

# Item #4: Best Practices in Data Collection and Patient Protection

*Ignatius Bau, Health Equity Subject Matter Expert, HCAI Consultant;  
Dannie Ceseña, MPH, Director, California LGBTQ Services Network*



# Guiding Principles & Strategic Priorities

**Person centered • Equity focused • Data driven**

## **1. Focus on Equity**

We will lead in advancing equity and strive to create programs that address systemic inequities. We will work to achieve a California where race, ethnicity, gender identity, sexual orientation, disability and other forms of social categorization no longer predict a person's or community's health and life outcomes. We will remove barriers so that all Californians have a fair opportunity to meet their needs and achieve their goals.

## Mission

HCAI expands equitable access to quality, affordable health care for all Californians through resilient facilities, actionable information, and the health workforce each community needs.

## Vision

A healthier California where all receive equitable, affordable, and quality health care.

## OUR VALUES



**Service**



**Equity**



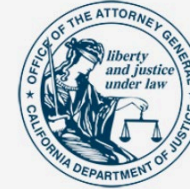
**Innovation**



**Professionalism**

## **Hospital Equity Reporting Program**

Assembly Bill 1204 (Chapter 751, Statutes of 2021) requires the Department of Health Care Access and Information (HCAI) to develop and administer a hospital equity report program to collect and post hospital equity reports. These annual reports are required to include measures on patient access, quality, and outcomes by race, ethnicity, language, disability status, sexual orientation, gender identity, and payor as recommended by the newly created Health Care Equity Measures Advisory Committee (Advisory Committee). The reports are also required to include a plan to prioritize and address disparities for vulnerable populations identified in the data and as specified by the Advisory Committee.<sup>1</sup>



**ROB BONTA**  
*Attorney General*

The Civil Rights Enforcement Section is committed to the strong and vigorous enforcement of federal and state civil rights laws. The Section addresses a broad array of civil rights issues, including, but not limited to:

- Discrimination by business establishments, including discrimination on the basis of race, color, religion, sex, ancestry, national origin, disability, medical condition, genetic information, sexual orientation, citizenship, primary language, immigration status, and other protected classifications

## Attorney General Bonta Reminds Hospitals and Clinics of Anti-Discrimination Laws Amid Executive Order on Gender Affirming Care

[Press Release](#) / [Attorney General Bonta Reminds Hospitals and Clinics of Anti...](#)



Wednesday, February 5, 2025

# Attorney General Bonta Provides Guidance for Businesses on Diversity, Equity, Inclusion, and Accessibility Initiatives in the Workplace

Press Release / Attorney General Bonta Provides Guidance for Businesses on D...



Thursday, February 13, 2025





# Your Patient Privacy Rights

## A Consumer Guide to Health Information Privacy in California

### *Tips for Consumers*

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Consumer Information Sheet 7 • June 2015

# Executive Orders and Actions

- Reinterpreting Diversity, Equity, Inclusion, and Accessibility
- Redefining Gender as Biological Sex Rather than Gender Identity; Limiting Gender-Affirming Care
- Designating English as Official Language of the U.S.
- Increasing Immigration Enforcement
- Redefining 14<sup>th</sup> Amendment Birthright Citizenship

*Executive orders are not laws; cannot unilaterally re-interpret laws*





U.S. Department of  
**Health and Human Services**

Enhancing the health and well-being of all Americans

# Civil Rights Laws, Regulations, and Guidance for Providers of Health Care and Social Services

This page covers civil rights laws and regulations enforced by the Office for Civil Rights (OCR). OCR enforces nondiscrimination regulations that apply to programs, services, and activities receiving HHS Federal financial assistance. We also enforce nondiscrimination provisions of other laws as they apply to programs and activities receiving HHS Federal financial assistance.



## Lau v. Nichols

**In 1974, Chinese American students established right to language access under 1964 Civil Right Act**

*Executive Order 14224: Agency heads are not required to amend, remove, or otherwise stop production of documents, products, or other services prepared or offered in languages other than English.*



U.S. Department of  
**Health and Human Services**

Enhancing the health and well-being of all Americans

# The HIPAA Privacy Rule

The HIPAA Privacy Rule establishes national standards to protect individuals' medical records and other individually identifiable health information (collectively defined as “protected health information”) and applies to health plans, health care clearinghouses, and those health care providers that conduct certain health care transactions electronically. The Rule requires appropriate safeguards to protect the privacy of protected health information and sets limits and conditions on the uses and disclosures that may be made of such information without an individual’s authorization. The Rule also gives individuals rights over their protected health information, including rights to examine and obtain a copy of their health records, to direct a covered entity to transmit to a third party an electronic copy of their protected health information in an electronic health record, and to request corrections.



In 1898, US Supreme Court affirmed  
Wong Kim Ark's birthright citizenship under 14<sup>th</sup> Amendment





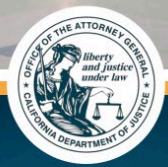
**ROB BONTA**  
*Attorney General*

# Resources for California's Immigrant Communities

**Know Your Immigration Rights and Protections Under the Law**

## Promoting Safe and Secure Healthcare Access for All

Guidance and Model Policies to Assist California's Healthcare Facilities in Responding to Immigration Issues



Rob Bonta  
California Attorney General  
December 2024

# Why Does Sexual Orientation and Gender Identity (SOGI) Data Collection Matter?

# Why SOGI Data Collection Matters

SOGI data collection in health care settings helps ensure equitable and high-quality care for LGBTQ+ individuals. It helps identify health disparities, improve care delivery, and guide resource allocation, which ultimately leads to better health outcomes.



# Why SOGI Data Collection Matters

## Health Disparities:

LGBTQ+ individuals experience unique health disparities compared to non-LGBTQ+ individuals, including higher rates of chronic conditions, mental health needs, and disparities in healthcare access.

## Improved Care:

SOGI data helps healthcare providers understand a patient's individual needs and tailor care accordingly. For example, knowing a patient's gender identity can help with proper pronoun use, appropriate screenings, and avoid misgendering.

# Why SOGI Data Collection Matters

## Quality Improvement:

SOGI data can help identify areas for improvement within healthcare organizations, such as inadequate training or resources related to LGBTQ+ competency.

## Research and Policy:

Collecting SOGI data enables researchers and policymakers to study health outcomes, disparities, and develop evidence-based interventions for LGBTQ+ individuals.

# Why SOGI Data Collection Matters

## Affirmative Care:

SOGI data helps ensure that LGBTQ+ patients receive affirming care and services, including the use of correct pronouns and names.

## Resource Allocation:

SOGI data can inform decisions about funding and equipment needed to address the unique needs of LGBTQ+ patients.

# How SOGI Data Can Be Used:

## Clinical Decision Support:

SOGI data can be used in clinical decision support systems to remind providers about specific screenings or interventions appropriate for LGBTQ+ patients.

## Electronic Health Records (EHRs):

SOGI data can be integrated into EHRs to provide a comprehensive view of a patient's health information.

# How SOGI Data Can Be Used:

## Quality Improvement Programs:

SOGI data can be used to monitor and track the quality of care provided to LGBTQ+ patients.

## Research and Policy Development:

SOGI data is essential for research on health disparities and developing policies to address them.

# What Are The Legal Requirements of SOGI Data Collection

In California's healthcare system, there are legal requirements for collecting SOGI (Sexual Orientation and Gender Identity) data, primarily driven by state laws and regulations.

# What Are The Legal Requirements of SOGI Data Collection

## **AB 959 (Chapter 565, Statutes of 2015) & AB 1163 (Chapter 832, Statutes of 2023): Lesbian, Gay, Bisexual, and Transgender Disparities Reduction Act**

These laws mandates the collection of voluntary SOGI data by state agencies, including DHCS, CDPH, and others, when collecting demographic information.

## **SB 957 (Chapter 869, Statutes of 2024): SOGI Data Collection**

Requires the California Department of Public Health (CDPH) to collect sexual orientation and gender identity (SOGI) data from third-party entities, including local health jurisdictions, on any forms or electronic data systems unless prohibited by federal or state law.



# What Are The Legal Requirements of SOGI Data Collection

## **Public Health Requirements:**

The California Department of Public Health (CDPH) has regulations (17 CCR Section 2500 et seq.) requiring healthcare providers and local health jurisdictions to report SOGI data when reporting on certain communicable diseases or conditions. This includes requiring local health officers to report SOGI data in both summary reports and individual case or outbreak reports. (17 CCR Section 2502).

# What Are The Legal Requirements of SOGI Data Collection

## **Annual Reporting**

Many state departments are required to report annually to the Legislature on their efforts to collect SOGI data and make the data available to the public in accordance with state and federal laws. [Government Code Section 8310.8(c)(1)].

CDPH is required to annually report to the public and the Legislature its efforts to collect, analyze, and report SOGI data. (Health and Safety Code Section 152000)

This helps identify and address disparities experienced by the LGBTQ+ community, improve services and programs, and ensures transparency.

# Building Trust With The LGBTQ+ Community

How do we build trust so we may collect SOGI Data?

# Building Trust With The LGBTQ+ Community

## Transparency and Purpose:

**Explain the "Why":** Clearly communicate the purpose of collecting SOGI data and how it will benefit the community, for example, for research, policy development, or improving services.

**Transparency about data use:** Be transparent about how the data will be used, who will have access to it, and how it will be kept confidential. This includes making information publicly available in multiple languages.

# Building Trust With The LGBTQ+ Community

## Ensuring Privacy and Confidentiality:

**Implement Strong Security Measures:** Adopt strict data security standards for secure data transfer and storage, ensuring data is used ethically, without bias or discrimination.

**Emphasize Confidentiality:** Assure individuals that their personal information will be treated with utmost care and that their privacy rights will be respected.

**Clear Policies:** Adopt and post clear non-discrimination and confidentiality policies to indicate the protections in place and how collected data will be used and kept confidential.

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# Building Trust With The LGBTQ+ Community

## Inclusive Data Collection Practices:

**Use inclusive language:** Ensure survey questions and forms use respectful and affirming language for all gender identities and sexual orientations.

**Allow for self-identification:** Provide options for respondents to self-identify their SOGI in a way that accurately reflects their experience.

**Include a write-in option:** Offer a free-form input field for respondents to provide their SOGI in their own words, especially when standard categories may not fully capture their identity.



# Building Trust With The LGBTQ+ Community

## Inclusive Data Collection Practices Continued:

**Offer "prefer not to say" or "I do not know" options:** Respect individuals' privacy and allow them to decline answering questions they are not comfortable with.

**Avoid "othering" language:** Use terms like "another gender" instead of "other" or "something else".

**Consider the "two-step" approach:** For collecting both gender identity and sex assigned at birth, consider the "two-step" approach to provide a more nuanced understanding of transgender identities.

# Building Trust With The LGBTQ+ Community

## Example:

What is your sex assigned at birth?

- Male
- Female
- Intersex

## Example:

What is your gender identity?

- Male
- Female
- Transgender Male
- Transgender Female
- Gender Queer
- Tell us how you identify: \_\_\_\_\_
- Prefer not to say

# Building Trust With The LGBTQ+ Community

## Example:

What is your sexual orientation?

- Heterosexual (neither gay nor lesbian)
- Gay or Lesbian
- Bisexual
- Demisexual
- Asexual
- Tell us how you identify: \_\_\_\_\_
- Prefer not to say

# Building Trust With The LGBTQ+ Community

## **Cultural Competence and Training:**

**Train staff:** Ensure staff collecting data are trained on LGBTQIA+ cultural competence, including appropriate terminology and communication strategies.

**Foster an affirming environment:** Create a safe and welcoming environment where individuals feel comfortable sharing sensitive information.

**Display inclusivity symbols:** Consider displaying symbols of inclusivity like LGBTQIA+ pride flags or non-discrimination policies to show support.

# Building Trust With The LGBTQ+ Community

## Community Involvement:

**Collaborate with community partners:** Engage with LGBTQIA+ community organizations and advocates to ensure data collection practices are culturally sensitive and respectful.

**Include community members in question development:** Involve LGBTQIA+ individuals in the design, testing, and evaluation of SOGI questions.