



Eye Bank of South Australia

Eye Donors

Giving the gift of sight.

Eye Bank of South Australia

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Submission by the Eye Bank of South Australia (EBSA) - Review of Human Tissue Laws.

The Eye Bank of South Australia (EBSA) welcomes the opportunity to provide feedback on the discussion paper for the proposed Human Tissue Laws.

Equity of Access and Funding

EBSA agrees with the objects listed in Proposal 5 and supports the need for equitable access to all areas of tissue donation, transplantation and research.

One of the barriers to accessing tissue and donation-related services is geographic location, with rural and remote populations experiencing limited opportunities.

Funding models also vary significantly between jurisdictions, particularly between public and private systems. Increased and more equitable funding is required to support a sustainable, nationally consistent tissue sector.

Protection of Donors and Respect for Decision-Making

New tissue legislation should continue to protect potential donors and ensure that individual donation decisions are upheld. Open, transparent discussions and the provision of clear options for individuals and families are essential to maintaining trust in the donation system.

The changing nature of family structures must be acknowledged, with broader inclusion in the definition of an authorised decision-maker as well as recognising the wider support network of the donor.

Provision for flexibility to approach the next authorised decision maker on the hierarchy list if the higher delegation is not 'available'.

Families should be supported and encouraged to share their donation experiences and stories, recognising the significant role these narratives play in community understanding and engagement.

Definitions and Ethical Foundations

The definition of tissue should include cells, organs, and tissue of human origin. A clear emphasis must remain on the ethical sourcing of all tissue.

Donation involving Vulnerable Populations

Clear and sensitive provisions should exist for the donation of tissue by children, ensuring decisions are made in the child's best interests and with appropriate authorisation.

Legislation should clearly outline consent and authorisation pathways for adults who lack decision-making capacity, including safeguards to support ethical and timely donation and the use of tissue in research.

Committee Composition and Governance

Potential committee members could include:

- Transplant medical practitioners
- Designated officers
- Transplant coordinators
- An Organ and Tissue Authority (OTA) representative (or equivalent)
- A consumer engagement representative
- A research representative

Membership should include representation from all jurisdictions.

Where matters are referred to the committee, mechanisms must be in place to ensure timely consideration and decision-making so as not to hinder the donation process.

Consent and Authorisation After Death

Designated officers play a critical role in family discussions, facilitation of donation pathways and provision of time-critical information. Their involvement provides an additional safeguard, for the donor, donation coordinator and the public's perception of the sector as a whole – through secondary review prior to tissue donation.

Designated officers may also provide authority for donation to proceed where there is no adult with decision-making capacity or where no senior available next of kin can be identified.

For these reasons, we oppose the view that the role of the designated officer is no longer required; their role has evolved beyond their intended purpose to only ensure there are no objections to donation, expanding into the critical roles described above.

Clear guidelines are required for donation processes occurring in out-of-hospital or mortuary settings. Legislative formats should remain flexible to accommodate differing clinical and jurisdictional contexts.

Pre-Mortem Interventions

A separate consent for pre-mortem procedures or interventions could be implemented.

This should be part of the discussion with families/the next of kin/authorised decision maker prior to any donation pathway.

Donors must be treated with dignity and respect at all times and should not be subjected to unnecessary or overly invasive procedures.

Coronial and Post-Mortem Considerations

Coronial consent may be required where donation could affect post-mortem coronial investigations.

All individuals should have the right to provide consent whilst alive, to authorise a non-coronial post-mortem examination.

Clear guidance should be provided regarding the permissible use of tissue removed during post-mortem examinations.

Consent and authorisation for use of tissue samples.

Consent should be obtained for all each intended uses of tissue, exceptions may be in the absence of an authorised decision maker. The format of the consent should be flexible to allow for differing clinical scenarios.

Consent and authorisation should be obtained for tissue removal for research purposes from living persons.

Regulation of Stored Tissue Collections

Individuals should have the right to access their own stored tissue. Requests should be supported by a clear, documented purpose. Appropriate guidelines should govern access, assessment, approval, and permitted uses.

National guidelines for the regulation of research biobanks or educational collections of tissue would be beneficial to avoid misuse of tissue.

Exceptions to Prohibitions on Exchange for Reward

Any exceptions to the prohibition on the exchange of human tissue for reward must be clearly defined and tightly regulated.

Advertising and Trade

Only to increase the awareness of organ and tissue donation pathways.

Improving Access to Data

EBSA supports increased access to data and greater transparency across the tissue sector.

Currently, defining consistent data points is challenging due to variable operating parameters across jurisdictions. Nationally agreed data standards would support improved oversight and planning.

National Regulator

The establishment of a national regulatory oversight body would promote consistency across eye and tissue bank jurisdictions.

Potential areas of focus:

- Donor facilitation: standardising processes to support donors and families.
- Education and training of donor coordinators, including expansion of authorised recovery personnel and implementation of recognised training programs.
- Workforce safeguards to support donor coordinators and promote retention.
- Cost recovery to ensure fair and sustainable financial practices across jurisdictions.
- Clearer guidelines surrounding tissue for research.

Mandatory reporting requirements should be implemented with clear, nationally consistent guidelines.

Compliance and Monitoring

If reforms are legislated, organisations need to be supported to practice within the new parameters.

Compliance systems should operate in conjunction with existing bodies such as OTA, TGA, and NBA to ensure that duplication of controls and overburdening of the system does not occur.

The type and level of compliance monitoring should be proportionate and clearly defined.

Implementation Timeframes

Priority should be given to reforms relating to authorised persons, designated officers and consent practices.

Consideration should also be given to whether additional reforms are urgent and require staged or accelerated implementation.