Apologies, I have never responded to such a review, or written such a submission before and I hope this is an appropriate format, tone and level of detail.

Proposal 1-3
The role of a National Regulator as listed in proposal 3 demonstrates duplication with multiple existing entities including in research. From a practical and a financial point of view, the proposal for unified regulation across all of these domains is impractical, unwieldy and unnecessary.

Proposal 10
Section X definitions are suitable.
I have heard it said that it might not be suitable on a day to day basis for most doctors who declare death by assessment of circulation. I disagree with this as a doctor who declares death on a reasonably regular basis. The assessment performed currently includes assessment of critical brain functions (pupil reaction, responsiveness, apnoea) and an assessment to confirm a sufficient cause for the absence of critical brain functions (central pulse, heart sounds). There would be no need for doctors to modify the means by which they assess and declare death using the proposed definition.

Question 8: I cannot think of a circumstance where these provisions should not apply. That is to say, yes it would be appropriate for these provisions to apply for all purposes.

It is necessary for clarification (or sufficient leeway) to allow digital vs handwritten means for declarations and for consents and other documentation purposes.

Proposal 25
The list of decision makers should closely resemble State Guardianship Acts/existing health care decision making legislation. This should include the standing of wishes documented in a valid Advance Health Directive (which in Qld does include deceased organ donation for the purposes of transplantation). If there was a situation where there was no living NOK but an AHD existed, then perhaps this is the situation where there is a role for a Designated Officer to confirm the AHD wishes and authorise proceeding with donation. An AHD consent would not cover authorisation for deceased donation for educational, research or other medical purposes however.

The NT Health Care Decision Making Act 2023 is the better list of any that I have seen proposed. I applaud the inclusion of the need for a close and continuing relationship with the person within d) to i). In relation to c) on its list, I wonder if there is a need for additional information e.g., that the person without capacity self-identifies as part of that culture and custom and community and that the person deemed to be the health care decision maker is acknowledged by the community and/or family to be that appropriate person. The definition needs to apply to all cultures and customs within Australia, including all migrant populations and across religions, in addition to being fit for purpose for our First Nations population. I have cared for a number of patients who are Aboriginal and/or Torres Strait Islander and the NT hierarchy fits situations that I

have encountered (e.g., in the Torres Strait, there can be a complex adoption system where an aunty becomes the mother who raises the person and there is continuing connection with biological parents; I have cared for Aboriginal patients where the decision maker lies outside of the parents and siblings and so c) would fit these situation). I can also think of situations where a dominant and intimidating orthodox figure who does not have close ties with the person exerts their dominance over members in their community in situations where the person has separated themselves from the culture in which they grew up – and I worry that there is insufficient protection for this situation.

Question 20.
This is a challenging situation where two 'equal standing' NOK disagree. This is faced in Guardianship/Substitute Decision Maker law currently and perhaps having different approach to disagreement for one health care related decision and another approach for deceased donation is undesirable. Why should it be different?

Question 22
Limits are required. I have heard it suggested that 'routine' tests should be allowed – whilst these would represent minimal harm to the person, there is a broad variation of what clinicians may consider to be routine.
Working in intensive care, I struggle to think of a situation where it is necessary to perform additional tests (that haven't already been done as part of the patients routine initial care) that are prior to consent/a discussion with NOK about donation. The tests that are being referred to are those usually done to exclude the patient from being medically suitable to donate. The reason put forward is that it may be harmful to the family to raise the possibility of donation and then discover there is a contraindication and take that opportunity/hope of donation away from the family. I believe that if a test is required to assess for suitability for donation, then an honest and compassionate conversation with the NOK about donation can and should precede the test. The exception would be where the person has indicated their wish to donate (e.g., AHD or AODR). And obviously the person who has capacity to consent to their own tests.

If access to patient information is considered in this legislation, the transplant teams should not be able to view patient medical images prior to consent.

Proposal 29
The term authorised technicians should be sufficient. There does not need to be a national regulator. Training and experience is required, but specifying a 'qualification' is unnecessary (and may not exist if this is intended to mean a diploma/certificate/degree).