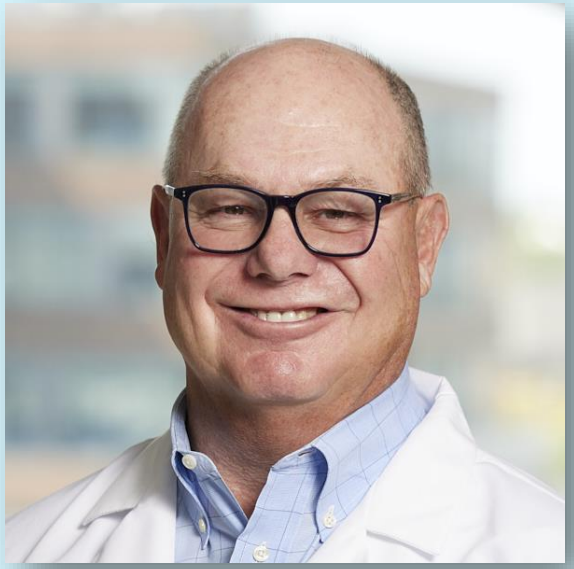
Family History & Early Age Onset Colorectal Cancer

Strategic Priority Team Meeting
November 20, 2025
3:45-5:00pm ET

American Cancer Society

NATIONAL COLORECTAL CANCER ROUNDTABLE

Co-Chairs



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City of Hope National Cancer Center
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Today's Agenda Items

1 Welcome & Introductions

2 Strategic Priority Team Overview

3 Activities

4 Small Group Discussion

5 Large Group Discussion

Strategic Priority Team Overview

Team Charge: To identify key issues and areas of need around familial, inherited, and early onset colorectal cancer for the purpose of identifying opportunities for the Roundtable to be a catalyst for change.

Themes:

- Help clinicians develop a system-based approach to the identification and management of patients at familial and genetic risk, as well as the recommendation for early diagnostic evaluation of those presenting with signs or symptoms of CRC at any age.
- Improve EHRs to help facilitate needed screening and/or counseling recommendations for patients with a family history.
- Increase clinician-patient and intra-family communication about familial/heritable risk.
- Improve “on time” screening according to recommended guidelines for both average (age 45+) and high-risk persons.
- Address the increase in CRC in young adults through strategic planning and interactions with key stakeholders and thought leaders.

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History & Accomplishments

- Family History Task Group founded in 2012
- Hosted a Family History Symposium in 2014
  Proceedings published in an article entitled "Understanding the contribution of family history to colorectal cancer risk and its clinical implications: a state-of-the-science review. (Lowery J, et al. Cancer. 2016;122:2633-4).
- Hosted Electronic Health Record Meeting in 2015 to develop consensus statement, core components and outline NCCRT Strategy on improving FH collection in EHRs
- Expanded to include Early Onset CRC in 2016

HHS Public Access

Author manuscript

Cancer. Author manuscript; available in PMC 2017 September 01.

Published in final edited form as:

Cancer. 2016 September 01; 122(17): 2633–2645. doi:10.1002/cncr.30080.

Understanding the Contribution of Family History to Colorectal Cancer Risk and Its Clinical Implications: A State-of-the-Science Review

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History & Accomplishments

- Hosted an Early Onset CRC Summit in 2017

  Proceedings published in an article entitled "A strategic plan to address the rising burden of colorectal cancer in younger adults". (Lowery J, et al. Colorectal Cancer 2020;9(Suppl): https://doi.org/10.2217/crc-2020-0004.

- Developed the comprehensive "Risk Assessment and Screening Toolkit" to facilitate detection of familial, inherited and early onset CRC.

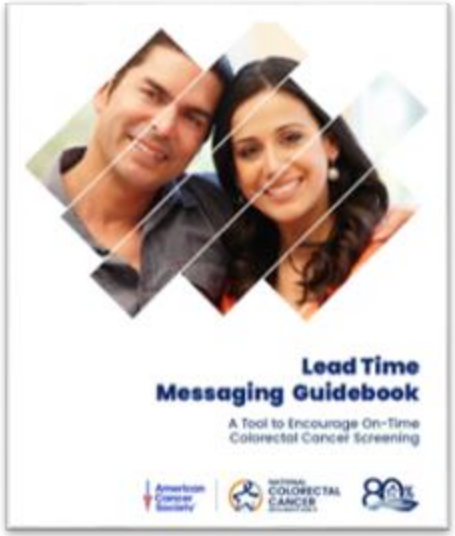
- Hosted ACS NCCRT Blue Star Conversation: *What Proportion of Early-Onset Colorectal Cancer is Potentially Preventable Based on Family History and Genetics?*

- Hosted ACS NCCRT Blue Star Conversation: *Leveraging the Electronic Health Record for Cancer Prevention: A Look at How Yale New Haven Health System is Systematizing Risk Assessment and Risk Stratification to Identify Candidates for Genetic Testing*

Resources & Publications

- Identifying High Risk Patients and Families in Your Practice" (Supplement to "What can Gastroenterologists and Endoscopists Do to Advance 80% by 2018") a/k/a "GI Brief"
- ACS NCCRT "Advanced Colorectal Polyps/ GI Brief"
- Article in the American Journal of Gastroenterology (2019) entitled "*Advanced Colorectal Polyps on Colonoscopy: A Trigger For Earlier Screening of Family Members*" (Molmenti, Kolb, Karlitz)
- Commentary in Cancer (2019) entitled "*Improving On-Time Colorectal Cancer Screening Through Lead-Time Messaging*" (Jones, Ahnen, Schroy)
- Lead Time Messaging Guidebook: A tool to encourage on-time colorectal cancer screening (2023)


Improving On-Time Colorectal Cancer Screening Through Lead Time Messaging



Recent Activities

- Published a manuscript in **Digestive Diseases and Sciences**, titled “Decision on "Knowledge, attitudes & perceptions around colorectal cancer screening and risk among 20-49 year olds.”
- Based on conversations at last year’s meeting, we are working to update the Advanced Polyp Brief.
  - Includes simplified, and easy-to-follow guidance for clinicians
  - Updated letter templates
  - Hosting an informational webinar to coincide with its release
- Developing a new resource for primary care clinicians that will summarize the recent literature on EAO CRC and emphasize the importance of timely diagnostic testing for individuals presenting with symptoms.

Takeaways From Last Year's Meeting

1. Promote Lead Time Messaging for CRC Screening

Priority Item #1: Launch a social media campaign to promote key messages

Priority Item #2: Identify strategies for implementation in novel settings (e.g., schools, walk-in/urgent care clinics, Wellness centers, etc).

Priority Item #3: Survey membership regarding Lead-Time Messaging Guidebook (assess awareness, adoption, strengths, weaknesses, suggested revisions)

Priority Item #4: Ensure consistency across NCCRT's messaging guidebooks

2. Review, Edit & Re-Promote ACS NCCRT Resources

Priority Item #1: Identify which resources to update

- Advanced Polyp Brief *(currently being updated)*
- Risk Assessment Toolkit
- Messaging Guidebooks

Priority Item #2: Adopt effective strategies to re-promote top resources

- Better promote the NCCRT Resource Center to members and partners
- Crowd source to uncover what people want/need
- Update resources with supplemental case studies and best practice examples
- Short bulleted recap of webinars & Blue Star Conversations
- Better promote partner resources

Priority Item #3: Incorporate additional messaging into these resources

- Patient perspective
- Messaging related to early-age onset CRC
- Symptom identification

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3. Revisit FH&EAO Mission, Theme, & Charge

Priority Item #1: Develop a one-page handout for early onset (or all) CRC patients of things they may want to ask about

- Fertility preservation options
- QOL for surgical & treatment options
- Biomarker testing
- Ask about DPYD testing if treatment is going to include 5-FU (genetic cause of toxicity to 5-FU). Pharmacists could be a potential partner on this topic

Priority Item #2: How to get providers to listen to young people with CRC symptoms:

- Promote anoscopy performed by PCPs immediately for patients with blood in the stool to rule in/out hemorrhoids (may not be popular with young patients).
- Close the loop on symptoms – i.e. if they don't resolve in 3 months – refer for colonoscopy.
- Access issue – many young people don't have a PCP.
- Suggest working with ACOG (potential partner) as young women often use their Ob/Gyn as their PCP and endometrial cancer is often the sentinel cancer in Lynch syndrome
- *Clinician's Reference on symptom identification and timely action is currently being developed*

Priority Item #3: Who is keeping track of positive family history patients and if/when they are getting screening and are on time?

Priority Item #4: Promote Universal MSI (IHC for the MMR proteins) testing on all CRC patients

Priority Item #5: Promoter germline genetic testing for all CRC patients now that NCCN recommends it for patients dx <50 and says it can be considered for those dx >=50

Looking Ahead

ACS NCCRT's 2026-2029 & Priority Areas

We are dedicated to reducing **colorectal cancer mortality & mortality disparities** by focusing our efforts around these five priority areas:

1	2	3	4	5
MOBILIZE	**IMPROVE**	**SUPPORT**	**PROMOTE**	**IDENTIFY**
national and community-level efforts that will lead to health equity across the colorectal cancer continuum.	timely action for early-age onset colorectal cancer signs and symptoms.	on-time screening as soon as eligible and continued participation per screening recommendations.	timely colonoscopy follow-up to positive (abnormal) non-colonoscopy tests.	areas to ensure timely initiation of quality colorectal cancer treatment.

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Activity: We'd like to host an in-person or virtual summit focused on early-age onset CRC.

A Call to Action: Improving Outcomes Related to Early-Onset Colorectal Cancer

Objective: Develop a multidisciplinary implementation plan for improving outcomes related to early-onset CRC that includes strategies for increasing public awareness, accurate risk stratification, on-time guideline-concordant screening and timely diagnostic evaluation of symptomatic patients.

Our Tasks Today

- Review meeting objectives
- Agree on agenda outline
- Determine discussion topics (small groups)
- Identify associations, organizations, and professional groups we'd like to have at the table.

Summit Working Agenda

- Overview:
  - Epidemiology
  - Etiology
  - Risk stratification/Screening/Genetic Testing
- Review of NCCRT Activities:
  - Family History & EAO CRC Priority Team
  - Resources
- Minimizing Delays in Diagnosis
- Risk Assessment & Communication
- Increasing Public Awareness & Lead Time Messaging
- Next Steps for the ACS NCCRT

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Possible Attendees

- NCCRT Steering Committee, member representatives, & subject matter experts
- NCCRT Priority Team Chairs (FH EAO, Professional Ed, Public Awareness, Community Health Centers)
- Primary Care members (AAFP, SGIM, ACP, ACOG)
- Advocacy Organizations (Fight CRC, CCA, CRC Coalition)
- GI Societies (ACG, AGA, ASGE)
- American College of Emergency Room Physicians, American Association of Emergency Medicine and/or Society for Emergency Medicine
- American Academy of Urgent Care Medicine, College of Urgent Care Medicine and/or Urgent Care Association
- American College Health Association

**Who are we missing?*

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Breakout Activity

Small-Group Discussion (30 minutes)

Activity: Split into 3 Groups (Minimizing Delays in Diagnosis, Risk Assessment, or Increasing Public Awareness) to brainstorm which topics would be most relevant to discuss at the summit.

1. Individually brainstorm topic ideas & speakers
2. Affinity exercise to group like topics:
    - Group representative will help to collect and consolidate with the group's feedback
    - Rewrite if necessary to clarify and consolidate similar topics
    - End with top recommendations to share back with larger group
3. Identify your group's top three ideas

Large Group

Large Group Discussion (10 minutes)

Activity: *Share top topic recommendations from each breakout group. Solicit and incorporate additional feedback.*

Breakout groups report back and offer feedback

1. 3- min- Report back from each group
2. 5 min- Prioritize the top 3 overall topic ideas through dot vote

Next Steps & Close