Enhancing Demographic Questions and Response Choices

National Virtual Focus Group #2
February 21, 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: SOGI, Pronouns, and Relationship Status

- 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 SOGI
  - Breakout Session 1
  - Group Report Out 1
- Review of Proposed Questions and Response Choices for Pronouns and Relationship Status
  - Breakout Session 2
  - Group Report Out 2
- Next Steps and Closing

Program Partner Introductions

Civitas Networks for Health
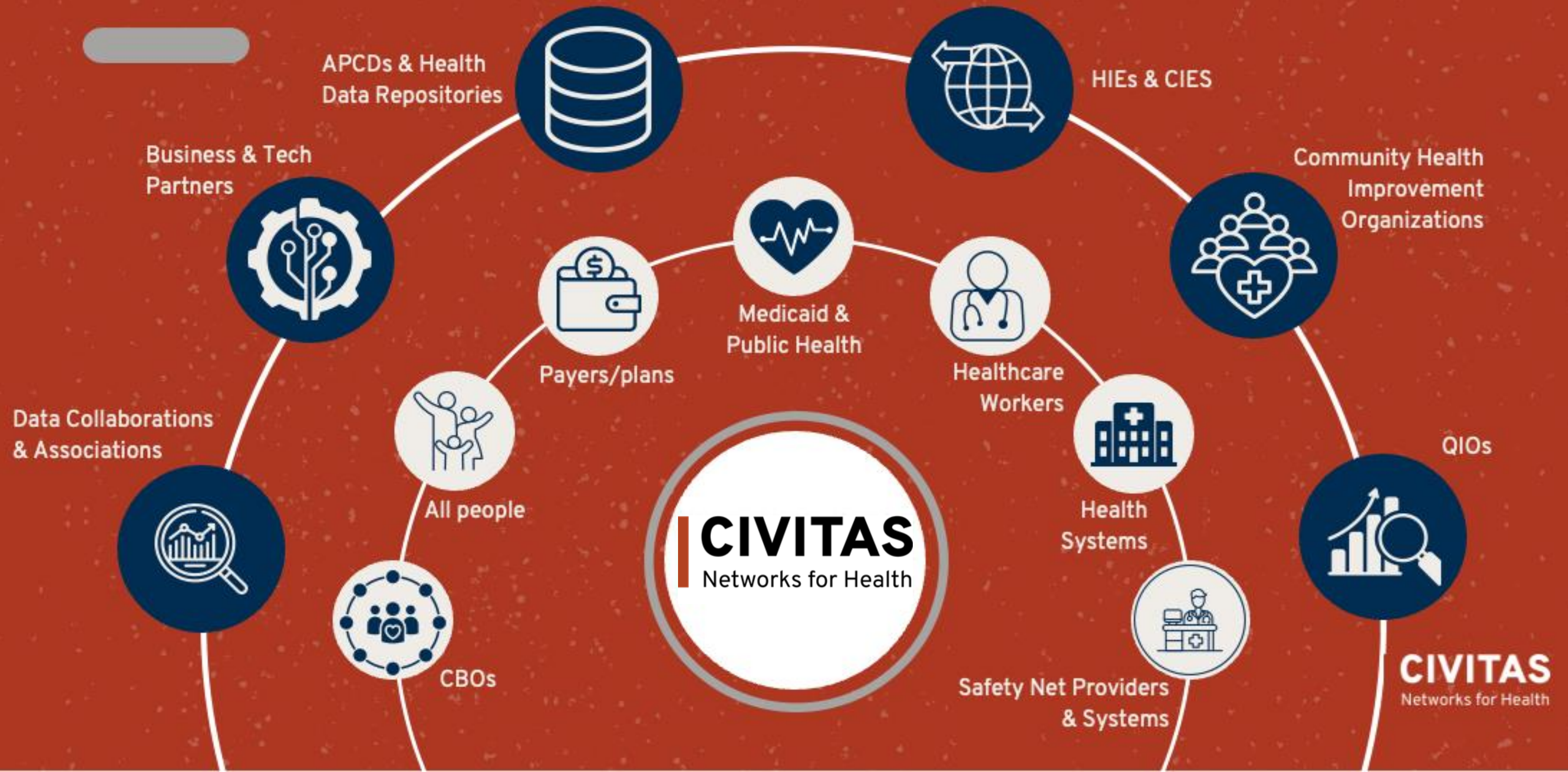
Health Level Seven® International (HL7®)

- 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.
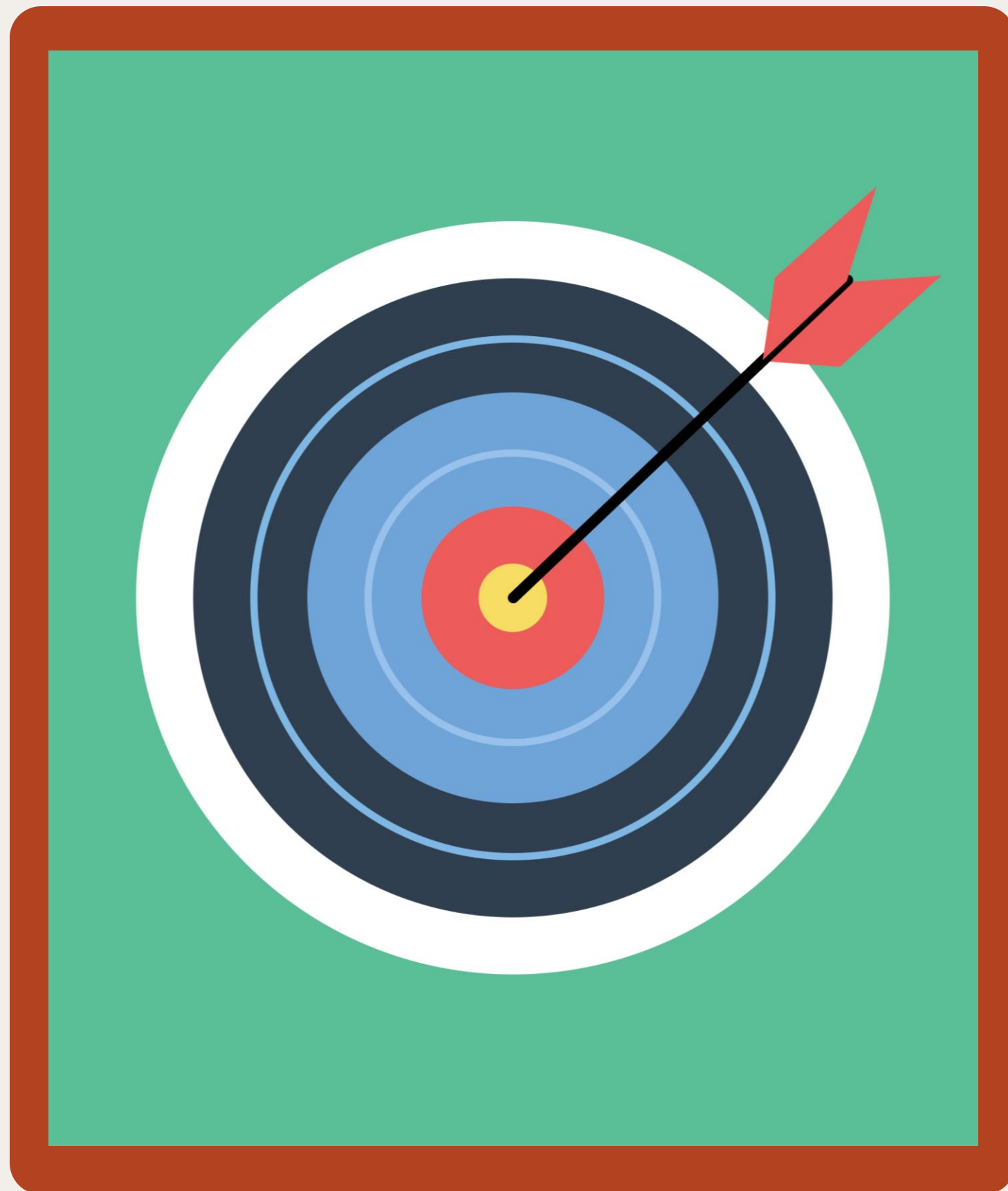
Our Goal

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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Why Us?

Healthcare Ecosystem

Accrediting Organizations

Payers

Standards Development Organizations

Academia

Community Based Organizations

Vendors

Hospitals

Patients

Government

Providers

Pharmacies

Public Health

Manufacturers

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How We'll Get There:

Phase 1:
Align &
Inform

Phase 2:
Scope
& Build Consensus
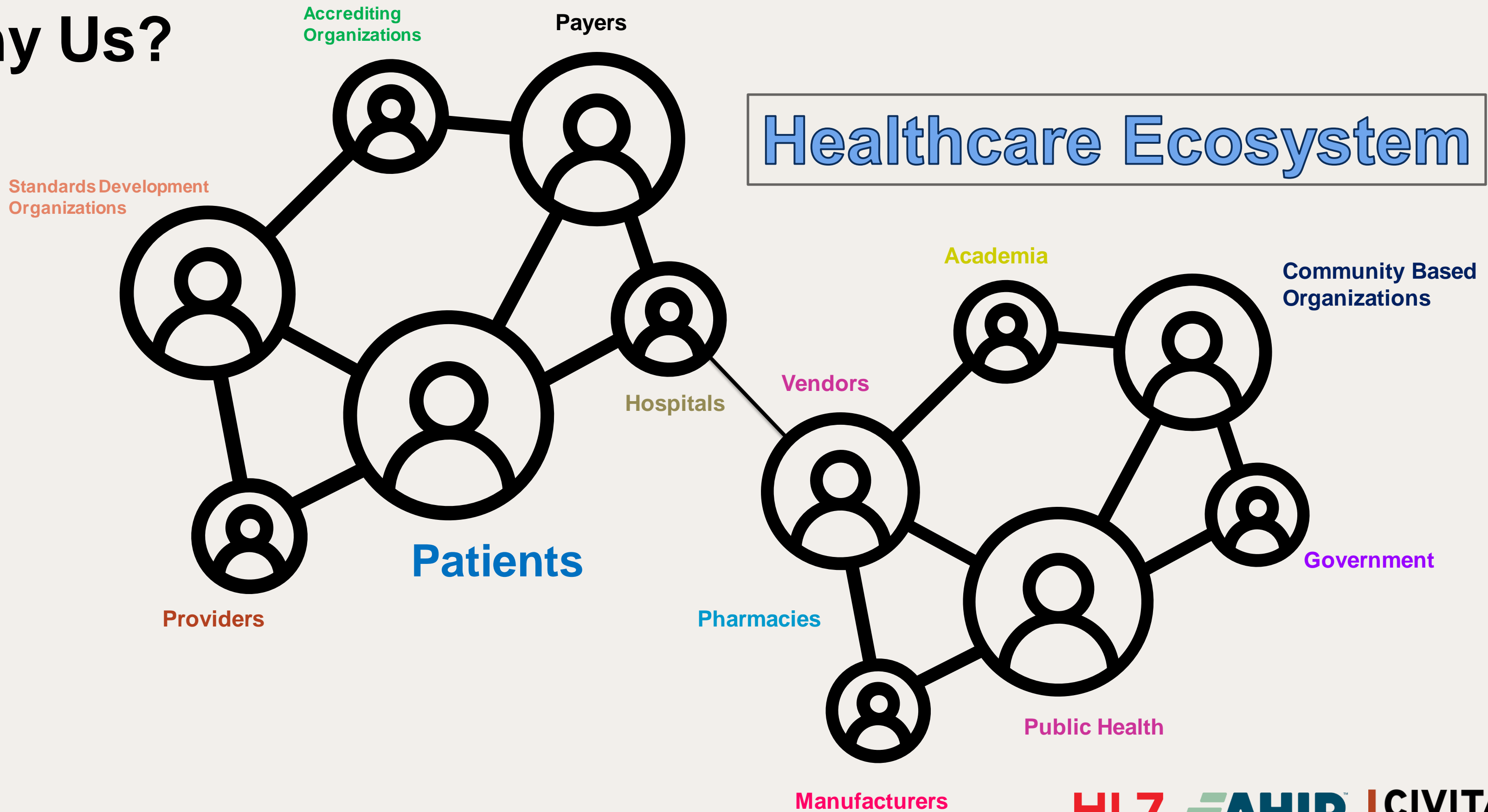
Phase 3:
Implement
& Integrate
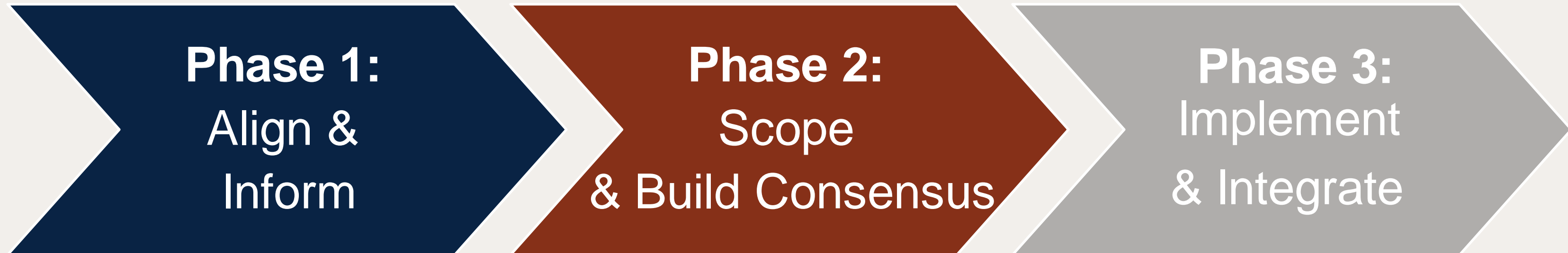
1. Align Data Elements
- Race and Ethnicity
- Sexual Orientation & Gender
- Disability Status
- Language Preference
- Military Experience
- Spirituality

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.

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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 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

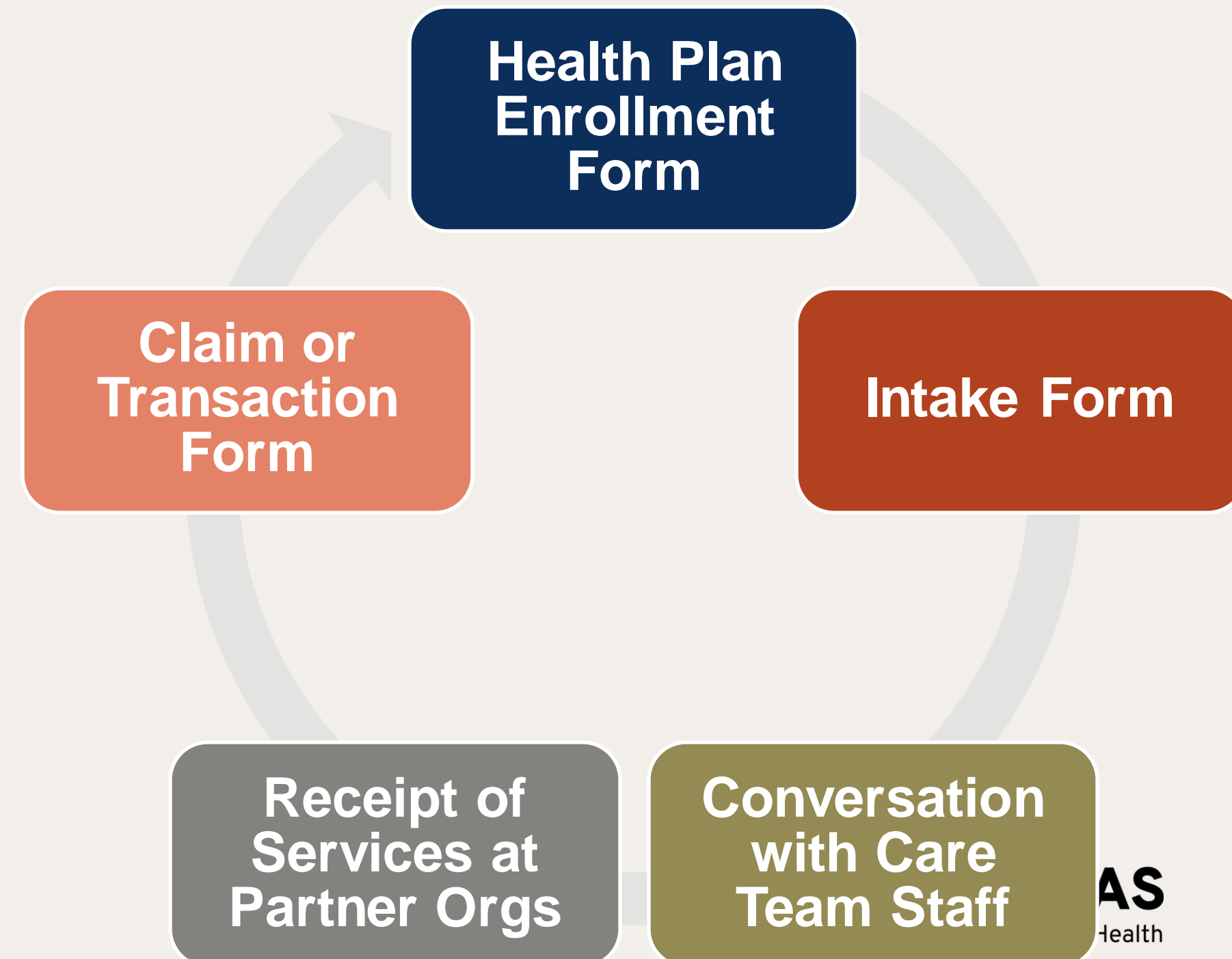HL7 International | AHIP | CIVITAS Networks for Health

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
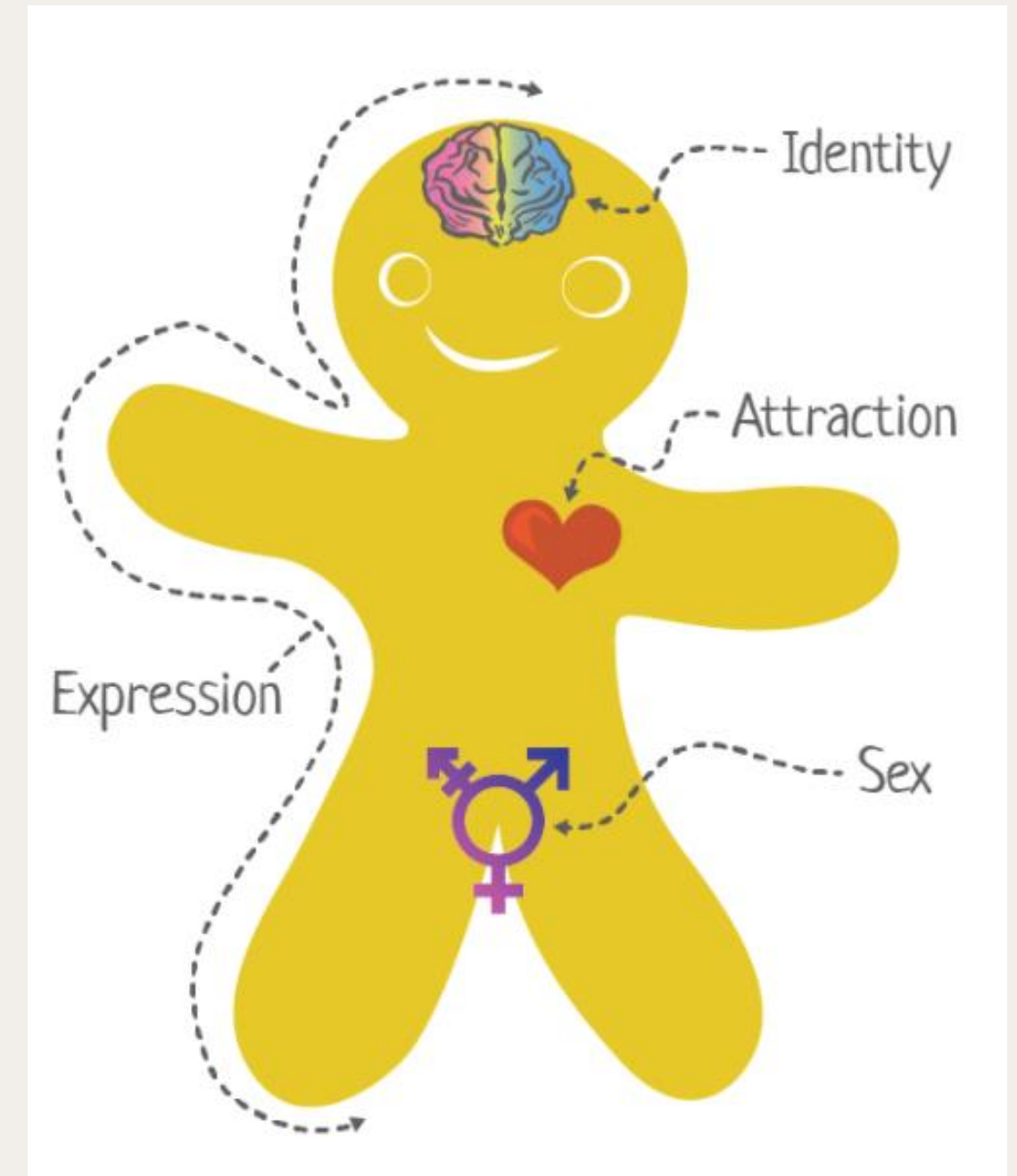
Sexual Orientation and Gender

Sexual Orientation, Sex, and Gender

- Why is it important to collect data on sexual orientation, sex, and gender?
  - Inform care and appropriate services.
  - Improve patient experience by creating safe and welcoming environment.
  - Provide affirming care.
  - Identify disparities and improve quality and accessibility of care.

https://med.stanford.edu/news/all-news/2023/06/sexual-orientation-lgbtq.html

https://operations.du.edu/inclusive-teaching/sexual-orientation-and-gender-identity

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 genders 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 LBTQIA+ 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 and Gender Harmony

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Key Differences & Considerations on Sexual Orientation & Gender
Decided by AHIP Health Equity Workgroup

- **Key Differences from Existing Questionnaires**
  - Ask for both sex and gender in case response on gender differs from response on sex.
  - Used term non-binary rather than genderqueer given its clear definition. Genderqueer is an umbrella term and has many definitions.
  - Sex for Clinical Use is NOT included in these proposed questions because it's not self-reported but rather documented by a healthcare provider based on observation of organs, hormone levels, or chromosomes.

- **Considerations**
  - Terminology in these areas of identity can change rapidly. We need to be flexible to adjust accordingly.
  - Be mindful and protective of small sample sizes to ensure individuals cannot be identified.
  - NOT including gender expression since more about how one presents gender through appearance and mannerisms.

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HL7 Crosswalk of SOGI to Existing Technical Standards

Sexual Orientation

Proposal

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

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

HTI-1 new SNOMED CT code set will replace current value sets in Jan 2026.

Gaps & Collisions

Match
- Question supported for 5 of the 8 proposed answers.

Gaps
- SNOMED does not include Other, Pansexual or Asexual choices.

Collisions
- Proposal allows up to 8 answers and HL7 FHIR R4 US Core R6.1 only allows 1 answer.

Match
- None

Gaps
- HL7 FHIR R4 US Core R6.1 does not include a text option for Proposal's Other, please specify answer.

Collisions
- None

HL7 FHIR R4 US Core R6.1

Sexual Orientation:
StructureDefinition-us-core-observation-sexual-orientation
ValueSet-us-core-sexual-orientation

Response Choices:
- Homosexuality
- Heterosexual state
- Bisexual state
- Unknown
- Asked but no answer

No Representation in US Core R6.1

Gender

Proposal

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

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

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

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

What is your gender? (Please select one)

Response Choices:
- Male, Man
- Female, Woman
- Transgender Male, Trans Man
- Transgender Female, Trans Woman
- Non-Binary, neither exclusively male nor female
- Additional gender category (Please Specify):
- Don't know
- I choose not to respond

HTI-1 new SNOMED CT code set will replace current value sets in Jan 2024.

Gaps & Collisions

Match
- Question supported for 3 of the 4 proposed answers.

Gaps
- Codeset doesn't include Intersex.

Collisions
- None

Match
- Question supported for 7 of 8 proposed answers

Gaps
- No support for Don't know answer

Collisions
- None

HL7 FHIR R4 US Core R6.1

Birthsex
Us-core-birthsex
ValueSet-birthsex

Response Choices:
- Female
- Male
- Asked but Unknown
- Other
- Unknown

Patient Gender
patient.gender
Valueset-administrative-gender

Response Choices:
- Female
- Male
- Other
- Unknown

Patient Gender Identity
Extension-patient-genderidentity
Valueset-gender-identity

Response Choices:
- Female
- Male
- Non-binary
- Transgender-male
- Transgender-female
- Other
- Not Disclosed

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Level Setting Expectations

Groups will have 20 minutes…

Structure:

- There will be **two breakout group sessions** during this meeting - one to discuss Sexual Orientation and Gender, the other to discuss Pronouns and Relationship Status.
- Participants will be divided evenly into **four breakout groups** for each.
- 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 10 minute group report out at the end of each breakout discussion** – each group will have ~2 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.

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Breakout Group Discussions

Group Report Out

Pronouns and Relationship Status

Importance of Asking for Pronouns and Relationship Status

- **Why Is It Important to Collect Data on Pronouns and Relationship Status?**
  - Shows respect and can improve patient experience.
  - Identify potential health insurance eligibility as partner.
  - Provides affirming and inclusive care.

- **Commonly Used Questions and Definitions:**
  - Common pronouns.
  - Neopronouns.
  - Marital Status as opposed to more inclusive "relationship" status.

https://today.umd.edu/how-use-pronouns-appropriately-fad1b19c-4ff9-4ed0-9cf1-7494c4ea7707

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, hirs • Ze, zir, zirs • Additional pronouns, please specify: _____ • I don't know • I choose not to respond

Adapted from Fenway Health's National LBTQIA+ Education Center

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

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Key Differences & Considerations on Pronouns & Relationship Status: *Decided by AHIP Health Equity Workgroup*

- **Key Differences from Existing Questionnaires**
  - Existing questionnaires often have open-ended questions on pronouns, do not have neopronouns, or have many neopronouns listed.
    - Trying to balance culturally appropriate response choices with data burden.
  - Most questions revolve around "Marital" status which isn't as inclusive as "Relationship" status.

- **Considerations**
  - Terminology in these areas of identity can change rapidly. We need to be flexible to adjust accordingly.
  - Ensure data is shared appropriately with care team to ensure patient-centered approaches. Don't ask for pronouns if they will not be used appropriately.

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HL7 Crosswalk of Pronouns and Relationship Status to Existing Technical Standards

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Preferred Pronouns

Proposal

Optional: What pronouns do you use to identify yourself? (Select all that apply)

Response Choices:
- He, him, his
- She, her, hers
- They, them, theirs
- Ze, Zir, Zirs
- Additional pronouns, please specify:
- Don't know
- I choose not to respond

Gaps & Collisions

Match
- Question supported for 3 of 7 proposed answers

Gaps
- ValueSet doesn't include Ze, Zir, Zirs; Additional pronouns, don't know, or I choose not to respond options.
- ValueSet doesn't include a text answer associated with and Other answer.

Collisions
- None

HL7 FHIR R4 US Core R6.1

**Individual-pronouns
structureDefinition-individual-pronouns
ValueSet-pronouns**

Response Choices:
- He, him, his
- She, her, hers
- They, them, theirs

HTI-1 requirement for LOINC codes by Jan 2026.

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Relationship Status

Proposal

Optional: relationship status

Response Choices:
- Married
- Registered domestic partnership
- Partnered, but not Registered as a legal domestic partnership
- Single
- Divorced
- Widowed
- Other (please specify):
- Choose not to respond

Gaps & Collisions

Match
- Question supported for 5 of 8 proposed answers

Gaps
- ValueSet doesn't include "Partnered, but not Registered as a legal domestic partnership", "Other", or "Choose not to respond"
- ValueSet doesn't include a text answer associated with and Other answer

Collisions
- None

HL7 FHIR R4 US Core R6.1

Marital Status
Patient.maritalStatus
Valueset-marital-status

Response Choices:
- Annulled
- Divorced
- Interlocutory
- Legally Separated
- Married
- Polygamous
- Never Married
- Domestic partner
- Unmarried
- Widowed
- Unknown
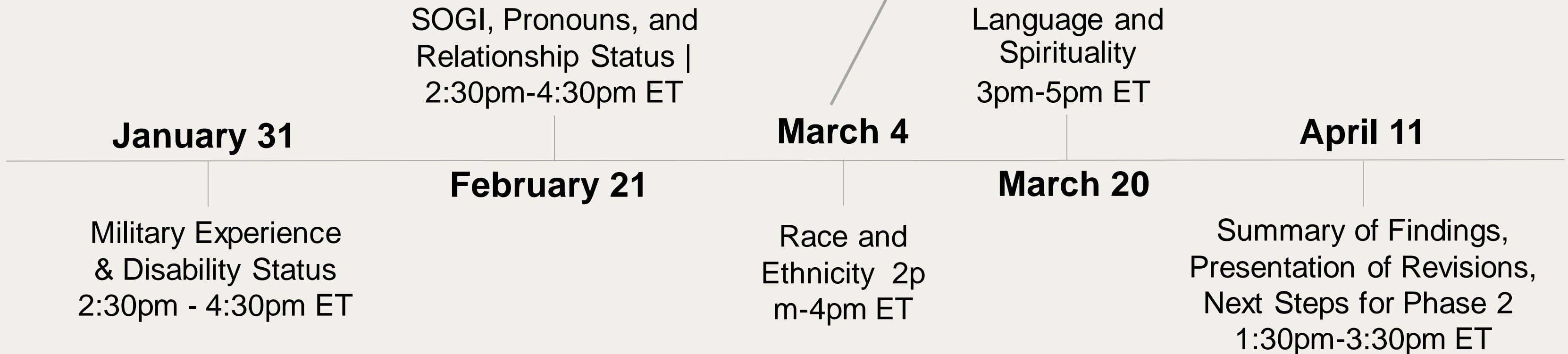
No Current Regulations.

Breakout Group Discussions

Group Report Out

Appendix

Next Steps!

Next Session: Race and Ethnicity

Date/Time: March 4, 2024 | 2:00-4:00pm ET

Registration Link: https://civitasforhealth-org.zoom.us/meeting/register/tZYsce-spzsiHNDhIgVgZUxYxcaAjsX9BREi#/registration

Schedule

2024

January 31

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

Language and Spirituality 3pm-5pm ET

March 4

February 21

March 20

April 11

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.

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Coming Soon - HL7 Trainings

Mark Your Calendars!

- FHIR 101 | March 6, 2024 at 12pm ET (Virtual)
- HL7 Standards Lifecycle | March 27, 2024 at 2pm ET (Virtual)

Once available, a registration link will be shared with all registered participants.

Evaluation Survey