Enhancing Demographic Questions and Response Choices

National Virtual Focus Group #3
March 4, 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.

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**

Agenda

Topic Domains: Race and Ethnicity

- Welcome
- Introduction to Program Partners
- Goals and Planned Phases of Program
- AHIP's Work to Data on Demographic Data + Use Cases
- Review of Proposed Questions and Response Choices for Race and Ethnicity
  - o Breakout Session
  - o Group Report Out
- Next Steps and Closing

Program Partner Introductions

ABOUT CIVITAS

<u>Civitas Networks for Health</u> 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.

in **Civitas Networks for Health** 𝕏 **@civitas4health**

HL7® International   **≡AHIP**™ | **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.
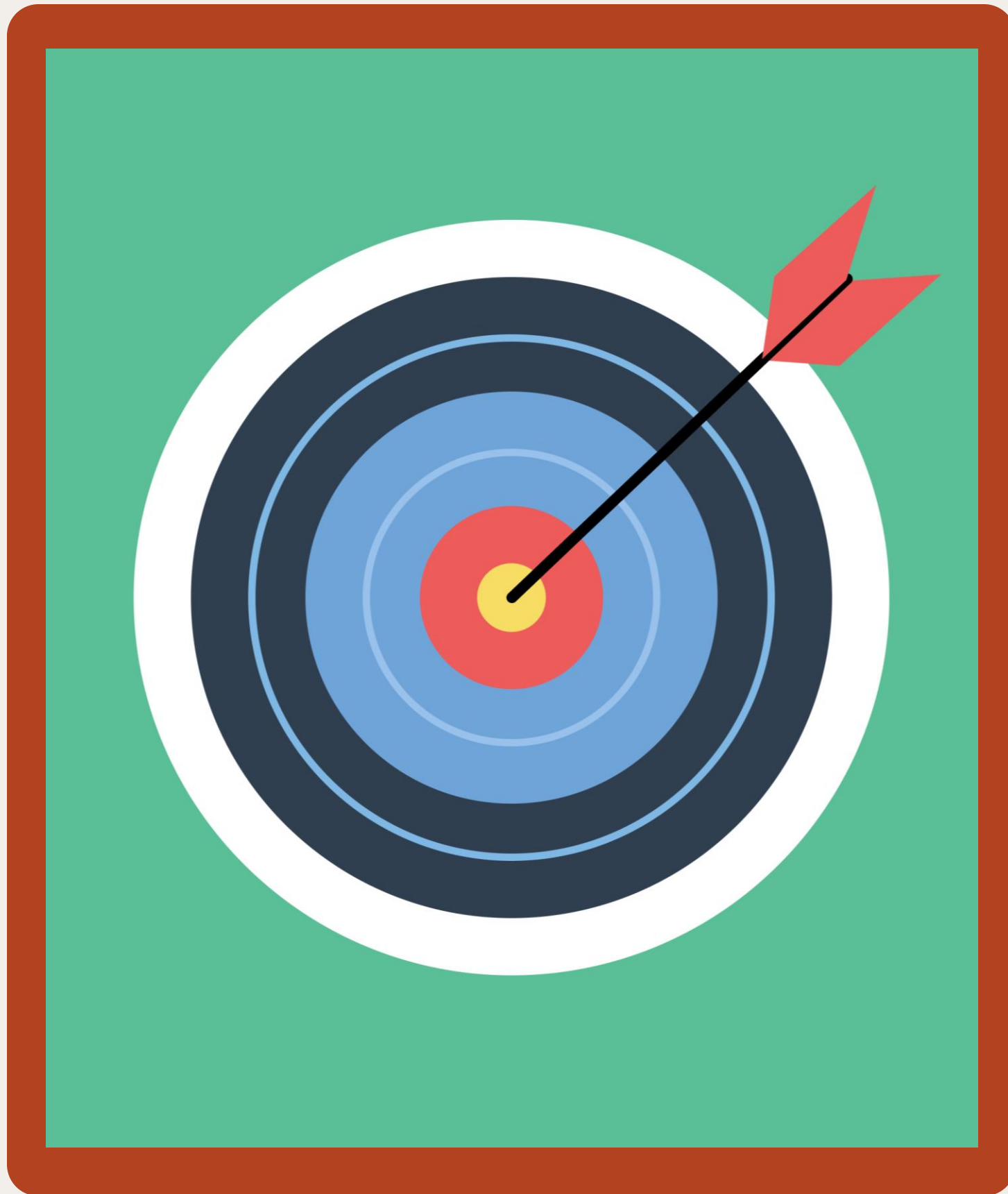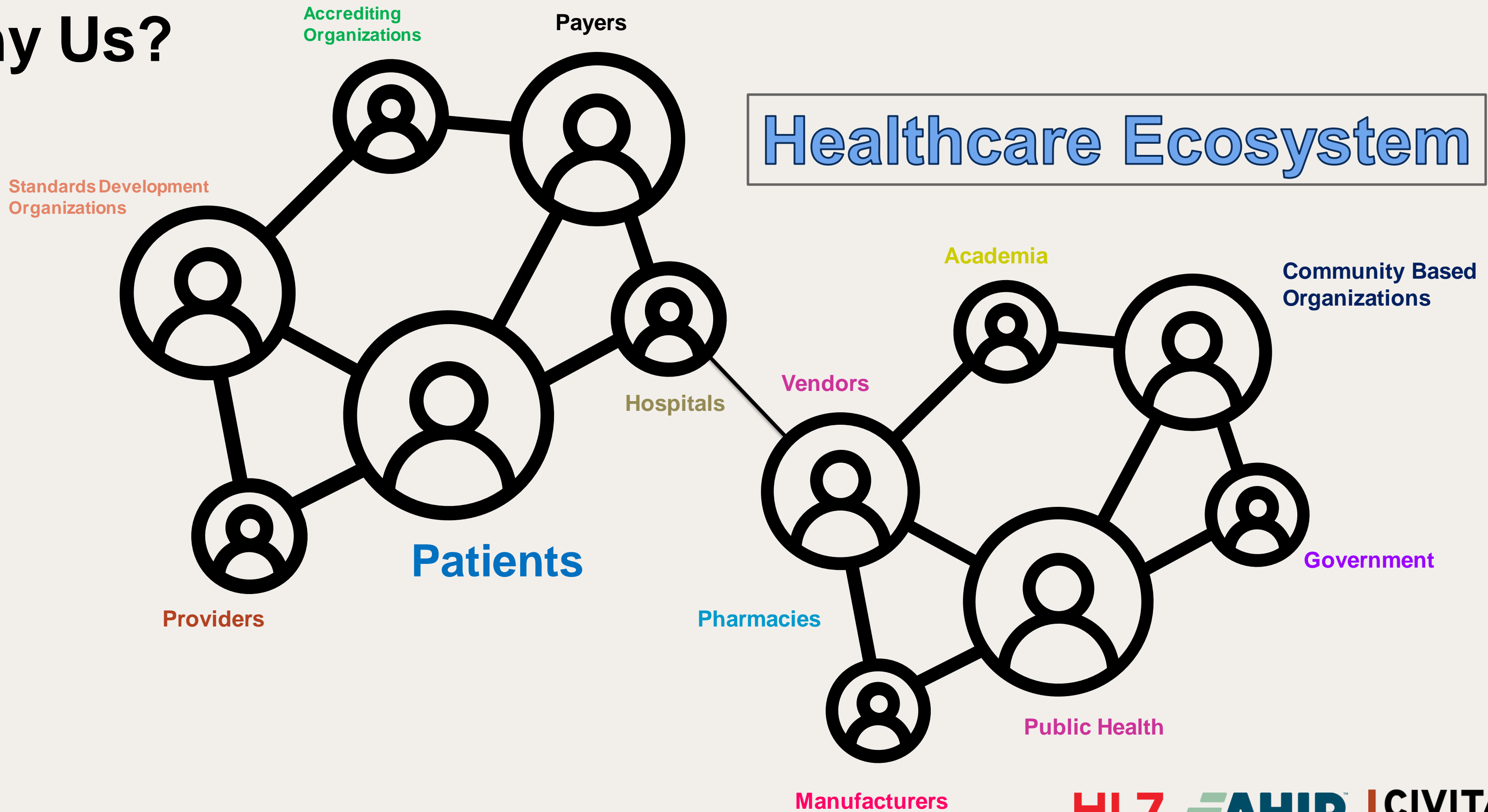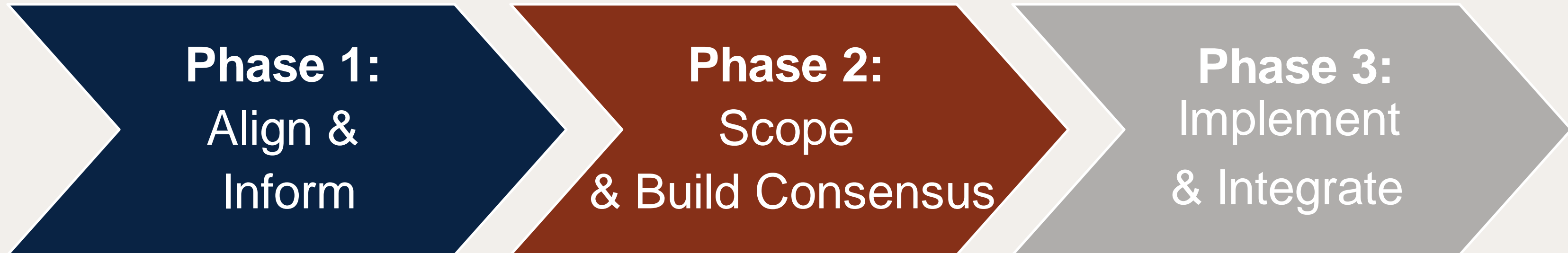
Our Goal

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.

Why Us?

Healthcare Ecosystem

Accrediting Organizations

Payers

Standards Development Organizations

Academia

Community Based Organizations

Vendors

Hospitals

Patients

Government

Providers

Pharmacies

Public Health

Manufacturers

HL7 International AHIP CIVITAS Networks for Health

How We'll Get There:

Phase 1:
Align &
Inform

Phase 2:
Scope
& Build Consensus

Phase 3:
Implement
& Integrate

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.

HL7 International **AHIP** | **CIVITAS** Networks for Health

Scope of Phase 1

What **IS** included in this phase:

- Introduction of proposed demographic data questions and response choices.
- Information gathering from stakeholders (domain expertise not required) on proposed questions and response choices to inform future phases.
- Uncovering areas of alignment.
- Thinking about content and not about building standards.

What is **NOT** included in this phase:

- Development of any data elements that are recommended as part of this alignment process.
- The HL7 standards development process, including HL7's own consensus building process.

OF NOTE: *The development of data standards, and utilization of the HL7 standards development process may be included in future phases.*

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 existing 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

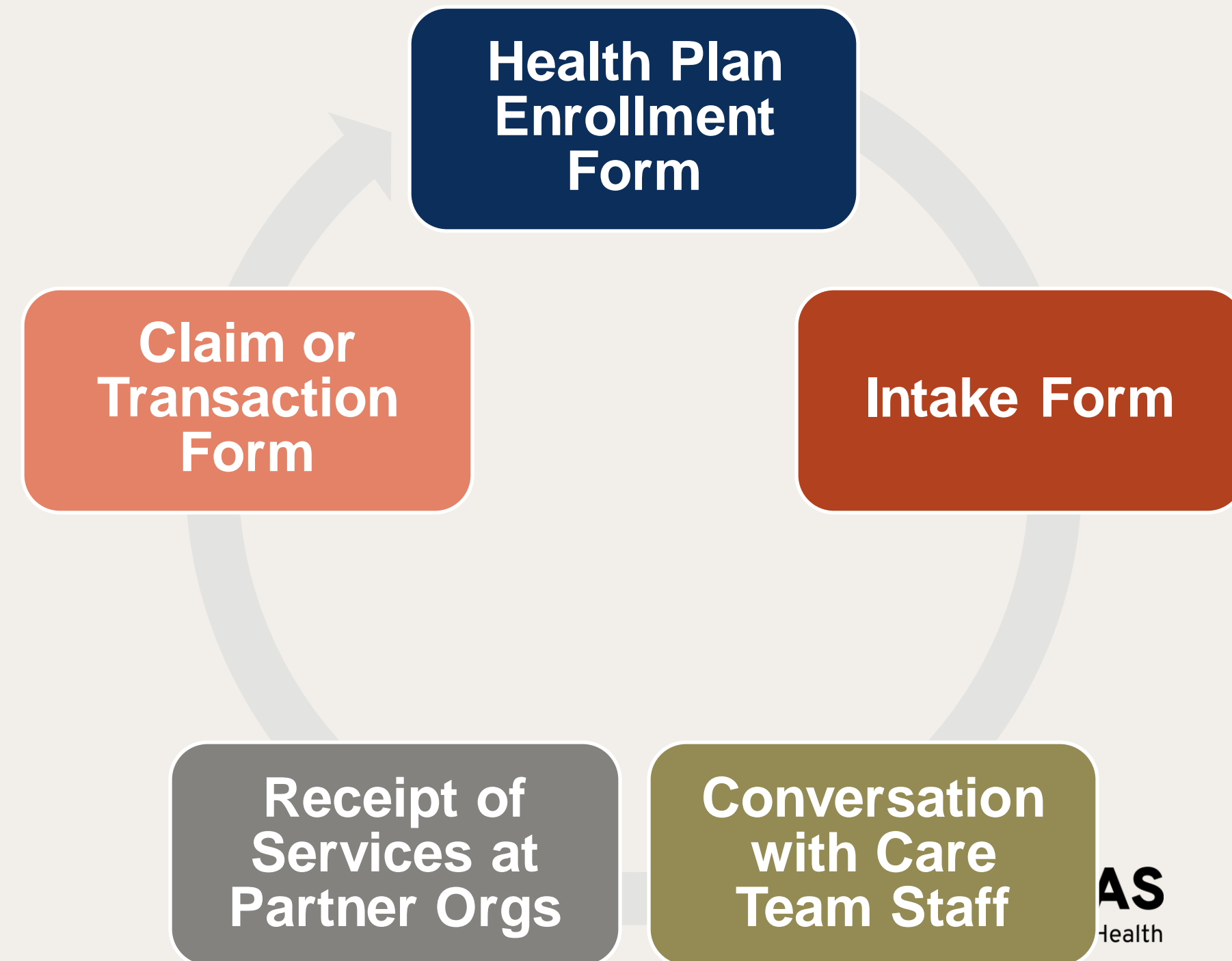HL7 International AHIP CIVITAS Networks for Health

Commonalities Across Proposed Demographic Data

- Used existing questionnaires as starting point but revised to include more appropriate terms/language and more relevant and actionable response choices.

- Person-Centered:
  - 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.

Use Cases for These Demographic Data

- Focus on demographic characteristics rather than social risks or needs.

- High-level introductory demographics we want standardized across health care ecosystem to identify disparities and to inform care.
  - Balance data needed with data burden.

- Initial data
  - Avoid being overly granular.
  - Each demographic characteristic could have additional f/u questions to better identify needs or risks.

Opportunities for Demographic Data Collection across Healthcare Ecosystem

Health Plan Enrollment Form

Intake Form

Claim or Transaction Form

Receipt of Services at Partner Orgs

Conversation with Care Team Staff

AS
Health

Race and Ethnicity

Race and Ethnicity

- **Why Is It Important to Collect Data on Race and Ethnicity?**
  - Better understand the people we serve and provide more culturally respectful care.
  - Better identify and act on disparities with culturally appropriate solutions to improve care and outcomes.

- **Commonly Used Questions**
  - Often just high-level and not very accurate or inclusive. Leads to large numbers of "Other" or "Unknown".
    - No option for Middle Eastern or North African. No option for only identifying as Hispanic or Latino/a/e.
  - Granularity often not sufficient or applicable across areas or regions.
    - Only for Hispanic/Latino and AANHPI. Not other high-level categories like Black or African.
  - Open-ended for granularity which make it difficult to aggregate and analyze.

https://www.nursingcenter.com/ncblog/july-2022/race-and-ethnicity

https://www.oprahdaily.com/life/a28787295/race-vs-ethnicity-difference/

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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)*

- Argentinian
- Bolivian
- Brazilian
- Chilean
- Colombian
- Costa Rican
- **Cuban**

- Dominican
- Ecuadorian
- Guatemalan
- Honduran
- **Mexican or Chicano**
- Nicaraguan
- Panamanian

- 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 **RED** 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
- African American
- Angolan
- Barbadian
- Cabo Verdean
- Congolese
- Dominican
- Ethiopian
- Ghanaian
- Haitian
- Jamaican
- Kenyan
- Liberian
- Nigerian
- Somali
- Sudanese
- Trinidadian
- Other:_____

Asian
- Afghan
- Bangladeshi
- Burmese
- Cambodian
- **Chinese**
- **Filipino**
- Hmong
- **Indian**
- Indonesian
- **Japanese**
- **Korean**
- Lao
- Nepalese
- Pakistani
- Sri Lankan
- Thai
- **Vietnamese**
- Other:_____

Native Hawaiian or Pacific Islander
- Chuukese
- **Chamorro**
- Fijian
- French Polynesian
- Marshallese
- Native Hawaiian
- Palauan
- Papua New Guinean
- **Samoan**
- Tongan
- Yap
- Other: _____

White or European
- Danish
- Dutch
- English
- French
- German
- Greek
- Irish
- Italian
- Lithuanian
- Norwegian
- Polish
- Portuguese
- Russian
- Scottish
- Spanish
- Swedish
- Ukrainian
- Welsh
- Other: _____

Middle Eastern or North African
- Egyptian
- Emirati
- Iraqi
- Iranian
- Jordanian
- Kurdish
- Kuwaiti
- Lebanese
- Libyan
- Palestinian
- Saudi
- Syrian
- Yemeni
- Other: ____

Native American, Alaska Native, or Indigenous
- 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?

Key Differences & Considerations on Race and Ethnicity
Decided by AHIP Health Equity Workgroup

- **Key Differences from Existing Questionnaires**
  - o Has both separate and combined race and ethnicity questions so those who only identify as Hispanic or Latino/a/e can do so.
  - o Includes category for Middle Eastern and North African.
  - o Has more granularity while balancing data burden.
  - o Uses more culturally appropriate terms.

- **Considerations**
  - o Can never be fully inclusive. Better to just have open-ended question on race and ethnicity on "Please tell us about your background." Or, "How do you identify?"
  - o Go more granular to ethnicities and tribal affiliations? Or, is it already too granular?
  - o Allow organizations to select own granular options based on prevalence of communities in their area or do we want granularity standardized across care ecosystem?
  - o Consider paper forms in addition to electronic forms with data burden.
  - o Not focusing on religious groups for these questions.
  - o Have presented these to OMB and other federal agencies. Will continue conversations.

HL7 Crosswalk

Ethnicity

Proposal

Q1: Do you identify as Hispanic or Latino/a/e? (select one)

Response Choices:
- 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 Q1A:
If you are Hispanic or Latino/a/e, what is your background?. (Select from the list or write down your response if your background is not listed)

Response Choices:
- Argentinian
- Bolivian
- Brazilian
- Chilean
- Colombian
- Costa Rican
- Cuban
- Dominican
- Ecuadorian
- Guatemalan
- Honduran
- Mexican or Chicano
- Nicaraguan
- Panamanian
- Peruvian
- Puerto Rican
- Salvadorian
- Venezuelan
- Other (please specify): _____

Gaps & Collisions

Match
- Question supported for 2 OMB ethnicity categories.

Gaps
- US Core value set representing "I choose not to respond"?

Collisions
- None

Match
- 17 response choices supported.

Gaps
- US Core detailed ethnicity value set does not include Brazilian.

Collisions
- None

HL7 FHIR R4 US Core R6.1

Ethnicity Extension:
https://hl7.org/fhir/us/core/STU6.1/StructureDefinition-us-core-ethnicity.html
https://hl7.org/fhir/us/core/ValueSet-omb-ethnicity-category.html

Response Choices:
- Hispanic or Latino
- Not Hispanic or Latino
- Asked but unknown (ASKU)
- Unknown (UNK)

Detailed Ethnicity value set:
https://hl7.org/fhir/us/core/STU6.1/ValueSet-detailed-ethnicity.html

Response Choices:
- 41 ethnicities
- Other

HTI-1/USCDI v3 specify CDC Race and Ethnicity Code Set Version 1.2 (US Core Race Extension based on Version 1.0)

Race

Proposal

Q2: 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

Option 2A: Please tell us your background. Check all that apply. If your background is not listed write on the blank line.

Middle Eastern or North African
- ….
Asian
- ….
Native Hawaiian or Pacific Islander
- ….
White or European
- ….

Black or African
- ….
Middle Eastern or North African
- ….
Native American, Alaska Native, or Indigenous
- ….

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

- What you want us to know:_____

Gaps & Collisions

Match

US Core support for at least 4 of proposed answers:
- Asian
- Native Hawaiian or Pacific Islander
- Black or African
- Native American, Alaska Native
- White
- I don't know
- Choose not to response

Gaps

- Way to only identify as Hispanic or Latino/a/e separate from OMB ethnicity: "I am Hispanic or Latino/a/e"
- FHIR US Core does not include Middle Eastern or North African
- Some AHIP proposed ethnicities not represented (e.g. Sudanese)
- CDC Race and Ethnicity codes (e.g. Does not include Sudanese)

Collisions

- None

HL7 FHIR R4 US Core R6.1

Race Extension:
https://www.hl7.org/fhir/us/core/Structure
Definition-us-core-race.html

Response Choices:
- Black or African American
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander
- White
- Other Race
- Asked but unknown (ASKU)
- Unknown*
*ValueSet expansion to include refusal

No Representation in US Core R6.1

- Middle Eastern or North African
- I only identify as Hispanic or Latino/a/e
- Cultural Identity

HTI-1/USCDI v3 specify CDC Race and Ethnicity Code Set Version 1.2 (US Core Race Extension based on Version 1.0)

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Level Setting Expectations

Groups will have 45 minutes…

Structure:

- Participants will be divided evenly into **four breakout groups** for the discussion.
- Each breakout group will be presented with the same set of questions to consider when thinking about the specific domain(s) being discussed.
- **Each group will be using Miro Board** to allow for written responses to the questions.
- Each breakout group will have a dedicated note taker and facilitator from a member of the program team.
- Each breakout group will identify a representative to report out to the full group on key themes that arose throughout the discussion.
- **There will be a 20-minute group report out at the end of the breakout discussion** – each group will have ~5 minutes to report out.

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.
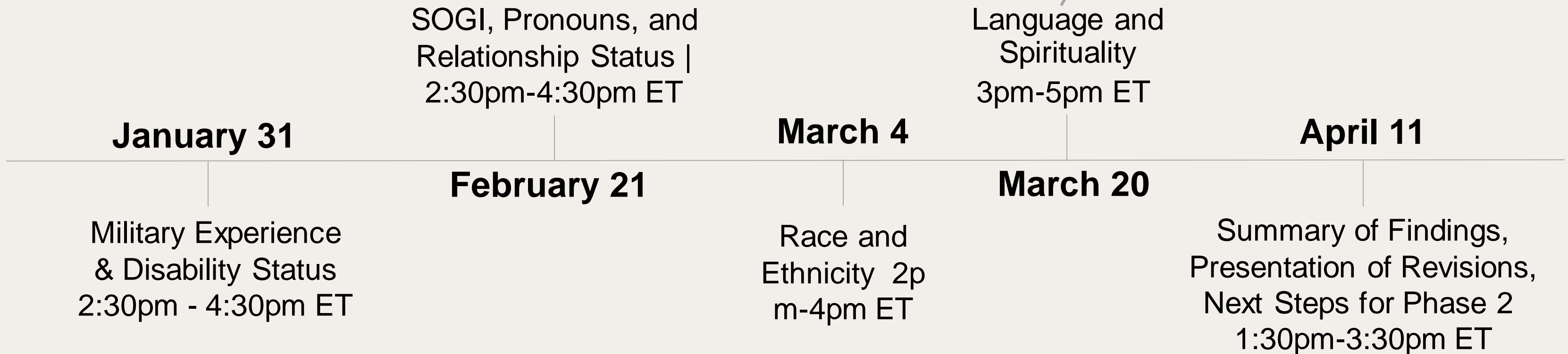
Breakout Group Discussions

Group Report Out

APPENDIX

Next Steps!

Schedule

2024

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

Language and
Spirituality
3pm-5pm ET

January 31

March 4

April 11

February 21

March 20

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

Race and
Ethnicity 2p
m-4pm ET

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

ICYMI: The slide deck
can be found HERE.

HL7 Trainings

Join Us!

- FHIR 101 | March 6, 2024 at 12pm ET (Virtual)
- HL7 Standards Lifecycle | TBD (Virtual)

Registration for March 6th Session Here: https://civitasforhealth-org.zoom.us/webinar/register/WN_Uu8jIZ8vTtiKVkCrVC1vnA#/registration

Evaluation Survey