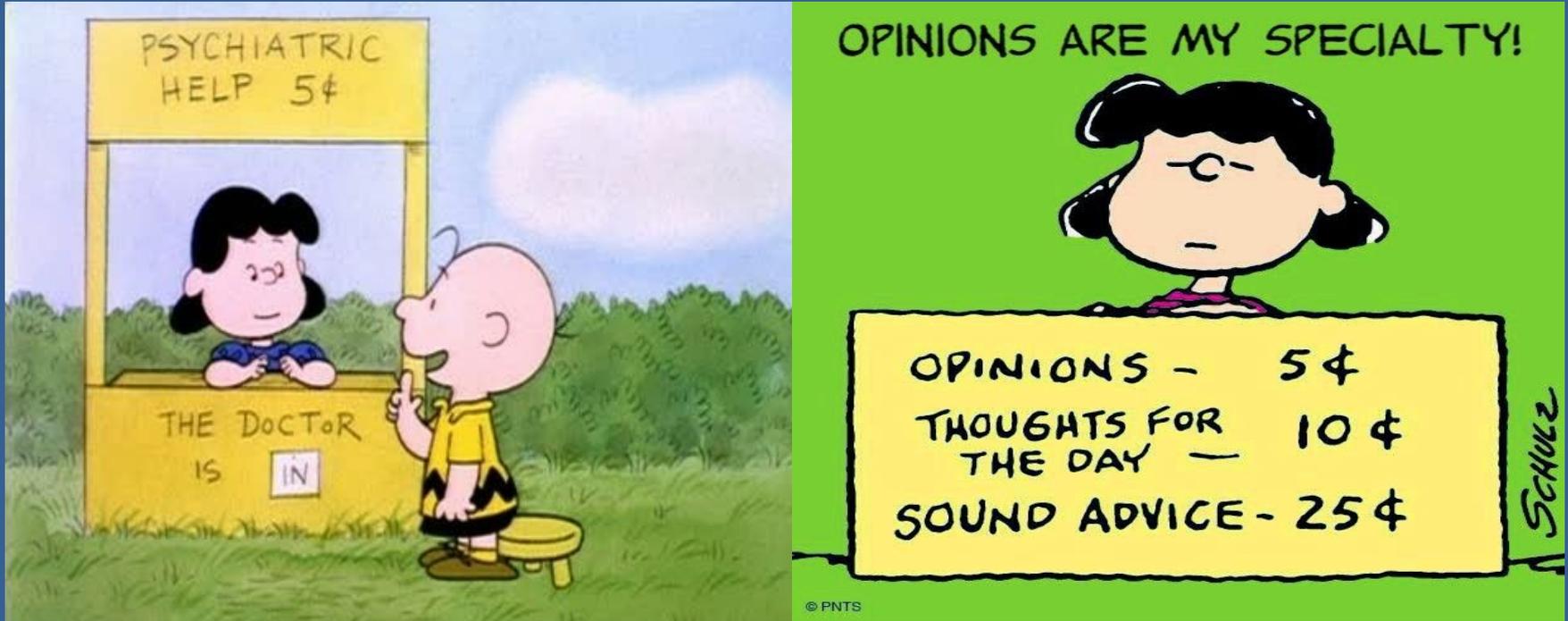


Achieving Health Equity in the NIH  
HEAL Initiative, Virtual Workshop  
February 1, 2021

“One Patient’s Perspective” On the Challenge To  
Achieve Diversity & Inclusion”  
Errol R. Patterson

# Disclaimer and Acknowledgement



## General Observation: The concern regarding the lack of diversity and inclusion in clinical trials is not new

- Since the 1980s, the FDA has been working to increase participation of subgroups in clinical trials.

<http://www.fda.gov/AboutFDA/Transparency/Basics/ucm443930.htm>

- In 1993, the National Institutes of Health (NIH) Revitalization Act mandated the inclusion of racial and ethnic minorities in federally funded biomedical research.

<https://acsjournals.onlinelibrary.wiley.com/doi/full/10.1002/cncr.28575>

- In 2012, the Food and Drug Administration Safety and Innovation Act , required FDA to report on the diversity of participants in clinical trials.

<https://www.fda.gov/regulatory-information/food-and-drug-administration-safety-and-innovation-act-fdasia/fdasia-section-907-inclusion-demographic-subgroups-clinical-trials>

# So What Gives ?

“It’s not that minorities are hard to reach but that they're hardly reached.”

Lindsey Konkel, *Racial and Ethnic Disparities in Research Studies: The Challenge of Creating More Diverse Cohorts* (quoting Moon Chen, a cancer health disparities expert at the University of California, Davis.) (2015).

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4670264/>

# A Wise English Proverb Says:



# Potential Barriers Standing “In The Way” To D&I

1. The multi-cultural divide
2. Identifying sufficient numbers of patients in the community
3. Lack of meaningful engagement within the community
4. Patient mis-trust (e.g. the “Tuskegee Syphilis Experiment”)
5. Lack of understanding and appreciation within the community of:
  - a. prevalence and risk of disease
  - b. potential benefits

# Potential “PathWAYS” To Success

Direct Engagement, Involvement and  
Recruitment Within The African  
American Community

# Alliances/Support from Historically Black Medical Schools

1. Charles R. Drew University of Medicine and Science (LA, Ca.)
2. Howard University College of Medicine (Wash., D.C.)
3. Meharry Medical College (Nashville, Tenn.)
4. Morehouse School of Medicine (Atlanta, Ga.)

- Long tradition of medical research on diabetes, cancer, sickle cell, hypertension and other diseases within the Black community

Demonstrated community based healthcare capacity:

- Establishing testing sites
- Providing medical care
- Doing research

*“Nation’s four Black medical schools battle COVID-19,”* <https://www.thecrisismagazine.com/single-post/four-black-medical-schools-battle-covid-19>

# Alliances/Support from African American Churches

- National Black Clergy Leadership Health Council

ChooseHealthyLife Initiative.  
<https://www.choosehealthylife.org/>

- Local Area Community Churches

Choose Healthy Life Initiative goals:

- Awareness and Education
- Infrastructure
- Scale
- Black Church Public Health Navigators (BCPHN)™

# Alliances/Support from African American Professional Health Organizations

- U.S. Department of Health and Human Services. Office of Minority Health (OMH).
- OMH has published a list of 25 African American “National Minority Organizations” that are available as information sources.

<https://minorityhealth.hhs.gov/omh/content.aspx?ID=147&lvl=1&lvlID=3>

# Financial Considerations Can Impact the “Will” and the “Way” To Achieving D&I

- Patient Compensation:
  1. Benefits the patient
  2. Signals that the patient is highly valued
  3. Shows the importance of the study
- Specific funding of study components related to:
  - D&I recruitment and retention
  - Meeting D&I goals (e.g. bonuses and penalties)