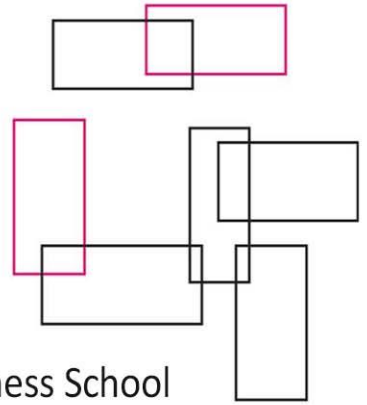
ACTA Summit 2018

Building a self-improving healthcare system



29-30 November 2018 I The University of Sydney Business School

Challenges and Successes in Clinical Research with Aboriginal and Torres Strait Islander Australians

Professor Alan Cass Director Menzies School of Health Research

Australian Government
National Health and Medical Research Council

NHMRC AND ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH RESEARCH

National Health and Medical Research Council (NHMRC) is the Australian Government body for supporting health and medical research since 1937

NHMRC

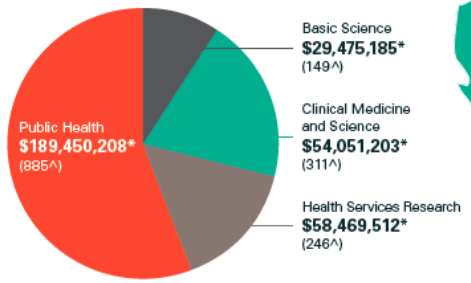
546
Indigenous health research grants since 2010

$331,446,108
has been spent on Indigenous health and medical research since 2010

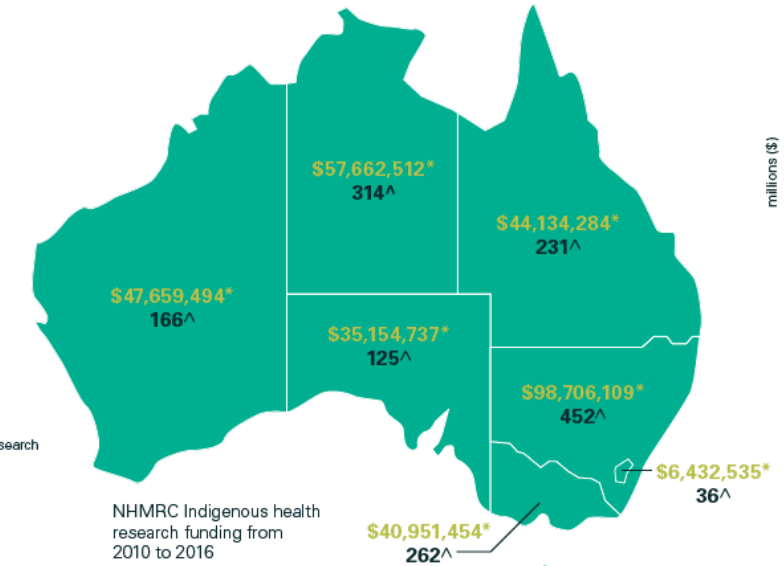
137
grants led by Indigenous researchers since 2010

Dr Catherine Chamberlain **A/Prof Gail Garvey** **Dr Sandra Campbell**

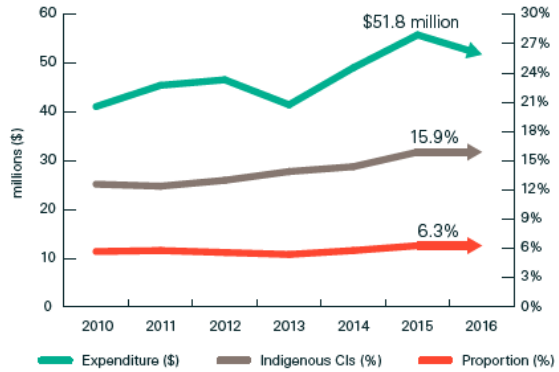
NHMRC has been recognising top-ranked Indigenous researchers in the Early Career Fellowship scheme since 2014



Broad research areas of funding for Indigenous health research since 2010



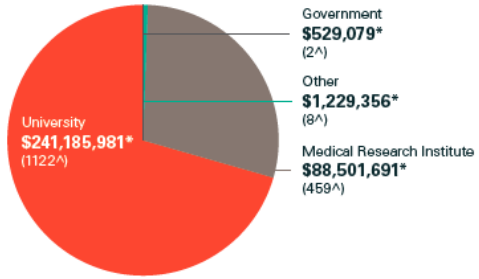
NHMRC Indigenous health research funding from 2010 to 2016



Indigenous health research funding and Indigenous chief investigators

NHMRC has a Tripartite agreement on International Indigenous health with Health Research Council of New Zealand (HRC) and Canadian Institutes of Health Research (CIHR)

The top research areas for Indigenous health research grants since 2010



Recipients of funding in Indigenous health research by category since 2010

*** Expenditure** **^ Active grants**

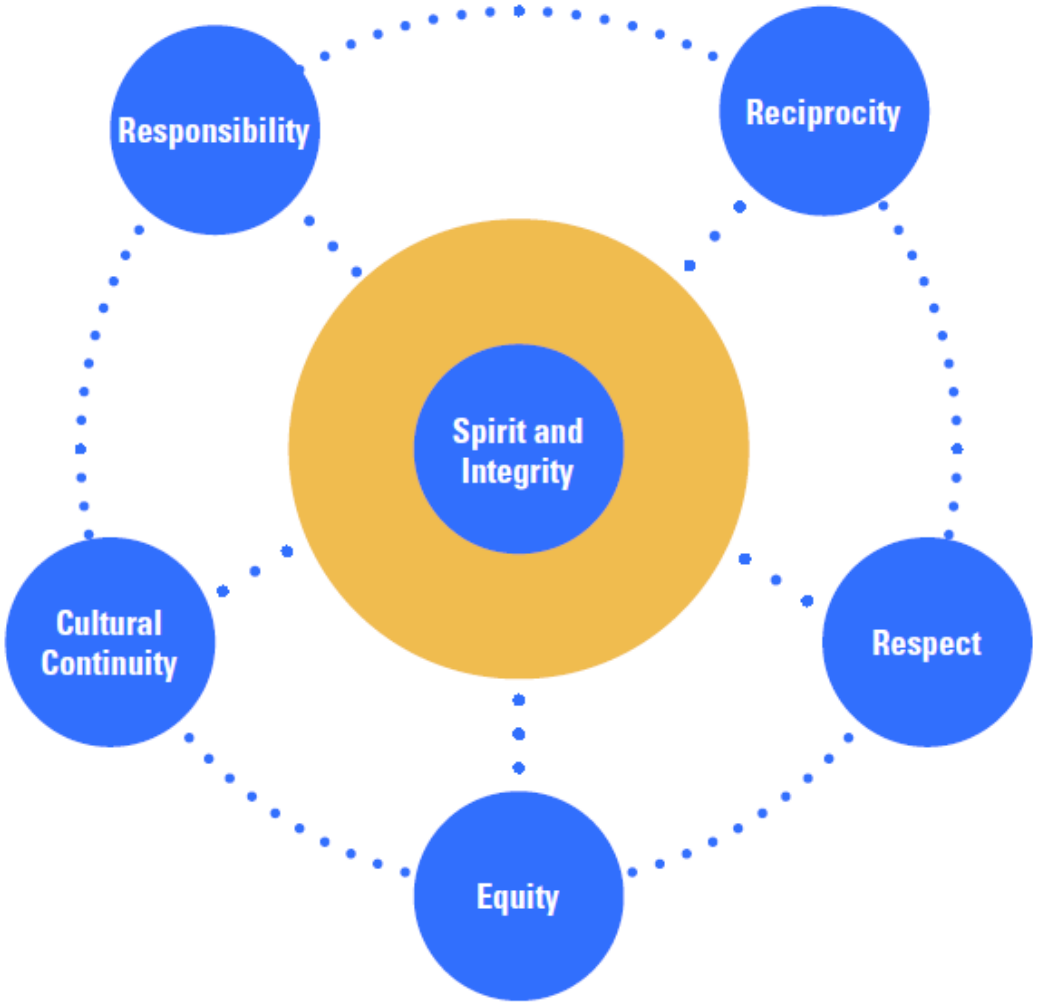
Since 2008 NHMRC's target of 5% funding for Indigenous health research has been met and exceeded

Source: NHMRC Research Grants Management System (RGMS) database from 2010–2016

Australian Government
National Health and Medical Research Council

NHMRC

Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders

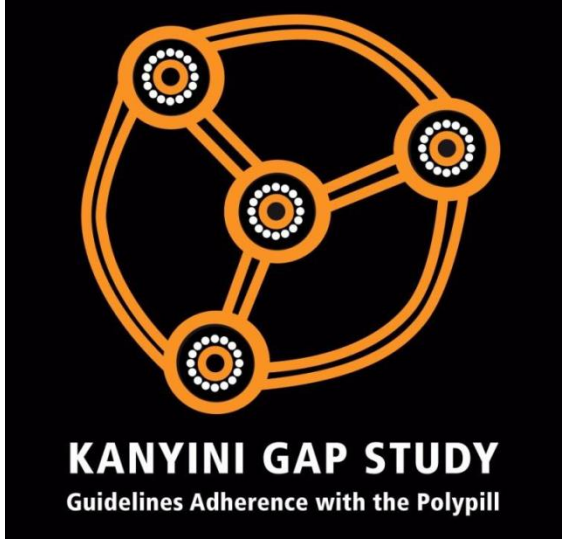


Principles Underpin Research among Indigenous Australians (Jamieson et al *MJA* 2012)

- Addressing priority issues as determined by community
- Conducting research within a mutually respectful partnership framework
- Capacity building is a key focus of research partnership, with sufficient budget to support this
- Flexibility in study implementation while maintaining scientific rigour
- Respecting communities' past and present experience of research

Principles Underpin Research among Indigenous Australians (Jamieson et al *MJA* 2012)

- Recognising the diversity of Indigenous Australian populations
- Ensuring extended timelines do not jeopardise projects
- Preparing for community leadership turnover
- Supporting community ownership
- Developing systems to facilitate partnership management in multi-centre studies



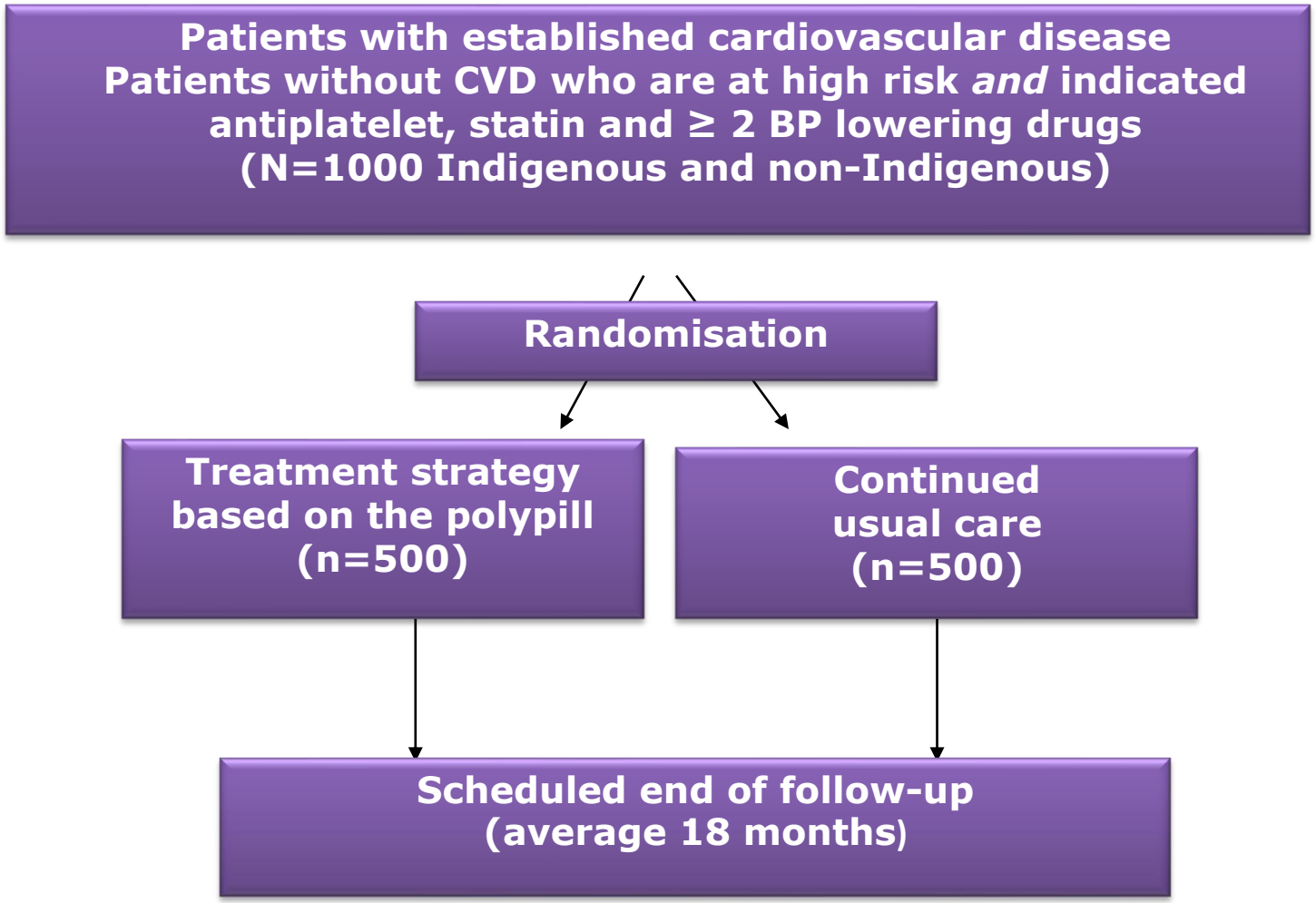
Kanyini Guidelines Adherence with the Polypill (Kanyini GAP) Study

Primary Hypotheses

- Among individuals at high risk of a cardiovascular event, a polypill-based strategy compared with usual care would result in:

  - Greater use of indicated combination treatment (use of antiplatelet, statin and at least two blood pressure lowering medications)
  - Lower systolic blood pressure
  - Lower total cholesterol

Study design




Darwin
Nothern Territory
Queensland
Western Australia
South Australia
Brisbane
New South Wales
Perth
Adelaide
Sydney
ACT
Canberra
Victoria
Melbourne
Tasmania
Hobart

Baseline characteristics

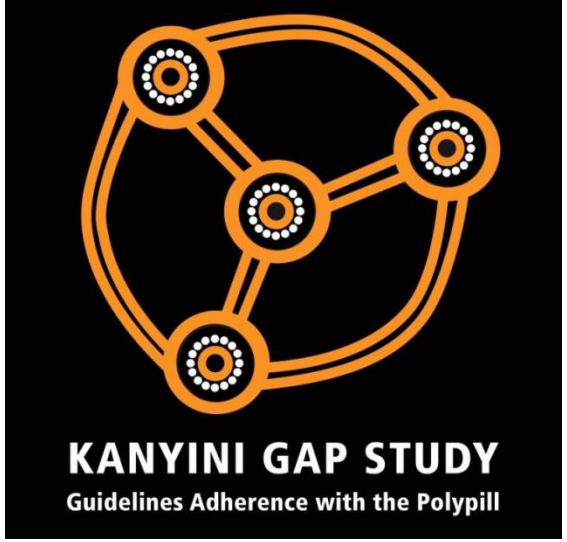
	Polypill strategy n=311	Usual care n=312
Age (years)	63.4 (12.5)	63.7 (12.7)
Male	197 (63.3%)	195 (62.7%)
Indigenous identification	153 (49.2%)	162 (52.1%)
Established CVD	183 (58.8%)	198 (63.4%)
SBP (mmHg)	143.4 (18.5)	142.5 (20.5)
Total cholesterol (mmol/L)	4.4 (1.1)	4.5 (1.2)
Combination treatment*	151 (48.6%)	160 (51.3%)

* Self-reported use of aspirin + a statin + at least 2 BP lowering medications

Primary outcomes

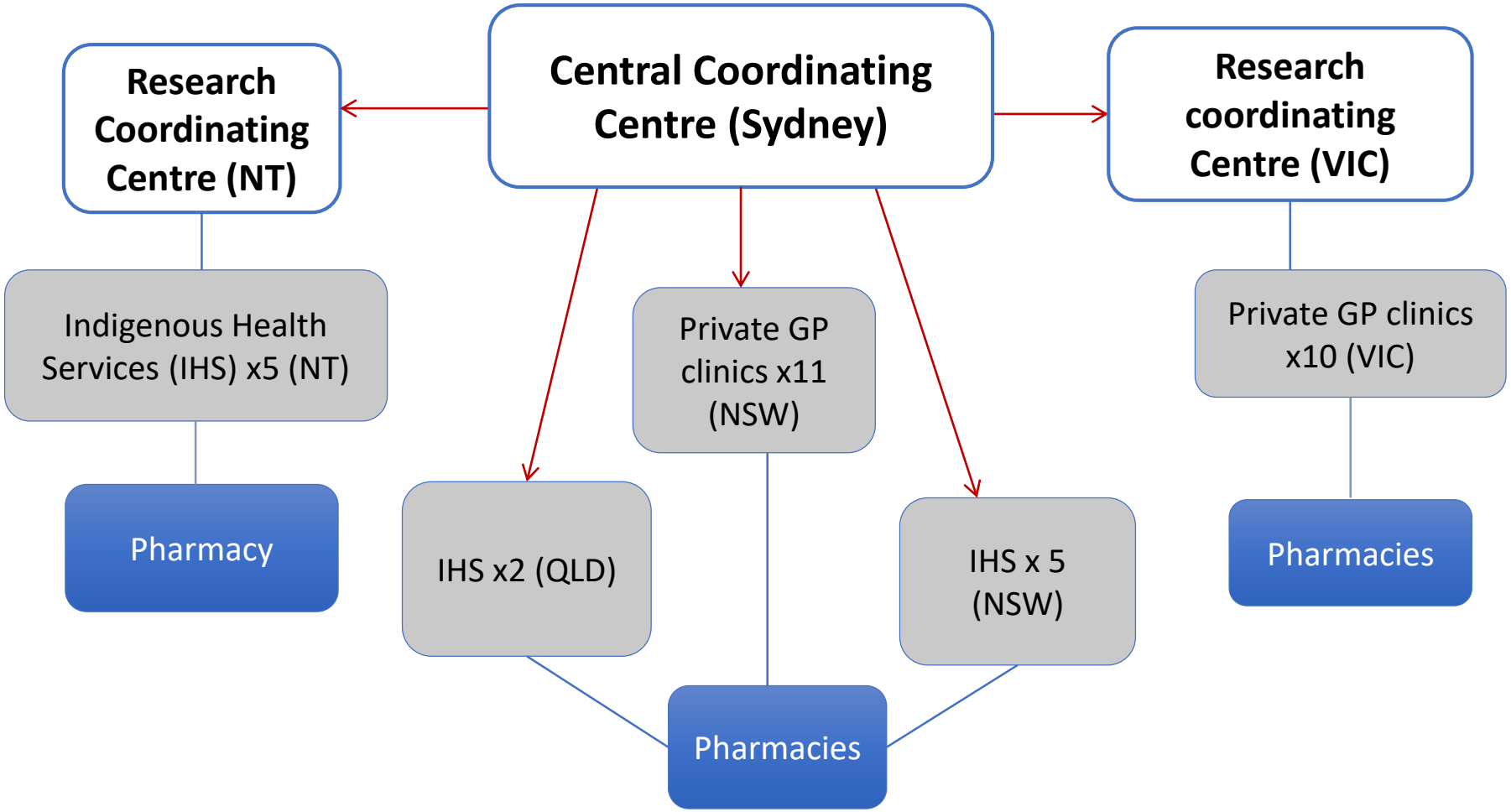
Outcome	Polypill n=311	Usual n=312	Treatment effect (95% CI)	P-value
Use of combination treatment*	70.1%	46.9%	1.49 (1.30, 1.72)	<0.001
Systolic blood pressure (mmHg)	139.0	140.5	-1.5 (-4.0, 1.0)	0.24
Total cholesterol (mmol/L)	4.39	4.31	0.08 (-0.06, 0.22)	0.26

* Self-reported use of aspirin + a statin + at least 2 BP lowering medications



Process Evaluation of Adherence in the Kanyini GAP (PEAK) Study

K-GAP Organisational Structure



Methods – Qualitative Study

- 53 qualitative interviews conducted
  - 32 health care providers (GPs, pharmacists, nurses and AHWs)
  - 21 patients (both study arms)
  - Interview team of 7

Governance of Research

- Existing relationships
- MOU
- Capacity Building

In the past the research that's been conducted has left some scars….what has helped has been being more organised about having our own research agenda ….so if you want to do research [with us then] this is what's important to us. (AHW, urban service)

Motivation to Participate

- Health issue represents a priority
- Part of established collaborative research program
- Staff champions

> *you're contributing to something, and it's not just about you; it's about how it might help the rank and file right across the nation....if I can help my people live longer, live better lifestyles, healthier lifestyles, then I want to be a part of that. (Patient)*

Balance service delivery and research requirements

- Lack of research infrastructure
- Already stretched services
- Remote compared to urban sites

> *You cannot compare it to an AMS (Aboriginal Medical Service) in Sydney….because we are serving about 200,000 square kilometres at this AMS. … our patients might come into town but they could be based 500 kilometres away…and it's a very transient place for many of our patients. (GP, remote service)*

Challenges in research capacity building

- Organisational not individual benefits
- Indigenous Research Fellows
- Additional onsite support beneficial

I think it's been really well implemented research. There's been support at every point along the way, and particularly having people on site who were able to troubleshoot and…knew what our needs were…(GP, urban service)

Challenges: Remote areas greatest need

- Disease burden increases with increasing remoteness
  - Less well resourced areas
  - High staff turnover
  - Most challenging environments in terms of cross-cultural care, health literacy, disadvantage
  - Dealing with complex chronic diseases far removed from major centres
  - Need for innovative approaches to build, sustain appropriately skilled clinical and research workforces

Challenges

- Social determinants of health
  - Poverty
  - House crowding
  - Food insecurity
- Complex comorbidities
- Young age and aggressive onset chronic disease

Indigenous Patient Voices Symposium 2017

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

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

Indigenous Data Sovereignty Summit June 2018

- In Australia, '*Indigenous Data*' refers to information or knowledge, in any format or medium, which is about and may affect Indigenous peoples both collectively and individually.
- '*Indigenous Data Sovereignty*' refers to the right of Indigenous peoples to exercise ownership over Indigenous Data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination and reuse of Indigenous Data.
- '*Indigenous Data Governance*' refers to the right of Indigenous peoples to autonomously decide what, how and why Indigenous Data are collected, accessed and used. It ensures that data on or about Indigenous peoples reflects our priorities, values, cultures, worldviews and diversity.

Concluding Thoughts

- Collaborative clinical research addressing health priorities for communities can be and has been successfully conducted
- The capacity of health services to participate in clinical research remains a fundamental challenge
- Indigenous people often do not fit usual requirements for participation in clinical research
- Issues of research governance, authority and control over the use of data are of fundamental importance
- Indigenous leadership within research teams is vital
- Need to establish and sustain authentic partnerships
- Engagement with consumers essential but very different approaches are needed
- Knowledge translation core consideration throughout research process
- Who defines success?

Acknowledgements

- Gail Garvey, Heather D’Antoine, Jaqui Hughes, Louise Maple-Brown
- K-GAP and PEAK research teams especially Anushka Patel, Alex Brown, Stephen Jan, Hueming Liu, David Peiris and Sam Togni
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- Aboriginal Health Service and community partners in research
- NHMRC funding K-GAP and PEAK studies