



## **The Australian Society for Medical Research**

Report and recommendations from the

### **ASMR Indigenous Health Forum “*Better Health Outcomes for Mums and Bubs*” Adelaide Convention Centre, 26 November 2012**

October 2013

## **The Australian Society for Medical Research (ASMR)**

ASMR is the peak professional body representing the nation's health and medical research (HMR) sector. In addition to more than 1700 direct members, the ASMR represents the sector through 57 affiliated professional societies and medical colleges representing an additional 18,000 people actively involved in HMR. Our corporate and disease related foundation memberships bring a further 100,000 people into association with ASMR. Our mission is to foster excellence in Australian HMR and to promote community understanding and support of the sector through public, political and scientific advocacy.

ASMR has a demonstrable knowledge and understanding of the HMR community as a result of it being closely connected to its members and actively involved in research concerning the sector's productivity [1,2,3,4], workforce conditions and planning [5,6] and plans for alleviating current and future health challenges facing our nation [7]. One of the most unacceptable health issues in Australia is the disproportionate level of poor health and disease amongst Australian aboriginal and Torres Strait Islander people.

The Society strongly supports new initiatives in health and medical research that have the capacity to improve the health of Indigenous Australians. During the 50<sup>th</sup> anniversary year of ASMR in 2011, our Society chose the theme 'Indigenous Health: Action on Prevention' to highlight the importance of research for improving the long-term health outcomes of Indigenous Australians [8].

To continue ASMR's advocacy for Indigenous health research, our Society conducted an Indigenous Health Forum to look at '*Better health outcomes for mums and bubs*' [9]. This public forum explored issues surrounding women's and children's health within the context of broader health and social issues faced by Australian Indigenous people. As a result of listening to the voiced messages in respect of Indigenous health, ASMR has generated a set of realistic recommendations designed to achieve better outcomes for maternal and child health. Our report and recommendations are provided below.

### **Indigenous Health Forum: *Better Health Outcomes for Mums and Bubs.* Adelaide Convention Centre, Adelaide, 26 November 2012.**

**Chair: Mr Joshua Creamer**, Barrister-at-Law and President Indigenous Lawyer Assoc. QLD

**Welcome to country: Elder, Uncle Lewis O'Brien**

#### **Invited Speakers**

- **Prof. Bronwyn Fredericks**, Pro-Vice Chancellor Indigenous Engagement, Central Queensland University.
- **Prof. Ngiaire Brown**, Professor Indigenous Health and Education, University Wollongong.
- **Ms Sandra Campbell**, PhD student University of South Australia.
- **Prof. Roger Smith**, Director Mothers and Babies Research Centre, University Newcastle.
- **Prof. Sue Kildea**, Professor Midwifery Mater Health Services and Australian Catholic University.

## **Executive Summary**

The health status of Australian Aboriginal and Torres Strait Islander people remains unacceptable, with a significantly higher incidence of disease and morbidity, as well as lower life expectancy than the average Australian population [10,11]. At the foundation of these health disparities are numerous challenges facing Indigenous women before, during and after pregnancy [12,13,14,15].

A focus on early life events during the year before and after birth, is critical for improving disparities in Indigenous life-long health outcomes – a message echoed by all speakers at the *2012 ASMR Indigenous Health forum*.

Poor nutrition, smoking, alcohol and stress in pregnancy, are linked to preterm birth and growth restriction of the newborn baby, as well as increased risk of diabetes, heart and kidney disease, and premature death in adulthood [16,17]. In addition, there is growing evidence that some of these harmful lifestyles during pregnancy may modify the baby's genetic makeup, giving rise to trans-generational health disadvantage [18,19,20].

Maternal and child health should be a priority for improving the health status of our nation's future generations of Indigenous people.

Current Indigenous maternal and early child care is not working at a satisfactory level. So what needs to be done for improving mothers and babies health, and how do we go about implementing these changes? The answer lies within listening to Indigenous Australians and leading health advocates. Voiced recommendations from the *2012 ASMR Indigenous Health forum* include:

- ***Engaging Aboriginal and Torres Strait Islander communities with emerging Indigenous health centres in all facets of women's health.***
- ***Developing effective models for the transfer of knowledge and evidence in relation to Indigenous women's and children's health, from Elders to women and children and across society.***
- ***Ensuring we have culturally safe and responsive maternity care, including primary birthing centres for low risk women across Australia.***
- ***Providing low cost but healthy food in both urban and remote Indigenous communities.***

To make a realistic plan for improving health of Indigenous people, our thinking and policy should be based around children with social and cultural engagement from parents and elders. The following report outlines the voiced recommendations from some of Australia's leading advocates for improving the maternal and child health of Aboriginal and Torres Strait Islander people.

We provide this report as a catalyst for discussion and action between Indigenous communities, public health leaders, State and Federal Governments and ASMR.

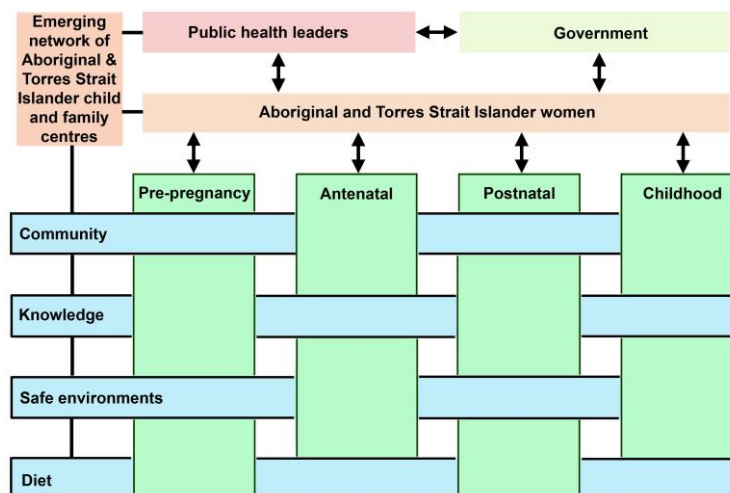
## Introduction

Over the past three decades, numerous research studies have documented the health status of Australian Aboriginal and Torres Strait Islander people [21,22]. Many of these studies have focussed on illness and the health disparities between Indigenous and non-Indigenous people. Indeed, there is a large body of evidence to show that Indigenous people have the poorest health, lowest level of income/socioeconomic status and difficulty in accessing health services anywhere in Australia [11].

Whilst many recommendations for improving the health of Australia's Indigenous people have been made, most of these recommendations have not been implemented or further discussed [23,24]. This has led to significant frustration for both Indigenous communities and health researchers, including the speakers at the 2012 ASMR Indigenous Health forum, who emphasised:

- “Most recommendations have yet to be taken up; it’s as if this information isn’t valued”
- “When just knowing the evidence isn’t enough”
- “Move from having the will to willingness to make a change”
- “Issues keep being repeated – still having the same conversations”
- “You mob just don’t listen”

The large number of recommendations and suggestions made, coupled with loss of corporate memory due to changing Governments, may be a contributing factor to the slow implementation of recommendations. Accordingly, this forum report has been prepared as an advocacy tool with realistic recommendations that focus on the beginning of life, which has an enormous health influence on the rest of life. Importantly, we need to ensure that Aboriginal and Torres Strait Islander people have more input into designing and monitoring maternal infant health services, together with constructive dialogue between Government, public health leaders, Indigenous women and Indigenous child and family centres (Figure 1).



**Figure 1.** Involving and engaging Indigenous women in all aspects of women's health programs before, during and after pregnancy – with public health leaders and Government listening to, and acting upon, the evidence-based recommendations from networks of Aboriginal and Torres Strait Islander child and family health centres.

## 1. Engage Aboriginal and Torres Strait Islander communities with emerging Indigenous health centres in all facets of women's health.

Community-level health promotion plays a pivotal role in the development of culturally safe and responsive maternity care for Aboriginal and Torres Strait Islander women in any setting. At the forum, there was strong consensus that in order to improve disparities in health outcomes, it will be essential to focus on adequate resourcing and education, as well as community control and participation in planning and decision making from the outset.

Of concern is the slow progress to act on recommendations, as highlighted by the following critical questions posed by the forum speakers:

- “*Why don't we follow evidence in relation to Indigenous women's and children's health, and the teaching about Indigenous health?*”
- “*How come we don't see public health leaders focusing more on Indigenous health?*”
- “*At a community level, how do we develop strategies to improve pre-pregnancy health among young women for improving health in the course of pregnancy, birth outcomes and intergenerational health?*”
- “*We don't realise at a national level that we've failed*”

One approach towards increasing the implementation of recommendations is to establish a group of Public Health Leaders, who act as champions for driving collaboration amongst health researchers, health networks, Indigenous communities and Government, as well as educating everyone to understand and act on the evidence in all its forms. Importantly, there needs to be a culturally safe and responsive flow of knowledge and action between all groups involved in the proposed framework (Figure 1). In addition, continual monitoring of health outcomes will be important to identify as soon as possible, those processes and interventions which do not improve Indigenous health outcomes, or at worst are detrimental to health and social well-being.

The emerging network of Aboriginal and Torres Strait Islander Child and Family Centres provides a valuable resource of evidence-based data on Indigenous health. Whilst much of this data is focussed on illness and deficits, and provides a wealth of information for guiding recommendations, there was consensus at the forum that future research should focus on wellness and community strengths for improving maternal and child health. Despite the importance of maternal and child health to the rest of life, it is remarkable that “*A Healthy Start to Life*” has dropped off the priorities for NHMRC, and this forum report advocates the benefits of reinstating it.

### 1. Recommendations

- 1.1 Utilise the emerging network of Aboriginal and Torres Strait Islander Child and Family Centres, to explore “*whole of life*” wellbeing, including how cultural and community connections build resilience and contribute to improved maternal and child health outcomes.
- 1.2 Reinstatement NHMRC's “*A Healthy Start to Life*” priority, including a focus on Indigenous maternal and child health.

**1.3** Establish a Public Health Leader group, whose role is to encourage Government and Indigenous communities to understand and act on the evidence generated from recommendations 1.1 - 1.2.

## **2. Transfer of knowledge and evidence in relation to Indigenous women's and children's health, from Elders to women and children and across society.**

Culturally, it's difficult to get mums to seek medical advice early in pregnancy. For some Indigenous women, their first visit to a hospital or medical centre is on the day they go into labour.

Developing 'Safe women's places' is one strategy for providing support networks for expecting Indigenous mothers, allowing women to connect with each other, Elders and health professionals. A good example of a centre that brings Indigenous women together in safety to exchange knowledge among themselves and Elders is '*The Gomerai Gaaynggal Program*'. This particular program allows women to come together to do art and receive health services at the same time. It also provides a relaxed and safe environment, where young women talk to mums and reconnect with their Elders, which is an important cultural aspect because some women have lost all Elders from their branch of the family. These centres also help health researchers connect with the communities and find out what the communities want.

Together, this approach focuses on the key role of young knowledgeable women in determining the health of their children. Establishing 'safe women's places' across Australia also builds parenting capacity, and provides improved availability and accessibility for reproductive health services.

## **2. Recommendations**

**2.1** Establish 'safe women's places' across Australia for involving and engaging Elders with Aboriginal and Torres Strait Islander women in all facets of women's health.

**2.2** Improve the availability and accessibility of acceptable sexual and reproductive health services for Aboriginal and Torres Strait Islander women, including maternal education, antenatal and postnatal care.

## **3. Culturally safe and responsive maternity care, including primary birthing centres for low risk women across Australia**

Australia is considered to be one of the safest countries in the world to be born. However, it's not equal for all people. The number of mothers dying in childbirth is starkly elevated for Indigenous Australians [10]. Many of the birthing Indigenous women are living in rural and remote areas – upwards of 60%. One example is Palm Island, where in some years up to 25% of women give birth on the island yet no birthing service is provided. If this happened in any other rural population, the health service would be forthcoming. There is a need to develop and expand culturally safe maternity health centres in remote, rural and urban areas – as highlighted at the *2012 ASMR Indigenous Health forum*, and by the National Maternity Services Plan (2011) [25].



For over 20 years, we have been told (by Indigenous communities) that our maternal infant health services do not meet the needs of Aboriginal and Torres Strait Islander families. Currently, we ask Indigenous women to travel away from their families to larger cities. Anyone who has worked in Aboriginal health will understand the importance of family, country and culture. Rarely are these three aspects incorporated into maternal infant health services. Elders are concerned that inappropriate birthing experiences for Indigenous women are directly linked to 'weakening of the baby's spirit'.

The privileging of Western medical definitions of "risk in pregnancy" over Aboriginal and Torres Strait Islander voices has led to abject failure of health services to meet the needs of this group of Australians across the country. The fear of things going wrong during birth and the legal side of medicine has a significant influence on resisting women's wishes to 'birth on country' (in their own communities). As late as 1998, 'birthing on country' was common for Indigenous women. However, over recent years this has changed as health services have closed their birthing services without consideration for the importance of the Indigenous value of birthing close to family, country and culture.

The similarities between the Indigenous populations of Australia and Canada are striking. Both populations face challenges in maternity health care. Research from the *Inuulitsivik Midwifery Service* in Northern Quebec suggests that we should consider translating the successes of 'birthing on country' from the Inuit experience [26,27]. The service covers several discrete communities across a large geographical area in northern Quebec, with on-site birthing centres and competency based midwifery training. Strong referral links remain with tertiary services and when identified as necessary, women, with both their understanding and consent, can be referred to these tertiary services. The first of these services began in 1986 following an escalation in suicides and recognition by the leaders that the community was in crisis [28]. It has proven to be a sustainable model, with excellent outcomes despite being many hours from the nearest surgical (caesarean) services [27]. Based on 3,000 births since opening, the perinatal mortality rate has fallen [29] and a further seven years of data (another 1,388 births) has since been reported and shown a continuation of excellent outcomes and a sustainable service [27]. Several more services have opened in communities that range from 1-2000 in population. Reports from these communities described: improved health care and outcomes; greater social functioning of the community; the building of community relationships and intergenerational support whilst promoting respect for traditional knowledge, both within the local community and with non-local health care providers. A key factor supporting the change process appears to have been the open dialogue and debate around risk in childbirth [30].

The research from northern Canada has shown that childbirth in very remote areas can offer a safe, culturally competent and sustainable alternative to routine transfer of women to regional centres, in spite of initial fears about safety and opposition to these services [27,29,31,32]. With such evidence it is now incumbent upon others where similar Indigenous disadvantage exists to bring about such service reform through the planned introduction of similar models. Culturally appropriate health care requires respect for the choice of community based child birth and may also

challenge the world view of medically trained health workers. The way ahead – ***Aboriginal voices must influence the authoritative knowledge of safe birthing services.***

### **3. Recommendations**

- 3.1 Establish a National Steering Committee to oversee the establishment of culturally sensitive primary maternity centres.
- 3.2 Establish primary maternity centres that include birthing for low risk women in 12 sites (urban, rural and at least 6 remote centres) across Australia, as centres of excellence.
- 3.2 Fund a research and evaluation framework for monitoring these primary maternity centres.

### **4. Healthy food in both urban and remote Indigenous communities**

There is now ample evidence that poor maternal nutrition is associated with poor intrauterine growth and increased risk of diabetes and heart disease for the child in later life, as well as increasing evidence that this also predisposes to kidney disease. This has become even more important when the potential for trans-generational disadvantage through epigenetic change is considered. A growth retarded baby girl carries her eggs already formed in her ovary that are affected by her poor intrauterine environment that will affect their future development and therefore the next generation.

A healthy diet is an essential step for improving health outcomes in mothers and babies. In remote areas of Australia, the high costs associated with transporting fresh healthy food mean that a healthy diet is unaffordable for many people, including Indigenous pregnant women and children. *“A healthy food basket in Cape York costs 30% more than in a major city”*. Providing healthy food at subsidised prices in remote areas would be one strategy towards improved maternal and child health. In addition, economic disadvantage also occurs in urban as well as remote settings and it is important to recognise the need to develop mechanisms that provide low cost but healthy food in these urban environments too. This is highly relevant to the biggest populations of Indigenous people living in urban areas. *“The Aboriginal and Torres Strait Islander population living in Brisbane is approximately 50,000 and rising”*.

Ideally, improving nutrition needs to be made prior to conception but during pregnancy would be a good start. Approaches for educating young Indigenous women on the importance of healthy diet before, during and after pregnancy, are addressed in the above recommendations 1-3.

### **4. Recommendations**

- 4.1 Provide low cost but healthy food in both urban and remote Indigenous communities.
- 4.2 Help young mothers learn how to prevent poor health in their children through improved diet and health literacy programs before, during and after pregnancy.



## **Summary**

The disproportionate level of poor health and disease amongst Australian Aboriginal and Torres Strait Islander people is one of the most unacceptable health issues in Australia.

The 2012 *ASMR Indigenous Health Forum: Better Health Outcomes for Mums and Bubs*, was a timely forum to focus on maternal and child health, which has enormous influence on 'whole of life' and generational health outcomes.

Improving health outcomes for Indigenous people is anticipated to take years, if not generations. Accordingly, the willingness to act on long-term commitments together with careful planning and decisions from both community and Government are vital if we are serious about improving the health and well-being of the future generations of Aboriginal and Torres Strait Islander people.

We have the responsibility to ensure that Government receives clearly articulated and evidence-based advice from Indigenous Australians and leading health advocates. ASMR looks forward to working with the Federal and State Governments, Public Health Leader champions, Indigenous Health Networks and Indigenous communities to progress the implementation of recommendations that will improve health outcomes for Aboriginal and Torres Strait Islander people.

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