

Access Procedure to Advance Care Planning and/or Advance Care Directive documents on My Health Record

1. What is My Health Record?

My Health Record is a secure online summary of a person's health information. The person can control what goes into it, and who has access. A person's My Health Record allows them and their doctors, hospitals and other healthcare providers to view and share their health information to provide the best possible care.

2. Advance Care Plan (ACP) and Advance Care Directive (ACD) stored on My Health Record

The My Health Record allows a person to upload an ACP **and/or** ACD as part of their health information under the 'Advance Care Planning Documentation' section.

3. What is an Advance Care Directive (ACD)?

An ACD is a way for a person to say what healthcare treatments they would like to have or refuse, should they be in a position where they are unable to make or communicate decisions about their healthcare and treatment.

An ACD is legally enforceable in NSW. By not complying with a valid ACD, a health practitioner may be breaching his or her duty of care to their patient and could be sued for negligence.

The NSW Ministry of Health's *Making an Advance Care Directive* package provides information on ACDs: <http://www.health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf>.

4. What is an Advance Care Plan (ACP)?

An ACP can be written by the person or by someone else on their behalf. It documents the person's values and preferences for healthcare and preferred health outcomes. The ACP is prepared and used as a guide for future healthcare decision making, if the person is unable to speak or otherwise communicate their wishes. It is not a legally binding document but should be considered when determining treatment and care.

5. Accessing an ACD and/or ACP on My Health Record

NSW Health staff must only access My Health Record if this access is required in order to fulfil the duties of their role in providing healthcare. NSW Health staff should seek as much information from the person, or their family, during presentation on any relevant ACD or ACP documents that are stored and viewable in their My Health Record.

6. What should clinicians do when they find an ACD and/or ACP on My Health Record?

The clinician must confirm the ACD is valid, relevant, accurate and up to date.

Where there is only an ACP, and the patient lacks capacity, the health professional will need to consider the ACP and consult their Person Responsible under the Guardianship Act (NSW), as part of determining treatment and care decisions.

As the My Health Record is patient controlled, access to some patient records may be withdrawn over time. Staff should take a copy of an ACD or ACP on the My Health Record and store it in the local record. If a copy cannot be taken, a note summarising the relevant content of the ACD/ACP and the decision made based on the ACD/ACP must be included in the local record.

7. Determining the validity of an ACD

Under NSW law, a person does not need to use a specific form to record their wishes. ACDs can be provided electronically, in hard copy or by other means. In NSW an ACD is valid if it is:

- made voluntarily by a capable adult (with decision making capacity),

- is clear and unambiguous about the treatments that the person would accept or refuse,
- it is current and extends to the clinical situation at hand.

A valid ACD must be followed. Health professionals and Persons Responsible have no authority to override a valid ACD. However, if there is any doubt as to the validity of an ACD and the person lacks capacity, treatment should be given to the person in accordance with the emergency principle and the Guardianship Act until the validity of the ACD is confirmed.

8. What should be done if there is doubt about the validity of an ACD?

When there is genuine and reasonable doubt as to the validity or application of an ACD, an application can be made to the NSW Supreme Court to seek clarification and guidance. If a decision is needed urgently, then the case can be expedited. In the meantime, treatment can be provided in accordance with the emergency principle and the Guardianship Act (NSW). Legal advice should be sought.

9. Can anyone upload an ACD on behalf of a person on their My Health Record?

For ACDs and ACPs, only the consumer, their authorised representative or nominated representative (who has full access control) can upload such documents on the My Health Record.

10. Can another person have access to a patient's My Health Record?

Yes, there are two types of people that a person can allow access to their My Health Record:

(1) The nominated representative: is when the person allows someone they trust to view and help manage their information eg family, carers or friends. They may have general access, restricted access, or full access. A nominated representative who has full access to a person's My Health Record can view all documents, as well as add information such as any new allergies or emergency contacts. Only a nominated representative who has full access can add or remove an ACP and/or ACD on behalf of the consumer.

(2) The authorised representative: is someone who can make decisions on how a person's My Health Record is managed. The authorised representative must act in accordance with the will and preference of the person they represent. They can access, view and update information, and add/remove other people. This includes an ACP and/or an ACD. The authorised representative (unlike the nominated representative) must apply to, and satisfy, the Australian Digital Health Agency (system operator for the Australian Government) that they have parental or legal authority, or is otherwise appropriate, to act.

To gain Authorised Representative status one must show to the system operator:

- Evidence that the person does not have capacity to manage their own My Health Record (for adults). A medical practitioner or psychologist will make a determination on their capacity.
- Enduring power of attorney, Enduring guardianship, or Guardianship order.
- parental responsibility for people under 18 years age, by showing documentation such as: Birth certificate, Medicare card (with both names), order from an Australian court or tribunal.

11. Can an authorised representative upload an ACD to a person's record?

Yes, the authorised representative can upload an ACD on behalf of the person, however, this doesn't mean the ACD is not valid. The health practitioner should still determine the validity of the ACD according to the criteria in Question 7 at the time when the ACD will be applied.