PANEL 6: INCREASING DIVERSITY AMONG PATIENT POPULATIONS AND CARE SYSTEMS

Genomic Medicine VIII

This meeting will help NHGRI and its Genomic Medicine Working Group (GMWG) examine our genomic medicine portfolio in light of evolving scientific knowledge and opportunities.

June 8-9, 2015
Rockville, Maryland

Panel members

- Cynthia Powell, M.D.
  - Departments of Genetics and Pediatrics, School of Medicine, UNC Chapel Hill
- Vence Bonham, Jr., J.D.
  - NHGRI Social and Behavioral Research Branch
- Craig Hanis, Ph.D.
  - University of Texas Health Science Center, Houston
- Carol Bult*, Ph.D.
  - The Jackson Laboratory, Maine

* Genomic Medicine Working Group Member

1. Importance and Impact for Genomic Medicine Implementation

- Gender and ethnicity are important factors in disease presentation and treatment
- Ethnic-specific and trans-ethnic studies enhance understanding of underlying mechanisms of disease
- Safety and efficacy of medicines require data from clinical trials with participants that represent the full spectrum of genetic diversity in the US population
- By 2020, ethnic minorities will constitute ~35% of the American population
- Racial/ethnic disparities in health and health care well documented
- African Americans make up 12 percent of US population but just 5% of clinical trials participants
- Hispanics make up 16 percent of the US population, but just 1% of clinical trials participants

http://www.phrma.org/catalyst/increasing-clinical-trial-participation-among-diverse-patient-populations

http://associationforum.org/files/LC/album/images/IRCDocs/Access_09102010.pdf

2. Related Research Programs

NIH/NHGRI

- *Precision Medicine*
  - http://www.nih.gov/precisionmedicine/workshop-summary.pdf
- Clinical Sequencing Exploratory Research (CSER)
  - http://www.genome.gov/27546194
- Electronic Medical Records and Genomics (eMERGE)
  - http://www.genome.gov/27540473
- Implementing Genomics in Practice (IGNITE)
  - http://www.genome.gov/27554264
- Population Architecture using Genomics and Epidemiology (PAGE)
  - http://www.genome.gov/27541456
- ENCyclopedia of DNA Elements
  - http://www.genome.gov/encode/

- Discovery of variants (PAGE)
- Genomics and medical records (EMERGE)
- Functional characterization of variants (ENCODE)
- Interpretation of results (CSER)
- Returning genomic results (CSER)
- Integration into EMR and CDS (IGNITE)

3. Barriers and Opportunities

Barriers to increasing diversity among patient populations and care systems

- Influence of genomics data on concept of race and ethnicity
- Physician attitudes/beliefs about race, health, and genetics
- Mistrust of research motives among minority communities
  - little visible return to the community; lack of continuity into the future
- Lack of involvement of minority investigators and physicians
- Lack of community stakeholders
- Language barriers
- Awareness of clinical trials
- Time (associated with all aspects of recruitment of patients)
- Access to clinical research coordinators
- Access to technology (i.e., high speed internet)
- Geography and transportation (proximity to medical and research centers)

The Project IMPACT Experience to Date: Increasing Minority Participation and Awareness of Clinical Trials

2008

James H. Powell, MD; Yolanda Fleming, BA; Cheryl Lynn Walker-McGill, MD, MBA; and Michael Lenoir, MD

Table 3. Barriers and facilitators to physician participation in a clinical trial (n=200)

Barrier or Facilitator	Frequency	%
Interested in Participating in a Clinical Trial	141	70.5
Invited to Participate in a Clinical Trial	136	68.0
Attempted Participation but Denied	23	11.5
Barriers Faced When Attempting to Participate*		
Lack of access to a clinical research coordinator	57	28.5
Lack of awareness of clinical trials opportunities	86	43.0
Lack of time	75	37.5
Concerns about patient safety	21	10.5
Inadequate reimbursement	37	18.5
Not affiliated with a major academic center	36	18.0
Lack of access to an institutional review board	18	9.0
None	29	14.5

* Some respondents provided multiple responses

http://impact.nmanet.org/downloads/7-325-print.pdf

Recruitment of minorities in research studies - recommendations

- Form consultant group for researchers and physicians
- Recruiters who are culturally adept and fluent in the language
  - Training and funding for clinical research coordinators
- Do community assessment
  - Barriers will be different for different communities
- Awareness of population beliefs
- Community advisory boards
- Local consultants from the community
- Partnerships with communities
  - Illustration of benefit; continuity

4. Potential Synergies

NIH-centric

- Precision Medicine
  - http://www.nih.gov/precisionmedicine/workshop-summary.pdf
  - ***RFI on the Precision Medicine Cohort http://grants.nih.gov/grants/rfi/rfi.cfm?ID=44***
- Implementing Genomics in Practice (IGNITE)
  - http://www.genome.gov/27554264
- Population Architecture using Genomics and Epidemiology (PAGE)
  - http://www.genome.gov/27541456
- NCI Center to Reduce Cancer Health Disparities
  - http://www.cancer.gov/about-nci/organization/crchd
- NIH Common Fund: Enhancing the Diversity of the NIH-Funded Workforce
  - http://commonfund.nih.gov/diversity/index

Community

- National Minority Quality Forum
  - http://www.nmqf.org/
  - Clinical Trial Engagement Network
- National Medical Association Project IMPACT
  - http://www.impact.nmanet.org/about.html
- EMPACT
  - http://www.empactconsortium.com/

5. Training Opportunities and Needs Addressing the Problem of (lack of) Diversity

- Initiatives and Resources for Minority and Special Populations (NHGRI; 2001-2008)
  - http://www.genome.gov/10001192
- NHGRI Action Plan for Increasing the Number of Underrepresented Minorities Trained in Genomics and ELSI Research (2008)
  - http://www.genome.gov/10001707/
- Investing in the future: NIGMS Strategic plan for biomedical and behavioral research training (2011)
  - http://publications.nigms.nih.gov/trainingstrategicplan/theme4.htm
- Ginther report: Race, Ethnicity, and NIH Research Awards (2011)
  - Science 19 August 2011 Vol. 333 no. 6045 pp. 1015-1019
- NIH – Draft Report of the Advisory Committee to the Director Working Group on Diversity in the Biomedical Research Workforce (2012)
  - http://acd.od.nih.gov/Diversity%20in%20the%20Biomedical%20Research%20Workforce%20Report.pdf
- NIH – Draft Report of the Advisory Committee to the Director Working Group on Diversity in the Biomedical Research Workforce (2012)
  - http://acd.od.nih.gov/Diversity%20in%20the%20Biomedical%20Research%20Workforce%20Report.pdf
- Yang et al. A bibliometric analysis of academic publication and NIH funding (challenges Ginther findings)
  - Journal of Informetrics Volume 7, Issue 2, April 2013, Pages 318–324
- Current programs in the NIGMS Division of Training, Workforce, Development and Diversity (TWD)
  - http://www.nigms.nih.gov/Training/Pages/TWDPrograms.aspx
- Enhancing the Diversity of the NIH-Funded Workforce (2014)
  - http://commonfund.nih.gov/diversity/index

Recruitment of Post-Docs and Faculty

- Outreach to Historically Black Colleges and Universities (HBCU) to recruit students to be trainees
  - Personal contact is essential
  - Utilize existing collaborative relationships with HBCUs
  - Division of Minority Student Affairs (funded by NIGMS)
  - Liaison – find the key person at an institution who can channel good students to your training program
  - Look at individuals who have received F-31's from NIH
- Utilize existing programs at research university
  - Examples: https://www.med.unc.edu/facultyaffairs/professional-development/simmons-scholars-program
  - AAUP: http://www.aaup.org/issues/diversity-affirmative-action/resources-diversity-and-affirmative-action/how-recruit-and-promote-minority-faculty-start-playing-fair

Retention of Post-Docs and Faculty

- Supportive environment
- Mentoring teams
- Have minority members on faculty/on mentoring teams
- Meet frequently
- Be conscious of terminology
- Cultural sensitivity

Resources

- ASHG/FASEB Underrepresented Scientist Travel Awards Program
  - http://www.ashg.org/2015meeting/pages/awards.shtml
  - postdoctoral fellows, graduate students, and undergraduate students from minority institutions and historically black colleges and universities in the United States.
- AAMC
  - https://www.aamc.org/initiatives/diversity/
- University of Alabama at Birmingham Minority Health and Health Disparities Research Center
  - http://mhrc.dopm.uab.edu/genetics-core.html
- Stanford Graduate student diversity efforts
  - http://genetics.stanford.edu/outreach/diversityresources.html
- FASEB/MARC program Maximizing Access to Research Careers
  - http://www.faseb.org/MARC-and-Professional-Development/MARC-InfoNet.aspx

Main Points for Panel 6

- Diversity is important for discovery of variants **an**d understanding their health relevance
- Many training initiatives underway @NIH to increase the diversity in the biomedical field workforce
- Barriers to increasing minority/ethnic diversity are diverse
- Efforts to increase diversity at all levels of scientific inquiry, medical practice, and clinical trials participation need to continue
- The new Precision Medicine Initiative provides another opportunity to improve outreach/inclusion among ethnic/minority populations in the US
  - Synergies to overcome known barriers possible through existing efforts within NHGRI, NIH, and in the community (professional associations, etc.)
- NHGRI program portfolio is comprehensive - covers everything from basic discovery of variants to functional characterization to clinical use

Discussion