

# Family History & Early Age Onset Colorectal Cancer



**Strategic Priority Team Meeting  
November 15, 2023  
3:30–5:00pm ET**

# Today's Agenda Items

- 1 Welcome & Introductions
- 2 Strategic Priority Team Overview
- 3 Share updates, opportunities & barriers
- 4 Recap of 2022 Meeting
- 5 Looking Ahead

# Co-Chairs



**Paul Schroy, MD, MPH**  
Boston University School of Medicine  
Emeritus Professor of Medicine



**Heather Hampel, MS, LGC**  
City of Hope National Cancer Center  
Professor-Clinician and Assistant  
Director, Division of Human Genetics

# 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 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.

# 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/ncr.30080.

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

Jan T Lowery, PhD, MPH<sup>1</sup>, Dennis J Ahnen, MD<sup>2</sup>, Paul C. Schroy III, MD, MPH<sup>3</sup>, Heather Hampel, MS, LGC<sup>4</sup>, Nancy Baxter, MD<sup>5</sup>, C. Richard Boland, MD<sup>6</sup>, Randall W Burt, MD<sup>7</sup>, Lynn Butterly, MD<sup>8</sup>, Megan Doerr, MS, LGC<sup>9</sup>, Mary Doroshenk<sup>10</sup>, W. Gregory Feero, MD, PhD<sup>11</sup>, Nora Henrikson, PhD, MPH<sup>12</sup>, Uri Ladabaum, MD, MS<sup>13</sup>, David Lieberman, MD<sup>14</sup>, Elizabeth G McFarland, MD<sup>15</sup>, Susan K Peterson, PhD, MPH<sup>16</sup>, Martha Raymond, MA, CPN<sup>17</sup>, N. Jewel Samadder, MD, MSc<sup>18</sup>, Sapna Syngal, MD, MPH<sup>19</sup>, Thomas K. Weber, MD<sup>20</sup>, Ann G Zauber, PhD<sup>21</sup>, and Robert Smith, PhD<sup>22</sup>

# 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?*



# Resources & Publications

- Identifying High Risk Patients and Families in Your Practice” (Supplement to "What can Gastroenterologists and Endoscopists Do to Advance 80% by 2018”)
- 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)



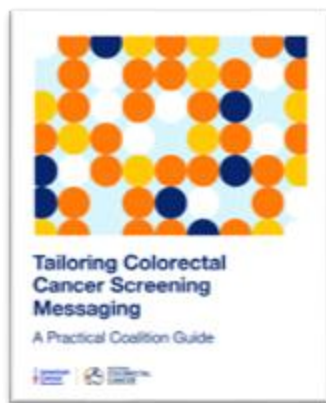
# 2023 Policy Updates & Challenges

- USPSTF decided that they are not going to pursue the "Lynch Syndrome-Related Cancers: Risk Assessment, Genetic Counseling, and Genetic Testing" topic at this time.
  - A recommendation would have raised awareness of Lynch syndrome and ensured health insurance coverage of Lynch testing with no cost-sharing for patients who qualify (if it received a Grade B or higher recommendation).
  - The Task Force appreciates the interest and public comments received and remains committed to learning what the evidence tells us about these important topics. The timing of when and whether they will be revisited is dependent on a variety of factors, including limited timing and budget.
- COC Accreditation Standard
  - CoC declined to consider the measure since they did not have a formal relationship with Fight CRC and the measure portfolio for colon and rectum disease has already been established
  - Trying to find out if they would consider it if submitted by a membership organization
- The AGA/CAP proposed Medicare Merit-based Incentive Payment measure around universal tumor screening for Lynch syndrome was approved and is in use this year. So far, they are seeing good uptake of it.



# 2023 Updates: Lead Time Messaging Project

- Research components completed
  - Swati Patel, MD recruited to draft 1-2 manuscripts
  - First manuscript describing knowledge, attitudes, and health behaviors of target audience (ages 20-44) in preparation.
- Guidebook has been drafted, reviewed by ACS and submitted to design team for completion.
- Compliments other ACS NCCRT's Messaging Guides:



# New Guidebook Contents



Key Definitions & Screening Recommendations



Nation Data on CRC Screening & Rates



Recommended Lead Time Messages



Helpful Tactics to Use for Effective Messaging



Focus on Family History

# 2022 Takeaways & Looking Ahead:

## Task #1: Review Our Charge

### Key Takeaways

- Make it more actionable
- Expand inclusivity
- Create a problem statement that leads into the charge to help identify barriers

## Task #2: Review the Themes

### Key Takeaways

- Be clear with language we're using – e.g. “on time,” “lead time,” “at any age/at average age”
- Clarify where we align and delineate between early onset and familial/inherited
- Call to broaden language to include:
  - Others in the health care team
  - Genetic testing/counseling
- Expand beyond EHR to other technologies / digital solutions
- Be actionable with our early onset areas of focus

# Looking Ahead:

## Identified Opportunities:

### Lead Time Messaging

- Frequency and timing of messaging
- How do we include younger voices into our planning efforts?
- Dissemination of our future messaging guidebook and any follow-up research in the area

### Blue Star Conversation

- Guidance & action plan for how patients can talk to their family
- Capturing family history in EHR (nudge behavior theory)
- Reviews of existing NCCRT resources

### Expanded Areas of Interest

- Messaging/tools outside healthcare setting
- Symptom awareness
- Role of genetic counseling & addressing barriers
- Separation of early onset from familial/inherited

# GROUP DISCUSSION

- Promoting the new **ACS NCCRT Lead Time Messaging Guidebook**
  - Implement detailed dissemination plan
  - Initiating follow-up research
  - Should we also consider alternative strategies for promoting lead-time messaging?
- Review, update and re-promote important **ACS NCCRT resources** (i.e. Risk Assessment & Screening Toolkit).
- Revisit our SPT mission
  - Why we focus on both FH and EAOCRC (and not just from the perspective of screening)
  - Should we consider wordsmithing our charge/mission?
- Explore **opportunities to partner** with other organizations

# In your groups

Discuss:

- Where are there opportunities?
- What could NCCRT be doing? What about your own organization?
- What are we missing?



**Close**

# Standardized Resource Dissemination

## Objectives

- Ensure all partners are aware and have access to new resources
- Reach new partners with relevant resources and up-to-date information
- Continue to promote the roundtables as the leading think tanks on certain cancers



## PRIORITY

### owned media

- website
- newsletter + emails
- live presentations
- blog posts

### shared media

- social media channels



## SECONDARY

### earned media

- press releases
- conference announcements
- bylines



## TERTIARY

### paid media

- paid social media campaign



# Resource Dissemination Through Owned Media

Timing	Tactic	Notes
Week 1-3 (in first newsletter after new resource release)	Newsletter	Include information and link to new resources in newsletter
Day 1	Post to website	Allows for easy access to download resource
Ongoing	Share in live presentations (webinars/meetings)	Sharing resources (hard copies or QR code-based materials) during live presentations allows for a more in-depth exploration of purpose and impact of new resource
Week 1-2	Blog post	Blog posts can increase SEO and reach of new resources. A templated blog post can be shared with partners so they can create their own blog posts to promote new resources
Week 1	Share with ACS staff	Request a Cancer Control or Society Source article, ask regional VPs to distribute

# Resource Dissemination Through Shared Media

Timing	Tactic	Messaging Focus	Creative
Launch day	1 tweet 1 LinkedIn post	Focus messaging on the fact that it's brand-new and what its use case is	Graphic with visual of the report and CTA
Day 1	1 tweet	Draw audience in with most interesting data point, mention brand-new release	Graphic with data point
Day 2	1 tweet 1 LinkedIn post	ICYMI-style messaging with a look into what the resource contains	Animated video outlining information in the resource
Day 3-17 (next two weeks)	1 tweet every other day 3-4 total LinkedIn posts	Focus on data snippets and contents, call out that it is a brand-new resource	Combination of still and animated pieces spotlighting a snippet of content, like a data point or specific recommendation
Day 18-32 (next two weeks)	1 tweet/week 1 LinkedIn post/week	"Have you seen our newest resource" and ICYMI style messaging	Still graphics with CTA
Ongoing	Occasional reminders (i.e. awareness days)	Draw attention with data points or relevant observances and link to resource	Graphic with data point and/or linked to observance

Timing	Tactic	Notes
Day 1	Partner tools	a small toolkit should be made available on the website along with the resource with 2-4 post copy samples along with graphics to choose from, intended for partners to be able to use as is or customize as they see fit
Day 1	Email recommendations	send email solely focused on the new release with a bullet-pointed overview
Post Launch		Next 3-4 emails should include reminders about the new release

# Resource Dissemination Through Earned Media

Timing	Tactic	Notes
Week 1-3	Pitch to trade publications	Create press release on relevant topic, include link to online resources
Ongoing	Pitch to conferences	Find and pitch speaking opportunities at health-focused conferences and seminars

# Resource Dissemination Through Paid Media

Timing	Tactic	Notes
Week 1-3	Paid social	Paid placements on LinkedIn with retargeting existing roundtable audiences and prospective targeting by job title and groups
Week 1-3	Sponsored content	Sponsor content with established trade publications
Week 1-3	Email	Purchase email lists of healthcare professionals, promote new resources to new audiences