

The Improving Access to Kidney Transplant (IMPAKT) study – presented by Dr Alan Cass and Dr Jeannie Devitt of the George Institute – used in-depth interviews at 26 sites across Australia to explore barriers to achieving optimal outcomes with renal care, including access to transplant as perceived by Indigenous and non-Indigenous patients, nurses, allied health staff and nephrologists. These barriers include patient education, an increase in staff training, appointment of Indigenous staff and the need for targeted collaborative research to conclusively identify the most important factors predicting outcomes for Indigenous transplant recipients.

In highlighting the low rates of deceased organ donation among Indigenous Australians, Dr Dianne Stephens from the Royal Darwin Hospital noted that there are currently no frameworks to improve understanding of cultural requirements in this area. Likewise, there is an absence of culturally appropriate educational tools that would allow Indigenous families and communities to discuss the role of deceased organ donation. She called for further collaborative initiatives to address this important issue.

Policy responses focus on collaboration and consolidation

At the policy level, Ken Wyatt – Director of the WA Office of Aboriginal Health – discussed the “reality of a noble cause”. While he acknowledged that government needed to rethink strategies for improving health for Indigenous Australians, the groundwork is lacking. He called for an evidence-based approach and increased collaboration, given that many local programs are being created and implemented in isolation. His plea was supported by Lesley Podesta, First Assistant Secretary of the Federal Office for Aboriginal and Torres Strait Islander Health. She suggested that while existing research is beginning to change policy, government initiatives will necessarily gravitate toward a judicious use of available resources. With a focus on chronic disease and CKD, she expressed hope that stakeholders can work together to provide a multidisciplinary response that will bridge the gap between primary and tertiary health services.

An action plan to improve Indigenous kidney health

In concluding the 2008 National Indigenous Symposium, the organising committee mapped out a series of recommendations to move forward.

1. Form an Australian Indigenous Kidney Disease Network to co-ordinate and facilitate initiatives across all areas of interest.
2. Collect a standard dataset – including biological and socio-economic data – to inform service provision and quality, with local support for data collection and timely reporting cycles.
3. Refine current service models and support further innovations to provide renal replacement treatment as close to home as possible.
4. Improve interfaces between primary healthcare providers and tertiary renal services.
5. Facilitate a national approach to transplantation for Indigenous patients, including:
 - gathering nationwide results
 - setting a research agenda
 - developing information for patients and staff
 - promoting discussion of kidney donation within the Indigenous community.
6. Explore all possible avenues to increase the medical, nursing and allied health workforce, including:
 - education and training
 - support for remote area staff
 - increasing recruitment and developing the roles of Indigenous staff in renal services
 - other initiatives.
7. Maintain interaction with state, territory and federal agencies to promote the above objectives.



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National Indigenous Dialysis and Transplantation Symposium

16–18 May 2008, DARWIN

Sharing stories, sharing strategies

Sharing information is key to optimising the management of advanced kidney disease across Australia’s Indigenous communities. By sharing individual stories and outlining the results of collaborative programs, the 2008 National Indigenous Symposium empowered participants to come away with new ideas, inspirations and strategies. Delegates acknowledged that the burden of chronic kidney disease (CKD) is shared across the community, meaning that successful programs have to extend beyond the medical aspects to address social and cultural issues including late diagnosis, patients’ ownership of their treatment, family support, and a focus on kidney donors as well as transplant recipients. Rather than proposing ‘one size fits all’ models, the experiences and data shared at the symposium provided a resource for communities and health workers to draw upon in meeting their own unique challenges.

The organising committee would like to recognise and thank the traditional owners of the Larrakia land on which the National Indigenous Symposium was held. The organising committee would also like to thank Janssen-Cilag Australia, a leading research-based pharmaceutical company, for their essential support and dedication to improving the health and well-being of all Australians. This highlights bulletin summarises some of the selected sessions from the meeting.

Putting ideas into action

Effective care for Indigenous Australians with CKD must begin with acknowledging the need for culturally sensitive approaches, stated Djapirri Mununggirtji, Manager of the Yirrkala Women’s Centre (NT).

In particular, she explained that for Aboriginal people with end-stage kidney disease (ESKD), the pain associated with dialysis is not just physical, but also emotional and spiritual. By taking positive elements from the symposium to address these needs on a community-by-community basis, Ms Mununggirtji said delegates should be prepared to “stop talking and put ideas into action”.

These sentiments were echoed by NT Deputy Chief Minister and Member for Arafura, the Honourable Ms Marion Scrymgour, MLA. While she confirmed the need for additional research and data, Ms Scrymgour stated that the effect of CKD across Indigenous communities is obvious and demands immediate action. In particular, while survival rates during dialysis in the NT are on par with the national average, the incident rate of ESKD remains disproportionately high among Aboriginal people. In addition to calling for an Indigenous advisory council to oversee closing this gap, Ms Scrymgour said she hoped that policy makers could acknowledge that Aboriginal communities want to move forward. While she warned that “one size does not fit all”, she affirmed that the most successful policies are those that encourage Aboriginal people to take greater ownership of their condition.

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Speakers at the National Indigenous Dialysis and Transplantation Symposium



Successful home HD relies on the entire community

“Location, location, location” is the most obvious challenge to home haemodialysis (HD), according to Vicki Nebbia from the Townsville Hospital in Queensland. The remote nature of many Aboriginal communities can compromise many aspects of dialysis, including stock delivery (especially in the wet season), water quality and carer training. To facilitate home HD, she has focused on solutions that include intensive carer training, sourcing reliable transport routes and scheduling frequent medical staff visits to local hospitals or patients’ homes.

Despite the lack of infrastructure, Dorothy Brown from Nightcliff Renal Unit in the NT has successfully overcome logistical issues by coordinating transport and stores delivery, designing relocatable units to enable several self-care patients to undertake treatment in the same community. She has also developed an environmentally friendly medical waste disposal system utilising a 44-gallon drum! Although Dorothy has managed to transition many patients from satellite centres to home HD, she acknowledges that there remain areas for improvement, including more effective communication, monitoring treatment without disempowering patients and the need for regional drop-in centres.

Operating since 1989, the WA Remote Area Dialysis Program (RADP) has faced similar challenges in supporting community-based home HD, including a lack of space, running water or reliable power supplies. By developing area-specific policies, protocols and guidelines – and recognising the important role of the Aboriginal health care workers – Angelina Villarba from WA Home Therapies of Fresenius Medical Care explained how the RADP provides patients with local treatment support.

Creative approaches can overcome logistic hassles

Careful patient training and a creative approach to logistics have benefited renal units in Far North Queensland. According to Phil Wilson from the Department of Renal Medicine at Cairns Base Hospital, approximately 35% of patients on renal replacement therapy perform their own treatment at home. This requires persistence in the face of language barriers to ensure that patients understand their therapy and know what to do if problems arise. The unit therefore provides basic anatomy and physiology training while building patients’ competency to safely perform dialysis outside of the clinical setting. To ensure adequate dialysis supplies, the Cairns team charters aircraft and ferry stock between islands via ‘tinny’, encouraging patients to stay on islands that still hold stock until the next delivery arrives.

Similarly, Robyn Powell and her team from the Kimberly Aboriginal Medical Service Council in Queensland have developed a hub-and-spoke support model using Broome as the hub, thus reducing the need for direct patient training in Perth. They have overcome stock problems by pre-packaging all the needed peritoneal dialysis (PD) supplies into one box, which remains on-site with local communities where dialysis occurs. Literacy issues are minimised by adjusting products so that there are no text-based instructions, only pictures to illustrate the correct usage.

As a clinical nurse consultant, Marion Shaw of NT Renal Services – Top End, discussed the value of buried PD catheters. This approach aims to promote PD uptake by pre-siting catheters in anticipation of need and minimising the need for prolonged dressings. These measures reduce the time to first shower and lessen the risk of infection, while allowing patients to commence full-volume dialysis without a break-in period. While potential complications include haematoma formation, catheter erosion or poor placement, the service’s efforts have increased the number of patients commencing PD as the modality of first choice and reduced the incidence of post-operative ileus.

To facilitate home HD, the focus was on solutions that include intensive carer training, sourcing reliable transport routes and scheduling frequent medical staff visits to local hospitals or patients’ homes.

Innovative models of service delivery

Proactive approaches to CKD management can improve clinical outcomes and reduce costs. According to Anne Blong, the multidisciplinary CKD program at Townsville Hospital (Queensland) has increased earlier home support by utilising GPs or community health services. The program also facilitates appropriate access to specialists and links in with communities to promote education. Similarly, the Central Queensland Health Service District has developed a community-based CKD service that focuses on delaying the progression of nephropathy. Katrina Duff commented that her community team includes a dietitian, a social worker and a pharmacist in addition to the medical staff. By creating a surveillance system in partnership with the local diabetes and cardiac outreach programs, the unit can proactively address clients’ needs.

Patients in the NT home HD program are also clinically healthier, as demonstrated by a decrease in acute admissions, plus increased outpatient attendance and treatments completed per month.

Another proponent of the multidisciplinary team approach is Karen Brown, a renal social worker from the NT. Her group includes a CKD coordinator, a dietitian, a social worker and a vascular access nurse who provide regular outreach clinics to promote patient engagement, independence and responsibility for self-management. Regular clinic sessions and a 1800 toll-free number also strengthen the team’s relationships with each patient. As a result, she reports that patients are better prepared – physically and psychologically – for their arrival in Darwin and the commencement of dialysis.

Maree Wearne of the Kimberly Renal Support Services discussed her unit’s application of the hub-and-spoke dialysis model to encourage patients to dialyse as close to home as possible. This structure marries renal primary health care with a dialysis program, resulting in a single renal service under Aboriginal community control. While this culturally appropriate program is tailored to local needs, standardised renal protocols and educational resources have resulted in an increased understanding of CKD and dialysis.

Good outcomes as self-care HD helps connect patients to their community

Self-care HD may not be as expensive as generally thought, reported Gillian Gorham of the NT Department of Health and Community Services. She explained that each of the sites within the NT home HD program is allocated a budget which allows for establishment costs – including up to three community visits to negotiate sites and operational set up – plus recurrent costs such as freight, consumables, staff visits and patient respite. Audited costs per client were reduced, although they remain sensitive to external factors such as construction, freight and dialysis waste management costs for remote communities. Patients in this program are also clinically healthier, as demonstrated by a decrease in acute admissions, plus increased outpatient attendance and treatments completed per month.

Novel strategies involving the creative arts can also enhance outreach and funding of patient support programs. For instance, Sarah Brown spoke of the work of the Western Desert Nganampa Walytja Palyantjakt Tjutaku Aboriginal Corporation in raising money through Indigenous art to fund their program and return patients to their communities. This helps patients

maintain links with family and the land, gives them another tangible reason to comply with their treatment regimen, reduces hospitalisations for missed dialysis and enables people to take part in community life. Pam Wood and her team from the NT Department of Health and Community Services have also pushed boundaries in providing short-term dialysis for patients in their community. They organised holiday dialysis sessions for Darwin-based patients throughout the length of the 2007 Garma Festival in East Arnhem Land, while also setting up an educational stand to raise awareness about renal health amongst attendees.



Transplantation: Better education and an improved ability to predict outcomes are needed

While it has been universally acknowledged that kidney transplantation offers the best option for many patients with ESKD, only 3.5% of transplants in 1991–2006 went to Indigenous Australians (Indigenous Australians represent 2.5% of Australia’s total population, yet this group is 10 times more likely to have kidney disease¹). According to Dr Ashley Irish, this under-representation is due to a variety of reasons such as comorbidities, delays in listing and significant tissue matching issues. Overall, Indigenous outcomes after transplant are worse than for non-Indigenous patients, primarily due to infectious complications. Nevertheless, there are some indications from ANZDATA that survival rates may be more favourable than with prolonged dialysis, leaving scope for improved transplant outcomes via careful candidate selection and judicious immunosuppressive regimens. It was suggested that greater research and improved data collection are required to further explore this uncertainty. Analysis of preliminary NT data indicated the need for a definitive review of long-term outcome results for Indigenous live donors, added Dr Natasha Rogers from the Queen Elizabeth Hospital in Adelaide.

¹Australian Bureau of Statistics (ABS), 2005 ‘SELECTED CHRONIC CONDITIONS AMONG ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES’. Accessed: 2nd July, 2008. <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/5AB12BE9F12ABB07CA25732C002082BD?opendocument>