

The Signature Studies

Frequently Asked Questions

1. Who is conducting this research?

These three studies — the Holistic Understanding Study, the For Me trial, and the TailorED trial — are being conducted and coordinated by the Australian Eating Disorder Research and Translation Centre (AEDRTC), in partnership with the University of Sydney, Monash University, La Trobe University, and Sydney Local Health District.

Our research team consists of experts with lived experience, and highly experienced clinicians and researchers, who will monitor and provide intensive support to participants throughout the studies.

2. What are the Signature Studies?

The Signature Studies are three studies that will make a valuable contribution to eating disorder research. They include the Holistic Understanding Study, a broad research study, and two clinical trials: the For Me trial and the TailorED trial.

These studies have been co-produced and co-designed from the very beginning by AEDRTC alongside people with lived experience and carers, clinicians, and research experts in treatment design, neuroscience, biostatistics, and clinical psychology. This means lived experience has informed all aspects of the studies' research priorities, design, and intended impact.

3. What does this research hope to achieve?

All three studies aim to build a more complete picture of eating disorders and increase our understanding of these illnesses, in order to develop more effective and personalised treatments. We know current treatments do not work for everyone, and we currently don't have all the answers. Your contribution to this important research can help us identify the many characteristics of eating disorders across all diagnoses to improve treatments, and ultimately save lives.

4. What are the difference between the studies?

The Holistic Understanding Study is a research study that provides a comprehensive clinical and biological assessment of each person's unique experience of an eating disorder. This helps us build a detailed picture of both individual experiences and eating disorders more broadly.

For Me and TailorED are clinical trials testing personalised treatment approaches tailored to the individual. They are evaluating the effectiveness of these treatments, with the hope of improving care for people living with eating disorders.

The For Me trial is testing a personalised treatment approach for young people in the early stages of anorexia nervosa (including atypical anorexia nervosa).

The TailorED trial is testing a personalised treatment approach for people living with bulimia nervosa or binge eating disorder.

These studies are designed to work together, with participation in the Holistic Understanding Study providing the baseline assessment for participants enrolled in the clinical trials.

5. Who can participate?

Eligibility varies between studies. Factors such as your age, eating disorder symptoms, treatment history, and location will be considered. Those over the age of 14 and living in Australia can complete the screening questionnaire on the website, or speak to a researcher to determine eligibility.

6. Do I need to have a formal diagnosis to participate?

No. If you think you may have an eating disorder, you may still be eligible. Our research team will assess your personal circumstances and help determine whether one of our studies is suitable for you. Start by completing the screening survey or contacting a researcher via our website.

7. What if I'm not sure if I have an eating disorder?

That's ok, once you have taken our screening survey, our research team is happy to help determine whether one of our studies is suitable for you. Start by completing the screening survey or contacting a researcher via our website.

8. I am currently receiving treatment for my eating disorder; do I have to stop?

Eligibility requirements differ between studies, and our team can discuss your individual circumstances. If you decide to proceed with one of our free treatment trials, there are some active treatments you may need to stop for a period of time. You do not need to alter any treatments to participate in the Holistic Understanding Study.

9. Can I choose which treatment trial I join?

Participation in the treatment trials depends on eligibility criteria and the study requirements. We need to make sure that the study is suitable to your needs, so our team will discuss the most appropriate option with you. The Eligibility Checker on our website can also help indicate which trials you can participate in.

10. What if I'm not eligible for a treatment trial?

You may still be eligible to participate in the Holistic Understanding Study, which is still a valuable contribution to research and provides a comprehensive clinical and biological assessment of each person's unique experience of an eating disorder. Our team can also provide information about other support and treatment options, where appropriate, and can tell you about other trials we have open that may be right for you.

11. I just want free treatment — why do I have to enrol in the Holistic

Understanding Study?

The information gathered through the Holistic Understanding Study helps us personalise the therapy you will receive in the clinical trial. Without this key information, we would not be able to tailor treatment to your specific needs — it would be like any other treatment. The data gathered will also help us build a more complete picture of eating disorders, improve our understanding of the illness, and help us personalise treatments and make new discoveries into the future.

12. What is atypical anorexia?

Atypical anorexia is a serious eating disorder where someone may severely restrict their eating, lose a significant amount of weight, and be very worried about gaining weight or their body shape, even though they are not underweight. Despite appearing to be at a 'normal' weight, they can experience the same physical and emotional health problems as someone with anorexia.

13. How long does the screening survey take?

The screening survey will take approximately 25 minutes to complete.

14. How long does the study take?

The length depends on which study or studies you enrol in. Participation takes place over the course of up to 12 months. This includes questionnaires and computer tasks once every three months, with some assessments requiring in-person visits at the start and then again at 6-month intervals. Further details will be provided during the screening process so you can make an informed decision and understand how long each part might take.

15. What happens after I apply?

A member of the research team will be in touch via phone or email about the next steps, and will guide you through the whole process. You can withdraw or decide you are not interested at any point.

16. Do I have to meet in person?

In-person requirements depend on which study you enrol in. The treatment trials generally involve at least one in-person visit, and sometimes weekly visits to receive therapy. Our research team will work out with you exactly what is needed. The Holistic Understanding Study generally requires less in-person time — usually two visits — or can also be completed fully remotely. Our research team will discuss what, if any, in-person assessments are required, and which location is suitable for you.

17. Where are the study sites?

Our research is being conducted at a number of leading institutions. These include:

- The University of Sydney, Camperdown (NSW)
- Westmead Hospital, Western Sydney Local Health District (NSW)
- Turner Institute for Brain and Mental Health, Monash University (VIC)
- Albury-Wodonga Campus, La Trobe University (VIC)

Only certain sites are equipped to conduct specific assessments for each trial. The location of any in-person assessments will be discussed with you during your conversation with one of our researchers.

18. I'm not comfortable doing some of the assessments, can I skip them?

We will work with you to choose which assessments you feel comfortable completing. We have options for all assessments, interviews, and questionnaires — or questionnaires only if you would prefer limited contact with the research team.

Those participating in the clinical trials and receiving free treatment will be required to complete all the assessments; however, the research team will work with you to make sure you are comfortable throughout the trial.

19. Can I withdraw from the trial?

Yes. Participation is voluntary, and you can withdraw at any time

20. Will I be able to continue with treatment after the study ends?

Although you won't be able to continue the study treatment after the study ends, you are free to access other treatments if you wish. You can discuss the treatment options available to you with your regular doctor or clinicians and choose any treatment that is appropriate for your needs.

Taking part in this study will not affect your access to future medical care or treatment.

21. Will I definitely receive treatment if I apply?

Not everyone who applies will be eligible for a treatment trial. Our studies have strict eligibility criteria that have been put in place for safety and efficacy reasons. A screening process helps determine whether a study is the right fit for you. If our studies are not right for you, we can help you find other treatment.

22. What type of treatment is provided?

Treatment varies depending on the trial. It will include support from experienced clinicians, evidence-based psychological treatment, and tailored care approaches.

23. What is TMS therapy?

As part of the TailorED trial, some participants who do not respond quickly to standard treatment may be offered a therapy called Transcranial Magnetic Stimulation (TMS). TMS involves applying a localised, pulsed magnetic field to specific areas of the outside of the skull, which induces small electrical currents that stimulate nerve cells in the brain.

During the procedure, you wear a cap that delivers the pulses through a coil placed on your head. The precise mechanism is not yet fully understood, although studies suggest that stimulating these nerve cells alters brain function in ways that can be therapeutic.

TMS is a well-tolerated and safe medical procedure delivered by experienced clinicians. When appropriate procedures are followed for participant selection and treatment, the risks are minimal, and side effects are usually mild, transient, and easily managed.

For more information, see the RANZCP guidance:

<https://www.ranzcp.org/clinical-guidelines-publications/clinical-guidelines-publications-library/repetitive-transcranial-magnetic-stimulation>

A clinician will walk you through the full procedure and answer any questions before you start the TailorED trial.

24. Is treatment actually free?

Yes. Participants accepted into one of our treatment trials receive study-related treatment at no cost for the full duration. Other related costs you incur may be reimbursed, and your time on some of the Holistic Understanding Study assessments will be reimbursed.

25. Will I be paid for my participation?

Yes. All participants will be compensated for their time as part of the Holistic Understanding Study.

26. Is my information confidential?

Yes. All information collected is handled confidentially and in accordance with approved research and privacy requirements.

27. Has this study been approved by an ethics committee?

Yes. All three studies have been approved by the Ethics Review Committee (RPAH Zone) of the Sydney Local Health District and also approved at the Monash and La Trobe sites. Any person with concerns or complaints about the conduct of this study can contact the Executive Officer on 02 9515 6766 or SLHD-RPAEthics@health.nsw.gov.au.

28. I have more questions — who can I talk to?

Our research team is here to help you answer any questions or concerns.

You can email or call us:

University of Sydney, NSW:

E: holistic.understanding@sydney.edu.au

P: 0480 054 255 (Amber/Tia – Holistic Understanding)

P: 0489 990 589 (Steph – For Me Trial)

P: 0489 990 587 (Angela – For Me Trial)

Monash University, VIC:

E: holisticstudy.eatingdisorders@monash.edu

P: (03) 9905 1029 (Courtney)

La Trobe, Albury-Wodonga, VIC:

E: holisticstudy.ed@latrobe.edu.au

P: (02) 6024 9635 (Rachael – Holistic Understanding Study & TailorED)