2021

Topic Brief

Data Access Governance for Health Data
HEALTH DATA AND ANALYTICS HAVE THE POWER TO TRANSFORM HEALTHCARE SOLUTIONS

The quality, safety, and efficiency of patient care are predicated on having the most relevant and up to date information available at the right time. Data and information held across different areas of the health system can be applied to empower patients’ and clinicians’ decision making, as well as facilitate research and quality improvement activities. An example is provided in Appendix A. Ultimately, data can drive building health systems that are world class and sustainable.

The COVID-19 pandemic has highlighted the need for real-time data during rapidly evolving public health emergencies, the importance of data-driven health service response, and most of all, society’s expectation of open and transparent data.

Facilitating partnerships with researchers and industry is essential. However, the confidential and sensitive nature of health data means that appropriate safeguards will always be critical. But continuing with existing restrictive approaches to data access for research carries the risks of not fully realising benefits, both immediate and future, for healthcare users and health system efficiency and value by achieving a transformed model of data access governance.

Establishing a new innovative framework to enable data access across Queensland Health will require long term commitment and a concerted effort of shifting attitudes towards a data-driven and person-centred healthcare system. Along this journey there are opportunities for “nudges” to achieve results and create real, sustainable change, particularly in enabling more open access to and use of data.

QUEENSLAND’S INTEGRATED ELECTRONIC MEDICAL RECORDS

Queensland is in an enviable position with the implementation of a single electronic medical record (EMR) across 70% of all health care in the public system. In addition to our EMRs, there is extensive public health surveillance and system performance data at Queensland Health (e.g. notifiable conditions such as COVID, wait-times for elective surgeries).

In the near future, all public hospitals will share one integrated Electronic Medical Record (ieMR). It contains an extensive and rich repository of information that could be used to facilitate clinical practice improvement and clinical research.

CURRENT AND FUTURE CHALLENGES

This rich data remains challenging to access for researchers and critical stakeholders, who are only able to request static, retrospective, specific data sets.

The ability to access and harness these vast datasets, and produce the knowledge needed to drive evidence-based healthcare innovation, is significantly hampered by a general risk aversion to provide researchers with access to data, as well as a lack of standardised understanding across the myriad data areas of what could be provided under the current legislative instruments.

Consequently, access to and use of data by critical stakeholders (including but not limited to researchers) remains challenging. For example, data custodians are reluctant to provide data without seeking legal advice for each specific project. And any changes to project scope necessitate further briefings and negotiations. A costly and inefficient process.
Work is underway to develop a “single source of truth” as guidance material or a decision support tool to clearly articulate what legislative, regulatory and policy pathways are enabled around use of and access to health data.

These tools are ultimately intended to reduce variability in practice, encourage greater use of data for research purposes by ‘demystifying’ available pathways and reduce the associated resource burdens, for example the need to obtain bespoke legal advice on individual circumstances.

The tools will need to cater for a range of diverse audiences, including data custodians, clinicians, researchers, executives, lawyers in QH and universities, industry partners, amongst others.

Challenge 1 - With such variation in relevant stakeholder understanding, motivation and level of engagement how should Queensland Health best present this information in a way that most resonates and maximises understanding with these diverse stakeholder groups?

In principle, broad and blanket initial consent may facilitate the conduct of research. While some people will be happy to provide this broad future consent upfront, others may wish to make informed decisions on each research and quality improvement project that uses their data.

Dynamic consent is an approach to informed consent that enables on-going engagement and communication between patients and the users and custodians of their data. Such platforms are primarily designed to achieve two objectives: 1) facilitate the consent process and 2) facilitate two-way, ongoing communication between researchers, data custodians and consumers. Work is underway to develop a web-based dynamic consent portal to enable participants from all parts of Queensland to consent for Queensland Health to obtain and link their primary and secondary medical records for research, agree to be contacted for further research opportunities and track the research application on their data. Further information on this platform is available in Appendix B.

Another approach is to contact patients individually to seek their consent for their data to be utilised for a specific purpose. An example is provided in Appendix C regarding the COVID-19 Athena Study.

Challenge 2 – Ongoing engagement of patients through a dynamic consent approach requires a participant to receive adequate disclosure and have competent understanding to give informed consent. How can these platforms be designed to achieve these requirements?
**The 2021 Nudgeathon Presentations**

Your ideas will be evaluated on five equally weighted dimensions –

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<td>Feasibility with respect to (technological and legal) constraints &amp; implementation (being effective on a mass scale)</td>
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Furthermore, for the use of PowerPoint during your presentation you are permitted to use up to a **maximum of eight (8) slides in total**, not including your title slide with team details.

You will also be required to provide a **two (2) A4 page “Problem brief document”** at the start of the Tuesday morning presentations. You may use the 2 A4 pages for any text, images, references you wish.

Both your slides and A4 document must be provided to the Nudgeathon 2021 Judging panel via email one hour prior to the first presentation commencing.

Good luck!

*The Nudgeathon Team*
APPENDIX A:
THEOGRAPHIC DIGITAL PATIENT JOURNEYS

As an illustration of how data can be utilised to better understand patient experience and deliver an optimal outcome, the Theographic Digital Patient Journey project has visually mapped the contacts that individual patients have with health care services longitudinally and prospectively (see Figure 1). By bringing together disparate data sources such as pathology and medication (and genomics data in the near future), individualised theographs enable a holistic view of patient’s health and wellbeing over time. The data, machine learning, artificial intelligence and visualisation tools form a cornerstone for precision health that drives better system and patient outcomes.

Figure 1. Theographic Digital Patient Journey
APPENDIX B: WEB-BASED DYNAMIC CONSENT PORTAL AIMS

- A simple, rapid method of obtaining and managing consent that permits the collection and use of primary and other healthcare data for use in approved medical research studies.

- A validated simple, rapid method of obtaining and managing additional consent to re-contact health consumers to discuss participation in approved future clinical trials.

- A secure research asset to rapidly identify and contact patients for research opportunities through the use of securely stored and managed personal details and linked healthcare data of large numbers of health consumers who have provided consent.

- A secure research asset which enables health services analysis and population health research by linking consented health consumers’ healthcare data to:
  - other Queensland Health datasets
  - Queensland clinical registries
  - other national datasets and/or
  - other national clinical registries.

- Enhance the competitiveness of regional sites enabling greater access to clinical trials for Queenslanders living in regional, rural and remote parts of the Sunshine Coast and subsequently additional health regions within Queensland.

- Increase the overall clinical trial activity in Queensland by reducing the following barriers:
  - screening times
  - rejection rates
  - recruitment times

- Support people residing in regional, rural and remote parts of Queensland to take part in research.

- A safe and secure method for the release of de-identified data to approved third parties for the purposes of medical research and participation in clinical trials only.
APPENDIX C:
LINKING DATA WITH PATIENT CONSENT

The COVID-19 ATHENA Study aims to describe outcomes in all people diagnosed with COVID-19 in Queensland, over time and in relation to patient characteristics. The Study links Queensland COVID-19 notification, hospital and death registry data, as well as patient’s healthcare information held within general practice.

As part the Study, patients who have or have had COVID-19 are being contacted by Queensland Health staff and invited to provide consent to access their GP held health information for this and other research projects. GP held patient health information, in comparison to hospital data, contains additional, more detailed and up to date information on patient characteristics, including health conditions and medications at the time of infection.

As of the end of June, the patient recruitment is being finalised, approximately 550 of the Queensland COVID-19 patients contacted have consented to participate in the study. Overall, the Study demonstrates that contacting/re-contacting health consumers to consent and re-consent their data for research and quality improvement activities is not only feasible, but welcomed by the general population.
RESOURCES:

Integrated Electronic Medical Record (ieMR)

A 10-year story: visualising patient journeys

Choice architecture in prescribing practices:

Behavioural intervention on antibiotic prescribing:
https://jamanetwork.com/journals/jama/fullarticle/2488307?tab=cme

Organ donation and consent:

Presumed consent and health information exchanges:

MINDSPACE:
https://www.bi.team/publications/mindspace/

EAST:
https://www.bi.team/publications/east-four-simple-ways-to-apply-behavioural-insights/