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Reagan-Udall Foundation for the FDA Publishes RAISE Action Framework to Improve Race and Ethnicity Data Collection in Health Care

Federally supported project's new Framework provides examples and counsel on improving collection and curation of race and ethnicity data in health care research

(July 26, 2024) The Reagan-Udall Foundation for the FDA (the Foundation) launched a new tool for leaders in health care delivery—the RAISE Action Framework. Developed through the Real-world Accelerator to Improve the Standard of collection and curation of race and Ethnicity ([RAISE](#)) project, this new Framework will facilitate action toward improving the collection, curation, and exchange of race and ethnicity data in health care settings.

Available on the [Foundation website](#), the RAISE Action Framework includes priorities such as incentivizing race and ethnicity data collection, standardizing data collection methods, aggregating data collected locally, and training the health care workforce on best practices. Real-world examples in the Framework guide organizations in implementing effective community-centered strategies tailored to meet each health priority.

"The RAISE Action Framework is a roadmap for health care organizations to improve how they engage with communities to collect data that supports community needs for more equitable care and research. The Action Framework offers successful examples that organizations can use to build an infrastructure to support the collection, curation, and exchange of race and ethnicity data that is grounded in cultural humility," said Carla Rodriguez-Watson, PhD, MPH, Director of Research at the Foundation and the Principal Investigator of RAISE. "It is a tool designed to meet the urgent need to address gaps in race and ethnicity data and to support health care organizations to enter the Framework at the point that most aligns with their unique needs."

Key strategies to support the RAISE priorities:

- Address the need for cultural humility in health care
- Address distrust and misalignment between question and answer
- Address resource limitations
- Improve the exchangeability of race and ethnicity information
- Improve representativeness without overwhelming respondents and existing information architecture

RAISE aims to address the critical issue of incomplete and inconsistent collection of race and ethnicity data, which is vital for improving care and addressing health equity gaps. Through stakeholder meetings and the creation of this multi-dimensional Action Framework, the initiative, in collaboration with the Food and Drug Administration's Office of Minority Health and Health Equity (OMHHE), focuses on understanding, aligning, and disseminating best practices to improve real-world reporting, collection, curation, and integration of race and ethnicity data.

"Community partnership has been central in our RAISE work, and the RAISE Action Framework summarizes our findings to identify and implement strategies to support health equity at all

levels of health care and research," said Susan C. Winckler, RPh, Esq., the Foundation's CEO. "By fostering further collaboration and innovation, our Foundation aims to equip stakeholders with tools and strategies to drive meaningful change and improve health equity."

Recently, the Foundation hosted a webinar about the RAISE Action Framework, highlighting successful initiatives to standardize data collection and emphasizing the importance of addressing health disparities and improving the representation of underrepresented populations in health care data. Moderated by Dr. Rodriguez-Watson, panelists included [health care information experts](#) from Yale School of Medicine & Yale New Haven Health System, Blue Cross Blue Shield Association, Harvard Medical School & Harvard Pilgrim Health Care Institute, and Amgen. The recorded webinar can be viewed on the Foundation's [webpage](#).

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The Reagan-Udall Foundation for the FDA (the Foundation) is an independent 501(c)(3) created by Congress to advance regulatory science to help the U.S. Food and Drug Administration accomplish its mission. The Foundation works to improve health and safety through stakeholder engagement and public-private partnerships that facilitate innovation, foster the use of real-world evidence, and identify modern tools and policies to keep pace with today's rapidly evolving science.