Kidney health and Menzies engagement in Central Australia

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Dialysis and transplant: Australians treated
Age-specific incident RRT rates

Australia

Graphs by age group

Rate

95% CI
Treatment uptake in elderly (AIHW 2011)

Source: Linked ANZDATA Registry, AIHW National Mortality Database and National Death Index.
Prevalent cases treated

Between 27,013 and 30,293 Australians receiving RRT at Dec 31st, 2020
In 2009 dollars the cumulative cost of RRT between $11.3 billion and $12.3 billion by the end of 2020.
Use of RRT — RR 1.21 (1.00 to 1.45), p = 0.04
Boxed warning on \( \uparrow \) mortality and severe renal injury

Recommendations for Health Professionals

- Do not use HES solutions in critically ill adult patients including those with sepsis, and those admitted to the ICU.
- Avoid use in patients with pre-existing renal dysfunction.
- Discontinue use of HES at the first sign of renal injury.
- Need for renal replacement therapy has been reported up to 90 days after HES administration. Continue to monitor renal function for at least 90 days in all patients.
Costly treatment

Total Medicare ESRD expenditures per person per year, by modality

- Hemodialysis: $82,285
- Peritoneal dialysis: $61,588
- Transplant: $29,983
This report was commissioned by Kidney Health Australia with the objective being to undertake comprehensive research into the economic burden of kidney disease in Australia.

THE ECONOMIC IMPACT OF END-STAGE KIDNEY DISEASE IN AUSTRALIA
3. What are the likely additional health care costs and benefits resulting from an increase in the number of ESKD patients receiving a transplant?

The following cost-effectiveness analyses were based on the achievement of an increase in the number of kidney transplants by 10% to 50% above current transplant rates, by the year 2010. Although this increase would not meet the level of demand for kidney transplantation, increasing the number of transplants by 50% would lift our kidney transplant rate to approximately equal that in the most successful transplanting countries (Spain, the United States and Norway). Increasing the number of kidney transplants by 10% to 50%, by the year 2010, would save $5.8 million to $25.9 million (in today’s dollars), and increase quality-adjusted life years by between 130 QALYs and 640 QALYs.

Increasing the transplant rate would result in considerable health sector savings and would also significantly improve health outcomes for Australians with ESKD.

Organ and Tissue Authority established Jan 1st 2009 to establish a nationally coordinated approach to organ and tissue donation for transplantation.
Costly treatment
(Estimated expenditure NSW 2007-8)

Figure 2 - Total service costs - Per person per year 2007-08 (including direct dialysis provision PLUS medical, pharmaceutical and pathology)
Home dialysis % by state
Home dialysis % by unit
Policy settings for dialysis in Australia

- Policies set state by state — no national policy on dialysis
- Significant changes to practice have occurred without an agreed or explicit policy/strategy
  - Changing age acceptance criteria
- Targets set for home dialysis in several states
- Reimbursements to patients for costs vary by state
- Capital investment for new haemodialysis units is a barrier
Examples of state/federal policies

- MBS item no. 13104 – < $150/month
  - For the planning and management of dialysis and the supervision of a patient on home dialysis by a physician
  - *Does not impact on substantive barriers to home dialysis*
- Queensland established targets home dialysis 50%
  - Established dialysis modality funding adjustment to promote delivery of dialysis in the home
  - Set lower home dialysis reimbursement and when in-centre dialysis volumes above 50%, units paid at lower home rate
  - *Stick resulting in estimated >$20 million saving*
  - *Failed to address support required to get people home*
Critical failing of Australian health system

- Gap in life expectancy for Indigenous Australians
  - 12 years for men and 10 years for women
- 80% of the mortality gap amongst people aged 35 to 74 years due to chronic diseases
- Heart disease, diabetes and kidney disease major contributors
Kidney disease burden

Incidence (cases per million)

- 0 to 99
- 100 to 299
- 300 to 469
- 470 to 769
- 770 to 1,300
- > 1,300

MJA 2001, 175: 24 - 27
What drives the burden of disease?

Rank of socioeconomic disadvantage

(circle size proportional to regional population)

Standardised incidence ratio

Rank from 1 = least to 36 = most disadvantaged region

SIR = 1 for total Australian resident population

Ethnicity & Disease 2002; 12 (3): 373-8
# Early life determinants

*(White et al AJKD 2009)*

<table>
<thead>
<tr>
<th>Author</th>
<th>Country of origin</th>
<th>Year of publication</th>
<th>Participant sex</th>
<th>OR (95% CI)</th>
<th>% Weight</th>
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<tbody>
<tr>
<td><strong>Albuminuria</strong></td>
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<tr>
<td>Hayes et al.</td>
<td>Australia</td>
<td>NA</td>
<td>M &amp; F</td>
<td>0.95 (0.81, 1.12)*</td>
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<tr>
<td>Ramires et al.</td>
<td>Singapore</td>
<td>2001</td>
<td>M &amp; F</td>
<td>2.39 (0.46, 9.56)*</td>
<td>6.31</td>
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<tr>
<td>Rudberg et al.</td>
<td>Sweden</td>
<td>1998</td>
<td>M &amp; F</td>
<td>2.77 (0.77, 9.95)*</td>
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<tr>
<td>Vasarhelyi et al.</td>
<td>Hungary</td>
<td>2000</td>
<td>M &amp; F</td>
<td>0.71 (0.20, 2.55)*</td>
<td>8.35</td>
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<tr>
<td>Yudkin et al.</td>
<td>UK</td>
<td>2001</td>
<td>M &amp; F</td>
<td>3.10 (0.67, 10.96)*</td>
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<td>Nilsson et al.</td>
<td>USA</td>
<td>1998</td>
<td>M &amp; F</td>
<td>4.30 (8.07, 21.8)*</td>
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<tr>
<td>Painier et al.</td>
<td>Netherlands</td>
<td>2005</td>
<td>M &amp; F</td>
<td>3.22 (1.55, 7.05)*</td>
<td>13.05</td>
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<tr>
<td>Hoy et al.</td>
<td>Australia</td>
<td>1999</td>
<td>M &amp; F</td>
<td>2.82 (1.26, 6.30)*</td>
<td>15.26</td>
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<tr>
<td>Fagerström et al.</td>
<td>Finland</td>
<td>2006</td>
<td>M &amp; F</td>
<td>0.93 (0.61, 1.41)*</td>
<td>23.47</td>
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<td><strong>Subtotal (I-squared = 35.1%, p = 0.1)</strong></td>
<td></td>
<td></td>
<td></td>
<td>1.83 (1.19, 2.77)*</td>
<td>100.00</td>
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<thead>
<tr>
<th><strong>ESKD</strong></th>
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<th>OR (95% CI)</th>
<th>% Weight</th>
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<tbody>
<tr>
<td>Dyck et al.</td>
<td>Canada</td>
<td>2003</td>
<td>M &amp; F</td>
<td>1.57 (0.68, 3.65)*</td>
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<tr>
<td>Fan et al.</td>
<td>USA</td>
<td>2000</td>
<td>M &amp; F</td>
<td>1.56 (1.02, 2.39)*</td>
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<tr>
<td>víkse et al.</td>
<td>Norway</td>
<td>2000</td>
<td>M &amp; F</td>
<td>1.23 (1.14, 1.33)*</td>
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<tr>
<td>Lackland et al.</td>
<td>USA</td>
<td>2000</td>
<td>M &amp; F</td>
<td>1.40 (1.09, 1.79)*</td>
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<tr>
<td><strong>Subtotal (I-squared = 0.0%, p = 0.4)</strong></td>
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<td>1.50 (1.03, 2.18)*</td>
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<tr>
<th><strong>Low GFR and other CKD</strong></th>
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<th>OR (95% CI)</th>
<th>% Weight</th>
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<tr>
<td>Al-Saabi et al.</td>
<td>Australia</td>
<td>2007</td>
<td>M &amp; F</td>
<td>3.56 (1.80, 7.11)*</td>
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<tr>
<td>Hallen</td>
<td>Norway</td>
<td>2006</td>
<td>Maes</td>
<td>1.08 (0.57, 2.09)*</td>
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<tr>
<td>Hallen</td>
<td>Norway</td>
<td>2006</td>
<td>Maes</td>
<td>2.35 (1.40, 4.20)*</td>
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<td>Al-Saabi et al.</td>
<td>Australia</td>
<td>2007</td>
<td>Maes</td>
<td>3.40 (2.13, 5.62)*</td>
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<tr>
<td>Al-Saabi et al.</td>
<td>Australia</td>
<td>2007</td>
<td>Females</td>
<td>2.04 (1.45, 2.85)*</td>
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<td>Poulsen et al.</td>
<td>Norway</td>
<td>2008</td>
<td>Maes</td>
<td>1.57 (0.87, 2.80)*</td>
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<td>Li et al.</td>
<td>USA</td>
<td>2006</td>
<td>Maes</td>
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<td>2008</td>
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<tr>
<td><strong>Subtotal (I-squared = 83.3%, p &lt; 0.001)</strong></td>
<td></td>
<td></td>
<td></td>
<td>1.79 (1.11, 2.85)*</td>
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</table>

*NOTE: Weights are from random effects analysis.*

*Heterogeneity between groups: p = 0.4*

*Overall (I-squared = 83.3%, p = 0.001): 1.79 (1.11, 2.85)
Energy density and cost

- Energy-dense low-cost
- Nutrient-dense high-cost

Brimblecombe MJA 2009
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.

MJA 2002; 176: 466–470
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.

You don’t go knocking on their door, [that’s the] danger one. The door is locked. They sit behind closed doors.
“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)
Challenges of research translation

Australian Department of Health and Ageing

Central Australia Renal Study

June 2011

Executive Summary
Projected ESKD cases
Costs of service provision

• No published estimates of the costs of respite dialysis

• CARS provides first published estimates of the cost of respite dialysis using the mobile bus and nurse-supported community-based dialysis
  – Annual cost of service provision
  – To provide access to how many communities, for how many patients, for what period

• Capital costs, relevant to conditions in the CA region, for the establishment of new satellite units, mini-satellites in communities, renal ready rooms attached to primary care services and using relocatable units

• Estimates of costs of patient housing and staff housing for community-based dialysis were also provided
<table>
<thead>
<tr>
<th>Service</th>
<th>Expenditure</th>
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<tbody>
<tr>
<td>In-centre</td>
<td>$111K</td>
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<tr>
<td>Satellite</td>
<td>$86K</td>
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<tr>
<td>Self-care HD</td>
<td>$64K</td>
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<tr>
<td>Self-care PD</td>
<td>$75K</td>
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<tr>
<td>Mini-satellite HD (with nursing)</td>
<td>$103K</td>
</tr>
<tr>
<td>Mobile dialysis (maintenance)</td>
<td>$130K</td>
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</table>
Pre-requisites for renal plan

1. Activities to prevent CKD and progression to ESKD essential
2. Services need to be provided in ways that recognise the social and cultural determinants of treatment uptake, adherence and outcome
3. A Tri-State service model was advocated
4. Protocols for dialysis treatment closer to home should be agreed and formalised
5. Full suite of safety and quality requirements, appropriately customised for region, should be built in
6. Addressing workforce requirements of the service delivery model must be a priority
7. Strategic monitoring and evaluation should be a core component of implementation
Evidence-based policy making: what is it and how do we get it?

- Evidence can neutralise political obstacles
- It needs to be the right evidence
- It needs to occur at the right time
- It needs to be seen by the right people
Menzies vision

• To improve the health of Aboriginal and Torres Strait Islander Australians and disadvantaged populations across our region

• These improvements will be *measurable* and *sustainable* and make the greatest difference in the lives of as many people as possible
How do we make this real?

• Undertake highest quality research targeted at priority health issues
• Focus on research translation into change in policy and practice
• Worked with more than 60 Aboriginal communities across Top End and Central Australia for almost 30 years
• Partner with communities to build capacity
• Attract, retain and develop the best researchers
• Developing pathways into higher education, science and research for Indigenous Australians
Where do we work?
Child Health

- **Program of work middle ear infection impact on hearing, language and learning**
  - NHMRC 2013 $2.17M - Indigenous Healthy EARs: BEtadine, Tissues and Antibiotics (I HEAR BETA)
- CRE in Respiratory Health of Aboriginal and Torres Strait Islander children
- Centre for Child Development and Education:
  - Conducted nationwide consultations on Indigenous suicide prevention to inform national prevention strategy
  - Data linkage partnership with NTG focused on health and education
ABC Study

- Darwin Birth Cohort
- 1987 to 1989
- 686 babies
- Received $2.2 million NHMRC grant in 2012
- 2013 Wave 4 – 24 to 26 year olds
Naplan Yr 3 reading 2012
Age at birth and NAPLAN (% above national minimum standard)

SA-NT Datalink preliminary data
Epidemiology and Health Systems

• Funded for a Centre for Research Excellence in Indigenous Cancer control

• CRE seeks to reduce disparities in early diagnosis, treatment and survival rates for Indigenous Australians with cancer

• ABCD research partnership – particularly strong with primary care services across NT
Improving Health Service Delivery

Overall Delivery of Diabetes Services by Health Centre

Average Health Centres

Overall delivery of diabetes services (%)
Wellbeing & Preventable Chronic Disease

• Nutrition program
  – Julie Brimblecombe

• Smoking cessation – stop the smokes
  – David Thomas

• Alcohol and mental health
  – Peter D’Abbs alcohol management plans and petrol sniffing
  – Trish Nagel and mental health

• Preventable chronic disease
  – Louise Maple-Brown diabetes
  – Jaqui Hughes, Paul Lawton kidney disease
  – Cardiovascular disease
Our expertise in the Asia Pacific is internationally recognised

- Funding from AusAID, NIH (US), Wellcome Trust, Gates, NHMRC ...

Knowledge Hub for NT in Global health

This hub attracts and retains quality professionals to Darwin (research and clinical)

- Those working in Australia looking for overseas experience
- Experts with overseas experience looking to return to Australia

Main agendas: Malaria, TB, Nutrition, Child Survival

Global Health $5-6m grant funding per year
A stepped wedge design project 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 and in reducing the purchase of sweetened soft drinks among residents in remote Aboriginal communities in the Northern Territory.

- Partnership with remote community store boards, ALPA and Outback Stores
- Intervention in 20 communities across NT
- Provide evidence on the effectiveness and cost-effectiveness of price discounts on food and drink purchasing
- Intervention in a socio-economically disadvantaged population in a real-life setting
There are currently no national, evidence-based guidelines for thiamine dosing regimens for treatment and prevention of Wernicke-Korsakoff’s syndrome (WKS).

This RCT aims to determine the optimum thiamine dose required for treatment of acute symptomatic WKS among alcohol-dependent patients and to reduce or prevent subclinical WKS-related brain damage in at-risk alcohol-dependent patients.

- This study compares low, medium and high doses of IV thiamine for each group, administered over 5 and 3 days respectively.
- The study assesses change in cognitive and neurological function.
A partnership between Menzies, NT Department of Health, AMSANT, BakerIDI, Healthy Living NT

Recognising that chronic disease risk begins in utero, this study aims to improve models of care & health outcomes by reducing risk as early as possible in life course.

Components of partnership program:
1. NT Diabetes in Pregnancy Clinical Register
2. Models of care
3. PANDORA: Pregnancy And Neonatal Diabetes Outcomes in Remote Australia
The eGFR Study

An NHMRC-funded study of 600 Indigenous Australians across NT, FNQld & WA

The aims and phases of the study:
1. To assess accuracy of common tests of kidney function
2. To assess which factors contribute to rapid progression of kidney damage
3. To design intervention to prevent progression of kidney damage
STRIVE is a partnership between NCHECR, Menzies, Melbourne Sexual Health Centre, University of SA, AMSANT, Congress, NT Health, Apunipima Cape York Health Council, Cape York Health Council, QLD Health, Western Australian Country Health Service and Kimberley Aboriginal Medical Services Council

A stepped wedge cluster RCT investigating whether a Sexual Health Quality Improvement Program (intervention) can achieve best practice targets in clinical sexual health service delivery and reduce community STI prevalence

The **primary outcome** for this trial is for a sustainable decrease in STI prevalence among the target population of 16 to 34 year

**Secondary Outcomes**
- Exploring barriers and motivators related to the uptake of STI clinical services
- Diagnosis and management of pelvic inflammatory disease (PID) and other STIs
- Trial acceptability - systematic STI clinical practice
Rheumatic heart disease

New learning modules encourage best practice for RHD management

RHD Australia created a series of five online interactive modules designed to provide the health workforce with an introductory-level understanding of best practice approaches to the prevention, diagnosis and management of ARF and RHD.

To engage users, the modules use interactive elements such as avatars (animated characters), case studies and online tests. The objective is completion of the modules by all Australian healthcare workers and clinicians involved in the diagnosis and management of ARF/RHD.

In addition, an app was developed for use with iPhone, iPad and Android based on the national ARF and RHD guidelines – *The Australian guideline for the prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (2nd edition)*. This tool provides easy access to key information from the guideline.

New interactive e-modules equips the health workforce with best practice approaches for the prevention, diagnosis and management of ARF and RHD.
NT renal collaboration

- Regular Menzies, RDH and ASH research meetings
- Perio-renal study
- IKTO workshop
- NHMRC partnership project remote dialysis
- Exploring potential involvement in range of national clinical and health services research projects