

About the Eating Disorders Genetics Initiative (EDGI)

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- The Eating Disorders Genetics Initiative (EDGI) is the world's largest genetic investigation of eating disorders ever performed.
- The Australian arm of EDGI aims to identify the hundreds of genes that influence a person's risk of developing the complex, devastating illnesses of anorexia nervosa, bulimia nervosa and binge-eating disorder, to improve treatment, and ultimately, save lives.
- Identification of the genes that predispose individuals to eating disorders will revolutionise future research into causes, treatment and prevention of the illness.
- EDGI follows the ground-breaking advances made recently through the collaborative Anorexia Nervosa Genetics Initiative (ANGI), in which researchers, including the EDGI team, have identified both psychiatric and metabolic causes for anorexia nervosa.
- QIMR Berghofer Medical Research Institute in Brisbane is leading the Australian arm of the study.
- Geneticist and Head of the Genetic Epidemiology Research Group at QIMR Berghofer, Professor Nick Martin, is leading the Australian arm of the EDGI study. Clinical Psychiatrist and Distinguished Professor of Eating Disorders in the Department of Psychiatry at the University of North Carolina, USA, Professor Cynthia Bulik, is leading the international study.
- Australia, New Zealand, the United States, United Kingdom and Denmark each have centres contributing to this important initiative.
- **The Australian researchers aim to recruit more than 3,500 Australians, including people who have experienced an eating disorder and a control group (those who have never had an eating disorder) by March 31, 2022.**
- This ground-breaking research should identify hundreds of genes that influence a person's risk of developing an eating disorder.
- Cracking the genetic code of eating disorders will enable the development of new, and more effective, personalised treatments that will target the problem directly.
- Many international studies to date have explored an individual's genetic predisposition to eating disorders. However, only a handful of the specific predisposing genes have been identified, and there are many more to be found.
- Study researchers will analyse DNA from saliva samples collected through the study to find specific genes associated with eating disorders.
- Before analysis can begin, DNA will be extracted from the saliva sample and genotyped to provide a 'read out' of each participant's genetic code.
- The analysis process, known as a 'genome-wide association study (GWAS)', involves comparing the genotypes of people with experience of an eating disorder, to the genotype of those yet to experience an eating disorder.



- The study will allow the researchers to identify genetic factors that determine why some people experience eating disorders, while others do not, and why some people living with eating disorders respond to certain treatments, while others do not.
- Comparing the results of the EDGI study with the results from studies into other conditions will also help the researchers to understand the genetic relationship among eating disorders and commonly co-occurring conditions such as clinical depression, anxiety or substance use problems, or some metabolic conditions or other health problems.
- This knowledge will be used to improve existing treatments and to develop new treatments for eating disorders.



Study participation

- Participating in this study could make a genuine contribution to the future diagnosis, management and treatment of eating disorders.
- All participants need to be aged 13 years and over.
- Children aged 13 to 17 years wishing to volunteer for the study must be supervised by a guardian.
- Study participation is strictly confidential. All participant information provided will be maintained in accordance with the Commonwealth Privacy Act (1988) and National Health and Medical Research Council (NHMRC) Guidelines.
- Study participation involves providing informed consent and completing a short online 15 minute survey.
- After completing this core survey, eligible participants will be asked to donate a saliva sample.
- Study participants will also be given the option to complete further short modules on important topics related to their eating disorder experience including mood, treatment, and personality.
- Researchers will send a saliva collection kit together with a pre-paid return envelope to selected participants.
- EDGI researchers will extract DNA from saliva samples to identify specific genes associated with eating disorders.

To volunteer for, or learn more about the Eating Disorders Genetics Initiative, head to www.edgi.org.au or email edgi@qimrberghofer.edu.au.

Should you suspect that you, or a loved one, may be living with an eating disorder, speak to your local healthcare practitioner without delay, or head to www.insideoutinstitute.org.au to complete their screener and assessment, and to access more information and professional support.

Australian professional patient support services offering 24/7 helpline services include:

- **Beyond Blue: 1300 22 4636**
- **LifeLine: 13 11 14**
- **Men's Line Australia: 1300 78 99 78**
- **Kids Help Line: 1800 55 1800.**

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