



Australian Government
National Health and Medical Research Council



Chair
Community Affairs Legislation Committee
c/- Committee Secretary
Senate Standing Committees on Community Affairs

via email: community.affairs.sen@aph.gov.au

Dear Chair

RE: Inquiry into the Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023

Thank you for the opportunity to make a submission to the above inquiry that is considering the Australian Organ and Tissue Donation and Transplantation Authority Amendment (Disclosure of Information) Bill 2023, which seeks to broaden the disclosure of information provisions in the *Australian Organ and Tissue Donation and Transplantation Authority Act 2008* (the OTA Act).

I note that the Bill proposes to amend the OTA Act to allow the Australian Organ and Tissue Donation and Transplantation Authority (OTA), DonateLife agencies, grant recipients and “authorised family members” to publish, disseminate or disclose information about deceased organ or tissue donors or recipients without breaching law of a state or territory. Specifically, the amendments would allow the OTA and DonateLife staff to obtain consent for the disclosure of information from an extended list of “authorised family members” of a deceased donor, or deceased recipient, before including information about the respective donor or recipient in their community awareness and educational activities, and for family members to commemorate their loved ones in remembrance services. I note that the disclosure of information is restricted to the purposes of the activities and by the people defined in the legislation.

The National Health and Medical Research Council (NHMRC) is the Australian Government’s lead agency for funding health and medical research. We invest in the creation of new knowledge about the origins, prevention, diagnosis and treatment of disease, drive the translation of health and medical research into evidence-based health practice and policy and provide guidance on responsible research practices and ethical issues that fosters the highest standard of ethics, quality and integrity in health and medical research.

NHMRC has been involved in the development of ethical guidelines for organ and tissue donation for many years. The availability of donor organs and tissues for transplantation relies mainly on the generosity of individuals and their families to donate. For a system of altruistic donation to flourish, it is important that donation processes are underpinned by ethical principles and values. Similarly, for the ongoing success of the transplantation system, decisions about eligibility, suitability and allocation must be ethically robust, transparent and guided by ethical principles and values.

Through the work of the Australian Health Ethics Committee (AHEC), NHMRC has issued five guidelines¹ to provide an overarching framework to guide ethical practice and inform decision-making by everyone involved in organ and tissue donation and transplantation:

- *Organ and tissue donation after death, for transplantation – Guidelines for ethical practice for health professionals, 2007*

¹ Available at: www.nhmrc.gov.au/research-policy/ethics/ethical-guidelines-organ-and-tissue-donation-and-transplantation

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- *Making a decision about organ and tissue donation after death, 2007*
- *Organ and tissue donation by living donors – Guidelines for ethical practice for health professionals, 2007*
- *Making a decision about living organ and tissue donation, 2007*
- *Ethical guidelines for organ transplantation from deceased donors, 2016.*

In consultation with OTA the Australian Health Ethics Committee (AHEC) is reviewing all five ethical guidelines for currency and relevance, with a view to consolidating them into a single guideline; this work is ongoing.

In relation to the amendments proposed by this Bill, I draw the Committee's attention to the final guideline listed above, the [Ethical guidelines for organ transplantation from deceased donors, 2016](#). These Ethical Guidelines set out an overarching framework to guide ethical practice and inform decision making by everyone involved in assessing the eligibility of an individual for transplantation, assessing the suitability of donor organs for transplantation and allocating organs from deceased donors. These Ethical Guidelines include information about the provision of information the need to respect the privacy of donors, recipients and their families, including about maintaining confidentiality of all records and require compliance with all relevant legislation. The Ethical Guidelines are also intended to inform the [Clinical Guidelines for Organ Transplantation from Deceased Donors](#) which are maintained by The Transplant Society of Australia and New Zealand.

NHMRC, through AHEC, is pleased to be able to contribute to the effectiveness of the organ and tissue system in Australia, through the development of these important ethical guidelines.

If you have any queries or wish to discuss NHMRC's submission, please contact ethics@nhmrc.gov.au.

Yours sincerely

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National Health and Medical Research Council

27 June 2023