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# 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
<b>Check the "must have" features for your practice:</b>																	
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:

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# COLORECTAL CANCER RISK ASSESSMENT CHECKLIST

## POSSIBLY HIGH RISK

- Patient or first-degree relative<sup>1</sup> 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<sup>2</sup> 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<sup>2</sup> before age 50
- Three members on the same side of the family (may include the patient) with any of the Lynch-associated cancers<sup>2</sup> at any age
- Patient or a relative with any of the Lynch-associated cancers<sup>2</sup> 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

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

<sup>2</sup> 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
<b>1.</b> Have you had either of the following conditions diagnosed before age 50?		
Colon or rectal cancer		
Colon or rectal polyps		
<b>2.</b> 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		
<b>3.</b> 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)		
<b>If YES to any question → Refer for additional assessment or genetic evaluation.</b>		
<b>If NO to all → proceed with the following questions:</b>		
<b>4.</b> Do you have any first-degree relatives (mother, father, brother, sister, or child) with cancer of the colon or rectum?		
<b>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)*</b>		
<b>If YES to #4, proceed with the following questions:</b>		
<b>5.</b> Was the first-degree relative under age 60 when CRC was diagnosed?		
<b>6.</b> Do you have more than one first-degree relative with CRC?		
<b>If both NO → Intermediate risk family. Provide risk-based screening guidelines to patient and their family members.</b>		
<b>If either YES → High risk family. Provide high risk screening guides for patient and their family members.</b>		

*\*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.

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# ACCESSING GENETIC SERVICES TOOL

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## 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](http://www.nsgc.org))
- American Board of Medical Genetics Directory ([www.abmgg.org](http://www.abmgg.org))
- International Society of Nurses in Genetics ([www.isong.org](http://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.