

## Discussion outputs from DIGITAL HEALTH LEADERSHIP SUMMIT, March 2021

### Topic 5: Integrating data standards: The carrot or the stick – which comes first?

This topic was discussed by groups in Auckland, Wellington and Christchurch.

#### Auckland delegates' responses

<b>Challenges/barriers</b>	<ul style="list-style-type: none"><li>• Why hasn't integration been achieved? It's a dry topic and business processes need to change. It needs clearly defined outcomes/benefits to show the benefits of changing</li><li>• ISO standards are a "guideline" and DHBs all use different systems</li><li>• Who wields the stick? Regulators, funders, providers? There's no one "law of the land"</li><li>• Legacy systems, much harder/expensive to transition to standards? Funders? The greatest barrier to standardisation is cost</li><li>• Why do aviation and telco have standards but not health? Health is so complex</li><li>• Is the stick about democracy? For example, for participants from China and Malaysia the government would dictate</li><li>• Do any countries have data standards? NHS is one. They have standards for contracts for procurement. If SNOMED is required by Ministry, in NZ it's only a guideline, no control over private health</li><li>• Who is the boss? Each DHB works differently. Who will mandate the standards? If the MoH must lead the charge, DHBs want to be paid to comply</li><li>• There are no terminology or data standards for recording allergies → this may be a stick for Covid vaccine administration</li><li>• Email + Internet standards are adhered to worldwide, why not the same for health?</li><li>• Data collected at one point is not understood at another and data is used to inform funding, healthcare, diagnosis, gaps, services, e.g., there is no system to recognise learning (of nurses) that is location/DHB agnostic</li><li>• We are good at measuring activities – not benefits – better healthcare needs to measure both</li><li>• Why are agreed data standards not adopted? (SNOMED as example):<ul style="list-style-type: none"><li>○ Deployment is not good</li><li>○ SNOMED - no tools for using it are shared/available</li><li>○ Absence of governance and leadership</li><li>○ Absence of user experience in the software – what is user doing?</li></ul></li></ul>
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	<ul style="list-style-type: none"> <li>○ Standards are disconnected from outcomes</li> <li>● Stick – you can't take a stick to someone rejecting a "crappy" standard/product</li> <li>● Data: People capturing data don't know what it will be used for (DHBs) and they never get the data back from MoH. So, disconnect between data collection between DHBs and difficult to do quality analysis at MoH to inform decisions around funding, gaps, service levels etc.</li> <li>● Non-operability: Makes everything harder for people. A nurse can't have a career plan and learning that follows them to each place of work (DHB). There's no single database to see what registrations a nurse has. There is no clear picture of their workforce.</li> <li>● Silos make for duplication</li> <li>● Why has it not been achieved? <ul style="list-style-type: none"> <li>○ Is sharing data to improve patient care against my business model/commercialisation?</li> <li>○ It's in the too hard basket to gain agreement (Google etc.)</li> <li>○ If we knew how the data would be used, transparently, then it would be easier to decide</li> <li>○ Requires leadership from the centre</li> <li>○ A lot of data comes from devices: Data standards across devices may not be standardised</li> <li>○ Ministry hasn't provided a carrot or a stick</li> <li>○ Self-interest by individual organisations</li> </ul> </li> </ul>
<b>Ideas/solutions</b>	<ul style="list-style-type: none"> <li>● Integrated – standard format, sharing possible and useful</li> <li>● Defined: <ul style="list-style-type: none"> <li>○ A set of standards</li> <li>○ Data in same format and systems talk to each other</li> </ul> </li> <li>● Purpose: <ul style="list-style-type: none"> <li>○ Access to data</li> <li>○ Consistency</li> <li>○ Quality of data</li> </ul> </li> <li>● Start with stick: <ul style="list-style-type: none"> <li>○ Mandated standards (gets ball rolling). Becomes carrot enables participation (sustainable)</li> <li>○ because there are no standards for data collection, what kind of stick do you build? Will the stick ever be built?</li> </ul> </li> <li>● Health should be centred on the patient and they should be the owner. Currently, a range of providers hold parts of patient data for themselves – not for the patient. Integration should be built on the patient and the centre</li> </ul>

- Insurance has a code of conduct/standards you must comply to operate. So do builders, aviation etc., why not health? At least have a minimum standard
- Standardise the presentation of data (form fields) standardises interpretation of data. Standards provide a platform for innovation, it's good for business → carrot
- Carrot is being in the game and getting cost benefit. Stick is FOMO
- Carrot can be made into a stick → you can have this but if you don't comply to standards, we will take it away
- Should be non-negotiable minimum standards, e.g., cybersecurity and consent
- What is the one great idea? It's patient driven - health points for your data?
- Why have data standards:
  - Drives quality. Information for funding
  - Interoperability - like a game of rugby, there are rules, management and outcomes
  - We need a common language so we can communicate a story and meaning accurately, and we can keep speaking that language in the future as systems evolve
  - We can't address equality without it
- Terminology standards: Health is complex, a common terminology informs sharing and insights which enables better outcomes for patients (what about te reo?)
- Where does leadership come from? The community → that's where FHIR came from
- FHIR will surface New Zealand data quality issues
- Interoperability – sharing information
- Ability to roll out people, process and technologies in a standard way
- Carrot: \$ to adopt is not a good carrot – a toolset is what is needed from MoH
- Stick:
  - To submit RFP, just comply with standard
  - To be on a list of vendors with MoH must comply to standards
- Leadership from whom? Lead from where benefits will be derived, e.g., communities., workforce
- Vendors: Legacy vendors will have the greater expense to change than start-ups, but legacy vendors have the \$ and industry relationship. Start-ups have the energy
- A standard dataset/standard information across healthcare
- Timely treatment
- More balance between stakeholders

	<ul style="list-style-type: none"> <li>• Wishful: A data superset → relevant bits accessed – centralised</li> <li>• Is data about health only or other services like Justice and WINZ, whānau ora, whānau tahi? Can we take any of these models and scale it?</li> <li>• Digital identity gives power to individual – owns their own data – the shared data is anonymous</li> <li>• Estonia started with digital identity and standards and it works across all services</li> <li>• Each person has a unique identifying number they own, and it's anonymous (COVID tracer is a nod to this concept)</li> <li>• You can sign into a website with Google, it is not anonymous, but we allow it because it's so useful</li> <li>• Fitbit and Apple watch are collecting data – but we allow it because it is useful</li> <li>• Blockchain is democratised. Can we do that with digital identity?</li> <li>• Standards save money for the government – compliance with standards should be a requirement</li> <li>• “Look at Estonia. Let's just do what they have done”</li> <li>• Decide first, what is the outcome we want → then develop standards, build digital identity on the standards</li> </ul>
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### Christchurch delegates' responses

<b>Challenges/barriers</b>	<ul style="list-style-type: none"> <li>• Privacy Act is a barrier and data sovereignty</li> <li>• COVID lens needed</li> <li>• Patient consent</li> <li>• Central government needs to fund change</li> <li>• How do you inform the minister?</li> <li>• Need integrated data standards</li> <li>• Fragmented</li> <li>• Need to mandate – this word is just given lip service</li> <li>• Standards are boring to implement</li> <li>• Need quality data</li> <li>• Need integration</li> <li>• Need outcomes</li> <li>• What's the drive to adhere to standards?</li> <li>• Health is complex</li> </ul>
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	<ul style="list-style-type: none"> <li>• No standardisation of healthcare knowledge</li> <li>• Standardise for compliance vs. commercial pressure</li> <li>• How do we encourage/inspire practices to champion the cause?</li> </ul>
<b>Ideas/solutions</b>	<ul style="list-style-type: none"> <li>• Free exchange of integrated trends</li> <li>• Co-sharing of information</li> <li>• A standard requirement should be integration</li> <li>• Standards: Need to be governed, should be cheaper and faster, need to create a way forward for vendors to adhere to standards</li> <li>• National Repository of records</li> <li>• We need leadership and leaders who know what is needed</li> <li>• Education</li> <li>• More than health data, e.g., social data points to be joined up</li> <li>• Portability</li> <li>• Need to look at collation of different data sets</li> <li>• Legislation needs to be put in place to mandate and the government can pass legislation during the current term</li> <li>• Ability to reuse data</li> <li>• Care Capacity Demand Management (CCDM) – safe nursing</li> <li>• Ease of use</li> <li>• Conformity</li> <li>• Foundations on platforms</li> <li>• Need feedback loop</li> <li>• Forum for key vendors to come together</li> <li>• Carrots: \$\$\$</li> <li>• Business model for healthcare workers</li> <li>• Generation of market demand – compliance of software to ↑ market demand</li> <li>• Consumer pressure/functionality apps</li> </ul>

## Wellington delegates' responses

<b>Challenges/barriers</b>	<ul style="list-style-type: none"><li>• There is no mandate for what can be beneficial to the patient</li><li>• Lack of strong leadership to give direction</li><li>• Need to work against global standards</li><li>• Standards: Development, implementation, without standards we are not measuring the same way</li><li>• Different priorities between groups</li><li>• What's the clinical impact?</li><li>• There is no ownership</li><li>• Capability gap for implementing standards</li><li>• Too much repetition/duplication</li><li>• No alignment of incentives</li><li>• No consistent procurement process → enforcing collective view</li><li>• \$\$ - cost of change</li><li>• Not aligned 'system-wise'</li><li>• Job protection</li><li>• To many 'cooks'/silos/ disagreements between regions</li><li>• Physical infrastructure incompatibility</li><li>• Fractured ecosystem</li><li>• Need to be able to trust the system – right data, right place</li><li>• Adoption within who benefits from the standard – little wins along the way help for consumers, funders, clinicians, vendors</li><li>• Understanding the limitations (e.g., health literacy) and the process for change</li><li>• Establishing a shared goal, establishing credibility for the audience</li><li>• Foundation and basic housekeeping</li><li>• Egos across the sector</li><li>• Funding for data</li><li>• No reward</li><li>• Understanding definition, e.g., telehealth</li><li>• Overcomplicating</li></ul>
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	<ul style="list-style-type: none"> <li>• Be prepared to fail</li> </ul>
<b>Ideas/solutions</b>	<ul style="list-style-type: none"> <li>• Safety and efficiency. Everyone speaks and understand the same language of business – interoperability, and putting patients first</li> <li>• Data is not all clinical</li> <li>• Standards create advocacy, business cases</li> <li>• Standards allow sharing across systems. Rules need to be established</li> <li>• Blend of the two – funded plus mandated (“carrot”)</li> <li>• Carrot: <ul style="list-style-type: none"> <li>○ Accreditation</li> <li>○ Funding</li> <li>○ Training</li> <li>○ Real life examples</li> <li>○ Data sharing</li> <li>○ Patient safety</li> <li>○ Certification</li> </ul> </li> <li>• Stick: <ul style="list-style-type: none"> <li>○ Mandate</li> <li>○ Affiliation</li> <li>○ Funding</li> <li>○ Risk</li> <li>○ Ethics</li> <li>○ Rating system</li> <li>○ Certification</li> </ul> </li> <li>• Little system changes</li> <li>• Understanding why people don’t follow standards</li> <li>• Mandate with reward on delivery</li> <li>• Collaboration</li> <li>• Encourage innovation for organisation to take advantage</li> <li>• Tiering of certification, national process</li> <li>• Trusted sources of data that is standards based</li> </ul>

	<ul style="list-style-type: none"><li>• More stick, less carrot</li><li>• Held accountability</li><li>• Partnerships with vendors</li><li>• National ID system for data</li></ul>
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