

Your Privacy

Background

Aotearoa Clinical Trials (ACTT, us, we) is committed to taking all reasonable steps to protect your privacy. This Privacy Policy describes the personal information that we collect and how we may collect, store, use, share (disclose) and protect your personal information.

ACTT staff and contracted third parties are legally and ethically duty-bound to safeguard clinical trial participants' privacy and confidentiality. ACTT complies with the New Zealand Privacy Act 2020, Health Information Privacy Code 2020, and National Ethical Standards (Health and Disability Ethics Committee (HDEC)) or any subsequent versions of these acts or standards.

How does ACTT collect personal information?

ACTT collects information, including personal information, when you register your interest in a clinical trial by completing the online registration form or when you respond to a text invite. We may also sometimes receive your details from a health professional who has identified you as a potential participant. If we receive your information indirectly, we will contact you as soon as practicable to confirm your agreement and the accuracy of the information that was shared.

What information does ACTT collect and store?

The information ACTT collects and stores when you register for a clinical trial may include, but not be limited to, the following:

- Your first and last name;
- Your date of birth;
- Your biological sex at birth;
- Your contact details, for example your email address, phone number and address;
- Information about your health, including any medical conditions and medications;
- Information about your lifestyle, such as smoking, alcohol consumption, use of drugs, and diet;
- Research specific questions such as your weight and height.

Why does ACTT collect your personal information?

ACTT collects your personal information to:

- check whether you are eligible for the clinical trial (research) that you have expressed interest in;
- contact you if you are potentially eligible for the clinical trial that you have expressed interest in;
- add your personal information to our secure Research Contact List of people who have expressed interest in a clinical trial, provided you have expressly agreed to this future use. ACTT staff check this List regularly to see whether you may be eligible for existing or new clinical trials. People who may be eligible for clinical trials are contacted, usually via text message, and are offered the opportunity to take part. Whether you choose to take part in any clinical trial is entirely your decision. You do not have to take up the offer of participating in any clinical trial that ACTT contacts you about;
- send you updates or newsletters;

- invite you to take part in participant feedback or quality improvement surveys

If you provide ACTT with your personal information (including sensitive health information), you consent to us collecting, storing, using, and disclosing your personal information in accordance with this Privacy Policy.

Who might ACTT disclose personal information to?

We may share or disclose any of your personal information to other persons as required or permitted by law for example if we believe there is a risk to your personal safety.

Data security

At ACTT, we take the security of your personal information seriously. ACTT therefore takes all reasonable steps to protect the personal information we hold about you from misuse, loss, unauthorised access, modification, or disclosure. However, we cannot guarantee the security of your personal information despite the measures we have put in place. If you are concerned about a breach of security, please email info@aotearoatrials.nz.

How can you access or ask for your personal information to be corrected/ updated?

ACTT takes reasonable steps to ensure that the personal information that we collect and store is accurate and complete. However, over time the information we hold may become out of date. Please feel free to advise us of any changes to your personal information to help us maintain accurate and complete information. If you wish to know what personal information, we hold about you or would like to request a correction to the personal information that we hold about you, please email info@aotearoatrials.nz.

For us to respond to your request, you will need to provide us with your full name, email address, date of birth, address, mobile phone number and a description of the information you wish to access and/or specify the information you would like amended. This is to ensure the legitimacy of the request and to protect your information.

Unsubscribe/ Opt Out of receiving information about clinical trials

You can opt out (unsubscribe) of receiving information about clinical trials at any time. If you no longer wish to receive information about clinical trials, please email info@aotearoatrials.nz. If you unsubscribe, we will keep minimal information to prevent future contact. You can request your profile to be reactivated at any time by emailing info@aotearoatrials.nz. Please note that this is a manual process and may take up to 5 working days to complete.

If you want us to remove all your details from our systems, please tell us by email to info@aotearoatrials.nz —unless we must retain certain records by law, we will action your request.

Please note, that if you have participated in a clinical trial (i.e., you have signed a consent form), while we can unsubscribe you from receiving information about future clinical trials, the information you provide to ACTT for the clinical trial will be held by us in accordance with clinical trial requirements (as described in the trial-specific Participant Information Sheet and Consent Form (PISCF)). This information cannot be removed or deleted at your request as we may need to contact you in the future if there is any new or important information about the trial you participated in. The information collected for the clinical trial must be kept for at least 15 years from the end of the trial or longer as required by the trial sponsor (the company organising or paying for the trial).

Changes to our Privacy Policy

We reserve the right, at our discretion, to alter this Privacy Policy at any time. Please check this privacy policy regularly for changes and updates. Changes to this Privacy Policy will take effect immediately once they are published on the ACTT website. Continuing to use this website or providing personal information after the Privacy Policy is updated, will indicate your acceptance of any such changes.

Privacy Breach

ACTT will take all reasonable steps to prevent a personal information data breach and to prevent any recurrences if possible.

Under the Privacy Act 2020, ACTT must notify the Privacy Commissioner and any affected people as soon as practically possible of any privacy breach that has either caused or is likely to cause anyone serious harm. We may be required to report the breach to other regulatory bodies under applicable clinical trial requirements.

Privacy Complaints

All privacy complaints should be emailed to info@aotearoatrials.nz. Privacy complaints will:

- be treated seriously;
- be acknowledged within 2 working days;
- be treated confidentially;
- not impact on any care, or future care that you may receive, while you are a participant on an ACTT clinical trial.

ACTT will investigate your complaint and notify you of the outcome of your complaint once the investigation is complete. If you are not satisfied with the outcome of your complaint, you may refer your complaint to the Office of the Privacy Commissioner, PO Box 10094, Wellington 6143.

Contact Us

If you have any questions or concerns about this Privacy Policy or would like to change or access the information that we hold about you, please email info@aotearoatrials.nz.

References

- Privacy Act 2020
- Health Information Privacy Code 2020
- National Ethical Standards for Health and Disability Research and Quality Improvement
- <https://policies.google.com/technologies/partner-sites?hl=en>