

2022

**THE LEGISLATIVE ASSEMBLY FOR THE
AUSTRALIAN CAPITAL TERRITORY**

HEALTH LEGISLATION AMENDMENT BILL 2022

GOVERNMENT AMENDMENT

SUPPLEMENTARY EXPLANATORY STATEMENT

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Minister for Health**

Health Legislation Amendment Bill 2022

SUPPLEMENTARY EXPLANATORY STATEMENT

This supplementary explanatory statement relates to a Government amendment to the Health Legislation Amendment Bill 2022 (the Bill) as presented in the ACT Legislative Assembly on 4 May 2022.

This supplementary explanatory statement has been prepared in order to assist the reader of Government amendment to the Bill and to help inform debate on it. A more detailed explanation of the purposes and intended operation of the Bill are set out in the Explanatory Statement for the Bill.

The Statement is to be read in conjunction with the Bill and Government amendment. It is not, and is not meant to be, a comprehensive description of a proposed law. What is said about a provision is not to be taken as an authoritative guide to the meaning of a provision, this being a task for the courts.

OVERVIEW OF THE GOVERNMENT AMENDMENT

Currently, the *Transplantation and Anatomy Act 1978* (TA Act) does not clearly permit the release of information about organ or tissue donors with consent. Clause 10 of the Bill seeks to resolve technical legal compatibility issues between the TA Act and the *Births, Deaths and Marriages Registration Act 1997* (BDMR Act). This TA Act amendment would enable the lawful release of this information when a request is received from a bereaved family for acknowledgement of a person's donation for the purposes of the BDMR Act.

The Government amendment to the Bill seeks to ensure that, with appropriate consent, the stories of donors and donor families' can also be shared by the clinical organ and tissue donation service (DonateLife ACT) to raise awareness of organ donation and commemorate donors' gifts without committing an offence under the TA Act.

To achieve this, the Government amendment seeks to substitute section 49 (4) (c) of the TA Act to expand the list of people who would be able to provide consent for a person's information to be published regarding the donation of body tissue or organs by the donor. Currently, section 49 (4) (c) allows the person to whom the information relates to consent to the disclosure of information.

The Government amendment seeks to include the following people under section 49 (4) (c) of the TA Act:

- the person to whom the information relates (the relevant person); or

- if the relevant person is a child or young person—a person with parental responsibility for the relevant person; or
- if the relevant person is a legally incompetent person—a guardian of, or power of attorney for, the relevant person; or
- if the relevant person is a deceased person to whom subsection (1) (a) applies—the relevant person’s next of kin or legal personal representative.

The changes will allow for DonateLife ACT, with consent, to share stories of individuals and their loved ones at its organ donor remembrance ceremonies such as the annual DonateLife ACT Service of Remembrance and Thanksgiving. The changes will also allow for DonateLife ACT, with consent, to help raise awareness of organ donation through other activities where stories of individuals and their loved ones are shared.

Reasonable precautions will be required when sharing stories to manage the risk of inadvertent identification of recipients.

COSTS AND BENEFITS STATEMENT

The Government amendment makes technical changes to the TA Act, section 49 (Disclosure of information) to address an identified deficiency in how the TA Act support donor stories to be shared.

The Government amendment has no financial implications.

CONSISTENCY WITH HUMAN RIGHTS

This section provides an overview of the human rights which may be engaged by the Government amendment. The proposed amendment has been considered in the context of the objects of the *Human Rights Act 2004* (HRA).

Rights Promoted

Recognition and equality before the law

The Government amendment promotes recognition and equality before the law by enabling open communications regarding organ and tissue donation.

The amendment acknowledges that everyone has the right to recognition as a person before the law, is equal before the law and is entitled to the equal protection of the law without discrimination. By increasing the exemptions to the restrictions on the disclosure of information in section 49 (4) (c) of the TA Act, living adults, children, legally incompetent people and deceased donors are all recognised as being equal before the law and they and their families are afforded the same rights to disclose information. Prior to the proposed amendment, only living donors and adult transplant recipients were able to consent for their stories to be shared. This discriminates against the families of children, legally incompetent and deceased donors, as they are not provided with the same rights to share their loved ones’ stories.

The right to life

The Government amendment promotes the right to life by enabling open communications about organ and tissue donation and facilitating acknowledgment of the significant gift of organ and tissue donation.

The amendment will support the clinical organ and tissue donation service (DonateLife ACT) to comply with the relevant disclosure section of the TA Act when donor stories are shared by individuals and loved ones at occasions such as Organ Donor Remembrance Ceremonies. The proposed amendment expands the list of people eligible to provide consent to disclose such identifying information. The amendment will also enable DonateLife ACT to provide best practice support and care for donor families.

Rights Limited

The measures in the Government amendment may engage and limit the right to presumption of innocence and the right to privacy (section 22(1) and section 12, HRA).

The preamble to the HRA notes that few rights are absolute and that they may be subject only to the reasonable limits in law that can be demonstrably justified in a free and democratic society. Section 28 (1) of the HRA provides that in deciding whether a limit on human rights is reasonable, all relevant factors must be considered, including the following:

- a) the nature of the right affected;
- b) the importance of the purpose of the limitation;
- c) the nature and extent of the limitation;
- d) the relationship between the limitation and its purpose; and
- e) any less restrictive means reasonably available to achieve the purpose the limitation seeks to achieve.

Right to presumption of innocence (section 22(1) HRA)

The right to be presumed innocent is engaged by the Government amendment to section 49 of the TA Act in a similar fashion to the Bill. As in the Bill, the engagement creates an exception to the offence of disclosing identifying personal information of people who have donated tissue, in certain circumstances.

This engagement is necessary and rationally connected to the purpose of ensuring that disclosures of identifying information are reasonably limited.

Although the provision may engage and limit the right to be presumed innocent, any engagement is reasonable and proportionate due to the construction of the offence and its pursuit of a legitimate purpose.

Right to privacy and reputation (section 12 HRA)

The right to privacy is engaged due to the disclosure of the relevant person's identifying information. The disclosure of this information, if consented to by a person identified in new section 49 (4) (c), is voluntary and is for the purposes of recognition and education.

This statement does not intend to adjudicate that the deceased person has privacy rights. However, to the extent that the right to privacy is potentially engaged, it is noted that disclosure is voluntary, not mandatory. As disclosure can only be consented to by those persons identified in new section 49 (4) (c), this limits the engagement.

In the context of organ donation, where family and friends may already be aware of a relevant person's donation, there is not a less restrictive means for the further voluntary release of information. It should be noted that information about individuals may already be released informally by the relevant person's family and friends. The amendment removes potential legislative conflict in the TA Act that is a barrier to DonateLife ACT's involvement in supporting and celebrating gifts of organ donation. DonateLife ACT will only share stories when considered appropriate to do so and with consent.

The right to privacy of the recipient is engaged due to the disclosure of the relevant donor's identifying information. Information about individuals may already be released informally by the donor families. Reasonable precautions will need to be exercised by DonateLife ACT to minimise the inadvertent identification of recipients.

This amendment is necessary and rationally connected to the purpose of promoting organ donation, which promotes the right to life of the broader community. Any potential limitation is necessary for the purposes of acknowledging the gift of organ donation at public services. For these reasons any limitations on the right to privacy are reasonable, justified and proportionate.

Health Legislation Amendment Bill 2022

Detail

Government Amendment 1

Clause 11

Proposed new section 49 (4) (c)

This clause substitutes the existing section 49 (4) (c) which currently provides that identifying information about a person, or a deceased person, may be disclosed ‘with the consent of the person to whom the information relates’. The proposed amendment expands the list of people eligible to provide consent to disclose such identifying information. The amendment seeks to enable DonateLife ACT to provide best practice support and care for donor families. This amendment will allow for donor stories to be shared by individuals and loved ones at occasions such as Organ Donor Remembrance Ceremonies without engaging an offence under sections 49 (1) and 49 (2) of the *Transplantation and Anatomy Act 1978*.

Clause 12

Proposed new section 49 (5) and (6)

To facilitate the proposed new section 49 (4) (c), this clause provides supporting definitions of key terms. The proposed new section 49 (5) provides that the Act dictionary definition of ‘next of kin’ does not apply to the amendments to section 49 (4) (c) of the TA Act.

The Act dictionary definition of ‘next of kin’ is only relevant for a deceased donor and does not apply to living donors who are not legally competent. The proposed new section 49 (6) provides additional definitions to enable the interpretation of proposed amendments made by clause 11.