

ALRC SUBMISSION PAPER RESPONSE - JANUARY 2026

National Legislative Framework

The Australian Government must establish an independent National Regulator if it is to regain the trust of the community. We need nationally consistent legislation that is enforceable. The OTA were well aware they were breaking the law in regard to Donor Family privacy yet despite the law no one held them to account. They put forward the new amendments that only sought to protect themselves without any thought to one of their major stakeholders, donor families. The OTA should hold less power not more than they currently do. The OTA was started with the best of intentions but has now declined into an organisation that does not reflect community needs and expectations. If the intention is to increase organ and tissue donation we need a body that is open to its failing, thinks outside the square, implements new strategies and is transparent and accountable. If we continue in the same manner we can expect exactly the same outcomes. Relying solely on increasing the numbers on “The Register” will not cut it. Better education that is honest is required. The NHMRC must be a part of the regulator. Community representation from Donor Families and Recipients is a must so those with the lived experience are represented and not just the medical profession. Representation from our Indigenous community and differing faiths is important to ensure the wider community is represented at the table. There must be transparency in all areas. A clear link for complaints with access to the ombudsman. It is important that the community is made aware when legislation is changed that may affect them directly; eg; the WA legislation change that allows for other medical personnel other than doctors to remove tissue. Any changes at State/Territory level must go through the regulator to ensure consistency of legislation across Australia.

Consent and Authorisation for Removal of Tissue after Death

When deciding whether to give consent it is important that the decision maker take into consideration their loved ones wishes. But where is the protection for the donor’s family? Whilst we knew our sons wishes it in no way prepared us for what was ahead and nor do most donor families; especially those whose donation is subject to cardiac death. No family should bear additional grief because they consented to organ donation. If you save one person and destroy another what has the community gained?

On page 133 you state that Proposal 23 means families are “obliged” to consent if their loved one was on the Register. The Register in its current format does not meet the NHMRC guidelines for informed consent so much must change.

If valid consent is reliant on the decision makers capacity at the time who decides this and what are the protections for the family? In our experience we were sleep deprived, obviously very distressed, had travelled for 5 hours and really felt that we were not given the time to step back and give measured thought to our decision. We felt outnumbered by medical staff very keen for donation to proceed and often forgotten.

You state that the person consenting be “informed” about the “nature and effect”. Informed by who? What does nature and effect actually mean? The family of the donor must be told the intended use of the tissue and how and who will remove it and their qualifications. They must also be told if the tissue is going to a private tissue bank or a not for profit. The NHMRC ethical guidelines must be considered.

The role of the designated officer is very important for independence and cannot be involved with either patient.

Proposal 29 – This information should be provided firstly to the person signing the Register so they understand this when making their decision and discuss this with their family. This would give people the chance to seek further information or clarification. You don’t know what you don’t know. At the time of the donation the donor family must be told who and what the qualifications are of the person removing tissue. For families who may choose to few their loved one’s body after donation the skill of the personnel removing the tissue is imperative to avoid a negative experience.

Prohibiting the exchange of human tissue for reward within Australia

I was quite surprised about the amount of plasma we import. Not something the community is told and perhaps we should be. It is hypocritical that we import from the USA where their donors are paid. Would a cash incentive entice new donors or would we simply be paying the 48% who currently donate? I’m not sure the wider community would accept this as we would not like to impact negatively on our blood donation donors. Given the extra amount of time involved in plasma donation

perhaps this could be rewarded by a donation to a charity of their choosing?

There is currently no regulatory compliance and transparency within this sector.

Private tissue banks should not be able to function at the detriment of the Not for Profit ones. The whole “costs recovery” must be reviewed. The community must be told if their donation has the potential for commercialisation.

Reforms relating to the advertising the trade of human tissue

I would not like to see any advertisements where individuals are publicly seeking a donor. Perhaps those wanting to be involved in the Living Donor program (for those not donating to family or friends) could be placed on a list. Thus assisting those without a wider circle of potential donors and not undermining our current system. This way you could promote and advertise for a list of altruistic donors not individuals.

Reforms relating to tissue importation ethics and oversight

The community must know not only where the tissue is being sourced from but that it is being ethically sourced as well. We should not be exploiting people from other countries.

Within this section we need to consider the poor education currently around tissue donation (rather than solid organs) if we want to increase domestic supply. Much more education and information about how and by whom tissue will be removed, how its stored and its uses is needed. We do not tell families that this request will probably come as a “cold call”; no wonder they say no. All this information must be available prior to registering so it can be discussed and understood.

Reforms relating to data transparency

We need a reporting mechanism that provides the necessary data for planning and how the sector is operating. This must be mandatory with the power to conduct checks at any time. The NHMRC states that transplant

activities should be open to scrutiny. It is imperative that we watch over the financial operations of those in the sector.

Reforms relating to how information can be disclosed and shared

I want to be able to talk about my son Brett and his donation in any way I choose. If that means posting on a Facebook page to share his story or to post at a time when I am looking for support that must be okay.

I want to be able to use his first name in a letter to his recipients. He was so much more than the sum of his organs.

I want it to be possible to enable Births, Deaths and Marriages in Victoria (and other States/Territories) to acknowledge his donation on his Death Certificate.

I want the ability for consenting adults (donor families and recipients) to meet if they so choose through a structured process like is currently available for adoptees. This has the potential for healing for both parties.

Compliance

The new regulator must be able to ensure compliance of the new HTA's and must be independent. Self regulation has not worked.

I have concerns with Proposal 23 (following the deceased wishes) and families being "obliged" to follow the register. How this may be managed at the bedside of the dying patient could be quite confrontational. No family or medical profession should be placed in this position. We have a duty of care to those involved that no moral injury occurs.

The Register is in urgent need of a total overhaul. Several of the proposals and questions raised in this paper relate to the Register in its current form. It does not meet the guidelines as stated in the NHMRC Guidelines 2025. "Promoting impartiality in ethical decision making requires attention to how and what information is gathered, evaluated, communicated and used

in decision making”. This decision must be without undue influence, manipulation or deceit.

We must stop blaming families for not upholding their loved ones wishes to donate. Rather we should be asking what can we do better to educate people PRIOR so they feel empowered in their decision making. It’s unfair and cruel to ambush families at this very stressful time about procedures when they are least receptive to understanding. As a society our death literacy is not great. We need to be brave enough to have these very important discussions well before they may be needed. It’s not as simple as ticking a box in only a minute!!

I would like to thank the committee for the chance to have input into this discussion paper. It’s a mammoth task but one that is well overdue. I look forward to reading the final report.

Leanne Campbell
Donor Mum