



Te pae tika: E tūhura ana i ngā ara hou me ngā uauatanga e pā ana ki te āta matapaetanga, te haukotinga, te kitenga me te rongōātanga o ngā mate ki Aotearoa

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

He whakawhitinga kōrero ki te iwi whānui hei whakawhanake i tētahi Kupu Whakamārama mō te Tirohanga Roa

Public consultation on a topic for a Long-term Insights Briefing

2022

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Whakatauki

Whaowhia te kete mātauranga

Fill the basket of knowledge

Foreword by the Director-General of Health

Kia ora koutou katoa

Across the reformed health system we're working towards a simple but ambitious goal - to deliver pae ora | healthy futures for all New Zealanders. We know achieving this goal requires us to do things differently and to look for new and innovative ways to deliver health care into the future.

Precision health is an exciting and rapidly developing field that holds the potential to significantly improve the health and wellbeing of individuals, whānau and communities across Aotearoa. The benefits of precision health are increasingly evident from international research and practice, from directly improved health outcomes, to cost savings within the health system and productivity gains to society.

Translating the potential of precision health into future health gains for Aotearoa requires a deliberate and comprehensive approach. If implemented responsibly with Te Tiriti and equity considerations at the forefront, precision health may be a tool to reduce existing health inequities. On the other hand, ad-hoc adoption could worsen inequities or create new ones.

There is much to think about as we consider the role and future direction of precision health in delivering more effective health care for all New Zealanders. Your feedback is essential to ensure we understand the opportunities, challenges and barriers that exist, and how we can address these to continue our journey to deliver pae ora | healthy futures for all New Zealanders.

We look forward to exploring this Long-term Insights Briefing topic with you.

Ngā mihi maioha

Dr Diana Sarfati
Director-General of Health

He pēhea ō whakaaro? | What are your views?

Manatū Hauora (Ministry of Health) is seeking written feedback on the proposed topic of its Long-term Insights Briefing (the briefing) by **5pm on Friday 27 January 2023**.

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

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

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

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

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Wāhanga Tuatahi: Ko wai mātou, he aha hoki te Kupu Whakamārama mō te Tirohanga Roa? | Part One: Who are we and what is a Long-term Insights Briefing?

Manatū Hauora | Ministry of Health

Manatū Hauora is the chief steward of New Zealanders' health and of the health system. We set the direction for health, advise the Government on health policy, funding and legislative settings, regulate the health system, and monitor health outcomes and system performance.

Our role includes scanning the horizon for future issues and opportunities, setting long-term strategies for health and advising the Government on changing priorities, policies, funding and other matters that affect how the health system operates. The Long-term Insights Briefing is one of the ways in which we carry out these roles.

He aha hoki te Kupu Whakamārama mō te Tirohanga Roa? | What is a Long-term Insights Briefing?

Long-term Insights Briefings are a new requirement for the public service of Aotearoa. Introduced by the Public Service Act 2020, the briefings need to be completed at least once every 3 years.

Chief executives in the public service have a statutory duty to produce the briefings independently of ministers. The briefings differ from the advice that the public service provides ministers, and from the accountability and planning documents prepared for Parliament. They are not government policy.

Instead, the briefings are 'think-pieces' on the future. Their purpose is to strengthen the public service's focus on the long term, by making available:

- information about medium- and long-term trends, risks and opportunities that affect or may affect Aotearoa
- information and impartial analysis, including on policy options for responding to these matters.

The Department of the Prime Minister and Cabinet (DPMC) guidance recommends the briefings look at least 10 years into the future. If you want to learn more about these briefings, please visit the **Policy Project website**.

Opportunities for you to contribute to the Manatū Hauora Long-term Insights Briefing

This document is your first opportunity to contribute to Manatū Hauora's Long-term Insights Briefing. Feedback we receive will help us better shape the topic and questions we explore during the drafting process for the briefing.

You will have several opportunities to provide feedback as we develop this briefing:

- **November 2022 to January 2023** — this public consultation on the proposed topic and areas you want us to explore in this field
- **November 2022 to March 2023** — targeted engagement as we draft the briefing
- **April 2023** — public consultation on the draft briefing
- **June to July 2023** — final briefing presented to the Minister of Health and referred to the Select Committee.

Our commitment to you

Throughout the briefing development process, we are committed to engaging in a way that:

- honours our commitment to Te Tiriti o Waitangi — this includes seeking out and understanding tangata whenua perspectives
- supports a flexible approach to facilitate engagement for individuals, groups and communities to share their views, in ways that are appropriate to them
- is responsive to your feedback and provides updates to those who have engaged in the process.

Wāhanga Tuarua: He aha rā te kaupapa kei mua i te aroaro? | Part Two: What topic are we proposing?

Our proposed topic is:

Precision health: Exploring opportunities and challenges to predict, prevent, diagnose, and treat disease more precisely in Aotearoa New Zealand.

Part of our role as steward of the Aotearoa health system is to anticipate and address long-term opportunities and risks to health from global forces and trends that shape our world and impact our future.

Forces and trends relevant to health include trends such as population and demographic change, climate change and resource stress, high expectations of health care at the individual level, emerging health technologies and the changing workforce.

We have chosen our proposed topic with these trends and opportunities in mind. Based on this topic, we could investigate:

- the influence that precision health research and technology might have on how we predict, prevent, diagnose and treat disease in the future — which we could explore through case studies identified during consultation
- how we can incorporate precision health into our models of care more effectively — with attention to the policy changes, system design and incentives we would need in the long term
- how Te Tiriti, equity, and information and privacy considerations could shape our use of precision health
- what approaches to using precision health might support more equitable health outcomes across Aotearoa.

He aha te pae tika? | What is precision health?

For this briefing, we have proposed a broad definition of precision health:

Precision health is a growing field that aims to use emerging technology, and all available information (such as an individual's genome, current biophysical

measures, and environment) to predict, prevent, diagnose, and treat disease more precisely, for people and whānau.¹

Advances in precision health have the potential to contribute to more effective prevention and interventions across the care continuum, including how we screen for, diagnose, and treat diseases.

Imagine a future where...

- Routine genomic screening tests available early in your mother's pregnancy can identify genetic variants indicating any diseases you are at a higher risk of developing later in life. These tests show you are at risk of a certain type of cancer. Over your life, you have regular, non-invasive screening checks for any signs of cancer developing and, if a tumour develops, you receive targeted intervention so that it does not become a life-threatening disease.
- You have type 1 diabetes. You receive biologic and genomic testing to identify how your diet will impact your blood glucose, and any specific changes to your care plan that you need. The results will tell you, for example, whether you are getting the right insulin analogue, considering the impact of your expected diet.
- Regular wastewater surveillance identifies an outbreak of a novel virus in your local community. Local authorities and community health providers are notified and they put public health measures in place to prevent a large-scale outbreak.
- Your activity tracker identifies you have high blood pressure and an irregular heart rhythm so you contact your primary care provider for a check-up. Using data from your activity tracker, your provider identifies early signs of heart disease and works with you to lower your risk of a heart attack.

Many of these scenarios are already possible but are not widely available or used in Aotearoa. In future, advances in science and technology related to disease mechanisms, the human body, and the connection with the wider determinants of health will have an impact on our ability not only to treat diseases, but also to prevent them from happening at all. In cases where diseases cannot be prevented, it will be possible to diagnose them earlier and treat them more effectively.

The term 'precision health' is often used interchangeably with 'precision medicine', but it differs in some important ways. Precision health complements precision medicine, or genomic medicine, but puts a greater emphasis on health promotion, disease prevention and using technological advances in data science, and personal and medical devices.²

For this briefing, we think the distinction between the 2 terms that Lloyd Minor (Dean, Stanford University School of Medicine) has made is useful:

¹ This definition draws from: Minor L, Rees M. 2020. *Discovering Precision Health: Predict, Prevent, and Cure to Advance Health and Well-being*. Wiley; and Centers for Disease Control and Prevention, Precision health: improving health for each of us and all of us. URL: [cdc.gov/genomics/about/precision_med.htm](https://www.cdc.gov/genomics/about/precision_med.htm) (accessed 1 November 2022).

² Minor and Rees (2020), above note 1.

NOT GOVERNMENT POLICY

“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.”³

The field of precision health includes applying current and emerging technologies such as genomics, pharmacogenomics and digital health to precision health areas, to provide more effective and efficient health care to people and whānau.

We have proposed a briefing that focuses on the broader field of precision health because it supports a more comprehensive view of health and wellbeing, beyond treating disease. It aligns well with a population health approach, and is in line with Government's objectives to achieve pae ora (healthy futures) for all New Zealanders and the health sector principles in the Pae Ora (Healthy Futures) Act 2022.

³ Minor and Rees (2020), above note 1.

Wāhanga Tuatoru: He aha te hirangatanga o tēnei kaupapa? | Part Three: Why is our proposed topic important?

Precision health has significant potential to benefit health outcomes. In Aotearoa, however, this potential is underdeveloped compared with other countries.

Globally, advances in precision health are improving capacity to accurately screen for risk of disease, diagnose rare conditions and, for health professionals, tailor treatment more effectively for their patients. A broad base of research in this area is available internationally and it is expanding. Research shows that, at system and societal levels, precision health offers potential for long-term benefits, such as improved health outcomes, cost savings to the health system and productivity gains to society.⁴

However, this field is underdeveloped in Aotearoa. We have also have no national strategy or system-wide effort to coordinate initiatives exploring aspects of this topic. As a result, our health system has generally not been able to adapt as well or take advantage of current precision health options to the same extent as some other countries, such as Australia and the United Kingdom. This also means we are less prepared than we could be to consider future precision health opportunities.

At a population level, precision health offers an opportunity to think differently about what effective health care looks like for Aotearoa in the future. This has exciting implications for how we work towards more equitable outcomes for all populations, particularly Māori, Pacific peoples, disabled people, and other groups who currently experience higher burdens of poor health. At the individual level, advances in precision health offer opportunities to empower people to self-monitor and self-manage their own health and wellbeing.⁵

Exploring future application of precision health will also need to consider robust and comprehensive methods of assessing new precision health technologies, including considering the evidence of effectiveness, size of potential benefit, impact on inequities, cost effectiveness, feasibility and competing demands in health. Where appropriate, we may want to adopt and adapt technologies in a way that supports equity and fits the unique context of Aotearoa.

⁴ Deloitte Access Economics. 2021. *Valuing the Impact of Genomics on Healthcare in Australia: Industry Genomics Network Alliance (InGeNA)*. Brisbane: Deloitte Access Economics. URL: www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-economics-valuing-impact-genomics-healthcare-australia-20122021.pdf (accessed 27 October 2022).

⁵ Swan M. 2012. Health 2050: the realization of personalized medicine through crowdsourcing, the quantified self, and the participatory biocitizen. *Journal of Personalized Medicine* 2(3): 93–118. DOI: 10.3390/jpm2030093 (accessed 27 October 2022).

If we are to take up and implement precision health successfully, we will also need to consider other key enablers in this field — including research and innovation, digital health, big data, artificial intelligence, and the determinants of health.

Adopting technologies in precision health also has the potential to disrupt existing service delivery models or spur the development of new models of care that deliver improved outcomes. We will need to carefully consider the issue of access to new technologies so that we can avoid perpetuating inequities in outcomes, as well as considering the costs and benefits associated with precision health.

The case in favour of Aotearoa becoming faster at adopting and adapting future precision health advances is based on demonstrated benefits that other countries have achieved from present advances and on expected benefits that result from offering more effective health care into the future.

Precision health will also contribute to the Government's reform objectives

The health system in Aotearoa is currently undertaking major reforms. The aim of these reforms is to create a system that is more collaborative, better tackles inequity and variation in service quality, embeds the voice of our communities at all levels of the system and honours Te Tiriti o Waitangi.

Our proposed topic is well aligned with the Government's health reform objectives and the principles of the Pae Ora (Healthy Futures) Act 2022, which include harnessing new technology to improve health services.

In the reformed system, we will have a renewed opportunity to explore emerging research along with the barriers holding us back from taking up this field. With this understanding, it will be possible to share future advances in precision health in a more coordinated way across the health system.

A national approach to implementing precision health is likely to offer opportunities to achieve consistent access to and economies of scale in health services. It will also help us to focus on the complex ethical, social and legal issues in this area that we need to address — particularly those relating to Te Tiriti o Waitangi and equity.

Our role as system steward places an obligation on Manatū Hauora to provide a platform for these conversations. We see this briefing as a good vehicle to begin this process.

Questions for consultation:

1. Do you think precision health is a worthwhile topic to explore in our Long-term Insights Briefing? Why or why not?
2. What opportunities does precision health create for more effective health care in the future (more than 10 years ahead)?
3. What barriers or restrictions do you see in the health system that might hold it back from adapting future precision health advancements?

Wāhanga Tuawhā: Ko ēhea ngā wāhanga o tēnei kaupapa hei tiroiro mā tātou? | Part Four: Which areas should we explore in our briefing?

Our discussion of the future of precision health must address the present challenges that exist in this field.

There are substantial challenges and barriers to implementing the emerging field of precision health in a coordinated way in Aotearoa.

Overseas, commonly identified challenges in using precision health include the availability of robust evidence about applying precision health across various health settings, addressing data-sharing and infrastructure needs, incorporating sensitive patient information into clinical care and research, reconciling cost and economies of scale in a public health care system, and building public engagement and trust.

Equity

To navigate the challenges of implementing precision health, we will need to look at it through an equity-focused lens. In so doing, our aim is to ensure that any new approaches we apply contribute towards achieving equity in health outcomes for all population groups in Aotearoa⁶.

Communities that would benefit the most from new technologies, including for diagnosis and treatment, often face barriers to accessing and benefiting from them because these communities are already disadvantaged in terms of their access to current health services and decisions about their treatment. In the case of precision health, these challenges may be exacerbated if the relevant communities are not well-represented in considerations informing the clinical application or use of the new technologies. For this reason, our briefing will need to consider what action is needed

⁶ Manatū Hauora. 2019. *Achieving equity*. Wellington: Ministry of Health. URL: <https://www.health.govt.nz/about-ministry/what-we-do/work-programme-2019-20/achieving-equity>. (accessed 25 November 2022).

to address these challenges so that precision health does not perpetuate existing equity issues.

An equity lens would also help in making decisions on which areas of precision health to prioritise. Health areas to consider include those where significant inequity exists, or where changes could lead to the greatest benefit in health outcomes.

Te Tiriti o Waitangi

Our adoption of precision health must align with Te Tiriti o Waitangi so that any advances in health technology reflect the health needs and aspirations of Māori, and hauora Māori achieves equitable outcomes.

Manatū Hauora recognises the 5 principles of Te Tiriti o Waitangi as set out in the Waitangi Tribunal's Hauora report: tino rangatiratanga, equity, active protection, options and partnership.⁷ In exploring our proposed topic, we will need to consider how precision health relates to these principles. For example, the difference in perspectives between te ao Māori and other worldviews in relation to DNA and human tissue has implications for our understanding of the appropriate way to collect, store and share individuals' genetic information (which in turn creates an obligation to consider data sovereignty).

Other ethical, legal, and social issues

Exploring how to apply precision health in the future also raises broader ethical, legal and social issues that the briefing could address, including how we assess cost-effectiveness and affordability of precision health interventions, and how we use, store and share patient information. For example, misuse of information associated with precision health, especially individuals' genomic information, could occur through privacy violations, discrimination in employment and insurance, inappropriate financial gain, and reinforcing ethnic disrespect and health disparities. We acknowledge that without careful planning and consideration, some people are likely to experience these challenges more than others. Exploring these issues therefore provides an opportunity to test how acceptable these technologies are to our communities — and what some implications may be for those who do not want to participate.

In considering our proposed topic, we see an opportunity to start a conversation about how we address present challenges to offer more effective health care for all population groups in the future.

⁷ This report responded to Stage One in the Wai 2575 claim: Waitangi Tribunal. 2019. *Hauora Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry*. Wai 2575. Wellington: Waitangi Tribunal. URL: waitangitribunal.govt.nz/inquiries/kaupapa-inquiries/health-services-and-outcomes-inquiry/ (accessed 18 November 2022).

Questions for consultation:

4. What concerns or issues do you have with precision health, or how we may adapt it in Aotearoa in the future?

Using case studies may help to identify critical issues to address

As we've identified, precision health is a broad topic. To enable a focused conversation about future opportunities and challenges in precision health, we want to identify 2 areas where we undertake detailed case studies of existing research, technologies and practices, locally and internationally.

Through these case studies, we will be able to provide an overview of the value of precision health to the Aotearoa health care system and society more broadly by profiling the use, opportunities and challenges of precision health technologies across the care continuum. Part of this work will include learning how we use emerging precision health interventions at a population level to predict disease before it occurs or prevent it altogether.

Another aspect of these case studies will be to identify what has helped other countries to apply these technologies successfully that we may benefit from by adopting new approaches in the context of Aotearoa.

The following are just some examples of case studies we might choose.

- **Precision medicine / genomic medicine:** Precision medicine involves tailoring medical treatment to the individual characteristics of each patient. It does not literally mean creating drugs or medical devices that are unique to a patient. Rather, it is concerned with classifying individuals into subpopulations that differ in their susceptibility to a particular disease, in the biology or prognosis of diseases they may develop, or in their response to a specific treatment. Based on these classifications, it is possible to concentrate preventive or therapeutic interventions on those who will benefit, while sparing expense and side effects for those who will not. Examples of advances in this field include whole genome sequencing to identify Covid-19 variants, or to test for breast cancer risk genes at birth.
- **Pharmacogenomics:** Pharmacogenomics is the analysis of how genes impact a person's response to drugs. This relatively new field combines pharmacology (the science of drugs) and genomics (the study of genes and their functions) to develop effective, safe medications and doses that will be tailored to a person's genetic make-up. An example of an advance in this field is pharmacogenetic testing to guide the choice of drug treatments for patients with depression.
- **Digital health:** Digital health uses accessible data and digital technologies to improve our ability to accurately diagnose, monitor and treat disease. Digital health technologies have also been identified as a key way of encouraging uptake of precision health in the future. Examples of current technology increasingly used in

this field to improve health include artificial intelligence, self-tracking devices, wearables, smartphone applications and virtual reality.

- **Computational medicine/biology:** Computational medicine aims to advance health care by developing computational models of disease, personalising these models using data from patients, and applying these models to improve the diagnosis and treatment of disease. This field uses patient models to discover novel risk biomarkers, predict disease progression, design optimal treatments and identify new drug targets for applications such as cancer, cardiovascular disease and neurological disorders.

We are seeking your feedback on which of these areas (or others) the briefing should consider.

Questions for consultation:

5. Which case study areas do you think the briefing should explore? Why? You can indicate one or more of the following (or identify any other areas of interest to you):
 - a. Genomics
 - b. Pharmacogenomics
 - c. Digital health
 - d. Computational biology

The briefing could consider the government response

The Government is likely to have opportunities to influence how we make precision health part of our efforts not only to treat disease more effectively but also to enable people to stay well for longer.

Options that the briefing could consider for how the Government responds to precision health in the future include:

- leadership roles across government and the private sector
- changes to legislation or regulatory settings
- advising on the cost-effectiveness and affordability of new interventions and initiatives within precision health
- cross-sector policy setting and investment frameworks
- funding, co-investment and partnership opportunities with health providers, industry and researchers
- expansion of expected health care services delivered through the public system.

Wāhanga Tuarima: Me pēhea te whakawhanake mai i ngā kōrero | Part Five: How will we develop the briefing?

We will develop our briefing by:

- building an evidence base — reviewing local and international literature and research on the selected case studies within precision health, including policy options other countries use to implement precision health effectively
- engaging with stakeholders to hear feedback and insights on:
 - the themes selected for case studies and the content of these
 - likely future trends, the opportunities they present and their implications for more effective health care in Aotearoa
 - possible solutions to the current challenges related to Te Tiriti, equity, information and privacy
 - identifying possible future states based on observed trends, research and consultation and using these to identify potential solutions and implications.

Me pēhea te mahi ngātahi ki ētahi atu? | How will we work with others?

Manatū Hauora is working with other public service agencies and entities whose priorities align with our proposed topic. We will look for opportunities to work closely with non-governmental organisations that can share their insights with us on our topic areas and/or challenge our assumptions.

For the first public consultation, including with Māori, we will be making use of our existing relationships, networks and advisory groups. For example, we will work with Te Pou Hauora Māori (Māori Health Directorate) at Manatū Hauora and with Te Aka Whai Ora | Māori Health Authority to identify and engage with relevant groups throughout the initial consultation, as well as in drafting the briefing after that. In shaping our approach, we are mindful of other priorities across the health sector, particularly related to implementing the health reforms and developing strategies required by the Pae Ora (Healthy Futures) Act 2022.

For more information on the topics other agencies have chosen for their briefings, see [Te Kawa Mataaho website](#).

Wāhanga Tuaono: Me pēhea te tuku urupare mai? | Part Six: How can you provide feedback?

We want to hear from you about your views on the proposed topic of precision health for the Long-term Insights Briefing, and your response to the specific questions below.

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

- Complete the online form (Citizen Space).
- Email **LTIB@health.govt.nz** with your submission, including your response to the consultation questions.
- Write your response and mail it to:

Strategy Group
Ministry of Health
PO Box 5013
Wellington 6140

Please indicate if you wish to participate in ongoing consultation as we develop the Precision Health Long-term Insights Briefing.

Ngā pātai hei whakautu māu | Questions for your feedback

Precision health now and in the future

1. Do you think precision health is a worthwhile topic to explore in our Long-term Insights Briefing? Why or why not?
2. What opportunities does precision health create for more effective health care in the future (more than 10 years ahead)?
3. What barriers or restrictions do you see in the health system that might hold it back from adapting future precision health advancements?
4. What concerns or issues do you have with precision health, or how we may adapt it in Aotearoa in the future?

Areas of focus for case studies

5. Which case study areas do you think the briefing should explore? Why? You can indicate one or more of the following (or identify any other areas of interest to you):
 - a. Genomics
 - b. Pharmacogenomics
 - c. Digital health
 - d. Computational biology

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

We will use the information provided in submissions in developing our briefing. Manatū Hauora may contact you directly if we need to clarify any matters you raise in your submission

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

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

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

While we collect submitters' names and contact information, please note that personal contact details and names will **not** be shared or published through the summary of submissions.

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

Private information

The Privacy Act 2020 establishes certain principles about how various agencies can collect, use and disclose information about individuals. Any personal information you supply to Manatū Hauora in making a submission will only be used for the purpose of helping to develop the Long-term Insights Briefing.