**NEW YORK CITY DEPARTMENT OF
HEALTH AND MENTAL HYGIENE**
Michelle Morse, MD, MPH
Acting Health Commissioner

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Gotham Center
42-09 28th St.
Long Island City, NY 11101

January 28, 2025

Via Electronic Submission- healthregcomments@dfs.ny.gov

Re: Minimum Standards for the Form, Content and Sale of Health Insurance, Including Standards of Full and Fair Disclosure – I.D. No. DFS-49-24-00014-P

Dear Mr. Dankwa,

The New York City Department of Health and Mental Hygiene (NYC Health Department) submits the following comment in response to the New York State Department of Financial Services (NYS DFS) proposed rule to identify disparities in quality and utilization of care experienced by underrepresented populations through demographic data collection.

We support NYS DFS' actions to request demographic data to understand insurance benefit use and develop policy solutions to better serve the needs of all New Yorkers. This additional data will help to identify health inequities between populations based on demographics or geography. Furthermore, the data can help policymakers and insurers to allow payors and providers to tailor interventions to drive equity and improve outcomes. [1]

New York City (NYC) has a population of about 8.8 million people[2] and a majority (95%) of New York State (NYS) residents have health insurance.[3] Despite having a relatively high rate of coverage, inequities persist among New Yorkers based on factors such as race, ethnicity, country of origin, sexual orientation and gender identity, and presence of a chronic condition, among others. Understanding these health inequities is imperative to our ability to address them.

Although New York has a high rate of insurance coverage and demographic data is already collected for Medicare, Medicaid, Children's Health Insurance Program (CHIP) and health exchange plans in NY, there are approximately 9 million people or 47.2% of the total state population whose demographic data are unknown since they are covered by employer-sponsored insurance.[4]

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[1] https://www.manatt.com/Manatt/media/Documents/Articles/BSCA_Unlocking-Race-and-Ethnicity-Data-to-Promote-Health-Equity-in-CA-April-2021_c.pdf

[2] https://www.nyc.gov/assets/planning/download/pdf/planning-level/nyc-population/population-estimates/population-trends-2023-Jun2024-release.pdf

[3] https://www.kff.org/statedata/election-state-fact-sheets/new-york/

[4] https://healthjournalism.org/wp-content/uploads/2023/12/New-York-Insurance-Media-Guide.pdf

Health inequities among New Yorkers

In 2022, 12.2% of NYC adults had diabetes, with people of color twice as likely to experience it than their White counterparts. In the same year, 29.6% of adults had hypertension. Hypertension is also higher among people of color compared to their white counterparts.[5] Black New Yorkers experience the highest number of deaths related to heart disease and diabetes.[6]

NYC has more than 3 million foreign-born residents from more than 200 different countries, half of all New Yorkers speak a language other than English at home and almost 25% (1.8 million), are not English proficient.[7]

Beyond racial inequities, LGBTQ+ adults represent a larger segment of demographic groups that are more likely to experience negative health outcomes due to social determinants and structural inequities. Compared to New York State's overall adult population, the occurrence of mental health conditions is more common among LGBTQ+ adults; they are also more likely to report being uninsured or underinsured and not having a regular health care provider.[8]

Demographic Data Collection

All states and the District of Columbia already collect enrollee data from Medicare, Medicaid and Children's Health Insurance Program (CHIP). Data from claims, encounters, and beneficiary demographics are used by states to identify patterns and trends in service utilization, allowing them to target specific populations and interventions to improve overall health outcomes.[9]

The Affordable Care Act (ACA) also established a Quality Improvement Strategy (QIS) program and Quality Rating System (QRS) for health coverage sold through the ACA marketplaces to improve health care quality by requiring plan providers to outline strategies for improving healthcare quality and rates their performance quality.[10]

Health plans authorized to participate in the New York State of Health (NYSOH) marketplace already collect demographic data for enrollees upon application. For plan year 2023, California and Washington implemented enrollee demographic data collection that includes race and ethnicity. California's health insurance exchange, "Covered California," is in the process of phasing in requirements for all participating health insurance plans to collect self-reported race, ethnicity, and preferred spoken and written language data for at least 80% of enrollees by plan year 2025. The exchange plans to expand

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[5] https://www.nyc.gov/assets/foodpolicy/downloads/pdf/nycfoodbythenumbers.pdf

[6] https://www.nyc.gov/site/doh/about/about-doh/healthynyc.page#:~:text=Chronic%20and%20diet%2Drelated%20diseases%2C%20such%20as%20heart%20disease%2C,1

[7] https://www.nyc.gov/site/planning/about/language-access.page

[8] https://www.health.ny.gov/press/releases/2022/2022-06-07_pride_month.htm

[9] https://nashp.org/how-states-access-and-deploy-data-to-improve-sud-prevention-treatment-and-recovery/#:~:text=In%20order%20to%20better%20coordinate%20care%20and,physical%20health%20integration%20and%20promote%20team%2Dbased%20care.&text=Matching%20HMIS%20data%20with%20Medicaid%20utilization%20data,and%20have%20received%20services%20related%20to%20SUD.

[10] https://www.cms.gov/medicare/quality/health-insurance-marketplace-initiatives#:~:text=Quality%20Improvement%20Strategy%20%2D%20QIS,health%20and%20health%20care%20disparities.

self-reported data collection to include disability status, sexual orientation and gender identity; it intends to proceed with efforts to stratify measures by income for disparities identification and monitoring purposes.[11]

Washington set a goal to achieve 70% self-identification of race and ethnicity data for enrollees in plan year 2023 and reach data completeness threshold of 80% directly reported enrollee race and ethnicity data for 2024.[12]

Both states implemented a QIS program and set standards for data collection to identify and reduce racial and ethnic health inequities. For example, Washington began requiring issuers to present cervical cancer screening rates and antidepressant medication adherence measurement results stratified by race and ethnicity to identify health inequities. In California, financial penalties are imposed if insurers do not meet required clinical measures of the rating system. Additional penalties are imposed if less than 80% of enrollees' spoken and written language are collected.[13]

Although the Centers for Medicare and Medicaid services (CMS), ACA and some states have already implemented demographic data collection, we acknowledge that the requested data is sensitive and as such enrollees may be hesitant to share demographic information. In a survey of U.S. adults, 59% cited concerns about sharing data with a healthcare provider, insurance company, and/or community-based health organization due to discomfort about how the information would be shared with or sold to others without their consent.[14] The survey also found White respondents tended to feel less discomfort with sharing data than those identifying as Asian, Black, or Latino/a.

Based on public statements and prior policies of the incoming federal administration, collecting demographic data may be even more challenging. During president-elect Trump's first term, many adults in immigrant or mixed-status families avoided safety net programs for fear of potential immigration consequences.[15] As fear around immigration enforcement, people may again avoid interacting and sharing information with providers and agencies.

Due to these concerns, we recommend that proposed section 52.52(a)(4) rule be amended to require insurers to provide written and, where feasible, verbal communication explaining the data is to be utilized to identify inequities, develop targeted interventions and ultimately improve health outcomes. This communication should also explain and emphasize what the collected data cannot be used for, e.g., to sell, eligibility determinations, for discrimination or for immigration enforcement.

We also recommend that notice about protection against discrimination based race, color, creed, national origin, or disability in accordance with Insurance Law section § 2606 and sex or marital status pursuant to Insurance Law section § 2607 should also state that there is protection against

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[11] https://hbex.coveredca.com/stakeholders/plan-management/library/2023-2025_QHP_IND_Attachment_1_1-24-22_Clean.pdf

[12] https://www.wahealthplanfinder.org/content/dam/wahbe-assets/plan-certification-workgroup/Final%202024%20QHP%20Guidance%20for%20Participation.pdf

[13] https://www.commonwealthfund.org/blog/2024/raise-bar-state-based-marketplaces-using-quality-tools-enhance-health-equity

[14] https://www2.deloitte.com/us/en/blog/health-care-blog/2022/trust-inclusivity-may-be-key-to-richer-race-ethnicity-data.html

[15] https://www.urban.org/sites/default/files/2024-08/Mixed-Status-Families-and-Immigrant-Families-with-Children-Continued-Avoiding-Safety-Net-Programs-in-2023.pdf

discrimination based on pregnancy and pregnancy outcomes. Demographic data collected cannot be used to discriminate against pregnancy statuses in addition to race, color, creed, national origin, or disability in accordance with Insurance Law section § 2606 and sex or marital status pursuant to Insurance Law section § 2607.

We recommend that proposed section 52.52(a) of the rule be amended to require that insurers provide a DFS-mandated range of response options to demographic questions. This will ensure appropriate ability to disaggregate demographic data by specific subcategories – such as race, ethnicity, and language – to inform analysis of the data by DFS, public health authorities, and researchers. To define the range of response options, we recommend that DFS adopt the framework reflected in NYC Charter § 15(i)-(k) or a similar framework that requires disaggregated data options across the various demographic data elements to be captured pursuant to this rule.

We recommend that proposed section 52.52(d) be amended to provide a procedure to make deidentified data available to county and city public health authorities and to researchers, consistent with applicable law.

Implementing systems to collect demographic data from people using the health care system is key to assessing needs and closing gaps in care and identifying and addressing health inequities. This practice has been supported by non-profit groups who work to achieve equity through research, analysis and advocacy including Community Service Society and the Urban Institute.[16],[17]

Adopting this rule would provide a more comprehensive data set and understanding of the full picture of health inequities in New York. Since nearly half of the state's population has employer-sponsored coverage with demographic data that is not currently being collected, it is not currently possible to know and address the issues faced by such a large portion of the state's population.

DOHMH appreciates the opportunity to submit these comments on the proposed regulations and looks forward to partnering with the New York State Department of Financial Services on further efforts to promote health equity in our ongoing collaborations.

Sincerely,

[redacted]

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New York City Department of
Health and Mental Hygiene

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[16] https://smhttp-ssl-58547.nexcesscdn.net/nycss/images/uploads/pubs/Promoting_Equity_May2009.pdf

[17] https://www.urban.org/sites/default/files/2023-10/Using%20Race%20and%20Ethnicity%20Data%20to%20Advance%20Health%20Equity.pdf