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Select Committee on Stillbirth Research and Education
Department of the Senate
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Thank you for the opportunity to provide a submission to the Select Committee on Stillbirth Research and Education on the future of stillbirth research and education in Australia.

The Centre for Midwifery, Child and Family Health, UTS

This response is made by the University of Technology Sydney through the **Centre for Midwifery, Child and Family Health.** UTS has educated midwives for more than 25 years – both undergraduate direct-entry and post-graduate after a nursing qualification. We estimate we have educated more than 1000 midwives in this period and they work in every state and territory across Australia. The Centre for Midwifery, Child and Family Health was established in 2001 and has consistently undertaken research and supervision of PhD and Masters by Research students. We have been funded by the National Health and Medical Research Council, the Australian Research Council and from external agencies, for example, Health Workforce Australia and the NSW Ministry of Health. In addition, the Director of the Centre, Professor Caroline Homer, has been the co-chair of the Expert Advisory Group for the Clinical Practice Guidelines for Antenatal Care since 2008. Our Director is also a member of the Centre for Research Excellence in Stillbirth and we have published in this area:

Smith R, Homer A, Homer D, Homer CSE. Learning about grief and loss through Harper's story *MIDIRS Midwifery Digest* 2011;21(1):19-21.

Homer C, Malata A, ten Hoope-Bender P. Supporting women, families, and care providers after stillbirths. *Lancet* 2016;387(10018):516-7. doi: 10.1016/s0140-6736(15)01278-7 [published Online First: 2016/01/23]

We have incorporated the experiences of real families who have experienced stillbirth in our midwifery education programs. For example, each year a couple who have experience a stillbirth come and talk with students. They tell their story, share photos and experiences. Students consistently report that this is a significant part of their education and makes an important difference to their midwifery practice.

We would also like to commence by acknowledging the loss of stillbirth experienced by so many families in Australia and offer our condolences to all those impacted by the stillbirth of a baby, especially the parents, siblings and grandparents. We also pay tribute to the midwives, doctors, social workers and other health care professionals across the country who every day work with families providing quality care, walking into the grief of families and trying to provide the best care and support.

We have addressed our response in line with your Terms of Reference.

a. consistency and timeliness of data available to researchers across states, territories and federal jurisdictions

The Australian health system is consistently challenged by the eight (nine if the Commonwealth is included) different ways of collecting, collating, analysing data and releasing reports especially related to the death of babies, both those who are stillborn and those who are born alive but die in the first month of life.

Each state and territory has different data collection systems and different laws regarding sharing of data. Each jurisdiction also has different processes or systems to review the details of the deaths of babies; some states and territories have established committees receiving all available information from the hospitals whereas others can only share summary information.

This makes an analysis of the outcomes and being able to apply lessons learned from good and poor outcomes challenging. For example, National Perinatal Morbidity and Mortality report (which includes stillbirths) takes more than 18 months after the deaths to collate and does not include an analysis of contributing factors to the deaths in a way that will change or improve practice. Only 99 deaths out of the total of 6,037 (1.6%) in the most recent report included information on contributing factors in relation to the deaths of babies across Australia. It is likely that the majority of deaths would have undergone some analysis of contributing factors however the systems across the 8 jurisdictions means this cannot be shared and so valuable lessons that could improve care are lost.

While making such data available to policy makers and health systems is important, it is equally critical for researchers. There is essentially no national dataset relating to stillbirth which significantly hampers progress. As an example, we have spent 5 years collating data from each state and territory using linked data to create a national dataset about where women give birth. This includes the rate of stillbirth in women who choose to give birth in hospital, in a birth centre or at home. This has been very expensive and time consuming process and has highlighted the differences between almost every state and territory in the definitions used, the process of collation and linking and the legislation associated with sharing de-identified data.

The data collected across Australia is a wasted resource at the moment. So much more could be understood through research if there was more harmonisation across states and territories and a real commitment to share data and knowledge. This needs to be a Council of Australian Government (COAG) priority to ensure that the precious data Australia has can be put to best use. Every stillbirth is precious, all data on every baby and mother needs to be able to be analysed to improve care for other families and prevent this occurring for others.

b. coordination between Australian and international researchers

Australian and international researchers are already excellent at collaboration and building links and connections. The NHMRC funded Centre for Research Excellence in Stillbirth Research is an excellent example of this collaboration nationally. Australia is a leader in international research in this area as evidenced by the two series form The Lancet on Stillbirth which includes many Australian researchers.

Despite our successes, there is still much to be done and this requires more dedicated funding and support. Reducing the rate of stillbirth requires greater emphasis including addressing broader issues in the whole maternity service.

Australian researchers also have an opportunity to contribute to, and support research to reduce stillbirth in our region. Countries in our region like Papua New Guinea, Solomon Islands and Timor Leste have significantly higher rates of stillbirth than in Australia and more research is needed to understand the causes and interventions to address prevention.

c. partnerships with the corporate sector, including use of innovative new technology

There is very little in the way of partnerships with the corporate sector in undertaking research and development activities. One of the reasons for this is the complexity of the eight jurisdictions and so the national corporate sector is often challenged in undertaking or supporting initiatives of programs which will make a difference to all Australians.

It is also important the technology is appropriately and carefully used and listening to women should be the first technology used. The risk is that clinicians tend to concentrate on the technology (the machines that say everyone is alright or that things are going wrong) and often forget to prioritise what the woman feels or is experiencing. Very often, women say that 'they knew something was wrong' but that all the tests they had showed no problems and she was sent home. Listening to women should be the first technology applied in this area.

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

Research funding in Australia has not reflected the significant need and burden of stillbirth. Given 6 families are affected every single day, very little emphasis in terms of specific and general research finds are directed towards stillbirth, or maternity care in general.

In addition, it is essential that broader research is funded and supported that aims to improve the overall quality of maternity care. For example only about 10% of Australian women have access to midwifery continuity of care – having a midwife that the woman knows and trusts providing care throughout pregnancy and labour and birth. There is now high quality research (more than half from Australia, that shows that Women were also less likely to have a baby born preterm and their babies were at lower risk of death (including deaths before and after 24 weeks and neonatal deaths).

This research is highlighted in the publication available online:

Sandall J, Soltani H, Gates S, et al. Midwife-led continuity models versus other models of care for childbearing women. *Cochrane Database of Systematic Reviews* 2016;Issue 9:Art. No.: CD004667. DOI: 10.1002/14651858.CD004667.pub4.

The benefits, including women being 16% less likely to lose their baby is illustrated in the infographic below which is from *the Sheila Kitzinger symposium at Green Templeton College.* Oxford, 2016:

Sandall J, Coxon K, Mackintosh N, Rayment-Jones H, Locock L, Page L. Relationships: the pathway to safe, high-quality maternity care. *Report from the Sheila Kitzinger symposium at Green Templeton College*. Oxford, 2016, Green Templeton College. Online: https://www.gtc.ox.ac.uk/images/stories/academic/skp_report.pdf

The infographic is based on high quality research in this review:

Sandall J, Soltani H, Gates S, Shennan A, Devane D. Midwife-led continuity models versus other models of care for childbearing women. Cochrane Database of Systematic Reviews 2016, Issue 4. Art. No.: CD004667. DOI: 10.1002/14651858.CD004667.pub5. http://cochranelibrary-wiley.com/doi/10.1002/14651858.CD004667.pub5/full

This review includes 15 trials involving 17,674 women. Of the 15 trials, 6 were from Australia including the most recent trials conducted at The Royal Women's Hospital (Melbourne), the Royal Hospital for Women (Sydney) and The Mater Mothers Hospital (Brisbane). The inclusion of so many Australian studies makes this review highly relevant to this country.

We have previously written in the *Medical Journal of Australia* that "despite the need for more research into ways to effectively implement this model of care into practice, given the strength of evidence, the policy documents and the demand from women, is it ethical to withhold midwifery continuity of carer to the majority of women across Australia?"

Homer C. Models of Maternity Care: Evidence for midwifery continuity of care. *Medical Journal of Australia* 2016;205(8):370-74.

Given the link between midwifery continuity of care and the reduction in preterm term birth (a significant contributor to stillbirth) and early stillbirth, this is the time to invest in implementation

research to get this evidence into practice for all women. We need to put research funds into the science of how to implement this model of care widely across the country.

Again this needs to be a COAG responsibility as models of maternity care are a state and territory responsibility. However, **the Commonwealth has a significant opportunity to drive policy reform and innovation** through the allocation of funds that focus on the implementation or translation of research into real-life practice.

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

Innovation has been sadly missing in the stillbirth research. This is possibly as it is seen as a taboo subject that is difficult to research. There are likely to be many opportunities where innovation can play a significant role in the prevention of stillbirth and also in support families who have experienced this tragedy.

A national coordinated approach is needed that brings together the data and highlights the opportunities is needed. Large scale trials are required especially as stillbirth in particular groups is not as common as some other outcomes. This is why a coordinated research investment is essential, especially in partnership with the private sector. It is essential that women, both those who have experienced stillbirth and those who have not, are involved in this research.

A significant challenge with research and education in this area is to provide quality care focussed on the needs of the woman while not increasing the fear for all women about pregnancy birth. While it is true that 6 women per day will lose a baby to stillbirth, 838 will have a live born baby, the vast majority who will grow up to be healthy children. That fact does not remove the tragedy for those who do experience stillbirth, we must be careful not to create fear and anxiety for all women as that carries risk within itself.

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

While there has been a progressive decrease in the difference between perinatal mortality rates for babies born to Aboriginal and/or Torres Strait Islander and non-Indigenous mothers as documented in the latest Perinatal Deaths in Australia report, the disparities remains startling.

The perinatal death rate (which includes stillbirths) in 2013-2014 was 15.8 per 1000 births in Indigenous babies compared with 9.2 per 1000 births in non-Indigenous babies. More details are provided in the recent AIHW report:

> Australian Institute of Health and Welfare 2018, *Perinatal deaths in Australia: 2013–2014 (Cat. no. PER 94)*, AIHW, Canberra. https://www.aihw.gov.au/reports/mothers-babies/perinatal-deaths-in-australia-2013-2014/contents/maternal-indigenous-status

There remains an urgent need to address these disparities through the implementation of evidence into practice (eg. Access for all women to midwifery continuity of care models that include an Aboriginal Health Worker, or preferably, access to an Aboriginal midwife), more focussed research led and undertaken in partnership with Indigenous researchers and communities and better culturally safe care and support for Indigenous families.

Communication with families, especially those who are Aboriginal and Torres Strait Islander or from migrant and refugee communities is critical. The translation and transfer of materials into culturally appropriate forms is expensive and sometimes not possible due to resource constraints.

Partnerships with groups such as The Stillbirth Foundation, Still Aware and maternity consumer groups is important to ensure the views and voice of women are included in all communication materials. These consumer led groups are generally without dedicated funding to support their work. They work because dedicated and committed women and families give of their time voluntarily and often in a time of grief. Funding support to such consumer organisations is needed to ensure that they can continue this important work and ensure that women's views are always included.

g. quantifying the impact of stillbirths on the Australian economy

Most research quantifying the economic effects of stillbirth has not been conducted in Australia. In addition, it is only recently that the economic costs have been realised as being real and potentially likely to impact on social, emotional and economic life of the country.

The research published in The Lancet's Series on Stillbirth in 2016 - Stillbirths: economic and psychosocial consequences (Heazell A, Siassakos D, Blencowe H, et al. Stillbirths: economic and psychosocial consequences. *Lancet* 2016;387(10018):604-16. doi: 10.1016/s0140-6736(15)00836-3) highlighted the substantial direct, indirect, and intangible costs that resulted from stillbirth and impacted on women, their partners and families, health-care providers, the government, and the wider society. Australians contributed to the research that was undertaken as part of the paper by Heazell et al (2016) paper making comments like:

- "My family and my friends were a great help to us. They were always there to listen and offer support when I needed it. They got me through a lot of the time" (#4583, Australia).
- "I am depressed, saddened, hurt, empty, guilty and lonely. I cry every day. I will mourn him forever. (Australia)
- "Each woman struggled with her sense of identity. Although each felt she was a mother, she was a mother without a child, and did not have tangible evidence of her motherhood" (Australia)
- "This perceived lack of social understanding left these mothers alone and uncomforted. Added to this, the silence was aggravated by the failure of friends and family to acknowledge the loss and grief as real. They experienced people avoiding them, or treating them as though they had never been a mother" (Australia)

The latter quote is especially telling of the experiences of women and their partners and wider family after a stillbirth.

More research needs to be supported in this area so that the impact can be articulated, explained and families can be supported in whatever way is best for them.

Ways of ensuring a high level of support from the community, especially from employers of families affected by stillbirth also needs to occur. Employment laws – federal and state/territory, need to be examined with a 'stillbirth' lens to ensure that families (both the woman who gave birth and her partner) are protected and supported in legislation.

h. any related matters.

Stillbirth takes a toll on everyone involved. Of course the woman, her partner are her immediate family are most effected but the ripple effect of impact goes much wider. Midwives and doctors who care for women who experience stillbirth often struggle with their own fears that they have either missed something that could have prevented this outcome or have directly contributed to the outcome. The amount of support that providers need to deal with their own grief or fears should not be under-estimated.

A number of qualitative studies have explored providers' experiences related to perinatal loss including stillbirth.

Nallen K. Midwives' needs in relation to the provision of bereavement support to parents affected by perinatal death: Part two. *MIDIRS Midwifery Digest* 2006;17(1):105-12.

Modiba LM. Experiences and perceptions of midwives and doctors when caring for mothers with pregnancy loss in a Gauteng hospital. *Health SA Gesondheid* 2008;13(4):29-40.

McCool W, Guidera M, Stenson M, et al. The pain that binds us: Midwives' experiences of loss and adverse outcomes around the world. *Health Care for Women International* 2009;30:1003-13.

Farrow V, Goldenberg R, Fretts R, et al. Psychological Impact of Stillbirths on Obstetricians. *J Matern Fetal Neonatal Med* 2012; Nov 6.

These studies highlight that midwives and doctors often experience guilt as they feel that their role is about saving lives rather than being around death. Guilt is also tied up with blame and sometimes, blaming one another for not doing enough to give emotional support to the woman and families. Personal grief has been found to be common in obstetricians following the care of a woman experiencing a stillbirth. Self-doubt, self-blame and depression were also frequent reactions experienced by health care providers. These feelings, if not addressed and staff supported, can lead to midwives and doctors leaving their professions. This means that a very valuable part of the health workforce is wasted as training and supporting midwives and doctors is expensive. **More research on how to support the staff involved as well as the women and families is needed.**

Finally, there needs to be a balance between providing women and families with information, especially about risk factors, and the use of interventions (like early induction of labour) and not creating unnecessary fear in every pregnant woman for their whole pregnancy. Stress in pregnancy is likely to impact on the health of the unborn baby and these effects are probably long-lasting. We do not want to create unintended consequences in our effects to improve care and services.

Conclusion

We believe all Australian States and the Commonwealth need to be committed to and have a consistent approach to sharing data and knowledge about stillbirth. Access to and sharing data will provide insight into some of the causes and prevention of stillbirth. Dedicated funding in Australia must continue to be allocated to enhance the collaboration between international researchers in this important area.

The rate of stillbirth in Australia will only be reduced through the redesign of maternity services including all women having access to midwifery continuity of care, as we know this decreases the risk of stillbirth.

Consumer groups do excellent work in supporting women and families who have lost a baby however this work would be enhanced through more funding. Government funding of these groups would help to produce culturally and linguistically appropriate care and resources for Indigenous and migrant groups. Funding would also increase the visibility of these groups attracting further funding from the national corporate sector.

Finally we need to support the midwives and doctors who are working alongside women and their families during such a devastating experience. Funding for education, dissemination of research results and support of these professions in the area of stillbirth is critical to support women and their families.