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## **PRELIMINARY FINDINGS: MEASURING HEALTH EQUITY IN MASSACHUSETTS**

### **I. OVERVIEW**

#### **THE CHALLENGE**

The Massachusetts Taxpayers Foundation's (MTF) May 2021 report "[\*Closing the Racial Divide in the U.S. and Massachusetts: A Baseline Analysis\*](#)" documented the clear need for better data to measure – and ultimately eliminate – ongoing racial disparities. In conducting research for its report, MTF identified lapses in data that made it incredibly difficult to quantify disparities in Massachusetts. In several instances, information collected was outdated, unavailable, or incomplete.

#### **THE GOAL**

MTF's goal with this analysis is to improve and expand the data available to measure changes in racial and ethnic inequalities in Massachusetts. In the long-term, MTF aims to:

1. Identify metrics and data sources to measure disparities in wealth, income, education, health care, and criminal justice;
2. Conduct research and discussions with experts to reach a consensus of which metrics best measure changes in racial and ethnic disparities;
3. Determine what data are unavailable, and;
4. Recommend how best to collect and/or augment the data for future analyses.

This specific analysis touches on one area of inequity: Health. Public and private sector leaders in the Commonwealth have made clear their commitment to eliminating racial and ethnic health-related disparities. By producing more organized and accessible data, the state would make it possible for these leaders to target disparities and, ultimately, make Massachusetts more equitable for all residents. Taking this first step is essential to ensuring that meaningful progress is made to further health equity.

#### **ROLE OF WORKING GROUPS**

Since many organizations are engaged in this work, MTF established a working group comprised of subject matter experts to lead this effort. These experts are familiar with available data, ongoing efforts around equity, metrics to measure progress, and federal and state

requirements traditionally used to quantify racial and ethnic disparities. MTF managed these efforts by convening interested parties, aggregating data and ideas, continuously soliciting feedback, and drafting preliminary recommendations for review. The first working group MTF assembled focused on health care.

## **II. HEALTH CARE DATA INTRODUCTION**

Better data is crucial to identifying the specific drivers of persistent racial and ethnic disparities. Currently available data to measure health and health care disparities are limited. While there are legitimate and difficult barriers to collecting data, this must change if we are to identify inequities and monitor improvements to inform policy decisions. As MTF reported in *“Closing the Racial Divide,”* important measures show wide disparities among white, Black, and Hispanic patients in Massachusetts. These include access to health care coverage and services, the quality of services received, and outcomes for patients with similar diagnoses. For example, a white child is more likely to receive safe, reliable, continuous treatment for asthma in Massachusetts than a Black or Hispanic child is.

These findings came from state and national patient surveys which confirm that across a wide variety of metrics, major disparities exist between patients of color and white patients. These range from the likelihood of being uninsured, to cost barriers to care, to the prevalence of negative experiences with health professions. Black and Hispanic patients, for instance, are less likely to trust medical professionals than white patients. Consequently, Black and Latino individuals are less likely to take medical advice, keep follow-up appointments, or fill prescriptions than their white counterparts.

While surveys provide essential information regarding the patient’s qualitative experiences and expectations with the health care system, surveys alone cannot provide a thorough assessment of health and health care disparities. What is needed is access to current patient/member data from providers and insurers. This will provide deeper insights into disparities that officials, activists, and all interested parties can analyze to compare gaps over time across the health care system.

Currently, the available data are inadequate and insufficient. Collection requirements and standards vary in numerous circumstances, such as between state and federal agencies. This leads to incomplete records, as sources of data are often unknown and cannot be verified for quality. Current data reporting to state and federal agencies, furthermore, do not include a majority of patient visits.

Over the past four months, MFT’s health care working group has deeply considered how the state may address this conundrum. The working group has worked to identify the gaps and barriers to data collection, the best sources for data completeness and quality, and changes necessary for improvement.

## **A DEARTH OF HEALTH CARE DATA IN MASSACHUSETTS**

In its 1115 Medicaid waiver extension request, the Executive Office of Health and Human Services in Massachusetts (EOHHS) presented its plans to collect race, ethnicity, language, and disability (RELD) data along with sexual orientation and gender identity (SOGI) data to measure health equity. The EOHHS Quality Measure Alignment Taskforce is expected to manage the implementation. While these developments are critically important to improving data collection, others must build upon the state's efforts to further improve data collection.

Additional state and federal funds can and must also be used to bolster data collection, and ultimately, the fight against inequity.

## **THE CHALLENGE TO MEASURING HEALTH DISPARITIES? DATA**

Despite this recent progress, significant barriers remain to collecting the necessary data. While COVID-induced collection of racial and ethnic data demonstrate that improvements are possible, these lessons may not readily translate to a larger and fundamental requirement of the entire health care system.

Some of the hurdles identified include:

- Multiple federal standards that do not align.
- Electronic health record (EHR) systems' restrictions and limitations.
- Difficulty in acquiring self-reported data / potential patient reluctance to provide information.
- Growth in multiracial population, particularly among children, complicates the collection of race and ethnic data.<sup>1</sup>
- Time and privacy limitations during intake procedures.
- Inadequate training and turnover of personnel who are responsible for data collection.
- Data provenance – inability to discern how the data were obtained and, therefore, its integrity.
- Lax requirements of data collection with limited enforcement.
- Lack of a shared goal across stakeholders articulating why the data is needed, how it will be used, and with whom it will be shared.

## **III. STATE COMMITMENT TO HEALTH EQUITY – PRELIMINARY FINDINGS**

Time and resources will be required to address these barriers. EOHHS, together with the health care community, must commit the requisite support to measure health equity if we are to close gaps in care. The recent infusion of federal funds and higher-than-expected state revenues could provide some of the necessary financial resources.

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<sup>1</sup> See [Multiracial in Greater Boston, The Leading Edge of Demographic Change](#), Boston Indicators, November 2021.

Given the urgency of the issue and the availability of resources, the state should commit to four major deliverables in the immediate future:

- An annual report on health equity;
- A program to work with the health care community to improve data collection and help overcome the reluctance of people to provide self-identified data;
- Regularly updated health equity data set for independent research and analysis; and
- Programs to support collaboration between health care entities in best practices to identify, prioritize and eliminate health disparities.

#### 1. ANNUAL HEALTH EQUITY REPORT

CHIA, working DPH, MassHealth, HPC, and MHQP, should issue an annual report on racial and ethnic health disparities in Massachusetts with year-over-year comparisons. The report should include measures of health care quality for children and adolescents.

- The report should analyze metrics as recommended by the EOHHS Quality Measure Alignment Taskforce and the core set of Children’s Health Care Quality Measures for Medicaid and CHIP which becomes mandatory in 2024. The report could include metrics around the care in areas such as:
  1. Diabetes (adults and children)
  2. High blood pressure
  3. Infant mortality
  4. Prenatal and postpartum care
  5. Well-child visits
  6. Developmental screening
  7. Immunizations and vaccines (adults and children)
  8. Clinical depression
  9. Behavioral health
  10. Asthma (adults and children)
  11. Breast, cervical, and colorectal cancers
  12. Social determinants of health such as housing, social services, geographical location, and education
- Eventually, the report should analyze those health and health care disparities that are largest and most impactful on peoples’ well-being.
- Results from statewide patient experience surveys conducted by CHIA and MHQP that address disparate experiences or outcomes should be included in the report.
- EOHHS, working with CHIA, DPH, MassHealth and HPC, should utilize imputed data from a surname geocoding method in the Health Equity Report until race and ethnicity data are sufficiently complete and valid data become available.

- In regard to the report on the use of telehealth services required in Chapter 260 of the Acts of 2020, HPC, working with CHIA, EOHHS, and the Division of Insurance, should analyze racial and ethnic disparities in access and outcomes from the use of interactive audio and video telehealth services. Surveys of patient and clinician experiences that may impact telehealth’s ability to reduce inequities should be included in the findings.

## 2. DATA COLLECTION REQUIREMENTS, STANDARDS, AND ASSISTANCE

- Ideally, the federal government would standardize reporting requirements for race, ethnic, language and disability (RELD) and sexual orientation and gender identity (SOGI) data that would improve the completeness and quality across federal health programs.<sup>2</sup>
- Until such federal actions are taken, EOHHS, MassHealth, and CHIA should announce plans to phase in and enforce statewide reporting requirements for RELD and SOGI data to supersede differing standards from health care organizations and municipalities.
- CHIA should collect these patient/member data as part of the All-Payer Claims Database and Case Mix Data from insurers and providers, respectively.
- EOHHS/CHIA should phase in reporting of outpatient hospital, physician office, and ambulatory surgery centers care data where more patient care is provided.
- EOHHS/CHIA should phase in reporting requirements of federally qualified health centers (FQHC) and other community centers.
- Data standards to measure disparities in health and health care should be guided by the work of the Quality Measure Alignment Taskforce.
- Data standards should align with federal standards such as those of OMB, HRSA, CMS and FHIR.
- As state disability data collection requirements are being developed, close attention should be paid to the federal government’s Six Standard Disability Questions currently used by the Departments of Health and Human Services, Education, Housing and Urban Development, Justice and the U.S. Census Bureau (see [here](#)).
- CHIA, working with insurers and providers, should issue an annual report on the number of health care records provided, the number of records missing RELD and SOGI values, and estimates of the data’s validity.
- EOHHS should provide resources and assistance that includes training of healthcare professionals on how best to collect self-identified RELD and SOGI data and educate patients and consumers why sharing this data is essential to their health. This leadership and oversight by EOHHS will expedite and improve data collection.

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<sup>2</sup> See [Federal Action Is Needed to Improve Race and Ethnicity Data in Health Programs](#), Grantmakers In Health (GIH) and the National Committee for Quality Assurance (NCQA), with support from The Commonwealth Fund.

- Recognizing that adults will likely intermediate the reporting of children’s data, extra care should be given to the collection of sexual orientation and gender identity data from children and adolescents to monitor health care issues and potential disparities.
- EOHHS should partner with community leaders and trusted community organizations to educate patients and consumers as to why sharing this data is essential.
  - Develop training programs on what data to collect, best practices in their collection, and how to share data throughout the organization. These training programs should educate staff and patients as to why collection of this information is vital for safety, quality and health equity.
- EOHHS should review and discuss RELD and SOGI data collection methods and practices with insurers and providers to identify ways to improve their completeness and validity. This may require resources from the state to:
  - Provide incentives for data collection from patients/members comparable to those offered to ACOs and ACO-participating hospitals to collect “standardized and comprehensive social risk factor data” described in the upcoming five-year 1115 waiver agreement (see [here](#), slide 36).
  - Develop training programs on what data to collect, best practices in their collection, and how to share data throughout the organization.
  - These training programs should educate staff and patients as to why this information is vital for safety, quality and health equity.
  - Promote quality assurance plans to inspect, test, track defects and train personnel.
  - Support quality control plans to verify data conformance and quality.
  - Encourage patient/member surveys through digital apps for self-identification or hard copy to supplement records.
  - Conduct patient/member surveys through an independent, experienced third party selected by the state who would provide consistency across organizations.

### 3. HEALTH EQUITY DATA SET

- CHIA, working with DPH, MassHealth, and MHQP, should publish a continuously updated and anonymized health equity data set in open formats that can be retrieved, downloaded, indexed, and searched by the public to measure racial and ethnic health and health care disparities.
- The public health equity data set should be expanded over time to include all metrics in the health data report. Additional information may be added as determined by CHIA, working with MassHealth, HPC, DPH, and MHQP, for external review and analyses to refine data collections and their ability to measure health care disparities.

- Separately, EOHHS should explore the development of an identified race and ethnicity data set to be shared, with provenance codes, under strict data use permissions and protections, similar to the Massachusetts Immunization Information System (MIIS) and other mandatory-exchange highly sensitive health care data. Such a shared system would substantially improve the integrity of health equity data while reducing data collection costs and disagreements over equity statistics.

#### 4. HEALTH EQUITY AND DISPARITIES EDUCATION

- EOHHS, working with HPC, CHIA, DPH, MassHealth, and MHQP, should collaborate with expert organizations, health systems and academia that have created health equity training, certificates, and fellowships to offer learning opportunities and sharing best practices to identify, prioritize and eliminate disparities.
- Best practices within an organization should be guided by the National Culturally and Linguistically Appropriate Service Standards (National CLAS), which is designed to “advance health equity, improve quality, and help eliminate health care disparities by establishing a blueprint for health and health care organizations” (see [National CLAS Standards](#)).

#### IV. CONCLUSION

In order for Massachusetts to eliminate health inequities, the state must bolster its data collection capabilities. As this analysis highlights, state health care leaders must make health and health care data more complete, valid and accessible. Only then will the state truly have the power to reduce and eliminate racial and ethnic disparities.

Massachusetts was a leader in the collection of race, ethnicity and language data due to a state regulation implemented in 2007. This regulation required all acute care hospitals to report patients’ race, ethnicity and preferred language using standardized methodology based on self-reported information from patients.<sup>3,4</sup> We can become a leader again with a clear-cut mandate and an ongoing focus. In doing so, we may not only become a more just state, but we may bolster the economic opportunities of all residents too.

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<sup>3</sup> [Measuring Racial And Ethnic Health Care Disparities In Massachusetts](#), Robin M. Weinick, Jacquelyn M. Caglia, Elisa Friedman, and Katherine Flaherty, Health Affairs, October 2007.

<sup>4</sup> [Responses of Massachusetts hospitals to a state mandate to collect race, ethnicity and language data from patients: a qualitative study](#), Selena Jorgensen, Ruth Thorlby, Robin M Weinick, and John Z Ayanian, BMC Health Services Research, December 2010.

## **A NOTE OF APPRECIATION**

MTF thanks the members of the health care working group for providing their expertise and experiences in the collection of racial and ethnic patient data. Their knowledge of available data, ongoing efforts on equity, metrics to measure progress, and federal and state requirements have been indispensable in guiding MTF towards its goal of measuring changes in health and health care disparities in Massachusetts.

We appreciate their time, effort and candor.

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## **DISCLAIMER**

The preliminary findings in this report are the work of MTF and its staff. We ask our readers to respond with any errors, misinterpretation of facts, or implausible requests made of organizations and institutions in Massachusetts.

We also ask that you share any ideas, alternative approaches, or modifications to these findings that would accelerate the state's path to health equity. Thank you.