Discussion outputs from DIGITAL HEALTH LEADERSHIP SUMMIT, March 2021

Topic 11: Data governance underpins quality analytics: How do we move forward on this?

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

Auckland delegates' responses

Goals	• Who is data governance for? • Creating a framework and data structure → includes access and trust considerations • Expectations of government vs. other parties • What do quality analytics look like? ○ Solid basis for decision making and policy making ○ Enable improvement • Are you achieving what you set out to do?
Barriers/challenges	• Definition of governance and applying principles is always changing • Political, policy, social views are not constant • Data life cycles are getting shorter • Generating insight quickly but also accurately • Differences in perspectives and timeframes – solving current vs. long term challenges • PHO and GPs think they can own the data • Health system is Kaitiaki (steward), not owner of data • Data is taonga • Centralised vs. decentralised data control – use of block chain • Consent is authorisation to share, not own, data • Data is only effective with context • What I do with your data is my IP, e.g., notes or observations → how do we mandate the interpretation? • What is happening in communities and DHBs? • Treating people in health system as customers • I want access to know who has accessed it

	• Data is for life – follows you and so how do you plan for future ownership? • Tension between compliance and pragmatics of operating environments • We need people, patients and practitioners to buy-in • Where is data coming from and where is it going to end up? i.e., aggregation • Health and social care as two different departments → creates barriers • Data accuracy is key • How do we better explain what and why we are capturing and using data to patients and providers? • Pendulum has swung toward security and privacy – consumer assumption is that data is shared for their benefit already – not the case? Also assume privacy and security is in place • Decision-making and risk management takes place at organisational level, whereas the patient interacts with the wider system • Assumption that once collected, we will have the capability/capacity to use it for generating meaningful outcomes • Still dependent on manual data gathering • What to measure to what end? • Ethical choices and consequences expressed as numbers • Where is that data – what is its journey? • Who is analysing and why? • Formal governance vs. implicit governance • Contextual knowledge of data
Solutions/ideas	• Be open to change and iteration in approach • Consider standards for data governance • Open data models and standards permissions through APIS • Native interoperability • Long term funding of maintaining open standards • “Certification – lite” agree minimum standards → an agreed baseline • Raise understanding and knowledge of data at consumer level → take ownership • D.G. cannot exist in a vacuum, must be in context of capabilities of organisation delivering to all stakeholders • GP transfer of patient records → data quality issues? How to improve → get vendors together to enable consistency • Multi-layered:

    - Government policy
    - DHB level
    - GP
    - Patient
- Defining data sets – what matters?
- We have not yet started a mature discussion with the population on use of data → not engaged and not empowered – “what’s in it for me?” → social media campaign
- Engage the diversity of our population
    - Visibility of data sharing, transaction builds accountability and trust
    - Interoperability standards opt in by everyone
    - Tighten up:
        - Data accuracy and quality
        - Standards
            - how do you deliver context without extended effects?
- Quality analytics tell us about the quality of an outcome, not just that it happened
- KPI for data quality for directors or services – what does that look like and who sets and enforces it
- Single point of accountability for data gathering and quality
- Data quality improves as it is used and tested
- More automation of data capture
- Service planning at community level needs to feed into data governance and management in that community
- “Patient” (community) + provider + funders in same room to achieve common understanding of what and why
- Opacity of usage and access is challenge → better communication needed
- Use the Office of the Privacy Commissioner and involve in our governance process to give reassurance
- Insights from what you can gather, rather than what you could gather → governance defines who, what and how we gather
- Broad based conversation is key to understanding and outcomes

Christchurch delegates' responses

Goals	• Governance data/information • Flexible governance structure to align with strategy • An enabling process – trust • Transparent – easy to understand and easy to implement • Flexible • Process driven • Continuous improvement • Validated data sets • Error recognition • Governance/leadership • Data governance board: ○ Define sovereignty: ▪ Technical standard for NGOs ▪ Education/advocacy ○ Ownership ○ Stewardship
Barriers/challenges	• Collaboration? Get the basics right • Correct data collected and shared • Real time insights/client facing • Historic insights/analysis • Data quality: Real and Up to date • Analysis: ○ Solutions ○ Projections: 'Poor' analysis – technique/misunderstanding • Data collection: ○ How can it be used? ○ How often can it be used? ○ Whose data is it?

	• Ownership: ○ No ownership of errors ○ No ownership of direction ○ No ownership of policy ○ No ownership of review cycle • Governance board: ○ Qualify – legal/privacy ○ Consultative – equitable • Data analysis – equity/availability • Mitigating and monitoring risk • Unconscious bias • Tension – data users vs. data inputters • Data collection: ○ From where/audience? ○ Submissions – multiple, duplicated, rational? • No formal guidance: ○ Reporting priorities vary: ▪ No history is kept ▪ Other data points – ID ▪ Review equity ▪ Historic analysis ▪ Data responsibility vs. age ▪ Data validation • Data consent – who owns it? – Māori data sovereignty • Not one body for governance but an agreed data governance – formal for organisation to advise/adhere – national level • Data, rather than reporting – how is that advised on? Data is ringfenced intentionally
Solutions/ideas	• Multiple views • Transparency • NZ level → local level • Process → data collection → data collection → validation → analysis

  - P/A ethics/NZ standardisation
  - Guidance – developed by multi-led parties – reference group
- Formal vs. QA research
- Access to ‘reliable’ data – to approved requestors
- Acknowledgement of errors/corrections (trusted source)
- AI – automated validation
- ‘Uber governance – NZ wide
- Multi-level Board from ‘family → MoH’ representation:
  - lay person
  - consumer expert
  - reach out to minority
- Data use:
  - Private
  - Clean
- Single ‘ID’ number (Denmark):
  - Banking
  - Medical
  - Tax
- Governance (professional):
  - Not analyst
  - Bring in subject matter experts
- SMEs – might be vendors, clinicians, patients/clients, + end-to-end users – consider
- Understanding the risk in using certain data sets, e.g., MoH and reported for other users
- Continuous improvement → feedback into education
- T-o W principle
- Standardised process:
  - Research consent
  - Reporting
  - Non-anonymised data ethics
- Educate:

	○ Data literacy ○ Data entry ○ Data analysis ○ Data auditing • Advising on data collection/source integration • Emergency board to approve data set reasons – measles • Technical standard: ○ Practical in use ○ Accessible to all organisation ○ NZ - regional – community conversations

Wellington delegates' responses

Goals	• Difference between data governance and sovereignty? • What is the context for our discussions, e.g., broader/international vs. local • What does good data governance look like? What are principles? • What is the pathway for aligning sector groups in application and use of data? • What does a sector framework look like? • How do you get governance in the conversation? • What does personal data ownership mean for data governance?
Barriers/challenges	• Governance: Is about overseeing and determining use of data. About transparency → should support sovereignty • How do existing data collection models deal with gender diversity and other emerging diversity issues? • There are accessible models of data governance out there, but no best practice/standardised model across sector. Everyone doing their own thing • How does Māori data sovereignty inform discussions and policies on data governance? • Taking principles of Māori data governance and applying them practically • How does governance lead to interpretation of data that doesn't lead to victim blaming and do community harm? • How does algorithm governance relate to data governance? • Challenge of governance. How and what data do we collect and what do we do with it?

	• How can we use data to address equity issues in health? How do we fulfil Treaty obligations? What data do we need to collect? • Insights limited to data we collect • Data collection and analytics algorithms can reinforce institutional racism and lead to confirmation bias • We’re not collecting the right data to solve the equity problems • DHBs and health sector analytics/data collection is driven by MoH requirements • Most boards still don’t take data governance seriously • Difference between research ethics and operational ethics. Is there a difference? How do we apply ethics practically? • Who we choose and use as tools for data has implications for ownership and stewardship of data, e.g., big platforms are useful but what are they doing with the data? Who can make a claim on it? • How do we make sure that poor insights are not being generated from the data? Data governance needs to oversee and review insights for quality. • Ensuring people have control of their data • Limited access to your own data. Must go through process. Can’t read it without going through the process. Is that ethical? • Who are privacy laws/considerations protecting: the patient or the practitioner? • How do we ensure our data governance has patients’ best interests at heart in this capitalist society? • How do you shape data governance oversight? • Lack of toolsets and frameworks. Having these would be key to success • Digital literacy and barrier to getting good data • Using data to predict resourcing needs, otherwise you’re just guessing • Data could identify issues beyond health sector if combined with other data • Tension between individual rights and public good • Need an enabling framework. Take data out of domain of IT departments and give it to managers to empower and generate insights for the organisation • Changing attitudes to privacy. Dealing with sensitive data. Data governance needs to put patients first • Kaitiaaki/stewardship/protection of data and people need to be centred to discussions • The capacity for data governance varies between each group/DHB/organisation • IT seen as a foreign body in health sector • Implementers seeing value of how data could be applied, but boards can be quite fearful due to risks

	- Without data governance, there is no strategic approach to gathering data leading to not great data. We could be gathering a whole lot of data that isn’t useful and isn’t used - A centralised or even regionalised data governance policy would inhibit creativity and dynamism of individual DHBs/organisations. - Getting agreement across sector
Solutions/ideas	- Canada a good example to look at as nation considering sovereignty in data governance - Co-design data governance frameworks and policies with Māori. Bring Māori sovereignty into discussion early. - To what extent should data governance be centralised? - Central framework – support guidance, localised application/implementation - For all the consultation that goes on, you’ve got to pay people for their time, so you’ve not relying on people giving up their time. - Centralised guidance and contextualised implementation, with prioritised investment will deliver quality analytics - Governance considers value vs. risk equation - Change needs to come from MoH in terms of providing guidance on what data should be collected to meet equity goals. DHBs etc. will follow their lead - Start by talking to organisations where data governance is done well and adds value - Choose a data governance framework (e.g., DAMA) and use it! - Data analytics is a very specialised discipline. Needs to be standardised. Need centralised support and guidance for localised practitioners - Teach data quality analytics courses in health-related qualifications, so health professionals bring an understanding of analytics to their role - Should be treating data as taonga - Education of people: Take care of your data like you would take care of yourself - Data governance should be on behalf of patient, not practitioner - Need to have participation from patients, e.g., if doctor writes a note, they should get assent from patient and allow them to contribute - Apps like Manage My Health allow for greater transparency of notes with patient - Key is good consultation and stakeholder engagement - Checklists of things to consider - Trust is essential to good analytics. Data governance should build trust

	• Use ManageMyHealth to send message to users for permission request to use data for, e.g., research purposes • IT departments need to work with business owners to determine best way forward for utilising data for analytics • People trust the COVID app because they see positive results. Trust is essential • Data governance needs to set standards for data gathering, e.g., taking notes on patients • Important to come up with shared data definitions across health sector to enable data governance standards