

Confidentiality – adults with incapacity

It is a presumption that every adult patient has the mental capacity to make choices and decisions concerning the disclosure of their personal information, unless proved otherwise. No clinician should assume that a patient lacks the capacity to make their own decisions solely because of the existence of a condition or illness that affects their cognitive abilities or because they make a decision that you disagree with.

Any assessment of a patient's capacity should be undertaken at the time when a specific clinical decision needs to be made. Be aware that fluctuations in a patient's condition may affect their ability to understand, retain or weigh up information and communicate their wishes, and this should be taken into account when undertaking an assessment.

Basic Considerations

Personal information may be disclosed if it is considered to be of overall benefit or in the best interests to a patient whose capacity is lacking. In coming to a decision about whether to disclose personal information where capacity is lacking, you must make the care of the patient your first priority. You should also consider and respect the patient's dignity and privacy, and also encourage the patient to be involved in the decision about disclosing their personal information as far as they are able and willing to.

Is it possible to consult with others who are close to the patient (such as family and close friends) concerning matters relating to their beliefs and values, when coming to a decision on whether the disclosure being considered would be in the best interests of the patient? Likewise, do the wider healthcare team know of any relevant information concerning the patient's wishes? While there may be benefit in sharing information with a patient's relatives, friends or carers in order to properly assess capacity, this does not provide a general right of access to a patient's personal clinical data. Care must be taken not to disclose sensitive or otherwise irrelevant information about the patient's medical history.

It is important to consider whether a lack of capacity is permanent or temporary in nature – and if it is thought to be temporary then any decision should be deferred until the patient regains capacity. A patient may also have expressed a particular preference before losing capacity regarding how their personal information may be shared and this should be taken into account in any disclosure decision.

The views of anyone with legal authority in regard to the health and welfare of a patient, such as someone with legal power of attorney, must also be considered when coming to a decision. It is permissible to share relevant personal information with such an individual and this might include a welfare attorney, court-appointed deputy or guardian. If a patient has no-one else available to support them, give consideration to involving an independent mental capacity advocate.

It is good practice to tell the patient before disclosing information and the reasons for doing so – and these should be documented in the patient's records.

Common pitfalls

- Assuming that a patient lacks capacity to make any decisions about how their personal information is used and shared on a continuing or permanent basis.
- Failing to put the benefit of the patient at the centre of any decision to share their personal information.
- Assessing a patient's capacity at a time when they may be known to be particularly confused, tired or affected by prescribed medication.
- Placing insufficient weight on the opinions or wishes a patient with incapacity.
- Deciding that a patient lacks capacity when a cognitive deficit is temporary in nature.
- Failing to check and consider any previous wishes or decisions made by a patient when they had capacity.
- Failure to check the legal status and entitlement of other individuals who may claim to have legal authority to act on behalf of a patient who lacks capacity. The Office of the Public Guardian may be able to assist in confirming any legal entitlement that exists.

Key points

- Presumption of capacity is the overriding principle and starting point when assessing an individual's ability to consent to the sharing of personal information.
- Capacity may fluctuate in patients and this must be taken into account when undertaking assessments.
- Capacity is situation specific, and cannot be applied in a blanket manner. Patients with incapacity may retain the ability to make some decisions and choices.
- Previous wishes and choices made by patients before they lacked capacity on how their personal information is shared should be considered and respected, where appropriate.
- Consider any relevant information that can be obtained from family, friends and carers.

Further guidance

- Adults with Incapacity (Scotland) Act 2000: <https://www.legislation.gov.uk/asp/2000/4/contents>
- GDC. *Focus on standards* (Principle 3 Obtain valid consent): <https://standards.gdc-uk.org/pages/principle3/principle3.aspx>
- GMC. *Confidentiality: good practice in handling patient information* (Disclosing information when a patient lacks the capacity to consent): <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality/disclosing-patients-personal-information-a-framework#paragraph-16>
- Mental capacity (amendment) Act 2019: [Mental Capacity \(Amendment\) Act 2019 \(legislation.gov.uk\)](https://www.legislation.gov.uk/ukpga/2019/21/contents)
- Office of the Public Guardian (England and Wales): <https://www.gov.uk/government/organisations/office-of-the-public-guardian>

- Office of the Public Guardian (Scotland): <http://www.publicguardian-scotland.gov.uk/>

MDDUS Training & Consultancy resources: <https://www.mddus.com/training-and-cpd>