



PMSEIC Working Group on Aboriginal and Torres Strait Islander health focusing on maternal, fetal and post-natal health

The health of the adult
begins in the womb

**A report of the PMSEIC working group
April 2008**

“I want to see an Aboriginal baby born today growing up to have the same life opportunities as any other child growing up in this great country of ours.”

The Hon Kevin Rudd MP, Speech on the future of reconciliation - 40th anniversary of the 1967 referendum, 27 May 2007

Cover photo: Edward Billy and Gail Garvey, Coconut Island

Photographer Daphne Cox

This report is about Aboriginal and Torres Strait Islander mothers and babies and we use the term Aboriginal and Torres Strait Islander where possible. However, when referencing particular reports that use the term ‘Indigenous Australians’ in their title we take it to refer to Aboriginal and Torres Strait Islander people.

We are aware that there is some controversy about the use of the word ‘Indigenous’ (because it is very generic), so we use it sparingly.

We always use capital letters for the words ‘Aboriginal’, ‘Torres Strait Islanders’ and ‘Indigenous’, as a sign of respect.

The independent working group is committed to treating Aboriginal and Torres Strait Islander cultures with respect in line with the Cultural Respect Framework for Aboriginal and Torres Strait Islander Health.

This report may contain references or images of deceased persons.

A paper prepared by an independent working group of the Prime Minister’s Science, Engineering and Innovation Council (PMSEIC). The views expressed in this paper are those of the group and not necessarily those of the Australian Government.

TABLE OF CONTENTS

Chair's comments	v
Terms of reference	vi
EXECUTIVE SUMMARY	vii
Recommendations	ix
Introduction	1
CHAPTER 1 THE HEALTH OF THE ADULT BEGINS IN THE WOMB	3
Introduction	3
Maternal nutrition and fetal growth	4
<i>Case Study Fetal Alcohol Syndrome</i>	5
Molecular Genetics some answers may lie in the DNA	6
CHAPTER 2 STATE OF PLAY	9
Risk factors and opportunities for improving maternal and child health	10
Services in relation to maternal, fetal and post-natal health	15
<i>Case Study Healthy for Life</i>	17
Maternity Workforce	18
CHAPTER 3 INVESTING IN THE FUTURE	20
Why research is important	20
<i>Case Study The Case of Dog Scabies</i>	21
Principles in planning a Research Agenda	22
Research priorities in Aboriginal and Torres Strait Islander maternal, fetal and post-natal health	23
<i>Case Study Home Visiting The Case for Evidence</i>	25
How can we address the gaps in evidence?	26
Priorities in capacity building issues to be addressed	27
Translating research into policy and practice	29
CHAPTER 4 CONCLUSION - CLOSING THE GAP	30

APPENDICES	33
APPENDIX 1 Draft principles of a Virtual Centre on Aboriginal and Torres Strait Islander health focusing on maternal, fetal and post-natal health	33
APPENDIX 2 Research (recent, underway or imminent) into Aboriginal and Torres Strait Islander maternal, fetal or post-natal health	35
APPENDIX 3 Working group members	42
APPENDIX 4 Contributors to the report	43
APPENDIX 5 Definitions	44
APPENDIX 6 Acronyms	48
APPENDIX 7 References	49
FIGURES	
Figure 1 The consequences of gestational exposure to an adverse environment	4
Figure 2 Epigenetics	6
Figure 3 Cost range of a basket of groceries in Northern Territory for a fortnight for a family of six	11
Figure 4 Comparison of two full term Aboriginal babies - one with growth restriction, and the other with normal growth	14
Figure 5 Perinatal and Infant Mortality, by Aboriginal and Torres Strait Islander Status of the Mother 1998-2002	15
Figure 6 Building the evidence about Aboriginal and Torres Strait Islander maternal, fetal and post-natal health	23
Figure 7 Summary Principles and Priorities	26
TABLES	
Table 1 Aboriginal and Torres Strait Islander and non-Indigenous population distribution by remoteness category, 2001	2
Table 2 Comparisons of Aboriginal and Torres Strait Islander and Non-Indigenous maternal and infant health	10
Table 3 Australian comparisons with low birth-weight estimates in world regions	14

CHAIR'S COMMENTS

This PMSEIC Working Group was tasked to describe the current status of maternal, fetal and post-natal health of Aboriginal and Torres Strait Islanders; discuss the role and rationale for research; consider/assess the organisation of research resources and suggest mechanisms to translate research to improve the health and build Aboriginal and Torres Strait Islander research capacity.

In preparing the report and presentation, members were very diligent and many robust discussions were had around the table. I thank my Deputy Chair, Professor Cindy Shannon, all the members of the Working Group and the Secretariat for their commitment and hard work.

On behalf of the Working Group, I thank the Aboriginal and Torres Strait Islander people who have contributed to the discussions and note, as highlighted in this report, that further consultation is required.

I would also like to thank the many people who assisted the Working Group in preparing the report and presentation. Your experience and wisdom have contributed greatly.

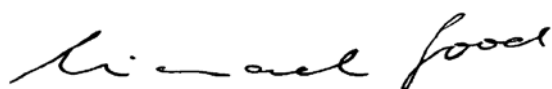
The Working Group, along with the peer reviewers and other contributors, were looking for a practical way forward. This report identifies immediate actions to reduce the gap in maternal and infant mortality, emphasises the need for research that makes a difference and recommends that a dedicated Virtual Centre be established that can translate research into practical tools and solutions and assist in the setting of targets for Aboriginal and Torres Strait Islander health care. We believe that with this action it will be possible within 10 years to halve the gap that currently exists between the health of Indigenous and non-Indigenous Australians.

All Australians should recognise that the wellbeing of Aboriginal and Torres Strait Islanders needs to be comparable to that of other Australians. The future for Aboriginal and Torres Strait Islander children should be as bright as that of non-Indigenous children.

I commend this report to the Prime Minister, Cabinet and the Prime Minister's Science, Engineering and Innovation Council.

*"Past sorrows let us moderately lament them
For those to come seek wisely to prevent them"*

John Webster's The Duchess of Malfi, 1616



Michael Good

Chair, PMSEIC Working Group on Aboriginal and Torres Strait Islander Health
focusing on maternal, fetal and post-natal health

TERMS OF REFERENCE

1. Describe the current status of the maternal, fetal and post-natal health of Aboriginal and Torres Strait Islanders and key associated risk factors relative to the non-Indigenous population and Indigenous groups elsewhere.
2. Discuss the role and rationale for health/scientific research and evidence-based strategic action in improving the health of Aboriginal and Torres Strait Islander mothers and their newborns.
3. Consider/assess the existing organisation of research resources and coordination mechanisms in Aboriginal and Torres Strait Islander health (including social as well as basic population health) and the effectiveness of such organisation.
4. Suggest mechanisms to best implement and translate current and future research and evidence into improved maternal, fetal and post-natal health outcomes.
5. Suggest how best to build Aboriginal and Torres Strait Islander research capacity in this area of science.



Executive Summary

Aboriginal and Torres Strait Islanders are the first peoples of Australia. Health and socio-economic indicators clearly demonstrate that Aboriginal and Torres Strait Islanders are disadvantaged and that this has inhibited their full participation in the enjoyment of Australia's prosperity as a leading developed nation.

This report identifies exciting new knowledge and key opportunities for overcoming that disadvantage through a novel focus on the core of our next generation – the mother and the developing child.

The Health of the Adult Begins in the Womb

Maternal illness, poor diet and exposure to toxins adversely affect the health of the growing fetus and can have long term consequences into childhood and adult life. The social, emotional and physical environment in the early years of life also has a significant impact on health in later years.

Recent developments in our understanding of the biology of the fetus and young infant are enabling us to unravel causal pathways that explain why a healthy start to life is absolutely essential for a lifetime of good health. In particular, epigenetics may explain how the environment in the womb and in the early years can modify the genetic blueprint and set life on a different health course. Harnessing this new knowledge should lead to significant improvements in the health of all Australians and in particular those who are socially disadvantaged.

This has particular relevance for Aboriginal and Torres Strait Islander people, in whom deleterious environmental factors during pregnancy and early life (resulting in low birth-weight and poor health outcomes in young infants) are likely to contribute to the high rates of chronic disease and early death.

The State of Play

Some gains have been made in this area, but significant disadvantage remains.

Mothers

- Five percent of total births registered in Australia during 2005 had at least one parent of Aboriginal or Torres Strait Islander origin.
- 22.7 per cent of all Aboriginal and Torres Strait Islander mothers are teenage mothers, compared with 3.9 per cent of non-Indigenous mothers.
- Aboriginal and Torres Strait Islander mothers are more likely to smoke during pregnancy and five times more likely to die around the time of delivery.

Babies

- Compared to non-Indigenous babies, Aboriginal and Torres Strait Islander babies are:
 - three times as likely to die before their first birthday
 - twice as likely to be of low birth-weight
 - almost three times as likely to suffer from fetal growth restriction, and
 - almost twice as likely to be born preterm.

With respect to health services, Aboriginal and Torres Strait Islander mothers and babies have:

- Poor access to, and uptake of, antenatal care
- Lack of options for safe, culturally appropriate birthing, and
- Fragmented care during pregnancy, the delivery and the post-natal period.

Investing in the Future

There are three ways in which science and innovation can contribute to improving the health of Aboriginal and Torres Strait Islander mothers and babies:

- Develop and implement a research program that will improve our understanding of the link between early life experiences and later health outcomes
- Invest in evidence-based health interventions, and therefore invest in research to provide a better evidence-basis for existing and new interventions, and
- Improve the capacity of research institutions, health services and Aboriginal and Torres Strait Islander communities to develop and implement successful research programs and to translate the evidence into policy and practice.



RECOMMENDATIONS

The Working Group concludes that immediate action is required to address the risk factors for poor maternal and infant health in parallel with high quality research that will underpin an evidence-based response. We make the following recommendations:

Recommendation 1 – Immediate Action

Steps must be taken to close the gap in infant and maternal mortality and low birth weight in Aboriginal and Torres Strait Islander communities by 50 per cent within the next 10 years.

This will require a concerted national program to address the major risk factors prevalent in the community which adversely impact on the health of the mother and her baby.

Immediate action needs to be taken to address poor nutrition, smoking and alcohol as the major risk factors.

This will require an inter-sectoral approach by all levels of government. The following specific actions are required:

Nutrition

- Ensure access to healthy food at affordable prices.
- Deliver educational and promotional programs on healthy eating and cooking.

Smoking

- Develop innovative approaches to programs targeting Aboriginals and Torres Strait Islanders, for example: the Quit program adapted to Aboriginals and Torres Strait Islanders.
- Deliver culturally appropriate images and messages used in promotional materials.

Alcohol

- Investigate the extent and consequences of binge drinking during pregnancy.
- Implement a culturally appropriate and nationally coordinated education program to prevent alcohol consumption during pregnancy.
- Determine the prevalence of Fetal Alcohol Syndrome, which is largely under-diagnosed, and develop an inter-sectoral response.

Recommendation 2 – Research that Makes a Difference

In recent years, there has been an upheaval in the way we think about the biological mechanisms underlying healthy development of the fetus. Australia leads the world in this research.

It is important and timely that these new developments in basic and clinical research connect with existing population-based research to improve the maternal and fetal health of Aboriginals and Torres Strait Islanders.

At the same time, there are still major gaps in the basic demographics of Aboriginal and Torres Strait Islander health that need to be addressed.

We recommend that a Virtual Research Centre of Aboriginal and Torres Strait Islander Maternal and Child Health is established to:

- Harness the very best and new research in Australia to improve Aboriginal and Torres Strait Islander maternal, fetal and post-natal health.
- Coordinate, monitor, evaluate and translate research into policy and practice.
- Improve national surveillance and provide regular reports on trends and outcomes in maternal and infant health.
- Build national workforce capacity in Aboriginal and Torres Strait Islander health and research.
- Develop evidence-based clinical guidelines relevant to conditions affecting maternal and fetal health.

Appendix 1 provides further information on the Centre.

Recommendation 3 – Consultation

While the Working Group has consulted with stakeholders, broader consultation is required. We therefore recommend that the NHMRC, in partnership with relevant community organisations, conducts a national consultation process about the establishment of the Virtual Centre. Aboriginal and Torres Strait Islander communities are critical stakeholders in this process.

Introduction

Australia's national wellbeing depends on the health of our people, our society and our economy.

Health and socio-economic indicators clearly demonstrate that Aboriginal and Torres Strait Islanders are disadvantaged. This report identifies new knowledge and key opportunities for overcoming this disadvantage by focusing on the next generation – the mother and the developing child.

Some notable improvements in the health of Aboriginal and Torres Strait Islander mothers and children have been achieved in recent years, in particular fewer instances of missed antenatal care, lower birth-weight babies, and infant deaths. However, a significant and unacceptable gap still exists with many indicators still two to three times worse than rates for other Australians.

Evidence shows that factors affecting child development – before, during and after pregnancy – have a sustained effect throughout the life of that child and into adult years.⁹ New research is beginning to show how interactions between our genes and our early environment can influence our health for life. Better understanding of these interactions will enhance our ability to explain the reasons behind ill health, and to develop culturally responsive programs aimed at the causes.

Across the world, health outcomes improve as individuals move up the socio-economic gradient in housing, employment and education. Improvements in all of these factors are required to prevent an intergenerational transfer of disadvantage in health among Aboriginal and Torres Strait Islanders. Providing excellent health care for mothers and children and ensuring an environment in which children are safe and can learn, are fundamental and indeed are the essential first steps in closing the gaps in health outcomes.

Health systems need to be re-engineered, and consumers, health services, researchers and policy makers need to be involved in innovation to ensure that Aboriginal and Torres Strait Islander children receive the benefits available to Australians generally.

Science must be focussed and coordinated in partnership with communities to translate research into effective programs. This report seeks to demonstrate how that can be achieved.

It is important to note that the distribution of the Aboriginal and Torres Strait Islander population raises issues of access to services and the health workforce. Table 1 shows that a significant proportion of the total population live in major urban areas. However, it should also be noted that there is an over-representation of Aboriginal and Torres Strait Islanders in some remote and very remote areas.

Table 1 | Aboriginal and Torres Strait Islander and non-Indigenous population distribution by remoteness category, 2001^b

	Non-Indigenous	Indigenous	Indigenous as a % of regional population	Indigenous as a % of total Aboriginal and Torres Strait Islander population
Major city	12,732,492	138,494	1.1	30.2
Inner regional	3,932,907	92,988	2.3	20.3
Outer regional	1,907,688	105,875	5.3	23.1
Remote	284,160	40,161	12.4	8.8
Very remote	97,473	81,002	45.4	17.7
Total	18,954,720	458,520	2.4	100.1*

* Due to rounding



Chapter 1

CHAPTER 1 | THE HEALTH OF THE ADULT BEGINS IN THE WOMB

“The healthy future of society depends on the health of the children of today and their mothers, who are guardians of that future”

The World Health Organisation Report 2005 – Make Every Mother and Child Count

Fast facts:

- The fetus adapts to challenges in the womb but these adaptations can result in poor health outcomes for the baby.
- There are lifetime consequences of poor fetal development.
- The environment in which the fetus grows can affect whether certain genes are active or inactive. These ‘epigenetic’¹ changes are likely to underlie the fetal adaptations and subsequent poor health.

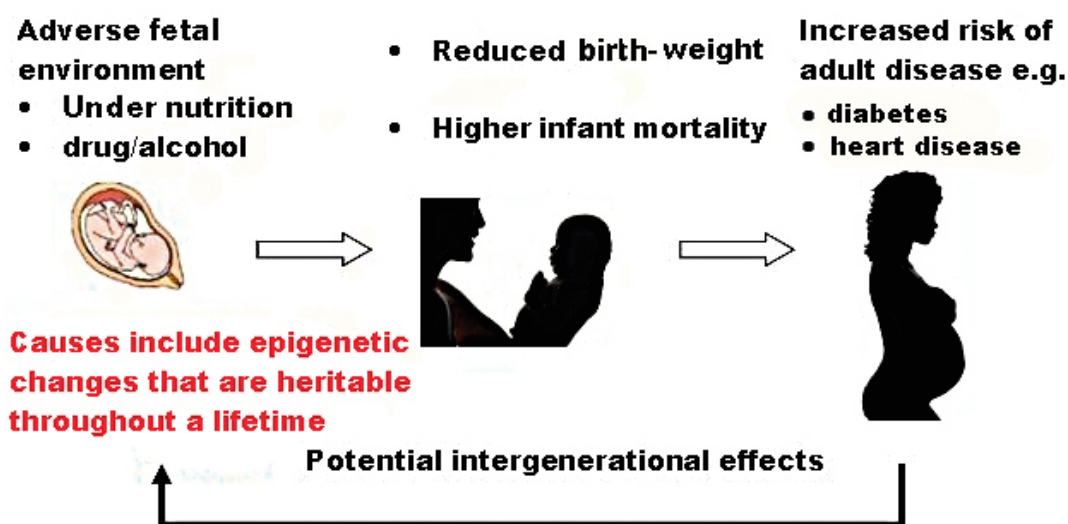
Introduction

We know that maternal health, diet and exposure to toxins affect the health of the growing fetus and can have long term consequences on childhood and adult life. Recent developments in our understanding of fetal physiology and genetics, in particular epigenetics, are enabling us to unravel potential causal pathways which explain why a healthy start to life is essential for a lifetime of health. Harnessing this new knowledge should lead to significant improvements in the health of all Australians and in particular those who are socially disadvantaged.

There is now increasing evidence of the relationship of poor intrauterine growth to chronic disease later in life. Numerous studies have found that low birth-weight is associated with coronary heart disease, stroke, hypertension, type 2 diabetes, insulin resistance and dyslipidaemia (abnormal fat profiles that can lead to heart attacks and strokes),^c in the adult, see Figure 1. This has particular relevance for Aboriginal and Torres Strait Islander people because of the high prevalence of low birth-weight babies and the current high rates of chronic diseases such as coronary heart disease and type 2 diabetes which contribute significantly to their shortened life expectancy.^d

¹ Epigenetics is the study of molecules involved in turning genes on or off

Figure 1 | The consequences of gestational exposure to an adverse environment



Maternal nutrition and fetal growth

The relationship between maternal nutrition, fetal nutrition and growth is complex.

International research shows that if you are born too small and gain excessive weight in childhood you are at significant risk of developing cardiovascular disease and diabetes later in life. It has been suggested that in small babies, post-natal growth acts to restore infant size back towards their genetic growth trajectory by the age of two. Infants who are growth restricted in fetal life and show early catch up growth tend to have a higher Body Mass Index (BMI), fat mass and truncal fat distribution later in life.^e

Research needs to be undertaken to investigate how these environmental factors before birth influence the onset of adult disease in the Aboriginal and Torres Strait Islander community. This could lead to cost-effective preventive strategies being implemented – the earlier the interventions occur the more likely they are to be effective (see Figure 1). Compromised adult health might, in turn, affect the next generation (i.e. set up an intergenerational cycle of poor health) through biological and societal pathways.

Exposure of the fetus to high levels of alcohol or other drugs can also result in abnormal development of the brain and mental health problems, which persist into adulthood^f (see Case Study – Fetal Alcohol Syndrome). These findings have changed the way we think about the ability of the human baby to overcome past adversity; our biology retains a memory of early insults, in some cases forever.

Case Study | Fetal Alcohol Syndrome

Exposure to alcohol in the womb can cause stillbirth, miscarriage and a spectrum of abnormalities in the unborn child, known as fetal alcohol syndrome.^g Fetal alcohol syndrome may include abnormalities of brain function, impaired growth (including after birth), a specific pattern of facial characteristics and developmental delay. Physical, behavioural and mental health problems persist into adulthood but the risk of adverse outcomes is reduced by early diagnosis.^h

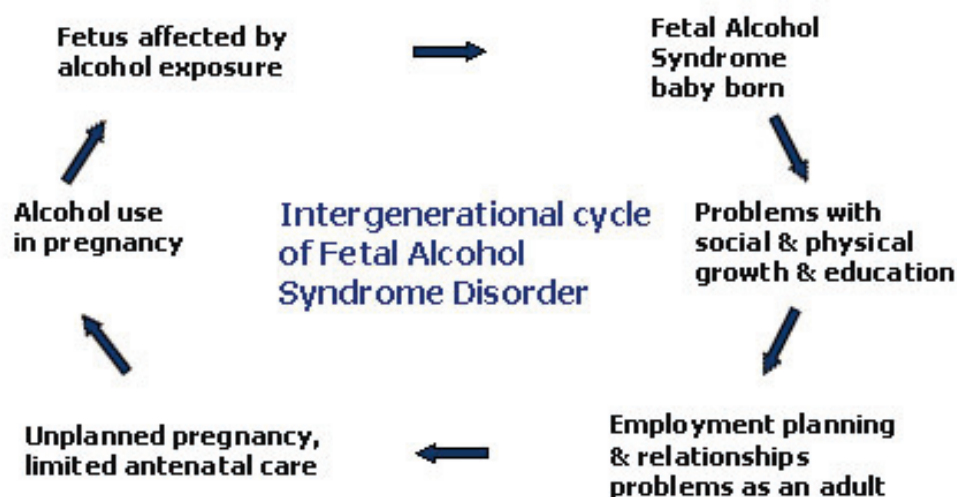
No 'safe' limit for alcohol consumption during pregnancy has been established

A 'safe' lower limit for alcohol consumption has not been established for these outcomes.ⁱ The draft Australian Alcohol Guidelines for Low-Risk Drinking released in October 2007 state that for women who are pregnant, hoping to become pregnant or breastfeeding, the safest choice - based on scientific evidence - is not to drink alcohol.^j

State of Play with Fetal Alcohol Syndrome in Australia

It is likely that many fetuses are inadvertently exposed to alcohol during early pregnancy: rates of drinking at risky levels are increasing in Australian women of child-bearing age; up to 80 per cent report drinking in the three months before pregnancy, and 14 per cent report binge drinking during pregnancy.^k In a recent national study of fetal alcohol syndrome, Aboriginal and Torres Strait Islander children were over-represented, many children were in out-of-home care and many had an affected sibling, suggesting missed opportunities for prevention.^l There is also data to suggest that fetal alcohol syndrome is under-diagnosed and that health professionals do not know what to advise regarding alcohol use in pregnancy.^m

Intergenerational cycle of Fetal Alcohol Syndrome



Although the concept of early life events affecting later health and disease is now well established, the mechanisms involved are still not clear. We know that when fetal nutrition is poor survival is enhanced by limiting the physical growth of the fetus, accompanied by a sparing of brain development and growth. This occurs through dynamic physiological processes involving enzyme systems and endocrine factors which redirect the blood supply away from abdominal and musculo-skeletal systems to the brain. These adaptations lead to permanent structural and physiological effects that may be the underlying cause of disease in later life. These permanent adaptations are achieved through a range of mechanisms including epigenetic changes but further research is needed.

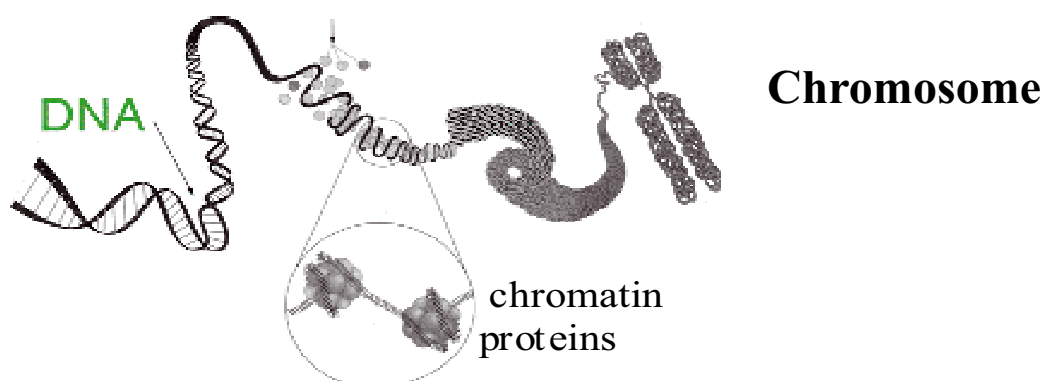
Molecular Genetics | some answers may lie in the DNA

Variations in genetic make-up may exacerbate the effects of the intra-uterine environment.⁹ There may be correlations between specific genes and susceptibility to environmental exposures in utero. In the future, DNA analysis may provide opportunities for personalised health care.

Recently it has been shown that the environment of the early embryo can alter development by modifying the DNA. These changes are referred to as epigenetic changes (see Figure 2). Such changes can last for the life of the individual and may even be passed onto subsequent generations. Animal studies have shown that changes to maternal diet (e.g. increased folate, vitamin B12) can influence the epigenetic makeup of the developing fetus, leading to permanent changes to the adult.⁹ Through this mechanism, adversity during the adult life of the parent may program future adversity for the child.

Figure 2 | Epigenetics

DNA is packaged by chromatin proteins to form chromosomes. These proteins switch genes on and off. Thus changes to these proteins can affect the way your genetic blueprint is expressed. These changes can have long term health consequences.



Epigenetics | a new field of science

The field of epigenetics is only just developing and we need to understand more about the basic principles of how and when these epigenetic marks are established during development. The simplest way to do this is to use animal models. Physiologists and molecular biologists studying these events in animals have the ability to interrogate cause and effect. These findings can then be translated to the human situation. For example, one can feed a pregnant mouse a modified diet in a controlled way and measure the effects on offspring (birth-weight, weight trajectories, behaviour, blood pressure etc). The animals are all genetically identical, reducing the confounding effects of genotypic differences.

The role of epigenetics in human embryonic development

In general, humans differ from one another with respect to their genetic make-up; we are each genetically unique. The only exception to this is monozygotic (MZ) twins. MZ twins arise from one fertilised egg (one egg and one sperm) that splits into two separate embryos within the first few days of its existence. Interestingly, MZ twins are often not physically identical to one another. Indeed numerous cases of discordance have been reported for height, foot size, body weight, IQ, and various congenital abnormalities.^p A recent study of a pair of MZ twins, in which one twin had a birth defect and the other did not, identified differences in epigenetic modifications as the possible cause of the discordance.^q Similarly, two independent studies using larger cohorts of MZ twins have found significant within-twin pair differences in epigenetic marks.^r These findings are consistent with the theory that environment contributes to the epigenetic profile and, in turn, the physical traits of humans.

New methods are being developed that will allow us to see the pattern of epigenetic modifications across the entire genome (all the genes of any individual). It is hoped that within the next five years we will have the capacity to obtain unique epigenetic profiles for any individual relatively simply and cheaply. This will enable us to understand much more about the role of epigenetics in humans.

Ultimately, we should be able to use this information in a predictive manner: the genetic and epigenetic signatures will inform us about an individual's risk of developing particular diseases as an adult.

Epigenetics may also help us understand the observed social inequalities in health outcomes across many diseases. How does social disadvantage influence so many different diseases from infections to diabetes, heart disease and mental illness? It may be that the stress pathways, mediated via the hypothalamic-pituitary-adrenal axis and which affect most body organs and systems, begin their influences in utero by influencing gene expression. Whilst excessive stress, such as that associated with domestic violence, insecure living conditions and very young teenage pregnancy, is more common in Aboriginal and Torres Strait Islander situations, it is also relevant and very important in any disadvantaged group.^s

Research Gaps

- How to break the intergenerational cycles of poor health.
- The mechanisms through which the interaction between poor prenatal and rapid post-natal growth lead to adverse outcomes.
- The roles of nutrient-gene interactions in ensuring a healthy start to life.



Chapter 2

CHAPTER 2 | STATE OF PLAY

“The health statistics reflect children who do not have the same chance at life as their non-Indigenous friends.”

Tom Calma, Aboriginal and Torres Strait Islander Social Justice Commissioner,
Human Rights and Equal Opportunity Commission at the Menzies School of Health Research 2007 Oration Darwin,
8 November 2007

Fast facts:

- There were 12,100 births registered in Australia during 2005 with at least one parent of either Aboriginal or Torres Strait Islander origin, accounting for five per cent of total births (whereas Aboriginal and Torres Strait Islanders make up 2.5 per cent of the Australian population).
- Aboriginal and Torres Strait Islander infants are three times as likely to die before their first birthday as non-Indigenous infants.
- Despite improvements, Aboriginal and Torres Strait Islander low birth-weight rate (birth-weight <2,500 grams) and preterm birth rates remains double that for non-Indigenous Australians; outlined in Table 2.
- Aboriginal and Torres Strait Islander newborns are more than twice as likely to have fetal growth restriction as non-Indigenous newborns. This is illustrated in Figure 4.
- Maternal mortality is five times higher for Aboriginal and Torres Strait Islander mothers; 46/100,000 compared with 9/100,000 for non-Indigenous mothers.

Table 2 provides key statistics for maternal and infant health.

Table 2 | Comparisons of Aboriginal and Torres Strait Islander and Non-Indigenous maternal and infant health

Maternal	Aboriginal and Torres Strait Islander	Non-Indigenous	Source *
Fertility rates ^t	2.1 /1,000	1.8 /1,000	National 2005
% Teenage pregnancy ^u	23	4	National 2003
% Smoking during pregnancy ^v	51	17	Five jurisdictions 2006
% with first antenatal visit after 20 weeks ^w	22	13	NSW 2000
% receiving intervention at birth ^x	29	41	National 2005
Maternal Mortality ^y	46 /100,000	9 /100,000	National 2000-2002
Infant	Aboriginal and Torres Strait Islander	Non-Indigenous	Source *
Mean birth-weight (grams) ^z	3,162	3,381	National (excluding Tasmania)
% Low birth-weight ^{aa}	13	6	National (excluding Tasmania) 2001-2003
% Fetal growth restriction ^{ab}	27	10	NT 1987-1990
% Preterm ^{ac}	12.3	5.8	National 2001-2003
Perinatal mortality ^{ad}	13.4 /1,000	8.2 /1,000	Four jurisdictions 2002-2004
Infant mortality ^{ae}	12.2 /1,000	4.4 /1,000	Four jurisdictions 2000-2004
Sudden Infant Death Syndrome (SIDS) mortality ^{af}	1.3/1,000	0.3/1,000	Four jurisdictions 2000-2004

Aboriginal and Torres Strait Islanders identification is incomplete in all states and territories. Only four jurisdictions (Queensland since 1998, Western Australia, South Australia and Northern Territory) are assessed as having adequate identification in terms of the indicators of relevance to this report. This is of continuing concern. Hence national figures and trends in this regard are likely to be under-estimated (see definitions in Appendix 5).

Risk factors and opportunities for improving maternal and child health

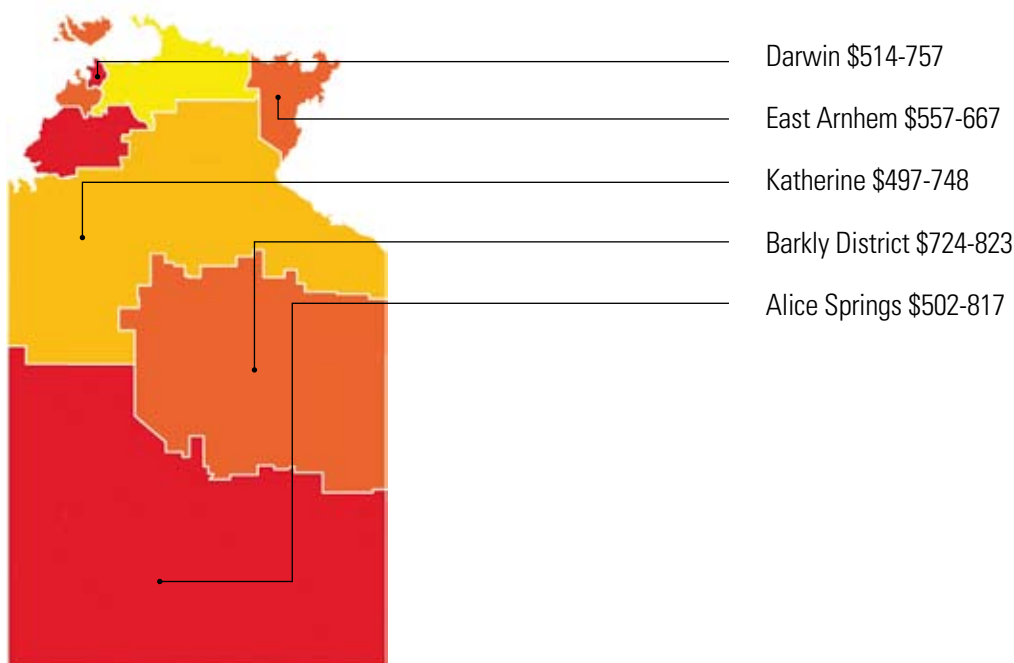
A continuum of factors prior to conception affect physical, maternal and child health and wellbeing

Underpinning maternal and child health are biological, psychological and social factors that are interconnected and intergenerational. Prior to conception, the health and wellbeing of an individual develops in response to a continuum of these factors occurring over the life course. Opportunities for intervention exist throughout life. However, because of the permanent changes brought about by experiences in the womb and during the first few

years of life (see CHAPTER 1 | the health of the adult begins in the womb), interventions made prior to conception, during fetal life and in early childhood will have the most long-lasting effects.

The life long impacts of maternal nutrition shown in Chapter 1 emphasize the need to address maternal nutrition well before child bearing commences. Data from the Northern Territory in 2007 for children less than 5 years of age in rural and remote areas show 14 per cent of children are underweight compared to the expected 2.3 per cent population distribution.^{ag} At 11 years of age, which is an important time for adequate nutrition immediately prior to reproduction, a study in the Darwin Health Region showed 10 per cent of children were underweight^{ah} with a marked urban–rural differential (2 per cent versus 13 per cent). In the same region 15 per cent of mothers were classified as undernourished immediately after delivery of their baby.^{ai} In this regard it is worth noting that there is often poor access to healthy food at affordable prices in Aboriginal and Torres Strait Islander communities (see Figure 3 for the range in price for a basket of groceries in Northern Territory).

Figure 3 - Basket of groceries in the Northern Territory | Cost range for a family of six for a fortnight^{aj}



Apart from nutrition, other community factors have an important impact on potential parents prior to conception. Infant mortality rates fall with the increasing education of parents, particularly of mothers.^{ak}

Data from Townsville suggests that many Aboriginal and Torres Strait Islander women who smoke tobacco (60 per cent), report using alcohol at hazardous or harmful levels at the first antenatal visit (15 per cent),^{al} that 1

in 10 pregnancies are unwanted, and that 1 in 8 women experience domestic violence. Good antenatal care can lead to the modification of smoking behaviour, treatment of medical conditions, early identification of high risk pregnancies and empowerment about birth options. All of these factors contribute to improved health outcomes. Many Aboriginal and Torres Strait Islander women value cultural and spiritual aspects of care highly. The separation from land, language, culture and family during birth can be distressing and affect use of services and result in poor health outcomes.^{am}

Members of 'at risk' families tend to have a cluster of features that are predictable: poor attendance at antenatal care; worse perinatal outcomes; socioeconomic disadvantage and adolescent or itinerant mothers.^{an} Established risk factors, particularly poor nutrition, smoking and alcohol need to be emphasised and managed antenatally, and many mothers do make changes when pregnant in response to antenatal care.^{ao} A number of antenatal care services have been successfully established for Aboriginal and Torres Strait Islander women using a team approach with a midwife or doctor and Aboriginal Health Workers working together.

Some of these services include Congress Alukura, Daruk Antenatal program, Northern Women's Community Health Centre, the New South Wales Aboriginal Maternal Infant Health Strategy, Northern Territory Strong Women, Strong Babies, Strong Culture Program, Ngunytyju Tjitji Pini in Kalgoorlie and Townsville Aboriginal and Islander Health Service Mums and Babies Program.^{ap}

The health of the mother

In 2001–2004, compared with non-Indigenous mothers, Aboriginal and Torres Strait Islander mothers:^{aq}

- were younger—mean age of 24.8 years compared with 29.7 years
- were much less likely to give birth in private hospitals—3 per cent compared with 32 per cent
- had a higher proportion of spontaneous onset of labour—70 per cent compared with 57 per cent
- had a lower proportion of induced labours—17 per cent compared with 26 per cent
- were less likely to have a caesarean section—22 per cent compared with 28 per cent, and
- were three times as likely to have smoked during pregnancy—51 per cent compared with 17 per cent.

In addition, there are a number of medical conditions in pregnancy that impact on Aboriginal and Torres Strait Islander fetal and post-natal outcomes at greater rates than other Australians. For example, anaemia has been reported in a number of Australian studies of Aboriginal and Torres Strait Islander pregnancy, with prevalence rates varying from 26 per cent to 34 per cent^{ar as} suggesting that nutrition may be compromised in Aboriginal and Torres Strait Islander women. Neural tube defects are more common in Aboriginal and Torres Strait Islander women^{at} and folate supplementation has been shown to reduce the prevalence of neural tube defects.^{au} The prevalence of sexually transmitted infections varies across regions, but has been linked with poor perinatal outcomes in Western Australia and Queensland. Rates of diabetes in women of child bearing years are as high as 20 per cent in some Aboriginal and Torres Strait Islander communities.^{av}

A study in the Darwin Health Region provides evidence of the disproportionate rates of medical conditions among Aboriginal and Torres Strait Islander women:

- 63 per cent of mothers had one or more medical conditions
- More than a quarter were anaemic, and
- A fifth had a urinary tract infection, or evidence of genital infection.^{aw}

Social and emotional wellbeing

In 2001–2004, Aboriginal and Torres Strait Islander mothers living in areas of greater disadvantage had more babies than those living in more advantaged areas.^{ax} The relative socio-economic disadvantage experienced by Aboriginal and Torres Strait Islander people compared with non-Indigenous people place them at a greater risk of exposure to behavioural and environmental risk factors.^{ay} This increased risk impacts on the individual, family and communities social and emotional wellbeing. A project conducted by *Beyond Blue* on post-natal depression amongst Indigenous mothers found that “High levels of ‘daily hassles’, problems in the family, history of depression and emotional problems, financial insecurity, major life events, a history of physical and emotional abuse, relationship problems with a current partner, were significantly related to increased risk of peri-natal depression”.^{az} The prevalence of gestational diabetes and hypertensive disorders of pregnancy in the Aboriginal and Torres Strait Islander population is higher than that amongst non-Indigenous women.

In the Western Australia Child Health Survey, one in four children were living in families with poor quality parenting. These children were four times more likely to be at high risk of behavioural or emotional difficulties. Over a third of children were cared for by a sole parent and this was also identified as a risk factor for a high risk of emotional or behavioural difficulties.^{ba}

The prevalence of gestational diabetes and hypertensive disorders of pregnancy in the Aboriginal and Torres Strait Islander population is higher than that amongst non-Indigenous women. Both of these conditions can alter the growth trajectory for these babies. Data for psychosocial stressors, and post-natal depression is lacking with some work from the *Beyond Blue* initiative due soon.

Mental health of the mother

There are limited programs specifically designed for treating mental illness in Aboriginal and Torres Strait Islander women during the perinatal period. Current assessment tools used for diagnosing depression during and after pregnancy have not been validated for a remote population where English is not the first language. The latest maternal deaths report supports this, describing three women who committed suicide in early pregnancy. This reflects the higher rates of distress and suicide in Aboriginal and Torres Strait Islanders.^{bb}

Low birth-weight rates

Low birth-weight is important as it can lead to cardiovascular and metabolic disease later in life. Low birth-weight babies may be small due to early birth (preterm) or small because of poor intrauterine growth (fetal growth restriction, see Figure 4). When low birth-weight rates are over 10 per cent it is predominantly due to fetal growth restriction.^{bc}

Accurate gestational age estimations are needed to avoid the common misclassification of babies whose growth was restricted in fetal life being categorised as preterm births. Such growth restricted babies may weigh more than 2,500 grams and hence not be classified low birth-weight. In a prospective study in the Northern Territory using Australian birth-weight for gestational age reference standards and careful post-natal gestational assessment, 25 per cent of Aboriginal newborns were classified as being restricted in fetal life compared to the 10 per cent expected for non-Indigenous Australians.^{bd}

An example of fetal growth restriction can be seen in Figure 4

Figure 4 | Comparison of two full term Aboriginal babies - one with growth restriction, and the other with normal growth

Causes of fetal growth restriction:

- Maternal undernutrition
- Smoking
- Teenage pregnancy
- Alcohol and other drugs
- Maternal health and infection



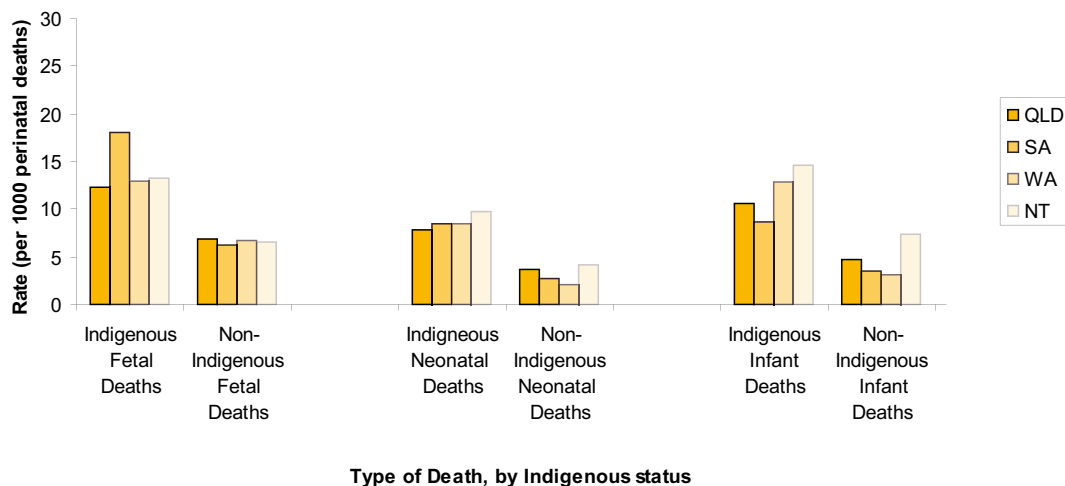
Table 3 compares Aboriginal and Torres Strait Islander birth-weight outcomes with other regions in the world.

Table 3 | Australian comparisons with low birth-weight estimates in world regions^{be}

World regions	% of infants with low birth-weight (less than 2,500g)
Non-Indigenous Australians	6.1
Industrialised countries	7
Aboriginal and Torres Strait Islanders	13
Developing Countries	16
Least developed countries	19
World	15

Figure 5 compares Aboriginal and Torres Strait Islander fetal, neonatal and infant deaths with that of non-Indigenous Australians.

Figure 5 | Perinatal and Infant Mortality, by Indigenous Status of the Mother 1998-2002^{bf}



Services in relation to maternal, fetal and post-natal health

Many societal issues affect the capacity of individuals to make informed decisions about becoming pregnant. These include differences in gender norms regarding sexual behaviour and its negotiation, and peer pressure on adolescent decision-making.^{b9} The benefits of pregnancy planning and preconception care include improved folate status and abstinence from smoking and alcohol consumption. This leads to a decrease in the prevalence of birth defects and increases in the number of babies born with acceptable birth-weight.^{bh} There is considerable scope to develop and deliver culturally appropriate education programs in relation to pregnancy planning and contraception in Aboriginal and Torres Strait Islander communities.

Maternal, birthing and infant health services are core features of universal health services in Australia. They vary across urban, rural and remote settings. Typically, the services are organised around antenatal, birthing, post-natal and early childhood periods, and generally require mothers and infants to visit institutional settings. Despite the availability of hospital and antenatal services in the cities and towns, barriers to access remain.^{bi}

Service provision is highly dependent upon factors such as funding levels, composition, size and skill level of the workforce, infrastructure available to support such programs and linkages with other providers such as community health centres and maternity hospitals. Some centres may have a community based midwifery and/or an Aboriginal Medical Service. However, in more remote areas, antenatal and post-natal services around the birth are often only available via a plane journey or long drive away from home, in unfamiliar surroundings with limited family support, and with cultural and social dislocation. Data from Queensland shows that 23 per cent of the Aboriginal and Torres Strait Islander mothers were transferred for delivery while 3 per cent of non-Indigenous mothers were transferred. Of the Aboriginal and Torres Strait Islander mother transfers, less than 20 per cent were for medical reasons.^{bj}

Recently, the Department of Health and Ageing has invested in a new approach to improving primary health care for Aboriginal and Torres Strait Islander people, including a particular emphasis on maternal and child health (see Case Study – *Healthy for Life*). The *Healthy for Life* program illustrates how a research-based intervention can be implemented in a service setting, from research synthesis, to dissemination, implementation and measurement of impacts.

Case Study | *Healthy for Life*

Healthy for Life requires service providers to undertake an assessment of current client population needs, and an extensive 'stock-take' of existing model/s of care and systems of service delivery. This establishes a base-line against which to measure progress and a platform for re-design or enhancement of the service delivery model. Service providers use the information obtained through the 'stock-take' to develop their own model of child and maternal health care and associated action plans.

***Healthy for Life* targets include:**

- An increase in first attendance for antenatal care in first trimester (in 1-4 years)
- An increase in mean birth-weight to within 200g of the non-Indigenous population (in 5-10 years)
- A decrease in incidence of low birth-weight by 10 per cent (in 5-10 years), and
- A reduction in selected behavioural risk factors in pregnancy (e.g. smoking, harmful alcohol intake and others) in pregnancy by 10 per cent (in 5-10 years).

An example of *Healthy for Life* in action: Wellington Aboriginal Corporation Health Service Inc (WACHS)

Wellington Aboriginal Corporation Health Service Inc (WACHS), located in western New South Wales, has participated in the *Healthy for Life* Initiative since 2006 and since the formulation and implementation of its *Healthy for Life* Action Plan, a range of quality improvement and service activities have been introduced up to September 2007. For example:

- Maternal and antenatal health protocols have been reviewed and updated
- Data collection processes have improved, and patient information and recall software is currently being upgraded to improve tracking of antenatal care
- Workforce development has occurred and staff trained in the use of patient management systems
- Services have been widely promoted in the community, and
- Barriers to service access have been overcome through the provision of transport and expansion of the antenatal clinic times.

This case study illustrates the complete cycle of research transfer supported by the *Healthy for Life* program, from research synthesis, to dissemination, implementation and measurement of impacts.

For more information on *Healthy for Life* go to www.health.gov.au/healthyforlife

The active engagement of men increases their ability to parent confidently^{bk}

Although there are some gender related cultural constraints to males actively participating in the specific “women’s” business, elements of child and maternal health, the active participation and engagement of males as partners in antenatal programs is welcome. Some Aboriginal and Torres Strait Islander Health Services have actively conscripted male partners in programs, as the key support person for their partner in the maternal health program. This serves to both educate the male partner in key issues such as parenting skills, but also to promote a healthy environment for the mother. This includes supporting the female to cease smoking and avoid alcohol and encourage and support good nutrition during the pregnancy.

The home environment of the mother is possibly the most influential aspect of encouraging and supporting positive lifestyle behaviour for the duration of the pregnancy and for early childhood. All aspects of modifying unhealthy lifestyles need to be proactively addressed including educating the male partner in supportive measures for a healthy neonate. The role of the father is obviously important in influencing a healthy childhood environment for growing infants.

Discontinuity of post-natal care

After birth, women are generally advised to present to a local primary health care services for a post-natal check, and for regular child health checks, which are often organised around the immunisation schedule. Instead of being a continuum of care, all too often birth marks a disjunction between services, service providers, records and facilities. Poor communication between the hospital and health centres regarding discharge information can leave the primary caregivers without the information needed to provide the most appropriate care.^{bl}

Maternity Workforce

An accessible, competent and culturally appropriate health workforce is vital to ensuring that the health system has the capacity to provide culturally safe services that are receptive to the diverse needs of Aboriginal and Torres Strait Islander mothers and babies. Whilst the existing Aboriginal and Torres Strait Islander Health Workforce National Strategic Framework has made attempts to reform and consolidate the health workforce, more specific targeted strategies are required with a focus on the maternity workforce.

Aboriginal and Torres Strait Islander women and their babies receive health services from a combination of service providers. Developing effective partnerships between these providers is essential to improving the integration of maternal health services for Aboriginal and Torres Strait Islander women.

Shortage of work force

Australia’s health care system is reliant upon the commitment and skills of approximately half a million Australians employed in health occupations. Approximately 50 per cent of this workforce is made up of nurses, about 12 per cent of medical workers and 9 per cent of allied health workers. There is a continuing workforce shortage across a number of health professional groups despite Australia’s growing reliance on overseas trained

health workers.^{bm} A joint review conducted by the Australian Competition and Consumer Commission and the Australian Health Workforce Officials Committee (AHWOC) highlighted a number of medical shortages, of which obstetrics and general practice were listed.^{bn}

Uneven urban to rural distribution

The workforce distribution is also of concern as, 'apart from nurses, the relative number of health professionals diminishes for communities located further away from major centres'.^{bo}

Shared care

There are a number of health professionals working in maternity care with obstetricians, midwives or GPs able to be lead carers during a woman's pregnancy and labour. Alternatively, care may be shared by a combination of providers, who may work in a range of settings, from private practice to Aboriginal Health Services to public hospitals. GP obstetricians are of particular importance to the availability of rural and remote obstetric services.^{bp}

Aboriginal Health Workers

Aboriginal Health Workers who work with Aboriginal and Torres Strait Islander pregnant and post-natal women play a pivotal role in clinical care, education, advice and guidance and work in collaboration with other maternity and health care providers.^{bq} However, all Aboriginal and Torres Strait Islander health professionals combined make up only 0.9 per cent of the Australian health workforce, despite Aboriginals and Torres Strait Islanders making up 2.5 per cent of the population.

Gaps in knowledge

- Quality health data and management
- Evaluation of multidisciplinary, shared care models both for antenatal care and birthing, and of models providing a range of birthing options (including birthing closer to home) for Aboriginal and Torres Strait Islander women.
- Research at points in the life cycle at which intervention is likely to be effective, including the effectiveness of sex education to delay first pregnancies in adolescence and teenage years.
- The effectiveness of interventions in the preconception period, including improving the nutritional health of the woman.
- National data with regional and urban variations on the nutritional status of adolescent girls.

Chapter 3

CHAPTER 3 | INVESTING IN THE FUTURE

Knowledge is powerful. The health of all Australians relies on the outcome of high quality research

Why research is important

Aboriginals and Torres Strait Islanders have just as much right as the rest of the population to high quality care based on the best available evidence. However, the history of Aboriginal and Torres Strait Islander health care contains many examples of programs and interventions that were not evidence based (see Case Study | The Case of Dog Scabies).

There is limited 'high quality' evidence available to demonstrate the effectiveness of Aboriginal and Torres Strait Islander health programs or interventions that improve health outcomes for mothers and their babies.

Given the gaps in knowledge, international evidence could be used to change service design and delivery. However, the success of transferability of interventions may be limited by cultural appropriateness and acceptability, and community participation. The Australian Government recently announced a program of nurse-led home visiting in Aboriginal and Torres Strait Islander communities because there is strong evidence that in high-risk populations overseas that it has dramatic and long-lasting positive outcomes (see Case Study | Home Visiting | The Case for Evidence).

It is important to note that the evidence on continuity of care,^{br} safety of home birth^{bs} and the safety of small birthing units^{bt} in general has been considered strong enough to change service delivery in non-Indigenous populations and internationally.^{bu} This knowledge has not been transferred to services generally provided for, or available to, Aboriginal and Torres Strait Islander women. Moreover, there are also significant long standing problems with the identification of Aboriginal and Torres Strait Islander births across Australia, which undermine our efforts to monitor progress.^{bv}

Where good evidence does exist to improve health outcomes, such as smoking cessation advice and support in pregnancy,^{bw} and screening and treatment for genital and urinary tract infections, these practices are underutilised for Aboriginal and Torres Strait Islander women by health providers.^{bx}

Therefore, there is an urgent need to apply the evidence that already exists, but also to undertake applied health services research to address the gaps between evidence and practice, and between articulated policy and actual programs on the ground.

Case Study | The Case of Dog Scabies

Genetics prove mites on dogs and humans are different

For centuries, humans living in close contact with dogs have blamed animals with scabies (mange) for infecting people. This view was widely held by residents, health care staff and policymakers in remote Aboriginal communities in northern and central Australia. This resulted in programs in almost all communities to treat, de-sex and/or cull dogs in attempts to reduce the reservoir of infections. These programs were often expensive, and largely conducted with the intention of improving human health. Although these programs reduced mange and hookworm in dogs, there was no evidence that they improved human health. Research during the 1990s at the Menzies School of Health Research used genetic fingerprinting of the tiny mites that cause scabies to prove that the scabies mites found on dogs were of different lineages (non overlapping populations) to those found on humans.^{by}

This research changed practice

In other words, this research demonstrated the folly of spending health dollars on programs to reduce rates of dog scabies in the belief that this would result in reductions in rates of human scabies, and led to changes in public health practice. Since then, the scabies mite genotyping system has been used to demonstrate that treatment schedules with the anti-scabies drug Ivermectin were inadequate in very severe scabies patients – i.e. that treatment failures were due to relapse rather than reinfestation.^{bz} This resulted in changes to the treatment schedule and improved patient outcomes.

A research approach was used to develop a different strategy, that has resulted in dramatic reductions in scabies rates – and also reductions in associated bacterial skin infections in many communities.^{ca} This protocol, in which all community members are treated for scabies whether or not they have the disease, and further cases are detected by focused screening of children and re-treatment, is sustainable, effective, and the basis for current Northern Territory policy.



Principles in Planning a Research Agenda

Understanding causal pathways is important

There is no reason to believe that Aboriginals and Torres Strait Islanders are more susceptible to the diseases they suffer from at dramatically increased rates compared to the wider population. Research into causal pathways – particularly into the links between influences in the womb and the first few years of life outside the womb and health problems in adulthood – is important for the following reasons:

- The definitive proof of the long-term impact of early-life influences is not yet available – data relies on inferences from research in animals, and from observational studies in humans. Physiological, genetic and epigenetic research has the potential to provide this proof. This line of research is as relevant for Aboriginal and Torres Strait Islanders as it is for any other group.
- It gives credence and impact to interventions designed to change outcomes. When a biological explanation can be offered, an intervention is more likely to be accepted.

Priority needs to be given to interventional studies

A significant amount of information is available about the poor health outcomes of Aboriginals and Torres Strait Islanders, and about the likely causes of these outcomes, on which to base potential interventions to improve the situation. However, there is minimal information about what interventions work. Descriptive research should be embedded within interventional studies (e.g. new cohort studies should preferably incorporate aims that include interventions that have the potential to improve outcomes).

Quality research is paramount

Studies using rigorous methodologies may be resource-intensive in Aboriginal and Torres Strait Islander communities,^{cb} but they can be done. An example of a rigorous study is a randomised controlled trial of an intensive smoking intervention for pregnant Aboriginal and Torres Strait Islander women is currently underway in New South Wales. The major results of this study will be available in mid 2009, but the project has already demonstrated that 68 per cent of women asked by their doctors to attempt to quit smoking during pregnancy agreed to do so.^{cc}

There are considerations unique to Aboriginal and Torres Strait Islander research

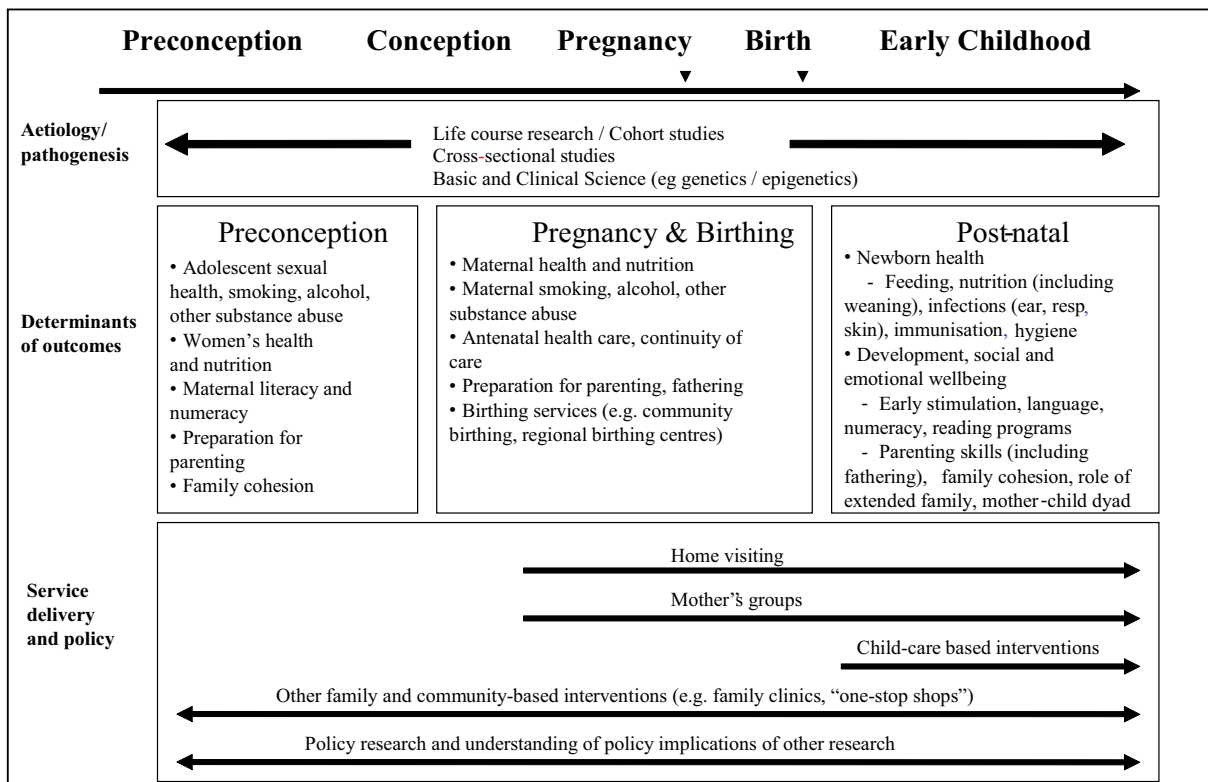
These considerations are listed along with others in documents related to Aboriginal and Torres Strait Islander health research produced by the Australian Government.^{cd} Research specifically involving Aboriginal and Torres Strait Islander people should adhere to the following points:

- Community involvement in the entire research process, from planning to completion.
- Approval by Ethics Committees that represent the opinions of the Aboriginal and Torres Strait Islander communities participating in the research, and embrace the principles in the NHMRC Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research.^{ce}
- Building the capacity of Aboriginal and Torres Strait Islander researchers in this area.

Research priorities in Aboriginal and Torres Strait Islander maternal, fetal and post-natal health

Recent or ongoing research into Aboriginal and Torres Strait Islander maternal, fetal and post-natal health is in Appendix 2. In summary, there are substantial descriptive data already available documenting poor health outcomes among Aboriginal and Torres Strait Islander mothers and babies, and a range of risk factors contributing to these outcomes. However, there are few studies that provide good evidence relating to interventions aimed at preventing poor outcomes, or alleviating their effects once established. Figure 6 provides a framework for building evidence and planning research to improve health.

Figure 6 | Building the evidence about Aboriginal and Torres Strait Islander maternal, fetal and post-natal health



Descriptive studies provide a good basis for hypothesis, and hence on which to base future interventional research. Some examples of descriptive research that have contributed to the evidence base include:

- The Aboriginal Birth Cohort Study in the Northern Territory is a life course study of 686 Aboriginal babies born at the Royal Darwin Hospital between 1987- 1990. To date, participants have been examined at the mean ages of 5 years, 11 years (572 traced) and more recently 18 years (467 traced). The primary focus of the study is the relationships of in utero and early life factors on the later development of chronic disease. The most recent follow-up has included assessments of growth and nutrition and measures of biomedical markers, cognitive function, emotional well-being and oral health.
- The Western Australian Aboriginal Child Health Survey of 5,300 Aboriginal and Torres Strait Islander children under the age of 18 living in 2,000 families across Western Australia, aimed to establish the prevalence, risk and protective factors associated with chronic medical conditions and disabilities, emotional and behavioural problems, health risk behaviours (smoking, alcohol, drug and volatile substance misuse), success in school learning and achievement, and resilience in Aboriginal children and young people.

Interventional and applied research includes some focused randomised controlled trials and other carefully designed and controlled prospective studies and a larger number of uncontrolled evaluations of health service interventions, often using before and after comparisons to demonstrate effectiveness. An example of the latter includes the Mums and Babies Program conducted by the Townsville Aboriginal and Islanders Health Service which demonstrated an increase in the number of antenatal visits per pregnancy from three to six and was associated with a significant reduction in perinatal mortality.^{6f}

However, it is possible to conduct high-quality research into complex interventions that span the different social, emotional as well as physical determinant of maternal and child health. An example is nurse-led home visiting (see Case Study – Home Visiting, the Case for Evidence). The challenge facing Australian researchers is to replicate the rigour of the research that underpins that intervention, but to do so in the setting of providing services to Aboriginal and Torres Strait Islander mothers and babies.

Case Study | Home Visiting | The Case for Evidence

Health@Home Plus is a nurse-led home visiting program to support Aboriginal and Torres Strait Islander children in targeted remote and outer regional areas. Commencing in the pre-natal period, health professionals will provide home visiting services to pregnant women, continuing until the child is two years old.

Unlike most other potential interventions in this age group, home visiting has a solid evidence basis. Models of home visiting have been tested in at least 17 randomised trials involving more than 14,000 families. The benefits of nurse-based home visiting programs have been dramatic. Mothers and children in these studies have been followed up for 15 years or more, and significant social, economic and health benefits have been demonstrated for participants. Moreover, the benefits are greatest for the most socially disadvantaged. **This research demonstrates that high quality research can be done on complex interventions and that research can feed directly into policy and practice.**

Although the home visits in themselves may have some therapeutic value, by and large home visiting is just a tool for delivering services. Its success depends on the types of services that are provided at the visits and the skills of the staff doing the visiting. The real appeal of home visiting is that it can incorporate a myriad of specific interventions that transcend the health, developmental, educational, social and emotional spheres (e.g. ensuring that growth and development of the child are on track and intervening early when they are not, providing advice and social support to the mother and linking in with social services).

Role of further research for home visiting

The research available to date is conclusive only for populations similar to those in which it has been tested such as in the USA. Circumstances in rural and remote Indigenous Australian communities are very different from African-American neighbourhoods in US cities. The level of poverty and illiteracy, cultural considerations, remoteness, availability of services, and many other factors give reason to believe that the US model will need substantial adaptation for the Australian setting, and that the results from US studies cannot automatically be assumed to apply in Indigenous communities. Hence there is a need for research to underpin each aspect of the program instituted in Australia, and for a thorough evaluation to ensure that we have a clear idea whether and to what extent it is achieving its aims.



How can we address the gaps in evidence?

We propose four broad areas of priority research in Aboriginal and Torres Strait Islander maternal, fetal and post-natal health:

1. Studies that continue to unravel the early-life biological determinants of later-life health or illness. These include studies into the physiology, genetics and epigenetics of the fetus and child.
2. Intervention studies aimed at improving preconception, pregnancy, birthing, and early childhood determinants of poor outcomes.
3. Intervention studies aimed at evaluating new models of service delivery that encompass a broad range of components, grounded in solid evidence and informed by the research outlined in point 1.
4. Studies into the practicalities of implementing and maintaining interventions, including policy, health economic, and health systems research, to better understand how evidence can be used to improve health outcomes.

Figure 7 | Summary Principles and Priorities

Principles of researching Aboriginal and Torres Strait Islander maternal, fetal and post-natal health

- Understanding causal pathways is important.
- Priority needs to be given to interventional studies.
- High-quality research is paramount.
- There are considerations unique to Aboriginal and Torres Strait Islander research.

Priority areas of research into Aboriginal and Torres Strait Islander maternal, fetal and post-natal health

1. Studies of early-life biological determinants of later-life health or illness.
2. Intervention studies aimed at improving determinants of poor outcomes.
3. Intervention studies aimed at evaluating new models of service delivery that encompass a broad range of components.
4. Studies into the practicalities of implementing and maintaining interventions.



Building capacity and translating research

NHMRC recognises the importance of capacity building for Aboriginal and Torres Strait Islander health research and these are reflected in its policy and planning documents. The Roadmap for Aboriginal and Torres Strait Islander Health Research was developed in close consultation with Aboriginal and Torres Strait Islander communities and has as one of its 6 research themes that of capacity building. This theme has been accorded high priority by the NHMRC and as a result, its Strategic Framework for Building Capacity in Aboriginal and Torres Strait Islander Health Research has been developed and endorsed by NHMRC.

Priorities in capacity building | issues to be addressed

If the research agenda in terms of Aboriginal and Torres Strait Islander maternal, fetal and post-natal health is to be achieved, there are a number of levels at which research capacity needs to be built: researcher, research team, Aboriginal and Torres Strait Islander community and institutional.

Researcher

There is a need to grow the pool of Aboriginal and Torres Strait Islander researchers. The importance of Aboriginal and Torres Strait Islander researchers as leaders and role models has been recognised. However, these leaders need support themselves, to balance their own academic outputs against mentoring, management, teaching and administrative roles. In particular, Aboriginals and Torres Strait Islanders often enter research mid-career, when they have family and other financial obligations that preclude accepting a PhD scholarship.

There is also a need to develop flexible formal training pathways for people to enter research training at different stages of development, with bridging courses, and to ensure that a career structure exists beyond the training.

The role of non-Indigenous researchers in Aboriginal and Torres Strait Islander health is also very important. However, it has changed over time, and given the increasing emphasis on building Aboriginal and Torres Strait Islander research capacity, community self-determination and outcomes-oriented research, there has been a shift away from traditional investigator-driven type research to community oriented, action based research in Aboriginal and Torres Strait Islander communities.

Research Team

The nature of research required in this area lends itself to interdisciplinary approaches and a range of partnerships, often across institutions. Maintaining good communication and adequate resources can be a challenge, as can be dealing with competition rather than collaboration between groups.

The role of Aboriginals and Torres Strait Islanders in the group process also needs to be more clearly defined. Often the Indigenous team member is expected to be the “Aboriginal expert” for the research group to access, and not recognised for the skills that they possess as an individual. They might be relatively junior or inexperienced, yet expected to perform at the level of a senior researcher. Clearly, the Aboriginal and Torres Strait Islander team member is critical to the implementation of the research process, but their role is often poorly defined or too ambitious in terms of expectations placed on them.

Aboriginal and Torres Strait Islander Community

Established relationships with Aboriginal and Torres Strait Islander communities are a key requirement for research in this area. Success in this regard depends upon the nature of the research and the relationship that the research team has with the community involved.

There is also increasing evidence of communities wanting to project-manage research within their communities.

This requires specific capacity building strategies and partnership approaches..

Institutional

The performance and capacity of institutions such as universities and medical research institutes varies across the country.

There is a need to build a culture within universities and research institutes that is supportive of Aboriginal and Torres Strait Islander researchers. It is also important to recognise that the growing pool of Indigenous higher degree research students has resulted in two key issues:

- There is a limited pool of academics that possess the necessary experience and understanding of working with Aboriginal and Torres Strait Islander students and communities in research supervision processes, and
- There is often an expectation that research in Aboriginal and Torres Strait Islander health will be supervised by an Indigenous person. This is currently unrealistic as the pool of potential supervisors is very small. In some

instances it may be more appropriate to include an Aboriginal and Torres Strait Islander person as a mentor with the supervisory team. This further highlights the growing need to support groups or teams of researchers in this area. There is also a need to develop non-Indigenous researchers' capacity to supervise Aboriginal and Torres Strait Islander researchers.

Translating research into policy and practice

The translation of research into policy and practice is critical. There is a need to invest more resources in this area and ensure greater accountability, as well as to develop and evaluate new models (e.g. web-based resources).

Future research should ensure that a policy research and translation strategy is embedded within each project, and that funding is allocated for these tasks.

Ethics approval processes for research in Aboriginal and Torres Strait Islander health vary across States and Territories. Investigation into best practice and a more nationally consistent approach is required.



Chapter 4

CHAPTER 4 | CONCLUSION – CLOSING THE GAP

The Working Group concludes that immediate action is required to address the risk factors for poor maternal and infant health in parallel with high quality research that will underpin an evidence-based response. We make the following recommendations:

Recommendation 1 – Immediate Action

Steps must be taken to close the gap in infant and maternal mortality and low birth weight in Aboriginal and Torres Strait Islander communities by 50 per cent within the next 10 years.

This will require a concerted national program to address the major risk factors prevalent in the community which adversely impact on the health of the mother and her baby.

Immediate action needs to be taken to address poor nutrition, smoking and alcohol as the major risk factors.

This will require an inter-sectoral approach by all levels of government. The following specific actions are required:

Nutrition

- Ensure access to healthy food at affordable prices.
- Deliver educational and promotional programs on healthy eating and cooking.

Smoking

- Develop innovative approaches to programs targeting Aboriginals and Torres Strait Islanders, for example: the Quit program adapted to Aboriginal and Torres Strait Islanders.
- Deliver culturally appropriate images and messages used in promotional materials.

Alcohol

- Investigate the extent and consequences of binge drinking during pregnancy.
- Implement a culturally appropriate and nationally coordinated education program to prevent alcohol consumption during pregnancy.
- Determine the prevalence of Fetal Alcohol Syndrome, which is largely under-diagnosed, and develop an inter-sectoral response.

Recommendation 2 – Research that Makes a Difference

In recent years, there has been an upheaval in the way we think about the biological mechanisms underlying healthy development of the fetus. Australia leads the world in this research.

It is important and timely that these new developments in basic and clinical research connect with existing population-based research to improve the maternal and fetal health of Aboriginals and Torres Strait Islanders.

At the same time, there are still major gaps in the basic demographics of Aboriginal and Torres Strait Islander health that need to be addressed.

We recommend that a Virtual Research Centre of Aboriginal and Torres Strait Islander Maternal and Child Health is established to:

- Harness the very best and new research in Australia to improve Aboriginal and Torres Strait Islander maternal, fetal and post-natal health.
- Coordinate, monitor, evaluate and translate research into policy and practice.
- Improve national surveillance and provide regular reports on trends and outcomes in maternal and infant health.
- Build national workforce capacity in Aboriginal and Torres Strait Islander health and research.
- Develop evidence-based clinical guidelines relevant to conditions affecting maternal and fetal health.

Appendix 1 provides further information on the Centre.

Recommendation 3 – Consultation

While the Working Group has consulted with stakeholders, broader consultation is required. We therefore recommend that the NHMRC, in partnership with relevant community organisations, conducts a national consultation process about the establishment of the Virtual Centre. Aboriginal and Torres Strait Islander communities are critical stakeholders in this process.



APPENDICES

APPENDIX 1 | Draft principles of a Virtual Centre on Aboriginal and Torres Strait Islander health focusing on maternal, fetal and post-natal health

Vision: this national centre will embody the principles of collaboration and evidence-based research excellence and capacity building.

The Centre will have an international reputation for excellence in the field of Aboriginal and Torres Strait Islander maternal, fetal and post-natal health. The organisation will provide a focus of the efforts, nationally and internationally in this field. It needs to play an important role in policy advice and advising Government. It needs to foster and conduct research in priority areas, for example; biomedical and health service delivery research.

The Centre will leverage the capacity of institutions across Australia. The Centre will collaborate with other institutions that are internationally recognised in this field and will build on existing agreements such as the NHMRC Tripartite Agreement in International Indigenous Research.

The Centre will be committed to the principles – as identified and described in the National Medical and Health Research Council Values and Ethics: Guidelines for the ethical conduct of research in Aboriginal and Torres Strait Islander communities.

Centre Governance

The oversighting group will consist of a Board drawn from the Aboriginal and Torres Strait Islander community, the research community, service providers and government.

The majority of the Board members should be Aboriginal or Torres Strait Islanders. The Centre must support Aboriginal and Torres Strait Islander leadership.

The Centre will:

- Determine and monitor the program of work and allocation of funding, to ensure that all of the priority areas in service delivery, research and capacity building are addressed.
- Ensure that the organisations within the Centre work collaboratively.
- Enhance the intersectoral work of the Centre, particularly linking the health, education and community services sectors.
- Ensure that there is representation of Indigenous communities, governments, professional bodies and other key stakeholders in the governance structure.
- Provide a direct link to the bodies responsible for implementing policies and practices that might arise out of research findings.

A. Research and Research Capacity

1. Prioritise research areas, fitting into the principles and priority areas outlined in Figure 7.
2. Monitor research to ensure that priority areas are addressed.
3. Enhance the collaborative nature of the work done by the institutions.
4. Ensure that there is representation of Indigenous communities, governments, professional bodies and other key stakeholders in the governance structure.
5. Build Aboriginal and Torres Strait Islander researcher capacity.
6. Develop a national Aboriginal and Torres Strait Islander research code with the NHMRC.

B. Translation

1. Translate evidence based research into improved health outcomes. Modules may vary between different geographic regions and urban and rural and remote Aboriginal and Torres Strait Islanders.
2. Suggest appropriate targets appropriate for different geographic regions and urban and rural and remote Aboriginal and Torres Strait Islanders.
3. Monitor, together with Aboriginal and Torres Strait Islander communities, the health outcomes.
4. Take on a clearing house function of national data collections.
5. Facilitate ownership of local data collections by Aboriginal and Torres Strait Islander communities.

C. Service delivery

1. Audit national workforce demands.
2. Promote continuum of care service delivery model.

D. Training

1. Respond to national workforce demands.
2. Set national benchmarks for training.
3. Coordinate continuing education and training.

APPENDIX 2 | Research (recent, underway or imminent) into Aboriginal and Torres Strait Islander maternal, fetal or post-natal health

National

Cooperative Research Centre for Aboriginal Health (CRAH)

The Cooperative Research Centre for Aboriginal Health is a partnership between 12 Aboriginal community organisations, government departments and research organisations that works to priorities identified by Aboriginal and Torres Strait Islander people and industry partners such as health services which can make use of the research. A range of projects have been carried out as part of the following program areas:

1. Comprehensive Primary Health Care, Health Systems and Workforce
2. Chronic Conditions, and
3. Social and Emotional Wellbeing.

This CRC's core partners are:

1. Australian Institute of Aboriginal and Torres Strait Islander Studies
2. Central Australian Aboriginal Congress
3. Charles Darwin University
4. Danila Dilba Medical Service
5. Commonwealth Department of Health and Ageing
6. La Trobe University
7. Menzies School of Health Research
8. Northern Territory Department of Health and Community Services
9. Queensland Institute of Medical Research
10. The Flinders University of South Australia
11. The University of Queensland
12. The University of Melbourne

CRAH research is conducted by its partner organisations, and therefore many of the projects listed below should be considered CRAH projects as well.

Northern Territory

Menzies School of Health Research

Predominantly interventional research including randomised controlled trials with some descriptive, policy-oriented research:

1. Role of continuous quality improvement as a tool for improving primary care services for mothers.
2. Development, implementation and evaluation of national indicators for primary maternal and child health care.
3. Interventional studies to prevent and treat ear disease in children (antibiotics, maternal immunisation, infant immunisation, new approaches to research translation).
4. New approaches to managing respiratory diseases including cough, pneumonia and airways disease.
5. Impact of rotavirus vaccines on severe diarrhoea.
6. Burden of influenza and other respiratory diseases, with a view to developing new immunisation strategies.
7. Burden of scabies and skin infections, and community based approaches to control by focusing on identification and treatment of infected young infants and their families.
8. New approaches to preventing early childhood caries (collaboration with the Australian Research Centre for Population Oral Health, Adelaide University).
9. Impact of polycystic ovary syndrome on fertility in Indigenous Women in Darwin.
10. Fetal fibronectin as a predictor of onset of labour at term, with a view to having a test to improve timing of transfer of women for birthing (Collaboration with Charles Darwin University).
11. Understanding barriers to screening for congenital anomalies in Indigenous Women (Collaboration with Charles Darwin University).
12. National Institute of Clinical Studies Collaborative – research transfer and knowledge brokering in the Indigenous health context.
13. Aboriginal Birth Cohort Study.

Charles Darwin University, Graduate School for Health Practice and School for Social and Policy Research

A combination of epidemiology, ethnography, randomised controlled trials, participatory action research and descriptive research.

1. A comprehensive study of maternal and child health care for Indigenous people in the NT, including:
Documenting existing maternal care services for remote Indigenous women in the NT; Investigating the application of population data as a basis for improving maternal and child health services in two remote communities; Computer-assisted patient journey modelling to improve continuity of care; Understanding why Indigenous women present late or not at all for antenatal care.

2. Descriptive studies of the history, ethnography, and current status of maternal and child health services for Aboriginal people, including an analysis of how policy changes have affected Aboriginal birthing since the 1930s.
3. Development of parenting support interventions for Indigenous families.
4. Evaluation of Irrkerlantye Learning Centre: A town based integrated health and education program.

Central Australian Aboriginal Congress

1. Evaluating antenatal care services in the Central Australian region.
2. Grow Well Project.
3. Maternal and Child Health Project.

Western Australia

Telethon Institute for Child Health Research (which includes the Kulunga Research Network)

1. Cohort studies of ear disease in Aboriginal children in the Eastern Goldfields investigated living conditions, maternal smoking, family risk factors, immune function, organisms involved, natural history and impact of pneumococcal vaccine.
2. Impact of swimming pools in remote Aboriginal communities which demonstrated improved health and wellbeing.

Telethon Institute for Child Health Research and the University of Western Australia

1. The value of breast feeding.
2. Otitis media in Aboriginal communities.

Telethon Institute for Child Health Research, the University of Western Australia, the Combined University Centre for Rural Health and Curtin University

1. Build the capacity of Indigenous health researchers and increase population health research outputs and achievements, evidence of research into practice, links to policy and dissemination of information.

Telethon Institute for Child Health Research and Kulunga Research Network

1. An Evaluation Framework to facilitate the assessment of the Leaping Lizards project that is being implemented in Onslow under the Building Healthy Communities (BCH) program.
2. Evaluation of the Strong Women, Strong Babies, Strong Culture (SWSBSC) program across the Pilbara region.
3. Development of a Mental Health Textbook which will provide culturally appropriate approaches to the assessment and interventions of Aboriginal and Torres Strait Islander social and emotional wellbeing and mental health issues.
4. Monitor and evaluate early childhood programs and interventions in the Pilbara region, specifically targeting the areas of Hedland and Newman.
5. Whole of Government Plan for Indigenous Generational Change.

6. Increase awareness among Indigenous women about the effects of passive smoking on the fetus and infant with a particular focus on asthma.
7. Applying Genetic Research to Epidemiology in Aboriginal Communities - A collaborative effort to investigate the potential application of genetic research in Aboriginal communities within Western Australia.

Telethon Institute for Child Health Research and Rio Tinto

1. Providing an evidence base for future policy and decision-making, as well as service provision.
2. Focusing on prevention and effective intervention and the development of tangible outcomes, and
3. Advocating for collaborative political and community action and social change by gathering and making available key data and research.

Western Australian Aboriginal Child Health Survey

1. Large-scale investigation into the health, wellbeing and development of a random sample of over 5,000 Western Australian Aboriginal and Torres Strait Islander children.

Telethon Institute for Child Health Research and Curtin University

1. Restor(y)ing Aboriginal Parenting: Development and evaluation of a culturally relevant program to support Aboriginal parents.

Edith Cowan University

1. Develop a project which focus' on the social and emotional development of Aboriginal and Torres Strait Islander children, teaching good health habits and community engagement.

New South Wales

National Centre for HIV Epidemiology and Disease

1. Ongoing national analyses of the rates of diagnosis of BBVs and STIs, according to Indigenous status, age, sex and geographic area, with a particular focus on HIV, hepatitis B and C, gonorrhoea, chlamydia and syphilis.
2. A repeat annual survey of HIV, hepatitis C and injecting risk behaviour among people attending needle and syringe programs.
3. National network to monitor uptake and outcome of testing for chlamydial infection among people attending Aboriginal community controlled health services.
4. Research project funded by NHMRC on the role of resiliency in responding to BBVs and STIs in Indigenous communities, that has a particular focus on adolescents and young adults.

The University of Newcastle

1. Developing a Type 2 diabetes and obesity prevention program for Indigenous primary school children in rural areas.

The University of Sydney

1. Investigate the relationship between environmental determinants of health in a cohort study. This will involve 800 urban Indigenous families and approximately 2000 children.
2. Randomised controlled trial of smoking cessation in pregnant Aboriginal women (in collaboration with Newcastle and Townsville and now includes Perth as well).

National Perinatal Statistics Unit

1. Australian Institute of Health and Welfare report, Indigenous Mothers and their babies, Australia 2001–2004.
2. Australian Institute of Health and Welfare report, Australia's mothers and babies 2005 scheduled for public release December 2007.
3. 2007 The urban-remote divide in Indigenous perinatal outcomes, Medical Journal of Australia.

The Sax Institute

1. Prevention of type 2 diabetes among Aboriginal people.
2. Study of Environment on Aboriginal Resilience and Child Health.
3. Research program into lupus in Aboriginal communities in NSW.
4. Conduct randomized controlled trials to test public health interventions in Aboriginal communities including smoking interventions for pregnant women.

Victoria

University of Melbourne, Onemda VicHealth Koori Health Unit

1. Content and method for a Victorian Aboriginal Child Health Survey that addresses community and policy information needs.
2. A mortality profile of Victoria's Aboriginal (and non-Aboriginal) children 1998-2008 using an innovative method and research process.

Queensland

Queensland Aboriginal and Islander Health Council

1. Descriptive analysis of maternal and child health services in Aboriginal community controlled health services in Queensland.

University of Queensland and the Perinatal Research Centre

1. Development of the Babyhelp resource based on research to define the educational needs of mothers and carers of Indigenous infants aged 0-2 years.
2. Identification of risk factors and resource development of resource materials for prevention of SIDS in Aboriginal communities.

University of Queensland

1. Analysis of immunisation rates among Aboriginal and Torres Strait Islander children in Queensland.

Queensland Institute of Medical Research

1. Biological processes of epigenetics.
2. Asthma Education Intervention Study in the Torres Strait.
3. Bronchiectasis in Indigenous Children Study.
4. Clinical trial of zinc and vitamin A supplementation in Australian Indigenous children with acute diarrhoea and pneumonia.
5. Diabetes type 2 in children in the Torres Strait.
6. Group B Streptococcus rapid PCR test optimization and evaluation and Indigenous Non-Indigenous Group B Colonisation/Prevalence Comparison Study.
7. Cancer diagnosis, treatment and survival in Indigenous compared with non-Indigenous Australians treated in public hospitals.
8. Malaria and Scabies.
9. Rheumatic Fever and Rheumatic Heart Disease.

South Australia

Flinders University

1. An evaluation of a nutrition program in a remote community in Central Australia.
2. An analysis of a community response to child nutrition problems at Kintore.
3. Maternal education and child health: An exploratory investigation in a Central Australian Aboriginal community.
4. The Antenatal Medical Imaging Training project for remote Health professionals in Central Australia – report to DOHA being finalised.
5. Development of educational resources on the effects of smoking, drinking and marijuana use during pregnancy and promotion of breastfeeding and appropriate weaning food – Red Cross consultancy in final stages.

University of Adelaide - Australian Research Centre for Population Oral Health (ARCPHO) – School of Dentistry

1. Evaluation of a primary health care model to prevent dental decay in Aboriginal pre-school children.
2. An investigation of oral health among Aboriginal people involved in a longitudinal study.
3. Risk indicators for periodontal disease in an urban Aboriginal and Torres Strait Islander population.

University of Adelaide - Discipline of Obstetrics and Gynaecology

1. Polycystic ovary syndrome in Indigenous women [PhD study in Darwin].

Spencer Gulf Rural Health School [joint venture with University of South Australia and the University of Adelaide]

1. Regional Family Birthing and Anangu Bibi Birthing Program: The First 50 Births.
2. A breastfeeding study in a rural population in South Australia.
3. Nunyara: working together to promote a healthy and vibrant community.

University of South Australia

1. Epigenetic programming of the Hypothalamo-Pituitary-Adrenocortical Axis.
2. Intrauterine growth restriction and development of the peripheral and coronary vasculature.
3. Early origins of obesity.
4. Mechanisms involved in reduced cardiac contractility as a consequence of growth restriction during fetal development.
5. Consumer co-payments for subsidised medicines: impact on access and health outcomes.
6. Developing new methods for building health policy capacity in Australia.
7. Building a cohort of Indigenous research leaders in community health development.
8. Community capacity for health development.
9. Evaluation of the JCU - Maternal & Antenatal Skills Transfer Program.

Australian Capital Territory

National Centre for Epidemiology and Population Health (Australian National University)

1. What will Assist Indigenous women in the Peel Health District to access antenatal care?

APPENDIX 3 | Working group members

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Presenters and contributors (in chronological order)

Prof Elizabeth Elliott, Paediatrics and Child Health, Children's Hospital, Westmead, *Fetal alcohol spectrum disorders*, 16 August 2007

Prof Lesley Barclay, Chair, Health Services Development, Charles Darwin University, *Breaking the cycle*, 29 August 2007

Prof Helen Milroy, Director Centre for Aboriginal Medical and Dental Health, University of Western Australia, *Perinatal Health*, 29 August 2007

Prof Fiona Stanley, Telethon Institute for Child Health Research, *Aboriginal Child Health Research*, 14 September 2007

Ros Kneebone (Manager), Glenys McCarrick (Registered Nurse) and Mellissa Malley (Aboriginal Health Worker) Aboriginal and Islander Community Health Service, *Family and Child Health Program - AICHS Brisbane*, 14 September 2007

Mark Moore, Aboriginal and Islander Community Health Service, *verbatim*, 14 September 2007

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Dr Mark Wenitong, Senior Medical Officer, Wuchopperen Health Service, Cairns, Queensland

APPENDIX 5 | Definitions

Antepartum fetal death: fetal death occurring before the onset of labour.

Apgar score: numerical score used to indicate the baby's condition at 1 minute and 5 minutes after birth.

Assisted vaginal/instrumental delivery: vaginal delivery using forceps or vacuum extraction.

Augmentation of labour: intervention after the onset of labour to assist the progress of labour.

Baby's length of stay: number of days between date of birth and date of separation from the hospital of birth (calculated by subtracting the date of birth from the date of separation).

Birth status: status of the baby immediately after birth.

Birth-weight: the first weight of the baby (stillborn or liveborn) obtained after birth (usually measured to the nearest 5 grams and obtained within one hour of birth).

Caesarean section: operative birth by surgical incision through the abdominal wall and uterus.

Confidence interval: a range of values for a variable of interest with a specified probability of including the true value of the variable.

DNA: Deoxyribonucleic acid. One of two types of molecules that encode genetic information.

Early neonatal death: death of a liveborn baby within seven days of birth.

Epidural: injection of anaesthetic agent into the epidural space of the spinal cord.

Episiotomy: an incision of the perineum and vagina to enlarge the vulval orifice.

Extremely low birth-weight: birth-weight of less than 1,000 grams.

Fetal death (stillbirth): death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 400 grams or more birth-weight. The death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles.

Fetal growth restriction: Birth-weight below the 10th centile of weight for gestation.

Gene: a DNA segment that contributes to phenotype/function. In the absence of demonstrated function a gene may be characterised by sequence, transcription or homology.

Gestational age: the duration of pregnancy in completed weeks calculated from the date of the first day of a woman's last menstrual period and her baby's date of birth, or via ultrasound, or derived from clinical assessment during pregnancy or from examination of the baby after birth.

Grand multipara: pregnant woman who has had four or more previous pregnancies resulting in a live birth or stillbirth.

Induction of labour: intervention to stimulate the onset of labour.

Intrapartum fetal death: fetal death occurring during labour.

Late neonatal death: death of a liveborn baby after seven completed days and before 28 completed days.

Live birth: the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which, after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached; each product of such a birth is considered liveborn (WHO definition).

Low birth-weight: birth-weight of less than 2,500 grams.

Maternal age: mother's age in completed years at the birth of her baby.

Mode of separation: status at separation of patient (discharge/transfer/death) and place to which patient is released (where applicable).

Mother's length of stay: number of days between admission date (during the admission resulting in a birth) and separation date (from the hospital where birth occurred). The interval is calculated by subtracting the date of admission from the date of separation.

Multipara: pregnant woman who has had at least one previous pregnancy resulting in a live birth or stillbirth.

Neonatal care levels: Level I care is for normal healthy term babies, some of whom may need short-term observation during the first few hours of life. Level II refers to a nursery that generally has babies born at 32–36 weeks gestation weighing around 1,500 to 2,500 grams at birth. It includes care for babies who require intravenous therapy or antibiotics, and/or those who are convalescing after intensive care, and/or those who need their heart rate or breathing monitored, and/or those who need short-term oxygen therapy. Level III or intensive care refers to the care of newborn infants who require more specialised care and treatment. It includes most babies born at less than 32 weeks gestation or less than 1,500 grams birth-weight, and others who may require such interventions as intravenous feeding, and/or surgery, and/or cardiorespiratory monitoring for management of apnoea or seizures, and/or require assisted ventilation, and/or supplemental oxygen over 40 per cent or longterm oxygen (Abeywardana 2006).

Neonatal death: death of a liveborn baby within 28 days of birth.

Neonatal morbidity: any condition or disease of the baby diagnosed after birth and before separation from care.

Normal fetal growth: Defined as the expression of the genetic potential to grow in a way that is neither constrained nor promoted by internal or external factors.

(NB: It is difficult to identify real or true variation from normal growth in an individual fetus).

Parity: number of previous pregnancies resulting in live births or stillbirths, excluding the current pregnancy.

Perinatal death: a fetal or neonatal death of at least 20 weeks gestation or at least 400 grams birth-weight.

Perineal status: status of the perineum after the birth. May involve surgical suturing of perineal laceration or episiotomy incision.

Plurality: the number of births resulting from a pregnancy.

Postneonatal death: death of a liveborn baby after 28 days and within one year of birth.

Post-natal depression: Post-natal depression is a term used to describe mood disorders occurring to women in the first year after birth of a child, there may be a fine line between what is considered normal and abnormal. Fathers can experience symptoms of post-natal depression. There are 3 different post-natal disorders that can appear.

Post partum Psychosis: Post partum psychosis is the least common of post-natal disorders. This condition usually appears within the first couple of months following childbirth and may occur in mothers with a personal or family history of schizophrenia or bipolar disorder (manic depression). This is a medical emergency and help should be sought immediately.

Post-term birth: birth at 42 or more completed weeks of gestation.

Presentation at birth: presenting part of the fetus at birth.

Preterm birth: birth before 37 completed weeks of gestation.

Related birth-weight definitions: Low birth-weight <2,500 g; Very low birth-weight <1,500 g; Extremely low birth-weight <1,000 g. Low birth-weight can be due to preterm birth, constitutionally small infants or growth restricted infants.

Spontaneous vaginal: birth without intervention in which the baby's head is the presenting part.

Stillbirth: see Fetal death (stillbirth).

Teenage mother: mother aged less than 20 years at the birth of her baby.

Teratogen: Any agent that can disturb the development of an embryo or fetus. Teratogens may cause a birth defect in the child or a teratogen may halt the pregnancy outright. The classes of teratogens include radiation, maternal infections, chemicals, and drugs.

Very low birth-weight: birth-weight of less than 1,500 grams.

APPENDIX 6 | Acronyms

ACER: Australian Council for Educational Research

AFWA: Asthma Foundation of Western Australia

AHMAC: Australian Health Ministers' Advisory Council

AHW: Aboriginal Health Worker

AHWOC: Australian Health Workforce Officials Committee

APSU: Australian Paediatric Surveillance Unit

ARBD: Alcohol-Related Birth Defects

ARC: Australian Research Council

ARCPOH: Australian Research Centre for Population Oral Health

ARND: Alcohol-Related Neurodevelopmental Disorders

BBV: blood borne viral

BHC: Building Healthy Communities program

BMI: Body Mass Index

CRCAH: Cooperative Research Centre for Aboriginal Health

CRG: Clinical Reference Group

DEST: Department of Education, Science and Training

DoHA: Department of Health and Ageing

DMO: District Medical Officer

DNA: Deoxyribonucleic acid

ERG: Evaluation Reference Group

FAS: Fetal Alcohol Syndrome

FASD: Fetal Alcohol Syndrome Disorder

GP: General Practitioner

HIV: Human immunodeficiency virus

ICBG: Indigenous Capacity Building Grant

ICHR: Telethon Institute for Child Health Research

IV: Intra-venous

LRG: Local Reference Group

MREA: Medical Research Endowment Account

MZ: Monozygote

NCRIS: National Collaborative Research Infrastructure Strategy

NFP: Nurse Family Partnership

NHMRC: National Health and Medical Research Council

OATSIH: Office of Aboriginal and Torres Strait Islander Health

OCS: Office of the Chief Scientist

QIMR: Queensland Institute of Medical Research

RANs: Remote Area Nurses

RANZCOG: Royal Australian and New Zealand College for Obstetricians and Gynaecologists

RCT: Randomized Controlled Trial

(SIDS): Sudden Infant Death Syndrome SNP: Single nucleotide polymorphism

STIs: Sexually transmitted infections

SWSBSC: Strong Women, Strong Babies, Strong Culture

TAIHS: Townsville Aboriginal and Islanders Health Services

UQ: University of Queensland

UTI: Urinary Tract Infection

UTS: University of Technology, Sydney

UWS: University of Western Sydney

UNSW: University of New South Wales

WAACHS: Western Australian Aboriginal Child Health Survey

WACHS: Wellington Aboriginal Corporation Health Service Inc

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