STILLBIRTH RESEARCH AND EDUCATION

Response to the Inquiry

June 2018

RESEARCH AUSTRALIA

CONNECTING ▪ ENGAGING ▪ INFLUENCING

ABOUT RESEARCH AUSTRALIA

Our vision: Research Australia envisions a world where Australia unlocks the full potential of its world-leading health and medical research sector to deliver the best possible healthcare and global leadership in health innovation.

Our mission: To use our unique convening power to position health and medical research as a significant driver of a healthy population and contributor to a healthy economy.

Our goals:

Engage

Australia in a conversation about the health benefits and economic value of its investment in health and medical research.

Connect

researchers, funders and consumers to increase investment in health and medical research from all sources.

Influence

government policies that support effective health and medical research and its routine translation into evidence-based practices and better health outcomes.

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There is a range of existing programs and mechanisms that can be utilised to support partnerships between the research and private sectors to promote the development of innovative new technology to help prevent stillbirths. In addition to the development of commercial products, this could be done via non commercial programs or interventions that many in the corporate sector are willing to participate in as part of their corporate social responsibility or philanthropic programs.

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Existing schemes can be utilised or adapted to support the development and provision of programs and products by the private sector and/or in partnership with public sector and not for profit organisations. This can be done at a national and/or international level.

Summary of recommendations

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Australian researchers, including those in the health economics discipline, are well placed to assist in quantifying the economic impact of stillbirths. Utilising international studies in this area would also provide a useful starting point, albeit translated into an Australian context.

STILLBIRTH RESEARCH AND EDUCATION

RESPONSE TO THE INQUIRY

Introduction

Research Australia is pleased to respond to the invitation to make this submission to the Inquiry. We acknowledge the enormous emotional toll that stillbirth takes on affected Australian families every year and the grief and anguish it causes. It is a universal issue and notably, Australians are actively participating in the global effort to prevent stillbirth, improve levels of care for parents and families affected by stillbirth, and raise awareness. However, there is much more that remains to be done, and Australian researchers are well placed to make a greater contribution.

As the national peak body for health and medical research and innovation, our expertise lies in our understanding of the research and innovation ecosystem and the opportunities that exist within this ecosystem to address the Inquiry's Terms of Reference. We have briefly addressed the Terms of Reference from this perspective.

We hope that the information about the existing ecosystem provided in this submission will assist the Committee in the formulation of its recommendations by enabling it to take advantage of existing programs, structures and networks that can be utilised and/or adapted to better support and advance stillbirth research and education.

Research Australia offers its expertise to assist the Committee in any way that we might be of help.

Response to the Terms of Reference

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

In 2014, the Australian Institute of Health and Welfare released a report on Stillbirths in Australia over the 20-year period from 1991 to 2009.[1] The first report of its kind, it was compiled for the AIHW by the National Perinatal Epidemiology and Statistics Unit (NPESU) which is an affiliated institution of the University of New South Wales (UNSW). The report, and in particular Appendix C, provide an insight into the difficulties with collecting this data in Australia. The fact that this report, released in 2014, uses data for a period ending in 2009, speaks eloquently to the Committee's interest in the timeliness of data.

There is an increasing recognition of the importance of accurate and comprehensive data to all fields of research. Advances in our capacity to analyse large datasets, including through machine learning and deep learning, have given us an appreciation of the unexpected insights and discoveries that can be made from the analysis of large datasets. We are also increasingly realising that these datasets do not always exist where we want them. The good news is that from a technological viewpoint, these datasets ae cheaper, easier and faster to create, share and analyse than they have ever been before.

This Inquiry is also occurring against a backdrop of action being taken by the Australian Government to create a Framework for utilising the My Health Record for research and a commitment to making better use of public data more generally. It is Research Australia's expectation that this will lead to a more 'research friendly' policy framework for the use of publicly held data that will facilitate research of the type required to understand the epidemiology and impact of stillbirth in the Australian economy. However, this expectation is not a foregone conclusion and there is much work remaining to be done to convince governments across all jurisdictions to commit the necessary resources to the collection of relevant data and to the curation and linkage services required to facilitate this research, as well as the creation of the necessary policy and legislative frameworks. In the case of stillbirth, obtaining access to consistent, uniform and comprehensive data, which is collected by state and territory jurisdictions, remains a significant challenge. Engagement with State and Territory governments in this regard is essential.

Research Australia submits that this is a favorable climate for action by Commonwealth, State and Territory Governments, health providers and researchers on any recommendations the Committee may make in relation to better collection, use and availability of data.

We encourage the Committee to draw on the many experts in the research and health sectors to identify the relevant datasets. This includes health services professionals at the local health district levels as well as academic researchers working in the fields of perinatal and neonatal health.

[1] AIHW: Hilder L, Li Z, Zeki R & Sullivan EA 2014. Stillbirths in Australia, 1991–2009. Perinatal statistics series no. 29. Cat. no. PER 63. Canberra: AIHW National Perinatal Epidemiology and Statistics Unit.

b. coordination between Australian and international researchers

Generally speaking, Australian researchers are good international collaborators. The Organisation for Economic Cooperation and Development (OECD) has undertaken studies of the most cited scientific publications and patterns of international collaboration. (High levels of citations of a scientific paper are an indication of scientific excellence.) Of the 41 OECD countries, Australia ranks 9th for domestic authors leading highly cited publications with international scientific collaborations.[2]

Australia has developed a number of models for supporting international research collaborations, including formal partnerships with overseas institutions and collaborations. For example, the National Health and Medical Research Council (NHMRC) supports Australia's associate membership of the European Molecular Biology Laboratory, which enables Australian researchers to access EMBL's facilities and to collaborate with European researchers at the EMBL. At the other end of the scale, Australian researchers are able to access grants to travel internationally in support of their research.

The level of Australia's international involvement with stillbirth is evident in the membership of the International Stillbirth Alliance. There are 13 Australian member organisations, including professional colleges, foundations and consumer groups, a number equaled only by the USA.[3]

The Centre of Research Excellence in Stillbirth (Stillbirth CRE), funded by the NHMRC, is a good example of coordination and collaboration between Australian and international researchers, health service providers and the community.[4] Hosted by the Mater Institute at the University of Queensland, its partners include four other Australian universities, a medical research institute and nine other groups across the health system and community. It has research collaborators from around the globe and serves as the Australasian Regional Office of the International Stillbirth Alliance. It is also the coordinating centre for the Perinatal Society of Australia and New Zealand (PSANZ) Stillbirth & Neonatal Death Alliance (SANDA).

The need to recruit large numbers of participants in clinical trials means that international cooperation and recruitment is essential if they are to be successful and provide meaningful data. Local expertise and international relationships of the type established by the Stillbirth CRE are essential to participation in international trials.

Research Australia submits that there are strong opportunities to utilise the Stillbirth CRE and other existing programs and mechanisms to further enhance and encourage coordination between Australian and international researchers, and the participation of Australian families in multinational clinical trials. Global education and awareness campaigns and joint funding opportunities could also be explored.

[2] OECD, OECD Science, Technology and Industry Scoreboard 2017: The Digital Transformation. Analysis of underlying data available at StatLink http://dx.doi.org/10.1787/888933618821
[3] http://stillbirthalliance.org/about-us/member-organisations/
[4] https://www.stillbirthcre.org.au

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

Research Australia agrees that there is a role for the private sector and technology in addressing stillbirth. While Australian researchers have in the past been criticised for the failure to partner with the private sector, the situation has changed for the better in the last few years. The Australian Council of Learned Academies' report into Australia's Research Training System, commissioned by the Australian Government, has helped set the direction towards greater engagement between higher education and industry.[5] A number of initiatives under the umbrella of the National Innovation and Science Agenda are also seeking to improve connections and support commercialisation. These include the Medical Research Future Fund's Biotech Horizons Program, administered by MTP Connect, and the recently announced Frontier Health and Medical Research Program which was initiated in response to a recommendation by Research Australia[6].

The Cooperative Research Centre (CRC) Program is a large existing program with a long history in supporting both commercial and non-commercial health innovations. A current example is the CRC for Living with Autism, which is taking a whole-of-life approach to autism, focusing on diagnosis, education and adult life.[7] CRC Projects are a more recent and smaller scale model, with more limited objectives and shorter timeframes.[8]

Research Australia submits that there is a range of existing programs and mechanisms that can be utilised to support partnerships between the research and private sectors to promote the development of innovative new technology to help address stillbirths. In addition to the development of commercial products, this could be done via non commercial programs or interventions that many in the corporate sector are willing to participate in as part of their corporate social responsibility or philanthropic programs.

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

Research Australia agrees there are many opportunities for the funding of research into specific areas, and through a variety of channels. We have outlined several opportunities to illustrate how specific areas of research have been successful in attracting funding, suggesting some opportunities for this Inquiry to consider.

Currently, the preeminent source of funding for Australian health and medical research is the National Health and Medical Research Council (NHMRC). While the NHMRC's main funding programs are investigator-led and focus on funding research excellence, the NHMRC also administers targeted calls for research to address the need for research into specific areas. Current and recent examples include:

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[5] https://www.education.gov.au/review-australia-s-research-training-system
[6] https://researchaustralia.org/frontier-medical-innovations/
[7] https://www.autismcrc.com.au
[8] https://www.business.gov.au/assistance/cooperative-research-centres-programme/cooperative-research-centres-projects-crc-ps

- nutrition for Aboriginal and Torres Strait Islander Peoples;
- debilitating symptom complexes attributed to ticks; and
- depression, anxiety and suicide among elderly Australians.

The NHMRC has also initiated or undertaken large programs of targeted work, including in Dementia (the Boosting Dementia Research Initiative).

The NHMRC Centres of Research Excellence (CRE) Scheme supports collaborative research by teams of researchers 'to pursue collaborative research and develop capacity in clinical, population health and health services research.' As noted above, there is currently a Centre of Research Excellence in Stillbirth. Other current CREs include the Centre of Research Excellence in Newborn Medicine at the Murdoch Children's Research Institute.[9]

The Medical Research Future Fund is priority driven. Since its inception in 2015, several programs of targeted research have been instigated including:

- research into antimicrobial resistance,
- funding for clinical trials in rare cancers, rare diseases and areas of unmet need, and
- the Australian Brain Cancer Mission.

The latter is an example of a program that is jointly funded by the Australian Government through the MRFF and by matching funding from philanthropic sources.

Another model used to jointly fund cancer research is the Priority-driven Collaborative Cancer Research Scheme.[10] This program combines funding from the Australian Government's priority driven Cancer Agency, Cancer Australia, with funding from philanthropic groups. The application process is administered by the NHMRC.

Targeted funding programs provided by philanthropy or a government can build research capacity in a particular area, helping to ensure that future applications for open and contestable funding programs are more competitive. Examples include grants that support early and mid-career researchers, giving them the opportunity to build the track record in a particular area that is necessary to be successful in securing further research funding from agencies like the NHMRC. In 2017, the NHMRC partnered with BeyondBlue to offer a funding opportunity for research into depression and anxiety associated with childhood adversity.[11]

Funding can also be targeted in other ways. For example, there has been a growing concern about the need for more health professionals to become involved in research, either on a full-time basis or in conjunction with maintaining a (reduced) clinical workload. Both the NHMRC and the MRFF fund clinical research fellowships, targeting clinicians who want to become more involved in research.[12]

As noted earlier, the CRC Program leverages Australian Government funding to secure private sector investment in the commercialisation of research. It is just one example of Australian Government programs designed to support and encourage private sector investment in research and innovation.

Research Australia submits that there is a range of existing programs that could be used to fund future research into stillbirth, drawing on funding from the Commonwealth Government, the private sector and philanthropy.

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9 https://www.mcri.edu.au/research/centres/centre-research-excellence-newborn-medicine
[10] https://canceraustralia.gov.au/research-data/research/priority-driven-research/
[11] https://www.nhmrc.gov.au/grants-funding/apply-funding/centres-research-excellence-cre
[12] https://www.nhmrc.gov.au/grants-funding/apply-funding/translating-research-practice-trip-fellowships

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

The Stillbirth CRE incorporates a broad range of partners and already plays a coordinating role in relation to stillbirth research in Australia.

In relation to the involvement of the private sector, this submission has already pointed to schemes that support the engagement of academic researchers and the private sector in translating and commercialising research discoveries into new therapies and products. This includes CRCs and CRC Projects. The ARC Linkage Program may also be an option, particularly in relation to educational objectives and the development of new technologies.[13]

There is also the potential to raise awareness on a topic that is often 'hidden' due to the gravity and tragic circumstance of stillbirth. Grief and privacy must of course be considered and respected, however, societal taboos are often only broken through raising awareness and following that, the opportunity to advocate for more research or funding because of it.

Research Australia submits that these schemes (and others) could be utilised or adapted to support the development and provision of programs and products by the private sector and/or in partnership with public sector and not for profit organisations. This can be done at a national and/or international level.

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

The effective communication of research and research findings in a manner that empowers the public and enables them to take appropriate action, including seeking assistance, is critical.

There is significant Australian expertise in the development, trialing and evaluation of different communication strategies, messages and media for public health and health education purposes. This includes the tailoring of communication for specific demographics.

For example, Social Marketing at Griffith is a research unit within the business school at Griffith University. '*We conduct qualitative and quantitative research in-house to ensure quality and cutting-edge findings that provide unique insights. We use those insights to create, plan, implement, deliver and evaluate programs designed to change behaviour for the better.*'[14] The School of Advertising, Marketing and Public Relations at Queensland University of Technology has developed programs to educate about and change breast feeding

[13] http://www.arc.gov.au/linkage-program
[14] https://www.griffith.edu.au/griffith-business-school/social-marketing-griffith/what-we-do

practice.[15] Deakin University's Institute for Physical Activity and Nutrition has a range of programs designed to educate families and individuals about health and nutrition and to change behaviour.[16]

Local health districts are also funded by state government led initiatives in the educational awareness space, particularly in publicly funded hospitals and midwifery clinics. These should be considered as avenues of opportunity to raise awareness and share information.

Research Australia urges the Committee to take an evidence-based approach to programs designed to communicate about stillbirth and stillbirth research, drawing on the social marketing and behavioural expertise present in Australian research organisations and health service delivery programs.

g. quantifying the impact of stillbirths on the Australian economy

Understanding the societal impact of stillbirth is incredibly complex; not least of all, because of the tragic nature of it, but also the hidden nature of it. The physical and emotional fallout will have an economic impact; the associated health services that form part of the perinatal and neonatal health system bring with it an economic impact. Understanding the various economic impacts of this tragic phenomenon can help us understand how research allocation could lead us toward deeper understanding and ultimately, prevention.

Health Economics is a discipline that helps inform and guide policy and decision making in relation to the provision of health services and programs. Part of this work involves establishing the baseline-understanding the impact of particular conditions and diseases on the Australian health system and the economy more generally. Australia has many health economists and several specialist health economics research teams that undertake health economics research and analysis. Of particular relevance to this Inquiry, Associate Professor Emily Callander is a Principal Research Fellow, Health Economics at the Australian Institute of Tropical Health & Medicine at James Cook University. She is collaborating with the Stillbirth CRE on its Health Economics research element, assessing the full economic cost of stillbirth.[17]

Research Australia submits that Australian researchers, including those in the health economics discipline, are well placed to assist in quantifying the economic impact of stillbirths. Utilising international studies in this area would also provide a useful starting point, albeit translated into an Australian context.

[15] https://www.qut.edu.au/business/about/schools/school-of-advertising-marketing-and-pr/news/news?news-id=79382
[16] http://www.deakin.edu.au/ipan
[17] https://www.aithm.jcu.edu.au/exploring-the-full-cost-of-stillbirth-4pg5wv/

Conclusion

Australia has significant capacity and expertise in stillbirth research. As noted previously, Australians are actively participating in the global effort to prevent stillbirth, improve levels of care for parents and families affected by stillbirth, and raise awareness. However, there is much more that remains to be done, and Australian researchers are well placed to make a greater contribution.

We have a broad and deep research capacity within Australia across many disciplines that is able to contribute to stillbirth research in a range of different areas. This ranges from basic research and the commercialisation of new technologies to the evaluation of the effectiveness of health interventions and supporting bereaved families.

We also have a strong research infrastructure and a range of existing research programs which can be utilised to further support every aspect of stillbirth research.

Research Australia is willing to contribute further information and use its convening power in the health and medical research and innovation sector to respond to any further questions the Committee may have.

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