Creating Safe Space I: Reporting Race 101
RAISE Community Workshop 4
Thursday, March 2, 2023; 2- 3 PM ET

Summary

Overview of RAISE Community Workshop IV

During RAISE workshop IV, we had welcome remarks from Susan Winckler, CEO of the Reagan-Udall Foundation, and Dr. Christine Lee-Flemming, Strategic Research Engagement Lead of the Office of Minority Health and Health Equity at the FDA. During the session we heard three presentations. First, Dr. Carla Rodriguez-Watson, RAISE PI, summarized our previous RAISE workshops and their connection to workshop IV. Then, Silas Buchanan of the Institute for eHealth Equity described how cultural humility and community partnerships can be used to improve health equity. Finally, Aparna Sridhar of Epic Systems presented on technology at Epic Systems that meet workflow and individuality needs. The session closed with a discussion moderated by Dr. Elizabeth Cohn of Hunter College.

Connecting the Dots: From Collecting Better Data to Creating Safe Space

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

To level set, the RAISE project begins with the assumption that race and ethnicity (R&E) are critical for understanding population, health and the real-world utilization and performance and medical products across racialized groups. We acknowledge that race and ethnicity alone do not answer all the questions; but are critical to understanding population health and the real-world utilization and performance of medical products across racialized groups. As such, R & E are important to the FDA. The question of whether or when race or ethnicity is, or is not, the appropriate variable is not in the scope of the RAISE project. And though issues of access to care frame our conversation, addressing access to care is not the focus of RAISE. The focus of RAISE is the part of the data continuum that includes reporting collection, curation, and integration of R&E data (where the bolus of real-world data is generated/lost).

During Workshop I: "Improving Race and Ethnicity Data in Health Care" , we laid the foundation of a continued discussion on "Trust - How to get it; How to keep it." The emerging concept is one of **cultural humility**, - a dynamic and lifelong process that includes self-reflection, personal critique and acknowledging one's own biases. So, we challenge ourselves to come to this work with humility and to check our bias. We come with the curiosity to learn from the community how to partner (not just engage) with them to create solutions that align with their definition of health.

In our last workshop, "Collecting Better Data II: System Infrastructure", we shared that part of cultural humility is taking the time to meet people where they are with things like flexible technology (like SMS text) and being true to what you have conveyed about how those data will be used. Today, the Institute for eHealth Equity will continue that conversation with more insight into the centrality of cultural humility and the curation of long-standing community partnership. Then, Epic Systems will pick up the conversation started in Workshop I on process and workflow challenges to collecting R & E workflow and share how they helped create technology that meets the needs of workflow and individuality.

Building bridges: Cultural Humility and Community Partnerships to Improve Health Equity
Silas Buchanan, Founder and CEO
Institute for eHealth Equity

The Institute for eHealth Equity is a social impact consulting firm based in Cleveland, Ohio. The Institute works with underserved communities to raise literacy around the benefits of adopting and utilizing technology to improve health outcomes and with creators of health tech to ensure their solutions are culturally appropriate.

- The communication gap between communities of color and healthcare organizations is clear, prevalent, and wide-reaching. For example, we know that communities of color are disproportionately affected by diabetes. As such, there is nothing more frustrating than to see a TV commercial for diabetes medication without a person of color in it.
- We believe that the solution lies in partnership between community and health care stakeholders that will have permanence, as opposed to the current standard of episodic engagement. We're building, in partnership with the Morehouse School of Medicine, a world-class, geographically expandable, culturally appropriate web-based collaborative space for faith leaders in underserved communities and community-based organizations. Our desire is to work both secularly and non-secularly alike so we've set up two platforms: Our Health Ministry and Our Healthy Community. Our Healthy Community is designed to work with the secular community, and Our Health Ministry is designed to work with our faith community. The focus in this meeting is on Our Health Ministry, which is currently getting traction in Cleveland, Chicago, New Orleans, and Atlanta.
- We know that our faith-based organizations (FBO) are known, loved, and trusted by community members and historically embedded in communities. We know that historically our FBO have been doing or addressing the social determinants of health for years. Church vans have been taking people to doctor, organizing after school program, and feeding and clothing the underserved communities. Our Health Ministry gives each organization that is partnering with us their own landing page to highlight the leader of their FBO or house of worship (not just Christian or a church) to share a little bit about who they are and who leads their Health ministry, share healthy recipes and to engage the community through their social media channels. We are also interviewing faith leaders across the markets that we're currently piloting Our Health ministry.
- Additionally, we give our health ministers more tools to disseminate information and capture data in in their communities. For this, we're using Text4Wellness, a pilot completed through a grant with the Aetna Foundation. Text4Wellness is a two-way, real-time, text messaging campaign that leverages relationships with faith and community-based organizations to deliver culturally relevant, actionable text messages to members of underserved communities and communities of color.

Text4Wellness Program Goals

- Demonstrate the potential of mobile health technology to address a critical national health priority: Reducing health disparities
- Demonstrate the potential of mobile health technology to consistently outreach and engage underserved populations with critical health information.
- Develop a base of evidence on the efficacy of mobile health interventions with targeted populations.
- Catalyze new models for public-private partnerships by leveraging mobile health to outreach and engage targeted populations.
- Educate, motivate, activate and empower targeted communities to make healthy choices.
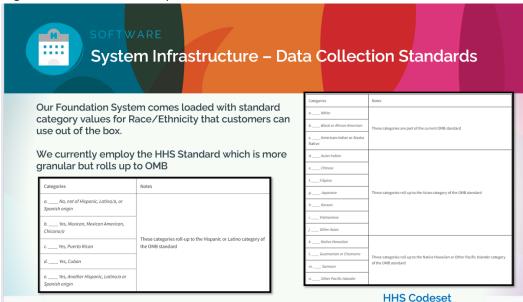
- The program goals are listed on the slide above. Pastors agreed to discuss the program from the pulpit and ask parishioners to text healthy to our short code. We immediately asked 8 enrollment questions: zip code, age, gender, are you insured, do you smoke, how do you rate your health currently, race/ethnicity and the name of your church. Participants were then texted 3 times a week (MWF) with Friday as the data collection day for healthy eating and physical activity questions. To summarize the results:
  - Over 6-months, the Text4Wellness pilot had 2,500 participants from 5 FBOs across 3 states.
  - 25,000 messages were sent or received, and 500 links were sent.
  - There were 0 opt-outs and a 43% response rate to text questions.
  - There was a 72% response rate for the initial 8 enrollment questions.
- Text4Wellness demonstrated that texting can be an efficacious approach when driven through the culturally appropriate channels to reach community members.
- Planned future campaigns include:
  - Improving clinical trial and research participation. We're currently working with the National Library of Medicine to better understand trepidation around participating clinical research.
  - Maternal morbidity and mortality work
  - Cardiometabolic syndrome, more inclusive of hypertension and better understanding diabetes
  - Hereditary cancer detection
- Cultural humility and building trust in communities is paramount to the success of healthcare stakeholders, and meeting people where they are through the organizations that are known, loved, and trusted by community members is critical.
- A relatively healthy individual spends about 20 minutes a year in a healthcare institution for their annual physical, but 70 hours a year in church. In that regard, it's important that we arm our FBOs and leaders with the tools they need to partner more equitably with the capture of both R/E and social determinants of health data in ways that are interoperable and can be shared back into the electronic medical record system.

The Tech that Supports Workflow and Individuality
Aparna Sridhar, Product Lead, Cadence Scheduling
Epic Systems

- Epic Systems has a well-established health equity strategy that supports our customers' needs to provide more equitable outcomes to their patient population, including:
    - Accurate and respectful data collection tools for including race, ethnicity, language, disability, and other social determinants of health.
    - Analytics to track disparities. Examples include maternal health equity outcomes and eGFR.
    - Interventions to promote equity.
- Epic enables healthcare organizations to capture R & E data using two major workflows:
    - Patient registration. When the patient registers with an organization, their registration information is captured.
    - Patients can enter this data themselves through our patient portal .
- Epic Systems capture R & E data with 2 major fields, one for race and one for ethnicity, which align with OMB categories and allow for multiple race selections.

SOFTWARE
System Infrastructure – Data Collection Standards

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, Latino/a, or Spanish origin	These categories roll-up to the Hispanic or Latino category of the OMB standard
b. ____ Yes, Mexican, Mexican American, Chicano/a	
c. ____ Yes, Puerto Rican	
d. ____ Yes, Cuban	
e. ____ Yes, Another Hispanic, Latino/a or Spanish origin	

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

HHS Codeset

- Many customers vary in the use of standards for collecting race/ethnicity - from minimalist of the OMB categories to a very granular category list (CDC). The slide above demonstrates the R &E selections in the Epic system. (I.e. HHS standard with roll up to OMB).
- Dashboards and reports support exploration of population trends to address gaps.
- Scripting guides address common challenges to collecting R & E information, such as distrust, inability to identify with the categories, etc. and facilitates ways that users can present the intended use for the data and ways to pose questions of R &E with cultural humility. For example, among Spanish-speaking users, one academic medical center found a 90% improvement in collection of R & E data when they implemented multiple interventions, and another found increased Ethnicity collection by using the phrase "where is your family from?" rather than "with what race do you identify?".
- Other communication and collaboration tools to consider to increase cultural sensitivity and process roadblocks:
    - Software developers can sit with staff to observe workflow in order to develop customized interfaces. The developers' observations inform future designs and updates.

        o   There are specific *Brain Trusts* to identify best practices for documenting and abstracting data within Epic, with R/E being a large focus of the equitable care brain trust.

        o   *Strategy handbooks* are available to support several different areas for data collection.

        o   Forums are available for community discussion on specific topics Or on user projects using the system.

        o

Moderated Discussion

Moderator: Elizabeth Cohn, RN, PhD, FAAN

                     Rudin Professor of Community Health

                     Hunter College, City University of New York

Discussants:

➢ *Workshop Champion: James E.K. Hildreth Sr, PhD, MD (President and CEO, Meharry Medical College)*

➢ *Citizen Voice: Marjorie Innocent (Director of Learning and Impact, NAACP)*

➢ *Silas Buchanan*

➢ *Aparna Sridhar*

The moderated discussion incorporated questions from the chat as well as those posed by our moderator to further expand on the workshop's presentations. The importance of cultural humility both in the workforce and in data collection was emphasized repeatedly. The moderated discussion reinforced that trust is critical. One way to build trust is to incorporate community organizations as equitable partners in healthcare. Highlights from the discussion:

• Clinicians should acknowledge that faith and community can play a role in one's overall health and well-being. This should be incorporated into how clinicians are trained.

• We should "Lead from Behind" by engaging community organizations. They've established the trust that is needed to make a difference. Keep in mind that the community needs to be engaged in a way that appreciates the diversity of the community, both within and outside the community organization.

• Structural racism exists, cuts across everything, and must be addressed at all points that "touch" the person engaging with that system: from the parking valet to the clinical team and to the pictures of the Board of Directors on the wall if we are to build trust. R & E data collection needs to be approached with transparency to increase people's willingness to share information. Explain why R & E data are being collected and how those data will be used. This suggestion was repeated in the discussion and the chat! We also need to demonstrate a benefit that ultimately is about their lived experience. It's not just about improving systems according to metrics defined by the system, but defined by and for the people they are intended to impact.

• Aggregated data is critical to make sure resources flow to where they are most needed. That's what equity is about. Communities have different levels of need.

• Allow patients to report R & E in ways they see fit and to inform future categorizations of race (or closely linked constructs). Kiosks and self-reporting mechanisms can assist in lowering the intimidation factor.

• At the end of the day, everything comes down to trust− who's asking, the context of what they're asking and why. Our community organizations are historically embedded and need to be more equitable partners with health care to help build trust.

Hot Takes and links from the Chat

- It's important to acknowledge that not everyone goes to church, and not everyone who goes to a place of worship is Christian.
- Make your opinions on federal R & E categories heard: https://www.whitehouse.gov/omb/briefing-room/2023/01/26/initial-proposals-for-revising-the-federal-race-and-ethnicity-standards/: There is a proposal to combine "Hispanic" into race as an ethno-racial category. Some questions around how those responses will be treated and whether a data entry person will categorize based on some hierarchy because some data models do not allow for multiple response.
- Scripts for the collection of R & E are extremely beneficial, especially the emphasis on why the data is being collected.
- There are emerging needs for building cultural humility not just in the exam room - but among the administrators, drivers, kitchen, etc. Cultural humility begins when the patient makes the initial attempt to schedule an appointment.
- Our current discussions echo a lot of experiences seen and heard with LGBTQ+ health - it's a luxury to assume trust that many can't afford to grant to their providers/healthcare interactions.
- We should include the voice of members of the community, potentially through Advisory Boards. There should be more researchers at the Community Table instead of the other way around.

Please join us for future RAISE Workshops:

RAISE

Community Workshop Series

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

#	Date / Time (ET)	Key Theme
1	Jan 26 / 2-4 pm	Opportunities to Improve Race & Ethnicity Data in Health Care
2	Feb 2 / 2-3 pm	Collecting Better Data I: Incentives, Framework, Mission
3	Feb 16 / 2-3 pm	Collecting Better Data II: System Infrastructure
4	Mar 2 / 2-3 pm	Creating Safe Space I: Reporting Race 101
5	Mar 16 / 2-3 pm	Creating Safe Space II: Capturing Race and Ethnicity Data
6	Apr 6 / 2-3 pm	Technical challenges in the transfer of information
7	Apr 20 / 2-3 pm	Factors & Impact of Missingness, Misclassification, and Measurement Bias
8	May 4 / 2-3 pm	Advanced Analytics – Novel Ways to Apply Existing Race & Ethnicity Data
9	May 18 / 2-3 pm	Advanced Analytics - Interim Solutions When Race & Ethnicity are Missing
10	Jun 1 / 2-3 pm	Reactions to Barriers, Opportunities & Proposed Solutions
11	Jun 15 / 2-4 pm	Summary - Visioning & Next Steps