RISK ASSESSMENT AND SCREENING TOOLKIT

TO DETECT FAMILIAL, HEREDITARY, AND EARLY ONSET COLORECTAL CANCER

American Cancer Society®

National Colorectal Cancer Roundtable

The Jackson Laboratory

Leading the search for tomorrow's cures

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CHAPTER 1

Introduction

THE VALUE OF FAMILY HISTORY IN CANCER RISK ASSESSMENT

Family history is a powerful screening tool.

In conjunction with the patient's medical history, family history can inform diagnosis, promote risk assessment, and prevent, detect and manage disease. This is especially true for cancer.

When it works

Family history is most useful when it is available in a structured format in the medical record and of course, when it is accurate and complete to support risk assessment. Not all family history information is equal. Seeing that a patient has a "family history of cancer" in the medical record is not specific enough to allow for immediate analysis; seeing documentation that the patient's mother had colon cancer at age 53 allows for personalized risk assessment and possibly, a change in screening regimen.

How it works

The goal of family history risk assessment is to identify individuals with strong and moderate genetic predispositions to disease so that they can adopt prevention or screening activities to reduce risk and detect disease early. The risk assessment process starts by identifying red flags and patterns in the patient's family history, and then uses that information to stratify individuals into average, increased, or high risk.

Necessary for guidelines-based screening

National guidelines recommend earlier and more frequent screening for individuals at increased risk for CRC. For individuals at high (hereditary) risk, additional evaluations and health services may be indicated, such as genetic testing or prophylactic surgery. In order to accurately identify the best cancer management plan for each patient, clinicians must assess the family history.

Extra benefits

In addition to its critical role in risk assessment, the act of family history collection can be a benefit to the patient, as can the discussion about the family history between patient and provider. The process of eliciting a family history provides an excellent opportunity to build a relationship with the patient and to become aware of the patient's motivations and concerns. Such information can be beneficial as the provider helps the patient make health-related decisions. The emphasis on disease prevention and management based on the family history may motivate changes in behavior that forestall disease or reduce its adverse effects.

Eliciting and summarizing family history information can:

- help the patient understand the condition in question,
- clarify patient misconceptions,
- demonstrate variation in disease expression (such as different ages at onset),
- provide a reminder of who in the family is at risk for the condition, and
- emphasize the need to obtain medical documentation on affected relatives.

See best practices in family history collection and risk assessment for primary care in the Appendix.

THE IMPORTANCE OF IDENTIFYING COLORECTAL CANCER FAMILY HISTORY

Colorectal cancer can be prevented when we know who is at increased risk.

Colorectal cancer (CRC) is the second leading cause of cancer deaths in the United States. In 2018, there are predicted to be 140,250 new cases of CRC in the United States.[2] Individuals who have a first-degree relative with CRC are at least two times more likely to develop CRC themselves, with the risk increasing with earlier ages of diagnosis and the number of relatives diagnosed with CRC.[3,4] Therefore, knowledge of and adherence to screening guidelines is important to improve morbidity and mortality from CRC in these families at increased risk.

Routine screening has been shown to be effective in prevention and early detection of CRC. Early detection of CRC saves lives. The survival rate for patients with stage 1 (local) CRC is 90% but drops to 14% for patients with stage 4 (metastatic) disease.[2] Approximately 4,600 lives could be saved per year if individuals with CRC under age 50 are diagnosed at a localized stage.

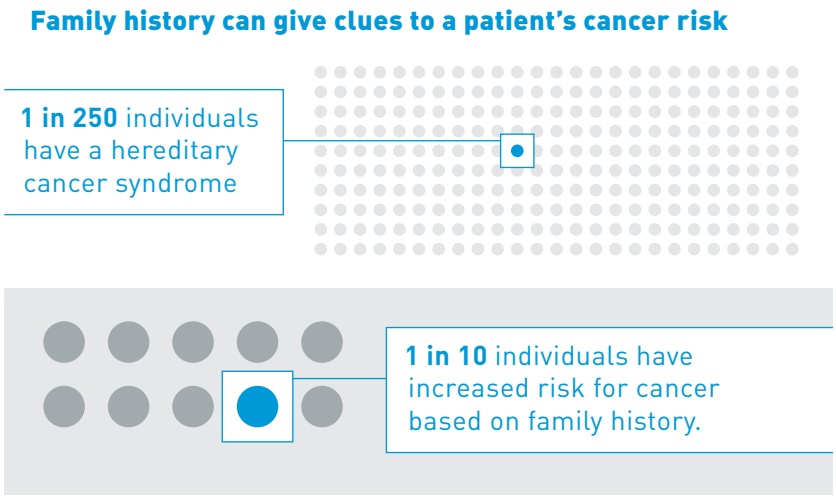


Figure 1. Incidence of familial and hereditary cancer risks for colon and breast cancers.

National screening guidelines exist for the general population at average risk, for individuals at moderately increased risk due to a positive family history and/or personal history, and for those at high risk due to a hereditary cancer syndrome. However, fewer than half of individuals with a family history of CRC or advanced adenoma (> 1 cm) receive personalized counseling and follow risk-based screening guidelines.[4,5]

This concerning state is due in part to a lack of family history collection among a significant number of patients. Less than 40% of individuals with a family history of CRC have talked with a healthcare provider about their family history.[5] Even in symptomatic patients with rectal bleeding, family history is not always adequately collected, with 38% of cases lacking necessary information for risk evaluation.[6] Expanding beyond CRC to include additional common conditions in primary care, one study showed that less than 4% of patients' medical records had sufficient family history information to assess risk.[7]

Limited or inaccurate family history collection and risk assessment is a major barrier to successful cancer screening. In order to focus screening and prevention efforts on those with familial or hereditary risk, these individuals must first be identified as having an increased risk, which requires collecting the necessary family history information for risk assessment. Primary care clinicians play a pivotal role in identifying people at increased CRC risk and facilitating recommended screening. This toolkit aims to help the clinician implement best practices in CRC family history collection, risk assessment, and management to prevent cancer or detect it at the earliest possible stage.

EARLY ONSET COLORECTAL CANCER

The incidence of CRC is increasing in individuals under age 50.

Recent data show a rising rate of CRC under the age of 50, despite an overall decrease in the rate of CRC diagnoses across older age groups. One in ten colorectal cancers are now diagnosed in patients younger than 50.[8] CRC is often under- and misdiagnosed in younger patients. Younger individuals are significantly more likely to be diagnosed with late stage disease compared to older individuals, due in part to delayed work-up of symptoms by the patient and/or provider.[9]

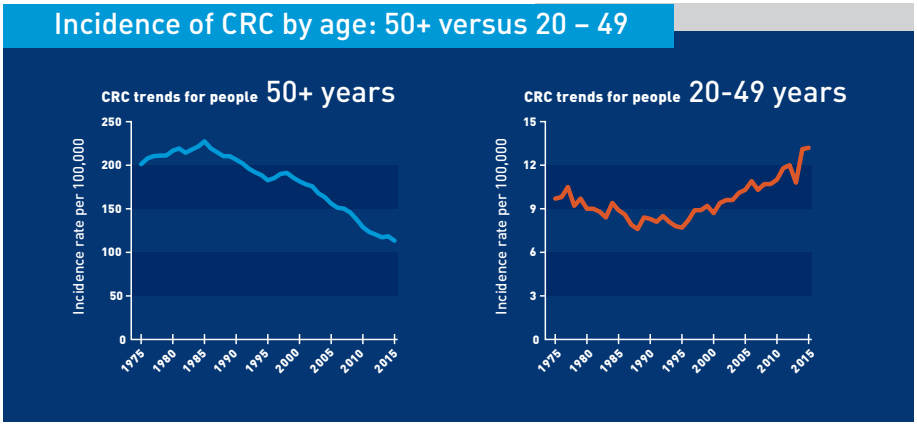


Figure 2. Incidence of CRC by age.[5]

A substantial proportion of early onset CRC may be preventable by taking a family history and screening individuals with an increased risk earlier and more frequently. Approximately 16% of cases occur in individuals with a hereditary condition, such as Lynch syndrome, and 14% have a family history of CRC.[10] Additionally, a currently undefined portion of this group has a family history of advanced adenomas that would warrant earlier screening. Early onset CRC may also develop due to personal risk factors such as chronic inflammatory bowel disease (e.g., ulcerative colitis), lifestyle factors such as limited exercise, a diet low in fruits and vegetables and high in fat, overweight and obesity, tobacco use and alcohol consumption, and other as of yet unknown causes.

In addition to routinely using family history to identify people at increased risk, primary care clinicians can help reduce CRC mortality by promoting primary prevention and early detection as well as considering CRC in the evaluation of a patient with possible alarm signs and symptoms, regardless of age.

UPDATE ON COLORECTAL CANCER SCREENING

in the general population from the American Cancer Society

The American Cancer Society (ACS) now recommends that CRC screening begin at age 45, while the US Preventative Services Task Force (USPSTF) recommended in 2016 that CRC screening should begin at age 50.[11, 12] The difference in these two recommendations is due to new data about rising incidence in younger birth cohorts that was published in 2017. See Table 1 for a comparison of the two recommendations and view an FAQ about the new guideline at NCCRT.

The ACS firmly believes that the evidence, including a concerning trend in CRC incidence in younger adults discussed in this toolkit, now points to CRC initiation starting at age 45. Having said that, ACS does anticipate that implementation will be a multi-year process, as measurement and coverage issues are worked out. ACS recognizes that many organizations will continue to follow the USPSTF recommendations for the time being. For practices that do start screening at age 45, those individuals should still be assessed for risk, as it may determine screening frequency or test selection.

Table 1. CRC screening guidelines for average risk adults: Comparison of American Cancer Society (ACS, 2018) and US Preventative Services Task Force (USPSTF, 2016) recommendations. Q = Qualified Recommendation, S = Strong Recommendation, A = A Evidence Grade, C = C Evidence Grade.

Recommendations	ACS[11]	USPSTF[12]
Age to start screening (Level of evidence)	45y Starting at 45y (Q) Screening at 50y and older (S)	50y (A)
Choice of test	High-sensitivity stool-based test or structural exam	Different methods can accurately detect early stage CRC and adenomatous polyps
Acceptable test options	FIT annually HSgFOBT annually mt-sDNA every 3y Colonoscopy every 10y CTC every 5y FS every 5y All positive non-colonoscopy tests should be followed up with colonoscopy.	HSgFOBT annually FIT annually sDNA every 1 or 3 y Colonoscopy every 10y CTC every 5y FS every 5y FS every 10y plus FIT every year
Age to stop screening (Level of evidence)	Continue to 75y as long as health is good and life expectancy 10+y (Q) 76-85y individual decision-making (Q) >85y discouraged from screening (Q)	76-85y individual decision making (C)

HOW TO USE THIS TOOLKIT

Purpose of the toolkit

The primary goal of this toolkit is to enable primary care clinicians to implement a structured family history collection system to identify individuals at increased or high risk of CRC and develop a management strategy for those individuals. A secondary goal is to facilitate timely diagnostic evaluation of patients with signs or symptoms of early onset CRC.

Learning objectives

1. Create a system to integrate family history collection and screening into practice flow
2. Identify patients at increased or high risk of CRC based on personal and/or family history
3. Apply screening guidelines to patients at increased and high risk
4. Refer high risk patients to genetic services for further evaluation, counseling, and testing
5. Include CRC in the differential diagnosis of adults under age 50 with alarm signs and symptoms

Who should use the toolkit

The toolkit is intended for primary care clinicians and administrators, including physicians, nurse practitioners, and physician assistants who specialize in internal medicine, family practice, and obstetrics/gynecology, and office managers or administrators working in these settings. Components of the toolkit may also be used by other primary care staff, such as nurses and medical assistants, who may be involved in family history collection and other associated activities.

This toolkit is designed to be used by a clinical champion or administrator to identify and implement a CRC risk assessment solution that works for the practice. The toolkit also contains guidance and education for clinicians and staff who are interested to learn more about family history collection, CRC risk assessment and risk management, and the detection of early onset CRC.

Approach towards practice change

There are different philosophies about how to introduce a new program in practice. This toolkit recommends a systemic approach with buy-in of practice or health system leadership. Other approaches could include encouraging providers and patients to engage with the program based on their interest, rather than directing a practice-wide implementation. In these cases, elements of this toolkit can still be helpful to help clinicians implement activities of interest.

Implementation and practice change are complex processes. Clinicians and staff may be able to leverage quality improvement experts from their practice or health system to assist in implementation. They may also consider additional training on evidence-based approaches that can augment the information in this toolkit. See the Appendix for select training opportunities.

Personalize the toolkit for your needs

The toolkit is designed so that you can customize your experience. Each page provides the information you need to complete a task so you can create a customized toolkit by assembling only the pages that are relevant to your practice needs.

The toolkit can be used by practices that are considering a systematic family history collection process for the first time, as well as those that may have already begun implementation who are looking for guidance on a specific issue. New and experienced users may use the toolkit in different ways. For example, practices that are new to systematic family history collection may want to read the entire toolkit prior to implementing processes, while those who have already embarked on implementation may wish to use only the tools and pages to build clinical skills around family history collection and identification of early onset colorectal cancer.

Opportunities to build on the toolkit instruction

Risk assessment beyond colorectal cancer. Recognizing that family history collection and interpretation is ideally an integrative and comprehensive process that considers risk for multiple conditions, this toolkit provides suggestions for how to implement a system for general family history collection that would allow the provider to assess a broad range of conditions. Beyond family history collection, the information about risk assessment and cancer management is specific to CRC. Practices may wish to expand their activities to include other cancers and health conditions when developing a risk assessment process.

Cancer genetic testing. Most primary care clinicians refer high risk individuals to a genetic specialist for genetic counseling and genetic testing. However, some clinicians and practices perform these processes in the primary care office, due to provider interest, patient demand, and/or limited access to genetic services. This toolkit does not provide instruction on how to integrate genetic testing into the primary care practice. Page 42 summarizes important considerations for practices considering ordering genetic testing in-house.

Navigating the toolkit in Adobe Acrobat

The toolkit contains links to external web sites and links to pages within the document. If you use internal links you may want to return to the page you were previously viewing.

You can find PDF pages that you viewed earlier by retracing your viewing path. It's helpful to understand the difference between previous and next pages and previous and next views. In the case of pages, previous and next refer to the two adjacent pages, before and after the currently active page. In the case of views, previous and next refer to your viewing history. For example, if you jump forward and backward in a document, your viewing history retraces those steps, showing you the pages you viewed in the reverse order that you viewed them.

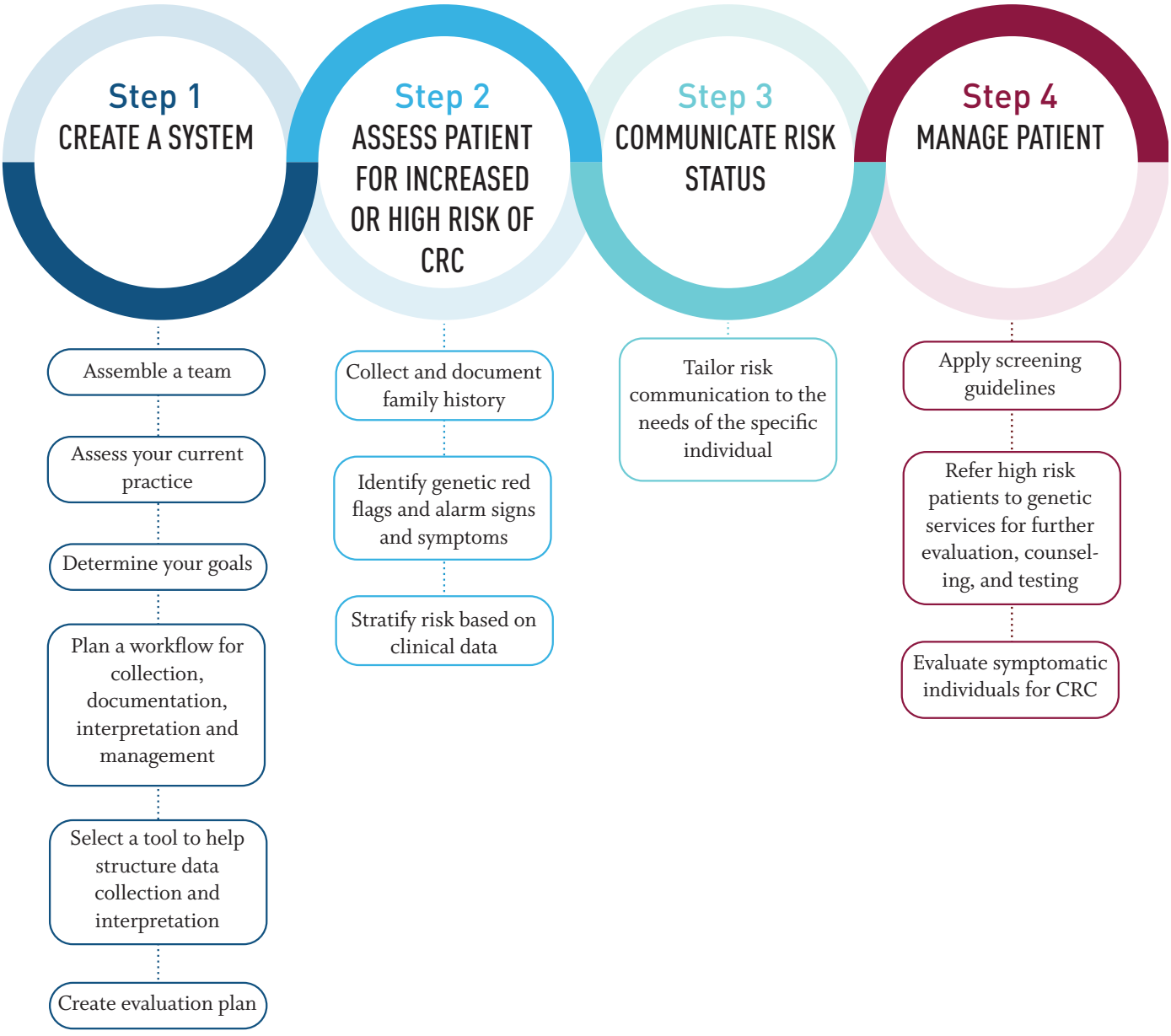
Steps

1. Choose View > Page Navigation > Previous View.
2. To continue seeing another part of your path, do either of the following:
   - Repeat step 1.
   - Choose View > Page Navigation > Next View.

Note:
You can make the Previous View button and Next View button available in the toolbar area by right-clicking the Page Navigation toolbar and choosing them on the context menu, or choosing Show All Tools.

You can also use the keyboard shortcut. "Alt+Left Arrow" on a PC or "Command+Left Arrow" on a Mac.

OVERVIEW OF THE FAMILY HISTORY COLLECTION AND CRC RISK ASSESSMENT PROCESS

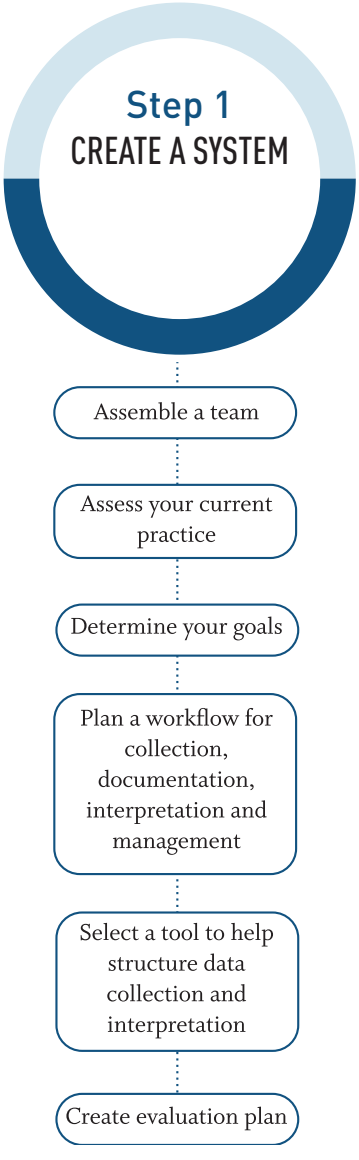


CHAPTER 2

Establish a System for Structured Assessment Across the Practice

ESTABLISH A SYSTEM FOR STRUCTURED ASSESSMENT

A cancer risk assessment system includes a standardized process for family history collection and interpretation as well as guidance for developing a personalized management plan for patients.



To improve identification of individuals at increased risk of colorectal cancer, primary care clinicians need to recognize those patients who have a personal and family history that increases their cancer risk and identify the appropriate cancer screening and genetic services indicated for a given patient. The most successful programs are those that engage the entire practice in developing and implementing a systematic, team-based approach to family history collection and interpretation.

Chapter 2 is intended to help practices establish a system for cancer family history collection and risk assessment. This process can and should be customized to the needs of your practice. It can also be adapted to coordinate with other initiatives, such as assessing risk for a more comprehensive list of conditions, promoting cancer screening among eligible patients, or rapid diagnosis of individuals presenting with alarm signs and symptoms of cancer.

This chapter will guide practices through setting goals for family history collection, assessing current processes, and working through best practices and different methods for family history collection and risk assessment to identify opportunities for improvements to the clinic workflow, if needed. Generally, a family history process identifies when to collect and where to document family history data, the team members who are involved in collection and interpretation, and any tools used to aid the patient or provider in collecting or assessing family history. Practices should also consider CRC screening protocols based on professional society guidelines for increased risk individuals and collaboration with genetic and other cancer specialists for referral and consultation for individuals at high risk.

Adopting a new process in clinical practice is a major endeavor. Before embarking on the planning activities outlined in Chapter 2, you should take stock of your organization and its resources to determine whether you are ready to make this change. A precursor activity may be to conduct a needs assessment within the practice or health system, which could include formal or informal surveying of staff as well as calculating baseline risk assessment and screening rates for the increased risk population. Even with compelling needs assessment data, you still may find that your organization is not yet fully ready to adopt a new system and thus needs to take intermediate steps to prepare.

The following sections were adapted with permission from AHRQ[1]:

- Assembling a team
- Assessing your existing workflow
- Setting goals and the Goals Worksheet
- Identifying opportunities for improvement and defining new workflow
- Training
- Planning for launch
- Monitoring and evaluation

ASSEMBLING A TEAM

Identify core members of the implementation team and engage them in planning sessions.

Successful programs utilize the team in creating, supporting, and following the plan for family history risk assessment. Your team should have a provider champion and an implementation manager. The provider champion will act as the lead change agent within the practice. At a minimum, the champion will lead decision making during the planning stages, negotiating consensus among stakeholders. During implementation, he or she will maintain communication and enthusiasm among the other providers. The champion should be a respected and recognized leader within the practice as well as a practitioner who will ultimately use the system alongside his or her colleagues.

The implementation project manager will drive the implementation process by tracking and supervising the activities that need to take place. In the planning stages, the project manager will ensure that the necessary information is gathered and provided to the key decision makers and that decisions are made in a timely and appropriate manner. During the later implementation phases, this person will, at a minimum, create and oversee the timeline for setup, training, and launch. In some practices, the office manager may step into the project manager role. In some instances, the same person may act both as champion and as implementation project manager.

PARTICIPANTS
Clinical champion, implementation lead, stakeholders

WHAT YOU'LL NEED
Goals Worksheet

BARRIERS
Competing priorities, time, staff, infrastructure

STEPS

1. Identify the clinical champion and implementation project manager.
2. Identify the additional stakeholders that should be included in team meetings and project planning. Which clinicians and staff should be involved in discussions about goals for cancer family history collection and assessment? Determining which stakeholders to engage should be based, in part, on who has relevant expertise (i.e., anyone whose job is affected by current processes), whose job will be affected by the new process, or who will be involved in the implementation process (e.g., the office manager). Consider including patients as stakeholders.
3. Engage stakeholders throughout the planning process to set shared goals, identify the pain points in the current process, brainstorm potential solutions, and define desired outcomes.

ASSESSING YOUR EXISTING WORKFLOW

Review and describe your existing workflow to identify potential improvements.

Understanding your current workflow will enable you to examine what is happening in your office, diagnose any workflow problems from the perspectives of those involved or impacted, and develop an updated process that will work successfully with available staff, space, and resources. In general, there are three main processes involved in assessing a family history: (a) collection and updating over time, (b) documentation, and (c) risk assessment. Practices are likely to have different workflows for family history processes, with specific people carrying out tasks, such as eliciting the family history, transcribing the data in the medical record, and analyzing the data for risk assessment. Regardless of the specific system established at your clinic, your workflow should address the three processes above.

As you assess your workflow, consider possible improvements to processes, needs for staff training and streamlining of tasks, and points where using a family history tool may help.

PARTICIPANTS
Implementation lead, staff involved in family history processes

BARRIERS
Competing priorities, time, infrastructure

LEARN MORE
AHRQ Workflow Assessment for Health IT Toolkit

STEPS

1. Gather information on the current workflow. Observe providers and staff involved in collecting, documenting, and assessing family history information. During the observation process, ask the following questions:
   - Where are potential problems or delays likely to occur in the current process?
   - Where in the process are opportunities to achieve more benefits from family history collection?
   - Where could patient handouts or resources help the process?
2. Organize the information into the basic processes of: (a) collection, (b) documentation, and (c) risk assessment.
3. Summarize the sequence of tasks in a workflow diagram. A workflow is the set of sequenced tasks used to reach a specific goal, such as identifying patients at increased risk of disease based on family history. The workflow may include factors that affect the completion of the task, such as the staff involved, materials and equipment needed, methods used, and physical environment (e.g., the layout of the site where the process occurs). See the example workflows Patient Collection (Figure 3) and Nurse Collection (Figure 4) as a starting point for how you might develop your practice's family history workflow, with more or less detail as needed.
4. You may learn you have multiple workflows depending on the visit type, such as annual preventative health vs. sick visit, or other variables, new patient vs. established patient. Sketch out workflows for each of the different ways family history is collected in your practice.

SETTING GOALS

Establishing your goals and desired outcomes for risk assessment will help you identify the best process and tools for your practice.

After you have assessed your current workflow, you should identify your desired goals and outcomes for cancer risk assessment and CRC screening. This toolkit is designed to help you reach these goals:

- Identify patients at increased or high risk based on personal and/or family history
- Apply screening guidelines to patients at increased and high risk
- Refer high risk patients to genetic services for further evaluation, counseling, and testing

Your practice may have additional goals, which can be defined during planning. The implementation process will take time, especially for users to become comfortable with new tools and work processes. Having clear goals and realistic expectations helps to ensure that the team will persist in achieving these changes because they know why the changes are occurring. Further, discussion of goals and expectations can ensure that stakeholders are "on board" with the changes, have reasonable expectations regarding the disruption of existing routines, and are ready to recognize the changes when they occur.

PARTICIPANTS
Clinical champion, implementation lead, stakeholders

WHAT YOU'LL NEED
Goals Worksheet

BARRIERS
Competing priorities, time, staff, infrastructure

STEPS

1. Read about goals that are commonly considered achievable. See the next page for suggestions.
2. Working with the previously identified stakeholders, choose the three or four goals that are most important and achievable for your practice. These should be goals that would help you improve patient care, perform as a practice, or streamline the daily work of the practice. Write these goals down in the Step 2 section of the Goals Worksheet (available in the Appendix).
3. For each goal, set a specific, measurable "target" for what level of performance can be achieved to improve the existing conditions. Write these targets down in Step 4 of the Goals Worksheet.
4. Next, you will develop your "measurement plan." This means you will determine how you will measure the progress in reaching the explicit targets of your goals, and who will be responsible for collecting these measurements.
5. Consider feasibility. Feasibility is usually determined by having sufficient staff and opportunities to collect the data. Be sure to discuss feasibility with the stakeholders in your office who will be assigned responsibility for monitoring. Are the expectations for measuring progress towards the goal realistic? Rate the feasibility from 1 (not very feasible), 2 (somewhat feasible) or 3 (very feasible) and record under Step 4 of the Goals Worksheet.
6. Set a target date by which the measurable goal will be met. You may find you need to adjust this date further into planning, but it can be helpful to set an agreed-up date with stakeholders. Write this down under step 4 of the Goals Worksheet.
7. Communicate the final goals, expected outcomes, and timeframe to stakeholders and team members.

GOALS FOR FAMILY HISTORY CANCER RISK ASSESSMENT

Review these with an eye towards choosing goals that are important to your practice. The list of goals provided below is intended to provide examples, but is not exhaustive.

- Increase identification of patients who qualify for earlier or more frequent cancer screening
- Increase identification of patients for referral to genetic counseling and genetic testing
- Increase identification of patients for genetic testing (if in-house genetic counseling is available)
- Standardize cancer screening and surveillance practices
- Improve care coordination for patients at high risk of cancer
- Improve patient compliance with cancer screening and/or genetic referrals
- Reduce time spent on family history collection and/or risk assessment
- Systematize cancer risk assessment
- Improve the quality of patient-provided family history information
- Improve access to patient educational and decision support resources

For goals related to risk assessment, consider the additional questions to target your efforts:

- Will your risk assessment integrate personal and family history risk factors, or create separate processes?
- What conditions will be included in the risk assessment process? A specific cancer such as colorectal or breast cancer, all cancers, and/or a broader panel including non-cancer conditions (e.g., cardiovascular disease)?

GOALS WORKSHEET

Step 1. Review goals. Consider how these goals align with practice and stakeholder priorities.

Review what goals can be achieved with cancer family history collection and risk assessment.

Step 2. Pick the most relevant goals for your practice.

- Goal: Reduce time spent on family history collection and/or risk assessment
- Goal: Collect sufficient family history data to inform cancer risk assessment
- Goal: Automate cancer risk assessment
- Goal: Increase identification of patients who qualify for earlier or more frequent cancer screening
- Goal: Increase identification of patients for referral for genetic counseling and genetic testing

Step 3. Choose priorities.

Meet with stakeholders to frame the three highest-priority goals. Rewrite the goals in language that resonates with them. Record the top three goals here:

- Goal 1. Collect sufficient family history data to inform cancer risk assessment
- Goal 2. Increase identification of patients who qualify for earlier or more frequent cancer screening
- Goal 3. Increase identification of patients for referral for genetic counseling and genetic testing

Step 4. Plan. Set a target date for when you want to achieve the goal.

Determine an explicit target for each goal, plan to measure how well you achieve each target, and rate the feasibility of measuring each (1 = not feasible, 3 = very feasible).

Goal	Target	Measurement Plan	Measurement Responsibility	Measurement Feasibility (1, 2, 3)	Goal Completion Date
Goal 1	75% of patients seen since implementation will have cancer family history included in the medical record	Review of patient records using spreadsheet	Population Health	2	May 1, 2019
Goal 2	100% of patients with a first-degree relative with CRC will receive a recommendation for increased screening	Review of patient records using spreadsheet	Population Health	2	May 1, 2019
Goal 3	75% of patients with a family history of CRC will have documented cancer risk assessment 100% of patients who are identified to be at high risk will receive a recommendation for genetic referral	Review of patient records using spreadsheet	Population Health	2	May 1, 2019

Step 5. Communicate the final goals to stakeholders and team members.

WHEN TO COLLECT

Figure out when family history should initially be collected and assessed, and how often it should be updated.

Family history information by nature changes over time. Once collected, it is only valuable so long as it is an accurate representation of health and disease states among the patient's family members. Your practice should establish a plan for how to collect an initial family history on existing patients and how to update the family history over time. To the degree possible, work with your practice to automate the steps so they are part of standard workflows and templates.

PARTICIPANTS
Implementation lead, staff involved in family history processes

WHAT YOU'LL NEED
Family history collection tool, knowledge of the type of information to collect

BARRIERS
Time, staff, infrastructure, IT

LEARN MORE
Collecting Sufficient Family History

STEPS

For initial collection

1 Include family history collection as a standard activity for all new patients entering the practice.

2 Determine how to best roll out your family history collection system to active patients in the practice, such as:

- Incorporate it into preventive visits.
- For patients that do not complete annual check-ups, run a report in the EHR to identify who has not participated and take action to include them (either through a separate appointment or adding family history collection into their next sick visit).
- If your family history collection system does not center around an appointment with a provider, send a letter to patients and post flyers in the office advertising this new service for interested patients.

For updating

1 Encourage the patient to share changes to the family history over time, providing concrete examples, such as a new cancer diagnosis in a relative.

2 Update family history regularly. For adults aged 30-60 years, the family history should be updated annually in order to identify individuals that may benefit from increased cancer screening. It may be helpful to incorporate a standard question about updates to the family history as part of annual preventive visits, or setting a flag in the EHR to prompt updating the family history at the designated interval.

3 Ask about any new cancer diagnoses in the family when the patient presents with symptoms or concerns that may suggest cancer. For colorectal cancer, concerning signs or symptoms include blood in stool, anemia, and a change in bowel habits, among others.

WHERE TO DOCUMENT

Choose a documentation method that allows for easy retrieval, assessment and updating, as family history changes over time.

There are different approaches to documenting family history information, including in narrative or list form, a structured table, and visual representations such as a pedigree. Recording information in a pedigree can help you see patterns of disease more easily, but pedigrees are not typically supported in most EHRs. If you prefer to have the option of viewing family history information in a pedigree or genogram format, consider evaluating different family history tools as well as the capability of your EHR system.

Family history data can be entered into the EHR in numerous ways, and methods may be different even among providers in the same office. Standardizing how and where family history data is recorded in the EHR will increase the usability of this information. It is generally considered best practice to record family history data in preset structured fields rather than as free text, when structured data collection is an option.

PARTICIPANTS
Implementation lead, staff involved in family history processes, IT vendor or EHR superuser

WHAT YOU'LL NEED
Family history collection tool, clinic workflow, EHR

BARRIERS
Time, varying preferences among providers, EHR functionality

LEARN MORE
Collecting Sufficient Family History

Documenting Family History Information

STEPS

1. Work with your EHR and/or family history tool vendor to learn about available reports and what kinds of fields can be included in reports, that will help your practice monitor family history activities. The outcome of this discussion may impact decisions you make about where and how to document family history data.
2. Determine where practice staff will enter family history data in the EHR: the family history section, problem list, visit summary, and/or progress report. There may be different rules for the comprehensive information collected and information deemed relevant for the patient's risk assessment.
3. For practices that use a paper questionnaire or stand-alone electronic family history tool, establish a process for how these forms or reports get scanned or uploaded in the EHR for reference over time.

TIPS FOR DOCUMENTING FAMILY HISTORY IN THE ELECTRONIC HEALTH RECORD

These tips can help streamline documentation to result in family history data that can be utilized for risk assessment over time.

Record family history data in structured fields rather than as free text to enable the use of clinical decision support and accurate reporting, when possible. This usually means recording the family history in the family history section, rather than in the narrative progress note.

Add family history through ICD10 diagnoses to the patient's medical history or problem list. This will support the use of alerts and clinical decision support.

Work with your EHR vendor to determine whether red flags or alerts can be generated based on known risk factors.

Explore ways to adapt existing EHR functionality and workflows with your vendor, in order to maximize the benefits of collecting family history.

Note:
The Electronic Health Record has the potential to be a powerful tool for family history collection, documentation, and risk assessment as well as to facilitate the use of family history information in medical decision making through clinical decision support systems. While significant advances are being made by some vendors and researchers, many EHRs currently lack the functionality necessary to support the clinician in recording the necessary family history data in structured fields to perform accurate risk assessment or to use the collected family history information for medical decision making. For this reason, some clinicians look to external vendors for a family history tool solution that can collect family history in structured and usable way, and also perform varying degrees of automated risk assessment. Such external tools may or may not be designed to interface with the EHR and even when they are, the level of integration is often limited to importing a PDF report into the EHR as a static document.

Efforts are ongoing to improve standards and EHRs capabilities in this area. In 2012, the Stage 2 Meaningful Use rules addressed collecting a structured family history for the first time. NCCRT and other national organizations are currently working towards a set of best practice recommendations for both the process and content of cancer family history collection that should be included in high quality EHRs.

METHOD IN ACTION

Using an electronic patient questionnaire to collect cancer family history.

University Women's Care is an obstetric and women's health practice affiliated with an academic teaching hospital in an urban setting. Staff include attending physicians, nurse practitioners, and nurses. OBGYN residents and medical and nursing students participate in rotations. After an initial pilot project with the medical genetics department, the practice adopted a family history collection approach that is based on an electronic collection and risk assessment tool.

New patients are asked to arrive 15 minutes early to their appointment to check in and fill out paperwork. This includes completing a short electronic questionnaire on a tablet computer in the waiting room. The questionnaire collects information about the family history of cancer. When the patient is done, the questionnaire data is automatically run through the tool database to perform cancer risk assessment and a report is generated and imported into the EHR.

During the clinical encounter, the provider reviews the risk assessment results and clarifies family history information with the patient as needed. Using the risk assessment results, the provider and patient discuss red flags in the family history and next steps, which can include a recommendation for cancer screening and/or a referral for genetic counseling and further evaluation. The provider documents the encounter and any referrals in the EHR.

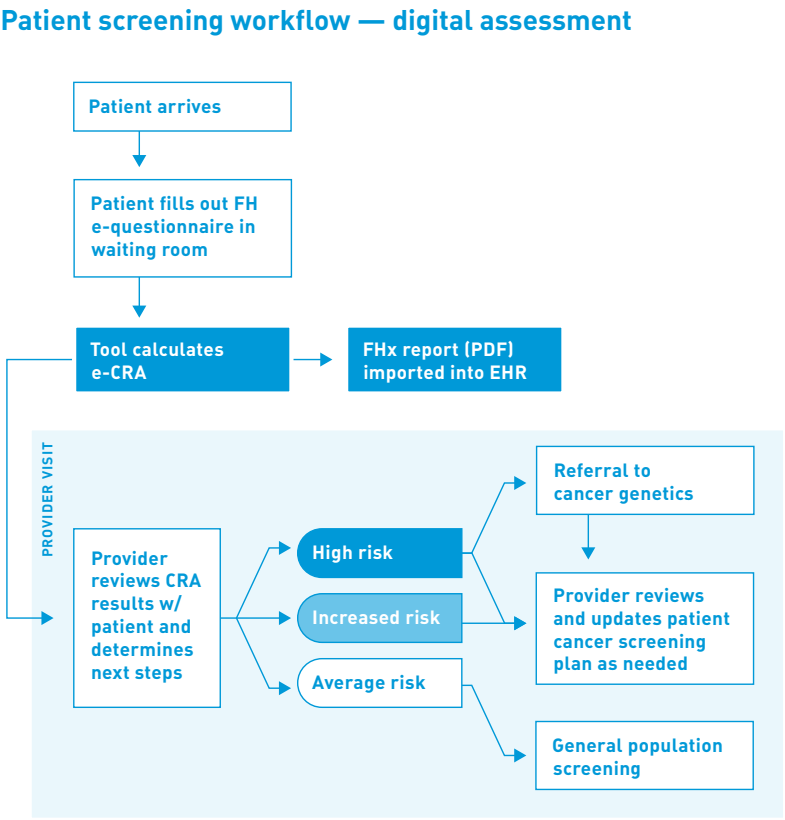


Figure 3. Workflow with patient-entered family history collection in the waiting room and provider risk assessment using an electronic tool. CRA = cancer risk assessment. FH = family history. EHR = Electronic Health Record.

This example was adapted from published reports[13,14,15] and commercial tools, such as CRA Health, Family Healthware, MyLegacy, and Progeny. See the Family History Features Worksheet for additional family history tools.

WHO WILL COLLECT

Work with your team to determine who will collect the family history: the patient him- or herself, allied health professional, the primary provider, or some combination of the three.

Consider how to best execute the initial family history collection for patients in your practice. Selecting tools to assist you should be closely tied to determining who will actually be involved in collecting the family history. Could your average patient complete a questionnaire to document his or her family history for you? Do you have Medical Assistants or Nurses on staff who can be trained to interview the patient to collect the necessary information? The answers to these questions can help determine a time efficient solution for your practice.

PARTICIPANTS
Implementation lead, staff involved in family history processes

WHAT YOU'LL NEED
Family history collection tool, clinic workflow

BARRIERS
Competing priorities, patient and provider knowledge, time, institutional role restrictions

APPROACHES

1 *Patient collection*

To save time in the face-to-face clinical encounter, many practices prefer for patients to collect family history information prior to their appointment, either through a mailed questionnaire (or emailed electronic questionnaire), or in the waiting room. Collecting this information prior to the visit allows patients to research their family histories more completely.

2 *Allied health professional collection*

Some practices have developed innovative models for family history collection, with or without a triaging component, in which a nurse or medical assistant interviews the patient to collect standard family history information. This may include the allied health professional administering a screening tool to the collected information to triage whether the patient should be seen by a provider for further risk assessment and management. In these models, the health professional conducting the family history interview receives training on what information to collect and how to document it.

3 *Provider collection*

Family history collection as part of the visit intake by the primary care provider is the most common method used in practice. This process can be streamlined by using a tool or template in the clinic note and educating the provider on the essential elements to collect and red flags to recognize for individuals with increased cancer risk.

METHOD IN ACTION

Utilizing nurse wellness visits for cancer family history risk assessment.

Family Care USA is a large family medicine residency program in a rural setting. Staff include attending physicians, physician assistants, family medicine residents, and nurses. The practice recognized a need to improve the identification of at-risk individuals for hereditary cancer syndromes, including hereditary breast and ovarian cancer syndrome and Lynch syndrome. A new telegenetics satellite office recently opened in the community, reducing access barriers for patients to be seen in cancer genetic clinic.

Family Care developed a cancer risk assessment model that utilized an existing clinic infrastructure for nurse wellness visits. The RN received specialized training on collecting and assessing family health history information for cancer. To systematize the risk assessment criteria, the practice, in collaboration with the genetic clinic, developed a Red Flags Checklist for the nurse and a Genetic Referral Checklist for the provider.

There are two points of entry into the Cancer Family History Nurse Wellness visit: (1) the provider recognizes a potential concern and refers the patient for more thorough family history collection and risk assessment or (2) the patient initiates the appointment request after receiving education through materials in the waiting room.

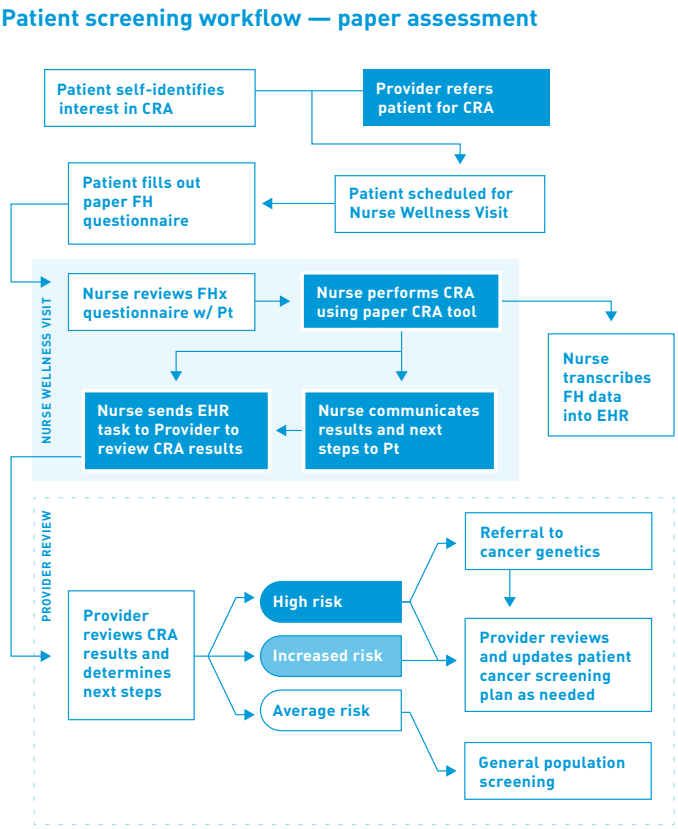


Figure 4. Workflow with 2-tiered risk assessment utilizing nurse appointment and secondary provider review of family history and paper family history collection and risk assessment tools. CRA = cancer risk assessment. FH = family history. EHR = Electronic Health Record.

In the Wellness Visit, patients complete a paper family history questionnaire that elicits structured family history information. The nurse reviews the family history, asking for additional information as needed, and completes a Red Flags Checklist to determine if the patient should be considered for changes in screening and/or a referral to genetic clinic.

The nurse submits a task in the EHR for the provider to review the patient's family history and nurse recommendation. The provider can use a Genetics Referral Checklist to determine if the patient should be referred to cancer genetic clinic. The patient is scheduled for a follow-up appointment after the Nurse Wellness Visit and genetic appointment to review any recommendations for changes in management.

This example was based on Maine Dartmouth Family Medicine Residency's model for cancer risk assessment in family practice. For more information, contact Dr. Greg Feero at W.Gregory.Feero@MaineGeneral.org.

WHO WILL INTERPRET

Family history interpretation and risk assessment may be performed by the primary care provider, but can also be aided by other team members and specialists.

After the family history is collected, determine who in the practice will be involved in interpretation of the data and performing risk assessment. This decision, too, may be made in coordination with selecting a family history tool. An electronic risk assessment tool can perform initial assessment of the family history based on algorithms, but a clinician should also review the results before changing patient management.

PARTICIPANTS
Implementation lead, staff involved in family history processes

WHAT YOU'LL NEED
Risk assessment tool

BARRIERS
Competing priorities, knowledge, infrastructure

LEARN MORE
Assessing Risk and Identifying Red Flags

Categorizing Cancer Risk

Provider Education Resources

APPROACHES

1 *Provider interpretation*

The primary care provider will always have an important role in reviewing and interpreting collected family history and performing risk assessment. These activities may fall solely on the provider, or may be shared with one (or more) of the methods described below.

2 *Two-tiered: Allied health provider and provider*

As previously described, some practices may utilize another team member to perform family history collection, which can also include initial or preliminary risk assessment. This information is shared with the provider through the EHR or another channel, and the provider reviews the initial interpretation to make a final risk assessment and recommendation to the patient.

3 *Genetic expert review*

Some practices have established relationships with local genetic clinics or commercial genetic services to assist in risk assessment. A genetic specialist reviews charts at regular intervals to identify candidates for further genetic evaluation, and communicates the recommendations back to the practice for review and follow-up.

Figure 3. Workflow with patient-entered family history collection in the waiting room and provider risk assessment using an electronic tool. CRA = cancer risk assessment. FH = family history. EHR = Electronic Health Record.

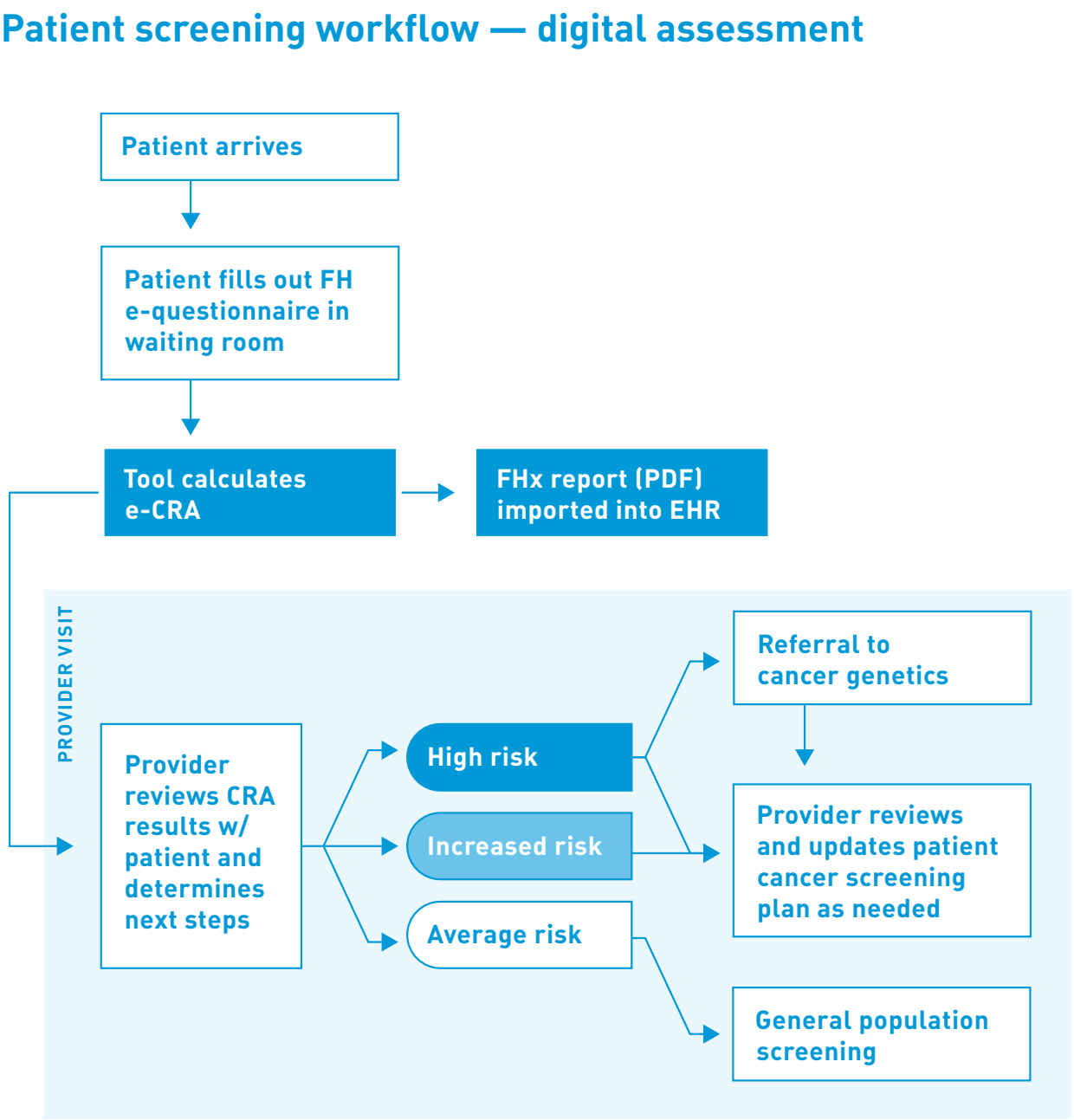
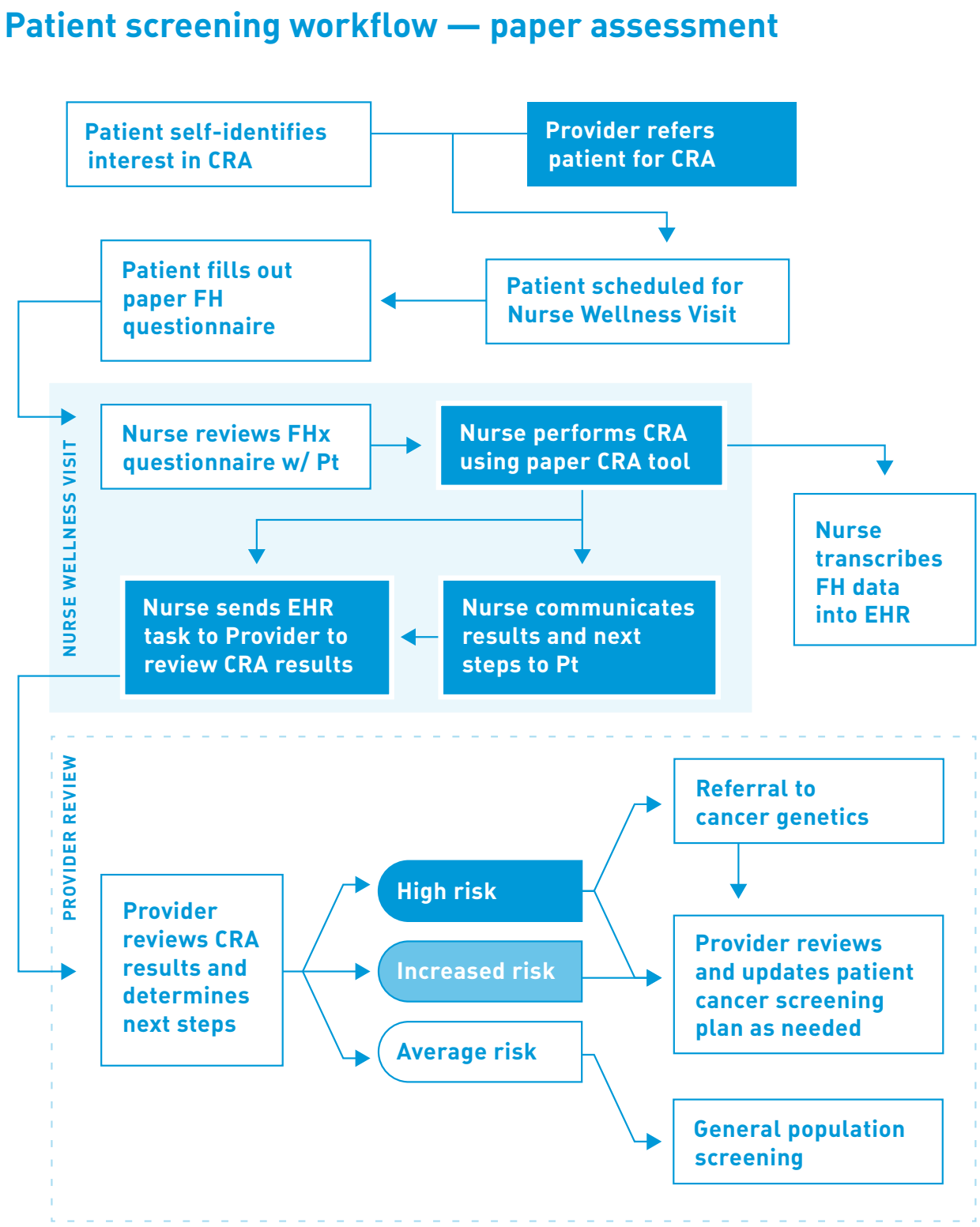


Figure 4. Workflow with 2-tiered risk assessment utilizing nurse appointment and secondary provider review. In this scenario a paper family history and risk collection tools are used. CRA = cancer risk assessment. FH = family history. EHR = Electronic Health Record.



IDENTIFYING OPPORTUNITIES FOR IMPROVEMENT AND DEFINING NEW WORKFLOW

Identify opportunities to improve your current workflow through incorporation of best practices and integration of a family history tool.

While thinking through your current and future workflows as well as best practices and examples from other clinics, you should be able to identify potential improvements to your process. Develop a new or updated workflow that will help achieve your practice's goals for using family history.

PARTICIPANTS
Implementation lead, staff involved in family history processes

WHAT YOU'LL NEED
Understanding of existing workflow

BARRIERS
Competing priorities, staff, time, infrastructure

PATIENT MATERIALS
Patient Education Materials

STEPS

1. Identify the points where delays and waste occur. Perhaps some current steps can be eliminated, such as gathering data that is never used, duplicating forms, repeating questions for patients, and storing paperwork unnecessarily.
2. Identify all the steps that you want to change with a new family history system.
3. Define a new family history workflow and summarize it in a new workflow diagram. Note the differences between your current and future workflows. You will refer to the proposed workflow as you select and implement your new system.
4. Depending on the scope of your planned changes, you may need to identify additional resources for the initial infrastructure development and/or supporting the process over time. Some practices have been successful in applying for small grants or tying cancer family history collection to institution-wide financial metrics to obtain funding.
5. Plan the change from the current system to the new one. Identify where the workflow changes occur and whether there are any intermediate transitional changes, as well as the time sequence of changes.
6. Review the proposed new system, particularly changes and new assignments, with management and all concerned parties to ensure that all issues have been resolved, to gain consensus on key decisions, and to ensure readiness to implement.

IDEAS FOR IMPROVING YOUR WORKFLOW

Consider the following steps that have been helpful for other practices.

- Have the patient collect family history information before the provider visit, and/or identify another team member such as a nurse or medical assistant who can help collect this information. Collecting this information prior to the visit allows the patients to research their family history more completely and provide more accurate information.
- Identify time for a team member to review the patient's provided family history and clarify any information, as needed.
- Provide patient education before and/or during family history collection, at the appropriate literacy level and in the patient's preferred language, to help the patient understand why it is important to share family health history with the provider and how to learn more about the family history. See page 39 and the Appendix for suggested patient materials.
- Use a tool to aid in standardized family history collection and/or risk assessment.
- Document family history in the medical record consistently across the practice.

SELECTING AND EVALUATING TOOLS FOR COLLECTION AND RISK ASSESSMENT

There are a number of tools available to aid in family history collection and family history risk assessment, with different strengths and limitations. You should pick the tool that best fits the needs of your practice.

Once you have established your goals for family history collection and risk assessment and considered your ideal workflow, it is time to determine what systems or tools you will need to aid in collection and/or risk assessment. Some EHRs provide robust family history collection systems, including pedigree generation, while the family history documentation capacity in others will be limited. In these cases, practices may consider identifying an external tool to collect the necessary information for risk assessment, or to run risk algorithms automatically. Selecting an external tool may be complex, especially if you are seeking to integrate with or adapt features of your EHR. It may involve searching out vendors who offer a solution that will do what you need to fulfill your goals at a price that fits your budget.

Start by taking inventory of what you want the tool to do. This is the point at which you review your goals for family history collection and risk assessment (page 17), as well as the workflows that you expect to have after the new process is implemented (page 29). If you want a risk assessment tool that ties to screening guidelines, you may want to review page 35, Identifying Screening Protocols, before you begin evaluating tools. Planning your workflow before you select family history tools may help you choose a tool or system that can support the workflows you need, but these activities can also be planned in parallel.

PARTICIPANTS
Implementation lead, stakeholders

WHAT YOU'LL NEED
Goals for family history; Family History Tool Features Worksheet

BARRIERS
Time, cost, competing priorities, lack of validated tools for the practice environment

LEARN MORE
Global Alliance Family History Tool Inventory

Review and Comparison of Electronic Patient-Facing Family Health History Tools

STEPS

1. Begin to find out what your options are by examining some example tools and reviewing the features shown in the Family History Tool Features Worksheet. Once you have a sense of the features available, select those that are required to enable your desired workflows. This would constitute your "must-have" list of features.
2. Generate a list of tools you will initially evaluate based on key features important to the practice, for example, an electronic collection questionnaire, or a freely available tool. You can start with tools identified in the Family History Tool Features Worksheet and add additional ones through your own search. Include your EHR on your list of tools to evaluate if appropriate.
3. Test your short list tools to evaluate what will work best for your practice.
4. Select a tool, or a set of tools, to use in your practice.

ADDITIONAL CONSIDERATIONS

Additional considerations when evaluating a family history tool

Your patient population's health literacy and language may impact required features for a family history tool. Additionally, baseline risk factors in your population may influence their needs for a tool. A tool that considers patient race and ethnicity as part of risk assessment may be important in some populations, such as those with a high proportion of African Americans.

Consider evaluating tools separately for collection and risk assessment needs. You may find that combining two tools is a better solution for your practice than just using one of the currently available tools.

If you can't find a tool that addresses all of your "must have" features, you may also need to widen your search or reevaluate your desired features, and rank them in order of importance to your patients, your office, and your goals.

If you have decided to pursue a tool that integrates with your EHR system, rather than stand-alone, evaluating and selecting a tool can be more complicated, and you may need to work with a Health IT expert to determine how to customize a solution for your practice, which is beyond the scope of this toolkit.

FAMHX TOOL FEATURES WORKSHEET

To download the spreadsheet and navigate to the tools: https://tinyurl.com/ycqeko6h

Tool Name	Collection Features				Risk Assessment					Scope			Other				
	Collection of all 1st- and 2nd-degree relatives	Patient entered collection	Electronic questionnaire	Paper questionnaire	Includes risk assessment (vs. just a collection tool)	Electronic risk assessment	Stratification to 3 categories: average, increased, high	Stratification to 2 categories: average, increased/high	Links to provider management recommendations	Includes personal as well as family history risks	Assessment of multiple cancers beyond CRC	Assessment of non-cancer conditions	Free	Spanish/ other language versions available	Validated for primary care	Maintained technology and clinical content	EHR integration
Check the "must have" features for your practice:	X	X	X		X								X				
Does It Run in the Family?	YES	YES	NO	YES	NO	n/a	NO	n/a	NO	NO	n/a	n/a	YES	YES	YES	YES	NO
Family Health History Workbook	YES	YES	NO	YES	NO	n/a	NO	n/a	NO	NO	n/a	n/a	YES	NO	NO	YES	NO
AMA Adult Family History Form	YES	YES	NO	YES	NO	n/a	NO	n/a	NO	NO	n/a	n/a	YES	NO	NO	YES	NO
Family History Questionnaire	YES	YES	NO	YES	NO	n/a	NO	n/a	NO	NO	n/a	n/a	YES	NO	NO	YES	NO
My Family Health Portrait	YES	YES	YES	YES	PARTIAL	YES	NO	YES	NO	NO	PARTIAL	PARTIAL	YES	YES	YES	YES	NO
It Runs in My Family	YES	YES	YES	NO	NO	n/a	NO	n/a	NO	NO	n/a	n/a	YES	NO	NO	YES	NO
MyLegacy	YES	YES	YES	NO	YES	YES	NO	NO	YES	YES	YES	YES	NO	NO	YES	YES	YES
Family Healthware	YES	YES	YES	NO	YES	YES	YES	NO	YES	YES	YES	YES	NO	NO	YES	YES	NO
MeTree	YES	YES	YES	NO	YES	YES	YES	NO	YES	YES	YES	YES	NO	NO	YES	YES	YES
Myriad Family History Tool	YES	YES	YES	NO	YES	YES	NO	YES	NO	NO	YES	NO	YES	NO	NO	YES	NO
Progeny/Ambry	YES	YES	YES	NO	YES	YES	NO	NO	NO	YES	YES	YES	PARTIAL	NO	NO	YES	YES
CancerGene Connect/Invitae	YES	YES	YES	NO	YES	YES	NO	NO	NO	YES	YES	NO	YES	YES	NO	YES	NO
CancerIQ	YES	YES	YES	NO	YES	YES	NO	NO	YES	YES	YES	NO	NO	NO	NO	YES	NO
CRA Health	YES	YES	YES	NO	YES	YES	NO	NO	NO	YES	YES	NO	PARTIAL	YES	NO	YES	YES
NCI CRC Risk Assessment Tool	NO	YES	YES	NO	YES	YES	NO	YES	NO	YES	NO	NO	YES	NO	NO	YES	NO
MMRPRo	NO	NO	NO	NO	YES	YES	NO	NO	NO	NO	NO	NO	YES	NO	NO	YES	NO
PREMM5	NO	YES	YES	NO	YES	YES	NO	NO	NO	NO	YES	NO	YES	NO	NO	YES	NO
MMRPredict	NO	NO	YES	NO	YES	YES	NO	NO	NO	NO	NO	NO	YES	NO	NO	YES	NO
MyRisk Hereditary Cancer Questionnaire	NO	YES	NO	YES	YES	NO	NO	NO	NO	NO	YES	NO	YES	NO	NO	YES	NO
Columbia University 3-question survey	NO	YES	NO	YES	YES	NO	NO	YES	NO	NO	NO	NO	YES	NO	NO	YES	NO
Families Sharing Health Assessment and Risk Evaluation (SHARE) workbook	NO	YES	NO	YES	YES	NO	NO	YES	NO	NO	NO	NO	YES	NO	NO	YES	NO
User-friendly Lynch syndrome risk assessment tool	NO	YES	NO	YES	YES	NO	NO	YES	NO	NO	NO	NO	YES	NO	NO	YES	NO
University of Michigan 5-question survey	NO	YES	YES	YES	YES	NO	NO	YES	NO	NO	NO	NO	YES	NO	NO	YES	NO
Simple Family History Screening Tool for CRC (See Appendix)	NO	YES	NO	YES	YES	NO	YES	NO	YES	NO	NO	NO	YES	NO	NO	YES	NO
CRC Risk Assessment Checklist (See Appendix)	NO	NO	NO	n/a	YES	NO	YES	NO	NO	YES	NO	NO	YES	NO	NO	YES	NO

Instructions

1. Identify the "must have" features for your practice, from the table above and others important to you.

   Collection of 1st and 2nd degree relatives, patient-entered collection, electronic questionnaire option, includes risk assessment, free

2. Use the Family History Tool Table to identify available tools that meet your criteria. Write down the names of your top tools below.

3. Test your list of tools to evaluate what will work best for your practice.

Tool 1: My Family Health Portrait

Tool 2: Myriad Family History Tool

Tool 3: Progeny/Ambry

Tool 4: CancerGene Connect/Invitae

Tool 5: CRA Health

IDENTIFYING GENETIC & CANCER SPECIALISTS FOR CONSULTATION

Collaborate with specialists to deliver cancer services to your patients.

One of the outcomes of risk assessment should be to identify individuals with a high cancer risk based on their personal and family histories, who should undergo further genetic evaluation for hereditary cancer syndromes. Cancer care providers and genetic experts can be a source for answers about risk assessment, genetic testing, risk communication, surveillance and risk reduction. You may develop a relationship in which you can call on these team members directly for consultation, as well as referring patients for specialty care.

PARTICIPANTS
Implementation lead

WHAT YOU'LL NEED
Accessing Genetic Services Tool

BARRIERS
Limited access to genetic services, lack of knowledge of local specialists

LEARN MORE
Referring to a Genetic Expert

STEPS

1. Identify a team of specialists who can collaborate in your patient's diagnosis, treatment, and management. Collect this information in one place to make referrals and care transitions more efficient.

2. Find your local genetic providers. Genetic counselors, clinical geneticists, and physicians, nurses, and physician assistants with specialty genetic training/expertise may be available in your institution or you may need to contact someone elsewhere. You can find a genetic specialist through:

   - National Society of Genetic Counselors (www.nsgc.org)
   - American Board of Medical Genetics (www.abmgg.org)
   - International Society of Nurses in Genetics (www.isong.org)

   It can sometimes be challenging to find a genetic expert locally. There are some opportunities available for telecounseling through academic institutions and businesses. The National Society of Genetic Counselors search function includes information about telegenetics options.

   If your practice has a relationship with a genetic testing laboratory, the lab may provide access to genetic experts to support the provider and/or provide direct patient counseling.

3. Consider contacting your local genetic and/or cancer specialists prior to making a referral to learn more about their services.

4. Inform genetic specialists about your practice's risk assessment program and referral protocols. Ideally this should be a collaborative process, with bidirectional patient and information flow over time.

IDENTIFYING SCREENING PROTOCOLS FOR INCREASED AND HIGH RISK PATIENTS

Pick the set of guidelines your practice will use to determine screening recommendations for patients with a positive family history of cancer or polyps.

There are at least eight organizations that provide guidelines for CRC screening for individuals with a family history of cancer or polyps. There is a consensus across guidelines regarding recommended screening in certain scenarios. Individuals with a first-degree relative with CRC at any age should start CRC screening at age 40. Guidelines also recommend colonoscopy at age 40, or 10 years younger than the earliest diagnosis in the immediate family, when the first-degree relative had CRC under 60 years, or when two or more first-degree relatives have CRC at any age. However, the guidelines vary in their recommendations for individuals with other patterns of family history, such as a first degree relative with history of large or advanced adenomatous colon polyps.

To develop a standardized system for CRC risk assessment and screening, providers should decide how they will consistently recommend cancer screening for patients with certain family and personal history patterns across the practice population. The evaluation of guidelines and selection of a single set of recommendations for the practice may depend on the organization(s) publishing the guidelines (e.g., single vs. multi-society, primary care vs. specialty organizations), publication year, the organizations' guideline development process, availability of evidence to support recommendations, and other factors.

PARTICIPANTS
Implementation lead, providers, specialists who may be receiving referrals or performing screening

WHAT YOU'LL NEED
Professional Society Guideliness

BARRIERS
Conflicting guidelines

LEARN MORE
NCCRT Steps for Increasing CRC Screening Rates

ACS CRC Screening Algorithm

STEPS

1. Review professional society guidelines of interest (see Table 2).
2. Select a guideline to apply to patients with a family or personal history of cancer and polyps.
3. Be aware that patients with a genetic diagnosis that significantly increases cancer risk, such as Lynch syndrome, should undergo high risk screening and surveillance per specialty guidelines (see Table 2). Management plans for such patients are often developed in coordination with cancer genetic and gastroenterology experts.

METHOD IN ACTION

Identify Screening Protocols for Increased Risk Patients

Greenville Family Medicine is a private family medicine practice in a suburban community outside of a large city. Greenville recently went through a process to establish a standardized system for CRC screening across its three locations. In addition to targeting the general population for screening, Greenville also wanted to include specific screening schedules for individuals with a positive family history of CRC or polyps according to guidelines.

The clinical champion physician and office manager started by looking for guidelines from primary care societies, and reviewed the American College of Physicians (ACP) 2012 Guidance Statement on Screening for Colorectal Cancer and American Academy of Family Physicians (AAFP) 2018 guidelines on Colorectal Cancer Screening and Surveillance in Individuals at Increased Risk.[17,19] They evaluated the guidelines focusing on the recommendations for those with a family history. ACP recommends screening with colonoscopy at 40 or 10 years prior to the youngest cancer diagnosis in the family for "high risk" patients, but does not define what family history scenarios meet criteria for high risk. AAFP also recommends colonoscopy at 40 or 10 years prior to the youngest cancer diagnosis in the family, specifying this should be for individuals with a first-degree relative* with CRC or advanced adenoma prior to 60 years of age, with repeat every 5 years. AAFP also recommends specific screening plans for additional family history scenarios, including a single first-degree relative over age 60 (colonoscopy starting at 40), multiple first-degree relatives at any age, and two second degree relatives at any age.

To confirm the population of patients who should be offered earlier screening, the practice team then expanded their review to include additional organizations. They reviewed guidelines from the National Comprehensive Cancer Network (NCCN), updated in 2018, and the Colorectal Cancer Screening Multi-Society Task Force (MSTF; includes the American College of Gastroenterology, American Gastroenterological Association, American Society for Gastrointestinal Endoscopy), published in 2017.[22,23] These guidelines were consistent with AAFP in recommending CRC screening at 40 for individuals with a first-degree relative with CRC or advanced adenoma at any age, although the recommended screening modalities vary when CRC occurs > 60 years. For those with a first-degree relative with CRC < 60, all guidelines agree that colonoscopy should begin at 40 or 10 years prior to the youngest cancer diagnosis in the family, whichever is earlier. However, while AAFP and NCCN recommend colonoscopy as the screening test for all patients with a first-degree relative with CRC regardless of age of onset, the MSTF states that individuals with a first-degree relative > 60 could be offered any of CRC screening tests used for average risk patients. The repeat screening intervals were also somewhat discordant between AAFP, NCCN and MSTF for the different risk categories (5-10 years).

After reviewing ACP, AAFP, NCCN, and MSTF, the practice ultimately adopted the AAFP guidelines, which are aligned with the others but with more detailed criteria for at-risk individuals.

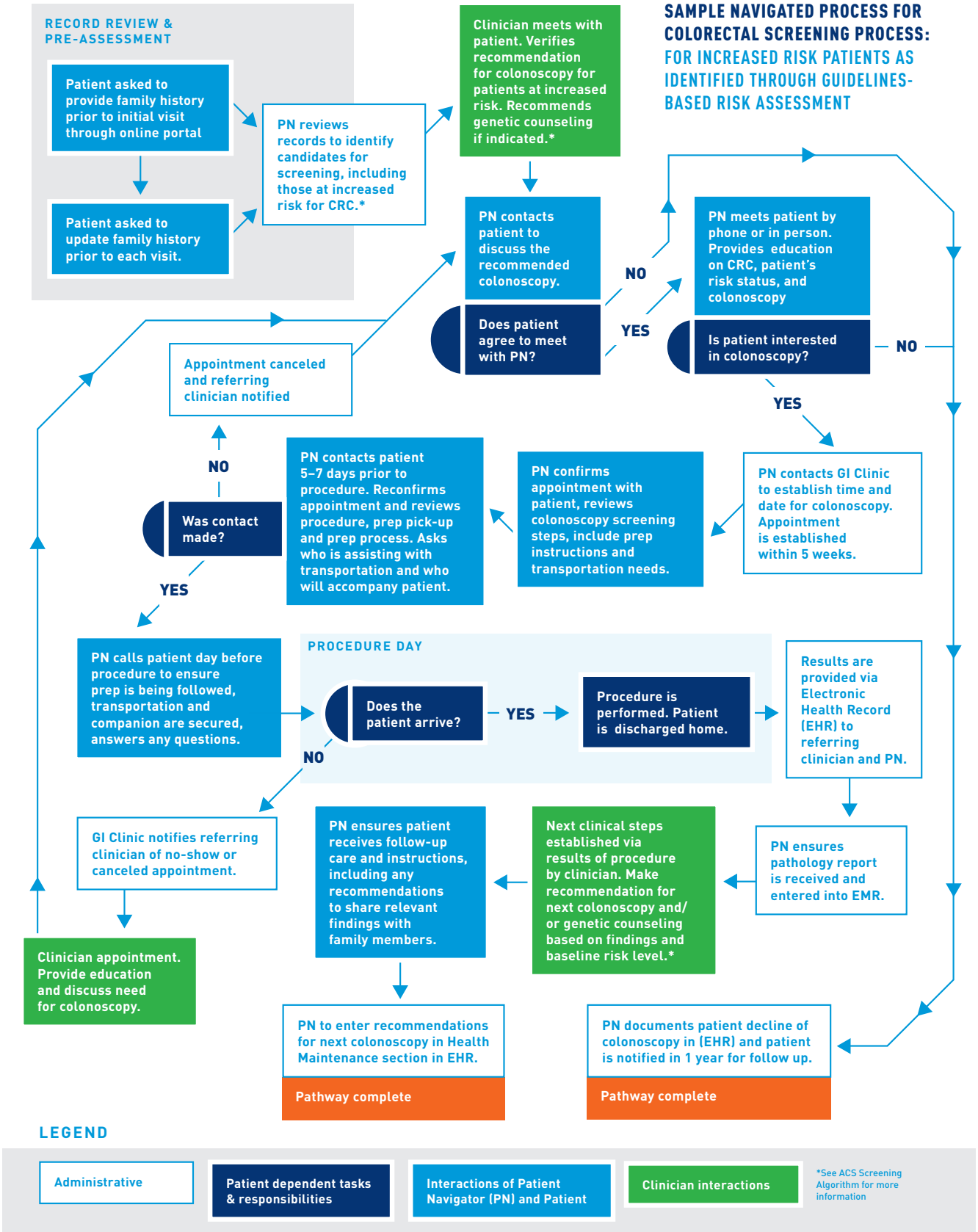
*First-degree relatives (FDR): Parents, siblings, children. Second-degree relatives (SDR): Grandparents, aunts, uncles, nieces, nephews, half-siblings, grandchildren.

PROFESSIONAL SOCIETY SCREENING GUIDELINES

Table 2. Select professional society guidelines that address screening for individuals with a family history of CRC or polyps or a high-risk cancer predisposition syndrome. See the Appendix for more detail. LS = Lynch syndrome, BMMRD = biallelic mismatch repair deficiency syndrome.

ORGANIZATION	YEAR OF PUBLICATION	
	Family history of CRC or polyps (Increased risk)	Cancer predisposition syndrome (High risk)
American Academy of Family Physicians	2018[17]	2018[17]
American College of Gastroenterology	2009[18]	2015[24]
American College of Obstetricians and Gynecologists		2014[25]
American College of Physicians	2012[19]	
American Gastroenterological Association		2015[26]
American Society for Gastrointestinal Endoscopy	2006[20]	
American Society of Clinical Oncology		2015[27]
Institute for Clinical Systems Improvement	2014[21]	
Multi-Society Task Force (American College of Gastroenterology, American Gastroenterological Association, American Society for Gastrointestinal Endoscopy)	2017[22]	LS 2014[28] BMMRD 2017[29]
National Comprehensive Cancer Network	2018[23]	2018[23]

Figure 5. Sample navigated process for colorectal screening: For increased risk patients as identified through guidelines-based risk assessment



IDENTIFYING PATIENT MATERIALS

Engage the patient with patient-friendly education and information.

Patient brochures and websites can be helpful to provide more information and reinforce your discussions about family history risk assessment, genetic evaluation, cancer screening, and healthy lifestyle.

PARTICIPANTS
Implementation lead

WHAT YOU'LL NEED
Workflow

BARRIERS
Patients with low literacy levels and non-English language, limited patient-focused educational and decision support resources

PATIENT MATERIALS
Patient Education Materials

STEPS

1. Review your clinical workflows to identify the points of the process at which patient materials are indicated. This may include education about:
   - Family health history. Resources to help the patient collect family history information. This may be part of or independent from your selected family history collection tool.
   - Cancer risk factors and prevention. Resources that address cancer risk factors and strategies for disease prevention.
   - Genetic counseling referral. Resources to help prepare the patient for a genetic counseling appointment.
   - Colorectal cancer screening. Resources to educate the patient about CRC screening and to support shared medical decision making.
2. Review and select materials that address the needs of your patient population. See the curated list of resources in the Appendix as a starting point and identify additional materials as needed. Consider your patients' general health literacy, preferred languages, and culture when selecting resources.

IDENTIFYING EVIDENCE-BASED INTERVENTIONS TO FACILITATE SCREENING ADHERENCE IN INCREASED RISK PATIENTS

Increase CRC screening through interventions tailored to the patient's health beliefs and barriers.

In addition to establishing a system for family history collection and risk assessment, primary care practices can consider interventions to promote cancer screening in the increased and high risk populations. Like other areas of medicine, a proportion of patients will not follow through with appropriate screening despite a clinician's recommendation. Studies have shown that more intensive, personalized interventions, which are built on an awareness of patient barriers and motivators, are most likely to have a positive impact on CRC screening adherence in individuals with a family history of cancer.

PARTICIPANTS
Implementation lead, staff involved in family history processes

BARRIERS
Time, infrastructure, funding, limited patient-focused educational and decision support resources

LEARN MORE
NCCRT How to Increase Preventive CRC Screening Rates in Practice

NCCRT Messages to Reach the Unscreened

STEPS

1. Review recommended interventions for individuals with a family history of CRC. Select programs that have been shown to increase screening rates are listed on the next page.
2. Review recommended interventions for general population screening. See the How to Increase Preventative CRC Screening Rates in Practice Clinician's Guide from NCCRT for recommendations.
3. Work through the implementation process to integrate interventions into practice: Set goals, select interventions, develop or adapt workflows, launch, and evaluate.

RECOMMENDED INTERVENTIONS

Recommended interventions for individuals with a family history of CRC. Select programs that have been shown to increase screening rates are listed below.

Combination of a culturally sensitive face-to-face health counseling intervention, print materials, and follow-up phone calls.[30]

Print and telephone interventions tailored to patient response on a baseline survey and also to demographics of marital status, gender, and ethnicity.[31]

Telephone and in-person consults for noncompliant individuals.[32]

Combination of letters, face-to-face counseling and phone calls.[33]

Telephone interventions tailored to patient response on a baseline survey.[34,35]

A remote, tailored-risk communication and motivational interviewing intervention delivered by a genetic counselor. The program also included an arm with free or low-cost colonoscopy to individuals who were noncompliant and had previously reported that cost was a barrier (Tele-Cancer Risk Assessment and Evaluation; TeleCARE).[36,37,38]

A printed booklet with personalized risk assessment, ethnically targeted to African American, Latino, White and Asian patients and tailored to patient response on a baseline survey, followed by a tailored telephone intervention to unscreened individuals.[39]

A tailored intervention in which patients fill out a health behaviors self-questionnaire and then received personalized printed materials to share with their primary care clinicians.[40]

CONSIDERATIONS FOR PROVIDING DIRECT GENETIC COUNSELING AND TESTING

Cancer genetic testing can be complex, and should be done in conjunction with genetic counseling by qualified providers.

Patients at risk of a hereditary cancer syndrome should undergo further cancer risk assessment, genetic counseling, and genetic testing. The genetic counseling process helps people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease. This process integrates risk assessment, education, and counseling. In some cases, it includes the offer of genetic testing, decision-making support and interpretation of results. Genetic counseling is best provided by specialists with knowledge and experience in clinical genetics, such as board certified genetic counselors, physician geneticists, and physicians, advanced-practice nurses, and physician assistants with dedicated training and expertise in cancer genetics.

This toolkit does not provide instruction on how to integrate genetic testing into the primary care practice, but interested practices may consider the following issues when deciding to offer counseling and testing in-house.

PARTICIPANTS
Implementation lead, providers

BARRIERS
Provider and staff training, time

LEARN MORE
Provider Education Resources

CONSIDERATIONS

Education. Primary care clinicians that offer genetic counseling and genetic testing do so after advanced training, which may include participation in specialized training programs, seeking out relevant education courses, finding a mentor, and education and support through a genetic testing laboratory. Clinicians should continually keep abreast of rapidly changing information and guidelines in cancer genetic testing. See the Appendix for a select list of education and training.

Genetic testing labs. Many laboratories offer cancer genetic testing. Select a reputable, CLIA-certified lab that can work with your institution and the patient's insurance company. In addition, consider the level of guidance you and your patient will need and investigate the support services the lab offers throughout the testing process. Labs may offer provider training, genetic counseling, a family history tool, and assistance with test ordering.

Implementation. Just as you would for other clinical processes, incorporating genetic counseling and genetic testing into practice requires an implementation plan that includes administrative and workflow planning. This may include defining certain scenarios in which the office would offer testing (for example, for hereditary colon and breast cancers) with a policy to refer other and more complex cases to a specialist. It should also include protocols for providing pre- and post-test genetic counseling. Systems must be in place to track insurance issues, advancements in genetic testing technology, and evolving clinical science.

Management. Practices that order genetic testing should be well versed on management protocols for high risk patients.

TRAINING

Prepare the whole team for success by providing adequate training.

Now that you have selected your system, planned the transition and any work process changes that will be needed, and started the system setup, you are ready to train the members of your practice for transition to the new system.

PARTICIPANTS
All team members

WHAT YOU'LL NEED
Workflow, family history tool

BARRIERS
Time, infrastructure, funding

STEPS

1. Identify training goals and what is needed for different members of the team. Depending on their roles and existing skills, the following training might be needed:
   - How to use the family history tool
   - Orientation to new workflows
   - Orientation to the value of the new system
   - Education about how to collect family history information, cancer genetic red flags, and criteria for increased and high risk.
2. Perform a needs assessment to inform what level of education is needed for staff and how to best deliver training.
3. Provide opportunities for hands-on practice with the family history tool and interpretation of family history risks. Use example patient histories to move through risk assessment and management workflows to ensure team members are comfortable with the steps of the process.
4. Consider when to provide training refreshers for the team and how you will train any new staff joining the practice after implementation.

PLANNING FOR LAUNCH

Prepare staff and patients for launch.

Make plans for launching the new system in practice. Consider other practice, health system, and community events when deciding when to deliver training and launch the new system. Try to avoid initial implementation at the same time as major initiatives are launching, such as significant EHR updates or other quality improvement projects.

PARTICIPANTS
Implementation lead

STEPS

1. Establish a launch date and create a transition plan leading up to launch.
2. Plan for forms, hardware and internet needs. If your workflow requires a new form or the use of tablet computers for patients to fill out their family history, create a plan for obtaining and setting up these components.
3. Schedule and deliver training.
4. Communicate to patients and clinical partners. You may find it helpful to announce the initiative to patients through a poster in the waiting room or message through your portal. If you anticipate increased referrals to genetic or other specialists, let them know what to expect.

MONITORING AND EVALUATION

Evaluation and iteration will promote improvement.

Monitoring and iterative program improvement are arguably the most important implementation steps, yet are frequently overlooked. The areas that you decide to measure and monitor should be directly related to the goals that you originally set. Now you or someone in your practice will need to compile data on these measures, review the results, and decide whether or not action is needed to achieve (or better achieve) your original goals.

PARTICIPANTS
Implementation lead

WHAT YOU'LL NEED
Measurement plan

BARRIERS
Time, competing priorities

LEARN MORE
NCCRT Evaluation Toolkit

STEPS

1. Review and update the measurement plan you first identified when goal-setting. As needed, further define the metrics and outcomes you will assess to monitor progress towards your goals.
2. A simple tracking system will help you follow up as needed. Track actions taken over time, such as referrals to genetic and cancer specialists and screening and surveillance procedures for those individuals at increased risk. Maximize the capacity of your EHR to assist with tracking.
3. Keep up with clinical knowledge. Some guidelines are updated multiple times a year. Ensure that updates are made to the clinic process when risk assessment or management guidelines are changed, and that staff are kept abreast of relevant changes in clinical knowledge.
4. Evaluate patient and provider satisfaction and suggestions for change. Consider modifying your workflow or providing focused training on areas identified for improvement.

Chapter 3

Clinical Skills and Tools for Patient Care

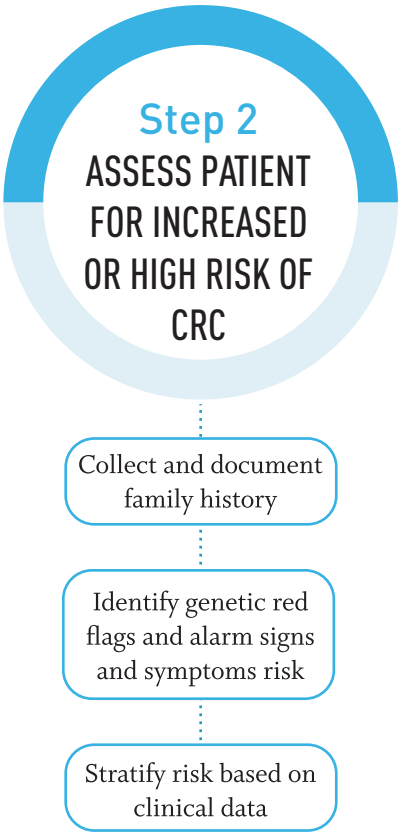
ASSESS PATIENT FOR INCREASED OR HIGH RISK OF CRC

Approximately 1 in 10 individuals has a family history of cancer that would warrant earlier screening. In order for these patients to benefit from the preventative and risk reducing benefits of cancer screening, primary care clinicians need to collect and interpret family health history, identify next steps in management based on risk, and evaluate for CRC. The steps in Chapter 3 can help clinicians build essential knowledge and skills related to the collection, assessment, and management of cancer risk, regardless of the specific workflow in place in the office.

In order to identify patients with an increased or high risk of CRC, the clinician needs to collect family history information with enough detail to inform accurate risk assessment. It is also important that this family history data is documented in the medical record in a way that can be easily accessed and updated over time.

Family history risk assessment involves interpreting the patient's family history as well as personal history to identify red flags and patterns that may suggest predisposition to CRC and then using that information to stratify risk into average, increased, and high risk categories to inform personalized management. Risk assessment for CRC may also include looking for alarm signs and symptoms of a possible presenting cancer.

As you work through the following sections on risk assessment, visit the links to online education on the left side-bar for opportunities to practice these skills.



COLLECTING SUFFICIENT FAMILY HISTORY

Collect history that indicates family structure and manifestations of disease.

Most patient family history forms and EHR templates are not specific enough to allow you to assess for cancer risk appropriately. It is important to ask additional questions about any relatives who have been diagnosed with cancer to assess the potential for underlying genetic risk. A good tool can help structure your questioning.

PARTICIPANTS
Provider, patient

WHAT YOU'LL NEED
Family history collection tool

BARRIERS
Lack of complete family history knowledge, misattributed family relationships (e.g., paternity), time

PRACTICE THIS SKILL
Web module on Collecting Family History

LEARN MORE
Selecting and Evaluating Tools for Collection and Risk Assessment

ACS Understanding Your Pathology Report: Polyps

STEPS

1. Determine who is in the family. Include at least parents, children, siblings, grandparents, aunts/uncles and nieces/nephews on both the maternal and paternal side. Expand to more distant relatives, such as first cousins, when it will help clarify your risk assessment. Asking about additional relatives can be helpful in situations in which there is an unusual cancer history, such as a rare or single early-onset cancer, or where there is limited family history information on closer relatives. Asking about each individual is more effective than just asking if anyone in the family has had cancer.
2. Ask about all types of cancer history, not just CRC. Cancer syndromes can include risk for multiple types of cancers. CRC is not always a presenting cancer. Ask about age of onset, history of more than one cancer, whether cancer is multifocal (multiple primary foci of cancer in the same organ at the same time) or bilateral. Ask about detailed polyp history, including the total number of polyps removed, ages at removal, and polyp type.
3. Ask if any relatives have had genetic counseling and/or genetic testing.
4. Ask about ancestry and ethnicity. African American ethnicity may be considered a risk factor for CRC.

DOCUMENTING FAMILY HISTORY INFORMATION

Record the collected family history in a way that is easy to read and update by anyone on the team.

In addition to the family structure and details about cancer history in the family, include documentation about when the information was collected or updated and who provided it. See the sidebar link for guidance on standardizing where to document family history in the medical record.

PARTICIPANTS
Provider, patient

WHAT YOU'LL NEED
Family history collection tool, EHR

BARRIERS
EHR limitations, time

PRACTICE THIS SKILL
Web based module on Collecting Family History

LEARN MORE
Where to Document

STEPS

1. Include date of collection (or date of update), and the name of collector (or updater).
2. Identify the patient, the historian (person providing the information). The historian may be the patient or someone else, such as a parent.
3. Include the detailed information you collected about family and cancer history.
4. Include a legend or key, if symbols are used to designate disease.

ASSESSING RISK AND IDENTIFYING RED FLAGS

Accurate risk assessment involves a synthesis of multiple data points, including family and medical history, patient race or ethnicity and lifestyle, behaviors, and exposures.

Risk assessment begins with identifying genetic red flags and looking for patterns in the family history, as well as considering any alarm signs and symptoms for a present cancer. The next step will be to stratify risk. The next page includes the risk factors that may change risk from one level to another, for example, from average to increased risk. See the resources on the left side-bar to learn more about cancer risk factors.

PARTICIPANTS
Provider, patient

WHAT YOU'LL NEED
Risk assessment tool

BARRIERS
Incomplete or missing family history information, misattributed family relationships (e.g., paternity), complex family relationships and structure, small families, adoption, early deaths due to other causes, prophylactic surgeries that may prevent cancers, and lack of medical record documentation

PRACTICE THIS SKILL
Web based module on Identifying Red Flags and Patterns that Increase Cancer Risk

Web based module on Identifying and Managing Lynch Syndrome

LEARN MORE
NCI CRC Prevention PDQ

STEPS

1. Identify personal risk factors that may change risk level.
2. Identify genetic red flags in the family history.
3. Identify patterns in the family history that can point to inheritance patterns, familial clustering of cancer, or specific high-risk syndromes.
4. Identify alarm signs and symptoms in the patient's current clinical presentation that may be indicative of underlying CRC. Don't ignore these signs because the patient is young; though less common, young adults can develop CRC.

RISK FACTORS THAT INFLUENCE RISK STRATIFICATION

PERSONAL RISK FACTORS THAT MAY CHANGE RISK LEVEL

- past cancer, especially colorectal or endometrial
- past advanced adenomas or serrated colon or rectal polyps (confirmed by pathology reports)
- inflammatory bowel disease
- African American ethnicity may change risk level, but guidelines are conflicting on this point

GENETIC RED FLAGS IN THE FAMILY HISTORY

- early onset (< 50 years) cancer or advanced adenomatous colorectal polyp (> 1 cm, confirmed by pathology)
- multiple relatives with the same or associated cancers* on the same side of the family
- multifocal (multiple primaries) or bilateral cancer
- individual with greater than 10 adenomatous colorectal polyps (confirmed), or polyps with unusual histology (e.g., juvenile polyps, Peutz-Jeghers polyps, or ganglioneuromas)
- known genetic syndrome in family

PATTERNS IN THE FAMILY HISTORY

- several colon, rectal, endometrial, gastric, small bowel, ovarian, urinary system, renal pelvis, pancreatic, brain (usually glioblastoma) and/or sebaceous cancers on the same side of the family
- associated cancers* in multiple generations (dominant inheritance)
- predominately siblings affected (recessive inheritance)

ALARM SIGNS AND SYMPTOMS IN THE PATIENT'S CURRENT CLINICAL PRESENTATION THAT MAY BE ASSOCIATED WITH CRC REGARDLESS OF AGE OR FAMILY HISTORY

- blood in stool
- recent onset, persistent or progressive diarrhea and/or constipation
- persistent or progressive abdominal pain
- unexplained iron deficiency anemia
- abdominal mass
- unexplained weight loss

**colon, rectal, endometrial, gastric, small bowel, ovarian, urinary system, renal pelvis, pancreatic, brain (usually glioblastoma) and/or sebaceous skin lesions and keratocanthomas*

CATEGORIZING CANCER RISK

Stratify patient cancer risk into average, increased (moderate) or high risk to determine management and next steps.

The risk assessment process starts by identifying red flags and patterns in the patient's family history, and then uses that information to stratify individuals into average, increased, or high risk. The goal of this simplified 3-tiered stratification is to identify individuals who should 1) consider more frequent and/or earlier screening (increased risk) or 2) be referred to genetics for further evaluation and undergo high risk cancer screening (high risk). Remember that anyone presenting with alarm signs and symptoms of CRC should move straight to further evaluation (see page 61), but still might need to see genetics in the future for cancer genetic risk assessment. See guidelines for specific increased and high risk criteria.

The steps below are educational in nature and address general patterns seen in hereditary and familial cancers. As discussed in Chapter 2, you can customize your process and select tools to help you assess and stratify risk that align with the goals of your practice.

PARTICIPANTS
Provider, patient, IT

WHAT YOU'LL NEED
Risk assessment tool

BARRIERS
Incomplete or missing family history information, misattributed family relationships (e.g., paternity), complex family relationships and structure, small families, adoption, early deaths due to other causes, prophylactic surgeries that may prevent cancers, and lack of medical record documentation

PRACTICE THIS SKILL
Web based module on Categorizing Cancer Risk

LEARN MORE
Establish a System for Structured Assessment

Professional Society Guidelines

STEPS

1 Based on the red flags identified in the patient history, assign a risk category.

High risk: individuals at risk for a hereditary cancer syndrome.
Individuals at high risk for a hereditary cancer syndrome typically have one or more of these general family history features:

- 3 or more relatives with similar or related cancers
- 2 generations of cancer cases, and
- 1 or more individuals diagnosed at a younger than usual age (< 50 years) or with a rare presentation, such as > 10 adenomas or a known hereditary cancer syndrome

Moderate/increased risk: those with personal or familial risk factors.

A patient may be at increased risk for cancer because of a family history contribution, or personal and lifestyle risk factors, or a combination of the two.

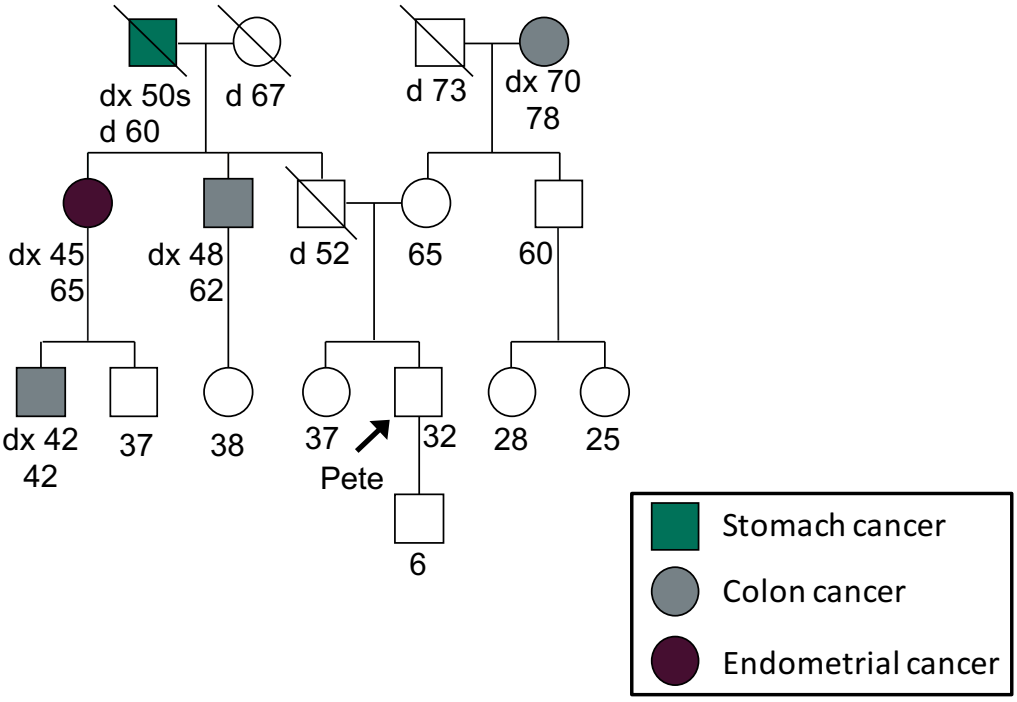
- Family histories suggestive of increased risk may show familial clustering of cancer but do not meet the criteria for high risk.
    - One first-degree relative with CRC at average age (> 60 years), or
    - Two second-degree relatives with CRC at any age
- Consider risk factors in personal history, such as inflammatory bowel disease and ethnicity.

Average risk: those with few or no risk factors.

WORKED EXAMPLE OF RISK ASSESSMENT TOOLS

Patient presents with the following collected family history:

Paternal uncle with CRC dx at 48, living at 62
Paternal aunt with endometrial cancer dx at 45, living at 65
Paternal cousin with CRC dx at 42, living at 42
Paternal grandfather with stomach cancer in 50s, died at 60
Maternal grandmother with CRC dx at 70, living at 78



COLORECTAL CANCER RISK ASSESSMENT CHECKLIST

POSSIBLY HIGH RISK

- ☐ Patient or first-degree relative[1] with colon or rectal cancer before age 50
- ☐ Patient or first-degree relative with uterine cancer before age 50
- ☐ Patient or relative with more than one of the Lynch-associated[2] cancers (in the same person) (Lynch-associated cancers include: Colon, rectal, uterus, stomach, small intestine, ovary, urinary system, renal pelvis, pancreas, brain (usually glioblastoma), and sebaceous skin lesions and keratoacanthomas)
- ☐ Patient with cancer and an abnormal tumor screening test for Lynch syndrome
- ☐ Patient with 10 or more precancerous polyps (adenomas), 2 or more hamartomatous polyps, or 5 or more serrated polyps
- ☒ One member of the family (may include the patient) with colon cancer at or after age 50 and a first- or second-degree relative on the same side of the family with any of the Lynch-associated cancers[2] before age 50
- ☒ Three members on the same side of the family (may include the patient) with any of the Lynch-associated cancers[2] at any age
- ☐ Patient or a relative with any of the Lynch-associated cancers[2] at any age with a limited family history due to early death, a small family or adoption
- ☐ A known mutation in a colon cancer gene (*MLH1, MSH2, MSH6, PMS2, APC*, others) in the family

POSSIBLY INCREASED RISK

- ☐ Personal history of CRC
- ☐ Personal history of adenomas or sessile serrated polyps
- ☐ Personal history of inflammatory bowel disease (Ulcerative colitis or Crohn's colitis)
- ☐ African American ancestry
- ☐ One or more first-degree relatives with CRC or confirmed advanced adenoma at any age
- ☒ One or more second degree relatives with CRC <50

AVERAGE RISK

- ☐ Absence of the above risk factors

1 First-degree relatives (FDR): Parents, siblings, children. Second-degree relatives (SDR): Grandparents, aunts, uncles, nieces, nephews, half-siblings, grandchildren.

2 Colon, rectal, uterus, stomach, ovary, small intestine, pancreas, ureter and renal pelvis, brain (usually glioblastoma), as well as sebaceous skin lesions and keratoacanthomas.

Adapted with permission from work by Gregory Feero, MD, PhD and Susan Miesfeldt, MD. Disclaimer: This checklist was developed by primary care and genetic experts based on NCCN guidelines but has not been validated. These risk criteria are designed to assist in the clinic-based evaluation of patients and families. They do not reflect all increased and high risk criteria, and may not reflect guidelines that have been updated past the date of this publication. For questions regarding individual patients and families, contact your local cancer genetic provider.

SIMPLE FAMILY HISTORY SCREENING TOOL FOR CRC

	YES	NO
1. Have you had either of the following conditions diagnosed before age 50?		
Colon or rectal cancer		
Colon or rectal polyps		
2. Do you have a first-degree relative (mother, father, brother, sister, or child) with any of the following conditions diagnosed before the age of 50?		
Colon or rectal cancer		
Cancer of the uterus, ovary, stomach, small intestine, urinary tract (kidney, ureter, bladder), bile ducts, pancreas, or brain		
3. Do you have three or more relatives with a history of colon or rectal cancer? (This includes parents, brothers, sisters, children, grandparents, aunts, uncles, and cousins)	X	
If YES to any question → Refer for additional assessment or genetic evaluation.		
If NO to all → proceed with the following questions:		
4. Do you have any first-degree relatives (mother, father, brother, sister, or child) with cancer of the colon or rectum?		
If NO → Average risk family. Provide average risk screening guidelines to patient and their family members (start screening with any acceptable test at age 50)*		
If YES to #4, proceed with the following questions:		
5. Was the first-degree relative under age 60 when CRC was diagnosed?		
6. Do you have more than one first-degree relative with CRC?		
If both NO → Intermediate risk family. Provide risk-based screening guidelines to patient and their family members.		
If either YES → High risk family. Provide high risk screening guides for patient and their family members.		

**The 2018 ACS guidelines for CRC screening now recommend that CRC screening start at age 45 for average risk individuals, while the USPSTF recommends starting at age 50. Please adjust the chart as needed, per your practice's protocol.*

Published by:
Kastrinos et al. Am J Gastroenterol. 2009;104:1508.
Giardiello et al. Am J Gastroenterol. 2014;109:1159.
Patel et al. Dig Dis Sci. 2015;60:748.

COMMUNICATING RISK

Tailor conversations about levels of risk to patient learning styles and needs.

Talk with your patient about their level of cancer risk (average, increased, high) based on your assessment. People understand risk differently, and it can be helpful to communicate risk in multiple ways to facilitate patient understanding.

PARTICIPANTS
Provider, patient, possibly family members

BARRIERS
Provider ability to tailor risk communication, patients with limited health literacy, patients with limited numeracy, patients may not be in contact with at-risk relatives, limited existing resources to aid in family communication

PRACTICE THIS SKILL
Web based module on Categorizing Cancer Risk

LEARN MORE
Communicating Risk Factsheet

Understanding Cancer Risk

STEPS

1. Tailor risk communication to the specific individual. People interpret and react to risk numbers differently based on many factors. Try to frame risk in multiple ways to facilitate understanding: quantitative or qualitative, which may include absolute and relative risks (see examples below). It can be helpful to compare the patient's risk to the general population to promote understanding of the increase in risk based on your assessment.

2. Consider using visuals and teaching tools. Illustrations and factsheets may be helpful to reinforce important information. Visual representations of risk such as pictographs and bar graphs can help the patient understand his or her personal risk.

3. Recommend that your patient share risk information with relatives. When your patient's history affects his or her relatives' risk, clinicians have a duty to warn their patients about the risk of the condition among relatives and encourage the patient to communicate about their risk. This is especially important if there is a positive genetic test result.

Table 3: Risk Communication Examples

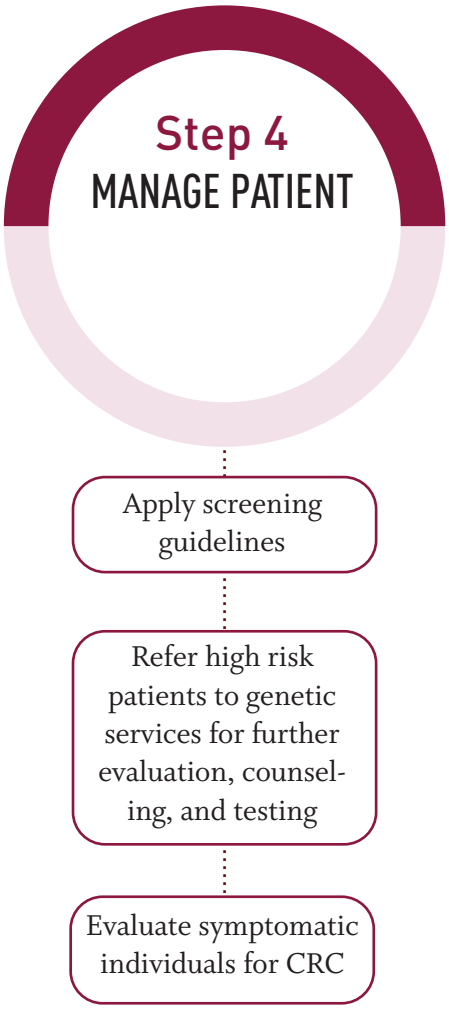
For an individual with about a 10% lifetime risk of colorectal cancer when the general population risk is about 5%.		
Quantitative:	Risk given in fractions or percentages	
	Absolute	"You have about a **10% chance** to develop colon cancer in your lifetime, compared to the average person with a 5% chance."
		"You have about a **1 in 10 risk** of colon cancer."
	Relative	"Your chance to develop colon cancer is **doubled**."
		"You are **twice as likely** to develop colon cancer than an individual without your risk factors."
Qualitative	Risk given in descriptive terms	
		"Your risk is **increased** compared to the general population."

MANAGE PATIENT BASED ON RISK LEVEL AND CLINICAL SIGNS AND SYMPTOMS

Management of patients with increased risk can include a range of tests, services, and clinical actions. Generally speaking, individuals at increased risk of CRC should undergo earlier and/or more frequent CRC screening and individuals at high risk should be referred for genetic counseling and possible genetic testing and may be candidates for high-risk cancer screening, surveillance, and prevention practices. In the following sections, you will read more about cancer screening, surveillance, and prevention practices for individuals at different risk levels.

Patient communication is also a key element of effective management. In addition to communicating about CRC risk and prevention in a patient-friendly way, the patient should have a clear understanding of the management plan outlined by his or her clinician. A clinician's recommendation is the main factor influencing whether or not a patient undergoes CRC screening.

The management activities discussed in this toolkit are for the most part focused on mitigating risk for a future cancer. However, the section on evaluating symptomatic patients for CRC has an additional context: the presenting patient may actually have cancer at the time of the clinical encounter. When the presenting patient exhibits alarm signs or symptoms of a possible cancer, clinicians should follow guidelines about evaluation and diagnosis of cancer, regardless of the patient's age and other risk factors. Screening guidelines that identify when and how at-risk individuals should undergo screening do not apply to the symptomatic individual.



USING FAMILY HISTORY TO INFORM MANAGEMENT

Family history information can help guide management decisions for increased and high risk patients.

In general, increased risk patients are candidates for earlier or more frequent CRC screening and high risk patients should be referred to genetics for further evaluation and care coordination. The steps below are educational in nature and summarize general components of a management plan as outlined in national guidelines. Always consult the most recent guidelines for patient management. As discussed in Chapter 2, your practice may wish to identify a set of cancer screening guidelines that will be used consistently across the practice.

In some cases, professional guidelines about management for different risk levels are inconsistent. Especially in these cases, providers should use family history information to help facilitate informed decision-making by the patient about screening, and may contact an expert if in doubt.

PARTICIPANTS
Provider, patient

WHAT YOU'LL NEED
CRC screening algorithm

BARRIERS
Conflicting guidelines, changing recommendations

PRACTICE THIS SKILL
Web based module on Using Family History to Inform Management

Web based module on Identifying and Managing Lynch Syndrome

LEARN MORE
Cancer Screening Factsheet

Identifying Screening Protocols for Increased and High Risk Patients

Professional Society Guidelines

NCCRT Steps for Increasing CRC Screening Rates

PATIENT MATERIALS
Patient Education Materials

STEPS

1. Develop an appropriate risk reduction plan based on personal and family history assessment. See next page for ideas.
2. Communicate your recommendations to the patient and engage the patient in shared-decision making about screening and management options. **A provider's recommendation is the #1 factor influencing the patient's decision to undergo screening. See the example script that follows.**
3. Colonoscopy, rather than other CRC screening tests, is generally recommended for patients at increased or high risk based on personal and/or family history. As always, a screening test should be selected through shared-decision making with the patient to discuss the benefits, risks, limitations, and alternatives.
4. Encourage individuals at increased or high risk to communicate with their family members about the cancer risk in the family, so that relatives can also talk with their providers about cancer screening and genetic testing as appropriate.
5. Provide patient education materials about the next steps, such as a colonoscopy or referral to genetics.
6. Identify a plan to follow-up and discuss additional patient questions and medical management issues as needed. Document plan in medical record and provide patient with a written copy of the plan.

RISK REDUCTION PLAN

Always consult the most recent guidelines for patient management.

AVERAGE RISK

- Regular CRC screening at age 45 or 50 according to recognized guidelines and the practice's desired protocol.*
- Other screening as recommended by recognized guidelines
- Advise that specific lifestyle changes may modify the risk for cancer

INCREASED (MODERATE) RISK

- CRC screening at earlier ages/more frequent intervals than average risk individuals, such as screening at 40 or 10 years earlier than the youngest diagnosis in the immediate family (dependent on family/medical history and polyp burden)
- Consider chemoprevention, such as aspirin
- Regular updates of family history are important (diagnosis of colon or a Lynch-associated cancer** in one or more family members may change risk category)
- Advise that specific lifestyle changes may modify the risk for cancer

HIGH (STRONG) RISK

- More intensive and frequent colonoscopy and screening for other related cancers (often annually) beginning in the twenties or earlier
- Consider chemoprevention, such as aspirin for CRC risk and oral contraceptives for ovarian cancer risk
- Prophylactic surgery as an option for risk reduction
- Participation in clinical trials
- Examinations to detect other manifestations of the hereditary syndrome
- Cancer genetic counseling (if not already done)
- Advise that specific lifestyle changes may modify the risk for cancer

** The 2018 ACS guidelines for CRC screening now recommend that CRC screening start at age 45 for average risk individuals, while the USPSTF recommends starting at age 50.*

***colon, rectal, endometrial, gastric, small bowel, ovarian, urinary system, renal pelvis, pancreatic, brain (usually glioblastoma) and/or sebaceous skin lesions and keratocanthomas*

SAMPLE INCREASED-RISK COUNSELING SCRIPT[42]

"Because you are at increased risk for colorectal cancer [state the reasons], I recommend that you have a colonoscopy. A colonoscopy is an exam in which the doctor inserts a thin, flexible tube to look at the inside of the intestine. This procedure is usually painless and allows us to find and remove growths (polyps) in the colon. If you have a polyp, it can be removed right there during the time of the colonoscopy, and taking it out may help prevent cancer. The main risks are perforation (making a small hole), complications from anesthesia, or bleeding following removal of a polyp. These risks are very uncommon. If we do find cancer, then treating it early may help save your life."

REFERRING TO A GENETIC EXPERT

A genetic expert can provide comprehensive cancer risk assessment, facilitate genetic testing, and interpret and communicate results to the patient.

Genetic experts are medical geneticists, genetic counselors, and physicians, advanced practice nurses, and physician assistants with specialized genetic expertise and training. Through patient education and shared-decision making, the genetic expert will facilitate genetic testing when indicated, and interpret results in context of the patient's personal and family history. Genetic experts are also a resource for you for guidance on cancer genetic risk assessment as well as management.

PARTICIPANTS
Provider, patient, genetic expert

WHAT YOU'LL NEED
Accessing Genetic Services Tool

BARRIERS
Lack of knowledge of where to refer, lack of patient follow-up

PRACTICE THIS SKILL
Web based module on Pre-test Decisions and Counseling

LEARN MORE
Components of a GC Session Factsheet

Identifying Genetic & Cancer Specialists for Consultation

PATIENT MATERIALS
Patient Education Materials

STEPS

1 Communicate the reason for the referral. Patients are more likely to adhere to the recommendation to undergo genetic counseling if they understand the potential benefits of the process.

2 Prepare your patient for what to expect during a genetic visit. A genetic counseling appointment may seem very different compared to other medical encounters, due to the length, detailed discussions, and involvement of family members. Review the main components and logistics of a genetic counseling visit to help prepare the patient and set expectations.

> Tip | For all patients and especially those that are uncertain about genetic testing, reassure them that genetic counseling is the process to help them decide if genetic testing is right for them. Genetic testing is optional, and the appointment is an opportunity to learn more.

3 Provide contact information for genetic services and identify next steps in the referral process. If you don't already know your local genetic providers, you can identify them on these websites, which include information about telegenetics:

- National Society of Genetic Counselors (www.nsgc.org)
- American Board of Medical Genetics (www.abmgg.org)
- International Society of Nurses in Genetics (www.isong.org)

4 Facilitate the flow of necessary information to the specialist. A genetic consultation is most effective and efficient when you can share the collected family history and reason for referral. This may be sent to the specialist's office in advance and/or printed for the patient to bring to the appointment.

5 Schedule a follow-up to discuss the outcomes of the genetic appointment, and to implement personalized management as indicated. Two months may be a good time to bring the patient back, although the specific time frame will depend on the genetic clinic and type of testing ordered.

EVALUATING THE SYMPTOMATIC INDIVIDUAL FOR CRC

CRC incidence and mortality are rising in young adults.

While CRC is decreasing nationally, it is actually rising in individuals under the age of 50, for reasons not yet understood. Additionally, younger individuals are more likely to be diagnosed with late stage disease compared to older individuals, due in part to delayed work-up of alarm signs and symptoms. Primary care clinicians can help reduce CRC mortality by considering CRC in the evaluation of a patient with possible signs and symptoms, regardless of age or family history, in addition to preemptively identifying people with risk factors based on personal and family history risk assessment.

PARTICIPANTS
Provider, patient

BARRIERS
Patient lack of awareness, patient willingness to present to provider and/or undergo physical exam and colonoscopy; CRC is not the most likely explanation for patients with nonspecific symptoms and/or no other risk factors

STEPS

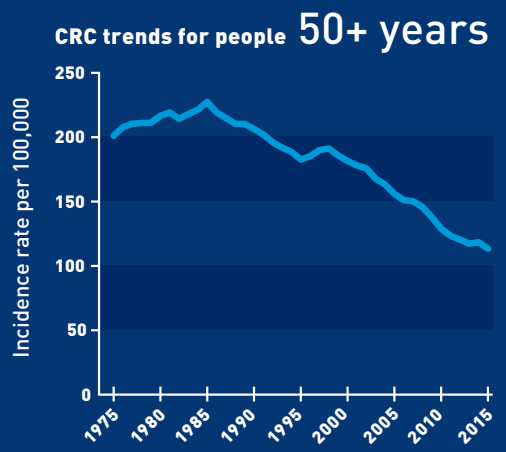
1. Consider evaluation for CRC in individuals with any of the following signs or symptoms, regardless of age, and even in the absence of other personal or family history risk factors:
   - blood in stool
   - recent-onset, persistent or progressive diarrhea and/or constipation
   - persistent or progressive abdominal pain
   - abdominal mass
   - unexplained iron deficiency anemia
   - unexplained weight loss
2. Evaluate for CRC per guidelines. This may include a physical exam, including a rectal exam, and assessing CBC and iron levels.
3. Colonoscopy is a recommended diagnostic procedure for patients presenting with the alarm signs and symptoms discussed above. Note that a fecal occult blood test (FOBT) is not indicated as a diagnostic test for symptomatic patients, and a negative FOBT does not rule out the possibility of CRC.

Colorectal cancer (CRC) in adults under 50 is on the rise

74% growth in incidence since 1988

1 in 10 CRC patients are under 50

Incidence of CRC by age: 50+ versus 20 – 49



AVERAGE TIME
to diagnose is delayed for those under 50

~1 in 3 early onset colorectal cancers **may be preventable** by taking a family history and screening those at increased risk

Don't minimize symptoms in young patients

The Jackson Laboratory
Leading the search for tomorrow's cures

American Cancer Society®

National Colorectal Cancer Roundtable

SOURCES
Siegel et al. JNCI. 2017, 109:djw322.
Scott et al. AM J Surg. 2016, 211:1014.
NCI SEER, seer.cancer.gov

EDUCATING THE PATIENT ABOUT RISK FACTORS AND CANCER PREVENTION

Cancer risk is affected by environmental and genetic factors. Patients should know what risk factors they can control, and be aware of signs and symptoms of cancer, especially when they have an increased risk.

Patient understanding of the factors contributing to cancer risk can increase motivation for lifestyle changes and acceptance of screening and risk-reducing measures to lower morbidity and mortality from cancer. After you communicate your CRC risk assessment and management recommendations, it is important to educate the patient about ways to mitigate cancer risk.

PARTICIPANTS
Provider, patient

WHAT YOU'LL NEED
Knowledge of cancer risk factors & prevention strategies

BARRIERS
Patient compliance, limited support resources

LEARN MORE
Colon cancer prevention (NCI)

PATIENT MATERIALS
Patient Education Materials

STEPS

1 Discuss actions the patient can take to reduce cancer risk factors and increase cancer prevention practices. This may include lifestyle changes such as modifications in diet regarding consumption of processed meat, red meat, fruits, and vegetables, exercise, weight loss, alcohol consumption, and smoking cessation as well adherence to his or her recommended screening regimen.

2 Educate the patient about cancer signs and symptoms. Patients at risk of CRC should be aware that the following symptoms can be associated with a CRC: blood in stool, recent-onset, persistent or progressive diarrhea and/or constipation, persistent or progressive abdominal pain, abdominal mass, and unexplained weight loss.

CHAPTER 4

Key Messages and Limitations of the Toolkit

KEY POINTS FROM THE TOOLKIT

Early onset colorectal cancer

- Recognize that the incidence of CRC is increasing in individuals under age 50.
- Be aware that a substantial proportion of early onset CRC may be prevented or detected at an earlier stage by identifying people with a family history of cancer and adenomas.
- Regardless of age, consider CRC in the evaluation of patients with alarm signs and symptoms, including blood in the stool, recent-onset and persistent or progressive diarrhea/constipation, persistent or progressive abdominal pain, abdominal mass, unexplained iron deficiency anemia, and/or unexplained weight loss.
- Promote awareness among young patients.

Developing a system for family history collection

- Collect history that indicates family structure and manifestations of disease.
- Develop a systematic, team-based approach to family history collection and interpretation. This should include a standardized process for family history collection and interpretation as well as guidance for developing a personalized management plan for patients.
- Use a tool (and/or EHR) to assist in family history collection and risk assessment. There are a number of tools available to aid in family history collection and family history risk assessment, with different strengths and limitations. You should pick the tool that best fits the needs of your practice.
- Standardize how and where family history data is recorded in the medical record to increase the usability of this information.

CRC risk assessment & management of risk

- Assess patterns and red flags. Accurate risk assessment involves a synthesis of multiple data points, including family and medical history, patient race or ethnicity and lifestyle, behaviors, and exposures.
- Assign to risk category: Average, increased (moderate or familial), high (hereditary).
- Tailor risk communication to patient learning styles and needs.
- Use patient risk to adapt plan for cancer screening, surveillance, and prevention, and genetic referral. Average risk individuals should follow general population guidelines for cancer screening. Increased risk individuals typically should undergo earlier and/or more frequent screening, and individuals with a first-degree relative with CRC should begin CRC screening at age 40. Individuals at high risk should be referred for genetic counseling and genetic testing. Depending on the results of genetic evaluation, the patient may undergo high-risk cancer screening and surveillance and consider additional treatments.
- Be aware that cancer genetic testing can be complex, and should be done in conjunction with genetic counseling by qualified providers.
- Select a set of CRC screening guidelines for use in practice. There are numerous organizations that have developed guidelines for individuals with a family history of cancer or polyps. Pick the set of guidelines that aligns with your practice's and patient's needs and use this across your patient population.
- Consider implementing evidence-based interventions tailored to the patient's health beliefs and barriers in order to increase CRC screening adherence.
- Track clinical actions taken over time, including (a) referrals to genetic and cancer specialists, and (b) screening and surveillance procedures for those individuals at increased risk.
- Ensure that updates are made to the clinic process when risk assessment or management guidelines are changed.

LIMITATIONS OF THIS TOOLKIT

Practice variation. While we have tried to provide steps and resources that could be applicable to diverse primary care practices, one size does not fit all. Some practices may find that their needs related to family history collection, cancer screening and/or detection are not addressed within this toolkit.

Best practices. Evidence-based best practices are limited in certain areas of cancer risk management in primary care practice, particularly how to implement family history collection and risk assessment, and how to detect early onset CRC. The toolkit presents recommendations and experiences based on current practices and expert opinion where evidence-based guidelines are not available. See the best practices recommendations in the appendix.

Family history tool. The ideal risk assessment tool will stratify risk into average, increased/moderate, and high risk categories and be validated for primary care use. At the time of developing this toolkit, such a tool was not available. Additionally, many providers prefer algorithms and tools that are electronic and integrated with the Electronic Health Record, which are not widely available. We have provided examples and a list of currently available tools that primary care practices may wish to evaluate for their needs. This is a rapidly developing area of health IT, and additional tools may become available in the near future.

A comprehensive risk assessment process. Ideally, CRC family history collection and risk assessment should be integrated into risk assessment for other conditions relevant to the primary care clinic. The scope of this toolkit is to support CRC best practices, recognizing that clinicians may choose to expand their efforts to include other cancers and health conditions.

Ongoing evaluation and iteration. Just as one educational program cannot sustain behavior change over time, implementation of a new clinical process without monitoring and iterative improvement is unlikely to be successful. Practices should continue to evaluate their family history and cancer screening workflows and processes to identify areas for update and improvement.

CHAPTER 5

Appendix

GOALS WORKSHEET

Step 1. Review goals. Consider how these goals align with practice and stakeholder priorities.

Review what goals can be achieved with cancer family history collection and risk assessment.

Step 2. Pick the most relevant goals for your practice.

Step 3. Choose priorities.

Meet with stakeholders to frame the three highest-priority goals. Rewrite the goals in language that resonates with them. Record the top three goals here:

Step 4. Plan. Set a target date for when you want to achieve the goal.

Determine an explicit target for each goal, plan to measure how well you achieve each target, and rate the feasibility of measuring each (1 = not feasible, 3 = very feasible).

Goal	Target	Measurement Plan	Measurement Responsibility	Measurement Feasibility (1, 2, 3)	Goal Completion Date
Goal 1					
Goal 2					
Goal 3					

Step 5. Communicate the final goals to stakeholders and team members.

FAMHX TOOL FEATURES WORKSHEET

To download the spreadsheet and navigate to the tools: https://tinyurl.com/ycqeko6h

Tool Name	Collection Features				Risk Assessment					Scope			Other				
	Collection of all 1st- and 2nd-degree relatives	Patient entered collection	Electronic questionnaire	Paper questionnaire	Includes risk assessment (vs. just a collection tool)	Electronic risk assessment	Stratification to 3 categories: average, increased, high	Stratification to 2 categories: average, increased/high	Links to provider management recommendations	Includes personal as well as family history risks	Assessment of multiple cancers beyond CRC	Assessment of non-cancer conditions	Free	Spanish/ other language versions available	Validated for primary care	Maintained technology and clinical content	EHR integration
Check the "must have" features for your practice:																	
Does It Run in the Family?	YES	YES	NO	YES	NO	n/a	NO	n/a	NO	NO	n/a	n/a	YES	YES	YES	YES	NO
Family Health History Workbook	YES	YES	NO	YES	NO	n/a	NO	n/a	NO	NO	n/a	n/a	YES	NO	NO	YES	NO
AMA Adult Family History Form	YES	YES	NO	YES	NO	n/a	NO	n/a	NO	NO	n/a	n/a	YES	NO	NO	YES	NO
Family History Questionnaire	YES	YES	NO	YES	NO	n/a	NO	n/a	NO	NO	n/a	n/a	YES	NO	NO	YES	NO
My Family Health Portrait	YES	YES	YES	YES	PARTIAL	YES	NO	YES	NO	NO	PARTIAL	PARTIAL	YES	YES	YES	YES	NO
It Runs in My Family	YES	YES	YES	NO	NO	n/a	NO	n/a	NO	NO	n/a	n/a	YES	NO	NO	YES	NO
MyLegacy	YES	YES	YES	NO	YES	YES	NO	NO	YES	YES	YES	YES	NO	NO	YES	YES	YES
Family Healthware	YES	YES	YES	NO	YES	YES	YES	NO	YES	YES	YES	YES	NO	NO	YES	YES	NO
MeTree	YES	YES	YES	NO	YES	YES	YES	NO	YES	YES	YES	YES	NO	NO	YES	YES	YES
Myriad Family History Tool	YES	YES	YES	NO	YES	YES	NO	YES	NO	NO	YES	NO	YES	NO	NO	YES	NO
Progeny/Ambry	YES	YES	YES	NO	YES	YES	NO	NO	NO	YES	YES	YES	PARTIAL	NO	NO	YES	YES
CancerGene Connect/Invitae	YES	YES	YES	NO	YES	YES	NO	NO	NO	YES	YES	NO	YES	YES	NO	YES	NO
CancerIQ	YES	YES	YES	NO	YES	YES	NO	NO	YES	YES	YES	NO	NO	NO	NO	YES	NO
CRA Health	YES	YES	YES	NO	YES	YES	NO	NO	NO	YES	YES	NO	PARTIAL	YES	NO	YES	YES
NCI CRC Risk Assessment Tool	NO	YES	YES	NO	YES	YES	NO	YES	NO	YES	NO	NO	YES	NO	NO	YES	NO
MMRPRo	NO	NO	NO	NO	YES	YES	NO	NO	NO	NO	NO	NO	YES	NO	NO	YES	NO
PREMM5	NO	YES	YES	NO	YES	YES	NO	NO	NO	NO	YES	NO	YES	NO	NO	YES	NO
MMRPredict	NO	NO	YES	NO	YES	YES	NO	NO	NO	NO	NO	NO	YES	NO	NO	YES	NO
MyRisk Hereditary Cancer Questionnaire	NO	YES	NO	YES	YES	NO	NO	NO	NO	NO	YES	NO	YES	NO	NO	YES	NO
Columbia University 3-question survey	NO	YES	NO	YES	YES	NO	NO	YES	NO	NO	NO	NO	YES	NO	NO	YES	NO
Families Sharing Health Assessment and Risk Evaluation (SHARE) workbook	NO	YES	NO	YES	YES	NO	NO	YES	NO	NO	NO	NO	YES	NO	NO	YES	NO
User-friendly Lynch syndrome risk assessment tool	NO	YES	NO	YES	YES	NO	NO	YES	NO	NO	NO	NO	YES	NO	NO	YES	NO
University of Michigan 5-question survey	NO	YES	YES	YES	YES	NO	NO	YES	NO	NO	NO	NO	YES	NO	NO	YES	NO
Simple Family History Screening Tool for CRC (See Appendix)	NO	YES	NO	YES	YES	NO	YES	NO	YES	NO	NO	NO	YES	NO	NO	YES	NO
CRC Risk Assessment Checklist (See Appendix)	NO	NO	NO	n/a	YES	NO	YES	NO	NO	YES	NO	NO	YES	NO	NO	YES	NO

Instructions

1. Identify the "must have" features for your practice, from the table above and others important to you.

2. Use the Family History Tool Table to identify available tools that meet your criteria. Write down the names of your top tools below.

3. Test your list of tools to evaluate what will work best for your practice.

Tool 1:

Tool 2:

Tool 3:

COLORECTAL CANCER RISK ASSESSMENT CHECKLIST

POSSIBLY HIGH RISK

- ☐ Patient or first-degree relative[1] with colon or rectal cancer before age 50
- ☐ Patient or first-degree relative with uterine cancer before age 50
- ☐ Patient or relative with more than one of the Lynch-associated[2] cancers (in the same person) (Lynch-associated cancers include: Colon, rectal, uterus, stomach, small intestine, ovary, urinary system, renal pelvis, pancreas, brain (usually glioblastoma), and sebaceous skin lesions and keratoacanthomas)
- ☐ Patient with cancer and an abnormal tumor screening test for Lynch syndrome
- ☐ Patient with 10 or more precancerous polyps (adenomas), 2 or more hamartomatous polyps, or 5 or more serrated polyps
- ☐ One member of the family (may include the patient) with colon cancer at or after age 50 and a first- or second-degree relative on the same side of the family with any of the Lynch-associated cancers[2] before age 50
- ☐ Three members on the same side of the family (may include the patient) with any of the Lynch-associated cancers[2] at any age
- ☐ Patient or a relative with any of the Lynch-associated cancers[2] at any age with a limited family history due to early death, a small family or adoption
- ☐ A known mutation in a colon cancer gene (*MLH1*, *MSH2*, *MSH6*, *PMS2*, *APC*, others) in the family

POSSIBLY INCREASED RISK

- ☐ Personal history of CRC
- ☐ Personal history of adenomas or sessile serrated polyps
- ☐ Personal history of inflammatory bowel disease (Ulcerative colitis or Crohn's colitis)
- ☐ African American ancestry
- ☐ One or more first-degree relatives with CRC or confirmed advanced adenoma at any age
- ☐ One or more second degree relatives with CRC <50

AVERAGE RISK

- ☐ Absence of the above risk factors

1 First-degree relatives (FDR): Parents, siblings, children. Second-degree relatives (SDR): Grandparents, aunts, uncles, nieces, nephews, half-siblings, grandchildren.

2 Colon, rectal, uterus, stomach, ovary, small intestine, pancreas, ureter and renal pelvis, brain (usually glioblastoma), as well as sebaceous skin lesions and keratoacanthomas.

Adapted with permission from work by Gregory Feero, MD, PhD and Susan Miesfeldt, MD. Disclaimer: This checklist was developed by primary care and genetic experts based on NCCN guidelines but has not been validated. These risk criteria are designed to assist in the clinic-based evaluation of patients and families. They do not reflect all increased and high risk criteria, and may not reflect guidelines that have been updated past the date of this publication. For questions regarding individual patients and families, contact your local cancer genetic provider.

SIMPLE FAMILY HISTORY SCREENING TOOL FOR CRC

	YES	NO
1. Have you had either of the following conditions diagnosed before age 50?		
Colon or rectal cancer		
Colon or rectal polyps		
2. Do you have a first-degree relative (mother, father, brother, sister, or child) with any of the following conditions diagnosed before the age of 50?		
Colon or rectal cancer		
Cancer of the uterus, ovary, stomach, small intestine, urinary tract (kidney, ureter, bladder), bile ducts, pancreas, or brain		
3. Do you have three or more relatives with a history of colon or rectal cancer? (This includes parents, brothers, sisters, children, grandparents, aunts, uncles, and cousins)		
If YES to any question → Refer for additional assessment or genetic evaluation.		
If NO to all → proceed with the following questions:		
4. Do you have any first-degree relatives (mother, father, brother, sister, or child) with cancer of the colon or rectum?		
If NO → Average risk family. Provide average risk screening guidelines to patient and their family members (start screening with any acceptable test at age 50)*		
If YES to #4, proceed with the following questions:		
5. Was the first-degree relative under age 60 when CRC was diagnosed?		
6. Do you have more than one first-degree relative with CRC?		
If both NO → Intermediate risk family. Provide risk-based screening guidelines to patient and their family members.		
If either YES → High risk family. Provide high risk screening guides for patient and their family members.		

**The 2018 ACS guidelines for CRC screening now recommend that CRC screening start at age 45 for average risk individuals, while the USPSTF recommends starting at age 50. Please adjust the chart as needed, per your practice's protocol.*

Published by:
Kastrinos et al. Am J Gastroenterol. 2009;104:1508.
Giardiello et al. Am J Gastroenterol. 2014;109:1159.
Patel et al. Dig Dis Sci. 2015;60:748.

ACCESSING GENETIC SERVICES TOOL

Patient talking points about referral

The following points are important for you to convey to the patient in order for him or her to fully benefit from a genetic counseling appointment.

Reason for referral

Explain the reason you are referring the patient to help to set expectations and increase the likelihood of follow-through.

- Reason for referral. Some common reasons include: follow-up on family history information, discussion of risk and preventative/screening measures, assessment of appropriateness for genetic testing, or discussion of benefits and risks of genetic testing.
- Possible benefits of seeing a genetic counselor. Some benefits include: determining if you are at increased risk, determining whether genetic testing is appropriate.
- Possible harms of not pursuing the referral. Some possible harms include: not knowing about certain cancer screening or prevention services you might qualify for, continued anxiety or uncertainty of not knowing if you or others in the family (such as your children) are truly at risk or not.
- The expected outcome. Some outcomes include diagnosis, information, testing, risk assessment.

What to expect

Review what will be covered during an appointment, and how the patient can prepare.

- Components of a cancer genetic counseling session. This may be a long appointment (30-60 minutes), and can include:

  Detailed medical and family history

  Risk assessment and risk counseling

  Addressing psychosocial issues and emotional concerns

  Directing an in-depth consent process for genetic testing, when applicable

  Discussing insurance coverage and cost for genetic testing, if indicated

  Disclosing results of genetic testing, when applicable

  Determining and communicating screening and management plans

  Summarizing and planning for follow up

- Know that genetic testing is always optional. The appointment may or may not include genetic testing, and if it is offered, the genetic expert will discuss the benefits and risks of testing for supported decision-making.
- Be aware testing may be recommended for affected relatives first.
- How to prepare for the appointment. It can be helpful for patients to learn more about their family health history and to talk to affected family members about their interest and willingness to undergo genetic evaluation, in case that is recommended.

Logistics of referral

- Provide names, roles and credentials of genetic professional(s) involved
- Discuss insurance coverage of genetic appointment
- Give directions and contact information
- Make a plan for how the patient will follow-up with you after the consult

Finding a genetic professional

General resources

Genetic counselors, clinical geneticists, and nurse specialists in genetics may be available in your institution or you may need to contact someone elsewhere. You can find a genetic specialist through:

- National Society of Genetic Counselors Directory (www.nsgc.org)
- American Board of Medical Genetics Directory (www.abmgg.org)
- International Society of Nurses in Genetics (www.isong.org)

It can sometimes be challenging to find a genetic expert locally. There are some opportunities available for telecounseling through academic institutions and private businesses. In some cases, insurance companies will pay for these services.

PROFESSIONAL SOCIETY GUIDELINES

that Address Screening for Individuals with a Cancer Predisposition Syndrome or a Family History of CRC or Polyps

American Academy of Family Physicians. Wilkins T, McMechan D, Talukder A et al. Colorectal cancer screening and surveillance for individuals at Increased risk. Am Fam Physician. 2018;97(2):111-116. PMID: 29365221.

American College of Gastroenterology. Rex DK, Johnson DA, Anderson JC, et al. American College of Gastroenterology guidelines for colorectal cancer screening 2009 [corrected]. Am J Gastroenterol. 2009;104:739-750. PMID: 19240699.

Syngal S, Brand RE, Church JM. ACG Clinical Guideline: Genetic Testing and Management of Hereditary Gastrointestinal Cancer Syndromes. Am J Gastroenterol. 2015; 110:223–262. PMID: 25645574.

American College of Obstetricians and Gynecologists. Committee on Practice Bulletins-Gynecology; Society of Gynecologic Oncology. American College of Obstetricians and Gynecologists Practice Bulletin No. 147: Lynch syndrome. Obstet Gynecol. 2014;124(5):1042-54. PMID: 25437740.

American College of Physicians. Qaseem A, Denberg TD, Hopkins RH, et al. Screening for Colorectal Cancer: A Guidance Statement From the American College of Physicians. Ann Intern Med. 2012;156:378–386. PMID: 22393133.

American Gastroenterological Association. Rubenstein JH, Enns R, Heidelbaugh J, et al. American Gastroenterological Association Institute Guideline on the Diagnosis and Management of Lynch Syndrome. Gastroenterology. 2015;149(3):777-82. PMID: 26226577.

American Society of Clinical Oncology. Stoffel EM, Mangu PB, Limburg PJ, et al. Hereditary colorectal cancer syndromes: American Society of Clinical Oncology clinical practice guideline endorsement of the familial risk-colorectal cancer: European Society for Medical Oncology clinical practice guidelines. J Oncol Pract. 2015; 33(2):209-17. PMID: 25829526.

American Society for Gastrointestinal Endoscopy. Davila RE, Rajan E, Baron TH, et al. ASGE guideline: colorectal cancer screening and surveillance. Gastrointest Endosc. 2006;63:546-557. PMID: 16564851.

Institute for Clinical Systems Improvement. Preventive Services for Adults guideline: Colorectal Cancer Screening (Revised October 2014). https://www.icsi.org/guideline_sub-pages/preventive_services_adults/level_i__colorectal_cancer_screening/.

PROFESSIONAL SOCIETY GUIDELINES

that Address Screening for Individuals with a Cancer Predisposition Syndrome or a Family History of CRC or Polyps

Multi-Society Task Force (American College of Gastroenterology, American Gastroenterological Association, American Society for Gastrointestinal Endoscopy). Rex DK, Boland CR, Dominitz JA, et al. Colorectal Cancer Screening: Recommendations for Physicians and Patients from the U.S. Multi-Society Task Force on Colorectal Cancer. Am J Gastroenterol. 2017 Jul;112(7):1016-1030. Epub 2017 Jun 6. Review. PMID: 28555630.

Giardiello FM, Allen JI , Axilbund JE et al. Guidelines on genetic evaluation and management of Lynch syndrome: a consensus statement by the U.S. Multi-Society Task Force on Colorectal Cancer. Gastrointest Endosc. 2014; 80: 197 – 220. PMID: 25043945.

Durno C, Boland CR, Cohen S, et al. Recommendations on Surveillance and Management of Biallelic Mismatch Repair Deficiency (BMMRD) Syndrome: A Consensus Statement by the US Multi-Society Task Force on Colorectal Cancer. Am J Gastroenterol. 2017;112(5):682-690. PMID: 28349994.

National Comprehensive Cancer Network. Colorectal Cancer Screening (v1.2018). www.nccn.org.

For additional guidance for screening individuals at average risk, see the **U.S. Preventative Services Task Force recommendations, ACS guidelines,** and **NCCRT Steps for Increasing CRC Screening Rates manual.**

For additional guidance for managing individuals with high risk cancer syndromes, see GeneReviews.

PROVIDER EDUCATION RESOURCES

Assessing Your Existing Family History Workflow

AHRQ Workflow Assessment for Health IT Toolkit, by the Agency for Healthcare Research and Quality. Learn how to plan, design, implement, and use health IT in ambulatory care.

Selecting and Evaluating Tools for Collection and Risk Assessment

Global Alliance Family History Tool Inventory, by the Global Alliance for Genomics and Health. View a catalogue of family history tools currently available for documenting family health history information.

Review and Comparison of Electronic Patient-Facing Family Health History Tools, by Welch BM, Wiley K, Plieger L, et al. A paper that evaluates and discusses 17 electronic family history tools.

Identifying Screening Protocols for Increased Risk Patients

Steps For Increasing CRC Screening Rates: A Manual for Community Health Centers, by the National Colorectal Cancer Roundtable. A step-by-step manual to help implement processes that will and increase CRC screening in the general population.

Identifying Evidence-based Interventions to Facilitate Screening Adherence in Increased Risk Patients

How to Increase Preventative CRC Screening Rates in Practice, by the National Colorectal Cancer Roundtable. A practical guide containing evidenced-based tools, sample templates and strategies that help practices improve their screening performance.

Messages to Reach the Unscreened, by the National Colorectal Cancer Roundtable. A guidebook designed to help educate, empower and mobilize key audiences who are not getting screened for colorectal cancer.

Monitoring & Evaluation

How To Evaluate Activities To Increase CRC Screening And Awareness: Evaluation Toolkit, by the National Colorectal Cancer Roundtable. Apply the seven basics of evaluation to CRC screening programs and other implementation projects.

Collecting Sufficient Family History Information

Collecting Family History with Sufficient Detail Online CME, by The Jackson Laboratory. Practice asking the right questions to elicit enough information to assess family history disease risk and get tools to implement your skills.

Understanding Your Pathology Report: Colon Polyps (Sessile or Traditional Serrated Adenomas), by the American Cancer Society. Review explanations of common polyp pathologies.

Documenting Family History Information

Collecting Family History with Sufficient Detail Online CME, by The Jackson Laboratory. Practice asking the right questions to elicit enough information to assess family history disease risk and get tools to implement your skills.

Assessing the Personal and Family History to Identify Red Flags and Patterns

Identifying Red Flags and Patterns that Increase Cancer Risk Online CME, by The Jackson Laboratory. Practice identifying risk factors in case scenarios and receive tools to help make this task easy to implement in your practice.

Identifying and Managing Lynch Syndrome Online CME, by The Jackson Laboratory.
Practice recognizing Lynch syndrome red flags, communicating about the Lynch syndrome testing process, and incorporating increased screening into patient care.

Colorectal Cancer Prevention (PDQ®), by National Cancer Institute (NCI). Provides comprehensive, peer-reviewed, evidence-based information about colorectal cancer prevention.

PROVIDER EDUCATION RESOURCES

Categorizing Cancer Risk

Categorizing Cancer Risk Online CME, by The Jackson Laboratory. Analyze family histories and classify patients' risk into average, increased (moderate), or high risk for cancer.

Communicate Risk

Categorizing Cancer Risk Online CME, by The Jackson Laboratory. Analyze family histories and classify patients' risk into average, increased (moderate), or high risk for cancer.

Communicating Risk Factsheet, by The Jackson Laboratory. A factsheet with information about types of risk and key communication points.

Understanding Cancer Risk Tutorial, by Research Advocacy Network. A publication that explores aspects of cancer risk, including risks associated with developing cancer, risks related to cancer treatment, and the risk of cancer recurrence .

Using Family History to Inform Management

Using Cancer Family History to Inform Management Online CME, by The Jackson Laboratory. Practice determining appropriate management based on family history risk stratification.

Cancer Screening Factsheet, by The Jackson Laboratory. Summarizes professional society guidance about screening for individuals at average, increased, and high risk for breast, prostate, and colorectal cancer.

Steps For Increasing CRC Screening Rates: A Manual for Community Health Centers, by the National Colorectal Cancer Roundtable. A step-by-step manual to help implement processes that will and increase CRC screening in the general population.

Referring to a Genetic Expert

Cancer Pre-test Decisions & Counseling Online CME, by The Jackson Laboratory. Practice deciding when and if genetic testing is appropriate given a patient's clinical and personal context.

Components of a Genetic Counseling Session Factsheet, by The Jackson Laboratory. Discusses the core components of a cancer genetic counseling session.

Educate the Patient about Risk Factors and Cancer Prevention

Colorectal Cancer Prevention (PDQ®), by National Cancer Institute (NCI). Provides comprehensive, peer-reviewed, evidence-based information about colorectal cancer prevention.

Additional Educational Resources for Providers

Cancer Risk Assessment, Testing and Management, by The Jackson Laboratory. Free, self-directed online program for continuing education credit.

Intensive Course in Cancer Risk Assessment, by the City of Hope. Advanced training in cancer risk assessment, management, and prevention.

Webinars for Medical Professionals, by Hereditary Colon Cancer Foundation. Learn about best practices for screening and treating individuals with Lynch syndrome and familial adenomatous polyposis syndrome through multiple webinar presentations.

Adenomatous Polyposis Case Study (Gabe), by the Global Genetics and Genomics Community (G3C). Practice evaluating a virtual patient with adenomatous polyps for a hereditary cancer syndrome in an interactive case study.

Genetics and Gynecologic Cancers Toolkit, by the Society of Gynecologic Oncology. Learn about cancer risks and management for hereditary cancer syndromes through case studies.

PDQ Cancer Information Summaries: Genetics, by the National Cancer Institute. Learn about topics in cancer genetics, including genetic risk assessment and counseling and the genetics of colorectal cancer.

IHI Open School Online Courses, by the Institute for Healthcare Improvement. Learn about topics in Quality Improvement.

PATIENT EDUCATION MATERIALS

Family History

Have You or a Family Member Had Colorectal Cancer?, by the Centers for Disease Control. An overview of the importance of family history collection for colorectal cancer risk assessment and Lynch syndrome.
www.cdc.gov/features/lynchsyndrome
Spanish-language version: www.cdc.gov/spanish/especialesCDC/SindromeLynch/

Knowing is Not Enough—Act on Your Family Health History, by the Centers for Disease Control. Education and resources about family health history.
www.cdc.gov/features/familyhealthhistory/index.html
Spanish-language version: www.cdc.gov/spanish/especialesCDC/AntecedentesMedicos/index.html

Does It Run in the Family? Toolkits, by Genetic Alliance. Two customizable booklets about family history and genetics and health for a patient or community: 1) A Guide to Family Health History and 2) A Guide to Genetics and Health. Available in English, Spanish, and Tagalog. www.geneticalliance.org/publications/fhhtoolkit

Family Health History Toolkit, by the Utah Department of Public Health. A booklet explaining why it is important to know family health history, and tips on how to gather this information. Includes a list of ten helpful questions to ask relatives. http://health.utah.gov/genomics/familyhistory/documents/Toolkit/new%20entire%20toolkit.pdf
Spanish-language version: http://health.utah.gov/genomics/familyhistory/documents/Toolkit/Final%20Spanish%20Toolkit.pdf

Cancer Risk Factors

Six Ways to Lower Your Risk for Colon Cancer, by the American Cancer Society. A list of ways to reduce the risks you can change, and the familial risk factors that you cannot change.
www.cancer.org/latest-news/six-ways-to-lower-your-risk-for-colon-cancer.html

What Are the Risk Factors for Colon Cancer?, by the Centers for Disease Control. A resource that lists medical, familial and lifestyle risk factors for colorectal cancer.
www.cdc.gov/cancer/colorectal/basic_info/risk_factors.htm
Spanish-language version: www.cdc.gov/spanish/cancer/colorectal/basic_info/risk_factors.htm

Colorectal Cancer Factsheet, by the Prevent Cancer Foundation. A short but comprehensive resource that outlines information about colorectal cancer, risk facts and how to reduce risk, screening, symptoms, and treatment.
preventcancer.org/wp-content/uploads/2015/06/Colorectal-Cancer-Fact-Sheet-2013.pdf
Spanish-language version: preventcancer.org/wp-content/uploads/2015/06/Colorectal-Cancer-Fact-Sheet_Spanish_Prevent-Cancer-Foundation.pdf

Genetic Counseling & Genetic Testing

Genetic Counselors: Personalized Care for Your Genetic Health, by the National Society of Genetic Counselors. Describes the training and skills of genetic counselors, and includes information on what to expect during an appointment and how to locate a genetic counselor.
www.aboutgeneticcounselors.com

The Genetics of Cancer, by the National Cancer Institute. An overview of cancer genetics and genetic testing, designed for the general public and patients.
www.cancer.gov/about-cancer/causes-prevention/genetics

Genes in Life, by Genetic Alliance. A website where patients can learn about how genetics impacts their lives and their families.
genesinlife.org/

Genetic Counselors for Hereditary Colon Cancer Syndromes, by the Hereditary Colon Cancer Foundation. Describes the genetic counselor role on the care team, including how a genetic counselor can help individuals make personalized decisions regarding genetics and their

health.
www.hcctakesguts.org/about-genetic-counselors

Colorectal Cancer Screening

Screen for Life, by the Centers for Disease Control and National Colorectal Cancer Roundtable. A web-based quiz to test knowledge on who should be screened, how often, types of screening, insurance coverage, and symptoms of CRC.
www.cdc.gov/cancer/colorectal/sfl/quiz/index.htm
Spanish-language version: www.cdc.gov/spanish/cancer/colorectal/sfl/quiz/index.htm

Colorectal Cancer Screening Brochure, by the Centers for Disease Control (English). A guide to CRC screening, including how to identify low-cost or free screening programs.
www.cdc.gov/cancer/colorectal/pdf/no_pocket_brochure.pdf
Spanish-language version: www.cdc.gov/spanish/cancer/colorectal/pdf/no_pocket_brochure.pdf

CRC Early Detection, Diagnosis, and Staging, by the American Cancer Society (English). Provides information about screening, early detection, staging, and questions to ask the provider.
www.cancer.org/content/cancer/en/cancer/colon-rectal-cancer/detection-diagnosis-staging.html
Spanish-language version: https://www.cancer.org/es/cancer/cancer-de-colon-o-recto/deteccion-diagnostico-clasificacion-por-etapas.html

ACS Recommendations for Colorectal Cancer Early Detection, by the American Cancer Society. A resource that outlines screening recommendations based on details of an individual's personal and family history.
www.cancer.org/content/cancer/en/cancer/colon-rectal-cancer/detection-diagnosis-staging/acs-recommendations.html
Spanish-language version: https://www.cancer.org/es/cancer/cancer-de-colon-o-recto/deteccion-diagnostico-clasificacion-por-etapas/recomendaciones-de-la-sociedad-americana-contra-el-cancer.html

Hereditary Colon Cancer Support and Advocacy Groups

Hereditary Colon Cancer Foundation. A nonprofit organization serving patients with hereditary colon cancer and healthcare providers with provision of educational, social, and financial resources, including booklets about Lynch syndrome and familial adenomatous polyposis syndrome for patients.
www.hcctakesguts.org/

AliveAndKickn. A patient organization that aims to improve the lives of individuals and families affected by Lynch syndrome and associated cancers through research, education, and screening.
https://aliveandkickn.org/

Lynch Syndrome International. A patient organization that aims to provide support for individuals with Lynch syndrome, raise awareness of the condition, educate the public and healthcare providers, and provide support for Lynch syndrome research.
https://lynchcancers.com/

Stupid Cancer A patient organization that seeks to empower, support, and improve health outcomes for the young adult cancer community.
www.stupidcancer.org/

BEST PRACTICES

in family history collection and risk assessment for primary care

This toolkit was developed based on a set of best practices in family history collection and risk assessment in the primary care setting. This effort focused on cancer, specifically colorectal cancer risk assessment, but the same principles apply to other diseases. These best practices were derived from national guidelines and expert consensus, which included primary care clinicians. The upcoming chapters of the toolkit provide more detail on how to achieve the best practices below.

Clinical Skills Best Practices (Chapter 3)

Family history collection

- Collect sufficient family history information to assess underlying cancer risk. This includes clarifying family structure for at least the patient's and parents' generations and grandparents at a minimum. Depending on the patient's age, collect information about additional relatives (e.g., cousins). Identify cancer history in affected individuals, and identify if anyone in the family has had genetic testing.
- Ask about cancer (all types) and polyps and ages of onset on both sides of the family. An individual does not have to be affected with a condition to pass on genetic risk factors to the next generation.
- Remember to ask about any types of cancer in the family, not just CRC. Cancer syndromes can include risk for multiple types of cancers. CRC is not always a presenting cancer.
- Be aware of factors that can complicate family history collection and interpretation (e.g., patients with incomplete or missing family history information such as early deaths, complex family relationships and structure, small families, adoption, surgeries that may prevent cancers).

Personal history risk assessment

- Identify personal and lifestyle risk factors, including: past cancer, especially colorectal or endometrial; past adenomatous or serrated colon polyps (confirmed by pathology reports); inflammatory bowel disease.
- Identify red flags in the patient's current clinical presentation that may be signs or symptoms of CRC: blood in the stool, recent-onset and persistent or progressive diarrhea/constipation, persistent or progressive abdominal pain, abdominal mass, unexplained iron deficiency anemia, and/or unexplained weight loss.

Family history risk assessment

- Identify red flags in the personal and family history that indicate increased cancer risk: early onset cancer or (confirmed) adenomatous or serrated colon polyps; multiple relatives with the same or associated cancers on the same side of the family; bilateral or multifocal disease; individual with greater than 10 (confirmed) adenomatous colon polyps; disease in the absence of known risk factors; ethnic predisposition to certain disorders.
- Identify patterns in the family history that can point to inheritance patterns, familial clustering of cancer, or specific high-risk syndromes , such as Lynch syndrome.
- Stratify patient cancer risk into average, increased (moderate) or or high risk according to guidelines-based criteria to determine management and next steps.
- Consult with a genetic expert when you have questions about risk assessment.

Management based on risk assessment

- Develop an appropriate evaluation plan based on personal and family history assessment. Patients

with increased risk of cancer should be considered for earlier and/or more frequent screening. Patients at high risk of having a hereditary cancer syndrome in the family should be referred for genetic evaluation. Patients with a diagnosis of a hereditary cancer syndrome should undergo disease prevention and be managed based on syndrome-specific guidelines.
- Educate the patient about risk factors, prevention strategies, and CRC signs and symptoms.
- Incorporate specialist consultant input and recommendations from guidelines into the patient's personalized management plan as needed.

Patient-centered communication

- Communicate risk assessment and management guidelines tailored to the patient's comprehension and needs.

Clinical Processes Best Practices (Chapter 2)

- Develop a systematic, team-based approach to family history collection and interpretation.
- Use a tool (and/or EHR) to assist in family history collection and risk assessment.
- Consider using or developing a standardized tool for risk assessment that can be used by members of the care team to streamline the work of physician, nurse practitioner, and/or physician assistant team members.
- Maximize your EHR's capacity to support family history collection and risk assessment.
- Incorporate CRC risk assessment into standard data collection and risk assessment processes for other conditions (e.g., breast cancer, diabetes).
- Develop a professional relationship with local genetic professionals, and oncologists and gastroenterologists with interest and/or expertise in hereditary cancer, and seek consultation around management issues as needed.
- Develop systems and workflows that connect risk assessment outcomes to clinical actions.
- Develop systems and workflows to track actions taken over time, including (a) referrals to genetic and cancer specialists, and (b) screening, surveillance, and prevention procedures for those individuals at increased risk.
- Develop systems to ensure that updates are made to the clinic process when risk assessment or management guidelines are changed.
- Update the family history over time. Relatives' health and disease status may change, which may affect your patient's risk assessment.

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