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Senate's Select Committee on  
Stillbirth Research and Education

**June 25, 2018**

We welcome the opportunity to make a submission to the Senate's Select Committee on Stillbirth Research and Education. Our group has a research interest in stillbirth, particularly among Aboriginal and Torres Strait Islander Women. Terms of reference specific to our submission is (f) "*Communication of stillbirth research for Australian families, including culturally and linguistically appropriate advice for Indigenous and multicultural families, before and during pregnancy.*"

The title of our submission: *Closing the gap in the stillbirth rate: Understanding the issues and challenges in gaining permission for an autopsy*

### **Background**

Over the past 30 years, the perinatal mortality rate (PMR) in Australia has been reduced to almost a quarter of that observed in the 1970s. To a large extent, this decline in the PMR has been driven by a reduction in neonatal mortality. **However, stillbirth rates have remained relatively unchanged, and stillbirth rates for Aboriginal or Torres Strait Islander mothers have remained approximately twice that for non-indigenous women over the last ten years.** The causes for this difference remains to be fully established. The fetal autopsy is the single most important investigative tool to determine the cause of fetal demise. While facilitators and barriers to gaining consent for autopsy have been identified in a non-Indigenous context, these are yet to be established for Indigenous families. To address the gap in stillbirths between Indigenous and non-Indigenous mothers, it is essential to identify culturally appropriate ways when approaching Aboriginal and Torres Strait Islander families for consent after fetal death. Culturally safe and appropriate counselling at this time provides the basis for respectful care to families while offering an opportunity to gain knowledge to reduce the PMR. Identifying the cause of preventable stillbirth is an important step in narrowing the disparity in stillbirth rates between Indigenous and non-Indigenous mothers.

### **What are the important next steps?**

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To address the challenges for parents and health professionals in the autopsy consent process, several important steps must be taken. Firstly, it is essential to identify the factors that Indigenous and non-Indigenous parents take into consideration when asked to give consent for an autopsy after stillbirth. From these understandings, culturally-sensitive clinical practice guidelines can be developed to guide health care professionals when asking Aboriginal and Torres Strait Islander women and families for consent for autopsy. Further, professional programs must be developed that detail how health professionals can apply the culturally-sensitive clinical practice guidelines. In conjunction with these important steps, educational information resources must be developed that are appropriate for Aboriginal and Torres Strait Islander people regarding stillbirth and autopsy to raise awareness and help them make informed decisions about the autopsy.

Other terms of reference relevant to our submission:

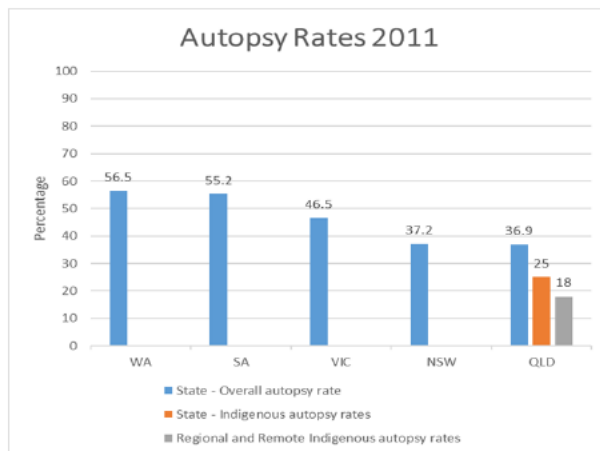
***a. consistency and timeliness of data available to researchers across states, territories and federal jurisdictions;***

There is very little research done in this area. However, we are very pleased to report that we have recently completed a preliminary study on the areas. The study was funded by The *Townsville Hospital Health Services Study, Education and Research Trust Account (SERTA)*. The title of this study is “*Closing the gap in the stillbirth rate: Understanding the issues and challenges in gaining permission for autopsy*”. The study was limited to the Townsville Health District due to funding limitations. We sought to understand 1) rates of Indigenous autopsy; 2) risk factors for Indigenous stillbirths and 3) reasons for not performing an autopsy. There is little accurate data across states to inform our care for these women and families, and very few autopsies are conducted to enhance our understanding of the causation of stillbirth or potential risk factors. However, results of pilot research data shed some light for women in our region

When communicating stillbirth research to vulnerable women and families, the essential questions are:

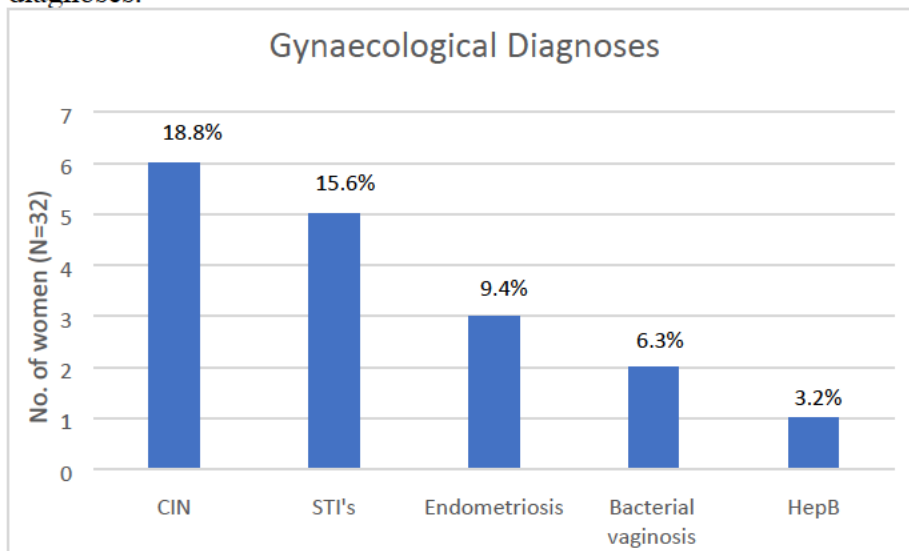
- 1) What are my chances of experiencing stillbirth (Rates);
- 2) What causes stillbirth? (Risk factors); and
- 3) If I experience a stillbirth, how can I find out what caused it? (Gaining permission for autopsy).

32 women had experienced stillbirth in this pilot study. Preliminary results show that autopsy rate of 25%. While this rate matches that of Indigenous autopsy rates in Queensland, this rate is well below the overall Queensland and other state rates (see Figure 1.).



*Figure 1. 2011 autopsy rates.*

Of the 32 women in this pilot study, approximately 19% had been diagnosed with Cervical intraepithelial neoplasia (CIN), 15.6% with an STI (sexually transmitted illness), and other gynaecological diagnoses (see Figure 2). This preliminary information provides some correlational between stillbirth and other gynaecological diagnoses.



*Figure 2. Rates of gynaecological diagnoses.*

Unfortunately, not all women were approached to provide consent for autopsy. However, for those women who were contacted, opinions were divided: there were those who did consent and those for whom nothing would make them consent. Below outlines the main reasons why women and their families did or did not permit autopsy (see Figure 3).



*Figure 3. Reasons women and families gave or declined permission for an autopsy.*

Health professionals will need to take these rates, risk factors, and decision-making points into consideration when communicating stillbirth research to vulnerable women and families. We are planning to develop these factors into educational materials for Health Professionals who engage with women and their families.

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

The Commonwealth has been very generous and supportive in the past. It has supported research in stillbirth through NHMRC research grants, such as the establishment of The Centre of Research Excellence in Stillbirth (The Stillbirth CRE), the University of Queensland in Brisbane.

As the tertiary perinatal referral services for North Queensland, The Townsville Hospital and Health Service (THHS) perinatal services, if provided with adequate resources have the expertise and unique opportunity to progress stillbirth research with a focus on Aboriginal and Torres Strait Islander families. THHS in partnership with JCU could complement efforts of The Stillbirth CRE and focus on closing the gap in stillbirth rate in Northern Australia.

**Reference:**

Y Kandasamy, M Kilcullen, D Watson Fetal autopsy and closing the gap  
Australian and New Zealand Journal of Obstetrics and Gynaecology 56 (3), 252-254

Ibiebele I, Coory M, Boyle FM, Humphrey M, Vlack S, Flenady V. Stillbirth rates  
among Indigenous and non-Indigenous women in Queensland, Australia: is the gap  
closing?. *BJOG* 2015;122:1476–1483.

Thank you

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