



8<sup>th</sup> July 2024

**RE: Inquiry into support for health and medical research funding and priorities - submission from Western Australian Cohorts Network**

Dear Education and Health Standing Committee members,

We have prepared this submission on behalf of the three largescale cohort studies operating within Western Australia (WA): The Busselton Health Study, The Raine Study and The ORIGINS Project. These cohort were initiated as independent research entities, however, have united to form the Western Australian Cohorts Network. Each cohort represents a world-class research endeavour: The Busselton Health Study (BHS) holds 56 years of cross-sectional and longitudinal population health data collected from more than 30,000 individuals. The Raine Study remains one of the first and longest running pregnancy and birth cohort studies in the world, having collected life course data across four generations of West Australians since 1986. The ORIGINS Project, commenced in 2017, is a comprehensive long-term birth and early childhood cohort study that will achieve its recruitment target of 10,000 families, including children, their mothers, and their partners, by the end of 2024.

### **Cohort Studies**

Western Australia is fortunate to be the home of three of the longest running longitudinal population health cohort studies with some of the highest participation and retention rates globally. Combined, these studies collect and maintain valuable health data from more than 60,000 West Australians and have forged collaborations with over 1,000 affiliated, national, and international researchers and clinicians. Cohort studies operate in a different manner from typical research or epidemiological studies which are often cross-sectional and interpret participant data from a single point in time. In contrast, cohort studies follow people (and sometimes multiple generations) over long periods of time, tracking divergence of experiences throughout the lifespan and allowing manifestations of disease in later life to be attributed to some aberration at an earlier time point. **The scope of data/samples collected during cohort studies are kept deliberately broad to allow for the exploration of many potential hypotheses in sub-studies.**

Cohort studies are seen as **research-enabling platforms** rather than hypotheses-generating projects

themselves, and function to enable and support researchers to conduct their own project. The curated data and biospecimens stored by cohort studies **save researchers as much as 70% of data collection and recruitment costs** and many months, or years, of project development time. It can take decades to assemble enough cases to explore genetic and environmental determinants of health and systematically examine the role of risk factors and causal pathways. This is also true of mechanisms contributing to cardiovascular, respiratory, and metabolic disease (obesity, diabetes, stroke), depression, cancer, and degenerative conditions such as Alzheimer's disease. The WA Cohorts Network have already invested the time and money into recruiting and collecting information/samples from participants, freeing researchers to commence their studies more expeditiously and at a lower cost. Further benefits will be realised as the cohorts work to undertaken analysis of the biological samples they hold and convert these into accessible and readily stored data files.

Annually, the WA Cohorts Network facilitate research by over 700 West Australian researchers. In addition, the success rates of researchers applying to funding bodies for research utilising these cohorts is significantly higher than the general success rate of other West Australian researchers. Despite this, prior to 2023, these cohorts had no mechanism to receive funds from the WA State government. As vital research infrastructure, upon which hundreds of WA researchers rely, we argue that **ongoing government investment in "keeping the lights on" for these integral research platforms should be a priority**. We are pleased to have been working with the WA Department of Health Office of Medical Research and Innovation, the WA Minister for Health and Medical Research, and the FHRI fund, however putting these cohorts on a more solid footing would help improve WA success rates, overall.

Please find our joint response to the inquiry into support for health and medical research funding and priorities below:

## **1. Western Australia's small share of national competitive funding**

WA suffers from reduced exposure and performs poorly relative to size in national competitive funding schemes. Cohort studies, whose core business is to enable rather than conduct research, are further disadvantaged as scoring for funding is measured consistently by publication output. Furthermore, while research funding callouts typically target discrete disease and medical issues, cohort studies tend to cast a broader net in terms of research possibilities and are seldom limited to a specific, individual condition which are typically the focus of funding bodies, but also explore the root causes of diseases and health burden. What funding is available is often bundled with intervention studies, particularly clinical trials in the National Health and Medical Research Council (NHMRC) funding schemes.

Considering cohort studies as **research-enabling platforms** rather than discrete research studies, it becomes immediately apparent that there are limited national funding programs available to target the operational costs required to run, maintain, and continue to expand the cohort infrastructure. Whilst we recognise the value of translation science and the importance of rapid translation of research findings into health outcomes, **cohort studies require a long-term, forward-thinking approach and provide unparalleled evidence about population health, life course development and intergenerational transfer of risk and resilience to health issues, that will be lost if they are left unsupported.**

For traditional forms of research, the high cost of recruitment and collection of comprehensive data from the population can impede progress, and this is where the WA cohorts provide the most value. **The WA cohort studies are designed as collaborative research eco-systems, with structures and processes in place to support multiple projects, reduce start-up times and induce the rapid translation of proposals into projects, and ultimately research discovery.** The faster that projects can be completed, the sooner research can be translated into improved community outcomes and cost burdens can be reduced in healthcare systems globally. For project funders this means more research can be funded from the same level of investment and makes WA a more attractive proposition for research funding, and commercial investment opportunities.

**Cohort studies therefore serve to attract research funding into the State and make Western Australian researchers more competitive in national and international funding schemes.** Already, ORIGINS has attracted over \$19 million worth of additional research funding to support research that uses ORIGINS' samples/data, and The Raine Study has attracted over \$40M in category 1 funds. An analysis commissioned by BPMRI (Busselton Population Medical Research Institute) found cohorts studies act as a multiplier for research investment: for every dollar invested in WA cohort studies, \$11 of collaborative research funds are generated from sources outside WA and the social return on investment to the WA community is \$3.20 per \$1.00 invested. **Leveraging the use of these unique WA-based assets would provide a competitive edge for Western Australian researchers in national funding schemes.**

## **2. How the state's health and medical research priorities are determined**

Western Australia operates under two discrete research funding strategies: the WA Health and Medical Research and Innovation Strategy, which has no funding attached, and the Future Health Research and Innovation (FHRI) grant body with a separate research strategy that determines where those funds are allocated. It is not clear how those two strategies can and will intersect and what the process will be of determining an overarching strategic focus for the FHRI funds shaped by the State strategy.

At present the research priorities for the FHRI Fund have considerable input from the Advisory Council, however other determinants are not clear. In relation to these concerns, the increased dialogue between the two strategies and stakeholders (particularly researchers and community groups) is greatly welcomed. The WA Cohorts Network represent not only a resource for data and specimens but **a means of facilitating collaborations between research groups, institutions and directly with local communities.**

The absence of research priorities directed towards a life course philosophy of disease aetiology is problematic. Many conditions that manifest in mid- to later- adulthood have their origins in childhood which offers a window of opportunity to prevent the occurrence and progression of these conditions. A focus on the early years gives a 13% return on investment (\$7 dollars for every dollar spent) by promoting health and preventing poor health across the lifespan<sup>1</sup>. Additionally, while health and medical research

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<sup>1</sup> Heckman, J. (2019). *The Economics of Human Potential*. <https://heckmanequation.org/>

priorities are often dictated by the patients that present to our hospitals, for many conditions their onset often lie outside the remit of the health authorities in the social determinants of health (e.g. socioeconomic status; educational attainment; financial/job insecurity etc.) **Identifying and ameliorating these risk factors will require a concerted cross-agency strategy and funding effort to ensure appropriate research is conducted in this space.**

### **3. The impact on specific types of research and areas of need**

Funding often tends to drive researchers - as evidence by the popup opportunities during the COVID-19 pandemic. In recognition of the unique points of difference in our State, the WA government should celebrate and champion what sets Western Australia apart on the research stage. Our cohort studies are world renowned, as are our Data Linkage capabilities. **The WA Health and Medical Research Strategy highlights the importance of making the most of WA's unique research assets and infrastructure.** Additional benefits of the cohort studies can be leveraged by funding their intersection with State and national linked data and ensuring that the capability exists to facilitate intersectoral collaboration in governance policy.

We need to harmonise governance and management processes to facilitate cross-cohort applications to obviate delays in start-up procedures. We need to ensure we have the right health economics and population health research capabilities to leverage from these complex, longitudinal, and intergenerational data. That includes making sure we have appropriate data storage and analysis services that can facilitate national and international research collaborations. We need to support the secure storage and thorough analysis of the rich biosample collections held by each cohort. Furthermore, with the consumer at the centre of any research strategy, cohort studies - who consistently and continuously consult with their participant communities - are well placed to understand unmet needs and to determine research priorities.

**As a genuine and forward-thinking collaborative Network, we are looking for the State to embrace the unique opportunities of our data assets and to advocate for increased funding and support. We offer unparalleled access to world-leading data repositories, both retrospective and prospective – these rich data assets can provide unique insights into intractable health challenges.**

**We would welcome continued infrastructure/operational funding for these cohorts that often run from year to year not knowing whether they can continue operating. Strategically, it makes sense that the State and Commonwealth Governments invest in the critical research infrastructure that is the WA Cohorts Network and ensure that WA researchers can continue to leverage the nest data, from some of the best cohorts in the world.**

On behalf of the WA Cohorts Network:

*Professor Alan James, Chair Busselton Health Study*

*Richard Marsh, Vice Chair, Busselton Health Study*

*Dr Jennie Hui, Director Busselton Health Study*

*Dr Jacqueline Davis, Co-Director ORIGINS*

*Professor Desiree Silva, Co-Director ORIGINS*

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*Dr Debra Turner, Chair WA Cohorts Network*

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For further information or clarification, please direct initial queries to [REDACTED]