



# **Te Pae Tika: E tūhura ana i ngā ara hou me ngā uauatanga e pā ana ki te āta matapaetanga, te haukotanga, te kitenga me te rongoātanga o ngā mate ki Aotearoa**

## **Precision Health: Exploring opportunities and challenges to predict, prevent, diagnose, and treat disease more precisely in Aotearoa New Zealand**

Public consultation on a draft long-term  
insights briefing

May 2023

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# Foreword from the Director-General of Health

Tēnā koutou katoa

I am proud to share our first draft long-term insights briefing (LTIB) on precision health: exploring opportunities and challenges to predict, prevent, diagnose and treat disease more precisely in Aotearoa New Zealand.

Our health system is undergoing significant changes to improve health and wellbeing outcomes for all New Zealanders. To achieve our goal of pae ora | healthy futures, we need to be willing to do things differently and look for new and innovative ways to deliver health care into the future.

Precision health is an exciting and rapidly developing field that holds the potential to significantly improve the health and wellbeing of individuals, whānau and communities across Aotearoa New Zealand. However, such new developments can come at considerable cost, and not all applications are necessarily beneficial. The prominence of precision health in the international sphere has prompted us to think more deeply about how these emerging technologies might impact Aotearoa New Zealand.

Our unique population and global position mean that we are well placed to influence and lead the development of precision health technologies both here and overseas. However, we need to be cautious in adopting new technologies to ensure they will be used equitably to benefit all New Zealanders. We also need to work carefully and in partnership with Māori to honour Te Tiriti o Waitangi in any approaches to precision health.

I am grateful to all those who shared their feedback with Manatū Hauora (the Ministry of Health) when we consulted on the topic for this briefing. Your input has helped shape our suggestions about the future of precision health in Aotearoa New Zealand – including the opportunities and risks that we need to be particularly aware of and areas where we may need to consider making changes to ensure equitable and effective use of new technologies in our health system.

However, this LTIB is still only a draft, and we want to hear your views on what we have suggested here. My hope is that this briefing represents the start of a broader conversation about precision health in Aotearoa New Zealand that will need to take place across communities, iwi, academic institutions and government in the coming years.

We look forward to exploring this LTIB topic with you.

Ngā mihi maioha

**Dr Diana Sarfati**  
Director-General of Health

# He pēhea ō whakaaro? | What are your views?

Manatū Hauora (the Ministry of Health) is seeking written feedback on this draft of its long-term insights briefing (the briefing) by 5pm on 19 June 2023.

This is the second phase of a 2-phase public consultation approach to develop our briefing. You can make your submission by:

- completing the form provided on Citizen Space
- emailing your feedback to: [LTIB@health.govt.nz](mailto:LTIB@health.govt.nz)
- posting it to: Strategy Group, Ministry of Health, PO Box 5013, Wellington 6140.

Please include your name, the name of your organisation (if applicable) and your contact details in your submission. You may also include links to relevant evidence, for example, research references, or outline the values that underpin your comments.

For more information on how we intend to use and publish your feedback and how we will protect your private information, see Annex 1: Use of information.

# He whakarāpopoto | Summary

All public service departments are required by the Public Service Act 2020 to produce long-term insights briefings (LTIBs). LTIBs are independent of Ministers and aim to look at the medium- and long-term trends, risks and opportunities that may affect Aotearoa New Zealand over the next 10 years and beyond.

This briefing is a draft of our inaugural LTIB and focuses on the topic of precision health. Precision health is an umbrella term for the use of technology and information to develop more precise ways of keeping people healthy. In our briefing, we have focused on two (2) examples of precision health that stakeholders such as clinicians, academics, and researchers in the field, were particularly interested in: genomics and artificial intelligence (AI). These technologies are developing rapidly and present a range of new ways to think about treating health issues and disease and using health promotion and prevention tools.

Precision health is increasingly being used in both individual and population health interventions internationally, but its use in Aotearoa New Zealand is currently limited. However, we have heard from stakeholders who believe widespread use of precision health technologies is coming – and in some cases is already here.

There is significant potential for precision health technologies to help us in working towards achieving our health system vision of pae ora | healthy futures. Specifically, we have heard that there are opportunities to: partner with Māori from the outset in the design and implementation of new technologies; create more equitable outcomes through targeted interventions and tailored care for individuals and whānau; and make our health system more efficient. The advancement of technology must ensure that Māori needs and aspirations are being met (including the protection of taonga such as DNA, whakapapa and data). Inequities could be exacerbated without a consistent approach to technology and workforce development and access; and our regulatory environment may not be fit for the purpose of keeping people and whānau safe. Precision medicines could also unnecessarily displace effective treatments that are currently in use.

Our research and discussions with stakeholders through consultation on our LTIB topic have identified key areas where changes will be needed to make the most of the opportunities offered by precision health and mitigate risks over the next 10 years and beyond. These are:

- developing infrastructure (both data and physical) that is sustainable, resilient and fit for purpose
- developing effective rules and regulations that keep whānau safe and anticipate emerging technologies
- considering both public and private investment in precision health technologies and research
- building a skilled and diverse workforce that can deliver precision health for Aotearoa New Zealand

- rethinking how individuals and whānau give informed consent for precision health interventions.

We are seeking your feedback to inform our final version of this briefing, which will serve as a guide for future discussions and policy work on implementing precision health in Aotearoa New Zealand. You will find several specific questions for you to consider throughout the paper – including whether we have identified all the relevant risks and opportunities of precision health, and whether other changes will be needed as we look to the future. We are eager to explore these questions with you as we develop our final briefing and consider the future of precision health in Aotearoa New Zealand.

## He Mihi | Acknowledgements

We would like to acknowledge all the people and organisations that have submitted feedback, sharing their thoughts, aspirations, and experiences and helping us develop our draft briefing.

This is the start of an important conversation, and we are looking forward to continuing this engagement to ensure we are well placed to achieve our vision of pae ora by exploring the possibilities for precision health into the future.

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# Kupu whakataki | Introduction

## He aha hoki te Kupu Whakamārama mō te Tirohanga Roa? | What is a long-term insights brief?

All government departments are required to produce an LTIB under the Public Service Act 2020. LTIBs contribute to future decision-making by improving public sector thinking around future opportunities and challenges and put such opportunities into the public domain for discussion and debate. The LTIB is independent of Ministers and is not government policy.

The LTIB considers the medium- and long-term trends, risks and opportunities that affect, or may affect, Aotearoa New Zealand society over the next 10 years and beyond, and provides an impartial analysis of potential policy options that enable effective response in the future.

The LTIB is not designed to determine government policy or produce solutions or definitive actions to deal with immediate issues. Instead, its purpose is to support direction-setting by provoking thought and encouraging meaningful conversations as a starting point for any potential long-term considerations as we look over the horizon.

## Te kaupapa | Our chosen topic

For this inaugural LTIB, we have selected the topic of 'precision health'.

Our analysis of consultation feedback, targeted engagement, and research highlighted two areas of transformation as being particularly pertinent in our exploration of precision health. These are:

- genomics and precision medicine (to increase our understanding of how genetic factors contribute to wellbeing and risk of disease, and more effectively target care to individuals and populations)
- artificial intelligence (AI) and machine learning (for collecting and analysing large quantities of data and automating or augmenting ways we support health and wellbeing).

While these technologies are already in use internationally, they have relatively limited use in Aotearoa New Zealand. We have an opportunity to explore the current uses, future opportunities and potential benefits, risks, and challenges each pose.

This briefing is a draft; we are seeking your feedback on our analysis to inform the final version. The final LTIB will outline key factors to be considered in developing precision health to ensure precision health can be used effectively and equitably in the Aotearoa New Zealand health context.

## Why have we chosen this topic?

A key part of our role as the chief kaitiaki (steward) of the Aotearoa New Zealand health system is to anticipate and address long-term opportunities and risks to the health of our people from global forces and trends that shape our world. In considering the health landscape over the next 10 or more years, we aim to ensure we are at the forefront of innovation and are well positioned to proactively consider what such 'innovation' might mean for Aotearoa New Zealand.

There is considerable interest in increasing the adoption of emerging precision health technologies. However, significant uncertainty also exists in this fast-developing field. Manatū Hauora has a duty to explore the potential impacts of these technologies and ensure systems are in place, so that any progress in the precision health field is intentionally designed to support our goals for health and wellbeing and risks are mitigated.

## **Kua rapu mātou i ngā whakaaro o te marea** **| We asked for public feedback on our choice of topic**

We undertook public consultation on our proposed topic between 30 November 2022 and 27 January 2023, in line with the Public Service Act 2020. We asked three key questions in our consultation.

- Is the topic worthwhile exploring?
- What opportunities, barriers, or concerns do you see in precision health now and into the future?
- Which areas of precision health should our briefing explore in more detail?

We received 71 written responses, largely from Pākehā stakeholders. Respondents included individuals and groups across health and related sectors, clinicians, researchers, peak bodies (such as sector organisations), and industry.

Responses indicated strong support for this topic. Some of the key messages that we heard were as follows.

- It is important to understand the impact of precision health on equity, particularly for Māori and Pacific peoples, women, people living in rural communities and people with disabilities.
- Significant investment will likely be required, including in data infrastructure, workforce capacity and diversity, and research pathways to support a nationally consistent approach.
- We need to examine our regulatory frameworks to support future design, development, and implementation of precision health technologies.
- We will need bespoke governance and security arrangements to ensure the purpose and use of precision health meet the needs of the population of Aotearoa New Zealand into the future.

- There is potential for significant harm if we do not carefully consider precision health; with risks of discrimination, financial costs and privacy issues all needing to be measured and mitigated.
- We will need to engage and partner with Māori and Pacific communities to guide the purpose and use of precision health.
- Widespread use of precision health technologies is coming – some precision health technologies are already here.

These themes have informed this draft briefing. The feedback also highlighted the need for ongoing conversations and collaboration to ensure precision health services continually reflect and respond to the needs and aspirations of all New Zealanders, including those that have not been served well by our health system to date.

In addition to requesting written feedback on the questions listed above, we set up targeted engagements with select groups identified throughout the consultation, including Māori and Pacific experts, in order to amplify voices underrepresented in the initial consultation. We also supplemented the feedback with insights from other engagements being undertaken by Manatū Hauora, particularly engagements on the pae ora strategies.

The nature of the topic presents a high barrier to entry, so our ability to obtain meaningful feedback from a broad range of stakeholders was restricted. Precision health is a complex topic and, whilst we have endeavoured to reduce the jargon and restrictive terminology in our engagement, we recognise that it is not necessarily accessible to those without a medical, scientific, or related background. Where possible, we have reflected feedback from these initial conversations throughout this LTIB.

The LTIB draft was developed during the engagement period. This enabled real-time amendments and allowed us to use the feedback as we received it to shape the draft, giving us the best opportunity to accurately maintain the viewpoints of our stakeholders.

## **He aha ngā kōrero o tēnei kupu whakamārama? | What does this briefing cover?**

There are three sections to this briefing.

Section 2 outlines our definition of precision health, how it fits within the reformed health system and how precision health is used in the current health systems.

Section 3 highlights the most significant benefits and risks associated with precision health, as identified by stakeholders throughout consultation and engagement.

Section 4 sets out the changes that will be required in the health system (and the various legal and ethical frameworks that underpin it) to realise the benefits and mitigate the potential risks in using precision health in Aotearoa New Zealand.

# He aha rā te kaupapa o Te Pae Tika, he aha anō hoki ngā momo whakamahinga ki Aotearoa? | What is precision health and how is it being used in Aotearoa New Zealand?

**Precision health is an umbrella term that is about using technology and information to develop more precise ways to keep people healthy**

We have defined precision health as a growing field that aims to use current and emerging technology, and all available information (such as an individual's genome, current biophysical measures, and environment) to predict, prevent, diagnose, and treat disease more precisely for the benefit of individuals and their whānau.

This field is being influenced by several key factors, including:

- increasing the availability, acceptance and adoption of electronic health records and use of non-traditional information (collected outside the health setting), data, and digital technologies
- increasing the focus on approaches to health led by the individual and their whānau
- increasing the focus on preventative health approaches, with an emphasis on addressing the determinants of health
- renewing the focus on the underlying causes of inequitable health outcomes and addressing the systems and conditions holding these disparities in place
- rapidly developing research, science, and innovations, such as genomics, big data and artificial intelligence, which are changing the nature of health care delivery.<sup>1</sup>

<sup>1</sup> Ministry of Business, Innovation and Employment and the Ministry of Health. 2017. *New Zealand Health Research Strategy 2017–2027*. Wellington: Ministry of Business, Innovation and Employment and the Ministry of Health. URL: [nz-health-research-strategy-jun17.pdf](#) (accessed 8 May 2022).

Precision health is not new. In many ways, it can be seen as an expansion of what our health sector and health professionals do currently. However, with recent advancements in the application of emerging technologies and exponential growth of health data, there are new ways of doing health work on a larger scale that are becoming more widely used, presenting questions for our legal and ethical frameworks and the capability of the health system.

This briefing does not seek to define a new field of health. It uses precision health as an umbrella term to: think about how technology and information use are evolving in the health arena, identify common opportunities and risks that should be considered, and highlight what might be required to help precision health support our vision of *pae ora* | healthy futures for all New Zealanders.

The term 'precision health' is often used interchangeably with 'precision medicine', but the two terms differ in some important ways. Precision health complements precision medicine, or genomic medicine, but puts a greater emphasis on applying the tools of precision medicine to promote health, prevent disease and use technological advances in data science and personal and medical devices.

Lloyd Minor (Dean, Stanford University School of Medicine) made a useful distinction between the 2 terms when he said:

While precision medicine implies that individuals who get sick are treated precisely, precision health is focused on a holistic approach to keeping people healthy through targeted interventions and stopping disease before it starts. It seeks to understand the features of disease that explain why some people get sick, but others do not, and which treatments, tests, and lifestyle changes will help prevent disease in individuals. When it isn't possible to prevent a disease, precision health seeks to improve diagnostics such that diseases are detected much earlier and treated more effectively.<sup>2</sup>

Precision health also sits within an emerging field known as 'personalised health'.<sup>3</sup> While there is considerable overlap between these terms, we have chosen to focus on the term 'precision health', to avoid confusion with the word 'personalised' being misinterpreted to imply interventions or medicines are being developed uniquely for each person.

<sup>2</sup> Minor L, Rees M. 2020. *Discovering Precision Health: Predict, prevent, and cure to advance health and well-being*. Wiley. See also Precision health: improving health for each of us and all of us on the Genomics & Precision Health webpage of the Centers for Disease Control and Prevention website at URL: [cdc.gov/genomics/about/precision\\_med.htm](https://www.cdc.gov/genomics/about/precision_med.htm) (accessed 1 November 2022).

<sup>3</sup> Precision health and personalised health concepts draw on common principles, known as the 4 Ps – focused on health approaches that are predictive, personalised, preventive, and participatory. This approach also prioritises a focus on population: shifting from our typically reactionary approach to a health care system focused on treatment of illness and disease, to that of a proactive, preventative ecosystem that focuses on enhancing the conditions of health and supports individuals to achieve their aspirations of wellbeing.

## How does precision health fit within the health reforms?

The health system in Aotearoa New Zealand is being transformed to support all New Zealanders to have better health outcomes. Our vision is pae ora | healthy futures – where all individuals and their whānau live long, fulfilling lives in good health; are supported to maintain their health and wellbeing, are part of healthy and inclusive communities and live in richly resourced environments designed to enhance their quality of life and reduce stressors.

Pae ora is a holistic concept of health and wellbeing that is grounded in Te Tiriti o Waitangi. It recognises the interwoven elements of wai ora (healthy environments), whānau ora (healthy families) and mauri ora (healthy people).

Integral to this vision is equity, which recognises that different people have unique needs and aspirations, and experience different levels of advantage.

Precision health may have the potential to accelerate progress toward the priorities and outcomes we seek as part of our vision for pae ora and the system shifts that we aim to achieve in a reformed health system – including enhanced use of data and digital technologies; high-quality and sustainable care, and approaches to health care that are centred on the individual and their whānau. However, without appropriate oversight and measures in place, there is also the potential for significant negative impacts.

## Translating the potential of precision health into future health gains for Aotearoa will require a deliberate and comprehensive approach which gives practical effect to Te Tiriti and advances health equity for all groups. Looking over the horizon: What are the key trends that may affect the way precision health is used in the future?

There is an opportunity for precision health to support our vision for pae ora while navigating the global and domestic trends that will affect our health over the coming decades. These trends will require us to be more innovative, efficient, and focused on the individual and their whānau. Exploring new ways of working, such as using preventative care, data and digitally enabled care, and addressing health inequities will be crucial in meeting these challenges for our health system.

In the coming decades, our population's health is likely to be impacted by several key trends.

- Our population is ageing. The proportion of the population aged 65 years and over is projected to increase from 15% in 2021 to 21% in 2036.<sup>4</sup> Maintaining the health of our aging population will be important for sustaining wellbeing and enabling individuals and their whānau to achieve their aspirations.
- We are becoming more ethnically diverse. The proportion of our population who are part of Māori, Pacific, and Asian ethnic groups will increase over the next 20 years.<sup>5</sup> As our ethnic profile changes, there is likely to be an associated shift in the needs and aspirations for health in Aotearoa New Zealand.
- Around 80% of all deaths in Aotearoa New Zealand are due to chronic diseases (such as diabetes, heart disease and cancer), and this burden is expected to increase in the future. Cancer is the leading cause of death in Aotearoa New Zealand, with some 25,000 people diagnosed each year, including nearly 3,000 Māori, and approximately 9,000 deaths from cancer annually. Māori experience higher mortality rates from cancer than non-Māori.<sup>6,7</sup>
- Globally, health systems are not meeting peoples' needs; they are unsustainable, and costs are increasing, which is exacerbating inequitable health outcomes. We are not immune. The Treasury projects that health expenditure will grow from around 7% of GDP in 2020/21 to over 10% of GDP by 2061 if there are no changes to our current health service model, which currently focuses a high proportion of spending on treatment and secondary health care.<sup>8</sup>
- The number and size of cities continues to grow across the globe. The United Nations anticipates that 68% of the world's population will reside in cities by 2050.<sup>9</sup> This level of urbanisation can exert pressure on infrastructure and resources.
- Technological advancements and increases in accessible information are shifting consumer expectations. The rise in connectivity, information availability and personalised service experiences are increasingly challenging health providers to see people not as 'patients', but as health care 'consumers'. Individual and whānau expectations are also shifting; with demand for increased access to information, digital engagement, and transparency. There is a growing expectation for health services to be more convenient and personalised.

<sup>4</sup> Stats NZ. 2021. Population projected to become more ethnically diverse. News story. Wellington: Stats NZ. URL: [www.stats.govt.nz/news/population-projected-to-become-more-ethnically-diverse](https://www.stats.govt.nz/news/population-projected-to-become-more-ethnically-diverse) (accessed 8 May 2023).

<sup>5</sup> Stats NZ. 2021. Population projected to become more ethnically diverse. News story. Wellington: Stats NZ. URL: [www.stats.govt.nz/news/population-projected-to-become-more-ethnically-diverse](https://www.stats.govt.nz/news/population-projected-to-become-more-ethnically-diverse) (accessed 11 May 2023).

<sup>6</sup> Manatū Hauora Mortality 2016 Data Tables (published online April 2020). URL: [www.health.govt.nz/publication/mortality-2016-data-tables](http://www.health.govt.nz/publication/mortality-2016-data-tables) (accessed 11 May 2023).

<sup>7</sup> See Te Aho O Te Kahu report: He Pūrongo Mate Pukupuku o Aotearoa 2020 (The State of Cancer in New Zealand 2020). URL: [https://teaho.govt.nz/static/reports/state-of-cancer-in-new-zealand-2020%20\(revised%20March%202021\).pdf](https://teaho.govt.nz/static/reports/state-of-cancer-in-new-zealand-2020%20(revised%20March%202021).pdf) (accessed 11 May 2023).

<sup>8</sup> See the Treasury's combined Statement on the Long-term Fiscal Position and Long-term Insights Briefing. URL: [www.treasury.govt.nz/publications/ltfp/he-tirohanga-mokopuna-2021](http://www.treasury.govt.nz/publications/ltfp/he-tirohanga-mokopuna-2021) (accessed 11 May 2023).

<sup>9</sup> Department of Economic and Social Affairs, United Nations. 2018. 68% of the world population projected to live in urban areas by 2050, says UN. News story. URL: [www.un.org/development/desa/en/news/population/2018-revision-of-world-urbanization-prospects.html](http://www.un.org/development/desa/en/news/population/2018-revision-of-world-urbanization-prospects.html) (accessed 8 May 2023).

- There are various unknowns that will continue to impact health and other areas of society globally. Examples of this are climate change, which will alter our natural environment and add to resource stress, and the COVID-19 pandemic, which has challenged how we think about health into the future, including the potential pace of change and the benefits of global and local collaboration between scientific institutions, pharmaceutical companies, and governments.

## How is precision health currently being used in New Zealand and overseas?

Aotearoa New Zealand has started moving toward implementing precision health through increasing use of emerging technologies, such as genomics and AI and machine learning in health. However, we have heard throughout our engagements that we are still in the early stages of these areas, with relatively little uptake on a national level and implementation largely occurring in an unplanned manner.

We have decided to focus on 2 areas of precision health in this briefing: genomics, and machine learning and AI. This section provides more detail on how they are currently being used in Aotearoa New Zealand and overseas.

### Genomics

Genomics is used in health to understand how our genes can cause certain health issues or diseases and how different people or populations might respond to particular treatments.<sup>10</sup> Genomics is distinct from genetics, which examines the functioning and composition of the single gene. Genomics examines all genes and their interrelationships to identify their combined influence on growth and development.<sup>11</sup>

#### How is genomics used in health?

Genomic testing is becoming an increasingly important facet in our understanding of disease. Rapid advances in research, sequencing and diagnostic technologies are better enabling people and health professionals to understand the potential impact of their genetic make-up on current and future health risks.

Increasing understanding of genetic contributions has led to the development of diagnostic tests to identify the presence or risk of disease. Developments in gene editing technologies, such as CRISPR-Cas9 and CAR-T cell therapy can target genetic

<sup>10</sup> See the What is precision medicine? webpage on the Genomics Aotearoa website at URL: [www.genomics-aotearoa.org.nz/education-events/precision-medicine](http://www.genomics-aotearoa.org.nz/education-events/precision-medicine)

<sup>11</sup> See the Genomics questions and answers webpage on the World Health Organization website at URL: [www.who.int/news-room/questions-and-answers/item/genomics#:~:text=The%20main%20difference%20between%20genomics,and%20development%20of%20the%20organism](http://www.who.int/news-room/questions-and-answers/item/genomics#:~:text=The%20main%20difference%20between%20genomics,and%20development%20of%20the%20organism)

elements predisposing people to these diseases, offering new avenues for treating cancer or potentially curing genetic diseases.<sup>12</sup>

Genomics may be applied across the life course, from reproductive carrier screening, prenatal testing and new-born screening offering preventative and early testing opportunities, to testing for genetic variants predicting risk of cancer, rare diseases, and chronic conditions (such as diabetes or cardiovascular disease). However, the complexity of interpreting the results of genomic testing will often require specialised expertise, and there are currently limited numbers of genetic tests and treatments with proven clinical utility. Many genetic variants are of unknown significance and their clinical relevance is still uncertain.

Currently, large-scale genomics is being used internationally for a range of applications, from disease diagnosis and treatment to population genetics research.

- The United Kingdom has established a national genomic medicine service, which intends to provide consistent and equitable care as part of routine clinical care, informed by a strong research interface.<sup>13</sup>
- The United States of America has several initiatives to advance the use of genomics in health care, including the Precision Medicine Initiative®<sup>14</sup> and the All of Us research program<sup>15</sup>. These are supported by companies and research institutions developing new genetic tests and therapies.
- Australia has a strong genomics research community and has launched initiatives such as Australian Genomics<sup>16</sup> and the Australian Genomics Health Alliance<sup>17</sup> to advance the use of genomics in health care.
- Canada has also made significant investments in large-scale population genetics research, including Canadian Partnership for Tomorrow's Health (CanPath).<sup>18</sup>

## Despite widespread uptake internationally, use of genomics is limited in Aotearoa

While genomic and other molecular testing is available in Aotearoa New Zealand, feedback suggests this is limited in comparison with other countries, unevenly distributed, and lacking the infrastructure or workforce capability to become part of routine health practices. The areas of most advancement locally are in precision oncology and paediatric genetics, with genetic testing for genes that increase risk of familial breast, bowel and stomach cancers becoming more widely used.

<sup>12</sup> Chenggong L, Heng M, Yu H. 2020. Applications and explorations of CRISPR/Cas9 in CAR T-cell therapy. *Briefings in Functional Genomics*, 19, 3, 175–182. DOI: <https://doi.org/10.1093/bfgp/elz042> (accessed 8 May 2023).

<sup>13</sup> See the webpage NHS Genomic Medicine Service on the NHS website at URL: [www.england.nhs.uk/genomics](http://www.england.nhs.uk/genomics)

<sup>14</sup> See the webpage NCI and the Precision Medicine Initiative® on the National Cancer Institute website at URL: [www.cancer.gov/research/areas/treatment/pmi-oncology](http://www.cancer.gov/research/areas/treatment/pmi-oncology)

<sup>15</sup> See the National Institutes of Health (NIH) All of Us Research Program website at URL: <https://allofus.nih.gov>

<sup>16</sup> See the Australian Genomics website at URL: [www.australiangenomics.org.au](http://www.australiangenomics.org.au)

<sup>17</sup> See the Australian Genomics Health Alliance webpage on the Garvan Institute of Medical Research website at URL: [www.garvan.org.au/research/kinghorn-centre-for-clinical-genomics/research-programs/genomics-health-alliance](http://www.garvan.org.au/research/kinghorn-centre-for-clinical-genomics/research-programs/genomics-health-alliance)

<sup>18</sup> See the CanPath website at URL: <https://canpath.ca>

Respondents from our November 2022 consultation round noted that genetics services were under-funded and under-resourced with many genetic and other related molecular tests being processed overseas. This is due to the cost barriers to conducting tests locally, resulting from a lack of coordinated local infrastructure investment. This carries issues for data and tissue/DNA sovereignty, particularly for Māori.

In Aotearoa New Zealand, there is also currently no dedicated national leadership or system governing genomics or other forms of molecular testing, or a national data repository for genomic information. Approaches aimed at providing this in Aotearoa New Zealand are ongoing. We have a growing body of genomic research emerging locally. This is largely led by different academic and research bodies, including Genomics Aotearoa, an alliance of 5 universities and 5 Crown Research Institutes (CRIs), that conduct research into genomics across health, the environment and primary production. Feedback from stakeholders has indicated that this research is highly valuable, but that there is a disconnect between research and pathways for implementation into routine clinical practice.

There are a growing number of Māori and Pacific experts in genomics leading significant research programmes (for example, Rakeiora<sup>19</sup> and the Aotearoa New Zealand genomic variome<sup>20</sup>). However, feedback suggests such experts are limited in both numbers and capacity to lead research that is genuinely responsive to communities' aspirations and give effect to Te Tiriti o Waitangi. Capability is being nurtured through local projects such as Summer Internship for Indigenous peoples in Genomics (SING Aotearoa),<sup>21</sup> however, this will take time. More work needs to be done to increase the responsiveness of tauīwi (non-Māori/non-Pacific) experts to ensure the future needs and aspirations of Māori and Pacific communities is being met while Māori and Pacific expert capacity and capability grows.

## Future trends affecting the use of genomics in health

With the decreasing costs of genome sequencing and growing potential for automated analysis and clinical interpretation of genomic findings, increasing use of genomics will enable more effective use of diagnostics across the care continuum. Initially, the focus will likely be on rare diseases and cancers, but as capability and capacity to incorporate routine and population-level genomics develop across the health system, evidence suggests the application could be extended into preventative strategies for common late-onset diseases, such as heart disease and diabetes.

Potential future use of genomics in health could include:

- more efficient targeting of drugs
- foetal diagnostics
- cancer detection

<sup>19</sup> See the health projects webpage Rakeiora: A pathfinder for genomic medicine in Aotearoa/New Zealand on the Genomics Aotearoa website at URL: [www.genomics-aotearoa.org.nz/our-work/health-projects/rakeiora-pathfinder-genomic-medicine](http://www.genomics-aotearoa.org.nz/our-work/health-projects/rakeiora-pathfinder-genomic-medicine)

<sup>20</sup> See the health projects webpage Aotearoa New Zealand genomic variome on the Genomics Aotearoa website at URL: [www.genomics-aotearoa.org.nz/our-work/health-projects/aotearoa-nz-genomic-variome](http://www.genomics-aotearoa.org.nz/our-work/health-projects/aotearoa-nz-genomic-variome)

<sup>21</sup> [www.singaotearoa.nz](http://www.singaotearoa.nz)

- influencing the gut microbiome (as genomics also relates to our ability to read the genomes of pathogens, transforming our understanding of microbiology)
- use of genome-editing techniques, such as CRISPR-Cas9 and synthetic biology tools, to help in writing genomic information, leading to cures for previously untreatable rare diseases and targeted therapies.

#### **Aotearoa New Zealand case study: The Rakeiورا pathfinder project**

- In 2019, the Ministry of Business, Information and Employment (MBIE) commissioned Genomics Aotearoa to run Rakeiورا, a proof-of-concept initiative looking for the best ways to incorporate new genomic-based medicine into Aotearoa New Zealand's health care system. Its vision is to improve wellbeing and encourage equity in health outcomes by accelerating research and the practice of precision medicine in our country.
- Rakeiورا has been co-designed and led by Māori and non-Māori leaders. The aim has been to weave mātauranga Māori science and biomedical science together to generate a better way to use all available information about genes and health, including whole genome sequences, whakapapa, and health care information. This includes building on tikanga and Te Tiriti o Waitangi frameworks that will allow all people to participate in the research comfortably and with confidence in the control, safety, and sovereignty of their data.
- Rakeiورا comprises 2 research projects in primary and tertiary health to collect real-time data, and the development of a plan to use health and whakapapa data to test computational systems and create a pilot precision medicine research platform.
- The pilot project seeks 4 outcomes: accessible genome sequences, data linking to the National Health Index database, recommendations for scaling the project nationally, and learnings about how to apply the research for health benefits. Rakeiورا is approaching completion and aims to share findings and recommendations with MBIE in May 2023. Lessons from this project could help us understand the potential impact of genomics on health outcomes in Aotearoa New Zealand and the conditions and enablers required to position genomics to achieve health equity into the future.

## Machine learning and artificial intelligence

Artificial intelligence (AI) and machine learning involve applying algorithms and other cognitive technologies to health settings.

AI and machine learning are increasingly being used to improve diagnosis, treatment, and health outcomes. They can help health professionals and providers analyse large amounts of patient data, identify patterns and correlations, and personalise treatment recommendations.

AI and machine learning are starting to be used across our health system, from digital pathology to hospital workflow processing. Over the next 10 years, there is high

expectation that AI and machine learning will be adopted more and more to enhance the way care is offered across the care continuum. A report completed by the AI Forum in 2019 estimated that AI has the potential to manage 20% of unmet clinical needs, increase access to health care services and improve equity in Aotearoa New Zealand.<sup>22</sup>

Examples of AI and machine learning in health currently in use include:

- predictive analytics (Machine learning algorithms can be used to analyse large amounts of data and identify patterns to predict future health outcomes. This can help health care providers intervene early and prevent the development of chronic diseases)
- personalised care (Machine learning algorithms can be used to analyse an individual's medical history, genetic data, and lifestyle factors to develop personalised treatment plans. This can help improve treatment outcomes and reduce health care costs. For example, a recent study found that a machine learning algorithm was able to accurately predict which patients with chronic obstructive pulmonary disease (COPD) would benefit from bronchodilator therapy)
- image analysis (Machine learning algorithms can be trained to analyse medical images, such as X-ray and magnetic resonance imaging (MRI), to identify signs of disease. This can improve diagnostic accuracy and increase timeliness in the interpretation of medical images)
- telemedicine (AI-powered chatbots and virtual assistants can provide patients with personalised health advice and support. This can help improve access to health care, particularly in rural areas)
- public health surveillance (Machine learning algorithms can analyse data from electronic health records, social media and other sources to track and monitor the spread of infectious diseases. This can help public health officials identify outbreaks and develop effective control measures. Machine learning algorithms have been used to predict the spread of COVID-19 in Aotearoa New Zealand).

<sup>22</sup> AI Forum. 2019. *Artificial Intelligence for Health in New Zealand: Hauora i te Atamai Iahiko*. Auckland: AI Forum. URL: <https://aiforum.org.nz/wp-content/uploads/2019/10/AI-For-Health-in-New-Zealand.pdf> (accessed 9 May 2023).

# He ara a Te Pae Tika ki te whakatutukinga o tō mātou wawata o Pae Ora — heoi, kei reira anō ngā tāpokopokotanga me ngā take hei āta kaupare atu | Precision health presents opportunities for achieving our vision of pae ora – but there are risks and considerations that will need to be carefully managed

We received a great deal of feedback in our consultation, regarding the growing evidence of the potential opportunities, benefits, and risks offered by precision health. However, such evidence is largely from other countries, with different health systems, funding and incentives, workforce composition and technology mixes, meaning the actual impact of precision health in Aotearoa New Zealand is less certain. This section outlines some of the risks and benefits of using precision health in Aotearoa New Zealand.

If applied in a careful, considered way in partnership with all stakeholders and through engagement with communities, precision health has the potential to realise many benefits for Aotearoa New Zealand. There is, however, also significant potential to exacerbate existing issues within the health system if the risks are not effectively mitigated. Above all, the implementation of precision health technologies such as genomics, AI and machine learning raises important ethical and social issues, which need to be carefully considered and addressed.

We have focused our analysis of risks and benefits on the following 3 key areas that will be critical in terms of implementing precision health technologies in Aotearoa New Zealand.

- **Embedding Te Tiriti o Waitangi:** In Aotearoa New Zealand, where Māori are a Crown partner under Te Tiriti o Waitangi, bringing te ao Māori and perspectives and mātauranga Māori to genomics, algorithms and AI in health care will be

fundamental. The health sector principles outlined in the Pae Ora Act 2022 provide a framework for embedding an approach based around Te Tiriti-o Waitangi and ensuring progress reflects tino rangatiratanga, equity, active protection, partnership, and options for Māori.

- **Achieving health equity:** While ensuring equity of access and outcomes should be a foundational priority in applying precision health technologies, it is also one of the most significant challenges. We need to focus on Māori, Pacific peoples, women, people living rurally and people with disabilities, as well as alleviating stressors for the health workforce.
- **Empowering individuals, whānau and communities:** Building trust and confidence with patients and the public based on transparency and high-quality ethical standards will be an ongoing imperative for any exploration of precision health. This will likely require new approaches in the way we conduct research and communicate findings across our health and research ecosystems, and to the wider public.

The benefits and risks set out across the following pages are not exhaustive but represent some of the most significant factors identified through our research and consultation. We are keen to test if our analysis is in line with existing perceptions.

We will pose some specific questions for you to consider as you read through the following sections. You can use these questions to help inform your feedback. These questions are repeated at the end of this LTIB under section 8 Ngā pātai he whakautu māu | Questions for your feedback.

<b>Working in partnership with Māori</b>	
<b>Opportunities</b>	<b>Risks and Considerations</b>
<i>Māori-Crown partnerships provide opportunities to advance precision health to achieve more equitable outcomes for Māori ...</i>	<i>... but to ensure meaningful partnerships are achieved, this will require relationship building, and resourcing.</i>
In practice, this means ensuring Māori are involved in decision-making at every stage of the design and development of precision health initiatives. Solutions for Māori should be led by Māori, through appropriate engagement with Māori, hapū, and supported by Te Aka Whai Ora and Iwi Māori Partnership Boards. Through these mechanisms, there is the opportunity to reflect Māori needs and aspirations in the design and commissioning of new precision health initiatives and approaches.	Cultural considerations are particularly important when exploring gene technologies for Māori, as well as political and scientific considerations. The Pae Ora Act requires the health system to protect and promote the interests and rights of Māori. To improve equity, Māori leadership, governance, and practices need to be strengthened within the health system, including mātauranga Māori knowledge, and Māori data sovereignty. Māori have shared concerns that for innovations in precision health to be realised, both within and beyond the

<b>Working in partnership with Māori</b>	
<b>Opportunities</b>	<b>Risks and Considerations</b>
<i>Māori-Crown partnerships provide opportunities to advance precision health to achieve more equitable outcomes for Māori ...</i>	<i>... but to ensure meaningful partnerships are achieved, this will require relationship building, and resourcing.</i>
Māori cultural concepts and values are fundamental to Māori engagement. Whakapapa, mauri, mana and kaitiakitanga provide a cultural framework for considering philosophical, moral, and technical considerations relevant in the use of precision health technologies, particularly genomics and gene editing. <sup>23</sup>	health system, robust Māori data governance and partnership needs to be enabling, and transparent to Māori, and that the appropriate accountabilities are in place to ensure precision health initiatives uphold Te Tiriti o Waitangi.

<b>Health equity</b>	
<b>Opportunities</b>	<b>Risks and Considerations</b>
<i>Precision health could create more effective outcomes ...</i>	<i>... but could exacerbate poor health outcomes if it is not implemented well</i>
As precision health technologies such as AI and genomics mature, they will increasingly offer new ways of working within the health system, with potential benefits for access and outcomes. If implemented well, precision health presents a tangible opportunity to move away from a one-size-fits-all approach to health, to holistic population health care systems and preventive models that will achieve more equitable health outcomes.  Precision health tools could address inequitable access to health. For example, as AI capability to support activities such as medical imaging grows, we could be able to deploy AI to support health professionals working in rural and other remote areas, increasing the	Precision health technologies need to reflect the populations they aim to serve, therefore any implementation of these technologies in Aotearoa New Zealand needs to be appropriate for all populations across the country. Current genomics research primarily relates to Western European and East Asian populations and, as evidence indicates significant genetic variance between global reference data and the genomes of Māori, Pacific peoples and populations not included in genomics research to date, this could mean that advances in technology do not offer the same benefits for Māori, Pacific peoples, and other ethnic minority populations.  Understanding our social and cultural licence across different applications of

<sup>23</sup> Kathlene L, Munshi D, Kurian P, Morrison S. 2022. Cultures in the laboratory: mapping similarities and differences between Māori and non-Māori in engaging with gene-editing technologies in Aotearoa, New Zealand. *Humanit Soc Sci Commun*, 9, 100. DOI: <https://doi.org/10.1057/s41599-022-01104-9> (accessed 9 May 2023).

<b>Health equity</b>	
<b>Opportunities</b>	<b>Risks and Considerations</b>
<i>Precision health could create more effective outcomes ...</i>	<i>... but could exacerbate poor health outcomes if it is not implemented well</i>
<p>timeliness of care for individuals and whānau in these locations.</p> <p>Increasing access to genomic testing could benefit population groups with rare diseases because it could allow treatment to be more targeted and personalised.</p> <p>As an emerging field, there is an opportunity to apply precision health in partnership with communities who have historically been underserved and excluded from decision making.</p>	<p>precision health will be critical. Communities need to feel confident that the precision technologies being considered or used are safe; any risks have been mitigated; and the data informing their use is robust and unbiased.</p> <p>Workforce capacity and diversity across a number of specialised professions related to precision health (for example, bioinformaticians, genetic counsellors, genetic scientists) is constrained and does not represent the Aotearoa New Zealand population. Without supporting sustainable and diverse capability development in precision health, these technologies risk becoming utilised inconsistently, undermining the health system goals of achieving equity in access for all groups.</p> <p>A lack of workforce capacity could also lead to interventions moving to secondary and tertiary health care services and away from the community (often seen when prioritising delivery of volume in particular centres over patient access).<sup>24</sup></p>

<b>Financial sustainability (efficiency)</b>	
<b>Opportunities</b>	<b>Risks and Considerations</b>
<i>Precision health offers opportunities to improve efficiencies in health spending ...</i>	<i>... but it will require investment, and costs are currently high</i>
While the cost of genomic testing and related technologies has been relatively	Precision health technologies are emerging as the financial sustainability

<sup>24</sup> PPP and AstraZeneca. 2021. *The Operationalisation of Precision Medicine*. London: Public Policy Projects (PPP) and AstraZeneca. URL: <https://publicpolicyprojects.com/wp-content/uploads/sites/6/2021/07/The-Operationalisation-of-Precision-Medicine-report.pdf> (accessed 9 May 2023).

<b>Financial sustainability (efficiency)</b>	
<b>Opportunities</b>	<b>Risks and Considerations</b>
<i>Precision health offers opportunities to improve efficiencies in health spending ...</i>	<i>... but it will require investment, and costs are currently high</i>
<p>high in the past, there is potential for these costs to decrease over time with technological advancements and economies of scale.</p> <p>Estimates made in 2019 projected that AI would contribute over \$700 million in value and savings to the Aotearoa New Zealand health system by 2026, reduce nurse workload by 20% and allow doctors to see more patients.<sup>25</sup> While it is hard to quantify this impact directly, the use of AI to reduce administrative burden through automation, for example, has been seen to offer more care centred around the individuals and their whānau by allowing more time for patient contact, which could reduce hospitalisations and readmissions.</p> <p>Modelling cost analyses on population-level genomic screening has also indicated a potential for efficiency improvements in a single payer system.<sup>26</sup></p>	<p>of health systems is being challenged, and there are competing priorities for public funding investment.</p> <p>Genomic testing and personalised treatments can be expensive, which will limit access for some individuals and increase health disparities – including increasing demand for privately funded precision health technologies.</p> <p>To ensure reasonable costs for precision health treatments, other current services could see an increase in associated fees, such as for general practitioner (GP) appointments and prescriptions, in an effort to balance costs. This could result in less affordable basic services for some, in turn, reducing health equity or accessibility.</p>

<b>Person and whānau led care</b>	
<b>Opportunities</b>	<b>Risks and Considerations</b>
<i>Precision health offers opportunities to tailor care to individuals and their whānau ...</i>	<i>... but technologies are still evolving, and our regulatory frameworks may not be fit for the purpose of keeping individuals and whānau safe</i>
Precision health offers opportunities to tailor care to individuals and their whānau based on their genetic, lifestyle	Variation in data quality, collection practices and interoperability between multiple systems will challenge our

<sup>25</sup> AI Forum. 2019. *Artificial Intelligence for Health in New Zealand: Hauora i te Atamai Iahiko*. Auckland: AI Forum. URL: <https://aiforum.org.nz/wp-content/uploads/2019/10/AI-For-Health-in-New-Zealand.pdf> (accessed 9 May 2023).

<sup>26</sup> Zhang L, Bao Y, Riaz M et al. 2019. Population genomic screening of all young adults in a health-care system: a cost-effectiveness analysis. *Genetics in Medicine*, 21: 1958–4968. DOI: <https://doi.org/10.1038/s41436-019-0457-6> (accessed 9 May 2023).

Person and whānau led care	
Opportunities	Risks and Considerations
<i>Precision health offers opportunities to tailor care to individuals and their whānau ...</i>	<i>... but technologies are still evolving, and our regulatory frameworks may not be fit for the purpose of keeping individuals and whānau safe</i>
<p>and environmental circumstances and other health data.</p> <p>Ensuring the voice of individuals, whānau and communities is present in conversations about what precision health might look like will be key to reaching fit-for-purpose solutions.</p> <p>There is also an opportunity to improve population health outcomes through increasing use of genomic testing, AI, and machine learning to identify more specific treatment pathways for different population groups.</p>	<p>ability to use precision health in Aotearoa New Zealand.</p> <p>Health care providers' ability to incorporate precision health in clinical decision-making is currently limited.</p> <p>Diagnoses based on genomic testing, for example, are only as good as the underlying data and the individual clinician's ability to interpret that data. Each individual's genomic data will behave differently, so it could be difficult to derive any reliable patterns or general conclusions about the impact of a particular genetic variant or behaviour. This increases the risk of false positive or negative results, which may lead to unnecessary treatments or a lack of required treatments (for example, a false positive genetic test for breast cancer leading to unnecessary surgery).</p> <p>Submitters noted a perceived absence of relevant regulation to support precision health. Other countries' regulatory systems are being challenged by new health technologies.<sup>27</sup></p> <p>Multiple respondents from our November 2022 consultation round expressed concern about the ability to maintain data privacy and the need to ensure appropriate governance and security is in place, specific to the needs of the Aotearoa New Zealand population.</p>

<sup>27</sup> OECD. 2017. *New Health Technologies: Managing access, value and sustainability*. Paris: Organisation for Economic Co-operation and Development (OECD) Publishing.  
DOI: <https://doi.org/10.1787/9789264266438-en> (accessed 9 May 2023).

“Our greatest concern is how quickly the science is going – the mismatch between what’s important in the discovery phase and how to take appropriate and measured steps as we move forward. There is a sense that the appetite for scientific innovation is greater than the current appetite or ability to have tikanga at the centre of that.”

- Feedback from LTIB engagement.

It is important to note that the risks and opportunities are unlikely to be clear cut in practice, and there will be nuances that apply to any benefits, dependent on the specific circumstances, and the same is true for the risks.

**This LTIB lists the most urgent and immediate opportunities and risks based on stakeholder feedback to date. Are there any other opportunities or risks posed by implementing precision health that we should include in this LTIB?**

# He aha ngā āhuatanga hei whakarerekē kia pai ai tā tātou whai i ngā ara o Te Pae Tika ā ngā rā ki tua | What might need to change to make sure that we make the most of precision health opportunities in the future?

An ideal future would see Aotearoa New Zealand implementing precision health in a way that realises the benefits offered toward our vision of pae ora, whilst mitigating or avoiding the key risk areas. The other end of the spectrum would present a worst-case scenario where the risks are realised and very few people are able to benefit from the opportunities. Ultimately, it is likely that a combination of these will occur, and we will have to balance out the most impactful benefits and be vulnerable to some risk.

This section identifies some areas where changes will be needed to best realise the opportunities presented by precision health and identify what needs to happen over time to create conditions for success. These are initial suggestions for your feedback. They would need further exploration before being progressed. Creating and sustaining change requires meaningful partnership, learning and collaboration with all areas of society and our partners on the global stage. This starts with the public, academics, researchers, and professionals of Aotearoa New Zealand through review of this LTIB.

Trust and collaboration will be key enablers for precision health. Decisions made about precision health technologies will need to be open and transparent, and informed by meaningful engagement with impacted groups. There must be opportunity for open discussion, differences in perspective to be exchanged in safe ways, and trade-offs to be made.

**We have created a list of essential changes that will be needed to mitigate the risks and realise the opportunities of precision health. Are there other changes we should consider?**

## Infrastructure must be sustainable, resilient, and fit for purpose to support precision health

Implementation of precision health technologies in Aotearoa New Zealand will require:

- data infrastructures that allow us to use the vast quantities of health data being generated by new technologies to improve health outcomes
- the physical infrastructure to house equipment and support analysis, research, and training.

Any investment in data and physical infrastructures will need to cover modernising consent processes, and enabling Te Tiriti o Waitangi compliant systems. This could involve investment in cybersecurity measures, data encryption and strict access permissions. Data infrastructure will need the capacity to handle 'big data' and be interoperable across the health and other sectors.

Aotearoa New Zealand will need to continue developing our National Health Index (NHI) and supporting infrastructure to bring together patient information from across the health and social sectors, such as through the HIRA programme<sup>28</sup>. Continuing to develop the quality and consistency of our data will improve our ability to understand the health needs across the population.

Alongside digital infrastructure, we will need to consider the capacity and capability of the physical infrastructure. Additional facilities will be needed to house equipment and provide appropriate accommodations for analysis work, research, and training to take place. Machinery and tools will need adequate space to be set up and operated to ensure Aotearoa New Zealand has the capability to collect and interpret data locally rather than outsourcing to other jurisdictions. Being able to carry out this work locally will decrease uncertainties about who is accessing and controlling the data and create more roles in this field for locals.

### Example: Health technology assessment

One example of an approach to understand, assess value, and assign funding is health technology assessment (HTA). HTA aims to provide a consistent, systematic and multi-stakeholder platform to produce and use evidence on the effectiveness and value of new technologies and interventions. Importantly, HTA can be used to inform decisions with multiple objectives including improving health and patient experience, improving equity, enabling innovation, and maintaining financial sustainability. Aotearoa New Zealand's Pharmaceutical Management Agency Ltd (Pharmac) conducts HTA on some pharmaceuticals, medical devices, and vaccines. However, there is currently no national, consistent approach for how we assess the value of different types of emerging health technologies such as genomics, machine learning and AI in Aotearoa New Zealand. There are likely opportunities to learn from what other countries are doing in this

<sup>28</sup> For more details on this programme, see the webpage Hira work programme on the Te Whatu Ora website at URL: [www.tewhatauora.govt.nz/our-health-system/digital-health/hira-connecting-health-information/hira-work-programme](http://www.tewhatauora.govt.nz/our-health-system/digital-health/hira-connecting-health-information/hira-work-programme)

space (for example in the United Kingdom, the HTA agency National Institute for Health and Care Excellence (NICE) has developed assessment frameworks for multiple technology types). However, the approach applied in Aotearoa New Zealand will need to be tailored to our unique requirements and context, including existing decision-making bodies, health service and financing models, information and data availability, and Crown obligations under Te Tiriti o Waitangi.

**What are the most pressing data infrastructure issues that will need to be addressed to enable the safe introduction of emerging precision health technologies?**

## We need responsive mechanisms to ensure safe governance of data

Alongside a robust and fit-for-purpose data infrastructure, we will need mechanisms to ensure safe governance of data.

Respondents from our November 2022 consultation round told us that data sovereignty is a critical part of data governance for Māori, and will require careful consideration as precision health technologies emerge that increasingly involve the collection, storage, use and sharing of data.

Indigenous data sovereignty recognises the rights and interests that indigenous population have over their own data, and the need for structures to enable control over how this data is used. Māori data sovereignty recognises that Māori data should be subject to Māori governance that supports tribal sovereignty and the realisation of Māori and iwi aspirations.<sup>29</sup> The rapid development of Aotearoa New Zealand's health data and emerging technologies presents opportunities and challenges for Māori needs, aspirations and outcomes within our health system.

There is a growing body of research and work, with many experts within Aotearoa New Zealand, such as Te Mana Raraunga (Māori Data Sovereignty Network) and the Data Iwi Leaders Group (DILG), a part of the Iwi Chairs Forum, already leading discussions about the role of Māori in the data ecosystem, with implications for how we might proceed in the health sector. These discussions provide a platform to enable and strengthen Māori data sovereignty at local, regional, and national levels.

In the context of precision health, it is vital to recognise Māori data sovereignty; the importance of Māori control over collection, storage, use and dissemination of data; and the need for decisions impacting this to be empowering for future generations.

<sup>29</sup> Te Mana Raraunga – Māori Data Sovereignty Network Charter available online at URL: <https://static1.squarespace.com/static/58e9b10f9de4bb8d1fb5ebbc/t/5913020d15cf7dde1df34482/1494417935052/Te+Mana+Raraunga+Charter+%28Final+%26+Approved%29.pdf>

Ensuring Māori data sovereignty within a precision health technology and data ecosystem will require ongoing and active partnership to ensure Māori needs and aspirations are incorporated in the design and function of precision health.

Pacific data sovereignty will also be critical with exploration of any precision health technologies and associated data governance arrangements needing to ensure Pacific communities have a unified voice and collective guardianship of data and information about Pacific peoples living in Aotearoa New Zealand. This includes protecting Pacific knowledge, improving Pacific participation in the data ecosystem, and promoting the value of Pacific methodologies and cultures in the data journey.

**What are some steps we could take to enable Māori data sovereignty and ensure robust data governance, including Pacific people's autonomy over their data?**

## Rethinking the way individuals and their whānau give informed consent for precision health interventions

Respondents told us the approach to data collection will need to change to balance individual rights and privacy rights against the risks and benefits of data and to allow collective Māori rights to take precedent over individual rights. The data ecosystems need to be designed in a way that benefits Māori and those responsible for the design (as well as collection, use, and storage of data) must be accountable to their communities. This is an area of global interest, with research about 'dynamic consent' internationally<sup>30</sup> and locally<sup>31</sup> finding there is little governance in place to guide the use of new data sources that may contribute to a more holistic understanding of health needs, or allow individuals more control over how their data is used.

"We need to work out what the relative rights and interests of different groups are. Individuals have rights around consent, but where do rights around whānau sit, what are the limits of what is reasonable (to the extent they can consent on behalf of individuals)? We need to think about what accessible by right vs by consent (at iwi, national and system levels). Relative use rights. There also needs to be ways people can say 'no' to some elements."

- Feedback from LTIB engagement

Consent and respect are the key underpinning components in data collection. Data should be stored in a way that reinforces the capacity of Māori to exercise kaitiakitanga over the data, with Māori controlling the access restrictions.

<sup>30</sup> Teare HJA, Prictor M, Kaye J. 2021. Reflections on dynamic consent in biomedical research: the story so far. *Eur J Hum Genet* 29, 649–656. DOI: <https://doi.org/10.1038/s41431-020-00771-z> (accessed 9 May 2023).

<sup>31</sup> See the webpage Dynamic Consent on the Precision Driven Health website at URL: <https://precisiondrivenhealth.com/dynamic-consent/>

**Feedback suggests that existing consent processes are often inconsistent, inaccessible, and not always culturally appropriate - particularly for Māori, Pacific peoples, and those with language barriers. What would culturally appropriate consent look like in the context of precision health?**

## Effective rules and regulations that keep individuals and their whānau safe and anticipate emerging technologies

The innovative use of precision health technologies will need rules and oversight to guide and monitor the use of such technologies. Regulation is usually justified on the basis that a market or sector alone is not able to achieve certain desired policy objectives without some form of intervention. Regulatory settings need to be fit for purpose to protect individuals, their whānau and others across the health system, and to achieve the best possible outcomes.

We will need to ensure mechanisms are in place to support the safe, ethical use of emerging technologies and approaches. Respondents' feedback highlighted that any future exploration of precision health will require an innovative and values-led regulatory framework to guide decision-making and ensure the purpose and use of precision health meets our ethical, legal and moral obligations.

As the line is blurred between medicines, medical devices, and other precision health technologies, we face questions about how we can effectively regulate hybrid technologies that fall outside traditional categories.<sup>32</sup> For example, AI algorithms and mobile health applications available directly to consumers are increasingly blurring the line between wellness and medical advice.

To respond to these emerging trends in a way that balances protecting individuals without hindering appropriate innovations, we will need to ensure our regulatory frameworks are iterative and continually fit for purpose. These frameworks will need to ensure safety through mitigation of any clinical, privacy or security risks, while encouraging high-value innovation and preventing the market proliferation of ineffective, unsafe, and low-value applications and products.<sup>33</sup>

In some cases, regulations might not have caught up with the ethical challenges faced by establishing precision health technologies and the supporting systems. In such instances, we may need to identify 'red lines' that we shouldn't cross or an issue we should consider, even if it isn't yet necessarily mandated by law.

<sup>32</sup> OECD. 2017. *New Health Technologies: Managing access, value and sustainability*. Paris: Organisation for Economic Co-operation and Development (OECD) Publishing. DOI: <https://doi.org/10.1787/9789264266438-en> (accessed 9 May 2023).

<sup>33</sup> OECD. 2017. *New Health Technologies: Managing access, value and sustainability*. Paris: Organisation for Economic Co-operation and Development (OECD) Publishing. DOI: <https://doi.org/10.1787/9789264266438-en> (accessed 9 May 2023).

One example of where further regulation could be needed is described below.

## Example: Protecting against genomic discrimination

Increasing use of genomic testing in Aotearoa New Zealand raises risk of genetic discrimination.<sup>34</sup> Genomic information may reveal genetic predispositions to certain diseases. This could lead to stigmatisation and discrimination of individuals, which could impact future insurance and employment opportunities. International evidence suggests fear of genetic discrimination has led to individuals declining genetic testing or participation in genetic and genomic research.<sup>3536</sup>

While it is unclear how often this occurs in Aotearoa New Zealand, at-risk individuals choosing not to get tested or access cutting-edge treatment may result in significant health impact. Aotearoa New Zealand currently has no rules to prevent misuse of genetic information, which is particularly significant for Māori and Pacific communities, but we could explore some of the international legislative mechanisms. Canada, Germany, and the United States of America have implemented legislation, while the United Kingdom has a Code on Genetic Testing and Insurance<sup>37</sup>. Meanwhile, Australia has a voluntary moratorium on genetic discrimination.<sup>38</sup>

**Which areas of our regulatory and legislative settings will require further attention to enable us to harness innovations in precision health technologies while ensuring safety risks are sufficiently mitigated?**

**How could we design regulations that will be fit for purpose for technologies that may not exist yet? What should our guiding principles be and who needs to be involved in deciding those principles?**

<sup>34</sup> Shelling AN, Bicknell LS, Bohlander SS, et al. 2022. Genomic discrimination in New Zealand health and life insurance. AGenDA: Against Genomic Discrimination in Aotearoa. *New Zealand Medical Journal*. URL: <https://journal.nzma.org.nz/journal-articles/genomic-discrimination-in-new-zealand-health-and-life-insurance-agenda-against-genomic-discrimination-in-aotearoa-open-access> (accessed 10 May 2023).

<sup>35</sup> Keogh LA, Niven H, Rutstein A, et al. 2017. Choosing not to undergo predictive genetic testing for hereditary colorectal cancer syndromes: expanding our understanding of decliners and declining. *J Behav Med*; 40 (4): 583–94. DOI: <https://doi.org/10.1007/s10865-016-9820-0>. Epub 2017 Feb 14. PMID: 28197815; PMCID: PMC6057776 (accessed 10 May 2023).

<sup>36</sup> Keogh LA, van Vliet CM, Studdert DM, et al. 2009. Is uptake of genetic testing for colorectal cancer influenced by knowledge of insurance implications? *Med J Aust*; 191 (5): 255–8. DOI: <https://doi.org/10.5694/j.1326-5377.2009.tb02778.x>. PMID: 19740045 (accessed 10 May 2023).

<sup>37</sup> See the webpage Code on Genetic Testing and Insurance on the GOV.UK website at URL: [www.gov.uk/government/publications/code-on-genetic-testing-and-insurance](http://www.gov.uk/government/publications/code-on-genetic-testing-and-insurance)

<sup>38</sup> Global Alliance for Genomics & Health. 2022. *Genetic Discrimination: Implications for data sharing projects (GeDI) (Ver 1,0)*. URL: [www.ga4gh.org/wp-content/uploads/Genetic-Discrimination-Dec.-2-2021.docx.pdf](http://www.ga4gh.org/wp-content/uploads/Genetic-Discrimination-Dec.-2-2021.docx.pdf) (accessed 10 May 2023); Genetic Discrimination Observatory (GDO). A Geographical Overview of Approaches Adopted around the World to Prevent Genetic Discrimination. URL: <https://gdo.global/en/gdo-map-approaches> (accessed 10 May 2023). <https://gdo.global/en/gdo-map-approaches>

## Opportunities for private and public investment in precision health

During our first consultation, submitters noted that substantial and careful investment will be needed to enable precision health to be of value to Aotearoa New Zealand. Some areas that may require exploration are discussed below.

**Research, science, innovation and mātauranga Māori:** Uptake of precision health will involve enhancing partnerships between government, academia, research groups and industry to accelerate the development and adaptation of precision health technologies. This might include increasing investment in genomics research and education to improve our understanding and application of genomic information in clinical practice, with a focus on increasing representation for Māori, Pacific and other ethnic groups that are currently underrepresented in databases.

Other countries also have capability that could be utilised to support Aotearoa New Zealand in developing different applications of precision health technologies. This might include continuing development of strategic international partnerships that may offer lessons to test within our local context.

**Public/private partnerships:** Given the size of our country, it is unlikely that Aotearoa New Zealand will ever achieve the scale of investment, infrastructure and capability required to keep pace with emerging applications of precision health. Moreover, we know that many technological innovations emerge from the private sector. To help us keep up with the pace of innovation and ensure these benefits are experienced equitably across our population, we may want to consider how we enable public and private organisations to work together to invest in precision health. These partnerships are starting to emerge already. We need to address questions around how such partnerships might work and how to identify and mitigate concerns about industry involvement.

**Where should we look to strengthen our international relationships to ensure that Aotearoa New Zealand keeps up with international advancements?  
Are there areas of precision health where Aotearoa New Zealand could lead on a global level?**

**Where should we focus more investment and funding to realise our vision of pae ora in emerging precision health technologies and why?**

## A skilled and diverse workforce to deliver precision health for Aotearoa New Zealand

Investment in training and education programmes to build workforce capability, including around cultural safety, digital literacy and to leverage precision health technologies, are a key precondition to the introduction of precision health in Aotearoa New Zealand. This will include developing new skills, competencies, and career pathways, to ensure our health workforce is supported to grow the necessary skills. For example, feedback has highlighted that successful implementation of genomics will require training new and existing health professionals in genomics and bioinformatics to effectively incorporate genomic data into clinical decision-making. This may include continuing education programmes, workshops, and online training modules.

The new roles we may need to incorporate into our system and models of care include: geneticists, bioinformaticians, data scientists and software developers, to source and develop data intelligence that measures policy priorities and informs new policy.

Alongside training for additional roles, our health workforce will need to be upskilled to understand what precision health is, to use precision health tools and technology, and to raise awareness of different conditions and settings such technologies will be applied in (such as rare diseases). The cost of this education must be considered in any future planning.

A focus on equity will also require continued training and support to enable clinicians to work effectively and more flexibly with a range of communities, including Māori and Pacific peoples.

“Our hope is to create a landing place for young people that don’t necessarily want to do research but could get into the workplace and learn [precision health] skillsets and tikanga and contribute to the work being developed for communities. This would be right across the continuum, from discovery phase to community-based projects.”

- Feedback from LTIB engagement

We will need to increase data, digital and genomics literacy amongst the health workforce, patients, and the public. This forms a key part of other international genomics strategies. Digital literacy will likely be a baseline requirement for most regulated and unregulated workforce roles in a data- and digital-driven future. Digitally capable leaders and workforces will be critical to ensure precision health and other health technologies are adopted, once foundational infrastructure and systems are in place.

Equitable access to precision health will be enabled by growing a diverse workforce that reflects the population it serves and supports the use of Māori and Pacific approaches to health. We have heard there is strong desire for culturally diverse and representative leadership and governance from the outset of research, right through to implementation across all aspects of precision health – particularly for Māori and Pacific communities. Māori stakeholders shared aspirations of a bespoke genomics research system for Māori that is led by Māori.

“We need leaders to provide tikanga as a ‘brake’ system to ensure that progress is made in the right way and does not create additional or worsen existing inequities. This needs to have a strong foundation – led by Māori, not just for Māori.”

- Feedback from LTIB engagement

**How does health workforce education and training need to change to keep pace with developments in precision health?**

**What can we do to support a more diverse workforce in both the health delivery sector (clinicians) and academia (researchers, scientists), particularly in relation to precision health?**

# Te Whakakapinga | Conclusion

## Me aha ināianei? | What next?

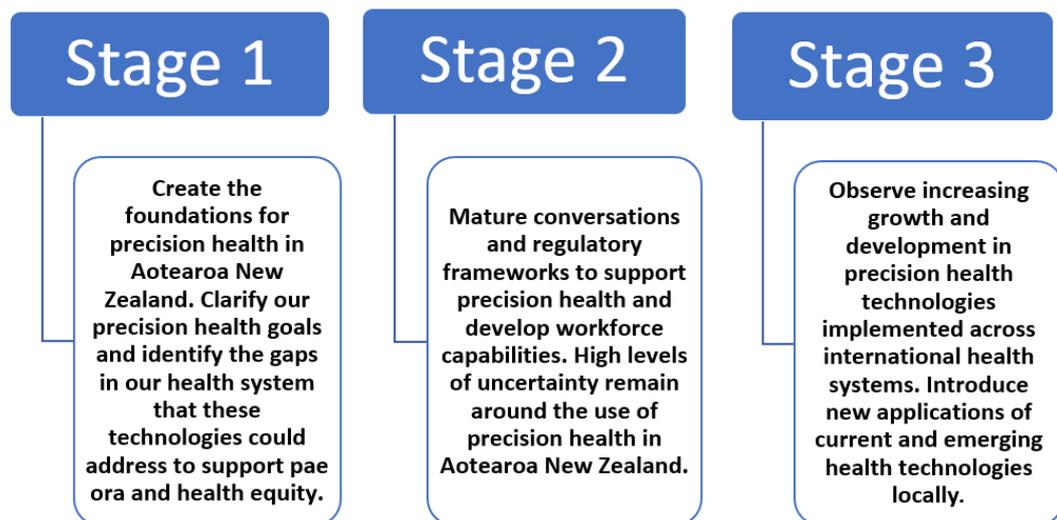
To ensure any precision health tools and technologies are introduced safely and in a way that aligns with and supports our health outcomes, Aotearoa New Zealand needs confidence we have an enabling environment that supports the use of precision health to achieve health equity and our vision of pae ora. This requires us to make sure we have the necessary systems, processes, investments, and regulation in place to mitigate risks and use tools for collective benefit.

Any policy decisions will require balancing trade-offs between different groups, priorities, and generations, while giving practical effect to Te Tiriti o Waitangi through the health sector principles to achieve our vision of pae ora.

The following section provides an opportunity to consider possible actions and next steps in the short-, mid-, and longer-term to introduce precision health tools and technologies appropriately to Aotearoa New Zealand over 3 different stages.

# Te ara whakamua mō Te Pae Tika ki Aotearoa | A potential roadmap for precision health in Aotearoa New Zealand

There are a number of steps and considerations to take into account in planning for any implementation of precision health technologies in Aotearoa New Zealand. Feedback throughout our engagements has indicated that any progress in this space needs to happen in stages with consistent testing and monitoring of activities throughout. We have identified there to be three key stages, and outlined below what we believe to be the focus of each stage.



**What are the primary activities that should take place at each stage to support equitable implementation of precision health technologies within Aotearoa New Zealand; to ensure services are comparable with international systems but appropriate for the New Zealand context?**

## **The wider conversation around how the health system in Aotearoa New Zealand is changing**

This LTIB represents the start of a conversation about how we use current and emerging technologies for precision health. However, it is also part of a much larger conversation that is happening across Aotearoa New Zealand following the health reform, to understand the actions we need to take to ensure all individuals and whānau live long, fulfilling lives in good health, are supported to maintain their health and wellbeing, are part of healthy and inclusive communities, and live in richly resourced environments designed to enhance their quality of life and reduce stressors.

The feedback we receive on this draft briefing will help us develop the final briefing that will be submitted to Parliament and form a platform to influence our work into the future.

# Me pēhea te tuku urupare mai?

## | How can you provide feedback?

We want to hear your views on this draft briefing, and your response to the specific questions below.

This is the second phase of the 2-phase public consultation approach to develop our briefing. You can make a submission in any of the following ways.

- Complete the online form (Citizen Space).
- Email **LTIB@health.govt.nz** with your submission, including your response to the consultation questions.
- Write your response and mail it to:  
Strategy Group  
Ministry of Health  
PO Box 5013  
Wellington 6140

Please indicate if you wish to participate in ongoing consultation as we develop the final precision health long-term insights briefing.

# Ngā pātai hei whakautu māu | Questions for your feedback

We welcome all your ideas and suggestions for ways we can improve this LTIB. The questions we have listed below are a consolidation of the questions raised throughout the briefing, and aim to help you formulate your feedback. You might have other points you also wish to discuss.

1. This LTIB lists the most urgent and immediate opportunities and risks based on stakeholder feedback to date. Are there any other opportunities or risks posed by implementing precision health that we should include in this LTIB?
2. We have created a list of essential changes that will be needed to mitigate the risks and realise the opportunities of precision health. Are there other changes we should consider?
3. What are the most pressing data infrastructure issues that will need to be addressed to enable the safe introduction of emerging precision health technologies?
4. What are some steps we could take to enable Māori data sovereignty and ensure robust data governance, including Pacific people's autonomy over their data?
5. Feedback suggests that existing consent processes are often inconsistent, inaccessible, and not always culturally appropriate, particularly for Māori, Pacific peoples, and those with language barriers. What would culturally appropriate consent look like in the context of precision health?
6. Which areas of our regulatory and legislative settings will require further attention to enable us to harness innovations in precision health technologies while ensuring safety risks are sufficiently mitigated?
7. How could we design regulations that will be fit for purpose for technologies that may not exist yet? What should our guiding principles be and who needs to be involved in deciding those principles?
8. Where should we look to strengthen our international relationships to ensure Aotearoa New Zealand keeps up with international advancements? Are there areas of precision health where Aotearoa New Zealand could lead on a global level?
9. Where should we focus more investment and funding to realise our vision of pae ora in emerging precision health technologies and why?
10. How does health workforce education and training need to change to keep pace with developments in precision health?
11. What can we do to support a more diverse workforce in both the health delivery sector (clinicians) and academia (researchers, scientists), particularly in relation to precision health?

12. What are the primary activities that should take place at each stage to support equitable implementation of precision health Technologies within Aotearoa New Zealand; to ensure services are comparable with international systems but appropriate for the New Zealand context?

# Āpitianga Tuatahi: Te whakamahinga o ngā kōrero | Annex 1: Use of information

We will use the information provided in submissions to develop our final long-term insights briefing. We may contact you directly if we need to clarify any matters you raised in your submission.

## Publishing information in a summary of submissions or under the Official Information Act 1982

We will publish a summary of the feedback we receive through this consultation.

By making your submission, we consider that you have consented to us publishing material contained within your submission, unless you clearly specify otherwise in your submission. If your submission contains any information that is confidential or you wish us not to publish it for another reason, please indicate this at the top of your submission and mark any confidential information clearly within the text.

While we collect submitters' names and contact information, we will **not** share or publish personal contact details and names in our summary of submissions document.

Submissions remain subject to requests under the Official Information Act 1982. If you have concerns about your response and name being released, please note this in your submission, with a reason why your name or parts of your submission should be withheld from any future request under the Official Information Act 1982. We will take such objections into account and will consult with submitters who have raised objections to the full release of their submission under the Official Information Act 1982. Note: the Official Information Act 1982 recognises the privacy of natural persons as a reason for withholding information, such as their contact details.

## Private information

The Privacy Act 2020 establishes certain principles about how various agencies can collect, use and disclose information about individuals. Any personal information you supply in making this submission will only be used to help develop this long-term insights briefing.