

COMPREHENDING CONSENT



INFORMING AND ENGAGING PATIENTS IN RESEARCH

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In literature, dynamic consent emphasises the research participants' right to make their own informed choices and is often used to describe personalised online consent and communication platforms. Such design facilitates the online process and two-way communication between researchers and participants. In addition, the dynamic consent process offers opportunities for ongoing communication between researchers and participants that creates a positive impact. Dynamic consent can be routinely available however, the implementation will require researchers to consider the relationship with participants and adapt procedures. With the intention of having a successful dynamic consent procedure, it is important to consider following; (1) ensure users have complete understanding in order to give informed consent, (2) reduce applicant screening times and rejection rates, and (3) ensure the platform is accessible to as many potential participants as possible.

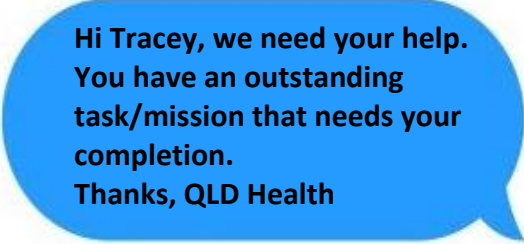
To encourage participation in this dynamic consent platform, several strategies will be employed. To target the younger generations, advertising will be done through social media in the form of targeted advertisements that direct users to the platform. Research depicts that the older generation is less familiar with social media so conventional methods such as paper leaflets, meeting with a local representative, radio advertisements and posters have proven to be a success. The ideal person for health representative meetings would be local GP's who would encourage patients to get involved and answer questions about what the platform entails. This method incorporates the **messenger effect** as the healthcare professional is a trustworthy source of information. This outreach will direct users to an online platform via a QR code or a web address. On this platform, users are required to sign in with their full name and phone number or email address for future contacting purposes. Also, this webpage will contain links to social media and accessibility options.

A percentage of participants might struggle and will need help accessing the dynamic consent platform. For example, this group could include participants with disabilities, who don't speak English, are located in rural and remote areas or have limited knowledge of online platforms. Therefore, the platform will include options for subtitles, text-to-voice and translation services to suit the needs of users who require accommodations. Participants who struggle with maintaining a stable internet connection or have difficulty navigating the platform will primarily be supported through a technical support call centre, where staff can guide the user through completing required details and answer any relevant questions. Other than the technical support personal, the local GP's office will help participants complete the program. This platform will be accessible to a wider audience as it uses **simple language** rather than the use of medical and legal jargon.

In order for the participant to consent to a study, they are required to have a clear understanding of risks and benefits, available alternatives, and relevant facts pertaining to the data collection. One of the methods that can achieve informed consent is through an interactive video with short bullet points that summarise essential details and provide audio and video content to clarify risks and benefits. The short video will contain relevant information regarding the description, purpose of the research and how the data will be used. Also aims to include a short questionnaire that will cross examine the understanding of the consent procedure which will make sure the user is aware of the data that will be collected, utilised and protected. It is important to be aware that too much information will lead to **cognitive overload**. To avoid this the information presented in the video and questionnaire is summarised, highlighting the important points.

Keeping an audience engaged long enough to understand and make decisions regarding their health data is key. It is known that 45% of people get easily side-tracked from what they are doing, and half will turn to their phones when nothing is occupying their attention. Therefore, it is convenient to convey this information quickly and engagingly over a short amount of time. Once the users have successfully passed the questionnaire, they are then directed to a quiz platform similar to BuzzFeed Quizzes. BuzzFeed Quizzes have had significant success with their short, interactive and mobile-friendly design. Having a personalised approach is a way to keep people engaged as customisation across all industries becomes increasingly popular. The BuzzFeed Quiz design will provide recommendations on which studies users' data could support and which areas they can help in while providing an option to share results to social media to reach a wider audience. As these quizzes are typically only 2 minutes long, it is a fantastic way to keep the audience engaged whilst decreasing applicant screening times. Data from the BuzzFeed quiz can also be collected and analysed. With a short and positive experience, the audience will be more likely to continue communication through social media or other means to maintain ongoing consent.

We aim to show images of people helping community members to ensure the correct values of the platform are portrayed. Each research project will include personalised highlights of the benefits of participating in the given project in the BuzzFeed quiz. Through **Behavioural Insight** (BI), we understand that individuals prefer to participate in projects that support the impression of a positive and consistent self-image and are more likely to participate if others are also involved. This method will therefore increase in participation.



**Hi Tracey, we need your help.
You have an outstanding
task/mission that needs your
completion.
Thanks, QLD Health**

Ongoing participation and consent is also important in communication with participants; for example, emails or text messages like the one shown. These entertaining yet essential messages encourage participants to engage further. This is applicable in situations where research projects change, requiring updated communication to the participants. If the participants do not wish to continue via the platform they are able to **'opt-out'**. In terms of collecting consent, stakeholders involved in creating such a system need to invoke regulatory oversight, particularly when it comes to the safety and protection of users' behavioural data.

RECOMMENDATIONS

1. **Design a short instruction video with interactive components that outline and explain.**
2. **Design a "Buzzfeed" quiz to actively engage participants.**
3. **Set up a technical support network that can deal with any potential problems.**
4. **Inform and train GP's regarding the program in order to assist the user.**

Our strategies are practical, straightforward and cost effective. Following these key steps will lead to successful data collection and a higher participant retention rate.

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