CONSENT ARCHITECTS

(INFORMED CONSENT)[2]

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Several issues have been identified when it comes to informing and engaging patients in research. Information asymmetry between patients and researchers will impact the patient's decision, especially when consenting to their health data being used for research purposes. Our solution involves the implementation of three strategies; when integrated with the web-based consent portal, they will provide a representative group of Queenslanders with the comprehension to give informed consent regarding the use of their medical data.

We have identified the following barriers to dynamic consent:
1. Lack of representative sample of Queenslanders in research.
2. Difficulty in understanding the consequences of consenting.
3. Loss of engagement over time.

To solve these issues, we have developed a variety of nudges.

Strategy 1

To overcome the issue of under-representation, and to ensure that the program has a broad reach we propose a two-phase rollout:

- **Phase 1** - Motivating health care workers, particularly in rural and regional Queensland, to engage with the portal. To facilitate this, healthcare staff can receive training in their continuing professional development.
- **Phase 2** - Expansion of the program to all patients within the Queensland health system. Additionally, healthcare workers will be asked to facilitate patient comprehension and the consenting process.

We anticipate high levels of participation among healthcare workers, as they observe the actual benefits of research in improving health outcomes. This acceptance flows on to the patients, as they place a greater amount of trust in healthcare workers especially in rural communities (Sunstein and Thaler, 2021).

Strategy 2

We will utilise a system of visual aids to simplify the benefits and risks associated with informed consent.

We have developed information-labels aimed at notifying participants of the most crucial elements involved when giving consent. Examples are displayed below:

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Retention Time	Data Location	Third-party Access

Linking to Another Database	Deidentified Data	Revoke Consent

This nudge will tap into people's automatic system of thinking and allow for association with relevant information needed to give consent (Sunstein and Thaler, 2021).

To complement the labels, we will incorporate subtitled videos to assist culturally and linguistically diverse (CALD) groups, and individuals with low literacy levels to make a fully informed decision.

Strategy 3

For continuous engagement of users after registration we suggest implementation of an online community, and a method of gamification:

- **Online community** - providing a forum for testimonials, shared experiences, and insights from researchers.
- **Gamification** - giving individuals nominal badges and rewards for participating in research projects, as well as providing normative feedback upon consenting.

These tools incorporate the most important elements of the SCIENCE of lasting behaviour (Young, 2017). In addition, they work to create social capital which has been shown to reinforce actions.

The strategies identified are low cost, easy to implement, and will allow individuals to give consent confidently. This will enable Queensland Health to be at the forefront in health research, and innovation.

Bibliography

Sunstein, C. R., & Thaler, R. H. (2021). *Nudge: Improving Decisions About Health, Wealth, and Happiness.* London: Penguin.

Young, S. (2017). *Stick with it: The science of lasting behaviour.* London: Penguin.