"The main message we want to send to government is we want to have treatment on our own country”

Listening to the Voices of Indigenous Australians with Kidney Disease

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discovery for a healthy tomorrow
Burden of chronic disease

• 80% of the mortality gap amongst people aged 35 to 74 years due to chronic diseases

• Disease rates higher – in 2012-13, among Indigenous adults:
  – CVD 1.3 times higher (27% v 21%)
  – Diabetes 3.5 times higher (18% v 5%)
  – CKD 2.2 times higher (22% v 10%)

AIHW/ ABS 2011, 2013 and 2015
CKD Deaths 2013-2015
(underlying or associated cause)

Indigenous females X5
Indigenous males X2.8

AIHW National Mortality Database
Relative incidence rate indigenous vs non-indigenous
Australia 2010-2014

2015 ANZDATA Annual Report, Figure 12.3
Global trends in overweight children (WHO)
Children and adolescents

- Recent global increase in elevated BP, obesity and Type 2 diabetes (T2DM) in the young
- Rates disproportionately ↑ amongst socio-economically disadvantaged groups
- Rapid ↑ in prevalence of youth-onset T2DM amongst Indigenous populations
Follow-up of children of mothers pregnancy affected by DM

- Pima: 70% of offspring have diabetes age 25-34yr vs <15% in offspring of non-diabetic mothers
- Canadian First Nations: in children of mothers with pre-pregnancy DM (<18yo):
  - at age 10-19 years, 43% DM
- Continuing cycle of diabetes and DIP:
  - Offspring have diabetes at younger age than their parents
  - then diabetes pre-conception in mother and father and during mother’s pregnancy

DIP and Youth Type 2DM

• SEARCH case-control study: 47% of type 2 diabetes in youth attributed to intra-uterine exposure to maternal diabetes and obesity\(^1\)

• Youth Type 2\(^2\):
  - 4x ↑ risk of renal failure (CKD and ESKD) vs youth T1
  - 23 x ↑ risk of renal failure vs age, sex, post-code matched controls

1. Dabelea et al, Diab Care 2008; 2. Dart et al, Diab Care 2012
Figure 1—Renal survival in youth-onset diabetic cohorts. Patients at risk are the number of patients in each group with follow-up to that time period. T1DM, ---; T2DM, ----.
What drives the burden of disease?

Improving health care should not be seen as an alternative to—but rather as complementary to—action on social determinants of health.

Rank of socioeconomic disadvantage

Ethnicity & Disease 2002; 12 (3): 373-8
### LBW and CKD (White et. al. AJKD 2009)

<table>
<thead>
<tr>
<th>Author</th>
<th>Country of origin</th>
<th>Year of publication</th>
<th>Participants</th>
<th>OR (95% CI)</th>
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<td>Haysom</td>
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<td><strong>Subtotal (I-squared = 35.1%, p = 0.1)</strong></td>
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<td></td>
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<td>1.81 (1.19, 2.77)</td>
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#### ESKD

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<tr>
<th>Author</th>
<th>Country of origin</th>
<th>Year of publication</th>
<th>Participants</th>
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#### Low eGFR and other CKD

<table>
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<th>Author</th>
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<th>Year of publication</th>
<th>Participants</th>
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<td>2007</td>
<td>Males</td>
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<td>Li</td>
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**NOTE:** Weights are from random effects analysis
A stepped wedge design study to test the impact and cost effectiveness of a store-based price reduction intervention in promoting the purchase of fruit, vegetables and low joule soft drinks/water among residents in remote Aboriginal communities in the NT

- Partnership with remote community store boards, ALPA and Outback Stores
- Intervention in 20 communities across NT
- Provide evidence on the effect of price discounts on food and drink purchasing
- Intervention in a disadvantaged population in a real-life setting

*Price discount associated with 12.7% (4.1% - 22.1%) increase in purchase of fruit and vegetables*
Recurrent infection and CKD

Infectious episodes per child <15 yr

- Skin
- Chest
- Gastro
- Ear

Number of episodes.
CKD Screening in people with CD risk factors

Excluding those with kidney disease diagnosis (U88/U99)
Patterns of health care delivery

Indigenous Australians are high users of hospital services, the majority of which are accessed via public hospitals
• In 2013–14, 408,000 hospitalisations were reported for Indigenous Australians
• After adjusting for age, Indigenous Australians were 2.3 times more likely than other Australians to be hospitalised

*Much of this difference (86%) was due to the substantially higher rate of hospitalisation for dialysis among Indigenous Australians*
• Excluding dialysis, Indigenous Australians were hospitalised at 1.2 times the rate of other Australians
Non-Indigenous ESRD Patients and Renal Service Providers

Map prepared by GISCA
Adelaide University
March 2001
Experiences of mainstream services

**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.

MJA 2002; 176: 466–470
IMPorkT Study

Interviewee numbers

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<th>SA</th>
<th>QLD</th>
<th>NSW</th>
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<td>45</td>
<td>43</td>
<td>10</td>
<td>38</td>
<td>10</td>
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<td>Non-indigenous patients</td>
<td>20</td>
<td>6</td>
<td>16</td>
<td>25</td>
<td>28</td>
<td>95</td>
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<td>Health professionals</td>
<td>36</td>
<td>23</td>
<td>15</td>
<td>31</td>
<td>9</td>
<td>114</td>
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<tr>
<td>Total</td>
<td>101</td>
<td>72</td>
<td>41</td>
<td>94</td>
<td>47</td>
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Service centres: T = hospital transplant, = hospital dialysis, = satellite dialysis
• Reported feeling excluded from information:
  
  – *There’s a whole lot of us who just don’t understand what’s going on. They know though, the doctors and the nurses know, but they don’t tell us.*
  
  – *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.*
  
  – *You don’t go knocking on their door, [that’s the] “danger one”. The door is locked. They sit behind closed doors.*
Assumptions based on Stereotypes

• Recent studies suggest patient aversion or disinclination might contribute to differential transplant access by particular ethnic groups
  – Medication burden, fear of surgery, fear of organ rejection, doing fine on dialysis, disinclination to ask someone to donate

• Little is known of Indigenous Australians’ views on kidney transplantation or organ donation

• In the IMPAKT study we sought to address this gap:
  – In-depth interviews exploring patients’ knowledge of, and attitudes towards kidney transplantation, and their experiences of progressing/ not progressing towards transplantation
Results

• Four inter-related themes emerged from patient commentary:
  – Interest in transplant as a treatment option
  – Becoming informed and communicating with clinicians and carers
  – Importance of family support in transplant decision-making
  – Negotiating cultural sensitivities
I really want one: Interest in Transplant

• 115/132 who gave a view, expressed definite interest in transplant as a treatment option

• Most common reason transplant potential to restore their life to ‘normal’ and, in particular, to ‘get home’
  – I really want one. I really want to go home
  – I’d love to get a transplant and get off this machine
  – I can’t go home and I’m really missing my friends and family … in my spirit I really want to go home … I’m really suffering

• Nine patients not currently interested, but not opposed

• Four patients opposed to the idea of transplant: not believing in it, going against my Christian faith, fearful of harm from deceased donor’s spirit, preferred own kidney
  (Four patients had a functioning transplant)
I have no idea: Becoming Informed

• Almost half the patients described themselves as not being well informed or not understanding about key aspects of their treatment
• Processes and procedures relating to getting a transplant were unclear for the majority
• Patients did not know when, how or with whom to discuss transplantation
  – I have no idea. To tell you the truth, I don’t even know what transplant they’re talking about
  – I would like to be spoken to clearly in an understandable way, by doctors who like Aboriginal people
We all need information: The Role of Family

• Patients described themselves as poorly informed, yet their families, who provide the primary support network for patients, had fewer opportunities for education
  – Now my family are talking about a transplant. They need some information. We need to talk together about this ...

• Patients reported family and community reservations about transplantation. Some described extended, stressful negotiations to achieve consensus:
  – And I’ve talked to people from outside, like, whose got good kidneys, and they said, “Don’t go on it, don’t put yourself on the list”. And they kept talking me the other way. They don’t like the idea, especially the family... (but) I’m keen to have it. I’m excited to have it.
It’s a new thing: Negotiating Cultural Sensitivities

• Patients described sensitivities that flow from cultural, social and spiritual dimensions of transplantation:
  – [Someone] should tell the doctor because some Aboriginal people who are dialysing are finding it hard from what the ancestor say ... if they give us a kidney and we die middle of that, maybe after 9 years, or whatever, we pass away and we’ve got their kidney. They think we will haunt them ...

• However, patients invoked another traditional rubric – a person’s right to act autonomously in relation to their own body and health:
  – Now I have to get a kidney from someone else... That’s my decision. It’s my body and I want to go ahead.
  – I’m choosing my own choice, I’m choosing the transplant... I said: “Yes, that’s me, that’s my identity!”
“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)
“So today I’m in the middle—there is a right hand, like the prime minister and the left hand, like other people, but I’m only in the middle you know. People of different nationalities or culture or countries have a different (world) view of the ways things should be. I have an important and wise worldview of the ways things should be for my family and my community, and my homelands… the ways kidney treatments would work better”… “I’ve got other things to talk about still, but there is another thing to do now, we have to drive to meet our health minister after this at Parliament House”.
Improving Delivery ESKD Services

• How we deliver services

‘The main message we want to send to the government is that we want to have our treatment on our own country.’

• MBS Review recommendation:
  – Very remote dialysis item: Address the access gap by creating an item to fund the provision of dialysis in very remote areas, including nurse/appropriately trained health worker supervision. The proposed item would help to address this problem by funding the ongoing costs of providing dialysis in very remote areas.

• Community-based Indigenous workforce

• Improve access to and outcomes with transplantation
Transplant Access

ANZDATA, data to end 2015
Australia only
Access to Transplant
1995 to 2015

Adjusted Likelihood of Transplant over Time by Indigenous Status

Time Cohort
For women from major capital cities; adjusted for age, late referral & comorbidities
(Effect similar for males; 5 year follow-up not complete, data to end-2015)
Access to Transplant by Remoteness

Adjusted Likelihood of Transplant for Remoteness Categories by Indigenous Status

- Indigenous
- Non-indigenous

Hazard Ratio

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<th>Remoteness Category</th>
<th>Hazard Ratio</th>
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<td>Major Cities</td>
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<tr>
<td>Inner Regional</td>
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<tr>
<td>Remote</td>
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<td>Very Remote</td>
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For women in 2011-2015 cohort; adjusted for age, late referral & comorbidities
(Effect similar for males; 5 year follow-up not complete, data to end-2015)
Is a Transplant Beneficial?

Risk of Death if Non-Indigenous, by Transplantation

Risk of Death if Indigenous, by Transplantation

Kaplan-Meier failure method, comparing 1:1 propensity-matched patients
* from log-rank test
Conclusions

1. Burden of chronic disease necessitates an integrated whole of system response or the gap in life expectancy will widen
2. Prevention across the life-course must address social determinants AND
3. Need to improve identification, early intervention, management and prevention of progression of CKD
4. Should question and challenge stereotypical assumptions about what patients want, how and where we should deliver services, how different groups benefit from treatment
5. Must listen to and empower patient voices