

Unique Masters by Research projects in the field of genetic testing / genetic counselling with the Centre for Precision Health.

The Centre for Precision Health (CPH) at ECU is excited to offer two projects exploring public perceptions of genetic testing and patient satisfaction with genetic counselling services. The two projects listed below will be primarily supervised by leading private genetic counsellors and supported at ECU by supervision from researchers in the CPH. The projects are on offer for 2025 for Semester 1 or Semester 2 enrolment, so please make contact with an expression of interest for either project, addressing the desired capabilities.

Project One: Public perceptions and expectations of genetic testing in Australia

This project aims to explore the expectations and perceptions of what a genetic test can provide from the perspective of people seeking out private genetic testing. Exploring what people perceive genetic testing can do will allow for a greater understanding of the gap between current technology and expectations.

A qualitative assessment of expectations will be undertaken and can then be used in more public education and health communication. The overall goal is to contribute to developing tailored communication strategies detailing the expectations and understanding of the limitations of genetics for patients and clinicians. Other implications include ethical practices, expectations that are aligned with society values, driving policy development if gaps are found to exist, as well as improving accessibility to high-demand tests. Once it is known what people want, we can aim to see where genetics can be embedded and work with public awareness and regulation to ensure safe practices and equitable healthcare outcomes.

Project Two: Patient satisfaction with Private genetic counsellor service across all areas of service

This project aims to examine patient satisfaction with private genetic counselling services across all areas of service, i.e., familial cancer, reproduction, adult, paediatrics and pharmacogenomics. While the public services in Australia have carried out these studies, only one private service has published in this area and that was restricted to familial Cancer Genetics. A more holistic look at the services provided by a private genetic service and patient satisfaction will enable private practice to better meet the needs of clients and improve outcomes to patients. Clinical genetics is the last bastion of health to be significantly privatised to any extent and comes with it a low level of acceptability from clinicians. Demonstrating patient perspectives and satisfaction may drive change within the industry leading to better healthcare outcomes in genetic health of the population.

Previous research has shown high satisfaction levels with private genetic counselling for familial cancer genetics. Demonstrating the acceptability of private practice will assist with the promotion of widespread acceptance of private genetic health and drive future innovation in the field of genetics with access to current technology that public health can't or may be reluctant to implement.



Student capabilities sought:

We are looking for a self-motivated candidate interested in acquiring and applying qualitative research skills. This includes interviewing patients, transcribing interviews, and coding data to explore themes using inductive content analysis. The right person will have exceptional interpersonal skills, and previous interview skills are desirable. They will also need genetic knowledge and an understanding of current technologies and testing available in clinical practice.

The supervisory team:

Sarah Long is a genetic counsellor with over 16 years of clinical experience. She is currently completing a PhD and is at the point of thesis submission. Her PhD was mixed methods and involved both qualitative and quantitative data analysis. Sarah Long is also responsible for supervising three genetic counsellors through the process of Board Supervision for the Human Genetics Society of Australia and is also a qualified professional supervisor, having attended training through the Australian Society of Genetic Counsellors. She currently works two days a week in clinical practice and three days a week as the Senior Genetic Counsellor for the PreGen research study.

Katrina Harrison is a registered Board-Certified Genetic Counsellor with over 25 years of experience in both the public and private clinical genetic sector, and she now owns and runs her own private clinical genetic practice, working alongside clinical geneticists to provide a comprehensive Australia-wide service. Katrina sits on several committees including the ASGC Professional Practice Committee and the Professional Issues Committee and at ECU she is a member of the Medical and Biomedical Science Consultative Committee and the Centre for Precision Health External Advisory Board. She has supervised students working towards certification in genetic counselling. Her research experience extends to multiple peer reviewed journal articles in the area of consanguinity, congenital heart defects, willingness to pay for genetic testing and more recently, publications from the Mackenzie's Mission reproductive genetic carrier screening study supported by Australian Genomics.

Professor Simon Laws is the Professor of Translational Genomics and Director of the Centre for Precision Health at Edith Cowan University. He has over 25 years' experience in genetic research with a focus on understanding the role of genetics in human health and disease, with a focus on neurological conditions, particularly Alzheimer's Disease. Prof Laws will be your ECU principal supervisor, and additional ECU academics may be included at the discretion of the supervisory team.

If you are interested in undertaking one of these Masters by Research projects, please contact Prof. Simon Laws (<u>s.laws@ecu.edu.au</u>) with an expression of interest and your curriculum vitae (CV) and address the desired capabilities.

<u>Please review the entrance requirements of this course</u> and ensure that these can be met. Please note that if you are a domestic student enrolled in a Higher Degree by Research program you won't be required to pay tuition fees. These are offset by the Australian Government Research Training Program.

Once your EOI has been reviewed, we will advise applicants on the next steps for enrolment and commencement of the Masters program.