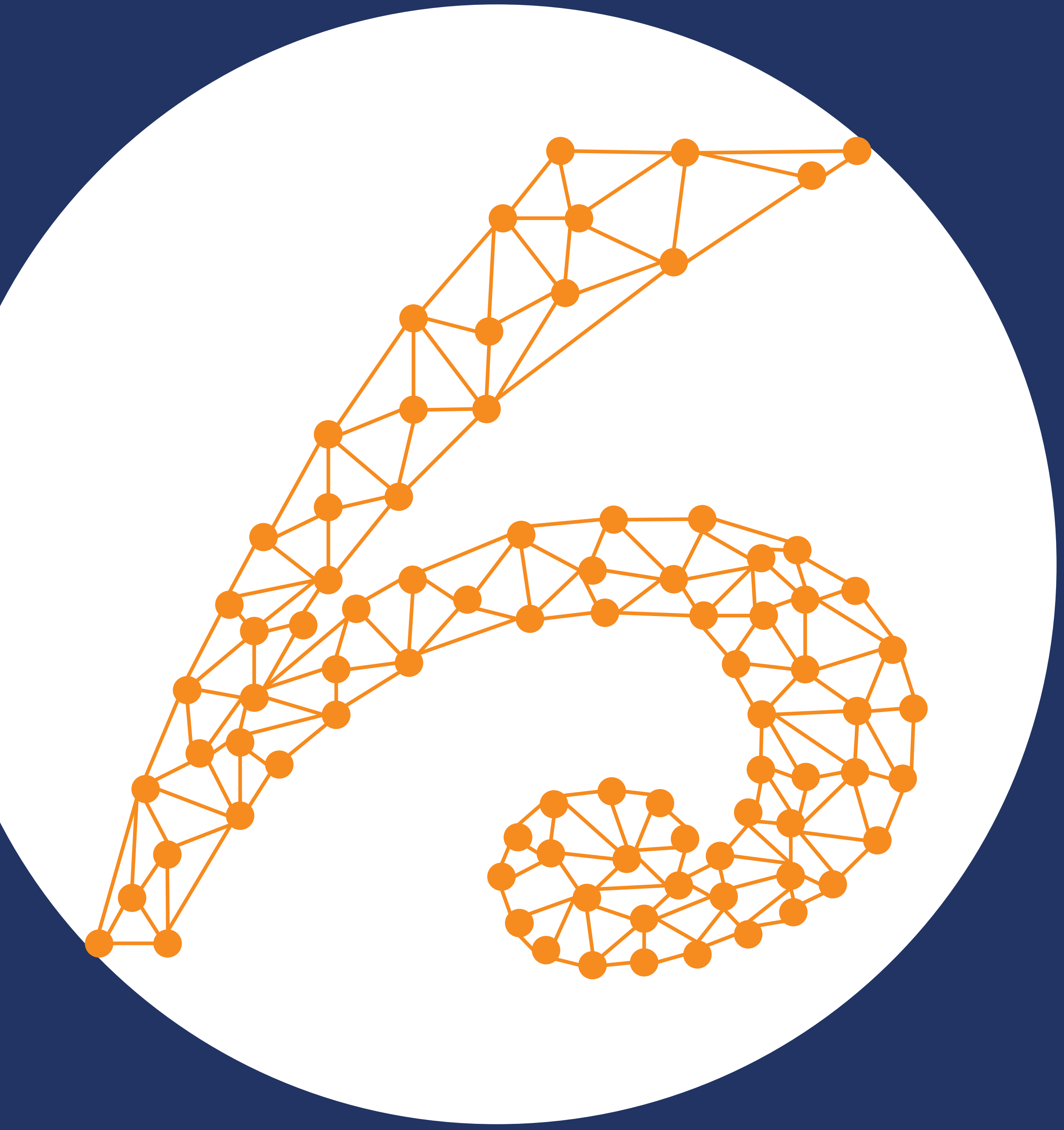
MINISTRY OF HEALTH
MANATŪ HAUORA



Health Data NZ 2019

National Health Information Platform

Data considerations

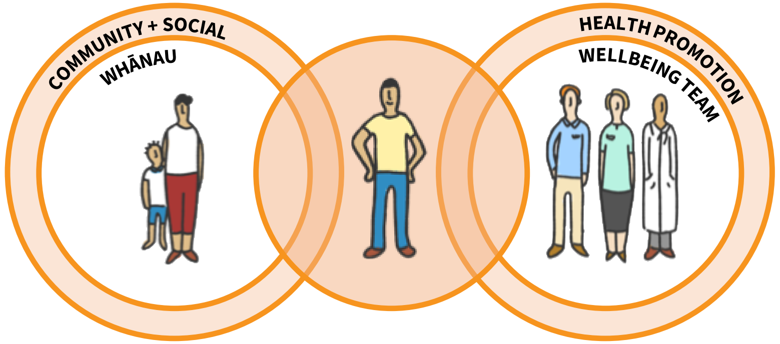
November 2019

The Shift

EPISODIC ILLNESS

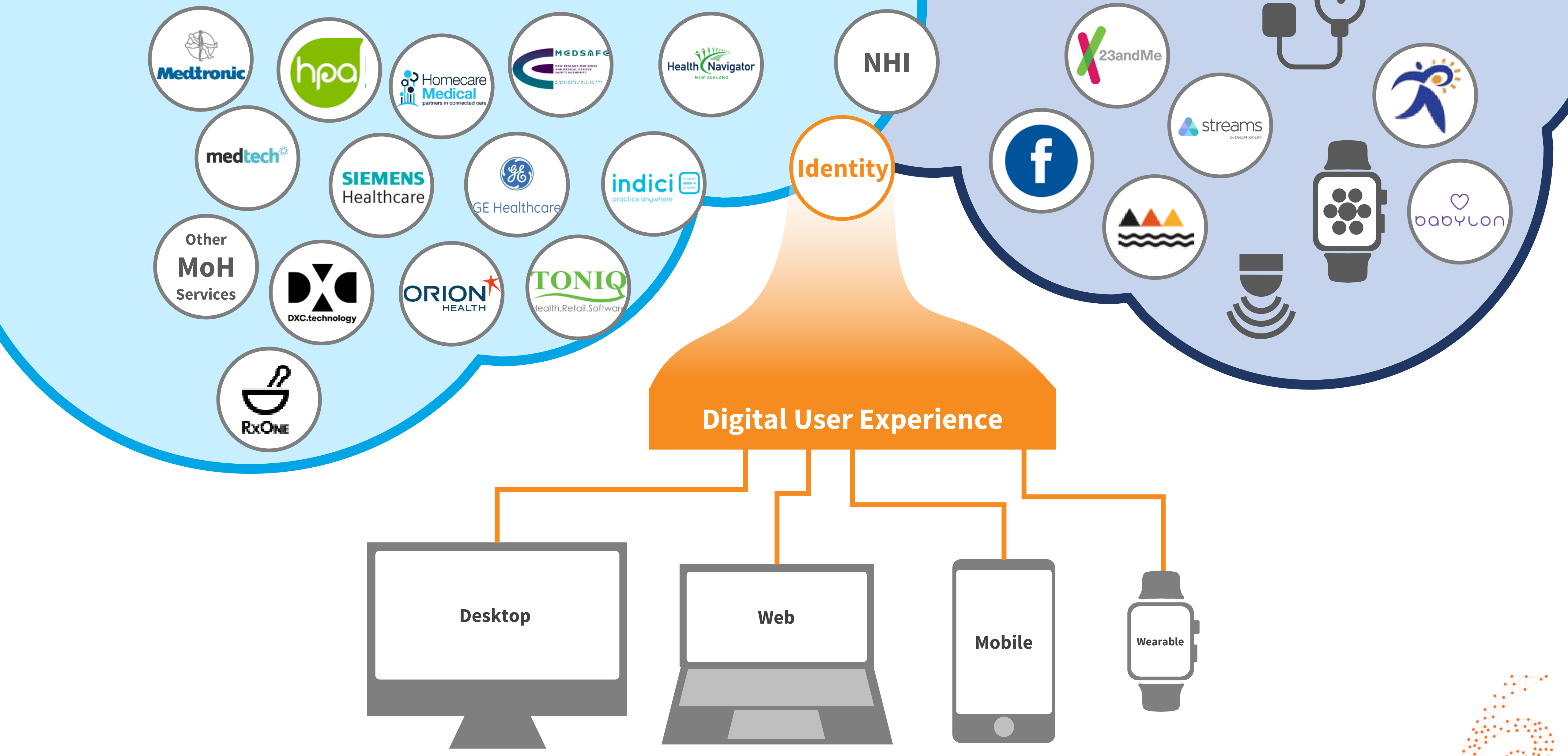
View (Portal, Letter, TXT, Facsimile)

WELLBEING



Do (Actionable, Accessible and Interactive)

Creating a Digital User Experience



NHI

Other MoH Services

Identity

Digital User Experience

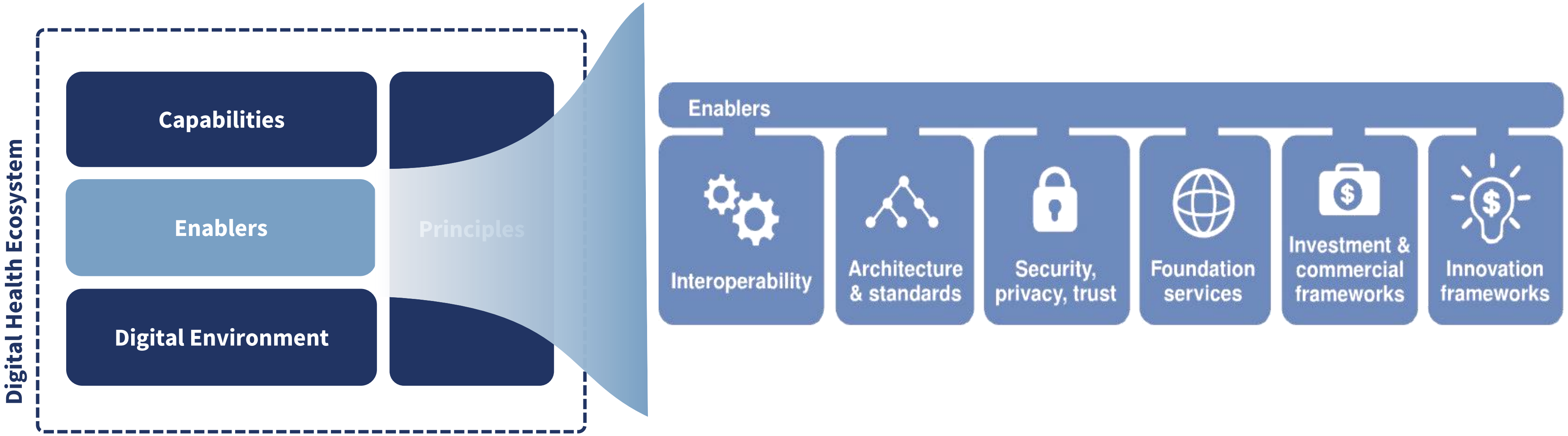
Desktop

Web

Mobile

Wearable

Strategic context



Digital Health Ecosystem

Capabilities

Enablers

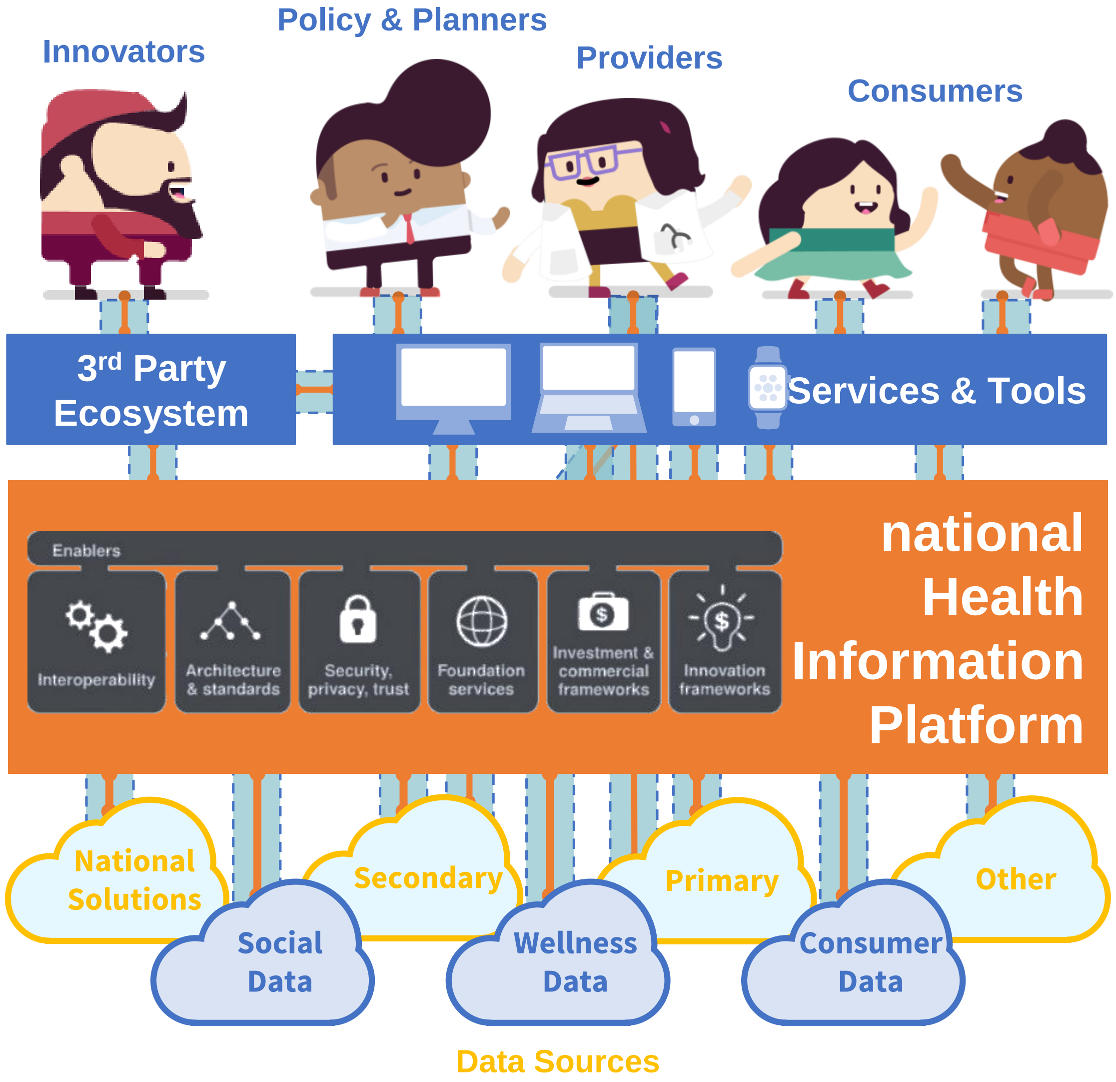
Digital Environment

Principles

Enablers

- Interoperability
- Architecture & standards
- Security, privacy, trust
- Foundation services
- Investment & commercial frameworks
- Innovation frameworks

What is a national Health Information Platform?



Innovators

Policy & Planners

Providers

Consumers

3rd Party Ecosystem

Services & Tools

Enablers

- Interoperability
- Architecture & standards
- Security, privacy, trust
- Foundation services
- Investment & commercial frameworks
- Innovation frameworks

national Health Information Platform

National Solutions

Secondary

Primary

Other

Social Data

Wellness Data

Consumer Data

Data Sources

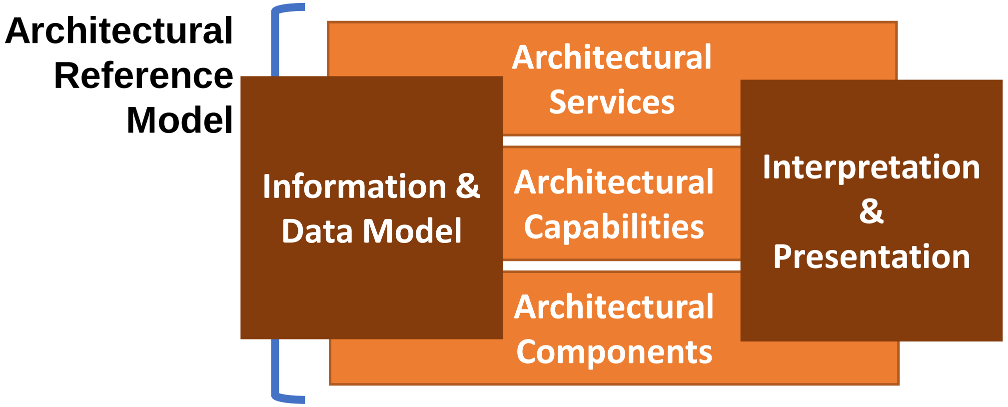
	Tranche 1: Must	*Should*	*Could*
nHIP endorsed • Sector delivered • MoH supported exemplars	• Identify and support sector uptake and innovation using nHIP enablers	• Online ACC claiming service	•
nHIP products • MoH commissioned	• Universal consumer service • Universal provider service • nHIP data service	•	•
nHIP certified • Market delivered • MoH certified	• Patient portals • DHB clinical portals • GP PMSs • Key NGO systems	•	•
nHIP enablers • MoH accountable	• Target digital equity challenges • Establish Digital Health Identity • Standards development • Establish data governance and privacy framework • Establish and maintain social license • View data access history • Consent to data access by 3rd party provider • Commercial and innovation frameworks	• Link to available sources of trusted health information • Link to available sources of trusted health service information • Export patient summary record utility • Directory service to enable vendor agnostic data exchange	• Enable delegation of access and controls authorised by the patient • Data anonymisation service • Bulk data download service
nHIP data • MoH accountable	• View/update demographics • View medicines • View immunisations • View lab diagnostics	• View allergies • View screening results • View eligibility and entitlement details • View/update self reported adverse drug reactions • View forward appointments and planned events • View encounter and event history	• View radiology reports and images • View advanced care directives • Book/update forward appointments and planned events • View diagnoses • View current conditions/problem list

nHIP Business Case development workstreams

Architecture
Peter Marks
Manager Architecture & Standards

Operating Model
Michael Dreyer
GM National Digital Services

Research & Discovery
Jon Herries
GM Emerging Health Technology



Key relevant Architecture Principles/Definitions

- Data remains at source
- Publish and Subscribe
- System of Record
- Source of Truth

Architecture
Peter Marks
Manager Architecture & Standards

Information and Data

Health Data

- Demographics
- Medications
- Immunisation
- Alerts
- Allergies and Adverse Reactions
- Conditions and Diagnoses
- Procedures
- Appointments and Orders
- Results and Observations
- Clinical Summaries
- Transfer of Care (ADT)
- Care Team (incl. whanua)
- Care Plans
- Health Events and Encounters
- Medical Equipment

Health Support Data

- Eligibility
- Entitlements
- Capacity and Availability
- Notifications
- Enrolment
- Claims
- Knowledge and Analytics

Foundation Data

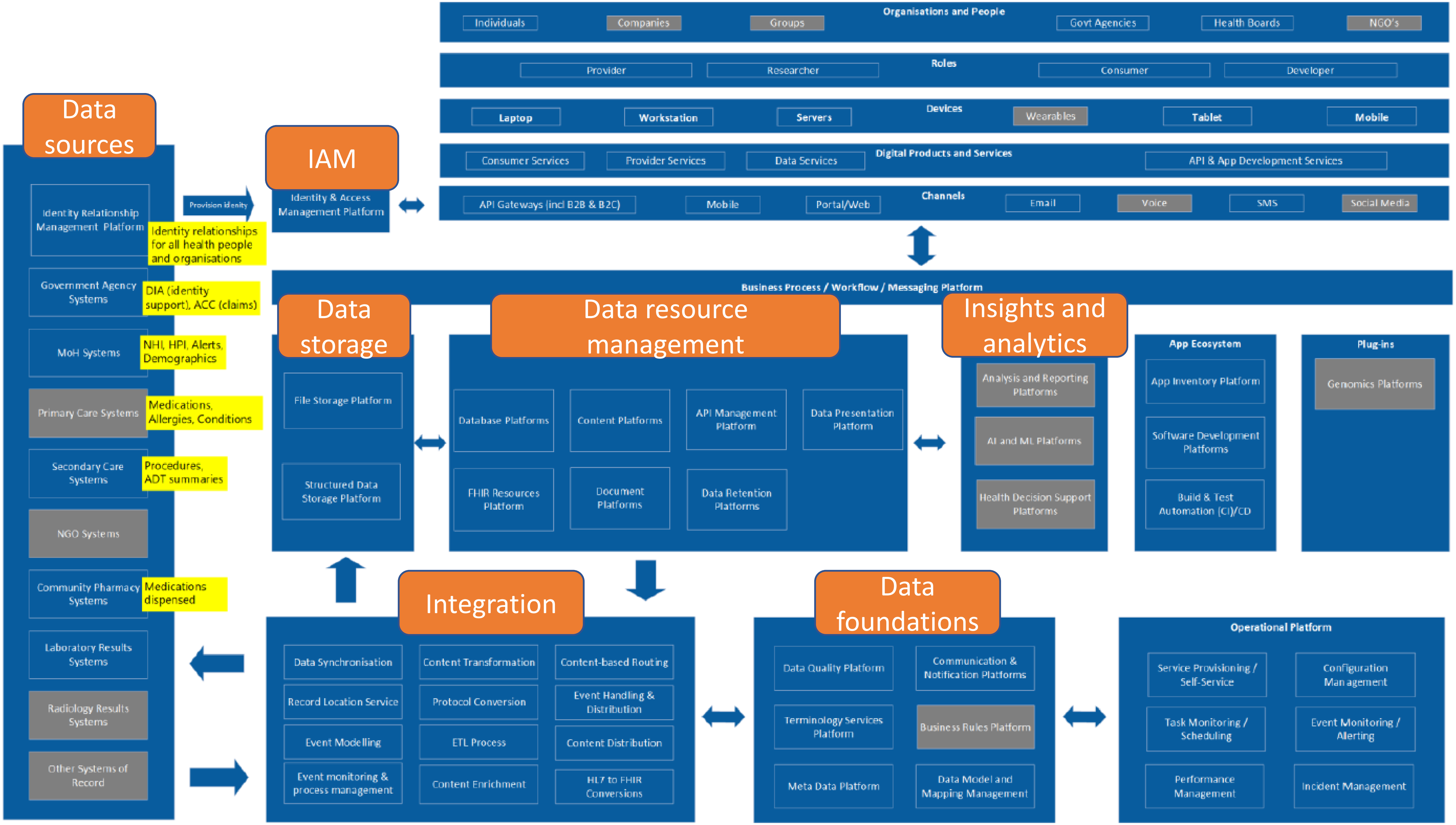
- Identity
- Consumer
- Provider
- Facility
- Organisations and Roles
- Security, Access and Audit
- Healthcare Services
- Assurances

Wellness Data

- Social Determinants
- Family History
- Environmental
- Financial

Technical architecture

Architecture
Peter Marks
Manager Architecture & Standards



Organisations and People
- Individuals
- Companies
- Groups
- Govt Agencies
- Health Boards
- NGO's

Roles
- Provider
- Researcher
- Consumer
- Developer

Devices
- Laptop
- Workstation
- Servers
- Wearables
- Tablet
- Mobile

Digital Products and Services
- Consumer Services
- Provider Services
- Data Services
- API & App Development Services

Channels
- API Gateways (incl B2B & B2C)
- Mobile
- Portal/Web
- Email
- Voice
- SMS
- Social Media

Business Process / Workflow / Messaging Platform

Data sources

- Identity Relationship Management Platform — Identity relationships for all health people and organisations
- Government Agency Systems — DIA (identity support), ACC (claims)
- MoH Systems — NHI, HPI, Alerts, Demographics
- Primary Care Systems — Medications, Allergies, Conditions
- Secondary Care Systems — Procedures, ADT summaries
- NGO Systems
- Community Pharmacy Systems — Medications dispensed
- Laboratory Results Systems
- Radiology Results Systems
- Other Systems of Record

Provision identity

IAM

- Identity & Access Management Platform

Data storage

- File Storage Platform
- Structured Data Storage Platform

Data resource management

- Database Platforms
- Content Platforms
- API Management Platform
- Data Presentation Platform
- FHIR Resources Platform
- Document Platforms
- Data Retention Platforms

Insights and analytics

- Analysis and Reporting Platforms
- AI and ML Platforms
- Health Decision Support Platforms

App Ecosystem
- App Inventory Platform
- Software Development Platforms
- Build & Test Automation (CI)/CD

Plug-ins
- Genomics Platforms

Integration

- Data Synchronisation
- Content Transformation
- Content-based Routing
- Record Location Service
- Protocol Conversion
- Event Handling & Distribution
- Event Modelling
- ETL Process
- Content Distribution
- Event monitoring & process management
- Content Enrichment
- HL7 to FHIR Conversions

Data foundations

- Data Quality Platform
- Communication & Notification Platforms
- Terminology Services Platform
- Business Rules Platform
- Meta Data Platform
- Data Model and Mapping Management

Operational Platform
- Service Provisioning / Self-Service
- Configuration Management
- Task Monitoring / Scheduling
- Event Monitoring / Alerting
- Performance Management
- Incident Management

Standards

Architecture

Peter Marks
Manager Architecture & Standards

CORE PERSONAL HEALTH INFORMATION

September 2019

Draft data requirements for the national Health Information Platform (nHIP)

DEMOGRAPHICS

Consumer characteristics that will help with identification and categorisation

Useful for: *helping to ensure the right individual is in context when interacting with the healthcare system.*

Supporting policy, investment and planning at a population health level

May include: *gender, DOB, blood type, ethnicity, contact information, emergency contact and GP details, enrolled PHO, care programme eligibility and insurance information where relevant*

CONSUMER GENERATED

Any information that is contributed by consumers and/or their carers that could be clinical or non-clinical information that the consumer finds important

Useful for: *enabling consumers to contribute directly to their own record through wearables and home monitors, and to capture relevant information and story from their perspective*

May include: *a consumer's story which could include personally relevant and translated information from clinical notes, personal, family and social history, preferences, beliefs, interaction channels, notes and annotations, data from wearables, appointments, reminders. Consumer satisfaction/outcome measure scores, height, weight, blood pressure, daily living activities*

MEDICATIONS

A consolidation of medications information that may have been prescribed, dispensed and/or taken by a consumer

Useful for: *understanding the range of drugs that the consumer currently should/is taking to treat their health condition/manage their wellness*

May include: *prescribed medications, non-prescribed drugs being taken, alternative & traditional medicines, supplements, different medications from different providers and events, consumer contributed over the counter medications*

MEDICAL HISTORY

Historical information and events that the consumer/whānau has previously encountered including primary, community and acute instances to understand and help formulate the overall health picture

Useful for: *getting a more comprehensive overview of a consumer's healthcare interactions that could improve clinical diagnosis, treatment, and condition management*

May include: *relevant diagnosis, problems (including general and mental health and social) and treatments or therapies a consumer has undergone (eg, type of surgery, specialist care), relevant medical events (incl. adverse), oral health, medical devices*

ALLERGIES

A list of all known allergies/reactions a consumer has for particular medications/substances through any of the senses

Useful for: *ensuring that where possible, clinical procedure and medication prescribed/dispensed will not harm the consumer given their allergies*

May include: *medication allergies, seasonal allergies (ie, pollen during spring), materials (eg, certain materials used in syringes), bee stings, food allergies*

IMMUNISATIONS

The vaccines, medicines and treatments associated with making a consumer immune/resistant to certain complications/diseases

Useful for: *understanding what common diseases/complications a consumer is immune or prone to and helps design treatment (including providers' safety)*

May include: *vaccination names, types and dates (including due dates for repeats), administration method and provider details*

FLAGS

Flags/signals set to prompt when a certain attribute is triggered that could be used for warning, workflow and notification purposes

Useful for: *improving interactions with consumers (eg, mental health flags, notification of death), prompting necessary action and monitoring*

May include: *changes in a consumer's condition, existence of a mental or sexual health record, availability of other existing records (eg, ACC), enrolment status in other programs (eg, Well Child or Oral Health), eligibility for services and funding, safety*

DIAGNOSTICS

Information related to laboratory samples, tests, imaging and research associated with a consumer's health/wellness

Useful for: *Understanding the scientific and detailed diagnosis of a person's health/wellbeing (where data exists) in order to help problem identification and diagnosis. Identifying/avoiding duplicate tests, and reports*

May include: *pathology results such as blood and tissue samples, lumbar puncture results, hair and saliva samples, medical imaging, endoscopic reports, consumer entered diagnostics*

CARE PLAN

A planned set of directions that have been co-created to help consumers and their carers/whānau address a consumer's specific health and wellbeing needs, and supporting care co-ordination across different speciality and care providers

Useful for: *providing meaningful ways to improve consumer's wellbeing through shared communication with providers, coordinating care, monitoring progress and condition management, improving the health literacy of consumers and their carers*

May include: *maternity, dental, diabetes, complex conditions, palliative, aged residential and Allied Health created care plan; action plans; and follow-up plans, progress notes and outcomes*

TRANSFER OF CARE

Documents or artefacts associated with the transfer/continuity of care moving from one care setting to another

Useful for: *ensuring consumer doesn't have to repeat their health story and clinicians understand the reason, medical diagnosis and justification for transferring care from one setting to another*

May include: *shared health documents, discharge summaries, birth summaries, referrals, event summaries, specialist letters*

SOCIAL/ENVIRONMENTAL

Contextual social or environmental information that could help inform or add to more holistic and timely view of a consumers changing needs

Useful for: *understanding the other contributors to an individual's health/wellbeing that could help identify root causes prompting appropriate actions and referring or recommending consumer to relevant supporting services*

May include: *notes on a consumer's living conditions such as home, socioeconomic, observations and warning signs from home visits and conversations*

ENCOUNTERS

Summary information about planned and unplanned use of health services, including past events and upcoming appointments

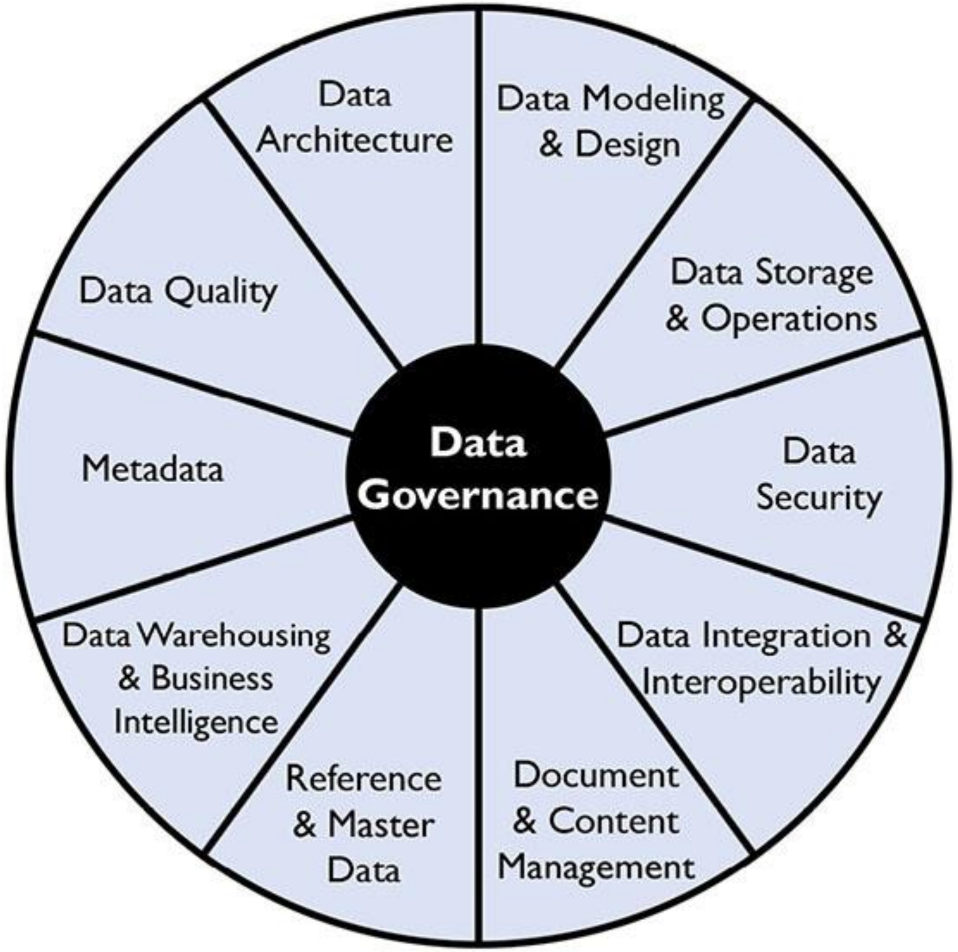
Useful for: *understanding sequences of events in the patient's health pathway and valuing their time in their interactions with health services*

May include: *time, place and service details for each event, reason for presenting and other event- and pathway-related information*

hiso
Health Information Standards Organisation
PAEREWA PĀRONGO HAUORA

Patient Summary Standards Set

Data considerations



DAMA-DMBOK2 Data Management Framework

Health Information Standards Organisation
PAEREWA PĀRONGO HAUORA

Operating Model
Michael Dreyer
GM National Digital Services

HISO 10064:2017

Health Information Governance Guidelines

August 2017

Information Governance Principles	
Quality and Trust	Consumer right to access Consumer right to correction and annotation *Consumer right to contribute*
Privacy and Transparency	Consumer visibility of access and sharing Consumer control over sharing preferences
Disclosure	Provider right to access if required and consented
Security	Compliance with HISF

“People have rights over health information about themselves and health agencies have obligations over the health information they hold.”

Health Information Privacy Fact Sheet 1: https://privacy.org.nz/news-and-publications/guidance-resources/health-information-privacy-fact-sheet-1-overview/

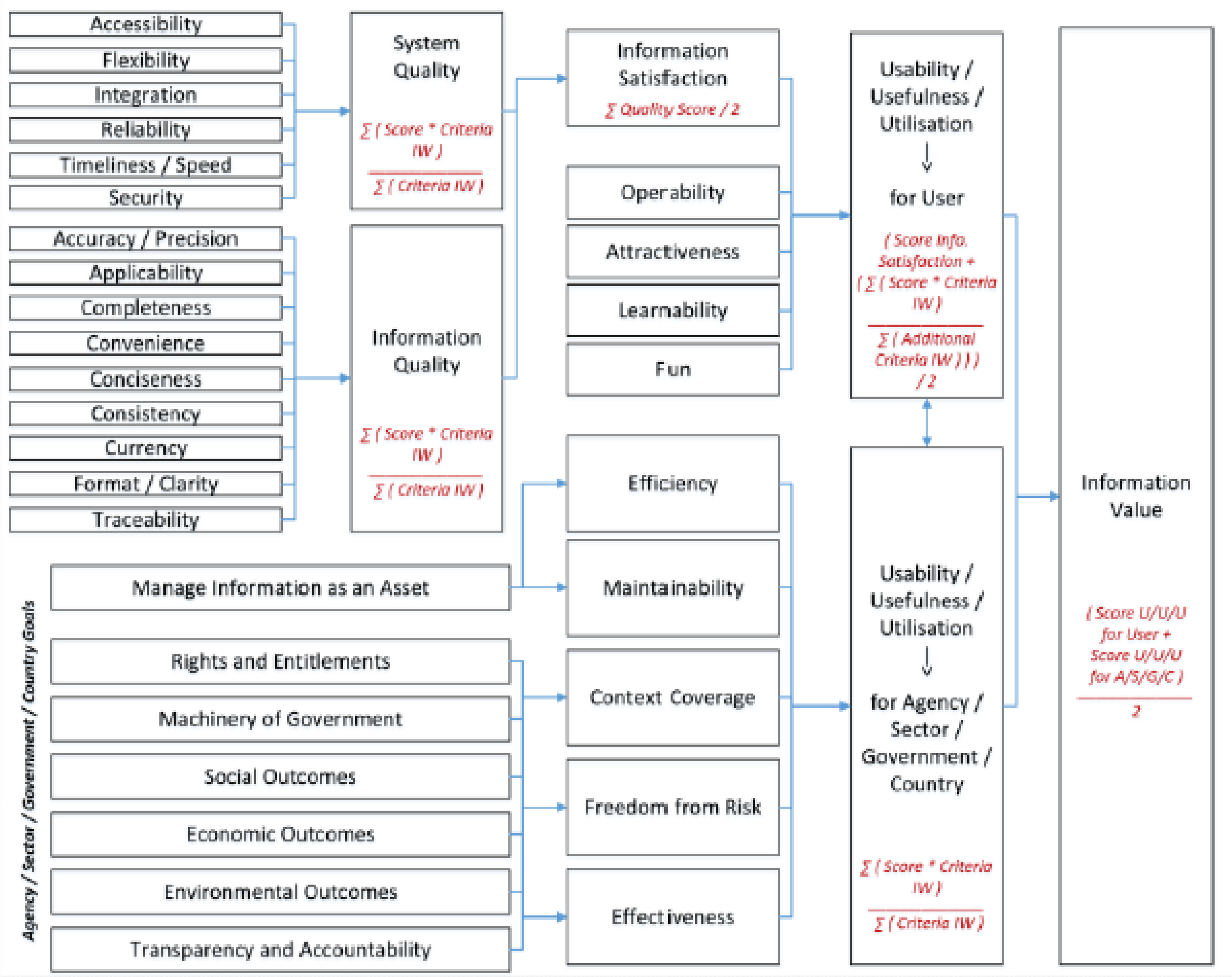
Data considerations

Operating Model
Michael Dreyer
GM National Digital Services

Data & Information Management Framework
Guide
New Zealand Government

Principles for High Quality Information

- Accuracy
- Consistency
- Relevance
- Completeness
- Timeliness
- Provenance
- Value
- Usefulness
- Trust



Data Protection and Use Policy to support the respectful, trusted and transparent use of people's data and information

Operating Model

Michael Dreyer
GM National Digital Services

Policy Principles: articulate the values and behaviours that underpin the respectful and transparent use of people's data across the social sector.

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

Strive to create positive outcomes from any collection, sharing or use of data and information. Use appropriate checks and balances and ensure that information is suitable and reasonably necessary for the intended outcome.

Mana whakahaere

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

Where possible, give people choices and respect the choices they make. Give people easy access to and oversight of their information wherever possible.

Manaakitanga

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

Recognise and incorporate diverse cultural interests, perspectives and needs. Include and involve services users whenever possible. Incorporate the needs and priorities of people with a special or particular interest in what is done with their data and information.

Mahitahitanga

Work as equals to create and share valuable knowledge

Confidentially share relevant information between professionals so people get the support they want and need. Make sure there is a two-way street of sharing (de-identified) data, analysis, results and research findings to grow collective knowledge and improve services.

Kaitiakitanga

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

Recognise you are a kaitiaki, rather than an owner of data and information. Be open and transparent; and support people's interest or need to understand. Keep data and information safe and secure and respect its value.

Policy Guidelines: describe good practice in undertaking key activities in accordance with the five Principles above.

Purpose Matters

Be clear about the purposes of collecting personal information, only collect what's needed, and consider how collection and use could affect people's wellbeing.

Transparency and Choice

When collecting information from people, help them understand why it's being collected, how that might help them or people in similar circumstances, and what rights they have to access and request changes. Provide them with choices whenever possible.

Access to Information

Help people to understand what personal information is held about them, to access it, to request correction of it and, where possible, to correct it themselves.

Sharing Value

Work together and be inclusive to ensure that information used to create insights is relevant and usefully describes real experiences. Share insights that deliver value and improved wellbeing.

Data considerations

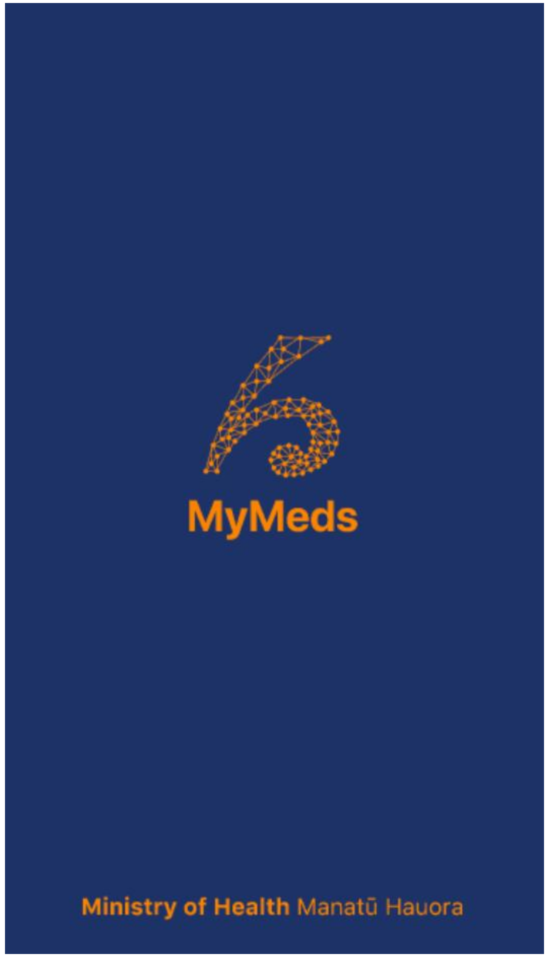
Research & Discovery
Jon Herries
GM Emerging Health Technology

“Explaining my medications” is consistently the lowest scoring answer in the national patient experience survey. **Only 52% of patients answer most positively** – cf. 85% overall (Aug 2018)

It has been estimated that medicine related harm currently costs the NZ health system **$222.5m per year**.

New Zealand received **300** consumer reported side effects for medicines in 2018

It is estimated that non adherence to medicines for chronic conditions costs the health system **$317 billion** globally each year.

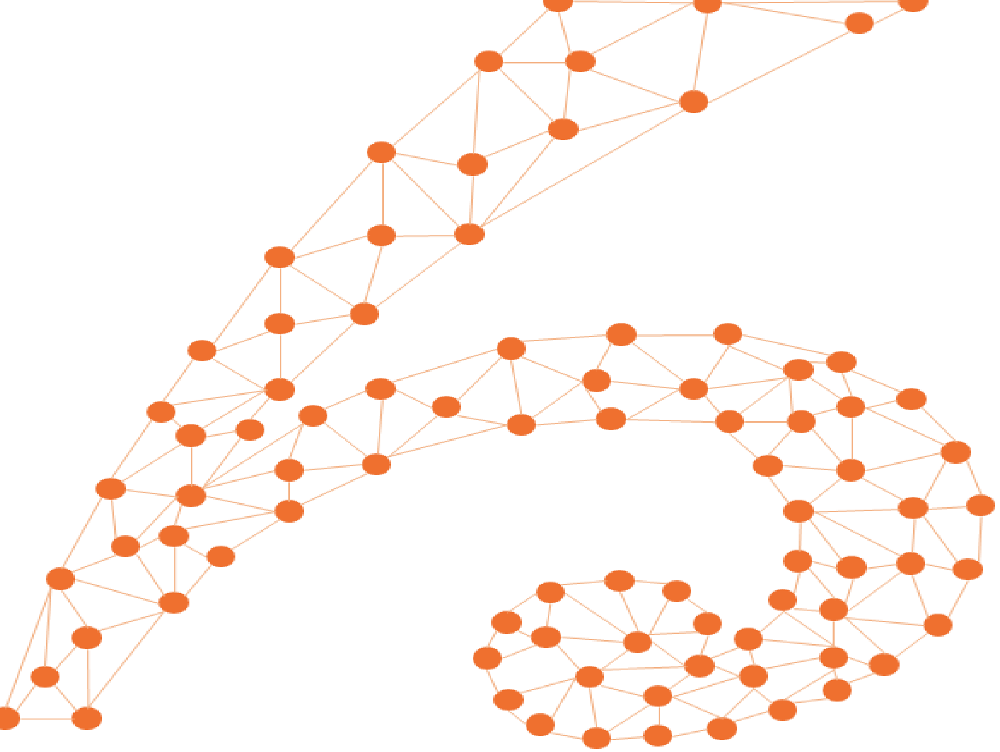


Our information is **focused on clinicians not consumer**. Only **70/100** most prescribed medicines have a PIL

There is little in the public domain about **how to interpret and present health information** to consumers

Using an agile approach and public cloud tools is cheap and fast to build and run

We need **“do” not “view” services** to drive engagement



- Health Information and Data sharing (Interoperability)
- Architecture and Standards
- Privacy, Security, Trust
  - Data stewardship
  - Consent and Social License for data use
  - Data and Information Governance
  - Data Protection and Use
  - Maori Data Sovereignty
- Enabling Foundation services and technology
    - Identity
    - Access Management
    - Integration
- Data and Information Management
  - Data acquisition and collection, Data storage, Data curation, Metadata management, Data quality management, Business rules, Data presentation etc
- Data insights and analytics

How do we engage effectively with you?