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Citizen jury will deliberate on gene-editing regulation and ethics

A citizen jury of 24 will be at the centre of a new research project which will examine the best way to gather community opinion on the use of innovative gene-editing technologies.

The study is one of two new projects announced today that will be led by University of Tasmania researchers and funded through the Federal Government's Medical Research Future Fund Genomics Health Futures Mission.

The two-year citizen jury study is titled *Genome Editing: Formulating an Australian Community Response* and will receive up to \$472,107 in funding.

The citizen jury, chosen for diversity, will hear from experts and advocates about gene-editing technologies and will deliberate on how public policy should regulate them.

The Chief Investigator of the project, Professor Dianne Nicol, Director of the Centre for Law and Genetics at the University of Tasmania, said gene therapy had long been touted for its potential to transform the lives of people affected by genetic disorders. However, progress has been slow, in large part due to uncertain safety and efficacy.

"New genome-editing techniques offer huge advances but raise large ethical, legal and social questions," Professor Nicol said. "Understanding the community's attitudes and concerns about gene editing has been widely recognised as the next step needed to bring these therapies into use, but the best way to engage the public in this discussion is yet to be worked out."

The citizen jury's deliberations will be analysed using the research team's bespoke social scientific methods. The assessment of their deliberations will be reported to government and publicised.

Professor Nicol said the project had parallels in other countries and the potential to feed into a larger global citizens' deliberation. A planned documentary series by

Genepool Productions, an award-winning filmmaker, will help share these citizen deliberations with broader public audiences. Professor Nicol will work with collaborators from Swinburne University and the University of Canberra.

The second project, led by Associate Professor Jane Nielsen, will receive up to \$403,096 and is titled *Returning Raw Genomic Data: Patient Autonomy or Legal Minefield?*

The project will examine patient requests for the return of raw genomic data after genome sequencing. “There is anecdotal evidence that, increasingly, patients and their families are seeking to access their genomic data from clinicians or researchers, and then seeking alternative diagnoses. Sometimes these alternative diagnoses are through third-party interpretive services that may be unregulated,” Associate Professor Nielsen said.

The study will map the regulatory landscape around the return of raw genomic data to patients and evaluate how frequently such requests are occurring. Interviews will explore the reasons patients seek to access their data.

Evidence obtained will assist in developing protocols for dealing with this issue, and in providing policy recommendations for regulators. Professor Margaret Otlowski and Dr Rebekah McWhirter from the University of Tasmania are also part of the research team.

Professor Nicol and Professor Otlowski are also members of research project teams, led by Swinburne University and Monash University respectively, that received grants for genetics research in today’s announcement.

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