

July 16, 2024, from 2 - 3 pm ET



This webinar is supported by the Food and Drug Administration (FDA) Office of Minority Health and Health Equity (OMHHE) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award [FAIN] totaling \$875,000 with 100 percent 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.

### Housekeeping





Due to the meeting size, your microphone and video will remain off during the meeting.



This public meeting is being recorded. The slides, transcript, and video recording will be available on the FDA Foundation website after the meeting.



Please share your questions and comments for the speakers using the Zoom Q&A function.

### Agenda



**2 pm** Welcome & Opening Remarks

**2:10 pm** Overview of Action Framework

**2:20 pm** Panel Discussion

2:55 pm Closing Remarks

**3 pm** Adjourn

### Why Are We Here Today?



Provide an overview of the RAISE Action Framework and share experiences of Community Partnership in operationalizing elements of the Action Framework





### Opening Remarks

Christine S. Lee, PharmD, PhD

Acting Associate Commissioner for Minority Health

Office of Minority Health and Health Equity U.S. Food and Drug Administration





# Overview of Action Framework

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





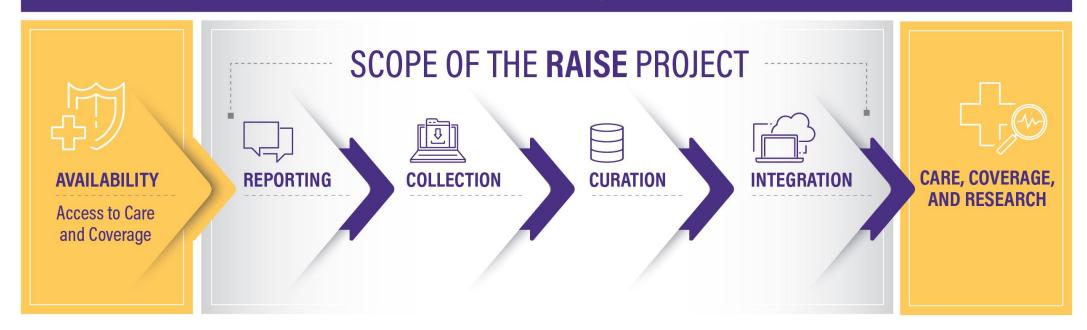
- Implementing targeted interventions and streamlined health care processes can improve patient outcomes and optimize value in healthcare.
- Health equity strategies are key to optimizing value and require community partnership, data collection and analysis to identify inequities, help set priorities, and drive improvement.
- Data can also inform research activities that support quality care and medical product innovation and safety.
- Unfortunately, many health care settings have incomplete capture of key data elements, like race and ethnicity, which can limit opportunities to support health equity strategies





#### 1st & 3rd Thursday of the month at 2 pm ET

#### **Continuum of Race/Ethnicity Data in Health Care**



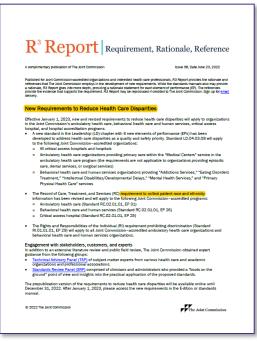














### **Good Solutions Exist**

...but require identification and investment.





#### RAISE **PRIORITIES & STRATEGIES**

The priorities to better collect and manage race and ethnicity data are not sequential. Organizations can enter the framework at the priority that most aligns with their current needs. Click on each priority to see real-world examples of the steps in action! These examples are not exhaustive, but illustrative.



We have mapped each priority to the strategies that can advance it. The priorities are not sequential, but

















Address the need for cultural humility in healthcare

- Develop & implement standardized training protocols that include key concepts:
- The purpose of collecting the data
- The data's relation to health equity
- Who can access the data and why
- How collecting the data benefits the community

Improve representativeness without overwhelming respondents & existing information architecture

- Tailor data options to local contexts; involving community stakeholders for patient-centered options and data governance
- Identify and validate race & ethnicity categories
- Engage community to custom-fit for locale
- Use a process to develop tools to prioritize data options
- Update and pilot data options in the community

- Using a robust process of **polling and review**, the findings were summarized into this **Action** Framework to facilitate improving the collection, curation and exchange of race and ethnicity data.
- The Framework includes **priorities** that leaders can use to guide their efforts.
- **Specific strategies** map to each of the priorities.
  - We encourage readers to use this framework, and the examples provided, to engage colleagues at your institution in further dialogue to build an infrastructure for health equity that considers the strengths and challenges of your organization and the communities you serve.

## PRIORITIES & STRATEGIES









Organizations should **partner with communities** to improve data collection for health equity! The priorities to better collect and manage race and ethnicity data are not sequential. Organizations can enter the framework at the Priority that most aligns with their current needs. **Click on each Priority** to see real-world examples of the steps in action! These examples are not exhaustive, but illustrative.



#### RAISE PRIORITIES





#### Standardize data collection:

The American Hospital Association hosts the Health Research & Education **Disparities Tool Kit** 



Train the workforce on data collection: Mt. Sinai Case Study to improve collection of race & ethnicity data to address health disparities.



#### Incentivize data collection:

Health Care Transformation Task Force: Building the **Business Case for Health Equity Investment: Strategies to** Secure Sustainable Support



Collect data locally then aggregate: CDC IDEAL





### **STRATEGIES**

## Address the need for cultural humility in healthcare

- Develop & implement standardized training protocols that include key concepts:
  - The purpose of collecting the data
  - The data's relation to health equity
  - Who can access the data and why
  - How collecting the data benefits the community













- Tailor data options to local contexts; involving community stakeholders for patient-centered options and data governance:
  - Identify and validate race & ethnicity categories
  - Engage community to custom-fit for locale
  - Use a process to develop tools to prioritize data options
  - Update and pilot data options in the community



## Address distrust & misalignment between question & answer

- Be transparent in why race and ethnicity data are collected, how it will be used, & who can access. Build tools & training resources that incorporate:
  - Messaging about the purpose and intended use of the data
  - A choice to opt out of providing the data
  - Information in diverse formats (e.g., web-based, tablet, paper, video) and languages





- Promote standardized collection and exchange methods to align information and overcome technical hurdles:
  - Identify technical stress points to understand the causes
  - Develop strategies to alleviate technical stress points
  - Incentivize the implementation of data standards



#### Address resource limitations

- Commitment from the top to address health equity, share available resources to do so, and map out required investments to access funding (e.g. adoption of alternative payment models):
  - Familiarize top executives with unmet need and opportunity posed by disparities in health equity & the role of race and ethnicity data to address gaps and Identify & share funding sources
  - Discuss opportunities, required investments, and return on investment
  - Prepare funding proposals

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#### Panel Discussion





Moderator
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### Thank you!