

AMA Code of Medical Ethics

4.1.3 Third-Party Access to Genetic Information

The rapid pace of development and dissemination of genetic testing has made it possible to generate information about individuals across a wide and growing spectrum of genetic variations associated with disease risk. The prospect of access to and use of such information by third parties who have a stake in an individual's health raises ethical concerns about confidentiality and potentially inappropriate use of genetic information.

Patients who undergo genetic testing have a right to have their information kept in confidence, and a variety of state and federal laws prohibit discrimination by employers, insurers, and other third parties based on genetic information they obtain about an individual.

Physicians who provide and interpret genetic tests, or who maintain patient records that include the findings of genetic tests, have professional ethical obligations to:

- (a) Maintain the confidentiality of the patient's health information, including genetic information.
- (b) Release a patient's genetic information to third parties only with the patient's informed consent.
- (c) Decline to participate in genetic testing at the request of third parties (for example, for purposes of establishing health care or other benefits or coverage for the individual) except when at the patient's request and with their informed consent.

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