Data are just summaries of thousands of stories
- Chip & Dan Heath

Establishing an innovative framework that enables data access across Queensland Health will require long-term, concerted effort in shifting attitudes towards a data-driven and person-centred approach. To achieve this, we propose leveraging Queensland's ieMR to create a unified Data Donor Portal that facilitates two-way information flow between health consumers and researchers. Although there will be a plethora of benefits and opportunities from this data-driven future, we cannot lose sight of the individual stories that ultimately fuel these innovations.

As behavioural scientists we have a deep understanding of the evidence-based principles that drive individual change. Change begins with choice, and the true value of a choice architect involves narrowing options down to a manageable size. This empowers individuals to make informed choices. In line with this, we propose several solutions to encourage meaningful individual change. These solutions are proposed in accordance with the EAST Principles:

Opportunity 1: Motivating health consumers to engage with a Data Donor Portal

Initial Intention
This touchpoint is designed to establish an initial buy-in from the health consumer. We will appeal to their pro-self and pro-social motivates through becoming a Data Donor. Approaches will include:

- Priming
  By placing subtle cues around the hospital environment, including badges and posters, we will subconsciously prime health consumers to be familiar and comfortable with the Data Donor program.

- Framing
  We will use statements that describe the positive or negative features of choices and outcomes to appeal to consumers’ emotions and influence decisions. This includes benefits to individuals’ family and friends, as well as consequences relating to disengagement.

- Escalation of Commitment
  By starting with an initial and easy commitment, we will be more likely to achieve greater commitments in the future.

- Diffusion of Responsibility
  We will make consumers’ identity salient by highlighting that they are part of a smaller cohort, ensuring that they feel as if their contribution is valued.

- Personalisation
  By leveraging social identity theory, we will appeal to the various in-groups of health consumers, promoting a personalised experience.
Opportunity 2: Facilitating dynamic, informed consent between health consumers and researchers

Informed Consent
Our design establishes two-tiers of consent. The first pertains to generalised consent of a health consumers existing data using ieMR. The second relates to dynamic consent. Approaches will include:

**Escalation of Commitment**
We will build on consumers' commitment to becoming a Data Donor by encouraging engagement in the dynamic consent process.

**Reducing Cognitive Effort**
By having health consumers' ieMR pre-populated onto the portal, we will reduce their cognitive effort.

**The Process Principle**
We will use small wins, in the form of progress bars, to indicate progression and motivate consumers to verify the accuracy of their health data.

**Smart Disclosure**
By standardising the content and presentation of study information, health consumers are empowered to make informed decisions.

**Activation of System 2**
We will shorten and simplify consent questions to reduce cognitive overload, ensuring consumers are better equipped to use System 2 thinking when considering their consent.

The collection and sharing of data is critical to on-going research and development. It is essential to remember that data is not just a collection of facts and figures, it is the aggregation of communities and their stories. At the heart of these stories, lies an individual's joys, pains, losses, and gains. Ultimately, the journey to a digitised health environment is impossible without the individual and what motivates them.

References


