

The future of stillbirth research and education in Australia

The Australian Longitudinal Study on Women's Health submission to the Select Committee on Stillbirth Research and Education, Department of the Senate

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About the Australian Longitudinal Study on Women's Health

The Australian Longitudinal Study on Women's Health is a longitudinal population-based survey examining the health of over 57,000 Australian women. The study is funded by the Australian Government Department of Health and managed by the University of Newcastle and the University of Queensland.

The study aims to clarify cause-and-effect relationships between women's health and a range of biological, psychological, social and lifestyle factors, and to assess women's use of health services and the effects of changes in health policy and practice. The study follows four cohorts of women through critical life stages:

- 1989-95 cohort – women aged 18-23 at their first survey in 2012-13
- 1973-78 cohort – women aged 18-23 at their first survey in 1996.
- 1946-51 cohort – women aged 45-50 at their first survey in 1996
- 1921-26 cohort – women aged 70-75 at their first survey in 1996

Response to terms of reference

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

Access to self-reported stillbirth data from the study

Women's experience of stillbirth is tracked in the 1973-78 cohort and the 1989-95 cohort. The study is a national research resource and its data are freely available to researchers through a formal request process. Survey data from the study are available to researchers on average two to three months after each survey round closes.

In the 1973-78 cohort, women were asked how many times they had experienced stillbirth at:

- Survey 2 in 2000 when they were aged 22 to 27, total number (N) of women surveyed 9688
- Survey 3 (in 2003, aged 25-30, N=9081)
- Survey 4 (in 2006, aged 28-33, N=9145)
- Survey 5 (in 2009, aged 31-36, N=8199)
- Survey 6 (in 2012, aged 34-39, N=8009)
- Survey 7 (in 2015, aged 37-42, N=7186).

This question has also been included in Survey 8, which is currently open (women are now aged 40-45 years).

In the 1989-95 cohort, women have been asked how many times they have experienced stillbirth at:

- Survey 1 (in 2012-3, when aged 18-23, N=17011)
- Survey 3 (in 2015, when aged 20-25, N=8961)
- Survey 5 (in 2017, when aged 22-27, N=8495)

The surveys will continue to track women's experience of stillbirth throughout their reproductive years. The 1989-95 cohort survey 6 will be deployed in 2019.

Consistency of stillbirth data

In 2009, researchers noted that the rate of self-reported stillbirth was higher in the study dataset than national figures (11.0 vs. 7.8 per 1000 live births)¹. A more recent paper published in 2015 tested the validity and reliability of self-reported stillbirth data from the survey and linked administrative data from three New South Wales based datasets. The researchers found that no single source was entirely accurate and reliable – 70% of cases could be classified as either a stillbirth or a false negative². Previous research has shown that mothers who experience stillbirth face social stigma that can lead to underreporting. However, the researchers found that participants in the Australian Longitudinal Study on Women's Health who had a stillbirth always reported it (i.e. 100% sensitivity). However, the accuracy of the self-reported data was reduced because some women reported late spontaneous miscarriage or medical termination as a stillbirth.

The 2015 paper highlights some of the issues involved using administrative datasets for perinatal research. Although there is overlap in the content recorded, each dataset is considered independent and records are entered by different staff in the health system. While the study had 14 years of prospective data on stillbirths from the 1973-78 cohort, there was only four and half years overlap in available data from all four datasets. In addition, the Midwives Data Collection (MDC) does not receive notification when a mother from NSW gave birth in another state. The Admitted Patient Data Collection (APDC) does not include patient names and addresses so data cannot be included in record linkage studies. The Perinatal Death Review Database (PDRD) classifies stillbirth as 500g or 22 weeks gestation compared to 400 grams and 20 weeks gestation in MDC and ADPC².

Linking survey data with administrative perinatal datasets

The Australian Longitudinal Study on Women's Health routinely links women's survey data to administrative datasets providing perinatal data (study participants can opt-out of data linkage if they wish). Linkage with perinatal records from all states is expected to be completed by early 2019, making the study one of the few programs with the capacity to do this research nationally.

The study currently holds linked perinatal records for:

- NSW for the period from 1994 to 2015 for the 1973-78 cohort
- ACT for the period from 1997 to 2012 for the 1973-78 cohort (public hospitals only)
- WA for the period from 1989 to 2014 for the 1973-78 cohort and 1985-91 cohort
- QLD for the period from 2002 to 2017 for the 1973-78 cohort and 1985-91 cohort

In addition to survey data and linked perinatal data, the study also sources hospital admission and cancer registry data from each state as well as Medicare Benefits Schedule and Pharmaceutical Benefits Scheme data, at the national level. This extends the utility of perinatal data, as perinatal outcomes in relation to other health conditions and events, as well as health service use, can be explored.

However, access and timeliness of linked data can vary and sometimes data are two years old on supply. There is no nationally linkable dataset. Data have to be sourced from each individual jurisdiction, and often require the approval of different Human Research Ethics Committees, liaison with different Data Linkage Units, as well as the approvals of Data Custodians and sometimes Chief Health Officers or Heads of Department. In Victoria, access to perinatal data is under the control of the Consultative Council on Obstetric Morbidity and Mortality, and subject to different regulations, which limits accessibility,

timeliness and comparability. This is an issue for the study as around 25% of participants reside in that state.

Once approvals are in place, bureaucratic processes can result in delays in supplying the data, and procedures for getting further updates, or adding new researchers can also lead to delays. These factors impact on the ability to produce current, nationally comprehensive research. In some states (for example, the ACT and NT), only public hospital data is linkable as names have not been collected from private patients. Harmonising data from multiple sources is also an issue, as the duration of coverage, the variables supplied, and the sensitivity of the linkage methodology can vary from state to state.

While Australian state and territory Departments of Health have signed a Memorandum of Understanding for [mutual acceptance of ethical and scientific review](#), we have had limited success in streamlining the number of ethical reviews required via this process. To date, the procedures involved in gaining agreement between jurisdictions have been lengthier than those required for separate approvals.

The Productivity Commission Inquiry into Data Availability and Use (Report No, 82, 31/3/2017) recommended a [suite of substantial reforms](#), however, it will be some time before these will be established and benefits realised by researchers, and ultimately, the wider community.

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

The ALSWH is funded until at least 2020 and will continue to collect stillbirth data from women in the youngest two cohorts. The data are available free of charge for use by researchers worldwide.

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

The Australian Longitudinal Study on Women's Health aims to identify the risk factors that contribute to women's health outcomes and to inform policymakers, clinicians and women so that they can make informed decisions and take action. Recognised risk factors for still birth include smoking, alcohol, drug use, obesity. Hypertension during pregnancy and gestational diabetes account for a small, proportion of stillbirths. However, with up to 60% of stillbirths unexplained, increasing our knowledge of the risk factors associated with stillbirth and educating women and clinicians about preventative measures to reduce risks is critical.

The study offers researchers unique data enabling insight into a broad range of psycho-social, demographic, and health-related factors related to the risk of stillbirth, and long-term outcomes for women experiencing stillbirth. The study has close to 250 active projects researching all aspects of women's health. Active projects from the study's collaborators are currently investigating stillbirth as a factor in relation to:

- Polycystic Ovarian Syndrome
- Unintended pregnancy and contraception in women with chronic disease
- Substance abuse and sexual behaviours among young Australian women

- Mental health after pregnancy loss

Preconception health is a broad theme of developing research within the study. Women (and to some extent men's) nutrition, health and lifestyles in the months and years leading up to conception have far-reaching consequences in terms of maternal complications and foetal/child development.

In 2018, the study contributed to an overview of international research on preconception health, published in the Lancet. The paper (the first in a three-part series) brought together the latest research on health interventions before and during pregnancy, with new data from women's health studies in the United Kingdom and Australia. The authors found that health and diet interventions made after conception were too little and too late to reduce the risks of pregnancy complications³.

The paper highlighted international research indicating that folate supplementation and lower BMI before conception both reduced the risk of stillbirth. Included data from the Australian Longitudinal Study on Women's Health showed that only 10 per cent of Australian women ate the recommended daily serve of fruit and vegetables during their key childbearing years. In our 1973-78 cohort, the overall obesity rate rose from 27 per cent at age 18 to 23 to almost 40 per cent by age 36 to 42. Women in the study who were planning a pregnancy did cut back on cigarettes and alcohol, but they weren't increasing their fruit and vegetable intake and had higher body mass index and exercised less than women who weren't planning a pregnancy³.

Additional research from the study in the field of preconception health has revealed that women following a Mediterranean diet before pregnancy have a reduced risk of gestational diabetes in large part due to their lower Body Mass Index (BMI)⁴. In our 1973-78 cohort, women who gained as little as 2.5 per cent of their body weight each year in the years leading up to pregnancy had almost triple the risk of gestational diabetes compared to women who maintained a stable weight⁵. The same weight gain led to a 2.3 times greater risk of hypertensive disorders of pregnancy⁶.

The final paper in the Lancet series focused on recommended interventions to improve preconception health. The authors noted that 40% of pregnancies globally are unplanned and current intervention's focus on personal responsibility do not address the obesogenic environment and complex social and cultural influences. They recommended public health education to raise awareness of the importance of preconception health and suggested that the food industry and retailers work alongside government, NGOs and research organisations. They further recommended that education programs start in the school years when adolescents are cementing health-related behaviours and attitudes⁷. The importance of early education and intervention is underscored by the fact that young women in the study born in 1989-95 have higher BMIs and are gaining weight more rapidly than the generation before them⁸. With the result that the prevalence of stillbirth related risk factors will increase rather than decrease.

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

The Department of Health funds the Australian Longitudinal Study on Women's Health as a resource for researchers and policymakers. We endeavour to ensure that our research results are also accessible to the general public. The study translates and disseminates research conducted by its management team at the University of Newcastle and the

University of Queensland. Results are disseminated through our website, social media, newsletters, annual reports, and through submissions and policy briefs to state and federal governments. We utilize the media reach of the University of Newcastle (Hunter Medical Research Institute) and the University of Queensland's media teams to distribute media releases nationally and internationally.

In 2017, the study had over 250 active projects using study data, with almost 60 papers published from these projects. We work closely with collaborators and their institution's media teams to translate and disseminate results to the public. Researchers frequently attend NGO and other conferences to disseminate information and are readily available for comment regarding stillbirth and any other women's health issues.

The study collaborates with a network of industry associations and NGOs (such as Jean Hailes for Women's Health, the Australian Women's Health Network and its state bodies) to amplify communication of research outcomes to relevant audiences.

Quantifying the impact of stillbirths on the Australian economy

A project investigating the economic impact of adverse birth outcomes (including stillbirth) has published two papers in the last 12 months. The researchers found that adverse births (including stillbirths) are a risk factor affecting maternal hospital costs in the public system⁹. A companion paper investigated risk factors for out of hospital costs covered by Medicare. The data indicated that stillbirth is a risk factor for higher out of hospital Medicare costs¹⁰. However, due to the small sample size, the researchers urge caution interpreting the results.

In the future, a focused project may be able to estimate the financial impact that stillbirth has on the public health system by linking women's survey data with MBS, PBS and PDC. It could also be used to assess the indirect impact on women's short and long-term quality of life.

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