address the dearth of holiday options ([Holiday Dialysis Scotland](#)). The company operates a centre in Edinburgh in a shopping strip, rather than in a hospital. It is staffed with two nurses and fees are usually payable by the persons' usual provider (Smith, 2003). Another service in England offers dialysis in the seaside town of Bournemouth and provides potential users links to local accommodation.

International

A number of privately run services that operate as holiday brokers for people on dialysis, both nationally and internationally. The extent to which there is awareness of these amongst patients is not known. The independent [Global Dialysis](#) has operated since 2000, offering holiday travel information. [Holiday Dialysis International](#), an organisation owned by Fresenius Medical Care (providers of dialysis equipment) offers a free world-wide brokering-booking service for dialysis sessions to HD patients. [IDO Tourism](#), a French-based not for profit organisation, is one of several agencies offering assistance in booking holidays worldwide. Their 'Eurodial' guide lists information about dialysis sites worldwide. Although many countries have English speaking staff, the IDO tourism website has lists of useful phrases for HD patients, such as "the arterial needle is placed here", "I normally dialyse atmn Hg positive and ...mn Hg negative pressure" and "May I have a blanket" in French, Spanish, German and Italian. The [Dialysis Escape Line Australia](#), a not for profit company based in South Australia, supported by Fresenius Medical Care, offer cruises to New Zealand and Fiji and a holiday based at the Sheraton, Port Douglas. Such options are often costly and therefore not accessible to all.

Dialysis equipment and renal service companies offer resources to connect patients to centres worldwide. For example, details of [B.Braun dialysis centres](#), [MHL Ltd](#) and [Diaverum](#)'s brokering services can be accessed on-line. Most of dialysis units are located in a hospital and so provide access to a more extensive medical care network, if required. Fresenius Medical Care North America (FMCNA) operates a Patient Travel Service, handling patient travel requests. Its services are available to all dialysis patients. The Patient Travel Service deals with thousands of enquiries from both domestic and international patients. Since 2011, FMCNA has opened two units in popular US holiday

destinations, the Smoky Mountains, Tennessee and Myrtle Beach, Southern California, for transient patients.

Big Red Kidney Bus project

Kidney Health Australia's Big Red Kidney Bus project is a world first initiative for people on dialysis. The Big Red Kidney Bus will be staffed by two renal nurses, contain three chairs and will stay in one popular Victorian tourist destination for 6 weeks and then move to another. The service can support up to 36 people per week. The project complements those discussed in this review because of the following features:

- The project was initiated and has been driven by consumers, in partnership with Kidney Health Australia
- The service is mobile, enabling users to access different holiday destinations
- The service is fully staffed by specialist nurses and a renal technician
- The service will operate in places where affordable accommodation is available
- The service will be for people on dialysis seeking a holiday, those travelling because of work or family commitments, and for local residents who would otherwise have to travel long distances for dialysis
- The project will incorporate a treatment booking scheme operated by Kidney Health Australia and Monash Health
- The project will include school and community education on kidney health at the Bus locations

Concluding comments

This overview of the current information available on service arrangements to enable people requiring haemodialysis to access dialysis services when on holiday suggests that a model such as the Big Red Kidney Bus project doesn't currently operate. Whilst there is information about mobile or satellite services, services for 'transient' patients and specialised vacation booking brokering systems, there is a paucity of data regarding their effectiveness and their impact upon the health and wellbeing of people on dialysis. The evaluation that is to accompany this review will begin to address this crucial gap in the scientific evidence base. There is clearly great scope for research to assess the clinical impact, quality, consistency, generalisability and applicability of such services for people on dialysis.

The Big Red Kidney Bus project has already addressed many of the technical challenges to operating the service. These will be further assessed and evaluated during the pilot implementation phase. This also benefits from input from consumers and other key stakeholders. Their feedback on addressing attitudinal barriers to accessing the service will be critical to the project's successful implementation.

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