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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[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. 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[2].

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[3].

The most recent data that is available from the Australia and New Zealand Dialysis Transplant (ANZDATA) Registry[4] 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

[1] 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.
[2] www.anzdata.org.au
[3] 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
[4] ANZDATA. Australia and New Zealand Dialysis and Transplant Registry Interim Summary. 2012. www.anzdata.org.au

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course, this represents a national average – the cost of delivering these services is much higher in the more rural locations 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.[5] In 2010, KHA undertook the Consumer Perspectives on Dialysis survey which included questions regarding transport.[6] 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 need for greater levels of support

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.

There are a number of patients in South Australia who rely on alternative travel schemes, other than PATS, for a range of reasons. However, recently the Red Cross Transport notified renal units and key stakeholders that they were are no longer in a position to provide transport for new patients to, and from, dialysis. With the recent reduction in this service, greater pressures are likely to be placed on existing alternative services, carers and family members to ensure their loved one attends each dialysis treatment. Kidney Health Australia has also been made aware of situations where patients are now driving themselves to their dialysis treatments, due to the inability to access taxis or other services, which is raising many safety

[5] Kidney Health Australia 2007 Dialysis Consumer Transport Survey
[6] Kidney Health Australia 2010 Consumer Perspectives on Dialysis, p38

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concerns, as well as potentially adding pressure to the PATS scheme. In some cases, these patients have had to be admitted to hospital, in part, due to transport concerns.

This situation has highlighted the current inconsistencies in the services available to public and private patients. Essentially new private patients in satellite units are no longer able to access transport services, and there have been situations where private dialysis patients are considering returning to the public system for treatment. If this occurs, patients could access transport though the hospitals transport provider, but the implications for the public dialysis unit would result in more patients in their care, which also has cost considerations.

In South Australia, the current Patient Assistance Travel Scheme assists residents with travel, escort and accommodation costs to residents of South Australia who are required to travel more than 100kms to the nearest specialist medical treatment.

The current rates of payment are 16 cents per kilometre and $30 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 100 kilometres, one way, to the nearest specialist medical treatment. It also requires that patients make a co-contribution of $30, which is deducted from the claim.

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 South Australia, which is twice this level, puts South Australian 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[7] 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[8] 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 South Australia 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 South Australia, unless each trip exceeds 100 kilometres – one way – patients cannot obtain financial assistance. As a result of this, dialysis patients who may travel short of 100 kilometres one way, but who still travel well in excess of 100 kilometres per week for dialysis treatment are rendered ineligible.

[7] http://www.mynrma.com.au/motoring/buy-sell/buying-advice/car-operating-costs/about-car-operating-costs.htm
[8] http://www.ato.gov.au/individuals/content.aspx?doc=/content/33874.htm

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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**'.

We therefore request strong consideration by the review team and the South Australian 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 South Australia.

<u>The need to support all dialysis patients and their carers</u>

For those undertaking home dialysis travel is significantly lessened, as they can undergo dialysis in their place of residence. This saves the government not only in the PATS reimbursement, but significant amount (more than $30,000 per person, per year in costs in some cases) in costs and associated burdens on the health system.

However, before commencing home dialysis, patients need training at a specialist centre which is usually centralized to metropolitan areas. Home peritoneal dialysis training takes an average of one week, and home haemodialysis takes 6-10 weeks. A carer is usually involved in the training process. Once trained the patient will no longer be required to travel to a centre for dialysis, saving them three return journeys, associated costs and many hours travelling each week.

Currently for country patients in South Australia they are able to claim $30 per day for themselves and $30 for their career/escort. In Western Australia the subsidy is $60 per patient with a $75 reimbursement including a career/escort, and in Queensland the subsidy is $60 per patient with the same amount available for the career/escort.

The costs of accommodation exceed even the most generous reimbursements and this disadvantages those country patients, who not only have to take time off work to train for home dialysis but also have to

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live away from home during this period, only to then return to dialyze at home with out of pocket expenses such as electricity, water, storage and capital costs associated with running the dialysis machine.

The need to support organ donors and transplant recipients

Kidney Health Australia is aware of a number of scenarios where those involved in the kidney transplant process are currently excluded from the PATS scheme. Noting the critical role that organ donation plays in allowing people to discontinue dialysis (a very high cost treatment) and also lessen the burden on the transplant waiting list (which will never meet demand), more should be done to support these people.

For example, to further assist kidney patients Western Australia has sought to further improve incentives for live donors to transplant patients with the introduction of a live donor transport scheme which reimburses individuals for up to $222.30 per day in order to encourage organ donation.

Another issue for live donor reimbursement which has only been addressed in Tasmania is reimbursements across states. A Tasmanian resident can claim PATS for accommodation and travel when they donate a kidney to a family member in another state. Whilst this may only be necessary for a small number of kidney transplant operations it is a vital component in supporting this process.

Indeed, there are a range of specific examples where those involved in the organ donation space 'slip through the cracks'. To assist the review team to examine how the current eligibility criteria fails to account for these individual, we have presented a number of examples at Attachment A.

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 South Australian 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 100kms 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, to travel and stay overnight, particularly the very rural and remote patient groups in South Australia, and the limited locations in which to undertake dialysis;
- The review team consider now changing alternative transport schemes, such as community services such as that provided by the Red Cross, are being discontinued and what alternative arrangements are going to be needed;

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- 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.

- That the review team **strongly consider** the way in which the current scheme does not meet the needs of those involved in organ donation as outlined in the attached examples, and ensure that the forthcoming consultation paper reflect these concerns.

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. I understand from the recently released 'Terms of Reference' that a review paper including options will be circulated for public consultation during August 2013. Kidney Health Australia would like to offer to organise a phone discussion or face to face 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. In addition, noting Kidney Health Australia's strong role in patient representation we would be able to arrange for a range of patient perspectives and specific examples to be provided the review team as to how the current system needs improvement, and what those improvements could entail.

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Examples of Transplant Patients currently ineligible under the PATS scheme

Below are a number of real world, de-identified examples Kidney Health Australia is aware of that highlight some of the current inequities for kidney patients under the current Patient Assistance Travel Scheme (PATS).

Kidney Health Australia is aware of these examples through our connections with kidney patients, carers, families and medical staff. We would ask that if you intend to publicise these examples that you remove any identifying features deemed necessary to protect the privacy of those outlined below, including location details. Kidney Health Australia has removed the names, but maintained location and other features to highlight the detail necessary to the review team of where the current scheme needs addressing, and has done so for the purpose of the review, rather than public dissemination.

- Currently patients are strongly encouraged to return to Westmead Hospital, Sydney, New South Wales for 6 month and 12 month reviews (post Kidney/Pancreas Transplants). At present, Kidney Health Australia understands that patients are only being reimbursed by PATS for their six month review (accommodation), and not their 12 month review.

- Kidney Health Australia is aware of a recent patient from Jervois had an intellectual disability and was not eligible for PATS as the individual lives under 100 kilometres from Adelaide. As a result, the patient was not eligible for accommodation or petrol assistance for time required in Adelaide post-transplant. Kidney Health Australia is aware that the individual struggled financially with the high cost of fuel transiting to and from Jervois for ongoing outpatient appointments post operation.

- A recent patient from the Barossa area and other regions just under 100 kilometres from Adelaide are not eligible for PATS. Post-transplant, it is a long way for them to drive to attend daily outpatient clinics. Patients are unable to drive 2 weeks post operation, and can therefore be required to remain in Adelaide for up to 3 months post operation. Indeed, Kidney Health Australia has been advised that many of the most difficult situations arise from patients who are bordering the 100 kilometre distance mark from Adelaide. These patients often need to be in Adelaide for up to 3 months post-transplant. This is very expensive for patients and their families (fuel and accommodation wise).

- Patients that are on a Disability Support Pension, and who have a household to manage in their home town, (mortgage or rent), have the burden of trying to pay for alternative accommodation and covering petrol in Adelaide. Often these patients do not have any sick leave or annual leave to fall back on, in addition to difficult employers, meaning that the period is not often very difficult but has the added concern of no income.

- Non-Australian donors are also impacted from the scheme. The non-Australian residents are donating to spouses and brothers in Australia, and are not eligible for PATS. In these situations there is not active mechanism to support the overseas donor, who is assisting their Australian

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relative (not to mention removing an Australian from the ongoing high cost of ongoing dialysis and lessening the burden on the current donation waiting list). Often the donor is not able to stay with the family member due to lack of space. These patients were not eligible for the live donor payment scheme either.

- There is also a lack of flexibility for cases where there are exceptional circumstances. For example, one example is when an escort also has a carer role for another individual in the immediate family. Kidney Health Australia has been made aware of the example where patient and his wife have a son with Asperger's. The wife is the full time carer for the son with Asperger's and did not have anyone else to care for the child while her husband was admitted for a transplant. The wife needed to be the escort for the patient while he underwent a transplant and therefore had to bring their son with her to Adelaide (due to school holidays). As a result, the accommodation costs are higher for the family.

- As Kidney Health Australia currently understands it, escorts are paid for two weeks post-transplant (as they have an active role of carer and assist with transport). However after this time, we would like to propose that an escort is still paid if required in Adelaide for emotional support. Everyone's journey is different post-transplant and often an escort is involved in assisting with the patient learning new and changing medications. The escort also supports the patient at their ongoing outpatient appointments (including transporting them to the appointments). There are biopsies which look for rejection (a patient requires an escort for emotional support). There are stages when kidneys do not start working, and on occasion post-transplant, a kidney has been removed.