Making a difference

The Health Research Council Investment Impact Report



April 2019

The Impact the HRC Delivers

The Health Research Council of New Zealand (HRC) is the principal funder of health research in Aotearoa/New Zealand. Excellent research must be at the heart of tackling the challenges that face our society now and in the future. HRC delivers research that informs policy and practice to improve the quality and equity of the healthcare system, that powers a thriving, collaborative innovation ecosystem, and that enhances wellbeing for individuals, whānau and communities. HRC generates the knowledge and discoveries to bring a healthier future for all New Zealanders and secures New Zealand as a leader in high-impact, high-value health research.

This report highlights some examples of the impact the HRC delivers.



Making a difference

HRC generates new knowledge with clear pathways to impact for health and economic gain.

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HRC builds a health research ecosystem, with the people, capacity, skills and opportunities that we need for a healthier, more prosperous future.

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Purpose of this Investment Impact Report

The HRC defines impact for health research as the direct and indirect influence of excellent research on individuals, communities or society as a whole, including improvements to health and equity, and other social, economic, cultural or environmental benefits for New Zealand.

This report demonstrates the effectiveness of the HRC's investment in health research by highlighting a diversity of research impacts in health outcomes and beyond to include economic, environmental, and broader social benefits.

We demonstrate the benefits of health research to New Zealand to ensure accountability and transparency, key to substantiating on-going support for health research from the Government.

How the HRC Delivers Impact

As well as investing in research with potential to impact the health and wellbeing of New Zealanders, the HRC takes strategic and operational action to maximise the impact of research.

Our work to ensure the impact of our investment aligns with the New Zealand Health Research Strategy (2017-2027; NZHRS)¹, which aims to increase the impact of government investment in health research.

THE HRC'S ASPIRATION AND CONTRIBUTION

The HRC is a Crown agent and the government's principal funder of health research with its own board, the HRC Council. We are answerable to the Minister of Health and the Minister of Research, Science and Innovation. Our functions are set out in the Health Research Council Act 1990 and include advising our Ministers on priorities for health research, negotiating funding for health research, fostering the health research workforce and initiating and supporting health research. Please see the HRC website for more information about the HRC².

DELIVERING ON OUR VISION

New Zealand is a leader in high-value, highimpact health research.

We provide internationally recognised and independently audited, best-practice processes to ensure that only high-quality research that will deliver important health, social and environmental outcomes is supported. Our investment makes a difference to the health. wellbeing and productivity of New Zealanders through research that generates new knowledge, solutions and innovations, and improves the quality and cost-effectiveness of the healthcare system. By keeping New Zealanders healthy and productive, we support economic growth. We also support innovative research that results in new products and processes with commercial value. To make all this happen we balance our investment so that we can deliver knowledge and solutions with immediate impact, yet also seed the ideas and support the exploration that will generate the health gains and innovations of the future.

Everything that we do is ultimately designed to tangibly improve the health and wellbeing of those that need it the most.

THE HRC'S ROLE IN IMPLEMENTING THE NEW ZEALAND HEALTH RESEARCH STRATEGY (2017-2027)

The publication of the New Zealand Health Research Strategy (2017-2027) was a watershed moment for our national health research effort. The NZHRS represents a once in a generation opportunity to create a more integrated sector that better addresses the needs of our country in health research, and research-informed healthcare and policy.

¹ Available at:

https://www.health.govt.nz/system/files/docum

ents/publications/nz-health-research-strategyjun17.pdf

² Available at: <u>http://www.hrc.govt.nz/</u>

Implementing the New Zealand Health Research Strategy 2017-2027:

Strategic Priority 1 - Invest in excellent research that addresses the health needs of all New Zealanders

Action One: Prioritise investments through an inclusive priority-setting process.

Throughout 2018 the HRC:

- ran a public consultation on the process for national priority-setting,
- convened an independent Development Group (DG) selected for their mana, expertise and different world views and experience to oversee the prioritisation process,
- ran a **public consultation on the draft prioritisation model**, including meeting in person with Māori, Pacific and disability communities to hear their feedback.

2019 has seen the DG further refine the prioritisation model based on consultation feedback and release the **revised prioritisation model for final consultation**. Further steps to complete Action One include:

- DG finalise prioritisation model
- Steering Group approve final model
- Final prioritisation model translated and published in both Te Reo Maori and English
- Ministers Woods and Clark jointly announce the final model for prioritisation of health research in New Zealand.

Action Two: Invest in research for healthy futures for Māori

- In 2018, the HRC established a new annual medal celebrating research excellence and contribution to Māori health.
- The HRC established a new Fellowship for Māori Emerging Leaders in 2018, in partnership with the Ministry of Health, with a specific emphasis on equity and social investment.
- The HRC has **ratified the Tripartite Agreement on Indigenous Health Research** between New Zealand (HRC), Canada (CIHR) and Australia (National Health and Medical Research Council, NHMRC).
- The HRC has convened a working group who are responsible for developing a new Māori Health Advancement criterion, that all research applications will be assessed against, with the aim of advancing Māori health outcomes across all health research disciplines.
- The HRC is **ensuring partnership with Māori** as part of the priority-setting process, identifying research that achieves health equity for Māori and reflects the principles of He Korowai Oranga and Vision Mātauranga.

Action Three: Invest in research that results in equitable outcomes for Pacific peoples and helps them to lead independent lives.

- The HRC has established ring-fenced funding for Pacific projects through the Annual Funding Round, in 2019 it approved additional investment in Pacific Health Projects and expanded the number of Pacific clinical training awards.
- The HRC is ensuring Pacific voices are heard as part of consultation on priorities for health research, and that the process considers research that will advance the health of Pacific peoples.
- Plans to develop a stocktake of Pacific research will build on the New Zealand Research Information System currently in development by the Ministry of Business, Innovation and Employment (MBIE).

Action Four: Develop and sustain a strong health research workforce.

- In partnership with Precision Driven Health, the HRC launched a two-year postdoctoral fellowship award in 2018 to build capacity and capability in data science to understand the massive volume of information being captured by health information systems, consumer devices, genetic testing and other sources.
- In 2017 the HRC facilitated a networking event for past recipients of the HRC Hercus Fellowship, our future leaders of health research in NZ. Discussion focused on how we could better support our emerging post-doctoral and mid-career scientists. Feedback from the day was very positive and following suggestions raised by Fellows, in 2019 the HRC increased the value of the Hercus Fellowship and committed to facilitating an annual workshop for fellows to provide on-going career development support and opportunities to network with other Fellows and established health research leaders.
- The HRC continues to invest in career development across every career stage.

The collective vision for New Zealand is a worldleading health research and innovation system that is founded on excellent research and improves the health and wellbeing of all New Zealanders.

THE HRC IS DEMONSTRATING LEADERSHIP ACROSS THE SECTOR

Collectively, the Ministry of Health, MBIE and the HRC are charged with working collaboratively to implement the NZHRS. Each agency is responsible for leading the implementation of respective strategic priority areas of the NZHRS.

THE HRC IS LEADING THE IMPLEMENTATION OF STRATEGIC PRIORITY 1: INVESTMENT IN EXCELLENT HEALTH RESEARCH THAT ADDRESSES THE HEALTH NEEDS OF ALL NEW ZEALANDERS.

Beyond Strategic Priority 1, the NZHRS calls for system-level structural co-ordination and change that, once implemented, will ensure that investment in health research is used more effectively and efficiently, with knowledge translated to deliver impact and meaningful change. Collectively, these actions should enable us to better attract and retain talented health researchers and support careers in both the research and health sectors.

How the HRC drives an impactful HEALTH RESEARCH SYSTEM

The HRC has three 'Key Decision Drivers', which capture our goals and drive what we do:

- Making a difference: new knowledge with clear pathways to impact for health and economic gain
- Stimulating growth: building a healthy research ecosystem, with the people, capacity, skills and opportunities that we need for a healthier, more prosperous future
- Increasing engagement and connection: adding value to realise our collective potential.

The HRC defines impact as the direct and indirect influence of excellent research on

individuals, communities or society as a whole, including improvements to health and equity, and other social, economic, cultural and environmental benefits for New Zealand.

The HRC's 'pathway to impact' model demonstrates the value we place on connecting research with the wider community to maximise potential health and societal impact. The impact of research is influenced by early involvement of knowledge users, embeddedness of projects in existing stakeholder networks, and wellconstructed dissemination plans to reach identified research users.

Figure 1: The HRC pathway to impact model



The pathway recognises the creation of interim benefits for New Zealand, including the development of human capital, and allows producers of research for use within academia to plot their course to impact, describe how they add value along the chain and how they can realistically plan to maximise the benefits of their research.

Our model offers a simplified representation of a complex and dynamic science system, and the non-linear, cyclical nature of research, including constant feedback and reflection. It is vital to acknowledge that future impact is inherently uncertain. The full extent of impact is often unknowable at the time research is conducted, may take decades to be fully realised and is moderated by external factors beyond the research team's direct influence. The HRC pathway to impact model seeks to avoid overpromising and under-delivering, by encouraging researchers to consider a line of sight to the impact that their research *may* have, and to embed actions and recognise opportunities that increase the likelihood for the use and influence of their research. See Appendix 1 for a quick reference guide to the impact of HRC research and see Appendix 2 for a pathway to impact schematic example for two of the case studies featured later in this report.

THE HRC IS INVESTING FOR IMPACT

The HRC is primarily funded by the Crown through four parliamentary appropriations.

Over 95 per cent of our research investment expenditure is drawn from the Science and Innovation: Health Research Fund with the aim of 'benefiting New Zealand through health research', and a vision of improved health and quality of life for all. The Health Research Fund represents the engine room of our investment. We put this Fund to work primarily through our Annual Contestable Funding Round, which delivers to four Research Investment Streams (RIS) that signal New Zealand's health research needs to the community. The RIS funding mechanism is designed to capture bright, innovative ideas of high quality that will make both a national and international impact. Through the RIS, we prioritise research translation and uptake, with a strong focus on our at-risk populations and the areas of greatest need.

The HRC Research Investment Streams

 Health and wellbeing in New Zealand – Preventing illness and injury and reducing the burden on our health system. Keeping New Zealanders healthy and independent for longer is the major focus, but highly innovative research on how the human body functions in health and disease is also

³ Note that high-quality Māori health research that upholds rangatiratanga and uses and advances Māori knowledge and resources contributes to Māori health gains is important in supported, often leading to new diagnostics, drug targets or medical technologies.

- Improving outcomes for acute and chronic conditions in New Zealand – Understanding, prevention, diagnosis and management of acute and chronic conditions, particularly those causing the greatest burden for New Zealand people.
- New Zealand health delivery Research impacting on the health system and service delivery in the short term. Designed to make a real difference fast, this research will improve the health system and service delivery within three to five years.
- Rangahau Hauora Māori Improving Māori health outcomes and quality of life by building the knowledge and skills needed to reduce health disparities and realise the benefits of Māori paradigms and traditional knowledge for all New Zealanders.³

The HRC invests approximately \$2 million annually from the Science and Innovation: Vision Matauranga Capability Fund to specifically foster Māori development research and build capacity and capability to undertake health research that is unique in New Zealand. We further drive investment into Māori health research with specific Project and Programme contracts and a raft of Career Development Awards that encompass every career stage. A portion of the Vision Mātauranga Capability Fund is discretely administered to support the development of people and organisations undertaking research that supports the Vision Mātauranga: Hauora/Oranga, health and social wellbeing theme. Our Ngā Kanohi Kitea research contracts focus on strengthening capability, capacity, skills and networks between Māori and the science and innovation system, and increasing understanding of how research can contribute to the aspirations of Māori organisations and deliver benefit for New Zealand. See page 44 for further detail about the NKK grants which unlock the innovative potential of Māori knowledge,

all investment streams, not just the Rangahau Hauora Māori stream. resources and people to improve the health and social wellbeing of Māori communities.

Approximately \$1 million annual investment is drawn from the Science and Innovation: Catalyst Fund. The Catalyst Fund supports activities that initiate, develop and foster collaborations leveraging international science and innovation for New Zealand's benefit. The HRC partners with organisations internationally so that New Zealand researchers can be at the centre of global initiatives and have access to opportunities, expertise and infrastructure that are not available here. We also do this to ensure that our funding supports New Zealanders to influence global research efforts and make international and national contributions. See pages 20 and 40 for some examples of the impact of several Catalyst Fund projects administered by the HRC.

The remaining balance of Crown funding from Vote Health and the Science and Innovation: Research Contract Management appropriation is allocated to operational expenses, detailed in the HRC's Statement of Performance Expectations (SPE).⁴

In order to meet the objectives specified in our founding legislation⁵ the HRC invests in tangibly improving the health and wellbeing of New Zealanders through directing funding across four key health research outputs:

Health Research Contracts: Investment in knowledge and solutions proposed by our brightest minds through our Annual Contestable Funding Round. These investigator-led, applied research contracts represent the majority of our investment and return outstanding results from allowing researchers to use their creativity to address the signals that we send through our RIS. The HRC offers the following health research contract funding opportunities:

> Capability in Independent Research Organisation Fund is an initiative providing longer-term stable funding for four New Zealand organisations doing

nationally significant work outside of the Crown Research Institute and university sector. See the following pages for examples of the currently funded IROs' unique contributions to the health research ecosystem: Malaghan Institute of Medical Research (page 33), Medical Research Institute of New Zealand (page 27), Te Atawhai o te Ao: Independent Māori Institute for Environment & Health (page 41), and Whakauae Research Services (pages 42 and 44).

- Longitudinal Studies, such as the Dunedin Multidisciplinary Health and Development Study and the Christchurch Health and Development Study, seek to follow cohorts of people across time to answer how and why certain experiences influence our later life. Longitudinal studies have been supported by the HRC through the Annual Contestable Funding Round as recipients of either Programme or Project grants. See page 32 for an example of the impacts of the HRCfunded Pacific Islands Families longitudinal study.
- **Programmes** provide support for the long-term development of a health research field by a group of established investigators with an outstanding track record of achievement. They have a strategic, long-term vision that will contribute to significantly improving health outcomes for New Zealanders. Many case studies in this report provide examples of the impact of HRC Programme funding on the health and wellbeing of New Zealanders (including pages 16, 18, 20, 22-23, 27, 29, 31, 38, 40-41, 43).
- **Projects** cover a diverse range of areas and have the potential to vastly improve our health system and the health of New Zealanders. Examples of such impact from HRC-funded projects are

http://www.legislation.govt.nz/act/public/1990/ 0068/latest/DLM213017.html

⁴ Available at: <u>http://www.hrc.govt.nz/news-and-publications/publications/corporate</u>

⁵ The Health Research Council Act 1990. Available at

available on pages 16, 18-20, 22-23, 27, 29, 32, 35 and 43.

- Emerging Researcher First Grants are designed to support emerging researchers who are seeking to establish independent careers in health research and have not previously held a competitive research grant of more than \$105K.
- Feasibility Studies are intended to be for situations where there is already strong evidence to justify an HRCfunded trial, but where critical practical information is needed first to make a potential trial clearly fundable. Feasibility Study funding was vital to getting the eventually impactful projects on pages 18 and 27 off the ground in the early stages.
- Explorer Grants support transformative research ideas that have a good chance of making a revolutionary change to how we manage New Zealanders' health. Pages 23 and 24 further describe some examples of our Explorer Grants.

Career Development Contracts: Investment in building people, skills and careers - recruiting and retaining future leaders to address health challenges and create innovations for New Zealand. We allocate nearly a tenth of our investment to career development because we see it as critical and take responsibility for ensuring that this capacity is built and maintained. The HRC launches research careers with postgraduate Summer Studentships, Masters and PhD scholarships. Emerging researchers are then supported through postdoctoral fellowships, and fledging leaders are fostered through mid-career fellowships, ensuring that succession planning for our future workforce is addressed. See pages 19-20, 22-23, 27, 29, 31-33 and 40 for some examples of the impact of HRC career development awards. HRC career development opportunities include:

- The Sir Charles Hercus postdoctoral health research fellowship is intended to build New Zealand's future capability to conduct world-class research.
- The Girdlers' New Zealand HRC fellowship offers an exciting

postdoctoral opportunity for two years advanced research experience in the UK at the University of Oxford.

- The Foxley fellowship provides a salary to enable a health sector professional to undertake a research sabbatical at a tertiary institution to enhance links between HRC-funded research and health care delivery or health policy.
- The Clinical research training fellowship provides an opportunity for medical, dental and allied health professionals to undertake a PhD or equivalent qualification.
- The Clinical practitioner research fellowship provides an opportunity for a clinician with a proven track record of research, and who is currently practising and employed by a healthcare organisation, to undertake a programme of research that is relevant to their clinical practice and will enhance clinical care delivery.
- The Rangahau hauora training grant is intended for Māori active in their community, and with no prior research training, to undertake practical research training on a large research project.
- Māori health research postdoctoral fellowships provide a salary, working expenses, a tikanga allowance and an annual conference allowance for outstanding graduates who have recently completed a doctoral degree and propose conducting health research in New Zealand. Available fellowships include the Irihapeti Ramsden research fellowship for clinical or medical research with a focus on Māori nursing; the Erihapeti Rehu-Murchie research fellowship to support emerging leaders conducting research with a focus on Māori women's and children's health, te whare tapa wha health model, or Māori and indigenous human rights health promotion or health policy; the Eru Pomare research fellowship in Maori health; and the Hohua Tutengaehe research fellowship for research in Māori community health development, mātauranga Māori, te reo me ona tikanga, te ao wairua, urban Māori or rangitahi.

- The Pacific clinical research training fellowship provides an opportunity for medical, dental and allied Pacific health professionals to undertake a PhD or equivalent qualification.
- Pacific health research postdoctoral fellowships provide support for outstanding graduates who have recently completed a degree at the doctoral level to conduct research in any discipline related to improving the health of Pacific peoples.
- The Sir Thomas Davis Te Patu Kite Rangi Ariki health research fellowship supports emerging Pacific researchers who have demonstrated outstanding potential to develop into highly-skilled researcher to contribute towards better health outcomes for Pacific peoples, families and communities.

Co-funding Relationships: Engaging and connecting to bring together the people, agencies and resources needed to tackle important health and social issues and invest in knowledge and solutions. The HRC's investment in co-funding relationships is small comparative to the opportunities offered through Health **Research Contracts and Career Development** Contracts. However, this investment is doubled by funding partners, meaning that the HRC can maximise the returns on a relatively small investment. This is the area in which the greatest shift in spending is likely to occur after the national prioritisation model is published, as the HRC seeks to address specific issues with crossgovernment partners. Current funding opportunities available through co-funding relationships include those administered through:

- The Partnership Programme our major vehicle for initiatives that work across sectors to deliver evidence directly to decision-makers. See pages 17, 19, 23, 37-38 and 40 for examples of the impact of HRC investment in joint research partnerships.
- Research Partnerships for New Zealand Health Delivery (RPNZHD) – targeted

support for research that involves health providers and decision-makers and will be taken up to improve the quality and efficiency of healthcare for New Zealanders. See pages 16 and 27 for examples of the impact of RPNZHD investment.

• International collaborations supported through the Science and Innovation: Catalyst Fund (described previously on page 9). See pages 20 and 40 for examples of the impact of HRC Catalyst Fund investment.

Contribution to Policy, Regulatory and Ethical Frameworks: *Our committees are a key national resource, providing advice on research ethics, monitoring and regulation.* Our funding for activities relating to policy, regulatory and ethical guidance is provided by the Ministry of Health and is sufficient to run the committees that play a critical role in ensuring the safety of the health research environment in New Zealand.

THE HRC EVALUATES IMPACT

The need to demonstrate return on investment has become a major policy issue for funders of research, both in New Zealand and internationally. As the primary agency for publicly-funded health research in New Zealand, the HRC has a responsibility to use taxpayers' money effectively, and to demonstrate to the public that health research improves quality of life for New Zealanders, and ultimately saves lives. It's crucial that we demonstrate to government and taxpayers that health research can also reduce healthcare costs, generate revenue from innovation, and upskill our workforce.

By incorporating performance metrics,⁶ monitoring and evaluation the HRC ensures our contribution to health research tangibly improves opportunities for health and wellbeing for the people who need it most, now and in the future.

We incorporate prospective assessment and retrospective capture of research impact at an individual grant level, to encourage applicants to

⁶ See the Statement of Intent, Statement of Performance Expectations and Annual Reports

available at: <u>http://www.hrc.govt.nz/news-and-publications/publications/corporate</u>

consider and realise all potential ways in which their proposal can add value for New Zealand, and ultimately, to increase the collective benefits and impacts from the portfolio of research that we fund.

Applicants for certain funding opportunities in the Annual Contestable Funding Round are required to identify their line of sight to eventual impact and identify what is realistically achievable within their sphere of influence, including planned actions to realise this benefit. This forms a specific part of our assessment process, which focuses on how outputs are transformed to outcomes, for example the utilisation, uptake, adoption or implementation of the research findings. This is a key interim step between the generation of knowledge deliverables (outputs) and the generation of tangible benefits to New Zealanders (impacts).

Figure 2 highlights some of the routes through which HRC-funded researchers are changing policy and practice by working with those who use or could benefit from the research findings to maximise the impact on the health of New Zealanders.

Figure 2. Proportions of the types of products and processes HRC-funded researchers are using to change policy and practice 2014-2018



- Health policy improvements
- Improvement in health care delivery
- New or improved public health intervention
- New or repurposed drug or biologic
- New or updated clinical guidelines
- New or upgraded technology, tool or device

The research that we invest in returns tangible improvements and, in the following section of this report, we share some stories of impact to illustrate how the HRC makes a difference, stimulates growth and increases engagement and connection.

The Impact of HRC-funded Research

To tangibly improve the health and wellbeing of all New Zealanders, our research efforts must have impact – by making a difference, stimulating growth and increasing engagement and connection. That means ensuring that research outcomes make their way to the most suitable next-user, whether that be other researchers, policy and decision-makers, clinicians, or future investors, among others.

Research impact is not created by researchers alone; but rather, requires communication, relationships and actions that connect academic research to people from organisations beyond academia.

The HRC works in partnership with our researchers and partners, to capture the results of completed research, to support the feedback of the new knowledge gained from research into the science system and to ensure that our best examples of impact are appropriately conveyed to government, and the general public. The outcomes that we report on here are only a fraction of the total, and more good news about the health research investment is regularly posted on the HRC website: www.hrc.govt.nz and regularly disseminated in our *Update* online newsletter.

Innovation thrives when knowledge is diffused and shared.⁷

The first step along the pathway to realising the collective benefits and impact from research is how new knowledge resulting from research is shared and disseminated. Figure 3 illustrates the types and proportion of research outputs generated by HRC-funded researchers to advance the knowledge gained through research and drive the key findings of the research we support to the people and organisations that need them.

Figure 3: Proportions of the types of research outputs HRC-funded researchers report using to share knowledge 2014-2018



⁷ The people's prescription: Re-imagining health innovation to deliver public value. UCL Institute for Innovation and Public Purpose, October 2018. Available at: <u>https://www.ucl.ac.uk/bartlett/public-</u> <u>purpose/sites/public-</u> <u>purpose/files/peoples_prescription_report_final_</u> <u>online.pdf</u>

Research Findings have Made a difference

HRC generates new knowledge with clear pathways to impact for health and economic gain.



As shown by our definition of research impact, the HRC supports a broad social perspective of the potential value added for New Zealand by the research we fund. Key areas of focus include investing in research that:

- responds to and improves the current and future needs of New Zealanders,
- is ethical, methodologically sound, original, relevant, purposeful and impactful - our vision of excellent research,
- focuses on achieving equity of health outcomes across New Zealand's diverse populations and communities. and
- is highly innovative with the potential to be disruptive and transform the way we address health challenges.

Research addresses New Zealand health needs

The leading causes of health loss in New Zealand are cancers, cardiovascular disease (CVD), mental health disorders, musculoskeletal disorders, and injuries. Mental health and musculoskeletal disorders are accounting for a growing proportion of total health loss as survival from cancer and CVD improves.⁸ Figure 4 demonstrates how HRC investment responds to the health needs of New Zealand when focusing specifically on primary health issue.

Our health and our ability to lead healthy lifestyles is strongly influenced by the social, economic, and physical environments where we live, learn, work, or play. Directing funding towards research that addresses the health needs of New Zealand requires consideration of social determinants, historical contexts and power differentials for marginalised communities, especially Māori and Pacific which there is a large body of knowledge showing that poor experience of services and differences

in treatment are resulting in major inequities in health outcomes.

Figure 4: Proportion of investment by primary health issue for Programmes and Projects 2014-2018 9



The HRC recognises the importance of addressing determinants of health within and across generations. Health equity concerns form the basis of funding decisions to ensure that HRC investment delivers research that responds to the needs of our communities and improves both health outcomes and participation in and the efficient and effective running of the health system.

https://www.health.govt.nz/publication/healthand-independence-report-2017

⁹ Based on number of contracts and amount of funding awarded between 2014-2018.

peoples, as well as those with mental health issues and those that live in rural areas, for

⁸ Ministry of Health (2018) Health and Independence Report 2017. The Director-General of Health's Annual Report on the State of Public Health. Wellington: New Zealand. Available at:

ADDRESSING NEW ZEALAND HEALTH NEEDS CASE STUDY: SAVING LIVES THROUGH HEALTHIER HOUSING

HRC Funding: Annual Funding Round – Programmes and Projects.

Impact: Change to clinical practice; Improved health outcomes; Growth beyond academic roles to lead international policy change; International recognition of New Zealand's research leadership and expertise.

HRC researchers have been instrumental in building the body of evidence that shows the profound impact that cold, damp, mouldy homes have on the health of families, and particularly children. Likewise, overcrowding profoundly contributes to the spread of infectious illness contracted due to these poor living conditions – including respiratory diseases, rheumatic fever and meningococcal disease. Children and the elderly are at the greatest risk, and a quarter of Māori households and nearly half of Pacific families are living in overcrowded homes.

The University of Otago He Kainga Oranga Programme, led by Professor Philippa Howden-Chapman QSO, has proven the link between meningococcal disease and household overcrowding, and shown that uninsulated houses negatively impact on school attendance, sickness and hospitalisation, and that retrofitting insulation not only improves health and wellbeing but also produces energy savings and reduces carbon emissions.

The team of public health, medicine, building science, architecture and Māori health experts influenced both policymakers and community perceptions of the importance of warm, dry houses on health, providing evidence to support the NZ Healthy Homes Initiative (HHI) between Housing NZ, Auckland Regional Public Health Institute and NZ Institute of Architects. A 2018 evaluation of the HHI¹⁰ found that

families/whānau/aiga expressed a high level of confidence in and gratitude for the service which contributed to them living in warmer, drier and less crowded homes and made a difference to their health and wellbeing.

The research results also underpin the Government's Warmer Kiwi Homes insulation programme (replacing the previous Warm Up NZ: Healthy Homes programme) offering insulation grants for low-income homeowners, and the Rental Warrant of Fitness, an app that will allow tenants and landlords to check their house against minimum housing and health standards, currently utilised by Wellington and Dunedin City Councils.



This programme of work highlights the wider benefit to NZ from investment by the HRC in building researcher careers. Director Howden-Chapman's leadership expertise, cultivated over years of HRC funded research projects, has gained international reach through her chairing of the 2018 WHO Housing and Health Guidelines,¹¹ contributing to the achievement of Sustainable Development Goals 2 (Ensure healthy lives and promote wellbeing for all at all ages) and 11 (Make cities and human settlements inclusive, safe, resilient and sustainable).

The research is undertaken with the principle of 'no survey without service' with participating households linked with local collaborating agencies who can offer advice and sometimes subsidies for heating and insulation.

¹⁰ Available at:

https://www.health.govt.nz/system/files/docum ents/publications/healthy-homes-initiativeevaluation-apr-2018.pdf

¹¹ Available at: <u>https://www.who.int/sustainable-</u> <u>development/publications/housing-health-</u> <u>guidelines/en/</u>

ADDRESSING NEW ZEALAND HEALTH NEEDS CASE STUDY: BETTER QUALITY OF LIFE FROM IMPROVED GOUT CARE

HRC Funding: Annual Funding Round – Programme and Project; Research Partnerships for New Zealand Health Delivery

Impact: Change to clinical practice; Change to community practice; Improved quality of life.

The HRC funded Professor Lisa Stamp at the University of Otago to lead the first-ever randomised controlled trial demonstrating an improved dosing strategy using allopurinol to help more patients to manage their gout symptoms. Gout is the most common form of inflammatory arthritis and is more prevalent in New Zealand than any other country. Over 160,000 patients in New Zealand suffer from gout, the majority of whom are Māori or Pacific people.

The key management goal of long-term treatment is the reduction of blood uric acid levels to <0.36mmol/l. If this treatment target is maintained, gout attacks will cease. Allopurinol is the most common urate-lowering therapy both in New Zealand and worldwide; however, there is no one size fits all dosage. For many people with gout, doses have historically been restricted based on kidney function. Yet, this restriction results in many people failing to achieve the treatment target. Increasing the dosage has not been a suitable solution because of an associated increased risk of adverse effects.

Professor Stamp's research showed that gradual dose increases of allopurinol over time was safe, could prevent on-going attacks of the painful disease, dramatically improved patients' lives, and could also help stop the disease from progressing to a chronic state in many patients. The dosing strategy has been translated into clinical practice at both primary and secondary care level and is now reflected in national and international gout management guidelines (the American College of Rheumatology (ACR) Gout Guidelines and the European League Against Rheumatism Gout Guidelines). Professor Stamp continues to update Canterbury Health Pathways, an initiative for facilitating translation of findings into clinical care, with results from her HRC-funded research on managing gout in the community. Professor Stamp, supported by a research partnership with Kaikoura Medical Centre, successfully piloted the delivery of a package of care incorporating education, gout treatment and appropriate screening and management of important comorbidities associated with gout such as heart disease and diabetes, in a rural general practice environment. Her research was undertaken with considerable community participation and engagement including Te Tai o Marokura (Māori Health Providers), Māori health promoters, the local Marae and local pharmacies.

Given the breakthrough research of both the clinical treatment and community management of gout, for which she received the Medicines NZ 2017 Value of Medicines Award, Professor Stamp and her colleague Professor Tony Merriman are now focused on prevention. Supported by the HRC, their innovative research has already identified gene variants that explain some of why Māori and Pacific people have the highest rates of gout worldwide, fuelling their exploration for how existing medications could specifically target the gene the team has identified.

ADDRESSING NEW ZEALAND HEALTH NEEDS CASE STUDY: ENHANCING MENTAL HEALTH CARE WITH CULTURALLY APPROPRIATE PRACTICE

HRC Funding: Joint Research Partnerships – HRC/Ministry of Health Pacific Health Research Partnership; Pacific Health Knowledge Translation Grant

Impact: New practice guidelines; Government level Pacific leadership; Growth beyond academic roles to lead policy change.

Heilala Malu, the Tongan Framework for Suicide Prevention, was launched in May 2017 in a ceremony with The Ministry of Pacific Peoples, the Ministry of Health, and Tongan community and church leaders. The idea for the Framework came from participants in University of Auckland researcher Dr Jemaima Tiatia-Seath's work on suicide prevention for Tongan youth in New Zealand, funded by a joint HRC and Ministry of Health Pacific Research Partnership Grant.

Dr Tiatia-Seath concluded the project with recommendations for the development of practical guidelines/protocols for suicide prevention to equip Tongan families, communities and services to appropriately respond to Tongan community youth suicide prevention needs. With the help of a follow-on HRC knowledge translation grant, Dr Tiatia-Seath translated these recommendations into the Heilala Malu framework.

The evidence-based bilingual resource has now been adopted by health service providers, community centres and churches across the country. This project highlights the wider benefit to NZ from our investment in researchers, with Dr Tiatia-Seath's particular expertise and experience seeing her named on the panel for the Government Inquiry into Mental Health and Addiction.

RESEARCH EXCELLENCE DELIVERS IMPACT

Excellence is a foundation principle of the HRC. Our assessment processes are evolving to make sure that we can continue to identify excellent health research in all its forms. The HRC has a broad and inclusive approach to excellence for health research. It recognises the value of indigenous knowledge and kaupapa Māori methodologies, the need for new research models to be developed, and existing models to change and evolve. We see excellent research being ethical, methodologically sound, original, relevant, purposeful and impactful.

We seek excellent research across the entire spectrum of innovation, from very basic to very applied and practical research – and across a full range of research disciplines including biomedical, clinical, health services, public health and social and data sciences.

EXCELLENCE DELIVERS IMPACT CASE STUDY: TARGETED TREATMENT THROUGH PREDICTION OF CARDIOVASCULAR RISK

HRC Funding: Annual Funding Round – Programmes, Projects and Feasibility Study

Impact: Change to national and international clinical practice; Improved health outcomes; More effective and efficient use of healthcare; Cost savings; Economic returns through commercialisation.

The HRC has invested over a decade of funding into the development of algorithms and software to be used to prevent cardiovascular disease. The PREDICT tool, developed by Professor Rod Jackson and his team at the School of Population Health, the University of Auckland (also received funding from Heart Foundation and Healthier Lives NSC) places New Zealand at the forefront of the new field of computer-based clinical decision-making.

PREDICT allows clinicians and hospitals to target limited resources to the right patients, preventing 30 per cent of cardiac events occurring compared to standard practice. It is based on research findings that the prediction equations previously used (the USA-based Framingham Score) substantially over-predict the risk of cardiovascular disease in New Zealand leading to unnecessary distress and overtreatment of the healthy majority.



By 2009 the PREDICT system was used by 80 per cent of Auckland and Northland PHOs and was being adopted in other areas of New Zealand and internationally.

The algorithms have now been implemented nationwide with the Ministry of Health publishing updated recommendations in 2018 for cardiovascular disease risk assessment and risk management based specifically on the New Zealand population using PREDICT cohort data.

PREDICT has led to a significant reduction in healthcare costs, including hospital and posthospital care. Auckland DHB estimate cost savings of between \$10M and \$20M a year. Extrapolated across all the DHBs adopting PREDICT, this could save our health system \$300M a year.

PREDICT has also been integrated into MedTech, the leading New Zealand medical records system used by New Zealand GPs and PREDICT has been sold to Australia, Singapore and Canada. 2018 saw the research team publish their landmark study in the prestigious medical journal *The Lancet* with findings based on over 400,000 primary care patients in NZ.

EXCELLENCE DELIVERS IMPACT CASE STUDY: TRANSFORMING CARE OF SUSPECTED HEART ATTACK INTERNATIONALLY

HRC Funding: Annual Funding Round – Projects and Career Development Award; Joint Research Partnership – HRC/Ministry of Health Innovation Partnership

Impact: Change to national and international clinical practice; Improved health outcomes; Cost savings

Acute myocardial infarction (AMI; heart attack) is a major cause of death and morbidity in New Zealand and the world. Patient outcomes can be significantly improved by earlier initiation of treatments, and consequently, the public are encouraged to seek urgent medical help in the event of symptoms such as chest pain, which may indicate a developing heart attack. Patients with chest pain symptoms are amongst the most common patient groups presenting to the emergency department (ED). However, only about 10 to 15 per cent of those who present to ED with chest pain, are actually having heart attacks. Due to the difficulty in rapidly assessing chest pain presentation for AMI, 90 per cent of patients being assessed end up being admitted to hospital overnight or longer, despite only a 20 per cent diagnosis of AMI resulting.

Nearly 10 years of HRC funding, including a Clinical Practitioner Research Fellowship and a Health Innovation Partnership Project co-funded by the Ministry of Health, supported emergency medicine clinician Dr Martin Than and his team at Canterbury DHB to develop and test an accelerated diagnostic pathway (ADP), based on earlier blood tests in a targeted low-risk group of presenting patients. Initial translation of the ADP into practice at Christchurch Hospital was extremely successful, nearly doubling the proportion of patients who could be discharged to outpatient care within 6 hours of arriving in the ED.

There are benefits to be had in accelerating the initial decision-making required to diagnose a heart attack, which requires onward cardiac tests. Doing so can prevent hospital admission and facilitate early discharge. As a result, many patients can be reassured earlier that a heart attack has been excluded and avoid the inconvenience, distress and risks of hospital admission. It is beneficial for the health service, which avoids unnecessary admissions, duplication of staff activities and pressure on urgent care services. Based on the average cost and length of stay of an acute case admission, researchers estimated a cost saving of \$3 million for the Christchurch Hospital study, extrapolating to an annual saving to the country of \$9.5 million.

Following the success in Christchurch Hospital the Ministry of Health requested all EDs in New Zealand implement an ADP. HRC and Ministry of Health Partnership funding supported the team to evaluate the scale-up of the project to every urban hospital in New Zealand, securing local clinical champions and offering sustained implementation support. The success of the national roll-out led to a further Ministry of Health initiative to implement similar pathways into all rural hospitals, primary care and acute care centres.

Findings suggest that after implementation of ADPs in New Zealand, patients spend a total of approximately 165,000 hours less in hospital per

year, and a 10 per cent absolute increase in the number of patients discharged home from the ED within 6 hours. Strong collaborative links have also been developed internationally with a growing number of hospitals adopting ADPs based on the New Zealand research success, including all Queensland and many other Australian EDs, the largest provider of EDs, Kaiser Permanente, in Northern California, two sites in Canada, three sites in Iran and one each in Singapore, Hong Kong, UK and Ireland.

RESEARCH PROMOTES HEALTH EQUITY

Health inequity is one of the biggest issues that New Zealand is currently facing. A key focus for the HRC is investing in research that will aid health providers and policy-makers in improving health outcomes for those whose needs are not currently being met due to poverty, lack of access to services, or services that do not meet their cultural or disability needs. Research led by Māori, Pacific, persons with disabilities and communities facing major health disparities, discrimination or exclusion is fundamental to achieving health equity. Promoting health equity recognises that different people with different levels of advantage require different approaches and resources to get equitable outcomes.

This section sets out some examples of the impact resulting from our commitment to improving health equity. In addition, we have recently invested in the following research addressing unmet health needs:

- Professor Jackie Cumming's Programme award looking into enhancing primary health care services to improve health in Aotearoa/New Zealand. Professor Cumming's research will focus on New Zealand health policy to identify where changes to policy and practice need to be made if New Zealand is to better achieve the goals of improved health, reduced inequities in health, lower health system costs, and better integration both within health services and between health and social services.
- The Ministry of Health and HRC research partnership award led by Professor Nicolette Sheridan involves the first comprehensive evaluation of general practice models of

care since primary health organisations (PHOs) were introduced in 2001. The research will provide evidence for which model of primary care can best be linked to improved outcomes for Māori, Pacific and other defined populations in New Zealand.

 Two contracts held by Professor Ross Lawrenson (a clinician with Waikato DHB) looking into improving early access to lung cancer diagnosis for Māori and rural communities, reducing delay and increasing access to early diagnosis for colorectal cancer.

ADDRESSING INEQUITY CASE STUDY: BUILDING HEALTHIER FOOD ENVIRONMENTS

HRC Funding: Annual Funding Round – Programmes, Projects and Career Development Awards; HRC/Ministry of Health Pacific Health Research Partnership; Science and Innovation Catalyst Fund – US-NZ Enabling Grant

Impact: Government policy support and equity advocacy; International adoption of research materials; Change in community practice; Growth beyond academic roles to lead international policy change.

The HRC has funded several projects and programmes focusing on practical interventions to support healthier food choices. Unhealthy diet is the leading preventable risk for poor health in New Zealand, particularly for non-communicable diseases such as obesity. New Zealand has the third highest rate of adult obesity in the OECD and our rates are rising. Obesity has strong links to health inequalities: Maori and Pacific peoples experience obesity rates 1.6 and 2.3 times higher than non-Māori, non-Pacific people, and a parallel pattern is seen by deprivation. Children living in the most socio-economically deprived neighbourhoods were 2.1 times as likely to be obese as children living in the least deprived neighbourhoods, after adjusting for age, sex and ethnic differences. 12

¹² The 2017/18 New Zealand Health Survey

In 2018, researchers from three HRC-funded research programmes at the University of Auckland and the University of Otago (BODE3, DIET, and INFORMAS)¹³, came together to host a symposium co-sponsored by the Healthier Lives National Science Challenge on the evidence and actionable priorities for tackling diet-related disease. The symposium was opened by the Minister for Health and attended by 170 representatives from government, NGOs, health providers, and the food industry (such as McDonalds and Progressive Enterprise).

Through the INFORMAS project, HRC supported the implementation of the first-ever national survey mapping the health and equity impacts of New Zealand food environments. led by Professor Boyd Swinburn at the University of Auckland. The research developed 'environmental equity' indicators on items such as food taxes, cost of diets, children's exposure to food marketing, e.g. advertising on Facebook, and provision of food in schools and hospitals, to assess progress towards diet-related health inequalities. The survey found that disadvantaged communities have almost three times the density of fast food outlets, more ads for junk food around schools, and supermarkets that devote more space to unhealthy foods.

Positive findings identified included the work done by DHBs to improve the food on offer in hospitals for both patients and the public. Researchers noted that the strong and comprehensive national policy written by DHBs was a very good exemplar for schools to look to improve nutrition practice.

The wealth of knowledge gained from the INFORMAS food environments survey has formed the basis of the priorities of the newly-formed umbrella group of health Non-Governmental Organisations (NGOs) and academics – Health Coalition Aotearoa led by Professor Swinburn, The Coalition provides a collective voice and expert support for effective evidence-informed policies and actions to reduce the harm from tobacco, alcohol and unhealthy foods, and to promote equity through a focus on the determinants of health.

Professor Swinburn also co-chaired the 2019 Lancet Obesity Commission report ¹⁴ conceptualising the triple threat of obesity, undernutrition and climate change as "The Global Syndemic" representing the paramount challenge for humans, the environment and our planet. Global action to mitigate the effects of The Global Syndemic will need to address underlying societal, political, socio-economic, and commercial drivers.

The survey protocols from the INFORMAS food environments project are currently being used by 30 countries, including the UK, Ireland, Norway, Singapore, USA, Canada, China and Australia. Twelve more European countries plan to implement the protocols in early 2019, indicating a substantial contribution to global capacity building and demonstrating the great value international researchers place on this New Zealand work. This is another programme of work that highlights the wider benefit to NZ from investment by the HRC in building researcher careers. Based on the collective work undertaken by HRC-funded researchers, the World Health Organisation (WHO) and Food and Agriculture Organisation of the UN (FAO) have turned to the INFORMAS network to help deliver an accountability framework for measuring progress on the UN Decade of Action on Nutrition and the Sustainable Development Goals.



Obesity / Non-communicable Diseases (NCDs) Research, Monitoring and Action Support.

 ¹³ BODE³ – Burden of Disease Epidemiology,
 Equity and Cost-effectiveness Programme; DIET
 – Dietary Interventions Evidence and Translation;
 INFORMAS - International Network for Food and

¹⁴ Available at: <u>https://www.foodpolitics.com/wp-content/uploads/ObesityCommission_Policy-Brief_Lancet_19.pdf</u>

Starting with an HRC Pacific Health Career Development Award and building up to leading a Pacific Health Research Partnership and HRCfunded Projects, Dr Gerhard Sundborn, has been working with Pacific communities to **fight obesity through reducing sugar consumption**. Extreme obesity, where the physical, psychological, social and financial consequences of obesity are much higher, is 10 times higher in Pacific children compared to NZ-European children.

Sugar-sweetened beverages (SSBs) have been identified as the single largest driver of unhealthy weight. New Zealanders consume high quantities of SSBs and Māori and Pacific people are twice as likely to be high consumers of SSBs than other New Zealanders. Along with obesity and dental decay, SSBs also increase the risk of diabetes and gout. Identifying a successful intervention to reduce SSB intake will also decrease the burden of many health concerns.

Starting in the west Auckland suburb of Kelston in 2015 and branching out to more schools in South Auckland in the following years, Dr Sundborn continues to work with Pacific youth through co-designed community initiatives to highlight how much sugar is in drinks and food, and support changes by peer leadership. The research made headlines in 2018 with wellknown hip hop, R&B and reggae artist Che Fu working alongside the researchers to engage students and the wider community in the research through a rap/spoken verse competition.

Based on these initiatives, many schools are adopting a healthy beverage policy and aiming to be 'sugar-free'. Dr Sundborn is currently working on evaluating school-based 'water only' and 'healthy kai' policies to determine their effectiveness on student BMI, behaviour, truancy, absenteeism and achievement. Researchers work closely with Healthy Family New Zealand (HFNZ) Auckland sites to coordinate with their efforts and ensure that the learnings are rapidly applied in the HFNZ work.

ADDRESSING INEQUITY CASE STUDY: BETTER QUALITY OF CARE IN ANTENATAL SERVICES

HRC Funding: Annual Funding Round – Programme and Projects.

Impact: Change to clinical practice; Improved health outcomes; Government policy support

The HRC has funded a series of studies led by Professor Beverley Lawton addressing the stark disparities between Māori and non-Māori mothers and their newborn childrens' health outcomes, access to health services, and mortality. This includes a study of severe maternal health events (SAMM or 'near misses' - strongly associated with maternal mortality, stillbirth and neonatal death and harm, particularly for Māori), which found that almost 40 per cent of cases were potentially preventable and most of these were due to clinical error. Professor Lawton's work has been translated to inform reviews of the Ministry of Health's and DHB's pregnancy and antenatal services.



The Ministry of Health took the findings forward into practice with a \$2 million investment for the introduction of a sustainable nation-wide severe acute maternal morbidity audit programme led by the Health Quality and Safety Commission. Professor Lawton is currently leading an ambitious research Programme supported by the HRC's Rangahau Hauora Māori investment stream to investigate the health care delivery system and the structural determinants of health – including housing, racism, transport, income, and education – that impact on the health of Māori women and their babies and whānau.

The research team has been involved in the formation of an international network of researchers, the International Research Group for Indigenous Women's Health, which aims to develop best practice models that align with the United Nations Declaration on the Rights of Indigenous Peoples, along with informing government and health sector policy and practice through locally relevant and culturally appropriate recommendations. The network has already consulted with the Ministry of Health regarding barriers to accessing health services as part of the National Travel Assistance Scheme Review.

THE HRC CATALYSES TRANSFORMATIVE RESEARCH AND INNOVATION

Innovation is a foundation principle of the HRC. The health services of tomorrow are built on health research that was often commenced decades before. It is vital that we feed the innovation pipeline with novel research that challenges and shifts established knowledge and identifies new possibilities. The HRC supports transformative research that shifts established knowledge and identifies new frontiers for future exploration. We have many opportunities that support transformative research and innovation. An example is our Explorer Grants, which are designed to support early stage, high-risk, highreturn research. Not only is the research itself innovative, but the innovative funding process developed by the HRC for Explorer Grants continues to draw international attention, including articles in both *Nature*¹⁵ and *Times*

¹⁵ Sinkjaer, T. Fund ideas, not pedigree, to find fresh insight. *Nature*. 555, 143 (2018). Available at: <u>https://www-nature-</u>

com.ezproxy.aut.ac.nz/articles/d41586-018-02743-2 Higher Education¹⁶ journals. Investment in the potentially transformative, high-risk, high-return research has continued to increase since the introduction of the Explorer Grant funding mechanism (see Figure 5)

TRANSFORMATIVE RESEARCH AND INNOVATION CASE STUDY: GETTING AHEAD OF ANTIBIOTIC RESISTANCE.

HRC Funding: Annual Funding Round – Programmes and Projects; Joint Research Partnerships – Trans-Tasman Initiative: Rheumatic Fever Vaccine; Explorer Grants; Career Development Award.

Impact: Established infrastructure to fast track innovation; Capability building; Growth beyond academic roles to lead international policy change.

The Ministry of Health and the Ministry of Primary Industries jointly published the New Zealand Antimicrobial Resistance Action Plan¹⁷ in 2017 addressing the Government's response to the growing public health threat of antimicrobial resistance (AMR). Supporting research to strengthen the knowledge and evidence base on AMR was highlighted as one of the five priority action areas.

Professor John Fraser of the University of Auckland is acknowledged as the discoverer of bacterial superantigens, first identifying them in the late 1980s. The HRC have supported his research into the superbug Staphylococcus aureus (S. aureus) a major human pathogen with strains that are now resistant to most common antibiotics. The World Health Organisation has named this superbug as a "bacteria of international concern" and the principal cause of hospital-acquired infections worldwide.

¹⁶ Matthews, D. Radical ideas required to cut research grant waste, funders told. *Times Higher*

Education (2018). Available at:

https://www.timeshighereducation.com/news/ra dical-ideas-required-cut-research-grant-wastefunders-told

¹⁷ Available at: <u>https://www.health.govt.nz/publication/new-</u> zealand-antimicrobial-resistance-action-plan

New Zealand holds the unenviable position of having the highest reported rates of S. aureus disease in the developed world and has experienced an alarmingly dramatic rise in an antibiotic-resistant strain of the disease. Alternative treatments are needed to complement new antibiotics that minimise the spread of resistance. Professor Fraser's recent HRC-funded research has focused on identifying potential vaccines for Group A Streptococcus (GAS) infection which can cause rheumatic fever.

Due to the continued high rates of acute rheumatic fever in Māori and Pacific Island children in NZ and Aboriginal children in Australia, the HRC extended our support of Professor Fraser's work in partnership with the NHMRC to jointly fund pre-clinical and early clinical research into the leading GAS vaccine candidates. The Trans-Tasman coalition has significantly improved the pathway for effective GAS vaccine development through the provision of a clinical 'roadmap' to fast-track vaccine development, an economic evaluation to encourage industry investment and has worked with WHO to re-established GAS vaccine development as a global priority.

The HRC continues to fund innovative research that could potentially transform how practitioners around the globe tackle AMR:

 An Explorer Grant supporting the development of a unique real-time test that doctors could use on patients at their bedside to quickly find out if a strain of bacteria will be resistant to a particular antibiotic. Doctors are often not able to determine resistance in a timely way and therefore use broad-spectrum antibiotics that have a higher chance of working. Eventually, resistance to these important 'last resort' antibiotics develops. However, this could be prevented if clinicians had a reliable and cost-effective test to determine if certain bacteria are sensitive to specific drugs, meaning they could use a more targeted antibiotic.

- A Māori Health Research Scholarship supporting the examination of communication processes within bacteria that control the spread of antibiotic-resistant genes in order to subsequently reduce the threat of infectious disease among Māori communities. Māori are disproportionately burdened by infectious diseases and antibiotics are dispensed to a higher proportion of Māori than non-Māori.
- Support for a New Zealand-based project with strong international collaboration from Australia and the UK aimed at unmasking the genetic mutations that lead to the antibiotic resistance in the superbug Pseudomonas aeruginosa. P. aeruginosa causes hundreds of thousands of infections each year internationally, particularly in people with a wide range of predisposing conditions such as severe burn wounds, cancer, and chronic lung disease due to cystic fibrosis or other forms of bronchiectasis.



Figure 5: Number of Explorer Grants funded since inception of the funding mechanism for potentially transformative, high-risk, high-return health research.

Research Findings have Stimulated growth

HRC builds a health research ecosystem, with the people, capacity, skills and opportunities that we need for a healthier, more prosperous future.



Our investment provides research opportunities and training for approximately 2000 individuals every year. We support people in universities, polytechnics, DHBs, non-government organisations, Māori and Pacific research, health and community organisations, and private research institutes. We train, maintain, and retain a research workforce with the skills and capability to address our current and future health challenges.

THE HEALTH RESEARCH SYSTEM ENABLES NZ RESEARCH TEAMS TO THRIVE

Multidisciplinary and multi-stakeholder collaborative approaches are increasingly acknowledged as necessary to address some of our most pressing health challenges. The HRC provides opportunities for our health researchers to work with networks of world-class research teams focusing on issues of importance to New Zealanders and the New Zealand health and science ecosystem. Thriving research teams include health professionals and stakeholders to increase the utility and uptake of the research.

The HRC improves the quality of our healthcare system through working with the Ministry of Health and DHBs to embed a research ethos in everyday practice and draw clinicians into multidisciplinary teams that will find solutions to our specific national issues. The HRC has invested considerable effort in recent years to encourage clinicians to become engaged in research. Practising clinicians are often best placed to identify research questions and apply research findings, bridging the gap between discovery and delivery. Offering research opportunities for clinicians not only improves the design and uptake of research, it is also a vital tool in attracting the best practitioners to our health institutions and universities. Figures 6 and 7 highlight that over recent years consistent data show approximately a quarter of new HRC contracts have been led by a practising clinician (principal investigator based at a DHB or PHO) and at the time of the 2018 workforce analysis just over half of all current contracts have at least one clinician involved in frontline health delivery on the research team (named investigator based at a DHB or PHO).

A critical success factor for embedding research within the healthcare system is the interaction

between research and clinical practice. Clinical trials and clinical networks nurture coordinated and effective research teams, providing opportunities for enhancing the relevance and quality of research, reach and equity of the research process, translation of evidence, culture of research in the health sector, skill and sustainability of the workforce, and the international competitiveness of New Zealand. There is huge value to be gained from achieving synergy between clinical research, education and practice.

Figure 6: Proportion of HRC contracts led by a Principal Investigator based at a DHB/PHO



Figure 7: Proportion of HRC contracts with a named investigator based at a DHB/PHO



THRIVING HEALTH AND INNOVATION SYSTEM CASE STUDY: ENHANCING PRACTICE IN INTENSIVE CARE UNITS ACROSS THE GLOBE

HRC Funding: Capability in Independent Research Organisations Fund; Annual Funding Round – Projects and Feasibility Studies; Research Partnerships for New Zealand Health Delivery

Impact: Change to national and international clinical practice; Improved health outcomes; International recognition of New Zealand's research leadership and expertise; Cost savings.

An example of the impact that clinician-led research can have for New Zealanders is evident in work funded by the HRC and the NHMRC and led by the Australia and New Zealand Intensive Care Society Clinical Trials Group (ANZICS CTG). ANZICS CTG recognises that adequately powered, definitive clinical trials to answer important clinical questions for the treatment of the critically ill can only be undertaken collaboratively, as part of multi-centre trial teams. The result in this case is estimated to have saved the New Zealand health care system well over \$150 million per year over the past 10 years, with hundreds of people admitted to New Zealand's ICUs every year now surviving as a result of the practice changes that have occurred in response to the groups' trial findings. Dr Colin McArthur, a clinician based in Auckland DHB, and Dr Paul Young, a clinician based in Capital and Coast DHB and the Medical Research Institute of New Zealand have led gamechanging HRC-funded research:

ANZICS CTG has made a substantial contribution to worldwide clinical practice through their research in fluid therapy. Findings from the SAFE study (Saline versus Albumin Fluid Evaluation) have influenced ICU practice around the world. They showed that the expensive albumin fluid (\$332/litre) was not better than more affordable saline fluid (\$1.60/litre), and that it was actually harmful in patients with traumatic brain injury, increasing their risk of disability and death. Saline is now preferred to albumin in

ICUs, leading to better health outcomes for patients and an estimated cost savings of ~\$137 million per year for the NZ health system.

The NICE-SUGAR study (Normoglycemia in • Intensive Care Evaluation - Survival Using Glucose Algorithm Regulation) evaluated the effect of "tight" control of blood sugar - the global standard of care at the time for treating blood sugar levels, which are commonly elevated in critical illness. Contrary to expectations, the research team found that tight blood sugar control of ICU patients - where insulin is used to keep blood sugar in the normal range, which costs more and is highly resource-intensive actually increased mortality. As a direct result of this study, tight blood sugar control is not routinely practiced in New Zealand and has changed clinical practice around the world. Every year this research is estimated to prevent three deaths for every 100 patients treated in ICUs.



THRIVING HEALTH AND INNOVATION SYSTEM CASE STUDY: SAVING THE LIVES OF BABIES AROUND THE WORLD

HRC Funding: Annual Funding Round – Programmes, Projects, Feasibility Study and Career Development Awards

Impact: Change to national and international clinical practice; Improved health outcomes; International recognition of New Zealand's research leadership and expertise; Cost savings.

For three consecutive years from 2015 to 2017, the prestigious HRC Beaven Medal for excellence in translational research has been awarded to clinician-researchers whose work has saved thousands of new-born babies' lives, both in New Zealand and around the world.

At least 1 million babies per year worldwide die or survive with disability from lack of oxygen to the brain at birth, a condition known as hypoxicischemic encephalopathy (HIE). In New Zealand, it's estimated that between 50 and 70 babies per year have moderate to severe brain injury at birth due to HIE. Professor Alistair Gunn from the University of Auckland led the development of the first ever practical treatment for brain injury in babies - brain cooling (therapeutic hypothermia) - supported by an HRC grant. This simple, practical and effective treatment is now in routine use in New Zealand and all developed countries around the world. Current treatment protocols, including the use of therapeutic hypothermia, increase survival without disability and correspondingly, reduce the rate of the most severe complications such as cerebral palsy. The number of children with severe disability due to birth complications in New Zealand has reduced by 6 to 8 per year, saving approximately \$231-385 million in lifetime costs each year.

Low blood sugar levels in babies are common in the first few days after birth. About 30 per cent of New Zealand babies - or 21,000 babies a year need testing for low blood sugar under current guidelines. Half of these babies will develop low blood sugar, which can sometimes cause brain damage, and 10 per cent will need to be admitted to a neonatal intensive care unit (NICU) at a cost of about \$9.4 million a year. HRCfunded research undertaken at Waikato Hospital by Distinguished Professor Jane Harding from the Liggins Institute at the University of Auckland, found that an inexpensive (\$2) and easy to administer dextrose gel massaged into the inside of a baby's cheek is more effective than feeding alone for treating low blood sugar. A follow-up study of these babies at two years of

¹⁸ Pham et. al. *Randomised clinical trials in perinatal health care: a cost-effective investment.* Med J Aust 2017; 207 (7): 289-293.

age confirmed that the treatment was safe in the longer term.

A 2016 national survey has shown that 75 per cent of birthing units in New Zealand are now using oral dextrose gel to treat low blood sugar levels, and they are reporting a decrease in the number of babies admitted to NICU for this condition. Similar reports are appearing around the world, including in the UK, Australia, and the US. The research received a significant boost in 2018 with a National Institute of Health (NIH) grant of US\$2.75 million to extend the study from treatment to prevention of hypoglycaemia. This grant is a win for New Zealand researchers as it is highly unusual for the NIH to offer funding to non-US based collaborations. If successful, the study will not only be the first to report a viable method of preventing neonatal hypoglycaemia but benefit the thousands of babies who would otherwise require admission, separation from family and interruption to early breastfeeding every year.



Professor Harding's high-profile **"Sugar Babies"** study was one of six Australia or NZ-based clinical trials in perinatal health included in a 2018 analysis of health and economic impacts of research where new treatments were proven to be superior to existing practice.¹⁸ The costeffectiveness analysis showed that if these six superior treatments were to be put into practice it would save the health system NZ\$290.4 million over five years – a thirteen-fold return on the NZ\$22.4 million in health research funding investment. Ongoing funding for clinical trials is essential for supporting a thriving health

Available at:

https://www.mja.com.au/journal/2017/207/7/r andomised-clinical-trials-perinatal-health-carecost-effective-investment

research system and resulting healthcare delivery where clinicians can be confident they are offering the most effective and safest care to patients, as well as allowing for swift disinvestment if standard care is proven to be unsafe, ineffective and potentially more costly to the system.

The national "back to sleep" public health programme was initiated in New Zealand on the back of ground-breaking HRC-funded research into cot death (previously known as sudden infant death syndrome [SIDS] and now known as sudden and unexplained death of an infant during sleep [SUDI]), led by University of Auckland Professor Ed Mitchell. Within a year of launching the programme mortality rates (previously at 250 deaths per year) dropped by half, and many Western countries followed suit taking up the campaign. Current SUDI rates are 40 per year, and on-going HRC-funded research aims to bring that figure down further to 6 deaths per year. Continued promotion of the "safe sleep programme" has translated to change in practice with health providers in all primary care and DHBs now offering information on the use of Wahakura (flax bassinets) and Pepi-pods (plastic alternatives developed as safe portable sleeping spaces) which support safe bed-sharing for vulnerable families.

A new prevention campaign "sleep on side when baby's inside" was launched in June 2018 encouraging pregnant women to sleep on their sides during their last trimester. The campaign is a collaborative effort between Cure Kids (a notfor-profit organisation), the Ministry of Health and the University of Auckland, and is the result of the findings of HRC-funded research led by Professor Lesley McCowan CNZM. The campaign aims for a 10 per cent decrease in late stillbirths nationally, saving at least 16 of the 160 New Zealand babies who are stillborn every year, following research showing that women can avoid restricting blood flow and oxygen supply to their babies by sleeping on their sides in the final 3 months of pregnancy. Internationally, this change in sleeping position has the potential to save up to 100,000 babies a year.

THRIVING HEALTH AND INNOVATION SYSTEM CASE STUDY: DRIVING THE GLOBAL QUEST TO MAP A VIRTUAL PHYSIOLOGICAL HUMAN

HRC Funding: Annual Funding Round – Programmes, Projects and Career Development Awards.

Impact: New tools and technology to transform patient care; International recognition of New Zealand's research leadership and expertise; International and private investment to scale-up innovation.

Multidisciplinary networks of physiologists, clinicians, researchers with discipline-specific skills (computational modelling, bioengineering and device technology), industry partners with knowledge of local and international regulatory markets, and commercialisation specialists have co-ordinated across the globe to work towards creating a digital human (the Physiome Project / the Virtual Physiological Human).

With a strong foundation of decades-long HRC funding in basic science, researchers at the Auckland Bioengineering Institute (ABI), led by Professor Peter Hunter, are working to create computational models for each organ system. These models will allow clinicians to predict how organs will react to a given event, such as the administration of a drug or in response to surgery. If drugs can first be tested in computermodelled virtual organs, that are programmed to do everything a real organ will do naturally, the risk to patients and the cost of drug development can be greatly reduced. This has great benefits not just for predicting how a patient will respond to a certain treatment, but also for surgical planning and diagnostic tests.

The Auckland research team were the first in this global project to complete their organ modelling – with a virtual heart – leading them to be recognised as world leaders in computational physiology. ABI researchers continue the Physiome Project work:

- The world-leading research capability represented by the multidisciplinary team at ABI was recognised recently with the USbased NIH awarding US\$4 million to Professor Hunter to contribute to an international programme of research aimed at mapping the autonomic nervous system how peripheral nerves send out electrical signals to a particular organ. This significant international investment highlights the unique expertise offered by ABI and advanced through HRC support - for foreign (non-US) investigators to gain funding, the NIH requires applicants offer unusual talent and resources not otherwise readily available in the US.
- The multidisciplinary team at ABI foster and nurture the entrepreneurial capacity of their workforce who learn to build companies from the ground up and experience seeing research through the commercialisation cycle. Multiple spin-out companies have been established to commercialise the products and processes developed. FlexiMap, from the team mapping the virtual stomach, offers an innovative system to measure the bioelectrical activity of the gut the world's first accurate and reliable solution for quantifying and diagnosing gastric dysrhythmias. The new technology has been patented and is already earning revenue from international clients. In acknowledgement of the leading-edge New Zealand engineering and medical research, Dr Peng Du of the Gastrointestinal Research Group at the ABI was awarded the 2018 Prime Minister's MacDiarmid Emerging Scientist Prize.
- The American Institute for Medical and Biological Engineering (AIMBE) College of Fellows is comprised of the top two per cent of medical and biological engineers in the world. ABI's Professor Merryn Tawhai, Director of New Zealand's Medical Technologies Centre of Research Excellence (MedTech CoRE) was inducted in 2018 for her outstanding contributions to the development and use of computational models for the virtual lung. Professor Tawhai

¹⁹ A full list of HRC career development opportunities available at:

has pioneered the creation of multi-levelled computational models of the lungs, spanning from individual cells to the entire structure, providing a virtual window into this complex organ.



WE TRAIN, MAINTAIN AND RETAIN A SKILLED AND DIVERSE HEALTH RESEARCH WORKFORCE

The HRC offers awards at every stage in the career development pathway to help foster and sustain a strong health research workforce in New Zealand. A range of awards are available to support the career development of researchers each aimed at addressing a gap in the health research workforce and building vital capacity.19 We provide significant career development opportunities for Māori and Pacific people, along with those involved in healthcare delivery. Having a strong Māori health research workforce is important to ensure Māori responsiveness and participation as we strive for greater health equity: acknowledging that Māori knowledge, people and resources have much to offer all New Zealanders. The HRC ensures that Pacific health researchers have opportunities along the career pathway with scholarships and fellowships designed to cultivate the Pacific health research workforce and in turn, advance Pacific health outcomes. Awards aimed at allied health professionals such as the HRC Clinical Research Training Fellowship and the HRC Clinical Practitioner Research Fellowship, strengthen the clinical research environment and ensure that we have all the skills and competencies to tackle current and future health challenges.

http://www.hrc.govt.nz/fundingopportunities/career-development SUSTAINING A SKILLED AND DIVERSE HEALTH RESEARCH WORKFORCE CASE STUDY: ADVANCING MĀORI HEALTH RESEARCH OPPORTUNITIES

HRC Funding: Annual Funding Round – Programme; Career Development Awards.

Impact: Community empowerment; Capability building; Growth beyond academic roles to lead policy change.

As part of recent HRC Programme funding led by Professor Peter Shepherd, Deputy Director of the Maurice Wilkins Centre for Molecular Biology, investment in ground-breaking nationwide research into the potential links between people's genetics and their risk of developing metabolic illnesses like diabetes and heart disease has begun in partnership with two Māori research organisations - the recently opened Waharoa ki te Toi research facility - the Moko Foundation base at Kaitaia Hospital in the Far North; and Te Rangawairua o Paratene Ngata Research Centre - the Ngati Porou Hauora Charitable trust base at Te Puia Springs Hospital in Tairawhiti on the East Coast. The research centres have been formed with the intention that they serve as a catalyst for growing sustainable research partnerships with local communities to co-design research to meet local priorities, to generate new knowledge and better health outcomes that empower Maori and Pacific people to live well and longer. A key part of the kaupapa to empower Māori communities is that the centres also deliver local employment opportunities, and build capacity for Maori students, practitioners and researchers to develop training in research skills of relevance to Māori and rural health.

The HRC works with the sector to identify critical gaps in career paths and support opportunities to address them. One such example is the 2018 Māori Emerging Leader Fellowship established in partnership with the Ministry of Health to ensure the growth and ongoing development of our Māori health research workforce. The fellowship currently supports two Māori health researchers, Dr Jason Gurney and Dr Reremoana Theodore (both University of Otago) to develop their Māori

health research knowledge with a specific emphasis on equity and social investment. Dr Jason Gurney (Ngāpuhi, Ngāti Hine) started his academic journey with an HRC Maori Health Summer Studentship award back in 2004 and the financial support that the HRC grants offer along the career pathway (including a Māori PhD Scholarship and Eru Pomare Maori Health Postdoctoral Fellowship) have been essential for Dr Gurney to build his portfolio of research confronting disparities in health outcomes between Māori and non-Māori. Dr Gurney now sits on the Ministry of Health Urological Cancers working group and Tumour Standards working group, as well as being an elected member of the Board of Hei Āhuru Mōwai (the National Māori Cancer Leadership Group), established to ensure Māori experience high-quality, equitable cancer services.

Ever since 2004, the HRC Summer Studentship that opened a new world to me, that it was possible to do this thing I loved [research] and actually get paid to do it, everything I've done has been looking at health inequalities for Māori. Having that consistent funding opportunity made available through the HRC to support my development as a researcher, has been absolutely critical."

Dr Jason Gurney (Ngāpuhi, Ngāti Hine), Māori Health Emerging Leader Fellow and 2018 Project Principle Investigator.



SUSTAINING A SKILLED AND DIVERSE HEALTH RESEARCH WORKFORCE CASE STUDY: FOSTERING PACIFIC HEALTH RESEARCH CAREERS HRC Funding: Annual Funding Round – Projects and Career Development Awards

Impact: Community empowerment; Capability building; Government and clinical practice policy support; Growth beyond academic roles to lead policy change.

The Pacific Islands Families (PIF) Study, which commenced in 2000 at Middlemore Hospital in South Auckland, follows a birth cohort of over 1000 Pacific children over their lives within their family environment. Consultation within Pacific communities has contributed to the development of a multidisciplinary project emerging at a time when Pacific peoples were not adequately represented in the evidence base shaping and influencing health policies and practice decisionmaking. The PIF study, founded by Professor Janis Paterson at Auckland University of Technology, aims to address this knowledge gap by providing Pacific-specific evidence for strategic recommendations to improve the health and wellbeing of Pacific children and families, and to address the social disparities they face in New Zealand.



²⁰ Quote from HRC media release, *Pacific fathers cultivating the future*, 20 June 2013. Available

While addressing health and wellbeing outcomes for the Pacific community, this longitudinal, multidisciplinary programme of research has also proved to be a thriving hub for building capacity and capability of Pacific Island researchers and has created a strong platform for Pacific Island health research in New Zealand.

The PIF study provides a model for how to support and nurture researchers throughout their career and create a space for researchers to grow and belong. A shining example of this can be seen in the study's current Director, Dr El-Shadan Tautolo. Dr Tautolo, born and raised in South Auckland with Samoan and Cook Island heritage, first received funding in 2004 with an HRC Summer Studentship. With continued HRC support, Dr Tautolo has cultivated his academic career within the PIF study, through PhD and post-doctoral research grants and onwards to leading two HRC Project grants as Principal Investigator, being welcomed on to the HRC Pacific Health Research Committee in 2016 and becoming PIF Director.

It's important for me to do my part to support the next group [of Pacific Island researchers] coming through. Building that research capacity is not only vital to the future of the PIF Study, but also for ensuring our work can make a significant contribution to the betterment of our Pacific families and communities. Dr El-Shadan Tautolo, Director of the Pacific Islands Families study.²⁰

PIF research findings on physical activity, food patterns, diabetes risk factors and the physical, social, built and family environment within which these children live their lives has informed both policy and practice:

- PIF researchers work with the Pacific Heartbeat team of the Heart Foundation to deliver a Ministry of Health-funded, and AUTdelivered, certificate in Pacific Nutrition.
- PIF findings have continuously informed the curriculum to train those who work in the Pacific community on solutions to improve the health of Pacific peoples.

at: <u>http://www.hrc.govt.nz/news-and-</u> media/news/pacific-fathers-cultivating-future

 As part of the Pacific Islands Food and Nutrition (PIFN) Action Group, PIF researchers are working with the City Mission to lead the development of a monograph on the lived experiences of food poverty and food insecurity for Pacific people for the Child Poverty Action Group. The (PIFN) Action Group includes representation from the Heart Foundation, the Stroke Foundation and ProCare.

ECONOMIC RETURNS ARE REALISED FROM HRC-funded research

Investing in world-leading health research has the potential to not only positively improve the health and wellbeing of the population but it can also boost the economy. As well as the translation of research findings into policy and practice leading to a more effective and efficient health system, direct economic gains can be realised through the sale of commercialised research outputs and from leveraging New Zealand's unique research leadership and expertise for additional international investment (both public and private).²¹ Innovative research can lead to new commercially valuable products, processes and practices with that can be marketed both in New Zealand and offshore.

The HRC has been working with MBIE and the Ministry of Health to strengthen innovation pathways in order to advance innovative ideas and capitalise on commercial opportunities for turning health research investment into economic returns. In order to more effectively realise economic returns from health research. the HRC is introducing a new process to identify research with high potential for generating commercial value. This new process is designed in partnership with university Technology Transfer Offices, the Commercialisation Partner Network (e.g. KiwiNet and Return on Science) and Callaghan Innovation. Through increasing coordination and connectivity, the HRC will further strengthen the early stages of the commercialisation pathway.

INNOVATION AND ECONOMIC RETURNS CASE STUDY: AT THE CUTTING-EDGE OF CANCER IMMUNOTHERAPY

HRC Funding: Capability in Independent Research Organisations Fund; Career Development Award

Impact: International recognition of New Zealand's research leadership and expertise; Infrastructure development; Capability development; International and private investment to scale-up innovation; New knowledge that could transform patient care to improve health outcomes.

Immunotherapy has shifted the landscape of oncology in recent years. As scientists have untangled the complexity of the immune microenvironment surrounding tumour cells, several promising therapeutics have made their way through trials and into the clinical setting. CAR T-cell is one such therapy.

CAR T-cell therapy genetically modifies a patient's immune cells (T-cells) to express the Chimeric Antigen Receptor (CAR), and in the process, re-educates the immune cells to identify and attack cancer cells selectively, similar to a vaccine. As T-cells are a dynamic and 'living' part of a patient's immune system, CAR T-cell therapy has the potential to provide self-sustaining and long-term protection against cancer cells. The second generation of CAR T-cell therapies have been licenced for treatment in the US and Europe, showing strong response rates in specific forms of leukaemia and lymphoma. The therapy is a game-changer for forms of non-Hodgkin's lymphoma otherwise non-responsive to treatment, which demonstrate impressive response rates to CAR T-cell therapy. However, despite the promising response rates, many patients only achieve partial remission - for which the outlook remains bleak.

²¹ See previous sections detailing US NIH investment obtained by Professor Jane Harding and Professor Peter Hunter, and the following

section detailing UK Department for International Development funding attained by Professor John Crump.

Continued HRC-funding of basic research over 20 years has led to world-leading discoveries in the field of cancer immunotherapy for researchers at the Malaghan Institute of Medical Research, an independent biomedical institute based in Wellington. The Malaghan is leading the charge in improving the effectiveness and applicability of CAR-T therapies. In 2018/2019 Dr Robert Weinkove, the Clinical Director at the Malaghan Institute, was awarded the HRC's **Clinical Practitioner Research Fellowship to** support pivotal research into developing a thirdgeneration CAR T-cell therapy. On the back of pre-clinical findings that third-generation CAR-T cells with additional co-stimulatory domains are more effective and persistent in selectively scoping out and attacking cancer cells, Dr Weinkove is leading a research programme to test the safety and efficacy of a third-generation therapy in patients with B-cell Non-Hodgkins Lymphoma. Clinical trials are planned for 2019 and mark an important step towards developing the cell-therapy for clinical application, as well as paving the way for further research into the potential for CAR T-cell use in other forms of cancer, such as myeloma.

Think of being able to beat cancer, with little else but our own immune system. Think of a world where we and our loved ones don't have to suffer through the pain of surgery or chemotherapy. [We're] witnessing the first waves of a revolution. *Professor Graham Le Gros, Director Malaghan Institute of Medical Research.*²²

As CAR T-Cell therapies are personalised, requiring temperature-logged transport from the site of collection to manufacturing and back to the clinic, the logistical and regulatory challenges are sizeable. A central and essential objective of Dr Weinkove's work is to establish the regulatory, ethical and clinical frameworks to ensure the safe delivery CAR T-cell therapies in New Zealand. By strengthening linkages between different stakeholders, both nationally and internationally, and developing the infrastructure to carry out the clinical trials, Dr Weinkove's programme will expand the national capacity for the future application of CAR T-cell therapy in New Zealand.

Dr Weinkove's strong international ties and commitment to developing a global network to conduct further co-operative studies will be essential in bringing down the costs of monitoring and managing any potential complications of CAR T-cell therapy. Another major impediment to adoption in the New Zealand context has been the price of the treatment, with US list prices of CAR T-cell therapy being in excess of USD\$300,000. As such, New Zealand-based clinical trials present the opportunity for eligible participants, who have run out of treatment options and would otherwise be unable to self-fund the costs of treatment overseas, to gain access to the treatment here in New Zealand.



The expertise and capability gained from the HRC-funded vaccine clinical trials is of such international profile that it has attracted and leveraged significant overseas investment to New Zealand. A leading Chinese biotech company Hunan Zhaotai Medical Group (HZMG) has formed a multi-million-dollar partnership with the Malaghan Institute to trial and manufacture new third-generation CAR T-Cell therapies. As well as HRC funding, the new biotech joint venture Wellington Zhaotai Therapies was supported by MBIE Pre-Seed Accelerator Funding administered by the Kiwi Innovation Network (KiwiNet).

²² Quote from NZ Herald article, *Has cancer finally met its match*? 28 May 2017. Available at:

https://www.nzherald.co.nz/nz/news/article.cfm ?c_id=1&objectid=11844889

The pathways to impact of Dr Weinkove's HRCfunded research are extensive. From accelerating the availability of innovative immunotherapies in New Zealand, to commercialising viable therapeutics, building infrastructure for future research and improving researchers' links with experienced private sector partners such as HZMG, all of which will strengthen the commercial capabilities of New Zealand's scientists. The research programme consolidates the Malaghan Institute as a world leader in teasing apart the complicated relationship between the immune system and cancer biology. And New Zealanders stand to reap both the health and economic gains.

In 2018 a Financial Times article²³ highlighted the growing commercial interest in New Zealand and Australian biotech stating "The close neighbours produce some of the most innovative medical research in the world. New Zealand ranks fourth and Australia fifth globally in the Scientific American Worldview ranking of biotech innovation, ahead of the UK but behind the US, Singapore and Denmark."

INNOVATION AND ECONOMIC RETURNS CASE STUDY: BLAZING A TRAIL IN GLOBAL CANCER DIAGNOSTICS

HRC Funding: Annual Funding Round – Project

Impact: Change to national and international clinical practice; Improved health outcomes; Economic gains through commercial returns; International recognition of New Zealand's researchers' commercialisation expertise.

Technology developed by researchers from the Centre for Translational Cancer Research at Otago University with HRC funding, has been commercialised through their NZX-listed spin-off biotech company Pacific Edge Ltd, of which Professor Parry Guilford is chief scientific officer. In 2011 the company launched their diagnostic testing kit for bladder cancer, Cxbladder, which has been rolled our across New Zealand DHBs and has recently been launched into the Singapore and North American market.



Bladder cancer was previously diagnosed using a highly invasive and expensive endoscopic procedure. Cxbladder is a non-invasive laboratory test which is conducted on urine samples and consistently outperforms competing products. 2018 was a particularly good year for the company. Shares rose 6.5 per cent with the announcement of the commercial deal to supply Cxbladder tests in Singapore; and they attracted an NZD\$2.6 million investment from the US, with investors citing the company's expanding US presence and growing adoption of Cxbladder tests by urologists. The Financial Times named Pacific Edge fifth on their 2018 FT1000 High Growth Companies Asia-Pacific list with 5,453 per cent revenue growth from 2013-2016.

²³ Available at:

https://www.ft.com/content/55cb1be8-1261-11e8-a765-993b2440bd73

Research Findings have Increased engagement and connection

The HRC adds value to realise our collective potential.



We work together with organisations across the health, science, innovation and wider social sector to deliver excellent, valuable and relevant research that helps New Zealanders live healthier lives. Our researchers collaborate across disciplines, institutions, communities, and countries to harness a diversity of skills and perspectives to respond to the health needs of New Zealanders and contribute discoveries to help fight global challenges.

PARTNERING TO STRENGTHEN TRANSLATION

HRC partners with a range of national and international agencies across the health, science and social sector to maximise the utility and reach of health research. Partnerships with government ministries, health charities and healthcare providers work to embed a culture of research within policy and practice to ensure a clear pathway for the timely uptake and translation of research findings. The partnership model also allows for the pooling of resources to support more substantive research than any one agency could offer alone. Figure 8 illustrates the types of organisations the HRC partner with across the health, science and social sector to direct innovation and collectively facilitate translation.

PARTNERSHIPS TO STRENGTHEN TRANSLATION CASE STUDY: BETTER QUALITY OF CARE WITH PRIMARY HEALTH SERVICE ENGAGEMENT

HRC Funding: Joint Research Partnership – HRC/CIHR International Partnership

Impact: Primary care and community practice service improvement.

A joint initiative between the HRC and the Canadian Institutes for Health Research (CIHR) was established to support community-based primary healthcare. Cross-jurisdictional and interdisciplinary research was funded to develop, implement, evaluate, and compare innovative models for access to care for vulnerable populations.



Figure 8: Examples of HRC cross-sector partnerships

Principal Investigators Professor Nicolette Sheridan of Massey University and Associate Professor Tim Kenealy of the University of Auckland partnered with Canadian colleagues in a project spanning three international locations (NZ, Quebec and Ontario) and using methods codesigned with local service providers (Hospice NZ) focused on implementation of successful models of integrated community-based primary health care that address the health and social needs of older adults with complex care needs (such as those requiring care from multiple health providers including family physician, home, secondary or tertiary care). Working in partnership with 32 hospices in 17 clusters across New Zealand, the researchers contributed to service improvement with a systematic evaluation of 'what works'. Successfully implemented innovations include:

- Hospices partner with whānau to support care at home through kaitiaki, carer network facilitator, and kaiāwhina roles.
- DHBs fund linked services between aged residential care and palliative care (Hospice services).
- Hospices collaborate nationally to ensure all palliative care services integrate cultural frameworks.

Professors Sheridan and Kenealy encourage a central focus on equity and community partnership throughout the research process.

It's about reciprocity and giving back. It takes a lot of effort and work to build relationships, but it's always better in the long-term.

The researchers acknowledged that consumers need to be part of the research team to responsibly address equity issues. Consumers bring cultural balance due to a breadth of experiences, values, priorities and relationships that can disrupt the assumed wisdom of traditional researchers.

A continual process of negotiation and exchange with openness, transparency and respect leads to clear and honest communication, and ultimately ensures research addresses equity, cost-effectiveness and health system sustainability priorities. PARTNERSHIPS TO STRENGTHEN TRANSLATION CASE STUDY: IMPROVING NEW ZEALAND'S EMERGENCY RESPONSE PLANNING

HRC Funding: Joint Research Partnership – HRC/CMRF Canterbury Earthquake Partnership; Annual Funding Round – Programme

Impact: Change in emergency response clinical management guidelines.



In response to the Canterbury earthquakes, the HRC and the Canterbury Medical Research Foundation (CMRF) made a joint investment in five research projects exploring the health implications of the Canterbury earthquakes. Since the first major quake in September 2010 there have been almost 15,500 earthquakes in the Canterbury region. GNS Science has warned that a relatively quiet seismic period in New Zealand since the 1950s appears to be over, and an increasingly active period has begun with more frequent severe earthquakes likely to occur. Research into lessons learnt from past experiences will prove invaluable for on-going emergency response planning and preparation.

Research supported by the partnership established a database detailing the total burden of injury and illness resulting from the earthquakes in Christchurch, Seddon (2013), and Kaikoura and Wellington (2016). In 2018 the database was extended and is now a central repository of up-to-date information that describes the health impact of all natural disasters in New Zealand. The insights provided by this database have led to changes in health system disaster response planning with the implementation of management strategies that take into account:

- people arriving at emergency departments by unusual means and without pretreatment,
- people being reluctant to enter hospital buildings for treatment, and
- the necessity for manual registration and tracking of patients in the event of full loss of power.

Research supported by this partnership also highlighted that the majority of frontline workers suffering PTSD following the Canterbury earthquakes were not those uniformed workers trained to respond (Police, Fire and Ambulance services), but rather a subset of the oftenoverlooked providers of social service continuity, teachers. Teachers tend to find themselves in leadership and management roles during a crisis and over the much longer recovery phase. This includes mobilising to provide emotional and social support for pupils and their families, particularly in assessing and supporting child mental health. Teachers are tasked with maintaining day to day normality for their students while concurrently dealing with their own personal disaster-related issues.

Researchers have shared the findings with the teacher's unions, New Zealand Educational Institute (NZEI) Te Riu Roa and the New Zealand Post Primary Teachers' Association Te Wehengarau to help schools plan the provision of support mechanisms for their staff.

With regards to research on the longer-term effects of the earthquakes on health and wellbeing outcomes, outside of the scope of the HRC/CMRF partnership, the long-running HRCfunded Christchurch Health and Development Study is uniquely placed to explore long-term mental health outcomes. Research currently underway includes novel methodologies such as the ability for project investigators to present "participant-researcher" accounts of mental health and psychosocial adjustment following the Canterbury earthquakes to the PTSD Research Centre at the United States Veterans Administration in Boston.



Figure 9: Worldwide collaborations on HRC-funded research: building a global health research ecosystem

INTERNATIONAL OUTLOOK AND CONNECTIVITY

International connectivity is vital to NZ health research. HRC recognises the clear and direct benefits associated with international research collaboration at a research, policy, capacity and capability level. As a small, but high-performing workforce, NZ health researchers have much to gain from, and contribute to, international research. International collaborations offer our researchers a wider range of facilities and resources and allow them to conduct research at a global level, participating in innovative projects and cutting-edge activity with leaders in their field. International connectivity improves our ability to address complex and transboundary health research problems and improves our ability to implement an internationally competitive healthcare system. See Figure (previous page) for the global reach of HRCfunded research collaborations.

INTERNATIONAL COLLABORATION CASE-STUDY: REVOLUTIONISING HEALTH SECURITY FOR NEW ZEALAND AND SOUTH EAST ASIA

HRC Funding: Science and Innovation Catalyst Fund – e-Asia Joint Research Programme; Career Development Award

Impact: Change to clinical practice; Improved health outcomes; Improved prevention and management strategies for health security threats; Scientific and Government policy partnerships formed; Leveraged research success with major international grants

The e-Asia programme was initiated by the Japan Science and Technology Agency (JST) and is currently the only opportunity that enables direct engagement and science collaborations to develop within the South Asian region via a multilateral forum. The programme also provides the opportunity for developing further relationships with key partners in the region, such as Japan, Australia and the US, and enhances New Zealand's status as a collaborator and mentor.

The HRC has become a respected and valued voice amongst the member organisations.

Research that the HRC has funded to date. led by Professors Gregory Cook and John Crump from the University of Otago, discovered that most of the drugs currently used to treat multidrug-resistant Tuberculosis (TB) in Myanmar are ineffective. The result of these findings has been unprecedented interaction with Myanmar Government officials and policymakers and the introduction of new TB diagnostic methods and drugs for the treatment of critically ill drugresistant TB patients. New Zealand has provided cutting-edge technical support to facilitate evidence-based healthcare policymaking in Myanmar. In turn, this has benefited New Zealand's approach to engaging in global health issues and placed New Zealand in a strong strategic position to further strengthen our investment and economic ties with South East Asian countries. Current New Zealand-ASEAN (Association of South East Asia Countries) trade and investment are worth approximately NZD\$17 billion.



The experience in Myanmar has led to researchers collaborating with the NZ Tuberculosis Reference Laboratory to incorporate next-generation whole-genome sequencing into the routine diagnosis of drugresistant TB in New Zealand. Approximately 30 per cent of total TB cases in New Zealand are from cases born in the South East Asia region. The scientific collaboration with major centres of health education and research in South East Asia, puts New Zealand researchers in a position to identify strategies to mitigate major infectious disease-related health security threats to New Zealand arising in the Asia-Pacific region and is building strong scientific partnerships for addressing other regional public health emergencies, that cannot be effectively studied within New Zealand alone.

This e-Asia collaborative work builds scale and capacity for advanced molecular techniques to address the global health issue of antimicrobial resistance and maintains our ability to retain world-class New Zealand researchers with expertise in infectious diseases, medical microbiology, epidemiology and global health in New Zealand. One such researcher is Dr Htin Lin Aung, a Myanmar born researcher at the University of Otago, who was awarded a New Zealand ASEAN award by the New Zealand Government in recognition of his commitment in strengthening the bilateral relationship between Myanmar and New Zealand. Dr Aung is now undertaking an HRC Sir Charles Hercus Fellowship to further build on the foundations laid by the e-Asia research collaboration.

The research leadership and expertise grown within the e-Asia programme has been further recognised internationally with New Zealand researchers finding success with major international grants off the back of HRC-funded e-Asia research. Professor John Crump is now helping to lead an NZD\$18 million international project, believed to be the largest of its kind, funded by the UK Department for International Development, to tackle antimicrobial resistance and develop a blueprint for treatment of drugresistant fever in sub-Saharan Africa and South East Asia. Professor Crump credits the HRCfunded e-Asia work as essential to building and maintaining major and critical partnerships for securing such on-going global health research collaborations.

COMMUNITY ENGAGEMENT AND UPTAKE

Engaging with and partnering with community enables research to respond effectively to the needs of our people. Building and strengthening community relationships ensures that research finds relevant solutions to local community and wider societal questions and creates space for people to have empowering experiences codesigning and participating in the research process. Science is too important, valuable and fascinating to be left to professional scientists alone...For the good of society, the public and scientific progress itself, science needs a broader community. *Imran Khan, Head of Public Engagement, Wellcome Trust.*²⁴

Research doesn't speak for itself. To ensure benefit is gained from both the process of undertaking research and from the utilisation of research findings, HRC-funded researchers engage and partner with 'research users' (endusers or next-users of research whether that be other researchers, community members, policy and decision-makers, health professionals or future commercial investors) to facilitate the uptake of knowledge gained from research and to maximise the impact of new knowledge for the health of New Zealanders.

COMMUNITY ENGAGEMENT CASE STUDY: ENHANCING WELLBEING ACROSS GENERATIONS

HRC Funding: Annual Funding Round – Programme; Capability in Independent Research Organisations Fund

Impact: Change to national discourse; Service improvement; Change in policy and practice; Professional and community training

In 2011, Te Atawhai o Te Ao (TAOTA) – a kaupapa Māori research institute based in Whanganui, made history as the first ever community-based host to be awarded HRC Programme funding, and the second ever Māori led Programme with *He Kokonga Whare: Māori Intergenerational Trauma and Healing*. In 2014 their programme was rolled into independent research organisation funding.

TAOTA are leaders at working with whānau, hapū and iwi on setting research objectives, undertaking research within the community, and helping their communities to disseminate and

²⁴ Quote from Guardian essay, Science: Not just for scientists, Tues 1 December 2015. Available at:

https://www.theguardian.com/science/politicalscience/2015/dec/01/science-not-just-forscientists

implement findings. TAOTA engage with Ministers, policymakers in Government agencies, and others on the results and implications of their research.

Through their research programme, TAOTA have changed the national discourse within Aotearoa through the acknowledgement of historical and intergenerational trauma and improvements in Māori trauma-informed care, including:

- Improving integration and collaboration across clinical, community, and government organisations to build relationships and set shared goals.
- Training for corrections staff, police, schools and Oranga Tamariki on identifying, acknowledging and understanding intergenerational trauma.
- An intergenerational wellbeing/healing focus for models of care within community and residential programmes (particularly within Māori Health Providers and with Māori clinical psychologists).

They have actioned policies on the reintegration of Māori prisoners into the community, improving services for Māori as victims of sexual violence, the impact of land loss for a range of iwi including Ngāi Tahu, and the ways in which Māori health services and Whānau Ora respond to and work with trauma.

COMMUNITY ENGAGEMENT CASE STUDY: BETTER CARE AND PROTECTION OF OUR TAMARIKI

HRC Funding: Capability in Independent Research Organisations Fund

Impact: Change in policy and legislation; Community empowerment

Whakauae Research Services is the only independent, iwi-owned (Ngāti Hauiti) and mandated kaupapa Māori health research centre in New Zealand. Their practice is based on enacting their own rangatiratanga by embedding health research within the community.



Their community-based research has directly impacted social policy legislation, such as that initiated by family court lawyer Tania Blyth on the care and protection of Māori children (E Tipu E Rea) funded by the Lotteries Commission, with underpinning support from the HRC using the Capability in Independent Research Organisations Fund. Researchers worked with whānau who had children removed by the state to help identify how the system can better support them to make a positive contribution to the safe care and protection of their tamariki/mokopuna. The research findings have been used to influence the drafting of the Oranga Tamariki legislation, through the Justice lwi Leaders Group of the Iwi Chairs Forum and through the Whānau Ora Partnership Group.

The model developed through the research, putting iwi back in a kaitiaki role and restoring decision-making mana to the whānau, led to the establishment in 2015 of the Mokopuna Ora Initiative – a partnership between Waikato-Tainui and Oranga Tamariki that keeps local tamariki connected with their whānau, hāpu and iwi. The significant benefit derived from Mokopuna Ora led to an expansion of the programme to south Auckland in 2017.

COMMUNITY ENGAGEMENT CASE STUDY: WORKING WITH WHĀNAU TO SAVE LIVES

HRC Funding: Annual Funding Round – Programme and Projects

Impact: Change to clinical practice; Improved health outcomes; Community empowerment

Gastric (stomach) cancer is the third greatest cause of cancer death worldwide.²⁵ In New Zealand, its incidence is three times greater in Māori and Pacific people than in non-Māori, non-Pacific people.

When members of an affected North Island Māori whānau with a strong history of fatal gastric cancer approached researchers back in the 1990s, HRC funding allowed the researchers, led by Professors Parry Guilford and Tony Reeve at the University of Otago, to work in partnership with the whānau to identify the first known gene for fatal inherited gastric cancer. With the help of on-going HRC funding, the research team have since developed a successful genetic screening test for early detection.

Prior to the development of the test, there was a 70 per cent death rate for carriers of the aggressive hereditary mutations involved. Now most carriers lead largely normal lives – including Kiwi recording artist Stan Walker whose documentary about his stomach removal surgery following positive testing for the gene mutation was one of the highest rated documentaries of 2018.

The next step for the researchers will be identifying a drug treatment to inhibit cancer growth so that in the future, those affected have choices other than preventative stomach removal surgery. The research team believe that gastric cancer morbidity and mortality in New Zealand can be significantly reduced through an improved understanding of environmental and genetic risk factors, better diagnostic methods, more accurately targeted treatments and improvements in health delivery, particularly for our highest risk populations.



Stan Walker reflects on his experience with cancer on The Project, TV3

COMMUNITY ENGAGEMENT CASE STUDY: LEADING GLOBAL INDIGENOUS DATA SOVEREIGNTY

HRC Funding: Vision Mātauranga Capability Fund – Ngā Kanohi Kitea Full Project Grant, Ngā Kanohi Kitea Development Grant

Impact: Change in national and international practice and policy; Community empowerment; Capability development

The volume and variety of health data available is expected to grow with continuing advances in information and communications technology, mobile networks and imaging technologies. Health research increasingly relies on the integration of large datasets to provide evidence for personalised medicine, improved health services, integrated care, public health prevention and health policy. However, a data revolution predicated on systemic exclusion and populated with data obtained via unjust practices will only serve to increase health and social inequalities further.

²⁵ Information available from: <u>https://www.who.int/news-room/fact-sheets/detail/cancer</u>

The twin problems of lack of reliable data and information on indigenous peoples and the biopiracy and misuse of their traditional knowledge and cultural heritage"

Dr Tahu Kukutai and John Taylor, editors. Indigenous Data Sovereignty: Toward an Agenda.²⁶

In 2015 Te Mana Raraunga was initiated, an independent Māori Data Sovereignty Network in response to the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) for the collection, ownership and application of data pertaining to indigenous peoples. A number of HRC-funded researchers are involved with the network with HRC-funded projects addressing issues relating to indigenous data consent, use, ownership and storage initiated by the very communities whose voices have historically been missing from these critical conversations.

Supported through the Vision Mātauranga Capability Fund – Ngā Kanohi Kitea (NKK) community research grants provide an opportunity for iwi, hapū and community groups to investigate a well-defined area of Māori health need or gain, while supporting the development of Māori research capability. Projects are hosted and led by iwi, hapū or other community-based organisations and must address communityidentified health needs. A 2016 evaluation of the NKK programme found that all survey respondents believed research capacity and capability had grown amongst researchers and those in the community as a result of their involvement in the NKK grant. HRC evidence supports this, with 45 per cent of recipients of completed NKK projects continuing to receive HRC funding as Named Investigators or HRC award holders. Survey respondents saw value in the ability their NKK projects gave them to engage in research that had relevance to their community, and how the process supported selfdetermination and empowerment of whanau, iwi and hapū. The grants were also viewed as positive in allowing researchers to remain within

their community without having to move to the location of a research institution.

Te Kete Tū Ātea framework - an exemplar for collecting, analysing and using quantitative data at the iwi level – grew out of a 2012 NKK Grant with Whakauae Research Services. The iwi making up the Rangitikei lwi Collective (Ngāti Whitikaupeka, Ngāti Tamakōpiri, Ngāti Apa, Ngāti Hauiti and Ngāi Te Ohuake) had identified a shared need to access good quality information about their respective iwi populations to support decision-making. Presentation of the framework to the Minister of Finance, Statistics NZ and Treasury resulted in the Government's decision to review the geographical census spatial units with the introduction in the 2018 census of Rangitīkei Iwi Collective tribes, not previously included in the New Zealand Census iwi affiliation list. Project lead Ms Kirikowhai Mikaere noted "this study has supported Maori to move from being data suppliers and data customers to being data designers".27

COMMUNITY ENGAGEMENT CASE STUDY: MĀORI GENETIC TAONGA: GUIDING ETHICAL RESEARCH PRACTICE

HRC Funding: Annual Funding Round – Project; Vision Mātauranga Capability Fund

Impact: Development of local and international guidelines; Capability building; infrastructure development; Growth beyond academic roles to lead international policy change

The HRC-funded **Te Mata Ira project**, led by Associate Professor Māui Hudson at the University of Waikato, produced the world's first indigenous-led guidelines for genomic research and biobanking. The *Te Mata Ira Guidelines for Genomic Research with Māori*²⁸ and the *He*

https://www.whakauae.co.nz/uploads/publicatio ns/publication279.pdf?1551922985

 ²⁶ Tahu Kukutai & John Taylor (eds.) Indigenous data sovereignty: toward an agenda. 2016.
 Available at: <u>https://press-</u>files.anu.edu.au/downloads/press/n2140/pdf/b

<u>ook.pdf</u>

²⁷ Quote from Whakauae 2017 Annual Report (pgs 6-7), available at:

²⁸ A genome is the entire complement of genes in an organism. Genetic research looks at the

Tangata Kei Tua Guidelines for Biobanking with Māori²⁹ were developed in consultation with iwi, Māori communities, biomedical researchers, and biobanking institutions. The guidelines provide the foundation for stronger collaborations between Māori and genomic researchers with a framework for working together and a shared understanding of the cultural and ethical expectations of good behaviour.

Launched across Australasia in 2016 at the Healthier Lives Korero Tahi event and the Australasian Biospecimens Network Association conference, the guidelines are now on their third reprint with demand from organisations such as the Ministry of Health, MBIE, MFAT, the Law Commission and multiple universities. 30 International organisations working in indigenous contexts in Australia, the United States and Canada have also engaged with the researchers, attracted by their expertise developed during the project. Investigators on the original HRC-funded project now sit on the international advisory group for the CAD\$10.4 million-dollar Silent Genomes Project aimed at reducing access barriers to diagnosis of genetic disease and specialised genomic treatments for First Nations, Inuit and Métis people in Canada.

Kawa (principles) and tikanga (practices) of the Te Mata Ira and He Tangata Kei Tua guidelines have been integrated into the Draft National Ethical Standards for Health and Disability Research set out by the National Ethics Advisory Committee, a final copy of which is expected to be published in July 2019. The guidelines are being operationalised around the world with upcoming publications in journals such as *The Lancet Oncology* describing international experiences of setting up indigenous biorepositories and implementing indigenous governance processes within established biobanks.³¹

Through their HRC funding and follow on project funding from the Vision Mātauranga Capability Fund,³² Te Mata Ira project investigators established the Summer Internship for Indigenous Peoples in Genomics (SING) Aotearoa. The SING Aotearoa initiative is now in its fourth year running capacity building internships that give Māori participants experience with DNA laboratories, biological samples, biostatistics, cultural perspectives and ethical issues. SING Aotearoa has secured ongoing sponsorship from Genomics Aotearoa, a collaborative platform ensuring New Zealand is leading the world in the rapidly developing frontiers of genomics and bioinformatics.

Another spin-off of Te Mata Ira project is Te Nohonga Kaitiaki, a Vision Mātauranga Genomics Aotearoa initiative extending ethical practice frameworks to guide those working with Taonga native species. The guidelines aim to deliver wide benefits to those working with indigenous species in New Zealand and will serve as a model for indigenous groups internationally to develop means to protect their data in the biosphere.

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<sup>30</sup> Available at:
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https://www.waikato.ac.nz/__data/assets/pdf_fi

<u>le/0018/321534/Te-Mata-Ira-Genome-</u> <u>Research-Guidelines.pdf</u> and <u>https://www.waikato.ac.nz/__data/assets/pdf_fi</u> <u>le/0019/321535/He-Tangata-Kei-Tua-</u> <u>Biobanking-Guidelines.pdf</u>

³¹ Henare, et al. Mapping a route to Indigenous engagement in cancer genomic research. *The Lancet Oncology* (in press).

³² Te Waka o Tama-rereti Network of Māori in Genomics, Informatics and Technology.

function of specific genes. Genomic research is the study of groups of genes and their interactions.

²⁹ Biobanking is the storage of biological Taonga (human tissue, fluids, blood, cells). Biological Taonga is available for research purposes. (Biobanking is different from organ donation and does not include the storing of flora & fauna samples).

Appendix 1: Pathways to Impact Reference

The HRC funds more than individual research projects, we deliver more than health research, our investment contributes over and above creating a learning health ecosystem for New Zealand clinical practice and patient care. Our researchers are achieving far beyond their academic research roles to build the next generation of health professionals and scientists who not only educate and train but also lead and advise on national and international policy to tackle both local and global health research and health system challenges.

Broad social, economic, cultural or environmental impacts of HRC funding			
We enhance New Zealand's reputation in global science leadership.	Pages 16, 18, 21, 23, 27-30, 33, 35, 40, 42		
We improve people's wellbeing ³³ and quality of life, both in New Zealand and around the world, including action towards achieving the United Nations Sustainable Development Goals ³⁴ .	Pages 16, 18-19, 27-28, 35, 40, 41		
We create a thriving commercialisation environment, growing economic gains by catalysing private sector investment, both national and international, in the med-tech and bio-tech innovation sector.	Pages 18, 27-30, 33, 35		
Health, health system and equity impacts of HRC funding			
We improve accessibility, safety, effectiveness, efficiency, cost-effectiveness and responsiveness of health and social services.	Pages 16-19, 23, 27-28, 39-44		
We work to achieve health & social equity for priority populations with respect to life expectancy, burden of disease and quality of life measures.	Pages 16-17, 21-23, 28, 31, 41-44		
Interim benefits generated from HRC funding through influence on decision-making and agenda-setting			
We encourage collaboration with DHB or PHO networks leading to the development or updating of clinical/best practice guidelines.	Pages 16-18, 22, 27-28, 31, 44-45		
We develop new devices or techniques that lead to changes in treatment or management protocols.	Pages 17-19, 21-22, 27- 28, 31, 35, 38, 40, 43		
We grow our researchers' expertise beyond academic research with involvement, representation or leadership of government policy-setting forums.	Pages 16-17, 21, 23, 28- 32, 40-42, 44-45		
We amplify international perception of New Zealand's research capability and expertise.	Pages 16, 19, 21, 23, 27-33, 35, 38, 40, 44-45		

³³ Improving wellbeing involves nourishment of interacting capitals including natural, human, social, cultural and financial/physical capital. For further information see The Treasury Living Standards Framework available at https://treasury.govt.nz/information-and-services/nz-economy/living-standards/our-living-standards-framework

³⁴ For more information please see <u>https://www.un.org/sustainabledevelopment/sustainable-development-goals/</u>

We support the development of partnerships and networks to offer coordinated approaches across multiple organisations or agencies (e.g. Councils, schools, marae, church) to introduce responsive and appropriate health and social policies	Pages 16-17, 19, 21-22, 31-32, 38, 41-45
We empower communities to drive research focused specifically on actions for local or national change.	Pages 17, 21-22, 31-32, 41-44
Research-related benefits gained through HRC funding	
We build capacity and capability for a stronger research sector to address current and future health research challenges.	Pages 16-17, 19, 21-23, 27-33, 39-40, 43-45
We improve the research capacity of the health sector with clinicians able to generate and implement research findings, and we contribute to training or professional development of health or social services staff.	Pages 16-19, 23, 27-30, 33, 42
We create enduring benefits from international engagement such as leveraging international investment from overseas funding streams or providing access to markets and resources unavailable in New Zealand.	Pages 27-30, 33, 40
We create enduring benefits through fostering collaboration (national and international) between academia and industry, policy or community organisations.	Pages 16-17, 21, 27-33, 38, 40-45
Our research methodologies and findings influence or transform research fields	Pages 17, 21-23, 27, 29- 30, 33, 41, 43-45



Appendix 2: Schematic Pathways to Impact