Patient confidentiality

'All that may come to my knowledge in the exercise of my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and will never reveal.' (Hippocrates, 4th century BC)

This well-known tenet of medical ethics begs the question: what can or should be 'spread abroad'? Or, to put it another way, what are the exceptions to the general duty of confidentiality and, in particular, how can doctors decide if the public interest in disclosing a patient's personal information outweighs both the individual patient's privacy rights and the public interest in a confidential health service? It is this balancing exercise that lies at the heart of perhaps the most challenging decisions doctors have regularly to make.

In very brief summary, information doctors learn from or about patients in a professional capacity, and not just 'medical' information, may be disclosed if that is required by law (statute law or if ordered by a judge), if patients consent (either implicitly for the sake of their own care or expressly for other purposes), or if it is justified in the public interest. The first two are relatively straightforward. It is the last that causes doctors difficulty, for example:

- Should the police be informed whenever a patient presents with a gunshot or knife wound, even if the patient objects to disclosure? Might this deter people from seeking medical attention when they most need it?
- For research, how hard must doctors try to find (former) patients to seek their consent before it is acceptable to disclose without consent information from which those patients can be identified? Is the work needed to track them down a poor use of limited resources, when the researchers with whom the information is to be shared have no real interest in their identities, or does it represent an important respect for patients' privacy?

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It may be no surprise that confidentiality tops the list of ethical enquiries received by the General Medical Council, the British Medical Association and the medical defence organizations. And that is why the General Medical Council has reviewed its advice and published new guidance (General Medical Council, 2009): to help doctors identify the relevant legal and ethical considerations, and to make decisions that respect patients' privacy, autonomy and choices and that also benefit the wider community of patients and the public.

Guidance, not rules

The guidance is issued in accordance with the General Medical Council's statutory power, as per the Medical Act 1983, 'to provide, in such manner as the Council think fit, advice for members of the medical profession on - (a) standards of professional conduct; (b) standards of professional performance; or (c) medical ethics'. It is guidance, not a rulebook, with scope for doctors to exercise judgement in applying the standards in their area of practice and to individual cases. That is not to suggest it is merely advisory: serious or persistent failure to follow the guidance without justification will put doctors' registration at risk.

But why does confidentiality matter? Not because Hippocrates (might have) said so; nor even simply because the law requires respect for private and family life (European Convention on Human Rights) and protection of data about living individuals (Data Protection Act 1998) (the duty of confidentiality [*A-G v Guardian Newspapers* 1988; *W v Egdell* 1990; *X v Y* 1998; *Campbell v MGN Limited* 2004] continues after a patient's death (*Lewis v Secretary of State for Health* 2008), even if data protection law does not). Rather it is because confidentiality is central to trust between patients and doctors. Without assurances about confidentiality, patients might not seek medical attention when they need it, or they might not share with doctors the sensitive personal information needed to provide safe, effective care. As the guidance says:

> **'There is a clear public interest in having a confidential medical service. The fact that people are encouraged to seek advice and treatment, including for communicable diseases, benefits society as a whole as well as the individual… However, there can also be a public interest in disclosing information: to protect individuals or society from risks of serious harm, such as serious communicable diseases or serious crime; or to enable medical research, education or other secondary uses of information that will benefit society over time.'**
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> **'Personal information may, therefore, be disclosed in the public interest, without patients' consent… if the benefits to an individual or to society of the disclosure outweigh both the public and the patient's interest in keeping the information confidential…' (General Medical Council, 2009)**

Four countries, endless variety

The General Medical Council's advice is for all doctors, whether they work in the NHS, or in the private or any other sector, regardless of specialty, and whether or not they routinely see patients. It is also for doctors in all four countries of the UK, where health policy and law are increasingly different. This difference is exemplified in the advice on disclosing information to protect competent adult patients, for example from domestic violence or elder abuse:

> **'It may be appropriate to encourage patients to consent to disclosures you consider necessary for their protection, and to warn them of the risks of refusing to consent; but you should usually abide by a competent adult patient's refusal to consent to disclosure, even if their decision leaves them, but nobody else, at risk of serious harm.' (General Medical Council, 2009)**

Respect for autonomy is increasingly regarded as preeminent among the conflicting principles underpinning ethical decision making, pushing paternalism (and perhaps beneficence) aside (Gillon, 2003). Certainly the law has generally appeared to favour this approach: respect is demanded for competent adult patients' refusal of life-prolonging treatment, and disclosure of confidential information in the face of a competent adult's refusal is usually only countenanced when there is a risk of serious harm to others. But the Adult Support and Protection (Scotland) Act 2007 requires health boards in Scotland to report to local authorities if they know or believe that an adult is at risk of harm and that action needs to be taken to protect them, even if the patient competently objects. There may be a tension here between law and ethics, but the guidance is clear that doctors must act in accordance with the law where they work.

Capacity, carers and consent

The disclosure of information about patients who lack capacity to make relevant decisions, or whose capacity is fluctuating, may be even more problematic. The General Medical Council's guidance emphasizes the importance of establishing with patients what information they want shared, with whom, and in what circumstances, while they are able to participate in meaningful discussion, so as to avoid misunderstandings, offence or inappropriate disclosures later on.

It can be very difficult for relatives and carers if a patient refuses to allow them access to private information, and it may hamper their ability to care for the patient. It can also be difficult for doctors to maintain effective relationships with both patients and their carers in particular, or to fulfil their duty to be 'sensitive and responsive in providing information and support' to relatives, carers, partners and others close to the patient (General Medical Council, 2006).

Decisions about disclosing confidential information about a patient who lacks capacity to consent should be made in that patient's best interests (Mental Capacity Act 2005) or for his/her benefit (Adults with Incapacity (Scotland) Act 2001), taking into account: whether the incapacity is permanent or temporary (and if the decision to disclose could wait until they regain capacity), any evidence of their previously expressed preferences, and the views of any proxy decision makers, others close to the patient, and the rest of the health-care team. A patient's partner, relatives or friends may be able to provide some insight into the patient's likely wishes, e.g. on whether their personal information should be used for teaching or research purposes. They will need information about the patient's condition in order to make a meaningful contribution to treatment decisions, too; and unless there is reason to think otherwise it is reasonable to assume that patients would want those closest to them to be kept informed of their general condition and prognosis. Confidential information about patients who lack capacity can also be disclosed in the public interest, e.g. to assist the police in the prosecution of serious crime in which the patient was involved. In any case, disclosure should be limited to what is relevant and necessary: it is rarely appropriate to disclose the whole record (General Medical Council, 2009).

Guidance on specific issues

Complementing the main guidance, the General Medical Council has published shorter, even more accessible, supplementary guidance on:

- Reporting concerns about patients to the Driver and Vehicle Licensing Agency
- Disclosing records for financial and administrative purposes
- Reporting gunshot and knife wounds
- Disclosing information about serious communicable diseases
- Disclosing information for insurance, employment and similar purposes
- Disclosing information for education and training purposes
- Responding to criticism in the press.

This guidance can be accessed via the General Medical Council's website (www.gmc-uk.org/confidentiality). It addresses some of the specific issues that regularly cause uncertainty, such as primary care organizations' access to records to verify Quality and Outcomes Framework payments, reporting knife injuries, and when and how doctors can counter inaccurate reporting in the media.

Informing a patient's partner that he/she is at risk of a sexually transmitted serious communicable disease is a controversial example of disclosure specifically permitted in the guidance, even if it risks others avoiding testing and treatment. But disclosure is only acceptable if there is a real risk to the partner (of transmission or non-treatment through ignorance) and the patient cannot be persuaded to tell his/her partner him-/herself. What if the patient is a young refugee who acquired human immunodeficiency virus (HIV) through parental abuse and who is now in an abusive sexual relationship with a man who refuses to use condoms? Should she be encouraged to tell him her status? Should the doctor tell him if she refuses? What might be the consequences of disclosure or a failure to disclose?

Research and other secondary uses

It isn't only the occasional disclosure about an individual patient that requires doctors to exercise their public interest balancing skills. Reflecting the House of Lords decision in the Source Informatics case [*R v Department of Health* 2001], the guidance is clear that anonymised information may be disclosed without consent, and that aggregated, anonymised or coded information or coded data should be used whenever practicable. That may be all that is required for many research or educational uses of data, but exceptionally it may not be practicable to anonymise or anonymised data just won't do. And while patients' express consent should be sought to use identifiable information for 'secondary uses', the age of records, problems in tracking down patients, and the possibility of introducing bias because of a low response rate or because particular groups of patients refuse or do not respond to requests to use their data, means that is not always workable either.

Disclosures for secondary uses are sometimes thought to be of little interest or concern to patients, but patients and the public trust doctors and believe they keep their medical information confidential (Singleton et al, 2007), and they expect explicit consent to be sought for the disclosure of their records to researchers (Armstrong et al, 2007). For some there is a strong sense 'ownership' of the information and that researchers must ask for access; most simply feel that permission should be sought, if only as a matter of courtesy or as an element of a relationship of trust (Singleton et al, 2007).

In addition to the infringement of patients' autonomy, there are both obvious and more subtle utilitarian arguments against unconsented disclosure if that leads patients to withhold information or avoid seeking medical assistance altogether: illness, including communicable diseases, may go untreated, and the very information researchers need may be lost or distorted.

In the period between the decision of the Court of Appeal in the Gillick case and that of the House of Lords [*Gillick v West Norfolk and Wisbech AHA* 1985], during which time doctors were required to tell children's parents about contraceptive advice and treatment sought, 'the number of females aged under 16 who sought advice on contraception fell from 1.7 per resident thousand to 1.2 per resident thousand, which was a striking and disturbing reduction. In addition, the rates of attendance at places where contraception advice and treatment were given did not return until 1988–89 (or until 1990 according to the Brook Organisation) to their previous levels prior to the Court of Appeal decision in December 1984' [*R (Axon) v Secretary of State for Health and Anon* 2006]. (See also *Z v Finland* 1997; Wellings and Kane, 1999; Jones, 2003.)

Researchers who want to access confidential information about patients in England and Wales should seek approval under section 251 of the NHS Act 2006 from the Ethics and Confidentiality Committee of the National Information Governance Board. The Ethics and Confidentiality Committee considers whether such access should be permitted in the interests of improving patient care or in the public interest, where anonymised information is not sufficient and where patient consent is not practicable. Doctors in Scotland and Northern Ireland can turn to Caldicott Guardians and the Privacy Advisory Committee respectively for advice, but must make their own decisions about whether disclosure is justified, bearing in mind the nature of the information sought, what use will be made of it, who will have access to it, how it will be protected and the potential for causing harm or distress to patients (General Medical Council, 2009). **BJHM**

Conflict of interest: Mr M Keegan: none; Ms R Levenson is a member of the Ethics and Confidentiality Committee of the National Information Governance Board. She is also an independent researcher and policy consultant working on health and social care issues.

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KEY POINTS

- Confidentiality is central to trust between doctors and patients. Without assurances about confidentiality, patients may be reluctant to seek medical attention or to give doctors the information they need in order to provide safe, effective care.
- The duty of confidentiality is important, but not absolute: confidential information can be disclosed if that is required by law, if the patient consents or if disclosure is justified in the public interest.
- The General Medical Council publishes guidance setting out the principles of confidentiality that doctors are expected to understand and follow, along with short guides to frequently encountered dilemmas, case studies and other learning materials.