



New Zealanders for
HEALTH RESEARCH
*Ngā Tāngata o Aotearoa mō
te Rangahau Hauora*

Ka Whakarauoratia te Hunga e te Rangahau Hauora! Health Research Saves Lives!

Newsletter of New Zealanders for Health Research (NZHR)
July 2021

“New Zealand’s peak body representing the entire health and medical research pipeline”

Greetings and tēnā koutou from Chief Executive Chris Higgins



Mānawatia a Matariki!

Ka mahuta a Matariki I te pae, ka mahuta ō tatou tūmanako ki te tau

When Matariki rises above the horizon, our aspirations rise to the year ahead...

... and so it has been with NZHR as we have sought to re-articulate our vision and mission and focus on what really matters for our new year commencing on 1st July. In addition to sharing our intentions for the next twelve months this issue of “Health Research Saves Lives” features:

- Our take on future pathways for New Zealand’s research, science and innovation system
- NZHR’s submission to the PHARMAC review
- Further developments in New Zealand’s clinical trials sector
- A celebration of the decision to fortify New Zealand’s flour with folic acid
- Health research in New Zealand and around the world
- Health research opportunities
- News from NZHR’s global family
- How to support our cause
- Benefits of NZHR membership

Future aspirations: New Zealanders for Health Research



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As NZHR enters a new financial year we have been taking stock of where we should be focussing our energy and resources and have come up with a work-in-progress vision of New Zealand as a country which achieves best possible health outcomes from pulling, and punching above, its weight in undertaking and translating results of health research. To realise this vision our mission is to fight for increased investment in, and uncompromised application of the results of, health and medical research as an essential and embedded component of all parts of New Zealand’s health system. In the coming twelve months therefore we will:

1. Fight to have health research embedded as an essential component of a reforming and reformed health system
2. Push for direct government investment in health research to be lifted to 2.4% of health care costs
3. Advocate for increased participation in clinical trials
4. Mobilise stakeholder and community support to assist in achieving strategies 1 - 3
5. Develop NZHR as an effective fit for purpose organisation optimally positioned to support the achievement of strategies 1 - 4

Our sole source of income is membership subscriptions, and we are indebted to our current members who believe in the importance of our cause and support us both financially and/or in other ways, including University of Otago, AUT, Malaghan Institute, Cure Kids, Douglas Pharmaceuticals, Kantar, MSD (Merck), Roche, AbbVie, Multiple Sclerosis Society, MS Research Trust and Research Australia.

With awareness of the value of health research and the importance of getting better outcomes from our health system being top of mind for many people, it's even more important for organisations to become NZHR members and to support and invest in our cause. If this is something you think you should consider please get in touch, and read the "how to support our cause" and "membership benefits" sections below.

Whither Research, Science and Innovation?



The government's strategy for research, science and innovation (RSI) is important for, among other things, the context it provides for the development of the health and medical research sector. Back in November 2019 therefore NZHR made a [submission](#) on MBIE's draft RSI strategy. It was due to be finalised early in 2020 but has since been put on hold.

We understand that responding to the Crown Research Institutes (CRI) review has taken precedence, and that the outcome of the CRI review is being considered along with both the future of the National Science Challenges and the final shape of the RSI strategy. We also understand that MBIE is undertaking a programme of work relating to these issues, have heard that a Green Paper has been developed as an initial response for discussion, and have become aware of the Minister for Research, Science and Innovation's Cabinet paper on future pathways for the RSI system, as referenced in and reportedly aligned with the Education Minister's final Cabinet [paper](#) proposing changes to the tertiary sector Performance Based Research Fund (Executive Summary point 10).

NZHR has asked MBIE for further information including, if it exists, a copy of the Green Paper. The 29th July response is as follows:

"... the development of the RSI Strategy was interrupted by the COVID-19 pandemic. It was put on hold firstly as a response to the pandemic, and then subsequently as the Strategy obviously needed to be looked at again in light of the pandemic. As you know, the world is a very different place now to what it was when the Strategy was being developed.

That work, alongside the report into Crown Research Institutes - Te Pae Kahurangi, has led to the need to look at the system more broadly. The Minister [Hon Dr Megan

Woods, pictured] *has signalled her intention to release a discussion document later in 2021.*

I understand that the Minister has indicated that an inclusive, deliberate and methodical approach will be taken for engagement with the sector, to make sure all views are considered and implications of any potential system changes fully understood.

More information on the timing of that engagement (including the scope of the work and ways to provide feedback) is expected to be available in the coming months, once Cabinet has agreed.”

We'll keep stakeholders apprised of any further information as it comes to hand, and would also appreciate it if that could be reciprocated.

PHARMAC Review



PHARMAC REVIEW
Te Arotake i Te Pātaka Whaioranga

NZHR believes that PHARMAC, as an integral component of New Zealand's health system, should be strengthening its support for the country's health research and innovation

ecosystem, and we welcome the PHARMAC review as an opportunity for NZHR to recommend how this should occur. In response to the Review's [terms of reference](#) we have [submitted](#) that:

1. PHARMAC takes steps to reduce the time it takes to assess, prioritise and fund new treatments so as to retain a sufficiently long on-patent period to avoid disincentivising company investment in clinical research;
2. PHARMAC's decision making processes, its cost benefit model, and decision's themselves transparently take into account any impact on clinical research including clinical trials, and the flow on patient outcome and cost savings that could result from such research;
3. PHARMAC be required to actively engage with and positively respond to both the imperatives of the New Zealand Health Research Strategy and the emerging expectations of the wider research, science and innovation ecosystem; and
4. PHARMAC's analysis of therapies' costs and benefits to society is set out openly and transparently so that it can be held accountable for the quality of its decision making and enhance the prospects of more clinical research being translated into clinical practice.

Clinical Trials



In our [June issue](#) of *Health Research Saves Lives!* we mentioned that NZHR had been extended an opportunity to contribute to the “consumer needs” component of an MoH/HRC funded [initiative](#) to identify the strengths, gaps and areas of need for clinical trials systems and data infrastructure in the New Zealand public healthcare system.

We have since participated in a consumer focus group discussion facilitated by [Sapere](#) which identified that: location acts as a significant barrier for consumer involvement;

there is a distinct lack of information, dissemination, and awareness for clinical trials; meaningful consumer, community, whānau, and iwi engagement is necessary throughout the process; and, better quality of and access to information about all aspects of clinical trials is required.

NZHR has subsequently accepted an invitation to participate in a further workshop in September to identify the infrastructure options needed for making clinical trials more equitable and accessible. Participants will include consumer focus group representatives and a broad group of clinical trial researchers/trialists, including Māori, Pacific, DHB, and university researchers.

Folic acid



In November 2019 NZHR responded to an MPI discussion document [submitting](#) that fortification of flour with folic acid should be supported because: it is unequivocally supported by the results of health research which has been undertaken both internationally and in New Zealand; it will have a significant impact on the incidence and prevalence of neural tube defects, including spina bifida, resulting in improved population health outcomes, a lowering of the burden of disease on society, families and individuals, and reduced health care costs; and that it will be challenging to rely on people voluntarily opting to proactively and consistently include folic acid in their diets at appropriate and effective doses.

We're delighted that a [decision](#) has now been made that fortification of flour with folic acid will now become mandatory, and we look forward to seeing the improved population health outcomes that will result. Although it has taken a long time this is a good example of health research being translated into policy and practice. *(photo: Royal Society)*

Health research in New Zealand and around the world

Mānawatia a Matariki! and NZMJ



The 30 July 2021 issue of the New Zealand Medical Journal (NZMJ, Vol 134 No 1539) welcomes Matariki with its editors expressing the hope that changes outlined below will be “sentinel measures allowing the editorial team to develop, refine and strive towards a culturally responsible publication process”.

The editors have committed to: developing a framework for potential authors to align their submissions with the cultural expectations of the NZMJ; utilising a Treaty of Waitangi framework to advocate for a minimum target of articles that report on Hauora Māori outcomes; ensuring the ongoing retention of themed issues in health equity; increasing the number of Hauora Māori expert peer reviewers; providing a template for peer reviewers to align articles with the cultural expectations of the NZMJ; and, overseeing all publications and providing further peer review, or having the right to reject publications that do not align with the cultural expectations of the NZMJ.

Plan to eliminate hepatitis C



A plan to eliminate hepatitis C as a major health threat by 2030 has been recently [released](#) by Associate Health Minister Hon Dr Ayesha Verrall.

Noting that hepatitis C is preventable and curable Dr Verrall said that “around 45,000 New Zealanders have hepatitis C, but only around half know they have it....symptoms often don’t appear until much of the damage has been done. Without treatment, most people will develop progressive liver damage. Hepatitis C is the leading cause of liver transplants in New Zealand, and the second leading cause of liver cancer - behind hepatitis B.”

“At the same time, many of those with hepatitis C are from our most marginalised communities, and face significant barriers to getting tested and treated - including stigma around the virus.”

Work has already begun under the Action Plan, with a focus on key initiatives including:

- Developing a national awareness campaign
- Upscaling the distribution of free injecting equipment to people who inject drugs, to focus on hepatitis C prevention and reducing new infections
- Increasing access to testing through more nurse-led clinics and point of care testing delivered in the community, and through mobile clinics
- Increasing uptake of testing and treatment
- Developing a surveillance system and virtual registry that will connect diagnosed cases with the treatment they need

In the words of MoH Chief Science Advisor Ian Town “If you ever wanted an example of science saving lives this is a gold medal 🏆 for sure!!”

“Cancer Revolution”



“Cancer Revolution: science, innovation and hope” is the name of a cutting-edge, world-first exhibition about cancer, curated by Cancer Research UK and the UK’s Science Museum Group.

Cancer Research UK have been looking for ways to talk about cancer science in stimulating and engaging ways, but knew that the science can sometimes come over as a bit impenetrable. They responded with the idea of an experience that would showcase “the incredible scientific and medical progress we’ve seen in recent decades and our optimism for the future, while also bringing out the enormous impact cancer has on those it affects, and the importance of continuing to make progress against the disease.”

Underpinning the idea was a belief shared by both organisations, that a public that is engaged with scientific progress is a public that is more supportive of science itself - “something we have seen to be of huge importance lately”, noting that the development of vaccines against the coronavirus is a chapter in history of which the research community can be immensely proud.

The exhibition will open its doors in [October 2021 at Manchester's Science and Industry Museum](#), before relocating to the [Science Museum in London in May 2022](#). More information is available on Cancer Research UK's website [here](#).

Openness in animal research



Following up from our tribute to animals in the last issue of Health Research Saves Lives the Royal Society [reports](#) that 21 universities, institutes of technology, non-profits, Crown Research Institutes, government organisations, umbrella bodies, research funding organisations and learned societies have committed to communicate openly about animal use.

Associate Professor Siouxsie Wiles said: "I am delighted that Aotearoa New Zealand finally has an Openness Agreement and applaud the many organisations and institutions that have signed up to it. I hope the Agreement will encourage and support researchers and organisations to be more open about their work that involves animals. In doing so, the public will be better informed not just about the incredible research being done in New Zealand for the benefit of both humans and animals, but also about the dedication and care of the many researchers and technical staff involved."

Opportunities



August

Queenstown Research Week.

New Zealand's pre-eminent health research event, Queenstown Research Week, will be going ahead in 2021 on Monday 30th August to Thursday 2nd September. Emerging details are being posted [here](#), so now's a good time to save the dates.



Sir Hugh Kawharu Scholarship for Innovation in Science. August

Administered by Royal Society Te Aparangi, this \$10,000 [scholarship](#) is for study at master's level in the sciences. The scholarship is applicable across a broad range of science disciplines, including health. The closing date is 31st August.



HQSC Quality Improvement Symposium. November

The Commission's seventh annual quality improvement scientific symposium is on 17 November in Christchurch. The theme, 'Whakahohe, whiria te muka tangata: Recharge, inspire and connect,' focuses on taking time to connect with colleagues to reflect on the inspirational work done in an environment with a high degree of uncertainty and complexity.



Melanoma Summit. September

Get out from behind your screen and join MelNet at the sixth national [New Zealand Melanoma Summit](#), 10 - 11th September in Auckland. This is your chance to discuss latest developments in melanoma management, identify priorities for action for New Zealand and connect with other melanoma professionals across the country. MelNet is also aiming to use the Summit to formally launch the long awaited 'Quality Statements for Melanoma Care in New Zealand'

News from NZHR's global family



Research Australia's July 8 [INSPIRE magazine](#) "A focus on collaboration in Health and Medical Research" is a great read.

Research Australia's Chief Executive Nadia Levin says that "one way of looking at the importance of collaboration in national and international health and medical research is that none of us are as smart as all of us. The events of the COVID-19 have shown Australia and other countries, that collaboration is vital to propelling advances in health and medical research. Top minds and top practitioners across the globe have come together to deal with this one in 100-year challenge. While it is not yet solved, we are well on the way to finding the best possible solution for us all".

Uniquely this issue features contributions from all global sibling health research advocacy organisations including ourselves; Research!America; Research!Canada; and Research Sweden.

NZHR's contribution notes that direct government investment in health research in New Zealand currently stands at 0.61% of government health care costs - and falling, and we estimate that total investment in health R&D from all sources is 1.2% of the total government, business and society costs of living with and responding to ill health. "This places New Zealand as the worst family of five performer, which is all the more concerning given that all of us are dissatisfied with our respective countries' investment levels. Moreover, the figures also suggest that as a contributor to the global health research effort New Zealand should be doing more to ensure that it is pulling its weight internationally"

Extracts from the contributions of other sibling organisations are as follows:



Research America said that "our sense of urgency, high in any year, was greater than ever. Together with our alliance members from academia, patient groups, scientific societies and industry, we worked hard to push for the resources needed to propel COVID-19 R&D and bolster the public health response to the pandemic."

They also promoted technological transfer as critical to ensuring basic research is translated into medical advances; raised awareness about the critical roles both the public and private sectors play in fueling medical and public health progress, as exemplified by the public-private partnerships working to overcome COVID-19; and stood in vocal opposition to sidelining science in federal decision-making and compromising the international diversity of STEM students at U.S. universities.

"Our alliance had tangible impact. Working closely with partners across the R&D and public health ecosystem, and we boosted financial support of the National Institute of Health, building on the agency's decades of growth, among other policy accomplishments."



Research Canada: An Alliance for Health Discovery describes itself as "a multi-stakeholder alliance often likened to the Lighthouse in the Canadian health research and innovation ecosystem, calling divergent interests from the academic, private and voluntary sectors to a common shore and effecting a collaborative advocacy process that

simplifies and streamlines health research and innovation advocacy messaging to government.”

“Ultimately, our mission is to improve the health and prosperity of Canadians by championing Canada’s global leadership in health research and innovation. Our philosophy is simple—health research is a shared benefit and shared responsibility, and all Canadians are its steward. As a multi-stakeholder alliance, our more than 90 members are drawn from all sectors dedicated to advancing science and developing innovative solutions to improve our health and well-being, including health research institutes, health charities, regional health authorities, scientific societies, universities and their faculties, colleges, health professional associations and health and biosciences companies. Thanks to this wide-reaching representation, Research Canada is uniquely positioned to educate policymakers and the public about the entire health research and innovation ecosystem”.



Research Sweden report that they have developed proposals for measures that need to be implemented to strengthen Sweden’s crisis preparedness, by taking greater advantage of medical research and development in the event of future health threats.

Their key areas of policy advice for greater benefit from research and development for future health threats are gathered into four areas: a resilient research environment is required to cope with future unknown crises; sharing of health and care data must work in both crisis and normal situations; research competence in healthcare must be secured in the face of future health threats; and there must be an infrastructure that allows clinical studies to be performed even in a health crisis situation

How to support the NZHR cause

Join or encourage other organisations to join NZHR’s alliance to be part of lifting New Zealand’s investment in health and medical research and to advocate for:

- increased government investment in health research
- embedding health research as an essential component of the health system, creating clear pathways for results to impact on New Zealanders’ health outcomes
- an environment which encourages the opportunity for industry organisations’ health and medical research initiatives to flourish and grow
- a well informed society which highly values health and medical research

Membership benefits

In addition to enhanced organisational profile through publicly supporting a great cause and a brighter future for kiwis through increased investment in health and medical research, NZHR membership benefits include:

Lobbying and advocacy

- Peak body lobbying support for your organization’s pan-sector issues
- Opportunity to benefit from increased investment in health research
- Opportunity to contribute to and have brand acknowledgement on NZHR advocacy and lobbying position papers

NZHR Influence

- Contribute to NZHR strategic and work plans
- Participation in NZHR governance including Board representation and general meeting voting rights

NZHR Kantar annual public opinion polls

- Request poll questions
- Customised poll data
- Free attendance at presentation events

NZHR communications

- Enhanced members only versions of newsletters and publications
- Contributions to newsletter and website content
- Newsletter, publication and website advertising, profiling and branding
- NZHR promotional collateral branding

Workshops and conferences

- Complementary registrations
- Speaker nominations
- Collateral and activity/event branding
- Prior access to delegate lists

Membership is open to any organisation with an interest in health or medical research and its outcomes. Potential new members can email Chris Higgins, ceo@nz4healthresearch.org.nz for more information and a membership application form. Logos of current members and supporters are displayed below.

We hope you appreciate reading our newsletters, and we welcome any suggestions both for topics to cover and for improving how we do things. Feedback can be given to us by clicking [here](#)

Visit our website www.nz4healthresearch.org.nz to find out more about what we do and like and follow us on [Facebook](#), [LinkedIn](#) and Twitter

Ngā mihi, stay safe and until next time

Chris Higgins
Chief Executive

Our partners and supporters

Platinum



Gold



Silver

KANTAR

Bronze

abbvie



Foundation

