Submission to the Australian Law Reform Commission

Review of Human Tissue Laws: Issues Paper 51

From:Tereasa Trevor - Board Member, Egg Donation Australia
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Re: Response to ALRC Issues Paper Questions 1-8

Executive Summary

This submission addresses the eight questions posed in the ALRC Issues Paper from both personal experience and the perspective of Australia's largest egg donation community. My journey from being told egg donation was "nearly impossible" in Australia to finding three donors within two weeks of joining Egg Donation Australia (EDA) perfectly illustrates the systemic problems created by our fragmented regulatory framework.

As a board member of EDA, I represent over 16,000 Australians navigating donor conception, including egg donors, recipients, donor-conceived individuals, and supportive professionals. Over 100 Australians successfully find egg donors through our platform annually, yet they face substantial legal barriers due to state-by-state variations that force interstate travel, create geographic inequities, and generate unnecessary costs and complexity.

The current fragmented system fails everyone it touches. Urgent reform is needed to create a consistent, equitable, and effective national framework that reflects contemporary Australian values while protecting the rights and interests of all involved, particularly donor-conceived individuals who deserve access to their genetic identity regardless of which state they were born in.

Question 1: Personal Experience of Human Tissue Use in Australia

From "Nearly Impossible" to Finding Community

In 2012, at age 37, I discovered through IVF that I had only one egg remaining. This devastating news led me into the world of egg donation, where I immediately encountered the first major failure of our current system. My fertility specialist told me that egg donation was "nearly impossible" in Australia and directed me to commercial resources in California as my primary option.

The California materials felt deeply troubling to me because they essentially involved buying human tissue from women who were often financially vulnerable. This commercial approach felt fundamentally wrong - it reduced one of the most generous acts a woman can perform to a financial transaction, stripping away the relational and emotional aspects that make donation meaningful.

Fortunately, I found EDA through my own online research. Within just two weeks of joining, I was offered eggs by three different donors. This stark contrast between being told donation was "nearly impossible" and actually finding multiple willing donors immediately exposed the first major problem with our current system: professional misinformation that serves commercial interests rather than patient wellbeing.

The Reality of Interstate Donation Complexity

My donor lived in Western Australia while I was in Queensland, which meant navigating the complex interstate legal framework that creates unnecessary barriers for families. The geographic separation added significant financial burden through flights and accommodation costs, but more importantly, it created communication difficulties between my donor and the clinic that could have been avoided with better regulatory coordination.

This experience taught me that while our altruistic, relationship-based model works exceptionally well when properly supported, the legal inconsistencies across states create confusion and additional costs that many families cannot afford. The interstate journey also highlighted how the current system forces people to become experts in multiple jurisdictions' laws simply to access basic reproductive care.

The Success of Community-Based Support

After multiple miscarriages due to overstimulation issues, I eventually achieved pregnancy through surrogacy using my surrogate's eggs and my husband's sperm. My daughter was born in 2015, three years after I first started trying, and throughout this journey, EDA provided the community support that the formal system failed to offer.

The contrast between the struggling formal system and the thriving informal support network was stark. While fertility specialists promoted expensive overseas options and state governments created bureaucratic barriers, EDA members were connecting, sharing resources, and successfully creating families through genuine relationships built on mutual support and understanding.

This experience motivated me to become more involved with EDA, eventually joining the board, because I recognized that we had developed something precious - a model that actually worked, based on care ethics and community support rather than commercial transaction or bureaucratic control. Over the past decade, this model has proven its effectiveness by facilitating over 100 successful matches annually while maintaining the integrity of altruistic donation.

The Broader Community Experience

Through EDA's 16,000+ members, I witness daily how the fragmented regulatory framework creates barriers and inequities that harm all participants. Recipients often receive contradictory advice depending on which state they consult professionals in, while donors face uncertainty about which laws apply to them when they want to help families in other states.

The most heartbreaking aspect is that these barriers are entirely artificial. The desire to help exists, the medical expertise exists, and the community support exists. What doesn't exist is a coherent legal framework that supports rather than hinders these generous relationships.

Question 2: Personal Experience of Human Tissue Laws

The Patchwork Problem: State-by-State Complexity

My experience navigating WA and Queensland laws simultaneously revealed how poorly the current state-by-state system serves families. Victoria operates under the most progressive framework with mandatory known donation since 1998 and retrospective access rights implemented in 2016, yet it requires Minister approval for recipient advertisements, creating bureaucratic delays that make people feel like they're doing something ethically wrong when they're simply trying to build their family.

Meanwhile, NSW and WA impose artificial 5-family limits that force donors to cycle interstate if they want to help additional families, creating what I call "donation tourism" within our own country. This makes no medical or ethical sense when other states allow 10 families nationally, but it demonstrates how arbitrary differences in state laws create unnecessary complexity and inequity.

Queensland and Tasmania have historically relied on unenforceable NHMRC guidelines where specific legislation is absent, creating uncertainty about legal protections for everyone involved. While Queensland has been implementing recent reforms, the practical implementation remains unclear, leaving families unsure about their rights and obligations.

South Australia provides only non-identifying information at 16, with identifying information possible only with consent through unclear processes. This creates second-class access rights for donor-conceived individuals whose only "crime" was being born in the wrong state.

The Practical Problems I See Daily

Through my work with EDA, I regularly encounter families forced to move between states to access different legal frameworks, creating inequality based on geographic location and financial resources. We have members who spend thousands of dollars on interstate travel not because of medical necessity, but because of legal inconsistency.

The consent requirements differ dramatically between states, creating situations where consent valid in one state may not be recognized in another. This creates liability concerns for fertility clinics operating across borders and confusion for donors and recipients who don't understand why the same act requires different legal processes depending on location.

Most concerning is the enforcement gap where NHMRC guidelines lack legal force in states without specific legislation. Professional bodies have varying standards and enforcement mechanisms, leaving unclear recourse when problems arise. This creates a system where some participants have strong legal protections while others rely on voluntary compliance.

The information access inequity is perhaps the most troubling aspect I witness.
Donor-conceived individuals have dramatically different rights depending on their state of birth, with no mechanism for accessing information across state boundaries. This creates genuine risk of inadvertent consanguineous relationships due to poor information sharing between jurisdictions.

Question 3: Good Aims and Objectives for Human Tissue Laws

Learning from EDA's Success: A Care Ethics Framework

EDA's 14-year track record demonstrates that altruistic donation thrives when supported by consistent, transparent frameworks that prioritize relationships and community support. Our success in facilitating over 100 matches annually while maintaining ethical integrity shows that Australia already has a proven model - it simply needs legal recognition and support rather than the current barriers.

National consistency must be the primary objective. We need uniform consent and authorization processes across all jurisdictions, consistent donor limits and family definitions, standardized information sharing requirements, and harmonized rights for donor-conceived individuals regardless of their state of birth. The current system where a donor's obligations change based on geography makes no ethical or practical sense.

Transparency and rights of donor-conceived individuals must be central to any reform. Every donor-conceived person deserves a universal right to access genetic information at 18, supported by a national donor registry that prevents inadvertent consanguineous relationships. We also need retroactive access rights for historical donations where possible, because genetic identity is a fundamental right that shouldn't be limited by when someone was born.

Supporting Rather Than Hindering Altruistic Donation

Our experience shows that altruistic donation works when people feel supported rather than criminalized or bureaucratized. We need clear boundaries around reasonable expense reimbursement that prevent commercialization while ensuring donors aren't financially penalized for their generosity. This means protection against coercion while safeguarding donor autonomy and informed consent.

The current system often feels punitive toward generous people rather than supportive. EDA members frequently ask questions like "Can we give a gift card for their favourite shop? Can we pay for a massage? How much is too much?" These questions arise because the current frameworks provide no clear guidance, leaving everyone uncertain about how to express appreciation appropriately. One way we see that this could happen is a compensated model. Not a commercial model, but a fair and reasonable, not overly onerous compensation for time and other associated costs that occur in egg donation.

Equity and Access for All Australians

Geography should not determine reproductive choices. We need to remove barriers that force interstate travel, ensure equal access regardless of location, and support diverse family forms and relationship structures. This includes addressing socioeconomic barriers that prevent some families from accessing donation while others can afford interstate travel.

The current system creates a two-tier structure where wealthy families can navigate interstate complexity while others cannot. This contradicts Australia's values of equality and fairness, particularly when the barriers are artificial rather than necessary.

Question 4: Principles to Guide Human Tissue Law Reform

Respect for Persons and Genuine Autonomy

EDA's community-based model demonstrates that respect for persons flourishes when people have genuine autonomy rather than paternalistic protection. Donor autonomy requires genuine informed consent without coercion, but it also requires access to community support and honest information about all options, including successful local models.

Bodily integrity must recognize that egg donation involves significant physical and emotional investment that deserves respect and support, not bureaucratic barriers. The dignity principle requires treating all parties - donors, recipients, and donor-conceived individuals - as ends in themselves, not merely means to policy objectives or commercial profit.

Non-commodification doesn't mean ignoring the real costs that generous people incur. Our altruistic model succeeds because it maintains the relational aspects while ensuring fair expense reimbursement that doesn't penalize donors for their generosity.

Equity and Justice in Practice

Geographic equity means equal access regardless of state residence, which requires federal coordination or harmonization rather than the current patchwork. Socioeconomic equity means removing financial barriers to both donation and access, which the current interstate travel requirements violate.

Information equity requires consistent rights to genetic information for all donor-conceived individuals, because genetic identity is a fundamental right that shouldn't depend on birth location. This principle alone justifies comprehensive reform of the current fragmented system.

Effective Laws Based on Evidence

EDA's success provides evidence that community-based, relationship-focused models work better than bureaucratic or commercial alternatives. Future-proofing requires building on what works rather than creating new barriers, with adaptability to technological and social change while maintaining core ethical principles.

The laws must work in practice, not just in theory. This means minimal barriers that reduce unnecessary administrative burden while maintaining genuine safeguards, informed by the experience of people who actually navigate these systems rather than theoretical policy preferences. We also want to question the motivations that drive a purely commercial model that commodifies human tissue to make it an ‘easier’ solution to the need for egg donation. We prefer the more complex but deeply rewarding relational model where families are built through relationships and care. We have successfully built this model with very few arenas for concern and believe that we could apply our care ethics approach for a larger audience if we were better supported and recognised for the outstanding achievements we already perform for the industry and the community.

Question 5: Priority Reform Areas Focus

Strong Support for Priority Areas with Critical Additions

The definition of tissue issue is absolutely critical for egg donation because current uncertainty about whether gametes fall under Human Tissue Acts creates serious regulatory confusion. Different states interpret the scope differently, creating regulatory gaps and overlaps that force fertility clinics to operate under inconsistent frameworks. We need clear delineation between reproductive tissue laws and general tissue laws, with explicit coverage of gametes to end the current confusion.

Living donation issues represent our highest priority because egg donation uniquely involves living donors with no medical benefit to themselves. Current regenerative and non-regenerative distinctions don't fit egg donation well, creating inadequate protections against coercion and inconsistent cooling-off periods. We need enhanced consent processes designed specifically for reproductive tissue donation, with clear standards for expense reimbursement that support rather than criminalize generosity.

Information disclosure provisions are fundamental to donor conception, where current inconsistencies cause serious problems for families and donor-conceived individuals. We need national standards for information sharing, integrated donor registries across states, consistent access rights regardless of birth location, and clear protocols for ongoing information updates as medical knowledge evolves.

Critical Gap: Interstate Coordination

The priority areas don't sufficiently address the practical problems of interstate donation cycles and jurisdictional shopping that define current practice. My experience traveling from Queensland to access a Western Australian donor illustrates how interstate coordination failures create unnecessary barriers, costs, and complexity for families.

This gap is critical because donation doesn't respect state boundaries. Generous donors and families in need exist across Australia, but artificial state-based barriers prevent optimal matching and create inequities based on geography and financial resources rather than medical need or donor choice.

Question 6: Other Issues for Inquiry Focus

Urgent Need for National Donor Registry

Australia desperately needs a single national donor conception register that records all births from gamete donation, provides both non-identifying and identifying donor information from birth, tracks sibling connections and family limits across states, offers medical updates as needed, and supports ongoing contact with appropriate safeguards.

The current fragmentation creates serious social and medical risks. Donor-conceived individuals cannot access their genetic information when donors or records are in different states, creating potential for inadvertent consanguineous relationships and medical emergencies without genetic history.

Interstate Legal Coordination

We need streamlined processes for interstate donation cycles, mutual recognition of consent and authorization between states, coordinated approaches to donor limits and family counting, and unified professional standards for fertility clinics. The current system forces families to become experts in multiple jurisdictions' laws simply to access reproductive care.

Recognizing Successful Community Models

The inquiry should examine how online platforms like EDA have succeeded where formal systems have failed. We need regulation that supports rather than undermines successful community matching platforms, with standards for digital consent and record-keeping that enhance rather than replace community-based support.

Our 16,000+ member community demonstrates that relationship-based models work when properly supported. Rather than creating new infrastructure, Australia should recognize, support, and scale what already succeeds.

Professional Accountability and Education

The inquiry must address how some professionals mislead patients about local options while promoting overseas alternatives that may serve commercial rather than patient interests. We need regulation of financial incentives that bias professional advice, standardized counseling requirements that include information about successful local options, and accountability measures that ensure informed consent includes all viable alternatives.

Question 7: Additional HTA Inconsistencies

Consent Validity and Cross-Border Recognition

Different states have varying requirements for consent validity periods, forcing donors to re-consent when cycling interstate and creating unnecessary barriers and confusion. We need mutual recognition of consent between jurisdictions with standardized validity periods that respect the reality of interstate donation.

Expense Reimbursement Inequities

The absence of consistent definitions for "reasonable expenses" across states creates different reimbursement levels depending on jurisdiction, generating inequity for donors and confusion for recipients. EDA members regularly ask whether they can provide gift cards, pay for massages, or cover specific costs, but receive different answers depending on location rather than ethical principles.

Information Sharing Failures

Donor registries don't communicate across state boundaries, creating incomplete genetic information for donor-conceived individuals and potential for inadvertent consanguineous relationships. We need integrated national registry systems with mandatory cross-referencing to protect both donor-conceived individuals and their families.

Professional Standards Variations

Fertility specialists have different legal obligations in different states, creating inconsistent advice to patients and potential liability issues for practitioners. This contributes to the misinformation problem I experienced when told egg donation was "nearly impossible" despite EDA's obvious success.

Question 8: Issues "Unlikely to Focus On

Why "Excluded" Issues Are Critical for Egg Donation

The ALRC indicates it's unlikely to focus on regulation of human gametes, yet egg donation fundamentally is the regulation of human gametes. Excluding this creates a major regulatory gap that perpetuates the current confusion about whether egg donation falls under HTA regulation or ART regulation.

The separation between HTA regulation and ART regulation creates the very confusion that forces families like mine to navigate multiple legal frameworks simultaneously. We need explicit coordination mechanisms or integration to prevent the regulatory gaps that currently harm families.

Safety considerations should include donor safety protocols and welfare provisions within HTAs while maintaining TGA technical oversight. The current framework provides no clear approach to protecting egg donors from medical risks or ensuring appropriate medical oversight beyond technical standards.

Cultural and Community Considerations

Current frameworks don't adequately address cultural protocols for First Nations communities and other cultural groups who have specific considerations around genetic material and family formation. This oversight ignores the diverse approaches to genetic material and family formation that exist within Australian communities.

The community-based success of EDA demonstrates that cultural competence requires recognizing and supporting diverse approaches rather than imposing one-size-fits-all solutions. Reform should include cultural consultation requirements and acknowledge these diverse approaches.

Recommendations for Reform Implementation

Immediate Priorities That Can Start Today

Australia should immediately establish interim mutual recognition agreements between states for consent validity and donor limits, create national guidelines for expense reimbursement that provide clarity for families and donors, implement emergency protocols for information sharing across borders when medical needs arise, and begin formal consultation on national donor registry frameworks.

These changes require policy coordination rather than legislative reform and could begin addressing the most urgent problems while longer-term solutions are developed.

Medium-Term Reforms for Systemic Change

Within one to three years, Australia should develop a comprehensive national donor registry that integrates existing state systems, harmonize consent processes and validity periods to eliminate interstate barriers, establish consistent professional standards that address the misinformation problem, and create integrated regulatory frameworks that address HTA and ART overlaps.

These reforms require legislative coordination but build on existing successful models rather than creating entirely new systems.

Long-Term Vision for National Excellence

Australia should consider constitutional referral for national regulation if state coordination proves insufficient, implement a comprehensive national framework that becomes a global model for ethical reproductive medicine, establish ongoing review and adaptation mechanisms that incorporate community expertise, and develop international cooperation agreements that protect Australian families while maintaining ethical standards.

Conclusion

The fragmented nature of egg donation laws in Australia creates unnecessary barriers, risks, and inequities that harm all participants while serving no legitimate purpose. My personal journey from being told egg donation was "nearly impossible" to finding multiple donors within weeks, combined with EDA's success in facilitating over 100 matches annually, demonstrates that the problems are systemic rather than inherent.

The ALRC has an unprecedented opportunity to create a coherent, equitable, and effective national framework that reflects contemporary Australian values while protecting the rights and interests of all involved. This reform should prioritize national consistency, protect donor-conceived individuals' rights to genetic information, maintain the integrity of altruistic donation, and ensure that geographic location does not determine access to reproductive choices.

EDA's 14-year track record proves that Australia already has a world-leading model for ethical, community-based donor conception. Rather than creating new barriers or bureaucracies, reform should recognize, support, and scale what already works while addressing the artificial legal barriers that currently prevent optimal outcomes.

The egg donation community stands ready to support this vital reform process and contribute to the development of laws that truly serve the Australian community. We urge the ALRC to prioritize the lived experiences of families who navigate these systems daily over theoretical policy preferences, and to build on Australia's existing success rather than undermining it through continued fragmentation.

Priority should be given to establishing national consistency, protecting the rights of donor-conceived individuals to genetic information, maintaining the integrity of the altruistic donation system, and ensuring that geographic location does not determine access to reproductive choices. These principles, grounded in the successful experience of thousands of Australian families, should guide comprehensive reform that positions Australia as a global leader in ethical reproductive medicine.

Please feel free to contact me for further clarification, or comments.

Tereasa Trevor
Board Member, Egg Donation Australia
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