

Challenge 2: Informing and Engaging Patients in Research

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Health data is increasing in volume, variety and velocity. Better data management and real time data collection has led to huge opportunities for health researchers, and the potential for more flexible projects that change their processes as they encounter new discoveries and look to overcome obstacles. However, such flexibility in research design requires flexibility in consent processes, empowering participants to give informed consent in response to project changes. A dynamic consent portal is one part of the solution – an online platform that provides participants with a way to track how their information is used and provide their consent for new and changing projects. In designing this tool, it is particularly important to support informed consent through providing the right information in a format that can be easily understood and to maintain participant engagement with the platform.

Given the online nature of the portal, we have focused on solutions that will be effective for participants aged 18-45. We have also conceptually simplified part of the problem into addressing cost-benefit issues. Costs are uncertain and benefits are not obvious, leading to participants feeling needlessly unsure about the consequences of giving consent and becoming alienated from a sense of contribution to the research impacts that would not have been possible without access to their data and that of people like them. To address the problem of dynamic consent, it is necessary to give participants control over the timing of the messages they receive and to provide them with messages that prompt action and remind them of the benefits that would be lost without their continued support.

Overemphasis on Costs

People are more concerned about costs and focus on minimizing the costs. In terms of dynamic consent, the primary cost is the misuse use of individuals' health data. Individuals are ambiguity averse about what data is being collected, how these data is being used and by whom these data are used, and so individuals may be reluctant to provide their consent (Fox and Tversky, 1995). Moreover, these costs come into their mind at the point of providing consent and hence are more salient, as most people suffer from present bias (O'Donoghue & Rabin, 2015).

Undervaluing Benefits

The social benefits provided by the use of their health data is not made explicit enough to participants compared to costs. In their mind, the benefits are less salient. In the short run, benefits are more societal (eg: research on new cure) and not individualistic. Hence only experts in the relevant fields would acknowledge the benefits of providing consent to use their health data. Therefore, the solutions need to encourage prosocial behaviors. Further, the benefits of providing these data are realised in the long run and present biased individuals may not value these benefits. Therefore, to encourage individuals to provide consent and engage, immediate benefits should be made clear.

Solutions to Address Costs and Benefits

Overcome overemphasise on costs

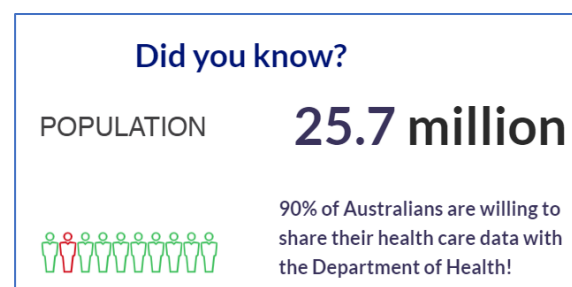
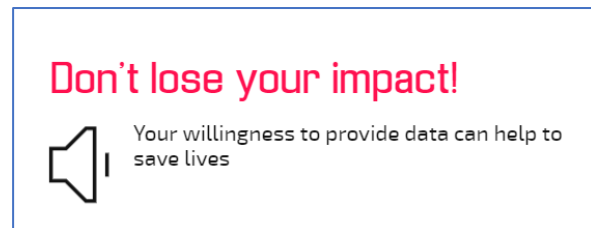
- Emphasize on anonymity/confidentiality of data → minimize ambiguity averse
- Explicit information on what and how data is collected and by whom and for what data is used → minimize ambiguity averse
- Information should not be overloaded (Bawden & Robinson, 2009; Jacoby, 1984).

Provide short run benefits

- A certificate appreciating their contribution → short term tangible return

Increase engagement

- Provide peer information (how many have provided consent) → this information may work as a reference point, as social norm, and would help to overcome cognitive uncertainty (Akerlof & Kranton, 2000; Enke & Graeber, 2019; Smith, Windmeijer, & Wright, 2015)
- A badge to share in social media after consenting → Peer attention
- Reminder to provide consent → overcome procrastination / time inconsistency (Thaler & Benartzi, 2004).



Dynamic engagement

Dynamic consent requires both contact with participants over time and timely engagement after that contact. Given excessive contact can decrease engagement, it is important to manage expectations and not overwhelm people with requests. To achieve this, we propose that the consent portal asks for people to give preferences over how often they should be asked to renew their consent and which kinds of projects they should receive updates about. As some potential project changes are foreseeable, we also propose that forward consent options are available when giving the initial consent, allowing people to pre-consent to some potential project changes and thus not be contacted again. Finally, the messages will emphasize the lost benefits of disengaging – “Don’t lose your impact!” This will prompt people to act now and renew their sense of pride in contributing to health research.

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