

Engaging Multiracial Community in Genomics Research: What Does it Mean?*

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Background

- Genetics research has historically excluded individuals from non-European ancestries, limiting understanding and healthcare applications for diverse populations
- Multiracial individuals have particularly been overlooked due to exclusive social practices and restrictive scientific methodologies
- Despite community engagement proving effective in diversifying genetics research, few studies have examined its impact on Multiracial individuals, the fastest-growing racial group in the US
- Exclusionary practices, on top of a lack of frameworks for how to define, recruit, and engage Multiracial individuals pose serious implications for future research involving this community

Aims

- To investigate Multiracial individuals' viewpoints on the Multiracial community and the implications of genetics research for this population
- To explore Multiracial individuals' perspectives about which stage(s) in the genetics research process is most important for their community to engage with
- To assess the importance participants' Multiracial identities play within the healthcare setting MULTIPOUS

Recruitment flier and screening survey posted in Facebook groups

Consent form emailed to eligible participants

Demographic survey emailed to participants who signed consent form

Formal invitation to participate emailed to those who completed demographic survey

17 participants interviewed (4 two-on one & 9 one-on-one interviews)

Data Analysis

- <u>Codebook:</u> Inductive & Deductive Approaches
- <u>Content Analysis:</u> Constructivist Grounded Theory & Interpretive Description

Concerns Regarding Accuracy of Genetics Research

Translation to Clinical Practice

"It's a little more complex, like, I got a mix of Colombian, Irish, Hungarian, and German, like, who has that? It's not like an easy... "Oh, well you're fully Columbian, so we can just tell you what the health probabilities or concerns would be" (ID 9)

Statistical Power

"I'd be surprised if the research is at that level that it's able to say, 'okay, because you're a mix of these two backgrounds, therefore, your risk is X percent as opposed to... I just don't think that the sample size of the data that we have out there is large enough to give informed estimates that are meaningfully gonna change whether I get screening for a certain condition or not" (ID 10)

Omission of Data / Lack of Specificity

"I feel like a lot of times researchers don't look at Multiracial people. Like they ask you to identify one race, or if they have you identify that you're Multiracial, they don't ask any like, follow up questions... it's just "two"...

but it doesn't actually ask what" (ID 11)

Discussion

- Evolving Population: No single definition emerged from the data on how to characterize the Multiracial community, suggesting that it is a unique and rapidly evolving population.
- Concerns Regarding Accuracy: Participants concerns stemmed from their unique backgrounds, exclusionary practices, or a lack of sophisticated tools for analyzing diverse data sets. These concerns strongly align with existing limitations in the field of genetics.
- Community Engagement: Participants' preferences for engaging with research vary according to their skills and interests, therefore, providing participants with the option to choose how they would like to be involved in research could lead to more meaningful, strength-based participation.

Results

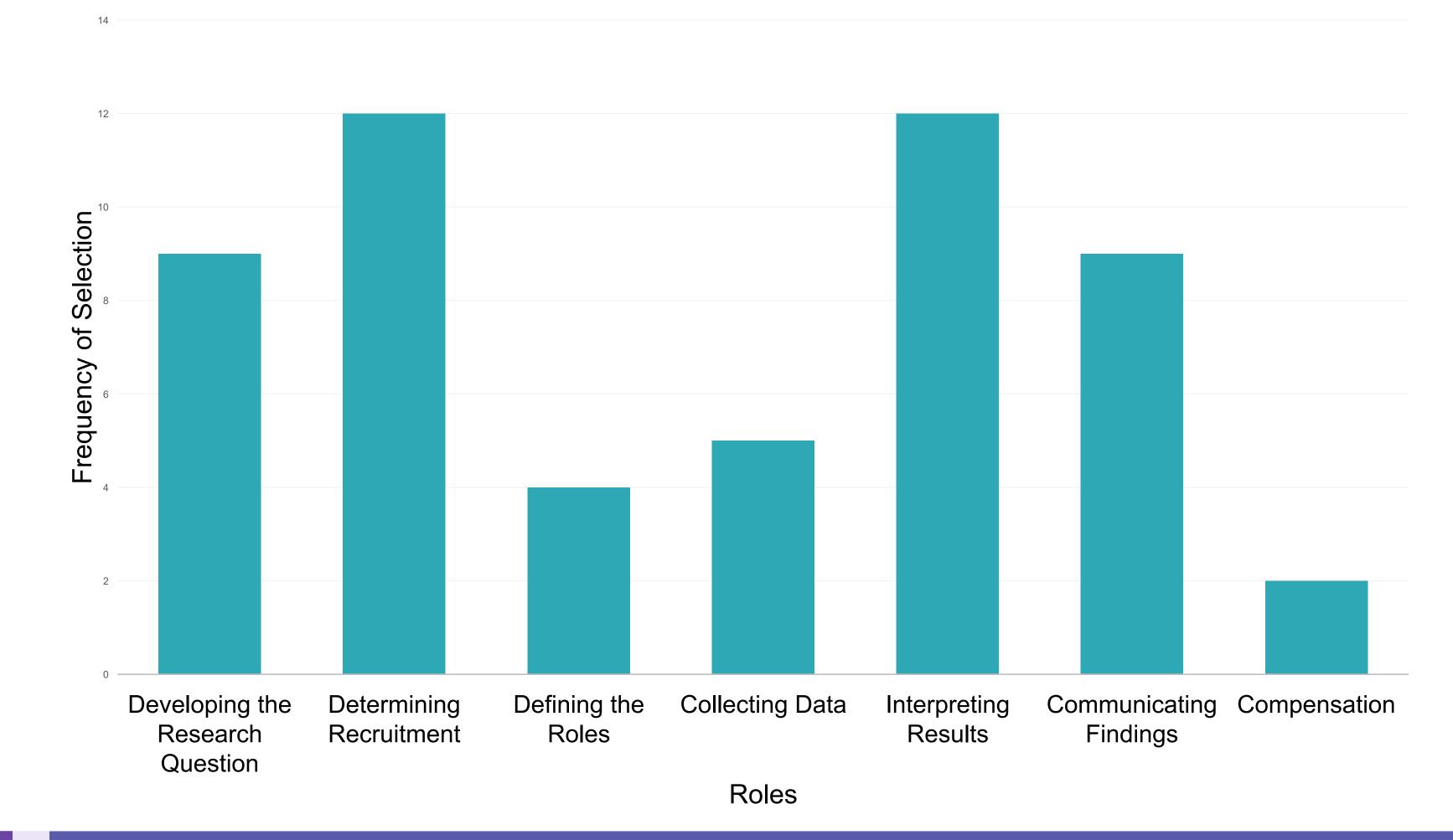
Perceived Importance of Multiracial Identity in Healthcare

""I think it just adds a little more insight to.. who I am as a person" (ID

"I feel any time that they have a full picture of who you are as a patient, it helps to properly diagnose" (ID 16)

"[It's important] not because of the race itself, but the cultural context" (ID 6

Preferences for Engaging with Genetics Research



Research Implications

- Participants' concerns about accuracy and the historical underrepresentation of diverse backgrounds in genetics emphasize the urgent need to include Multiracial individuals in genetics research.
 - ★This is especially important given that most participants (n=11) believe that their Multiracial identity should be considered in healthcare settings
- As perspectives on characterizing the Multiracial community evolve alongside the expected growth of this population, it will be vital to:
 - ★Avoid rigid categorization practices
- ★ Adopt a more creative approach to meaningfully engage Multiracial individuals in genetics research
- ★Be flexible with changing definitions, honor participants' unique