

Submission to:	Pae Ora Legislation Committee <sup>1</sup>
Subject:	Pae Ora (Healthy Futures) Bill
From:	New Zealanders for Health Research $(NZHR)^2$
Date:	9 <sup>th</sup> December 2021

### Overview

This submission sets out NZHR's concerns about the New Zealand health system's apparent historical indifference to the most fundamental of health outcomes - the country's high and increasing levels of premature mortality - coupled with a longstanding systemic resistance to embracing health research and innovation as a key enabler of improvement. We argue that the Pae Ora (Healthy Futures) legislation is a once in a generation opportunity to address both of these shortcomings. We therefore recommend that the legislation be strengthened by including:

- a requirement for all components of the reformed health system to adopt an overt evidence base to their functions and strategies;
- provision for a health research and innovation strategy covering all aspects of health research and innovation together with all sources of funding and investment;
- non-discretionary opportunities to contribute and be consulted

## Historical health system indifference to premature mortality and health research and innovation

Health research and innovation (or health R&D) is the single most important way in which we improve our health and healthcare - by identifying and implementing the best means to prevent, diagnose and treat conditions.

Yet New Zealand's health system falls short for Māori and non-Māori alike when it comes to both discovering new interventions and translating the results of health research into practice and policy, which will result in realisation of that most fundamental of health outcomes - the right of all New Zealanders to live well to a "ripe old age". This "falling short" is illustrated in the following non-amenable and amenable<sup>3</sup> premature mortality charts<sup>4 5</sup> which indicate that approximately 7000+ New Zealanders are dying early because we haven't done the research to know how to effectively treat them, and that a further 6000+ per year are dying early and unnecessarily because of systemic and personal factors which militate against implementation of the research when it has been done.

Moreover, despite the apparent similarity of the Māori and non-Māori trend lines, the source documents cited below indicate that age standardised Māori premature

<sup>&</sup>lt;sup>1</sup> Pae Ora Legislation - New Zealand Parliament (www.parliament.nz)

<sup>&</sup>lt;sup>2</sup> https://www.nz4healthresearch.org.nz/

<sup>&</sup>lt;sup>3</sup> Amenable mortality is defined as premature deaths (deaths under age 75) that could potentially be avoided, given effective and timely health care. That is, early deaths from causes (diseases or injuries) for which effective health care interventions exist and are accessible to New Zealanders in need. Non-amenable premature mortality is total deaths under age 75 minus amenable premature deaths.

<sup>&</sup>lt;sup>4</sup> amenablemortality\_2016\_dhb\_ethnicity\_years\_rates\_summary\_202106.xlsx (live.com)

<sup>&</sup>lt;sup>5</sup> https://www.health.govt.nz/publication/mortality-2017-data-tables and earlier tables



mortality rates per 100,000 population are running at about twice the rate for non-Māori for both non-amenable and amenable mortality. Given that premature deaths for Māori are evenly split between amenable and non-amenable mortality it would appear that the pursuit of equity of health outcomes for Māori should focus both on improving the health system's responsiveness to Māori (which is addressed by the Pae Ora legislation) and discovery of new Māori responsive therapies and interventions (which is barely addressed at all by the proposed legislation).



NZHR acknowledges that our figures represent the tail end of what up until 2016 had been a notable 26 year downward trend in age-standardised rate of years of life lost per 100,000 population<sup>6</sup>, and that our estimated up-ticking trend line post-2017 is based on only a few years' data. Nevertheless, there should be no complacency as the figures presented in the above graphs are still high in absolute terms, and New Zealand's rate of years lost is higher than nine out of thirteen selected socio-demographically comparable countries cited in the MoH (2020) report. Furthermore, NZHR's premature mortality figures represent the tip of a much bigger iceberg of morbidity. It is difficult

<sup>&</sup>lt;sup>6</sup> Ministry of Health. 2020. Longer, Healthier Lives: New Zealand's Health 1990-2017. A report on the health loss estimates of the 2017 Global Burden of Disease Study <u>https://www.health.govt.nz/system/files/documents/publications/longer-healthier-lives-new-zealands-health-1990-2017.pdf</u>



to quantify the extent of this from the MoH (2020) report for the under 75-year-olds specifically, but for all ages the report notes that the number of years people are living with poor health has shown little change since 1990.

These less than satisfactory outputs from New Zealand's health system may be attributed in part to a long history of government indifference to the value of health R&D. For example:

- The 1993 health reforms specifically excluded RHAs from funding clinical trials and other research, something which continues to this day through there not being an allowance in the Population Based Funding formula for DHBs to undertake health research, including clinical trials.
- Following its 2011 review of clinical trials the Health Committee's recommendation that health research be considered a core front line service component of health service delivery was specifically rejected by Cabinet
- Pharmac's rationing and pricing practices have not had regard for their negative impact on industry investment in clinical trials
- The final report of the Health and Disability System Review (HDSR)<sup>7</sup> failed to make any recommendations on the value of health R&D being embedded as an essential component of a reformed health system, despite NZHR's submission that it should<sup>8</sup>, and tellingly in its interim report<sup>9</sup> did not include in its 468 citations any mention of the government's own Health Research Strategy<sup>10</sup>.
- Similarly, the subsequent health reforms White Paper<sup>11</sup> also failed to acknowledge health research and innovation as a component of the proposed reformed health system

## The Pae Ora Bill is a start, but....

NZHR believes that the Pae Ora legislation represents a once in a generation opportunity for the health system to break this pattern of indifference to health research and innovation, to bend all of the above premature mortality curves, and to bring about significantly improved health outcomes as a result. While the Bill does make a start, it does not go nearly far enough, and we urge the government to seize the unique opportunity that it now has.

We acknowledge that the Bill explicitly intends to improve and bring about equitable health outcomes for Māori, and as noted above premature non-amenable and amenable mortality rates for Māori are tracking at about double those for the rest of the

https://systemreview.health.govt.nz/final-report/

<sup>8</sup> NZHR. May 2019. Submission on the Review of the New Zealand Health and Disability System.

https://www.nz4healthresearch.org.nz/wp-content/uploads/2019/05/NZHR-submission-Health-System-Review-final-280519-Final.pdf

<sup>10</sup> New Zealand Health Research Strategy 2017 - 2027. June 2017. Ministry of Health and MBIE.

https://www.health.govt.nz/system/files/documents/publications/nz-health-research-strategy-jun17.pdf

<sup>11</sup> Health and Disability Review Transition Unit. April 2021. Our health and disability system: Building a stronger health and disability system that delivers for all New Zealanders. <u>https://dpmc.govt.nz/sites/default/files/2021-04/heallth-reform-white-paper-summary-apr21.pdf</u>

 $<sup>^{7}</sup>$  Health and Disability System Review. June 2020. Final report / Pūrongo whakamutunga.

<sup>&</sup>lt;sup>9</sup> Health and Disability System Review. 2019. Health and Disability System Review - Interim Report. Hauora Manaaki ki Aotearoa Whānui - Pūrongo mō Tēnei Wā.Wellington: HDSR <u>Health and Disability System Review: Interim report</u>



population. But even if or when the Pae Ora legislation does eventually lead to equitable premature mortality outcomes for Māori there would still be about 5000+ avoidable and about 6000+ currently unavoidable premature deaths across all population groups each year. In the same way that the country has gone to extraordinary lengths to implement health research based measures to prevent what would otherwise be significant levels of Covid-19 related mortality, we should and could be using the opportunity of the health reforms to go to equally extraordinary lengths to invest in and implement the results of health R&D to prevent and address the existing significant premature mortality from all other causes.

We also acknowledge that the Bill defines the health system as comprising, among other agencies, the Health Research Council, including the activities it funds. The Bill also states that the required New Zealand Health Plan (to provide a 3-year costed plan for the delivery of publicly-funded services) must take into account the role of the Health Research Council within the health system. These provisions are unique to the Pae Ora legislation, and are not, for example featured in the current New Zealand Public Health and Disability Act which the new legislation is intended to replace. Although NZHR welcomes this feature of the Bill, given that Health Research Council investment comprises only 25% of the country's total investment in health and medical research<sup>12</sup> this development does not go far enough.

#### ....the legislation must be strengthened

So, although the Bill is a start it is only the beginning, and it needs strengthening to require the Māori Health Authority, Health New Zealand and the Ministry of Health to embed health research and innovation as an essential component of how they collectively govern, lead and manage the New Zealand health system so that it truly does bring about significantly improved health outcomes. Given that it has been estimated to take 17 years for 14% of medical research evidence to affect clinical practice<sup>13</sup> there is an urgent and immediate need to put things right.

NZHR is not the only agency that believes health R&D should be embedded as an essential component of the health system. The Productivity Commission's "Frontier Firms" report<sup>14</sup> to the Ministers of Finance, Economic Development and Trade and Export Growth recommends that "the Government should use its intended major health system reform to improve the mandate, funding and incentives for [government funded health service providers] to participate in the healthtech innovation ecosystem [aka health research and innovation], for the mutual benefit of the healthtech sector, and the efficiency, effectiveness and accessibility of New Zealand's health and disability system".

Furthermore, the Government's own New Zealand Health Research Strategy<sup>15</sup> states that "A world-leading health research and innovation system has a vibrant research

https://www.productivity.govt.nz/assets/Documents/Final-report-Frontier-firms.pdf <sup>15</sup> New Zealand Health Research Strategy 2017 - 2027. June 2017. Ministry of Health and MBIE.

<sup>&</sup>lt;sup>12</sup> NZHR. November 2020. Briefing Paper for the incoming Ministers of Health and Science, Research and Innovation. <u>https://www.nz4healthresearch.org.nz/wp-content/uploads/2020/11/NZHR-briefing-paper-for-incoming-Ministers-241120.pdf</u>. Page 22.

<sup>&</sup>lt;sup>13</sup> Institute of Medicine. 2001. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: The National Academies Press <u>https://doi.org/10.17226</u>

<sup>&</sup>lt;sup>14</sup> New Zealand Productivity Commission. April 2021. New Zealand Firms: Reaching for the Frontier. Final report.

https://www.health.govt.nz/system/files/documents/publications/nz-health-research-strategy-jun17.pdf



environment in the health sector. The health sector is a key part of New Zealand's national innovation system, performing research, generating knowledge and making the most of innovations. All levels of care...have a role to play in the health research and innovation system." (NZHRS Strategic Priority 2).

We also draw attention to Waitangi Tribunal claim Wai 1315 which was heard by the Waitangi Tribunal in 2018 and which recommended in 2019 the co-design with Māori health experts of a primary health research agenda, measures to collect data relevant Māori Health outcomes, and separate and public reporting on Māori Health outcomes<sup>16</sup>. This reinforces our contention that the Pae Ora legislation should require the health system to translate into policy and practice results of the best available, credible contemporary health research including mātauranga Māori and health research undertaken through a te ao Māori lens.

NZHR also adds that the Productivity Commission's 2022 "inquiry into the drivers of persistent disadvantage within people's lifetimes and across generations"<sup>17</sup> will also without doubt require health research and innovation to be embedded as an essential component of the health system.

Much of what the reformed health system will look like will be embedded in "strategic, accountability, and monitoring" documents such as the Government Policy Statement on Health, the National Health Strategy, the New Zealand Health Plan, national health strategies for Hauora Māori, Pacific Health and Disability Health, locality plans, the New Zealand Health Charter, and a Code of Consumer Participation. With the partial exception of the New Zealand Health Plan there is no specific requirements for any of the documents to promote or be informed by the results of health research, and none of them are required to be subject to general public consultation.

In seeking to ensure that the legislation fully supports the embedding of not only the Health Research Council but also health research generally as an essential component of the reformed health system NZHR's focus is on:

- 1. Ensuring that all principles, plans and strategies required by the legislation are themselves required to be evidence based, with their purported effectiveness supported by results of best available, credible contemporary research (as we successfully did in our submission on the Mental Health and Wellbeing Commission Bill)<sup>18</sup>
- 2. The need for an updated version of the already existing Health Research Strategy to be included in the legislation's suite of strategy documents, and for all sources of health research investment (not just the Health Research Council) to be included as part of the health system
- 3. The importance of guaranteed (rather than discretionary) opportunities to participate in the development of strategic, accountability and monitoring documents. This will ensure that agencies with important contributions to offer (such as NZHR) will have unfettered opportunity to do so.

 <sup>&</sup>lt;sup>16</sup> Waitangi Tribunal. 2019. HAUORA Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry. P168. <u>https://forms.justice.govt.nz/search/Documents/WT/wt\_DOC\_152801817/Hauora%20W.pdf</u>
 <sup>17</sup> See for example <u>Consultation-paper-A-fair-chance-for-all-v2.pdf</u> (productivity.govt.nz), <u>A fair chance for all: Breaking the</u>

 <sup>&</sup>lt;sup>17</sup> See for example <u>Consultation-paper-A-fair-chance-for-all-v2.pdf (productivity.govt.nz)</u>, <u>A fair chance for all: Breaking the</u> <u>disadvantage cycle</u>, <u>PowerPoint Presentation (productivity.govt.nz)</u>
 <sup>18</sup> NZHR. 2019. Submission on Mental Health and Wellbeing Commission Bill. <u>NZHR-submission-re-mental-health-and-well-being-</u>

<sup>&</sup>lt;sup>18</sup> NZHR. 2019. Submission on Mental Health and Wellbeing Commission Bill. <u>NZHR-submission-re-mental-health-and-well-being-</u> <u>commission-bill-111219.pdf (nz4healthresearch.org.nz)</u>



#### **Recommendations**

# Evidence based principles, plans, strategies and implementation of functions

Health research and innovation is a key enabler of the purpose of the reforms as identified on page 1 of the Bill, and will play a key role in planning, delivery and monitoring of health services to ensure that they are continually fit-for-purpose. Furthermore, achievement of equity of outcomes requires enabling access by all New Zealanders to the latest, novel preventive and therapeutic interventions.

Principles, plans, strategies and implementation of functions should therefore be evidence based and supported by results of best available, credible contemporary research.

NZHR recommends that:	section/ url
Section 4 be amended to include:	Interpretation
<i>"evidence based"</i> means has regard to all available evidence including results of best available, credible contemporary research including mātauranga Māori and research undertaken through a te ao Māori lens	
Section 7 be amended to include an additional health system principle:	Health system principles
(f) all health system strategies, policies, practices, services, programmes and interventions are innovative and evidence based, with their effectiveness supported by results of best available, credible contemporary research including mātauranga Māori and research undertaken through a te ao Māori lens	
Section 7(1)(d)(iii) be amended to	
harnessing clinical leadership, research and innovation, and technology to continuously improve services	
Section 13 (a) be amended to:	Objectives of
The objectives of Health New Zealand are— (a) to design, arrange, and deliver innovative evidenced based services to achieve the purpose of this Act in accordance with the health system principles	<u>Health New</u> <u>Zealand</u>
Section 14(1) be amended to include	<u>Functions of</u> Health New
(h) undertake, and translate into policy and practice the results of, health research and innovation activity	Zealand



NZHR recommends that:	section/ url
Section 14(2) be amended to:	
Health New Zealand must give effect to the GPS, the New Zealand Health Plan and the Health Strategies when performing its functions	
Section 18 be amended to:	<u>Objectives</u> of Māori Health
The objectives of the Māori Health Authority are to— (a) ensure that planning and service delivery are innovative, evidence based and respond to the aspirations and needs of whānau, hapū, iwi, and Māori in general	Authority
Section 37(3)(c) be amended to:	Health Strategies
The New Zealand Health Strategy must(c) set out innovative evidence based opportunities and priorities for improving the health system over at least the next 5 to 10 years, including health and health research workforce development.	
Section 41(1) be amended to include	
When preparing a health strategy, the Minister must— (c) have regard to all available evidence including results of best available, credible contemporary research including mātauranga Māori and research undertaken through a te ao Māori lens	
Section 57(1)(c) be amended to:	Improvement plan
If the Minister believes on reasonable grounds it is necessary to improve the performance of a health entity, the Minister may by written notice to the health entity(c) require the health entity to prepare an evidence based improvement plan for the Minister's approval.	
Section 62(1) be amended by adding:	<u>Pharmac</u>
(d) to work in conjunction with the Health Research Council of New Zealand and other funders of health research to promote research within the public health system as a means to embed evidence-based practice, knowledge-translation and innovation, and earlier access to therapeutic innovation	

### Include health research and innovation strategy

The New Zealand Health Research Strategy and all health research and innovation activity should be encompassed within the legislation, recognising their essential role within the health system



NZHR recommends that:	section/ url
Section 4 be amended so that:	Interpretation
"health strategy" also includes:	
(e) the New Zealand Health Research and Innovation Strategy	
"health system" means: (c) the Mental Health and Wellbeing Commission, the Health and Disability Commissioner, the New Zealand Artificial Limb Service, the Health Research Council of New Zealand and any other entities which fund or invest in health and medical research	
Sections 10(1)(a) and 29(1)(b) be amended by adding:	<u>Health</u> Strategies
(v) New Zealand Health Research and Innovation Strategy	Strategies
The Bill be amended to insert a new section 41:	<u>Health</u> Strategies
41 Health Research and Innovation Strategy	
(1) The Minister must prepare and determine a Health Research and Innovation Strategy.	
(2) The purpose of the Health Research and Innovation Strategy is to provide a framework to guide the health system in undertaking and applying the results of health research to improve health outcomes for all population groups.	
<ul> <li>(3) The Health Research and Innovation Strategy must—</li> <li>(a) contain an assessment of the current state of New Zealand's health and medical research and innovation system, including mātauranga Māori, and the adequacy of government, commercial and philanthropic investment; and</li> <li>(b) contain an assessment of the medium and long-term trends that will affect the efficacy of the health research and innovation system, including in respect of health system performance; and</li> <li>(c) set out how health research will address priorities for services and health system improvements relating to achieving best possible health for all population groups, including workforce development.</li> </ul>	
(4) <b>Subsection (3)</b> does not limit what may be included in the Health Research Strategy.	
Section 45(g)(iii) be amended to	<u>New Zealand</u> Health Plan
The New Zealand Health Plan mustset out how Health New Zealand and the Māori Health Authorityhave been guided by the	



NZHR recommends that:	section/ url
health system principles and health strategies in the development and content of the New Zealand Health Plan	

#### Guarantee consultation and participation opportunities

There should be guaranteed (rather than discretionary) opportunities to participate in the development of strategic, accountability and monitoring documents

NZHR recommends that:	section/ url
Section 31(d) be amended to:	Government Policy Statement on
When preparing a GPS, the Minister must— (d) engage fully with health entities, groups and individuals that the Minister considers appropriate. who wish to be consulted.	<u>Health</u> (GPS)
Section 41(1)(b) be amended to	Health Strategies
When preparing a health strategy, the Minister must— (b) engage fully with health entities, groups and individuals that the Minister considers are reasonably likely to be affected by the health strategy who wish to be consulted; and	
Section 47(1)(c) be amended to	<u>New Zealand</u> <u>Health Plan</u>
In preparing the New Zealand Health Plan, Health New Zealand and the Māori Health Authority must engage with(c) health entities, groups and individuals that Health New Zealand and the Māori Health Authority consider appropriate who wish to be consulted	

## New Zealanders for Health Research

New Zealanders for Health Research (NZHR) was established in November 2015 to bring about increased investment in health research from government, industry and philanthropy. We believe that health research has the potential to both save and improve peoples' lives. We are therefore committed to ensuring that the results of health research are translated into policy, practice and individual decision making, and for there to be a level of investment in health research to enable this to happen as optimally as possible.

In developing this submission we have consulted with our Platinum to Bronze partners and members as set out below (and from whom we derive 100% of our funding).



