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American Society of Clinical Oncology Expert Statement: Collection and Use of a Cancer Family History for Oncology Providers

Karen H. Lu, Marie E. Wood, Molly Daniels, Cathy Burke, James Ford, Noah D. Kauff, Wendy Kohlmann, Noralane M. Lindor, Therese M. Mulvey, Linda Robinson, Wendy S. Rubinstein, Elena M. Stoffel, Carrie Snyder, Sapna Syngal, Janette K. Merrill, Dana Swartzberg Wollins, and Kevin S. Hughes

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Karen H. Lu, Molly Daniels, and Cathy Burke, MD Anderson Cancer Center, Houston; Linda Robinson, Simmons Comprehensive Cancer Center, Dallas, TX; Marie E. Wood, University of Vermont, Burlington, VT; James Ford, Stanford University Medical Center, Stanford, CA; Noah D. Kauff, Memorial Sloan-Kettering Cancer Center, New York, NY; Wendy Kohlmann, Huntsman Cancer Institute, University of Utah, Salt Lake City, UT; Noralane M. Lindor, Mayo Clinic, Scottsdale, AZ; Therese M. Mulvey, Southcoast Centers for Cancer Care, Fall River; Sapna Syngal, Dana-Farber Cancer Institute, Brigham and Women's Hospital; Kevin S. Hughes, Avon Comprehensive Breast Evaluation Center, Massachusetts General Hospital, Boston, MA; Wendy Rubinstein, National Center for Biotechnology Information, National Library of Medicine, National Institutes of Health, Bethesda, MD; Elena M. Stoffel, University of Michigan, Ann Arbor, MI; Carrie Snyder, Creighton University, Omaha, NE; and Janette K. Merrill and Dana Swartzberg Wollins, American Society of Clinical Oncology, Alexandria, VA.

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K.H.L. and M.E.W. contributed equally to this work.

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Corresponding author: Marie Wood, MD, University of Vermont, Hem/Onc, Given E214, 89 Beaumont, Burlington, VT 05405, e-mail: marie.wood@uvm.edu.

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INTRODUCTION

Approximately 5% to 10% of cancers are attributable to a hereditary cancer predisposition syndrome. Identifying those patients with cancer who have an inherited cancer predisposition syndrome has significant benefit both to the patient and to at-risk relatives. In addition, oncology patients' short- and long-term management can be personalized based on their genetic status. For example, in the short term, *BRCA1/BRCA2*-positive genetic test results can affect surgical decisions and may soon have an impact on systemic treatment options. In the long term, oncology patients' survivorship plans can be tailored to incorporate surveillance and prevention for their increased risk of second malignancies. Furthermore, the ability to perform predictive genetic testing on patients' family members results in a more precise risk assessment and initiation of appropriate screening and prevention strategies.

Family history is key to the identification of those individuals who have an inherited predisposition to malignancy or who are at increased risk for additional primary cancers. The goals of any cancer family history should be to provide enough information to make a preliminary determination of the risk of a familial predisposition and to develop a preliminary management plan. A cancer family history taken at the first visit with the oncology provider can raise the suspicion of a hereditary cancer syndrome and prompt further investigation. After the initial visit, the ongoing relationship between the oncologist and the patient provides multiple opportunities for reassessment and updating of family history. This can prompt changes in recommended cancer screening. Additionally, the field of hereditary cancer predisposition is advancing rapidly. The long-term relationship between the oncologist and cancer survivor affords repeated opportunities for reassessment and recognition of newly defined cancer susceptibility genes and new opportunities for more advanced genetic testing that may apply to patients who have previously undergone genetic testing.[1]

Not only is hereditary risk assessment part of good oncology care, but there is also an increasing focus on the area of quality improvement with regard to the provision of genetic testing and counseling services. For example, the American College of Surgeons Commission on Cancer (CoC) grants accreditation only to facilities that are committed to excellence in cancer care and are able to comply with established CoC standards. The 2012 CoC program standards require that cancer risk assessment, genetic counseling, and testing services be provided to patients either on site or by referral by a qualified genetics professional. Furthermore, the American Society of Clinical Oncology (ASCO) Quality Oncology Practice Initiative (QOPI) includes measures regarding the collection and interpretation of cancer family histories and whether appropriate testing was ordered.

ASCO has taken a lead in providing guidance and education regarding identification and management of individuals with inherited predisposition to malignancy. In 1996, ASCO published a policy statement on genetic testing for cancer susceptibility to foster expanded access to medical care for at-risk patients and their families, as well as to enhance continued advances in the quality of that care.[2] This statement was updated in 2003 and again in 2010.[3,4] Over the last two decades, ASCO has developed two editions of an educational syllabus (ASCO Curriculum: Cancer Genetics and Cancer Susceptibility Testing), has held numerous workshops and symposia, and has fostered a growing number of online education modules at ASCO University (http://university.asco.org/).

Over the last several years, ASCO has assisted oncology professionals in responsibly integrating genetic testing into clinical oncology practice. A primary objective of this work has been to increase oncologists' core knowledge about hereditary cancer susceptibility syndromes, methods of cancer risk

assessment and risk management, and risks and benefits of genetic testing. A challenge in developing guidance for practicing oncologists in this area is that there is no clear evidence base from which to define how a family history should be taken or what constitutes the right amount of information for an initial cancer screening family history. To address this need, the ASCO Cancer Genetics Subcommittee, under the auspices of the Cancer Prevention Committee, has developed this statement for oncology providers to

- Define a minimum cancer family history
- Provide guidance regarding interpretation and next steps
- Identify current barriers to accurate family history taking and interpretation

To be clear, this consensus statement does not formulate specific guidelines for referral but seeks to provide clarification to the practicing oncology provider and other specialists on how and what to collect for a cancer family history and how to interpret the family history in the context of other information. To develop this statement, the Cancer Genetics Subcommittee convened a group of 15 experts in the areas of oncology, cancer genetics, and genetic counseling. A consensus conference was held in February 2012, and the deliberations from this meeting were used by the Cancer Genetics Subcommittee to generate this statement.

DEFINITION OF AN ADEQUATE FAMILY HISTORY

Family history information, in combination with the patient's personal history of cancer, should allow the oncology provider to determine whether the patient may have a hereditary cancer susceptibility syndrome, benefit from genetic counseling, and be a candidate for genetic testing for cancer susceptibility genes or may not be a candidate for genetic testing for known susceptibility genes but still requires more intensive follow-up than a patient with sporadic cancer.

The gold-standard family history is the comprehensive, three-generation pedigree used in medical genetics, genetic counseling, and research settings.[5] However, this evaluation is labor intensive and thus unlikely to be obtained for every patient in a busy clinical oncology practice.[6] Another important consideration is that reported family history is most accurate in close relatives and loses accuracy in more distant relatives.[7-9] A National Institutes of Health consensus conference regarding adequate family history in the primary care setting identified the need for a "parsimonious series of questions (key elements) for use as a family history screening tool."[5p18] Family history information should be sufficient to meet the goals stated here without imposing an impractical level of detail.

For the most part, hereditary cancer predisposition syndromes exhibit autosomal-dominant inheritance and high penetrance. In the context of this inheritance pattern, family history of cancer in close relatives is most relevant. Guidelines for consideration of genetic risk assessment, such as the National Comprehensive Cancer Network breast cancer genetic risk assessment guidelines[10] and the Society of Gynecologic Oncologists/American College of Obstetricians and Gynecologists hereditary breast cancer and Lynch syndrome referral criteria,[11-13] focus on first- and second-degree relatives, although they may optionally incorporate family history in third-degree relatives. For some individuals, the family history of cancer does not meet criteria for a hereditary cancer syndrome but may warrant changes in cancer screening. For individuals without cancer (or individuals with cancer who are at risk for a second primary cancer), risk can be estimated using minimal family history information. In the case of breast cancer, risk can be estimated using models such as the Claus model (which incorporates first- and second-degree family history information and age at cancer diagnosis). This and other models can be used to help guide decisions regarding addition of screening breast magnetic resonance imaging and consideration of chemoprevention.[14] In addition, colorectal cancer screening recommendations can be derived from family history of colorectal cancer.[15] Thus, family history of cancer in first- and second-degree relatives is often sufficient to assess a patient's empiric risk of common cancers or a patient's risk of a second primary cancer. Relatives' age at cancer diagnosis should also be assessed because this factors into both genetic risk assessment guidelines as well as empiric cancer screening recommendations. Maternal and paternal lineages should be assessed separately. Even for sex-specific cancers such as breast and ovarian cancers, both paternal and maternal lineages require evaluation because autosomal-dominant transmission by definition can come through the father or the mother.

MINIMUM FAMILY HISTORY FOR INDIVIDUALS WITH CANCER

ASCO recommends that the minimum adequate family history for patients with cancer be defined as family history of cancer in first- and second-degree relatives. First-degree relatives are parents, children, and full siblings. Second-degree relatives are grandparents, aunts/uncles, nieces/nephews, grandchildren, and half siblings. For each relative with cancer, the following should be recorded:

- Type of primary cancer(s)
- Age at diagnosis of each primary cancer
- Lineage (maternal and/or paternal)

Patients should be asked if there is a known hereditary cancer predisposition syndrome, prior genetic testing, and for any information regarding ethnicity that may be relevant. For example, individuals of Jewish ancestry (particularly Ashkenazi Jewish ancestry) have a higher background prevalence of *BRCA1* and *BRCA2* mutations than the general population.[16,17] Therefore, patients with breast and/or ovarian cancers should be specifically asked if they have any Jewish ancestry on either the maternal or paternal side. If so, a much lower threshold for testing should be adopted. The elements of a minimum family history for individuals with cancer are summarized in Table 1.

Table 1. Recommended Key Elements for Minimum Adequate Cancer Family History

First-degree relatives: siblings, parents, children
Second-degree relatives: grandparents, aunts, uncles, grandchildren, nieces, nephews, half siblings
Both maternal and paternal sides
Ethnicity
For each cancer case in the family, establish:
Age at cancer diagnosis
Type of primary cancer
Results of any cancer predisposition testing in any relative

NOTE. Family history should be taken at diagnosis and updated periodically.

Table 2. Cancers for Which Genetic Counseling and Testing Should Be Considered, Even in Absence of Family History*

Tumor Diagnosis	Genetic Loci
Common adult cancers	
Triple-negative (ER/PR/HER2-neu negative) breast cancer, particularly if diagnosed at age < 60 years[20]	*BRCA1/BRCA2*
Epithelial ovarian, fallopian tube, or primary peritoneal cancer (most commonly, high-grade serous histology)[21]	*BRCA1/BRCA2*
Colorectal cancer demonstrating mismatch repair deficiency (via tumor studies including microsatellite instability analysis and/or immunohistochemistry, excluding known somatic causes including hypermethylation of *MLH1* promoter and somatic *BRAF* mutation)[22,23]	*MLH1/MSH2/MSH6/PMS2/EPCAM*
Endometrial cancer demonstrating mismatch repair deficiency (via tumor studies including microsatellite instability analysis and/or immunohistochemistry, excluding known somatic causes including hypermethylation of *MLH1* promoter[24]	*MLH1/MSH2/MSH6/PMS2*
Rare tumors	
Adrenocortical carcinoma,[25] choroid plexus carcinoma[26]	*TP53*
Pheochromocytoma, paraganglioma[27]	*VHL*, *RET*, multiple *SDH* loci
Retinal or cerebellar hemangioblastoma, endolymphatic sac tumor[28]	*VHL*
Medullary thyroid cancer[29]	*RET*
Pediatric cancers	
Retinoblastoma[28,30]	*RB1*
Optic pathway tumor, malignant peripheral nerve sheath tumor, juvenile myelomonocytic leukemia[28]	*NF1*
Atypical teratoid/rhabdoid tumor[28]	*INI1/SMARCB1*
Acoustic or vestibular schwannomas[28]	*NF2*
Pulmonary pleuroblastoma[31]	*DICER1*
Multiple gastrointestinal polyps[32]	*BMPR1A, SMAD4, EPCAM, MLH1, MSH2, MSH6, PMS2, PTEN, APC, STK11, MYH*

Abbreviations: ER, estrogen receptor; HER2, human epidermal growth factor receptor 2; PR, progesterone receptor.
*The cancer types included here are examples of those more commonly encountered by the oncology provider. This list is not intended to be exhaustive and should not be interpreted as guidance to limit the consideration of additional counseling or testing to only those identified. Furthermore, as an increasing number of genes become discovered, this list is likely to change with time.

TIMING OF FAMILY HISTORY TAKING

Cancer family history information should be gathered and assessed at the initial visit and should be reassessed periodically. Reassessment consists of both elicitation of any new family history information from the patient as well as clinician re-evaluation of that family history in light of new medical information and technologic advances. Reassessment is important because cancer family histories change significantly over time.[18] Patients may also know more about their family history once they have moved beyond the stress of their initial diagnosis and are more able to actively engage in gathering this information, and conversation surrounding their diagnosis has occurred within the family. Points at which the patient and oncologist are engaged in decision making or planning are opportune moments to reassess the family history. These key time points include: the end of the first phase of therapy, the time of post-treatment summary, and the beginning of post-treatment survivorship. The point of transition from active treatment to post-treatment survivorship is of particular importance because long-term screening plans and prevention are discussed, patient concerns may shift toward welfare of their family, and patients are open to education.[1]

INTERPRETATION OF FAMILY HISTORY AND INTEGRATION OF RISK ASSESSMENT INTO PRACTICE

The recommendations described here regarding the minimum family history to be obtained by oncology providers will enable a preliminary cancer risk assessment. Red flags for hereditary cancer predisposition include early age of onset of cancer, multiple affected relatives with cancer on the same side of the family, and multiple primary tumors, especially in the same organ (such as breast, colon, or kidney), in a single individual. In addition, emerging research suggests that individuals with specific tumor types should be considered for genetic testing regardless of family history.[19] A clinically important proportion of these tumors is caused by germline susceptibility genes, and prevention interventions are available that affect cancer risk in the patient and his or her relatives. For this reason, individuals with these tumor types should be referred for genetic counseling and possible genetic testing regardless of family history. Some of the more common cancer types in this category are listed in Table 2. The cancer types included here are examples of those more commonly encountered by oncology providers. This list is not intended to be exhaustive and should not be interpreted as guidance to limit the consideration of additional counseling or testing to only those identified. Furthermore, as an increasing number of genes become discovered, this list is likely to change with time. Several prediction models and clinical criteria exist to aid the clinician in determining which patients should undergo genetic testing, as summarized in Table 3.

The family history should be interpreted in the context of the patient's personal history of cancer, and this assessment should be recorded and shared with the patient. Clinicians should determine a practice approach for those patients with cancer for whom a more complete genetic risk assessment is warranted. Oncologists offering genetic testing should consider whether a health care professional experienced in cancer genetics is available to provide or make available additional genetic education and counseling. Otherwise, they should consider referring the patient and family for these services. Resources

Table 3. Risk Assessment Tools to Guide Referral for Comprehensive Genetic Evaluation

Disease	Gene	Models/Criteria
Lynch syndrome[33,34]	*MLH1*, *MSH2*, *MSH6*	PREMM model: http://premm.dfci.harvard.edu MMRPRO model: http://bcb.dfci.harvard.edu/bayesmendel/mmrproqa.html
Breast and ovarian cancer syndrome[35]	*BRCA1*, *BRCA2*	BRCAPRO model: http://bcb.dfci.harvard.edu/bayesmendel/brcapro.php PENN2 model: http://www.afcri.upenn.edu/itacc/penn2 MYRIAD risk calculator and prevalence tables: http://www.myriadtests.com/provider/brca-mutation-prevalence.htm BOADICEA Cambridge University Web site: http://ccge.medschl.cam.ac.uk/boadicea/web-application/
Melanoma[36]	*CDKN2A* (p16)	MELAPRO model: http://bcb.dfci.harvard.edu/bayesmendel/melapro.php
Pancreatic cancer[37]		PANCPRO model: http://bcb.dfci.harvard.edu/bayesmendel/pancpro.php
Li-Fraumeni syndrome[38]	*TP53*	CHOMPRET criteria: http://jco.ascopubs.org/content/27/26/e108.full.pdf
Cowden syndrome[39]	*PTEN*	PTEN risk model: http://www.lerner.ccf.org/gmi/ccscore/

to locate cancer genetics specialists are listed in Appendix Table A1 (online only). A select listing of available guidance for genetic testing is provided in Table 4.

Risk assessment and counseling regarding genetic testing can be conducted by several types of medical care providers, as long as they receive adequate training and are motivated to learn, given the rapid changes in the field of cancer genetics. Important competencies include: general recognition of the hallmarks of hereditary cancer syndromes, knowledge of existing guidelines and models for risk assessment, cancer screening and prevention guidelines for those at increased risk for specific syndromes, and the ability to engage in the process of thorough informed consent for cancer susceptibility testing (Table 5).[3] A variety of cancer genetics training opportunities are available through ASCO as well as other specialty societies and medical institutions. For example, the ASCO curriculum and educational activities at the ASCO Annual Meeting are designed to assist oncology

Table 4. Additional Guidance on Cancer Genetic Testing: Selected List

All cancers
www.genereviews.org
NIH PDQ cancer information summaries, genetics: http://www.cancer.gov/cancertopics/pdq/genetics
NIH Genetic Testing Registry: http://www.ncbi.nlm.nih.gov/gtr/
Breast and ovarian cancers
Lu et al[12,13]
NCCN Clinical Practice Guidelines in Oncology: Genetic/familial high-risk assessment—Breast and ovarian, version 1.2012. http://www.nccn.org/professionals/physician_gls/pdf/genetics_screening.pdf
BRCA1 and *BRCA2* hereditary breast and ovarian cancer: www.genereviews.org
NIH PDQ: Genetics of breast and ovarian cancer: http://www.cancer.gov/cancertopics/pdq/genetics/breast-and-ovarian/HealthProfessional
Colorectal cancer
NCCN Clinical Practice Guidelines in Oncology: Colorectal cancer screening, version 2.2012. http://www.nccn.org/professionals/physician_gls/pdf/colorectal_screening.pdf
Weissman et al[40]
Berg et al[41]
Lynch syndrome: www.genereviews.org, http://www.ncbi.nlm.nih.gov/books/NBK1211/
NIH PDQ: Genetics of colorectal cancer: http://www.cancer.gov/cancertopics/pdq/genetics/colorectal/HealthProfessional

Abbreviations: NCCN, National Comprehensive Cancer Network; NIH, National Institutes of Health; PDQ, physician data query.

Table 5. Components of Informed Consent for Cancer Susceptibility Genetic Testing[3]

1.	Purpose of the testing
2.	Information on the specific genetic mutation(s) or genomic variant(s) being tested, including whether the range of risk associated with the variant will impact medical care
3.	Implications of a positive (mutation confirmed to be deleterious), negative (no identified change in the genetic sequence), or uncertain (genetic variant of unknown clinical significance) result
4.	Possibility the test will not be informative
5.	Risk that children and/or other family members may have inherited the genetic condition
6.	Technical accuracy of the test including, where required by law, licensure of the testing laboratory
7.	Fees involved in testing and counseling and, for DTC, testing, whether the counselor is employed by the testing company
8.	Psychological implications of test results (benefits and risks)
9.	Risks and protections against genetic discrimination by employers or insurers
10.	Confidentiality issues, including DTC testing companies, policies related to privacy, and data security
11.	Possible use of DNA samples for future research
12.	Options and limitations of medical surveillance and strategies for prevention after genetic or genomic testing
13.	Importance of sharing genetic and genomic test results with at-risk relatives so that they may benefit from this information
14.	Plans for disclosing the test result and providing follow-up

NOTE. Reprinted with permission.[3]
Abbreviation: DTC, direct-to-consumer testing.

providers (oncologists, nurse practitioners trained in genetics, genetics counselors) to gain or retain their abilities to provide genetic risk assessment relevant to their practice. It is recommended that oncology practices identify providers with cancer genetics expertise who can provide counseling and testing to their patients; this may be either within or outside of the practice.

GENETIC TESTING

Germline genetic testing should be performed in the context of appropriate pre- and post-test counseling. Patients and health care providers should engage in the informed consent process before cancer susceptibility testing is conducted, in accordance with the basic elements of consent, as listed in Table 5.[3]

Obtaining informed consent is an interactive process between the health care provider and the patient and includes a thorough discussion of the possible outcomes of genetic testing and the implications of these results for the patient and his or her family members. The process begins with an explanation of the genetic testing being offered and its purpose. Patients should understand whether the testing is being offered to plan cancer treatment, develop future cancer screening and preventive strategies, and/or determine risk for family members. For example, a newly diagnosed patient with breast cancer may be offered *BRCA1* and *BRCA2* genetic testing for the purpose of surgical planning, whereas the purpose of testing an unaffected person for a familial mutation may be to formulate screening recommendations.

Genetic test results need to be effectively communicated to patients and their health care teams so that the potential benefits of genetic testing are realized. Providers of genetic risk assessment and testing should ensure that mechanisms are in place within the practice to facilitate communication of genetic test results.[42] Medical management recommendations based on the genetic test results should be documented in the medical record so that they are accessible to relevant providers. Patients' understanding of how genetic test results affect their medical care and the implications for family members should be assessed. The psychosocial impact of the results should also be assessed and addressed. When a hereditary cancer predisposition has been identified, providers should communicate to patients the risk to family members, emphasizing the importance of sharing this information with family members. When genetic testing does not identify a hereditary cancer predisposition syndrome, the personal and family histories should be periodically reassessed to determine the best screening and prevention management plan for the individual.

BARRIERS TO FAMILY HISTORY TAKING AND HEREDITARY CANCER RISK ASSESSMENT IN ONCOLOGY PRACTICE

Several challenges exist to the effective collection and use of family history taking and appropriate risk assessment in oncology practices. Addressing these barriers at the patient, provider, and care delivery system level is necessary.

Patient Barriers

Providers cite limitations to patient knowledge of their family medical history, indicating that patients often give inaccurate or incomplete information.[43,44] Specifically, paternal lineage seems less complete, likely because men are frequently less cognizant of their family history.[45] Patients may have small families, making it more difficult to assess the presence or absence of a heritable condition. Patients may choose not to explore their family history because of fear or be unaware of how important family history is to their care. Furthermore, patients may not understand the important elements of a complete family history of cancer and may not know what type of cancer information they should report.[46] However, a recent literature review conducted by Doerr and Teng[44] determined that patients' reports are in fact reliable in their accounts of first- and second-degree relatives for most types of cancer. This may be a result of increased awareness of the importance of detailed and accurate documentation of health problems within a family.

Increased education and awareness are needed for patients on why family history is important and the significance of cancer risk assessment for themselves and for their family. Beginning in 2004, as part of the Family History Initiative, the US Surgeon General declared Thanksgiving to be National Family History Day, encouraging families to take advantage of their time together to discuss and document recurrent health problems.[47] Clinicians should stress the need for accurate and updated information at each visit.

Provider Barriers

Clinicians may lack the adequate tools and expertise to collect, access, and interpret family history to evaluate cancer risk. The increasing use of electronic health records (EHRs) could help to alleviate this obstacle if they had appropriate family history sections with a usable family history interface. The guidelines for what data fields need to be available were defined by the American Health Information Community.[48] To date, the American Health Information Community core data set has not been adopted for any EHR, and most family history sections are inadequate for risk assessment.

Available tools, mostly paper based, are often not practical for use in a busy oncology practice. As summarized in Table 6, a growing number of electronic tools are available that allow data collection directly from the patient in the waiting area, alleviating clinician workload (some produce the HL7 standard family history message for consultation by electronic systems).[50] One of the barriers to utility of this system is that no EHR is yet able to consume the HL7 message, even though it is the recognized standard. Making collection tools available and easily accessible will improve the ability of clinicians to better gather family history during patient visits, and interoperability of these tools with EHRs is critical. Implementation of existing standards for data sets and data exchange, increased usability (improved clinician interface), and adoption of patient data entry (a proposed requirement for Meaningful Use Stage 3) are needed in EHRs. ASCO will focus on the development of tools and resources for providers to help them efficiently integrate cancer genetics assessment into oncology practice.

Readily available and easy-to-use guidelines and model resources are essential to improving clinicians' capabilities for interpreting detailed family history reports. Guidelines and models currently require time-consuming data entry that must be performed in addition to documentation in the EHR. A modular approach to this may enable $\geq$ 600 certified EHRs to accomplish this goal rapidly, compared with the development of individual models and clinical decision support for each EHR.[51]

Table 6. Family History Collection Resources and Tools[50]

Resource	Description
AMA: Genetics and molecular medicine	Family health history resources, including prenatal genetic screening questionnaire, pediatric clinical genetics questionnaire, and adult family history form: http://www.ama-assn.org/ama/pub/physician-resources/medical-science/genetics-molecular-medicine.page
CancerGene	Windows-based program to estimate likelihood of a cancer-predisposing gene: http://www4.utsouthwestern.edu/breasthealth/cagene/
CDC: Family health history	Family history collection tools and background information: http://www.cdc.gov/genomics/famhistory http://www.cdc.gov/genomics/resources/index.htm
Genetic Alliance	"Does it Run in the Family?" (toolkit in English and Spanish); "A Guide to Family History" (available in Chinese); customizable booklets for family, organization, or community: http://www.geneticalliance.org/fhh
Hughes RiskApps	Cancer risk assessment software: http://www.hughesriskapps.com/
MyGenerations	Extensive family cancer history assessment using peer-reviewed algorithms: http://www.northshore.org/genetics/mygenerations
National Archives	Resources for genealogists/family historians: http://www.archives.gov/research/genealogy/index.html
National Society of Genetic Counselors	Instructions for collecting family history and pedigree nomenclature: http://www.nsgc.org/About/FamilyHistoryTool/tabid/226/Default.aspx
NIH State-of-the-Science Conference: Family history and improving health	Expert assessment of family history in primary care: http://consensus.nih.gov/2009/familyhistory.htm
US Department of Health and Human Services	Surgeon General's Family Health History Initiative: http://www.hhs.gov/familyhistory/ My Family Health Portrait Tool: https://familyhistory.hhs.gov/fhh-web/home.action

NOTE. Data adapted.[49]
Abbreviation: AMA, American Medical Association; CDC, Centers for Disease Control and Prevention; NIH, National Institutes of Health.

In their recent study, Sussner et al[52] found that of 143 clinicians surveyed, only 1.7% demonstrated confidence in their ability to interpret risk from family history and make appropriate preventive, screening, and treatment recommendations. Forthcoming educational efforts by ASCO will focus on increasing the preparedness of oncologists and other health care providers to interpret family history and recommend appropriate follow-up care. Furthermore, awareness of recent advances in cancer genetic testing, including the uses and limitations of genetic profiling in assessing cancer risk, will be increased. These educational efforts should extend beyond the oncology community to other health care providers, patients, and individuals, including those considering direct-to-consumer tests.[4]

SYSTEMIC BARRIERS

Clinicians are increasingly asked to do more with less time and insufficient reimbursement. The process of cancer risk assessment and counseling is time consuming, and it is not clear how best to bill for this service. Payer policies are not firmly established, especially with respect to counseling individuals without a personal history of cancer. Clarification of these policies is critical because of concerns about adequate reimbursement, which presents a barrier to the provision of preventive services, such as counseling for inherited risk. In addition, as cancer risk assessment and risk reduction become more complex, the burden on oncologists to fully explain these issues to patients will also intensify.[1]

Existing electronic health systems lack the functionality needed to capture adequate family history data, and dissimilar programs are unable to easily exchange information.[50] Additionally, because of the number of different electronic platforms in use by both clinicians and patients, interoperability of the patient tools, such as My Family Health Portrait, and physician office applications becomes an issue.[50] Ideally, the electronic applications would include the core information required to establish family history as well as built-in decision support for the clinician.[44,50] EHR vendors should integrate family history platforms into their programs, preferably with the ability to run risk models and draw pedigrees. Additionally, vendors should incorporate the ability to interact with external risk model and pedigree drawing software packages using the HL7 pedigree standard.

DISCUSSION

In conclusion, the collection and use of family cancer history are vital for the identification of individuals with cancer who are at increased risk for additional primary cancers and can affect treatment plans, screening practices, and prevention options for cancer patients and their at-risk relatives. The recommendations described here are designed to provide guidance to oncology providers on what constitutes the minimum family history that should be collected for every patient with cancer, as well as to provide the next steps for integration of risk assessment and genetic testing into clinical practice. Although barriers to incorporating family history taking and hereditary risk assessment into the oncology practice do exist, they can be addressed with attention to the needs of the patient, provider, and health care system. We propose that incorporation of a minimum family history into the evaluation of all oncology patients is an achievable near-term goal for

oncology practices. Developing EHR software that allows creation and interpretation of family history and improving payer policies and reimbursement for genetic risk assessment are midterm goals that ASCO supports. As the field of hereditary cancer predisposition advances, ASCO will continue to assist oncology providers in implementing practical methods to integrate family history and risk assessment into practice.

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AUTHOR CONTRIBUTIONS

Conception and design: Karen H. Lu, Marie E. Wood, Molly Daniels, Cathy Burke, James Ford, Wendy Kohlmann, Noralane M. Lindor, Therese M. Mulvey, Linda Robinson, Wendy S. Rubinstein, Elena M. Stoffel, Carrie Snyder, Sapna Syngal, Dana Swartzberg Wollins, Kevin S. Hughes

Administrative support: Janette K. Merrill, Dana Swartzberg Wollins

Collection and assembly of data: Karen H. Lu, Marie E. Wood, James Ford, Noah D. Kauff, Linda Robinson, Wendy S. Rubinstein, Janette K. Merrill, Dana Swartzberg Wollins

Data analysis and interpretation: Karen H. Lu, Marie E. Wood, James Ford, Noah D. Kauff, Linda Robinson, Wendy S. Rubinstein, Carrie Snyder, Kevin S. Hughes

Manuscript writing: All authors

Final approval of manuscript: All authors

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Appendix

Table A1. Resources for Locating Cancer Genetics Specialists

Resource	Web Site
National Society of Genetic Counselors	http://www.nsgc.org/tabid/68/Default.aspx
National Cancer Institute Cancer Genetic Services Directory	http://www.cancer.gov/cancertopics/genetics/directory
American College of Medical Genetics Provider Directory	http://www.acmg.net/GIS/Disclaimer.aspx
American Board of Medical Genetics	http://www.abmg.org/pages/searchmem.shtml
American Board of Genetic Counselors	https://abgcmember.goamp.com/Net/ABGCWcm/Find_Counselor/ABGCWcm/PublicDir.aspx?hkey=0ad511c0-d9e9-4714-bd4b-0d73a59ee175