



Mitochondrial Donation Licensing Scheme – Privacy and the protection of your personal information

In Australia, research into mitochondrial donation techniques and its use can only be undertaken when it is authorised by a mitochondrial donation licence issued by the National Health and Medical Research Council's (NHMRC) Embryo Research Licensing Committee (ERLC) in accordance with the *Research Involving Human Embryos Act 2002* (Cth) (RIHE Act).

NHMRC will receive and process licence applications. ERLC will receive all information provided in licence applications in order to properly assess the application. NHMRC is responsible for providing secretariat assistance to ERLC to assist with the assessment of licence applications.

The *Privacy Act 1988* (Privacy Act) requires entities bound by the Australian Privacy Principles to have a privacy policy. NHMRC's Privacy Policy is available on our website at: www.nhmrc.gov.au/privacy. Our privacy policy outlines the personal information handling practices at NHMRC.

When applying for a mitochondrial donation licence under the RIHE Act the name and professional details of the nominated embryologist, principal investigators, principal supervisors and other staff who will carry out activities under the licence are collected. This information is required to allow ERLC to properly assess the application. Under section 28H(5) of the RIHE Act an application for a mitochondrial donation licence must nominate one or more embryologists who will be authorised to use the technique permitted under the licence. Under section 28J(5)(d) of the RIHE Act ERLC must not issue a clinical trial licence unless it is satisfied that the staff, other than the embryologists, who will carry out activities directly connected with the clinical trial are appropriately qualified, trained and competent to do so. ERLC has determined that it is appropriate to extend this consideration to all mitochondrial donation licences.

If the names and professional details of embryologists, principal investigators, principal supervisors and other staff carry out directly related activities are not provided with a licence application ERLC will not be able to consider the licence application.

When assessing a licence application ERLC may request advice from relevant experts and NHMRC may disclose your personal information to experts from overseas countries, where there is a need, and in accordance with the Privacy Act and NHMRC's Privacy Policy.

Applicants are required by the licence conditions to comply with the Privacy Act, including the Australian Privacy Principles, and impose the same privacy obligations on any subcontractors engaged by the applicant to assist with the licensed activity.

The *Research Involving Human Embryos Act 2002* includes stringent provisions that apply to holders of mitochondrial donation licences, and others covered by such licences, which seek to ensure the protection of privacy of parties involved in mitochondrial research and training; especially clinical trial participants and persons born using mitochondrial donation. Any licences issued will include conditions relevant to these provisions. A licence holder must ensure there are appropriate systems in place to keep secure information that identifies, or that is reasonably capable of being used to identify, any participant in the clinical trial, or any child born as a result of the clinical trial. This will be in addition to the usual confidentiality arrangements that ordinarily apply in relation to clinical trials and medical practice more generally.

NHMRC may share information provided to it by licence applicants with other Commonwealth agencies for any purposes including government administration, research or service delivery and according to Australian laws, including the *Public Service Act 1999*, *Public Service Regulations 1999*, the *Public Governance, Performance and Accountability Act 2013*, the *Crimes Act 1914*, and the *Criminal Code Act 1995*.

When we may disclose personal information

We may disclose personal information to:

- ERLC and our Commonwealth employees and contractors, to allow the licence application to be assessed
- the Auditor-General, Ombudsman or Privacy Commissioner
- the responsible Minister or Assistant Minister
- a House or a Committee of the Australian Parliament.

We may also disclose personal information if:

- we are required or authorised by law to disclose it
- you agree to the information being disclosed.

NHMRC's Privacy Officer can be contacted by email to nhmrc.privacy@nhmrc.gov.au or by writing to the following address:

Privacy Officer NHMRC
GPO Box 1421
CANBERRA ACT 2601



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