

REVIEW OF THE HUMAN TISSUE LAWS

NSW Organ and Tissue Donation Service - Submission

JULY 2025



The NSW Organ and Tissue Donation Service (OTDS), welcomes the opportunity to provide feedback to the Australian Law Reform Commission on the aims and key priorities of the Review of the Human Tissue Laws.

The OTDS, hosted by South Eastern Sydney Local Health District is the state-wide NSW Health agency responsible for increasing organ and tissue donation for transplantation in NSW.

In addition to facilitating solid organ donation in line with national priorities and practices, the OTDS also has an extensive tissue banking and manufacture program incorporating eye; amnion and musculoskeletal banking and retrieval for manufacture. Additionally, OTDS has the capacity to retrieve skin should it be needed for state or national emergencies.

OTDS facilitates ethical research by supplying tissue not used for transplantation to approved research.

Summary of Feedback

OTDS agrees that the Human Tissue Laws (HTLs) should be harmonised following the principles laid out in the discussion paper including increased access; respect for the human body; equitable participation and access; and trust.

Whilst total consistency is unlikely to be achieved, it should be a goal of the work of the Commission to align the Acts where possible. Harmonisation will support best practice in clinical delivery and assist with interjurisdictional movement of tissues for transplant.

We agree that reform is needed to maximise opportunities for donation, better recognise the wishes of donors and ensure stronger adherence to ethical principles, particularly around living tissue donation and importation of tissue for manufacturing.

The Acts should support greater transparency around how and when tissue is used and should address issues related to emerging commercial uses of human tissue.

Suggested increase in scope of review to consider/tighten laws around access to and use of living donor tissue

The OTDS sees a possible gap in the scope of the review in relation to donation of tissue from living donors. There are currently limited checks and balances around which organisations can partner with medical practitioners to procure tissue from living donors within health services. There is potential for conflicts of interest to exist in this space in relation to removal of tissue for commercial purposes.

Jurisdictions need to ensure safeguards are in place to protect consumers/stop manufacturers, or agents of manufacturers from procuring tissue for export or profit or both. Emerging alternative medical, cosmetic and complementary therapies which have tissue in their supply chains make access to tissue from living donors potentially lucrative.

Authorisation for removal of tissue from living donors may need to be updated to ensure not only legal and ethical safeguards are in place; but that a designated officer/senior executive or other independent authority oversees tissue removal from living donors so exploitation does not occur and/or to ensure that consent is truly informed.

Specific issues

There are a range of specific issues related to the Acts which OTDS would like to see addressed. Although the Commission may not require the detail at this stage, we have included the following for reference:

1. Updated, contemporary and consistent definitions of death are needed
2. The definitions of the Senior Available Next of Kin (SANO K) are out of date and don't reflect contemporary families and kinship
3. Acts need to facilitate Donation after Circulatory Determination of Death (DCD) and permit antemortem investigations - allowing SANO K to consent on behalf of people still living
4. Definitions or clarity of "available" around the SANO K would assist practitioners to understand how much searching is required to find the next of kin.
5. Clarity on the legal status of estranged family members, separated partners, stepchildren, estranged family members, adopted/fostered children or children that were raised by the deceased in unusual circumstances, biological children who have been adopted by others or who the deceased was not aware of, and de facto partners will also assist practitioners with supporting end of life decisions.
6. Clarification on seniority in cases of:
 - a. Apprehended Violence Order (should perpetrators be excluded as next of kin?)
 - b. Equal next of kin's (e.g. siblings) where one person has enduring guardianship
 - c. Deceased who are in polygamous relationships (e.g. have multiple defacto's), make next of kin rights equal
 - d. Closest social relationship vs. closest genetic relationship
 - e. Polygamous relationships with multiple defacto partners
7. Role of Power of Attorney and Enduring Guardian could be recognised to extend post death for donation purposes
8. Consent to 'Therapeutic, Medical or Scientific' purposes (TM&S) as a concept needs to be more clearly defined.
9. Clarity about which documents must be in writing/ which can be provided and witnessed electronically.

Opportunities to Increase Tissue Donation

Consider increasing the weight of a personal AODR Registration of wishes regarding donation

- a. Ideally it would carry the same weight as an Advanced Care Directive (ACD)
- b. Person registering and executor of the directive should be notified of same
- c. Include confirmation of who has final say as part of the ACD, e.g.
 - Do they want the next of kin to give their blessing
 - What is the weight given to the family's wishes?