Genomics and Population Health Action Collaborative
Implementation Working Group

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The goal of the action collaborative is to integrate evidence-based genomics tests at the population/public health level in order to:

- Improve health
- Reduce health disparities
- Increase genomic literacy

Deciding Where to Begin

- **BRCA1/2**
- **Lynch syndrome**
- **Familial hypercholesterolemia (FH)**

Year 1: Focus on Hereditary Cancer
2014 CDC Funding Announcement


- **CDC Cooperative Agreement, 2014-2019**
  - Awarded to Michigan, Oregon, Connecticut, Utah, Colorado
- **Purpose:** Enhance state health department’s capacities to promote and apply evidence-based breast and ovarian cancer genomics guidelines in public health practice
  - Develop, enhance and evaluate education, surveillance and policy/systems change
  - Emphasis on partnerships
    - Required collaborations with relevant funded CDC programs (i.e., BCCCP, cancer registries, comprehensive cancer control programs)
    - Required collaborations with external partners (i.e., academic medical institutions, non-profits, clinical cancer genetics clinics)
  - Focus on *BRCA* but may also include *Lynch* syndrome
  - May identify target populations disproportionately affected and lacking genetic services
• **Purpose:**
Reduce breast, ovarian, colorectal and endometrial cancer incidence and mortality rates by overcoming barriers and advancing health system changes to promote cancer genomics best practices

- **Short- and intermediate term outcomes** (by 2019):
  - Increase knowledge among key clinical and policy stakeholders about cancer genetic best practices; improved access to and coverage of cancer genomics best practices. **[Policy/system change]**
  - Improve ability to assess the burden of hereditary cancers and use of cancer genomics best practices; increased production and dissemination of periodic cancer surveillance reports. **[Surveillance]**
  - Increase knowledge of hereditary cancers and appropriate use of cancer genomics best practices among the public and health care providers. **[Education]**
  - Improve partnerships and coordination among key stakeholder groups regarding cancer genomics services and care. **[Partnerships]**
Michigan residents at risk for or with HBOC/LS

National Health Partners:
- CDC DCPC
- CDC OPHG
- NCCN Experts
- ASHG/Jackson Laboratory
- LSSN
- Kintalk.org/UCSF

State Health Partners:
- MDCH Cancer Genomics
- MDCH Cancer Prevention & Control
- MCSP (State Cancer Registry) & Vital Records
- Michigan Medicaid
- MiBRFS
- Michigan Cancer Consortium
- Michigan Association of Health Plans
- Michigan Cancer Genetics Alliance

Local Health Partners:
- BCBSM
- Priority Health
- WSU Genetic Counseling Program
- GVSU
- Local cancer registrars

Clinical Practices:
- BRCA/Hereditary Cancer Clinical Network
- Health systems/clinical practices that diagnose cancer
- Health systems that perform universal/routine LS screening
- Health systems/practices that collect family history

Providers of individuals at risk or with HBOC/LS:
- Primary Care Providers especially in ‘counties of interest’
- Providers who care for cancer patients and cancer survivors
- Providers who care for family members of cancer patients

Michigan residents at risk for HBOC/LS

Providers of individuals at risk or with HBOC/LS:

Implementation Working Group - Members

- Cat Davis Ahmed, The FH Foundation
- Erica Bednar, MD Anderson Cancer Center
- Bruce Blumberg, Kaiser Permanente
- Vence Bonham, National Human Genome Research Institute
- Bev Burke, Connecticut Department of Public Health
- David Chambers, National Cancer Institute
- Kee Chan, University of Illinois, Chicago
- Toby Citrin, University of Michigan School of Public Health
- Mindy Clyne, National Cancer Institute
- Summer Cox, Oregon Health Authority, Public Health Division, Center for Protection & Health Promotion
- Mike Dougherty, American Society of Human Genetics
- Debra Lochner Doyle, Washington State Department of Health
- Greg Feero, Maine Dartmouth Family Medicine Residency Program
- David Flannery, American College of Medical Genetics and Genomics
- Sue Friedman, Facing Our Risk of Cancer Empowered (FORCE)
- Ted Ganiats, Agency for Healthcare Research and Quality
- Ridgely Fisk Green, CDC Office of Public Health Genomics
- Jill Hagenkord, Color Genomics
- Heather Hampel, Ohio State University
- Candace Henley, The Blue Hat Foundation
- Sharlene Hesse-Biber, Boston College
- Georgia Hurst, ihavelynchsyndrome.com
- Katie Johansen Taber, American Medical Association
- Kim Kaphingst, University of Utah
- Marissa Levine, Virginia Department of Health
- Nita Limdi, The University of Alabama at Birmingham
- Greta Massetti, CDC Division of Cancer Prevention and Control
- Ellen Matloff, MyGene Counsel
- Colleen McBride, Emory University
- George Mensah, National Heart, Lung, and Blood Institute
- James O’Leary, Genetic Alliance
- Vicky Pratt, Indiana University
- Alex Ramsey, Washington University of St. Louis
- Juan Rodriguez, CDC Division of Cancer Prevention and Control
- Joan Scott, HRSA
- Laura Senier, Northeastern University
- Sam Shekar, Northrup Grumman
- Cathy Wicklund, Northwestern University; National Society of Genetic Counselors
- Bob Wildin, National Human Genome Research Institute
- Janet Williams, The University of Iowa; American Academy of Nursing
- Doris Zallen, Virginia Tech Carilion School of Medicine
- Heather Zierhut, University of Minnesota

*Group continues to grow – always accepting new members!
Collaboration Among Many Stakeholders

- Patient Advocates
- Government Agencies
- Professional Associations
- Private Companies
- State Public Health Officials
- Clinicians/Health Care Delivery Systems
- Academic Researchers
The Working Group Process

- Monthly Conference Calls
- Share updates and ideas; get feedback from group
- Offshoot groups host additional calls and carry out work
PROJECT 1
• Assess factors that determine the ‘readiness’ of states to carry out genomics programs
• Perform qualitative interviews with state health officials to identify barriers & facilitators

Led by: Laura Senier and Ridgely Fisk Green

PROJECT 2
• Using principles of implementation science, design a set of outcome measures for public health-based genomics programs

Led by: David Chambers and Deb Lochner Doyle

PROJECT 3
• Examine health disparities related to hereditary cancer screening.
• Outline possible approaches for public health genomics programs to alleviate those disparities.

Led by: Georgia Hurst and Laura Senier
Project 1: Engaging State Public Health Officials

Work Performed To Date

– Created a case definition of “Genomics Activities” for state officials
– Organized states into unofficial categories of readiness (e.g., high, medium, unknown)
– Compiled a list of contacts in all states and territories
– Contacted officials in a small number of states (to begin with)
– Performed information gathering interviews with officials in Georgia, Utah, and Michigan
– Received OMB clearance to continue state interviews beyond the first group of states

Possible Next Steps

– Schedule additional interviews with state officials across all the readiness categories
– Compile information into a format that would be useful for state officials
– Upload to the action collaborative website
Project 2: Developing Outcome Measures

Work Performed To Date

– Compiled a table of performance targets and outcome measures for consideration by state public health departments in designing genomics programs
  • Focused on Lynch syndrome and Hereditary Breast and Ovarian Cancer
  • Applied an implementation science-based framework from Enola Proctor et al (2009) to public health genomics programs
– Drafted a written summary/introduction that corresponds to the outcome measures table
– Both are included in the Briefing Book

Possible Next Steps

– Consider adding more outcome measures related to equity
– Possibly link the outcome measures to examples activities in CDC-funded states
– Submit for publication in a peer-reviewed journal or house these materials on an appropriate website (e.g., action collaborative or CDC)
Project 3: Addressing Health Disparities

Work Performed To Date

– Organized into small groups to prepare two perspectives
  • **Paper 1:** *Using a Public Health Framework to Understand and Eliminate Disparities for Hereditary Cancer Screening* (led by: Laura Senier, Colleen McBride)
    – Abstract and framework figure are included in Briefing Book
  • **Paper 2:** *Advocating for a Community-Based Approach to Lynch syndrome and HBOC-related Health Disparities Among the African American Population* (led by: Georgia Hurst)
    – Outline is included in Briefing Book

Possible Next Steps

– Small groups will continue to convene to flesh out and draft the perspective papers
– Submit for publication to appropriate journals
Expanding the Focus in Year 2

Health Care Delivery Systems
- Look for opportunities to engage with health care delivery systems
  - Partnerships are critical
  - Important stakeholders in this discussion

Thinking Beyond Cancer
- Widen the focus; include familial hypercholesterolemia, a Tier 1 application that is ready for prime-time but needs attention

Implementation and Dissemination
- Continue to look for opportunities to apply principles of implementation science and dissemination research to the group’s activities