

Confidentiality

What is Confidentiality?

Within the context of professional ethics, observing the principle of confidentiality means keeping information given by or about an individual in the course of a professional relationship secure and secret from others. This confidentiality is seen as central to the maintenance of trust between professional and service-user.

The obligation to maintain confidentiality does not normally end with the individual's death. Confidentiality is owed equally to mature and immature minors, and adults who lack the capacity to make decisions for themselves. It also applies to fellow professionals and students studying to enter one's profession. It applies to all forms of transmission; verbal, written, digital, manual or hardcopy records, videos and illustrations *etc.* – wherever they can be identified with a specific individual.

Within research, the Governance arrangements for NHS Research Ethics Committees state that a favourable opinion from a Research Ethics Committee will only be given if include that they be adequately reassured about the Protection of research participants' confidentiality. This includes:

- A description of an individuals who will have access to personal data of the research participants, including medical records and biological samples.
- The measures taken to ensure the confidentiality and security of personal information concerning research participants.
- The extent to which the information will be anonymised.
- How the data/samples will be obtained, and the purposes for which they will be used.
- How long the data/samples will be kept.
- To which countries, if any, the data/samples will be sent.
- The adequacy of the process for obtaining consent for the above¹.

When does disclosure not constitute a breach of confidentiality?

Disclosure to the individual to whom confidentiality is owed.

The principle of confidentiality is not intended to justify withholding information from a person about themselves. For example, within the doctor-patient relationship, sharing information about the patient's health and treatment is held to be an essential part of good practice and will only constitute a breach of confidentiality if disclosure reveals previously unknown information about another identifiable person, such as a relative².

In some circumstances the law may impose specific restrictions on the disclosure and use of certain types of information, and professionals are expected to be aware of these distinctions where they apply to their own professional practice.

¹ <http://www.dh.gov.uk/assetRoot/04/05/86/09/04058609.pdf>.

² See GMC guidance on confidentiality: <http://www.gmc-uk.org/standards/default.htm>

Disclosure to others

Disclosure of information about an individual to others will constitute a breach of confidentiality only if that information was previously unknown to the recipient. Confidentiality applies to personal information³. General information may be disclosed without breaching confidentiality. For example the GMC states that where relatives:

*'are already aware of an individual's condition or diagnosis, an explanation of the possible options for that patient does not breach confidentiality but revealing an individual's views of those choices would do so'*⁴.

Disclosure with consent

The principle of confidentiality can be waived with the consent of that individual and in practice, an obligation to maintain confidentiality would often work against their interests if it could not be so waived.

The consent given must be informed but the definition of what constitutes informed consent is ethically and legally complex. Correct application of the principle confidentiality to professional behaviour will therefore require a complimentary understanding of informed consent and the principles of confidentiality and informed consent can be usefully taught together. For further information on consent see <http://www.prs-ltsn.ac.uk/ethics/documents/consent.html>.

In some circumstances the law may impose higher standards of consent in relation to the disclosure and use of certain types of information, for example, consent relating human fertilisation and embryology⁵.

Disclosure of information to other professionals

The BMA holds that the confidentiality owed to person within the doctor-patient relationship covers disclosure to other health professionals. Information should only be shared with health professionals who need access in order to fulfil their own duty of care to the patient. Data circulated for other purposes than the duty of care to the individual to whom that data relates should be done either with their consent or in an anonymised form (see below for further information on anonymising data).

Breaching confidentiality.

Professional ethics (and in some cases statutory obligations) will sometimes require confidentiality to be breached for other reasons such as the risk of "serious harm" to identifiable individuals or to society at large. However, there is no consensus on what constitutes a harm which is serious enough to outweigh the obligation of confidentiality so this is an area for ethical discussion and deliberation with students rather than an issue on which clear guidelines can be issued. Any cases relevant to the student's primary discipline that have been subject to a ruling in law, or by a governing professional body would offer a useful starting point.

³ Within medicine, personal information is defined as information relating to the physical or mental health of any person from which that person can be identified.

⁴ See GMC guidance on confidentiality:

<http://www.gmc-uk.org/standards/default.htm>.

⁵ Consent and the law review of the current provisions in the Human Fertilisation and Embryology Act 1990. See <http://www.dh.gov.uk/PolicyAndGuidance/fs/en>.

Circumstances in which confidentiality might be breached for ethically or legally justifiable reasons for consideration might include:

- Cases in which the professional knows or suspects that an individual is acting illegally.
- Cases in which the professional knows or suspects that an individual is harming others*.
- Cases in which the professional knows or suspects that an individual might harm others* in future.
- Cases in which the professional knows or suspects that an individual is harming themselves.
- Cases in which the professional knows or suspects that an individual might harm themselves in future.
- Cases in which the professional knows or suspects that a minor is being exploited or abused by others*.
- Cases in which the professional knows or suspects that a competent adult is being exploited or abused by others*.

***Others** may here refer to:

- People with whom that individual has a personal relationship
- Members of the general public.
- Professionals with whom that individual has a service-provider/service-user relationship.

It will be useful to consider whether the status of the other person affected affects the outcome of deliberation. For example, if the person being harmed or at risk is a child, does this make a breach of confidentiality more or less justifiable than if a fellow professional is at risk?

Even more complex are issues where maintaining confidentiality means accepting continuing harm or the risk of harm to non-human interests such as animals, the environment or property.

There are also decisions to be made regarding procedure where a decision to breach confidentiality is made. Professional codes normally advise their members to try to get consent for disclosure first, but in some cases an indication that the professional is considering disclosure the information to others will subvert the reasons for making the disclosure.

These issues are contested and remain subject to constant revision within the law and professional codes of conduct. Even if clear guidelines exist, they may be challenged or shown to be inadequate in the light of future events. It is therefore important that students develop some facility with the issues and arguments, and are able to engage in ethical deliberation regarding the circumstances in which a breach of confidentiality might be justified, so that they can take personal responsibility for future decisions regarding their own conduct.

Caldicott Principles

These principles are based on the recommendations of the Caldicott Committee Report. See *Protecting and Using Patient Information: A Manual for Caldicott Guardians* on: <http://www.dh.gov.uk/assetRoot/04/06/81/36/04068136.pdf>.

The principles define protocols governing the receipt and disclosure of patient/client information, and for controlling access to patient/client information. Key requirements with regard to the use of confidential information are:

- Justify the purpose for using it.
- Only use when absolutely necessary.
- Use the minimum required.
- Access should be on a strict 'need to know' basis.
- Everyone should be aware of their responsibilities.
- Understand and comply with the law.

Research which makes use of existing patient identifiable data (and stored samples) must have the permission of the Caldicott Guardians, who are responsible for agreeing, monitoring and reviewing protocols.

Anonymised information

Information is anonymised if it does not identify, directly or indirectly, the individual to whom it relates. This requires more than simply changing or removing names as combinations of partial identifiers such as initials, date of birth, sex, postcode *etc.* can reliably identify many individuals. Aggregating data will often serve to anonymise it.

For information on anonymising data see the MRC's Guidance in: <http://www.mrc.ac.uk/pdf-pimr.pdf>.

Sources of Information on Confidentiality

Information Commissioner Data Protection Act: <http://www.dataprotection.gov.uk/>.

The UK Clinical Ethics Network provides information and support to both developing and existing clinical ethics committees within the health service. It has information on Confidentiality on: <http://www.ethics-network.org.uk/Ethics/econfidential.htm>.

NHS Code of Practice on Confidentiality can be viewed on: <http://www.dh.gov.uk/assetRoot/04/06/92/56/04069256.pdf>.

The **British Medical Journal** Collected Resources includes a 'Confidentiality' category. <http://bmj.bmjjournals.com/cgi/collection/confidentiality>.

The **GMC** guidance on confidentiality can be viewed on: <http://www.gmc-uk.org/standards/default.htm>.

The **BMA** provides detailed guidance on Confidentiality and Disclosure of Health Information on:

<http://www.bma.org.uk/ap.nsf/Content/Confidentiality+and+disclosure+of+health+information?OpenDocument&Highlight=2,confidentiality>.

Joint guidelines from the **BMA and the Association of British Insurers**: December 2002: <http://www.bma.org.uk/ap.nsf/Content/MedicalInfoInsurance>.

MRC (Medical Research Council) Ethics Series: Personal Information in Medical Research. See: <http://www.mrc.ac.uk/pdf-pimr.pdf>.

The **Pharmacy Law and Ethics Resource Centre**: For information on confidentiality see: http://www.nottingham.ac.uk/pharmacy/applet/teachers_confid.html.

Review of an article by Joseph S. Ellin on confidentiality in the teaching of medical ethics. See: <http://www.prs-ltsn.leeds.ac.uk/philosophy/reviews/articles/tp8ellin.html>.