1. What is your personal experience of how human tissue is obtained or used in Australia? AND
2. What is your personal experience of how human tissue laws work in Australia?

Our son's accident occurred in the very early morning in regional Victoria, and he was taken to a small local hospital with limited resources. He had been struck by a friend riding a pushbike down a boat ramp and had fallen back and hit his head on the concrete ramp. His friends called to tell us of the accident and that he was on his way to the hospital. We were advised by the hospital that they were doing more tests. At 3.30am we received a call and at that point the Doctor responded with "er, ah, um" to which I replied you are going to ask about organ donation. This should not have been raised without us having seen our son and discussed his medical status in person. From this point on we felt it became about the donation and not about whether there was anything that could be done for our son. This country hospital did not have, or access to a trained nurse donation specialist to guide us on our journey; but the staff here were exemplary in their care for us. We had not been to bed since the previous night. We drove 2 1/2 hours so we could see our son as they were unsure whether he would survive the flight to Melbourne. He was flown to Melbourne whilst we made the 2 ½ hour journey back. This did not put us in a good head space to begin the process with.

By the time we reached this point we were already exhausted and mentally fatigued. No parent expects to lose a child and dealing with their imminent death is extremely traumatic. Having to wake his siblings to advise them of the accident and the likely outcome was very hard. The body produces the stress hormone cortisol, which raises your heart rate and blood pressure; it is your natural "flight or fight" response. It is very hard to take in, process and retain information at this time.

We were phoned when he arrived safely at the Melbourne hospital.
Upon our arrival we were taken to the ICU area and met by the DonateLife Nurse. We had not seen our son nor the attending doctor. She then proceeded to go through the paperwork. Brett was not a registered organ donor but only 2 weeks prior we had had this discussion. We were unaware that legal consent must be gained for each organ to be donated. Whilst this "shopping list" approach was very confronting we would not have been prepared to say yes to everything. Unfortunately for us this discussion took place in front of our other children (16 and 22 at the time). Their brother was so much more than the sum of his organ's and this greatly distressed them. They organised for a friend to collect them from the hospital and never returned to say a final goodbye to their brother. As parents this left us in an untenable situation; do we stay with our dying son or leave to support our other children. We chose to take time out to see our children, but I am left with a terrible guilt about this decision that I still carry to this day. She also assisted us with a letter to the coroner requesting that a full autopsy not be completed as the police were satisfied that it had been an accident.

Finally we were able to see our son but were advised he was going off for tests in regard to his brain function. We were placed in a room to wait and were left there by ourselves for 2 hours. My husband decided to investigate what was happening; being mindful you are in an ICU with other critical patients. Brett had returned from his tests but we had been forgotten!! It was then that we finally spoke to the doctor and were shown his brain scans; it was believed his life would not be sustainable. We do not recall meeting with an independent doctor but they may have been present at this time.

Having to learn about organ retrieval and how the body will look after surgery at the time of imminent death is not ideal. We did not donate his eyes (at the request of his sister) nor his bone or tissue. It is very confronting, and I believe may attribute to families declining donation.

We were unaware of the two pathways to deceased donation. Our son did not meet the criteria for brain death (now referred to as donation after neurological determination of death - DNDD) but rather it would be a donation after cardiac death (now referred to as donation after circulatory determination of death-DCDD). These two pathways lead to very different experiences for donor families. For us, not knowing how long death may occur after removal of life support (and whether donation would still be possible) and then upon death having him taken to surgery straight away added to our trauma. He died 50 mins after the removal of life support. It may sound strange, but you are not dead until your dead (accepting death) and then to have your loved one taken from you so quickly is traumatic and affects the natural grieving process. Brett was taken off to surgery and we were left standing in the empty space his bed had been in. No one came to support us. We looked at each other and said I guess we go home. As we were leaving the hospital my husband (who says very little normally) said “they got what they wanted and we didn’t matter.”.

We were given the opportunity to return to the hospital after the retrieval surgery. This was very important to us as we had not been able to spend time with him immediately after his death. I made the decision not to view any of the surgical sites as that was not a snapshot I wanted. I believe the perception is that families have an infinite amount of time to spend and prepare for the death of their loved one, but this may not be the case with the hospital’s donation timeframes.

On reflection and in considering this review, I feel totally let down by the law and the subsequent processes. After consenting to donation we felt like a rat on a wheel, unsupported and uncared for. Where was the accountability and protection for our son and us at a time when we were the most vulnerable and needed it? We would NEVER have agreed to donation if we were told we would lose the ability to own Brett’s information.

NO donor family should bear any additional grief for having consented to organ donation.

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

    - The priority should be to protect the rights and dignity of the donor and donor family and the right to a peaceful death.

    - If we are to increase donation we have to better educate the community about the process (prior to being in this decision) and how this will impact their loved ones end of life and their grieving process. As a society we do not readily discuss death and dying. The OTA/DonateLife need to be open, transparent and honest and provide all the information. People really have no idea what they are actually signing up for. Ambushing families at a time of great stress and grief is not acceptable. The Register is not the panacea for increasing donation that people think. You do not have to be on the Register to donate.
    - Does the qualification of criteria for the Transplant List meet all potential recipients or could it be done differently? My son's liver and pancreas were wasted because there was not a match on the list. What if the match was not yet on the list but someone very close? This could have been their chance and they deserved the right to be availed of this opportunity and make a decision accordingly.

4. When we think about reforming human tissue laws, what principles should guide reform?
    - Transparency and honesty in all areas. People should be given all the facts not just what they feel we are capable of handling. (NHMRC Guidelines 2025 "So where staff are worried that the family member is too emotional to understand the consent process they must stop not change the information they are going to give)". If we are to truly make an informed decision and one we can comfortably live with this must be adhered too.
    - Laws should be harmonious across Australia. Which State or Territory we reside in should not dictate our rights and how we are treated or discriminated against.
    - Accountability must be a very strong aspect of these laws. If the relevant government departments, institutions and hospitals are not held to account for following the laws correctly (rather than interpreting them to meet their own needs) then the community will not have their rights protected.

The Importance of Public Trust in the framework

I would never sign onto the OTD Register as I do not trust the government to change the law and bypass families in regard to consent. You do not need to be on the Register to donate.

How do you have trust in an organisation (OTA/DonateLife) that should have been there to protect my family? I would NEVER have agreed to donation if I knew I was giving up the basic human right to own my son's information and speak freely. This deception has had long lasting implications. The recent amendment to Federal Legislation sort only to protect themselves and so easily should have included the rights of the Next of Kin.

Why is there no mechanism of accountability? Eg:The DF/Rec letter writing procedure policy that was jointly worked on with Donor Families Australia and agreed to by OTA/DonateLife and published on their website is not being adhered too. This failure comes at great cost to both DF and Rec who put so much time and emotion into their letters but never know whether they have been received.

At the recent DonateLife Community Forum held in Melbourne the ALRC Review was not even mentioned? WHY !!! With over 200 people present this was the perfect opportunity for those with the lived experience to contribute. We often learn more from our mistakes than our successes.

5. 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.

Who should be able to authorise tissue donation when a person dies?

The family SHOULD NEVER BE BYPASSED. Whilst the Register is a great tool it does not meet the criteria for informed consent as per the NHMRC 2025 Guidelines. It may not be current; it's unlikely a medical professional was present to guide them through the process. The self - guided nature does not confirm that proper and adequate information has been reviewed. The campaigns of DonateLife where they state it only "Takes a Minute" reinforce this. It must be mandatory that people are fully informed, make the decision voluntarily and are competent to make the decision and in no way coerced.

No family or medical professional should be placed in a situation where they are arguing over donation/consent at the time of a loved ones' imminent death. Moral distress as it appears in the NHMRC 2025 Guidelines must be a consideration. "Moral distress may be linked to burnout and staff turnover, and to moral injury. Prevention of moral distress is a key component of care for patients, their families and health professionals". This area of medicine can be challenging to work in and requires a special set of skills learnt over time. If families are to be cared for properly it is imperative we maintain these very valuable members of staff and care for their mental health.

Who should be authorised to remove tissue?

Solid organs should only be removed by a medical practitioner; tissue donation by appropriately qualified medical professionals. The definition of which must be very clearly defined. These qualifications must be provided to donor families at the time of making their decision. Should a family wish to view their loved ones' body after donation, it's imperative that the removal of tissue be done professionally so as not to negatively impact the family. This must be consistent across all States and Territories.

How should we ensure potential donors are identified in hospital?

This must begin with comprehensive education of donation/transplantation to our potential new medical professionals during their training at university. This should be continued in the hospital setting in conjunction with other skills development. We need to normalise "routine referrals" and not just in the ED or ICU to capture every potential donor across the whole hospital.

How should steps and interventions that occur before death be regulated?

Investigative steps such as reviewing medical records, possible screening tests and treatments that may be necessary to help donated organs work in the recipient, should be discussed with the next of kin as they would be with a patient in the hospital setting.

How should donor and recipient information be handled?

Donor Families must have the right to own and use their loved ones' information however they see fit. No government department or authority should disclose any information without the consent of the Next of Kin. This would allow for the acknowledgement of their donation on their Death Certificate (with relevant amendment to the Births Death and Marriage Acts across Australia).

Donor Families and Recipients should be allowed to use their first names in their correspondence with each other. A first name is not identifying and allows some humanity in the process which can be healing for both parties. My son Brett was far more than the sum of his organs and deserves to be treated with respect.

Consenting adult Donor Families and Recipients should be allowed to meet if they wish to do so. This has the potential to be a very healing experience for both parties. I find it farcical that I was asked to consent to donation at a time of extreme stress and be happy with it; but years later I am not capable of making a conscience decision for myself in very different circumstances. Possible risks could be mitigated with counselling and a controlled setting. This would be like the process of adopted people seeking contact with their biological family. With news and social media it is very important that potential matches of DF and Rec are indeed correct. Refer NHMRC Guidelines 2025 7.3.1

6. What, if any, other issues should we be focusing on in this Inquiry?

   I feel there should be safeguards put into place to protect Donor Families during the decision making process. In our experience we had been awake for well over 24hours (receiving the call very late at night and not having been to sleep from the night before) including 5 hours of travel to and from country Victoria. Were all the staff made aware of this? This lack of sleep can cause difficulty concentrating, impaired judgement and the similar effects to those of being legally intoxicated. I would be advised not to sign any contract under these circumstances; yet I was expected to absorb new information, understand it and process it at a time of great stress and in brain fog. Does the lack of capacity due to sleep deprivation open the grounds for consent to be challenged? This all occurred on the hospitals timeframe. Being advised his life support would be turned off at a set time and then 5 minutes prior advising they were putting it back 2 hours because they weren’t ready.