

The First 1000 Days Researchers' Forum Report

Kerry Arabena, Stacey Panozzo and Rebecca Ritte



Goal of the First 1000 Days

To provide a coordinated, comprehensive intervention to address the needs of Aboriginal and Torres Strait Islander children from conception to two years of age, thereby laying the foundation for their future health and wellbeing.



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Abbreviations

ACCHO	Aboriginal Community Controlled Health Organisations
AEDC	Australian Early Development Census
AHCSA	Aboriginal Health Council of South Australia
AIHW	Australian Institute of Health and Welfare
BMI	Body Mass Index
CKD	Chronic Kidney Disease
CVD	Cardiovascular Disease
CVS	Cardiovascular System
DOHaD	Developmental Origins of Health and Disease
GDM	Gestational Diabetes Mellitus
IDA	iron deficiency anaemia
MCRI	Murdoch Childrens Research Institute
NCDs	Non-communicable Diseases
NHMRC	National Health and Medical Research Council
STIs	Sexually Transmitted Infections

Terminology

In this report the terms 'Aboriginal' and/or 'Torres Strait Islander people' or 'First Peoples' are used to identify the First Peoples of Australia and to refer to and recognise the two unique Indigenous populations in Australia. The term 'Indigenous' refers collectively to the First Peoples of Australia, New Zealand, North America, and other countries around the globe. 'Non-Indigenous' is used to refer to those who do not identify as a member of the community of First Peoples of their respective countries.



Executive Summary

This report details the program, proceedings and outcomes of the First 1000 Days Researchers' Forum, the second of four symposiums to be held at, and led by, the University of Melbourne. The aim of the Forum was to enable researchers and implementers of projects operating across different national sites to develop both an understanding of what data is currently being collected and why it is being collected. Further to this, the Forum provided the opportunity to discuss current datasets and birth cohort studies and the development of core data that can be used in comparisons across jurisdictions and regions in Australia.

The focus on the First 1000 Days is important because while the family life of Aboriginal and Torres Strait Islander people is predominantly centred around complex kinship systems and clan structures, with clear lines of rights and obligations to others, an increasing number of our children are vulnerable and at risk. We recognise that, until recently, the education and socialisation of young children took place within the rhythms of family life, the extended family and their Country. We also recognise the intrinsic value of children within our communities.

However, we also acknowledge that these ideals have been radically disrupted for some families, particularly those who have suffered the separation of their children, the destruction of extended family networks, and decades of living in oppressive circumstances – as evidenced by poor health and early deaths, sub-standard housing, poor educational outcomes, high unemployment and large numbers of Aboriginal and Torres Strait Islander people in custody. Despite these hardships, family remains the primary and preferred site for developing and protecting culture and identity in our children.

We also acknowledge, then, the importance of family-strengthening initiatives, the crucial role played by men in raising children and the importance of the First 1000 Days to the future prosperity of Aboriginal and Torres Strait Islander societies. By initiating an early and continued investment in the next generation, we can mitigate connections between adverse early experiences

and a wide range of costly problems, such as lower educational achievement and higher rates of criminal behaviour and chronic disease. The First 1000 Days focuses on reducing the burdens of significant adversity on families with young children.

About the Researchers' Forum

The First 1000 Days Researchers' Forum was held at Rydges on Swanston on Wednesday 26 August 2015. The second of a four-part series, participants at the Forum heard from researchers working with datasets and birth cohort studies that focus on different aspects of (pre)conception, conception and early years across a range of Australian jurisdictions and regions. The Forum provided a continuation of discussions concerning the development of a clear, evidence-based strategy to support vulnerable parents and their children in Australia through the First 1000 Days, with a focus on Aboriginal and Torres Strait Islander communities.

The aim of the Researcher's Forum was to develop an understanding both of what data is being collected and of why it is being collected, and to develop core data and data linkages that enable comparisons across jurisdictions and regions. The meeting also considered how current datasets, birth cohorts and longitudinal studies can be used.

More than 50 participants representing 24 different institutions across seven States and Territories of Australia were present at the Researchers' Forum, which was chaired by Professor Kerry Arabena (Chair of Indigenous Health and Director of the Indigenous Health Equity Unit in the Melbourne School of Population and Global Health at the University of Melbourne). The presenters, all of whose presentations are included herein, provided highlights of regional initiatives that encourage service-specific enhancements at local levels to ensure that supports are equitably available for vulnerable families. They also focused on what aspects of data are being collected to measure the impact of these initiatives. Examples of regional initiatives included: the development of the

Goulburn–Murray Algabonyah Data Unit through the Kaiela Institute; the Baby One Program in Cape York, Queensland; and the Nini Helthiwan Project coordinated by the Rural School of Western Australia to improve primary care for Aboriginal mothers and babies. Approaches to, and support for, harmonising measurements and outcome data, and creating the ability to compare across dataset, were presented by the ActEarly Group and the University of Melbourne.

The developing Ecological Framework and preliminary research questions and outcomes for the First 1000 Days

The Researchers' Forum also provided the opportunity for group discussions to build on the First 1000 Days Ecological Framework, informed by the Scientific Symposium (Arabena et al. 2015), and to develop preliminary research questions to be answered in early life studies. These questions led to the emergence of several research themes, which are outlined below.

Community governance

Community governance, engagement and partnerships with community are essential to ensure that research and interventions are led by and include Aboriginal and Torres Strait Islander people as co-designers, co-implementers and co-knowledge translators of research and research outcomes. Community governance also ensures that research is designed to increase the number of opportunities for community leadership in agenda setting and decision making, thereby growing the number of Aboriginal and Torres Strait Islander leaders in this field, and the cultural responsiveness and capacity of health service systems to meet the needs of Aboriginal people.

Increasing antenatal and early years engagement

Poor antenatal engagement among Aboriginal and Torres Strait Islander women leads to poorer health at birth and throughout childhood. There is evidence that decreased self-efficacy results in health service avoidance, and cultural strengthening

improves self-efficacy. Interventions focused on increasing antenatal and early years engagement, and incorporating a case management approach, provide the opportunity for a measure of pre- and post-delivery outcomes for Aboriginal and Torres Strait Islander women and children. These include birth weight, maternal/paternal smoking rates, breastfeeding rates, attained height at age two years, and the impact of knowledge translation and delivery leading to increased antenatal engagement.

Family environment

The context of the family environment in raising resilient and flourishing Aboriginal and Torres Strait Islander children is well recognised and was a priority identified by participants both at the earlier Scientific Symposium and throughout the Researchers' Forum. It also focuses on identifying and describing 'gaps', thereby making the collective research story about early childhood one of deficits within the Aboriginal and Torres Strait Islander community (Bowes et al. 2014). Nonetheless, by addressing family violence, enabling family mentoring, understanding how to be the best parents, and learning how to raise motivated children, the First 1000 Days' focus on the family environment can prevent any lifelong discrepancy in health outcomes, educational achievement and wellbeing. Building Aboriginal and Torres Strait Islander leadership in this area is important in creating a shift from child and maternal health services to 'maximising protective factors in families'. Effective services that engage and support families of Aboriginal children during the First 1000 Days will enhance outcomes in relation to a child's engagement with school, the promise of health equity and strengthening the resilience of families.

Service use and provision

Service use and provision will include the development of a First 1000 Days workforce through building the capacity of Aboriginal Health Workers and midwives in this area. A major focus will be directed towards developing a case management approach to service provision so as to improve access to, and use of, comprehensive primary health care services for Aboriginal and Torres Strait Islander women, men and families in the First 1000

Days. Education, capacity building and further interventions will be informed through conducting needs assessments and evaluations of existing services, staff and users.

Data for evidence

Data for evidence provides a focus for establishing data linkage and the collection of baseline and outcome measures. To enable accurate reporting of the associated impacts, and to maintain researcher accountability to the development of an Australian Model of the First 1000 Days program, robust and rigorous measurements of the educational, health, cultural and wellbeing outcomes for Aboriginal and Torres Strait Islander children and families are required. To quantify the impacts of First 1000 Days interventions for Aboriginal and Torres Strait Islander people complete, accurate and consistent data will be needed. This will include improving the coordination, collection and monitoring of population data and working with governments and the Aboriginal and Torres Strait Islander health sector. It will also include assessing the process of implementing, initiating and recruiting at study sites in addition to ensuring the acceptability of the survey methods. A systematised data collection and analysis methodology will enable a comprehensive, rigorous and consistent empirical evidence base that will inform the social transformation needed to enable Aboriginal and Torres Strait Islander children, families and communities not just to survive – but to thrive.

Interventions

The first and primary feature of the Australian Model of the First 1000 Days is the development of holistic interventions that will improve the health and wellbeing outcomes of Aboriginal and Torres Strait Islander children from (pre)conception to the age of two. These are best delivered through the family environment, and by increasing antenatal and early years engagement along with service use and provision. Such interventions will have a primary focus that may include, but are not limited to, areas that address: preconception; improving nutrition; increasing engagement with services through a case management approach; parenting and mentoring; education and early life literacy; drug and alcohol use; justice and child safety; and building resilience.

Moving the agenda forward: Where to from here?

The third Symposium to progress the First 1000 Days research agenda, also held in August 2015, gave community people and organisations an opportunity to focus on the development of community governance frameworks for the First 1000 Days research sites being negotiated across Australia. Discussions focused on identifying how to engage with and support families, how to take and use strengths-based approaches and to identify key methods for engaging fathers and extended family members in modelling activities, and the early years workforce. A report from the Community Governance Symposium is available from the [Indigenous Health Equity Unit website](#).

The fourth and final Symposium will be held in November 2015 and targets policy makers and implementers to identify ways in which policy processes can respond to the evidence generated from First 1000 Days sites, and replicate these findings into other areas of activity across Victoria and nationally. The engagement and consultation process enabled through these four Symposiums provide a practical underpinning for the development of the Australian Model of the First 1000 Days.

The Evidence

The First 1000 Days between a woman's pregnancy and her child's second birthday offers a unique window of opportunity to shape healthier and more prosperous futures (1,000 Days 2014). In recent years the perceived importance of the First 1000 Days has gained traction as new evidence emerges as to the impact of maternal nutrition on brain development, the neuroscience of infants, the long-term impacts of early childhood experiences such as stress permanently affecting characteristics usually considered genetic ('epigenetics'), and the capacity of infants to begin structured learning earlier than previously supposed (Arabena 2014).

The evidence shows that:

- Ensuring that the brain achieves its optimum development and nurturing during this peak period of growth is vitally important, as it enables babies to achieve the best start in life (Leadsom et al. 2014).
- From birth to 18 months, connections in the brain are created at a rate of 1,000,000 per second. A baby's earliest experiences shape its brain development and have a lifelong impact on that baby's mental and emotional health (O'Connell, Boat & Warner 2009).
- A baby or foetus exposed to toxic stress can have their responses to stress distorted in later life. Such early stress can come from the mother suffering from symptoms of depression or anxiety, having a bad relationship with her partner or from an external trauma such as bereavement (CDCHU 2011).
- When a baby's development falls behind the norm during the first years of life, it is then much more likely to fall behind even further in subsequent years than to catch up with those who have had a better start in life (AMA 2010).
- A baby's social and emotional development is strongly affected by the quality of their attachment – that is, the bond between a baby and its caregivers (Malekpour 2007).
- Babies are disproportionately vulnerable to abuse and neglect. A number of our children are living in complex family situations, or at heightened risk in households with problems such as substance misuse, mental illness or domestic violence. Many of the statistics show that serious case reviews involve children under the age of 12 months (Morgan & Chadwick 2009).

When children have opportunities to develop executive function and self-regulation skills – which are crucial for learning and development – both individuals and society as a whole benefit. In vulnerable families, we need to build the capabilities of adult caregivers in order to achieve good outcomes for the children in their care. By supporting the development of children's and caregiver's self-regulation skills, mental health and executive functioning, we can improve the economic and social stability of the family, thereby maximising the health benefits that will positively impact on young children across their life-course (CDCHU 2015).

The First 1000 Days

A radical change is required in how we think about and enhance the early outcomes for Aboriginal and Torres Strait Islander children in Australia (SNAICC 2013). Too many children and young people do not have the start in life they need. As our understanding of developmental science improves, it becomes clearer and clearer that adverse events in a child's life lead to structural changes in brain development that have life-long and societal ramifications (TLRP [n.d.]). We now also know these ramifications are intergenerational (Lee & Macvarish 2014). Not intervening will affect not only this generation of children, but also the next. Those who suffer adverse childhood events achieve less educationally, earn less and have worse health outcomes – all of which makes it more likely that the cycle of harm is perpetuated in the following generation (Leadsom et al. 2014).

The First 1000 Days Scientific Symposium was a call to consider the implementation of new interventions founded in rigorous science, and to consider the opportunities inherent in the 'critical window of opportunity' from conception to the age of two. International research shows that early intervention programs during pregnancy and in the early months and years of a child's life have tremendous positive impacts on health later in life. The physiological, educational and emotional environment of the child in this 'First 1000 Days' has been shown to exert a profound impact on long-term developmental and life trajectories (Illig 1998; The Lancet 2013; The Save the Children Fund 2013).

In our communities, pregnancy, birth and the first 24 months can be tough for every mother and father. Some parents find it difficult to provide the care and attention their baby needs (Arabena et al. 2015). This same time period can also be a chance to affect great change as parents are usually receptive to offers of advice and support, and agencies are able to provide seamless services emphasising community leadership, workforce development, and coordination of effort, partnerships and collaboration.

In the Australian context, early intervention support for mother and baby is not always available to Aboriginal and Torres Strait Islander children. As a result, they can be subject to poorer health and cognitive development than non-Indigenous infants. This has life-long health and wellbeing implications that impact at the individual, family, community and societal level (McHugh & Hornbuckle 2010). Thus, the First 1000 Days framework is being developed as an approach to improving health outcomes for Aboriginal and Torres Strait Islander children and to maximising the potential of all children. Coordinated by Professor Kerry Arabena, the Framework will focus attention on preconception, maternal antenatal and postpartum nutrition and healthy lifestyle strategies, and nutritional, social, environmental, educational and family supports for the developing infant and child (The University of Melbourne 2015).

Recent evidence demonstrates there are many areas that could be used to guide the development of targeted interventions for the Framework including:

- impact of maternal nutrition on brain development
- neuroscience of infants
- long-term impacts of early childhood experiences such as stress, which may permanently affect characteristics usually considered genetic ('epigenetics')
- capacity of infants to begin structured learning earlier than previously supposed
- building the capabilities of adult caregivers in vulnerable families
- developing executive function and self-regulation skills in the child.

This approach will also involve health care workers, community organisations and all levels of government to address local and systemic-level issues contributing to the growing gap in infant and parental health between Aboriginal and Torres Strait Islander and non-Indigenous Australians. These issues include preconception, maternal and child health, parental support, early childhood education, housing availability and quality, and poverty reduction.

The impact of capacity building in these areas can be global and enduring. For example, when children have opportunities to develop executive function and skills in self-regulation – crucial for learning and development – the positive outcomes and health benefits to the child extend to improvements in the economic and social stability of the family, and to society as a whole (Vimpani, Patton & Hayes 2004).

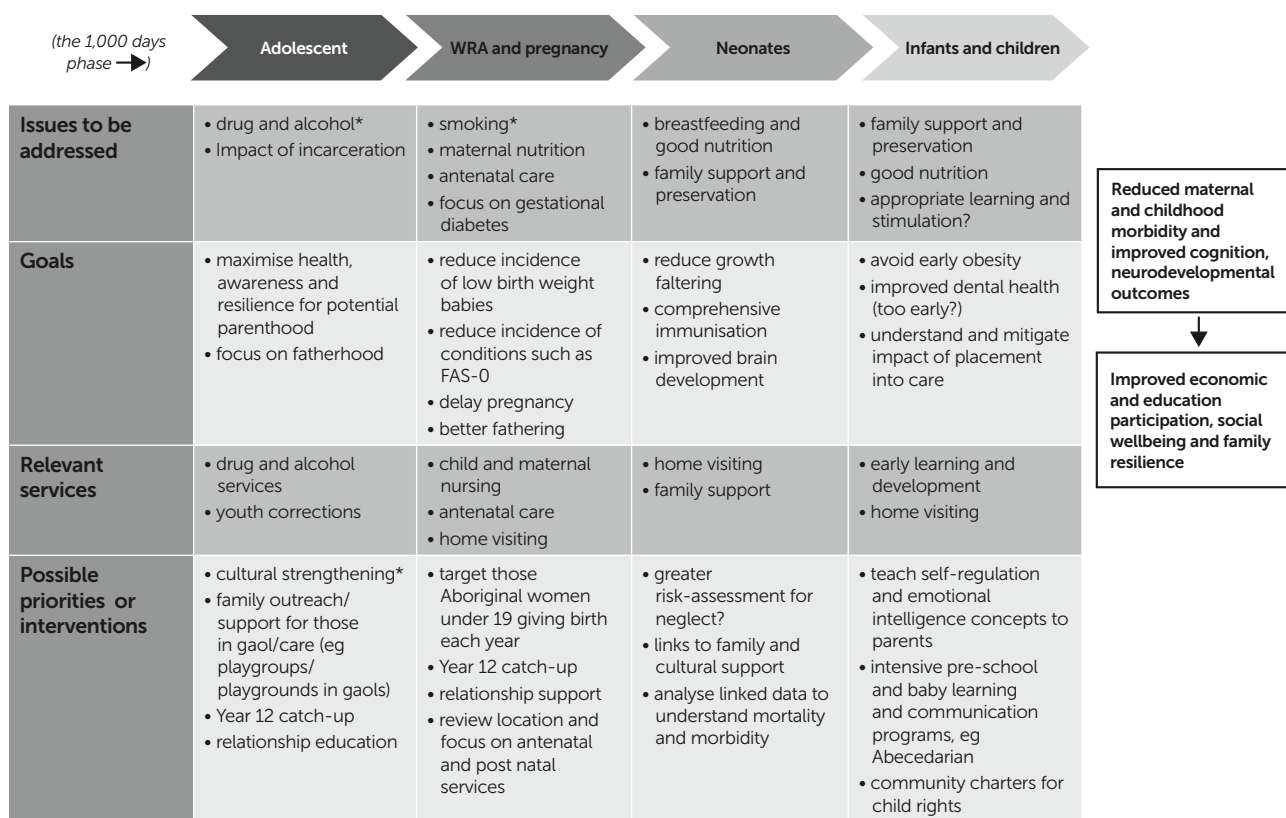
Furthermore, interventions in the First 1000 Days have already shown demonstrable and far-reaching outcomes (1,000 Days 2014), such as:

- saving lives
- significantly reducing the human and economic burden of communicable diseases such as tuberculosis, malaria and HIV/AIDS

- reducing the long-term risk of developing some non-communicable and chronic diseases including diabetes
- improving educational achievement and earning potential
- improving a nation's gross domestic product.

Figure 1 (on next page) provides a summary of the possible actions under a First 1000 Days approach that focuses on Aboriginal and Torres Strait Islander Infants and those caring for them.

By giving children the best start in the First 1000 Days of life we are enabling them to develop to their full potential as psychologically and physically healthy, socially engaged, well-educated and productive adults. By contrast, adverse experiences for the child in this period can derail healthy development, and create learning, behavioural and health challenges that place a heavy burden at the individual, family, community, and national level.



*Note: a number of issues will need to be addressed across all phases

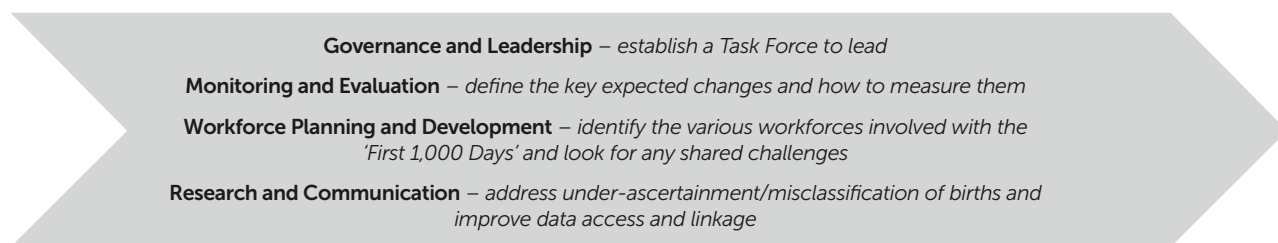


Figure 1: Summary of possible actions under a First 1000 Days approach for Aboriginal and Torres Strait Islander Infants and those caring for them

Overview of Presentations at the Researchers' Forum

The following section provides a brief overview and summary of the presentations given at the First 1000 Days Researchers' Forum. These are grouped under the following headings:

- Harmonising measures and outcome data: Regional snapshots
- Aboriginal birth cohorts and longitudinal studies.

Videos of the presentations in their entirety are available on the Indigenous Health Equity Unit's website.

Harmonising measures and outcome data: Regional snapshots

Algabonyah Empowered Communities data approach: Goulburn–Murray, Victoria

Ms Felicia Dean and Mr Ben Tan, Kaiela Institute, Shepparton, Victoria

Empowered Communities is an Indigenous empowerment agenda, working with community and corporate leaders and government from eight regions across Australia, to reform how Indigenous policies and programs are designed and delivered. The Empowered Communities agenda is a long-term policy reform based on Indigenous empowerment, with a focus on the need for regionally specific, accurate data to determine Indigenous regional priorities. The Empowered Communities agenda has two main goals:

- To close the gap on the social and economic disadvantage of Indigenous Australians living in the Empowered Communities regions.
- To enable the cultural recognition and determination of these Indigenous Australians so that we can preserve, maintain, renew and adapt our cultural and linguistic heritage and transmit our heritage to future generations (Empowered Communities 2015).

The Goulburn–Murray region in Victoria is one of the eight regional Empowered Communities to be developing regionally specific governance arrangements. In the Goulburn–Murray region, these arrangements take the form of the *Algabonyah* (or the Goulburn–Murray Community Cabinet), the Yorta Yorta word for 'meeting place'. *Algabonyah* is bringing together local Indigenous leaders and other members of the community/government to set a reform agenda based on a set of place-based regional priorities. It is focused on five main principles, including: a safe community that takes responsibility for the wellbeing and developmental needs of our kids; a 90 per cent attendance rate at school from early childhood through to the completion of secondary school; a 90 per cent participation rate in career opportunities in industries in the Goulburn–Murray; safe and affordable housing options that allow people to aspire to owning their own houses, to welcome others into their homes, and to take pride in where they live; and strong leadership and affirmative role modelling within and across the Aboriginal and broader Goulburn–Murray communities (Empowered Communities 2015).

Access to relevant regional-level data remains a challenge, with the Goulburn–Murray community unable to access disaggregated data that is either specific to the region/local government or to the Aboriginal population in the region. Furthermore, there are legal/confidentiality issues preventing access to certain government-held data. Current indicators on Aboriginal disadvantage are not locally relevant, do not detail information on the complexity and scope of disadvantage, and do not identify the positive outcomes and achievements in the community.

To determine place-based regional priorities, the *Algabonyah* Data Unit has been established to enable the collection and analysis of local data, which will provide a baseline and an opportunity to report on progress and to keep Aboriginal and mainstream service delivery organisations accountable (Empowered Communities 2015). Datasets will also include demographic, housing, governance, cultural

participation and recognition, justice, early years and health, education, training and employment details. Further to this, the Algabonyah Data Unit will seek financial transparency in the collection of data on funding and government financial investments in the Goulburn–Murray region. This financial transparency and associated data will increase accountability and better inform future government investments at a regional level. With the establishment of a Data Management Taskforce, the Data Unit will be responsible for preparing an annual Report Card as an evidence base for identifying community priorities, strengths and weaknesses, and informing programs, policy, accountability measures, information sharing and detailed regional strategic planning.

Empowered Communities provides opportunity for a richer story-telling that truly reflects the region. The Algabonyah (Murray–Goulburn Community Cabinet) and its Data Unit allow for the inclusion of community indicators – such as cultural aspirations, traditional language proficiency, and attitudes to work – and for an Aboriginal voice in data interpretation and policy development that will enable an Aboriginal lens through which to view the reporting process. This will enhance the interpretation of both the results and reporting procedures, thereby ensuring that local community leaders and members are involved in the process of facilitating community investment, and ownership and empowerment over outcomes.

The Baby One Program: A new chapter in child and maternal health in Cape York, Queensland

Ms Rachael Ham (Researcher), Ms Jenny Sewter (Team Leader), Ms Lorraine Ahmat (Coordinator), Baby One Project, Cape York, Queensland

The Baby One Program is an Indigenous Health Worker-led program developed by Apunipima Cape York Health Council to promote better health outcomes for mothers, babies and their family in communities across Cape York, Queensland. The Baby One Program, named for the youngest child in a family, focuses on the first 1000 days of life from conception to age two.

The Baby One Program encourages holistic, family-based antenatal and postnatal care driven by Indigenous Health Workers and the local community. A dedicated Health Worker conducts home visits, in addition to the family's routine clinic visits (15 visits in total), providing families with a continuity of care throughout the pregnancy and up to their baby's second birthday. This home visiting model allows for mothers, babies and family members to be more comfortable and receptive, and enables pregnant Aboriginal and Torres Strait Islander women to have earlier and more frequent engagement with antenatal and postnatal health services. This enhanced engagement gives Health Workers a greater opportunity to impart health education and promotion, and to provide the seven 'clinical engagement tools' (e.g. mother and baby baskets/bags and fruit and vegetable vouchers). In addition, Baby One Program Health Workers also benefit through ongoing professional development and education on best practice models of care.

The Australian Medical Association has identified access to appropriate programs, primary health care services and home visits as having an important role in improving outcomes for Aboriginal and Torres Strait Islander maternal and child health (AMA 2013). Apunipima's Maternal and Child Health Business Plan has similarly prioritised effective, culturally competent maternity care. The program is culturally specific to Aboriginal and Torres Strait Islander people, with a dedicated Indigenous workforce that is aligned to Apunipima's new Primary Health Care Model of Care (see Figure 2 on next page) and to delivering services through a community and family-centred approach (also including men's health).

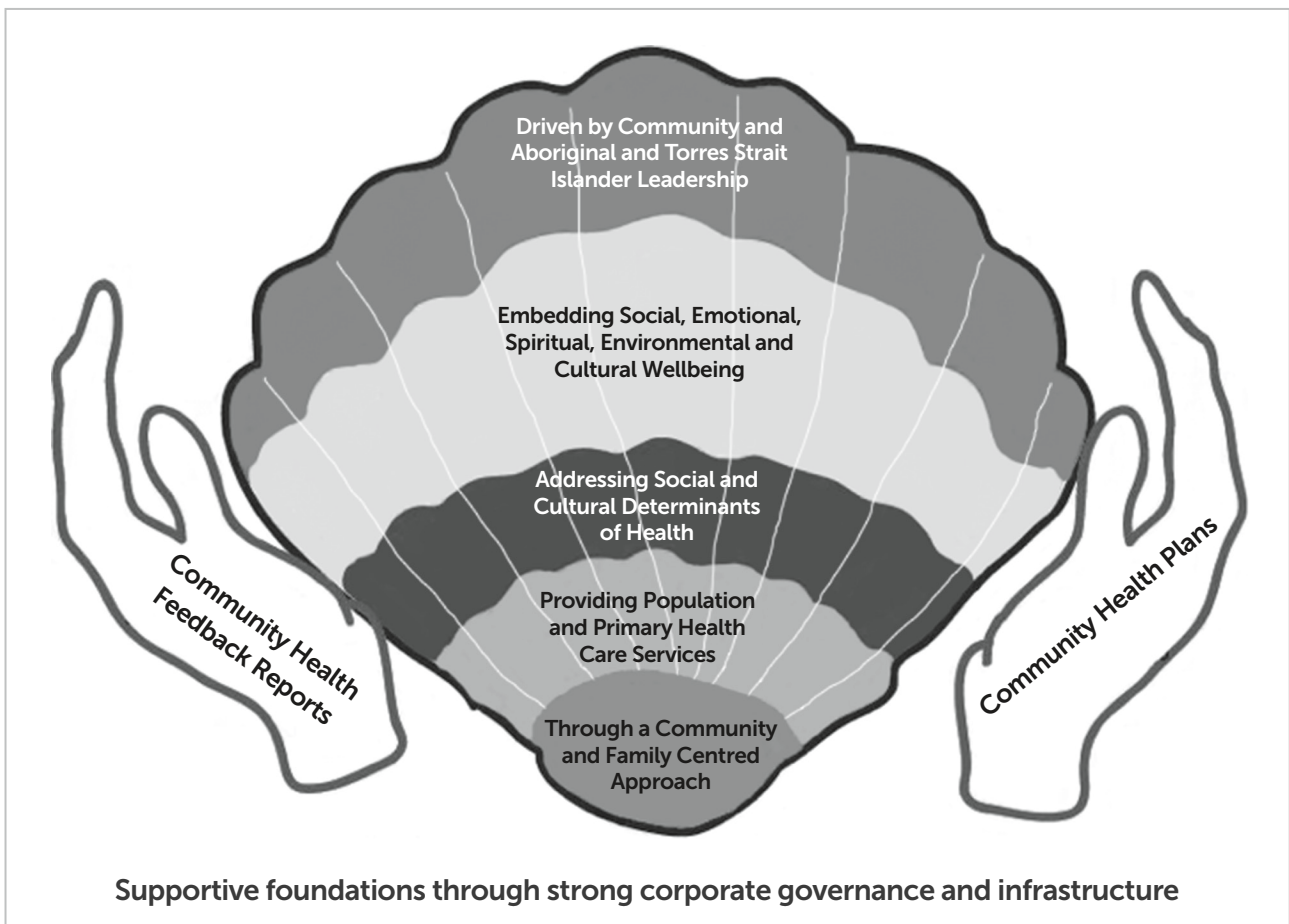


Figure 2: Apunipima's Primary Health Care Model of Care

The Baby One Program has been delivered for more than 12 months (based on a revised model of the Apunipima's previous Baby Basket Program). A program evaluation is now being planned to assess the impact on families and children. Some of the desired outcomes and assessments will include:

- Standard child health checks (715)
- ↑ Smoking rates, ↓ Drug & Alcohol use, ↑ nutrition, measuring anaemia, ↑ birth weight, BCG vaccine rates, ↓ diabetes
- Social and emotional wellbeing assessments (↑ home visits including birthing in Cairns)

- Social Worker as part of the team and delivery of health services
- Additional contacts with mothers and early presentations for antenatal care
- Benefits of fruit and vegetable vouchers.

To ensure access to the necessary information for this evaluation, information will be sourced from the Apunipima Baby One Program electronic clinical database and through relevant data linkages with key registers, such as immunisation records, pathology, Medicare and other health professionals/ organisations.

BABY1000 Study: Before, during and beyond the baby years – The influence of the First 1000 Days, Hunter Valley Region, New South Wales

Dr Adrienne Gordon, Charles Perkins Centre, The University of Sydney

Healthy child development is the product of gene-environmental interactions that begin before pregnancy, particularly with the health of the mother, and are significantly influenced by the *in utero* environment.

Maternal and paternal obesity, weight trajectory during pregnancy, sub-optimal nutrition, lack of exercise, gestational diabetes mellitus (GDM), sleep disturbances, dysregulated gut microbiome, immune system challenges and depression are all factors likely to impair fetal outcomes. However, the why and how are still largely unknown. Thus, understanding and manipulating these conditions represents the next wave of improving childhood and long-term health.

The BABY1000 Study is a prospective longitudinal project run by the Charles Perkins Centre, which

aims to identify the modifiable risks and interventions prior to and during pregnancy that will impact on later life health. This study will:

- involve preconception recruitment of both men and women
- assess stimuli within appropriate critical windows
- run interventional studies alongside the cohort
- translate evidence into practice
- utilise technology to collect exposure data.

Until now, most health initiatives have focused on obesity, diabetes and cardiovascular disease (CVD) as medical conditions, concentrating on their complex biology at the levels of genes, cells and organs. The outcomes of the BABY1000 study will provide an unprecedented resource for designing and implementing interventions that guard against non-communicable disease (NCDs) and associated co-morbidities in childhood and beyond, with key research areas reflected in Figure 3 (below).

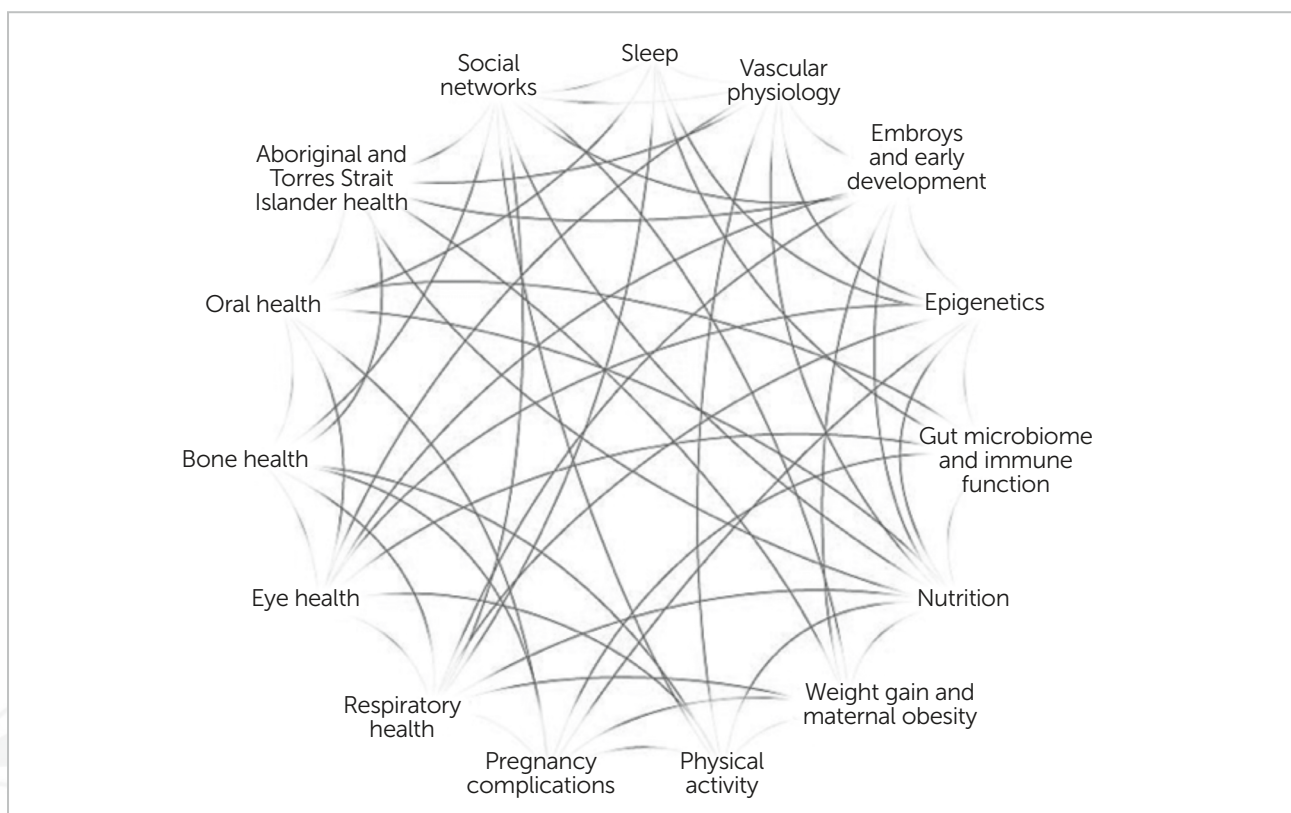


Figure 3: BABY1000 Study key research areas and factors

Data linkage and recruitment will occur across five major sites throughout New South Wales, with all births included as part of the BABY1000, with families given an opportunity to 'opt-out' during the period of recruitment. A Pregnancy Planning Clinic will be established both to provide support for women and families during preconception, and a means of recruiting participants to study the preconception time period. The study will incorporate interventional trials, with parents and their offspring followed from preconception and early pregnancy through to the first 1000 days of life.

Initial research workshops have been undertaken with clinicians, researchers and consumers over the past 12 months. It is envisaged that a scheduled pilot study will provide further insight and assist in the: development of recruitment and retention methods for participants; understanding preconception and engagement with primary care; and testing of measures, methodology and data collection processes.

The Nini Helthiwan Project: Improving primary care for Aboriginal mothers and babies in the Kimberley region of Western Australia – A population- and region-based cluster randomised trial driven by local health service providers

Dr Julia Marley, The Rural Clinical School of Western Australia

There is increasing concern that more than 50 per cent of pregnant women/mothers and breastfed young infants in disadvantaged areas globally have micronutrient malnutrition and iron deficiency anaemia or IDA (WHO 2013), with similar rates found in Aboriginal and Torres Strait Islander communities. Although substantial investments in Continuous Quality Improvement programs have been made in the past decade, many barriers still remain to providing good quality antenatal and postnatal care in remote areas of Australia. As yet, for example, there has not been research to assess the effectiveness of peer-led clinical governance to improve antenatal and postnatal care in those remote and disadvantaged communities that are likely to benefit most.

The Nini Helthiwan project, recently funded by the National Health and Medical Research Council (NHMRC), focuses on a new locally driven enhanced support model (clinical governance and peer-led targeted support) to reduce anaemia rates and improve the quality of maternal and infant primary care. Based in the Kimberley region of Western Australia, the intervention is clinical governance and peer-led targeted support for maternal and early infant care delivered by dedicated local midwife coordinators.

The project will evaluate this model of enhanced support using a rigorous, stepped wedge, randomised trial approach and structured questionnaires to assess acceptability, feasibility and sustainability. The primary outcome measure is that the new model of enhanced support for antenatal and postnatal care will significantly reduce IDA in infants aged six months of age. The secondary outcome measures are for: improved IDA in mothers and infants at six months postpartum; higher Bayley neurodevelopmental scores in infants aged six months; and greater satisfaction for mothers in their experience of maternal health care. The cost effectiveness of the model of enhanced support will also be assessed.

The study will be conducted over a five-year period in partnership with service providers in the Kimberley, and will be the first population- and region-based study of clinical governance and targeted, peer-led support in a remote region of Australia. The findings from this study will be used to develop better primary care models and to improve health outcomes for Aboriginal and Torres Strait Islander mothers and infants.

Community child health service delivery for vulnerable children in Western Australia

Professor Karen Edmond, School of Paediatrics and Child Health (SPACH), The University of Western Australia

The aims of the Community Child Health Service Delivery reform are to improve health services for vulnerable children in Western Australia, to reorient these services to enhance current social and

emotional wellbeing strategies, to better support vulnerable families, and to promote equity. There is a need for the provision of universal services to all 160,000 children in Western Australia under the age of five, of whom approximately 8600 (5%) are Aboriginal and Torres Strait Islander. Plans for this reform are currently being developed, with major drivers including the WA Department of Health, the University of Western Australia collaborators and Aboriginal Medical Services across the State.

Key activities to ensure the improvement of services – such as home, clinic and day-care based community child health – will include being inclusive, integrated, able to work in partnership, supportive and very flexible. This reform will aim to provide services in all areas with a focus on early intervention, from antenatal care through to 2.5–3 years of age.

In addition, this new reform will seek to address the delivery of high-quality universal services to meet the (new) needs of vulnerable families, proportionate to need, so as to promote equity (Marmot 2010). The reform will also concentrate on diverting resources to, and increasing resources for, vulnerable families to increase their choices and to focus on family and child needs (Marmot 2010).

A key integrated review and assessment of developmental vulnerability for children at 2–2.5 years of age will be undertaken using the adapted ASQ-TRAK tool, rather than waiting until the school entry assessment by the Australian Early Development Census (AEDC). This earlier focus will provide a more pre-emptive understanding of developmental progress for children, and allow for plans to be developed to enhance their social and emotional wellbeing. The active primary prevention will focus in high-impact areas, which includes supporting:

- social and emotional wellbeing of families (reducing 'toxic stress')
- responsive social interaction (child, parent, family led)

- the promotion of attachment (secure base, exploration, safe haven)
- the promotion of social learning ('time-in circle of security' and nurturing care giving).

The reform will have a family-centred care approach and establish partnerships with Aboriginal Community Controlled Health Organisations (ACCHOs) and the Aboriginal Health Council of Western Australia to identify further desired key outcomes, to improve service delivery and to meet the needs of families (Griew et al. 2008). The reform will focus on a birth cohort of 32,000 children per year, including approximately 1700 Aboriginal and Torres Strait Islander children, with 40 per cent of children living in metropolitan regions and a further 15 per cent in remote or very remote areas.

Data linkage will be established with existing data systems (routinely collected data), including: hospital admissions; midwife services; birth notifications; emergency department presentations; the Pharmaceutical Benefit Scheme; the AEDC; the justice system; the Medical Benefits Schedule; and others.

Measuring health outcomes for young Indigenous Australian exposed to the criminal justice system: Challenges and opportunities

Professor Stuart Kinner, Griffith Criminology Institute, Brisbane

Aboriginal and Torres Strait Islander men and women, particularly young people, are dramatically over-represented in the Australian criminal justice system. On any given day the number of young Aboriginal and Torres Strait Islander people under youth justice supervision is 15 times the number of non-Indigenous people, and in the adult justice system the ratio is 13 to 1 as shown in Figures 4 and 5 (on next page) (Avery & Kinner 2015; Dennison et al. 2013).

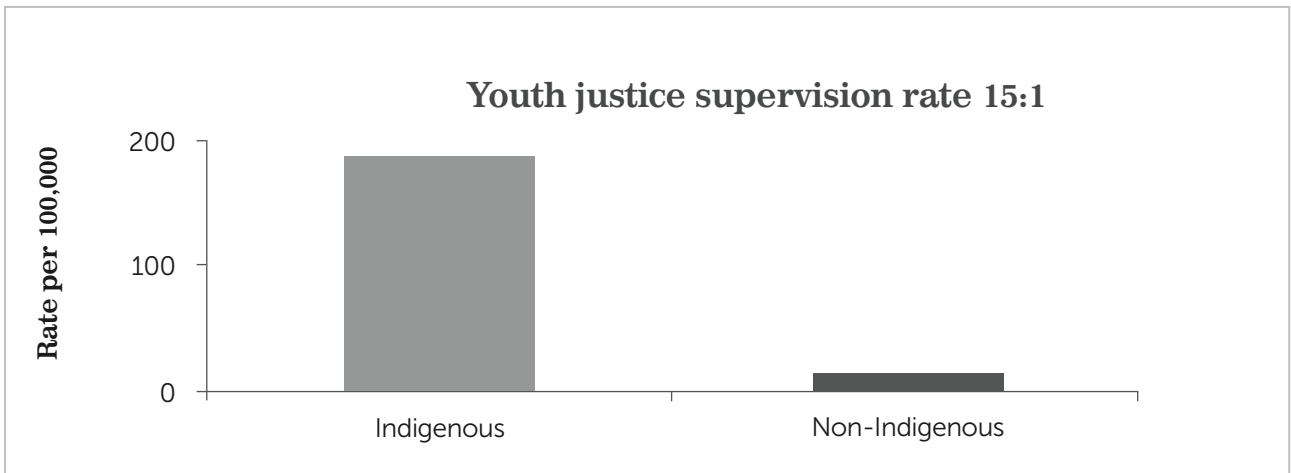


Figure 4: Youth justice supervision rates per 10,000 people

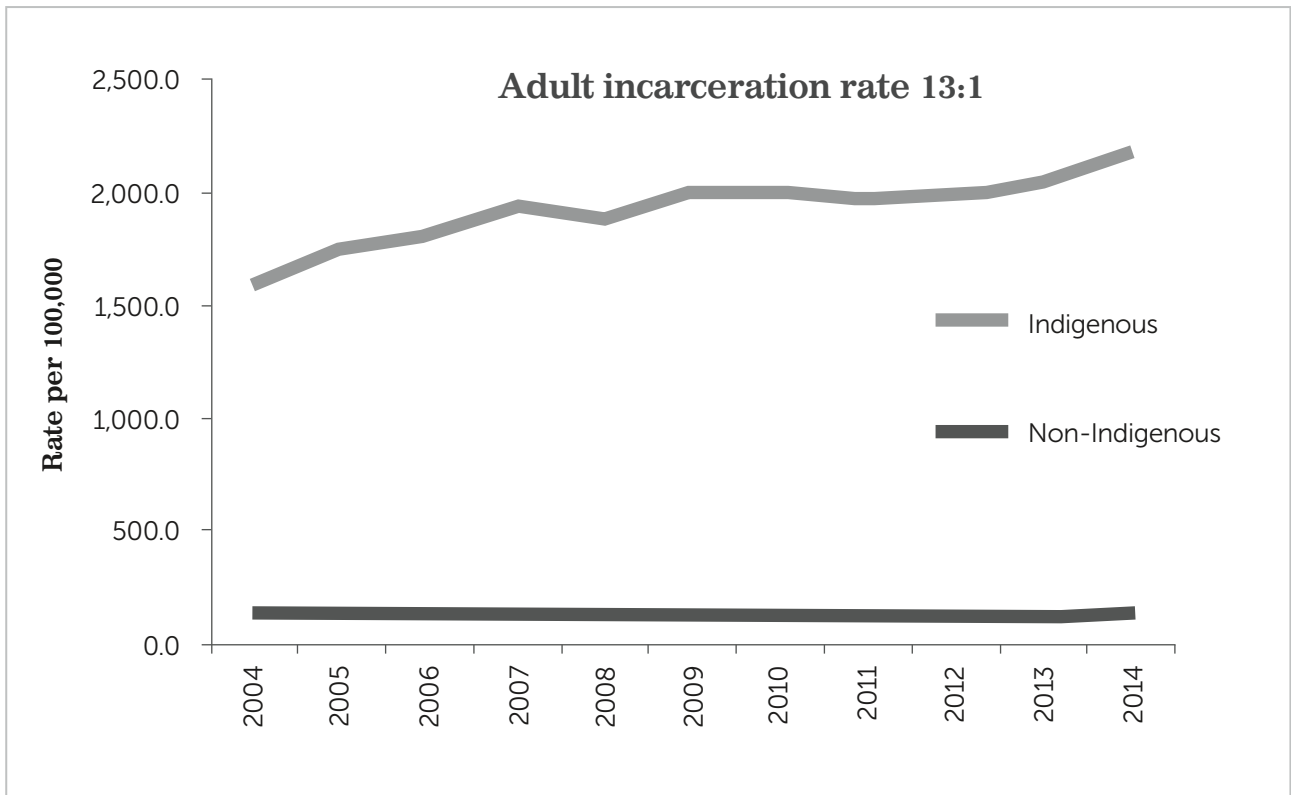


Figure 5: Adult incarceration rates per 100,000 from 2004 to 2014

Research estimates have also revealed that there is a profound over-exposure to the criminal justice system, particularly among young Indigenous people and among Indigenous women (Avery & Kinner 2015). However, accurate throughput data of people moving through our prisons is not yet publicly available from the criminal justice system, as it is for other large State-based systems such as public hospitals (Avery & Kinner 2015). Access to this throughput information is critical if we are to understand the extent of incarceration both for Indigenous and non-Indigenous adults and young people, and the prison population's characteristics (including family/children in the community), needs, and health and other outcomes following release (Avery & Kinner 2015).

Recent research in Queensland has estimated that Indigenous children are nine times more likely than non-Indigenous children to experience the imprisonment of their father in one year, and four times more likely to experience paternal imprisonment by age 17 (Dennison et al. 2013). This exposure to parental incarceration can have profound and long-term effects on the health and social and emotional wellbeing of these children.

Incarceration rates for Indigenous Australians are continuing to rise and there is growing evidence of poor outcomes after release from prison, with the experience of incarceration typically being health depleting for individuals (Kinner & Wang 2014; Fazal & Baillargeon 2011; van Dooren et al. 2013). Growing evidence indicates that release from prison is a critical time during which people are at a dramatically elevated risk of death, with this risk considerably greater for young people (Kinner et al. 2012). It is imperative that while we pursue approaches to decreasing and preventing incarceration for people, attention also needs to be given to the pressing health and social needs of those already engaged with the justice system.

The Australian Institute of Health and Welfare (AIHW) national report on the health of Australia's Indigenous and non-Indigenous prisoners is now in its fourth iteration, and has focused policy makers' attention on the pressing health needs of this group (AIHW 2013). However, despite emerging evidence of similar health disadvantage among juvenile detainees, there is as yet no comparable investigation for those caught up in the youth justice system. Given the renewed attention by policy

makers and human rights advocates on reducing the incarceration rates of Indigenous people, particularly the young, it is timely to take stock of current information regarding the health of this group, and to make a concerted effort to fill information gaps where they exist.

Working with communities across South Australia to identify issues for Aboriginal people in urban, regional and remote areas to include in studies

Assoc Prof Stephanie Brown, Healthy Mothers Healthy Families Group, Murdoch Children's Research Institute (MCRI), Melbourne

Healthy Mothers Healthy Families Research Group, MCRI and the Aboriginal Health Council of South Australia (AHCSA)

The Aboriginal Families Study is a population-based study of women giving birth to an Aboriginal baby in South Australia between July 2011 and June 2013. This study has been conducted by the MCRI in collaboration with the AHCSA.

The Aboriginal Families Study was preceded by extensive State-wide community consultations with ACCHOs and other members of the community. The consultation process was assisted by the AHCSA, and a newly established Aboriginal Advisory Group, to ensure that community knowledge both led and informed the focus and development of the research measures and methods to be used. This consultation also ensured that research questions were based on pressing issues identified by the community as being important for Aboriginal women in pregnancy, and provided an understanding of how this research could be beneficial to them and their communities.

The Aboriginal Advisory Group, set up under the auspices of the AHCSA, has guided the study since 2007. It has met every eight weeks to advise on the: design of community consultations; guiding of Aboriginal researchers in this process of consultation; interpretation of information from communities; and design both of a pilot study and of a study protocol to inform a successful three-year NHMRC grant application.

Following the initial community consultation, a 12-month pilot of the questionnaire was conducted for acceptability and face validity. Consultations revealed that the community preferred to complete the questionnaire by sitting down and going through it with an Aboriginal researcher. The pilot allowed for several iterations of questions to be tested, as feedback was received from participants, and ongoing changes made throughout this process to inform the design of the final study questionnaire.

A total of 344 women living in metropolitan, regional and remote communities across South Australia participated in the study and completed a booklet-based interview with an Aboriginal research interviewer at 4–12 months postpartum. Study participants were representative of Aboriginal women giving birth in South Australia, in relation to

the age of women at the time of giving birth. Over half of the women who took part were under 25 years of age. Questions about stressful events and social health issues during pregnancy were well completed by women participating in the study. The findings revealed the following commonly reported experiences: death of a family member/friend (41%); housing problems (43%); left home because of family argument (27%); being pushed, shoved or assaulted during pregnancy (16%) (see Figure 6 below). The findings also revealed that it is family connections that keep women strong.

Partnerships with communities and an ongoing process of community consultation, facilitated by Aboriginal researchers and the Aboriginal Advisory Group, have been key to the success of the Aboriginal Families Study.

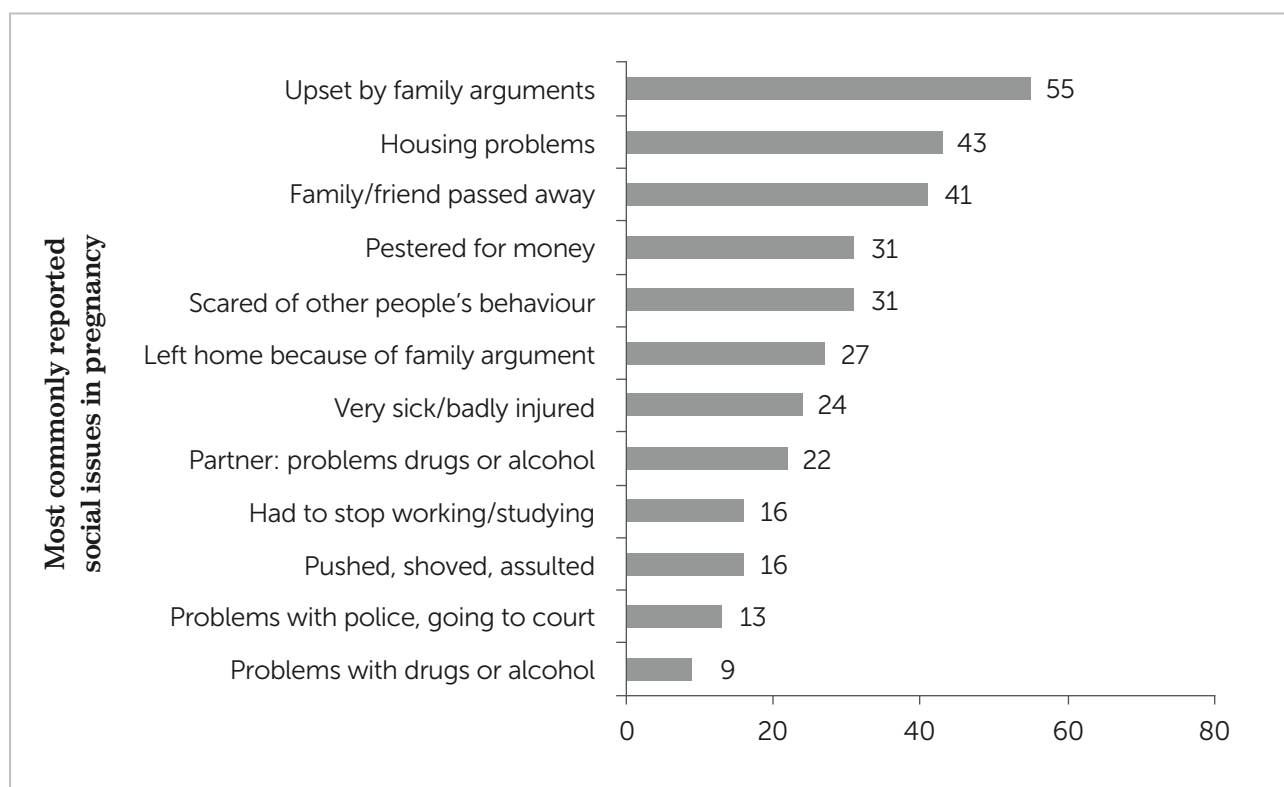


Figure 6: Most commonly experienced social health issues in pregnancy (Aboriginal Families Study)

Aboriginal birth cohorts and longitudinal studies

The Australian Aboriginal Birth Cohort Study: Lessons across the life course

Ms Belinda Davison, Menzies School of Health, Darwin, Northern Territory

The Australian Aboriginal Birth Cohort (ABC) Study was established in 1987 by the Menzies School of Health Research in Darwin, and is recognised as the longest-running and largest prospective study of Aboriginal people in Australia. The central aim of this prospective longitudinal study is to examine the influence of early-life factors on adult health and disease, and to provide early identification of those most at risk of developing chronic diseases such as diabetes, CVD, chronic kidney disease (CKD) and mental ill health, thereby

enabling intervention strategies to be targeted at the most appropriate age group.

The study cohort of 686 participants was recruited at birth at the Royal Darwin Hospital, and participants continue to be followed up at their specific places of residence across more than 40 different communities in northern Australia. Following the initial recruitment (Wave 1), the study has included several follow-up 'waves' at specific intervals since birth (see Table 1 below), including at the mean ages of 11.4 years (Wave 2), 18.4 years (Wave 3) and 25 years (Wave 4). The most recent wave of data collection (Wave 4) was conducted between 2013 and 2015 and included obtaining physical health and emotional wellbeing information from 67 per cent of the original cohort (follow-up with some others was restricted due to extreme/remote locations), with participants' ages ranging from 22–28 years.

Table 1: Stages (waves) in the Aboriginal Cohort Study 1987–2015

Stages	Date	No. of participants	Mean age (years)	Measurements
Wave 1	1987–1990	686	At birth	<i>Baby:</i> weight, length, head circumference, gestational age, abnormalities, risk factors <i>Mother:</i> socio-demographics, place of residence, education, substance use, smoking habits, medical history, antenatal and other past medical history
Wave 2	1998–2001	572	11.4	Socio-demographics, body size and shape, and respiratory, CKD, CVD and metabolic measures
Wave 3	2006–2008	469	18.4	Socio-demographics, body size and shape, respiratory, CKD, CVD, and metabolic and inflammatory measures, surrogate cardiovascular system (CVS) markers, grip strength, emotional wellbeing, substance use, dental, Hepatitis B immunisation status, iodine status
Wave 4	2013–2015	459	25	Socio-demographics, body size and shape, respiratory, CKD, CVD, and metabolic and inflammatory measures, surrogate CVS markers, muscle and bone strength, emotional wellbeing, lung function, substance use, biomarkers of stress, Hepatitis B immunisation status, iodine status

The study has grown, and each interval or wave of follow-up has been further developed and/or expanded to reflect the lessons learned in the conduct of the previous wave(s), age-appropriate measures, biomedical advances, and the harmonising of research methods to reflect changes across the 28-year time span. Each wave of the study has involved the collection of core biomedical measures, with Waves 3 and 4 expanding the biomedical model to include measures of emotional wellbeing, cognition, dental, socio-economic markers and biomarkers of stress. Difficulties have been identified in the direct comparison of results with national statistics due to limited age-specific data and geographic differences within the cohort.

Despite challenges due to the vast distances and sparse populations, the study has been successful in following 70 per cent of its participants thus far, and in obtaining detailed physical health and emotional wellbeing information directly from each of them. Plans are underway to undertake a further wave of the study in the future.

ActEarly Group: Support for longitudinal studies

Mr Will Siero, Murdoch Childrens Research Institute, Royal Children's Hospital, Melbourne

The problems we face as a society are complex. In the area of health alone, the dramatic rise in non-communicable diseases globally has been described as 'an emergency in slow motion'. Australia, and in particular our Aboriginal and Torres Strait Islander population, has one of the highest prevalence of NCDs in the developed world, representing 85 per cent of our total burden of disease in 2010. NCDs pose major health challenges in a country with a growing population, increasing health care costs and stagnating budgets.

The Developmental Origins of Health and Disease (DOHaD) Society of Australia and New Zealand has a coordinated interdisciplinary approach to the growing burden of NCDs. This approach focuses

on the known links between maternal, perinatal and early childhood factors, and the risk of developing NCDs later in life. Early interventions aimed at promoting a 'healthy start to life' can reduce the risk of early and later development of these diseases.

In the face of these challenges, new approaches are urgently needed that cut across traditional boundaries. They require large collaborative multi-sector solutions to understand why NCDs occur, what to do about them and how best to manage them. No longer can we afford to start new research projects in isolation, as these provide an incomplete picture of the factors that influence the health and wellbeing of individuals and communities.

In response to this, researchers through the DOHaD Society of Australia and New Zealand have initiated the ActEarly initiative. ActEarly aims to bring cohort studies and researchers together in order to:

1. Share knowledge of what studies are in existence and development.
2. Develop a platform to share what works and the problems encountered, with assistance to overcome these challenges.
3. Harmonise measures across existing and future studies and produce life-course data.
4. Provide an opportunity to harmonise data and systems in studies going forward.
5. Offer a platform to assist with combined grant applications and publications.
6. Support joint translational projects, and government implementation, of combined study findings.

ActEarly provides a new and innovative platform that facilitates the bringing together of multiple longitudinal cohort studies for researchers and institutions across Australia to benefit from shared knowledge, past experience, and ongoing and future developments in this area.

Creating the ability to compare

Dr Catherine Chamberlain, Aboriginal Health Domain, Baker IDI Health and Diabetes Institute and the Indigenous Health Equity Unit, The University of Melbourne

There is a growing recognition among researchers for the need to create and improve the ability to compare outcomes between birth cohorts and synthesise evidence. Birth cohorts have a key role to play in generating evidence around the First 1000

Days. The importance of early environments for later health and improving health equity is reflected in the Aboriginal and Torres Strait Islander Health Plan (Commonwealth of Australia 2013), which recommends 'strengths-based, family-focused interventions using life-course approaches which address social determinants'. Birth cohorts play an important role in life-course epidemiology, as they are one of the few research models that have the capacity to illuminate health trajectories and highlight opportunities for prevention.

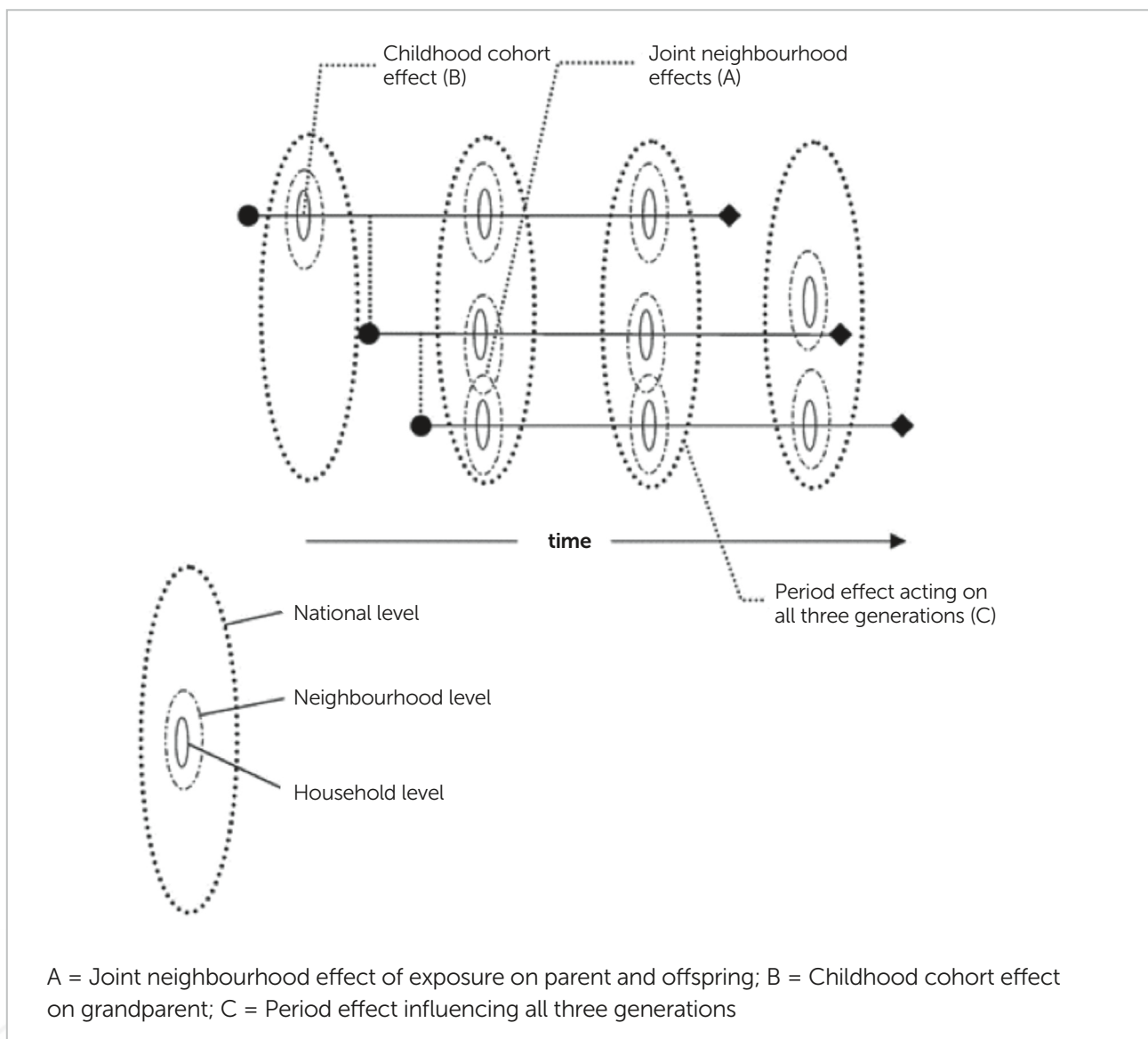


Figure 7: Multi-generational schema illustrating the possible influences of hierarchical and life course exposures on disease risk (Ben-Shlomo et al. 2002)

However, for the evidence to be useful for policy and practice decision-making, it needs to be published in a form that can be collected and synthesised within the context of the whole body of relevant evidence. This is particularly important in research related to the First 1000 Days.

Despite the potential benefits of illuminating health trajectories and highlighting opportunities for prevention, there are several challenges both to synthesising evidence and to ensuring the effective

use of evidence from systematic reviews. These challenges include issues as to the quality of the primary research and the lack of uniformity in reporting in research trials and reviews. There is a growing recognition among clinical researchers that what is needed is an agreed standardised collection of outcomes, such as core outcomes datasets and generic protocols. Key elements for developing core outcomes include collaboration with experts (including policy and practice), a conceptual framework, a clear systematic process and flexibility.



Developing the Research Questions in Early Life Studies: First 1000 Days Ecological Framework

Symposium participants were asked to discuss the First 1000 Days Ecological Framework and develop potential research questions around early life studies. The development of the First 1000 Days Ecological Framework has been a deliberate and dynamic process, informed through consultation and engagement with key stakeholders, and involving scientific research, program evaluation and on-the-ground experience. Initially informed by the First 1000 Days Scientific Symposium (Arabena et al. 2015), and further developed at the Researchers' Forum, the Ecological Framework now includes a portfolio of preliminary research questions that provide a starting point for areas of investigation in the First 1000 Days program.

The following section outlines the Ecological Framework and the developing research questions that emanated from the Researchers' Forum, and highlights the intrinsic and strong connections between each of these research themes as the holistic model of the First 1000 Days. The six themes of the Ecological Framework are:

- Community governance
- Increasing antenatal and early years engagement

- Family environment
- Service use and provision
- Data for evidence
- Interventions.

Community governance

Theme description

Community governance, engagement and partnerships with community are essential to ensure that research and interventions are led by, and include, Aboriginal and Torres Strait Islander people as co-designers, co-implementers and co-knowledge translators of research and research outcomes. Community governance also ensures that research is designed to increase the number of opportunities for community leadership in agenda setting and decision making, thereby growing both the number of Aboriginal and Torres Strait Islander leaders in this field, and the cultural responsiveness and capacity of health service systems to meet the needs of Aboriginal people.

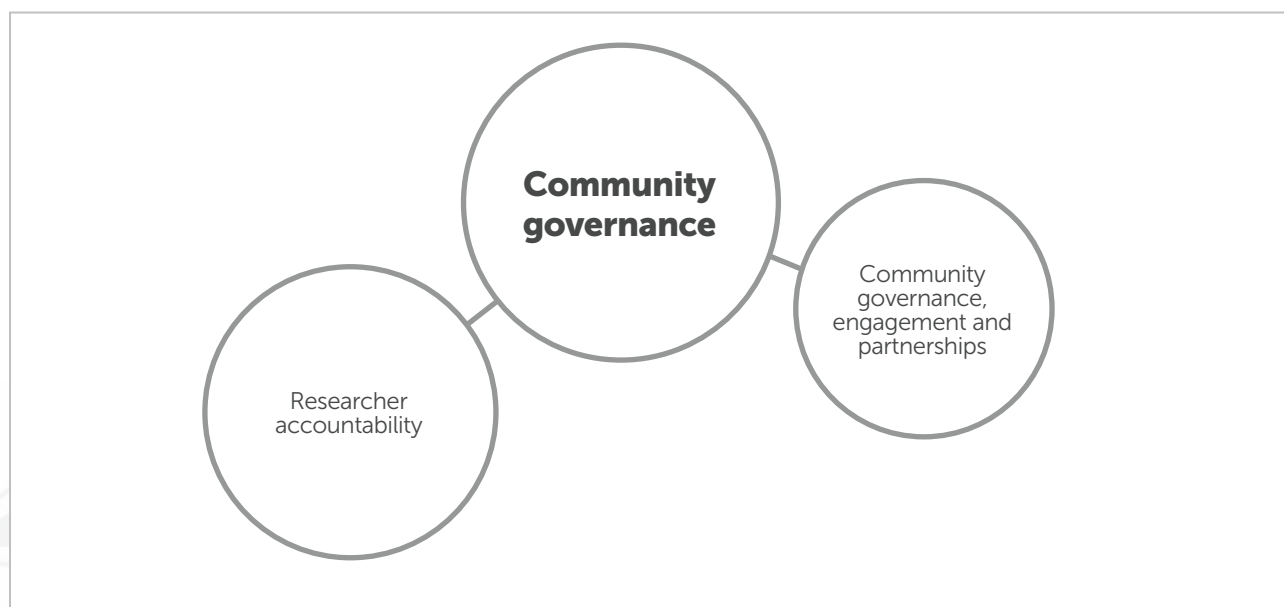


Figure 8: Identified Ecological Framework themes and sub-themes relating to community governance

Participant discussions during the Researchers' Forum highlighted the importance of, and current need for, community governance, engagement and the establishment of ongoing partnerships with communities. In emphasising the importance of community governance, participants also highlighted the need for establishing culturally appropriate methods of community consultation to guide this process. This need was reflected in key questions posed by participants regarding how consultation, engagement and partnership is achieved with Aboriginal and Torres Strait Islander communities, what is involved in this process for varying research types – i.e. short- vs long-term research programs; ongoing interventions; longitudinal cohort studies – and what constitutes effective and meaningful consultation.

From the researchers' perspective, it was recognised that a better understanding and awareness of existing approaches to community consultation, engagement and establishing partnerships could be gained by examining successful examples of these. Researchers suggested finding and evaluating examples of best practice community consultation methods and engagement processes, particularly where children are flourishing, while also acknowledging that the diversity of communities means that one size will not necessarily fit all.

Participants indicated there were also financial challenges for researchers in accessing adequate funding to intentionally include a process of community consultation and engagement that would both precede and carry on during and after research programs. Another challenge centred on the issue of how researchers can demonstrate benefits and outcomes of meaningful consultation with communities, rather than it being seen as just another 'box to tick' in the research process.

Further to this, participant discussions reflected on the need for accountability of both researchers and research institutions working with Aboriginal and Torres Strait Islander people and communities to ensure that families and communities remain engaged in the entire research process and benefitted from the research undertaken. In addition, researchers needed to guarantee that any data collected would be used and not collected for the sake of data collection.

Benefits identified by the researchers included the empowerment of communities and community leaders, and the improvement of services within and for the communities involved. It was also seen as important for researchers to avoid placing a burden of research on community workers and communities by coordinating their efforts prior to engaging with communities. Participants indicated the need for a shared network of knowledge regarding what other researchers and/or institutions are investigating, and the research questions, methods and measures being used.

Overall, the First 1000 Days program needs to allow adequate time and funding to ensure community governance processes are informed and can guide the course and direction of the Australian Model of the First 1000 Days. The successful impact of the model within communities will be dependent upon the preliminary and ongoing engagement and consultation of community members and advisory groups to ensure relevance, ownership and partnership.

Interconnections

Community governance is an integral and overarching theme across the wider Ecological Framework. Community governance, engagement and partnerships, together with researcher accountability, are the pivotal components informing and driving all other aspects of the Framework, for example:

- Community consultation will help to inform and guide the provision of care during preconception and the antenatal, postnatal and early years leading to *increasing antenatal and early years engagement*.
- Community consultation with family members, mothers, fathers and young people will help researchers to understand more fully the nature of the *family environment* and the concerns of parents, the intergenerational knowledge and mentoring needed to help raise motivated children, and the importance of cultural identity and connectedness to Country, people and culture.
- Engagement and partnership with community members, leaders and health workers will direct *service use and provision* to play a key role in the development of appropriate and effective

workforces, and the provision of comprehensive primary health care during preconception, antenatal, birth and early years engagement.

- *Community governance* and researcher accountability will guide the direction and processes of data linkage, baseline measures and outcomes within the theme of *data for evidence*, with community engagement and partnership informing linkage, data records and

evaluation. Researchers will be answerable to both the First 1000 Days Scientific Committee and the Community Governance Committee.

- Engagement and partnership with communities throughout the development, implementation and evaluation of key *interventions* will ensure these are culturally appropriate and will achieve greater impact for children and families throughout the communities.

Table 2: The developing research questions to be answered in early life studies relating to community governance

Questions raised by researchers regarding community governance	Potential challenges
<p>How would increased engagement with community stakeholders improve participation and the success of the program?</p> <p>Beyond publications: How do we ensure that women, men, children, families and/or community benefit from data collected and research undertaken?</p> <p>Researchers need to be more accountable, and to show how the research is going to benefit not just the community health services, but also how it will empower the communities themselves.</p> <p>What constitutes effective and meaningful consultation with Indigenous communities? How is this consultation best evaluated to demonstrate an improved quality of health outcomes?</p> <p>What do we know about engaging with those communities where children are flourishing? How has this engagement and consultation process made a difference to the community and the programs/ services being provided?</p> <p>How do we engage with communities to ensure ownership, the identification of culturally appropriate processes and an acceptability of each step of the research/intervention process?</p> <p>What does preliminary and ongoing engagement, ownership and partnership in working together with the community involve, in particular for long-term programs, ongoing interventions and longitudinal research?</p> <p>How can communities design and direct the development of First 1000 Days interventions?</p> <p>What constitutes effective and meaningful consultation with Indigenous communities? How is this consultation best evaluated to demonstrate improved quality of health outcomes?</p>	<p>Important for researchers to avoid creating a burden of research on communities. Organisations and researchers need to coordinate efforts prior to engaging with communities.</p> <p>The importance of translation/translators to be involved where appropriate throughout (before, during and after) the research process to provide information in a clear and understandable way.</p>

Increasing antenatal and early years engagement

Theme description

Poor antenatal engagement among Aboriginal and Torres Strait Islander women leads to poorer health at birth and throughout childhood. There is evidence that decreased self-efficacy results in health service avoidance, and cultural strengthening improves self-efficacy. Interventions focused on

increasing antenatal and early years engagement, and incorporating a case management approach, provide the opportunity for a measure of pre- and post-delivery outcomes for Aboriginal and Torres Strait Islander women and children. These include birth weight, maternal/paternal smoking rates, breastfeeding rates, attained height at age two years, and the impact of knowledge translation and delivery leading to increased antenatal engagement.



Figure 9: Identified measures and/or outcomes relating to increasing antenatal and early years engagement

Participant discussions highlighted the need to provide, support and enable appropriate preconception interventions for (young) men and women to improve family planning and pregnancy outcomes. The importance of holistic considerations for family planning was also discussed, which included aspects of health (i.e. genetics, gender, sexually transmitted infections or STIs, fertility), the physical environment, a loving family context (e.g. safe space), and quality relationships within family and community. Questions were raised concerning potential challenges to embedding these interventions into the school curriculum, the availability of appropriate resources to support them and the most effective method(s) for their delivery.

A potential research focus and questions were discussed as to the importance of nutrition during pregnancy, the role of traditional cultural foods versus that of processed foods, and the possible impact of antenatal nutrition programs for mothers and fathers. Other health promotion/education and support concerning breastfeeding was also considered important to empower parents and families to make informed choices about the role of, and their approach to, breastfeeding.

Investigating the impact of different stressors, throughout preconception and in utero, on the birth, growth and development outcomes of children were considered a major focus for First 1000 Days. In addition, discussions also centred on measuring the effect of caesarean birth vs vaginal birth outcomes on intestinal microbiota/microbiotic diversity, the developing immune system and long-term birth, growth and development outcomes.

Regarding postnatal and early years engagement, discussions highlighted the need to assess the impact of the First 1000 Days interventions through measures of growth outcomes, chronic disease outcomes for children, and also the assessment of the Abecedarian approach and its impact on child literacy rates.

Interconnections

Increasing antenatal and early years engagement is strongly interconnected with other themes within the Ecological Framework, including:

- *Community governance, engagement and consultation will help to inform and guide the provision of care during preconception, antenatal, postnatal and early years leading to **increasing antenatal and early years engagement**.*
- *Increasing antenatal and early years engagement during the First 1000 Days will assist in researchers gaining a better understanding of the **family environment** and the family mentoring, relationships, connectedness and supports that exist for the mother, father and child(ren).*
- *Service use and provision will play a key role in capacity building and the development of an appropriate and effective workforce (e.g. Aboriginal Health Workers, midwives, First 1000 Days case managers, etc.) responsible for the provision of care during preconception, antenatal, birth and early years engagement. An assessment and evaluation of current services will identify enablers and barriers to accessing services, ways in which to increase engagement with them, and help to inform best practice and provision of care.*
- *Data for evidence in the form of baseline measures, data linkages and outcome measures will provide a clear profile and measure of impact for the regions/communities that the First 1000 Days program seeks to impact by **increasing antenatal and early years engagement**.*
- *Key interventions will be developed and implemented that will focus on increasing antenatal and early years engagement in the First 1000 Days, including during preconception, pregnancy, and the postnatal and early years.*

Table 3: The developing research questions to be answered in early life studies relating to increasing antenatal and early years engagement

Research questions	Possible interventions	Potential challenges
<p>Would embedding preconception interventions into the school curriculum improve family planning and pregnancy outcomes for young men and women?</p> <p>Does the Abecedarian approach change child literacy outcomes?</p> <p>Does attendance at antenatal programs for mothers and fathers (that includes information on nutrition, breastfeeding, GDM, gestational age) change birth outcomes?</p> <p>What effect do the First 1000 Days interventions have on growth outcomes?</p> <p>What effect do the First 1000 Days interventions have on chronic disease outcomes?</p> <p>What is the best way to deliver preconception messages?</p> <p>Do STIs impact on fertility rates in the community?</p> <p>What is the effect of caesarean vs vaginal birth outcomes on intestinal microbiota/microbiotic diversity, the developing immune system and long-term birth, growth and development outcomes?</p> <p>What role does stress and the interaction of stress (and/or stressors) and nutrition have on birth, growth and development outcomes?</p> <p>What role does in utero stress and the interaction of stress (and/or stressors) and nutrition have on birth, growth and development outcomes?</p> <p>What do we understand about the nutritional needs of pregnant women and how traditional cultural foods/practices can address these needs compared to processed foods?</p> <p>Does a health literacy intervention delivered by Indigenous Health Workers have a positive impact on child and family health (mothers and fathers) during the First 1000 Days?</p> <p>Would embedding preconception interventions into the curriculum improve outcomes for young men and women?</p> <p>What are the key components of incentivised, home-visiting, health-seeking behavioural programs that would support men and women to become engaged in early pregnancy, antenatal and early life programs?</p> <p>What programs would be effective to improve a preconception intervention for young men and women who are hard to reach? How can we measure this success?</p>	<p>Preconception interventions in school</p> <p>Community centre family planning programs</p> <p>Nutritional (parental cooking, nutrition baby basket)</p> <p>Child safety</p> <p>Justice based</p> <p>Family violence</p> <p>Drug and alcohol</p> <p>Abecedarian literacy</p> <p>Child learning in the home</p> <p>Informed and supportive decision making in breastfeeding</p> <p>Traditional practices, knowledge, celebrations and ceremony</p>	<p>Involving schools</p> <p>How do we define a 'healthy outcome pregnancy' (e.g. birth weight, GDM; etc.)?</p> <p>How to develop an appropriate discussion concerning family planning that includes STIs and contraception (role of individual, caregivers and community in the discussion)?</p> <p>How to apply latest and relevant evidence into interventions?</p> <p>How do we engage pregnant young women who might not be living in a family home environment?</p> <p>How do we measure connectedness and involvement in culture, Country and people?</p>

Family environment

Theme description

The context of the family environment in raising resilient and flourishing Aboriginal and Torres Strait Islander children is well recognised and was a priority identified by participants both at the earlier Scientific Symposium and throughout the Researchers' Forum. It also focuses on identifying and describing 'gaps', thereby making the collective research story about early childhood one of deficits within the Aboriginal and Torres Strait Islander community (Bowes et al. 2014).

Nonetheless, by addressing family violence, enabling family mentoring, understanding how to be the best parents, and learning how to raise motivated children, the First 1000 Days' focus on the family environment can prevent any lifelong discrepancy in health outcomes, educational achievement and wellbeing (see Figure 10 below). Building Aboriginal and Torres Strait Islander leadership in this area is important in creating a shift from child and maternal health services to 'maximising protective factors in families'. Effective services that engage and support families of Aboriginal children during the First 1000 Days will enhance outcomes in relation to a child's engagement with school, the promise of health equity and strengthening the resilience of families.

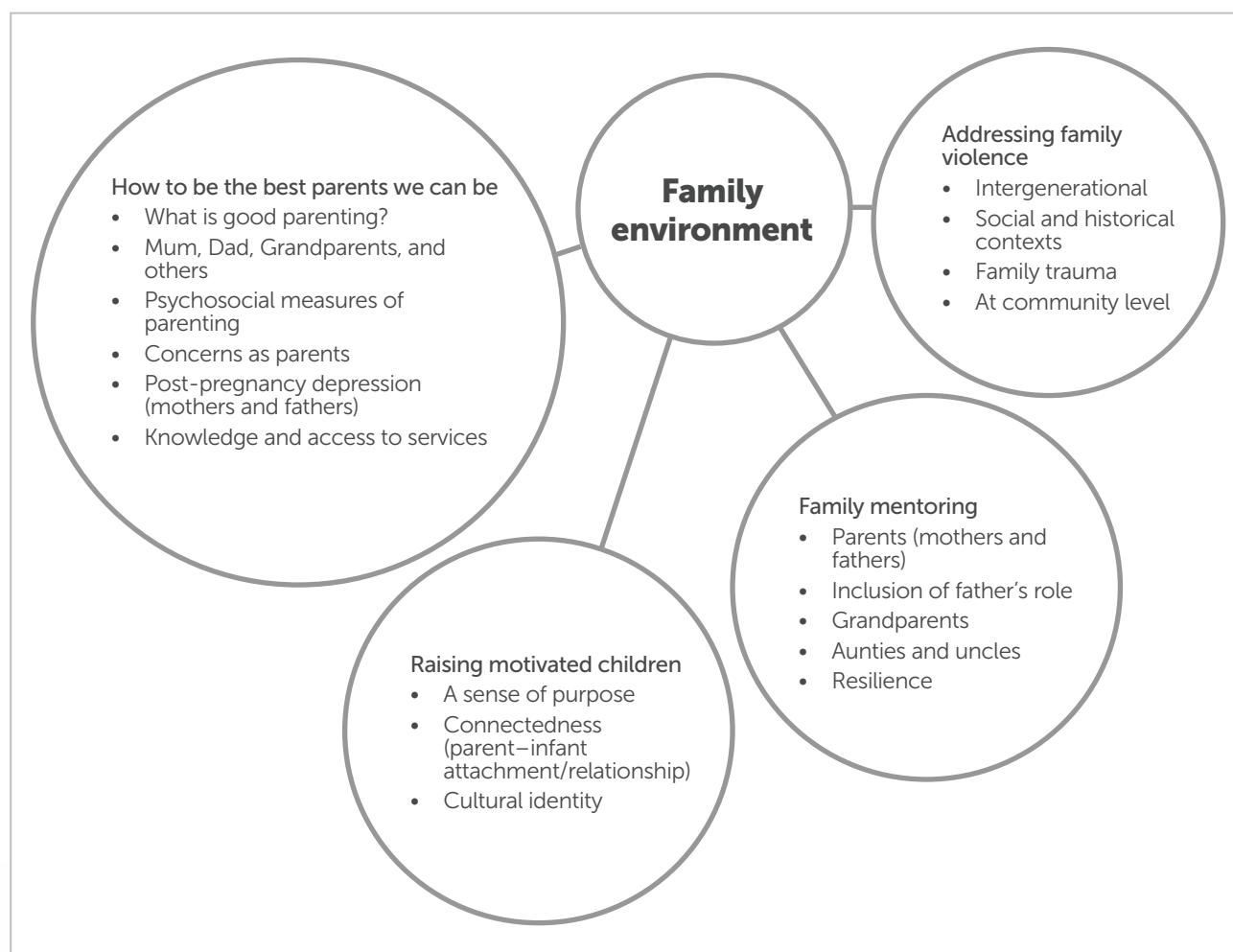


Figure 10: Identified measures and/or outcomes according to family environment

Participant discussions emphasised the need for research that explores the impact of intergenerational trauma and the subsequent loss of cultural knowledge on aspects of preconception, pregnancy, and the antenatal care and early years development of children. Research into family violence and violence interventions has direct implications for child protection and child deaths. Identifying what currently works in family violence interventions, and using an approach that recognises the spectrum of violence that addresses both physical and emotional violence, involves community consultation so as to address specific community needs and goals.

Identification of cultural protective factors for coping with stress is also essential. A good understanding of both generational and present family stressors during the First 1000 Days is currently lacking. This includes modifiable and familial stressors such as domestic violence and the impact of family violence on mothers, fathers, children and other family members. A validated instrument(s) to measure the impact of family violence needs to be developed, in addition to identifying ways in which to link/assess the impact of family violence and other related stressors on cortisol levels and early child health outcomes (i.e. birth weight, etc.). Participants were also interested in furthering research that focuses on the impact of maternal/paternal incarceration on health and educational achievement, and how it shapes future health outcomes.

Regarding aspects of family mentoring, participant discussions concentrated primarily on the lack of data/research focusing on the role of fathers during the period from (pre)conception through to early childhood. The inclusion of young men and fathers is needed to view the family in its entirety, rather than focusing exclusively on mothers and babies/children. Participants highlighted the need for the First 1000 Days program and family mentoring intervention(s) to consider:

- ways in which to nurture better relationships with men/fathers and to include fathers in antenatal education
- how and where (young) men get support for this transition into fatherhood

- how men engage with and work on developing trusting, loving relationships with their partners and children
- fathers' current involvement in family planning, child birth and child rearing
- how fatherhood (and motherhood) may be protective to individual health and protective to child(ren)'s health.

Finally, researchers were unsure what paternal data is currently collected among administrative datasets, and the roles fathers have within the context of the family environment, and how this role has changed/ is changing.

Another focus within the family environment is raising motivated children. Participants discussed the importance of education and parenting as the biggest determinants of whether young people flourish in the future. They emphasised the need for avoiding a deficit model of comparison, and instead using positive and successful examples within Aboriginal communities, and researching what is needed to raise strong and flourishing children. Discussions further highlighted the current lack of research into how Aboriginal and Torres Strait Islander communities develop and nurture resilience and what keeps individuals (including children and parents) and families strong. Forum participants also identified the possibility of interventions that develop and/or nurture resilience – particularly in the management of, and reaction to, stress for individuals, families and communities – and understanding how this can be achieved.

Good parenting is multi-factorial and involves the home, extended family, the community, antenatal and early postnatal care, and engagement with allied health and health professionals. The power of connecting to culture can provide good outcomes for children with vulnerabilities, even those in out-of-home care. However, the participants acknowledged challenges in identifying what cultural protective factors need to be in place during the First 1000 Days for mothers, fathers and their children, and how to support and/or build these in communities.

Interconnections

Family environment is strongly interconnected with other themes within the Ecological Framework, for example:

- Community consultation with family members, mothers, fathers and young people will help researchers to understand more fully the nature of the *family environment* and the concerns of parents, the intergenerational knowledge and mentoring needed to help raise motivated children, and the importance of cultural identity and connectedness to Country, people and culture.
- *Increasing antenatal and early years engagement* during the First 1000 Days will assist researchers in gaining a better understanding of the *family environment* and the family mentoring, relationships, connectedness and support that exists for the mother, father and child(ren).
- *Service use and provision* will play a key role in capacity building and the development of an appropriate and effective workforce (e.g. Aboriginal Health Workers, First 1000 Days case managers, etc.) to provide support and knowledge, and facilitate access to services that assist with issues of family violence, family mentoring and good parenting for those mothers, fathers, child(ren) and family members within the *family environment* during the First 1000 Days.
- *Data for evidence* in the form of baseline measures, data linkages and outcome measures will provide a clear profile and measure of impact for the regions/communities in which the First 1000 Days seeks to provide support and knowledge, and facilitate access to services that assist with issues of family violence, family mentoring and good parenting for those mothers, fathers, child(ren) and family members within the *family environment*.
- *Key interventions* will be developed and implemented that will focus on the *family environment* and the provision of support, knowledge and access to services that assist with issues of family violence, family mentoring and good parenting for those mothers, fathers, child(ren) and family members within the First 1000 Days.

Table 4: The developing research questions to be answered in early life studies relating to family environment

Research questions	Possible interventions	Potential challenges
<p>How do young men make the transition into being fathers? How and where do they get support for this transition? How do they engage with and work on developing trusting, loving relationships with their partners? What kind of health and wellbeing information do men require to be positive and effective partners and parents?</p>	<p>Developing and/or nurturing resilience particularly in the management and reaction to stress for individuals, families and communities.</p>	<p>How do we identify communities where children are flourishing/resilient?</p>
<p>How can we more effectively include fathers in antenatal education? What are the benefits of including men in the First 1000 Days program?</p>	<p>Developing an instrument(s) to measure the impact of family violence.</p>	<p>How to we develop a <i>validated</i> instrument(s) to measure the impact of family violence?</p>
<p>How do we nurture better relationships with men? What do men need to build, develop and maintain their relationships? How do we find out about fathers' current involvement in child birth and child rearing and get them more involved and empowered from preconception onwards?</p>	<p>Establishing a family mentoring program.</p>	<p>Identifying historical vs contemporary practices of fathers being present during birth.</p>
<p>What is the effect of maternal/paternal incarceration on health and educational achievement? How does it shape future health outcomes?</p>	<p>Including fathers in antenatal education.</p>	
<p>How can we ensure that children in care (and out-of-home care) remain connected to culture?</p>	<p>Identifying how and where (young) men get support for this transition into being fathers, including how men engage with and work on developing, trusting and loving relationships with their partners and children.</p>	
<p>What do we know about engaging the communities where kids are flourishing? What's the difference between these communities and ones in which kids are not flourishing?</p>		
<p>What kind of cultural protective factors need to be in place during the First 1000 Days for mothers, fathers and their children? Where can they get support with cultural protective factors? How do we build these in our communities? How do we make parents feel empowered to the point of activism about their child's health?</p>		
<p>What is fatherhood/motherhood, and how is fatherhood/motherhood protective to your health?</p>		
<p>What effect does the family environment have on the incidence of chronic disease?</p>		
<p>What aspects of culture and community enable the raising of positive and motivated children? What is needed to raise strong and flourishing children?</p>		
<p>What combination of social determinants strategies are required to underpin and support the health and wellbeing of families through the First 1000 Days to reduce stress? e.g. safe and affordable housing, poverty alleviation, family violence, drug and alcohol addiction?</p>		
<p>What do new parents want so that they feel supported?</p>		

Service use and provision

Theme description

Service use and provision will include the development of a First 1000 Days workforce through building the capacity of Aboriginal Health Workers and midwives in this area. A major focus will be directed towards developing a case management

approach to service provision so as to improve access to, and use of, comprehensive primary health care services for Aboriginal and Torres Strait Islander women, men and families in the First 1000 Days. Education, capacity building and further interventions will be informed through conducting needs assessments and evaluations of existing services, staff and users.

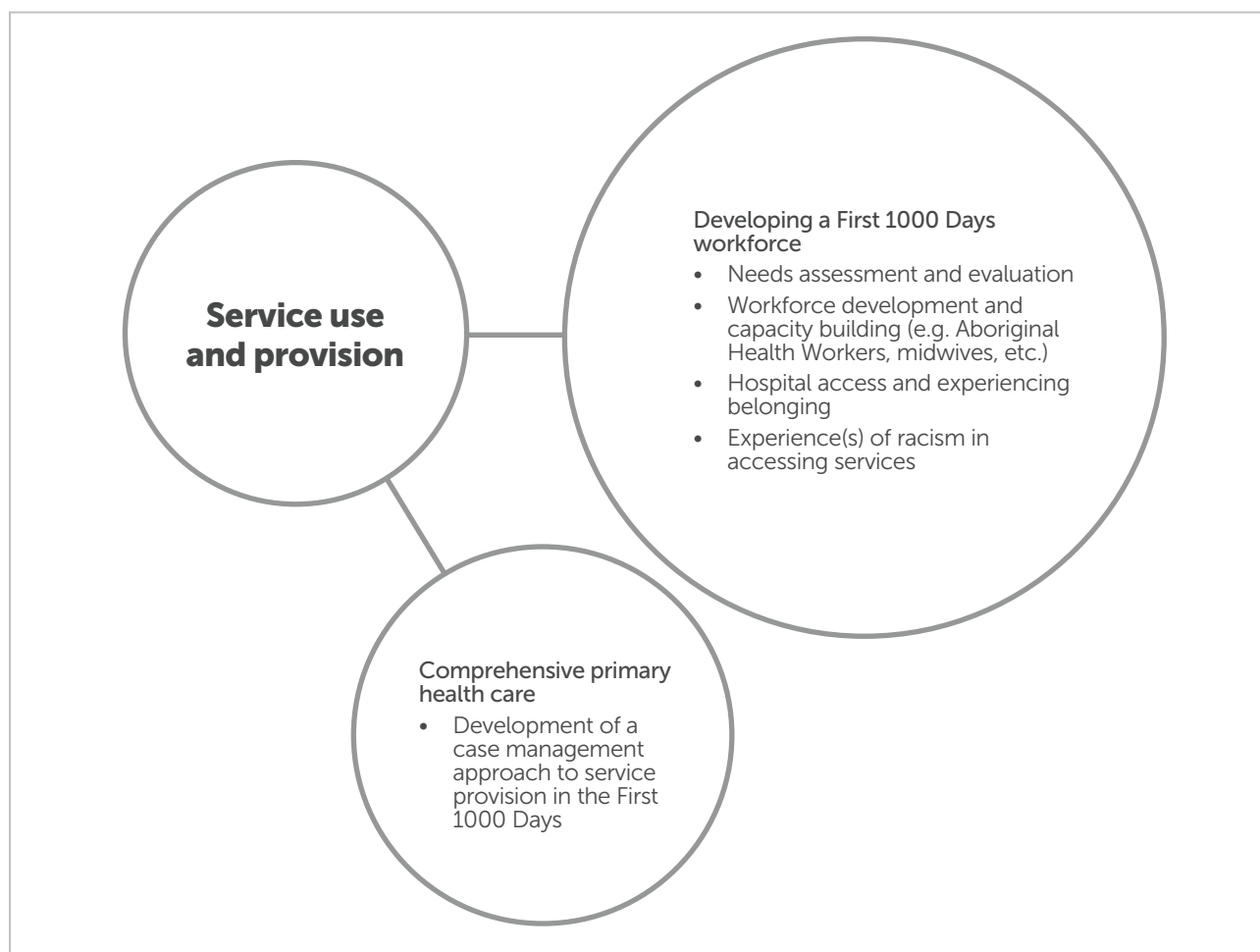


Figure 11: Identified measures and/or outcomes relating to service use and provision

Discussions during the Researchers' Forum emphasised the need for a multi-sectoral workforce model (such as education, health, justice, child protection, housing) to assist in implementing evidence-based approaches during the First 1000 Days and creating a positive impact on mother and father, and family health and wellbeing outcomes. This can be achieved through developing a case

management approach to service provision, ensuring a continuity of care, and meaningful collaboration between multi-sectoral services and families. Cultural safety interventions in health care systems was also perceived as an important element in overcoming barriers that prevent Aboriginal and Torres Strait Islander people from accessing health care services.

The importance of a continuous quality improvement approach, through assessment and evaluation of existing services and programs, was highlighted by participants, with the intention of informing best practice standards in the provision of care and services. This includes responding to feedback from families and individuals accessing (or attempting to access) these services. Furthermore, there is a need to assess what additional workforce capacity building is required within the existing health care workforce, in addition to practising self-care. Finally, potential interventions need to be assessed prior to their implementation so as to avoid an excessive workload burden on health care workers and other personnel.

Interconnections

Service use and provision has strong links and interconnection with other themes within the Ecological Framework, including:

- Engagement and partnerships with community members, leaders and health workers will ensure that *service use and provision* play a key role in the development of an appropriate and effective workforce, and in providing comprehensive primary health care during preconception, antenatal, birth and early years engagement.
- *Service use and provision* will play a key role in capacity building and the development of an appropriate and effective workforce (e.g. Aboriginal Health Workers, midwives, First 1000 Days case managers, etc.) responsible for the provision of care during preconception, antenatal, birth and early years engagement. Assessment and evaluation of current services will identify enablers and barriers to accessing and increasing engagement with services, and help to inform best practice and provision of care.

- *Service use and provision* will play a key role in capacity building and the development of an appropriate and effective workforce (e.g. Aboriginal Health Workers, First 1000 Days case managers, etc.) to provide support and knowledge, and facilitate access to services that assist with issues of family violence, family mentoring and good parenting for those mothers, fathers, child(ren) and family members within the *family environment* during the First 1000 Days.
- *Data for evidence* in the form of baseline measures, data linkages and outcome measures will provide a clear profile of *service use and provision* within First 1000 Days regions/communities, including information on existing services and their accessibility and identifying gaps in service provision.
- *Service use and provision* of comprehensive primary health care services will be achieved, in part, through the development and *intervention* of a case management approach in the First 1000 Days.

Table 5: The developing research questions to be answered in early life studies relating to service use and provision

Research questions	Possible interventions	Potential challenges
<p>What multi-sectoral approaches (education, health, justice, child protection) are needed to positively impact on mothers and fathers, and family health and wellbeing outcomes? How do families and communities define health and wellbeing outcomes in the First 1000 Days?</p> <p>How can health equity be achieved through an integrated model of care for women, men and children during the first 1000 Days? Are these interventions working for the benefit of those engaged as end users? If so, how?</p> <p>How can communities design and direct the development and implementation of these interventions?</p> <p>Are there gaps in service coordination that impact negatively on families during this First 1000 Days? How can these be 'turned around'?</p> <p>How are we collecting and responding to client satisfaction statements in the development and delivery of First 1000 Days programs? How will service providers know when people are satisfied (or not) with the services they provide, particularly given cultural differences?</p> <p>What supportive structures do health services need to provide to front-line health workers to increase engagement with families who are already using established services?</p> <p>What are the barriers and enablers to child and family health services within communities for mothers, fathers and/or families from the perspective of Aboriginal Health Workers?</p> <p>What are the important health service issues/needs in the First 1000 Days from the perspective of women, men and families in their respective communities? What can health services do to provide more effective support to women, men and families to reduce poor outcomes?</p> <p>How do women, men and families experience existing services?</p> <p>What are the barriers and enablers to child and family health services for mothers, fathers and/or families? Why are women, men and families not engaging in primary and secondary health services? What are their experiences of care in the First 1000 Days? Are their needs currently being met?</p> <p>How do women, men and families experience the First 1000 Days intervention program(s)?</p> <p>What does best practice in Aboriginal and Torres Strait Islander health services look like?</p>	<p>Development of a comprehensive primary health care case management approach for the First 1000 Days.</p>	<p>How do we describe the experience of racism in accessing services?</p> <p>How do we measure 'belonging' in the experience of accessing health care services?</p> <p>How do we show that we are empowering health workers to do their job better?</p> <p>How do we ensure a healthy and detailed discussion of previous/existing programmatic failures to ensure that lessons learned help to inform the development of new interventions/programs (e.g. designs, methodologies, etc.)?</p> <p>How do we define care coordination?</p>

Data for evidence

Theme description

Data for evidence provides a focus for establishing data linkage and the collection of baseline and outcome measures (see Figure 12 below). To enable accurate reporting of the associated impacts, and to maintain researcher accountability to the development of an Australian Model of the First 1000 Days program, robust and rigorous measurements of the educational, health, cultural and wellbeing outcomes for Aboriginal and Torres Strait Islander children and families are required. And to quantify the impacts of First 1000 Days interventions for Aboriginal and Torres Strait

Islander people complete, accurate and consistent data will be needed. This will include improving the coordination, collection and monitoring of population data and working with governments and the Aboriginal and Torres Strait Islander health sector. It will also include assessing the process of implementing, initiating and recruiting at study sites in addition to ensuring the acceptability of the survey methods. A systematised data collection and analysis methodology will enable a comprehensive, rigorous and consistent empirical evidence base that will inform the social transformation needed to enable Aboriginal and Torres Strait Islander children, families and communities not just to survive – but to thrive.



Figure 12: Identified measures and/or outcomes relating to data for evidence

Group work discussion provided a forum for participating researchers to discuss and develop research questions for a prospective longitudinal birth cohort study that included the family and social environment from (pre)conception to the age of two with additional follow-up to six years of age encompassing school entry. The main topics raised by participants included:

- formulated research topics
- the methodologies employed while undertaking research including data collection
- identified challenges in measuring the social environment, and health and wellbeing outcomes rather than deficit outcomes
- identifying the need for a holistic community profile to inform measures of change
- ensuring the inclusion of health economics and policy implications into research questions
- the importance of engaging Aboriginal and Torres Strait Islander people in the design, implementation and knowledge translation of research programs
- ensuring the accountability of researchers.

Specific research questions, possible outcome measures, additional data sources and their associated potential challenges as raised by participants at the Forum are noted in Table 6 (see page 37).

Particular topics raised by participants concerned the measurement of biomarkers from blood, cheek swabs, urine, hair, nail, faeces and cord blood as well as growth and development markers. Specific markers of interest included anaemia, inflammation, exposure *in utero*, stress, the nutrition of mother and child, metabolic, haematological, gut microbiota, genetics, and indicators of growth, speech and hearing development. Health outcomes that could also be measured included infections – such as STIs, diarrheal disease, acute respiratory infection, skin infection, and rash with fever or illness and outbreaks – and early onset markers of chronic diseases such as diabetes, CVD, CKD, cancer and mental illness.

Technical challenges identified by the participants included ensuring quality data collection and

management, the cost of processing and storing biological samples, and the future usage of samples given the challenge of researcher hindsight and the ethics of collecting, storing and using a biological sample from a child. They also debated issues involving the appropriateness of genetic analyses and whether exploring epigenetics and non-modifiable associations would be necessary. The importance of methodology was highlighted throughout the participants' discussions, in particular, aspects of ethics in research (such as using bio samples and sampling children) and how to integrate the community governance of data usage and research direction in order to maintain community protection and researcher accountability.

In addition, data linkage was proposed as an alternative or additional source of data, such as linking with existing administrative datasets as well as combining cohort studies. Examples given included the Centre for Disease Control (Department of Health); National Minimum Perinatal Data Sets; AIHW mortality and morbidity data; Murdoch Life-Course Survey; 10 to Men (The University of Melbourne); Maternal and Child Health services (local council and State levels); Australian Early Development Census; Births and Pregnancy Outcomes; and National Key Performance Indicators. Strong collaborations and standardised protocols with existing cohorts (including international cohorts) would be required to harmonise measurements and outcome data. Participants indicated the need for a shared network of knowledge regarding what other researchers and/or institutions are investigating, research questions, and the methods and measures being used.

Participants also identified the challenge of using and building alternative measures of wellbeing and cultural strength, and highlighted the importance of identifying cultural protective factors that move away from a deficit model of health. Adopting novel approaches would be needed to measure:

- social context (socio-economic status, violence, overcrowding, incarceration, family networks, extended family and carers, connections to culture and community)
- resilience
- service use and measuring access

- key milestones for child development (including educational achievement at home and in school)
- exposure to racism
- parent and child attachment
- a sense of belonging.

Outcomes to be measured in the First 1000 Days program need to keep in mind translation of the data gathered. The program will generate important evidence needed by policymakers to enact social change. To do this, evaluation should be embedded into all programs and include their future cost effectiveness and other benefits.

Participants also proposed building mixed-methods baseline and follow-up community profiles for communities involved in the Australian Model of the First 1000 Days. This would include measures of the community catchment area and reflect the 'footprint' or profile of the community. Aspects that would be important to measure for these community profiles are outlined in Table 6.

Interconnections

Data for evidence is critical for all elements within the Ecological Framework, for example:

- *Community governance* and researcher accountability will guide the direction and processes of data linkage, baseline measures and outcomes within the theme of *data for evidence*, with community engagement and partnerships informing linkage, data records and evaluation. Researchers will be answerable to both the First 1000 Days Scientific Committee and the Community Governance Committee.

- *Data for evidence* in the form of baseline measures, data linkages and outcome measures will provide a clear profile and measure of impact for those regions/communities that the First 1000 Days seeks to impact by *increasing antenatal and early years engagement*.

- *Data for evidence* in the form of baseline measures, data linkages and outcome measures will provide a clear profile and measure of impact for those regions/communities in which the First 1000 Days seeks to provide support and knowledge, and to facilitate access to services that assist with issues of family violence, family mentoring, and good parenting for those mothers, fathers, child(ren) and family members within the *family environment*.

- *Data for evidence* in the form of baseline measures, data linkages and outcome measures will provide a clear profile of *service use and provision* within First 1000 Days regions/communities. This will include information on existing services and their accessibility, and identify gaps in service provision.

- The baseline data and data linkages achieved through *data for evidence* will help to inform the development of the First 1000 Days *interventions*, and will form a basis for measuring the impact/outcomes of these interventions.

Table 6: The developing research questions to be answered in early life studies relating to data for evidence

Research questions	Possible outcome measure(s) to assess	Possible additional data sources	Potential challenges
Can we combine bio-marker tests (saliva tests, hair and nail collection) to identify stress with qualitative research and cohort studies to better understand and respond to the impact and influencers of stress?	<p>Demographics and baseline factors</p> <ul style="list-style-type: none"> Residences: urban, remote, postcodes Age of mother and father Employment Education Source of income Parents Grandparents Family incarceration history Safe sex practices/behaviours Age at sexual initiation Age at first pregnancy Age of mother at the birth (i.e. for subsequent births) Age at fatherhood Age of father at the birth Antenatal attendance Breastfeeding Nutritional markers Midwife visits Level of connectedness with and involvement in Country, community and culture 	<p>Data linkage</p> <p>State data linkage</p> <ul style="list-style-type: none"> Departmental datasets <ul style="list-style-type: none"> Justice Human services Health Koori Heritage Database National Assessment Program – Literacy and Numeracy (NAPLAN) 	<p>Evaluation of existing tools to measure questions needed, e.g. measures of identity, cultural, community, country.</p> <p>How do we measure wellbeing or wellness?</p> <p>How do we measure cultural strength?</p> <p>How do we measure doing well, i.e. a baby thriving/flourishing?</p>
What nutritional parameters are key indicators of mother and child health?			
Which datasets need to be linked in order to answer research questions, e.g. Centrelink data with hospital and education data?			
How do we design an ethical observation study? Is it ethical and/or appropriate to do purely observational studies?			
How can we use Key Performance Indicators, parallel data or informal data and incorporate this additional information to measure outcomes and influence government?			
Why are Aboriginal and Torres Strait Islanders more prone to diabetes and what can be done to prevent this in the First 1000 Days?			
What is the impact of being born in detention on mothers, fathers, babies and families in the First 1000 Days?			
To what extent is the community and activities within it an indicator of health (e.g. Garma Festival's influence on the local and wider community)?			
What are the most effective ways to engage with policy makers in Aboriginal and Torres Strait Islander people's First 1000 Days?			
What are the barriers and enablers for policy makers on enacting the social determinants of Indigenous health?			
		<p>National data linkage</p> <ul style="list-style-type: none"> National Coroners Information System Centrelink <p>Using already measured data with alternative data sources</p> <ul style="list-style-type: none"> Australian Bureau of Statistics (ABS) <ul style="list-style-type: none"> National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) National Aboriginal and Torres Strait Islander Social Survey (NATSISS) Household, Income and Labour Dynamics in Australia (HILDA) Survey 	<p>Can we adapt the 'Growth and Empowerment Measure' (GEM) to incorporate 'cultural strength'?</p> <p>How to measure:</p> <ul style="list-style-type: none"> Resilience Parent–infant attachment–relationship with infant Racism Access – belonging in hospitals Community environment – Grandparents A sense of purpose, connectedness, cultural identity What do we want to modify now and what do we want to modify later?

Table 6 cont...

Research questions	Possible outcome measure(s) to assess	Possible additional data sources	Potential challenges
	<p>Clinical and biological measurements (biomarkers from blood, cheek swabs, urine, hair, nail, faeces and cord blood as well as growth and development markers)</p> <ul style="list-style-type: none"> • Markers of adult disease • Growth (Body Mass Index or BMI, anaemia, height, ears, nose and eyes) • Oral health • Biomarkers: cortisol for stress markers at birth and of mother (<i>in utero</i> exposure) • Clinical outcomes of pregnancy (e.g. birth weight, gestational age, APGAR 1 and 5 (Appearance Pulse Grimace Activity and Respiration), GDM) 	<ul style="list-style-type: none"> • Existing cohort studies • Twin Registry • Aboriginal Birth Cohort • Australian Association of Social Work have information about incarcerated youths • Longitudinal Study of Indigenous Children – Footprints in time • Victorian Aboriginal Childhood Mortality Study • The Gudaga Study 	<p>How do we foster resilience?</p> <p>How can we measure short- vs long-term outcomes as a result of interventions?</p> <p>What set of core indicators at age 2 years does the First 1000 Days want to achieve?</p> <p>How to build rapport between Aboriginal Health Workers, researchers and the First 1000 Days families and child(ren), particularly in relation to recruitment of families and also the request for sensitive information (e.g. early biomarkers, family trauma, etc.)?</p>
	<p>Impact measures and baseline factors</p> <ul style="list-style-type: none"> • Specific novel Intervention indicators <p>Outcomes</p>		
	<p>Success stories</p> <ul style="list-style-type: none"> • Parental outcomes • School outcomes • Adolescent outcomes 		
	<p>Measures of wellbeing</p> <ul style="list-style-type: none"> • Identity • Cultural • Community • Country • Individual • Family • Stress 		

Table 6 cont...

Research questions	Possible outcome measure(s) to assess	Possible additional data sources	Potential challenges
	<p>Clinical outcomes</p> <ul style="list-style-type: none"> • Growth (BMI, anaemia, height, ears, nose and eyes) • Chronic disease (CVD, CKD, post-traumatic stress disorder, depression) • Infectious disease • STIs • Morbidity • Mortality • Biomarkers • <i>Early origins of chronic disease</i> • Nutritional markers • Oral health <p>Birth outcomes</p> <ul style="list-style-type: none"> • Birth weight • Gestational age baby particulars • Novel clinical measures (e.g. ultrasound of kidneys) • Breastfeeding <p>Policy</p> <p>Health economics</p>		

Table 7: The measurement of baseline community profile

Research questions	Possible outcome measure(s) to assess	Potential challenges
<p>Community Profile</p> <p>What effect did the First 1000 days have on the community?</p> <p>How do women, men and families experience existing services?</p> <p>What are the barriers and enablers to child and family health services for mothers, fathers and/or families?</p> <p>Why are women, men and families not engaging in primary and secondary health services?</p> <p>What are women, men and families' experiences of care in the time period during (pre)conception to age 2 years?</p>	<p>Baseline</p> <p>Community centres catchment area profile</p> <ul style="list-style-type: none"> • Health workforce/services • Funding • Incarceration rates • Teenage pregnancies • ACCHOs <p>Community centre programs and attendance</p> <p>Incarceration rates</p> <p>Sudden Infant Death Syndrome (SIDS) rates</p> <p>Employment</p> <p>Education</p> <p>Age structure</p> <p>General age at first pregnancy</p> <p>Rates of STIs</p> <p>Rates of children in care</p> <p>Crime rates (e.g. drug offences/violence)</p> <p>School attendance</p> <p>School outcomes (Yr10, Yr11, Yr12, tertiary enrolment)</p> <p>Alcohol availability</p> <p>Community survey</p> <p>Demographics</p> <p>Experience of growing up (qualitative)</p> <p>Measures of wellbeing (quantitative/qualitative)</p> <p>Infrastructure</p> <ul style="list-style-type: none"> • Health workforce and information technology system well designed <p>Inter-service and inter-agency linkages</p> <ul style="list-style-type: none"> • Interagency referrals – number of referrals provided and referral uptakes • Follow-up visits and discharge summaries <p>Follow-up</p> <p>Intervention markers</p> <p>Post-intervention profile (as per baseline)</p>	<p>How do we define wellbeing?</p> <p>Identifying and gaining access to available data on the community.</p>

Interventions

Theme description

The first and primary feature of the Australian Model of the First 1000 Days is the development of holistic interventions that will improve the health and wellbeing outcomes of Aboriginal and Torres Strait Islander children from (pre)conception to the age of two. These are best delivered through the family environment, and by increasing antenatal and early years engagement along with service use and provision. Such interventions will have a primary

focus that may include, but are not limited to, areas that address: preconception; improving nutrition; increasing engagement with services through a case management approach; parenting and mentoring; education and early life literacy; drug and alcohol use; justice and child safety; and building resilience (see Figure 13). Throughout the Researchers' Forum, participants developed research questions, possible interventions, and possible outcome measures within the developing themes of the First 1000 Days (see Tables 2 to 7).

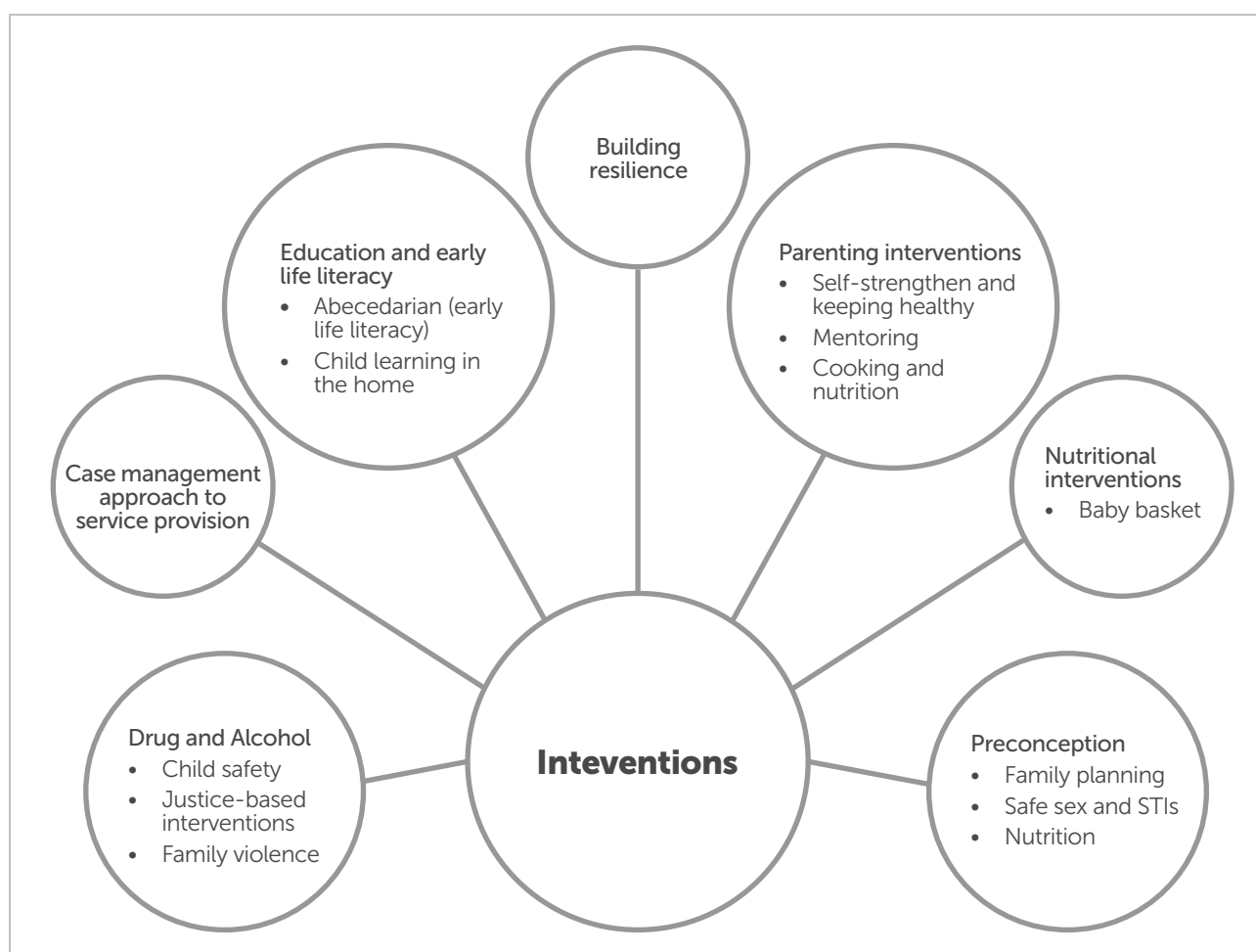


Figure 13: Identified measures and/or outcomes relating to interventions

Interconnections

The *interventions* element of the Ecological Framework is closely connected with other themes, for example:

- Engagement and partnership with communities throughout the development, implementation and evaluation of key *interventions* will ensure these are culturally appropriate and achieve greater impact for children and families in the communities.
- Key *interventions* will be developed and implemented that will focus on *increasing antenatal and early years engagement* in the First 1000 Days, including preconception, pregnancy and the postnatal and early years.
- Key interventions will be developed and implemented that will focus on the *family environment* and the provision of support, knowledge and access to services that assist with issues of family violence, family mentoring and good parenting for those mothers, fathers, child(ren) and family members within the First 1000 Days.
- *Service use and provision* of comprehensive primary health care services will be achieved, in part, through the development and *intervention* of a case management approach in the First 1000 Days.
- The baseline data and data linkages achieved through data for evidence will help to inform the development of the First 1000 Days *interventions* and form a basis for measuring the impact/outcomes of these interventions.

Moving the Agenda Forward

The Australian Model of the First 1000 Days involves two major interwoven projects. The first and primary feature of the program is the development of holistic interventions focusing on (pre) conception to the age of two to improve health and wellbeing outcomes for Aboriginal and Torres Strait Islander children through the family environment, increasing antenatal and early years engagement, and service use and provision. Interventions will have the primary focus of, but are not limited to:

- preconception
- improving nutrition
- increasing engagement with services through a case management approach
- parenting and mentoring
- education and early life literacy using the Abecedarian approach
- drug and alcohol education
- justice and child safety
- building resilience.

The second feature of the First 1000 Days program is the quantitative collection and measurement of the associated impacts of the First 1000 Days interventions. The quantitative arm incorporates the establishment of an Aboriginal and Torres Strait Islander prospective longitudinal birth cohort study following 1000 babies and their families from birth and, secondly, a baseline, mixed methods community profile at collaborating sites.

The engagement and consultation process enabled through these four Symposiums provide a practical underpinning for the development of the Australian Model of the First 1000 Days.

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Appendix 1: Program of the First 1000 Days Researchers' Forum

Time	Presenter	Presentation Title
9.00am		Acknowledgment of Country and Welcome, Introductions
9.10am	Professor Kerry Arabena The University of Melbourne	First 1000 Days Journey and Scientific Symposium (Ecological Framework, Strengths Based Approaches)
9.30am	Harmonising Measures and Outcome Data Regional Snapshots: What Measurements, What Data and Why?	Regional Initiatives
9.30am	Ms Felicia Dean and Mr Ben Tan Kaiela Institute, VICTORIA	Algabonyah Empowered Communities Data Approach – Goulburn Murray, Victoria
9.40am	Ms Rachael Ham Research Coordinator Ms Jenny Sewter Team Leader, Baby One Program Apunipima Cape York Health Council, Cairns, QLD Ms Lorraine Ahmat Coordinator, Baby One Program	Baby One Project, Cape York, Queensland
9.50am	Dr Adrienne Gordon Project Leader Charles Perkins Centre, University of Sydney	BABY1000 Study, Hunter Valley Region, NSW
10.00am	Dr Julia Marley The Rural Clinical School of Western Australia	The Nini Helthiwan Project: Improving Primary Care for Aboriginal Mothers and Babies in the Kimberley Region of Western Australia: A Population and Region Based Cluster Randomised Trial Driven by Local Health Service Providers
10.10am	Professor Karen Edmond School of Paediatrics and Child Health (SPACH) The University of Western Australia	Review of community-based ('universal') programs for vulnerable children in WA
10.20am	Professor Stuart Kinner Griffith Criminology Institute, Brisbane	Measuring health outcomes for young Indigenous Australians exposed to the criminal justice system: Challenges and opportunities.
10.30am	A/Professor Stephanie Brown Head, Healthy Mothers Healthy Families Group, Murdoch Childrens Research Institute, Melbourne	Working with communities across South Australia to identify issues for Aboriginal people in urban, regional and remote areas to include in studies

10.45am	<i>Morning Tea</i>	
11.15am	Birth Cohorts and Longitudinal Studies	Aboriginal Birth Cohorts in Australia
11.20am	Ms Belinda Davison Project Manager, Menzies School of Health, Darwin, NT	Darwin Aboriginal Birth Cohort: the Aboriginal Birth Cohort study is a prospective, life-course study of Indigenous newborns, with an emphasis on early causes and preventative interventions
12.00pm	Mr Will Siero Project Manager, Population Health, Murdoch Childrens Research Institute, Royal Children's Hospital Melbourne	Act Early Group: Supports for longitudinal studies
12.30pm	Group Work	Developing research questions to be answered in Early Life Studies: Themes from Scientific Committee Workshop and Regional Presentations
1.00pm	<i>Lunch</i>	
1.30pm	Group Work	Developing research questions to be answered in Early Life Studies cont...: Themes from Scientific Committee Workshop and Regional Presentations
2.00pm	Dr Catherine Chamberlain The University of Melbourne Group Work and Discussion	Creating the Ability to Compare Harmonising measurements and outcome data Generic Protocols and Core Outcomes Sets LSIC and other Data sets Preconception measures
3.30pm	Moving the Agenda Forward	Community Governance Forum
3.45pm	<i>Close</i>	

Appendix 2: First 1000 Days Researchers' Forum Registered Attendees

Title	First Name	Surname	Organisation/Institution
Mrs	Dina	Abdelsalam	The University of Melbourne
Miss	Lorraine	Ahmat	Apunipima Cape York Health Council, Cairns
Ms	Shawana	Andrews	Faculty of Medicine, Dentistry and Health Sciences, The University Of Melbourne
Dr	Gregory	Armstrong	Melbourne School of Population and Global Health, The University of Melbourne
Ms	Sharon	Atkinson-Briggs	Onemda, The University of Melbourne
Mr	Peter	Azzopardi	Centre for Adolescent Health & Wardliparingga Aboriginal Research Unit, South Australian Health and Medical Research Institute, Adelaide
Dr	Adrian	Bickerstaffe	Melbourne School of Population and Global Health, The University of Melbourne
Ms	Carlina	Black	Victorian Aboriginal Child Care Agency, Melbourne
Dr	Jacqueline	Boyle	Monash Health, Melbourne
Ms	Viki	Briggs	Onemda, The University of Melbourne
Miss	Isabel	Brookes	The University of Melbourne
Dr	Stephanie	Brown	Murdoch Childrens Research Institute, Melbourne
Dr	Catherine	Chamberlain	Onemda, The University of Melbourne
Dr	Sandy	Campbell	Apunipima – Cape York Health Council
Professor	Jeffrey	Craig	Murdoch Childrens Research Institute, Melbourne
Mrs	Belinda	Davison	Menzies School of Health Research, Darwin
Ms	Felicia	Dean	Kaiela Institute, Shepparton
Professor	Karen	Edmond	Child and Adolescent Health Service, The University of Western Australia, Perth
Mrs	Doseena	Fergie	Australian Catholic University, Melbourne
Dr	Sharon	Goldfeld	Royal Children's Hospital, Melbourne
Dr	Adrienne	Gordon	Charles Perkins Centre, The University of Sydney
Ms	Rachael	Ham	Apunipima Cape York Health Council, Cairns
Dr	Suzanne	Hood	ARACY – Australian Research Alliance for Children and Youth
Ms	Natalie	Ironfield	Centre For Adolescent Health & Wardliparingga Aboriginal Research Unit, The University of Melbourne
Dr	Rob	James	Western Health, Melbourne
Professor	Margaret	Kelagher	Centre for Health Policy, The University of Melbourne

Title	First Name	Surname	Organisation/Institution
Professor	Stuart	Kinner	Griffith University, Queensland
Dr	Shereen	Labib	Alfred Health, Melbourne
Dr	Chris	Lawrence	Onemda, The University of Melbourne
Ms	Jo	Luke	Onemda, The University of Melbourne
Ms	Maria	Luteria	Commonwealth Department of Health
Ms	Jasmine	Lyons	Onemda, The University of Melbourne
Dr	Jacki	Mein	Apunipima Cape York Health Council, Cairns
Dr	Julia	Marley	Kimberley Aboriginal Medical Services, Broome
Mr	Luke	Martin	Indigenous Health & Equity Unit, Department of Forensic Medicine, Monash University, Melbourne
Dr	Janya	McCalman	James Cook University, Cairns
Dr	John	McKenzie	Menzies School of Health Research, Darwin
Ms	Luella	Monson-Wilbraham	The Lowitja Institute, Melbourne
Ms	Chelsea	Motlic	
Professor	Joan	Ozanne-Smith	Department of Forensic Medicine, Monash University, Melbourne
Dr	Stacey	Panozzo	Onemda, The University of Melbourne
Miss	Ella	Perlow	The University of Melbourne
Dr	Megan	Power	Australia Indonesia Centre, Monash University, Melbourne
Dr	Alan	Ruben	Apunipima Cape York Health Council & Improving Services for Aboriginal Children, Cairns
Mrs	Jenny	Sewter	Apunipima Cape York Health Council, Cairns
Mr	Will	Siero	Murdoch Childrens Research Institute, Melbourne
Dr	Natalie	Strobel	School of Paediatrics and Child Health, The University of Western Australia, Perth
Ms	Sue	Sutton	Department of Prime Minister & Cabinet, Canberra
Mr	Ben	Tan	Kaiela Institute, Shepparton/KPMG, Melbourne
Ms	Jan	Thomas	
Dr	Jacinta	Tobin	Faculty of Medicine, Dentistry and Health Sciences, The University of Melbourne
Dr	Michael	Tynan	The Lowitja Institute, Melbourne
Ms	Donna	Weetra	Murdoch Childrens Research Institute, Melbourne
Ms	Jane	Yule	Onemda, The University of Melbourne





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