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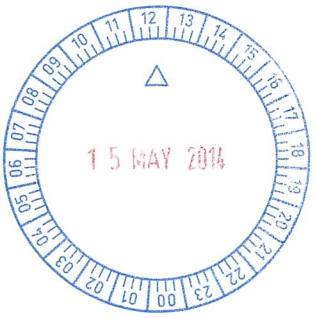

Standing Committee on Public Administration
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15 May 2014

Inquiry into the Patient Assisted Travel Scheme (PATS) in Western Australia

Kidney Health Australia requests this submission be accepted as part of the 'Inquiry into the Patient Assisted Travel Scheme' (PATS), undertaken by the Western Australian Parliament's Standing Committee on Public Administration.

Kidney Health Australia is the peak national body representing the needs of those with kidney disease in Australia. As the lead organisation in the kidney sector, Kidney Health Australia advocates on matters relating to the welfare of kidney stakeholders and the delivery of services to people affected by chronic kidney disease (CKD), in all its stages. Furthermore, Kidney Health Australia has close ties with consumers, the medical community, renal units around the nation and is a member of the Australian Chronic Disease Prevention Alliance (ACDPA) and the National Vascular Disease Prevention Alliance (NVDPA). Kidney Health Australia has also previously represented the views of dialysis patients and those suffering from kidney disease, and experience with such travel schemes in other jurisdictions.

Kidney Health Australia would like to declare that we operate two accommodation houses in Perth which were established to provide a gap in housing availability for living kidney transplant donors. In 2006, two houses were leased by Kidney Health Australia from Foundation Housing to provide accommodation for live kidney donors from rural Western Australia towns. Feedback from major Western Australia hospitals had highlighted the need for patient accommodation for live donors who were often paying for rent or a mortgage back home as well as for the accommodation they needed post-surgery in Perth.

These two houses named Haywood and Hutchison after two senior nephrologists are the only private, fully furnished and fully subsidised living quarters for live donors in Perth. The Western Australia Patient Assisted Transport Scheme (PATS) cover the cost of accommodation and Kidney Health Australia covers utilities, cleaning and insurance ensuring a zero cost for patients and a stress-free comfortable stay. In 2013, nine families were housed and the occupancy rate was 95%.

Kidney Health Australia would like to declare this at the beginning of the submission, so the committee are aware of our involvement and interaction with the PATS system, including our role in filling an identified need in accommodation, in part, through funding supplied by PATS. However, we strongly believe that the views expressed below represent our best advice in respect to the PATS

system as a whole – regardless of our involvement in supplying some accommodation to those who need it - and that these views were arrived at through consultation with the wider medical and health sector.

The State of Kidney Disease in Australia

It is estimated that approximately 1.7 million Australians over the age of 18 years have at least one clinical sign of existing CKD[1]. CKD may further deteriorate into end-stage kidney disease (ESKD), when renal replacement therapy (RRT) - dialysis or transplantation - is required to stay alive. Without kidney function death will occur in a matter of days. A total of 20,756 people were receiving renal replacement therapy – dialysis or kidney transplantation – at the end of 2012[2]. This represents a 6.6% increase from 2011. Currently, 1,106 people are waiting for a kidney transplant in Australia[3]. The most recent data that is available from the Australia and New Zealand Dialysis Transplant (ANZDATA) Registry shows that 2,534 people started kidney replacement therapy (dialysis or treatment) in 2012[4].

The cost of treating ESKD is equally daunting. Economic modelling commissioned by Kidney Health Australia conservatively estimates that the cumulative cost of treating all current and new cases of ESKD from 2009 to 2020 Australia wide to be between $11.3 billion and $12.3 billion[5]. It can cost up to $80,000 (2009 prices) per annum for one person to be on dialysis 'in-centre'. It can cost in excess of that in rural and remote areas. Kidney disease contributes to approximately 15% of all hospitalisations in Australia[6].

ESKD is unique in that unlike like many other chronic illnesses, patients who are treated in centre (hospital or satellite) have to travel a great deal more regularly to maintain treatment. On Dec 31st 2012, there were 1,144 patients on dialysis[7] in Western Australia. Of these 884 were attending a satellite or hospital haemodialysis unit for their treatment. These patients require three dialysis treatments per week, each treatment lasting 4-5 hours.

The requirement for transport to centre based dialysis is a major hurdle for many Western Australians. It is felt more acutely by the elderly, those with poor social networks and those who live great distances from dialysis units. Longer travel times have been shown to be associated with increased mortality and a diminished quality of life. Transport options are lacking and this further complicates the situation by requiring relocation to larger centres for treatment, away from home.

Indigenous Populations and CKD

Kidney disease is a significant health problem for all Australians, but severe kidney disease is more common among Indigenous people than among non-Indigenous people. In particular, the prevalence of CKD ESKD among Aboriginal and Torres Strait Islander peoples are consistently

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[1] Australian Bureau of Statistics. Australian Health Survey: Biomedical Results for Chronic Diseases, 2011-12. ABS, Canberra; 2013.
[2] ANZDATA. Summary of Australia and New Zealand Dialysis and Transplantation, 2012. Australia and New Zealand Dialysis and Transplant Registry, South Australia, Adelaide; 2013.
[3] www.anzdata.org.au/anzod/v1/waitinglist2014.html
[4] ANZDATA, 2013, op.cit.
[5] Cass A, Chadban S, Gallagher M et al. The economic impact of end-stage kidney disease in Australia: Projections to 2020. Kidney Health Australia, Melbourne, Australia; 2010.
[6] Australian Institute of Health and Welfare. *Australian hospital statistics 2009-10.* Canberra: Australian Institute of Health and Welfare; 2011.
[7] ANZDATA, Summary of Australia and New Zealand Dialysis and Transplantation, 2012. 2013, op.cit.

reported as significantly higher than among other Australians[8]. People living in remote areas of Australia, have a much higher rate of ESKD than their metropolitan counterparts[9]. Data from the Australian Institute of Health and Welfare shows the rate of ESKD in remote and very remote Australia was up to four times as high as the rate of ESKD in major cities with rates of ESKD highest in northern Australian Indigenous communities[10]. Rural patients who have kidney disease therapy such as dialysis face unique challenges that affect outcomes. According to the ABS, over half a million people in Western Australia live in rural and remote locations, and over 40% of the Aboriginal population in Western Australia lives outside metropolitan centres[11].

People with CKD require extensive hospital services; as such, CKD is a significant cause of hospitalisation for the Indigenous Australian population. This is particularly the case for dialysis. In 2009-10, care involving dialysis was the most common reason for the hospitalisation of Indigenous Australians: they were hospitalised at 11 times the rate of other Australians[12]. Indigenous people have substantially higher death rates than other Australians from the majority of causes and diseases of the kidney and urinary system. Indigenous people are more likely to die from kidney disease that non-Indigenous people, with the death rate ratios being particularly high after the age of 25 years for both Indigenous males and females compared with rates for non-Indigenous Australians[13].

In light of these challenges, Kidney Health Australia is calling for improved forward planning that considers patient transport needs and service availability, in light of the fact there is not adequate access to resources to provide minimum standards of care for the growing number of Indigenous people dependant on dialysis. A comprehensive approach that addresses the gap in transport services and accommodation for Indigenous Australians with kidney disease should be an immediate priority.

The Western Australia CKD Challenge

The treatment of CKD in Western Australia is not dissimilar to the challenges faced in other mainland states, given Western Australia's vast physical geography, significant population of Aboriginal peoples and a metropolitan population centred in a main capital. Both northern based remote Aboriginal populations and those from the Pilbara and Goldfields are required to travel significant distances, should they need treatment in major population centres. If dialysis facilities or suitable housing are not available regionally many of these people have to relocate to Perth for treatment.

To put this in perspective, as of the end of April, Kidney Health Australia has been notified of 76 Indigenous patients in Perth waiting for placement in remote/rural satellite facilities, closer to their families. The patients on record as waiting the longest are five years. In the meantime they are required to stay in Perth, where there are significant accommodation shortages, not to mention the impact of social and psychological aspects of being away from home for such prolonged periods.

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[8] Stumpers S, Thomson N. Review of kidney disease among Indigenous people. *Australian Indigenous Health Bulletin* 2013;13(2)

[9] Australian Institute of Health and Welfare. Chronic kidney disease: regional variation in Australia. Cat. no. PHE 172. Canberra: AIHW; 2013.

[10] AIHW, Chronic kidney disease: regional variation in Australia. 2013, op.cit.

[11] http://www.ausstats.abs.gov.au/ausstats/subscriber.nsf/0/526FE126443EBCC6CA257718001D547F/$File/47130_2006_reissue.pdf

[12] AIHW, *Australian hospital statistics 2009-10.* 2011, op.cit.

[13] Australian Bureau of Statistics. *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples.* Canberra: Australian Bureau of Statistics, 2010.

Recommendation 1: Address the Need for Greater Financial Support in Western Australia

In order to tackle kidney disease in Western Australia, the PATS scheme in Western Australia must be equitable, consistent – and ideally better – to what is offered in other states, noting the specific challenges outlined above.

Greater distances travelled for treatment can create barriers to employment, and affect access to family and social support. Distance from health care facilities has been identified as a barrier associated with Aboriginal populations in Western Australia. Those that pay the most for travel are disproportionately represented in regional areas.

Payment per kilometre

Under the current Western Australian scheme, the payment rate per kilometre is the lowest in the country. At 16 cents per kilometre in reimbursement it sits at almost half of Queensland's 30 cents. It should be noted that the NRMA estimate that the actual cost of running a small car is roughly 56 cents per kilometre, and a large car can be in excess of 97 cents per kilometre. For taxation purposes, the Australian Tax Office offers claiming rates of 63 cents for a small car and 75 cents for a large car. Both these figures far exceed the rates of even the most generous state scheme in Queensland – highlighting that these schemes are at best, a contribution to costs accrued, rather than representing a true measure of reimbursement. The current rate of reimbursement in Western Australia therefore falls substantially short.

Threshold travelled

Although Western Australia has adopted a lower 'per trip' threshold with a 70-100 kilometre range and a flat payment more needs to be done to assist dialysis patients.

Other states have recognised and addressed this issue through the introduction of a cumulative weekly figure. By modifying the guidelines they have ensured that those who travel the most kilometres in a given week, such as dialysis patients – can be given access, at the full payment rate. In New South Wales, for example, the "Isolated Patients Travel and Accommodation Assistance Scheme" (IPTASS) is now modified to outline that patients travelling at least 100km each way, or at least 200km per week cumulative distance, are eligible to apply. Therefore a dialysis patient in reality, only needs to travel 33kms each way, before being eligible for the payment rate.

Kidney Health Australia therefore requests the committee strongly consider adopting higher payment rates for those who need to travel for treatment, and include a cumulative weekly distance figure into the eligibility criteria. Western Australia should be in line with other state jurisdictions, such as the Queensland government, in recognising the need to increase funding in this area. Currently to be eligible a patient needs to travel 70km each way, or 420 km cumulative per week, and is paid a flat rate under the provision for the lowest threshold. We request that the government adopt a cumulative figure in line with other jurisdictions of 200km per week in cumulative distance.

Widening the criteria for eligibility and need for support

Currently, patients on dialysis or undergoing tests prior to transplantation may need to attend appointments such as a scan that do not involve a medical specialist consultation. Under the current PATS scheme, patients and doctors are reporting in practice that in order to claim travel reimbursements the person must actually have a specialist appointment. We are aware of people attending Perth for an investigation who book a specialist appointment in order to be eligible for PATS and the specialist appointment is used to sign the PATS form only.

Costs to patients themselves are also rising as fuel and accommodation subsidies have not consistently kept pace with rising costs, particularly in north and west of Western Australia. It has been acknowledged[14] that the scheme does not meet all of the costs associated with accessing specialist services. There are a variety of other out-of-pocket costs that impact on patients who travel, such as the costs for carers, child care, and time off from employment, which further exacerbate financial difficulties.

Not providing an equitable or adequate PATS scheme in Western Australia also potentially bears a greater cost - patients may choose to forego treatments and present later for more acute and costly treatment.

Recommendation 2: Greater Support for Accommodation

Accommodation costs – and general costs of living – have increased substantially in recent times, with little to no change to the basic reimbursements under the PATS scheme. These increasing costs have diminished the benefit of the current PATS entitlements, as they struggle to keep pace with the rising cost of accommodation.

Another issue facing patients in Western Australia is the carer claim. The way Kidney Health Australia currently understands the Western Australia PATS scheme, there is the option to claim $60 for a single traveller, and only $75 for two (patient plus carer). In other jurisdictions, such as the Northern Territory, patients are able to claim $60 per person. Western Australia should seek to match what other states are offering to carers under the scheme.

Equally as important though is the fact that support for accommodation rests on the premise that there is vacancy residing in the system for a patient to stay and use. The situation in Western Australia is showing that in addition to lower accommodation rates than some counterparts, the vacancy rates in areas where patients are seeking treatment are extremely low – making the basic concept of housing during dialysis for some, a luxury.

The situation of those on dialysis and the low to negligible vacancy rate of accommodation in Perth has come under public scrutiny and publicised though the local Western Australian broadcast of the 7:30 report[15]. This report made clear that the situation and plight of those from regional Western Australia, and predominately from Aboriginal backgrounds, that are currently on dialysis but forced to seek treatment in Perth as there is no availability in their regional location. We are aware that the Autumn Centre which is an Aboriginal hostel for renal patients from remote regions is constantly full. Some patients have, and still are, being accommodated in Nursing Homes while they wait to return home.

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[14] 730 Report, Previous PATS review 2001

[15] http://www.abc.net.au/news/2014-03-28/salvation-army-fights-to-fix-homeless-crisis-in/5353774

This is leading to a problem where groups of people, mainly of Aboriginal decent are left homeless in areas surrounding treatment centres because of lack of accommodation services, lack of funds to secure accommodation, the inability for the family to stay with the patient, and the cost of getting the patient to the city for said treatment. Issues that further impact upon the ability access accommodation are individual needs of particular patients, cultural/language issues, socio-economic status, urgency of care, need for support from family – factors that are felt more acutely in the Aboriginal community.

Changing support measures for accommodation in Western Australia should consider factors such as cultural sensitivity; the need to have family with the person receiving dialysis; the potential need to for escorts where the length of stay interstate is lengthy and often; the use of public road transport between visits; travel by road or air at the patient's expense; and the fact that many Aboriginal families might not have access to a vehicle or sufficient financial means to meet the costs of travel, however much it is subsidised.

The 730 report shows clearly that the objectives of a policy to assist patients gain safe access to service can have quite the opposite effect if it is developed without knowledge about the social, demographic, environmental and cultural contexts for Aboriginal patients.

Recommendation 3: Addressing Time Limits

Under the current scheme in Western Australia, those who meet the eligibility criteria face a six-month limit to the provision of continuous PATS accommodation assistance. There is currently no long term accommodation option for dialysis patients who are unable to return home for their dialysis treatments.

Kidney Health Australia is aware of various cases in Western Australia of patients who have used up their six month entitlement and are now unable to return to their home for various reasons. This has left these patients in a precarious position of alternating between hostels and homelessness. We are aware that the Autumn Centre in Perth, for example, is constantly full with renal patients, and many are going between other hostels where there is little to no vacancy. We have been advised that another hostel commonly used under the PATS scheme, Jewell House, has announced its closure at the end of this year[16]; Jewell House is a main centre of accommodation for those utilising the PATS scheme from rural areas. Two floors of the centre is earmarked for PATS clients, requiring dialysis treatment. This announced closure also adds further strain on the system.

Patients who must travel for treatment should not be financially penalised or forced into homelessness, especially when patients in Perth are not there by choice. This situation is borne heavily on those of an Aboriginal background in Western Australia; other than becoming homeless the next alternative is hotel/hostel accommodation which is at least at three to four times the current PATS scheme subsidy.

There is ample justification for directing resources towards improving access to the PATS scheme, one of which is removing the time limit of six months, and giving those facing chronic illness long term support and accommodation.

[16] http://www.perthnow.com.au/news/western-australia/ymca-perth-forced-to-vacate-jewell-house-after-wa-health-department-terminates-lease/story-fnhocxo3-1226878056293

Recommendation 4: Expanding modes of transportation options for patients

Kidney Health Australia understands that air travel is provided under the current PATS scheme when the journey to the nearest specialist is more than 16 hours (one way) by road. In order to seek approval for air travel, a patient needs sanction from a health services manager, in order to approve that air travel is essential to the patient's medical condition. However, it is an added burden to kidney patients to not provide air travel as an option when those patients are facing chronic long term illness. Arguably, the driving distance within Western Australia required to qualify excludes a vast majority of the state to the possibility to travel by air.

Under the current scheme, CKD is also not viewed on equivalence to other illnesses. PATS currently allows for cancer patients undergoing cancer treatment to subsidised air travel for trips associated any treatment if the journey would take more than four hours by road. Patients with CKD facing long journeys should also be able to seek travel and assistance for that travel through flights. Providing this benefit would bring kidney patients in step with other illnesses and options for treatment.

Conclusion

Kidney Health Australia would be available to be consulted further by the Committee, should the Committee request further information.

In summary, the key issues facing those who live with kidney disease, and who are currently using the PATS scheme, which the Committee should, in our opinion, investigate and make recommendations are:

- the payment rates per kilometre to be reflective of the true cost of travelling, and be nationally consistent – in Western Australia the rates are below what is offered in other states, and considerably lower than the actual costs of running a vehicle;
- accommodation rates should at minimum, meet the other rates offered by other jurisdictions, for both the patient and a carer to travel and stay overnight – particularly the very rural and remote groups in Western Australia who face limited locations in which to undertake dialysis;
- the six month limit for claiming accommodation assistance should be removed, and it should be recognised that this constraint is adding a socio-economic burden to the state and causing unnecessary homelessness (as publicised by the 730 report);
- those attending Perth for specialist tests should be eligible if the test is ordered by a specialist physician, even when they do not require review by the physician; and
- the distance travelled prior to eligibility for flights is reduced and consistent to what is offered to other illnesses (i.e. cancer treatment).

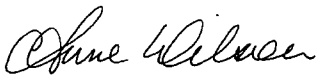
Furthermore, while likely outside the scope of the Committee's ability to make recommendations as it relates to PATS – it is clear that actions needs to be taken to address the short supply of accommodation, regardless of the payment rates.

Kidney Health Australia understands there is room to improve outcomes for patients that utilise the PATS scheme by not only addressing each point as mentioned above, but by also further strengthening remote medical services in Western Australia. Providing greater access to rural

medical services might eliminate the need for many regional patients who currently utilise PATS to seek treatment for as long or as often in a metropolitan centre, such as Perth.

Please feel free for your staff or the review team to contact Mr Luke Toy, National Manager for Government Relations and Policy on 0409 076 576 or luke.toy@kidney.org.au at any stage to discuss. Kidney Health Australia would also be able to arrange for our Medical Director, Dr Tim Mathew and our National Project Manager for Home Dialysis, Ms Debbie Fortnum to also be available so as to provide a medical and patient perspective, noting that Kidney Health Australia is the peak body and has a strong role in representing people with kidney disease.

For your consideration,



Anne Wilson
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