



**Australian Government**  
**National Health and Medical Research Council**

# Senate Select Committee on Stillbirth Research and Education

## NHMRC Submission

### Introduction

The National Health and Medical Research Council (NHMRC) is Australia's peak body for supporting health and medical research, for developing health advice for the Australian community, health professionals and governments, and for providing advice on ethical behaviour in health care and in the conduct of health and medical research.

NHMRC aims to achieve improved health and medical knowledge, including through funding research, translating research findings into evidence-based clinical practice, administering legislation governing research, issuing guidelines and advice for ethics in health, and the promotion of public health. These functions reflect the role for NHMRC set out under the *National Health and Medical Research Council Act 1992* (the NHMRC Act).

It comprises the CEO<sup>1</sup>, Professor Anne Kelso AO, the Council of NHMRC, Principal Committees and its staff.

As a national body, NHMRC has a responsibility to cover the breadth of health and medical research needs. NHMRC distributes grants through a range of schemes with specific aims, e.g. to create knowledge, to build capability, to accelerate translation of research findings into policy and practice, to foster collaboration, to strengthen international research links and to build partnerships with industry, policy makers and other research users.

NHMRC supports the best research across the full spectrum of topics in health and medicine. It does not set budgets for specific diseases or conditions. NHMRC does not generally determine the subject of research grant applications. Applications are investigator-initiated and therefore based on the expertise and research interests of those applying for funding. Research teams decide their research area and strategy prior to submitting an application to receive NHMRC funding. Grants are awarded following independent review from a panel of experts.

Since 2007, NHMRC has expended \$5.9 million in funding for grants relating to stillbirth research. Please see [Attachment A](#) for annual expenditure.

## Responses to Terms of Reference

### **a) Consistency and timeliness of data available to researchers across states, territories and federal jurisdictions**

NHMRC acknowledges the importance of data availability for researchers and supports the use and optimisation of publicly funded data for health-related research.

In 2016, NHMRC released *Principles for Accessing and Using Publicly Funded Data for Health Research* (the Principles) to make sure the use of data is optimised for the benefit of all Australians. The Principles were developed to help improve consistency and timeliness of data available to researchers and provide a framework for researchers and data custodians. They provide information and guidance for researchers and organisations on requests or applications for access to existing publicly funded datasets for the purposes of research (for example the National Perinatal Data Collection collected by the Australian Institute of Health and Welfare (AIHW)).

The Principles have the support of the Consumer Health Forum of Australia, the Australian Government Department of Health, AIHW, the Australian Bureau of Statistics, the Australian Government Department

<sup>1</sup> The CEO is accountable to the Minister for Health.

of Human Services, the Australian Electoral Commission, the Australian Institute of Aboriginal and Torres Strait Islander Studies and Universities Australia.

NHMRC also supports the sharing of outputs from NHMRC-funded research including publications and data. NHMRC's [Open Access Policy](#) aims to mandate the open access sharing of publications and encourage innovative open access to research data. Recipients of NHMRC grants must comply with all elements of the NHMRC Open Access Policy.

Stillbirth research supported by NHMRC includes projects focused on obtaining better and more accurate data. See *Attachment B* for a list of NHMRC-funded stillbirth research.

### **b) Coordination between Australian and international researchers**

NHMRC acknowledges that no single country has the resources, skills and capacity to address all health and medical research challenges and, therefore, recognises the need to encourage and support international collaboration with countries and researchers around the globe.

NHMRC has established a strategy for prioritising engagement in new and existing international activities that align with Australian Government policy and NHMRC's strategic objectives (particularly the NHMRC Act 1992 and Corporate Plan). The [NHMRC International Engagement Strategy 2016-2019](#) outlines NHMRC's approach to working with our international partners.

NHMRC's funding schemes are designed to have sufficient flexibility to support international engagement by researchers and the majority of schemes have provisions such as:

- investigators located overseas can be named as co-investigators on applications for research grants
- NHMRC grant funding may be used overseas where this is necessary to achieve the aims of the research support, and for networking activities between grant holders and similarly focussed research groups located overseas
- opportunities for career development by supporting a meaningful period of training at an overseas research institution.

### **c) Partnerships with the corporate sector, including use of innovative new technology**

NHMRC recognises that support from individuals, industry, other government agencies and the wider public and private sectors is crucial to delivering improvements in individual and population health. This support can take many forms such as philanthropy (donations and bequests), contributing to the development of health guidelines, promoting standards in ethics and the conduct of research, and identifying research priorities through participation in committees and expert groups, amongst others.

The following are examples of NHMRC-funded stillbirth research partnering with the corporate sector and using innovative technology:

- A 2017 NHMRC Practitioner's Fellowship (Grant Id 1136418) is set to develop a universal blood test for all pregnant women that could help them avoid stillbirth. Fetal growth restriction is a major cause of stillbirth as it reflects placental insufficiency. The researcher has developed several innovative approaches (starting with bioinformatics) to measure circulating proteins that are likely to be of placental origin. The researcher hopes to develop a clinically useful test which may also have significant commercial potential.
- A 2017 NHMRC Fellowship (Grant Id 1136537) has identified the biochemical processes within the placenta that lead to fetal growth restriction and placental aging, the forerunners to stillbirth. This finding may have the potential to decrease the incidence of stillbirth worldwide.
- A 2013 Project Grant (Grant Id 1067363) is trialling a mobile phone software program designed to increase pregnant women's awareness of fetal movements (My Baby's Movements-MBM app). It is also developing an educational program for clinicians on its use and on management of women reporting decreased fetal movement. The goal is a reduction in late gestation stillbirth through earlier reporting and improved clinical care. A collaboration with researchers in the UK has begun to combine data from similar trials to explore differential effects in higher risk subgroups of women.

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

##### NHMRC Support for Research on Stillbirth

NHMRC supports research through a competitive, merit-based process across the full spectrum of health and medical research. Only the best ideas and the best researchers (individuals and teams) are funded. The level of funding for a particular disease therefore depends on the number and quality of the research proposals received by NHMRC.

Application numbers for stillbirth research are small and fluctuate from year to year, so it is difficult to draw strong, statistically robust conclusions about success rates. In 2017, NHMRC received eight applications that listed stillbirth in their titles, three of which were funded. Across all NHMRC grant schemes, less than 20 percent of applications are funded each year.

Stillbirth is a common and devastating outcome with long lasting psychosocial impact for women and families. NHMRC would welcome high quality, competitive applications from researchers to find causes, preventions and treatments that will improve the chances of women having healthy babies.

The current total commitment of stillbirth grants is \$13.4 million. Stillbirth research supported by NHMRC includes projects focused on obtaining better and more accurate data, genomic sequencing and developing tests to predict stillbirth. Please see [Attachment B](#) for a list of NHMRC grants related to stillbirth.

##### Progress on stillbirth research from NHMRC-funded researchers

NHMRC requested further information from its funded researchers on progress with their stillbirth research. Much of this research is already providing outcomes likely to help reduce the risk of stillbirth. Examples of such outcomes include:

- identifying babies at risk through improved prediction and detection of contributors to stillbirth in late pregnancy, for example via a blood test to help detect small fetuses, an ultrasound to help detect placental insufficiency, and a mobile phone app (My Baby's Movements) to help women detect their babies' movements. Some of these have attracted further philanthropic support.
- improved uptake of best clinical practice resulting in a reduction in stillbirth and severe adverse neonatal outcomes in late pregnancy.
- examining the entire DNA sequence of patients, using a genomic approach, to identify the genetic causes that underlie stillbirth.

##### Centres of Research Excellence

NHMRC's range of funding schemes provides the flexibility necessary for targeting research and capacity building in key areas of need in the health system.

NHMRC is currently funding the [Centre of Research Excellence in Stillbirth](#) (Stillbirth CRE—Grant Id 1116640) which brings together parents, parent advocates, health care professionals, researchers, professional colleges, and policy makers. The grant aims to strengthen collaborations locally and internationally, reduce stillbirths and improve the quality of care for women and families after stillbirth. The Stillbirth CRE program focuses on research that translates into improved maternity care and better health outcomes for women and their babies. The CRE grant, administered through the University of Queensland, began in 2016 and is worth \$2.6 million over 5 years.

In a recent progress report, the Stillbirth CRE advised of the development of a number of initiatives including:

- a Fetal Growth Restriction Program, a clinical face-to-face training program for health professionals, to improve detection and management of women at risk of fetal growth restriction, and
- a national placental biobank register in partnership with the Australian and New Zealand Placental Research Association.

### NHMRC Support for Preterm Birth and Maternal Health During Pregnancy

In addition to grants directly related to stillbirth, NHMRC funds research into preterm birth and maternal health during pregnancy. Since 2007, expenditure on this research totals \$140 million. Examples include:

- a \$1.1 million NHMRC Partnership Grant (Grant Id 1151853) awarded in April 2018, for an Australian multi-state partnership for research and implementation related to a preterm birth prevention program
- a \$1.7 million NHMRC Project Grant (Grant Id 1144040) to trial a “screen & treat” program for pregnant women at risk of premature birth.

### NHMRC’s New Grant Program

NHMRC is implementing structural reforms to the way it funds health and medical research, through a new grant program. These reforms aim to:

- encourage greater creativity and innovation in research
- provide opportunities for talented researchers at all career stages to contribute to the improvement of human health, and
- minimise the burden on researchers of application and peer review so that researchers can spend more time producing high quality research.

The new grant program comprises four funding streams reflecting the philosophy that health and medical research is best supported by a diverse portfolio of schemes that:

- fund across the spectrum of health and medical research
- invest in people with outstanding research achievement and promise
- support the most innovative research to solve complex problems, and
- meet specific strategic objectives.

The [new grant program](#) offers increased flexibility to invest in areas of particular research need.

The new Investigator Grant and Synergy Grant schemes embed opportunities to fund research and researchers in priority areas. In particular, Synergy Grants provide \$5 million per grant and are designed to support outstanding multidisciplinary research teams to work together to answer major questions. Importantly, NHMRC encourages partnerships with other research funders, including in the not-for-profit and philanthropic sectors, to jointly fund agreed priorities through the Synergy Grants scheme.

NHMRC’s Targeted Call for Research (TCR) scheme focuses on research that has the potential to improve health outcomes for the community, reduce the burden of disease on the health system and Australian economy and contribute to the global research effort. Typically, TCRs are relatively narrow in scope, thereby enabling focussed research on specific health topics. They complement a new, dedicated funding scheme for clinical trials and cohort studies.

The aim of a TCR is to stimulate or greatly advance research in a particular area of health and medical science that will benefit the health of Australians. Through the TCR program, NHMRC has an opportunity to identify and subsequently fund emerging health problems in Australia.

### Medical Research Future Fund

The Australian Government’s Medical Research Future Fund (MRFF) is providing grants of financial assistance to support health and medical research and innovation, with the objective of improving the health and wellbeing of Australians. NHMRC is working with the Department of Health to implement a number of disbursements from the MRFF. This assistance draws on NHMRC’s high quality application and assessment processes and the expertise available to NHMRC through the health and medical research sector. Further information about the MRFF is available on the Department of Health website: <https://beta.health.gov.au/initiatives-and-programs/medical-research-future-fund/about-the-mrff>.

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

NHMRC receives more research proposals each year than it is able to fund. Many of these are high quality and well-suited to funding through third parties.

NHMRC offers a range of funding pathways and is uniquely positioned to work with individuals, philanthropic trusts and foundations, government agencies and other funders to effectively and efficiently direct funds by drawing on NHMRC's expertise and services.

The NHMRC-funded Stillbirth CRE provides a number of educational and research opportunities for care providers, researchers and students. Some examples of education programs developed (or being developed) by the Stillbirth CRE include:

- a Fetal Growth Restriction (FGR) Program which provides education to obstetric medical staff, general practitioners and midwives to improve detection and management of women at risk of fetal growth restriction. The program consists of a clinical face-to-face training program (rolling out in Victoria in 2018) and an online eLearning program.
- educational programs for clinicians to raise awareness of risk factors for stillbirth around maternal sleep position and decreased fetal movements. This involves a partnership with [Tommy's UK](#) and will also include a public awareness campaign.
- the IMPROVE (IMproving Perinatal Mortality Review Outcomes Via Education) educational program, which is a nationally run program designed to address the educational needs of health professionals involved in maternity and newborn care in managing perinatal death. The IMPROVE program is a collaboration with the Perinatal Society of Australia and New Zealand - Stillbirth and Neonatal Death Alliance (PSANZ-SANDA), with teachings based on the Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death.

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

NHMRC has a legislated role to provide high quality evidence based health advice to government and the community. In addition to developing our own guidelines, third party organisations can apply for NHMRC approval of their clinical, public and/or environmental health guidelines.

Stillbirth CRE researchers have advised that they will be seeking NHMRC approval on their suite of stillbirth guidelines. These will include the recently published [Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death](#) and the [Clinical Practice Guidelines for the Care of Women with Decreased Fetal Movements](#), as well as new guidelines under development by the Stillbirth CRE.

In February 2018, the Department of Health released the [Clinical Practice Guidelines—Pregnancy Care Guidelines](#) (the Guidelines); the recommendations of which were approved by NHMRC. The Guidelines aim to promote best practice in antenatal care, including:

- providing optimal care for Aboriginal and Torres Strait Islander women
- consideration of lifestyle factors that have the potential for harm to the developing baby (substance use)
- assessment of clinical and social factors (weight and body mass index, family violence, fetal growth and wellbeing, risk of pre-eclampsia, risk of preterm birth)
- screening of maternal health (hepatitis C, diabetes, vitamin D status, thyroid dysfunction), and
- screening for fetal chromosomal anomalies.

The Guidelines were released for a 30-day public consultation, as required in the NHMRC Act, 1992. There was considerable support, through the 55 submissions received, for coverage throughout the document of issues relevant to Aboriginal and Torres Strait Islander women, migrant and refugee women and women from culturally and linguistically diverse backgrounds. The consultation process resulted in:

- information on improving the experience of antenatal care for these women
- additional resources included for specific population groups

- the inclusion of one additional review topic (antenatal care for Aboriginal and Torres Strait Islander women) and some additional research questions, and
- additional practice points relating to migrant and refugee women to highlight the importance of using accredited interpreters and involving multicultural health workers.

#### **g) Quantifying the impact of stillbirths on the Australian economy**

A 2016 report commissioned by the Stillbirth Foundation on the economic impact of stillbirth in Australia<sup>2</sup> suggests a cost of stillbirth to the Australian economy of \$681.4 million annually. An important part of the NHMRC-funded MBM Trial (Grant Id 1067363) is an economic evaluation of the costs per stillbirth averted.

The findings of this evaluation may contribute to quantifying the impact of stillbirths on the Australian economy.

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<sup>2</sup> <http://stillbirthfoundation.org.au/wp-content/uploads/2016/10/Economic-Impacts-of-Stillbirth-2016-PwC.pdf>

## Conclusion

NHMRC thanks the Committee for this opportunity to provide a submission on this important public health issue, where every day six babies in Australia are stillborn.

NHMRC's major role is to support health and medical research and training for the improvement of individual and population health. NHMRC is committed to ensuring that its funding program supports the breadth of research needed to address Australia's current and future health challenges.

NHMRC continues to support stillborn research as well as research on preterm birth and pregnancy care. With NHMRC's new grant program, there will be ongoing support for priority-driven and other strategic research priorities via a dedicated strategic and leveraging grants stream (e.g. enhanced TCR schemes, CREs, international collaborative schemes).

NHMRC welcomes high quality, competitive applications from researchers to find causes, preventions and cures that will improve the chances of women having healthy babies and improve care for parents and families whose baby is stillborn. NHMRC-funded researchers are partnering with the corporate sector and collaborating with international researchers to provide outcomes likely to help reduce the risk of stillbirth.

NHMRC supports the use and optimisation of data for health-related research as well as the sharing of outputs from NHMRC funded research. The suite of Stillbirth CRE guidelines and the Pregnancy Care Guidelines, approved by NHMRC, help to promote best practice care for the prevention and management of stillbirth and provide a reliable and standard reference for health professionals providing antenatal care.

**ATTACHMENT A**

The following table presents NHMRC expenditure on stillbirth research between 2007 and 2017\*.

<b>Summary of NHMRC Expenditure on Stillbirth Research 2007-2017*</b>	
<b>YEAR</b>	<b>EXPENDITURE</b>
2007	\$31,422.00
2008	\$34,875.00
2009	\$106,125.00
2010	\$72,508.00
2011	\$110,099.14
2012	\$268,194.36
2013	\$206,766.15
2014	\$751,455.25
2015	\$913,266.13
2016	\$1,023,035.52
2017	\$2,339,351.38
<b>TOTAL</b>	<b>\$5,857,097.93</b>

\*Note: Expenditure is moneys spent in a given year, not total commitment. The keywords used to identify funding data for stillbirth research included: stillbirth, stillborn and fetal death, with the search on the titles, keywords or media summaries. See [Attachment B](#) below for the full list of grants.

**ATTACHMENT B**

The following table presents NHMRC grants between 2007 and 2017 that relate to stillbirth research.

<b>List of NHMRC grants relating to stillbirth research 2007-2017</b>					
<b>Grant Id</b>	<b>CIA Name*</b>	<b>Title</b>	<b>Admin Institute</b>	<b>App Year</b>	<b>Commitment</b>
511984	A/Prof Camille Helen Raynes-Greenow	The trends and risk factors of stillbirth	University of Sydney	2007	\$324,854.79
1018072	Dr Sarah Hanieh	Evaluating the causes of newborn illness and death in Papua New Guinea	University of Melbourne	2010	\$133,351.09
1029613	Prof Vicki Jane Flenady	Investigating causes of stillbirths	University of Queensland	2011	\$567,508.33
1038070	Dr Ibinabo Boma Ibiebele	Better data to inform interventions to reduce the risk of stillbirth in Australia	Mater Medical Research Institute	2011	\$95,843.82
1065854	Prof Susan Philippa Walker	Improving the prediction and detection of contributors to term stillbirth	University of Melbourne	2013	\$570,358.01
1067363	Prof Vicki Jane Flenady	My Baby's Movements	University of Queensland	2013	\$1,431,444.34
1062016	Dr Natalie Hannan	Corin, a cardiac enzyme, is critical to pregnancy success	University of Melbourne	2013	\$487,735.79
1084782	Prof Roger Smith	Is placental aging the key to understanding, predicting and preventing stillbirth?	University of Newcastle	2014	\$473,861.60
1089898	Dr Adrienne Gordon	OPTIMUM - Optimising pregnancy by translating information for pregnant women	University of Sydney	2014	\$190,445.68
1116640	Prof Vicki Jane Flenady	Centre for Research Excellence in Stillbirth	University of Queensland	2016	\$2,558,900.74
1123611	Prof Vicki Jane Flenady	A national program to address stillbirth	University of Queensland	2016	\$481,731.62
1127074	A/Prof Camille Helen Raynes-Greenow	The impact of cleaner cookstoves to reduce adverse pregnancy outcomes in low resource settings	University of Sydney	2016	\$2,093,469.95

<b>List of NHMRC grants relating to stillbirth research 2007-2017</b>					
<b>Grant Id</b>	<b>CIA Name*</b>	<b>Title</b>	<b>Admin Institute</b>	<b>App Year</b>	<b>Commitment</b>
1127265	Dr Carrington Clifford Joseph Shepherd	Pathways to avoidable and unexplained deaths in the early life course	University of Western Australia	2016	\$1,134,474.66
1123341	Prof Hamish S Scott	Genetic autopsy of perinatal death: diagnosis and discovery by Genome Sequencing	University of South Australia	2016	\$1,013,018.90
1136418	Prof Stephen Tong	Translating new therapeutics and diagnostics for major pregnancy complications	University of Melbourne	2017	\$487,891.70
1136537	Prof Roger Smith	Optimising Future Human Health by Optimising Birth Outcomes	University of Newcastle	2017	\$888,269.05
1142380	Dr Clare Louise Whitehead	Placental function testing to prevent stillbirths	University of Adelaide	2017	\$423,193.32
				<b>Total</b>	<b>\$13,356,353.39</b>

\*Chief Investigator A (CIA) is responsible for completion and lodgement of an NHMRC application and is the project leader who is responsible for the successful completion of the research proposal.