



Australian College of Nursing

The future of stillbirth research and education in Australia

The Australian College of Nursing (ACN) submission to the Select
Committee on Stillbirth Research and Education, Department of the
Senate

ACN position on stillbirth research and education in Australia

General comment

The Australian College of Nursing (ACN) acknowledges that the neglected epidemic of stillbirths in Australia is of critical concern. ACN adopts the World Health Organization (WHO) definition of stillbirths which is 'a baby born with no signs of life at or after 28 weeks' gestation.¹ The rate of stillbirths in Australia is roughly 6 stillbirths per day (or 2,200 per year).^{2 3} The rate is often higher in women from Aboriginal and Torres Strait Islander (ATSI) and South Asian backgrounds, disadvantaged groups or over 35 years of age.^{4 5} Compared to other developed countries, Australia's stillbirth rate is 30% higher and has shown little improvement in the last 20 years.⁶

ACN recognises that stillbirth is not only a tragedy for parents but a major public health issue. A poor response to stillbirth has long-term psychosocial and economic consequences on parents, families, carers, health systems and communities. There is an increased risk of anxiety, depression, post-traumatic stress, and suicidal thoughts for parents who have experienced a stillbirth, impacting their ability to work, care for their families and function as members of society.⁷ It is reported that the economic impact of stillbirth will be in the range of \$681 million by 2020, which includes both direct (e.g. hospital fees, counselling) and indirect costs (e.g. funeral costs, work absenteeism, lost productivity).^{8 9}

ACN strongly believes that greater opportunities and investments are required to prevent stillbirths. Roughly 25% of stillbirths are unexplained.¹⁰ Stillbirths are generally not adequately investigated leading to a lack of diagnosis, which could provide families with closure during their grief, valuable information in addressing preventable risk factors for subsequent pregnancies and assisting the broader community in understanding preventable risk factors. Currently, data on

¹ World Health Organization 2018, *Maternal, newborn, child and adolescent health. Stillbirths*, http://www.who.int/maternal_child_adolescent/epidemiology/stillbirth/en/.

² <http://stillbirthfoundation.org.au/portfolio-item/senator-kristina-keneally-talks-stillbirth-inquiry-on-studio10/>

³ <https://www.stillbirthcre.org.au/resources/stillbirth-facts/>

⁴ Flenady V, Wojcieszek AM, Middleton P, Ellwood D, Erwich JJ, Coory M, et al, for the Lancet Ending Preventable Stillbirths series study group. Stillbirths: recall to action in high-income countries. *The Lancet*. 2016;387(10019):691-702

⁵ Flenady V, Middleton P, Smith GC, Duke W, Erwich JJ, Khong TY, et al. Stillbirths: the way forward in high-income countries. *The Lancet*. 2011; 377(9778):1703-17.

⁶ Flenady V, Wojcieszek AM, Middleton P, Ellwood D, Erwich JJ, Coory M, et al, for the Lancet Ending Preventable Stillbirths series study group. Stillbirths: recall to action in high-income countries. *The Lancet*. 2016;387(10019):691-702

⁷ Hezell AEP, Siassakos D, Blencowe H, Burden C, Bhutta ZA, Cacciatore J, et al, for the Lancet Ending Preventable Stillbirths series study group. Stillbirths: economic and psychosocial consequences. *The Lancet*. 2016; 387(10018):604-16.

⁸ <https://www.theguardian.com/australia-news/2016/oct/06/stillbirths-to-cost-australian-economy-680m-over-next-five-years-report-finds>

⁹ Stillbirth Foundation Australia & PwC (2016). The economic impacts of stillbirth in Australia. Accessed from: <http://stillbirthfoundation.org.au/wp-content/uploads/2016/10/Economic-Impacts-of-Stillbirth-2016-PwC.pdf>

¹⁰ <https://cerebralpalsynewstoday.com/2016/11/02/university-of-queensland-awarded-13-95-million-cerebral-palsy-stillbirth-research>

stillbirth babies or from women during pregnancy is either lacking or not obtained in a timely, consistent and useful manner to address these issues. Inconsistencies exist between data reported from the Australian Bureau of Statistics and the Australian Institute of Health and Welfare. In addition, funding for stillbirth research is often limited, coming from parents, families and friends who have experienced loss.

ACN seeks to address the data discrepancies and funding boundaries that limit educational and research opportunities around stillbirths in Australia. Targeted government funding, along with corporate investment, toward stillbirth education and research would prove crucial in accessing reliable data, identifying preventable risk factors and establishing programs that educate pregnant women on these risks. More so, ACN strongly believes support services should become more inclusive of people from Aboriginal and Torres Strait Islander (ATSI) and culturally and linguistically diverse (CALD) backgrounds, given the higher rates experienced by women in these demographic groups.

ACN response to terms of reference:

(a) consistency and timeliness of data available to researchers across states, territories and federal jurisdictions;

There are currently two national data collections that provide information about stillbirths: the Australian Bureau of Statistics (ABS) which collates data for all deaths (including stillbirths) registered in Australia to form the ABS Death Registrations collection;¹¹ and the Australian Institute of Health and Welfare (AIHW) which collates data from state and territory Perinatal Data Collections to form the National Perinatal Data Collection (NPDC).¹² The ABS and AIHW currently report markedly different annual stillbirth rates and overall numbers of stillbirths. ACN recommends that data is collated directly from the maternity care providers themselves (i.e. NPDC) and that ABS links to AIHW perinatal outcome reports in order to avoid duplicating data collection and conflicting data. ACN also strongly supports the need for a national perinatal mortality audit program to identify preventable risk factors and reduce the number of stillborn deaths. As part of access to data availability, ACN strongly believes that nurses and midwives on maternity wards should be included in dialogue/conversations and public forums relating to their experiences with stillbirth; and be more involved in providing strategies and educational material for improving care to parents/families following a loss.

More so, while the major causes of stillbirth in Australia (e.g. infection, spontaneous preterm birth, congenital abnormality) and risk factors (e.g. women over 35 years, of ATSI and South Asian background, pregnancy beyond 41 weeks) are well documented, roughly 25% of stillbirth causes

¹¹ <http://meteor.aihw.gov.au/content/index.phtml/itemId/396126>

¹² <http://meteor.aihw.gov.au/content/index.phtml/itemId/392479>

are not known,^{13 14 15 16} necessitating timely and consistent access to data relating to stillbirth death. The issue has been longstanding for researchers across states, territories and jurisdictions, prompting the establishment of the NHMRC funded Centre for Research Excellence in Stillbirth (Stillbirth CRE), at the Mater Research Institute, University of Queensland (2016). The Stillbirth CRE runs a national cohesive program of research and implementation by collaborating with researchers from across the country; Griffith, La Trobe, Monash and Sydney universities, the Hudson Institute of Medical Research, the Kolling Institute of Medical Research and the South Australian Health and Medical Research Institute.^{17 18} ACN believes that Stillbirth CRE must continue to receive NHMRC funding to maintain data availability across jurisdictions. Specifically, there needs to be national transparency when it comes to research that produces data around stillbirth, as well as for data made available from national data collections.

(b)coordination between Australian and international researchers;

As a regional office of the International Stillbirth Alliance (ISA), the Stillbirth CRE has established national and international multidisciplinary collaborations with experts in stillbirth prevention and care ensuring they can impact the incidence and consequences of stillbirth.¹⁹ This ensures Australia contributes to the international appeal to action for stillbirths as outlined in the Every Newborn Action Plan. ACN believes that Stillbirth CRE must continue to receive NHMRC funding to maintain international collaborative research relationships.

¹³ Flenady V, Wojcieszek AM, Middleton P, Ellwood D, Erwich JJ, Coory M, et al, for the Lancet Ending Preventable Stillbirths series study group. Stillbirths: recall to action in high-income countries. *The Lancet*. 2016;387(10019):691-702

¹⁴ Flenady V, Middleton P, Smith GC, Duke W, Erwich JJ, Khong TY, et al. Stillbirths: the way forward in high-income countries. *The Lancet*. 2011; 377(9778):1703-17.

¹⁵ Davies-Tuck ML, Davey MA, Wallace EM. Maternal region of birth and stillbirth in Victoria, Australia 2000-2011: A retrospective cohort study of Victorian perinatal data. *PloS one*. 2017; 12(6):e0178727.

¹⁶ <https://www.stillbirthcre.org.au>

¹⁷ <https://cerebralpalsynewstoday.com/2016/11/02/university-of-queensland-awarded-13-95-million-cerebral-palsy-stillbirth-research>

¹⁸ <https://www.stillbirthcre.org.au/about-us/>

¹⁹ <https://www.stillbirthcre.org.au>

(c) partnerships with the corporate sector, including use of innovative new technology;

In terms of innovation, ACN sees value in approaching private sector industries to build technology capable of collecting data throughout pregnancy. For example, fitbit™ technology is currently capable of tracking a range of health measures for real time information over a 24-hour period. Specifically, these devices can track activity (e.g. steps or distance travelled), exercise (e.g. calories burned), food, weight, sleep, and your heart rate throughout the day.²⁰ The data collected would prove invaluable in stillbirth research. A variety of health measures tracked through the fitbit™ could be triangulated with stillbirth outcomes to determine any specific correlations or associations. ACN also supports testing of a mobile phone program developed by the Stillbirth CRE to help raise awareness about decreased foetal movements in pregnant women.

(d) sustainability and propriety of current research funding into stillbirth, and future funding options, including government, philanthropic and corporate support;

ACN believes that in order to achieve sustainability around stillbirth education and research, there must be targeted government funding, along with corporate investment. ACN also supports renewal of NHMRC funding for the Stillbirth CRE to continue its work.

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

ACN believes there should be a national discussion about the content of foetal surveillance monitoring and training relating to intermittent auscultation, continuous electronic foetal monitoring, and maternity care provider response when mothers report changes in their baby's activity. There needs to be a national approach, development of policy and guidelines with consensus agreement over the content, duration and frequency of training as well as whether competency should be formally assessed for all maternity care providers who provide care during pregnancy and during labour and birth.

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

Stillbirth CRE facilitates effective and meaningful parent engagement through partnerships with the Stillbirth Foundation Australia, Sands, Still Aware, Bears of Hope, Red Nose and WHA. Sands Victoria operate as a charity for miscarriage, stillbirth and neonatal death. It has expanded services

²⁰ <https://www.fitbit.com/au/whyfitbit>

to become more inclusive of cultural diversity. People from culturally and linguistically diverse (CALD) backgrounds including new migrants and refugees have access to face-to-face support visits with interpreters and help-sheets translated into community languages. More so, health professionals are able to access seminars raising awareness and capacity about culturally and linguistic advice.²¹

ACN believes that access to this type of support should be available across Australia to people from CALD backgrounds and an emphasis on expanding services to people of ATSI backgrounds particularly in rural and remote areas is necessary.

(g) quantifying the impact of stillbirths on the Australian economy;

It has been reported that stillbirth will cost the economy greater than \$680 million by 2020. This includes both direct and indirect costs associated with stillbirth loss. A third of cost are linked to lost productivity in the workplace. Given that stillbirth is the most common form of child mortality in Australia and one in three stillbirths is preventable, greater public and private investment in research and prevention is necessary to reduce the financial burden, which has been determined to be of measurable impact.²²

ACN supports the need for "Improving access to child bereavement counselling, targeted interventions to reduce the impact on mental health, and raising awareness of the topic to minimise the social stigma attached to stillbirth could potentially result in a positive impact on people who have experienced stillbirth".²³ ACN believes nurses are well placed to raise awareness about preventable risk factors, counseling services and research opportunities. A publically funded health campaign used for educating parents, families, clinicians, obstetricians and the hospital system as a whole, would be beneficial.

²¹ <http://www.sands.org.au/cultural-diversity-sands-victoria>

²² <https://www.theguardian.com/australia-news/2016/oct/06/stillbirths-to-cost-australian-economy-680m-over-next-five-years-report-finds>

²³ <http://stillbirthfoundation.org.au/wp-content/uploads/2016/10/Economic-Impacts-of-Stillbirth-2016-PwC.pdf>

(h) any related matters.

The Stillbirth CRE continues to work towards “building a strong health and medical workforce to ensure sustained improvement in care and outcomes for future families”.²⁴ ACN believes that nurses and midwives, as frontline staff in maternity wards, emergency departments and primary and community health settings should be made a priority in providing optimal support to families affected by stillbirth loss.

²⁴ <https://www.stillbirthcre.org.au/about-us/>