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# **European Guidance for Healthcare Professionals on Confidentiality and Privacy in Healthcare**

## ***Introduction***

All patients have the right to privacy and the reasonable expectation that the confidentiality of their personal information will be rigorously maintained by all healthcare professionals. Each patient's right to privacy and the professional's duty of confidentiality apply regardless of the form (for example, electronic, photographic, biological sample) in which the information is held or communicated. This guidance applies to all healthcare professionals and addresses the areas of healthcare confidentiality and informational privacy. It forms part of the European Standards on Confidentiality and Privacy in Healthcare which elaborate this Guidance and provide Recommendations to healthcare provider institutions, based on ethical and legal foundations. The Standards also contain a Glossary. The text of the Standards and the Guidance are available in various languages at [www.eurosocap.org](http://www.eurosocap.org).

The European Standards are primarily ethical standards, developed within the legal context in which healthcare professionals make decisions about the protection, use and disclosure of confidential information. Not all healthcare professionals are bound by the same legal obligations of confidence, but all are under the same ethical obligations to maintain confidentiality.

The Guidance gives detailed consideration to the needs of vulnerable patients. The needs of vulnerable patients are greater with respect to confidentiality—there is greater risk of it being breached than is the case for other patients. Particular care is needed on the part of healthcare professionals to ensure that the right to privacy of vulnerable patients is respected and that their duty of confidentiality toward them is fulfilled.

In this Guidance three areas of protections, uses and disclosures are considered:

- protections, uses, and disclosures of patient information for their healthcare;
- protections, uses, and disclosures of patient information for healthcare purposes not directly related to their healthcare; and
- obligations and justifications for the disclosure of patient identifiable information for purposes not related to their healthcare.

## **Protection, Use and Disclosure of Patient Information—General Considerations**

1. **Key principles of healthcare confidentiality.** Healthcare professionals should respect the following three key principles of healthcare confidentiality.
  - Individuals have a fundamental right to the privacy and confidentiality of their health information.
  - Individuals have a right to control access to and disclosure of their own health information by giving, withholding or withdrawing consent.
  - For any non-consensual disclosure of confidential information healthcare professionals must have regard to its necessity, proportionality and attendant risks.
2. **Support for the vulnerable.** Healthcare professionals should ensure that vulnerable people are given all necessary support to enable them to understand the complexities of confidentiality issues and to help them to express their wishes.
3. **Protecting the vulnerable.** Whenever a patient is identified as vulnerable by a healthcare professional, that identification, its specific nature and the justification for it, should, with the consent of the patient or their legal representative\*, be recorded in their case notes.
4. **Incapacity.** Where a healthcare professional thinks that disclosure would be in the best interests of a patient unable to consent, he/she should raise this with the patient's legal representative (including the parent/guardian of a minor). If the consent of the legal representative is withheld, the healthcare professional should follow the current best practice of their country in resolving the dispute.
5. **Emergency situations.** In emergency situations, uses or disclosures of confidential patient information may be made, but only the minimum necessary information should be used or disclosed to deal with the emergency situation.
6. **Disclosure after death.** The confidentiality of patient information must be maintained after the death of the patient.

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\* A legal representative is a person provided for by law to represent the interests of, and/or take decisions on behalf of, a person who does not have the capacity to consent.

7. Where a competent patient has made an explicit request before his or her death that their confidence be maintained, then that request should be respected.
8. Where a healthcare professional considers that disclosure after the death of a patient may be necessary, desirable, or receives a request for disclosure and has no specific instructions from that patient, the professional should consider this as a situation of possible disclosure to third parties or disclosure for a legally protected public interest. (See Guidance points 19-23.)
9. **Patient access to their healthcare information.** Healthcare professionals must respect patients' requests for access to their healthcare information and comply with their legal obligations under Data Protection laws.

### **Protection, Use and Disclosure of Patient Information for Their Healthcare**

10. **Keeping patient's informed.** Healthcare professionals must ensure that patients and/or their legal representative are informed in a manner appropriate for the patient's communication needs:
  - of what kinds of information are being recorded and retained;
  - of the purposes for which the information is being recorded and retained;
  - of what protections are in place to ensure non-disclosure of their information;
  - of what kinds of information sharing will usually occur;
  - of the choices available to them about how their information may be used and disclosed;
  - about their rights to access and where necessary to correct the information held about them within healthcare records;
  - the information required to be provided to them by national law implementing Directive 95/46/EC; and
  - country specific legal provisions or principles governing disclosure.
11. Patients, or where appropriate their legal representative, must be informed of what information sharing is necessary for the patient's individual healthcare. Provided they are informed in this way, explicit consent is not necessary, implied consent is sufficient for the ethical sharing of patient information for their healthcare.
12. **Clinical audit.** Healthcare professionals should strive to ensure that institutional policies for clinical audit are compatible with the ethical requirement for confidentiality.

13. **Carers.** The potential benefits of information sharing with their informal carer should be discussed with the patient and/or their legal representative. However, the fact that such information sharing may be beneficial does not diminish the duty of confidentiality owed to the patient by the healthcare professional.
14. **Multidisciplinary teams.** The healthcare team may include temporary members for particular functions and the healthcare professionals must not disclose information to temporary members unless they are under a sufficient obligation of confidentiality for that level of disclosure.

Multidisciplinary teams should agree strategies for any disclosure of confidential information beyond the team.

Healthcare professionals may have different criteria and thresholds for the disclosure of confidential information, for example in relation to public safety. It is essential that each healthcare professional familiarise him or herself with such differences and moderate disclosures accordingly.

15. **Inter-agency teams.** Where it is planned to involve staff from other agencies this should first be discussed with the patient and/or their legal representative. The purpose of involving the other agency should be clarified along with the purpose of the contemplated information sharing.

Where a patient or their legal representative refuses to consent to the involvement of other agencies their refusal should be respected unless there are overriding interests. (See Points 19-23.)

Where other agencies request information about patients, healthcare professionals should first seek the consent of the patient or their legal representative about such sharing, including the content of information to be disclosed.

16. **Dual roles and responsibilities.** Healthcare professionals should avoid situations with dual responsibilities and obligations to the same patient wherever possible.

Where a healthcare professional has dual responsibilities it is important that they explain at the start of any consultation or assessment to the patient and/or their legal representative on whose behalf they are seeing the patient and the purpose of the consultation or assessment. It should also be made clear to the patient and/or their legal representative that the information given will not be treated as confidential.

## **Protection, Use and Disclosure of Patient Information for Healthcare Purposes not Directly Related to their Healthcare**

17. **Consent for secondary uses.** Express consent from the patient or their legal representative should where possible be obtained before any proposed secondary uses of their personal information. Where there is agreement to disclosure, only the minimum necessary patient identifiable information should be used for each legitimate healthcare purpose.
18. **Protecting the identity of the patient.** Healthcare professionals should strive to ensure that appropriate policies and protocols to protect the identity of the patient are in place and operational in their hospitals and units and among commissioners of services for secondary healthcare uses of patient identifiable information.
19. **Anonymisation.** Information should only be kept in forms that enable the patient to be identified if this is necessary for the purposes for which it is being kept. Data which has been rendered anonymous means that the patient can no longer be identified directly or indirectly by anyone from that data. Whenever it is intended to render data anonymous, patients and/or their legal representative must be informed by the healthcare professional of this intention and the precise effect that this will have, specifically the ability of patients to access their data and to know what it is being used for and hence to object to such uses. Patients and/or their legal representative should be informed of the purposes of the intended processing of data after it has been rendered anonymous.

## **Obligations and Justifications for the Disclosure of Patient Identifiable Information for Purposes not Related to their Healthcare**

20. **Legal obligations to disclose.** Where in the course of the healthcare professional-patient relationship a legal obligation to disclose is clearly becoming relevant, this should be discussed with the patient and/or their legal representative as early as possible unless such discussion would itself undermine the purpose of the disclosure. Before complying with any possible legal obligation to disclose, healthcare professionals must satisfy themselves that the situation clearly falls under the category of cases for which disclosure is legally required. They must ensure that every argument that can properly be put against disclosure is put before the authority to which disclosure needs to be made. Any disclosure must be limited to what is strictly necessary.

21. **Justifications to disclose.** Healthcare professionals should ensure that they are aware of any country specific legal provisions or principles according to which the weighing of interests needs to be performed.
22. In situations involving disclosure to protect overriding rights of third parties, each case must be considered on its merits. The test is whether the release of information to protect the interests of a third party exceptionally prevails over the duty of confidence owed to the patient in the public interest. Decisions to disclose patient identifiable information outside the health services where no obligation to disclose information exists, are matters of balanced judgement.

Factors to consider when reaching such a decision are, among others:

- the importance of the interest that is at risk without disclosure, for example disclosure might be more easily justified where the life or integrity (physical or psychological) of a third party is at risk;
- the likelihood of the harm occurring in the individual case, that is, disclosure might be justified where there is a high likelihood of harm to the life of another, but not necessarily justified where there is a low likelihood of harm;
- the imminence of the harm, that is, disclosure might be justified where protection of the third party requires immediate action, but not where there is no more than a possibility that at some future point the patient might pose a threat to another;
- the existence of a sufficiently appropriate authority to whom disclosure can be considered;
- the necessity of the disclosure to avert the harm, that is, that there is no possibility of averting the harm without disclosure;
- the likelihood that disclosure can avert the harm, which requires that the healthcare professional be satisfied that the harm to the third party or to the legally protected public interest is sufficiently likely to be averted by disclosure.

23. **Disclosure to protect the best interests of the incompetent patient.** Where a patient is incompetent, disclosure can be justified to protect the best interests of that patient. Whether disclosure is justified in the individual case depends on a careful weighing of the patient's interest in having the confidentiality of his/her information maintained and the interests that are at risk without disclosure.
24. **Good practice for justified disclosures.** In all instances where judgment is involved, healthcare professionals are urged to discuss the case with colleagues without revealing identifiable details of the patient and, if necessary, to seek legal or other specialist advice. Most of the situations where decisions to disclose are reached require good communication with and support for patients whose

confidentiality is to be breached. Once a decision to disclose has been reached the usual procedure would be as follows.

- An explanation of the reasons for sharing information should be given to the patient and/or their legal representative.
- The healthcare professional should encourage the patient (and/or where appropriate, their legal representative) to inform the relevant authority (for example, police or social services). If the patient or legal representative agrees, the healthcare professional will require confirmation from the authority that such disclosure has been made.
- If the patient or their legal representative refuses to act, the healthcare professional should then tell them that he or she intends to disclose the information to the relevant authority or person. He or she should then inform the authority, disclosing only relevant information and make available to the patient and/or their legal representative the information that he or she has disclosed.
- Healthcare professionals who decide to disclose confidential information (with or without prior informing of the patient and/or their legal representative) should be prepared to explain and justify their decision to the authority if called upon to do so. The healthcare professional should record in the healthcare record details of all conversations, meetings and appointments involved in the decision to disclose or not to disclose such information.

The exception to this normal procedure is where informing the subject of the disclosure in advance that the disclosure will be made would prevent achieving the justified aim of the disclosure.

## **Security**

25. **Security.** Given the healthcare professional's responsibility to maintain patient confidentiality, professionals should strive to ensure that appropriate policies and protocols are in place and operational in their institutions and among commissioners of services for maintaining the security of patient information.

Healthcare professionals should be mindful of strict privacy and security obligations when communicating with patients, their legal representatives, carers and colleagues, particularly where indirect methods are being used such as telephones, e-mails and faxes.