



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.

Table of Contents

Overview.....	2
Background.....	2
I. Project Specifications.....	3
II. Findings and Considerations.....	3
Technology.....	4
Reporting.....	5
Training.....	5
III. Recommendations.....	6
Technology.....	7
Reporting.....	7
Training.....	7
IV. Additional Considerations.....	7
Changing EHR products.....	7
Practice Management System (PMS).....	7
Language - written.....	8
Sexual orientation.....	8
V. Acknowledgements.....	8
VI. Sources and References.....	9

Overview

The U.S. Department of Health and Human Services defines health equity as “Attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and healthcare disparitiesⁱ.” Gaps in quality health and healthcare have been identified across racial, ethnic, sexual orientation and socioeconomic groups at all levels – state, regional, and national. Improving health equity among and across patient populations is a state, local, regional, and national 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 breakdown 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.

Collection and reporting of REL data is required by a number of state, local, and national initiatives including:

- **Meaningful Use** – A core measure required in the Centers for Medicare & Medicaid Services (CMS) Electronic Health Record (EHR) Incentive Programⁱⁱ and the Minnesota EHR Incentive Program (MEIP).
- **Minnesota State Health Care Reform** – Submission of REL data is required for reporting health care quality measures to MN Community Measurement (MNCM) as part of the Minnesota State Health Care Reform.
- **Accountable Care Organizations (ACOs), Patient Centered Medical Homes (PCMH), etc.** – The ability of healthcare providers to capture and report quality measures by REL is an integral component of Accountable Care Organizations (ACOs), Patient Centered Medical Homes (PCMH), and other state and national health care reform initiatives.

Equity of Care, a collaboration lead by the American Hospital Association, stated:

“While the ultimate goal of collecting REAL (Race, Ethnicity and Language) data is to reduce healthcare disparities, the immediate focus for hospitals and care systems should be insuring data is standardized and collected appropriatelyⁱⁱⁱ.”

The intent of this report is to inform stakeholders, policy makers, governmental entities, EHR vendors, and providers, of barriers 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 barriers.

Background

Current U.S. Census Bureau data indicate over 30% of the population is composed of racial and ethnic minorities.

Advancing Health Equity in Minnesota report stated:

“For over 15 years, Minnesota has been tracking disparities in populations of color and American Indians, children, adolescents, immigrants and refugees, and the LGBTQ (Lesbian, Gay, Bisexual, Transgender, Queer/Questioning) population. These data reveal that serious health inequities persist in Minnesota, despite efforts on the part of many organizations and programs to improve health^{iv}”

In 2008, MNCM in collaboration with Minnesota medical groups came together to develop guidance for collection of REL data. The *Handbook on the Collection of Race/Ethnicity/Language Data^v* drew

on earlier work of the Health Research and Education Trust Disparities Toolkit^{vi}. The handbook outlined a timeline for reporting REL data (required in 2011) and highlighted three best practices for collecting REL data:

- **Patients self report** – Asking patients to identify their race, ethnicity, and language; not inferring based on name or observation
- **Select more than one race category** – Providers have the ability (within the EHR) to select all individual race categories identified by the patient
- **No “multi-racial/more than one race” category** – Providers and/or the EHR product do not use a “multi-racial/more than one race” category for patients who identify more than one race

Efforts to report statewide quality measures stratified by REL data were put on hold in February 2013 due to technical barriers. MNCM has been validating that REL data is collected according to best practices, and discovered during the validation process that although many medical groups were following best practice in reporting REL, many EHRs lacked the capability to capture and report all race categories.

Working with providers across the state, Stratis Health, a partner in the Regional Extension Assistance Center for HIT (REACH) and Minnesota’s Medicare Quality Improvement Organization (QIO) have become increasingly aware of barriers to collect and report REL information for quality measures.

To better understand 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.

I. Project Specifications

Timeframe: January 2013 thru May 2014

Participants:

Clinics in the project represent practices/organizations from:

- Urban and rural areas
- Federally Qualified Health Centers
- Large integrated delivery systems
- University-based practices

EHR vendor products represented: Allscripts, Epic, GE, and Success EHS.

Participation in the project included:

- Completion of a short survey
- Review of participant tools for collection and reporting REL data (policies, procedures, scripts, reports)
- Onsite interview of participants

II. Findings and Considerations

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 will be 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 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.

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

III. 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,^{vii} 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^{viii}"

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	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • 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^{ix}”) 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	<p>Put into practice a comprehensive training program for accurate collection of REL data that includes:</p> <ul style="list-style-type: none"> • 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

IV. 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.

V. Acknowledgements

We want to acknowledge and thank the participants in this project. Their involvement provided a deeper understanding of issues and barriers clinics face to accurately collect REL data, as well as insight to how REL data is used to improve health equity.

We acknowledge that findings in this report only represent a small number of Minnesota health care providers and that a larger, more robust, project may be needed to fully understand the scope and extent of the issues on a state, local, regional, and national basis.

Participants

Community-University Health Care Center HealthEast Rice Street Clinic Neighborhood Healthsource	Sanford Clinic - Windom and Mt. Lake University of Minnesota Physicians
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UCare

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.

Other collaborators

MN Community Measurement (MNCM) is a nonprofit organization working with partners statewide and nationally to increase quality and value in health care.

Regional Extension Assistance Center for HIT (REACH) is a nonprofit federal Health Information Technology Regional Extension Center dedicated to helping providers in clinics, small hospitals, and other settings implement and effectively use electronic health records.

VI. Sources and References

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- Equity of Care, <http://www.equityofcare.org>
- National Prevention Strategy, Elimination of Health Disparities, National Prevention Council, <http://www.surgeongeneral.gov/initiatives/prevention/strategy/elimination-of-health-disparities.pdf>
- Reducing Disparities, two-part webinar, offered by Minnesota Hospital Association,
 - The Importance of Collecting Standardized Data on Patient Race, Ethnicity and Language, <http://www.mha-apps.com/media/1-15-13MHA.wmv>
 - Moving to Action to Reduce Disparities in Health Care, <http://www.mha-apps.com/media/1-22-13MHA.wmv>

ⁱ National Partnership for Action to End Health Disparities, Health equity and disparities, US Department of Health and Human Services, March 4, 2011, <http://minorityhealth.hhs.gov/npa>

ⁱⁱ Stage 1 and Stage 2 Meaningful Use Core Measure, Record Demographics, EP/EH/CAH, CMS

ⁱⁱⁱ *Reducing Health Care Disparities: Collection and use of Race, Ethnicity and Language (REAL) data*, Equity of Care, August 2013

^{iv} *Advancing Health Equity in Minnesota: Report to the Legislature*, MDH, February 2014

^v Training and guidance, Data Collection tab, MNCM, <http://mncm.org/submitting-data/training-and-guidance/>

^{vi} HRET Disparities Toolkit, <http://www.hretdisparities.org/WhyC-4162.php>

^{vii} *Advancing Health Equity in Minnesota: Report to the Legislature*, February 2014

^{viii} *Advancing Health Equity in Minnesota: Report to the Legislature*, February 2014, Chapter 2, Recommendations.....

^{ix} *Collecting and using race, ethnicity and language data in ambulatory settings, Recommendations for EHR systems*, The Commission to End Health Care Disparities, 2011