



RAISE

REAL-WORLD ACCELERATOR TO IMPROVE THE STANDARD OF COLLECTION AND CURATION OF RACE AND ETHNICITY DATA IN HEALTHCARE

The public meeting will begin shortly

This project is supported by the Food and Drug Administration (FDA) Office of Minority Health and Health Equity of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award (FAIN) totaling \$499,514 (100% funded by FDA OMHHE/HHS). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by FDA/HHS, or the U.S. Government.





REAL-WORLD ACCELERATOR TO IMPROVE THE STANDARD OF COLLECTION
AND CURATION OF RACE AND ETHNICITY DATA IN HEALTHCARE



Welcome!

Susan C. Winckler, RPh, Esq.

CEO

Reagan-Udall Foundation for the FDA



Thank you for joining us today!



Your microphone and video will remain off during the workshop.



This workshop is being recorded. The recording, slides and summary will be available on the FDA Foundation website.



If you'd like to ask a question, please enter it in the Zoom Q&A. We will get to as many questions as time allows.



Speakers will not address questions regarding any pending regulatory action nor discuss specific companies or medical products by name.

Thank you for
 joining us for
 the RAISE
 Workshop
 series!

February 2023

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
			1	2 2-3 PM ET	3	4
5	6	7	8	9	10	11
12	13	14	15	16 2-3 PM ET	17	18
19	20	21	22	23	24	25
26	27	28				

March 2023

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
			1	2 2-3 PM ET	3	4
5	6	7	8	9	10	11
12	13	14	15	16 2-3 PM ET	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

April 2023

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
						1
2	3	4	5	6 2-3 PM ET	7	8
9	10	11	12	13	14	15
16	17	18	19	20 2-3 PM ET	21	22
23	24	25	26	27	28	29

May 2023

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	1	2	3	4 2-3 PM ET	5	6
7	8	9	10	11	12	13
14	15	16	17	18 2-3 PM ET	19	20
21	22	23	24	25	26	27
28	29	30	31			

June 2023

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
				1 2-3 PM ET	2	3
4	5	6	7	8	9	10
11	12	13	14	15 2-4 PM ET	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	



Agenda

- 2:00 PM** Welcome and Introduction
- 2:05 PM** Barrier-Facilitator-Solution Triads: A Roadmap to Address Missing/Misclassified Race & Ethnicity Data in Health Care
- 2:30 PM** Panel 1: Considerations for Roadmap Implementation
- 3:05 PM** Panel 2: Potential Impact of Roadmap to Advance Community-Driven Data Governance and Inclusivity in Medical Product Development & Safety
- 3:40 PM** Closing Remarks: Takeaways & A Call to Action
- 4:00 PM** Adjourn



REAL-WORLD ACCELERATOR TO IMPROVE THE STANDARD OF COLLECTION
AND CURATION OF RACE AND ETHNICITY DATA IN HEALTHCARE



Opening Remarks

RDML Richardae Araojo, PharmD, MS
Associate Commissioner for Minority Health
Director, Office of Minority Health and Health Equity
U.S. Food and Drug Administration



REAL-WORLD ACCELERATOR TO IMPROVE THE STANDARD OF COLLECTION
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Barrier-Facilitator-Solution Triads: A Roadmap to Address Missing/Misclassified Race & Ethnicity Data in Health Care

Alecia Clary, PhD, MSW
Founder and President, Evidence to Practice
Co-Investigator, RAISE



REAL-WORLD ACCELERATOR TO IMPROVE THE STANDARD OF COLLECTION
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The RAISE Roadmap

A Roadmap towards the Complete and Accurate Collection of Race and Ethnicity
Data

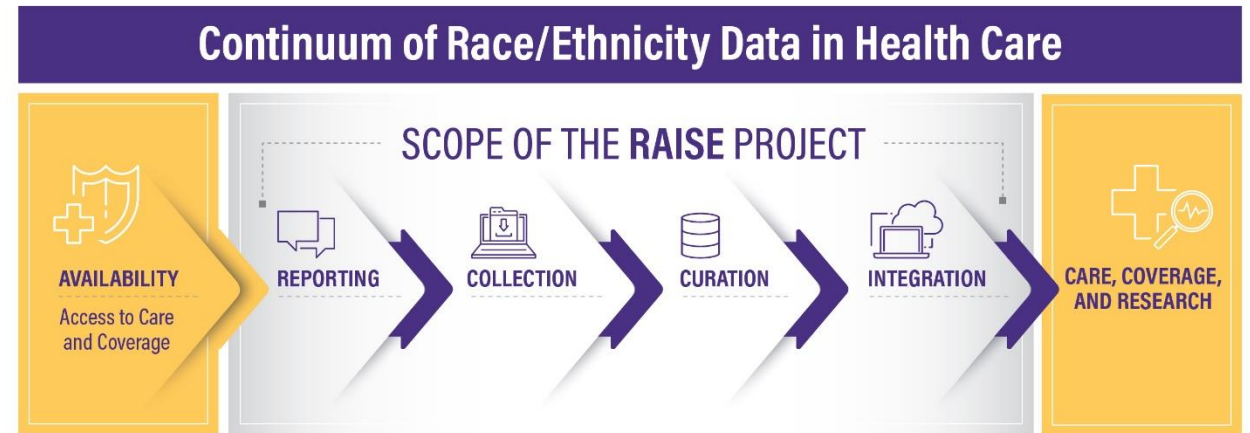
Alecia Clary, PhD, MSW
Evidence to Practice
June 15, 2023



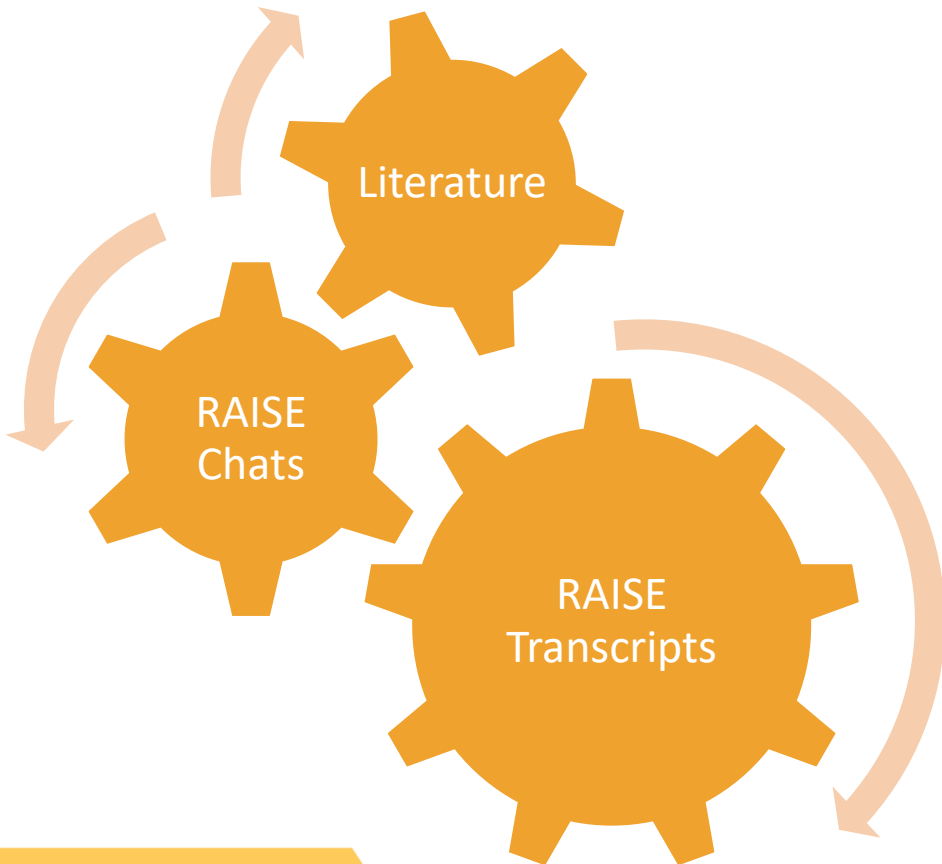
This project is supported by the Food and Drug Administration (FDA) Office of Minority Health and Health Equity of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award (FAIN) totaling \$499,514 (100% funded by FDA OMHHE/HHS). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by FDA/HHS, or the U.S. Government.

Race and Ethnicity Data are Incomplete and Inconsistently Collected in Clinical Datasets

This poses a significant limitation to our ability to understand the distribution, safety, and effectiveness of FDA-regulated products in the population.



Methods



- Data collected from RAISE (transcripts and chats) and the literature
- Inductive approach to coding RAISE materials
- Barriers identified via template analysis
- Summarized themes, organizing them in a logical manner
- Solutions and facilitators similarly identified, via coded transcripts and the literature
- The RAISE community identified a specific set of actionable facilitators
- ★ The RAISE community will help quantify the costs and impact of acting on each facilitator



Barrier

Obstacle that prevents collection and management of race and ethnicity data.



(Potential) Facilitators

Circumstances that allow for material means to aid in overcoming obstacles preventing the collection and management of race and ethnicity data.



(Potential) Solutions

Material means that aid in overcoming obstacles preventing the collection and management of race and ethnicity data

Standardize Data
Collection

2

1

Incentivize
Data
Collection

The Roadmap

Specific steps towards more complete
and accurate collection and
management of race and ethnicity
data

3

Collect Data Locally *then*
Aggregate

4

Conduct
Workforce
Training and
Provide Data
Collection Tools
and Resources

**Misaligned
funding/incentives**

**Solution: Update
existing payment
models and measures
to incentivize the
collection of these
data**

Potential Facilitator

- Incentivize improving health equity

Next Steps

- Make improving health equity a goal
- Define the purpose of updating the payment model or measure
- Convene workgroups to understand the data and opportunities to update or create new payment models/measures
- Update or develop new payment models/measures
- Monitor use of new payment models/measures, identifying opportunities to improve reporting

**Lack of transparency
regarding intended use
of the data**

**Solution: Inform
patients/members and
staff about why these
data are being
requested and how
these data may be
used**

Potential Facilitators

- Use a multi-stakeholder approach to understanding how race and ethnicity data may be used
- Develop resources that describe why patients/members are being asked to provide these data, how the data may be used, the benefits of sharing these data, and who may access these data, incorporating this information into data collection tools and resources

Next Steps

- Acknowledge the risk of bias or harm in reporting these data
- Define “race” to facilitate shared understanding
- Understanding WHY we are collecting the data
- Establish workgroups to develop messaging
- Pilot the messages in the community, collect feedback, and update

Tensions with data options -- simultaneously too few and too many.

**Solution:
Data collection options should align with the local context, but be aggregated, per data standards**

Potential Facilitators

- Leverage a multi-stakeholder approach to developing response options such that they are appropriate for the local community
- Modernize data standards such that more granular categories can be systematically collected and aggregated

Next Steps

- Collect data about options that are currently used and preferred options
- Engage a workgroup to develop a menu of options
- Develop a tool to help organizations systematically prioritize options based on their community. Options should be:
 - *Respectful of people*
 - *Reflective of the local community*
 - *Complementary (not redundant)*
- Update and pilot options in the community, testing approaches to aggregation

Insufficient workforce training

Solution: Develop workforce training and education

Potential Facilitators

- Develop cross-organizational approaches to collecting these data towards establishing a single source of truth, support staff, and leverage best practices to standardize the process
- Develop workshops, trainings, and other materials that can be used to educate staff about the importance of these data, why they are collected, and how they should be collected

Next Steps

- Collect data about existing training and identify training needs
 - Understand the barriers and facilitators to the consistent collection of these data
 - Understand whether the approach collection of these data be made similar to the collection of clinical data
 - Understand where data collection might best fit into existing workflows
- Engage a workgroup to develop learning objectives and design a training curriculum
 - Tailor training to different roles
 - Offer certifications and CEUs
- Evaluate training effectiveness
- Update trainings to ensure they remain relevant

Resource Constraints

Solution:
Optimize language appropriate data collection tools, scripts, decision aids, and other tools

Tools should inform patients/members and staff about why patients/members are being asked to provide these data and how the data might be used

Potential Facilitators

- Assess community needs for language services (including the languages that are needed)
- Use language services to support staff in the collection of these data
- Develop tools that can be used to standardize and routinize the process and the message

Next Steps

- Collect data regarding existing tools
- Engage a workgroup to adapt or develop tools that incorporate intended use of the data, response options, and the workflow
 - Translate into diverse languages
- Test and validate tools
- Train data collectors and users
- Monitor use of the tools

Lack of standardization regarding the collection and reporting of these data

- Insufficient systems for the collection and storage of these data

Solution:

Align information, techniques, and strategies to bridge technical stress points

Build interoperable data systems with adequate granularity

Potential Facilitator

- Create a forum for technical experts to exchange information, develop standards & best practices, and troubleshoot issues related to interoperability of race and ethnicity data, including the potential expansion of existing frameworks (e.g., Fast Healthcare Interoperability Resources and U.S. Core Data for Interoperability)

Next Steps

- Identify technical stress points of current systems
- Establish a clear goal of wanting to improve the collection and management of race and ethnicity data
- Understand existing data standards' and protocols' strengths and limitations
- Refine existing data standards
- Develop mechanisms to map:
 - Between different standards
 - Between previous standards and new/updated standards
- Monitor and evaluate progress

Each of the proposed next steps suggests a need to

- Fund these efforts
- Understand why these data are being collected and how they might be used
- Identify and engage the relevant stakeholders
- Align on specific objectives for workgroups and convenings
- Identify a mechanism to disseminate and increase uptake and adoption of new tools and resources

*This work begins with a **framework of trust** that guarantees that there aren't unintended consequences, harms, or bias*

- Patients and members should be a key stakeholder for each convening
- Data collection is local
- Take the problem to the community who can be a part of the solution
- Disseminate the results to the community

*Enable the community to feel seen, be heard, and be counted. This will generate enthusiasm within the community and **lead to increased and deeper engagement**. Use data that can be shared back with the community so that the community experiences a return of value.*



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Panel Discussion





REAL-WORLD ACCELERATOR TO IMPROVE THE STANDARD OF COLLECTION AND CURATION OF RACE AND ETHNICITY DATA IN HEALTHCARE

Panel 1: Considerations for Roadmap Implementation



Moderator

Carla Rodriguez-Watson, PhD, MPH
RAISE Principal Investigator
Director of Research
Reagan-Udall Foundation for the
FDA



Discussant
Health Care Delivery

Allen Hsiao MD, FAAP, FAMIA
Chief Health Information Officer,
Yale School of Medicine & Yale New
Haven Health



Discussant
Community Participatory Research

Rachele Hendricks-Sturup, DHSc,
MSc, MA
Research Director of Real-World
Evidence (RWE), Duke-Margolis
Center for Health Policy



Discussant
Payor/Health Info Exchange

Lenel James, MBA
Business Lead (Health Information
Exchange & Innovation)
Blue Cross Blue Shield Association

All in National Survey, 2021

*Data Across Sectors for Health, All In: Data for Community Health, National Alliance against Disparities in Patient Health

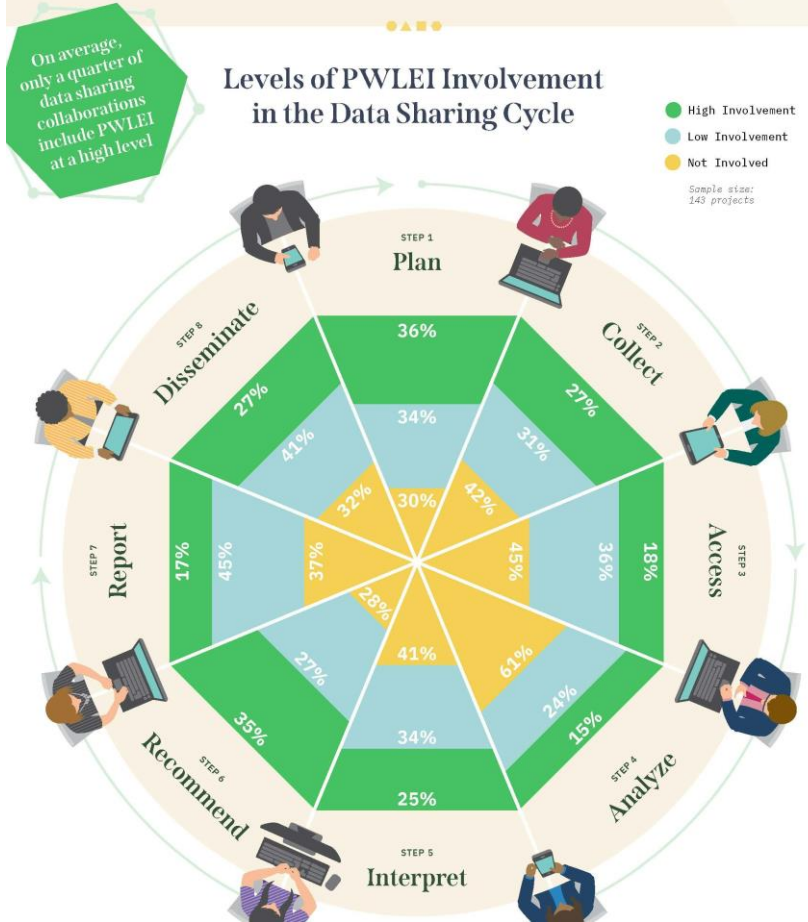
A SEAT AT THE TABLE:
People with Lived Experiences of Inequity in Data Sharing Projects
Findings from the 2021 All In National Inventory

Higher involvement of PWLEI in data sharing collaborations is correlated with data practices that advance health equity.

There is growing evidence about the benefits of including people with lived experiences of inequity (PWLEI) in public health decision-making and affording PWLEI positions of authority to shape expectations, decisions, and outcomes.

PWLEI often know best what needs to happen in the community to improve health and wellbeing. Indeed, higher involvement of PWLEI in data sharing collaborations is correlated with data practices that better contribute to the advancement of health equity.

It is essential that data projects include PWLEI in meaningful ways in the data sharing cycle.



Positive effects of PWLEI inclusion on data practices

COLLABORATIONS WITH HIGH LEVELS OF PWLEI INCLUSION

- Assess Risks of Sharing** (Sample size: 60 projects): **74%** assessed how the risk of data sharing could vary by identity group
- Include Community Level Data** (Sample size: 65 projects): **68%** incorporated community level data into their analyses
- Address Data Biases** (Sample size: 61 projects): **74%** addressed potential biases within the data collected

COMPARED TO COLLABORATIONS WITH LITTLE TO NO PWLEI INCLUSION

- Assess Risks of Sharing**: 35%
- Include Community Level Data**: 48%
- Address Data Biases**: 34%

Potential benefits of PWLEI engagement

- Equity** (Scales icon): Draw focus on historically underfunded areas; Identify and address biases and harms of existing data systems and processes; Identify gaps that prevent addressing structural racism and inequities
- Sustainability** (Refresh icon): Provide feedback to help minimize harm in future data collection; Promote further PWLEI inclusion and minimal barriers to participation; Address power relations and create environment that fosters trust
- Analysis** (Magnifying glass icon): Discover new ways to interpret data; Provide qualitative stories to contextualize quantitative data; Improve the understanding of community beliefs and practices among partners
- Systems Change** (Gears icon): Identify needs unique to each community; Facilitate and expedite the development of locally relevant initiatives; Report data in actionable form to improve lives of those represented in data



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Panel 2: Using the Roadmap to Elevate Race & Ethnicity Data in Health Care and Advance Community-Driven Data Governance and Inclusivity in Medical Product Development



Moderator

Susan C. Winckler, RPh, Esq.
CEO
Reagan-Udall Foundation for the
FDA



Discussant

Payor/Population Health

Louis Cabanilla, MSc
Director of Clinical Analytics
Point32Health



Discussant

Data Privacy/Security

Bradley Malin, PhD
Accenture Professor, Vanderbilt
University



Discussant

Community Engagement/Bioethics

Krystal Tsosie, PhD, MPH, MA
Indigenous Geneticist-Bioethicist
Assistant Professor
Arizona State University

"In 2018, Indian Health Services spent an average of \$3,779 per patient.
The national spending per capita that same year was \$9,409"

National Indian Health Board

"It is not profit-generative" to use Indigenous peoples' DNA to create
therapeutics that specifically impact Indigenous peoples.

Pharmaceutical Companies to Indigenous Scientists

Simply recruiting more Indigenous peoples into datasets is not going to solve the health equity problem. We need to think more structurally about the power dynamics of the disciplines in which we inhabit.

RAISE Workshop 9 /May 18, 2023

Excerpt from Presentation: Genomics for Everyone? Considerations for Equity & Benefit-Sharing for Indigenous Peoples



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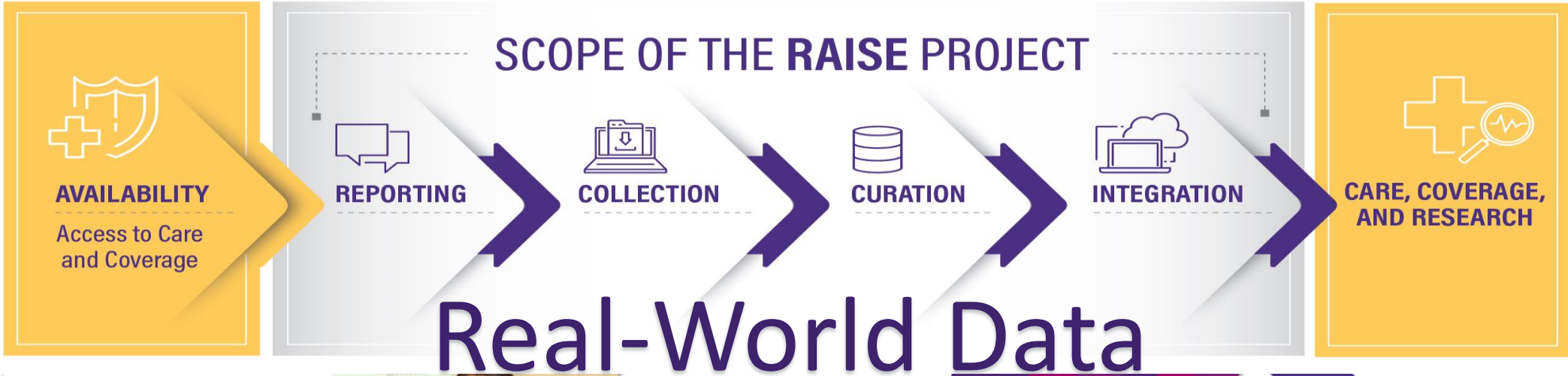


Closing Remarks: Takeaways & A Call to Action

Carla Rodriguez-Watson, PhD, MPH
Director of Research, Reagan-Udall
Foundation for the FDA
Principal Investigator, RAISE



Continuum of Race/Ethnicity Data in Health Care



Improving Data on Race and Ethnicity:
A Roadmap to Measure and Advance Health Equity

DECEMBER 2021

GRANT MAKERS HEALTH

NCQA

THE ETHICAL AND TRANSPARENT USE OF DATA TO REDUCE HEALTH DISPARITIES

R³ Report | Requirement, Rationale, Reference

A complementary publication of The Joint Commission | Issue 36, Date June 23, 2022

New Requirements to Reduce Health Care Disparities

Effective January 1, 2023, new and revised requirements to reduce health care disparities will apply to organizations in the Joint Commission's ambulatory health care, behavioral health care and human services, critical access hospital, and long-term accreditation programs.

- A new standard in the Leadership Standard Chapter with 10 new elements of performance (EPs) has been identified to address health care disparities as a quality and safety priority. Standard LD.04.03.08 will apply to the following Joint Commission-accredited organizations:
 - All critical access hospitals and hospitals
 - Ambulatory health care organizations providing primary care within the "Medical Center" service in the ambulatory health care program (the requirements are not applicable to organizations providing specialty care, dental services, or surgical services)
 - Behavioral health care and human services organizations providing "Addictions Services," "Eating Disorders Treatment," "Intellectual Disability/Developmental Delay," "Mental Health Services," and "Primary Physical Health Care" services
- The Record of Care, Treatment, and Services (RCTS) requirement to collect patient race and ethnicity information has been revised and will apply to the following Joint Commission-accredited programs:
 - Ambulatory health care (Standard RC.02.01.01, EP 2)
 - Behavioral health care and human services (Standard RC.02.01.01, EP 2)
 - Critical access hospital (Standard RC.02.01.01, EP 2)
- The Rights and Responsibilities of the Individual (RI) requirement prohibiting discrimination (Standard RI.01.01.01, EP 2) will apply to all Joint Commission-accredited ambulatory health care organizations and behavioral health care and human services organizations.

Engagement with stakeholders, customers, and experts

In addition to an extensive literature review and public field review, the Joint Commission obtained expert guidance from the following groups:

- Technical Advisory Panel (TAP)** of subject matter experts from various health care and academic organizations and professional associations
- Discussion Groups** of clinicians and administrators who provided a "tools on the ground" point of view and insights into the practical application of the proposed standards.

The population version of the requirements to reduce health care disparities will be available online until December 31, 2022. After January 1, 2023, please access the new requirements in the eLibrary or Standards manual.

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Charting a Course for an Equity-Centered Data System:

Recommendations from the National Commission to Transform Public Health Data Systems

OCTOBER 2021

GOVERNORS | Duke | MARSHALL CENTER for Health Policy | LEAD

ACHIEVING PROGRESS TOWARD HEALTH EQUITY USING RACE AND ETHNICITY DATA:
State Strategies and Lessons Learned

WOLFGANG | WOLFGANG 2022

INTRODUCTION

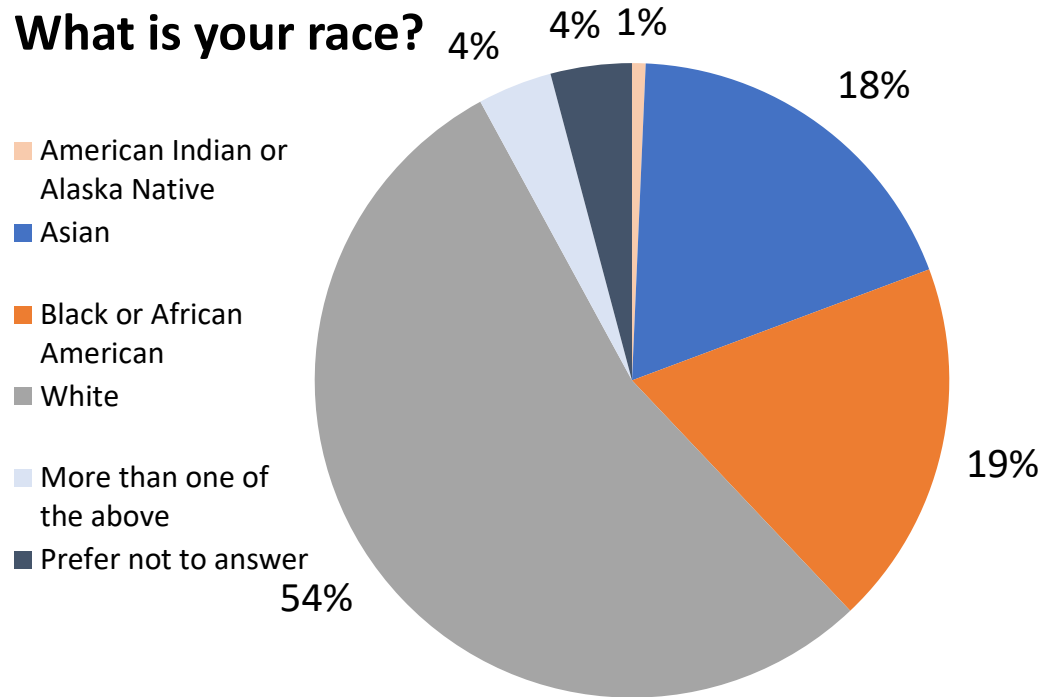
Race and ethnicity data are essential tools to identify and address health inequities. During the COVID-19 pandemic, race and ethnicity data revealed significant disparities across historically-marginalized populations, Black, Latinx, American Indian and Pacific Islander populations experienced higher rates of exposure, hospitalizations and mortality. Similarly, data also exposed wide disparities in vaccination rates across racial and ethnic groups, particularly among Black and Latinx populations. Although some of these gaps have narrowed, more work is needed. States have made progress in collecting and reporting race and ethnicity data that has enabled the targeting of efforts and resources to communities. For example, the number of states reporting vaccine data by race and ethnicity increased from 17 states in January 2021 to 47 states in September 2021. This increase in public reporting of COVID-19 vaccine data by race and ethnicity data has informed state strategies to narrow racial and ethnic gaps in vaccination rates.

RAISE Meeting Statistics

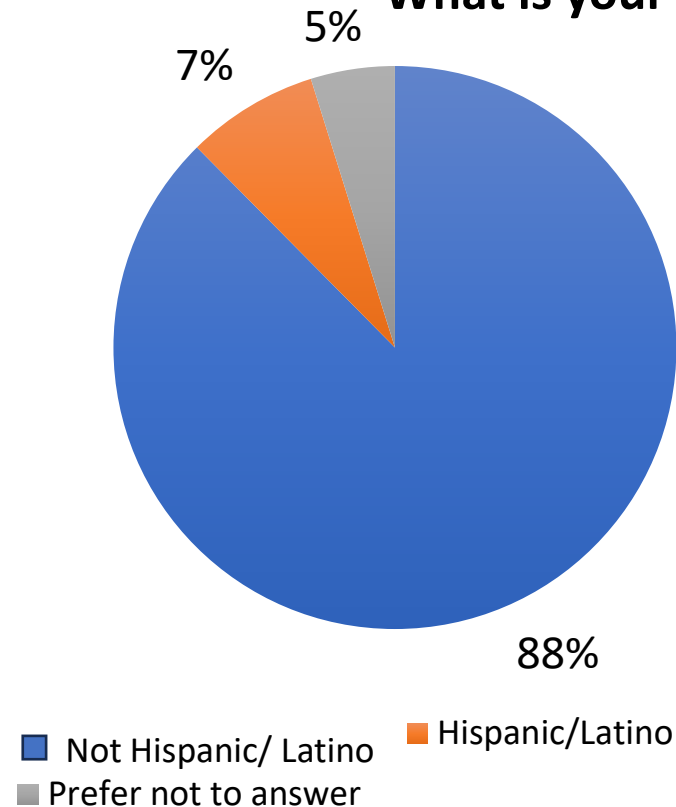
REAL-WORLD ACCELERATOR TO IMPROVE THE STANDARD OF COLLECTION AND CURATION OF RACE AND ETHNICITY DATA IN HEALTHCARE

*549 unique persons registered for the series
- plus additional 200+ registered today*

What is your race?

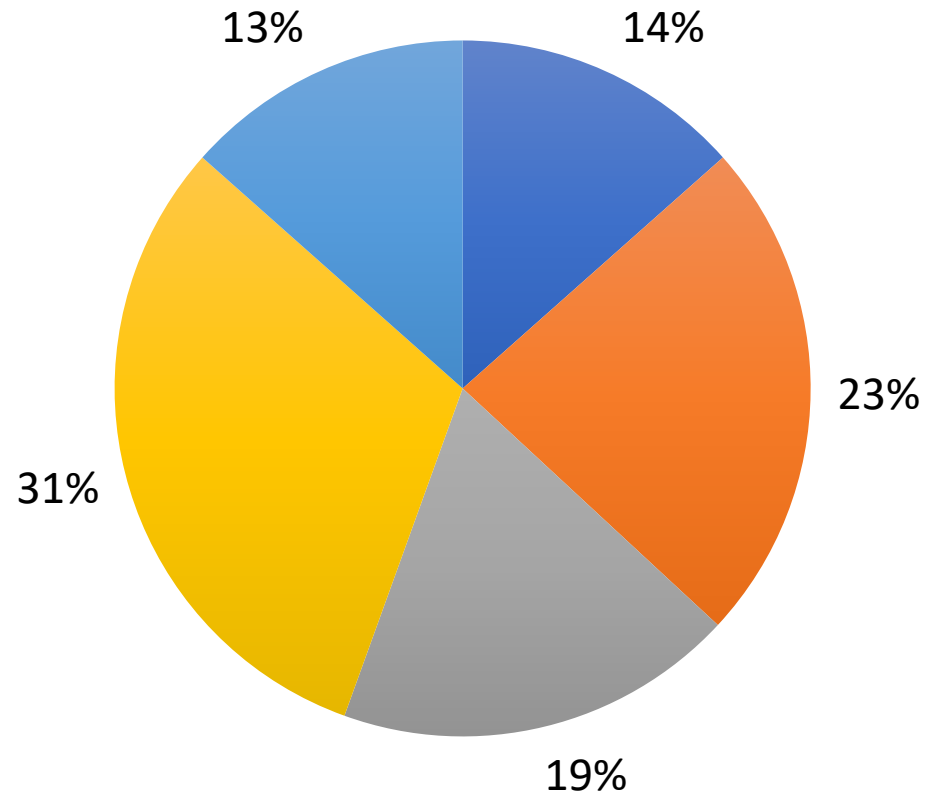


What is your ethnicity?



Which of these groups describes your career sector best?

- Government, Ethics & Law
- Healthcare
- Life Sciences & Technology
- Research
- Prefer not to answer



R

Respect for community autonomy, acknowledgment of structural inequity, and cultural humility facilitate a better understanding of the importance of partnership between systems and people.

I

Intentionality and transparency in collecting race and ethnicity data can help address mistrust, misinterpretation, misclassification, and missingness.

S

Standards that are safe, contextually relevant, and interoperable should be implemented.

E

Education is needed to increase awareness of incentives and resources for infrastructure, technical resources, and best practices.

U

Understanding and alignment to address the dissonance between:

- why R&E are collected, how R&E questions are answered, and how R&E data are used;
- how communities vs. health systems define health equity

P

Payors can collect race & ethnicity data too.





Respect for community autonomy, acknowledgment of structural inequity, and cultural humility to facilitate a better understanding of the importance of partnership between systems and people.

Workshop Summaries: 1, 3, 4, 5

In Partnership with

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Supporting Faith Based Health Ministries

Get To Know Us

Barriers to data collection

	Common Challenges	Solutions	Impacts
	Limited or no capabilities to conduct outreach	Personalized, multi-touchpoint outreach	Reach members at scale using their preferred method. Learn about member preferences and build upon that using behavioral economics and modalities proven effective.
	Struggle to reach all non-English-speaking members	Multicultural Community Health Guides	Dedicated team of experts from the same cultures and backgrounds as the members. Helps build trust, elevates the member experience, and increases satisfaction.
	Lack of resources to build trust and get responses	Engage members in a personalized journey that empowers	Utilize a multimodality approach that builds trust, gives the time and space for members to feel comfortable reporting, and visit the data over time.
	Lack of knowledge around the person's perspectives	Personalized engagement that meets the member where they are	Learn from interactions and continue to update your data collection strategy, therefore driving better data collection and a refined strategy.
	Inability to store the data or act upon the information	Invest in the data storage or work with partners	Data can be stored in a meaningful way, and over time, you are able to better understand the members and act upon it in a culturally appropriate way.

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- Middle Eastern or North African (For example: Algerian, Egyptian, Iranian, Lebanese, Moroccan, Syrian, etc.)
Branching Logic: when "Middle Eastern or North African" selected, then select:
 - Afghan
 - Algerian
 - Egyptian
 - Iranian
 - Iraqi
 - Israeli
 - Lebanese
 - Moroccan
 - Syrian
 - Tunisian
 - None of these fully describe me
Branching Logic: when "None of these fully describe me" selected, then: Please specify.²
 - (display optional free text)

This effort had an impact beyond simply securing a new category in a federal survey. It resulted in a community feeling seen & included

- Ronnie Tepp, Pyxis |RAISE Workshop 5

The screenshot shows the ACCESS website homepage. At the top, there is a navigation menu with links for ABOUT, NEWS, CAREERS, GET INVOLVED, and CONTACT, along with a search bar and social media icons for Facebook, Twitter, YouTube, and Instagram. The main header features the ACCESS logo (a stylized globe) and the tagline "assisting. improving. empowering." Below the header, there are three prominent buttons: "DONATE" (with a heart icon), "GET INVOLVED" (with a hand icon), and "EVENTS" (with a calendar icon). The main content area is divided into three columns. The left column features a photo of five people holding signs that read "Global Health Champion", "I am Public Health", "Health Equity: Every Community", "Health is a Human Right", and "Social Justice Advocate". Below the photo is the text: "Addressing challenges of data scarcity in the Middle East North Africa (MENA) region: How World RePORT can identify research disparities and pave the path for the future". The middle column features a graphic with the text "WE ALL COUNT" and "CENSUS 2020". Below the graphic is the text: "The 2020 Census is live, starting March 20th. The time is NOW! CLICK HERE TO LEARN MORE CLICK HERE". The right column features a photo of a man and a woman standing next to a large poster. Below the photo is the text: "Research at ACCESS. For information on conducting research with ACCESS. CLICK HERE.".



Intentionality and transparency in collecting race and ethnicity data can help address mistrust, misinterpretation, misclassification, and missingness.



Systematic Reviews and Meta- and Pooled Analyses

Conceptualization, Operationalization, and Utilization of Race and Ethnicity in Major Epidemiology Journals, 1995–2018: A Systematic Review

1% of studies collecting R & E data specifically defined terms

Rae Anne M. Martinez*, Nafeesa Andrabi, Andrea N. Goodwin, Rachel E. Wilbur, Natalie R. Smith, and Paul N. Zivich

“the more they study me, the more they know how to get rid of me”

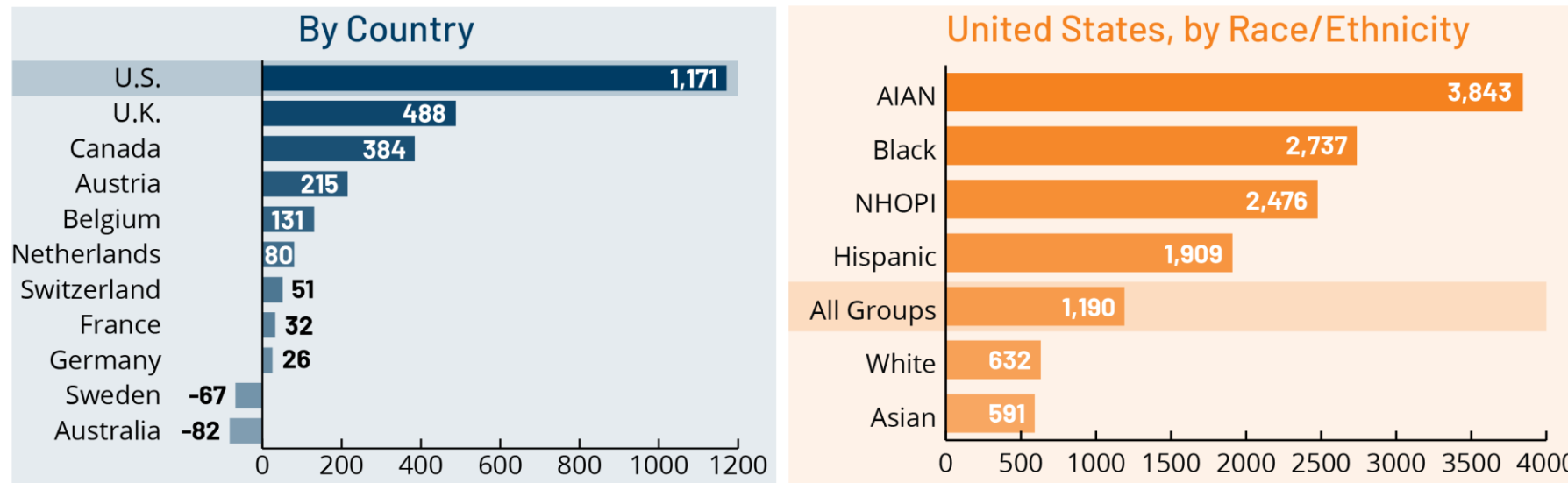
- *Consumer Listening Session, Vaccine Confidence Project, Reagan-Udall Foundation for the FDA*



Beyond the Boxes, Part 1: Guiding Questions for Thoughtfully Measuring and Interpreting Race in Population Health Research

Higher Excess Deaths During Pandemic in the U.S. Were Partly Driven by Racial Disparities

Excess Potential Years of Life Lost in 2020, Ages 0-74, per 100,000 People



NOTE: *Left side:* Excess potential years of life lost rates are per 100,000 people within age group in each country. Excess potential years of life lost were calculated up to age limit of 75. Excess deaths were summed within each age group for 2020 MMWR weeks 1-52. *Right side:* Excess potential years of life lost rates are per 100,000 people within age group in each race/ethnicity category, and were calculated up to age limit 75. Excess deaths in 2020 MMWR weeks 1-52 were used. Persons of Hispanic origin may be of any race but are categorized as Hispanic; other groups are non-Hispanic. SOURCE: *Left side:* KFF analysis of the Human Mortality Database. *Right side:* KFF analysis of CDC data.



Example 2 of Limitations: eGFR

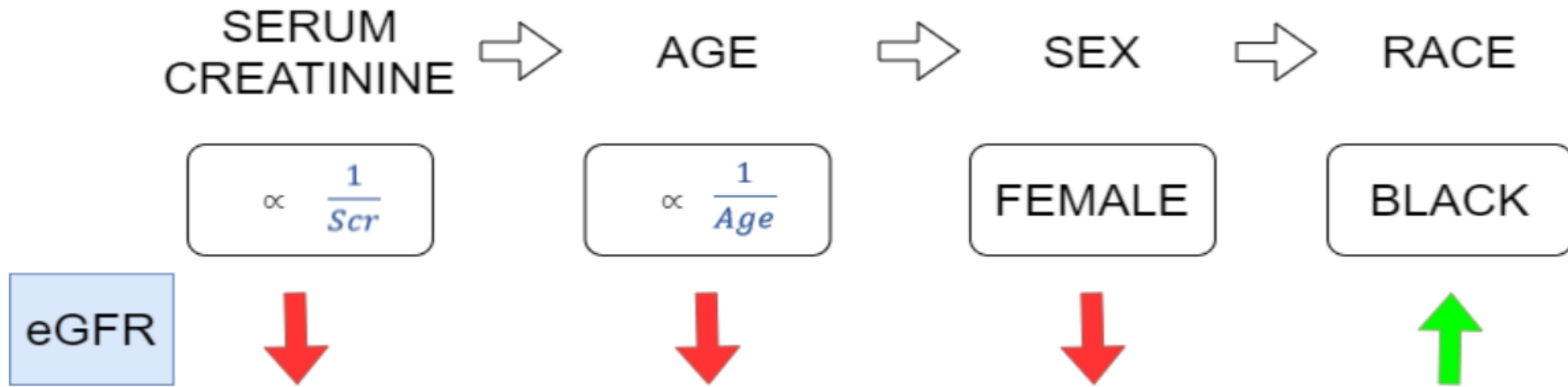
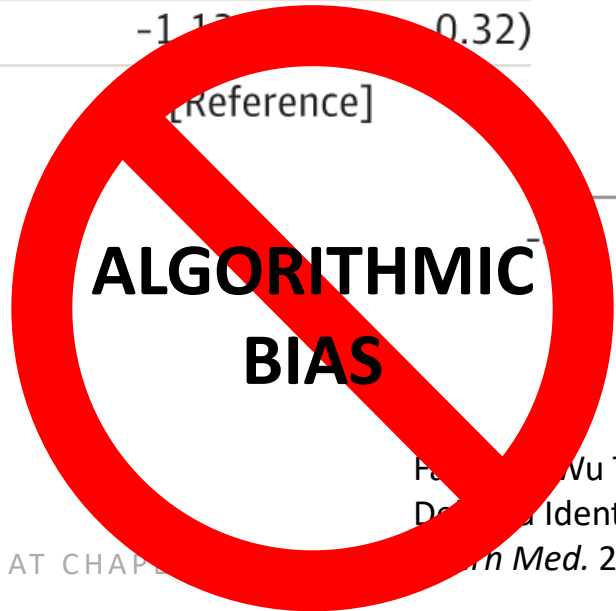
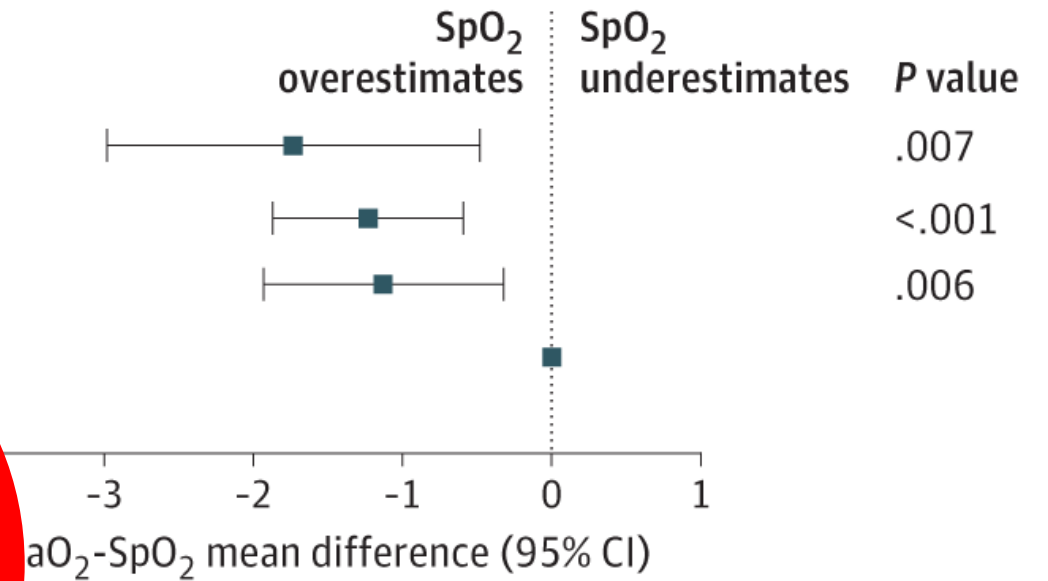


Figure 1. Variables in eGFR Calculation: The figure illustrates factors that influence eGFR calculations. Increasing serum/plasma creatinine, increasing age, and female sex decrease eGFR, while African American race increases eGFR calculations.

<https://health.ucdavis.edu/blog/lab-best-practice/race-and-egfr-addressing-health-disparities-in-chronic-kidney-disease/2021/04>

Pulse oximeters overestimate blood O₂ in non-white patients with COVID-19

Race and ethnicity	Patients, No.	Observations, No.	Mean difference (95% CI)
Asian	54	1696	-1.73 (-2.98 to -0.48)
Black	399	10517	-1.23 (-1.87 to -0.59)
Hispanic	188	6693	-1.17 (-1.81 to -0.52)
White	363	8461	[Reference]



Fan L, Wu TD, Wang K, et al. Racial and Ethnic Discrepancy in Pulse Oximetry and Deep Learning Identification of Treatment Eligibility Among Patients With COVID-19. *JAMA Intern Med.* 2022;182(7):730–738. doi:10.1001/jamainternmed.2022.1906

Example: COVID-19 patients treated with Paxlovid, Jan–Jul 2022 — Combine Race and Ethnicity

Race and Ethnicity separately

Race or Ethnicity	Percent treated	Absolute difference	Relative difference
White	13.5	Ref	Ref
Black	7.0	-6.5	-48.0
Asian	11.9	-1.6	-11.9
AI/AN/NH/OPI	7.9	-5.5	-41.1
Multiple/ other	8.5	-5.0	-37.3
NonHispanic	12.8	Ref	Ref
Hispanic	6.6	-6.2	-48.4

Race and Ethnicity combined

Race and Ethnicity	Percent treated	Absolute difference	Relative difference
NH, White	14.3	Ref	Ref
NH, Black	7.1	-7.2	-50.4
NH, Asian	12.0	-2.2	-15.8
NH, AI/AN/NH/OPI	8.0	-6.3	-43.9
NH, Multiple/ other	10.7	-3.6	-25.1
Hispanic	6.6	-7.7	-53.8

Abbreviation: NH, Non-Hispanic; AI/AN/NH/OPI, American Indian, Alaska Native, Native Hawaiian, Other Pacific Islander

Source: Unpublished data from PCORnet. See Boehmer et al. Racial and ethnic disparities in outpatient treatment of COVID-19. MMWR 2022;71:1359-65.



Standards that are safe, contextually relevant, and interoperable should be implemented.



Our Foundation System comes loaded with standard category values for Race/Ethnicity that customers can use out of the box.

We currently employ the HHS Standard which is more granular but rolls up to OMB

Categories	Notes
a. ___ No, not of Hispanic, Latina/o, or Spanish origin	
b. ___ Yes, Mexican, Mexican American, Chicano/a	
c. ___ Yes, Puerto Rican	These categories roll-up to the Hispanic or Latino category of the OMB standard
d. ___ Yes, Cuban	
e. ___ Yes, Another Hispanic, Latina/o or Spanish origin	

Categories	Notes
a. ___ White	
b. ___ Black or African American	These
c. ___ American Indian or Alaska Native	
d. ___ Asian Indian	
e. ___ Chinese	
f. ___ Filipino	
g. ___ Japanese	These
h. ___ Korean	
i. ___ Vietnamese	
j. ___ Other Asian	
k. ___ Native Hawaiian	
l. ___ Guamanian or Chamorro	These categories roll-up to the Native Hawaiian or Other Pacific Isla of the OMB standard
m. ___ Samoan	
n. ___ Other Pacific Islander	

HHS Codeset

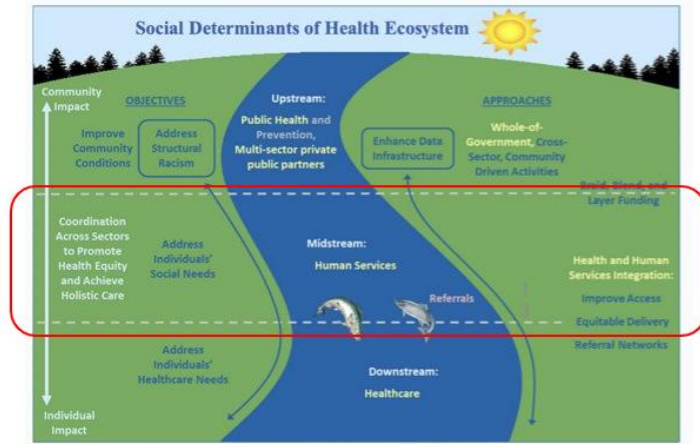
“Utility”

Minority

Superminority

“Privacy”

HHS Approach to Addressing SDOH to Advance Health Equity



Data standards to support health and human services integration

HL7

THEGRAVITYPROJECT.NET



United States Core Data for Interoperability
DRAFT VERSION 4 (JANUARY 2023)

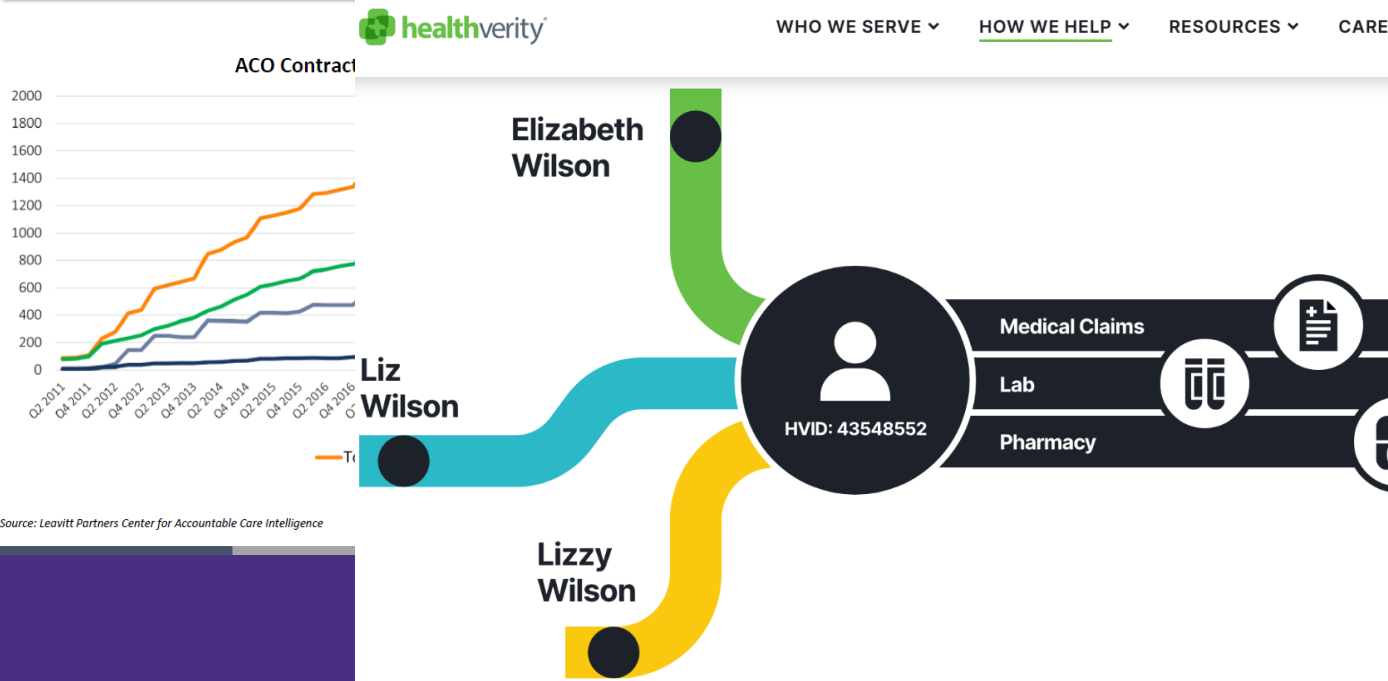
E

Education is needed to increase awareness of incentives and resources for infrastructure, technical resources, and best practices.

ACO Growth by Payer Type



The majority of ACO volume, measured in the number of contracts and covered lives, is commercial (contracts with private payers). Expect even greater private adoption as MA population grows and value-based contracting matures.



Source: Leavitt Partners Center for Accountable Care Intelligence





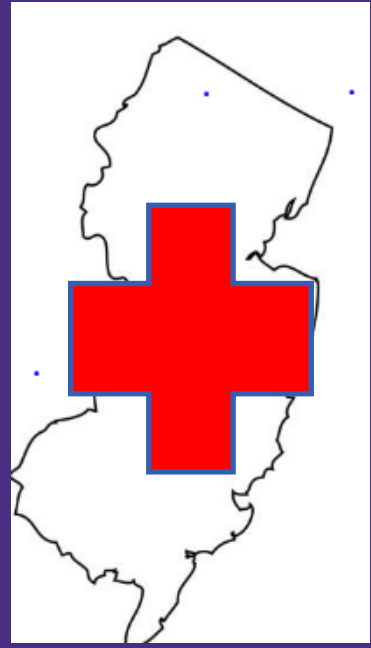
Understanding and alignment to address the dissonance between:

- why R&E are collected, how R&E questions are answered, and how R&E data are used;
- how communities vs. health systems define health equity





Payors can collect race & ethnicity data too.



R

Respect for community autonomy, acknowledgment of structural inequity, and cultural humility facilitate a better understanding of the importance of partnership between systems and people.

I

Intentionality and transparency in collecting race and ethnicity data can help address mistrust, misinterpretation, misclassification, and missingness.

S

Standards that are safe, contextually relevant, and interoperable should be implemented.

E

Education is needed to increase awareness of incentives and resources for infrastructure, technical resources, and best practices.

U

Understanding and alignment to address the dissonance between:

- why R&E are collected, how R&E questions are answered, and how R&E data are used;
- how communities vs. health systems define health equity

P

Payors can collect race & ethnicity data too.



Thank you!



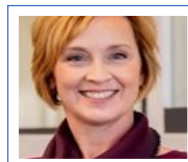
Dr. Rachele
Hendricks- Sturup



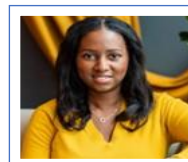
Louis Cabinilla, MSc



Dr. Elise Berliner



Sandy Leonard, MPH



Dr. Alecia Clary



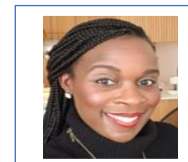
Dr. Krystal Tsosie



Dr. Ali Mokdad



Dr. Francisco De La
Vega



Dr. Cleo Ryals



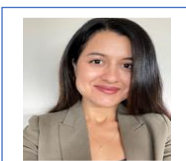
Dr. Phillip Febbo



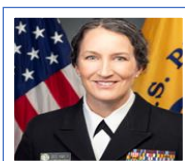
Dr. Susan Zickmund



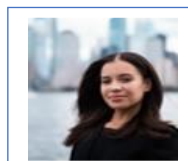
Dr. April Mohanty



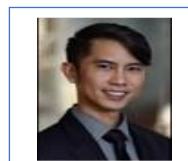
Dr. Diana Naranjo



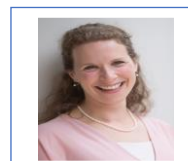
Dr. Tegan Boehmer



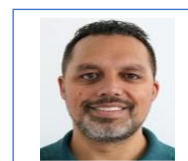
Dionna Andean
(Attinson)



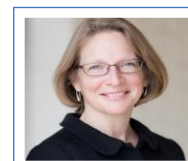
Dr. Rodney Samaco



Dr. Anne-Marie
Meyer



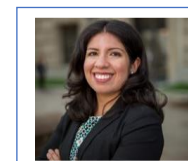
Dr. Aaron Kamaau



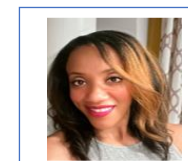
Dr. Michele Johnson-
Funk



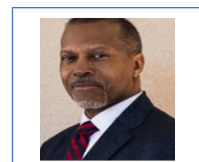
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Dr. Andrea Thoumi



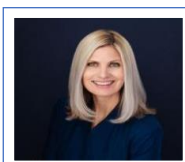
Dr. La Keita Carter



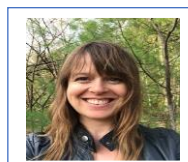
Lenel James, MBA



Dr. Bradley Malin



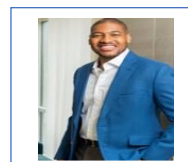
Ryan Argentieri



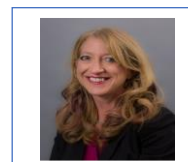
Sarah C DeSilvey,
DNP, FNP-C



Dr. Kathy Cronin



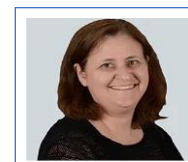
Dr. Warren Whyte



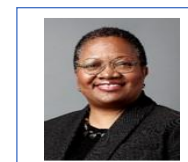
Sarah Green, MPH



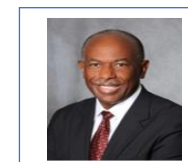
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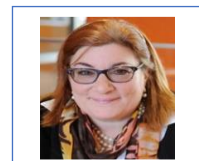
Ronnie Tepp



Dr. Marjorie
Innocent



Dr. James Hildreth



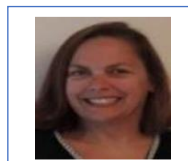
Dr. Elizabeth Cohn



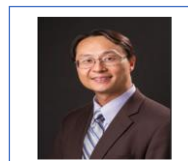
Aparna Sridhar



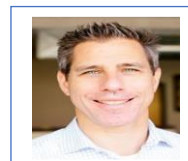
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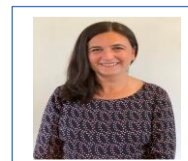
Carmela Couderc



Dr. Allen Hsiao



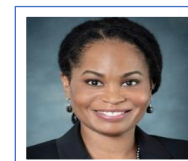
Andrew Kress



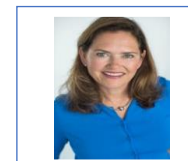
Meredith Welsh



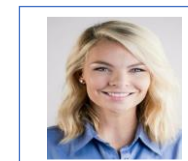
Lt Col Rob Flemming



Yasmeen Long



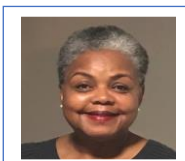
Dr. Amy Abernathy



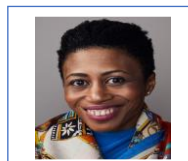
Kate de Lisle



Dr. Leo Russo



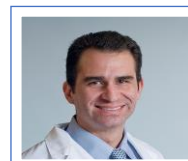
Claudia Withers, JD



Dr. Michelle
McMurray-Heath



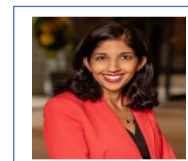
Deanna Fulp



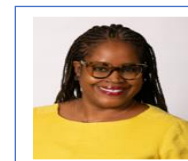
Dr. Oscar Benevidez



Dr. Gary Puckrein



Hemi Tewarson, JD



Nicole Evans, MPH



Dr. Georges
Benjamin



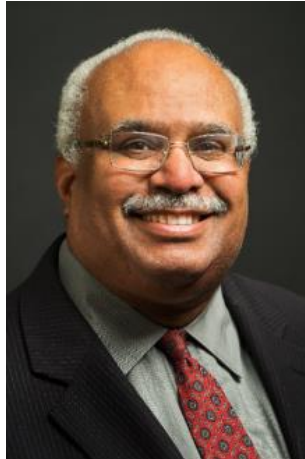
Many Thanks to our Expert Panel!



Amy P. Abernethy,
MD, PhD



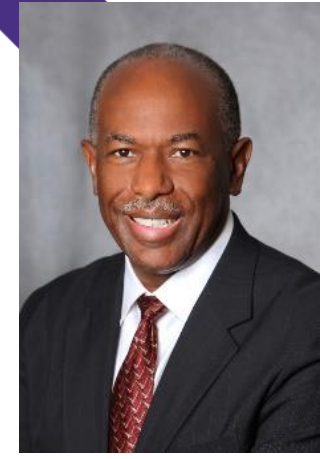
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Jessica Palfreyman (Communications)

Alex Sullivan (Engagement) Emari Thompson (Operations)

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Alecia Clary (Co-I)

Carly Johnson (Research)

Jamiyla Bolton-Cubillan (Engagement)



REAL-WORLD ACCELERATOR TO IMPROVE THE STANDARD OF COLLECTION
AND CURATION OF RACE AND ETHNICITY DATA IN HEALTHCARE

Many thanks for your participation in our Workshop series! Our work is not done-- look for more to come!



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