Genomics and Population Health
Action Collaborative

March 28, 2019

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Director, Office of Public Health Genomics, CDC
Origins and Goals of the GPHAC: 2015 - 2019

Objectives

• **Identify** opportunities for genomics to improve population health now and in the near future

• **Inform** and communicate with population health policy makers and program officials

• **Integrate** evidence-based applications into practice at the clinical/public health interface

GPHAC Meeting, March 2018
<table>
<thead>
<tr>
<th>Year</th>
<th>Month</th>
<th>Event Description</th>
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<tbody>
<tr>
<td>2015</td>
<td>November</td>
<td>First meeting to determine if an action collaborative should be established</td>
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<tr>
<td>2016</td>
<td>January</td>
<td>Academies staff Began building the collaborative</td>
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<td>March</td>
<td>2 Working Groups begin meeting monthly:</td>
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<td></td>
<td>- Evidence</td>
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<td>- Implementation</td>
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<td>March-December</td>
<td>Projects and writing got underway:</td>
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<td>- Outcome measures</td>
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<td>- Interviews with states</td>
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<td>- Health disparities</td>
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<tr>
<td>2017</td>
<td>February</td>
<td>Second meeting of action collaborative</td>
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<td>2 new groups are formed:</td>
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<td>- Cascade Screening</td>
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<td>- Population Screening</td>
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<td>April</td>
<td>Evidence Group finalizes paper and disbands</td>
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<td>July</td>
<td>Presentation at ELSI congress on health disparities work from the Implementation Group</td>
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## GPHAC Timeline, continued

<table>
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<th>2018</th>
<th>2019</th>
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| **January**  
Outcome measures paper is published in *Genetics in Medicine* | **December**  
NAM perspective published, *A Proposed Approach for Implementing Genomics-Based Screening Programs for Healthy Adults* |
| **March**  
Third meeting of the action collaborative | **March**  
Fourth meeting of the action collaborative to develop proposals for implementation science-based screening programs |
| **May**  
Delivery Of Cascade Screening For Hereditary Conditions: A Scoping Review Of The Literature is published in *Health Affairs* | **April - July**  
Wrap up of existing working group projects; finding next steps for the ideas generated today |
| **August**  
Completion of the collaborative under the National Academies |
Genomics and Population Health Action Collaborative: 2015-2019

**Implementation**
- Deb Duquette and David Chambers, Co-Chairs
  - **Project:** Perform information gathering interviews of state public health officials
    - **Deliverable:** Session at March 2018 meeting; paper in progress
  - **Project:** Develop outcome measures for genomics programs at state public health departments
    - **Deliverable:** Published in *Genetics in Medicine* (January 2018)
  - **Project:** Explore health disparities related to genomic screening for Tier 1 conditions
    - **Deliverable:** Presented at ELSI Congress (June 2017); paper in progress

**Population Screening**
- Jim Evans and Mike Murray, Co-Chairs
  - **Project:** Addressing Important Questions about Genomic-Based Screening Programs in Health Care Systems
    - Which genes should be screened?
    - In what setting should screening take place?
    - What is the optimal age for screening?
    - What's the best way to communicate/engage with participants?
    - What are the ethical concerns?
    - Are these programs cost effective?
    - **Deliverables:** NAM perspective paper published (December 2018); possible paper on paper on economic analysis for genomic-based screening programs

**Cascade Screening**
- Heather Hampel and Katherine Wilemon, Co-Chairs
  - **Project:** Literature review of past cascade screening work for hereditary conditions
    - **Deliverable:** Published in *Health Affairs* (May 2018)
  - **Project:** Framework for implementing cascade screening
    - **Deliverable:** Poster presentation at D&I conference (December 2018)
  - **Project:** HIPAA case studies and cascade screening
    - **Deliverable:** Paper in progress
  - **Project:** Patient perspectives on cascade screening
    - **Deliverable:** Survey of patients through advocacy organizations (FORCE, FH Foundation, LSI)

**Project:** Public health, communicable diseases, and genetic conditions
- **Deliverable:** Paper in progress
Action Collaborative Products

Evidenced Working Group Paper
Available on the GPHAC website

Proposed outcomes measures for state public health genomic programs

Debra Lochner Doyle, MS, LCGC\textsuperscript{1}, Mindy Clyne, MHS, CGC\textsuperscript{2}, Juan L. Rodriguez, MPH, MS\textsuperscript{3}, Deborah L. Cragun, PhD, MS\textsuperscript{4}, Laura Senier, MPH, PhD\textsuperscript{5}, Georgia Hurst\textsuperscript{5}, Kee Chan, PhD\textsuperscript{7} and David A. Chambers, DPhil\textsuperscript{2}

Deb Lochner Doyle et al.
Genetics in Medicine (2018)
ABSTRACT

Cascade screening is the process of contacting relatives of people who have been diagnosed with certain hereditary conditions. Its purpose is to identify, inform, and manage those who are also at risk. We conducted a scoping review to obtain a broad overview of cascade screening.
Action Collaborative Products

- Product of the Genomics and Population Health AC
- 1,689 page views
- 235 PDF downloads
- Altmetric score = 53 (6th highest for all NAM perspective papers)
- Others released on the same day:

  Burnout and Job and Career Satisfaction in the Physician Assistant Profession
  - Altmetric score: 26
  - 2,473 page views
  - 159 PDF downloads

  Business Engagement to Promote Healthy Communities Through Child and Family Well-Being
  - Altmetric score: 16
  - 378 page views
  - 37 PDF downloads
Issues/Questions to Consider During Today’s Meeting
How can GPHAC apply principles of implementation science to achieve improved implementation successes and outcomes in genomic medicine?
Context Matters: Funding Initiatives and Opportunities

Emphasis on Top 3 Tier 1 Genomic Applications Can Leverage and Synergize With Ongoing Initiatives

- 2018: NCI Cancer Moonshot Implementation Science in Hereditary Cancers
- 2018: NHLBI T4 Translation Research Funding Announcement
- 2018: NHGRI IGNITE 2.0
- 2018: All of Us Research Initiative
- 2018: NHLBI Implementation Science Workshop on FH
- 2018: NHLBI Workshop on Implementation Science and FH
- Ongoing: NIH Implementation Science Opportunities
- 2019: Emerging dialogue between genomics population health community (NASEM)
- 2019: Emergence of precision public health
What do we want to have accomplished with this collaborative? What will be the legacy of GPHAC?

GPHAC’s efforts will be the end of the beginning and not the end!