

MIDNIGHT LAW:

Disclosure of Genetic Information to a Relative without a Patient's Consent



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?

CONSIDERATIONS

Patient confidentiality

GMC guidance and case law states that your duty of confidentiality continues after a patient has died. However, there are circumstances when relevant information about the patient may be disclosed including where disclosure is justified in the public interest to protect others from a risk of death or serious harm.

Professional guidance

The General Data Protection Regulation (GDPR) defines personal data as "any information relating to an identified or identifiable person," and perceives genetic information as sensitive personal data.

For genetic information, the GMC states that if a patient refuses to disclose relevant information to relatives, clinicians need to balance their duty to make the care of their patient their first concern against their duty to help protect another person from serious harm. It suggests that doctors should not reveal the patient's identity when disclosing information to relatives, thus acknowledging that familial and individual information might be separable.

The law

English law, like professional guidelines, imposes a duty of confidentiality on clinicians and courts can direct Trusts to pay compensation to patients for breaching confidentiality.

A recent Court of Appeal ruling found that the 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 from experienced colleagues + the legal department. The balancing act involved in

KNOW THE LAW:

General Data Protection Regulation + Data Protection Act 2018
http://www.bailii.org/uk/cases/UKIT/2007/EA_2006_0090
<http://www.bailli.org/ew/cases/EWHC/QB/2020/455.html>

FURTHER READING:

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
General Medical Council. Confidentiality: Disclosing genetic and other shared information 73 - 76