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August 19, 2021

Commissioner Jessica Altman and Commissioner Lara  
Chairs, Workstream 5  
NAIC Special (EX) Committee on Race and Insurance  
Sent via email to: Jolie Matthews at: [JMatthews@naic.org](mailto:JMatthews@naic.org)

Re: AHIP Comments - Draft Principles for Data Collection

Dear Commissioners Altman and Lara,

On behalf of AHIP<sup>1</sup>, thank you for the opportunity to comment on Workstream Five's [July 7 Draft Principles for Data Collection](#).

AHIP and our members believe every American deserves access to affordable, comprehensive coverage that allows them to access affordable, equitable, high-quality care. For far too long, discrimination and systemic racism have served as barriers to health equity for minority and underserved communities. Achieving health equity is a priority for AHIP and our members and health insurance providers know that ending barriers to care is key to an equitable healthcare system. We are proud to serve all Americans, working hand in hand with partners and community leaders across the entire healthcare system to ensure the needs of all consumers addressed.

AHIP commends the NAIC Special (EX) Committee on Race and Insurance for taking concrete steps aimed to reduce healthcare disparities and promote health equity and we applaud Workstream's Five work to examine and determine which practices and barriers exist in health insurance that potentially disadvantage people of color and/or historically underrepresented populations. The Draft Principles for Data Collection are an important step in the NAIC's work to identify disparities and promote equitable care. We appreciate this work, and the continued stakeholder engagement process as this work moves forward. We welcome the opportunity for open and honest dialogue to ensure our collective work effectuates consequential changes across the entire healthcare delivery system.

We offer the following comments on the [July 7 Draft Principles for Data Collection](#).

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<sup>1</sup> AHIP is the national association whose members provide health care coverage, services, and solutions to hundreds of millions of Americans every day. We are committed to market-based solutions and public-private partnerships that make health care better and coverage more affordable and accessible for everyone. Visit [www.ahip.org](http://www.ahip.org) to learn how working together, we are Guiding Greater Health.

## Data Collection

- a) **Health insurance companies should be expected to systematically collect, maintain, protect, and report on, at minimum, enrollee data on race, ethnicity, preferred language, sex (including gender identity), sexual orientation and disability.**

Demographic data is foundational to identifying, measuring, benchmarking, and mitigating disparities in health care. It is also important to understand the impact that socioeconomic, sociodemographic, and other factors have on health outcomes and on perpetuating health disparities. With this information, the healthcare system can work together to develop solutions that address barriers to health and disparities in health care at the individual, system, and structural levels.

The NAIC, state insurance departments, and health insurance providers play a critical role in this large and diverse ecosystem. In collaboration with each other and with patients and healthcare providers, we need to collectively identify ways to collect demographic data efficiently, accurately, and sensitively by harnessing our respective strengths, capacities, and opportunities to benefit consumers. Data on sensitive demographic attributes such as race, ethnicity, language, sexual orientation, and gender identity must be collected in a trusted relationship. Thus, efforts to obtain and use such data, even for laudable goals, will require rebuilding eroded trust in the healthcare and social services systems. Consumers must understand the purpose of the data collection and use of the data. The entire healthcare industry should collectively develop a blueprint for building consumer trust, generating self-reported aggregate data, sharing accurate information, and ensuring that all stakeholders are acting collaboratively and consistently to mitigate harmful bias and improve care.

For example, given the high level of trust patients have in their caregivers, healthcare providers are well-situated to collect these data during the course of care. Health insurance providers have an important opportunity at enrollment or through care management relationships to collect key self-reported data. It is imperative, however, that the data be collected using uniform standards and reported to trusted parties (whether that be the health insurance provider, healthcare provider, or others) through interoperable data systems. By subscribing to the notion of “collect once, use many times,” we will avoid consumers “having to” self-report demographic data multiple times with every different actor in the healthcare system. Repeated requests for sensitive information may undermine trust and increase the likelihood of inaccurate and potentially conflicting data.

As you know, state and national policy leaders are advancing comprehensive discussions about the definition, collection, and use of demographic data across a broad and diverse set of constituencies. The recent Medicare Inpatient Prospective Payment System (IPPS), Outpatient Prospective Payment System (OPPS) and Physician Fee Schedule (FFS) proposed rules, the Office of Management and Budget (OMB) Request for Information as directed by recent Executive Orders, and the No Surprises Act are examples of the scope and breadth of work currently underway to utilize demographic data through data collection to identify and help address healthcare disparities.

AHIP has been deeply engaged in these efforts on a number of fronts including through the regulatory comment process, engagement with federal stakeholders on the intersection of quality, health equity and

value based purchasing and other activities.<sup>2</sup> For example, AHIP partners with the Centers for Medicare & Medicaid Services (CMS) and the National Quality Forum (NQF) on the Core Quality Measure Collaborative (CQMC), which is a multi-stakeholder initiative to align quality measures across public and private payers to improve the quality of care, reduce the burden associated with quality measurement, and establish consistent signals about which providers deliver high quality care to consumers. As part of this initiative, the CQMC began a workstream to identify new measures of equity and to consider statistical techniques to identify disparities in existing measures. In addition, a workgroup was formed devoted to digital measurement to identify barriers and solutions to sharing data in a secure, private, and interoperable way across the ecosystem to improve health and health care.

We recognize that the NAIC’s regulatory authority is limited to health insurance providers and thus we appreciate the NAIC’s focus on the health insurance industry; however, the shared responsibility for achieving health equity among all actors in the healthcare system cannot be ignored. It is imperative that the NAIC work hand in hand with leaders across the healthcare system to advance meaningful demographic data standards and collection and support the growing body of laws and regulations aimed at addressing health disparities. Healthcare leaders must work collectively and collaboratively to ensure there is alignment across the healthcare ecosystem in demographic data standards, collection, interoperability, and data exchange.

- b) Health insurance companies should use data collection strategies and question language that has been consumer-tested and is widely recognized for increased accuracy and responsiveness.**

The development of evidence-based, stakeholder driven demographic data standards is vital. The NAIC should support the HHS and Office of Management and Budget (OMB) in employing a multi-stakeholder process and consider emerging work in this area, such as the Gravity Project. Multi-stakeholder groups should be convened to improve data collection for race, ethnicity, and language data by refining, where appropriate, the granularity of race and ethnicity beyond the current OMB standards to allow consumers to more accurately report how they identify, if they so choose. It is vital to ensure consumers are part of the process to identify strategies and develop questions, and that all the materials are psychometrically tested. Just because a question has been in widespread or long-time use, does not mean it is valid or reliable or comfortable for consumers to answer.

It is also important to recognize that Sexual Orientation and Gender Identify (SOGI) recommendations may be based on academic convenings or research rather than “community-based lessons learned” and thus policymakers should also ensure consumer have vetted and support these recommendations. The CMS Accountable Health Communities demonstration project proved this point when they incorporated questions on safety and domestic violence into their standardized assessment tool. In that case the questions had been validated by research but were extremely uncomfortable for consumers to answer—thus leading to non-responses and drop-outs from the program.

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<sup>2</sup>[AHIP FY 2022 IPPS Comment Letter](#); [AHIP OMB Equity July 2021 RFI Comment Letter](#)

- c) The disclosure of demographic data by prospective insured and enrollees must always be voluntary and based on self-identification or disclosure. Submission of such information should always be optional.**

Despite the challenges of collecting self-reported data, AHIP believes that self-reported data is the gold-standard. However, this information is not just data; this sensitive information represents a person's identity, life story, and lived experience. The NAIC should ensure that its policies do not result in the unintended consequence of compelling consumers to report this sensitive information. Health insurance providers have been working diligently for many years to collect these data in a manner that is consistent with individual agency and respectful of personal needs and preferences.

While there may be different options for collecting data from members, we know that protecting trust and clearly explaining the purpose for which the data will be used are essential. As health insurance providers continue to explore options for achieving this balance, the following have been important takeaways: (1) surveys that include questions on demographic data can be met with negative reactions and responses from consumers; (2) there may be a perception of potential discrimination for benefit or service eligibility, distrust, or lack of understanding of the purpose of the questions; and (3) there may also be a negative reaction to the collection of this data if the timing seems inappropriate or if the data collections seem irrelevant to what the patient is experiencing at the time the question is asked.

- d) Health insurance companies should be encouraged to pursue the NCQA's Distinction in Multicultural Health Care (or an equivalent current NCQA product that addresses how organizations meet diversity, equity and inclusion goals for employers, members, and enrollees).**

Many health insurance providers have chosen to prove their commitment to promoting access to culturally appropriate care through their achievement of NCQA's Multicultural Healthcare Distinction Program. This Distinction in Multicultural Health Care is currently in the process of becoming a two-level Health Equity Accreditation through a comprehensive stakeholder engagement process. AHIP is deeply engaged in this important work through not only our comment letters but also through participation in numerous committees<sup>3</sup> and we are closely monitoring timelines for a finalized program. There are also several requirements to the base accreditation standards under consideration that seek to measure disparities and enhance equity. Similarly, URAC is currently in the process of adding an elective Health Equity Designation to their health plan certification and AHIP is similarly involved in URAC's comment processes. As a result, we suggest that the NAIC not be bound to the NCQA program as the sole method by which a health insurer may prove their commitment to promoting access to culturally appropriate care.

### **Data Use and Regulation**

- a) Insurance departments should confirm that neither state nor federal law prohibits an insurer from collecting, race, ethnicity, language, sex (including gender identity) sexual orientation, and disability information. Such clarification should distinguish between the**

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**collection of demographic data and the prohibited use of demographic data in rating, underwriting practices, and benefit determinations.**

AHIP applauds the NAIC’s directive to state insurance departments to confirm that neither state nor federal law prohibits an insurer from collecting race, ethnicity, language, sex (including gender identity) sexual orientation, and disability information. A legal analysis by state departments of insurance is critically important, and we appreciate the NAIC’s recognition that this work must be done before a state seeks to implement data collection guidance or recommendations.

**b) Health insurance companies should consider HIPAA protections to apply to demographic data and should consider the collection of demographic data as part of any plans that address protected health information. Health insurance companies should be prohibited from reporting demographic data that would permit the identification of individuals. In these limited circumstances – when privacy protections prevent reports on disaggregated demographic data – health insurance companies and regulators should clearly state that this is the reasons why the data is not reported.**

AHIP appreciates the NAIC’s deep commitment to consumers’ protected health information and understanding that the privacy and security of these data are an essential component of the increased use of data on race, ethnicity, and other sociodemographic factors. Health insurance providers adhere to strict statutory and regulatory privacy and security requirements. To coordinate with transparency and interoperability efforts, privacy requirements should be designed and applied across all entities maintaining health and health-related information to allow appropriate communication and sharing of information without reducing privacy protections.

For example, the same sensitive information collected and held by a third-party application (app) developer is currently outside the reach of HIPAA as such technology was not contemplated at the time the law was created. We urge the NAIC to weigh in with federal lawmakers or establish laws and policies at the state level that hold apps accountable to privacy and security requirements comparable to HIPAA.

**c) Insurance departments and health insurance companies should coordinate on acceptable uses of demographic data within company operations. Acceptable uses may include evaluating algorithms for bias; analyzing claims, enrollment, and complaint data to better understand healthcare disparities or to evaluate the efficacy of programs intended to reduce healthcare disparities; provider network development and coordination of care; reporting requirements; quality improvement of services; assessing or planning to meet the need for health-related social services and supports, including trauma-informed care; and targeted outreach to underserved populations, among other uses.**

Health insurance providers are committed to not only meeting our legal obligations but to taking a hard look at their own operations and that of their networks to identify and act on disparities. Recently, AHIP worked with the Consumer Technology Association to develop ANSI-accredited, voluntary standards applicable to the use of Artificial Intelligence that can be adopted to demonstrate human, technical, and

regulatory trustworthiness, including steps to identify and mitigate bias.<sup>4</sup> In addition, AHIP has been sharing best practices developing anti-bias training among other activities across members and collaboratively. We understand that state departments of insurance have limited expertise and resources to evaluate algorithms and thus stand ready to work with the NAIC and state insurance departments as they engage with health plans and other stakeholders to determine legal and ethically accepted use cases and application of this data to ensure health equity. In determining best practices and use cases, we note that in artificial intelligence, not all types of bias are negative, and it is possible to manage bias that may have harmful impact to specific groups or individuals.

**d) Insurance departments, individually and collectively through the NAIC, should collect and review demographic data from health insurance companies to better understand the marketplace and efforts and opportunities for health insurance companies to advance and improve services and advance health equity.**

The NAIC understands the challenges with data accuracy. As we have stated above, consumers may not feel comfortable disclosing data in all situations, leading to potential discrepancies and underreporting, which will impact how insurance departments individually or collectively can utilize, evaluate, and rely upon this information.

In addition to the accuracy challenges, the standardization of data collection is critical for direct (or apples-to-apples) comparisons for regulators, the NAIC, and policymakers. AHIP's Health Equity Workgroup, which is comprised of member health plans, has developed a set of evidence-based and stakeholder-driven best practices and recommendations for collecting demographic data for race, ethnicity, language, disability, status, sexual orientation, gender identity, veteran status, and spiritual beliefs that we offer as recommendations to federal agencies for their consideration.

Despite these challenges, AHIP believes in the power of leveraging data to identify and mitigate disparities. More complete and accurate aggregated information could help policymakers better understand if intervention is necessary to improve health equity. This data can also help to identify consumers' preferences related to the delivery of healthcare services. To be actionable, it will be important to develop evaluation measures that accurately discern whether individuals had equitable opportunities to receive services and to make informed decisions about whether to receive such services rather than on the actual receipt of services.

In closing, we are grateful for the opportunity to provide comments on the Draft Principles for Data Collection. The draft is an important step in the NAIC's work to identify disparities and promote equitable care. The outlined concepts also serve to reiterate the importance of NAIC working collaborative and collectively with leaders across the healthcare system to support and advance consequential data collection. AHIP stands ready to partner with other healthcare system participants to identify and close disparities.

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<sup>4</sup> <https://shop.cta.tech/products/the-use-of-artificial-intelligence-in-healthcare-trustworthiness-cta-2090>; <https://www.cta.tech/Resources/Newsroom/Media-Releases/2021/February/CTA-Launches-New-Trustworthiness-Standard-for-AI-i>



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These comments are provided to advance the NAIC's work and to ensure underserved individuals and communities can fully benefit from these efforts.

If you have any questions, please feel free to contact me at [mmotter@ahip.org](mailto:mmotter@ahip.org).

Sincerely,

Miranda Creviston Motter  
AHIP  
Senior Vice President, State Affairs and Policy