

# Creating a sustainable health care model for assisted dialysis in very remote Australia

JT Hughes<sup>1,2</sup> and A Cass<sup>1</sup>.

<sup>1</sup>Wellbeing & Preventable Disease, Menzies School of Health Research. <sup>2</sup>Division of Medicine, Royal Darwin Hospital

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*Dr Cliff van der Oest, member of RACP Committee NT invited Dr Hughes to share her knowledge about the development of the MBS item number for assisted-dialysis in very remote Australia, and the potential next activities to support the uptake of this health service innovation.*

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The Northern Territory has the highest incidence and prevalence of dialysis-requiring end stage kidney disease (ESKD) in Australia [1]. Almost 1 in 40 Indigenous adults require ongoing dialysis. Antecedents of ESKD include low birthweight, diabetes, hypertension and glomerulonephritis.

Locally, and in regions across Australia with a heavy ESKD burden, we have established and followed a community-based cohort of Aboriginal and Torres Strait Islander people (the eGFR Study) to explore key issues around the development and progression of kidney disease. Key findings include:

1. The estimating equation of kidney function, eGFR<sub>CKDEPI</sub> formula, provides a reasonably accurate and unbiased measure of kidney function across all stages of kidney function [2],
2. The overall annual decline in kidney function was 3ml/min/1.73m<sup>2</sup> (three times the rate expected for normal ageing) [3].
3. Macroalbuminuria, from as low as 30mg/mmol, is a powerful predictor of kidney function decline over three years [3].
4. Albuminuria is strongly associated with abdominal obesity and metabolic syndrome [4].
5. Regular screening for kidney function is recommended from the age of 18 years, in Aboriginal and Torres Strait Islander peoples, even in those without diabetes [3].

Some patients have extraordinarily rapid loss of kidney function, more than 5ml/min/1.73m<sup>2</sup> annually [5], and up to 14ml/min/1.73m<sup>2</sup> annually [6]. This may be related to heavy albuminuria, diabetes, persistent inflammation (without overt infection) [5], recurrent infection and the occurrence of severe acute kidney injury [7].

## **Partnering with Health Care Users to inform policy**

Aboriginal and Torres Strait Islander patients and families are seeking a greater voice in the delivery of health services, to raise priorities for care and how renal services operate [8]. Patients ask for safe, accessible and effective health services that treat them with respect. In 2018, national consultation commenced to gather feedback from patients and carers to inform the inaugural KHA-CARI Guidelines for the Management of Chronic Kidney Disease in Aboriginal and Torres Strait Islander Peoples [9]. The Northern Territory consultation for these guidelines development is being led through the Catching Some Air project, funded by the Lowitja Institute.

Key and repeated recommendations have included that dialysis services be provided close to home, and that there is increased representation of Aboriginal and Torres Strait Islander people within the renal workforce (<https://vimeo.com/267732848>). Living away from key supports while accessing dialysis care – cultural support, family support, appropriate accommodation and country – represent significant challenges for patients wanting to live well with kidney disease. Such essential supports have not been built into the renal health care model [8].

## **Assisted Dialysis in Community**

Provision of dialysis services has been the responsibility of State and Territory governments. Although independent home haemodialysis and peritoneal dialysis have been successfully supported by NT Health Services, most patients need assistance in the provision of dialysis.

Dialysis assisted by nurses, Aboriginal Health Practitioners and allied health staff has predominantly been provided in close proximity to hospitals. This has been a constant challenge for those Territorians living in remote and very remote areas, who are at highest risk of ESKD[10]. Yet we know assisted dialysis has been sustained in very remote Australia - the first example was the Wurrumiyanga Dialysis Unit, which was established in 1999 with strong leadership from the Tiwi Island community, and in which Aboriginal Health workers played a key role in supporting dialysis patients.

### **Creating a funded model for very-remote area dialysis**

The patient and carer recommendations heard at the Indigenous Patient Voices Symposium in September 2017 strongly aligned with a proposed Medicare Benefit Schedule item number for assisted-dialysis in very remote Australia. The MBS Renal Clinical Committee, established in early 2016, proposed a new MBS item for assisted-dialysis in remote areas. The Committee's report was made available for public consultation in mid-2017 (Table 1).

The Close the Gap Campaign Steering Committee was directly engaged as key recipients of the Indigenous Patient Voices Symposium Report and supported the symposium recommendations.

Findings were also presented to the Commonwealth Minister for Indigenous Health – Minister Ken Wyatt – and staff. Advocacy for this item number was strongly supported across the kidney health sector - from patient voices, primary care, hospital renal services, the Aboriginal Community controlled health sector, and Kidney Health Australia.

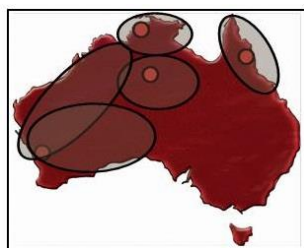
The Federal Government announced on 29<sup>th</sup> April 2018, the item-number for assisted dialysis would be supported, from 1st November 2018.

### **Key factors of the MBS item number include:**

1. That it will apply for patients living in very-remote Australia
2. Patients must be served by a primary health care service
3. Patients will be under the care of the appropriate regional specialist renal unit, with ongoing and regular medical review
4. The item will support a price per treatment for haemodialysis provision supported by an appropriately trained
  - a. Nurse
  - b. Aboriginal Health Practitioner
  - c. Aboriginal Health Worker

### **Supporting health in very remote Australia**

The MBS item number has created a sustainable funding model to support ESKD patients to receive care close to home, in accordance with their clearly expressed preferences, and industry and employment development for Aboriginal and Torres Strait Islander people and communities in very remote areas. Our next priorities include communicating this opportunity widely; enhancing collaboration between primary and tertiary care to coordinate efforts in facilitating the shift from hospital- to community-based care; engaging with other key stakeholders to identify remote communities that want to host dialysis services, to identify their capacity and readiness, and to support their needs to host dialysis; and to build Indigenous renal workforce capacity to achieve optimal health outcomes for patients in all stages of kidney health and using all modalities of kidney treatment.



The eGFR Study is a longitudinal study of kidney health in Aboriginal and Torres Strait Islander people. Information about this Menzies-led research is found at



<https://bit.ly/2vU6Lu1>

*Acknowledgments: Dr Hughes is a clinician and researcher based in Darwin. She is leading the Lowitja Institute funded "Catching Some Air-Asserting Indigenous Information Rights in Renal Disease" project (2017-2019). Sharing information about health policy development affecting Aboriginal and Torres Strait Islander peoples is a focus of Catching Some Air. Dr Hughes is supported by an NHMRC Fellowship #1092576. Professor Alan Cass was the chairperson for the Medicare Benefits Schedule Renal Clinical Committee (2016-18).*

**Table 1. Timeline of key events preceding the announcement of the approved MBS item number for assisted dialysis in very remote Australia**

<b>2016</b>	Mid-2016	MBS Renal Clinical Committee first met in mid-2016. MBS Renal Clinical Committee chaired by Prof Alan Cass
<b>2017</b>	Mid-2017	MBS Renal Clinical Committee finalized its report, and was released for public consultation. The Report recommended an assisted-dialysis item number for very remote Australia
	6-Sep	Indigenous Patient Voices Symposium hosted in Darwin
	16-Oct	Symposium recommendation presented to Royal Darwin Hospital Grand Rounds. Following this, Top End Health Services convenes a strategic working party, chaired by Executive Director Medical Services, Dr Charles Pain.
	12-Nov	The Indigenous Patient Voices Symposium Report launched (hosted on Menzies website). Key themes and Action plan were strategically identified.
	13-Nov	The Symposium Report was tabled to the Close the Gap Campaign steering committee, and to Minister Wyatt's office.
	22-Nov	Kidney Health Australia led a delegation advocating for Care Close to Home to federal politicians in Canberra. This included meetings with Minister for Health Hon Greg Hunt MP and Minister for Indigenous Health Hon Ken Wyatt AM MP.
	24-Nov	Submission to Medicare Benefits Schedule Review Taskforce, recommended the taskforce support the proposed MBS item number for nurse assisted dialysis in very remote areas of Australia.
	Late Nov	MBS Taskforce adopted the Renal Committee report, and presented it to the Department of Health and Minister for Health.
	10-Dec	Minister Wyatt AM quoted by Marie McInerney (from Croaky News) " <i>I am totally committed to working with communities and health practitioners across our nation to reduce the impact of renal failure and, even more importantly, to prevent it happening in the first place</i> ".
	12-Dec	Close the Gap Campaign Steering Committee wrote a letter of support for the Report, and invited further presentation to the committee, stating " <i>We look forward to hearing more about this important work and we thank you for your commitment to achieving true health equality in this country</i> "
	13-Dec	Presentation to the Northern Land Council Executive Council made by Dr Jaqui Hughes, and Ms Ada Parry (Indigenous Patient Voices Symposium carer delegate)
<b>2018</b>	12-Feb	The Indigenous Patient Voices Symposium Report was published as free open access by Nephrology Journal ( <a href="https://onlinelibrary.wiley.com/doi/10.1111/nep.13233">https://onlinelibrary.wiley.com/doi/10.1111/nep.13233</a> )
	22-Feb	National Renal Health Roundtable convened by Hon Minister Wyatt AM MP
	Early 2018	The Department of Health and Minister for Health considered the MBS Taskforce report which recommended funding the MBS item number for assisted dialysis in very remote Australia.
	6-Mar	Hon Minister Wyatt AM MP meets with expert working party from Transplant Society of Australia and New Zealand, to progress action towards equitable access to and outcomes of kidney transplantation.
	8-May	Federal government Budget announced a new Medicare item number for assisted dialysis in very remote Australia. Scheduled to commence 1 <sup>st</sup> November 2018.
	1 Nov	Funding for assisted dialysis to commence

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**The Indigenous Patient Voices Symposium & Report logo (above) was designed by Larrakia elder and artist, Ms June Mills.**