HEALTH EQUITY
DATA COLLECTION GUIDE

Asking Sensitive Questions in the Quest to Reduce Health Disparities

2018
Acknowledgements

The Connecticut State Medical Society, with funding from the Connecticut Health Foundation and in collaboration with the Community Mental Health Affiliates, and SEET Consulting, developed this training guide for collecting sensitive information to identify and address health disparities based on cumulative social disadvantage. It is well documented that social and personal bias and discrimination negatively impacts the health and health outcomes minority populations.

About the Connecticut Health Foundation (CT Health)
The Connecticut Health Foundation is a private foundation created in 1999 and is dedicated to achieving health equity. They focus on improving health outcomes for people of color and assuring that all Connecticut residents have access to affordable and high-quality care. Through public policy, grantmaking, and leadership development, Connecticut Health Foundation is committed to making lasting changes that improve lives.

About the Connecticut State Medical Society (CSMS)
The Connecticut State Medical Society has begun its third century as the voice and focus in our state for the men and women who inhabit the ever-changing world of medicine. Since its founding, the Connecticut State Medical Society has worked to serve these physicians and their patients. The mission of the Connecticut State Medical Society is to be the voice of all Connecticut physicians; to lead physicians in advocacy; to promote the profession of medicine; to improve the quality of care; and to safeguard the health of our patients.

About the Community Mental Health Affiliates (CMHA)
CMHA is a leading provider of an integrated health and behavioral health care system for children, families and adults. CMHA is headquartered in New Britain, with 11 locations in 3 cities and towns throughout northwest and central Connecticut, and we have more than 40 years’ experience as one of the largest behavioral health care providers in the state. Dedicated to improving the quality of life for Connecticut’s residents, CMHA offers a continuum of programs that change the lives of 6,100 children and adults annually. CMHA is the state’s first fully Joint Commission accredited Behavioral Health Home.

About the SEET LLC
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Nationally, there is a call for the healthcare industry to thoroughly document disparities and tailor interventions to improve the quality of care received by patients. The Connecticut State Medical Society (CSMS) sees value in the collection of this kind of data and the documentation of any inequities/disparities in healthcare. In fact, the drive toward measuring healthcare quality is based on the idea that performance measures can help patients, consumers, providers, and purchasers understand what high-quality healthcare is and increase demand for it. Identifying disparities becomes complicated when patients self-report multiple demographic categories. The reality is we have an increasingly blended society where patients identify with more than one race, ethnicity, language, etc. This makes accurate reporting and identifying health and healthcare disparities challenging.

The Patient Protection and Affordable Care Act (aka Affordable Care Act) invested in the improvement of data collection and analysis. Section 4302 contains provisions to strengthen data collection efforts by requiring all federal agencies to gather information on race, ethnicity, sex, primary language, and disability status. The law also provides the U.S. Department of Health and Human Services (DHHS) the opportunity to collect additional demographic data to further improve our understanding of population-based disparities. Currently, identifying disparities and effectively monitoring efforts to reduce them are limited by a lack of specificity, uniformity, and quality in data collection. Thus, standardized methodology for collecting, capturing, monitoring, and analyzing demographic data will better characterize the nature of health problems (e.g. homelessness impacting health) among populations experiencing health and healthcare disparities.

CSMS is proud to produce this toolkit to help physicians and other healthcare professionals and providers collect race, ethnicity, and language data, as well as gender identity and sexual orientation to bring consistency across healthcare settings to drive performance and quality measures. In collaboration with the Connecticut Health Foundation (CHF) and Community Mental Health Affiliates (CMHA), practices were identified and pilot tested for the direct collection of equity data. This toolkit is designed as a training resource and provides recommendations to standardize the collection accuracy of equity data as the foundation of achieving health equity. By knowing more about patients, everyone is better able to deliver culturally responsive and linguistically appropriate services.

Matthew C. Katz, EVP/CEO

The fundamental step to address health and healthcare disparities is collecting data that adequately describes populations, allowing for the stratification of quality measures at a level of detail that can identify variations among those at-risk.

— Institute of Medicine of the National Academies 2009
Pilot Staff Training Introduction

**GOAL:**
To collect race, ethnicity, and language (equity) data consistently across different healthcare sites to drive quality measures that reduce health disparities.

**Objective:** Identify best practices for the direct collection of equity data

- Who should ask patients and enrollees questions about race, ethnicity, and language and communication needs.
- How to ask patients and enrollees questions about race, ethnicity, and language and communication needs.
- How to elicit this information in a respectful and efficient manner taking into consideration social, cultural, and generational reactions that may find the questions offensive.
- How to address the discomfort of physicians, hospital or clinic employees, or call center staff (health plans) about requesting this information.
- How to respectively address potential patient or enrollee pushback.

The expected outcome of this training is the development of confident and competent staff to collect equity data in a respectful and efficient manner.

The expected time needed may vary from training to training. The topics and exercises presented here are organized into half-day sessions. The facilitator should review the material ahead of time and plan the amount of time that fits the needs of the training.

**Data Collection Readiness Assessment**
The Hospital and Healthcare System Readiness Assessment was developed and distributed in collaboration with the Connecticut Hospital Association (CHA). The electronic survey has 13 multiple choice questions, each with an area to write a comment. Twenty-three healthcare organizations (19 hospital and 4 health systems) responded to the survey. Most respondents represented management positions and there was one response from each organization.

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Almost 70% of the respondents have a written protocol in place to collect race and ethnicity and 26% collect the information through electronic prompts without a written protocol. There was one organization not collecting equity data at the time of the survey. In terms of what data is captured, the respondents collecting this information use the major categories recommend by the Federal Office of Budget and Management (OBM), including American Native/Alaskan Native; Asian; Black or African American; Hawaiian or Other Pacific Islander; and White. Ninety percent have an Unknown category, and only 65% (15 out of 23) have “some other race” as a category, which limits patients’ self-identification options. Further, unknown is typically used by staff when they are checking a category by observation at the time of registration, and are not sure of an individual’s race. Regarding Hispanic/Latino ethnicity, 52% (12) collect this information and use it in a separate category (from race), while 44% have ethnicity as a choice under Race. The current recommendation is to offer both race and Hispanic/Latino ethnicity as two separate categories, with ethnicity being asked first to clarify they are not the same.

The best practice for data collection is self-report and it’s preferable to ask patients. However, 52% (12) of the organization have staff check off race and ethnicity during registration, clinical visit and 27% (6) use a standard form (paper or electronic) completed by patients and entered or scanned into medical records. Data retrieval is problematic with scanning information into the patient record, and registration data is not always linked to care management systems. This may account for why only 22% (5) organizations report utilizing race and ethnicity data for both clinical performance and care experience measures. Further, 65% (15) are not utilizing race and ethnicity data now to identify potential health disparities.

It was surprising to see that 82% (19) have a language access plan in place that includes collecting patient language preference and level of English proficiency. Overall, only 30% (7) have a position assigned to monitor patient records and make corrections/reconcile conflicting information regarding race, ethnicity, and language needs. Another surprise was an equal division among those who have a mechanism to collect sexual orientation and gender identity (43% or 10) and those who do not (43% or 10). Three organizations were not aware that SO/GI information need to be collected. We did not expect so many organizations to have a mechanism in place.

However, upon closer inspection it was found that the best practice categories were not routinely used. For example, some healthcare practices added an “other” category under gender (sex) or added transgendered under gender. There is wide-spread confusion regarding the concepts of sex assignment at birth and gender as a concept of feminine and masculine self-identification. Regarding the social determinates of health (SDH), 48% (11) organization currently collect this data (e.g., employment status or income, housing or homelessness, educational level, income level) for population health analytics. Additionally, 17% (4) were not collecting this information and 35% (8) were not sure. The comments were informative with homelessness being captured because there is not a street address and employment was collected for health insurance.

Some respondents scan a SDH assessment form completed by patients into their medical records, but again, scanned information is not easily retrievable to identify internal health disparities or population health analysis. The pressing question for this project was to discern the challenges to prepare healthcare organizations to collect race and Hispanic/Latino ethnicity. One of the most challenging barriers was to train staff to elicit this information in a respectful and efficient manner, while taking into consideration social, cultural, and generational reactions. Fortunately, 44% (10) of the respondents stated that making changes to include specific races and ethnicities following the Office of Management and Budget (OMB) broad categories, was not seen as challenging as other initiatives.

However, follow up discussions with several potential pilot sites for this project exposed challenges unforeseen by the managers working with us. For example:

- There is a lack of knowledge of the best practice data definitions and categories (e.g. adding transgendered as a sex).
- There may be costs and/or internal disagreements to expand functionalities that capture recommended data sets (e.g. allowing multiple choices, identifying specific nationalities).
- There may be complications ensuring data is captured in a manner it can be extracted for health disparity and population health analysis (e.g. bridging registration and scheduling platforms where the information is collected, with the electronic patient medical record).
- There are complications with affiliate sites having EHRs that do not communicate with each other.
- There is a significant concern regarding staff skill-building to stratify quality measures by patient characteristics, to identify potential health disparities and variations in outcomes among those at-risk.

### Curriculum Development and Pilot Test

The Community Mental Health Affiliates in New Britain was selected as a pilot location for the OMB broad categories. Their EHR was being prepared and staff was aware of this new initiative so it was good timing for CSMS and CMH to collaborate on pilot testing a staff training program. To get started with the curriculum, those who are already responsible to collect this information, were sent the Equity Data Collection Survey to help CSMS develop appropriate training materials. The data collectors included front office staff, case managers conducting intake/assessments in the community, clinicians, and supervisors of those staff positions. By far the majority of the 38 respondents think that race and ethnicity are important aspects of care. Less than 3% disagreed with the statement and 14% were neutral. Additionally, 67% agreed or strongly agreed with the statement: I think a person’s race/ethnicity can affect their quality of healthcare. And 85% disagreed or strongly disagreed with the statement: I can tell a person’s race/ethnicity by looking at them. This information suggested we do not need to “convenience” staff of the importance of race data collection, other than to have a good explanation of why the information is being used and how to communicate that to patients.

Further, survey results demonstrated that most of the respondents disagreed with the statement: I think talking about race/ethnicity is uncomfortable. Respondents were less likely to agree with the statement: I feel comfortable talking sexuality (11% vs 25% retrospectively). While it may be true that knowing race and ethnicity can impact the quality of healthcare and feeling comfortable talking about race, these such statements reflect the racial diversity among staff and their positions as case managers and clinicians. The concepts of collecting gender identity and sexual orientation is a much newer discussion than collecting race data, and therefore, discomfort is expected. The less diverse the audience, perhaps the more attention should be paid to presenting health disparity information and how social exclusion (e.g. racism) impacts health and health outcomes.

The results for “I understand the meaning of the term ‘race’ vs ‘ethnicity’ and “I understand the meaning of sexual orientation vs. gender identity,” were virtually identical. CSMS had noticed that in previous discussions and presentations, people believe they understand these terms in a social context — how they are commonly used, and not necessarily understood in the context of health equity. Therefore, we thought it was important to have clear definitions and descriptions of relevant terms and concepts in the toolkit.

Finally, respondents were asked to rate a list of potential barriers which may affect their ability or the organization’s ability to collect this data. The three primary barriers were identified as follows:

- Confusion about the race categories.
- Limitations on health information technology (HIT).
- Patients reluctant to provide this information.

This information suggested the curriculum materials needed to provide staff with time to practice explaining why collecting this information is important, explaining how it will be used, and who will have access to it, and how to help patients make decisions that feels most comfortable to them. Critical to this process are communication skills, including non-verbal body language. Staff must be aware of their own body language, as well as interpreter others. Awareness of body language is important whenever personal values and attitudes are in conflict or when stereotypes are broadly applied to groups of people, by either/or both parties. The pilot training included each staff (i.e., data collector) person asking five patients to participate in the data collection trial.

This toolkit is a training program to be delivered by experienced trainers/facilitators with expert knowledge and skills in racial and ethnic health disparities, and health equity concepts and research. This toolkit provides information and practical guidance on preparing healthcare staff responsible for collecting equity data.
How To Use This Manual

OVERVIEW

The toolkit is intended to be a flexible resource. You can use sections of the toolkit to support existing training or activities which you currently deliver, or plan specific programs depending on your organization’s needs.

- One section is geared toward Self-Training
- Another section is geared toward Group Training with a Trainer

Each unit has an aim, learning outcome, suggested session plan with activities and delivery times, references, and supporting materials. This tool kit is designed to be used by a person who is doing a “Self-Training,” or by a Facilitator in a “Group Training” for discussing, practicing, and debriefing communication skills. It is more than a “play book” on what to say, it includes skill-building and practical application of lessons learned to elicit information in a respectful and efficient manner.
Why We Collect Health Equity Data

Healthcare organizations must collect patient-level demographic data on race and ethnicity to identify the needs of individual patients and to eliminate disparities in the patient population. This critical data provide information on the potential cultural needs of each patient, as well as an opportunity to monitor and analyze health disparities at the population level. Data on race and ethnicity may be used for a variety of possible purposes beyond the detection of disparities in the quality of clinical care, such as, who is accessing health services, the health status of different populations, utilization rates of services to which racial and ethnic groups have access, the effectiveness of public health interventions among different racial and ethnic groups, and, of course, racial and ethnic disparities in diagnosis and treatment. All these purposes for which race/ethnicity data can be used also apply to data on sexual orientation and gender identity.1

Research has shown that asking people to identify their own race or ethnicity yields the most reliable data. In addition, they often give specific responses that provide more detailed information than is captured through broad, standardized categories. Allow patients to use as much of their own description as possible or add to the choices available. When patients identify themselves as being from a certain group, they may also have beliefs, healthcare use patterns, and perspectives common to that community. For example, knowing that a patient is Polish and not just white, or Cuban and not just Hispanic, can lead to more informed interactions and enable providers to offer more patient-centered care.

What are health disparities?

Health disparities refer to the differences in disease risk, incidence, prevalence, morbidity, and mortality and other adverse conditions, such as unequal access to quality health care, that exist among specific population groups in Connecticut. Population groups may be based on race, ethnicity, age, gender, socioeconomic position, immigrant status, sexual minority status, language, disability, homelessness, and geographic area of residence. Specifically, health disparities refer to those avoidable differences in health that result from cumulative social disadvantages.2

What is health equity data?

There is strong evidence that the quality of health care varies as a function of race, ethnicity, sex, sexual orientation/gender identity, language, and social determinants of health (e.g. income, education, etc.). A short-hand way to communicate these data categories when referring to the identification of health disparities, are referred as equity data. Having quality metrics stratified by a variety of demographic characteristics will help to improve the overall quality and equity in health outcomes.

LEARNING OUTCOMES

- Interpret the important role data collectors have in identifying and reducing health disparities.
- Confident in ability to ask patients for equity data and explain terms when necessary.
- Recognize patient discomfort about providing equity data and adjust approach to ease discomfort.
- Display professionalism and utilize communication skills when personal biases or preferences conflict with patient choice and patient care.

PRE-TRAINING SURVEY

The Equity Data Collection Pre-Training Survey should be taken prior to the training to obtain a baseline level of self-reported knowledge, attitudes, and perceived skills regarding issues to be covered in the training. The survey may give insight on areas to focus personally, or insight on areas for the trainer to focus. For example, if the survey response shows that you or participants do not believe race and ethnicity are important to know in the healthcare arena, you should address at the start of the training. Everyone using this toolkit should answer questions from their own perspectives.

This is an anonymous survey. The information we collect will not be shared with any supervisors or administrator. It is for research purposes only and will be used to determine and evaluate methods used in the collection of race, ethnicity, language, and SO/GI information.

Adapted from Data Collection on the Race, Ethnicity and Primary Language of Organization Patients Survey by Health Insight and the Robert Wood Johnson Foundation’s Race, Ethnicity and Language of Patients: Organization Practices Regarding Collection of Information to Address Disparities in Health Care.

What is your position in the organization?

a. Registration or other support staff
b. Mental health professional
c. Supervisor or manager
d. Senior Manager
e. Healthcare provider
f. Other-Please List

Attitude

Please circle the attitude which most identifies with your feelings towards each statement.

1. I think race/ethnicity is an important aspect of healthcare.
   1 2 3 4 5

2. I think a person’s race/ethnicity can affect their quality of healthcare.
   1 2 3 4 5

3. To determine a patient’s race/ethnicity I observe the patient’s physical characteristics or surname.
   1 2 3 4 5

4. I think talking about race/ethnicity is uncomfortable.
   1 2 3 4 5

5. I can tell a person’s race/ethnicity by looking at them.
   1 2 3 4 5

6. I understand the meaning of the term ‘race’ vs ‘ethnicity’.
   1 2 3 4 5

7. I think sexuality is an important aspect of healthcare.
   1 2 3 4 5

8. I think a person’s sexuality can affect their quality of healthcare.
   1 2 3 4 5

9. To determine a patient’s sexuality, I observe the patient’s physical characteristics.
   1 2 3 4 5

10. I think talking about sexuality is uncomfortable.
   1 2 3 4 5

11. I understand the meaning of sexual orientation vs. gender identity.
   1 2 3 4 5

12. I think I have an important role in collecting a patient’s information.
   1 2 3 4 5

Barriers

The following list identifies potential barriers to the collection of race/ethnicity/SO/GI data. Identify the barriers which affect you and your organization. Please mark all that apply and rank your selected barriers from smallest to largest barrier on the line next to each letter.

1 = smallest barrier, 10 = largest barrier

1. Confusion about race/ethnicity categories
   1 2 3 4 5 6 7 8 9 10

2. Reluctance of staff to ask this type of information
   1 2 3 4 5 6 7 8 9 10

3. Reluctance of patients to provide this type of information
   1 2 3 4 5 6 7 8 9 10

4. Concerns that collection of these data may expose the organization to legal liability
   1 2 3 4 5 6 7 8 9 10

5. Lack of funding to support the collection of these data
   1 2 3 4 5 6 7 8 9 10

6. Limitations of health information technology system to capture this type of data
   1 2 3 4 5 6 7 8 9 10

7. No demonstrated need to collect these data
   1 2 3 4 5 6 7 8 9 10

8. Lack of agreement of executive leadership on the need to collect these data
   1 2 3 4 5 6 7 8 9 10

9. Lack of staff time to collect these data
   1 2 3 4 5 6 7 8 9 10

10. Other

1 Adapted from the Healthcare Cost and Utilization Project (HCUP) pronounced “Hi-Cup”, a family of health care databases and related software tools and products developed through a Federal-State-Industry partnership and sponsored by the Agency for Healthcare Research and Quality (AHRQ).


Federal Data Categories

WHAT ARE THE DATA CATEGORIES AND WHERE DID THEY COME FROM?

The Federal Office of Management and Budget (OMB) served as the starting point for data standards representing minimum (i.e., broad) categories (2000). Agencies were permitted to collect as much additional detail as desired, provided that the additional detail could be aggregated back to the minimum categories.

The Centers for Disease Prevention & Control (CDC) code set is based on current OMB minimum standards, adding a detailed set of race and ethnicity categories maintained by the U.S. Bureau of the Census (BC).

In 2010, the Affordable Care Act Section 4302 invested in health data collection and analysis strategy by requiring EHR to capture OMB categories and CDC code sets. In 2015 the Centers for Medicare and Medicaid Services (CMS) and the Office of the National Coordinator for Health Information Technology (ONC) issued rules requiring all electronic health record (EHR) systems certified under the Meaningful Use Incentive program to have the capacity to record, change, and access structured sexu-al orientation and gender identity (SOGI) information. In 2016, the Health Resource Services Administra-tion (HRSA) recommended the SOGI data standards.

Why is it important for me to know?

As a front-line admissions or registration staff, nurses, medical assistants, case managers, and others able to capture equity data, you are vital to the patient experience in helping your organization better serve their patients and the community.

One of the key responsibilities you have is to accurately collect each patient’s personal information, including race, ethnicity, sexual orientation and gender identity, language abilities and preferences. Collecting this information is part of the process by which your organization can identify and address unique patient needs.

Collecting data by self-report

Self-reporting is the most accurate source of information. Self-reporting will increase accurate reporting and improve usefulness of data.

- Common uses of health equity data.
- Ensuring availability of interpreter services.
- Quality improvement in disease management programs.
- Enhanced care coordination.
- Program/benefit design for cultural and linguistic appropriateness.
- Marketing to a broad range of potential consumers/patient populations.
- Recruiting to a broad range of potential employees targeting workforce diversity.

Understanding Your Role

Why is my role important?

Patients are more likely to share personal information when asked by respectful, knowledgeable staff. The organization is better able to serve its patients when this information is collected for everyone in a consistent manner. Information that you help collect during the registration process will become a part of the patient’s medical record. This information helps the care team communicate effectively with patients and their families in a cultural context, which may affect their health and wellbeing. It can also help policy experts and providers understand conditions that affect specific populations and then develop appropriate treatment programs. It is therefore critical to collect this information, and you play a key role in this process.

What should I say?

“We want to make sure that all our patients get the best care possible. We would like you to tell us your racial/ethnic heritage so that we can review the treatment that all patients are offered and receive to make sure everyone gets the highest quality of care.”

“We are using this information to better meet the needs of our patients, including you, and their families and show the community that we deliver the best care possible to them. The information is confidential, and a limited number of people have access to it.”

Health systems may use different rationales in explaining to patients why they are being asked to provide this information. It’s important that everyone is using the same rationale. The key message is how the information is being used and that it is confidential.

What skills will I need?

Active Learning
Use training/instructional methods to improve your technique.

Active Listening
Give full attention to what other people are saying and respond to their questions and concerns.

Assessment
Assess your own performance and make improvements.

Comprehension
Understand how to complete forms and know the terms and concepts.

Critical Thinking
Use logic and reasoning to collect sensitive data and adjust your technique as the situation requires.

Instruction
Teach others what is working best for you as the data collector. Listening to and interpreting non-verbal behavior, Management of personal non-verbal language.

Negotiation
Bring others together and try to reconcile challenges to stay focused on the goal.

Persuasion
Influence others to change their minds or behavior.

Service Orientation
Look for ways to help people answer questions and complete forms.

Social Perceptiveness
Be aware of others’ reactions and adjust your response.

Time Management
Manage your own time and the time of others.
Best Practices

Patients should have the opportunity to select more than one ethnicity and/or more than one race.

Patients may prefer not to answer without consequence.1

Self-report takes precedence over other data sources if there is disagreement.

Ethnicity and race do not need to be updated.

SOGI data does need to be periodically updated.

In some instances, people may have questions or may be confused. The best course of action is to use a non-confrontational approach and to take care not to push the issue if the patient does not want to respond to the questions. Remember: challenging questions generally indicate a decline code.

Directly Asking Sexual Orientation and Gender Identity (SOGI)

- If patients leave SOGI questions unanswered on registration forms, health care providers (e.g. assign to medical assistant, nurse, and or physician) should re-ask these questions during the clinical encounter.
- Do not assume someone’s gender or sexual orientation based on how they look or sound.
- Open-ended questions allow patients to feel comfortable to disclose SOGI information. “Tell me a little bit about yourself.” “Do you have any concerns or questions about your sexual orientation, sexual desires, or gender identity?”
- SOGI questions can also be asked during the social or sexual history taking by the medical assistant or provider. Healthcare providers can normalize this process by saying “this is something I ask all of my patients.”
- Add preferred name to other documents such as: Patient Instructions, Internal labels, Chart Summary.

General Rule

If a person does not want to answer these questions, move on. Do not force the issue. Simply record “Decline.” As in decline to answer or prefer not to answer (i.e., instead of unknown).

Recommendations from your peers

This list of recommendations below was generated by the staff members in the pilot test.

Practice answering questions.

Know terms and definitions, especially regarding gender and sexuality.

Remind people these categories are not ideal and do not define who they are as a person.

Think of it as not just an interview, but as a dialogue (when collected in the clinical setting).

Model and mirror comfort with the discussion.

- Start with asking about family life to get sense of culture/traditions, before starting data collection.
- Connect with patients through culture.
- Show genuine interest in each person.

Know how you self-identify.

Explain people have options to be more than a general category, and can identify on a deeper level if they want.

Know that people may identify as their families’ because they hold to their culture.

Know that people in the same family may self-identify differently from each other.

Open a discussion with patients to check is current information is accurate (previous information may have been entered upon observation).

Remember to go back into the record and make corrections if there are any discrepancies and fill in missing information.

Remember terms and definitions change over time and self-identifications change, so this information needs to periodically updated.

Entering the Data

How will I enter the data?

Each organization needs to decide whether it will provide a list of categories or whether patients will self-report based on their own descriptions. Respect their descriptions or choices if providing categories.

Facilities vary in how and when health equity data is collected and at this point research does not support one practice over another.

- Written registration form
- Verbal inquiry by staff

Different venues for collecting information is okay if the questions and options are consistent across the organization or system.

What will my supervisor be looking for?

- Accuracy
- Consistency
- Timeliness
- Completeness

The Health Research and Educational Trust Disparities Toolkit is a web-based tool that provides hospitals, health systems, clinics, and health plans information and resources for systematically collecting race, ethnicity, and primary language data from patients.

http://www.hretdisparities.org

Case Study

IMPROVING HEALTHCARE QUALITY WITH WEB-BASED TECHNOLOGY: CAN HEALTH INFORMATION TECHNOLOGY HELP REDUCE RACIAL AND ETHNIC HEALTH DISPARITIES?


When the health information technology was employed to identify disparities within a large group practice and target interventions were made, there were significant and sustained improvements in healthcare outcomes for all patients and some patients of color.

Poorly Controlled A1C

Missing wellness visits was a significant factor among patients, particularly among people of color.

Interventions

Case managers called and scheduled appt.
- HIT modified to flag missing wellness visits.
- Combined wellness and physical exams to give patient more education.
- Fotonovella—typical Spanish print educational format.

Results

- Pre-Intervention: 60% of adult patients were in control of their A1C.
- Post-Intervention: 12% of populations demonstrated improvements.
- Of improved patients, the most dramatic were among Asian (38%) and Hispanic patients (21%).
- Whites and Blacks were identical in their modest rates of improvement.
Definitions of Ethnicity, Race, Sexual Orientation, and Gender Identity

ETHNICITY AND RACE

Latino Ethnicity
To avoid confusion on race and ethnicity as defined by OMB, Hispanic or Latino origin is asked before race identification. Latino is a person of Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race. The term, “Spanish origin,” can be used in addition to “Hispanic or Latino.”

This standard includes the option of NO to Are you of Hispanic or Latino origin or Not of Hispanic or Latino origin.

Race
American Indians and Alaska Natives have their origin in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

Asians have their origin in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippines Islands, Thailand, and Vietnam. This breakdown can be added as granular choices to roll-up into Asian for people to select their nationalities.

Black or African Americans have their origin in any of the black racial groups of Africa. National recognition such as Jamaican, Haitian or West Indian may be self-selected and/or added to “Black or African American” as granular (sub) categories depending on the populations in the communities you serve.

White does not include granular options as seen in the other race categories currently defined by the Federal Office of Management & Budget (OMB); but there are granular level categories in the Center for Disease Control and Prevention (CDC) Ethnicity Codes. These granular level categories include: Arab, Middle Eastern and Northern Africa, and European, which can be further broken down.

Some other race: ____________________________________________

However, race categories under consideration for Census 2020 include Persian-American and Arab-American. Advocates for these additions express their dissatisfaction with identifying as White. Middle East/North Africa designation (also called MENA) includes: Egypt, Iraq, Israel, Lebanon, Palaste, Syria, etc.

Native Hawaiians and Other Pacific Islanders have origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands. This breakdown can be added as subcategories for people to identify their country of origin.

How will I enter the data? Each organization needs to decide whether it will provide a list of categories or whether patients will self-report based on their own descriptions. Respect their descriptions or choices if providing categories.

Facilities vary in how and when health equity data is collected and at this point research does not support one practice over another:
- Written registration form
- Verbal inquiry by staff

Different venues for collecting information is okay if the questions and options are consistent across the organization or system.

Some other race should include a write in option for patients to identify themselves when their race is not listed.

GENDER, SEXUAL ORIENTATION & GENDER IDENTITY4

Sex
The classification of people as male or female. At birth infants are assigned a sex, usually based on the appearance of their external anatomy. (This is what is written on the birth certificate.) However, a person’s sex is a combination of bodily characteristics including: chromosomes, hormones, internal and external reproductive organs, and secondary sex characteristics.

Gender Identity
One’s internal, deeply held sense of one’s gender. For transgender people, their own internal gender identity does not match the sex they were assigned at birth. Most people have a gender identity of man or woman (or boy or girl). For some people, their gender identity does not fit neatly into one of those two choices.

Cisgender
Gender identity aligns with sex assigned or designed at birth.

Transgender man
Transgender Male: Female-to-Male (FTM): Designated female sex and identifies as a male. People who were assigned female at birth but identify and live as a man may use this term to describe themselves. They may shorten it to trans man. (Note: trans man, not “transman.”) Some may also use FTM, an abbreviation for female-to-male. Some may prefer to simply be called men, without any modifier. It is best to ask which term an individual prefers.

Transgender woman
Transgender Female: Male-to-Female (MTF): Designated male sex and identifies as a female. People who were assigned male at birth but identify and live as a woman may use this term to describe themselves. They may shorten it to trans woman. (Note: trans woman, not “transwoman.”) Some may also use MTF, an abbreviation for male-to-female. Some may prefer to simply be called women, without any modifier. It is best to ask which term an individual prefers.

Genderqueer
Genderqueer = neither exclusively male nor female.
A term for people who reject notions of static categories of gender and embrace a fluidity of gender identity and often, though not always, sexual orientation. People who identify as genderqueer may see themselves as being both male and female, neither male nor female or as falling completely outside these categories.

Asexual
An asexual is someone who does not experience sexual attraction. Unlike celibacy, which people choose, asexuality is an intrinsic part of who someone is. There is considerable diversity among the asexual community; each asexual person experiences things like relationships, attraction, and arousal somewhat differently.

Intersex
“Intersex” is a general term used for a variety of conditions in which a person is born with a reproductive or sexual anatomy that doesn’t seem to fit the typical definitions of female or male. Intersex is a socially constructed category that reflects real biological variation. Some people live and die with intersex anatomy without anyone (including themselves) ever knowing. When born intersex, babies are typically assigned a sex as male or female, though this may change some day.

Other
People whose gender is not male or female use many different terms to describe themselves, with non-binary being one of the most common.

Sexual Orientation
How a person identifies their physical and emotional attraction to others.

Describes an individual’s enduring physical, romantic and/or emotional attraction to another person. Gender identity and sexual orientation are not the same. Transgender people may be straight, lesbian, gay, or bisexual. For example, a person who transitions from male to female is attracted solely to men would identify as a straight woman.

What’s the difference between sexual orientation and gender identity?
Gender identity and sexual orientation are two different things. Gender identity refers to your internal knowledge of your own gender—for example, your knowledge that you’re a man, a woman, or another gender. Sexual orientation has to do with whom you’re attracted to. Like non-transgender people, transgender people can have any sexual orientation. For example, a transgender man (someone who lives as a man today) may be primarily attracted to other men (and identify as a gay man), may be primarily attracted to women (and identify as a straight man), or have any other sexual orientation.

Example Sexual Orientation Choices
Straight or heterosexual; Lesbian; gay, or homosexual; Bisexual; Something else; Don’t know; Choose not to disclose
Managing Your Own Nonverbal Behavior

Sometimes you may want to modify your nonverbal behavior to help your listener(s) connect with you.

1. Eye contact
2. Tone of voice
3. Gestures and body language
4. Facial expressions

Interpreting Nonverbal Behaviors

NONVERBAL BEHAVIORS

- Are strong communication tools
- Are partial clues — not the whole picture
- May conflict with a person’s actual intent or feelings
- May be misread — ask about confusing or contradictory cues
Sample Staff Script

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 and ethnicity, and your sexual orientation and gender identity so that we can give the best treatment to all our patients and make sure that everyone 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.

Q.1 Are you Hispanic or Latino?
☐ Yes
☐ No
☐ Don’t know / Not sure
☐ Decline to answer

Q.2 If yes, which country or countries do you identify with?
☐ Mexican, Mexican American, Chicano/a
☐ Puerto Rican
☐ Cuban
☐ South American
☐ Central American
☐ Other Spanish origin: ____________________________

Q.3 Which one or more of the following would you say is your race?
Check all that apply. Read the primary groups and only the subgroups if the client identifies with that group:

3.1 AMERICAN INDIAN or ALASKA NATIVE
☐ Alaska Native
☐ American Indian

3.2 ASIAN
☐ Asian Indian
☐ Cambodian
☐ Chinese
☐ Filipino
☐ Hmong
☐ Japanese
☐ Korean
☐ Laotian
☐ Vietnamese
☐ Other Asian

3.3 BLACK OR AFRICAN AMERICAN
☐ African
☐ African American
☐ Bahamian
☐ Barbadian
☐ Dominican
☐ Haitian
☐ Jamaican
☐ Tobagonian
☐ Trinidadian
☐ West Indian
☐ Other

3.4 NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER
☐ Maltese
☐ Micronesian
☐ Polynesian
☐ Other Pacific Islander: __________________________

3.5 WHITE
☐ Arab
☐ European
☐ Middle Eastern or North African

3.6 SOME OTHER RACE: __________________________

3.7 DECLINE TO ANSWER

Q.4 Assigned sex at birth
☐ Female
☐ Male

Q.5 Do you identify with the LBGTQI community?
If no, skip to Q6.
If yes, please continue to the next question.

☐ Yes
☐ No
☐ Decline to answer

5.1 SEXUAL ORIENTATION
☐ Straight or heterosexual
☐ Lesbian, gay, or homosexual
☐ Bisexual
☐ Something else
☐ Don’t know
☐ Choose not to disclose

5.2 GENDER IDENTITY
☐ Transgender Male
☐ Transgender Female
☐ Non-binary
☐ Other, please specify: __________________________

☐ She/Her
☐ He/Him
☐ They/Them

5.4 Preferred Name: __________________________

Q.6 Do you speak a language other than English?
☐ Yes
☐ No

6.4 If yes: What is this language? (5 years old or older)
Check all that apply

Listed in order of frequency spoken in the state
☐ Spanish
☐ Portuguese
☐ Polish
☐ Italian
☐ French
☐ Chinese
☐ Other Asian
☐ French Creole
☐ Other Indo-European
☐ Hindi
☐ Other Language (Identify): __________________________

6.5 How well do you speak English or how satisfied are you with your ability to speak English? (5 years old or older)
☐ Very well
☐ Well
☐ Not well
☐ Not at all

6.6 What language do you feel most comfortable speaking with your healthcare provider? __________________________
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 and ethnicity, and your sexual orientation and gender identity so that we can give the best treatment to all our patients and make sure that everyone 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.

Mark all boxes that apply

### Q. 1 Are you Hispanic or Latino?

- [ ] Yes
- [ ] No
- [ ] Don’t know / Not sure
- [ ] Decline to answer

### Q. 2 If yes, which country or countries do you identify with?

- [ ] Mexican, Mexican American, Chicano/a
- [ ] Puerto Rican
- [ ] Cuban
- [ ] South American
- [ ] Central American
- [ ] Other Spanish origin: __________

---

Q. 3 Which one or more of the following would you say is your race?

Check all that apply. Read the primary groups and only the subgroups if the client identifies with that group:

<table>
<thead>
<tr>
<th>3.1 AMERICAN INDIAN or ALASKA NATIVE</th>
<th>3.2 ASIAN</th>
</tr>
</thead>
<tbody>
<tr>
<td>You may leave the question open (how do you identify your race?) or you may read the five major categories.</td>
<td>More than one racial group may be selected. Once the major race category is stated, you can ask: Would you like to further define their nationality? If the patient seems unsure what you mean or asks you directly, read a few of the granular level ethnicities.</td>
</tr>
<tr>
<td>[ ] Alaska Native</td>
<td>[ ] Asian Indian</td>
</tr>
<tr>
<td>[ ] American Indian</td>
<td>[ ] Cambodian</td>
</tr>
<tr>
<td>[ ] African</td>
<td>[ ] Chinese</td>
</tr>
<tr>
<td>[ ] African American</td>
<td>[ ] Filipino</td>
</tr>
<tr>
<td>[ ] Bahamian</td>
<td>[ ] Hmong</td>
</tr>
<tr>
<td>[ ] Barbadian</td>
<td>[ ] Japanese</td>
</tr>
<tr>
<td>[ ] Dominican</td>
<td>[ ] Korean</td>
</tr>
<tr>
<td>[ ] Haitian</td>
<td>[ ] Laotian</td>
</tr>
<tr>
<td>[ ] Jamaican</td>
<td>[ ] Vietnamese</td>
</tr>
<tr>
<td>[ ] Melanesian</td>
<td>[ ] Other Asian</td>
</tr>
<tr>
<td>[ ] Micronesian</td>
<td>[ ] Other Pacific Islander</td>
</tr>
</tbody>
</table>
| [ ] Polynesian | [ ] Other

<table>
<thead>
<tr>
<th>3.3 BLACK or AFRICAN AMERICAN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Remember more than one race and nationality may be selected.</td>
</tr>
<tr>
<td>[ ] African</td>
</tr>
<tr>
<td>[ ] African American</td>
</tr>
<tr>
<td>[ ] Bahamian</td>
</tr>
<tr>
<td>[ ] Barbadian</td>
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<tr>
<td>[ ] Borneoan</td>
</tr>
<tr>
<td>[ ] Haitian</td>
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<tr>
<td>[ ] Jamaican</td>
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<tr>
<td>[ ] Laotian</td>
</tr>
<tr>
<td>[ ] Tobagonian</td>
</tr>
<tr>
<td>[ ] Trinidadian</td>
</tr>
<tr>
<td>[ ] West Indian</td>
</tr>
<tr>
<td>[ ] Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.4 NATIVE HAWAIIAN or OTHER PACIFIC ISLANDER</th>
</tr>
</thead>
<tbody>
<tr>
<td>As the organization discovers more information about who lives in the community, and as immigration and migration patterns change, data categories may be added.</td>
</tr>
<tr>
<td>[ ] Melanesian</td>
</tr>
<tr>
<td>[ ] Micronesian</td>
</tr>
<tr>
<td>[ ] Polynesian</td>
</tr>
<tr>
<td>[ ] Other Pacific Islander</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.5 WHITE</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ] Arab</td>
</tr>
<tr>
<td>[ ] European</td>
</tr>
<tr>
<td>[ ] Middle Eastern or North African</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.6 SOME OTHER RACE:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please fill in the other race</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3.7 DECLINE TO ANSWER</th>
</tr>
</thead>
</table>

---
Q.4 Assigned sex at birth
Do not assume someone’s gender or sexual orientation based on how they look or sound.

- Female
- Male

Q.5 Do you identify with the LBGTQI community?
If no, skip to Q6.
If patients leave SOGI questions unanswered on registration forms re-ask these questions during the clinical encounter.

- Yes
- No
- Decline to answer

5.1 SEXUAL ORIENTATION
An option is to ask this question and if no, skip to language. If yes, continue with SOGI. Staff checks for answered if this question was answered.

- Lesbian, gay, or homosexual
- Bisexual
- Something else
- Don’t know
- Choose not to disclose

5.2 GENDER IDENTITY
Open-ended questions allow patients to feel comfortable to disclose SOGI information. “Tell me a little bit about yourself.”
M and F can be removed from the list if you are only asking people who identify with the LBGTQI community.

- Transgender Male
- Transgender Female
- Non-binary
- Other, please specify ________

5.3 What is your preferred pronoun?
SOGI questions can also be asked during the social or sexual history taking by the medical assistant or provider. Health care providers can normalize this process by saying “this is something I ask all of my patients.”

- She/Her
- He/Him
- They/Them

5.4 Preferred Name:
If there isn’t an automatic flag in the system for preferred pronoun and name, use color label or alert.

Q.6 Do you speak a language other than English?
If yes, please continue to the next question.

- Yes
- No

Listed in order of frequency spoken in the state

- Spanish
- Portuguese
- Polish
- Italian
- French
- Chinese
- Other Asian
- French Creole
- Other Indo-European
- Hindi
- Other Language (Identify): ____________________________

6.2 How well do you speak English or how satisfied are you with your ability to speak English? (5 years old or older)

- Very well
- Well
- Not well
- Not at all

6.3 What language do you feel most comfortable speaking with your healthcare provider? ____________________________
Leading a Training Session
Workshop Opening

The workshop starts with a brief welcome from the host organization. This gives organizers an opportunity to explain the purpose of the workshop and to give the participants any additional information about the training sessions or about special arrangements and housekeeping issues.

Introduction of Trainers and Participants

Members of the training team should introduce themselves and briefly tell the participants about their background and training, emphasizing their enthusiasm for the opportunity to work with this group. Trainers should make sure that the participants are given a voice during this important first meeting. At the very least, the trainees should each be invited to introduce themselves to the whole group.

Icebreakers help the educators play and learn together and set the stage for continued training together.

Warm-up activities are usually used to begin a session on a positive note or to ‘recharge’ if the group’s energy seems to be low. Some groups begin with a simple stretching exercise to get warmed up.

Participants’ Expectations & Concerns

Participants are given an opportunity to speak about their expectations for the training session and to state any concerns regarding peer education that they would like to have addressed. Responses are recorded on a flip chart.

Assess which expectations are likely to be met during the training workshop and which ones may go beyond its scope. At the end of the workshop, a review of these initial expectations should be part of the evaluation.

Training Methodology

Group discussions play a major role in an interactive training program. To lead group discussions effectively, facilitators should know how to deal with different types of participants and uncomfortable discussions. The purpose of discussions is to share knowledge and experiences, generate questions and answers, share values and ideals, and clarify misconceptions.

Highlighting the relationships between subject matter (e.g. race categories) and real-life experiences is another important training method. Trainers should be aware of how institutionalized racism operates and how reliance on stereotypes can negatively affect judgment and interactions with others.

Common Ground Rules

- Respect each other, even when you disagree
- You have the right not to participate in an activity that makes you feel uncomfortable
- Use sentences that begin with ‘I’ when sharing values and feelings (as opposed to ‘you’)
- Say “OUCH!” if something is said that is hurtful
- Respect confidentiality
- Put away cell phones

Applying knowledge acquired is critical for effective learning and developing confidence and competence to collect equity data. Participants should have opportunities to practice during class time and with patients. Trainers should debrief practice periods and facilitate peer feedback and recommendations.

Wrap-up each session with a brief review of the topics covered during the day. Participants are asked to think back on the session’s activities and discuss some of the central themes. They can give feedback on how they feel the training is going.

The example data collection form should be modified to resemble the EHR used by the organization in training. While limitations of an EHR are being worked out, staff can be trained and prepare for the launch by using paper forms and/or entering data in electronic format outside the EHR for practice.

Post Training Survey and Training Evaluation

Evaluation can take place in multiple ways to obtain feedback from staff. The Equity Data Collection Post-Training Survey is aligned with the pre-test to measure change, if any, on attitudes regarding demographic data collection. It also gathers feedback on how prepared staff felt once they started pilot testing the collection process.

Feedback from patients covers their comfort level when answering questions, question clarity, concerns about confidentiality, and the option to add any other concerns. It is important to remember when addressing health inequities, patient engagement (i.e., meaningful participation) is paramount.

Focus group questions are also available to further discuss the organization’s plan to collect equity data. These evaluation tools may provide critical information as the organization plans and implements the roll-out of such an initiative.

Training Agenda Example

Warm Up — 15 min
- Who is in the room?

Introduction — 30 min
- Summarize the rationale
- Review the learning outcomes
- Describe the concept of health equity data
- Describe why their role is important

What to Say (facilitate discussion) — 45 min
- Explain the data standards and reference best practices to accommodate for self-identification.
- Discuss why the information is being collected and how it will be used.
- Reference the Frequently Asked Questions.

Terms & Definitions — 30 min
- Discussion of terms and how to convey their meaning.
- Know the Terms activity may be used during class or self-study assignment.
- Thought Exercise — Thinking About Your Own Gender may be used as an activity during class or as a self-study assignment.

Nonverbal Behavior Presentation — 30 min
- PowerPoint — Reading nonverbal clues

Active Listening Activity — 45 min
- The listener (staff) collects data using the Staff Script and the speaker (patient) has challenges in the activity that makes you feel uncomfortable
- Instructions from your supervisor
- Debrief with large group discussion

Gender Identity and Creating a Neutral Environment — 45 min
- Thought Exercise
- Discussion with large group (handout)

Important Next Steps — 15 min
- Trial with patients on paper or directly into the EHR – two weeks to a month
- Instructions from your supervisor
- Assign someone to collect feedback from patients on how they felt about the new questions and if they felt safe/respected in answering truthfully.
- Debrief as staff with supervisor and other key personnel to work through problems encountered with workflow, staff perceptions, patient/family reactions.
- Prepare roll-out workflow processes.

Post-Assessment emailed within 24 hours
Activity: Interpreting Nonverbal Behavior

PURPOSE
Strengthen skills in identifying others’ emotions through body language and facial expressions.

Strengthen skills in managing personal nonverbal language to send appropriate and consistent messages.

Strengthen awareness of personal bias and reflective response.

Nonverbal behaviors
- Are strong communication tools
- Are partial clues — not the whole picture
- May conflict with a person’s actual intent or feelings
- May be misread — ask about confusing or contradictory cues

List factors that influence nonverbal behavior
- Facial expressions
- Gender
- Body posture
- Gestures
- Situation
- Culture
- Age
- Health
- Physical limitations

Consider context and other variables (such as rank and culture). You may want to modify your nonverbal behavior to help your listener(s) connect with you.

Eye contact

Tone of voice

Gestures and body language

Facial expressions

Activity: Active Listening

PURPOSE
Active listening occurs when the “listener is genuinely interested in the speaker’s message. He or she sincerely wants to know what the speaker thinks, how the speaker feels, and what the speaker wants. The listener actively confirms that he or she understands these things before reacting. Active listening is an interactive process.”

Instructions
Break into groups of three. Choose one person to be the following:

Speaker
- Will respond to directions (i.e., assign Challenging Response from Activity).

Active Listener
- Will practice the skills of active listening (i.e., assign question from the Staff Script).

Observer
- Will quietly observe the interaction and summarize feedback.

The speaker will have 3 minutes to respond to the directions and the listener should assist the speaker with asking a few questions and paraphrasing.

Participants will switch roles so that each person has an opportunity to practice each.

Debrief and Reflect
In following the active listening rules, what were you aware of about yourself during the discussion?

How well do you think you paraphrased the speaker based on their reaction?

What would you like to do better next time?

Rules for Active Listening

Stop talking!
- Listen with undivided, supportive and focused attention.

Put the other person at ease
- Give them the space and time to speak.

Listen to understand the other person and their words
- Do not just wait for your turn.

Remove distractions
- Being focused means that you are willing to stop other activities.

Be patient
- Sometimes it takes a moment to find the right words.

Be aware of your own emotions
- As we get emotional, it is often more difficult to concentrate on what is being said and we may miss critical parts.

Paraphrase what was said
- Be sure you have understood.

Assist the speaker in staying on time and task
- If there is confusion, or you need more information, be sure to convey this to the speaker.
- Ask for clarification or ask the speaker to rephrase what was said in another way.

Maintain eye contact and be conscious of body language
- Sit up straight, facing toward the speaker.
- Remain relaxed with your arms uncrossed.

Do your best to remain empathetic and non-judgmental
- Do not debate.
- Do not interrupt with your own comments or stories.

Continue to concentrate on what is being said, even when you disagree.

Activity: Know the Terms and Use Them Correctly

PURPOSE
Build confidence in talking to people about race and gender identity as concepts, and explain terms so they can self-identify.

Instructions
Individually or in pairs, write a short statement for each of the four questions. Check with the definitions on pages 6-8 to see if you capture the important information.

1. Describe the difference between gender and sex.

2. Describe why the phrase assigned or designated sex at birth is used instead of “born male or female.”

3. Describe the difference between gender identity and sexual orientation.

4. Describe the term transgender and include the preferred terminology when referring to a transgender person.

5. Describe the term genderqueer and the fluidity of gender roles.

6. What is the difference between race and ethnicity?

Debrief and Reflect
Are some of these terms new to you, and if so, what do you think about them?
What personal stereotypes do you hold that will be important to be aware of?
What would you want others to know about you in order to provide you with the best possible healthcare?

Activity: Thought Exercise

PART A: THINKING ABOUT YOUR OWN GENDER

PURPOSE
It can be difficult for people who are not transgender to imagine what being transgender feels like. Imagine what it would be like if everyone told you that the gender you’ve always known yourself to be was wrong.

Instructions
The two questions below should be done individually, giving the class 5 to 10 minutes to write a response. Response can be shared between neighbors sitting next to each other or ask for a few volunteers to share with the whole class.

1. What would you feel like if you woke up one day with a body that’s associated with a different gender? How does this situation connect to your fears and hopes? What are your fears? What are your hopes? Which of your needs are met or not met in this situation?

2. What would you do if everyone else—your doctors, your friends, your family—believed you’re a man and expected you to act like a man when you’re a woman, or believed you’re a woman even though you’ve always known you’re a man?

Debrief and Reflect
What are some things that heterosexuals can do in every day life that LGBTQIs cannot?
How important or unimportant do you think those things are to LGBTQIs?
Compare the African American struggle for civil rights with that of the LGBTQI community. Is there anything similar about the respective movements? Different?
PART B: SUGGESTIONS FOR GENDER NEUTRAL ENVIRONMENTS

Group Discussion

Trainer may read the question, Instead of... and have participants think of their own responses. Distribute afterwards.

Avoid assuming gender or sexual orientation with new patients

### Instead of:
- How may I help you, sir?
- He is here for his appointment.
- Do you have a wife?
- What are your mother and fathers’ names?

### Say:
- How may I help you?
- The patient is in the waiting room.
- Are you in a relationship?
- What are your parents’ names?

Offensive Language

**Offensive:**
- “Transgenders,” “A transgender”
- “Sex change,” “Pre-operative,” “Post-operative”
- “Biologically male,” “Biologically female,” “Genetically male,” “Genetically female,” “Born a man,” “Born a woman”

**Preferred:**
- Transgender people, a transgender person
- Assigned male at birth, assigned female at birth

### Derogatory Terms and Offensive Language:

This language dehumanizes transgender people and should not be used in mainstream media. The criteria for using these derogatory terms should be the same as those applied to vulgar labels used to target other groups: they should not be used except in a direct quote that reveals the bias of the person quoted.

<table>
<thead>
<tr>
<th>Offensive Language</th>
<th>Preferred:</th>
</tr>
</thead>
<tbody>
<tr>
<td>“She-male”</td>
<td>When did you decide to be a man/woman?</td>
</tr>
<tr>
<td>“He-she”</td>
<td>“You look so real. I never would have known.”</td>
</tr>
<tr>
<td>“It”</td>
<td>Have you had/do you want THE surgery?</td>
</tr>
<tr>
<td>“Trannie or tranny”</td>
<td>What is your real name?</td>
</tr>
<tr>
<td>“Real” woman or “real” man</td>
<td>You’re so attractive, why would you want to…?</td>
</tr>
<tr>
<td>“Queer”</td>
<td>“That’s so gay.”</td>
</tr>
<tr>
<td>“Fairy”</td>
<td>When did you decide to be gay?</td>
</tr>
<tr>
<td>“Queen”</td>
<td>Is this a phase you are going through?</td>
</tr>
<tr>
<td>“Homo”</td>
<td>Why can’t you choose one gender to be attracted to?</td>
</tr>
<tr>
<td>Gay/homosexual agenda</td>
<td>Who do you see yourself ending up with?</td>
</tr>
</tbody>
</table>
Activity: Responding to Challenging Comments

PURPOSE
Challenging responses to race and Latino ethnicity questions are to be occasionally expected. The responses below are common challenges and this activity is time to practice a thoughtful response.

Instructions
Break into small groups or pairs and write down short responses to the challenging questions that you think are appropriate to the situation and helpful to encourage the type of answer desired.

Alternate Instructions: Use the Challenging Comments for the Active Listening Activity.

Patient Response | Suggested Response
--- | ---
“I’m American. “ | Would you like to use an additional nationality, or would you like me to just put American?

“Can’t you tell by looking at me? “ | Well, sometimes I can but we think it’s important for people to tell us how they identify themselves. It is also more accurate than stuff making a guess.

If using open-ended option: “I don’t know. What are the responses?” | You can say Asian, American Indian or Alaska Native, Black or African American, Pacific Islander or Native Hawaiian, White or some other race; or any combination of these. You can also use more specific terms like Irish, Jamaican, or Chinese.

“I was born in Nigeria, but I’ve lived here most of my life. What should I say? “ | That is up to you. It is fine to say that you are Nigerian. (If Nigerian is not an option write in the response under Other).

A patient returning for care with the “UNKNOWN” or “Unable to provide information” code. | Proceed to ask for the information per routine. Unknown should not be used when a person declines to answer any of the questions. Prefer not to answer or decline to answer is appropriate, and the person should not be asked again.

“I’m human. “ | Yes, we are all human and we ask this information as one way to better know you as a person. If you rather not answer I can just say that you didn’t want to answer.

“It’s none of your business. “ | I’ll just put down that you didn’t want to answer, which is fine.

“I don’t know, I’m adopted. “ | We want to know you better by how you think of yourself when thinking about race and ethnicity. This is not about your ancestry so there is no wrong answer.

Frequently Asked Questions

Q: What does my race and ethnicity/sexual orientation and gender identity have to do with my health or my medical treatment?
A: Although we are all individual people, our backgrounds may place us at differing risks for some diseases. We can work to reduce these risks by making sure that everyone gets high quality health care.

Q: Why am I being asked these questions?
A: We are collecting this information from all our patients. By knowing more about your background, we can get a better idea of health risks you may have, and we will be better able to meet your health needs.

Q: Who are you collecting this information from?
A: We are collecting this information from all our patients.

Q: What will my information be used for?
A: By providing us with information you are helping us to provide better services and programs to you and others like you. For example, with this information, we can provide health information in languages spoken by our patients and offer effective programs that can improve health.

Q: What if I don’t want to answer these questions?
A: It is perfectly alright if you do not want to answer some or all the questions. However, this information does help us provide better care to you. Regardless of whether you answer these questions, we will provide you the very best possible medical care and treatment.

Q: Who can I ask questions about this?
A: The registration staff and their supervisors are happy to answer any questions that you may have about why you are being asked these questions.

Q: Who will see my information?
A: The only people who will see your information are members of your care team and others who are authorized to see your medical record.

Q: What if I belong to more than one race?
A: You can check off all the races you belong to.

Q: What if I don’t know my race or ethnicity?
A: You can answer don’t know.
Resources

Obtaining Data on Patient Race, Ethnicity, and Primary Language in Health Care Organizations: Current Challenges and Proposed Solutions.
Hasnain-Wynia, R and Baker, D.
Health Research and Educational Trust DOI: 10.1111/j.1475-6773.2006.00552.x.

Health Research and Educational Trust Disparities Toolkit.
hretdisparities.org

Improving Data Collection to Reduce Health Disparities.
https://minorityhealth.hhs.gov/assets/pdf/checked/1/Fact_Sheet_Section_4302.pdf

The National LGBT Health Education Center’s website offers training, webinars, and tools for SO/GI data collection.
www.lgbthealtheducation.org/topic/sogi

Focus on Forms and Policy: Creating an Inclusive Environment for LGBT Patients.

Health Professionals Advancing LGBT Equality (previously known as the Gay & Lesbian Medical Association) is the world’s largest and oldest association of lesbian, gay, bisexual and transgender (LGBT) healthcare professionals.
www.gplta.org

Toolkit for Collecting Data on Sexual Orientation and Gender Identity in Clinical Settings.
www.dosaskdotell.org

The U.S. Centers for Disease Control and Prevention (CDC) has prepared a code set for use in coding race and ethnicity data.

The U.S. Department of Health and Human Services Implementation Guidance On Data Collection Standards For Race, Ethnicity, Sex, Primary Language, And Disability Status.
HEALTH EQUITY
DATA COLLECTION GUIDE

For more information:
203-865-0587
www.csms.org