WELCOME TO CTRL

Australian Genomics Dynamic Consent Platform

Australian Genomics is committed to improving the experience of participants enrolled in genomic research programs and undergoing genomic testing. We recognise that traditional models of consent are not optimal, and in many respects don't convey the complexities of medical genomics. This is why we have developed a new online research consent and engagement platform for our participants called **CTRL** (control).

The platform is inspired by **dynamic consent** – a mechanism which enables study participants to give and revoke consent in real time and to engage more fully in research, if they choose[1].

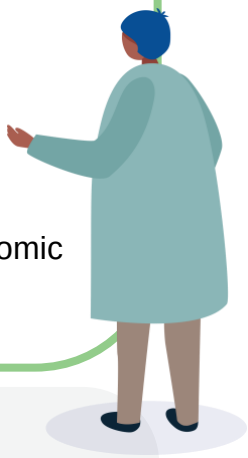
DYNAMIC CONSENT – A SNAPSHOT

For **patients**, dynamic consent platforms aim to provide:

- more appropriate, granular and flexible consent options,
- access to better study information,
- opportunity to increase scientific and medical literacy, and
- two-way communication between participants and researchers, building trust in the process.

For **research organisations**, dynamic consent facilitates:

- better electronic consent records,
- retention of participants in longitudinal studies,
- clearer data sharing frameworks for health information, and
- working toward addressing ethical, legal and social issues relevant to genomic studies.



OUR PROGRESS

The **CTRL Phase I** release has been approved for research use by our HREC and allows participants to update their profile and contact details; make and change consent choices; access patient experience surveys; initiate contact with the researchers; access study news and information, and follow their progress through the study.

Expansion plans for **Phase II** are already underway and include representing genomic reports in a format accessible to participants, providing opportunities for self-reporting health information, as well as promoting other approved research projects.

1. Kaye et al. EJHG (2015) 23

WELCOME TO THE CTRL DEMONSTRATION SITE!

https://demo-ctrl.australiangenomics.org.au/

A demo of the CTRL platform is available to view and interact with. You can access the demo-CTRL site by registering using the instructions below.

If you have any questions, comments or suggestions about CTRL, please get in touch with us by emailing info@australiangenomics.org.au.

HOW TO REGISTER

Go to the CTRL demonstration website: https://demo-ctrl.australiangenomics.org.au/

Register by entering the following details:

Email address * (Must be unique and have an @ symbol)

Name *

Your choice of password (Minimum 6 characters, no requirement for number, symbols or upper case letters)

Select a date of birth in the past

Study ID: A1234123

Check the icon agreeing to the terms and conditions

T&C and the Privacy Policy can be viewed by clicking on the blue writing

CTRL DEMONSTRATION SITE FUNCTIONS

CTRL functions available on the demo site

✓ Register
✓ Select and change preferences
✓ Complete and update contact details

CTRL functions <u>not</u> available on demo site

× Genetic counsellor interaction
× Study surveys
× Genomic results
× Participant updates

**** Please note:** The demo-CTRL site is not linked to the study database (REDCap), so your registration details and preference information will not be actively reviewed. Fictitious details can be entered.*