

Demographic Data Collection

Special (EX) Committee on Race and Insurance Health Workstream

October 24, 2024



Danielle A. Lloyd
SVP, Private Market Innovations & Quality Initiatives
dlloyd@ahip.org
202-778-3246



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.

Demographic Data Collection

Challenges with Demographic Data Collection

Inaccurate, Incomplete Data

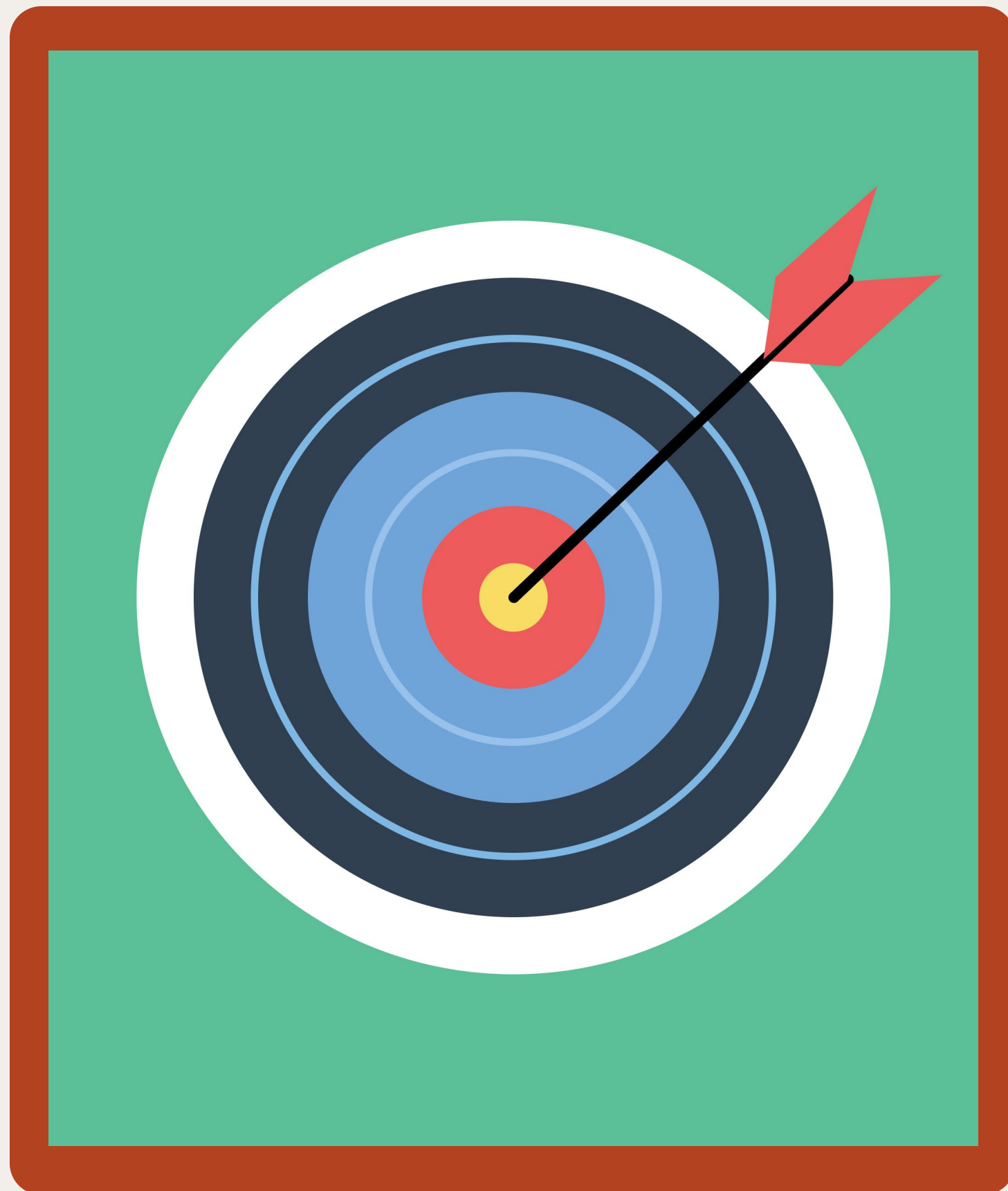
- Responses to surveys low
- Answers are often missing, or individuals chose “Other,” or “Unknown”
- Not all necessary domains are covered

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



Demographic Data Element Modernization (DEMo) Initiative

Mission:

- Advance Health Equity through Better Demographic Data.

Goal:

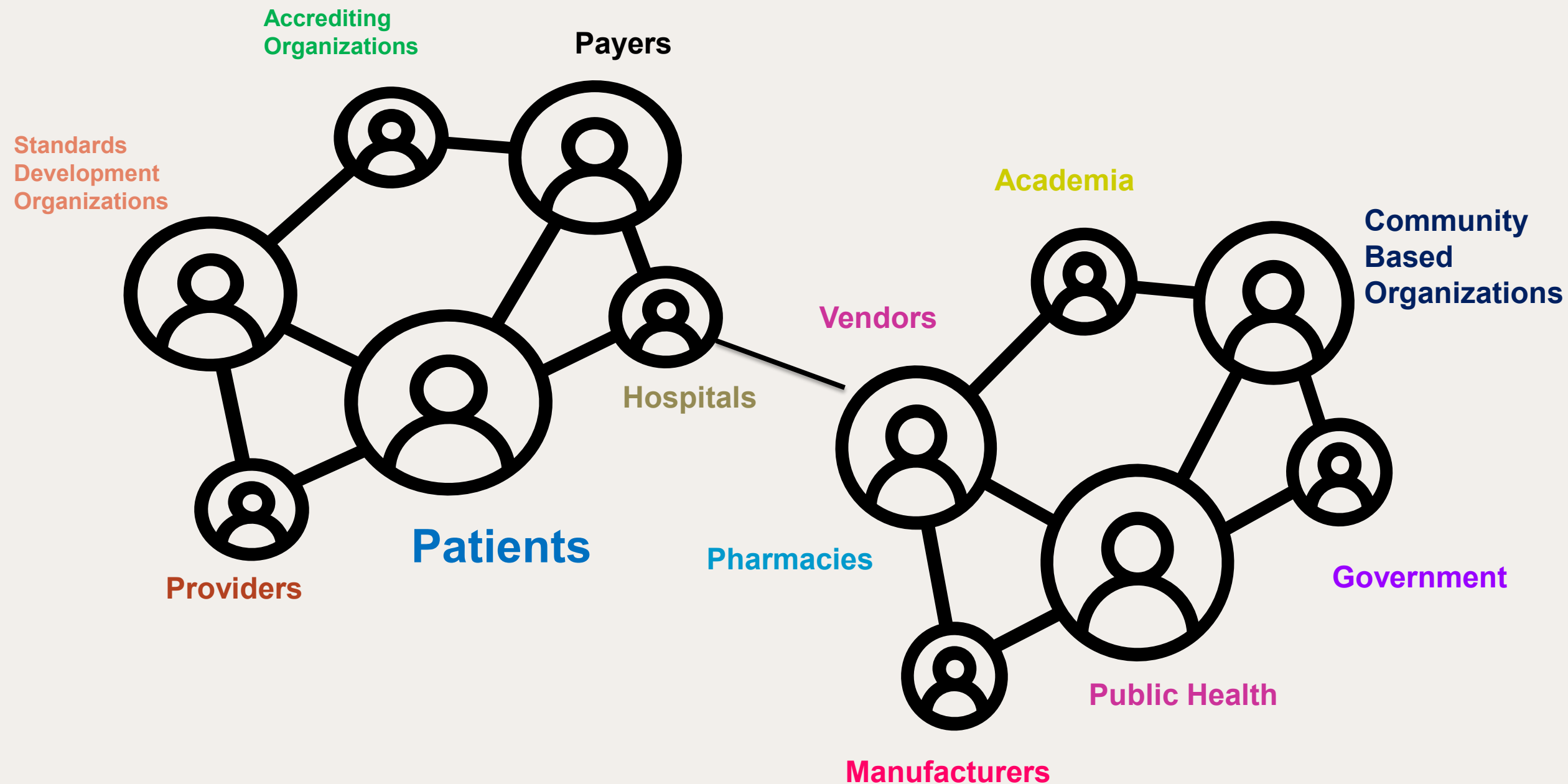
- Modernize and enhance national demographic data content and exchange standards so that they are culturally sensitive, sufficiently granular, and allow for alignment across stakeholders.

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.

[FIND US HERE: www.civitasforhealth.org/demographic-data-standards](http://www.civitasforhealth.org/demographic-data-standards)

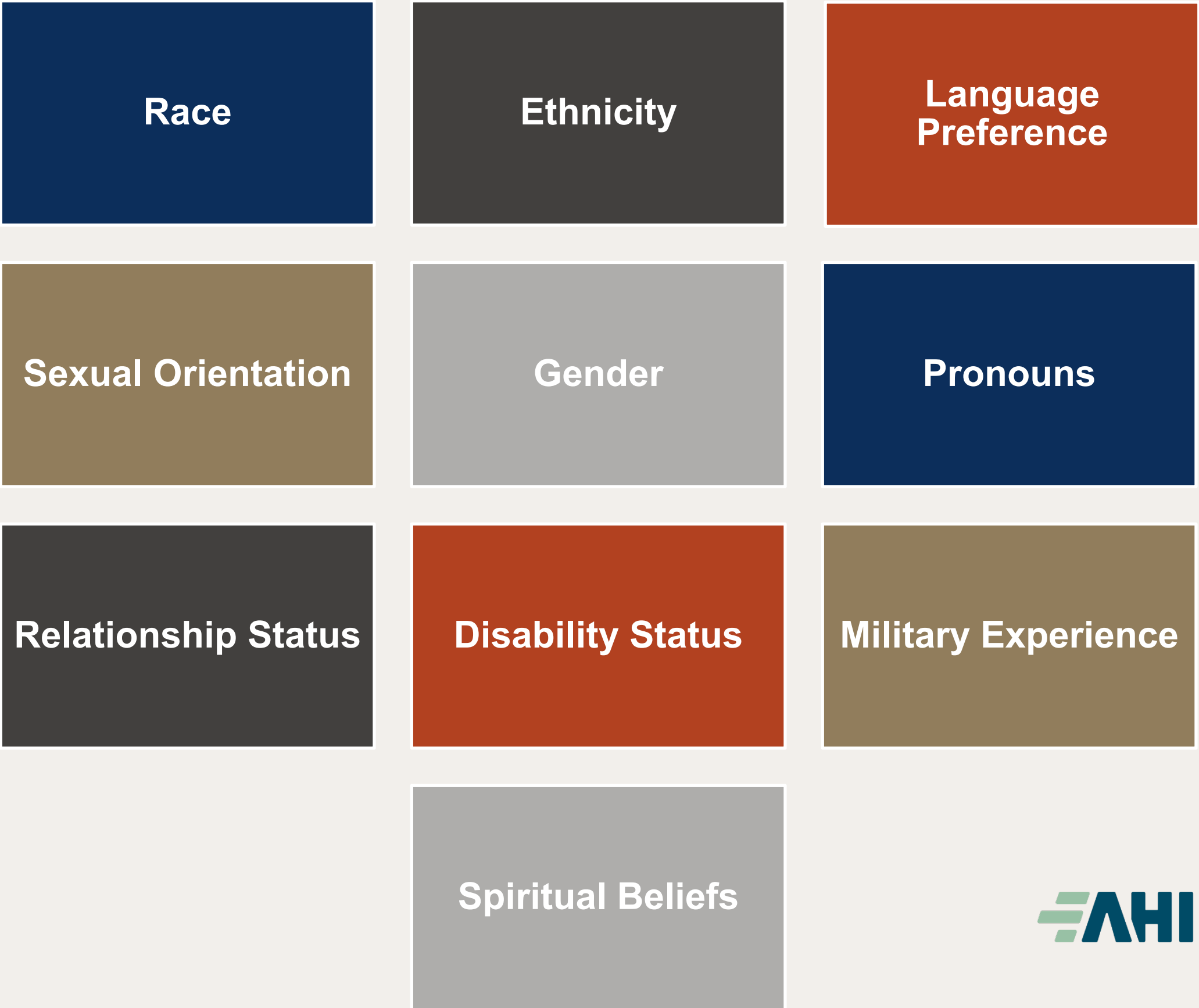
Standards Will Be Most Effective if Adopted Across the Healthcare Ecosystem



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

Domains of Focus for Inclusive Representation of Identity



Guiding Principles

Focus on Demographic Characteristics Not Health-Related Social Needs

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

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

General Feedback

- Across all domains, participants heavily emphasized the need to clearly state the reason for asking these questions, how this data/information will be used, who will have access to this data, and how this data will be protected.

Template Script

We understand that many things in life can affect your health. We are always looking to better understand our members' needs to improve the services we can offer. Would you be willing to help us learn more about you? It should only take 5 – 10 minutes. Some of the questions are personal and you don't have to answer them if you don't want to. We protect everything that you share just like how we protect your health information. Only members of the care team and other support service staff will have access to this information. This information will be used to help inform care and services that we provide you, whether now or in the future. It will also help us make sure you're getting the care you want and need. Your decision to answer or to refuse to answer will NOT impact your ability to receive care.

[If administered in-person or orally over the phone: Do you have any questions before we get started?].

[If administered on paper form: Please let us know if you have any questions or concerns by contacting XYZ].

Q

Figure 2: Disability Status – Initial Strawman Questions

Disability Status
<p>Do you have difficulty with any of the following? Check all that apply.</p> <ul style="list-style-type: none">• 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 language• Other difficulties when doing activities throughout your day (please describe)• 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.

Figure 2A: Disability Status – Version 2

Disability Status
<p>Because of a physical or mental health condition, do you currently have difficulty with any of the following? Check all that apply.</p> <ul style="list-style-type: none">• 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

A

Results from the National Convenings:

Examples of Changes

Military Experience

- Further delineated the options for when did you serve
- Removed “Discharged” from the question
- Split out family member experience into its own question

Disability Status

- Expanded the list of basic activities of daily living (ADLs)
- Separated out ability to communicate versus being understood
- Added the word “currently” to the question

Sexual Orientation, Sex, Gender

- Included “at this time” after “I choose not to respond”
- Removed the question about *legal* sex
- Included “Gender fluid” and “Two-Spirit” as responses choices

Results from the National Convenings:

Examples of Changes

Pronouns, Relationship Status

- Included a response choice for “Use my name”
- Included “dating” as a response choice and other relationship types such as polyamorous

Race, Ethnicity

- Race and Ethnicity were combined into a single question
- Created second granular optional question

Language Preference

- Included an option for “select all that apply”
- Added additional languages

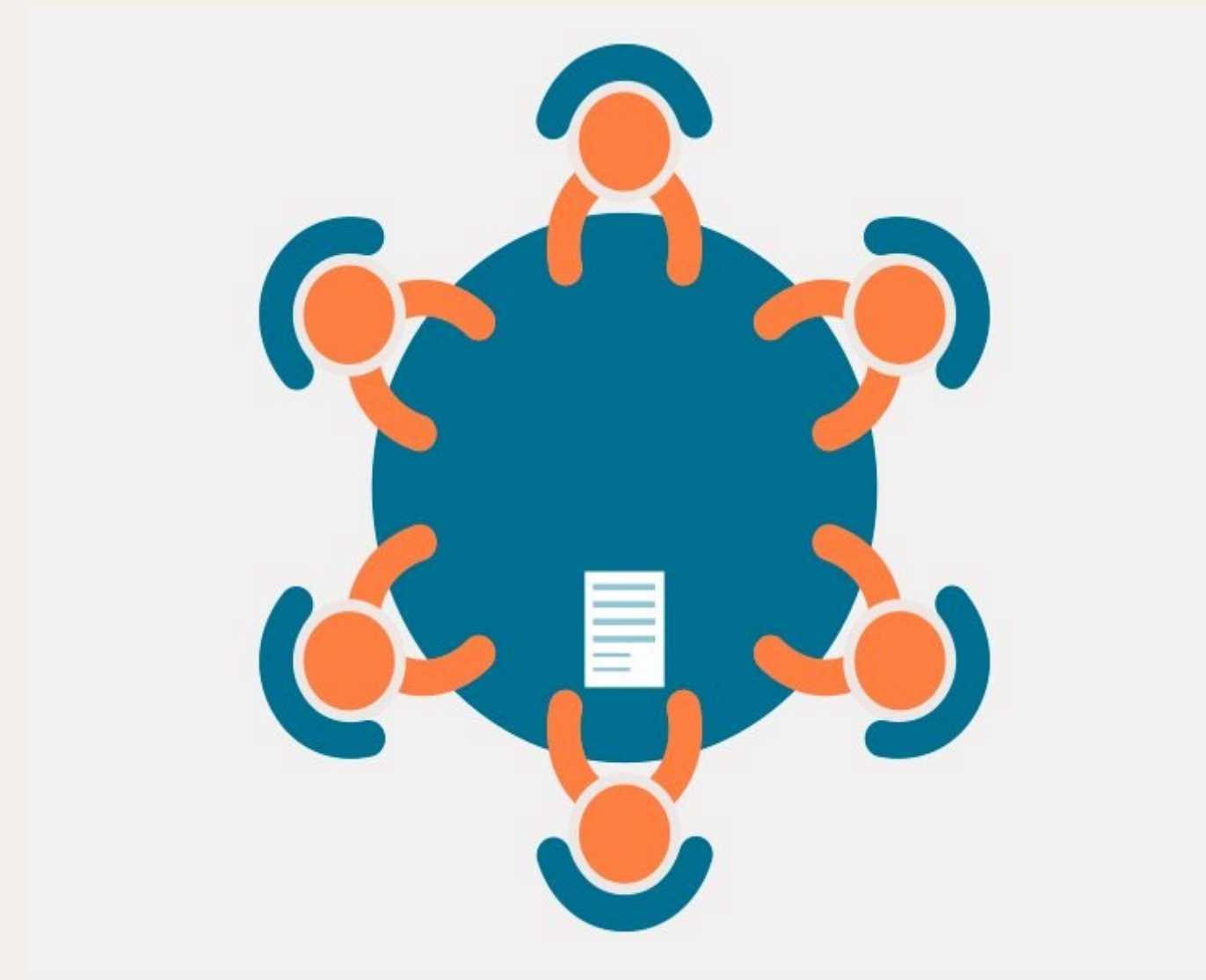
Spiritual Beliefs

- Removed question asking if religion, spirituality, or a belief system was integral to health or receiving health care
- Replaced with a question asking about beliefs a providers should know about

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
- **Returning to workgroups to consider revisions as a result**



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

How We'll Get There:



1. Align 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

5. Adopt

- Seek adoption of standards by state, federal, & other organizations:
 - ONC
 - CMS
 - CDC
 - NCQA
 - NAIC



Danielle A. Lloyd, MPH

Senior Vice President, Private Market Innovations & Quality Initiatives
Pronouns: she, her, hers

AHIP – Guiding Greater Health

601 Pennsylvania Avenue, NW, South Building, Suite 500
Washington, D.C. 20004

dlloyd@ahip.org
202.778.3246

Questions?