



Mitochondrial donation licensing scheme Privacy Impact Assessment: Response to recommendations

PIA Recommendation (APP4): Staff involved in the licence application process be provided with instructions on how to deal with unsolicited personal information contained in licence applications.

NHMRC Response: AGREED. All NHMRC staff are required to complete annual privacy awareness training. Staff involved in the licence application process must comply with the standard operating procedure (SOP) for managing a licence application. This SOP includes compliance with the [NHMRC Privacy Policy](#) and its SOPs, including the SOP on receipt of unsolicited personal information.

PIA Recommendation (APP5): Impose compliance with the Privacy Act as a licence condition in all mitochondrial donation licences.

NHMRC Response: AGREED. The standard licence conditions for mitochondrial donation licences require licence holders to comply with the Privacy Act (Commonwealth).

PIA Recommendation (APP5): Make it a requirement in a mitochondrial donation licence application form that any individual who is required to provide personal information for the purposes of the licence application must be provided with a privacy collection notice in a form set by the NHMRC.

NHMRC Response: AGREED. A [privacy collection notice](#) for the mitochondrial donation licensing scheme is available on the [NHMRC website](#). All mitochondrial donation licence application forms require the Organisation Representative to confirm that to the best of their knowledge each person named on the application has been provided with the Privacy Collection Notice. Each person named on the licence application must also confirm that they have been given a copy of the privacy collection notice.

PIA Recommendation (APP5): Make it a condition of all issued licences that, even when the licence holder is collecting personal information from an individual that will not be required to be disclosed to NHMRC under the Scheme, the individual must still be provided with a form of privacy collection notice.

NHMRC Response: AGREED. It is a condition of mitochondrial donation licence that the licence holder must provide a Privacy Collection Notice to any person they collect personal information from when delivering specified activities under the mitochondrial donation licence.

PIA Recommendation (APP5): That page 2 of the draft Privacy Collection Notice titled ‘Mitochondrial Donation Licensing Scheme – Privacy and the protection of your personal information’, be amended by deleting the reference to the ERLC, and the reference to ‘confidential information’ be replaced with ‘personal information’.

NHMRC Response: AGREED. Updated Privacy Collection Notice is accessible on [mitochondrial donation licensing scheme](#).

PIA Recommendation (APP8): Make it a requirement of the licence application process that the applicant must secure the consent of any embryologists and staff members nominated or noted in a licence application to the overseas disclosure of their personal information by NHMRC when it considers it necessary for verification purposes.

NHMRC Response: AGREED. The Privacy Collection Notice that each person named on a licence application is required to read, states that personal information may be provided to experts overseas to allow the assessment of the licence application.

PIA Recommendation APP8: The licence application form itself should also contain an item for each nominated person to formally confirm their consent.

NHMRC Response: AGREED. Each person named on the licence application must confirm that they have been given a copy of the Privacy Collection Notice. The Organisation Representative and the Principal Supervisor must also confirm that the information in the application is true and correct. The nominated embryologist must confirm their consent to being nominated on the application.

PIA Recommendation (APP 1.4 & APP 8): That the following changes be made to the NHMRC’s Privacy Policy to reflect the application of the NHMRC’s privacy regime to the mitochondrial donation licensing scheme:

- a. That the section headed ‘Collection of your personal information’ be amended to refer to mitochondrial donation licence applications – viz ‘NHMRC may also collect your personal information via a third party, such as when an institution...*applies for a mitochondrial donation licence*’. [APP 1.4(b)] [page. 6]
- b. That the section headed ‘Dealing with NHMRC anonymously or pseudonymously’ be amended to include reference to mitochondrial donation licence applications, viz *‘In the case of applications for research grants or mitochondrial donation licences, it is not practicable for NHMRC to deal with you on an anonymous or pseudonymous basis. NHMRC will not accept a grant or licence application or report that is anonymous or not in your real name.’* [APP1.4(f)], [page 7] [*We note NHMRC has already advised that it proposes to include a statement in its privacy collection notices developed for this scheme to the effect that individuals will not be able to take advantage of anonymity or pseudonymity*]
- c. That the section headed ‘Disclosure of Personal Information to Overseas Recipients’ on page 10 be expanded to include a reference to potential disclosure of personal information contained in mitochondrial licence applications. [APP8]

NHMRC Response: AGREED.

This amendment will be included in the 2023 review and update of the NHMRC Privacy Policy.

PIA Recommendation (APP8): As a matter of consistency, NHMRC amend its Privacy Policy to refer to the consent requirement for overseas disclosure of personal information in relation to mitochondrial licence applications similar to the disclosure statement used for grant application processes.

NHMRC Response: AGREED. This amendment will be included in the 2023 review and update of the NHMRC Privacy Policy.

PIA Recommendation (APP10): NHMRC consider the imposing of a licence condition requiring licence holders to advise the agency when any of the personal information it provides in its licence application changes.

NHMRC Response: AGREED. ERLC as the licensing authority imposes licence conditions. The standard conditions of mitochondrial donation licence require the licence holder to inform ERLC within 7 days of a person named on the licence is no longer involved in the licensed activities or is temporarily unable to perform their duties under the licence. The licence holder is required to inform ERLC no less than 7 days before a proposed change in their organisation's or their primary contact person's telephone number, email address or postal address.

PIA Recommendation (APP11): That the NHMRC's licence inspection program includes review of the level of security over personal information held by a licence holder.

NHMRC Response: AGREED. NHMRC Licence Inspectors appointed under the *Research Involving Human Embryo Act 2002* will seek regular confirmation from licence holders that they are storing personal information securely and in compliance with the expectations of the Privacy Act (Commonwealth) and licence conditions.