# ISSUE BRIEF

**SOCIAL RISK FACTORS DATA COLLECTION:**
*Lessons Learned from Minnesota's Experience Collecting Race, Ethnicity, Language and Country of Origin*

**MN Community MEASUREMENT**

## OVERVIEW

As an independent nonprofit that has been collecting, validating, analyzing, and reporting information on health care quality, cost, and disparities since 2005, MN Community Measurement (MNCM) convenes stakeholders from across the health care spectrum – health care providers, health plans, employers, consumers, and state government – to prioritize and agree on measurement and data collection efforts to drive improvement in health care quality and affordability.

MNCM has one of the most robust data collection and reporting efforts for health care disparities by race, ethnicity, language, and country of origin (RELC) in the nation.[1] With increasing interest in addressing "upstream" social risk factors that affect health outcomes, this issue brief summarizes key lessons learned related to collection of information related to race, ethnicity, language, and country of origin, as well as considerations related to broader collection and use of information on health-related social needs.

Currently, there is high interest among Minnesota health care stakeholders in standardizing the collection of data on social risk factors. In order for the effort to be successful there are several concerns that will need attention. These include:

**Completeness of data**

**Data quality and accuracy**

**Comparability of data across providers**

**Burden of data collection**

This issue brief summarizes relevant lessons MNCM has learned from over a decade of collecting standardized data on race, ethnicity, language, and country of origin using agreed-upon best practices. It is a companion to separate briefs on the status of collecting data on health-related social needs in Minnesota, and a scan of the national landscape on data standards and collection for health-related social needs.

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# HISTORY OF MNCM DATA COLLECTION AND REPORTING ON DISPARITIES

Minnesota consistently ranks as one of the healthiest states in the nation, according to rankings published by groups such as the United Health Foundation[2] and the Commonwealth Fund[3]; however, this overall high level of performance obscures some very wide disparities in outcomes.[4] For example, communities of color experience significantly higher rates of infant mortality, chronic illness, and premature death. Measurement and data are important tools that can be used to call attention to the problem, motivate efforts to improve, and enable tracking of progress over time.

MNCM's effort to standardize the way that health care providers collect data on race, ethnicity, language, and country of origin began in 2008. The lack of standard data definitions and consistent collection of RELC data had created challenges for developing and evaluating programs to address and eliminate health disparities. MNCM collaborated with stakeholders to develop and implement standards for data collection and public reporting of variations in health care quality by RELC. This was not the first effort to standardize RELC data collection, but MNCM's previous work to build a robust infrastructure to collect and validate clinical health care quality data from health care providers served as a solid foundation from which to tackle the challenge of RELC data standardization. This effort was funded by a grant from the Robert Wood Johnson Foundation's "Aligning Forces for Quality" program.

In 2008 and 2009, MNCM convened an Early Adopters Workgroup to create standards for RELC data. This workgroup included members from local medical groups who were already collecting RELC data and who were willing to share best practices. Using the National Institute of Medicine standards, the workgroup established local standards for data elements and best practices and shared their expertise on overcoming obstacles to implementation.[5] The end result of this process was the creation of MNCM's Handbook on the Collection of Race/Ethnicity Data in Medical Groups,[6] which includes a common set of data elements, the rationale for why the work is important, and best practices for data collection. Specific to race, for example, the standard includes information not just on what the categories are, but how the information should be collected and reported – the agreed-upon standard for "best practice" is that the data must be self-reported by the patient, that the patient must be allowed to report multiple categories, and that the medical record must be able to store and report multiple race categories for an individual patient.

A key lesson learned from this work was that decisions about specific data definitions to use for race, language, and country of origin had to strike a balance between meaningful information and the effort involved in data collection. For example, the Minnesota definition for required elements for language is tailored to the largest immigrant communities in Minnesota (there are 33 languages included in the standard, plus a category for "other").

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Just as quality measurement efforts require that health care providers have confidence in the integrity and comparability in the data, the same is true for collecting and reporting RELC data. Building on the infrastructure that MNCM had developed to collect and validate data for clinical quality measures, MNCM developed policies and procedures to ensure the quality and integrity of the RELC data. These included a data completeness threshold that RELC data be reported for at least 75% of a medical group's patients, and a threshold for public reporting that at least 60% of medical groups had to be reporting using best practices and meeting the data completeness threshold before MNCM would report any data publicly. Data validation is conducted in conjunction with validation of clinical information, and includes post-submission data quality checks, audits of source data as needed, and validation of the processes used to collect data from patients.

### Reporting of Race Using Best Practices
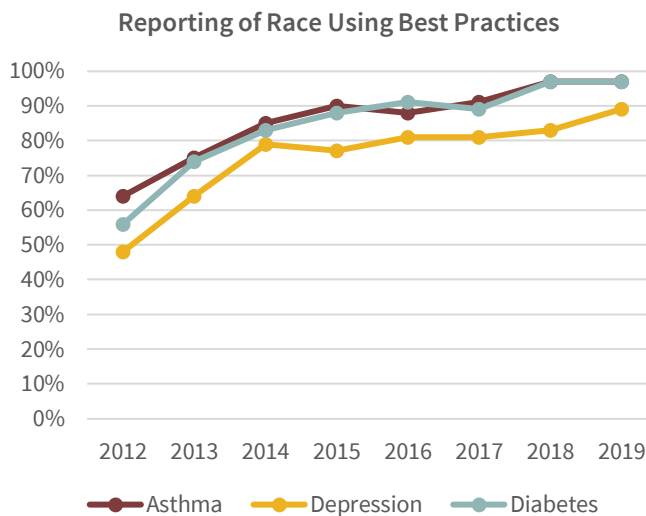


For care provided in 2019, about 97 percent of medical groups submitting clinical data to MNCM submitted race data in accordance with the agreed-upon best practices.[7] However, it took several years to get to the point where the best practices were being used widely enough and the data were consistent enough for MNCM to report publicly (see chart with examples for race data over time for asthma, depression, and diabetes measures). At the time, some EHRs were not set up to capture and report more than one race, which was required as a best practice. This delayed MNCM's ability to publicly report RELC data by a few years. In consultation with MNCM's multi-stakeholder Measurement and Reporting Committee (MARC), it was decided that MNCM would not publicly report RELC information until at least 60 percent of medical groups were following best practices. In the interim, MNCM created a system for private reporting to providers so that they could compare their own data to statewide averages and results for other medical groups. Beginning in 2015, MNCM publicly reported aggregate results for quality measures by RELC and began making this information public by medical group in 2016.

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In summary, the key lessons learned from MNCM's efforts over more than a decade to collect and report on disparities by RELC include the following:

- Multi-stakeholder collaboration is critically important

- Leadership is also important – the issue must be important enough for stakeholders to make it a priority and to be willing to make change

- To build and maintain trust, it is important to have robust processes in place to ensure the quality and consistency of the data – not just what is collected but how it is collected

- As with implementing any new data collection, health care providers should have the ability to review their results compared to others privately prior to any public reporting that might be contemplated

- Funding support to develop, implement, and maintain the standards was also an important component of success

## INTEREST IN MEASURING SOCIAL RISK FACTORS

Currently, there is a high level of interest among Minnesota health care stakeholders in standardizing the collection of data on social risk factors. Similar to standardizing the collection of RELC data, in order for the effort to be successful there are several concerns that will need attention. These include:

**Completeness of data**

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In 2018, MNCM asked its Health Equity Advisory Council to advise on the potential of adding data elements related to social risk factors.[8] At that time, the Council was skeptical that the benefit would be worth the effort required to do so. Key questions raised by the Council included the following:

- Whether having the data would really lead to accountability for action and improvement over time

- Whether the data would be actionable for providers (including, but not limited to, whether there are appropriate resources for providers to refer patients to once a need has been identified)

- Burden to providers of collecting the information from patients and reporting it to MNCM

- Burden and comfort level of patients in providing requested information

- Whether similar information could be obtained more efficiently from other sources where it already exists (e.g., community-based organizations, local public health departments, or social service agencies)

Much has changed since 2018, and many stakeholders in Minnesota are currently prioritizing health equity and addressing health-related social needs as one strategy for improving equity. Also worth noting is that MNCM's new PIPE data collection infrastructure has been designed to minimize the burden on providers of reporting quality data.

However, it is still the case that it will take substantial effort to standardize data collection and to implement systems for ensuring that information is collected from patients in a manner that is relatively complete, comparable across providers, efficient, culturally sensitive, and creates minimal additional burden for patients and providers.

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## ENDNOTES

1   U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. Developing Health Equity Measures. 2021. Retrieved from https://aspe.hhs.gov/reports/developing-health-equity-measures

2   United Health Foundation. America's Health Rankings. 2021. Retrieved from https://www.americashealthrankings.org/

3   Radley D.C., Collins S.R., Baumgartner J.C. 2020 Scorecard on State Health System Performance. 2020. Commonwealth Fund. Retrieved from https://www.commonwealthfund.org/publications/fund-reports/2020/sep/2020-scorecard-state-health-system-performance

4   Radley D.C., Baumgartner J.C., Collins S.R., Zephyrin L., Schneider E.C. Achieving Racial and Ethnic Equity in U.S. Health Care: A Scorecard of State Performance. 2021. Commonwealth Fund. Retrieved from https://www.commonwealthfund.org/publications/scorecard/2021/nov/achieving-racial-ethnic-equity-us-health-care-state-performance

5   A wide range of implementation considerations were addressed, including gaining leadership support, staff training, data collection, addressing administrative concerns, IT/systems, audit/compliance, and community engagement.

6   The handbook is publicly available on MNCM's website.

7   This varies by measure because different medical groups submit different measures. One exception is reporting for depression measures, where only 89 percent meet this standard for race data. Preferred language meets best practice for about 98-99 percent of medical groups, with depression again an outlier at 93 percent. Performance for country-of-origin reporting ranges from 83 to 91 percent, with all measures except depression above 87 percent.

8   MNCM currently collects data on date of birth, country of origin, gender, insurance status, Hispanic ethnicity, preferred language, race, and zip code. Area-level socioeconomic status indicators by zip code are added to the data for risk adjustment of quality measures.