This submission contains information that may be upsetting for some people.

The Australian Law Reform Commission: Review of Human Tissue Laws

Personal submission: Holly Northam OAM, 7th July, 2025

1. **What is your personal experience of how human tissue is obtained or used in Australia?**

I have had an extensive clinical career as a registered nurse and midwife, with extensive experience in neonatal, paediatric and adult critical care environments. My experience of caring for children and young people dying from organ failure in the early 80's and subsequently caring for organ donors who saved the lives of others- and whose families were amazing in their compassion for others enhanced my understanding of the lifesaving humanity and power of the donation- transplantation equation.

I was invited to set up the ACT Organ and tissue Donation Service in 2002 where for the next 8 years I was manager and full-time donor coordinator; the agency transitioned to DonateLife ACT in 2009. I was on the Board of Sharelife commencing 2006, mentored by the then Governor General, Michael Jefferies regarding the importance for community that the process of donation was clear and supportive for donation to enable transplantation. I worked at a national level on the Advisory Group to the National Organ Donation Collaborative as well as on the National Clinical Task force into Organ donation and many other groups. A 2006 Churchill Fellowship (Donation after Cardiac Death- UK, Spain, USA, 2006) enabled me to implement DCD in the ACT including advocating and working with the coroners and others regarding legislation, consent processes and forms etc against significant barriers expressed by clinicians and forensic pathologists. The report and recommendations are attached. I transitioned to academia in 2010 following 33 years' clinical experience, postgraduate study. I completed my PhD in 2016, 'Hope for a peaceful death and organ donation' which provided evidence to understand why families agree and decline deceased organ donation on behalf of their relatives (attached). In more recent years I have worked as a consultant ethicist to support the assessment of live donors involved in Altruistic Organ Donation at Cedars Sinai Hospital. I have remained working to advocate for Donation over many years and remain on the Board of Donor families Australia, and in contact with many Donor families and recipients. I co-authored the Australian Critical Care text chapter on organ donation and transplantation (2024) and I am invited on a national transplant conference panel in Philadelphia US to speak of organ donation and transplantation in Australia later this year. In 2019 I received an OAM for my work in this space.

I have been present, sometimes 'fighting' to ensure legal requirements are maintained in all the clinical aspects on caring for the deceased including teaching about the declaration of death, providing oversight of this process in emergency departments,

ICU's, operating theatres and mortuaries including forensic. I have the experience of halting a case where the medical officer had not followed the protocol properly and had declared a patient deceased when they were not; supporting the team to ensure that eventually that situation was appropriately managed and the patient who went on to become brain dead subsequently became a donor- and saved lives- their family having trust in the process despite our efforts to undermine that trust. I have extensive experience engaging in the conversations about donation, and the legalities, seeking and gaining consent when doctors were too busy, completing the consent forms and process- a deeply harrowing experience for the family when done poorly and caring for donors including tissue recovery and advocating for the deceased through that process. Battling to engage and then gaining the support of cardio thoracic specialists to undertake tissue donation and meet legislative requirements… and more. I feel I really need to write a book on this, but I have very limited time available to complete my submission despite the generous extension. I know in Australia we are very good in some respects, and exceedingly poor in others regarding the legislative requirements and practices of organ and tissue donation.

2. **What is your personal experience of how human tissue laws work in Australia?**

I have learnt through experience and many grey hairs that our clinicians and policy makers have a very poor understanding of the topic of organ and tissue donation, the laws around it and end of life care and the legislation that is a support or barrier to its therapeutic benefits. My first role in 2002/2003 when I started in the role as coordinator was to bring to the attention of my colleagues in NSW that the ACT legislation was different to theirs and that when working in the ACT, they needed to follow our legislation. Our coronial system was complex and seeking coronial approval for donation in the ACT was often difficult. In recent years I have worked with ACT Attorney General Tara Cheyne to ensure families can have the fact their loved one was a Donor recorded on their death certificate and the opportunity to receive a letter of thanks from the Chief Minister included in the ACT Legislation.

My experience doing the Churchill Fellowship guided in Spain by Dr David Paradies, a leader in organ donation in Spain at the Barcelona Clinics Hospital. I was with the team along with medical staff as they were facilitating an organ donation that required judicial approval. The experience remarkable in its support for donation – effectively, 'mind blowing' for me.

Their process to request judicial approval to proceed with donation was to send a fax (2006 technology), if they received no response within 30 minutes the donation could proceed. Lifesaving!!!!! It is truly upsetting to the family of potential donors who will sometimes withdraw their consent because the suffering they perceive in the extended delay to donation is too difficult to manage anymore; and the staff involved in the care

of the deceased are also distressed in these cases, and the flow on impact includes critical care bed availability when our process in regulation cause delays that cause suffering and hurt that is avoidable.

I had many difficulties with our coronial processes with one of our forensic pathologists always saying ‘no’ as she was personally averse to the idea.

A scenario I was part of that was devastating- but instructive ..

Event around 2 am, weekend. A young man in single motorcycle accident came off his bike with his head impacting concrete gutter- witnessed by friend who called for help. He had CPR at the scene, transfer to hospital. Assessed and in ICU, clearly showing imaging signs and clinical signs of brain death. Early notification to forensic on-call officer that we would be asking the family to donate - this was an established relationship to help ensure no barriers to donation; He indicated that it depended on which of the forensic pathologists was on…as (sadly) I already knew. It turned out the one who was averse was one.

There had been senior pressure for her not to immediately say no, so instead, the process unfolded. She needed to 'think' about it. In the next few hours- her family asked to donate without being asked- they believed it was what he would want to do, and they thought it the best thing to do- not on register.

Over the next few hours brain death was confirmed, and we got permission to share information with the transplant teams, meanwhile awaiting final permission. Time ticked on… early hours next morning we were advised the forensic pathologist would decide over breakfast. Meantime the police had completed all the inquiries they thought were needed to clarify it was an accidental death.

We had transplant teams ready, sitting on the ground in aircraft to coincide with 'breakfast' and what we hoped would be an approval. The pathologist finally agreed, close to 9 in the morning- meantime the family had to endure this process- I constantly checked in to check if they wanted to stop- they hung in there. Approval was given for abdominal organs only- (not heart or lungs) a very sad loss.

Our constant care and advocacy, including the support from the police officer helping us created a better outcome than expected. The family were amazing, but they and everyone supporting them suffered undue harm, including the risk that we couldn't continue to support the organ function, and most importantly, it wasn't respectful for the deceased young man. The decision could have been made at the time when death was determined.

This is why I am also passionate about ensuring regulatory accountability of the coronial process.

I have attached an article that is 2020 and highlights the issues that I recommend you draw from.

I argue strongly that the revised legislation must address coronial barriers and place the onus of responsibility on the coroner to account for a timely response (30 minutes is a great model) and justify clearly- and transparently for the family, any refusals.

One of the US states brought in similar legislation following the death of a person who wanted to donate- but couldn't.

We also need the DO to protect from conflict of interest- situations that happen in the US as recently reported in the US were the OPO was over-riding the concerns of the clinical staff caring for the patient, regarding the failure to properly determine the death of the donor.

3. **When we think about the laws governing how human tissue is obtained and used, what are good aims or objectives for these laws?**

- To hold authorities to account for donor and recipient experiences.
- To ensure families aren't blamed for saying no.
- To hold authorities to account for community trust building and education
- For the principles of compassion, equity, justice and transparency to be paramount.
- To recognise the vulnerability and power imbalance experienced by the community who believe donation is 'the right thing to do' and patients who are desperate for life saving and improving interventions.
- To ensure accountability for humane, respectful, culturally safe therapeutic healthcare relationships for consumers at both ends of the organ donation and transplantation 'equation'.
- To recognise in law that the people who donate and their families, and those who are waiting, receive transplants and their families should be recognised as healthcare consumers.

4. **Do you agree that the issues set out in the section 'Priority reform areas' should be a focus for our Inquiry? Please tell us about why you think these issues should or should not be a focus.**
   Sorry, out of time.

5. **What, if any, other issues should we be focusing on in this Inquiry?**
   Community acceptance- thinking about what is reasonable and why it is important to ensure an open and positive conversation about this topic in the public sphere. Australians want to donate, let them help with this. Focussing on

honouring donation decisions and accountability for ongoing support for donor families and recipients who are consenting to meet in a supported way. Families must be able to share the first name of their loved one in correspondence to recipients. The Australian public would be distressed to know that they cannot.

The AODR should not be the centre of organ donation activity, it is a tool that is poorly used and misunderstood, regulation needs to make it clear.

6. **Are there inconsistencies between the HTAs that we have not identified in this Issues Paper that are causing problems and should be a reform focus for us?**

There are many challenges regarding the use of the names of the individual; please see the DFA 2023 Senate submission. Terminology and definitions need to be consistent and harmonised across Australia. The current arrangements are harmful to donation and humanity.

7. **Do you think it is important that we consider any of the issues in the section 'Issues we are unlikely to focus on in this Inquiry'? If so, why?**

Sorry, out of time.

Thank you for this opportunity.

Please don't hesitate to contact me with any questions of regarding further information,

Sincerely,

Holly

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Conjoint appointment: Director: Leaders of Indigenous Nursing & Midwifery Education Network (LINMEN), Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM) https://catsinam.org.au/
Adjunct Professor: University of Canberra, Faculty of Health.
Board member: Donor Families Australia https://www.donorfamiliesaustralia.org/
Australian Committee member: International Coalition to End Transplant Abuse in China https://endtransplantabuse.org/
Convenor: Canberra Restorative Community