New Zealand Health Research Strategy

Action One: National Priority Setting

Summary of submissions and consultation

Released March 2019

Executive Summary

Action one of the New Zealand Health Research Strategy is to *'prioritise investments through an inclusive priority-setting process'*. The Health Research Council of New Zealand (HRC) is leading implementation of this action, with support from the Ministry of Health and MBIE.

In June 2018, an independent Strategic Development Group comprised of 13 thought leaders and community representatives were convened to develop a prioritisation framework that would apply to all health research in New Zealand, and to oversee the consultation process.

In September 2018, a discussion paper on setting New Zealand's first health research priorities was published. The five draft Strategic Investment Areas (SIAs) that formed the basis of consultation were:

- SIA 1: Strong foundations of health and wellbeing in children and youth
- SIA 2: Sustaining health and wellbeing throughout adulthood and ageing
- SIA 3: Fostering the health and disability system NZ needs
- SIA 4: Innovating for health and wealth
- SIA 5: Meeting the challenges of our changing world

Online consultation ran for 6 weeks and over 4,000 stakeholders were directly contacted and informed of the opportunity, including: all District Health Boards (DHBs) and Public Health Organisations (PHOs); Māori health service providers; tertiary education institutions, health research providers and funders; professional and industry bodies; government and non-government organisations; and clinicians, allied health professionals and researchers.

Consultation workshops were held with Māori, Pacific and disability communities in four centres: Auckland, Wellington, Christchurch and Dunedin. The workshops were aimed at reaching communities that may not otherwise engage with an online process, and where it was culturally important to provide a face-to-opportunity.

This paper presents a summary and analysis of submissions received and key themes that emerged from the online and community consultations.

Who participated?

A total of 183 submitters produced written responses, and almost 80 individuals attended the consultation workshops, which included members of the public and community representatives.

How was the first draft prioritisation framework received?

In general, the framework was widely endorsed. Each of the five SIAs received over 80% support and 78% felt the overall framework was clear and easy to understand. In particular, these stakeholders expressed views that the framework:

- reflected the principles of the Treaty of Waitangi
- recognised the importance of health equity
- identified areas that will make the biggest difference to the health and wellbeing of all New Zealanders
- supported excellent and high impact research
- endorsed knowledge translation and mobilisation
- reflected the need to take a broader 'systems-level' approach and address the wider social determinants of health

- reflected the importance of intervening early in life and a preventative approach
- signaled the significance of mental health as a priority
- saw New Zealand's role in the global research effort through international collaboration as vital
- captured the importance of environmental health and preparedness for environmental health impacts, both now and in the future
- identified the digital-age and the opportunities and challenges associated with 'big data' as an important focus
- was aspirational
- reflected government priorities, and
- would contribute to sending stable signals about the priorities for health research in NZ

Feedback on where the draft prioritisation framework could be strengthened, included the following recommendations:

- greater focus on discovery research and new knowledge
- more emphasis on supporting excellent research
- a stronger social and wellbeing lens
- a stronger focus on the health of children in the context of family and their social, cultural and environmental contexts
- greater emphasis on the role of Mātauranga Māori
- greater visibility and opportunity for Pacific peoples and Pacific research
- greater visibility and opportunity for the disabled community and disability research
- stronger emphasis on the importance of community driven, owned and led research
- being more inclusive of the rainbow, LGBTQI and Asian communities
- utilising language that better reflects the voices of community
- better reflecting the needs of rural populations
- greater consideration of infrastructure priorities
- the need to enhance interdisciplinary research
- explicitly acknowledging that all methodologies are important and valid, including evaluation
- better utilising existing research
- the opportunity to adapt international research for the unique NZ context

How the model was conceptualised also generated a great deal of discussion and constructive feedback. Conceptually, we heard the model did not reflect a Te Ao Māori worldview because its structure was siloed, medicalised and failed to recognise lived experience and importance of the family, social and intergenerational context. These aspects were considered by many to be counterproductive to efforts to work collaboratively across complex health issues and social contexts that pose risk throughout life.

Whilst some considered prioritisation of any sort should be avoided, this view was not widely held. There was however consistent feedback on the importance of any prioritisation framework empowering communities to set their own health research agenda which will ensure relevant research questions are being asked; knowledge is mobilised for meaningful impact; and there is commitment to building the research capacity and capability needed to achieve this.

A number of constructs were identified as crucial elements within each of the SIAs, and therefore proposed to be incorporated as cross-cutting components, such as: innovation; a future focus; and consumer, community and end-user engagement.

The first round of consultation was **intended to start a conversation** on health research priorities. The Strategic Development Group have drawn strongly from the consultation feedback to develop the final prioritisation model for consultation, which commences mid-March 2019. The detailed analysis and breakdown of the consultation results in this paper provides a strong foundation for understanding and interpreting the scope and direction of the revised prioritisation framework that the Strategic Development Group have developed for this final round of consultation.

We thank all those who participated and have contributed to the next iteration of how best to prioritise health research for New Zealand which is currently out for consultation (http://www.hrc.govt.nz/news-and-publications/publications/consultation) and we look forward to your views and input. Whilst the revised approach has moved on from the initial discussion document, we undertook to share all information and so present here a record of that consultation.

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1 Introduction

1.1 Background to New Zealand Health Research Strategy

In June 2017, the *New Zealand Health Research Strategy 2017-2027* was published. For the first time, the Government is bringing together the science, health, research and innovation sectors to create a cohesive, collaborative and well-connected health research system, to maximise the impact of health research in New Zealand.

The Strategy is a partnership between the Health Research Council of New Zealand (HRC), the Ministry of Health, and the Ministry of Business, Innovation and Employment (MBIE), who are working to implement a set of co-ordinated and complementary actions that will enhance the funding, conduct and uptake of health research.

The 10 actions that make up the Strategy are:

1.2 Overview of the prioritisation process

Action one of the NZHRS, to *'prioritise investments through an inclusive priority-setting process'*, is being led by the HRC in line with its strategic role as the government's primary funder of health research, with support from the Ministry of Health and MBIE. The outcome of this process will be a model to prioritise health research that ensures government funding of health research is targeted to address the big issues that New Zealand faces now, and in the future. It is important to note that ***these health research priorities are not just for the HRC, but all of government investment in health research***.

The prioritisation model will be published in June 2019, and will inform the investment plans of the HRC, the Ministry of Health, and MBIE. It will also be used to guide other areas of

Government funded, mission-led research such as the National Science Challenges, health sector agency research and health research commissioned by other government agencies.

Other funding mechanisms in New Zealand's health research and innovation system, such as academic institutional funding, the Centres of Research Excellence and the Marsden Fund, will continue to support curiosity-driven health research that may or may not fit with these priorities.

An independent Development Group has been formed to oversee the priority-setting process. The 13 members of the group represent researchers, innovators, advisors and health delivery experts with mana, knowledge, expertise from a range of health-related fields, and different world views and experience. Crucially, they all share an ability to think strategically for the benefit of all New Zealanders. The members of the Strategic Development Group were:

Fepulea'i Margie Apa

Professor Michael Baker

Emeritus Professor Richard Bedford (Co-Chair)

Dr Dale Bramley

Professor Vicky Cameron

Dr Kyle Eggleton

Dr James Hutchinson

Professor Margaret Hyland

Ms Rose Kahaki (Co-Chair)

Mr Philip Patston

Professor John Potter

Professor Stephen Robertson

Professor Linda Tuhiwai Smith

These 13 individuals are tasked with considering feedback from stakeholders across the health, science and innovation sectors. This consultation process is designed to ensure the final prioritisation model is inclusive and responsive to the health concerns of New Zealand's diverse populations and communities.

2 Consultation overview

2.1 Consultation process

In September 2018, the HRC published a discussion paper on setting New Zealand's first health research priorities. This paper formed a basis for online consultation (open from 4 September until 12 October 2018) and consultation meetings with Māori, Pacific and disabled communities in Auckland, Wellington, Christchurch and Dunedin (from 1 October until 10 October).

The discussion document contained a draft framework for health research priorities, consisting of five Strategic Investment Areas (SIA), each with six 'Dimensions' of research activity (see Appendix 1). 'Thought provokers' or questions were included to prompt considerations of the scope that was envisaged for each Dimension and to signal the Strategic Development Group's thinking.

Consultation on the five draft Strategic Investment Areas, or the *framework,* was **intended to start a conversation**, New Zealand's first conversation, on health research priorities.

Consultation sought to understand if stakeholders:

- endorsed the **overall framework** and found it clear and easy to understand,
- had suggestions for **additional SIAs, or recommended removing** an SIA,
- felt there are any **Dimensions** that were cross-cutting and therefore should be included within every SIA,
- **endorsed each individual SIA** and its' Dimensions, proposed any changes or identified health research priorities to be included, or
- had **any suggestions for health research priorities** that did not fit within the current draft SIAs.

Submitters were required to give a response to a closed-end quantitative questionnaire followed by an optional open-ended qualitative questionnaire to allow explanatory feedback.[1] Qualitative feedback was analysed by generating a list of codes and then coding the feedback.

Consultation was aimed at being as inclusive as possible, and approximately **4000 stakeholders were directly contacted during the consultation period**, including:

- all **DHBs** (to the CEO, Research Manager, Māori Health Manager and Pacific Health Manager where possible),
- all **Primary Health Organisations** (PHOs),
- all **Māori health service providers** listed on the Ministry of Health website,
- universities and researchers,
- health-related **Centres of Research Excellence** (CoREs),
- health-related **Crown Research Institutes** (CRIs),
- **Independent Research Organisations** (IROs),
- the **National Science Challenges**,
- professional and industry bodies,
- all health research funders,

[1] Refer to the consultation document for the full list of questions by response type.

- **health-related Non-Government Organizations** (NGOs), and
- the HRC's Update, Pānui and Malama newsletter distribution lists.

Information about the consultation opportunity was widely circulated via:

- HRC's newsletter Update,
- HRC's Facebook and Twitter pages,
- New Zealand Government's consultation listings page,
- DHB communications advisors,
- the Royal Society's Te Aparangi 'Alert' and 'Science Deadline' newsletters, and
- articles published online in the New Zealand Doctor magazine and Health Central.

2.2 Consultation submissions

A total of **183 online submissions** were received, with an 81% full completion rate:[2]

- 120 submitters gave consent to have their submission published,
- 28 submitters do not wish to have their submission published, and
  35 submitters did not complete all questions and by doing so, did not give permission for their submission to be published, however, their views were considered

Of these:

- **91 submissions** were made by **individuals**,
- **58 submissions** were made by **institutions or groups**, and
- 34 submissions did not specify due to being incomplete.

Breakdown of online submissions

Group or institutional submissions	Number
TOTAL	**58**
Non-governmental organisations[3]	16
University research groups	13
Government agencies	9
Research organisations	8
Other	6
Clinical organisations or organisations representing the health workforce	4
Researchers working in an unspecified field	1
Research funder	1

Individual submissions	Number
TOTAL	**91**
Researchers working in Universities	41

[2] There were 35 submitters who did not complete the full online submission process, completing only some of the questions. Their responses were checked for their validity and included on the basis that not all submitters may have wished to provide comment on all Strategic Investment Areas or wished to remain anonymous.
[3] Including, but not limited to, the Blind Foundation, Cure Kids, Disabled Persons Assembly, Hāpai Te Hauora, Cancer Society of New Zealand, CCS Disability Action, Pharmacy Guild of NZ, Te Rau Matatini, Te Pou o te Whakaaro Nui, Alzheimers NZ and Te Kupenga Hauora – Ahuriri.

Clinicians or allied health workers	19
Individuals working for non-governmental organisations	8
Other	8
Individuals working for government agencies	3
Researchers working in organisations outside of Universities	2
Researchers working in an unspecified field	2

A further **19 offline submissions** were received directly by the HRC. These submissions did not follow the online submission format, with submitters preferring to provide either unstructured feedback or comment only on select areas of relevance. These have been included in the list of online and offline submitters and the feedback and views incorporated in to the consultation data presented in this paper.

Offline submissions	Number
TOTAL	**19**
Non-government organisations (group)	8
Researchers working in Universities (individual)	3
Clinicians or allied health workers	2
Government organisations	2
District Health Boards (group)	1
Individuals working for DHBs	1
External advisory group	1
Researchers working in organisations outside of Universities	1

2.3 Community consultation meetings

Consultation meetings were held with Māori, Pacific peoples and the disabled community and their advocates in the major centres from 1 to 10 October 2018.

Almost **80 individuals** attended workshops in Auckland, Wellington Christchurch and Dunedin. The consultation meetings provided a lot of highly engaging and invaluable feedback. By comparison with the online submission process, the consultation meetings had a much greater representation of community members, NGOs and service providers, at 57% of attendees compared with 32% of online submitters representing these interest groups.

The consultation workshops also provided an opportunity to establish connections with key stakeholders that are keen to be engaged throughout this process, with the potential for these relationships to be built upon throughout the life of the Strategy.

2.4 Analysis of submissions

Data from online submissions is reported in three ways:

- percentages and numbers to convey the overall agreement with aspects of the draft

- areas of common interest / key themes accompanied by the number of submissions in concurrence, including both positive and negative feedback, and
- specific quotes and suggestions

Offline submissions, which mostly consisted of unstructured written responses, were analysed by incorporating ideas, quotes and simple statements of approval and disapproval into the general areas obtained by analysis of online submissions. Key themes were extracted from the longer written online questionnaire answers by reviewing each individual submission and coding according to the theme addressed. After this, submissions addressing the same coded theme were aggregated and analysed according to areas of agreement and disagreement.

Responses were also reviewed and coded according to whether the submission did or did not endorse each SIA. Each submission was then aggregated and common reasons for endorsement and lack of endorsement were identified.

Throughout this document, groups of submitters expressing the same opinion are characterised by demographic where possible. Confidential information and submissions made by groups or individuals who did not wish for their thoughts to be published, have been removed.

4 Feedback on the overall framework

Key feedback on

The overall framework

Clear & easy to understand

78%
of respondents thought it was

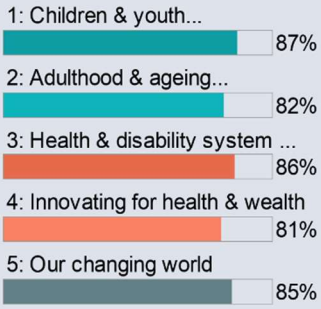
What was not clear

How will the framework:

- Support discovery research?
- Support excellent research?
- Support interdisciplinary research?
- Impact on the existing workforce?
- Use existing research?
- Adapt international research for the NZ context?

Percentage of respondents endorsing each SIA*

>80%
of those commenting endorsed each SIA



Concerns expressed

- How will the priorities be funded?
- Will those involved in priority-setting have the required expertise?
- Will an evidence-based approach be used to set priorities?
- Will existing areas of strength and capacity be considered?

Is the framework fit for purpose?

Most respondents either 'agree' or 'strongly agree' that the framework:

- Reflects the principles of the Treaty of Waitangi
- Identifies areas that will make the greatest difference to the health and wellbeing of all NZers
- Supports high-impact research
- Is clear and easy to understand
- Is aspirational.
- Will contribute to sending stable signals about the priorities for health research in NZ
- Reflects Government priorities

Feedback from public meetings with Māori, Pacific and disability communities

The framework:

- Doesn't reflect a Māori worldview in the way that it has been developed (Māori only see themselves in the Rangatiratanga dimension)
- Sufficiently focus on Pacific people and their research needs, or reflect their holistic view of health and the central role of the family
- Largely represents the medical model of disability and does not adequately focus on people with disabilities and their needs

All groups thought that the framework should be more holistic and the Pacific and disability communities thought that rangatiratanga should also embrace them

* Some respondents endorsed an SIA but also provided caveats and detailed aspects that they didn't endorse, see write-up of individual SIAs for details of feedback

4.2 Interpretation of Framework

A total of 143 or **78% of submitters feel the overall framework is clear and easy to understand.** Those who feel the framework is ***not clear and easy*** to understand, raise issues relating to a lack of clarity based on how discovery research will be supported, the language used, the overall process for setting health research priorities, and how the framework will be implemented.

4.3 Conceptual challenges of the framework

There was significant discussion at all consultation meetings with Māori, Pacific peoples and the disabled community, about the conceptual challenges of the framework regarding their respective world views and models of health and wellbeing, with significant intersection between the feedback given by all three communities. The following feedback was also echoed in the online submissions:

- The framework represents **too medical** an approach to health (medicalised systems and disease focused).
- The framework **does not completely reflect a Te Ao Māori world view** (e.g. holistic Whānua ora and Māori models of care are absent).
- There is concern that 'Rangatiratanga' is the only Dimension 'for' Māori. This limits the participation or involvement of Māori communities in the other Dimensions, and people need to be able to see themselves reflected in all SIAs and Dimensions, not confined to one 'box'. Therefore, there is support for the inclusion of the Rangatiratanga Dimension ***as well as* a standalone Māori health SIA** by both community workshop participants and many online submitters. An *SIA:*
    - *'solely prioritising, valuing and reflecting our Māori worldview and mātauranga Māori, as an effective solution to health and well-being, should be added to the framework. This will be a true reflection of the principles within Te Tiriti o Waitangi and ensure true and real outcomes for our Māori communities, who are the biggest clientele of the current health system.*
- The framework needs to be reconceptualised from a **social or wellbeing lens**. A **'whole system' approach to health** needs to be more explicitly woven in (acknowledge cross-government policy and inter-disciplinary research needs: housing, education, welfare, justice).
- The structure is too siloed. SIA 1 and 2 **fail to recognise the importance of an intergenerational, family context approach** by separating children and young people from the adult life course. Division by age-group has not worked well in the past as it leads to fragmentation; minimises collaboration; is artificial and does not realistically reflect how health issues affect individuals and families.
- Pacific peoples are only specifically named in one Dimension within one SIA, and representation and visibility are important. **The Pacific community needs to be more explicitly acknowledged across all SIAs**.
- It is important to acknowledge the diversity of Pacific ethnicities and identities.
- The Pacific community supports **Rangatiratanga** and **Equity** across all SIAs because of the overrepresentation of the Pacific people in health statistics.

- The framework needs to be restructured to **raise the visibility of persons with disability and disability research** (better reflecting the social model of disability).
- The **language, terminology and icons** utilised need to better reflect the voices and perspectives of disabled people.
- One community workshop advocated for an additional SIA specifically targeted to safeguard the (social model of) disability research, centred around how to best implement the UN Convention on the Rights of Persons with Disabilities. Another community workshop echoed this, suggesting the inclusion of a **specialist stream** without the loss of inclusion within the mainstream.
- Reflecting the **social model of disability**, and broadening the definition of determinants of health, was strongly advocated for by attendees of the disability research community meetings in Auckland, Wellington, Christchurch and Dunedin.
- Across all SIAs **the principles within the Rangatiratanga Dimension are equally valid and important for people from the Pacific people with a disability** in terms of community-driven, owned and led research.
- Echoing the suggestion from many of the community workshops, some online consultation submissions suggest a reframing of **Rangatiratanga to encapsulate priority populations in New Zealand** (specifically Māori, Pacific peoples and persons with disabilities, but also including the Asian community and LGBTQI and rainbow community) and **broadening the scope of the Equity Dimension** (away from 'health' equity) to more specifically reference gender, sexual orientation, and geographic location in this Dimension across all SIAs. Acknowledgment was also needed of the lived experience of inequalities for those who identify at the intersection of different groups (e.g. Māori with a disability).

4.4 Structural changes to the framework

Submitters were asked several questions about any structural amendments they would recommend be made to the framework. The majority of respondents (75%) wanted to retain the proposed SIAs in the framework. Beyond the overarching concerns identified in the overall framework graphic (p,13) there was a low level of support for existing SIAs to be removed from, or additional SIAs to be included in, the framework, at 25% and 30% respectively.[4] The majority of recommended structural changes are based upon suggestions for **incorporating existing SIAs as cross-cutting Dimensions**, namely SIAs 3, 4, and 5.

Merging SIA 3 within SIAs 1 and 2

- As SIA 3, "Fostering the health and disability system NZ needs", focuses on **structural, or infrastructure priorities**, it should not be a standalone SIA but rather should **form a Dimension of SIAs 1 and 2**. Therefore the funding allocation to SIA 3 should be proportional (smaller) than the health (thematic) priorities included in SIAs 1 and 2.
- As SIA 3 represents research that is operational or implementation-science in nature, submitters felt that **this research is the remit of the Ministry of Health or the core work of government, and not within the funding remit of the HRC**. This structural health-system level work is a priority, however, it should be undertaken by the Ministry

[4] A total of 47 and 39 out of 154 submitters, respectively.

of Health (or DHBs) under the NZHRS Actions they are leading, rather than being conceptualised as a health research priority within the scope of Action 1.

It is important to note that, although this critique was common, it represents a misunderstanding of the purpose of the prioritisation process and the parties involved. The proposed framework is for all of New Zealand and is not exclusive to HRC, therefore inclusion of this research is appropriate. In addition, some research classified as operational research, evaluation or implementation-science, could fall within the remit of the HRC.

Merging SIAs 4 and 5 as Dimensions within SIAs 1, 2 and 3

- Dimensions within SIA 4 and 5 such as **innovation, a future-focus, and advancing Pacific research are core to the overall framework** and these concepts should be **integral cross-cutting components of all SIAs**.
- The current format of SIA 5, "Meeting the challenges of our changing world", is not equivalent in scope and comprehension to the other SIAs; it is somewhat speculative; does not represent a health research priority of equal measure to concerns such as diabetes, obesity, suicide and cancer; and therefore, does not deserve equal weight (or to receive equal funding) as SIAs 1, 2 or 3.

Inclusion of additional SIAs or Dimensions that should be elevated across all SIAs

- Strongly related to the existing Dimensions within SIA 3 of 'People-centred care' and 'Knowledge translation and mobilisation' was discussion around a cross-cutting Dimension related to **consumer/community/end-user voice or engagement**. Discussion about this additional Dimension also links to the discussion at community workshops around broadening of the scope of the Rangatiratanga Dimension – the importance of ensuring the centrality of the ultimate beneficiaries of research. There was a strong message across community workshops on **the importance of infrastructural priorities empowering communities** to set their own health research agenda which will ensure:
    - that relevant research questions are being asked,
    - that knowledge is mobilised for meaningful impact, and
    - that there is a commitment to building Māori, Pacific and disability researcher workforce capacity and capability.

- There was support for the inclusion of a **mental health** (including addictions and suicide prevention) focussed Dimension across all SIAs or as a standalone SIA. Submitters considered there to be a **persistent underfunding of mental health research in New Zealand**, and that Māori and Pacific peoples are disproportionately affected, perpetuating health inequities. Submitters would like to see funding increased so that it is proportional to the burden of disease mental illness represents, with a dedicated mental health SIA as a vehicle to achieving this. Submitters would like to see included within the scope of a mental health SIA the perspective of Māori and Pacific researchers and people with lived experience.

5 Feedback on individual SIAs and Dimensions

5.1 Strategic Investment Area 1: Strong foundations of health and wellbeing in children and youth

Overall, SIA 1: *Strong foundations of health and wellbeing in children and youth*, is **endorsed by 87%** submissions. In addition to endorsing the importance of the named Dimensions, submitters **endorse**:

- **The logic of intervening early in life to improve future health outcomes**.
  This was endorsed by a vast range of submitters, including clinicians, researchers, DHBs, Universities, government agencies and NGOs. Submitters particularly highlighted the flexibility of this concept, giving the following examples of specific implementations:
    - Dietary intervention
    - Management of chronic issues
    - Ageing well throughout many life stages

- Taking a **preventative**, **holistic**, or **intergenerational** approach.
  The majority of submissions that endorsed a preventative approach were made by researchers. Many of the submitters who endorsed a preventative approach also referenced a specific significance to Māori communities, and two submitters highlight the importance of a holistic and intergenerational approach to the Māori world view and thus to Māori definitions of health. One submitter extended this idea, suggesting that the definition of health by various demographics should be a research topic of its own.

- A focus on the **impact of the digital age.**
  The exploration of this idea was most notably supported by an organisation specifically for at-risk youth, however representatives of the research and clinical sectors concur.

- The **emphasis on mental health.**
  Many submitters further highlighted **mental health as the primary issue** within this SIA and some advocated for it to be a specific Dimension. Submitters primarily advocated for research to address social determinants and outcomes of mental health problems, examples of which included:
    - Social and healthcare disparities
    - The significance and maintenance of a stable family
    - Cultural connectedness, particularly in Māori communities
    - Minority genders and sexualities
    - Addiction
    - Suicide risk
    - Increased risk associated with the pre-birth environment
    - Childhood trauma

  In addition, many highlighted the benefits of obtaining New Zealand specific data on mental health, due to the need to better understand indigenous populations and the potential issues involved in applying research outcomes from other social and cultural contexts to New Zealanders. The potential for incorporation of a **nation-wide survey** to address the causes of mental health issues and outcomes, and to gain a better

understanding of engagement with the healthcare system for youths suffering with mental health problems was identified as a potential area of focus. Both psychiatrists in clinical roles and community organisations highlighted the potential benefits of incorporating such a survey into the priorities. Mental health as a whole was a common interest to a broad range of individuals and organisations, including clinicians, government agencies, NGOs, researchers and universities.

- The Pacific researcher community highlighted this SIA to be of great importance because around half of the Pacific population is under the age of 21. They also identified the importance of this SIA focusing a reasonable amount of energy towards **mental health** and **epigenetic research** to be able to provide early interventions.

However, feedback highlighted areas that lack clarity, or perceived gaps or exclusions including:

- The need to take a **broader systems-level focus** (including determinants of health such as poverty and education), and the communities and services which support health habits, rather than emphasising personal responsibility. This indicates that a **co-ordinated approach across all of government** is necessary, including the Ministries of Health and Education. This point is mostly highlighted in submissions made on behalf of clinicians and researchers, with only one organisation (an NGO), and no governmental organisations, choosing to advocate for this broader focus.

- A **lack of focus on creation of new knowledge** within this SIA, particularly representations of biomedical or discovery science as well as a perceived lack of room for pre-clinical or translational research. Approximately 10 percent of submitters expressed this concern. Several submitters highlighted genomic research as a specific area of discovery that would benefit from a greater focus on new knowledge.

- Submitters placed particular emphasis on **excess body weight and diabetes being a key concern for NZ youth**. This was predominantly highlighted by Universities and researchers who advocated for this issue to be a research priority.

- **Mātauranga Māori** should be reflected within each Dimension of the SIA; that Pacific children and youth need to be emphasised; and there needs to be better alignment with the principles of te Tiriti o Waitangi. Those submissions that mentioned a lack of alignment with te Tiriti o Waitangi came from an organisation for Māori wellbeing, members of the Māori research community and a researcher experienced in the field of social inequality. No submissions argued for less emphasis on te Tiriti o Waitangi within the framework.

- **Population specific gaps,** including immigrant children; rural children and rural pregnant mothers; children with acute and chronic conditions; youth risk-taking, and injury prevention and control. Submitters who drew attention to these specific communities were mostly representatives of NGOs for these communities, or researchers who work with these populations.

- The need for a specific **definition of the time period "before birth"**, with two submitters suggesting that the concept of intervention "before birth" should also be generalised to sexual and reproductive health of parents prior to conception.

- The use of **disability adjusted life years (DALYs)** was challenged by participants at the disability research community meetings in Dunedin, Wellington, and Christchurch, due to the lack of sensitivity of this concept for persons with a disability. Attendees of the Dunedin meeting instead suggested Quality Adjusted Life Years as a better term.

- Attendees of the Māori research community meetings in Auckland and Christchurch agreed that the life course approach is not a suitable approach when **whanau** should be considered together (children, mothers and the elderly).

Feedback on the dimensions within SIA 1

In addition to the overarching dimensions of Rangatiratanga and Equity, the proposed draft of SIA 1 consisted of the following four dimensions:

- Intervention before birth
- The first 1000 days of life from conception
- Healthy, happy and resilient children and young people
- A life-course approach to health and wellbeing

Please refer to Appendix A for the full draft that was circulated for consultation.

Overall, **79% of respondents endorsed these dimensions**[5]. With respect to the cross-cutting Dimension of Equity, respondents felt this should include mention of minority genders and sexualities, and children with a disability or inherited/congenital illnesses and disease. The importance of being inclusive of methodologies appropriate to reach vulnerable populations was also highlighted.

Changes to the scope of 'The first 1000 days of life from conception' and 'Intervention before birth' dimensions were also recommended. The timeframe of 1000 days was seen as an arbitrary delineation and therefore too prescriptive or a restrictive 'slogan' that is not consistent with understandings of human health and development. There should also be allowance for an 'extension' to the timeframe for children who have development delays due to biological or social factors, such as 'the first 2000 days', or a more general phrasing.

Attendees of the Auckland disability research community meeting who endorse a life-course approach to health, highlighted the need for emphasis on longitudinal data extending beyond the arbitrary "first 1000 days" and to address the overlap between the 2 dimensions.

The scope of 'intervention before birth' should be expanded to include **pre-planning for pregnancy and the impact of prenatal paternal health on health outcomes**. However, this was a highly sensitive topic for attendees from Dunedin and Wellington expressing concern that **this concept is too close to eugenics**. Attendees from Dunedin highlight the need to

[5] A total of 137 out of 173 submissions.

acknowledge the inevitable differences in gestation, birth and perinatal care of a child with a disability both in this dimension and in the 'first 1000 days.'

Feedback pertaining to the dimension of **'healthy, happy and resilient children and young people'** mostly highlighted a need for further clarification of the definitions and terminology, and for further consideration of how this language can be limiting in terms of certain demographics and adapting to new technologies. Attendees of the Wellington disability research community meetings particularly highlighted the individualistic nature of the word "resilient", expressing concern that this would devalue and blame individuals for having a disability.

The importance of taking new technology into consideration was also emphasised in the **'life-course approach to health and wellbeing'** dimension, particularly as a method to engage younger communities.

5.2 Strategic Investment Area 2: Sustaining health and wellbeing throughout adulthood and ageing

Overall, **82% endorsed at least some aspects of the SIA**, especially the strong focus on **wellbeing**; the **ageing population**; the use of quality **linked data**; the focus on **stratified medicine**, (although some argued that this should be represented across the framework); and **Māori and Pacific health outcomes** as a strong driver for alignment between health and social agencies.

The following areas of comment, concern or caution represent the most prominent themes in submissions:

- The **outcomes of this SIA are political goals** and should not be the focus of the HRC.
- The framework will result in a **disconnect from front-line clinicians** and thus an inability to produce significant clinical outcomes.
- Too little focus on **palliative care and death**, which should be elevated in status and also acknowledge terminal illness.
- **Lack of consultation with biomedical researchers**, and a lack of focus on biomedical contributions to health outcomes.
- The **knowledge to achieve the outlined goals already exists**, inhibiting the acquisition of new knowledge and innovation.
- Several submissions state that, in contradiction to those who support international collaboration, **reliance on international data** hinders New Zealand's researchers and may result in a lack of fundamental research being undertaken locally.
- The SIA is too limited in terms of the defined ages it encompasses, preventing the use of a life-time approach to wellbeing.
- The SIA is too broad in terms of the vast array of illnesses that can be classified under it.

Feedback on the dimensions within SIA 2

In addition to the overarching dimensions Rangatiratanga and Equity, the proposed draft of SIA 2 consists of the following four dimensions:

- Addressing the greatest burden of disease
- Stratified medicine
- Determinants of health
- Shifting treatment horizons

Please refer to Appendix A for the full draft that was circulated for consultation.

There was strong support for all of the proposed Dimensions within the SIA, in that the dimensions seem **sensible, cover the important areas, and are comprehensive.** There was particularly strong **support for the 'addressing the greatest burden of disease' dimension,** and for the **prevention focus** of the 'determinants of health dimension', while others endorsed the **global and international connection** focus of the 'shifting treatment horizons' dimension. Overall, the **Rangatiratanga and Equity dimensions were well accepted**.

The following areas of comment, concern or caution represent the most prominent themes in submissions:

- **Data (large and linked datasets use and capabilities)** – represented an area of considerable discussion amongst individual researchers. Some felt data and data use is relevant across all SIAs and should be elevated to a cross-cutting Dimension. Some endorsed the dimension with caveats around the importance of ethics, consent and **data equity and quality**; equity of access to big data sets; the appropriateness of sharing datasets across agencies; and the risks of relying on data that might be poor quality. Caution was raised regarding groups that are not well represented in current big datasets, such as people of advanced age and those of minority genders and sexualities. These sentiments were echoed in the community workshops.

- A quantity-based measure of disease burden can further **skew inequity**. There needs to be **inclusivity for people who are not in the 'greatest burden of disease'** category but nonetheless require health support, namely: those of lower socioeconomic status who may not present to healthcare services; those suffering from NZ-specific diseases; older individuals, as they tend to feel the burden of common diseases more than younger individuals; those suffering from rare diseases, including those suffering from uncommon but extremely debilitating conditions that are excluded from this definition despite great personal burden; and rural communities, who are likely to be burdened more by the same diseases.

- There must be a **future focus**: an understanding of the likely future burden of disease in 10, 20 and 50 years' time, and the need to adapt to changing attitudes towards ageing.

- '**Stratified medicine**' was seen as having too narrow a focus on large datasets, and should be broadened to 'population health' or 'better use of real world information,' including the use of single biomarkers, not just modelling of large multi-dimensional linked datasets. Comments suggest that **stratified medicine is an area that is less well**

understood than the other Dimensions, which is understandable given that it is a rapidly developing area and the terminology is not yet common place.

- Broadening the focus of the 'determinants of health dimension to **more explicitly include social determinants of health**. This particular point was expressed predominantly by organisations concerned with Pacific and Māori health, and was also of concern to attendees of the disability research community meetings.

- The '**shifting treatment horizons'** dimension was not clear to all submitters and the link to critical mass was not well understood. Some felt the name was too vague and one submitter suggested a big empty aspirational box to encourage discovery.

5.3 Strategic Investment Area 3: Fostering the health and disability system New Zealand needs

Overall, SIA 3: *Fostering the health and disability system New Zealand needs*, is **endorsed by 86% of submissions**. Overall, this SIA received strong support because the New Zealand health and disability system spends over $18b per annum but **very little research is done in this area**; it represents the link between people, health outcomes, service delivery, and the health and research workforce and it has a **much needed focus on equity**. Submitters who endorse the 'Health and Disability System SIA' were predominantly individuals working in the research sector or currently practising as clinicians.

However, while there was agreement on the importance of this area of research for the New Zealand health system and New Zealanders more generally, there was a lack of consensus on how it is best incorporated in to the framework, the likelihood of meaningful outcomes and the most effective method of implementation.

The following areas of comment, concern or caution represent the most prominent themes in submissions:

- The likelihood of generating meaningful outcomes due to the **lack of long-term focus**; the problem of **research waste** (due to lack of collaboration with DHBs and other organizations who must implement the findings to create change); **lack of engagement with non-English speaking communities**; and inappropriate involvement of HRC in outcomes that should be the concern of other organizations.

- The need for greater acknowledgement that **some groups within the community are a higher priority because their needs are not well served** by the current system, e.g. Māori who have a disability. Incorporating the education sector was seen as highly important in order to address this.

- Concern that the 'system-wide' focus would **further marginalise research by and for disabled people,** as the benefits are targeted to a particular population and will not be widely applicable.

Feedback on the dimensions within SIA 3

In addition to the overarching dimensions Rangatiratanga and Equity, the proposed draft of SIA1 consists of the following four dimensions:

- People-centered care
- Continuous cycle of improvement
- Knowledge translation and mobilization
- Launching innovations

Please refer to Appendix A for the full draft that was circulated for consultation.

78% agree[6] with the proposed dimensions of this SIA. In particular, submitters endorse 'Person-centred care' while highlighting that it could be strengthened by amending it to **'People-driven care'** which, similarly to the Rangatiratanga dimension, would **acknowledge human rights models of care**. This point was most pertinent for clinicians and allied health workers whose responsibility it would be to implement this model of care. The broadened perspective of People-driven care would also move away from overtly medicalised models and systems of care and include other relevant community supports (NGO and wider government policies – e.g. justice, welfare).

There was also strong endorsement for the **'Knowledge translation and mobilisation'** Dimension, especially from researchers. Many submitters commented that the New Zealand health research system is not good at research translation currently (both the doing of, and the investing in) and that a focus on building capacity and capability for research translation in the NZHRS is welcome and overdue. Issues identified included the need for **national system-level co-ordination** for accessible research findings, **building capacity and capability** around knowledge mobilisation and brokering relationships (in policy, practice and the community), and national **evidence-based practice guidelines**.

Submitters supported the inclusion and recognition of the need for evaluation within the **'Continuous cycle of improvement'** dimension. This was seen as particularly important with respect to **innovation** in policy and practice (rather than just technological innovation) and the ability to effectively invest in what is working and dis-invest in what is not. Evaluation was identified as a core component for each SIA and therefore should not be limited to system-level research, and that this is particularly important with respect to equity.

A number of submissions emphasised the importance of **engaging with research users at the conception or problem definition stage** and of **strengthening expectations in the area of fostering relationship-building, engagement, collaboration and partnership**. A co-ordinated approach is needed at the national level (links with other Ministry of Health and MBIE led Actions of the NZHRS).

Overall, very few submissions made specific mention of the '**Launching Innovations**' dimension, instead opting to comment on **innovation** as a concept that should be **cross-cutting** and incorporated within all 5 SIAs. **Technology** was a common theme, with one submitter (a

[6] A total of 123 out of 157 submissions.

government agency) specifically expressing a need to access and advance presently available technology to support innovation in science.

5.4 Strategic Investment Area 4: Innovating for health and wealth

There was wide endorsement of SIA 4: *Innovating for Health and Wealth* at **81%**. The majority of those endorsing SIA 4 were clinicians/allied health professionals, followed by researchers, DHBs and NGOs. The rational provided for endorsement included the **scope being wide**, comprehensive and valid, having a **future focus** , that it **will have benefits for the health system** and new health care technologies, and that it **supports basic and discovery research** needed to feed the innovation pipeline.

Those who did not endorse all aspects of SIA 4, provided the following comment:

- The **focus on innovation is too narrow**. Submissions from the research sector predominantly proposed that "innovation" should be expanded to encompass discovery research more generally.
- One submission felt it **lacked the long-term implementation strategy** needed to make it viable.
- Another remarked that this was outside the scope of the HRC and fell within MBIE's remit and therefore **HRC funds should not be diverted away from discovery research** to support innovation.
- 9 submissions did **not endorse the inclusion of 'wealth' in the title** and would like to see it removed on the basis that accumulation of wealth should not be a consideration in health strategy and that innovation does not always equate to economic gains or prosperity. Another submission called for a clearer link to be made between wealth and health outcomes, while others sought clarification over whether wealth was intended in economic terms only, or if health gains were also included here as increasing the 'wealth of a person.'
- Some researchers commented that SIA 4 was the **only place in the framework biomedical and discovery research was clearly identifiable**. Recommendations were made to reframe the SIA to focus on blue skies research and for the HRC to concentrate its funding here.
- Another submission noted an inconsistency is that **SIA 4 is the only SIA in the framework to make an explicit mention of a research discipline** (biomedical research) and commented that SIA 4 was inappropriate given that it did not focus on specific outcomes and was not priority-driven like the other SIAs.

Feedback on the dimensions within SIA 4

In addition to the overarching dimensions Rangatiratanga and Equity, the proposed draft of SIA1 consists of the following four dimensions:

- Feeding the innovation pipeline
- Developing and applying innovations

- Innovating with data and methods
- Culture and ethics of innovation

Please refer to Appendix A for the full draft that was circulated for consultation.

In general, feedback indicates support for the breadth of issues covered by the **Dimensions**, with particular endorsement by health organizations, independent researchers and health professionals for the **inclusion of equity and ethics** under the dimension **'Culture and ethics of innovation'**. The issues of equity, rangatiratanga and ethics were seen as interrelated in that collectively these Dimensions would increase access to, and the representation of, marginalised groups such as minority genders and sexualities, disabled, or rural communities in healthcare innovations and big data.

With regard to Rangatiratanga, **data sovereignty** was endorsed as a key issue for Māori. A few submitters suggested that this dimension could be strengthened so that a Māori world view is better prioritised, as a paradigm shift is needed to achieve this.

Those who did not endorse all aspects of the dimensions for SIA 4 made the following comments:

- the **research scope is too narrow** and should focus on basic and discovery research more generally; the **methodological scope is too narrow** and focuses on the collection of big data, or randomised control trials, and the **scope is unclear or not properly defined**,
- there are **already adequate ethical processes** in place for the development of innovations,
- the **meaning of the culture and ethics of innovation is unclear** and,
- the **dimensions do not represent research goals**,
- the **'feeding the innovation pipeline'** should incorporate international collaboration, and there is too much focus on commercialisation within this dimension.
- the **'innovating with data and methods'** dimension needs to incorporate **qualitative methodologies, community-based and led approaches**, such as kaupapa Māori methodologies, and **ensuring data quality** is essential.

5.5 Strategic Investment Area 5: Meeting the challenges of our changing world

As many as **85%** of submissions endorsed having an SIA focused on meeting the challenges of our changing world. Those who broadly support this SIA particularly endorsed:

- New Zealand playing a part in **global initiatives** through international, multidisciplinary collaboration; and highlighting the importance of building **New Zealand specific capacity and capability** in this area,
- the **future focused lens**,
- the explicit emphasis on the **environment and climate change**,
- the explicit call for research **collaborations with the Pacific,** and
- the potential to address **novel research** ideas.

However, some submissions had concerns about scope and prioritizing the impact of climate change on health:

- The **scope of this SIA is outside HRC** and would be better met by other agencies.
- **Climate change should not be a health priority** as there are other more pressing health epidemics which could have a greater impact on population health.
- That the intersection between health and environment **should not be a standalone SIA** as this could be a cross-cutting dimension in SIAs 1, 2 and 3.

While the future focus of this SIA was largely endorsed by the online submissions received, community meetings with Māori and Pacific identified a strong **need to focus efforts on more current challenges**, such as self-harm, post-natal depression, family violence, homelessness, food and spiritual poverty, overcrowding, urbanisation and disconnection from community. Concern was expressed that SIA 5 is less relevant for Māori and Pacific peoples because future planning is difficult when there are communities struggling to generate income for survival.

Feedback on the dimensions within SIA 5

In addition to the overarching dimensions Rangatiratanga and Equity, the proposed draft of SIA1 consists of the following four dimensions:

- Responding to climate change
- Emerging and re-emerging diseases
- Future-proofing New Zealand
- Advancing research in the Pacific

Please refer to Appendix A for the full draft that was circulated for consultation.

Overall, submitters recommended broadening the focus of the dimensions which were described as overly specific in comparison to the other SIAs, and placing greater emphasis on the importance of a **flexible and agile system** to address future challenges and opportunities that cannot yet be known or identified.

The '**Responding to climate change**' dimension in particular was viewed as too limited and should be expanded to include more general environmental health concerns (including both mitigating and responding to climate change). This could be strengthened through consideration of the principles of kaitiakitanga (guardianship, stewardship) which would **broaden the focus to environmental protection** (rather than just environmental health). Additional issues to consider include food safety and security such as over fishing, air pollution, drinking water quality, changes in farming practices (reducing carbon emissions) and associated changes in diet (less dairy and meat consumption).

Submitters also recommended the '**Future-proofing New Zealand**' dimension having stronger links to the health topics covered in SIA 1 and 2, in particular, our **changing population needs**, such as New Zealand's diverse Asian population and their service needs; the changing needs of rural communities; our ageing population and the likely increase in multi-morbidities and prevalence of long-term conditions; and increasing levels of physical inactivity. Additional recommendations included:

- More emphasis on the impact and effectiveness of **technological advances**, including industry and commercial applications and use of biochemicals.
- The advance of **personal medicine** needs to be more specifically acknowledged in this SIA and recognition that rapid technological change also includes the impact of new techniques for genetic diagnoses and for repairing genes.
- Broadening the language to make mention of **artificial intelligence, gene technologies, new communication technologies, robotics and the Internet of Things**, specifically in relation to health service delivery.
- Reference to **mental health** when discussing the **impacts of migration and after-effects of disasters.**

For the **'emerging and re-emerging diseases'** dimension, submissions recommended the following improvements:

- Acknowledging that increasing **urbanisation and density, population mobility and sophisticated technology** can aid in spread of infectious diseases.
- Specifically identifying **antimicrobial resistance is a health priority**.
- Recognising the importance of sexual health, emerging and re-emerging diseases, infectious diseases, and the need for preventative medicine in this context.

For the **'advancing research in the Pacific'** dimension, specific feedback included:

- Placing more emphasis on New Zealand researchers **building ties with Pacific** researcher.
- Pacific-specific health burdens should constitute a large part of this SIA. This includes more clearly identifying in the Equity dimension the **populations that will be affected the most by climate change** (i.e. Pacific peoples and those with a disability).
- A reference to the UN Convention on the Rights of Persons with Disabilities should be added to this dimension.

6 Appendix A: Draft Strategic Investment Areas consulted on

Note: these represent the original areas consulted on. For the revised approach see: http://www.hrc.govt.nz/news-and-publications/publications/consultation

Draft Strategic Investment Areas for Implementation of the New Zealand Health Research Strategy

1. Strong foundations of health & wellbeing in children & youth

The importance of intervening early and taking a life-course approach to prevention and good health

2. Sustaining health & wellbeing throughout adulthood & ageing
3. Fostering the health & disability system NZ needs
4. Innovating for health and wealth
5. Meeting the challenges of our changing world

Rationale

Ensuring that our youngest New Zealanders grow and develop well depends on more than simply the absence of disease, it means understanding how we can intervene early, even across generations, to set healthy patterns. It means addressing all determinants of physical and mental health and wellbeing – bridging government sectors - and drawing on all research disciplines. We must understand the complex and varied needs of children and young people from every group that makes up our unique New Zealand population to promote an equitable start to life. Finally, we need to understand how each stage in the life-course impacts on future health and bring that understanding to the way we design interventions and services.

Dimensions

and 'thought provokers' for what this Strategic Investment Area might encompass...

Bridging all Strategic Investment Areas

Rangatiratanga

What are the priorities for kaupapa Māori research to **improve outcomes for tamariki and rangatahi**?

Equity

How do the dimensions below differ according to ethnicity, socio-economic status, disability and geographic location?

How do we **promote health equity in New Zealand's children and youth** and recognise and celebrate diversity?

How do we **reduce intergenerational** harm?

Intervention before birth

How are our bodies modified by our environment to influence our health and wellbeing prospects, even before we are born?

What can we apply or develop from **existing knowledge to improve maternal and fetal health**?

How can we **better support prospective parents and pregnant mothers** to improve outcomes?

The first 1000 days of life from conception

How can we **apply what we already know** about the crucial factors in the first 1000 days of life?

What will work to **combat high rates of infectious disease, injury and maltreatment** in New Zealand's children?

Where do the **greatest opportunities to intervene early** for better outcomes lie?

Healthy, happy & resilient children & young people

What are the priorities for research to address **health and social issues** for New Zealand children and youth?

How do we **better utilise the knowledge we have** to design, target, refine and implement interventions and policies?

What is the impact of **the digital world** on our children and youth?

How do we address New Zealand's high rate of **youth suicide**?

A life-course approach to health & wellbeing

Why do **improvements in health and wellbeing for children and youth lag behind** adults in New Zealand?

How do we set and maintain **healthy habits for life**?

How can a **life-course approach** to health and wellbeing help us to better understand and manage life's transitions?

Links to SIA 2: Sustaining health and wellbeing throughout adulthood and ageing

Note: The word health embraces both the physical and mental states

Research characteristics

Novel approaches will be needed that go beyond describing the problems to devising, trialing and evaluating solutions. Projects will be needed that build upon advances and effectively implement our wealth of existing knowledge. Different models, conceptualisations and methodological approaches to understanding health and wellbeing will be needed, including those that build on linked datasets and longitudinal data. Engaging with stakeholders, communities and end-users, and across disciplines and sectors, will be key to meeting the aspiration of this Strategic Investment Area.

Draft Strategic Investment Areas for Implementation of the New Zealand Health Research Strategy

2. Sustaining health & wellbeing throughout adulthood & ageing

Drawing on international knowledge & generating research that addresses the greatest issues for New Zealand adults

1. Strong foundations of health & wellbeing in children & youth
2. Innovating for health & wealth
3. Fostering the health & disability system New Zealand needs
4. Meeting the challenges of our changing world

Rationale

All New Zealanders aspire to live a healthy, happy and independent life, free from acute and chronic diseases. This strategic area is about focusing on the issues that unnecessarily compromise this aspiration for some, and reducing the impact of illness, injury and adverse determinants of physical and mental health. A strong focus on prevention and understanding what contributes to ageing well will be core to this. Most of us will experience illness, injury and disability at some stage in adult life, but research gives us the hope that much can be prevented and optimal, increasingly individualised treatment will be available for that which cannot. Better understanding of where the greatest gains can be made for adult health is key, to ensure that we make the best use of resources. Improvements in adult health and wellbeing have meant that many more of us will live to old age, making ageing well and quality of life in advancing years a major focus of health research around the globe. Much of this research can inform what we do in New Zealand, but there are specific questions for our people that need to be answered by research that is done here.

Dimensions

and 'thought provokers' for what this Strategic Investment Area might encompass...

Bridging all Strategic Investment Areas

Rangatiratanga

What are the key health and wellbeing priorities to **promote positive ageing for Māori**?

Are there opportunities to **adapt existing public health interventions to align with Te Ao Māori** for use in Maori communities?

Equity

What are the most pressing **research priorities for Māori**, **Pacific people, older people and disabled people**?

How do we use existing priorities across the health sector for **Māori and Pacific health outcomes as a driver for alignment between health and social agencies**?

Addressing the greatest burden of disease

What are the **most pressing research priorities** to improve adult health and wellbeing in New Zealand - for young, middle-aged and older adults?

What international research findings could be adopted and adapted in New Zealand to improve outcomes in acute and chronic diseases?

What have we learned already that can be applied now to improve prevention, diagnosis and treatment?

Stratified medicine*

What are the **greatest opportunities to utilise large datasets** to improve precision of diagnosis, prognosis and treatment in New Zealand?

How do we **enhance the capability to use large datasets** at both population and individualised levels?

Links to SIA 1: Strong foundations of health and wellbeing in children and youth - when children and youth benefit from precision-treatment approaches

Determinants of health

What existing knowledge could be used to inform interventions to prevent illness and injury?

What **successful public health interventions** exist that could be scaled up and implemented nationally?

What are the **priorities for new knowledge** on factors that affect health and wellbeing?

What can we do to promote **ageing well** in all New Zealand populations and what questions need to be answered here?

Links to SIA 1: Strong foundations of health and wellbeing in children and youth - when longitudinal approaches across the life-course are the focus

Shifting treatment horizons

What are the **opportunities to make major advances** in the treatment of and rehabilitation from adult diseases and injury?

How can **linked data** be used to gain insights into adult care and design better interventions?

Where does New Zealand have **key strengths and a critical mass** of capacity to address adult health and wellbeing and make a strong contribution to global research efforts?

Links to SIA 1: Strong foundations of health and wellbeing in children and youth - for advances related specifically to early life

Note: The word health embraces both the physical and mental state

* Often called 'personalised medicine', stratified medicine refers to treatment that is optimised for groups of patients that share the same characteristics

Research characteristics

This strategic area covers all determinants of health and acute and chronic mental and physical illness. Meeting the aspiration will require input from all health research disciplines - working together - to address the complex needs of our unique New Zealand adult and ageing population. Capacity and capability needs to be built to better understand and utilise advances in treatment approaches, such as the use of big data and linked datasets, and training will be an important expectation where new techniques and technologies are employed. The prime focus on addressing health equity will also require involvement of Māori and Pacific researchers and the need to work with communities to ensure that we develop 'citizen scientists' in New Zealand whose input is wanted and valued by health researchers and funders.

Draft Strategic Investment Areas for Implementation of the New Zealand Health Research Strategy

3. Fostering the health & disability system New Zealand needs

Research that will deliver better more agile, personal, efficient and cost-effective health services and empower New Zealanders to manage their own health

1. Strong foundations for health & wellbeing in children & youth
2. Sustaining health & wellbeing throughout adulthood & ageing
4. Innovating for health & wealth
5. Meeting the challenges of our changing world

Rationale

Uptake of research findings is highly dependent on the culture that underpins the health system, and the institutions and individuals working within it. A culture where support for, and responsiveness to, research is embedded (e.g. formal arrangements to drive collaboration with end-users) alongside continuous quality improvement practices is a prerequisite for maximising the results of health research. We need effective and efficient services, underpinned by the strongest and most current evidence. A focus on people-centred care highlights the importance of connecting with communities, recognising and respecting diversity, and the interconnectedness of both health service users and the people who work within the health system.

Dimensions

and 'thought provokers' for what this Strategic Investment Area might encompass...

Bridging all Strategic Investment Areas

Rangatiratanga

How can we increase understanding of and **adherence to the principles of Te Tiriti o Waitangi** and cultural safety at all levels of our health system?

How do we foster **stronger linkages and co-ordination between Māori PHOs and DHBs**?

What is working and not working for Māori in our health and disability services?

Equity

How do we ensure **equal access to health and disability services** for all New Zealanders?

How do we ensure that **all New Zealanders enjoy the same standards** of intervention and care?

How do we promote understanding and acceptance of **diversity** and gender choices in decisions on care?

People-centred care

How do we increase **community owned and driven services**?

How can we promote connections between community service providers, PHOs and DHBs to **design services that are well-integrated** in the communities they serve?

How do we make sure that **aged-care and disability services** are meeting increasing need and empowering users to live independently and make their own choices about care?

How can we better use technology and other tools to **assist people to take control of and manage their own health**?

Continuous cycle of improvement

How do we **build evaluation into all research** designed for implementation in our health system?

Where do we need more **evidence of effectiveness** for current practices?

How can we systematically identify what's not working and **disinvest early** to save money for more effective interventions?

What are the **priorities for health systems** research?

Knowledge translation & mobilisation

What are the **key knowledge needs of health practitioners** that should be answered through new research?

How do we create **a research system that continuously identifies and delivers on knowledge needs** identified at the front-line of care?

What have we learned already that can be applied now to increase efficiency, cost-effectiveness and standards of care?

How do we increase the **pace of knowledge translation** in the health system?

Launching innovations

What innovations currently exist that could be utilised in our health system to improve treatment, cost-effectiveness, patient safety or standards of care?

How do we **facilitate the uptake of new technologies** and innovations and establish utility, cost-effectiveness and benefit?

How can we build capability, safety and efficacy in healthcare systems as they become increasingly reliant on **advanced informatics**?

Links to SIA 4: Innovatiing for health & wealth

Note: The word health embraces both the physical and mental state

Research characteristics

This strategic area focuses on putting people right at the heart of services, using existing knowledge well and mobilising new discoveries for rapid impact. Research should be designed so that evaluation is built in and services providers can have confidence that resulting solutions will make a positive difference. A strong focus on partnership with communities will be important, early involvement of anticipated research users, and a continuous focus on outcomes for patients and the wider community. Research users include clinicians, industry, policy-makers, health service staff, the public and other researchers.

Draft Strategic Investment Areas for Implementation of the New Zealand Health Research Strategy

4. Innovating for health & wealth

Harnessing our great ideas and potential for innovation to deliver better health outcomes, a world-class, future-fit health system and a prospering society

1. Strong foundations of health & wellbeing in children & youth
2. Sustaining health & wellbeing throughout adulthood & ageing
3. Fostering the health & disability system NZ needs
5. Meeting the challenges of our changing world

Rationale

Globally, health technologies and practices are changing at a rapid pace. To realise the potential for these to improve health outcomes and increase prosperity for New Zealanders, we need to prepare our people and systems to identify, adapt and accept those innovations that will serve us best. We need research that will fuel the innovation pipeline with important discoveries, novel interventions and technological developments that keep our healthcare and population health services agile, responsive and future-focused and contribute to New Zealand's commercial success in the global health market.We need to develop a dynamic research and innovation system that supports the generation, development and testing of innovative ideas created in New Zealand, including those based on cutting-edge technologies and those that emerge from the health sector. We also need the ability to future-scan and identify promising new developments from other countries or sectors; and the expertise to transfer or adapt those innovations for our local populations and health settings. We need agile people and processes to support the implementation of innovations, and to use evidence from evaluation to either scale up what works across the health system, or rapidly disinvest.

Dimensions

and 'thought provokers' for what this Strategic Investment Area might encompass ...

Bridging all Strategic Investment Areas

Rangatiratanga

How do we realise the potential for unique ideas that originate from **te Ao Māori and Rongoā Māori**, to improve health outcomes?

How should **Māori data sovereignty** be addressed and what processes should be followed by all researchers compiling Māori data?

Equity

What are the issues around access to new technologies for lower socio-economic and marginalised groups and how do we **avoid compromising health equity as we drive innovation**?

Feeding the innovation pipeline

How do we best identify and support **discovery research** that will underpin biological, chemical & technological innovation?

What is the role of **high-risk, high-impact science**?

How can we **adapt innovation from other sectors** to advance health and wellbeing, such as veterinary science and engineering?

Developing & applying innovations

How can we identify and adapt **innovations developed internationally** to improve effectiveness, efficiency or cost-effectiveness of care in New Zealand?

How can we **harness the potential for novel or disruptive ideas** that emerge from the New Zealand science and health sectors?

How do we build capacity for participation in local or international **randomised controlled trials?**

How do we build on New Zealand's strengths to develop **innovations for the global health market**?

Innovating with data and methods

How can we utilise new **datasets** or linked, existing datasets to gain new insights or knowledge?

How can New Zealand best contribute to, and benefit from, advances in **'big data' science**, such as 'omics' research, physiological modelling, and biobanks?

What areas require the development of **new health research methodologies**, or adaptation of methods used in other research sectors?

Culture and ethics of innovation

What new approaches are needed to successfully **embed innovation in the health system**?

How do we **prepare New Zealand society for rapid innovation**?

How do we address the **ethical issues around collection & use of big data & linked datasets**?

What are the **ethical implications of innovations that eliminate disabilities** or substantially change the lived experience of disabled people?

Note: The word health embraces the mental and physical state

Research characteristics

This strategic area is about transforming New Zealand through excellent research building on ambitious and visionary ideas. All research disciplines can contribute to the innovation pipeline.'Blue skies' science is essential to drive new ideas, and research that crosses disciplines or sectors is encouraged to capitalise on existing technological advances. Health providers should help to drive the research agenda, by partnering directly with researchers to develop innovative solutions for identified needs. Engagement with the commercial sector is critical to developing the thinking and priorities that lead to more effective health outcomes. Ethical considerations are paramount as the way in which research is conducted and used, continues to evolve. If these issues are not addressed in tandem, they will constitute major barriers to the uptake of innovation.

Draft Strategic Investment Areas for Implementation of the New Zealand Health Research Strategy

5. Meeting the challenges of our changing world

Preparing New Zealand for the health impacts of future events

1. Strong foundations of health & wellbeing in children & youth
2. Sustaining health & wellbeing throughout adulthood & ageing
3. Fostering the health & disability system NZ needs
4. Innovation for health & wealth

Rationale

Our world is rapidly changing and with those changes come an altered environment, population, burden of disease and new risks that we must prepare for to minimise or negate adverse health impacts as much as possible. As a nation, we must be prepared for changes that we are not driving - unlike those we are seeking to initiate under Strategic Investment Area 4: Innovation for Health and Wealth. We need to be part of the international conversations and research endeavours on issues such as strengthening resiliency in the face of natural disasters, preparing for pandemics and dealing with resistance to drugs used to treat bacterial, viral and fungal infections. Diseases that have been controlled are re-emerging and infections will continue to cross the boundary between species and pose a threat to humans. This Strategic Investment Area is about preparing for what may lie ahead and linking with global initiatives wherever New Zealand will benefit or can make a strong contribution.

Dimensions

and 'thought provokers' for what this Strategic Investment Area might encompass...

Bridging all Strategic Investment Areas

Rangatiratanga

What will be the **impact of climate change on traditional Māori food sources** and collection practices?

What does a flourishing and robust society look like for Māori in the future?

How can Māori researchers use their expertise in international efforts to make **a better future for indigenous peoples**?

Equity

How can we learn from and contribute to international programmes relating to a more equitable future, such as the **UN Sustainable Development Goals of Reducing Inequalities, No Poverty and Zero Hunger?**

How can we apply knowledge gleaned nationally and internationally to ensure **more equitable health and social systems in the future?**

Responding to climate change

How do we prepare for **changes in disease patterns** resulting from insect or human carriers?

What are the implications for **food safety and security in New Zealand,** e.g. toxins from mould, algae blooms, pesticides and pollutants?

How do we prepare for **exposure to more extreme weather** events and their health and social impact?

How do we prepare for **migration due to climate change**?

What are the priorities for **environmental health** research?

Emerging & re-emerging diseases

What do we need to do and know to prepare for **global pandemics?**

How can we contribute to the global efforts to tackle **resistance to drugs used to treat infections?**
- link internationally, support public education, and retain knowledge over time?

How do we understand and act on factors driving **emerging & re-emerging infectious diseases**
- What can we apply from what is already known?

How do we protect New Zealand from **infections transmitted by animals**?

Future-proofing New Zealand

How do we improve our ability to **predict the biggest health challenges** in the future?

How can we prepare for the long-term impact of **changes in the age and composition of the New Zealand population**?

How will **changing migration patterns** affect health and health service delivery?

What are the implications of **rapid technological change**?

What are the health and wellbeing implications of **changes to the way that we live and work** in the future?

How will **artificial intelligence** change New Zealand life and health service delivery?

Advancing research in the Pacific

How do we meet our commitment to **support the health and well-being** of our Pacific citizens living in the Pacific and our Pacific neighbours?·

What are the **key health health and social issues for Pacific peoples** related to our changing world?·

How do we **link New Zealand researchers with those based in the Pacific Islands** to address health and disability issues and build research capacity?

Note: The word health embraces both the physical and the mental state

Research characteristics

All research disciplines will be needed to address the dimensions of this strategic area. A strong focus on international collaboration will be important, as well as inter-disciplinary approaches that bring together the diverse skills needed to tackle complex issues, such as climate change. Linking with international efforts, building on what is already known and improving our ability to future-scan and predict possible outcomes will all be crucial in preparing New Zealand for a changing world.

7 Appendix B: Suggested health research priorities

The consultation process required submitters to list any health research priorities they believe should be included in the framework, by each SIA and their respective dimensions. Below the health research priorities submitters suggested have been aggregated into common themes.

The total value in the first row reflects the total number of *submissions* that made at least one suggestion that engaged with the theme. As the vast majority of submitters made more than one suggestion, the "total number" column will not total the number of submissions made. Note that the total number does not include suggestions from submitters who chose not to make their submission publicly available.

7.1 Dimensions

7.1.1 Equity

	Total Number
TOTAL	*5*
Māori and Pasifika people	2
Bias	2
At-risk communities	1
Climate change and its social implications	1

7.1.2 Future Focus

	Total Number
TOTAL	*1*
Prioritisation of future risks	1
Multi-dimensional approach to the dimensions	0

7.1.3 Innovation

	Total Number
TOTAL	*1*
Technology	1
New knowledge	0
Health workforce	1

7.1.4 Health systems

	Total Number
TOTAL	*22*
Access to care	7

Quality improvement	6
Outcomes focus	4
Youth	4
Equity	3
Cost effectiveness	5
Preventative measures, including screening and risk assessment	1
Transitions between providers	4
Technology for health access (e.g. e-health)	2
Pacific research	2
Primary care	0
Education and training of providers	2
People-centred care	1
Pharmacy	1
Integration of innovative ideas	0
HIV treatments	1
Disability	0
Clinical guidelines	1
Education of the population	1
Pre-natal care	1
Rural populations	1
Critical illness	1
Public vs private healthcare	1

7.1.5 Rangatiratanga

	Total Number
TOTAL	*1*
Partnership/participation	1
Sharing knowledge	1

7.2 Framework

7.2.1 Research Methodology

	Total Number
TOTAL	*1*
Communication and involvement/Consumer led approaches	6
Biomedical science	4

Clinical trials facilities	4
Cell Biology	0
Co-design	1
Randomised control trial	1
Preclinical and clinical research	1
Comparative effectiveness research and cost effectiveness	1

7.3 Funding

7.3.1 MoH funding

	Total Number
TOTAL	*1*
Community led organisations	1

7.3.2 Implementation

	Total Number
TOTAL	*1*

7.3.3 Government Policy

	Total Number
TOTAL	*4*
Health system	2
Cost effectiveness	1
Impact of the Health and Disability Act	1
Taxation	1

7.3.4 Health Workforce

	Total Number
TOTAL	*16*
Researcher training and research quality	5
Allied health	3
Wider education of workers (eg on nutrition, breast cancer and new therapies)	2
Infrastructure	2
Resourcing	2
Use of technology	2
Preparedness for possible future scenarios (e.g. natural disaster, pandemic, changing population)	2

Disability	2
Breast cancer	2
NZ specific research and data	0
HIV care and surveillance	0
STI care and surveillance	0
Palliative care	1
Pacific focus	1
Mental health and addiction	1
Workforce migration and its implications	1
Pre- and Antenatal care	1
Dementia and other cognitive conditions	0
Preventative / early intervention healthcare	1

7.4 Health Issues/ Thematic Priorities

7.4.1 Aging Population

	Total Number
TOTAL	*18*
Dementia and other age-associated cognitive problems	8
Death / palliative care	4
Cultural and sexual diversity of older adult samples in research	3
Community support in old age (outside of public health)	3
Living well with disability or chronic illness in old age	2
Housing options and quality	2
Responding to change in composition of the population	2
Sustaining work ability in old age	1
Hearing loss	1
Oral health	1
Diabetes	1

7.4.2 Burden of disease

	Total Number
TOTAL	*6*
Morbidity	3
Mortality	3
Locating and targeting the greatest burden of disease	3
Cardiovascular health	2

Chronic disease	1
Obesity	1
Cancer	1
Smoking	0
Exercise	0
Mental health	0
Rare diseases	0

7.4.3 Cancer

	Total Number
TOTAL	*12*
Supporting novel alternative treatments (new drug targets and technologies, i.e. transformative and translational research) and emerging researchers with novel ideas	18
Breast cancer	5
Genomics / gene-based approaches	4
Quality of research (e.g. international collaboration, trial design)	4
Equity	3
Improvement of early detection methods	3
Skin cancer	3
Healthcare system	2
Gynaecological cancers and women's health	1
Rare diseases	1
Prevention methods	1
Cancer in childhood	1
Lung cancer	1
Colorectal cancer	1
Smoking and alcohol	1

7.4.4 Child Health

	Total Number
TOTAL	*34*
Prenatal health (including maternal health during pregnancy)	12
Life course approach (including management of risk factors and early intervention)	13
First 1000 days	5
Mental health	5

Drug discovery / development of novel treatments for youth specific disease	4
Health care system, including access to resources and education	4
Trauma	3
Equity	3
Reproductive health and education	3
Genomic screening	2
Chronic disease management	2
Labour and birth	2
Congenital disease	2
Family	1
Genetic disorders	1

7.4.5 Chronic Illness

	Total Number
TOTAL	*14*
Neurological disease	3
Cardiovascular disease	2
Day to day management	3
Diabetes	2
Obesity	2
Healthcare system	2
Coeliac disease	2
Asthma	1
Rheumatoid arthritis	1
Palliative care	1
Immunology	1
Antibiotics	1
Genetics	1
Mental health	1
Degenerative diseases	1

7.4.6 Climate Change

	Total Number
TOTAL	*7*
Environmental health	3
Pacific focussed research	3
Future-proofing	2
Drug resistance	2

Collaborative research	0
Tuberculosis and viral disease	1
Meteorological events	0

7.4.7 Diagnosis

	Total Number
TOTAL	*3*
Genetic screening	1
HIV	1
Stratified medicine	1

7.4.8 Disability

	Total Number
TOTAL	*14*
Wellbeing with disability	6
Youth	5
Social relations and development, including support from social sources	4
Accessibility of the research process	2
Vision or other cognitive impairment	2
Māori focus	1
Inclusive urban planning	1
Novel approaches to disability prevention	1
Engagement with healthcare	1
Learning and development	1
Mental health	0

7.4.9 Evaluation

	Total Number
TOTAL	*2*
Evaluation of interventions	1
Youth	1
Definition of wellbeing and how to obtain it	1

7.4.10 Existing treatments

	Total Number
TOTAL	*2*
Complementary and integrative medicines	1

Medication-induced morbidity and mortality	1
Medication delivery	1

7.4.11 Infectious Disease

	Total Number
TOTAL	*7*
Sexually Transmitted Diseases	2
Immunology	1
Children	2
Prevention	0
Equity	0
Vaccine	1
Respiratory	1
Disease mechanism / physiology	3

7.4.12 Injury

	Total Number
TOTAL	*3*
Mortality/Morbidity	2
Prevention	2
Trauma	0
Disability	1
Rehabilitation	1
Children and young people settings	1

7.4.13 Lifecourse approach

	Total Number
TOTAL	*1*
Climate change	1

7.4.14 Māori Health

	Total Number
TOTAL	*13*
Smoking (/vaping)	3

Natural/tradition medicine	1
Burden of Disease	1
Artificial intelligence	1
Disabilities/ disability services	1
Childhood obesity	1
Matauranga Māori	1
Renal Disease/Failure	1
Lung Cancer	1
Maternal Alcohol consumption	1
Health Care delivery	1
Public health	1
Non-communicable diseases	1
DNA mapping	1

7.4.15 Mental Health

	Total Number
TOTAL	*25*
Youth	15
Mental Health services/treatment/early intervention	7
Addiction	5
Suicide	5
Māori/Pacific	2
Exposure/ Experience (childhood)	1
Biologics	1
Physical activity	0
Epidemiology	1

7.4.16 NCDs

	Total Number
TOTAL	*6*
Children/young people well being	1
Chronic disease (Obesity/ Diabetes/ CVD)	3
Epigenetics	2
Headache disorders	2

Chronic Fatigue Syndrome/ Myalgia encephalomyelitis	1
Mental Health	1
Coeliac Disease	1
General	0

7.4.17 Nutrition

	Total Number
TOTAL	*5*
Political & socioeconomic relationships and factors	1
GMO food safety	1

7.4.18 Obesity

	Total Number
TOTAL	*10*
Childhood/maternal obesity	3
Implications (metabolic disorders, cancer, CVD etc)	1
Māori/Pacific Islanders	1
Sugar tax	1
Health promotion	1

7.4.19 Oral Health

	Total Number
TOTAL	*0*
Childhood obesity & oral health	0

7.4.20 Pacific Health

	Total Number
TOTAL	*13*
Children and young people	3
Pasifika equity	2
Immigrants (epigenetics)	2
Elder care/ palliative	1
Nutrition	1

7.4.21 Prevention

	Total Number
TOTAL	*19*
Nutrition (children)	2
Physical activity (children & adults)	2
Sexually Transmitted Diseases	2
Injury/illness & disease	1
Healthcare system	0
Genetic	2
Living conditions	1
Obesity	1
Health determinants	1
Oral health	1
Population knowledge	1
Skin cancer	1
Lung cancer (smoking)	1
Vaccination	0
Chronic illness	1
Hazardous chemicals	0

7.4.22 Rehabilitation

	Total Number
TOTAL	*1*
Online programmes and devices	1

7.4.23 Social Determinants of Health

	Total Number
TOTAL	*20*
Family/ whānua	8
Gender equity and diversity	8
Children/young people	5
Equity/ At-risk groups	6
Education	2

Housing	3
Lifestyle (diet, physical activities. Etc)	2
Community research /interventions	2
Social connection	2
Low socio-economic status	0
Environment	0
Occupation health	0
Chronic diseases	0

7.4.24 Treatment

	Total Number
TOTAL	*16*
Pharmacy	6
Technology	6
Complementary and alternative medicine	2
Antibiotics resistance	2
Comparative effectiveness	0
New therapies for children	1
Stratified medicine	1

7.4.25 Wellbeing

	Total Number
TOTAL	*1*
Health promotion	1
Male health	0

7.5 New Zealand Health Research Strategy

7.5.1 Strategic Priority 2

	Total Number
TOTAL	*3*
Action 6 – translation of science to clinical trials	0
Action 5 & 6 -	3
Mental health	1
Addiction	1

Community health	1
Models of healthcare	1
Action 7 – Health care delivery	2

7.5.2 Strategic Priority 3

	Total Number
TOTAL	*3*
Action 7 -	3
Impact	1
Barriers to implementation/translating	2

7.6 Structural Priorities

7.6.1 Data

	Total Number
TOTAL	*10*
Comprehensiveness of data (cultural and sexual diversity)	5
Data mining	3
Linked data	3
Data quality	3
Large datasets	2
Mental health data	2
Collaborative effort (both international and with public health data)	1
Longitudinal data	1
Measurement of quality of life	1
Primary care data	1
Aetiology	1

7.6.2 Where Research is done

	Total Number
TOTAL	*11*
NZ research	7
International research	4

7.6.3 Research Workforce

	Total Number
TOTAL	*10*
Methodology development/upskilling workforce	3
Support career development	3
Recruiting a commercial partner	1
Māori workforce	1
Diversity	1

7.6.4 Research Translation

	Total Number
TOTAL	*20*
Evaluation	5
Impact	2
Barriers to implementation	2
Health economics	1
Updating knowledge	1

7.6.5 Health Systems

	Total Number
TOTAL	*22*
Access to care	7
Outcomes focus	4
Quality improvement	6
Cost effectiveness	5
Youth	4
Equity	3
Transitions between providers	4
Preventative measures, including screening and risks	1
Rural populations	1
Technology for health access (eg e-health)	2
Pacific research	2
Primary care	0
Knowledge of providers	2
Education of the population	1
People-centred care	1
Pharmacy	1

Integration of innovative ideas	0
HIV treatments	1
Disability	0
Clinical guidelines	1
Pre-natal care	1
Critical illness	1
Public vs private healthcare	1