

AMA Code of Medical Ethics

4.1.1 Genetic Testing & Counseling

Genetic testing can provide valuable information to support informed decision making about personal health risks and care options as well as reproductive choices. The fact that genetic information carries implications for others to whom the individual is biologically related raises ethical challenges of balancing confidentiality against the well-being of others.

Because genetic contribution to disease can be complex and highly variable, interpreting findings and helping patients understand the implications for their health and health care requires special skill and attention.

Genetic testing is most appropriate when the results of testing will have meaningful impact on the patient's care. Physicians should not encourage testing unless there is effective therapy available to prevent or ameliorate the condition tested for. Whether a genetic test is performed to help diagnose an existing health condition, or to predict future health risks, or to provide information for managing a disease, it is important that the patient receives appropriate counseling.

Physicians who order genetic tests (individually or as part of a multi-test panel or large-scale sequencing) or who offer clinical genetic services should:

- (a) Have appropriate knowledge and expertise to counsel patients about heritable conditions, risks for disease, and implications for health management, and to interpret findings of individual genetic tests or collaborate with other health care professionals who can provide these services, such as licensed genetic counselors.
- (b) Adhere to standards of nondirective counseling and avoid imposing their personal moral values or judgment on the patient.
- (c) Discuss with the patient:
 - (i) what can and cannot be learned from the proposed genetic test(s) and reasons for and against testing, including the possibility of incidental findings. Physicians should ascertain whether the patient wishes to be informed about findings unrelated to the goal of testing;
 - (ii) medical and psychological implications for the individual's biological relatives;
 - (iii) circumstances under which the physician will expect the patient to notify biological relatives of test findings; and
 - (iv) that the physician will be available to assist in communicating with relatives.
- (d) Obtain the individual's informed consent for the specific test or tests to be performed.
- (e) Ensure that appropriate measures are taken to protect the confidentiality of the patient's and their biological relatives' genetic information.