Genomics and Population Health Action Collaborative

Leadership Meeting
March 19, 2018

Muin J. Khoury
Director, Office of Public Health Genomics
Origins and Goals of the GPHAC

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 Deliverable (in-progress):

**An online toolkit** for states and health care systems interested in integrating genomics into population health programs
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<thead>
<tr>
<th>Year</th>
<th>Month</th>
<th>Event</th>
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<tr>
<td>2015</td>
<td>November</td>
<td>First meeting of the action collaborative</td>
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<tr>
<td>2016</td>
<td>January</td>
<td>Academies staff begin recruiting stakeholders</td>
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<td>March</td>
<td>2 Working Groups begin meeting monthly:</td>
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<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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<td>2018</td>
<td>January</td>
<td>Outcome measures paper is published in <em>Genetics in Medicine</em></td>
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<td>March</td>
<td>Third meeting of the action collaborative</td>
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Genomics and Population Health Action Collaborative - 2018

**Implementation**
Deb Duquette and David Chambers, Co-Chairs

- **Project 1:** Perform information gathering interviews of state public health officials
  - **Deliverable:** Session at March 2018 meeting; possible paper

- **Project 2:** Develop outcome measures for genomics programs at state public health departments
  - **Deliverable:** Published in *Genetics in Medicine* (January 2018)

- **Project 3:** Explore health disparities related to genomic screening for Tier 1 conditions
  - **Deliverable:** Presented at ELSI Congress (June 2017); possible paper

**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?
  - **Deliverable:** Paper for the GPHAC website; short commentary for peer-reviewed journal

- **Project 1:** Literature review of past cascade screening work
  - **Deliverable:** Paper submitted to *Health Affairs* (February 2018)

- **Project 2:** Considerations for future cascade screening pilot projects
  - **Deliverable:** Implementation framework and paper for the GPHAC website; short commentary for peer-reviewed journal

- **Project 3:** Policies and ELSI issues surrounding cascade screening
  - **Deliverable:** Policy summaries for select states and a HIPAA brief

- **Project 4:** Patient perspectives on cascade screening
  - **Deliverable:** Survey of patients through advocacy organizations (FORCE, FH Foundation, LSI)

**Cascade Screening**
Heather Hampel and Katherine Wilemon, Co-Chairs

- **Project 1:** Patient perspectives on cascade screening
  - **Deliverable:** Survey of patients through advocacy organizations (FORCE, FH Foundation, LSI)
Action Collaborative Products

Evidence Working Group Paper Available on the GPHAC website

Genomics and Population Health Action Collaborative
Building the Evidence Base for Genomics in Public Health: Implications for Decision Making, Public Policy, and Population Health Planning

EVIDENCE WORKING GROUP MEMBERS
Chair: Ned Calonge, The Colorado Trust

Proposed outcomes measures for state public health genomic programs

Debra Lochner Doyle, MS, LCGC¹, Mindy Clyne, MHS, CGC²; Juan L. Rodriguez, MPH, MS³; Deborah L. Cragun, PhD, MS⁴; Laura Senier, MPH, PhD⁵; Georgia Hurst⁶; Kee Chan, PhD⁷ and David A. Chambers, DPhil²

Coming soon...

- Literature review on cascade screening
- “A Guide for Considering Genomic-Based Screening Programs” (Population Screening Working Group)
- State and HIPAA policy briefs on cascade screening
Context Matters

Important Issues/Questions to Consider During Today’s Meeting
Context Matters: Medicine vs. Public Health

Genomics “Action” is in health care systems at the interface with academia.

Genomics in public health is mostly about infectious diseases (CDC Advanced Molecular Detection).

Most public health entities are not investing in human genomics and more often than not genomics is still viewed as hype or distraction.

How can GPHAC foster collaborations between public health and healthcare systems to achieve better implementation and outcomes in genomic medicine?
Context Matters: Synergizing GPHAC with the Genomics Roundtable

The Roundtable On Genomics and Precision Health is Exploring Relevant Topics:

November 2017 Workshop: *Implementing and Evaluating Genomic Screening Programs in Health Care Systems*

- Workshop proceedings released: March 16, 2018
- Companion piece in *JAMA* and *Nursing Outlook*

June 2018 Workshop: Genomics and Healthcare Disparities

How can GPHAC synergize with the Roundtable (and other NASEM Roundtables/Forums)?
Context Matters: Funding Initiatives and Opportunities

Emphasis on Top 3 Tier 1 Genomic Applications Can Leverage and Synergize With Existing Funding 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

How can GPHAC explore current/near term funding opportunities?
How can GPHAC expand and leverage investigators already funded in this space?
Context Matters: Leveraging Implementation Science

The Success of Genomic Medicine Requires Implementation Science

Not enough research investment or research publications at the intersection of genomics and implementation science

How can GPHAC leverage existing training and workforce development initiatives in implementation science to feed the genomic medicine implementation pipeline?
Direct-to-consumer Personal Genomic Tests are Really Taking off!

- FDA Recent Approval of select BRCA mutations in DTC testing
- DTC market covers a wide spectrum of offerings (the Good, the Bad, and the Ugly!)
- Number of consumers seeking DTC genetic testing is going way up (e.g., Black Friday)
- Need for provider and public education is more important than ever

How can GPHAC synergize with existing educational initiatives (e.g., NHGRI-led Genetic Literacy, Education and Empowerment Initiative (GLEE))?
Where do we Want to be in 1, 3, and 5 Years?

Perhaps the Most Important Question to Consider During Today’s Meeting