Collection of Race and Ethnicity Data for Use by Health Plans to Advance Health Equity

Annotated Bibliography

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In the report *Collection of Race and Ethnicity Data for Use by Health Plans to Advance Health Equity*, we cite some resources relevant to the collection of race and ethnicity data for use by health plans and other stakeholders. Here we present an annotated bibliography of these resources and other key scholarly research on related issues.

Cross-Cutting Essential Reading

Grantmakers In Health. 2021."Federal Action Is Needed to Improve Race and Ethnicity Data in Health Programs." Washington, DC: Grantmakers In Health and the National Committee for Quality Assurance.

> This paper presents findings and recommendations based on an environmental scan of selected health programs and more than "20 interviews with key informants representing federal, state, and local health agencies, commercial insurance plans, public and private health systems, and health information technology organizations." The authors report that "the examination of federal and state health care and public health programs reveals an absence of complete, standardized, self-identified race and ethnicity data sufficient to monitor equity."

McAvey, Kevin, and Alisha Reginal. 2021. "Unlocking Race and Ethnicity Data to Promote Health Equity in California: Proposals for State Action." Washington, DC: Manatt.

> This paper provides a quick and comprehensive overview of the challenges to collecting race and ethnicity data while also highlighting potential solutions.

National Commission to Transform Public Health Data Systems. 2021. *Charting a Course for an Equity-Centered Data System*. Princeton, NJ: Robert Wood Johnson Foundation.

"To work toward a modernized health data system, the Robert Wood Johnson Foundation established a National Commission to Transform Public Health Data Systems to reimagine how data are collected, shared, and used, and identify the investments needed to improve health equity. Commissioners examined both the systems and the data needed to ensure public health information works for all, including who the data we collect elevates, who is being centered in our data, who is being excluded, and why."

More information about the commission is available at Robert Wood Johnson Foundation. n.d. "Transforming Public Health Data Systems." Accessed June 23, 2022. https://www.rwjf.org/en/library/research/2021/09/transforming-public-health-data-systems.html.

Ng, Judy H., Faye Ye, Lauren M. Ward, Samuel C. "Chris" Haffer, and Sarah Hudson Scholle. 2017. "Data on Race, Ethnicity, and Language Largely Incomplete for Managed Care Plan Members." *Health Affairs* 36 (3): 548–52. https://doi.org/10.1377/hlthaff.2016.1044.

"The Affordable Care Act requires the federal government to collect and report population data on race, ethnicity, and language needs to help reduce health and health care disparities. This article assessed data availability in commercial, Medicaid, and Medicare managed care plans using the Healthcare Effectiveness Data and Information Set. Data availability varied but remained largely incomplete."

Public Health Insurance Coverage

Medicaid

Bailit Health. 2022. "Medicaid Managed Care Contract Language: Health Disparities and Health Equity." Princeton, NJ: State Health and Value Strategies.

This document provides excerpts of health disparities and health equity language from Medicaid managed-care contracts and requests for proposals from 17 states and the District of Columbia.

Lukanen, Elizabeth, and Emily Zylla. 2020. "Exploring Strategies to Fill Gaps in Medicaid Race, Ethnicity, and Language Data." Princeton, NJ: State Health and Value Strategies.

This piece provides an overview of current race, ethnicity, and language data collection standards and ideas for increasing the completeness of these data by engaging enrollees and enrollment assisters and modifying enrollment and renewal interfaces. It also provides suggestions for how states could leverage alternative data sources to improve the completeness of race, ethnicity, and language data.

Machledt, David. 2021. "Addressing Health Equity in Medicaid Managed Care." Washington, DC: National Health Law Program.

This brief discusses ways data disaggregation can be used as a fundamental instrument to make visible the effects of policies aimed at confronting and eliminating health inequities.

Melendez, Mitzi, Suzanne Campanella, Samantha Rosner, Tabitha Pyatt, Bryan Gustafson, Jordan Katz, and Emily Tcheng. 2022. "The State of the Collection of Race, Ethnicity, and Language Data in Medicaid." Chicago: NORC at the University of Chicago.

This paper describes states' processes for obtaining information on race, ethnicity, and language spoken at home for their Medicaid beneficiaries; uses Transformed Medicaid Statistical Information System, or T-MSIS, data from the Data Quality Atlas to identify 15 states that have collected race and ethnicity data on their beneficiaries; summarizes state efforts to improve such data collection, including efforts in California, Michigan, Pennsylvania, and Washington State; and identifies lessons learned and recommendations for states to improve data collection that supports health equity initiatives.

Raslevich, Amy, and Youngmin Kwon. 2022. "Improving Health Equity in Medicaid: Data Needs, Challenges, and Opportunities." AcademyHealth blog. March 21, 2022. https://academyhealth.org/blog/2022-03/improving-health-equity-medicaid-data-needs-challenges-and-opportunities.

This blog post describes the Harnessing Medicaid to Improve Health Equity: A Research and Policy Agenda meeting, where "researchers, policy administrators, and other key stakeholders discussed the various data challenges that hamper progress toward health equity, and shared resources and approaches to improve data definitions, collection, and utilization."

State Health Access Data Assistance Center. 2020. "Race/Ethnicity Data in CMS Medicaid (T-MSIS) Analytic Files Updated December 2021 – Features 2019 Data." State Health Access Data Assistance Center blog. Published August 2020 and updated January 2022. https://www.shadac.org/news/raceethnicity-data-cms-medicaid-t-msis-analytic-files-updated-december-2021-%E2%80%93-features-2019.

This blog post highlights the potential of the Transformed Medicaid Statistical Information System, or T-MSIS, Analytic Files to assess the availability and quality of race, ethnicity, and language data for Medicaid beneficiaries across the country.

State Health Access Data Assistance Center. 2021. "Collection of Race, Ethnicity, and Language Data in Medicaid Applications: A 50-State Review of the Current Landscape." Princeton, NJ: State Health and Value Strategies and State Health Access Data Assistance Center.

This issue brief provides an overview of race, ethnicity, and language data collection standards and examines state Medicaid applications' question structures, response options, and instructional language. The authors also outline some limited research on the best ways to collect this information.

Medicare

Grafova, Irina B., and Olga F. Jarrín. 2020. "Beyond Black and White: Mapping Misclassification of Medicare Beneficiaries' Race and Ethnicity." *Medical Care Research and Review* 78 (5): 616–26. https://doi.org/10.1177/1077558720935733.

The objective of this article is to examine state-level variation in racial and ethnic misclassification of enrollment database and Research Triangle Institute race codes when compared with self-reported data collected during home health care. The authors found "substantial variation between states in Medicare administrative data misclassification of self-identified Hispanic, Asian American/Pacific Islander, and American Indian/Alaska Native beneficiaries."

RAND Health Care. 2021. *Developing Health Equity Measures*. Washington, DC: US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation; RAND.

This report for the US Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation identifies and evaluates health equity measures for Medicare value-based purchasing programs. The authors suggest that although these recommendations are intended for Medicare health equity measures, these findings can be applied more broadly to other public and private health plans.

Marketplace

Pons Pérez, Luis A., Jessica L. Maksut, Loida Tamayo, Meagan T. Khau, and Amaya Ramzi. 2021. *Report of Consumers' Race, Ethnicity, and Language Preference Selections during the 2019 Health Insurance Marketplace Open Enrollment Period*. Baltimore: Centers for Medicare & Medicaid Services, Office of Minority Health.

This report examines the detailed (at the US Department of Health and Human Services data standards level) race and ethnicity (including subgroup) and preferred spoken and written language selections made by federally facilitated Marketplace consumers during the 2019 open enrollment period.

For more information, see Guerino, Paul, and Cara James. 2017. "Race, Ethnicity, and Language Preference in the Health Insurance Marketplaces 2017 Open Enrollment Period." Baltimore: Centers for Medicare & Medicaid Services.

Commercial Health Insurance Coverage

America's Health Insurance Plans. 2005. *Tools to Address Disparities in Health*. Washington, DC: America's Health Insurance Plans.

America's Health Insurance Plans designed this toolkit to assist in broadening its members' (health plans) understanding of issues surrounding data collection and its promising impact on improving care.

American Medical Association. n.d. "Reducing Disparities in Health Care." Accessed June 22, 2022. https://www.ama-assn.org/delivering-care/patient-support-advocacy/reducing-disparities-health-care.

Collecting valid and reliable demographic data on patients served in ambulatory practices is the first step in identifying and eliminating heath care disparities. This article details the importance of collecting demographic data and provides recommendations on how to do so. It aims to "guide providers, electronic health record systems, policymakers, purchasers, hospitals, and health plans in data collection by discussing the value of these efforts in directly improving ambulatory practices."

Institute of Medicine. 2009. *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. Washington, DC: National Academies Press.

In this report, the Institute of Medicine goes beyond standard Office of Management and Budget racial and ethnic categories and provides examples of granular categories for race, ethnicity, and language data collection. It also provides guidance for collecting these data. Key recommendations include

- expanding the six Office of Management and Budget race categories to include a "some other race" option;

- including granular ethnicity categories that reflect the population of interest; and

- at a minimum, collecting data on a patient's spoken English language proficiency.

Sherman, Bruce W., Irene Dankwa-Mullan, Hema Karunakaram, Leah Kamin, Tiffani J. Bright, and Kyu Rhee. 2020. "Race and Ethnicity Must Be Included in Employee Health Data Analyses." *Health Affairs Forefront*. December 21, 2020. https://www.healthaffairs.org/do/10.1377/forefront.20201217.850341.

The authors of this article propose that race and ethnicity should be included as essential fields in employee and population health data collection. They recommend that organizations expand the use of race and ethnicity data beyond just reporting diversity and equity within their businesses to better evaluate the effectiveness of their health benefit offerings.

Health Equity Efforts by Health Plans

Aetna, Racial and Ethnic Equality Initiative. n.d. "Our Commitment to Reducing Disparities in Health Care." Accessed June 22, 2022. http://www.aetna.com/diversityannualreport/pdf/AetnaHealthDisparities.pdf.

This presentation explains Aetna's efforts to gather self-reported information on race, ethnicity, and language to help Aetna understand its members' wellness and health care needs.

Blue Cross Blue Shield of Massachusetts. n.d. "Health Equity Report." Accessed June 22, 2022. https://www.bluecrossma.org/myblue/equity-in-health-care/health-equity-report.

In 2021, Blue Cross Blue Shield of Massachusetts reviewed 2019 data for more than 1.3 million commercial members in the state. It found racial and ethnic inequities in the quality of care in the majority of measures, outlined strategies to combat these inequities, and committed to publishing these results annually.

For more information, see Blue Cross Blue Shield of Massachusetts. n.d. "Turning Equity into Action." Accessed June 22, 2022. https://www.bluecrossma.org/myblue/equity-in-health-care.

Data Collection by Health Systems and Health Care Organizations

American Hospital Association. 2013. "Reducing Health Care Disparities: Collection and Use of Race, Ethnicity and Language Data." Washington, DC: American Hospital Association.

This guide addresses both the collection and implementation of race, ethnicity, and language data. It provides a four-step approach to obtaining accurate data that includes

- determining appropriate data categories,

- developing a methodology for data collection,

- training staff members on methodology, and

- assigning accountability and monitoring the progress of data collection efforts.

The guide also discusses the benefits of implementing race, ethnicity, and language data collection within health care organizations.

American Hospital Association. 2014. "A Framework for Stratifying Race, Ethnicity and Language Data." Washington, DC: American Hospital Association.

"Collecting and stratifying patient R/E/L [race, ethnicity, and language] data are crucial for hospitals and health systems to understand the populations they serve and to implement the appropriate interventions for improving quality of care. While each health care system will stratify data in different ways to meet its own institutional needs, using the five-step framework recommended by this report can help systems to stratify R/E/L data to more effectively identify health care disparities. This report summarizes the framework and provides dashboard templates."

Weissman, Joel S., Joseph R. Betancourt, Alexander R. Green, Gregg S. Meyer, Aswita Tan-McGrory, Jacob D. Nudel, Jessica A. Zeidman, and J. Emilio Carrillo. 2011. *Health Disparities Measurements.* Boston: Massachusetts General Hospital, Disparities Solutions Center; Harvard Medical School.

This report provides practical recommendations for health care organizations to increase their portfolio of race, ethnicity, and language data collection strategies and to use those data to develop disparity-sensitive measures. Intended to guide organizations in measuring disparities and quality, the report discusses the following:

- building the foundation for data collection

- determining measures and indicators to measure

- methodological approaches to measuring and monitoring disparities

- public reporting of health care disparities and priorities and options for quality improvement

Opportunities for Improved Data Collection to Promote Progress

Center for Health Care Strategies. n.d. "Learning and Action in Policy and Partnerships." Accessed June 22, 2022. https://www.chcs.org/project/learning-and-action-in-policy-and-partnerships/.

"In a second round of Learning and Action in Policy funding, CHCS [Center for Health Care Strategies] and DASH [Data across Sectors for Health] are supporting five sites in establishing sustainable, coordinated local or state government and community partnerships as they invest COVID-19 relief funds to advance policies for data sharing and data-integration, improve a culture of health, and advance equity."

DeMeester, Rachel, and Roopa Mahadevan. 2021. "Using Data to Reduce Disparities and Improve Quality." New York: Advancing Health Equity.

This paper highlights how using stratified quality data allows health care organizations and multistakeholder coalitions to strategically (1) discover and prioritize differences in care, outcomes, and/or experiences across patient groups; (2) plan equity-focused care transformations and measure their impact; and (3) tell the story of how patients experience health care.

O'Kane, Margaret, Shantanu Agrawal, Leah Binder, Victor Dzau, Tejal K. Gandhi, Rachel Harrington, Kedar Mate, et al. 2021. "An Equity Agenda for the Field of Health Care Quality Improvement." NAM Perspectives Discussion Paper. Washington, DC: National Academy of Medicine. https://doi.org/10.31478/202109b.

The authors of this paper outline current key barriers to equity in health care, including "the impact of racism and discrimination, inadequate attention to social determinants of health, lack of data, and lack of trust—while also providing strategies to advance equity in health care quality."

Rubin, Victor, Danielle Ngo, Ángel Ross, Dalila Butler, and Nisha Blaram. 2018. *Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health*. Washington, DC: PolicyLink.

This report analyzes the key focus areas in data disaggregation to "advance a culture of health and recommends changes and improvements to the conduct of research and data collection and to the government and corporate policies that define priorities and allocate resources."

Data Collection Best Practices

Centers for Medicare & Medicaid Services. 2022. "Inventory of Resources for Standardized Demographic and Language Data Collection." Baltimore: Centers for Medicare & Medicaid Services.

This resource outlines best practices and guidelines for health care organizations implementing standardized data collection, including information to address key challenges in collecting these data.

Grantmakers In Health and National Committee for Quality Assurance. 2021. *Improving Data on Race and Ethnicity: A Roadmap to Measure and Advance Health Equity*. Washington, DC: Grantmakers In Health and National Committee for Quality Assurance.

This report, informed by an environmental scan and informant interviews, points to several consistent barriers faced by health care organizations in collecting race and ethnicity data, including

- legal and privacy concerns around the collection and use of these data,

- a lack of standardized collection procedures and category definitions,

- technical barriers to collecting and storing data,

- the cost of collection and lack of financial incentives or program requirements to collect race and ethnicity data,

- a lack of staff and resources in health care organizations to analyze and use data once collected, and

- resistance from patients and clinical providers to collect and use race and ethnicity data.

The report concludes with recommendations for federal and state regulators and legislators, health systems and health insurance companies, and other health-sector stakeholders.

Kiran, Tara, Priya Sandhu, Tatiana Aratangy, Kimberly Devotta, Aisha Lofters, and Andrew D. Pinto. 2019. "Patient Perspectives on Routinely Being Asked about Their Race and Ethnicity: Qualitative Study in Primary Care." *Canadian Family Physician* 65 (8): e363–e369.

This study centers on understanding patients' perspectives on responding to a question about their race and ethnicity in a primary care setting. The authors report that "patients attending a primary

care clinic were not uncomfortable responding to a question about race and ethnicity. However, patients had different interpretations of what was being asked. Future research should explore perspectives of patients in other primary care settings and test different methods for collecting data about their race and ethnicity."

National Academy for State Health Policy staff, Duke Margolis Center for Health Policy, and National Governors Association. 2021. "Achieving Progress toward Health Equity Using Race and Ethnicity Data: State Strategies and Lessons Learned." Washington, DC: National Academy for State Health Policy, Duke University, and National Governors Association.

"In June 2021, the National Governors Association Center for Best Practices, the Duke-Margolis Center for Health Policy, and the National Academy for State Health Policy co-hosted a virtual summit on data and health equity. The summit convened state leaders from 20 states to discuss challenges and strategies for collecting, reporting and using race and ethnicity data to improve health equity during and beyond the COVID-19 pandemic. This issue brief summarizes state strategies and experiences shared during the convening, as well as lessons learned during the COVID-19 pandemic."

National Committee for Quality Assurance. 2021. "Health Equity and Social Determinants of Health in HEDIS: Data for Measurement." Washington, DC: National Committee for Quality Assurance.

This issue brief reports on the results of an environmental scan conducted by the National Committee for Quality Assurance to inform the direction of health equity measurement. It also describes the challenges and opportunities related to race, ethnicity, and social needs data sources that support these efforts.

Stein, Daniel, Brian Handspicker, Matt Bishop, Christine Alibrandi, Jennifer Bernstein, Dan Chavez, Pooja Babbrah, et al. 2021. "Modernizing Consent to Advance Health and Equity: A National Survey of Key Technologies, Legal Issues and Promising Practices: Executive Summary." Centerport, NY: Stewards of Change Institute.

This national scan offers the first examination and aggregation of the consent-related activities of health institutions and health care stakeholders.

US Department of Health and Human Services. 2011. *HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status*. Washington, DC: US Department of Health and Human Services.

This guidance describes uniform data collection standards outlined in Section 4302 of the Affordable Care Act.

State Examples

Breslin, Ellen, Dennis Heaphy, Tony Dreyfus, Anissa Lambertino, and Jeff Schiff. 2021. *Advancing Health Justice Using Medicaid Data: Key Lessons from Minnesota for the Nation.* Washington, DC: AcademyHealth.

This report provides information to support state Medicaid programs in measuring and addressing health disparities; highlights one state Medicaid program's essential contribution to the evidence base; underscores racial injustice, discrimination, bias, and stigma in our health care system; and urges state Medicaid programs to invest in data and analysis to measure health disparities.

McAvey, Kevin, and Alisha Reginal. 2021. "Unlocking Race and Ethnicity Data to Promote Health Equity in California: Proposals for State Action." Washington, DC: Manatt.

This paper provides a quick and comprehensive overview of the challenges to collecting race and ethnicity data in California while also highlighting potential solutions.

MN Community Measurement. 2022. "Social Risk Factors Data Collection: Lessons Learned from Minnesota's Experience Collecting Race, Ethnicity, Language and Country of Origin." Minneapolis: MN Community Measurement.

This issue brief summarizes key lessons learned related to collecting information like race, ethnicity, language, and country of origin and provides considerations related to the broader collection and use of information on health-related social needs.

Oregon Health Authority, Office of Equity and Inclusion. n.d. "Race, Ethnicity, Language, and Disability (REALD) Implementation." Accessed June 22, 2022. https://www.oregon.gov/oha/OEI/Pages/REALD.aspx.

Oregon requires the collection of race, ethnicity, language, and disability status data. This requirement helps the state understand which communities have been most affected by the pandemic so the state can get more funding and services. In 2020, the Oregon legislature passed a law that requires health care providers to

- collect race, ethnicity, language, and disability status information at health care encounters related to COVID-19 and

- to share this information with the Oregon Health Authority.

Planalp, Colin. 2021. "New York State of Health Pilot Yields Increased Race and Ethnicity Question Response Rates." Minneapolis: State Health Access Data Assistance Center.

New York set out to improve the rate of response to race and ethnicity questions on applications for Marketplace coverage by piloting changes to such questions. Based on the pilot findings, New York is "expanding changes to the race and ethnicity questions system-wide for the next open enrollment period, and the state is considering additional revisions in hopes of further enhancing the quality and completeness of its data."

Additional Foundational Reading

Bocchino, Carmella. 2004. "Racial and Ethnic Data Collection by Health Plans." In *Eliminating Health Disparities: Measurement and Data Needs*, edited by Michele Ver Ploeg and Edward Perrin. Washington, DC: National Academies Press.

This appendix details the landscape of racial and ethnic data collection by health plans, including barriers to data collection. Staff from 30 plans were interviewed and asked about their thoughts regarding the availability and quality of data collected and the consumer benefits derived from the use of this information.

National Research Council Panel on DHHS Collection of Race and Ethnic Data. 2004. "Private-Sector Collection of Data on Race, Ethnicity, Socioeconomic Position, and Acculturation and Language Use."

In *Eliminating Health Disparities: Measurement and Data Needs*, edited by Michele Ver Ploeg and Edward Perrin. Washington, DC: National Academies Press.

This book chapter is an overview of private-sector data collection systems, the legal frameworks that guide health plans' data collection, and data collection practices.

Pittman, Mary A., Debra Pierce, and Romana Hasnain-Wynia. 2004. *Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals*. New York: Commonwealth Fund.

This report summarizes the results of the nationwide American Hospital Association Annual Survey. The survey aims to identify the number of hospitals that collect race and ethnicity data, how and why those data are collected, which categories are used, and what the barriers and concerns are related to race and ethnicity data collection. One thousand hospitals were also interviewed to provide a summary of recent developments and a current view from the field of data collection.

Acknowledgments

For more information on this project, see the underlying report *Collection of Race and Ethnicity Data for Use by Health Plans to Advance Health Equity: Opportunities, Barriers, and Solutions*, available at https://www.urban.org/collection-race-and-ethnicity-data-use-health-plans-advance-health-equity.

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