

Relevant Disclosure

- I have nothing to disclose

The Meaning of Diversity and Use of Race and Ethnicity in U.S. Biomedicine

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THE RISE OF DIVERSITY

Diversity projects—*programs or plans of action focused on promoting or celebrating ideas of diversity*—spreading across academia, employment law, popular culture, and politics

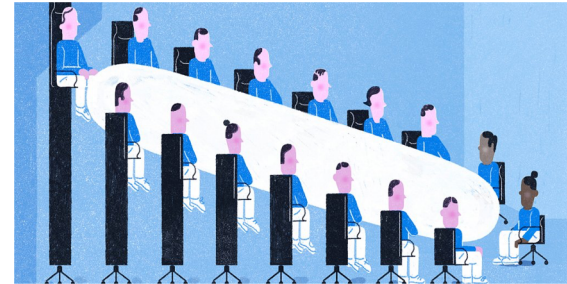


About

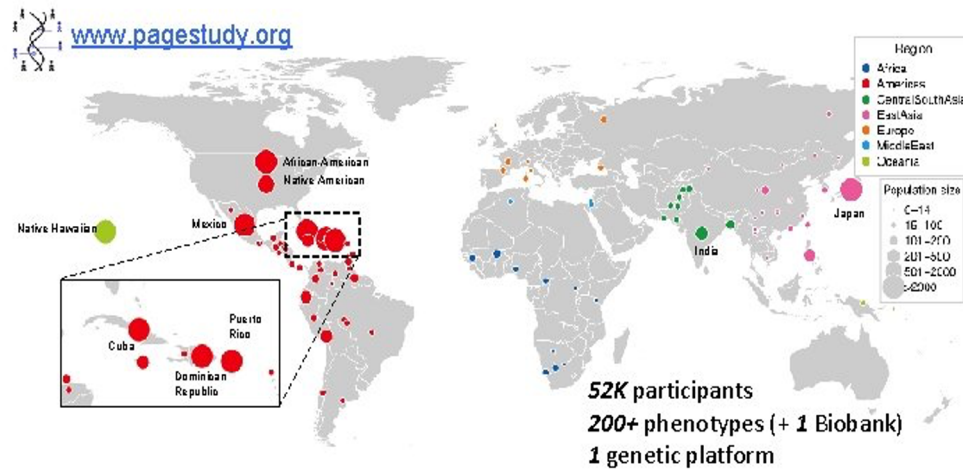
About Rutgers
Facts & Figures
Our History
Points of Pride

We Are Diverse

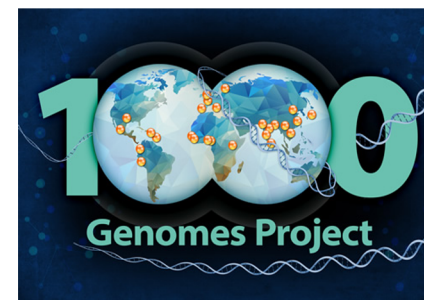
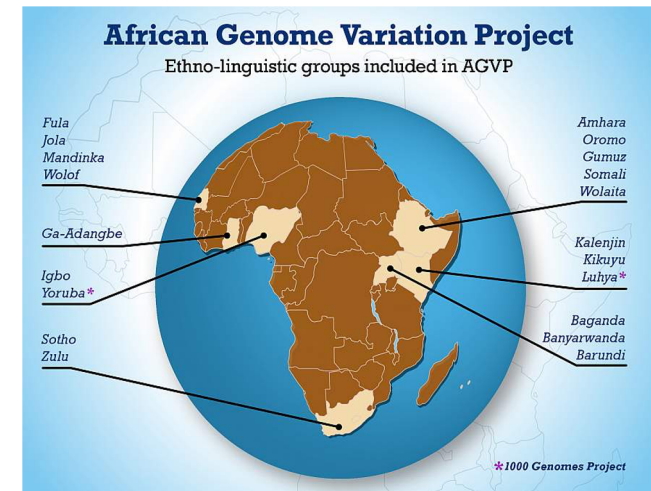
For Rutgers University–New Brunswick **diversity is an everyday ingredient** of university life and one of our greatest strengths. Rutgers' diversity—and there are all kinds, from age to sexual orientation to ethnic background to whether you grew up on a farm or city block—reflects the rich array of people who choose New Jersey as the place to build a better future.



NHGRI Population Architecture using Genomics and Epidemiology (PAGE) Study



Wojcik et al. "Genetic diversity turns a new PAGE in our understanding of complex traits" (2017) *bioRxiv*

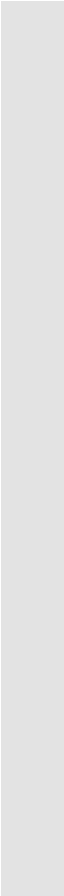
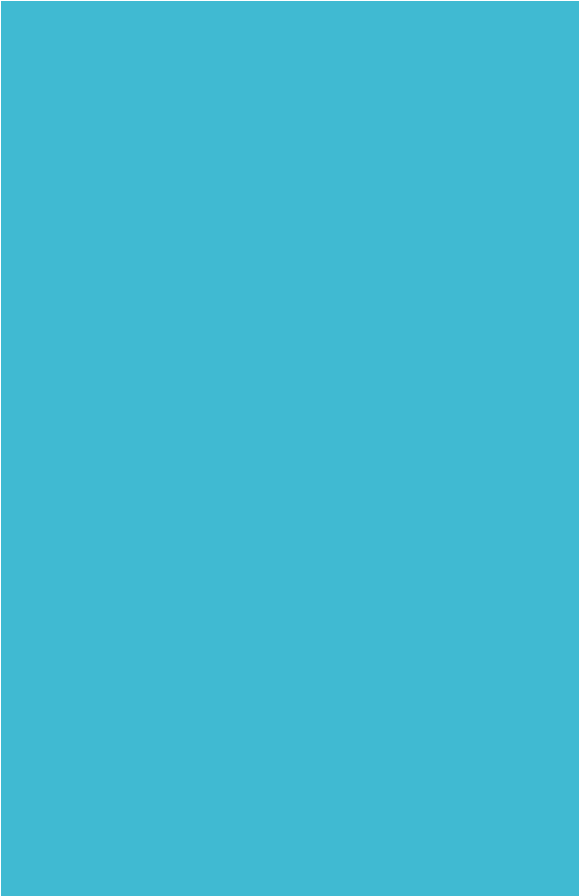


<https://riseofdiversity.netlify.app>

Regulatory Guidelines, Standardization of Race, and Rise of Population & Geographic Terms

- 1993 NIH Inclusion Mandate
- OMB Directive 15
- Standardization in data
- Move toward ancestry and continental labels (Byeon et al. 2021; Fujimura and Rajagopalan 2011) and “statistical notions of difference among populations” (Shim et al. 2014)
- Polyvocality of race: blend racial schemas with geographical terms (Panofsky and Bliss 2017)

- What does diversity mean?
 - How do people talk about diversity
- *Can attention to diversity address racial and ethnic health disparities?*



What does diversity mean in biomedical research?

Computational Text Analysis

Study conducted with Brandon Kramer, PhD

What does diversity mean in biomedical research?

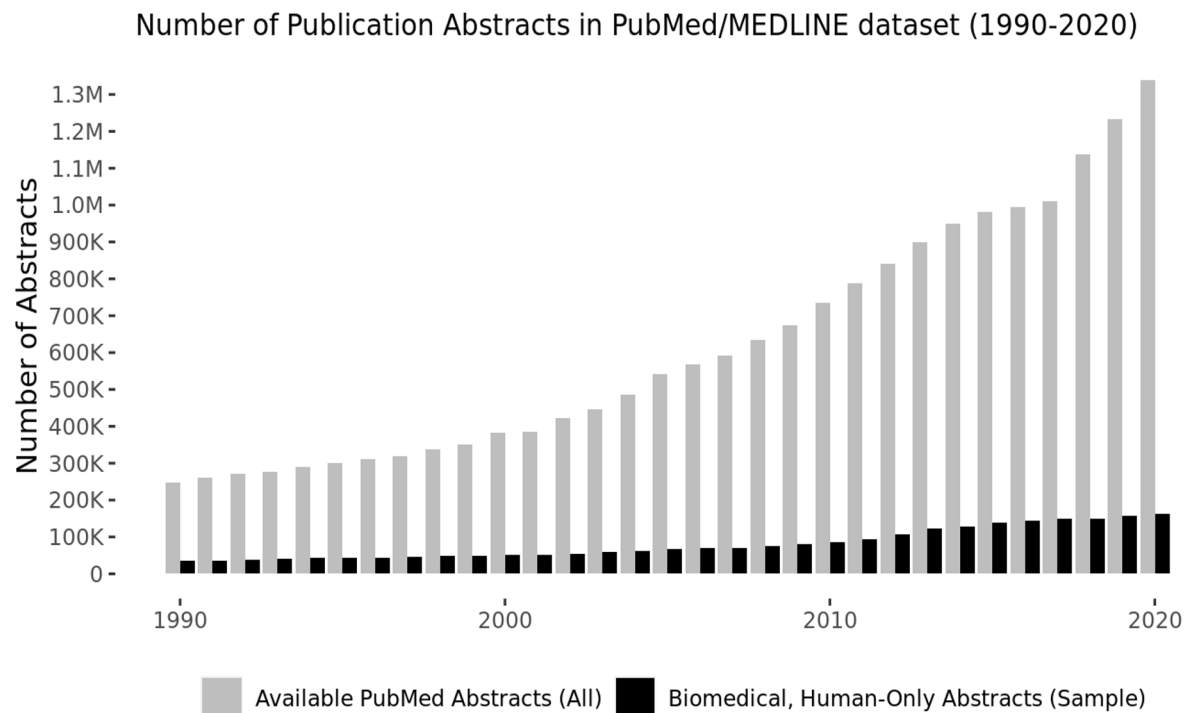
- Hypothesis 1: The use of the term diversity and related terminology has increased in biomedical abstracts since 1990
- Hypothesis 2: The use of US-specific racial and ethnic categories outlined in the OMB Directive 15 has grown
- Hypothesis 3: The use of population terminology, especially national and continental labeling practices, has increased in biomedical abstracts since 1990

What does diversity mean in biomedical research?

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- Hypothesis 3: The use of population terminology, especially national and continental labeling practices, has increased in biomedical abstracts since 1990
- Hypothesis 4: Diversity has become less semantically similar to race and ethnicity while becoming more semantically similar to population terminology

Data & Methods

~2.5 million biomedical abstracts from PubMed



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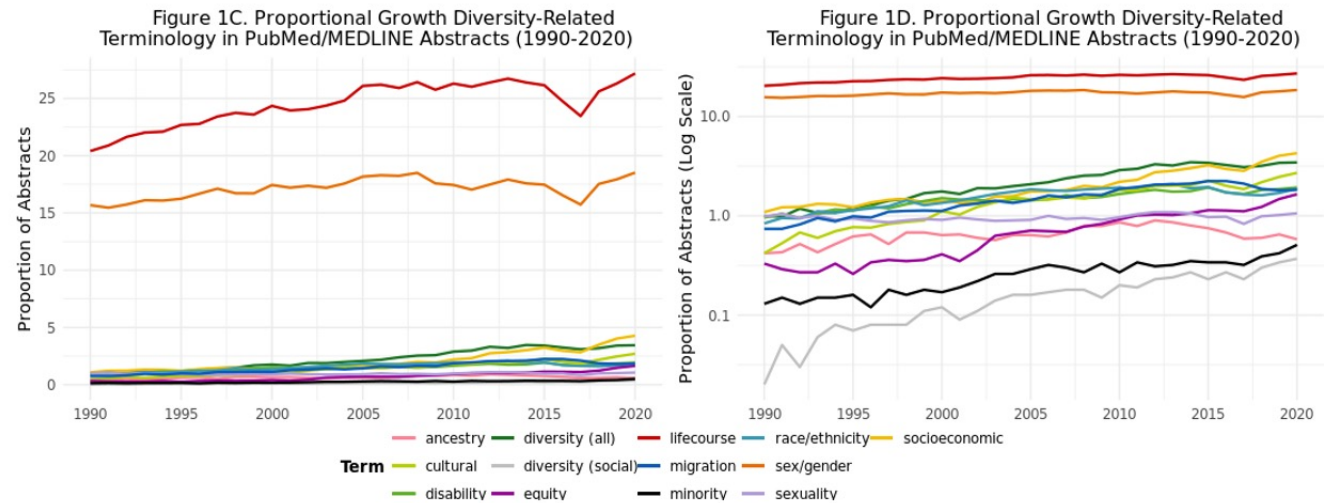
HI: Diversity Rising

Largest increase:

- Lifecourse
- Sex/gender
- Socioeconomic
- Diversity

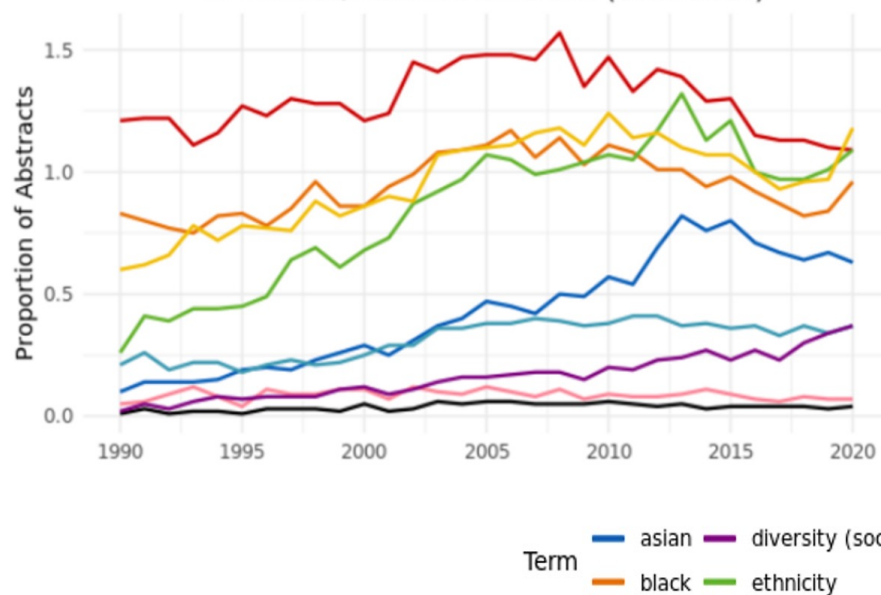
Plateauing:

- Ancestry
- Race/ethnicity
- Sexuality



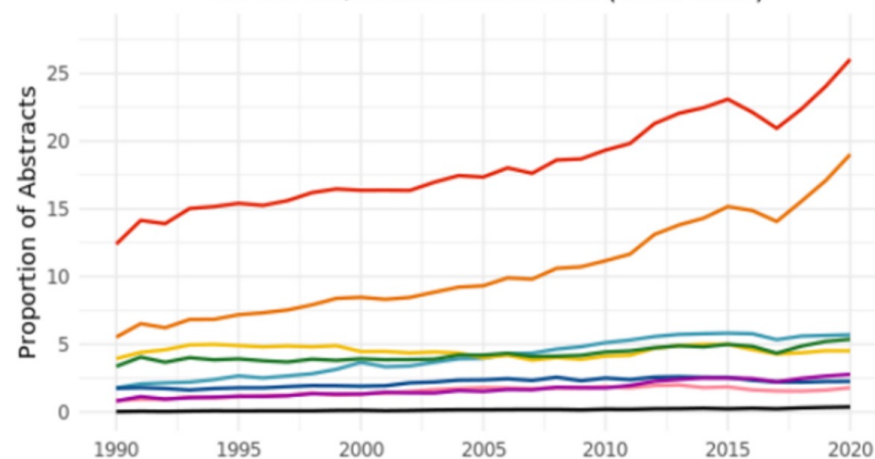
H2: OMB Race and Ethnicity Categories Declining

Figure 2B. Proportional Growth of US OMB Terms in PubMed/MEDLINE Abstracts (1990-2020)



H3: Population and Geographic Terms Rising

Figure 3B. Proportional Growth of Population Terms in PubMed/MEDLINE Abstracts (1990-2020)

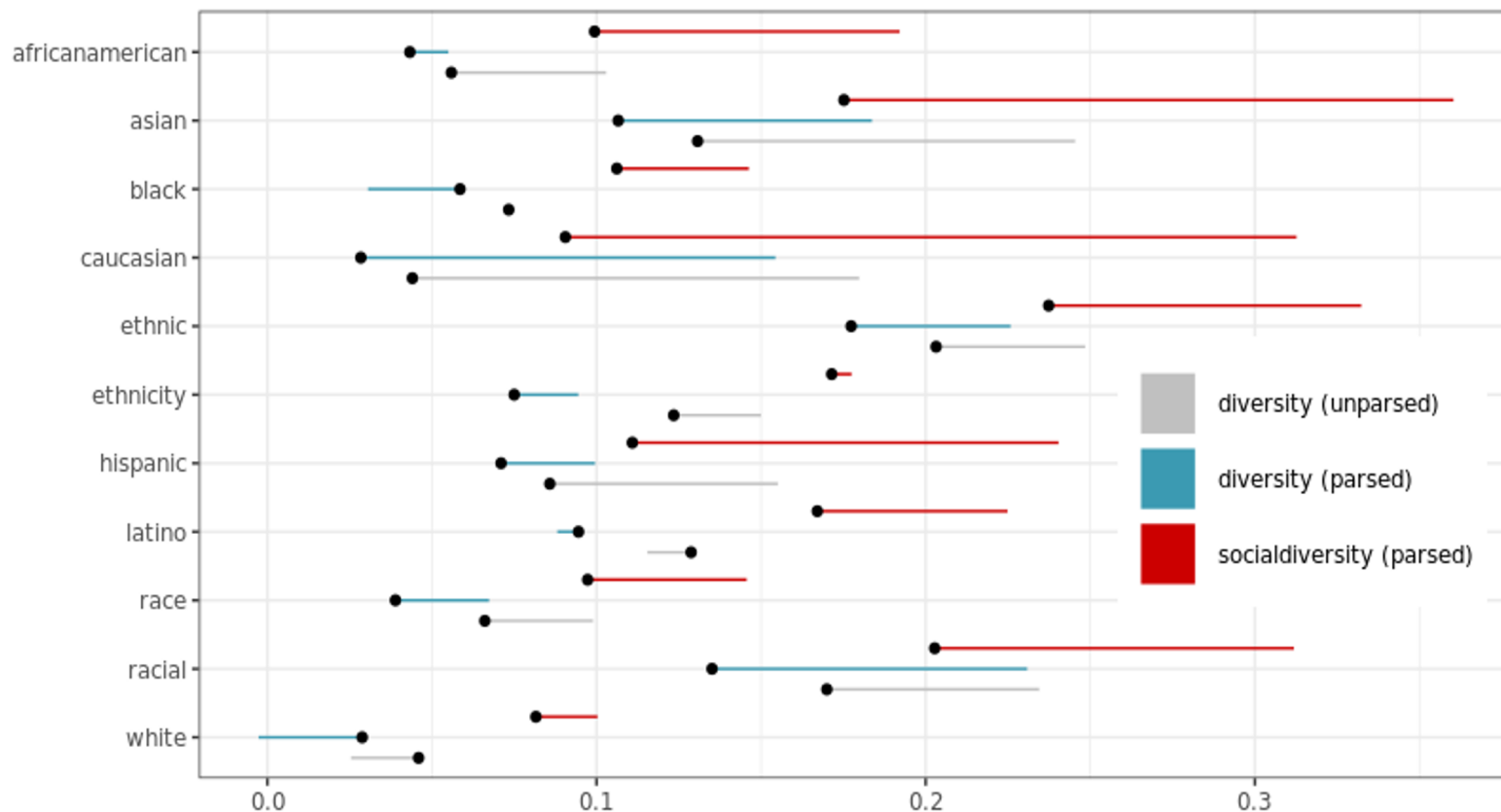


H4: Semantic Similarity

Are are race and ethnicity semantically similar to diversity?

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Figure 4. Comparison of Racial and Ethnic Vectors Relative to Diversity and Social Diversity Vectors for 1990-2000 and 2010-2020 Models



Note: The black point on each line designates the word vector coordinates for the 2010-2020 model

H4: Term Comparisons – Analysis I

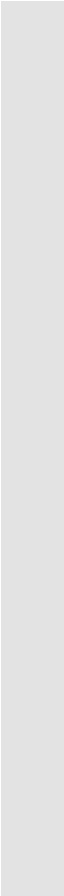
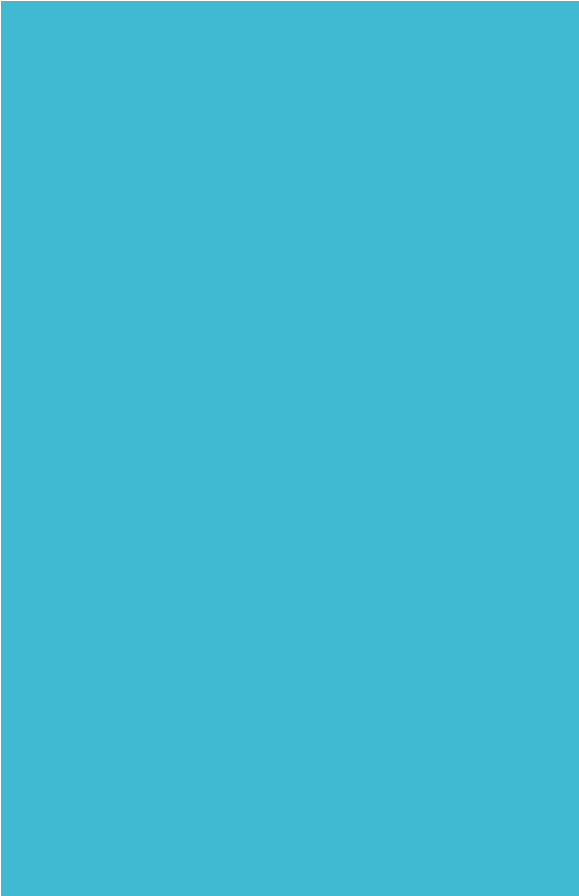
H4: Semantic Similarity

- Diversity now more similar to:
 - Sexuality & socioeconomic terms
 - Directional & subnational terms
- Diversity now less similar to:
 - Racial/ethnic & Census/OMB terms
 - Equity/justice terms

Main Takeaways

- **The use of diversity in biomedical research is increasing**
 - Lifecourse, sex/gender, and socioeconomic terms
- **The use of racial/ethnic/OMB labels have started to decline**
- **National/continental labels are supplanting racial/ethnic labels**
- **Diversity discourse is not racial equity discourse**
 - Diversity not used alongside race/ethnicity and equity/justice
 - Diversity used to describe national populations outside of Europe & Asia

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How do stakeholders talk about diversity?

Interview analysis

Data and Methods

Interviews with individuals from healthcare and pharmaceutical organizations

- Leading or implementing diversity programs (D&I officers, CMOs, project/product developers)
- Daily work of orgs (physicians & scientists)
- Marketing (marketers and advertisers)

Diversity Defined

“When we think about diversity today ... it's much broader than race and ethnicity.”

-- Carl, D&I officer and former physician

“It can mean a hundred things, all the way from religion to race, ethnicity, language, and every combination thereof.”

--Mario, physician and minority community clinic health director

Diversity Defined

Three narrative arcs:

1. Diversity as regulatory work
2. Diversity as social justice project
3. Diversity as economic enterprise

1. Diversity as Regulatory Work

What's “most important” is “defining the disease area first.”

“[The FDA and other regulatory agencies] have requirements” that determine which population subgroups are identified.

-- Sharon, Chief Medical Officer, pharmaceutical company

The healthcare system “requires you to fit things into a box, because you have to measure it or you have to address it in some form.”

-- Frank, D&I officer, healthcare

2. Diversity as Social Justice Project

“for me, that issue around diversity, equity goes hand in hand. They're not actually separate things. The more diverse people you have, the more likely that environments going to change.”

--Teo, physician and scientist at leading medical school

3. Diversity as Economic Enterprise

“If you’re not relevant to these fastest growing groups, you’re going to be on the sidelines in 20 years or faster. You’re going to see that deterioration ... You need to know a lot about your patients because patients are becoming consumers. If you don’t serve them well quickly, and right the first time, you may not get a repeat customer.”

-- Carl, D&I officer and former physician

Main Takeaways

- *What does diversity mean?*
 - Diversity can mean many things
 - It is increasingly less about just race and ethnicity
- *How do people talk about diversity*
 - Diversity can be both the means and goals
 - Goals are not always about health equity

Conclusion

- In biomedical research and in stakeholders' discourse, reference to diversity may be more a reflection of regulatory requirements, market conditions, and organizational structure of U.S. biomedicine than concerns over racial health inequities