

Data and Information Strategy for Health and Disability:

Roadmap 2021–2024

Stronger evidence, better decisions,
improved health and wellbeing



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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: Develop equity measures for health data standards
		National: Extend engagement and co-design approaches to work with relevant experts and communities on Pacific data sovereignty

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.



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