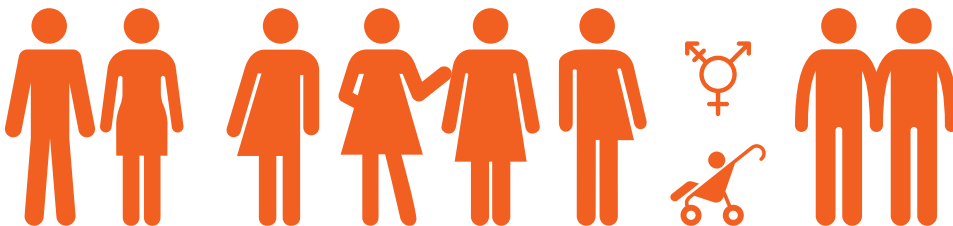




Trends in Demographic Data Collection and Use in Healthcare

A Field Guide for Serving Lesbian, Gay, Bisexual and Transgender Patients



This field guide is part of a series focused on demographic data collection and use within healthcare systems. Increasingly, health systems are collecting race, ethnicity and language (REAL) demographics not only to fulfill various data collection requirements, but also to use the data to improve access, services, care quality and research.

This series considers current trends in the collection of various demographic data points beyond the categories of REAL. Using insights from organizations that are successfully expanding their efforts to better understand specific patient populations, this field guide explores the best practices of expanded demographic data collection and its potential benefits for population health management and value-based payment arrangements.

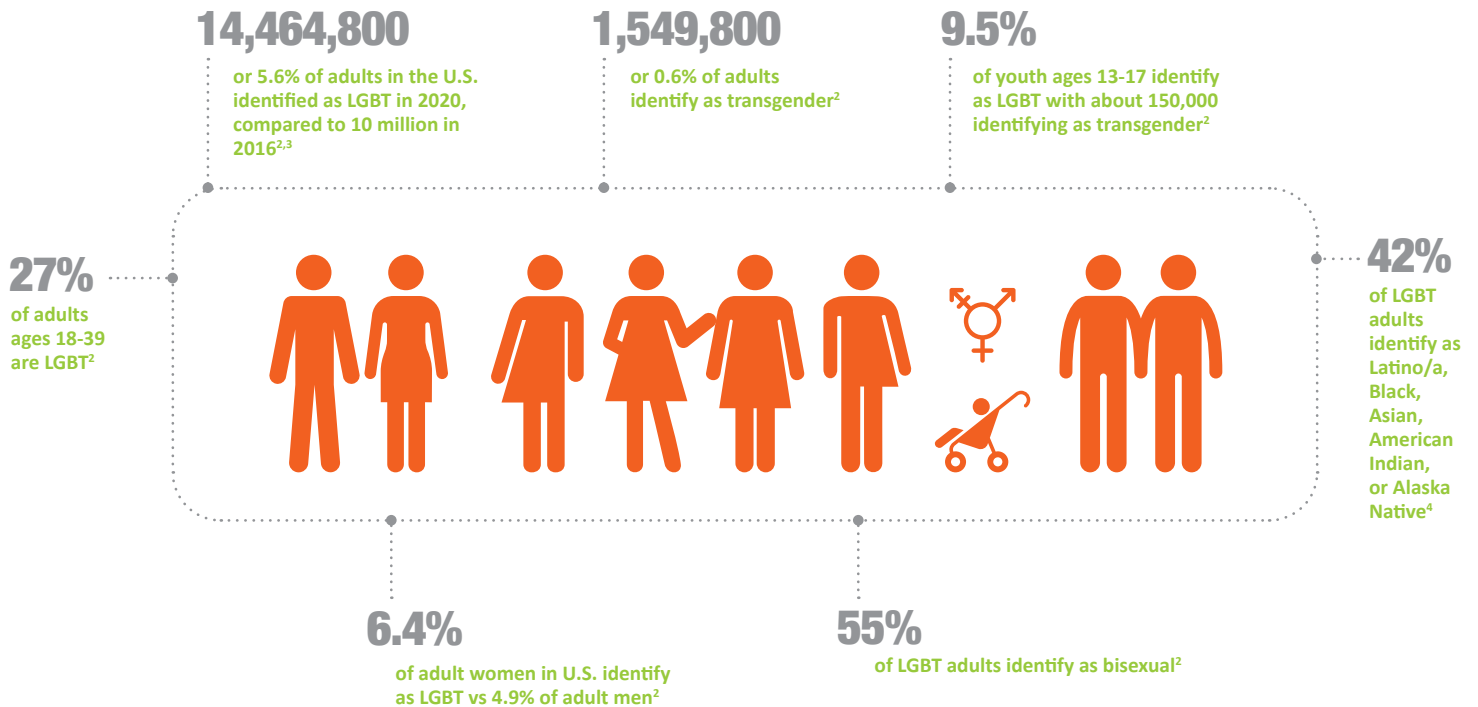
Healthcare staff and providers are often encouraged to treat all patients equally, regardless of their sex, race, ethnicity, sexual orientation, gender identity and other social identifiers. However, trends in demographic data collection and use are revealing that

unique patient populations have distinct needs. A one-size-fits-all approach to healthcare can leave vulnerable patient groups overlooked and underserved.

This part of the series focuses on the collection and use of sexual orientation and gender identity (SOGI) information while highlighting the work of two health systems, the University of New Mexico Health System (UNMHS) and the University of California Irvine Health (UC Irvine Health). Both organizations are collecting SOGI data from patients as part of their efforts to provide better care and services to the lesbian, gay, bisexual and transgender (LGBT) patient population.

Sexual and Gender Minority Demographics

There is an upward trend in people coming out as LGBT. The demographics of who is coming out and when are also changing. This may be related to greater social acceptance, illustrated by the 2015 Supreme Court decision on marriage equality.¹



Notably, both the growing non-white population and LGBT population are under the age of 40.⁵ Average percentages of LGBT people vary regionally, so a healthcare system may serve more or less LGBT patients than the 5.6% national average.⁶

LGBT Health Disparities

When providers know the sexual orientation and gender identity of their patients and understand their susceptibility to certain conditions, they can recommend proper health screenings and interact with LGBT patients in a manner that is culturally responsive and informed.

Patients who are LGBT are vulnerable to health disparities, including:

- Lesbian and bisexual women are more likely to be obese and get breast and cervical cancer.^{7,8}
- LGBT individuals experience disproportionate rates of behavioral health issues, cardiovascular disease, cancer risk factors, substance abuse and HIV/AIDS cases.^{7,8}
- Gay and bisexual men of color and transgender women of color have the highest risk of contracting HIV.^{9,10}
- LGBT youth have poorer physical health compared to heterosexual youth and are disproportionately affected by behavioral health issues, including eating disorders.^{11,12}

Because of fear of negative experiences, some LGBT patients distrust providers and delay medical care.¹³ But, if LGBT patients feel respected and affirmed, then the opportunity for more open dialogue may follow. Asking about sexual orientation and gender identity can help providers build trust with LGBT patients and may help improve health outcomes and reduce disparities.



University of New Mexico Health System

Originally founded as Bernalillo County Indian Hospital, UNMHS in Albuquerque has always served a racially and ethnically diverse community. It has a long, connective history with Native American pueblos, tribes and nations of New Mexico. Since 2005, UNMHS has been continuously improving their interpreter services. Approximately 17 percent of UNMHS patients have limited English proficiency (LEP). About 95 percent of these LEP patients speak Spanish and the other five percent speak a variety of languages including Vietnamese and Native American languages.

Since 2011, UNMHS has been successfully collecting and using REAL data. Stratifying quality outcomes by race, they were able to identify and reduce a diabetes-related disparity their Native American patients were experiencing. The standardization of REAL data collection through the 2010 Patient Protection and Affordable Care Act (ACA) confirmed what leaders at UNMHS already knew about the importance of responding to the cultural and linguistic needs of the communities they serve.

The ACA's non-discrimination provision and emphasis on health disparities, combined with the increased visibility of the LGBT community, prompted leaders at UNMHS to revise their strategic plans to include considerations for sexual and gender minority patients. In 2010, they created the Office of Diversity, Equity and Inclusion (DEI) and an LGBT collaborative was born from the office's community taskforce. The collaborative was initially composed of members of the LGBT community, but quickly evolved into an employee resource group (ERG) when UNMHS staff and providers joined.

The ERG was instrumental in helping UNMHS change their policies, training and perspectives to be more LGBT-inclusive. The group also recommended changes to the patient demographics data collection form to make it easier for LGBT patients to disclose their sexual orientation and gender identity. Many of the changes suggested by the ERG were adopted for UNMHS's intake form and registration system. They were later added to the electronic health record (EHR).

LGBT-Inclusive Healthcare

Leaders at UNMHS started planning the process for SOGI data collection in 2015. The project took time and required buy-in from hospital leadership, staff and providers. With the support of a committed administrative team, Kristina Sanchez, UNMHS's Chief Business Development Officer, helped carve out the resources that have facilitated the growth of the DEI office and its programs. Sanchez reflected, "You must have core groups of people focused on doing the work of diversity, equity and inclusion, but your goal overall is to ensure that the message of equity and inclusion is woven throughout every practice system-wide. The responsibility doesn't just sit with one department. We all do this work."

Providing education and training about LGBT health issues and SOGI vocabulary lays the groundwork for routine SOGI data collection practices and LGBT-inclusive care. Misty Salaz, UNMHS's Director of DEI and Native American Health Services, is responsible for driving the messaging and the curriculum for SOGI data collection. For Salaz, provider support has been crucial. She relies on the assistance of

Cameron Crandall, MD, the UNMHS Health Science Center's Associate Vice Chancellor for DEI, Director of LGBT Diversity and Inclusion and an emergency room physician. As a gay man, Crandall felt that the community lacked role models to support LGBT students, faculty and staff, so he took on that role and has helped to train over 1,300 frontline staff. These trainings help staff understand SOGI concepts and terms, implicit bias and how to create a welcoming environment for LGBT patients and families.

Early in 2017, UNMHS officially began collecting SOGI data. Frontline staff are responsible for providing patients with an intake form where they self-report. Staff then enter the SOGI information from the form into the EHR. To ensure confidentiality, staff do not ask about

SOGI verbally at check-in or over the phone, but sometimes they field questions from patients seeking clarification or assistance in filling out the form. Salaz said, "It's critical that staff adopt an inclusive attitude, refrain from judgment and feel comfortable responding to questions about the intake form content." Among adult patients at UNMHS, the response rate is already over 50 percent for sexual orientation and nearly 60 percent for gender identity.

Routine SOGI data collection is recommended by both The Joint Commission and the Human Rights Campaign (HRC).^{14,15} These organizations have influenced some hospitals like UNMHS to collect SOGI demographics and use the data to ensure the best possible care is received by all patients. Since 2013, UNMHS has reached Top Performer or Leadership Status on HRC's annual survey, the Healthcare Equality Index, which has earned them a reputation for excellence in LGBT-inclusive healthcare.



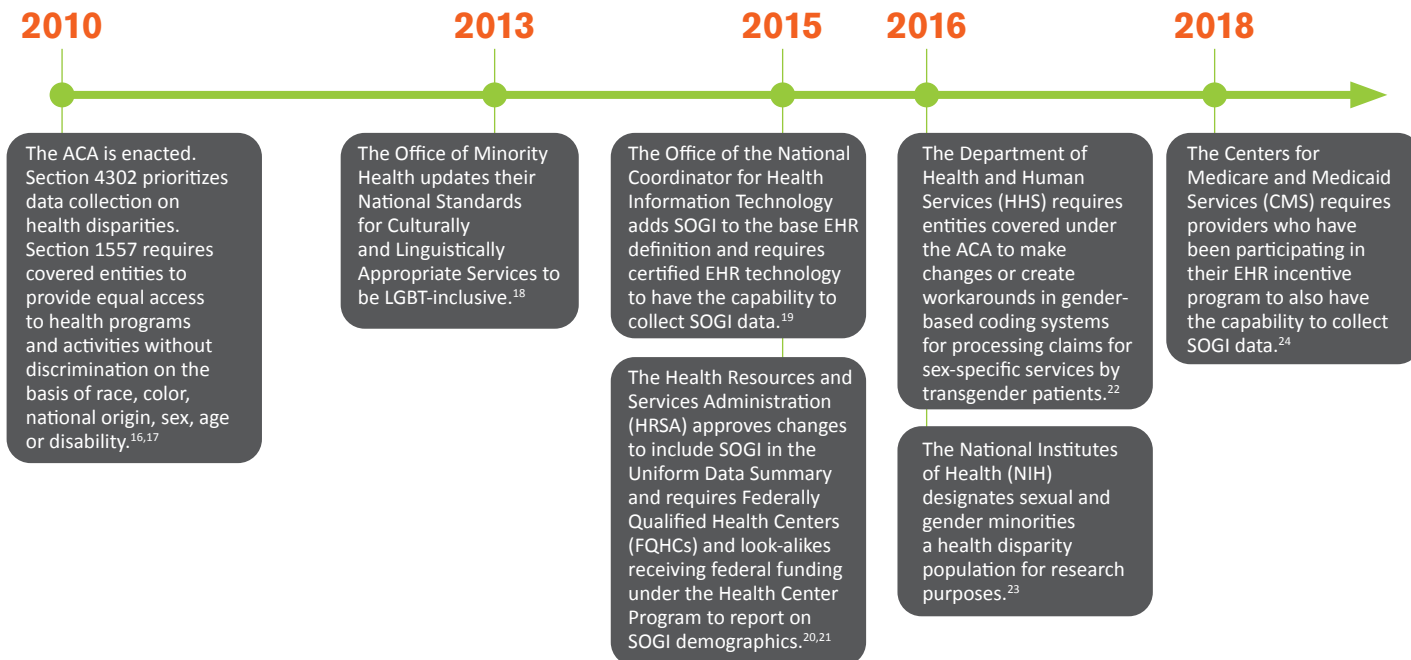
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Kristina Sanchez, Chief Business Development Officer at UNMHS

Legislative and Policy Background

While the decision to collect SOGI data at UNMHS was partially influenced by the nondiscrimination provision of the ACA, UNMHS is not legally required to collect. On the other hand, some healthcare facilities covered under the ACA are either required to collect SOGI data or are required to have EHR software that has the capability to collect it. Here is a timeline of significant events leading to current SOGI data collection requirements:



Some states that have adopted a CMS Medicaid waiver program may also require healthcare facilities to collect and report on SOGI demographics. Capturing data about the sexual orientation and gender identity of patients and measuring quality outcomes is the only way to know if hospitals are addressing LGBT health disparities appropriately.




University of California (UC) Irvine Health

Overall, California is known for its racial and ethnic diversity and also has an LGBT population slightly higher than the national average. Based in Southern California in Orange County, UC Irvine Health has been largely affected by the new HHS rules. UC Irvine Health includes the UC Irvine Medical Center, which is home to the UC Irvine Family Health Center, an FQHC, with locations in Santa Ana and Anaheim. For UC Irvine Health, the collection of SOGI data has become an extension of REAL data collection. Since both REAL and now SOGI data collection are requirements for their FQHCs, leaders at UC Irvine Health started thinking about implementing SOGI data collection practices across their entire health system.

California also adopted a Medicaid waiver program and UC Irvine Health participates in the Public Hospital Redesign and Incentives in Medi-Cal (PRIME) program. SOGI data collection became a recognized PRIME measure, so in 2016 UC Irvine Health started collecting SOGI demographics from patients at their primary care sites in an application used on a tablet. However, the patient response rate on the tablets was only around seven percent. In 2017, leaders decided to move SOGI data collection to the patient-provider interview. They also adopted a new EHR system and gave providers tip sheets for documenting SOGI, which has made capturing the data more efficient. Since then, the overall response rate for SOGI has increased to 38 percent.

While frontline staff at UC Irvine Health have been trained on how to collect REAL data from patients, they have not been formally trained in communicating with patients about SOGI, which was one factor in shifting the responsibility for collection to the clinical team. Tami Wiley, UC Irvine Health's Program Manager of Ambulatory Administration thinks the value of collecting is related to patient engagement. Wiley said, "SOGI data collection helps us identify those areas where we are lacking in communication with patients and enables providers to establish more of a connection with their LGBT patients."




"SOGI data collection ...enables providers to establish more of a connection with their LGBT patients."


Tami Wiley, Program Manager of Ambulatory Administration at UC Irvine Health

Best Practices for SOGI Data Collection

Leaders at both UNMHS and UC Irvine Health advise that SOGI data collection implementation should not be rushed. The proper tools, processes and workflows must be put in place alongside careful strategic messaging across the organization. Erwin Altamira, the Senior Director of Ambulatory Administration at UC Irvine Health remarked, “Getting at the forefront of SOGI data collection and socializing it before you start collecting will actually speed up the process and improve accuracy.”

The following best practices can help increase an organization’s chances for successful SOGI data collection:

 Prepare staff	
	For better patient experience, roll out training about SOGI-related terms and how to use them prior to routine collection. Also, provide staff with scripts and tips to increase their comfort level in asking the questions and documenting answers. Explanations about why the questions are being asked and issues of confidentiality are important topics for both staff and patients.
	Educate providers about the importance of knowing when to ask about SOGI and why, because sometimes it is relevant to treatment and sometimes it is not. For pediatric patients, institutions may need to tailor SOGI data collection according to individual patient needs.
	Provide staff training that raises awareness of implicit bias, LGBT health disparities and issues in clinical care to help improve services for LGBT patients and families.

 Adapt SOGI Intake Questions	
	Field test and tailor intake questions and answer options concerning SOGI to suit the service area. Organizations should seek input from the LGBT community because SOGI terms are dynamic and vary across regions and cultures. Care must be taken to ensure that SOGI terms on forms have the same meaning when translated into different languages.
	Consider asking patients about SOGI once per year, because both sexual orientation and gender identity can shift over time. Also, let patients know they can request to update or change any information at any time or at any visit.
	To screen for gender non-conforming patients who may not identify as transgender, it is a best practice to use the two-step approach of first asking about gender identity, followed by “sex assigned at birth” (SAB) or “sex listed on birth certificate.” Also, some states allow legal changes to gender markers on identity documents, so consider also making a distinction between SAB and “legal sex.” ²⁵

Healthcare systems implementing routine SOGI data collection practices should be prepared for both compliments and complaints. One challenge that may arise with standardized intake forms is that questions about SOGI are not always appropriate in different environments within a health system. For example, in a pediatric setting, staff might need to let caregivers know that all questions may not apply to everyone. Gender identity is salient, although not fixed, early in a child’s life and stabilizes around age four, while sexual orientation typically begins to emerge between middle childhood and early adolescence.^{26,27,28}

Looking Toward the Future

While UNMHS is still in the initial stage of surveilling the SOGI data they are collecting, they have already started adapting the information to use. They have modified the demographic banner in the EHR to alert providers of the sexual orientation and gender identity of patients. Any patient can use a preferred name, which is then printed on patient logs and identity armbands. Notably, UNMHS works with insurance companies and state Medicaid providers to use a code modifier, to facilitate timely coverage of claims for sex-specific services for transgender patients.

Like all patients, transgender patients need access to preventive medical care such as prostate exams, pap smears and mammograms. At the same time, service lines for gender-affirming hormone therapies and surgeries are expanding.²⁹ These services don't always align with



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the sex marker listed on the identity documents of transgender patients. Gender-based coding systems often require alignment between the sex listed on a patient's insurance enrollment form to cover sex-specific services. If there is not a match, the processing of claims can be delayed or denied, resulting in disparate treatment of the transgender patient population.

To avoid temporary billing workarounds, like switching a gender marker then switching it back, many private insurance companies are adopting the CMS model of using billing code modifiers to prevent these issues.³⁰ Crandall commented, "We have taken the approach that if these services are medically necessary, then a patient's sex assigned at birth or gender identity doesn't matter. These services should be covered, and patients shouldn't have to change their sex marker to submit a bill." Even if

transgender individuals legally change their gender marker, there is still potential for misalignment.

Recently, UC Irvine Health adjusted the way the sex/gender field is displayed in their EHR. In October 2017, California signed into law the Gender Recognition Act, which legally recognizes a third gender.³¹ State issued identity documents such as birth certificates and drivers licenses will now have a "non-binary" option added to the sex/gender category. The law also makes it easier for individuals to change their gender marker legally. Leaders at UC Irvine Health had to consider these developments and update their patient forms and EHR system to reflect these changes.

Leaders at UC Irvine Health are also planning how they will analyze the SOGI data collected alongside other information they collect such as veteran status and socioeconomic status. Altamira is excited about these expanded data collection efforts and the possibilities for more predictive tools in the future. He envisions building patient profiles and registries that include additional information about social determinants of health. He believes this will enable UC Irvine Health to tackle specific diseases that might trend by certain populations and provide equal opportunity healthcare access points and services to these patient populations. Altamira remarked, "If we can move from a reactive to a proactive approach we can prevent instances of institutionalization, hospital admissions and unnecessary ER visits." Looking ahead to the future of population health management, the possibilities and opportunities are promising.

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Erwin Altamira, Senior Director of Ambulatory Administration at UC Irvine Health

Additional Resources

The last decade has ushered in SOGI laws and policies that have resulted in new insights, interactions and understanding among healthcare professionals. MIH has published additional resources to assist healthcare administrators in their efforts to create culturally responsive care environments for LGBT patients and families.

Please visit [MIH's Learning Hub](https://moreinclusivehealthcare.com/resources/) at <https://moreinclusivehealthcare.com/resources/> and sign up to receive:

- ***Sexual Orientation and Gender Identity Across the Spectrum—A Hospital Leader's Guide to Policy Adoption and Implementation for Lesbian, Gay, Bisexual and Transgender (LGBT) Patients and Families***
- ***SOGI in Healthcare: Seven Policies Required or Recommended by Key-Driving Organizations***
- ***Definitions for SOGI Affirmation***

These resources offer other best practices that can help hospital leaders ensure that all patients are treated with respect and receive outstanding service and care.

Endnotes

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Acknowledgements

More Inclusive Healthcare associates thank the University of New Mexico Hospitals and the University of California Irvine Health for assisting in the development of this field guide.

University of New Mexico Health System serves a diverse population and strives to improve New Mexico's health outcomes through academic specialty programs and community-responsive, culturally competent, patient care, education and clinical research programs. They are recognized as being in the top five percent nationally for excellence in clinical care. Learn more at: <https://hsc.unm.edu/health/index.html>

University of California Irvine Health is a multifaceted organization dedicated to the discovery of new medical frontiers, to the teaching of future healers and to the delivery of the finest evidence-based care. They provide compassionate healthcare driven by passion for innovation, grounded in the best medical and scientific knowledge. Learn more at: <http://www.ucirvinehealth.org/>

More Inclusive Healthcare associates also thank the Vizient team for their dedication to providing their member organizations with rich, relevant educational content and for their interest in improving the quality of healthcare for patients nationwide.

The Vizient Hospital Improvement Innovation Network is supported under Contract Number HHSM-500-2016-00076C, Hospital Improvement Innovation Network, sponsored by the Centers for Medicare & Medicaid Services, Department of Health and Human Services. The contents provided are solely the responsibility of the authors and do not necessarily represent the official views of HHS or any of its agencies.

Recommended Citation: More Inclusive Healthcare. (2018/2021). *Trends in Demographic Data Collection and Use in Healthcare: A Field Guide for Improving Care for Lesbian, Gay, Bisexual and Transgender Patients*. Cincinnati, Ohio.