



the
Lowitja
INSTITUTE

Australia's National Institute for Aboriginal
and Torres Strait Islander Health Research

*Incorporating the Cooperative Research Centre
for Aboriginal and Torres Strait Islander Health*

The Lowitja Institute
National Roundtable on
Aboriginal and Torres Strait Islander Child and Maternal
Health Research: Priorities for Interventions
Melbourne, 8 March 2012



An Australian Government Initiative



CRC
AUSTRALIA

OVERVIEW

Around 40 people attended the Lowitja Institute National Roundtable on Aboriginal and Torres Strait Islander Child and Maternal Health Research: Priorities for Interventions, which was held in Melbourne on 8 March 2012.

Those attending represented a diverse range of organisations with an interest in child and maternal health from across the country, including the Aboriginal community controlled primary health care sector, government agencies/clinics, universities and research institutes. The meeting was hosted by the Lowitja Institute and supported with funding from the CAGES Foundation (www.cagesfoundation.org).

The purpose of the Roundtable was to:

- bring together researchers, health service providers (including community based or community controlled services) and government agencies
- share information from different States about current research findings, tools and expertise in Aboriginal and Torres Strait Islander child and maternal health
- identify the opportunities for research that can contribute to improved outcomes in child and maternal health for Aboriginal and Torres Strait Islander people
- identify the opportunities for implementation of research through a collaborative effort (for example, a joint program or partnership grant application).

ORGANISING COMMITTEE

Janelle Stirling, Gail Garvey, Alana Gall and Liz Izquierdo (The Lowitja Institute)

REFERENCE GROUP

Roz Walker (Coordinator)	Telethon Institute for Child Health Research and The University of Western Australia
Kathleen Clapham	Australian Health Services Research Institute, University of Wollongong
Lisa Shipley	The University of Newcastle
Jennifer Reith	University of Western Sydney
Rhonda Marriot (Facilitator)	Kulbardi Aboriginal Centre, Murdoch University, Telethon Institute for Child Health Research and The University of Western Australia

ROUNDTABLE THEMES

The Roundtable focused on four priority areas in child and maternal health informed by the research experiences and scope of work and findings of the Healthy Start, Healthy Life program, and the priorities identified by the National Aboriginal and Torres Strait Islander Health Equality Council (NATSIHEC, formerly NIHEC). The themes were:

- The importance of data linkage to inform programs, policies and interventions (theme 1)
- The need for an understanding of the factors that impact across the life-course for Aboriginal and Torres Strait Islander groups (theme 2)
- Addressing the impacts of smoking and substance use during and after pregnancy (theme 3), and

- Education to empower and strengthen women to improve child and maternal health outcomes (theme 4).

Associate Professor Roz Walker gave a conceptual framework for the Roundtable by delivering the presentation 'An overview of Aboriginal and Torres Strait Islander maternal and child health research in Australia'. She was followed by four presentations covering the Roundtable themes. For each theme/presentation a question was developed to initiate/facilitate the discussion. Each presenter discussed important background information and raised key questions in their respective areas.

PRESENTATIONS

Theme 1: Using data to inform interventions, develop collaborations and improve health outcome — 'The power of data: Data, policy, practice' by Associate Professor Jane Freemantle, The University of Melbourne

Q1: How do we ensure governments work in a more coordinated way, and organisations and services have capacity and skills to collect quality data to measure outcomes?

Theme 2: Adopting a causal pathway approach to improving the health and educational outcomes of Indigenous children, Associate Professor Roz Walker on behalf of Professor Sven Silburn, Menzies School of Health Research

Q2: How can we engage more effectively with communities to address social determinants such as education, employment and socio-economic status that influence maternal and child health outcomes?

Theme 3: Perinatal health: use of alcohol, tobacco and other substances and their impact on child development, 'Alcohol, tobacco and cannabis and their impact on child development', Dr Megan Passey, University of Sydney.

Q3: How can we nurture the strengths of Aboriginal and Torres Strait women and communities in making good health choices for themselves and their children?

Theme 4: Parental education and improved outcomes in Aboriginal and Torres Strait Islander maternal and child health, Lisa Shipley, Indigenous Researcher, The University of Newcastle

Q4: How can we nurture the strengths of Aboriginal and Torres Strait women and communities in making good health choices for themselves and their children?

In addition to the presentations, a number of poster presentations relevant to addressing maternal and child health outcomes were exhibited at the Roundtable.

Following the presentations based on the four themes outlined above, participants were grouped on to four tables. Each table was asked to discuss one of the themes focusing on the specific questions posed for that theme and to consider:

- the overriding question as to how we can, as practitioners, policy personnel and services providers, incorporate and build on Indigenous knowledges and strengths in our work, and
- the possible gaps and other critical issues that emerge in the discussions or are not covered by the key themes.

All groups were asked to develop suggested strategies and/or recommendations around future activities as well as identifying who would be best placed to implement the recommendations (taking into account the gaps and critical issues identified in their discussion).

Finally, as a plenary group, participants were asked to consider how we can use what we have learned from the presentations and poster exhibitions to inform/improve policies, programs and practices among stakeholders represented at the Roundtable. The list developed from this reflective exercise will form the basis of a briefing paper for the relevant Ministers.

EXPECTED ROUNDTABLE OUTCOMES

- A list of identified gaps and priorities in key areas
- A set of strategies and recommendations to address the key issues, priorities and gaps
- The potential to form a sub-group to prepare a funding proposal to address some of issues identified above
- The potential to call for submissions to develop a comprehensive evidence base of 'what works' in improving maternal and child health
- A final paper for publication and dissemination capturing the Roundtable discussion.

EXPECTED ROUNDTABLE OUTPUTS

- A funding proposal involving diverse organisations across the country
- A national network of stakeholders (including researchers, practitioners, professional associations and communities) involved in improving maternal and child health outcomes
- A selection of evidence-based research to be implemented and evaluated.

Summaries of the ideas discussed at the Roundtable are listed in the following pages, including the rationale behind each of them and possible action/s to address those priorities.

PRIORITIES IDENTIFIED

Theme: Importance of data linkage to inform programs, policies and interventions

Registering an Indigenous Birth

Priority timeframe: HIGH

Responsible person:

Rationale:

Aboriginal and Torres Strait Islander births are not registered accurately in hospital records. The reasons are multifactorial and include issues such as: problems with accurately identifying Aboriginal and Torres Strait Islander mums/families in the system, processes being unclear, Aboriginal and Torres Strait Islander women not readily self-identifying among some of the reasons.

The registration of a birth and the process of how to do this also vary between States and Territories (<http://australia.gov.au/topics/law-and-justice/births-deaths-and-marriages-registries>).

Additionally, some States have a 'birth registration package' involving a fee (~\$45, this also varies across the country). The package includes a 'fancy' certificate. Consequently, many Aboriginal and Torres Strait Islander mums think they have to pay the \$45 fee to register their baby, which is not the case. This confusion has resulted in many Aboriginal and Torres Strait Islander births not being registered and an underestimation of births for the respective jurisdictions.

Aims:

- To increase identification of Indigenous births in birth registers and improve hospital records of Aboriginal and Torres Strait Islander births.
- To engage with the Australian College of Midwives (ACM) to increase the registration of Aboriginal and Torres Strait Islander births.
- To increase understanding of how to register births by Aboriginal and Torres Strait Islander mums.
- Improved data linkage at the regional level.

Possible action:

Address the under-identification of Aboriginal and Torres Strait Islander births in birth registries*:

- Scoping out the current situation and issues including differences between States and Territories legislation and Closing the Gap documents
- Investigating ways to enhance the understanding of Aboriginal and Torres Strait Islander mums/families of how to register a birth:
 - Firstly, scoping current situation
 - Secondly, addressing gaps, e.g. developing brochures outlining steps how to register specifically for Aboriginal and Torres Strait Islander mums/families.

*Work towards a standardisation of birth certificates across the country.

- Work with the Australian College of Midwives (ACM) to inform midwives and engage them in having a more active role in providing guidance to Indigenous mums on how to register a birth and the importance of this.

Theme: Importance of data linkage to inform programs, policies and interventions

Data Infrastructure and linkage

Priority timeframe: HIGH

Responsible person: Jane Freemantle

Rationale:

Information on Indigenous births and child and maternal health is available from specific studies or specific jurisdictions. As a result of the variation in the collection process across different health systems – such as AMS, hospital data – it is difficult to gain a complete jurisdictional or national picture of the current situation in this area. Ownership and access of these data is also difficult as a result of varying Federal, State and Territory legislation.

Aims:

- Opportunities to close data gaps through data linkage should be expanded, including the linking of registry and administrative databases across jurisdictions.
 - *Better communication/collaboration across the different health systems to improve data linkage capacity, possible interventions and sharing.
- Improving data linkage at a regional level.

Possible action:

Use Jane Freemantle's paper about data linkage as a background to plan two workshops/roundtables on:

- Advocacy related to demystifying privacy legislation and its implications for data flow
- Data linkage and access. Topics to include are management, ownership and sharing. Invite multi-disciplinary groups – legal, health, communities etc. – to give a regional/State and national overview, as different jurisdictions have different guidelines.

Theme: Education to empower and strengthen women to improve child and maternal outcomes

Community level literacy programs

Priority timeframe: Outside the scope of P1. It has been taken up by P3 Enabling Policy and Systems

Responsible person:

Rationale:

Education is a powerful way to empower people. Using education as a tool, there are multiple strategies that may be used to empower Aboriginal and Torres Strait Islander mums, e.g. education, literacy programs.

However, this is beyond the scope of the Lowitja Institute's Healthy Start, Healthy Life program (P1), but P2/P3 have a couple of initiatives related to literacy and capacity building that covers some of the discussion from the Roundtable. In addition, Aboriginal and Torres Strait Islander capacity building is embedded in all CRCATSIH and Lowitja Institute research programs.

Possible action (no further action required):

Literacy program: www.lowitja.org.au/aboriginal-adult-literacy-campaign-stage-1

Theme: Impact of smoking and substance use during/after pregnancy

Priority timeframe: Outside the scope of P1. The Lowitja Institute has two tobacco-related projects, 'Starting to smoke: Experience of Indigenous youth' (Vanessa Johnston, Menzies School of Medecinal Research) and Aboriginal Tobacco Control (David Thomas, NAHRU–Lowitja Institute)

Responsible person:

Rationale:

Smoking in Aboriginal and Torres Strait islander communities, and in particular in pregnant and breastfeeding mothers, is a major health issue. To date a number of strategies have been implemented to address these issues, but with limited success. It was suggested at the Roundtable that a more achievable strategy is to promote the use of nicotine patches as they are less damaging.

Aims:

- To re-vamp current health promotion programs that are focused on these issues to make them more positively worded, e.g. 'ciggs bad for baby' to 'not having that cigarette is good for your baby'
- Offer alternatives to decrease smoking
- Take a whole-of-family approach to quitting/minimising smoking if possible (it cannot be extrapolated to all).

Possible action:

The Lowitja Institute has supported some initiatives that target smoking. These include, but are not limited to:

- Roundtable to develop a monitoring framework for the National Indigenous Tobacco control program; the initiative was then taken by DoHA
- Project 'Starting to smoke: Experience of Indigenous youth' (Vanessa Johnston, David Thomas).

If participants are interested in these, they should contact the respective project contacts.

Theme: Factors that impact across the life-course

Evaluation of interventions in child and maternal health

Priority timeframe: HIGH

Responsible person: Jane Freemantle

Rationale:

Several initiatives/interventions on child and maternal health have been developed and much more are still developing. However, there has not been a systematic review of most of those initiatives, what has worked, and what the reasons are behind successful or failed stories. An evaluation of them will improve our learning on the topic, make better use of resources and identify priorities for future planning.

Aims:

- Review and evaluate existing interventions in this area
- Utilise this information to develop new initiatives

- Publish the evaluation and make it available more widely for people working in the area
- Use findings to optimise/pool Indigenous cohort studies already in place and establish an adolescent preconception cohort.

Possible action:

Develop a Centre for Research Excellence application for the NHMRC to contribute to the evidence about effective interventions and research capacity building in the communities. This should include evaluation methodologies, evaluation of interventions, learning outcomes, a framework to allow comparisons between programs/initiatives and building capacity so organisations can adequately plan their evaluations.

Theme: Prenatal/Antenatal care

Antenatal Care (Baby Basket)

Priority timeframe: MEDIUM

Responsible person: EOI

Rationale:

How to engage Indigenous women in antenatal care is a challenge. The 'Baby Basket' is a program used in some remote communities as incentives to women if they come in earlier and/or regularly for a check-up during their pregnancy. Three baskets are given over the course of their pregnancy. The contents of the baskets include fruit and vegetable vouchers, pamphlets, baby clothes, spoons, toothbrushes, toys for bub, 'Safe and Secure' sleeper bags, etc. This program also provides an opportunity to talk to the family about what is in basket and how to use some of the items and other topics, e.g. Sudden Infant Death Syndrome (SIDS).

Aims:

- Encourage pregnant women and mothers to visit the clinic earlier and more regularly throughout pregnancy and for antenatal care.
- Improve the health literacy and education of mothers about their pregnancy and babies and other important and relevant health issues.

Possible action:

- Review current 'Baby Basket' and similar initiatives across States/Territories, select some for detailed evaluation, validation and improvement
- Promote findings.

Theme: General

Integration of Child and Maternal Health services

Priority timeframe: HIGH/MEDIUM

Responsible person:

Rationale:

Currently there is not an extensive or strong connection between hospitals, primary health care services and community settings and this has an impact on the continuity of care for mothers and their babies. Work towards developing a model of care connecting

primary health care patients more effectively and appropriately is of paramount relevance. This is related to Continuous Quality Improvement (CQI).

Possible action:

Develop a paper on the relevance of integration of services (model of care), the role of building evaluation as part of the model, and evaluating some examples of models of care in Australia.

Child and maternal network

Priority timeframe: HIGH

Responsible person:

Rationale:

There are many projects and programs occurring across the country on Aboriginal and Torres Strait Islander child and maternal issues. However, some of the efforts are not occurring across all regions. A space where all activities and people working on these issues connect will bring benefits to all for better planning and knowledge of what is missing, where more is needed and where the capacity building for it is, etc.

There is also dispersed data from reports, small projects ('grey literature'), etc. that is not widely available or disseminated. This material should be compiled and accessible to a wider audience working in child and maternal health.

Aims:

- Improve collaboration and connection among people working on child and maternal health (e.g. through the setting up of a 'yarning place')
- Increase the visibility of local and regional projects and programs through a clearing house for projects and programs on child and maternal health.

Possible action:

Develop a network on Indigenous child and maternal health from this forum to share ideas, develop joint grant and project applications, share literature and compile 'grey literature'. This could be developed through HealthInfoNet platform.