

# Submission to the Senate Select Committee on Stillbirth Research and Education

29 June 2018

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## Executive Summary and Recommendations

Stillbirth is not a rare event. It affects more than 2,000 Australian families each year. The personal, health system and economic costs are enormous. Many stillbirths are preventable, and Australia is underperforming in the challenge to reduce deaths and improve care and support for those who experience stillbirth.

This submission aims to inform the task of reducing stillbirth in Australia. It has been prepared by the [NHMRC Centre of Research Excellence in Stillbirth \(Stillbirth CRE\)](#), in partnership with:

- [Perinatal Society of Australia and New Zealand \(PSANZ\)](#),
- [Australian College of Midwives \(ACM\)](#),
- [Women's Healthcare Australasia \(WHA\)](#),
- [Sands Australia](#),
- [Still Aware](#), and
- [International Stillbirth Alliance](#).

Stillbirth is an issue of national significance that requires coordinated leadership and action across all levels of Australian government to improve the current and future wellbeing of Australian women, their families and our wider society.

We strongly urge the Council of Australian Governments (COAG) to make stillbirth research and education a national priority. Our recommendations are based on detailed knowledge and expertise in research, policy, and healthcare practice in Australia and internationally. Specifically, we recommend COAG works with relevant agencies to ensure the following:

### Using data to drive change

1. Implementation of a standardised national electronic reporting system to ensure real-time data collection on all births across Australia. This should include agreement on a single definition of stillbirths, and the systems to report on stillbirths, and any factors that could have prevented the deaths.
2. Annual national reports on perinatal deaths focussing on stillbirths, including reporting on deaths among Aboriginal and Torres Strait babies and other high risk groups, to monitor the impact of programs and policy on health inequities.
3. Inclusion of stillbirth rates as key performance indicators in all state and territory annual perinatal outcomes reports.
4. Implementation of hospital level audits into contributory factors relating to care for stillbirths and neonatal deaths, with jurisdictional and national reporting linked to practice improvement.

### Improving practice

5. Establishment of specialist bereavement care in all major maternity hospitals with outreach services to smaller and regional/rural hospitals.
6. Strategies to address the evidence-practice gap in relation to stillbirth prevention and care. This includes a process for effective guideline development and implementation of the Australian 'bundle of care' in stillbirth prevention, which focusses on antenatal care around smoking cessation support, fetal growth restriction, and decreased fetal movements.

7. Access to models of maternity care that are culturally-relevant and provide continuity of care with the aim that every woman in Australia has access to a known care provider.
8. Investment for sustained engagement with Aboriginal and Torres Strait Islander communities and services, and representatives of other population subgroups that experience high rates of stillbirth, to improve the cultural safety of clinical education programs, identify and facilitate community-led solutions, and tailor public education campaigns to the specific needs of these groups.
9. Increase in Overseas Development Assistance in countries neighbouring Australia that have extremely high stillbirth rates (e.g. Papua New Guinea, Timor Leste).

### **Investing in research**

10. Investment for research into new technologies to identify women at increased risk of stillbirth and other adverse pregnancy outcomes including funds to develop a national biobank.
11. Ongoing funding to continue and enhance the priority driven national program for stillbirth commenced by the Stillbirth CRE partners.
12. Development of a national strategy on preconception care, with support to primary care services for its provision, and investment in a national campaign on the importance of preconception care.
13. A review of Human Research Ethics Committee requirements for biobanks and access to other large repositories of research data (e.g. linked datasets) to enhance collection and sharing of data to hasten discoveries in stillbirth prevention.
14. Implementation of a streamlined approach to research governance approval processes to enable more large-scale studies into stillbirth. This would reduce delays in findings answers to important questions related to stillbirth.
15. Nationally consistent educational programs to ensure current and future health professionals are equipped to deliver best practice care for women and families after stillbirth.

### **Increasing public awareness**

16. A cohesive public awareness program on stillbirth for Australia that includes promotion of a national consensus on mechanisms to reduce stigma surrounding stillbirth and is targeted to social and cultural groups at greatest risk of stillbirth.

### **Improving perinatal pathology services**

17. An increase in the number of appropriately trained perinatal pathologists.
18. Access to a high-quality autopsy service for all parents without charge.

## Background

On behalf of the NHMRC Stillbirth Centre of Research Excellence - in partnership with the Perinatal Society of Australia and New Zealand (PSANZ), Australian College of Midwives (ACM), Women's Healthcare Australasia (WHA), Sands Australia, Still Aware and the International Stillbirth Alliance (ISA) - we provide this submission to assist in tackling the problem of stillbirth in Australia, and to reduce the unacceptably high burden of stillbirths for future families and the community.

Stillbirth is a serious public health problem in Australia and we welcome this Senate Committee Inquiry as an indication of the seriousness with which it is now being treated. As the highly prestigious medical journal, The Lancet, has stated,

**“Not all global health issues are truly global, but the neglected epidemic of stillbirths is one such urgent concern”<sup>1</sup>.**

The sorrow and sadness associated with a stillbirth has a profound rippling effect across communities that is long-lasting and is acknowledged to have significant social, emotional and economic impacts.

In Australia, over 2,000 families each year experience the birth of a stillborn baby, and there has been no significant change in overall stillbirth rates for over 20 years. One in every 137 Australian women who reach 20 weeks' of pregnancy will have a stillborn baby<sup>2</sup>. Australia lags behind other high-income countries; our stillbirth rate (beyond 28 weeks of pregnancy) is 35% higher than the best performing countries.

In addition, women from Aboriginal and Torres Strait Islander backgrounds experience double the rate of stillbirths as other Australian women, highlighting the urgent need for targeted action for this population.

**Stillbirths are thirty times more common than Sudden Infant Death Syndrome (SIDS)** and occur 1.25 times more often than the total number of infant and childhood deaths (0-14 years)<sup>3</sup>, but receive far less public or government attention. Bereaved parents identified the need for a 'cure' for stillbirth as their priority in a series of priority-setting meetings held with parents and researchers who subsequently formed the Stillbirth CRE.

The Stillbirth CRE is an NHMRC funded initiative, through the Faculty of Medicine, University of Queensland. Research led by the Stillbirth CRE collaborators shows that many stillbirths are preventable, particularly beyond 28 weeks of pregnancy, where survival for babies born alive approaches 100%<sup>4</sup>. Up to half of stillbirths at term in Australia are unexplained and further research into understanding why these deaths occur is needed.

The message that **stillbirths are NOT inevitable** has never been clearer. Recent Australian and international research and reports show that prevention is possible and that the number of deaths can be reduced through improved quality of care. The recent Bacchus Marsh review into cases of substandard care in Victoria, Australia and confidential inquiries in the United Kingdom<sup>5</sup> and New Zealand<sup>6</sup> provide incontrovertible evidence that **many stillbirths are avoidable**. With a coordinated approach it will be possible to reduce the rate of term stillbirth by 30% by 2025.

Urgent action is needed to raise awareness of the risk factors for stillbirth<sup>7</sup> and to implement effective interventions for women at increased risk. The implementation of these actions will yield multiple returns on investment that extend well beyond stillbirth prevention to include reductions in a range of other adverse maternal and neonatal outcomes.

Stillbirth exacts an enormous psychological and social toll on mothers, fathers, families and society<sup>8</sup>. It is estimated that 60-70% of affected women will experience grief-related depressive symptoms at clinically significant levels one year after their baby's death. These symptoms will endure for at least four years after the loss in about half of those women. Similar data are not available for other family members but it is likely that partners, siblings and grandparents are also profoundly affected.

Finally, the care of women and families after stillbirth is often inadequate. Health professionals are doing their best but many feel they lack the specific skills and expertise required, and often carry their own personal and professional burden after stillbirth.

## Response to the Inquiry Terms of Reference

### a) Consistency and timeliness of data available to researchers across states, territories and federal jurisdictions

Access to timely, high quality information on causes and factors contributing to the stillbirth are critically important for parents struggling to understand 'what went wrong', for future pregnancy planning and to inform effective prevention strategies at the population and health service level. Our research indicates significant room for improvement in investigation into causes of stillbirth with low compliance with recommended investigations<sup>8</sup> and 50% of affected parents reporting that they felt more could have been done to find out why their baby died<sup>7</sup>.

Autopsies are essential in helping find out why babies have died and what could be done to prevent other deaths. While national data are incomplete on whether an autopsy was performed, it is estimated that only 40% of stillbirths have full or limited autopsy. Only around 20% are known to have a full autopsy<sup>9</sup>. Autopsy rates are higher in some jurisdictions, such as Western Australia (WA), which has a rate of 60%<sup>10</sup>. Barriers to autopsy include the lack of qualified pathologists and poor counselling of parents by health professionals about the option of having the procedure performed. Parents face many critical decisions following stillbirth, including whether to consent to autopsy for their baby<sup>31,32</sup>. Parents and their clinicians need more support and guidance at this terrible time, to facilitate decisions that incorporate parents' values and minimise the likelihood of later regret about the decisions made. Often, parents accessing private maternity care are charged for the autopsy. This is unacceptable and inequitable. Coordinated public services, such as those in WA and South Australia, may be associated with higher autopsy rates and lower rates of unexplained stillbirths. Such a comprehensive autopsy service includes the provision of perinatal pathologists as well as clinical geneticists with interest in paediatric and reproductive genetics.

**In 20-30% of stillbirths, deficiencies in the quality of care in pregnancy and labour are implicated.** National perinatal mortality audit programs to identify substandard care contributing to stillbirths can reduce these deaths through an on-going cycle of practice improvement<sup>11,6</sup>. Without such a program in Australia, opportunities for prevention are often lost and the consequences for future families is high. An on-line system to enhance detailed investigation and reporting of

stillbirths and neonatal deaths has been developed by the Stillbirth CRE team in partnership with the Victorian Health Department and may hold the solution to the need for rapid action to reduce repetition of substandard care and risk of stillbirths. In both New Zealand and the UK national audit data and timely feedback has led to reduced perinatal deaths through quality improvement.

Better data are needed for all births, not only those with adverse outcomes, to improve care and outcomes. Current national practice in data collection is suboptimal and requires urgent attention, and is summarised in the report *Perinatal deaths in Australia 2013-2014*<sup>9</sup>. **Major impediments to timely, quality data to inform effective prevention strategies for stillbirth include significant duplication of effort and disparate approaches across and within states and territories.**

Stillbirth data in Australia are collected and reported in different ways by different groups. National rates and causes of stillbirths are reported by two government agencies that use different sources of information and report findings in different ways:

- The Australian Bureau of Statistics (ABS) report data on stillbirths that is collected as part of Vital Registrations based on death certificate data.
- In parallel, the Australian Institute of Health and Welfare (AIHW) reports stillbirth data from data collections on all births within the states and territories.

In addition, all states and territories have developed different approaches to collecting data on all births within their jurisdictions and different mechanisms for clinician review of perinatal deaths (stillbirths and neonatal deaths)<sup>12</sup>.

When the same definition of stillbirth is used, the stillbirth rate reported by the ABS is 5.5/1000 births<sup>13</sup> compared with the AIHW reported rate of 7.1/1000<sup>9</sup>. This equates to around 500 fewer stillbirths being reported annually by the ABS. This under-reporting is thought to be due to parents not notifying their local registrar of the stillbirth (required in addition to notification by the attending clinician) and the limited capacity of registrars to follow-up on partially registered stillbirths<sup>12</sup>.

With several different definitions of stillbirths and perinatal deaths in use<sup>14</sup>, we see wide variation in reported rates across jurisdictions. For example, stillbirth rates can vary if terminations of pregnancy (TOP) are included or excluded. Internationally, many countries exclude TOP from their stillbirth rates.

Variation in reported causes of stillbirth is also evident. ABS reports triple the proportion of unexplained stillbirths than AIHW – with ABS reporting 64%<sup>15</sup> versus AIHW reporting 20%<sup>9</sup>. This is because ABS use information on the death certificate issued at the time of the stillbirth, which is prior to the results of investigations into the causes of stillbirth being conducted. Data from AIHW are based on classification of causes following review of all available post-mortem investigations. A further issue is the use of the International Classification of Diseases (ICD) by ABS which limits the value of data on causes of stillbirth reported due to deficiencies in this system for perinatal deaths<sup>16,17</sup>. In response to these problems, PSANZ along with the Stillbirth CRE have developed a comprehensive system for classifying the causes of stillbirth and neonatal deaths to be applied to every death by a multidisciplinary panel<sup>18</sup>. However, development of a better classification system is not sufficient as variation in reported causes indicates a need for additional training and support to ensure greater consistency.

The PSANZ/Stillbirth CRE Clinical Practice Guideline for *Care around stillbirth and neonatal death*<sup>19</sup> highlights the need to improve data quality on stillbirths in Australia. This guideline targets clinicians in maternity services, promoting standardisation of investigation, classification and

reporting of stillbirths to improve the quality of data on stillbirths. However, uptake of the guideline into clinical practice across maternity services is variable. To address this problem we have developed a clinical training program targeting midwives and doctors; IMPROVE (IMproving Perinatal Mortality Review and Outcomes Via Education) Program<sup>13</sup> which addresses each area of the guidelines. This program is highly valued by participants and maternity services, but lack of funding has limited its availability across the country.

In recent years, AIHW has improved reporting of stillbirths through publication of a comprehensive report *Stillbirths in Australia*<sup>12</sup> and biennial reports on perinatal mortality<sup>9</sup>. However, the value of these reports is restricted by the limitations in consistency and comprehensiveness of existing data collections. Access to good data on stillbirths and live births is essential for researchers and policy makers, and current arrangements need to be improved. Additionally, as highlighted in the AIHW's *Australian Mothers and Babies* report<sup>20</sup>, there are still no common definitions for many data items collected across jurisdictions. Some important data items are not collected in all jurisdictions. This is a critical issue as variations in definitions between jurisdictions for important perinatal indicators impacts on the accuracy of comparisons and capacity to benchmark key outcomes. Differences in the definitions also has flow-on effects. It means that data are not available in a timely manner to facilitate policy decisions. Commonly, there is a time lag of two to three years between data collection and publishing in state/territory and national perinatal mortality reports<sup>14</sup>. The timeliness of data availability could be improved significantly by streamlining the processes for accessing de-identified data at the local, state and national level, including agreement on definitions and the processes used.

#### **b) Coordination between Australian and international researchers**

There is an extensive and highly collaborative international research community working together to try to reduce the burden of stillbirth. The International Stillbirth Alliance (ISA) was established in 2005 and provides a collaborative structure between researchers, health care providers, parent organisations and global health organisations. The ISA organises annual conferences and workshops, develops guidelines, and advocates on behalf of bereaved parents, but this organisation relies solely on funding from its members and from charitable donations. The Stillbirth CRE is the Australasian Regional Office of the ISA, and its co-directors are both past-Chairs of ISA and continue to participate actively in various ISA activities. ISA is in prime position to build further on existing and collaborative efforts to reduce stillbirth, and to establish new initiatives, particularly if further financial support is made available.

In 2020 the combined ISA and International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) global conference will be held in Brisbane, and many of the CRE researchers are members of the organising committee. Again, this is a significant opportunity to raise the visibility of stillbirth in Australia. Additional funding/sponsorship support is needed, especially to build on our current collaborations.

Much of the current and planned Stillbirth CRE research involves international collaborations, especially with UK-based researchers from the Tommy's Centre in Manchester (UK), and with various USA-based groups. There is also a strong trans-Tasman connection between the Stillbirth CRE and Auckland-based researchers through the Perinatal Society of Australia and New Zealand (PSANZ).

All international collaborations are necessarily limited by the available funding. Yet it is vital that international collaborations continue to be strong, as a truly global effort is needed to reduce

stillbirth. Health professionals, researchers and parent organisations from high income countries can learn from each other how to introduce best practice methods and can also assist low and middle-income countries to achieve the best possible outcomes, even in areas of limited resources.

Over the last 5 years, members of the Stillbirth CRE research group have been involved in running workshops in a range of settings including Canada, Ireland, Netherlands, Georgia, Sri Lanka, and Vietnam. It is the intention of the Stillbirth CRE to broaden its activities over the next 2 to 3 years to include research projects in some of Australia's neighbouring countries with high stillbirth rates. To do this, funding and Overseas Aid Development support is needed. Australia has an important part to play in the region to reduce stillbirth and to address care after stillbirth occurs.

### **c) Partnerships with the corporate sector, including use of innovative new technology**

Apart from some notable exceptions, such as the partnership between Stillbirth Foundation Australia and Price Waterhouse Coopers (PWC), there has been little involvement of stillbirth researchers with the corporate sector. The current focus of innovation is on devices to detect changes in fetal movement, although it is unclear if this has real potential to change outcomes. There are other examples of new technology in which biomarkers might either predict the pregnancies 'at risk' or detect the vulnerable fetus late in gestation, but both of these require much more research.

The Stillbirth CRE is very keen to partner with the corporate sector and continues to explore opportunities in the area of potential future uses of new technologies. Areas of particular interest are:

- improving detection of the unborn baby who is at-risk
- detailed evaluation of potential harms, including anxiety, of unnecessary intervention (such as preterm delivery)
- prevention of spontaneous preterm birth (which contributes to around 15-20% of stillbirths)

The economic impact of stillbirth is significant and far reaching and extends further than just the direct costs to the healthcare sector. One important area in which major employer groups might see benefit from targeted stillbirth research is in the impact of pregnancy loss on women and their families in terms of time off work, altered work performance, and other employment-related impacts. Improving bereavement care and recovery after stillbirth has potential beneficial spin-offs for employers and the broader economy, and this could encourage investment from the corporate sector.

### **d) Sustainability and propriety of current research funding into stillbirth, and future funding options, including government, philanthropic and corporate support**

To ensure maximum gains from research funding and therefore benefit for families, we strongly believe that a unified national priority driven approach, building on the Stillbirth CRE model, is needed. The CRE's program is based on research priorities developed through consultation with parents, parent-based support and advocacy organisations, the world's foremost expert researchers and clinicians, and the community in Australia<sup>21</sup>. It is essential that there is national agreement on research priorities, so that all funding bodies (government, philanthropic and corporate) can work together to produce the best possible outcomes. As well as the funding of 'discovery projects' which might explore new technologies, there has to be support for implementation. Major gains can be made by simply doing better what is already known to be best practice, and although implementation projects may not be as attractive to funding bodies, it is vitally important that there is a rigorous approach to translating new ideas into practice.



The Stillbirth Foundation Australia (SBFA) is partnering with the Stillbirth CRE in providing additional funding for research largely gained through community and corporate engagement. As with other significant public health issues, a focussed effort is needed and investments that could bring a wider group under one umbrella would have significant benefits. The Stillbirth CRE has taken initial steps to coordinate activity and effort but a clear direction from governments to ensure that all research and public awareness campaigns are cost-effective and achieve maximum impact would be highly beneficial.

**e) Research and education priorities and coordination, including the role that innovation and the private sector can play in stillbirth research and education**

The NHMRC has provided \$2.6 million over 5 years for the Stillbirth CRE to run a national program to address stillbirth, focussing on prevention and care after stillbirth. While this has provided a sound basis, additional funding and support at the government policy level is needed to see meaningful and ongoing change.

The Stillbirth CRE has a priority driven national program that addresses four major priority areas:

- 1: Improving care and outcomes for women with risk factors for stillbirth
- 2: Developing new approaches for identifying women at increased risk of stillbirth
- 3: Implementing best practice in care after stillbirth and in subsequent pregnancies
- 4: Improving knowledge of causes and contributors to stillbirth.

In recognising that many stillbirths can be prevented through improving maternity care, priority area 1 focusses on addressing the gap between *what is known* and *what is done* in every day clinical care of women having a baby in Australia. Education of health care professionals to improve early detection and best care for women at increased risk of adverse pregnancy outcome is paramount to addressing stillbirth, as is education of future and expectant parents on stillbirth including how to reduce the risks.

***Implementation of best practice in stillbirth prevention across health settings***

**Bundles of care combining key recommendations for practice across these areas in the UK, through the *Saving Baby's Lives* bundle of care<sup>22</sup> and the Scottish Maternity and Children Quality Improvement Collaborative (MCQIC), have shown a reduction in stillbirths<sup>23</sup> which was associated with increased obstetric intervention. Minimal data were available on women's experiences with care around the bundle and further work is required to ensure such packages of care meets women's needs.**

Discussions have been taking place for some time between the Stillbirth CRE and health departments across three of the largest jurisdictions in Australia about implementing a bundle of care (the "*Safe Baby Bundle*") to address priority evidence practice gaps in stillbirth prevention in Australia. These priority areas focus on improving early detection and care for women with risk factors for stillbirth including the following:

- women who are of advanced maternal age;
- who smoke;
- have a high body mass index;
- those who experience decreased fetal movement; and
- those at risk of fetal growth restriction.

The bundle of care will be accompanied by educational programs for midwives and doctors on best practice care including existing modules on decreased fetal movement (DFM), fetal growth

restriction (FGR), and care after stillbirth or neonatal deaths to supplement the PSANZ/Stillbirth CRE guidelines.

However, different funding arrangements across jurisdictions continue to present significant barriers to the efficient and effective implementation and evaluation of the bundle across diverse maternity services. In essence, we know how to reduce the stillbirth rates in Australia—we just need to implement that knowledge into clinical care across the nation.

New ways of getting evidence into practice need to be found with support from the Commonwealth. For example, funds from the Medical Research Future Fund (MRFF) could be allocated to address the evidence-practice gap in hospitals in relation to stillbirth prevention and care. Further barriers are encountered in running effective large-scale trials and studies including large data linkage projects, with fragmented jurisdictional ethics and governance processes often contributing to project delays and large financial outputs. The development of the NHMRC National Mutual Acceptance Scheme has streamlined submission processes, however improvements are still required. A centralised approach to both ethics and governance submissions is recommended to assist researchers carry out large scale trials more effectively.

### *Communication barriers*

**Fragmentation of care and issues of communication** with women (including those with a language other than English) are commonly reported contributors to lower quality care according to best practice guidelines<sup>24</sup>. Models of maternity care that enable every woman in Australia to have access to a known care provider, if desired, who provides care throughout the childbirth continuum will reduce the rate of stillbirth. For example, continuity of midwifery care (CMC) is a model of care in which a known midwife or small group of known midwives provide care to women from conception until at least six weeks post-partum<sup>25</sup>. CMC models are provided through either the public system or by privately practising midwives. A review of maternity services provision in Australia should focus on ensuring that all women have continuity of care provider, whether that provider is a midwife, a GP obstetrician, or a specialist obstetrician.

Within the Stillbirth CRE, the ‘My Baby’s Movement’ clinical trial addresses communication around decreased fetal movements (DFM) through a mobile phone application for pregnant women. While information brochures for this project are available in multiple languages, translation of the mobile application itself was not feasible due to lack of funding. This highlights that more action and funding is needed to ensure equitable access to care, including counselling to all women about risk factors associated with stillbirth.

### *Developing new approaches for identifying women at increased risk of stillbirth*

Similar to other high-income countries, a high proportion of stillbirths in Australia occur unexpectedly in late pregnancy and many are linked to undetected fetal growth restriction and placental pathology. Many of the predisposing factors for stillbirth are closely linked and overlap with those responsible for other serious perinatal outcomes including hypoxic and traumatic injury to unborn babies.

Globally, hypoxia (a lack of oxygen to the brain) remains a major contributor to stillbirth and to two other conditions with long-lasting impacts on babies - hypoxic ischemic encephalopathy (HIE) and cerebral palsy. The Royal College of Obstetricians & Gynaecologists (UK), the Gates Foundation, The Lancet and the World Health Organisation (WHO) are urging focused research in this area. A major 2017 UK report (‘Each Baby Counts’) investigating stillbirths, neonatal deaths and perinatal

brain injury occurring as a consequence of incidents during term labour, has set an ambitious 50% reduction target to be achieved by 2020.

The Stillbirth CRE has instigated a national collaboration to establish a **national biobank to develop and increase innovative discoveries from the benchtop to improving the clinical care of women during pregnancy**. A biobank stores samples from a woman and her baby (with consent from both parents) including blood and placental samples, so that ongoing research and collaboration can occur. A biobank in this area would provide a large-scale collection of samples enabling future studies access to large numbers—thus increasing the potential to find important causes and problems that will never be found by just studying one or two samples. With no clinically useful tests for early predictors of stillbirth<sup>26</sup>, research funding is urgently needed to support this endeavour. Biobanks require ongoing funding to ensure that they are accessible and of the greatest benefit. It is very difficult to fund biobanks through conventional funding mechanisms (like NHMRC) as they require long-term dedicated funding and support. MRFF funding is one alternative to supporting long term initiatives that will have significant long-term benefits. While there has been support by individual families for research to be carried out where an adverse pregnancy outcome has arisen, Human Research Ethics Committee (HREC) requirements are restrictive particularly around sharing of data across centres. Such data are urgently needed if large scale collection of samples, amenable for later research, is to be permitted by HREC under a possible waiver of consent, or similar approach.

### ***Best practice in care after stillbirth***

The care that parents receive around the time of stillbirth strongly influences their immediate and future wellbeing—but unfortunately the quality of that care is inconsistent. Evidence-based perinatal bereavement care guidelines for maternity services have been available for some time<sup>27</sup> but their uptake has been variable. Our Lancet series survey showed one-third of bereaved parents rated their care as poor and that deficits in care were common<sup>28</sup>. A written response from one mother captured the experiences of many:

*"It was like I'd never been pregnant and hadn't delivered a full-term baby. Because she never took a breath she wasn't real and I was never a mother. Had to organise my own 6-week check-up and when I arrived at [the doctor's] rooms his staff didn't know that my daughter had been stillborn and asked me how the baby was doing."*

Poor integration of hospital and community services following stillbirth is of particular concern and our studies show that many parents do not get appropriate support when they transition from hospital to community care. Several improved approaches would be helpful. Again, models of care such as CMC could address immediate issues as midwives could provide continuity across all sectors, liaise with agencies etc., and continue care into the postnatal period at home and ensure appropriate referral to the next level of services. Longer term ongoing support requires links to other support networks and systems, including dedicated support groups through non-government organisations or parent associations and community supports such as a maternal and child health nurse. Investment in appropriately targeted mental health support is required for effective early intervention. Bereaved families need access to support services at the right time.

Through the Stillbirth CRE partnership, the national PSANZ guidelines on respectful and supportive care after stillbirth have been newly revised and an implementation plan and resources to assist maternity services to embed the guidelines are under development. Jurisdictional and national endorsement, and the translation of these guidelines to national standards, are required to drive the widespread change needed to ensure all women and families receive best practice care regardless of

where in Australia stillbirth occurs. Sands Australia has worked in partnership with the Stillbirth CRE to develop ‘Sands Australian Principles of Bereavement Care’ and we will continue to work in partnership and seek funding to implement and deliver high quality training to improve care after stillbirth and neonatal death.

Providing care after stillbirth is a challenging area of practice for many health care professionals. Education, training, resources and support are critical enablers and organisational support and financial commitment are both required to create the conditions and structures for the implementation, monitoring and evaluation of best practice care. Training for clinicians in the care of women and families after stillbirth is urgently needed.

The **clinical training program to improve care after perinatal death: the IMPROVE (IMproving Perinatal Mortality Review and Outcomes Via Education) Program**<sup>13</sup> provided by PSANZ/Stillbirth CRE addresses each area of the PSANZ guidelines including respectful and supportive care and investigation into the causes including counselling parents about autopsy. This program has been well-received, however uptake is constrained by funding limitations. Consideration should be given to incentivising uptake at a hospital level, as has been undertaken recently by the Victorian Managed Insurance Authority (VMIA) for other maternity improvement programs such as fetal surveillance training. In the VMIA program, Victorian public hospitals will receive a discount on their indemnity premium if they can attest that their workforce (midwives, obstetricians) have undertaken suitable training.

The impact of stillbirth extends well beyond the initial period of grief. Women who have experienced a stillbirth embarking on subsequent pregnancies have a five-fold increased risk of stillbirth<sup>33</sup>. Heightened anxiety and fear in subsequent pregnancies is common<sup>34</sup>, yet there is little guidance for clinicians on how to provide optimal clinical care for these women<sup>35</sup>.

While most parents received additional ultrasound scans, only a small proportion received additional psychosocial support. Only half of parents who had a pregnancy subsequent to stillbirth felt their concerns were always taken seriously in that next pregnancy<sup>29</sup>. The Stillbirth CRE partnership aims to generate evidence to inform clinical practice to improve the quality of care that women and families receive across Australia in a pregnancy after stillbirth, through an evidence-based approach to monitoring of maternal health, fetal surveillance, and psychosocial support.

**f) Communication of stillbirth research for Australian families, including culturally and linguistically appropriate advice for Indigenous and multicultural families, before and during a pregnancy**

Rates of stillbirth for Aboriginal and Torres Strait Islander babies are double those of other women in Australia (13/1000 versus 6/1000 births) and are a major driver of the current gap in mortality among children under 5—one of the key ‘Close the Gap’ targets set by the Australian Government in 2008.

Progress in reducing the disparity in stillbirth for Indigenous women varies across Australia. A study from Queensland shows a narrowing of the discrepancy while a WA study shows no improvement<sup>30,31</sup>. The most recent data from Victoria suggest that the rate of stillbirth among indigenous women has fallen to that of non-indigenous women<sup>32</sup>. The present inability to access timely data (which ideally would be real-time data) does not allow areas of most need to be targeted. Nor can we develop a good understanding of the reasons for differences between jurisdictions and regions.

However, we do know that there are many causes for the huge discrepancies between stillbirth rates in Aboriginal and Torres Strait Islander people and the rest of Australia. Most are rooted in entrenched poverty, disadvantage, racism (individual and institutional) and manifest through chronic disease pathways such as diabetes, obesity, hypertension and poor nutrition. Poor health behaviours, such as smoking, alcohol and other substance abuse also contribute.

These issues are preventable and require responses that address entrenched social inequality as well as inadequate health system performance, with processes to ensure Aboriginal and Torres Strait Islander peoples are at the forefront of decision-making about policy, service delivery and research priority setting.

Several models of care have the potential to improve birth and later outcomes for Aboriginal families. These models address the social needs of women, as well as their health needs, and involve Aboriginal and Torres Strait Islander providers caring for Aboriginal and Torres Strait Islander women and families, such as Aboriginal and Maternal Infant Care workers in South Australia's Aboriginal Family Birthing Program<sup>33</sup>. Social support is as important as clinical support—in fact without social support being offered first or contemporaneously, women may be less likely to engage in care and the clinical services may be less effective<sup>34</sup>.

However, funding for these models of care is often not available or is 'stop-start' at best, which clearly impedes development of a sustainable model and a skilled workforce.

Some specific areas in stillbirth prevention to target include:

- Early and adequate antenatal care for Aboriginal women to ensure health and social issues are addressed early and supported with appropriate models of care (e.g. with Aboriginal and Torres Strait Islander practitioners and services as the preferred providers).
- Infection prevention and control: a cogent example is the recent outbreak of syphilis in remote areas of QLD, NT and SA, which may have been prevented by improved testing, treatment and notification of partners (syphilis is a known cause of stillbirth in some women).
- Smoking-cessation programs: counselling and support combined with nicotine replacement therapy is likely to be effective in smoking cessation if health system barriers and costs are addressed. Incentive schemes are effective and may provide the best solution.
- Obesity (and nutrition) strategies: approximately 60% of Aboriginal and Torres Strait Islander women aged 18-24 are overweight, which often contributes to poor health outcomes and difficulties in assessing growth of the unborn baby. The Aboriginal Family and Baby Bundles (ABFABB), within the SA Aboriginal Family Birthing Program, is offering comprehensive nutrition support but many more such programs are needed across Australia.

Broader priorities include:

- Culturally safe bereavement care information and counselling of Aboriginal and Torres Strait Islander families regarding autopsy consent.
- Research in partnership with Aboriginal and Torres Strait Islander researchers and communities into culturally relevant strategies to support social and emotional wellbeing, recognising that pregnancy is a key window to address the intergenerational impacts of racism, trauma and disadvantage.

- Support for national and local/State initiatives that enable Aboriginal and Torres Strait Islander participation in decision making about research such as the Lowitja Institute and the SA Aboriginal Family Health Research Partnership.

Care of migrant and refugee families is another area where service provision needs to be improved. Gaps in identifying families of refugee background in maternity services impedes the provision of tailored service responses such as the use of interpreters, longer appointments and ensuring the same health professional is seen at subsequent visits. One community-based model of group pregnancy care in Melbourne is showing promise in improving health and social outcomes<sup>35,36</sup>. However broader application of this model across the health system is currently limited by funding constraints.

More generally, the impact of socio-economic disadvantage on stillbirth requires further attention from all health and social services. Complex issues such as obesity and support issues such as isolation, poverty, housing and family violence need to be addressed if we are to reduce the incidence of stillbirths across the entire population<sup>37</sup>.

Finally, **raising public awareness around risk factors for stillbirth** is important for families considering or planning for a baby. The ‘Reduce the Risks’ campaign for SIDS resulted in a massive reduction of SIDS deaths and it is hoped that public awareness campaigns will similarly reduce stillbirths. Further, **raising public awareness to dispel general misinformation and misconceptions to overcome the stigma of silence** around stillbirth is important to improving care for parents and families who have a stillborn baby and will help to mobilise action in stillbirth prevention. The Stillbirth CRE is currently partnering with Safer Care Victoria in an evidence-based campaign to raise awareness of the importance of fetal movements among women and their care providers, but again funding limitations impedes progress in this area. With evidence now supporting the link between women going to sleep on their backs and stillbirth, a cross-Tasman public awareness campaign on maternal safe sleep practices is being developed in partnership with the Stillbirth Foundation Australia. Additionally, the Stillbirth CRE consults with partners for advice around stillbirth awareness, and an example of this is engagement with national stillbirth awareness charity Still Aware to develop shared resources for women.

#### g) Quantifying the impact of stillbirths on the Australian economy

Despite recent efforts, little is known about the true financial costs of stillbirth<sup>38</sup>. The aftermath of stillbirth can be associated with withdrawal from normal social activities, including labour force participation, which can have extensive lifetime impact on the economic status of women and their families. It also has a societal impact from lost productivity and increased welfare dependence<sup>39,40</sup>. The annual cost of even one mother missing from the labour force as a result of stillbirth is \$33,000 in GDP (investigators’ calculation based on Australian Treasury’s GDP formula). However, the additional economic costs of stillbirth need to be quantified for efficient health service planning.

A study conducted in the United States (US) found that women whose babies were stillborn had significantly higher hospital costs during labour and birth than women with live births<sup>41</sup>. The Lancet series reported that the direct financial cost of care associated with a stillbirth is 10-70% greater than the cost of care for a livebirth, with the costs predominantly being met by the government<sup>42</sup>. Care for subsequent births may also require more intensive surveillance, with costs rising up to £4,654-5,616 per birth<sup>38</sup>, with a total average annual cost to the National Health Service (NHS) of £943,846,000<sup>43</sup>.

Preliminary results for Australia produced by the Stillbirth CRE indicate that direct hospitalisation costs associated with the time of birth is AU\$9,630 for women who had a stillbirth, and AU\$6,690 (or 30% lower) for women who did not. These costs do not consider the ongoing costs of support, bereavement care and counselling or the difficulty in returning to work. These latter costs impact on both parents. To reduce the financial burden to parents of stillbirth the following is needed:

- Minimum paid period of time off work;
- Respite child care if other children or care responsibilities;
- Medicare reimbursement for psychiatric or psychological referral;
- Equity of parental leave support post stillbirth for both mothers and fathers.

#### h) Other related matters

Over the last 5 to 10 years there has been an increased interest in, and funding of, stillbirth research. In many aspects of this Australia has led the way, with Stillbirth CRE investigators having a major role in the 2011 and 2016 Lancet stillbirth series. It is vital that the current momentum is maintained to ensure a sustainable, national approach so that Australia reaches the lowest stillbirth rate possible. Parents must remain at the centre of all future research as they inform research priorities and can provide invaluable advice on how to most effectively involve parents and families in appropriate ways.

Even with the lowest possible stillbirth rates, stillbirths will continue to occur. Currently there is no mandate for hospitals to provide high quality bereavement care despite the huge difference it can make to families. An evidence-based national approach to this is urgently required if we are to reduce the overall impact in terms of psychological and economic wellbeing.

Finally, some elements of the stillbirth research agenda may need radically new approaches. Recent data from the Stillbirth CRE has shown progress in reducing late gestation stillbirths, but there has been an increasing proportion of earlier deaths at the ‘pre-viable’ stage of pregnancy. We need a better understanding of why these deaths occur, and clinical trials of targeted interventions that could prevent them.

This Senate Inquiry presents a unique opportunity to shine a light on a major public health problem, which has enormous ramifications for women, their families and the wider society. **The tragedy of stillbirth touches all of us and one of the greatest tragedies is that many of these deaths are avoidable.** Working together, it should be possible for Australia to do much better and to be an example to the rest of the world in stillbirth prevention and bereavement care.

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