

# Modernizing Demographic Data Standards to Advance Health Equity



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*Wednesday, October 16, 2024*



# Overview, Rationale, and Goals of This Work

# Challenges with Demographic Data Collection

## Inaccurate, Incomplete Data

- Responses to surveys low
- Answers are often missing, or individuals chose “Other,” or “Unknown”
- Not all necessary domains are covered

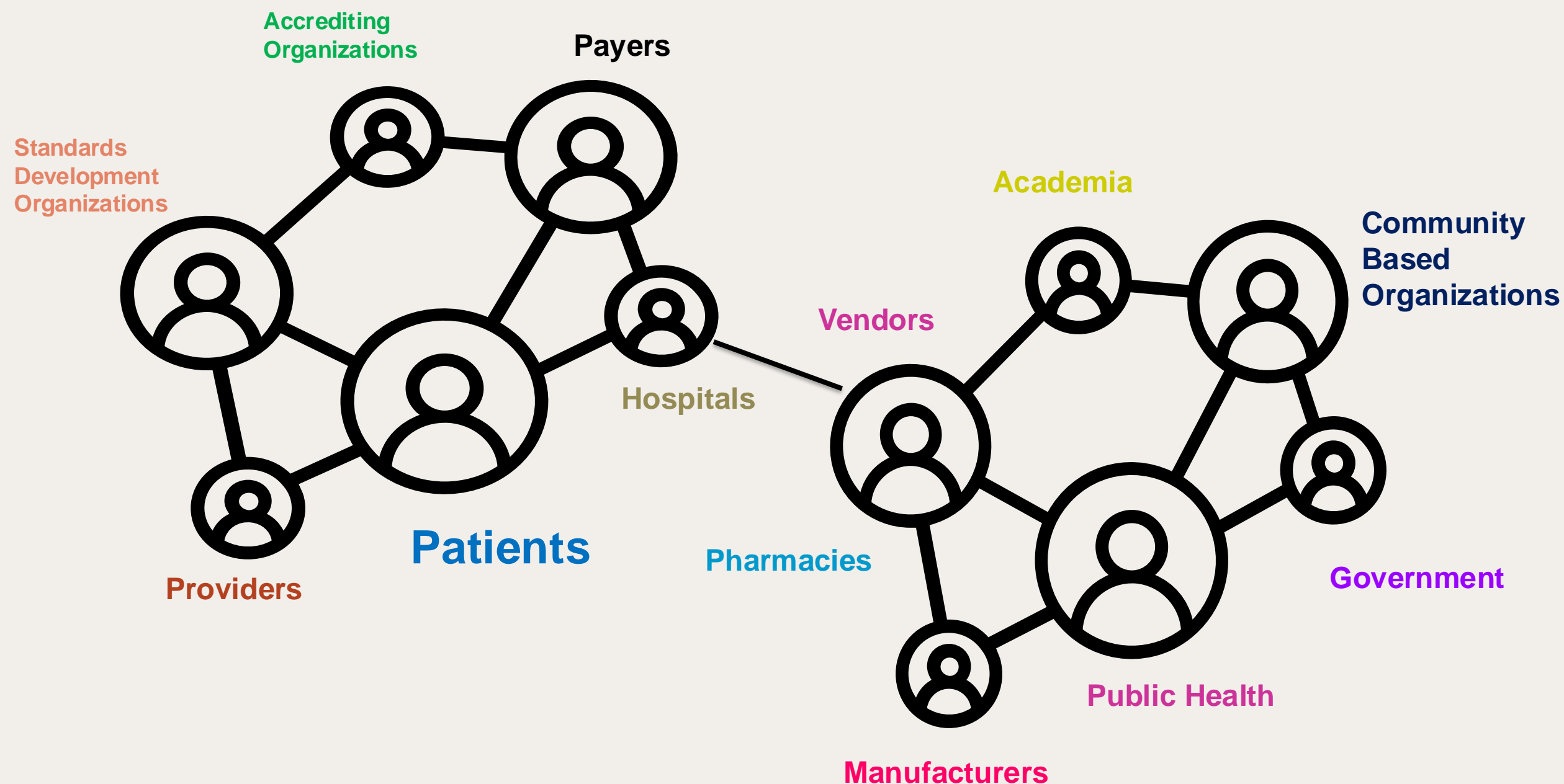
## Lack of Interoperability

- Multiple standards that do not align
- Significant Resources Invested
- Multiple stakeholders are collecting the same data

## Process Not Patient-Centric

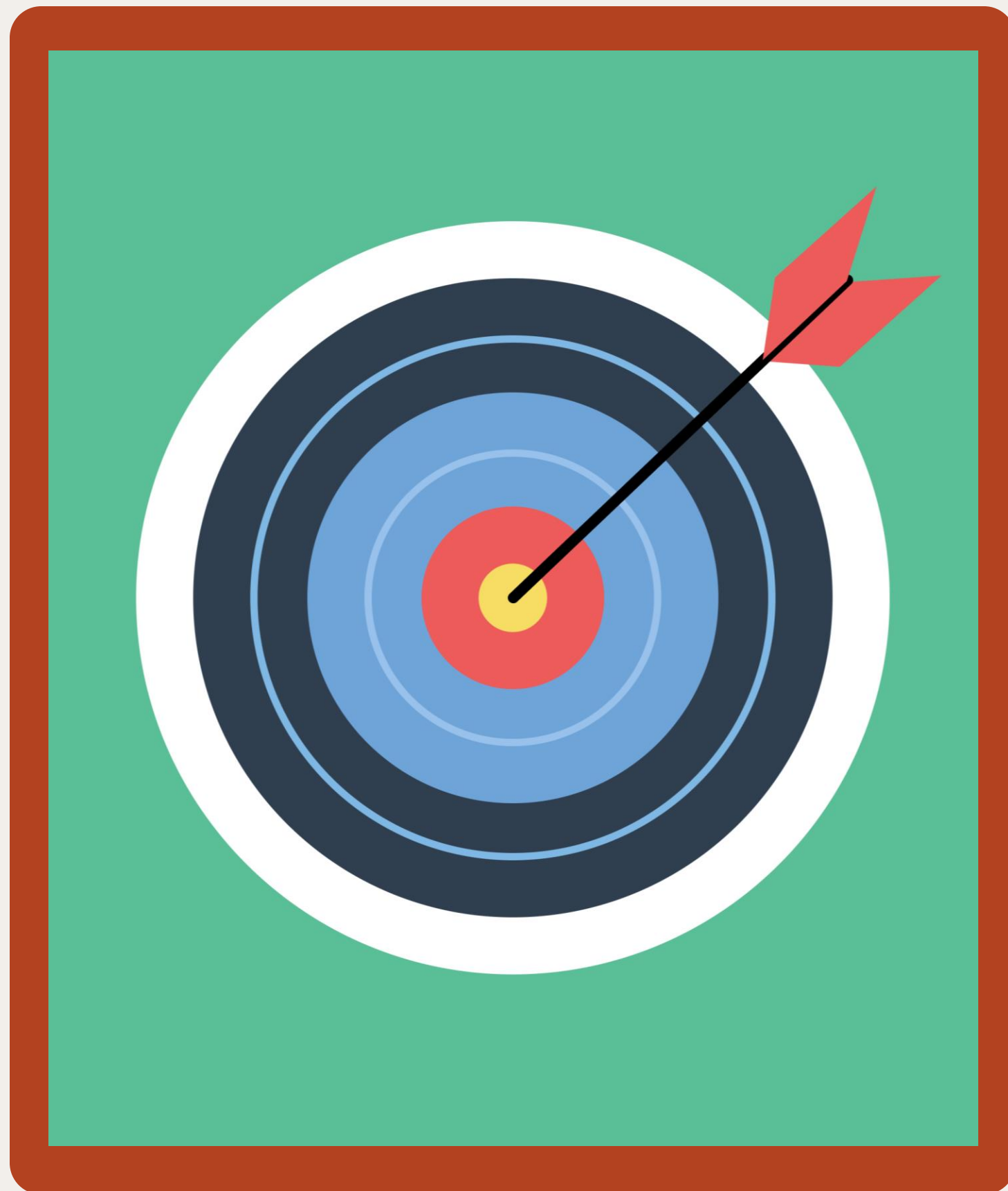
- Data not inclusive of how people identify
- Patients must answer questions repeatedly
- Leads to Patient Burden
- Leads to Mistrust

# Standards Will Be Most Effective if Adopted Across the Healthcare Ecosystem



## Stakeholders represented:

- 15 Patient/Consumer/Community Groups
- 20 Regional & National Medical Associations
- 10 Provider Groups
- 22 Hospitals/Health Systems/Community Health Centers
- 19 Public and Private Payers
- 8 Federal Agencies
- 5 Measure Developers
- 10 Software Solutions Companies
- 12 Health Information Exchanges
- 7 Regional Health Improvement Collaboratives
- 3 Quality Improvement Organizations
- 6 Purchasers/Employer Groups



# Demographic Data Element Modernization (DEMO) Initiative

## Mission:

- Advance Health Equity through Better Demographic Data.

## Goal:

- Modernize and enhance national demographic data content and exchange standards so that they are culturally sensitive and sufficiently granular that allow for alignment across stakeholders.

## Objective:

- Facilitate the collection of accurate, complete, comparable, actionable, and interoperable data that supports better outcomes, fewer disparities, improved patient trust, and enhanced operational efficiency.

# How We'll Get There:



## 1. Align Data Elements

- Race and Ethnicity
- Sexual Orientation & Gender
- Disability Status
- Language Preference
- Military Experience
- Spirituality

## 2. Test & Prepare

- Conduct cognitive testing
- Educate on HL7 process
- Prepare HL7 application

## 3. Build Standards

- Utilize HL7 standards development process.
- Explore development of FHIR Questionnaire
- Revise or develop new HL7 Implementation Guides (IGs).

## 4. Pilot

- Pilot test
- Harvest lessons learned
- Develop materials for putting standards into practice

# Findings from the National Virtual Focus Groups

# Guiding Principles

**Align with National Questionnaires but Improve Upon Them When Necessary**

**Standardize at High-Level while Allowing for Local Customization**

**Aim for Actionability while Minimizing Data Burden**

**Focus on Demographic Characteristics Not Health-Related Social Needs**



# Domains of Focus for Inclusive Representation of Identity



# Overarching Discussion Themes

How Granular to Make Response Choices

How to Order Response Choices

Use of Terms and When to Explain Terms

Whether and Where to Include "I Do Not Know" as a Response

How to Appropriately Word "Write-In" Response

# Race and Ethnicity

# Version 2: Race and Ethnicity

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

- Asian or Asian American
- Black, African, or African American
- 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 at this time

# Version 2: Race and Ethnicity at More Granular-Level

**OPTIONAL: 1A. 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).*

<b>Asian or Asian American</b>	<b>Black, African, or African American</b>	<b>Hispanic or Latino</b>	<b>Middle Eastern or North African</b>	<b>Native Hawaiian or Pacific Islander</b>	<b>Native American, Alaska Native, or Indigenous</b>	<b>White or European</b>
<ul style="list-style-type: none"> <li>• Afghan</li> <li>• Bangladeshi</li> <li>• Burmese</li> <li>• Cambodian</li> <li>• Chinese</li> <li>• Filipino</li> <li>• Hmong</li> <li>• Indian</li> <li>• Indonesian</li> <li>• Japanese</li> <li>• Korean</li> <li>• Lao</li> <li>• Nepalese</li> <li>• Pakistani</li> <li>• Sri Lankan</li> <li>• Thai</li> <li>• Vietnamese</li> <li>• Please specify if not listed above: _____</li> </ul>	<ul style="list-style-type: none"> <li>• African American</li> <li>• Angolan</li> <li>• Barbadian</li> <li>• Cabo Verdean</li> <li>• Congolese</li> <li>• Dominican</li> <li>• Ethiopian</li> <li>• Ghanaian</li> <li>• Haitian</li> <li>• Jamaican</li> <li>• Kenyan</li> <li>• Liberian</li> <li>• Nigerian</li> <li>• Somali</li> <li>• Sudanese</li> <li>• Trinidadian</li> <li>• Please specify if not listed above: _____</li> </ul>	<ul style="list-style-type: none"> <li>• Argentinian</li> <li>• Brazilian</li> <li>• Chilean</li> <li>• Colombian</li> <li>• Costa Rican</li> <li>• Cuban</li> <li>• Dominican</li> <li>• Ecuadorian</li> <li>• Guatemalan</li> <li>• Honduran</li> <li>• Mexican or Chicano/a</li> <li>• Nicaraguan</li> <li>• Panamanian</li> <li>• Peruvian</li> <li>• Puerto Rican</li> <li>• Salvadorian</li> <li>• Spanish</li> <li>• Venezuelan</li> <li>• Please specify if not listed above: _____</li> </ul>	<ul style="list-style-type: none"> <li>• Egyptian</li> <li>• Emirati</li> <li>• Iraqi</li> <li>• Iranian</li> <li>• Israeli</li> <li>• Jewish (Mizrahi)</li> <li>• Jordanian</li> <li>• Kurdish</li> <li>• Kuwaiti</li> <li>• Lebanese</li> <li>• Libyan</li> <li>• Palestinian</li> <li>• Saudi</li> <li>• Syrian</li> <li>• Yemeni</li> <li>• Please specify if not listed above: _____</li> </ul>	<ul style="list-style-type: none"> <li>• Chuukese</li> <li>• Chamorro</li> <li>• Fijian</li> <li>• French Polynesian</li> <li>• Marshallese</li> <li>• Native Hawaiian</li> <li>• Palauan</li> <li>• Papua New Guinean</li> <li>• Samoan</li> <li>• Tongan</li> <li>• Yap</li> <li>• Please specify if not listed above: _____</li> </ul>	<ul style="list-style-type: none"> <li>• Apache</li> <li>• Athabascan</li> <li>• Aztec</li> <li>• Blackfeet</li> <li>• Cherokee</li> <li>• Cheyenne</li> <li>• Chippewa</li> <li>• Choctaw</li> <li>• Comanche</li> <li>• Haudenosaunee</li> <li>• Inupiat</li> <li>• Lumbee</li> <li>• Lingít (Tlingit)</li> <li>• Mayan</li> <li>• Muscogee (Creek)</li> <li>• Navajo</li> <li>• Osage</li> <li>• Sioux</li> <li>• Taino</li> <li>• Yu'pik Eskimo</li> <li>• Please specify if not listed above: _____</li> </ul>	<ul style="list-style-type: none"> <li>• Danish</li> <li>• Dutch</li> <li>• English</li> <li>• French</li> <li>• German</li> <li>• Greek</li> <li>• Irish</li> <li>• Italian</li> <li>• Jewish (Ashkenazi)</li> <li>• Jewish (Sephardic)</li> <li>• Lithuanian</li> <li>• Norwegian</li> <li>• Polish</li> <li>• Portuguese</li> <li>• Russian</li> <li>• Scottish</li> <li>• Swedish</li> <li>• Ukrainian</li> <li>• Welsh</li> <li>• Please specify if not listed above: _____</li> </ul>

- I don't know
- I choose not to respond at this time

**OPTIONAL 1B. Cultural Identity: Are there things about your culture or cultural identity that you would like us to know?**

# Preferred Language

# Version 2: Language Preference – Speaking

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

# Version 2: Language Preference – Reading and Writing

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



# Version 2: 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

## 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

# Sexual Orientation, Sex, Gender

# Version 2: Sexual Orientation

## Sexual Orientation

At this time, do you think of yourself as (select one):

- Asexual (little or no attraction to any gender)
- Bisexual (attracted to same gender as your own and gender different from your own)
- Gay or lesbian (attracted to the same gender as your own)
- Pansexual (attracted to any gender)
- Straight or heterosexual (attracted to gender different from your own)
- Please specify if not listed above: \_\_\_\_\_
- I don't know
- I choose not to respond at this time

# Version 2: 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)

- Female, Woman
- Intersex (having external body parts or reproductive organs that are not only male or female)
- Male, Man
- I choose not to respond at this time
- I do not know

*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):

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

# Pronouns

# Version 2 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 do not identify as either male or female, can be used in singular form)
- Ze, hir, hirs (non-binary, often used by people who do not identify as either male nor female)
- Ze, zir, zirs (non-binary, often used by people who do not identify as either male nor female)
- Please specify if not listed above: \_\_\_\_\_
- Use my name
- I don't know
- I choose not to respond at this time

# Disability Status

# Version 2: Disability Status

## Disability Status

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

- Hearing
- Seeing (even when wearing glasses)
- Concentrating, remembering, or making decisions
- Walking or climbing stairs
- Dressing or bathing
- Cooking for oneself
- Feeding oneself
- Using the toilet
- Doing errands alone such as shopping or visiting a doctor's office
- Communicating 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 at this time



# Spiritual Beliefs

# Version 2 Optional: Other Care Considerations

**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 at this time

<https://prapare.org/>

# Version 2 Optional: Religion and/or Spiritual Beliefs

## Spiritual Beliefs

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

- Ancestral, indigenous, or tribal beliefs (such as Animism, Obeah, Shamanism, Vodou, among others)
- Agnostic (not sure if there is a God)
- Atheist (do not believe in God)
- Baha'I
- Buddhism
- Christianity: Protestant (such as Anglican, Baptist, Calvinist/Reformed, Episcopalian, Lutheran, Methodist, Nondenominational, Pentecostal, Presbyterian, or Seventh-day Adventist).
- Christianity: Catholic
- Church of Scientology
- Hinduism
- Islam, Nation of Islam (Muslim)
- Jehovah's Witnesses
- Judaism (Jewish)
  - \* Orthodox Judaism
- Mormon (Church of Jesus Christ of Latterday Saints/LDS)
- Orthodox Christian (Coptic Christian, Greek Orthodox Church, Russian Orthodox Church, or other orthodox church)
- Pagan or nature-based beliefs (such as Wicca, Druidism, among others)
- Philosophical beliefs (such as Confucianism, Epicureanism, Humanism, among others)
- Rastafarianism
- Sikh
- Taoism
- Unitarian Universalist
- Zoroastrianism
- Spiritual but not religious
- Please specify if not listed above: \_\_\_\_\_
- I do not know
- I choose not to respond at this time

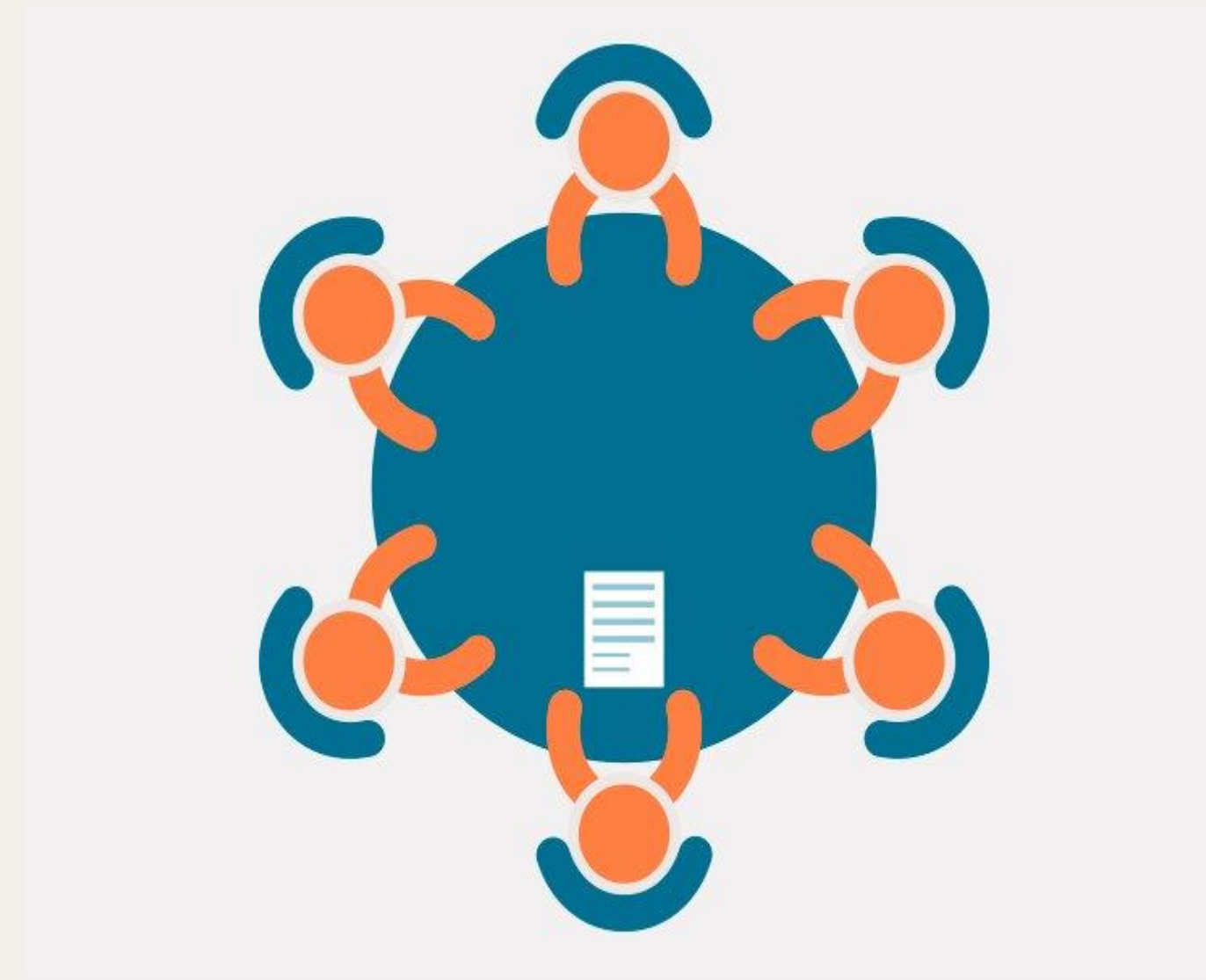
Adapted from 2014 Religious Landscape Survey: [https://assets.pewresearch.org/wp-content/uploads/sites/11/2018/06/12094008/Appendix-D.pdf?ut\\_source=content\\_center&ut\\_source2=how-to-ask-about-religion-in-your-surveys&ut\\_source3=inline](https://assets.pewresearch.org/wp-content/uploads/sites/11/2018/06/12094008/Appendix-D.pdf?ut_source=content_center&ut_source2=how-to-ask-about-religion-in-your-surveys&ut_source3=inline)

# Next Steps

# Phase 2

## *Cognitive Testing*

- Partnering with the Patient Advocate Foundation to test face validity
- Ensure individuals:
  - Understand the questions
  - What is being asked of them
  - Feel comfortable answering the questions
  - Believe response choices offered allow them to appropriately identify themselves
- Ensure staff administering questions:
  - Understand the questions
  - Feel comfortable asking the questions
- Complete by Fall 2024
- **Potential minor revisions may result from this testing**



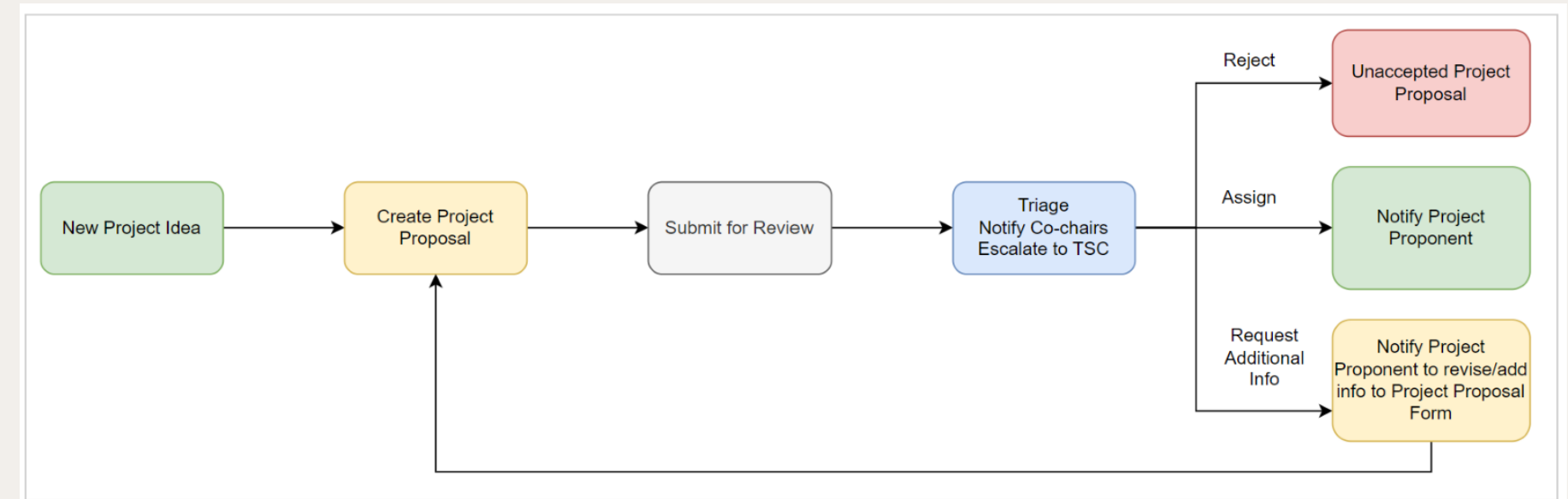
<https://www.how-paid-research-works.com/what-are-paid-focus-groups>

# Phase 3

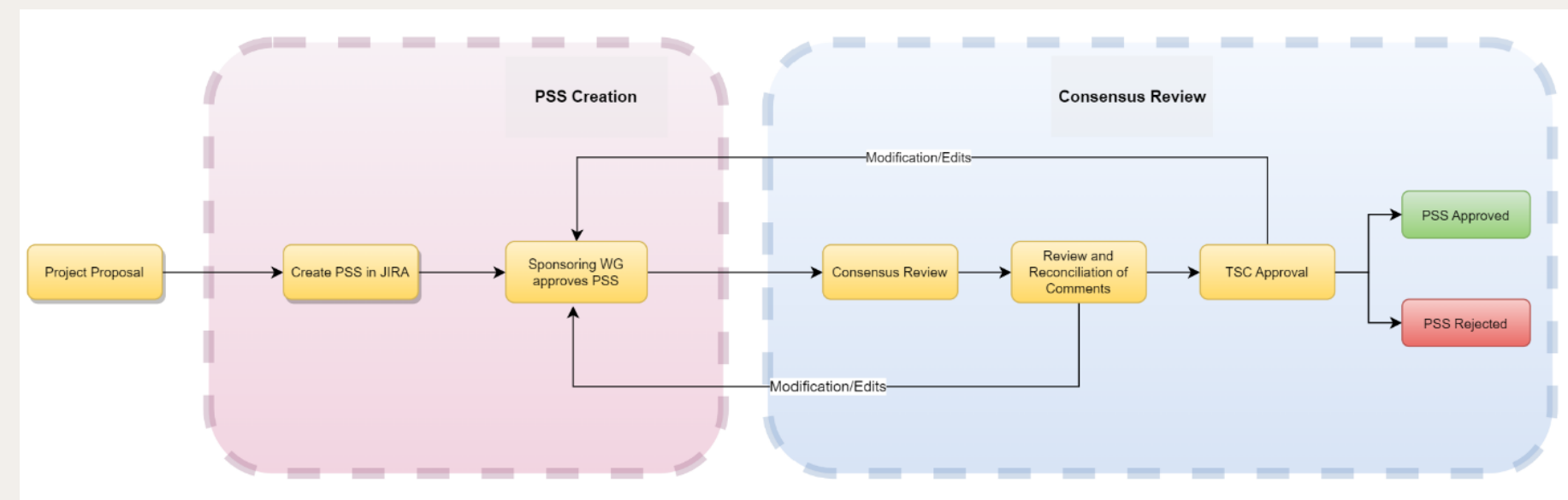
## *Building Consensus on Technical Standards*

- 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).

**HL7 Project Proposal Workflow**



**HL7 Project Scope Statement Flow**





# Thank You!

## Questions?

- For more information and to access the Phase 1 Report, please visit:
- [www.civitasforhealth.org/demographic-data-standards.](http://www.civitasforhealth.org/demographic-data-standards)

#Civitas2024

# Appendix



# Relationship Status

# Version 2 Optional: Relationship Status

## Relationship Status

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

- Dating (in a non-committed relationship with one person or more than one person)
- Divorced
- In a committed relationship with one person but not married (monogamous relationship)
- In a committed relationship with more than one person (polyamorous relationship)
- In a registered domestic partnership (a legal relationship between two people who live together and share a domestic life, but are not married or in a civil union and are not blood relatives)
- Married
- Separated
- Single
- Widowed
- Please specify if not listed above: \_\_\_\_\_
- I don't know
- I choose not to respond at this time

# Military Experience

# Version 2: U.S. Veteran Status and Other Military Experience

## U.S. Veteran Status

**Have you ever served in the United States Armed Forces, military Reserves, or National Guard? Select one.**

- Yes, I served in the United States Armed Forces, military Reserves, or National Guard
- No, I have never served in the United States Armed Forces, military Reserves, or National Guard
- I don't know
- I choose not to respond at this time

**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? \_\_\_\_\_**

**Optional: Did an immediate family member who you live or lived with ever serve in the United States Armed Forces, military Reserves, or National Guard? (i.e., parent, guardian, spouse, partner, child, sibling etc.) Select one.**

- Yes, an immediate family member that I live or lived with served the United States Armed Forces, military Reserves, or National Guard
- No, no immediate family member that I live or lived with has never served in the United States Armed Forces, military Reserves, or National Guard
- I don't know
- I choose not to respond at this time

# Version 2: U.S. Veteran Status and Other Military Experience

## Optional: Other Military Experience

**Optional: Have you ever served in the armed forces of a country other than the United States? Select one.**

- Yes, I served in the armed forces of another country
- No, I have never served in the armed forces of another country
- I don't know
- I choose not to respond at this time

**Optional: When did you serve? \_\_\_\_\_**

**Optional: Where did you serve? \_\_\_\_\_**

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

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