HEALTH MANAGEMENT ASSOCIATES

Million Hearts Learning Collaborative
REL and SOGIE Data Collection and Utilization Strategies for Health Care Services

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- ➢ Welcome and Introductions

- ➢ REL and SOGIE Data Collection and Utilization Strategies for Health Care Services

- ➢ General Program Updates, Grantee Q & A

REL and SOGIE Data Collection and Utilization Strategies for Health Care Services

PRESENTED BY:

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TODAY'S TRAINING TOPICS

- Understanding the need for and implications of collecting, updating, and utilizing REL and SOGIE data.

- Assessing the quality and completeness of REL and SOGIE data collection methods.

- Understanding of the terminology and differentiators related to SOGIE.

- Best practices in REL and SOGIE data collection.

- Using cultural information and terminology to establish trusting clinical relationships and create safe, welcoming and inclusive healthcare environments for patients and their loved ones.

INVENTORY OF RESOURCES FOR STANDARDIZED DEMOGRAPHIC AND LANGUAGE DATA COLLECTION
https://www.cms.gov/about-cms/agency-information/omh/downloads/data-collection-resources.pdf

RACE, ETHNICITY, & LANGUAGE DATA: THE BASICS

What is REL data?

Race, Ethnicity and Language (REL) data. It allows providers to:

- Capture information on a patient's race, ethnicity and language preferences
- Understand clinically relevant and unique aspects of their patient and communities
- Apply culturally informed care that that does not vary with a patient's race, ethnicity or language

Why collect REL data?

- Elimination of disparities: It is the just and equitable thing to do
- Every patient deserves quality care that meets their unique needs
- Quality Implications: Hospitals/Providers understand their patient populations and work to make quality improvements across individual patient groups to improve their outcomes
- Financial Implications: Disparities may increase the cost of care provided to patients

Adapted from: Addressing Health Care Disparities through Race, Ethnicity and Language (REaL) Data
https://www.aha.org/system/files/media/file/2020/06/ifdhe_real_data_resource.pdf

WHAT IS SOGIE DATA?

Sexual orientation – a person's identity in relation to the gender or genders to which they are sexually attracted (straight, gay, lesbian, asexual, bisexual, pansexual)

Gender identity and/or expression - internal perception of one's gender; how one identifies or expresses oneself.

>> **Cisgender** – a person whose gender identity aligns with those typically associated with the sex assigned to them at birth

>> **Transgender** – an individual whose current gender identity and/or expression differs from the sex they were assigned at birth

>> **Gender Expansive** - an individual who expresses identity along the gender spectrum

WHY COLLECT SOGIE DATA?

The collection of SOGIE data is a critical step in systematically documenting and addressing health disparities affecting LGBTQIA+ persons. Patient–provider discussions about SOGIE can facilitate a more accurate assessment of self-reported health and behaviors.

Streed CG Jr, Grasso C, Reisner SL, Mayer KH. Sexual Orientation and Gender Identity Data Collection: Clinical and Public Health Importance. Am J Public Health. 2020 Jul;110(7):991–3. doi: 10.2105/AJPH.2020.305722. Epub 2020 Jul. PMCID: PMC7287564.

A comprehensive list of terms has been included in the resources section of this PPT.

QUESTIONNAIRE

Are you currently collecting REL data?	
How would you rate your EHR's ability to capture REL data? (1-5)	
Are providers trained on how to use REL data to improve care?	
Do you enter REL and SOGIE data using different systems?	
Are you currently collecting SOGIE data?	
How would you rate your EHR's ability to capture SOGIE data? (1-5)	
How comfortable do you feel asking patients about REL and SOGIE data? (1-5)	

CHATTERFALL
Share some challenges you have encountered in capturing and using REL and SOGIE data?

REL DATA COLLECTION

"The foundational step towards reducing health disparities is the establishment of the basic information needed to identify and measure those differences, i.e., the accurate capture of race and ethnicity information of all patients."

Ruben Vega Perez, Lyndia Hayden, et al.

How to collect REL data?

Ensure that REL data collection is systematic and reliable

- **Step 1:** Determine the appropriate data categories
- **Step 2:** Develop a methodology for data collection
- **Step 3:** Train staff members on methodology for data collection
- **Step 4:** Assign accountability and monitor progress of data collection efforts

Key strategies for collecting patient REL 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

Source: https://www.aha.org/system/files/media/file/2020/06/ifdhe_real_data_resource.pdf
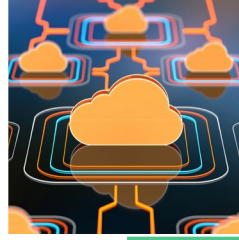
USING REL DATA AS A QUALITY DRIVER

Use the data to stratify quality metrics

- Step 1: Assemble a working group
- Step 2: Validate the REL data
- Step 3: Identify the highest priority metrics
- Step 4: Determine if the selected metrics can be analyzed
- Step 5: Analyze the data

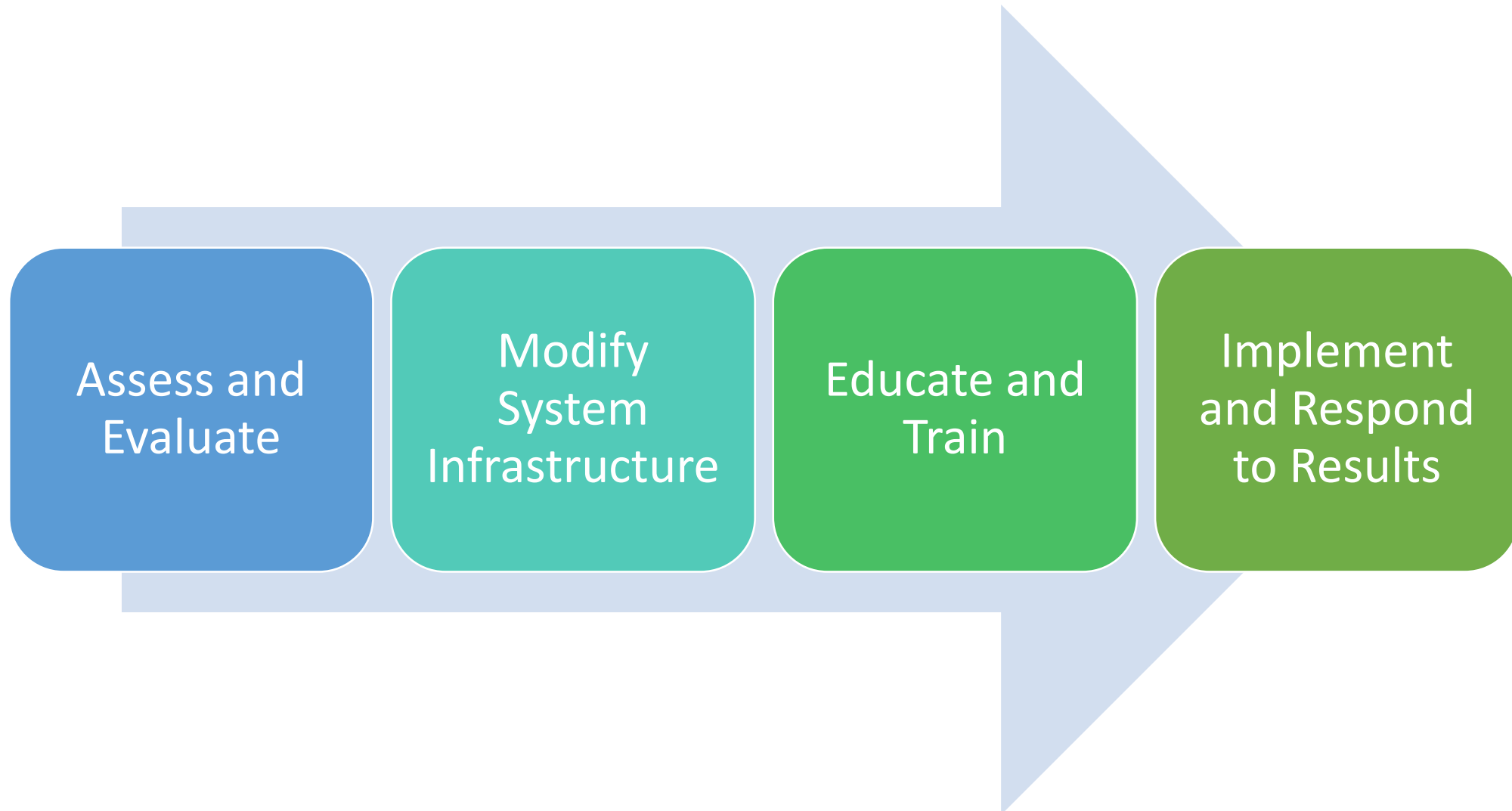**How can REL data be more effective?**

- Identify where the greatest disparities exist and prioritize initiatives
- 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

Leading practices for using patient REL 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

Source: https://www.aha.org/system/files/media/file/2020/06/ifdhe_real_data_resource.pdf

FOUR PHASES OF PATIENT REGISTRATION DATA COLLECTION IMPROVEMENT PROCESS

Assess and Evaluate → **Modify System Infrastructure** → **Educate and Train** → **Implement and Respond to Results**

Vega Perez RD, Hayden L, Mesa J, Bickell N, Abner P, Richardson LD, Ngai KM. Improving Patient Race and Ethnicity Data Capture to Address Health Disparities: A Case Study From a Large Urban Health System. Cureus. 2022 Jan 5;14(1):e20973. doi: 10.7759/cureus.20973. PMID: 35154951; PMCID: PMC8815799.

Setting the stage for REL Data Questions

"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, so that we can review the best treatment that our patients can receive and make sure that everyone 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

SAMPLE QUESTIONS

How to ask questions about patient race, ethnicity and tribal affiliation:

First, ask ethnicity: **"Do you consider yourself Hispanic or Latino?"**
Yes / No / Declined / Unknown

Next, ask race: **"Which category(ies) best describe your race?"**
American Indian or Alaska Native / Asian / Black or African American / Native Hawaiian or Other Pacific Islander / White / Declined / Unknown / Other Race

If the patient describes his/her race as **American Indian or Alaska Native**, then ask tribal affiliation: "What is (are) your tribe(s) or pueblo(s)?"

- Acoma Pueblo
- Cochiti Pueblo
- Isleta Pueblo
- Jemez Pueblo
- Jicarilla Apache Nation
- Kewa/Santo Domingo Pueblo
- Laguna Pueblo
- Mescalero Apache Nation

- Nambe Pueblo
- Navajo Nation
- Ohkay Owingeh Pueblo
- Picuris Pueblo
- Pojoaque Pueblo
- San Felipe Pueblo
- San Ildefonso Pueblo
- Sandia Pueblo

- Santa Ana Pueblo
- Santa Clara Pueblo
- Taos Pueblo
- Tesuque Pueblo
- Zia Pueblo
- Zuni Pueblo
- Other Tribal Affiliation
- Declined
- Unknown

EXAMPLE PATIENT DEMOGRAPHICS QUESTIONNAIRE

ETHNICITY: Indicate whether they are Hispanic, Latine, or Spanish Origin or not.
For patients who answer "Yes": are they asked to **specify their place(s) of origin?**

RACE: Are patients who choose one or more racial category asked **which race they most identify with.**
- **White**—Person having origins in any of the original peoples of Europe, the Middle East, or North Africa.
- **Black or African American**—Person having origins in any of the black racial groups of Africa.
- **American Indian or Alaska Native**—Person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.
- **Asian**—Person having origins 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, Thailand, and Vietnam.
- **Native Hawaiian or Other Pacific Islander**—Person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

PRINCIPAL LANGUAGE
- Language that a person usually or regularly uses, and most closely corresponds with the language that a person is most conversant in.
- Language for which he/she would need an interpreter.

Is this information sufficient to obtain accurate racial/ethnic/cultural patient information?

https://hcup-us.ahrq.gov/datainnovations/raceethnicitytoolkit/ca14.pdf

CLAS STANDARDS: COMMUNICATION AND LANGUAGE ASSISTANCE

Standard #5. Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to all health care and services.

- Ensure that clients with LEP or other communication needs receive **equitable access to services**

- Help **clients** understand their health care and service options and allow them to **participate in health care decision-making**

- Increase satisfaction with care

- Improve adherence to recommendations and treatments

- Improve client safety and **reduce miscommunications** that contribute to medical errors

- Comply with requirements, such as Title VI of the Civil Rights Act of 1964, the Americans with Disabilities Act of 1990, and other relevant policies.

HMA FACILITATED DISCUSSION

How are you currently using REL data?

Any innovative approaches

Opportunities for REL Data Collection Improvement

Collaborative Learning

Creating Welcoming Environments for LGBTQIA+ Patients
&
Data Collection Strategies/Best Practices

SOGIE DATA COLLECTION: CREATING WELCOMING ENVIRONMENTS
BEST PRACTICES & CHALLENGES

- Create a physical environment in your practice that shows inclusivity. Posters, printed materials, welcome packets, signatures, provider profiles, etc.

- Explain the "Why?"

- Consider allowing the patient the opportunity to disclose any personal privacy considerations.

- Adding SOGIE data collection requirements to contracts with providers, mandatory training and expected competencies.

- Flag missing SOGIE data: Develop discrete strategies to collect the data (Oral inquiry only in long-standing, trusting relationships).

- EHR - Allowing patients to enter their own SOGIE data in an online patient portal before getting to the clinic.

- Create an Internal and External Advisory Committee.

The EQUALITY Study revealed that approximately **80% of clinicians** believe patients would refuse to provide SOGIE [data], yet only **10% of patients** reported they would refuse to do so.
Standardized collection of SOGIE is viewed as a step toward recognition as an individual as well as normalization of SGM (sexual and gender minorities).

SOGIE DATA COLLECTION
BEST PRACTICES & CHALLENGES

Sample Preface and Privacy Statement

Why is my sexual orientation and gender identity information needed?

Simply Healthcare realizes that every member has a unique set of health needs. We feel that it is most important to respect an individual's choice about how to identify, and we would like to address you in the most respectful way based on your responses. These questions are asked of **all our members**, and most are completely voluntary.

How do I choose the correct information?

There are no right or wrong answers. If you don't find an answer that exactly fits, choose one that comes closest. This information will help us give you the best care possible.

Who will see this information?

Your provider will see this information, and it will become part of your medical record. In addition to your provider, limited other staff will have access to this information. Your information is confidential and protected by law just like all your other health information. Thank you for taking the time to complete the registration form.

Sexual Orientation

Gender identity

What is your current gender identity? (Check all that apply):
❑ Female
❑ Male
❑ Transgender Woman/Transgender Female
❑ Transgender Man/Transgender Male
❑ Additional category (e.g. non-binary, genderqueer, gender-diverse, or gender fluid). Please specify _____.
❑ Choose not to disclose

What sex were you assigned at birth? (Check one):
❑ Male
❑ Female

Were you born with a variation in your physical sex characteristics?

This is sometimes called being intersex or having a **Difference in Sex Development** (DSD)

❏ No   ❏ I don't know

❏ Yes, my chromosomes, genitals, reproductive organs, or hormone functions were observed to be different from the typical male/female binary at birth and/or I have been diagnosed with an intersex variation or DSD

CMS OMH Supports the Intersex Status question developed by interACT & Williams Institute at UCLA School of Law

One (1) in 58 people have a DSD or is intersex.

Intersex people are born with a variety of differences in their sex traits and reproductive anatomy. There is a wide variety of difference among intersex variations, including differences in genitalia, chromosomes, internal sex organs, hormone production, hormone response, and/or secondary sex traits.
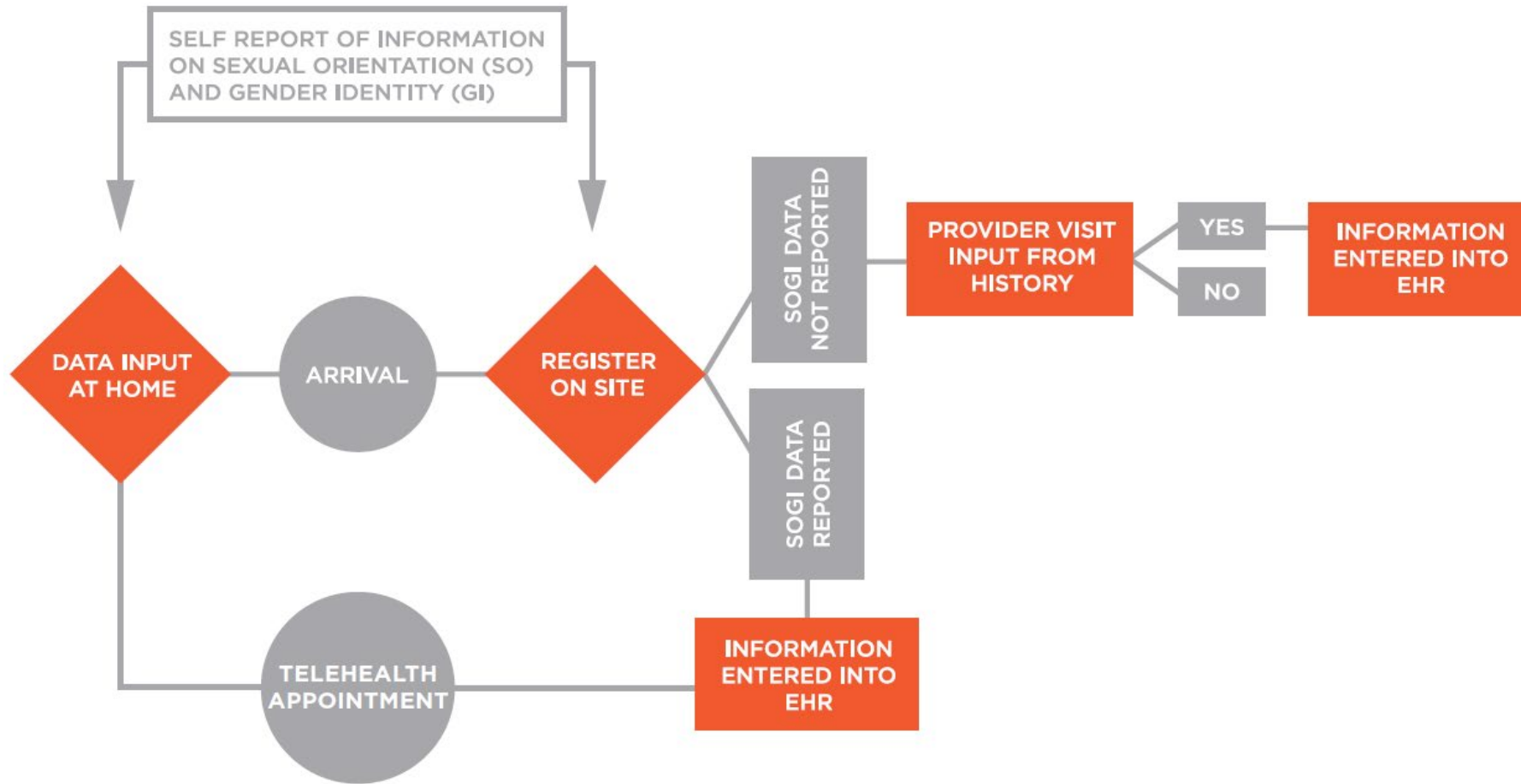
To practice **cultural humility** in interactions with intersex patients, it is important for clinicians to listen with sensitivity to their patients and acknowledge that:

- Sex development exists on a continuum
- Human fetal development is complex;
- An individual born with DSD may or may not identify as intersex or as LGBTQIA+

SOGIE and Health History Data Collection Best Practices

Figure 6: Sample Process of Collecting SOGI Data

Electronic Health Record (EHR) Customization

- Customize EHR to accommodate SOGIE data collection workflow and patient population needs.

- Talk to EHR vendor— several vendors have already helped other customers with similar needs.

- Connect with other organizations that use the same EHR and may have already developed solutions.

- For "missing" data, differentiate between the possible reasons why the data may be missing: Is it due to the data not being collected? Or to a patient skipping/refusing to answer?

SOGIE and Health History Data Collection Best Practices

EHR Customization (Continued)

Changes to the EHR that can facilitate patient-centered care:

- Decide which staff will have permission to enter, modify, or view data
- Ideally, clinical staff will have access to SOGIE information when meeting with patients so they can ask appropriate questions
- Clinicians should be able to edit the fields in case patients give them new information
- Create fields for name used and pronouns and ensure staff are able to see them
- Creating banners or alerts in the EHR that show a patient's name and pronouns

EHR Customization (Continued)

Additional Customizations to Consider
(transgender and gender diverse populations focus)

- **Use Dear Patient**. Adjust mailing systems so that they do not automatically fill in salutations, such as Mr. and Ms.

- For prescriptions, patient instructions, and chart summaries, etc., **develop a way to add name used and pronouns adjacent to the name on the person's insurance**. This will help with staff interactions without interfering with insurance claims.

- Create additional forms, such as **anatomical inventories**, to support clinical decisions based on a patient's anatomy rather than assigned sex at birth or gender identity.

SOGIE and Health History Data Collection Best Practices

Breasts □ **Present** □ **Absent**
- □ Chest reconstruction
- □ Bilateral mastectomy
- □ Unilateral mastectomy, R
- □ Unilateral mastectomy, L
- □ Breast augmentation/implants

Uterus □ **Present** □ **Absent**
- □ Hysterectomy—cervix removed
- □ Hysterectomy—cervix remains

Ovaries □ **Present** □ **Absent**
- □ Bilateral salpingo-oophorectomy
- □ Unilateral salpingo-oophorectomy, R
- □ Unilateral salpingo-oophorectomy, L

Cervix □ **Present** □ **Absent**

Vagina □ **Present** □ **Absent**
- □ Colpocleisis—closure of the vagina
- □ Vaginoplasty

Penis □ **Present** □ **Absent**
- □ Phalloplasty/penile implant
- □ Metoidioplasty
- □ Erectile device
- □ Penectomy

Testicles □ **Present** □ **Absent**
- □ Testicular implant(s)
- □ Bilateral orchiectomy
- □ Unilateral orchiectomy, R
- □ Unilateral orchiectomy, L

Urethra □ Present □ Absent
- □ Urethral lengthening

Prostate □ Present □ Absent
- □ Prostatectomy

Clinical Dashboards for Transgender and Gender Diverse (T/GD) Patient Data

- Aggregate population data on key metrics.

- Are easy to understand.

- Identify T/GD patients through a cross-check of the gender identity field with the sex assigned at birth field.

- **Suggested metrics for T/GD dashboards include**:
  - # of new patients
  - # and % of returning patients
  - # of patients by service and provider panel
  - % of patients taking gender-affirming hormones
  - % of patients receiving recommended behavioral health screenings
  - % of patients with common health concerns (including HIV)

DATA

Thank you!

HMA

Additional Resources

Terminology

Bisexual | A person emotionally, romantically or sexually attracted to more than one sex, gender or gender identity though not necessarily simultaneously, in the same way or to the same degree. Sometimes used interchangeably with pansexual.

Cisgender | A term used to describe a person whose gender identity aligns with those typically associated with the sex assigned to them at birth.

Gay | A person who is emotionally, romantically or sexually attracted to members of the same gender. Men, women and non-binary people may use this term to describe themselves.

Gender dysphoria | Clinically significant distress caused when a person's assigned birth gender is not the same as the one with which they identify.

Terminology *(Continued)*

Gender expression | External appearance of one's gender identity, usually expressed through behavior, clothing, body characteristics or voice, and which may or may not conform to socially defined behaviors and characteristics typically associated with being either masculine or feminine.

Gender-fluid | A person who does not identify with a single fixed gender or has a fluid or unfixed gender identity.

Gender identity | One's innermost concept of self as male, female, a blend of both or neither – how individuals perceive themselves and what they call themselves. One's gender identity can be the same or different from their sex assigned at birth.

Gender non-conforming | A broad term referring to people who do not behave in a way that conforms to the traditional expectations of their gender, or whose gender expression does not fit neatly into a category. While many also identify as transgender, not all gender non-conforming people do.

Terminology *(Continued)*

Genderqueer | Genderqueer people typically 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.

Intersex | Intersex people are born with a variety of differences in their sex traits and reproductive anatomy.

Lesbian | A woman who is emotionally, romantically or sexually attracted to other women. Women and non-binary people may use this term to describe themselves.

Genderqueer | Genderqueer people typically 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.

Terminology *(Continued)*

Intersex | Intersex people are born with a variety of differences in their sex traits and reproductive anatomy. There is a wide variety of difference among intersex variations, including differences in genitalia, chromosomes, gonads, internal sex organs, hormone production, hormone response, and/or secondary sex traits.

Non-binary | An adjective describing a person who does not identify exclusively as a man or a woman. Non-binary people may identify as being both a man and a woman, somewhere in between, or as falling completely outside these categories. While many also identify as transgender, not all non-binary people do. Non-binary can also be used as an umbrella term encompassing identities such as agender, bigender, genderqueer or gender-fluid.

Terminology *(Continued)*

Pansexual | Describes someone who has the potential for emotional, romantic or sexual attraction to people of any gender though not necessarily simultaneously.

Queer | A term people often use to express a spectrum of identities and orientations that are counter to the mainstream. Queer is often used as a catch-all to include many people, including those who do not identify as exclusively straight and/or folks who have non-binary or gender-expansive identities.

Sexual orientation | An inherent or immutable enduring emotional, romantic or sexual attraction to other people. Note: an individual's sexual orientation is independent of their gender identity.

Transgender | An umbrella term for people whose gender identity and/or expression is different from cultural expectations based on the sex they were assigned at birth. Being transgender does not imply any specific sexual orientation. Therefore, transgender people may identify as straight, gay, lesbian, bisexual, etc.

Leveraging SOGI and REAL Data to Advance Equity in Behavioral Health: Key Learnings

Https://deltacentercalifornia.jsi.com/updates/leveraging-sogi-and-real-data-advance-equity-behavioral-health-key-learnings

This webinar was held on February 22nd, 2023:
Leveraging SOGI and REAL Data to Advance Equity in Behavioral Health.
Hosted by the California Institute for Behavioral Health Solutions (CIBHS) and co-sponsored by the California Primary Care Association (CPCA) and the County Behavioral Health Directors Association of California (CBHDA) in partnership with JSI, the webinar came to fruition as a part of Delta Center California.
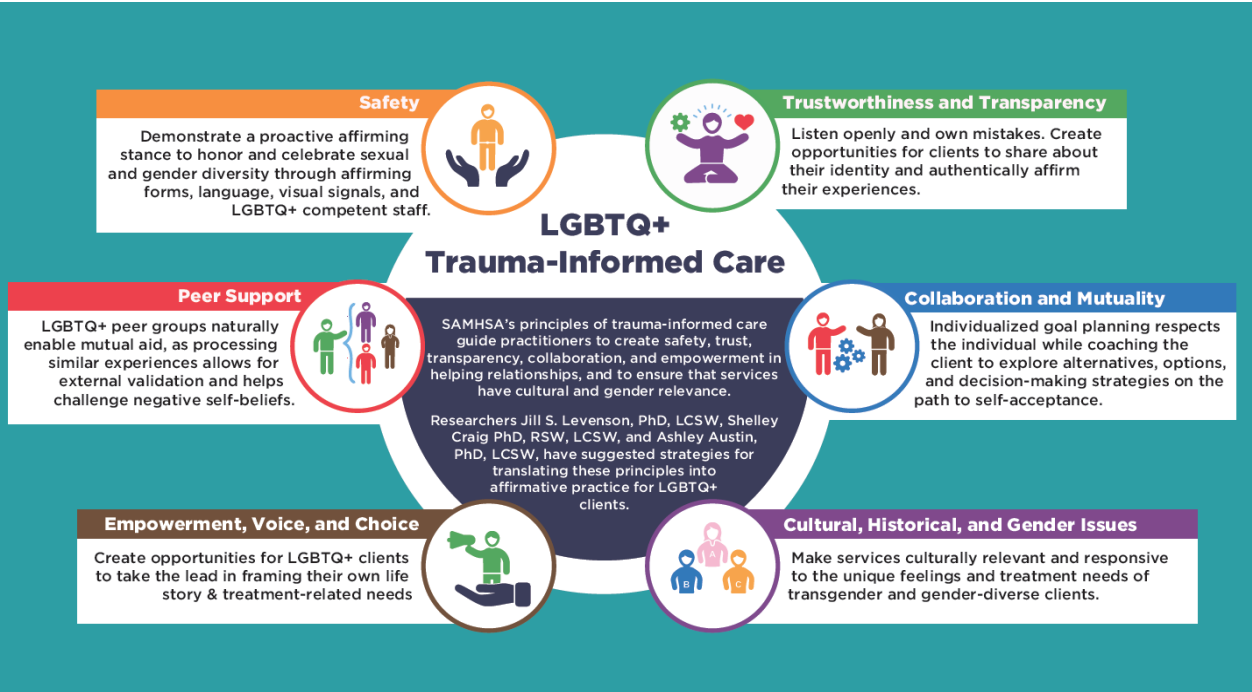
CENTER of EXCELLENCE
LGBTQ+ BEHAVIORAL HEALTH EQUITY

Sample Resources (free learning opportunities)
- The Holiday Checklist for LGBTQ+ People
- Things to Consider When Your LGBTQ+ Clients Plan to Attend Family Gatherings
- Eating Disorders in LGBTQ+ Populations
- Black LGBTQ+ Mental Health
- Practice Considerations: Use of the SBIRT Model Among Transgender & Nonbinary Populations
- Language Guidance When Serving LGBTQ+ Populations
- Resources for Supporting the Bisexual Community
- Supporting the Behavioral Health Workforce to Implement Best Practices for LGBTQ+ People
- FAQs on Medicaid Financing for LGBTQ+-Affirming Behavioral Health Services
- Minority Stress & Coping for LGBTQ+ Adolescent Health

https://lgbtqequity.org/resources/

Additional Links

- **The Sexual Orientation, Gender Identity, and Health (SOGI Health) Research Group | University of Maryland | School of Public Health (umd.edu)**

- **CMS Framework for Health Equity 2022–2032**

- **Affirmative Services For Transgender and Gender-diverse People: Best Practices For Frontline Health Care Staff (Updated Winter 2020). This is a very good resource to conduct internal training. It includes recommendations for human resources staff. Link to Site: https://www.LGBTQiahealtheducation.org/wp-content/uploads/2020/03/TFIE-40_Best-Practices-for-Frontline-Health-Care-Staff-Publication_web_final.pdf**

- **Providing Inclusive Services and Care for LGBT People: A Guide for Health Care Staff from the National LGBTQ+ Health Education Center. This publication is also endorsed by CMS. Link to Site: https://www.LGBTQiahealtheducation.org/publication/learning-guide/**

- **The National Resource Center On LGBTQ+ Aging. https://www.lgbtagingcenter.org/**

Training Resources

- The **National LGBTQ+ Health Education Center** provides educational programs, resources, and consultation to health care organizations with the goal of optimizing quality, cost-effective health care for lesbian, gay, bisexual, transgender, queer, intersex, asexual, and all sexual and gender minority (LGBTQ+) people.

    Link : https://www.thehrcfoundation.org/professional-resources/the-national-lgbt-health-education-center.

- The **Center for Affiliated Learning** (The CAL). The CAL is an education and training platform owned and operated by Affiliates Risk Management Services, Inc. They offer a range of free online trainings ranging from basics of LGBTQ+ patient-centered care to more specialized topics such as serving trans youth. CME/CEU credits are available after completing the training courses.

    Link : https://www.thehrcfoundation.org/professional-resources/the-center-for-affiliated-learning-the-cal

- **CMS Medicare Learning Network**: Improving Health Care Quality for LGBTQ+ People. This 1-hour course is designed to provide education for health care providers and staff who are responsible for collecting Medicare patient data from LGBTQ+ persons. Throughout this course, these providers will be called health care providers. This training also provides guidance on how to document SOGI data in your EHR.

    Link : https://www.cms.gov/Outreach-and-Education/MLN/WBT/MLN3390633-OMH-LGBTQ+/OMHLGBTQ+/sogi/index.html

Self Reflection...

Reflect on your own reactions and feelings

- Foster equity in your practices / organizations

- Educate yourself and others (resources listed on appendix)

- Speak up when you see discriminations, insensitivity, and gaps in knowledge

- Advocate for policy changes that are LGBTQIA+ affirmative and post it

- Include SOGIE in a zero-tolerance discrimination policy and post it

- Examine your language

- Education and training

- Come out as an ally

- Accept and celebrate diversity

- Understand intersectionality

QUESTIONS/DISCUSSION

1. **To what extent did the session meet the stated objectives?**
(1 - not at all to 5 - met all objectives)

2. **How would you rate the session overall?**
(1 - poor to 5 - excellent)

We are here to help you !

✓ For 1:1 site specific coaching, contact an HMA team member.

✓ To access previously recorded sessions and tools, visit https://livingwell.dc.gov/page/million-hearts-providers or see the technical assistance inventory document sent via email.