MITIGATING INEQUITIES IN SCREENING FOR HEREDITARY CANCER SYNDROMES

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February 10, 2022
A growing body of evidence has shown that screening for hereditary cancer syndromes can improve clinical care and enhance overall population health.

Routinizing appropriate screening remains difficult.
DISPARITIES IN UTILIZATION OF HBOC SCREENING

- Advent of genomic technologies may exacerbate health disparities, if those technologies are not available to everyone.

- The American BRCA Outcomes and Utilization of Testing (ABOUT) study showed that among women whose clinicians ordered comprehensive BRCA testing, most were white, college educated, married, and wealthier (Armstrong et al. 2015).

- White women are far more likely to receive screening than racial/ethnic minorities.

- Concerns that low-income and uninsured patients also face barriers accessing services.
Genomics, Health Disparities, and Missed Opportunities for the Nation’s Research Agenda

The completion of the Human Genome Project occurred at a time of increasing public attention to health disparities. In 2004, Sankar and colleagues suggested that this coincidental timing resulted in an inappropriate emphasis on the contribution of genomics to health disparities, conflating racial patterns of disease with genetic ancestry, and distracting attention from the large and compelling body of scientific evidence pointing to social determinants of health disparities.

For example, genomic research has emphasized discovery of genetic contributors to diabetes risk, but the recent increase in the prevalence of obesity and type 2 diabetes, which disproportionately affects minority populations, cannot be attributed to genetic changes and rather reflects social forces affecting diet, food access, and patterns in physical activity. The introduction of new genomic health technologies could also exacerbate disparities in access to health care if insufficient attention is paid to the considerable attention among policy makers and the general public. Yet this large body of knowledge is absent from genomics discourse, which remains largely focused on biological causes and biomedical interventions.

Health care plays a crucial role in decreasing morbidity and mortality once disease processes are under way, but accounts for only a minor portion of population health status. A study comparing the major determinants of health estimated that only 10% to 15% of premature mortality could be prevented by improved or more medical care. The limits of health care were demonstrated in a statistical experiment, comparing deaths potentially averted if people were to have a college education vs those potentially averted by advances in health care technology and an 8-fold difference was found favoring education. Moreover, the kind of health care that makes the largest difference to population health often is the less costly and less technical forms of health care.
Genomics, Health Disparities, and Missed Opportunities for the Nation’s Research Agenda

Health disparities are generally understood to refer to systematic differences in health effects resulting from social disadvantage, but the term is often used in genomics to refer to differing health outcomes associated with population genetic variation. This usage argues contributors to diabetes risk, but the recent increase in the prevalence of obesity and type 2 diabetes, which disproportionately affects minority populations, cannot be attributed to genetic changes and rather reflects social forces affecting diet, food access, and patterns in physical activity. The introduction of new genomic health technologies could also exacerbate disparities in access to high-quality health care if specific populations’ characteristics lead them to gain less from advances in health care technology and an 8-fold difference was found favoring education. Moreover, the kind of health care that makes the largest difference to population health and extends lives could be dominated in genomics.
Health inequities are a subset of health disparities that are modifiable, associated with social disadvantage, and considered ethically unfair.

Arcaya, Arcaya, and Subramanian, 2015

Health inequities should be viewed as the end result of a chain of events signified by difference in:

- Environment
- Access to, utilization, and quality of care
- Health status

Involves assessing:

- Avoidability
- Ethical judgments
We propose an integrated framework for future research, intervention, and policy work that will mitigate inequities in genomic medicine, including for cascade screening.

- Hereditary Breast & Ovarian Cancers (HBOC) as a case example.

**Article**

**Blending Insights from Implementation Science and the Social Sciences to Mitigate Inequities in Screening for Hereditary Cancer Syndromes**

Laura Senier ¹,²,* , Colleen M. McBride ³, Alex T. Ramsey ⁴, Vence L. Bonham ⁵ and David A. Chambers ⁶
THE CONSOLIDATED FRAMEWORK FOR IMPLEMENTATION RESEARCH
GENOMICS, POPULATION HEALTH, AND HEALTH INEQUITIES

When is public health action warranted?
### CDC’S FRAMEWORK FOR ACTION IN PUBLIC HEALTH GENOMICS

<table>
<thead>
<tr>
<th>Genomic Application</th>
<th>Tier 1: Clinical Practice Guidelines / Systematic Review</th>
<th>Tier 2: Clinical Practice Guidelines / Insufficient Evidence</th>
<th>Tier 3: Clinical Practice Guidelines Recommends Against</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example</td>
<td>Hereditary breast &amp; ovarian cancers</td>
<td>FHH in primary care</td>
<td>Genetic tests marketed DTC</td>
</tr>
<tr>
<td>Public health burden</td>
<td>5-10% of all cases annually; early age @ onset</td>
<td>FHH common risk factor for many chronic diseases</td>
<td>Numerous companies selling such tests</td>
</tr>
<tr>
<td>Expert panel recommendation</td>
<td>Offer genetic counseling to women with a strong family history of the disease (USPSTF 2005)</td>
<td>FHH can prompt behavior change; unclear impact on outcomes (NIH 2009)</td>
<td>Insufficient evidence on clinical validity/utility (CDC-NIH conf 2009)</td>
</tr>
<tr>
<td>Public health action</td>
<td>Promote implementation; Develop clinical decision support tools</td>
<td>Provide info; educate patients and providers</td>
<td>Measure use of DTCA tests; discourage use by patients and providers</td>
</tr>
</tbody>
</table>

Adapted from Khoury et al., American Journal of Preventive Medicine, 2011: 40: 486-493; and Tier Classification Guidelines Database (available at https://phgkb.cdc.gov/PHGKB/tierFinder.action?Submit=about)
IMPLEMENTATION SCIENCE

- Methods to implement evidence-based interventions, policies, and practices into routine clinical care public health programming.
  - Subject those interventions to rigorous evaluation

- Identify things that promote or hinder the adoption of evidence-based practices and policies.

- Leverage this knowledge to improve healthcare delivery and healthcare quality.
THE CONSOLIDATED FRAMEWORK FOR IMPLEMENTATION RESEARCH
## SIX CATEGORIES OF IMPLEMENTATION STRATEGIES

<table>
<thead>
<tr>
<th>Category</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning</td>
<td>• Build buy-in (involve patients/family; conduct local consensus meetings)</td>
</tr>
<tr>
<td></td>
<td>• Develop relationships (coalition building; develop resource-sharing agreements)</td>
</tr>
<tr>
<td>Educating</td>
<td>• Develop/distribute materials; Inform local opinion leaders</td>
</tr>
<tr>
<td>Financing</td>
<td>• Reduce/increase patient fees; penalize providers for failure to follow best practices</td>
</tr>
<tr>
<td>Restructuring</td>
<td>• Create new clinical teams; change service sites</td>
</tr>
<tr>
<td>Managing Quality</td>
<td>• Audit/provide feedback; remind clinicians; use data warehousing techniques</td>
</tr>
<tr>
<td>Attending to the Policy Context</td>
<td>• Change accreditation/membership requirements; create/change credentialing standards or licensure requirements</td>
</tr>
</tbody>
</table>
Social conditions should be viewed not as nuisance variables to be controlled for, but as conditions that are fundamentally related to disease causation.

1. Related to multiple disease outcomes
2. Operate through multiple risk-factor mechanisms
3. Involve access to resources that can be used to avoid risks
   - “people with superior resources can use those resources to garner health advantages.”
4. New intervening mechanisms reproduce the association between causes and outcomes over time
   - “the specific mechanisms that allow advantage to accrue change from place to place and from time to time.”
Institutional Level

Health System Level

Interpersonal Factors

Patient Level
- knowledge & beliefs
- social support
- stressors

Family Level
- biological relatedness
- health literacy
- knowledge of FHH

Provider Level
- knowledge & expertise
- psychosocial factors

Area Level

Community Level

Knowledge Synthesis Enterprises

Clinic Level

Health Policy

Fundamental Causes

Geographic maldistribution of primary and specialty healthcare services

Inequities in power and ability to influence healthcare policy

Inequitable distribution of wealth, educational opportunities, employment opportunities

Key Outcomes

Healthcare Inequities

Health Inequities
ADAPTING IMPLEMENTATION SCIENCE FRAMEWORKS TO ADDRESS HEALTH INEQUITIES
THE CONSOLIDATED FRAMEWORK FOR IMPLEMENTATION RESEARCH
Inner Setting
Clinic Level
Individuals

Outer Setting
Area Level
Community Level
Health Policy
Knowledge Synthesis

Fundamental Causes
Maldistribution of services
Inequities in resources
Power differentials

Key Outcomes
Healthcare Inequities
Health Inequities
Public Health Agencies

Professional Societies
- Attending to the Policy Context
- Managing Quality
- Restructuring

Academic Researchers
- Planning
- Educating
- Financing

Integrated Healthcare Systems

Patient Advocacy Groups

Key Outcomes
- Healthcare Inequities
- Health Inequities

Inner Setting
- Fundamental Causes

Outer Setting
APPLYING THE INTEGRATED FRAMEWORK TO IDENTIFY BARRIERS IN HBOC SCREENING
Public Health Agencies

Academic Researchers

Professional Societies

Integrated Healthcare Systems

Patient Advocacy Groups

**Inner Setting**

- Engage providers in learning collaboratives
- Conduct basic and applied research
- Conduct ongoing training
- Change service sites
- Use data warehousing techniques

**Outer Setting**

- Conduct education and outreach
- Prepare patients to be active participants
- Involve patients and family members
- Use mass media/media campaigns

**Fundamental Causes**

Healthcare Inequities
Health Inequities

Key Outcomes
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Inner Setting

Fundamental Causes

Key Outcomes

Healthcare Inequities

Health Inequities
We argue that mitigating health inequities will require addressing not only individual-level influences but also action at the community-, clinic-, and health policy-levels.

Analyzing health inequities through a multi-level, public health framework provides a foundation for more robust and comprehensive approaches to improving population health.

Implementation science frameworks can be useful at identifying possible avenues for action and key stakeholders.
QUESTIONS?

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