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**KIDNEY  
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**Patron-in-Chief**  
Her Excellency Ms Quentin Bryce, AC  
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## Review of the Patient Assistance Travel Scheme

As you are aware, Kidney Health Australia is the only 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).

### **The State of Kidney Disease in Australia**

It is estimated that approximately 1.7 million Australians over the age of 25 years have at least one clinical sign of existing CKD<sup>1</sup>. 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. At the end of 2011 a total of 10,998 Australians were on dialysis, and according to the Australian Institute of Health and Welfare this figure is expected to increase 80 per cent by 2020. Currently, 1,080 people are waiting for a kidney transplant in Australia<sup>2</sup>.

The cost of treating CKD 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<sup>3</sup>.

The most recent data that is available from the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry<sup>4</sup> shows that 2,453 people started kidney replacement therapy (dialysis or transplant) in 2011. The number of people on dialysis has increased by 4% from 2010 to 2011, therefore resulting in the nearly 11,000 people receiving dialysis treatment at the end of 2011.

With dialysis costing up to \$79,072 for hospital haemodialysis, \$65,315 for satellite, home haemodialysis \$49,137 and peritoneal dialysis \$53,112, it is clearly an expensive treatment (2009 dollars). Current breakdowns indicate that 22% of Australian's receive dialysis at a hospital, 28% were dialysing at home 50% in satellite centres. However, despite the cost effectiveness to government and potential health benefits of home dialysis for the patient, there are significant state-by-state variations, ranging from 38% in NSW to as little as 12% in the Northern Territory and 19% in South Australia.

Even when averaging out the different modalities and their respective usage, Kidney Health Australia estimates that the average cost of supplying dialysis is still a considerable \$65,000 per person, per year. Of course, this represents a national average – the cost of delivering these services is much higher in the

<sup>1</sup> White SL, Polkinghorne KR, Atkins RC, Chadban SJ. Comparison of the prevalence and mortality risk of CKD in Australia using the CKD Epidemiology Collaboration (CKD-EPI) and Modification of Diet in Renal Disease (MDRD) Study GFR estimating equations: The AusDiab (Australian Diabetes, Obesity and Lifestyle) Study. *Am J Kidney Diseases* 2010;55(4):660-70.

<sup>2</sup> [www.anzdata.org.au](http://www.anzdata.org.au)

<sup>3</sup> Cass A et al. The Economic Impact of End Stage Kidney Disease in Australia: projects to 2020. Published 2010. Available at: <http://www.kidney.org.au/LinkClick.aspx?fileticket=vave4WFH73U%3d&tabid=635&mid=1837>

<sup>4</sup> ANZDATA. Australia and New Zealand Dialysis and Transplant Registry Interim Summary. 2012. [www.anzdata.org.au](http://www.anzdata.org.au)



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Northern Territory where a range of other factors make the delivery of this life saving treatment more expensive.

### **Current Patient Assistance Transport Schemes**

End stage kidney disease requires dialysis or transplantation as a long-term treatment. Transplantation is limited by the age of the person and the availability of kidneys for transplantation. Dialysis is available as a self-managed home therapy or in a centre where health professionals perform the dialysis. The majority of these patients require three dialysis treatments per week. This requirement for transport to centre based dialysis is a major hurdle for many Australians. It is exacerbated in the elderly, those with poor social networks and those who live great distances from dialysis units.

In 2007 Kidney Health Australia (KHA) undertook a consumer survey that determined the distances being travelled, the associated costs and the preferred modality of transport.<sup>5</sup> In 2010, KHA undertook the Consumer Perspectives on Dialysis survey which included questions regarding transport.<sup>6</sup> Both surveys confirmed an ongoing issue with transport availability and the financial commitment required to attend dialysis. Both of these can be provided to the review team upon request.

Going to dialysis treatment therefore requires a high degree of commitment, and for many people this may mean utilizing different modes of transport throughout the week, with a strong reliance for many on the Patient Assistance Transport Scheme. Indeed our survey has shown that overall it was via private transport by car that accounted for 74.4% of dialysis travel – 39.5% being driven by another person and 34.9% driving themselves. For dialysis patients however, unlike patients who may travel less regularly for treatments of other illnesses, dialysis for in-centre patients is characterized by regular travel – at minimum, three times a week, every week, to stay alive.

The fact that such regular treatments often means reduced working hours, or unemployment, and on top of the added associated medical costs, it soon becomes very clear that the level of financial reimbursement available to patients for travel becomes very significant to their ongoing financial viability. It should come as no surprise that our survey highlighted that for the nearly 75% of consumers who drive or who are driven, incur costs for travel that comprise approximately 15% of their pension. Furthermore, those who pay the most for travel – over \$50 per week – are disproportionately represented in regional areas.

In the Northern Territory, the current Patient Assistance Travel Scheme assists residents to access a range of essential specialist medical / surgical services, where services are not available locally, from within the Northern Territory or from a visiting service. The current scheme provides assistance with travel, and if applicable, accommodation costs to residents of the Northern Territory who are required to travel more than 200kms to the nearest specialist medical treatment.

The current rates of payment are 15 cents per kilometre (for up to three patients travelling together) and \$35 per night as a contribution to accommodation costs in a commercial setting. However, current requirements stipulate that in order to be eligible for these payments, patients are required to travel more than 200 kilometres, one way, to the nearest specialist medical treatment.

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<sup>5</sup> Kidney Health Australia 2007 Dialysis Consumer Transport Survey

<sup>6</sup> Kidney Health Australia 2010 Consumer Perspectives on Dialysis, p38



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As Patient Assistance Travel Schemes are administered by State and Territory Governments, each state has a differing scheme, payment rates and eligibility requirements. Currently, Queensland and Tasmania offer the lowest overall thresholds for the distance to be travelled, before patients are able to access the payments – with 50 kilometres the minimum threshold. The current rate in the Northern Territory, which is four times this level, puts Northern Territory patients at a clear disadvantage to their counterparts in other jurisdictions.

Queensland also offers the current highest rate of payment, providing from 1 January 2013 a doubling of the vehicle mileage subsidy from 15 cents per kilometre to 30 per kilometre. It should be noted that the NRMA<sup>7</sup> estimate that the actual cost of running a small car is at minimum 56 cents per kilometre, and large car can be in excess of 97 cents per kilometre. For taxation purposes, the Australian Tax Office<sup>8</sup> currently offers claiming rates of 63 cents for a small car and 75 cents for a large car. Both of these figures far exceed the rates of even the most generous State and Territory schemes, highlighting that these schemes are at best, a contribution to assisting in the covering of costs, rather than representing a true measure of reimbursement. The current rates of reimbursement in the Northern Territory therefore fall considerably short.

### **The need for a cumulative weekly kilometre figure**

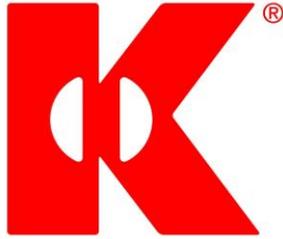
For patients on dialysis, as outlined above, travel for in-centre dialysis is at minimum three times a week, resulting in patients travelling a great deal, often much more than many other patients receiving less regular treatments for other chronic conditions. However, as Kidney Health Australia currently interprets the scheme in the Northern Territory, unless each trip exceeds 200 kilometres – one way – patients cannot obtain financial assistance. As a result of this, dialysis patients who may travel short of 200 kilometres one way, but who still travel well in excess of 200 kilometres per week for dialysis treatment are rendered ineligible.

For example, a patient who travels 80 kilometres each way for dialysis treatment would therefore travel 160 kilometres per dialysis session, which when dialysing three times a week, would result in 480 kilometres travelled for essential medical treatment. However, they would not, under current guidelines be able to claim for travel assistance, where as someone travelling much less for other forms of medical treatment would be able to do so. This creates a clear inconsistency in the scheme, which is designed to support those who travel most for essential medical treatment, but currently renders many of them ineligible.

Other States have recognised this obvious oversight in schemes that are structured in such a manner, and have modified their guidelines to ensure that those who travel the most ‘cumulative’ kilometres in a week – dialysis patients – now have access to their respective patient assistance travel schemes. In NSW the Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS) is now modified to outline that ‘patients travelling at least 100kms each way, **or at least 200km per week cumulative distance, are eligible to apply**’.

<sup>7</sup> <http://www.mynrma.com.au/motoring/buy-sell/buying-advice/car-operating-costs/about-car-operating-costs.htm>

<sup>8</sup> <http://www.ato.gov.au/individuals/content.aspx?doc=/content/33874.htm>



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***We therefore request strong consideration by the review team and the Northern Territory Government to consider adopting a 'cumulative' weekly distance travelled figure into the eligibility criteria, in addition to a revised one way threshold.***

Other states that have begun to recognise the special circumstances around dialysis patients and their need to travel more regularly include Western Australia and Victoria. In Western Australia, a lower 'per trip' threshold has been adopted for dialysis patients and in Victoria the scheme includes eligibility based upon either a single trip distance, or like NSW, a cumulative total per week. Noting the existing precedence set by other states, most notably NSW, we would request strong consideration by the review team to adopting a similar approach in the Northern Territory.

### **Conclusion**

Kidney Health Australia requests the opportunity to be consulted by the review team so as to provide input into the review, as part of the broader consultation process underway by the Northern Territory Government.

In advance to that consultation occurring, the below represents a short summary of some of the key issues that Kidney Health Australia would like to flag for further discussion with the review team:

- That the review team consider raising the current payment rates per kilometre noting that they are currently below what is offered by other States, and considerably below the actual costs of running a vehicle, based on a number of estimates;
- That the review team consider lowering the current 'one-way threshold' from 200kms to a lower figure, noting that a number of other States have adopted figures as low as 50kms, and in some cases an additional 'stand alone' one way figure adopted for dialysis patients;
- The review team consider raising accommodation rates to meet the higher rates offered by other State and Territories, particularly noting that there is a significant proportion of Northern Territory residents required to travel and stay overnight, particularly the very rural and remote patient groups in the Northern Territory, and the limited locations in which to undertake dialysis;
- That the review team **strongly considers** the need to introduce a 'cumulative' distance travelled per week figures, so that those who are travelling very significant distances per week for regular dialysis treatments are eligible under the scheme, noting they represent some of those who most need this support.

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](mailto:luke.toy@kidney.org.au) to arrange a mutually suitable time for a phone discussion with the review team. Kidney Health Australia would be able to arrange for our Medical Director, Dr Tim Mathew, our National Health Programs Manager, Ms Anne Revell and Ms Debbie Fortnum to also be available so as to provide a medical and patient perspective to the review as part of that process.