Family History and Early Onset CRC Task Group Report

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 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

  State University of New York Health Sciences Center
  Colon Cancer Challenge Foundation,
  Chair Emeritus, NCCRT

Roster

First Name	Last Name	Organization
Deborah	Alsina	Bowel Cancer UK
Melanie	Bird	American Academy of Family Physicians
Lori	Blanton	American Cancer Society
Frank	Bright	NACDD
Amy	Brunson	AMSURG
Anne	Carlson	Colon Cancer Coalition
Mary Ellen	Conn	West Virginia University Cancer Institute
Lee	Dranikoff	AS
Seth	Glick	ACR
James	Keresztury	Mountains of Hope Cancer Coalition
Stephanie	Guiffre	Colon Cancer Alliance
Heather	Hampel	National Society of Genetic Counselors
Whitney	Jones	Colon Cancer Prevention Project
Jordan	Karlitz	ACG
Lauren	LeFew	Colon Cancer Alliance
Beth	McFarland	ACR
Dale	Mintz	AliveAndKickin
Trena	Mitchell	Arkansas Cancer Coalition
Kathryn	Pierce	Cigna
Martha	Raymond	The Raymond Foundation & Michael's Mission
Diana	Redwood	ANTHC
Amanda	Smart	CCPP
Michelle	Tropper	Health Center Network of NY
Jennifer	Weiss	UW Health
Krista	Wilson	The Colon Club
David	Yavin	Medial EarlySign

FY16 Accomplishments

Published a "state-of-the science" manuscript

- **Provides a comprehensive review of the literature and identifies key gaps in research to 6 key questions:**
  1. What are the risks for CRC associated with family history?
  2. What are the existing screening recommendations for persons with a family history of CRC?
  3. What are the rates of adherence to screening recommendations among persons with a family history of CRC?
  4. What are the known predictors and barriers to screening among persons with a family history of CRC?
  5. What interventions to improve screening in high risk persons are effective?
  6. What family history screening tools are currently available for use in clinical or public health practice?
- **A draft highlighted in the Snapshot session and discussed in detail during a Workshop at 2015 meeting.**
- **Webinar scheduled for December 8th, 2016**
- **Working on several of the recommendations**

FY16 Accomplishments (cont)

- **Provider Education**
  - Drafted a supplement to the NCCRT resource, *What can Gastroenterologists & Endoscopists Do to Advance 80% by 2018?*, entitled "Identifying High Risk Patients and Families in Your Practice" (a/k/a "GI Brief")
  - Published a Letter to the Editor in *CGH* in response to an article entitled "Colorectal Cancer Screening Quality Measures: Beyond Colonoscopy"

FY16 Accomplishments (cont)

- **EHR**
  - Delphi Survey
    - Revised based upon feedback from participants.
    - Obtained IRB approval for publishing the results.
    - Disseminated to a broader audience of PCPs.
  - Endorsed efforts to identify and document specific best practice workflows related proper utilization of family history data in the EHR Best Practices and Workflow Guide for NextGen.
  - Joined ACS CAN task group to improve EHRs

FY16 Accomplishments (cont)

- Participation in the Early Age Onset Colorectal Cancer Summit/Family History Symposium co-sponsored by the Colon Cancer Challenge Foundation and Michael's Mission (*NYC, March 18-19)*
  - Provided content for "Understanding Early Age Onset Colorectal Cancer", EndoEconomics, Summer Edition

- Participation in the Family Health History Tool Meeting sponsored by the Genomic Healthcare Branch (GHB), National Human Genome Research Institute *(D.C., June 14-15)*.

Discussion

- **Delphi Survey**
  - Revised approach to achieve “expert” consensus
  - Initial results similar to previous round- broad consensus
  - Next steps:
    - Revise questions based on feedback.
    - Work on areas of differences between PCPs and GCs?
    - 2nd iteration to reach consensus
    - Generate report to NCCRT
    - Write up paper
    - Assess current EHRs for the consensus elements?
    - Discuss with EHR vendors?
    - Collaborate with EHR vendors/others to develop and incorporate standards?

Discussion

- **GI Brief (Supplement to "*What can Gastroenterologists & Endoscopists Do to Advance 80% by 2018?*")**
  - *Key elements*:

1. Take a focused family history annually for every patient in your practice.
2. Keep abreast of the colorectal cancer screening guidelines for patients with a family history of colorectal cancer or colonic adenomas.
3. Establish a process for referral or care for patients who meet high-risk family history criteria.
4. Identify intermediate/high risk families through the endoscopy suite.
5. Use or develop tools to provide screening recommendations to first degree relatives of patients identified to be at intermediate or high colorectal cancer risk.

  - *Next steps:* Format, add to toolkit, disseminate through GI societies/others

Discussion (cont)

- **NHGRI/Family History Meeting**
- Dr. Wilden will attend the NCCRT and present at the FH EAO Workshop on Friday.
- Take Home from the NHGRI FHH Tools Meeting:
  - Abundance of excellent Family Health History Tools – that work!
  - DEARTH of EHRs that can upload FHH information
  - Very difficult to find commercial, large health care systems HER platforms that can upload the FHH Tool information – or collect it directly.
  - EHR links to evidence based surveillance and screening recommendations are lacking.
- Collaboration with Dr. Wilden's Team and the NHGRI Network very important for the NCCRT.

Discussion (cont)

- **Early Onset CRC**
  - Need for strategies for identifying high-risk individuals for whom early screening and/or aggressive diagnostic evaluation might be beneficial.
    - Modeling- Does microsimulation modeling suggest that screening should be started earlier in African Americans?
    - Next steps:
      - If yes, promote empiric data related to starting screening earlier in AAs
      - If no, promote development of multifactorial risk prediction models

What would be likely to influence USPSTF?

Discussion (cont)

- **Early Onset CRC**
  - **PCP education**
    - Rising incidence
    - Importance of early risk assessment (e.g., hand off from pediatrician to PCP)
    - Low threshold for referring patients with alarm signs and symptoms for diagnostic evaluation.

Discussion (cont)

- **Optimizing screening message through lead time: Begin screening discussion by age 40, if not earlier.**
  - Dramatic improvement in "on-time" screening for both average and high-risk individuals.
  - More timely diagnostic testing for those with signs or symptoms of colon cancer before age 50.
  - Risk reduction through counseling about importance lifestyle modification.

Discussion (cont)

- **Toolkit**
  - Funding approved
  - *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.
  - Briefly reviewed preliminary outline of key sections and next steps
  - Group expressed strong desire to play a key role in development even if outsourced.

Gaps/Needs

- A strategic plan for engaging EHR vendors.
- A cohesive message and plan for increasing clinician-patient and intra-family communication about familial/heritable risk.
- Accurate risk prediction/stratification tools for identifying individuals age <50 at increased risk of early onset.
- Effective strategies to educate medical students and residents about the importance of family history, risk assessment and existing guidelines

pportunities/FY18 NCCRT Projects

- Collaborate with key EHR vendors to forge a commitment to enhance the functionality of their products related to familial risk assessment, documentation and decisional support.
- Work collaboratively with survivorship and professional society members to develop a cohesive message and strategies for increasing clinician-patient and intra-family communication about familial/heritable risk.
- Support efforts to develop and implement accurate risk prediction/stratification tools for identifying individuals age <50 at increased risk of early onset CRC.
- Engage appropriate stakeholders to develop a strategic plan for educating medical students and residents about the importance of family history, risk assessment and existing guidelines.

FY17 Project Plan

- 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

Immediate Next Steps

- **Provider Education:**
  - Incorporate final revisions of GI Brief and submit for inclusion in the NCCRT resource, *What can Gastroenterologists & Endoscopists Do to Advance 80% by 2018?*
  - Assemble working group for the Family History Toolkit project and decide whether to outsource work via an RFP mechanism
- **EHR Project**
  - Complete Delphi Survey
- **EO CRC**
  - Participate in planning for the 2017 Summit

New brief for GIs on identifying high risk patients and families

Available at nccrt.org/80by2018