

Demographic Data Collection

NAIC Special Committee on Race and Insurance

September 9, 2024

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BlueCross
BlueShield
Association

Blue Cross Blue Shield Association is an association of independent Blue Cross and Blue Shield companies.

BCBSA's National Health Equity Strategy

BCBSA NATIONAL STRATEGY

- Our [National Health Equity Strategy](#) aims to change the trajectory of health disparities and build a more equitable health care system
- One of the core pillars is to influence policy decisions in Washington and in the states
- This platform will enable us to advocate strong, consensus-based solutions and effectively position BCBSA as a trusted partner and key leader in health equity

2024 TOP SOLUTIONS

- **Maternal Health Equity:** Congress should provide funding to the Centers for Disease Control and Prevention for technical assistance to states to establish, coordinate and manage SMM Review Committees.
- **SDOH:** Congress and CMS should offer MLR flexibilities to ensure health plans have the tools to address SDOH
- **Data:** The Administration should standardize REL and SOGI data collection categories

Data Equity Coalition (DEC)

Addressing Health Equity Challenges through Inclusive Data Collection

STEERING INDUSTRY DATA STANDARDS

- National Minority Quality Forum (NMQF), BCBSA and 17 other market leaders formed a coalition to close gaps in data specificity and inform modernization on national standards (Sept. 2023)
- **Problem to be Solved:** Standards last set in 1997 by Office of Management & Budget (OMB); disjointed standards / collection methodology creates limitations for design / implementation of initiatives to close health equity gaps
- **Approach:** Set standards to collect better, more accurate and representative data on race, ethnicity, and language (REL) and sexual orientation and gender identification (SOGI); the Coalition will focus on:
 - **Education** around data as critical to advancing health equity
 - **Acceleration** of data advocacy to influence policy standards
 - **Effective data collective standards** as a necessity to improve health outcomes

Data Equity Coalition (DEC)

Data Coalition

Standardizing Data to Advance the Health Equity Movement

OUR MISSION:

Develop and recommend policy solutions that advocate for race, ethnicity, language, sexual orientation and gender identification standards in support of advancing equity in care and health outcomes.

OUR GOALS:



OUR PLATFORMS: <https://dataequitycoalition.com>

Data Equity Coalition (DEC)

Stakeholders that have joined the Data Equity Coalition:

- Advocates for Community Health
- Alliance for Women's Health and Prevention
- American Benefits Council
- American Cancer Society Cancer Action Network
- American Diabetes Association®
- American Heart Association
- Asian & Pacific Islander American Health Forum
- AAMC Center for Health Justice
- Association of Black Cardiologists
- Association of Black Health-system Pharmacists
- Black Women's Health Imperative
- Blue Cross Blue Shield Association
- Families USA
- Go2 for Lung Cancer
- Leukemia & Lymphoma Society
- Mental Health America
- Minority Health Institute, Inc.
- National Hispanic Medical Association
- National LGBTQ Task Force
- National Minority Quality Forum
- National Rural Health Association
- Urban Institute

DEC's Letter to HHS



January 26, 2024

The Honorable Xavier Becerra
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Re: Data Equity and Expansion of Language and SOGI to Statistical Policy Directive No. 15

Dear Secretary Becerra,

The National Minority Quality Forum and the Blue Cross Blue Shield Association submit this letter on behalf of the Data Equity Coalition, including patient advocacy, health care, and business leadership organizations collaborating to advance a stakeholder-informed data equity movement. We appreciate sharing our recommendations from the public comment opportunity to OMB for inclusion in the updated Statistical Policy Directive No. 15, due for release in Summer 2024:

- Directive No. 15 should provide clear and consistent requirements for collecting REL (race, ethnicity, language) and SOGI (sexual orientation and gender identification) data that include a minimum standard for disaggregated race and ethnicity collection that are compatible with industry interoperability standards (e.g., Fast Healthcare Interoperability Resources (FHIR) standards).
- OMB should incorporate the current data standards promulgated by the Department of Health and Human Services (DHHS) Assistant Secretary for Planning and Evaluation/Office of Minority Health into Directive No. 15, outlining a framework of two separate questions for race and ethnicity with seven categories and six subcategories, including the addition of a Middle Eastern or North African (MENA) ethnicity category, and require that these be the minimum standard categories for collecting disaggregated REL data.
- OMB should intentionally and proactively elicit and accept additional input from diverse stakeholders regarding SOGI data collection and utilization in the Directive No. 15 update.
- OMB should enforce non-voluntary, uniform, and universal adoption of the updated OMB Directive No. 15 standards upon release in 2024 for all government agencies and all private sector healthcare stakeholders, including payers and providers.

The process that resulted in these recommendations and a more detailed discussion of the attendant issues is included in the issue brief, ["Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy,"](https://dataequitycoalition.com/wp-content/uploads/2023/07/NMQF_Brief_Paper.pdf) which was released in March by the National Minority Quality Forum and the Blue Cross Blue Shield Association.

¹ Blue Cross Blue Shield Association and National Minority Quality Forum. March 28, 2023. "Standardizing Data to Advance the Health Equity Movement: A Multi-sectional Strategy." https://dataequitycoalition.com/wp-content/uploads/2023/07/NMQF_Brief_Paper.pdf.



Data Equity Coalition (DEC)



THE WHITE HOUSE
WASHINGTON

MARCH 28, 2024

OMB Publishes Revisions to Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity

Recommendations

1. Upon release of the updated SPD 15 by OMB, HHS should act as efficiently and effectively as possible to adopt the standards as the minimum requirement for all HHS programs, existing and new, that collect data in the covered domains of race and ethnicity.
2. HHS should require private-sector program participants to use the new minimum SPD 15 standards and provide technical assistance to help implementation.
3. HHS should build on SPD 15 by creating minimum standards for collecting language and SOGI data promulgated by Executive Order 14075 and 2022 NASEM Report, and intentionally and proactively elicit and adopt input from diverse community stakeholders within and external to the federal government.

Understanding Consumer Perspective on Demographic Data Collection

BCBSA National Health Equity Strategy: Data Collection

Increasing Efficacy of Self-Reported Data – 2022/23

APPROACH

Utilizing consumer research and Consumer Experience design methods to gain an understanding of consumer's perception on the collection and utilization of Race, Ethnicity, Language (REL) and Sexual Orientation /Gender Identity (SOGI) data.

OBJECTIVES

- Provide Systemwide learnings on self-reported data collection techniques.
- Help Plans increase the effectiveness of self-reported data collection.
- Inform gaps, opportunities and considerations in transparency of data use, from members perspective.
- Bring human lens and approach into how to improve the efficacy of collecting self-reported data.
- Identify actionable learnings to inform development of industry standards that impact consumers.



BCBSA National Health Equity Strategy: Data Collection

Increasing Efficacy of Self-Reported Data – 2023/24

The overall **objective** is to **improve health outcomes** by improving the efficacy of self-reported REL/SOGI data

RESEARCH OBJECTIVES

- Identify the **optimized** way of asking for REL/SOGI data to maximize responses
- **Pressure test barriers** to providing personal and sensitive information and how to best overcome them
- **Identify messages or content** to improve opt-in rates



RESEARCH

METHODOLOGY

- 1** **Large scale, quantitative** online survey, with views by key subgroups, e.g., race, gender, region, sexual orientation, etc.
- 2** **N=15,000 completed online surveys*** (Nationally represented)
- 3** **Experimental design**, to understand how people value different attributes related to SOGI/REL
- 4** Augmented learnings via surveys among followers of **LGBTQ social influencer** via Instagram

* Conducted in English only



BCBSA National Health Equity Strategy: Data Collection

Four Key Themes Emerged

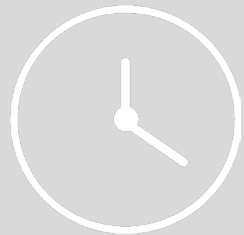
Data Are Points In Time, It Will Evolve

Where possible, we provide a perspective that takes a forward-looking view.



Generational Trends are Evident

The younger generations favor more options and more inclusive language than the older generations.



Marginalized Communities Are Most At Risk

LGBTQ and non-whites are most likely to not answer, especially without context.



Center Benefits on Personalization

Linking data requests to personal benefit in messaging is key. What's in it for me?

BCBSA National Health Equity Strategy: Data Collection

Key Insights

1

Healthcare organizations, such as Health Insurance companies, **are viewed as trustworthy** sharing personal information (PI) **relative to other organizations**

2

Underrepresented groups are not as comfortable sharing personal information

3

Results are a snapshot in time that **reflect stark differences** in preferences **across specific sub-groups**

4

Reasons for asking that are **personalized tend to resonate more strongly** vs. broader messages

BCBSA National Health Equity Strategy: Data Collection

Key Findings

1

“Which of the following best describes you?” is the preferred question stem for **SO, GI, and Race** whereas more direct questions are preferred for ethnicity and language (e.g., “What is your ethnicity or ethnic background?”)

2

More inclusive response options (e.g., straight or heterosexual, etc.) are preferred across all 5 domains especially among marginalized/underrepresented groups

3

GI is the most polarizing of the 5 domains while **language is the least polarizing**

4

SO is an evolving and more sensitive topic based on varied responses provided

BCBSA National Health Equity Strategy: Data Collection

DESIGN PRINCIPLES



Personalize Context

Consider the situation and context from an individual's perspective

Implications

- Consider different approaches to asking for personal data for different populations
- Ensure reasons for asking are valued, believable, and personally impactful
- Convey a personal benefit to individuals or groups holding similar views



Look Forward Flexibly

Be mindful of the evolving societal norms and demographic shifts impacting collection

Implications

- Look to the younger/future members' preferences to see trends
- Make back-end data collection systems and survey tools flexible to include more categories in the future



Engage Authentically

Be genuine and honest to establish rapport and trust

Implications

- Include why we are asking for the data
- Use clear and simple language
- Disclose what the data will and will not be used for
- Ensure privacy and data security



Empathetically Respond

Respond inclusively and meaningfully to the data provided

Implications

- Share communications in preferred language
- Use inclusive language
- Use correct pronouns
- Build services that support the data shared



Meet People Where They Are

Consider BCBS members' unique perspectives when providing survey choices

Implications

- Adjust questions, options, or reasons, for the subgroups whose opinions wholly or partially differ from the general population (e.g., by political affiliation, age, or gender/sexual orientation)

Contact

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