Victoria
125 Cecil Street
South Melbourne VIC 3205
GPO Box 9993
Melbourne VIC 3001

www.kidney.org.au
vic@kidney.org.au
Telephone 03 9674 4300
Facsimile 03 9686 7289

KIDNEY HEALTH AUSTRALIA

Patron-in-Chief
Her Excellency Ms Quentin Bryce, AC
Governor-General of the Commonwealth of Australia

Patrons
Sir Jack Brabham, AO, OBE
Lady Margaret Brabham

Review of the Patient Travel Subsidy Scheme in Queensland

As discussed on 11 December 2013, Kidney Health Australia understands the Queensland Department of Health is currently conducting a review of the Patient Travel Subsidy Scheme (PTSS). Kidney Health Australia requests that this submission be accepted as part of this review, noting our representation of dialysis patients and those suffering from kidney disease. Therefore please find below a brief summary of Kidney Health Australia's position regarding travel assistance as it relates to Queensland, prepared in the limited time available.

In making these suggestions, Kidney Health Australia would like to recognise that the Queensland Government did make significant improvements to the payment rates of the PTSS in 2012, and applauds the initiative and commitment to further build upon these and improve the system through this initial review.

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 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, 1,076 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.

---

[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

Victoria
125 Cecil Street
South Melbourne VIC 3205
GPO Box 9993
Melbourne VIC 3001

www.kidney.org.au
vic@kidney.org.au
Telephone 03 9674 4300
Facsimile 03 9686 7289

KIDNEY HEALTH AUSTRALIA

Patron-in-Chief
Her Excellency Ms Quentin Bryce, AC
Governor-General of the Commonwealth of Australia

Patrons
Sir Jack Brabham, AO, OBE
Lady Margaret Brabham

Current Patient Transport Subsidy Schemes

End stage kidney disease requires dialysis or transplantation as a long-term treatment. Transplantation is limited by the age and health 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 PTSS. Indeed our survey has shown that overall it was via private transport by car that accounted for 66% of dialysis travel – 31% being driven by another person and 35% 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 66% of consumers who drive or who are driven, costs for travel incurred comprise approximately 15% of their pension. Furthermore, those who pay the most for travel – over $50 per week – are disproportionately represented in regional areas. As such, Kidney Health Australia would like to make the following recommendations regarding improving the PTSS.

Recommendation 1: The introduction of 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 Queensland, unless each trip exceeds 50 kilometres – one way – patients cannot obtain financial assistance. As a result of this, dialysis patients who may travel short of 50 kilometres one way, but who still travel well in excess of 50 kilometres per week for dialysis treatment are rendered ineligible.

For example, a patient who travels 40 kilometres each way for dialysis treatment would therefore travel 80 kilometres per dialysis session, which when dialysing three times a week, would result in 240 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

[5] Kidney Health Australia 2007 Dialysis Consumer Transport Survey
[6] Kidney Health Australia 2010 QLD Consumer Perspectives on Dialysis, p125

Victoria
125 Cecil Street
South Melbourne VIC 3205
GPO Box 9993
Melbourne VIC 3001

www.kidney.org.au
vic@kidney.org.au
Telephone 03 9674 4300
Facsimile 03 9686 7289

KIDNEY HEALTH AUSTRALIA

Patron-in-Chief
Her Excellency Ms Quentin Bryce, AC
Governor-General of the Commonwealth of Australia

Patrons
Sir Jack Brabham, AO, OBE
Lady Margaret Brabham

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.

Currently, many of our new patients who require frequent visits for specialist treatment and dialysis in-centre in hospital, cannot access these services in their local hospital due to capacity issues. These patients are not only new patients learning about the new health environment they have entered, they also can have the physical and financial burden of having to travel significant distances, due to the frequency of their specialist visits.

Other states and territories 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 '**at least 200km per week cumulative distance, are eligible to apply**'.

We therefore request strong consideration by the review team and the Queensland Government to consider adopting a 'cumulative' weekly distance travelled figure into the eligibility criteria.

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. The Northern Territory has also responded to Kidney Health Australia's call and introduced a cumulative weekly figure this year. 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 Queensland.

Real examples supporting the introduction of a cumulative figure.

Patient A: A new patient, who cannot access their local Satellite Renal Unit, due to capacity constraints at that unit, travels from North Ipswich to the Princess Alexandra Hospital (38km each way) three times per week. This equates to an accumulative total 228km per week, or 11,856km per year, just for dialysis treatment (in addition to all other renal specialist and other Health related specialist appointments necessary when living with a chronic illness). Under the current scheme this patient is not entitled to PTSS. This patient is struggling emotionally and financially due to this additional strain.

Recommendation 2: Address current administrative issues

Kidney Health Australia has been advised, through the kidney community, that a review of the labour intensive administrative approval process would be beneficial. As discussed above for dialysis patients, frequency of visits to the health service is high, with a minimum of 3 visits per week. It becomes an unnecessary administrative burden for the renal specialist to physically sign off on each hospital visit if it is a recurring event such as dialysis. For example, during the year the renal specialist physically signs the patient's PTSS forms 156 times solely for dialysis sessions, in addition to the number of times PTSS is required for renal specialist/renal outpatient appointments. This is major administrative cost and time burden placed upon the specialist, where a *delegation of authority and a diary system* for recurring treatment could be effectively implemented to create immediate efficiencies in the process.

Victoria
125 Cecil Street
South Melbourne VIC 3205
GPO Box 9993
Melbourne VIC 3001

www.kidney.org.au
vic@kidney.org.au
Telephone 03 9674 4300
Facsimile 03 9686 7289

KIDNEY HEALTH AUSTRALIA

Patron-in-Chief
Her Excellency Ms Quentin Bryce, AC
Governor-General of the Commonwealth of Australia

Patrons
Sir Jack Brabham, AO, OBE
Lady Margaret Brabham

The suggestion has also been made that the forms could be modified so as to not require multiple parties involved in the sign off process, which can currently include: Patient, GP, Specialist and PTSS Officer in the hospital. Kidney Heath Australia would like to provide the below example of additional administrative issues currently being experienced by patients.

Patient B: A patient, who is located in Bribie Island, has recently been advised they were not entitled to PTSS, as the patient was not visiting the health service in their allocated area. The patient was required to access the service at the Royal Brisbane & Women's Hospital (RBWH), three times per week for their dialysis treatment (75km each way). For the patient however, it was far more cost and time effective for them to travel to access service at the Nambour General Hospital (reduced parking costs and quicker drive) which would be only 5km extra distance. Because Nambour isn't deemed the closest hospital and is in a different Hospital and Health Service they are not eligible for PTSS assistance for this journey.

Throughout the State, the inability for the PTSS to be flexible where geographical boundaries are concerned is an area with administrative reform would benefit the patient, without creating a significant additional cost.

Conclusion

Kidney Health Australia requests that this submission be considered by the review team, and welcomes the opportunity of a face to face consultation to elaborate. In summary, Kidney Health Australia would recommend:

- The introduction of an accumulative weekly total figure of 200km, recognising the high frequency of travel required by those on dialysis and noting they represent some of those who most need this support; and
- Administrative stream lining to address authorisation issues (particularly where it is a result of capacity issues, geographic boundaries or multiple signatories) and a diary system for recurring visits.

Noting that the 2012 ANZDATA Report states that of the 2,005 patients requiring dialysis at the end of 2011 in Queensland, 1,458 of these undertook haemodialysis in a hospital or satellite setting. It must be considered as well that many of these 1,458 patients would be based in a metropolitan area and would not require or claim PTSS reimbursement. As such we believe any move to adopt the above recommendations would be limited their budgetary impact.

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 request that we be added to the stakeholders list so we may be alerted to future reviews of policy and programs that may impact upon those living with kidney disease.