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How Purchasers are using REaL and SOGI Data to Advance Health Equity

Introduction

Health Disparities were first raised to public consciousness as early as 2003 with the Institute of Medicine’s landmark report, “Unequal Treatment,” and have persisted in the intervening 20 years through to the present.¹ Public health efforts aimed at reducing health disparities have often ignored workers and families that are covered by employer-sponsored insurance, despite clear data indicating inequities impact individuals across all income and insurance types. More than 170 million Americans rely on employers and public purchasers for their health and health care.

Employers and public purchasers are committed to reducing disparities and are working to ensure their workers and families receive equitable care and services regardless of race, ethnicity, gender identity, sexual orientation, cultural background, etc. Despite purchasers’ commitment to advancing health equity, private employers have seen slow progress in measuring equitable health care services.

Private employers and public purchasers can ensure accountability for equitable outcomes by leveraging Race, Ethnicity, and Language (“REaL”) and Sexual Orientation and Gender Identity (“SOGI”) data to identify disparities and develop strategies to address inequities in health care access, experience, and ultimately, outcomes. One of the key challenges in measuring equitable performance across populations has been inconsistent methods for defining and collecting REaL and SOGI data.

To advance health equity in the US, an aligned methodology for operationalizing and measuring health equity is required to accelerate improvement and accountability across all care delivery models. The Biden Administration began implementing a whole-of-government approach to rethinking how patient data is collected, understood, and used to advance health equity through informed decision-making.² The Office of Management and Budget (“OMB”) announced March 2024 revisions to its standards for REaL data collection across the federal government.³ These standards help set consistency in data reporting and collection. SOGI data is still in development and does not yet have a national standard for data collection.⁴ In the meantime, CMS’s SOGI Health Exchange exists as a reference.⁵

OMB’s March 2024 changes from the 1997 Directive are to:

1. Collect race and ethnicity information using a single combined race/ethnicity question while allowing multiple responses;
2. Add Middle Eastern or North African (“MENA”) as a new minimum reporting category;
3. Require collection of more detail beyond the minimum race and ethnicity categories by default; and
4. Whenever possible, replace the current “Another group” detail category checkbox with a write-in field that allows respondents to self-identify on their own terms.

For employers to align with OMB’s new standards, they should collect self-reported race and ethnicity data from their health plan population according to the following schema:

Q: What is your race and/or ethnicity? Select all that apply and note you may report more than one group.

- | | |
|---|--|
| <input type="checkbox"/> American Indian or Alaska Native | <input type="checkbox"/> Middle Eastern or North African |
| <input type="checkbox"/> Asian | <input type="checkbox"/> Native Hawaiian or Pacific Islander |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> White |
| <input type="checkbox"/> Hispanic or Latino | <input type="checkbox"/> Another Group (self-identify on your own terms) |

Private employers and public purchasers must solve for REaL and SOGI data collection, sharing, and reporting to identify and reduce disparities and improve health equity within the population for which they are responsible.

This action brief highlights known barriers and case studies where purchasers are taking meaningful steps to use REaL and SOGI data, resulting in more inclusive benefits and health care partner accountability for health equity. The brief closes with a call to action that outlines next steps for purchasers to collect and act on identifying and addressing health inequities.

Problem Statement

Despite the commercial market providing coverage to 57.5% of the U.S. population,⁶ and there being clear data that inequities impact individuals across income and insurance types,⁷ public health efforts aimed at improving health inequities have focused mainly on Medicaid and often ignored those who are commercially insured.

Private employers and public purchasers that desire to collect, interpret, and use REaL and SOGI data have faced an array of challenges for implementation:

- **Definitional Inconsistency of Data Collection:** Due to the lack of established frameworks, there are differences in defining and collecting data on race and ethnicity categories. This limits data matching and health care quality reporting stratification. Health plans often supplement with derived

information to assign race and ethnicity, but self-reported data is the gold standard.⁸ Health plans with available data are still reluctant to provide employers with quality metrics stratified by REaL and SOGI data.

- **Lack of Quality Reporting Stratification by REaL and SOGI Data:** Private employers have seen slow progress by their health plans and vendors in measuring REaL and SOGI data.
- **Legal / Privacy Concerns of Collecting and Sharing REaL and SOGI Data:** Many purchasers are reluctant to share REaL and SOGI data with their health plans and vendors out of an abundance of caution for employee privacy.^{9,10}

For health care purchasers to be successful in advancing health equity and reducing disparities, they must navigate these challenges. Such navigation requires careful coordination between reforming internal organizational policies and exercising new accountability and oversight over external partners. This brief highlights purchasers that have been successful in navigating some of these challenges.

Purchaser Case Studies

During a PBGH webinar held in June 2024, private employers and public purchasers shared their approaches to REaL and SOGI data collection and use, notwithstanding the inherent challenges. These three exemplar case studies demonstrate progress toward robust REaL and SOGI data collection and sharing, partner accountability, and inclusive benefit design changes.

Case Study #1:

Using Employee Race and Ethnicity Data to Identify Benefit Design Improvements to Advance Health Equity

Industry Profile: Insurance

Geography: National

Size: 4,000 employees

Key Takeaways: Sharing and analyzing ethnicity and salary band data can identify plan design changes needed to address health inequities.

This private employer’s core values include promoting and supporting well-being, health equity, and social and environmental impact. To advance these values, the company began collecting and sharing employees’ ethnicity and salary band information to ensure their vendors’ key performance indicators were stratified by different demographic categories to identify inequities and gaps in care. As a result of this data, they identified the need for several plan design changes. To address affordability, they moved from a high deductible health plan to a low deductible plan and implemented salary-banded employer based HSA contributions that increased contributions to lower salaried employees. To increase access to patient-provider concordant care, they worked with their health plan to improve provider directories by sharing the diversity of network providers. To improve preventive screenings, they implemented a new “enrichment” time off for employees to use for wellness screenings, expanded coverage for follow up mammograms at no cost, and eliminated the age criteria for colonoscopies. This company compliments its data analytics with feedback from their Employee Resource Groups to inform benefit design improvements needed to meet the diverse needs and lived experiences of its workforce.

Case Study #2:

Driving Health Plan Accountability Using REaL and SOGI Data

Industry Profile: Public Purchaser

Geography: California

Size: 1.5 million plan members

Key Takeaways: Accountability metrics through health plan contracting can be used to identify disparities and target disparity reductions.

A strategic goal of this public purchaser is to provide access to equitable, high-quality, and affordable health care to its members. As part of its effort to advance and drive accountability for health equity, they will begin holding their health plans financially accountable for equitable outcomes using race and ethnicity data. This purchaser collects self-reported REaL and SOGI data from enrolled members over the age of 18 in a health demographic profile, which may be updated to add a disability category and reflect the new OMB guidelines. They also require their health plans to collect race, ethnicity, written and spoken preferred language, and sexual orientation and gender identity data from their members. The health plans’ demographic data collection must improve year over year until they hit 80% of REaL data and 50% for SOGI data. As part of their contracts, health plans are held financially accountable for meeting five quality measure targets each year and will be required to stratify these measures by race and ethnicity, which will help set the plans’ initial disparity reduction targets. Each plan will be required to meet the NCQA HEDIS commercial 66th percentile benchmark for each subpopulation that meets the minimum denominator size. This purchaser has also made two benefit design changes in 2025, adding doula coverage and travel benefits to address inequities identified through a recent health equity benefit design analysis for their basic plans.

Case Study #3:

Using Demographic Data to Improve Employee Health and Financial Well-Being

Industry Profile: Pharmaceutical Manufacture/Medical Diagnostic Company

Geography: Global

Size: 24,000 employees

Key Takeaways: Collecting and analyzing demographic data can support improvements to health and well-being.

This private employer views benefits as a key enabler to fostering a culture in which their employees can thrive. As a commitment to advancing health equity, they began collecting self-identified data from employees on race, age, gender, tenure, exempt status, wage, and business location and have data on 90% of their employees. They integrate this demographic data in their data warehouse to identify disparities in health care and 401(k) benefits. As a result, they identified four gaps they will be targeting to drive improvements to their benefit offerings: 1) Disparities between hourly and salaried employees, 2) Latina women receiving less prenatal care, 3) Black women being diagnosed at later stage cancers, and 4) Retirement savings being depleted more by Black and Hispanic/Latinx employees. This employer added several benefit enhancements to create more inclusive benefits such as lifestyle accounts, emergency withdrawals from 401(k), a 401(k) match on student loan payments, LGBTQ+ and Black health care navigation, menopause benefits, adoption and surrogacy benefits, caregiver paid leave, a floating holiday, increased vacation and extended parental leave. Many of the benefit enhancements they implemented were informed by reviewing national data on health inequities and were in advance of having these new demographic data analytic capabilities, demonstrating that purchasers can take action to address inequities even without having advanced analytics with REaL and SOGI data.

Call to Action

Purchasers finance a significant portion of the American health care system, and as a result occupy a unique and influential position for ensuring employees and their families are receiving equitable care. Purchasers can exert influence by partnering with their health plans and vendor partners to ensure accountability for equitable outcomes on key performance indicators and implement improvement strategies to address identified inequities.

Once purchasers have access to credible and reliable REaL and SOGI data, the emphasis shifts to how they put it to use. Purchasers should analyze this information for insights into disparities in care, experience, access, affordability, and outcomes across their population, and then form an action plan for addressing these disparities. Suggested actions include:

- Select a strategy for collecting and reporting on REaL and SOGI data by either collecting employee demographic data and/or requiring plan partners to collect REaL and SOGI data on plan beneficiaries.
- Require transparent reporting and stratification on selected demographic categories for health care partners' key performance indicators. Use these reports to identify disparities and develop an improvement plan to address inequities.
- Create equity goals and accountability metrics on mutually agreed upon performance goals, once baseline data has been established.
- Monitor new data collection standards and adapt as needed to align to new national standards.
- Assess health care partners annually for performance on health equity and disparity reduction and partner with vendors to build improvement plans to advance health equity.

Conclusion

Purchasers have a vital role to play in advancing health equity. To accomplish this, they will need to ensure they are purchasing equitable care and services for their plan beneficiaries, which will require a measurement and accountability strategy. With credible REaL and eventually SOGI data, purchasers can identify disparities in health care access, experience, and outcomes – and can then act on these insights to reduce these health disparities. Progress on advancing health equity in the commercial market is necessary, possible, and required to ensure equitable outcomes for all Americans.





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About the Purchaser Business Group on Health (PBGH)

PBGH is a 501(c)(3) non-profit coalition of health care purchasers comprised of members that include the largest public and private purchasers of health care in the United States. Collectively, these organizations spend roughly \$350 billion annually buying health care for nearly 21 million employees and their families. PBGH supports its members in implementing innovative solutions to improve health care outcomes and value. PBGH's members operate at the forefront of advancing affordability, quality, accountability, and equity in health care purchasing practices.

Endnotes

- 1 Institute of Medicine (2003) “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care” Washington, DC: The National Academies Press <https://nap.nationalacademies.org/catalog/12875/unequal-treatment-confronting-racial-and-ethnic-disparities-in-health-care>
- 2 White House (Jan. 2023) “Recommendations on the Best Practices for the Collection of Sexual Orientation and Gender Identity Data on Federal Statistical Surveys” <https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf>
- 3 U.S. OMB (Mar. 2024) “Revisions to OMB’s Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity” Federal Register <https://www.federalregister.gov/documents/2024/03/29/2024-06469/revisions-to-ombs-statistical-policy-directive-no-15-standards-for-maintaining-collecting-and> (See also, [Final Recommendations Report](#))
- 4 The White House has only issued [recommendations](#) on best practices that “do not mandate any particular approach or create any new requirements for agencies.” See also, (SHADAC, May. 2024) “Sexual Orientation and Gender Identity Data: New and Updated Information on Federal Guidance and Medicaid Data Collection Practices” https://www.shvs.org/wp-content/uploads/2024/03/SHVS_Collection-of-Sexual-Orientation-and-Gender-Identity-Data-FINAL.pdf (“Although there is no uniform federal standard for the collection of SOGI data, various SOGI data collection practices are in place at the federal level. This includes joint CMS and Office of the National Coordinator [standards](#) for certified electronic health record technologies (CEHRT)” and “Health Resources and Services Administration (HRSA) [standards](#)”)
- 5 U.S. CMS (N.D.) “New Sexual Orientation and Gender Identity (SOGI) Questions on the Marketplace Application” <https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/Sexual-Orientation-Gender-Identity-Application.pdf>
- 6 Kaiser Family Foundation (N.D.) “Health Insurance Coverage of Nonelderly 0 – 64) *State Health Facts* <https://www.kff.org/other/state-indicator/nonelderly-0-64/?dataView=1¤tTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D> (Sourced with data from a 2022 American Community Survey, the most current information as of August 2024)
- 7 Advisory Board (Jul. 2024) “NASEM: Despite 20 Years of Effort, Health Inequities Persist in the U.S.” *Daily Briefing* <https://www.advisory.com/daily-briefing/2024/07/10/health-inequities#:~:text=people%20of%20color%20received%20worse%20care%20%E2%80%94%20regardless%20of%20their%20income%2C%20social%20status%2C%20or%20education.> (“People of color receive worse care – regardless of their income, social status, or education.”)
- 8 California Quality Collaborative (CQC) (Mar. 2022) Health Equity Work Group, in discussion with Lindsay Petersen; and Larry McNeely et al. (May 2022) “Primary Care: A Key Lever to Advance Health Equity, Primary Care Collaborative” *Morehouse School of Medicine and National Center for Primary Care* <https://thepcc.org/sites/default/files/resources/PCC-NCPC%20Health%20Equity%20Report.pdf>
- 9 For example, a [September 2022 study](#) published by Ropes & Gray and Out Leadership found in a survey of 38 companies that 77% “identified data privacy as the biggest challenge in implementing LGBT+ self-ID” for SOGI data collection. The report later [elaborates](#), “Legal and regulatory challenges due to employment and data privacy laws add a layer of complexity to self-ID . . . In the U.S., businesses that are capturing data must study the results, identify issues and act on any employment problems identified. Ignoring issues creates legal liability” as well as “reputational issues.”
- 10 Collins and Hutzler (May 2021) “Pitfalls for U.S. Businesses Collecting Diversity Data Abroad” *Bloomberg Law* <https://news.bloomberglaw.com/daily-labor-report/pitfalls-for-u-s-businesses-collecting-diversity-data-abroad>

