White Paper
Challenges and Barriers:
Race, Ethnicity, and Language (REL)
Data Collection and Quality Reporting

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Stratis Health, based in Bloomington, Minnesota, is a nonprofit organization that leads collaboration and innovation in health care quality and safety, and serves as a trusted expert in facilitating improvement for people and communities.

Contents

Executive Summary

Gaps in quality health and health care are visible across racial, ethnic, sexual orientation and socioeconomic groups at local, state, regional, and national levels. Improving health equity among and across patient populations at all levels is a priority that can only be accomplished with accurate Race, Ethnicity, and Language (REL) data collection and capacity for reporting.

In its most basic form, REL data is used as a statistical demographic to break down patient populations. Integrated with quality measures, it becomes an integral tool to define and measure health disparities, ultimately developing a bridge to address and improve health equity across patient populations. The intent of this white paper is to inform stakeholders, policy makers, governmental entities, electronic health record (EHR) vendors, and providers, of challenges to accurate collection and reporting of REL data and to encourage them to implement necessary policy, technology, and practice changes to address and overcome those challenges.

The project focused on three areas related to data collection and reporting REL information:

- **Technology** - vendor product capability to collect REL
- **Reporting** - provider/organization ease to report quality measures by REL and frequency of reporting
- **Training** - type and extent of staff training to collect REL information

Below are the project's recommendations for advancing the accurate collection and reporting of REL data:

Technology	• Provide comments to the Office of the National Coordinators' HIT Standards Committee on the technology needed for greater granularity and data collection standards in order to collect more accurate REL data. • Work with EHR vendors to ensure products have the capability to collect multiple race categories (and not have a category of "multi-racial/multiple race").
Reporting	• Provide comments to the Office of the National Coordinators' HIT Standards Committee on the reporting standards needed for ease and flexibility ("two-click access to displays of performance data stratified by any key demographic group[i]") to report REL data within quality measures. • Work with EHR vendors to ensure products have standard reporting capabilities that include REL for quality measures at the provider practice level. • Inform and educate practices/organizations of the need to report quality measures based on REL, at all levels – system, clinic site, and provider level to ensure health equity.
Training	Institute a comprehensive training program for accurate collection of REL data that includes: • Purpose for collecting REL data • Use of REL data to improve quality and decrease disparities • Creation and use of scripts for REL questions • Role playing for staff (to instill confidence/comfort to ask REL questions) • Engaging and educating the community about issues related to health equity including overcoming barriers to REL data collection

This white paper describes in detail the findings and recommendations for the three areas related to data collection as well as additional considerations for improving REL data. A full report on the REL project is also available for download at http://culturecareconnection.org/documents/REL-Report.pdf

I. Findings and Considerations

To understand better the challenges with REL collection and reporting, Stratis Health enlisted the assistance of five clinics from around the state to gather detailed information on challenges and barriers related to REL data collection and quality reporting.

The project focused on three areas related to data collection and reporting REL information:
- **Technology** - vendor product capability to collect REL
- **Reporting** - provider/organization ease to report quality measures by REL and frequency of reporting
- **Training**- type and extent of staff training to collect REL information

This section details the findings in each of these areas followed by considerations to alleviate or improve identified barriers or challenges.

Technology

Technology, in this instance, refers to the ability of the EHR to allow providers/organizations to accurately collect detailed REL information. Race, ethnicity, and language, and country of origin are addressed individually.

Race

EHR vendor products utilized by two clinics did not allow for the selection of multiple race categories, rather the product utilized a "multiple/more than one race" category. This does not align with best practice - the ability to capture all race categories identified by the patient.

Considerations
- Practices/organizations should work with their EHR vendor to understand the product's capability and to make the vendor aware when the product does not meet their needs – meaningful use; quality measures; grant proposals; state, local, federal requirements, etc.
- Vendors need to ensure their technology keeps pace with user needs and policy mandates.
- Certification bodies should consider the capacity of the EHR product to collect race information when certifying EHR products for Meaningful Use.

Ethnicity

Collection of "Hispanic or Latino" or "Not Hispanic or Latino" ethnicity was consistent and uniform across EHR vendor products.

Language

Collection of preferred (spoken) language was consistent and uniform across EHR vendor products.

Country of Origin

Collection of country of origin was consistent across participants. All vendor products had a set of countries to select from; some products had more expansive lists.

One participant's EHR vendor product had been modified to capture regions, tribes/clans, American Indian Nations and Tribes, and distinct nationalities. This granular level of information can be crucial

3

for practices to better understand the healthcare, interpretative, social, and cultural background and needs of their patient populations.

Considerations
One participant gave a note of caution when collecting country of origin. They noted that patients from countries in conflict, experiencing political upheaval or where persecution was prevalent may not wish to associate themselves with a "country of origin." Practices, organizations, and reporting entities will need to consider how best to approach these situations.

Reporting

Reporting quality measures based on REL allows providers/organizations to identify health disparities and develop plans for improvement. Two components are required to do this effectively:

- **Ease of Reporting** - The EHR reporting capabilities must be easy to use and flexible. Reports need to detail quality measures by REL from the corporate level to an individual site/provider level.
- **Frequency of Reporting** - Providers/organizations need to report, communicate, evaluate, and address REL quality measures on a regular basis.

Participants reported varying degrees of reporting capabilities and frequency of reporting.

Ease of Reporting
Larger organizations' EHR products have the capacity to deploy corporate-wide standard reports but frequently have minimal or no ad hoc report capabilities at the practice site level. Smaller organizations usually employed a staff member trained in the EHR reporting tool and therefore had more reporting flexibility.

Frequency of Reporting
All participants reported some degree of REL data and quality measures to state, local, or federal entities. Participants also regularly reported individual practice site and/or provider quality level measures, albeit without REL, as part of their quality improvement initiatives.

Reporting quality measures based on REL information was infrequent at the practice site level, and none of the participants reported these at the provider level.

Considerations
- The ease of the EHR product to allow for detailed REL reporting at the practice site level will be crucial for individual practice sites to improve health equity since the REL mix may vary considerably from one practice site to the next.
- The frequency of reporting REL information to track and monitor quality measures is necessary to identify inequities, develop approaches for improvement, and gauge the success of those efforts.

An interesting suggestion from one practice/organization, in lieu of EHR reporting capabilities, was to add REL information to their registry to track and monitor quality measures through that mechanism.

4

Training

Training staff is necessary to develop a level of comfort when asking patients the REL questions and to empower staff with an understanding of why this is important: to improve health quality and decrease health disparities.

Training of staff to collect REL data ranged from:
- Minimal - no formal training, policies, procedures, to
- Extensive - formal, organization-wide training

Regardless of the level of training, the most persistent challenge participants identified was how to respond to the patients who asked: "Why do you need that information?" most commonly related to the question of race.

Most participants utilized some form of a script to ask REL questions. This usually would explain the information was being collected to insure all patients receive high quality care. However, even those who utilized a script identified the race question as a "sticky issue." Many participants reported that American-born white patients frequently asked "Why?" when the question of race was asked.

Considerations

In addition to a training program that explains the purpose for collection of REL and how REL data will be used, practices / organizations may wish to consider:
- **Role Playing** - Add role playing to the training process to give staff an opportunity to practice asking REL questions
- **Engage Staff** – Engage staff in discussions of how to respond to questions about why REL is being collected
- **Quality Measures** – Report quality measures by REL to generate discussion and enhance awareness
- **Engage Community** – Engage members of the community for ideas on how to ask/approach REL in general and the race question specifically
- **Articles / Information** – Post and disseminate information that discuss health care issues more prevalent in particular race and ethnic groups to help staff and patients understand the importance of collecting REL data

II. Recommendations

One of the recommendations to address accurate collection of REL data from the Minnesota Department of Health (MDH) 2014 Legislative Report, Advancing Health Equity in Minnesota,[ii] was:

> ***"Steps to be considered (include): Implement a race/ethnicity/language (REL) data collection standard in MDH with emphasis on adding granular ethnicity, language and birthplace data to the current data collection standard[iii]"***

Accurate collection and reporting of REL data to improve health equity, achieve meaningful use, and meet state, local, and federal reporting requirements will become a higher priority in the future. However, this cannot be accomplished without advances in technology, staff training, and patient education. Efforts to improve REL data collection and reporting and decrease health disparities requires a commitment from EHR vendors, health systems, providers, staff, patients, and policy makers to be successful.

Recommendations to advance the accurate collection and reporting of REL data:

Technology	• Provide comments to the Office of the National Coordinators' HIT Standards Committee on the technology needed for greater granularity and data collection standards in order to collect more accurate REL data. • Work with EHR vendors to ensure products have the capability to collect multiple race categories (and not have a category of "multi-racial/multiple race").
Reporting	• Provide comments to the Office of the National Coordinators' HIT Standards Committee on the reporting standards needed for ease and flexibility ("two-click access to displays of performance data stratified by any key demographic group[iv]") to report REL data within quality measures. • Work with EHR vendors to ensure products have standard reporting capabilities that include REL for quality measures at the provider practice level. • Inform and educate practices/organizations of the need to report quality measures based on REL, at all levels – system, clinic site, and provider level to ensure health equity.
Training	Put into practice a comprehensive training program for accurate collection of REL data that includes: • Purpose for collecting REL data • Use of REL data to improve quality and decrease disparities • Creation and use of scripts for REL questions • Role playing for staff (to instill confidence/comfort to ask REL questions) • Engaging and educating the community about issues related to health equity including overcoming barriers to REL data collection

III. Additional Considerations

Changing EHR products

Organizations that implement a new EHR system need to consider processes to update REL data in particular when the previous EHR system did not have the capability to capture detailed REL information. Dependent on the system, the old data may populate the new system which will then need to be updated. REL information that is stored in a data warehouse may need to be refreshed. Both may affect accurate REL reporting.

Practice Management System (PMS)

Practices or organizations that utilize a practice management system (PMS) for collecting REL data that is not integrated with their EHR product will need to evaluate and address how this may impact REL collection and quality reporting.

Language - written

Written – versus spoken language is not currently part of REL data collection; however, there is discussion of whether or not this may be an important piece of data to collect. Participants in the REL project indicated they had not considered collecting written language but will bring forward for further internal discussion.

A good example of the value of collecting written language was one participant who gave their pediatric patients a book, in their preferred language, to promote reading.

Sexual orientation

Participants in the REL project were not collecting GLBTQ information; however, some utilized the EHR to make special notations such as how a patient wished to be addressed. Participants indicated this warranted further discussion regarding collecting GLBTQ data.

The REL project was funded by UCare, an independent, nonprofit health plan providing health coverage and services to more than 400,000 members in Minnesota and western Wisconsin and serves more people from diverse cultures than any other health plan in Minnesota.

Sources and References

[i] *Collecting and using race, ethnicity and language data in ambulatory settings, Recommendations for EHR systems*, The Commission to End Health Care Disparities, 2011

[ii] *Advancing Health Equity in Minnesota: Report to the Legislature*, February 2014

[iii] *Advancing Health Equity in Minnesota: Report to the Legislature*, February 2014, Chapter 2, Recommendations…..

[iv] *Collecting and using race, ethnicity and language data in ambulatory settings, Recommendations for EHR systems*, The Commission to End Health Care Disparities, 2011