

Cancer Predisposition Genetic Testing and Risk Assessment Counseling

The ability to identify individuals who are at increased risk for developing cancer because of an inherited altered (mutated) cancer predisposition gene is possible through cancer predisposition genetic testing. However, while providing the capability to target those individuals who might benefit from intensive screening and preventive services, cancer predisposition genetic testing also raises ethical, legal, and social issues associated with revealing one's genetic makeup.

It Is the Position of ONS That

- Risk assessment counseling and cancer predisposition genetic testing are components of comprehensive cancer care.
- All healthcare providers offering these services to patients and family members must have educational preparation in both human genetic principles and oncology.
- Cancer predisposition genetic testing requires informed consent and must include pre- and post-test counseling by qualified individuals (e.g., advanced practice oncology nurses or oncologists with specialized education in hereditary cancer genetics, certified genetic counselors with specialized training in oncology).
- Ethical principles of beneficence, nonmaleficence, respect for autonomy, and justice must form the foundation for counseling services, guide the development of standards of care in cancer genetic counseling, and be included in criteria used to identify potential problems arising from cancer predisposition genetic testing and the counseling process.
- Comprehensive cancer genetic counseling must occur in a manner consistent with individual cultural and healthcare beliefs.
- Efforts must be made to include family members in the counseling process.
- Legislation to provide protection from genetic discrimination in both employment and insurance and to provide reimbursement of and access to genetic counseling, cancer predisposition genetic testing services, and appropriate medical management must be introduced and implemented.
- Educational resources for healthcare providers, those individuals at increased risk, and the lay public must be developed.

- A research plan related to all aspects of cancer genetics, including the efficacy of programs for prevention and early detection, the psychological impact of cancer predisposition genetic testing, and long-term outcomes of testing and risk management strategies must be developed.
- Efforts to improve the standardization and regulation of laboratories that provide cancer predisposition genetic testing must be undertaken.

Background

The rapid evolution of cancer predisposition genetic testing technologies has led to an increased number of individuals and laboratories involved in cancer predisposition genetic testing. Although cancer predisposition genetic testing currently is available commercially and through investigative research settings, access to testing and counseling services is limited because of cost and reimbursement issues. Limited data are available regarding the psychosocial impact of testing as well as the optimal screening, preventive, and surveillance measures for individuals with hereditary predisposition to develop cancer. Informed consent is crucial to an individual's understanding of the risks and benefits of cancer predisposition genetic testing. It is essential that healthcare professionals who are knowledgeable about all areas of genetic cancer risk counseling provide pre- and post-test counseling for both comprehensive patient care and as a component of the informed consent process.

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To obtain copies of the ONS position "Cancer Predisposition Genetic Testing and Risk Assessment Counseling," contact the Customer Service Center at the ONS National Office at 501 Holiday Drive, Pittsburgh, PA 15220-2749 (412-921-7373). Positions also may be downloaded from ONS Online (www.ons.org).