

RISK ASSESSMENT AND SCREENING QUICK START

*TO DETECT FAMILIAL, HEREDITARY, AND EARLY
ONSET COLORECTAL CANCER*



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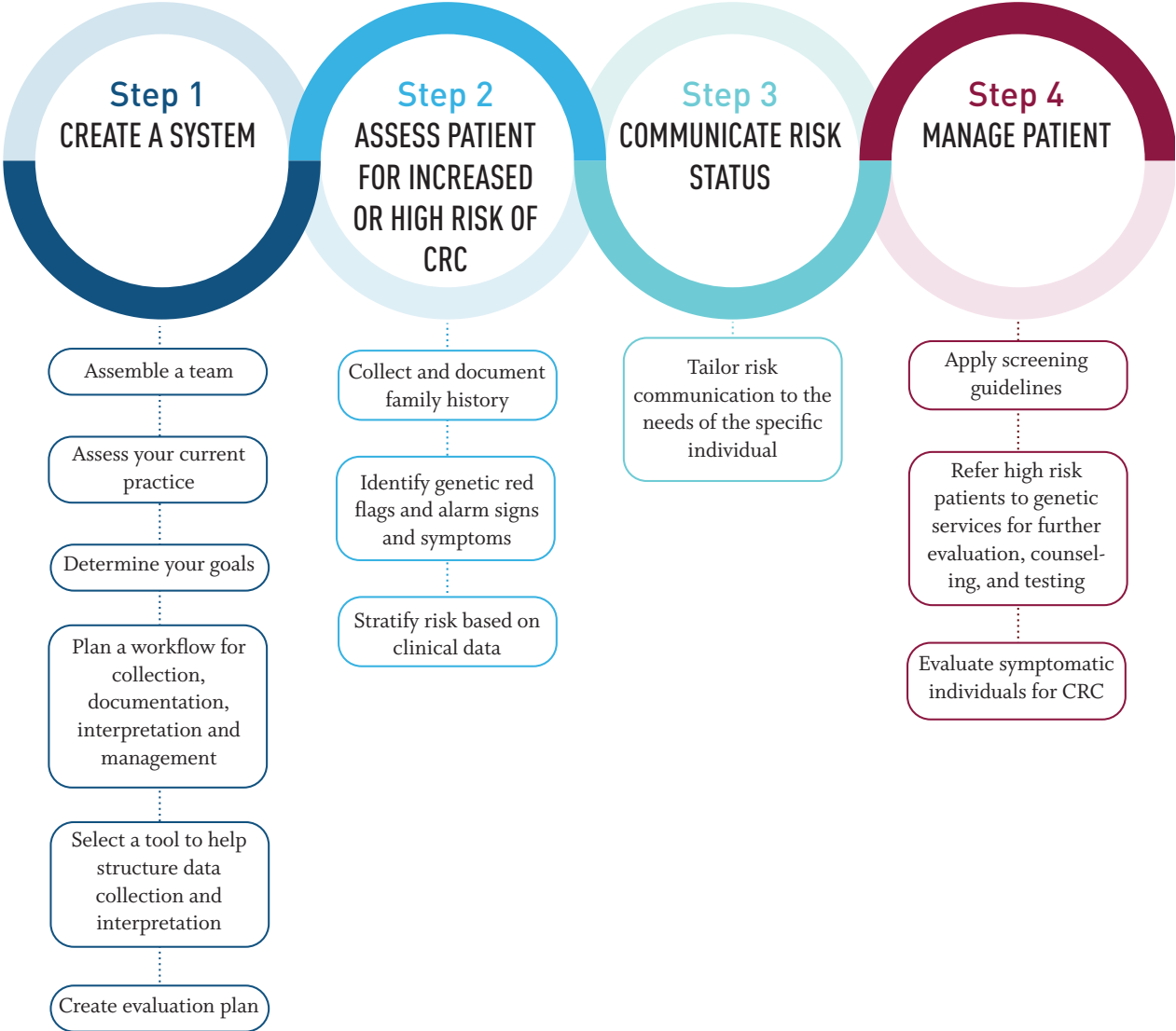
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USING THE QUICK START GUIDE

Purpose of the quick start guide

The primary goal of this guide is to provide primary care clinicians just the essential steps needed to implement a structured family history collection system to identify individuals at increased or high risk of CRC and facilitate timely diagnostic evaluation of patients with signs or symptoms of early onset CRC.

It can also serve as an overview (see diagram below) so that primary care clinicians and administrators can evaluate if they want to pursue a more detailed investigation into the full version of the Risk Assessment & Screening toolkit. See the full version for additional guidance and background, clinical tools, worksheets, resources, and references.



QUICK START 1

*Establish a System for
Structured Assessment
Across the Practice*

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 in the full toolkit, 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

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 (see full
toolkit)

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 (see full toolkit).
- 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)?

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 (see full toolkit)

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 the full toolkit 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 7](#)), as well as the workflows that you expect to have after the new process is implemented ([page 9](#)). If you want a risk assessment tool that ties to screening guidelines, you may want to review Identifying Screening Protocols in the full toolkit 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 (see full toolkit)

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 (see full toolkit.) 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.

QUICK START 2

*Clinical Skills and Tools
for Patient Care*

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
(see full toolkit)

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 (see full toolkit)

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 22](#)), 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 of the full toolkit, 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 (see full toolkit)

Professional Society Guidelines (see full toolkit)

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.

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

<i>For an individual with about a 10% lifetime risk of colorectal cancer when the general population risk is about 5%.</i>	
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."

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 the full toolkit, 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 (see full toolkit)

Professional Society Guidelines (see full toolkit)

[NCCRT Steps for Increasing CRC Screening Rates](#)

PATIENT MATERIALS

Patient Education Materials (see full toolkit)

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 SCRIPT⁴²

"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 (see full toolkit)

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 (see full toolkit)

PATIENT MATERIALS

Patient Education Materials (see full toolkit)

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.abmgb.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.