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
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

- 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
History & Accomplishments

• Hosted an Early Onset CRC Summit in 2017


• 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”


- 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.
  o 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).
  o 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
  o 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
  o 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
  o Swati Patel, MD recruited to draft 1-2 manuscripts
  o 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:
  o Others in the health care team
  o 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 being 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
  - enewsletter + 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

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<thead>
<tr>
<th>Timing</th>
<th>Tactic</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Week 1-3 (in first newsletter after new resource release)</td>
<td>Newsletter</td>
<td>Include information and link to new resources in newsletter</td>
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<tr>
<td>Day 1</td>
<td>Post to website</td>
<td>Allows for easy access to download resource</td>
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<tr>
<td>Ongoing</td>
<td>Share in live presentations (webinars/meetings)</td>
<td>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</td>
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<td>Week 1-2</td>
<td>Blog post</td>
<td>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</td>
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<tr>
<td>Week 1</td>
<td>Share with ACS staff</td>
<td>Request a Cancer Control or Society Source article, ask regional VPs to distribute</td>
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## Resource Dissemination Through Shared Media

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

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<tr>
<td>Week 1-3</td>
<td>Pitch to trade publications</td>
<td>Create press release on relevant topic, include link to online resources</td>
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<tr>
<td>Ongoing</td>
<td>Pitch to conferences</td>
<td>Find and pitch speaking opportunities at health-focused conferences and seminars</td>
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## Resource Dissemination Through Paid Media

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