Australian Government
Australian Law Reform Commission
Australia Capital Territory, Canberra

2nd July 2025

Dear Committee Members,

We thank the Committee for the opportunity to provide a submission to the Inquiry into the review of Human Tissue laws, Issues Paper 51.

This submission is informed by the findings arising from a PhD being undertaken by Mr Anthony Cignarella at Griffith University, where a sequential mixed-methods national study titled *Identity disclosure in organ donation: insights from donor family members, transplant recipients, healthcare professionals, and the Australian community* has been conducted. This PhD is supervised by Professor Andrea Marshall and Dr Jayne Hewitt from Griffith University, and Associate Professor Kristen Ranse from Queensland University of Technology. External co-supervision is provided by Associate Professor Helen Opdam, Senior Intensivist from Austin Health, Melbourne, and National Medical Director of the Australian Organ and Tissue Authority, Canberra.

Following a review of the international literature, this PhD involved three specific studies:

i. A law and policy analysis to explore the Australian legislative and policy position on the disclosure of identifying information between donor family members and organ transplant recipients.
ii. A qualitative study using semi-structured interviews with donor family members, organ transplant recipients, and healthcare professionals to explore their beliefs, attitudes and perceptions regarding the disclosure of identifying information in the context of solid organ donation/transplantation.
iii. A national survey of the Australian community to explore their attitudes and perceptions regarding the disclosure of identifying information between donor family members and organ transplant recipients (analysis in progress).

This submission is informed by the findings of the qualitative study, where data were obtained from 23 donor family members, 25 transplant recipients, and 16 healthcare professionals. Representation across all Australian states and territories was achieved.

In this submission, we identify issues related to the donation of solid organs after death, specifically in response to points 76, 77, and 78 in the Issues Paper that explore how donor and recipient confidentiality and information that enables identifiable contact should be handled.

The findings of our research suggest that:

1. Diverse views exist about whether deceased organ donors, their families, and organ transplant recipients should be identifiable to each other.
2. Members of the Australian donation and transplantation community support the availability of choice regarding identifiable contact between donor family members and organ transplant recipients.
3. Many healthcare professionals support law reform to enable individual choice regarding identifiable contact. Healthcare professionals also suggested that guidelines and resources to support donor family members and organ transplant recipients' requests for identifying information would be required.
4. There is a need for practical strategies, systems, processes, and support to protect individuals' right to privacy while promoting individual autonomy and enabling choice within a framework of mutual and informed consent if identifiable contact is to be pursued.
5. Anecdotally, some donor family members and organ transplant recipients have independently arranged identifiable contact.
6. Potential benefits of identifiable contact include:
    a. sharing, by the donor family, who their loved one was, which humanises the otherwise anonymous donor;
    b. family members finding meaning in their loss and providing comfort during their grief through direct observation and experience of the positive impact a donation decision might have on the organ transplant recipient's life;
    c. conveying the organ transplant recipient's appreciation in a personalised and meaningful way, thereby alleviating possible feelings of survivor's guilt;
    d. provide opportunities for meaningful connections and a sense of closure for donor family members and transplant recipients.
7. Potential risks for donor family members and organ transplant recipients were also identified by participants, including:
    a. exacerbation of grief for some donor family members;
    b. experience of survivor's guilt by organ transplant recipients for having their life prolonged by the death of another person;

   c. emotional distress or disappointment for the donor family, particularly in the context of unsuccessful transplants or where a patient might require a liver transplant due to alcoholic liver disease;
   d. fear of rejection, mismatched expectations, misaligned values, and invasion of privacy.

Recommendations

Study participants identified the following potentially helpful strategies to support donor family members and organ transplant recipients in the context of pursuing identifiable contact, which the Committee may wish to consider:

1. Having the choice to pursue identifiable contact should be further explored and considered to support autonomy in decision-making.
2. Law reform would be required to enable the exchange of identifiable written correspondence and/or face-to-face meetings between donor family members and transplant recipients.
3. Identifiable contact should only be pursued where there is mutual informed consent.
4. Establishment of a national register to facilitate identifiable contact, ensuring that there is community and stakeholder consultation in its development, should be considered.
5. If identifiable contact were to be permitted, this should occur within a structured framework with robust systems and processes to support those involved. Existing systems and processes that support de-identified contact, for example, services via Donor Support Nurse Coordinators, as well as those that support identifiable contact between adult adopted children and their biological parents, or donor-conceived children with their biological donors could inform the development of systems and processes specific to identifiable contact in the context of solid organ donation/transplantation.
6. Participants identified specific actions that could be used to support identifiable contact. These included:
   a. Providing counselling to donor family members and organ transplant recipients, both before and after the exchange of identifiable information.
   b. Using a trained intermediary during face-to-face interactions.
   c. Establishing a designated waiting period to mitigate risks.
   d. Implementing controlled communication channels.
   e. Establishing formal support networks for donor family members and organ transplant recipients.
   f. Using a framework to navigate cultural differences that assists health professionals in providing tailored support.

Additional Information

This research focuses specifically on solid organ donation and transplantation, exploring societal perspectives relating to identity disclosure between donor family members and transplant recipients. The research questions and studies were developed in collaboration with a consumer with lived experience of organ transplantation, Ms Pam Ingram. Associate Professor Helen Opdam (external supervisor) provided intellectual input, content expertise and ongoing support throughout the research. Co-authors of our publications included the expertise of Ms Lorena Romero, Medical Librarian at Alfred Health in Melbourne, who assisted with developing a rigorous search strategy in paper #1, and Associate Professor Tom Buckley from the University of Sydney, who provided guidance with undertaking a policy analysis in paper #2.

References to our recent work in the field are provided, which we hope the Committee may find of assistance.

1. **Cignarella, A., Ranse, K., Hewitt, J., Opdam, H., & & Romero, L. (2022). Identity disclosure between donor families and organ transplant recipients: an integrative review of the international literature. *Psychology, Health & Medicine, 27*(2), 1-23. https://doi.org/10.1080/13548506.2022.2050272**

This article provides a review of the international literature in relation to identity disclosure between donor family members and organ transplant recipients.

Key findings:

i. Across and within groups of donor family members, organ transplant recipients, and healthcare professional's different views towards identity disclosure in the context of organ donation exist.
ii. There are both benefits and burdens associated with connecting donor family members and organ transplant recipients through written correspondence.
iii. Less is known about the impact of face-to-face meetings between donor family members and organ transplant recipients. However, for some donor family members, meeting with the organ transplant recipient(s) may provide a range of positive emotions.

2. **Cignarella, A., Marshall, A., Ranse, K., Opdam, H., Buckley, T., & Hewitt, J. (2023). Identity Disclosure Between Donor Family Members and Organ Transplant Recipients: A Description and Synthesis of Australian Laws and Guidelines. *Journal of Bioethical Inquiry*, 1-21. https://doi.org/10.1007/s11673-023-10287-y**

   This article provides an overview of Australian laws and guidelines regarding identity disclosure between donor family members and organ transplant recipients.

   Key findings:

   i. Using a policy analysis framework, 19 documents were identified and included in this synthesis.
   ii. Nine documents related to state-based legislation. All jurisdictions have enacted laws prohibiting healthcare professionals from disclosing identifying information. In three states, the prohibition extends to all members of the public, including donor family members and organ transplant recipients.
   iii. Of the 10 guidelines identified, six referred to and were consistent with current legislation regarding identity disclosure, while the remaining four did not address identity disclosure in the organ donation context.
   iv. Restrictions on identity disclosure have implications for the public promotion of donation and transplantation, where the sharing of stories and images of organ donors and transplant recipients is common.

3. **Cignarella, A., Marshall, A., Hewitt, J., Opdam, H., Ingram, P., Ranse, K. (2025). Identity disclosure in organ donation: balancing choice, benefits, and risks. *Journal of Nursing Ethics.* [accepted for publication 23rd February 2025]**

This publication highlights the views of Australian donor family members, organ transplant recipients and healthcare professionals in relation to choice, benefits and risks associated with identifiable contact. Several risk minimisation strategies are proposed, informed by our research findings, that the committee may wish to consider.

Key findings:

i. Many healthcare professionals who participated in this study support the notion of choice. Likewise, some donor family members and organ transplant recipients would like the choice to pursue identifiable contact and see potential benefits.
ii. Many donor family members suggested that identifiable contact may provide comfort during their grief, while organ transplant recipients saw this as a way of conveying their appreciation in a personalised manner, thereby alleviating feelings of survivor's guilt.
iii. Perceived risks to donor family members and organ transplant recipients include mismatched expectations, invasion of privacy, fear of rejection, misaligned values, and exacerbated grief. Several risk minimisation strategies were proposed, such as implementing controlled communication channels, establishing formal support networks, offering tailored guidance from healthcare professionals, and considering cultural differences.
iv. If identity disclosure were to be permitted, a national contact registry, implementation of a designated waiting period, individual counselling both before and after contact, use of a trained intermediary during face-to-face interactions, and ensuring participants can withdraw their consent at any time were identified as additional strategies.

Thank you for the opportunity to contribute to this Inquiry.

Kind regards,

[redacted]

Mr Anthony Cignarella
Griffith University
[redacted]

[redacted]

Professor Andrea Marshall
Griffith University
[redacted]

[redacted]

Dr Jayne Hewitt
Griffith University
[redacted]

[redacted]

Associate Professor Kristen Ranse
Queensland University of Technology
[redacted]