Cardiovascular disease in Aboriginal Western Australians: findings from a decade of research and current initiatives

Dr Judith Katzenellenbogen
Heart Foundation Future Leader Fellow
Aboriginal heart disease and stroke
I acknowledge the Traditional Owners of country throughout Australia and pay my respect to their elders past and present.

In particular, the Ngunnawal-Ngambri people - the Traditional Custodians of the land Canberra is built on.
Burden of disease using Disability-Adjusted Life Years; Australia 2011

Percentage contribution of leading disease groups to the gap in burden, 2011

27% of gap in fatal burden

Source: Australian Burden of Disease Study: Impact of causes of illness and death in Aboriginal and Torres Strait Islander people 2011. AIHW 2016
Projects making a difference in WA and beyond

Bettering Aboriginal Heart Health in WA Project

2008 – current

- Built around a strong CVD network
- Focus on disparities in CV health and medical care in Aboriginal people
- Series of detailed studies - State-wide
- Emphasis on health system
- Commitment to research translation

Close That Gap!
Upstream determinants, risk factors, disease and outcomes
Key Result 1:
AMI, heart failure, stroke and atrial fibrillation in Aboriginal people are characterised by higher rates, earlier onset, multi-morbidity

Incidence of Myocardial Infarction (WA, 2000-09)
Multi-morbidity: first-ever hospitalised cases of Atrial Fibrillation in WA

Katzenellenbogen JM, et al. Initial hospitalisations for AF. Heart 2015
Key Result 2:
Complex patient and service factors cause delays in receiving prompt, effective hospital treatment
DELAYS IN ACCESSING ACUTE CARE – KIMBERLEY & PILBARA (2009)

Taylor KP, et al

PATIENT factors

- Poor symptom recognition
- Normalisation of poor health

SERVICE factors

- Clinical complexity
- Difficulty in diagnosing
- Limited access to urban cardiologists for advice/consultation
- Problematic flow of patient information
- Limited cultural training for clinicians
- Limited or inappropriate treatment protocols
- Unreliable access to urban cardiologists for advice/consultation

Patient factors:

- Fear of implications → avoidance
- Depression linked with fatalism
- Stoicism: ongoing hardship → health low priority
- Gender roles: Females take care of family, Males = be strong/proud
- Prioritisation of cultural responsibilities & lore time
- Limited access to telephones & cars

Service factors:

- Geographic isolation
- Clinical complexity
- Difficulty in diagnosing
**Result 3:** Discharges against medical advice: indicator of quality of care for Indigenous people

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<th>Factor</th>
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<th>Adjusted OR</th>
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</table>
Result 4: Health outcomes significantly worse even adjustment for multiple factors

Risk-adjusted 1-year mortality after First-ever Heart Failure admission

Under 55 years age-group

1-year mortality in HF patients under 55 years

HR=1.92, 95% CI(1.14-3.23)

p=0.014

Teng et al. reference

55 years and over age-group

1-year mortality in HF patients 55 years and over

p=0.314

Non-Aboriginal    Aboriginal
System barriers to optimal Aboriginal cardiac health care

- Vertical service delivery
- Urban centric systems of care
- Inadequate systems to address logistic complexity
- Fragmented efforts, stand-alone services
- Short hospital stays
- Short-term & siloed funding
- Lack of culturally safe practice
- Aboriginal people’s reluctance to attend
Trap: Deficit model in Indigenous health

- Disparity research can reinforce deficit
  • Overlooks strengths
  • Can overwhelm with negativity
- Disempowering health messages

"You're always hearing about the stats ... death happens so often.“
Decisions for strategic level dissemination

- Broad dissemination
- Solutions focused
- Stakeholder report - easy-read
- Collaborative development
- Particular focus on policy and practitioners
Partnerships

• BAHWA Project (WACRH, UWA) & researchers
• Heart Foundation
• CVD Health Networks
• Aboriginal Health Improvement Unit
• Rural Health West
• Aboriginal Division, WA Health
• Epidemiology Branch, WA Health
• WA Primary Health Alliance (PHNs)
• Clinicians
• GP hospital liaison and GP networks
• Patient Assistance Transport Scheme, manager
• WA Consumer Council (Aboriginal manager)
• Aboriginal community organisations
Consultation for solutions

→ ‘Information for Action’ workshops
   – Representatives from diverse sectors (research, policy, health services, Aboriginal health organisations & Aboriginal community)
   – Shared ideas, knowledge, experience

→ Stakeholder reference group
The report

Part II - Strategies to improve Aboriginal heart health

Actions for change at three levels (integrated and aligned)

1. Individual-family-community
2. Organisational
3. Government/policy

- Case studies - AHLOs; audits
- Resources to help translate recommendations to practice
Building blocks of solutions

Pyramid of Aboriginal Heart Disease

- Evidence-based treatment for heart disease
  - Access to specialists
  - Cardiac rehabilitation
  - Connect hospital to community care
  - Continuity of care in community

- Early diagnosis and treatment
  - Good access to culturally appropriate primary care
  - Screening at young age
  - Family involvement

- Healthy lifestyle
  - Community initiatives and support
  - Opportunities for healthy choices
  - Access to affordable lifestyle programs
  - Pregnancy & parenting programs

- Social, policy & system change
  - Healthy environments - incl intra-uterine
  - Social and economic opportunities
  - Culturally appropriate systems
  - Aboriginal workforce capacity
  - Community building

Building Blocks of Solutions
Collaboration is essential

ABC Kimberley WA

Kalgoorlie Miner

Call for co-ordinated effort against heart disease

MEDICUS


National Indigenous Times

Mulga Mail
Ongoing Legacy

Updated linked data and analysis:
- Impact of CtG on cardiac outcomes (current)
- Contribution to other national analyses

Ongoing contribution to CVD networks in WA

Workforce education workshops and resources
Educational videos for Aboriginal people and health professionals

# The BAHHWA team

<table>
<thead>
<tr>
<th>WA Centre for Rural Health-WACRH</th>
<th>POPULATION HEALTH UWA</th>
<th>CURTIN</th>
<th>HEART FOUNDATION</th>
<th>OTHER/CLINICAL</th>
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<tbody>
<tr>
<td>Sandy Thompson (CI)</td>
<td>Frank Sanfilippo</td>
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<td>Lyn Dimer</td>
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<td>Joe Hung (SCGH)</td>
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<td>Tiew-Hwa Teng</td>
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Projects making a difference in WA and beyond

Bettering Aboriginal Heart Health in WA Project

RHD: towards the Endgame

2016- current

Description of the epidemiology of RHD in Australia

Close That Gap!
RHEUMATIC HEART DISEASE PATHWAY

PREVENTABLE

Strep infection of throat/skin → Acute rheumatic fever → Chronic heart disease → Stroke, endocarditis → Cardiac surgery → Death → Heart Failure
Aim: to produce a roadmap of what it will take to close the gap in RHD
Overall Aim:
To characterise the epidemiology and management of ARF/RHD in selected jurisdictions using linked health data.

Methodology:
Case identification using ICD 10

RHD linked data analysis (WA, QLD, SA, NT, NSW)

Burden of ARF/RHD (Stage 1)
- Incidence
- Prevalence
- Mortality/Survival

Outcomes (Stage 2)
- Progression,
- Complications
- Impact of interventions
- Service utilisation & costs

Health Systems Research
What factors impact on implementation of known strategies?

Mixed methods
- Intervention mapping
- Document review
- Qualitative interviews with stakeholders
Broad collaboration

- **WA**: Nick de Klerk, Frank Sanfilippo, Joe Hung, Dawn Bessarab, Jonathan Carapetis, Catalina Lizama; Lee Nedkoff, Matthew Knuiman; Deborah Kruger; Angelita Martini; Elizabeth Geelhoed, Jeff Cannon; Chris Reid
- **NT**: Anna Ralph; Karen Dempsey, Marea Fittock, Keith Edwards, Kalinda Griffiths, Jess de Dassel
- **SA**: Alex Brown, Jen Cottril
- **QLD**: Daniel Williamson, Trisha Johnson
- **NSW**: Melanie Middleton, Vicki Wade
- **VIC**: Andrew Steer, Jane Oliver, Graeme Maguire

**AMS peak bodies:**
AMSANT, AHCWA, AHCSA, AH&MRC

**Linkage units**
- SANT Link
- WA Data Linkage Branch
- QLD Data linkage
- CHeReL
END RHD Coalition

• Broad-based national alliance of health and community organisations
• Advocating for a commitment from the government to prioritise the end of RHD in Australia

• Working with the communities most at risk
• Securing funding and the political
• Educating and empowering Australians about the role they can play in ending RHD.

Find out more at the END RHD website www.endrhd.org.au
Projects making a difference in WA and beyond

Bettering Aboriginal Heart Health in WA Project
2008 - current

RHD: towards the Endgame
2016 - current

Stroke
2017 – current
Healing Right Way Trial
(rehabilitation for Aboriginal brain injury)

Close That Gap!
Healing Right Way: Enhancing rehabilitation services for Aboriginal Australians after stroke & TBI

NHMRC Partnership Project: 2017-2021
Addressing needs of Aboriginal patients with stroke/TBI and their families

**Missing Voices (WA)**
- Patients want more rehab
- Complex pathways to navigate
- Disconnect between patients and non-Indig staff
- Health prof under-confident: want more culturally approp resources
- Need for more AHLOs and interpreters

**SAINTS study (SA,NT)**
- Signif impact on lives
- Information overload
- Family involvement NB
- Limited access to AHLOs
- Lack of staff cult training
- Need for approp assessment tools
- Lack of rehab post-disch
- Return to work for young


‘Healing Right Way Trial’: Partnership project:

• **Improve overall health outcomes** for Aboriginal survivors of acquired brain injury in WA
  – Primary outcome: Improved quality of life

• **Delivery of culturally appropriate rehabilitation services** to Aboriginal people post-acquired brain injury in WA

• **Economic model**
  – support the business case for funding improved rehab services

• **Process evaluation**
‘Healing Right Way Trial’: Partnership project:

Intervention components:

1. **Training and employment of Aboriginal Brain Injury Coordinators** provide an in-reach service to support acute and post-discharge care.

2. **Cultural security training** for hospital staff tailored to service delivery to Aboriginal people with BI.

**Components of Cultural Security Training**
- Communication skills
- Local protocols
- Aboriginal cultural constructs surrounding brain injury
- Culturally appropriate assessment and therapy tools
- Personal story videos
- Building local Aboriginal network
## ‘Healing Right Way’
### Stepped Wedge RCT

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4 metro and 4 regional hospital sites
Process evaluation nested in the trial

Rationale: Complex intervention in complex context
Aim: To investigate project operations to inform implementation of trial and interpretation of results
Research Team

- Elizabeth Armstrong  ECU
- Deborah Hersh  ECU
- Judith Katzenellenbogen  UWA
- Sandra Thompson  UWA
- Natalie Ciccone  ECU
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- Deborah Woods  GRAMS
- Neil Drew  ECU
- Meaghan McAllister  ECU
- Sanita Kratina  ECU

Project Partners

- Western Australian Department of Health
- Royal Perth Hospital Medical Research Foundation
- Geraldton Regional Aboriginal Medical Service
- Kimberley Aboriginal Medical Services
- Bega Garnbirringu Health Services, Kalgoorlie
- * Stroke Foundation
- * Neurological Council of WA
Linked data to monitor CVD

• Need for good quality national linked data
• Useful for studying small and dispersed populations → allows sufficient number of events for more detailed analysis
• Monitoring of progress towards goals like CtG
• Negative: prohibitive delays
• Multi-jurisdictional studies underway
Overview of linked datasets for key CVDs

ARF/RHD
States: WA, SA, NT, QLD, NSW
Cohort Sources: (2001-17)
- Hospital
- RHD register
- Deaths

Acute Coronary Syndrome
States: WA, SA, NSW
Cohort Sources: (2001-17)
- Hospital
- Deaths

Stroke
States: WA, SA, NT, QLD
- Cohort Sources: (2001-17)
- Hospital
- Deaths

Aspirational national monitoring CVD dataset
* available to researchers & government **without long delays**
* Sufficient rural/remote and Indigenous persons
* Available for high level policy

Development of disease-specific linked data methods

Data Linkage
Conclusion

- Range of CVD research supporting CtG agenda
- Evidence base built over the years
- Increased collaborations across States
- Increased utilisation of linked data as a resource
- Primary prevention – major challenge
- Secondary prevention - discharge care, cardiac/stroke rehab and case management
- Trial innovative ways of improving services and systems for Aboriginal patients
Translational Research
Acknowledgements

• All collaborators
• Funders: grants and fellowships

[Logos of NHMRC, Heart Foundation, Stroke Foundation, END RHD CRE, HeartKids]