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October 17, 2022

The Hon. Xavier Becerra
Secretary
Department of Health and Human Services
200 Independence Ave, SW
Washington, DC 20201

The Hon. Shalanda Young
Director
Office of Management and Budget
1650 Pennsylvania Ave, NW
Washington, DC 20503

RE: Improving Demographic Data Standards to Advance Health Equity

Dear Secretary Becerra and Director Young:

AHIP appreciates the Administration's focus and leadership on health equity. Achieving health equity is also a priority for AHIP and its health insurance provider members as well as many other organizations, such as the National Association of Health Insurance Commissioners (NAIC), accreditation organizations, and providers. Aligning on this shared goal and harnessing multistakeholder efforts in a coordinated public-private fashion could avoid fragmentation, duplication, and inefficiency to move the field further and faster to the benefit of patients nationwide.

Robust, accurate, actionable, and standardized demographic patient data is fundamental to advancing health equity. Collecting consistent demographic data allows health care entities to better understand the populations they serve and informs more culturally and linguistically appropriate patient-centered care. It also allows health care entities to better identify disparities in care and outcomes as well as understand the social drivers of health to better promote equitable care, devise innovative solutions, operationalize telehealth, and measure the effectiveness of interventions for continuous improvement.

We applaud the data collection efforts that currently exist across the federal government, states, and accreditation requirements. However, we believe these could be enhanced with improved demographic data standards that are consistent and aligned across the health care industry. Aligning these efforts at the ecosystem level across public and private health care stakeholders around demographic data content and exchange standards would facilitate electronic data capture, sharing, aggregation, and analysis. Collecting the information once and sharing it seamlessly across trusted entities would lead to a more efficient, effective, collaborative, and patient-centered system. Under such a system, the burden on patients, providers and health insurance providers would be minimized, as information regarding sensitive identity and socioeconomic questions would only need to be collected once. It would also permit a broader understanding of populations and geographic differences with larger sample sizes, as well as the creation of national benchmarks.

Numerous Challenges Resulting from Current Data Standards

Current data content standards, (e.g., OMB, CMS, 2020 Census, the 2011 HHS recommendations proposed in the ACA), while robust, unfortunately continue to lead to varied, inaccurate, incomplete or missing data. Challenges with current data standards include:

- Questions on race do not have a response option for "Arab, Middle Eastern, or North African", forcing respondents to select a race with which they may not identify. Similarly, those who identify as only "Hispanic/Latin(o/a/x)" in terms of ethnicity are required to select an additional race with which they may not identify.
- The granular options in the 2011 HHS recommendations and in the 2020 U.S. Census may not be applicable across all regions, states, or local communities. For example, current granular data standards would not allow Minnesota to collect actionable data on their relatively large Hmong or Somali populations. Almost every state would experience similar issues, which could lead to additional data collection burden with little relevant actionable utility at a local level. To avoid this, granularity should be customizable at the local level.
- Granularity currently being used in the 2011 HHS recommendations and in the 2020 U.S. Census only include more granular options for "Hispanic/Latin(o/a/X)", "Asian", and "Pacific Islander". Current data standards do not include granular options for "Black or African American", "Native American or Alaska Native", "White", or "Arab, Middle Eastern, or North African" despite the cultural and linguistic differences within these groups.
- Demographic questions often do not have a "I choose not to respond" option to respect a person's agency in providing personal information on their identity or lived experiences. Moreover, the lack of an explanation as to how the data will be used, shared, and protected can lead to mistrust.
- Numerous required standards for health care stakeholders and health insurance providers to each separately collect sociodemographic data lead to inconsistent results and place an unnecessary burden on patients as well as the entities collecting the data.

AHIP and Stakeholder Goals for Improving Existing Demographic Data Standards

To improve upon existing demographic data standards, AHIP convened diverse groups of health insurance providers and other stakeholders (e.g., patients representing different communities, providers, community-based organizations, and others) for over 18 months from 2020 – 2022 and employed an evidence-based and stakeholder-driven process with goals to:

1. Align with national standards as much as possible while improving national standards when necessary;
2. Standardize data at a high-level while allowing for local customization and granularity; and
3. Aim for actionability while minimizing data burden.

We are pleased to share the demographic data standards that resulted from this process (Appendix A), which include:

- Race (including high-level standards and optional customizable granular options),
- Ethnicity (including high-level standards and optional customizable granular options),
- Language Preference (including written, reading, and speaking preferences),
- Sexual Orientation (also including a more inclusive relationship status question),
- Gender (also including a question on pronouns),
- Disability Status (including vision, hearing, cognitive, ambulatory, communication, self-care, and independent living, among others),
- Veteran Status (including history of service in both the U.S. military or in the military of another nation), and
- Spiritual Beliefs.

Enabling Electronic Demographic Data Exchange: Key Success Factor in Equity Efforts

Enabling the electronic exchange of demographic data through standardized content is pivotal to successful equity efforts. Having interoperable patient demographic data would allow the health care ecosystem to collect this data when most appropriate and convenient for the patient and share the information with other partners with patient consent to inform patient care and population health management efforts as well as to more effectively address disparities in access to care and outcomes. To promote interoperability, AHIP also mapped the demographic data standards to standardized codes (e.g., LOINC, SNOMED, ICD-10) and developed a data documentation that provides guidance on how frequently each question should be asked and how various responses should be coded, particularly when an individual selects "I do not know," "I choose not to respond," or when the individual leaves the question blank.

Reducing Fragmentation to Achieve Greater Alignment: Key Revisions and Updates

While health insurance providers can voluntarily adopt these standards today, that will not decrease the fragmentation across the health care sector. Our hope is that this work can serve as a foundation to achieve greater alignment through:

- Revisions to the federal data standards OMB adopted in 1997 (62 FR 58782 - 587890) based on the high-level categories presented in Appendix A,
- Changes to the Centers for Disease Control and Prevention Public Health Information Network Vocabulary Access and Distribution System (PHIN VADS) codes and value sets for race and ethnicity to fill in gaps—both at a high-level and at a granular-level,
- Adoption as part of the U.S. Core Data for Interoperability by the Office for the National Coordinator for Health Information Technology (ONC),
- Inclusion in the 21st Century Cures Act Information Sharing regulation by ONC,
- Collection by the Centers for Medicare & Medicaid Services (CMS) for enrollment in original Medicare and Medicare Advantage plans,
- Collection by States at enrollment for Medicaid or Children's Health Insurance Programs,

- Adoption by OCR for civil rights and non-discrimination tracking,
- Recommendations to NCQA to include these as allowable data standards as part of its Health Plan, Health Equity, and Health Equity Plus accreditations,
- Recommendations to the NAIC to encourage state Insurance Commissioners to adopt these data standards, and
- Counting such data collection efforts as Quality Improvement Activities under the Medical Loss Ratio by CMS.

We believe this type of alignment of demographic data standards at an ecosystem level through such policy changes is crucial to advance equity. An aligned and standardized approach to interoperable demographic data will empower the health care ecosystem to collaborate on shared health equity goals, measure progress towards those goals, and better serve individuals and communities. With consistent and interoperable data standards, great strides can be made in reducing inequities and addressing social drivers of health while improving outcomes and minimizing the data burden placed on individuals and on the larger health care ecosystem.

Thank you for the opportunity to raise this important issue. AHIP stands ready to engage collaboratively with the Administration and other health care stakeholders on this meaningful work. If you have any questions, please contact Danielle Lloyd at (202) 778-3246 or at dlloyd@ahip.org.

Sincerely,

Matthew Eyles

Matthew Eyles
President and CEO

CC:
Hon. Admiral Rachel Levine, Assistant Secretary, Department of Health and Human Services
Hon. Chiquita Brooks-LaSure, Administrator, Centers for Medicare & Medicaid Services
Dr. Karen Orvis, Chief Statistician, Office of Management and Budget
Dr. Micky Tripathi, Director, Office of the National Coordinator for Health Information Technology
Dr. Felicia Collins, Assistant Secretary and Director, Office of Minority Health
Hon. Melanie Fontes Rainer, Director, Office of Civil Rights
Dr. Rochelle Walensky, Director, Centers for Disease Control and Prevention
Dr. Wanda Jones, Acting Director, Office of Research Integrity

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Appendix A: AHIP's Recommended Demographic Data Standards

The following demographic data standards are the result of AHIP's evidence-based and stakeholder-driven process that occurred with diverse stakeholders over an 18-month period from 2020 – 2022.

Ethnicity: For Higher-Level Standardized Reporting

1. Do you identify as Hispanic or Latin(o/a/X)? (select one)
o I am Hispanic or Latin(o/a/X)
o I am not Hispanic or Latin(o/a/X)
o I choose not to respond

Optional Ethnicity Question for Additional Granularity: Allow organizations to choose which populations to include when asking optional, more granular race/ethnicity questions based on most common populations in their areas.

1A. If you are Hispanic or Latin(o/a/X), what is your background? If you are not Latin(o/a/X) or Hispanic, please skip this question. ***(Select all that apply from the list below or write down your response if your background is not listed)***

• Argentinian • Brazilian • Chilean • Columbian • Cuban • Dominican • Ecuadorian	• French Guianan • Guatemalan • Haitian • Honduran • Mexican or Chicano • Indigenous Mexican American • Nicaraguan	• Peruvian • Puerto Rican • Salvadorian • Venezuelan • Other Indigenous Central American • Other Indigenous South American • Other (please specify): _____

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Race: For Higher-Level Standardized Reporting

2. Please tell us which race(s) you identify with (select all that apply):
o Arab, Middle Eastern, or North African
o Asian
o Native Hawaiian or Pacific Islander
o Black or African American
o White or European
o Native American, Alaska Native, or Indigenous
o I only identify as Hispanic or Latin(o/a/X)
o I choose not to respond

Optional Race Question for Additional Granularity: Allow organizations to choose which populations to include when asking optional, more granular race questions based on most common populations in their areas.

2A. Please tell us your background. ***(If your background is not listed, please write it on the blank line).***

Black or African	**Asian**	**Native Hawaiian or Pacific Islander**	**White or European**	**Arab, Middle Eastern, or North African**	**Native American, Indigenous, or Alaska Native**
• African American	• Bangladeshi	• Chuukese	• Balkan	• Egyptian	• Apache
• Barbadian	• Burmese	• Chamorro	• Dutch	• Emirati	• Athabascan
• Cameroonian	• Cambodian	• Fijian	• English	• Iraqi	• Chinook
• Eritrean	• Chinese	• French Polynesian	• French	• Iranian	• Choctaw
• Ethiopian	• Filipino	• Guamanian	• German	• Jordanian	• Chickasaw
• Ghanaian	• Hmong	• Marianan	• Greek	• Kurdish	• Cherokee
• Haitian	• Indian	• Marshallese	• Irish	• Kuwaiti	• Creek
• Jamaican	• Indonesian	• Native Hawaiian	• Italian	• Lebanese	• Hopi
• Kenyan	• Japanese	• Palauan	• Lithuanian	• Libyan	• Iroquois
• Liberian	• Korean	• Papua New Guinean	• Polish	• Palestinian	• Navajo
• Nigerian	• Lao	• Samoan	• Russian	• Saudi	• Sioux
• Somalian	• Pakistani	• Tongan	• Scandinavian	• Syrian	• Wichita
• South African	• Thai	• Yap	• Scottish	• Yemeni	• Yakima
• Sudanese	• Vietnamese	• Other: _____	• Slavic	• Other: ____	• Other: _____
• Other:_____	• Other:_____		• Other: _____		

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Language Preference

Paper Form or Paper HRA	Health Care Setting Specific Questions[1]
What language do you feel most comfortable speaking about your health care? This can include a specific language and/or different types of sign language. • English - Cantonese - Arabic • Spanish - Mandarin - Hindi • French - Tagalog - Farsi • German - Vietnamese - Somali • Russian - Korean - Swahili • Portuguese • American Sign Language • Other Sign Language (please specify): • Other Language (please specify): • I choose not to respond What language do you prefer to use when reading materials related to your health care? This can include a specific language, Braille, large print, and/or digital documents that can be spoken out loud. Select all that apply. • English - Cantonese - Arabic • Spanish - Mandarin - Hindi • French - Tagalog - Farsi • German - Vietnamese - Somali • Russian - Korean - Swahili • Portuguese - Large Print - Braille • Digital documents that can be read out loud • Other Language (please specify): • I choose not to respond **Outreach Preferences:** How would you prefer to be contacted with information related to your health care? - Phone Call - Text Message - Secure Email - Mailed Letter - I choose not to respond	**Speaking:** What language do you feel most comfortable speaking with your doctor or nurse? This can include a specific language or different types of sign language. • English - Cantonese - Arabic • Spanish - Mandarin - Hindi • French - Tagalog - Farsi • German - Vietnamese - Somali • Russian - Korean - Swahili • Portuguese • American Sign Language • Other Sign Language (please specify): • Other Language (please specify): • I choose not to respond If an interpreter in your preferred language was available right now, would you choose to use one for your health care visit? Y/N Are you comfortable using an interpreter if they are only available through: - Telephone: Y/N - Video: Y/N - In-person: Y/N - I choose not to respond **Reading and Writing:** What language do you prefer to use when reading materials related to your health care? This can include a specific language, Braille, large print, and/or digital documents that can be spoken out loud. • English - Cantonese - Arabic • Spanish - Mandarin - Hindi • French - Tagalog - Farsi • German - Vietnamese - Somali • Russian - Korean - Swahili • Portuguese - Large Print - Braille • Digital documents that can be read out loud • Other Language (please specify): • I choose not to respond

[1] Adapted from AHRQ

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Sexual Orientation

Do you think of yourself as (check all that apply):[2]
o Gay or lesbian (predominantly attracted to the same gender as your own)
o Straight or heterosexual (predominantly attracted to gender different from your own)
o Bisexual (attracted to same gender as your own and genders different from your own)
o Asexual (little or no attraction to any gender)
o Something else, please specify: _____
o Don't know
o I choose not to respond

Optional: Relationship Status

What is your relationship status? (Select all that apply)[3]
o Married
o In a registered domestic partnership
o Partnered, but not registered as a legal domestic partnership
o Single
o Divorced
o Widowed
o Other (please specify): _____
o I choose not to respond

[2] Adapted from Fenway Health's National LBTQIA+ Education Center. Aligns with USCDI V2 Additions on SOGI but uses more culturally appropriate terms. Some state BRFSS have similar questions as of 2018 and 2016 (CA and GA) but others do not (ND).
[3] Adapted from Fenway Health's National LBTQIA+ Education Center.

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Gender

What sex were you assigned at birth on your original birth certificate? (Please select one)[4]
o Male, Man
o Female, Woman
o Intersex
o I choose not to respond

What is your gender? (Please select one)[5]
o Male, Man
o Female, Woman
o Transgender Male, Trans Man
o Transgender Female, Trans Woman
o Non-Binary, neither exclusively male nor female
o Additional gender category (please specify): _____
o Don't know
o I choose not to respond

Optional: What is your legal sex? (Please select one)[6] *While we recognize a number of genders, many legal entities unfortunately do not yet. Please be aware that the name & sex you have previously listed on your insurance must be used on documents pertaining to insurance, billing, & correspondence. If your preferred name and pronouns are different from these, please let us know so that we can update our system.*
o Male, Man
o Female, Woman
o Additional sex category (please specify): _____
o I choose not to respond

[4] Adapted from Fenway Health's National LBTQIA+ Education Center.
[5] Adapted from Fenway Health's National LBTQIA+ Education Center. Aligns with USCDI V2 Additions on SOGI but uses more culturally appropriate terms.
[6] Adapted from Fenway Health's National LBTQIA+ Education Center.

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Optional: Preferred Pronouns

We would like to be respectful. What pronouns do you use to identify yourself? (Select all that apply)[7]
o He, him, his
o She, her, hers
o They, them, theirs
o Ze, hir, hirs
o Additional pronouns, please specify: _____
o Don't know
o I choose not to respond

[7] Adapted from Fenway Health's National LBTQIA+ Education Center. Aligns with USCDI V2 Additions on SOGI but uses more culturally appropriate terms.

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Disability Status

Separate Questions on Disability Status[8]	Single Question on Disability Status Collapsed
o **Hearing:** Do you have difficulty hearing? Y/N o **Vision:** Do you have difficulty seeing, even when wearing glasses? Y/N o **Cognitive:** Because of a physical or mental health condition, do you have difficulty concentrating, remembering, or making decisions? Y/N o **Ambulatory:** Do you have difficulty walking or climbing stairs? Y/N o **Self-Care:** Do you have difficulty dressing or bathing? Y/N o **Independent Living:** Because of a physical or mental health condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? Y/N o **Communication:** Using your usual (customary) language, do you have difficulty communicating, understanding, or being understood? Y/N o **Other:** Do you have other functional limitations or impairments that prevent you from doing activities of daily living? Y/N If Yes, please describe:_____ o I choose not to respond	Do you have difficulty: (check all that apply) o Hearing o Seeing, even when wearing glasses o Concentrating, remembering, or making decisions because of a physical or mental health condition o Walking or climbing stairs o Dressing or bathing o Doing errands alone such as shopping or visiting a doctor's office because of a physical or mental condition o Communicating, understanding, or being understood using your usual customary language o Other (please explain): _____ o I choose not to respond

[8] Adapted from ACA Sec. 4302: collapses NHIS survey questions-based on ICF model

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U.S. Veteran Status and Other Military Experience

Have you or your spouse ever served or have been discharged from the armed forces of the United States? (Check all that apply)
o Yes, I served in the armed forces of the United States
o Yes, my spouse served in the armed forces of the United States
o No, neither I nor my spouse served in the armed forces of the United States
o Don't know
o I choose not to respond
Optional: When did you serve? _____

Optional: Other Military Experience

Have you or your spouse ever served or have been discharged from the armed forces of a country other than the United States? (Check all that apply)
o Yes, I served in the armed forces of another country. Please specify which country: __
o Yes, my spouse served in the armed forces of another country. Please specify which country: ___
o No, neither I nor my spouse served in the armed forces of another country
o Don't know
o I choose not to respond
Optional: When did you serve? _____

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Optional: Mind, Body, Spirit Questions

o **Is religion, spirituality, or a belief system a key part of your health or how you like to receive health care?** Y/N
o **Is there anything you would like us to know about your religion, spirituality, or belief system to better inform your health care?** Please specify: _____

What is your current religion, spirituality, or belief system, if any?[9] (Check all that apply)	
o Christian: Roman Catholic o Christian: Protestant (such as Baptist, Methodist, Presbyterian, Episcopalian, Lutheran, Pentecostal, Nondenominational, Reformed, etc.) o Jewish (Judaism) o Muslim (Islam, Nation of Islam) o Buddhist o Hindu o Sikh o Orthodox (Greek, Russian, or other orthodox church) o Mormon (Church of Jesus Christ of Latterday Saints/LDS)	o Unitarian o Jehovah's Witnesses o Baha'I o Wicca o Ancestral, indigenous, or tribal beliefs o Other modern pagan beliefs o Atheist (do not believe in God) o Agnostic (not sure if there is a God) o Something else (please specify: _____) o Nothing in particular o I choose not to respond

[9] Adapted from 2014 Religious Landscape Survey: https://assets.pewresearch.org/wp-content/uploads/sites/11/2018/06/12094008/Appendix-D.pdf?ut_source=content_center&ut_source2=how-to-ask-about-religion-in-your-surveys&ut_source3=inline