



THE MISSING LINK – BETTER DATA SHARING

ON 21 APRIL 2021, HEALTH MINISTER ANDREW LITTLE ANNOUNCED SWEEPING REFORMS OF NEW ZEALAND'S HEALTH SYSTEM, ENVISIONING A FUTURE WHERE SERVICES WILL BE INTEGRATED AND LINKED AND PATIENTS WON'T HAVE TO CONSTANTLY REPEAT THEIR INFORMATION. WHY ISN'T PATIENT INFORMATION ROUTINELY SHARED AND ARE THEIR PLANS FOR THAT TO CHANGE? CONNECT EDITOR REBECCA MCBETH INVESTIGATES.

In announcing plans for a newly reformed health system Minister Little said, "with appropriate safeguards in place, you should be able to turn up anywhere in the health system and know that the health professional seeing you has access to relevant health information about you".

The fact this is not currently the case comes as a surprise to many patients who assume that relevant information is already routinely shared between health professionals involved in their care, says Health Consumer Advisory Service member Kylie Head.

She says patients get extremely frustrated having to repeat their story time and again to every new person they see in the health system and there is an inherent danger in patients forgetting things.

The solution

The government's plan to enable better data sharing is to develop an ecosystem of trusted digital services named Hira (previously called the national Health Information Platform).

While the detailed business case is still awaiting approval, Hira has been funded in the 2021 Budget as part of an investment of \$385 million over four years for health sector data and digital infrastructure and capability.

One solution for being able to view every New Zealander's health information in one place is to pull all the relevant information into a single system that patients and health providers can access.

New Zealand has chosen to pursue a data led strategy based on standards and interoperability, where information continues to be held in

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Having to repeat their medical history, identify other health providers involved and coordinate care plans with someone they do not know also creates stress and anxiety for people, particularly those with mental health issues.

"If there was a fluid transition of medical data throughout all health services, that would be the nirvana," she says.

multiple systems, but can be drawn together as needed to create a 'virtual electronic health record'.

Once the detailed business case is approved, work on Hira will begin and the first tranche is expected to run until late 2023 or early January 2024. This first phase of investment will develop data services that enable health information to be viewed in certified applications used by health

WE SPOKE WITH...



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"I COULDN'T IMAGINE PRACTISING WITHOUT HEALTHONE IN MY HOSPITAL CLINICS – IT JUST WOULDN'T BE SAFE." – MARTIN WILSON

professionals across the health and disability system.

Also, applications and websites which will allow consumers to securely access their own information and health providers to access relevant information for their patients.

A siloed system

Patients want to own their own data, allowing them to both access it themselves and control who else can access it within the health service.

But patient data is tied up in thousands of siloed systems that often cannot, or will not, 'talk' to each other. This means relevant information is not always available to help patients receive the care they need, impacting on clinical decision making, timely intervention and coordination of services.

In some parts of the country, information sharing between hospitals and with other care providers is routine, but in others it is not and sharing beyond regional borders is rare.

New Zealand has 20 DHBs, grouped into four 'regions' – Northern, Midlands, Central and Southern – which are all in different stages of developing their own regional

approaches to allow information sharing between hospital systems, but these do not often exchange information across their geographical boundaries.

The South Island's hospital clinical portal is called Health Connect South and connects the region's five DHBs, to enable connected care irrespective of healthcare facility.

The South Island also has a common patient record called HealthOne, which provides an integrated view of primary care information about every person, including GP records, prescribed and dispensed medications, classifications and some health measurements.

HealthOne records are securely accessed around 200,000 times a month by registered healthcare providers involved in a patient's care. The shared record system's clinical lead Martin Wilson says this level of access could be said to be validation of its usefulness to front line clinicians.

Having access to HealthOne has shifted his interaction with new patients at his hospital clinic from 'please tell me about your medical history so I can care for you safely?' to 'this is what I know about your health history, what am I missing?'

He believes this is a paradigm shift which supports the patient belief that medical information is known where appropriate across the system to healthcare providers and goes some way towards addressing the very frequent complaint from patients of 'telling their story over and over and

over again' to different providers.

"That's a huge shift," Wilson says.

"I couldn't imagine practising without HealthOne in my hospital clinics – it just wouldn't be safe.

Building social license

Key to getting information sharing right, is addressing issues around privacy, security and confidentiality first and ensuring everyone understands the rules for sharing information safely.

Consumer advisor Kylie Head, who suffered a stroke in 2003, believes better information sharing would lead to more rapid interventions for patients and even prevent some events from occurring, by allowing clinicians to view a medical event within the context of a patient's history.

However, she says there is a lack of understanding amongst patients about what data is held about them, where it is held and who owns it, and consumers need to be involved in open discussions about this.

Ministry of Health manager data governance Simon Ross agrees, saying we need to build 'social license' to use health data for things such as quality improvements, planning and funding and policy making, and this can be done via better and more consistent communication with consumers.

"Data is valuable for everybody who works in the system, but everybody has a different interest in it," says Ross.

"Consumers want good quality services, and you want people to be

"CONSUMERS WANT GOOD QUALITY SERVICES, AND YOU WANT PEOPLE TO BE SOLVING YOUR PROBLEMS WITH THE RIGHT INFORMATION AT THE RIGHT TIME." – SIMON ROSS

solving your problems with the right information at the right time.

"If you're a clinician, you want the data that's generated through the system to be helping to improve your practice.

"And if you're involved in planning, making policy or delivering services, then you want the information that is generated through the running of the system to help you develop a better, more efficient, more equitable system over time," he explains.

Ross is leading the development of a national data and information sharing strategy and a framework with a roadmap of actions to help guide how organisations in the health sector manage, use and share data, which will be released later this year.

Speaking the same language

Data sharing only works if data collected at one point in the system can be understood at another. Systems need to be speaking the same 'language', which makes implementation of national standards crucial.

When Covid-19 first hit New Zealand, laboratories were coding a Covid-19 test differently across the country, making it hard to pull together a national view of Covid test results, until a national standard was agreed upon.

New Zealand is adopting international standards in healthcare, such as SNOMED-CT, Health Level 7 (HL7) and Fast Healthcare Interoperability Resources (FHIR) to make it easier for systems to exchange information.

Hira's first tranche will also deliver digital identity and interoperability services to support ease of access, security and quality assurance across the integration of systems.

Chair of HL7 New Zealand Peter Jordan says implementing modern international standards utilises the work of a huge worldwide community. Cross-border healthcare exchanges are also becoming more important, such as the various Covid-19 vaccine credentials, for which standards are critical.

"I am optimistic that there will be better sharing of health information in the future because it's an essential pre-requisite for the move to a consumer-centric, closer-to-home, healthcare system that can respond to the exponential growth in demand," says Jordan.

"From a technology and standards viewpoint, the tools are already there: what is now required is a cultural shift to remove the various barriers imposed by legacy systems and siloed thinking." ©

ABOUT HIRA

HIRA WILL ENABLE ACCESS TO A VIRTUAL ELECTRONIC HEALTH RECORD BY DRAWING TOGETHER A PERSON'S LATEST HEALTH DATA FROM TRUSTED SOURCES.

HIRA IS A TE REO MĀORI WORD THAT MEANS 'TO HAVE A SIGNIFICANT BEARING ON FUTURE EVENTS', AND TO HAVE A 'WIDESPREAD EFFECT'.

HIRA WILL TRANSFORM THE WAY PEOPLE INTERACT WITH HEALTH SERVICES AND USE THEIR HEALTH INFORMATION AND IS A CRITICAL ENABLER OF THE GOVERNMENT'S UPCOMING REFORMS OF THE HEALTH AND DISABILITY SYSTEM.

THE INTERIM CLINICAL AND TECHNICAL DIRECTORS FOR HIRA ARE WORKING CLOSELY WITH KEY STAKEHOLDERS TO ENSURE THE DEVELOPMENT OF, AND ALIGNMENT TO, STANDARDS FOR INFORMATION AND DATA.

WORK UNDERWAY, ALIGNING TO THE INTERNATIONAL PATIENT SUMMARY, IS BEING USED TO ENSURE SUMMARY HEALTH DATA IS BOTH CONSISTENT AND VIABLE FOR EVOLUTION IN THE FUTURE.

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