Family History and Early Age Onset Colorectal Cancer Strategic Priority Team

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-Clinical and Assistant Director, Division of Human Genetics
**Agenda**
- Welcome
- Overview (“Who are we”)
- Recap of 2021 meeting
- Review 2022 activities
- Discussion
- Looking ahead
Family History Task Group founded in 2012

- Expanded to include Early Onset CRC in 2016

- Our charge is 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.
Prior Accomplishments

- Hosted a Family History Symposium in 2014

- Hosted Electronic Health Record Meeting in 2015 to develop consensus statement, core components and outline NCCRT Strategy on improving FH collection in EHRs

- 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.
Resources

- “Identifying High Risk Patients and Families in Your Practice” (Supplement to "What can Gastroenterologists and Endoscopists Do to Advance 80% by 2018")
- “Advanced Colorectal Polyps: GI Brief”

Publications

- Commentary in Cancer (2019) entitled “Improving On-Time Colorectal Cancer Screening Through Lead-Time Messaging” (Jones, Ahnen, Schroy)
Recap of 2021 SPT Meeting

- **Updates**
  - Lead-time Marketing Research Project
  - Family Hx Advanced Adenoma/EAO/CRC Study
  - Young-Onset Colorectal Adenoma (YOCA) Study
  - Request that USPSTF consider a Lynch Syndrome Review

- **Discussion**
  - Risk Assessment and Screening Toolkit
  - Promote universal tumor screening for Lynch syndrome
2022 Planned Activities

- **“Risk Assessment and Screening Toolkit”**
  - Form working group to consider expanding scope to include other familial and inherited cancers;
  - Survey NCCRT membership to gather feedback about the toolkit and any dissemination, implementation and/or evaluation activities;
  - Explore opportunities for further dissemination.

- **Promote universal tumor screening for Lynch syndrome**
  - COC Accreditation Standard
  - Education of Tumor Registrars regarding MSI and IHC for the MMR proteins
  - Continue to support the AGA/CAP proposed Medicare Merit-based Incentive Payment measure around universal tumor screening for Lynch syndrome
  - Support of state or federal legislation to prevent life insurance discrimination based on genetic test results or family history
2022 Activities/Accomplishments

- Promoting universal tumor screening for Lynch syndrome (*Heather Hampel*)
- Blue Star Conversation (*Heather*)
- Family Hx Advanced Adenoma/EAO CRC Study (Christine Molmenti)
- Lead-Time Messaging Campaign (*Michelle Aubertine*)
2022 Updates

- "Lynch Syndrome-Related Cancers: Risk Assessment, Genetic Counseling, and Genetic Testing" topic was added to the list of preventive services under consideration by USPSTF.
  - NCCRT supported this nomination
  - It may take years but this is a move in the right direction
  - A USPSTF recommendation will raise awareness of Lynch syndrome and ensure health insurance coverage of Lynch testing with no cost-sharing for patients who qualify (if it gets a Grade B or higher recommendation).

- COC Accreditation Standard
  - Fight CRC developed a white paper on the topic and submitted it to COC for consideration
  - Organizations can sign on in support of the topic on the Fight CRC website (NCCRT has not signed on yet)- https://fightcolorectalcancer.org/gfhac/

- Continue to support the AGA/CAP proposed Medicare Merit-based Incentive Payment measure around universal tumor screening for Lynch syndrome
  - Comment period last December
  - MAP Coordinating Committee almost always accepts the recommendation of the Clinician Workgroup and we made it through that evaluation.
2022 Activity Highlight: Blue Star Conversation

- Each Blue Star Conversation is hosted by an NCCRT Strategic Priority Team each session includes a brief, timely, topical presentation (generally 15-20 minutes) followed by small group discussions among participants, and a sharing of key takeaways with the larger group.

- 66 attendees

- 91% of respondents indicated the learned something new from this session, and 100% of respondents indicated they can felt the session was well organized and would recommend this session to a colleague.
Advanced polyp prevalence among first degree relatives of early age onset colorectal cancer (EAO-CRC) patients

Feasibility Study
Funded by Fight CRC

- First-degree relatives of patients with ≥1 advanced polyp carry:
  - 4-6-fold increased risk of being diagnosed with an advanced polyp
  - 2-4 fold increased risk of developing CRC

- USMSTF and NCCN guidelines - screening at 40 or earlier for FDRs of advanced colorectal polyp patients, regardless of the age at diagnosis of the affected relatives

- Unique cohort of EOCRC patients; OCCPI USLS (PI: Hampel)
  - EAO-CRC patients recruited 2013-2016; considered otherwise sporadic

Research Question: What is the prevalence of advanced adenomas among EAO-CRC cases?
**Study Design, EOCRC Cohort (n=536)**

### OSU

**Step 1. Contact EOCRC probands n=536 (random selection)**

**Eligibility**
- <50 years of age (N=536)
- No known CRC susceptibility gene
- No known FDR with CRC
- Considered “sporadic” cases

**Recruitment methods**
- Email
- Mailed letter
- Follow up phone call

**Data collection**
- Collect FDR contact information

### NORTHWELL/FEINSTEIN

**Step 2. Contact FDRs**

**Eligibility**
- ≥ 18 years of age
- Colonoscopy prior to EOCRC diagnosis

**Recruitment methods**
- FDRs were contacted if: Proband said yes or “not sure” that FDR had colonoscopy
- Email and/or mailed letter
- Follow up phone call

**Data collection**
- Collect colonoscopy location/physician name to obtain records

### NORTHWELL CRC SURGERY/GI

**Step 3. Collect and verify colonoscopy records**

**Eligibility**
- Colonoscopy records performed prior to EOCRC diagnosis will be collected

**Recruitment methods**
- Send signed medical release forms to endoscopy practice
- Follow up with phone call

**Data collection**
- Verified advanced adenoma cases
Feasibility - Primary aims

Aim 1. Determine feasibility of recruiting 50 EOCRC probands (Proband response rate)

Aim 2. Determine the feasibility of contacting and enrolling FDRs of EOCRC probands (FDR response rate)

Aim 3. Determine the feasibility of collecting colonoscopy reports of FDRs to verify ACP diagnosis (Colonoscopy collection rate)

Secondary aims

1. Average length of time to obtain EMR records
2. Accuracy of self-reported colonoscopy results
3. Reasons probands and FDRs refuse participation

Results

EOCRC PROBANDS (n=536)
- ~30% cohort deceased
- 113 enrolled (21.1%)
- 67 completed the survey (59.3%)
- 67 probands provided names of 280 FDRs (4.2 FDRs per proband)
- \( \frac{67}{536} = 12.5\% \) response rate among probands overall

FDRs (n=280)
- 114 eligible (40.7%)
- 37 enrolled (32.5%)
  - 30 completed survey (80.1%)
- \( \frac{30}{114} = 26.3\% \) response rate among FDRs overall

- Colonoscopy collection rate - 30/37 (81.08%) of FDRs provided colonoscopy history information
- The average length of time to obtain colonoscopy and pathology reports was 6.64 days
Results

The proportion of advanced adenomas among first degree family members was determined by the number of complete families:

<table>
<thead>
<tr>
<th>Complete Family</th>
<th>Incomplete Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>• At least one advanced polyp in any FDR</td>
<td>• Any FDR 18+ not accounted for</td>
</tr>
<tr>
<td>• All FDR ineligible</td>
<td>• FDR declined or unable to reach</td>
</tr>
<tr>
<td>• Contact with all FDRs provided in OCCPI unless anyone missing is under 18</td>
<td>• FDR didn’t provide contact information for all FDRs</td>
</tr>
<tr>
<td>• No FDRs had a colonoscopy (self-report by proband)</td>
<td>• FDR lost to follow up</td>
</tr>
<tr>
<td></td>
<td>• FDR Adopted</td>
</tr>
</tbody>
</table>

Barriers

• Refusal to release contact or health information
• Lack of time and/or interest
• Discomfort participating on behalf of deceased family members
• Lack of information on colonoscopy history or on family members (in the case of adopted probands)
• Some colonoscopy reports were inaccessible due to facility recordkeeping length and/or incorrect/lack of information provided by FDRs

Summary & Next Steps

• Future studies with prospective recruitment likely improve recruitment and data collection rates
• Post colonoscopy communication among close relatives of advanced colorectal polyp patients is critical
• Continues to be priority area for EAO-CRC prevention research
• Finalize manuscript
• Submission to Gastroenterology
Family Hx of Advanced Colorectal Polyps / EAO-CRC Team

Thank you for all of your amazing work
Encouraging On-time Screening Research

Michelle Aubertine
Project Manager, KS&R
Looking Ahead: Lead-time messaging research

- Build advisory group for the creation of a messaging guidebook
- Author and publish a manuscript
Date: November 16-18th, 2022
Location: Sheraton Inner Harbor Hotel, Baltimore, MD
Meeting Information & Agenda: https://nccrt.org/event/nccrt-annual-meeting-2022/

An in-person session for the Family History & Early-Age Onset CRC Strategic Priority Team is being held in-person on Wednesday, November 16th, from 3:30pm-5:00pm ET in Loch Raven II.
The 2023 80% in Every Community National Achievement Awards

Submit your nominations by Nov. 22!

nccrt.org/awards