



10 January 2025

Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Via email: community.affairs.sen@aph.gov.au

Health Legislation Amendment (Modernising My Health Record – Sharing by Default) Bill 2024

Submission from Advance Care Planning Australia

Dear Secretary,

Advance Care Planning Australia (ACPA) is funded by the Australian Government Department of Health and Aged Care to promote awareness and uptake of advance care planning nationally. ACPA works with the community, health and aged care professionals, and at the systems level, to achieve this. Advance care planning involves a person articulating their wishes and preferences about future health care in case there comes a time when they are unable to make or communicate these decisions for themselves.

ACPA would like to make the following points about advance care planning and My Health Record.

1. ACPA supports the intent of the Modernising My Health Record Bill 2024.

ACPA supports the intent of the Bill, which is to improve sharing of health information to support informed decisions about health care.

ACPA supports efforts to ensure that health care is person-centred. Sharing by default is an effective and efficient mechanism to facilitate important and relevant information being accessible as needed. This helps ensure that decisions about health care and treatment are informed by individualised and up to date information.



2. ACPA recommends repeal of Rule 32A in the My Health Record Rule 2016.

ACPA notes that the Bill, once enacted, will be operationalised through Rules made under the My Health Records Act 2012.

Under the My Health Record Rule 2016 (made under section 109 of the My Health Records Act 2012), a health practitioner is not able to upload advance care planning information to My Health Record on behalf of a patient unless the patient has provided explicit consent or instructions:

32A Uploading advance care planning information

A healthcare provider organisation may only upload to a repository advance care planning information where the healthcare recipient instructs the healthcare provider organisation to upload the information. (My Health Record Rules 2012)

ACPA believes that Rule 32A is a barrier to the effective use of advance care planning information and is not in line with the intent of the Modernising My Health Record Bill.

Advance care planning information is used when a person does not have capacity to make or communicate their own decisions about health care and treatment. Advance care planning information can include information about a person's:

- Legally binding instructions about specific health care treatments they consent to or refuse,
- Legally appointed substitute decision-maker(s) for health care matters, and
- Values, wishes and preferences about their future health care.

Health practitioners must seek consent for health care treatments and therefore, in the case of a person who is unable to consent for themselves, must identify and seek consent from an appropriate substitute decision-maker. Health practitioners, and substitute decision-makers, are also expected to ascertain and take into account a person's wishes and preferences when making a decision about their health care.

Furthermore, in Victoria¹ the legislation imposes an obligation on health professionals to make reasonable efforts to find out whether a person has an Advance Care Directive, or an appointed medical treatment decision-maker. Similarly, in Tasmania², the legislation imposes an obligation on health professionals to make reasonable efforts to find out whether a person has an Advance Care Directive.

If required, it may be time-critical to locate advance care planning information.

¹ Medical Treatment Planning and Decisions Act (Vic) 2016, section 50.

² Guardianship and Administration Act (Tas) 1995, section 35O.



If advance care planning information exists but it is not located or considered when health care is provided to a person who is unable to make their own decisions, there is the risk that:

- A health practitioner fails to follow a person’s legally binding instructions about their health care (for example, they provide life-sustaining measures such as cardio-pulmonary resuscitation (CPR) to a person who has refused this)
- A health professional in Victoria or Tasmania is in breach of their state legislation
- A representative who consents to (or refuses) health care or treatment on a person’s behalf is not the substitute decision-maker appointed by the person (for example, a health practitioner relies on consent provided by an adult child, when the person has legally appointed their sibling to that role)
- A person is provided with treatment that they did not want or indeed, explicitly refused.

People who make an effort to document their wishes, preferences, and instructions for future health care do so with the explicit intent of this information being used to inform decisions about their health care in the event that they are unable to do so for themselves.

As the only national repository for advance care planning information, My Health Record should facilitate and support effective sharing of this information. Rule 32A is a barrier to effective sharing of advance care planning information. Rule 32A is also not aligned with the share by default approach of the Health Legislation Amendment (Modernising My Health Record – Sharing by Default) Bill 2024.

ACPA recommends:

When Rules made under the My Health Records Act 2012 are being amended following the enactment of the Health Legislation Amendment (Modernising My Health Record – Sharing by Default) Bill 2024, that Rule 32A of the My Health Record Rule 2016 is repealed.

Please do not hesitate to contact me if you would like any further information. We would be happy to speak with the Committee if it would be of assistance in your inquiry.

**Dr Greg Parker MBBCh, FRACGP, FACHPM
Director, Advance Care Planning Australia**

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