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 genomic medicine. This is why we have developed an 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.

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 implications relevant to genomic studies.

As an **open-source** platform, CTRL is freely accessible on GitHub, allowing researchers to adapt and implement it according to their specific project needs. Its opensource nature fosters collaboration and innovation within the research community, supporting diverse study requirements. To explore its features, or access the source code, visit this <u>link</u>.





CTRL Demonstration Site

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 in the next page.

https://demo.ctrl.dsp.garvan.org.au/

Available functions on CTRL demo site:

- 🗸 Register
- \checkmark Select and change preferences
- ✓ Complete and update contact details
- ✓ View glossary
- \checkmark View news and education content

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.

HOW TO USE CTRL?



There are some questions that are optional where you can choose your response. Complete you personal details from the dashboard by clicking the 'complete' button.

Asstration	My Activities	My Personal Details	Contact Us	News and Information	Glossary
Your pers	sonal details nee	ed to be completed	Complete		

If you have any questions, comments or suggestions about CTRL, please get in touch with us by emailing <u>ctrl-australiagenomics@mcri.edu.au</u>



CTRL Demonstration Site

	RE	GISTRATION PAGE	
		First & Last	
	First Name	Family Name	name Of the person
Email Address Must be unique and have an @	→ Email	completing the portal	
symbol	Password	Re-enter Password	Password Your choice of password
DOB Must be date in the past	Date of Birth DD-MM-YYYY		(Minimum 6 characters, no requirement for number,
Study ID A1234123 (this gets reset every night)	Participant ID		upper case letters)
ingit.	Are you registering	as a parent/guardian or carer? No	Yes Button If completing
First & Last name Of the nominated	Nominated alternate	guardian click to 'yes'. Then	
Next-of-Kin	First Name	Family Name	fill out child's details below.
Email Address Of the nominated Next-of-Kin	Email		
Checkbox Icon	x 1a	agree to the Terms and Conditions	
turns blue		Register Now	Policies Links to the terms and conditions
	lf you alr	ready have an account, please Log in	and privacy policies
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