

California Needs Standards for Demographic and Social Needs Data to Reduce Disparities and Advance Health Equity



Background

The collection of self-reported, comprehensive, disaggregated, and granular demographic and health-related social needs data is a necessary first step to identifying and then reducing disparities.ⁱ There are an increasing number of calls to action on improving the collection and use of disaggregated demographic data and social needs data by national health care quality organizations,ⁱⁱ and the federal Center for Medicare and Medicaid Services (CMS) has recognized collecting and using disaggregated data as an essential strategy for reducing disparities and advancing health equity.ⁱⁱⁱ

After years of advocacy by the California Pan-Ethnic Health Network (CPEHN) and our partners,^{iv} California's two major public purchasers Medi-Cal^v and Covered California^{vi} now require health plans to stratify and report quality performance measures by race and ethnicity. Additionally, Covered California requires plans to have self-reported race and ethnicity data from at least 80 percent of their members, which is based on the CMS requirement for documentation of demographic data for 80% of beneficiaries in electronic health records by providers and hospitals.^{vii}

However, the lack of industry wide requirements and standards for the collection and reporting of this data across multiple payers has hindered the ability of California and health care purchasers to make actionable progress on advancing more equitable health outcomes, and racial and ethnic and other disparities still persist.^{viii} The imperative to address data shortcomings is especially critical, as the Department of Managed Health Care (DMHC) works to establish a set of statewide enforceable standards for assessing health plan performance on annual equity and quality goals as part of new requirements beginning in Measurement Year 2023.^{ix} These recommendations may also include "approaches to stratifying reporting of results by factors, including, but not limited to, age, sex, geographic region, race, ethnicity, language, sexual orientation, gender identity, and income..." as well as recommendations on "measures of social determinants of health, such as housing security, food insecurity, caregiving, and other nonmedical determinants of health."

This brief provides recommendations for state policymakers to improve the collection and reporting of demographic and social needs data which are critical to reducing health disparities and addressing the social drivers and determinants of health.

Demographic Data: Race, ethnicity, language and other socio-demographic variables that are used to address disparities in health outcomes due to systemic racism, discrimination and exclusion.

Health Related Social Needs: Unmet social needs, such as unstable housing, food insecurity, and lack of reliable transportation, that can exacerbate poor health and quality-of-life outcomes.

Problem

In late 2021, CPEHN conducted a landscape assessment of the state of demographic data collection and reporting in California. As part of this assessment, we conducted interviews with eight health care industry experts and leaders to gather their thoughts on the types of challenges and solutions needed to strengthen the collection and reporting of this data and advance racial equity (see list of interviewees at end of this issue brief). Our interviews highlighted several key findings:

- **Lack of standardization:** Every single interviewee we spoke with described difficulties collecting and reporting demographic data due to the lack of an industry wide standard. As one interviewee shared: "The lack of standardization occurred even within the plans themselves and down to the provider level too. There needs to be an investment made in standardizing not just across Medi-Cal but all the different payer sources." Additionally, while some health plans who own their own physician groups are beginning to collect social needs data, Electronic Health Records (EHRs), an electronic version of a patient's medical history, are still not consistent in how data about housing, food, finances etc. are collected.
- **Need for more granular data categories:** When payers and providers do collect race and ethnicity data, they are generally rolled up to the minimum federal Office of Management and Budget (OMB) categories.^x While there is a concerted effort to encourage the Biden Administration to revisit these categories, California should take the lead in adopting alternatives such as the 2017 U.S. Census and OMB proposal which combines the race and ethnicity categories, creates a Middle Eastern and North African (MENA) category and includes additional granular categories for all race and ethnicity categories.^{xi}

Senate Bill 1033 (Pan), sponsored by CPEHN and introduced in February 2022, would build on the foundation of California's landmark language access bill, Senate Bill 853 (enacted in 2003), to improve the collection and reporting of demographic data and data on health-related social needs. SB 1033 would:

- Require private health plans to develop a demographic profile of their members for the purpose of addressing racial and ethnic health disparities, improving quality and addressing population health.
- Require health plans to meet National Committee for Quality Assurance Health Equity Accreditation which will help plans to formalize internal structures, processes and goals for identifying and addressing health disparities.
- Require private health plans to identify and address health disparities by employing research methods that are compatible with small groups, including, oversampling and the use of multi-year pooled data, amongst other strategies.
- Require the DMHC to establish standardized categories for the collection and reporting of demographic data (race, ethnicity, language, sexual orientation, gender identity, and health-related social needs) for quality improvement purposes to inform California's Health Information Exchange and the Department of Health Care Access and Information (HCAI's) Health Care Payments Data Program (HPD).
- Establish a program to provide technical assistance and other incentives to health plans and providers to improve their data practices which will lead to more equitable health outcomes; the program will include training for providers and staff on data collection, its legality and uses and how to work with patients to improve comfort levels in sharing this data at all points of care.

- **Need for better reporting requirements:** There is often insufficient data from smaller racial and ethnic populations to meet the minimum sample size for the most commonly used HEDIS quality measures (n=400). Without sufficient sample sizes for all racial and ethnic stratifications, identification and reduction of disparities cannot be achieved. Because chronic conditions only impact a percentage of a health plan's total population, larger sample numbers enable a more accurate measure of plan performance. This includes complete and accurate data about a health insurers' entire book of business which is critical to understanding how well a plan is doing at treating and preventing avoidable conditions such as diabetes, hypertension, asthma and mental health across various populations. An obvious solution is to require plans to oversample or use other statistical methods (such as pooling data from multiple years) to overcome the small sample size challenge. Most health systems and larger practices now have population health management departments in recognition of the need for this data. Collecting and reporting the data should not be a problem for larger commercial plans.
- **Multiple platforms:** Interviewees shared frustration about the degree to which data platforms don't talk to each other. Often data must pass through several different platforms and layers where it gets cleaned and modifiers may get dropped. The result is an incomplete file that is rejected and goes into a circular situation where it never gets fixed.
- **Fixing incomplete/wrong data:** Since the Department of Health Care Services (DHCS) is the "single state Medicaid agency," the 834 enrollment files are considered the "source of truth" for who is enrolled in Medi-Cal each month. This is a huge problem both in Medi-Cal and Covered California as the programs jointly use the California Healthcare Eligibility, Enrollment, and Retention System (CalHEERs) system to track enrollment. As a result, much of the demographic information gets re-written every month making it very difficult to correct the data. To counteract this, many health plans have created two demographic fields for things like contact information. Fixing the current system to allow external parties to update their data is going to take years, but there may be some patches that would allow for conflict resolution in the short-term. One of our interviewees suggested, "another solution would be to just continue to use the 834 files for eligibility but strip out/separate the other data (contact information, demographic data etc.) and move that to another system." DHCS' new population health management data system that's currently being built as part of Cal-AIM^{xii} might potentially be an appropriate place to allow for a separate portal where Medi-Cal individuals and/or community health workers (CHWs) plans and providers could collect/report self-reported demographic data.
- **Stronger data-sharing requirements:** Even when state purchasers institute requirements for advancing health equity, some health plans and providers still treat data on their members as proprietary, hindering state collection and reporting efforts. A single data portal for demographic information would help to break down these types of silos which are perpetuating unhelpful barriers to accessing this information.

Several of these key findings, including inconsistent use of race/ethnicity standards and the need for stronger regulations that govern and incentivize the collection of this data across all lines of business, were also cited by Manatt Health in research conducted recently in partnership Blue Shield of California.^{xiii}

Recommendations

Based on our interviews, review of national and state publications on this issue, and analysis of the California health care landscape, CPEHN proposes the following policy recommendations:

- **Adopt statewide standards for data collection and reporting that include disaggregation and interoperability:** California public purchasers and regulators should adopt and enforce statewide standards for the collection, use, and reporting of self-reported, comprehensive, disaggregated, and granular demographic and social needs data, consistent with federal standards for electronic health records (EHRs) and health data interoperability.^{xiv} SB 1033 (Pan) requires the Department of Managed Health Care (DMHC) to lead these efforts.
- **Ensure consumer and community-based organization (CBO) assister access and ability to correct and update demographic data:** California's Health and Human Services Agency's Data Exchange Framework^{xv} should ensure that such demographic and social needs data is interoperable among all users throughout the state. The Data Exchange Framework should also ensure consumer access to, and user-friendly ability to correct and update health data, including demographic and social needs data. DHCS' Population Health Management initiative under Cal-AIM provides a critical opportunity to pilot this type of consumer-centered portal that could be accessed by individuals and those assisting them.
- **Strengthen contract requirements to include both financial penalties and incentives to create an enforced floor of minimum data collection requirements and pathways for collecting additional data:** California public purchasers, in alignment with commercial purchasers such as managed care health plans/qualified health plans, should develop and implement both contract requirements and payment incentives, to create an enforced floor of minimum demographic and social needs data collection requirements (race and ethnicity data for no lower than 50% for all health plan members), and pathways for collecting additional data (race and ethnicity data for up to at least 80% of all health plan members, and additional data about language, disability, sexual orientation, gender identity, and social needs). The Department of Health Care Services and Covered California are proposing new and updated contract requirements on plans. SB 1033 (Pan) broadens these requirements to include a commercial plan's entire lines of business.
- **Establish a program to provide technical assistance, capacity building and peer support and learning on best practices for demographic data collection and reporting:** California public and private purchasers should establish a five-year pooled fund to support technical assistance, capacity-building, and peer support and learning that supports demographic and social needs data collection and reporting by providers, including federally qualified health centers, advanced primary care practices, patient-centered medical homes, school-based health centers, public hospitals and health systems, local health departments, and solo and small group physician practices. The technical assistance and capacity-building should be available through local and regional hubs to ensure access and tailoring to local needs, and utilize best practices in practice improvement and quality improvement. SB 1033 (Pan) requires DMHC to establish and lead this technical assistance program.

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ⁱ Kauh TJ. Racial Equity Will Not Be Achieved Without Investing in Data Disaggregation, Health Affairs Forefront, November 29, 2021, <https://www.healthaffairs.org/doi/10.1377/forefront.20211123.426054> and Asian & Pacific Islander American Health Forum, Access, UnidosUS, National Urban League, National Congress of American Indians, Health Equity Cannot Be Achieved Without Complete and Transparent Data Collection and the Disaggregation of Data, 2021, <https://www.apiahf.org/wp-content/uploads/2021/02/APIAHF-Policy-Recommendations-Health-Equity.pdf>

ⁱⁱ National Committee for Quality Assurance and Grantmakers for Health, Improving Data on Race and Ethnicity: A Roadmap to Measure and Advance Health Equity, 2022, <https://www.ncqa.org/wp-content/uploads/2022/01/GIH-Commonwealth-Fund-federal-data-report-part-2-1.pdf>; National Quality Forum, A Roadmap for Promoting Health Equity and Eliminating Disparities: The Four “I’s” for Health Equity, 2017, https://www.qualityforum.org/Publications/2017/09/A_Roadmap_for_Promoting_Health_Equity_and_Eliminating_Disparities__The_Four_I_s_for_Health_Equity.aspx; and

Institute for Healthcare Improvement, Achieving Health Equity: A Guide for Health Care Organizations, 2016, <http://www.ihl.org/resources/Pages/IHIWhitePapers/Achieving-Health-Equity.aspx>

ⁱⁱⁱ CMS Equity Plan for Medicare, 2015, <https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/equity-plan>; CMS Health Equity Data Access Program, <https://www.cms.gov/About-CMS/Agency-Information/OMH/equity-initiatives/advancing-health-equity/health-equity-data-access-program>; and CMS Center for Medicare and Medicaid Innovation, Driving Health System Transformation: A Strategy for the CMS Innovation Center’s Second Decade, 2021, <https://innovation.cms.gov/strategic-direction-whitepaper>

^{iv} CPEHN, Improving Collection, Reporting, and Utilization of Beneficiary Demographic Data, 2020, https://cpehn.org/assets/uploads/2020/02/cpehn_data_mini_brief_-_final.pdf and CPEHN, Centering Equity in Health Care Delivery and Payment Reform, 2020, <https://cpehn.org/what-we-do-2/our-projects/health-equity-system-transformation-project/>

^v California Department of Health Care Services, Comprehensive Quality Strategy, 2022, <https://www.dhcs.ca.gov/services/Documents/DHCS-Comprehensive-Quality-Strategy-2022.pdf>

^{vi} Covered California, 2022 Amended Qualified Health Plan Contract Attachment 7, https://hbex.coveredca.com/stakeholders/plan-management/PDFs/proposed-2022/Proposed%202022%20Attachment%207%20QHP%20IND%20Clean_3-18-21.pdf

^{vii} https://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/downloads/Stage2_EPCore_3_RecordingDemographics.pdf (the Stage 1 requirement was 50%)

^{viii} Aurrera Health Group, Health Disparities by Race and Ethnicity in California: Pattern of Inequity, 2021, <https://www.chcf.org/publication/2021-edition-health-disparities-race-ethnicity-california/#related-links-and-downloads> and California Department of Health Care Services, 2020 Health Disparities Report, 2021, <https://www.dhcs.ca.gov/Documents/MCQMD/CA2020-21-Health-Disparities-Report.pdf>

^{ix} Department of Managed Health Care, Health Equity and Quality Committee, <https://www.dhmc.ca.gov/AbouttheDMHC/DMHCPublicMeetings/OtherMeetings/HealthEquityAndQualityCommittee.aspx>

^x U.S. Office of Management and Budget, Revisions to the Standards for Classification of Federal Data on Race and Ethnicity, 62 Fed. Reg. 58782–58790, October 30, 1997, <https://www.gpo.gov/fdsys/pkg/FR-1997-10-30/pdf/97-28653.pdf>

^{xi} U.S. Office of Management and Budget, Proposals from the Federal Interagency Working Group for the Revision of the Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity, 82 Fed. Reg. 12242–12247, March 1, 2017, <https://www.gpo.gov/fdsys/pkg/FR-2017-03-01/pdf/2017-03973.pdf>

^{xii} <https://www.dhcs.ca.gov/CalAIM/Pages/calaim.aspx>

^{xiii} Kevin McAvey, Director Manatt Health, Alisha Reginal, Manager Manatt Health, “Unlocking Race and Ethnicity Data to Promote Health Equity in California Proposals for State Action,” April 2021. https://www.manatt.com/Manatt/media/Documents/Articles/BSCA_Unlocking-Race-and-Ethnicity-Data-to-Promote-Health-Equity-in-CA-April-2021_c.pdf

^{xiv} U.S. Department of Health and Human Services Office of National Coordinator for Health Information Technology, 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications; Final Rule, 80 Fed. Reg. 62602– 62759, October 16, 2015, <https://www.gpo.gov/fdsys/pkg/FR-2015-10-16/pdf/2015-25597.pdf> and U.S. Department of Health and Human Services Office of National Coordinator for Health Information Technology, U.S. Core Data for Interoperability, V2, 2021, <https://www.healthit.gov/isa/uscdi-data-class/patient-demographics#uscdi-v2>

^{xv} <https://www.chhs.ca.gov/data-exchange-framework/>