

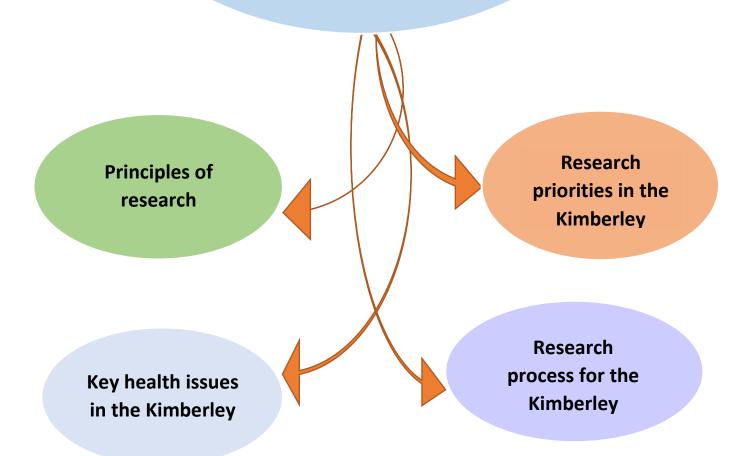






# KIMBERLEY ABORIGINAL CHILD & FAMILY HEALTH RESEARCH FORUM

**8-9 September 2016** 



### Acknowledgement

The organisers and participants of the Kimberley Aboriginal Child & Family Health Research forum wish to acknowledge the traditional custodians, the Yawuru people, on whose land we gathered, and pay respects to the Elders past, present and future.

The vital importance of strong cultural identity in improving Aboriginal health and wellbeing was highlighted throughout the forum.

It was acknowledged that a relationship of trust, working as partners towards agreed outcomes, paves the way to enable powerful and collaborative, community led research for the benefit of Aboriginal people and communities in the Kimberley.

#### **WELCOME TO COUNTRY**

Dianne Appleby delivered a very warm and moving Welcome to Country in Language and English. Such a heart-felt welcome set the scene for a very worthwhile and productive 2 day forum.

Dianne is a highly respected Yawuru Traditional Custodian and Cultural Coordinator for Nyamba Buru Yawuru. She was born on the West Kimberley coast of Broome WA and comes from the salt water country of the Yawuru and Karajarri people.

#### ABOUT THE FORUM

The first ever Kimberley Aboriginal Child & Family Research Forum was hosted by the Kimberley Aboriginal Medical Services (KAMS) in Broome from 8-9 September 2016.

The forum was a collaboration between KAMS, the Telethon Kids Institute (TKI) and the Rural Clinical School of WA (RCSWA). It brought together over 40 representatives from Aboriginal health stakeholders, including community members, clinicians and researchers to:

- Identify Aboriginal child and family health research priorities for the Kimberley
- Agree on a process for introducing new research ideas, conducting agreed research and translating research into improved practice, policy and health systems outcomes

Held over one and a half days, the Forum consisted of a mixture of presentations and workshops designed to generate robust discussion between participants about current Kimberley Aboriginal child and family health research priorities and how best to work together to design, conduct and translate Aboriginal health research in the future.

It was acknowledged that Kimberley Aboriginal people continue to have strong ties to land, law, culture and customs. Research practice and translation with Kimberley Aboriginal communities must acknowledge and build upon these strengths.

#### **OUTCOMES OF THE FORUM:**

The key outcomes of the Forum were:

- An emerging set of key principles for research in the Kimberley
- A list of priority areas for Kimberley Aboriginal child and family health research
- A detailed understanding of the complex and inter-related health issues facing Aboriginal children, youth and families in the Kimberley region
- Next steps for the participants to progress the research priorities

Further detail on each follow.

#### KEY PRINCIPLES OF RESEARCH

"Talk to us on the ground properly in a proper way" (Forum participant)

Participants in the Forum recognised the importance of research to improve health. Presentations on research and research process were given by Dr Lynette Henderson-Yates (Derby Aboriginal Health Service), A/Professor Julia Marley (KAMS/ RCSWA) and Mr Glenn Pearson (TKI). However, strong concerns were raised that many Aboriginal people still feel over-researched. Also, that research is being conducted without people in the community understanding the purpose of the research and how it benefits them. From the Forum a consensus emerged about the importance of the following **principles of research**:

- Research must be community owned
- Communities and researchers must be engaged as equal partners at every step of the way
- Genuine consultation needs to happen directly with the community from the beginning of the research process and should include culture, Elders and young people
- Researchers must regularly check back with communities, include communities in the interpretation of results, and communicate research progress and outcomes
- All stakeholders must adhere to local protocols in initiating, conducting, evaluating and translating projects into practice
- Research projects should also build the capacity of Aboriginal people to do research through transferring research skills, mentoring and delivering tailored training
- Research results must be translated into improved practice, policy and health systems that benefit Aboriginal people

#### **RESEARCH PRIORITIES**

Workshop groups first identified key health issues, then refined those issues into three to five research priorities per group. From those, the following broad research themes emerged.

• "Revitalising culture through health practices": Understanding, exploring and promoting the connection between health and culture is a theme that cuts across all research priorities. Participants also emphasised the importance of incorporating culture in health and research.

"Being Aboriginal people we must always include culture and that is important to us. Cultural revitalisation through health practice. Any research that comes through must include culture, Elders and young people. Across the Kimberley is diverse and you need to take into account Aboriginal people language and family." (Forum participant)

Building resilience in young people: Both hope and deep concern was expressed around youth social
and emotional wellbeing and identity. Emphasis was placed on research around understanding,
preventing and responding to self-harm, suicide, drug and alcohol misuse, bullying and the links
between social media and anxiety, stress and depression. We were asked to take a strengths-based
approach and explore ways to build resilience in young people and coping skills.

"When we talk about youth, we should be talking about the whole family & how families can support each other. We're not here to tell youth what to do. They have to tell us what they want, their goals and aspirations." (Forum participant)

• Supporting families and positive parenting: This priority area focused on research into supporting families and young parents to begin addressing the intergenerational transmission of trauma, improve child social and emotional development, early childhood health and school readiness.

"The beginnings of a young family, young couple, how to help support them to get that early childhood in their home front? .... You have to start from parents, they are educating the child. Educate from grassroots level." (Forum participant)

"How do we teach male and female children their culture, to be proud of their culture, and promote good relationships between men and women." (Forum participant)

• **Healthy lifestyles and chronic disease**: This thematic area focuses on preventing chronic disease. As part of that, a need for research was identified that takes us beyond education promoting healthy diet, nutrition and exercise to *action*. What can be done to support families and communities to adopt healthier lifestyles?

"If I had a million dollars I'd teach family members to cook healthy food and read labels in stores. How do we know what is healthy for us? Action, not just education. For mothers and families." (Forum participant)

- The environment, health and disease: Research into the health impacts of the environment (housing, water etc), including links with infectious (ears, skin, lungs, eyes) and chronic diseases. And what can be done to reduce the health impact.
- **Health Services:** Key questions included: How do we get culture into services? How do we support people to access services early? How do we ensure services are effective?

"Evaluate programs using data. We have to be better than we are now. We've had some good outcomes when we've used those evaluations." (Forum participant)

• **Data**: Analysing currently available data, with the participation of communities and stakeholders, to understand what is happening at the community level, identify communities that are doing well and learn why. Develop baseline data to help target and prioritise services and identify good practice to improve outcomes for children and families.

"How do we empower communities with baseline data to support the research? They can identify their priorities because they have information."

"Need to have a baseline health indicator. What are we looking at? What are we measuring?"

"What the picture is today?" (Forum participant)

#### **HEALTH ISSUES**

"Whatever happens at parent/family/ community level has an impact on kids – overcrowding in houses, economy, employment, depression, drug and alcohol, nutrition. It leads to mental health and wellbeing, broken family units, lack of community cohesiveness." (Forum participant)

Prior to identifying research priorities, participants were asked to list key health issues facing Aboriginal children, youth and parents/ families across the four domains of physical, emotional, social and cultural health. A clear message from the Forum is that all are inter-connected and whatever happens at the parent, family and community level has an impact on the health and wellbeing of children.

The list of health issues raised is set out in Appendix 2. A summary follows:

Colonisation, government policy, intergenerational trauma and racism: The ongoing effects of colonisation, past and present government policies and intergenerational trauma on social and emotional wellbeing, loss of knowledge about how to be parents, loss of family and cultural structures, disconnection from culture, loss of language, stress, disempowerment, disengagement, ongoing removal of children, neglect, abuse, self-harm, suicide, sorry times, shame, incarceration, depression and mental health issues, drug and alcohol misuse, and racism were identified as significant contributors to poor health outcomes.

"Generational trauma, stolen generations, these have a big impact across. How do you break that cycle, not go around and around? Think about our kids for today and tomorrow."

"Talk about inter-generational trauma but where do you start? How do you pick one thing?" (Forum participant)

**Poverty, housing, employment and education**: The additional interlinked impacts of poverty, housing, unemployment and a lack of education on stress, depression and mental health issues, physical health, incarceration, drug and alcohol use and poor nutrition were also highlighted. Participants discussed the financial burden of health, being able to pay for food that makes you healthy and the lack of services for family support, drug and alcohol rehabilitation (youth and adult) and juvenile justice facilities.

"If we don't have housing, employment and economy – our kids are failing. Who suffers with overcrowding – the children and the rest of the family" (Forum participant)

Families, parenting, family support, and a safe home environment: The importance of rebuilding and supporting families was consistently highlighted, particularly for children. Health issues included the acceptance of negative parenting as normal, young people having children, grandparents minding lots of kids but not getting any time out, not enough young men in families, parents not knowing their identity, domestic violence, children not being safe in the home environment, walking the streets and stealing stuff, kids moving from place to place and falling through the cracks, loss of respect for Elders, no cultural support and the impact of lots of deaths on the family structure.

"Cultural roles and obligations about growing up our children. Grandparents have the right and obligation to grow up kids. But they don't realise the way it plays out. They are acting from their trauma. Growling by carers is sometimes not nice growling. What happens in a young child's brain? Do they think it's normal? What happens when they grow up? Do they think it's normal and now I can growl at my kids? Trauma starts from there." (Forum participant)

**Children:** Childhood diseases were consistently highlighted: skin diseases (scabies, sores); ear disease (otitis media, hearing and surgery); lung diseases (cough, breathing difficulties, asthma); rheumatic heart disease; and trachoma. Also, highlighted were issues related to low birth weight babies, poor nutrition, anaemia, obesity, dental health and earlier onset of diabetes. From a healthcare perspective, issues included children not getting child health checks, accessing services and the limited availability of specialist services and child chronic disease nurses. Child development, school readiness, attending

school, disability and FASD was also key and interconnected with discussions around the health impact of parenting and family support.

"From FASD we need to look more at child development, treatment and support for families, especially around emotional and behavioural support." (Forum participant)

**Youth:** Key issues for youth included: alcohol and drug use; sexual health; obesity and a lack of physical activity; road trauma; FASD and disability; and not accessing healthcare. The strongest focus, however, was on suicide and self-harm and the need for emotional resilience. Related key issues raised included knowing identity, peer pressure, bullying, social media, shame, jealousy, anxiety, depression, body image, a lack of positive role models and hope.

"Why does suicide cross our minds? We've been grown into this thing called suicide. We need to identify with country outside the towns and cities. In the bush. What do you want to do? We need to help build their identity, anger management, how to self-regulate and make healthy choices to be strong leaders for their families." (Forum participant)

**Parents/ Adults:** By far the greatest focus on physical health was on early and preventable deaths from lifestyle, especially diabetes, renal failure and heart disease. A number of other key issues were similar to youth including alcohol, smoking and drug use, road trauma and disabilities. Aged care and dementia were also raised. Emotional issues included lateral violence, fear, lack of control, having no hope, the number of deaths, cycles of grief and loss and needing more opportunities to celebrate success.

"Diabetes, high blood pressures, chronic diseases. Kids growing up thinking there is one road and they'll end up with all that. Self-esteem down, mindset. It affects health and social and emotional wellbeing." (Forum participant)

#### **BUILDING CAPACITY IN ABORIGINAL HEALTH RESEARCH**

"Aboriginal people and communities are the key component to successful, meaningful and beneficial research projects." (Presenter quote)

The quote above comes from the presentation given by Ms Patricia Bushy and Ms Tara Pierson, Aboriginal Health Council of WA (AHCWA) who presented together with A/Professor Roz Walker (TKI) on building Aboriginal researcher capacity. The importance of this was highlighted throughout the Forum. The benefits of Aboriginal participation mentioned included creating ownership and pride in the research and its outcomes, building trust and rapport, incorporating cultural concepts, respecting cultural ways of working and better quality data. Cultural safety in research and culturally relevant research methods were also discussed.

Steps to igniting an interest and passion for research at the community level and increasing Aboriginal participation and ownership were presented. These included regularly promoting research at a community level and forming, strong, proactive and jointly beneficial partnerships that include Aboriginal communities, Aboriginal organisations, funders and research institutes. Suggestions for developing specific, tailored training were endorsed by participants.

#### **WAY FORWARD**

Based on all that had been discussed, presented and workshopped during the forum, the participants developed a number of Follow-Up Actions set out below.

- Work on the identified research project priorities
  - e.g.: KAMS, RCSWA, TKI & Others to form Kimberley Child & Family Health working group
    - Highlight research project priorities and share with others
    - Assess research already done in priority areas
    - o Determine which areas are amenable to research approaches and how this might look
    - o Identify potential partners with interest and expertise in priority areas
    - o Identify structures for disseminating research related to the priorities
- Strengthen the research processes
  - Provide direct feedback to the NHMRC on how the current grant application system effects efforts to conduct community-owned research, build local capability in research, and how it can be improved
  - Hold a face-to-face meeting of the members of the KAHPF Research Subcommittee to review its membership and processes
  - Create a pooled database of research projects done in Kimberley KAMS, AHCWA, TKI, RCSWA, WA Country Health Services (WACHS)
- Meet with AHCWA to discuss a State-wide training framework for researchers with regional and local models
- Hold an annual Kimberley Aboriginal health research forum, which includes reporting on progress made towards research priorities and processes identified at this Forum

Thank you to all who participated in the forum; your very busy schedules and in many cases long distances travelled is acknowledged and appreciated.

#### Kimberley Aboriginal Child & Family Health Research Forum 8-9 September 2016 <u>APPENDIX 1 - AGENDA</u>

DAY 1				
0830 – 0900	Coffee and registration			
0900 – 0910	Welcome to country			
0910 – 1000	Introduction and background of forum  Vicki O'Donnell  CEO - Kimberley Aboriginal Medical Services			
	Jonathon Carapetis Director - Telethon Kids Institute			
	David Atkinson  Head - Rural Clinical School of Western Australia			
1000-1030	What do we mean by research and what are the potential benefits for the Kimberley?  Dr Lyn Henderson-Yates - CEO Derby Aboriginal Health Service			
1030-1100	Break			
1100-1120	Overview of KAMS health research A/Professor Julia Marley – Principal Research Officer - Kimberley Aboriginal Medical Services			
1120-1200	Kimberley health status snapshot  Glenn Pearson - Telethon Kids Institute			
1200-1300	Lunch			
1300-1545	Research priorities - translating health issues to research priorities  Rob McPhee – Kimberley Aboriginal Medical Services			
1545-1600	Summary and close of day 1 Vicki O'Donnell - Kimberley Aboriginal Medical Services			
DAY 2				
0830-0845	Recap from day 1 Vicki O'Donnell - Kimberley Aboriginal Medical Services			
0845-0915	Overview of existing process in the Kimberley  A/Professor Julia Marley - Principal Research Officer - Kimberley Aboriginal Medical Services			
	Kimberley Aboriginal Health Planning Forum			
0915-1030	Refining the research process  Glenn Pearson - Telethon Kids Institute			
1030-1100	Break			
1100-1200	Building researcher capability  Trish Bushby – Aboriginal Health Council of WA			
	Roz Walker - Telethon Kids Institute			
1200-1230	Summary, close and lunch Vicki O'Donnell - Kimberley Aboriginal Medical Services			

#### APPENDIX 2 - KEY HEALTH ISSUES: Children / Young People / Parents & Families

#### **Overview**

On the first day, participants were asked to form tables of mixed community members, representatives from service organisations and researchers together to list the key health issues confronting:

- Children
- Young People
- Parents and Families

The issues identified by each table have been collated into below.

#### APPENDIX 2 - KEY HEALTH ISSUES: Children / Young People / Parents & Families

EMOTIONAL:  Poisoned by trauma and stress — Early experiences in life "fright, fight, flight"  Shame  Understanding about: Who is my family Who is my primary carer Who is my nurturer Who is my disciplinarian Compounded stress Who is accountable Who is responsible Kids fall through support net  Community familiarity with suicide  Lack of hope/ inevitability  Equal treatment of children in families	EMOTIONAL:  Intergenerational trauma  Stress  Babies having babies  Perpetual grief – sorry business  Peer pressure / bullying  Racism  Anxiety / Depression / Body Image  Sexual Health  Shame from being classified at school, not able to be who they are  Identity – where do they fi?  Lack of hope/ inevitability  Resilience  Self-esteem	<ul> <li>Fewer adults compared to young people</li> <li>Parenting skills/ family support</li> <li>Broken family unit – fractured community – community cohesiveness</li> <li>No drug rehabilitation facilities</li> <li>Dysfunctional homes – abuse normalised and accepted, overcrowding</li> <li>Single parent families</li> <li>EMOTIONAL:         <ul> <li>Lateral violence</li> <li>Fear of the unknown</li> <li>Lack of control</li> <li>Lack of hope/ inevitability</li> <li>Cycle of grief</li> <li>Fear of judgement</li> <li>Racism</li> <li>Passivity</li> <li>Social media</li> </ul> </li> </ul>
CULTURAL:  Popular Culture:  Fast Food instead of hunting  Fatigue IT  Social Media  Kinship & Care:  Know your Grannie  Norms  Use / Abuse  Right way / wrong  Discipline account  Anger  Circle of growling  Liyan  History  Trauma Triggers  Yelling /  Growling  Traditional tribal vs nuclear	Walking the fine line between culture & mainstream society	<ul> <li>Stolen generation         <ul> <li>Displacement</li> <li>Fragmentation of families</li> <li>Loss of language</li> </ul> </li> <li>Fighting for country &amp; how it separates family</li> <li>Out of the loop-exclusion from information</li> <li>Emerging Aboriginal class structures</li> <li>Acceptance of negative parenting</li> <li>Loss of respect for Elders:         <ul> <li>Elders feeling excluded</li> </ul> </li> <li>Lack of cultural control</li> <li>Link mainstream with Liyan</li> </ul>

ART, CULTURE, HUNTING, LAND, COUNTRY, LORE VERY STRONG IN THE KIMBERLEY

family:

- Intergenerational stressors

#### Kimberley Aboriginal Child & Family Health Research Forum 8-9 September 2016 <u>APPENDIX 3 – RESEARCH PRIORITIES</u>

#### **Overview**

After listing the key health issues facing children, young people and parents/ families, tables were ask to list their top 3-5 research priorities. The outcomes from each table are collated below.

KEY THEMES	KEY ELEMENTS of RESEARCH PRIORITIES			
Culture and	How do we get culture into services?			
health	Cultural revitalisation through health practices			
Resilience in Young People	Social & emotional wellbeing is comprimised when our young people don't have coping mechanisims. What should be in the Building Resilience Tool Kit / success factors?			
	How do we prevent self-harm and suicide, and enhance spiritual sense and healing?			
	How can we reduce the suicide risk in Aboriginal Adolescents?  • How can we build resilience in Adolescence?			
	<ul> <li>What prevention strategy in young might work? (social emotional wellbeing / resilience)</li> </ul>			
	<ul> <li>Focus on young men and women (separately?)</li> <li>Anger management, self-regulation, Identity, On Country (multifactorial intervention)</li> </ul>			
	Impact of suicide on family/ community (Resilience): causes, prevention, responses			
	What is the impact of ice on Kimberley communities? How can we prevent/reduce this? Why are Aboriginal people using ice?			
	Negative health impacts of IT and social media: depression, anxiety and stress on young people.			
	What can be done to improve school attendance of Aboriginal children? Bullying of Aboriginal children in school as a risk for non-attendance.			
Supporting families and positive	How do we teach male and female children their culture, to be proud of their culture, and promote good relationships between men and women?			
parenting	Young parents – does a parenting program for parents under 20 years old improve early childhood health and school readiness?			
	Child social and emotional development – supporting families			
Healthy Lifestyles &	How do we prevent chronic disease?			
Chronic Disease	What social supports are required to promote good nutrition and food options?  Action, not just education.			
	I.e. Community hub? Health retreat? Promote sports and craft?			

#### Kimberley Aboriginal Child & Family Health Research Forum 8-9 September 2016 <u>APPENDIX 3 – RESEARCH PRIORITIES</u>

Environmental Health & Diseases	Environmental health and chronic health issues I.e. Is there a link between high rates of contaminated water and high prevalence of renal failure and other chronic diseases?  Health impacts of overcrowding: causes and prevention		
Data	Shared baseline data and analysis at community and stakeholder level  Using data and analytics to support good outcomes for research  Identify research priorities  For evaluation of programs		
Services	Access to Services  How do we support people to access services early?  How do we ensure services are effective?		

#### Kimberley Aboriginal Child & Family Health Research Forum 8-9 September 2016 APPENDIX 4 – RESEARCH PROCESS

#### **Overview**

On the second day of the Forum, participants heard presentations on the research process. Each table was then asked to select one research priority and to use the stages of research process to outline the steps and considerations needed in each stage to ensure that it is consistent with doing research Kimberley Way. The results are set out below by table.

- Conceptual and Consultation
- Co-design of Research Project
- Conducting Research
- Analysis of Data
- Planning for Possible Implications of Findings
- Exit and/or Recommence

#### Impacts of IT & Social Media of People 25 years & under - (Table 1)

#### **Conceptual & Consultation:**

- Lit review previous research, Aboriginal partners
- Consultation with the community:
  - Review which communities have access
  - Preliminary consultation
- Clear guidelines about the proposal / privacy (negotiated):
  - Cultural awareness / safety considerations
- Relationship building with cultural groups

#### **Co-design of Research Project:**

- Working collaboratively with partners
- Identify hypothesis
- Framework & processed / Governance / Ethics
- Funding / resources / training for staff
- > Research methodology
- Consent form, Participant Information forms (draft):
  - Aboriginal involvement / Endorsed / Company logos

#### **Conducting Research:**

- > Follow methodology, notify partners / participants
- Aboriginal involvement: Assist with conducting interviews
- Plan for unexpected events be flexible

#### **Analysis of Data:**

- > Translation i.e.: into practice
- Interpretation of the data
- Inclusion of people in analysis different perception / views

#### **APPENDIX 4 – RESEARCH PROCESS**

#### How do we Improve Attendance of Aboriginal Children at School - (Table 2)

#### **Conceptual & Consultation:**

- Share initial data with community (size & scale of issues)
- Meet with AMS, Education (schools & principals), District Leadership Groups, Aboriginal leaders from different organisations & corporations (check with resource centre), meet with parents / guardians, engage with current students & young people
- Check with community about other existing research programs dealing with same issues past & present
- Ring first & organise meetings

#### **Co-design of Research Project:**

- Principles
- Meeting with those (All) influencing or impacted by the Qn / issue:
  - Parent YP School Community
  - Context
  - Location representation from local people
- ➤ Look at patterns & reasons ground truthing
- ➤ Community Reference Group endorse or approve steps / design → shift power in design decisions
  - Community Champion → enable / empower & value this work
  - Local research sub committee
  - Contingency process for finding significant worry

#### **Conducting Research:**

- Local Aboriginal people employed to do this work Food / venue No survey without service Interpreters Protocols to visit contact prior & check
  - Supported
  - Capacity building
  - Inform cultural framework this is valued
     Avenues for continuous checking & room to change ways that are right for the Kimberley
  - Learn in process be prepared to be wrong
  - Flexibility

#### **Analysis of Data:**

- Checked back with Community Reference Group / Elders:
  - Positive / negative \imp what will you do if Analysis shows big impact
- ➤ How to protect small areas if findings significant negative / deficit

#### Planning for possible implications of findings:

- Preparing for positive / negative findings & keep feeding information back to community & sub committee
- > Take it to relevant stakeholder groups
- Ability to get involved in creating change services, Education Department, community programs, funding etc.

#### FLEXIBILITY & ADAPTABILITY

#### Kimberley Aboriginal Child & Family Health Research Forum 8-9 September 2016 APPENDIX 4 – RESEARCH PROCESS

### Integrating Health & Non-Health Services – Test Model – (Table 3) Family Centre / 3 x Aboriginal Case Workers (social)

#### Baseline (0-8yrs)

- > environmental / social indicators
- normal birth weights
- ➤ KPI Specialist attendance rate 5% each year

#### **Consultation:**

- ➤ KAMS
- ➤ GPs / Nurses
- ➤ MMEX
- Research / evaluation
- Specialists
- > Allied Health

- > AHW
- ➤ Community → Board: Reference Group
- Clients
- Other Service Providers: DCP (Social Workers), Yawuru, Nirrumbuk, Clontarf, Centrecare / Link

#### Co-design:

- Gap analysis
- Workshops group / individuals/whiteboard
- Included all BRAMS staff

- ➤ Ethics approval proposal
- > KAHPF Research sub committee

#### **Conducting:**

- Research clinician analysis
- > Embedded with BRAMS part of everyday work
- ➤ Manager interviews

#### **Analysis Interpretation:**

- > Research clinician
- > Interpretation: workshops, Board, Millya Rumurra, senior staff
- ➤ MMEX
- Experienced researcher to facilitate
- Researchers

#### **Implementation / Translation:**

- Embed funding
- Reports for others to learn Longitudinal study == exit / recommence

#### APPENDIX 4 – RESEARCH PROCESS

#### Dental Health – (Table 4)

#### **Conceptualisation:**

➤ What is causing poor dental health in children age 4-12yrs

#### Co-design:

- Consult with AMS on scope, parameters
- ➤ How can research identify extent of problem
  - Funding & service gaps identified
- Research needs to link to positive community outcome
- > Target is the community (not academic)

#### **Conducting:**

- > Local people part of the project
- Community to agree to methodology include mix methodology
- Hypothesis should be agreed with community:
  - Consequences of poor dental for long term problems

#### Data:

Existing data, use stories

#### **Planning for Implications:**

- Defining extent of problem case for more services
- ➤ Long term strategy re education

#### **Translation:**

- Practical outcomes
- > Inform practice
- > Inform policy
- Further work / evaluation of changes, research

#### How do we teach children their cultures? – (Table 5) How do we incorporate culture into all research practices? How do we measure how well this is being done?

- > Transition of knowledge from Elders to Youth
- Ensure the checklist of requirements is ticked off
  - More clearly define the expectation of the community
- > Only allow new research if past research was compliant with KAMS expectations
- > Engagement which is different from engaging organisations

#### Action:

- Review membership of research committee
- Facilitate potential researchers (at their expense) to engage with communities to discuss their proposed research then get the community to feedback to sub-committee whether they are interested or not. Soon.

#### Kimberley Aboriginal Child & Family Heath Research Forum 8-9 September 2016 <u>APPENDIX 5 – LIST OF PARTICIPANTS</u>

NAME		ROLE	ORGANISATION
Andre	SCHULTZ	Lung Health Researcher	Telethon Kids Institute
Anna	DWYER	Researcher	Nulungu Research Institute University of Notre Dame
Asha	BOWEN	Skin Health Researcher	Telethon Kids Institute
Audriana	SHADFORTH	Director	Kimberley Aboriginal Medical Services
Bec	SMITH	Kimberley Director	WA Country Health Service
Bob	MAHONY	Chief Executive Officer	Broome Regional Aboriginal Medical Service
Brenda	GARSTONE	Chief Executive Officer	Yura Yungi Medical Service
Darren	MINYARDIE	Director	Kimberley Aboriginal Medical Services
Darryl	KICKETT	ACCARE Member	Telethon Kids Institute Aboriginal Collaboration Council Advising on Research & Evaluation (ACCARE)
David	ATKINSON	Head of School	Rural Clinical School of WA
Erica	SPRY	Research Officer	Kimberley Aboriginal Medical Services
Gavin	CLELAND	Head of Department	WA Country Health Service Kimberley Regional Paediatric Service
Glenn	PEARSON	Head, Aboriginal Research Development (KARDU)	Telethon Kids Institute Kulunga Aboriginal Research Development Unit (KARDU)
lan	TRUST	ACCARE Member	Telethon Kids Institute Aboriginal Collaboration Council Advising on Research & Evaluation (ACCARE)
Isabelle	ADAMS	Unit Coordinator (KARDU)	Telethon Kids Institute Kulunga Aboriginal Research Development Unit (KARDU)
Janine	DUREAU	Deputy Chief Executive Officer	Aarnja Ltd
Janine	MCNAMARA	Administration Support	Telethon Kids Institute
Jeanette	WARD	Consultant Public Health Medicine	WA Country Health Service Kimberley Population Health Unit
John	GREEN	Chairperson Director	Yura Yungi Medical Service Kimberley Aboriginal Medical Services
John	JACKY	Kimberley Coordinator (KARDU)	Telethon Kids Institute  Kulunga Aboriginal Research Development Unit (KARDU)
Jonathan	CARAPETIS	Director	Telethon Kids Institute
Jonathan	FORD	ACCARE Member	Telethon Kids Institute Aboriginal Collaboration Council Advising on Research & Evaluation (ACCARE)
Josie	JANZ-DAWSON	ACCARE Member	Telethon Kids Institute Aboriginal Collaboration Council Advising on Research & Evaluation (ACCARE)
Julia	MARLEY	Principal Research Officer	Kimberley Aboriginal Medical Services Rural Clinical School of WA
Kerr	WRIGHT	Medical Director	Kimberley Aboriginal Medical Services

#### Kimberley Aboriginal Child & Family Heath Research Forum 8-9 September 2016 <u>APPENDIX 5 – LIST OF PARTICIPANTS</u>

NAME		ROLE	ORGANISATION
Kristen	ORAZI	Senior Project Officer	Department of Regional Development Regional Services Reform Unit
Kristen	WHITE	Program Manager (KARDU)	Telethon Kids Institute Kulunga Aboriginal Research Development Unit (KARDU)
Lionel	QUARTERMAINE	Project Officer	University of Western Australia Aboriginal & Torres Strait Islander Suicide Prevention Evaluation Project (ATSISPEP)
Lynette	HENDERSON- YATES	Chief Executive Officer	Derby Aboriginal Health Services
Mara	WEST	Unit Coordinator	Telethon Kids Institute Kulunga Aboriginal Research Development Unit (KARDU)
Maxine	ARMSTRONG	Chairperson of Board	Kimberley Aboriginal Medical Services
Melanie	THOMPSON	Paediatrician	WA Country Health Service
Melissa	WILLIAMS	Maternal and Child health Coordinator	WA Country Health Service Kimberley Population Health Unit
Myrtle	WARD	Chairperson Director	Ord Valley Aboriginal Health Service Kimberley Aboriginal Medical Services
Patricia	BUSHBY	HSIU Manager	Aboriginal Health Council of WA
Phillip	MATSUMOTO	Director Chairperson	Kimberley Aboriginal Medical Services Broome Regional Aboriginal Medical Service
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