CIVITAS Networks for Health HL7 International AHIP

Enhancing Demographic Questions and Response Choices

National Virtual Focus Group #4

March 20, 2024

**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

Topic Domains: Language and Spirituality

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

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Program Partner Introductions

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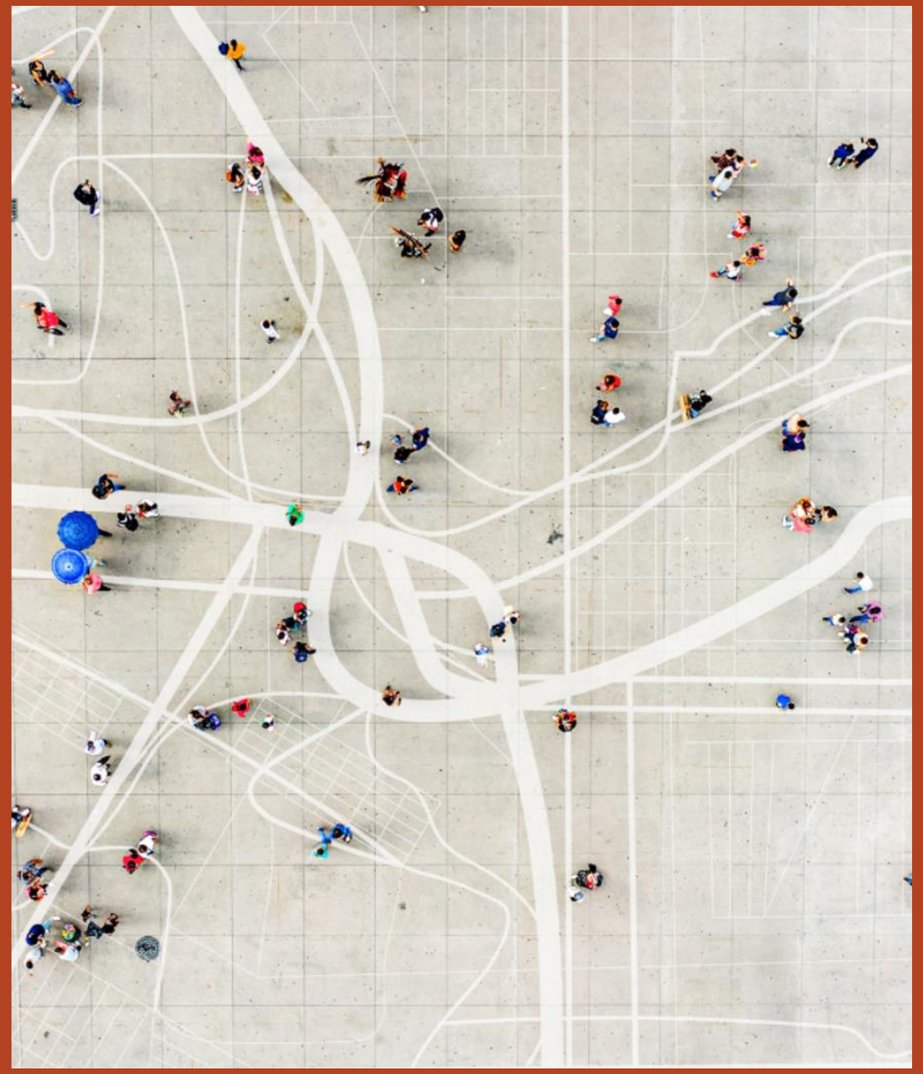

ABOUT CIVITAS

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

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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

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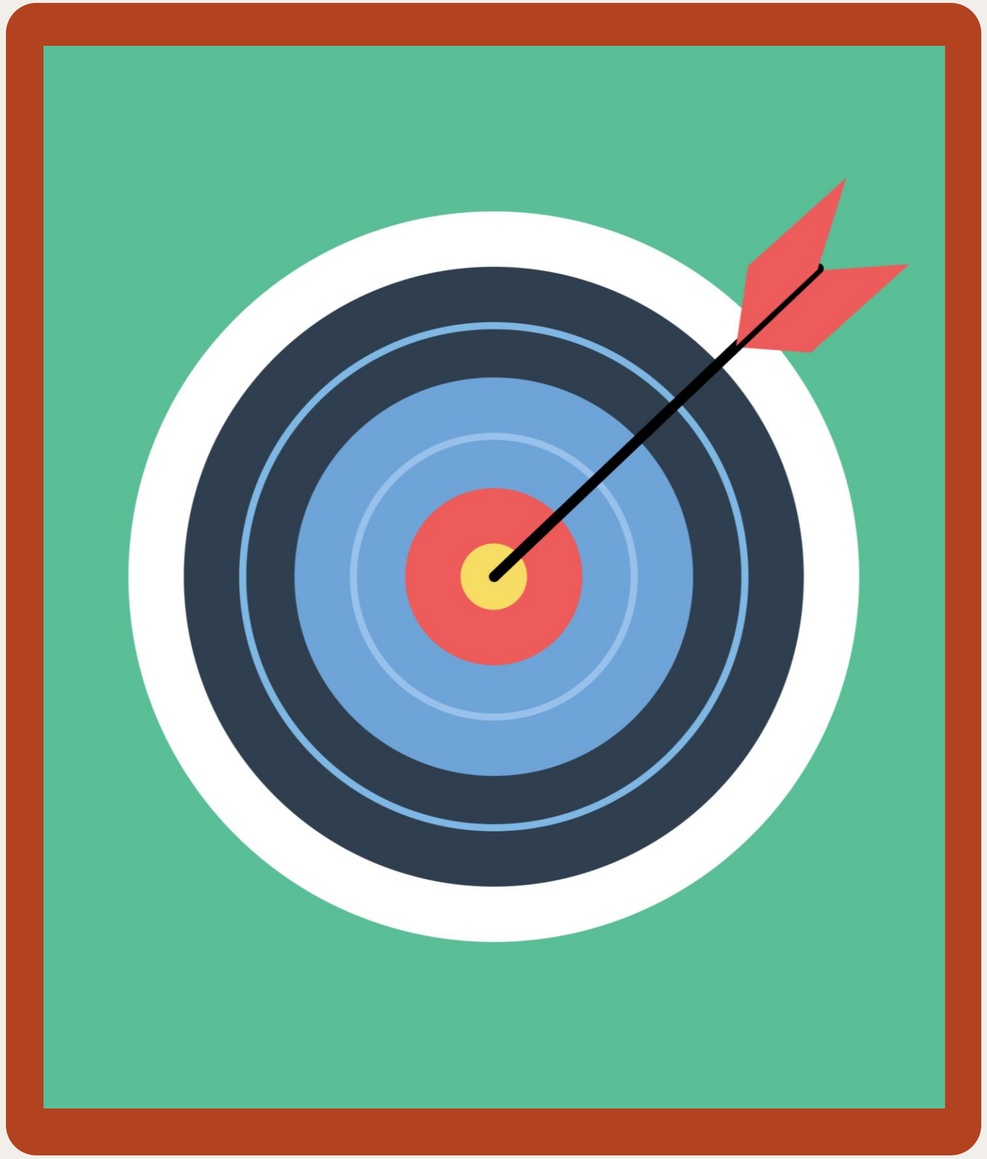
About AHIP

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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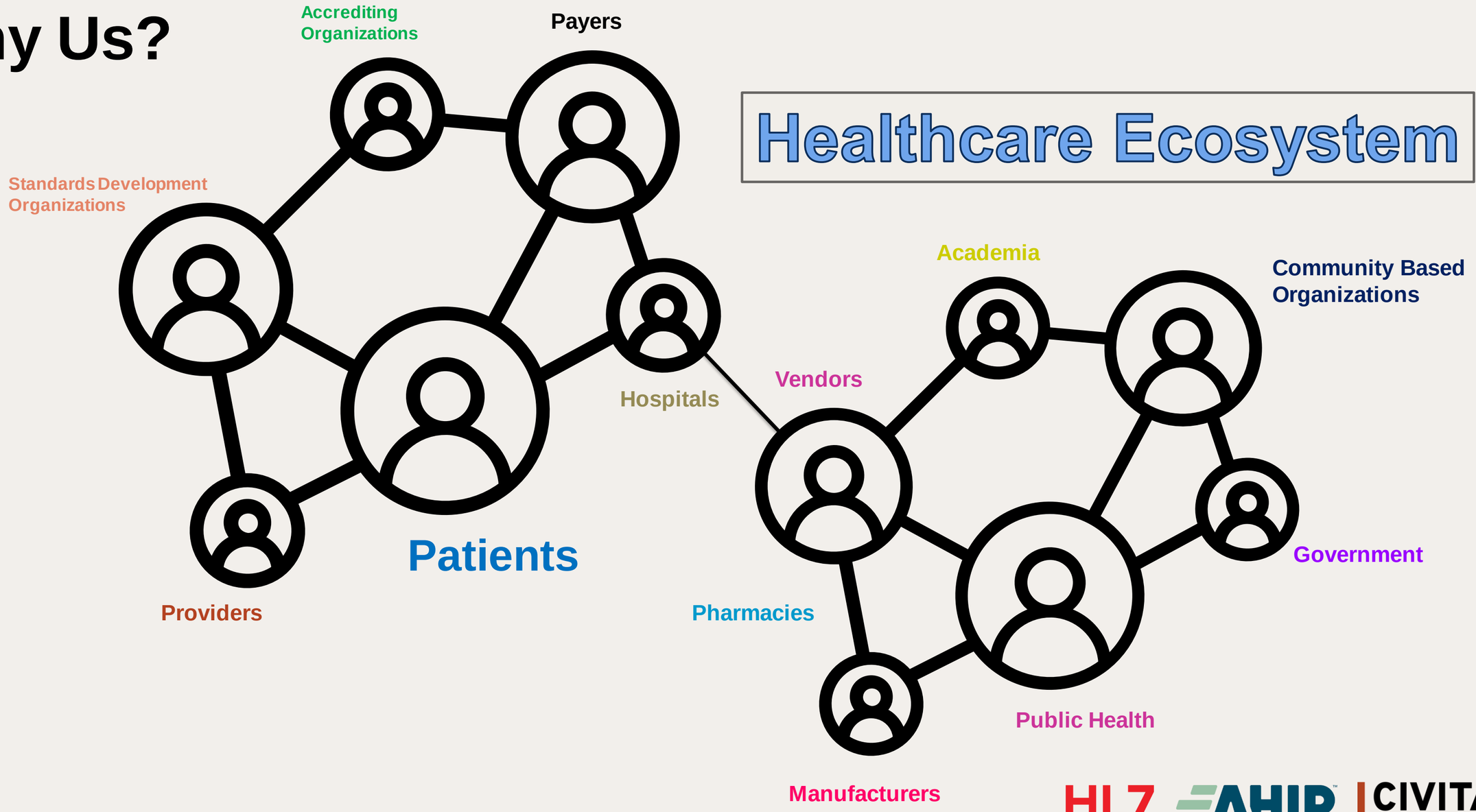
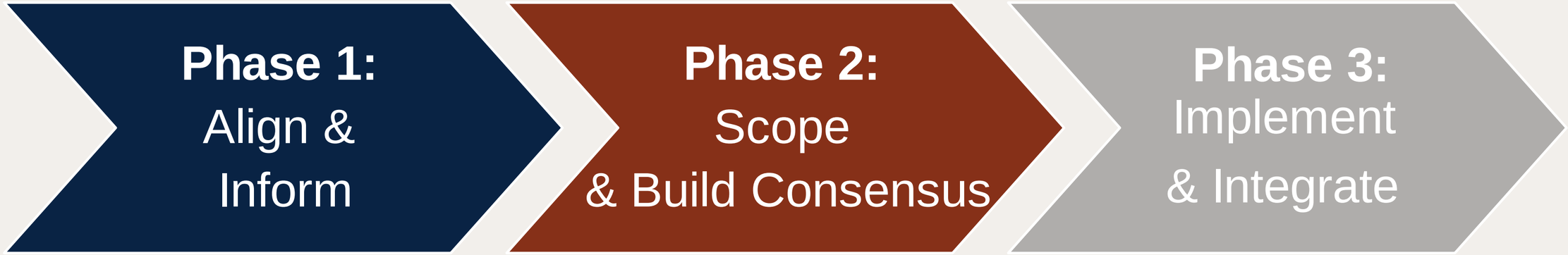
Why Us?


Accrediting Organizations
Payers
Healthcare Ecosystem
Standards Development Organizations
Academia
Community Based Organizations
Vendors
Hospitals
Patients
Providers
Pharmacies
Government
Public Health
Manufacturers

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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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.*

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AHIP's Work to Date on Demographic Data

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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

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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.

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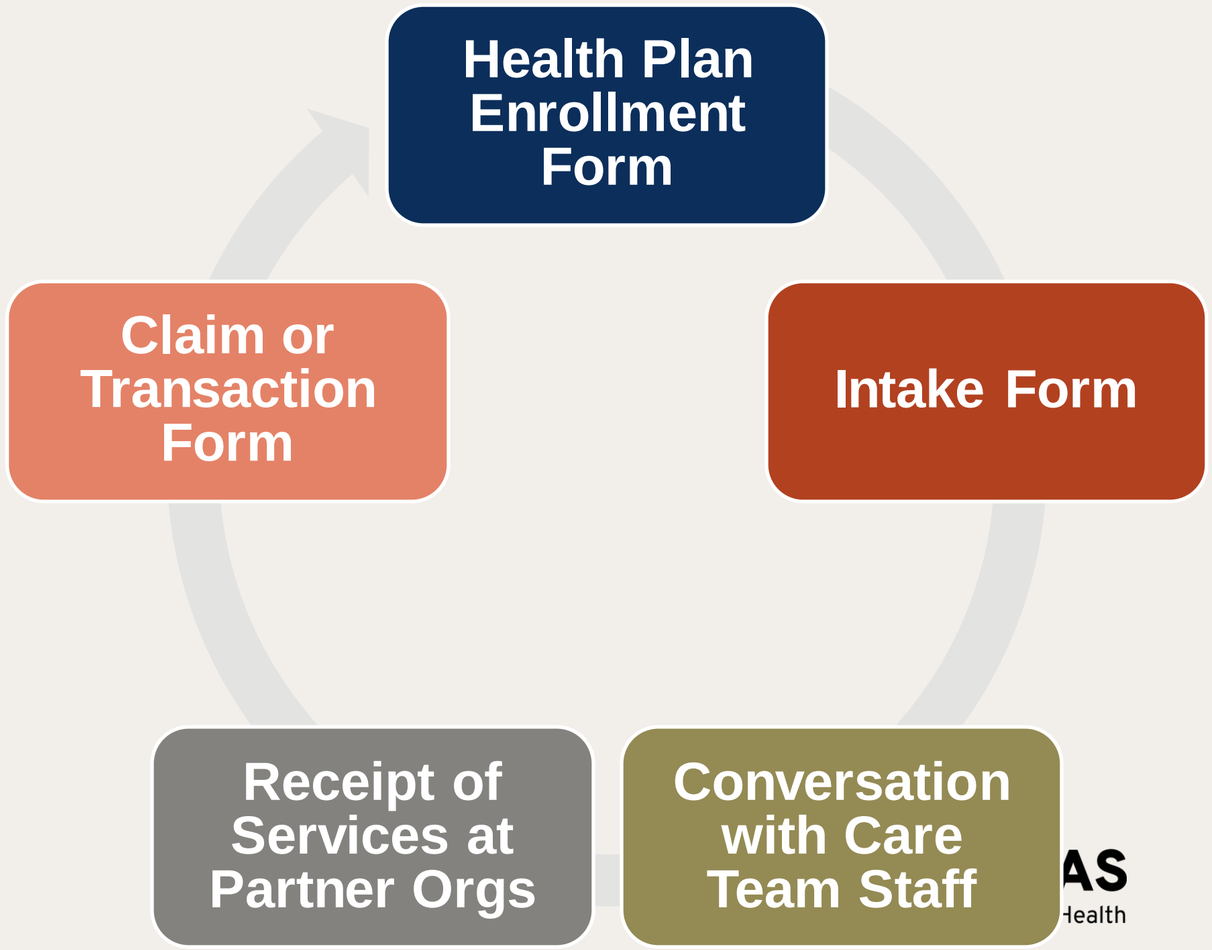
Use Cases for These Demographic Data

- 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



Language

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Language Preference

https://abroadlink.com/blog/how-many-languages-are-spoken-in-the-world

Why Is It Important to Collect Data on Language?

- Improve person-centered care: Meet individual where they are and provide information (in written or spoken form) in language that individual would most likely understand to better manage health.

Common Questionnaires:

- Often open-ended or high-level of 5-15 most common languages across U.S.
- Often focus on "English proficiency" (judgmental & not actionable) rather than "language preference".

Considerations:

- Consider additional questions may need to ask on a paper form to inform communications outreach and/or to receive care in-person with interpreter.
  - Plan for contingencies if cannot meet individual's particular preference.
- Meant for health care setting.

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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)					
• Dutch • English • French • German • Greek • Italian • Pennsylvania Dutch (Pennsylvania German) • Polish • Portuguese • Russian • Spanish • Yiddish	• Bengali • Burmese • Cantonese • Dari • Hindi • Hmong • Japanese • Karen • Karenni • Khmer • Korean • Lao • Mandarin • Pashto • Tagalog • Vietnamese	• Amharic • Arabic • Farsi • Haitian Creole • Hebrew • Somali • Swahili	• Chuukese • Hawaiian • Marshallese • Samoan • Tongan	• Cherokee • Crow • Dakota • Inupiaq • Lakota (Sioux) • Muscogee • Navajo (Diné • Ojibwe • O’oodham • Western Apache • Yu’pik • Zuni	• 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

<u>Speaking:</u> 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)					
• Dutch • English • French • German • Greek • Italian • Pennsylvania Dutch (Pennsylvania German) • Polish • Portuguese • Russian • Spanish • Yiddish	• Bengali • Burmese • Cantonese • Dari • Hindi • Hmong • Japanese • Karen • Karenni • Khmer • Korean • Lao • Mandarin • Pashto • Tagalog • Vietnamese	• Amharic • Arabic • Farsi • Haitian Creole • Hebrew • Somali • Swahili	• Chuukese • Hawaiian • Marshallese • Samoan • Tongan	• Cherokee • Crow • Dakota • Inupiaq • Lakota (Sioux) • Muscogee • Navajo (Diné • Ojibwe • O’oodham • Western Apache • Yu’pik • Zuni	• 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?
  - Phone Call
  - Text Message
  - Email
  - Mailed Letter
  - I do not know
  - I choose not to respond

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Language

Proposal

What language do you feel most comfortable speaking about your healthcare?

Response Choices:
- English
- Spanish
- ……
- Amharic
- American Sign Language
- Other Sign Language: _____
- Other Language: _____
- I choose not to respond

If an interpreter in your preferred language was avaialble right now, would you choose to use one for your healthcare visit?

Response Choices:
- Yes
- No

Are you comfortable using an interpreter if they are only available through:

Response Choices:
- Telephone – Yes
- Video – Yes
- In-Person - Yes
- **Telephone - No**
- Video – Yes
- In-Person - Yes

What language do you prefer to use when reading materials related to your health care?

Response Choices:
- English
- Spanish
- ……
- Amharic
- Braille
- Large Print
- Digital Documents
- Other Language: _____
- I choose not to respond

Outreach Preferences: How would you prefer to be contacted with information related to your hrealthcare?

Response Choices:
- Phone Call
- Text Message
- Email
- Mailed Letter
- I do not know
- I choose not to answer

Gaps & Collisions

Match
- 17 of 22 answer choices available

Gaps
- Cantonese, Mandarin, Farsi, American Sign Language, and I choose not to respond are not supported in ISO639-1 or ISO639-2

Interpreter Needed is proposed in USCDI v5

HL7 FHIR R4 US Core R6.1

StructureDefenition-us-core-patient.html

ValueSet

Response Choices:
- English
- Spanish
- Chinese
- French
- ...
- Tagalog

Not supported in FHIR US Core

Not supported in FHIR US Core

Not supported in FHIR US Core

Not supported in FHIR US Core

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Spiritual Beliefs

Spiritual Beliefs

Why Is It Important to Collect Data on Spiritual Beliefs?

- Improve person-centered care: Spiritual beliefs can impact how an individual manages their health and how/when/where someone seeks health care.

https://www.globaldisciples.ca/blog/world-religions-and-cults/

Common Questionnaires:

- Don't tend to exist or is not asked.

Considerations:

- Optional.
- Meant for health care setting.
- Try to balance open ended actionable questions with structured data question.
- Plan for contingencies if cannot meet individual's particular preference.

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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'I
- 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

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

Spirituality

Proposal

What is your current religion, if any?

Response Choices:
- Christian: Roman Catholic
- Christian: Protestant
- Jewish (Judaism
- …
- Atheist (do not believe in God)
- Agnostic (not sure if there is a God)
- Something else: _____
- Nothing in particular
- I choose not to respond

Is religion, spirituality, or a beliefv system a key part of your health or how you like to receive healthcare?

Response Choices:
- 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 healthcare?

Response Choices:
- _____

Gaps & Collisions

Match

- FHIR Core Extension - Religious Affiliation Value Set includes16 of 20 proposed answers

Gaps

- Religious Affiliation Value Set does not include answers for Something Else, Nothing in particular, or I choose not to respond

Collisions

- Value Set includes Native American when proposal is for Ancestral, indigenous, tribal beliefs

No Government Regulations for this Data Element.

HL7 FHIR R4 US Core R6.1

Not supported in FHIR US Core
But available via extension in FHIR Core
StructureDefinition-patient-religion.html

Response Choices:
- ReligiousAffiliation/vs.html

Not supported in FHIR US Core

Not supported in FHIR US Core

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Level Setting Expectations

Groups will have 45 minutes…

Structure:

- Participants will be divided evenly into **three 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 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.

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Breakout Discussions

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Group Report Out

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Next Steps!

Next Session: Summary of Findings and Presentation of Revisions

Date/Time: April 11 | 1:30pm-3:30pm 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 2pm-4pm ET

March 20
Language and Spirituality 3pm-5pm ET

April 11
Summary of Findings and Presentation of Revisions 1:30pm-3:30pm ET

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HL7 Trainings

Join Us!

- HL7 Standards Lifecycle | April 9 from 3-4pm ET

Registration Link Here: https://civitasforhealth-org.zoom.us/webinar/register/WN_LB5_Quw3RkaTxPF5N9JmkA

Evaluation Survey

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