<table>
<thead>
<tr>
<th>Contents</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>World Kidney Day 2015</strong></td>
<td>2</td>
</tr>
<tr>
<td>Recommendations</td>
<td>4</td>
</tr>
<tr>
<td><strong>Purpose</strong></td>
<td>6</td>
</tr>
<tr>
<td>Structure of Report</td>
<td>7</td>
</tr>
<tr>
<td><strong>Section 1</strong></td>
<td></td>
</tr>
<tr>
<td>View of Parliament</td>
<td>8</td>
</tr>
<tr>
<td>Excerpts from WKD Speech by Senator the Hon Fiona Nash, representing</td>
<td>8</td>
</tr>
<tr>
<td>the Prime Minister</td>
<td></td>
</tr>
<tr>
<td>Excerpts from WKD Speech by The Hon Bill Shorten MP, Leader of the</td>
<td>9</td>
</tr>
<tr>
<td>Opposition</td>
<td></td>
</tr>
<tr>
<td>Summary Points of Roundtable Address by Senator Rachel Siewert,</td>
<td>10</td>
</tr>
<tr>
<td>Australian Greens</td>
<td></td>
</tr>
<tr>
<td>Key Messages</td>
<td>11</td>
</tr>
<tr>
<td><strong>Section 2</strong></td>
<td></td>
</tr>
<tr>
<td>Setting the Scene</td>
<td>12</td>
</tr>
<tr>
<td>What is the burden of kidney disease in Aboriginal &amp; Torres Strait</td>
<td>12</td>
</tr>
<tr>
<td>Islander communities?</td>
<td></td>
</tr>
<tr>
<td><strong>Section 3</strong></td>
<td></td>
</tr>
<tr>
<td>Prevention of Chronic Kidney Disease</td>
<td>14</td>
</tr>
<tr>
<td>Current Status of Prevention Programs</td>
<td>14</td>
</tr>
<tr>
<td><strong>Section 4</strong></td>
<td></td>
</tr>
<tr>
<td>Renal Dialysis</td>
<td>18</td>
</tr>
<tr>
<td>Models of Care for Aboriginal and Torres Strait Islander Australians</td>
<td>18</td>
</tr>
<tr>
<td><strong>Section 5</strong></td>
<td></td>
</tr>
<tr>
<td>Kidney Transplantation</td>
<td>22</td>
</tr>
<tr>
<td>Access and Outcomes for Aboriginal and Torres Strait Islander</td>
<td>22</td>
</tr>
<tr>
<td>Australians</td>
<td></td>
</tr>
<tr>
<td><strong>Recommendations</strong></td>
<td>24</td>
</tr>
<tr>
<td><strong>Bibliography</strong></td>
<td>30</td>
</tr>
<tr>
<td><strong>Appendices</strong></td>
<td></td>
</tr>
<tr>
<td>Appendix A:</td>
<td></td>
</tr>
<tr>
<td>World Kidney Day 2015 Policy Roundtable attendees</td>
<td>31</td>
</tr>
<tr>
<td>Appendix B:</td>
<td></td>
</tr>
<tr>
<td>What is the burden of kidney disease in Aboriginal &amp; Torres Strait</td>
<td>33</td>
</tr>
<tr>
<td>Islander communities?</td>
<td></td>
</tr>
<tr>
<td>Appendix C:</td>
<td></td>
</tr>
<tr>
<td>Prevention and Treatment of CKD in Aboriginal Australians: what is</td>
<td>37</td>
</tr>
<tr>
<td>currently in place?</td>
<td></td>
</tr>
<tr>
<td>Professor Wendy Hoy</td>
<td></td>
</tr>
<tr>
<td>Appendix D:</td>
<td></td>
</tr>
<tr>
<td>The Institute for Urban Indigenous Health (IUIH) by Ms Jodie Currie</td>
<td>81</td>
</tr>
<tr>
<td>Appendix E:</td>
<td></td>
</tr>
<tr>
<td>Dialysis access, issues and outcomes for Indigenous Australians by</td>
<td>105</td>
</tr>
<tr>
<td>Professor Alan Cass</td>
<td></td>
</tr>
<tr>
<td>Appendix F:</td>
<td></td>
</tr>
<tr>
<td>Kidney Transplantation Among Aboriginal &amp; Torres Strait Islander</td>
<td>125</td>
</tr>
<tr>
<td>Australians</td>
<td></td>
</tr>
</tbody>
</table>
World Kidney Day 2015 provided a key point-in-time to initiate a high level discussion about Aboriginal and Torres Strait Islander kidney health, the impact on patients, their families, and the wider communities.

World Kidney Day is celebrated each year on 12 March to raise awareness about the importance of our kidneys to our overall health and to reduce the frequency and impact of kidney disease and its associated health problems worldwide. The theme of ‘Kidney Health for All’ was selected for World Kidney Day 2015.

In Australia, World Kidney Day 2015 focussed on highlighting the devastating impact of chronic kidney disease (CKD) in Aboriginal and Torres Strait Islander communities. The date was changed to 26 March 2015, to coincide with the sitting of Federal Parliament in order to enable greater advocacy, awareness and education of our members of parliament.

Kidney Health Australia (KHA), with support from the Australian and New Zealand Society of Nephrology (ANZSN) and the Close the Gap Campaign hosted a Parliamentary Breakfast attended by members of parliament, senior departmental officials, leading nephrologists, Aboriginal and Torres Strait Islander service providers and other key kidney community members.

Keynote speeches were provided by:
• Senator the Hon Fiona Nash representing the Prime Minister
• The Hon Bill Shorten MP, Leader of the Opposition
• Professor Tom Calma, Close the Gap Campaign
• Professor Alan Cass, ANZSN
• Ms Anne Wilson, KHA

A Policy Roundtable was held after the Parliamentary Breakfast to promote evidence-based research, programs and policy solutions across the spectrum of prevention, renal dialysis and transplantation for Aboriginal and Torres Strait Islander kidney health.

This report is informed by the Policy Roundtable and provides an overview of the issues experienced by Aboriginal and Torres Strait Islander people with kidney disease. A range of policy-focused recommendations are provided for consideration by the Federal Government, State and Territory Governments, key health organisations working in Aboriginal and Torres Strait Islander health and the kidney community.
Recommendations

Recommendation 1: National Taskforce on Indigenous chronic kidney disease
A National Taskforce on Indigenous chronic kidney disease be convened by the Federal Government with the States and Territories to address the complex issues leading to the devastating impact of kidney failure on Aboriginal and Torres Strait Islanders. An agreed new Closing the Gap target with States and Territories aimed at halving the incidence of end-stage kidney disease by 2031 will have significant impact on the Indigenous life expectancy and mortality rates.

Recommendation 2: Education about chronic kidney disease
Culturally appropriate educational resources need to be developed that facilitate understanding about kidney functions of the kidney, kidney health, and chronic kidney disease. The primary target group are early adolescent and young adults. For those at-risk chronic kidney disease. The primary target group are the functions of the kidney, kidney health, and early stage CKD patients, information support needs to be developed that articulate the patient pathway for Aboriginal and Torres Strait Islanders.

Recommendation 3: Prevention of CKD
Continue to invest in community-based health programs which are known to have impacted on the health outcomes of Aboriginal and Torres Strait Islanders, including chronic disease prevention and education (such as Deadly Choices), mothers & babies, infant and early childhood, and smoking cessation. Further, there is intrinsic value in continuing to invest in community-based health programs which are known to have impacted on the health outcomes of Aboriginal and Torres Strait Islanders including:
- antenatal services and management of gestational diabetes
- early childhood development initiatives
- improving housing infrastructure
- community-based scabies control programs
- food supply initiatives to improve access to affordable healthy food
- culturally appropriate healthy nutrition, physical activity and quit smoking programs and legislative initiatives to regulate tobacco advertising.

Recommendation 4: Early Detection and Management of CKD
Improved early detection and management of CKD for Aboriginal and Torres Strait Islanders be promoted through general practice, primary healthcare services, and Aboriginal Community Controlled Health Services (ACCHSs). The care pathway to include:
- integrated health check screening that specifically includes kidney testing
- establishment of a CKD register (regional scope for national reporting)
- self-management strategies
- early education regarding renal replacement therapy (RRT) management choices
The use of web-based, online & e-technologies needs to be explored with reference to overcoming geographic distance, low language and literacy rates.

Recommendation 5: Dialysis Modality
The range of appropriate dialysis care options for Aboriginal and Torres Strait Islander renal patients, which incorporate and are sensitive to regional cultural practices and beliefs. For example, there are only two models of palliative care focusing on and developed in Aboriginal communities that have been implemented. Cultural competence training of the technical staff to provide dialysis services in remote communities

Recommendation 6: Workforce & Education
A range of workforce training and development initiatives to regulate tobacco advertising

Recommendation 7: Social Support Services
A place-based model be explored to identify the scale of need for social support in regard to relocating Aboriginal and Torres Strait Islander kidney patients and their families, in regional hubs where dialysis services are provided.

Recommendation 8: Kidney Transplantation
A targeted, national approach is needed which will focus on improving transplant outcomes and addressing reversible health systems barriers to equitable access to kidney transplantation for suitable Aboriginal and Torres Strait Islander patients, which includes:
- A national audit of transplant outcomes for Indigenous Australians
- Setting a research agenda for developing specific new knowledge and technologies
- Developing, implementing and evaluating culturally appropriate education materials regarding organ donation and transplantation
Our aim is to increase awareness of the burden of kidney disease experienced by Aboriginal and Torres Strait Islander Australians and to work towards the development and implementation of a multi-faceted strategy that will deliver real solutions on the ground to improve outcomes.

We seek to stimulate and facilitate the implementation of programs to prevent and slow the progression of CKD so that fewer Aboriginal and Torres Strait Islander people need dialysis, improve the quality of life of people receiving treatment and design and deliver services that will better meet the health, social and cultural needs of Indigenous Australian with kidney disease. We argue that working together to achieve these aims should be a national health priority.

### Purpose

This report provides an overview of the key messages and recommendations presented by some of the leading researchers, nephrologists and Aboriginal Community Controlled Health Services (ACCHSs).

**Section 1** provides excerpts from the World Kidney Day Parliamentary Breakfast speeches provided by Senator the Hon Fiona Nash representing the Prime Minister the Hon Bill Shorten MP; Leader of the Opposition, and at the Policy Roundtable by Senator Rachel Siewert, Australian Greens.

**Section 2** provides a summary of the Burden of Kidney Disease in Aboriginal and Torres Strait Islander Communities presented by Dr Tim Mathew, Medical Director Kidney Health Australia.

**Section 3** provides an overview of prevention activities that are currently in place for Aboriginal and Torres Strait Islanders drawing on the depth and breadth of experience of Professor Wendy Hoy Centre for Chronic Disease, University of Queensland. Ms Jody Currie, Institute for Urban Indigenous Health (IUIH) showcased their work to improve access to primary health care, screening for kidney disease and community engagement.

**Section 4** provides an overview of Dialysis Access, Issues and Outcomes for Aboriginal and Torres Strait Islanders presented by Professor Alan Cass, President Australia & New Zealand Society of Nephrology (ANZSN) and Director Menzies School of Health Research.

**Section 5** provides an overview of Kidney Transplantation among Aboriginal and Torres Strait Islanders presented by Professor Stephen McDonald, Director of Dialysis and a Senior Staff Nephrologist at The Central Northern Renal and Transplantation Service, Royal Adelaide Hospital.

In conclusion, Kidney Health Australia provides a summary list of recommendations which are consolidated at the front for consideration by governments and other key organisations working in Aboriginal and Torres Strait Islander kidney health.
Views of Parliament

Excerpts from WKD Speech by Senator the Hon Fiona Nash, representing the Prime Minister:

“The Coalition Government is extremely aware of the burden that chronic kidney disease places on individuals, families and communities. We’re committed to preventing kidney disease where possible and optimising treatment and management for those affected.

“We value the important role played by non-government organisations in achieving better health outcomes for Australians living with chronic disease.

“Current Government funding initiatives aim to improve access to comprehensive primary healthcare, essential medicines, medical aids and services; promote the role of care coordinators; fund multi-disciplinary outreach services; and use continuous quality improvement processes to improve systems of care.

“Recently I announced that the Government is providing $1.4 billion over three years to enable the continued delivery of primary health care to Aboriginal and Torres Strait Islander communities.

“This Government recognises the important role that comprehensive primary healthcare plays in prevention and managing chronic disease such as Chronic Kidney Disease.”

Excerpts from WKD Speech by The Hon Bill Shorten MP, Leader of the Opposition:

“In recent years, a great deal of good work has been done to measure and map the disadvantage that blights the lives of the First Australians.

“And while there have been some improvements in reducing the impact of chronic disease, it remains a serious impediment in closing the gap in life expectancy and other health outcomes.

“But unless our improved awareness and understanding delivers better outcomes – we can’t claim this as real progress.

“Now I believe that Closing the Gap, delivering equal opportunity for Aboriginal and Torres Strait Islander people, is Australia’s unfinished business.

“What it means is that health is not just a social justice issue, although it fundamentally is, it’s an economic issue. The beneficial consequence of good health spreads to every other measurement.

“Now today we stand here today with solutions in our grasp.

“Addressing vision loss alone would close 11 per cent of our health gap.

“Tackling smoking by boosting preventative programs reduce the rate of cancer and heart disease, and it increases life expectancy.

“Smoking is a key risk factor for developing chronic kidney disease along with poor nutrition, poor living conditions, low birth weight and dare I say it, a lack of empowerment.

“The prevention and early detection of chronic disease must be front and centre in the pursuit of closing the gap in health outcomes.

“The full implementation of the National Aboriginal and Torres Strait Islander Health Plan is another irreplaceable step.

“There must be the voices of local people and local providers.

“This is about building partnership, trusting the community, listening to the people that know and live this great shared endeavour.

“If we don’t match our determination to deliver constitutional change with an equal effort to close the gap in health, life expectancy, education, employment and of course justice, anything less runs the very risk of rendering recognition meaningless for people to whom it should mean the most.”
Summary Points of Roundtable Address by Senator Rachel Siewert, Australian Greens:

“I have been advocating for Aboriginal and Torres Strait Islander issues for about ten years in Parliament. My colleagues will know that this (Aboriginal and Torres Strait Islander kidney health) is an issue I’ve particularly focussed on.

“Chronic Kidney Disease (CKD) and end stage kidney disease (ESKD) are huge issues facing many Aboriginal and Torres Strait Islander communities. It continues to be a growing issue.

“As Members of Parliament, all political parties need to be engaged if we are to close the gap in Indigenous disadvantage.

Members can and do work across all parties on such issues as Aboriginal and Torres Strait Islander health. Members can also work across Federal and State boundaries, through their electorates.

To make a difference in Aboriginal and Torres Strait Islander kidney health, prevention is key to slowing the progress and decreasing the impact.

We need to have the most up-to-date, evidenced-based information about what is best practice in order to develop the best policies and strategies. I welcome the opportunity the Policy Roundtable on Aboriginal and Torres Strait Islander kidney health presents in bringing together the leading experts, service providers and Members of Parliament. I look forward to receiving the report.”

Key Messages

From the excerpts and summary address provided by representatives of the Liberal-National Party, Australian Labor Party and the Australian Greens, it is evident that:

- Aboriginal and Torres Strait Islander health is a priority across the major political parties
- Non-government organisations play a valued role in facilitating and presenting information, data and evidence of best practice in health
- While there has been good work undertaken, there is much that still needs to be done to target the shared risk factors and comorbidities for chronic kidney disease to reduce the burden of disease.
- Prevention and early detection of chronic kidney disease is the area that will demonstrate the greatest long-term health outcome and economic benefit
- A comprehensive primary healthcare model provides the best prevention and management of chronic disease, including CKD for Aboriginal and Torres Strait Islander people.
What is the burden of kidney disease in Aboriginal & Torres Strait Islander communities?

Dr Tim Mathew  
Medical Director, Kidney Health Australia

There are a plethora of studies, reports and journal articles documenting and quantifying the extent to which chronic kidney disease (CKD) and particularly end stage kidney disease (ESKD) significantly and more frequently impacts Aboriginal and Torres Strait Islander Australians.

We know that when compared to non-Indigenous Australians, CKD presents more frequently, is more severe at an earlier age, is more strongly associated with diabetes and multiple co-morbidities and has greater social and medical impact on Aboriginal and Torres Strait Islanders.

CKD usually develops slowly over years. The vast bulk of the ESKD disease burden presents within the ages of 35 and 65, traditionally periods of maximum family responsibilities, productivity, community contribution and leadership. This creates significant life-changing challenges for many young Aboriginal and Torres Strait Islanders, particularly young families.

Early CKD is often asymptomatic, which makes it hard to recognise. The diagnosis of CKD requires blood and urine testing which is simple and cheap.

In 2011, the estimated resident Aboriginal and Torres Strait Islander population was 669,900 people, of whom, the proportion of Aboriginal and Torres Strait Islander people aged 15-64 years was 61%. This indicates an approximate adult population of 462,231 people.

Recent Australian Bureau of Statistics (ABS) data, found that the actual prevalence of kidney disease in Aboriginal and Torres Strait Islander adults was 18%.

If we use this percentage and apply that to the approximate adult Indigenous population, it can be estimated that approximately 83,201 people are currently at high risk of kidney disease. Furthermore, based on these numbers:

- Approximately 67,000 will progress to Stage 1-3 CKD
- 4,400 to Stage 4 CKD
- 1,700 to Stage 5 CKD

It is important to note that the proportion of Aboriginal and Torres Strait Islander adults with CKD dramatically increases with age after the age of 35 years. Self-reporting of chronic kidney disease remains low 1.6% (2004) to 1.7% (2012), indicating that there are likely many Aboriginal and Torres Strait Islander adults who are unaware that they have kidney disease.

When end stage kidney failure develops and a person requires either ongoing dialysis or a kidney transplant to stay alive, there is a huge impact on life expectancy and quality of life.

For Aboriginal and Torres Strait Islander Australians with ESKD, there is an increased prevalence of significant medical co-morbidities, including complications of diabetes and vascular disease.

Amongst Aboriginal and Torres Strait Islanders, the heaviest disease burden impacts on people living in very remote (36.7%) and remote (27.6%) regions. Outer regional areas (17.7%) remains high. Inner regional (10.7%) and major cities (11.8%) are less likely to be impacted as greatly.

For the majority of remote and very remote patients, the need to re-locate to treatment centres often hundreds of kilometres from their community and country, has a devastating impact on families. Families are often separated or whole families relocate, sometimes across State and Territory borders in order to access dialysis treatment.

For some, the need to relocate from family and country may lead to a decision to forego treatment.

In almost all people, the impact of kidney failure on the patient and their family is severe with prolonged ill health, a heavy symptomatic burden, loss of job opportunities and ability to work, financial hardship and very real social disruption.

There are major challenges in the health and social support area for Aboriginal and Torres Strait Islanders accessing renal dialysis services away from home.

From a provider and a patient perspective, the patient pathway particularly for Aboriginal and Torres Strait Islander kidney patients is often fragmented, confusing, isolating and burdensome.

This is a national issue that requires a national response of Federal, State and Territory governments to develop approaches to health and non-health issues impacting significantly on access to treatment.
Current Status of Prevention Programs

Of greatest impact has been the Medicare Aboriginal and Torres Strait Islander Health Check (Item 715) - established in response to the higher mortality and morbidity levels, earlier onset and more severe disease progression.

The Aboriginal and Torres Strait Islander Health Check provides access to other Aboriginal and Torres Strait Islander specific health measures, including Indigenous Health Incentive under the Practice Incentive Program (PIP) including: General Practice Management Plan (GPMP), Care Coordination and Supplementary Services – funding for additional allied and specialist services outside of normal Medicare limits.

What can be improved?

Recent evaluations, as part of the Closing the Gap in Indigenous Health Outcomes – Indigenous Chronic Disease Package (ICDP) indicate that integrated chronic disease testing must be repeated through adult life in all Aboriginal and Torres Strait Islander adults, for timely diagnosis and to slow the progress of chronic disease.12 13 14

Example:
The KHA-CARI Guidelines seeks to improve the quality of care and outcomes for patients with kidney disease in Australia & New Zealand by facilitating the development and implementation of clinical practice guidelines based on the best available evidence and effectiveness.

This requires all political parties committing to staying the course for improving Aboriginal and Torres Strait Islander health by providing stability of policy and funding for longer terms (10 year cycle), particularly those programs and services that are impacting on the ground.

There are evidence of substantial evidence-practice gaps in the management of pre-dialysis CKD. Amongst people indicated by national guidelines for screening for CKD, approximately 40% are being screened.16 For Aboriginal and Torres Strait Islanders, this would significantly reduce premature cardiovascular mortality and likely impact on the progression and burden of ESKD.

Primary healthcare services need to be better supported to implement evidence-based practice in screening for and managing CKD.

In providing equitable services for those in very remote, remote, rural and urban areas, a health workforce needs to be trained to manage the complexity of health and social issues facing Aboriginal and Torres Strait Islanders.

The establishment of a register for CKD patients will enable the monitoring of trends in the incidence and prevalence of CKD and progression to renal replacement therapy.

Key Challenges

While significant success has been achieved through improving access to quality antenatal healthcare, maternal and child health services, there are still high rates of foetal, infant and childhood risk factors. High rates of intra-uterine growth retardation and persisting excess prematurity at birth remains an issue. There is also a heavy burden of infections among infant and children, and indeed across the life course, propagating a persistent inflammatory milieu.

Social and behavioural factors impact considerably. Inadequate housing causing overcrowding continues to be a significant issue and contributing factor to high rates of infection and illness.

Again, while some progress has been made in recent years to address smoking rates, the proportion of Aboriginal and Torres Strait Islander Australians smoking remains high.

High sugar consumption is a modifiable behaviour that continues to be a challenge. For example, in 2007 the Coca-Cola Amatil website claimed that for every standard can of Coca-Cola consumed per capita, an extra 45 standard cans of Coke were consumed per capita.20 The penetration of Coca Cola Amatil into communities is also a heavy burden of infections among infant and children, and indeed across the life course, propagating a persistent inflammatory milieu.

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Current Status of Prevention Programs

The Institute for Urban Indigenous Health (IUIH)

Ms Jodie Currie
Manager, Institute for Urban Indigenous Health

Overview
The Institute for Urban Indigenous Health (IUIH) was established in 2009 as a strategic response to population growth and dispersion across southeast Queensland (SEQld).

IUIH provides regional leadership for implementation of close the gap measures and coordinated efforts across the health system.

IUIH is an Aboriginal and Torres Strait Islander Community Controlled Health Service (ACCHS) owned by four (4) ACCHS in SEQld:
- The Aboriginal and Torres Strait Islander Community Health Service (ATSICHS) Brisbane
- Kalwun Health Service
- Kambu Medical Service
- Yulu-Burri Ba Health Service

In Queensland, almost one-third of all Indigenous people reside in the south east pocket. The estimated population of Aboriginal and Torres Strait Islander across SEQld is approximately 60,000. This is known to be an under-count. A more realistic estimate is approximately to be up to 70,000, with 16% growth in numbers over last 5 years. “Until the establishment of the IUIH, there was little understanding of or interest in the disadvantages experienced by urban Aboriginal and Torres Strait Islander peoples and their access to health services by government nor the wider community. This was mostly due to the incorrect belief that urban Indigenous populations enjoyed easy access to ‘mainstream’ health services and that the need to close the gap in life expectancy between Indigenous and non-Indigenous Australia was only an issue in remote areas.”

Adrian Carson – CEO, IUIH

The Facts
- Since 2009, IUIH has created:
  - 13 new medical clinics
  - 360% increase in GPMPs
  - 100% increase in the number of annual health assessments
  - 220% increase in new patients
  - 360% increase in patient visits to doctors
  - 150+ tertiary student placements each semester

The IUIH delivers a broad range of primary health care, allied health, education and engagement initiatives to meet current urban Indigenous health issues while concurrently striving to change behaviour and ultimately reduce chronic disease rates in future years.

Deadly Choices is a chronic disease prevention and education program developed on the principle of empowering young people to become positive leaders and make healthy choices. The program uses sport and physical activity to encourage attendance and deliver health messages. It has been incorporated into the curriculum at state schools, private schools, the Aboriginal and Islander Community Independent School (Muri School) and is regularly delivered at the Brisbane Youth Detention Centre. The program is also delivered to men’s groups and fathers’ groups at Kambu Medical Service.

Deadly Choices has yielded a high uptake by young men (65-70%) of all active clients are up to date with comprehensive health checks; 55% of all checks in young adult age range are male). In 2013-14, a total of 8311 health checks were completed. A total of 1461 school children participated in the program across 171 schools with 497 health checks being undertaken and 719 completing the education program.

Each year, over 20 Community Health Days are held with an average attendance of 400 people. Community Health Days address four key health areas (chronic disease, nutrition, physical activity & tobacco) through a range of family-focused, sporting, cultural and nutritional activities. They are held regularly throughout the south east corner and comprise a range of activities including group fitness, health testing, art programs and nutrition education.

IUIH research found the Deadly Choices campaign to be highly successful, with 93% awareness among the target audience. Message recall was clear, consistent and on strategy, and resonated and engaged the audience – resulting in increased attendance at ACCHSs.

Evaluation of Deadly Choices by participants indicate:
- 100% now eat breakfast more
- 57% increased their physical daily exercise after completing the program
- smoking decreased by 14%
- 100% did not understand chronic disease before the program
- 100% said they would undertake the program again.

What can be improved?
The issues and needs of urban Aboriginal and Torres Strait Islander Australians are not well understood. The focus of funding allocation by governments continues to focus on remote communities. This creates the risk of mainstreaming service delivery for non-remote communities and continuing the invisibility of the urban population.

The Aboriginal and Torres Strait Islander population continues to grow and shift to outer-urban areas with poor access to primary health care.

Coordination of primary health care across the range of providers in SEQld is challenging. Shifts in the population creates a blurring of the traditional service area boundaries of ACCHSs.

At the clinic and service level, there are gaps identified in population data which can inform the need to establish new or expand existing ACCHSs within the regional network.

Specifically in relation to CKD, there is a need for improvement and understanding about CKD, diseases progression, ESKD, impacts on self, family and community.

Key Challenges
Developing and maintaining a skilled and knowledgeable workforce is a huge challenge when working in Aboriginal and Torres Strait Islander health.

In particular, the number of Aboriginal Health Workers is declining nationally. This creates problems for the model of care, particular chronic disease in ACCHSs, which is heavily reliant and utilises the wider range of AHWer community and clinical skills.

The burden of type 2 diabetes is at such a prevalence that it is entrenched in the Aboriginal and Torres Strait Islander community. There is a need to address the passivity and victimhood that is normalising and enculturating the diagnosis of type 2 diabetes in communities.
Renal Dialysis

Models of Care for Aboriginal and Torres Strait Islander Australians

Dialysis access, issues and outcomes for Indigenous Australians

Professor Alan Cass
President Australian & New Zealand Society of Nephrology
Director Menzies School of Health Research

Overview

Although Aboriginal and Torres Strait Islander people currently represent approximately 3% of the national population, they account for approximately 9% of people commencing kidney replacement therapy each year. Aboriginal and Torres Strait Islander people with treated end stage kidney disease (ESKD) are known to have earlier onset of disease, experience a multiplicity of barriers to receiving equitable treatment and have worse prognosis than the general population.21

The number of prevalent Aboriginal and Torres Strait Islander peoples with treated ESKD increased to 2603, continuing a gradual increase.22 The incidence of ESKD for Aboriginal and Torres Strait Islander people is especially high in remote and very remote areas of Australia, with rates almost 18-times and 20-times those of comparable non-Indigenous peoples.23 24

Dialysis access, issues and outcomes for Indigenous Australians and access to kidney disease among Indigenous Australians 47 The proportion of people with treated ESKD who are accessing haemodialysis therapy each year.

21 Preston-Thomas, Cass, & O’Rourke 2007 Trends in the incidence of haemodialysis in Australia among Aboriginal and Torres Strait Islander people.

The lack of treatment available in remote areas and the availability of transplant facilities create geographical barriers to treatment with 78% of patients in remote areas having to relocate, compared with 39% of those who live in rural areas and 15% of urban Indigenous ESKD patients.26

From 1999 to 2001, half of the 476 Aboriginal and Torres Strait Islander patients starting haemodialysis had to relocate to access treatment.24 The consequences of relocation have included loss of social and cultural connectedness, loss of autonomy and control and loss of status and authority.

Because of the location of renal dialysis centres, there is inequitable access to ESKD treatment services for a significant proportion of Aboriginal and Torres Strait Islander patients.24 The lack of treatment available in remote areas and the availability of transplant facilities create geographical barriers to treatment with 78% of patients in remote areas having to relocate, compared with 39% of those who live in rural areas and 15% of urban Indigenous ESKD patients.26

Example:

The Salvation Army in Port Augusta described a case-management, staged approach to support people – including Aboriginal renal patients – into public housing tenancies. People move from their initial, short-term accommodation into a transitional property, owned by The Salvation Army.

They are provided with a range of services to support them in achieving a stable sustained tenancy including: living skills assistance, personal care, house maintenance and managing social disruption. The Salvation Army supports tenants to manage issues that threaten the tenancy.

Key Challenges

Aboriginal patients moving to town are generally accompanied by immediate family carers and dependents. Research has estimated that as many as five people may follow a person going for dialysis. This presents significant complications and pressures for accommodation, social support services, employment and education in regional town centres.

At the time of conduct of research for the Central Australia Renal Study, among renal patients living in Alice Springs, 50 to 55 patients were living in hostels, 60 in public housing and up to 50 were living either permanently or temporarily in town camps. It is believed that 30 to 35 patients (15-20%) were without secure housing of any kind.

Example:

“I was born and bred on these lands. How on earth could I go all the way to the city, away from my family and country, knowing there was no possibility for them to come down and stay with me, no accommodation, no facilities … Theres no way I could think about being so far away … I’d just be in total despair all the time.”

For Aboriginal people in remote communities, lack of access to haemodialysis services closer to home and the need to relocate are key determinants to uptake of RRT and adherence to treatment regimens. Where the decision to access treatment requires people to move away from family and community, a proportion of patients will choose not to have treatment.

Example:

The Kimberley Renal Service, which has reported excellent adherence to dialysis prescription, has suggested the factors contributing to their success include:

• A sense of ownership/involvement patients have for the organisation providing the service
• Extensive involvement of Aboriginal staff
• A regional renal social worker
• A dialysis patient transport service run by an AWH who, as a community member, has close knowledge of family networks and movements
• On-site primary health care and
• Provision of dialysis closer to home

Centres located in communities offering treatment as close to home as possible have been endorsed in the NT renal services strategy. Both renal ready rooms attached to local health facilities and relocatable haemodialysis facilities are other practical options for dialysis infrastructure.

Alternative models of haemodialysis service delivery which have provided some positive benefits are the mobile bus and community-based, nurse-supported dialysis.
However, attracting and retaining nursing staff to provide dialysis services in remote communities is a key challenge. The recent review report on the Patient Assisted Transport Scheme in Western Australia found:

"one of the other vital things that we need to do is get more nurses working in renal medicine in regional areas. Not all nurses want to work in renal medicine and you cannot force them to work in renal medicine and there is no incentive to encourage nurses to work in renal medicine...

The ability to sustain a live-in dialysis nursing workforce nationally remains a concern, especially outside of metropolitan areas.

Peritoneal dialysis take-up is variable across remote communities in the Northern Territory and nationally. This is due to negative perceptions and concerns about peritoneal dialysis amongst some Aboriginal patients and poor outcomes, in particular high rates of infectious complications.

Improving communication between Aboriginal patients and healthcare workers is a huge challenge. Poor levels of understanding about dialysis options, potential consequences, and/or disbelief about risks of missing dialysis sessions, appear to be significant. Indeed, approximately one (1) in four (4) patients commencing RRT are referred late, which compromises planning and preparation of RRT.

The IMPAKT Study interviewed 355 patients and health professionals nationally about the quality of care for Aboriginal and Torres Strait Islander renal patients and found that Indigenous patients reported poor understanding about their treatment options and a frustration regarding their ability to engage with their healthcare providers.

"There’s a whole lot of us who just don’t understand what’s going on. I don’t know how to talk to the nurse or doctor. He comes down here and just checks out how we’re looking after our body. It’s not enough time.”

The Sharing the True Stories project, which involved videotaping of key interactions between Aboriginal patients and healthcare providers and exploration of the extent of miscommunication, found that shared understanding of key concepts was rarely achieved and miscommunication often went unrecognised. Sources of miscommunication included lack of patient control over the language, timing, content and circumstances of interactions; differing modes of discourse; dominance of biomedical knowledge and marginalisation of Yolngu knowledge; absence of opportunities and resources to construct a body of shared understanding; cultural and linguistic distance; lack of staff training in intercultural communication; and lack of involvement of trained interpreters.

Competent professional interpreters with appropriate training, adequate kidney disease knowledge and covering the range of languages relevant to Indigenous patients with kidney disease are essential to improving health outcomes.

There are limited or no carer respite services for those carers carrying a considerable burden supporting their family and caring for a dialysis patient. Inadequate resources for social workers, support and advocacy services for patients and their families, and the lack of coordination between the relevant social service providers, are a critical barrier to comprehensively addressing renal patients’ social and cultural needs.
Kidney Transplantation

Access and Outcomes for Aboriginal and Torres Strait Islander Australians

Kidney Transplantation Among Aboriginal & Torres Strait Islander Australians

Professor Stephen McDonald
Director of Dialysis and a Senior Staff Nephrologist, The Central Northern Renal and Transplantation Service, Royal Adelaide Hospital
Clinical Director of Renal Services for the Country Health region, SA Health

Overview

It is universally acknowledged that kidney transplantation offers the best option for many patients with ESKD. Transplantation allows greater freedom from dialysis, and patients generally feel better and live longer.

All available information indicates that the prevalence of CKD among Aboriginal and Torres Strait Islander people is high and increasing – with earlier age of onset evident among those aged 40 and over in the past 20-30 years. However, the number of transplantations to Aboriginal and Torres Strait Islander people is high and increasing – prevalence of CKD among Aboriginal and Torres Strait Islander people is high and increasing.

The reasons for poor access to transplantation experienced by Aboriginal and Torres Strait Islander Australians are complex and can be attributed to:

- The greater burden of comorbid illness amongst Aboriginal and Torres Strait Islander dialysis patients leading to fewer patients being judge medically suitable
- The shortage of living and deceased donors from within Aboriginal and Torres Strait Islander communities
- The length of time on the waiting list and matching system
- The challenges in delivering appropriate health services to people living in remote areas who might also have low health literacy and not speak English as a first language
- The dislocation that follows from moving to transplant centres in distant capital cities
- The high complication rate, particularly in terms of early infectious complications leading to poor transplant outcomes, including substantially higher death and graft loss rates.

The poorer outcomes among those who receive transplants are due to higher rates of rejection, less well-matched kidneys, higher rates of infection and infection-related deaths.

There are downsides to transplantation. Prior to transplantation, these include a requirement for significant work up tests and assessments which require visits to major centres. After transplantation there is the prospect of a post-operative stay and side effects away from home and supports. The number of medications usually increases, and there is an increased risk of infections and cancers.

In terms of outcomes, there are important differences between Indigenous and non-Indigenous Australians. Indigenous transplant recipients have substantially higher rates of infections and related deaths and loss of transplant than non-Indigenous people. Nevertheless, there are some indications from ANZDATA that survival rates may be more favourable than with prolonged dialysis, leaving scope for improve transplant outcomes via careful candidate selection and judicious immunosuppressive regimes.

In highlighting the low rates of deceased organ donation among Indigenous Australians, it’s noted that there are currently no frameworks to improve understanding of cultural requirements in this area.

There is also an absence of culturally appropriate educational tools that would allow Indigenous families and communities to discuss the role of deceased organ donation.

This area presents a challenge – how to transform transplantation so that the enormous advantages seen among non-Indigenous people are realised for Indigenous patients.

Greater research and improved data collection are required to further explore this uncertainty and improve health outcomes for Aboriginal and Torres Strait Islander renal patients including:

- Pool and evaluate present experience (consistent clinical data collection, case control study for novel risk factors)
- Develop specific new knowledge (allocation technologies evolving – eplets, microbiological virulence factors, best approaches for sharing knowledge)
- Pragmatic clinical trials’ (immunosuppression approaches, infective prophylaxis)

Key Challenges

- The good outcomes from dialysis treatment
- The lack of transplantations to Aboriginal and Torres Strait Islander patients
- The shorter waiting time for deceased donor transplants
- The shortage of living and deceased donors from within Aboriginal and Torres Strait Islander communities
- The lower survival rates among Aboriginal and Torres Strait Islander patients
- The need for longer-term follow-up of Indigenous transplant recipients

Importantly, the outcomes from transplantation are considerably poorer than among non-Indigenous people.

To improve access to transplantation by Aboriginal and Torres Strait Islander renal patients, there needs to be a better understanding of how to address the barriers. There also needs to be improved support services for patients.

Kidneys for transplantation are largely from deceased donors. There are very few living kidney donors in Aboriginal and Torres Strait Islander communities, due to burden of disease and likelihood of comorbidities evident. Increasing live donations or listing more people on the waiting list is very unlikely to see improvements, given the burden of disease experienced and current barriers in the system.

Key Challenges

- The reasons for poor access to transplantation experienced by Aboriginal and Torres Strait Islander Australian are complex and can be attributed to:
  - The greater burden of comorbid illness amongst Aboriginal and Torres Strait Islander dialysis patients leading to fewer patients being judge medically suitable
  - The shortage of living and deceased donors from within Aboriginal and Torres Strait Islander communities
  - The length of time on the waiting list and matching system
  - The challenges in delivering appropriate health services to people living in remote areas who might also have low health literacy and not speak English as a first language
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- Develop specific new knowledge (allocation technologies evolving – eplets, microbiological virulence factors, best approaches for sharing knowledge)
- Pragmatic clinical trials’ (immunosuppression approaches, infective prophylaxis)
Recommendations

As the national peak body working to ‘save and improve the lives of all Australians affected by kidney disease’, World Kidney Day 2015 provided us with an opportunity to focus on Aboriginal and Torres Strait Islander kidney health issues, and commit to tackling kidney disease in partnership with our First Australians.

The challenges that need to be addressed for Aboriginal and Torres Strait Islander people to enjoy better kidney health are complex. CKD is amongst the most prevalent and high impact of all chronic medical conditions affecting Australia’s Indigenous peoples. Certainly, this is an area of health where national leadership and partnership with the States and Territories is required and an area ripe for attention in the forthcoming National Aboriginal and Torres Strait Islander Health Plan’s implementation.

Furthermore, there are existing strategies such as the National Diabetes Strategy and the National Chronic Disease Strategy through which a greater focus on Aboriginal and Torres Strait Islander health can be a matter of priority.

Given the frequency of kidney disease in Aboriginal and Torres Strait Islanders and its profound clinical and social impact on patients and their families, we contend that a special focus on these complex problems needs to be mounted through a specific National Taskforce charged with overseeing the introduction of measures to reduce the number of people affected of CKD and its burden.

Recommendation 1: National Taskforce on Indigenous Chronic Kidney Disease

A National Taskforce on Indigenous Chronic Kidney Disease be convened by the Federal Government with the States and Territories to address the complex issues leading to the devastating impact of kidney failure on Aboriginal and Torres Strait Islanders. An agreed new Closing the Gap target with States and Territories aimed at halving the incidence of end-stage kidney disease by 2031 will have significant impact on the Indigenous life expectancy and mortality rates.

The terms of reference for the National Taskforce may include:

• Provision of advice to Federal, State and Territory Ministers on improving Indigenous Kidney Health awareness and education, through the National Aboriginal and Torres Strait Islander Health Plan (NATSIHP)

• Engaging health services about detection and early intervention to slow the progression of CKD in Aboriginal and Torres Strait Islanders.

• Planning of existing dialysis infrastructure and workforce support in remote & regional areas

• Coordination of patient support services and models to address short-term accommodation, public housing supply, travel and transport inconsistencies

• Developing key strategies to address the challenges in prevention, early identification, management, treatment and transplantation.

Raising the awareness, education, prevention and early detection of CKD is critical when recent research indicates that around 9 in 10 Aboriginal and Torres Strait Islander people with signs of CKD are not aware they have it.40 Educational resources for Aboriginal and Torres Strait Islander people need to facilitate understanding about the functions of the kidney, kidney health, renal treatments and chronic kidney disease prevention. Any health educational products need to go beyond paper-based materials that demand a high level of literacy.

Given the emerging use of mobile-based applications, social and other multi-media applications need to be explored.

For those at-risk or early stage CKD patients, information support tools need to be developed that articulate the patient pathway for Aboriginal and Torres Strait Islanders. The patient pathway needs to also accommodate the cultural and social dimensions for Aboriginal and Torres Strait Islanders to be of maximum utility. For example, when approximately 78% of Aboriginal people in remote locations need to relocate to commence haemodialysis this presents a significant decision-making point with cultural, social and economic impacts for the patient, family and community.

Some preliminary work has been undertaken by the Northern Territory Government and the Aboriginal Health and Medical Research Council (AHMRC) in NSW, which can be built on.

Recommendation 2: Education about chronic kidney disease

Culturally appropriate educational resources need to be developed that facilitate understanding about the functions of the kidney, kidney health, and chronic kidney disease. The primary target group are early adolescent and young adults. For those at-risk or early stage CKD patients, information support tools need to be developed that articulate the patient pathway for Aboriginal and Torres Strait Islanders.

The success of projects such as the strengths-based, culturally-appropriate, chronic disease prevention and education campaign Deadly Choices needs to be extended. Through their community events and outreach programs they engage at-risk and marginalised Aboriginal and Torres Strait Islander young people with local ACCHSs. Integrated health screening at an early age enables local ACCHSs to detect and monitor risk factors and early markers of CKD.

Further, there is intrinsic value in continuing to invest in community-based health programs which are known to have impacted on the health outcomes of Aboriginal and Torres Strait Islanders.

Evidence indicates that the following initiatives have a positive health impact and would affect intermediate outcomes known to be associated with the development of CKD:41

1. Increased access to antenatal services to improve fetal and maternal health and reduce the rates of low birthweight

2. Screening and intensive management of diabetes in pregnancy and encouragement of breastfeeding to help prevent the development of obesity and early onset of type 2 diabetes

3. Prevention of obesity in early childhood, particularly due to ‘catch up growth’ in those with low birthweight, as these people are at greatest risk of developing diabetes and CKD

4. Early childhood development initiatives to improve educational achievement and life-skills

5. Training community members to improve housing infrastructure to maintain improvements

6. Community-based scabies control programs

7. Food supply initiatives to improve access to affordable healthy food

8. Culturally appropriate healthy nutrition, physical activity and quit smoking programs and legislative initiatives to regulate tobacco advertising.

40 ABS 2014

For further reading:
Kidney Health for All
Kidney Health Australia & ANZSN
Recommendations

The high levels of sugar and sugary drink consumption remain a significant concern, given the high rates of Type 2 diabetes. More community-based education and nutrition awareness is needed more broadly.

**Recommendation 3: Prevention of CKD**

Continue to invest in community-based health programs which are known to have impacted on the health outcomes of Aboriginal and Torres Strait Islanders, including chronic disease prevention and education (such as Deadly Choices), mothers & babies, infant and early childhood, and smoking cessation.

Further, there is intrinsic value in continuing to invest in community-based health programs which are known to have impacted on the health outcomes of Aboriginal and Torres Strait Islanders including:

- antenatal services and management of gestational diabetes
- early childhood development initiatives
- improving housing infrastructure
- Community-based scabies control programs
- Food supply initiatives to improve access to affordable healthy food
- Culturally appropriate healthy nutrition, physical activity and quit smoking programs and legislative initiatives to regulate tobacco advertising.

A continuing increase in the number of Aboriginal and Torres Strait Islander peoples with treated ESKD is forecast. The majority will commence haemodialysis, with many of these being unplanned.

Primary healthcare services, including ACCHSs need to be supported to detect and manage Aboriginal and Torres Strait Islander patients with CKD. This includes commencing a program of health check-screening, detection and management of CKD from early adulthood. This will continue across the life course with the development of GP management plans, medication management, and developing a patient plan for commencement of renal replacement therapy.

The establishment of a national register of Aboriginal and Torres Strait Islander CKD patients, consolidating regional data summaries will enable the monitoring of trends in the incidence and prevalence of CKD and progression to renal replacement therapy. This will assist to forecast the demand for health services both primary and tertiary and future planning needs of population-based primary care and tertiary infrastructure in kidney health.

For example, the Rheumatic Heart Disease (RHD) Register databases are intended to support registration of people with rheumatic fever and rheumatic heart disease and report disease in the community. Specifically, the registers help to identify people requiring high level acute care and those who need long-term treatment. The NT RHD register is a key element of the RHD program and is recognised internationally as having played a pivotal role in reducing the burden of disease in the NT since its introduction.  

**Recommendation 4: Early Detection and Management of CKD**

Improved early detection and management of CKD for Aboriginal and Torres Strait Islanders be promoted through general practice, primary healthcare services, and ACCHSs. The care pathway to include:

- integrated health check screening that specifically includes kidney testing
- establishment of a CKD register (regional scope for national reporting)
- self-management strategies
- early education regarding RRT management choices

The use of web-based, online & e-technologies needs to be explored with reference to overcoming geographic distance, low language and literacy rates.

The lack of access to haemodialysis services in remote and very remote regions necessitates the relocation to regional centres. This has tremendous cultural, psychological social and economic impact on many Aboriginal and Torres Strait Islander families and communities.

A range of closer to home haemodialysis options need to be explored in order to reduce the impact of dislocation. There are a number of renal dialysis models that are working and achieving solid health outcomes:

- In Broome, there is a facility for dialysis located next to the Broome Regional Aboriginal Medical Service (BRAMS). Clinical research data has indicated they are achieving similar health outcomes for Aboriginal and Torres Strait Islander renal patients, as those of non-Indigenous patients.
- The Western Desert Dialysis model in Alice Springs has developed a community-based, nurse-supported model of care that is being utilised by patients in Central Australia.
- Research is needed to examine the range of dialysis care options, including the sustainability and cost-effectiveness of community-based dialysis provision. The social impact of various models on family, employment and education is necessary to identify the most cost-effective solution. Some of this work is being researched by the Menzies School for Health Research in partnership with government departments, renal services, primary care and community organisations.

The NT have made significant effort to promote and enable self-care, yet there still needs more in-community support for patients and families. More cultural appropriate, patient-centre support and follow-up services at home are required.

For a range of reasons, a proportion of Aboriginal and Torres Strait Islander renal patients will choose not to have treatment or withdraw.

At these very sensitive decision-making points, options for palliative and end-of-life care services that meet the needs of Aboriginal and Torres Strait Islanders are required.

Some work has been undertaken by the Northern Territory Government on palliative care for renal patients in remote settings, which can be built on.
Recommendations

Recommendation 5: Dialysis Modality
The range of appropriate dialysis care options for Aboriginal and Torres Strait Islanders are critically assessed with regard to focussing on sustainability, clinical suitability, cost-effectiveness, health and social impact for people in remote, regional and urban settings. Innovative, closer-to-home, place-based models of dialysis need to be considered taking into account the local circumstances and the appropriate resource and staffing requirements. Development of models of palliative and end-of-life care services appropriate to meet the needs of Aboriginal and Torres Strait Islander renal patients, which incorporate and are sensitive to regional cultural practices and beliefs. For example, there are only two models of palliative care focusing on and developed in Aboriginal communities that have been implemented.

Recommendation 6: Workforce & Education
A range of workforce training and development strategies be explored and prioritised for remote, very remote and regional centres, including:
- Increasing the training, recruitment and utility of Aboriginal Health Workers nationally
- Incentives to attract and retain nursing and technical staff to provide dialysis services in remote communities
- Integrating cultural competence training of the non-indigenous health workforce in curriculum and continuous professional development (CPD)
- Training and use of local interpreters with adequate kidney disease knowledge to facilitate RRT planning

Relocating to access treatment presents significant complications and pressures for accommodation, social support services, employment and education in regional town centres. Social workers, support and advocacy services often have inadequate resources to work with Aboriginal and Torres Strait Islander patients and their families to coordinate services to comprehensively address the needs. A wide range of support services for Aboriginal and Torres Strait Islander kidney consumers and their families need to be accessible and better integrated to limit the severity of dislocation including:
- Psychological support services
- Housing and accommodation
- Travel and transport
- Respite Care

Recommendation 7: Social Support Services
There is much need for improvement and understanding about CKD progression, ESKD, impacts on self, family and community. Greater research and improved data collection are required to further explore this uncertainty and improve health outcomes for Aboriginal and Torres Strait Islander renal patients.

Kidney transplantation rates to Aboriginal and Torres Strait Islander renal patients are low. This has been attributed to a range of complex issues. To improve access to transplantation by Aboriginal and Torres Strait Islander renal patients, there needs to be a better understanding of how to address the barriers.

A national audit of transplant outcomes for Indigenous Australians Setting a research agenda for developing specific new knowledge and technologies
- Implementing pragmatic clinical ‘trials’ of immunosuppression approaches & infective prophylaxis
- Developing, implementing and evaluating culturally appropriate education materials regarding organ donation and transplantation

Recommendation 8: Kidney Transplantation
A targeted, national approach is needed which will focus on improving transplant outcomes and addressing reversable health systems barriers to equitable access for suitable Aboriginal and Torres Strait Islander patients, which includes:
- A national audit of transplant outcomes for Indigenous Australians Setting a research agenda for developing specific new knowledge and technologies
- Implementing pragmatic clinical ‘trials’ of immunosuppression approaches & infective prophylaxis
- Developing, implementing and evaluating culturally appropriate education materials regarding organ donation and transplantation

Kidney transplantations are largely from deceased donors. One priority is the need to develop culturally appropriate educational tools that would allow Indigenous families and communities to discuss the role of deceased organ donation and better understand treatment options including kidney transplantation.
Anderson, K; Devitt, J; Cunningham, J; Preece, C & A. Cass 2008, “All they said was my kidneys were dead”: Indigenous Australian patients’ understanding of their chronic kidney disease” in MJA 2008; 189:499-503


Australian Bureau of Statistics (ABS) 2014, Estimates and Projections: Aboriginal and Torres Strait Islander Australians 2006 to 2026, Cat. no. 4831.0.55.001, Canberra: ABS.


Hoy, W; Davy, R; Sharma, S; Hoy, P; Smith, J & J. Kondalsamy-Chennakesavan 2009, ‘Cardiovascular disease profiles in remote Aboriginal and Torres Strait Islander health care settings: the challenges for mainstream services, Rural and Remote Health 13: 2338. (Online) 2013.


Rix, E; Barber, L; Stirling, J; Tong, A; & S. Wilson 2014, ‘Treat the alternative but it messes up your life’: Aboriginal peoples experience of haemodialysis in rural Australia’, in BMJ Open 2014 Apr 26 DOI: 10.1136/bmjopen-2013-004545


The purpose of the Policy Roundtable was twofold:
1. To highlight the critical issues across the spectrum of health care impacting on Aboriginal and Torres Strait Islander chronic kidney disease.
2. To showcase and discuss strategies and ways forward in addressing these issues.

The Policy Roundtable brought together Australia’s leading researchers, nephrologists, Aboriginal and Torres Strait Islander health services and consumers with Members of Parliament including:

- Senator Rachel Siewert
- Senator the Hon Doug Cameron
- Senator Deborah O’Neill
- The Hon Shayne Neumann MP
- The Hon Warren Snowdon MP
- Mr Stephen Jones MP
- Mr Mark Coulton MP
- Ms Melissa Price MP
- Chief of Staff, Senator O’Neill
- Adviser to Assistant Minister the Hon Fiona Nash

Invitations to the Roundtable were extended to all members of the Indigenous and Health Parliamentary Committees.

Other Departmental and non-government representatives included:
- Department of Health (DoH)
- Australian Organ & Tissue Authority (AOTA)
- Aboriginal Hostels Limited (AHL)
- National Health and Medical Research Council (NHMRC)
- Australian and New Zealand Society of Nephrology (ANZSN)
- Menzies School of Health Research (Menzies)
- South Australian Health and Medical Research Institute (SAHMRI)
- University of Queensland
- Institute for Urban Indigenous Health (IUIH)
- Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)

What is the burden of kidney disease in Aboriginal & Torres Strait Islander communities?

Dr Tim Mathew
Setting the scene: What is the burden of kidney disease in Aboriginal and Torres Strait Islander communities?
March, 2015
Timothy Mathew
Medical Director, Kidney Health Australia

Conceptual model for chronic kidney disease

Levey et al. Lancet 2012 379:165
The clinical stages of chronic kidney disease (CKD)

Setting the scene:
In Indigenous Australians v non-Indigenous:

Early and late kidney disease is:

- Is more frequent
- Is more severe at an earlier age
- Increases with age
- Increases with remoteness
- Is strongly associated with diabetes
- Is associated with multiple co-morbidities
- Has greater impact (social and medical)

Relativity is one thing: the absolute impact is another
How much CKD?: Self reporting
(non age-standardised)

Has the doctor ever told you that you have chronic kidney disease?

2004: Yes - 1.6%

2012: Yes - 1.7%

But 18% actually have CKD on testing urine and blood.

Early Chronic kidney disease is a silent condition
NATSHIS + HMS

CKD prevalence (% of population)
Indigenous Australians v Non-Indigenous

ABS: AHS 2011-12
Albuminuria prevalence (% of population)
Indigenous Australians v Non-Indigenous

ABS: AHS 2011-12

eGFR prevalence (% of population)
Indigenous Australians v Non-Indigenous

ABS: AHS 2011-12
Aboriginal and Torres Strait Islander adults – Proportion with chronic kidney disease by remoteness

ABS: 2012 ATSIHS

The overlap in screened findings in remote aboriginal communities – the overlap increases with age

Hoy W et al. Kid Int 68 (598):76. 2005
Australians accepted onto dialysis by decade and Indigenous status

<table>
<thead>
<tr>
<th>Decade</th>
<th>Non Indigenous</th>
<th>Indigenous</th>
</tr>
</thead>
<tbody>
<tr>
<td>1963-70</td>
<td>706</td>
<td>1</td>
</tr>
<tr>
<td>71-80</td>
<td>3996</td>
<td>22</td>
</tr>
<tr>
<td>81-90</td>
<td>6519</td>
<td>262</td>
</tr>
<tr>
<td>91-00</td>
<td>11470</td>
<td>1072</td>
</tr>
<tr>
<td>2001-10</td>
<td>17498</td>
<td>1900</td>
</tr>
</tbody>
</table>

The Gap in new dialysis starts 1986-2013
Indigenous Australians v Total (rate per million population)
% of Indigenous Australians >40 yrs starting dialysis have Diabetes, CVD or lung disease

Source: All-W analysis of ANZDATA Registry data.

Figure 5.5: New cases of KRT-treated ESKD patients with a comorbidity of CVD, diabetes or lung disease at first treatment, by Indigenous status and age, 2007–2008

Relative incidence rate indigenous vs non-indigenous
Australia 2009-2013

Relative rate (95% CI)

Female
Male
ESKD Incidence of Canadian Aboriginal v NZ Maori and Pacific Islanders v Australia Indigenous by age

Incidences ratio c/w majority population

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Canada</th>
<th>New Zealand</th>
<th>Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–14 years</td>
<td>1.9</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>15–29 years</td>
<td>2.5</td>
<td>2.4</td>
<td>3.2</td>
</tr>
<tr>
<td>30–44 years</td>
<td>2.2</td>
<td>2.9</td>
<td>10.1</td>
</tr>
<tr>
<td>45–64 years</td>
<td>3.8</td>
<td>9.5</td>
<td>15.9</td>
</tr>
</tbody>
</table>


ESKD Incidence by cause and by region

Incidences ratio c/w majority population (Adults age 45-64 yrs)

<table>
<thead>
<tr>
<th>Cause</th>
<th>Canada</th>
<th>New Zealand</th>
<th>Australia</th>
</tr>
</thead>
<tbody>
<tr>
<td>DM2</td>
<td>8.5</td>
<td>30</td>
<td>48</td>
</tr>
<tr>
<td>Gn</td>
<td>1.8</td>
<td>3.8</td>
<td>8</td>
</tr>
<tr>
<td>High BP</td>
<td>1.5</td>
<td>7.8</td>
<td>6.3</td>
</tr>
<tr>
<td>PKD</td>
<td>0.4</td>
<td>0.5</td>
<td>0.3</td>
</tr>
<tr>
<td>Other</td>
<td>1.4</td>
<td>2.1</td>
<td>4.7</td>
</tr>
</tbody>
</table>

Lifetime risk of ESKD in remote dwelling Australian Aboriginal people

*Impact of diabetes (increase from 7% to 41%)*

![Graph showing the lifetime risk of ESRD](image)


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**Setting the scene:**

*In Indigenous Australians v non-Indigenous:*

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**Early and late kidney disease in Aboriginal and Torres Strait Islander people:**

- Is more frequent (*overall X4*)
- Is more severe at an earlier age (*2 decades earlier*)
- Has greater impact (*social and medical*)
- Increases with age (*50% have it at age 65 yrs*)
- Increases with remoteness (*up to 40 times*)
- Is strongly associated with diabetes (*6 times more frequent*)
- Is associated with multiple co-morbidities (*majority*)

---

**To Close the Gap it is essential to reduce the burden of Chronic Kidney Disease**
Burden of Disease
AIHW Definition

- *Burden of disease* is a measure used to assess and compare the relative impact of different *diseases* and injuries on populations by quantifying health loss due to *disease* and injury that remains after treatment, rehabilitation or prevention efforts of the health system and society generally.

Problems with assessing burden of disease in Chronic Kidney Disease (CKD)

- Most CKD is asymptomatic and unrecognised - doesn’t contribute to burden of disease studies.

- But even while asymptomatic, CKD is associated with increased co-morbidities (eg CVD).

- CKD is more frequent in older years.

- In those with CKD the risk of dying of a heart attack is 20 times that of developing kidney failure.
Appendix C:

Prevention and Treatment of CKD in Aboriginal Australians: what is currently in place?

Professor Wendy Hoy
Prevention and Treatment of CKD in Aboriginal Australians: what is currently in place?

Wendy Hoy
Centre for Chronic Disease,
University of Queensland
And a cast of thousands.

Especial thanks to participating community members and councils, and our sponsors.

Average annual incidence of treated ESRD per million in Aboriginal people in the NT
Average annual incidence of treated ESRD per million
in Aboriginal people in the NT

Annualised costs $107,000 per patient in 1996/1997:
• $78,600 for dialysis,

Constituted 32% of hospitalisations, 9% of all costs for, (for 0.7% of all patients)

Compare with primary care budget then of <$400 per person.

Chronic Kidney Disease (CKD)

Almost never occurs alone

Is usually multideterminant (>one cause)

A delicate sensor of overall microvascular health

Reflects “the overall force of mortality”
analyses of aboriginal and non-aboriginal deaths in metropolitan, rural and remote areas.
Chronic Kidney Disease (CKD)

Almost never occurs alone

Is usually multideterminant (>one cause)

A sensitive marker of cardiovascular health and general health

Reflects "the overall force of mortality"


Incidence of RRT per million in Indigenous people by state/territory, 1997-2001

Deaths per 1000, Indigenous people, 2001

Similarly hospital separations:

The CKD continuum

No CKD
- Prevention
- Understanding risk factors
- Reducing risk factors

Clinical CKD
- Timely detection
- Disease modification

End stage kidney failure
- Choosing the best options
  - to extend life
  - but optimise QOL
  - minimise futile treatment
  - contain costs
Infant and childhood risk factors

Number of infections before 15th birthday, among 450 children (4 of 8 organ systems)

Detection

Chronic disease profiles in Borroloola

Implications for health services

- Regular screening as subjects age
- Integrated screening (for all conditions)
- Integrated treatment
- Most need treatment by middle age
- Many will need treatment for decades
- Processes will embrace everyone
- Chronic disease becomes “core business”
- Embedded in primary care

Hoy et al., ANZJPH, 2010
Treatment

With RAS blockers for
- Everyone with albuminuria/proteinuria
- Everyone with hypertension
- Everyone with diabetes
- Everyone with cardiovascular disease

Plus additional meds as needed for
- Blood sugar controls
- Lipid management
- More blood pressure management
- Aspirin

Tiwi kidney treatment program: 1998-2001: (3.4 yr)

Clinical results
- 50% reduction in nonrenal deaths
- 57% fewer people starting dialysis
- Number needed to treat to avoid one person starting dialysis = 27.
- Reduced blood pressure in most
  Hoy et al, MJA 2003
  Hoy et al, Kidney Int 2005

Cost savings
In dialysis avoided, from in treating 228 people over 4.6 years
- $3,400,000 total,
- $14,912 per patient treated
- $1,888 per community member
Potential Treatment Innovations

Multicomponent dose polypills
  ACEi, ARBs, statins, diuretics, calcium channel & beta blockers
  statins, hypoglycemics, aspirin, folate
  half dose / full dose

Reminder systems
  Mobile phones, beepers
  reminders at work place, card games
  sports practice, women's centre, club.

Simplified delivery systems
  Patches: implantable drugs

Extended delivery systems
  monthly, 6 monthly

Developments over the last 13 years

Endorsement of need for systematic CD surveillance and management

Protocols incorporated into standard primary health care plans

Reimbursable Medicare service items for regular screening (Item 715)

Reimbursable Medicare items for treatment and case management

More responsibility, autonomy & reimbursement for nurses and health workers

Free or subsidised medications of people in remote areas (S100, QUMAX)

Increasing adoption of IT and IT support

Increasing dialogue about outcomes and accountability

Specifications of targets and performance indicators

Hoy, BMJ, 2013
Respect for needs-based funding

Incidence of RRT per million in Indigenous people by state/Territory, 1997-2001

Deaths per 1000, Indigenous people, 2001

Odds ratios (CI) for conditions with AusDiab, adjusted for age adjusted
Hoy et al. ANZJPH, April 2007

Incidence or Treated RSKD (RRT) in Indigenous Australians, cases per million, by state/territory, since 2003,
2 year rolling average, ANZDATA reports
Mortality of Indigenous Australians

Between 2001 and 2011, there was a 5% fall in death rates for Indigenous Australians, and a narrowing of the gap between Indigenous and non-Indigenous Australians.

Indigenous People in Remote Australia

Wang and Hay, ANZJPRI, 2015

Things to work on...
Points to emphasise

We have evidence-based approaches, now embedded in primary care.

Things are improving.

Policy and practices well ahead of mainstream care.

Our programs are internationally respected and emulated.

Stay the course with multi-party support, stability of policy (10 year cycles).

Need sustained, adequate funding over long term.

Appropriate modifications as progress and findings dictate.

Reconcile different jurisdictions for operation and budget allocations for primary care (rural) and hospital budgets (NPSR).

Supported by:

The Tiwi Land Council
Kidney Health Australia
NHMRC of Australia
Servier Australia
The Colonial Foundation of Australia
Territory Health Services
Office of Aboriginal and Torres Strait Islander Health
NIDDK, National Institutes of Health

Amgen
Janssen Cilag
Helen Hayes, Jackson Mass, USA
Kidney Care
Rico Tinto
Helen Hayes, Jackson Mass, USA
American Heart Association
NIDDK, National Institutes of Health

The Hon Michael Wooldridge
Appendix D:

The Institute for Urban Indigenous Health (IUIH) by Ms Jodie Currie
Kidney Health Roundtable Parliament House
25 March 2015

IUIH – Background

IUIH established in 2009 as a strategic response to population growth and dispersion within SEQ AND provide regional leadership for implementation of CTG Measures and effort across the health system

IUIH ‘owned’ by the four (4) Community Controlled Health Services in SEQ:

- the Aboriginal & Torres Strait Islander Community Health Service (ATSICHS) Brisbane Ltd;
- the Kalwun Health Service;
- the Kambu Medical Service; and
- the Yulu-Burri- Ba Health Service
Challenges & Opportunities – CTG in Urban SEQ

§ Continued growth of Aboriginal and Torres Strait Islander population/s and ‘shift’ to outer-urban areas – concentration of populations in areas with poor access to primary health care

§ Shift/s of population ‘blurred’ CCHS service area boundaries

§ Coordination of primary health care across range of providers

§ Focus of ‘Indigenous specific’ investment by Government on remote communities – risk of ‘mainstreaming’ service delivery in Urban areas

Aboriginal & Torres Strait Islander Population of SEQ

§ Minimum of 60,000 – with ‘under-counts’ estimate to total up to 70,000

§ More than the total Indigenous population of Victoria

§ More than the total Indigenous population of South Australia

§ More than two thirds of the total Indigenous population of Northern Territory

§ More than half of the total Indigenous population of the Western Australia
### Indigenous Population of SEQ

<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Brisbane</td>
<td>14,629</td>
<td>13%</td>
</tr>
<tr>
<td>Ipswich</td>
<td>6,416</td>
<td>36%</td>
</tr>
<tr>
<td>Gold Coast</td>
<td>6,196</td>
<td>35%</td>
</tr>
<tr>
<td>Logan</td>
<td>7,774</td>
<td>21%</td>
</tr>
<tr>
<td>Moreton Bay</td>
<td>8,482</td>
<td>42%</td>
</tr>
<tr>
<td>Redland</td>
<td>2,617</td>
<td>34%</td>
</tr>
<tr>
<td>Lockyer Valley</td>
<td>1,012</td>
<td>-12%</td>
</tr>
<tr>
<td>Scenic Rim</td>
<td>932</td>
<td>43%</td>
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<td><strong>TOTAL</strong></td>
<td><strong>48,058</strong></td>
<td><strong>16%</strong></td>
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### MBS Health Checks 2008/2009

<table>
<thead>
<tr>
<th>Division of GP</th>
<th>No of 708 checks</th>
<th>% of eligible children screened</th>
<th>No of 710 checks</th>
<th>% of eligible adults screened</th>
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<tbody>
<tr>
<td>South East Alliance</td>
<td>59</td>
<td>3.4</td>
<td>126</td>
<td>4.5</td>
</tr>
<tr>
<td>Brisbane South</td>
<td>195</td>
<td>12.3</td>
<td>452</td>
<td>17.3</td>
</tr>
<tr>
<td>Gold Coast</td>
<td>35</td>
<td>1.5</td>
<td>28</td>
<td>2</td>
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<tr>
<td>Logan Network</td>
<td>42</td>
<td>1.1</td>
<td>67</td>
<td>2.2</td>
</tr>
<tr>
<td>Ipswich</td>
<td>74</td>
<td>2</td>
<td>52</td>
<td>2</td>
</tr>
<tr>
<td>Moreton Bay</td>
<td>0</td>
<td>0</td>
<td>14</td>
<td>0.6</td>
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<tr>
<td>GP Partners</td>
<td>27</td>
<td>3</td>
<td>35</td>
<td>0.8</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>432</strong></td>
<td><strong>3</strong></td>
<td><strong>774</strong></td>
<td><strong>4.1</strong></td>
</tr>
</tbody>
</table>

*Source: Medicare Australia, ABS Census 2006*
IUIH Strategic Priorities 2011-2014

1. To facilitate improved access to comprehensive primary health care for Aboriginal and Torres Strait Islander populations of SEQ

2. To ensure a coordinated and integrated approach to planning, development and delivery of primary health care services to Aboriginal and Torres Strait Islander populations of SEQ

3. To ensure development of a competent and appropriate workforce in Aboriginal and Torres Strait Islander health

4. To build sustainable partnerships in Aboriginal and Torres Strait Islander health

5. To contribute to building the evidence base for urban Aboriginal and Torres Strait Islander health

Highlights – Improving access to PHC

§ ‘Creating visibility of urban need through data’:

§ Development of comprehensive profiles of client populations of CCHSs (Practice Health Atlas);

§ Development of SEQ Regional Profile, combing data from CCHSs with data from QH (where available), ABS/AIHW and Medicare Australia data to identify ‘gaps’ and monitor progress/highlight success

§ Development of ‘Access’ and ‘Quality’ Targets for CCHSs (‘IUIH Dashboard Targets’)
Highlights – Improving access to PHC

§ Establishment of ‘new’ and expanded PHC (CCHS) Clinics in key priority locations throughout SEQ:
  § Logan/Woodridge
  § Brisbane North/Strathpine
  § Bayside Region/Capalaba/Wynnum
  § Gold Coast Region/Oxenford/Billinga
  § Lockyer Valley/Laidley
  § Western Corridor/Goodna/Browns Plains
  § Brisbane North/Northgate (Clinic Expansion)
  § ‘Murri School’/Acacia Ridge Clinic
  § Moreton Bay Region/Morayfield/Caboolture
  § Moreton Bay Region/Deception Bay

SEO Regional Report Card

Since 2019/20 the Aboriginal Medical Services of SEQ have significantly increased access to comprehensive primary health care for Indigenous peoples within the region. The DHM and its partners are committed to reporting on progress to our communities with the results of the 2021/22 year captured within this report card.

SEO2 Regional Report Card (continued)
Rates of kidney disease amongst SEQ ATSICCHS active Aboriginal and Torres Strait Islander adult clients:
• High rates of screening
• Proteinuria / signs of early kidney disease – 22% of all clients
• Chronic kidney disease – 3%
• Clients with diabetes: early kidney disease / proteinuria: 42%; Chronic kidney disease: 11%

Highlights – Improving understanding of Kidney Health in SEQ

• High uptake by young men (around 65-70% of all active clients are up to date with comprehensive health checks; in some clinics, 55% of all checks in young adult age range are male)

Standard evidence-based protocols for SEQ:
• chronic disease cycle of care,
• care coordination, access to specialist and allied health services in one-stop-shop;
• refinements to health information system to prompt evidence-based monitoring, recall and care; continuous quality improvement activities including data collection / collation / analysis / feedback / action to address identified gaps.
South-East Queensland CCHS patient access patterns (2011)

South-East Queensland CCHS patient access patterns (June 2014)
The ‘IUIH Model’

It’s about providing more high quality comprehensive primary health care services to more Aboriginal and Torres Strait Islander people with more independence from government grants and more autonomy in determining how and where to re-invest self-generated revenue... towards a goal of eliminating disparities in health outcomes

Core workforce components

Using some initial science, a little guess-work and some trial and error, arrived at a core workforce per FTE GP of:

X1 Practice Manager
X1 Community Liaison Officer
X2 Reception / admin staff
X2 Clinic RNs
X2 AHWs
X1 Transport officer
X1 GP
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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<tbody>
<tr>
<td>1</td>
<td>Meeting and sign off with Board</td>
</tr>
<tr>
<td>2</td>
<td>Discussion of IUH Model, agreement on overall roll-out plan</td>
</tr>
<tr>
<td>3</td>
<td>Establishment of Joint Management Committee</td>
</tr>
<tr>
<td>4</td>
<td>Joint presentation to all staff</td>
</tr>
<tr>
<td>5</td>
<td>Delivered by IUH and member CCHS managers and board, discussion of reform process and IUH model implementation, opportunity for Q&amp;A</td>
</tr>
<tr>
<td>6</td>
<td>First meeting of the JMC - confirmation of TOR, process, meetings, etc.</td>
</tr>
<tr>
<td>7</td>
<td>Assessment phase = 3-4 weeks</td>
</tr>
<tr>
<td>8</td>
<td>Data collection - key volume and access indicators</td>
</tr>
<tr>
<td>9</td>
<td>Workforce assessment and functions mapping</td>
</tr>
<tr>
<td>10</td>
<td>HR assessment</td>
</tr>
<tr>
<td>11</td>
<td>Assessment of clinical data and clinical governance framework</td>
</tr>
<tr>
<td>12</td>
<td>Community engagement analysis</td>
</tr>
<tr>
<td>13</td>
<td>Second meeting of JMC - endorsement of detailed implementation plan based on assessment outcomes</td>
</tr>
<tr>
<td>14</td>
<td>Implementation - 3-6 months</td>
</tr>
<tr>
<td>15</td>
<td>Spearhead(s) leading implementation according to agreed plan</td>
</tr>
<tr>
<td>16</td>
<td>Monitoring - continuous throughout</td>
</tr>
<tr>
<td>17</td>
<td>Feedback through monthly meetings of the JMC, adjustment of plan as needed</td>
</tr>
<tr>
<td>18</td>
<td>Transition phase - 4 weeks</td>
</tr>
<tr>
<td>19</td>
<td>Development of exit strategy, establishment of maintenance plan</td>
</tr>
<tr>
<td>20</td>
<td>Presentation from JMC to Board of exit report and maintenance plan</td>
</tr>
</tbody>
</table>

**Quality tracking**

Lead Clinician Group has a key role to play in developing and supporting implementation of regional quality improvement activities and measures.

Current activities being implemented regionally across SEQ include:

- Inclusion of quality indicators in team Incentive Plan targets
- Allocation of time for monthly CQI meeting at each location [2] opportunity for data feedback, review, discussion re service improvements etc.
- Development of CQI framework and standard clinical indicators
- Regular clinical audits
- Clinical governance tracking tool

**Resourced and regionally supported**
DEADLY CHOICES

A DEADLY CHOICE IS A HEALTHY CHOICE

SOCIAL MEDIA

% Growth in Likes/Followers

Facebook

Instagram

Twitter

Social Media Growth

Facebook Likes

Twitter Followers

Social Media Growth
COMMUNITY EVENTS

<table>
<thead>
<tr>
<th>Community Days</th>
<th>Attendance</th>
<th>Health Screens</th>
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<tbody>
<tr>
<td>Strathpine</td>
<td>300</td>
<td>110</td>
</tr>
<tr>
<td>Wynnum</td>
<td>200</td>
<td>26</td>
</tr>
<tr>
<td>Ipswich</td>
<td>700</td>
<td>6 Full H/C 18 New</td>
</tr>
<tr>
<td>Browns Plains</td>
<td>300</td>
<td>72</td>
</tr>
<tr>
<td>Goodna</td>
<td>400</td>
<td>86</td>
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TOBACCO

<table>
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<tr>
<th>Programs</th>
<th>Participants</th>
<th>Deadly Choices sessions</th>
<th>Surveys</th>
<th>Smoking Stalls</th>
<th>STMBS Workshops</th>
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<tr>
<td>24</td>
<td>239</td>
<td>108</td>
<td>2,881</td>
<td>30</td>
<td>4</td>
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</table>
### Appendix E:

Dialysis access, issues and outcomes for Indigenous Australians by Professor Alan Cass

<table>
<thead>
<tr>
<th>Term</th>
<th>Participants</th>
<th>Health Checks</th>
<th>Completed Program</th>
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<tbody>
<tr>
<td></td>
<td>Primary</td>
<td>Secondary</td>
<td>Primary</td>
</tr>
<tr>
<td>1</td>
<td>224</td>
<td>110</td>
<td>23</td>
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<td>2</td>
<td>133</td>
<td>469</td>
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<td>3</td>
<td>87</td>
<td>126</td>
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<td>4</td>
<td>15</td>
<td>1354</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>1354</td>
<td>1354</td>
<td>1354</td>
</tr>
</tbody>
</table>
Dialysis access, issues and outcomes for Indigenous Australians

Professor Alan Cass
President Australia and New Zealand Society of Nephrology
Director Menzies School of Health Research
alan.cass@menzies.edu.au

discovery for a healthy tomorrow

Indigenous Australians with ESKD

Stage 5 CKD
1700

Stage 4 CKD
4400

Stage 1 - 3 CKD
67,000

Hypertension, Diabetes, ++

400,000 At High Risk

Estimates based on ABS: NATSIHMS 2012-3
Aboriginal and Torres Strait Islander adults – Proportion with chronic kidney disease by remoteness

<table>
<thead>
<tr>
<th>Remoteness</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major Cities</td>
<td>11.8</td>
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<tr>
<td>Inner Regional</td>
<td>10.7</td>
</tr>
<tr>
<td>Outer Regional</td>
<td>17.7</td>
</tr>
<tr>
<td>Remote</td>
<td>27.6</td>
</tr>
<tr>
<td>Very remote</td>
<td>36.7</td>
</tr>
</tbody>
</table>

Kidney disease burden

MJA 2001, 175: 24 - 27
Haemodialysis – 4.1% non-Indigenous compared to 79% Indigenous
Home-based treatment – 64% non-Indigenous compared to
27% Indigenous

Treatment modality

1,700 Indigenous

18,500 Non-Indigenous

Dialysis modality by ethnicity

Indigenous

Non-Indigenous
Peritonitis by ethnicity

Months per episode


Non-Aboriginal
Aboriginal

95% CI
95% CI

Episodes per year

Early artificial kidney
Sharing the true stories: improving communication between Aboriginal patients and healthcare workers

Results: A shared understanding of key concepts was rarely achieved. Miscommunication often went unrecognised. Sources of miscommunication included lack of patient control over the language, timing, content and circumstances of interactions; differing modes of discourse; dominance of biomedical knowledge and marginalisation of Yolngu knowledge; absence of opportunities and resources to construct a body of shared understanding; cultural and linguistic distance; lack of staff training in intercultural communication; and lack of involvement of trained interpreters.

Conclusions: Miscommunication is pervasive. Trained interpreters provide only a partial solution. Fundamental change is required for Aboriginal patients to have significant input into the management of their illness. Educational resources are needed to facilitate a shared understanding, not only of renal physiology, disease and treatment, but also of the cultural, social and economic dimensions of the illness experience of Aboriginal people.
There’s a whole lot of us who just don’t understand what’s going on.

I don’t know how to talk to the nurse or doctor. He comes down here and just checks out how we’re looking after our body. It’s not enough time.

MJA 2008; 189: 499–503
You don’t go knocking on their door, [that’s the] danger one. The door is locked. They sit behind closed doors.

MJA 2008; 189: 499–503

I was born and bred on these lands. How on earth could I go all the way to the city, away from my family and country, knowing there was no possibility for them to come down and stay with me, no accommodation, no facilities ... There’s no way I could think about being so far away ... I’d just be in total despair all the time.

(Senior community member, September 2010)
Appendix F:

Kidney Transplantation Among Aboriginal & Torres Strait Islander Australians by Professor Stephen McDonald
Kidney Transplantation among Aboriginal & Torres Strait Islander Australians

Prof Stephen McDonald

Pathways to transplantation

- End-stage kidney disease
  - Dialysis
  - Pre-emptive LD
  - Waiting list
    - Referral/assessment/acceptance
    - Allocation
  - Living donor transplantation
  - Deceased donor transplantation
Why transplantation?

Pros
• Freedom from dialysis
  – No dietary restrictions
  – No fluid restrictions
  – Travel much easier
• Feel better
• Live longer (maybe)

Cons
• Surgery in a remote location
  – And postoperative stay
  – Side effects
• Tablets +++
• Increased risk of
  – Infections
  – Cancers
• Workup tests, assessments, waiting list

Number of transplants

[Graph showing number of transplants for Non-Aboriginal and Aboriginal populations, with bars for deceased, live related, and live unrelated donors, data up to end 2013, Australia only.]
Remoteness & kidney transplantation

<table>
<thead>
<tr>
<th>Non-Aboriginal</th>
<th>Aboriginal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>73%</td>
<td>25%</td>
</tr>
<tr>
<td>17%</td>
<td>23%</td>
</tr>
<tr>
<td>9%</td>
<td>8%</td>
</tr>
<tr>
<td>3%</td>
<td>18%</td>
</tr>
</tbody>
</table>

Inner Regional Australia
Outer Regional Australia
Very Remote Australia
Major Cities of Australia
Remote Australia

Remoteness category of transplant recipients
ANZDATA, DD1 transplants to 2013

Where are recipients?

Indigenous kidney transplant recipients 2003-2013
Time to waitlisting

Adjusted for age, measured comorbidities etc. HR for listing 0.18 [95% CI 0.13—0.26] in first year, then 0.35 [0.27-0.44] thereafter.

Time to first transplantation

Time to kidney transplantation, Australia

All kidney tx from 1/1/2001
Graft outcomes

Graft survival, DD1 grafts, Australia, 2003-2013, ANZDATA Registry.

When does trouble come?

Are we getting better?

Outcomes: death vs loss of graft function
Mortality rates

Mortality among patients by as-treated modality, 2008-13
ANZDATA, prevalent Australia ESKD patients

Causes of death

(including deaths up to 90 days after transplant fail)
What do we know?

- Fewer indigenous people receive kidney transplants
  - Fewer on waiting list
    - Multiple contributing factors
    - Not entirely explained by measured factors
- Poorer outcomes among those who receive transplants
  - Higher rates of rejection
  - Less well-matched kidneys
  - Higher rates of infection and infection-related deaths
  - Suggestion of some improvement over time

What can be done?

- Improving outcomes:
  - Pool & evaluate present experience
    - Consistent clinical data collection
    - Case control study for novel risk factors
  - Develop specific new knowledge
    - Allocation technologies evolving – eplets
    - Microbiological virulence factors
    - Best approaches for sharing knowledge
  - Pragmatic clinical “trials”
    - Immunosuppression approaches
    - Infective prophylaxis
What can be done?

- Improve access
  - Better understanding of how to address barriers
  - Support services
    - Locally & in transplant centres
    - At times, burdensome on primary care

- Unlikely to help
  - Increasing LD programs
  - Listing more people without understanding & addressing barriers

Acknowledgements

- Australian Organ & Tissue Authority
- NZ Ministry of Health
- Kidney Health Australia
- SA Department of Health
- Contributing renal units