

MIDNIGHT LAW

Disclosure of genetic information to a relative without a patient's consent (England & Wales)



SITUATION

A patient is admitted to ICU following a devastating brain injury. They have an inherited neurodegenerative condition, the details of which they have refused to disclose to their children. The patient dies without regaining consciousness. Do you owe a duty of care to the children to inform them of their genetic risk so breaching the patient's confidentiality?

POINTS TO CONSIDER

Patient confidentiality

- Doctors are under a legal and ethical duty to protect patients' personal information from improper disclosure.
- This duty of confidentiality continues after a patient's death, however, it is not absolute. It is balanced by a duty of disclosure including where disclosure is justified to protect others at risk from death or serious harm; although that level of risk is not defined.
- The genetic risk of inheriting a condition can be considered as familial information rather than being confidential to the index patient. General Data Protection Regulation (GDPR) considers genetic information as sensitive personal data.
- Clinicians need to balance the harms of disclosure with the benefits of relatives having information that may fundamentally affect life choices.
- The decision of whether to disclose is challenging and advice should be sought from experienced colleagues, a Caldicott or data guardian and the legal department. The rationale involved in reaching a decision should be clearly documented.
- Where possible, if information is to be disclosed, it should be done in such a way as to reduce the chance that the familial genetic information is seen to have come from the index patient.

The law

- There is no overarching law governing the disclosure of confidential information.
- The law governing the use and disclosure of personal information is complex involving common law, data protection law and human rights law.
- A High Court ruling found a claimant was owed a duty of care to balance her interest in being informed of her genetic risk against her father's and the public interest in maintaining confidentiality.
- The scope of that duty extended to any action undertaken in accordance with the outcome of the balancing exercise.
- The Court was clear that this was not a free-standing duty of disclosure or a broad duty of care owed to all relatives in respect of genetic information and was to be exercised following GMC guidance.

GUIDING PRINCIPLES

- (i) A duty of confidentiality continues after death but there are exceptions including where disclosure is justified to prevent others from a risk of death or serious harm.
- (ii) Clinicians need to balance the harms of disclosure with the benefits of relatives having information that may fundamentally affect life choices.
- (iii) The genetic risk of inheriting a condition can be considered as familial information rather than confidential to the patient
- (iv) The Court of Appeal has stated that, depending on the circumstances of the case, clinicians may have a duty to consider the interests of at-risk relatives.
- (v) The decision of whether to disclose is challenging and advice should be sought. The balance sheet drawn up to aid decision making should be documented in detail.
- (vi) Information should be disclosed in such a way as to reduce the chance that the familial genetic information is seen to have come from the index patient.

KNOW THE LAW

General Data Protection Regulation (GDPR)
Data Protection Act 2018
<https://www.bailii.org/ew/cases/EWHC/QB/2020/455.html>

FURTHER READING

1. Royal College of Physicians, Royal College of Pathologists and British Society for Genetic Medicine. Consent and confidentiality in genomic medicine: Guidance on the use of genetic and genomic information in the clinic. 3rd edition. Report of the Joint Committee on Genomics in Medicine. London: RCP, RCPATH and BSGM, 2019
2. General Medical Council. Confidentiality: Disclosing genetic and other shared information 73 – 76

