Module 7
The Ethics of Confidentiality and Privacy
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1. Module 7 Key points

1.1 Confidential information is private information
that a person shares with another on the understanding that it will not be disclosed to
third parties. It includes identifiable patient information – written, computerized, visually or
audio recorded – that health professionals have access to. Keeping patient confidentiality is
important because it builds trust, respects patient autonomy and privacy and contributes to
good patient outcomes.

1.2 Confidentiality is protected by professional codes and laws
Ancient and modern medical and nursing codes stress the duty of confidentiality as a ‘time
honoured principle’ that extends beyond death. Health professionals are also legally obliged
to protect patient confidentiality under the Irish Constitution, the European Convention and
the common law: legal sanctions are in place for breaches of patient confidence.

1.3 The principle of confidentiality is not absolute
Exceptional circumstances where health professionals may ethically and legally qualify the
principle of confidentiality centre on concerns about protecting the wellbeing of the patient
themselves and protecting others from harm.

1.4 Health professionals should ask competent patients for permission to share
information
with third parties. In exceptional circumstances, such as abuse or threatened suicide, it
may not be appropriate to seek permission on medical grounds. These circumstances have
not been considered by the Irish courts but they are likely to look for very strong evidence
regarding the medical grounds as to why it was not considered desirable to seek the
patient’s consent.

1.5 If patients lack the capacity to consent to sharing information, health professionals
may need to share information
with relatives, friends or carers in order to enable them to be involved in decisions about
the patient’s best interests. The sensitivity of the information and any known wishes of
the patient in regard to it must be taken into account. The Irish law in relation to patients
who lack capacity is currently unclear though a forthcoming Mental Capacity Bill will help
to clarify the position. Under the current Irish law, those close to the patient – spouses,
partners, family members, friends have no legal status in relation to healthcare decisions (and
information in relation to decisionmaking) on behalf of people lacking capacity.
While hospitals may routinely seek the consent of the ‘next of kin’ in relation to a healthcare
decisions, this consent has no legal basis. Ultimately, the lawfulness of sharing of information about a patient without capacity is likely to depend on whether it can be shown that it is in the patient’s best interests that information about his or her condition should be shared with those close to them.

1.6 In exceptional circumstances, health professionals may breach patient confidentiality in order to avoid serious risk of considerable harm to others (identifiable individuals and the public in general). The decision to disclose patient information should not be made in haste or without due care and consideration of all concerned in the situation. Where disclosure is necessary; only information necessary to avoid harm should be provided.

1.7 The duty of confidentiality extends beyond death
Guidelines that protect living patients equally apply after patients have died. Exceptions to confidentiality also equally apply. National and international guidelines governing the release of medical records of deceased patients generally consider: the known wishes of deceased patients in relation to their information; the impact of non-disclosure on the wellbeing and welfare of third parties – avoiding harming them or benefitting them; the impact of disclosure on the reputation of the deceased; the possibility of anonymising the information. The impact that posthumous breaches of confidentiality may have on the care of dying patients is also a concern.

1.8 Family members of deceased patients may ask for information and/or medical records because they may be anxious about a misdiagnosis, negligence or hereditary condition. Third parties may also request medical records because they are contesting a patient’s will. Where disclosure is considered to be consistent with the wishes of the patient or to advance the best interests of the patient it is generally viewed as acceptable. Conflict arises where patients, while alive, did not consent to disclosure. In these circumstances, as with living patients, patients’ rights to confidentiality are important but not absolute and the rights of others’ wellbeing and welfare must also be taken into account. Recent legislation in relation to Freedom of Information confirm that access to information about deceased people may be obtained in some circumstances.

1.9 Privacy is valued in ethics and law
(e.g. Irish Constitution and European Convention). Protecting someone’s privacy involves protecting them from unwanted access or control by others. In this way it is linked with personal autonomy and it is also viewed as a key element of personal identity. Privacy can be thought of in terms of five dimensions: physical privacy, informational privacy, decisional privacy, personal property and expressive privacy.
2. Module 7 Definitions

2.1 Anonymised Data:
Data from which the patient cannot be identified by the recipient of the information. The name, address, and full post code must be removed together with any other information which, in conjunction with other data held by or disclosed to the recipient, could identify the patient. Unique numbers may be included only if recipients of the data do not have access to the ‘key’ to trace the identity of the patient.

2.2 Principle of Confidentiality:
obliges health professionals to respect the confidences that patients share with them. By extension, health professionals are also obligated to keep confidential, information that they might gain from sources other than the patient in their care, e.g., medical records or other health professionals.

2.3 Minimalist Principle:
where the interests of individuals or the general public require that patient confidentiality is qualified in some circumstances, the minimalist principle obliges health professionals to disclose to third parties only the patient information that is relevant to ensure their welfare or wellbeing.

2.4 Privacy:
refers to what belongs to individuals e.g. bodily integrity, property, information, space. A right or claim to privacy is a right to control access to one’s personal domain.

2.5 Right:
an entitlement that prohibits or obliges the actions of others. It is a justified claim that individuals or groups can make on other individuals or society generally. If a person is considered to have a right – to confidentiality, for example – they may be considered to be inviolable in some sense. In addition, a right may entitle a person to make certain claims on others for support or service – that their confidences will not be shared or that their medical records will be protected.
Module 7 The Ethics of Keeping Confidentiality

3. Module 7 Background

3.1 Confidential Information
Confidential information is usually understood to be private information that a person shares with another on the understanding that it will not be disclosed to third parties. Keeping patient confidentiality is considered important because of its role in building patient trust and protecting patient privacy and autonomy. It is also considered important because the consequences of respecting patient confidentiality are generally seen as positive.

The British Medical Association (BMA) offers a useful list of what is considered confidential between health professionals and patients:

‘All identifiable patient information, whether written, computerised, visually or audio recorded or simply held in the memory of health professionals, is subject to the duty of confidentiality.

It covers:

- any clinical information about an individual’s diagnosis or treatment;
- a picture, photograph, video, audiotape or other images of the patient;
- who the patient’s doctor is and what clinics patients attend and when;
- anything else that may be used to identify patients directly or indirectly so that any of the information above, combined with the patient’s name or address or full postcode or the patient’s date of birth, can identify them. Even where such obvious identifiers are missing, rare diseases, drug treatments or statistical analyses which have very small numbers within a small population may allow individuals to be identified. A combination of items increases the chance of patient identification.

- Whilst demographic information such as name and address are not legally confidential, it is often given in the expectation of confidentiality. Health professionals should therefore usually seek patient consent prior to sharing this information with third parties.’

(BMA, 2008, p.5-6)

3.2 Confidentiality is Important
Confidentiality is a core element of all human relationships and, so, is basic to building trust between patients and health professionals. Keeping confidences is a form of keeping a promise or bond. In effect, the health professional promises the patient that they will keep a bond of trust – the patient trusts the health professional to keep confidence and the health professional trusts the patient to tell the truth (See Case 5)
Secondly, the assurance of confidentiality enables patients to be open about personal issues, concerns and questions and enhances their capacity to make decisions about their health care. Respecting a patient’s choice to keep certain information about them confidential, e.g., deciding not to tell a family member about their illness, recognizes the patient’s right to autonomy and privacy (See Privacy). It also acknowledges that it is the patient who must live with the consequences of their decision (not the health professional).

Finally, not only is the keeping of confidentiality considered worthwhile because it is viewed as an implicit part of the health professional/patient relationship, it is also seen as a means of ensuring other important benefits. For example, the trust engendered through confidentiality

- creates an open and supportive environment that encourages patients to disclose more of their symptoms and worries, fears and phobias.
- ensures a better diagnosis and a higher quality of care – secures greater agreement and compliance with procedures and treatment.
- encourages individuals, in particular, vulnerable individuals to seek help and increases their contact with the health services.

In sum, the keeping of patient confidentiality is considered important because it is basic to a relationship built on trust and respect. It is important also because the consequences of keeping confidentiality are generally beneficial to patients in that it ensures better outcomes for them.

3.3 Professional and Legal Accountability

3.3.1 Professional Codes

Because it has long been held as an honoured bond between health professionals and patients, the keeping of confidentiality has been enshrined in both professional and legal codes. It was first articulated in the Hippocratic Oath (c.5th Century BC):

‘What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about.’ Translated by Ludwig Edelstein (1943), cited in University of Virginia Historical Collections (2007).

Florence Nightingale also set high standards for the nurse/patient relationship in relation to confidentiality. In 1859, she advised nurses in the following terms:

‘And remember every nurse should be one who is to be depended upon, in other words, capable of
being a “confidential” nurse. She does not know how soon she may find herself placed in such a situation; she must be no gossip, no vain talker, she should never answer questions about her sick except to those who have a right to ask them.’ (Nightingale, 1859, 1992, p.70)

While the ancient oath points to shamefulness on the part of the health professional for breaking confidence, Nightingale draws attention to breaches of confidentiality that can happen through gossip and self-aggrandizement. Nightingale also indicates that anyone who asks for information about a patient must have a right to do so.

Modern codes of professional conduct for health professionals echo both Hippocrates’ and Nightingale’s stress on the professional/patient relationship and they also place emphasis on the notion of a presumed right on the patient’s part to confidentiality. For example, the Irish Medical Council describes confidentiality as ‘a fundamental principle of medical ethics [that] is central to the trust between patients and doctors’.

(Medical Council, 2009, p.26, section 24.1)

However, where contemporary codes differ from earlier ones, is in the acknowledgement they make that some circumstances may give rise to the need for the principle of confidentiality to be qualified in some way. Such circumstances include situations where the well-being of the patient or the rights of those other than the patient may be at risk. These codes are discussed in detail in the following sections.

3.3.2 Legislation

In addition to ethical obligations and professional codes, confidentiality is also protected by law, through legislation, in particular the Data Protection Acts 1988 and 2003, on the basis of court decisions and also on appeal to such mechanisms as the Irish Constitution and the European Convention on Human Rights. There is a legal duty on health professionals to respect the confidence of their patients. In the English case of Hunter v Mann (1974), the Court set out the nature of the duty as follows: ‘the doctor is under a duty not to [voluntarily] disclose, without the consent of the patient, information which he, the doctor, has gained in his professional capacity.’ (See Privacy below)

Failure to respect the duty of confidentiality may lead to an action for breach of confidence and the award of damages to the patient. It may also cause a complaint to be made to the regulatory body responsible for the healthcare profession in question.
4. Qualifying the Principle of Confidentiality

While the principle of confidentiality holds an honoured place in professional codes and laws, serious extenuating circumstances occasionally call for the principle to be qualified in some way. The challenge for health professionals, faced with such circumstances is to consider them carefully, to examine the implications of relevant codes and laws and to decide a course of action that they think best fulfils their various obligations as carers, professionals and citizens.

4.1 Disclosure with Consent

Health professionals do not breach the rule of confidentiality when they disclose information with the patient’s permission. The least controversial circumstance that might arise is one where confidential information is shared between health professionals working in a multidisciplinary team (Medical Council, 2009, p.30). However, while many might presume that it is acceptable for members of a team to disclose confidential information about a patient to each other, even here, care needs to be taken (BMA, 2008; Medical Council, 2009). The An Bord Altranais, Code of Professional Conduct (2000a), for example, advises nurses to use their professional judgement in relation to such disclosure:

‘Information regarding a patient’s history, treatment and state of health is privileged and confidential. It is accepted nursing practice that nursing care is communicated and recorded as part of the patient’s care and treatment. Professional judgement and responsibility should be exercised in the sharing of such information with professional colleagues.’

(An Bord Altranais, 2000a, p.5)

The UK General Medical Council (2009) advises doctors to ensure that patients are aware that information might be shared:

‘You should make sure that information is readily available to patients explaining that, unless they object, their personal information may be disclosed for the sake of their own care and for local clinical audit’ (p.6, section 7)
The Irish Medical Council advises that information shared among health professionals in relation to clinical audit, quality assurance systems and education and training should be anonymised as far as possible (2009, p.30). Where anonymisation is not possible, patients should be made aware of the possibility that identifiable information may be disclosed and that any patient’s subsequent objections to such disclosure must be respected (2009, p.30).

In relation to end-of-life care, where a patient with the capacity to make healthcare decisions gives his or her consent to the sharing of information, then provided that the information sharing is done in accordance with the patient’s instructions and does not exceed these, the health professional will not be in breach of her or his legal duties.

In other situations, patients are also likely to agree with disclosure to third parties when it is required to protect their interests e.g, where insanity is a defence in a criminal action or for insurance purposes.

### 4.2 Disclosure without Consent

While these situations might be more contentious and troubling, there is considerable international consensus on what might be deemed grounds for qualifying the principle of confidentiality without the permission of a patient. Generally, codes delineate three circumstances where a health professional might, justifiably, share confidential information with people other than the patient or the multi-disciplinary team. These circumstances relate to the interests of; the law, the patient and other individuals and society. All three are explicitly detailed in the Irish Medical Council’s Guide to Professional Conduct and Ethics for registered medical practitioners:

1. Disclosure required by law
2. Disclosure in the interest of the patient or other people
3. Disclosure in the public interest (Medical Council, 2009, p.27-29)

#### 4.2.1 When Obligated Under the Law

Circumstances where the law can require a health professional to disclose confidential information include criminal investigations where the records of a suspected individual in a crime (e.g., road traffic offence, shooting offence) may be sought and legal actions where a professional might be asked to testify in a court or tribunal. They may also relate to Infectious Diseases Regulations which place an obligation on doctors and other health professionals to disclose information about ‘notifiable’ diseases to the public health authorities (Health Protection Surveillance Centre, 2009)
4.2.2 To Protect the Interests of the Patient or Other People

Patients with Capacity

Ethical problems arise if the health professional and the patient disagree as to whether or not disclosing information is in their best interests. On such occasions, health professionals might find themselves torn between maintaining a patient’s trust on the one hand and their duty to protect a patient from harm on the other. Circumstances where such conflicts arise might involve patients who share information in relation to abuse, neglect or suicidal intentions. In cases of abuse or neglect, the patient – young or old – may feel so dependent or fearful that they refuse to permit their doctor or nurse to disclose the abuse (Medical Council, 2009, p.7; Department of Health and children, 2004). In cases of threatened suicide, the patient may be so severely depressed that they cannot rationally decide where their best interests lie.

Some commentators, for example Mason and Laurie (2006, p.259) suggest that, in some limited circumstances, it may also be legally permissible for a health professional to share information about a capable patient without the patient’s consent where it is in the best interests of the patient that the information be shared and it is not desirable on medical grounds to seek the consent of the patient. Possible examples where this would arise would be sharing information between professionals responsible for the patient’s care or sharing information with a close family member.

However, others, for example Brazier and Cave (2007, p.80) argue that paternalistic motives to protect the patient cannot justify the sharing of information about a patient with capacity without the patient’s consent. The matter has not been considered by the Irish courts. However, even if the courts did adopt the first position, it is likely that the courts would take a strict view of the circumstances in which this exception would be allowed to arise and would look for very strong evidence regarding the medical grounds as to why it was not considered desirable to seek the patient’s consent.

Temporary or Permanent Incapacity

If the patient lacks the capacity to consent to sharing information, health professionals may need to share information with relatives, friends or carers in order to enable them to be involved in decisions about the patient’s best interests. In such circumstances, it is permissible for health professionals to provide information to those close to the patient. But caution is advised. According to the BMA (2008):

‘Where a patient is seriously ill and lacks capacity, it would be unreasonable to always refuse to provide any information to those close to the patient on the basis that the patient has not given explicit consent. This does not, however, mean that all information should be routinely shared,'
and where the information is sensitive, a judgement will be needed about how much information the patient is likely to want to be shared, and with whom. Where there is evidence that the patient did not want information shared, this must be respected.’ (BMA, 2008, p.28)

The Irish Medical Council advises the following:

‘While the concern of the patient’s relatives and close friends is understandable, you must not disclose information to anyone without the patient’s consent. If the patient does not consent to disclosure, you should respect this except where failure to disclose would put others at risk of serious harm.

If the patient is considered to be incapable of giving or withholding consent to disclosure, you should consider whether disclosing the information to family and carers is in the best interests of the patient.’ (Medical Council, 2009, p.26)

Unfortunately, Irish law in respect of patients who lack capacity is both unsatisfactory and unclear. The law is currently in the process of being reformed. A Mental Capacity Bill is due to be published but does not look like becoming law until well into 2010. Under the current law, a person who lacks capacity may be made a ward of court. If this happens, a committee of the ward (usually one person) is appointed to act on the person’s behalf. The committee has the legal right to consent to some medical treatment for the ward provided that the treatment is not serious – the committee does not have the legal right to consent to serious treatment. Although the matter has not been considered by the Irish courts, where a person is a ward of court, it would seem to be ethically appropriate and legally permissible for health professionals to share information with the ward’s committee.

Wardship is still relatively uncommon in Ireland and most patients who lack capacity will not have a committee. Under the current Irish law, those close to the patient – spouses, partners, family members, friends have no legal status in relation to healthcare decisions on behalf of people lacking capacity. While hospitals may routinely seek the consent of the ‘next of kin’ in relation to a healthcare decisions, this consent has no legal basis. If a person is nominated by a patient as their next of kin, such a person may provide valuable insight to health professionals as to the patient’s wishes. However they have no right to the patient’s records nor can they consent to disclosing information about the patient to third parties.

Ultimately, the lawfulness of healthcare decisions about patients who are incapacitated depends on whether the decisions are in the best interests of the patient. It is likely that the best interests principle will also apply to the sharing of information about a patient without capacity. If it can be shown that it is in the patient’s best interests that information about
his or her condition should be shared with those close to them, then it is likely that the sharing of information will be legally permissible. The lack of clear legal guidance can create difficulties for health professionals especially in situations of family conflict. The new capacity legislation is likely to clarify the position considerably. It will allow for the appointment of adult guardians who will be the relevant people for all actions in respect of the person lacking capacity.

Health care surrogacy laws in many states in the US give decision-making authority for incapacitated patients to appointed surrogates where advance directives or living wills have not been executed. In these cases, surrogates are often granted access to patients’ medical records. This might be ethically justified on the ground that it assists surrogates to make informed healthcare decisions which are consistent with the patient’s own wishes and are also in their best interests.

The key test highlighted by Jansen and Friedman Ross (2000) is the degree to which the information that the patient does not want disclosed is relevant to the treatment decisions that the surrogate must make. Where it not relevant; there is no justification for breaching confidentiality. Where adequate care requires information disclosure, then it would seem that the interests of the patient’s welfare should be prioritized over his confidentiality. In cases where clinicians might reasonably disagree as to the relevance of certain information to treatment decisions, Jansen and Friedman Ross advise consultation with an ethics committee and tend to favour disclosure out of respect for the decision making authority of the surrogate. However, we would urge caution in this regard on the grounds that it could be argued that, while the surrogate represents the patient, they are not themselves the patient and, so, their right to information is more limited. In any case, currently in Ireland, there are no legal means of appointing surrogates and, if there were, the level of decision-making authority is uncertain.

In addition, the Freedom of Information Act 1997 (section 28(6) Regulations 2009 (SI 387/2009) allow access to information about people lacking capacity in some situations. Regulation 4 says that a request for personal information shall be granted where the requester is a parent or guardian of the individual to whom the information relates and the person has not reached the age of 18 or is a person with a mental condition or mental incapacity or severe physical disability provided that access to the information is in the person’s best interests.

To Protect the Interests of Another Individual
These circumstances concern, not the public at large or society as a whole, but particular identifiable individuals who are at serious risk of harm which disclosure of information
might avert or minimize. The widely reported court case which first stipulated that health professionals had a legal obligation to breach confidentiality in circumstances where identifiable third parties were at risk is the United States case of Tarasoff v. the Regents of the University of California (1976) (See Section 7. Further Discussion for details). The case was initially dismissed but, after several appeals, the California Supreme Court overturned the dismissal. In 1976 it stated:

‘[O]nce a therapist does, in fact, determine, or under the applicable professional standards reasonably should have determined, that a patient poses a serious danger of violence to others, he bears a duty to exercise reasonable care to protect the foreseeable victim of that danger.’

(Tarasoff v. the Regents of the University of California, 1976)

The court noted that the duty to protect might be fulfilled in different ways, such as issuing a warning to the presumed intended victim or others likely to tell the potential victim of the danger, notifying the police, or initiating steps reasonably necessary under the circumstances.

The duty or obligation on the part of health professionals to warn an identifiable person who is at risk of serious harm that was articulated by the Californian Supreme Court in the Tarasoff case has also been expressed in many contemporary codes. The Irish Medical Council, for example, puts it in the following way.

‘Disclosure of patient information without their consent may be justifiable in exceptional circumstances when it is necessary to protect the patient or others from serious risk of death or serious harm. You should obtain consent of the patient to the disclosure if possible. If you consider that disclosing patient information is justifiable, you should carefully consider whether anonymisation of the information (sharing it without revealing the patient’s identity) would achieve the same potential benefits. You must also be careful to disclose the information to an appropriate person (or body) who understands that the information must be kept confidential. You should only disclose the minimum information that is necessary in the circumstances. In the preceding instances, you should inform patients of the disclosure unless this would cause them serious harm.’ (Medical Council, 2009, p.28)

The position of the Medical Council in relation to disclosure in these circumstances is supported by the Irish Data Protection Acts 1988 and 2003 and the EU Data Protection Directive 1995 (Council of Europe 1995). Specifically, the Irish Acts permit disclosure of otherwise confidential information where ‘required urgently to prevent injury or other damage to the health of a person’ (Data Protection Acts 1988 and 2003, Section 8 [d]).
A duty to warn: Whom? When? How? What?

While the law (legislation and court decisions) and professional regulations clearly stipulate a duty on the part of health professionals to warn those at risk, there remains some uncertainty in relation to the precise circumstances that would prompt the disclosure of information (who to warn) and also in relation to the process of carrying out such a duty (when, how and what). However, some guidelines exist.

In relation to whom to warn:
The Californian Supreme Court stipulates that the person at risk must be identifiable, and that the risk to them must be one of a serious danger of violence (Tarasoff v. Regents of the University of California, 1976).

In relation to when and how:
The Data Protection Act 1988 permits disclosure in urgent circumstances to prevent injury or other damage.

The Irish Medical Council cites ‘serious risk of death or serious harm’ as a condition of disclosure (2009, p. 29, section 28.1).

The Californian Supreme Court advises taking steps that are reasonably necessary under the circumstances (Tarasoff v. Regents of the University of California, 1976).

In relation to what:
If a health professional decides to disclose confidential information to a third party, either in the interests of the patient or to protect other individuals from harm, they might ask themselves a further question: what should they tell them? This question is based on a rule of thumb, the minimalist principle of disclosure. The principle can be formulated in the following way: ‘Only tell a relevant third party the minimum that is necessary to achieve the end of disclosure.’ This can afford protection of patient confidence as much as possible, while recognising an obligation to disclose pertinent information to protect patients, or others, from harm.

What these provisos indicate is a general concern that confidentiality is not breached lightly: that the decision to disclose is not made in haste without due care and consideration of all concerned in the situation.

4.2.3 In the Interests of the General Public
As Module 4, 3.4 indicated, the right of an individual to exercise autonomy is limited by the similar rights of others to live autonomously. So also, in the case of confidentiality,
the interest of a patient in having their confidences protected is limited by the legitimate interests of others. Those interests may be deemed to outweigh an individual’s right to confidentiality in circumstances where nondisclosure threatens the well-being and welfare of others. The discussion in the previous section relates to the interests of identifiable other individuals but a health professional also has obligations in relation to society in general. For example, a health professional might be justifiably concerned if she or he becomes aware that an airline pilot or bus driver suffers from epilepsy or that a patient has murderous intentions and seems capable of carrying them out. In these circumstances, the health and even lives of members of the public are at risk if the health professional does not disclose what she or he knows to other relevant parties.

4.3 Deceased Patients

The status of deceased patients in uncertain in ethics and law, but there is general consensus that the obligation to respect patient’s confidentiality extends beyond death. Guidelines from the US and the UK:

4.3.1 US Guidelines

Opinion 5.051 - Confidentiality of Medical Information Postmortem

All medically related confidences disclosed by a patient to a physician and information contained within a deceased patient’s medical record, including information entered postmortem, should be kept confidential to the greatest possible degree. However, the obligation to safeguard patient confidences is subject to certain exceptions that are ethically and legally justifiable because of overriding societal considerations (Opinion 5.05, “Confidentiality”). At their strongest, confidentiality protections after death would be equal to those in force during a patient’s life. Thus, if information about a patient may be ethically disclosed during life, it likewise may be disclosed after the patient has died.

Disclosure of medical information postmortem for research and educational purposes is appropriate as long as confidentiality is maintained to the greatest possible degree by removing any individual identifiers. Otherwise, in determining whether to disclose identified information after the death of a patient, physicians should consider the following factors:

1. The imminence of harm to identifiable individuals or the public health
2. The potential benefit to at-risk individuals or the public health (e.g., if a communicable or inherited disease is preventable or treatable)
3. Any statement or directive made by the patient regarding postmortem disclosure
4. The impact disclosure may have on the reputation of the deceased patient
5. Personal gain for the physician that may unduly influence professional obligations of confidentiality
When a family member or other decision maker has given consent to an autopsy, physicians may disclose the results of the autopsy to the individual(s) that granted consent to the procedure. (American Medical Association Council on Ethical and Judicial Affairs, 2000, p.5)

4.3.2 UK Guidelines

‘Your duty of confidentiality continues after a patient has died. Whether and what personal information may be disclosed after a patient’s death will depend on the circumstances. If the patient had asked for information to remain confidential, you should usually respect their wishes. If you are unaware of any instructions from the patient, when you are considering requests for information you should take into account:
(a) whether the disclosure of information is likely to cause distress to, or be of benefit to, the patient’s partner or family
(b) whether the disclosure will also disclose information about the patient’s family or anyone else
(c) whether the information is already public knowledge or can be anonymised or coded, and
(d) the purpose of the disclosure’ (General Medical Council, 2009, p.28, section 70)

‘You are personally accountable for your professional practice and must always be prepared to justify your decisions and actions’ (General Medical Council, 2009, p.2).

4.3.3 Irish Guidelines

The Irish Medical Council also addresses the issue briefly and confirms that the ethical duty of confidentiality extends beyond death:

‘Patient information remains confidential even after death. If it is unclear whether the patient consented to disclosure of information after their death, you should consider how disclosure of the information might benefit or cause distress to the deceased’s family or carers. You should also consider the effect of disclosure on the reputation of the deceased and the purpose of the disclosure. Individual discretion in this area might be limited by law.’ (Medical Council, 2009, p. 27, section 24.2)

What is at the heart of these guidelines is concern for the wishes of the patient, worry about harm to others and the need to anonymise information where possible.

Other good reasons for protecting confidentiality after death centre on the impact that posthumous breaches of confidentiality may have on the care that the dying patient receives. Robinson and O’Neill (2007) frame the problem in the following way:

‘Although certain ethicists may argue that the dead have no interests to protect, some individuals’ fear of disclosure of information posthumously may be as great as contemporaneous disclosure.'
Such fears affect patient behaviour and candor, which may result in suboptimal care during life. Individuals frequently withhold information from loved ones to protect them, and there is no reason to assume that this should be different after a person’s death. An expectation among the living that their private medical information may be released after death may inhibit the patient-clinician relationship. (Robinson and O’Neill, 2007, p.634)

This obligation is particularly weighty if the patient requested confidentiality when they were alive. The usual exceptions remain, however, that the patient’s right to confidentiality is not absolute, and confidentiality may be breached in certain circumstances. Of these, the possibility that non-disclosure of confidential information may cause serious harm to other individuals or the general public are the most pressing.

The legal position is less clear. There is some authority from the European Court of Human Rights that a duty of confidentiality survives after death: see European Court of Human Rights Plon v France (2004). However, in Rotunda Hospital v Information Commissioner (2009), McCarthy J held that there was no right of privacy in deceased people. This decision is currently on appeal to the Supreme Court.

Access to information about deceased people may be obtained in some circumstances. The Freedom of Information Act (1997) and the Freedom of Information Act 1997 (Section 28(6)) Regulations 2009 (SI 387/2009) allow access to information about deceased people to certain classes of requesters. These are: a personal representative of the deceased person acting in due course of the administration of the estate of the deceased person; a person upon whom a function is conferred by law in relation to the estate of the deceased person; the spouse or next of kin of the deceased person where in the opinion of the head of the body from whom the information is sought, having regard to all circumstances, the public interest, including the public interest in the confidentiality of personal information would, on balance be better served by granting than by refusing to grant the request.

The Regulations also define a ‘spouse’ and a ‘next of kin’. A ‘spouse’ includes a party to a marriage which has been dissolved or who is living apart from the deceased person under a deed of separation and a man or woman who is not married to the deceased but who has cohabited as husband or wife with the deceased person. A ‘next of kin’ is ‘the person or persons standing nearest in blood relationship’ to the deceased person in accordance with the order set out in the Succession Act 1965.
5. Privacy – a Space to Call One’s Own

5.1 Scope and Limits

‘Privacy’ is a rich concept that plays an important role in the assessment of healthcare policies and practices. The question of how to define privacy is a controversial one. Some say that privacy should be defined as a moral claim while others argue that privacy should be construed as a legal right. For a society to value individual privacy; it needs to specify and clarify what might be considered to be in the private domain and, therefore, worthy of protection. Bok offers a definition of privacy that is helpful when considering privacy in relation to end-of-life care:

‘the condition of being protected from unwanted access by others – either physical access, personal information, or attention. Claims to privacy are claims to control access to what one takes – however grandiosely – to be one’s personal domain.’ (Bok 1989, p.10-11)

The law also fleshes out the meaning of privacy and links it with dignity and autonomy. For example, the Irish courts recognize a right to privacy (and by implication, a right to confidentiality) which is loosely derived from the Irish Constitution:

‘Though not specifically guaranteed by the Constitution, the right to privacy is one of the fundamental personal rights of the citizen which flow from the Christian and democratic nature of the State […] The nature of the right to privacy must be such as to ensure the dignity and freedom of an individual in the type of society envisaged by the Constitution, namely, a sovereign, independent and democratic society.’ (Hamilton P. in Kennedy and Arnold v Ireland [1987] cited in Madden, 2002)

The European Convention on Human Rights also protects privacy under Article 8: ‘Everyone has the right to respect for his private and family life, his home and his correspondence.’ (Council of Europe, 1998, Art. 8.1, p.9).

However, just as professional codes consider exceptional circumstances where the principle of confidentiality might be qualified, so also, legal rights to privacy are not considered absolute. The European Convention, for example, also stipulates under Article 8 that:
‘There shall be no interference by a public authority with the exercise of this right except such as
is in accordance with the law and is necessary in a democratic society in the interests of national
security, public safety or the economic well-being of the country, for the prevention of disorder or
crime, for the protection of health or morals, or for the protection of the rights and freedoms of

What is at the heart of qualification of the right to privacy in Article 8 is a concern for the
interests of others and the public interest generally.

While private matters are often kept secret; there is an important difference between privacy
and secrecy. What is kept private does not have to be secret, and what is kept secret does not
have to be private. For example, a private house or a private life is not always a secret house
or life. In turn, a secret ballot for government elections is not a private concern, nor is a secret
plan to assassinate a president.

‘Control over secrecy provides a safety valve for individuals in the midst of communal life – some
influence over transactions between the world of personal experience and the world shared with
others. With no control over such exchanges, human beings would be unable to exercise choice
about their lives. To restrain some secrets and to allow others freer play; to keep some hidden
and to let others be known; to offer knowledge to some but not to all corners; to give and receive
confidences and to guess at far more: these efforts at control permeate all human contact.
Those who lose all control over these relations cannot flourish in either the personal or the shared
world, nor retain their sanity. If experience in the shared world becomes too overwhelming, the
sense of identity suffers.’ (Bok, 1989, p.20)

Why should we have some control over our secrets? One reason is that having control over
our secrets protects a key element of personal autonomy: identity.

‘[Secrecy] protects identity, the sacred, unique and unfathomable nature of human beings:
[Secrecy] protects vulnerable beliefs or feelings, inwardness, and the sense of being set apart; of
having or belonging to regions not fully penetrable to scrutiny, including those of memory and
dream; of being someone who is more, has become more, has more possibilities for the future
than can ever meet the eyes of observers. […] Human beings can be subjected to every scrutiny,
and reveal much about themselves; but they can never be entirely understood, simultaneously
exposed from every perspective, completely transparent either to themselves or to other persons.
They are not only unique but unfathomable.’ (Bok, 1989, p.20-21)
Bok, emphasises the importance of individual rights to privacy and, linking them with autonomy, argues that conflicts about concealing or revealing personal information should be understood as conflicts of power. She claims:

‘Conflicts over secrecy – between state and citizen, … or parent and child, [or between health professional and patient] or in journalism or business or law – are conflicts over power: the power that comes through controlling the flow of information. To be able to hold back some information about oneself or to channel it and thus influence how one is seen by others gives power; so does the capacity to penetrate similar defenses and strategies when used by others.[…] To have no capacity for secrecy is to be out of control over how others see one; it leaves one open to coercion. To have no insight into what others conceal is to lack power as well.’

(Bok, 1989, p.19)

5.2 Dimensions of Privacy

Judith DeCew (1997) analyses a range of privacy theories and privacy claims and believes that, rather than think of privacy as a single concept, we should look at it as an umbrella term or broad and multifaceted cluster concept for a wide variety of interests. Drawing on DeCew’s and Bok’s (1989) work on privacy, we suggest that there are five dimensions of privacy that health professionals might consider:

1. physical privacy
2. informational privacy
3. decisional privacy
4. personal property
5. expressive privacy

5.2.1 Physical privacy

Physical privacy is a popular usage of the concept of privacy and it means freedom from unwanted contact with other people. This sense of privacy recognises the need for bodily privacy and environmental privacy and protects a desire for limited accessibility from others.

Complete physical privacy is inconsistent with the requirements of modern healthcare. Patients know that medical and nursing care may involve touching, invasive probing, nudity, and observation as necessary aspects of many examinations, treatments and surgeries. This is the privacy price of hopefully gaining better health. Nevertheless, patients can rightfully expect doctors, nurses and other carers to take special care against unnecessary or insensitive bodily exposure or contact. When it is necessary to have physical examinations, it is important and courteous to offer a brief explanation of what is being done, why it is necessary and some indication of the time duration of the physical contact.
These are minimal markers of respect for bodily privacy. Because healthcare workers get accustomed to nudity and body exposure in various examinations and caring tasks they might too readily become inured to the customary embarrassment that patient modesty causes. Respect for physical privacy should alert health professionals to try and keep ‘alive’ their awareness of patient’s discomfort under examinations.

Physical privacy can also respect desires for seclusion and solitude that allow for peace of mind and intimacy. However, it does not imply that all patients would want to be in a room by themselves. While privacy is a most important value for patients, being in a room with two or three other patients can often help pass the time with friendly banter. People vary on what they would consider intrusive but individuals might consider some of the following as invasions of their physical privacy: unexpected and unexplained physical touch, telephone calls, other patients and their visitors coming in at will, their own visitors, chaplaincy visits, photography.

A commitment to the goal of protecting patients’ physical privacy will also alert staff to:

- Introduce physical touch with request and explanation.
- Minimise the duration and the extent of exposure.
- Minimise or get permission for the bedside presence of medical/nursing students, spectators, or cameras producing photographs for study purposes
- Provide explanations to patients of what happens during times when they are unconscious
- The importance of expanding the number of single over shared hospital rooms
- The sensitivity of many patients to rooms of mixed sexes
- The possible preference of some patients for doctors or nurses of their own sex

It may not always be possible to fulfil these aims but one can develop sharper sensitivity to these potential intrusions on patient privacy.

5.2.2 Informational Privacy

Secrecy, confidentiality, anonymity and protection of patient data would come under this meaning of privacy. Informational privacy calls for access to personal information to be limited and this is especially true with respect to health information, present and past. Limiting access to medical and insurance records are fundamental protections required under the principle of confidentiality in the professional-patient relationship.
5.2.3 Decisional Privacy

Decisional privacy can be understood as having control over intimate aspects of personal identity. Under decisional privacy a person can expect to be allowed, if not encouraged, to make their own decisions and act on their decisions if they so choose free from state, governmental or health professionals interference. There is, however, at least one important constraint on decisional privacy. A person cannot make a decision that causes harm to a third party and expect that the decision will have no interference or opposition. Obviously, what is covered by ‘harming third parties’ would need to be clarified if individuals are to observe care and consideration when making decisions (See Module 4, 3.4).

This area of decisional privacy in healthcare contexts is a central issue in ethics, medical and nursing codes and hospital administration guidelines. In the healthcare context, decisional privacy concerns responsibility for very important choices about treatment, termination of treatment, and involvement in clinical trials. Who has the authority to decide about treatment, commencement and termination is often a point of contention. Patients may not wish to have decisional authority in these matters and give permission to health professionals to make those decisions for them (paternalism with permission). Health professionals have expertise to advise patients in decisions about treatment or life supports and most patients appreciate such advice (See Module 3, Module 4 and Module 6 for more on patient authority over decision-making).

5.2.4 Personal Property

Respect for personal property includes all of a patient’s personal belongings and, especially, those items that are considered by them to be most important, e.g., personal diaries, letters, handbags and wallets.

5.2.5 Expressive Privacy

This dimension of privacy protects a realm for expressing one’s self-identity or personhood through activity or speech. Self expression is critical for lifestyle choices that contribute greatly to defining oneself and one’s values. If expressive privacy is a value that facilitates or supports self expression and self-identity, then as an element of expressive privacy we add a concept of personal space.

Iris Marion Young thinks privacy theories have given inadequate attention to material support for privacy in guaranteeing personal space. An essential element of privacy, for Young is:
‘[…] having a dwelling space of one’s own to which a person is able to control access and in which one lives among things that help support the narrative of one’s life […]’ Services and institutions giving shelter and care to needy persons fail to appreciate what is required for individuals not simply to stay alive, physically well and nourished but to have the life of a person’

(Young, 2005, p.155-156).

Studies of older people’s feelings of at-homeness emphasize the embodied understanding of security in oneself as surrounded by familiar things – especially those that form a connection with a life lived. The sense of personal integrity and sense of self is linked to control. Older people, like people of all ages, resist attempts of organisers and managers to direct their routines and activities. The same can be applied to patients, residents of long stay units or residents suffering from dementia.
6. Cases: Respecting Confidentiality of the Dying and Deceased

6.1 Case 1: The Rights of Relatives to Medical Records

Particular circumstances may arise where relatives of deceased persons may ask for information. The British Medical Association (BMA) cites a common example: ‘when the family requests details of the terminal illness because of anxiety that the patient might have been misdiagnosed or there might have been negligence.’ (BMA, 2008, p.47) Because such disclosure is likely to be what the deceased person would have wanted, and because it might also be a matter of justice, disclosure is usually justified in such cases.

Medical records may also be requested in circumstances where a will is contested on the basis of doubts raised as to the capacity of an individual to execute it. Again, disclosure in this case is generally viewed as acceptable because it is considered to advance the interests of the patient. Robinson and O’Neill (2007) note that the situation is less clear in cases where the disclosure of a hereditary or infectious condition might benefit those close to the patient.

Freedom of information legislation (FOI) in many countries, including Ireland governs access to personal information. In line with existing legislation protecting confidentiality, freedom of information laws protect private information but also allow for exceptions. The following case illustrates the balance that is sometimes struck between protecting patient confidentiality and the rights of interested others to access patient information.

The Rights of Relatives to Medical Records

Ms X requested access to her deceased brother’s records held by Cork University Hospital but was refused by the Irish Southern Health Board. In refusing access to the patient’s records the Board Submission made the following general observations:

• ‘that the doctor-patient relationship is inherently private and based on confidence;
• following the death of a patient, it is reasonable to assume that his/her privacy rights will continue to be respected;
• any public perception that medical records may be released to others, following the death of the patient, may inhibit the provision of relevant medical information by patients generally;
• once records are released under FOI there are no restrictions on the manner in which they may be used’ (5th December, 2002)
On appeal to the Office of the Information Commissioner; the rights of Ms X to access the medical records were upheld. Specifically, the Commissioner took the following into account:

- all of siblings, who were his nearest next of kin, agreed to the records being released to Ms X (Ms X had provided evidence that her two sisters agreed to the release of the records to her);
- the fact that Ms X’s sister was named as his next of kin and personal carer in his hospital admission records suggests that he had confidence in her judgement in relation to matters concerning him;
- the fact that the patient had good relations with his siblings and that there was no evidence of estrangement between them - all three sisters visited him in hospital and were with him when he died;
- there was no evidence that the patient would have objected to the release of the records;
- there was nothing of unusual sensitivity in the patient’s records; and nothing that Ms X was not aware of in general terms;
- the patient’s GP saw fit to release the records to Ms X  

(Office of the Information Commissioner, 2003, Case 020561)

6.1.1 Discussion

On the one hand, in this case, the Southern Health Board were concerned about patient privacy, the lack of restriction on how the records might be used and the worry that it might change the public’s trust that confidentiality is protected. On the other hand, the Information Commissioner focussed on the wishes of the patient, the non-sensitive nature of the information requested and evidence of the (good) relationship between the requester and the patient.

In Case 1, the family of the patient had concerns about the patient’ will. Considering the decision of the Commissioner in light of situations where patients’ relatives seek information because they are anxious about hereditary risks to themselves, Robinson and O’Neill propose that a more cautious approach to the release of information might serve to protect confidentiality and reassure relatives. They suggest ‘an expert review of the likelihood of genetic risk or of inadequate care’ rather than, necessarily, the release of full medical records (Robinson and O’Neill, 2007, p.635). Moreover, these authors suggest that such a review could form ‘part of a bereavement care program following death, ideally involving the patient’s personal physician’ who would have cared for the patient in the terminal phase.
of their illness (Robinson and O’Neill, 2007, p.635). They argue that such support could be supplemented by providing the advice of expert clinicians who are independent of the institutions and individuals at the centre of the situation.

However, while Robinson and O’Neill’s proposal goes someway towards balancing the obligation to protect patient confidentiality with the needs of those who might benefit from disclosure, critics of their position might see the reliance on ‘expert opinion’ to decide what should and should not be disclosed as overly paternalistic. Glen (1997) distinguishes between confidentiality, understood as respect for privacy, and confidentiality, understood as a means of control. She worries that the duty of confidentiality may be misused by health professionals and organisations in order to maintain control over information.

“Confidentiality” can become a somewhat embellishing signboard for paternalistic caring. In essence, one needs to distinguish between confidentiality as a respectful attitude to a patient/client, where it becomes credible that the caring professional will not misuse the information she or he obtains about the patient/client, and between confidentiality misused as an instrument of power to keep the patient/client outside the processes in which it might be important or advantageous for him or her to participate.” (Glen, 1997, p.403)

In a similar vein, Bok draws attention to the way in which maintaining confidentiality might not serve vulnerable populations well. She notes:

‘The sick, the poor, the mentally ill, the aged, and the very young are in a paradoxical situation in this respect. While their right to confidentiality is often breached and their most intimate problems bandied about, the poor care they may receive is just as often covered up under the same name of confidentiality. That is the shield held forth to prevent outsiders from finding out about negligence, overcharging, unnecessary surgery, or institutionalization. And far more than individual mistakes and misdeeds are thus covered up, for confidentiality is also the shield that professionals invoke to protect incompetent colleagues and negligence and unexpected accidents in, for instance, hospitals, factories, or entire industries.’ (Bok, 1983, p.30)
6.1.2 Suggested Professional Responsibilities

- Health professionals have an obligation to respect patient confidentiality which extends beyond the patient’s death.
- Consideration should be given to the wishes of the patient prior to their death in relation to the confidentiality of information relating to them if these are known or can be otherwise determined.
- The sensitivity of the information sought should be taken into account.
- Health professionals also have a duty of care in relation the wellbeing and welfare of those who are bereaved.
- Access to patient information should not be considered as an automatic right. In deciding access to patient information professionals should be aware of legislation pertaining to Freedom of Information.
- Health professionals should consider carefully the particular circumstances that give rise to relatives request for access to the patient’s records.
6.2 Case 2: The Patient with HIV – Silence of the Tomb

Consider the following case where the patient, Peter, has not made known whether or not information about his illness should be disclosed to anyone:

Silence of the Tomb

Peter died suddenly following a short illness. HIV was diagnosed post mortem. There had been no indication from Peter of his wishes with regards to telling his friends and family. Similarly, he had denied any risk factors for HIV. A week following his death, Peter’s sister, Ann visited from Australia and asked to see a doctor to discuss the cause of her brother’s death. She also wanted to know specifically if he had been infected with HIV. Ann was subsequently informed only of his heart failure and not of his HIV status […] Before seeing her, the treating physicians were told by a representative legal body that: ‘the duty of confidentiality of Peter persists after his death – we may talk to her about the cause of death only as it appeared on the death certificate (which did not mention HIV).’ (adapted from Wildfire, Stebbing and Gazzard, 2007, p.474).

6.2.1 Discussion

According to Wildfire et al. (2007), the advice to Peter’s doctors implies that only publicly available information may be shared and that Peter’s HIV status was no one else’s business as it had no bearing on the health or welfare of anyone else.

Wildfire et al pose a number of questions in relation to this scenario that might be considered here:

1. Do dead patients have a right to confidentiality?
   - if so, health professionals are obliged to respect their confidentiality but they must consider this duty in the light of their other duties to protect the health and wellbeing of others (individuals and society).
   - if dead patients are not considered to have a right to confidentiality, then health professionals ‘can primarily consider the mental and physical welfare’ of any other relatives or persons who might benefit from the information shared (Wildfire et al., 2007).
2. Do health professionals have a right to tell the truth or avoid deception?

If we accept that the duty of confidentiality persists beyond death, Wildfire et al. (2007) present one argument for maintaining Peter’s confidentiality in the following way:

'Patient P’s right to confidentiality has moral supremacy, as he is the patient with the problem and the vulnerable should be protected. His trust in the doctor, that was inherent in their professional relationship, is preserved by maintaining privacy and discretion. His right as the patient overrides the wishes of his sister, or the doctor’s right to tell the truth.' (Wildfire et al., 2007, p.475).

6.2.2 Suggested Professional Responsibilities

- Health professionals have a duty of care towards the living as well as the dead. In response to requests for information about deceased persons, health professionals need to determine whether or not the disclosure of that information has any implications for the health and wellbeing of others.

- In order to avoid situations where health professionals are torn between the duty of confidentiality and the duty to warn or protect others, those who treat HIV positive patients should discuss with them as early as possible the limits of patient confidentiality.

- Such a discussion could include making a plan for what might happen should the patient lose their capacity to make decisions about their care and who might be involved (and, perhaps, informed) about their status in order that their best interests are preserved.

- A balance has to be struck between respect for confidentiality and the legitimate interests of others.
6.3 Case 3: Refusing to Disclose – Don’t tell anyone until I’m gone
Consider a slightly different scenario for Peter. The following case relates to the duty to warn and illustrates some of the complex ethical tensions that arise when a health professional must contemplate breaching confidentiality in these circumstances.

Don’t Tell Anyone Until I’m Gone

Peter is imminently dying and staff are aware that he has HIV/AIDS. Peter is in a coma and, prior to lapsing into the coma, Peter specifically asked that the fact that he has AIDS not be shared with anyone until after his death. Peter’s partner Salma and his sister have been regular visitors to the ICU unit where Peter is being cared for. They are not aware of Peter’s condition. One morning, Salma asks the nurse who seems to be Peter’s main carer to tell her more about Peter’s condition.

6.3.1 Discussion
One morally significant difference between Case 2 and Case 3 is that, in Case 3, there is an identifiable person who is at risk of harm (and of harming others) if the information is not disclosed. As Peter has given his permission to disclose that he has HIV/AIDS after his death, disclosure post-mortem would be ethically acceptable. The question that arises here relates, primarily, to the ‘when?’ of disclosure.

In Case 3, the nurse must decide whether he should inform Salma about Peter’s condition or whether he should protect the confidentiality of the therapeutic relationship. It seems that he must choose between two competing moral obligations, the obligation to keep patient confidentiality and the obligation to protect another person whose life may be at risk if he fails to disclose. To help him in making the decision, he must ask himself the following questions about the situation.

1. Is it within the scope of his practice to give this kind of information to anyone?
2. What values are protected by the principle of confidentiality and are they relevant in this case?
3. Does he have an obligation to protect a third party who is not his patient?
4. If there is both a duty to a patient and a duty to a third party, which is the most compelling duty?
5. If he is considering telling Salma, how much should be told?
As indicated earlier, the principle of confidentiality is basic to all human relationships, is essential to the promotion of trust between health professional and patient and is an expression of respect for patient autonomy and privacy. The positive consequences to the patient of keeping confidentiality are also considered important. In Case 3, Peter has asked that no-one is told until after his death. In considering his situation, the nurse is obliged to maintain his trust in him as much as possible, he is also obliged to respect his autonomy, i.e., the decisions he makes in relation to his own life. (See Module 4. 3.2, 3.3)

In addition to these duties, the nurse must also consider the consequences of disclosure. Not everyone agrees that making exceptions to the principle of confidentiality is helpful in the longer run. Utilitarian ethicists, such as Helga Kuhse, are concerned that allowing exceptions to the rule of confidentiality with the intention of protecting third party interests will not achieve their intended effect in the long term (Kuhse, 1999, p.493-496). Kuhse’s basic concern is that a more relaxed confidentiality requirement on the part of health professionals will inhibit people, who are most in need of health services, from availing of them:

‘The point is that if known breaches of confidentiality are likely to prevent individuals from seeking treatment or to hinder them from seeking treatment in a timely fashion, then a rule requiring disclosure is likely to do more harm than good’ (Kuhse, 1999, p.495)

The cost of breaches of confidentiality is the loss of patient trust and (though this doesn’t apply to Peter’s case) the subsequent inability to support patients to modify behaviour that is harmful to others. In brief, on Kuhse’s view, while harm might be prevented on some occasions, in the longer term, the overall harm to society will not be reduced.

On the other hand, even though Peters partner is not his patient, it could be argued that the nurse also has a moral obligation to protect her. Not just Peter’s, but also, Salma’s autonomy is very much at risk in this situation. While the consequences of disclosure might be serious for Peter, the consequences of nondisclosure are also serious for Salma.

The most compelling argument for disclosure is a health related one based on general agreement that early access to anti-retroviral therapy and health care management are likely to prolong the health and welfare of individuals with HIV (Woodman, 2003, p.7). The nurse might also consult relevant professional and legal regulations. For example, the guidelines of the UK Society of Sexual Health Advisers (SSHA) (2004) acknowledge that sexual health advisers have a professional duty to protect third parties and an important function of GUM clinics in Ireland and elsewhere is the process of partner notification. Partner notification, or contact tracing, describes the process whereby individuals who may have been in contact with a sexually transmitted infection (STI) are contacted (by the partner...
or by the health professional) in order to prevent the spread of the infection.

From a legal point of view, the Tarasoff case and other legislation, indicate that there is a duty to warn an identifiable third party of serious danger. In this case, the third party is identifiable – the nurse needs to consider if she (and others) are also in serious danger: Salma may already be HIV positive and is in need of treatment. Additionally, the nurse needs to determine if she or other visitors need to take precautions against contracting the disease.

The ethical dilemma that the nurse is faced with then is very real; he has a duty to the patient and he has a duty to protect the patients partner. It seems that he cannot fulfil both duties at once, if he fulfils his duty to Salma, he must neglect his duty to Peter and vice versa. Case 3 seems to evolve into a ‘win-lose’ situation, where Peter wins and Salma loses or vice versa.

6.3.2 Suggested Professional Responsibilities

- Health professionals must balance a duty to respect patient confidentiality with a duty to warn identifiable others at risk of serious harm.

- The health professionals involved, must consider whether or not Peter will regain consciousness.

- In general, those who treat HIV positive patients should discuss with them as early as possible the limits of patient confidentiality.

- The health professionals in this case need to distinguish between the weight of two possible requests for information; from Salma and from Peter’s sister Ann. They must consider the health related argument in favour of disclosing information to Ann because she may benefit from access to anti-retroviral therapy and health care management.

- The nurse must consider who is best placed to talk to Salma about Peter’s situation.
6.4 Case 4: Trust and Confidentiality – Privacy, a Bond of Trust

Consider the following case which illustrates the links between trust, confidentiality, privacy and identity and demonstrates how health professionals can nurture and protect all of these.

Privacy, a Bond of Trust

Julie, an otherwise healthy 66-year-old woman, presents to her doctor with a three-month history of weight loss, sleep disturbance, and loss of appetite. The exchange with the busy physician is brief:
‘Do you live alone?’
‘Yes.’
‘What about your husband?’
‘He died twenty years ago.’
The physician diagnoses depression and prescribes an antidepressant with follow-up in two weeks. When Julie returns, a different doctor is covering that day.
‘Who do you live with?’
‘No one – I’m alone.’
‘Is that a change for you?’
‘Yes.’
‘Tell me about what has happened recently.’
‘Sheila died.’
‘Sheila … did she live with you?’
‘Yes.’
‘How long did the two of you live together?’
‘Eighteen years.’
‘Were the two of you close?’
‘Yes. Very.’ (patient in tears …)
In addition to the antidepressant, the physician offers Julie bereavement counselling. In future follow-up, Julie reveals a relationship with Sheila that the two women had hidden from their children and community, all of whom assumed they were ‘just roommates’.

(Peterkin and Risdon, 2003, p.25)
6.4.1 Discussion

Peterkin and Risdon (2003) draw attention to the need for health professionals to be especially sensitive and open to Lesbian, Gay, Bisexual and Transgender (LGBT) patients – this case illustrates the impact that a conversation that does not assume that all patients are heterosexual can have on the outcome for the patient.

The need for health professionals to be more sensitive to the lives and health of LGBT patients, family members and health professionals is supported by international research on the physical and mental dangers that many LGBT individuals must face in every part of the world. One recent and sobering example of this is found in a very comprehensive report on levels of discrimination and homophobia across the European member states, which includes very large surveys of individuals’ experiences at the hands of health professionals (European Union Agency for Fundamental Rights, 2009).

Recent Irish research indicates that LGBT people living in Ireland face particular challenges in relation to the recognition of partners in healthcare contexts. This is especially true in relation to decision-making around end-of-life care, for example, withholding and withdrawing treatment, last rites and hospital visits (Higgins and Glacken, 2009). In addition, as the Health Service Executive (HSE) Report on LGBT Health (2009a) and the Equality Authority (2002) indicate ‘the invisibility of older LGBT people may lead to a reluctance to disclose a same-sex relationship. This may impact on the ability to express grief when a partner dies or to be involved in the funeral arrangements.’ (HSE, 2009a, p.38)

6.4.2 Suggested Professional Responsibilities

- Don’t assume everyone is heterosexual (e.g. service users, carers, parents, colleagues).
- Respond positively when people disclose their sexual orientation and/or gender identity.
- Ensure respect, confidentiality and privacy is shown to all LGBT people.
- Address issues of same-sex partners and next-of-kin in care settings in a sensitive manner.
- Be informed about the health issues of LGBT people.
- Ensure all relevant paperwork uses language which is inclusive of LGBT people and their families (e.g. information leaflets, questions used in history taking).
- Address unacceptable, offensive or discriminatory comments and/or actions relating to LGBT people. (Drawn from HSE, 2009b)
7. Module 7 Further Discussion

7.1 The Tarasoff Case (1976)

In that case, the California Supreme Court imposed on a psychotherapist a limited duty to warn a presumed intended victim of a patient’s aggression. The case came about when the parents of a murdered student, Tatiana Tarasoff, sued the University of California and the professionals involved for their failure to notify them that their daughter was in grave danger. Her killer, Prosenjit Poddar, had been undergoing outpatient psychotherapy with the student health services during which he had admitted to having violent fantasies in relation to Tarasoff. The therapist, who learned from Poddar’s friend that he had purchased a gun, took steps to hospitalize him for further evaluation, against his will, if necessary. However, Californian law makes involuntary hospitalisation difficult and, while Poddar was still at large, he shot and killed Tarasoff and was subsequently convicted of second-degree homicide.

The parents claimed that the defendant (University of California, therapist and campus police) failed to notify them or their daughter that she was in danger. The providers involved claimed that they could not warn Tatiana Tarasoff because it would violate patient confidentiality.

(United States case of Tarasoff v. the Regents of the University of California, 1976)
8. Module 7 Summary Learning Guides

8.1 Confidential Information

Confidential information
- is private information that a person shares with another on the understanding that it will not be disclosed to third parties.

Keeping patient confidentiality is important because it
- builds patient trust
- protects patient autonomy and privacy
- contributes to good treatment and care outcomes

8.2 Professional Codes and Laws

- Professional codes stipulate that patients have a right to confidentiality.
- Confidentiality is also protected by law: court decisions, the Irish Constitution and the European Convention on Human Rights.

Qualifying the principle of confidentiality
The principle of confidentiality is not considered absolute. Exceptional circumstances where the principle may be qualified include:
- Disclosure required by law
- Disclosure in the interest of the patient or other people
- Disclosure in the public interest.
8.3 Privacy

Privacy can be defined as the condition of being protected from unwanted access by others. There are five dimensions of privacy that health professionals might consider:

1. physical privacy
2. informational privacy
3. decisional privacy
4. personal property
5. expressive privacy
9. Module 7 Activities

9.1 Consider again the principle of confidentiality:

a. Can you give one example from your professional experience where the breaching of a patient’s confidentiality undermined their trust in the health professions?

b. Re-read Bok’s argument that conflicts about disclosing or not disclosing personal information are about power. Can you think of any example from your professional experience that might support Bok’s view?

c. Nightingale suggests that confidentiality may be breached through ‘gossip’ and ‘vain talk’. Can you think of contemporary examples where such breaches might arise?

d. Can you think of any other circumstances where in the process of ordinary, everyday routine activities in a clinic or hospital, patient confidentiality might be breached?

9.2 Reflect back on the particulars of Case 1.

a. Jot down your own unanalysed response to the position of the HSE and the position of the Information Commissioner. Which position is closest to your own?

b. Give reasons for your answer.

c. Critically consider the more cautious approach towards information sharing with relatives that Robinson and O’Neill advise. Do you think that they are being overly cautious and/or paternalistic? Or, do they have the balance right between protecting patients and their families?

9.3 Reflect back on the particulars of Cases 2 and 3.

Consider the following questions that clinicians and nurses might ask themselves:

a. How do I treat the information that a patient shares with me?

b. How do I treat what I know about the patient from other colleagues or from the patient’s records?

c. How much of a say does the patient have in what I do with this information?

d. Where do my loyalties lie: to the patient or the patient’s family? To my profession, my colleagues, my employer, other affected parties?

e. If I were given a piece of information about a patient in the strictest confidence, would I be able to keep that confidence?

f. If I thought that not disclosing the confidential information of a patient might cause harm to another individual or individuals, what would I do? What level of harm is enough harm?
9.4 Reflect back on the particulars of Case 4.

a. Consider each of the HSE Good Practice Guidelines (2009). Decide the ways in which these guidelines might be applied to LGBT patients who are terminally ill and LGBT families of dying or deceased patients.

b. Check if the contact details, posters and literature of local and national LGBT services are displayed in the waiting areas of your place of work.

c. Consider what you might need to do to become familiar with local LGBT groups and services in order to develop working relationships with them.
10. Module 7 References and Further Reading


European Court of Human Rights (Second Section) case of Plon (Société) v. France Application no. 56148/00 of 18 May 2004.


Kennedy & Arnold v Ireland [1987] IR1 per Hamilton P.


Succession Act 1965 No. 27/1965.

Tarasoff v. the Regents of the University of California et al 551 P.2d 334 131 Cal Rptr 14 (1976) [Tarasoff II].


