

22 May 2023

Ref Number: MHA17497

Phil Pennington
RNZ Reporter
phil.pennington@rnz.co.nz

Tēnā koe Phil

Official information request in relation to Māori Data Sovereignty

I refer to your official information request dated 14 April 2023, which was transferred to Te Aka Whai Ora on 27 April 2023. You requested:

1. *The framework for Māori data sovereignty*
2. *The paper/s on the framework's privacy and security matters*
3. *Any privacy impact assessment done on this work*
 - *If not done, is one planned?*
4. *The results of the trial of the framework in phase one, and any other subsequent trials*
5. *Details of those trial/s including what was done, what was monitored, what was the point*
6. *Please explain what the plan is regards implementing it across the three agencies (Te Whatu Ora, Te Aka Whai Ora and Ministry) re "national collections first, extended to other collections over time"*
7. *Please explain what will/is expected to change re a patient's health data held currently at a district – formerly held by DHB – and where it will or may be held in future, over time*
8. *Please explain the range and volume of data*
9. *Is this only Māori-related data*
 - *What about non-Māori data and data sovereignty for that*
10. *Please detail the principles being followed/likely to be adopted, regards cloud computing, in relation to sovereignty, in particular (and please note where the following has already been decided on or actioned):*
 - *Use of public cloud computing (i.e., servers run by some other entity)*
 - *Use of offshore cloud computing*
 - *Use of cloud computing services owned by non-NZ entities*
11. *Please summarise briefly any and all consultation your agencies did over the framework*
 - *Please name all major Māori parties consulted with*
12. *Please summarise ANY and all existing deals, or ones currently under negotiation, to access cloud computing services of any kind, including the parties, duration, regards*
 - *Any data covered by this framework*
 - *Any other personal data outside this framework – it may be such you are OKing storing/processing such data in Australia, say, but not doing that with Māori-related data. Please make this clear*

Your request has been considered under the Official Information Act 1983 (the OIA). The response to your request is set out in this letter of response and attached.

Māori Data Sovereignty Framework and Te Aka Whai Ora role

To provide you with further context in terms of the information you have requested, please note there is currently no Māori Data Sovereignty Framework (the Framework) in place. Te Aka Whai Ora's role, working with Te Whatu Ora and Manatū Hauora is to facilitate and support Māori to exercise kaitiakitanga over the Framework's development. This means, in effect the Framework will be developed by Māori for Māori, iwi, hapū and whānau.

Māori Stakeholder Engagement

To support the development of the Framework we need to work with our key stakeholders in the hauora sector, including Iwi-Māori Partnership Boards (IMPBs), our hauora Māori partners and Māori data and digital leaders, with the first step being to determine what the data requirements are.

You may be aware that not all IMPBs have received recognition under section 31 of the Pae Ora (Healthy Futures) Act 2022. Te Aka Whai Ora considers Māori data sovereignty and the ability for Māori to access and use this data to drive better hauora outcomes is of the utmost importance. As such, this mahi will not progress to formal engagement phase until IMPBs are in place and resourced.

Te Aka Whai Ora mahi to date

While we have not commenced formal engagement, we have continued our mahi by preparing material to support the development of the Framework. Work completed in 2022 includes:

- reviewing existing information on Māori data governance
- reviewing and considering current relevant legislation and guidance, for example the Privacy Act 2020 and Digital and Data guidelines issued by the Department of Internal Affairs
- engaging with other government agencies, in particular our partner agencies Manatū Hauora and Te Whatu Ora
- engaging (informally) with Māori stakeholders to determine key themes on data and information.

This mahi contributed to a paper to the Te Aka Whai and Te Whatu Ora Boards in September 2022 and December 2022 respectively. The paper summarised work undertaken to seek approval for the next steps prior to engaging formally with Māori. This paper *Māori Data Sovereignty Framework* and the accompanying presentation *'Māori sovereignty framework: Health data, information, privacy and security'*, is attached.

Information has been withheld from these documents in accordance with section 9(2)(g)(i) of the OIA, to maintain the effective conduct of public affairs through the free and frank expression of opinions by or between or to Ministers of the Crown or members of an organisation or officers and employees of any public service agency or organisation in the course of their duty.

I have considered the withholding of this information is not outweighed by other considerations which render it desirable, in the public interest, to make that information available (section 9(1) of the OIA).

Current mahi to support the Framework

In 2023, we have continued to progress the Framework mahi and ensure future access to data and information for Māori. This has included:

- Work with Te Whatu Ora and Manatū Hauora on the establishment of a Te Tiriti model overarching data governance group that includes IMPBs and hauora Māori partners.
- Early-stage development of an Overarching Data Sharing Agreement (ODSA) to assist IMPBs and hauora Māori partners to have a single data sharing agreement for all collections held centrally.
- Feeding into the Request for Proposal and the selection process for the National Data Platform (Platform) design and implementation partner, to ensure vendors will work with Māori and that Māori data elements will be explicitly embedded in the design of the Platform.

Appendix One responds to the questions you have asked in points 1 to 12 above, and should be considered in light of the context we have provided.

If you wish to discuss this decision with us, please feel free to contact Te Aka Whai Ora Ministerial Services (mhagovernmentservices@health.govt.nz).

You have the right to seek an investigation and review by the Ombudsman of this decision. Information about how to make a complaint is available at www.ombudsman.parliament.nz or freephone 0800 802 602.

Nāku noa, nā



Kingi Kiriona
Maiaka Mātauranga | DCE, Mātauranga Māori
Te Aka Whai Ora

Appendix One: Response

A copy of the framework for Māori data sovereignty and the results of the trial of the Framework in phase one, and any other subsequent trials / Details of those trial/s including what was done, what was monitored, what was the point

As noted in our covering letter section 'Māori Data Sovereignty Framework and Te Aka Whai Ora role' there is no Māori Data Sovereignty Framework (the Framework) in place and therefore no details about the trials or results to release.

Copies of the paper/s on the Framework's privacy and security matters and any privacy impact assessments done on this work or planned

A high-level review of legislation and Government guidelines relevant to this mahi has been undertaken. This information will be provided to and will support Māori consider these issues as part of the development of the Framework. This high-level review included a review of the standards and guidelines set out by the Government Chief Digital Officer and the Privacy Act 2020.

The Framework itself will not hold data. However, when appropriate, Te Aka Whai Ora will support to Māori to assess the privacy impact on their data sets and systems.

Please explain what the plan is regards to implementing it across the three agencies (Te Whatu Ora, Te Aka Whai Ora and Manatū Hauora) re "national collections first, extended to other collections over time"

Currently, the Data Tripartite Agreement (DTA) is in place across the three health agencies, as endorsed by them in June 2022. This agreement reduces any access barriers that may arise following the health reforms. It allows for data held by any of the three agencies to be accessible to each other. It also supports Te Aka Whai Ora to be a conduit for Iwi-Māori Partnership Boards and hauora Māori partners to access data with our support.

As noted in our cover letter, engagement with Māori as kaitiakitanga of their data will further inform and guide the interaction between agencies once the Framework is in place.

Please explain what will/is expected to change re a patient's health data held currently at a district – formerly held by DHB – and where it will or may be held in future, over time

Patient health data will not be part of the Framework. Patient health data is held by Te Whatu Ora.

Please explain the range and volume of data. Is this only Māori-related data? What about non-Māori data and data sovereignty for that?

Decisions on the range and volume of data will be made when the Framework is developed and following appropriate consultation. However, the Framework will apply to data and information that is sourced from, or about Māori.

Please detail the principles being followed/likely to be adopted, regards cloud computing, in relation to sovereignty, in particular (and pls note where the following has already been decided on or actioned): Use of public cloud computing (i.e. servers run by some other entity); Use of offshore cloud computing; and Use of cloud computing services owned by non-NZ entities

Please summarise ANY and all existing deals, or ones currently under negotiation, to access cloud computing services of any kind, including the parties, duration, regards

- ***Any data covered by this framework***
- ***Any other personal data outside this framework – it may be such you are OKing storing/processing such data in Australia, say, but not doing that with Māori-related data. Please make this clear***

As noted above a high-level review has been undertaken of legislation and Government guidelines relevant to this mahi. This information will support the development of the Framework and any data storage considerations.

Please summarise briefly any and all consultation your agencies did over the framework and please name all major Māori parties consulted with

Details are provided in 3.2 and 7.1 of the attached Board paper and its accompanying presentation.

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Board paper

MĀORI DATA SOVEREIGNTY FRAMEWORK

Date: 14 September 2022 **Author:** Robyn Kamira, GM Data and Digital

For your: Decision **Approved by** Craig Owen, Corporate Services

1. Purpose

- 1.1 This paper seeks the Board's agreement to a staged approach to the roll-out of the Data Sovereignty Framework and engagement with Māori Health Providers and IMPB's to operationalise the framework in the sector.
- 1.2 The pre-draft version of the *Māori sovereignty framework: Health data, information, privacy and security* and a short slide deck accompanies this cover paper in your Pack.
- 1.3 This version provides you with an initial approach that reflects discussions in our sector, findings from our wānanga series with our *Māori Data and Digital Sector Working Group*, and learnings from similar Māori-led projects.

2. Recommendations

2.1. It is recommended that Te Aka Whai Ora Board:

- a. **Note** the pre-draft *Māori sovereignty framework for data, information, privacy and security* paper has been shared with Manatū Hauoura and Te Whatu Ora data and HIRA leads and their teams, who are engaged with Te Aka Whai Ora data and digital
- b. **Note** that a small central agency-only trial is underway to test the Stage 1 operationalising of the Framework – and to help inform the future rollout of the Framework
- c. **Note** that the previous Joint Boards Data and Digital working group requested that the Data Sovereignty Framework be considered initially by the Te Aka Whai Ora Board
- d. **Approve** the staging approach (3 agencies followed by Sector roll-out), and the scoping that makes it feasible to implement between the three agencies (national collections first, extended to other collections over time
- e. **Agree** that a health sector engagement process be initiated as part of Stage 2 (above) to understand the position of Māori health providers and Iwi Māori Partnership Boards (IMPBs) on:
 - i. sharing *identifiable* data
 - ii. their expectations of their roles, mandates and outcomes relating to central data governance, and
 - iii. sharing the data governance design (Te Tiriti model) work underway by a process of co-design between Te Whatu Ora DISH (Data & Information Strategy for Health & Disability) and DTA (Data Tripartite Agreement) teams and Te Aka Whai Ora Data and Digital and Policy teams.
- f. **Agree to** submit this paper to the Te Whatu Ora Board for their consideration

3. Background

3.1 In November 2021, the interim Māori Health Authority (iMHA) workplan committed to addressing Māori data sovereignty in the health system to be agreed with the Ministry of Health (MOH) and the Interim Health New Zealand (iHNZ) (APP 1, p. 13).

3.2 The Framework is informed by:

- i. contributions by Māori leaders active in drafting UNDRIP, the Wai 262 claims and several other Indigenous Peoples programmes during the 1990s and 2000s
- ii. review of previous Māori health data, information and privacy projects and programmes led by Māori from the 1990s onwards
- iii. the Privacy Act (2020) and a review of Māori-related Privacy Impact Assessments
- iv. Engagement with recent wānanga participants, Māori stakeholders by Māori Data leads in HNZ and MOH, ongoing engagement with Te Aka Whai Ora sector networks, and discussions with Te Aka Whai Ora Board members

3.3 It addresses four key areas drawn from discussions about what is most prominent for Māori when considering data and information.

3.4 Those four areas are: health data, information, privacy and security.

3.5 It seeks to move along a continuum to operationalise the Framework: From principles, policies, operations, and systems design – and it is proposed that future work will include toolkits for policy, technical and data people.

4. Discussion

The Framework is proposed to be implemented in a staged approach

- 4.1 Discussions across wider Māori sectors (industry, health, education, etc) indicate that sharing aggregated and unidentifiable data and information is a feasible first step to test how we govern and handle data and information that is sourced from, or about Māori – while protecting privacy (individual and collective) and security (online harm and data breaches).
- 4.2 It indicates this work can be staged. The Framework can be implemented initially by scoping what is more immediately acceptable and sharable between MOH, Te Whatu Ora and Te Aka Whai Ora, and external stakeholders including Providers and IMPBs – that is, aggregated and unidentifiable data and information.
- 4.3 This staging is 'agile' allowing the three agencies to implement the Framework in a scoped environment, and test the thinking, policies and tools that operationalise the Framework – prior to considering how it might be extended.
- 4.4 With Board guidance, a second stage could focus on *identifiable* data and information. However, this requires substantial engagement with the sector and a legal review. This is addressed in the next section.

The Process includes inter-agency collaboration

- 4.5 We are now receiving detailed feedback from the HIRA team, and Māori Data leads in Manatū Hauora, Te Whatu Ora and Te Aka Whai Ora.
- 4.6 The feedback is confirming where the more complex discussions and decisions need to take place, and where alignment between the three agencies will help strengthen this work.

- 4.7 The feedback indicates the more complex areas will be
- i. providers view on their mandates and data governance membership and structure,
 - ii. if, and/or when to include identifiable data, and
 - iii. sector engagement.

4.8 This pre-draft version seeks the Board's approval to:

- i. the staging approach
- ii. the scoping to make it feasible to implement it, and
- iii. whether to address the more complex discussions on identifiable data and information in the sector.

4.9 Your response will determine the extent and timing of our next steps including if and when to begin sector engagements, and on what topics – while ensuring that stakeholders are given proper time to understand the impacts and consider their positions.

5. Contribution to Te Tiriti relationship and achieving equity

5.1 This paper proposes that governance, operations, decisions and processes relating to data and information sourced from, or about Māori give effect to Te Tiriti o Waitangi, specifically when integrated into data, information, privacy and security requirements will enable the agencies to:

- i. protect Māori intellectual and cultural property
- ii. collect and make accessible data and information that is relevant to Māori values and models of health
- iii. act in the roles of kaitiakitanga, custodianship, stewardship, guardianship in relation to data – and how they each interact
- iv. set criteria for collection, analysis, and publication of information about Māori.

6. Financial implications

6.1 Narrative There are no particular financial implications resulting from this paper aside from Stage 2 engagement needing resources. We intend to consolidate the Te Whatu Ora programme with ours and set the path forward.

6.2 The sector engagement programme, when ready to commence, will require a minimum of FTEs 2 for a year to canvas IMPBs and provider requirements for this mahi.

7. Consultation

7.1 Narrative Internal/external stakeholders who were consulted:

- i. Leads and teams of data and digital including data governance of the three agencies.
- ii. Te Whatu Ora HIRA team, and Māori Data leads in Manatū Hauora, Te Whatu Ora and Te Aka Whai Ora.
- iii. Specialist group of Māori primary sector stakeholders, light engagement with Iwi Chairs, Māori health providers. A full and deep engagement is proposed in the recommendations.

- iv. Noting at the time of writing Te Aka Whai Ora staffing is in progress and some Te Whatu Ora staff we've engaged with may or may not move to Te Aka Whai Ora.

8. Next Steps

8.1 Narrative Stage 1 operationalising continued but is upgraded to formal engagement with the three agencies.

8.2 Stage 2 plan with a recommended approach for identifiable data, and full sector and legal engagement in 2023 is designed and a paper returned to the Board in December 2022 for its guidance.

9. Risk Analysis

Identified Risk	Risk likelihood	Consequence of risk	Mitigations
Legal and sector expectations regarding identifiable data may be in conflict	High	Loss of confidence in Te Aka Whai Ora ability to leverage data for IMPBs and Māori health providers	Staged approach and deep engagement with legal layer alongside

10. Appendices

10.1 A Māori Sovereignty Framework: Health data information, privacy and security

Craig Owen
Inteim Corporate Director
Date:

Te Aka Whai Ora

Māori Health Authority

A Māori Sovereignty Framework:

Health data, information, privacy and security

Te Pou Tarāwaho o te Rangatiratanga Māori:

Raraunga-oranga, mōhiohio, noho matatapu me te whakahaumaru

21 September 2022

GM Data, Digital & Innovation, Robyn Kamira



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1. Beyond just data to the whole conversation: data, information, privacy and security
2. Identifies issues
3. Sets an approach
4. **Stage 1:** Do-able now
(3 agencies & unidentifiable data)
5. Shows pathway to operationalising
(guide, policies, legal, toolkits)
6. Begins **Te Tiriti model data governance** design, puts government and providers at the same table
7. **Proposes Stage 2:** Sector engagement, explore solutions to biggest issues

What the Framework does

3 unique themes

Data Governance decisions to consider:

- 1. Collective ownership**
of data and information by whānau, hapū, iwi, populations and communities
- 2. Collective privacy**
when researching and reporting on whānau, hapū, iwi, populations and communities
- 3. First beneficiaries**
a commitment to benefit those from whom the data is sourced – responsible and constructive reporting and follow through

Legacy snapshot

From	Projects	Leads
1840	Te Tiriti o Waitangi: Article 2. Taonga.	Crown-led
1987-90s	Intellectual & Cultural Property Rights: Embedded in <i>United Nations Declaration on the Rights of Indigenous Peoples</i> & WAI 262 Waitangi Tribunal Claim, 1991 (flora, fauna)	Māori-led
2000s	Māori Creative Commons: New indigenous categories for sharing and protecting indigenous knowledge.	Māori-led
2000s	Māori Metadata Standards: Improving searchability for Te Reo me ōna tikanga artifacts (Dublin Core).	Māori & Government joint
2000s	Māori Privacy Impact Assessments: 'Ownership' of data & information redefined. Addressing gaps in the Privacy Act (1993, 2020), HIPC (1994, 2020) & other legislation/regulations.	Māori & Government joint
2000s	Māori Data Quality: Data quality redefined to encompass Māori views on data that is fit for purpose for IT projects. Attributes, assessments, reviews.	Māori & Government joint
2016	'Māori data sovereignty': Māori data principles and advocacy for Māori rights and interests in data.	Māori-led
2021	Whānau Ora High Court case: Māori health provider Te Pou Matakana and Whanau Ora Commissioning Agency sought judicial review of Ministry of Health's decision not to provide individual data of unvaccinated Māori for targeted COVID-19 vaccination services. The Court upheld on two grounds, and Ministry was directed to remake its decision, and complete its consideration of provision of data in areas where it had not yet agreed to provide it.	Māori-led
2021/22	Wai 1315, Wai 2575, Wai 2687... (noting data and information impact): Māori Primary Health Organisations and Providers claims to Waitangi Tribunal, several claims included. (Concluded that Crown breached Te Tiriti o Waitangi by failing to design and administer an equitable health system for Māori, stating Māori suffered significant prejudice in the primary health care system).	Māori-led

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Legacy snapshot

Selection of previous work with Māori stakeholders from '90s to now:

- Legislated **National Kaitiaki Group** for health data (90s)
- **Māori Land Court** tech, info and cultural issues report (1990s)
- **Waipareira** tech, info and cultural issues report (1990s)
- **KidzNet** Māori kaitiakitanga, data and information policies (1990s-2000s)
- **National Immunisation Register**, kaitiakitanga model (2000s)
- **Hepatitis B Screening & Surveillance Kaitiakitanga** Māori data policy model (2000s)
- **Several Māori information/data/commons/metadata** work in GLAM sector (galleries, libraries, archives and museums) (1990s to 2010s)
- **Toi Tangata** Digital strategy & kaitiakitanga policies, Māori data and information (2017)
- **Pasifika Futures** information policies (replicating and tailoring Māori models) (2021)
- **Te Pūkenga** Māori Sovereignty Model in Data and Digital Strategy (2021)

Key theme
Kaitiakitanga

We assume our rights, so we can focus on our needs.

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Proposed 'stake in the ground' governance for upcoming engagement & design

NOTE: Working alongside team for Data Tripartite Agreement (signed in June and which references Māori Sovereignty Framework).

Together, the 2 tiers ensure consistency at all levels. Both have strong ICT/data *and* tikanga presence.
Design for a 50/50 Te Tiriti partnership model started

TIER 1: Holds kaupapa for improved health outcomes, sets strategic governance, politically savvy

FOCUS: Set strategic governance focus for high-level health outcomes

WHO: Joint Boards Te Aka Whai Ora, Te Whatu Ora (for Te Manatū Hauora) & direct primary sector (IMPBs, Māori health providers) representation, *plus 2 minimum senior data and digital advisors.*

Meets less

Sets high-level strategic governance for Tier 2 to implement

Implements strategic governance and reports back to Tier 1

TIER 2: Implements Tier 1 governance strategy

FOCUS: Ensure consistency and integrity of Tier 1 strategy and governance decisions through to operations

WHO: Tier 2/3 leads from Te Aka Whai Ora, Te Whatu Ora (for Te Manatū Hauora) & direct primary sector (IMPBs, Māori health providers) representation. Tier 2/3 data/ICT leadership presence *plus 2 minimum senior tikanga leaders.*

Meets more

GOAL: GOVERNANCE TO OPERATIONS HAVE CLEAR SETTINGS.

1. Hundreds of requests & increases expected. Can delegate repeated, standard and agreed requests, or lower level decisions if necessary.
2. Noting, currently several data governance groups being proposed or in place 'programme-by-programme' - consolidating is out of our scope but work to invite others to fold into this group is underway.

Operationalising – the parts

'follow the data'

"from culturally-informed data principles and values – all the way to a name_field in a database that stores a tupuna name ..."

FOUNDATIONS

Governance and overarching mechanisms to guide decisions.

Examples:

- Te Tiriti o Waitangi
- Te Ao Māori worldview.
- Principles.
- Key legislation
- Strategies, priorities.
- **Governance (Te Tiriti model) started**

POLICIES

A mechanism for governance and staff.

The guides and rules by which we make decisions that are consistent with the Foundations.

Unique examples: Collective privacy, first beneficiaries, exercise of kaitiakitanga, etc.

OPERATIONS

Data functions that staff perform are consistent with the Foundations and Policies.

Data handling functions, responding to requests, guides, tool kits, roles, etc.

Consistency through induction, workshops, online learning.

SYSTEMS DESIGN

Designing systems is consistent with the Foundations and Policies.

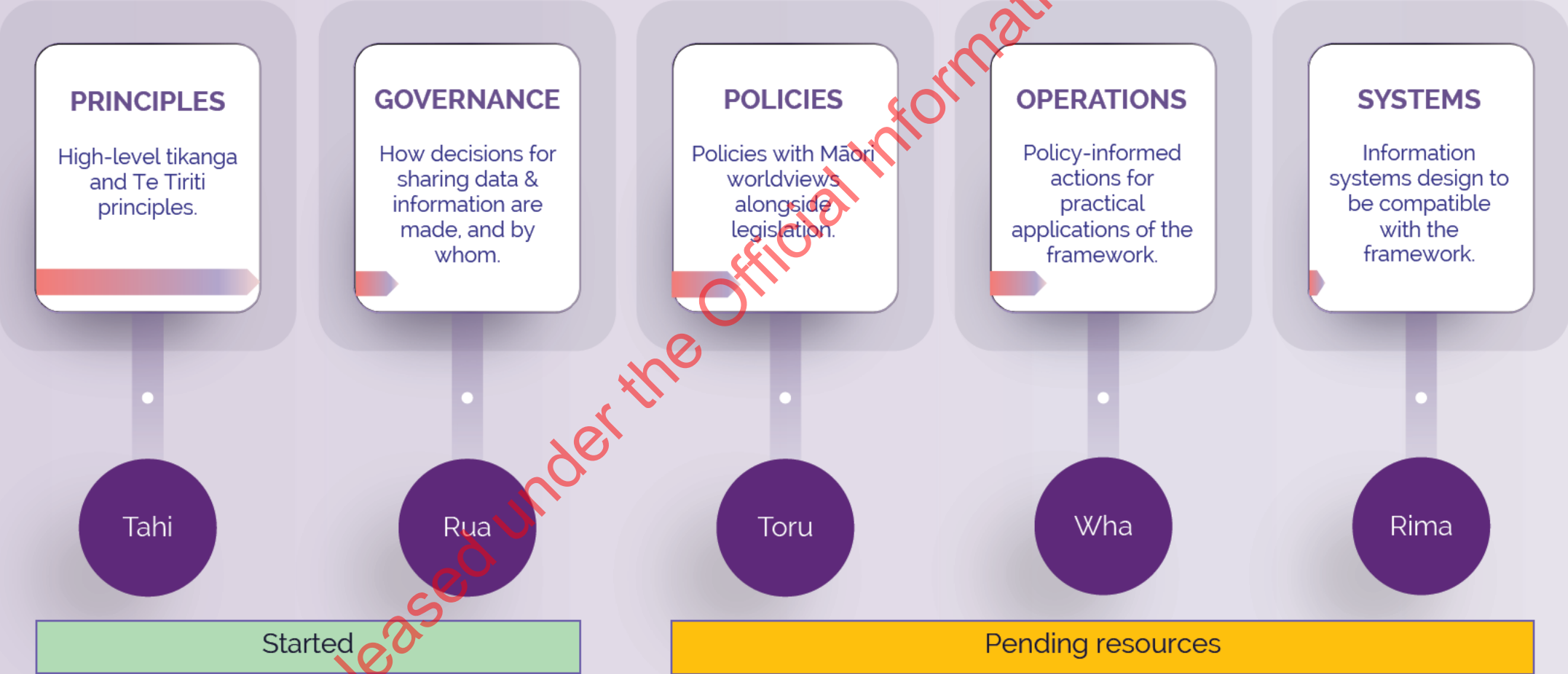
Example: Audit of technical and user specifications for a new system tests whether it is aligned with data governance approaches.

SUCCESS MEASURES

Tools and data that measure the success of this framework against its objectives.

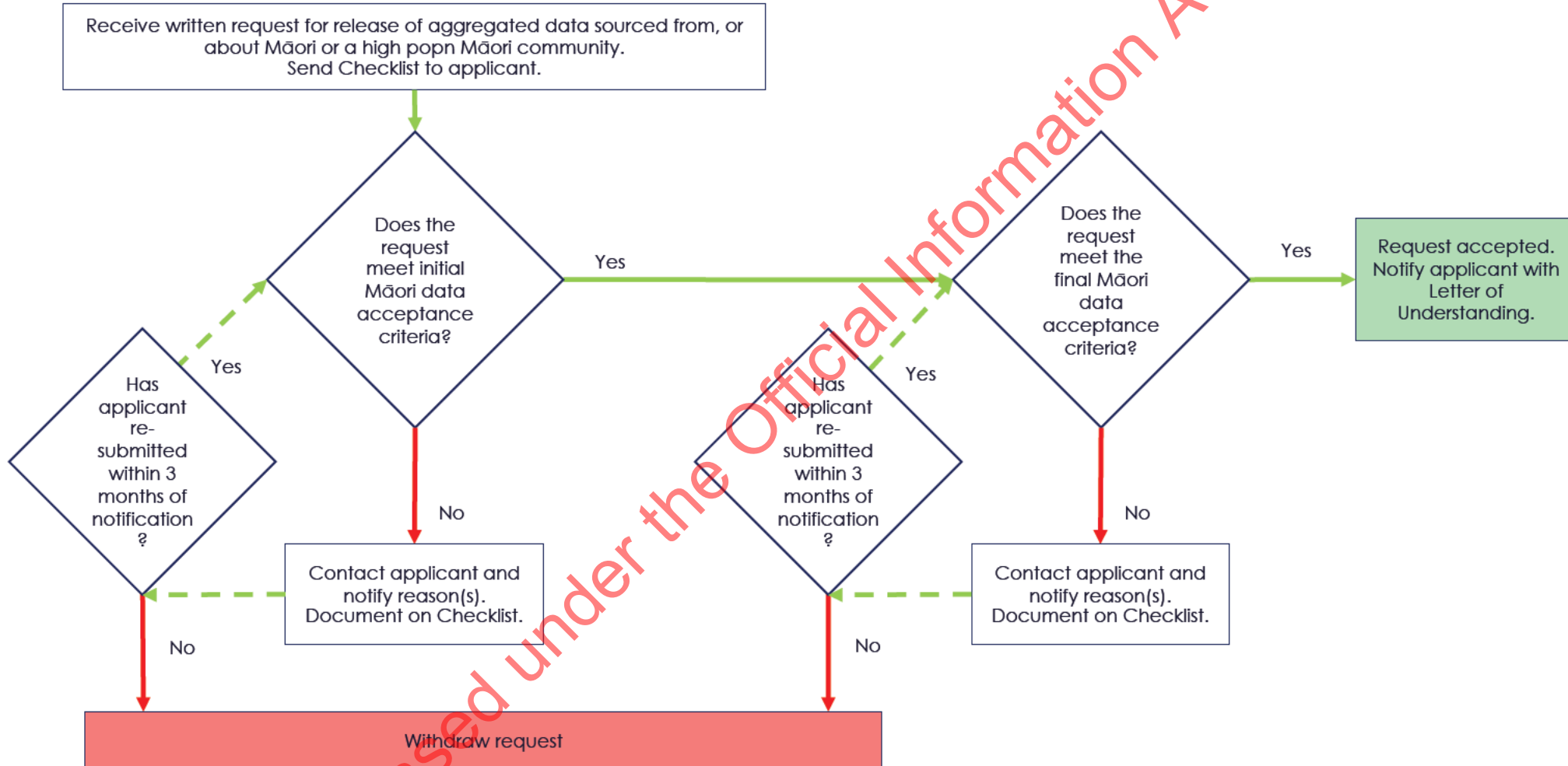
Emphasis on users and communities satisfied that their expectations are met and/or exceeded.

5 step pathway to build and operationalise a framework for health data, information, privacy and security



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Tools: Example decision flow chart



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Small internal trial (started):

- 1. Data Governance Group:** Te Aka Whai Ora staff joined existing DGG where decisions about releasing data from the national collections are made – chance to see existing systems, processes and requests up close - start to test our Framework in a 'live' environment, test discussions at governance table, inform design of Te Tiriti model Data Governance
- 2. Governance:** Actual Te Tiriti model governance design has started alongside Data Tripartite Agreement team.
- 3. Policies:** Refine and extend draft policies in the Framework. Focus on on governance and operations/release policies. Test and review.
- 4. Guides & tools:** Build, test, review (e.g. flowcharts, guides, workshops, induction ...)

Stage 1: Agencies Feasible & achievable

1. Te Aka Whai Ora will lead the MSF work for the three agencies (Data Tripartite Agreement ref to MSF, Joint Board signed off June 2022).
2. Applies to the three agencies only
3. Aggregated and/or unidentifiable (anonymised) data only
4. National collections first with ability to extend (e.g., NSU data may be next extension)
5. Timeframe: End 2022

Work beginning:

1. Scope and plan design started
2. Joined with *Primary Health Dataset Programme* (PHDP) for consistency, potential joint engagement and alignment
3. Light exploratory engagement so far with Iwi, MHPs and Māori stakeholder group identifying issues and needs – ongoing
4. The role they want Te Aka Whai Ora to play is practical, useful
(*“too much engagement, just give us the data and help to use it”* - an Iwi Chair, August '22)
5. Data capability across sector is uneven and tends towards low capability. Our workstream 4: *Virtual data team* will address this directly & reduce the need for data people in every organisation, and create a more equitable data capability environment amongst our providers and IMPBs.

Stage 2: Sector Feasible & achievable

1. To be scoped, staged
2. Pragmatic, useful, enabling, supportive
3. Focus on IMPBs and Māori health providers and interaction with central government (3 agencies)
4. Aggregated and identifiable data
5. Timeframe: TBC, 2023

How the Framework links to rest of our D&D work programme

- 1 Strategy, manage programme, investment, resource, recruit
- 2 ICT Interface with Te Whatu Ora (Agency facing)
- 3 Virtual ICT team (provider facing, MVP, borderless, skills transfer)
- 4 Virtual data team (provider & IMPB facing, MVP, borderless, skills transfer)
- 5 Find, Prove & Scale Innovation (equity, excellence)
- 6 Operationalise Māori Sovereignty Framework & Data Tripartite Agreement
- 7 Build Māori in-sector D&D workforce (100 by end of year)

Note: See next page for the workstreams that are impacted by the MSF workstream

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How the Framework links to rest of our D&D work programme

1

Strategy, manage programme, investment, resource, recruit

2

ICT Interface with Te Whatu Ora (Agency facing)

3

Virtual ICT team (provider facing, MVP, borderless, skills transfer)

4

Virtual data team (provider & IMPB facing, MVP, borderless, skills transfer)

5

Find, Prove & Scale Innovation (equity, excellence)

6

Operationalise Māori Sovereignty Framework & Data Tripartite Agreement

7

Build Māori in-sector D&D workforce (100 by end of year)

No siloes

assume
overlapping
kaupapa

Note:
Impacted
workstreams
are in gold, all
have a link to
this MSF
programme

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- 1. Te Aka Whai Ora**
(lead for the 3 agencies, sets an international precedence)
- 2. Te Whatu Ora (incl Te Manatū Hauora)**
(not yet aligned, disparate legacy work prior to reforms, its D&D will help operationalise to limited extent)
- 3. IMPBs, Māori health providers**
(have mandates, already have decades long approaches to data and information from or about Māori, continue to exercise kaitiakitanga. Want seats at the central government data governance table. S9(2)(g)(i)
[redacted]
[redacted] Many Iwi prefer to be engaged individually)
- 4. Other health, wellbeing, oranga agencies**
(focus on principles, asking for direction from us, not seeking mandate in health sector, just alignment)
- 5. Te Mana Raurunga**
(academics, principles focus, S9(2)(g)(i) [redacted])
- 6. National Iwi Chairs Forum (66 iwi) & its sub-group (Data Iwi Leadership Group)**
(aiming to influence across all government, S9(2)(g)(i) [redacted]
[redacted], DILG going to Māori health providers now. Many non-member iwi, mana whenua and all hapū not included)

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Many groups wanting this space

1. Te Aka Whai Ora
(lead for the 3 agencies in precedence)

2. Te Whatu
(not yet
D&D)

3.

4.

5.

6.

No
Iwi
(aiming
mandate
providers now
hapū not included)

**Recommend we
support & help
connect the
Eco-system**

and also assert that
Te Aka Whai Ora lead in its
own sector, while privileging
our Iwi and Māori health
providers, whānau,
communities and IMPBs

**Many groups
all wanting
this space**

Māori Sovereignty Framework

Health data, information, privacy & security for Māori

Te Aka Whai Ora

Māori Health Authority

Next steps

Many requests from central government agencies, our sector, and other organisations to see this work and consider aligning

Te Aka Whai Ora DDI will soon request Board support to:

1. **Share the Stage 1 work with all three agencies** to develop shared governance, policies and guides for consistent application
2. **Share the approach to the wider sector** – pragmatic & supported (e.g., virtual data team, data sharing templates, governance templates and toolkits)
3. **Enter into Stage 2, sector engagement** to assist to convert the biggest issues into solutions (e.g., identifiable data sharing, data capability)

we are here ...

and a little bit here

Te Aka Whai Ora

1. Draw from legacy work from UNDRIP and Wai 262, Māori providers and MOH work (90s-2020s).
2. Begin to align with similar teams and programmes in MOH and Te Whatu Ora.
3. Build out draft framework to operationalise.

Stage 1: 3 Agencies

1. Work with similar teams in MOH and Te Whatu Ora for consistency.
2. Progress towards all-agencies adoption.
3. Build out function: Governance, policy suite, processes for data requests, tool kits, training all staff, etc.

Stage 2: Sector

1. Share approach for the sector where they interface with our 3 agencies.
2. Help connect eco-system.
3. Build virtual data teams for sector for their data approaches, tool kits, data capability, etc.
4. Help find solutions for the biggest issues

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Te Aka Whai Ora is exploring its role in enabling and connecting the health sector and its communities, in support of their mana motuhake over data and information

(Noting, the eco-system is organic and evolving)

Recommended Te Aka Whai Ora messaging

Situation:

1. Disparate responses from Māori to sharing, privacy reveal we can't assume everyone will agree with one approach
2. "Māori data" not well-defined (e.g. legal, cultural)
3. The word "sovereignty" is receiving a negative reaction from some
4. Complex scenarios based on who holds data about Māori, where it is, and for what purposes is still to be mapped
5. Some IMPBs and providers fear their relationships with their communities will be at risk if the handling of data is not carefully managed
6. External groups wanting to lead but are not health sector and mandates being debated, some tension arising.

Te Aka Whai Ora should lead in its space, and also act as an enabler to help connect the health eco-system, look for alignments and offer tangible support to IMPBs and providers by offering shared resources (e.g. templates data sharing agreements, policies/toolsets), seats at central government governance table, and inclusion in the design of a Te Tiriti model for data governance.

Operationalising – the parts

NOTE	<p>a. Note the pre-draft Māori sovereignty framework for data, information, privacy and security paper is receiving feedback from MoH and Te Whatu Ora data and HIRA leads, and their teams, who are now engaging with Te Aka Whai Ora data and digital on this topic.</p> <p>b. Note a small central agency-only trial is underway to test the Stage 1 operationalising of the Framework – and to help inform the future rollout of the Framework.</p>
AGREE	<p>c. Agree the sequence of visibility of the next Draft of the Māori sovereignty framework: Health data, information, privacy and security paper for feedback to:</p> <ul style="list-style-type: none">• JOG: the LTs of MoH and Te Whatu Ora at their request;• Joint Boards committee, at their request.• Noting Te Aka Whai Ora LT and the Joint Boards requested it go to this Board first.
APPROVE	<p>d. Approve (1) the staging approach (3 agencies followed by Sector), and (2) scoping that makes it feasible to implement between the three agencies (national collections first, extended to other collections over time), while also meeting the iMHA workplan (November 2021) deliverable (see Remit section, point 3 below).</p>
AGREE	<p>e. Agree that a health sector engagement process be initiated as part of Stage 2 (above) to understand the position of Māori health providers and IMPBs on (1) sharing identifiable data and (2) their expectations of their roles, mandates and outcomes relating to central data governance, and (3) noting the data governance design (Te Tiriti model) work is underway by a Te Aka Whai Ora designed process of codesign between Te Whatu Ora DISH (Data & Information Strategy for Health & Disability) and DTA (Data Tripartite Agreement) teams and Te Aka Whai Ora Data and Digital and Policy teams.</p>