Health and Health Research in New Zealand

Background paper for the inaugural meeting of the Development Group

4 July 2018

Auckland, New Zealand

Introduction

This paper provides background reading and evidence that will act as a reference document for the Development Group asked to provide recommendations on priorities for health research in New Zealand to achieve the vision of the New Zealand Health Research Strategy 2017 – 2027 (the NZHRS):

Chapter One	The New Zealand Health Research Strategy and the inclusive process for setting national priorities for health research.
Chapter Two	The health of New Zealanders, including a focus on specific population groups and health issues.
Chapter Three	Structure of the health and health research sectors in New Zealand.
Chapter Four	Current context for innovation and commercialisation in health research.
Chapter Five	New Zealand within the international context of health research.
Chapter Six	Future trends in health, including emerging threats and opportunities.

For ease of reading, each Chapter has a summary which outlines the current strengths, capacity, gaps, and opportunities in health research.

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1.0: Action One of the New Zealand Health Research Strategy

The vision of the New Zealand Health Research Strategy (the NZHRS), is a ***world-leading health research and innovation system that responds to and improves the current and future needs of New Zealanders.***

Researchers already attempt to focus on areas where they can make the biggest difference. However, the Government, with other small or developing economies,[1,2] recognises the importance of coordinating investment and research activity to ensure 'the best possible use of available resources and to strengthen the ties between policy, health practice, scientific knowledge, and technological development.'[3]

By setting national priorities for health research, stakeholders across the research and innovation sectors will be able to focus their effort and resources to achieve the greatest benefit and value for New Zealanders. This includes identifying research that must be done in New Zealand as it cannot be done internationally, where international research will not meet our specific needs, areas where New Zealand can optimise its capability and capacity, and opportunities for strengthening the global position of New Zealand as a health research leader.

New Zealand's first priorities for health research will guide not only investment by the Health Research Council of New Zealand (the HRC), but other government-funded research. The priorities need to serve the interests of all New Zealanders, as well as Government, Māori and iwi, research funders, researchers, the healthcare sector, healthcare professionals, community organisations, health service consumers, industry, and other stakeholders across the science, technology, and innovation sectors. Therefore, the process for setting priorities must be inclusive.

1.1 Implementation of Action One

Extensive work has been undertaken to identify the right process for setting priorities, including:

1. determining the purpose and scope of the priorities;
2. identifying established priority-setting methods;
3. assessing the suitability of established methods for the New Zealand context;
4. designing a tailored approach that is fit for the intended purpose in New Zealand;
5. consulting on, and communicating the proposed process to, stakeholders; and
6. refining the proposed approach in response to their feedback.

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[1] Small Advanced Economies Initiative. (2015). *Discussion Paper: Prioritisation of Public Sector Research across the SAEI.*

[2] Reveiz, L., Elias, V., Terry, R. F., Alger, J., & Becerra-Posada, F. (2013). Comparison of national health research priority-setting methods and characteristics in Latin America and the Caribbean, 2002-2012. *Revista Panamericana de Salud Pública,* 34(1): 1-13.

[3] Reveiz, et al., 2013, p.2.

1.2 Summary of the priority-setting process

To be able to provide recommendations to the NZHRS Steering Group on priorities for health research for New Zealand, the Development Group will independently review consultation feedback and balance it against the advice of experts and international reviewers, at each stage set out below.

Figure 1: Summary of the priority-setting process

June – July 2018

Development Group will produce draft strategic investment areas (SIAs)

Development Group: Maximum of 13 people, who are representative of as wide a range of stakeholders as possible. Respected individuals with skills in strategic thinking and relevant expertise. At least one Māori Co-Chair.

Sept – October 2018

Public consultation on draft SIAs

Stakeholders will be invited to comment on the broad SIAs and to nominate targeted research objectives within them.

6-week web-based consultation, supplemented by focus Groups and webinars, including Māori stakeholders, Pacific health researchers, and those who use health services, including people with disabilities and those in rural communities.

Nov – December 2018

Expert Panels will refine SIAs and research themes

Some Expert Panels will focus on specific SIAs; others will review cross-cutting issues across all SIAs, such as Māori advancement.

International experts will review the draft SIAs and research themes in relation to global research

Feb – March 2019

Appeals process

After the SIAs have been approved by the NZHRS Steering Group, they will be published online to allow the public to appeal this decision.

Ministers will announce Strategic Investment Areas

The Minister of Research, Science and Innovation and the Minister of Health will be asked to approve and announce the final SIAs.

May – Aug 2019

The Development Group will refine research themes.

The Development Group will review inputs from Expert Panels and international reviewers to refine the themes, which will be refreshed every 3-5 years.

Themes released for public consultation.

3-week web-based consultation on research themes and objectives.

Oct – Dec 2019

Appeals process

After themes have been approved by the NZHRS Steering Group, they will be published online to allow the public to appeal this decision.

Ministers will announce research themes

The Minister of Research, Science and Innovation and the Minister of Health will be asked to approve and announce the final priorities, consisting of SIAs and research themes.

1.3 Role of the Development Group

At the inaugural meeting of the Development Group on 4 July, you will be tasked with developing ***draft 'Strategic Investment Areas' (SIAs) for consultation***, which will endure for the 10-year duration of the NZHRS. During consultation, stakeholders will suggest more specific research 'Themes', based on factors such as the burden of disease, opportunities for innovation, gaps in knowledge, and the evidence needs of New Zealand's health system. The Development Group will then work with Expert Panels to refine and finalise the Themes, which will be reviewed every 3 to 5 years. The combination of SIAs and Themes will make up the priorities for future health research in New Zealand. The Development Group is also asked to consider the purpose, uptake, implementation, monitoring, and funding of the priorities.[4,5,6]

The NZHRS specifies that the process for setting priorities should be inclusive, to promote uptake and implementation of the priorities. International best practice involves collaborative approaches between the 'producers' and 'users' of research, or those best able to represent and advocate within each stakeholder community.[7,8]

The process is to be ***transparent and published***, in line with the guiding principles of the NZHRS, with a framework to ensure that decisions are considered fair, reasonable, and legitimate even by those who disagree with the outcome.[9,10] Members of the Development Group are asked to help ***communicate the priorities*** across the health and science, technology and innovation sectors, and champion their uptake, including justifying the decisions made based on available evidence, agreed criteria, and inclusive consultation.

Table 1: Decisions for the Development Group

The priority-setting process	
Decisions made by the Steering Group	**Decisions for the Development Group**
○ The ***draft*** scope of priorities, termed Strategic Investment Areas (or SIAs) and more detailed research objectives, called Themes. ○ Input must be sought through: – public consultation – Expert Panels, and – international reviewers. ○ To gain agreement, there is to be an opportunity for stakeholders to review the priorities before they are announced by Ministers. ○ SIAs to be announced in early 2019 with Themes announced before the end of 2019.	○ To ***revise and finalise the scope*** of SIAs and more detailed research objectives, called Themes. ○ To independently review information and evidence to support the development of ***draft SIAs for consultation***. ○ To recommend the ***remit of, how many,*** and ***who*** will sit on the Expert Panels. ○ To recommend ***international reviewers***. ○ To independently review consultation feedback and balance Expert Panel recommendations to ***finalise SIAs*** and ***Themes.*** ○ To make recommendations and communicate to the sector, how the priorities should be implemented.

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[4] http://www.cohred.org/

[5] Glod, F., Duprel, C., & Keenan, M. (2009). Foresight for science and technology priority setting in a small country: The case of Luxembourg*. Technology Analysis & Strategic Management,* 21(8), 933-951.

[6] Small Advanced Economies Initiative. (2015).

[7] Glod, et al. (2009).

[8] Cooke, J., Ariss, S., Smith, C., & Read, J. (2015). On-going collaborative priority-setting for research activity: A method of capacity building to reduce the research-practice translational gap. Health Research Policy and Systems, 13(1): 25. DOI 10.1186/s12961-015-0014-y

[9] Kieslich, K., & Littlejohns, P. (2015). Does accountability for reasonableness work? A protocol for a mixed methods study using an audit tool to evaluate the decision-making of clinical commissioning groups in England. *BMJ Open*, 5(7): DOI:10.1136/bmjopen-2015-007908.

[10] Daniels, N. (1999). Decisions about access to health care and accountability for reasonableness. Journal of Urban Health, 76(2): 176-191.

1.4 Purpose and scope of the priorities

The ***purpose and scope of the priorities*** must be clearly understood. During consultation on the process, comment was sought on the characteristics of SIAs and Themes to gain some agreement and understanding on this point ahead of the release of draft priorities for consultation (see Figure 2 over page for the proposed SIA framework and selection criteria for Themes).

Given their interdependence, ***thematic priorities*** for research (e.g. research fields or health care issues) should be considered in the context of ***structural priorities*** (e.g. funding mechanisms, research infrastructure, higher education, innovation initiatives, industry, or system networking).[11,12] Structural factors affect the ability to do research in an identified thematic area. In general, the Actions set out in the NZHRS have been designed to strengthen structural aspects of the health research system in New Zealand, and therefore should enhance the uptake and feasibility of the priorities set in Action One. The Development Group is encouraged to discuss research themes in the context of structural areas (e.g. opportunities for rapid structural improvement that would enable research on specific themes).

The Development Group is also tasked with considering the ***level of detail*** needed in the research priorities: too broad and they could fail to provide guidance; too detailed and they risk being too prescriptive.[13] The Development Group must also work to ensure that the level of granularity is consistent across priorities.

The process has been designed to achieve a balance between stable signals which endure for the life of the NZHRS, and flexible responses to changing health needs. Therefore, the priority-setting process has been designed as a continuous, cyclical activity.[14,15] This will also allow priorities to respond to new data and changes in the production, capacity and use of research.

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[11] Glod, et al. (2009).

[12] OECD. (1991). Choosing priorities in science and technology. Paris, France: OECD

[13] McGregor, S., Henderson, K.J., & Kaldor, M. (2014). How are health research priorities set in low and middle-income countries? A systematic review of published reports. *PLoS ONE*, 9(10): e108787. Doi:10.1371/journal/pone.0108787.

[14] http://www.cohred.org/

[15] Cooke, et al., 2015, p.3.

Figure 2: The Strategic Investment Area framework and selection criteria for Themes

What does a SIA look like?

Five to ten broad areas of investment will endure for the life of the New Zealand Health Research Strategy (to 2027) and encompass a range of key knowledge needs that:

- address the current and future needs of New Zealanders, including future generations;
- consider health research underway in New Zealand and internationally;
- will develop workforce capability and capacity to enable New Zealand to address its future health research needs; and
- advance the principles of Te Tiriti o Waitangi.

The breadth of the Strategic Investment Areas means that they are likely to benefit from collaboration across health research disciplines, and the health, and science, and technology and innovation sectors.

How will Themes for research be selected?

Within 'Strategic Investment Areas', there will be more specific 'Themes' which should meet as many as possible of the following objectives:

- advance Māori health outcomes and research capacity;
- advance Pacific health outcomes and research capacity;
- achieve health equity for those populations experiencing the greatest inequities of access and outcomes;
- reduce the burden of disease in New Zealand and meet identified needs for improving health and wellbeing;
- have potential for translation into policy or practice to improve the standard of care;
- improve cost-effectiveness for the New Zealand health system;
- respond to unique opportunities (e.g. research that can only be done in New Zealand, or innovations with commercial potential);
- address confirmed knowledge gaps;
- build the health research workforce New Zealand needs; and
- be feasible, in terms of research capability, capacity, and strengths.

Themes will be refreshed every 3–5 years.

1.5 Governance of the NZHRS and Action One

Representatives from the Ministry of Business, Innovation and Employment (MBIE), the Ministry of Health, and the HRC formed a Working Group in October 2017. The Working Group is responsible for progressing the work associated with each Action. Once priorities have been established, the next step is to ensure the infrastructure, resources, capacity, and capability exist to address them, through Actions 2 to 10 of the NZHRS.

The Working Group reports to the NZHRS Implementation Steering Group (the Steering Group), comprising senior officials from MBIE, the Ministry of Health, and the HRC, with representation from Callaghan Innovation, District Health Boards (DHBs) and Universities NZ. The Development Group will make their recommendations on priorities for health research to the Steering Group. The Steering Group is the decision-making body for the NZHRS and will have final sign-off on the priorities before the priorities are approved by Ministers or seen by the public.

MBIE and the Ministry of Health, through the Steering Group, receive high-level advice from an External Advisory Group (the EAG), which meets twice a year, and had its inaugural meeting in February 2018. The NZHRS requires regular reporting to the Minister of Research, Science, and Innovation and Minister of Health on progress made towards the vision. The Steering Group will seek sign-off from Ministers at crucial points throughout the implementation of Action One.

1.6 Implementation and funding of the priorities

The process of setting health research priorities has been intentionally separated from the related process of adapting funding mechanisms to address those priorities. With regards to the HRC's response, it will develop a 3-yearly research investment plan to set out how the HRC's budget will be allocated across identified priorities. Other Government-funded, mission-led research, including through the National Science Challenges, research commissioned by health sector and other government agencies, will be similarly guided by the priorities. Each agency will make decisions about how they will do this, which will require coordination of government funding, as each research funder will likely address the priorities in different ways. The Government will develop new approaches for co-investment with the not-for-profit sector.

When the priorities are published in 2019, other stakeholders will decide how they will implement and fund them. Other funding mechanisms in New Zealand's health research and innovation system, such as academic institutional funding, the Centres of Research Excellence (CoREs), and the Marsden Fund, and as outlined in the Health Research Strategy, these will continue to support curiosity-driven health research that may or may not fit with the agreed priorities.

1.7 Monitoring, impact evaluation, and refreshing the priorities

The Development Group is asked to propose metrics that can be used to assess the uptake and fulfilment of each priority, so that priorities remain stable, but not stagnant. The NZHRS sets out Performance Indicators[16] to be evaluated and monitored during the implementation, including the amount of health research in different disciplines and research fields. Data sources include

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[16] For more information see Chapter 5 (pages 27-28) of the New Zealand Health Research Strategy.

the contracts kept by funding agencies, research institutions, and organisations in the healthcare sector. Government funders of health research will also be asked to map their investment to the priorities set and will request their researchers take part in regular impact evaluation.

Summary of the health of New Zealanders

Strengths

(What we can build on)

- **New Zealanders are living longer**, and are living longer **in good health** (i.e., both life expectancy and health expectancy are increasing).
- **Health loss is declining** – a major achievement for the health and wider social sectors.
- Less than 4% of health loss results from pre-epidemiological-transition causes (**infectious diseases, nutritional deficiency and neonatal disorders**).
- Burden is becoming decoupled from prevalence (i.e. diabetes) reflecting the complex interaction of disease prevalence and demographic trends, and **improvements in clinical care** that has reduced disease progression and fatality.
- Internationally, New Zealand achieved one of the **fastest rates of decline in health loss** from all causes combined among high-income countries.

Weaknesses

(What we need to improve now)

- Within New Zealand, **serious inequalities in health outcomes** persist between different genders, generations, ethnic and socioeconomic groups.
- Māori live fewer years than non-Māori.
- The proportion of Māori and Pacific peoples who live in the **most socioeconomically deprived areas** is greater than that of other groups.
- **Children are over-represented** in the most deprived areas.
- Health loss from **musculoskeletal disorders**, including neck and lower back disorders and arthritis, is increasing – partly because of **rising rates of obesity**.
- **Addressing cardiovascular disorders is an unfinished agenda**. Coronary heart disease still accounts for over 8% of all health lost. And stroke continues to account for over 3% of health loss. Both are potentially avoidable through a combination of prevention and treatment.
- No central body monitors the **strength or sustainability of the health research workforce** (aside from the workforce survey specific to HRC-funded research).

Opportunities

(What we need to do)

- The challenge for New Zealand is to meet the health needs of our **changing population**.
- **Achieving health equity**. Māori, Asian, and Pacific populations will continue to grow faster than New Zealand's population overall, increasing ethnic diversity.
- Transitioning the health system to **respond to multi-morbidity** (rather than addressing single diseases) is a key challenge.
- A greater focus on **addressing the impact of non-fatal disabling conditions**, whether through prevention or improved management, will enable people to live more of their 'extra' years of life in full health.
- **Strengthening prevention** could bring major benefits. **Over 1/3 of health loss is preventable.** Strengthening prevention could help the health system to become more sustainable clinically, fiscally and economically.

Threats

(Longer-term issues)

- An **ageing population** will **increase demand on the health system**.
- **Morbidity (ill health) is expanding;** we are living longer in poor health.
- An increasing proportion of frail older people will **survive for longer with multi-morbidity** and associated disability.
- Because **the population is growing and ageing**, improvements in health do not necessarily reduce health care expenditure.
- 88% of health loss is now caused by **non-communicable diseases.**

2.0: The health of New Zealanders

In relation to the health of New Zealanders, Action One of the NZHRS states that the priority-setting process should consider research priorities that will help to:

- advance the priorities of the New Zealand Health Strategy and/or the National Statement of Science Investment (NSSI);
- improve health outcomes and address the burden of disease;
- improve understanding of the various determinants of health, including social, environmental, and occupational factors; and
- achieve health equity across New Zealand's diverse populations and communities.

2.1 Overview

The following section details health loss and burden of disease data for New Zealand. This overview chapter is followed by more specific chapters for Māori health, the health of Pacific people, the health of Asian people, disability health and mental health, each with a corresponding summary. A consideration to keep in mind, for discussion on the day, will be whether identified health 'gaps' require more research, or merely better action and translation of the already existing research. Translation and uptake of health research findings is further discussed in Chapter 8.0: New Zealand health system and health research sector.

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.[17]

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. The New Zealand Index of Deprivation[18] highlights the unequal distribution of socio-economic deprivation in New Zealand, in that the proportion of Māori and Pacific peoples who live in the most socio-economically deprived areas is greater than that of other groups. Children are also over-represented in the most deprived areas, as well as being more likely to live in crowded households.

Average life expectancy and levels of health have been improving in New Zealand over the years. The average life expectancy for someone born in 2015 was 79.6 years for men and 83.3 years for women. [19] However, on average Māori live 7 fewer years than non-Māori, with Māori men having a life expectancy at birth of 73.0 years and Māori women 77.1 years. Pacific men have a life expectancy of 74.5 years and Pacific women 78.7 years.[20] Average health expectancy

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[17] Ministry of Health (2017a) *Health and Independence Report 2016. The Director-General of Health's Annual Report on the State of Public Health.* Wellington: New Zealand

[18] For information on available socioeconomic deprivation indexes please see https://www.otago.ac.nz/wellington/departments/publichealth/research/hirp/otago020194.html

[19] Ministry of Health (2017a).

[20] Ministry of Health (2015a) *Health and Independence Report 2015. The Director-General of Health's Annual Report on the State of Public Health.* Wellington: New Zealand.

(combining both mortality and morbidity)[21] is now 71.8 years for women and 69.9 years for men. However, increased health expectancy hides clear disparities in outcomes for the health of people with low socio-economic status, for Māori, and for Pacific people. In addition, New Zealand is recording increased disease burdens from injuries and long-term health conditions such as heart disease, respiratory conditions, cancer, obesity, and mental health conditions.

2.2 Demographic Trends

Demographic changes to the population present challenges for the health of New Zealanders and the health sector. **Ageing** has implications for the health sector, along with **increases in population size**, and **ethnic diversity**. Years added to life increasingly outweigh those lived in health. The health system is not currently well equipped to respond to multiple long-term conditions, or the resulting pressures in terms of cost and demand for services.

The causes for health loss are changing, as New Zealand advances along the epidemiological transition[22] and related 'disability transition.' Dementia has been the most significant increase in health loss, with observable differences in gender.[23] Only 4% of health loss is now attributable to pre-transitional causes (i.e. infectious diseases, nutritional deficiency disorders, and neonatal disorders); whereas 88% of health loss can be attributed to non-communicable diseases (NCDs) and 8% to injuries.

Up to 33% of health loss is preventable.[24] The 'New Zealand Burden of Diseases, Injuries and Risk Factors Study'[25] estimates that 38% of all health loss is attributable to modifiable risk factors. However, risk factors are declining,[26] despite an increase in prevalence (e.g. as seen in obesity). Similarly, many long-term conditions (such as diabetes) are increasing in prevalence although their age-adjusted per-capita burdens are stabilising or even falling.[27] This decoupling of prevalence from burden of disease and risk factors is due to improvements in clinical care that have reduced disease progression and case fatality, particularly for some diseases, and reduced exposure to other risk factors (such as tobacco).

The challenge for New Zealand is to meet the health needs of our changing population. Projections indicate that the Māori, Asian, and Pacific populations will continue to grow faster than New Zealand's population overall and will increase their share of the total population (Table 2, over page).

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[21] Statistics NZ, Health Expectancy NZ Progress Indicators. Health expectancy is an estimate of the average number of years a person will live without requiring assistance with everyday activities.

[22] The epidemiological transition is a phase of population development where pre-transitional causes of health loss, such as neonatal disorders, infectious disease and nutritional diseases decline, and non-communicable diseases become the predominant cause of health loss. The transition is associated with demographic transitions in fertility and mortality rates.

[23] Ministry of Health (2016) Health Loss in NZ 1990-2013: A report from the New Zealand Burden of Diseases, Injuries and Risk Factors Study.

[24] *Ibid.*

[25] *Ibid.*

[26] Except for illegal drug use which is increasing.

[27] Ministry of Health (2016).

Table 2: Current and predicted ethnic composition of the New Zealand population[28]

Ethnicity	2014 million	2014	2025 million	2025	2038 million	2038
European	3.36	76.0%	3.62	61.5%	3.82	58.2%
Māori	0.70	15.6%	0.91	15.4%	1.18	17.4%
Pacific	0.35	7.8%	0.48	8.1%	0.54	7.9%
Asian	0.55	12.2%	0.92	15.5%	1.26	18.5%
Total	**4.50**		**5.93**		**6.80**	

Increasing proportions of all four ethnic population groups will be aged 65 and older. This age group is expected to make up a quarter of New Zealand's population by 2030, and the number of people aged 65 years and older is projected to increase from 500,000 in 2005 to 1.33 million in 2051.[29]

Disability now accounts for 52% of total health loss, and morbidity is now the main cause of health loss, rather than premature mortality.[30] An ageing population with multi-morbidity means increases in demands and costs in the health care system.[31] The Government has therefore identified the next challenges for the health sector as:

- strengthening preventative measures to reduce pressure and expenditure on the system,
- transitioning the health system to respond to multi-morbidity,
- reducing inequities and achieving health equity, and
- addressing the challenges of an ageing population.

For the science sector, the Government has identified that health research should be part of its response to the changing burden of disease. A stocktake of health research funded by the three main government agencies which fund science: HRC, MBIE, and the Royal Society Te Apārangi (RSTA), from 2013 to 2017, showed how it maps to healthcare divisions (Figure 3), and data on burden of disease (Table 3).

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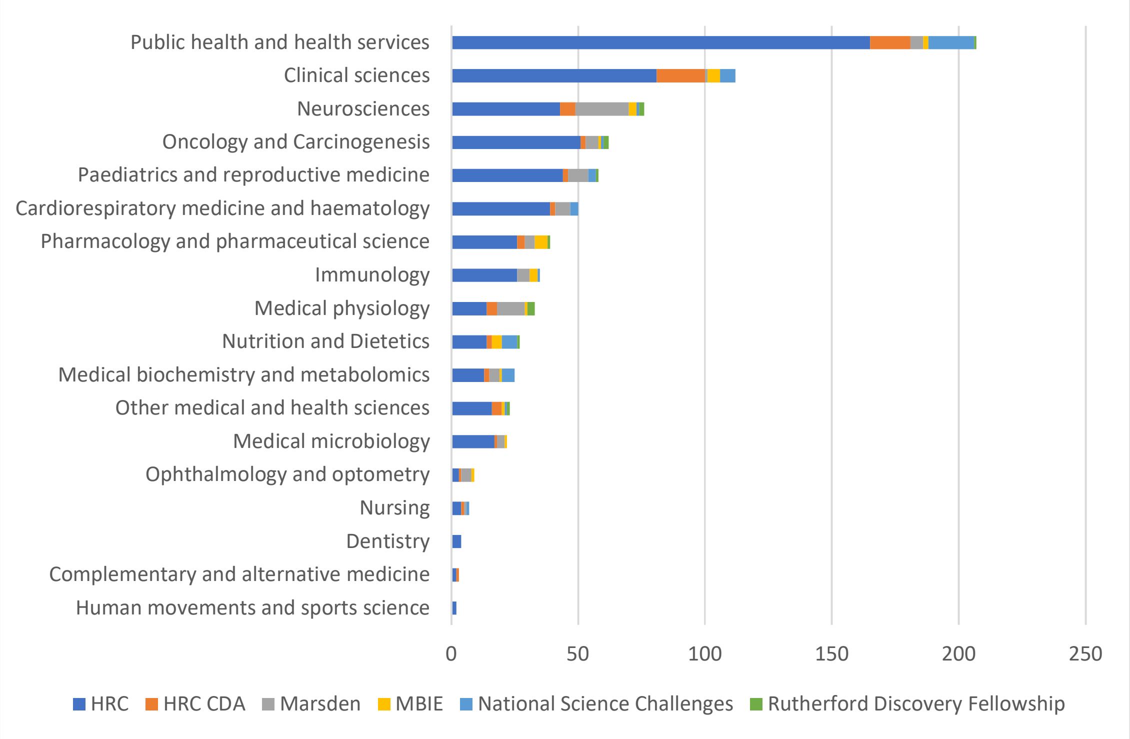
[28] Statistics NZ (2014) New Zealand in Profile and Stochastic population projections, median projection 2014 base (derived figures).

[29] *Ibid.*

[30] Ministry of Health (2016).

[31] Ministry of Health (2016).

Figure 3: Number of Government-funded research grants 2013–17, by funding agency.



This data comprises 691 grants or career development awards (CDAs) greater than NZ$150,000 in value. Healthcare divisions are from the Australia New Zealand Standard Research Classification (Health and Medical Division).

Table 3: Government investment in health research 2013–17, relative to burden of disease.

	% total DALYs	DALYS lost	Number of contracts	Total budget of contracts	Funds per DALY
Cancers	0.17	185,640	62	$66,482,522	$358
Cardiac and vascular diseases	0.14	152,880	45	$61,904,159	$333
Mental disorders	0.12	131,040	9	$9,262,058	$71
Neurological disorders	0.07	76,440	76	$82,053,428	$1,073
Musculoskeletal disorders	0.13	141,960	7	$12,778,819	$90
Injuries	0.08	87,360	7	$11,803,273	$135
Diabetes	0.03	32,760	18	$12,400,456	$379
All			**547**	**$535,814,876**	**$487**

Data from the analysis in Figure 3 was used to derive an estimate of the number of projects and levels of investment, relative to the burden of disease as measured in 2013 Disability-Adjusted Life Years (DALYs).[32]

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[32] Values for DALY were extracted from the Ministry of Health 2016 report: *Health Loss in New Zealand 1990–2013*, and the IHME: https://vizhub.healthdata.org/gbd-compare/

2.3 Health research workforce

There is no comprehensive national information on the numbers of health researchers in New Zealand, or their experience, qualifications, fields of study, gender, ethnicity, migrant status, or age. The HRC has some information on the individuals it funds based on the annual workforce survey (details in the box opposite), but this does not extend to researchers, or professions working in health research funded elsewhere which might include other disciplines or other fields of research. No central body monitors the strength or sustainability of the health research workforce. In the absence of reliable data, it is difficult to develop and evaluate options to ensure capacity to respond to the priority-setting process (e.g. in terms of workforce skills and characteristics).

Over the 2006 to 2015 period, the most commonly addressed health issues by HRC-funded researchers were in **oncology and cancer**, **cardiovascular and cerebrovascular disease** and **central nervous system** and **neurological disorders**. Currently, large programmes of research are most commonly spread across the 5 ANZSRC SEO codes of **Cancer and Related Disorders**; **Cardiovascular Systems and Diseases**; **Child Health**; **Neurodegenerative Disorders Related to Ageing**; and **Respiratory System and Diseases** (including Asthma).

2.4 Government and policy response to demographic health trends

As well as the strategies listed in Appendix A of the NZHRS, the following strategies and pieces of work relate to our growing ageing population:

The **Healthy Ageing Strategy** (2016)[33] recognises the need to improve the knowledge base on the needs of the ageing population to ensure that the research informs policy, improvement of services, and development of the workforce. The Healthy Ageing Strategy identifies a need for innovations and research in acute and restorative care to support best-practice triage, assessment, integrated care, discharge planning, rehabilitation strategies, and follow-up support.

The **Ageing Well National Science Challenge** aims to create New Zealand-specific interventions, technology, policy and environments that support active ageing. The Challenge has five research strands: maintain wellness, independence, and autonomy; promote social integration and engagement; value older people in all settings; reduce disability and the impact of disability; and enhance age-friendly environments. In recognition of the specific challenges and opportunities faced by Māori and Pasifika peoples to age well, the Challenge approved $3.25 million of contestable funding for research that investigates aspects of ageing well for these groups.

The **Life and Living in Advanced Age (LiLACS) longitudinal study** (commenced in 2010) has identified predictors of quality of life, physical function, disability, depression, and cognition in those in advanced age. The Ministry of Health and the Ministry of Social Development have used

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[33] Associate Minister of Health. (2016). *Healthy Ageing Strategy.* Wellington: Ministry of Health.

the results of the study to inform policy in areas such as transitions in care, balancing formal and informal care, falls and injuries and service inequalities.

Summary of Māori health

Strengths

(What we can build on)

- **Guiding principles are already in place** – through *Te Tiriti o Waitangi* and *He Korowai Oranga.* **Priorities will be set in partnership with Māori.**
- **Māori researchers are recognised as world-leaders in indigenous health research** and have formally linked with indigenous researchers in Australia and Canada.
- **The 'whakapapa' of Māori health research.** A lot has been achieved since the funding of the two Māori health research centres in the mid-1990s
- There is a large and growing body of knowledge on **kaupapa Māori research methodologies.**
- **Māori health outcomes are a priority across multiple areas of the health sector**, a driver for alignment between research priorities and health and social agencies and health professionals.
- **The HRC has systems already in place to support 'by Māori for Māori' research**, through Māori-led and developed assessment processes, ring-fenced funding and community engagement initiatives.
- **The NZ Government is committed to health equity for Māori** and the 20 DHBs were set up with this expectation.
- **Māori concept of hauora and worldviews use methods and approaches that work across a diverse range of disciplines** and methodologies language, education and justice.
- **Some iwi have developed their own health research strategies**, such as Ngati Porou.

Weaknesses

(What we need to improve now)

- **Failure of the system to acknowledge that Māori researchers work on community transformation rather than publication**. This takes time, and should be acknowledged and embraced
- There is a **gap between research findings and the translation into action** that results in real benefits and gains to the community
- There is **no Māori evidence-based clearing house** that could help improve translation and assist in setting the research agenda.
- **Some research funding processes don't acknowledge that the research career pathway for Māori is different**, impacting on the assessment of track record in funding mechanisms.

Opportunities

(What we need to do)

- Support for researchers to **co-produce healthcare services that reflect Māori cultural values and are based on te Ao Māori.**
- Fulfilling the Treaty promise through **creating and sustaining a strong and vibrant Māori health research sector** that links academics, policy and community to reduce inequalities.
- **Learning from the Waitangi Tribunal Health Services and Outcomes Kaupapa Inquiry** to identify issues that can be addressed through Māori-led research.
- **Whānau Ora cross-government work programme** places whanau at the centre of service delivery, requiring the integration of health, education and social services, and providing opportunities for Māori-led cross-sectoral research.

Threats

(Longer-term issues)

- Research should aim to achieve health equity. **A lot of health research has the potential to increase inequities.**
- **Māori data sovereignty needs to be recognised with Māori users involved in the governance**. Māori researchers need to be able to access big datasets and communicate these results to communities for their use.
- **Ethical issues around Māori data in biobanks and other large data repositories** and the behaviour of researchers in accessing and distributing this data have to be addressed.

3.0: Māori Health

Māori health research is that which values Māori worldviews and builds Māori research capacity and leadership. Action One of the NZHRS states that the priority-setting process should consider research priorities that will help to achieve health equity for Māori and reflects the principles of He Korowai Oranga and Vision Mātauranga.

3.1 Burden of disease and health loss data

A strength-based approach builds on cultural factors that are essential to health, such as resilience, identity, and strong social support networks.[34] Comparisons of Māori health outcomes to those for non-Māori are inherently deficit-oriented, so the following information must be acknowledged in the context of a dominant cultural, systemic, and structural practices that are failing to advance Māori health.

Māori sustain greater health loss than non-Māori in most conditions. On an absolute scale, 26% of the excess burden experienced by Māori was caused by vascular disorders, 15% by cancers, 12% by mental illness, 11% by injury and 9% by diabetes or other endocrine disorders.[35] The total CVD[36] mortality rate among Māori is more than twice as high as non-Māori. Cancer mortality rates[37] for Māori are also higher than for non-Māori, which suggests that Māori have a higher risk of dying from their cancer than non-Māori. Asthma is a particular issue for Māori, with medication needed by nearly one in five Māori – both children (19%) and adults (17%). In respiratory disease,[38] the mortality rate for Māori aged 45 and over from chronic obstructive pulmonary disease (COPD) is almost three times that of non-Māori, and hospitalisation rates were over three and a half times more.[39]

Māori adults have higher rates than non-Māori for most health risks and conditions, such as smoking, hazardous drinking, obesity, being physically inactive, asthma, and psychological distress. Māori children also have comparatively high rates of obesity. Māori have a greater level of unmet need for primary care than non-Māori, which is largely attributable to the fact that 14% of Māori adults and 7% of Māori children miss out on prescriptions due to cost.[40]

Tamariki Māori have worse health than non-Māori children across a wide range of health status indicators and rates of hospitalisation, including higher death rates from injuries, poisonings, road traffic injuries, sudden infant death syndrome, respiratory conditions, and infectious diseases. The greatest disparity occurs in infants and children aged 1-4 years.

Socio-economic factors (for example, income, employment, housing, and education) make a major contribution to disparities between Māori and non-Māori health. Māori continue to live in

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[34] Auckland District Health Board. (2007) *Te Aratakina "A Pathway Forward" Māori Health Action Plan* 2006-2010.

[35] Ministry of Health: http://www.health.govt.nz/nz-health-statistics-and-data-sets/new-zealand-burden-dieases-injuries-and-risk-factors-study-2006-2016#healthlossspecific.

[36] Ministry of Health (2015b) *Tatau Kahukura: Māori Health Chart Book 2015*, 3rd Edition, October 2015

[37] *Ibid.*

[38] Ministry of Health (2013) *Health of Māori Adults and Children: Key findings from the New Zealand Health Survey*, March 2013.

[39] Ministry of Health (2015b).

[40] Ministry of Health. (2017b). Annual Data Explorer 2016/17: New Zealand Health Survey [Data File]. URL: https://minhealthnz.shinyapps.io/nz-health-survey-2016-17-annual-update

the most deprived areas in New Zealand. In 2013, 23.5% of Māori lived in areas classed as decile 10 for deprivation.[41] Māori adults have lower rates of school completion than non-Māori and much higher rates of unemployment. Relatively more Māori adults have a personal income of less than $10,000 and more receive income support. More Māori live in rental accommodation and in crowded households than non-Māori.[42]

3.2 Government and policy response to Māori health

Māori health outcomes are a priority across multiple areas of the health sector, which is a driver for alignment between research priorities and funding of research, health and social agencies, and frontline health professionals.

HRC investment in Māori health research

Māori health research has been identified as a high priority by the HRC for more than 20 years, and the HRC has directly addressed capacity in this area through Māori led and developed assessment processes, ring-fenced funding (e.g. Rangahau Hauora Māori research investment stream), funding for independent research organisations (IROs), and community engagement initiatives (e.g. Ngā Kanohi Kitea grants). The HRC also allocates specific funding to support capability and skills for Māori researchers with targeted career development awards. This approach has been successful in building capability: 13% of individuals supported by HRC research contracts in 2016/17 identified as Māori (with nearly half being senior researchers).[43] Over the last decade, almost 30% of investigator-initiated research funded by the HRC has been classified as relevant to Māori advancement (20.2%) and Māori development (8.7%).[44]

The HRC, the National Health and Medical Research Council (NHMRC) of Australia, and the Canadian Institutes of Health Research (CIHR) formed the *International Collaborative Indigenous Health Research Partnership* in 2002, and every 5 years the three research bodies have re-signed a trilateral letter of intent to work collaboratively to improve research capacity in indigenous peoples' health and to support a cadre of indigenous researchers to reduce the health disparities for indigenous peoples.

Broad Science Sector Support

A stocktake of health research funded by the three main government science funding agencies from 2013-2017 shows that while HRC is the primary government funder of Māori health research, with over 75 grants awarded, projects funded through the National Science Challenges also map and contribute to this category (see Figure 4). In the broader health sector, a total of 44 projects that identified as primarily relevant to Māori health received approval from Health and Disability Ethics Committees (HDECs) between 2014-2017.

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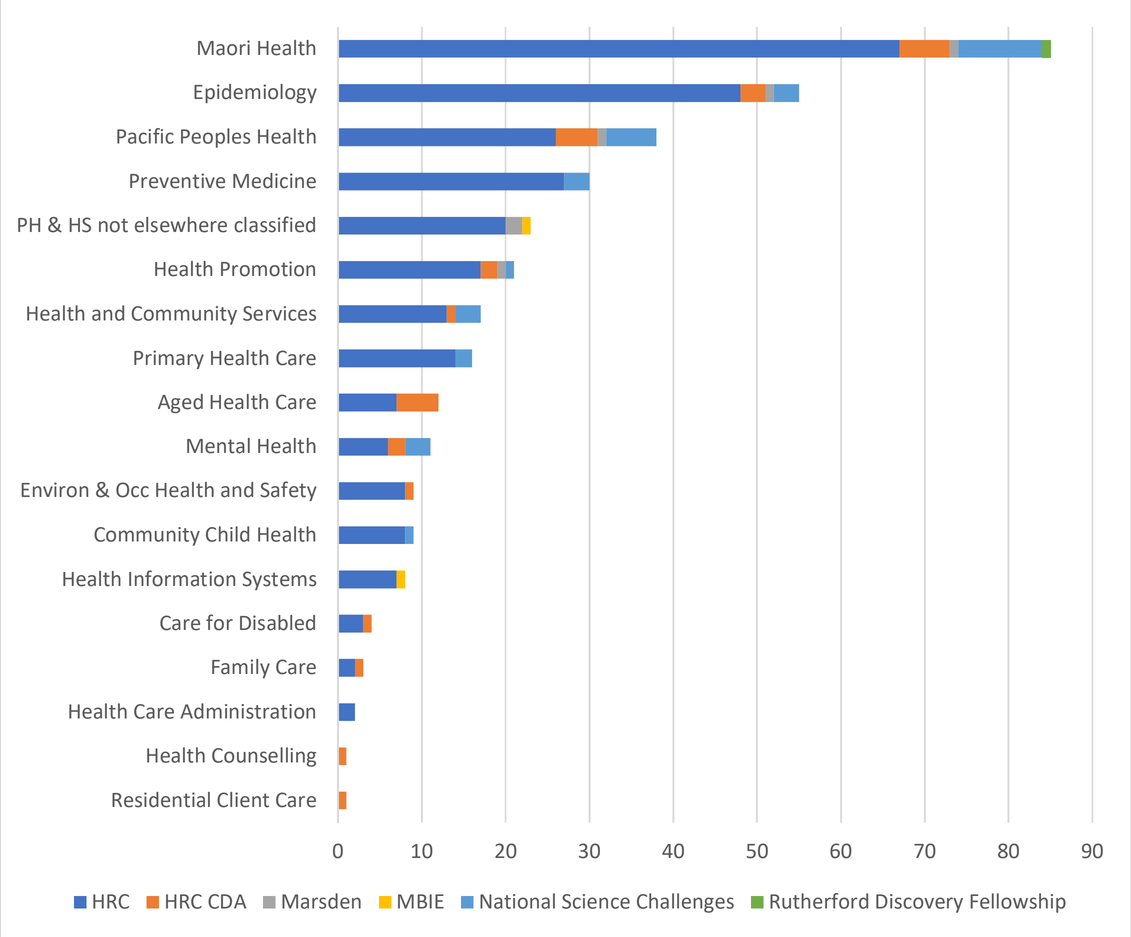
[41] Ministry of Health (2015b) *Tatau Kahukura: Māori Health Chart Book 2015*, 3rd Edition, October 2015

[42] *Ibid.*

[43] HRC (2015) Annual Report, p 32.

[44] Māori development research is research carried out to consolidate and develop Māori knowledge and to deepen the Māori research skill base. Māori advancement research addresses the significant disadvantage of Māori relative to non-Māori. HRC (2010). *Guidelines for Researchers on Health Research Involving Māori* version 2. Auckland: Health Research Council of NZ.

Figure 4: Number of Government grants, 2013-17, by funding agency.[45]



National Strategies

The Ministry of Health and MBIE provide key direction in Māori health research through the approaches described in the following section.

He Korowai Oranga The Māori Health Strategy (2002) sets the overarching framework that guides Government and the health and disability sector to achieve the best health outcomes for Māori. The overall aim of He Korowai Oranga is Pae Ora (Healthy Futures), building on the initial foundation of Whānau Ora (Healthy Families) to include Mauri Ora (Healthy Individuals) and Wai Ora (Healthy Environments). Health research is integral to achieving this overall aim. He Korowai Oranga recommends support for researchers to co-produce healthcare services that reflect Māori cultural values and are based on te Ao Māori (the Māori world – including language, values, practices and community). The key threads to enable He Korowai Oranga are:

1. Rangatiratanga**:** Māori have control over their own health and wellbeing, as well as the direction and shape of their own institutions, communities and development as a people.

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[45] Healthcare divisions are from the Australia New Zealand Standard Research Classification (Public Health and Health Sciences Division).

2. Whānau ora:[46] A healthy whānau is one that has the knowledge, skills, and resources to participate effectively in, and contribute to, te Ao Māori and the institutions of wider New Zealand society.
3. Equity**:** Better health for all New Zealanders – achieving health equity as a minimum.

Comprehensive high-quality information about Māori health is needed to support effective self-management, service delivery, monitoring, and achievement of Māori health objectives. He Korowai Oranga calls for new efforts to understand where Māori stand with regard to indicators of mortality, morbidity, and disability; levels of income, housing, education, and access to social support; environmental measures; measures of participation in society, including te ao Māori; and their identity, sense of belonging, self-esteem, and autonomy. Research in support of Whānau Ora should also incorporate appropriate comparisons of wellbeing between Māori and non-Māori over time, and measures of whānau potential, functioning, adversity, and capacity.

The **Vision Mātauranga** (**2005)** policy framework guides research investment decisions made by Vote Research, Science and Technology funding (Vote RS&T is the share of Government's annual Budget that is dedicated to supporting research). The mission is to unlock the innovation potential of Māori knowledge, resources, and people.[47] Vision Mātauranga supports whānau ora as the overall goal for Māori health. Hauora/Oranga: Improving Health and Social Wellbeing is one of four themes through which the policy provides strategic direction on how research can be used to:

1. develop the body of indigenous knowledge;
2. develop innovative and distinctive products and processes that can contribute to New Zealand's economic growth;
3. achieve environmental sustainability through healthy communities; and
4. improve health and social wellbeing for Māori.

Vision Mātauranga aims to move research beyond participation; to recognise Māori as partners in science and innovation; and to actively build capacity and capability to enhance engagement in science and innovation. Health research should create and apply knowledge that will address health priorities and needs; enhance the ability of the health sector to increase quality of life for Māori; improve access to quality health and disability services for Māori; and decrease morbidity and mortality of Māori from preventable diseases and health conditions.

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[46] Further information about the cross-government Whānau Ora work programme is available from the Ministry of Health website https://www.health.govt.nz/our-work/populations/maori-health/whanau-ora-programme and Te Puni Kōkiri website http://www.tpk.govt.nz/en/whakamahia/whanau-ora

[47] Ministry of Research, Science and Technology [MoRST; now the Ministry of Business, Innovation and Employment, MBIE] (2007) Vision Mātauranga: Unlocking the innovation potential of Māori knowledge, resources and people. Available at http://www.mbie.govt.nz/info-services/science-innovation/agencies-policies-budget-initiatives/vm-booklet.pdf

Summary of the health of Pacific peoples

Strengths

(What we can build on)

- Pacific **communities are strong and connected.**
- **Pasifika research paradigms are increasingly being recognised** and implemented in health research.
- **Ala Mo'ui: Pathways to Pacific Health and Wellbeing** can be used as a starting point for developing Pacific health research priorities.
- The **HRC has systems in place to build Pacific health research capacity and identify priority research for Pacific peoples** that can be further refined.
- **The HRC is responsible for leading Action 3 of the New Zealand Health Research Strategy**: invest in research that results in equitable health outcomes for Pacific peoples and helps them to lead independent lives.
- The HRC has **funding models for Māori health research and career development which have been shown to be effective** and can provide a useful starting point for addressing Pacific issues with the current funding model.

Weaknesses

(What we need to improve now)

- Health **research workforce capacity is low** (3% of named investigators on HRC contracts identify as Pacific).
- **Lack of ring-fenced funding** for Pacific health research.
- Universities and other funders are seen as providing **inadequate support for Pacific health research** in general.
- **Lack of on-going, long-term funding** for Pacific health research.
- There is **insufficient monitoring, review and evaluation of what works for Pacific peoples**, and this needs to be made an integral part of Pacific health research projects.
- There is **insufficient recognition of Pacific world views and methodologies.**
- **Community-led initiatives**, including those that identify community needs, are limited in the current system.

Opportunities

(What we need to do)

- There is broad recognition and concern across government about the inequities in health outcomes that Pacific people face, and the will to consider any effective initiatives to improve health equity for Pacific groups. **Researchers have an unprecedented opportunity to influence policy and practice for improved outcomes.**
- **New Zealand has an important role in supporting Pacific health research across Pacific nations**, including building regional capacity.
- There are **opportunities to link up research across the Pacific** as many health issues are transnational, applying to Pacific people in New Zealand and in the Pacific islands.
- There are **many research questions for Pacific health that are either not clearly articulated or are not being addressed**.
- There needs to be a **sustainable mechanism across the health and academic sectors** (tertiary education organisations, the Ministry of Health, DHBs, and PHOs), relevant agencies and key thinkers **to identify the priorities, gaps and issues for Pacific health research to address**.

Threats

(Longer-term issues)

- Only a **small number of Pacific school leavers choose a career in science** (Counties Manukau DHB have initiatives to address this).
- **Funding models have a significant impact on Pacific health research**, as shown in 2011 when the HRC changed the investment framework and moved away from directly prioritising Pacific health research – and in the lack of sustainability of previous Pacific health research centres.
- **Climate change will have a profound effect on Pacific nations** – and is likely to significantly increase the Pacific population in New Zealand. This will greatly increase the impact of existing issues on the Pacific community.

4.0: Health of Pacific peoples

Action One of the NZHRS states that the priority-setting process should consider research priorities that are in an area in which New Zealand has a significant interest, such as Pacific health research.

4.1 Burden of disease and health loss data

Pacific peoples made up 7.4% of New Zealand's population in 2013 (latest available census data).[48] Most live in Auckland (66% of people who identified with at least one Pacific ethnicity in New Zealand's 2013 census). Pacific peoples represent the third largest ethnic group in Auckland (15% of the total Auckland population). The Pacific population is young, with 38% (100,344 people) aged under 15 years. Pacific peoples are disproportionately represented in low socio-economic areas and have low incomes and high levels of unemployment. A relatively high proportion of Pacific children and young people live in overcrowded households. Pacific peoples are exposed to higher levels of health risks and unhealthy behaviours such as obesity and poor nutrition than the general population. The incidence of CVD, diabetes, and respiratory illness is significantly higher among Pacific peoples than in other ethnic groups. Pacific people's mortality rates from CVD are not decreasing as fast as for the rest of the population.[49] Pacific peoples have the highest rate of hospitalisation for strokes.[50]

The health status of Pacific children is poor in several key areas. Rates of acute rheumatic fever (ARF) and meningococcal disease are markedly higher. Pacific children are nearly 50 times more likely than European children and young people and more than twice as likely as Māori to be admitted to hospital with ARF.[51] Pacific children are four times more likely to be admitted to hospital for meningococcal disease than European children.[52] Many hospitalisations are avoidable and could be prevented through primary care interventions and improvements in household conditions.

Current interventions have been relatively unsuccessful for is responding to the health needs of Pacific peoples. Clinicians and services could be tailored to cultural needs to enhance holistic patient-centred family-focused care and improve health-care quality and consequent outcomes.[53]

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[48] Statistics NZ (2013) Quick stats *About National highlights 2013.* Available from http://archive.stats.govt.nz/Census/2013-census/profile-and-summary-reports/quickstats-culture-identity/pacific-peoples.aspx

[49] Information gathered from Statistics New Zealand online web archive for Pacific Peoples. Available at http://stats.govt.nz/browse_for_stats/people_and_communities/pacific_peoples/

[50] Information gathered from Statistics New Zealand online web archive for Pacific Peoples. Available at http://stats.govt.nz/browse_for_stats/people_and_communities/pacific_peoples/

[51] Craig, E., Jackson, C., Han, D. Y., & NZCYES Steering Committee. (2007). *Monitoring the Health of New Zealand Children and Young People: Indicator Handbook*. Auckland: Paediatric Society of New Zealand, New Zealand Child and Youth Epidemiology Service

[52] Craig, et al. (2007).

[53] Statistics NZ and MPI (2011) *Health and Pacific Peoples in New Zealand - Pacific Progress*, Ministry of Pacific Island Affairs, Wellington.

4.2 Government and policy response to Pacific peoples' health

HRC investment in Pacific health research

HRC has a Pacific health research strategy and HRC's Pacific Health Research Committee has identified priorities which were refreshed recently to ensure that they support Action Three of the NZHRS to "invest in research that results in equitable outcomes for Pacific peoples and helps them to lead independent lives". HRC has ring-fenced funding to support Pacific health research projects that will contribute towards achieving better health outcomes for Pacific peoples, families, and communities. The HRC also allocates specific funding to support Pacific researchers' capability and skills. However, more support is needed since Pacific people make up only 3% of named individuals in the HRC-funded workforce (although 29% of these individuals are now classified as being senior researchers).[54]

Broader Science Sector Support

A stocktake of health research funded by the three main government science funding agencies from 2013 -2017 shows that while HRC is the primary government funder of Pacific health research. The National Science Challenges also contribute to this category (See Figure 4) In the broader health sector, only eight projects that identified as primarily relevant to Pacific health received approval from HDECs between 2014 and 2017.

National Strategies

Ala Mo'ui: Pathways to Pacific Health and Wellbeing (2014) set out a 5-year plan of the priorities to achieve better health outcomes for Pacific people, families, and communities. It aims to guide the health and disability sector in planning and prioritising methods for delivering high-quality services to Pacific people. The vision is that all New Zealanders, including Pacific peoples, will lead healthier and more independent lives. The four priority outcomes are that:

1. systems and services meet the needs of Pacific peoples;
2. more services are delivered locally in the community and in primary care;
3. Pacific peoples are better supported to be healthy; and
4. Pacific peoples experience improved broader determinants of health.

The holistic view of Pacific health recognises the impact of complex factors at the level of individual, community, the health and disability sector and the wider society.

The **Primary Care for Pacific People: A Pacific and Health Systems Approach (2012),** jointly funded by the Ministry of Health and the HRC, assessed how to increase Pacific peoples' access to and use of primary care and, ultimately, improve Pacific health outcomes. It recommended that publicly funded primary care organisations should provide appropriately anonymised data to enable the quality of health services for Pacific people to be improved; that data should be used to develop targeted interventions and local solutions; that evidence should inform action to achieve health equity and Pacific peoples; and that ethnic-specific research methodologies (e.g. the Talatalaga a Aiga model and the process of Talanoa) would help to promote the health of New Zealand's diverse communities.

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[54] HRC (2015) Annual Report, p 32.

5.0: Health of Asian peoples

As the number of people identifying as Asian is likely to exceed the number identifying as Māori from 2025, Asian health is an area in which New Zealand has a significant interest.

5.1 Burden of disease and health loss data

New Zealand's Asian population continues to grow and has almost doubled in size since 2001. In 2013, the percentage of New Zealand's population who identified as Asian was 11.8%.[55] The largest concentration of Asian people is in Auckland. Among this group, 30% were aged 20-34 years. Around 2% of Asian people living in New Zealand do not speak English.

Asian health is generally considered good, with Asian adults having comparatively low rates of obesity, mental health conditions, asthma, arthritis, and chronic pain.[56] This is possibly because Asian New Zealanders tend to be young and have yet to be affected by acculturation. This health advantage has previously been termed the 'healthy migrant effect',[57] and partly reflects health screening for immigrants to New Zealand.[58] However, longer periods of residence in New Zealand are associated with increased likelihoods of risk factors such as drinking alcohol, smoking, or being overweight or obese. Asian health trends are also affected by the fact that Asian people tend to underreport illness and health-care needs and engage less with primary health services than other adults.

The Asian ethnic group is very diverse and includes both Indian and Chinese people. Profiles within the health data differ depending on whether people were born in New Zealand or overseas.[59] Stereotypes and the 'averaging effect' may boost the health status of Asian people in New Zealand. When ethnic groups are disaggregated, concerns include high rates of cardiovascular disease and diabetes and low birth rates for Indian (South Asian) people, and a high risk of stroke among Chinese people.[60] Indians also have a higher prevalence of treated hypertension and high blood cholesterol than Europeans.

5.2 Government and policy response to the health of Asian peoples

A 2015 report, commissioned by the Health Promotion Forum of New Zealand (HPF)[61] noted that '*discourse on Asian health, including health promotion, is still relatively invisible on New Zealand's health agenda; its related policies and research.*'[62]

No summary on the health of Asian peoples is presented, because to date very little research has been targeted to this population despite the unique position they have in New Zealand.

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[55] Statistics New Zealand (2013) Quick stats "About National Highlights"2013

[56] Statistics New Zealand (2010)

[57] Wong, A. (2015), *Challenges for Asian health and Asian Health Promotion in New Zealand*. Health Promotion Forum of New Zealand.

[58] https://www.fmhs.auckland.ac.nz/en/soph/about/our-research/research-activities/healthy-migrant-status.html

[59] Wong (2015),

[60] Scragg and Maitra (2005)

[61] Wong (2015),

[62] *Ibid*, p. 3.

Summary of the health of people with disabilities

Strengths

(What we can build on)

- Good **information about knowledge needs and gaps.**
- **Mechanisms exist to change behaviour and promote greater inclusion** of disabled people in general health research.
- The **disabled community want to be engaged with health and disability research** and have given generously of their time in national consultations to help identify key issues and suggest solutions.
- **Current strategies outline the needs, aspirations and cultural differences of Māori and Pacific peoples.**
- Statistics New Zealand have improved the questions that will be asked in future surveys, meaning that **better data will be available to inform research and policy development.**
- The advent of **'big data' approaches and the development of skills to manage and analyse data will prove invaluable for disability research**. Work is currently underway to pull together cross-sectoral datasets using NHI numbers.

Weaknesses

(What we need to improve now)

- **Low capacity & capability** in the disability sector.
- **Few career development opportunities** for disability researchers – at any point in the career path.
- **Few avenues to disseminate existing disability research** – Ministry of Social Development have disestablished a journal that disability researchers previously relied on.
- Current disability and general health research **strategies do not include priorities for disability research.**
- There are no accepted **guidelines for inclusion of disabled people in general health research.**
- Up to this point, **little opportunity for people with disabilities to influence the research agenda and participate in health research** – 'nothing about us without us'.

Opportunities

(What we need to do)

- **Developing an acceptable model** for disability research and health research relevant to disabled people.
- Focusing on **social determinants of health that affect disabled people** – e.g. exclusion, unemployment, discrimination, and poverty.
- A large proportion of disabled people choose to live out of residential care with the 'New Model' of disability services, and need **innovative solutions to promote independent living.**
- There is a strong government emphasis on **working across sectors to find solutions** – this is particularly important for disability research and researchers.
- **Addressing the marked inequities in health outcomes** for disabled people, and seeking the knowledge and skills needed to address this.

Threats

(Longer-term issues)

- **Uncertainty about where disability research sits** (tensions between the medical model and the social model).
- **Disability research is not currently a focus** of any one research funding agency.
- Critically low workforce capacity means that there are **few senior researchers to recruit and mentor** emerging researchers.
- **Health research findings are often not accessible to the disabled community** because the media used are not sufficiently diverse to meet their needs.

6.0: Health of people with disabilities

One of the guiding principles of the NZHRS is 'collaboration for impact', including to *'involve communities, health consumers and disabled people in the research process'*. This speaks to the need to ensure that research priorities meet the needs of those living with disabilities and references the fact that people with disability are rarely included in the conceptualisation, conduct, or dissemination of research.

The social model of disability notes that society often fails to consider diversity in physical abilities, and thus creates an environment that is disabling. This is distinct from the medical impairment of the disability itself, which is the sole focus of the 'medical model' of disability - which seeks to ameliorate, eliminate, or prevent the impairment altogether.

The social model of disability challenges society to embrace the diversity of the human condition and expect, respect, and accommodate impairment in all aspects of life. This means removing physical, attitudinal, communication, social, and political barriers to differently abled people. The reality of the impairment is accepted, as is the impact on the individual, but prevention and treatment of a condition or injury that causes impairment is not considered to be disability research — it is health research.

> *"The social model seeks to change society in order to accommodate people living with impairment; it does not seek to change persons with impairment to accommodate society. It supports the view that people with disability have a right to be fully participating citizens on an equal basis with others."*
>
> People with Disability Australia

6.1 Burden of disease and health-loss data

Statistics New Zealand conducted a national Disability Survey in 2013,[63] which showed that 26% of New Zealanders identified as disabled. Māori have higher disability rates across all ages than European New Zealanders. The age-adjusted rate[64] for Māori was 32%; it was 26% for Pacific people, 24% for European people, and 17% for Asian people.

The statistics overleaf,[65] and the nature of the fundamental issues facing disabled people highlight the cross-sectoral nature of the challenges and inequities for the disabled community and the need for both researchers and service providers to collaborate if needs are to be met.

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[63] Statistics New Zealand (2014). Disability Survey 2013. Wellington: Statistics New Zealand. Available from http://archive.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx

[64] The age adjusted rate is the disability rate the ethnic group would have if their profile was the same as that of the total population

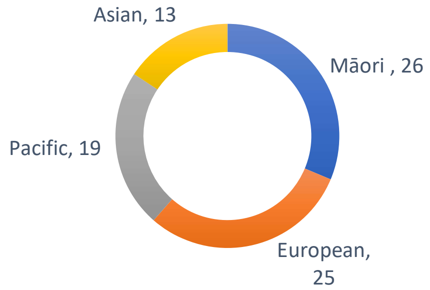
[65] All data sourced from either the Statistics New Zealand (2014). Disability Survey 2013. Wellington: Statistics New Zealand or the Convention Coalition Monitoring Group. (2015). Disability Rights in Aotearoa New Zealand: Acceptance in Society and Participation and Poverty, or reports on what disabled people in New Zealand say about their human rights. Findings of the Contract 2013-2016 with the Ministry of Social Development.

Figure 5: Infographic of key challenges and inequalities for disabled people in New Zealand.

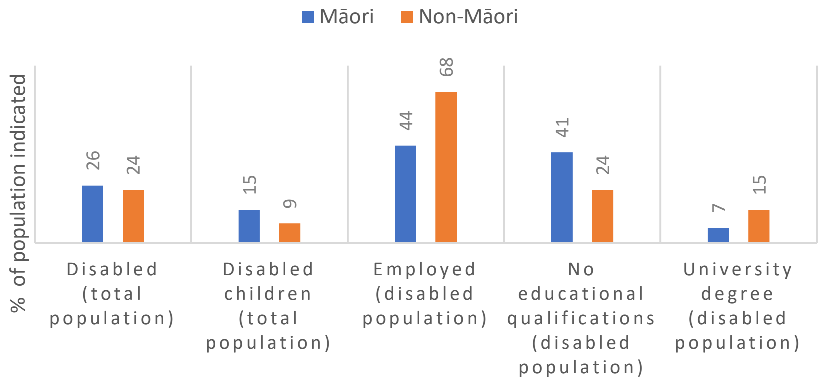
1.1 million people identify as disabled.

This figure is an under-estimate as it does not include those living with impairments who do not see themselves as disabled or are concerned about prejudice if they identify themselves as disabled.

Percentage disability rate for the for largest ethnic groups



Inequalities in outcomes for disabled Māori



Less than half of people disabled are employed

Compared to ¾ of non-disabled people – leading to social and economic disparities. Most disabled people work less than 30 hours a week.

Key health and disability service issues

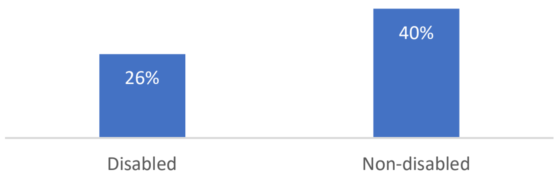
Disabled people:

- encountered **negative dignity**, **disrespect for difference**, **lack of autonomy**, **inequality**, **discrimination, segregation** and **isolation.**
- lacked **access to information** in alternative formats (e.g. easy reading).
- could not access mobile screening service vans.
- were **not informed of side-effects** of medications.

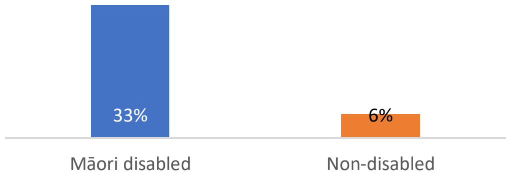
Issues of access included:

- **Denial of access to mainstream services** (e.g. breast and cervical screening and flu vaccinations)
- **Denial of access to treatments** for a range of illnesses
- Incorrect attribution of illnesses to the impairments (**diagnostic overshadowing**)

Identifying health as 'very good'



Identifying health as 'fair' or 'poor'



6.2 Government and policy response to disability health

The **New Zealand Disability Strategy 2016-2026**[66] signals clear directions for research and highlights that decision-making on issues regarding the health and wellbeing of disabled people should be informed by robust data and evidence. The Disability Strategy specifies that:

- researchers should actively consult and involve disabled people in the design and conduct of research that concerns their health and wellbeing;
- research should address issues that will make services for disabled people higher quality, more inclusive and more accessible, and
- take an ethical and informed approach to the participation and involvement of disabled people in research.

The research priorities set out in the Disability Strategy are to assess and improve the quality, inclusivity, and accessibility of services for disabled people, and to improve health outcomes for disabled people, with a specific focus on people with learning or intellectual disabilities.

Whāia Te Ao Mārama 2018 - 2022: The Māori Disability Action Plan. The New Zealand Disability Strategy states that most Māori disabled people (tāngata whaikaha) identify as Māori first, and disabled second. Cultural identity is paramount to them and defines how they live their lives in both Te Ao Māori and Te Ao Pākehā. The Ministry of Health's Māori Disability Action Plan[67] is predicated on this principle and sets six goals for tāngata whaikaha relating to inclusiveness, participating in the development of health and disability services, participating in Te Ao Māori and their communities, having control over support services for their disabilities, and living in informed and responsive communities.

Work towards the **Pacific Health and Disability Action Plan Review**,[68] showed that 72% of disabled Pacific people were living in the most socio-economically deprived areas, compared to just 42% of non-Pacific people with a disability. High levels of household crowding and low levels of household ownership contributed to a lower uptake of specialised equipment and residential modifications to support care for these people.

Support for disability research

> *"Health research is changing but disability is still an afterthought"*
>
> Stakeholder feedback: NZHRS Focus Group on Disability

There are very few opportunities for research funding or career development for disability researchers in New Zealand. Feedback expressed by members of the Disability Focus Group during consultation on the NZHRS revealed a tension between disability research and health of disabled people research. In reality, both are badly needed. It became clear that all researchers need to include disabled people in

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[66] Office of Disability Issues (2016). *New Zealand Disability Strategy 2016-2026.* Wellington: Ministry of Social Development.

[67] Ministry of Health. (2018a). *Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan*. Wellington: Ministry of Health.

[68] Ministry of Health. (2008). *Pacific Peoples' Experience of Disability: A paper for the Pacific Health and Disability Action Plan review*. Wellington: Ministry of Health.

health research, to ensure that it is truly representative and will deliver results that will help reduce the marked health inequalities for the disabled population and enable a truly inclusive society.

Disability research is often cross-sectoral and usually requires social science expertise. Social science research receives less funding than health research in New Zealand. There is no clear Government view on which agencies have a responsibility to fund disability research, and as a result, necessary infrastructure, and trained researchers, mentors, students, and leaders are all lacking.

> *"Nothing about us without us"* – *co-design and consultation is very important. A participatory action model is one best suited to disabled people. Weighting needs to be given to consulting with disabled people. Reviewers need to include disabled people."*
>
> Stakeholder feedback: NZHRS Focus Group on Disability

Summary of mental health

Strengths

(What we can build on)

- New Zealand **joined the Global Alliance for Chronic Diseases** (GACD) in 2017, which has identified mental health as a global development priority.
- A **Ministerial Inquiry into Mental Health and Addiction** is underway to identify unmet needs.
- 'Information, research, and evaluation' is one of five domains of workforce development targeted in the Ministry of Health's **Mental Health and Addiction Workforce Action Plan (2017–2021)**.

Weaknesses

(What we need to improve now)

- **Mental health research receives relatively little support** even though mental illness is one of the **major causes of health loss** in New Zealand.
- Data from the **Australian New Zealand Clinical Trial Registry (ANZCTR)** highlight that the observed number of registered New Zealand clinical trials in the field of mental health is only **55% of the expected number based on DALYs**.
- Mental health is the **main health challenge for youth.** Particularly addictive or substance use disorders (including alcohol and illegal drug use disorders), self-harm, anxiety, and depressive disorders.
- **Little progress has been made** on the effectiveness of services or outcomes identified as needing improvement in the Mental Health and Addiction Service Development Plan (2012–17).
- There are **inequalities in mental health outcomes** between different genders, generations, ethnic and socioeconomic groups. Māori adults are twice as likely as non-Māori adults to report a high or very high probability of having an anxiety or depressive disorder. The overall burden of mental health problems for Pacific people is double that of the overall population.

Opportunities

(What we need to do)

- Providing better care for people living with **mental illness, addiction, and dementia** – including care for their physical health – is a growing challenge for the health and social sectors.
- **Cultural and contextual factors (housing, physical wellbeing, and social wellbeing) need to be considered,** or the gap between the mental health status for Māori and non-Māori will never reduce.
- There is a need to improve the delivery of child and adolescent mental health services through **respectful partnerships**, **cultural support**, and **workforce development**.

Threats

(Longer-term issues)

- New Zealand's growing ageing population will see neuropsychiatric disorders (neurological disorders such as dementia, mental disorders, and addiction disorders) **become an increasing burden.**
- Mental health of migrants. Migration due to climate change (i.e. sea-level rises in the Pacific) and conflict, will see an increase in immigrants to New Zealand with the potential for an associated increase in **mental health disorders associated with displacement**.

7.0: Mental health

The NZHRS specifies that the priority setting process will take into account research that *'will improve health outcomes and address the burden of disease (e.g. in mental health); improve understanding of the various determinants of health, including social, environmental and occupational factors; and will contribute to achieving health equity across New Zealand's diverse populations and communities.'*

7.1 Burden of disease and health loss data

Mental illness is one of the major causes of health loss in New Zealand, with one in five people experiencing mental illness each year.[69] The most commonly diagnosed disorders are anxiety, depression, schizophrenia, and substance-use disorders.

Mental disorders feature in the top five leading causes of health loss in most age groups (based on percentage of total DALYs, 2013).[70] Young people (aged 15–24 years) and young adults (aged 25–44 years) are particularly affected, with most health loss being contributed by self-harm, addiction, depressive disorders, and anxiety disorders.

Causes of health loss vary with age, gender, and ethnicity, and mental disorders cause more health loss among females than males.[71] Rates of mental disorders are higher in woman across all age groups; however, more males die by suicide than females, with males and Māori both over-represented in suicide rates across all age-groups.[72] Māori adults are twice as likely as non-Māori adults to report a high or very high probability of having an anxiety or depressive disorder.[73] For Pacific peoples the overall burden of mental health problems is double that of the overall population.[74] Pacific young people are approximately twice as likely to have depression, be anxious, or to attempt suicide, compared with the rest of the youth population.

7.2 Government and policy response for mental health

HRC investment in mental health research

Between 2006 and 2017, the HRC allocated 9% of the total funding for Programmes and Projects to research focused on mental health or addiction. Related research, on the social determinants of poor health and risk factors (e.g. inequality, violence, abuse, neglect, trauma, isolation, or racism), represented 15.5% of the total Programmes and Projects funding from 2006 to 2017. In 2017, the New Zealand Government joined the Global Alliance for Chronic Diseases (GACD), which has identified mental health as a global development priority. The HRC's first GACD initiative, with the support of MBIE and the Ministry of Health, is to fund research worth up to $2 million to develop innovative strategies to support young Māori and Pasifika people who have mental health problems.

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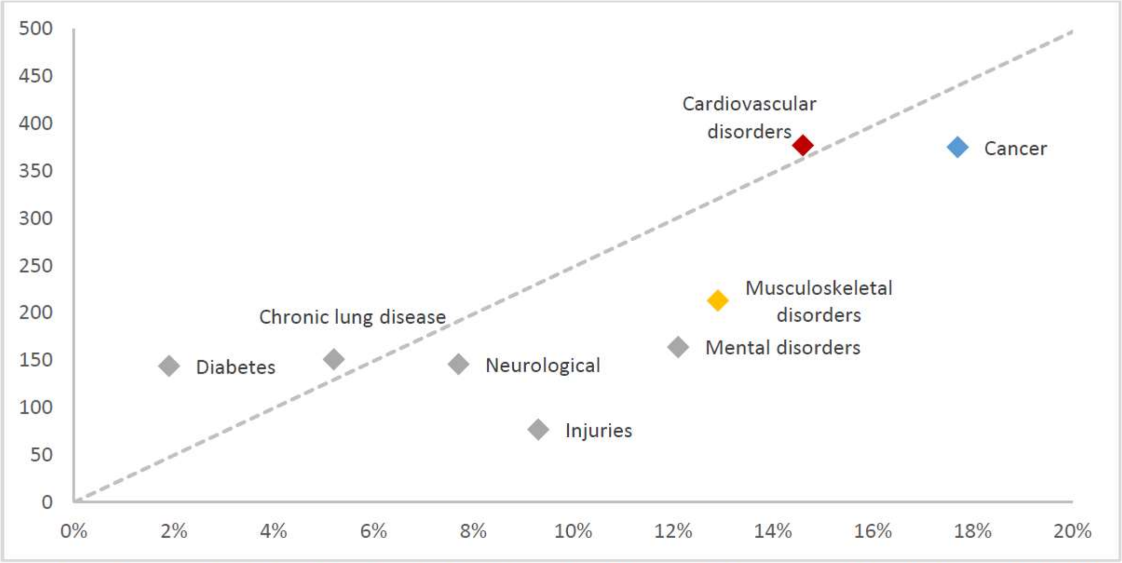
[69] Ministry of Health (2017a).
[70] Ministry of Health (2016a).
[71] *Ibid.*
[72] Ministry of Health (2017a)
[73] Ministry of Health (2015b),
[74] Statistics NZ and Ministry of Pacific Island Affairs (2011), *Health and Pacific Peoples in New Zealand- Pacific Progress.* Wellington: Ministry of Pacific Island Affairs and Statistics New Zealand. Available from http://archive.stats.govt.nz/browse_for_stats/people_and_communities/pacific_peoples/pacific-progress-health.aspx

Broader Science Sector Support

A stocktake of health research funded by the three main government science funding agencies from 2013 to 2017 shows that mental health disorders received relatively little support (Figure 4). This investment represents $71 per DALY (compared with $358 per DALY for cancer, for example – see Table 3). Data from the Australian New Zealand Clinical Trial Registry (ANZCTR) also highlight that the observed number of registered New Zealand clinical trials in the field of mental health is only 55% of the expected number based on DALYs (Figure 6). In the broader health sector, HDECs approved 43 mental health projects between 2014 and 2017, with a 1:2 ratio of interventional to observational studies.

Figure 6: Relationship between number of interventional clinical trials and relative burden of disease (%DALY) in New Zealand 2006–2015[75]



Diagonal line represents the line of equality, where %DALY is equal to trial number as a percentage of total registered trials. Markers below the line show conditions where the variable falls below the %DALY.

Support for mental health research

Rising to the Challenge: The Mental Health and Addiction Service Development Plan 2012-2017[76] identified the need to improve services for people with mental health and addiction issues through research on the effectiveness of services and the outcomes they delivered. A 2018 report from the Office of the Health and Disability Commissioner[77] identified little progress in achieving this plan, and the Government has subsequently launched an Inquiry into Mental Health and Addiction.

A **Ministerial Inquiry into Mental Health and Addiction** is underway to identify unmet needs and develop recommendations for a better mental health and addiction system for New Zealand. It will focus on equity of access to quality services and better outcomes, especially for

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[75] Figure extracted from report that draws on 2,485 New Zealand clinical trials registered on either the Australian New Zealand Clinical Trials Registry or the ClinicalTrials.gov registry between 2006 and 2015. Includes intervention trials with NZ listed as a recruitment country; excludes observational trials.

[76] Ministry of Health. (2012). *Rising to the Challenge: The Mental Health and Addiction Service Development Plan 2012–2017*. Wellington: Ministry of Health

[77] Health and Disability Commissioner. (2018). *New Zealand's Mental Health and Addiction Services: A monitoring and advocacy report of the Mental Health Commissioner*. Auckland: Office of the Health and Disability Commissioner.

Māori and other groups that have been previously identified as having the poorest outcomes, and its report is expected in October 2018.

'Information, research, and evaluation' is one of five domains of workforce development targeted in the Ministry of Health's **Mental Health and Addiction Workforce Action Plan**. Actions include developing the primary health, community, and specialist workforce, to design and deliver integrated and innovative responses to mental health.[78]

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[78] Ministry of Health. (2018b). *Mental Health and Addiction Workforce Action Plan 2017-2021* (2nd ed.). Wellington: Ministry of Health.

Summary of the health system and health research sector

Strengths

(What we can build on)

- The **National Health Index** (NHI) system assigns a unique number to people accessing all health and disability support services in New Zealand
- **NHI numbers are also linked to the Integrated Data Infrastructure (IDI) database** which provides an opportunity to study inequalities which is almost unparalleled internationally IDI data person-centred microdata from Statistics New Zealand survey and census data, government agencies and NGOs, to help target limited Government resources
- The **National Research Information System (NRIS)** will provide information on all research wholly or partially funded with government investment – leading to better co-ordination and connection across the health research sector
- A network of researchers, analysts and other helpful professionals has been established to gain value for the health and IDI datasets – **the Virtual Health Information Network**
- The **ethics and regulatory system** for health research in New Zealand is generally considered to be effective and safe.
- New Zealand has several **biobanks** that are crucial for research the **New Zealand Biobank** provides opportunities for research into rare diseases, the **Neurological Foundation Human Brain Bank** is an essential resource for research on degenerative neurological diseases, the **Middlemore Tumour Tissue Bank**, and the **Cancer Society Tissue Bank**
- A number of **DHBs have formed successful collaborative partnerships with University medical schools**
- New Zealand's **clinical trial process is advantageous** due to agile ethics and approval processes, diverse patient groups and research strengths
- **Trans-Tasman clinical trials networks** have been established in a wide range of clinical disciplines and disease groups
- There is strong research capability and a high degree of collaboration in the areas of the **National Science Challenges** and the Tertiary Education Commission **Centres of Research Excellence** (CoREs)

Weaknesses

(What we need to improve now)

- There is **no coherent set of signals for investment in health research**
- **Industry investment in research is low** compared to other OECD countries
- **Translation of evidence in to practice** is weak in New Zealand. National guidelines and principles are needed. Regional approaches could be adopted more broadly
- Translation of research findings is not considered to be the role of any one agency – so **resources, processes and mechanisms to support translation are missing**
- **Few clinical trials are registered** through the Australia-New Zealand Clinical Trials Registry
- **Joint appointments between universities and DHBs are currently only with doctors** and no other clinicians, such as nurses, pharmacists, physiotherapists and psychologists
- There is currently **no way to identify health research funded in New Zealand outside the remit of government purchase agents**
- The **health research system is not sufficiently 'linked-up' with end-users** in the health and commercial sector
- The **quantum of health services delivery research is small**, as is the capacity to conduct high-quality work
- The **funding for highly innovative and comparatively 'high-risk' research is limited**, as government funders tend to be conservative with public funds

Opportunities

(What we need to do)

- **Every clinical encounter is an opportunity to collect useful data** – and systems need to be designed so that all useful data can be used in research
- Create funding mechanisms that promote **multi-disciplinary approaches and early involvement of industry or healthcare providers**
- Explore mechanisms to **embed health research in the health system** e.g. formal arrangements to drive collaboration with end-users and integrated health research centres
- **Make research an integral part of the District Health Boards' business**, closely aligned with quality improvement and innovation.

- Research needs to be valued and 'normalised' by DHB and PHO management
- **Regulatory processes need to be in step with the directions of the New Zealand Health Research Strategy**, such as simple, consistent ethical rules that apply nationally
- **Greater involvement of patients in all facets of the research process and increased research literacy** in the patient population can help to improve care and change clinical practice
- Evidence shows that **clinical trials improve the clinical outcomes** of all those enrolled, treatment or control, and un-enrolled patients treated at the institution conducting the trial. **Research is also key in retaining clinical innovators and academics**
- Better **co-ordination and visibility of research activities enables capacities and infrastructures to be shared** across institutions and sectors – reducing costs
- **DHBs could form clusters with those facing similar challenges** and with similar populations e.g. rural location. They could then pull resources to identify innovative approaches and commission research
- **District Health Boards have no explicit mandate for clinical trials research**
- There is **no national network or co-ordinating body for clinical trials**
- **Tension between pharmaceutical companies and government bodies such as PHARMAC** mean reduced investment in clinical trials from industry. DHBs have also decreased sponsorship of clinical trials
- Develop a **mechanism to roll-out innovations across the DHB system,** and better co-ordinate research and innovation so that **knowledge diffuses across the system and unnecessary duplication is prevented**
- **Engage DHBs in both 'top-down' and 'bottom-up' research**
- **Pairing clinician-innovators with researchers** results in both better designed clinical research and better translation of findings
- **A clearing house of national and international knowledge** is key to translation of research findings
- Funding models are needed that **foster collaboration rather than competition** – to increase levels of multi-disciplinary research and translation of findings into policy and practice

Threats

(Longer-term issues)

- **Clinicians are disincentivised from engaging in research** through a lack of employer support and the long hours required to achieve this on top of clinical duties
- **Decreasing investment by pharmaceutical companies** in New Zealand clinical trials and decreased sponsorship of clinical trials by DHBs
- Some current **funding arrangements can inhibit joint Australia-New Zealand research programmes**
- **Providers are overwhelmed providing care** and don't have the resources or capacity to conduct research or implement findings, or the means to reduce costs and increase quality and efficiency of services.
- Poor co-ordination of research efforts means that **some population groups are seriously 'over-researched'**
- There are **very few health economists** in New Zealand to do the types of analysis needed to convince providers of the cost-effectiveness of research and demonstrate the economic returns from specific initiatives
- **Increasing costs and constrained budgets mean that health service providers see research as a luxury** that cannot be afforded, rather than a necessity.

8.0: New Zealand health system and health research sector

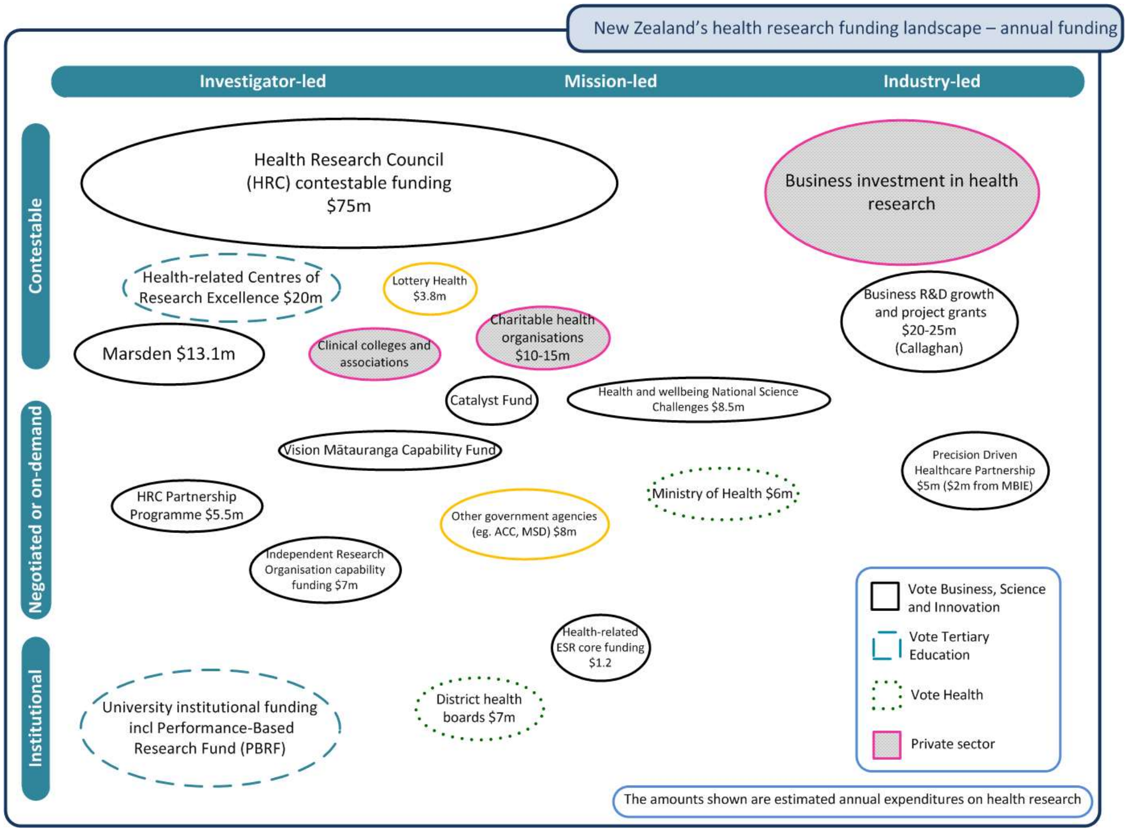
Priorities for health research should be considered in the context of the current infrastructure and capacity of the health research sector, and the ability of the health system to take up research findings.[79]

8.1 Government investment in health research

In 2016, total expenditure on health research in New Zealand was $362 million, accounting for 12% of New Zealand's expenditure on research and development (R&D). The higher education sector performs 57% of health research in New Zealand. The private sector is performing an increasing share of health R&D, rising from 26% in 2012 to 38% in 2016. However, R&D investment in health is low compared to other countries, primarily because the focus of New Zealand pharmaceutical manufacturers is on producing and distributing generic drugs, rather than novel drug discovery. Since DHBs, as independent Crown Entities, are not required to report on their research activities, only informal estimates are available that the value of research in DHBs is approximately $7–10 million a year.

Figure 7, below, shows best estimates for the sources of funding for health research in 2015.[80]

Figure 7: Sources of funding for New Zealand's health research in 2015



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[79] See section 1.4 of this paper for an explanation of thematic vs. structural priorities.

[80] Note, following the HRC Strategic Refresh (2015), in 2016 the HRC received a 50% increase on 2015/16 funding levels, taking funding to $93 million in 2017/2018, rising to $120.2 million in 2020/2021.

8.2 Government investment in health research infrastructure

In general, Government investment in research infrastructure is supported through full-cost funding of science contracts, with institutions primarily responsible for developing and maintaining research capability. However, the Government has developed research infrastructure through other platforms.

The **Strategic Science Investment Fund (SSIF)**[81] makes long-term investments in platforms of national significance, where the scale of data could not be feasibly collected and managed by a single institute. These include the National eScience Infrastructure (NESI) (high-performance supercomputing); Research and Education Advanced Network New Zealand (REANNZ) for (high-speed, high-capacity telecommunications for sharing resources and data); Genomics Aotearoa (a collaborative alliance between genomics and bioinformatics researchers and users such as health providers); and Nationally Significant Collections and Databases at Crown Research Institutes (CRIs).[82,83] MBIE is currently undertaking a review of the databases hosted by CRIs, which aims to evaluate the scope and role of such collections. Support for existing contracts is being continued while the review takes place.

The **National Health Index (NHI)** system assigns a number to every person who uses health and disability support services in New Zealand. This unique identifier (NHI number) links medical records of treatment and care across primary, secondary, and tertiary health-service providers. NHI numbers are also linked to the Integrated Data Infrastructure (IDI), providing rich research opportunities (e.g. to study inequalities).

The IDI is a database which centrally and securely links anonymised, person-centred microdata from Statistics New Zealand surveys and censuses, government agencies, and non-government organisations.[84,85] It has recently been expanded to include health data,[86] enabling researchers to address complex problems by linking frequently updated health data to economic and social data (e.g. education, welfare, crime, housing). Access to the IDI reduces the cost of research and assists Government with evaluation and costing exercises to help target limited Government resources. A barrier to including more patient data is the different IT systems currently used by DHBs and health providers, although moves to address this are underway.

The **National Research Information System (NRIS)** is currently under development, but once established will act as an information hub for research funded wholly, or in part, by Government. The System will allow the research community and the public, to easily identify what projects are underway, who is working on them, where to find experts in a given field, and

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[81] Before the Strategic Science Investment Fund was introduced in 2016, the Government's decisions to invest in national-scale research infrastructure were implemented on a case-by-case basis. The Fund aims to minimise gaps, overlaps, and limitations to support for high-priority science.

[82] Other platforms include the Australian Synchrotron, and geohazard monitoring.

[83] National Collections and Surveys relevant to health and disability are the responsibility of the Ministry of Health. See: https://www.health.govt.nz/nz-health-statistics/national-collections-and-surveys

[84] http://archive.stats.govt.nz/browse_for_stats/snapshots-of-nz/integrated-data-infrastructure/idi-data.aspx

[85] Atkinson, J., & Blakely, T., (2017) *New Zealand's Integrated Data Infrastructure (IDI): Value to date and future opportunities.* International Journal of Data Population Science, Issue 1, Vol 1. Proceedings of the IPDLN Conference (August 2016). DOI: https://doi.org/10.23889/ijpds.v1i1.124

[86] Health datasets in the IDI includes Ministry of Health National Collections data (e.g. hospital events and prescriptions) and encrypted NHI information.

where investment is focussed. This will help ensure better co-ordination and connection across the health research sector.

Ethics

Internationally, New Zealand is considered to have an effective ethics process for clinical trials. The New Zealand Public Health and Disability Act 2000 (Section 11) established a national system to review the ethical issues arising from health and disability research. The HRC's Ethics Committee (HRCEC) is responsible for accrediting other Committees around New Zealand, including four HDECs, which aim to ensure that research meets the standards of the National Ethics Advisory Committee (NEAC).[87] Researchers at tertiary institutions may also apply for ethics approval through Institutional Ethics Committees (IECs) (also accredited by the HRC).

An ongoing review of the Medicines Act is considering whether this regulatory framework should be extended to cover medical devices and technologies. It is also reviewing the ethical challenges associated with research on vulnerable populations; emerging technologies; data science; data sovereignty; new methodological paradigms; health research in the Pacific region; issues of privacy, participation, and confidentiality; changes in the regulatory environment; and the training and conduct of researchers.

Clinical trials and the Australian New Zealand Clinical Trial Registry (ANZCTR)

New Zealand has had a relative competitive advantage in clinical trials, due to its diverse patient groups, remote population, and scientific strengths and capabilities. However, the 2011 Report of the Health Select Committee '*Inquiry into Improving New Zealand's Environment to Support Innovation through Clinical* Trials'[88] made several recommendations for investment to improve infrastructure that have yet to be fully realised. Data suggest that since the Select Committee's report, investment by global pharmaceutical companies and DHBs has decreased. Reasons include PHARMAC's relatively low budget cap compared to other countries (which means new medicines are unlikely to be funded), the lack of incentives for research investment, and the lack of a coherent clinical trial network.

The NZHRS identifies the need to strengthen the clinical research environment.[89] The 2011 Inquiry recommended that the Government should work with key clinical leaders to develop a national strategy for clinical trials and research at DHBs, with the potential for DHBs to cluster research activities (e.g. Auckland, rural DHBs). Clinical trials are required to be registered, either on the **ANZCTR**[90] or an international approved registry.[91] A New Zealand-specific interface[92] has been designed to provide information to the public, health-care professionals, and industry about clinical trials in New Zealand.

8.3 Sector-led investment in health research infrastructure

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[87] For more information see: https://ethics.health.govt.nz/ethical-standards-health-and-disability-research

[88] https://www.parliament.nz/resource/en-z/49DBSCH_SCR5154_1/19f143ece9bbafc1f5970397e5d92a582e003faa

[89] This refers to the necessary human capital, financial support, facilities, patient participants, information systems, regulatory pathways, and institutional commitment.

[90] The Australian New Zealand Clinical Trials Registry is publicly owned and hosted by the University of Sydney. It receives funding in Australia from the National Health and Medical Research Council and the Federal Government, and from the HRC in New Zealand.

[91] See http://www.anzctr.org.au/ and https://www.clinicaltrials.gov/

[92] http://clinicaltrials.health.nz/, currently hosted by Callaghan Innovation.

Biobanks[93] are key infrastructure to support genetic research and require sustainable funding to maintain. In New Zealand, **biobanks** include the New Zealand Neurological Foundation's biobank[94] at the University of Auckland (which collects human brain tissue and cells along with clinical and physiological information); the Middlemore Tumour Tissue Bank, supported by Leukaemia & Blood Cancer New Zealand; and the Cancer Society Tissue Bank,[95] hosted by the University of Otago and the Canterbury DHB.

Trans-Tasman clinical trials networks have been established in a wide range of clinical disciplines and disease groups. The benefits of belonging to these co-ordinated networks include opportunities to increase the quality of research and access larger patient populations. The Australian Clinical Trials Alliance represents more than 50 clinical trials networks,[96] over half of which are bi-national with New Zealand. The Alliance is in the process of identifying and publishing **critical success factors for clinical trial networks,** and scoping a sector-wide **gap analysis** to guide targeted creation of new clinical trial networks.[97]

8.4 Connectivity between researchers and the health sector

Connection and alignment between researchers and the health sector (broadly defined in terms of the public health system, private health service providers, and the health industry) is key to ensuring that research is 'relevant' for the sector, with recommendation for increasing alignment between:

- health researchers with each other;
- health researchers and other research disciplines;
- health researchers and health system end-users (i.e. health professionals, healthcare providers, and patients);
- health researchers and community, including iwi;
- health researchers and the commercial health sector (i.e. pharmaceutical, medical device, and technology companies); and
- health research funding bodies with other research funders (domestic and international).

Enhanced collaboration would also help with translating and converting health research into health gains. Translation of research involves a multidisciplinary approach, early involvement with industry or health-care services (depending on the nature of the research), and a continuous focus on outcomes for patients and the wider community. There is growing will to not only establish 'connections', but to firmly embed health research within the health system, with integrated health research centres and more formal arrangements to drive collaboration with end-users, patients and industry (such as in the National Science Challenges).

Current HRC workforce analysis shows that over half of HRC contracts involve a practising clinician (58%), with approximately a third holding dual appointments within the tertiary

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[93] Systematic repositories of biological tissue with associated details about individuals' personal medical histories.

[94] https://www.fmhs.auckland.ac.nz/en/faculty/cbr/our-centre/human-brain-bank.html

[95] https://www.otago.ac.nz/mackenzie-cancer/tissue-bank/index.html

[96] http://www.clinicaltrialsalliance.org.au/wp-content/uploads/2015/12/ACTA_Networks_Report_2004-14_online.pdf

[97] There are currently notable absences of clinical trials in high burden areas, including CVD. Those that do exist represent various stages in maturity (in terms of capacity and capability).

sector and health sector. For the year 2016/17, 28% of new HRC-funded contracts were led by a principal investigator who is engaged in health delivery.

Other connections between researchers and the health sector include formal alliances between universities and DHBS such as the Auckland Academic Health Alliance (Auckland DHB and the University of Auckland)[98] and the Health Research South Alliance (University of Otago, Dunedin School of Medicine, and Southern DHB).[99]

8.5 Connecting health researchers with each other

The **Virtual Health Information Network**[100] is a network of researchers, analysts and other professionals, which has been established to gain value from New Zealand health and IDI data assets. The aim is to capture value by linking health data to enable research, development of policy, and planning and delivery of health services. The VHIN seeks to do this by building capability, quality and quantity of IDI analysis by sharing meta-data and code, new solutions, reducing duplication, and upskilling research in issues of data privacy and access. The Government-funded National Science Challenge on *'Healthier Lives – He Oranga Hauora'*, partly funds the VHIN as part of its efforts to capitalise on New Zealand health data.[101]

8.6 Translation and uptake of research findings

Dissemination and uptake of health research is highly dependent on the culture that underpins the health system and the institutions and individuals working within it. An embedded research and innovation culture in the health sector is a prerequisite for maximising the results of research, as detailed in Strategic Priorities 2 and 3 of the NZHRS.

Three factors influence the pace and level at which innovations diffuse throughout the health-care system – system characteristics, institutional factors, and front-line culture (outlined in Figure 8, below).[102] Institutional and cultural factors at the organisational level can change relatively quickly, while system characteristics take longer to change. Data show that uptake of new innovations in health services currently takes, on average, 17 years, and anecdotal evidence suggests that successful pilots at the DHB level are rarely scaled up or put into practice due to lack of strategic guidance or access to centralised information.[103]

In the HRC's 2016 and 2017, annual funding rounds, 41% of research could be classified as translational (able to be applied in the short to medium term or 'transformative' from one 'pipeline' category to the next).

Figure 8: Diffusion of Healthcare Innovation Framework

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[98] http://www.aaha.org.nz/en.html

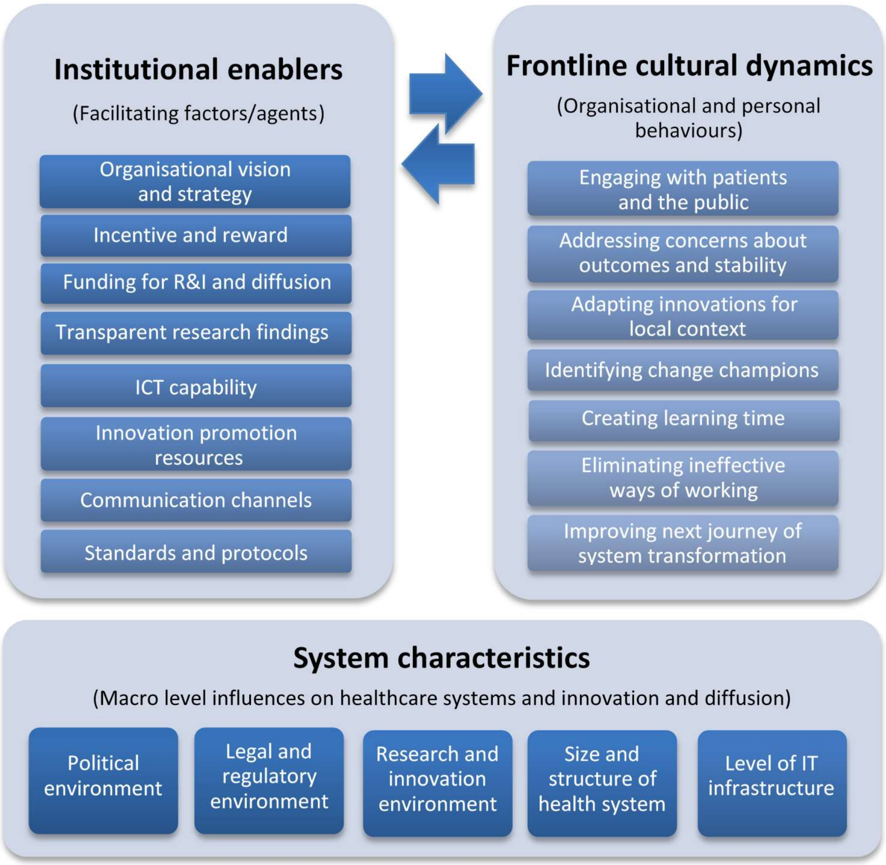
[99] https://www.otago.ac.nz/health-research-south/index.html

[100] The Network includes Massey, Auckland and Otago Universities and the Ministry of Health.

[101] https://healthierlives.co.nz/research/capitalising-on-new-zealands-health-data/

[102] Professor the Lord Darzi of Denham and Parston, G., (2013), *Global Diffusion of Healthcare Innovation Accelerating the Journey: Report on the Global Diffusion of Healthcare Innovation (GDHI) Working Group.* London: United Kingdom, Imperial College London, pp. 5-6.

[103] HRC (2016) Written communication to MBIE Science Policy, May 2016



8.7 Gaps in New Zealand's health research infrastructure

The consultation process undertaken to inform development of the NZHRS identified gaps in New Zealand's health research infrastructure, which if not addressed, could limit the uptake of the national health priorities.

The health research community perceives a need to not only strengthen the existing infrastructure, but to build more capacity and capability in the sector, through support and investment to address gaps in existing infrastructure:

- Ways to use existing data and evidence
- Clinical trial infrastructure
- Data infrastructure for longitudinal studies
- Data sharing and open access
- DHB support for and engagement in research
- Private-sector engagement in research
- Support for emerging and mid-career researchers
- Ways to translate research into clinical Guidelines or treatment pathways
- Incentives for collaboration (to balance competition)
- Systems to support an innovation culture
- Integration of health data
- International partnership opportunities

- Long-term stable funding platforms
- Methods to reduce waste and duplication in research
- Specialists in dissemination of research
- Efforts to increase research literacy
- Research translation centres/clearinghouses.

Summary of the commercialisation of health research

Strengths

(What we can build on)

- The medical devices and **health technology sector is one of the most commercially successful** in New Zealand – contributing an estimated **$1.3 billion to the economy.**
- There is a **considerable workforce** associated with the NZ health technology sector, with **3089 people employed in permanent roles** in businesses in 2015.
- There are approximately **140 medical device and health IT companies** in NZ.
- NZ was ranked as **number three on the list of the world's leading biotechnology countries for infrastructure and capabilities** by the Scientific American scorecard in 2015.
- NZ's **huge potential in the Health and Life Sciences start-up sector** has been internationally recognised – **ranked fourth in the world for biotech potential** in 2018.
- The **Consortium for Medical Device Technologies** – a national industry network – partners with universities and Callaghan Innovation to support innovation.
- MBIE supports the **Commercial Partner Network (CPN). KiwiNet** is part of CPN, uniting 16 publicly funded research organisation to provide support for ideas, training and connection with markets.
- Universities have developed commercialisation arms to assist their researchers in engaging with industry and commercialising their findings.
- The **New Zealand Health Innovation Hub** (a partnership between Auckland, Canterbury and Counties Manukau DHBs) aims to improve national performance through connecting pockets of innovation and giving them greater visibility.

Threats

(Longer-term issues)

- Innovative medical technology and pharmaceutical research is **complex to commercialise**, not least to ensure the safety and efficacy of new products.
- Typical **'travel time' from lab-based discovery to trial is approximately 20 years** in biomedical fields. This requires a long-term view from government funders.
- **DHBs have no mandate to drive innovation** and are not readily able to participate in potentially win-win partnerships because **frontline staff that could support such objectives are fully committed to service provision.**

Weaknesses

(What we need to improve now)

- **Gaps remain in existing partnership models with industry**, which focus on particular areas of research.
- **Health providers do not actively engage in, drive or demand innovation.**
- **Procurement rules and lack of infrastructure limit the ability of DHBs to innovate** through co-creating technologies with clinical validation or taking them up as early adopters.
- **There is no agreement on who should pay the cost of validating health technologies**. DHBs are not in a position to subsidise industry and smaller biotech and medtech companies are not in a position to pay.
- **The health sector does not evaluate and adopt medical technologies systematically.**
- The **Performance-based Research Fund (PBRF) can be a disincentive to commercialisation**, because this means deferring publications that are crucial for career advancement and PBRF scores.

Opportunities

(What we need to do)

- The NZ Institute of Economic Research recommends **prioritising areas of science where there is the potential to deliver advanced technology products.**
- Government funders can send a co-ordinated message that **good health outcomes require research and innovation** – and these must be viewed together.
- **The health system can be proactive rather than reactive – identify the questions they want answered and the outcomes that they need** and partner with researchers and industry to find solutions.
- **Develop a concept of a health technology industry** and recognise that this is a burgeoning area of the economy that needs coherent policies.
- **Take an 'action-orientated' view of the commercial sectors engagement in health research** and see the sector as a critical partner in developing the thinking and priorities that lead to more effective health outcomes.

9.0: Commercialisation of health research

New Zealand has accrued strength and capacity to commercialise health research in some areas such as the medical technology sector; further investment may be required in other areas. Action One specifies that the priority-setting process must consider research that has the potential to be disruptive and is highly novel and innovative; however, this may be affected by existing capabilities and infrastructure.

9.1 New Zealand's health technology sector

The medical devices and health technology sector is one of the most commercially successful in New Zealand, and in 2015 contributed more than a quarter of export earnings to our high-tech manufacturing sector (NZ $1.3 billion).[104] Health technology is also New Zealand's largest and fastest growing technology sector in dollar terms, with an average revenue growth of 29% for companies developing medical devices and 35% for those working on health information technologies.[105]

The *New Zealand Health Technology Review 2016*[106] reported that companies spent $129 million on R&D in 2015 (mainly health IT and medical devices) with 83% of this spent locally. Most of the devices were relatively low risk for regulatory approval.

The New Zealand Institute of Economic Research (NZIER) states that New Zealand should prioritise areas of science where it can play a leading role and deliver products of advanced technology.[107]

9.2 Innovation and commercialisation of health research

Research to develop medical technology and pharmaceutical products is complex to commercialise, not least because of the need to ensure the safety and efficacy of new products. A typical 'travel time' from lab-based discovery to the trial of a clinical solution is approximately 20 years (although, much shorter in newer, non-biomedical fields, such as health informatics), which far exceeds the duration of the priorities set for national health research.

However, commercialisation of health-related R&D presents significant potential for economic gain for New Zealand. New Zealand has a few large firms specialising in healthcare solutions, including Fisher and Paykel Healthcare, Douglas Pharmaceuticals, Orion Health, and NZ Pharmaceuticals Ltd. However, its health-research capabilities are primarily constituted by a range of small-to-medium enterprises, often affiliated with tertiary education institutes; developing support structures for this has been a challenge. MTANZ (the Medical Technology Association of New Zealand) reports around 140 medical device and health IT companies in New Zealand.

In 2015, the Scientific American scorecard ranked New Zealand as number three on its list of the world's leading biotechnology countries, in terms of infrastructure and capabilities.[108] New

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[104] New Zealand Health Technology Review (2016) *New Zealand companies innovating to improve people's health.* Auckland, New Zealand: New Zealand Health IT.

[105] New Zealand Health Technology Review (2016).

[106] https://www.cmdt.org.nz/file/file5767093a7b4d1/open.

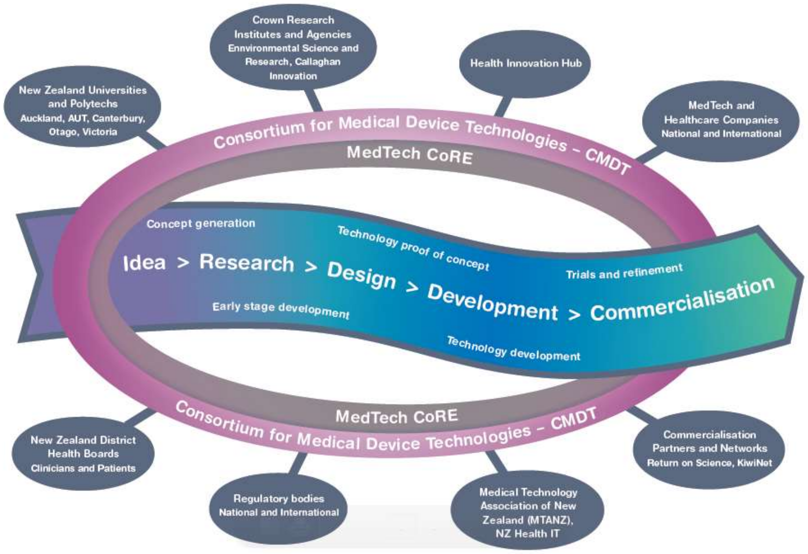
[107] HRC (2015) Investment Impact Report

[108] Scientific American (2015). *Worldview Scorecard - A global biotechnology perspective* p 36-65.

Zealand ranked first as the most PhD graduates in life sciences per capita. More recently, the Global Start-up Ecosystem Report 2018[109] also highlighted New Zealand's huge potential in the health sector, with the Health and Life Sciences start-up sector ranked fourth in the world for biotech potential, with activity clustered primarily in contract manufacturing and wellness.

Mechanisms to support the connections between research and industry in the medical technology sector (Figure 9) include Callaghan Innovation's MedTech cluster, the Consortium for Medical Device Technologies, and the MedTech Centre of Research Excellence.

Figure 9: New Zealand Health Innovation Pipeline and Ecosystem



MBIE funds some 'secondary agencies' that aim to transform science findings into commercially viable products. One key entity within MBIE's Commercialisation Partner Network (CPN) is KiwiNet, comprising 16 publicly funded research organisations[110] which collaborate to offer investment and support for commercialisation of ideas; to train researchers; and to connect them with markets and investors. KiwiNet's collaborative approach strengthens both research commercialisation and research organisations.

Another CPN entity is Return on Science,[111] a research commercialisation programme that offers researchers access to capital as well as expert guidance on topics ranging from assessment of the commercial potential of projects to strategic advice on managing the process of translation. Between them, KiwiNet and Return on Science aim to aggregate the technology transfer activities of all publicly funded research organisations around New Zealand. They have overlapping and complementary functions. MBIE is currently conducting a review of the CPN, which is due to be completed by mid-2019.

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[109] Startup Genome. (2018) *Global Startup Ecosystem Report 2018: Succeeding in the new era of technology*. Startup Genome LLC.

[110] KiwiNet's partners are Plant & Food Research, Callaghan Innovation, AgResearch, Otago Innovation, Landcare Research, Lincoln University, University of Canterbury, Viclink, WaikatoLink, AUT Enterprises Ltd, Cawthron Institute, Environmental Science & Research, NIWA, Scion and GNS Science.

[111] http://www.returnonscience.co.nz/

Academic researchers can struggle to find time to pursue commercial outcomes for their research, or to engage with business.[112] Research commercialisation services based within Universities offer a range of services including management of intellectual property, negotiation of contracts, access to technical experts, advice on funding and investment sources, and connections with industry and market data. Such hubs include **Auckland UniServices Limited** at the University of Auckland; **Otago Innovation Limited (OIL)** at the University of Otago; **AUT Enterprises Limited** at Auckland University of Technology; **Viclink** at Victoria University of Wellington; the University of Canterbury's Research and Innovation team. A large proportion of the research commercialised by these organisations tends to stem from health research; for example, in 2014, 37% of Auckland UniServices revenue was related to health.

The **New Zealand Health Innovation Hub[113]** was established in 2012 to help Auckland, Canterbury, and Counties Manukau DHBs to commercialise research developed by DHB employees. Other service innovation hubs within DHBs, include the Ko Awatea centre of excellence for education and innovation in health systems and services delivery, which partners strategically with Universities, and Middlemore Clinical Trials which has a partner agreement with Counties Manukau DHB allowing them to locate themselves in Middlemore Hospital and access clinical investigators and trial participants. There is great health sector innovation happening in New Zealand, however it is happening in pockets. Some connections and collaborations are occurring, but not consistently or with great visibility. The network aims to start addressing these issues by quickly connecting people and enabling connected conversations.

The New Zealand Health Research Strategy set strategic priorities for the science and innovation sector, one of which is to '*advance innovative ideas and commercial opportunities'* (Strategic Priority 4). MBIE is leading Strategic Priority 4, with the support of the Ministry of Health and the HRC. As part of this, MBIE is asked to *'create more industry partnerships'* and '*strengthen platforms for commercialising innovations'* (Action 10), including sourcing *'capital for advanced pre-clinical work and early phase clinical trials'* to enable commercialisation of new innovations.

As part of the implementation of these Actions, in the coming months the NZHRS Working Group will be bringing together key players across the health sector (DHBs, Universities, government agencies, industry, and commercialisation services). The purpose is to co-design collaboration and partnership models across the sector to advance innovative ideas and commercial opportunities from health research. New Zealand has a few good examples of partnership models with industry, research organisations and DHBs working together (for example the CMDT). However, these are focused on particular areas of research (i.e. MedTech) and significant gaps remain. Particularly with regards to the integration of DHBs with health researchers and industry providers. The workshop aims to identify what barriers are preventing these partnerships to form, and what role government might play to foster their formation.

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[112] http://www.educationreview.co.nz/magazine/september-2013/the-changing-face-of-new-zealand-research/#.VrJzlzZum70

[113] http://innovation.health.nz/

Summary of the international context

Strengths

(What we can build on)

- Based on publication measures, NZ is internationally competitive in **Clinical Sciences** (gastroenterology and hepatology, anatomy, rheumatology, surgery, nephrology, urology and critical care and intensive medicine), **Paediatrics and Reproductive Health** and **Immunology.**
- **NZ researchers are good at building connections and linking in to the global research effort**, with the rate of international collaborations well exceeding the world average at 52% of publications including an international collaborator.
- Major discoveries have also resulted from the work of New Zealand scientists in **neuroscience and from our multidisciplinary longitudinal studies**, particularly the Dunedin Multi-disciplinary Health and Development Study, which is an international resource.
- **NZ has world-class expertise in drug discovery** and national resources, such as The Malaghan Good Manufacturing Practice facility, GlycoSyn and MARS medical imaging.
- **We have high capacity to do FDA compliant trials fast and cost-effectively.**

Weaknesses

(What we need to improve now)

- **No detailed dataset of our international engagement/collaborations is available** as a resource for planning to ensure that we have the linkages in place to conduct research infields such a genomics, personalised medicine, rare diseases, neurotechnology, and big data.

Opportunities

(What we need to do)

- Involvement in international research builds research capacity and maintains research quality through **engagement with top international teams.**
- **Linking with international clinical trials** allows New Zealand patients access to the latest treatments and diagnostics.
- **Develop a more co-ordinated approach to international connections** and leadership to set-up and support the direction of international networks and collaborations.
- **Establish collaborations around the 9 targets of the United Nations Sustainable Development Goals** under Health and Wellbeing, which NZ must meet by 2030.
- The **development of new drugs, diagnostics, treatments and medical technologies by the pharmaceutical and medical technology sectors requires swift clinical trial processes** to achieve timely translation of benefits to the healthcare system. New Zealand is well place to do this.

Threats

(Longer-term issues)

- There are several **long-term issues that will require a pooling of global expertise across disciplines and a co-ordinated response**, these include: climate change, environmental health, pandemics and zoonoses, re-emergence of previously contained infections, antibiotic resistance, migration, and diseases of ageing and the science of ageing well.

10.0: International context

In relation to how New Zealand health research engages in the international context, Action One of the NZHRS states that the priority-setting process should consider research priorities that:

- respond to new and emerging threats to health
- are in an area where New Zealand has international standing or leadership
- have the potential to be disruptive and are highly novel and innovative
- complement offshore research
- are in an area in which New Zealand has significant interest (such as Pacific health research).

10.1 New Zealand research on the international stage

Based on bibliometric analyses from both HRC[114] and MBIE[115] New Zealand has several outstanding health research strengths.[116] Areas in which New Zealand research can be considered internationally competitive (based on the percentile ranking data and the relative citation impact data) include Clinical Sciences, Paediatrics and Reproductive Health, and Immunology**.** Drilling further into the 'clinical sciences' strength, based on average normalised citation impact score (MNCS),[117] New Zealand is particularly strong in the areas of gastroenterology and hepatology, followed by anatomy, rheumatology, and surgery. The percentage of New Zealand publications in the top 1% within the medicine field include gastroenterology (5.91), hepatology (5.39), rheumatology (4.45), critical care and intensive care medicine (4.43), surgery (3.68), urology (3.66) and nephrology (3.23). New Zealand outperforms other small advanced economies[118] in 15 fields of health research (based on average field-weighted citation impact).[119]

10.2 International connections and collaborations

New Zealand's remoteness means that our researchers need to be good at building connections to link into the global research effort, and access the data, equipment and expertise that the best collaborations afford them. They can contribute new methods and ideas that advance research beyond our boundaries. The ability of our health researchers to link into international studies also means that New Zealand patients can access the latest in medical diagnostics, treatments and advances. New Zealand health researchers appear to be well connected internationally, with Leiden rankings[120] that exceed the international average (52% rate of international collaboration on publications compared to a world average of 35%).[121]

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[114] HRC (2015). *Quantifying quality – the evidence: An analysis of the impact of HRC-funded research publications between 2005-2009.* Auckland: The Health Research Council of New Zealand.

[115] MBIE (2015). *The National Statement of Science Investment (NSSI) 2015-2025.* Wellington: MBIE.

[116] We acknowledge the valid criticism of relying too heavily on bibliometrics (publication counts, citation analysis) as a proxy for research quality. This data is provided for consideration alongside the further contextual information presented later in the chapter (not to be considered in isolation).

[117] MBIE system performance report – Scopus database: New Zealand Comparative Advantage within the MEDICINE field[117] Data source: Scopus Custom Data, 2002-2016 publications (articles, conference paper, review), extracted June 2017.

[118] The Small Advanced Economies Initiative includes New Zealand, Ireland, Israel, Finland, Norway and Singapore

[119] MBIE (2015, p.36).

[120] The Centre for Science and Technology Studies at Leiden University in the Netherlands publishes the rate of collaboration identified through indexed publications analysed across 500 universities.

[121] HRC (2015).

New Zealand's involvement in international research collaborations offers significant opportunities to build our health research capacity and maintain research quality through engagement with top international research teams. There are also real benefits to be leveraged by gaining access to infrastructure and resources not yet available in New Zealand, including equipment, technology, data, and IP — enabling New Zealanders to be early adopters of worldwide medical advances. Our international linkages also increase the opportunities for our researchers to access international funding streams and to attract international investment to New Zealand. For example, New Zealand has grown world-class expertise in drug discovery, with international collaborations and world-renowned expertise. The Malaghan Good Manufacturing Practice (GMP) facility, GlycoSyn[122], and MARS medical imaging are all national resources with high productivity of clinical trials, and high capacity to do quality FDA-compliant trials fast and cost-effectively.

However, in the health research sector there is no detailed dataset of our international engagement and collaborations, which could enable Government and others to determine the level of funding that should be going to support collaborative international research versus funding New Zealand-based research. International collaborations, involving academia, health sector, and industry, are likely to become increasingly important to enable research in fields such as genomics, personalised medicine, rare diseases, neurotechnology, and big data.
Given that so many new health innovations arise from research undertaken offshore, it could be cost-effective for New Zealand to identify ways to better connect with international research, to speed up translation of innovations into frontline health services. Improved identification of when New Zealand needs to engage in researching a health topic, rather than relying on current, proposed or past research undertaken internationally, could also enable funding to be better targeted to areas where New Zealand health research has a comparative advantage.

10.3 New Zealand's role in global health

The contribution that New Zealand can make to global health is bounded by our international treaty obligations, the knowledge and retention of our health researchers and our ability to provide key research to contribute to the global health knowledge.

There are multiple global strategies, human rights treaties,[123] and priorities pertaining to health such as the United Nationals Sustainable Development Goals (SDGs) and the GACDs. The priorities of many of these agreements and partnerships are informed by the Grand Challenges identified by a Delphi panel recruited from fifty countries around the world and published in Nature in 2007.[124] The Grand Challenges focus on chronic NCDs and highlighted the need to address the burden of CVD, type 2 diabetes, chronic respiratory diseases, and certain cancers. This group of conditions cause the greatest global share of death and disability, accounting for around 60% of all deaths worldwide.[125] In low- and middle-income countries, the burden is especially significant and is projected to rapidly rise.

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[122] GlycoSyn is the discovery and GMP manufacturing arm of Callaghan Innovation.

[123] Information on New Zealand's International Obligations available on the Human Rights Commission website at https://www.hrc.co.nz/your-rights/human-rights/international-human-rights-legislation/international-obligations/

[124] Daar et al. (2007). *Grand Challenges in Chronic non-communicable diseases*. Nature. (450): 494-496.

[125] Further information available from https://www.gacd.org/about/history

Summary of future and emerging trends

Strengths

(What we can build on)

- The **Precision Driven Health** Partnership is one of the **largest data science research initiatives** in NZ, between Orion Health, DHBs and the HRC (supported by MBIE). The research **involves applying new data science techniques to understand the data** being captured on an individual by health information systems, consumer devices, social networks, genetic testing and other sources. It will lead to **improved decision support tools for healthcare professionals**. It will also help **foster the health research workforce in data science** for New Zealand.

Weaknesses

(What we need to improve now)

- The ad **hoc implementation of genetic technology in clinical and research settings** means omics-based technologies are sometimes unregulated and the market is disorganised.
- **Research infrastructures** are needed to support omics-based technologies, including for the storage, analysis, and handling of data, and **ethics and privacy** regulations or protocols.

Opportunities

(What we need to do)

- To prepare for the potential, unpredictable **emergence of communicable diseases** in New Zealand, due to **new or changing organisms.**
- To **develop research capacity** and link our researchers to global expert networks as **transboundary problems** that have potential to affect health in New Zealand **can only be addressed with international cooperation**.
- To play a key role in the international collective action in **pandemic preparedness** and control methods such as a universal influenza vaccine, surveillance, and response systems, and production capacity for drugs and vaccines ahead of an outbreak.
- T make NZ's use of **big data** more efficient by enhancing **its interoperability and the standardisation of different datasets**, which will also improve the delivery of health services and maximise the opportunities for care and treatment provided through seamless access to timely patient information, diagnostics, and care arrangements.

Threats

(Longer-term issues)

- **Antimicrobial resistance** threatens the effective prevention and treatment of an increasing range of infections caused by bacteria, parasites, viruses, and fungi, with **research needed to find solutions**.
- **Climate change** will have numerous impacts on health, including for New Zealanders (e.g. the **re-emergence of infectious diseases** through an increase in immigrants to NZ).

11.0: Future and emerging trends

The priority-setting process will have to consider research that responds to new and emerging threats to health; has the potential to be disruptive; and is highly novel and innovative.

11.1 What is on the horizon?

Of all global health priorities, control of infectious disease (including microbial antibiotic resistance) and the health impacts of climate change stand out as emerging global, transboundary problems that have potential to affect health in New Zealand and can only be addressed with international cooperation. New Zealand must develop research capacity and link its researchers to global expert networks. New Zealand must also prepare for the potential, unpredictable emergence of communicable diseases in New Zealand, due to new or changing organisms.

11.1.1 Health impact of climate change

Climate change affects the social and environmental determinants of health – clean air, safe drinking water, sufficient food, and secure shelter. Between 2030 and 2050, climate change is expected to cause approximately 250,000 additional deaths per year, from childhood under-nutrition, malaria, diarrhoea, and heat stress in elderly people. The direct costs to health (i.e. excluding costs in health-determining sectors such as agriculture, water, and sanitation) are estimated to be US$2-4 billion/year by 2030. Areas with weak health infrastructure – mostly in developing countries – will be the least able to cope without assistance to prepare and respond.[126]

Natural disasters and variable rainfall patterns result in rising sea levels and extreme weather events. Floods are also increasing in frequency and intensity, and this trend is expected to increase throughout the 21st century. Floods contaminate the fresh water supply, heighten the risk of water borne diseases, create breeding grounds for disease-carrying insects, cause drownings and physical injuries, and disrupt the supply of health and medical services. While all populations will be affected by climate change, some groups are more vulnerable than others, including:

- small, low-lying island states and coastal regions;
- megacities;
- mountainous and other polar regions;
- children, particularly those living in poor countries; and
- areas with weak health infrastructures.

11.1.2 Climate change refugees and migrant health

Rising sea levels will cause loss of land and displacement of communities that live near the sea. Migration due to sea-level rises (particularly in the Pacific) will see an increase in immigrants to New Zealand, with the potential for an associated introduction of infectious diseases. There is an

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[126] Key facts on climate change and health available on the WHO website at http://www.who.int/en/news-room/fact-sheets/detail/climate-change-and-health

increased likelihood of vector-borne diseases[127] and waterborne diseases[128] spreading to New Zealand.

In 2015, the World Health Organization (WHO) endorsed a new work plan on climate change and health which includes two important objectives that may inform the process of setting health research priorities in New Zealand:[129]

1. Science and evidence: to co-ordinate reviews of the scientific evidence on the links between climate change and health and to develop a global research agenda.
2. Support for implementation of the public health response to climate change: to assist countries to build capacity to reduce health vulnerability to climate change and promote health while reducing carbon emissions.

11.1.3 Infectious diseases

Infectious diseases remain the leading cause of death and DALYS worldwide. Population growth, with expanding poverty, urban migration, increased movement of refugees, increasing international travel, and rapid advances in technology all affect the risk of exposure to infectious diseases and infection transmission within and between countries.

New human pathogens have emerged, and previously 'controlled' diseases have re-emerged or expanded their range.[130] Epidemic prone diseases such as Cholera, yellow fever, and epidemic meningococcal diseases – diseases that previously were thought to be largely eradicated – have made a comeback. Severe Acute Respiratory Syndrome, avian influenza in humans, Ebola, Marberg haemorrhagic fever and Nipah Virus have also spread rapidly. Importantly, there are emerging pathogens that have recently spread worldwide (such as chikungunya and Zika viruses), which are already present in the Pacific Islands and which could become more of a risk in New Zealand if climate change allows important disease-transmitting mosquitos to become established here.[131]

There is evidence to show that the spread of infectious and preventable diseases in New Zealand is attributable to New Zealand's poor housing stock, crowding in houses, low socio-economic status and correlated Deprivation Index deprivation levels. Ethnic and socio-economic inequalities are large and rising, with markedly higher rates of infectious diseases for Māori and Pacific peoples relative to European or other ethnicities.[132] These infectious diseases include respiratory, skin, and enteric infections.

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[127] Vectors are living organisms that can transmit infectious diseases between humans, or from animals to humans (commonly blood-sucking insects such as mosquitos). Further detail available from http://www.who.int/news-room/fact-sheets/detail/vector-borne-diseases

[128] Caused by bacteria, viruses, and protozoa such as Giardia and Cryptosporidium.

[129] WHO Workplan on Climate Change and Health. Aims and Objectives: 2014-2019. Endorsed by the Executive Board of the World Health Organization at its 136th Session, February 2015. Available from http://www.who.int/globalchange/health_policy/climate-change-and-health-workplan-2014-2019.pdf

[130] McVernon, J., Sorrell, T. C., Firman, J., Murphy, B., & Lewin, S. R., *Is Australia prepared for the next pandemic?* Med J Aust 2017; 206 (7): 284-286.

[131] Royal Society Te Apārangi (2017). *Human Health Impacts of Climate Change for New Zealand: Evidence Summary*. Wellington: Royal Society Te Apārangi (p.10).

[132] Baker, M.G., McDonald. A., Zhang. J., & Howden-Chapman, P. (2013). *Infectious diseases attributable to household crowding in New Zealand: A systematic review and burden of disease estimate*. Wellington: He Kainga Oranga/ Housing and Health Research Programme, University of Otago, 2013.

11.1.4 Pandemic planning

A number of viruses have pandemic potential. In terms of persistence, versatility, potential severity, and speed of spread, few viruses rival the influenza virus. Over the past decade, sporadic cases of severe influenza and deaths in humans have been caused by several avian influenza A viruses, including the H5N1 virus (first detected in 1997), and the H7N9 and H10N8 viruses (first reported in 2013). Endemic in a number of species, including humans, birds, and pigs, influenza virus cause annual outbreaks punctuated by occasional worldwide pandemics, which are characterised by sustained community spread in multiple regions of the world.[133]

A key role exists for international collective action in pandemic preparedness. Control methods such as a universal influenza vaccine, national and international surveillance and response systems, and intellectual property concerns and production capacity for drugs and vaccines should be addressed ahead of any outbreak. While New Zealand has a degree of geographic isolation, this should not lead to complacency. Factors such as increased migration and global connectedness mean that we must be part of the global community addressing pandemics.

11.1.5 Post-antibiotic era: Antimicrobial resistance

Antimicrobial (which includes antibiotic) resistance (AMR)[134] threatens the effective prevention and treatment of an increasing range of infections caused by bacteria, parasites, viruses and fungi. Resistant micro-organisms can withstand attack by antimicrobial drugs so that standard treatments become ineffective and infections persist, increasing the risk to others. This can prolong the illness, causing a longer period of infectiousness, and therefore higher health care expenses and sometimes deaths. In addition, AMR can jeopardise the health care gains made in society across the health sector and compromise the success of organ transplantations, cancer therapy, and those who are undergoing major surgery.

> *"A post-antibiotic era – in which common infections and minor injuries can kill – far from being an apocalyptic fantasy, is instead a very real possibility for the 21st Century."*
>
> WHO (2014) Antimicrobial resistance: global report on surveillance. Foreword: Dr Keiji Kukada Assistant Director-General Health Security. p.ix

An increasing number of governments around the world are devoting efforts to this problem, which is so serious that it threatens the achievements of modern medicine. However, surveillance of AMR is neither co-ordinated nor harmonised and there are many gaps in information on bacteria of major public health importance. Part of the action to tackle AMR recommended by the WHO includes policymakers, scientists, and industry fostering development of new vaccines, diagnostics, and treatment options. The NZ Government has a significant part to play by strengthening AMR surveillance and border responses to infectious diseases, enabling DHBs to take appropriate action within hospitals and primary health organisations (PHOs) to implement appropriate actions and safeguards.

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[133] Harvey V. Fineberg, Review Article, *Pandemic Preparedness and Response — Lessons from the H1N1 Influenza of 2009*, The New England Journal of Medicine, 2014;370:1335-42.

[134] Key facts on antimicrobial resistance available on the WHO website at http://www.who.int/en/news-room/fact-sheets/detail/antimicrobial-resistance

11.2: Harnessing novel solutions

11.2.1 Big data

The volume and variety of health data available is expected to grow with advances in ICT (information and communications technology), mobile networks, and imaging technologies. Future health research will increasingly rely on the integration of large datasets to provide the evidence for personalised medicine, improved health services, integrated care, public health prevention, and health policy.

Efficient use of big data requires interoperability and standardisation of different datasets – with datasets ranging from high-throughput 'omics' analyses of human specimens to electronic health records, personal monitoring devices, population and patient cohorts and registries, and data on environmental exposure, nutrition, and lifestyle, socio-economic status. Interoperability of health datasets for research is also required to improve the delivery of health services and maximise the opportunities for care and treatment provided through seamless access to timely patient information, diagnostics, and care arrangements.

These are some of the key questions that need to be resolved on the governance and guardianship of health data, particularly given the ethical and privacy issues associated with such data. Consideration also needs to be given to the specific needs of different groups (for example, Māori) regarding how such data is stored and used.

11.2.2 Personalised and precision medicine

The increasing availability of big data in the health space is expected to provide novel insights into health and disease, which can be translated into personalised plans for disease prevention and treatment, as well as on-going monitoring through digital therapeutic platforms.[135] The focus of precision medicine is on identifying which disease treatment and prevention strategies will be effective for which patients based on genetic, environmental, and lifestyle factors.[136]

The primary benefit of harnessing big data for precision medicine will be to challenge medical science in New Zealand to take a step forward at population level. Secondary benefits will include the commercialisation of studies, creating the capability to introduce and trial future therapies and to develop the data and IT solutions to further support precision medicine. The secondary benefits link to the government priority areas of encouraging business innovation and making the most of the digital economy.

The **Precision Driven Health (PDH)** Partnership, established in 2016, is one of the largest data-science research initiatives to be undertaken in New Zealand.[137] It is a multi-million-dollar public-private research partnership between Orion Health, DHBs, and HRC (supported by MBIE). The research undertaken by PDH involves applying new data-science techniques to understanding the massive volume of data that is being captured by health information systems, consumer devices, social networks, genetic testing, and other sources. This will lead to an

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[135] Yu K, Hart S, Goldfeder R, Zhang Q, Parker S, and Snyder M. (2017) *Harnessing big data for precision medicine: infrastructure and applications*. Pacific Symposium on Biocomputing. Vol 22:635-639.

[136] National Institutes of Health: U.S. National Library of Medicine. (2018). Genetics Home Reference: Precision Medicine. Available from https://ghr.nlm.nih.gov/primer/precisionmedicine.pdf

[137] Information about PDH available at http://www.precisiondrivenhealth.com/funding-opportunities/research-opportunities/

improved suite of decision support tools for healthcare professionals and individuals, predicting risk factors, and creating more effective care plans. The joint funding initiative will also help foster the health research workforce in data science for New Zealand.

11.2.3 Genomics

According to a 2015 report from the National Health Committee,[138] genomic technology has developed at a rapid pace, and its implementation in clinical and research settings has been *ad hoc* in New Zealand with new omics-based technologies being pushed into the market in disorganised, unregulated, and disconnected ways.

Technologies that measure some characteristics of a large family of cellular molecules (such as genes, proteins, or small metabolites) have been named by adding the term 'omics' as a suffix.

New Zealand does not have an agreed, organised, approach to identifying and introducing new omics-based technologies and ensuring that the health system can apply such technologies for maximum gains in health outcomes. The successful introduction and adaption of these technologies to real world application relies upon health and social system being ready to receive them.

Infrastructure needed to support omics-based technologies not only covers the physical costs of equipment infrastructure, but the storage, analysis and handling of vast data load that emerges from these technologies and the multi-skilled workforce required, as well as putting in place regulations or protocols to address issues of ethics, privacy and data security arising from this new field.

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[138] National Health Committee (2015). *The Introduction of Fit for Purpose Omics-based Technologies – Think Piece.* Wellington: National Health Committee. Available from https://www.health.govt.nz/system/files/documents/publications/nhc-think-piece-introduction-fit-for-purpose-omics-based-technologies.pdf

Abbreviations

ANZCTR	Australia New Zealand Clinical Trials Registry
ARF	Acute Rheumatic Fever
CDA	Career Development Award (HRC)
CIHR	Canadian Institutes of Health Research (Canada)
CMDT	Consortium for Medical Device Technologies
COPD	Chronic Obstructive Pulmonary Disease
CoRE	Centre of Research Excellence
CPN	Commercialisation Partner Network
CVD	Cardiovascular disease
DALY	Disability adjusted life year
DHB	District Health Board
EAG	External Advisory Group for the NZHRS
GACD	Global Alliance for Chronic Diseases
HDEC	Health and Disability Ethics Committees
HPF	Health Promotion Forum of New Zealand
HRC	Health Research Council of New Zealand
HRCEC	HRC Ethics Committee
IDI	Integrated Data Infrastructure
IEC	Institutional Ethics Committee
IP	Intellectual Property
IRO	Independent Research Organisation
LiLACS	Life and Living in Advanced Age longitudinal Study
MBIE	Ministry of Business Innovation and Employment
MNCS	Mean Normalised Citation Impact Score
MTANZ	Medical Technology Association of New Zealand
NCD	Non-Communicable Disease
NEAC	National Ethics Advisory Committee
NESI	National eScience Infrastructure
NZIER	New Zealand Institute of Economic Research
NHI	National Health Index
NHMRC	National Health and Medical Research Council (Australia)
NRIS	National Research Information System
NSSI	National Statement of Science Investment
NZHRS	New Zealand Health Research Strategy
OIL	Otago Innovation Limited (University of Otago)
PDH	Precision Driven Health
PHO	Primary Health Organisation
REANNZ	Research and Education Advanced Network New Zealand
RSTA	Royal Society Te Apārangi
SDG	Sustainable Development Goal
SIA	Strategic Investment Area
SSIF	Strategic Science Investment Fund
TEC	Tertiary Education Commission
VHIN	Virtual Health Information Network