



# CULTURAL ADAPTATION OF MEASURES AND TOOLS FOR SEXUAL ORIENTATION AND GENDER IDENTITY (SOGI) DATA COLLECTION

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# PURPOSE

This publication was designed as a companion resource to Ready, Set, Go! Guidelines and Tips for Collecting Patient Data on Sexual Orientation and Gender Identity (SOGI) to 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. This guide will help healthcare staff to identify procedures to translate and adapt SOGI data collection questions and patient education materials for multilingual patient populations accurately and affirmatively, with considerations for Spanish-speaking LGBTQIA+ patients as an example. The recommendations in this publication will assist health teams in planning 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.

**Sexual Orientation and Gender Identity Questions:**  
Information for Patients



We are asking you about your sexual orientation and gender identity in order to provide more patient-centered care. Read inside to learn what the questions mean, and how the information will be used to improve health care for all.

**Nuevas preguntas sobre la orientación sexual y la identidad de género:**  
Información para pacientes



Recientemente hemos añadido nuevas preguntas sobre la orientación sexual y la identidad de género a nuestros formularios de registro.

Nuestro centro de salud cree que es importante que conozcamos esta información sobre nuestros pacientes. A continuación, se encuentran algunas preguntas frecuentes sobre por qué estamos haciendo estas preguntas y cómo se usará esta información.

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# INTRODUCTION

Clinicians often do not feel comfortable asking SOGI questions and project that onto their patients. The reality is that patients know they will get asked a range of questions when they go to see their providers and they are almost always happy to answer these questions, particularly if they are asked in a sensitive and effective way.

Non-clinical staff, front-desk registration, and intake staff all need to be trained in sensitive, effective communication, how to field any concerns that patients may have about why they're being asked for this information, and how to enter it into electronic health records so that all members of the care team and the health center staff can then refer to the information in the future. Patients need to know why health care staff are asking for the information, that it is directly relevant to the care they receive, and that they can choose whether to share. Patients should also know that all patients are being asked SOGI questions, so they do not feel individually profiled or targeted in any way.

## **¿Cómo indentifica su orientación sexual?**

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

## **¿Cómo indentifica su identidad de género?**

1. Masculino
2. Femenino
3. Transgénero o transexual
4. Género diverso
5. Otra: \_\_\_\_\_

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# WHY COLLECT SOGI?

Lesbian, gay, bisexual, transgender, queer, intersex, asexual, and all sexual and gender minority (LGBTQIA+) people experience health disparities and require care and services tailored to their unique needs.<sup>1-4</sup> The process of asking all patients about their SOGI empowers health centers to get to know them better and provide them with the culturally responsive, patient-centered services they need. SOGI data collection also allows health centers to learn about the populations they serve and measure the access to care and quality of care provided to people of all sexual orientations and gender identities.<sup>5,6</sup> Health Center Program grantees and look-alikes are required to report SOGI data elements in the annual Uniform Data System (UDS).

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<sup>1</sup> Gonzales G, Przedworski J, Henning-Smith C. Comparison of health and health risk factors between lesbian, gay, and bisexual adults, and heterosexual adults in the United States: Results from the National Health Interview Survey. *JAMA Intern Med.* 2016;176(9):1344-13

<sup>2</sup> de Blok CJ, Wiepjes CM, van Velzen DM, et al. Mortality trends over five decades in adult transgender people receiving hormone treatment: a report from the Amsterdam cohort of gender dysphoria. *Lancet Diabetes Endocrinol.* 2021;9(10):663-670.

<sup>3</sup> Branstrom R, Pachankis JE. Sexual orientation disparities in the co-occurrence of substance use and psychological distress: a national population-based study (2008-2015). *Soc Psychiatry Psychiatr Epidemiol.* 2018;53(4):403-412.

<sup>4</sup> Reisner SL, Poteat T, Keatley J, et al. Global health burden and needs of transgender populations: a review. *Lancet.* 2016;388(10042):412-436.

<sup>5</sup> Cahill S, Makadon H. Sexual orientation and gender identity data collection in clinical settings and in electronic health records: A key to ending LGBT health disparities. *LGBT Health.* 2014;1(1):34-41.

<sup>6</sup> The Joint Commission. *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care for the Lesbian, Gay, Bisexual, and Transgender (LGBT) Community: A Field Guide.* Oak Brook, IL:2011.

## Will Patients Be Offended by SOGI Questions?

Although health care staff often assume patients will be offended by SOGI questions, this is rarely the case.<sup>7</sup> Seventy-eight percent of clinicians nationally believe patients would refuse to provide sexual orientation, however, only 10 percent of patients say they would refuse to provide sexual orientation.<sup>8</sup> Health centers report that few patients have complained about or skipped SOGI questions. Patients are much more likely to answer SOGI questions than they are to answer questions about income. This has been true in rural and urban health centers.<sup>9</sup>

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 believed the questions were important and reported they would answer these again in the future.<sup>10</sup>

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<sup>7</sup> Maragh-Bass AC, Torain M, Adler R, et al. Risks, benefits, and importance of collecting sexual orientation and gender identity data in healthcare settings: A multi-method analysis of patient and provider perspectives. *LGBT Health*. 2017;4(2):141-152

<sup>8</sup> Haider A, et al “Emergency department query for patient-centered approaches to sexual orientation and gender identity” *JAMA Intern Med* 2017; DOI: 10.1001/jamainternmed.2017.0906.

<sup>9</sup> Grasso C, Goldhammer H, Funk D, et al. Required sexual orientation and gender identity reporting by US health centers: First-year data. *Am J Public Health*. 2019;109(8):1111-1118.

<sup>10</sup> Cahill S, Singal R, Grasso C, et al. Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers. Prestage G, ed. *PLoS ONE*. 2014;9(9):e107104. doi:<https://doi.org/10.1371/journal.pone.0107104>



### Health is a Political and Cultural Experience

Our race and ethnicity are part of who we are, but they are not the only things that define who we are and how we interact with the world. We experience life in an intersectional way. Identities such as class, language, culture, gender, and age are experienced simultaneously and define who we are and how others perceive us.

We need to use culture to understand the people we serve at health centers, their world, and how their cultural experiences shape and frame their experiences. We also know that culture, alongside other social determinants of health, helps define health outcomes and experiences, including how people experience health encounters (i.e., how I talk with the health care provider, what questions I feel comfortable asking). It also helps to understand which diseases, behaviors, or practices are considered stigmatizing.

Understanding cultural values helps us do our job to promote health and ensure we use effective strategies for the patients we serve. When we look at the scientific literature and public health practices, there is an urgent need for culturally specific interventions.

## Cultural Adaptation

Cultural adaptation as an intervention is not simply translation. Changes made must ensure fidelity of the intervention or the necessary core elements. Culture and language are separate elements. Language informs and is part of culture, but language is not the only thing that defines culture. For example, there are different ways of doing things and differing values even across Hispanic and Latino cultures. When we effectively make cultural adaptations, we integrate all these elements that may vary by country, age, race, ethnicity, gender and more. When providers are aware of patients' experiences, they can modify attitudes, improve knowledge, and provide care that is consistent with the needs of our patients and populations.



### **Latinx** adjective

La·tinx | *primarily a written form ; often read as lə-ˈtē-neks*

: of, relating to, or marked by Latin American heritage : LATINE —used as a gender-neutral alternative to Latina or Latino

## Gender Neutrality vs. Gender Inclusivity: To Latinx or Not to Latinx?

As a way of being inclusive of different gender identities, Latinx (La-teen-ex) has become more popular, particularly in the continental US, as a way of expressing gender neutrality when referring to Hispanic populations. Sometimes using the proper gender to refer to the population and the people that we work with is necessary for visibility, affirmation, and for our ability to provide services that are consistent with our audiences' and our patients' values. We must ask if we don't know whether using Latino/Latina/Latinx is the best way to communicate with an individual or a group.<sup>11</sup>

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<sup>11</sup> María del Río-González A. To Latinx or Not to Latinx: A Question of Gender Inclusivity Versus Gender Neutrality. *American Journal of Public Health*. 2021;111(6):1018-1021. doi:<https://doi.org/10.2105/ajph.2021.306238>

A [2020 report from the Pew Research Center](#) found that **only 23 percent of U.S. adults who self-identify as Hispanic or Latino have heard of the term “Latinx,” and just 3 percent embraced the term for themselves.**<sup>12</sup> Those findings are consistent with the results of a [2021 Gallup poll](#), which reported that only 4 percent of respondents preferred the term “Latinx,” while 15 percent preferred “Latino” and 23 percent preferred “Hispanic.”<sup>13</sup>

With Latinx, specifically, the use of the X is mainly associated with gender identity. For some scholars, the use of Latinx is considered negatively as a way to colonize language, a way of making it easier for the people who have historically oppressed a population, and potentially a way of erasing identities. On the other hand, for some other scholars, using Latinx is more consistent with the way some Indigenous populations, particularly in North and Central America have used the letter X in ancestral languages.

### To Latinx or not to Latinx?

Yes, if you want to be gender neutral, but that doesn't mean that you're being inclusive. If you decide to use Latinx in any of your documents or patient-facing materials it is important to share why you are using Latinx. If you are collecting data, offer all the options. Let patients choose whichever best describes the way they want to be referred to.

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<sup>12</sup> Latinx Used by Just 3% of U.S. Hispanics. About One-in-Four Have Heard of It. Pew Research Center's Hispanic Trends Project. Published August 11, 2020. <https://www.pewresearch.org/hispanic/2020/08/11/about-one-in-four-u-s-hispanics-have-heard-of-latinx-but-just-3-use-it/>

<sup>13</sup> Inc G. No Preferred Racial Term Among Most Black, Hispanic Adults. Gallup.com. Published August 4, 2021. <https://news.gallup.com/poll/353000/no-preferred-racial-term-among-black-hispanic-adults.aspx>



## Tips About Spanish Language Usage

*Example: A label to describe gender-expansive people of Latin American origin or descent.*

- Use Latinx when intentionally acknowledging gender diversity
- Use Latina for women
- Use 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?”*

### **Cultural Adaption: 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.

**PACA:  
A Participatory Approach for Cultural and Linguistic Adaptations**

PACA is a transdisciplinary approach that can be used by practitioners and scientists to ensure that content and material being developed is consistent with the language and culture of the targeted populations. PACA was developed as part of an HIV prevention program in English and Spanish funded by the National Institutes of Health. The steps used for PACA include seeking out resources that are already culturally and linguistically appropriate, what research or literature exists, and how other scientists and practitioners working with the population have adapted their materials before proceeding. With the HIV prevention program, bilingual staff were hired, and a community group was created that included both monolingual and bilingual Spanish-speaking members. Once an adaptation of materials was drafted, it was shared with the community for their feedback and review. The process continues during implementation as changes are made. Many things can emerge as part of a transcultural experience, and people need to stay present and be agile with how participants respond to the materials.

**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.

The benefits of using PACA as a way of adapting for non-English speaking populations is that we are working with their language to communicate the way that they would like to see themselves reflected in the materials and the language that we use in our health care interventions. The community is also part of the decision-making process which increases the likelihood of having sexual and gender minorities feel seen and reflected in how services are designed and implemented.

**Sample PACA Process**

The PACA team collaborated with transdisciplinary public health practitioners, scientists, and members of the population served. PACA consisted of and was implemented following five steps which 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.**

- Review 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 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.

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# CONCLUSION

LGBTQIA+ people experience health disparities and require care and services tailored to their unique needs. The process of asking all patients about their SOGI empowers health centers to get to know their patients better, and to provide them with the culturally responsive, patient-centered services they need. This publication provides a pathway forward for health centers to better serve LGBTQIA+ patients when gathering SOGI information in a culturally inclusive and affirming way. For additional information and resources, see the Resources and Acknowledgements sections below.

## SOGI Patient Pamphlet Translations



- Arabic
- Brazilian Portuguese
- English
- Farsi
- Haitian Creole
- Polish
- Russian
- Simplified Chinese
- Somali
- Spanish
- Tagalog
- Tigrinya
- Vietnamese

## References

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12. Latinx Used by Just 3% of U.S. Hispanics. About One-in-Four Have Heard of It. *Pew Research Center's Hispanic Trends Project.* Published August 11, 2020. <https://www.pewresearch.org/hispanic/2020/08/11/about-one-in-four-u-s-hispanics-have-heard-of-latinx-but-just-3-use-it/>
13. Inc G. No Preferred Racial Term Among Most Black, Hispanic Adults. *Gallup.com.* Published August 4, 2021. <https://news.gallup.com/poll/353000/no-preferred-racial-term-among-black-hispanic-adults.aspx>

## Resources from the National LGBTQIA+ Health Education Center

### **Affirmative Services for Transgender and Gender Diverse People – Best Practices for Frontline Health Care Staff**

<https://www.lgbtqiahealtheducation.org/publication/affirmative-services-for-transgender-and-gender-diverse-people-best-practices-for-frontline-health-care-staff/>

### **LGBTQIA+ Implicit Bias Resources**

<https://www.lgbtqiahealtheducation.org/?s=implicit+bias>

### **LGBTQIA+ Glossary of Terms for Health Care Teams**

<https://www.lgbtqiahealtheducation.org/publication/lgbtqia-glossary-of-terms-for-health-care-teams/>

### **LGBTQIA+ Organizational Change Resources**

<https://www.glad.org/know-your-rights/>

### **Ready, Set, Go! Guidelines and Tips for Collecting Patient Data on Sexual Orientation and Gender Identity (SOGI) – 2022 Update**

<https://www.lgbtqiahealtheducation.org/publication/ready-set-go-a-guide-for-collecting-data-on-sexual-orientation-and-gender-identity-2022-update/>

### **Sexual Orientation and Gender Identity Questions: Information for Patients**

<https://www.lgbtqiahealtheducation.org/publication/sexual-orientation-and-gender-identity-questions-information-for-patients/>

### **SOGI Patient Pamphlets**

<https://www.lgbtqiahealtheducation.org/resources/in/collecting-sexual-orientation-and-gender-identity-data/>

### **SOGI Resource Home Page**

[www.lgbthealtheducation.org/resources/in/collecting-sexual-orientation-and-gender-identity-data](http://www.lgbthealtheducation.org/resources/in/collecting-sexual-orientation-and-gender-identity-data)

### **SOGI Training Videos**

<https://www.lgbtqiahealtheducation.org/courses/so-gi-data-collection-training/>

### **You've Built It... Now What? Applying SOGI Data to Clinical Quality Improvement and Decision Support**

<https://www.lgbtqiahealtheducation.org/wp-content/uploads/2020/01/Youve-Built-It-Now-What.pdf>

## Acknowledgements

This publication was based on research and conceptual work conducted by Carlos Rodriguez-Diaz, PhD, MPH, MCHES, Professor and Chair of the Department of Community Health Sciences at Boston University School of Public Health. For more information on this topic, see the webinar by Dr. Rodriguez-Diaz: [Cultural Adaptation of Measures and Tools for Sexual Orientation and Gender Identity \(SOGI\) Data Collection](#).

This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under cooperative agreement number U30CS22742, Training and Technical Assistance National Cooperative Agreements (NCAs) for \$625,000.00 with 0% of the total NCA project financed with non-federal sources. PACA was developed with support from the National Institutes of Minority Health and Health Disparities (U01MD011281; PI: B. Mustanski). This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government.