Listening Session on Social Determinants of Health Data Elements

Summary of Findings

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CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES

Listening Session on Social Determinants of Health Data Elements: Summary Report

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Summary

The Centers for Medicare & Medicaid Services Office of Minority Health (CMS OMH), with support from the National Committee for Quality Assurance (NCQA), convened a listening session to gain stakeholder feedback on measuring social determinants of health (SDOH).

A diverse group of stakeholder organizations, including representatives from health systems, research groups, government agencies, and advocacy organizations, participated in the session held in December 2018. The results of this activity will help CMS examine which SDOH CMS may prioritize for measurement to facilitate better care planning and coordination; better understand measurement barriers and challenges; and understand what resources, tools, or interventions are needed to effectively identify, collect, and analyze these data elements. Key themes that the participating stakeholders reported include:

Prioritize data elements under consideration
- Race, Ethnicity, and Spoken Language were discussed but omitted from consideration for ranking because they are commonly collected.
- Transportation, Health Literacy, and Social Isolation were ranked the three highest priority data elements.
- Sex, Educational Attainment and Social Isolation were ranked the three lowest priority data elements.
- Social Isolation emerged as a polarizing data element, appearing on both the highest priority and lowest priority lists.

Customize assessment tools by local needs
- Customizing assessment tools to fit local demographics and needs may ease transition to new types of assessment and new questions for some stakeholders. For example, in a community with a significant Hispanic population, clinics may want to offer expanded options when asking about ethnicity whereas in a community with a smaller Hispanic population, they may find it sufficient to ask if an individual identifies as Hispanic or Latino.
- However, local customization can also incur EHR customization costs and decrease the comparability of data across sites.

Allow patients to self-identify
- Stakeholders were in favor of self-reporting SDOH:
  - Questions should be phrased so that patients are asked to self-identify which category they feel represents them.
  - There should be enough specificity of categories so that all patients feel represented.
- Assess SDOH data at a granular level and roll up to the appropriate categories.

Broaden beyond medical care
- Ensure that questions are addressing variables beyond the clinical encounter.
- Ensure that questions assess interactions with non-medical members of the care team.

Best practices for question design
- Allow for non-response to the question.
- Assess whether an "I don't know" option is appropriate.
- Ensure the reading level of the question is appropriate.

Background

The Centers for Medicare & Medicaid Services Office of Minority Health's (CMS OMH) goal is to gather actionable information to guide the development of tools for standardized collection of data elements related to the social determinants of health. On behalf of CMS OMH, the National Committee for Quality Assurance (NCQA) sought input through a listening session designed to identify key themes, opinions, and recommendations from stakeholders around data elements related to the social determinants of health (SDOH). The results of this activity will help CMS OMH: 1) examine what categories of SDOH related data elements stakeholders find important to collect, 2) identify more specific information on the collection of these data elements such as recommended questions; and 3) understand what resources, tools or interventions are needed to effectively identify, collect, and analyze these data elements.

The purpose of this technical brief is to describe the approach we used to conduct the listening session and to present and summarize themes. This document contains the following sections:

- **Methods:** Describes stakeholders and perspectives represented, the stakeholder identification and outreach approach, and the content of the listening session materials.
- **Results:** Presents themes from the listening session.
- **Key Findings and Recommendations:** Summarizes themes.
- **Appendices:**
  - Appendix A provides a detailed list of stakeholders, including their current position and, if applicable, their affiliations with SDOH-related programs.
  - Appendix B displays the materials presented to the listening session participants.
  - Appendix C displays the materials presented to the participants who elected to submit written public comment.

Methods

Participants
For this listening session, CMS OMH sought to include a variety of stakeholders from different industries and organization types with experience and expertise in assessment of patient-level social determinants of health. To identify stakeholders, the project team reviewed participant lists from the National Academies of Sciences, Engineering, and Medicine (NASEM) Ad-Hoc

Committee on Integrating Social Needs Care into the Delivery of Health Care to Improve the Nation's Health, the National Quality Forum (NQF) Disparities Standing Committee as well as lists from other CMS health equity listening sessions. Additionally, we included representatives of organizations that have developed, tested, and implemented SDOH data elements.

We contacted all stakeholders via email to invite them to the listening session. Participants who were unable to attend were given the option of recommending a substitute participant or submitting written comment.

In total, 23 stakeholders participated, including 6 who attended in person, 14 who attended via WebEx, and 3 who participated by submitting written comments. These stakeholders represented health systems, research organizations, advocacy organizations, and state agencies.

Appendix A presents a detailed list of stakeholders, including their current position and, if applicable, their affiliations with SDOH-related programs.

Materials

Prior to the listening session, all stakeholders received one of two sets of materials:
- Stakeholders participating in the listening session in person or via WebEx were sent the materials in Appendix B.
- Stakeholders participating in the listening session via written comment were sent the materials in Appendix C.

We developed a listening session guide to provide participants with an overview of the data elements CMS OMH selected for discussion during the listening session. The materials highlighted various questions used in government-sponsored and other well-known surveys to collect the data elements of interest. For those providing written comments, an additional document was provided explaining what surveys the questions are used in and any other relevant background information.

Results

This section presents findings from the listening session, and highlights recommendations for CMS OMH when considering patient assessment of social determinants of health data. The results are categorized by subtopic.

General Comments
According to stakeholders, the person who asks the questions on SDOH and the setting in which the questions are asked could potentially affect the results. One stakeholder mentioned that this could be a potential area for further study. Another stakeholder recommended that basic social and demographic factors may be most appropriately asked at the time of registration or

plan enrollment, along with the patient's address, which can be linked to neighborhood characteristics data. More sensitive information could then be asked during the clinical encounter.

Additionally, stakeholders raised concerns about self-administered versus interviewer-administered questions, and the potential bias introduced by concerns about stigma. One stakeholder noted that if questions are orally administered, long questions will likely not be read verbatim, so shorter questions may be preferable.

Stakeholders found it challenging to provide comments without knowing the context of how questions will be used. One stakeholder suggested that it may be challenging to find data elements useful for quality measurement, care coordination, and transitions. One stakeholder urged inclusion of nationally-recognized survey methodologists in this conversation.

Another stakeholder suggested that whenever possible, SDOH should be assessed on a scale rather than the presence or absence of need. Finally, a stakeholder suggested to include "I don't know" as an option across SDOH elements.

Recommended Changes to Existing SDOH Data Elements

Key Themes: Spoken Language, Race and Ethnicity

- Assess spoken language first.

- Don't conflate race and ethnicity.

- Allow for self-identification.

- Allow non-response to the question.

- Local customization of response options may facilitate effective workflows but increase Electronic Health Record (EHR) customization costs

Three SDOH Data elements are currently collected in some CMS patient assessment tools and surveys. This includes the following SDOH Data elements: spoken language, ethnicity, and race. CMS may consider revising how the data is assessed because the method for collecting these data elements is inconsistent.

Please refer to Appendix B and C to review the question options for each topic.

Stakeholders recommended that spoken language be assessed first, to allow for communication. Ethnicity would then be assessed and then Race, in accordance to the recommendations by the OMB guidelines.[1]

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[1] Office of Management and Budget. (1997). Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity. Retrieved from https://obamawhitehouse.archives.gov/omb/fedreg_1997standards

Stakeholders were in favor of self-identification: patients should be asked to identify which category they feel represents them, and there should be enough specificity of categories that all patients feel represented. Categories can be aggregated at different levels for different purposes.

One stakeholder recommended alignment with the 2015 Office of the National Coordinator for Health Information Technology Certification Criteria (ONCHIT) which provide detailed standards for Electronic Health Record (EHR) collection of patient demographic categories, including race, ethnicity, and language.[2] This recommendation is supported by the fact that CMS already requires adoption of these standards for Promoting Operability performance category in the Quality Payment Program. However, these standards would be difficult to implement in a paper based format; for example, the ONCHIT standard uses the CDC race and ethnicity code set, comprising 900 categories[3,4] For spoken language, the standard requires use of the Internet Engineering Task Force list (RFC 5646) of language categories, comprising of all International Organization for Standardization (ISO) codes for spoken and written languages and dialects[,5].

Another stakeholder provided a list of best practices for Health Information Technology collection of race, ethnicity, and language data elements.[6]

Challenges
Stakeholders indicated that rural and small hospitals will have challenges collecting detailed data as they are often still collecting data on paper. However, stakeholders cautioned that some providers needing extra help should not limit the capabilities of other providers and indicated that we need to be able track progress over time on disparities.
Stakeholders highlighted the following categories of self-identified race/culture are not included in most questionnaires currently used or reviewed as part of this listening session:
- Latina/Latino as a race (rather than a separate question on ethnicity)
- Middle Eastern/North African groups
- Specific Asian populations (e.g., Vietnamese, Chinese, Taiwanese).

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[2]U.S. Department of Health and Human Services Office of National Coordinator for Health Information Technology (2015). 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications. Retrieved from https://www.federalregister.gov/documents/2015/10/16/2015-25597/2015-edition-health-information-technology-health-it-certification-criteria-2015-edition-base
[3] Centers for Disease Control and Prevention. (2000). Race and Ethnicity Code Set Version 1.0. Retrieved from https://www.cdc.gov/phin/resources/vocabulary/documents/cdc-race--ethnicity-background-and-purpose.pdf
[4] Phillips, A. & Davis, M. (2009). Tags for Identifying Languages. Retrieved from https://tools.ietf.org/html/rfc5646
[5] International Organization for Standardization. (2010). Language Codes ISO 639. Retrieved from https://www.iso.org/iso-639-language-codes.html
[6] Vizient. (2017). Equity Enhancement Program. 8 Health Information Technology Best Practices for REAL Data Collection.

Spoken Language

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Key Themes: Spoken Language

- Assess this first, before other assessments, to allow for effective communication.

- If only one question can be asked, spoken language assessment is prioritized over written language.

- Understanding the purpose of the question is vital in this case, as preferences may or may not indicate the need for interpretation services.

- Local customization of response options may facilitate effective workflows but increase EHR customization costs.

- Allow for self-identification.

- Allow non-response to the question.

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Purpose of Collection

Stakeholders felt is important to allow people to self-identify their preferred spoken language. This information will be used to provide care as well as for care planning, language line services, disparities monitoring, research, and population management.

Characteristics of a Good Question

Stakeholders recommended the following:
1) Allow for self-identification,
2) Include assessment of the desires and preferences of the patient rather than asking only about "needs," and
3) Allow "I choose not to answer this question" for every question.

Data Format

Stakeholders felt it is not patient-centered to have a short list with only broad categories of languages like English, Spanish, or Chinese. The stakeholders recommended a master list that can be ordered and filtered to represent the dominant languages spoken in the community, with an option to fill in "other". One stakeholder raised a concern about EHR customization costs if every organization needs to customize.

How is the Data Assessed?

Stakeholders agreed this question should be assessed at the beginning of the interaction, to allow for effective communication. One stakeholder provided an example of a language sign used at a children's hospital to allow people to point to their language of preference. A master

list that can be ordered and filtered to represent the dominant languages spoken in a community, with an option to fill in "other" was recommended by stakeholders.

Change over Time?
Stakeholders felt this question should be asked frequently. As patients age, or experience dementia, their response may change. Depending on the topic, patients may feel more or less comfortable speaking in a particular language.

Alternate Questions Suggested by Listening Session Participations
- In what language do you prefer to discuss your health or health care?
- In what language do you prefer to discuss your health or health care needs?

Challenges
Stakeholders raised three key concerns about assessment of spoken language. One concern is that written language preference may or may not align with spoken language preference. Many people forget the details of their clinical encounters, so a written summary is also important. One stakeholder noted that a traditional assessment of language proficiency incorporates spoken language, written language, and language comprehension. Stakeholders agreed that if asked to choose, they would choose spoken language over written language. One stakeholder noted that asking only about written language may produce data that is not how a patient instinctively responds when asked about their preferred language.

A second stakeholder concern was that patients who are deaf may not identify with a spoken language. Finally, a stakeholder mentioned that language preference should not be conflated with a patient needing interpretation services, nor should it be used as a proxy for English proficiency.

Ethnicity

Key Themes: Ethnicity
- Don't conflate race and ethnicity.
- Assess at a granular level and roll up to groupings appropriate for the use case.
- Consider other, non-Hispanic/Latino ethnicities.
- Allow individuals to self-identify.
- Allow non-response to the question.

Purpose of Collection
Stakeholders felt that ethnicity is important to collect for the dual purposes of providing culturally sensitive care and tracking disparities. It was noted that data can serve different purposes in different contexts. Some stakeholders noted that ethnicity is sometimes misused, such as using it as a proxy for preferred language.

Characteristics of a Good Question
Stakeholders recommended the following:
1) Don't conflate race and ethnicity,
2) Allow for self-identification with a high degree of specificity, and
3) Allow "I choose not to answer this question" for every question.

A stakeholder recommended combining race and ethnicity into one question, in alignment with the race question currently in the Outcome and Assessment Information Set (OASIS) used in home health agencies, and the Minimum Data Set (MDS) used in nursing homes.[7,8] The stakeholder noted that most people do not think of race and ethnicity as distinct concepts and identities so asking them separately often causes confusion. It was also noted that census research has shown that it is easier and more valid for people to self-identify race and ethnicity if they are in the same question as opposed to split.[9] This opinion was not shared by the majority of the stakeholders.

Challenges
Stakeholders questioned why only one type of ethnicity - Hispanic/Latino - was assessed. It was raised as confusing that Cuban is considered an ethnicity, but Korean is not.
Stakeholders expressed that balancing feasible and meaningful granularity levels is challenging. One stakeholder recommended that further health services research be conducted on this topic.

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[7] Centers for Medicare and Medicaid Services. (2018). Outcomes and Assessment Information Set (OASIS). Retrieved from https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/OASIS/index.html
[8] Centers for Medicare and Medicaid Services. (2017). Nursing Home Quality Initiative. Retrieved from https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/index.html
[9] National Academies of Sciences Engineering and Medicine (NASEM). (1995). Chapter 7: Data on Race and Ethnicity. *In Modernizing the US Census* (140 – 155). Washington, DC.: The National Academies Press.

Race

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Key Themes: Race

- Allow individuals to self-identify.

- Don't conflate race and ethnicity.

- Allow non-response to the question.

- Assess at a granular level and roll up to categories appropriate for the use case.

- Alphabetical order for race is preferred.

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Purpose of Collection

Stakeholders felt it was of primary importance to allow people to self-identify their race with a high degree of specificity. These specific categories can then be aggregated to other levels of granularity suited for other purposes such as care planning, disparities monitoring, research, and population management.

Characteristics of a Good Question

Stakeholders recommended the following:

1) Don't conflate race and ethnicity,
2) Allow for self-identification with a high degree of specificity,
3) Allow "I choose not to answer this question" for every question, and
4) Use alphabetical order for race categories.

Data Format

Some stakeholders desired the flexibility of a free-text response but acknowledged that this would limit the usability of the data. Stakeholders noted we have come too far in data collection to go backwards to free text.

A tiered list was preferred by stakeholders for electronic data collection, which could be grouped via an algorithm into other levels of specificity for other purposes. However, if data is collected via paper this approach would present challenges. In that case, stakeholders recommended that local entities select a list of most frequent answers and have a free text option to record other specific races.

In 2009, IOM (now The National Academies of Sciences, Engineering and Medicine) released *Race Ethnicity and Language data: Standardization for Health Care Quality Improvement.* The report recommends using the response options of Black or African American, White, Asian, American Indian or Alaska Native, Native Hawaiian or Other Pacific Islander and/or Some other race. The report recommends that this question be asked in conjunction with a question that

allows for the respondent to provide more granular information that can then be rolled up to the OMB categories.[10]

How is the Data Assessed?
Stakeholders recommended self-identification of race by patients as the preferred option. However, they felt that someone asking the patient was preferable to a third party identifying the patient's race.[11]

Do Answers Change Over Time?
Stakeholders recommended that once the information is collected, patients simply confirm those selections on each visit. Stakeholders noted that questions related to race and ethnicity are generally only asked to respondents once as they are unlikely to change, while other questions related to needs that may change over time, should be asked or followed up on as deemed appropriate by the organization.[12] Additionally, stakeholders noted it would be helpful to ask once in a standardized way and share this information across the continuum of care.

Alternate Questions Suggested by Listening Session Participations

Source	Item/Question
In 1997 a notice from the Office of Management and Budget (OMB) set out standards and recommendations for collecting race and ethnicity data. One key aspect of this was the creation of 5 race categories; White, Black or African American, American Indian or Alaska Native, Asian and Native Hawaiian or Other Pacific Islander.[13] Many organizations, including the Department of Health and Human Services (HHS), have taken these categories and expanded them to provide respondents with more specific response options.[14] The more specific responses can be rolled up to one of the 5 OMB race categories. HHS recommends using the following question and response options. White, Black or African American and American Indian or Alaska Native are OMB categories. Asian Indian, Chinese, Filipino, Japanese, Korean,	**What is your race? (one or more categories may be selected)** ☐ White ☐ Black or African American ☐ American Indian or Alaska Native ☐ Asian Indian ☐ Chinese ☐ Filipino ☐ Japanese ☐ Korean ☐ Vietnamese ☐ Other Asian ☐ Native Hawaiian ☐ Guamanian or Chamorro ☐ Samoan ☐ Other Pacific Islander

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[10] National Academies of Sciences, Engineering and Medicine. (2009). Race, Ethnicity and Language Data Standardization for Health Care Quality Improvement. Retrieved from https://www.nap.edu/read/12696/chapter/7#138

[11] Magaña López, M., Bevans, M., Wehrien, L., Yang, L., & Wallen, G.R. (2017). Discrepancies in Race and Ethnicity Documentation: a Potential Barrier in Identifying Racial and Ethnic Disparities. *Journal of Racial and Ethnic Health Disparities,* 4(5): 812 -818.

[12] National Association of Community Health Centers. (2016). PRAPARE Frequently Asked Questions (FAQ). Retrieved from http://www.nachc.org/wp-content/uploads/2016/07/PRAPARE-FAQ-7-26-16.pdf

[13] Office of Management and Budget. (1997). Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity. Retrieved from https://obamawhitehouse.archives.gov/omb/fedreg_1997standards

[14] U.S. Department of Health and Human Services Office of Minority Health. (2014). Explanation of Data Standards for Race, Ethnicity, Sex, Primary Language and Disability. Retrieved from https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=54

Vietnamese and Other Asian roll up to the OMB category Asian. Native Hawaiian, Guamanian or Chamorro, Samoan and Other Pacific Islander roll up to the OMB category Native Hawaiian or Other Pacific Islander.[16]	
The Protocol for Responding to and Assessing Patient Assets, Risks and Experiences (PRAPARE) assessment tool was developed to help health centers and other providers collect the data needed to better provide and understand patient's social determinants of health.[15]	**Which race(s) are you? Check all that apply.** [16] ☐ Asian ☐ Pacific Islander ☐ White ☐ Native Hawaiian ☐ Black/African American ☐ American Indian/Alaskan Native ☐ Other (please write) ☐ I choose not to answer this question.

Recommended Additions of SDOH Data Elements

Three SDOH Data elements are recommended as additions to standardized assessment: Health Literacy, Social Isolation, and Transportation. Please refer to Appendix B and C to review the question options for each topic.

Health Literacy

> **Key Themes: Health Literacy**
>
> 1) Assess more than the ability to read written materials or fill out forms.
>
> 2) Assess interactions with staff/care team as well as with the doctor.
>
> 3) Assess present and future confidence not only past experiences.
>
> 4) Allow non-response to the question.

Purpose of Collection
Stakeholders agreed that health literacy is important to understand so that communication between patient and provider can be effective. Some stakeholders highlighted that a patient

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[15] National Association of community Health Centers. (n.d). PRAPARE. Retrieved from http://www.nachc.org/research-and-data/prapare/
[16] National Association of Community Health Centers. (2016). PRAPARE: Protocol for Responding to and Assessing Patient Assets, Risks and Experiences. Retrieved from http://www.nachc.org/wp-content/uploads/2018/05/PRAPARE_One_Pager_Sept_2016.pdf

being literate does not mean that they understand healthcare specific information. Other stakeholders expressed concern that patient self-assessment of health literacy is less accurate than an actual test of health literacy.

Characteristics of a Good Question

Stakeholders recommended the following:
1) Health literacy is not just about written materials,
2) Health literacy is not just about interactions with the doctor,
3) Health literacy is not only about filling out forms,
4) It is important to assess whether people understand their conditions,
5) Assess present and future confidence not only past experience, and
6) Allow "I choose not to answer this question" for every question.

How is the Data Assessed?

Some stakeholders expressed concern that patient self-assessment of health literacy is less accurate than an actual test of health literacy.

Alternate Questions Suggested by Listening Session Participations

Source	Item/Question
Stakeholder recommendation.	Can you communicate with your health care team?
Watson and Coleman – Health Confidence In 2014 Watson & Coleman published the My Health Confidence Tool. This two-question screener identifies a patient's confidence in their ability to address their health problem and to what extent they were able to understand the information provided to them about the condition.[17]	**Health Confidence: How confident are you that you can control and manage most of your health problems?** (*Patient will rank 1 – 10; anything below a 7 has the follow up of what would it take to increase your score*) **Health Information: How understandable and useful is the information your doctors or nurses have given you about your health problems or concerns?** (*patient will rank 1 – 10; anything below a 7 has the follow up of what would it take to increase your score*)

Challenges

One stakeholder cautioned that the National Academy of Sciences, Engineering and Medicine (NASEM) is no longer recommending inclusion of a question on health literacy, as they now recommend health literacy universal precautions.[18] This means that practices should assume all patients may have difficulty comprehending health information and accessing health services.

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[17] Wasson, J. & Coleman, E.A. (2014). Health Confidence: A Simple, Essential Measure for Patient Engagement and Better Practice. *Family Practice Management,* 21(5): 8 – 12.

[18] Hudson, S., Rikard, R. V., Staiculescu, I. & Edison, K. (2017). Improving health and the bottom line: The case for health literacy. In Building the case for health literacy: Proceedings of a workshop. Washington, DC: The National Academies Press.

Social Isolation

Key Themes: Social Isolation

- Allow individuals to self-identify as socially isolated rather than asking the clinician to assess.

- There is interest in this topic, but no strong consensus on how to measure it; a variety of approaches were offered.

- Assess reading level of word choices for these questions.

- Allow non-response to the question.

Purpose of Collection
Stakeholders indicated that there is value in collecting this information independently for addressing as a social determinant of health, in addition to understanding social and caregiver support for purposes of care planning.

Characteristics of a Good Question
Stakeholders recommended the following:
1) Ask about isolation rather than companionship,
2) Ask from the perspective of the patient, not the clinician,
3) Allow "I choose not to answer this question" for every question,
4) Consider the reading level of "isolated" and "companionship", and
5) Consider focusing on the positive rather than on the negative.

Change Over Time?
Stakeholders advised that there may be a need for different questions at different points across the care continuum.

Alternate Questions Suggested by Listening Session Participations

Source	Item/Question
One stakeholder recommended asking in a more affirmative tone.	**How often do you have social interactions with family, friends or colleagues?**
The PRAPARE assessment tool was developed to help health centers and other providers collect the data needed to better provide and understand patient's social determinants of health.[19]	**How often do you see or talk to people that you care about and feel close to? (for example: talking to friends on the phone, visiting friends or family, going to church or club meetings)** ☐　Less than once a week;

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[19] National Association of community Health Centers. (n.d). PRAPARE. Retrieved from http://www.nachc.org/research-and-data/prapare/

	☐ 1 or 2 times a week;
	☐ 3 to 5 times a week;
	☐ 5 or more times a week;
	☐ I choose not to answer this question
Other stakeholders recommended asking more specifically about source of support.	• **Do you live alone at home?** • **Do you have someone who can help you with …**

Challenges

Some stakeholders felt that social isolation is challenging to assess. People may have interactions, but the interactions may not all be positive, and it is hard to know what number of interactions is sufficient for any given person.

One stakeholder advocated that depression is more generally assessed in the Patient Health Questionnaire-9 (PHQ9) and therefore there would not be great value in assessing social isolation elsewhere. Another stakeholder cautioned that with many people using the Patient Health Questionnaire-2 (PHQ2) as a screening tool, the full PHQ9 may not be assessed.

Transportation

> **Key Themes: Transportation**
>
> - Assess transportation needs for all health-related activity.
>
> - Assess difficulty of transportation in addition to the binary transportation available or not available.
>
> - Transportation need has a clear neighborhood-level component in addition to a person-level component.
>
> - Allow non-response to the question.

Purpose of Collection

Stakeholders had a variety of opinions as to the purpose of collecting information on transportation needs, however the majority agreed that it is a valuable data element to collect. Some stakeholders felt it wasn't for the health care provider to address, but rather it was their responsibility to help facilitate partnerships. Other stakeholders felt it was important to assess in order to recommend enabling services. All agreed that the field needs guidance on this topic, as a lot of different options are appearing in practice.

Characteristics of a Good Question

Stakeholders defined the following characteristics of a good question:
1) Assess transportation to more than simply medical appointments,

2) Consider assessing transportation to health-related activity, including grocery shopping, exercise, classes at the YMCA, etc.,
3) Allow for identification of difficulty in transportation that doesn't ultimately prevent the health-related activity. For example, if you must arrange for childcare, take three buses and walk 15 minutes, there is still transportation need even if you ultimately are able to attend the activity,
4) Allow "I choose not to answer this question" for every question, and
5) Consider the reading level of "lack of transportation".

Challenges

Stakeholders identified several challenges with transportation that could affect patient's experience:
1) Transportation service that is unreliable, late or does not arrive,
2) Neighborhoods without sufficient public transportation,
3) Accessibility to appropriate transportation for those with disability, and
4) Transportation for health-supporting activities other than direct healthcare appointments.

Additionally, some stakeholders indicated that there is still not consensus in the field that healthcare providers should have responsibility for resolving transportation needs.

Additional SDOH Data Elements Considered

> **Key Themes: Gender Identity, Sex, Sexual Orientation**
>
> - Assess gender identity first, and then sex, and then sexual orientation.
>
> - Allow for self-identification.
>
> - Allow non-response to the question.
>
> - There are still many different standards in use in the field in this area.

Four SDOH Data elements were considered as additions to standardized assessment: Gender Identity, Sex, Sexual Orientation, and Educational Assessment.

Please refer to Appendix B and C to review the question options for each topic.

The first three data elements are often considered together. We identified a few core themes across these three data elements. Stakeholders recommended that the questions be in the following order: gender identity first, sex second, and sexual orientation third.

Stakeholders were in favor of self-identification: patients should be asked to identify which category they feel represents them, and there should be enough specificity of categories that all patients feel represented. Categories can be aggregated at different levels for different purposes.

One stakeholder recommended alignment with the 2015 Office of the National Coordinator for Health Information Technology Certification Criteria (ONCHIT) which provide detailed standards for Electronic Health Record (EHR) collection of patient demographic categories, including gender identify and sexual orientation[20]. This recommendation is supported by the fact that CMS already requires adoption of these standards for the Quality Payment Program. One stakeholder noted that EHR vendors such as EPIC have begun to standardize how this information is assessed in EHRs.

Some stakeholders strongly urged consideration of gender identity, sex, and sexual orientation as basic demographic information that is essential to collect, similarly to language, ethnicity and race. They commented that focusing on other SDOH elements to the exclusion of these basic demographics might mask basic disparities.

Finally, one stakeholder highlighted key resources in the field.[21, 22,23] One important point from this body of work is that while there are still no federal (or other formal) standards for collecting these data, the sexual orientation question has come to be fairly standard, but the gender identity question landscape is very much in flux.

Gender Identity

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Key Themes: Gender Identity

- Ask for self-identification of gender identity first to frame the conversation.

- Gender identity, sex and sexual orientation are tightly connected and should be considered together.

- If this question is asked, it is important to address the answer.

- Allow non-response to the question.

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Purpose of Collection

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[20] U.S. Department of Health and Human Services Office of National Coordinator for Health Information Technology (2015). 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications. Retrieved from https://www.federalregister.gov/documents/2015/10/16/2015-25597/2015-edition-health-information-technology-health-it-certification-criteria-2015-edition-base

[21] Scott, K. & Dennis, D. (2017). Being Seen, Being Counted: Establishing Expanded Gender and Naming Declarations. Retrieved from http://www.bccat.ca/pubs/beingseen.pdf

[22] National Institutes of Health, Sexual and Gender Minorities Research Office. (2018). Methods and Measurement in Sexual & Gender Minority Health Research. Retrieved from https://dpcpsi.nih.gov/sgmro/measurement

[23] Federal Committee on Statistical Methodology. (n.d.). Interagency Reports. Retrieved from https://nces.ed.gov/FCSM/interagency_reports.asp

Stakeholders felt it is important to explain to patients why these questions are asked. A stakeholder recommended use of the "Ask Because We Care" posters and pamphlets.

Characteristics of a Good Question
Stakeholders recommended the following:
1) Allow for self-identification with a high degree of specificity, and
2) Allow "I choose not to answer this question" for every question.

Stakeholders indicated that gender identity, sex, and sexual orientation were tightly connected and should be considered together.

How is the Data Assessed?
These data could be assessed by anyone in the health care ecosystem: insurers, front desk personnel at a health system, online, or by a provider. Race and ethnicity may be easier to ask in the waiting room, where sex and gender identity may be more appropriate in the exam room. Stakeholders advocated for training and using the "Ask Because We Care" posters and pamphlets.

A study conducted by PCORI found that in an emergency department setting, self-administered assessment provides a more accurate answer than having a clinician assess these data elements. However, there is a trade-off: clinicians miss the opportunity for patient interaction.[24]

Alternate Questions Suggested by Listening Session Participations

Source	Item/Question
The University of California, San Francisco's Center of Excellence for Transgender Health recommends using a two-part question when asking patients about their gender.[25]	**1. What is your gender identity?** ☐ Male ☐ Female ☐ Transgender man / Transman ☐ Transgender woman / Transwoman ☐ Genderqueer / Gender nonconforming ☐ Additional identity (fill in) _____ ☐ Decline to state **2. What sex were you assigned at birth?** ☐ Male ☐ Female ☐ Decline to state

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[24] Patient-Centered Outcomes Research Institute (PCORI). (2018). Comparing ways to Ask Patients About Sexual Orientation and Gender Identify in the Emergency Room – The EQUALTIY Study. Retrieved from https://www.pcori.org/research-results/2013/comparing-ways-ask-patients-about-sexual-orientation-and-gender-identity

[25] Center of Excellence for Transgender Health. (2017). Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People. Retrieved from http://transhealth.ucsf.edu/pdf/Transgender-PGACG-6-17-16.pdf

Source	Item/Question
One stakeholder recommended a question based on research conducted at the Center for Excellence of Transgender Health at the University of California at San Francisco.[26, 27]	**Do you think of yourself as:** ☐ Male ☐ Female ☐ Female-to-Male (FTM)/Transgender Male/Trans Man ☐ Male-to-Female (MTF)/Transgender Female/Trans Woman ☐ Genderqueer, neither exclusively male nor female ☐ Additional gender category/(or Other), please specify: ____ ☐ Something else
Another stakeholder recommended a question based on the two-step process including one question on sex assigned at birth and another on current gender identity. This process was outlined in the GenIUSS report from The Williams Institute, a 2014 publication on best practices and is used in the California Health Interview Survey.[28,29]	**Item #1: What sex were you assigned at birth, on your original birth certificate?** ☐ Male ☐ Female **Item #2: How do you currently describe yourself? (check one)** ☐ Male ☐ Female ☐ Transgender ☐ Do not identify as female, male, or transgender
Other stakeholders recommended the following question.	**What is your current gender identity?** ☐ Male ☐ Female ☐ Transgender Male ☐ Transgender Female ☐ Not completely male or female ☐ Other: ☐ Don't want to answer

[26] Deutsch, M.B., Green, J., Keatley, J., Mayer, G.., Hastings, J., Hall, A.M. et al. (2013). Electronic medical records and the transgender patient: recommendations from the World Professional Association for Transgender Health EMR Working Group. *Journal of the American Informatics Association,* 20: 700 – 703.

[27] Deutsch, M.B. & Buchholz, D. (2015). Electronic health records and transgender patients--practical recommendations for the collection of gender identity data. *Journal of General Internal Medicine,* 30(6):843 – 847.

[28] Herman, J., Wilson, B.D. & Becker, T. (2017). Demographic and Health Characteristics of Transgender Adults in California: Findings from the 2015-2016 California Health Interview Survey. Retrieved from http://healthpolicy.ucla.edu/publications/Documents/PDF/2017/transgender-policybrief-oct2017.pdf

[29] Gender Identity in the US Surveillance Group (GenIUSS). (2014). Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys. Retrieved from https://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf

Sex

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Key Themes: Sex

- Some version of this question is commonly asked, but more precise wording would increase the usefulness of the data.

- Gender identity, sex and sexual orientation are tightly connected and should be considered together.

- Allow for self-identification.

- Allow non-response to the question.

</div>

Purpose of Collection

Stakeholders felt it is important to explain to patients why these questions are asked. A stakeholder recommended use of the "Ask Because We Care" posters and pamphlets.

Characteristics of a Good Question

Stakeholders recommended the following:
1) Allow for self-identification, and
2) Allow "I choose not to answer this question" for every question.

How is the Data Assessed?

This data could be assessed by anyone in the health care ecosystem: insurers, front desk personnel at a health system, online, or by a provider. Race and ethnicity may be easier to ask in the waiting room, where sex and gender identity may be more appropriate in the exam room. Stakeholders advocated for training and using the "Ask Because We Care" posters and pamphlets.

Alternate Questions Suggested by Listening Session Participations

Source	Item/Question
One stakeholder recommended a question based on research conducted at the Center for Excellence for Transgender health at the University of California at San Francisco. [30,31]	**What sex were you assigned at birth on your original birth certificate:** ☐ Male ☐ Female ☐ Decline to answer
Another stakeholder recommended a question based on the two-step process including one question on sex assigned at birth and another on current gender identity. This process was outlined in the GenIUSS report from The Williams Institute, a 2014 publication on best practices and is used in the California Health Interview Survey.[32,33]	**Item #1: What sex were you assigned at birth, on your original birth certificate?** ☐ Male ☐ Female **Item #2: How do you currently describe yourself? (check one)** ☐ Male ☐ Female ☐ Transgender ☐ Do not identify as female, male, or transgender

Challenges

One stakeholder noted that they ranked sex as a low priority data element given that it is already frequently collected, and that collection is unlikely to stop. However, they did acknowledge that when individuals provide this information it can be unclear if they are answering the question with the sex they were assigned at birth or with the gender they currently identify with.

[30] Deutsch, M.B., Green, J., Keatley, J., Mayer, G.., Hastings, J., Hall, A.M. et al. (2013). Electronic medical records and the transgender patient: recommendations from the World Professional Association for Transgender Health EMR Working Group. *Journal of the American Informatics Association,* 20: 700 – 703.

[31] Deutsch, M.B. & Buchholz, D. (2015). Electronic health records and transgender patients--practical recommendations for the collection of gender identity data. *Journal of General Internal Medicine,* 30(6):843 – 847.

[32] Gender Identity in the US Surveillance Group (GenIUSS). (2014). Best Practices for Asking Questions to Identify Transgender and Other Gender Minority Respondents on Population-Based Surveys. Retrieved from https://williamsinstitute.law.ucla.edu/wp-content/uploads/geniuss-report-sep-2014.pdf

[33] Herman, J., Wilson, B.D. & Becker, T. (2017). Demographic and Health Characteristics of Transgender Adults in California: Findings from the 2015-2016 California Health Interview Survey. Retrieved from http://healthpolicy.ucla.edu/publications/Documents/PDF/2017/transgender-policybrief-oct2017.pdf

Sexual Orientation

<div style="border:1px solid black; padding:10px;">

Key Themes

- Gender identity, sex and sexual orientation are tightly connected and should be considered together.

- If this question is asked, it is important to address the answer.

- Allow for self-identification.

- Allow non-response to the question.

</div>

Purpose of Collection

Stakeholders felt it is important to explain to patients why these questions are asked. A stakeholder recommended use of the "Ask Because We Care" posters and pamphlets. One stakeholder raised the concern that people can identify as straight or heterosexual, but their sexual activities may include behaviors not commonly associated with heterosexuality.

Characteristics of a Good Question

Stakeholders recommended the following:
1) Allow for self-identification
2) Allow "I choose not to answer this question" for every question

How is the Data Assessed?

This data could be collected by anyone in the health care ecosystem: insurers, front desk personnel at a health system, online, or by a provider. One participant raised the point that race and ethnicity may be easier to ask in the waiting room, where sex and gender identity may be more appropriate in a more private setting such as an exam room. Stakeholders advocated for training and using the "Ask Because We Care" posters and pamphlets.

Alternate Questions Suggested by Listening Session Participations

Source	Item/Question
A stakeholder suggested the following question. While this specific question and response set is not utilized in any government survey, the prompt "Do you think of yourself as" is used in the National Survey on Drug Use and Health (NSDUH), the Population Assessment of Tobacco and Health (PATH) and the National Survey on Family Growth (NSFG) among others. NSDUH and PATH also include similar response	**Do you think of yourself as:** ☐ Straight or heterosexual ☐ Lesbian or gay ☐ Bisexual ☐ Other: ☐ Don't know ☐ Don't want to answer

options, with variations in word choice, order of response options and neither survey include "other" as a response option.[34]	
One stakeholder recommended a question based on research conducted at the Center for Excellence for Transgender health at the University of California at San Francisco. [35, 36]	**Do you think of yourself as:** ☐ Straight or heterosexual ☐ Lesbian or gay ☐ Bisexual ☐ Something else ☐ Don't know
One stakeholder noted that under 2015 ONCHIT guidelines, sexual orientation should be coded in accordance with the version of SNOMED CT. SNOMED CT is one of a suite of designated standards for use in U.S. Federal Government systems for the electronic exchange of clinical health information and is also a required standard in interoperability specifications of the U.S. Healthcare Information Technology Standards Panel. Several SDOH Data elements were proposed as additions to standardized assessment.[37,38]	

Additional Data Element Topics Suggested by Stakeholders

Disability status was recommended by several stakeholders; mobility issues and restrictions to sight and hearing can have a significant impact on physical and mental health. Disability status was not included in our current list of SDOH elements as there are already mechanisms for CMS to assess this outside of a SDOH construct. Stakeholders clearly expressed their opinion that disability status should continue to be collected.

Several SDOH Data elements were proposed by stakeholders as additions to standardized assessment:
- Socioeconomic Position

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[34] Federal Interagency Working Group on Improving Measurement of Sexual Orientation and Gender Identity in Federal Surveys. (2016). Current Measures of Sexual Orientation and Gender Identity in Federal Surveys. Retrieved from https://nces.ed.gov/FCSM/pdf/current_measures_20160812.pdf

[35] Deutsch, M.B., Green, J., Keatley, J., Mayer, G.., Hastings, J., Hall, A.M. et al. (2013). Electronic medical records and the transgender patient: recommendations from the World Professional Association for Transgender Health EMR Working Group. *Journal of the American Informatics Association,* 20: 700 – 703.

[36] Deutsch, M.B. & Buchholz, D. (2015). Electronic health records and transgender patients--practical recommendations for the collection of gender identity data. Journal of General Internal Medicine, 30(6):843 – 847.

[37] U.S National Library of Medicine. (2018). SNOMED CT. Retrieved from https://www.nlm.nih.gov/healthit/snomedct/index.html

[38] U.S. Department of Health and Human Services Office of National Coordinator for Health Information Technology (2015). 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications. Retrieved from https://www.federalregister.gov/documents/2015/10/16/2015-25597/2015-edition-health-information-technology-health-it-certification-criteria-2015-edition-base

- o Income or disposable income, socioeconomic status (SES)
- o Financial Resource Strain
- o Food insecurity
- o Material security
- o Electricity
- o Utilities
- Social Relationships
  - o Safety
  - o Child care
  - o Adverse childhood experiences
  - o Social Support
- Racism and discrimination[39]
- Residential and Community Context
  - o Neighborhood or community trauma.
  - o Neighborhood deprivation index
  - o Number of people in household
  - o Exposure to violence
  - o Housing stability
  - o Homelessness
- Access
  - o Pharmacy Access
- Veteran status (also, US veteran vs. country of origin)
- Nativity and immigration status need to be assessed in a way that is politically safe and sensitive

Prioritization of SDOH Data Elements

In addition to reviewing the individual SDOH Data Elements, stakeholders were also asked to prioritize the elements, aside from race, ethnicity and spoken language which are currently collected, during the listening session.

Social Isolation emerged as a polarizing data element, appearing on both the highest priority and lowest priority lists. Transportation, Health Literacy, and Social Isolation were the three highest priority data elements. Sex, Educational Attainment, and Social Isolation were the lowest priority.

[39] Bichell, R.E. (2017). Scientists Start To Tease Out The Subtler Ways Racism Hurts Health. Retrieved from
https://www.npr.org/sections/health-shots/2017/11/11/562623815/scientists-start-to-tease-out-the-subtler-ways-racism-hurts-health

Exhibit 1: Stakeholder-identified Highest and Lowest Priority SDOH Data Elements for Collection
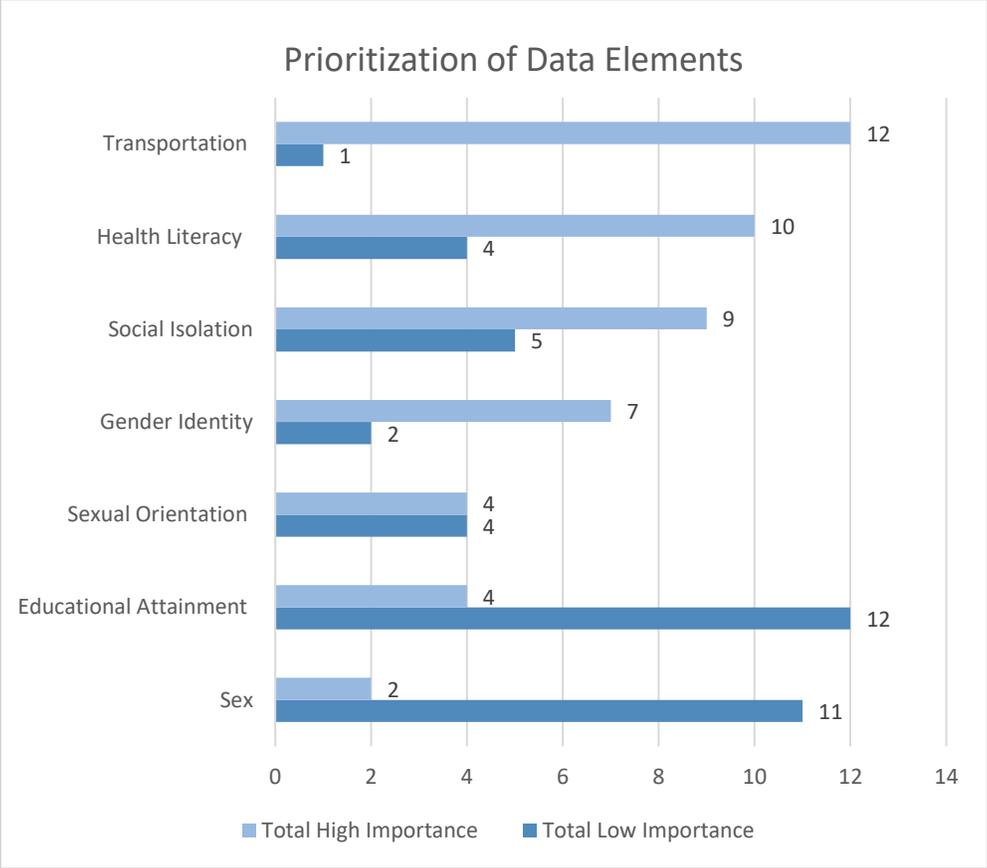
Appendix A: List of Stakeholders

Table 1: Stakeholders

Name	Title	Organization	Method	Researcher	Health System	State Agency	Advocacy
Philip Alberti, PhD	Senior Director of Health Equity Research and Policy	American Medical Colleges	WebEx				X
Chethan Bachireddy, MD, MSc	Chief Clinical Innovation Officer	Virginia Medicaid	WebEx			X	
Susannah Berhiem, MD, MHS	Director of Quality Measurement	Yale New Haven Health System Center for Outcomes, Research and Evaluation (CORE)	WebEx	X			
Akin Demehin	Director of Policy	American Hospital Association	In Person				X
Karen Dorsey, MD, PhD	Associate Research Scientist in the Department of Pediatrics	Yale University; Yale New Haven Health System Center for Outcomes, Research and Evaluation (CORE)	WebEx	X			
José Escarce, MD, PhD	Professor of Medicine; Professor of Health Policy and Management	David Geffen School of Medicine, University of California at Los	WebEx	X			

Name	Title	Organization	Method	Researcher	Health System	State Agency	Advocacy
		Angeles; UCLA Fielding School of Public Health					
Nancy Garrett, PhD	Chief Analytics Officer	Hennepin County Medical Center	WebEx		X		
Kellie Goodson, MS, CPXP	Director, HIIN, TCPI Delivery, Performance Management	Vizient	WebEx		X		
Sinsi Hernández-Cancio	Director of Health Equity	Families USA	In Person				X
Michelle Jester, MA	Deputy Director of Research	National Association of Community Health Centers	In Person				X
Tara Lagu, MD	Associate Director of the Institute of Healthcare Delivery and Population Science	Baystate Health	WebEx	X			
Pat Merryweather	Executive Director	Project Patient Care	In Person				X
Megan Morris, PhD, MPH, CCC-SLP	Assistant Professor, Director of the Qualitative Research Core, Adult and Child Consortium for Health Outcomes	Children's Hospital Colorado, University of Colorado Anschutz Medical Campus	WebEx	X			

Name	Title	Organization	Method	Researcher	Health System	State Agency	Advocacy
	Research and Delivery Science (ACCORDS)						
David Nerenz, PhD	Director of Center for Health Policy and Health Services Research,	Henry Ford Health System	WebEx		X		
Deborah Paone, DrPH, MHSA	Performance Evaluation Lead & Policy Consultant	SNP Alliance	WebEx				X
Cheryl Phillips, MD	CEO	SNP Alliance	In Person				X
Carol Scott	Ombudsman Specialist	National Long-Term Care Ombudsman Resource Center	WebEx				X
Kate Thomas	Director of Advocacy	American Association of Diabetes Educators	WebEx				X
Winston Wong, MD, MS, FAAFP	Medical Director, Community Health Director, Disparities Improvement and Quality Initiatives	Kaiser Permanente	In Person		X		
Mara Youdelman, JD, LLM	Managing Attorney (DC Office)	National Health Law Program	WebEx				X

Name	Title	Organization	Method	Researcher	Health System	State Agency	Advocacy
Amina Ferati	Senior Director of Government Relations & Policy	Asian and Pacific Islander American Health Forum	Written Comments				X
Thomas Sequist, MD, MPH	Chief Quality and Safety Officer; Professor of Medicine and Health Care Policy	Partners Healthcare System; Harvard Medical School Department of Health Care Quality	Written Comment		X		
Caroline Fitchenberg, PhD	Managing Director	SIREN (Social Interventions Research and Evaluation Network)	Written Comment	X			
Lisa Iezzoni, MD, MSc	Professor of Medicine; Director of Mongan Institute of Health Policy Center	Harvard Medical School; Massachusetts General Hospital	Could Not Attend – Suggested Replacement				
Leslie Kolb, RN, BSN, MBA	Chief Science and Practice Officer	American Association of Diabetes Educator	Could Not Attend – Suggested Replacement				
Cindy Mann, JD	Partner	Manatt Health	Could Not Attend – Suggested Replacement				

Name	Title	Organization	Method	Researcher	Health System	State Agency	Advocacy
Katherine Neuhausen, MD, MPH	Chief Medical Officer; Clinical Assistant Professor, Department of Family Medicine and Population Health	Virginia Department of Medical Assistance Services; Virginia Commonwealth University School of Medicine	Could Not Attend – Suggested Replacement				
Michelle Proser, PhD	Director of Research	National Association of Community Health Centers	Could Not Attend – Suggested Replacement				
Erika Rogan, PhD, MSc	Senior Associate Director	American Hospital Association	Could Not Attend – Suggested Replacement				
Lisa Cooper, MD, MPH, FACP	Processor of Medicine and Director of the Johns Hopkins Center to Eliminate Cardiovascular Disparities	Johns Hopkins University School of Medicine	Could Not Attend				
Marshall Chin, MD, MPH, FACP	Richard Parillo Family Professor of Healthcare Ethics	University of Chicago	Could Not Attend				
Karen DeSalvo, MD, MPH, MSc	Professor of Medicine; Senior Advisor	University of Texas, Austin Dell Medical School; Leavitt Partners	Could Not Attend				

Name	Title	Organization	Method	Researcher	Health System	State Agency	Advocacy
Jocelyn Guyer	Managing Director	Manatt Health	Could Not Attend				
Romana Hasnain-Wynia, PhD	Director of Addressing Disparities Program	Patient Centered Outcomes Research Institute	Could Not Attend				
Jeffrey Caballero	Executive Director	AAPCHO	No Response				
Aisahah Cold, MD	Chief Community Impact Officer	Atrium Health	No Response				
Daniel Dawes	Executive Director of Government Affairs and Health Policy	Morehouse School of Medicine	No Response				
David Gifford, MD, MPH	Senior Vice President, Quality and Regulatory Affairs	American Health Care Association	No Response				
Kedar Mate, MD	Chief Innovation and Education Officer; Faculty Member	Institute for Healthcare Improvement; Weill Cornell Medical College	No Response				
Pauline Kinney	Senior Director Health Care Quality Improvement	IPRO	No Response				
Thu Quach	Chief Deputy of Administration	Asian Health Services	No Response				

In advance of the listening session, those who planned to attend in-person or via WebEx received the following PowerPoint for review.

NCQA

Listening Session on Social Determinants of Health Data Elements

Thursday, December 13, 2018
8:45AM – 11:30 AM ET

Goals of Today's Listening Session

1. To obtain stakeholder feedback on social determinants of health (SDOH) data elements and question options in standardized patient assessment data.
2. To identify potential common standards and definitions that:
   a) facilitate comparability of quality measures and the exchange of standard patient information, and
   b) ensure data interoperability and high-quality care coordination and transitions in care settings.

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Agenda

Roll Call & Introductions	10 Minutes
Discussion of SDOH Data Elements and Question Options	100 Minutes
Prioritization of SDOH Data Elements	20 Minutes
Closing Remarks	10 Minutes

Introductions

CMS OMH:

Cara James, Jordan Luke, Meagan Khau, Sonya Bowen, Scott Yeager

NCQA:

Sarah Hudson Scholle, Keri Christensen, Jeni Soucie, Joy Park

Questions for Consideration

- Which SDOH data elements are most important to assess?

- Which data element question options should be considered when assessing SDOH?

- Which SDOH data elements should be the highest priorities when assessing social risk and why?

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Race, Ethnicity and Cultural Context

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Race

Option A	Option B	Option C
What is your race? (You may select one or more categories): ❑White ❑Black or African American ❑American Indian or Alaska Native ❑Asian Indian ❑Chinese ❑Filipino ❑Japanese ❑Korean ❑Vietnamese ❑Other Asian ❑Native Hawaiian ❑Guamanian or Chamorro ❑Samoan ❑Other Pacific Islander	What is your race? (One or more categories may be selected): ❑ White ❑ Black or African American ❑ American Indian or Alaska Native ❑ Asian ❑ Native Hawaiian or Other Pacific Islander	Race/Ethnicity: (Mark all that apply) ❑American Indian or Alaska Native ❑Asian ❑Black or African-American ❑Hispanic or Latino ❑Native Hawaiian or Pacific Islander ❑White

CMS

Ethnicity

Option A:	Option B:	Option C:
Are you of Hispanic, Latino/a, or Spanish origin (One or more categories may be selected): ❑No, not of Hispanic, Latino/a, or Spanish origin ❑Yes, Mexican, Mexican American, Chicano/a ❑Yes, Puerto Rican ❑Yes, Cuban ❑Yes, another Hispanic, Latino, or Spanish origin	What is your ethnicity: ❑ Hispanic or Latino/a ❑ Not Hispanic or Latino/a	Race/Ethnicity: (Check all that apply.) ❑American Indian or Alaska Native ❑Asian ❑Black or African-American ❑Hispanic or Latino ❑Native Hawaiian or Other Pacific Islander ❑White

CMS

Spoken Language

Option A:	Option B:
A. Does the patient need or want an interpreter to communicate with a doctor or health care staff? ❑ No ❑ Yes ❑ Unable to determine. B. Preferred language _____	What is your preferred spoken language? _____ [Fill In]

Gender

Sex

Option A:	Option B:	Option C:
Gender. ❑ Male ❑ Female	What sex were you assigned at birth, on your original birth certificate? ❑ Male ❑ Female ❑ Don't know ❑ Refused	What was your sex at birth? ❑ Male ❑ Female ❑ Intersex/ambiguous ❑ Don't Know ❑ Refuse to Answer

Gender Identity

Option A:	Option B:
How do you describe yourself? ❑ Male ❑ Female ❑ Transgender ❑ Refused	What is patient's/resident's current gender identity? ❑ Male ❑ Female ❑ Female-to-Male (FTM)/Transgender Male/Trans Man ❑ Male-to-Female (MTF)/Transgender Female/Trans Woman ❑ Genderqueer, neither exclusively male nor female ❑ Additional gender category, please specify:_____ ❑ Refused

Sexual Orientation

Option A:	Option B:
Which of the following best represents how you think of yourself? ❑Lesbian or Gay ❑Straight, that is, not Lesbian or Gay ❑Bisexual ❑Something else ❑I don't know the answer ❑Refused	Do you consider yourself to be: ❑ Heterosexual or "Straight" ❑ Homosexual, Gay or Lesbian ❑ Bisexual ❑ Don't Know ❑ Refuse to Answer

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Residential and Community Context

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Transportation

Option A:	Option B:
Has lack of transportation kept you from medical appointments, meetings, work, or from getting things needed for daily living? Check all that apply. ❑Yes, it has kept me from medical appointments or from getting my medications ❑Yes, it has kept me from non-medical meetings, appointments, work, or from getting things that I need ❑No ❑I choose not to answer this question	In the last 6 months, has patient/resident ever had to go without health care because they didn't have a way to get there? ❑ Yes ❑ No

Social Relationships

Social Isolation

Option A:	Option B:
How often do you feel lonely or isolated from those around you? ❑Never ❑Rarely ❑Sometimes ❑Often ❑Always	Does patient/resident often feel that they lack companionship? ❑ Yes ❑ No

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Socioeconomic Position

Educational Attainment

Option A:	Option B:
What is the highest grade or level of school that you have completed? ❏ 8th grade or less ❏ Some high school, but did not graduate ❏ High school graduate or GED ❏ Some college or 2-year degree ❏ 4-year college graduate ❏ More than a 4-year college degree	What is the highest degree or level of school the patient/resident has COMPLETED? Mark ONE box. ❏ No schooling completed ❏ Nursery school to 8th grade ❏ 9-12th grade; NO DIPLOMA ❏ High school graduate (high school diploma or the equivalent) ❏ Vocational/technical/business/trade school certificate or diploma (beyond the high school level)Some college, but no degree ❏ Associates Degree ❏ Bachelor's degree ❏ Master's degree, Professional degree beyond a bachelor's degree, or Doctorate degree

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Health Literacy

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Health Literacy

Option A:	Option B:	Option C :
How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy? ❑Never ❑Rarely ❑Sometimes ❑ Often ❑ Always	During this hospital stay, how often did doctors use medical words you did not understand? 1 ___ Never 2 ___ Sometimes 3 ___ Usually 4 ___ Always	How confident are you filling out medical forms by yourself? 1 = Not at all confident. 2 = A little bit confident. 3 = Somewhat confident. 4 = Quite confident. 5 = Extremely confident.

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Prioritization of SDOH Data Elements

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Prioritization of SDOH Data Elements

What 3 SDOH data elements do you believe should be of the *highest* priority?

- Sex
- Gender Identity
- Sexual Orientation
- Transportation
- Social Isolation
- Educational Attainment
- Health Literacy

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Prioritization of SDOH Data Elements

What 3 SDOH data elements do you believe should be of the *lowest* priority?

- Sex
- Gender Identity
- Sexual Orientation
- Transportation
- Social Isolation
- Educational Attainment
- Health Literacy

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Final Thoughts and Attendee Recommendations

Thank You!

Appendix C: Written Comment Participant Materials

In addition to the PowerPoint in Appendix B, those providing written comments were sent an additional document containing background information on the measures and the questions presented in the PowerPoint. This information was provided to in-person and WebEx participants by the moderator throughout the presentation.

Background Information

In the recent past there has been a lot of interest in the Social Determinants of Health (SDOH) but there is limited standardized collection. The Centers for Medicare & Medicaid Services, Office of Minority Health (CMS, OMH) are interested in understanding stakeholders' perspective on what SDOH-related data elements are of interest and importance.

In October 6, 2014, the Improving Medicare Post-Acute Care Transformation Act of 2014 (the IMPACT Act) was signed into law. The IMPACT Act requires the reporting of standardized patient data with regard to quality measures and standardized patient data elements. The Act intends for standardized data to improve Medicare beneficiary outcomes, which may be impacted by social determinants of health (SDOH). Additionally, ASPE is required to assess the impact of social risk factors on outcomes given the health care systems move towards value-based or alternative payment models, which tie payment to the quality and efficiency of health care delivered. Additional information on the IMPACT Act can be found here.

Topics for Discussion

CMS has identified the following SDOH data elements for discussion:

1. Race, Ethnicity and Cultural Context
   a. Race
   b. Ethnicity
   c. Spoken Language
2. Gender
   a. Sex
   b. Gender Identity
   c. Sexual Orientation
3. Residential and Community Context
   a. Transportation
4. Social Relationships
   a. Social Isolation
5. Socioeconomic Position
   a. Educational Attainment
6. Health Literacy
   a. Health Literacy

Some of these SDOH data elements are already assessed in CMS programs.

Below we provide background information on each topic. Stakeholder feedback on three key questions is requested:
   (1) Which SDOH data elements are most important to assess?

(2) Within each SDOH data elements, which question options should be prioritized for use?

(3) Which SDOH data elements should be the highest priority for use and why?

In addition to the above key questions, pertinent to every topic, we include some data element-specific questions below.

<u>Race, Ethnicity and Cultural Context</u>

1. **Race**

Option A	Option B	Option C
What is your race? (You may select one or more categories): ☐ White ☐ Black or African American ☐ American Indian or Alaska Native ☐ Asian Indian ☐ Chinese ☐ Filipino ☐ Japanese ☐ Korean ☐ Vietnamese ☐ Other Asian ☐ Native Hawaiian ☐ Guamanian or Chamorro ☐ Samoan ☐ Other Pacific Islander	**What is your race? (One or more categories may be selected):** ☐ White ☐ Black or African American ☐ American Indian or Alaska Native ☐ Asian ☐ Native Hawaiian or Other Pacific Islander	**Race/Ethnicity: (Mark all that apply)** ☐ American Indian or Alaska Native ☐ Asian ☐ Black or African-American ☐ Hispanic or Latino ☐ Native Hawaiian or Pacific Islander ☐ White

Rationale for Consideration: The United States Department of Health and Human Services (HHS) uses the level of granularity in Option A for race and ethnicity questions because it is important for documenting and tracking health disparities. Large federal surveys such as the National Health Interview Survey (NHIS), Current Population Survey (CPS) have implemented Option A. Additionally, the Medicare Health Outcomes Survey and the Medicare Current Beneficiary Survey utilize Option A for assessing race. Option B aligns with the OMB 1997 Standards as it includes at least 5 race categories and separates Hispanic or Latino/a from race (Office of Management and Budget, 1997). Option C also aligns with the OMB 1997 Standards as it includes at least 5 race categories, but the question does not separate race and ethnicity (Office of Management and Budget, 1997). Additional information on the OMB 1997 Standards can be found here.

Additional Information: Option A also closely aligns with the question related to race asked in both the ACS and the Decennial Census. However, they differ because the

recommended question included options to select "Native Hawaiian", "Guamanian or Chamorro", "Samoan" and/or "Other Pacific Islander" while ACS and the Decennial Census do not.

2. **Ethnicity**

Option A	Option B	Option C
Are you of Hispanic, Latino/a, or Spanish origin (One or more categories may be selected): ☐ No, not of Hispanic, No, not of Hispanic, Latino/a, or Spanish origin ☐ Yes, Mexican, Mexican American, Chicano/a ☐ Yes, Puerto Rican ☐ Yes, Cuban ☐ Yes, another Hispanic, Latino, or Spanish origin	**What is your ethnicity:** ☐ Hispanic or Latino/a ☐ Not Hispanic or Latino/a	**Race/Ethnicity: (Check all that apply.)** American Indian or Alaska Native Asian Black or African-American Hispanic or Latino Native Hawaiian or Other Pacific Islander White

Rationale for Consideration: HHS uses the level granularity in Option A for race and ethnicity categories because it is important for documenting and tracking health disparities. Large federal surveys such as the National Health Interview Survey (NHIS), Current Population Survey (CPS), and the ACS utilize Option A to assess ethnicity. Additionally, the Medicare Health Outcomes Survey and the Medicare Current Beneficiary Survey utilize Option A to assess ethnicity. Options A and B align with the OMB 1997 Standards as they separate being Hispanic or Latino/a from race (Office of Management and Budget, 1997). Additional information about these standards can be found here. Collection for data sets such as OASIS and MDS utilize Option C.

3. **Spoken Language**

Option A	Option B
A. **Does the patient need or want an interpreter to communicate with a doctor or health care staff?** ❏ No ❏ Yes ❏ Unable to determine B. **Preferred language** _____	**What is your preferred spoken language?** _____ [Fill In]

Rationale for Consideration: Understanding of preferred spoken language is important for facilitating effective communication about health care topics. Collection for data sets such as MDS utilize Option A. Option B is used in the Marketplace Health Insurance Application.

Additional Information: The Medicare Current Beneficiary Survey includes survey items with beneficiaries who spoke a language other than English at home to identify language status, language preference for medical care and health-related materials, and barriers to health care due to language.

Data Element Specific Questions:

What are the pros and cons of having a free text response for this question? Is there any risk of free text data inhibiting effective analysis of spoken language?

Do you consider it sufficient to assess spoken language preference rather than a more inclusive question including written language capability?

Gender

4. **Sex**

Option A	Option B	Option C
Gender. ☐ Male ☐ Female	**What sex were you assigned at birth, on your original birth certificate?** ☐ Male ☐ Female ☐ Don't know ☐ Refused	**What was your sex at birth?** Male Female Intersex/ambiguous Don't Know Refuse to Answer

Rationale for Consideration: Sex is important to capture since sex at birth may not match someone's gender identity.

Additional Information: The GenIUSS group recommended various measures and measurement approaches for identifying respondents as gender minorities in general population surveys. They recommended using the "two step" approach, which includes measures of self-reported assigned sex at birth (the sex recorded on one's original birth certificate) and gender identity at the time of the survey. When collecting data to identify transgender and other gender minority respondents, special considerations must be taken into account based on age, race/ethnicity, socioeconomic status, and intersex status. (GenIUSS, 2014). ONC's 2015 Edition Health IT Certification Criteria includes "Don't Know" as a required category in addition to male and female, in line with Options B and C. Additionally, Option B is utilized in the National Crime Victimization Survey. Option C is utilized in the National HIV Surveillance Survey.

5. **Gender Identity**

Option 1	Option 2
How would you describe yourself? ❑ Male ❑ Female ❑ Transgender ❑ Refused	**What is the patient's/resident's current gender identity?** ❑ Male ❑ Female ❑ Female-to-Male (FTM)/Transgender Male/Trans Man ❑ Male-to-Female (MTF)/Transgender Female/Trans Woman ❑ Genderqueer, neither exclusively male nor female ❑ Additional gender category, please specify:_____ ❑ Refused

Rationale for Consideration: Gender identity is important to capture since sex at birth may not match an individual's gender identity. Measuring gender identity and sexual orientation as a two-part question is a standard that has been implemented on a variety of surveys and health care settings.

Additional Information: The GenIUSS group recommended various measures and measurement approaches for identifying respondents as gender minorities in general population surveys. They recommended the "two step" approach, which includes measures of self-reported assigned sex at birth (the sex recorded on one's original birth certificate) and gender identity at the time of the survey. When collecting data to identify transgender and other gender minority respondents, special considerations must be taken into account based on age, race/ethnicity, socioeconomic status, and intersex status (GenIUSS, 2014). Option A is currently utilized by National Immunization Survey and National Crime Victimization Survey. Option B is currently utilized by the National HIV Behavioral Surveillance Survey.

6. **Sexual Orientation**

Option A	Option B
Which of the following best represents how you think of yourself? ☐ Lesbian or Gay ☐ Straight, that is, not Lesbian or Gay ☐ Bisexual ☐ Something else ☐ I don't know the answer ☐ Refused	**Do you consider yourself to be:** ☐ Heterosexual or "Straight" ☐ Homosexual, Gay or Lesbian ☐ Bisexual ☐ Don't Know ☐ Refuse to Answer

Rationale for Consideration: The Healthy People 2020 initiative (HP2020), aimed at improving the health of the nation, identified lesbian, gay, bisexual, and transgender (LGBT) Health as key health topic area for the first time. The current focus of the LGBT Health topic area is on increasing data collection on sexual and gender minority populations, although other topic areas recommend showing sexual orientation data where it is available (Centers for Medicare and Medicaid Services, 2016). Option A is currently used in National Health Interview Survey and the National Crime Victimization Survey. Option B is currently used in the National HIV Surveillance Survey.

Additional Information: Sexual minority patients in post-acute care may face social isolation, discrimination, and worse health outcomes. Sexual minorities were more likely than their sexual majority counterparts to experience substance use disorder and mental health issues (Medley et al., 2016).

Residential and Community Context

7. Transportation

Option A	Option B
Has lack of transportation kept you from medical appointments, meetings, work, or from getting things needed for daily living? Check all that apply. ☐ Yes, it has kept me from medical appointments or from getting my medications ☐ Yes, it has kept me from non-medical meetings, appointments, work, or from getting things that I need ☐ No ☐ I choose not to answer this question	**In the last 6 months, has patient/resident ever had to go without health care because they didn't have a way to get there?** ☐ Yes ☐ No

Rationale for Consideration: Lack of transportation is a key barrier to accessing care. Additional Information: Option A is currently used in The Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE), a tool created to assist providers in collecting the data needed to better understand and act on their patients' social determinants of health (NACHC, 2016). Option B is used on the Accountable Health Communities Assessment Tool (Centers for Medicare and Medicaid Services, n.d)

Social Relationships

8. Social Isolation

Option A	Option B
How often do you feel lonely or isolated from those around you? ☐ Never	**Does patient/resident often feel that they lack companionship?** ☐ Yes

☐ Rarely ☐ Sometimes ☐ Often ☐ Always	☐ No

Rational for Consideration: Social Isolation is increasingly understood to be a risk factor for poor health outcomes, especially mental health related outcomes (Yasamy et al, 2013; Connect2Affect, 2018).

Additional Information: Option A is part of UCLA's Loneliness Scale 20 Question assessment and is also used as 1 of 3 loneliness questions in the Health and Retirement Study (AARP, 2010). The Center for Medicare and Medicaid Innovation (CMMI) included Option B in the Accountable Health Communities Health Related Social Needs Screening Tool, taken from the PROMIS Item Bank on Emotional Distress. The screening tool was developed by a panel of interdisciplinary experts from around the country (Centers for Medicare and Medicaid, n.d).

<u>Socioeconomic Position</u>

9. **Educational Attainment**

Option A	Option B
What is the highest grade or level of school that you have completed? ☐ 8th grade or less ☐ Some high school, but did not graduate ☐ High school graduate or GED ☐ Some college or 2-year degree ☐ 4-year college graduate ☐ More than a 4-year college degree	**What is the highest degree or level of school the patient/resident has COMPLETED? Mark ONE box.** ☐ No schooling completed ☐ Nursery school to 8th grade ☐ 9-12th grade; NO DIPLOMA ☐ High school graduate (high school diploma or the equivalent) ☐ Vocational/technical/business/trade school certificate or diploma (beyond the high school level) Some college, but no degree ☐ Associates Degree ☐ Bachelor's degree ☐ Master's degree, Professional degree beyond a bachelor's degree, or Doctorate degree

Rational for Consideration: Educational attainment has a clear association with health outcomes. The differences in health outcomes by educational attainment has increased over the last 40 years (Goldman & Smith, 2011; Olshansky et al, 2012). Death rates are

declining for the most educated and increasing for the least educated (Jemal et al., 2008).

Education can create opportunities for better health because people with education tend to have jobs with higher wages, live in communities with resources that contribute to a healthier lifestyle (e.g. schools, food access, transportation, health services). Conversely, poor health also puts educational attainment at risk because of increased absences and difficulty concentrating. The environmental and social context can affect both health and education if it causes stress, illness, or is deficient in resources (Virginia Commonwealth University Center on Society, 2014).

Additional Information: Option A is currently utilized in the Medicare Health Outcomes Survey and the Consumer Assessment of Healthcare Providers and Systems Surveys. Option B is currently utilized by the Medicare Current Beneficiary Survey, the ACS and the Census.

Health Literacy

10. Health Literacy

Option A	Option B	Option C
How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy? ☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always	**During this hospital stay, how often did doctors use medical words you did not understand?** [1] __ Never [2] __ Sometimes [3] __ Usually [4] __ Always	**How confident are you filling out medical forms by yourself?** 1 = Not at all confident. 2 = A little bit confident. 3 = Somewhat confident. 4 = Quite confident. 5 = Extremely confident.

Rational for Consideration: Education, culture, language, and the characteristics of the health-related setting all mediate one's capacity to process health related information. Health literacy, a concept that focuses specifically on literacy concerns within the context of health, has many components including numeracy, oral literacy, print literacy, and cultural and conceptual knowledge (Institute of Medicine (US), Committee on Health Literacy, 2004).

Additional Information: There is increasing evidence supporting an association between limited reading ability, and increased utilization of health care services, decreased use of preventive health care services, and poorer health outcomes in adults with chronic disease. These findings suggest an association between reading ability and the quality and outcomes of health care and provide an impetus to identify individuals with limited reading ability for targeted interventions. (Institute of Medicine (US), Committee on Health Literacy, 2004).

Option A is the single item literacy screener (SILS) developed by Morris et al.(2006). The SILS performed reasonably well against the gold standard S-TOFHLA (Morris et al., 2006). Option B is currently included in the Supplemental Items for the CAHPS Hospital Survey: Health Literacy (AHRQ, 2017). In 2006, Wallace et al. found Option C a sufficient way to detect limited or marginal health literacy in clinic populations.

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