



October, 2022

Improving the Collection and Use of Race, Ethnicity and Language Data

A Key to Understanding and Addressing Health Disparities

Introduction

Stratifying health quality data by race, ethnicity, language and other factors is crucial for understanding how long-standing systems of privilege and oppression impact the health of populations and communities. Primary care, the doorway to our health system, is uniquely positioned to help identify and alleviate disparate care and outcomes. However, that power is inhibited by inadequate demographic data collection and loss of potential to connect it with data on quality, outcomes and patient experience.

This brief discusses the current availability of race, ethnicity and language (REaL) data across the health system, presents options for stratifying based on available data, offers a framework for assessing pros and cons depending on variables and goals, presents a case sample from a primary care measurement pilot project to illustrate stratification method trade-offs and provides recommendations for improving data collection and reporting systemwide to ensure it is meaningful and actionable. Conclusions are drawn from individual expert interviews, research and literature reviews.

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Identifying Health Disparities and Solutions Using Data Stratification

Primary care is the foundation of all high-functioning health care systems.¹ A person's primary care provider, team and office staff are often the first touch points within the broader health system. At its core, primary care is about building trusting relationships and caring for the whole person. The quality and frequency of these interactions directly impact an individual's use of the system, their level of comfort to share information that can help make health disparities more transparent and their overall health and well-being.

Advanced primary care² has the potential to improve outcomes for underserved communities and reduce health disparities.³ Through a variety of public and private efforts at the purchaser, health plan and provider levels, health care organizations in California are seeking to strengthen primary care and increase access to advanced primary care across the state.⁴

The more granular our understanding of primary care quality and variation, the better. Currently, most efforts to measure primary care quality involve gathering data at the provider group level that has already been combined across practices and locations. This obscures visibility into outcomes, quality and experience in the same way combining populations loses a large part of the picture. Stratifying across populations and at the practice level is the best way to create clarity for health care decision makers to identify disparities and possible solutions, set priorities and direct resources, such as technical assistance and workforce support.

Of note, there are other examples of equity-related demographic data besides REaL, notably sexual orientation and gender identification (SOGI) data. Though this brief focuses on REaL data, the recommendations for enhancing REaL data collection could be used to enhance SOGI and other equity-related data as well.

Health equity, health disparities and social determinants of health are different concepts and should not be used interchangeably. This brief uses the following definitions:

- **Health equity:** Everyone has a fair and just opportunity to be healthy. Equity is not the same as equality. Equity often requires additional efforts and investments for those who currently experience worse health and fewer opportunities.⁵
- **Health disparities:** Inequitable differences in health outcomes closely linked with social conditions. Both individuals and populations as a whole can experience health disparities. Health disparities are often associated with historical and current unequal distribution of social, political, economic and environmental resources, as well as structural racism and other discriminatory conditions.⁶
- **Social determinants of health:** The conditions in which people are born, grow, work, live and age. They are a wide set of forces and systems shaping conditions of daily life, including economic, political and social policies and systems.⁷

The Current Landscape of Available Data for Understanding Care Quality and Health Outcomes

REaL data is crucial for understanding, tracking and mitigating the impacts of health disparities. While there are many potential sources of REaL data, stakeholders in California and across the nation have confirmed that patient self-reported REaL data is the best “source of truth” for demographics.⁸

Variation exists in the availability of self-reported REaL data across health insurance markets and product lines. In 2019, approximately 76% of racial data and 94% of ethnicity data were incomplete for commercial product lines nationally.⁹ At the same time, 26% of racial data and 60% of ethnicity data were incomplete for Medicare.¹⁰ There is much higher availability of race and ethnicity data in California’s Medicaid program, Medi-Cal, with 83.6% known and 16.4% not reported based on enrollment and eligibility information.¹¹ The reason for higher Medi-Cal reported rates can likely be attributed to Senate Bill 853 from 2003, which required health plans to file an enrollee assessment of language, race and ethnicity beginning in 2009.¹²

These limitations of known race and ethnicity data in the commercial and Medicare markets hinder the ability to see where disparities exist and for the health system to react with meaningful interventions. For purchasers and payers to create effective interventions that will drive change, such as incentives or penalties related to payment, networks or distribution of resources, it is crucial to uncover as much variation as possible by stratifying quality data across race, ethnicity and language, by product and business lines and within and between individual practices.

In the absence of self-reported data, proxy methods exist for understanding disparities. One is imputation, or estimation, of race and ethnicity based on an algorithm that includes other known data, such as name and address. However, one drawback is that the estimates are not perfectly accurate, so decision makers must be cautious when considering the appropriateness of this approach in a given situation. Another method of stratifying quality performance to understand health disparities involves geographic retrofitting, or overlaying measures with known sociodemographic data in a region. However, this would reveal only broad brushstrokes of correlation and would not give insight into granular or individual outcomes, meaning there are limits to what could be done with the information. For example, a ZIP code that has a high proportion of residents who identify as Black and where a majority of practices tend to perform poorly on diabetes management measures can broadly illuminate a disparity, but this is not as accurate as a data set made up of information specific to the measure and the person.

Data Stratification Approaches: Summary, Trade-offs and Considerations

There are benefits, challenges, trade-offs and variables to consider for each approach to data stratification.

Self-Reported REaL Data

Patient self-reported data is information that has been individually collected based on a direct report by the patient or from a third party on the patient's behalf. Expert feedback has consistently reinforced that patient self-reported data is the best option when analyzing health outcomes across populations. This data is most actionable since it could apply down to individual care decisions. For example, a self-reported race indicator provided at the time of a screening or test is data that would apply directly to the patient.

There are, however, drawbacks. As mentioned above, self-reported REaL data availability is quite low in some health care markets, and improving self-reported data collection can be time and resource intensive.

A successful example using self-reported REaL data is the Public Hospital Redesign and Incentives in Medi-Cal (PRIME) program, which enhanced collection of self-reported data through incentives, with some hospital systems increasing up to nearly 100%.¹³ The programs then transitioned into disparity reduction initiatives based on data stratification performed and driven by each public hospital system.¹⁴

Imputation or Estimation

Imputation algorithm methods have been developed for estimating race and ethnicity for data sets that do not include or are lacking this information. RAND Corporation designed an approach called Bayesian Improved Surname Geocoding (BISG), which uses geocoded address and name and refines census data to predict race and ethnicity.¹⁵ The Centers for Medicare & Medicaid Services has successfully used a variant of this tool to address missing race and ethnicity data and improve existing data to compare Healthcare Effectiveness Data and Information Set (HEDIS) clinical quality of care measures.¹⁶ BISG has also been used to successfully estimate race and ethnicity of HealthCare.gov enrollees.¹⁷ It is important to note that patient-level data of name and ZIP code, and ideally street address to use the Census Block Group, is required to use the algorithm.

Imputation is a helpful tool for bringing REaL data into large legacy system data sets that may never have asked for it (e.g., IRS tax-related information) or where the data is incomplete. This can be helpful for informing an active policy discussion or legislation that needs an urgent decision. Imputed data can also be used in combination with self-reported data when available, and self-reported data can even be incorporated into race and ethnicity imputation models to improve calibration.¹⁸

BISG methodology is meant for population-level analysis and is not recommended for individual patient-level analysis. A limitation of BISG is that its performance at predicting race and ethnicity for smaller populations, such as American Indians and Alaska Natives (AIAN), may not be reliable enough to use for post-imputation analyses. There are limitations to how actionable the data can be if reliability is low, and it is important to consider whether the race and ethnicity data gleaned is accurate enough to be used for the analytic goals of the project.

Sociodemographic Data Overlay or Geographic Retrofitting

Additional data sources can be layered onto health data to understand how race, ethnicity, language and other variables relate to performance measurement. Examples of potential data sets to use include the California Health Interview Survey (CHIS) and the American Community Survey (ACS), a resource of the U.S. Census Bureau. This approach could be used to understand more about outcome results in the absence of self-reported REaL data or the ability to use an imputation proxy. It could also be layered onto data sets and outcomes that already stratify with self-reported or imputed data to gather additional insights.

One successful example is a 2018 Health Affairs study in which the California Pan-Ethnic Health Network (CPEHN), UCLA and UC Davis used CHIS demographic data and Integrated Healthcare Association (IHA) cost and quality performance data to review disparities within and between regions in California.¹⁹ Many data sets are publicly available and can be used to compare health program outcomes across important stratification areas to better understand where improvement is needed.

This approach, if used in the absence of other data stratification options, would show only correlation to measurement results by geography and ZIP code and would not have stratification of individual health-related measurement results. Since racially and ethnically diverse populations are often geographically dispersed, discrimination or adverse experiences may not be captured with this area-based measurement system.

Ethical Considerations and Avoiding Bias

There are ethical considerations around harming populations if stratification is not done thoughtfully. They include misrepresenting communities by using inappropriate input data or methodology; using data for purposes that harm people of color; violations of privacy and risk of reidentification that could inadvertently create harm, particularly for smaller or less data-visible groups of peoples (such as the AIAN population); not accounting for or not providing informed consent and excluding people and communities of color from ownership of their data and from decisions. Low accuracy in imputing race and ethnicity among certain groups may exacerbate these issues.

When a stratification option involves merging data sets, there is evidence of potential to incorporate racial biases present in input sources.²⁰ This risk can be harder to identify in complex approaches, like imputation, because of the layers of transformation between the input and output. It is crucial to consider bias inherent in the input data and other data sets being used as part of imputation and the potential for introducing bias at each step. Researchers should examine if the data set being used accurately represents the underlying population it aims to measure and how structural racism might fuel unrepresentativeness. In a non-health care data set example, over-policing of communities of color can result in arrest data that overrepresents these communities instead of representing true crime demographics.²¹

In addition, it is important to consider mismatches between data sets (e.g., the credit-visible population versus the overall population, to use another non-health care example) and attempt to adjust estimates to match.²² The trade-offs between potential harmful impacts to results and the overall value added should always be considered.

Considerations for applying stratification options to a health measurement project

Timeline: For scenarios where self-reported data is not adequately available and a decision is urgently needed, imputation or a sociodemographic overlay may be a more appropriate option than collecting self-reported data from scratch. It is important to consider trade-offs of potential risks from using a less precise stratification tool against the overall benefit of achieving a stratified view.

Level of granularity needed for the project goal:

Imputation methods may be an appropriate option for projects involving large data sets where broad brushstrokes are sufficient to meet the intended goal. However, because it is estimated, this data would not

be useful for populations with numbers too small to be reliable (such as AIAN or individuals who identify as mixed race) and would not be appropriate for individual patient-related actions, because it does not represent real patients.

Methodology and availability of required data: If self-reported data percentages are low or nonexistent in the data set needed to measure performance, options are limited. Additionally, imputation methods require data such as name and address to be used as a proxy for research and stratifying. Without appropriate input data, imputation algorithms would not be an option.



Stratification in Action: Advanced Primary Care Measurement Pilot

California Quality Collaborative (CQC) and the Integrated Healthcare Association (IHA), along with four large purchasers—Covered California, CalPERS (the California Public Employees' Retirement System), the City and County of San Francisco and eBay—initiated a [measurement pilot](#)²³ aimed at understanding if a practice is delivering high-quality primary care, or “[advanced primary care](#).”²⁴

The pilot, which uses existing data for a new purpose, will aggregate practice-level data across all IHA's Align. Measure. Perform. (AMP) participating health plans.²⁵ At present this includes 14 health plans reporting commercial claims across a mix of products (Health Maintenance Organization or HMO, Preferred Provider Organization or PPO and Exclusive Provider Organization or EPO).

The pilot's goal is to use this data and a new practice-level algorithm to understand variation in quality of primary care offered in California with the possibility of purchasers, plans and practices using the information to inform policy decisions such as resource allocation for improvement.

However, without stratifying REaL data into the measurement, a huge piece of the picture is missing. CQC gathered feedback from a work group of health equity experts, IHA and imputation experts to better understand the options for integrating REaL data into the analysis. Several approaches are considered.

APC Measurement Pilot: REaL Data Stratification Options Assessed

Self-reported data: Self-reported data availability is limited in the context of the Advanced Primary Care Measurement Pilot, where the percentages of REaL data are too low to provide meaningful information. Percentages of race and ethnicity data in AMP are close to the percentages of commercial data nationwide – 24% for race and 6% for ethnicity.²⁶

Imputation: No additional data collection or reporting would be needed since the necessary data for imputation is available through AMP. IHA is testing the feasibility of using AMP data for this purpose. However, imputation could pose a challenge for the practice-level assessment that is part of the pilot design, and some of the practice-level patient values for race and ethnicity would be quite small, causing concern about the reliability for small populations such as AIAN or individuals who identify as mixed race.

Self-reported data and imputation: This would use the available self-reported data and imputing to estimate the missing data. However, self-reported data percentages are very low with the specific mix of health plans participating in the pilot, so this option, at present, would be almost indistinguishable from full imputation as well as more resource intensive. As self-reported REaL data percentages increase, so does this option's utility.

Geographic Retrofitting: This involves using a data set that already has high amounts of self-reported REaL data (e.g. CHIS) and combining it with advanced primary care pilot data to understand how overall practice performance varies based on regional demographics. This would not enable actions that are practice or patient specific, but could reveal areas where access issues to high quality primary care and disparities may exist which could still inform decisions.

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Stratification in Action: Advanced Primary Care Measurement Pilot (continued)

Bringing a REaL Data Lens to the Advanced Primary Care Measurement Pilot

Given the limited availability of self-reported data in AMP, CQC does not recommend stratifying at the practice level with this approach. In the future, when the availability of self-reported race and ethnicity data increases, ideally within the system overall and within AMP, this would be the most appropriate data stratification option for the project, as was confirmed by the work group of health equity experts convened by CQC.

Imputation by itself raised concerns from stakeholders since estimates may not be reliable for small populations. Resulting health campaigns, interventions and other activities would need to be clarified accordingly. It was raised that imputation, in place as a proxy, could be a distraction from collecting the most accurate data, which is self-reported, but organizations that use BISG imputation extensively and effectively tend to be the ones that collect the highest proportion of self-reported data.²⁷

Stakeholders affirmed that a combination of self-reported data and imputation would be the second best option, as long as an appropriate emphasis is placed on continuing to increase collection of self-reported data. This approach may require more resources since it combines two data methods together. Information gleaned would, in general, not be appropriate for individual patient use since imputed data would be mixed in.

Given the stratification restrictions for this specific project, CQC will utilize geographic retrofitting and explore public data sources to overlay the practice performance results for the initial year of the pilot. This data stratification approach will be a stepping stone to employing more granular and patient-specific methods, such as self reported data plus imputation, in later cycles.

Better data would give a more nuanced understanding of disparity at the practice and community levels, and the lack of data in AMP and the commercial market points to the need to improve collection.



Recommendations for Increasing REaL Data Collection in the Health System

Legislation, Policy and Regulation

Legislation, policy and regulation have the potential to drive improvements in the collection and quality of self-reported REaL data. One example is a California bill introduced in 2022, SB 1033, which builds on SB 853 and would clarify requirements that private health plans must develop demographic profiles of their members while improving best practices for demographic data collection for the purposes of eliminating health disparities.²⁸ It would also establish clear, consistent categories for data collection for race, ethnicity, language and additional categories to more properly track health outcomes for lesbian, gay, bisexual, transgender, queer, intersex and asexual (LGBTQIA+) and disabled Californians.

In general, it is better for legislation to incentivize or require health plans, providers and other health system organizations to increase the collection and quality of self-reported demographic data, rather than report imputed data. Legislation and statute also have the potential to require standardization for data fields and definitions, which enables large-scale purchasers of health care to align with their health plan and provider industry partners to share data and achieve better stratification and improved health outcomes.

Both federal and state legislatures and regulatory bodies have the opportunity to set additional standards for collection and reporting of REaL data, but it is important to ensure that national and state standards do not evolve in a contradictory manner. The White House Office of Management and Budget (OMB) has broad standards that are used nationally, which California is building on to determine additional layers of specificity.

Contracting and Business Relationships

Contracting requirements and incentives as part of large-scale public and private purchaser and payer programs can increase the collection, reporting and use of REaL data and thereby bolster disparity mitigation efforts. As noted above, one success story involves the California Association of Public Hospitals and Health Systems (CAPH), which saw large increases in hospital system ability to collect and report REaL and SOGI data through financial incentives in the Public Hospital Redesign and Incentives in Medi-Cal (PRIME) program. Some systems were even able to leap from zero collection to almost 100% REaL data percentages in five years.²⁹ Collection of self-reported race and ethnicity data may never be available for 100% of members, meaning the need to impute small amounts may still exist.

Additionally, Covered California saw increases in percentages of REaL data reported across their plans when increases were tied to financial incentives. Though Covered California's plans are part of the commercial market, their self-reported race percentages range significantly higher than the 24% commercial average – approximately 66% to 99%.³⁰ Large-scale public programs could emulate work done by Covered California to add incentive payouts if plans are able to stratify measures across self-reported REaL data.

In addition, health plans, provider organizations and other payers that contract within the health system can use incentive payouts for better collection, stratification and disparity reduction efforts, or they can build tiered networks with preferential patient placements at providers that have proven to be stronger at collecting, reporting and using REaL data.

As an example of a payer using incentive payouts, Blue Cross Blue Shield of Massachusetts has published on their website performance data on 48 measures stratified by member race and ethnicity, using imputed race and ethnicity data (via the RAND BISG method). Based on disparity data found, they are adding equity measures with improvement incentives to alternative payment models with providers, through an accountable care organization (ACO)-like strategy.³¹

In a large and fragmented system, it is important for purchasers, payers and other large-scale health change drivers to avoid siloed initiatives that conflict with each other. Alignment among purchasers, payers and health system organizations is just as important as alignment between state and federal regulations.

Organizational Leadership, Systems Structure and Culture

Organizations that pay for services at the point of care (e.g., health plans and independent physician associations, or IPAs) have the potential to increase REaL data collection, reporting and use through assessing and enhancing data collection opportunities from members or patients, sharing data internally and creating a culture that values the collection of this information. This starts with organizational leadership.

It is important to normalize data collection into regular workflows to improve the quality and ensure the most accurate information possible. How a patient may report can depend on the circumstances and environment, the way the question is presented, how safe the individual feels in that moment and many other variables. It is also important for patients to have system access to adjust their demographic data on their own.

Purchasers, health plans and provider organizations can increase self-reporting by increasing awareness of how the data will be used and educating brokers and enrollment counselors on why it is important to collect this data.³² Stakeholder feedback did not reveal accepted standards for frequency of REaL

data collection; however, it is important to create a continuous process to collect this data because of variation in patient reporting due to the variables listed above. This requires more time and resources.

Payers can take inventory of all existing member-facing channels (e.g., enrollment, service center, case management, wellness or incentive programs) and assess if mechanisms exist to collect demographic data and how often it is collected. If member-facing channels do not have a collection mechanism, this should be added. If data is not collected consistently or if there is a high refusal rate, payers can train new and existing member-facing staff on the importance of collection, best practices for asking the questions and describing how the member data will be used. Trainings should include examples of how the data collected has been used by health systems to improve health care outcomes, so staff can relay this information to patients who may want to know. This can also enhance self-reported data quality and reduce third-party reporting, which can be based on perceived appearance and thus problematic.

Payers should connect systems to share demographic data internally. For example, REaL data collected three months ago by a case manager would show up in the system for the service representative when the patient calls the service center. It is also important to ensure that REaL data is flowing from health plans to contracted providers and vice versa.

As collection becomes more robust, organizations should develop better internal and cross-organizational approaches to data management and validation. If a data field for the same individual is different, it is important to consider which source to use within internal and external systems, also known as a “source of truth.” This might vary based on the scenario. It can be helpful for organizations to develop a “source of truth” policy to support staff and standardize the process. It is important to remember the most recently reported data may not be the most accurate. Differences in reporting from the same individual may not be an error, but rather due to variation in circumstances, environment, comfort level or other variables.

Certification Requirements

The National Committee for Quality Assurance (NCQA) has required plans to report their percentage of self-reported REaL data and to stratify five measures in 2022, with a goal of 80% self-reported data in the stratification by measurement year 2024.³³ This will increase to 10 measures in measurement year 2023 and 15 measures in measurement year 2024. Additional accrediting organizations, purchasers and others could adopt similar certification requirements to support reporting and stratification for the same measures and self-reported data goals as NCQA. This would increase the consequences for not aligning and support the overall goal of greater availability of self-reported REaL data. Covered California has already aligned with this NCQA requirement.³⁴

In addition, state data aggregators and health information exchanges potentially have a role to play in incentivizing or requiring that data reported include demographic indicators, enabling stratification, and in leading to help set reporting standards.

Advocacy and Education

It is crucial for decision makers in all organizations who play a role in the health care system to incorporate the lived experiences and perspectives from BIPOC (Black, indigenous and people of color) individuals and other underrepresented communities into education about the importance of stratifying REaL data and the most effective ways of enhancing collection and reporting.

Advocates and educators may also be able to identify and help prioritize new channels and mechanisms for data collection and/or reporting, making them essential in these efforts. For example, advocates and educators who understand the particular priorities and concerns of a given community may be able to suggest more accessible forms for reporting demographic data, identify locations that engender trust (such as community centers, enrollment centers or libraries) and advise on cultural sensitivities that are important to consider when training staff who will collect or share REaL data. This change lever is cross-cutting and crucial to supporting the work in all the previously mentioned change levers.



Summary of Change Levers for Increasing REaL Data Collection in the Health System

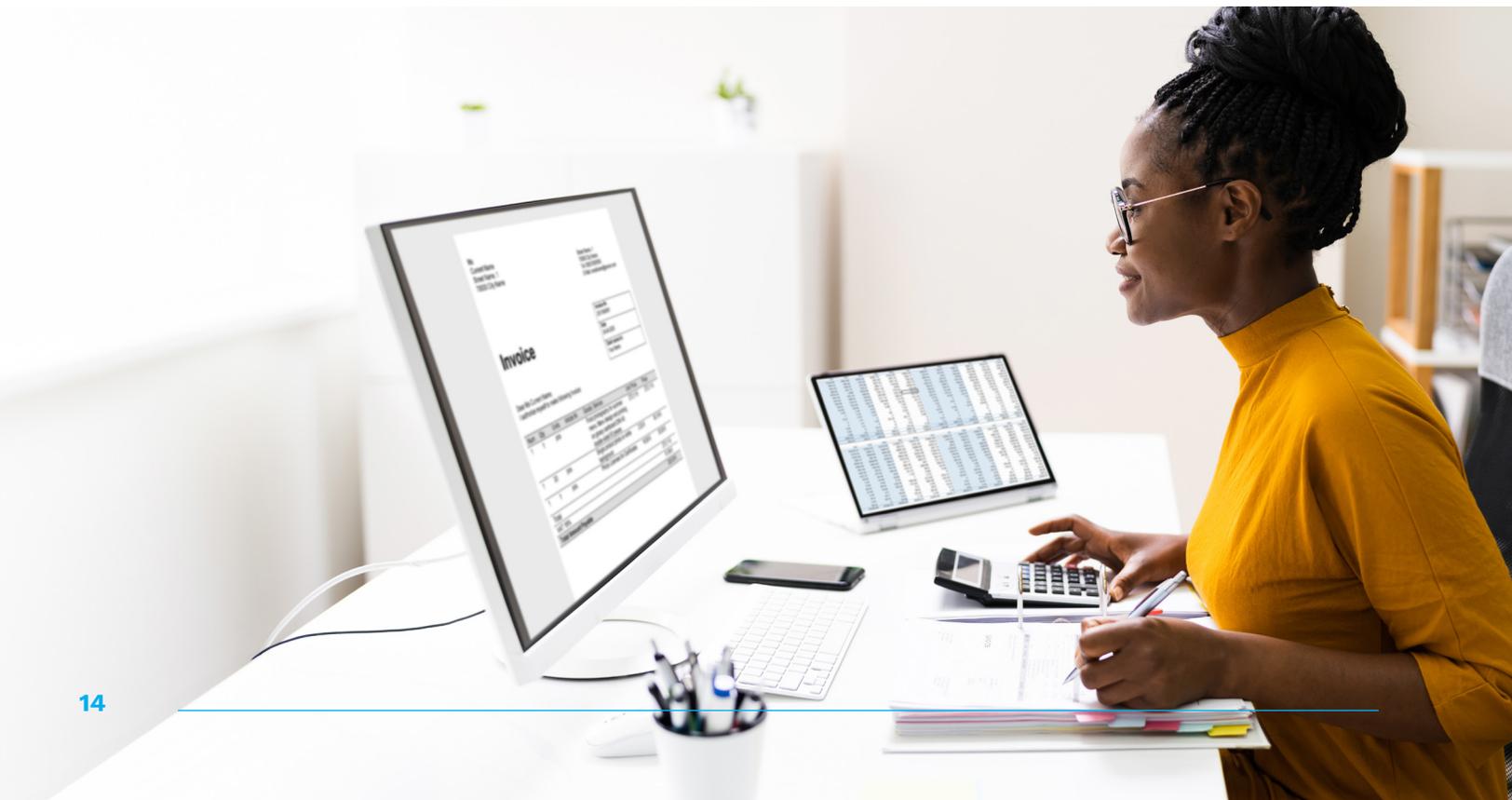
Change Lever	Benefits	Limitations	Actors
Legislation, policy and regulation	Required level for statewide, standard/universal change	High level, must have accountability mechanism and resources to assess	Lawmakers, decision makers at health agencies
Contracting and business relationships	Can be directly tied to payment, market share and other business incentives	Relies on organization to lead; changes in behavior (e.g., contracting and business processes) can be hard to negotiate. Optional.	Purchasers (public and private), health plans, provider groups
Organizational leadership, systems structure, and culture	Most immediate way to increase data collection, reporting and sharing	Requires change management. Unlikely to be standard across health systems. Optional.	Purchasers (public and private), health plans, provider groups
Certification requirements	A requirement for organizations that participate. May be tied to contracting, reimbursement or incentive benefits. May have reputational benefit (or, conversely, risk if applicant misses certification due to inability to collect or report stratified data). Standard application.	Accreditation may be optional	National accrediting bodies such as NCQA, purchasers (if applicable)

Conclusion

The ability to stratify health care quality, outcomes and experience data by race, ethnicity and language is crucial for understanding where primary care and our entire health care ecosystems are fulfilling the needs of patients and where they are falling short. Without a transparent lens into REaL data at the practice level, health system leaders, improvement advisors and care teams will not be able to see the variation in access, quality and outcomes that leads to health disparities. This lens enables state-level action to support disparity mitigation regionally and at even more granular levels, like individual practices.

Patient self-reported data is the best information to use toward this end. In the absence of self-reported data, imputation algorithms that estimate race and ethnicity may be appropriate in some circumstances, but it is important to consider privacy, ethics, reliability and usability of the data based on population size and the goals of the project.

There is no silver bullet to increasing the amount and quality of self-reported REaL data being exchanged and used for disparity mitigation within the health system. However, a combination of key levers working in tandem—legislation and implementation, direction setting from public and private purchasers, contracting and business strategies from payers, internal systems and culture at health care organizations and education and elevation of voices from the right advocates—can move us toward the change we need to see.



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**This brief was funded
by the California Health
Care Foundation.**

About the Purchaser Business Group on Health (PBGH)

Purchaser Business Group on Health (PBGH) is a nonprofit coalition representing nearly 40 private employers and public entities across the U.S. that collectively spend \$350 billion annually purchasing health care services for more than 21 million Americans and their families. PBGH has a 30-year track record of incubating new, disruptive operational programs in partnership with large employers and other health care purchasers. Our initiatives are designed to test innovative methods and scale successful approaches that lower health care costs and increase quality across the U.S.

About the California Quality Collaborative (CQC)

California Quality Collaborative (CQC), a program of PBGH, is a health care improvement program dedicated to helping care teams gain the expertise, infrastructure and tools they need to advance care quality, be patient-centered, improve efficiency and thrive in today's rapidly changing environment.

The program is dedicated to advancing the quality and efficiency of the health care delivery system across all payers, and its multiple initiatives bring together providers, health plans, the state and purchasers to align goals and take action to improve the value of health care for Californians.

Acknowledgments

CQC would like to thank the many experts who contributed to the content of this brief:

Marc Elliott, Ph.D., Senior Principal Researcher, RAND Corporation

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