

# Diversity, Equity, & Inclusion in Molecular Pathology

An online learning & membership engagement series  
from the AMP DEI Working Group

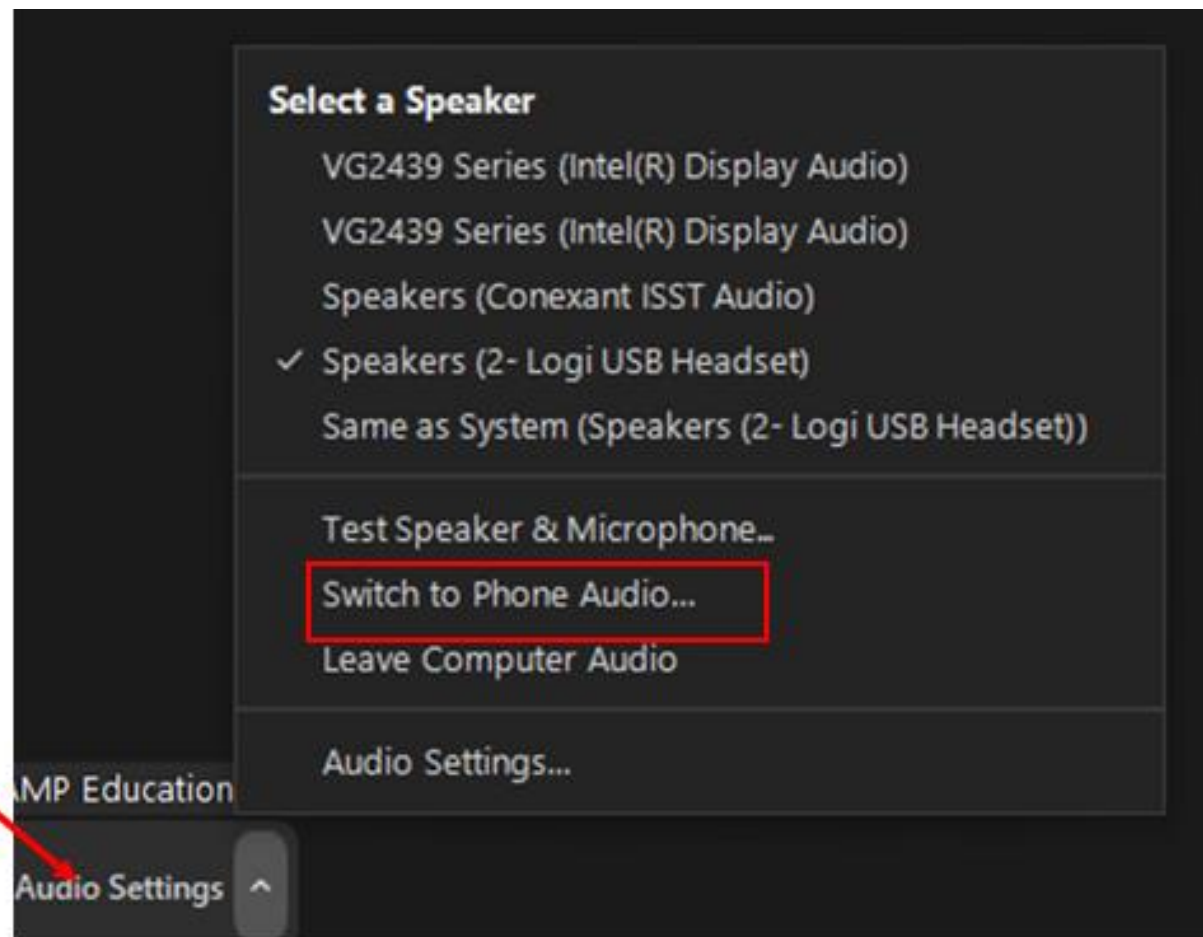


## Embracing Leadership Diversity

October 7, 2024



# Housekeeping





**Maria E. Arcila, MD**  
*Memorial Sloan Kettering Cancer Center*

# Learning Objectives

- Discuss some of the issues that lead to genomic gaps in discovery and care of patients with diverse backgrounds.
- Highlight the unique value of diverse leaders in the future of a genomically driven clinical practice and research.
- Role of AMP in helping its members network and connect with role models, mentors, and champions.

# Association for Molecular Pathology

## **Who we are**

- 2,900+ members - individuals from academic and community medical centers, government, and industry; including pathologist and doctoral scientist laboratory directors; basic and translational scientists; technologists; and trainees

## **Our mission**

- To advance the clinical practice, science, and excellence of molecular and genomic laboratory medicine through education, innovation, and advocacy to enable highest quality health care

# Our Core Principles

- Quality health care through excellence in clinical molecular testing
- Innovation to transform patient care
- Fostering a diverse and inclusive global community of molecular pathology professionals
- Collaboration to advance molecular pathology and improve equity in the delivery of molecular laboratory testing
- Advocacy that advances the field and practice of molecular pathology, protects patients, and improves the adoption of innovative technologies and tests

# Closing the Diversity Gap – at the core of our mission

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- Genomic medicine is rapidly evolving
- Not all patients are benefiting from these advances
- Some of the issues
  - Social challenges
  - Scientific challenges
  - Clinical challenges
  - Technical and logistical challenges

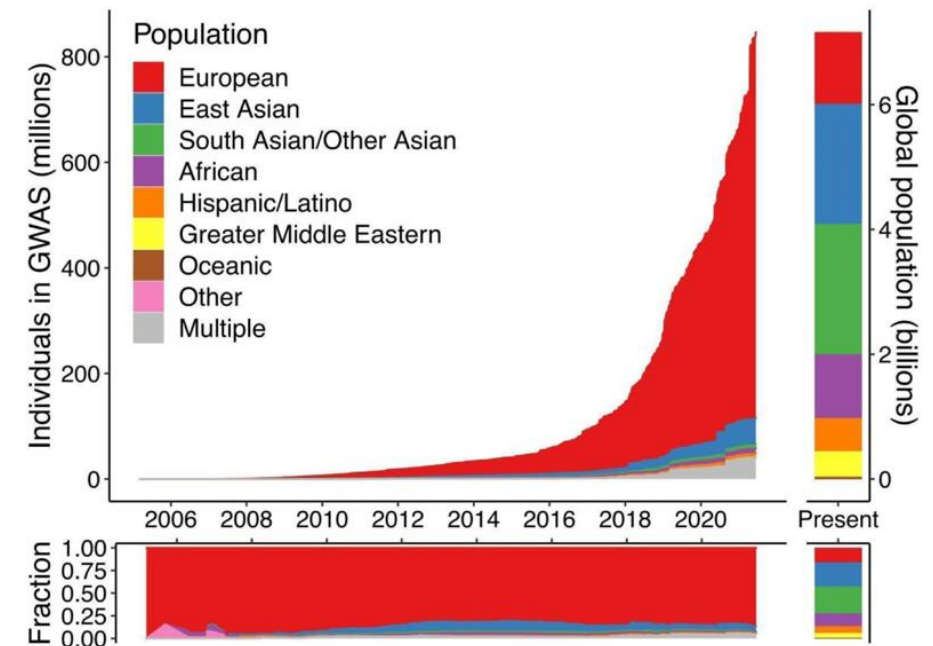


# The diversity gap in genomic data

## Early genomic research conducted mostly on individuals of European descent

- Academic institutions with high funding and resources
- Genome wide association studies (GWAS) ~ 80% European genetic ancestry

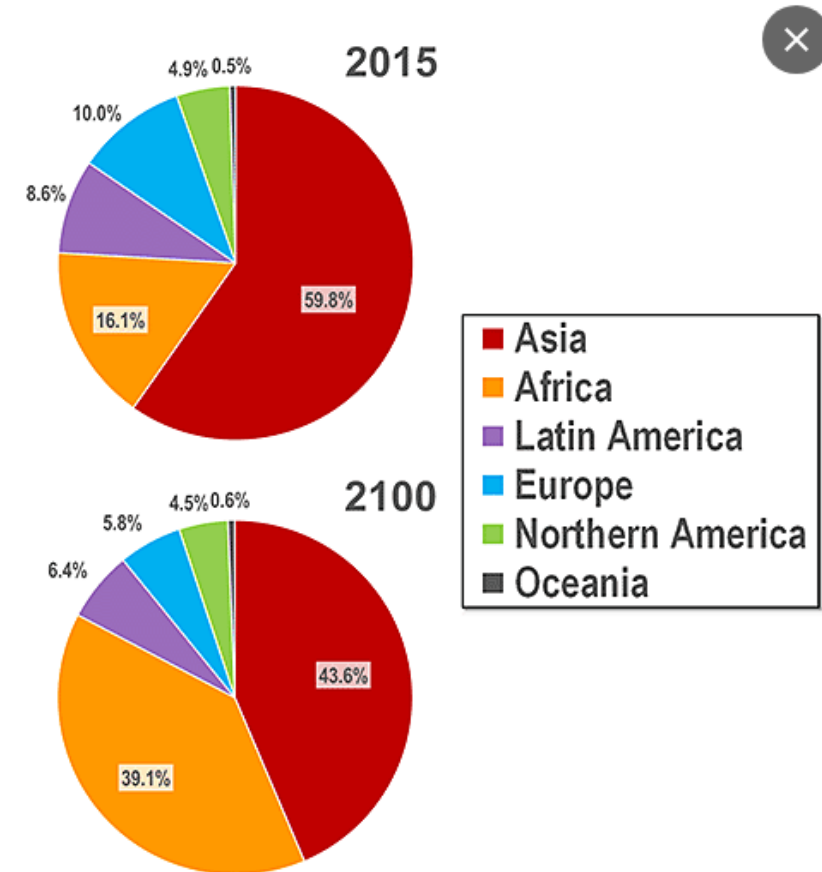
Proportion of samples from individuals cumulatively reported by GWAS Catalog<sup>1</sup> as of July 8, 2021.





# The diversity gap in genomic data

- The global majority is under-represented in genomic databases
  - Limitations on generalizing research findings
  - Limitations on viability of using genomics in the clinical care of persons of non-European ancestry
  - Exacerbation of health inequalities
- Significant implications in overall scientific understanding and on the patient care we can deliver



# Numerous barriers to global inclusion

- Social
- Cultural
- Logistical
- Regional
- Political
- Ethical
- Legal
- Biological
- Technical
- Many others

# Specific barriers to engaging diverse communities (for genomic-driven studies and for provision of services)

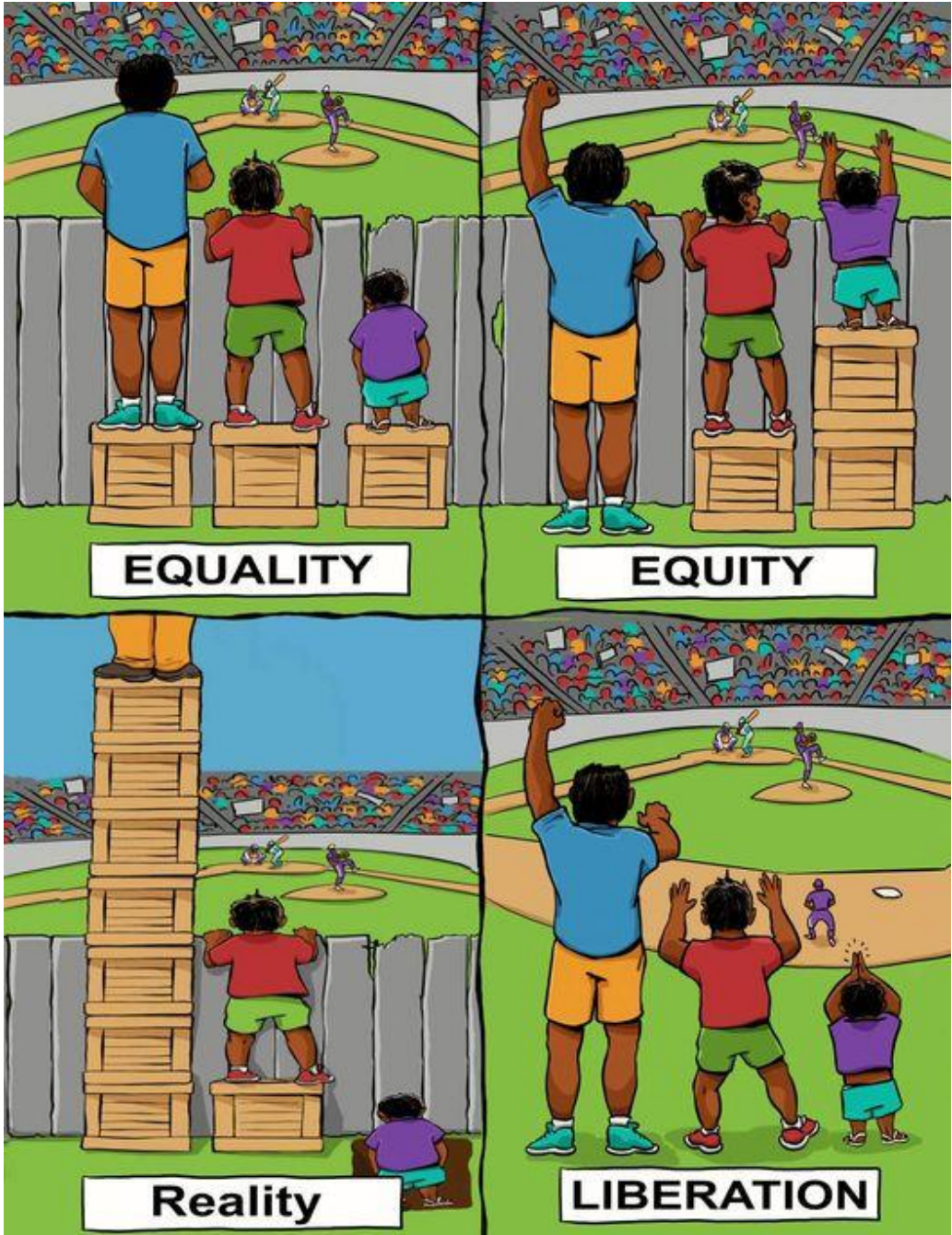


- Limited knowledge of genomic medicine and resources across many sectors of healthcare
- Lack of training by non-health care workers who support physicians and help make decisions about health care options – social workers, pharmacist, chaplains etc

- Limited awareness of extent of diversity
- Low cultural and religious awareness
- Conscious and unconscious biases by health care workers
- Lack of knowledge of the pivotal differences, situations and limitations of different groups

Artist: Angus Maguire  
([madewithangus.com](http://madewithangus.com)), Facebook

Equal treatment –  
does not produce  
same benefit



Equity – everyone gets  
the support they need to  
produce equity

One gets more than is  
needed, the others get  
less – large disparity

Justice – all 3 can see because  
inequities are addressed-  
systemic barriers removed

# Communication barriers with patients

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- **Language barriers:** Access to interpreters, translational accuracy, cultural variations
- **Literacy Barriers:** genomic terminology difficult to communicate and complex
  - impacts participation and engagement of medical services and research
    - health literacy
    - genomic literacy
    - Generational literacy
    - Digital literacy
- **Cultural and religious barriers:**
  - Cultural beliefs and concerns surrounding use and disposition of blood and tissue samples

# Mistrust of the health care professional

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- Historic unethical experimentation on minority populations
- Fear that genetic data and patient information may be disclosed and misused affecting further care
- Government policies and politics surrounding immigration
- Broad systemic inequities in accessing health care (often blamed on the physician)
- Experience of broad range of discrimination – due to race, gender, class and other social identities
- Health care is viewed as a business

# The (paradoxical) Depersonalization of Medicine

Limitations on how much time one can spend with the patient:

reduced time to develop patient doctor relationship

Sub-specialization and rapid growth of knowledge – insufficient subspecialty care, perception of dispassionate expertise

Foregoing the physical examination  
Embracing datafication

Interposing technology – use of workstations and computers on wheels further depersonalize interaction and eliminate opportunities to develop interpersonal trust and empathy

Many of the tasks now performed by impersonal questionnaires, answering machines



# The (paradoxical) Depersonalization of Medicine

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Radical transformation on the way health care is delivered -  
Effects of COVID 19 –

Virtual technologies and telehealth – emerging literature regarding the corrosive effect of telemedicine on empathy

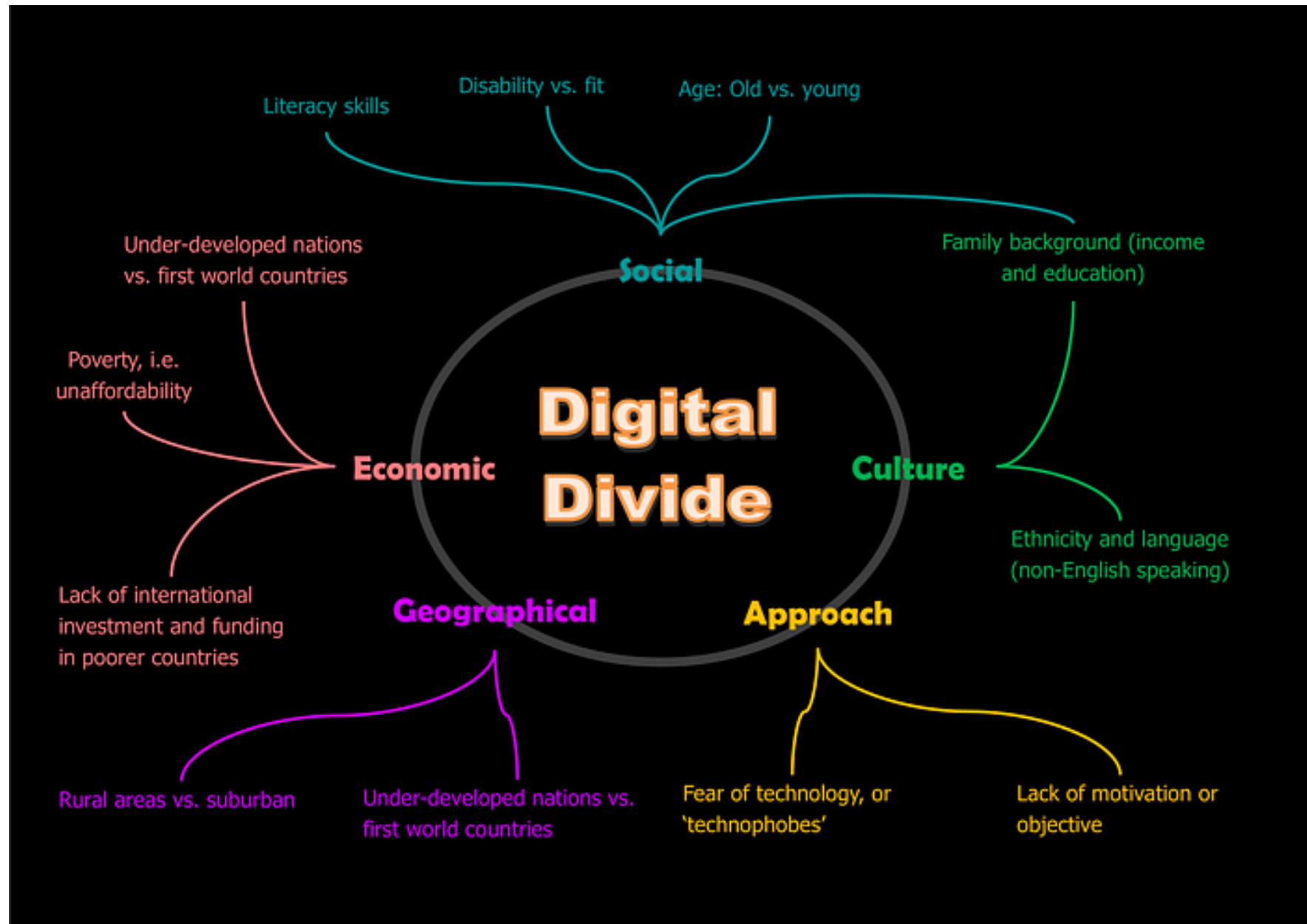
Medical visit - transactional, shallow, fragmented, inappropriate and disintegrated care -

Opportunities to leave behind the sensitive and vulnerable patients

# The digital divide

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- Gap between those with access and proper knowledge of digital technology
- The digital divide worsens inequality around access to information
- Exacerbates systemic marginalization of the same historically oppressed individuals we want to engage and provide care to
- Affects of location, educational disparities, lack of tech readiness
  - Those living in rural communities
  - Those living in poverty
  - The elderly
- Leads to patient isolation, barriers in education, gender discrimination, etc, etc
- Evident during the Covid 19 Pandemic:
  - 59% of children from lower-income families faced digital obstacles in completing school assignments, disproportionately affected minorities
  - Pharmacies transitioned to electronic assistance only – online or phone – affecting the elderly



# The potential and limitation of Artificial Intelligence

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- Emerging AI technologies are transforming the way we practice medicine
- Informed patient care, improved patient safety and innovative treatment options
- Physicians acknowledge the gap in knowledge
- Important for more leaders to learn how AI can make a difference in patient treatment and more importantly understand the limitations in underserved populations

# Dialogues drive everything in health care

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- App called Abridge
- Allows docs to offer their full attention to the patient
- App records, transcribes and summarizes the discussion—information the patient and doctor can both use
- Minimizes clerical work - being the first, second and third reasons for burnout in the US

## Shiv Rao uses AI to enhance the doctor-patient conversation

Written by Michael Aubele | Photography courtesy of Abridge



Shiv Rao's Abridge has formed partnerships with EHR company Epic and tech giant NVIDIA.

# 17 year old student from Veracruz, Mexico wins Global Student prize 2024

- AI program (Ixtlilton)
- Virtual assistant to diagnose 21 diseases through a series of questions
- Designed for indigenous communities in Spanish and native Tutunaku language
- Addresses issues of marginalized communities who struggle with shortage of doctors and medical facilities



Ángela Elena Olazarán won the award for an AI medical program she created for use in remote Indigenous communities. (Gobierno de México)

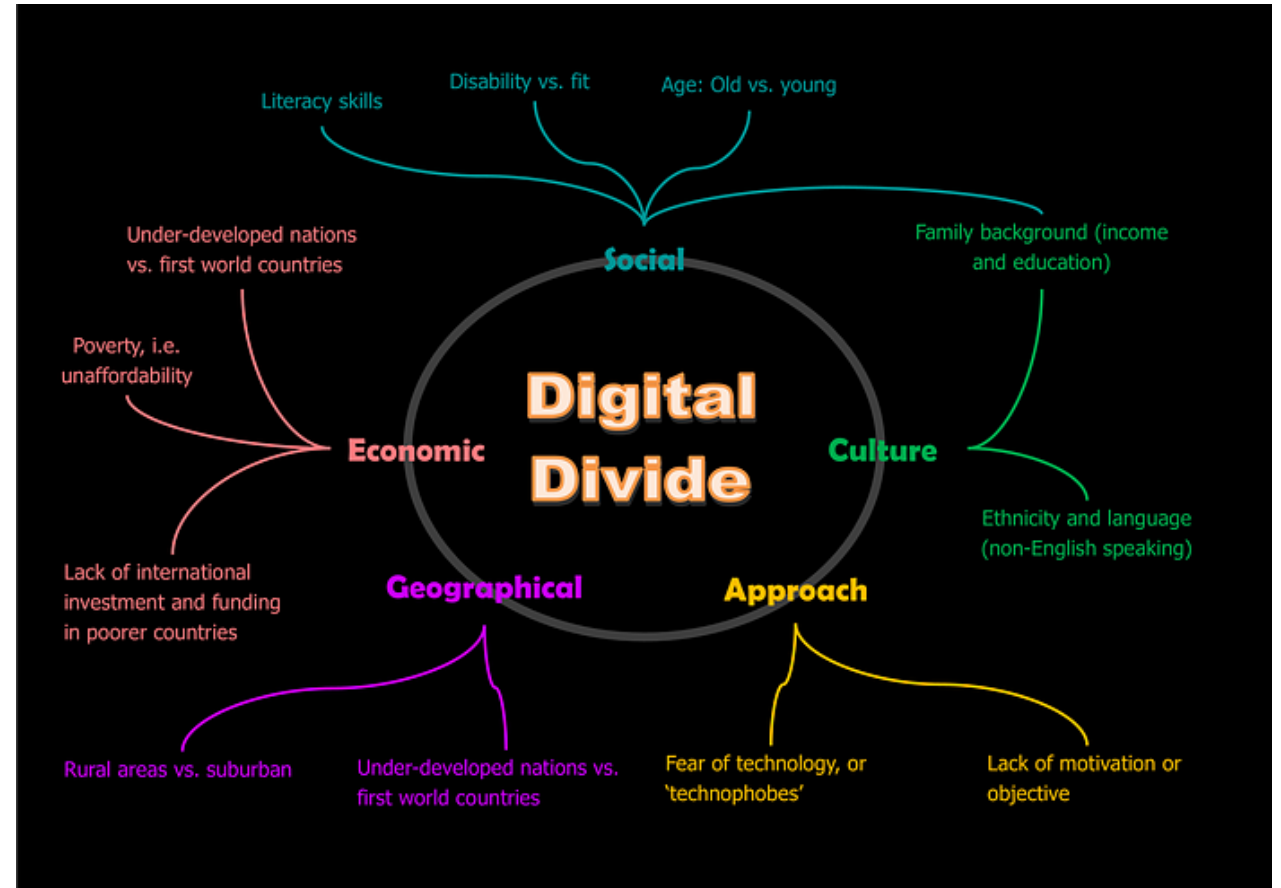


A 17-year-old Mexican student from Veracruz who created a program that diagnoses diseases using artificial intelligence is the winner of this year's Global Student Prize from Chegg.org.



# The issues

- Requirement for computers and modern cell phones
- The more complex the program, the higher the device capabilities required
- Basic devices not compatible with the programs
- Need to build the infrastructure – technological, educational

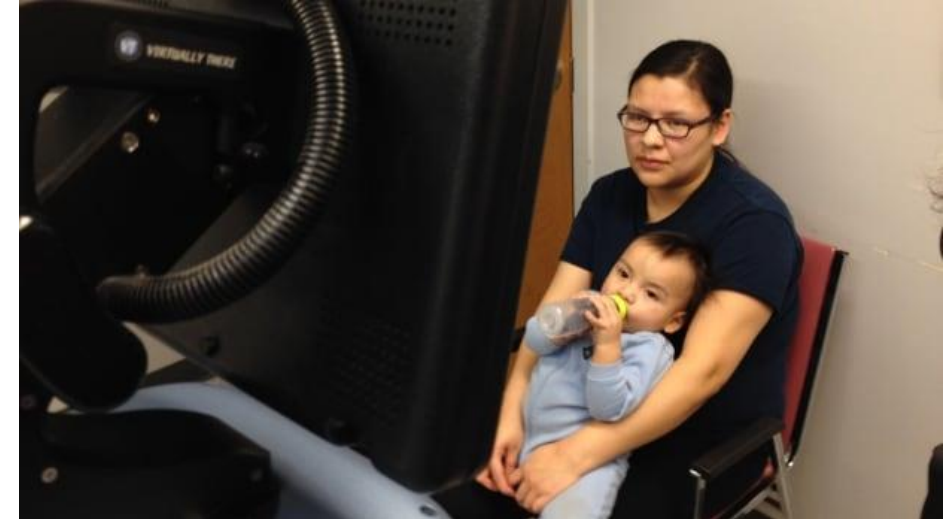




# Perception and beliefs surrounding genomic testing

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- Impact on the patient and the families: May marginalize individuals and families in their community
- Impact on family planning
- Stigma and effect on their social status within the community
  - Some genetic conditions may affect prospects of marriage in some communities
  - Mothers of children with genetic conditions may bear the burden of guilt or the blame



# On race, ethnicity and ancestry

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- Definitions are evolving – while distinctly different, the terms are often used interchangeably
- Race – largely socially constructed definition based on common phenotype – terminology without genetic basis and definition could vary significantly based on geography and cultural background
- Ethnicity relates to social and cultural aspects of identity also a social construct
- Genetic ancestry: genetic/biological concept – inherited origin often based on the DNA analysis - not affected by social constructs. Unfortunately often considered a proxy for ethnicity in genomic research

# Diverse leaders in the future of a genomically driven clinical practice and research

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- Diverse leaders are essential to building a framework of diversity, equity and inclusion in medicine
- Facilitate engagement of appropriate resources for patients
- Can provide Informed and direct understanding of the implications of genetic diversity and cultural awareness
- Guide and apply knowledge specifically tailored to communities to improve scientific understanding and promote equitable care

# Tailored community engagement

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- Focus on building trust and overcoming barriers
- Disseminate knowledge of genomic medicine, research opportunities and genomics services to providers and supporting services
- Bringing together entire communities to operationalize the outreach to under-represented communities and individuals as we work together in building the missing pieces of the science
- Build the infrastructure and overall planning for initiatives ensuring sustainability and scalability

# Advocate for the needs of the community and influence public policy

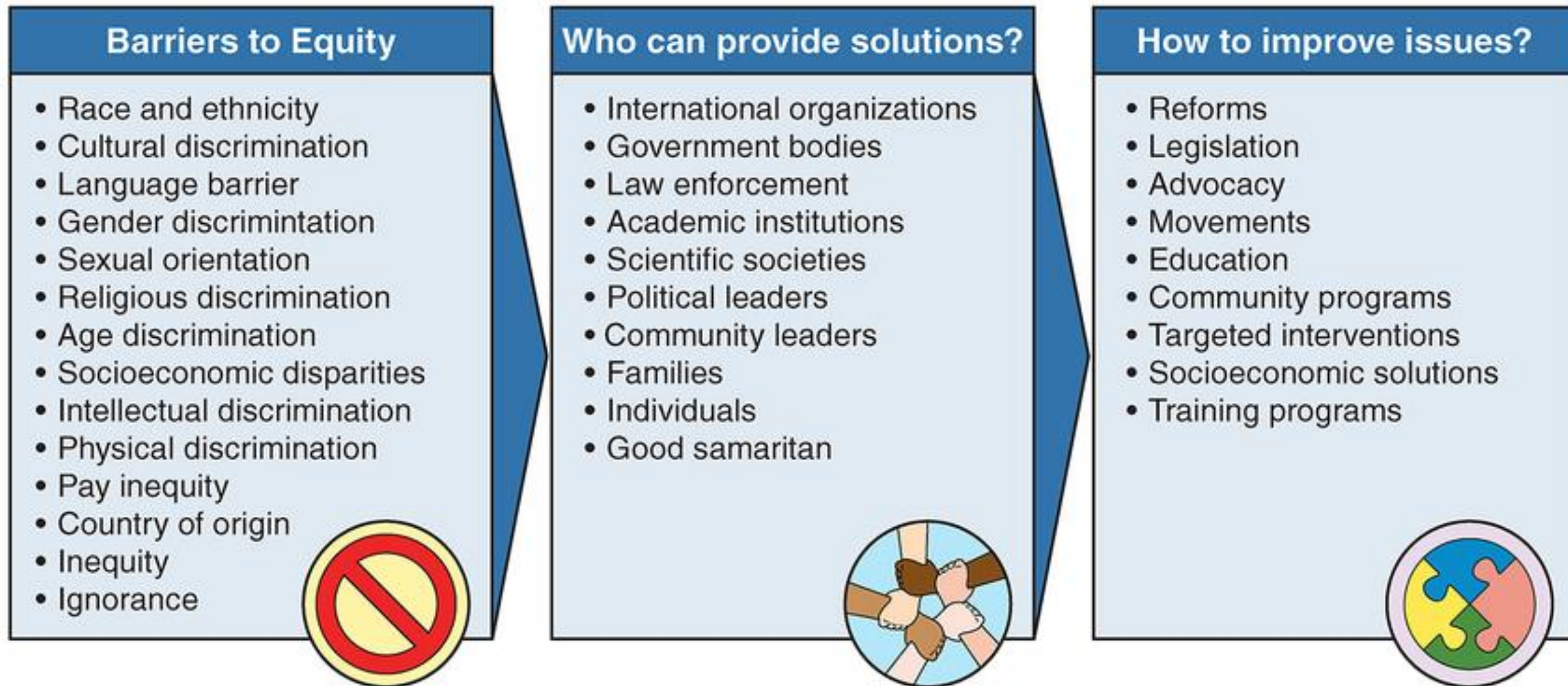
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- Provision of services tailored to specific communities
  - Better representation across the workforce to support minority groups
  - Enhance health care training to facilitate access and delivery of care
- Ensure patients receive the most appropriate service of the medical condition
- Appropriate access to testing and ancillary resources - Equal quality, equal care

# Diversification of research

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- Diverse leaders have first-hand understanding of unique community differences
- More personalized approach to Promote inclusive and consistent participation of diverse populations
- Could potentially address patient fears and negative perception of research practices in a culturally sensitive and informed fashion
- Cultural knowledge will enable tailored conversations and interactions with patients
- May enable higher community engagement and group specific support networks
- Can provide general training for other healthcare staff surrounding implications of genetic diversity and cultural awareness specific to the populations to be studied





# Role of AMP in fostering a diverse and inclusive global community

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- AMP is a highly diverse and collegial community
- Common goal of advancing the science and implementing high-quality molecular diagnostics to directly benefit patient care.

# Diversity, Equity and Inclusion (DEI)

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- Embedded within AMP's Core Principles and our strategic planning
- Concerted effort to incorporate diversity, equity and inclusion into the work of all AMP committees
- Built explicit directives into the policies that govern how we select speakers, volunteers, award winners and our leadership
- Our advocacy mission is driven specifically to ensure broad patient access to appropriate molecular testing for patients of all backgrounds
- Provide specific education and share resources with the AMP community to reduce disparities in testing and cultivate inclusion in the workplace and training programs

# ABOUT

[President's Welcome](#)[Who We Are](#)[Board of Directors](#)[Executive Committee](#)[Diversity, Equity & Inclusion](#)[► Diversity, Equity & Inclusion Resources](#)[25 Years of Innovation](#)[AMP Around the Globe](#)

## Diversity, Equity & Inclusion Resources

AMP has assembled a list of available resources on diversity, equity, & inclusion. This page will change as new information becomes available. Check back frequently for updates. Please send suggestions for additional resources to [dei@amp.org](mailto:dei@amp.org).

### AMP

- [AMP DEI Working Group](#)
- [AMP Statement on Dobbs v. Jackson Women's Health Organization](#) (August 2022)
- [AMP 2024 DEI Goals](#)
- [Overview of Recent AMP DEI Efforts](#) (May 2023)
- [AMP's Strategic Pillars and Existing Alignment with DEI - A Strong Foundation](#)
- [AMP Letter: Fostering Forward Movement Against Racism and Inequality](#) (June 2020)

### In-person Networking & Social Events

- Look for Networking & Social Events at the [AMP 2024 Annual Meeting & Expo!](#)

### Virtual DEI Engagement Events (Planned and coordinated by the DEI Working Group)

- Partner together, as a global community, with other organizations to disseminate knowledge of molecular medicine and support similar initiatives in other communities
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## International Affiliates

**The Hong Kong Society for Molecular Diagnostic Sciences**

**The Molecular Pathology Association of India**

**The Korean Society for Laboratory Medicine**

**The German Society of Pathology (DGP)**

**Brazilian Society of Clinical Pathology and Laboratory Medicine (SBPC)**

**The Italian Society of Pathology and Translational Medicine (SIPMET)**

**American University of Beirut Medical Center**

**Middle East Molecular Biology Sources**

**Asociacion Iberoamericana de Patologia Molecular (AIPM)**



## Founding members

- Sergio Sanchez-Sosa
- Federico Monzon
- Maria E. Arcila
- Juan Miguel Mosquera





# IAP2024

**A SCIENTIFIC PROGRAM  
BUILT FOR YOU!**

Explore multidisciplinary pathology  
research, science and innovation.

## Companion Meeting Symposium: Ibero- American Society of Molecular Pathology (AIPM)

### Long course

- Whole genome sequencing
- Epigenetics – solid tumors and lymphoid neoplasms
- Immuno-oncology

### Short course on cfDNA



# Take home points

## Research & discovery

Understand the data gap

## Community & engagement

Close the gap through implementation of equity enhancing strategies

## Sequencing & data mining

Increase the volume and depth of data on under-represented groups

Provide the tools and modify behaviors

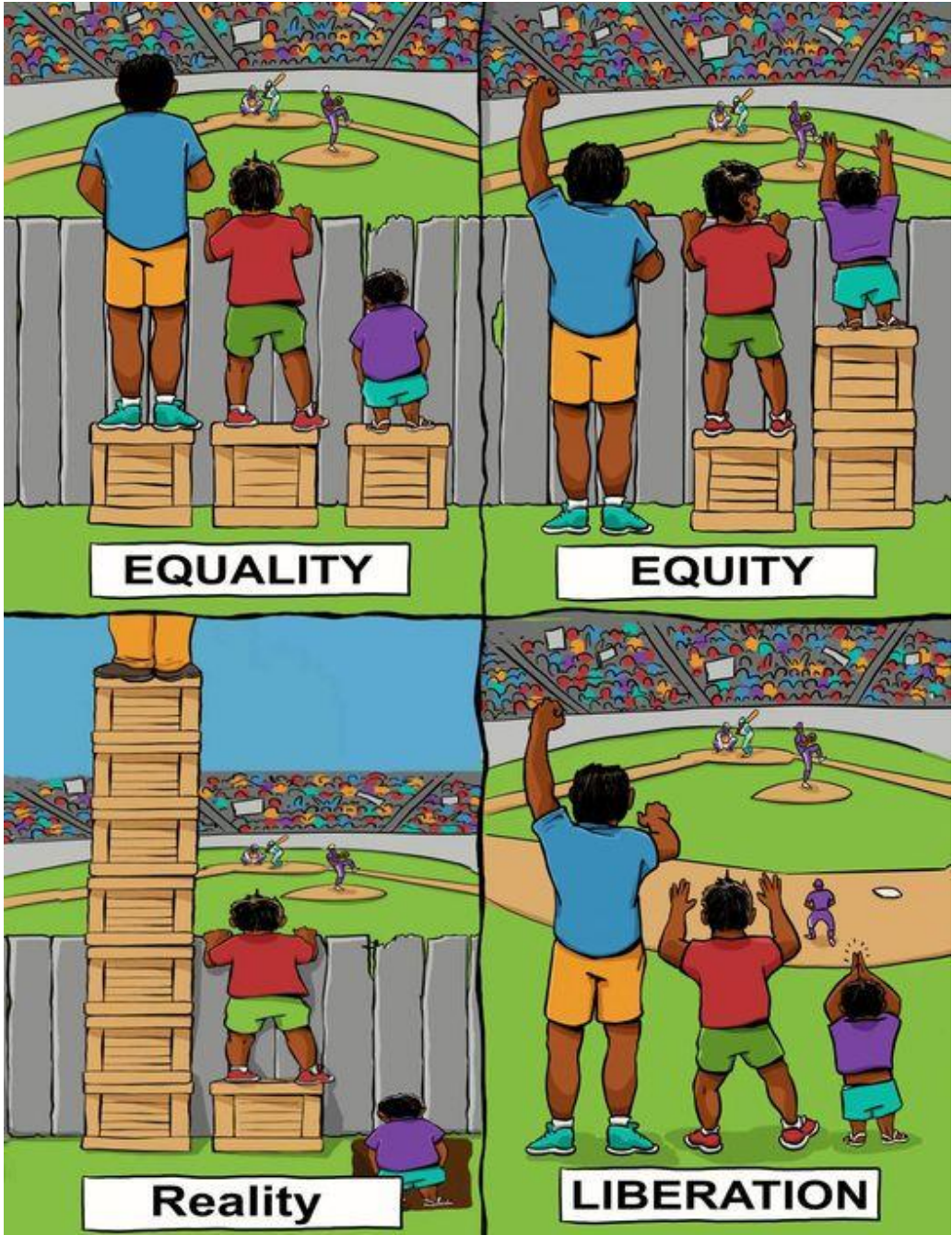
Work with clinicians, analysts and community to bridge the gap

Promote the delivery, create service delivery practices and educate others



Artist: Angus Maguire  
([madewithangus.com](http://madewithangus.com)), Facebook

Equal treatment –  
does not produce  
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Equity – everyone gets  
the support they need to  
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One gets more than is  
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Justice – all 3 can see because  
inequities are addressed-  
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# Q&A

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# Upcoming Webinars

## More webinars coming in 2024!

For additional information, please visit the AMP Diversity, Equity & Inclusion Resource Webpage



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- [Embracing Leadership Diversity with Dr. Maria Arcila](#)
  - When: Monday, October 7, 2024; 1:00pm – 2:00pm Eastern
  - This is the third webinar in a series that will focus on real-life stories of molecular laboratory professionals with highly diverse backgrounds. We will discuss how their experiences are helping to promote the education, training and practice of molecular pathology in communities of non-US background.
  - While the presentation is geared toward AMP members, [registration](#) is free and open to all, so please feel free to share this exciting offering with your colleagues.
- [Boosting Your Research Journey with Mentors & Champions with Dr. Tracy Costello](#) (May 2024); **Handout:** [Presentation slides \(PDF\)](#)
- [Building a Successful Career in a Diverse Cultural Environment with Dr. Honey Reddi](#) (December 2023); **Handout:** [Presentation slides \(PDF\)](#)
- [Reversing the Gender Leadership Gap: Taking Action for Meaningful Change with Dr. Jennifer Hunt](#) (March 2022)

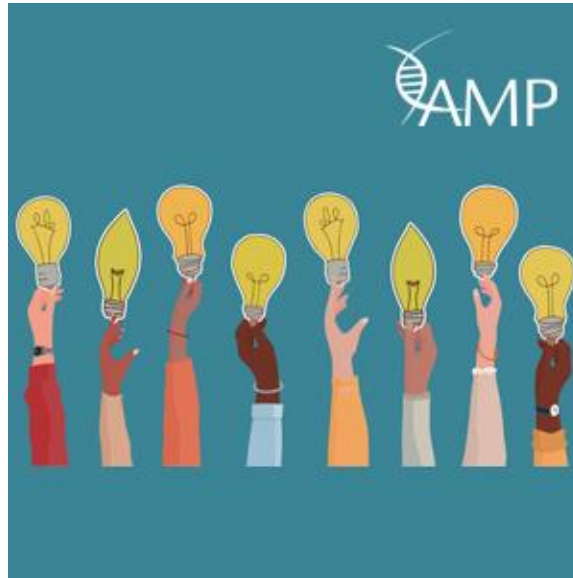


Please take  
our survey





*Thank you for participating!*



Submit post-webinar questions? Email [DEI@amp.org](mailto:DEI@amp.org)