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# New Zealand Health Research Strategy 2017–2027

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Summary of submissions  
and consultation

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Released February 2017

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## Executive summary

The *New Zealand Health Research Strategy 2017–2027* will set a 10-year strategic direction for the health research system. Its aim is to ensure that investments in health research make the greatest contribution to the lives of New Zealanders – to their health and their economic and social wellbeing.

In May 2016 the Government published the *New Zealand Health Research Strategy: Public discussion document*. This formed the basis for discussions with stakeholders throughout New Zealand on the directions and priorities of the Health Research Strategy.

The Ministry of Business, Innovation and Employment (MBIE), the Ministry of Health and the Health Research Council (HRC) met with a range of stakeholders in the health research system, mostly in May, June and July 2016. They held three government agency workshops, 10 regional consultations and 24 topic-specific workshops, including workshops for prioritisation, Māori health research, Pacific health research and disability research.

This document, *New Zealand Health Research Strategy 2017–2027: Summary of submissions and consultation*, presents the analysis of submissions received and the key themes that emerged from the public consultations and focus groups. MBIE and the Ministry of Health undertook the analysis, with assistance from the HRC.

A wide range of stakeholders provided 166 written submissions. These stakeholders included researchers, non-governmental organisations, universities, district health boards and health professional associations.

In general, submitters enthusiastically welcomed the development of a strategy for health research in New Zealand. Specifically they noted that the public discussion document provided a useful starting point for developing the strategy. Most stakeholders agreed with the broad direction of the document, while levels of support varied for the draft vision, mission and guiding principles.

Most submissions did not respond directly to the 16 specific questions raised in the *New Zealand Health Research Strategy: Public discussion document*. Typically, submitters used the questions to stimulate discussion around areas of interest to them. Therefore, this analysis identifies broad themes from the submissions rather than the specific responses to questions.

Officials will use the insights gained from the consultation process and the submissions to provide advice to Ministers on the New Zealand Health Research Strategy 2017–2027. MBIE and the Ministry of Health expect to publish the strategy in 2017.



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# 1 Introduction

1. This document presents key themes and actions from the written submissions and consultation meetings to inform the development of the New Zealand Health Research Strategy 2017–2027 (the strategy). The Ministry of Business, Innovation and Employment (MBIE) and the Ministry of Health, with assistance from the Health Research Council (HRC), prepared this document.

## 1.1 Background to the strategy

2. The development of a New Zealand Health Research Strategy was a key recommendation from the review of the HRC, completed in July 2015.
3. Developing a strategy provides an opportunity to build stronger connections across the health sector and the science and innovation system. It can strengthen these connections by describing the roles of all those involved in health research improving the uptake of knowledge and innovative solutions across the health sector, and signalling investment priorities.
4. The strategy provides New Zealand with the opportunity to:
  - set an **agreed direction** for health research
  - ensure health research **contributes to government strategies and priorities**
  - ensure the system has effective mechanisms for **translating research** findings into policy and practice
  - develop a **better-connected system** where strengths of all contributors are valued and used, and where health research better addresses the health needs of New Zealanders
  - articulate a set of **clear roles and responsibilities** for the various parts of the system
  - identify New Zealand's **unique roles in health research**
  - ensure New Zealand has the **health research skills** it needs
  - identify where New Zealand can **add greatest value** to the international research effort.
5. The strategy is being developed in an environment where the Government has significantly increased investment in health research. In May 2016, the Government announced an increase of \$97 million in health research funding to the HRC, which represents an increase of 56 percent over four years from \$77 million in 2015/16 to \$120m in 2019/20. This is the largest single increase in health research funding in New Zealand's history.

## 1.2 Key government roles in health research

### *Roles of the Minister of Health and the Minister of Science and Innovation*

6. The Government provides significant funding for health research in New Zealand. The primary funder for health research is the HRC. Following the 2015 review the HRC is now expected to also provide a strategic leadership role in the sector. The HRC is funded through Vote Business, Science and Innovation, which also supports health research through the National Science Challenges and to a lesser extent the Marsden Fund. In addition, the Tertiary Education Commission funds health research through the Centres of Research Excellence and indirectly through the Performance-Based Research Fund. The Ministry of Health and other government agencies, such as the Accident Compensation Corporation (ACC), commission specific studies on health research.
7. The Minister of Health and the Minister of Science and Innovation are jointly responsible for the efficient and effective functioning of the HRC. The Ministers recognise that to achieve maximum benefit from health research, New Zealand needs a dynamic and well-connected health research and innovation system with strategic leadership and oversight from both Ministers.
8. The Minister of Health and the Minister of Science and Innovation are jointly responsible for developing and overseeing the implementation of a Health Research Strategy for New Zealand. This strategy will provide a high-level and long-term strategic direction for the health research and innovation system, particularly for the HRC. The Ministry of Health and MBIE provide advice to their Ministers on the strategy.

### *Roles of MBIE and the Ministry of Health*

9. MBIE has a responsibility to ensure the HRC is part of a cohesive science and innovation system, that HRC funding aligns with other investments in the science system, and that the economic and scientific benefits of health research are maximised.
10. The Ministry of Health has a responsibility to ensure that the HRC is connected to the health sector and the research that it funds is responsive to the health needs of New Zealanders and the health system.

### *Role of the Health Research Council*

11. The HRC has both a funding and strategic leadership role in health research. It is the government's primary investor of funds dedicated to health research. This includes funding research in biomedical sciences, population and public health, Māori health, clinical care and health service delivery. The HRC is a Crown entity established by the Health Research Council Act 1990, under which the Minister of Health is the responsible Minister.



## 2 Consultation on the strategy

12. In May 2016 the Government published the *New Zealand Health Research Strategy: Public Discussion Document*. The Government undertook a public consultation on the public discussion document between 17 May 2016 and 7 September 2016. Written submissions could be made from 17 May 2016 until 29 July 2016.
13. The public discussion document provided an overview of the current state of health research in New Zealand. It also set out a draft vision, mission, guiding principles and five example strategic priorities for public comment.
14. Submitters were asked to provide feedback on:
  - a. the proposed vision, mission, guiding principles and strategic priorities and whether these provided the right direction for health research in New Zealand in 2027
  - b. how the Health Research Strategy could support the *New Zealand Health Strategy: Future Direction* (Ministry of Health 2016)
  - c. how to get more excellent science and high-impact research supporting the National Statement of Science Investment
  - d. the challenges and opportunities in health research in New Zealand
  - e. how to build a more cohesive and connected system
  - f. where health research could make the most difference to the health and wellbeing of New Zealanders
  - g. how to ensure health research helps to address the health needs of all New Zealanders
  - h. how to improve the uptake of research results and innovation.
15. In addition to calling for written submissions on the discussion document, MBIE, the Ministry of Health and HRC held the following consultation engagements (some outside the period stated in paragraph 12):
  - a. three specific government agency workshops held before public consultation (covering the roles of agencies in research, the issues that informed the development of the strategic priorities, and discussion on the strategic priorities)
  - b. 10 regional consultations (attended by 275 participants)
  - c. 24 topic-specific focus groups (attended by 252 participants).

### 2.1 Approach to analysis

16. Officials reviewed each submission and identified the broad themes in the responses. Some submissions specifically answered the 16 questions asked in the public discussion document, while others did not.

17. This document avoids placing simple counts of submissions next to statements. In general, submissions from groups and institutions provided more in-depth analysis and comments than those from individuals. Group and institutional submissions also represented a large number of people – sometimes thousands. They therefore received significantly more weight in forming this summary document. Those submissions representing a large organisation, such as an entire iwi, university, district health board or group of health professionals, received the most weighting in the analysis.
18. In many places this document discusses submission groups. The main groups making submissions are group or institutional submissions from non-governmental organisations, universities, district health boards and other health service providers, and health professional associations. Smaller groups making submissions are those from consumer organisations<sup>1</sup> and government agencies.
19. In addition to the submissions, the analysis includes key themes emerging from the government agency workshops, the public consultation meetings and the topic-specific focus groups.
20. Officials will use the insights gained from the consultation process and the submissions to provide advice to Ministers on the New Zealand Health Research Strategy 2017–2027. MBIE and the Ministry of Health expect to publish the strategy in 2017.

## 2.2 Overview of responses received

### *Written public submissions*

21. 166 written submissions were received on the public discussion document. Table 1 breaks down the submissions based primarily on the submitters' self-selection of the sector(s) that their submission represented. Some submitters indicated multiple affiliations and have therefore been counted more than once. Appendix 1 provides a full list of submitters.

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<sup>1</sup> The categories of not-for-profit organisations and consumer organisations overlap significantly, but some group submissions specifically selected the 'consumer' category.

**Table 1: Breakdown of written submissions**

<b>Group or institutional submissions*</b>	<b>Number</b>
Non-governmental organisations	33
Universities or their schools, faculties, departments or research groups	29
District health boards or their units	17
Health professional associations	15
Consumer organisations	7
Government agencies	7
Other health service providers (excluding district health boards)	3
Independent research organisations	2
Institutes of technology or polytechnics	2
Crown Research Institute	1
National Science Challenge	1
Other	3
<b>TOTAL</b>	<b>110</b>
<b>Individual submissions**</b>	<b>Number</b>
Researchers†	44
Tertiary education organisations††	32
Health service agencies	13
Independent research organisations	3
Elsewhere or unable to be determined	6
Individuals associated with health services agencies	8
Industry	1
Other	3
<b>TOTAL</b>	<b>56</b>

**Notes**

\* Of group submissions, five associated with Māori, three with Pacific and three with Asian communities.

\*\* Of individual submissions, three associated with Asian, two with Māori and one with Pacific communities. They include one submission from six individuals, which submitters marked as an individual submission. Where a researcher also selected other categories, such as consumer, the figures only count the submission as a researcher submission. This is to ensure consistent categorisation of individual submissions.

† Researchers can have multiple affiliations, so numbers add to more than 100%.

†† Nearly all researchers from tertiary education organisations were from universities.

*Regional consultation meetings*

22. Officials held 10 regional consultation meetings: four in Auckland, one in Hamilton, two in Wellington, one in Christchurch and two in Dunedin. Table 2 shows the affiliations stated by the 275 people who attended. Of this total, 34 indicated an iwi affiliation.

**Table 2: Affiliation of regional consultation attendees**

Affiliation	Number
Universities	132
District health boards	40
Not-for-profit organisations	27
Government agencies	16
Professional bodies	12
Institutes of technology and polytechnics	11
Members of the public	11
Industry	8
Crown Research Institutes	7
Māori organisations	6
Independent research organisations	4
Pacific organisations	1

### *Topic-specific focus groups*

23. Officials held 24 invitation-only focus groups covering the range of topics listed in Table 3.
24. In total, 252 people attended the focus groups. Potential attendees for each group were invited based on their expertise in the given area of discussion. The make-up of each group was deliberately designed to promote debate and discussion. For example, researchers, university commercialisation and research offices, firms, industry associations, district health boards and not-for-profit organisations attended the commercialisation workshops.

**Table 3: Number of attendees by focus group topic**

Topic	Number*
Prioritisation of health research	40
Role of health service agencies	39
Workforce	15
Commercialisation	24
Not-for-profit organisations	17
Government agencies and health research	8
Health research trends and opportunities	14
Māori health research	36
Pacific health research	14
Disability research	64

Note

\* Some focus groups discussed two topics. In these cases numbers have not been separated by topic.

## 3 Overview of key themes

### 3.1 Areas of common agreement

25. **Prioritising equity of health outcomes** –all group submissions and many individual submissions highlighted the need for health research to seek to improve health equity. These views were expressed in submissions from across the sector, including research organisations, individual researchers, health service agencies, health professional associations and groups representing particular communities such as Māori and Pacific peoples. Achieving equity in health outcomes must be central to the Health Research Strategy.
26. **Enhancing collaboration and engaging users** – all group submissions and many individual submissions emphasised the need for more collaboration across the system. This includes collaboration between researchers in New Zealand and offshore and with researchers and health service providers and health consumers. Various group submissions emphasised or focused on different aspects of collaboration. Health sector agencies and not-for-profit organisations tended to emphasise collaboration between researchers, the health sector and consumers. University submissions also identified the need for more of this sort of collaboration, but they placed greater emphasis on researcher-to-researcher collaboration and the need to encourage more international collaboration. Submissions also highlighted the need for communities, health consumers and their representatives to be engaged in health research from beginning to end through a co-design or co-development approach.
27. **Building a culture of research and innovation in the health sector** – all submission groups, including from the health sector and universities, called for the health sector to embrace research and innovation – to be ‘research and innovation ready’. In their view, the Government needs to provide support and leadership for research and innovation within the health sector, in particular district health boards. The current lack of engagement by DHBs is inhibiting the usefulness of research results, holding back certain areas of research and limiting the extent to which health professionals are taking up research findings and translating them into practice. More engagement of the health sector in research would also make it easier for the health sector to attract and retain leading practitioners.
28. **Engagement with Māori** – many submissions, including group submissions from across the sector, supported a strong focus on health research that improves Māori outcomes and on a system that supports working in partnership with Māori. Many submissions recognised Māori health research is a strength for New Zealand, but that the Government needs to provide ongoing support to strengthen research capacities. In addition, there was strong support for recognising the Treaty of Waitangi as central to the strategy. There was also support for research ‘By Māori for Māori’ as a way to improve Māori health and wellbeing and improve equity.
29. **Setting priorities for investment in health research** – there was broad support for having priorities that guide at least some of the government’s investment in health research. Some submissions also suggested various approaches to prioritising health research. These emphasised transparency and inclusiveness.

30. **Focusing on research translation** – the need for more effective ways of translating research findings into policy and practice was a key point of agreement in consultation focus groups and workshops and in submissions from across the sector. Many submissions included specific suggestions for translating research and some called for improvements to existing channels and mechanisms for research translation. Some submissions underscored the importance of embedding research into clinical practice. Others called for better use of existing research knowledge (national and international); making robust, high-quality research results accessible; and providing tools and resources for research translation.
31. **Developing the health research workforce and research skills of health practitioners** – making workforce development a central part of the strategy gained support from all main submitter groups, although the calls were strongest from individual researchers and universities. Many highlighted the need to retain either existing health researchers or health research graduates. Some submissions identified the need to provide pathways to develop and enable the research skills of health practitioners. Other submissions saw the need to address the gap in emerging and mid-career research opportunities.

## 3.2 Areas of difference

32. There were few areas where those providing feedback on the strategy expressed divergent views. Differences in submissions tended to be differences in degree of emphasis rather than opposing views.
33. Health researchers and universities were much more likely to highlight the need to continue support for investigator-initiated research. They were also the only group to highlight the importance of **excellent research** and maintaining New Zealand's **international reputation** for high-quality health research. Building and strengthening international connections, and joining international health research efforts, were other topics this group mentioned more frequently.
34. Views differed on the degree to which health research in New Zealand should focus on New Zealand-specific issues and whether to **target investment** at health issues facing New Zealanders. Submissions from universities were more likely to highlight the need to limit top-down, mission-oriented research and allow for more investigator-led research. Other submissions, in particular from community groups and the health sector, stated that health research in New Zealand must focus on improving health outcomes for New Zealanders.
35. Submissions from district health boards and health professional associations placed more emphasis on **clinical research, health service delivery, implementation, evaluation and behavioural studies**. These submissions were also more likely to call for support for investment in research infrastructure in district health boards. Several university submissions highlighted the importance of **basic research**, in particular biomedical research.
36. Not-for-profit organisations placed most emphasis on **engaging more with communities** throughout the entire research process.

### 3.3 Additional themes

37. **Pacific Health research** – submissions commenting on Pacific health research focussed on the need to include the social determinants of health and the sociocultural factors that influence the poor health outcomes of Pacific people. There was strong support for developing the Pacific health research workforce.
38. **Disability research** – submissions identified the need for there to be a clear focus on disability research and developing the disability research workforce. Some submissions focussed on the need for a consumer focus for disability research: ‘nothing about us without us’. There was a strong view expressed that the relationship between disability research and health research needed to be clarified.
39. **New Zealand clinical trials** – a strong clinical trials industry in district health boards was identified in many submissions as required to provide optimal care for patients and to turn med-tech and bio-tech industries into a mainstay for New Zealand. For this to happen, national-level networks and a coordinating body are needed.
40. **Funding health research** – a number of submissions identified the need to develop new funding models for excellent research that provide more stable funding to better support collaboration and co-design, engage health practitioners, allow for higher risk research and address evaluation and research translation funding gaps.
41. **Building infrastructure** – many submissions supported developing national level infrastructure for databases on health research and results, integrated health data, biobanks and translation infrastructure. There was strong support for the development of a clinical research infrastructure in district health boards.
42. **Improving ethics and regulatory systems** – there was a strong call from submissions to make ethics central to the New Zealand Health Research Strategy in order to improve protection for research participants, ethics around data and samples, regulation of medical devices and management of conflicts of interests.
43. The following sections provide details of stakeholder responses in relation to particular themes. Quotes serve to illustrate points raised in submissions. For privacy reasons the quotes are attributed to the categories set out on page 4.

## 4 Strengthening the health research system

### 4.1 Enhancing the roles of stakeholders

44. The role of health research stakeholders in enhancing health research and its uptake received significant comment in both written submissions and consultation workshops. People acknowledged that all stakeholders need to be research and innovation 'ready' for the system to function successfully.

Health research and development should be an integral part of the way in which we plan and deliver health services and population health initiatives. Health research can only be successful with widespread support and commitment of communities, consumers and providers of health services. (District health board)

45. Feedback from submissions indicated that work is required to enhance the role of the following stakeholder groups in the health research system.
- a. District health boards and other health and social service providers need to be more engaged in research and in implementing research.
  - b. Health practitioners, including nurses and allied health staff, need to be actively involved in health research and implementation.
  - c. Groups such as PHARMAC, the Pharmacology and Therapeutics Advisory Committee and Medsafe have key roles in research implementation.
  - d. The private sector needs to engage in research and use the results of research (including in social enterprises).
  - e. Community groups and not-for-profit organisations should be involved in setting the research agenda, undertaking research and implementing research.
  - f. The public, particularly the Māori, Pacific and disability communities, should be involved in setting the research agenda and as participants in health research.
46. Few submissions commented on enhancing the role of researchers. There was, however, detailed comment on developing and retaining health researchers in New Zealand (see section 6).
47. Most submissions on enhancing the role of stakeholders, across all submitter groups, focused on clarifying the role of district health boards in health research.

In an ideal system, the three pillars are service delivery, education of the current and future health workforce, and research. Without research, how do we know what care to deliver and how to deliver it? (District health board)

Currently DHBs are not required to facilitate research and, we understand, they are not sufficiently resourced to run effective research processes. Therefore, given competing priorities and targets, they cannot give research facilitation appropriate support ... Clinicians ... do not currently have appropriate opportunities to add to our evidence base of clinician research. Yet research-active clinicians are a critical resource in translation of research into clinical practice ... In not having a robust DHB research culture New Zealand is the anomaly.



The solution is in setting key performance indicators [KPIs] for research for DHBs, supported by mapping the funding available to achieve these KPIs, developing systems to use this better, and increasing funding if and where there are key gaps. (University)

The strategy should seek (1) to enable the DHBs, PHOs [primary health organisations] and other community-based health practitioners to engage in research; (2) to legitimise this engagement in the eyes of DHB management, the Ministry of Health and practitioners' other funding agencies. (University)

48. One submitter, representing a large district health board, summarised the range of barriers that would need to be addressed for district health boards to engage more with health research:

- a. the activity-based funding model of New Zealand health providers
- b. the short-term planning focus of New Zealand health providers
- c. the lack of research infrastructure (facilities, people, equipment)
- d. the lack of connectedness
- e. the absence of health research as a specific goal for district health boards.

49. The most common suggestion for addressing these barriers was to provide district health boards with a research KPI or specific requirement to engage in research (29 submissions).

Central direction is needed to ensure that DHB Boards and CEOs [chief executives] are given the mandate and accountability for the R&D [research and development] agenda. There is a lot of excellent research being undertaken in DHBs with a good ROI [return on investment], but often central and local policy settings do not encourage this. (Non-governmental organisation)

Research funding should be included in DHBs' measures of performance. This will remove barriers between knowledge generators and health service providers. (District health board)

50. Other suggestions were for:

- a. making health research a more integral part of audit, monitoring and evaluation so that its findings can be translated more effectively into practice
- b. district health boards taking an active role in creating partnerships with academic institutions
- c. giving district health boards a mandate to participate in technology validation and innovation
- d. district health boards developing closer linkages with industry and closer connectivity to the health research sector.

51. Related suggestions specific to health practitioners were for every health practitioner to engage in research, and potentially to have a KPI for research.

[I]t is imperative that mechanisms are put in place to enable busy clinicians to engage in research, research activity by clinicians is currently inadequate in part because there is no explicit commitment to research as part of DHB mandates nor is there sufficient resourcing in the system to allow clinicians to devote meaningful time to research. (Other)

52. Additionally, one primary health organisation expressed interest in engaging in health research.

Primary Health Organisations are part of New Zealand's innovative health services. We see the value of research in documenting and enhancing innovation. We would very much welcome support for stronger partnerships with research institutions that would enable us to be part of the agenda setting in research. (Other health service provider)

53. Some submissions saw an expanded role for a facilitator (possibly the HRC) to maintain collaborative relationships with, and between, the different sectors and institutions.

We recommend the governing body of the Health Research Strategy identify where the current and potential research expertise lies and commission the development of an organisational structure or tool with the purpose of facilitating collaborative researchers within and between different sectors and institutions. (Health professional association)

## 4.2 Setting priorities

54. The discussion document suggested setting priorities for health research and many submissions responded to that proposal. Most submissions, including a number of university submissions, supported identifying health research priorities. However, some submissions raised the following caveats.

- a. Top-down, priority-based research must not be at the expense of providing investigator-led research opportunities (a view mainly expressed by researchers and universities).
- b. It is necessary to set priorities using a transparent and robust methodology and allow for them to be updated regularly: 'priorities must be stable but not stagnant' (Comment from a participant at the Auckland prioritisation focus group).
- c. Priority setting must involve consultation across the health research and health policy/service sectors, including involving consumers and communities in creating a common research priority setting agenda.
- d. The prioritisation process must recognise the multiple outcomes of health research.

55. On the question of how to develop health research priorities, some suggestions were to:

- a. base priorities around the New Zealand Health Strategy and the National Statement of Science Investment (NSSI)
- b. use the NSSI pillars of excellence and impact (allowing for excellence to have different meanings across different disciplines)
- c. use data (for example, on hospital admissions, disease burden, health disparities)

Data on burden of disease is vital to this [priority-setting] process and it will be important to use QALYs [quality-adjusted life years] and DALYs [disability-adjusted life years] and their equivalent common metrics to allow comparison between different strategic health priorities. (Non-governmental organisation)

- d. identify gaps in clinical knowledge and practice (with district health boards and primary health organisations having a key role in this)

The strongest research is that started as a question in clinical practice, taken to expert researchers, then turned into an answerable research question, checked in the lab and then tested in the clinic or community. (University)

- e. use systemic reviews to identify knowledge gaps and avoid duplicating existing research

Systemic reviews are used to identify uncertainties that need to be addressed by health research. A database of research priorities thus identified may be utilised when taking funding decisions (e.g. [www.library.nhs.uk/duets](http://www.library.nhs.uk/duets)). (District health board)

- f. involve the community, not-for-profit organisations and health and social service providers

Huge opportunity to better align research practice with local service provision need. For example, the addiction sector could set 5 research priorities which get disseminated to universities/academic institutions with a view to someone there picking up on doing the research in partnership with service and sector needs. (District health board)

- g. enable equity of outcomes through the prioritisation process

Identification of the factors that determine an individual's vulnerability to belong in the health system. Unlocking factors to address health inequities.<sup>2</sup> (Other)

- h. use a nationally coordinated partnership with district health boards as a mechanism for involving district health boards in the prioritisation process.

The Dunedin research prioritisation focus group put forward this idea, as well as suggesting that a national coordinated partnership between district health boards and academics would be a useful mechanism for involving district health boards in the prioritisation process.

56. In addition to providing feedback on research prioritisation models, submissions identified the following specific health research priorities:

- a. research to achieve health equity across population groups in New Zealand (including equity of access to services): 44 submissions
- b. research on social, environmental and economic determinants of health (both national and international, such as climate change): 30 submissions
- c. research on delivery of health services and clinical innovations in both primary and secondary/tertiary care: 26 submissions
- d. research on specific groups or conditions (for example, mental health, palliative care, disability, community, rural populations): 26 submissions
- e. research focused on translating and implementing the results of health research (for example, clinical trials, and translational, implementation or evaluation research): 22 submissions
- f. research by Māori for Māori, acknowledging the Treaty of Waitangi and the special relationship between Māori and the Crown (particularly using Kaupapa Māori methodologies): 20 submissions

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<sup>2</sup> This submission represents the views of a tribal collective, currently comprising over 55,000 members.

- g. investigator-led excellent research (investing in areas of established excellence, internationally competitive high-impact research): 18 submissions
- h. research in areas of high burden of disease: 17 submissions
- i. research on population-wide, preventive interventions and protective factors: 12 submissions
- j. research acknowledging the diversity in the New Zealand population: 11 submissions
- k. basic, blue-skies research: 7 submissions
- l. longitudinal studies: 3 submissions
- m. internationally focused research to remain connected to international research, discoveries and opportunities (including commercial opportunities): 2 submissions.

### 4.3 Funding health research

- 57. Many submissions discussed the funding of health research. Submitters provided many suggestions for enhancing funding arrangements. However, several submissions that represented entire universities noted that New Zealand's health research system is, in general, working well to deliver excellent research and that sweeping changes are not required.
- 58. In a related point, submissions from several significant research institutions, as well as participants at consultation focus groups, emphasised the need to retain scientific excellence as the first criterion for funding. In addition, they saw it as important to retain a peer-reviewed competitive funding process.
- 59. Submissions offered a broad range of suggestions for new funding models. They ranged from having a non-competitive funding model for universities to aligning funding levels to the priorities agreed in the New Zealand Health Strategy.
 

Funding streams should be representative of the interaction with the healthcare system. (District health board)
- 60. The main issues with the existing funding environment for health research, as those providing feedback saw them, are a need for:
  - a. funding models that enable health practitioners to engage in research
  - b. longer-term funding models
  - c. funding models that actively support collaboration and/or co-design
  - d. funding for research translation and evaluation
  - e. funding for high-risk research (either innovative research or emerging researchers).
- 61. Some participants at the consultation meetings raised concerns with the National Science Challenges, while recognising the good intent of the mechanism. Concerns included a perceived lack of transparency on decision-making, the lack of engagement with district health boards, and the size of funding available relative to the outcomes sought.

### *Funding models that engage health care providers*

62. Many submissions and participants at consultation focus groups called for funding models that enable health practitioners to engage in research. Suggestions ranged from providing clinician fellowships to having separate streams of funding to enable research by health care providers (particularly district health boards) and professional associations.

Funding core research positions within DHBs ... our own research unit in [name removed] has shown that world class research can be undertaken in DHBs when you can invest in a permanent team to back investigator-led research. However, this requires the DHBs to be able to have access to some core research funding, similar to that available for universities. (District health board)

Funding of research at the community and health provider level – ground roots research – to support successful collaborations, e.g. between allied health providers. (Government agency)

### *Longer-term funding*

63. A number of submissions (from researchers, health practitioners and health consumer representatives) called for longer-term funding.

[I]dentifying competition as an important promoter of research excellence and innovation, however, is not simultaneously to suggest that funding should be short term and/or offered in small parcels, as is sometimes assumed. More desirably funding should be longer term and in significant sums so that researchers operate in a predictable environment where they can develop long term plans and strategies. (University)

64. Submitters suggested that the benefits of longer-term funding are that researchers and support staff have greater security, spend less time applying for grants, and have more opportunities to build collaborations and to achieve sustainable change.

[G]ame changing research discoveries result from a series of high quality building block moments. Short-term research funding does not always allow for this process to take place. (Health professional association)

Emphasise the building of research capacity and capability ... rather than the rounds of short-term contestable funding that promise heaps and deliver little in the way of supporting intentional and sustainable changes by and for people and communities. (District health board)

65. Some submitters suggested extending particular funding models as a way to maintain capability and lift the quality of research.

Need longer term funding (including COREs) to keep teams (not only researchers but also trained Ras [research assistants] and support staff together. (National Science Challenge)

Where capability develops [in areas of national priority] that could then become recognised as distinct national capability and granted longer-term funding. (Independent research organisation)

Establish more Centres of Excellence (not less) and consider a mechanism whereby small hubs of 4–5 investigators are selected for funding based solely on their track records (not science focus) for relatively long periods (e.g. 5 years). Make renewal of funding contingent on delivery of high-impact outputs. (Individual researcher)

### *Funding models supporting collaboration*

66. Submissions strongly emphasised prioritising research collaboration. Together they came up with 105 individual actions related to collaboration. One of the main themes was the need to support collaboration over competition in health research funding models as a way of increasing the volume of cross-disciplinary research and translating research into policy and practice more effectively.
67. Submitters indicated that collaboration needs to be fostered at two levels:
- a. research-funder level: by building relationships with the New Zealand health and social services sector (both policy and health care providers), health technology sector and world-leading research institutes (an internationally joined-up health research system)
  - b. research funding level: by designing funding models that encourage collaboration.  
  
Currently [fostering close relationships between world-leading research institutes and the health sector] is led by individual researchers. It would benefit from more support (not just financial) from government funders, universities and departments. (National Science Challenge)
68. To improve collaboration at the research-funder level, some suggestions were to:
- a. increase the number of research partnerships (like HRC's Partnership model)
  - b. create and fund academic alliances between district health boards and universities in New Zealand
  - c. develop researcher networks or clusters
  - d. develop cross-government alliances
  - e. develop international alliances (enabling access to collaborative funds)
  - f. develop public-private partnerships with industry (one submission).
69. At the research funding level, some suggestions for possible collaborative funding models (proposed along with 108 actions in total) were:
- a. funding models that encourage co-design/co-innovation and that build in collaboration – for example, researchers working seamlessly with health care providers (including public health units), patients, industry and communities
  - b. funding models that support New Zealand researchers to become involved in international collaborative research (multi-centre international research)
  - c. funding models specifically for collaborative multidisciplinary research teams such as university-industry-clinician partnerships. Te Tira Rangahau Hauora – Māori researchers in the health-related National Science Challenges – was highlighted as a good practice example.  
  
Involve the organisations that will utilise the research at every stage of the research process including scoping, development and dissemination. (Non-governmental organisation)

Provide structures that support researchers spending time with practitioners in practice environments to get a real sense of key problems and opportunities and to facilitate knowledge exchange. It may be that some buy-out time for both researchers and health practitioners is required for this to happen. (Individual researcher)

### *Funding for research translation and evaluation<sup>3</sup>*

70. Submissions and attendees at consultation workshops noted a significant gap in terms of funding for evaluation and implementation research. Some submitters observed the lack of any organisation responsible for funding research of this type in New Zealand, identifying this as a significant barrier to implementing and spreading good practice.

Cost-effectiveness/cost-benefit analyses should be an integral part of research discussion to evaluate innovative health programmes. Considering the public budget constraints these evaluation processes should guide policy decisions. (Non-governmental organisation)

Even if there are improvements in practice as a result of research findings, we will not necessarily know if anyone is better off unless we evaluate effectiveness. This process of evaluation is a legitimate and important branch of research in its own right and we think it is important to balance the emphasis on innovation in the draft strategy with evaluation of health programmes, policy and practice. (Non-governmental organisation)

71. Few suggestions were made for specific models for funding research of this type. However, one submission suggested having a specific funding pool for practical translation projects and participants at regional meetings proposed introducing knowledge translation funding (either as part of grants or as a separate funding stream). Several submissions also suggested DHB-based research translation centres (see section 4.5).

[C]urrently there is a funding and support gap for research uptake, between what researchers are funded and mandated to do; and what providers are funding and mandated to do. Resources ring-fenced for implantation are required in order to train staff, produce texts in bulk and so on. Basic biomedical research needs to be clearly matched to clinical implementation and vice versa. (University)

### *Funding for high-risk research*

72. A small number of submissions, predominantly but not exclusively from health researchers, discussed the difficulties of getting perceived higher-risk research funded in the current environment. Such difficulties apply both to high-risk research ideas and to emerging (and therefore untested) researchers.

[I]n the past, key players have dominated the research landscape and it has been difficult for emerging research streams to attract funding ... [A] better balance between innovative emerging ideas and the 'safe' support of past achievers is needed. (Individual researcher)

Consideration needs to be given to new ways to support high risk/high return research, and to be more 'entrepreneurial' and ambitious with funding decisions. (National Science Challenge)

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<sup>3</sup> This section addresses evaluation and translation funding models only. Section 4.4 is dedicated to research translation.

## Health research investment processes

73. In addition to suggesting specific funding models, many submissions commented on health research investment processes. Most of these indicated a need for more streamlined and simpler funding processes, funds that are better coordinated and aligned (noting a gap in clinical translation currently) and clearer information about funding available.

The funding system is not perfect but not completely broken. There is a need to communicate what is available and how to access it, rather than redesigning the system. Simplifying application processes and/or tapping into people who are skilled at applying for grants would help. (Comment at the Christchurch commercialisation focus group)

74. Other comments highlighted the importance of:
- a. having broad expertise on grant application panels
  - b. taking a broad view of the research impact when assessing proposals
  - c. valuing a range of different research approaches (not just X = Y causal examinations).
75. Some submitters, while applauding the increase in funding granted to the HRC, wanted funding for health research to increase further.

## 4.4 Sharing and translating health research

76. Effectively sharing health research findings and translating them into policy and practice comprised one of the most common themes in both written submissions and consultation workshops (with 71 actions suggested in total). Feedback indicated that health research could produce greater benefit if research results were more effectively and systematically used.

There has to be pro-active mechanisms and implementation resources to ensure systematic evaluation and uptake of research findings. (University)

Currently uptake [of technology] often depends largely on individual champions rather than a systematic supportive approach. (Other)

77. A key point, raised in a number of submissions and echoed in consultation workshops, was that excellent research is an essential precondition for achieving benefits through translation.

Excellence must be a key criterion for research funding in any area. It is important that excellence is not subordinated by the importance of the research field, immediacy of the problem, or potential economic benefits. Poor quality research in important areas is a poor investment and will not contribute, and may even undermine, improvements to the health and wellbeing of New Zealanders. (University)

78. Feedback on how to better translate research findings into practice covered the need to:
- a. involve research users in undertaking research
  - b. make best use of existing knowledge (including international research)
  - c. make research accessible



- d. provide mechanisms and resources to support research translation
- e. encourage literacy with health research.

### *Involving research users in research*

79. The subsection 'Funding models supporting collaboration'(paragraphs 4.366–69) has discussed feedback on the importance of collaborating with research users.
80. On the topic of research translation specifically, several submissions noted that one key benefit of engaging research users is that it helps to translate research into practice. When research users are involved from the outset, it is more likely that research topics will be relevant, research will be designed appropriately, and research users will have an 'investment' in using the results.
81. Submissions (from both health practitioners and health researchers) frequently mentioned involving health practitioners as a way of helping to integrate research into health care practice.
- Integration of research with clinical care delivery will make uptake easier. In some designs, such as adaptive Bayesian models, the change from research to implementation is built-in. (District health board)
82. A few submitters highlighted the need to engage policy makers.
- There is a need to promote an evaluation and evidence-based culture within policy and service delivery organisations. Part of this is to encourage skills in assessing and using evidence. (University)

### *Making best use of existing knowledge*

83. Several written submissions and participants at consultation workshops emphasised the importance of making effective use of existing health research knowledge. This includes using New Zealand-based research findings as well as international research for the benefit of New Zealand.
- In the short-term knowledge translation of already known effective healthcare technologies, treatments and systems would make the greatest difference ... we need to investigate how best to implement the health evidence we already possess. (Health professional association)
- Currently we have a situation where there is a great deal of research which sits on bookshelves or in e-files, and the same research questions get funded and answered time and time again with no impact on service delivery or there is minimal implementation of recommendations. (District health board)
- It is important to avoid reinventing the wheel. New research should be done only if it was necessary. Already published results should first be used to answer the present clinical question. This is done through 'systemic reviews' like those prepared by the Cochrane collaboration. (Individual researcher)

## *Making health research accessible*

84. Written submissions and the public consultations and focus groups gave a substantial body of feedback on making research and its results accessible. They suggested making research more accessible by:

a. establishing a centralised database of funded health research

A centralised information bank of health-related research, for example a clearing house, could be useful to consider. This would help identify current research and assist to make gaps in knowledge more visible. (Non-governmental organisation)

b. overcoming barriers to accessing published research

Once health workforce members leave their academic institutions, they face variable access to quality health information, with this access depending on the resources their organisation is willing or able to purchase. (University)

A particular issue for organisations outside the Universities is our access to journals and papers. This is a significant barrier in the translation of research into practice. We would very much welcome a centralised solution. (Other health service provider)

We support open access to all research results, the good and not so good. (Government agency)

c. providing a centralised database of health research findings

[Solution,] a core collection of electronic resources, mainly research literature, must be made available to all health professionals, centrally funded as is access to the Cochrane Library. (University)

What I would envisage is as follows: The doctor enters a patient's clinical problem into a database; he/she clicks on a link for 'best treatments'. If there is evidence to indicate what the best treatment is they are informed of this. (Individual health practitioner)

d. providing plain-English research summaries and syntheses of health research

By making results accessible. This means summarising and pulling out key indicators and presenting them in a way that is easily interpreted by all New Zealanders, not just researchers and ministries. (Individual researcher)

Communicating health information, especially research findings, accurately and in plain language, is a major obstacle to the uptake of research findings by the media, the public and, as a result, by policy and decision-makers. (Non-governmental organisation)

e. having research dissemination specialists

Sometimes researchers aren't the best people to disseminate their findings. Having skilled people present research results to media, ministries and decision makers would go a small way to improving knowledge and understanding. (District health board)

f. encouraging contact between researchers and research users.

Invest in a mechanism that allows regulator networking of ministry representatives with a broad range of health researchers (e.g. MoH reps [Ministry of Health representatives] to regularly attend national health conferences etc). (Individual researcher)

## *Supporting translation of health research*

85. A significant number of submissions indicated that making health research accessible is a critical, but not sufficient, step in translating research into practice. Mechanisms for integrating new knowledge into practice and a willingness to take on new knowledge are required.

Uptake and dissemination is a serious issue with research and needs to be addressed in the strategy. With over 2 million articles published in over 20,000 health-related journals, the issues with uptake is not due to lack of published evidence. (Non-governmental organisation)

86. To improve research uptake, submissions suggested:

- a. setting up a body specifically to support research translation, similar to the United Kingdom's National Institute for Health Research and the Canadian knowledge exchange/translation centres. Suggestions included both a national-level body and DHB networks

We strongly feel that a mechanism for implementing relevant findings from the research sector and ensuring they inform clinical service delivery and practice is missing in the NZ landscape and needs consideration. We would recommend the establishment of a standing committee comprising representatives from research, clinical service providers, Ministry of Health, Health Research Council and other stakeholders as appropriate to oversee the translation of research findings. (Independent research organisation)

Look at national coordination across health issues for facilitating knowledge transfer and evidence based best practice. E.g. Immunisation Advisory centre and the Family Violence Clearinghouse. These organisations are very successful at disseminating research findings to the practice communities. (University)

- b. providing analytical or research support (for example, biostatisticians, evaluation and health economists) for system-level decision-making (both policy and strategic decision-making at health care provider level)

Evaluation, when done well and in partnership with service providers, can enhance practice by providing practitioners with the knowledge and tools to critique their work and strive for continuous improvement. (University)

- c. establishing mechanisms or techniques for integrating health research (new knowledge) into clinical practice. This includes considering health pathways or guidelines, integrating research with quality improvement, implementation science and cost-effectiveness analysis

Clinical translation and implementation of research outcomes are different sciences and complementary. Efficacy demonstrated in a clinical environment is not the same as establishing sustainable change in practice and outcomes. Implementation science is relatively new but vital for the future of health research. (Non-governmental organisation)

We understand the importance of quality improvement approaches but feel that there is space for them to be informed by rigorous research approaches, and this could be reflected in the vision or mission of the strategy. (District health board)

There must be robust processes in place to analyse, assess, and prioritise effective research results in terms of value for money, lost opportunity costs etc. (Government agency).

We recommend including Health Impact Assessment as an essential tool, along with health technology assessment and systematic reviews [for development of public policy]. (Non- governmental agency)

d. establishing roles for knowledge brokers.

We need people who can act as new players in dynamic systems as enablers of industry/academic/leadership-driven programmes to allow research to touch down on the clinical interface. (District health board)

Application of existing research knowledge (putting research conclusions into practice). This may require a role of 'advisory scientists' who bridge the gap between science outputs and the clinical/management teams to whom the science is most relevant. (Non-governmental organisation)

### *Promoting health and health research literacy*

87. The importance of health research literacy was raised both in written submissions and in consultation workshops. People considered that public engagement and literacy increase the understanding of health issues, increase support for health research, and make health research more visible as a career choice.

We need to find better more effective ways to publicly communicate research findings, such as the recent TV documentary 'Why am I?' on the Dunedin study which has been both popular and successful at informing the public about the study. (Non-governmental organisation)

Require and facilitate public interaction by researchers, with open seminars, open days, properly informative releases in the media, support teaching in schools where children are most likely to absorb, and perhaps innovative promotional ways such as competitions and challenges. (Individual researcher)

Have lay people inform write up of research. (Non-governmental organisation)

## **4.5 Enhancing health research infrastructure (including data)**

88. Approximately one-fifth of submissions commented on New Zealand's health research infrastructure. In total, they proposed 56 separate actions.
89. Feedback covered the full spectrum of infrastructure from national health data to research translation tools. Most submissions indicated that some degree of centralisation of infrastructure would be beneficial, either through:
- a. developing national-level infrastructure

A host of nationally co-ordinated infrastructure and support networks are all required to support national collaborative health research efforts (IT support and commonality, big data networks and expertise, integrated imaging capability, co-ordinated training programmes) and these will require significant planning and investment. (Other)

- b. enhancing research infrastructure within and across district health boards.

To support a growth in research undertaken by or within DHBs an investment in infrastructure is indicated. Infrastructure support in DHBs is weak compared to universities and should be a mission priority. The new UK system may be a useful model. (District health board)

### *National-level infrastructure*

- 90. Specific suggestions for how to improve national-level infrastructure are listed below (for suggestions specifically related to clinical trials, see section 5.4). They are ordered from the most to the least frequently mentioned.
  - a. Improve the collection of, access to and integration of national health data (for example, integrate Statistics New Zealand data and the National Health Index (NHI) numbers).
  - b. Set up databases of funded health research and research results to support collaboration and translation.
  - c. Develop a national biobank. One of its key features could be links to Statistics New Zealand's Integrated Data Infrastructure (IDI) data and one or more national cohort studies.
  - d. Recognise the importance of e-infrastructure in its various forms, ranging from the genomic processing capability of a national genomics centre to health data integration.
  - e. Provide infrastructure to support collaboration supporting eSocSci and Community Research. The Australian 'Conversation' website is a successful example.
  - f. Provide infrastructure for evaluating current and new interventions. A successful example is the United Kingdom's 'What Works Network'.
  - g. Provide statistics and data management and health economics support.
  - h. Develop infrastructure to streamline application processes (for example, have similar research contract application forms across agencies).
  - i. Permanently resource infrastructure of national significance (taonga), such as longitudinal studies.
- 91. Several submissions noted that existing infrastructure could be used more efficiently if national pools of equipment were created and made available to research teams for a fee.

### *District health board infrastructure*

- 92. Specific suggestions for how to improve DHB-level infrastructure improvements are listed below. (For suggestions specific to clinical trials, see section 5.4.)
  - a. Set up DHB-based translational research centres.
  - b. Fund district health boards so that they can provide internal infrastructure for research (for example, to cover costs for time on scanners and other clinical equipment, pay for research nurses, and allow staff time to get research training qualifications).

- c. Fund district health boards for research coordinators who are not tied to specific projects or departments.
- d. Develop a unified research national health database common to all district health boards.

## 4.6 Improving ethics and regulatory systems

93. A small number of submissions focused on the ethics and regulatory systems supporting New Zealand health research. While the total number of submissions on this topic was relatively small, those that addressed it gave detailed feedback (20 suggested actions in total). Feedback covered:

- a. ethics review processes
- b. protection of research participants
- c. consent for ongoing use of data and biological samples
- d. regulation of medical devices
- e. management of conflicts of interest
- f. undertaking ethical research.

94. An overriding theme was that ethics and ethical research should be central to the New Zealand Health Research Strategy.

Working for the wellbeing of New Zealanders should be the ethical basis of the health research strategy. (Non-governmental organisation)

It is *impossible* to create a high functioning world leading health research system without robust ethics review processes. (Government agency)

### *Ethics review processes*

95. Some submitters indicated that the ethics system in New Zealand is relatively effective and efficient and has improved in recent years due to the changes made following the Health Select Committee's report to Parliament in 2011. However, others disagreed, stating that further work is needed to optimise ethics processes (using international best practice as a guide to achieving this).

Our attendances at HDEC [Health and Disability Ethics Committee] meetings have demonstrated over the past 6–7 years, consultation with Māori on research proposals that come before the ethics committees is either non-existent or consists of tokenism. (Consumer organisation)

A desirable future would involve efficient and robust ethics review processes where ethical research is facilitated while protecting patients. (Government agency)

## *Protection of research participants*

96. Several submissions noted a gap in New Zealand's protection of research participants when adverse events occur. Those participating in the consultations and focus groups also raised this concern.

[In New Zealand] there exists potential issues around indemnity for patients in the event of injury occurring in the setting of clinical trials which need to be resolved. These are brought about by the specific exclusion of coverage by ACC for injury incurred in the course of an industry-sponsored clinical trial. (Health professional association)

97. One submission provided specific suggestions to improve research participant protection during clinical trials:

- a. Consideration needs to be given to the Accident Compensation Corporation providing the *initial* and immediate cover for injury incurred, (as they do for treatment injury), but with provision for cost recovery from clinical trial sponsors and their insurers, which inevitably takes time.
- b. [T]here is a need for more prescriptive detailing of minimum levels of insurance to be provided by sponsors, and a clearer pathway for advocacy and advice for those who are injured in the course of a sponsored clinical trial. The HDEC [Health and Disability Ethics Committee] could relatively easily respond in these ways. A modest levy payable to HDEC per trial site could fund an advocacy service.
- c. Private health insurers ... should also be encouraged or required to remove any disincentives they provide to those volunteering for clinical trials (ie, [by] denying cover under their policies to volunteers in clinical trials) ... (Health professional association).

98. A few submissions also identified a need to review the procedures around enrolling unconscious patients in clinical trials.

## *Ethics related to data and biological samples*

99. Now that big data and linked data sets are in use, a common issue raised in submissions was maintaining protection of individual health information.

We must be cognisant of working alongside other projects such as the Cancer Health Information Strategy, National Patient Flow, and Electronic Health Records programmes of work to understand what 'routine data' is defined, the potential it has to offer in terms of research, and the most ethical ways to use that data. (Government agency)

100. Submissions raised the issues of:

- a. ensuring the public are informed about health and social sector data sets that may be linked for research purposes
- b. monitoring and auditing data to identify any risks to, or breaches of, privacy and security arrangements
- c. managing the risk of re-identifying individuals as multiple data sets are pooled.

101. One submission noted the need to consider how the Health Information Governance Framework will influence the collection of data for research purposes.

102. A few submissions mentioned consent issues in relation to biological samples.

[On the topic of biobanking,] some groups (including Iwi groups) are already considering the challenging governance aspects of genomic data, where the purpose of its collection today may not include consideration of all possible future research uses and how consent may be gained for future use. (Other)

### *Regulation of medical devices*

103. A few submissions from researchers, health providers and health consumers discussed regulation of medical devices in New Zealand. They expressed concerns from the perspective of both patient safety and the barriers against bringing devices to market.

For research undertaken on medical devices, New Zealand lacks some key regulatory mechanisms and processes. This is particularly true for devices engineered and developed within New Zealand that will require a regulatory body equivalent to SCOTT [HRC's Standing Committee on Therapeutic Trials] and Medsafe for medicines to examine safety around such translational research. For a sector that has ambitions to develop products in this space it is our experience that this is a significant gap and impediment to such research activity. (District health board)<sup>4</sup>

### *Managing conflicts of interest*

104. The management of conflicts of interest, particularly when commercial organisations are involved in research, was raised in several submissions. Their main concerns were ensuring disclosure of conflicts of interest and maintaining academic independence. Their suggestions for addressing these issues were to:
- require disclosures of conflicts of interest
  - have a robust and transparent assessment procedure
  - have independent reviews of assessment of adverse events and interpretation of results of clinical trials.

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<sup>4</sup> The New Zealand Health Research Strategy working group notes new legislation is currently being drafted.  
<http://www.health.govt.nz/our-work/regulation-health-and-disability-system/therapeutic-products-regulatory-regime>



## 5 Specific considerations for New Zealand health research

105. Submissions as well as participants at regional consultations and workshops highlighted several specific considerations for New Zealand health research that cut across the whole research system. This section details the feedback on each of these topics.

### 5.1 Māori health research

106. Feedback, both in submissions from all types of submitters and in consultation workshops, emphasised the importance of supporting Māori health research. In total, people proposed 69 actions for Māori health. One submission, representing the views of its 55,000 members, recommended that:

- a. the strategy meaningfully includes Māori as the Treaty partner and a role for iwi as decision-makers
- b. health information technology and research in New Zealand are targeted to lead to improvements in Māori health outcomes and reducing inequity
- c. Whānau Ora serves as the baseline for all research as the whānau ora approach is whānau centred and takes a Māori-driven, holistic approach to Māori health and wellbeing
- d. iwi work in partnership with the Crown and commissioning agencies to agree on the focus and strategic priorities for health research
- e. research approaches and methodologies give effect to and use Vision Mātauranga (Ministry of Research, Science and Technology 2007), coupled with whānau ora and innovation.

Inclusion of the Māori perspective should reflect the unique position of Māori as the indigenous peoples of New Zealand, to acknowledge both their indigenous rights and the Treaty of Waitangi-based partnership, as well as current health inequities due to the impact of colonisation. (University)

107. Many submissions indicated that the Treaty of Waitangi should be central to the strategy and that it should meaningfully include Māori methodologies, health research aspirations and wellbeing. Support was also very strong for linking the New Zealand Health Research Strategy with Vision Mātauranga and He Korowai Oranga (Māori Health Strategy – Ministry of Health 2014) to improve Māori health outcomes.
108. Several submissions suggested that a separate Māori Health Research Strategy would be appropriate. Others felt that the New Zealand Health Research Strategy should include Māori health research as a specific strategic priority.
109. In terms of setting research priorities, feedback indicated that Māori health research was a priority because:
- a. Māori experience considerable health inequity
  - b. supporting research ‘by Māori for Māori’ is consistent with the Treaty of Waitangi.

110. Several submitters saw a ‘by Māori, for Māori’ approach as the most effective way to improve Māori health and wellbeing and improve equity.
- A strong focus on Māori research that is identified by Māori as a priority for them, not necessarily focused on deficits but on building on their strengths. (Consumer organisation)
111. Submissions that were focused on Māori health research raised data and data sovereignty as an issue.
- Māori data sovereignty needs to be recognised with users involved in the oversight and governance of datasets. Māori researchers need to be able to access big datasets and communicate these results to communities for their use. Research conducted by non-Māori on Māori populations should have obligations to ensure results are communicated in meaningful ways to Māori communities. (Independent research organisation)
112. According to several submissions, engaging with Māori communities to involve whānau, hapū and iwi in research is vital. They noted that some funding mechanisms need to be adapted to support the development of these relationships.
113. Two submissions noted that a high-level group should oversee the implementation of results of research on Māori health. This group would be established to oversee a repository of Māori health research findings and monitor their implementation as well as to highlight gaps for future funding.
114. The development of the Māori health research workforce was a common issue in submissions. People considered that prioritising the development of Māori health research is critical, given the special role Māori play in the health research environment. They also noted that the career pathway for Māori health researchers may differ somewhat from that of others.
- Unless there is a specific strategic mission for Māori researchers and Māori research the strategic priority will not deliver what is urgently needed to address critical research and workforce gaps in Māori health research. (Individual researcher)

### *Suggested actions from Māori health research*

115. In summary, submissions from Māori groups and individuals and individuals and groups with an interest in Māori research proposed that:
- the strategy meaningfully includes Māori as the Treaty partner and affirms the role for iwi as decision-makers
  - research includes social research and diverse knowledge frameworks such as kaupapa Māori
  - Māori are included in decision and policy making
  - the health system is culturally responsive to Māori
  - research by Māori for Māori is prioritised
  - a Māori-led, evidence-based knowledge platform is established

- g. Māori be a specific strategic priority
- h. Māori health equity is a health research priority and guiding principle.

## 5.2 Pacific health research

116. Feedback on Pacific health research came through the submissions on the [New Zealand Health Research Strategy: Public Discussion Document](#), and from two focus groups on Pacific health research – one in Auckland and one in Wellington.
117. The main theme coming from the submissions and consultations with Pacific peoples was a concern about the lack of equity for Pacific peoples. This is reflected in their poor health outcomes. People felt that Pacific health should be prioritised and targeted on the basis of these poor health outcomes.
- Strategic priorities need to include improvements to child health, particularly for Māori and Pasifika children. (University)
- Pacific research needs to be at the forefront due to the health disparities Pacific communities experience compared to the total New Zealand population. (Health professional association)
- A health research system that addresses health disparities and inequalities is of particular importance to Pacific New Zealanders, who currently bear the burden of ill health. (Individual researcher)
118. Two other themes were common in both focus groups and submissions. First, Pacific health research lacks ongoing, long-term funding and this has adverse consequences for Pacific peoples.
119. Second, capacities in Pacific health research need to be strengthened. Universities provide little support for Pacific health research and contributors on this topic pushed strongly for ring-fenced funding for this area.
120. In terms of the health research workforce, both focus groups and submissions agreed that a strong pipeline of Pacific health researchers needs to be developed. This development should start at school by encouraging Pacific students to study sciences.
121. Young Pacific researchers need opportunities and support to pursue a career in health research. Pacific appointments to universities are critical to building capacity, supporting emerging researchers and connecting universities to Pacific networks.
- The health research strategy is well placed to not only acknowledge the need for more Pacific health research, but also provide mechanisms through which Pacific health research capacity can be strengthened. (University)
122. A number of submitters wanted Pacific frameworks for research to be recognised and supported. Some wanted social health and knowledge frameworks used for Pacific health.

[T]he emphasis on science and scientific quality risks sidelining the amazing strengths that New Zealand has in a) social research and b) various diverse knowledge frameworks including kaupapa Māori and Pasifika frameworks ... [S]ocial health research asks different questions ... therefore developing a language of social science ... seems vital. (Individual researcher)

123. Participants in both Pacific focus groups supported this view. They felt that many solutions to Pacific health lie in the social determinants of health, in systemic sociocultural factors and engagement with health services. The Health Research Strategy also needs to recognise the validity of different world views and methodologies, such as Pacific ones.

Need to ensure that health research is not focused on and influenced by disease symptoms alone. Culture, social, environment, lifestyle, physical, spiritual and mental wellbeing must be considered and factored. (Non-governmental organisation)

124. A number of submitters suggested using *'Ala Mo'ui: Pathways to Pacific Health and Wellbeing* (Ministry of Health 2014) to guide investment in Pacific health research.
125. The focus groups identified that Pacific health research is still emerging and 'genuinely young'. Because of the difficulties in competing with other areas for funding, a different, less competitive approach is needed.
126. The focus groups agreed, New Zealand has a responsibility for and an important role in supporting Pacific health research across Pacific nations, including building regional capacities. There are opportunities to link up research across the Pacific as many health issues are transnational, applying to Pacific peoples in New Zealand and in the Pacific islands region.
127. Another concern for focus groups was the need to increase monitoring, review and evaluation of what works for Pacific peoples and to make this an important part of Pacific health research projects. One submitter wanted to ensure that clinicians and researchers were culturally competent to interpret and translate research results relating to Pacific peoples.

### *Suggested actions for Pacific health research*

128. In summary, submissions and focus groups proposed:
- a. improving health equity for Pacific peoples
  - b. doing more research on the social determinants of health for Pacific peoples and on the systemic sociocultural factors and engagement with health services of Pacific peoples
  - c. recognising the validity of Pacific world views and methodologies
  - d. supporting Pacific health research across Pacific nations, including building regional capacities
  - e. building a strong pipeline of Pacific health researchers, starting at school by encouraging Pacific students to study sciences

- f. supporting young and emerging Pacific researchers to have opportunities to pursue careers in health research. Pacific appointments to universities are critical to building capacity.

### 5.3 Disability research

- 129. According to the 2013 Disability Survey, almost 1.1 million New Zealanders have a disability. An estimated 632,000 people have a physical impairment, 484,000 a sensory impairment and 89,000 a learning disability. Over half (53 percent) of disabled people have more than one disability. These statistics provide the backdrop to the submissions and workshop perspectives on disability research.
- 130. Responding to the question 'in what areas could health research in New Zealand make the greatest difference to the health and wellbeing of all New Zealanders in the short term into the longer term?', a submission stated:

[B]y addressing the disability barriers and pushing back disability thresholds. (National Science Challenge)
- 131. The main themes to come from the submissions and focus groups related to the current lack of disability research. People felt that no government agency had developed a publicly notified disability research agenda or funding guidelines. Some felt disability research should be a strategic priority.

The only significant policy statement regarding disability research is in the current NZ Disability Strategy Objective 10. (Non-governmental organisation)
- 132. One submission underlined that New Zealand had disability research obligations under the United Nations Convention on the Rights of Persons with Disabilities. Specifically article 4(f) and (g) and article 31 establish these obligations.
- 133. Some submissions expressed concern that the proposed strategy did not explicitly include research on disability.

This concerns us in two ways. Firstly, it fails to recognise rehabilitation and disability as part of the continuum of care for health and disability services as a whole. Secondly, the absence of references to disability indicates a failure to prioritise and fund research that has a potential to have a beneficial effect on the lives of hundreds of thousands of New Zealanders. (Non-governmental organisation)
- 134. A view in some submissions, which was reinforced in the focus groups, was that consumers need to be actively involved in research about them.

Nothing about us without us. (Non-governmental organisation)
- 135. Some submissions observed that, although the public discussion document specifically refers to Māori and Pacific research frameworks, it does not mention disability research frameworks. Others stated that the strategy should include the social determinants of health and that research should include the health effects of social phenomena such as social exclusion, unemployment, discrimination and long-term low incomes on disabled people. These views reflect the social model of disability.

136. In some submissions and the focus groups, people identified a need for more funding, better infrastructure and more researchers working on disability issues. This perspective came out strongly in one submission.

Targeting funding of disability health research must be included in a research framework. This includes research infrastructure and building capability and capacity among (disabled) researchers. (Non-governmental organisation)

137. Another submission stated that the health inequities and co-morbidities of disabled people should be addressed.

138. Those attending the disability workshops raised the following issues.

- a. It is necessary to understand the intersection between disability research and health research for disabled people. The World Health Organization's definition of health research includes disability.
- b. The Health and Disability Commissioner is working on informed consent for disabled people to protect them but also to enable them to participate in research.
- c. Disability research is dispersed and lacks critical mass. It has no home in the New Zealand research landscape. It needs a champion.
- d. There is a need to focus on building the capacity and capability of disability researchers.
- e. Because approximately 25 percent of the population of New Zealand has a disability, disability research should be funded to 25 percent of the health research budget.
- f. Equity of outcomes is complex but very important for disabled people. It is the same problem that Māori, Pacific peoples and migrants face.
- g. Disability is an afterthought in health research.
- h. Disability researchers face difficulties in getting research findings on published. For instance, the Performance-based Research Fund (PBRF) system favours publication of research in academic journals.

139. One submission suggested that agencies should collaborate more on disability data.

140. In submissions and the disability focus groups, there was a call for research data to be available in accessible forms. Data needs to be accessible in terms of cost, plain English and use of appropriate mediums for those who are hearing or visually impaired.

### *Suggested actions for disability research*

141. In summary, feedback on disability research was to:

- a. make disability research more visible within the body of the strategy
- b. improve health equity for disabled people
- c. build the capacity and capability of the health research workforce
- d. provide more funding, better infrastructure and more researchers working on disability issues

- e. include the social determinants of health in the strategy and conduct research that includes the health effects of social phenomena such as social exclusion, unemployment, discrimination and long-term low incomes
- f. involve people with disabilities in settling the research agenda and in undertaking research – ‘nothing about us without us’.

## 5.4 Fostering clinical research and clinical trials

- 142. Those engaged in clinical trials raised issues about undertaking this specialist area of health research.
- 143. They noted that New Zealand already has many of the key requirements for a successful clinical trial environment. In particular, it has patients who have not been exposed to medicines previously, diverse patient groups, ethnic sub-population groups, and an English-speaking health sector with high ethical standards and well-respected physicians.
- 144. However, submissions also detailed concerns with the existing system and possible actions to overcome these.
- 145. Submissions on clinical trials saw major value for New Zealand in further developing its clinical trials capacity and capability. They identified the following benefits.
  - a. Just taking part in clinical trials improves the standard of care, encourages excellence, and helps clinicians to interpret research findings and make more rational treatment decisions.
  - b. Clinical trials and translational studies translate findings into health benefits, and enrich and raise the impact of basic science.
  - c. Clinical trials boost the economy. A United States study estimates that every dollar spent on clinical trials brings at least a four-fold projected net economic benefit to society.
  - d. Positive clinical trial data adds significant value to intellectual property generated in the biotechnology, pharmaceutical, medical device, bioactive and functional foods sectors.
  - e. Collaborating with industry, including pharmaceutical companies, gives biomedical researchers opportunities to bring novel therapies to market. It is necessary to establishing a network of clinician researchers who are capable of conducting investigator-initiated trials to test new technologies related to health care, because this is fundamental to achieving commercial objectives as well as health outcomes.
  - f. Senior and specialist clinicians involved in clinical trials gain valuable experience and the opportunity to have a global presence in their field. Such opportunities are important in recruiting and retaining these professionals.
  - g. Junior doctors involved in clinical trials often go on to be leaders in their field of medicine.
  - h. Clinical trials make it possible to develop and train the nurse researcher workforce.

- i. Early-stage clinical trial activity should be encouraged, because this is an area where New Zealand can perform very well relative to many other potential competitor countries.

### *New Zealand must connect to international clinical trials*

146. Several submissions noted that if New Zealand is to contribute to cutting-edge research in the future, its researchers will need to join overseas trial groups, as high-impact research is increasingly involving collaborations across many countries.

There is a real crisis in running co-operative group trials, such as the Trans-Tasman Radiation Oncology Group (TROG) in New Zealand because of funding issues ...The New Zealand contribution to TROG studies has shown a dramatic decline from the historic level of 12% of patient accrual from 1989 onwards ... to 4.2% in 2015. [This] will affect the quality of radiotherapy treatments in this country ... [C]linical trials can be very cost-effective way to develop the technological basis of radiotherapy. (District health board)

147. As submissions identified, being involved in international clinical trials offers the benefits of:

- a. preventing New Zealand findings from being 'scooped up' by research groups from countries with larger populations, as they can recruit to trials much faster than we can
- b. supporting international investment in New Zealand
- c. potentially making a major difference to patient care. For example:

[T]he five-year survival for acute myeloid leukaemia in New Zealand improved from 2% to 42% within seven years of joining the UK MRC [Medical Research Council] trials group. (Health professional association)

148. Submissions suggested the following actions to encourage New Zealanders to become involved in international clinical trials.
- a. The vision for the strategy should refer to active and equitable access for patients to local and international clinical research or clinical trials, regardless of where they live – for example, access is open across district health board boundaries.
  - b. While access to local trials remains severely constrained, we need to negotiate access to Australian trials for New Zealand patients. For example, New Zealand breast cancer patients were given access to trials run at the Australian clinics by the Australia and New Zealand Breast Cancer Trials Group.

### *New Zealand needs a strong clinical trial industry in district health boards*

149. The general consensus across submissions and from focus groups was that access to clinical trials improves patient care and that achieving this requires a strong clinical trials industry in DHBs. Some submitters went as far as to state that the health system should have a goal of offering all patients treatment in a clinical trial.
150. A number of those providing feedback considered that research is not a priority for DHBs. In their view, DHBs currently see their main research activity as delivering on paid commercial contracts, mainly recruiting to international pharmaceutical company-funded trials.



151. However, at least one DHB wanted the strategy to emphasise the importance of sponsored clinical trials in New Zealand. It supported them on the grounds that clinical trials provide direct economic and clinical benefits to the health system. Clinical trials provide training opportunities for clinical staff within a highly structured environment and at low cost, the ability to cross resources over between sponsored and non-sponsored trials, and greater continuity of employment for the clinical research community.

[Agency name], the provider arm of the DHB receives \$650 million of public funding each year. It is essential that this money is spent wisely and by ensuring an active research culture, we ensure our clinicians are constantly questioning how they can improve the healthcare they provide ... However, (despite several academic alliances) lack of PBRF funding or the research support of a local medical school means that our clinicians have limited opportunities to pursue the research that is essential to improving health outcomes in our high needs population ... DHB hosts 9 active clinical trials groups but they are not co-ordinated and have little support to maximise their activities. (District health board)

152. Some comments focused on the way that DHBs determine the cost of research, and preferred a true cost approach to prevent clinical research from becoming uncompetitive with other countries. One respondent stated:

[S]ome DHBs charge a \$6,500 start-up fee, a \$2,000 pharmacy fee and 20% overhead charges. (Health professional association)

153. Those providing feedback suggested the following actions to encourage DHBs to engage in clinical trials.
- a. Clinical trials research should be considered a key priority (even a KPI) for district health boards. It should be weighted in favour of investigator-led, New Zealand-based research projects – because such research brings greater direct benefit to New Zealand.
  - b. Clinical trials should be embedded as a separate function within section 23 (Functions of district health boards) of the New Zealand Public Health and Disability Act 2000. Section 48 of that Act embeds research as a function of PHARMAC.
  - c. Investigator-led research and cooperative group trials should be a key priority for district health boards, accepting that they may continue to use paid commercial research to help fund them.

### *National level clinical trials networks and a national clinical trials body are needed*

154. Submissions and those at consultation workshops highlighted the need for national-level clinical trials networks and a clinical trials body. They noted the need to philosophically, practically and financially support the infrastructure required for clinical research in the public health system (including research assessment and approval, research coordination and ensuring equity of access).

Currently there are 20 DHBs, and clinical trial conduct requires that each DHB undertake costing, contracting, risk assessment etc. This results in duplication of effort, unnecessary bureaucracy and inefficiency, when effectively the state is the sponsor of all DHB clinical trials ... This is an impediment to leveraging commercial trials and subsequent income, as well as conducting research in rare disease types. Having the ability for sponsors to engage

with multiple DHBs as a single legal entity would improve efficiency, reduce red tape, and speed up research conduct and outcomes. (Non-governmental organisation)

155. As those providing feedback see it, establishing a world-class system of networks is necessary to make New Zealand an attractive destination for Phase III clinical trials. One submission suggested, for example, establishing centres of excellence for specific diseases and other areas is the most effective way to ensure excellence in research and integration with the clinic.
156. The following suggestions signalled the need for a national-level clinical trials body.
- a. The HRC should maintain a list of clinical trials funded by international funding agencies like the Australian National Health and Medical Research Council (NHMRC) and the United Kingdom's Medical Research Council (MRC) and clinicians should be allowed to choose which trials to participate in.
  - b. Establish a 'hub', incentivise leadership, provide additional resource or prioritise movement across boundaries or DHBs so that patients can access the necessary clinical trials.
  - c. Use patient registers to collect and store comprehensive data, sharable at research and clinical levels. Patient registers are a powerful tool to attract research investment from overseas, making it possible to quantify and identify patient subgroups for studies and clinical trials.
  - d. Develop a national clinical trial recruitment policy, as recommended by the 2001 Health Select Committee report on clinical trials, to ensure that recruitment happens on a national basis – unrelated to district health board structures.
  - e. A national clinical trials infrastructure could consider and manage issues such as database development, information security, standard operating procedures for clinical trials, randomisation technologies, monitoring of trials to ensure appropriate conduct, data and statistical advisory services, standard (pro-forma) contracts, good clinical practice training and monitoring compliance with good practice and data and safety monitoring committees (to ensure patient protection).
  - f. Interactions between research offices at the larger district health boards can be inefficient and administratively difficult. Much of the compliance cost goes into repeating locality impact assessments several times over, which frequently address similar questions. Research offices should develop harmonised procedures across district health boards, and some could adopt a lead role, such as in the form of a national coordinating entity, for certain national projects.
  - g. New Zealand's national patient numbering system (NHI) is a strength for doing clinical trials here. However, the increasing trend towards contracting care provision to private providers erodes this system – and our ability to exploit it for research and to improve health care provision. This could be addressed through the national coordinating entity suggested above.

- h. The United Kingdom and Australia have centralised infrastructure to co-locate experts who can conduct and organise randomised controlled trials. These centralised entities offer, among other benefits, databases and coordinated patient randomisation, as well as being repositories of statistical and good clinical practice expertise.
  - i. Research offices of universities need to interact efficiently with those of district health boards, but they do not always do so. The Dunedin-based Health Research South model works well, with staff co-located at both offices for efficient communication.
157. Funding options for clinical trials activity in New Zealand were the focus of the following suggestions.
- a. Establish a process that links New Zealand funding initiatives with overseas funding initiatives. For example, if a Trans Tasman Radiation Oncology Group, (TROG) research study is seeking National Health Medical Research Council (NHMRC) funding, a co-ordinated mechanism is needed to develop a dual application process simultaneously to NHRMC and HRC.
  - b. Provide an emerging medicines fund, combined with well-designed clinical trials to increase patients' access to new treatments and develop new knowledge to improve predictive and prognostic capability.
  - c. Make available seed funding for 'in-house' research, with two or three rounds a year. Encourage institutional meetings for staff to present and discuss their research with others, including the public.
  - d. The Government should seriously consider providing research and development (R&D) tax rebates to pharmaceutical and biotech companies undertaking R&D in New Zealand, as is the case in Australia.

## 5.5 Commercialising health research

158. The commercialisation of health research attracted some comment within submissions and during consultation workshops. Please note, however, that industry made very few submissions.
159. Much of the feedback on commercialisation suggested that commercialisation of research should be a secondary priority to improving the health of New Zealanders. People expressed concern that the drive to commercialise could 'capture' the research agenda. Feedback of this type came from a range of sources, particularly researchers, health practitioners and groups representing health practitioners.
- Health and social benefits to New Zealanders should be the first priority when determining investment settings. Economic benefits and enhanced recognition for NZ researchers should not be a driving force. (Government agency)
160. Conversely, participants at the two commercialisation workshop and some submissions highlighted the benefits and opportunities of embracing commercialisation of research. Workshop participants felt that the Ministry of Health and MBIE should coordinate the message that good health outcomes require research and innovation and that research and innovation need to be viewed together.

161. The need for health providers to actively engage in, and drive or demand, innovation was a theme in commercialisation workshops. The Auckland commercialisation focus group emphasised that the health system needs to identify the questions they want answered and the health outcomes they want to achieve. Then the health system should work with researchers and industry to find solutions.
162. Another point participants noted was the need to clarify what is meant by ‘economic outcomes’ as the term can cover both extrinsic, commercially focused outcomes and intrinsic, productivity gains to the health system.
163. Those providing feedback identified the following gaps in New Zealand’s existing health research funding environment as impacting on the efficient commercialisation of research findings.
- a. New Zealand needs to have a ‘concept’ of a health technology industry.  

For a long time the researchers, companies and individuals working in what is effectively a health-related industry have missed out on policy planning opportunities due to not being recognised as a burgeoning industry. I recognise the historic sensitivity of using the word ‘industry’ in health, but I believe that the scale, synergies, economic value and need for coherent policies justifies the concept of a health research and technology industry. (Other)
  - b. District health boards have no mandate to drive innovation.  

A key example is in the innovation space where commercial entities need clinical partners. Current systems do not readily enable DHB participation in potentially win-win partnerships as the frontline staff that could support such objectives are already committed to their contractual duties. (District health board)
  - c. Procurement rules and lack of infrastructure limit the ability of district health boards to co-create technologies through clinical validation or to take up (as early adopters) new technology developed in New Zealand. Yet such actions would enable organisations to provide ‘proof of concept’ in their own health system.  

Consideration is given to ensure that the need for clinical validation in healthcare settings is recognised as a key contributor to development of Medtech and biotech industries. (District health board)
  - d. There are difficulties agreeing on the cost of validation of technology and who pays.  

In the current funding environment, DHBs are not in a position to subsidise industry clinical validation and reference sites and smaller NZ biotech and Medtech companies are not in a position to pay. (Auckland Commercialisation Focus Group)
  - e. The health sector does not evaluate and adopt medical technologies in a systematic way.  

Pharmac is now involved but the effectiveness is yet to be established. (Non-governmental organisation)
  - f. The Performance-based Research Fund can be a disincentive to commercialisation.

Commercial application means deferring or not publishing, and publications are crucial for career promotion and PBRF scores, and delay in being allowed to demonstrate the outcomes of a person's research may make the choice not to go down the commercial route. (University)

164. The following actions to develop better support for commercialisation in the New Zealand health research environment were suggested.
- a. Link the Health Research Strategy to government economic strategies (Business Growth Agenda) to promote the creation of new biotech ventures.
  - b. Take a more 'action-oriented' view of the commercial sector's engagement in health research (for example, co-innovation, reciprocal relationships).

[I]ndustry needs to be seen as a critical partner in developing the thinking and priorities that lead to more effective research outcomes. (Non-governmental organisation)
  - c. Build a strong clinical trial industry to provide clinical evaluation and validation support.

One area of R&D spend that does continue and is capable of significant growth in the short term is the funding of clinical trials. (District health board)
  - d. Provide district health boards with a clear mandate to innovate (Auckland and Christchurch commercialisation workshops).
  - e. Develop district health board infrastructure to support clinical validation of new technology.

DHB infrastructure is acknowledged and funded as a critical contributor to clinical validation and provision of reference sites to support technology commercialisation and uptake. (District health board)
  - f. Amend the procurement roles for district health boards.

Establishment of a new category of procedure products/services and rules related to innovation partnerships between the health sector and industry which facilitate wider adoption and uptake of proven innovations. (District health board)
  - g. Address the cost of clinical validation.

(1) Employment grants for smaller NZ businesses seeking to jointly appoint clinical advisers with DHBs, (2) Explicit funding within research grants for DHB infrastructure required to support clinical validation/reference sites (3) Research and development tax breaks. (Auckland Commercialisation Focus Group)
  - h. Develop health technology specific incubators, accelerators, co-working spaces or similar initiatives to support the translation of concepts from research to accessible patient interventions.

The technical, regulatory, research, investment, intellectual property and other domains in bringing a health technology to market are highly specialised. (Other)
  - i. Improve investment settings, including tax incentives for early start-up companies that encourage collaboration between industry, the health sector and/or academic researchers in New Zealand. (Australia provides an example of this approach.)
  - j. Show the impact of innovation and intervention on clinical practice and cost, using health econometrics.

- k. Train the health research workforce to engage in commercial research .  

There are very limited pool[s] of senior clinicians and nurses credentialed to engage in commercial research. (District health board)
  - l. Help researchers to better understand the concepts and language of industry through internships and short-term secondments, mentoring, collaboration and physical co-location.
165. See section 4.6 for a discussion of ethical issues relevant to the commercialisation of health research.
166. One submission noted that New Zealand should align with (or at least be aware of) some of the international movements to support bringing technology through the research and development stages to clinical practice. This includes groups such as:
- a. Transcelerate – for pharmaceutical and biotech research
  - b. Excite International – for device and health information technology.

## 6 Developing the health research workforce

167. Submissions and participants in consultation workshops consistently mentioned the development of the health research workforce (suggesting 121 workforce-related actions in total).

Our health research workforce is aging, and if we are to safeguard the health research workforce in the future, we need to take steps now to make New Zealand an attractive, vibrant and collaborative place for emerging researchers to situate themselves. (University)

168. It was suggested that a health research workforce development plan would support a more strategic approach to workforce development.

A review of health research career planning is required to develop clear career routes through the doctoral, post-doctoral and early–mid career stages and beyond. (University)

### 6.1 Workforce development issues

#### *Health research workforce*

169. In identifying issues related to developing the health research workforce, those providing feedback noted the need to:

- a. retain and develop New Zealand health research graduates

It is widely acknowledged that in New Zealand we are lacking good career development of our early career scientists, especially at the post-doctoral fellow level, which should be the backbone of our research productivity. (University)

- b. retain New Zealand health researchers

We see a need to address the issue of ‘mid-career’ researchers, particularly those in research-only positions, through a mechanism that gives surety of position over longer periods of time (e.g. career excellence fellowships). (University)

- c. attract the best researchers to work in New Zealand

- d. develop the Māori and Pacific health research workforces (and acknowledge the special role of Māori and Pacific health researchers)

- e. develop the disabled health research workforce

- f. address skill gaps (for example, in biostatistics, health economics, epidemiology, implementation science, evaluation, and knowledge translation)

- g. retain support staff (for example, laboratory managers, statisticians and data managers).

The lack of a career structure and pathway ... for the retention of highly trained technical staff limits the workforce available to achieve the ambitious aims of the strategy. (Other)

## *Health professional workforce*

170. In identifying issues related to developing research skills and activity among health professionals, those providing feedback suggested:
- a. having pathways for clinicians and other health professionals to develop research expertise
  - b. encouraging and supporting health practitioners to engage in health research.

## 6.2 Improving workforce development

### *Suggested actions*

171. Suggestions to improve workforce development were to:
- a. promote science in schools to seed interest in a health research career
  - b. put greater emphasis on science in medicine in the medical student curriculum and other training for health professionals (for example, in programmes for a Doctorate of Medicine and of Philosophy, MD-PhD)
  - c. build research time into health practitioner contracts
  - d. increase the number of research fellowships (including post-doctoral, clinical, mid-career and repatriation fellowships)
  - e. provide national and international networking opportunities for emerging researchers
  - f. develop funding models with two levels – emerging and established (see Marsden Fund Fast-Start)
  - g. develop longer-term funding opportunities to provide job security
  - h. develop innovative funding mechanisms to support Māori and Pacific workforce development.
    - ... building capacity in a nursing research capable workforce; ... has to be supported ... pathways to take part in funded research [and] career pathways [that run] from ... clinical trials nurses through to becoming principal investigators on nurse led research programmes ... alongside clinical careers need to be created.’ (Health professional association)



## 7 Structural components of the strategy

172. Submissions and participants at the consultation meetings provided specific feedback on the vision, mission, guiding principles and strategic priorities outlined in the discussion document. This section describes the general themes from this feedback.

### *Feedback on the general structure of the framework*

173. Most submissions indicated that the vision, mission and guiding principles set the framework for a more cohesive and connected health research system (although they suggested many additions and amendments).
174. In a few submissions, people questioned the structure of, and delineation between, the vision, mission, guiding principles and strategic priorities. Particularly noted was a disconnect between the guiding principles and the mission.
- Proposed GPs [guiding principles] are uncoupled from the mission and as such GPs are actually devoid of any principles, more about process. (Non-governmental organisation)
- Mission statement is conceptual and repeats vision. Should be more directive in regards to informing researchers of the direction of travel, expectations and clarity of purpose. (University)
175. Some submissions indicated that the strategy should align more closely with the National Statement of Science Investment. Many felt that the strategy should align more closely with the *New Zealand Health Strategy* (Ministry of Health 2016).
176. A suggestion made in a few submissions was that ethics should be more prominent across the whole strategy. This includes reflecting principles of consumer participation and protection, and principles of equity.

### *Feedback on wording and terminology*

177. Many submissions indicated that the vision, mission, guiding principles and strategy priorities were too complex and wordy.
178. From some submissions came a call for clear definitions of key terms such as innovation, excellence, high impact, innovation system, value and end user.
179. A large number of submissions felt that the language of the strategy should be more strongly oriented towards being 'people powered' and be holistic.
- Proposed vision needs to acknowledge the importance of the patient or research participant putting them at the heart of health research ... Adding a guiding principle acknowledging the importance of the patient or research participant, places them at the heart of the health research strategy, and ensures that they are protected and their interests are served. (Consumer organisation)

180. Many submissions questioned the references to widespread adoption of technology and use of cutting-edge research techniques.

Use language such as ‘use the best approaches available to address research issues’ and where appropriate use cutting edge approaches and techniques. (Non-governmental organisation)

### *Feedback on the vision*

181. Some submissions thought the vision is too wordy and that some of its signals need to be clarified and highlighted.
182. Most university submissions considered that excellence should be brought into the vision.
183. Many submissions from across the sector thought that the vision needs to align more closely with the NSSI and the *New Zealand Health Strategy* (Ministry of Health 2016).
184. A request in a large number of submissions was for the vision to strongly emphasise health equity and the social determinants of health.
185. Several submissions indicated that the vision should recognise New Zealand as a multicultural nation by more strongly emphasising Māori and Pacific peoples in relation to both health inequities and valuing non-western paradigms.
186. A concern in several submissions was that ethics and ethical research should feature more strongly in the vision.

Add under vision statement two bullets. Science that addresses the major underlying determinants of poor health and health inequalities in NZ; and science that recognises the fundamental co-benefits of health and sustainability. (University)

Add in by 2026 we want to see – a research environment that works in partnership with and values the contribution of patients, consumers, and operates within a robust and independent ethical framework that has the protection of research participants as paramount. (Government agency)

### *Feedback on the mission*

187. Feedback on the mission statement was limited but offered a broad range of suggestions. Those providing feedback proposed the mission statement should cover:
- cultural elements of wellbeing
  - fostering close relationships with international research institutes
  - the need for workforce development
  - the importance of research dissemination
  - the broader determinants of health and improving health equity.

### *Feedback on the guiding principles*

188. Feedback on the guiding principles was relatively extensive and predominantly consisted of suggestions for additional guiding principles. The most common suggestions were to include as guiding principles:
- a. equity
  - b. the impact or translation of research
  - c. ensuring health research is patient-focused
  - d. ethics (including data protection)
  - e. workforce development
  - f. international focus (connections to international health research).

### *Feedback on the strategic priorities*

189. Feedback on strategic priorities (SPs) indicated support for the general themes of the priorities. People particularly supported the inclusion of determinants of health (SP2), collaboration (SP3), research translation (SP4) and workforce development (SP5).
190. Some felt that the example strategic priorities were too broad and that this reduced their impact.
191. Feedback ranged from very specific suggestions for wording changes to complete rewrites of the example strategic priorities.

## 8 Implementing the strategy

192. Some submissions recognised that the approach taken to implementing the New Zealand Health Research Strategy would be critical to its success. They highlighted the following areas as needing a considered approach:
- a. cross-government ownership

[W]e would like to recommend that input, implementation and (where appropriate) co-ownership of the health research strategy includes all government agencies and departments who may have an effect on, and be affected by, the health research system. (University)
  - b. leadership, particularly noting the issue of system leadership and governance to support integrating research into the health system

[T]he value of the strategy will be diminished if it is not explicit about which agency or agencies are responsible for its resourcing, review and accomplishment. (Individual researcher)
  - c. resourcing, with a need for clear information about what resources and systems will be put in place to implement the strategy
  - d. timing, specifically a clearer timeline/road map within the 10-year plan (for example, a three-year workplan)
  - e. monitoring, with a need for the strategy to address how change will be monitored and measured (evaluation)
  - f. communication, specifically a coordinated approach to communicating the importance of the science and research investment.
193. Many submissions highlighted the importance of building a clear line of sight between the New Zealand Health Research Strategy and New Zealand's foundational documents and Government strategies and initiatives. Of particular concern were its links to the:
- a. Treaty of Waitangi and the Crown's special relationship with tangata whenua
  - b. New Zealand Public Health and Disability Act 2000
  - c. New Zealand Health Strategy
  - d. New Zealand Disability Strategy
  - e. Vision Mātauranga strategy
  - f. National Statement of Science Investment
  - g. National Science Challenges.

194. Also noted was the importance of linking to the following international strategies and instruments:
- a. United Nations Universal Declaration of Human Rights (Article 25: Right to Health)
  - b. United Nations Convention on the Rights of Persons with Disabilities
  - c. United Nations 2030 Agenda for Sustainable Development
  - d. World Health Organization Strategy on Research for Health (WHO 2012)
  - e. World Health Organization guidelines for ethics (WHO 2011).

## References

Ministry of Health. 2014. *'Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2014–2018*. Wellington: Ministry of Health.

Ministry of Health. 2014, updated. *He Korowai Oranga*. Wellington: Ministry of Health. URL: [www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga](http://www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga) (accessed 26 November 2016).

Ministry of Health. 2016. *New Zealand Health Strategy: Future Direction*. Wellington: Ministry of Health.

Ministry of Research, Science and Technology. 2007. *Vision Mātauranga: Unlocking the innovation potential of Māori knowledge, resources and people*. Wellington: Ministry of Research, Science and Technology.

WHO. 2011. *Standards and Operational Guidance for Ethics Review of Health-related Research with Human Participants*.

WHO. 2012. *The WHO Strategy on Research for Health*. Geneva: World Health Organization.

## Appendix 1: Submitters and attendees at consultation meetings

### List of group or institutional written submitters

Acupuncture NZ  
Ageing Well National Science Challenge  
Auckland District Health Board  
Auckland District Health Board – Cancer & Blood Service  
Auckland District Health Board – New Zealand Emergency Medicine Research  
Auckland District Health Board – Radiology Department  
Auckland Regional Public Health Service  
Auckland UniServices  
Auckland Women’s Health Council of New Zealand  
Blind Foundation  
Brain Research New Zealand  
Breast Cancer Cure and Breast Cancer Aotearoa  
Capital & Coast District Health Board  
Capital & Coast District Health Board – Centre for Endocrine, Diabetes and Obesity Research  
Cancer Consumer NZ  
Cancer Society  
Cancer Trials New Zealand  
Canterbury District Health Board  
Cochrane New Zealand  
Consortium of Medical Device Technologies & MedTech Centre of Research Excellence  
Council of Medical Colleges in New Zealand  
Counties Manukau Health  
Cure Kids  
Department of Corrections  
Dietitians NZ  
Disabled Person’s Assembly New Zealand  
Federation of Women’s Health Councils  
Health Precinct Advisory Council – Christchurch  
Health Promotion Agency  
Health Quality and Safety Commission  
Health Research South  
Human Rights Commission  
Institute of Environmental Science and Research  
Library and Information Association of New Zealand Aotearoa (LIANZA) – Health Special Interest Group (health – SIG)

Lincoln University  
Malaghan Institute of Medical Research  
Massey University and College of Health  
Massey University – Speech and Language Therapy Programme  
Medical Research Institute of New Zealand  
MidCentral District Health Board  
Middlemore Clinical Trials  
Ministry of Health – Ethics Committee Secretariat  
Ministry of Health – National Ethics Advisory Committee  
National Council of Women of New Zealand  
National Health IT Board Consumer Panel  
New Zealand Acupuncture Standards Authority Inc  
New Zealand Association of Clinical Research  
The New Zealand Breast Cancer Foundation  
New Zealand Chiropractors’ Association  
New Zealand College of Midwives  
New Zealand College of Public Health Medicine  
New Zealand Drug Foundation  
New Zealand Family Planning  
New Zealand Food & Grocery Council  
New Zealand Medical Association  
New Zealand Nurses Organisation  
New Zealand Nurses Organisation – Nursing Research  
New Zealand Private Surgical Hospitals Association  
New Zealand Winegrowers  
New Zealanders for Health Research  
Northern Regional Alliance Asian, Migrant and Refugee Programme and Waitemata District Health Board eCALD® services  
OraTaiao: New Zealand Climate & Health Council  
Pan Pacific Nurses Association of NZ  
Pegasus Health  
Public Health Association of New Zealand  
The Royal Australasian College of Physicians  
Royal Australasian College of Surgeons  
The Royal Australian and New Zealand College of Psychiatrists  
The Royal New Zealand College of General Practitioners  
Royal New Zealand Plunket Society  
Royal Society of New Zealand  
Rural Women New Zealand



Spirits New Zealand  
Southern Cancer Network  
Southern Institute of Technology  
Sport Waitakere – Healthy Families Waitakere  
Stroke Foundation of New Zealand  
Te Pou Limited  
Te Pūtahitanga o Te Waipounamu  
Te Rau Matatini  
Te Rūnanga o Ngāi Tahu  
Trans-Tasman Radiation Oncology Group – Cancer Research  
Universities New Zealand Research Committee  
The University of Auckland  
The University of Auckland – FMHS Postdoctoral Society  
The University of Auckland – Health Systems Section, School of Population Health  
The University of Auckland – Paediatrics, Child & Youth Health; Growing up in NZ and Centre for Longitudinal Research  
The University of Auckland – Retirement Policy and Research Centre  
The University of Auckland, School of Population Health – Doctoral students  
University of Otago  
University of Otago – Department of Biochemistry  
University of Otago – Department of Public Health  
University of Otago – Division of Health Science  
University of Otago – Edgar Diabetes and Obesity Research Centre  
University of Otago – Faculty of Dentistry  
University of Otago, Christchurch  
University of Otago, Christchurch – Department of Psychological Medicine  
University of Waikato  
Victoria University of Wellington – Group within the School of Psychology  
Victoria University of Wellington – Graduate School of Nursing, Midwifery and Health  
Victoria University of Wellington – Health Policy & Management, HSR Centre, School of Government  
Victoria University of Wellington – Research Development Office  
Virtual Health Information Network  
Waikato District Health Board  
Waikato District Health Board and Midland Regional Trauma System  
Waikato District Health Board – Population Health  
Waitemata District Health Board – Research Governance Group  
Wintec Centre for Sport Science and Human Performance  
Women's Refuge

## List of individual written submitters

Note that 15 individuals requested their names be withheld.

Paul Aitkinson  
Scott Arrol  
Bruce Baguley  
Ettore Beghi  
Peter Bergin  
Graeme Campbell  
Alan Davidson  
Sally Dobbs  
Jeroen Douwes  
Hinemoa Elder  
Adib Essali  
Joanna Fadyl  
John Foreman  
Joshua Freeman  
Meriann Garcia  
Alistair Gunn  
Paul Hansen  
Allan Herbison  
Barbara Holland  
Sarah Hunter  
Rod Jackson  
Yvette Lamare  
Marivic Lauc  
Stephen Legg  
Merian Litchfield  
Ian Longley  
Shaun Lott  
Sally McQueen  
Barry Milne  
Suresh Muthukumaraswamy  
Janet Peters  
Sheridan Pooley  
Rhonda Powell  
Sue Purdie  
Bridget Robinson  
George Serber

Kevin Sheehy  
Sandra Sheene  
Mary Silcock  
Robert Weinkove  
Nick Wilson

## List of agencies at the government agencies focus groups

Accident Compensation Commission (ACC)  
Callaghan Innovation  
Department of Internal Affairs (DIA)  
Health Promotion Agency (HPA)  
Health Quality & Safety Commission (HQSC)  
Health Research Council  
Ministry of Business, Innovation and Employment (MBIE)  
Ministry of Defence  
Ministry of Health  
Ministry of Social Development (MSD)  
Ministry for Women  
National Health Committee (NHC)  
Office for Disability Issues  
Office for Senior Citizens  
PHARMAC  
Statistics New Zealand  
Superu  
Te Puni Kōkiri  
Tertiary Education Commission  
Veterans' Affairs

## List of attendees at regional consultation meetings, by affiliation(s)

Each list provides the number of attendees for each organisation.

### *Wellington 14/06/2016*

<b>Attendee</b>	<b>Number</b>
3 DHB Radioloft	1
Capital & Coast District Health Board	1
Health Quality & Safety Commission	2
Individual	1
The Kid's Fed Up	1
Massey University	3
Malaghan Institute of Medical Research	2
Medical Research Institute of New Zealand	1
Ministry of Health	2
Public Health Association	1
Regional Public Health	1
The Royal Australian and New Zealand College of Psychiatrists	1
The Royal New Zealand College of General Practitioners	1
The Cancer Society of New Zealand	1
Universities New Zealand	1
University of Otago	3
Victoria University of Wellington	3
Wellington Indian Association	1
Whitireia New Zealand	1
WorkSafe New Zealand	1

### *Auckland 16/06/2016\**

<b>Attendee</b>	<b>Number</b>
Auckland District Health Board	3
Auckland University of Technology	6
Breast Cancer Cure	1
Breast Cancer Aotearoa	1
Bruce A Scoggins and Associates Ltd	1
Callaghan Innovation	1
Community Alcohol and Drug Services	1
Individual	3
National Institute of Water and Atmospheric Research (NIWA)	1
The University of Auckland	4
Vensa Health	1
Waitemata District Health Board	2

Note: \* Some attendees provided multiple affiliations and have therefore been counted more than once.

### *Wellington 20/06/2016\**

<b>Attendee</b>	<b>Number</b>
Acupuncture NZ	1
Asthma and Respiratory Foundation New Zealand	1
Capital & Coast District Health Board	1
Central Cancer Network	1
Environmental Science and Research (ESR)	1
Ferrier Research Institute	1
Genetic Health Service New Zealand	1
Individual	1
Massey University	3
Ministry of Health (including Ethics and Medsafe)	5
New Zealand Nurses Organisation	1
New Zealand Acupuncture Standards Authority	1
New Zealand College of Public Health Medicine	2
Pacific Perspectives	1
Royal New Zealand Plunket Society	1
Te Pou o te Whakaaro Nui	1
University of Otago	2
Victoria University of Wellington (including IGPS)	9
Whitireia New Zealand	1

Note: \* Some attendees provided multiple affiliations and have therefore been counted more than once.

### *Dunedin 21/06/2016*

<b>Attendee</b>	<b>Number</b>
Dunedin School of Medicine	2
Invigorate Nutrition	1
Otago Polytechnic	2
University of Otago	18
Southern District Health Board	1

### *Christchurch 22/06/2016\**

<b>Attendee</b>	<b>Number</b>
A E Stewart	1
Arris 42 Limited	1
Canterbury District Health Board	1
Environmental Science and Research (ESR)	4
Health Precinct Advisory Council	1
Individual	1
Lincoln University	2
New Zealand Institute of Community Health Care	1
SKOPE Industries Ltd	1
University of Canterbury	5
University of Otago, Christchurch	5
University of Otago, Dunedin	2
YourCoach Ltd	1

Note: \* Some attendees provided multiple affiliations and have therefore been counted more than once.

### *Auckland 24/06/2016*

<b>Attendee</b>	<b>Number</b>
Auckland District Health Board	2
Auckland University of Technology	2
Counties Manukau District Health Board (including Ko Awatea)	1
Cure Kids	2
Individual	1
Massey University, Auckland	1
Middlemore Clinical Trials	1
National Ethics Advisory Committee	1
Robin Olds Research and Strategy Consulting	1
Te Pou o te Whakaaro Nui	1
The University of Auckland	4
University of Waikato	1
Waikato District Health Board	2
Waitemata District Health Board	2

### *Auckland 27/06/2016*

<b>Attendee</b>	<b>Number</b>
Auckland District Health Board	1
Auckland University of Technology	9
Cure Kids	1
Individual	2
Neurological Foundation of New Zealand	1
New Zealand Breast Cancer Foundation	1
Ngātiwai Trust Board	1
Plant & Food Research	1
The Royal Australasian College of Physicians	1
Unitec – Institute of Technology	2
The University of Auckland (including UniServices)	3
Waitemata District Health Board	2

### *Dunedin 28/06/2016*

<b>Attendee</b>	<b>Number</b>
AD Instruments	1
BPAC Clinical Solutions	1
Health Research South	1
Mercy Hospital	1
New Zealand Genomics Ltd	1
Victoria University of Wellington	1
Visual Impairment Charitable Trust Aotearoa NZ	1
University of Otago (including Dunedin School of Medicine)	13

### *Auckland 30/06/2016\**

<b>Attendee</b>	<b>Number</b>
Alcohol Healthwatch	2
Auckland District Health Board	4
Auckland University of Technology	4
Counties Manukau District Health Board	1
Healthy Families	1
Individual	3
Massey University	1
Maurice Wilkins Centre	1
MidCentral District Health Board	2
Ministry of Health	1
New Zealand Psychology Society	1
Ngāti Porou Hauora	1
Plant & Food Research	1
Rescare Homes Trust	1
Sport Waitakere	2
Te Whare Wānanga o Awanuiārangi	1
The University of Auckland (including Liggins Institute)	8
University of Otago, Wellington	1

Note: \* Some attendees provided multiple affiliations and have therefore been counted more than once.



### *Hamilton 01/07/2016\**

<b>Attendee</b>	<b>Number</b>
Auckland University of Technology	1
Bay of Plenty Polytechnic	1
Hikitia Consultants	1
Ministry of Health	2
REKA Trust	2
Te Pou o te Whakaaro Nui	2
Tuakana Teina Collective	1
The University of Auckland	2
University of Waikato	10
Waiariki Bay of Polytechnic	3
Waikato District Health Board	8
Wintec	1

Note: \* Some attendees provided multiple affiliations and have therefore been counted more than once.

### *List of attendees at targeted focus groups, by affiliation(s)*

#### *Commercialisation Focus Group – Auckland 12/07/2016*

<b>Attendee</b>	<b>Number</b>
Auckland UniServices Ltd	2
Callaghan Innovation	1
Counties Manukau District Health Board	1
Cure Kids Ventures	1
Healthvision	1
Im.Able	1
KiwiNet	1
LCT	1
NZHIT	1
Orion Health	2
Rex Bionics	1
The University of Auckland	1
University of Waikato	1

### *Pacific Focus Group – Auckland 12/07/2016*

<b>Attendee</b>	<b>Number</b>
Alliance Health	1
Middlemore Hospital	1
Ministry of Health	1
Pacific Perspective	1
Pasifika Medical Association	1
The University of Auckland	3
Victoria University of Wellington	1

### *Role of Health Service Agencies Focus Group – Auckland 13/07/2016\**

<b>Attendee</b>	<b>Number</b>
Allied Health Aotearoa New Zealand	1
Auckland District Health Board	3
Counties Manukau District Health Board	2
The University of Auckland	2
Waitemata District Health Board	2

Note: \* Some attendees provided multiple affiliations and have therefore been counted more than once.

### *Health Research Workforce Focus Group – Auckland 13/07/2016*

<b>Attendee</b>	<b>Number</b>
Australia and New Zealand College of Anaesthetists	1
Auckland District Health Board	1
Auckland Public Health Service	1
Auckland University of Technology	2
Health Navigator Charitable Trust	1
Health Workforce New Zealand	1
Ministry of Health	2
The University of Auckland	1
University of Waikato	1
Waitemata District Health Board	2

### *Not-for-profit Organisations Focus Group – Auckland 14/07/2016*

<b>Attendee</b>	<b>Number</b>
Auckland Medical Research Foundation	1
Breast Cancer Cure	1
Cure Kids	2
Leukaemia and Blood Cancer New Zealand	1
Neurological Foundation of New Zealand	1
New Zealand Breast Cancer Foundation	1
New Zealand Organisation for Rare Disorders	1
Unitec	1
Violence Fire Communications	1

### *Research Prioritisation Focus Group – Auckland 14/07/2016*

<b>Attendee</b>	<b>Number</b>
Auckland District Health Board	3
Auckland University of Technology	1
Cure Kids	2
Health Research Council	1
Massey University	1
Ministry of Health	1
The University of Auckland	2
University of Waikato	1

### *Māori Health Research Focus Group – Auckland 15/07/2016*

<b>Attendee</b>	<b>Number</b>
Auckland University of Technology	3
Former Health Research Council Board Member	1
Ngā Pae o te Māramatanga	1
Rauawaawa Kaumatua Charitable Trust	1
Te Rau Matatini	1
Te Whare Mātai Aronui	1
The University of Auckland	1
University of Waikato	1
Waikato District Health Board	1

### *Trends and Opportunities in Health Research Focus Group – Auckland 15/07/2016*

<b>Attendee</b>	<b>Number</b>
Auckland University of Technology	1
The University of Auckland	3
University of Waikato	1

### *Health Research Funding Opportunities Focus Group (1) – Wellington 19/07/2016*

<b>Attendee</b>	<b>Number</b>
Health Research Council	2
Ministry of Business, Innovation and Employment	3
Ministry of Health	1
Royal Society of New Zealand	1

### *Health Research Funding Opportunities Focus Group (2) – Wellington 19/07/2016*

<b>Attendee</b>	<b>Number</b>
ACC	1
Ministry for Women	1
Ministry of Business, Innovation and Employment	1
Ministry of Health	1
Ministry of Social Development	1
PHARMAC	2
Superu	1

### *Not-for-profit Organisations Focus Group – Wellington 20/07/2016*

<b>Attendee</b>	<b>Number</b>
Blind Foundation	1
Cancer Society	1
Heart Foundation	1
Problem Gambling Foundation New Zealand	1
Royal New Zealand Plunket Society	1
Stroke Foundation	1
Wise Group	1
Women's Refuge	1

### *Role of Health Service Agencies and Prioritisation Focus Group – Wellington 20/07/2016*

<b>Attendee</b>	<b>Number</b>
ACC	1
Capital & Coast District Health Board	1
Health and Disability Commissioner	2
Health Quality & Safety Commission	1
Institute of Environmental Science and Research	1
Malaghan Institute of Medical Research	1
Massey University	1
Regional Public Health	1
University of Otago	2
Victoria University of Wellington	4

### *Commercialisation of Health Research Focus Group – Christchurch 25/07/2016*

<b>Attendee</b>	<b>Number</b>
Canterbury District Health Board	3
CMRT	1
Foot Science	1
Medicines New Zealand	1
Navigator Ltd	1
Ossis	1
University of Canterbury	1

### *Role of Health Service Agencies Focus Group – Christchurch 25/07/2016\**

<b>Attendee</b>	<b>Number</b>
Canterbury District Health Board	4
Health Precinct Advisory Council	1
University of Otago	3
West Coast District Health Board	1

Note: \* Some attendees provided multiple affiliations and have therefore been counted more than once.

### *Role of Health Service Agencies Focus Group – Dunedin 26/07/2016\**

<b>Attendee</b>	<b>Number</b>
Auckland District Health Board	1
Canterbury District Health Board	1
Southern District Health Board	1
University of Otago	10

Note: \* Some attendees provided multiple affiliations and have therefore been counted more than once.

### *Health Research Prioritisation Focus Group – Dunedin 26/07/2016*

<b>Attendee</b>	<b>Number</b>
University of Otago	13

### *Health Research Trends and Opportunities Focus Group – Dunedin 26/07/2016*

<b>Attendee</b>	<b>Number</b>
University of Otago	9

### *Health Research Workforce Focus Group – Dunedin 26/07/2016*

<b>Attendee</b>	<b>Number</b>
University of Otago	5

### *Māori Health Research Focus Group – Wellington 28/07/2016\**

<b>Attendee</b>	<b>Number</b>
Katoa Limited	1
Massey University	1
The University of Auckland	2
University of Otago, Wellington	3
Whakauae Research Services	1

Note: \* Some attendees provided multiple affiliations and have therefore been counted more than once.

### *Pacific Health Research Focus Group – Wellington 28/07/2016*

<b>Attendee</b>	<b>Number</b>
Massey University	1
Ministry of Health	1
University of Otago, Wellington	2
Whitireia New Zealand	1

*Disability Research Focus Group – Wellington 28/07/2016\**

<b>Attendee</b>	<b>Number</b>
Atawhai	1
Auckland University of Technology	3
Blind Citizens New Zealand	2
Blind Foundation	1
Canterbury District Health Board	1
Capital & Coast District Health Board	2
CCS Disability Action	1
CCT Dunedin Support Centre	2
Children's Autism Foundation	1
Deaf Aotearoa	1
Deafblind New Zealand	2
Disabled Persons Assembly	3
DPO Representative	1
Emerge Supported Employment Trust	1
Human Rights for All Trust	1
Inclusive New Zealand	1
Interactionz	2
Kāpo Māori	1
The Lucy Foundation	1
Massey University, Palmerston North	1
Media Associates	1
The National Foundation for the Deaf	1
National Leadership Group Enabling Good Lives	1
Needs Assessment Service Co-ordination Association	1
Revision of New Zealand Disability Strategy Reference Group	6
The Ryder-Cheshire Foundation	1
Skillwise, Christchurch	1
Te Pou	1
The University of Auckland	1
University of Canterbury	1
University of Otago	4
University of Waikato	2
Victoria University of Wellington	3
Waitemata District Health Board	2
Wellbeing, Wellington	1
Wellington After-care Association	1
Wellington Sub-Regional Disability Advisory Group	1

Note: \* Some attendees provided multiple affiliations and have therefore been counted more than once.

*Maori Health Research Focus Group – Ngāti Porou Hauora 07/09/2016*

<b>Attendee</b>	<b>Number</b>
Ngāti Porou Hauora executive and management	5
Ngāti Porou Hauora Board members	3
Elder Te Reo, Kaumatua	1

*Māori Health Research and Health Services Delivery Focus Group 07/09/2016*

<b>Attendee</b>	<b>Number</b>
Ngāti Porou Hauora	1
The Doctors Te Whare Hāpara nurse and management	2
Turanga Health	1
Hauora Tairāwhiti	5