

Enhancing Demographic Questions and Response Choices – Summary of Draft Findings

National Virtual Convening #5

April 11, 2024

*This meeting is being recorded.



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- Allocation of customers, enrollees, sales territories, sales of any product or contracts with providers.
- Refusal to deal with any customer, class or group of customers.
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- What products or services will be offered to enrollees.
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- This is a Zoom meeting.
- Please mute yourself when you are not actively speaking.
- Please use the raise hand function to chime in with questions or comments and/or use the chat to share.
- Please share video if you are able.
- Please make sure your display name is correct on Zoom and feel free to introduce yourself via chat (name and organization).
- This session is being recorded for notetaking purposes.

For questions following the meeting, reach out to mvalu@civitasforhealth.org



Agenda

Summary of Draft Findings

- Welcome
- Introduction to Program Partners + Goals
- Timeline of Discussions to Date
- Review of Revised Script
- Review of Proposed + Revised Questions and Response Choices
 - Military Experience and Disability Status
 - SOGI, Pronouns, and Relationship Status
 - Race and Ethnicity
 - Language and Spirituality
- Next Steps and Closing

Program Partner Introductions



ABOUT CIVITAS

[Civitas Networks for Health](#) is a national collaborative comprised of over 170 member organizations working to use health information exchange, health data, and multi-stakeholder, cross-sector approaches to improve health.

Civitas educates, promotes, and influences both the private sector and policymakers on matters of interoperability, quality, coordination, health equity, and cost-effectiveness of health care. The network supports local health innovators by amplifying their voices at the national level and increasing the exchange of valuable resources, tools, and ideas.



[Civitas Networks for Health](#)



[@civitas4health](#)





Health Level Seven® International (HL7®)

- Not-for-profit
- ANSI-accredited standards development organization (SDO)
- Dedicated to providing a comprehensive framework and related standards for the exchange, integration, sharing, and retrieval of electronic health information that supports clinical practice and the management, delivery and evaluation of health services

Vision

- A world in which everyone can securely access and use the right health data when and where they need it.

Mission

- To provide standards that empower global health data interoperability.

[Education on Demand](#): HL7® training Straight from the Source

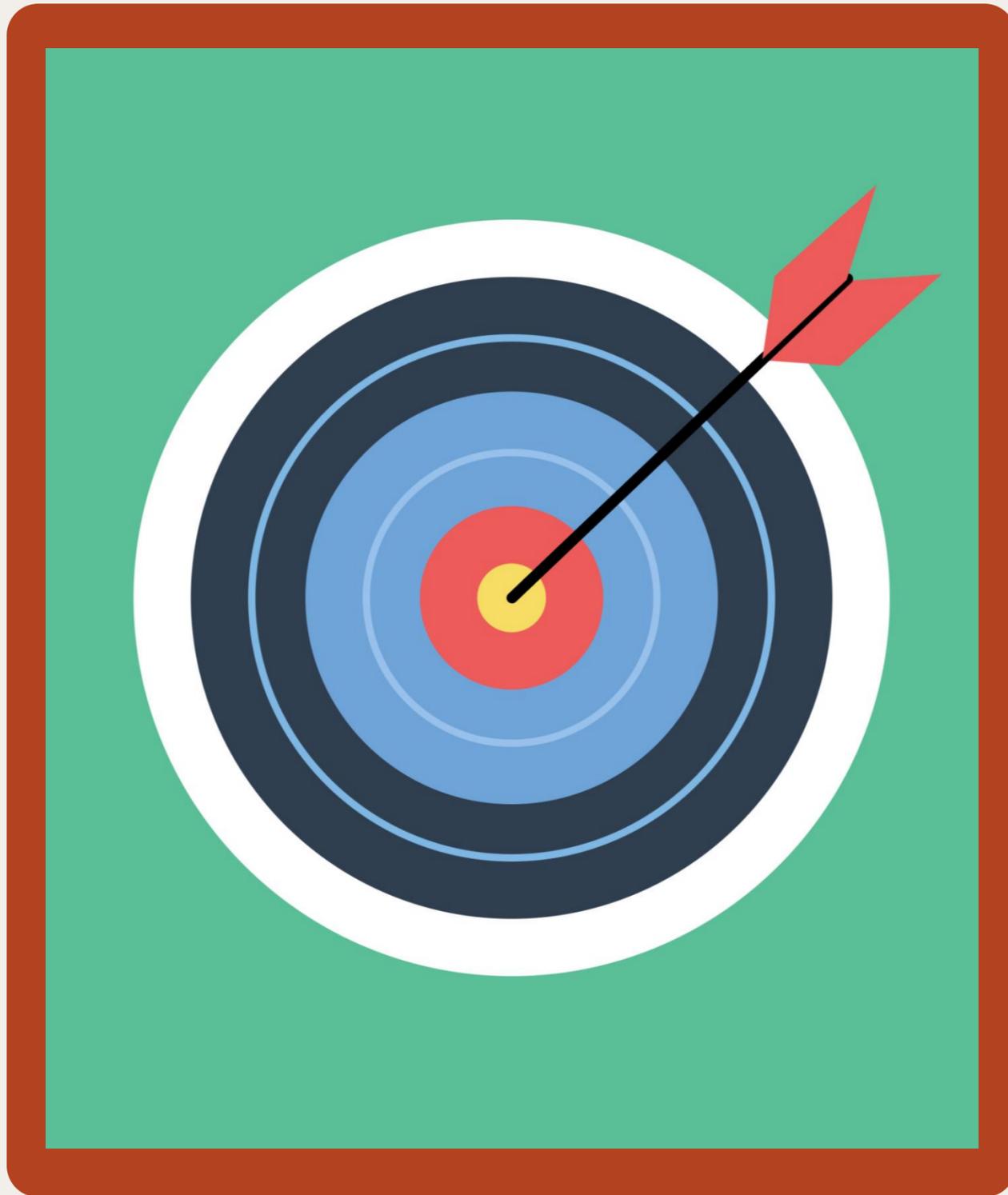


About AHIP

AHIP is the national association whose members provide health care coverage, services, and solutions to hundreds of millions of Americans every day. We are committed to market-based solutions and public-private partnerships that make health care better and coverage more affordable and accessible for everyone.

Visit www.ahip.org to learn how working together, we are Guiding Greater Health.



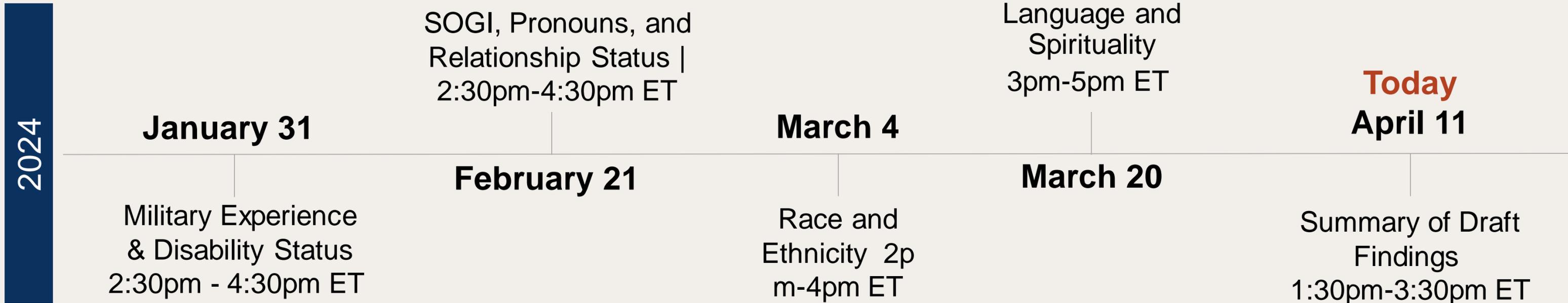


Our Goal

Modernize and enhance national demographic data content and exchange standards so that they are culturally sensitive, sufficiently granular, and aligned across stakeholders to permit the collection of accurate, complete, comparable, actionable, and interoperable data that supports better outcomes, fewer disparities, improved patient trust, and enhanced operational efficiency.

Discussions to Date

Schedule



Script on Why Collecting Demographic Data, How It Will Be Used, and How Will Honor Individual Agency

Revised Example Script:

We understand that many things in life can affect your health. We are always looking to better understand our members' needs to improve the services we can offer. Would you be willing to help us learn more about you? It should only take 5 – 10 minutes. Some of the questions are personal and you don't have to answer them if you don't want to. We protect everything that you share just like how we protect your health information. Only members of the care team and other support service staff will have access to this information. This information will be used to help inform care and services that we provide you, whether now or in the future. It will also help us make sure you're getting the care you want and need. Your decision to answer or to refuse to answer will NOT impact your ability to receive care.

[If administered in-person or orally over the phone: Do you have any questions before we get started?]

[If administered on paper form: Please let us know if you have any questions or concerns by contacting XYZ]

Explains why this data is being collected

Explains how data will be protected

Explains who data will be shared with

Explains how this data will be used

Honors individual's agency in voluntarily providing info about their identities

Proposed: Military Experience

Proposed: U.S. Veteran Status and Other Military Experience

U.S. Veteran Status

Have you or your spouse ever served or have been discharged from the armed forces of the United States? Check all that apply.

- Yes, I served in the armed forces of the United States
- Yes, my spouse served in the armed forces of the United States
- No, neither I nor my spouse served in the armed forces of the United States
- I don't know
- I choose not to respond

Optional: When did you serve? _____

Optional: Where did you serve? _____

Optional: Other Military Experience

Optional: Have you or your spouse ever served or have been discharged from the armed forces of a country other than the United States? Check all that apply

- Yes, I served in the armed forces of another country. Please specify which country: _____
- Yes, my spouse served in the armed forces of another country. Please specify which country: _____
- No, neither I nor my spouse served in the armed forces of another country
- I don't know
- I choose not to respond

Optional: When did you serve? _____

Optional: Where did you serve? _____

Revised: Military Experience

Introduction and Definitions for Military Experience

- Thank you for taking the time to complete these questions. The following questions will ask you about your experience, or an immediate family member's experience, serving in the armed forces of the United States. The armed forces of the United States include the Army, Navy, Marine Corps, Air Force, Coast Guard, and Space Force. There is also an optional question on your experience in the armed forces of another country other than the United States. This question is optional and will NOT affect your care should you choose not to answer. This information is being collected to identify potential eligibility for U.S. Veteran benefits and referrals, and to ensure you are receiving the treatment and services you need and want, now or in the future.

Revised: U.S. Veteran Status and Other Military Experience

U.S. Veteran Status

Have you ~~or your spouse~~ ever served ~~or have been discharged from~~ in the armed forces of the United States? **Check all that apply. Select one**

- Yes, I served in the armed forces of the United States
- ~~Yes, my spouse served in the armed forces of the United States~~
- No, ~~neither I nor my spouse~~ have never served in the armed forces of the United States
- I don't know
- I choose not to respond

Optional: When did you serve? (Check an option for EACH period in which you served, even if just for part of the period.)

- September 2001 or later (Post 9/11)
- August 1990 through August 2001 (including the Persian Gulf War)
- June 1975 through July 1990
- August 1964 through May 1975 (including the Vietnam War)
- February 1955 through July 1964
- June 1950 through January 1955 (including the Korean War)
- January 1947 through May 1950
- December 1941 through December 1946 (including World War II)
- November 1941 or earlier

Optional: Where did you serve? _____

Did an immediate family member who you live or lived with ever serve in the armed forces of the United States? (i.e., parent, guardian, spouse, child, sibling etc.) Select one

- Yes, an immediate family member that I live or lived with served in the armed forces of the United States
- No, no immediate family member that I live or lived with has never served in the armed forces of the United States
- I don't know
- I choose not to respond

Revised: U.S. Veteran Status and Other Military Experience

Optional: Other Military Experience

Optional: Have you ~~or your spouse~~ ever served ~~or have been discharged from in~~ the armed forces of a country other than the United States? Check all that apply

- Yes, I served in the armed forces of another country. Please specify which country: _____
- ~~Yes, my spouse served in the armed forces of another country. Please specify which country: _____~~
- No, ~~neither I nor my spouse have never~~ served in the armed forces of another country
- I don't know
- I choose not to respond

Optional: When did you serve? _____

Optional: Where did you serve? _____

Proposed: Disability Status

Proposed: Disability Status

Disability Status

Do you have difficulty with any of the following? Check all that apply.

- Hearing
- Seeing (even when wearing glasses)
- Concentrating, remembering, or making decisions because of a physical or mental health condition
- Walking or climbing stairs
- Dressing or bathing
- Doing errands alone such as shopping or visiting a doctor's office because of a physical or mental condition
- Communicating, understanding, or being understood using your usual language
- Other difficulties when doing activities throughout your day (please describe)
- I choose not to respond

Combined questionnaires from ACA Sec. 4302 (which collapses NHIS survey questions) and the Washington Group survey questions which are based on the International Classification of Functionalities model. Adapted for simplification and patient-centeredness.

Revised: Disability Status

Introduction and Definitions for Disability Status

- Thank you for taking the time to complete these questions. The following question will ask if you have difficulty doing certain things or completing certain tasks because of a physical or mental health condition that greatly limits your daily activities. This question will help to inform how your care team and others care for you and communicate with you about your care. It will also ensure that you receive the care and services you want and need, now or in the future. We recognize that this is a personal question and there is an option to not respond. Your care will NOT be affected in any way should you choose not to respond.

Revised: Disability Status

Disability Status

Because of a physical or mental health condition, do you have difficulty with any of the following?
Check all that apply.

- Hearing
- Seeing (even when wearing glasses)
- Concentrating, remembering, or making decisions ~~because of a physical or mental health condition~~
- Walking or climbing stairs
- Dressing or bathing
- **Cooking for oneself**
- **Feeding oneself**
- **Using the bathroom**
- Doing errands alone such as shopping or visiting a doctor's office ~~because of a physical or mental condition~~
- Communicating ~~understanding~~, or being understood using your usual language
- **Understanding when someone speaks in your usual language**
- Other difficulties when doing activities throughout your day (please describe)
- I choose not to respond

Proposed: Sexual Orientation, Sex, Gender

Proposed: Sexual Orientation

Sexual Orientation

Do you think of yourself as (check all that apply):

- Gay or lesbian (predominantly attracted to the same gender as your own)
- Straight or heterosexual (predominantly attracted to gender different from your own)
- Bisexual (attracted to same gender as your own and gender different from your own)
- Pansexual (attracted to any gender)
- Asexual (little or no attraction to any gender)
- Something else, please specify: _____
- I don't know
- I choose not to respond

Adapted from Fenway Health's National LGBTQIA+ Education Center. Largely aligns with USCDI. Some state BRFSS have similar questions as of 2018 and 2016 (CA and GA) but others do not (ND).

Proposed: Sex and Gender

Sex

What sex were you assigned at birth on your original birth certificate? (Select one)

- Male, Man
- Female, Woman
- Intersex
- I choose not to respond

Optional: What is your legal sex? (Select one)

- Male, Man
- Female, Woman
- Additional sex category, please specify: _____
- I choose not to respond

While we recognize a number of genders, many legal entities unfortunately do not yet. Please be aware that the name & sex you have previously listed on your insurance must be used on documents pertaining to insurance, billing, & correspondence. If your preferred name and pronouns are different from these, please let us know so that we can update our system.

Gender

What is your gender? (Select one):

- Male, Man
- Female, Woman
- Transgender Male, Trans Man
- Transgender Female, Trans Woman
- Non-Binary, neither exclusively male nor female
- Additional gender category, please specify:
- I don't know
- I choose not to respond

Adapted from USCDI v3.

Revised: Sexual Orientation, Sex, Gender

Introduction and Definitions for Sexual Orientation, Sex, and Gender

- Thank you for taking the time to answer these questions. The following questions will ask you how you think of yourself regarding your sexual orientation, sex, and gender. Sexual orientation means which gender you have an emotional, romantic or sexual attraction to. Sex means the sex you were assigned at birth by a doctor or midwife, based on external body parts. Gender is one's own sense of self and their gender, whether that is man, woman, neither or both. Your gender may differ from your sex assigned at birth. We recognize that these are personal questions and responses may change overtime. Your care will NOT be affected in any way should you choose not to respond.

Revised: Sexual Orientation

Sexual Orientation

At this time, do you think of yourself as (~~select one check all that apply~~):

- Gay or lesbian (~~predominantly~~ attracted to the same gender as your own)
- Straight or heterosexual (~~predominantly~~ attracted to gender different from your own)
- Bisexual (attracted to same gender as your own and gender different from your own)
- Pansexual (attracted to any gender)
- Asexual (little or no attraction to any gender)
- Something else, please specify: _____
- I don't know
- I choose not to respond **at this time**

Revised: Sex and Gender

Sex

What sex were you assigned at birth on your original birth certificate? (Sex assigned at birth is the sex (male, female or intersex) that a doctor or midwife uses to describe a child at birth based on their external body parts. Select one)

- Male, Man
- Female, Woman
- Intersex
- I choose not to respond at this time
- I do not know

~~Optional: What is your legal sex? (Select one)~~

- ~~• Male, Man~~
- ~~• Female, Woman~~
- ~~• Additional sex category, please specify: _____~~
- ~~• I choose not to respond~~

While we recognize a number of genders, many legal entities unfortunately do not yet. Please be aware that the name & sex you have previously listed on your insurance must be used on documents pertaining to insurance, billing, & correspondence. If your preferred name and pronouns are different from these, please let us know so that we can update our system.

Gender

What is your gender? (Select one):

- Male, Man
- Female, Woman
- Transgender Male, Trans Man
- Transgender Female, Trans Woman
- Non-Binary, neither exclusively male nor female
- Gender Fluid (non-fixed gender identity that may change overtime)
- Two Spirit (a person who identifies as having both a masculine and feminine spirit, traditionally used in Native American/Alaskan Native communities)
- Additional gender category, please specify:
- I don't know
- I choose not to respond at this time

Proposed: Pronouns

Proposed Optional: Pronouns

Pronouns

We would like to be respectful. What pronouns do you use to identify yourself?
(Select all that apply)

- He, him, his
- She, her, hers
- They, them, theirs
- Ze, hir, hers
- Ze, zir, zirs
- Additional pronouns, please specify: _____
- I don't know
- I choose not to respond

Adapted from Fenway Health's National LGBTQIA+ Education Center

Revised: Pronouns

Introduction and Definitions for Pronouns

- Thank you for taking the time to answer these questions. To make sure we are communicating with you respectfully, the following question will ask you to choose or write-in your pronouns. Pronouns are how you identify yourself apart from your name and how someone refers to you in conversation. We recognize that this is a personal question, and responses may change overtime. This is an optional question, and your care will NOT be affected in any way should you choose not to respond.

Revised Optional: Pronouns

Pronouns

We would like to be respectful. What pronouns do you use to identify yourself? (Select all that apply)

- He, him, his (for someone who might identify as a male)
- She, her, hers (for someone who might identify as a female)
- They, them, theirs (non-binary, for someone who might identify as neither male or female, can be used in singular form)
- Ze, hir, hirs (non-binary, noun-self pronoun, often used by people who do not identify as either male nor female)
- Ze, zir, zirs (non-binary, noun-self pronoun, often used by people who do not identify as either male nor female)
- ~~Additional pronouns,~~ Something else, please specify: _____
- Use my name
- I don't know
- I choose not to respond at this time

Proposed: Relationship Status

Proposed Optional: Relationship Status

Relationship Status

What is your relationship status? (Select all that apply)

- Married
- In a registered domestic partnership
- Partnered, but not registered as a legal domestic partnership
- Single
- Divorced
- Separated
- Widowed
- Other (please specify): _____
- I don't know
- I choose not to respond

Adapted from Fenway Health's National LBTQIA+ Education Center

Revised: Relationship Status

Introduction and Definitions for Relationship Status

- Thank you for taking the time to answer these questions. To make sure we have the information we need to identify potential health insurance eligibility and are considering lifestyle factors that can impact your health, the following question will ask you to identify your relationship status. This can include legal agreements with another person (marriage or a registered partnership) or relationships that are not legally recognized (in a committed relationship or dating). We recognize that this is a personal question, and responses may change overtime. This is an optional question, and your care will NOT be affected in any way should you choose not to respond.

Revised Optional: Relationship Status

Relationship Status

What is your relationship status? (Select all that apply)

- Married
- In a registered domestic partnership
- ~~Partnered In a committed relationship but not registered as a legal domestic partnership~~
- Single
- Divorced
- Separated
- Widowed
- Dating
- In a committed polygamous relationship with multiple people (or being in an intimate relationship with more than one person at a time)
- Other (please specify): _____
- I don't know
- I choose not to respond

Proposed: Race and Ethnicity

Proposed Ethnicity: Higher-Level and More Granular-Level

1. Do you identify as Hispanic or Latino/a/e? (select one)

- I am Hispanic or Latino/a/e
- I am not Hispanic or Latino/a/e
- I don't know
- I choose not to respond

OPTIONAL: 1A. If you are Hispanic or Latino/a/e, what is your background? If you are not Hispanic or Latino/a/e, please skip this question. (Select from the list below or write down your response if your background is not listed)

- | | | |
|---|--|---|
| <ul style="list-style-type: none">• Argentinian• Bolivian• Brazilian• Chilean• Colombian• Costa Rican• Cuban | <ul style="list-style-type: none">• Dominican• Ecuadorean• Guatemalan• Honduran• Mexican or Chicano/a• Nicaraguan• Panamanian | <ul style="list-style-type: none">• Peruvian• Puerto Rican• Salvadorian• Venezuelan• Other (please specify): _____ |
|---|--|---|

Responses in **PURPLE** indicate those that were recommended by HHS in the ACA in 2011 and are also in the 2020 U.S. Census.

Proposed: Race at Higher-Level

2. Please tell us which race(s) you identify with: *(select all that apply)*

- I only identify as Hispanic or Latino/a/e
- Asian
- Black or African
- Middle Eastern or North African
- Native American, Alaska Native, or Indigenous
- Native Hawaiian or Pacific Islander
- White or European
- I don't know
- I choose not to respond

Responses in **GREEN** indicate differentiations from existing race questions in OMB, CMS, U.S. Census, and ACA Recommendations.

Proposed: Race at More Granular-Level

OPTIONAL: 2A. Please tell us your background. Check all that apply.
(If your background is not listed, please let us know by writing on the blank line).

Black or African	Asian	Native Hawaiian or Pacific Islander	White or European	Middle Eastern or North African	Native American, Alaska Native, or Indigenous
<ul style="list-style-type: none"> • African American • Angolan • Barbadian • Cabo Verdean • Congolese • Dominican • Ethiopian • Ghanaian • Haitian • Jamaican • Kenyan • Liberian • Nigerian • Somali • Sudanese • Trinidadian • Other: _____ 	<ul style="list-style-type: none"> • Afghan • Bangladeshi • Burmese • Cambodian • Chinese • Filipino • Hmong • Indian • Indonesian • Japanese • Korean • Lao • Nepalese • Pakistani • Sri Lankan • Thai • Vietnamese • Other: _____ 	<ul style="list-style-type: none"> • Chuukese • Chamorro • Fijian • French • Polynesian • Marshallese • Native Hawaiian • Palauan • Papua New Guinean • Samoan • Tongan • Yap • Other: _____ 	<ul style="list-style-type: none"> • Danish • Dutch • English • French • German • Greek • Irish • Italian • Lithuanian • Norwegian • Polish • Portuguese • Russian • Scottish • Spanish • Swedish • Ukrainian • Welsh • Other: _____ 	<ul style="list-style-type: none"> • Egyptian • Emirati • Iraqi • Iranian • Jordanian • Kurdish • Kuwaiti • Lebanese • Libyan • Palestinian • Saudi • Syrian • Yemeni • Other: _____ 	<ul style="list-style-type: none"> • Apache • Athabascan • Aztec • Blackfeet • Cherokee • Cheyenne • Chippewa • Choctaw • Comanche • Haudenosaunee • Inupiat • Lumbee • Lingít (Tlingit) • Maya • Muscogee (Creek) • Navajo • Osage • Sioux • Taino • Yu'pik Eskimo • Other: _____

Option 2B. Cultural Identity: Are there things about your culture or cultural identity that you would like us to know?

Revised: Race and Ethnicity

Introduction and Definitions for Race and Ethnicity

- Thank you for taking the time to answer these questions. The following questions will ask you to identify your race and/or ethnicity. Race is one way our society groups people together. Categories of race have been made up over time. These categories are often based on things we can see, like a person's skin color, but do not indicate real biological differences. Ethnicity is based on how we identify with other people when we share certain experiences or backgrounds with them. This may include things like language, history, religion, or culture. There is also an optional question that will ask you about your specific race and/or ethnicity. We recognize that these are personal questions and there is an option to not respond. Your care will NOT be affected in any way should you choose not to respond.

~~Revised Ethnicity: Higher-Level and More Granular-Level~~

~~1. Do you identify as Hispanic or Latino/a/e? (select one)~~

- ~~• I am Hispanic or Latino/a/e~~
- ~~• I am not Hispanic or Latino/a/e~~
- ~~• I don't know~~
- ~~• I choose not to respond~~

Revised: Race and Ethnicity

1. Please tell us which race(s) **and/or ethnicities** you identify with:
(select all that apply)

- Asian
- Black, African, **or African American**
- ~~I only identify as~~ Hispanic or Latino/a/e
- Middle Eastern or North African
- Native American, Alaska Native, or Indigenous
- Native Hawaiian or Pacific Islander
- White or European
- I don't know
- I choose not to respond

~~Revised: Ethnicity at More Granular Level~~

~~OPTIONAL: 1A. If you are Hispanic or Latino/a/e, what is your background? If you are not Hispanic or Latino/a/e, please skip this question. (Select from the list below or write down your response if your background is not listed)~~

- ~~• Argentinian~~
- ~~• Brazilian~~
- ~~• Chilean~~
- ~~• Colombian~~
- ~~• Costa Rican~~
- ~~• Cuban~~
- ~~• Dominican~~

- ~~• Ecuadorian~~
- ~~• Guatemalan~~
- ~~• Honduran~~
- ~~• Mexican or Chicano/a~~
- ~~• Nicaraguan~~
- ~~• Panamanian~~

- ~~• Peruvian~~
- ~~• Puerto Rican~~
- ~~• Salvadorian~~
- ~~• Venezuelan~~
- ~~• Other (please specify): _____~~

Revised: Race and Ethnicity at More Granular-Level

OPTIONAL: 1B. Please tell us your background. Check all that apply.

(If your background is not listed, please let us know by writing on the blank line).

Asian	Black or African	Hispanic or Latino	Middle Eastern or North African	Native Hawaiian or Pacific Islander	Native American, Alaska Native, or Indigenous	White or European
<ul style="list-style-type: none"> Afghan Bangladeshi Burmese Cambodian Chinese Filipino Hmong Indian Indonesian Japanese Korean Lao Nepalese Pakistani Sri Lankan Thai Vietnamese Other: _____ 	<ul style="list-style-type: none"> African American Angolan Barbadian Cabo Verdean Congolese Dominican Ethiopian Ghanaian Haitian Jamaican Kenyan Liberian Nigerian Somali Sudanese Trinidadian Other: _____ 	<ul style="list-style-type: none"> Argentinian Brazilian Chilean Colombian Costa Rican Cuban Dominican Ecuadorian Guatemalan Honduran Mexican or Chicano/a Nicaraguan Panamanian Peruvian Puerto Rican Salvadorian Venezuelan Other: _____ 	<ul style="list-style-type: none"> Egyptian Emirati Iraqi Iranian Israeli Jewish (Mizrahi) Jordanian Kurdish Kuwaiti Lebanese Libyan Palestinian Saudi Syrian Yemeni Other: _____ 	<ul style="list-style-type: none"> Chuukese Chamorro Fijian French Polynesian Marshallese Native Hawaiian Palauan Papua New Guinean Samoan Tongan Yap Other: _____ 	<ul style="list-style-type: none"> Apache Athabascan Aztec Blackfeet Cherokee Cheyenne Chippewa Choctaw Comanche Haudenosaunee Inupiat Lumbee Lingít (Tlingit) Mayan Muscogee (Creek) Navajo Osage Sioux Taino Yu'pik Eskimo Other: _____ 	<ul style="list-style-type: none"> Danish Dutch English French German Greek Irish Italian Jewish (Ashkenazi) Jewish (Sephardic) Lithuanian Norwegian Polish Portuguese Russian Scottish Spanish Swedish Ukrainian Welsh Other: _____

■ Listed in OMB's required detailed categories.
 ■ Listed in OMB's required detailed categories as write-in options.
 ■ Additions based on participant feedback.

• I don't know

Option 2B. Cultural Identity: Are there things about your culture or cultural identity that you would like us to know?

Proposed: Preferred Language

Language Preference: Speaking

Speaking: What language do you feel most comfortable speaking about your health care? This can include a specific language and/or different types of sign language. (Granular options can be customized to local level)

- | | | | | | |
|--|---|---|---|--|---|
| <ul style="list-style-type: none">• Dutch• English• French• German• Greek• Italian• Pennsylvania Dutch (Pennsylvania German)• Polish• Portuguese• Russian• Spanish• Yiddish | <ul style="list-style-type: none">• Bengali• Burmese• Cantonese• Dari• Hindi• Hmong• Japanese• Karen• Karenni• Khmer• Korean• Lao• Mandarin• Pashto• Tagalog• Vietnamese | <ul style="list-style-type: none">• Amharic• Arabic• Farsi• Haitian Creole• Hebrew• Somali• Swahili | <ul style="list-style-type: none">• Chuukese• Hawaiian• Marshallese• Samoan• Tongan | <ul style="list-style-type: none">• Cherokee• Crow• Dakota• Inupiaq• Lakota (Sioux)• Muscogee• Navajo (Diné)• Ojibwe• O'odham• Western Apache• Yu'pik• Zuni | <ul style="list-style-type: none">• American Sign Language• Other Sign Language (please specify): ____• Other Language (please specify): ____• I do not know• I choose not to respond |
|--|---|---|---|--|---|

Language Preference: Reading and Writing

Reading/Writing: What language do you prefer to use when reading materials related to your health care? This can include a specific language, Braille, large print, or digital documents that can be spoken out loud. (Granular options can be customized to local level)

- | | | | | | |
|--|---|---|---|--|---|
| <ul style="list-style-type: none">• Dutch• English• French• German• Greek• Italian• Pennsylvania Dutch (Pennsylvania German)• Polish• Portuguese• Russian• Spanish• Yiddish | <ul style="list-style-type: none">• Bengali• Burmese• Cantonese• Dari• Hindi• Hmong• Japanese• Karen• Karenni• Khmer• Korean• Lao• Mandarin• Pashto• Tagalog• Vietnamese | <ul style="list-style-type: none">• Amharic• Arabic• Farsi• Haitian Creole• Hebrew• Somali• Swahili | <ul style="list-style-type: none">• Chuukese• Hawaiian• Marshallese• Samoan• Tongan | <ul style="list-style-type: none">• Cherokee• Crow• Dakota• Inupiaq• Lakota (Sioux)• Muscogee• Navajo (Diné)• Ojibwe• O'odham• Western Apache• Yu'pik• Zuni | <ul style="list-style-type: none">• Braille• Large Print• Digital Documents that Can Be Spoken Out Loud• Other Language (please specify): ____• I do not know• I choose not to respond |
|--|---|---|---|--|---|

Language Preference: Setting Specifics

In-Person at Care Setting:

- If an interpreter in your preferred language was available right now, would you choose to use one for your health care visit?
 - Yes
 - No
 - I do not know
 - I choose not to respond
- Are you comfortable using an interpreter if they are only available through:
 - Telephone: Yes or No
 - Video: Yes or No
 - In-person: Yes or No
 - I do not know
 - I choose not to respond

Paper Form:

- Outreach Preferences: How would you prefer to be contacted with information related to your health care? Check all that apply.
 - Phone Call
 - Text Message
 - Email
 - Mailed Letter
 - I do not know
 - I choose not to respond

Revised: Preferred Language

Introduction and Definitions for Language

- Thank you for taking the time to answer these questions. To ensure we are doing our best to communicate in a way that is understandable, and/or connect you to available translation services, the following questions will ask you to identify which language or languages you feel most comfortable speaking, reading, and writing in when it comes to your health care. The languages listed as response options are mostly based on a 2019 American Community Survey Report that identified more common languages used in the United States, other than English. If you do not see your preferred language, there is a space to write in a response. This question is meant to inform and improve our service responses now, or in the future.

Language Preference: Speaking

Speaking: What language do you feel most comfortable speaking about your health care? This can include a specific language and/or different types of sign language. (Granular options can be customized to local level. **Select all that apply.**)

- | | | | | | |
|--|---|---|---|--|---|
| <ul style="list-style-type: none">• Dutch• English• French• German• Greek• Italian• Pennsylvania Dutch (Pennsylvania German)• Polish• Portuguese• Russian• Spanish• Yiddish | <ul style="list-style-type: none">• Bengali• Burmese• Cantonese• Dari• Hindi• Hmong• Japanese• Karen• Karenni• Khmer• Korean• Lao• Mandarin• Pashto• Tagalog• Thai• Vietnamese | <ul style="list-style-type: none">• Amharic• Arabic• Farsi• Haitian Creole• Hebrew• Somali• Swahili | <ul style="list-style-type: none">• Chuukese• Hawaiian• Marshallese• Samoan• Tongan | <ul style="list-style-type: none">• Cherokee• Crow• Dakota• Inupiaq• Lakota (Sioux)• Muscogee• Navajo (Diné)• Ojibwe• O'odham• Western Apache• Yu'pik• Zuni | <ul style="list-style-type: none">• American Sign Language• Other Sign Language (please specify): ____• Other Language (please specify): ____• I do not know• I choose not to respond |
|--|---|---|---|--|---|

Language Preference: Reading and Writing

Reading/Writing: What language do you prefer to use when reading materials related to your health care? This can include a specific language, Braille, large print, or digital documents that can be spoken out loud. (Granular options can be customized to local level. **Select all that apply.**)

- | | | | | | |
|--|---|---|---|--|---|
| <ul style="list-style-type: none">• Dutch• English• French• German• Greek• Italian• Pennsylvania Dutch (Pennsylvania German)• Polish• Portuguese• Russian• Spanish• Yiddish | <ul style="list-style-type: none">• Bengali• Burmese• Cantonese• Dari• Hindi• Hmong• Japanese• Karen• Karenni• Khmer• Korean• Lao• Mandarin• Pashto• Tagalog• Thai• Vietnamese | <ul style="list-style-type: none">• Amharic• Arabic• Farsi• Haitian Creole• Hebrew• Somali• Swahili | <ul style="list-style-type: none">• Chuukese• Hawaiian• Marshallese• Samoan• Tongan | <ul style="list-style-type: none">• Cherokee• Crow• Dakota• Inupiaq• Lakota (Sioux)• Muscogee• Navajo (Diné)• Ojibwe• O'odham• Western Apache• Yu'pik• Zuni | <ul style="list-style-type: none">• Braille• Large Print• Digital Documents that Can Be Spoken Out Loud• Other Language (please specify): ____• I do not know• I choose not to respond |
|--|---|---|---|--|---|

Language Preference: Setting Specifics

In-Person at Care Setting:

- If an interpreter in your preferred language was available right now, would you choose to use one for your health care visit?
 - Yes
 - No
 - I do not know
 - I choose not to respond
- Are you comfortable using an interpreter if they are only available through:
 - Telephone: Yes or No
 - Video: Yes or No
 - In-person: Yes or No
 - I do not know
 - I choose not to respond

Paper Form: Outreach Preferences:

- ~~Outreach Preferences:~~ How would you prefer to be contacted with information related to your health care? Check all that apply.
 - Phone Call
 - Text Message
 - Email
 - Mailed Letter
 - I do not know
 - I choose not to respond

Proposed: Spiritual Beliefs

Optional: Mind Body Spirit Questions

- **Is religion, spirituality, or a belief system a key part of your health or how you like to receive health care?**
 - Yes
 - No
 - I do not know
 - I choose not to respond
- **Is there anything you would like us to know about your religion, spirituality, or belief system to better inform your health care?**

Optional: Spiritual Beliefs

Spiritual Beliefs

What is your current religion, spirituality, or belief system, if any?

- Christianity: Roman Catholicism
- Christianity: Protestant (such as Baptist, Methodist, Presbyterian, Episcopalian, Lutheran, Pentecostal, Nondenominational, Reformed)
- Judaism (Jewish)
- Islam, Nation of Islam (Muslim)
- Buddhism
- Hinduism
- Mormon (Church of Jesus Christ of Latterday Saints/LDS)
- Orthodox (Greek, Russian, or other orthodox church)
- Jehovah's Witnesses
- Unitarian Universalist
- Sikh
- Taoism
- Confucianism
- Baha'l
- Rastafarianism
- Zoroastrianism
- Church of Scientology
- Vodou
- Wicca
- Other pagan beliefs (please specify: ____)
- Ancestral, indigenous, or tribal beliefs (please specify)
- Other New Thought beliefs (please specify:_____)
- Atheist (do not believe in God)
- Agnostic (not sure if there is a God)
- Spiritual but not religious
- Nothing in particular
- Something else (please specify: _____)
- I do not know
- I choose not to respond

Revised: Spiritual Beliefs

Introduction and Definitions for Spirituality

- Thank you for taking the time to answer these questions. To make sure we are providing you with care that is appropriate and accommodating to your lifestyle and values, the following questions will ask you about any beliefs we should know about before we provide care. These beliefs can include religious, health, cultural or any others you feel are important to your care experience. There is also an optional question that will ask you to identify a specific religion, spirituality, or belief system you follow. These questions are meant to inform any services we provide you now or in the future. We recognize that these are personal questions and there is an option to not respond. Your care will NOT be affected in any way should you choose not to respond.

~~Optional: Mind Body Spirit Questions~~

- ~~• Is religion, spirituality, or a belief system a key part of your health or how you like to receive health care?~~
 - ~~○ Yes~~
 - ~~○ No~~
 - ~~○ I do not know~~
 - ~~○ I choose not to respond~~
- ~~• Is there anything you would like us to know about your religion, spirituality, or belief system to better inform your health care?~~

PRAPARE Question - Revised

Which of the following should we know about you before we provide care? Select all that apply.

- Health beliefs
- Cultural preferences
- Religious beliefs
- Spiritual beliefs
- Specific diet followed (e.g., Halal, Kosher, Pescatarian, Vegetarian, Vegan)
- Caregiving status
- Other (please write):
- I choose not to respond

<https://prapare.org/>

Revised Optional: Religion and/or Spiritual Beliefs

Spiritual Beliefs

What is your current religion, spirituality, or belief system, if any?

- ~~Christianity~~: Roman Catholicism
- ~~Christianity~~: Protestant (~~such as Baptist, Methodist, Presbyterian, Episcopalian, Lutheran, Pentecostal, Nondenominational, Reformed~~)
- Anglican
- Baptist
- Methodist
- Presbyterian
- Episcopalian
- Evangelical Christian
- Lutheran
- Pentecostal
- Christian Nondenominational
- Christian Reformed
- Judaism (Jewish)
- **Orthodox Judaism**
- Islam, Nation of Islam (Muslim)
- Buddhism
- Hinduism
- Mormon (Church of Jesus Christ of Latterday Saints/LDS)
- **Seventh Day Adventist**
- ~~Orthodox (Greek, Russian, or other orthodox church)~~
- Greek Orthodox
- Russian Orthodox
- Coptic Christian
- Jehovah's Witnesses
- Unitarian Universalist
- Sikh
- Taoism
- Confucianism
- Baha'l
- Rastafarianism
- Zoroastrianism
- Church of Scientology
- **Humanism**
- Vodou
- Wicca
- Other pagan beliefs (please specify: _____)
- Ancestral, indigenous, or tribal beliefs (please specify: _____)
- Other New Thought beliefs (please specify: _____)
- Atheist (do not believe in God)
- Agnostic (not sure if there is a God)
- Spiritual but not religious
- Nothing in particular
- Something else (please specify: _____)
- I do not know
- I choose not to respond

Next Steps

Deliverables

- Whitepaper – Pending Publication, Anticipated June 2024
- Crosswalk of HL7 Standards

Phase 2 – Build Consensus on Technical Standards

- Cognitive testing of questions and response choices with the Patient Advocate Foundation.
- Utilize HL7 standards development and consensus building process.
- Explore the development and publication of new FHIR Questionnaire representing the recommended data elements developed in Phase 1.
- Explore creation of corresponding HL7 Implementation Guides (IGs).

Next Steps

Schedule

2024	January 31				
	Military Experience & Disability Status 2:30pm - 4:30pm ET				
		February 21		March 20	
		SOGI, Pronouns, and Relationship Status 2:30pm-4:30pm ET		Language and Spirituality 3pm-5pm ET	
			March 4		April 11
			Race and Ethnicity 2p m-4pm ET		Summary of Draft Findings 1:30pm-3:30pm ET
					Date TBD
					Coming Up! Final Presentation of Findings 1:30pm-3pm ET