**The problem:** Broad and blanket initial consent may facilitate the conduct of research. But high-quality research to achieve patient-centered care requires not only ongoing collaboration but also effective co-creation process by consumers, clinicians and researchers.

**Our solution:** A platform that integrates with existing infrastructure developed by Queensland Health (QH). This platform is promoted at all QH facilities, especially those with outpatient and/or specialist services. It outlines the patient journey from passive participation to actively engaged, becoming a partner in the research process (from project creation to evaluation), and provides both information for education and consent purposes. It is designed as a vehicle for engagement and collaboration, not just to obtain a ‘tick in the box’ for consent. Knowledge and engagement leads to empowerment, and consent will naturally follow.

**Consumer experience:** The platform will inform consumers about data security, privacy and transparency, and accuracy. It is designed to be user-friendly (QR code scan, quizzes, modules and videos to deliver the information) and to enable consumers to have choice and control. Each individual will experience their own personalised research engagement journey, consent or withdraw (from already consented projects) when they wish to. The platform also has potential to further engage consumers for co-production of research ideas and health service implementation, to improve equity of access, patient outcomes, communication and experience.

**INITIATION:** Patients present at a QH facility in the waiting room and are intrigued by an image – our example here is a “tree” with a QR code that takes them to the platform. The “tree” branches and fruit contains facts and figures about research engagement by consumers, and the benefits of consumers being equal partners in the co-design process for healthcare research and implementation.

**Premises:**
- Waiting time for healthcare services can range from fifteen minutes to a few hours. Patients can feel anxious or bored and likely to be considering their health. This is an opportunity to engage them in a conducive environment to empower them to achieve better health and to be part of an impactful journey.
- Visual trigger is created by both the displayed tree and prompting videos (repeated) acts, giving them positive information about how patient data can make a difference (cure diseases), and what they can do to participate in research, and more importantly, to become a “partner in research”, to co-design research to improve their health, and the health of others.

**Format:** Repeated video playing on a display screen/dashboard, accompanied by a printed tree with a QR code. The videos contain facts in the form of questions to trigger curiosities.

**WHAT HAPPENS NEXT?** The QR code takes patients to a platform that contains an initial mix of facts and quizzes.

- Some repeated facts from the display board, and branches or fruit of the printed tree, plus updated facts about consumer engagement in research.
- A few short demographic questions (age, gender), self-reported health (how do you feel today?) and perceptions about data security.
- Some quizzes about their understanding of consent, data privacy, security and choice.

**Premises:**
The platform is supported by a decision tree that segments patients into cohorts where additional information can be used to tailor and present in the most relevant and digestible way. For instance, a woman aged 45 years will receive information about breast cancer studies and how research has contributed to fight breast cancer.
How to Grow your Tree? The tree reflects each individual’s journey in research engagement and consent.

- The sapling: reflects the broad and blanket consent and health information that is routinely collected through different parts of the healthcare system (e.g., iEMR, PBS, MBS) and will contribute to research through existing data linkage infrastructure.
- Small to big tree: new information about research and additional consent are presented in separate and snack-sized modules, as quizzes, mixed with facts (videos, infographics) about the disease of interest and treatment options, and consent statement. The more materials a person goes through (longer and deeper engaged), the more branches and leaves will grow. The reward is associated with engagement, not just consent.
- The fruit: it is possible for each individual to engage and consume the information presented and decide not to consent. But the tree only bears fruit if the person consents to engage in research. Contemporary (i.e., specific research project) consent will first appear as “faded” fruit and will glow when the consent is achieved. For projects with different engagement and consent phases, a branch can have more than one fruit.

What happens when you stop half-way?
- Your tree will not die. If you withdraw consent, the fruit will disappear, and some leaves or branches might be pruned back.
- Next time you log in, the modules that you engaged in the past will trigger the platform to release additional information about research in that area (priming), if any.
- Even if you don’t consent the first time engaging with the platform or some research projects, you still can grow the tree (by going through the information presented in the module), and then you decide whether or not you want to consent and be rewarded with some fruit.

Continuous engagement: Researchers who get access to patient data and/or involve patients further for their research, facilitated by this platform, are responsible for providing updated information in a consumer-friendly manner about the research process and results as a part of the dissemination duty and research accountability.

Bibliography