


Project Inclusive Genetics: Developing a Patient-Centered Counseling Approach



Shoumita Dasgupta, PhD

 @prof_dasgupta

ISCC In-Person Meeting

February 25, 2020

Explicit vs. Implicit Bias



Explicit bias – have awareness of this attitude

Implicit bias – no awareness of this attitude and may be opposed to declared views

We all have implicit biases.

Healthcare providers manifest implicit biases to a similar degree as the general population.

Implicit Bias in Medicine



Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites

Kelly M. Hoffman^{a,1}, Sophie Trawalter^a, Jordan R. Axt^a, and M. Norman Oliver^{b,c}

^aDepartment of Psychology, University of Virginia, Charlottesville, VA 22904; ^bDepartment of Family Medicine, University of Virginia, Charlottesville, VA 22908; and ^cDepartment of Public Health Sciences, University of Virginia, Charlottesville, VA 22908

Genetics and Disability

Tay-Sachs Disease

Spinal muscular atrophy

Cri-du-Chat

Down Syndrome

Rett Syndrome

Deafness

Charcot-Marie-Tooth Disease

Huntington's Disease

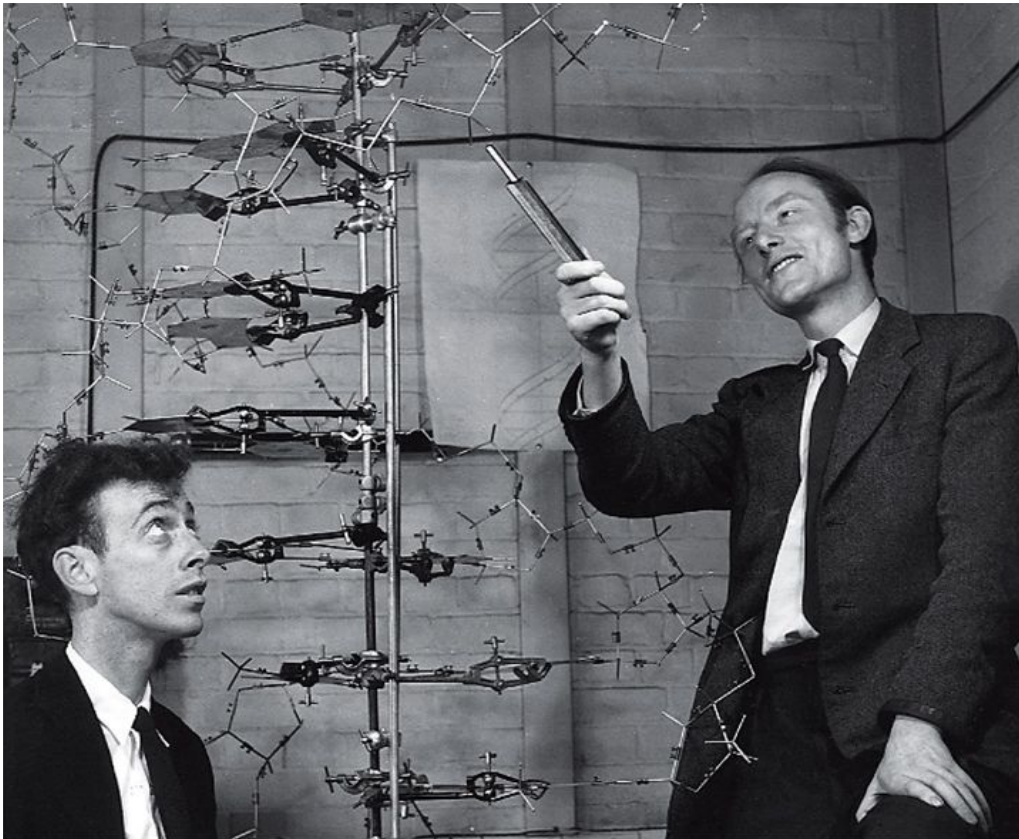
Fragile X Syndrome

Achondroplasia

Muscular Dystrophy

Many genetic diagnoses include physical or intellectual disabilities.

Evidence for Explicit Bias Against Disability in Genetics



“Seeing the bright side of being handicapped is like praising the virtues of extreme poverty.”

- James Watson

Prenatal Testing and Disability



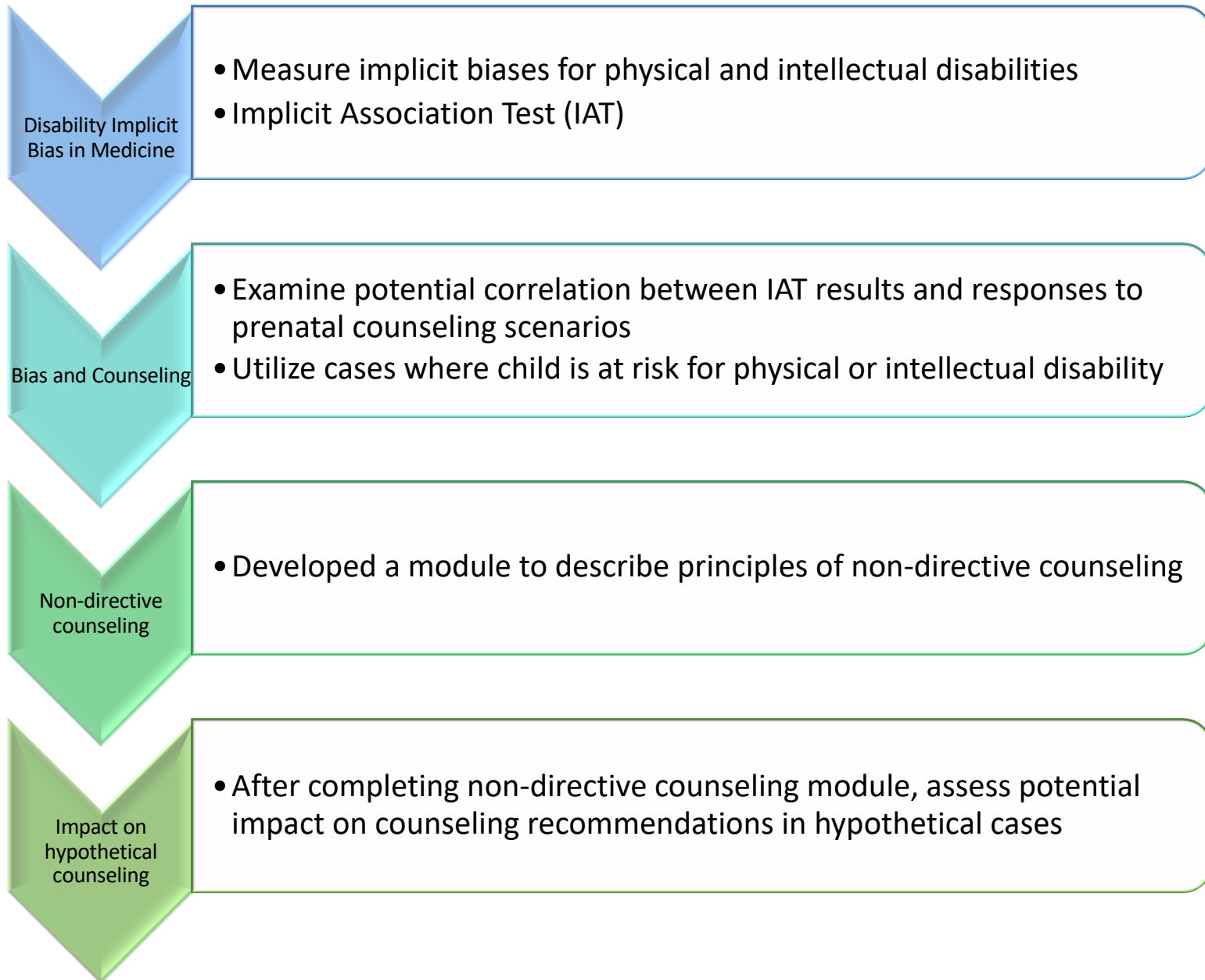
Does providing prenatal testing and opportunities for pregnancy termination for certain genetic conditions imply a belief that individuals with disabilities are defective?

Evidence for Implicit Bias Against Disability in Healthcare

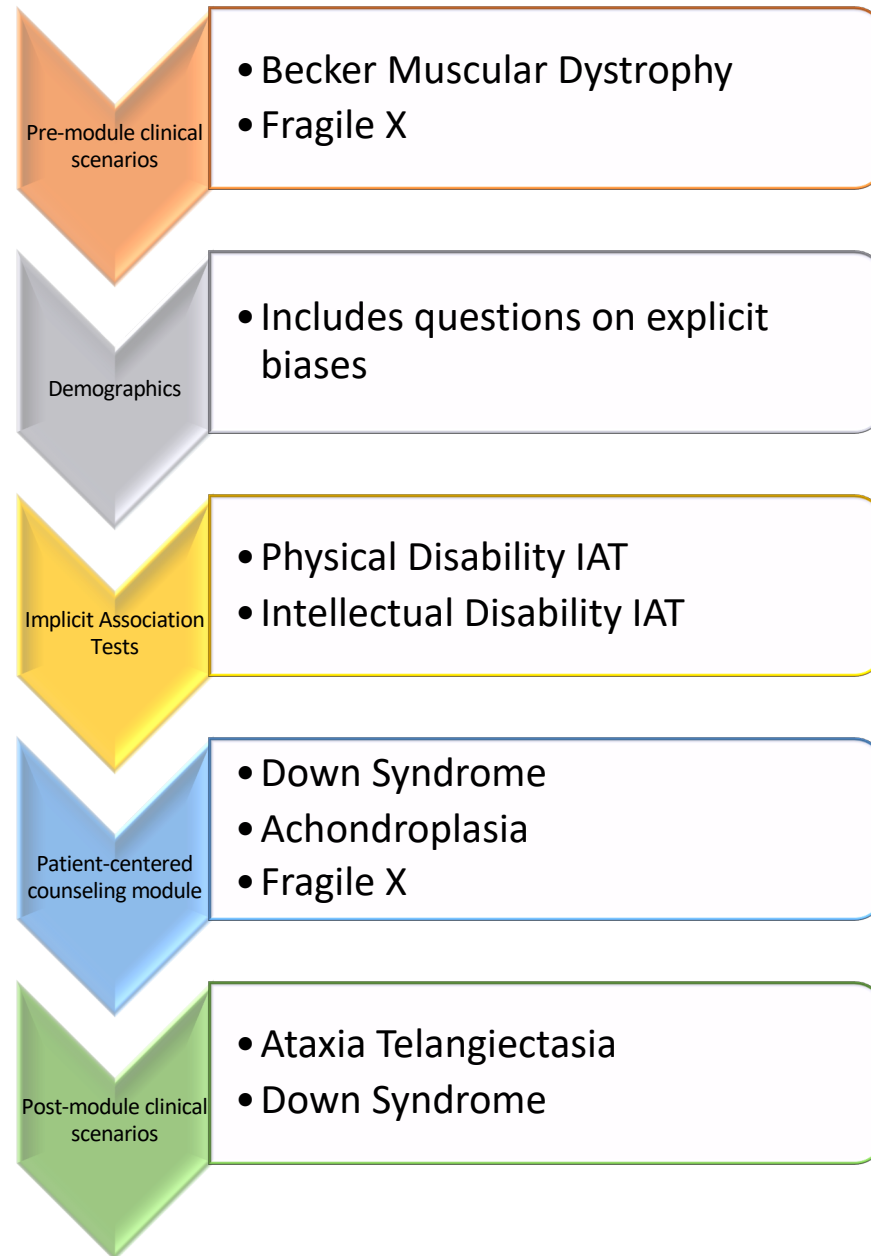
- Disconnect between personal views and understanding of role of physician in providing guidance to patients
- Misunderstanding of elements of patient-centered counseling
- Patients not receiving balanced information from counselors
- PA students demonstrate preference for abled individuals



ISCC Project Inclusive Genetics



Clinical Decision-Making in the Prenatal Setting



Enter Module

<https://www.bucme.org/activity/8001>

Patient-Centered Prenatal Genetic Counseling


 Print

 Save

Activity Progress: **1** ACTIVITY HOME ▶ **2** LEARN ▶ **3** GET CREDIT



Activity Details

- ▶ Credit Type: CME
- ▶ Credit Amount: 1.00
- ▶ Cost: Free
- ▶ Release: Jan 2, 2020
- ▶ Expires: Jan 1, 2021
- ▶ Estimated Time to Complete:
1 Hour(s)
- ▶ System Requirements:
 **Adobe Flash Player**
- ▶ Average User Rating:
★★★★★ (Ratings)

Faculty



Shoumita Dasgupta, PhD



Blair Stevens, MS, CGC

Accreditation

CME

Boston University School of Medicine is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

ACGME Competencies

- ▶ Patient care
- ▶ Practice-based learning and improvement
- ▶ Interpersonal and communication skills
- ▶ Professionalism

Acknowledgement

In collaboration with Biomedical Genetics Section, Boston Medical Center.

Implicit Bias Study design



Does implicit bias for both physical and intellectual disability exist among healthcare providers?

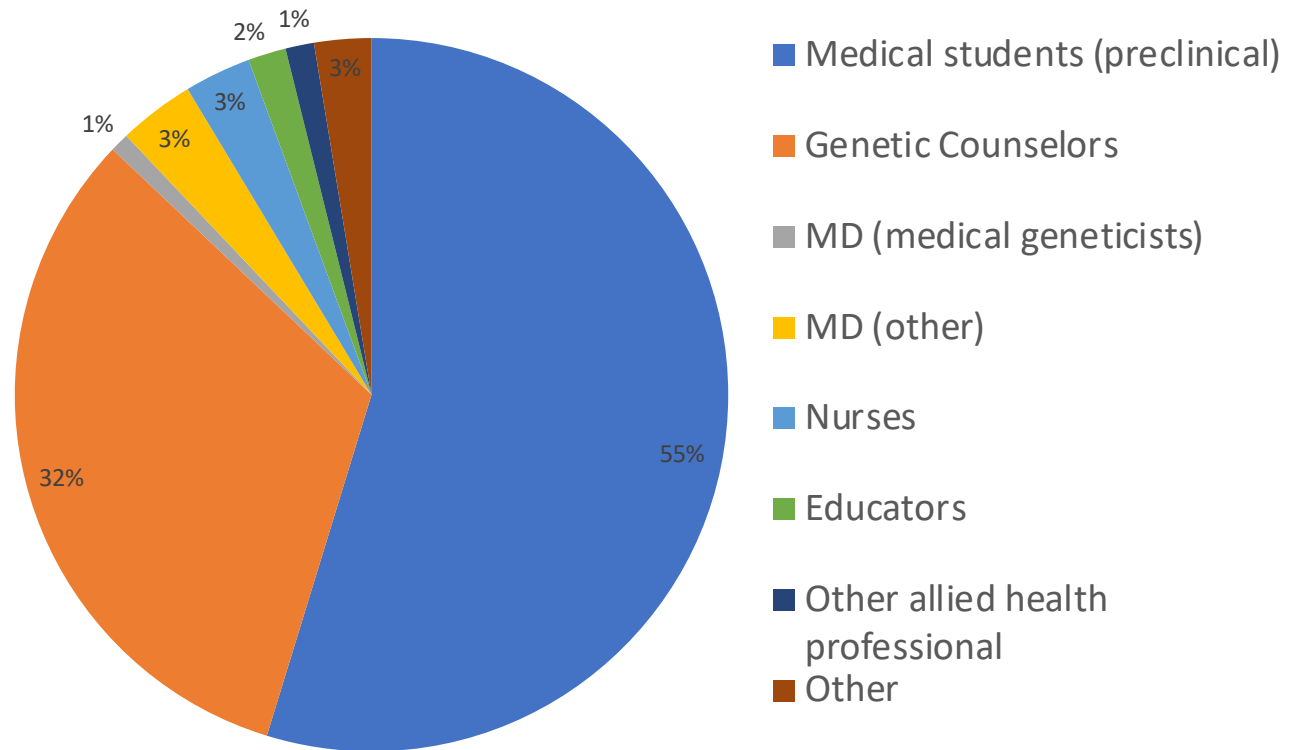
- Does it vary by physical vs. intellectual disability?
- Does it vary by demographics of provider?
- Does it vary by specialty of provider or stage of training?

Implicit Bias Study design



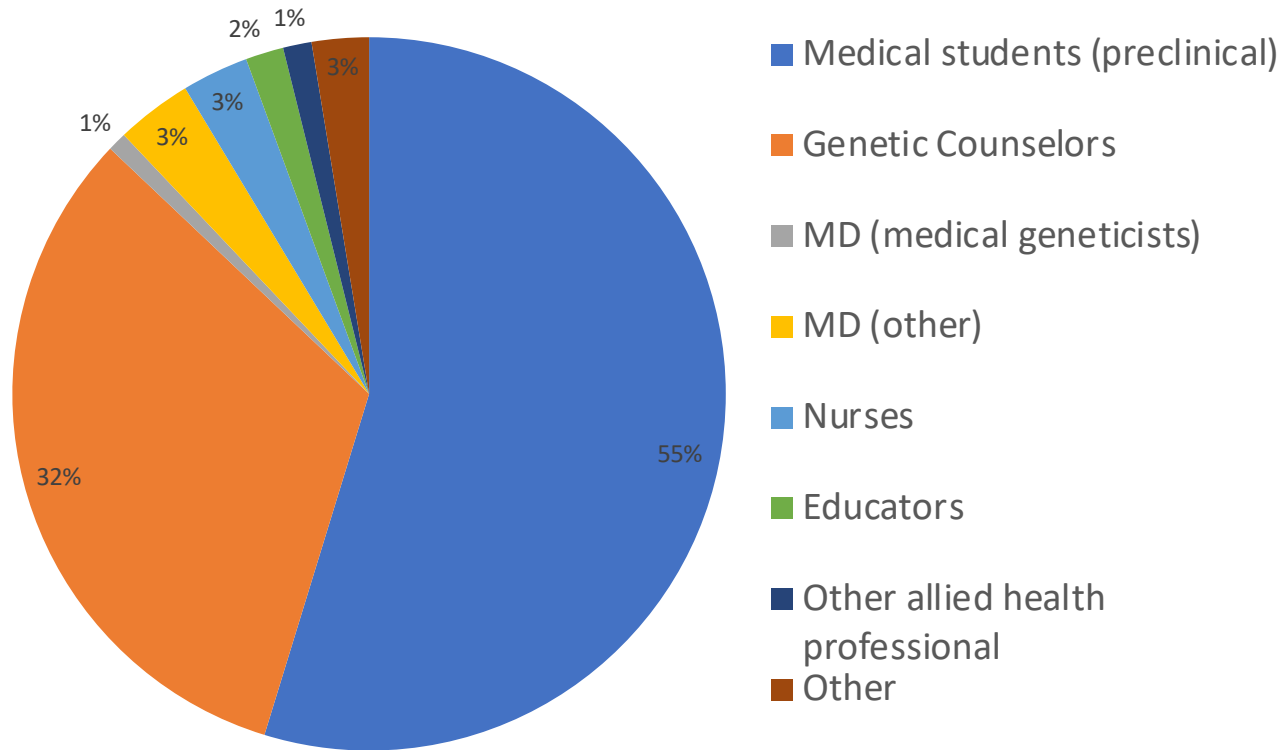
Does implicit bias for both physical and intellectual disability exist among healthcare providers?

- Does it vary by demographics of provider?



n = 232
Data from
2/14/2020

Study cohort



Action items and help with dissemination:

ACOG
ACMG
ISONG
NCEMNA
PAEA
AAPA
SMFM
etc.

Who is underrepresented?

- Physicians (medical geneticists and other specialties)
- Genetic counseling students
- Medical students (clinical years)
- Allied health professionals

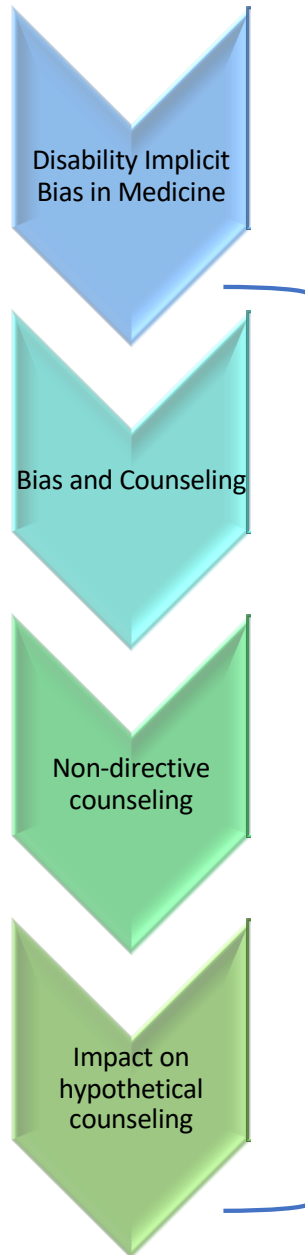
Implicit Bias Study design



Is there a correlation between implicit bias against disabled community and hypothetical prenatal genetic counseling of patients?

- Does it vary by physical vs. intellectual disability?
- Does it vary by demographics of provider?
- Does it vary by specialty of provider or stage of training?

Implicit Bias Study design



Are providers able to appropriately apply principles of non-directive counseling to hypothetical prenatal clinical scenarios?

- Does it vary by physical vs. intellectual disability?
- Does it vary by demographics of provider?
- Does it vary by specialty of provider or stage of training?
- Is the educational module effective at mitigating any potential deficiencies in this skill?

Implicit Bias Study design



Does implicit bias impact healthcare providers' ability to appropriately counsel patients in a prenatal setting, and can this be improved by training in non-directive counseling?

<https://www.bucme.org/activity/8001>



Your Participation is Important!

Thank you again for participating in this research study!

We have learned so much from people like you taking the time to be part of our work.

This module was developed with grant support from the American Association of Medical Colleges Northeast Group on Educational Affairs (AAMC NEGEA) and the National Human Genome Research Institute (NHGRI). The NHGRI Intersociety Coordinating Committee for Health Professional Education in Genomics (ISCC) provided interdisciplinary support and expertise for the development of this program.





Acknowledgements

- Emma Vaimberg
- Eric Ford
- Blair Stevens
- Tina Lockwood
- Maya Sabatello
- Susan Persky
- Donna Messersmith
- Rich Haspel
- Carla Easter
- Pilot testers and You!

<https://www.bucme.org/activity/8001>

RIVIERA RESORT, PALM SPRINGS, CA



2020 WORKSHOP
APRIL 29 - MAY 01

aphmg.org

Sessions include:

- “Scientific” racism and citizen science
- Prenatal and pediatric exome seq in underrepresented populations
- Wellness and burnout
- Course Directors, Lab Directors, and Residency Directors Group Meetings
 - Gamification of genetics concepts
 - Workshop creating polygenic risk score curricula