


Upgrade: **4Genetics** version 20.17

**Clinical Practice Guidelines:  
The Role of the Genetic Counselor**


Robert Pilarski, MS, LGC, MSW  
November 10, 2017



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## Disclosures

- I have no conflicts of interest to disclose.




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## Objectives

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- The participant will be able to:
  - Identify the main purposes of clinical practice guidelines
  - Describe the processes by which practice guidelines are established
  - Summarize the roles genetic counselors have played in establishing various practice guidelines



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## Clinical Practice Guidelines (CPGs)

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The Institute of Medicine defines **clinical practice guidelines** as "statements that include recommendations, intended to optimize patient care, that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options"

- *Clinical Practice Guidelines We Can Trust*, IOM 2011



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### Practice Guidelines - Two Components

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- The foundation is a systematic review of the research evidence bearing on a clinical question, focused on the strength of the evidence on which clinical decision-making for that condition is based.
- A set of recommendations, involving both the evidence and value judgments regarding benefits and harms of alternative care options, addressing how patients with that condition should be managed, everything else being equal



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### National Guideline Clearinghouse CPG Criteria

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(Agency for Healthcare Research and Quality)

- Are produced under the auspices of a medical specialty association, relevant professional society, public or private organization, government agency or health care organization or plan
- Are based on a systematic review and grading of the evidence [by a panel of experts]
- Contain systematically developed recommendations intended to optimize patient care and assist health care practitioners and patients to make decisions about appropriate health care
- Contain an assessment of the benefits and harms of recommended care and alternative care options.



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### Purposes of Clinical Practice Guidelines

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- Generally intended for use by healthcare providers to improve patient care.
- Also used by Insurers to set policies on payment for care.
- Used by administrators to set criteria to assess performance and care delivery.
- Lawyers may use in malpractice cases.



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### Guidelines, Recommendations, and Consensus Conferences, Oh My!

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There are various ways in which practice and policy are set, and this talk will address GC involvement in both official “practice guideline”-setting groups and other groups and organizations making recommendations affecting genetic practice, whatever they are called.



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## Why get involved?

**It provides an opportunity to influence genetics practice, and the role of genetic counselors in that practice, at a national level.**

(It also looks really great on your resume, helps you get recognized as an expert, and opens up opportunities for further involvement.)



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## Ways of Getting Involved

1. NSGC-specific practice guidelines
2. As a GC-expert on a national guidelines panel.
  - NCCN High Risk cancer guidelines
  - Huntington Disease Association guidelines
  - Heart Failure/ACMG guidelines
3. As an official NSGC representative to a guidelines panel
  - Commission on Cancer
  - NAPBC
4. As an NSGC or expert-GC representative on groups established to influence genetics practice.
  - Institute of Medicine



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## NSGC Evidence-Based Practice Guidelines



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## NSGC Practice Guidelines Committee


- Oversees development of NSGC's evidence-based practice guidelines.
- Accepts suggestions for new guidelines from the membership.
- Follows the criteria of the National Guidelines Clearinghouse
- Has developed a manual to assist in guideline development
  - Systematic review group
  - Guideline writing group
- Includes a period for NSGC member comment
- Requires COI Disclosure



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### NSGC Practice Guidelines Address:


- Recommended use of specific genetic information in healthcare, such as:
  - Referral practices
  - Disease screening
  - Predictive testing
  - Disease diagnosis
  - Treatment
- Access to, assessment of, or delivery of, genetic counseling services


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### Current NSGC Practice Guidelines

- Cancer Predisposition Evaluation
- Consanguinity (Reaffirmed 2014)
- Cystic Fibrosis
- Fabry Disease
- Fragile X Syndrome
- Pedigree Nomenclature (Reaffirmed 2014)
- Prenatal Screening


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### NSGC Practice Guidelines in Development

- Epilepsy
- Hypertrophic Cardiomyopathy
- Telegenetics

#### NSGC Practice Resources

(Less rigorous. Address genetic counseling best practices but do not require evidence-based recommendations)

- Alzheimer Disease
- Down syndrome


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## GC experts on national guidelines panels


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### Involvement as a GC Expert

- Serving as an individual genetic counselor with specific expertise in an area/issue:
  - NCCN High Risk Breast/Ovarian (multiple GCs) and High Risk Colon Cancer (Heather Hampel) Guidelines
  - ACMG Recommendations for Reporting Incidental Findings (Kelly Ormond, Julianne O’Daniel)
  - HD Society of America’s “Genetic Testing Protocol for Huntington’s Disease” (Robin Bennet, Allison Daley, Mara Sifry-Platt)
  - ACMG/Heart Failure Society joint practice resource/guideline on Hypertrophic Cardiomyopathy (in development) (Ana Morales)



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### National Comprehensive Cancer Network

- Not-for-profit alliance of 27 leading cancer centers.
- Established in 1995 to develop and institute standards of care for cancer treatment.
- Develops resources for the numerous stakeholders in the health care delivery system.
  - “NCCN recognizes the significance of creating clinical practice guidelines appropriate for use by patients, clinicians, and other health care decision-makers.”



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### NCCN Guidelines

- Intended to document evidence-based, consensus-driven management to ensure that all patients receive preventive, diagnostic, treatment, and supportive services that are most likely to lead to optimal outcomes.
- Their development is an ongoing and iterative process, which is based on a critical review of the best available evidence and derivation of recommendations by a multidisciplinary panel of experts in the field of cancer.
- Intended to assist in the decision-making process of individuals involved in cancer care—including physicians, nurses, pharmacists, payers, patients and their families...



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### NCCN Guidelines – Started in 1996

- Treatment of Cancer by Site (30)
  - Covers 97% of cancers affected patients in the US
- Supportive Care (11)
- Detection, Prevention & Risk Reduction (6)
  - Genetic: Colorectal Cancer Screening
  - **Genetic/Familial High-Risk Assessment: Breast and Ovarian** (first published in 1999)



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## NCCN Genetic/Familial High-Risk Assessment: Breast and Ovarian

The James  
THE OHIO STATE UNIVERSITY  
WEXNER MEDICAL CENTER

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### NCCN Guidelines Version 1.2018 Panel Members Genetic/Familial High-Risk Assessment: Breast and Ovarian

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† Medical oncology  
‡ Cancer/Medical genetics  
§ Internal medicine  
¶ Hematology/Hematology oncology  
|| Gynecologic oncology/Gynecology  
# Breast surgical oncology  
& Public health and preventive medicine  
\* Patient advocacy  
†† Discussion Writing Committee Member

## HBOC Guidelines Set Criteria for:

- Who to refer for genetic evaluation and counseling.
- Who should get genetic testing.
- Clinical management of individuals with gene mutations
- Clinical management of individuals with a clinical diagnosis/presentation.

Many insurance companies base their coverage for cancer genetic testing and cancer screening on NCCN guidelines.

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### NCCN Guidelines Version 1.2017 Panel Members Genetic/Familial High-Risk Assessment: Colorectal

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# Gastroenterology  
‡ Cancer genetics  
§ Internal medicine  
† Medical oncology  
¶ Pathology  
# Surgery/Surgical oncology  
\* Patient advocacy  
†† Discussion Writing Committee Member

## Involvement in Non-NSGC Guidelines

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**ACMG POLICY STATEMENT** | **Genetics in Medicine**

### ACMG recommendations for reporting of incidental findings in clinical exome and genome sequencing

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Genetics in Medicine 2013;15:565-574

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**Huntington's Disease Society of America**

### GENETIC TESTING PROTOCOL FOR HUNTINGTON'S DISEASE

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This revision of the "Genetic Testing Protocol for Huntington's Disease" reflects the collaboration and contributions of many people including:

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## Official NSGC representatives on guidelines panels

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## Commission on Cancer

### Cancer Risk Assessment and Genetics Testing Standard



## Commission on Cancer (CoC)

- Consortium of professional organizations dedicated to improving survival and quality of life for cancer patients through standard-setting, prevention, research, education, and the monitoring of comprehensive quality care.
  - Comprised of 100 individuals with a mix from ACoS and 50+ Member Organization affiliates
  - 70% of all cancer pts receive care at CoC accredited institution (~1500 institutions in US and Puerto Rico)
  - NSGC has been a member organization since 2004



## Background

- 2009 – CoC members were charged with updating the standards (last update 2004)
- Chair of this committee specifically believed that on-site genetic counseling should be a requirement at any CoC accredited cancer program
- Goals in creating the standard:
  - Differentiate cancer risk assessment/genetic counseling (CRA/GC) and genetic testing (GT)
  - Identify the minimum essential elements needed when performing a CRA/GC and GT
  - Identify who at a CoC-accredited institution is qualified to perform CRA/GC and GT




## Cancer Risk Assessment and Genetic Counseling

- **S 2.3** Cancer risk assessment, genetic counseling, and testing services are provided to patients either on site or by referral, by a qualified genetics professional







**Pretest Counseling**

- Collecting relevant information needed to assess a patient's personal and family medical history
  - A 3- to 4-generation pedigree, including detailed medical information about the patient's first-, second-, and third-degree relatives should be obtained. Gathering information about paternal and maternal family history, ancestry/ethnicity, and consanguinity, as available, is necessary.
- Evaluating the patient's risk
  - One aspect of risk assessment is discussing the absolute risk that the patient will develop a specific type of cancer or cancers based on the family history. The second aspect is the risk that the patient carries a heritable or germline mutation in a cancer susceptibility gene.
- Performing a psychosocial assessment
- Educating the patient about the suspected hereditary cancer syndrome, if appropriate
  - The provider reviews and discusses with the patient the cancer risks associated with gene mutations, including basic concepts such as genes and inheritance patterns and more advanced concepts of penetrance and variable expressivity and the possibility of genetic heterogeneity.
- Obtaining informed consent for genetic testing (if genetic testing is recommended).

**Posttest Counseling**

- Disclosure of the results and posttest counseling include a discussion of the results, significance and impact of the test results, medical management options, informing other relatives, future contact, and available resources. The test results and interpretation will be communicated to the provider. Guidelines and recommendations for cancer risk assessment and genetic counseling for hereditary cancer syndromes are available from the Agency for Healthcare Research and Quality (AHRQ) and the NCCN.

**SPECIFICATIONS BY CATEGORY**

All programs fulfill the standard as written.

**DOCUMENTATION**

The program completes the SAR.

During the on-site visit, the surveyor will discuss the process for providing cancer risk assessment and genetic counseling services either on-site or by referral.

**MEASURING COMPLIANCE**

**Rating**

(1) **Compliance:** The program fulfills the following criterion:

Cancer risk assessment, genetic counseling, and testing services are provided to patients either on-site or by referral, by a qualified genetics professional.

(5) **Noncompliance:** The program does not fulfill the following criterion:

Cancer risk assessment, genetic counseling, and testing services are provided to patients either on-site or by referral, by a qualified genetics professional.

**STANDARD 2.3 Risk Assessment and Genetic Counseling**

Cancer risk assessment, genetic counseling, and testing services are provided to patients either on-site or by referral, by a qualified genetics professional.

**DEFINITION AND REQUIREMENTS**

Cancer risk assessment and genetic counseling are the processes to identify and counsel people at risk for familial or hereditary cancer syndromes. The purposes of genetic counseling are to educate patients about their chance of developing cancers, help them obtain personal meaning from cancer genetic information, and empower them to make educated, informed decisions about genetic testing, cancer screening, and cancer prevention. Identifying patients at increased risk of developing cancer because of a family history of cancer or a known hereditary cancer syndrome can have dramatic effects on early detection and cancer outcome. For this reason, cancer risk assessment and genetic counseling are rapidly becoming standards of care for patients with personal and/or family history of cancer who are at high risk of having a hereditary syndrome.

The program provides cancer risk assessment and genetic counseling on-site or by referral to another facility or community-based organization.

Cancer risk assessment and genetic counseling are performed by a cancer genetics professional who has extensive experience and educational background in genetics, cancer genetics, counseling, and hereditary cancer syndromes to provide accurate risk assessment and empathetic genetic counseling to patients with cancer and their families.

Cancer risk assessment and the potential for referral may be discussed as part of the multidisciplinary cancer conference.

Genetics professionals include people with the following:

- An American Board of Genetic Counseling (ABGC) or American Board of Medical Genetics (ABMG) board-certified/board-eligible or (in some states) a licensed genetic counselor
- An American College of Medical Genetics physician board certified in medical genetics
- A Genetics Clinical Nurse (GCN) or an Advanced Practice Nurse in Genetics (APNG), credentialed through the Genetics Nursing Credentialing Commission (GNCC). Credentialing is obtained through successful completion of a professional portfolio review process.
- An advanced practice oncology nurse who is prepared at the graduate level (master or doctorate) with specialized education in cancer genetics and hereditary cancer predisposition syndromes\*. Certification by the Oncology Nursing Certification Corporation is preferred.
- A board-certified physician with experience in cancer genetics (defined as providing cancer risk assessment on a regular basis).


\*Please note, specialized training in cancer genetics should be ongoing; educational seminars offered by commercial laboratories about how to perform genetic testing are not considered adequate training for cancer risk assessment and genetic counseling.

The Cancer Committee defines the appropriate individuals who will provide risk assessment and counseling for major cancer disease sites (such as breast and colorectal). In addition, the programs not having immediate access to formal genetic counseling services should identify resources for referral.

Cancer risk assessment and genetic counseling involve pretest and posttest counseling. At a minimum, this counseling includes the following:

**NAPBC**

- Primary national organization providing accreditation to Breast Centers:
  - “Accreditation by the National Accreditation Program for Breast Centers (NAPBC) is granted only to those centers that have voluntarily committed to provide the highest quality care to patients with diseases of the breast. Each center must undergo a rigorous evaluation and review of its performance and compliance with the NAPBC standards.”
- NAPBC accreditation is highly sought after by Breast Centers.




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**NAPBC Board Member Organizations**

- American Board of Surgery (ABS)
- American Cancer Society (ACS)
- American College of Radiology Breast Imaging Commission (ACRBIC)
- American Cancer Radiology Imaging Network (ACRIN)
- American College of Surgeons (ACoS)
- American Institute for Radiologic Pathology (AIRP)
- American Society for Radiation Oncology (ASTRO)
- American Society of Breast Disease (ASBD)
- American Society of Breast Surgeons (ASBS)
- American Society of Clinical Oncology (ASCO)
- American Society of Plastic Surgeons (ASPS)
- Association of Cancer Executives (ACE)
- Association of Oncology Social Work (AOSW)
- College of American Pathologists (CAP)
- National Cancer Registrars Association (NCRA)
- National Consortium of Breast Centers (NCBC)
- National Society of Genetic Counselors (NSGC)**
- Oncology Nursing Society (ONS)
- Society of Breast Imaging (SBI)
- Society of Surgical Oncology (SSO)



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National Accreditation Program  
for Breast Centers

ACCREDITATION  
makes a difference

NAPBC  
Standards Manual  
2014 EDITION

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### Breast Center Components

The following is an outline of the Breast Center Components required for accreditation by the NAPBC, and the recommended breast services within each component. See specific standards for survey purposes.

- Imaging**
  - Screening mammography (digital or analog)
  - Diagnostic mammography (additional views beyond all standard mammograms)
  - Ultrasound
  - Specialized
- Needle Biopsy**
  - Needle biopsy - percutaneous-guided
  - Image guided - stereotactic
  - Image guided - ultrasound
  - Image guided - MRI
- Pathology**
  - Report Comprehensive CAP Practices
  - Biological/Pathology Consultation
  - Prognostic and predictive indicators
  - Same day/next business day
- Interdisciplinary Conference**
  - History and findings
  - Imaging studies
  - Pathology
  - Pre and post-treatment interdisciplinary discussion
- Patient Navigation**
  - Facilitates navigation through system for the patient
- Genetic Evaluation and Management**
  - Genetic risk assessment
  - Genetic counseling
  - Genetic testing
- Medical Oncology Consultation/Treatment**
  - Non-small cell
  - Chemotherapy
  - Biologics
  - Chemotherapy
- Radiation Oncology Consultation/Treatment**
  - Whole breast irradiation with or without boost
  - Regional node irradiation
  - Partial breast irradiation treatment or ancillary
  - Proton radiation for breast or systemic metastases
  - Stereotactic irradiation for localized or breast-conserving mastectomies
- Data Management**
  - Data collection and aggregation
- Research**
  - Cooperative trials
  - Institutional review board (IRB) approval
  - Industry sponsored trials
- Education, Support, and Rehabilitation**
  - Educational needs assessment of care team (treatment, staging, surveillance)
  - Psychosocial support
    - Individual support
    - Family support
    - Support groups
  - Symptom management
  - Physical therapy (for axillary, lymphedema risk reduction, posture, and management, shoulder ROM)

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## Genetic Evaluation and Management

Standard 2.16 Cancer risk assessment, genetic counseling and genetic testing services are provided or referred.

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Genetic counseling is provided by:

- An American Board of Genetic Counseling (ABGC) board certified/board eligible or (in some states) a licensed genetic counselor.
- An American College of Medical Genetics (ACMG) physician board certified in medical genetics.
- An advanced practice oncology nurse (APON) that is prepared at the graduate level (master's or doctorate) with specialized education in cancer genetics and hereditary cancer predisposition syndromes\*; certification by the Oncology Nursing Certification Corporation as AOCNP or AOCNS is preferred.
- A Genetics Clinical Nurse (GCN) credentialed through the Genetics Nursing Credentialing Commission (GNCC). GNC credentialing is obtained through successful completion of a professional portfolio review process.
- A board certified/board eligible physician or other trained healthcare professional with expertise and experience in cancer genetics (defined as providing cancer risk assessment on a regular basis) employing a model that includes both pre-test and post-test counseling.

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NSGC or expert GC  
representative on groups  
established to influence  
genetics practice.



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## Involvement in Policy Guidelines

US Dept of HHS Secretary in 1999 established the Secretary's Advisory Committee on Genetic Testing (SACGT).

- Chartered to help the department formulate policies on the development, validation and regulation of genetic tests, particularly DNA-based diagnostics.
- Members were selected from nearly 200 nominees who have distinguished themselves in the areas of genetic testing, medical genetics, genetic counseling, primary health care, public health, clinical laboratory management, diagnostic technology, ethics, law, psychology, social sciences, and patient/consumer advocacy.
- NSGC rep was Ann Happ Boldt, MS, CGC



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## Involvement in Policy Guidelines

Institute of Medicine/National Academy of Sciences  
Roundtable on Genomics and Precision Health

- Focuses on examining issues in genomics with various stakeholders at the national level.
- Holds public workshops to illuminate specific issues
- Does not specifically set guidelines.
- Cathy Wicklund, MS, CGC



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## Conclusions

- Practice guidelines and similar documents play important roles in setting policy and practice standards, determining who participates in that practice, and whether insurance will cover it.
- Genetic counselors can and should play an essential role in the process of setting genetics practice guidelines.
- There are multiple ways and levels at which counselors can participate in this process.



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### So How do I Get Involved?

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- Develop expertise.
- Be aware of policy and practice developments in your field.
- Volunteer!

