



Submission

Strategic Review of Health and Medical Research

The Telethon Institute for Child Health Research (TICHR) is pleased to provide comment on the Strategic Review of Health and Medical Research and this submission has been framed around what we believe are key recommendations applicable to a large child health research institute such as ours. We have provided case studies to support our comments where appropriate.

We also support a number of related submissions that we have been involved in or have been privy to:

(a) Association of Australian Medical Research Institutes submission

TICHR is a member of the Association of Australian Medical Research Institutes (AAMRI). We share AAMRI's vision and aspirations for a health and medical research sector that will underpin Australia's long term health and economic prosperity. We wholeheartedly support the "Optimal Model" for the health and medical research sector, and its strategic framework, presented in the AAMRI submission to the McKeon Review. In our submission, we do not intend to make additional comments on AAMRI's proposal for full funding of indirect costs of research, reform of the NHMRC, creation of a new health and medical research council (the Australian Health Research and Implementation Council – AHRIC – with a focus on strategic, priority driven research to maximise community benefit), or strengthening Australia's capacity to undertake and support high risk potentially breakthrough research through Iconic Centre Grants. We will make some additional comments building on AAMRI's recommendation to lift the scale of philanthropic funding in the Australian research sector.

(b) UWA / TICHR joint Consumer and Community Advisory Councils submission

TICHR is actively building partnerships with the community through our joint consumer and community participation program with the School of Population Health at the University of Western Australia (UWA). The Consumer and Community Participation Program, which is unique in Australia, is focused on increasing consumer and community participation in the research programs at the Institute. We strongly support the recommendations relating to consumer and community participation being integrated into all aspects of health and medical research in Australia (including funding criteria, systems, processes and mechanisms) and the call for establishment of a National Consumer and Community Support Unit, outlined in the submission of the Consumer and Community Advisory Councils of TICHR and the UWA School of Population Health to the McKeon Review.

(c) Western Australian submissions

TICHR is pleased to work closely with UWA, the Western Australian Institute for Medical Research (WAIMR), the Lions Eye Institute (LEI) and the Cancer Council of WA. Several of the submissions to the McKeon Review by our Western Australian colleagues highlight issues of particular relevance to the health and medical research sector in Western Australia and we acknowledge and support these views.

Background

TICHR is one of Australia's largest research facilities dedicated to child health. We have pioneered a multidisciplinary approach in child health research that brings together scientists from a wide range of expertise to examine the most costly, common, damaging or debilitating issues affecting young people today. Established in 1990, we are based in a purpose built research facility close to Western Australia's children's hospital and now have nearly 500 dedicated staff and students. We are grateful for the strong support of the Western Australian community through generous donations to the Institute or via the Channel 7 Telethon.

Based in Perth, Western Australia, we have collaborations with leading research organisations nationally and internationally. We are an independent, non-government, not-for-profit organisation with partnerships with the major universities in Western Australia including UWA, Curtin University, Murdoch University and Edith Cowan University. We are currently located in Subiaco, adjacent to the Princess Margaret Hospital for Children and the School of Paediatrics and Child Health (UWA). In 2015/6, we will relocate to a new facility which will be co-located with the New Children's Hospital on the QEII Medical Campus in Nedlands. Also located on the QEII Campus is the Sir Charles Gairdner Hospital, WAIMR, LEI, PathWest and the core of the Faculty of Medicine, Dentistry and Health Sciences (UWA).

Our researchers compete for scientific grants from the Australian Government (primarily through the NHMRC), the West Australian Government (primarily State Health Research Advisory Committee grants) and overseas scientific organisations to provide funds for our vital research. We also depend on the generous support of corporate organisations, philanthropists and individual donors who all share our vision.

Our mission is to improve and to promote the health and wellbeing of all children through the unique application of multidisciplinary research.

Our aims are: to conduct high quality research; apply research findings to improve the health of children, adolescents and families; teach the next generation of health researchers; and be an advocate for research and for children.

Our research is focussed around eight major streams and our priority in every area is on prevention – of disease, disability and disadvantage. Our research streams include Aboriginal child health; asthma, allergy and respiratory disease; children's cancers; healthy development; infectious disease; social and emotional wellbeing; the early years; and understanding disability.

Review questions

1. Why is it in Australia's interest to have a viable, internationally competitive health and medical research sector?

Australia needs a robust and internationally competitive health and medical research sector, not only for the public good and building a world class health system with a world class workforce. Australia has health needs (many of which are influenced by our climate, location and cultural heritage) that can only be addressed through research in Australia by Australian researchers. If we don't research these important issues, such as closing the gap between Aboriginal and non-Aboriginal Australians, who will?

As an example of this, TICHR is driving community-participatory action research programs in partnership with Aboriginal researchers and communities to better understand and address the complex factors affecting the health and wellbeing of Aboriginal children.

Case Study – WAACHS

The Western Australian Aboriginal Child Health Survey (WAACHS) is a large-scale investigation into the health, wellbeing and development of Western Aboriginal and Torres Strait Islander children and is the most comprehensive survey of its kind in Australia. The survey's primary objective was to identify developmental and environmental factors that enable competency and resiliency in Aboriginal children and young people. There was emphasis on defining priority areas for existing and future health, education and social services. Building an epidemiological knowledge-base from which preventive strategies could be developed to facilitate the social, emotional, academic and vocational competency of young people was a notable feature of this survey.

Four volumes of findings have been produced. Each volume builds on the findings of the preceding volumes and also makes specific suggestions of ways in which government agencies and departments can use the findings to inform their policies and practices. Following each volume launch, there was state-wide communication and dissemination of the findings via regional forums to Aboriginal communities, community based service providers and key staff of Australian and State government agencies. The four volumes relate to health; social and emotional wellbeing; education; and family and community.

<http://aboriginal.childhealthresearch.org.au>

Another important reason for Australia to have a viable, internationally competitive health and medical research sector is our unique data sets. For example, the Raine Study (West Australian Pregnancy Cohort <http://www.rainestudy.org.au/>), located at TICHR, is an ongoing health research project. From 1989 through to 1991, 2900 mothers enrolled in the study during their pregnancy. Over the past eighteen years they, and their children, have remained involved in the project. The families have provided environmental, developmental and health information, to provide a unique and valuable resource for scientists to research a wide range of health areas.

2. How might health and medical research be best managed and funded in Australia?

(a) Funding sources

Health and medical research in Australia has traditionally been funded through national competitive funding schemes with a much smaller proportion funded via philanthropy and private giving. In some other countries such as the United States there is a more ingrained tradition of private giving and philanthropic support of Universities and Institutes and Australia could learn from established University/Institute relationships about new avenues for funding of research while maintaining scientific independence. An example of this is the relationship between the University of Michigan Institute for Social Research (<http://www.isr.umich.edu/home/>) and the University of Michigan, whereby the Institute for Social Research is able to directly enrol students and enjoy all the benefits of being a University institute, but also maintains its scientific independence and accepts philanthropic funding

(b) National IT infrastructure

Sustainability of some national information technology infrastructure projects (physical infrastructure projects and enabling projects built on these) is a challenge for the data management and research sectors despite large amounts of money spent in this area. In general, projects (such as the Australian Research Collaboration Service, Australian National Data Service) are developed with fixed term funding, resulting in the creation of a resource that is then at risk of not reaching its full potential/ functionality before the funding source ceases. As in other areas of research, it may take several years for infrastructure

deliverables to be developed, which creates hesitancy for other stakeholders to get involved and results in limited uptake of the technology/resource.

To improve sustainability, data of national significance must be stored somewhere safe and accessible. There is an urgent need to recognise research data as an asset to be managed beyond a grant cycle. This raises the question of the best place to store such important information and how to fund this. The potential risk to data of national significance if managed by one or more Government departments is that changes in governments often lead to departmental restructure, whereas national archives are not typically affected by the political environment.

Traditionally, funding bodies do not adequately fund the often complex data requirements of research within existing grants e.g. funding for data management and analysis, storage and access beyond the life of the grant. This results in research institutes being forced to find other sources of funding to protect and develop data resources often via philanthropic support.

Recommendations:

1. We strongly support AAMRI's recommendation to create a Australian Health Research Charitable Trust and further propose Federal tax incentives similar to those used to stimulate investment in the Australian film industry (Clark 1999)
2. The newly proposed Australian Health Research and Implementation Council (AHRIC) should investigate how to maximise the benefit of collaboration between Universities and Medical Research Institutes while retaining scientific independence and the ability to attract private funding e.g. Michigan University Institute for Social Research
3. Long term funding is required for the appropriate development, testing and maintenance of national IT infrastructure (i.e. high speed networks, high performance computing, large scale data storage)
4. The Australian National Data Service (ANDS) and Research Data Storage Infrastructure (RDSI) together should recommend (with appropriate consultation) the most appropriate location for safe storage and maintenance of data of national significance, with the goal of establishing a sustainable data repository
5. We strongly recommend investment in development of platforms for data sharing and analysis as investment in these initiatives has the potential to make Australia a world leader in this area (Walport and Brest, 2011). AHRIC would be well placed to call for submissions for such platforms via a Request for Application process.

3. What are the health and medical research strategic directions and priorities and how might we meet them?

Based on the increasing evidence (Heckman 2008; Shonkoff and Garner 2012) regarding the importance of early development for later outcomes as well as the growing awareness and attention of policy makers, Australia needs an increased focus on early prevention of physical and mental health problems via increased investment in basic and applied research into preconception care, prenatal care and early childhood development. This need has been recognised sector-wide in WA through establishment of a 'Developmental Origins of Health and Disease' (DOHaD) consortium, led by UWA and involving TICHR, the Princess Margaret Hospital for Children, the King Edward Memorial Hospital for Women, Murdoch University, Curtin University and Edith Cowan University.

Other urgent priorities include studies to establish typical development baselines for physical and cognitive development. There is a need to establish the new 'normal' for Australian children, including

developmental baselines for Aboriginal and non-Aboriginal children as well as comparisons with global child development. This is basic research that underpins many other research programs and requires specific, targeted funding.

Recommendation:

That the newly suggested AHRIC considers promotion of:

Research into preconception, prenatal and early childhood development as a priority area for major national funding; with a focus on improving outcomes for children and their families.

Case Study – AEDI

The Australian Early Development index (AEDI) is a population measure of young children's development. Teachers complete a checklist for children in their first year of full-time school. The checklist measures five key areas of early childhood development: physical health and wellbeing; social competence; emotional maturity; language and cognitive skills; and communication skills and general knowledge. The AEDI results provide a snapshot of how children in a local area have developed by the time they start school and can help governments and communities understand what's working well and what needs to be improved or developed to better support children and families.

TICHR carried out the first trial of the AEDI in Western Australia in 2004 and it has now been rolled out nationally, with the Federal Government committing to collect this important information every three years

4. How can we optimise translation of health and medical research into both commercial and social outcomes?

TICHR is unique in its multi-disciplinary approach to research encompassing translational, applied and implementation research. We strongly recommend a harmonisation of definitions for these research disciplines and a framework for evaluation recognising the different outputs for each area. Our definitions are as follows:

- Translational research is part of the process of the research cycle that translates or applies the products of research into clinical or population based applications that lead to improvements in health and wellbeing.
- At its most basic level, applied research is designed to solve practical problems, rather than to acquire knowledge for knowledge's sake. It involves the practical application of science to solve specific questions or issues that are relevant to practice.
- Implementation research is the study of the methods and strategies that promote the uptake of research findings. It is similar to translational research and focuses on looking at what methods are most useful in promoting the uptake of research findings into policy and practice, while translational research is focused on a particular finding and transforming or applying it in a real world perspective.

Recommendations:

1. Harmonise definitions and develop a whole of system understanding of the meaning of translational, applied and implementation research – amongst funders, researchers, policy makers and consumers.

2. Consideration is given by the AHRIC to investigate new pathways into career support for researchers in non-traditional areas such as translational, applied or implementation research. These researchers are not as competitive with regards to track record when compared to colleagues from basic science areas as their outputs are difficult to assess e.g. how do you compare influences to policy and practice compared to peer review journal articles?
3. We strongly support the NHMRC Partnerships for Better Health scheme and encourage these types of funding initiatives to further support and grow translational research capacity. As suggested by AAMRI, this could be further developed under the auspices of AHRIC.

Case Study – CARE

The Collaboration for Applied Research and Evaluation (CARE) was established by TICHR in 2000 to progress the translation of research into policy and practice and to conduct high quality policy and practice relevant research based on the priorities of the health system.

CARE works on research projects and topics of interest to our policy and practice partners and where appropriate, draws on the expertise and experience of TICHR Senior Scientists and external researchers from other universities. Research ideas and the direction that CARE takes is determined in partnership with our policy and practice partners. These partners include policy and service delivery groups within the Western Australian Department of Health and Office of Aboriginal Health; Department of Education and Training; Office of Crime Prevention within Police Services; Commonwealth Department of Health and Ageing; Commonwealth Department of Family Services and Indigenous Affairs; and non-government organisations such as the Smith Family and Mission Australia.

The uniqueness of CARE researchers is in our ability to respond to the research needs of our partners in government and non-government sector; our linkage with researchers both internally and within external research institutions. The advantage to working in this way is that research projects are framed with partners who are in the system and therefore, the research is more likely to fit within a broader strategic agenda and has a greater chance of being translated into policy and practice.

References

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