Data Collection Basics for Providers

Operation Equity

Health is non-negotiable

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Fundamentals

- HIPAA Rules on Data Collection
- Key Terms
- How to collect REaL and SOGI Data
- Primary Language
- Guide to Asking Questions
- Utilization and Effectiveness of REaL and SOGI data

Introduction

Learning Objectives

By the end of this training, you will be able to:

- **Recognize HIPAA rules around data collection.**
- **Define key terms in race, ethnicity, language and SOGI (Sexual Orientation and Gender Identification) and OMB categories.**
- **Discuss the importance of gathering this information.**
- **Provide strategies/verbiage for collecting this data from members.**

Data Collection and Importance

What is Data Collection and why is it important we collect patients Race Ethnicity and Language (REaL) and Sexual Orientation and Gender Identity (SOGI) data.

Data Collection refers to the systematic way we gather information about patients, health insurance members, providers, services provided, and any other relevant information related to healthcare.

This information is crucial for making decisions for a variety of different healthcare purposes.
Hospitals and health systems nationwide are focused on addressing health care disparities and this begins with understanding their community and the unique needs of the patients they serve.

Data Collection and Importance

What is REaL and SOGI data?

Race, Ethnicity and Language (REaL) and Sexual Orientation and Gender Identity (SOGI) data allows hospital and health systems the ability to:

- Capture information on a patient's race, ethnicity and language as well as sexual orientation and gender identity preferences.
- Understand clinically relevant and unique aspects of their patient and communities.
- Apply culturally competent and inclusive care that does not vary with a patient's race, ethnicity, language, sexual orientation or gender identity preferences.

Data Collection and Importance

REaL and **SOGI** data collection and documentation are a **key component** of enhancing meaningful dialogue during clinical encounters and promoting the provision of high-quality care.

The collection of REL and SOGI data are a critical step in systematically documenting and addressing health disparities.

REaL and SOGI data allow hospitals and health systems to understand the challenges and barriers to accessing care.

Hospitals and health plans that understand their patient/member populations and work to make quality improvements across individual patient groups will improve their overall performance.

Disparities may increase the cost of care provided to patients and addressing and eliminating disparities is the just and equitable thing to do.

We know that obtaining this information can be difficult. This training was created to provide best practices and basics for providers and their staff to collect REaL and SOGI data from their patients.

HIPPA Rules on Data Collection

Highmark recognizes that REL and SOGI data is increasingly crucial to effectively understanding patients, members, and their communities and the specific outcomes that may be impacted by these factors. Therefore, Highmark treats REaL/SOGI data as though it is HIPAA-protected data.

HIPAA Privacy Rule

The HIPAA Privacy Rule establishes national standards to protect individuals' medical records and other individually identifiable health information (collectively defined as “protected health information”) and applies to health plans, health care clearinghouses, and those health care providers that conduct certain health care transactions electronically.

The Rule requires appropriate safeguards to protect the privacy of protected health information and sets limits and conditions on the uses and disclosures that may be made of such information without an individual’s authorization.

The Rule also gives individuals rights over their protected health information, including rights to examine and obtain a copy of their health records, to direct a covered entity to transmit to a third party an electronic copy of their protected health information in an electronic health record, and to request corrections.

The Privacy Rule is located at 45 CFR Part 160 and Subparts A and E of Part 164.

Key Terms

Key Terms

This section reviews key terms that will be essential for understanding and navigating the rest of the training content and when collecting data.

Minimum Race/Ethnicity Reporting Category and Definitions

Minimum Race/Ethnicity Reporting Category	Definitions
American Indian or Alaska Native	Individuals with origins in any of the original peoples of North, Central, and South America, including, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, and Maya.
Asian	Individuals with origins in any of the original peoples of Central or East Asia, Southeast Asia, or South Asia, including, for example, Chinese, Asian Indian, Filipino, Vietnamese, Korean, and Japanese.
Black or African American	Individuals with origins in any of the Black racial groups of Africa, including, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, and Somali.
Hispanic or Latino	Includes individuals of Mexican, Puerto Rican, Salvadoran, Cuban, Dominican, Guatemalan, and other Central or South American or Spanish culture or origin.
Middle Eastern or North African	Individuals with origins in any of the original peoples of the Middle East or North Africa, including, for example, Lebanese, Iranian, Egyptian, Syrian, Iraqi, and Israeli.
Native Hawaiian or Pacific Islander	Individuals with origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands, including, for example. Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, and Marshallese.
White	Individuals with origins in any of the original peoples of Europe, including, for example, English, German, Irish, Italian, Polish, and Scottish.

Key Terms and Definitions

Key Term	Definitions
REaL	REaL stands for Race, Ethnicity, and Language.
Race	Race often refers to a group sharing physical traits and a common cultural and historical background.
Ethnicity	Ethnicity describes shared cultural, traditional, and familial connections.
SOGI	SOGI data means self-reported sexual orientation and gender identity demographic data and sex characteristics data.
Sex Assigned at Birth	A multidimensional construct based on a cluster of anatomical and physiological traits (sex traits). Female. Male. A sex that's not listed: [free text]. Not sure. Prefer not to answer.

Key Terms and Definitions

Key Term	Definitions
Gender Identity	A multidimensional construct that links gender identity, gender expression, and social and cultural expectations about status, characteristics, and behavior that are associated with sex traits. Female. Male. Transgender female. Transgender male. A gender identity that's not listed: [free text]. Not sure. Prefer not to answer.
Sexual Orientation	A multidimensional construct encompassing emotional, romantic, and sexual attraction, identity, and behavior Lesbian or gay. Straight. Bisexual. A sexual orientation that's not listed: [free text]. Not sure. Prefer not to answer.
PHI	As individually identifiable health information that is transmitted or maintained in any form or medium (electronic, oral, or paper) by a covered entity or its business associates, excluding certain educational and employment records.

Key Terms and Definitions

Key Term	Definitions
Super PHI	Certain states have Super Protected Data such as Pennsylvania - Protected Health Information that, under Applicable Law, requires a higher level of consent for Use and Disclosure, including HIV- related information, under 35 P.S. § 7607 (also known as Act 148) and its implementing regulations, mental health treatment information under the Pennsylvania Mental Health Procedures Act, 50 P.S. §§ 7107- 7116, and its implementing regulations set forth at 55 Pa. Code.§ 5100, et seq., and the Pennsylvania Drug and Alcohol Control Act, 71 P.S. § 1690.108(c) and its implementing regulations at 4 Pa. Code § 255.5, et seq., as well as federal law and regulations governing the Confidentiality of Substance Abuse Disorder Patient Records, set forth at 42U.S.C. § 290dd-2 and 42 C.F.R. Part 2.
Office of Management and Budget (OMB)	The Office of Management and Budget is in charge of determining how the Census Bureau and all other agencies can ask about a person's racial and ethnic identities, as well as defining the checkboxes found on surveys.

How to collect REaL and SOGI Data

Ensure that REaL data collection is systematic and reliable.

Step 1: Determine the appropriate data categories

Use the Revised Definitions for Minimum Race/Ethnicity Reporting Categories in 2024 SPD 15 - Table below to determine the appropriate data categories.

Minimum Race/Ethnicity Reporting Category	Definitions
American Indian or Alaska Native	Individuals with origins in any of the original peoples of North, Central, and South America, including, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, and Maya.
Asian	Individuals with origins in any of the original peoples of Central or East Asia, Southeast Asia, or South Asia, including, for example, Chinese, Asian Indian, Filipino, Vietnamese, Korean, and Japanese.
Black or African American	Individuals with origins in any of the Black racial groups of Africa, including, for example. African American, Jamaican, Haitian, Nigerian, Ethiopian, and Somali.
Hispanic or Latino	Includes individuals of Mexican, Puerto Rican, Salvadoran, Cuban, Dominican, Guatemalan, and other Central or South American or Spanish culture or origin.
Middle Eastern or North African	Individuals with origins in any of the original peoples of the Middle East or North Africa, including, for example, Lebanese, Iranian, Egyptian, Syrian, Iraqi, and Israeli.
Native Hawaiian or Pacific Islander	Individuals with origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands, including, for example, Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, and Marshallese.
White	Individuals with origins in any of the original peoples of Europe, including, for example, English, German, Irish, Italian, Polish, and Scottish.

Step 2: Methodology

Develop a methodology for data collection.

The standards provide two formats that may be used for data on race and ethnicity. Self- reporting or self-identification using two separate questions is the preferred method for collecting data on race and ethnicity. In situations where self-reporting is not practicable or feasible, the combined format may be used. Two-question format

To provide flexibility and ensure data quality, separate questions shall be used wherever feasible for reporting race and ethnicity. When race and ethnicity are collected separately, ethnicity shall be collected first.

If race and ethnicity are collected separately, the minimum designations are:

RACE:

☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Native Hawaiian or Other Pacific Islander
☐ White

ETHNICITY:

☐ Hispanic or Latino
☐ Not Hispanic or Latino

Combined Format

The combined format may be used, if necessary, for observer-collected data on race and ethnicity. Both race (including multiple responses) and ethnicity shall be collected when appropriate and feasible, although the selection of one category in the combined format is acceptable. If combined format is used, there are 5 minimum categories:

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or other Pacific Islander
- White

When aggregate data are presented, data producers shall provide the number of respondents who marked (or selected) only one category, separately for each of the six categories. In addition to these numbers, data producers are strongly encouraged to provide the detailed distributions, including all possible combinations, of multiple responses. In cases where data on multiple responses are collapsed, the total number of respondents reporting " Hispanic or Latino and one or more races" and the total number of respondents reporting " more than one race" (regardless of ethnicity) shall be provided.

Step 3: Training Data Collection

Train staff members on methodology for data collection

Personnel who handle patient registration and admission are on the front lines of R/E/L and SOGI data collection in hospitals, and offices and are vital to the data quality improvement effort and require appropriate training to enable them to handle the process of collecting what many patients consider sensitive information. Training should educate admissions staff as to the correct procedures for collecting this information including scripts that they can use when asking patients for their R/E/L and SOGI information.

Example Script:
SCRIPT FOR HOSPITAL STAFF

This script is for registration staff to use in asking a patient questions on his/her race, ethnicity, language and SOGI. The script explains to the patient the importance and purpose of collecting this information and ensuring their confidentiality.

We want to make sure that all our patients get the best care possible. We're going to ask you some questions regarding your race, ethnicity, sexual orientation and gender identity so that we can review the best treatment that our patients can receive and make sure that every one of every background gets the highest quality of care. We'll keep this information confidential and will update it in your medical record. We are also going to ask you about the language(s) that you speak and understand. If you prefer a language other than English, we will try to find someone to speak to you in your preferred language about your health. The only people who see this information will be members of your care team and others who are authorized to see your medical record. Your answers will be confidential.

(Source - https://hcup-us.ahrq.gov/datainnovations/raceethnicitytoolkit/ca4.pdf
and https://hcupus.ahrq.gov/datainnovations/raceethnicitytoolkit/data_improve_edu.jsp)

HIPAA Privacy Rule

When data on race and ethnicity are collected separately, provision shall be made to report the number of respondents in each racial category who are Hispanic or Latino.

When aggregate data are presented, data producers shall provide the number of respondents who marked (or selected) only one category, separately for each of the five racial categories. In addition to these numbers, data producers are strongly encouraged to provide the detailed distributions, including all possible combinations, of multiple responses to the race question. If data on multiple responses are collapsed, at a minimum the total number of respondents reporting " more than one race" shall be made available.

Step 4: Accountability and Monitoring

Assign accountability and monitor progress of data collection efforts. Assign a person in the office staff with the responsibility of collecting REaL and SOGI data for every patient. Set goals and targets to track and monitor progress. You can use various tools and techniques to monitor the data collection process such as checklists, audits, charts, dashboards, feedback, and reviews. Compare actual data collection results with planned data collection objectives and targets.

Strategies for collecting REaL and SOGI Data

☐ Engage senior leadership

☐ Define goals for data collection

☐ Combine disparities data collection with existing reporting requirements

☐ Track and report progress on an organization-wide basis

☐ Build data collection into quality improvement initiatives

☐ Utilize national, regional, and state resources

☐ Review, revise, and refine process and categories constantly

Primary Language

What language do you feel most comfortable speaking with your doctor or nurse (patient's primary language)?

https://www2.census.gov/topics/language-use/appendix-a_language-code-list.pdf

Guide to Asking Questions

Step 1: Prepare

There is no single, best practice set of questions for soliciting information about a person's Race, ethnicity, language, sexual orientation, or gender identity. The context of the data collection, including planned uses for the data, alignment with other surveys or datasets, sample size, ability to code write-in responses, and ability to protect confidentiality should guide decisions about when and how to ask for this information. The AHA Institute for Diversity and Health Equity recommend that health care organizations/health plans provide a rationale for why they are asking patients/enrollees for information about their demographic and communications background.

Suggested wording for the rationale is:
"We want to make sure that all our patients get the best care possible. We would like you to tell us your racial/ethnic background so that we can review the treatment that all patients receive and make sure that everyone gets the highest quality of care."

Step 2: Frame Effectively

Some people feel comfortable responding to the question about race/ethnicity/primary language/disability status, sexual orientation and gender identity, but they sometimes have their own questions, wish for additional clarity, or perhaps prefer to not answer the question at all. AHA suggests using the Broad OMB Categories and asking which category best describes you such as:

1. **Which category best describes your race?**

One or more categories may be selected.

a. Female
b. Male
c. A sex that's not listed: [free text]
d. Not sure
e. Prefer not to answer

1. **What is your Sex, or What sex were you assigned at birth?**

One or more categories may be selected.

a. Female
b. Male
c. A sex that's not listed: [free text]
d. Not sure
e. Prefer not to answer

2. How do you currently describe yourself (mark all that apply)?

One or more categories may be selected.

a. Female
b. Male
c. Transgender
d. I use a different term

3. Which of the following best represents how you think of yourself?

One or more categories may be selected.

a. Gay or lesbian
b. Straight, that is not gay or lesbian
c. Bisexual
d. I use a different term [free-text]
e. I don’t know.

4. **Which of the following do you consider yourself to be?**

One or more categories may be selected.

a. Straight or heterosexual
b. Gay
c. Lesbian
d. Bisexual
e. Transgender

Step 3: Overall Example Questions

1. What is your ethnic background?

○ Not Hispanic or Latino.
○ Hispanic or Latino.
○ Choose not to answer.

2. What is your race (select one or more)?

○ Black or African American.
○ Native Hawaiian/Pacific Islander.
○ White.
○ Asian.
○ American Indian or Alaska Native.
○ Middle Eastern or North African.
○ Another race not listed, please specify.
○ Choose not to answer.

3. What is your preferred spoken language for health care?

- ○ English.
- ○ Spanish.
- ○ American Sign Language.
- ○ Other please specify.
- ○ Choose not to answer.

4. How well do you speak English? Note: Choosing a response lower than “very well” indicates limited English proficiency (LEP).

- ○ Not at all.
- ○ Not well.
- ○ Well.
- ○ Very well.
- ○ Choose not to answer.

6. What is your preferred language for written materials?

- ○ English.
- ○ Spanish.
- ○ Braille.
- ○ Other please specify.
- ○ Choose not to answer.

7. What sex was originally listed on your birth certificate?

- ○ Male.
- ○ Female.
- ○ Unknown.
- ○ Choose not to answer

8. What is your gender identity?

- ○ Male.
- ○ Female.
- ○ Transgender male/trans man/female-to-male (FTM).
- ○ Transgender female/trans woman/male-to-female (MTF).
- ○ Genderqueer, neither exclusively male nor female.
- ○ Additional gender category or something else? Please specify.
- ○ Choose not to answer.

9. What are your pronouns?

○ He/Him.
○ She/Her.
○ They/Them.
○ Something else, please specify.
○ Choose not to answer.

10. What is your sexual orientation?

○ Lesbian, gay, or homosexual.
○ Straight or heterosexual.
○ Bisexual.
○ Something else, please specify.
○ Something else, please specify.
○ Choose not to answer.

Step Four: Wrap Things Up

Using these guided questions should ensure that the patient feels comfortable and respected.

Lesson 7 of 8

Utilization and Effectiveness of REaL and SOGI data

How to use REaL and SOGI data

- Use an equity scorecard or dashboard to report organizational performance Inform and customize the language translation services you provide
- Review performance indicators such as length of stay, admissions and avoidable readmissions
- Review process of care measures Review outcome of care
- Analyze provision of certain preventive care
- Identify if physicians and office staff need additional training

How can REaL and SOGI data be more effective

- Identify where the greatest disparities exist and prioritize which initiatives to pursue
- Understand the demographic makeup of the patient population at a more granular level and develop tailored care plans
- Develop patient-centered, community-based interventions to reduce disparities
- Drive board-level decision making on where to invest and deploy resources

Summary and Key Takeaways

Now that you have taken this training, you will be able to:

- Recognize HIPAA rules around data collection.
- Define key terms in race, ethnicity, language and SOGI (Sexual Orientation and Gender Identification) and OMB categories.
- Discuss the importance of gathering this information.
- Provide strategies/verbiage for collecting this data from members.

Thank you for completing this course!