AMERICAN ACADEMY *of* ACTUARIES

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November 15, 2021

Commissioner Jessica Altman, Co-Chair
Commissioner Ricardo Lara, Co-Chair
Special (EX) Committee on Race and Insurance—Workstream 5 (Health)
National Association of Insurance Commissioners (NAIC)

Attn: Jolie H. Matthews, Senior Health and Life Policy Counsel, NAIC

Re: Comments on the Revised Exposure Draft of Principles for Data Collection

Dear Commissioners Altman and Lara:

On behalf of the American Academy of Actuaries[1] Health Equity Work Group (HEWG), I appreciate the opportunity to offer comments on the exposure draft of the Revised *Principles for Data Collection* (Principles) document released by the NAIC's Special (EX) Committee on Race and Insurance—Workstream 5 (Health) on October 15, 2021. Our suggestions reflect the need for uniformity and consistency across all types of entities assuming health insurance risk.

We recognize the need for consistent, accurate, and comprehensive collection of data to understand and quantify health disparities and evaluate the effectiveness of initiatives to address health inequity. We believe the Principles document will go a long way toward achieving your goals and would serve as a framework not only for state departments of insurance, but also for other governmental agencies regulating entities bearing health insurance risk as they develop criteria for the collection and use of demographic and other related policy-level data. We also acknowledge the need to start addressing this type of data collection sooner rather than later, yet we suggest that the framework should allow flexibility to refine these processes as our collective understanding of the issues and opportunities related to the collection and analysis of this type of data become more apparent.

Finally, we note that insurers following consistent principles could decide to use valid yet different sets of data collection questions. Unless data are collected in a uniform way, the ability to analyze the data at a market level or geographic area level could be compromised. Therefore, you may wish to encourage in the data collection principles uniformity in addition to consistency of the collection of the data addressed in the Principles document.

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[1] The American Academy of Actuaries is a 19,500-member professional association whose mission is to serve the public and the U.S. actuarial profession. For more than 50 years, the Academy has assisted public policymakers on all levels by providing leadership, objective expertise, and actuarial advice on risk and financial security issues. The Academy also sets qualification, practice, and professionalism standards for actuaries in the United States.

Please find our redlined edits and comments in Attachment A.

We note that the Academy's Health Equity Work Group is looking at health equity from a broader perspective, which includes race and ethnicity concerns across all types of health plans. The work group is also exploring issues related to algorithms and the use and collection of data as they relate to health equity. As we continue our work in these areas, we hope to have the opportunity to provide you with our findings and further recommendations and to learn from your experience as you work with states in launching these principles.

Thank you for the opportunity to provide input on the revised *Principles for Data Collection*. We welcome the opportunity to speak with you in more detail and answer any questions you have regarding these comments or on other topics related to health equity. If you do have any questions or would like to discuss further, please contact Matthew Williams, the Academy's senior health policy analyst, at williams@actuary.org.

Sincerely,

Annette V. James, MAAA, FSA, FCA
Chairperson, Health Equity Work Group
American Academy of Actuaries

CC: Brian R. Webb, Assistant Director, Life and Health Policy and Legislation, NAIC

Attachment A.

Draft: 10/15/21

Comments are being requested on this draft document on or before Monday, Nov. 15, 2021. Comments should be sent by email only to Jolie Matthews at jmatthews@naic.org.

DRAFT

National Association of Insurance Commissioners (NAIC)
Special Committee on Race and Insurance – Workstream 5 (Health)
Principles for Data Collection

RECOMMENDS that state insurance departments and all health insurance companies promote, consider, and uphold the following principles according to their respective roles; and

THIS DOCUMENT is intended to establish consistent high-level guiding principles for the collection and treatment of data on race, ethnicity, and other demographic characteristics in the business of health insurance. These principles are guidance and do not carry the weight of law or impose any legal liability. This guidance can serve to inform state insurance departments and health insurance companies of recommendations aimed at addressing disparities in health insurance and health care. This guidance begins with the premise that robust data collection must be a priority of state insurance regulators and the regulated health insurance companies to both quantify existing disparities and evaluate the effectiveness of initiatives to address those disparities.

Throughout this document, "health insurance companies" is intended to include all entities bearing health insurance risk and for which the health products and services provided are regulated by state insurance departments. This will differ by state and includes applicable health maintenance organizations, life insurance, casualty insurance, or other types of entities that offer health insurance products, as well as provider organizations that are regulated by state insurance departments due to the nature of the risk borne.

Data Collection

a) Health insurance companies should be expected to systematically collect, maintain, protect, and report on, at minimum, enrollee data on race, ethnicity, income, occupation, geographic location, highest level of education, preferred language, sex (including gender identity), sexual orientation, and disability.
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 Appendix provides specific language for health insurance company consideration and also directs companies to other widely recognized sources for data collection integrity.)
c) The disclosure of demographic data by prospective insureds and enrollees must always be

Commented [AAA1]: Consistency of the data collection process is paramount to the effective use of this data collected for the purpose of measuring and monitoring health disparities. As currently drafted, the first paragraph of this document limits applicability of these principles to "all health insurance companies", which we believe limits the ability of insurance departments to uniformly apply these principles to its regulated entities offering similar insurance products. In many jurisdictions, health maintenance organizations (HMOs) are not considered to be health insurance companies, and state insurance law usually carve out specific insurance provisions to ensure that HMOs are held to consistent standards that promote a level playing field. It is not clear whether these principles would apply to HMOs and other risk-bearing organizations. Additionally, because some entities licensed as life insurance companies or property and casualty companies offer health insurance products, it would be helpful to clarify whether these principles apply to non-health insurance companies that offer health insurance coverage. Coordination with the other workstreams focusing on life and P&C lines may be prudent to ensure consistency. Therefore, we recommend broadening the term used to describe the entities to which these principles would apply to allow for uniform application to similarly situated risk-bearing entities offering health products or services and that are regulated by the state insurance department.

In order to minimize the number of changes throughout the document, we suggest adding this paragraph, which is intended to allow the principles to apply consistently to all entities bearing health insurance risk, and which are regulated by state insurance departments. We recognize that the entities that are regulated by state insurance departments evolve over time and this paragraph is intended to be evergreen.

Alternatively, we would suggest using the term "health insurance entity" in the first paragraph and changing this definition accordingly. This alternative would require changing "health insurance company" to health insurance entity" in several places throughout the document.

Commented [AAA2]: We suggest including income, occupation, address (at least ZIP code), and highest level of education, as minimum data elements to be collected so that some of the basic elements of social and economic factors on health disparities could be captured in the data collected. This would help the user of the data collected to understand the various facets of disparities and the intersection of race, income, geography, and equity. We recognize that the data needs may evolve over time. Therefore, it may be prudent to allow for periodic revision of the minimum data elements collected.
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voluntary and based on self-identification or disclosure. Therefore, a "prefer to not answer" option should be included if insureds and enrollees are asked to answer demographic questions.

d) To the extent that insurers use staff to collect and/or analyze demographic data, insurers should develop and implement trainings on how to ask questions about race, ethnicity, and language (REL), and sexual orientation and gender identity (SOGI), including training on how to maintain privacy.

e) 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 employees, insureds, and enrollees).

    a. State-based exchanges should consider identifying insurers that have achieved the NCQA Distinction in Multicultural Health Care (or an equivalent current NCQA product) as part of the exchanges' public-facing websites.

Commented [AAA3]: This section appears to be limited to state-based exchanges. To ensure a level playing field, we suggest encouraging all insurance companies to pursue an appropriate designation which indicates the attainment of minimum equity standards. While we have no comment on the specific designation cited, we believe that to have consistency across similarly situated risk bearing entities, this standard should not be limited to insurers offering plans on the exchange.

f) Insurers should collect demographic data about participating providers in their networks to ensure network adequacy requirements are being met and to ensure that the provider network addresses the needs of the service area.

g) To the extent practicable, state departments of insurance should coordinate on uniform format and questions to facilitate the aggregation and analysis of this data across jurisdictions and across all regulated entities.

Data Use and Regulation

a) Insurance departments should confirm that neither state nor federal law prohibits an insurer from collecting race, ethnicity, income, occupation, geographic location, highest level of education, preferred language, sex (including gender identity), sexual orientation, and disability information. Such clarification should distinguish between the collection of demographic data and the prohibited use of demographic data in rating, underwriting practices, and benefit determinations.

Commented [AAA4]: We suggest including income, occupation, address (at least ZIP code), and highest level of education, as minimum data elements to be collected so that some of the basic elements of social and economic factors on health disparities could be captured in the data collected. This would help the user of the data collected to understand the various facets of disparities and the intersection of race, income, geography, and equity.

b) Health insurance companies should apply HIPAA protections to demographic data and should consider the collection of demographic data in measures 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 reporting on disaggregated demographic data—health insurance companies and regulators should clearly state that this is the reason why the data was not reported. State insurance departments and health insurance companies should coordinate on appropriate guidelines for defining the circumstances that would prevent reporting on disaggregated data due to privacy concerns.

Commented [AAA5]: Consider explicitly encouraging the development of guidelines for determining when privacy concerns may prevent disaggregation of data. This may include the development of uniform credibility standards for this purpose.

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 health care disparities or to evaluate the efficacy of programs intended to reduce health care disparities; provider network development and coordination of care; reporting requirements; service quality improvement ; 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.

d) Insurance departments and health insurance companies should coordinate on criteria for validating the data collected to ensure a uniform minimum level of quality.

~~d)~~e) Insurance departments and health insurance companies should coordinate on guidelines for ensuring that data collected for this purpose are not inadvertently comingled with data used for purposes for which the use of demographic data is prohibited.

~~e)~~f) Insurance departments, individually or collectively through the NAIC, or designated third parties, 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.

Commented [AAA6]: It may be helpful to suggest that companies validate the data collected based on minimum standards set by the state department of insurance.

Commented [AAA7]: We also suggest including suggestions to ensure that the data collected in accordance with these principles are not inadvertently comingled with data used for purposes for which the use of demographic data is prohibited.

Commented [AAA8]: Consider revising this section to allow for the use of a third party/parties to collect and/or review this data in accordance with these principles.

Appendix

Recommended Standards for Data Collection

This section provides specific recommendations for data collection standards for race and ethnicity. Though widely recognized for increased accuracy and responsiveness, these standards, examples, and sources are not the sole resources that health insurance companies may use to develop data collection systems and processes. As such, this section also provides a list of resources for data collection related to language, sexual orientation, gender identity, and disability. Health insurance companies should be familiar with long-standing guidance from the U.S. Department of Health and Human Services on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status. All questions should allow for the option to self-identify, including a “choose not to answer” option or a blank, fillable option.

a) On race and ethnicity
    a. In preparation for the 2020 Census, the U.S. Census Bureau conducted research to improve the collection of race/ethnicity data and found that providing a combined race/ethnicity question with detailed checkboxes decreased nonresponse and improved accuracy. In addition, as summarized by the State Health Access Data Assistance Center at the University of Minnesota, the research:
        i. Reinforced the importance of allowing multiple responses;
        ii. Suggested that “Mark all that apply” or “Select all that apply” is better than “Select one or more”;
        iii. Suggested that using “race/ethnicity” terminology is less confusing than using terms like “category,” which can suggest a hierarchy; and
        iv. Found that data collection is improved when there is a dedicated “Middle Eastern or North African” response category for race (currently classified as “White”).

    b. Data should be collected at a granular level to allow for disaggregation, particularly for Asian Americans, Native Hawaiians and Pacific Islanders (AANHPI), Hispanics, and Middle Eastern and Northern African (MENA) populations.

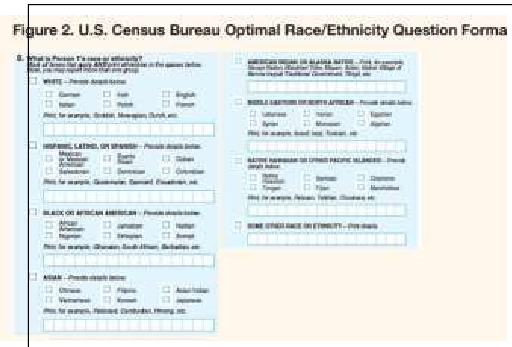


Figure 2. U.S. Census Bureau Optimal Race/Ethnicity Question Forma

Source: [Collection of Race, Ethnicity, Language (REL) Data in Medicaid Applications](), State Health Access Data Assistance Center at the University of Minnesota

WHAT IS THE PERSON'S RACE OR ORIGIN?

Mark all boxes that apply and print origins in the spaces below.
Note, you may report more than one group.

○ **White:**
Print, for example, German, Irish, English, Italian, Polish, French, etc.

○ **Hispanic, Latino, or Spanish origin:**
Print, for example, Mexican or Mexican American, Puerto Rican, Cuban, Salvadoran, Dominican, Colombian, etc.

○ **Black or African American:**
Print, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, Somali, etc.

○ **Don't Know**

○ **Unsure**

○ **Decline to State**

○ **Middle Eastern or North African:**
Print, for example, Lebanese, Iran
Egyptian, Syrian, Moroccan, Alger

○ **Native Hawaiian or Pacific Island**
Print, for example, Native Hawaiia
Samoan, Chamorro, Tongan, Fijiar
Marshallese, etc.

○ **Asian:**
Print, for example, Chinese, Filipir
Asian Indian, Vietnamese, Korean
Japanese, etc.

○ **American Indian or Alaska Native**
Print your tribal affiliation, for exan
Navajo Nation, Blackfeet Tribe, M
Aztec, Native Village of Barrow In
Traditional Government, Nome Es
Community, etc.

○ **Some other Race or Origin:**

Source: Policy Recommendations: Health Equity Cannot Be Achieved Without Complete and Transparent Data Collection and the Disaggregation of Data by Asian & Pacific Islander American Health Forum, UnidosUS, National Urban League, National Congress of American Indians, ACCESS

c. Sources

1. Asian & Pacific Islander American Health Forum (2021). *Policy Recommendations: Health Equity Cannot be Achieved without Complete and Transparent Data Collection and the Disaggregation of Data.* https://www.apiahf.org/wp-content/uploads/2021/02/APIAHF-Policy-Recommendationas-Health-Equity.pdf

2. State Health and Value Strategies (2021). Collection of Race, Ethnicity, Language (REL) Data in Medicaid Applications: *A 50-State Review of the Current Landscape*. https://www.shvs.org/wp-content/uploads/2021/05/SHVS-50-State-Review-EDITED.pdf

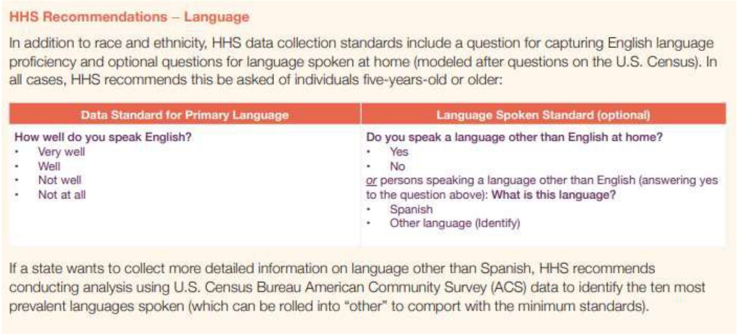
3. US Census Bureau (2017). *2015 National Content Test Race and Ethnicity Analysis Report: A New Design for the 21st Century*. https://assets.documentcloud.org/documents/4316468/2015nct-Race-Ethnicity-Analysis.pdf

4. Institute of Medicine (for AHRQ) (2021). *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. https://www.ahrq.gov/research/findings/final-reports/iomracereport/index.html

5. McGee, M.G. (2020). *Race, Ethnicity, Language and Disability (REALD) Implementation Guide*. https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/le7721a.pdf

b) On preferred language

a. The American Community Survey, consistent with recommendations from the Department of Health and Human Services, also captures data on English language proficiency and optional questions for the language spoken at home. These questions are recommended for anyone age 5 years or older.



HHS Recommendations – Language

In addition to race and ethnicity, HHS data collection standards include a question for capturing English language proficiency and optional questions for language spoken at home (modeled after questions on the U.S. Census). In all cases, HHS recommends this be asked of individuals five-years-old or older:

Data Standard for Primary Language	Language Spoken Standard (optional)
How well do you speak English? • Very well • Well • Not well • Not at all	**Do you speak a language other than English at home?** • Yes • No or persons speaking a language other than English (answering yes to the question above): **What is this language?** • Spanish • Other language (Identify)

If a state wants to collect more detailed information on language other than Spanish, HHS recommends conducting analysis using U.S. Census Bureau American Community Survey (ACS) data to identify the ten most prevalent languages spoken (which can be rolled into "other" to comport with the minimum standards).

Source: Collection of Race, Ethnicity, Language (REL) Data in Medicaid Applications, State Health Access

c) On sex, sexual orientation, and gender identity

a. The National Academies of Sciences, Engineering, and Medicine recently convened an expert panel entitled *Measuring Sex, Gender Identity, and Sexual Orientation* that will culminate in clear guidelines outlining the guiding principles and best practices for collecting sexual orientation and gender identity information. Recommendations will address collection and use of this information in research and non-research surveys, along with medical and other administrative records. These recommendations can help inform data collection by industry.

b. The Williams Institute at the UCLA School of Law has published several reports on best practices for asking questions about sex, sexual orientation, and gender identity. Key practices include:

    i. Sexual orientation survey items should be culturally appropriate, relevant, acceptable, and compatible with the respondent's understanding of the construct that the question is intended to measure. Sexuality can be understood differently in different racial/ethnic populations. It is recommended that surveys assess multiple dimensions of sexuality, such as measures of sexual behavior, sexual attraction, and self-identity. When measuring sexual diversity within racial/ethnic minority groups, researchers might also consider including additional response options for sexual orientation identity terms, such as two-spirit, same gender loving, homosexual, down low, or queer, that may turn out to be more relevant for non-white populations.

    ii. Conceptually, sexual orientation has three major dimensions – self-identification (gay, lesbian, bisexual, heterosexual, queer, or asexual), sexual behavior or the sex of partners (same sex, different sex, both sexes, neither), and sexual

    iii.

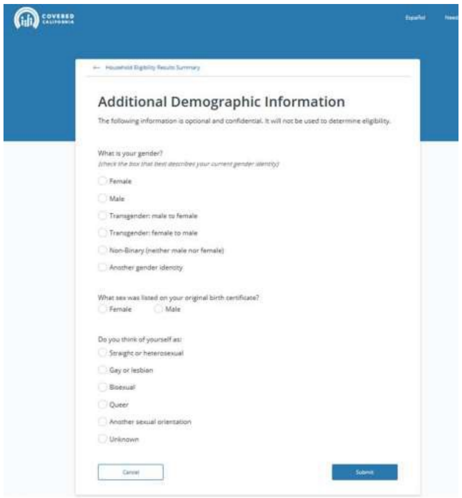
attraction (the sex or gender of people that the respondent feels attracted to). Surveys should allow for a wide range of responses.
When asking about sex, it is recommended to use a "two-step" approach. Respondents should be asked what sex they were assigned at birth or what sex is indicated on their birth certificate, and should also be asked how they describe their current gender identity. When describing current gender identity, respondents should be allowed to 'check all that apply' or fill in their own descriptor. If a respondent identifies as transgender, a follow-up question should be included to further identify whether male to female, female to male, or transgender gender nonconforming.

c. Sources:
    i. The GenIUSS Group. (2014). *Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys*. J.L. Herman (ed.). Los Angeles, CA: The Williams Institute. https://williamsinstitute.law.ucla.edu/wp-content/uploads/Survey-Measures-Trans-GenIUSS-Sep-2014.pdf
    ii. Cahill, S., Baker, K., Makadon, H. *Do Ask, Do Tell: A Toolkit for Collecting Sexual Orientation and Gender Identity Information in Clinical Settings*. Boston, MA: Fenway Institute. https://doaskdotell.org/

iii. Brown, T. N. T. and Herman, J. L. (2020). *Exploring International Priorities and Best Practices for the Collection of Data about Gender Minorities: A Focus on South America, Report of Meeting*. Los Angeles, CA: The Williams Institute. https://williamsinstitute.law.ucla.edu/wp-content/uploads/WPATH-English-Mar-2020.pdf

iv. The Sexual Minority Assessment Research Team (SMART) (2009). *Best Practices for Asking Questions about Sexual Orientation on Surveys.* Los Angeles, CA: The Williams Institute. https://williamsinstitute.law.ucla.edu/wp-content/uploads/Best-Practices-SO-Surveys-Nov-2009.pdf

v. Centers for Disease Control and Prevention (2020). *Collecting Sexual Orientation and Gender Identity Information.* https://www.cdc.gov/hiv/clinicians/transforming-health/health-care-providers/collecting-sexual-orientation.html



Additional Demographic Information

The following information is optional and confidential. It will not be used to determine eligibility.

What is your gender?
(check the box that best describes your current gender identity)
○ Female
○ Male
○ Transgender: male to female
○ Transgender: female to male
○ Non-Binary (neither male nor female)
○ Another gender identity

What sex was listed on your original birth certificate?
○ Female ○ Male

Do you think of yourself as:
○ Straight or heterosexual
○ Gay or lesbian
○ Bisexual
○ Queer
○ Another sexual orientation
○ Unknown

Based on many years of experience collecting and using patient SOGI data in Electronic Health Records (EHRs), advocating for inclusion of SOGI in national health IT systems, and training health centers and other organizations in how to collect and use SOGI to improve quality of care, the Fenway Institute recommends the following SOGI questions:

Sexual orientation
Do you think of yourself as (Check one):
- ☐ Straight or heterosexual
- ☐ Lesbian, gay, or homosexual
- ☐ Bisexual
- ☐ Something else (e.g. queer, pansexual, asexual). Please specify _______.
- ☐ Don't know
- ☐ Choose not to disclose

Gender identity
What is your current gender identity? (Check all that apply):
- ☐ Female
- ☐ Male
- ☐ Transgender Woman/Transgender Female
- ☐ Transgender Man/Transgender Male
- ☐ Other* (e.g. non-binary, genderqueer, gender-diverse, or gender fluid). Please specify ________.
- ☐ Choose not to disclose

What sex were you assigned at birth? (Check one):
- ☐ Male
- ☐ Female

**You may replace the term "other" on patient-facing forms with the term that is most affirming for the communities you serve (e.g. "something else" or "additional category").*

These questions and response options were developed by the National LGBTQIA+ Health Education Center and approved by the Bureau of Primary Health Care at HRSA for use with the Health Center Program.[38] These terms collect data that can be used to populate the Health Center Program's Uniform Data System.[39] They are also only slightly different from the minimal standards adopted by the Office of the National Coordinator of Health Information Technology in 2015,[40,41] based on research that the Fenway Institute and the Center for American Progress conducted with health center patients in South Carolina, Maryland, Chicago and Boston.[42] For more information please see https://www.lgbtqiahealtheducation.org/

Source: Letter to Dr. Rachel Levine, [LGBTQI Inclusion in COVID-19 Data Collection & Vaccination Planning]()

d) On disability

a. [Demographic questions]() about disability have been asked in the American Community Survey since 1999, with modifications over time. The most recent revisions to these questions were adopted in 2008 and endorsed by the U.S. Department of Health and Human Services, in guidance issued in 2011 pursuant to the requirements of section 4302 the Affordable Care Act. These questions are:

i. Are you deaf or do you have serious difficulty hearing?

    ii. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
    iii. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)
    iv. Do you have serious difficulty walking or climbing stairs? (5 years old or older)
    v. Do you have difficulty dressing or bathing? (5 years old or older)
    vi. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older).

b. Additional measures have been developed outside of the American Community Survey, such as the Washington Group Short Set of Questions on Disability. Those questions have been analyzed by the Centers for Disease Control and Prevention.

c. Sources:
    i. U.S. Department of Health & Human Services, Office of the Assistant Secretary for Planning and Evaluation. (2011) *U.S. Department of Health and Human Services Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status.* https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status
    ii. Centers for Disease Control and Prevention. (2020) *Disability Datasets: Population Surveys that Include the Standard Disability Questions.* https://www.cdc.gov/ncbddd/disabilityandhealth/datasets.html

    Kuper, H, Polack, S. Mactaggart, I. *How to Measure Disability and Why It Is Important*. https://www.futurelearn.com/info/courses/global- disability/0/steps/37579

e) In the event data collection remains low after best practices are implemented, regulators and insurers should engage consumers and consumer advocates, engage navigators /enrollment assisters, develop communications and trainings focused on the importance of demographic data collection, and modify enrollment and renewal interfaces.