

Cultural Adaptation Of Measures And Tools For Sexual Orientation And Gender Identity (SOGI) Data Collection

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He, Him, His Pronouns

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Any Pronouns



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Our Roots

Fenway Health

- Independent 501(c)(3) FQHC
- Founded 1971
- Mission: To enhance the wellbeing of the LGBTQIA+ community as well as people in our neighborhoods and beyond through access to the highest quality health care, education, research, and advocacy
- Integrated primary care model, including HIV and transgender health services

The Fenway Institute

- Research, Education, Policy



The National LGBTQIA+ Health Education Center

- Training and Technical Assistance
- Grand Rounds
- Online Learning
 - CE and HEI Credit
- Environmental Influences On Child Health Outcomes (ECHO) Programs
- Publications and Resources



Learning Module



Publication



Toolkit



Video



Webinar

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- Close the browser, and an evaluation will automatically open for you to complete
- We very much appreciate receiving feedback from all participants
- Completing the evaluation is **required** to obtain a CME certificate

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This activity has been reviewed and is acceptable for up to 1.0 Prescribed credits by the American Academy of Family Physicians. Participants should claim only the credit commensurate with the extent of their participation in this activity.

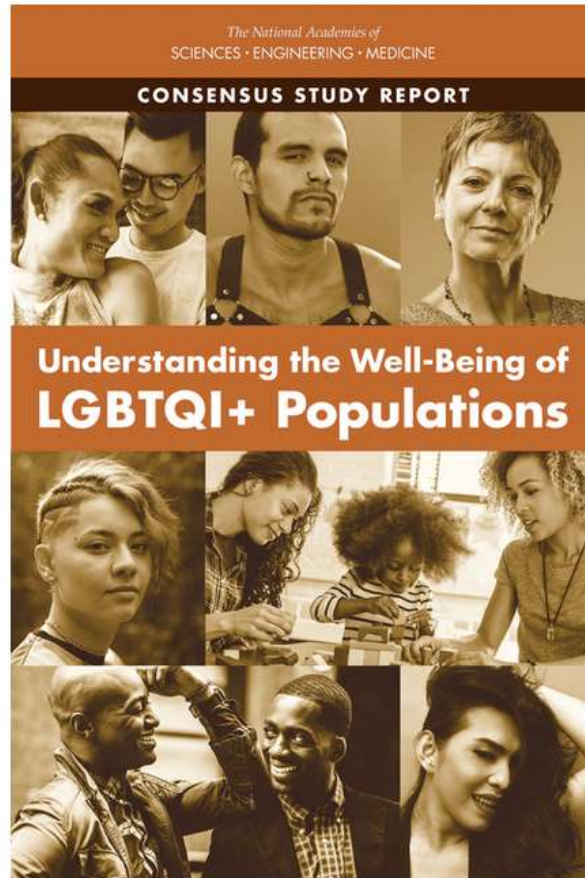
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Other Health Professionals	Confirm equivalency of credits with relevant licensing body.

Patient Sexual Orientation and Gender Identity Data Collection

Continuing Medical Education Disclosure

- Program Faculty: Alex S. Keuroghlian, MD, MPH;
- Current Position: Director of the Division of Education and Training at the Fenway Institute; Associate Professor of Psychiatry, Harvard Medical School
- Disclosure: Royalties as editor of a textbook with McGraw Hill on transgender and gender diverse health care.

Why Programs for LGBTQIA+ People?



BOX 1-1 Statement of Task

The Committee on Population (CPOP) of the National Academies of Sciences, Engineering, and Medicine will undertake a consensus study that will review the available data and future research needs on persons of diverse sexualities and genders (e.g., LGBTQ+ and MSM), as well as persons with differences in sex development (sometimes known as intersex), along multiple intersecting dimensions across the life course. Areas of focus will include, but are not limited to, the following:

- Families and social relationships
- Patterns of stigma, violence, and victimization
- Role of community, cultural, educational, healthcare, and religious organizations and institutions
- Civic engagement, political participation, and military service
- Socioeconomic status/stratification, housing, and workforce issues
- Justice and legal systems
- Social change and geographic variations in public attitudes and public policies
- Population health and well-being

L,G,B,T,Q,I,A,+ Concepts



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Sexual Orientation and Gender Identity are Not the Same

- All people have a sexual orientation and gender identity
 - How people identify can change
 - Terminology varies
- Gender Identity \neq Sexual Orientation



Sex Assigned at Birth

Female

Intersex

Male



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Gender Identity and Gender Expression

- Gender identity

- A person's inner sense of being a girl/woman, boy/man, beyond, or having no gender
- All people have a gender identity

- Gender expression

- How one presents themselves through their behavior, mannerisms, speech patterns, dress, and hairstyles
- May be on a continuum

Gender Identity Terminology

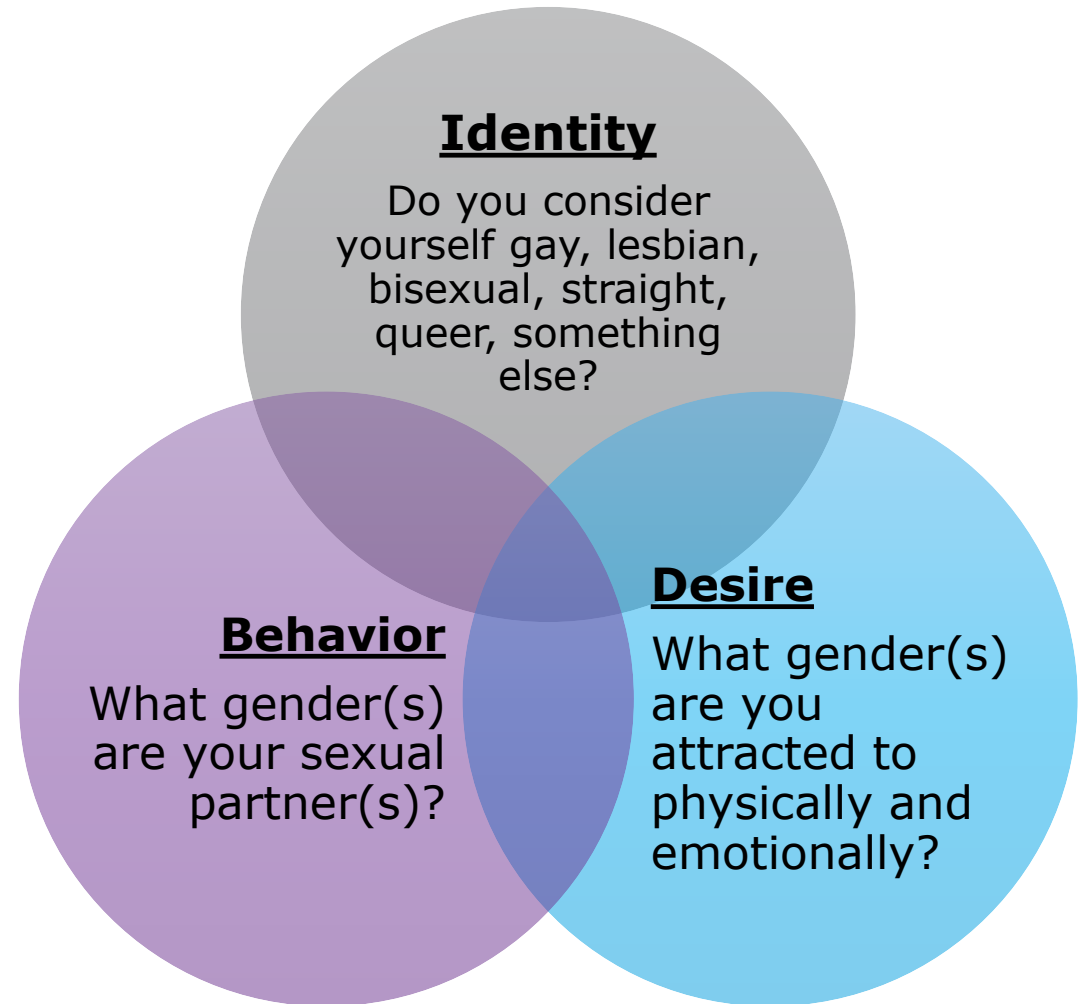
- Binary terminology
 - Transgender woman, trans woman
 - Transgender man, trans man
- Non-binary terminology
 - Genderqueer person, gender fluid person
- Trans masculine, Trans feminine
- Gender identity is increasingly described as being on a continuum



Sexual Orientation

- Sexual orientation: how a person experiences their physical, emotional and romantic attachments to others
- Desire
- Behavior
 - Risk of sexually transmitted infections is related to behavior, not identity
- Identity
 - e.g., straight, gay, lesbian, bisexual, queer, asexual, pansexual

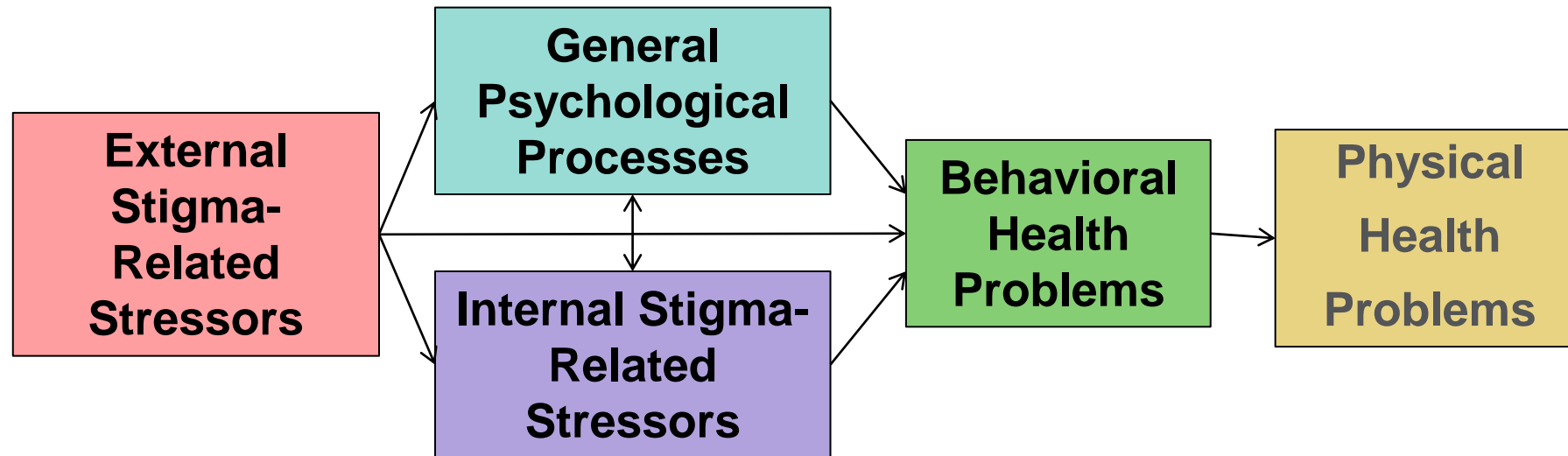
Dimensions of Sexual Orientation:



What Does 'Q' Stand For?

- 'Q' may reflect someone who is 'questioning' their sexual orientation or gender identity.
- 'Q' may stand for 'queer,' an inclusive term used by many sexually and gender diverse people. The term queer is particularly commonly used by younger people, and also by people of all ages.

Minority Stress Framework



Adapted from *Hatzenbuehler, 2009*

Interpersonal Stigma

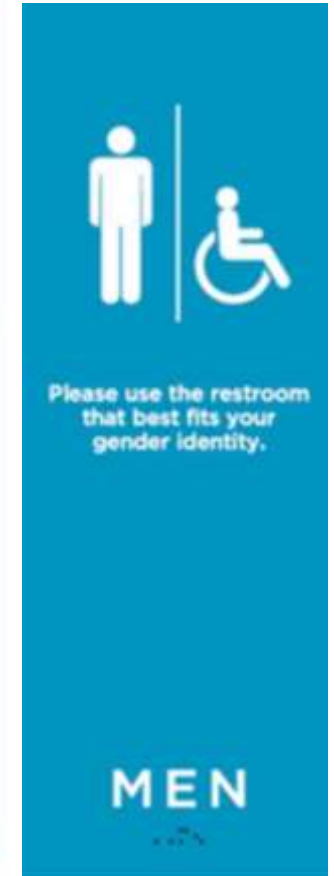


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Structural Stigma

- Structural, or institutional discrimination includes the policies of private and governmental institutions that intentionally restrict the opportunities of certain people, as well as policies that unintentionally restrict these opportunities.



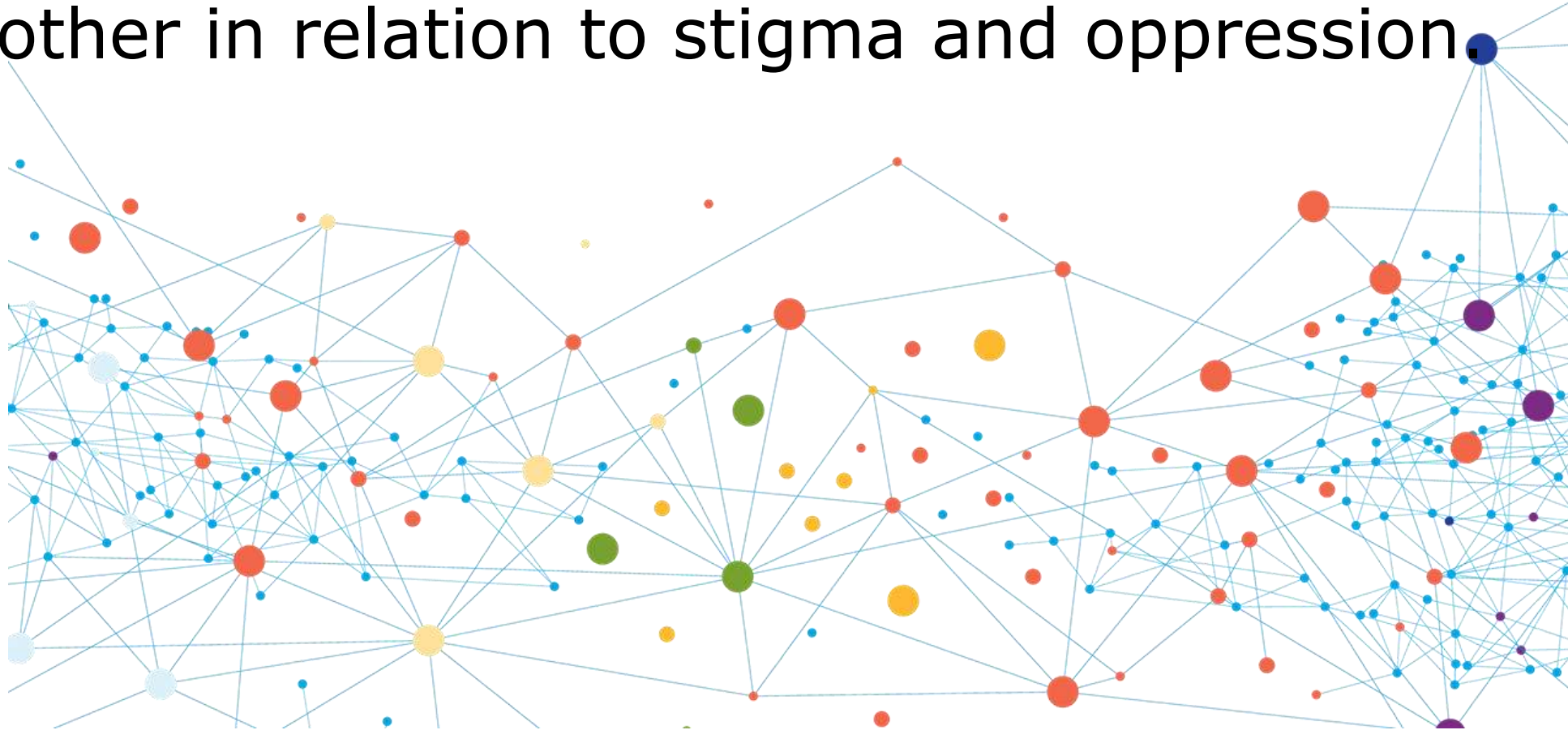
Intrapersonal Stigma

“...And to the degree that the individual maintains a show before others that they themselves does not believe, they can come to experience a special kind of alienation from self and a special kind of wariness of others.”

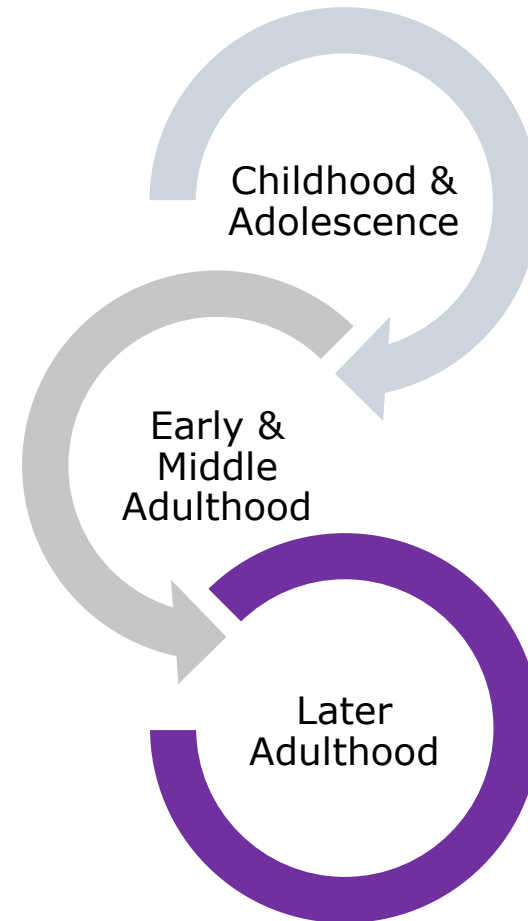


Intersectionality

A person's many identities which overlap with one another in relation to stigma and oppression.



Health Issues Throughout the Life Course



Resilience in the LGBTQIA+ Community

Despite the many challenges that LGBTQIA+ people often face, both internal and community-derived resilience can protect the health and well-being of LGBTQIA+ people.

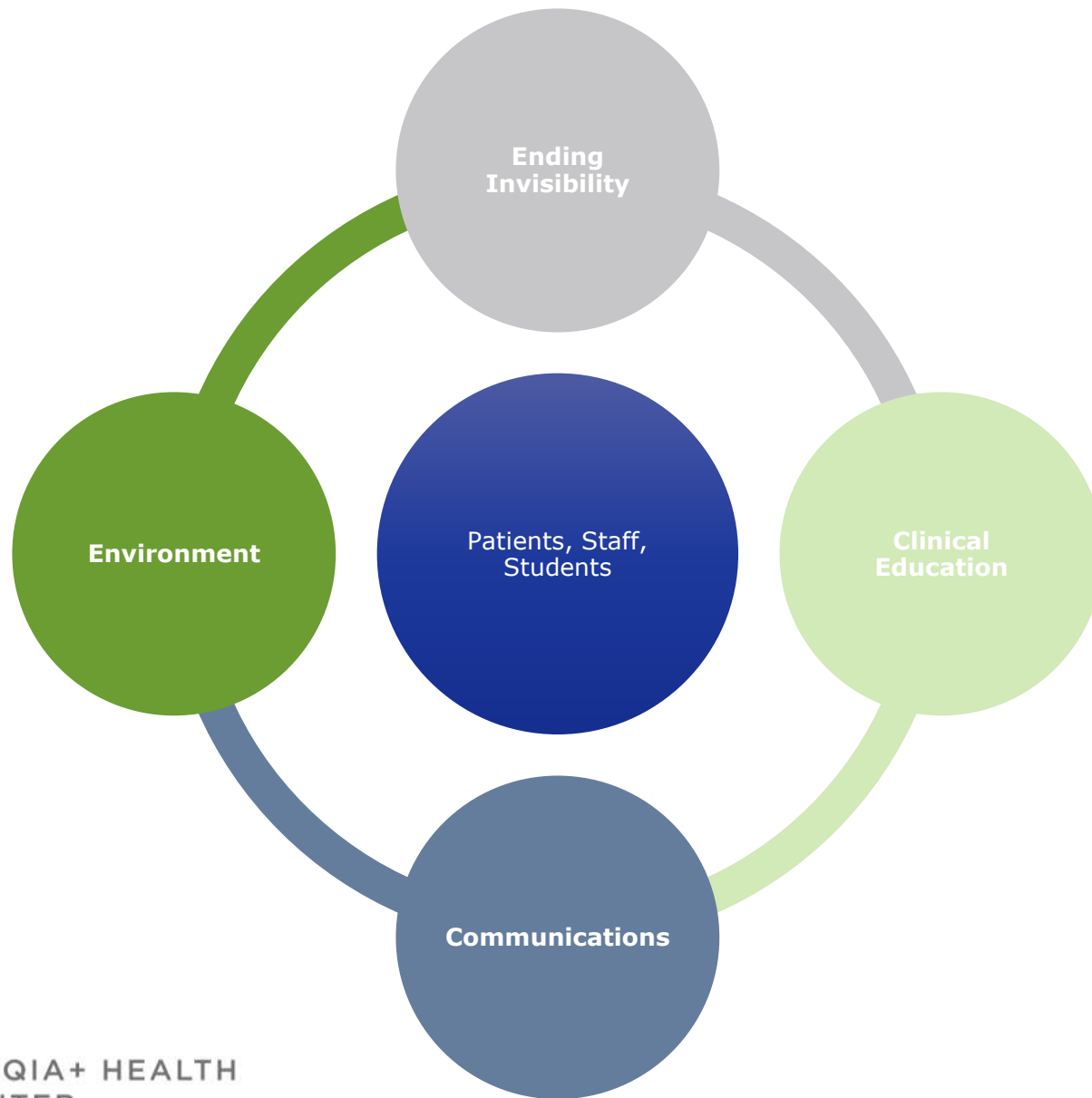


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Overcoming Barriers



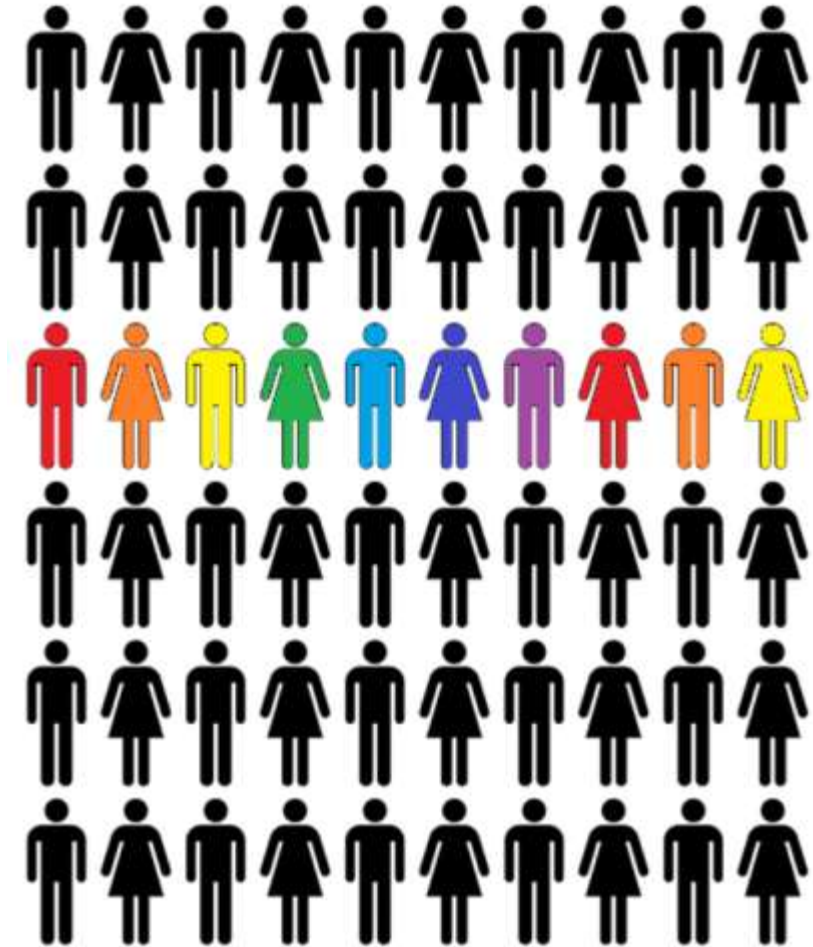


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Population Health: Ending LGBTQIA+ Invisibility in Health Care

- Has a clinician ever asked you about your history of sexual health, your sexual orientation or your gender identity?
- How often do you talk with your patients about their sexual history, sexual orientation, or gender identity?



Appropriate Screening: Rodrigo's Story

- 40-year-old trans man who came in with pelvic pain and spotting
- A biopsy determined that Rodrigo had cervical cancer
- No one had told Rodrigo that he needed routine cervical Pap tests



Are Patients Likely to be Offended by SOGI Questions?

- A study of 301 patients from four racially and geographically diverse U.S. health centers found high acceptability by patients of routine SOGI data collection: most expressed believing the questions are important and reported they would answer these again in the future (Cahill, et al., 2014).
- 78% of clinicians nationally believe patients would refuse to provide sexual orientation, however only 10% of patients say they would refuse to provide sexual orientation (Haider et al., 2017).
- No difference in patient attitudes toward registration forms that include SOGI questions vs. forms that do not; only 3% of patients reported being distressed, upset or offended by SOGI questions (Rullo et al., 2018).

Collecting Patient Sexual Orientation and Gender Identity Data



Preparation for Collecting Data in Clinical Settings

- **Clinicians:** Need to learn about LGBTQIA+ health and the range of clinically relevant experiences related to sexual orientation and gender identity.
- **Non-clinical staff:** Front desk and patient registration staff must also receive training on LGBTQIA+ health, communicating with LGBTQIA+ patients, and achieving quality care with diverse patient populations
- **Patients:** Need to learn about why it is important to communicate this information, and feel comfortable that it will be used appropriately

Responding to Staff Concerns

- Some staff may need extra coaching and reassurance
- Supervisors should explain that the health center is trying to provide the best care for all patients, and staff do not need to change their own values to collect SOGI data
- Regular check-ins with staff members will help identify and address their concerns

SOGI Data Collection Demonstration Videos



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SOGI Patient Pamphlet Translations



Arabic

Brazilian Portuguese

English

Farsi

Haitian Creole

Polish

Russian

Simplified Chinese

Somali

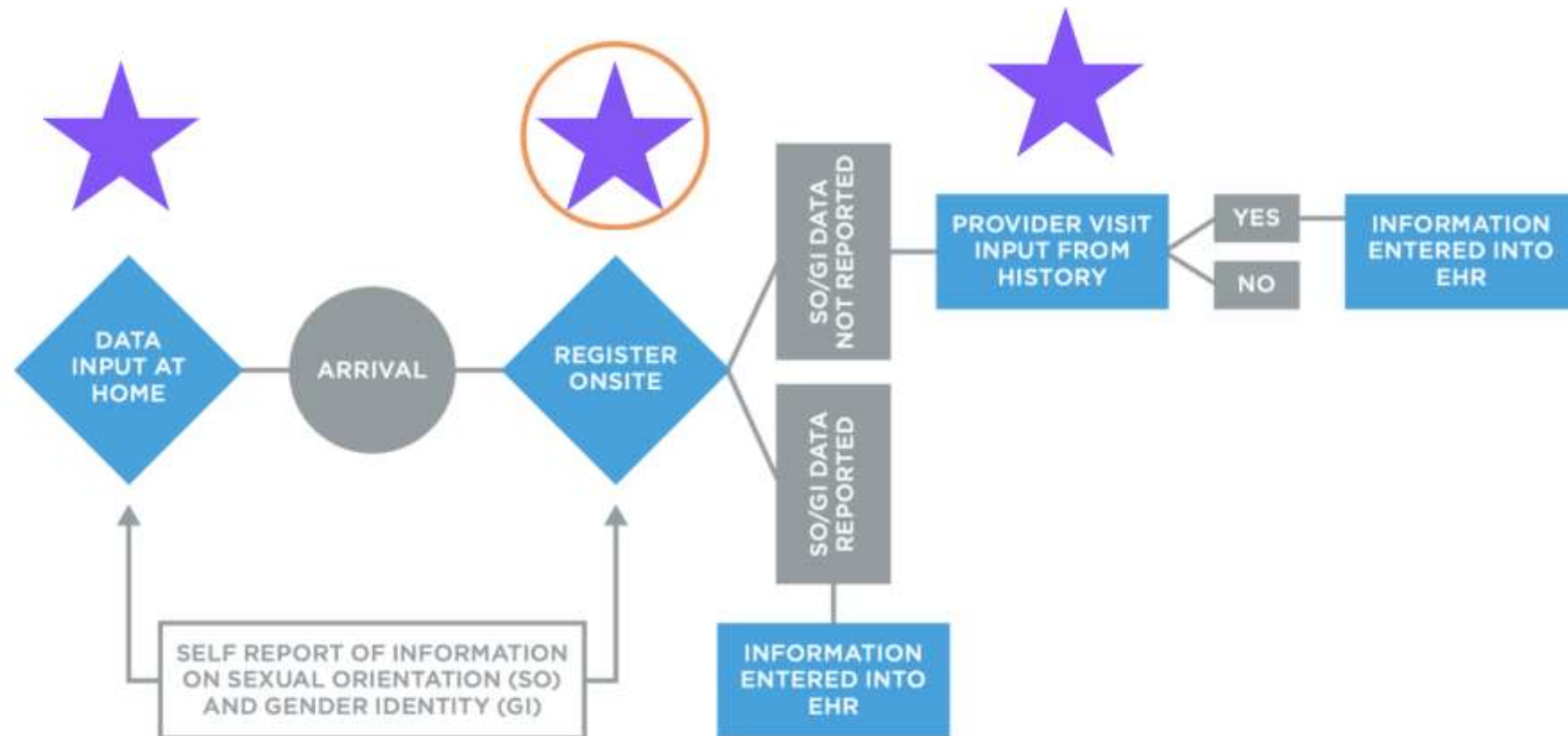
Spanish

Tagalog

Tigrinya

Vietnamese

Gathering SOGI Data During the Process of Care



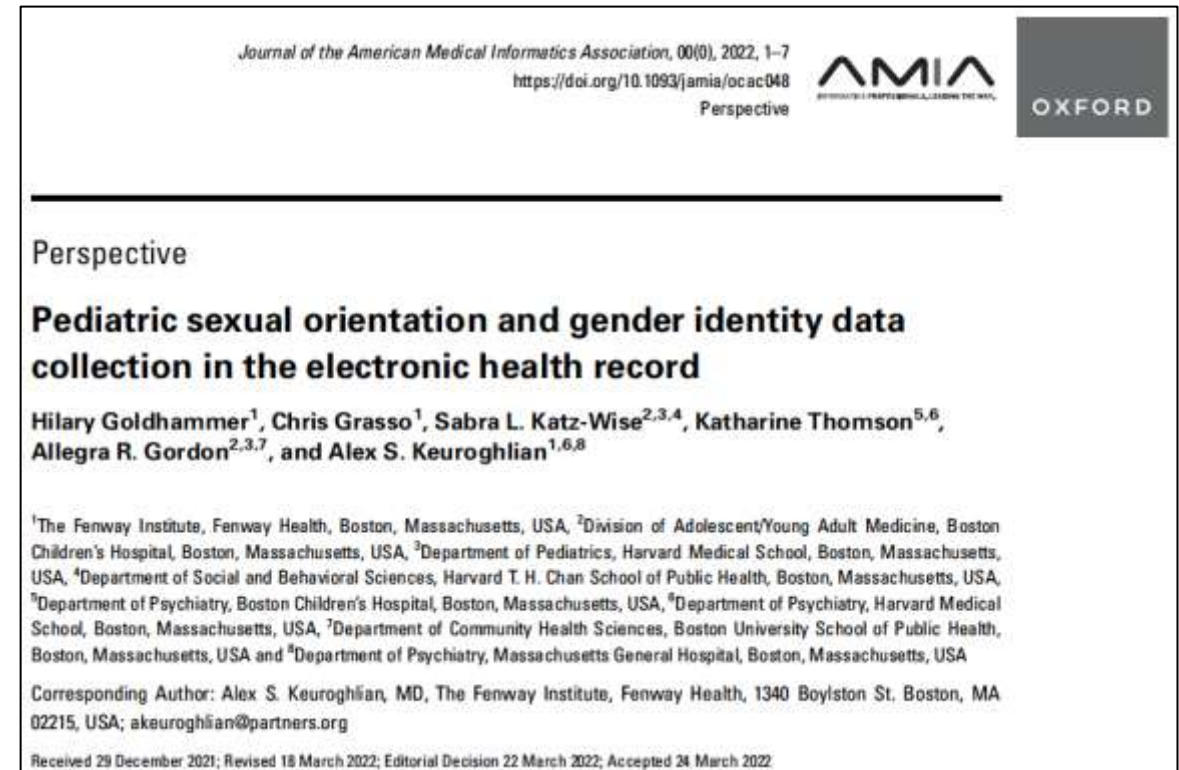
Collecting Data on Gender Identity

- What name do you go by?
- What are your pronouns (e.g., she/her, he/him, they/them)?
- What name is on your insurance records?
- What is your current gender identity?
- What sex were you assigned at birth?



SOGI Reporting for Pediatric Patients

- At what age do you start asking these questions?
 - Recommend asking GI <12yo
 - Recommend asking minors without parent/guardian in the room, and if they are comfortable having this information in health records
- Provider should re-ask after registration if initially filled out by parent/guardian or under their watch
- Many parents/guardians will answer “Don’t Know” or leave blank



Pronouns

People may have a range of pronouns, including she/her/hers and he/him/his, as well as less-common pronouns such as they/them/theirs and ze/hir/hirs (pronounced zee/hear/hears).



Subjective	Objective	Possessive	Examples
He	Him	His	He is in the waiting room. The doctor is ready to see him. That chart is his.
She	Her	Hers	She is in the waiting room. The doctor is ready to see her. That chart is hers.
They	Them	Theirs	They are in the waiting room. The doctor is ready to see them. That chart is theirs.
Ze	Hir	Hirs	Ze is in the waiting room. The doctor is ready to see hir. That chart is hirs.



Anticipating and Managing Expectations

- LGBTQIA+ people have a history of experiencing stigma and discrimination in diverse settings
- Don't be surprised if a mistake results in a patient becoming upset
- Don't personalize the reaction
- Apologizing when patients become upset, even if what was said was well-intentioned, can help defuse a difficult situation and re-establish a constructive dialogue

Avoiding Assumptions

- You cannot assume someone's gender identity or sexual orientation based on how they look or sound.
- To avoid assuming gender identity or sexual orientation:
 - *Instead of:* "How may I help you, Ma'am/Sir?"
 - *Say:* "How may I help you?"
 - *Instead of:* "He/She is here for his/her appointment."
 - *Say:* "The patient is here in the waiting room."
 - *Instead of:* "Do you have a boyfriend/girlfriend?"
 - *Say:* "Are you in a relationship?"



Objectives

- Explain the importance of SOGI data collection to identify and address the unique needs of sexual and gender minority patient populations, with special consideration for culturally and linguistically diverse patients who are part of LGBTQIA+ communities.
- Identify procedures to translate and adapt SOGI data collection questions and patient education materials for multilingual patient populations accurately and affirmatively.
- Plan next actions to implement culturally and linguistically affirming practices that are community informed, and integrated throughout the health experiences of multilingual, multiethnic, and racially diverse patients.





To Latinx or not to Latinx?

Gender neutrality does not equal gender inclusivity

The best way to know is by asking people how they self-identify

It's political – as an identity and as an example of colonizing language



To Latinx or Not to Latinx?

- Gender neutrality does not equal gender inclusivity.
- Provide a definition of “Latinx”.
 - Example:* A label to describe gender-expansive people of Latin American origin or descent.
- Use Latinx when intentionally acknowledging gender diversity.
 - Latina for women
 - Latino for men
- **Do not** use Latinx to refer to only men and women.
- **Do not** use Latinx when referring to transgender people who identify within the gender binary unless they themselves use the label.
- When collecting data, provide alternatives
 - Example: “Do you identify as Latina, Latino, or Latinx”?



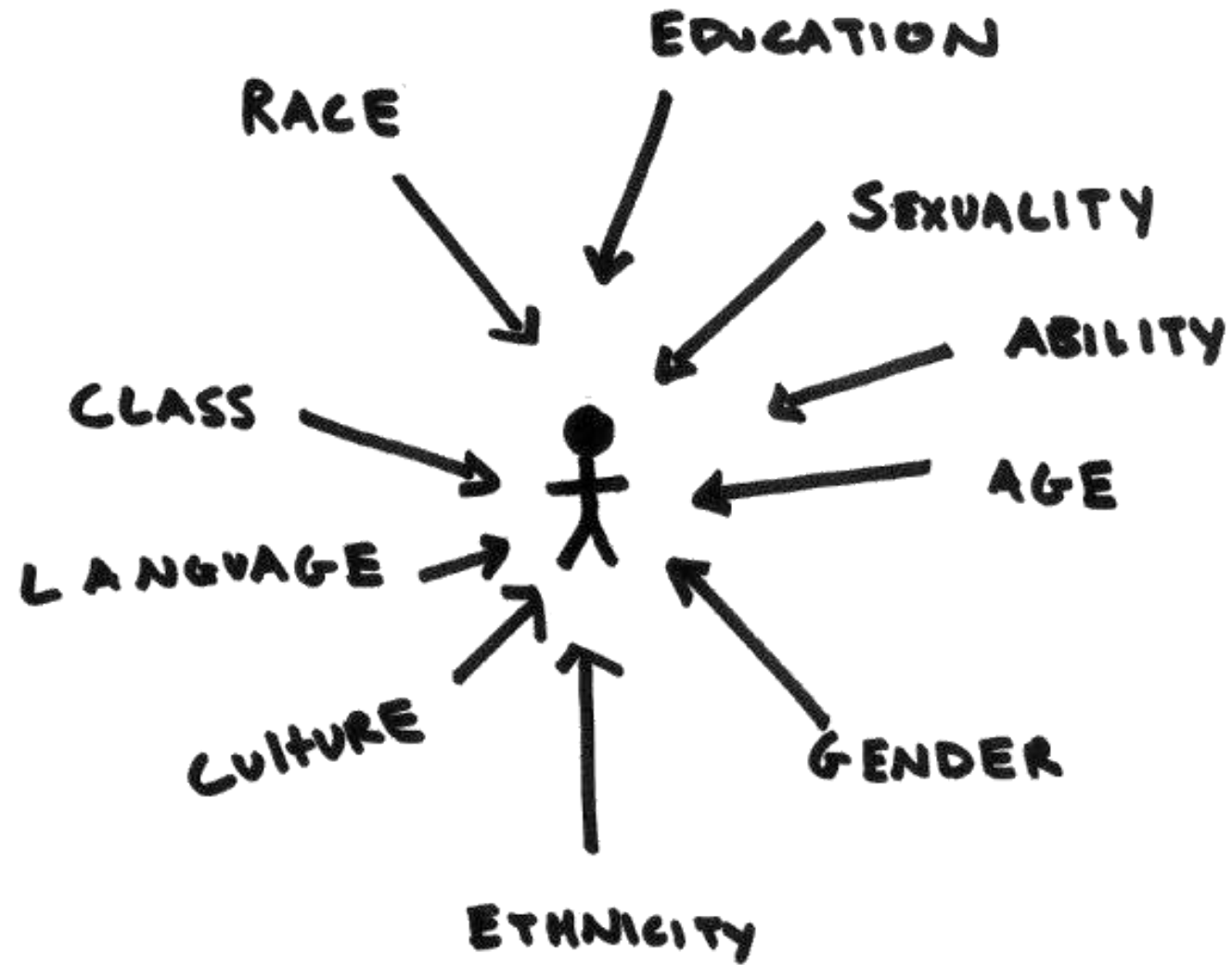
To Latinx or Not to Latinx: A Question of Gender Inclusivity Versus Gender Neutrality

Ana María del Río-González, PhD

ABOUT THE AUTHOR

The author is with the Department of Psychological and Brain Sciences, George Washington University, Washington, DC.

Definition of the population: As recommended by (del Río-González, 2021) we use “Latina/x/o” when referring to the community at large and “Latino” when referring to cisgender men, “Latina” when referring to cisgender women.

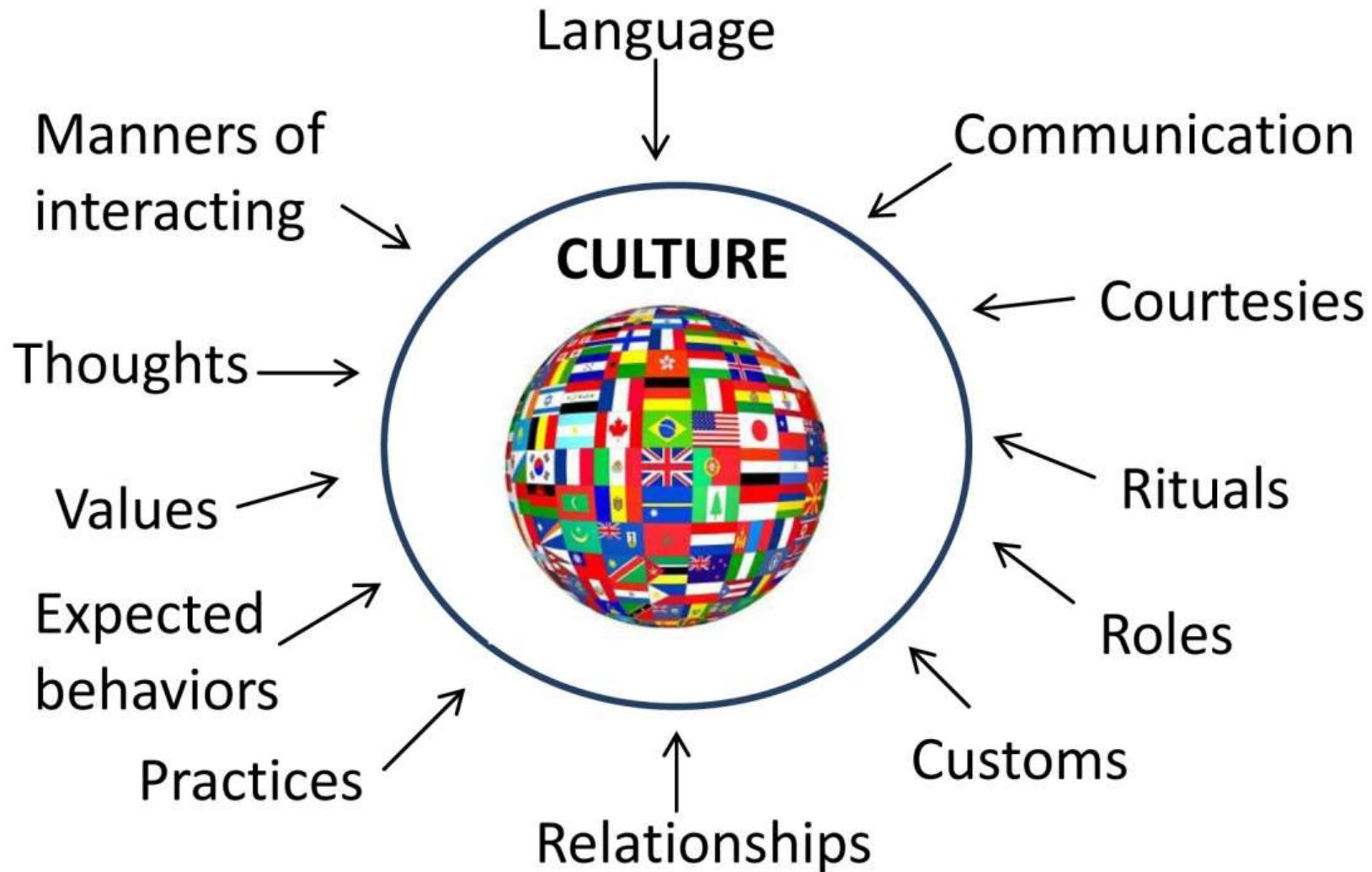


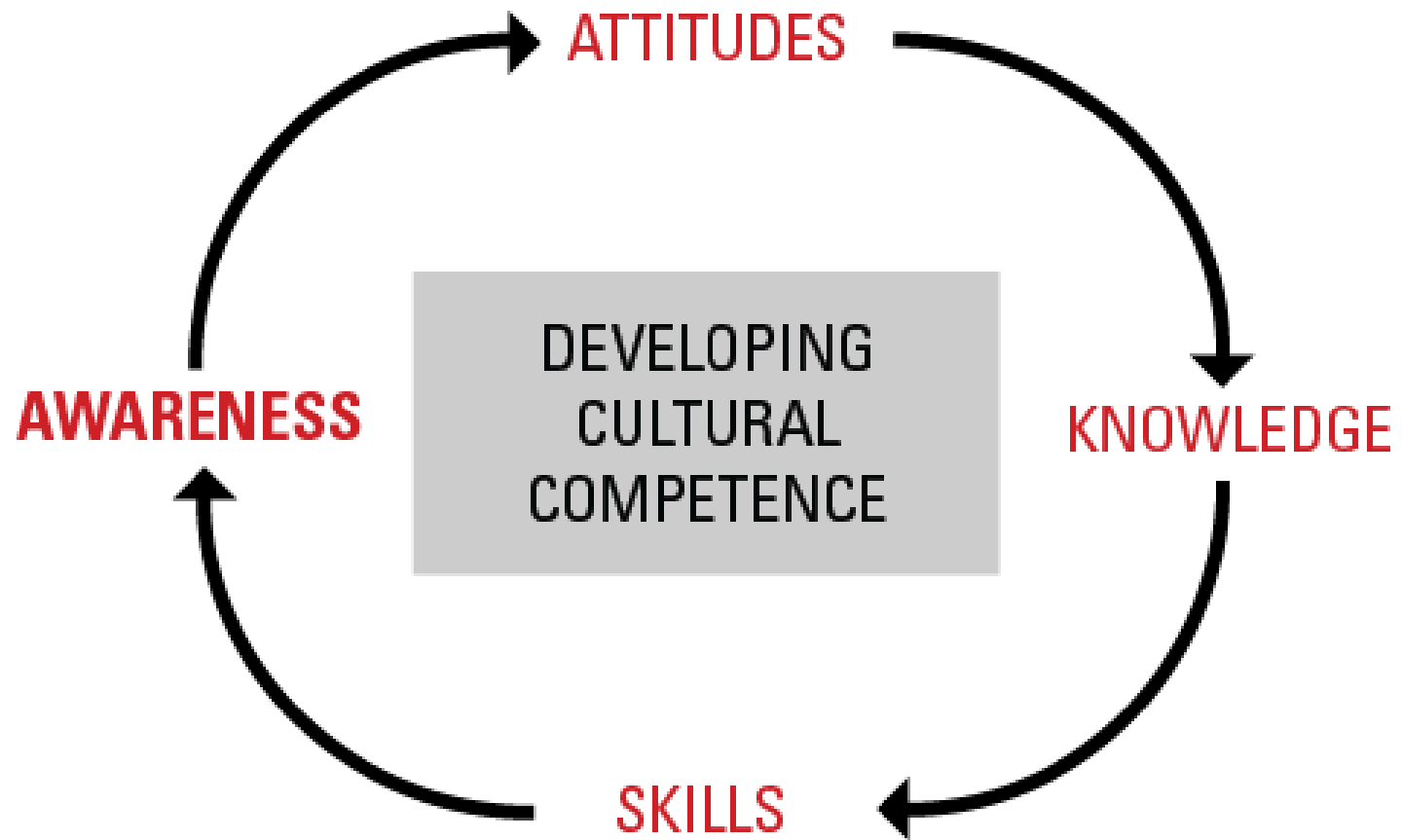
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Health is a political and a cultural experience

- Culture frames and shapes how we perceive the world and our experiences
- Along with other determinants of health and disease, culture helps to define:
 - Healthcare encounters
 - Which diseases or conditions are stigmatized
 - What health promotion strategies may work
- Culturally congruent interventions are urgently needed
 - Reflects the needs, idiosyncrasies, and overall values of specific populations

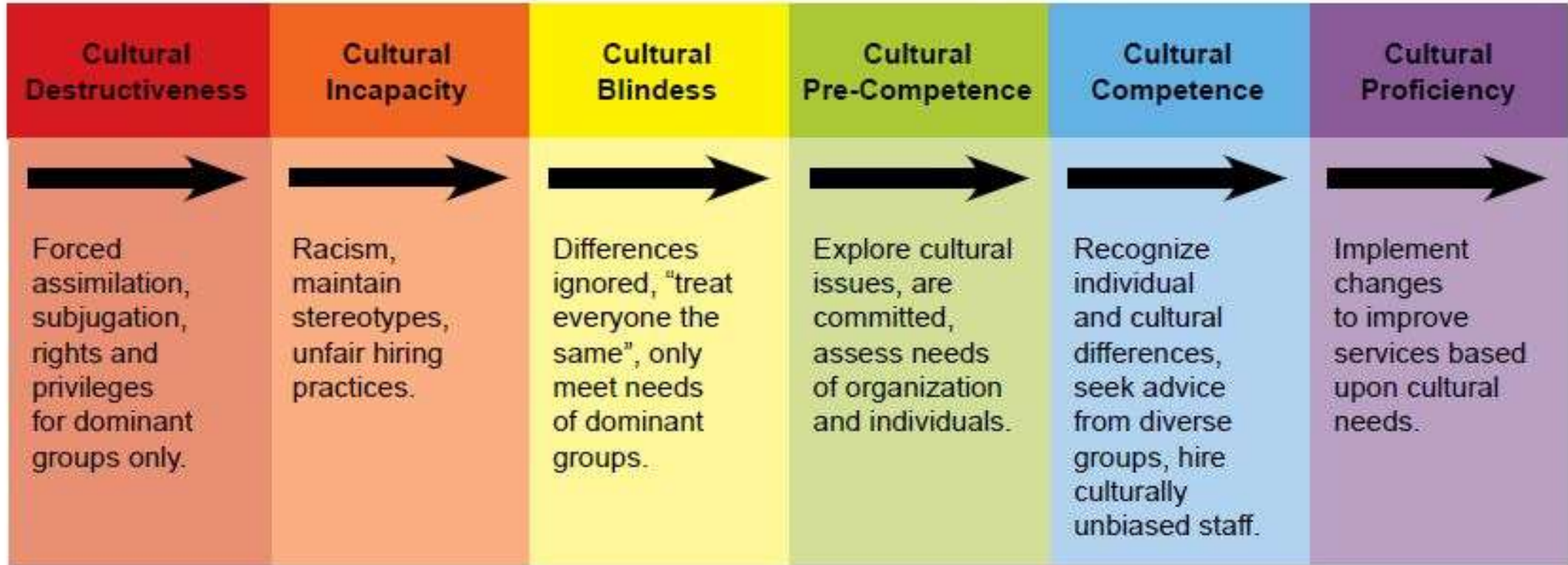




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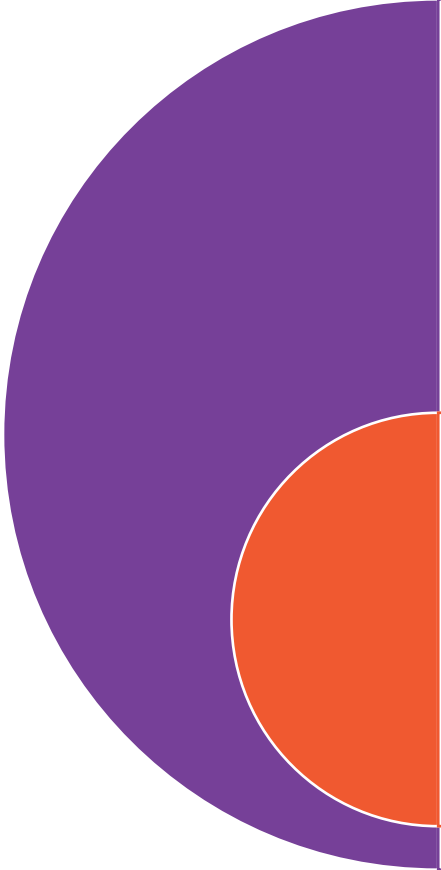
Continuum of Cultural Competency



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Cultural Adaptation: Why?



Culturally appropriate data collection instruments enhance services' relevance, effectiveness, and feasibility.

Effective data collection instruments take time from their testing to implementation with the intended populations.



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PACA: A Participatory Approach for Cultural and Linguistic Adaptations

PACA

Developed as part of implementing the SMART Program, a stepped-care eHealth HIV prevention program for diverse adolescent men who have sex with men (MSM) in the USA and territories.

The PACA team was a collaboration of transdisciplinary public health practitioners and scientists, and members of the target population. PACA consisted of and was implemented following five steps.

Those steps were part of an interactive process that allowed updating content as scientific knowledge and cultural experiences changed over time.

Gathering and Organization of Information

- Goal: Integrate cultural, ethnic, and language values.
- We reviewed the popular and scientific literature to integrate common core values and updated jargon among Spanish-speaking Young Latino Sexual Minority Men (YLSMM) into the intervention.

Translation and Linguistic Adaptation

- Goal: Keep consistency and comprehension of the intervention.
- A fully bilingual (English) native Spanish speaker translates all intervention components and materials. Attention is given to the use of language that represents the idiomatic and cultural experiences of different Spanish-speaking communities. A second team member reviews the translation making recommendations and notes for group discussion.
- The use of language is triaged with community members, and a group discussion is conducted to integrate recommendations.



Review and Development of Complementary Materials

- Goal: Address specificities of the intervention and research.
- Identify any intervention content that may need to be specifically created to make it relevant and address the population's needs.
- Develop content following a similar process as in the previous step; content is developed by a team member, reviewed by other team members, and by a member of the focus population.

Testing Adapted Content

- Goal: Test an integrated version of all adaptations made to the intervention.
- Conduct structured interviews or group discussions with participants to document their experiences and recommendations for the intervention.
- Recruit a small group of participants who meet the targeted audience's inclusion criteria and have yet to participate in earlier stages of the adaptation process.



Adaptation Refinement

- Goal: Integrate all recommendations captured during the adaptation process.
- Revisit any earlier step in the adaptation process to make changes as needed.
- Achieve consensus among the team and community members to the final version of the intervention



Collecting Sexual Orientation Data

Line	Patients by Sexual Orientation	Number (a)
13.	Lesbian or gay	
14.	Straight (not lesbian or gay)	
15.	Bisexual	
16.	Something else	
17.	Don't know	
18.	Choose not to disclose	
19.	Total Patients (Sum Lines 13 to 18)	

¿Cómo identifica su orientación sexual?

1. Homosexual (Gay o lesbiana)
2. Heterosexual
3. Bisexual
4. Pansexual
5. Otra: _____



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Collecting Gender Identity Data

Line	Patients by Gender Identity	Number (a)
20.	Male	
21.	Female	
22.	Transgender Male/ Female-to-Male	
23.	Transgender Female/ Male-to-Female	
24.	Other	
25.	Choose not to disclose	
26.	Total Patients (Sum Lines 20 to 25)	

¿Cómo identifica su identidad de género?

1. Masculino
2. Femenino
3. Transgénero o transexual
4. Género diverso
5. Otro: _____



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The Benefits of PACA

- Using a participatory and community-oriented approach, like PACA, allows for data collection instruments to be more compatible and relevant with participants' needs, cultural patterns, belief systems, meanings, values, and social context.
- Its participatory approach allows for the inclusion and collaboration of a diverse multi-sectorial team, facilitating a more robust, comprehensive adaptation process.



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Thank you! ¡Gracias!

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