May 4th, 1:30 PM - 3:00 PM

Inclusive Approaches for Measuring Demographics of Underrepresented Populations in STEM and Biomedical Research Training Programs

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https://pdxscholar.library.pdx.edu/studentsymposium/2022/presentations/18

Presenter Information

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Inclusive approaches for measuring demographics of underrepresented populations in STEM and biomedical research training programs

Paris, S.E., Lentz, B., Alvord, T.A., Marr, M.C., Setthavongsack, A., Dinno, A., Downing, J., Raz Link, A., Richardson, D.M., Espinosa, S.N., Nguyen, P.T., and Marriott, L.K.

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Portland State UNIVERSITY | SCHOOL OF PUBLIC HEALTH

SEPA SCIENCE EDUCATION PARTNERSHIP AWARD
SUPPORTED BY THE NATIONAL INSTITUTES OF HEALTH

We acknowledge the original inhabitants and traditional village sites of the land Oregon Health & Science University and Portland State University are occupying and built upon: the Multnomah, Kathlamet, Clackamas, Tumwater, Watlala bands of the Chinook, the Tualatin Kalapuya, Molalla, Wasco and many Indigenous nations of the Willamette Valley and Columbia River Plateau. We take this opportunity to thank the original caretakers of this land - past, present, and future.

Funded by a NIH Science Education Partnership Award (SEPA R25GM129840), National Cancer Institute Youth Enjoy Science grant (R25CA221741), OCTRI (1UL1TR002369), EXITO (RL5GM118963, TL4GM118965, and UL1GM118964), and a training award (F30MH118762).

Welcome! We are so glad you're here.

Normalizing Feelings

- This presentation is a **starting place** for ongoing conversations about how to measure demographics.
- Conversations can be **uncomfortable**. *Comfort and growth rarely co-exist.*
- **Ask questions** and for advice. It is a great thing to want to learn and improve.

Learning Objectives

In the next ten minutes, we hope you will…

- Recognize that **research definitions of diversity evolve**, reflecting the process of science.
- Recognize **flexibility** in demographic data collection is needed.
- Identify and share existing **tools and resources** for measuring demographics.
- *Stretch goal:* Develop **better** strategies and tools to compassionately gather data for populations that are being excluded, marginalized, or improperly aggregated in biomedical research training programs.

Housekeeping and Accessibility

Breathe. Relax with note-taking. Engage in your own way.

Content Anytime

Follow along with the slides on our presentation **website**.

https://sites.google.com/view/inclusivedemographics

Introvert's Delight!

Use Jamboard to **anonymously** ask a question or share comments, thoughts, resources or concerns.

https://jamboard.google.com/d/1hxjy47I2qzSZAjDgbam6cin-98Y7dxFULWhmCvlvIV4/edit?usp=sharing

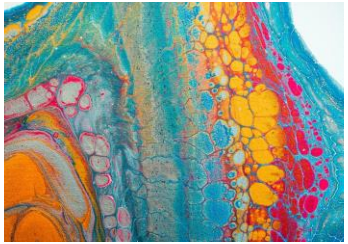
Contribute to Science

The audience today is helping build out **FAQs**. Interested in more? Stay involved with us.

https://ohsu.ca1.qualtrics.com/jfe/form/SV_aXypCXkEs4Ejwy2

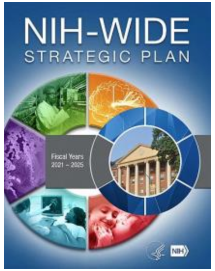
Introduction

Diversity increases research innovation



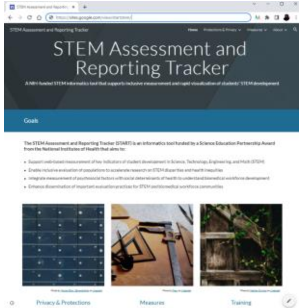
Hofstra et al., 2020

NIH aims to train a diverse biomedical workforce


NIH-WIDE
STRATEGIC PLAN
Fiscal Years 2021 – 2025

NIH Strategic Plan (2021-2025), p16-17

How to measure demographics has varied



STEM Assessment and Reporting Tracker

A NIH-funded STEM informatics tool that supports inclusive measurement and rapid visualization of students' STEM development

Goals

The STEM Assessment and Reporting Tracker (START) is an informatics tool funded by a Science Education Partnership Award from the National Institutes of Health that aims to:

START, 2022

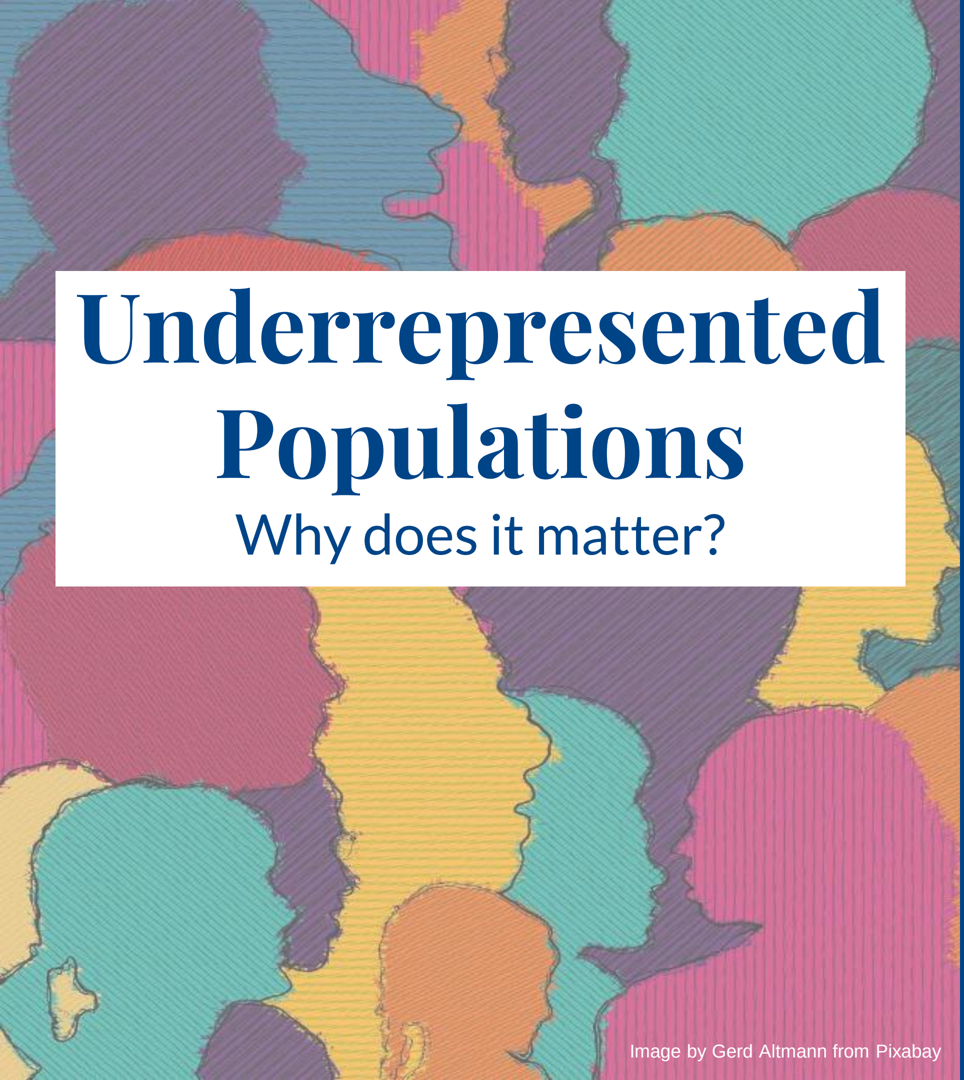
NIH training programs want guidance

Mekinda et al., in review

Trainees do not enter training programs with equal access, accommodations, or preparation.

Inclusive demographic measures can inform a nuanced set of program outcomes, facilitating research on intersectionality and supporting the recruitment and retention of underrepresented students in biomedical science.

Hofstra B, Kulkarni VV, Galvez SM, He B, Jurafsky D, McFarland DA. (2020). The Diversity–Innovation Paradox in Science. Proceedings of the National Academy of Sciences. 2020 Apr 28;117(17):9284-91.
NIH Strategic Plan 2021-2025:https://www.nih.gov/about-nih/nih-wide-strategic-plan
START (2021). START: STEM Assessment and Reporting Tracker. Retrieved from https://sites.google.com/view/startstem
Mekinda, M.A., Chaudhary, S., Vanderford, N.L., Burns White, K., Kennedy, L., and L.K. Marriott. (2022). Approaches for measuring inclusive demographics across Youth Enjoy Science cancer research training programs. In peer review with the Journal of STEM Outreach.



Underrepresented Populations

Why does it matter?

Image by Gerd Altmann from Pixabay

Underrepresented populations have historically been excluded from participating in biomedical science.

This exclusion may be intentional or unintentional, but may impact data quality, how we perceive, understand, or report on public and population health, the equity of programs, funding, public policy, and much more.

Underrepresented Populations

As defined by the National Institutes of Health (NOT-OD-20-031)

- **Racial and ethnic groups** underrepresented in biomedical research are defined as those that are
  - Black or African American
  - Hispanic or Latino
  - American Indian or Alaska Native
  - Native Hawaiian or other Pacific Islander
- Individuals with **disabilities** are defined as those with a physical or mental impairment that substantially limits one or more major life activities
- Individuals from **disadvantaged backgrounds** are defined as those who meet two or more of the following criteria:
  - Experienced past or present homelessness
  - Previously or presently in the foster care system
  - Eligible for the Federal Free and Reduced Lunch Program for 2+ years
  - First generation college students
  - Eligible for Federal Pell grants
  - Received WIC as a parent or child
  - Grew up in a rural area defined by either HRSA or HPSA locations (address/zip-related eligibility)

NOT-OD-20-031: Notice of NIH's Interest in Diversity. (2019, November 17). National Institutes of Health. https://grants.nih.gov/grants/guide/notice-files/NOT-OD-20-031.html

Race & Ethnicity

Why does it matter?

Image by Venita Oberholster from Pixabay

Not everyone receives the same access to or quality of healthcare, which results in race, ethnicity, language, and disability minority groups experiencing avoidable health inequities.

Greater resolution of data collection practices can help:

- Identify health inequities in subpopulations
- Guide development of culturally specific and accessible services
- Guide equitable allocation of resources to address inequities

McGee, M.G. (2020). Race, ethnicity, language and disability (REALD) implementation guide. Portland, Oregon: Oregon Health Authority, Equity and Inclusion Division. https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le7721a.pdf

Race & Ethnicity

In an effort to improve demographic data collection standards, Oregon Health Authority's **Race, Ethnicity, Language, and Disability (REALD)** offers a validated tool for collecting demographic information on race, ethnicity, language, and disability.

Notable race & ethnicity questions from REALD:

- Question 1: an open-ended question encourages respondents to identify in the way they choose without the **limitations** of predetermined categories.
- Question 2: respondents are asked to select their racial and ethnic identities from **34 options**. Another write-in option is available here to self-describe race and/or ethnicity. This helps to track emergent populations.

Pro: Inclusive tool; REALD answer options mapped to NIH categories

Balance: May take longer to answer; privacy concerns with small samples

McGee, M.G. (2020). Race, ethnicity, language and disability (REALD) implementation guide. Portland, Oregon: Oregon Health Authority, Equity and Inclusion Division.
https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le7721a.pdf
Mapping to NIH categories via START (https://sites.google.com/view/startstem/measures/demographics/race-ethnicity)

Disability

(Health and Service Differences)

Why does it matter?

Image by Gerd Altmann from Pixabay

Disabilities may be seen or unseen by others and may seriously impact an individual's quality of life.

Individuals with disabilities may experience discrimination and challenges living in a society not built for them, which impacts health and function.

McGee, M.G. (2020). Race, ethnicity, language and disability (REALD) implementation guide. Portland, Oregon: Oregon Health Authority, Equity and Inclusion Division. https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le7721a.pdf

Disability (Health and Service Differences)

Disability data collection helps to identify health and service differences to eliminate preventable social and health inequities.

Prompt for Participants:

“Your answers will help us find health and service differences among people with and without functional difficulties. Your answers are confidential.”

2-10 questions about hearing, vision, movement, communication, daily living, cognition, and mental health.

Pros: Inclusive tool; REALD answer options could be upcoded to NIH disability definitions; provides important information about how to provide accommodations to participants.

Balance: Takes longer to answer

McGee, M.G. (2020). Race, ethnicity, language and disability (REALD) implementation guide. Portland, Oregon: Oregon Health Authority, Equity and Inclusion Division. https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le7721a.pdf

Disadvantaged Background

Why does it matter?

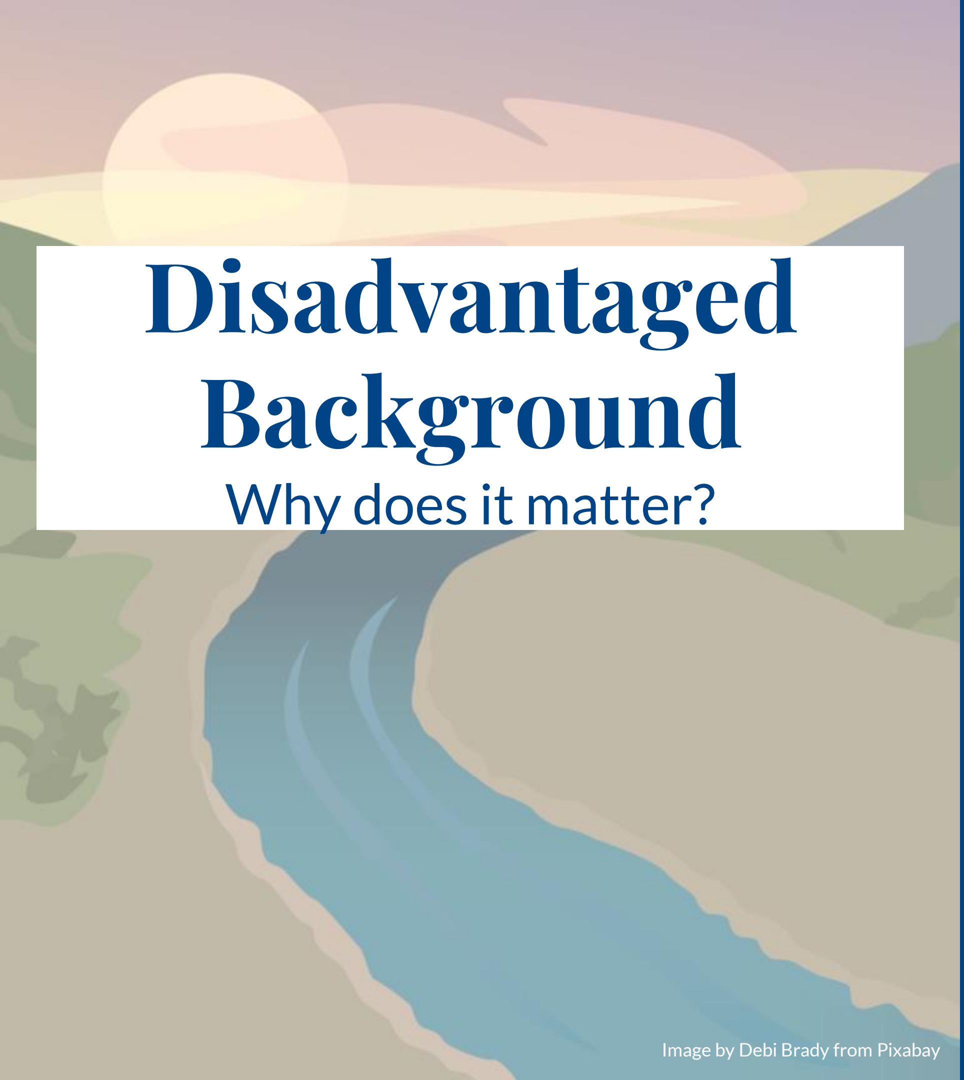


Image by Debi Brady from Pixabay

Disadvantaged background often describes socioeconomic or environmental conditions that impact access to education or training environments.

Disadvantaged background definitions have evolved over time.

NOT-OD-20-031: Notice of NIH's Interest in Diversity. (2019, November 17). National Institutes of Health. https://grants.nih.gov/grants/guide/notice-files/NOT-OD-20-031.html

Disadvantaged Background

NIH issued definitions in 2018 and changed them in 2019 (NOT-OD-20-031). NIH measures relate to socioeconomics and class.

- Experienced past or present homelessness
- Previously or presently in the foster care system
- Eligible for the Federal Free and Reduced Lunch Program for 2+ years
- First generation college students*
- Eligible for Federal Pell grants
- Received WIC as a parent or child
- Grew up in a rural area: either HRSA* or HPSA* locations (low-income and health professional shortage area)

*Eligibility underreported by students when verified

Pros: Definitions and general conditions are described. Suggested wording via START

Balance: No clearly defined approach. Students underreport their eligibility when verified (Marriott et al., 2022). Some backgrounds are missing (e.g. immigrants, refugees).

NOT-OD-20-031: Notice of NIH's Interest in Diversity. (2019, November 17). National Institutes of Health. https://grants.nih.gov/grants/guide/notice-files/NOT-OD-20-031.html

Marriott, L.K., Shugerman, S.R., Chavez, A., Crocker Daniel, L., Martinez, A., Zebroski, D.J., Mishalanie, S., Zell, A., Dest, A., Pozhidayeva, D., Wenzel, E.S., Omotoy, H.L., Druker, B.J., Shannon, J. (2022, in press). Knight Scholars Program: A tiered three-year mentored training program for urban and rural high school high school students increases interest and self-efficacy in interprofessional cancer research. Accepted to the Journal of STEM Outreach.

START Disadvantaged Background: https://sites.google.com/view/startstem/measures/demographics/expanded-demographics?authuser=0#h.o2rftxyshteq

Marr, Mollie (2021). Personal communication.

Sex & Gender

Why does it matter?

Conflating sex and gender in research practices excludes entire populations whose physical characteristics and/or identities do not fit within the constraints of male/female.

The erasure of sex and gender minority groups makes it impossible to provide services and accurate data for these populations.

Measuring sex and gender as independent variables allows researchers to collect more accurate data.

Hart, C. G., Saperstein, A., Magliozzi, D., & Westbrook, L.. (2019). Gender and Health: Beyond Binary Categorical Measurement. Journal of Health and Social Behavior, 60(1), 101–118. https://doi.org/10.1177/0022146519825749

Sex & Gender

Open-ended prompts are most supportive of gender and sex diversities and can be qualitatively coded. If coding an open-ended prompt is not possible (i.e., large studies), we suggest using the two question approach from Morrison, Dinno, & Salmon (2021).

What is your **gender identity**? (select all that apply):	Are you **transgender**?
- Feminine/Woman/Girl - Masculine/Man/Boy - Nonbinary/Genderqueer/Third Gender - Agender/Non-gender - Questioning - Prefer to self-describe:_______ - Prefer not to answer	- Yes - No - Questioning - Prefer not to answer

Morrison, T., Dinno, A., Salmon, T. (2021). The Erasure of Intersex, Transgender, Nonbinary, and Agender Experiences Through Misuse of Sex and Gender in Health Research, American Journal of Epidemiology, kwab221, https://doi.org/10.1093/aje/kwab221

Sexual Orientation

Why does it matter?

Image by Gordon Johnson from Pixabay

Sexual orientation exists on a spectrum and is independent from gender identity. The two are often conflated in research studies.

Measuring sexual orientation separately from gender and sex provides more accurate representation of populations.

Suen, L. W., et al., (2020). What Sexual and Gender Minority People Want Researchers to Know About Sexual Orientation and Gender Identity Questions: A Qualitative Study. Archives of Sexual Behavior, 49(7), 2301–2318. https://doi.org/10.1007/s10508-020-01810-y

Sexual Orientation

Sexual orientation is not included among NIH definitions of underrepresentation. Many training programs do not ask about sexual orientation, but research shows these populations face significant health disparities and discrimination.

Regardless of your sexual experience, how do you identify your sexual orientation? (select ALL that apply)

†Straight or heterosexual
†Gay or lesbian or homosexual
†Bisexual
†Pansexual
†Asexual
†Queer
†Fluid
†Questioning/unsure
†Prefer to self-describe: ______
†Prefer not to say

(A table containing sexual orientation definitions should be provided; example found on START website)

Diamant et al.(2000) http://dx.doi.org/10.1001/archfami.9.10.1043, Katz-Wise et al. (2016), https://doi.org/10.1080/00224499.2014.1003028, & Suen et al. (2020), https://doi.org/10.1007/s10508-020-01810-y.

Conclusion

Big Picture

Image by Gordon Johnson from Pixabay

1) Research definitions of **diversity evolve**, reflecting the process of science. There are still populations that are being excluded, marginalized, or improperly aggregated. Look for them. Include them. Advance science.

2) **Flexibility** in demographic data collection is needed (e.g., due to time burden, participate age, funder requirements, program reach, etc.). Consider ways to be more inclusive in your data collection approach.

3) Be **kind** to yourself and others as we all learn to do better. This is the process of science.

Resources & References

Diamant, A. L., Wold, C., Spritzer, K., & Gelberg, L. (2000). Health behaviors, health status, and access to and use of health care: A population-based study of lesbian, bisexual, and heterosexual women. Archives of Family Medicine, 9(10), 1043–1051. http://dx.doi.org/10.1001/archfami.9.10.1043.

Hart, C. G., Saperstein, A., Magliozzi, D., & Westbrook, L.. (2019). Gender and Health: Beyond Binary Categorical Measurement. Journal of Health and Social Behavior, 60(1), 101–118. https://doi.org/10.1177/0022146519825749.

Katz-Wise, S. L., Reisner, S. L., Hughto, J. W., & Keo-Meier, C. L. (2016). Differences in sexual orientation diversity and sexual fluidity in attractions among gender minority adults in Massachusetts. Journal of Sex Research, 53, 74–84. https://doi.org/10.1080/00224499.2014.1003028.

McGee, M.G. (2020). Race, ethnicity, language and disability (REALD) implementation guide. Portland, Oregon: Oregon Health Authority, Equity and Inclusion Division. https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le7721a.pdf

Morrison, T., Dinno, A., Salmon, T. (2021). The Erasure of Intersex, Transgender, Nonbinary, and Agender Experiences Through Misuse of Sex and Gender in Health Research, American Journal of Epidemiology, kwab221, https://doi.org/10.1093/aje/kwab221

NOT-OD-20-031: Notice of NIH's Interest in Diversity. (2019, November 17). National Institutes of Health. https://grants.nih.gov/grants/guide/notice-files/NOT-OD-20-031.html.

START (2021). START: STEM Assessment and Reporting Tracker. Retrieved from https://sites.google.com/view/startstem

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Thank you for joining us today!

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Contribute to Science

The audience today is helping build out **FAQs**. Interested in more? Stay involved with us.

https://ohsu.ca1.qualtrics.com/jfe/form/SV_aXypCXkEs4Ejwy2