



## Te pae tika:

e tūhura ana i ngā ara hou me ngā ārai ki te āta matapaetanga, te kauparenga atu, te kitenga me te rongoātanga o ngā take hauora ki Aotearoa

## Precision health:

exploring opportunities and challenges to predict, prevent, diagnose, and treat health needs more precisely in Aotearoa New Zealand

Long-term insights briefing

August 2023





**Te pae tika: e tūhura ana i ngā  
ara hou me ngā ārai ki te āta  
matapaetanga, te kauparenga  
atu, te kitenga me te  
rongoātanga o ngā take hauora  
ki Aotearoa**

**Precision health: exploring  
opportunities and challenges  
to predict, prevent, diagnose,  
and treat health needs more  
precisely in Aotearoa New  
Zealand**

Long-term insights briefing

Presented to the House of Representatives  
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# Foreword from the Director-General of Health

Tēnā koutou katoa

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

Our health system is undergoing significant changes to improve health outcomes for all New Zealanders and achieve equity for our diverse populations. To achieve these goals, 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 offers opportunities to significantly improve the health 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, best value for investment or equitable for vulnerable populations. The increasing prominence of precision health globally has prompted us to think more deeply about how these emerging technologies might contribute to improved health outcomes and the implications of their use in an Aotearoa New Zealand context.

Our unique population and global position mean we are well placed to influence and lead the development and application 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 and do not displace other interventions that may be more effective and economical. We also need to work 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) during consultations on both the topic and the draft 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.

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, private sector and government in the coming years.

We look forward to continuing to explore the future of precision health for Aotearoa New Zealand.

Ngā mihi maioha

**Dr Diana Sarfati**

Director-General of Health

# He whakarāpopoto | Summary

The Public Service Act 2020 requires all public service departments to produce a long-term insights briefing (LTIB). 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 inaugural LTIB focuses on the topic of precision health and has been shaped by the comments and ideas received during our public consultations on the topic itself and the draft briefing. '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 examples of precision health that stakeholders were particularly interested in: genomics and artificial intelligence (AI). These technologies are developing rapidly and present a range of new ways to diagnose, treat and prevent health issues and disease and to use health promotion tools.

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

There is significant potential for precision health technologies to help us in working towards achieving pae ora | healthy futures for all New Zealanders. Specifically, we have heard that there are opportunities to: partner with Māori and other groups 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.

However, we have also heard that the advancement and application of technologies must include ensuring Māori needs and aspirations are being met (for example, protecting taonga such as human tissue, which incorporates DNA, whakapapa, and data). Inconsistent approaches to technology, workforce development and access could exacerbate inequities, and our current regulatory environment may not be well equipped for keeping people and whānau safe. Precision medicines could also unnecessarily displace effective treatments currently in use. For these reasons, it is important to carefully consider and respond to both the risks and opportunities presented by precision health.

Our research and discussions with stakeholders have identified key areas where changes will be needed to realise the opportunities offered by precision health and mitigate risks over the next 10 years and beyond. These are:

- developing systems and processes to enable evidence-based decisions about precision health technologies and infrastructure
- developing a national infrastructure (data and physical) that is sustainable, resilient, and fit for its purpose
- developing effective safeguards and regulations that keep whānau safe and appropriately mitigates risks of emerging technologies

- influencing the design and development of precision health
- building a skilled and diverse workforce that can deliver precision health safely and effectively
- considering specific implications for Māori, both in terms of potential for widening inequities through differential access to new technologies as well as cultural and data sovereignty issues associated with the collection, storage and management of human tissue and genetic material
- rethinking how we can enable individuals and whānau to give informed consent for the use of precision health interventions.

Significantly, feedback also highlighted the need for our Government to provide robust strategic leadership to navigate Aotearoa New Zealand through the vast and complex issues that will arise as we work towards implementing precision health. Important steps are already being taken by universities, Crown Research Institutes and diagnostic labs across the country. However, several respondents in our consultation and engagement process noted that strategic direction setting and support from Government is needed to progress this work further.

This document elevates conversations about precision health in Aotearoa New Zealand, with the insights gathered throughout the LTIB's development providing guidance on what is most important to consider and discuss further.

## He mihi | Acknowledgements

We would like to acknowledge all the people and organisations that have submitted feedback and shared their thoughts, aspirations, and experiences to help us develop this final 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 explore the possibilities for precision health in the future.

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

There are five sections to this briefing.

The first section describes the purpose of the LTIB, our chosen topic and how we undertook this process.

The second section provides our definition of precision health and explains, how it fits within the reformed health system and how precision health is used in the current health system through two examples – genomics and artificial intelligence (AI).

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

The fourth section sets out areas of the health system that might require changes to realise the benefits and mitigate potential risks in using precision health more widely in Aotearoa New Zealand.

The final section lays out a potential pathway for precision health in Aotearoa New Zealand, including steps and factors to take into account in planning for any implementation of precision health technologies over the next 10 years and beyond.



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# Kupu whakataki | Introduction

## He aha hoki te Kupu Whakamārama mō te tirohanga roa? | What is a long-term insights briefing (LTIB)?

Section 8 of the Public Service Act 2020 requires all government departments to produce a LTIB at least once every three years. LTIBs contribute to future decision-making by improving public sector thinking around opportunities and challenges and put such opportunities into the public domain for discussion and debate. LTIBs are independent of Ministers and are not government policy.

LTIBs are intended to consider medium- and long-term trends, risks and opportunities that affect, or may affect, Aotearoa New Zealand over the next 10 years and beyond. They provide impartial analysis of potential policy options that will enable effective responses in the future.

LTIBs are not designed to determine government policy or produce solutions or definitive actions to deal with immediate issues. Instead, their purpose is to support direction-setting by provoking thought and encouraging meaningful conversations as a starting point for long-term considerations.

## Te kaupapa | Our chosen topic

For this inaugural LTIB, we have selected the topic of 'precision health', described in this document as the use of technology and information to develop more precise ways of keeping people healthy. The next section explains in more detail how we have defined 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 (to increase our understanding of how genetic factors contribute to health and risk of disease and more effectively target care to individuals and populations)
- artificial intelligence (AI) (for collecting and analysing large quantities of data and automating or augmenting ways we support health).

While both are already being used 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 posed by each area.

This LTIB outlines the key factors to be considered in developing precision health for implementation in an Aotearoa New Zealand context in a way that ensures effective and equitable use for our population.

## Why we chose 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 innovations and are well positioned to proactively consider what these might mean for Aotearoa New Zealand.

There is considerable interest in increasing the adoption of precision health. However, significant uncertainty exists in this fast-developing field. In our role as kaitiaki, we have a duty to explore the potential impacts of these technologies and ensure systems are in place that confirm any progress in the precision health field will support our goals for health and any risks are mitigated.

This briefing does not set an implementation plan for precision health in Aotearoa New Zealand. Its purpose is to elevate conversations about how we might support progress toward the vision of pae ora | healthy futures in new ways and benefit from the opportunities that emerging precision health technologies might provide, while ensuring we manage any risks. The LTIB aims to enable discussions around how such technologies could be best implemented in Aotearoa New Zealand and where support is needed to proceed.

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

We consulted with the public on our proposed topic between 30 November 2022 and 27 January 2023. We sought answers to some key questions, including whether the topic was worth exploring and what opportunities, barriers and concerns precision health could present.

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

There was strong support for precision health as a topic, with some key messages regarding the importance of understanding impacts on equity, particularly for Māori and Pacific peoples, women, people living in rural communities, rainbow communities and disabled people.

Feedback signalled the need for significant investment in data infrastructure, workforce capacity and diversity, and research pathways to support a nationally consistent approach.

Other key themes raised throughout the feedback included:

- the importance of examining current regulatory frameworks
- a need to consider bespoke governance and security arrangements to ensure the purpose and use of precision health meets the needs of Aotearoa New Zealand into the future
- the potential for significant harm, with risks of discrimination and insurance bias, financial costs limiting individuals' access to precision health technologies and privacy issues needing to be measured and mitigated
- the need to engage and partner with Māori to give practical effect to Te Tiriti o Waitangi (Te Tiriti) principles in any application of precision health and ensure new technologies do not contribute to the widening equity gap for Māori
- the need to engage with Pacific peoples and other underserved communities to guide the purpose and use of precision health toward health equity.

There was also an overall consensus that widespread use of precision health technologies is coming – noting that some technologies are already here.

These themes informed the draft briefing and highlighted the need for ongoing conversations and collaboration throughout implementation of precision health to ensure new approaches reflect and respond to the needs of all New Zealanders, including those who have not been served well by our health system to date.

We engaged with select groups throughout the drafting process, including Māori and Pacific experts, to amplify voices underrepresented in the initial consultation. This gave us the opportunity to change things as issues were identified and allowed us to actively acknowledge and address our stakeholders' viewpoints. We also supplemented the feedback with insights from other concurrent Manatū Hauora engagement exercises, in particular the engagement programme for the new pae ora health strategies.

The nature of the topic creates challenges to engagement with non-technical audiences, so our ability to obtain meaningful feedback from a broad range of stakeholders was limited. 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 conversations throughout this LTIB.

# I tono urupare mātou e pā ana ki te tauria hukihuki o te whakamārama | We asked for public feedback on our draft briefing

Between 19 May and 19 June 2023, we undertook public consultation on our draft briefing. We posed a series of questions to identify any gaps in our analysis or areas requiring additional input and to test our understanding of the insights provided by stakeholders throughout our engagements.

We received 29 submissions offering feedback on our draft briefing. Respondents reflected a cross section of groups with an interest in precision health, including medical laboratory scientists, researchers, stakeholder bodies and industry.

Themes that emerged from the feedback included:

- the importance of government engagement and leadership in providing the strategic direction, system settings and resources to enable precision health
- Te Tiriti and equity as fundamental starting points for any future implementation
- the need for major investment in infrastructure, workforce and education pathways to realise precision health
- the need for a robust and agile enabling environment and regulations to support the scaling of emerging technologies such as genomics and AI
- the ongoing need to grow our data quality, integrity and availability, particularly for Māori, disabled people, and populations
- the importance of conversations on data sovereignty led by Māori, with existing advisory groups involved at each step
- the importance of supporting our existing workforce to develop necessary skills and grow new roles and ways of working and working with local stakeholders and international partners to implement precision health more widely and in the appropriate way.

A recurring piece of feedback was that investment is needed in several areas to realise precision health into the future. The areas mentioned included:

- increased access to information to raise awareness throughout the community
- education and upskilling of the workforce at all levels, including creation of new roles and ongoing training programmes
- infrastructure for collecting, storing, integrating, testing and analysing data and for developing and implementing systems, tools and technologies
- local and international partnerships to support wider implementation of precision health in Aotearoa New Zealand through resources and adapting successful international framework models.

In response to feedback about a disease focus being treatment-centric, we have also adapted the title of our briefing to reflect a focus on health needs rather than disease and to ensure the title remains consistent with our more holistic definition of precision health (as discussed in the following section).

# 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 New Zealand?

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

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

The term 'precision health' is often used interchangeably with 'precision medicine', but the two terms differ in some important ways. Precision health incorporates 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>1</sup>

Precision health also sits within an emerging field known as 'personalised health'.<sup>2</sup> While there is considerable overlap between these terms, we have chosen to focus on the term 'precision health' to avoid confusion when the word 'personalised' is misinterpreted to imply interventions or medicines are being developed uniquely for each person.

While we have focused on genomics and AI as two key areas of transformation in this field, these are not the only applications of precision health. Other applications include increasing use of technologies such as other types of molecular testing, telemedicine, smartphone and smart home applications and wearables – all designed to enable and support more effective ways to maintain health and wellbeing and treat (as well as prevent and identify early) illness and disease.

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 more personalised approaches to health that are led by the individual and their whānau and are conducted closer to the home and community
- 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 innovation in areas such as genomics, big data and AI, which are changing the nature of health care and health care delivery.<sup>3</sup>

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

<sup>1</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 (CDC) website at URL: [cdc.gov/genomics/about/precision\\_med.htm](https://www.cdc.gov/genomics/about/precision_med.htm) (accessed 1 November 2022).

<sup>2</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 treating 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.

<sup>3</sup> MBIE, Ministry of Health. 2017. *New Zealand Health Research Strategy 2017–2027*. Wellington: Ministry of Business, Innovation and Employment (MBIE) and the Ministry of Health. URL: [nz-health-research-strategy-jun17.pdf](#) (accessed 8 May 2022).



# How precision health fits within the health reforms

Our health system is being transformed to achieve equity and 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 environments designed to enhance their health and quality of life.

Pae ora is a holistic concept of health and wellbeing that is grounded in Te Tiriti and reflects te ao Māori. It recognises the interwoven elements of wai ora (healthy environments), whānau ora (healthy families) and mauri ora (healthy individuals).

Integral to this vision is equity<sup>4</sup>, which recognises that different people have unique needs and aspirations and experience different levels of advantage.

As part of the health system reforms, Manatū Hauora recently published the six strategies of:

- New Zealand Health Strategy<sup>5</sup>
- Pae Tū: Hauora Māori Strategy<sup>6</sup>
- Te Mana Ola – the Pacific Health Strategy<sup>7</sup>
- Provisional Health of Disabled People Strategy<sup>8</sup>
- Women's Health Strategy<sup>9</sup>
- Rural Health Strategy.<sup>10</sup>

This suite of strategies sets the direction for improving the health of all New Zealanders over the next 10 years and identifies priority areas for change to improve health outcomes. Together, they guide collective efforts to achieve pae ora | healthy futures. This direction will inform future decisions on Government objectives and expectations and in turn guide service priorities and the performance of health entities.

Precision health was identified in the New Zealand Health Strategy as an area providing opportunities to enable our shift towards a learning culture that supports

<sup>4</sup> The Manatū Hauora definition of equity is:

In Aotearoa New Zealand, people have differences in health that are not only avoidable but unfair and unjust. Equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes.

<sup>5</sup> [www.health.govt.nz/publication/new-zealand-health-strategy](http://www.health.govt.nz/publication/new-zealand-health-strategy)

<sup>6</sup> [www.health.govt.nz/new-zealand-health-system/pae-ora-healthy-futures-all-new-zealanders/pae-ora-strategies/pae-tu-hauora-maori-strategy](http://www.health.govt.nz/new-zealand-health-system/pae-ora-healthy-futures-all-new-zealanders/pae-ora-strategies/pae-tu-hauora-maori-strategy)

<sup>7</sup> [www.health.govt.nz/new-zealand-health-system/pae-ora-healthy-futures-all-new-zealanders/pae-ora-strategies/te-mana-ola-pacific-health-strategy](http://www.health.govt.nz/new-zealand-health-system/pae-ora-healthy-futures-all-new-zealanders/pae-ora-strategies/te-mana-ola-pacific-health-strategy)

<sup>8</sup> [www.health.govt.nz/publication/provisional-health-disabled-people-strategy](http://www.health.govt.nz/publication/provisional-health-disabled-people-strategy)

<sup>9</sup> [www.health.govt.nz/new-zealand-health-system/pae-ora-healthy-futures-all-new-zealanders/pae-ora-strategies/womens-health-strategy](http://www.health.govt.nz/new-zealand-health-system/pae-ora-healthy-futures-all-new-zealanders/pae-ora-strategies/womens-health-strategy)

<sup>10</sup> [www.health.govt.nz/new-zealand-health-system/pae-ora-healthy-futures-all-new-zealanders/pae-ora-strategies/rural-health-strategy](http://www.health.govt.nz/new-zealand-health-system/pae-ora-healthy-futures-all-new-zealanders/pae-ora-strategies/rural-health-strategy)

ongoing innovation, research and evaluation leading to high-quality care. This includes enhanced use of data and digital technologies and approaches to health care that are sustainable, equitable and centred on the individual and their whānau.

However, without appropriate oversight and measures, there is also the potential for significant negative impacts, such as widening the equity gap for groups that have been historically underserved by the health system through accessibility barriers, genetic bias or insufficient genetic data to provide tangible results. Translating the potential of precision health into future health gains will require a deliberate and comprehensive approach that gives practical effect to Te Tiriti and advances health equity for Māori and other groups that currently experience poorer health outcomes.

## Looking over the horizon: key trends that might affect how 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 preventive 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 will be impacted by several key trends.

- Our population is ageing. The proportion aged 65 years and over is projected to increase from 15% in 2021 to 21% in 2036.<sup>11</sup> Maintaining the health of our ageing population will be important for sustaining wellbeing and enabling individuals and their whānau to achieve their aspirations and live independent, fulfilling lives.
- We are becoming more ethnically diverse. The proportion of our population that belongs to Māori, Pacific and Asian ethnic groups will increase over the next 20 years.<sup>12</sup> As our ethnic profile changes, there is likely to be an associated shift in the needs and aspirations for health.
- Around 80% of all deaths in Aotearoa New Zealand are due to non-communicable diseases (such as cancer, diabetes and heart disease), and this burden is expected to increase. 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

<sup>11</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>12</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).

9,000 deaths from cancer annually. Māori experience higher mortality rates from cancer than non-Māori.<sup>1314</sup>

- Globally, demand for health services is driving an increase in costs, which is exacerbating inequitable health outcomes. We are not immune. The Treasury projects that health expenditure in Aotearoa New Zealand will grow from around 7% of gross domestic product (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 higher proportion of spending on treatment and secondary health care rather than on preventive and primary health care.<sup>15</sup>
- The number and size of cities continue to grow across the globe. The United Nations anticipates that 68% of the world's population will reside in cities by 2050.<sup>16</sup> This level of urbanisation can exert pressure on infrastructure and resources. However, many communities in Aotearoa New Zealand, including a high proportion of Māori, are still living rurally. These communities will continue to experience challenges in accessing health services if significant focus is placed on locating services in urban areas.
- 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 as health care 'consumers' rather than as 'patients'. Individual and whānau expectations are also shifting; with increasing demand for access to information, digital engagement and transparency. There is a growing expectation for health services to be more convenient and personalised. Information growth is also creating challenges for health, with misinformation and disinformation (deliberate misinformation) impacting trust and confidence in public health services.
- As society becomes more reliant on technology, there is potential for a growing 'digital divide' between groups with differential access to the internet and digital devices. Māori, Pacific communities and disabled people have historically had less access to digital technology, and this may be a barrier to access and result in inequitable outcomes for some groups.<sup>17</sup>
- There are many other trends that will continue to create uncertainties and impact health and other areas of society globally. Examples include 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.

<sup>13</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>14</sup> See Te Aho o Te Kahu. 2021. *He Pūrongo Mate Pukupuku o Aotearoa 2020, The State of Cancer in New Zealand 2020*. Wellington: Te Aho o Te Kahu. 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>15</sup> See The Treasury's combined Statement on the Long-term Fiscal Position and Long-term Insights Briefing on the He Tirohanga Mokopuna 2021 webpage on The Treasury website at URL: [www.treasury.govt.nz/publications/lftp/he-tirohanga-mokopuna-2021](http://www.treasury.govt.nz/publications/lftp/he-tirohanga-mokopuna-2021) (accessed 11 May 2023).

<sup>16</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).

<sup>17</sup> Grimes A, White D. 2019. *Digital Inclusion and Wellbeing in New Zealand: A report to Department of Internal Affairs*. Wellington: Motu Economic and Public Policy Research.

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

Aotearoa New Zealand has started moving toward implementing precision health through the increasing use of emerging technologies, such as genomics and AI 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.

This briefing focuses on two areas of precision health: genomics and AI.

## 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>18</sup> Genomics is distinct from genetics, although the two terms are often used interchangeably. Genetics examines the functioning and composition of single genes. Genomics examines all genes and their interrelationships to identify their combined influence on growth and development.<sup>19</sup>

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

As knowledge of how genes contribute to the development of disease increases, new ways of testing and treatment are being developed, offering new avenues for treating cancer or potentially curing genetic diseases.<sup>20</sup> For example, Chimeric Antigen Receptor (CAR) T-cell therapy introduces new genes that redirect a person's immune cells (T-cells) to fight their own cancer. This therapy is used internationally for some types of blood cancer.<sup>21</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.

<sup>18</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>19</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](http://www.who.int/news-room/questions-and-answers/item/genomics)

<sup>20</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>21</sup> Weinkove R, George P, Ruka M, et al. 2021. Chimeric antigen receptor T-cells in New Zealand: challenges and opportunities. *NZ Med J*; 134, 1542: 96–108. PMID: 34531588.

## Genomics use internationally

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, building on the 100,000 Genomes Project.<sup>22</sup>
- Australia has a strong genomics research community and has launched initiatives such as Australian Genomics<sup>23</sup> and the Australian Genomics Health Alliance<sup>24</sup> to advance the use of genomics in health care.
- Singapore has established a 10-year national precision medicine (NPM) strategy, including a roadmap to accelerate biomedical research, improve health outcomes and enhance opportunities for economic value across sectors.<sup>25</sup> NPM is a whole-of-government effort to establish the necessary frameworks and infrastructure to realise precision medicine on a national scale to ultimately improve public health, enhance disease prevention and identify the right treatments for the right individuals and groups.
- Canada has also made significant investments in large-scale population genetics research, including Canadian Partnership for Tomorrow's Health (CanPath).<sup>26</sup>
- The United States of America has several initiatives to advance the use of genomics in health care, including the Precision Medicine Initiative<sup>®</sup><sup>27</sup> and the All of Us research program<sup>28</sup>. These are supported by companies and research institutions developing new genetic tests and therapies.

However, most genomics programmes have largely focused on European populations, and lack genetic diversity and relevance, thereby potentially disadvantaging Māori and Pacific communities in particular.

## Genomics use in Aotearoa New Zealand

While genomic and other molecular testing is available in Aotearoa New Zealand, consultation feedback suggests its use is limited compared with in other economically developed countries and is unevenly distributed. There is a dedicated medical laboratory scientist workforce and diagnostic laboratories in Auckland, Christchurch and Wellington are already carrying out specialist genomic tests and analysis. However, the ability to expand this work to make it part of routine health practice is impacted by a lack of appropriate infrastructure and limited workforce capacity. The greatest

<sup>22</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>23</sup> See the Australian Genomics website at URL: [www.australiangenomics.org.au](http://www.australiangenomics.org.au)

<sup>24</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>25</sup> See the press release Singapore launches next phase of National Precision Medicine Programme on the Singapore National Precision Medicine website at URL: [www.npm.sg/singapore-launches-next-phase-of-national-precision-medicine-programme](http://www.npm.sg/singapore-launches-next-phase-of-national-precision-medicine-programme)

<sup>26</sup> See the CanPath website at URL: <https://canpath.ca>

<sup>27</sup> See the webpage NCI and the Precision Medicine Initiative<sup>®</sup> 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>28</sup> See the National Institutes of Health (NIH) All of Us Research Program website at URL: <https://allofus.nih.gov>

advancements in our publicly funded health system have occurred in precision oncology, paediatric genetics and haematology, with genetic testing for genes that increase risk of familial breast, bowel and stomach cancers becoming more widely used.

Respondents to our November 2022 consultation noted that Aotearoa New Zealand's current genetics services are underfunded and under-resourced, with many genetic and other related molecular tests being processed overseas. This is often due to cost and timeliness barriers to conducting tests locally, resulting from a lack of coordinated local infrastructure investment. This carries potential risks and challenges 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 are ongoing. We have a growing body of genomic research emerging locally, largely led by academic and research bodies, including Genomics Aotearoa, an alliance of five universities and five Crown Research Institutes (CRIs) that conducts 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 often a disconnect between the research and pathways for implementing it into routine clinical practice.

There is a growing number of Māori and Pacific experts in genomics leading significant research programmes and building local infrastructure, training and capability to deliver genomics (for example, Genomics Aotearoa projects such as Rakeiora<sup>29</sup> and the Aotearoa New Zealand genomic variome<sup>30</sup>). However, feedback suggests such experts are limited in both numbers and capacity to lead research that is genuinely responsive to communities' aspirations and gives effect to Te Tiriti. Capability is being nurtured through local projects, such as Summer Internship for Indigenous peoples in Genomics (SING Aotearoa)<sup>31</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 are being met while Māori and Pacific expert capacity and capability grows, which will require deliberate planning and investment and coordination across multiple sectors.

Strengthening precision health research capability in Aotearoa New Zealand may also be supported by Te Ara Paerangi Future Pathways (Te Ara Paerangi) reform. Te Ara Paerangi is building a modern future-focused research, science and innovation system and setting national research priorities to enable the government to focus research funding and activities on the most important social, environmental, health and economic issues and opportunities for Aotearoa New Zealand. Te Ara Paerangi includes a specific focus on strengthening the role of mātauranga Māori and cultural knowledge within the research, science and innovation ecosystem.

<sup>29</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>30</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>31</sup> See the SING Aotearoa website at URL: [www.singaotearoa.nz](http://www.singaotearoa.nz)

## 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 health care continuum. Initially, the focus will likely be on rare diseases and cancers and precision medicines, 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
- cascade testing for health conditions that have a potential hereditary risk
- cancer screening and early detection
- population-level surveillance (such as more routine use of whole genome sequencing techniques, similar to those used to assess susceptibility for COVID-19)
- influencing the gut microbiome (as genomics also relates to our ability to read the genomes of pathogens, transforming our understanding of microbiology)
- use of gene-editing techniques, such as CRISPR-Cas9 and synthetic biology tools, to help in writing genomic information, leading to targeted therapies and cures for previously untreatable rare diseases.

### **Case study: The Rakeiora pathfinder project**

In 2019, the Ministry of Business, Information and Employment (MBIE) commissioned Genomics Aotearoa to run Rakeiora, a pathfinder initiative looking for the best ways to generate an infrastructure to enable use of linked genomic and health care information for high-impact precision health research in Aotearoa New Zealand. Its vision is to improve wellbeing and encourage equity in health outcomes by accelerating research and the practice of precision medicine in our country.

Rakeiora was co-designed and co-led by Māori and non-Māori leaders. The aim was 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 included building on tikanga Māori and Te Tiriti frameworks to allow all people to participate in the research comfortably and with confidence in the control, safety and sovereignty of their data.

Rakeiora comprised two research projects in primary and secondary health care respectively. Both projects collected real-time whole-genome-sequence information linked to health care data, then, in close collaboration with the New Zealand eScience Infrastructure (NeSI), used this combination to develop and test computational and governance systems, creating a precision medicine research

platform specific for Aotearoa New Zealand, hosted on NeSI's sovereign research community cloud platform.

Future development will allow incorporation of whakapapa information.

The pilot project sought four outcomes: accessible genome sequences; data linking to the National Health Index (NHI) database; recommendations for scaling the project nationally and understanding how to apply the research for health benefits.

The Rakeiora project shared draft findings and recommendations with MBIE in May 2023. Early findings detail a robust pilot research infrastructure consistent with international standards and a tikanga framework to uphold Māori data sovereignty principles. The findings also offer insight into the cultural, social and legal considerations that must be addressed for any national infrastructure to be scaled up in a way that gives effect to Te Tiriti.

The integration of indigenous values into a national research infrastructure in this way is internationally unique and generates a better infrastructure for Māori and non-Māori alike. Lessons from this project could powerfully inform the 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.

## Artificial intelligence

The Organisation for Economic Co-operation and Development (OECD) has defined an AI system as 'a machine-based system that can, for a given set of human-defined objectives, make predictions, recommendations, or decisions influencing real or virtual environments. AI systems are designed to operate with varying levels of autonomy'.<sup>32</sup>

AI is increasingly being used in health settings to improve diagnosis, treatment and health outcomes.<sup>33</sup> AI 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 increasingly adopted to enhance the way care is offered across the care continuum. A report completed by the AI Forum of New Zealand in 2019 suggested that scaling international analysis to Aotearoa New Zealand could enable AI to help manage 20% of unmet clinical needs, relieve workforce pressures, increase access to health care services and improve equity across Aotearoa New Zealand.<sup>34</sup>

<sup>32</sup> OECD. 2019. *Recommendation of the Council on Artificial Intelligence*. Organisation for Economic Co-operation and Development (OECD). URL: <https://legalinstruments.oecd.org/en/instruments/OECD-LEGAL-0449> (accessed 22 July 2023).

<sup>33</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>34</sup> AI Forum of New Zealand. 2019. *Artificial Intelligence for Health in New Zealand: Hauora i te Atamai Iahiko*. Auckland: AI Forum of New Zealand. URL: <https://aiforum.org.nz/wp-content/uploads/2019/10/AI-For-Health-in-New-Zealand.pdf> (accessed 9 May 2023).



There is growing interest in understanding and exploring the opportunities and risks AI might have for Aotearoa New Zealand. Work across government agencies and the wider ecosystem has resulted in guidance being released by the Office of the Privacy Commissioner, an algorithm charter for Aotearoa New Zealand and the recently published Māori Data Governance Model | Te Kāhui Raraunga<sup>35</sup>, all of which have implications when considering the impact of AI applications on health into the future.

This interest has also been seen in the public health sector. In the time we have been developing this LTIB, the Office of the Prime Minister's Chief Science Advisor has convened an expert panel to explore implications of AI on health care delivery<sup>36</sup> and Te Whatu Ora has mobilised an AI and Algorithms Expert Advisory Group.

## Future trends affecting use of AI in health

With the growing volume of health data and greater adoption of digital technologies across the health care continuum, increasing the use of AI will help people and whānau, service providers and the health system use data more effectively. As both people and AI capabilities grow, increasing use of AI offers the potential to both enhance and disrupt how we keep people healthy and generate new solutions to system challenges, such as accessibility (for example, location or language barriers) or local workforce shortages. With the increasing possibility of using AI to augment, and even replace aspects of the health journey currently carried out by people (such as administrative tasks or image analysis), we can expect to see more conversations about how AI can be used to alleviate system challenges.

Examples of AI we could see being used more widely in health care in the future include:

- **predictive analytics** e.g., machine learning algorithms could be used to analyse large amounts of data and identify patterns to predict future health outcomes. This can help health care providers intervene earlier and prevent the development of chronic diseases.
- **personalised care** e.g., machine learning algorithms could be used to analyse an individual's medical history, genetic data and lifestyle factors to develop personalised treatment plans. This could 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.
- **home care** e.g., AI technologies already in general use could be adapted for use in home settings. This could benefit the elderly or others needing access to medical services from their home. For example, wearable technology already exists and is used to monitor health, usually for fitness purposes. This technology could be further developed to monitor a broader range of health conditions in more specific, tailored ways to enable more effective self-management from the home, and alert

<sup>35</sup> See: Kukutai T, Campbell-Kamariera K, Mead A, et al. 2023. *Te Kāhui Raraunga: Māori Data Governance Model*. Te Kāhui Raraunga. URL: [www.kahuiraraunga.io/\\_files/ugd/b8e45c\\_803c03ffe532414183afcd8b9ced10dc.pdf](http://www.kahuiraraunga.io/_files/ugd/b8e45c_803c03ffe532414183afcd8b9ced10dc.pdf) (accessed 22 July 2023).

<sup>36</sup> For more information, see the webpage Artificial intelligence: Our current work on the Office of the Prime Minister's Chief Science Advisor website at URL: [www.pmcsa.ac.nz/topics/artificial-intelligence-2](http://www.pmcsa.ac.nz/topics/artificial-intelligence-2)

medical facilities in the event of a change in condition and other non-emergency events in addition to the current alerts for a fall or medical emergency.

- **image analysis** e.g., machine learning algorithms can be trained to analyse medical images, such as X-rays and magnetic resonance imaging (MRI), to identify signs of disease. This can improve diagnostic accuracy and increase timeliness in the interpretation of medical images. It has positive implications for cancer screening programmes, for example, AI is already being used to read lung cancer screening images overseas.
- **telemedicine** e.g., AI-powered chatbots and virtual assistants can provide patients with personalised health advice and support. If digital technology and connectivity issues for Māori and rural communities could be addressed, these services might be able to help improve access to health care, particularly in rural areas.
- **public health surveillance** e.g., machine learning algorithms can analyse data from electronic health records, social media and other sources to track and monitor the spread of infectious diseases, which helps public health officials identify outbreaks and develop effective control measures. Machine learning algorithms have already been used to predict the spread of COVID-19 in Aotearoa New Zealand.

# 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 – but there are risks and considerations that will need to be carefully managed

Through our consultation and engagement process, we received a great deal of feedback about the many potential opportunities, benefits and risks offered by precision health. However, much of the existing information and evidence is from other countries, which have different health systems, funding and incentives, workforce composition and technology mixes. The actual impact of precision health in an Aotearoa New Zealand context is less certain.

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. 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 considered and addressed.

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

- **Embedding Te Tiriti o Waitangi:** In our context, where Māori and the Crown are partners under Te Tiriti, bringing te ao Māori perspectives and mātauranga Māori to genomics, algorithms and AI in health care will be fundamental. The health sector principles outlined in the Pae Ora (Healthy Futures) Act 2022 provide a framework to guide our approach, based on the key outcomes and behaviours

derived from the principles of Te Tiriti, as articulated by the courts and the Waitangi Tribunal<sup>37</sup>.

- **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. It will likely require new approaches to how we conduct research and communicate findings across our health and research ecosystems and to the wider public.
- **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, disabled people and other underserved communities. We also need to consider ways to alleviate stressors for the health workforce. Strategic priorities for these groups have recently been published in the 6 pae ora strategies, and these should inform any future precision health considerations. We will also need to consider the implications of precision health for other groups, including rainbow communities and older people.
- **Efficiency and financial sustainability:** Precision health technologies are emerging as the financial sustainability of health systems is being challenged, and there are competing priorities for public funding of other health interventions, technologies and programmes that will improve health equity. For precision health to be introduced optimally in Aotearoa New Zealand, existing prioritisation processes need to be strengthened to enable evidence-based decisions about new technologies and infrastructures to ensure we are achieving long-term value for money and are meeting our health system objectives.

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. These are areas that will require ongoing engagement and consideration.

Embedding Te Tiriti o Waitangi	
Opportunities	Risks and considerations
<i>Embedding Te Tiriti obligations across precision health provides opportunities for Māori to exercise authority to improve their wellbeing and achieve equity ...</i>	<i>... but this requires a deliberate and comprehensive approach, involving meaningful partnerships with Māori, Māori leadership and governance and sufficient 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	Cultural considerations are particularly important when exploring gene technologies for Māori, as well as political and scientific considerations. The Pae Ora (Healthy Futures) Act 2022

<sup>37</sup> Waitangi Tribunal. 2019. *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry*. Wellington: Waitangi Tribunal. URL: [https://forms.justice.govt.nz/search/Documents/WT/wt\\_DOC\\_195476216/Hauora%202023%20W.pdf](https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_195476216/Hauora%202023%20W.pdf) (accessed 23 July 2023).

<b>Embedding Te Tiriti o Waitangi</b>	
<b>Opportunities</b>	<b>Risks and considerations</b>
<i>Embedding Te Tiriti obligations across precision health provides opportunities for Māori to exercise authority to improve their wellbeing and achieve equity ...</i>	<i>... but this requires a deliberate and comprehensive approach, involving meaningful partnerships with Māori, Māori leadership and governance and sufficient resourcing.</i>
<p>appropriate engagement with Māori, hapū and iwi and supported by Te Aka Whai Ora, Iwi Māori partnership boards and appropriate Māori expertise.</p> <p>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.</p> <p>Mātauranga Māori, including Māori cultural concepts and values, is fundamental when considering the potential benefits of precision health for Māori. 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>38</sup></p>	<p>requires the health system to protect and promote the interests and rights of Māori.</p> <p>To improve equity, Māori leadership, governance and practices need to be strengthened within the health system, including mātauranga Māori and Māori data sovereignty.</p> <p>Māori have shared concerns that, for innovations in precision health to be realised, both within and beyond the health system, robust Māori data governance and partnership needs to be enabling and transparent to Māori and the appropriate accountabilities need to be in place to ensure precision health initiatives uphold Te Tiriti. This includes addressing important issues related to collection, use and storage of human tissue and Māori data.</p>

<b>Empowering individuals, whānau and communities</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 genetics, lifestyle and environmental circumstances and other health data.	Variation in data quality, collection practices and interoperability between multiple systems will challenge our ability to use precision health in Aotearoa New Zealand.

<sup>38</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>Empowering individuals, whānau and communities</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>
<p>Ensuring the voice of individuals, whānau and communities is present in conversations about what precision health might look like will be key to developing precision health solutions that are flexible and appropriate to people's health needs and expectations. It will include identifying and responding to groups' differing needs or unanswered questions about what precision health might mean for them.</p> <p>There is also an opportunity to improve population health outcomes by increasing the use of genomic testing, AI and machine learning to identify more specific treatment pathways for different population groups.</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 those data. Neither genomic nor other data used in AI algorithms can predict outcomes with certainty for individuals. There will be risk of false positive or negative results, which may lead to unnecessary treatments (for example, a false positive genetic test for breast cancer leading to unnecessary surgery) or a person not receiving a required treatment.</p> <p>Feedback from our November 2022 consultation suggested a perceived absence of relevant regulation to support precision health. Other countries' regulatory systems are being challenged by new health technologies.<sup>39</sup></p> <p>Multiple respondents from our consultation 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>39</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).

<b>Achieving health equity</b>	
<b>Opportunities</b>	<b>Risks and considerations</b>
<i>Precision health could create more effective outcomes ...</i>	<i>... but could widen gaps in health outcomes if it is not implemented well.</i>
<p>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 towards holistic population health care systems and preventive models that will achieve more equitable health outcomes.</p> <p>Precision health tools could address inequitable access to health care. 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 remote areas, increasing the 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. This includes thinking about what an equity-led approach to precision health technologies might look like in Aotearoa New Zealand – such as designing precision health applications to address known equity challenges, through engagement with impacted groups.</p>	<p>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. Evidence indicates genetic variance between global reference data and the genomes of Māori, Pacific peoples and populations are not included in genomics research to date. This could mean that technological advances do not offer the same benefits for Māori, Pacific peoples and other ethnic minority populations.</p> <p>Understanding our social and cultural licence across different applications of 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 are robust and unbiased. In the case of AI, there is potential for algorithmic bias to amplify racism or stereotypes. It is critical diverse groups are represented at all levels in the design, governance and implementation of AI tools to ensure the precision health system does not perpetuate racism.</p> <p>Workforce capacity and diversity across a number of specialised professions related to precision health (for example, medical laboratory scientists, bioinformaticians, genetic counsellors, clinical geneticists) is constrained and does not represent the Aotearoa New</p>

Achieving health equity	
Opportunities	Risks and considerations
<i>Precision health could create more effective outcomes ...</i>	<i>... but could widen gaps in health outcomes if it is not implemented well.</i>
	<p>Zealand population. Without supporting sustainable and diverse capability development in the skills required to deliver precision health, these technologies risk becoming utilised inconsistently, undermining the health system goal 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>40</sup></p> <p>Digital connectivity and literacy can be variable within and between different groups, impacting equity of access. Increasing use of digital tools such as AI will need to consider this in any design approaches and ensure tools are accessible; tailored supports are in place to increase digital literacy appropriate for different groups and alternative options are available for those who cannot, or prefer not to, access digital tools.</p>

<sup>40</sup> PPP, 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).



Efficiency and financial sustainability	
Opportunities	Risks and considerations
<i>Precision health offers opportunities to improve efficiencies in health spending ...</i>	<i>... but it will require investment, with processes to ensure value for money in the long term.</i>
<p>Precision health may allow us to approach health care delivery and prevention in new ways that generate efficiencies for the health system.</p> <p>Estimates made in 2019 projected that AI would contribute over \$700 million in value to the Aotearoa New Zealand health system by 2026, reduce nurse workload by 20% and allow doctors to see more patients.<sup>41</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>42</sup></p> <p>While the cost of genomic testing and related technologies has been relatively high in the past, there is potential for these costs to decrease over time with technological advancements and economies of scale.</p>	<p>Genomic testing and personalised treatments can be expensive and may not deliver the expected benefits.</p> <p>Existing systems of health technology assessment (HTA) used to assess value for money and procure both pharmaceuticals and some vaccines and devices could be adapted for different forms of precision health, enabling us to target high-value interventions and restrict investment in interventions that aren't expected to be a good use of limited funds. Importantly, HTA processes assess interventions and technologies over the full life cycle and incorporate investments and cost offsets, enabling a long-term view.</p> <p>There may be growth in privately funded services which are not accessible to all (note this is true across health now).</p>

“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

<sup>41</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>42</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).

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 while we already know or can predict many of the risks and opportunities offered through precision health, some are unlikely to be clear-cut in practice. Unforeseeable risks and opportunities are also likely to emerge and will need to be considered and addressed. The specific circumstances of each application will impact its level of benefit or risk, and there will be no scenario in which a blanket set of benefits or risks can be predicted.

# 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 a safe and secure environment that allows precision health to be used in a way that realises its benefits whilst mitigating or avoiding its key risk areas. This will require a number of changes to the current health system and wider landscape for precision health over the long term.

To ensure that the use of precision health is driven toward this ideal future and in line with our priorities, we have assumed that some form of government intervention is likely to be required. This section identifies 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 areas would need further exploration before being progressed, and any changes will be subject to decisions made by the government of the day.

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 our existing health workforce, following publication of this LTIB.

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

## We need a clear strategic framework for assessing emerging applications of precision health

For precision health to be introduced successfully in Aotearoa New Zealand, we need to strengthen our existing systems and processes to enable evidence-based decisions about new technologies and infrastructures.

Decisions about adopting any precision health measures will involve balancing trade-offs in the way we use scarce public funding. It will be important to accurately assess the total value of precision health to ensure that any funding of new technologies does not preclude our ability to fund interventions and programmes that might have a greater impact on equity or offer more value for money. While we support assessments of possible precision health interventions and technologies to be introduced into the publicly funded system, we also need to support system-wide efforts to reprioritise resources toward high-value interventions to maximise efficiency and financial sustainability.

An evidence-based approach that is currently used in Aotearoa New Zealand to assess new and existing technologies is the health technology assessment (HTA). The 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, the HTA can help inform decisions with multiple objectives, including improving health and patient experience, improving equity, enabling innovation and maintaining financial sustainability.

The Pharmaceutical Management Agency (Pharmac) conducts HTAs on pharmaceuticals, some medical devices and vaccines, and there is ongoing work within Aotearoa New Zealand's health system to expand the HTA for different types of emerging health technologies.

There are also likely opportunities to learn from what other countries are doing in this space (for example in the United Kingdom, the National Institute for Health and Care Excellence, NICE, has developed assessment frameworks for multiple technology types). However, we'll need to tailor any approach we apply in Aotearoa New Zealand 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.

It is also important to recognise that while the HTA is commonly used for making decisions about specific products, decisions about significant infrastructure investment typically fall outside the scope of the HTA. Regardless, the same general principles will apply, such as the rational consideration of return on investment weighed against other important values stakeholders may have – such as impact on health equity.

## We need to influence the design and development of precision health

Through both phases of our public consultation and engagement, submitters noted that maximising the value of precision health would require working in different ways and building partnerships both domestically and internationally.

### 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 health databases. This might also include research focused on identifying how to translate overseas research into our unique context.

### Strengthening international relationships

We have identified countries that are already leading some applications of precision health technologies, such as Australia, the United Kingdom and Singapore. These countries may have capability that could be utilised to support us as we develop our own applications of precision health technologies. Strategic international partnerships could provide lessons to test within our local context. We could also learn about indigenous health requirements from the application of precision health in countries with indigenous populations, such as Canada and Australia.

### Public/private partnerships

Given the size of our country, it is unlikely that Aotearoa New Zealand will achieve the scale of investment, infrastructure, capacity and capability that is seen in other countries at the forefront of developing new precision health technologies. To help us keep up with the pace of innovation and ensure that we achieve the most relevant benefits 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.

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

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

- national data infrastructure that allows us to use and apply 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 include modernising consent processes and enabling Te Tiriti compliant systems to protect the rights and interests of Māori according to principles of Māori data sovereignty. 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>43</sup>. Continuing to develop the quality and consistency of our data will improve our ability to understand 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. Outsourcing of data analysis functions is an area of particular concern for Māori due to implications on Māori data sovereignty and cultural protection. 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 people living in Aotearoa New Zealand.

## 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. It will be critical that these governance mechanisms enable different groups to have agency over the collection, storage, use and dissemination of data about them.

Respondents from our consultation and engagement 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, including human tissue and genetic material.

Indigenous data sovereignty recognises the rights and interests that indigenous populations have over their own data and the need for structures to enable control over how these data are used. Māori data sovereignty recognises that Māori data should be subject to Māori governance that supports tribal sovereignty and the

<sup>43</sup> For more details on this programme, see the webpage Hira work programme on the Te Whatu Ora website at URL: [www.tewhaturora.govt.nz/our-health-system/digital-health/hira-connecting-health-information/hira-work-programme](http://www.tewhaturora.govt.nz/our-health-system/digital-health/hira-connecting-health-information/hira-work-programme)

realisation of Māori and iwi aspirations.<sup>44</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 National 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. The recently published Māori Data Governance Model | Te Kāhui Raraunga<sup>45</sup> sets clear expectations for the governance of Māori data and sets direction on the actions needed to meet these expectations. The model is future focused and includes a vision, measurable outcomes, values, authority and eight Māori data governance pou, with best practice exemplars and examples provided to guide innovative use of data that gives practical effect to Te Tiriti.

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 sovereignty to be empowering for future generations. 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. Exploration of any precision health technologies and associated data governance arrangements will need to ensure that 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 data conversations.

Other groups, including disabled people and Rainbow communities, will also need assurances around their personal data and governance arrangements. These arrangements will have an impact on these groups' trust and willingness to engage in treatment and care pathways developed through precision health technologies. Careful consideration and a collaborative, transparent approach to such arrangements will be needed to provide these assurances.

<sup>44</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>

<sup>45</sup> See: Kukutai T, Campbell-Kamariera K, Mead A, et al. 2023. *Te Kāhui Raraunga: Māori Data Governance Model*. Te Kāhui Raraunga. URL: [www.kahuiraraunga.io/\\_files/ugd/b8e45c\\_803c03ffe532414183afcd8b9ced10dc.pdf](http://www.kahuiraraunga.io/_files/ugd/b8e45c_803c03ffe532414183afcd8b9ced10dc.pdf) (accessed 22 July 2023).

# We need to rethink the way individuals and whānau give informed consent for precision health interventions

Respondents told us that 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. This will be particularly important in the case of genomics, where increased availability of genomic testing is likely to identify more patients with inherited diseases or strong predispositions to specific diseases and will require balancing the rights of individuals against the rights of whānau.

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>46</sup> and locally<sup>47</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 are 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 is 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 key underpinning components in data collection. As we move toward an increasingly digitally enabled future, we need to make sure that individuals' and groups' ability to control their data is at the forefront of any innovation considerations.

Data should be stored in a way that reinforces the capacity of Māori to exercise kaitiakitanga over those data, with Māori controlling the access restrictions.

<sup>46</sup> Teare HJA, Pictor 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>47</sup> See the webpage Dynamic Consent on the Precision Driven Health website at URL: <https://precisiondrivenhealth.com/dynamic-consent/>



## We need a skilled and diverse workforce to deliver precision health

Investment in training and education programmes to build workforce capability, including around cultural safety and digital literacy, and to leverage precision health technologies is a key precondition to the introduction of precision health. This will include proactively identifying any new skills, roles and multidisciplinary arrangements needed to support precision health into the future. For example, our consultation 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.

Many of the roles required to deliver precision health already exist – including medical laboratory scientists, pathologists, clinical geneticists, bioinformaticians, data scientists and software developers. However, consultation feedback suggests these professions face considerable capacity challenges and will require further investment to grow their professions and continually develop their skills if precision health is to be realised. Further work will be required to integrate these skills more effectively into models of care – from scaling existing usage to enabling new ways of working with other health professionals across the sector, such as the allied health workforce.

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 technologies and to raise awareness of the different conditions and settings these technologies will be applied in (such as rare diseases). The cost of this education must be considered in future planning. This will be particularly important for the workforce in areas where precision health is still in its infancy, such as primary and community health care.

A focus on equity will also require lifting capacity and capability across our Māori and non-Māori health workforce to respond to equity and Te Tiriti and enable our health workforce to work effectively and more flexibly with a range of communities. Educational institutions are already encouraging this through preferential placements for Māori, Pacific people and those from other diverse backgrounds. However, consultation feedback suggests further resources are required to enhance the diversity of our workforce.

Some educational pathways are not available in Aotearoa New Zealand. For example, genetic counselling is a post-graduate qualification only offered in Australian universities and is not eligible for student loan funding, which presents financial barriers to growing this profession and impacts on the availability of appropriate support for those receiving genetic testing.

“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 improve data, digital and genomics literacy amongst the health workforce, patients and the public. It 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 that there is a 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. In our consultation and engagement process, Māori stakeholders shared aspirations of achieving 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

## We need effective rules and regulations that keep individuals and whānau safe

The use of precision health technologies will need rules and oversight to guide and monitor their use. 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.<sup>48</sup> 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 during the consultation and engagement process highlighted that any future exploration of precision health would require an agile 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. The framework and settings would need to be developed in partnership with those groups most at risk of being negatively impacted from our adoption of precision health technologies, such as Māori, Pacific peoples and disabled people.

As the line between medicines, medical devices and other precision health technologies becomes increasingly vague, we face questions about how we can

<sup>48</sup> Manatū Hauora. 2023. Regulation of the health and disability system. URL: [www.health.govt.nz/our-work/regulation-health-and-disability-system](http://www.health.govt.nz/our-work/regulation-health-and-disability-system)

effectively regulate hybrid technologies that fall outside traditional categories.<sup>49</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. They will need to ensure safety through mitigation of any clinical, privacy or security risks, while encouraging high-value, scalable innovation and preventing the market proliferation of ineffective, unsafe and low-value applications and products.<sup>50</sup>

One example of this may be seen in the Therapeutic Products Act 2023. This new legislation was only recently enacted, and many of its provisions will not commence until 2026. It aims to protect, promote and improve the health of all New Zealanders by providing for the acceptable measures for safety, quality and efficacy or performance of medicines, medical devices and active pharmaceutical ingredients across their life cycle. The Act will also provide for the acceptable safety and quality of natural health products across their life cycle. The Act addresses regulatory gaps in therapeutic products, such as medical devices and advanced cell and gene therapies, and aims to do so in a way that is flexible and can adapt as new technologies emerge. The Act will provide for the regulation of therapeutic products in a way that is comprehensive and balances the risks and benefits of the products, including many applications of precision health technologies, such as genomics and aspects of AI. It will repeal most of the provisions of the existing legislation that enables access to safe medicines and medical devices (the Medicines Act 1981), excluding those relating to pharmacy ownership, and revoke the regulations made under that Act.

The Act provides a regulatory framework to:

- require therapeutic products to receive a market authorisation before they can be imported into, exported from or supplied in Aotearoa New Zealand
- allow products without a market authorisation to be imported into and supplied in Aotearoa New Zealand in limited circumstances
- provide for the regulation of a range of controlled activities
- establish a therapeutic products regulator and grant the regulator a range of compliance and enforcement powers.

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

<sup>49</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>50</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).

## Example: Protecting against genomic discrimination

Increasing use of genomic testing in Aotearoa New Zealand raises the risk of genetic discrimination.<sup>51</sup> Genomic information may reveal genetic predispositions to certain diseases. This could lead to stigmatisation and discrimination of individuals, which could impact insurance and employment opportunities. International evidence suggests fear of genetic discrimination has led to individuals declining to undergo genetic testing or be involved in genetic and genomic research.<sup>52,53</sup>

While it is unclear how often this occurs, it potentially presents a significant health impact for at-risk individuals choosing not to get tested or access cutting-edge treatment. Aotearoa New Zealand currently has no regulation to prevent misuse of genetic information, which is particularly significant for Māori and other groups who experience poorer outcomes, but we could explore some international legislative mechanisms. Canada, Germany and the United States of America have implemented legislation to protect against genetic discrimination, while the United Kingdom has a Code on Genetic Testing and Insurance<sup>54</sup>. Meanwhile, Australia has a voluntary moratorium on genetic discrimination.<sup>55</sup> However, a recent report investigating the effectiveness of the moratorium found that it was inadequate for addressing and preventing genetic discrimination in life insurance and recommended it be replaced with a legislative model of prohibition.<sup>56</sup>

<sup>51</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>52</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>53</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>54</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>55</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).

<sup>56</sup> Tiller J, Gleeson P, McInerney-Leo A, et al. 2023. *The A-GLIMMER (Australian Genetics and Life Insurance Moratorium: Monitoring the Effectiveness and Response) Project: Final stakeholder report*. Monash University. DOI: <https://doi.org/10.26180/23564538> (accessed 24 July 2023).

# Te Whakakapinga | Conclusion

## Me aha ināianei? | What next?

To ensure that any precision health tools and technologies are introduced safely and in a way that aligns with and supports the desired health outcomes for the people of Aotearoa New Zealand, we need to be confident we have an enabling environment that supports the use of precision health to achieve health equity and our vision of pae ora. We need 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 need to balance trade-offs between different groups, priorities and generations, while giving practical effect to Te Tiriti through the health sector principles.

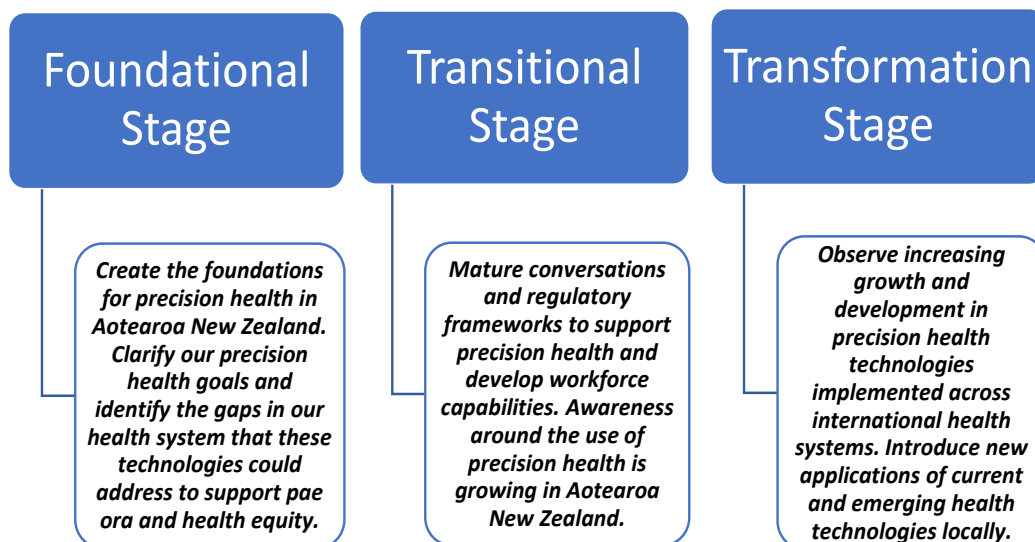
This section provides options for actions and next steps in the short, medium and longer term to introduce precision health tools and technologies appropriately over three stages – the foundational, transitional and transformation stages.

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

There are many steps and considerations to take into account over the next 10 years and beyond, and these will be subject to decisions made by the government of the day.

Feedback throughout our engagements has indicated that progress needs to happen in stages, with consistent testing and monitoring of activities throughout. Any changes will require cross-sector collaboration between Manatū Hauora, health entities and key stakeholders, partners and groups to ensure that research, innovation and implementation focus on the areas of highest priority, uphold Te Tiriti principles and advance health equity for Māori and other groups experiencing poorer outcomes.

We have identified three broad stages and outlined below what stakeholders told us they thought would be the ideal focal points of consideration for each stage.



In our draft briefing, we asked respondents for suggestions about what the primary activities at each stage should be, to support equitable implementation of precision health technologies and ensure services were comparable with international systems but appropriate for our context. Respondents provided the following ideas.

### Foundational stage activities

- Continue mapping the existing national and international precision health ecosystem to identify where action is needed first to uphold Te Tiriti and promote health equity.
- Expand and continue engagement with, within and between stakeholder groups and experts in precision health – including our existing workforce and particularly with Māori and Pacific experts and communities.
- Set up national governance arrangements in partnership with Māori.
- Review our current regulatory and legislative frameworks, including barriers and opportunities for addressing framework requirements (learning from international examples).
- Identify necessary skills for existing and future workforce – including in educational pathways and advanced scopes of practice where necessary.
- Update systems and evaluation frameworks, such as a national HTA function to enable flexible and adaptive decision-making for emerging technologies.
- Establish mechanisms to embed Te Tiriti through design and implementation of any settings (including through Māori data sovereignty protocols).

### Transitional stage activities

- Develop a national policy framework setting out key priorities for government and health entities.
- Align precision health priorities with cross-sector programmes of work, clinical services, health research priorities and linkages with the national research priorities process (such as Te Ara Paerangi Future Pathways programme).

- Establish funding for investment in necessary infrastructure and research to support the application of precision health in priority areas, including a national database infrastructure.
- Improve links and collaboration across the health sector through communities of practice/advisory groups to prioritise work and engage relevant stakeholders across the ecosystem, including cultural champions.

### Transformation stage activities

- Embed systems, regulations and frameworks to ensure safe and effective adoption of emerging technologies.
- Ensure that infrastructure and investment are in place to support nationally consistent implementation of precision health technologies.
- Continue investing in research on critical gaps of importance for Aotearoa New Zealand.
- Develop a precision health plan that considers workforce impacts and solutions.
- Grow awareness and confidence in applications of precision health with tangible benefits for Māori, Pacific and other groups currently experiencing poorer outcomes.

These suggestions are not exhaustive but provide important insights into aspirations for what happens following the conclusion of this LTIB process. They will provide a starting point for continued conversations about what precision health might look like in the future.

## The wider conversation around how the health system is changing

This LTIB elevates conversations about how we use current and emerging technologies for precision health. However, it is also part of a much broader conversation that is happening across Aotearoa New Zealand following the recent health reforms about understanding the actions we need to take to ensure all individuals and whānau live long, fulfilling lives in good health.

This LTIB will form a platform to influence our work and the work of the health system into the future.