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SPRING

2021

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

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## BACKGROUND

**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 racial and ethnic health 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’ race, ethnicity, or language preference (REL) to find inequities or intervene when changes could make a difference.**<sup>1</sup> 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 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 it can provide the information needed to identify problems and develop interventions specific to the gaps in care that people of color experience.

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<sup>1</sup> 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.

More broadly, data on patients' race, ethnicity, and language preference – and the analyses to identify inequities in access, care, and health outcomes – is critical to providing high-quality care. These capabilities are likely to be necessary to demonstrate quality in emerging payment systems.<sup>2</sup>

Standardized collection and analysis of REL data is challenging, but doable. Many health systems have already implemented REL data collection and analysis programs, and some states have 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.

## THE PURPOSE OF THIS ROADMAP

At the request of the Connecticut Health Foundation, the Institute for Healthcare Improvement (IHI) created this roadmap to improve the collection and use of REL data in the state. It is intended to help policymakers, advocates, health systems, and other providers and stakeholders advance standardized REL data collection and use by identifying the key steps to achieving this vision. While this work can appear daunting, having and using the data is necessary to move toward a more equitable health care system. Examples from other states demonstrate that it can be done and can help health care organizations deliver better, more equitable care.

This document offers a step-by-step guide but is not intended to be a blueprint to be followed to the letter. Instead, it is an organizing document to help guide stakeholders as they advance the collection, reporting, and analysis of REL data.

It is important to recognize that REL data itself will not solve health inequities. Rather, it is a core component in a broader strategy to achieve health equity and can provide key information to shape other work to address equity. It is most effective when it occurs in conjunction with:<sup>v</sup>

- Making health equity a strategic priority
- Building infrastructure to support equity work (human resources in addition to data)
- Addressing the multiple determinants of health
- Working toward the elimination of racism and other forms of oppression

## 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.**
- **Minnesota's statewide efforts to standardized REL data collection and analysis provide a strong model for Connecticut stakeholders to follow.**

- Partnering with the community to improve health equity (including sharing data)
- Advocating for policy change at the local, state, and national levels

While the focus of this roadmap is REL data, the process 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.

This roadmap was informed by literature reviews, interviews, and an expert meeting with state-level employees, health system leaders, and health disparities researchers in Connecticut, and REL data collection experts in other states (see Appendix A for full list of experts). It also includes perspectives from seven patients via a virtual focus group and a survey.

<sup>2</sup> To learn more about equity and emerging payment systems, see Chin M. Advancing health equity in patient safety: a reckoning, challenge and opportunity. *BMJ Qual Saf* Dec 29, 2020, and Patel S, Smithey A, McGinnis T, Tuck K. Leveraging value-based payment approaches to promote health equity: Key Strategies for Health Care Payers. *Center for Health Care Strategies* January 2021.

## 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.<sup>i</sup> 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.<sup>ii</sup> 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.<sup>iii</sup> 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.<sup>iv</sup> 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.**

that there is no quality in health care without equity; the two must be inextricably linked. Equity must be embedded into all quality and improvement efforts because the differences in health outcomes are not solely due to biological issues. Many systems including education, transportation, food supply, employment, social services, criminal justice, and health care contribute to these inequitable health outcomes. Health care systems must do their part to ensure that their processes and methods do not contribute to or result in inequitable health outcomes.

Many health systems have successfully implemented REL data collection programs and benefitted from them.

Examples include:

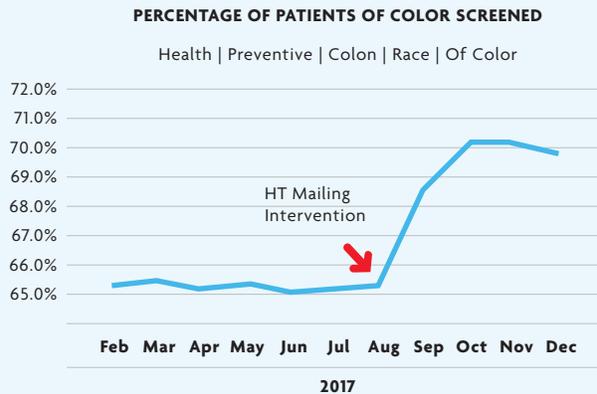
- **Henry Ford Health System, Michigan:** Henry Ford's commitment to eliminating health inequities allowed the health system to stand up successful REL data collection within just one year.<sup>vii</sup> The health system now uses REL data continuously for quality improvement and research purposes.<sup>viii</sup>
- **The Institute for Family Health (IFH), New York:** IFH used the country-of-origin data the system collected to develop a hepatitis B screening program.<sup>ix</sup> The health system identified patients coming from hepatitis B endemic countries and asked them to participate in screening that is not otherwise recommended for the general population.
- **UMass Memorial Hospital, Massachusetts:** UMass's REL analysis of COVID-19 data pinpointed health inequities between racial and ethnic groups in Worcester, MA, and allowed the hospital to intervene accordingly. For example, the Latinx population, which makes up 21% of the community, represented nearly one-third of positive cases. Weekly stratified COVID reports were sent to stakeholders across the system and community, and informed UMass's partnership with the Latino Education Institute at Worcester State University. Together, they hired seven youth community workers to help engage the Latinx community with outreach efforts.<sup>x</sup>
- **HealthPartners, Minnesota:** HealthPartners used REL data to identify an inequity in colorectal cancer screenings among its patients of color. The health system made this data publicly available and then set out to reduce the 12.3% gap between white patients and patients of color. As the chart shows, in just four months, HealthPartners was able to reduce the gap in screenings from 12.3% to 7.1%.<sup>xi</sup> (See chart on page 6.)

## WHY COLLECTING REL DATA MATTERS FOR HEALTH SYSTEMS

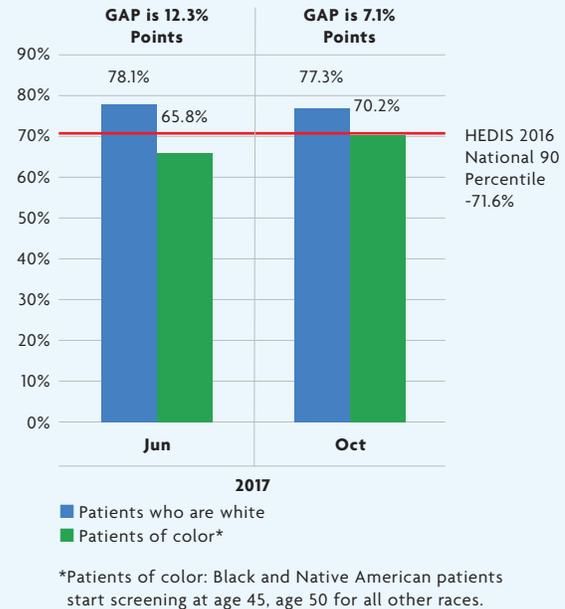
Health systems have missions to improve the lives of all patients in their care. Despite their efforts to treat all patients equally, inequities persist. Understanding the roots of these inequities, and finding ways to intervene, is critical to delivering safe and effective care. Indeed, eliminating 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**.<sup>vi</sup> IHI states

## Colorectal Cancer Screening



**756** more patients of color screened from June to October 2017.



Because inequities exist throughout virtually every system in the U.S., health systems should presume that these inequities are present in their systems. Collecting REL data allows individual health systems to uncover the health care inequities their system produces and view the findings as an opportunity to improve care delivery and fulfill commitments to their patients and their community. When REL data is standardized statewide and shared, it can be used to target inequities more broadly.

## WHAT'S HAPPENING IN CONNECTICUT

Connecticut does not yet have a standardized way for health care systems and clinics to collect, report, and use REL data. There is interest among state officials in advancing the standardization and use of REL data as a means to better identify inequities and address care quality. The state's new health information exchange (HIE), known as CONNIE, is expected to require REL data to be included in the clinical information providers submit.

In the absence of a state policy, many health systems are collecting REL data and, in some cases, analyzing it, but the extent varies. Feedback from health system officials during interviews and an expert meeting offers a snapshot of the range:

- **Yale New Haven Health System:** Data collection occurs but it is inconsistent, and, in some cases, the accuracy is unclear. The health system is piloting REL data collection in specific clinics, including one focused on hypertension. Officials view expanded REL data collection and use as part of a commitment to improve health equity.
- **Hartford HealthCare:** The health system is currently analyzing its baseline data collection and aims to have REL data inform its approach to other measures including readmissions, patient experience, and revenue cycles. The system recently added more granular fields and is training staff to answer questions patients or families might ask.

## INSIGHTS FROM CONNECTICUT PATIENTS

**In a focus group and survey among seven Connecticut patients, four answered 'yes' when asked if they had ever been asked what their race, ethnicity, or preferred language was at a hospital, office visit, or any other place where they were receiving health care services. Three of the four shared that they were asked about race and ethnicity, but not their preferred language, which they felt was a result of their ability to communicate in English. Some said if they had been asked for their preference, they would have not chosen English.**

- **Griffin Health Services:** Griffin has used REL data for several years to identify underserved and at-risk populations through the Medicare ACO program. Griffin also engaged in a hospital-wide awareness campaign to emphasize the importance of REL data. REL data collection allowed Griffin to take part in another grant focused on inequities in diabetes and wellness visits among African American patients.
- **Community Health Center, Inc.:** The community health center historically collected REL data but focused on larger categories and is now moving to more granular categories. Staff asking patients for REL information said doing so was not as difficult as they expected.

Several health care organizations in Connecticut advanced their data collection work through the Community and Clinical Integration Program (CCIP), which was led by the state and funded by the Office of Health Strategy (OHS) through the State Innovation Model. CCIP was designed to encourage health systems to integrate their work with other

organizations, including nonclinical partners, and its requirements included collecting, reporting, and analyzing standardized data stratified by subpopulations, including by race, ethnicity, and language.

Several participants in the expert meeting identified benefits from this work: Yale New Haven Health System representatives said collecting and analyzing REL data as part of CCIP allowed the system to better understand its patients. Hartford HealthCare used CCIP to investigate its existing collection process and identified the need to adapt the electronic health records to accommodate the entry of more than one race, as many patients identify more than one. Griffin Health used CCIP to improve its electronic health records to house REL data.

Overall, the CCIP program demonstrated that REL data collection in Connecticut is possible with appropriate technical and monetary assistance. However, CCIP also highlighted some challenges in REL data collection within Connecticut. Interviews with health systems that did and



did not participate in CCIP, along with representatives from the Office of Health Strategy, identified the following challenges in implementing REL data collection statewide:

- *Technology and infrastructure:* Not all health systems have the infrastructure to take part in REL data collection, particularly smaller, independent health systems. Not all systems have an electronic health record that is able to house the data required. It is not yet clear the scope of this issue and a statewide assessment of smaller health care providers could be useful to understand this challenge.
- *Leadership:* Health system leadership needs to support REL data collection for it to move forward. Interviewees in systems where there was support credited leadership as a large reason why data collection was able to move forward, whereas representatives from systems that lacked leadership buy-in mentioned that it was difficult to collect the data.
- *Putting the data to use:* Most of the health systems we spoke with had only just started to consider how to use REL data. They mentioned that implementing a REL data collection system is complex and that to actually use the data to implement equity interventions requires getting the first step (collecting REL data) right.

At the state level, OHS is spearheading a push toward using REL data to advance equity. One possible vehicle to advance this is the statewide HIE, which is designed to facilitate the sharing of patient information by allowing any provider to access records related to their patients.<sup>xii</sup> CONNIE, Connecticut's HIE, will require hospitals and clinical laboratories to connect within one year of it becoming operational; other health care providers who have electronic health records will be required to connect within two years.<sup>xiii</sup> Representatives from OHS hope that CONNIE can act as a neutral information broker to resolve differences in data storage, collection, and access between health care providers and different state agencies. The REL data collected and shared with CONNIE could potentially inform programs to address health inequities at a state level. Stakeholders we spoke to said that the longer-term benefits of this were clear. However, not all were familiar with CONNIE or convinced of its immediate benefits. To the extent that CONNIE can play a role in broader data standardization work, addressing provider awareness and buy-in will be an important part of will-building efforts.

There are three broad benefits of a coordinated, statewide effort:

1. **Making health inequities by race, ethnicity, and primary language visible.** Having disparities visible to many stakeholders at the patient level, provider level, and local/state-level would foster greater understanding of the inequities that produce disparities and help build will for action. Key players often have a vague sense of inequities from their experiences, but that does not always provide the whole picture. For examples of viewing REL data at each level, see Appendix B.
2. **The ability to use REL data to improve quality of care and health equity.** Once inequities are visible and accurately understood, providers, local and state governments, and advocates will be able to prioritize and target interventions. The data can also be used to show progress on reducing inequities over time, eliminating the need to develop additional measurement systems.
3. **Making the REL data collection and use process easier for both patients and health care providers.** With a coordinated system, patients only need to be asked for their REL data once, rather than by every provider they visit. Similarly, providers would not need to collect REL data for each patient they serve, because once in the system, it could be accessed by any provider serving that patient. All of this can be done while ensuring patient privacy and data protection.



# ROADMAP

The following roadmap is intended to serve as a guide for organizations and policymakers as they work to advance REL data collection and use.

## HOW TO USE THIS ROADMAP

We organized this report into seven stages<sup>xiv</sup>

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

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

In many cases, the questions will need to be answered at multiple levels – the state level (in partnership with health care systems), the health care systems/practice level, and, in some cases, in sub-divisions within health care systems.

The seven-stage process is an iterative one; decisions made at each stage inform the decisions at later ones. Conversely, it will be important to think about the later stages (e.g. using data at the state level) during the earlier stages so decisions align with overall goals for the later stages.

Some key questions are context-dependent and will be answered differently by different health care systems (e.g. who asks for REL data and when), while other questions (e.g. the specific data to collect) will need to be answered and then applied consistently across the state.

The first five stages are focused on a REL data collection initiative in an individual clinic or health system, while the final two stages look at REL data collection and use at the state level.

## CREATING THE FOUNDATION: IMMEDIATE NEXT STEPS

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 for this initiative that can:

- Serve as the lead convenor 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 and technical support
- Continually communicate the importance of this work and progress being made

For more information on building will, see Appendix C.

We also recommend that the Connecticut OHS and CONNIE:

- Develop a list of health care providers throughout Connecticut that includes:
  - > Their current work (if any) collecting, reporting, and using REL data
  - > For those already engaged in this work, a detailed list of the REL data they are collecting
  - > Their current interest in participating in this coordinated, statewide effort including any challenges or concerns they have
  - > Any challenges or concerns they have about connecting to CONNIE
  - > The electronic health record platform(s) they use, including any known limitations
- Clearly outline the benefits of participating in HIE, including the capabilities of the HIE
- Help ensure that the Five-Year Statewide Health Information Technology Plan aligns with these recommendations.

**In a focus group, one patient shared that her multi-racial children are often confused about how to indicate their race on forms.**

The process to decide upon standard REL data elements will build off existing efforts while ensuring consistency across health care providers. Before standardized data collection can begin, key decisions must be made about the type of data that will be collected, who will be responsible for collecting the data, and the workflow that outlines how the data will be collected.

This stage focuses on setting guidelines within health systems and clinics to be operationalized in later stages. The goal is to develop a process that enables patients to self-report race, ethnicity, and preferred language, which is in line with best practice.<sup>xv</sup> To prevent inaccurate data, it is important that patients self-report REL data rather than having staff rely on their own observations when recording data.

## WHO'S INVOLVED

Achieving the goals of this stage will require involvement from a variety of stakeholders including:

- Frontline staff
- Clinicians
- Hospital or practice administrators and clinical leadership
- State agencies (e.g., OHS)
- Researchers focused on health and/or equity
- Chief information officers
- Patients and families

## KEY QUESTIONS

By the end of this design stage, organizations should have clearly identified what type of data will be collected, who will be responsible for data collection, and the best data collection workflow. The following questions will be helpful for decision-making in these areas:

### THE DATA BEING COLLECTED

- Which (if any) of the variables recommended by the IOM will be adopted? (See Appendix D for the IOM recommended variables)
- Which racial categories will be included in the data collection standards?

- Which ethnic categories will be included in the data collection standards?
- Which languages will be included in the data collection standards?
- How will we collect granular ethnicity data?
- To what extent will the HIE be able to standardize the data after receiving it?
- Will country-of-origin data be collected?
- How can health systems engage the broader community for support in data collection?
- How will we use/define the categories “unknown,” “other,” and “decline to answer”?
- How will we assure that patients have the option to decline to answer/opt-out? How will we assure they know of their right to opt out?
- How will we learn from and adapt our systems based on what's written in alongside “other”?

### THE PEOPLE COLLECTING THE DATA

- Who will be responsible for asking the questions (if verbally) or handing patients forms?
- Who will be responsible for overseeing the management of the data from beginning to end?
- Are there multiple places and touchpoints during which the data can be collected? (e.g., lab, emergency department, routine visits)

### THE DATA COLLECTION WORKFLOW

- When will patients be asked for this information?
- Where will the data be stored?
- How will the data be collected? (e.g., verbally, paper form, patient portal, etc.)
- In what order will the questions be asked?
- How can we ensure patients aren't asked for their responses multiple times unnecessarily across Connecticut's health care systems?

- How can we co-design these processes (where they're asked, what the standards are) with patients?
- What can we learn from community-based organizations regarding the data they collect and their best practices?

Several of the health systems we interviewed and came across in the literature adopted the IOM recommendations for collecting REL data and included additional data elements such as country of origin or insurance status. Some stakeholders recommend using the CCIP REL data standards. For health systems using this roadmap to design their REL collection, we recommend including country of origin in the required data elements. Involving CONNIE from the beginning of these conversations could help with standardization.

Data collection can occur in many ways and be done by many different staff, depending on the organization. Health systems can consider having patient service representatives, registration staff, or medical assistants collect information from patients. Data collection may happen during registration, the rooming process, or even when patients access their electronic health record before checking in for an appointment. These decisions depend on what is feasible given each system's workflow and resources. Testing various options with the first organizations that implement this approach can build will and give a sense of what will work best in each individual context.

Interviewees recommended being aware of collection methods that could potentially introduce biases. For instance, Mass General Brigham tried a process that involved giving iPads to patients to self-report during the registration process and waiting period, but found that white patients were more likely to be given the iPad than non-white patients. Appendix E details further how health systems outside of Connecticut assessed their workflow and resources to answer some of the questions above.

Ideally, patients will only be asked these questions once (or perhaps once a year to verify) and the data will follow them to any provider they see in Connecticut. The statewide HIE could facilitate this among participating organizations; for example, as a patient uses another provider, the HIE could "push" the existing REL data to the new provider so that the new provider doesn't have to ask these questions again.

## CHALLENGES AND SOLUTIONS

### 1. BUILDING WILL AMONG STAKEHOLDERS

Building will among relevant stakeholders both at the health system and state level is an essential part of implementing a REL data collection initiative. In our interviews, several

## INSIGHTS FROM CONNECTICUT PATIENTS

### Who collects REL data:

- **In a focus group and survey, 5/7 patients indicated they were somewhat comfortable being asked by registration or reception staff.** One patient noted feeling unsure if receptionists were qualified and trained to ask those questions and skeptical of their agenda since they are not the ones providing care. Overall, explaining the "why" can help make a patient feel more comfortable. 2/7 felt very comfortable; one described feeling more comfortable during the registration process knowing their providers can check in advance of entering the room.
- **6/7 patients indicated they were very comfortable being asked by medical assistants and 5/7 patients indicated they were very comfortable being asked by their providers.** Most patients agreed that being asked directly by a member of the care team helps patients trust that the information will be used to improve their care. One patient indicated feeling uncomfortable being asked by medical assistants and providers, preferring registration staff.

### How REL data is collected:

- **2/7 patients preferred verbal collection,** because tone of voice can add comfort and the question can be used as a conversation starter to break the ice and understand more about the patient's background and health needs/desires. One patient worried about others overhearing verbal conversations.
- **3/7 preferred an iPad and 2/7 preferred a paper form.** One patient who preferred a paper form noted that patients are already used to receiving paper forms at the doctor's office, and that reading on paper allows them to better process the questions. The other mentioned technology hacking concerns when explaining preference for a paper form.
- In conversation, a patient noted that people visiting the doctor might not feel well and therefore may not feel up to answering these questions, recommending patient portals or other ways to ask outside of the visit.

health systems highlighted the need for senior leadership to make REL data collection a priority and commit to removing barriers, as well as for champion(s) to push forward the initiative. The unequal effects of the COVID-19 pandemic across race and ethnicity have shown that there is still a long way to go in ensuring equitable treatment for everyone, which many have used as a catalyst for building will.

Naming racism as a public health emergency is one way to build momentum around the need for REL data collection. This declaration by state and local leaders can create the impetus to allocate resources toward initiatives addressing racial health inequities.<sup>xvi</sup> This declaration should be coupled with an explicit mandate to develop more equitable policies to combat racism in health care and all other systems that contribute to inequitable health outcomes. Those responsible for responding to the public health emergency would use REL data to identify health inequities, help determine the policy changes needed across the contributing systems, and assess the impact of any policy changes. Individual health systems, along with state and local communities, can also use REL data to prioritize their efforts to eliminate any identified inequities. Through all methods of building momentum, it's important to have a clearly defined set of goals that REL data collection is intended to address and that various stakeholders have helped craft.

Another approach to building will is to make the case for this work. In Minnesota, the Governor's Health Care Disparities Task Force outlined the business and clinical cases for collecting REL data.<sup>xvii</sup>

- **Business Case:** Minnesota had the greatest proportion of immigrants in the nation, which has implications for future demographics. Effective REL data collection can improve the quality and cost-effectiveness of care by allocating a health system's limited resources where they are most needed.
- **Clinical Case:** Effective REL data collection allows for improved quality of care by targeting resources for populations at risk for specific conditions, identifying crucial support services (e.g., interpreters), or providing better access to preventative screenings for specific populations.

To build will among stakeholders, Connecticut could make a similar case that reflects the state's context.

## 2. STANDARDIZING REL CATEGORIES ACROSS ORGANIZATIONS

The overall goal of standardizing data collection and use is to collect REL data that can be used both at the individual health system level and be shared widely to inform state-level policies. Therefore, it is important that there are clear data collection standards.

Those leading this initiative will need to consider which state organizations will coordinate with health systems across the state to produce these standards. In Massachusetts, for example, the state and the city of Boston collaborated to develop a standard data collection tool.<sup>xviii</sup> We suggest that Connecticut follow a similar route but also include health systems, community organizations, and patients to provide needed input to design this standard data collection tool. This will ensure that there is consistency across different parts of the health system and between health systems more broadly. Connecticut should also explore the extent to which the HIE can assist with standardization of the data it receives.

## 3. DETERMINING APPROPRIATE REL CATEGORIES AT THE HEALTH SYSTEM LEVEL

When determining the appropriate racial, ethnic, and language categories to include, health systems describe the tension of trying to capture the data in a way that is usable but also reflects how patients describe themselves.<sup>xix</sup> Many turn to prepopulated lists, such as the CDC Race and Ethnicity Code Set, to inform the options presented. However, these lists can be overwhelming and difficult for both patients and staff to understand and use. We recommend that those leading this effort work with health systems to produce a master list of racial and ethnic categories as part of the REL data collection standards suggested above.

However, local health systems and clinics may need to narrow and refine these categories to prevent overwhelming patients and staff, as recommended by the IOM and reiterated by several people we interviewed. Looking at other data sets, such as city or county Census data, can help pare down the options to only include populations prominent in the area. Speaking to frontline staff about which races, ethnicities, and languages to include can be helpful, as they interact with patients the most. Community organizations interact with people outside the health care system more broadly and their experiences can help inform what to include. The aim should be to create lists for local health systems that reflect the surrounding community and can be reviewed and amended over time. Appendix E gives example of how health systems have addressed this.

The second stage involves looking at a health system's data infrastructure. The primary goal is ensuring health systems have data infrastructure that can properly record and store REL data.

REL data is typically recorded in electronic health records (EHRs). The variation among EHRs requires health systems to assess their readiness to collect REL data and make any necessary changes.

Any work to address EHR capabilities should be done with an awareness of the statewide HIE, which aims to create a centralized "system integrator" that can be accessed by any provider delivering care to patients, regardless of where they access care.<sup>xx</sup>

## WHO'S INVOLVED

- Chief information officers in health systems
- Health system analytics staff
- CT OHS
- Managers of the HIE
- Regulatory bodies
- Health plans

## KEY QUESTIONS

- Can the current EHRs adequately store REL data?
- What improvements in the existing EHR fields need to be made?
- What will be done with previously collected REL data?
- Will EHRs allow patients to select two or more racial and/or ethnic categories?
- Will there be a space to write in after selecting "other"?
- Will the EHR require staff to fill in REL fields?
- What policy and other barriers exist and how might we work to address them? What types of incentives might support this?
- How will any changes to EHRs ensure continued alignment with requirements of health plans/payors?

## CHALLENGES AND SOLUTIONS

### 1. LIMITED EHR CAPABILITY

Not all health systems and clinics have EHRs that can record and store REL data or make changes that will be needed to adopt an agreed-upon set of measures from Stage 1. OHS reported, as of September 2020, that it didn't yet have a complete picture of what systems and providers had an EHR that couldn't record REL data or that didn't have an EHR.<sup>xxi</sup> Because the extent of this issue is unclear, an important next step will be a more thorough canvassing of health care systems, including smaller and independent clinics, to understand the current capabilities and needs. This speaks to the importance of OHS and CONNIE administering a statewide survey of all hospital systems and health care providers to efficiently gather this and other baseline information. Once the full scope of the challenge is understood, providers with EHRs that cannot accurately record or store REL data will likely need resources to adopt newer EHRs and technical assistance to configure them to the needed settings. OHS will need to provide guidance and support around this.

### 2. LACK OF CLARITY ABOUT IMMEDIATE BENEFIT OF THE HIE

While all providers with EHRs will ultimately be required to connect to the HIE, providers do not have to do so immediately. Previous failed attempts to create a statewide HIE leave some providers skeptical that the current effort will succeed. OHS and CONNIE should communicate the benefits of the HIE and plans for viability to these health systems, especially independent systems that are not attached to academic health centers. Starting by adding academic health systems to the HIE may help generate use cases for smaller, independent health systems that will encourage them to join the HIE once they see its benefits. Smaller and less-resourced health care organizations might need financial support to join the HIE. CONNIE currently has federal funding to support this and should ensure providers are aware of this opportunity.

Training staff to collect REL data is a key step in implementing REL data collection initiatives. 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. Ideally, all staff will be trained on the importance of REL data collection.

Many experts we interviewed highlighted the need for staff training. Due to the sensitive nature of talking about race and ethnicity, staff often express discomfort with asking the questions. However, health system officials we interviewed stated that when staff are trained on how to ask these questions, including receiving scripts with answers to commonly asked questions, they feel more comfortable asking patients for REL information. Appendix F outlines sample scripts used by other health systems. Training to overcome staff discomfort is especially critical because of the importance of having patients provide the answers about their race, ethnicity, and language preference, rather than having staff estimate based on observations. The questions asked by staff should reflect the decisions made by health systems on what to collect in Stage 1.

## WHO'S INVOLVED

- Patients and families
- Frontline staff
- Hospital administrators
- IT staff
- Subject matter experts
- Quality assurance/quality improvement staff

## KEY QUESTIONS

- Who will be trained?
- Who will be responsible for/overseeing/administering the training?
- How will we train current staff? How frequently will we offer refresher trainings?
- At what point in a new hire's orientation will they be trained?

- How might we co-design questions and answers with patients?
- How will we ensure that patients know they can opt out?

Additionally, the following questions should be addressed in training sessions to help staff feel more comfortable collecting REL data:

- How will collection of this information be framed to staff, community, patients, and families?
- How will that framing differ for individuals who are new to the U.S. or who come from countries where these questions are never asked?
- In what order will staff ask the questions?
- What is the difference between race and ethnicity? (This should include education on race as a social vs. biological construct)
- What should staff do if patients decline to answer the questions?
- Will REL collection take significant time?
- Why does this data need to be collected?
- How do we plan to use these data?
- How can we ask these questions in a respectful and culturally appropriate way?
- How do we ask questions to confirm/update data already in the system?

The decision on exactly who to train will likely need to be made by each health system, in accordance with state and federal data and privacy protections. At a minimum, training should be provided to those who will be asking or otherwise obtaining the REL data, those who will be using the data, those who will be monitoring the process within a health system or clinic, and those who supervise these positions.

Framing the importance of REL data collection to staff, community, patients, and families is also critical during this stage. The “Why We Ask” campaign, used by several health systems, including Henry Ford Health System, provides a great example. Henry Ford provides a brochure in multiple languages that explains to patients that the system asks for REL data to reduce health inequities and improve care.<sup>xxii</sup> The brochures also include answers to frequently asked questions including how the data is collected and who sees the data.

**In a focus group of Connecticut patients, one patient shared that people often assume she is white but she is actually bi-racial, underscoring the importance of asking rather than guessing based on observations.**

**Another patient reflected that while they can see how understanding preferred language would be useful for their provider's care plan, they felt some discomfort and confusion about how knowing race or ethnicity would, highlighting the need for a clear articulation of the "why." Others in the group understood how asking these questions can be a gateway to improved care, agreeing that many understand the "why" because of COVID-19.**

There are several resources on training staff to collect REL data and respond to patient questions that can be adapted for each health system's needs. The Health Research and Educational Trust (HRET) Disparities Toolkit<sup>xxiii</sup> and the MN Community Measure (MNCM) Handbook on the Collection Race/Ethnicity/Language Data in Medical Groups<sup>xxiv</sup> provide examples of scripts to use as starting points, along with responses to questions commonly asked by staff.

## CHALLENGES AND SOLUTIONS

### 1. LACK OF BROADER PROVIDER TRAINING ON REL DATA COLLECTION

One study found that when REL data is collected by registrar staff or medical assistants, patients may later ask clinical providers why the data is collected.<sup>xxv</sup> If a health system decides that clinical providers are not responsible for collecting REL data, clinical providers should still have some form of training to help familiarize them with the data collection process and the reasons for collecting the data.

### 2. CONCERNS ABOUT PRIVACY

Staff may raise concerns about the legality of collecting REL data. Patients may also express privacy concerns about their information. Staff training should address the legality of REL data collection and its compliance in line with HIPAA guidelines and a patient's right to decline to answer/opt

out. Patients who are undocumented immigrants may also be concerned that information may be used against them. In addition to training staff to assure patients that the data will not be used in this way, hospital administrators can engage in campaigns that communicate the purpose behind information gathering, such as the "Why We Ask" campaign (also known as the "We Ask Because We Care" campaign).<sup>xxvi,xxvii</sup> These campaigns communicate the need to improve quality of care and reduce health inequities directly to patients.



# STAGE 4 MONITORING

The monitoring stage focuses on ensuring that data is being collected and checked for accuracy and completeness. The goal is to craft a workflow that supports analysts specializing in REL data to address challenges in collection. 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. As an example of a benchmark, participants in IHI's Pursuing Equity initiative determined that a goal of 5% of patients with missing race or ethnicity data is possible, with a lower percentage for missing preferred language data.<sup>xxviii</sup>

## WHO'S INVOLVED

- Hospital administrators
- Data analysis staff
- Chief information officers
- CT OHS
- Frontline staff
- Patient advisory groups

## KEY QUESTIONS

The following questions should be addressed to develop a robust monitoring function:

- Where will this function be housed?
- What are the target REL data collection rates?
- Who will be responsible for addressing high incompleteness rates?
- How will responses be validated?
- How will flaws in the data collection process be addressed?
- Will reporting to the state be required?
- How might patients and communities be involved in monitoring? How can we make the data publicly available?
- What sort of technical assistance and support will be needed to be successful?
- How might data be assessed and validated longitudinally?

The question of “where should the monitoring function be housed?” needs to be answered at several levels: the state level, the health system/hospital/practice level, and, in some cases, within different divisions of health systems.

Building the infrastructure for REL data monitoring can help set the system up for success. Organizations that participated in IHI's Pursuing Equity initiative engaged analysts who specialize in REL data to help address challenges in interpretation and application of the data. For example, Kaiser Permanente's national data analytics team has assigned a manager to be responsible for REL data applications, contributing to both national and regional equity improvement work. REL data should be treated like any other patient information in terms of quality assurance, integrity, stewardship, and confidentiality.<sup>xxix</sup>

## CHALLENGES AND SOLUTIONS

In the early stages of implementing a REL data collection initiative, data should be monitored frequently.<sup>xxx</sup> This will help to uncover any challenges in the process and focus efforts to create a standard, seamless workflow. Large health system will likely be able to embed this into existing analytics and/or quality assurance departments. However, smaller health systems and practices will need support to make progress in this stage. Other challenges that could arise in monitoring data include:



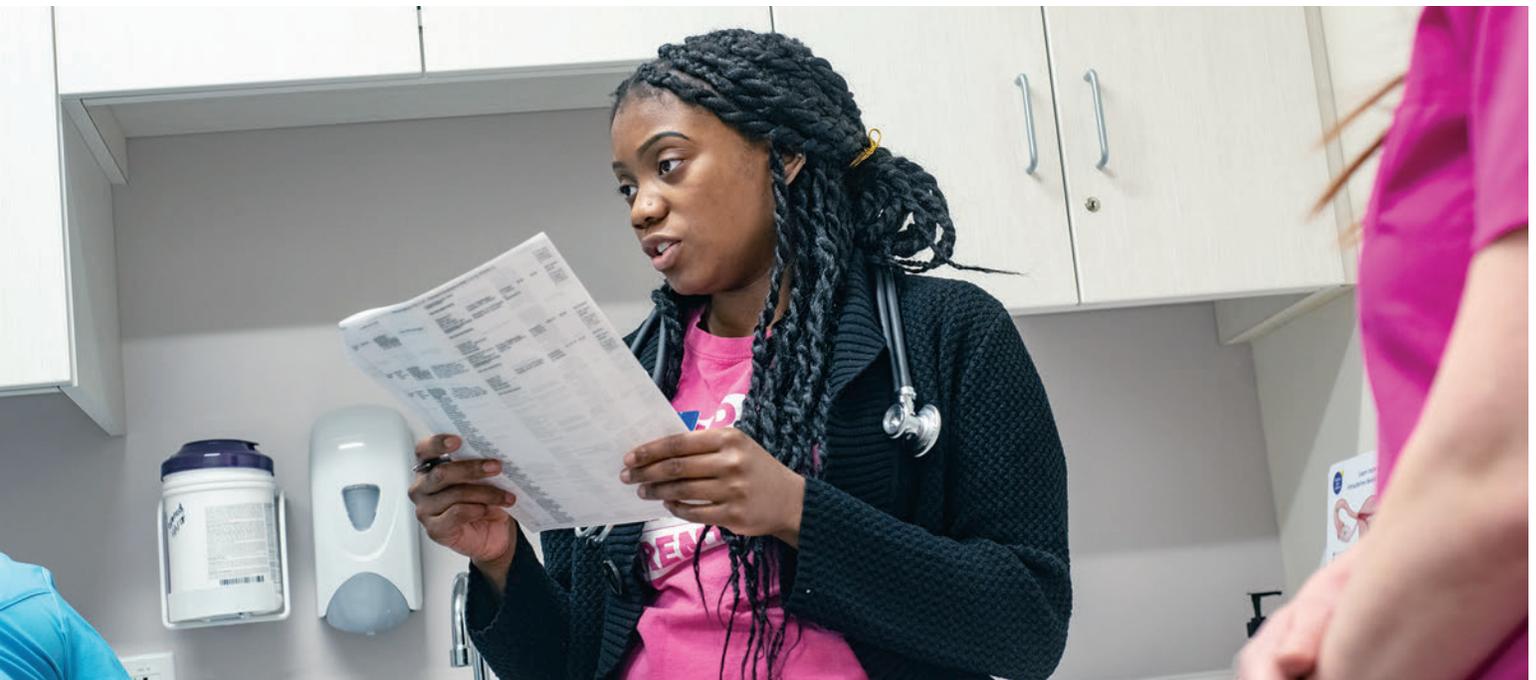
## 1. VALIDATION OF DATA

The best practice in REL data collection is having patients self-report their data to ensure accuracy. Confirming that staff are allowing patients to self-report can mitigate incorrect data collection. The following are additional ways that health systems can review data to ensure REL categories recorded in a patient's record match their choices, as practiced by organizations taking part in IHI's Pursuing Equity initiative:<sup>xxxii</sup>

- Validation sampling: Health systems can randomly select a sample of patients to ask about REL data categories and compare it to REL data information. Systems should determine an appropriate sampling and analysis plan with their experts in information and/or quality systems.
- Observation of patients: Having an observer watch the REL data collection process can help determine how well patients understand what is being asked. Making a point to learn from patients about how the process can be improved will help shape an efficient process.
- Observation of staff: Health systems can look at how consistently staff ask the REL questions to patients and whether the encounters are in line with organizational protocol. As few as five observations can reveal a lack of consistency.

## 2. HIGH RATES OF “DECLINED” OR “NOT COLLECTED” ENTRIES IN REL FIELDS

While some patients may decline to answer questions, research shows that most patients are comfortable answering questions about REL data.<sup>xxxiii</sup> Significant rates of “declined” or “not collected” answers or inconsistency in collection may indicate a lack of staff confidence in asking the questions and/or a lack of clarity around the reason for collection. Minnesota performed real-time data quality surveillance by monitoring the percentages of race distribution at each practice as they were submitting data. Clinics with very high proportions of white patients were flagged for further review. One solution to consider is offering refresher courses to the staff responsible for collecting the data. It may also be helpful to revisit the workflow for data collection. Some REL collection initiatives have found that asking patients the questions verbally is more successful than having them fill out a form.<sup>xxxiii</sup> Others found that patients using a tablet to fill out their answers had higher rates of success.<sup>xxxiv</sup> Data fields should be designed to require patients to specify their race, ethnicity, or language if they select “other.”



The fifth stage focuses on making sure that REL data is being used meaningfully at a clinical level. The primary goal of this stage is ensuring practices, health systems, and clinicians can review data and identify where inequities exist, prioritize specific areas, and change systems and processes to eliminate gaps between groups and improve care overall.

Collecting REL data is ultimately in service of improving health equity, particularly by eliminating racial and ethnic health inequities. However, many health systems fail to properly use the data they collect to these ends. Over 90% of hospitals in the American Hospital Association report collecting race, ethnicity, and language data, but only 23% say they use the data to identify inequities in clinical quality indicators.<sup>xxxv</sup>

One of the first steps in using data meaningfully is to create dashboards to monitor select clinical outcomes and process measures, with data stratified by race, ethnicity, and language. Stratifying these outcomes allows health systems to identify quality gaps and health inequities within and across subgroups and respond with appropriate interventions. These data can also help inform the services offered by hospitals, including interpreter services, screening for specific diseases, and tailoring the workforce to reflect the population served. Dashboards should be designed with the end objectives and use in mind to ensure they are optimal for analysis and intervention design.

Minnesota's dashboards are publicly available at <https://mncm.org>. They track data:

- On 12 priority health conditions (e.g. diabetes care, colorectal cancer screening)
- By race, ethnicity, preferred language, and country of origin
- By hospital

While the Minnesota<sup>xxxvi</sup> dashboards are statewide, health systems can create and use their own dashboards as well.

Minnesota also offers several powerful examples of how REL data can be used to improve care, including:

- In one of its clinics, HealthPartners identified a gap in mammography rates between white women and Black women. Further investigations revealed that offering same-day screening was a more effective way to increase mammography rates for Black women. With this change, the gap between the screening rates for white women and Black women decreased from 16% to 2%.<sup>xxxvii</sup>

- HealthPartners also developed customized scripts for talking with Black patients about the importance of colon cancer screening due to their increased risk of dying from the disease. Based on the success of this effort, HealthPartners created additional educational materials for patients based on their cultural values and health needs.<sup>xxxviii</sup>
- After analyzing its REL data, Allina Health System noticed that the hospitals in its system were not referring Black patients to hospice programs at the same rate as other populations. As a result, Allina's health equity team took steps to address these unequal referral rates, including training hospital staff on implicit bias.<sup>xxxix</sup>

## WHO'S INVOLVED

- Analytics or health IT staff
- Frontline workers
- Staff involved in patient outreach
- Population health teams
- Quality improvement teams
- Community partners
- Patient advocates
- Community health workers
- Health system leadership
- Payors, employers, state agency leaders

## KEY QUESTIONS

The following questions should be addressed to ensure the data is used to reduce health inequities:

- Who will create the dashboards?
- What are the high-priority clinical metrics that should be stratified?
- How can we measure non-clinical measures of equitable care (e.g., access and transitions)?<sup>xl</sup>
- How will we display this data?
- How will we explain why we see inequities in our health care processes and outcomes?
- Who/what team will be responsible for reviewing the dashboards to identify and eliminate inequities?

- How often will data be reported?
- Who will receive reports?
- Who will be responsible for developing interventions?
- How will we target interventions?
- How can we co-design use of this data and design of interventions with patients?
- How can our interventions integrate with community-based organizations and social services?

## CHALLENGES AND SOLUTIONS

### 1. TIME BETWEEN DATA COLLECTION AND CONTEXTUALIZED INTERVENTIONS

Interventions designed to eliminate racial and ethnic health inequities must be informed by trends seen in REL data. Analysis of REL data will help health systems decide which inequities to prioritize. However, it will be some time before this is available to health systems and interventions can be contextualized to address the inequities present in their specific community.

Fortunately, there are several areas that can be preliminarily identified for improvement using REL data collection. These

include informed interpreter and other language services, better aligning the health workforce, better understanding of the demographics of a community served by an organization, and determining workforce needs and satisfaction. For example, one clinic looked at its adherence rates after collecting REL data and learned it had a significant Portuguese-speaking population. This countered the clinic officials' assumption that they had a large Spanish-speaking population, and they began translating their material into Portuguese as a result.<sup>xii</sup>

In addition, any priority clinical metrics the health system focuses on can be stratified by REL measures and may reveal major areas for improvement that were masked when all patients were lumped together. Suddenly, a metric that was difficult to change might become one that is modifiable by targeting a specific subpopulation with poorer outcomes.

### 2. HOW TO MEASURE EQUITABLE ACCESS AND TRANSITIONS

While REL data is typically used to focus on clinical measures that inform quality improvement, there are other process measures that create a more complete picture of health inequities. Measures that focus on access to health care and transitions within the health system can highlight



areas where inequities can affect overall health outcomes.<sup>xlii</sup> Access to health care is defined as whether patients can gain entry to the health care system.<sup>xliii</sup> Transitions measures look at whether patients are being referred to services equitably as they move through the health care system. Examples of these process measures can include return visits and whether patients remain engaged in care and follow-up.

While there is no standard way to measure health care access or transitions, there are a few methods that could be useful. Potential measures for health care access include the number of days to appointment (i.e. how long it takes for a patient to receive an appointment), whether patients have a regular doctor, or whether patients who received care from primary care or cardiac units are coming back for follow-up appointments.<sup>xliv</sup> Potential measures for health care transitions include referral rates to services such as hospice or cardiology care. For example, an analysis conducted by Brigham and Women's Hospital's Department of Medicine Health Equity Committee using 10 years of REL data found Black and Latinx patients with heart failure were less likely to be admitted to cardiology for heart failure care compared to their white counterparts.<sup>xlv</sup> The finding was seen as a partial explanation for racial inequities in heart failure outcomes. Brigham and Women's Hospital is in the process of developing interventions to address this inequity.

### 3. USING THE RIGHT DATA, THOUGH IT MAY NOT BE PERFECT

While implementing a REL data collection initiative may take some time, it is important that health systems make use of the data rather than stopping at collection. Some health systems may want to delay using data to inform interventions until they know it is perfect and that all measures can be stratified, but that may take several months or even years.<sup>xlvi</sup> Though the data may be imperfect at the beginning, it is still important to translate the findings into actionable items.

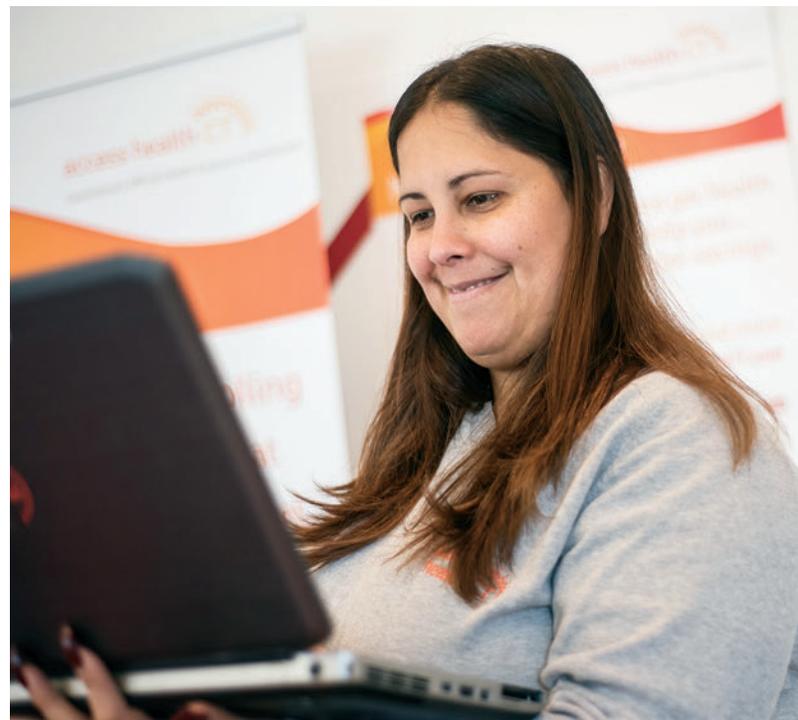
Capturing race can seem counterintuitive as race is a social construct and can be difficult to define. However, it is important to capture this data to properly display the role racism plays in health inequities and adequately address them. Health systems should refrain from using other measures, such 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.<sup>xlvii</sup> Additional measures can be valuable but should not be used in place of race.

### 4. USING THE DATA TO GET A FULL PICTURE

Once health systems have collected an appropriate amount of REL data, it is important to not solely rely on aggregate data for developing interventions. Disaggregating race or ethnicity data, specifically through the collection of granular ethnicity data, allows health systems to have a more complete picture of their population's health and illuminate blind spots of inequities. For example, one health system found that Cuban mothers had better maternal outcomes compared to other Latinx mothers.<sup>xlviii</sup> This result could have only been achieved by collected granular ethnicity and country-of-origin data and stratifying the results accordingly.

### 5. UNDERSTANDING AND ADDRESSING STAFF CONCERNS ABOUT THE FRAMING OF RESULTS

The initial results of this effort might be anxiety-provoking for providers as existing disparities are made visible. They might also feel responsible for or blamed for what are actually the end results of systemic racism (across many systems) and other barriers to optimal health. Those leading this effort should frame it as “data for improvement” and not “data for judgment” and promote the view that it is everyone's responsibility (not just health care's) to redesign the various systems that produce inequitable outcomes in Connecticut.



The previous five sections describe key stages to implement a REL data collection initiative in individual clinics and health systems with the aim of reducing inequities. However, to identify and 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. The goal of the sixth stage is scaling up REL data collection across the state.

In 2007, Minnesota began a process to implement a statewide collection of REL data.<sup>xlix</sup> The state’s process involved convening a small number of health systems, known as the “Early Adopters Work Group,” that were already collecting REL data. After discussing enablers and barriers to REL data collection in their systems, they drafted a set of recommendations for another group of health systems, known as the “Ready and Willing,” for feedback. These recommendations helped leaders at the “Ready and Willing” health systems to implement REL data collection initiatives of their own. After testing with the “Ready and Willing” group and working out any issues with REL data collection, the state allowed voluntary reporting of REL data in 2010 and made it mandatory in 2011. Connecticut should explore using a similar process to implement REL data collection across the state.

## WHO’S INVOLVED

- Hospital administrators
- Community organizations
- Patient advocates
- State agency leaders
- CT OHS
- CONNIE/HIEs
- Hospital IT services
- Relevant associations (i.e., Connecticut Hospital Association)
- Statewide multisector collaboratives

## KEY QUESTIONS

- Who will be the initial early adopters?
- In what phases will the scale-up occur?
- Who will coordinate this scale-up effort?
- What incentives will health care providers have to collect REL data?
- What resources will the state provide?
- How will data collection be regulated?
- How will Connecticut generate health care provider and community buy-in?
- How might we make data publicly available?
- How might we engage patients in statewide use of REL data?

## CHALLENGES AND SOLUTIONS

### 1. COMMUNICATING THE VALUE OF SHARED, COLLECTIVE DATA USE

The state should clearly articulate the importance and value of shared, collective data use. Some health care providers may see REL data collection as one more thing required by the state that will not have any impact on their day-to-day work, rather than a way to help them improve patient care.<sup>i</sup> This is especially true if the state fails to communicate what the data will be used for.<sup>ii</sup> Making a business and clinical case for REL data collection, as was done by Minnesota (detailed in Stage 1),<sup>iii</sup> can help address these concerns.

### 2. VARIATION AMONG HEALTH SYSTEMS IN ABILITY TO COLLECT DATA

It will likely be easier for larger, integrated health systems to implement a REL data collection initiative compared to unintegrated systems and smaller clinics. There will also be variation and limitations in different hospital IT systems across the state. It is important that the state government is aware of these limitations and works with health care providers to address them. Ensuring providers have adequate monetary and technical resources will be especially important, a lesson learned in the recent CCIP program, which catalyzed some REL data collection in Connecticut.<sup>iiii</sup> Technical experience from those outside of Connecticut who have implemented REL data collection initiatives would be helpful for health systems.

### 3. VARIATION IN DATA QUALITY

The aim of statewide REL data collection is being able to compare data. This requires the data collection initiative to produce comparable, reliable, quality data. But with differing priorities and standards for data quality and completeness, health systems and providers may provide data that is difficult to aggregate. Designing a system at the state level that explicitly outlines the minimum data collection requirements (as was recommended in Stage 1) can mitigate this challenge. Regulation by the state early on can ensure data is comparable between institutions. The HIE provides an opportunity to outline specific guidelines for data standards and quality.

### 4. ADDRESSING COMMUNITY CONCERNS

In 2018, Connecticut considered legislation that would have required the collection of granular ethnicity data in the health and education sectors. During the public debate of these bills, many community members expressed concern that the data would be used to discriminate against them.<sup>liv</sup> Ultimately, the bills were not passed. Were the state to sponsor a concerted effort to collect REL data that would include the collection of granular ethnicity data, these concerns would need to be addressed and concrete guardrails put in place to ensure data is not misused. Partnering with community stakeholders and patient advocates in the data collection and scale-up process can help facilitate community buy-in.



As was true at the local and health system level, the aim of REL data collection at the state level is to use the data in service of reducing inequities across the state. Therefore, the goal of the seventh 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.

This could ultimately occur even more broadly. For example, Connecticut’s OHS hopes to eventually expand this work to also include community-based organizations and social services for full community integration.

There are multiple ways REL data can be used at the state level, including but not limited to:

1. Informing policy recommendations to address the elimination of health inequities
2. Informing state-level interventions, such as funding and other resources, and assessing their impact
3. Comparing clinical quality performance and access among populations, provider groups, and accountable care organizations (e.g., using data in the HIE)
4. Identifying what health and other services are being provided to racial, ethnic, and language minorities, and determining if there are any gaps in services
5. Informing the selection of clinical quality metrics for Medicaid and other value-based payment programs
6. Looking at who is missing from data and who is not getting services (e.g., comparing the data to data from the all-payer claims database)
7. Learning from challenges and successes in the elimination of equity gaps

## WHO’S INVOLVED

The following actors should be involved in creating and maintaining this system:

- Department of Social Services
- Department of Public Health
- OHS
- Other local and state government agencies
- Relevant associations and groups (i.e., Connecticut Hospital Association and DataHaven)
- Community-based organizations
- Patients and families

## KEY QUESTIONS

The following questions should be answered when determining how REL data will be used at a state level:

- Which department(s) will be responsible for and oversee the statewide REL data collection and use initiative?
- Which department(s) are accountable for using the data and addressing the findings?
- Who will conduct state-level data analysis?
- How will measures be prioritized?
- How often will data be reported?
- How will data be used to support planning and priorities?
- How else will the state use this data?
- Who will receive reports?
- What feedback loops will exist to help determine what actions (if any) are taken as a result of the analysis?
- How might data be assessed and validated longitudinally?
- How will data be used for improvement and not for judgment?

States that have hospital systems collecting standard REL data are generally at early parts of this stage, so there are fewer best practices, promising practices, and anecdotes to share. The Minnesota State Legislature established the Eliminating Health Disparities Initiative (EHDI) with the charge of eliminating the equity gap in the following priority areas:<sup>lv</sup>

1. Breast and cervical cancer
2. Diabetes
3. Heart disease and stroke
4. HIV/AIDS and sexually transmitted infections
5. Immunizations for adults and children
6. Infant mortality
7. Teen pregnancy
8. Unintentional injury and violence

EHDI leaders recognized that the issues contributing to these health inequities are complex and result from an interplay of many economic, social, and individual factors.

Making progress on closing these equity gaps would, therefore, need to involve a core stakeholder group beyond health care and public health, including community-based organizations, community residents, and local, county and state government agencies that influence the social determinants of health. They also recognized that these initiatives would have to be community-based and community-driven. This led to a series of requests for proposals for local community-based efforts to reduce the equity gap in each of these eight priority areas beginning in 2017. It also led to the creation of The Center for Health Equity within the Minnesota Department of Health. To date, this work has included identifying local partners for each of the eight priorities, scaling up their programs, and building a shared measurement system needed to track progress. As of 2018, these community-based programs were reaching nearly 90,000 racial, ethnic, and language minorities directly and another 300,000 indirectly. Early outcomes include:

- 83% of pregnant women participating in EDHI-funded programs (all racial, ethnic and/or language minorities) began prenatal care in the first trimester (as compared to an 81.8% of mothers in Minnesota overall who initiated prenatal care in the first trimester in 2016).
- The clients participating in programs to reduce heart attack and stroke risks for racial, ethnic and/or language minorities report significantly more physical activity when participating in the program, compared to before the program (4.08 vs 2.86 days/week). In addition, prior to beginning the program, 39% of participants were not thinking about or planning to make changes to their physical activity levels. However, while participating in the physical activity program, that number reduced to 25%.

## CHALLENGES AND SOLUTIONS

### COORDINATION AT THE STATE LEVEL

Experts in other states emphasized the need to have a centralized office with leadership, a budget, and a set of priorities to have a robust and sustainable state-level REL data collection program. If no one takes ownership of the process, there is an increased likelihood that the data collected will not be used or will be used ineffectively. In Michigan, for example, the Department of Community Health houses The Health Disparities Reduction and Minority Health Program,<sup>lvi</sup> which funds targeted and evidence-based health promotion and screening services

to help reduce health inequities.<sup>lvii</sup> Michigan accomplishes this by working with various actors across the state, including community-based organizations, managed care organizations, and health systems.<sup>lviii</sup> A similar office in Connecticut with a clear objective and dedicated funding could help make inroads in eliminating health inequities.

## 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.



## APPENDIX A: INTERVIEW LIST

NAME	ORGANIZATION
Adriana Rojas, Tierney Giannotti	Community Health Center, Inc.
Cassandra Trice, Tracey Wilkie, Ryan Wilkie	UMass Memorial Health
Joseph Quaranta	Community Medical Group
Karen Wang	Equity Research Innovation Center at the Yale School of Medicine
Sabrina Selk	Office of Health Equity, MA Department of Health
Susannah Bernheim	Yale Center for Outcomes Research and Evaluation
Tekisha Dwan Everette	Health Equity Solutions
Todd Liu	Griffin Health Services
Romana Hasnain-Wynia	Denver Health
Victoria Veltri, Allan Hackney, Brent Miller, Sean Fogarty, Laura Morris	CT Office of Health Strategy
Collette Cole	MN Community Measurement
Polly VanderWoude, Darcey Cobbs-Lomax	Yale New Haven Health System
David Nerenz	Henry Ford Health System
Toktam Sadralodabai	Los Angeles Department of Public Health
Sarah Lewis, Quian Callendar	Hartford HealthCare
Jennifer Lo	Boston Public Health Commission



## APPENDIX B: BENEFITS OF A COORDINATED STATEWIDE EFFORT

One benefit of a coordinated statewide effort is making health inequities by race, ethnicity, and primary language visible.

At the patient level, this would mean the ability to see inequities related to accessing care and health outcomes as well as to identify groups of individuals with the greatest inequities. At the provider level, individual providers (from larger health care systems to small independent providers) would be able to understand inequities across their patient panels and identify inequities to target. Local governments and the state of Connecticut would be able to identify in which geographies (down to the zip code level) there are the most health inequities. Providers, policymakers, government and patients would be able to see health inequities by health condition/topic area (e.g. diabetes, birth outcomes, cancer screening). All stakeholders would be able to see the inequities at all of these levels

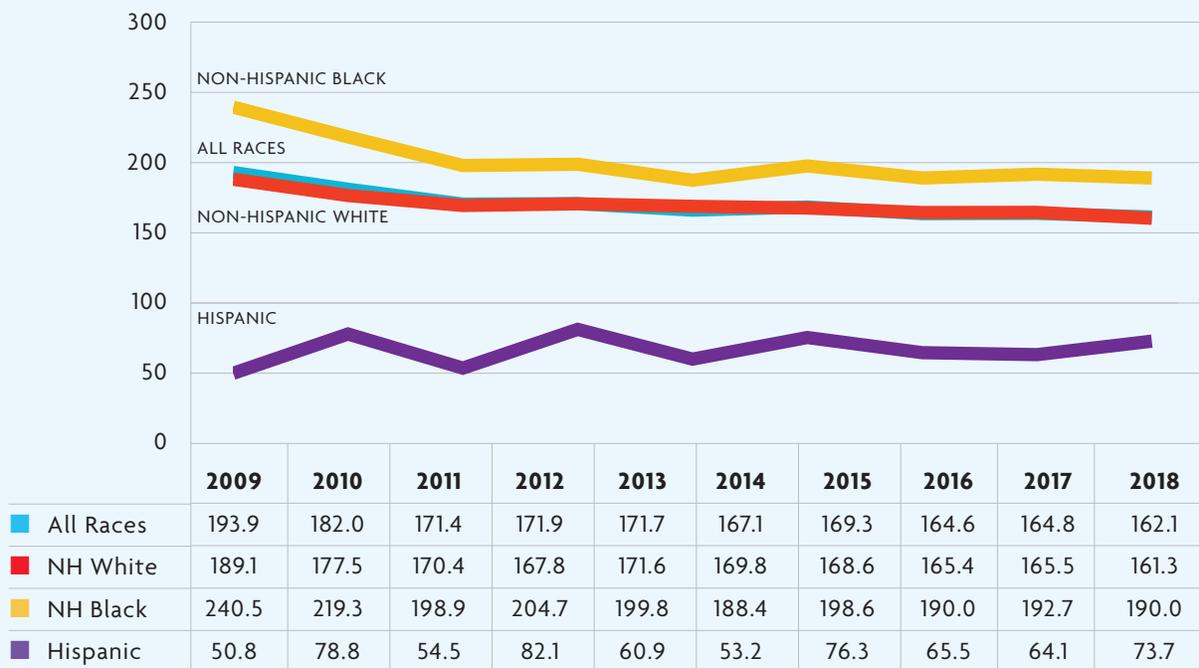
(e.g. access for Black people to diabetes care among and across providers in New Haven County).

As an example, Minnesota now makes publicly available a wide range of data on health inequities. The following chart shows the disparities in infant mortality for the period of 2012–2016.<sup>lix</sup>

Minnesota Infant Mortality Rates 2012–2016			
Group	White	Black	Native American
Infant Mortality Rate (Per 1,000 births)	4.0	9.0	10.1

Maryland also makes publicly available a wide range of health equity data and includes the data over time to show if disparities are improving or getting worse.<sup>lx</sup>

**Age-Adjusted Death Rate for Diseases of the Heart by Race and Hispanic Origin, Maryland, 2009–2018.**



## APPENDIX C: BUILDING WILL FOR COLLECTING, REPORTING AND USING REL DATA

An effort to have all health care systems in Connecticut collect, report, and use REL data requires substantial will-building at multiple levels and with multiple stakeholders. Whether this work is required by legislation or regulation or conducted voluntarily by health systems, those leading this effort will need to continually build will to ensure that this effort achieves its desired results – better health outcomes for people of color and for people whose primary language is not English. This includes having a clear and compelling message for why collecting, reporting, and using REL data is a critical component of improving health equity in Connecticut.

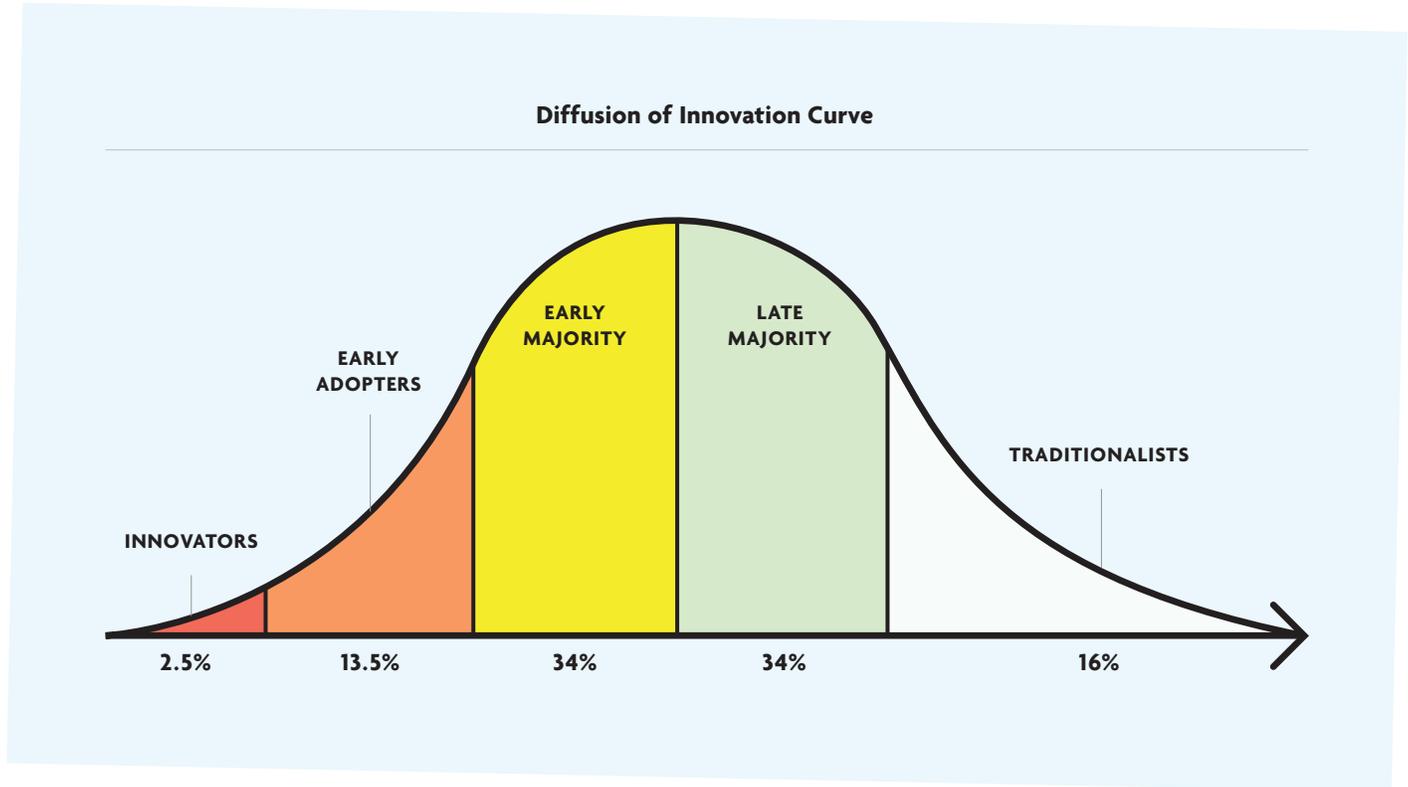
Even with a clear and compelling message, further will-building will be needed if all health care systems in Connecticut are to collect, report, and use standard REL data. Among the reasons for this are:

- Some health systems may doubt or even deny that these inequities are present in their practices.
- Other health systems may wonder if sharing this data could have legal repercussions or damage their reputations.

- Privacy advocates might have concerns and staff asked to collect REL data might feel uncomfortable.
- Some stakeholders may grasp the importance of REL data but have concerns that collecting and reporting standardized REL data is not feasible.
- Some providers are already collecting and using REL data and may not want to change what they are doing so that their efforts more closely align with others.

Therefore, we recommend being intentional about building will as part of this effort.

It is important to recognize that innovation does not require having all stakeholders on board. Typically, adoption of innovation starts with a small number of innovators who are ready to test the change, then followed by a group of early adopters. This can create a “tipping point” in which an early majority joins the effort. The “diffusion of innovation” curve illustrates this progression.<sup>ix</sup>



The effort to build will can also be accelerated by considering ways in which stakeholders' interests align with the goals of this work. This involves shifting from the question of "how can we get these stakeholders to do what we want them to do?" to the question "how can we get these stakeholders to do what they (and we) want to do?" To successfully make this shift requires understanding stakeholders. There are several tools for doing this including:

- Mapping actors (including stakeholders in the following groups):
  - > Leaders
  - > Supporters
  - > Competition
  - > Opposition
- Conducting a What's In it For Me Analysis (WIFM) to begin to understand not just what you want/need each stakeholder to do, but what they want, need and value – and using that to develop a strategy.
- Creating personas for different types of stakeholders and then developing a strategy for them, including messaging for help securing their buy-in.

As an example of this type of exercise, at the expert meeting, breakout groups developed a preliminary list of personas that will need to buy into the effort for it to be successful, including:

- A medical assistant working at a busy, hospital-system run COVID testing site who is balancing a long line of people hoping to get tested and doesn't want to be asked to do one more thing.
- A clinician in a leadership role at a smaller practice, without a robust EHR and practicing in a non-diverse setting, who believes this not a high-leverage investment for them/their practice.
- A larger health system that collects REL data but allows different parts of its system to collect data differently and doesn't want to have to standardize.
- Health care systems that already have established REL data collection processes and would have to change what they collect and how they collect it.
- Staff who will be asked to ask for or collect the REL data who are not comfortable asking for it.

For two of the personas, participants at the expert meeting began developing a strategy for securing their buy-in.



PERSONA	PRELIMINARY STRATEGIES
<p><b>Staff who will be asked to ask for or collect the REL Data who are not comfortable asking for that data</b></p>	Share the proposed language with the patient advisory board or similar to get their feedback
	Use a train-the-trainer approach including role playing
	Talking with and working with the social worker about how to ask these questions.
	Webinar with actual role-playing asking those questions
	Get early buy-in from the frontline staff. Why is it important? This is step 1.
	Recognize we are putting a lot of pressure on front line staff. But it doesn't necessarily have to fall to them.
	Can we use community health workers to do this or some of this? Hand them the "Choosing Wisely" info and having the conversations to prep patients for this and/or even collect that info.
	Customize existing messaging for staff e.g. "We Ask Because We Care"
	Building trust among patients
	Include education that can ground them in the inequities produced for their patients so they understand why it is important
	Personalizing it so they understand the problem and how this role will help fix these inequities
	Including training and materials that recognizes lack of trust and the need to build trust
	Build on existing work. The Connecticut Health Foundation commissioned a study to see if people of color were comfortable providing REL info. They were more comfortable at the provider space. Showing this data to staff
<p><b>Busy medical assistant working at a busy COVID testing site (run by a hospital system) that doesn't want to be asked to do one more thing.</b></p>	Hold virtual town hall events with employees to share aggregate outcome data plus stories, be on the same page about what the issues are and why this is important (frame how it is FOR the patients)
	Ensure that leadership promote racial equity to provide line of sight for frontline staff – bake it into culture, the way we do things at this organization
	Strategize about the workflow, efficiency, how to create the time in the process (scripts, utilize systems/portals, etc.)
	Messaging of "it's just what we do here" – it's part of what we do
	Find the root cause of the resistance – ask open ended questions.
	Important to be working on systems changes so that perhaps it's not just the medical assistant's responsibility to figure this out in their workflow, but it happens elsewhere in the system.

Check out IHI's White Paper on the Psychology of Change to learn more.

**APPENDIX D: IOM RECOMMENDED VARIABLES FOR STANDARDIZED COLLECTION OF REL**

<b>RACE AND ETHNICITY</b>	<b>OMB HISPANIC ETHNICITY</b>	<b>OMB RACE</b> (Select one or more)	<b>GRANULAR ETHNICITY</b>
	<ul style="list-style-type: none"> <li>• Hispanic or Latino</li> <li>• Not Hispanic or Latino</li> </ul>	<ul style="list-style-type: none"> <li>• Black or African American</li> <li>• White</li> <li>• Asian</li> <li>• American Indian or Alaska Native</li> <li>• Native Hawaiian or Pacific Islander</li> <li>• Some other race</li> </ul>	<ul style="list-style-type: none"> <li>• Locally relevant choices from a national standard list of approximately 540 categories with CDC/HL7 codes</li> <li>• “Other, please specify: _____” response option</li> <li>• Rollup to the OMB categories</li> </ul>

<b>LANGUAGE NEED</b>	<b>SPOKEN ENGLISH LANGUAGE PROFICIENCY</b>	<b>SPOKEN LANGUAGE PREFERRED FOR HEALTH CARE</b>
	<ul style="list-style-type: none"> <li>• Very well</li> <li>• Well</li> <li>• Not well</li> <li>• Not at all</li> </ul> <p>(Limited English proficiency is defined as “less than very well”)</p>	<ul style="list-style-type: none"> <li>• Locally relevant choices from a national standard list of approximately 600 categories with coding to be determined</li> <li>• “Other, please specify: _____” response option</li> <li>• Inclusion of sign language in spoken language need list and Braille when written language is solicited</li> </ul>

## APPENDIX E: DESIGNING FOR REL COLLECTION

The following are examples of how health systems outside of Connecticut assessed their workflow and resources to design their REL data collection and answer some of the questions posed in Stage 1.

### THE INSTITUTE OF FAMILY HEALTH, NEW YORK (IFH)<sup>lxii</sup>

In 2009, The Institute of Family Health adapted its REL data collection standards across its 17 sites to be in line with IOM guidelines. Due to staffing shortages, officials opted to have registration staff collect the data from patients, rather than nursing staff or medical assistants. The health center network originally designed a form for patients to select race, ethnicity, language, and granular ethnicity so that patients would have privacy. However, during the monitoring process, officials found that sites that asked patients verbally for their information were more successful. As a result, they encouraged their other sites to forgo the form and ask questions verbally.

The IOM recommends health care organization generate a “locally relevant list of granular ethnicities,” but IFH noted that would be challenging given the diversity across its 17 sites. Therefore, the network opted to use the full granular ethnicity list (page 1 and page 2) from the IOM and left the question open-ended for patients to answer to prevent being overwhelming.

### HENRY FORD HEALTH SYSTEM<sup>lxiii</sup>

Henry Ford Health System in Michigan uses the OMB categories to for ethnicity. However, the system also includes a question about Arab or Chaldean origin due to a large Arab population in Detroit. The system also collects granular ethnicity to reflect its patient population accurately. A copy of the questions presented to patients is displayed in Figure C1.

Figure C1 – Henry Ford Health System REL Data Collection Example

**BELOW ARE QUESTIONS YOU WILL BE ASKED AT YOUR APPOINTMENT.**

**1. Are you of Hispanic or Latino origin?**  
 Yes  No  Don't Know  Decline

**2. Are you of Arab or Chaldean origin?**  
 Yes  No  Don't Know  Decline

**3. Which of the following best describe your race? You may select up to two.**  
 Black  White  Asian  American Indian  
 Native Hawaiian/Pacific Islander  Other  
 Don't Know  Decline

**4. Please provide one or two nationalities or ethnic groups the best describe your ancestry.**  
(For example, Jamaican, African American, Haitian, Korean, Lebanese, etc. You will be provided with a list of more than 40 nationalities/ethnicities from which to choose.)

**5. How would you rate your ability to speak English?**  
 Very well  Well  Not well  Not at all  
 Don't know  Decline

**6. What language do you feel most comfortable using when discussing your health care?**  
 Albanian  Arabic  Bengali  Cantonese  
 English  Italian  Mandarin  
 Sign language (American)  Yemen Arabic  
 Other (specify) \_\_\_\_\_  Don't Know  Decline

## MINNESOTA – MN COMMUNITY MEASUREMENT (MNCM)<sup>lxiv</sup>

For Minnesota health systems, MNCM, the organization responsible for analyzing REL at the state level, requires the submission of the following data elements:

- Country-of-origin (including U.S. territories)
- Race and ethnicity
  - > MNCM deviates from the OMB standard by combining race and ethnicity into one question, as recommended by the Health Research and Educational Trust (HRET)
- Language
- Insurance coverage

MNCM also recommended health systems consider the following additional data elements:

- English proficiency
- Health literacy
- Religion

MNCM has also developed a set of questions to help health systems make the decision of who will collect REL data. These questions include:

- Who has access to the screens that contain the data fields for this data collection?
- Where does the line of questioning fit? For example, as appointment staff members are likely already asking questions about English proficiency and the need for interpreter services, this may be a good time to ask the other questions.
- Based on patient population and business process, where do you expect to get the most complete and accurate results – the anonymity of a phone call (appointment setting); face-to-face conversation (registration); or face-to-face with the added privacy of the treatment room (rooming staff)? This may vary for each facility.

## NATIONAL HEALTH PLAN COLLABORATIVE<sup>lxv</sup>

The National Health Plan Collaborative (NPHC) convened by the RAND corporation, the Center for Health Care Strategies, and the Robert Wood Johnson Foundation, has surveyed how its members collect REL data. Figure C2 displays the various methods used that health systems may want to adapt in their own data collection efforts. While this effort was for insurers, much of this could be applied to health care systems.

**Figure C2: NHPC Plan Methods for Collecting Race, Ethnicity, and Language Data – Direct Methods, Primary Sources**

Direct Data Collection Method	Primary Sources										
	Aetna	BMC Health Network	CIGNA	Harvard Pilgrim	HealthPartners	Highmark Inc.	Humana	Kaiser Permanente	Molina Healthcare	United Health Group	Wellpoint, Inc.
Enrollment	■			□		○	○	○		○	□
Disease Management Programs	□	□	■	○	□	□	○	□	□	□	■
Health Risk Assessment	□	□	■	□	□	□	□	□	□	■	■
Encounter (office, hospital, etc.)		○		□	■		■	□			
Health Plan Direct Outreach		○		□		○		□			○
Member Web Portal	■		○	□		○	○			□	□
Member Survey	□			□		■	○	□	□	□	■
Member Initiated Contact	□				□		○		□		□

■ Primary source of race, ethnicity and language data  
 □ Additional source of race, ethnicity and language data  
 ○ Considering use of this data source

## APPENDIX F: SAMPLE SCRIPTS

### HEALTHPARTNERS, BLOOMINGTON, MN<sup>lxvi</sup>

HealthPartners provides a common script for staff: “It is important that we are able to identify any health-related issues you may be at risk for based on your race, ethnicity, or country-of-origin so we can provide you with the best care. This information will remain confidential.”

### AMERICAN HOSPITAL ASSOCIATION (AHA) – HRET DISPARITIES TOOLKIT

AHA recommends providing a rationale to patients for why REL data is collected. For example:

“We want to make sure that all our patients get the best care possible. We would like you to tell us your racial/ethnic background so that we can review the treatment that all patients receive and make sure that everyone gets the highest quality of care.”

## INSIGHTS FROM CONNECTICUT PATIENTS

**When sharing these scripts with seven Connecticut patients, two preferred the first as it made more sense to them. Three patients preferred the second one, because to them it came from a more positive, strengths-based lens. The other two patients said both are acceptable, one adding that it’s more about the messaging. The question should come, in their opinion, from a physician who also gives the patient time to talk about their overall health.**

### SAMPLE SCRIPT FOR ASKING ABOUT GRANULAR ETHNICITY:

“We want to make sure that all our patients get the best care possible. We would like you to tell us your racial/ethnic background so that we can review the treatment that all patients receive and make sure that everyone gets the

highest quality of care. I would like you to describe your race or ethnic background. You can use specific terms such as Korean, Haitian, Somali, etc...”

#### ETHNICITY QUESTION

(OMB recommends asking ethnicity before race.)

##### Are you Hispanic, Latino, or Spanish origin?

- No, not of Hispanic, Latino, or Spanish origin
- Yes, Mexican, Mexican American, Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino, or Spanish origin
- Unavailable/Unknown
- Declined

#### RACE QUESTION

##### Which category best describes your race?

(One or more categories may be marked)

- American Indian/Alaska Native
- Asian
- Black or African American
- Native Hawaiian/Other Pacific Islander
- White
- Some other race
- Unavailable/Unknown
- Declined

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DESIGN CONSULTANT: Ritz Henton Design

PHOTOGRAPHY: Gale Zucker Photography



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