RAISE ACTION FRAMEWORK

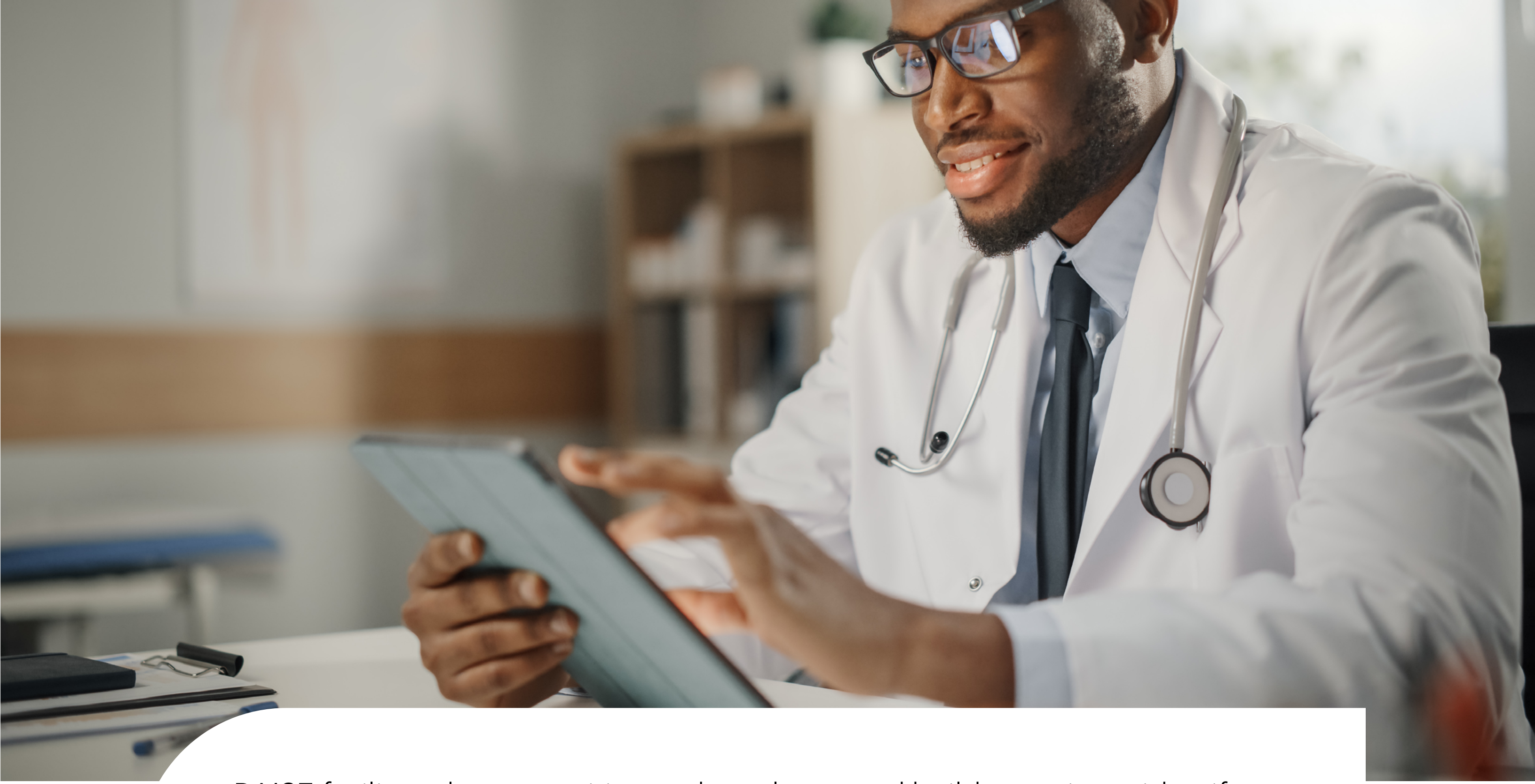
Real-world Accelerator to Improve the Standard of Collection and Curation of Race and Ethnicity Data in Healthcare

REAGAN-UDALL
FOUNDATION
for the Food and Drug Administration

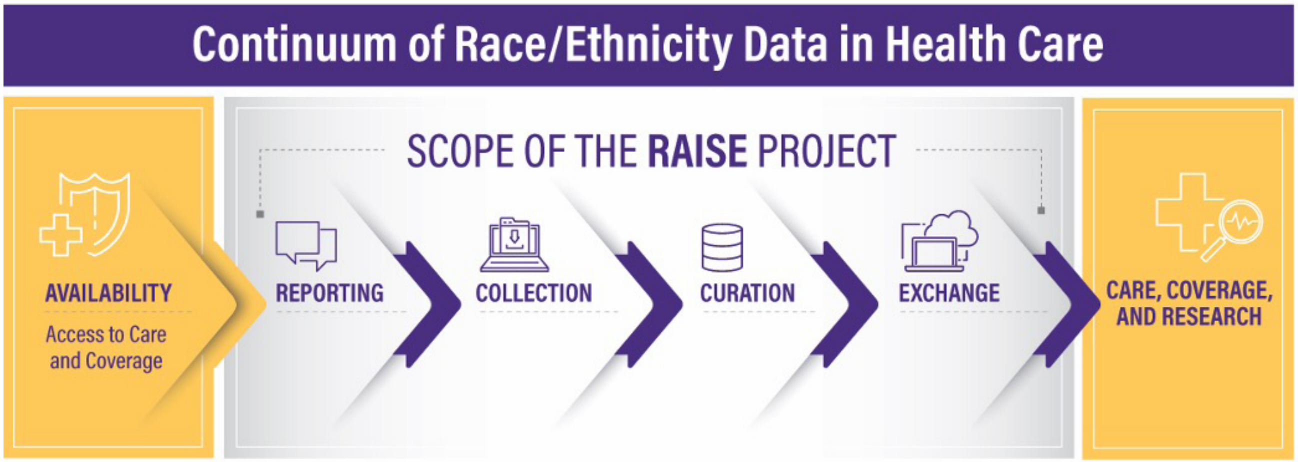
RAISE ACTION FRAMEWORK

Implementing targeted interventions and streamlined health care processes can improve patient outcomes and optimize value in care-delivery. Health equity strategies require data collection and analysis to identify inequities, help set priorities, and drive improvement. Data can also inform research activities that support clinical 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.

Implementing strategies to improve race and ethnicity data to support health equity requires buy-in from all levels of health care delivery. Improving the collection and curation of race and ethnicity data is increasingly being incentivized through alternative payment models that prioritize health equity, the Joint Commission's accreditation requirements, and federal reporting requirements.



RAISE facilitated opportunities to share, learn, and build capacity to identify and prioritize solutions to improve the inclusion of race and ethnicity data throughout the health care data continuum. Working with leaders across the health care ecosystem, RAISE launched a series of thoroughly researched and crafted workshops. Using a robust process of polling and review, the findings were summarized into this Action Framework to facilitate action toward 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.



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.

THE PRIORITIES

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

STANDARDIZE DATA COLLECTION

TRAIN THE WORKFORCE ON DATA COLLECTION PROCEDURES

INCENTIVIZE DATA COLLECTION

COLLECT DATA LOCALLY THEN AGGREGATE

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

RAISE PRIORITIES & STRATEGIES

CONTINUED

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

Improve exchangeability of race & ethnicity information

- 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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If you have resources you'd like to share, please submit those to raise@reaganudall.org & we'll get the word out.