CIVITAS Networks for Health | HL7 International | AHIP

# Enhancing Demographic Questions and Response Choices

National Virtual Focus Group #1

January 31, 2024

*Parts of this meeting will be recorded

# Anti-Trust Compliance Statement

It is the policy of America's Health Insurance Plans (AHIP) to conduct all its activities in compliance with federal and state antitrust laws.

During these meetings, including all informal or social discussions, each participating organization shall refrain from discussing or exchanging competitively sensitive information with any other participating organization. Such information includes, but may not be limited to:

- Prices, premiums, or reimbursement charged or paid for products or services.
- 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.
- Refusal to deal with any provider, class or group of providers.
- What products or services will be offered to enrollees.
- Any other competitively sensitive information that is proprietary to a participating organization.

**If you have any questions or antitrust concerns, please consult with legal counsel.**

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# Housekeeping Reminders

- 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.
- There will be a short evaluation survey at the end of the session.

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

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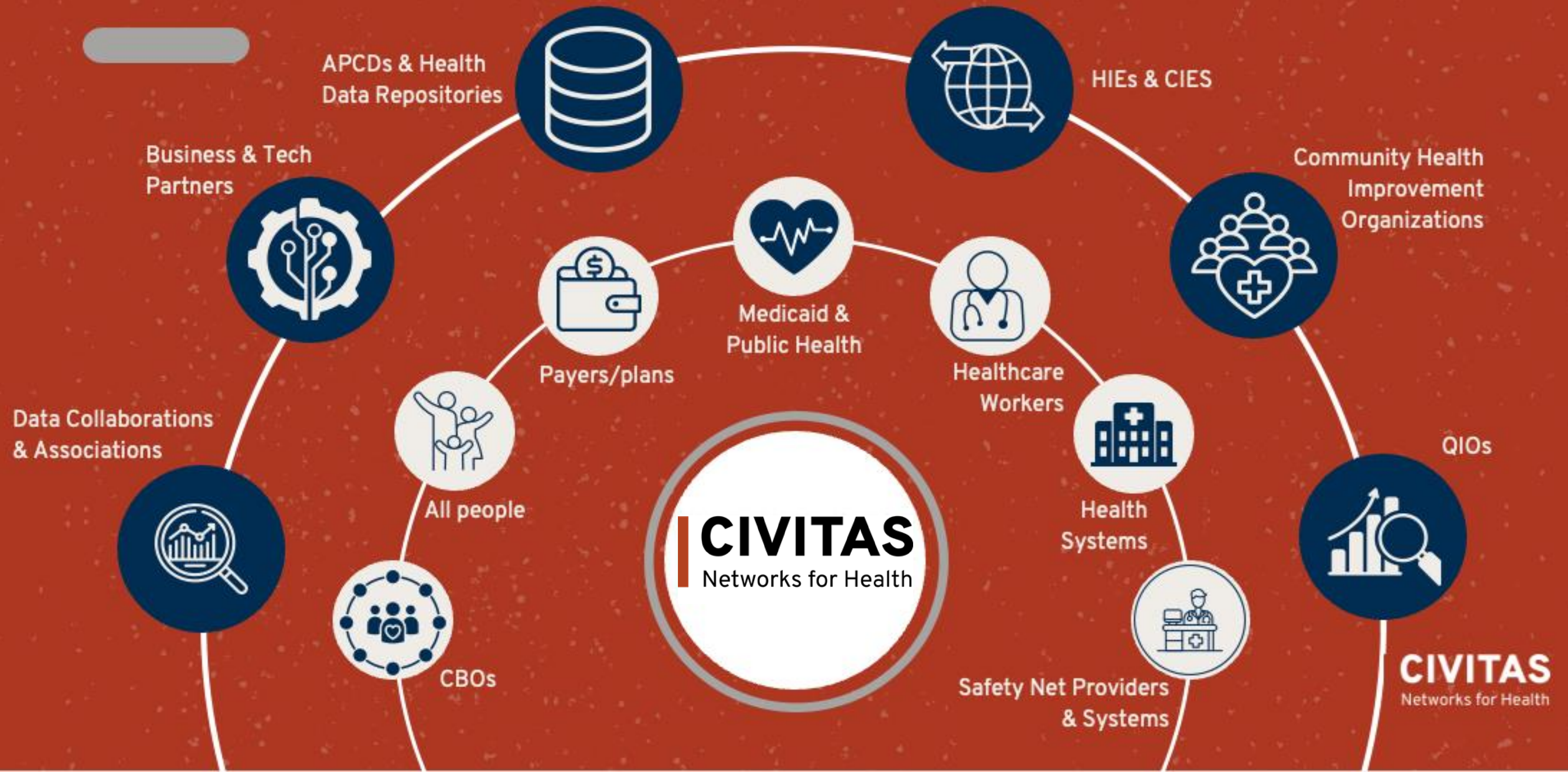
# Agenda

- Welcome
- Introduction to Program Partners
- Overview, Rationale, and Goals of This Work
- Review of Proposed Questions and Response Choices
  - January 31st Meeting Domains: Military Experience and Disability Status
- Review of Data Standards Crosswalk
- Breakout Sessions
- Full Group Report Out

# Program Partner Introductions

# Civitas Networks for Health



## 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

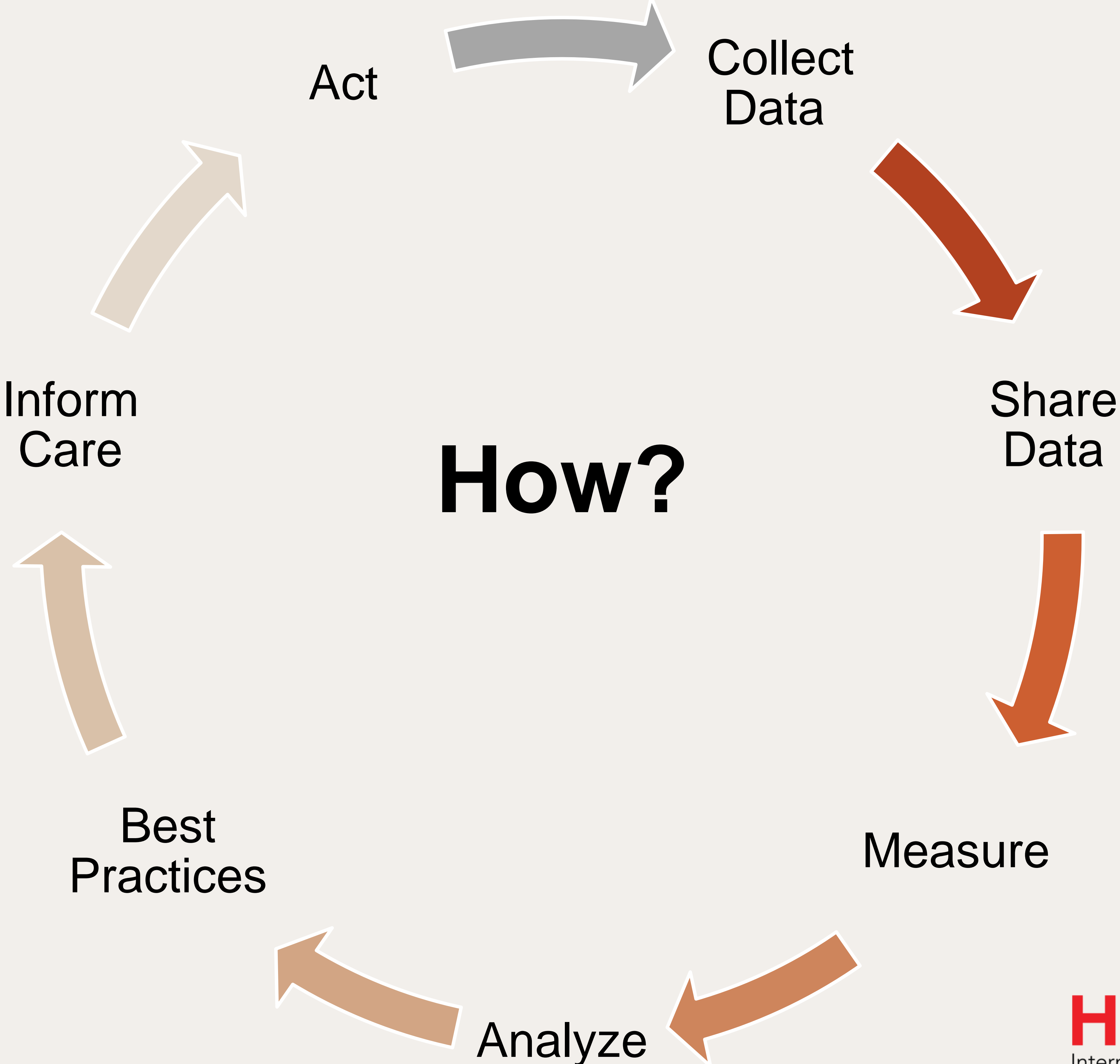
# About AHIP

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.

# Overview, Rationale, and Goals of This Work

# Mission: Advance Health Equity

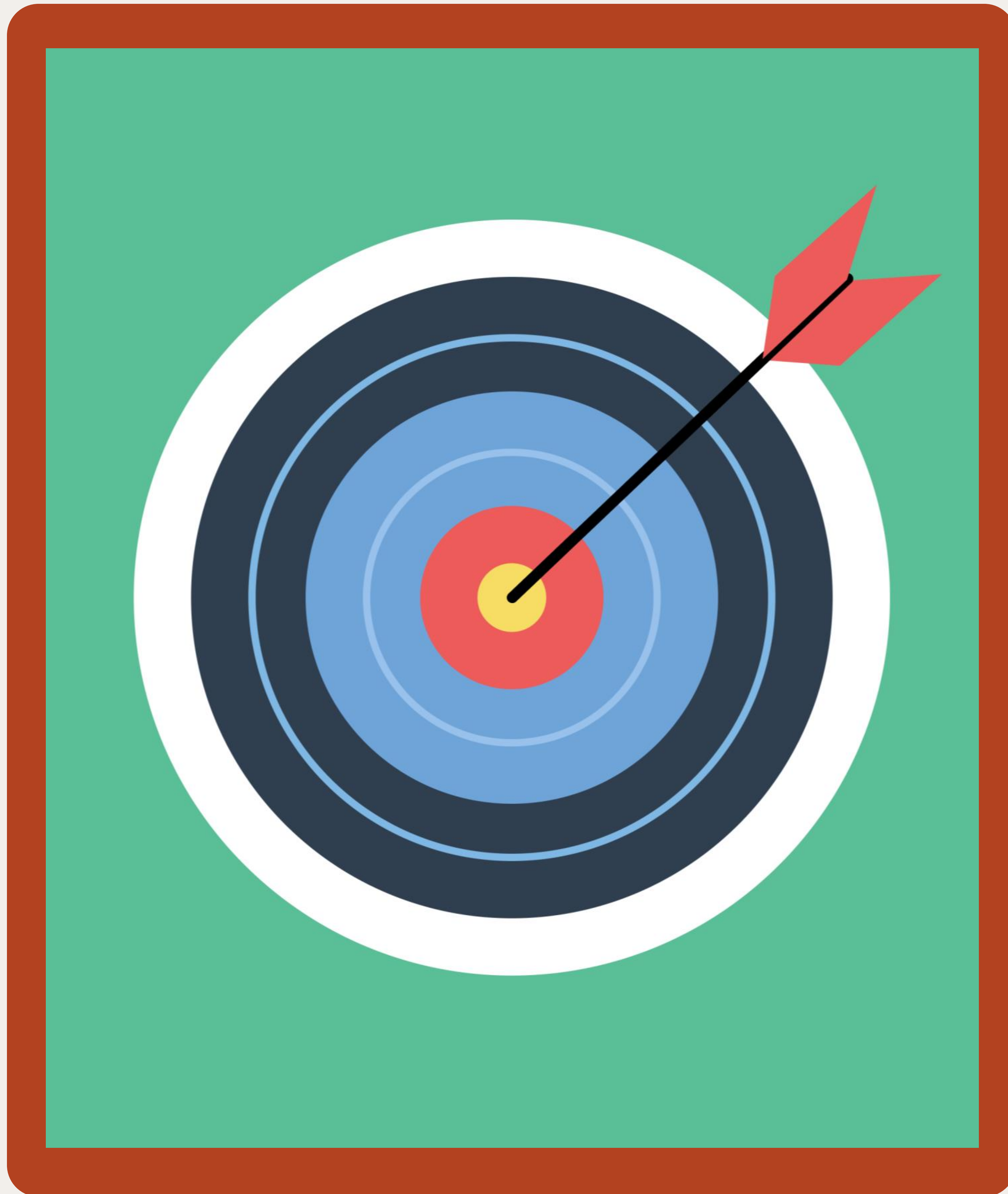


# Challenges with Demographic Data Collection

- Collection Instruments Lead to Inadequate Data
  - There are multiple disparate standards for collecting and sharing the data.
  - Large numbers of "Other" or "Unknown" because no response options for how people identify.
  - Granular options are often insufficient, inequitably applied, or not applicable or actionable across all regions, states, or local communities.
  - Language and terminology used may not be culturally appropriate or person-centered.
  - Response options are not actionable.
  - Open-ended free text responses hard to aggregate and analyze due to misspellings.
  - Data are not interoperable.

- Patient Burden and Lack of Trust

- Stakeholders Must Invest Significant Resources



# 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.

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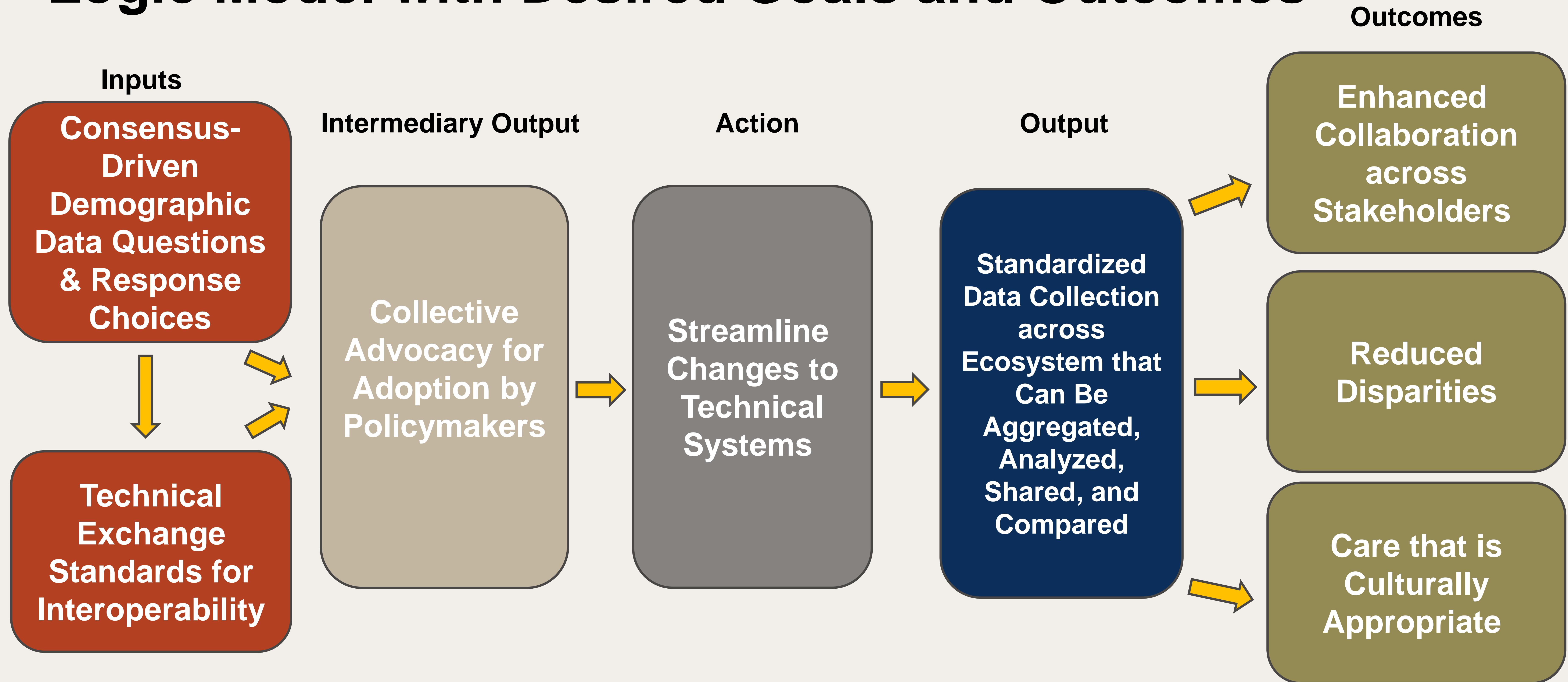
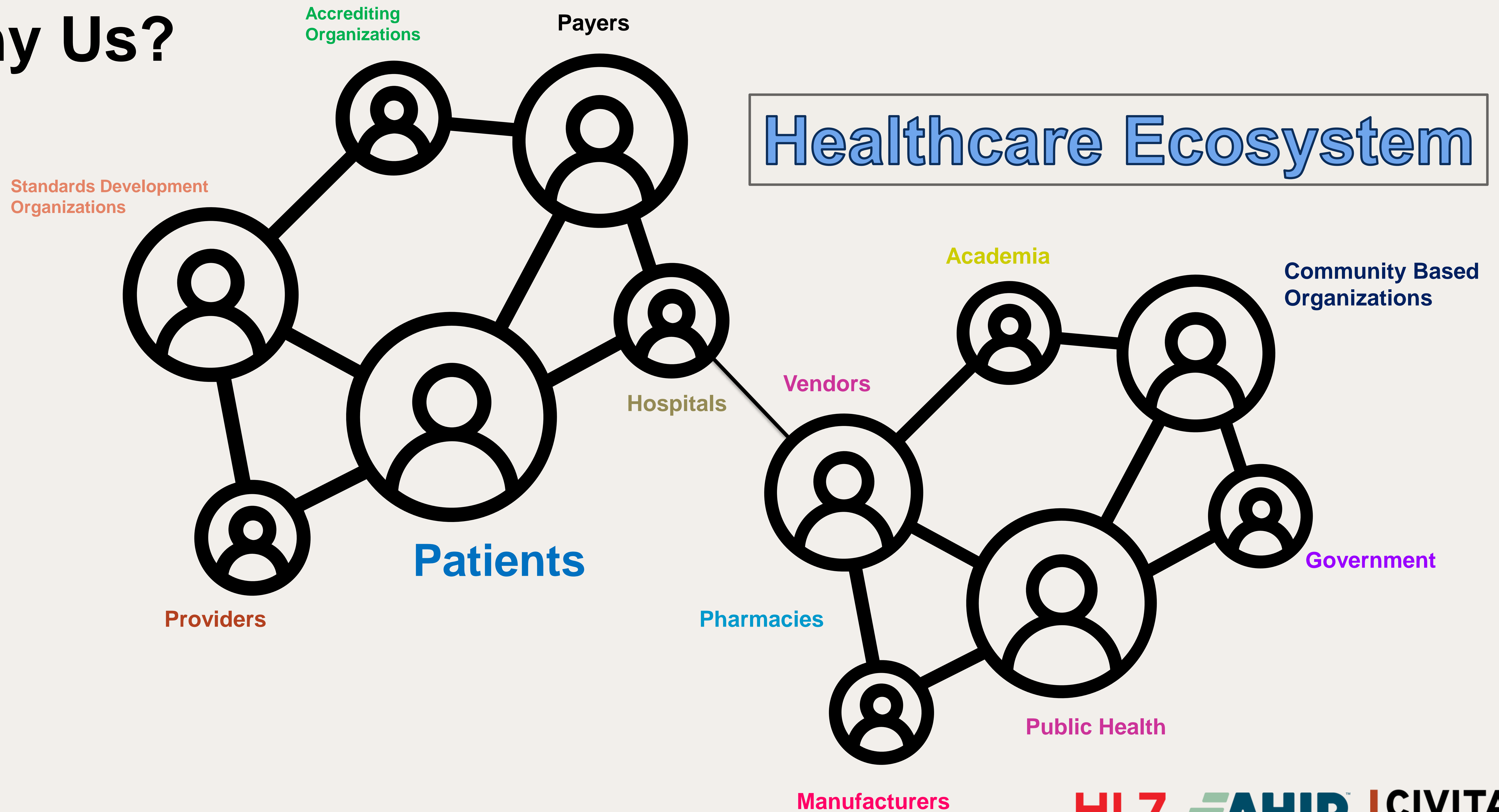
# Logic Model with Desired Goals and Outcomes



# Why Us?

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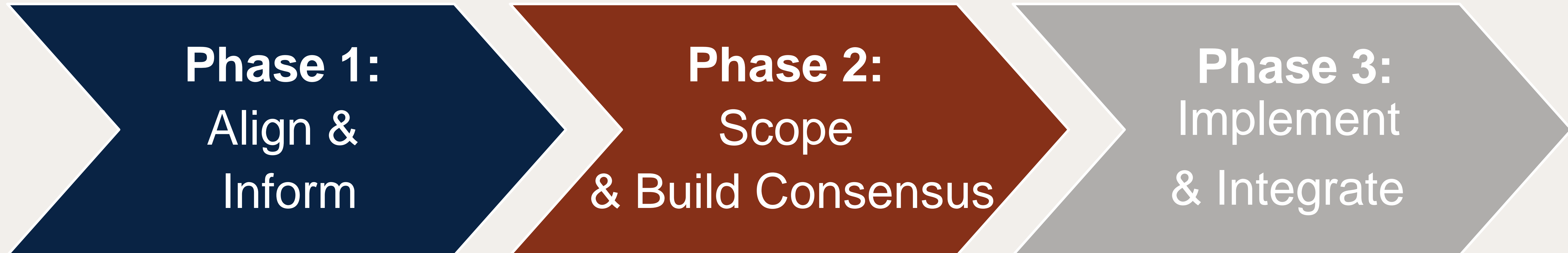
# How We'll Get There:




## 1. Align Data Elements

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

## 2. Build Consensus on Tech Standards

- Utilize HL7 standards development 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).

## 3. Pilot

- Curate existing materials and prioritize development of future materials for putting standards into practice.

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# HL7 Definitions

| Term | Definition |
|---|---|
| **Cardinality** | The number of elements in a set or other grouping, as a property of that grouping.<br><br>Examples:<br>1..1 – Must have 1 and only 1 of these elements.<br>0..n – Can be empty or be repeated an unlimited number of times. |
| **HL7 Standard** | An HL7 Standard is a specification, guide, or other material developed by the HL7 Working Group in accordance with processes described in the HL7 Governance and Operations Manual and the HL7 Essential Requirements following the HL7 consensus process as overseen by the Technical Steering Committee. HL7 standards are also referred to as Protocol Specifications.<br><br>HL7 Standards, or equivalently Protocol Specifications, encompass the following work products developed and supported by HL7: all Versions of the HL7 messaging standard; the Clinical Document Architecture (CDA); Arden Syntax; CCOW specifications; Service Oriented Architecture (SOA) standards; any other normative standards subsequently released by HL7; various functional models, implementation guides, Fast Healthcare Interoperability Resources (FHIR®), and Implementation Technology Specifications (ITS); the Reference Information Model (RIM); and those informative documents initiated and balloted by the various Work Groups. |
| **HL7 Consensus** | A critical step in the HL7 Standards Development Process that meets the requirements of and reflects the agreement of the various parts of the community that will participate in the workflow.  HL7 is an ANSI-Accredited SDO so all Normative Standards are submitted to ANSI for approval. (See HL7 Due Process). |
| **FHIR** | Fast Healthcare Interoperability Resources® (FHIR®) is a Health Level Seven International® (HL7®) standard for exchanging healthcare information electronically. It is the next generation exchange framework being adopted by the healthcare community to advance interoperability. |
| **HL7 Due Process** | Due process means that any party (organization, company, government agency, individual, etc.) with a direct and material interest has a right to participate by: a) expressing a position and its basis, b) having that position considered, and c) having the right to appeal. Due process allows for equity and fair play. ANSI ER defines the following as constituting the minimum acceptable due process requirements for the development of consensus for approval, revision, reaffirmation, or withdrawal of HL7 American National Standards (ANS). As such these represent the guiding principles for the HL7 ER. |

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# Level Setting Expectations

Groups will have 50 minutes…

**Focus Group Purpose:**

- Introduce base demographic questions and response choices.
- Seek feedback from stakeholders on potential revisions and refinements for alignment.

**Structure:**

- Participants will be divided evenly into four breakout groups.
- Each breakout group will be presented with the same set of questions to consider when thinking about the specific domain(s) being discussed.
- Each breakout group will have a dedicated note taker and facilitator from a member of the program team.
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**Considerations:**

- Don't expect unanimous agreement.
- Try to find areas where we can "meet in the middle" and feel most comfortable with framing of demographic data questions and granularity of response choices to inform development of technical exchange standards for interoperability.
- Advocate for "high-level" standardization while allowing for local customization and granularization.
- Don't worry about technical standards only content at this point.

# AHIP's Work to Date on Demographic Data

# AHIP Health Equity Workgroup's Approach to Enhance Demographic Data

- AHIP Health Equity Workgroup Goals:

1. **Align with national questionnaires if/when possible but improve upon them when necessary**
2. **Standardize at high-level while allowing for local customization and granularity:** ***What data is needed at high-level vs more local level?***
3. **Aim for actionability while minimizing data burden:** ***Why are we asking for this data?***

- Coding Crosswalk (with LOINC, SNOMED, ICD-10) and Data Documentation

**Race and Ethnicity**
- Higher-Level & Granular Options
- Includes separate and combined race and ethnicity

**Sexual Orientation and Gender**
- Pronouns
- Relationship Status

**Disability Status**
- Vision
- Hearing
- Cognitive
- Communication
- Ambulatory
- Self-Care
- Other Functional

**Language Preference (Reading & Speaking)**

**Military Experience**

**Spiritual Beliefs**

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# Commonalities Across Proposed Demographic Data

- Used existing questionnaires as starting point but revised to include more appropriate terms/language, more relevant and actionable response choices, etc.
- Meant to be self-reported.
- Revised to use 4th – 5th grade reading language.
- All include "I choose not to respond" option to honor individual agency in providing this information.
- Script on why collecting this information, how it will be used, and how it will be protected.
- Meant for health care setting.
- Focus on demographic characteristics rather than risks.

# Military Experience and Disability Status

# Military Experience

- **Why is it important to collect data on military experience?**
  - Determine eligibility for U.S. Veteran benefits
  - Inform trauma-informed care and mental health
  - Inform accessibility of care (e.g., limb loss, paralysis, TBI, etc.)
  - Flag exposure to health and occupational hazards
  - Assist with reintegration into civilian society (e.g., constant moving, skill sets, etc.)

- **Commonly used questions and definitions:**
  - Statutory definition: “A person who served in the active military, naval, air, or space service, and who was discharged or released therefrom under conditions other than dishonorable”[1]
  - Collected Data: Last branch of service, last entry date, future discharge date, last discharge date, discharge type, military service number, military history

https://www.aauw.org/resources/member/governance-tools/dei-toolkit/dimensions-of-diversity/veteran-status/

1. 38 U.S. Code § 101 - Definitions | U.S. Code | US Law | LII / Legal Information Institute(cornell.edu)

# 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? ___________**

# Key Differences and Considerations on Military Experience

***Decided by AHIP Health Equity Workgroup***

- **Key Differences from Existing Questionnaires**
  - Simplified: not collecting as much detailed information as what VA collects to determine eligibility for benefits.
  - Focus on all military experience—not just service in the U.S. military.
  - Focus on spouse of service member in addition to service member.

- **Considerations**
  - Could be triggering or trauma-inducing.
  - Sensitive data—particularly if individual served in military that fought against the U.S.

# Disability Status

- **Why is it important to collect data on disability status?**
  - Determine eligibility for U.S. disability benefits.
  - Inform accessibility of care.
  - Inform services that could help with activities of daily living.
  - Inform communication and outreach.

- **Commonly used questions and definitions:**
  - Statutory Definition (also used by ADA): a physical or mental impairment that substantially limits one or more major life activities
  - Social Security Administration: Inability to work or adjust to other work  because of a medical condition

https://en.m.wikipedia.org/wiki/File:Disability_symbols.svg

# Proposed: Disability Status

| Disability Status |
| --- |
| **Do you have difficulty with any of the following? Check all that apply.**<br>• Hearing<br>• Seeing (even when wearing glasses)<br>• Concentrating, remembering, or making decisions because of a physical or mental health condition<br>• Walking or climbing stairs<br>• Dressing or bathing<br>• Doing errands alone such as shopping or visiting a doctor's office because of a physical, mental or emotional condition<br>• Communicating, understanding, or being understood using your usual language<br>• Other difficulties when doing activities throughout your day (please describe)<br>• 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.

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# Key Differences and Considerations on Disability Status

***Decided by AHIP Health Equity Workgroup***

- **Key Differences from Existing Questionnaires**
  - Focus less on ability to work and more on ability to perform activities of daily living so as to inform appropriate services and accessibility of care.
  - Not disease-specific as considered too granular. Focus is on higher-level disabilities to inform appropriate services and accessibility of care.
  - Include response choices on cognitive and communication.

- **Considerations**
  - Consider adding an action-oriented question on whether an individual needs additional assistance or accommodation during their health care visit due to a disability.*
    - But be mindful if can't make those accommodations. Best to strategize various accommodations during planning phase.
  - Be mindful of terms used ("special needs", "differing ability") as often considered patronizing, offensive, or condescending. Use person-first language.

Recommended by the Disability Equity Collaborative https://www.disabilityequitycollaborative.org/wp-content/uploads/2022/10/221010_-DEC-IMPLEMENTATION-GUIDE.pdf

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# HL7 Crosswalk to Existing Technical Standards

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# Veteran Status

## Proposal

**Have you or your spouse ever served or have been discharged from the armed forces of the United States? (check all that apply)**

**Response Choices:**

- Yes, I served
- Yes, my spouse served
- No, neither I nor my spouse served
- Don't Know
- I choose not to respond

**Optional follow-up Questions:**

When did you serve? _(Text)_

Where did you serve? __(Text)_

**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)**

**Response Choices:**

- Yes, I served
- Yes, my spouse served
- No, neither I nor my spouse served
- Don't Know
- I choose not to respond

**Required follow-up Question if either or both Yes answers chosen:**

Which Country? _(Text)_

**Optional follow-up Questions:**

When did you serve? _(Text)_

Where did you serve? __(Text)_

## Gaps & Collisions

**Match**

- Proposed Question can be answered for self only

**Gaps**

- Proposed Question cannot be answer for spouse
- Proposed Question cannot be answered twice
- No support for When did you serve?
- No support for Where did you serve?

**Collisions**

- None

**Match**

- None

**Gaps**

- No support for this question

**Collisions**

- None

## HL7 FHIR R4 US Core R6.1

**Have you ever served or have been discharged from the armed forces of the United States?**

**Response Choices:**

- Yes
- No

**No Representation in FHIR**

No Government Regulations for this Data Element.

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# Disability

## Proposal

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

**Response Choices:**

- 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 customary language
- Other difficulties when doing activities throughout your day
- I choose not to respond

**Required follow-up Question if "Other difficulties when doing activities throughout your day"**
Describe Other: _(Text)_

**No Government Regulations for this Data Element.**

## Gaps & Collisions

**Match**

- Patient.Disability extension includes CodeableConcept described as Condition(s) limiting movement, senses, or activities

**Gaps**

- Terminology/Data Set not defined for this extension
- LOINC, SNOWMED, and ICD-10 include values related to disability status but do not include a "I choose not to respond" value

**Collisions**

- None

**Gaps**

- No support for this question

## HL7 FHIR R4 US Core R6.1

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

**Response Choices:**

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- Seeing – even when wearing glasses
- Concentrating, remembering, or making decisions because of a physical or mental health condition
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**No Representation in FHIR**

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# Poll Question

# Breakout Group Discussions

# Group Report Out

# Appendix

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# Next Steps!

**Next Session**: Sexual Orientation, Gender, Pronouns, and Relationship Status

**Date/Time**: February 21, 2024 | 2:30-4:30pm ET

**Registration Link**: https://civitasforhealth-org.zoom.us/meeting/register/tZYsce-spzsiHNDhlgVgZUxYxcaAjsX9BREi#/registration

**Schedule**

2024

**January 31**
Military Experience & Disability Status 2:30pm - 4:30pm ET

**February 21**
SOGI, Pronouns, and Relationship Status | 2:30pm-4:30pm ET

**March 4**
Race and Ethnicity 2p m-4pm ET

**March 20**
Language and Spirituality
3pm-5pm ET

**April 11**
Summary of Findings, Presentation of Revisions, Next Steps for Phase 2
1:30pm-3:30pm ET

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# Evaluation