KAMS

Kimberley Aboriginal Medical Services Ltd

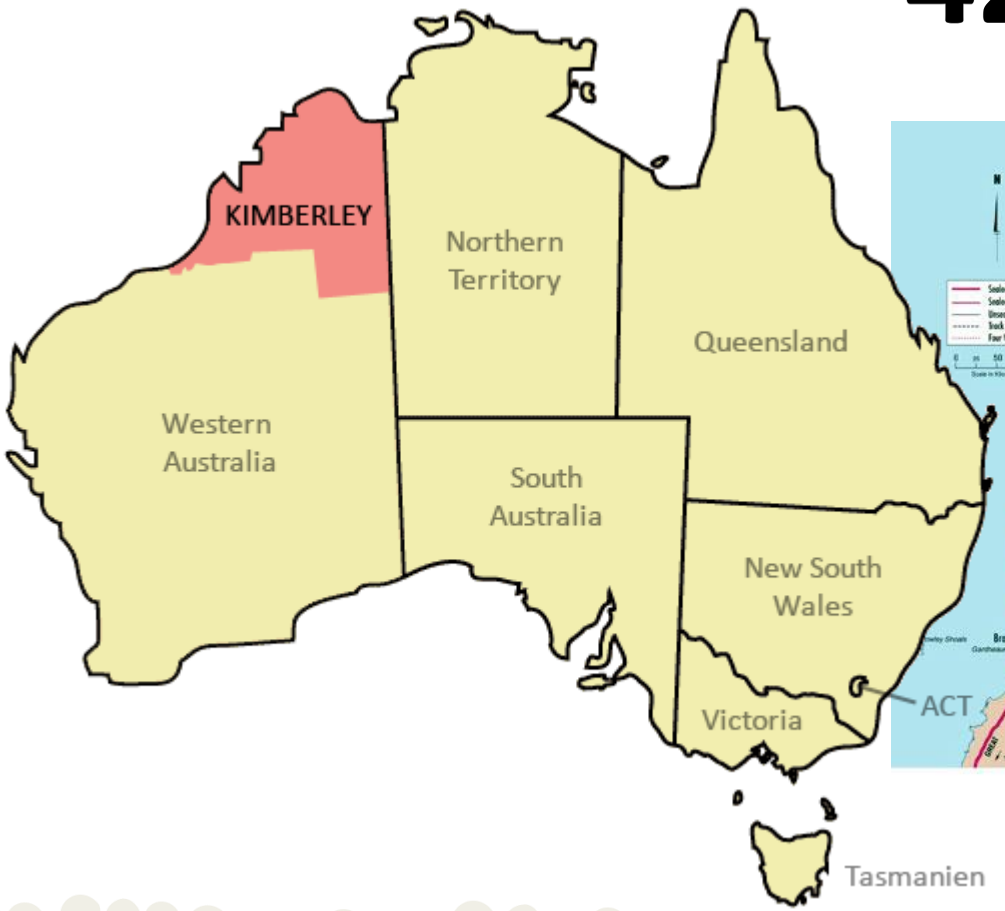
# Health Services in Research

Vicki O'Donnell

*CEO*

# Kimberley region

**421,000 sq km**




# Kimberley region

- Population - 39,890 (2013) with growth of 3-5% (80,000 by 2036)
- Population is generally younger (73% under 45 years old) and highly mobile
- Aboriginal people represented 44% of the region's population
  - younger age structure - almost 50% under 20 years
- Shire of Broome has 40% of the region's population , Derby-West Kimberley Shire 25%, Wyndham-East Kimberley Shire 22% and Halls Creek Shire 12%
- Aboriginal population is larger than the non-Aboriginal population in the Shires of Derby-West Kimberley and Halls Creek

# Kimberley region

- The Kimberley is the State's most northern region and forms one sixth of Western Australia's total landmass.

- The Kimberley is remote from metropolitan areas with major towns of Broome being 2,213km from Perth by road and Kununurra being 3,205km from Perth but only 829km from Darwin by road.

- Understanding these distances is important when looking at where people access health services. Other major towns include Derby, Halls Creek, Wyndham and Fitzroy Crossing.

- There are more than 100 Aboriginal communities throughout the region of varying population sizes. Based on the Accessibility/Remoteness Index of Australia (ARIA), the Kimberley region is classified as:
  - 97% very remote
  - 3% remote (areas around Broome and Kununurra)

# Kimberley region

- 20 per cent of Aboriginal adults living remotely were employed in 2011, compared to 43 per cent of Aboriginal adults in regional towns and 65 per cent of all West Australian adults

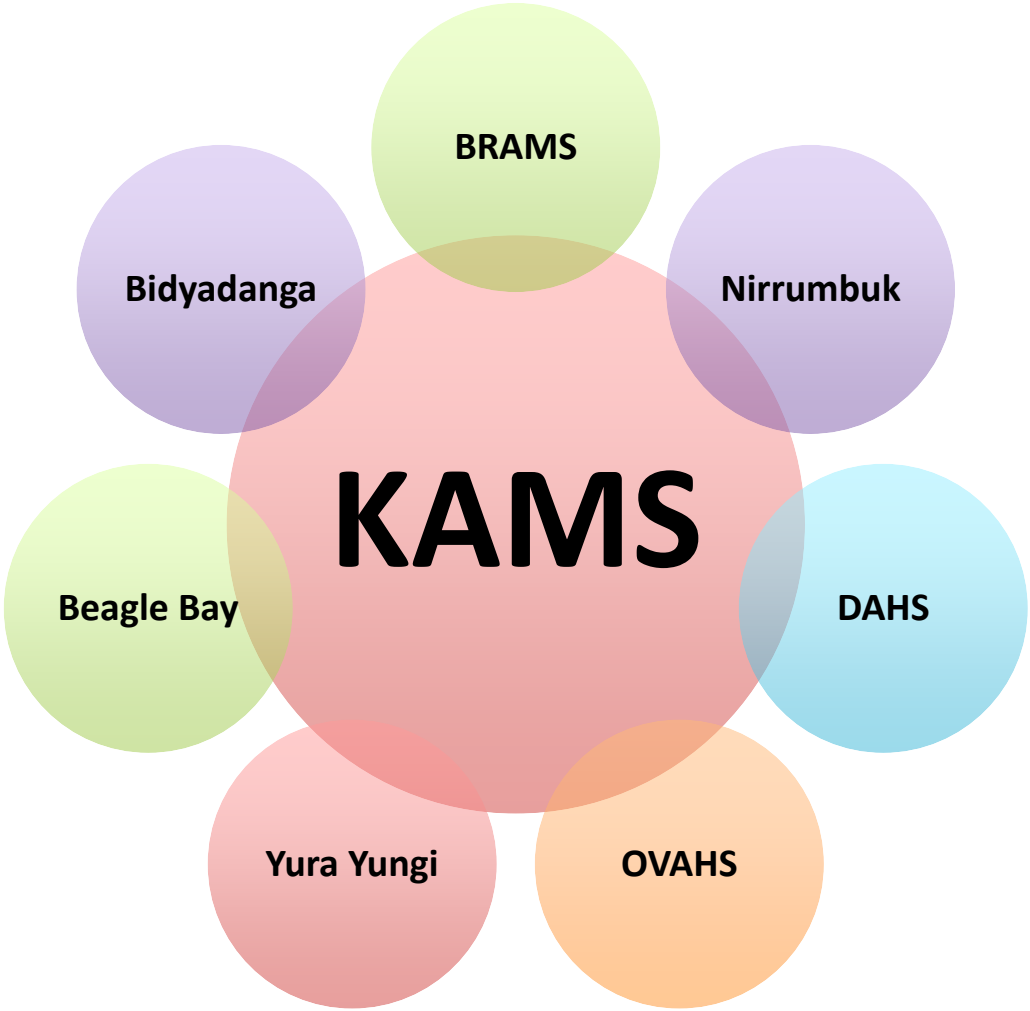
- 16 per cent of Aboriginal adults who live remotely have completed Year 12, compared to 24 per cent of Aboriginal adults in regional towns and 53 per cent of all West Australian adults

- 16 per cent of remote Aboriginal residents live in a house of eight or more people, compared to 5 per cent of Aboriginal residents in regional towns and 0.4 per cent of all West Australian residents

- Aboriginal residents in very remote Western Australia, relative to both Aboriginal residents elsewhere in the State and overall State averages, are more likely to have diabetes, cardiovascular disease and kidney disease

# KAMS Offices

# KAMS structure



# KAMS and KRS

Kimberley Renal Services

Kimberley Renal Services is a wholly owned subsidiary of Kimberley Aboriginal Medical Services Ltd

80


437 staff

# Kimberley Aboriginal Health Planning Forum

**Core Members:**

- Kimberley Aboriginal Medical Services
- WA Country Health Services
- Broome Regional Aboriginal Medical Service
- Ord Valley Aboriginal Health Service
- Milliya Rumurra Aboriginal Corporation
- Boab Health Services
- Nirrumbuk Environmental Health Services
- Derby Aboriginal Health Service
- Nindilingarri Cultural Health Service
- Yuri Yungi Aboriginal Medical Service
- Ngnowar Aerwah Aboriginal Corporation
- Jungarni Jutiya Indigenous Corporation
- Royal Flying Doctor Services

**Associate Members:**

- Aboriginal Health Council of WA
- Commonwealth Department of Health
- Rural Health West
- Men's Outreach Service Incorporated
- WA Department of Health – Aboriginal Health Improvement Unit
- Department of Prime Minister and Cabinet – Broome, Kununurra and Derby
- West Australian Primary Health Alliance
- Kimberley Stolen Generation Aboriginal Corporation

**Sub-Committees:**

- Chronic Disease
- Drug and Alcohol
- Environmental Health
- Health Promotion
- Health Workforce
- Kimberley Aboriginal Mental Health
- Maternal and Child Health
- Sexual Health
- Kimberley Research

# History

The Kimberley Aboriginal Health Planning Forum (KAHPF), originally called the Kimberley Aboriginal Health Plan Steering Committee, was formed in 1998 with the initial task of developing the first Kimberley Regional Aboriginal Health Plan 1999.

There were 8 original members: Kimberley Aboriginal Medical Services, Kimberley Health Region (now WACHS Kimberley), the Chairpersons of the 3 ATSIC Regional Councils, the Office of Aboriginal Health, the Dept. of Indigenous Affairs and the Dept. of Health and Ageing.

Since 2001 KAHPF has met regularly, usually 6 times a year, at sites across the region. Membership has expanded to 13 core and 7 Associate members. The Forum plays a crucial role in advocacy and the planning and development of primary health services in the Kimberley. KAHPF is chaired by the Kimberley Aboriginal Medical Services (KAMS).

## Objective of the Forum

The objective of the Kimberley Aboriginal Health Planning Forum (KAHPF) is to improve health outcomes for Aboriginal and Torres Strait Islander peoples in the Kimberley region of Western Australia through a co-ordinated approach to the planning and delivery of primary health and health related services.


# Kimberley Research Sub-Committee

## Research Guidelines and Priorities for the Kimberley

### Guidelines for Conducting Research in the Kimberley

Health research carried in the Kimberley:

- Must be of value to the region
- Does not duplicate previous research
- Follow-on implications must be considered
- Must have genuine community consultation and participation
- The research should increase research capacity in the region

### Research Priorities for the Kimberley

1. The health issue is common and / or serious in the Kimberley
2. The issue is important for the health and well-being of Aboriginal people
3. There is a lack of available information on important aspects of the issue and increasing knowledge through research is likely to lead to important outcomes for Kimberley people
4. Knowledge is available from mainstream research on the issue but there is reason to believe the evidence may not be generalisable to Aboriginal and / or Kimberley populations
5. The issue is important for quality improvement / development of primary health care services in a Kimberley setting
6. The skills and capacity (including human and financial) are available to be able to conduct the research

# How KAMS and Member Services Do Research

**Taking more control of Research**

- KAMS and Member Services apply research findings to improve the health of, and to improve services for, Aboriginal people in the Kimberley
- Provide evidence based best practice models of health care for Aboriginal people
- Documents and helps to improve the impact of ACCHS on health outcomes
- Develops strong, productive and ensuring research partnership – UWA, Rural Clinical School, Telethon Institute for Kids

**KAMS Research Model**

- Since August 2006 at least 1 FTE position dedicated to research
    - 1 FTE Principal Research Fellow (RCSWA) / 0.05 FTE Principal Research Officer (KAMS)
    - 0.7 FTE Aboriginal Research Officer (24 months funding)
    - Nini Helthiwan – 2 FTE Child Health "Date Collectors / 2 FTE Midwife "Intervention Coordinators"
    - 2Phd students (Derby and Broome)
- Academic support for research staff
- Support and involvement from ACCHS Senior Management and Clinical staff
- Ideas for research projects come from ACCHS' administrators and clinicians as well as researchers
- Involves Aboriginal people throughout the process

**KAMS process for conducting research and evaluation projects**

- To ensure cultural safety Aboriginal people must be involved at all stages of the research / evaluation process
- Projects should be supervised by a KAMS or Member Service staff member who has research experience
- Projects should incorporate capacity building for KAMS and Member Service staff
- Regular updates are to be provided to the working group who developed the proposal
- Progress reports are to be provided to the KAMS Clinical Services team as required (Member Services represented

# KAMS Research Projects: Major involvement and completed (Aug 2016)

1. The NACCHO Ear Trial (R Murray)
2. Sustained Retinal Screening Program(R Murray, S Metcalf, P Lewis)
3. Medical Workforce Needs and Distribution in the Kimberley(D Atkinson)
4. Blood from a Finger-prick is OK to Test for Diabetes (J Marley, C Nelson, D Atkinson)
5. Quality indicators of diabetes care at DAHS: 1999-2009 (J Marley, C Nelson, V O'Donnell, D Atkinson)
6. Audit of Kimberley Aboriginal Patients with Proteinuria, Chronic Kidney Disease and End Stage Kidney Disease (R Atkinson, D Atkinson, J Marley)
7. Haemodialysis Outcomes of Remote Kimberley origin Aboriginal Patients 2003-2007 (J Marley, C Fitzclarence, C Nelson, D Atkinson)
8. Folateintake and blood folatelevels in the Western Australian Aboriginal Population(M Lane, J Marley)
9. The Kimberley Eye Health Study (M Oh, C Nelson, J Marley, D Atkinson)
10. Pandemic Influenza (J Roberts, Thomas, R Billycan, C Nelson)
11. Early Childhood Nutrition and AnaemiaPrevention Project: TjiitjiMarrkaManguwa(J Marley, C Green, D Hector, L Mudgedell, S Moora, T Sunfly, M Tai-Roche, R Smythe)
12. BOABS Study (J Marley, T Kitaura, D Atkinson, C Nelson, S Clarke, E Hester, B Hunter, B Nelson, B Norman, M Lester, K List, T Page, A Ross, V Ryder, R Williams)
13. Peritoneal Dialysis Outcomes of Remote Kimberley origin Aboriginal Patients 2003-2010 (J Marley, S Moore, C Fitzclarence, D Atkinson)
14. Improving diabetes care and patient outcomes in Kimberley ACCHSs(A Stoneman, D Atkinson, J Marley)
15. BOLD(D Reeve, M Lane, D Atkinson, W Cavilla)
16. gECHOStudy (R Dawson, C Nelson, D Atkinson)
17. RhFFUSStudy(R Dawson, D Atkinson)
18. Evidence Brief: Primary care interventions that will reduce the onset and progression of kidney disease among Aboriginal Australians (J Marley, N Hadgraft, D Atkinson)
19. Review of the KAHPF Research Subcommittee (J Marley, N Hadgraft, D Atkinson)
20. Evaluation of Feed the Little Children(J Marley, K Parrish)
21. Investigation of the role of HbA1cin diabetes screening protocols (J Marley, M Oh, N Hadgraft, K Isaacs, S Singleton, D Atkinson)
22. Integrating best practice and filling knowledge gaps in remote Aboriginal diabetes detection and care: Improving case detection and service delivery (J Marley, S Singleton, E Griffiths, M Cutter, K Wright, L Falcocchio, N Houston)
23. Validating the Kimberley Mum's Mood Scale(C Engelke, J Marley, D Stephen, S Trust, S Coutinho)–first paper minor revisions requested b PloSOne

# KAMS Research Projects: In Progress (Aug 2016)

**Final analysis / write up phase**

1. DAHS Access Study (S Warwick, T Kitaura, Matthew, J Marley, D Atkinson)
2. Writing journal articles on the “Sprinkles” Project(J Marley)
3. Palliative care in end stage kidney disease: Are we meeting the needs of our Indigenous clients? (J Costigan, J Marley)

**Ongoing**

4. Implementing HbA1cscreening for diabetes(J Marley, S Singleton, E Griffiths, M Cutter, K Wright, L Falcocchio, L Scott, N Houston, J Martin, D Atkinson)
5. ORCHID: Predicting gestational diabetes mellitus in rural communities(J Marley, E Spry, S Singleton, E Griffiths, D Atkinson)
6. Kimberley Investigation and description of type 2 diabetes of young onset (KIDDY)(S Singleton, A Manifold, J Marley, D Atkinson)
7. Prevention of type 2 diabetes amongst young Aboriginal people in Derby(K Seear, J Marley, L Henderson-Yates, D Atkinson)
8. Progression of chronic kidney disease to end stage: A retrospective cohort study from the Kimberley region (E Griffiths, J Mohan, J Marley, D Atkinson)
9. Family Planning in the Kutjungka Region(E Griffiths, D Friello, A Sibosado, J Marley, D Atkinson) –first paper published in MJA
10. Nini Helthiwan: Developing an enhanced model of primary care for Aboriginal mothers in the Kimberley(D Atkinson, J Marley, S Trust, K Engelke, D Stephen, M Houtari, K Newett, P McCready, C Maslin, T MacIntosh, E Griffiths, K Edmond)
11. Clinical review of dialysis patients originating in the Kimberley region –audit of ANZDATA records of HD patients: 2003-2012(J Marley, D Atkinson)

# Exemplars Research Studies

**DAHS Diabetes Study**

- DAHS requested this study to be conducted
- DAHS staff were involved at all stages
- First study showing sustainable long-term improvements for Aboriginal people with diabetes (limited resources: 6 yrs to complete)
- Published in MJA 2012 – included in OATISH reports
- CQI processes identified gaps in:
    - Recording of clients with a confirmed diagnosis of diabetes on the register and registering patients with unconfirmed diabetes prematurely → **systems were implemented more consistently** → substantial net increase patients accurately record as having diabetes
    - Patients follow up after one abnormal screening test → **Kimberley HbA1c study**

**Kimberley HbA1c Study**

- Embedded with ACCHS and WACHS clinics across the Kimberley (limited resources: 5 yrs to complete)
- Compared to glucose using HbA1c was significantly more likely to detect diabetes, be completed, and be completed mre rapidly
- Face-to-face feedback to services and community
    - 13 in-services to clinic staff
    - Community members in Balgo, Bidyadanga, Billiluna and Mulan
- Changes to policy and practice:
    - HbA1c screening for diabetes replaced glucose screening (2015)
    - MMex updated to include POC HbA1c (auto-populate reports)
    - Developed patient education resources (Kimberley Renal Services)
    - Developing prediabetes care plan on Mmex
    - 2 x increase in KAMS patients who were screened with HbA1c

# Diagnosis of pre-diabetes and dabetes in KAMS clinics during 2014-2015 using HbA1c

| | Prediabetes ($HbA_{1c}$ 5.7-6.4%) | Diabetes ($HbA_{1c}$ ≥ 6.5%)* |
|---|---|---|
| 15-24 years old | 23 (8.4%) | 7 (5.3%) |
| 25-39 years old | 85 (32%) | 48 (18%) |
| ≥ 40 years old | 102 (41%) | 37 (15%) |
| TOTAL | 210 (35%) | 92 (16%) |

* Many patients audited (61%) had HBA1c measurements suggestive of uncontrolled diabetes (≥7.0%) as the first HbA1c measurement recorded in the audit period

# What we've learnt - Researchers

- "Research Coordinators": needs to be experienced and have the right qualification – independent / resilient / persistent
- Researchers need to respect ACCHS autonomy – understand and commit to grass roots driven research rather than prioritising academic career
- Expectation of a level of cultural safety amongst reserachers that is embedded into the research process
- Important to provide training and support to build a network of local researchers
- Research in the Kimberley take time: lots of time and consultation
- What keeps staff in research:  seeing research translated into better policies and practices for ACCHS

# Conclusions

- Research can be integrated into health services with limited resources
- Integration has resulted in changes to policy and practice in the Kimberley
- The power and ownership of research needs to be balanced between Aboriginal communities and large academic institutions
- More Aboriginal people being trained in research

**AND LASTLY**

**WE DON'T DO RESEARCH FOR THE SAKE OF RESEARCH**

# KAMS

Kimberley Aboriginal Medical Services Ltd

www.kamsc.org.au

# Questions?