Digital Consent in Healthcare workshop summary

The Ministry of Health Data & Digital Directorate recently hosted workshops with participants from across the healthcare network to uncover the various necessary considerations around Digital Consent in Healthcare. These initial sessions were conducted virtually using Microsoft Teams & the Miro collaboration tool.

The participants included a variety of wider government agencies, DHBs, healthcare practitioners, healthcare vendors, NGOs, researchers & students, and healthcare consumers.

Pre-workshop

Prior to the first session, we asked participants what questions they had about consent.
These were summarised into seven categories:

- *Purpose* – what are the priorities for giving people access to their data (why are we doing this?)
- *Process* – How can we realistically obtain and manage consent?
- *Data ownership* – How should data be considered under Te Tiriti o Waitangi?
- *Understanding/communication* – How will people be able to reasonably understand what is happening to meaningfully give consent?
- *Accessibility* – How do we consider the needs of different groups and ensure they can participate in the process?
- *Authorisation* – How can we ensure that we are getting consent from the right person?
- *Governance* – How can we ensure the process and underlying data is managed appropriately?

Workshop One – 12 April 2021

This session introduced participants to consent from a data, ethics, privacy and disability perspective.
Our session speakers were:

- Jon Herries (MoH) – Introduction and background
- Nic Aagaard (MoH) – Ethics of electronic consent
- Simon Ross (MoH) – Data, privacy and the role of consent
- Amy Evanson (MoH) – A disability perspective

The group then discussed "*What does consent mean in a health data context?*"

In the second half of the workshop, participants were assigned to breakout sessions to work through some of the more specific questions around:

- Ethics of Electronic Consent
- Data, privacy and the role of consent
- Disability consent for Heath data
- What else do we need to consider?

Workshop Two – 3 May 2021

Session two began identifying which areas of the healthcare system our participants represented.

Then, in the context of digital consent, they were asked to explore "*Why shouldn't we do this?*" to understand what potential risks may occur. The high-level outcomes summarised to:

- It is too complex
- It could restrict access to necessary information
- Transparency on use of data may be a better approach than consent
- Will it create new issues around engagement?
- Is It actually needed?
- Will it actually empower the consumer?

Part two of the workshop focussed on diving deeper into the seven categories identified in Workshop One. Two additional categories, Legislation/Laws and Consumer Perspective were suggested. Each group prioritised the category problem statements, provided real world examples, and identified the most affected groups and their impacts.

Workshop Three – 1 July 2021

The final session introduced participants to consent within Maori Data Sovereignty, health research and
Our session speakers were:

- Dr Donna Cormack (University of Auckland) – Maori Data Sovereignty and consent: Imagining alternative data futures
- Dr Rosie Dobson (University of Auckland) – Patient perspectives on individual health information
- Phil Knipe (MoH) – Digital Consent in a Healthcare setting – Information Sharing

Participants then explored the different perspectives on each presentation subject, including the key points that need to be considered, the different types of associated data and risk, and outlying issues that didn't within fit the risk matrix.

What next?

Historically, projects led within the health sector focus on the delivery of a service, not on the end users - healthcare consumers, patients and communities. Insights from these workshops are helping contribute to the Ministry's understanding of digital consent. The next phase is to test a range of ideas with different communities, through Proof of Concepts and Design Research.

Which communities could this be tested this with? What other work is happening in the digital consent space, and who else could/should to be involved?

Ben Briggs, Principal Advisor - Emerging Health Technology & Innovation, will be leading our Digital Consent work. Contact Ben (ben.briggs@health.govt.nz) to share your thoughts and feedback, and if you would like to be involved!