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A Roadmap for Race, Ethnicity, and Language Data Collection and Use in Connecticut

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The COVID-19 pandemic has taken a disproportionate toll on Black and Latinx Connecticut residents, magnifying inequities that existed before the virus and have long resulted in poorer health outcomes for people of color.

For many in health care, the experiences of the pandemic have inspired new or greater will to address the inequities that produce these disparities. Critical to advancing health equity is being able to identify and track the problems – something that does not currently occur consistently in Connecticut. While public health data clearly documents worse health outcomes for people of color, most health systems and other care providers do not consistently track data on patients' self-reported race, ethnicity, or language preference (REL) to find inequities or intervene when changes could make a difference.¹ The lack of standardized data can be particularly challenging for ethnic or racial groups with smaller populations, including Asian Americans and Native Americans, whose population-level outcomes are often not even reported in public health data.

A commitment by health systems and other care providers to collecting and analyzing self-reported race, ethnicity, and preferred language (REL) data – in a standardized way across the state – would be a significant step toward advancing equity. Collecting REL data will not solve health inequities on its own, but can provide the information needed to identify problems and develop interventions specific to the gaps in care that people of color experience.

This work is challenging, but doable. Many health systems nationwide have already implemented REL data collection and analysis programs, and some states have already implemented the standardized collection, reporting, and use of REL data statewide. There is no single model; there are many ways forward. What is most critical is committing to this work now and beginning down a path so that Connecticut has a strong foundation to better identify and eliminate health inequities.

KEY TAKEAWAYS

- **Collecting, reporting, and using race, ethnicity, and language data is a core component of any strategy to improve health equity.**
- **Health systems across the country have successfully implemented REL data collection programs and used them to advance quality initiatives and prioritize interventions to improve health equity.**
- **Connecticut currently has no statewide standardized way for health care systems and clinics to collect, report, and use patients' self-reported REL data. Many health systems collect relevant data, though the level varies, and fewer health care organizations in the state are using the data to address care.**
- **With appropriate technical and monetary assistance, REL data collection is possible in Connecticut, as was demonstrated through a recent grant program as part of the State Innovation Model initiative.**

¹ For more information on the connection between data collection and identifying areas of structural racism in systems, see Eberly L et al. Identification of Racial Inequities in Access to Specialized Inpatient Heart Failure Care at an Academic Medical Center. *Circulation: Heart Failure* November 2019.

THE PURPOSE OF THIS ROADMAP

At the request of the Connecticut Health Foundation, the Institute for Healthcare Improvement (IHI) created this roadmap. The roadmap has two goals: To encourage a commitment by health care stakeholders, advocates, and state leaders toward the standardized collection, reporting, and use of REL data; and to serve as an organizing document that can guide stakeholders as they move forward.

While the focus of this roadmap is REL data, it can also be used as a model for collecting, reporting, and using data on other factors that affect health outcomes (such as gender identity and sexual orientation).

The focus now on REL data is warranted. On virtually every measure of health, Connecticut produces worse outcomes for people of color. This can and should be viewed as a public health emergency.

WHY COLLECTING REL DATA MATTERS

Health systems have missions to improve the lives of all patients in their care. Despite their best efforts to treat all patients equally, disparities persist. Understanding the roots of these disparities, and finding ways to intervene, is critical to delivering safe and effective care. Indeed, eliminating racial and ethnic health inequities – and tracking data to guide this work – is an essential part of delivering high-quality care.

Equity is one of the Institute of Medicine (IOM)'s six domains of health care quality. According to the IOM, quality health care must be: 1) safe; 2) effective; 3) patient-centered; 4) timely; 5) efficient; and 6) **equitable**.ⁱ IHI states that there is no quality in health care without equity; the two are inextricably linked.

A coordinated, statewide effort to collect and use REL data can make it possible to identify and address inequities more broadly and effectively.

THE ROADMAP

The roadmap identifies the key steps to achieving a coordinated, statewide system for REL data collection and use, with focus on topics including identifying which data to collect, training staff who will be collecting the data, storing, and monitoring the data, and using it at the clinical level to inform care, both within organizations and statewide.

We organized the roadmap into seven stages:^{vi}

1. **Design**
2. **Data Storage**
3. **Training**
4. **Data Monitoring**
5. **Using Data at the Clinical Level**
6. **Scaling Up Data Collection Across the State**
7. **Using the Data at the State Level**

WHY RACE AND ETHNICITY

It is critical that health systems recognize that race is a social construct determined by society's perception. Race does not have any biological basis and therefore cannot produce natural health disparities due to genetic differences.ⁱⁱ Similarly, ethnicity is an evolving social construct with no biological basis. While some conditions are more common among people of certain heritage, disparities in conditions such as heart disease, diabetes, and adverse maternal outcomes have no genetic basis.

While genetics do not play a role in these inequitable outcomes, the extent to which inequities in the quality of care received by people of color contribute to inequitable health outcomes has been extensively documented.ⁱⁱⁱ These inequities are often a direct result of racism, particularly institutionalized racism – that is, the differential access to the goods, services, and opportunities of a society by race.^{iv} Racial health inequities are evidence that the social categories of race and ethnicity have biological consequences due to the impact of racism and social inequality on people's health.^v It is also critical to note that health care systems have policies, systems and procedures that unintentionally cause inequitable outcomes for racial, ethnic, and language minorities, in spite of genuinely striving to provide equitable care and produce equitable health outcomes.

Health systems should refrain from using other measures, such as income, as a proxy for race as research shows that racial health inequities affect anyone who identifies as a person of color, regardless of income.



For each stage, the detailed roadmap identifies the primary goal, the actors who should be involved, the key questions that need to be addressed, and specific actions to take. Each stage also includes potential pitfalls – based on interviews with representatives from systems and states that have already undertaken this work – and suggested solutions.

Before the stage-based work can begin in earnest, Connecticut stakeholders will need to decide who is leading this effort. Ideally, this would be a group of champions including representatives from government; large and small health care providers representing urban, suburban, and rural areas; patients; and other stakeholders. The champions should form a governing and/or coordinating body that can:

- Serve as the lead convener of the effort.
- Develop and implement an equitable process for decision-making related to this work.
- Build will to bring others on board to work through the stages outlined in this roadmap.
- Provide project management.
- Continually communicate the importance of this work and progress being made.

OVERVIEW OF THE STAGES

Stage 1: Design – The process to decide upon standard REL data elements will build off existing efforts while ensuring consistency across health care providers. Before data collection can begin, key decisions must be made about the standardized data that will be collected, who will be responsible for collecting the data, and the workflow that outlines how the data will be collected. The goal is to develop a process that enables patients to self-report REL data, which is in line with best practice.^{vii}

Stage 2: Data Storage – The second stage involves looking at a health system's data infrastructure, with the goal of ensuring health systems have data infrastructure that can properly record and store REL data, including collecting and reporting standardized REL data and meeting all requirements for data and privacy protections.

Stage 3: Training – Training staff to collect REL data is a key step in implementation. The primary goal is to ensure that the staff responsible for facilitating REL data collection are adequately trained and able to articulate the purpose of the data collection and respond to patient questions, including ensuring patients know that providing data is voluntary. Ideally, even staff who will not be collecting data directly will be trained on the importance of REL data collection to be able to address patient questions.

Stage 4: Monitoring – The monitoring stage focuses on ensuring that data is being collected and checked for accuracy and completeness. This includes quality assurance to ensure recorded REL data matches patient selection, monitoring the rates at which staff fill out the REL fields during an office visit, and assessing the completeness of the data.

Stage 5: Using REL Data at a Clinical Level – This stage focuses on making sure that individual practices, health systems, and clinicians can: 1) review data; 2) identify where inequities exist; 3) prioritize specific areas; and 4) change systems and processes to eliminate health inequities and improve care overall with culturally relevant clinical interventions.

Stage 6: Scaling-Up Data Collection – To address health inequities at a larger scale, REL data collection will need to be implemented in health systems across the state in a coordinated fashion.

Stage 7: Using REL Data at the State Level – The goal of this stage is to stand up a system to analyze REL data at the state level to inform population and community-level interventions to reduce health inequities.

LEARN MORE:

To read more about how other health systems have advanced REL data work and the current state of REL data in Connecticut, **see the first section of the report.**

The full details of each stage are available in **the roadmap.**

Examples from other health systems, including categories used for data collection and scripts for training staff to collect REL data, are available in **the appendices.**



CONCLUSION

Collecting and analyzing REL data in a standardized way across the state would provide the information needed to identify inequities and help better target resources and interventions. This seven-stage roadmap can be adapted to various contexts and serve as a guide for organizations, advocates, and policymakers as they advance and coordinate REL data collection and use. The first step is committing to this work and getting started to build a strong foundation.

It is critical to note that making progress on any equity gap will take time and that collecting REL data is part of a broader health equity strategy. This work involves making health equity a strategic priority, securing resources, developing multi-stakeholder and multi-sector partnerships, developing customized programs/initiatives, building effective and efficient mechanisms, co-designing with community residents, and using continuous improvement methods to improve results over time. IHI has worked with health care systems as part of the Pursuing Equity Initiative to develop *Achieving Health Equity: A Guide for Healthcare Organizations*.

In the wake of the COVID-19 pandemic, Connecticut has an important opportunity to take these key steps to collecting and using the data necessary to identify and eliminate health inequities.

References

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