

Family History & Early Onset Colorectal Cancer Task Group





Task Group Co-Chairs

- Paul Schroy, MD, MPH
Boston University School of Medicine
Director of Clinical Research, GI Section

- Dennis Ahnen, MD
University of Colorado School of Medicine,
Director of Genetics Clinic Gastroenterology of the Rockies

- Thomas K. Weber, MD, FACS
Northwest Region at Northwell Health
Colon Cancer Challenge Foundation,
Chair Emeritus, NCCRT



Charge:

- The charge of this task group is to identify key issues and areas of need around familial and early onset colorectal cancer for the purpose of identifying opportunities for the Roundtable to be a catalyst for change.



Task Group Themes

- Help clinicians systematize the identification of patients at familial risk and recommendation of early diagnostic evaluation of those presenting with 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 for the 50 to 55 population, according to recommended guidelines.
- Address the increase in CRC in young adults through strategic interactions with key stakeholders and thought leaders.



FY17 Project Plan (Nov. 2016)

- Finalize and disseminate GI Brief
- Complete Delphi Survey, analyze data and submit a manuscript for publication
- Develop practice transformation tool on family history and early onset
- Continue to work with other Task Groups on EHR improvements
- Participate in 2017 Early Age Onset CRC Summit



FY17 Accomplishments

- ❑ Commissioned Jackson Lab to develop Family History/Early Onset CRC Clinician's Module- Advisory Group.
- ❑ Completed and Disseminated GI Brief
- ❑ Hosted webinar on NCCRT "State of the Science" publication on CRC family history
- ❑ Restarted the Delphi Survey
- ❑ Continued to address family history issues with EHRs through participation in ACS CAN EHR work group
- ❑ Participated in 2017 Colon Cancer Challenge Foundation Early Onset Summit
- ❑ Promoted National Family Health History Day via NCCRT blog and joined the Twitter Thunderclap
- ❑ Held a preconference strategy session on Early Onset CRC at NCCRT Annual Meeting on 12/6/17.



Toolkit Goal & Objectives

Toolkit Goal

To bridge the existing knowledge gap and to provide a step-by-step, detailed tool for practices that are dedicated to improving their processes in the collection of family history and acting on that information according to recommended guidelines.

Objectives

1. Conduct a multi-faceted needs assessment to:
 - discover best practices in CRC screening for at-risk populations
 - identify key drivers influencing successful CRC screening programs
2. Develop a toolkit for PCPs to facilitate practical implementation of assessment, screening, and communication practices for detection of CRC



Schedule of Events

- RFP Released April 2016
 - Advisory Group formed from FH/EAO Task Group members oversee project development
- Phase 1 Project Completion Date: September 29, 2017
 - Literature review
 - Environmental scan
 - PCP recruitment (begin)
- Phase 2
 - PCP interviews (started 11/8)
 - Identification of best practices for PCPs
 - Analysis of activities and design of the toolkit
- Working draft to be reviewed at NCCRT Annual Meeting



Annual Meeting Workshop Details

Familial, Hereditary, and Early Age Onset Colorectal Cancer: A Module Designed to Assist Primary Care Clinician's in the Identification of Individuals at Increased Risk and Facilitate Earliest Possible Stage Diagnosis

Thursday, 3:30 PM – 5:00 PM

FY17 Accomplishments

GI Brief

- Focused FH for all patients
- Keep abreast of guidelines
- Establish a referral process
- ID high risk patients in Endoscopy Unit
- Develop/use tools to communicate with family

Available at nccrt.org/resource-center/



*What can Gastroenterologists & Endoscopists Do to Advance 80% by 2018?
Supplement - Identifying High Risk Patients and Families in Your Practice*



In *What can Gastroenterologists & Endoscopists Do to Advance 80% by 2018?*,¹ we describe the key role that gastroenterologists and endoscopists play in the national effort to make sure 80% of age-appropriate adults are regularly screened for colorectal cancer by 2018.

Identifying high risk patients and families is another key step you can take to ensure your patients and their families receive timely and appropriate screening.

This guide is meant to aid you in these efforts.





FY17 Accomplishments

- **Family History Brief Dissemination**
 - Released during the Dec. 8, 2016 webinar on familial risk and CRC:
<http://nccrt.org/resource/familial-risk-webinar/>
 - Sent email notification to NCCRT members and 80% pledged partners
 - Promoted on NCCRT's Facebook and Twitter social media channels
 - Issued call to action to GI society representatives and communications leads to promote



Delphi Survey

□ Progress

- Transition from “Broad Consensus” to “Expert Consensus”
- Completed first iteration of the survey.
- Received comments on low and high level agreement questions, currently working on those with mid level agreement.

□ Consensus items thus far

- **Goal-** ID patients who should be referred for further risk assessment and those at higher than average risk and need more intense screening
- **Data elements-** FDRs and SDRs, age of cancer dx, all cancer types that would change screening, entered as discrete elements in searchable fields, importable from FH tool and patient portal, updated whenever new information becomes available



Consensus Items (continued)

- **Links to Decision Making-** capacity to alert increased risk of hereditary cancer syndrome, for elevated cancer risk or need for different screening, provide links to current screening guidelines based on FH and generate best practice alerts for cancer screening for high risk pts
- **Development Process-** Elements of FH section should be guided by national standards, standardized across EHRs incorporated centrally by EHR vendors and updated by vendors as recommendations change
- **Incentives-** *Completing/Maintaining FH* section should be tied to performance measures for cancer screening. *Referral* of appropriate patients for genetic counseling/testing should be expected as part of high quality care



EAO Strategy Meeting

- **2017 Early Age Onset Colorectal Cancer Summit:** *What we know, what we don't know, and what we need to know*
 - ▣ Pre-conference, strategy and working meeting
 - ▣ Purpose of the meeting is to assess how the NCCRT and its partners, including clinical practitioners, researchers, and advocacy organizations, can most effectively align to address the issue in both the short and long term.
 - ▣ Portion of discussion will also address ongoing work from the NCCRT involving family history and the role of primary care providers.
 - ▣ Hopefully, a first in a series of conversations held by partners on addressing the issue.



FY18 Projects

- Help finalize, disseminate and validate the Clinicians Family History EAO Toolkit- Jackson Labs, RT, Lior
- Complete the darn Delphi Survey, analyze the data, share results with the NCCRT and ACS CAN and submit for publication- Ahnen
- Write Summary of EAO CRC Symposium- Lowery
- Organize FH Symposium at EAO CRC April 2017
- Identify strategies for optimizing communication about advanced adenomas - Working Group (Lead Molmeti)
- Work with NCCRT to change narrative regarding on-time screening- Need help here
- Ask NCCRT to convene and facilitate a meeting of leaders of Primary Care Organizations to discuss EAO CRC.

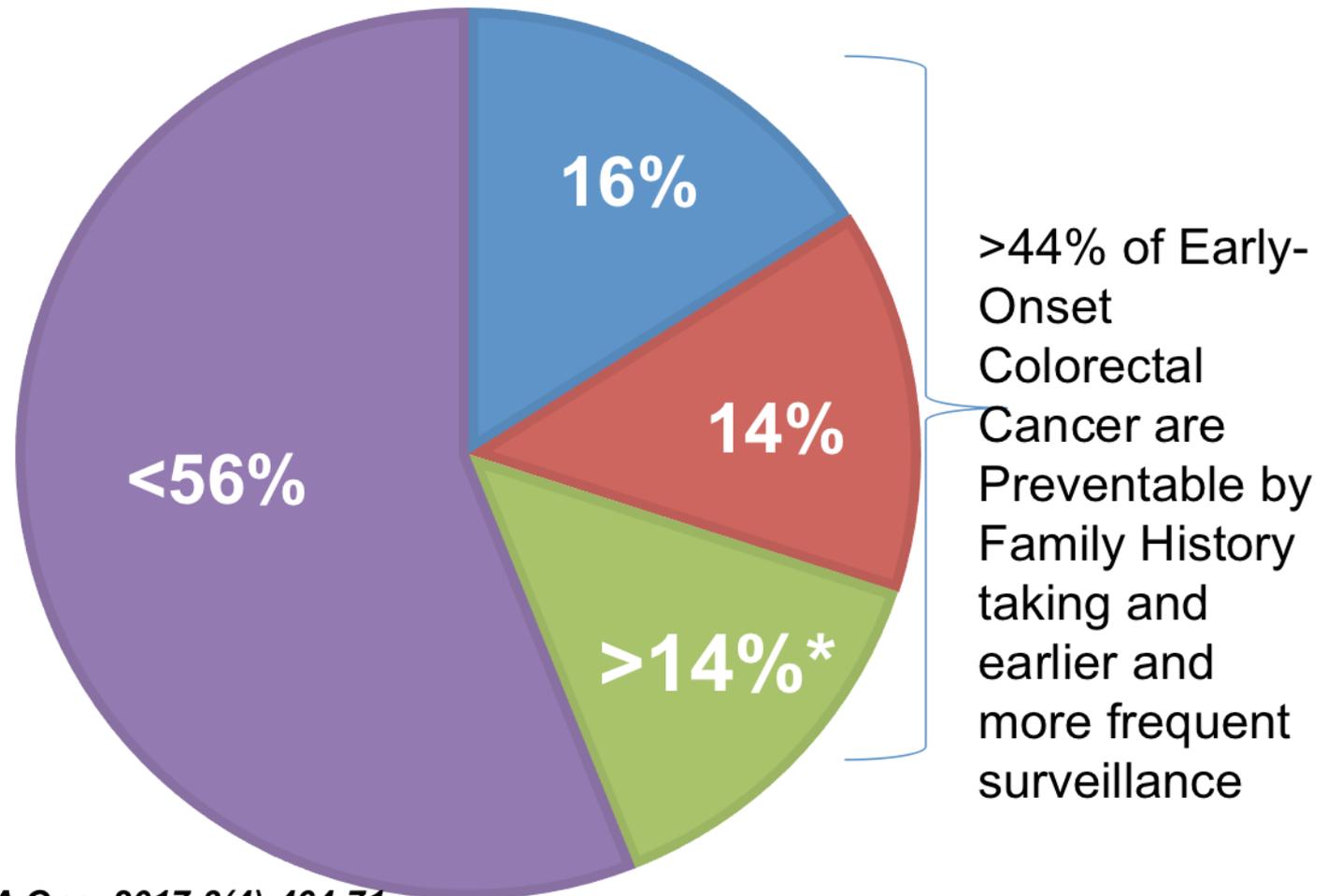


Key Points of Discussion

- Updates of FH/EO CRC Toolkit and Delphi Survey
- Possible next steps based on discussion at the Early Age Onset NCCRT Summit
 - Earliest possible diagnosis EO CRC- need for provider/public education
 - Causation- Survey ongoing cohorts/case control studies and consider Prospective Case Control Study
 - Increase universal MSI testing- how? pathologists?
 - Changing the narrative/"on time screening"- how?
 - Addressing the adenoma prevalence & dwell time for predictive models
 - Is it time for a controlled study of starting age for colon cancer screening? Who, How, Endpoints
 - Communication surrounding Advanced Adenomas

Communication of Adv Adenomas

■ Hereditary ■ FDR with Colorectal Cancer ■ FDR with Advanced Adenoma ■ Sporadic





Immediate Next Steps

- ❑ Finalize and disseminate the Clinicians Family History EAO Toolkit
- ❑ Complete the Delphi Survey
- ❑ Prioritize ideas of EAO CRC Symposium/Write summary
- ❑ Participate in the EAO CRC Summit in April 25/26
- ❑ Request that the Multi Society Task Force consider writing an opinion piece on the importance of early onset colorectal cancer and offering to help.
- ❑ Form a working group focused on the advanced adenoma communication issue chaired by Christine Molmenti, PhD



Advisory Groups/Volunteers

Advanced Adenoma Working Group.

Chair: Christine Molmenti PhD, MPH Hofstra Northwell SOM

Members:

Electra Packett

Paul Schroy

Cindy Borassi

Heather Hampel

Susan Peterson

Bill Wildin

Anne Carlson

Martha Raymond

Others



Gaps/Needs:

- Lack of Primary Care and EHR vendor representation in TG
- A cohesive message and plan for increasing clinician-patient and intra-family communication about familial/heritable risk
- A strategic plan for engaging EHR vendors- ACS CAN
- Causes of EO CRC
- Accurate risk prediction/stratification tools for identifying individuals age <50 at increased risk for sporadic EO CRC
- Effective strategies to educate medical students and residents about the importance of family history, risk assessment and existing guidelines.



FY19 Project Plan/Funding Request?

- Consider convening/facilitating a Summit of Primary Care Organizations on EO CRC and FH
- Concerted Educational Campaign earliest possible diagnosis for providers and public
- Concerted Educational Campaign- FH and on time screening
- Work on validation of family history/early onset clinician's toolkit



Parking Lot Issues:

- Engage appropriate stakeholders to develop a strategic plan for graduate and post graduate education about the importance of family history, risk assessment and existing guidelines
- Demystifying genetic testing
- Exploring the potential role for initiating screening before age 50 given the surge in early onset CRC- being done by others?