The Data Dilemma: Best practices for collecting demographic and language data across the pediatric life-course

Yarden S. Fraiman MD, MPH
Jessica Addison MD, MPH
No Disclosures

Learning Objectives

Develop

Develop a shared understanding of (a) race as a social construct and (b) identity formation across the pediatric life-course

Discuss

Discuss best practices for collecting demographic and language information across the life-course

Identify

Identify common obstacles in collecting demographic and language data, and discuss strategies for overcoming these challenges.

We acknowledge...

We acknowledge that Boston Children's Hospital sits on the original homelands of the Wampanoag, Nipmuc and the Massachuset nations. We acknowledge them as the original stewards of this land and recognize their absence as a result of their forced removal and ethnocide.

Furthermore, as the heirs to that legacy, we recognize our important collective role in reckoning with the past and promoting and securing justice for the future.

We acknowledge…

I acknowledge my own personal identity white, Latino, first-generation American, Jewish, gay, cis-gendered, and male and acknowledge that my identity informs my work, my lens, and my own biases.

I acknowledge my own personal identity as Haitian American, heterosexual, cis-gendered, and female, and recognize that these aspects of who I am influence the lens through which I engage in my work, the perspectives I bring, and the biases I must remain mindful of.

The ABC’s

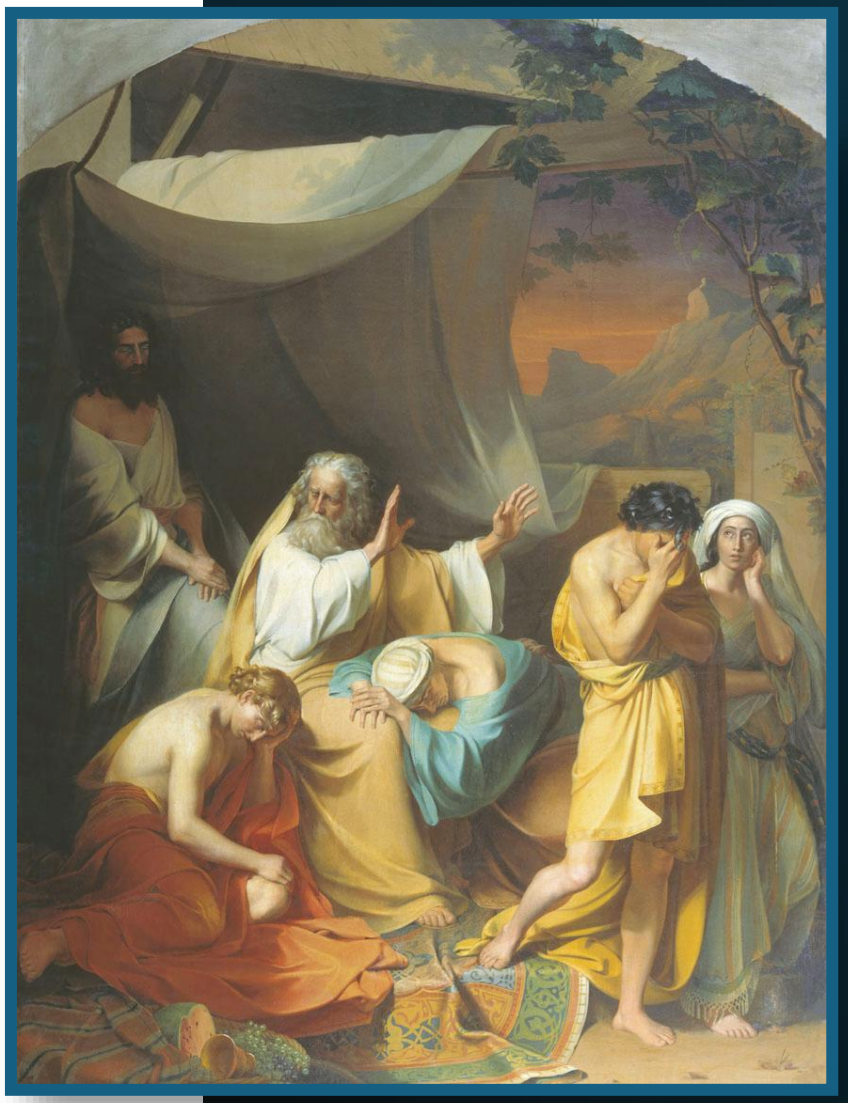
Assume best intentions

Brave space

Conversation not a lecture

Race as a social construct

- Race emerges in the 16th to 17th century as a result of European explorers arriving in the ”New World”



Race as a social construct

- Race emerges in the 16th to 17th century as a result of European explorers arriving in the ”New World”
- Racial categorizations evolve over time

1790—Free White Males; Free White Females; All Other Free Persons; Slaves
1800—Free White Males; Free White Females; All Other Free Persons, except Indians Not Taxed; Slaves
1810—Free White Males; Free White Females; All Other Free Persons; except Indians Not Taxed; Slaves
1820—Free White Males; Free White Females; Free Colored Persons, All other persons, except Indians Not Taxed; Slaves
1830—Free White Persons; Free Colored Persons; Slaves
1840—Free White Persons; Free Colored Persons; Slaves
1850—Black; Mulatto[a]
1860—Black; Mulatto; (Indian)[b]
1880—White; Black; Mulatto; Chinese; Indian
1890—White; Black; Mulatto; Quadroon; Octoroon; Chinese; Japanese; Indian
1900—White; Black; Chinese; Japanese; Indian
1910—White; Black; Mulatto; Chinese; Japanese; Indian; Other (+ write in)
1920—White; Black; Mulatto; Indian; Chinese; Japanese; Filipino; Hindu; Korean; Other (+ write in)
1930—White; Negro; Mexican; Indian; Chinese; Japanese; Filipino; Hindu; Korean; (Other races, spell out in full)
1940—White; Negro; Indian; Chinese; Japanese; Filipino; Hindu; Korean; (Other races, spell out in full)
1950—White; Negro; Indian; Japanese; Chinese; Filipino; (Other race—spell out)
1960—White; Negro; American Indian; Japanese; Chinese; Filipino; Hawaiian;
Part-Hawaiian; Aleut Eskimo, etc
; Filipino; Hawaiian;
Vietnamese; American
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or Alaska Native; Asian
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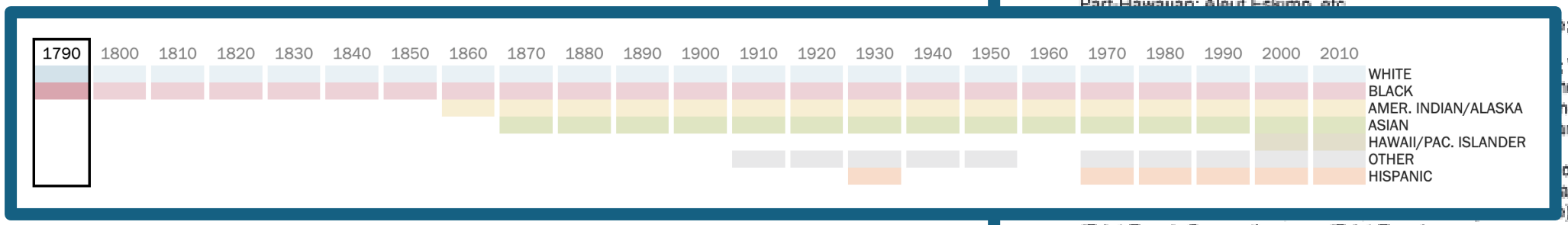
); Other Pacific Islander
(Print Race); Some other race (Print Race)



Race as a social construct

- **Race emerges in the 16th to 17th century as a result of European explorers arriving in the ”New World”**
- **Racial categorizations evolve over time**
- **Race is a political classification system**

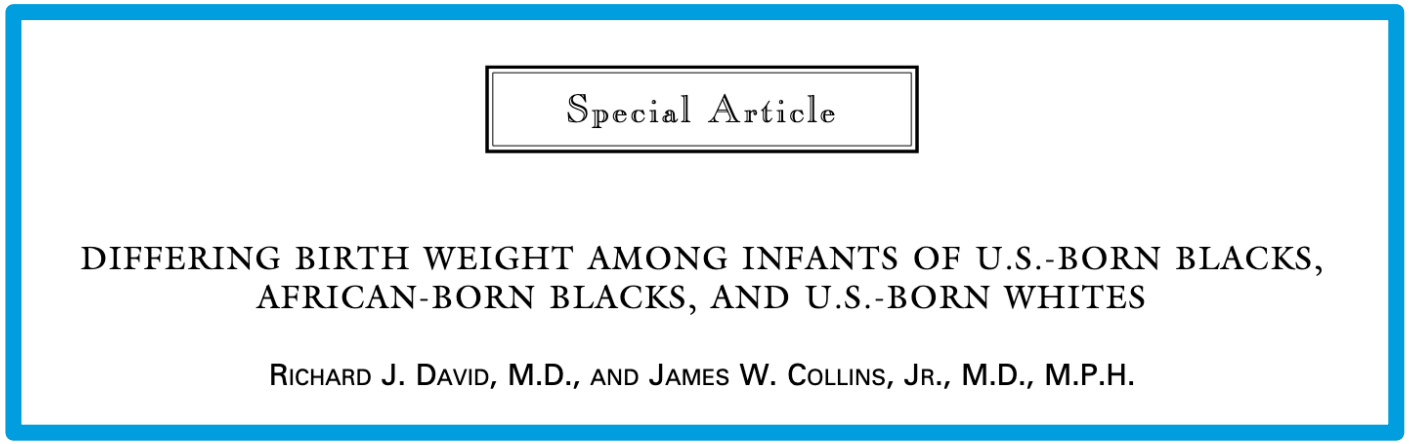
<u>Citizenship and Race</u>

Ozawa v. United States of America (1922)

Thind v. United States of America (1923)

Race as a social construct

- Race emerges in the 16th to 17th century as a result of European explorers arriving in the ”New World”
- Racial categorizations evolve over time
- Race is a political classification system
- Race is <u>not</u> biologic or genetic



Special Article

DIFFERING BIRTH WEIGHT AMONG INFANTS OF U.S.-BORN BLACKS, AFRICAN-BORN BLACKS, AND U.S.-BORN WHITES

RICHARD J. DAVID, M.D., AND JAMES W. COLLINS, JR., M.D., M.P.H.

Race as a social cons

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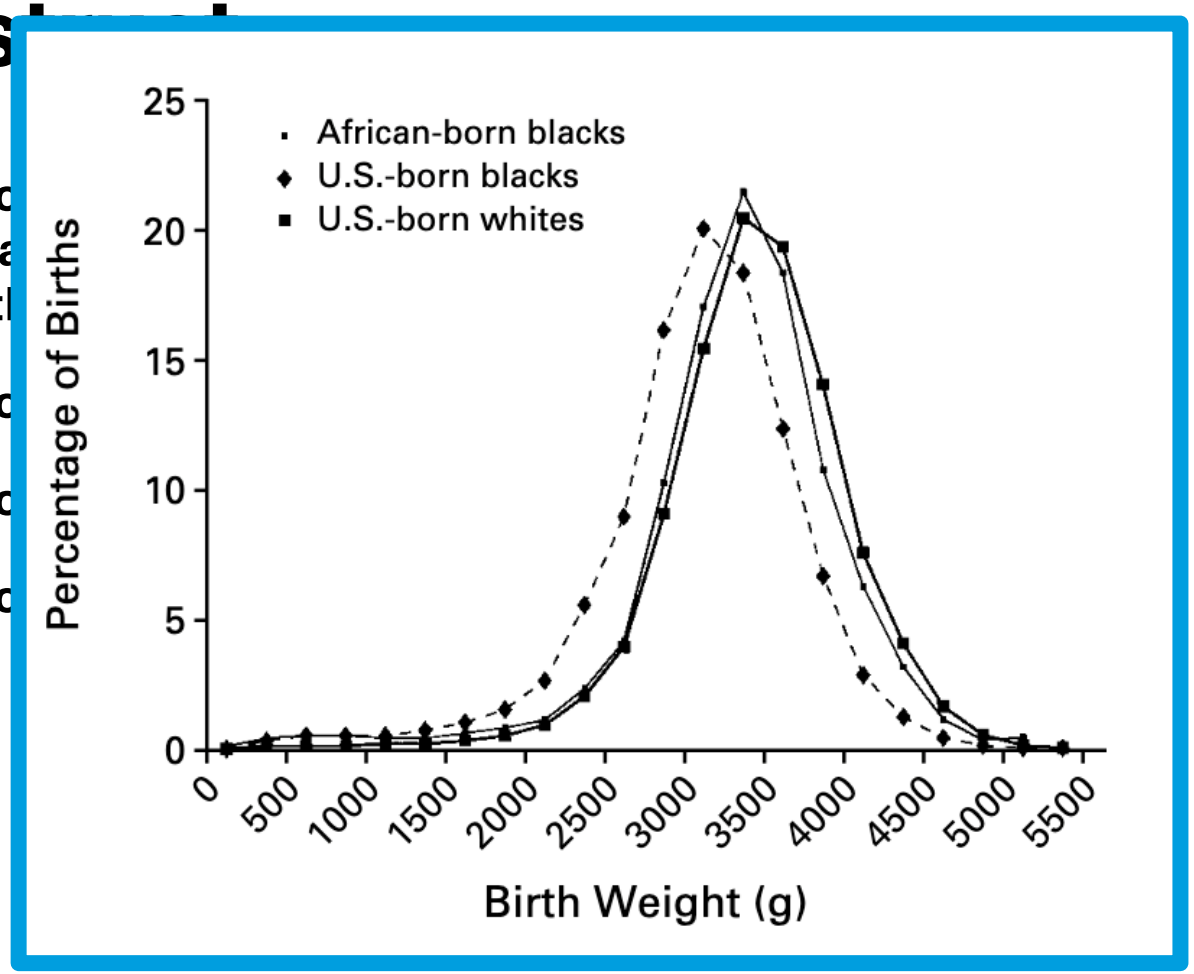

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Race as a social construct

- Race emerges in the 16th to 17th century as a result of European explorers arriving in the ”New World”
- Racial categorizations evolve over time
- Race is a political classification system
- Race is not biologic or genetic
- Race is not a surrogate for social factors such as socioeconomic status or education

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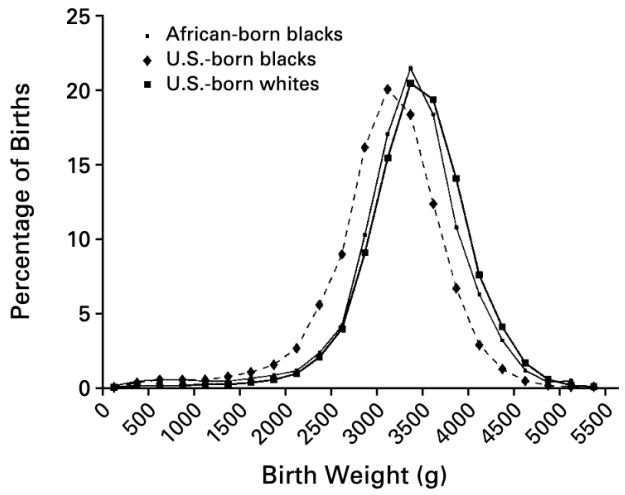

"Race is a social, not biologic category, referring to social groups, often sharing cultural heritage and ancestry, that are forged by oppressive systems of race relations, justified by ideology, in which one group benefits from dominating other groups."

"[Race leads to the] enforced marginalization [of people] from positions of power, coupled with assumption that white, economically-secure men are allegedly the norm."

- *Krieger, Soc. Sci. Med, 1994*
- *Krieger, J. Epi Com Health, 2001*

Why is it important to collect accurate demographic and primary language data?

- Understand the needs of the population
- Effectively managing the health care of patients
- Accurate information on patients' race, ethnicity, and language is essential to ensure the adequacy services and resources offered.

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•What obstacles have you encountered related to REaL (Race, Ethnicity, and Language) data collection ?

All responses to your question will be shown here

Each response can be up to 200 characters long

Turn on voting to let participants vote for their favorites

JA

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My first word cloud

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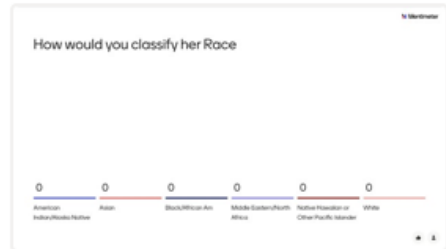

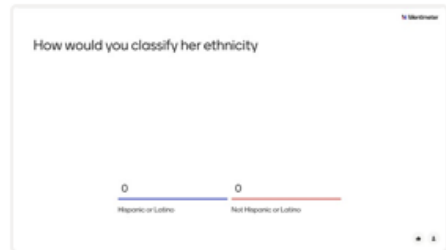

Common obstacles

- Lack of Trust
- Language Barriers
- Discomfort asking personal questions
- Lack of training or scripts
- Time constraints
- Conflicting info between teen and parent
- Limited EHR flexibility

- *Regenstein, M. et al. (2014). Collecting socio-demographic data in health care: a review of tools. The Milbank Quarterly.*

Best Practices for collecting data-systems

- **Standardized Collection:** Use clear, standardized scripts for staff
- **Clear Explanation:** Provide a rationale for why the data is being collected
- **Open-Ended Options: A**llow patients to describe their race and ethnicity in their own words
- **Integration with EHRs:** Integrate REL data into existing electronic health records (EHRs)
- **Monitoring and Improvement:** Use the collected data to monitor for disparities in care

- *Hasnain-Wynia, R. et al. (2011). Collecting and Using Race, Ethnicity and Language Data in Health Care. Robert Wood JohnsonFoundation.*

Best practices for collecting data-patients

- **Use Standardized and Inclusive Measures for Race and Ethnicity**
  - Gold Standard: Self-identified
- **Patient Trust**
  - Assure patients that their data will be kept confidential
- **Collect Language Data for Both Child and Caregivers**
  - Identify preferred spoken and written languages for both the child (age-appropriate) and caregivers.
- **Tailor Demographic Questions to Developmental Stage**
  - Data collection should reflect the child's developmental stage (e.g., proxy reporting by parents for infants vs. self-reporting by adolescents).
- **Ensure Cultural and Linguistic Validity in Tools and Procedures**
  - Use validated translations and back-translations of instruments.

- NIH. (2023). *NIH Policy and Guidelines on The Inclusion of Individuals Across the Lifespan as Participants in Research Involving Human Subjects*.
- Flores, G. (2005). The impact of medical interpreter services on the quality of health care: A systematic review. *Medical Care Research and Review, 62*(3), 255–299.
- Barrera, M., & Castro, F. G. (2006). A heuristic framework for the cultural adaptation of interventions. *Clinical Psychology: Science and Practice, 13*(4), 311–316.

Case Discussions: Collecting data across the pediatric life-course

Neonatal Case Vignette

- **You are responsible for entering demographic information in the Newborn Nursery**
- **The mother of a newborn baby is Black according to her medical record**
- **The father of the baby presents as white and speaks Spanish, but you don't have access to his medical record.**

The Neonatal Dilemma

Infants can't self-report their race or ethnicity

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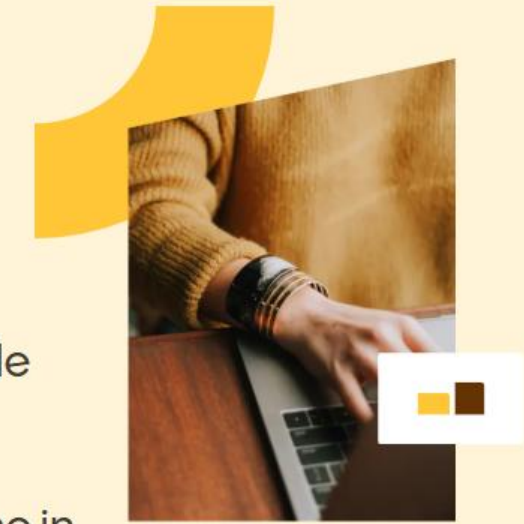

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The Neonatal Dilemma

Infants can't self-report their race or ethnicity

Why does this matter?

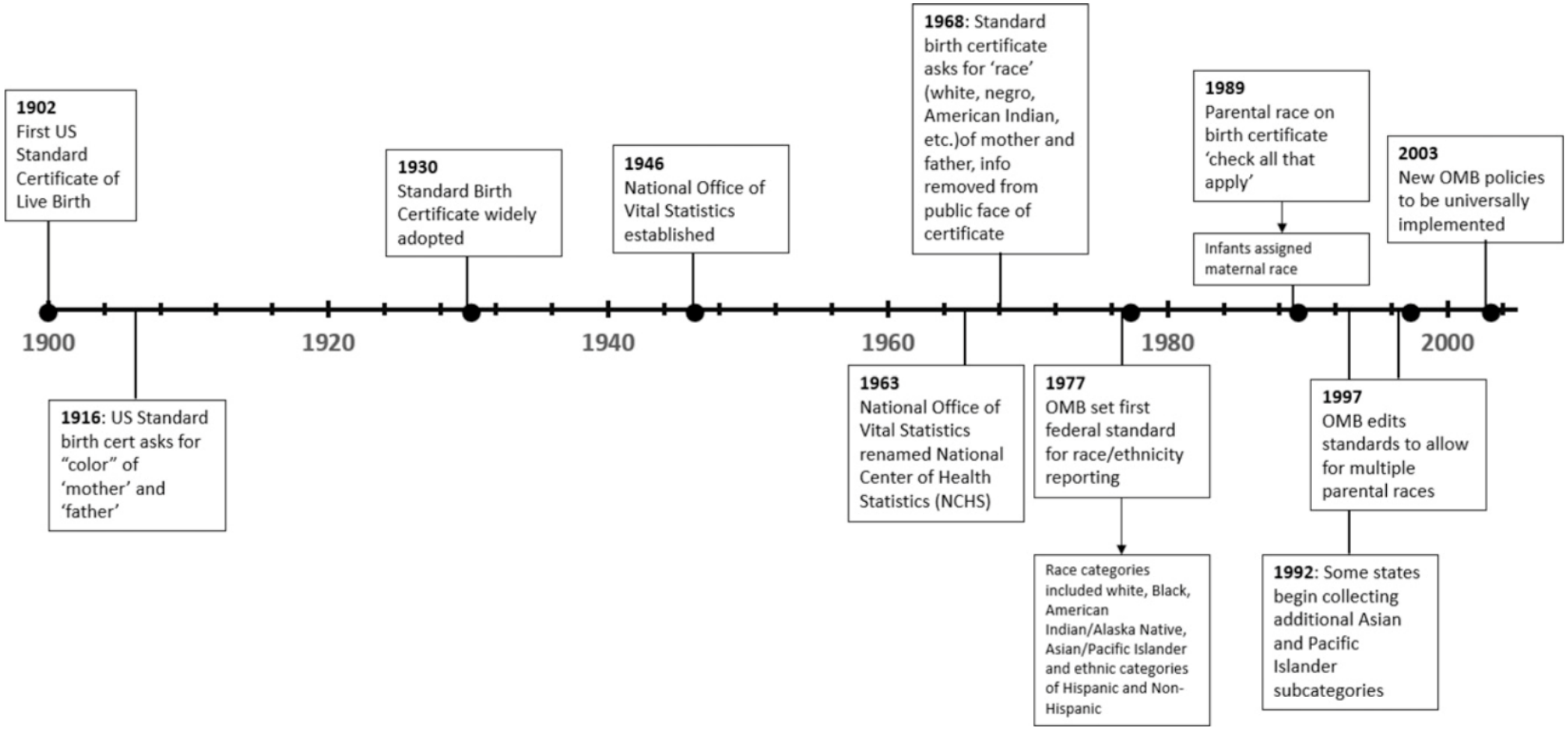
- Gold standard is the race and ethnicity of the birth parent

What this means?

- Limited role for non-birthing parent caregiver identity
- Contributes to the biologic fallacy of race
- Excludes nontraditional families

Standard of Care for Neonatal Demographic Information

- Race and ethnicity is typically defined as the birth parent's race and ethnicity
- Data is often used from birth certificate data



Defining an Infant's Race and Ethnicity: A Systematic Review

Blair W. Weikel, MPH,[a] Susanne Klawetter, PhD, LCSW,[b] Stephanie L. Bourque, MD, MSCS,[a] Kathleen E. Hannan, MD, MSCS,[a] Kristi Roybal, PhD, MSW, MA,[c] Modi Soondarotok, MSW, CSWA,[b] Marie St. Pierre, MLS,[d] Yarden S. Fraiman, MD, MPH,[e] Sunah S. Hwang, MD, MPH, PhD[a]

Standard of Care for Neonatal Demographic Information

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Neonatal Case Vignette

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What do you enter in the medical record for the race/ethnicity of the baby?

What would you do?

- You are designing the system in place for the Newborn Service at your hospital
- You have access to the birthing person's medical record
- You have access to the birth certificate
- When designing your system consider:
  - Traditional families with race and ethnicity that are different
  - Families that used donor egg/donor sperm
  - Families that use of gestational carriers

Adolescent Case

Maya presents to clinic with her mother to a participate in a research study.

Maya speaks Spanish and English. She has been to this clinic multiple times

- Intake form lists her race as “Hispanic.” (gathered from EHR)
- During the visit, Maya says, “I’m Afro-Latina.”

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How would you document Maya's identity?...these are the options in your HER

White- non Hispanic

Hispanic

African American- non Hispanic

Other

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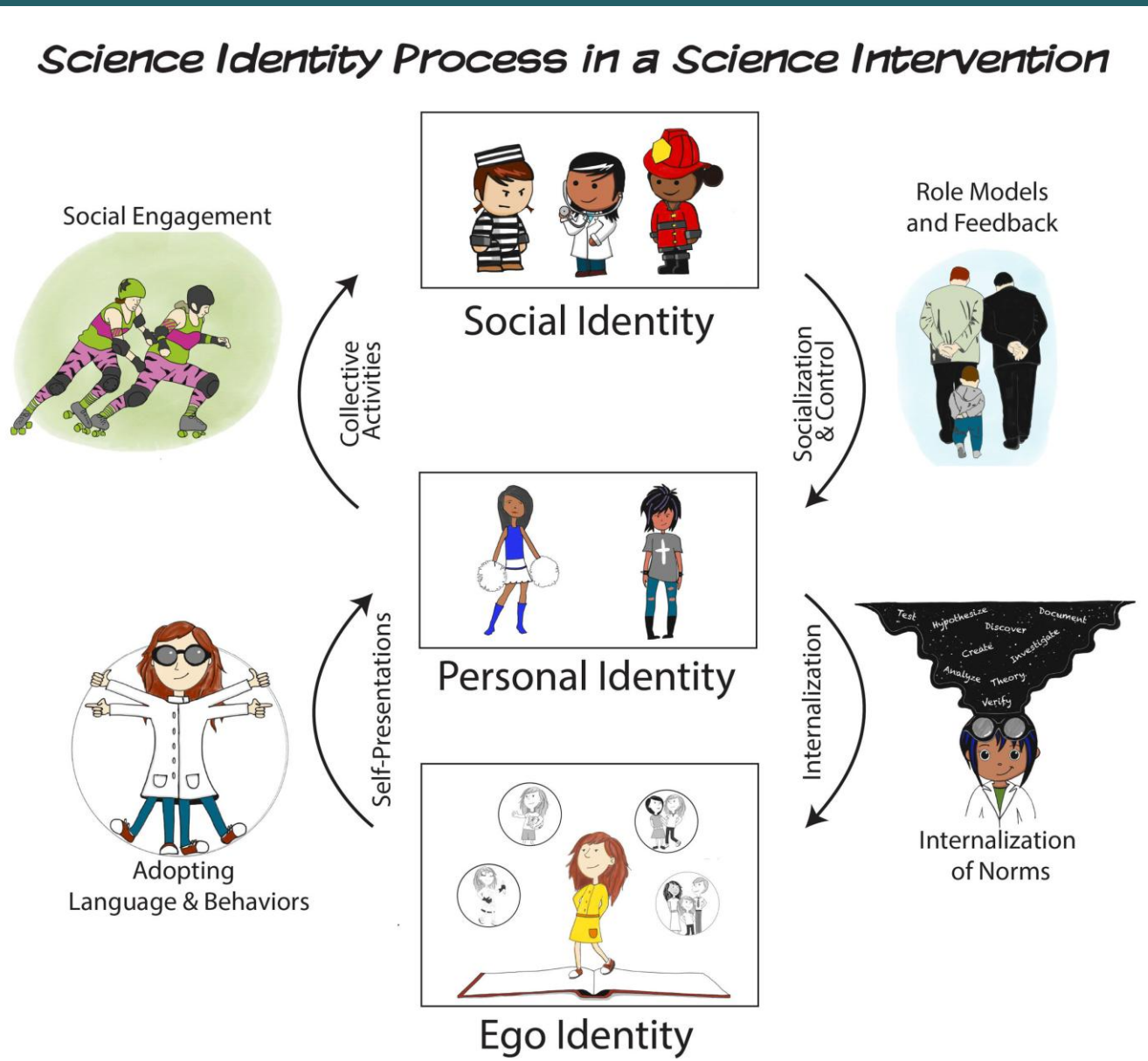
The Dilemma: Adolescence



The Dilemma- Adolescent

- Identity Development and Fluidity
- Response Bias and Social Desirability
- Confidentiality
- Self-reported vs. Observer-assigned demographic data
- Conflating Race and Ethnicity
- Incorrect Aggregation

- *Rodriguez-Lainz A, McDonald M, Fonseca-Ford M, Penman-Aguilar A, Waterman SH, Truman BI, Cetron MS, Richards CL. Collection of Dataon Race, Ethnicity, Language, and Nativity by US Public Health Surveillance and Monitoring Systems: Gaps and Opportunities. PublicHealth Rep. 2018 Jan/Feb;133(1):45-54. doi: 10.1177/0033354917745503. Epub 2017 Dec 20. PMID: 29262290; PMCID: PMC580510*

The Dilemma is Widespread

JAMA Netw Open. 2024 Sep 3;7(9):e2431073. doi: 10.1001/jamanetworkopen.2024.31073

Error Rates in Race and Ethnicity Designation Across Large Pediatric Health Systems

Gary L Freed [1,2,✉], Brittany Bogan [3], Adam Nicholson [4], Deborah Niedbala [5], Susan Woolford [1,2]

Author information · Article notes · Copyright and License information

PMCID: PMC11372483 PMID: 39226057

Techniques for engaging adolescents and young adults

- **Interactive Tools**:
  - Implement digital tools like apps and online surveys that appeal to them
- **Peer Support**:
  - Engage peer educators to facilitate discussions and data collection.
  - Create peer-led focus groups.
- **Environment**:
  - Create a safe, non-judgmental space for data collection.
  - Turni not pair share

Strategies to overcome barriers- systems

Patient-centered approach: Ask and document self-ID

EHR optimization: Separate race & ethnicity, allow multiple selections

Staff training: Cultural humility & validation

Inclusive documentation: Note form data + patient's words

Policy change: Update demographic collection standards

How does this apply to research?

You are an RA, you forgot to classify a patients race and ethnicity. This data is due in one hour. You decide to enter the data based on the picture you have of her below. How would you classify

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How would you classify her Race

0	0	0	0	0	0
American Indian/Alaska Native	Asian	Black/African Am	Middle Eastern/North Africa	Native Hawaiian or Other Pacific Islander	White

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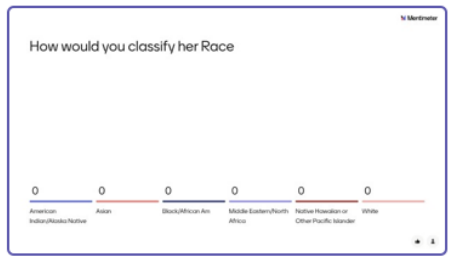
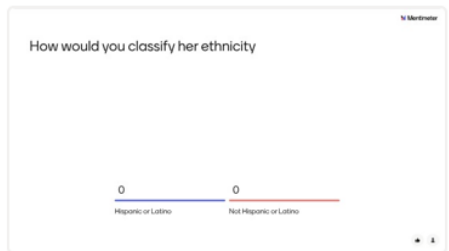
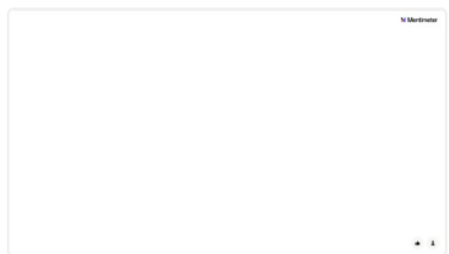
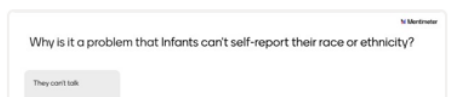
My first word cloud









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How would you classify her ethnicity?

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Hispanic or Latino	Not Hispanic or Latino

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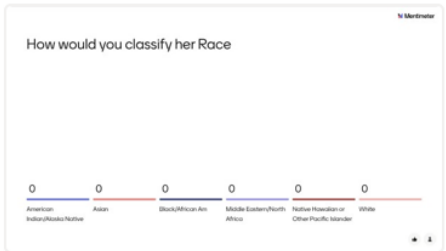
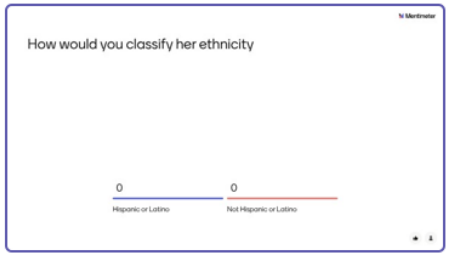




Physician–patient racial concordance and disparities in birthing mortality for newborns

Brad N. Greenwood[a,1,2], Rachel R. Hardeman[b,1], Laura Huang[c,1], and Aaron Sojourner[d,1]

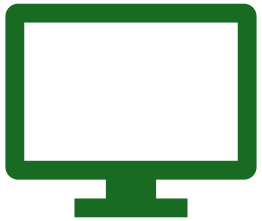
[a]School of Business, George Mason University, Fairfax, VA 22030; [b]School of Public Health, University of Minnesota–Twin Cities, Minneapolis, MN 55455; [c]Harvard Business School, Harvard University, Boston, MA 02163; and [d]Carlson School of Management, University of Minnesota–Twin Cities, Minneapolis, MN 55455

bidities, outcomes, the hospital where they are treated, and more. We also receive access to information about the attending physician in charge of the patient's care, e.g., name, specialty certifications, and date of licensure. Physician race is not coded by the data and is captured from publicly searchable pictures of the physician. Newborn arrival is directly coded by the AHCA and is defined as "a baby born within the facility or the initial admission of an extramural birth infant to an acute care facility within 24 h of birth." To ease interpretation, all newborns not White or Black, and all physicians not coded as White or Black, are dropped from the sample, isolating our examination to strictly White and Black patients and physicians. A discussion of

certifications, and date of licensure. Physician race is not coded by the data and is captured from publicly searchable pictures of the physician. Newborn arrival is directly coded by the AHCA

Questions to ask when doing your research

Why do I need this information?



How will I use this information?

Have I partnered with patients and families about the best ways to collect this information?

An Ethics and Social Justice Approach to Collecting and Using Demographic Data for Psychological Researchers

Christine C Call [1], Kristen L Eckstrand [1], Steven W Kasparek [2], Cassandra L Boness [3], Lorraine Blatt [4], Nabila Jamal-Orozco [4], Derek M Novacek [5], Dan Foti [6]; Scholars for Elevating Equity and Diversity (SEED)

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PMCID: PMC10235209 NIHMSID: NIHMS1844296 PMID: 36459692

Issue	Ethical/Social Justice Concern	Framework Response
Oversimplified categorization	Invalidates complex and intersectional identities	Offer inclusive, self-descriptive options
Exclusion of minoritized groups	Reduces representation and access to research benefits	Center community input and participation
Harmful interpretation	Can reinforce stereotypes or misdirect interventions	Engage stakeholders across the research ecosystem
Passive or tokenistic data use	Research benefits may not reach those represented	Design for transformation and participant empowerment

THANK YOU