Data and Information Strategy for Health and Disability

He Rautaki Raraunga, He Rautaki Pārongo mō te Pūnaha Hauora, Whaikaha hoki

Stronger evidence, better decisions, improved health and wellbeing | Hei whakapakari ake i ngā taunakitanga, ngā whakataunga me te hauora o te tangata

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Foreword

Delivering health care to New Zealanders in the future will require a significant shift in the way we think about data, including the very concept of what constitutes information.

We'll need a health and disability system capable of delivering equitable health outcomes for all New Zealanders, generating insights people can act on for good policy and decision-making, able to adapt more readily to the needs of the system and rapidly to changing situations (such as a pandemic), and up to the task of sharing health information securely in real-time and with appropriate authorisation.

As a sector, that means being smarter, more innovative and inclusive in how we define, collect, manage, use and share health data. We'll need to broaden our definition of data to include data produced by emerging technologies or existing technologies for new purposes. For instance, we'll increasingly draw on sources as varied as non-health sector information regarding the determinants of health, artificial intelligence, an array of images, and genomics to support improved diagnostics, population health management, more targeted interventions and to support communicable disease management, as we've done in the current COVID-19 pandemic.

Embracing these changes will challenge our thinking on a number of fronts, including the ethics of data use, issues around consent and access to information, the protocols for privacy and security, our obligations under Te Tiriti o Waitangi, and how the sector can address inequities in health rather than embedding them. We'll also need to think about the type of information collected and its value to health outcomes, and our role as stewards rather than owners of the information entrusted to us by individuals, whānau and communities.

These are big questions, and they require careful consideration. It's about finding the best ways to support New Zealanders to have lives of health and wellbeing, to manage their own health and to have input into the design of health and disability services. It's also about understanding how the health system as a whole is performing and whether it is capable of learning and adapting. It is particularly timely to consider these issues as the sector transitions to new structures and operating models under the Government's health reforms. Data and digital technologies have been identified as key enablers for the health and disability system.

This strategy and the accompanying roadmap are intended as guides to the actions needed within the sector (and beyond) to transform our management and use of health data. I encourage you to read both documents and consider how you might bring the recommendations to life within your own organisations and in support of whole-of-system efforts.

Shayne Hunter
Deputy Director-General
Data and Digital
Ministry of Health

Kupu Whakataki

Ko te manaaki i ngā iwi katoa o Aotearoa mō te taha hauora hei te anamata, me panoni nui ō tātou whakaaro mō tēnei mea te rarauranga, tae rā anō ki te tikanga o tēnei mea te pārongo.

Me whai pūnaha hauora, whaikaha hoki e āhei ana ki te whakatutuki i ngā putanga tōkeke hauora mō ngā iwi katoa o Aotearoa, e hua ai he māramatanga e taea ana e te tangata te whakatinana i roto i ngā kauapapa here, whakataunga hoki, e āhei ai te urutau i runga i te tere ki ngā hiahia o te pūnaha ki ngā panonitanga auau nei (pēnei me te urutā), ā, kia taea ai hoki te tohatoha pārongo i runga i te haumarutanga i te rere o te wā me te kupu whakaae e tika ana.

Hei rāngai, ko tōna tikanga me koi ake, kia whakahōu ake, ā, me nui ake te mahi tahi i tā tātou tautuhi, kohikohi, whakamahi me te tohatoha i ngā pārongo hauora. Me whakawhānui atu tā tātou whakamārama o te raraunga kia kuhu hoki ai nga raraunga e puta nei mā ngā hangarau te ara ake nei, ngā hangarau kē o te wā nei ki ngā aronga hōu. Hei tauira, ka nui ake tā tātou whakamahinga i ngā puna hōu tae ake ki ngā pārongo kore hāngai ki te ratonga hauora otiia, he pānga ki ngā putanga o te hauora, mōhiotanga horihori, he kohinga whakaahua me ngā huinga ira kia tautoko i ngā whakataunga, te whakahaeretanga hauora taupori, kia rahi ake ngā aro whai waahi atu ki te tautoko i ngā ārai mate hōrapa pēnei anō i tā tātou me te Mate Korona.

Ko te whakahiapo i ēnei panonitanga ka wero nei i ō tātou whakaaro i ngā tūmomo āhuatanga maha, arā ko te whakamahinga o ngā raraunga i runga i te matatika, ngā take mō te whakaaetanga me te whai waahitanga ki ngā pārongo, ngā tikanga matatapu, whakahaumaru hoki, ā tātou here ki te Tiriti o Waitangi, ā, ka pehea hoki te rāngai e taea ana te kōrero

ngā tōrite i te ao hauora engari anō tēnā i te whakatinana. Me whakaaro hoki e mātou ki te momo pārongo e kohikohi ai me ōna whai take ki ngā putanga hauora, ā, tā mātou tūranga hei kaitiaki engari anō hei rangatira i ngā pārongo kua whakaponohia mai mātou e te takitahi, e ngā whānau e ngā hapori.

He pātai nui ēnei me āta whakaaro iho. Ko te kimi i ngā ara pai ake ki te tautoko i ngā iwi o Aotearoa te aronga, kia whai oranga hauora, toiora hoki, mā te tangata anō tōna hauora e whakahaere, ā, kia whai waahi atu ki te āhua o ngā ratonga hauora, whaikaha hoki. Ko te noho mārama anō hoki e pehea nei te pai o te pūnaha hauora e mahi ana, ā, mēnā rā e āhei ana ki te akoako me te urutau. E ao ana te wā nei kia āta whakaarohia ēnei take nō te ratonga e whakawhiti ana ki ngā hanganga, me ngā whakahaeretanga tauira i raro i ngā whakahoutanga hauora a te Kawanatanga. Ko ngā rauranga me ngā hangarau matihiko kua tautohua hei mea whakakaha i ngā pūnaha hauora, whaikaha hoki.

Ko te rautaki me tōna mahere whakahaere hei ārahi i ngā mahi e hiahia ana i te rāngai (ki tua atu hoki) ki te whakahou i tā mātou whakahaere me te whakamahinga i ngā raraunga hauora. E ākina ana koe e au kia pānuihia ngā pukapuka e rua kia whaiwhakaaro e pehea ai koe e whakatinana i ngā whaikupu ki roto i ō ake roopu, ā, kia tautokona hoki ngā mahi o te pūnaha whānui.

Shayne Hunter
Deputy Director-General
Data and Digital
Ministry of Health

Executive summary

If we want a connected, equitable and sustainable health system that actively supports good health outcomes for all New Zealanders, we need to improve the way we collect, manage, use and share data and information. Ensuring people have access to and control of their own health information is essential, as well as making sure quality data is available for evidence-based decision-making. Data and information need to flow to the right parts of the health system, and to other sectors which influence and/or enable health and wellbeing.

This strategy describes the improvements we need to make to support better data management, governance and transparency. While this guidance is primarily for the health and disability sector, we intend for it to be of value to other sectors, social services, agencies, private providers and industries using health and disability data in New Zealand. The strategy should be read in conjunction with the accompanying roadmap.

The health sector is skilled at collecting vast amounts of data, but has struggled to convert this data into rich contextual information and useful insights. The transition from paper-based systems to digital health records has been slow, and most patient information collected cannot be easily accessed or shared across the system. Investment in digital technology has been ad hoc, and the sector as a whole is grappling with aging infrastructure.

At the same time, there are a number of significant drivers for change. These include obligations on the sector to address issues of equitable access and health outcomes and to act in accordance with the principles of Te Tiriti o Waitangi, increasing expectations of consumer participation, and new and emerging technologies. The Ministry of Health is collaborating with a wide range of sector organisations and industry partners to develop systems capable of responding to these drivers. In addition, the Government has announced structural changes for the sector that will also provide opportunities for improvement. Access to data to inform decision-making is going to be critical to realising the benefits of these changes.

Consultation across the sector (and beyond) during our development of this strategy identified the following areas in which we need to focus our effort: data foundations, equity and data sovereignty, consumer participation, people and leadership, and data accessibility.

Data foundations: stakeholders raised data quality as an issue requiring immediate action. Stakeholders saw a need for implementation of data standards within the sector and greater investment in data governance, data infrastructure and management practices.

Proposed actions include:

- establishing a national health data and information function to oversee implementation of the strategy and roadmap
- establishing a national terminology service and requiring use of Health Information Standards Organisation (HISO) standards and other health information, data and interoperability standards
- developing a national catalogue of health data compliant devices, tools and technology
- migrating national data collections to a new cloud platform designed for data science.

Equity and data sovereignty: robust and consistent data standards, collection methods, data quality and governance will help address disparities in health outcomes, such as those between Māori and non-Māori.

Proposed actions include:

- establishing a national health data sovereignty engagement framework and a wānanga to define a data and information approach that works for Māori
- developing equity measures for data standards
- developing resources and training to help address data bias.

Consumer participation: consumer representation in data governance is fundamental to ensuring that we make people-centred decisions.

Proposed actions include:

- providing a national health and disability data and information service to provide transparency for consumers in terms of the use and management of health data

- creating a way for consumers to manage authorisation of access to their health data
- encouraging greater consumer participation in data governance
- establishing a health consumer data right to provide clarity on issues such as data ownership
- ensuring that health information in electronic systems is available to consumers easily and free of charge.

People and leadership: the health and disability sector requires a health workforce skilled in data governance and use. We need to invest in building the sector's data literacy, governance and data capabilities.

Proposed actions include:

- developing training and resources to improve data literacy in the health and disability workforce
- encouraging greater sector investment in dedicated data roles
- establishing national and local health data governance councils, to partner with Māori and consumers, and to be representatives of local communities.

Data accessibility: we need to improve our ability to share health data within the sector and with others as appropriate (for example, with iwi and hapū, with private providers or with social services).

Proposed actions include:

- ensuring a national terminology service is integrated with the sector's new applications and platforms
- developing a health data sharing and accessibility framework.

The roadmap accompanying this strategy outlines our next steps and timeframes.

He whakarāpopototanga

Ki te hiahia tātou ki tētahi pūnaha hauora tūhono, tōkeke, toitū hoki e āta whai ana kia hua ake ngā putanga hauora mō ngā iwi katoa o Aotearoa, me whakapai ake te āhuatanga o te kohikohi, whakahaere, whakamahi me te tohatoha i ngā raraunga me ngā pārongo. He mea nui kia whai waahi ai te tangata ki tōna anō hauora me āna anō pārongo hauora, waihoki kia whakatūturu kia wātea ai ngā raraunga hei kōrero taunakitanga whakataunga. Me rere ngā raruranga me ngā pārongo ki ngā wāhanga tika o te pūnaha hauora, ā, ki rāngai kē atu e whai pānga ana, e whakakaha ana rānei i te toiora.

Ka whakamārama te rautaki i ngā whakapaitanga e hiahia ana mātou ki te tautoko i te whakahaeretanga pai ake i ngā raraunga, te mana whakahaere me te māramatanga. Ahakoa, whakawhaiti ana ēnei kōrero ārahi ki ngā rāngai hauora, whaikaha hoki, e takune ana kia whai take ai ki ētahi atu rāngai, arā ngā ratonga ā-iwi, ngā umanga, ngā ratonga o te tūmataiti me ngā ahumahi e whakamahi ana i ngā raraunga hauora, whaikaha hoki i Aotearoa. Me pānui tahi te rautaki me te mahaere whakahaere.

He tautōhito te rāngai hauora ki te kohikohi i ngā raraunga maha otiia, kua nonoke ki te whakatahuri i ēnei raraunga hei pārango whai take, hei mōhiohiotanga whai take hoki. He pōturi te whakawhitinga atu, mai i pūnaha pepa ki ngā pūnaha matihiko, ā, ko te nuinga o ngā pārongo mō ngā tūroro kua kohia mai he uaua ki te tomo, ki te toha haere hoki puta atu i te pūnaha. Kāore i āta maheretia te whakangao ki ngā haungarau matihiko, ā, ko te rāngai whānui e uaua ana te mahi me ngā rawa tahito.

I te wā kotahi anō, e ruarua ngā take nui hei panoni. Arā, ko ngā here ka tau ana ki te rāngai ki te kōrero i ngā take tōkeke tomo, ā, ngā putanga hauora me te whai i ngā mātāpono o te Tiriti o Waitangi, ngā kawatau nui o te tūroro whai waahi mai me ngā hangarau hōu te ara ake. E mahi tahi ana a Te Manatū Hauora me ētahi atu tūmomo roopu o te rāngai whānui me ngā hoa ahumahi ki te whakawhanake pūnaha e āhei ana ki te urupare atu i ēnei take. Waihoki, kua tauākītia e te Kawanatanga ka panoni nuitia ngā whakahaere mō te rāngai e puta ai ngā angitūtanga whakapaipai. Ko te tomo ki ngā raraunga kia whakamōhiotia ngā whakataunga e tino hira ana e pahawa ai ngā hua pai o ēnei panonitanga.

Ko te uiui haere puta i te rāngai (tua atu hoki) i te wā o tā mātou whakawhanaketanga i tēnei rautaki i tautohua ngā wāhanga e whai nei hei whakapau kaha mā mātou: ngā tuapapa raraunga, te tōkeke me te rangatiratanga o ngā raraunga, te whai waahitanga a te hunga kiritaki, ngā tāngata me te ārahitanga me te tomonga ki ngā raraunga.

 Ngā tuapapa raraunga: ko te hunga whaipānga i mea ake ko te kounga o ngā raraunga me huri tonu atu ki te whai hohenga. Ka kite i te hunga whaipānga i te hiahia kia whakatinana iho he taumata raraunga ki roto i te rāngai, ā, kia nui ake te whakangao mō te mana whakahaere o ngā raraunga, ngā rawa raraunga me ngā tikanga whakahaere.

Ngā tāpaetanga panonitanga e whai nei:

- ko te whakatū i tētahi mahinga raraunga, pārongo hoki kia whakahaere tikanga mō te

whakatinanatanga o te rautaki me te mahere whakahaere.

- ko te whakatū i tētahi ratonga kupu ā-motu, ā, e herea ana te whakamahi i tētahi Roopu Taumata Pārongo Hauora (HISO) taumata me ētahi atu pārongo hauora me ngā taumata whakawhitiwhiti.

- ko te whakawhanake i tētahi rārangi raraunga haora ā-motu me ngā ngohe pāraharaha, hangarau hoki.

- he whakawhitinga kohinga raraunga ā-motu ki tētahi kapua atamira hōu mō te pūtaiao raraunga.

Tōkeke me te rangatiratanga raraunga: ko ngā taumata raraunga kaha, auau hoki, ngā tikanga kohikohinga, ngā raraunga kounga me te mana whakahaere e tautoko ai i te whakatikahanga i ngā wehenga tōrite hua hauora, pēnei me ērā i waenga i te Māori me iwi kē atu ehara i te Māori.

Ngā tāpaetanga panonitanga e whai nei:

- ko te whakatū i tētahi anga raraunga hauora mana rangatiratanga ā-motu, ā, kia wānangahia he tikanga kohikohi raraunga, pārongo hoki e pai ai ki te Māori.

- ko te whakawhanake i ngā whakaine taumata tōkeke.

- ko te whakawhanake i ngā rauemi me ngā whakangungu e kite ai i te mariutanga raraunga.

Te whai waahitanga a te kiritaki: ko te whakakanohitanga kiritaki i te mana whakahaere raraunga he mea nui mā mātou kia noho ko te kiritaki hei uho o ngā whakataunga.

Ngā tāpaetanga panonitanga e whai nei:

- kia whakarawe mai he ratonga raraunga hauora, whaikaha hoki ā-motu kia mārama ai ngā kiritaki mō te āhua o te whakamahinga me te mana whakahaere o ngā raraunga hauora.

- kia waihanga ake he ara ki ngā kiritaki ki te whakaae atu ki te tomonga ki ā rātou raraunga hauora ake.

- kia ākina ngā kiritaki ki te uru ki ngā mahi mana whakahaere raraunga.

- kia whakatū mai i ngā matatika kiritaki kia mārama ai ki ngā take nā wai ngā raraunga.

- kia taea noatia ai e ngā kiritaki te toro atu ki ngā pārongo hauora i ngā pūnaha hiko, kia utu kore.

Ngā tāngata me te ārahitanga: me whai te rāngai hauora, whaikaha hoki tētahi hunga kaimahi e pūkenga ana ki te whakahaere raraunga, whakamahinga hoki. Me whakangao e mātou ki te mōhiotanga raraunga o te rāngai nei, mana whakahaere me ngā āheinga raraunga.

Ngā tāpaetanga panonitanga e whai nei:

- he whakawhanake whakangungu me ngā rauemi ki te whakapai ake i te mōhiotanga raraunga i te hunga kaimahi hauora, whaikaha hoki.

- he āki kia nui ake te whakangao rāngai ki ngā tūranga pūmau raraunga.

- ko te whakatūnga i ngā kaunihera mana whakahaere ā-rohe, ā-motu kia hoa haere ki te Māori me ngā kiritaki, ā, hei whakakanohi i ngā hapori.

Te tomonga raraunga: me whakapai ake e mātou tā mātou āheinga ki te toha i ngā raraunga hauora i roto i te rāngai me ētahi atu mēnā ia e tika ana (arā, ko ngā iwi, hapū me ngā ratonga tūmataiti, ratonga ā-iwi rānei).

Ngā tāpaetanga panonitanga e whai nei:

- ko te whakatuturu iho i te ratonga kupu ā-motu e kōtuia ana ki ngā pūmanawa tautono, atamira hōu o te rāngai.

- ko te whakawhanake he anga tohatoha, tomonga raraunga hauora.

Ko te mahere whakahaere i tēnei rautaki e whakamārama ana i ngā mahi te haere ake nei me ngā angawā.

Overview

Data is the bedrock of an evidence-based health and disability system.

Data can tell us about the health and wellbeing of people, whānau and communities and provide powerful insights into issues of health access, outcomes and equity. These insights can help transform the delivery of population health programmes and personal health services to improve the health of New Zealanders. Ensuring people have access to and control of their own health information is fundamental to this, as is ensuring clinicians, health managers, policy-makers and communities have the data they need for good decision-making.

Data and information need to flow in a timely way to the right parts of the health system, and to other sectors that influence or enable health and wellbeing.

If we want a connected, equitable and sustainable health system that actively supports good health

outcomes for all New Zealanders, we need to improve the way we collect, manage, use and share data and information. Improving our management of data and modernising our approach to data will improve our ability to deliver personalised and predictive health care and move from treating disease towards focusing on prevention and wellness.

This strategy aims to provide guidance for the health and disability sector by describing the improvements we need, the current context and challenges and the engagement we have undertaken to develop our priorities. We intend that this strategy will also be of value to other sectors, social services, agencies, private providers and industries using health and disability data or contributing to health and disability outcomes. The strategy should be read in conjunction with the accompanying roadmap, which outlines actions and timeframes for bringing this strategy to life.

The case for change

New Zealand's heath system generates large amounts of data, but collectively we are not effectively ensuring that data flows to the right places and is available to the right people in the right ways. Some important data is not collected, and we lack clarity on how best to use the data we do collect. Smarter use of existing data must be a focus, as well as collecting new data as a by-product of the system addressing unmet need.

We face the following challenges.

- The health sector is skilled at collecting vast amounts of data, but has struggled to convert it into rich, useful contextual information for decision-making.

- The transition from paper-based systems to digital health records has been slow and somewhat siloed across the sector.

- Successes in the past have left legacy systems that are no longer fit-for-purpose in domains where New Zealand was previously a leader (for example, primary care information systems and collation of national data collections).

- Most patient information we collect cannot easily be accessed and shared across the system.

- It is difficult for consumers to access their own health information or to consent to their personal information being shared with whānau and caregivers.

- Innovation in data management has not kept pace with demand or the development of tools to use and analyse data.

- Investment in digital technology has been ad hoc across the sector, affecting the quality of data we collect.

- While organisations generally understand their responsibilities regarding clinical data, they do not see that they have an obligation to routinely share data.

The sector as a whole is grappling with aging infrastructure, limited mechanisms for accessing data and information, workforce shortages and data literacy challenges.

The Ministry of Health's *Report 1* on the National Asset Management Programme (Ministry of Health 2020c) noted:

> *'New Zealand has lacked the investment levels necessary to embrace rapid changes in health IT technologies … IT strategy, governance and asset management have operated at a basic level. There are multiple versions and customisations of core applications, ageing infrastructure, limited network capacity and devices not fit for purpose. This reduces productivity, increases costs for maintenance and support and increases cyber security risk.'*

The Appendix to this document outlines the challenges and opportunities in more detail.

Drivers for change

Te Tiriti o Waitangi

Te Tiriti o Waitangi underpins all relationships between the Crown and iwi, hapū and whānau. The Crown is expected to act consistently with regard to the principles and articles of Te Tiriti o Waitangi. The health and disability sector has a commitment to fulfilling the special relationship between Māori and the Crown under Te Tiriti o Waitangi. This is necessary to realise the overall aims of He Korowai Oranga: Māori Health Strategy (Ministry of Health 2014) and Whakamaua: Māori Health Action Plan 2020–2025 (Ministry of Health 2020d).

This strategy aligns with the charter developed by Te Mana Raraunga, the Māori Data Sovereignty Network (Te Mana Raraunga 2016). Under that charter, all health professionals, organisations and agencies should respect, care for and share health data and information and recognise that:

- data is a living tāonga and is of strategic value to Māori

- Māori data refers to data produced by Māori or which is about Māori and the environments Māori have relationships with

- Māori data is subject to the rights articulated in Te Tiriri o Waitangi and the United Nations Declaration on the Rights of Indigenous Peoples, to which New Zealand is a signatory.

Health equity

The health and disability system has a core responsibility to address inequities in health and wellness. Differences in health outcomes for Māori, Pacific peoples, disabled people in particular are both long-standing and well-documented. Inequities in health outcomes are driven by socio-economic factors outside of health, but also by access to services and treatment within the health and disability system. The Ministry of Health has adopted the following definition of equity: "In Aotearoa New Zealand, people have differences in health that are not only avoidable but unfair and unjust. Equity recognizes that different people with different levels of advantage require different approaches and resources to get equitable health outcomes."

There is a role for better access to and use of data and information to assist with the goal of achieving equity. Monitoring of inequities requires the collection of good quality data and analysis using well-chosen metrics. Decision-making about how to address inequities within the system requires that data is fit-for-purpose and is used to bring about positive change. Access to data and information can be a powerful tool to empower groups to take greater control over their own health outcomes. To support this the system must be responsive to the data needs of consumers and communities. Action in each of these areas is more likely to be effective if we involve representatives of groups that experience significant health inequalities in the governance of data.

Consumer expectations

New Zealanders engaging with health and disability services have certain expectations that the current system only partially meets. People expect to be in control of their own health information and to be able to choose how they share this information. They do not want to provide the same information repeatedly to different health professionals in order to access care. They expect health professionals to have all of the information they need for diagnosis and treatment at their fingertips. As consumers of health services, they expect their interactions

with the health system to match or exceed the interactions they have in other parts of their lives.

When they have access to their own health information and are able to contribute to their health records, people can make decisions about their health and wellbeing and how they interact with the health system.

Sector change and system enablers

The health and disability system reforms (DPMC, 2021) commissioned by the Government emphasised the importance of ensuring consumers, whānau and communities are at the heart of the system, and identified data and digital technologies as key system enablers (among others). The Health and Disability System Review (HDSR, 2021) noted the need to move 'from an ecosystem of tens of thousands of systems that do not easily connect, to a system that routinely shares data and more effectively supports all those working in or using the system'.

The review identified quality data as critical for:

- consumer empowerment
- improved patient safety, care and outcomes – ensuring clinicians can see complete, up-to-date patient data across the continuum of care
- new models of care that require multiple clinicians across different settings to have access to real-time patient data to support multi-disciplinary care
- decision-making and research that require timely access and analytical capacity to extract meaning from large data sets.

In April 2021, the Government announced structural changes (Beehive, 2021) to improve the equitable delivery of health services and health outcomes.

The reform announcements included five key outcomes the Government expected of the system - equity of access and outcomes; partnership with Māori; sustainability via a focus on prevention of ill health; person and whanāu-centred care; and

excellence in leadership and quality of services. In practice, the system will need to:

- reinforce Te Tiriti principles and obligations
- provide access to a wider range of care and support in the community for everyone
- provide emergency and specialist care that is accessible and consistently outstanding
- enable digital services that are far more accessible, making close-to-home care far more common
- value and support for health and care workers.

To enable each of these outcomes, the government wants to build a system that is much more focussed on delivering value through data. To achieve this, a step-change in data capability is required, aiming to achieve higher quality data, more sharing, improved access, better insights and an enhanced capability to act on insights. The system must rapidly build new data infrastructure and platforms that support interoperability and sharing, implement common data standards to improve quality, and increase the capability for analytics and intelligence to inform planning and the delivery of care.

The reforms provide us with opportunities to further accelerate work within the sector to create an ecosystem of insight-rich data and interoperable digital technologies. The Ministry of Health has been collaborating with sector leaders and organisations, industry partners and developers, government agencies and clinical groups on a wide range of significant initiatives to this end.

The work under way with the sector on the Hira programme, for example, will transform consumers' access to and use of health and disability information. Hira will draw together a person's latest health information as needed to create a single view; a virtual electronic health record rather than a single electronic health record. This work will deliver key components of the Ministry's Digital Health Strategic Framework (Ministry of Health, 2019a).

Emerging technology

The potential benefits of digital technologies in health are limitless. We need a modern data-rich environment to make use of new and emerging technologies such as wearables, genomics and precision medicine, robotics, cloud services, natural language processing, machine learning and artificial intelligence. These tools, along with technologies not yet invented, will enable disruptive innovation and insights in health care, to optimise diagnosis and treatment and to give us a better understanding of how the system is performing and responding to change. Emerging technologies have the potential to enhance the consumer experience in health and further move us towards a consumer-centric approach to delivering health care.

The health and disability sector is complex. A range of drivers have influenced the development of this strategy. Figure 1 illustrates this.
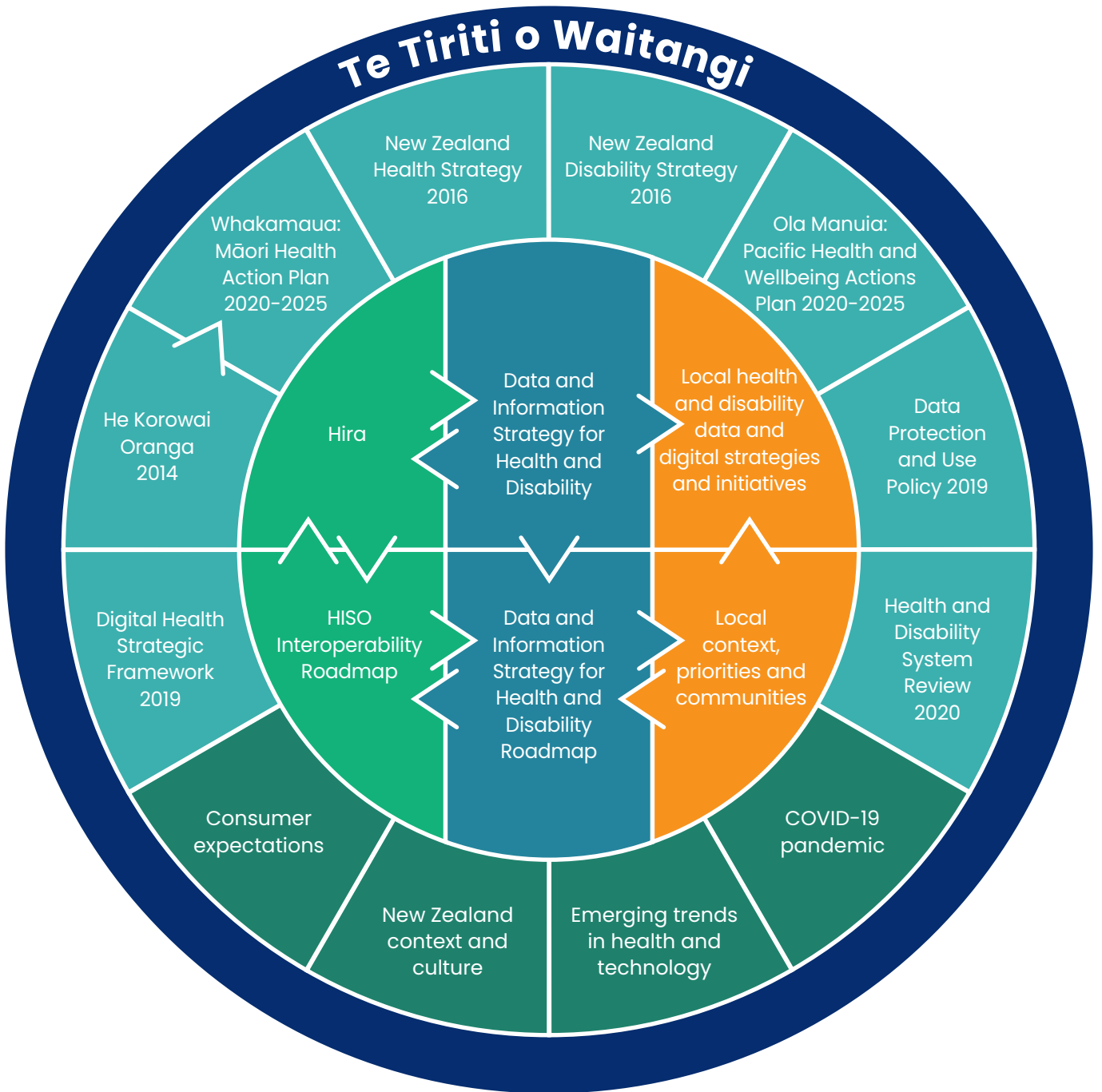
Values and behaviours

Underpinning this strategy is a set of guiding values and behaviours outlined in the Data Protection and Use Policy of New Zealand (Social Wellbeing Agency 2019), which was developed to ensure that the ways that social sector (including health and disability) organisations use and manage data reflects the expectations of New Zealanders.

The values and behaviours set out in the Data Protection and Use Policy are intended to reinforce each other and illustrate what 'doing the right thing' looks like in the context of collecting and using people's data and information. For example, people expect that:

- health and disability providers, organisations and agencies will share a common approach in the way they work with people and their information

- health and disability providers, organisations and agencies will work inclusively to develop and share valuable insights that result in the improved health and wellbeing of people and communities

- people who use health and disability services will know what to expect, and will have confidence in the way health providers use their personal information.

The five values and behaviours that underpin this strategy are as follows.

He tāngata: Focus on improving people's lives — individuals, children and young people, whānau, iwi, and communities.

Manaakitanga: Respect and uphold the mana and dignity of the people, whānau, communities or groups who share their data and information.

Mana whakahaere: Empower people by giving them choice and enabling their access to, and use of, their data and information.

Kaitiakitanga: Act as a steward in a way that is understood and trusted by New Zealanders.

Mahitahitanga: Work as equals to create and share valuable knowledge.

He tāngata has a special role: it wraps around all of the principles. It reminds us that everything we do with data and information should be done with the following question in mind: 'how does this contribute toward the health and wellbeing of the individual or community?' For example, we must:

- strive to create positive outcomes from any collection, sharing or use of health data and information

- use appropriate checks and balances, and ensure that information is suitable and reasonably necessary for the intended outcome.

Manaakitanga reminds us to:

- recognise and incorporate diverse cultural interests, worldviews, perspectives and needs

- include and involve consumers whenever possible

- incorporate the needs and priorities of people with a specific interest in what is done with their data and information.

Mana whakahaere reminds us to:

- give people easy access to and oversight of their information wherever possible.

Kaitiakitanga reminds us to:

- be open and support people's need to understand

- keep data and information safe and secure, and respect its value

- act swiftly in the event of a privacy breach.

Mahitahitanga reminds us to:

- confidentially share relevant information between professionals as needed

- share (de-identified) data, analysis, results and research findings to build collective knowledge and improve health and disability services.

Identifying what matters

A key task for the development of this strategy has been to understand the issues, barriers and priorities for consumers and people working in, and providing leadership to, the health and disability sector. We carried out consultation both online and face-to-face through video-conferencing, a digital survey and discussions within existing networks and regular meetings. We converted some planned in-person hui to digital engagements during the COVID-19 response. Our consultation process involved health and disability system organisations, government agencies and consumers.

1037
New Zealanders

720
Survey responses

43
In-person or virtual hui

Our consultation identified the following as important requirements in the context of the development of a data and information strategy for health and disability:

- a clear focus on improving health outcomes, addressing health inequities (particularly for Māori, Pacific peoples and disabled people) and providing consumer-centred care

- a need for better quality data and information across the health and disability system

- making data more accessible and able to be shared appropriately, and removing information silos

- improved access to de-identified data for research and innovation, and to develop modern public health and population health initiatives

- greater collaboration across health and social systems, to enable more effective use of data

- leadership to establish data governance across the health system, with an emphasis on data sovereignty, including partnering with consumers and Māori

- more explicit guidance from government agencies on data sharing and accessibility

- a mandate or regulation from government agencies to accelerate interoperability and data accessibility through the implementation of data standards, where applicable

- support and resourcing for the health and disability workforce to become more data literate, more innovative, better data leaders and more effective at data governance and stewardship.

Priorities for improvement

As a result of the consultation and engagement process, we developed five priority areas for improving data use and management: data foundations, equity and data sovereignty, consumer participation, people and leadership, and data accessibility. These are the focus of this strategy.

Data foundations	Equity and data sovereignty	Consumer participation	People and leadership	Data and information accessibility

The following sections describe these in more detail.

Data foundations

The health and disability sector needs good data foundations to achieve a modern data and information system, including quality national data collections, standards, and data collection and use that enables timely and accurate health research and innovation at national and local levels. During our engagement with the sector, stakeholders raised data quality as an issue requiring immediate action. Improvements in data quality would support greater interoperability and provide us with insights that could then drive system transformation. Stakeholders saw a need for implementation of data standards within the sector and greater investment in data governance, data infrastructure and management practices.

Improvements to our approach to managing data and information will ensure that data are more accessible and stored in more consistent formats, enabling data access and sharing so the system can develop and use real-time insights for decision-making. The system must ensure data informs performance improvements, new models of care, policy, investment and funding decisions.

Specifically, there is a need to:

- develop a consistent information management operating model
- accelerate the implementation of data standards
- publish consistent data architecture and models
- develop and publish data-sharing frameworks
- adopt a data-first approach to procurement whereby data quality, standards and interoperability are prioritised in requirements and selection.

The implementation of cloud technologies and platforms will improve data sharing capabilities and enhance business intelligence, data science and innovation.
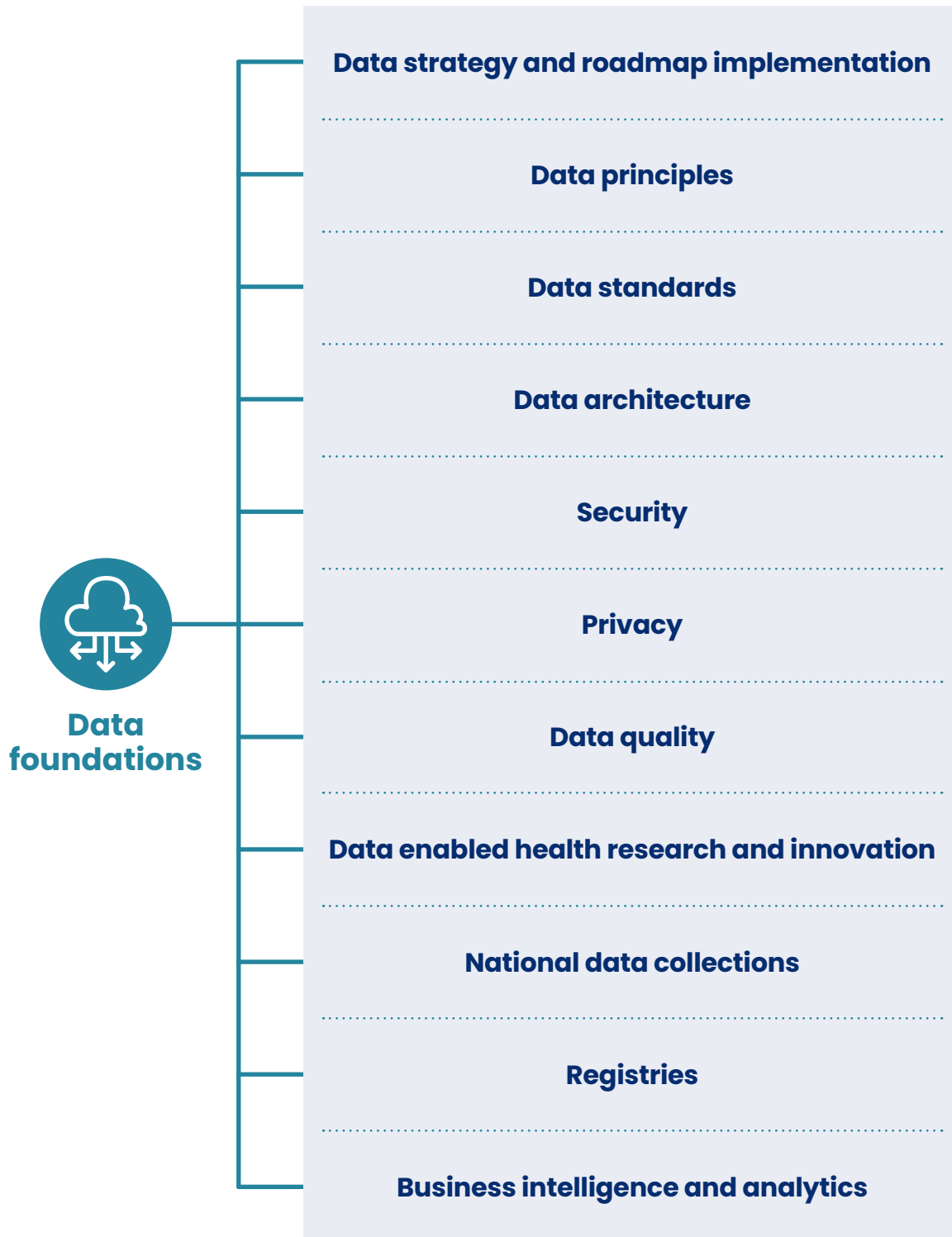

To adopt a consistent approach to the use and deployment of health information technology across New Zealand, the following **data architecture principles** should apply:

- Data is treated as a shared asset/resource: Data is an asset that has value to consumers, health providers and the health and disability system as a whole and is managed accordingly.

- Data is secure and accessible: Data is protected from unauthorised use and disclosure. As well as the traditional aspects of national security classification, this includes protection of sensitive, proprietary and evaluation information. Data is accessible for users to perform their functions.

- Data is understandable: Data is defined consistently throughout the health and disability sector, and users understand what it means.

- Data quality is specified and managed: Data standards specify the qualities of data elements required to meet business process needs, as well as clinical and organisational decision-making. Regular monitoring and measurement ensure compliance with data quality standards.

- Data copies are minimised: Any time data is moved or copied, precious time and resources are consumed and data fidelity is potentially compromised.

Enablers

In the roadmap that accompanies this strategy, the first two years focus on addressing the set of data foundation enablers we need to support a modern health and disability system. We will need to carry out ongoing work to maintain these data foundations.

We have identified the following enablers for data foundations:

Data foundations

- **Data strategy and roadmap implementation**
- **Data principles**
- **Data standards**
- **Data architecture**
- **Security**
- **Privacy**
- **Data quality**
- **Data enabled health research and innovation**
- **National data collections**
- **Registries**
- **Business intelligence and analytics**

Data strategy and roadmap implementation

We will establish a national health data and information function to oversee and manage implementation of the strategy and roadmap. This will include new roles and capability at a national level with support at the local level.

Responsibilities will include:

- confirming the data and information priorities for Health NZ, the Māori Health Authority, the Ministry of Health and other key agencies
- development of a data and information management operating model that can be reused and scaled across the sector
- development and publication of companion documents and activities to support the five themes of this strategy
- establishing a sector data and information maturity model and assessments for benchmarking and measuring progress that includes Māori data maturity and makes use of an all-of-government approach (Stats NZ, 2021a)
- refreshing the roadmap
- establishing sector working groups to support delivery
- reviewing, managing and coordinating the programme of work and delivery targets.

Data principles

We will support the sector-wide adoption of current data principles, including those outlined in the Data Protection and Use Policy and the data architecture principles. We will develop and publish information management principles.

Data standards

Data standards specify the qualities of data elements required to meet business process needs and decision-making. We need to undertake regular monitoring, measurement and change management to ensure compliance with data standards.

This enabler requires:

- the establishment and ongoing maintenance of a national terminology service
- increased requirements for the health and disability sector and industry to use HISO and other health information data and interoperability standards
- local organisations to implement tools and mechanisms to maintain data standards, and to document and audit data provenance.

Data architecture

We will establish a national health data architecture capability in the national health data and information group, and develop national tools such as shared platforms and apps to support the health and disability sector.

Security

We will develop a national catalogue of health data compliant devices, tools and technology.

Privacy

We will continue to implement protections and consumer controls over New Zealanders' health and disability data and information while ensuring data is safely accessible in the many places it is required.

Data quality

We will develop a national health data catalogue/dictionary and a framework detailing the minimum standards for data compliance in sector contracts and commissioning arrangements.

Data enabled health research and innovation

We will establish a data service for researchers and innovators, supporting health care improvements through near real-time data-driven insights.

National data collections

We will migrate national data collections to a modern national platform designed for data science that is able to efficiently perform machine-learning activities. The platform

will enable the Government to consolidate and transform large data sets so they are analytics-ready.

Registries

We will transition registries into modern domain-specific data services that support service quality assurance and improvement.

Business intelligence and analytics

We will collaborate across the sector, sharing and scaling tools, platforms and resources to reduce duplication. We will provide mechanisms for health professionals, researchers, innovators and decision-makers to access data-driven insights.

Equity and data sovereignty

This strategy supports the partnership between Māori and the Crown, underpinned by Te Tiriti o Waitangi. Disparities in health outcomes between Māori and non-Māori have been the subject of numerous reports ever since the 19th century. Good practices for data collection and the use and sharing of information are essential if we want to create a health and disability system that is more equitable.

Equity and data sovereignty are individually important themes that affect Māori and other groups in New Zealand. These two themes are intrinsically interlinked; we have therefore combined them into a single priority for the purposes of this strategy.

Inequities in health outcomes are prevalent in many specific population groups within New Zealand, including Pacific peoples, disabled people and people living in poverty. We need robust, reliable and consistent data standards, collection methods, data quality and governance to address these inequities.

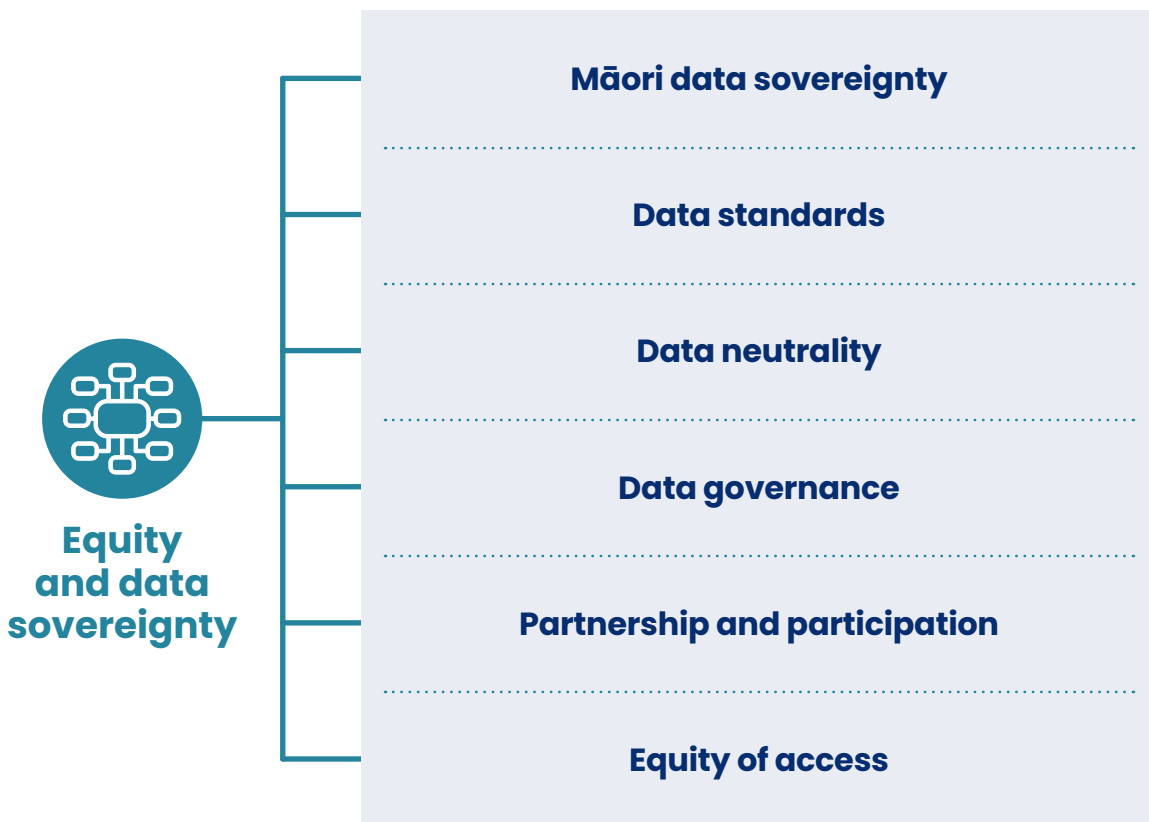One in four New Zealanders has a physical, sensory, learning, mental health or other impairment. The New Zealand Government has committed to collecting better data about disabled people and addressing health inequities between disabled and non-disabled people.

There is a risk of introducing more inequity into the health and disability system with the introduction of new digital technologies, if not all New Zealanders are able to access these technologies or benefit from them. At the same time, digital solutions can provide services, data and information that improve equity. The insights we can gain from data and information will help the sector to prioritise opportunities to target inequity and to improve health for those with the poorest outcomes. A key way we can do this is by partnering with Māori and embracing co-design of programmes of work that aim to ensure Māori have the information needed to make evidence-based decisions. This principle is about about collecting the right data for Māori and ensuring that it is available for use by iwi and Māori health providers.

Enablers

We have identified the following enablers for equity and data sovereignty:

Equity and data sovereignty

- Māori data sovereignty
- Data standards
- Data neutrality
- Data governance
- Partnership and participation
- Equity of access

Māori data sovereignty

We will establish a national health data sovereignty engagement framework and a wānanga to define the data and information approach that best works for Māori, by Māori. A Māori data sovereignty education/literacy approach should be included in data literacy initiatives.

Data standards

We will develop equity measures for data standards in collaboration with HISO and Stats NZ, covering data collection methods and data models that ethically capture data for all New Zealanders.

Data neutrality

Organisations and industry have a responsibility to understand, neutralise and mitigate disparities of health care provision and outcomes resulting from data bias and artificial intelligence and machine-learning design that may compound the effects of data bias. We will develop resources and training to help address data bias.

Data governance

We will prioritise co-design with Māori on health data governance approaches and decision-making as part of a national health data sovereignty engagement framework.

Partnership and participation

We will assist health organisations to meet their responsibilities to engage with local iwi and community groups, to better understand local requirements, to develop partnerships and to meet their obligations under Te Tiriti o Waitangi.

Equity of access

We will ensure equitable access to information by addressing issues pertaining to literacy levels, accessibility, mode of delivery and cultural differences.
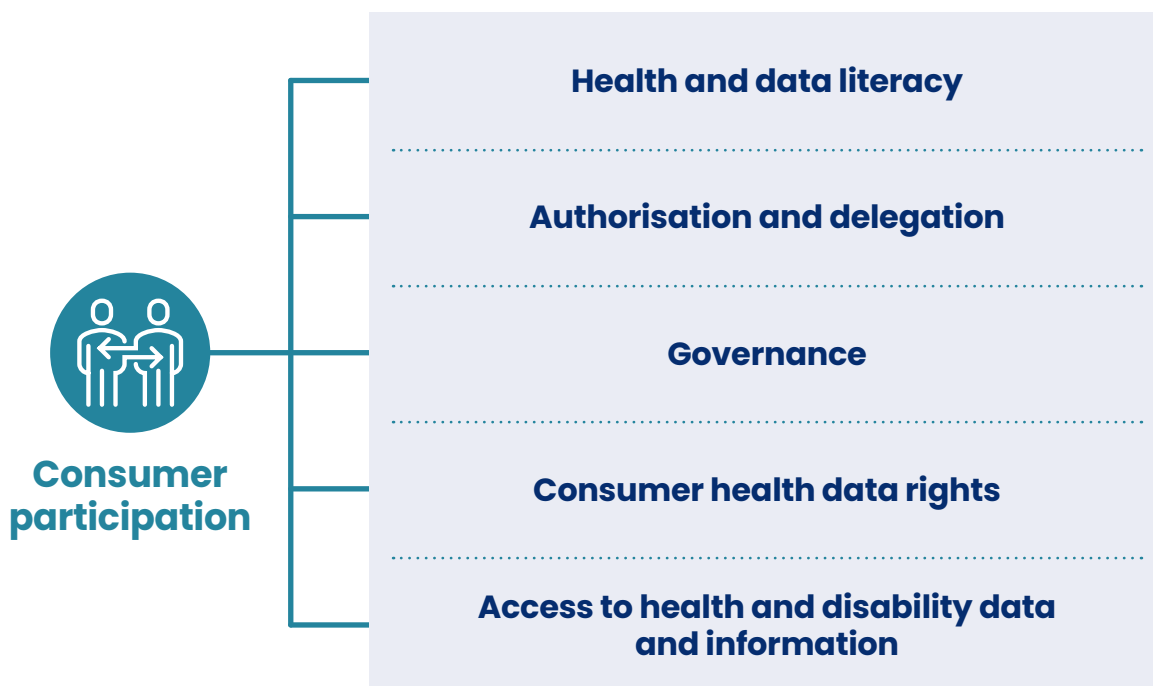
Consumer participation

All people should have access to their health records so they can actively manage their own health and wellbeing. Consumer representation in data governance is fundamental to ensuring that our approach to health data management meets consumer expectations.

New Zealanders currently have limited access to their own health and disability data and information. Due to the sector's fragmented and siloed approach to collecting, sharing and storing data, people are often asked to repeat their health information to a succession of providers as they navigate the health system. Differences in digital and data literacy, and a growing digital divide, mean that not all people are able to interact digitally with the health and disability system.

Improving data literacy is a key step to improving this situation. The health and disability sector should provide consumer-focussed information about how health and disability data is used, making sure to incorporate the perspectives of consumers and their whānau to show the value of data to health care. People should be able to trust in the quality, security and privacy of their health and disability data, and be able to access, update, contribute to and – as needed – correct their own health information. People need to be able to authorise or delegate access to their health information (for example, to whānau members), and see the details of access that has been granted to others. People also need to be able to report on their own health outcomes, through consumer experience and outcome measures.

Enablers

We have identified the following enablers for consumer participation:

Consumer participation

- **Health and data literacy**
- **Authorisation and delegation**
- **Governance**
- **Consumer health data rights**
- **Access to health and disability data and information**

Health and data literacy

We will provide a multi-channel national health and disability data and information service that enables people to find out how data is used and why, what safeguards are in place, how decisions are made and what they can expect from health professionals and health and disability providers regarding the use of their data. Such a service will ensure transparency and build the public's support and trust.

Authorisation and delegation

We will develop a way for consumers to manage authorisation of access (and delegated access) to their health data. This will require developing a national authorisation and delegation framework and implementing a national digital health identity programme.

Governance

We will provide education and support to encourage greater consumer participation in data governance at local and national levels.

Consumer health data rights

New legislation may be required to establish a health consumer data right and supporting health provider responsibilities. This would provide the sector with clarity on the question of data ownership and the mandate for data use for system stewardship, research and innovation.

Access to health and disability data and information

Health providers, policy-makers and industry must provide mechanisms that allow consumers to have full access to all of their health data and information, including all patient notes, test results, images, appointments, assessments, letters and reports. Additional legislation may be required for this purpose. Health information contained within electronic systems must be made available free of charge to consumers, and people must be able to update, contribute to and - as needed - correct their own health information.

People and leadership

The health and disability sector requires a workforce skilled in data governance and which uses and respects data as a taonga. Central to this is the sector's responsibility to act in accordance with its role as the kaitiaki, rather than the owner, of health data and information.

The Health and Disability System Review (HDSR 2020) advised that for the health and disability system to get the most value from investment in digital transformation, investment will be needed in people as well as processes and technology. The planned shift of much of the health workforce to Health NZ will require accurate workforce data. Investment in building human capability and a data-savvy workforce is essential to creating a data-driven health system. About 220,000 people currently work in the health and disability sector, with varying levels of data literacy. Improving data quality would benefit health leaders relying on evidence for decision-making, increase their confidence in the use of data, and improve the sector's workforce planning and development. New and emerging health data roles will also require investment and resourcing, so that we can improve the way we manage, use and interrogate data. We need to be able to make the most of emerging technologies reliant on rich data sets.

Data and information leadership and governance needs to take both system-wide and local approaches. If we wish to accelerate progress, sharing knowledge and resources, and scaling and reusing tools and capability will be essential.
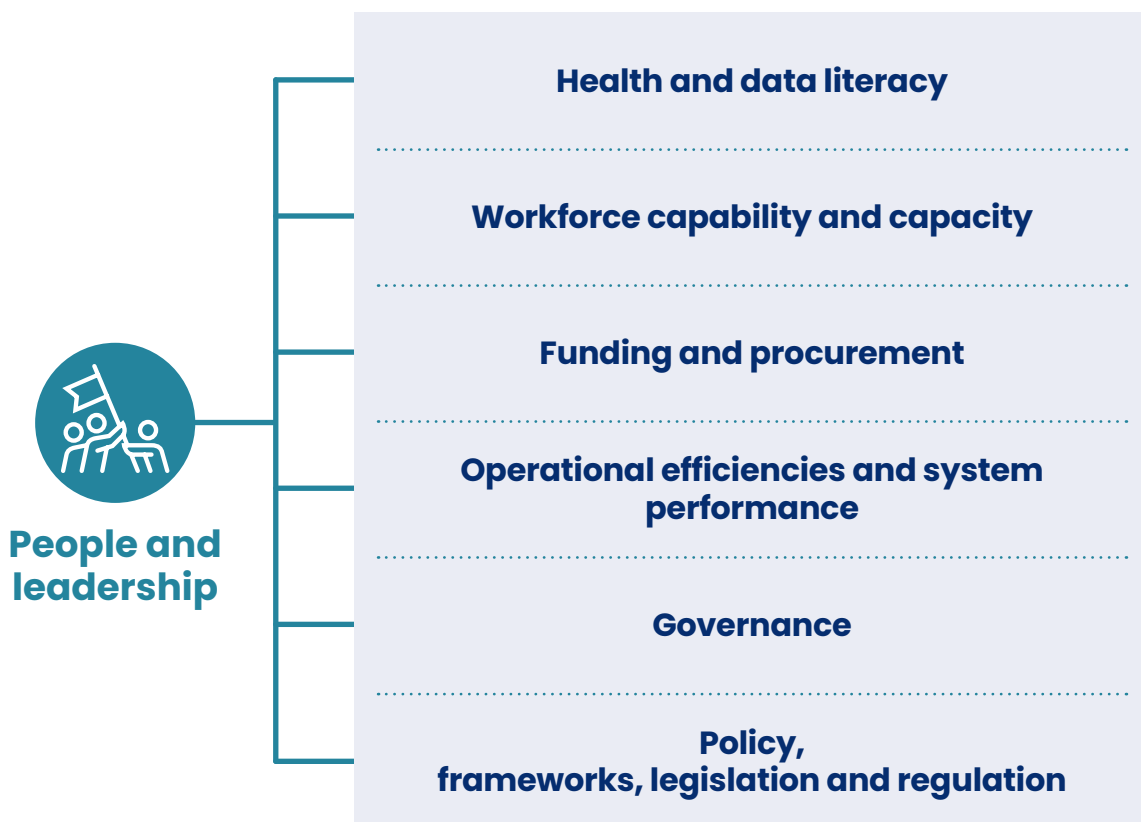
Specifically, we need to:

- work together at a systems level, developing a data governance network to coordinate and collaborate across the health and disability sector

- develop rules and guidance on who can share and access data and for what purposes, with clarity on decision-making powers and accountabilities

- ensure ethical use of data and information for secondary purposes, such as research

- develop guidance on how to store, access and manage data with respect for data sovereignty and consumer rights

- enable innovation and support the lifecycle from research to innovation to initial adoption and then enable the scaling of this via replication across the system

- use data to drive decision-making across the system to support operational performance gains and monitor system performance

- improve access to data for innovators and researchers by creating a data service that will help accelerate innovation within the sector

- enhance public trust and confidence by implementing good governance mechanisms, including clear information on good practices, terms of reference, roles and responsibilities

- ensure the participation of and representation from local communities, reflecting diversity and inclusive of consumers, family/whānau and Māori in data governance and the co-design of data management systems at both national and local levels.

Enablers

We have identified the following enablers for people and leadership:

People and leadership

- **Health and data literacy**
- **Workforce capability and capacity**
- **Funding and procurement**
- **Operational efficiencies and system performance**
- **Governance**
- **Policy, frameworks, legislation and regulation**

Health and data literacy

Data literacy is the ability to read, work with, analyse and communicate with data. Such literacy is a skill that empowers health workers at all levels to ask the right questions of data, build knowledge, make decisions and communicate with others. We could improve data literacy for health workers through a range of initiatives at all levels, from undergraduate and technical training providers through to local employers or national literacy programmes.

Workforce capability and capacity

New data roles are emerging, and more will be required in the future as the sector matures in its approach to data management. National and local organisations will need to invest in dedicated data roles to support better information management literacy, practices and capability.

Funding and procurement

Funding and procurement mechanisms need a data-first approach, making use of existing investment and embedding the approach into health system operations.

Operational efficiencies and system performance

Data-informed decision-making could lead to operational improvements and a better ability to monitor the system's performance. Access to real-time operational data allows business decision-making to happen at pace, and enables us to monitor and adjust the system in response to changing demands. A whole-of-system view of data will provide us with longer-term insights to enable strategic planning and new models of care.

Governance

This strategy and roadmap have identified a need for national and local health data governance councils, for partnership with Māori and consumers and for our systems to be representative of local communities, including Pacific communities.

Data governance is foundational to ensuring compliance with data standards, architecture, privacy, security and sharing requirements, and for improved collaboration, networking and sharing of scarce resources. Data governance that enables innovation and research through improved access to de-identified or synthetic data will support the development of new models of care and improve the way we deliver health and disability care. We will support our heath data governance through development of a framework that is co-designed with consumers and Māori. We will need to implement data governance training at board and executive levels, and for all people on data governance councils.

Policy, frameworks, legislation and regulation

We will work to define the regulatory, legislative and policy changes we need to make to accelerate implementation of this strategy and its companion roadmap. Legislative changes may be required to support improved data access for consumers and to meet the Crown's obligations under Te Tiriti o Waitangi with respect to health data and data sovereignty.
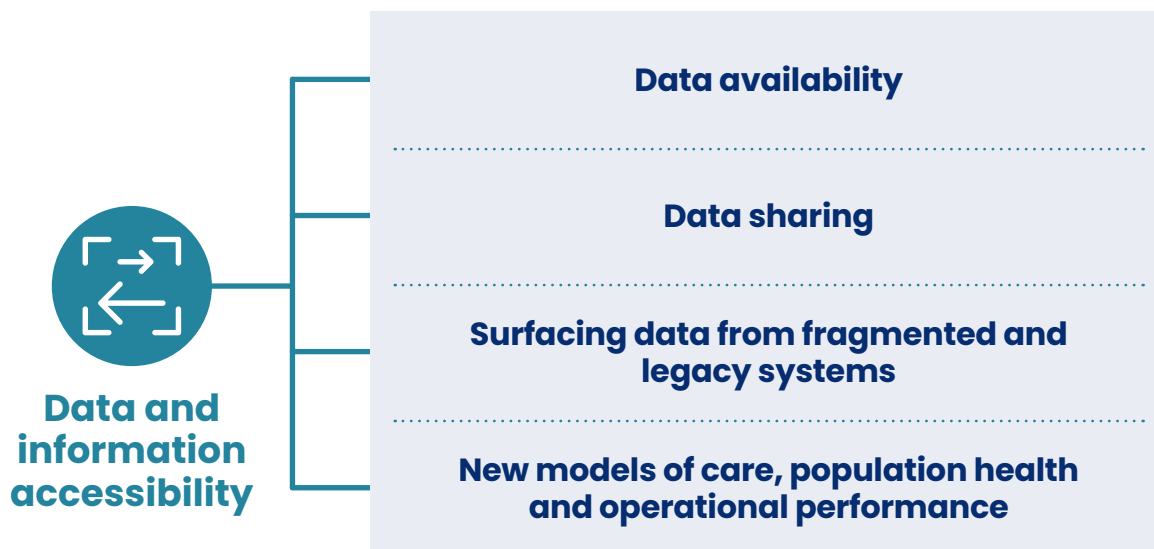
Data and information accessibility

Much health and disability data and information is siloed within organisations. While most organisations and providers understand their responsibilities regarding clinical data, they do not see that they have an obligation to routinely share data with consumers, other health providers or other services. While some parts of the health system have established mechanisms for sharing data between primary and secondary care, there is little access to health and wellbeing data in the community, for iwi and hapū, for private providers or social services, or to data held or generated by consumers. Making health data more accessible and useful is fundamental to improving the health outcomes of all New Zealanders.

We need effective data sharing frameworks, authorisation and delegation frameworks and sector contract requirements, along with mechanisms to better support innovation and research. Improving how the sector manages and codes health data will support data accessibility and interoperability. Much data is currently held in inconsistent formats and code sets. Providing mechanisms to share, reuse and maintain clinical data will support the quality of data being shared, the consistency of reporting and the quality of the insights we can gain through analytics and machine learning.

Enablers

We have identified the following enablers for data and information accessibility:

Data and information accessibility

- **Data availability**
- **Data sharing**
- **Surfacing data from fragmented and legacy systems**
- **New models of care, population health and operational performance**

Data availability

The use of a national terminology service will improve data quality at the point of care, and provide more context to health information for both clinicians and consumers. Providers would need to integrate this service with new applications and platforms through their contract and procurement arrangements.

Data sharing

If we want to create an ecosystem in which health data is effectively shared or made appropriately accessible, we will need to develop guidance for the sector, which in turn will require new frameworks. The development and implementation of a new health data sharing and accessibility framework will be critical to making data more accessible in ways that are consistent with public and consumer expectations. We will support new provisions for data sharing and accessibility through changes to contracts and procurement systems and a review of legislation, including the Privacy Act 2020 and Health Information Privacy Code.

Surfacing data from fragmented and legacy systems

There is a need for the system to provide access to data rapidly, even where application consolidation and the replacement of legacy systems can only happen in the longer term. We can realise the value from data in the short and medium term by ensuring data can flow from fragmented and legacy systems into modern platforms that provide access for analytical and decision-making purposes.

New models of care, population health and operational performance

We need to develop new models of care and population health measures to address inequities in care provision and outcomes and ensure all New Zealanders enjoy good health and wellbeing. We can use the insights we derive from big data sets to improve the health system's operational performance. We will need to develop access to big data and agreements about access and use.

Next steps

Improving the sector's governance, use and sharing of data and information will require a high degree of collaboration across organisations, nationally and locally. If health data is the bedrock of the health and disability system, then the priority areas outlined in this strategy are its essential components.

The accompanying roadmap outlines actions and timeframes for operationalising this strategy.

References

Beehive. 2021. Major reforms will make healthcare accessible for all NZers. URL: https://www.beehive.govt.nz/release/major-reforms-will-make-healthcare-accessible-all-nzers (accessed 28 June 2021).

Data Futures Partnership. 2019. *Trusted Data Use in Aotearoa New Zealand Guidelines.* Wellington: Data Futures Partnership.

Department of Prime Minister and Cabinet (DPMC). 2021. The new health system. URL: https://dpmc.govt.nz/our-business-units/transition-unit/response-health-and-disability-system-review/information (accessed 28 June 2021).

Durie M. 1994. *Whaiora: Maori Health Development.* Auckland: Oxford University Press.

Gwee S. 2021. The importance of increasing access to high-quality health data. URL: https://www.oecd-forum.org/posts/the-importance-of-increasing-access-to-high-quality-health-data (accessed 15 June 2021).

HDSR. 2020. *Health and Disability System Review: Final Report: Pūrongo Whakamutunga.* Wellington: Health and Disability System Review.

Health, Quality & Safety Commission New Zealand. 2011. The Triple Aim. URL: https://www.hqsc.govt.nz/news-and-events/news/126/ (accessed 15 June 2021).

Ministry of Business, Innovation and Employment. 2020. Consumer data right. URL: https://www.mbie.govt.nz/business-and-employment/business/competition-regulation-and-policy/consumer-data-right/ (accessed 15 June 2021).

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

Ministry of Health. 2014. He Korowai Oranga. URL: https://www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga (accessed 15 June 2021).

Ministry of Health. 2019a. Digital Health Strategic Framework. URL: https://www.health.govt.nz/our-work/digital-health/digital-health-strategic-framework (accessed 15 June 2021).

Ministry of Health. 2019b. Vision for health technology. URL: https://www.health.govt.nz/our-work/digital-health/vision-health-technology (accessed 15 June 2021).

Ministry of Health. 2020a. *Annual Report for the Year Ended 30 June 2020: Ministry of Health.* Wellington: Ministry of Health.

Ministry of Health. 2020b. *HISO 10083:2020 Interoperability roadmap: Driving the shift to a fully interoperable digital health ecosystem.* Wellington: Ministry of Health.

Ministry of Health. 2020c. *The National Asset Management Programme for district health boards. Report 1: The current-state assessment.* Wellington: Ministry of Health.

Ministry of Health. 2020d. *Whakamaua: Māori Health Action Plan 2020–2025.* Wellington: Ministry of Health.

Ministry of Health. 2020e. *Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025*. Wellington: Ministry of Health.

Ministry of Social Development. 2016. *New Zealand Disability Strategy 2016–2026.* Wellington: Office for Disability Issues.

NZ Tech. 2021. Digital skills for our digital future. URL: https://nztech.org.nz/reports/digital-skills-for-our-digital-future/ (accessed 15 June 2021).

Office of the National Coordinator for Health Information Technology (United States). 2020. 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program. https://www.healthit.gov/curesrule/ (accessed 15 June 2021).

Social Wellbeing Agency. 2019. *Data Protection and Use Policy.* Wellington: Social Wellbeing Agency.

Stats NZ. 2018. Data strategy and roadmap for New Zealand. URL: https://www.data.govt.nz/about/data-strategy-and-roadmap-setting-the-direction-for-new-zealands-data/data-strategy-and-roadmap/ (accessed 15 June 2021).

Stats NZ. 2020. *COVID-19 Lessons Learnt: Recommendations for improving the resilience of New Zealand's government data system*. Wellington: Stats NZ.

Stats NZ. 2021a. Mana Ōrite Relationship Agreement. URL: https://www.stats.govt.nz/about-us/what-we-do/mana-orite-relationship-agreement/ (accessed 28 June 2021).

Stats NZ. 2021b. *Government Data Strategy and Roadmap 2021.* URL: https://www.data.govt.nz/docs/data-strategy-and-roadmap-for-new-zealand-2021/ (accessed 15 September 2021).

Te Mana Raraunga. 2016. Te Mana Raraunga Māori Data Sovereignty Network Charter. URL: https://www.temanararaunga.maori.nz/ (accessed 15 June 2021).

Understanding Patient Data. 2017. Introducing patient data. URL: https://understandingpatientdata.org.uk/ (accessed 15 June 2021).

Waitangi Tribunal. 2019. *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry: WAI 2575*. Lower Hutt: Legislation Direct.

Appendix A: Challenges and opportunities

Current state	Future state	Outcomes
Health data and information is siloed and difficult to access, share or use for real-time insights	Health data and information is accessible and available in consistent formats, enabling synchronous data sharing and real-time insights and decision-making. System performance improvements, new models of care, policy, investment and funding decisions are data-driven	Improved quality, safety and experience of care
Data is not readily available for research, analytics or innovation	Data sets are available, supported by guidance on accessibility and governance	
Health care professionals cannot access a person's complete health care record	Complete health records, including contextual information as relevant from other agencies, are available when needed	
People cannot access or contribute to their own health records, and they have limited ability to access health care themselves or to consent to data sharing with whānau and care providers	People actively participate in their own health care. They can access and contribute to their own health records. They are able to schedule, manage and access care	
Aging infrastructure and investment is not coordinated, collaborative or consistent, affecting our ability to aggregate and analyse data	Accelerated adoption of cloud technologies results in efficiencies, collaboration at scale, and coordinated change	Best value for public health system resources
Health workforce shortages and a deficit in skilled leaders and data specialists contribute to a lack of sector-wide capability and capacity to manage, govern and use data effectively	A skilled and proficient health workforce governs, uses and respects data as a taonga. As new data management professions emerge, the health sector is seen as an aspirational place to work, and attracts and retains highly capable talent	
There is a risk of introducing more inequity into the system with new technology and advances in the use of data, and existing inequities in care and outcomes persist	Equity is measured, understood and addressed at a system-wide level and at a personal level with consumers. Māori and consumers are active participants in data governance, and their contributions create more effective data management	Improved health and equity for all populations

Data and Information Strategy for Health and Disability:

Roadmap 2021–2024

Stronger evidence, better decisions, improved health and wellbeing

Contents

Introduction

This companion document to the Data and Information Strategy for Health and Disability provides a roadmap that supports implementation of the strategy.

The ways we work together to deliver collective impact and solve common problems are important, and the strategy is intended to support people, individual organisations and the system to work more effectively together.

Some aspects of the strategy will need to be delivered at a national level, some will be delivered in partnership with the national health information platform, Hira, using the Health Information Standards Organisation (HISO) Interoperability Roadmap, and some will be implemented locally. This roadmap provides guidance on which actions are best delivered nationally and which should be undertaken by local health providers and organisations.

The strategy and roadmap are living documents, and the Ministry of Health will update them over time. We expect to review the roadmap every two years, while the strategy will provide more enduring direction.

Roadmap

We will deliver the strategy as an ongoing programme of collaboration nationally and locally.

A number of dependencies will influence the implementation of the strategy and roadmap, including:

- the decisions made by government on implementing the health and disability sector reforms
- the implementation of reform priorities by Health NZ and the Māori Health Authority
- funding availability
- local financial and organisational priorities
- resourcing and data capability across the health sector (recognising that we may need to recruit or procure additional capability and expertise)
- the Hira programme of work
- implementation of the HISO Interoperability Roadmap.

We have developed three initial horizons for delivery, corresponding to short, medium and longer-term goals, as follows.

Horizon Zero – 2021: Strategy and roadmap development

In this first year, we developed the strategy and this first roadmap through a sector-wide consultation process. The roadmap specifies activity for the first 24 months; we acknowledge that full implementation will take much longer.

Horizon One – 2022: Building strong foundations

During this period, we will focus on opportunities for quick-wins and the establishment of the national and local capabilities we need to implement the strategy. The focus of the first two years will be on building the national functions and capability required to support ongoing local initiatives in subsequent horizons.

Horizon Two – 2023: Supporting the health and disability system

Following the first year of establishment, our activity will shift to implementing the foundations laid down in Horizon One, building on existing initiatives and reflecting the priorities of Health NZ and the Māori Health Authority. The roadmap is a living document; during Horizon Two we will update the plan. This will include a review of progress made, emerging trends, innovation and requirements and consultation with the health and disability sector.

Future – 2023 onwards

During the first two horizons we will start building capability across the health and disability systems; however, we will need ongoing and prolonged effort across the sector to modernise and strengthen our use of data. This roadmap also identifies future enablers, for inclusion in the next iterations of the roadmap.

Priorities for improvement

The roadmap is based on five priority areas. These are interlinked; they work together to address the challenges that stakeholders identified. They set the direction of the strategy and the key enablers required to create a modern, collaborative, consumer-centric and innovative health and disability system.

Priority areas

Data foundations	Equity and data sovereignty	Consumer participation	People and leadership	Data and information accessibility

Two-year roadmap

The following table provides an overview across all priority areas of the key actions to be progressed in the next two years.

	Horizon One	
	First six months	**Second six months**
Data foundations	**National:** Establish national health and disability data and information implementation group	
	National: Current state health and disability data maturity model developed	**National and Local:** Current state health and disability data maturity sector assessment
	National: Establish the National Collections Data Service	**National:** Migrate all COVID-19 data and commence national DHB data collections migration
	Local: (Organisations and vendors) adopt existing HISO standards	
		National: Develop and publish a national health and disability data catalogue and dictionary
Equity and data sovereignty	**National:** Develop a Māori data sovereignty and governance engagement framework	**National:** Develop a co-designed Māori health and disability data governance and sovereignty wānanga and partnership approach
		National: Develop equity measures for health data standards
Consumer participation		**National:** Consult and co-design a consumer authorisation and delegation framework
	National: Consult on and co-design a consumer health data literacy service	**National:** Develop and implement the consumer health data literacy service
		National: Develop a health and disability consumer data rights programme
People and leadership	**National:** Establish health data governance council	
	National: Develop and publish a health and disability data governance framework	**National:** Implement a data governance training programme
		Local: Establish and network data governance councils
Data and information accessibility	**National:** Establish a national terminology service	**Local and National:** Syndicate federated local and vendor applications to a national terminology service
		National: Develop and publish a health data and information sharing and accessibility framework
	National: Develop exemplars of good data sharing practices	

Horizon Two	
First six months	**Second six months**
National: Develop and publish minimum data requirements for all contracts, procurement, applications and platforms	**Local and Industry:** Compliance with minimum data requirements for all new contracts and procurement
National: Decommission legacy national data collections service and complete migration to cloud service	
	National: Develop a new national data service to support research, analytics and innovation
	National: Develop Roadmap 2.0
	National: Transition registries
	National: Extend engagement and co-design approaches to work with relevant experts and communities on Pacific data sovereignty
National: Develop and publish the consumer authorisation and delegation framework	
Local: Implement the health and disability consumer data rights programme	
National: Review New Zealand health data workforce requirements and planning	
	Local: Adopt the data and information sharing and accessibility framework
National: Develop a health data sharing mediation service	

Data foundations

The data foundations priority supports the elements that we need to implement across the sector. We need to better collaborate to make data and information accessible for the benefit of consumers and the community. To improve data quality, we need to accelerate the implementation of data standards, publish consistent data architecture and models, develop and publish data sharing frameworks and adopt a data-first approach to procurement. The implementation of modern platforms will improve our data-sharing capabilities and enhance our business intelligence, data science and innovation.

Improvements to our approach to managing data and information will ensure that data are more accessible and stored in more consistent formats, enabling data access and sharing so the system can develop and use real-time insights for decision-making. The system must ensure data informs performance improvements, new models of care, policy, investment and funding decisions.

Two-year roadmap

The following describes in more detail the actions required to build good data foundations.

	Horizon One		Horizon Two	
Data foundations	**National:** Establish national health and disability data and information implementation group		**National:** Develop and publish minimum data requirements for all contracts, procurement, applications and platforms	**Local and Industry:** Compliance with minimum data requirements for all new contracts and procurement
	National: Current state health and disability data maturity model developed	**National and Local:** Current state health and disability data maturity sector assessment		
	National: Establish the National Collections Data Service	**National:** Migrate all COVID-19 data and commence national DHB data collections migration	**National:** Decommission legacy national data collections service and complete migration to cloud service	
	Local: (Organisations and vendors) adopt existing HISO standards			
		National: Develop and publish a national health and disability data catalogue and dictionary		
				National: Develop a new national data service to support research, analytics and innovation
				National: Develop Roadmap 2.0
				National: Transition registries

Horizon One

National: Establish a national health and disability data and information implementation function (DIIF)

This new capability will be accountable for the national implementation of the data strategy, and will support, connect and coordinate local implementation of the strategy.

Existing roles, along with some new roles and resourcing, will be required to establish this function, which will support a whole-of-sector uplift in capability.

This function will be accountable for:

- creating tangible useful content that organisations in the sector can use

and providing a mechanism for sector organisations to add capability

- confirming the data and information priorities for Health NZ and the Māori Health Authority

- developing a health data and information management operating model that can be reused and scaled across the health and disability sectors

- developing and publishing companion documents and activities to support and provide additional guidance within the five priorities of the strategy

- establishing a health and disability data and information maturity model and sector-wide assessments for benchmarking and measuring progress. This includes Māori data maturity, and will make use of an all-of-government approach

- establishing a review group of suitably qualified and diverse people to review the roadmap for Horizon Two

- establishing sector working groups to better network and coordinate activity across the sector

- reviewing, managing and coordinating the programme of work and delivery targets.

National: Carry out a current state health and disability data maturity model development and assessment

To measure progress against the strategy, and to benchmark the sector and organisations, we need a current state maturity assessment. Data maturity is defined as being the journey towards improvement and increased capability in using health data and information. The five strategic priorities will form the domains against which we will assess sector-wide data maturity. The DIIF will take responsibility for developing the model and assessment tool, and local organisations and providers will be responsible for participating in this activity.

This function will be accountable for:

- developing and publishing a baseline health and disability data maturity model using a recognised method and toolset

- making use of and contextualising an all-of-government approach to data maturity, including Māori data maturity

- developing and publishing a set of initiatives targeted at uplifting data maturity over the next one to three years, along with costs, quantified benefits and performance indicators.

National: Develop and publish a national health and disability data catalogue and dictionary

Data dictionaries describe the information available within data collections and promote consistency across collections, supporting the use of nationally agreed protocols and standards. The Ministry of Health has developed a number of data dictionaries; this body of work needs to be revised and expanded upon. Establishing a national health data model, catalogue and dictionary will provide a reference point for assured information standards. Nationally consistent business, administration and clinical definitions and data sets will support more consistent and accurate reporting and analytics. We anticipate that this work will continue through to Horizon Two.

This function will be accountable for:

- establishing a team of people skilled in developing a data catalogue and national data dictionary

- procuring a national data catalogue toolset, with consideration of how we can use it within a national and local context to improve the knowledge and documentation of health data assets

- securing funding to build sustainable communication and collaboration channels to ensure that health data catalogue operations are maintained.

National: Establish the National Collections Data Service

This enabler seeks to address concerns raised during the Health and Disability System Review regarding costly and cumbersome compliance requirements for sector reporting. This enabler

will comprise a migration of the National Collections to a modern ecosystem that will efficiently perform core data activities such as data transfer, transformation and integration. This will provide us with the ability to rapidly and efficiently consolidate and transform large data sets so that they are analytics-ready.

This function will be accountable for:

- establishing the National Collections Data Service
- migration of all COVID-19 data
- supporting the flow of relevant data from throughout the system into this service including the National Primary Care Data Service.

Local: (Organisations and vendors) adopt existing HISO standards

To support interoperability across the health and disability system, organisations and vendors have a role to play in adopting and implementing agreed national health information standards and policies. This enabler aligns with the HISO Interoperability Roadmap. We will measure compliance as part of the health and disability data maturity model.

Horizon Two

National: Develop and publish minimum data requirements for all contracts, procurement, applications and platforms

This enabler seeks to ensure local and industry compliance with minimum data requirements for all new contracts and procurement. This includes contractual arrangements for minimum data sets, standards, data governance and quality requirements. Contractual arrangements ensure data is made accessible to different parts of the system that require it in ways that are consistent with the expectations of consumers. This enabler supports a data-first approach to procurement, and is aligned to the HISO Interoperability Roadmap.

National: Develop a new national data service to support research, analytics and innovation

Recognising that health data across all sectors is an asset, a set of data services is required to support and sustain public health research and innovation in New Zealand.

This function will be accountable for:

- establishing a multi-disciplinary team to steward the new national data services

- developing the data services requirements for public health research and innovation across the sector, including requirements for free and paid services

- governance that includes the ethical use of data for secondary purposes, and new technologies

- selecting and procuring a platform for developing the data service

- developing an initial set of services based on prioritised requirements

- co-designing and marketing the availability and value of the data services to consumer communities

- extending data linkage and de-identification capabilities to provide access to data sets that meet privacy-by-design principles.

National: Develop Roadmap 2.0

This enabler entails a review and refresh of the existing roadmap.

This function will be accountable for:

- reviewing and documenting the progress made to date against the current roadmap

- developing a revised roadmap for the next two horizons.

National: Transition registries

This enabler involves the transition of registries into modern domain-specific data services that support service quality assurance and improvement.

This function will be accountable for:

- delivering solutions for clinical, administrative and research needs

- establishing national registry data standards and making use of international data standards

- establishing national registry governance standards, including standardised approaches to collecting and managing consent

- establishing efficient processes, including the collection, dissemination, access to and extraction of registry data

- developing guidance for how existing registries transition and how new data services take advantage of modern data acquisition tools and hosting platforms.

Future

Additional enablers that we have identified to support stronger data foundations include the following:

- a consistent adoption of the data architecture principles for making business decisions

- establishment of a national health data architecture capability

- establishment of local measures to audit and manage data provenance and tools and mechanisms to maintain and update data standards

- sector-wide business intelligence and analytics collaboration, sharing and scaling tools, platforms and resources

- mechanisms for self-service of data-driven insights

- sector guidance on health data retention policies and managing the health data of deceased persons

- identification of gains from successful data initiatives and then scaling and reusing them across the system.

Equity and data sovereignty

Digital health should provide services, data and information that improve equity. We will prioritise opportunities to target inequity, and improve health outcomes, through an improved understanding of inequities and the use of digital and data capabilities to address them.

While equity and data sovereignty are both individually important themes, they are intrinsically interlinked and related.

We need to partner with Māori to define and collect the right data for Māori, and then ensure that health data is available for iwi and Māori health providers so that they can self-govern and provide health and disability services for their own people.

We will address data and information inequity and data sovereignty for other population groups who experience some of the poorest health outcomes in New Zealand, particularly Pacific peoples and disabled people.

We will provide mechanisms for people to access health information that considers their requirements, including literacy, accessibility, mode of delivery and cultural and social differences.

Two-year roadmap

To better address inequities in health outcomes, and to honour the Crown's commitment to Te Tiriti o Waitangi, the roadmap has prioritised the following activities in the first two years.

	Horizon One		Horizon Two
Equity and data sovereignty	**National:** Develop a Māori data sovereignty and governance engagement framework	**National:** Develop a co-designed Māori health and disability data governance and sovereignty wānanga and partnership approach	**National:** Extend engagement and co-design approaches to work with relevant experts and communities on Pacific data sovereignty
		National: Develop equity measures for health data standards	

Horizon One

National: Develop a Māori data sovereignty and governance engagement framework

To work in partnership with Māori to define the approach that best addresses Māori needs, we will develop an engagement framework for the access and use of health data and identify opportunities for Māori self-governance of certain data. This framework will be developed by Māori, for Māori, in partnership with Te Mana Raraunga, the Māori Health Authority and Māori health and data leaders, and in accordance with Whakamaua: Māori Health Action Plan 2020–2025 (Ministry of Health, 2020).

Develop a co-designed Māori health and disability data governance and sovereignty wānanga and partnership approach

This function will be accountable for:

- establishing a framework and authority that is responsible for Māori data sovereignty.

National: Develop equity measures for health data standards

The health and disability system is currently inadequately set up to understand, measure, manage and mitigate inequity of outcomes through data-driven insights. To address this gap, we need to prioritise establishment of equity measures for health data standards and the proposed national data catalogue. These will address inequities experienced by Māori, Pacific people, disabled people, people from the rainbow community and others.

Horizon One includes the assessment of Māori data maturity within the development and assessment of a health and disability data maturity model.

Horizon Two

In Horizon Two, we will continue the work established in Horizon One to co-design and establish a framework and authority that is responsible as a caretaker for Māori data

sovereignty and the development of equity measures for health data standards.

Future

Addressing inequity in health and data sovereignty is a collective journey. Further enablers to be addressed in subsequent roadmaps include:

- inclusion of Māori data sovereignty in all data literacy initiatives

- inclusion of the Washington Group Short Set of Questions on Disability (contextualised for New Zealand) into health data collection tools and applications (Washington Group on Disability Statistics, 2021)

- local adoption and implementation of equity measures for health data standards

- national and local understanding and measurement of health data bias, and implementation of resources and training to address capability gaps in the identification of data bias and moving towards data neutrality

- development of mechanisms to disaggregate data by disability, so that disabled people become more visible in health and disability data

- local development of partnerships with local iwi to meet their obligations under Te Tiriti o Waitangi and to enable iwi governance of health data

- local development of partnerships with community groups to meet their local community needs regarding data and health information

- review of current data practices and improvements needed to mitigate health inequity

- implementation of mechanisms for all New Zealanders to access their health data, considering the equitable access of health information.

- creating tangible useful content that organisations in the sector can use.

Consumer participation

All people should have access to their own health records, to support their ability to actively manage their own health and wellbeing. Data and information should be used for the benefit of people, and data-informed decisions should lead to improved population health and wellbeing. Consumer representation in data governance is fundamental to ensuring that consumers have agency and control, and that decisions about health data management are made in a consumer-centric manner.

Two-year roadmap

The first two years of the roadmap will prioritise a health consumer data literacy initiative, a framework to support consent and delegation and the legislative and policy changes required to establish a health and disability consumer data right. Alongside these initiatives, we need increased consumer representation on data governance councils across the health and disability system.

		Horizon One	Horizon Two	
Consumer participation		**National:** Consult and co-design a consumer authorisation and delegation framework	**National:** Develop and publish the consumer authorisation and delegation framework	
	National: Consult on and co-design a consumer health data literacy service	**National:** Develop and implement the consumer health data literacy service		
		National: Develop a health and disability consumer data rights programme	**Local:** Implement the health and disability consumer data rights programme	

Horizon One

National: Consult on and co-design a consumer data literacy service

To improve access to consumer information supporting health and data literacy, the DIIF will be responsible for providing a national health data information service via a website. This will enable people to find out how their health data is used and why, what the safeguards are and how decisions are made. Considerations of accessibility, equity, te ao Māori and co-design are fundamental to this initiative.

This function will be accountable for:

- establishing a consumer data literacy programme, including an approved budget and timeline

- providing collateral that can be reused by other organisations and through other channels to provide better consistency of information in all places that consumers are accessing and using health services (both digitally and in person); this will require expertise and resourcing to develop materials, produce a

communications plan and influence local organisations to use this service

- reporting findings to government

- developing and implementing a funded consumer literacy programme.

National: Consult and co-design a consumer authorisation and delegation framework

Co-design through consultation a mechanism for consumers to manage authorisation and delegation of their health data. This will require the development and publication of a national authorisation and delegation framework in Horizon Two. This is dependent on implementation of a national digital health identity programme.

This function will be accountable for:

- establishing a consultation process to identify the consumer voice and views on health data access and use, with a particular emphasis on digital data

- establishing a framework with standards for measuring the implementation of authorisation across the digital landscape in New Zealand health.

National: Develop a health and disability consumer data rights programme

To provide health and disability consumers with greater choice and control over their data, we need to establish a health consumer data right through legislation, along with supporting health provider responsibilities. A health consumer data right will also provide sector clarity and direction on social licence regarding the use of health data for research and innovation. We need to engage with the sector to develop this programme of work.

This function will be accountable for:

- establishing a set of consumer data rights and health provider responsibilities with particular focus on how digital data is produced and consumed in the New Zealand health and disability systems

- definition of consumer data rights should build on the expectations of consumers expressed through the Data Protection and Use Policy, developed by the Social Wellbeing Agency (Social Wellbeing Agency, 2019).

Horizon Two

National: Develop and implement the consumer health data literacy service

Following the consultation process in Horizon One to establish the requirements of a consumer health data literacy service, we will develop and implement this in Horizon Two. The DIIF will be responsible for commissioning this body of work.

National: Develop and publish the consumer authorisation and delegation framework

During Horizon Two, work will continue on the consumer authorisation and delegation framework, culminating in completion and publication of this body of work.

Local: Implement the health and disability consumer data rights programme

Health providers and organisations will implement the consumer data rights programme following the policy change and enactment of supporting legislation. We will provide support for this at a national level.

Future

Further enablers we have identified to support consumer participation in subsequent roadmaps include:

- ensuring local organisations use the Data Protection and Use Policy principles (Social Wellbeing Agency, 2019) in their data management processes

- addressing equity of access to health data and information for people who require additional support, including accessibility requirements

- ensuring consumers are represented on all data governance councils and forums and that representation is reflective of local communities, so that decisions about consumers' health data are made in partnership

- implementing mechanisms through which consumers can contribute to and manage their health data and information, including by reporting on their outcomes and experiences, booking and scheduling appointments and interactions, finding out their National Health Index number, updating their demographic information when it changes and ordering repeat medications

- ensuring consumers are able to see who has accessed their health information and when

- ensuring consumers are able to receive information from health and disability systems in the mode that best meets their needs and accessibility preferences.

People and leadership

The health and disability sector requires a skilled and proficient health workforce that governs, uses and respects data as a taonga.

Health and disability care providers and organisations have a responsibility to behave in a manner that reflects their role as the kaitiaki of health data and information. The consultation process highlighted a need for improved sector capability to establish effective data governance and leadership practices. A modern health system needs a data literate health workforce and new data roles, literacy initiatives and workforce planning will be required. Across the health system, we have a collective responsibility to establish effective processes to keep data and information safe and respect its value.

Two-year roadmap

The first two years of the roadmap prioritise the establishment of effective data governance processes across the health and disability sector. Leadership and governance will be established following a system-wide approach.

	Horizon One	Horizon Two
People and leadership	**National:** Establish health data governance council	
	National: Develop and publish a health and disability data governance framework	**National:** Implement a data governance training programme
		Local: Establish and network data governance councils
		National: Review New Zealand health data workforce requirements and planning

Horizon One

National: Establish health data governance council

We will establish a national health and disability data governance council in Horizon One. This will bring together data governance thought leadership and best practices in governance, establishing a systems-level approach that supports the DIIF. We will prioritise consumer and Māori representation on this council.

This function will be accountable for:

- establishing terms of reference, accountability, reporting lines and decision-making responsibilities
- ensuring that all members undergo data governance training, to ensure a high level of governance capability.

National: Develop and publish a health and disability data governance framework

To provide national and local guidance on effective health data governance practices, we will develop a framework and guiding resources.

This function will be accountable for:

- co-design with consumers and Māori
- ensuring the framework can be implemented at both national and local levels
- conducting this activity in parallel with and linked to the establishment of a national data governance council.

National: Implement a data governance training programme

To uplift data literacy and governance capability, the DIIF will establish a new training programme for all people performing governance functions across the health and disability sectors.

This function will be accountable for:

- developing and implementing the training programme
- training health and disability leadership teams, decision-makers and members of data governance councils

- considering the literacy and accessibility requirements of participants, including consumers
- reviewing the outcomes and success of the programme and making improvements for subsequent training.

Horizons One and Two

Local: Establish and network data governance councils

During the two years of this roadmap, the DIIF will work with local providers to establish and support a network of local data governance councils. This will be a two-step process, as some regions and providers already have established and well-functioning data governance committees, which the DIIF will support in their work.

- Step 1: connect existing data governance initiatives together via online collaboration
- Step 2: shift the approach of local data governance so that it addresses the key issues within each organisation and locality, and includes representation from local community groups.

The Health and Disability Data Governance Framework will provide guidance on the evolution and function of data governance councils.

Horizon Two

National: Review New Zealand health data workforce requirements and planning

This enabler involves developing an understanding of future requirements for a health data workforce, including new and emerging roles, and planning for this growing workforce.

This function will be accountable for:

- developing multiple pathways into data roles, including internships, graduate programmes and the development of our existing workforce
- modelling workforce requirements and developing an understanding of skills gaps, including a consideration of workforce diversity
- developing a consistent approach to data workforce planning across the health and disability sectors.

Future

Further enablers to develop a skilled and data-literate health and disability workforce include:

- data literacy initiatives for the health and disability workforce, including employers, training providers and higher education providers, and a national data literacy programme

- investment in new data and information management workforce roles and capabilities at local and national levels

- establishment of health literacy training programmes for data specialists, to develop health domain knowledge

- collaboration with industry partners to establish data specialist industry training programmes

- implementation of real-time access to operational data to inform business and operational decision-making

- work to derive greater value from operational data through self-service tools to support strategic planning, developing new models of care and system performance efficiencies

- establishment of a data-first approach and business rules for health digital funding and procurement decisions

- establishment of governance frameworks to support and enable the appropriate use of data for research and innovation

- review of current regulations, legislation and policy to enable implementation of the data strategy.

Data and information accessibility

Much health and disability data and information is currently siloed within organisations. While most organisations and providers understand their responsibilities regarding clinical data, they do not see that they have an obligation to routinely share data with consumers, other health providers or other services. While some parts of the health system have established mechanisms for sharing data between primary and secondary care, there is little access to health and wellbeing data in the community, for iwi and hapū, for private providers or social services, or to data held or generated by consumers. Improving health data accessibility is fundamental to improving the health outcomes of all New Zealanders.

We need effective data sharing frameworks, contract requirements and consent and delegation frameworks, along with mechanisms to better support innovation and research.

Improving how we manage and code health data will support data accessibility and interoperability. Much data is currently held in inconsistent formats and coded using multiple competing code sets. Providing mechanisms to share, reuse and maintain clinical data will support the quality of data being shared and the quality of the insights we can gain through analytics and machine learning.

Two-year roadmap

The first two years of the roadmap will focus on improving the ability of digital services to be interoperable, through the use of a national terminology service, and through the development of nationally consistent data-sharing frameworks.

	Horizon One		Horizon Two
Data and information accessibility	**National:** Establish a national terminology service	**Local and National:** Syndicate federated local and vendor applications to a national terminology service	
		National: Develop and publish a health data and information sharing and accessibility framework	**Local:** Adopt the data and information sharing and accessibility framework
	National: Develop exemplars of good data sharing practices	**National:** Develop a health data sharing mediation service	

Horizon One

National: Establish a national terminology service

We are currently developing a new national terminology service; this may be ready in time for Horizon One. During Horizon One, the DIIF will be responsible for establishing access to this, either as a national service through government procurement or as a service.

This function will be accountable for:

- the provision and maintenance of a HISO standards-compliant terminology service
- regular server updates with New Zealand extensions
- establishing best-practice processes regarding terminologies
- sector change management to syndicate to this new service.

National: Develop and publish a health data and information sharing and accessibility framework

Widespread sector engagement and a review of existing data-sharing frameworks across the health sector will form the foundation of this initiative. Current arrangements have included primary and secondary care providers; consideration of data sharing and access more broadly is needed, to include social services, iwi and hapū, private providers, community organisations and consumers and their whānau.

This function will be accountable for:

- alignment with current regulations and legislation, including the Privacy Act 2020
- legislative changes that may be required to fully realise an ecosystem where health data flows more easily.

The DIIF will be accountable for commissioning and publishing this framework, along with supporting guidance on adoption by the sector.

Local and national: Syndicate federated local and vendor applications to a national terminology service

This enabler involves including requirements to syndicate to a national terminology service in contract and procurement arrangements. The DIIF will develop funding and incentivising mechanisms and make them available for local use.

National: Develop exemplars of good data sharing practices

This enabler involves collaboration with the Office of the Privacy Commissioner and the Ministry of Health to develop exemplars of good data sharing process and practice. The publication of these exemplars will provide guidance to other parts of the health and disability sectors.

Horizon Two

Local: Adopt the data and information sharing and accessibility framework

Local health care providers and organisations will be responsible for adopting the published Data and Information Sharing and Accessibility Framework, and will participate in its development during sector engagement.

National: Develop a health data sharing mediation service

This enabler entails the establishment of a data-sharing mediation service, to support organisations with unresolved differences regarding data access and sharing expectations. The DIIF will establish and provide this service.

Future

Further enablers we have identified to create an ecosystem in which health data and information is accessible include:

- changes to contracts and procurement to prevent information blocking and ensure that data is shared between people and organisations only as required and authorised
- auditing compliance with data sharing and accessibility requirements
- a review of existing legislation and regulation, including the Privacy Act 2020, and developing and implementing proposed changes to legislation
- bringing together insights from system-side operational big data to develop new services and models of care and improve operational and system performance
- making use of existing data sharing tools and platforms and reusing and scaling them for other providers and organisations.

References

Ministry of Health. 2020. *Whakamaua: Māori Health Action Plan 2020–2025.* Wellington: Ministry of Health.

Social Wellbeing Agency. 2019. *Data Protection and Use Policy.* Wellington: Social Wellbeing Agency.

Washington Group on Disability Statistics. 2021. WG Short Set on Functioning (WG-SS).
URL: https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/ (accessed 30 June 2021).