Hello Emma,

Thank you for taking my call two weeks ago, where we discussed the decline in the consent rate in Australia to its current rate of 53%. DFA sees this rate decline, the lowest in its history, as indicative of the community's falling trust in the system. Many recipients are losing their fight to stay alive because of this factor.

DFA sees this review as an opportunity to help restore the community's faith in the system. The whole consent process, where families give consent on behalf of their loved one, needs improvement. The experience families go through at the hospital will stay with them for life and will be often reflected upon as they continue their grief journey. DFA come across families months or even years later when they have had a chance to reflect on what happened. What DFA can confirm is that as an organisation we have never heard of a family being critical of having received too much information when asked for consent. By contrast DFA does hear, "We were not told that...". For families to trust the system, they need to be properly informed about the process at the time of being asked for consent. They don't want to feel they have not been given all the information necessary for valid informed consent.

" Valid consent is: given after the person consenting has been informed about the nature and effect of the removal of the tissue;" Discussion Paper Page 68 Proposal 23 4 (c)

DFA feels that the above line ignores the importance of family trust. The community will not be familiar with what is meant by 'nature and effect'. Staff using this phrase to justify their interaction with the family will lack legal support because the phrase is unclear. DFA fears that if this approach was to be taken within legislation an opportunity will be lost for the community to fully trust the system by having transparent informed consent.

At 4(c), DFA recommends the following in order of preference:

Valid consent is:

A. "Given after the person consenting has been clearly informed, using simple language, and with interpreter support if required, about what the deceased donation surgical process involves including its benefits and risks to both the donor, their family and the potential recipient. This should align with the standard expected when a living person is required to provide valid consent prior to surgery. The people who are asked to give their consent to deceased donation surgery must be informed of any intended and unintended effects or risks currently and into the future, both legislatively and in practice including the right to publicly use the deceased name in the context of their organ/ tissue donation". or

B. "given after the person consenting has been provided with information and support as described in the NHMRC Ethical Guidelines for Cell, Tissue and Organ Donation and Transplantation in Australia (2025)". https://www.nhmrc.gov.au/sites/default/files/documents/attachments/Ethical%20guidelines%20for%20cell%2C%20tissue%20and%20organ%20donation%20and%20transplantation.pdf or

C. "given the deceased organ and tissue donation decision makers are afforded the same rights as described as within the Australian Charter of Healthcare rights". https://www.safetyandquality.gov.au/our-work/partnering-consumers/australian-charter-healthcare-rights

Thank you again for listening throughout this process. We really do appreciate the opportunity to express the important views of those directly involved in and affected by this life-saving, life-improving system.

Kind regards

Bruce McDowell
Chairman