

● Advancing Equity through Robust Sexual and Gender Minority Representation through Data Collection

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Definition of SGM

Sexual and gender minority (SGM) populations may include, but are not limited to, individuals who identify as lesbian, gay, bisexual, asexual, transgender, non-binary, Two-Spirit, queer, and/or intersex. Individuals with same-sex or same-gender attractions or behaviors and those with a variation in sex characteristics are also included. These populations also encompass those who do not self-identify with one of these terms but whose sexual orientation, gender identity or expression, or biological traits are characterized by non-binary constructs of sexual orientation, gender, and/or sex.

[NIH Sexual & Gender Minority Research Office](https://grants.nih.gov/grants/guide/notice-files/NOT-OD-24-169.html)

Constructs to Consider

Sex

Anatomy

Physiology

Genetics

Hormones

Gender

Identity & Expression

Roles & Norms

Power Relations

Equity & Equality

Sexual Orientation

Attraction

Identity

Behavior

Visibility: Social & Scientific

1963: March
on Washington

1955:
Daughters of
Bilitis founded

1953: Evelyn
Hooker starts
research

1965: Philadelphia
Independence Hall picket
for “reminder day”

1905: Theory
of Sexuality
published

1886:
Psychopathia
Sexualis
published

1952: Christine Jorgensen
“Ex-GI becomes blonde
bombshell!”

1966: Compton’s
Cafeteria Riot

1897-1923: Havelock
Ellis publishes
volumes on
Psychology of Sex

~630-570 BC
Sappho

1950: Mattachine
Society founded

2012: APA removes
“disorder” from
gender identity

June 1969:
Stonewall Inn
Rebellion

1924: Society
for Human
Rights founded

1948: *Kinsey
Report* Published

1928: *Orlando* and
The Well of Loneliness
published

1973: APA removes
homosexuality from
mental disorders

Visibility: Legal

1964: Civil Rights Act signed

June 1965: Griswold v. Connecticut

~630-570 BC Sappho

June 1967: Loving v. Virginia

1989: Price Waterhouse v. Hopkins

1994: Don't Ask, Don't Tell enacted

1996: Defense of Marriage Act made law

1998: EO 10450 language banning gay fed employment repealed

1953: President Eisenhower signs EO 10450 banning homosexuals from federal employment

2003: Lawrence v. Texas

2010: Don't Ask, Don't Tell Repeal

2013: Windsor v. United States

2015: Obergefell v. Hodges

2020: Bostock v. Clayton County

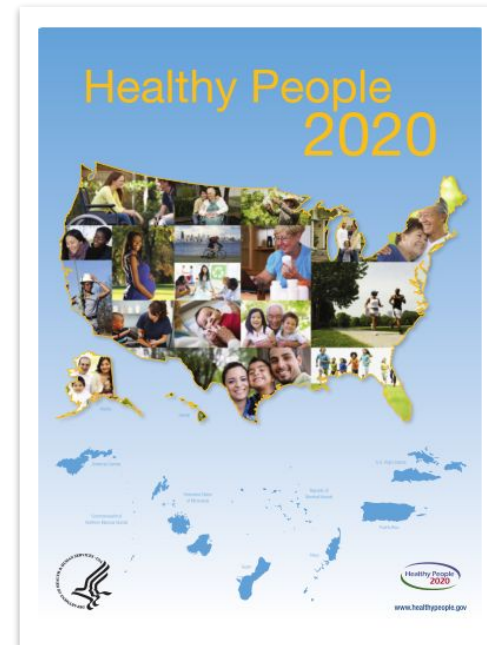
2022-Present: Onslaught of state-level anti-LGBTQ+

Visibility: Evolution & Change



How are We Counted?

- Most populations are counted via nationally representative surveys or the US Census.
- For federal data collection, like the Census, there is typically guidance about how the question should be asked and what the available response options should be.
- Healthy People tracks many health promotion and disease prevention metrics through nationally representative data systems, including the Census, surveys, and surveillance data.



5 measurable LGBT objectives

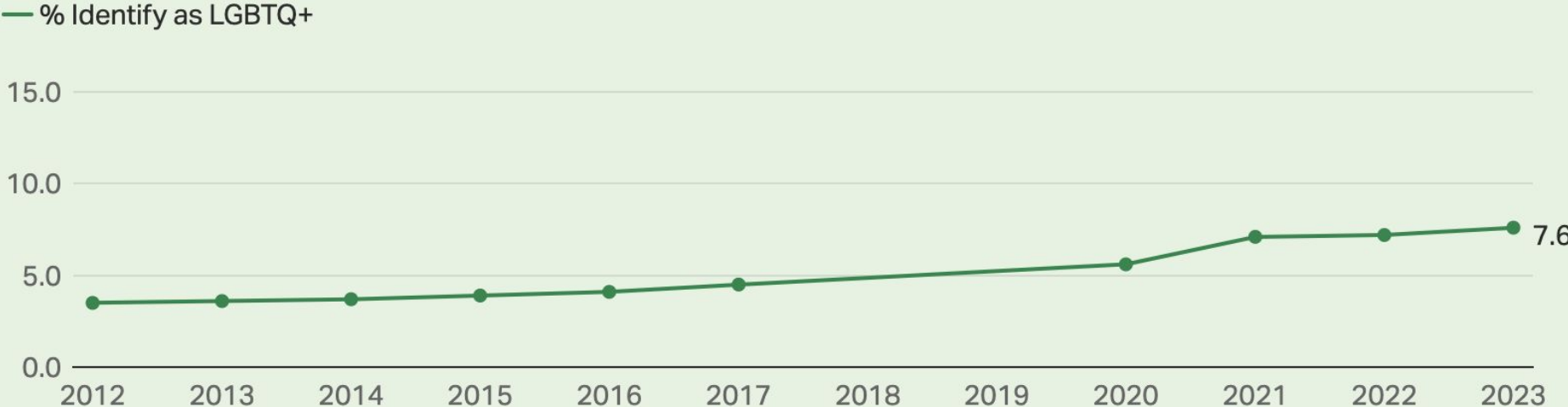


7 measurable LGBT objectives

Demography: Growing Numbers of LGBT People

Americans' Self-Identification as Lesbian, Gay, Bisexual, Transgender, or Something Other Than Heterosexual, 2012-2023

Which of the following do you consider yourself to be? You can select as many as apply. Straight or heterosexual; Lesbian; Gay; Bisexual; Transgender



Respondents who volunteer another identity (e.g., queer; same-gender-loving; pansexual) are recorded as "Other LGBTQ+" by interviewers. These responses are included in the LGBTQ+ estimate.

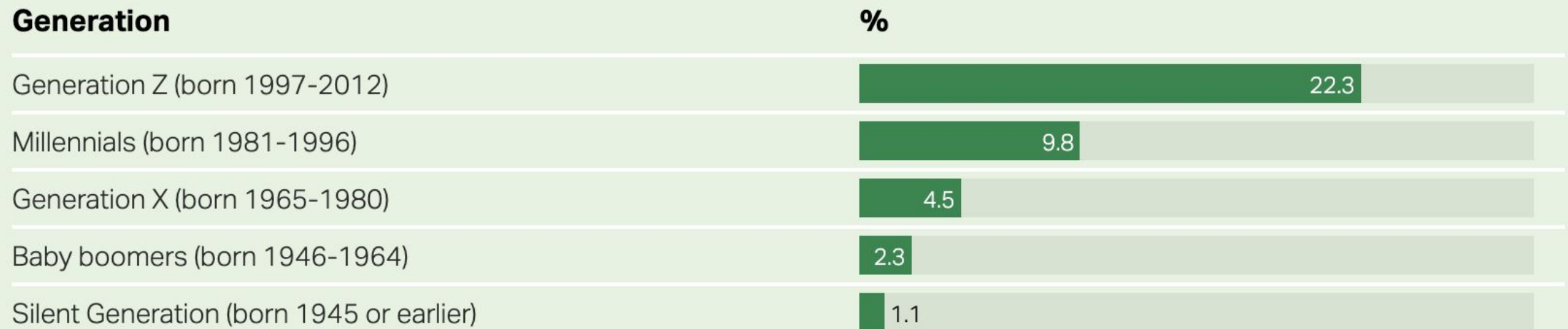
Data were not collected in 2018 and 2019.

2012-2013 wording: Do you, personally, identify as lesbian, gay, bisexual or transgender?

Demography: Generational Changes

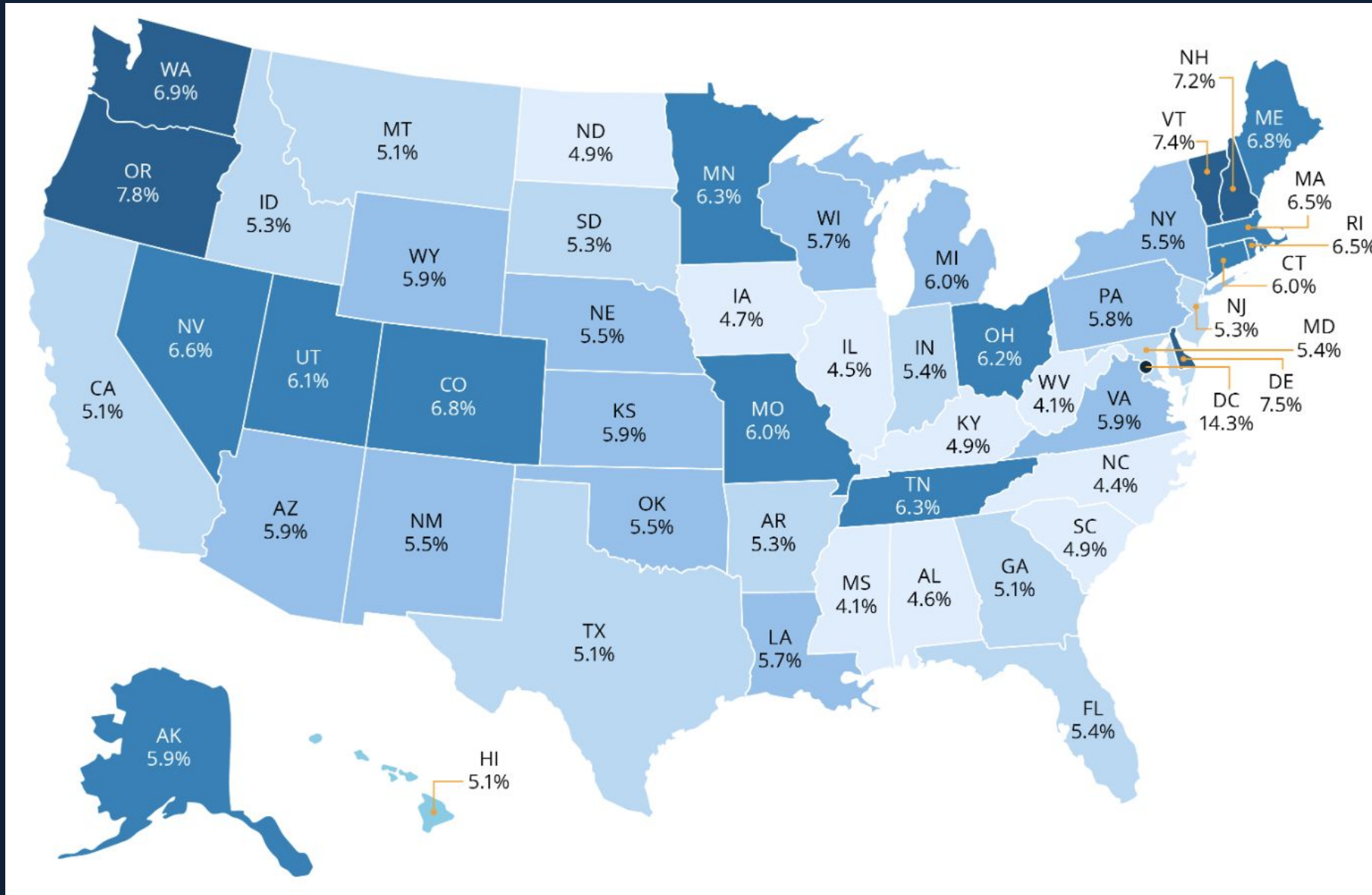
U.S. Adults' Self-Identification as LGBTQ+, by Generation, 2023

Figures are the percentage who consider themselves to be Lesbian; Gay; Bisexual; Transgender; or something other than heterosexual.



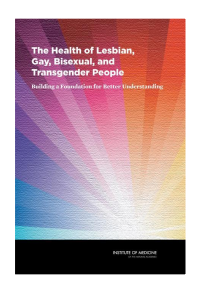
Based on aggregated data from 2023 Gallup telephone polls.

Demography: Estimated Percentage of LGBT People, by State

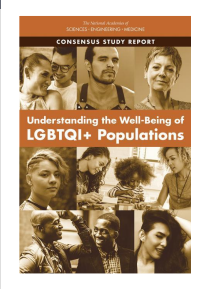


Overview: Federal Advances

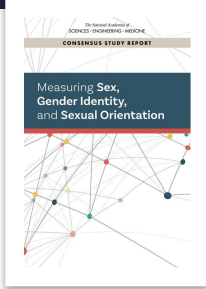
2011



2020



2022

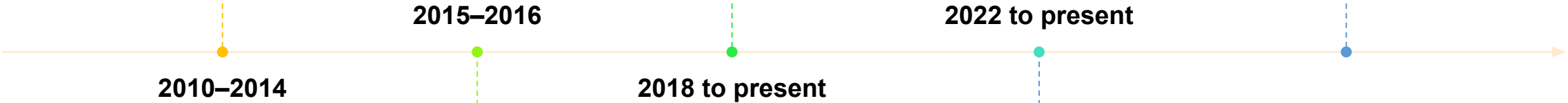


National Academies Consensus Studies are Foundational to LGBTQI+ Data Efforts Over Time

Interagency Working Group on Measuring Relationships in Federal Household Surveys (**MRFHS IWG**)

FCSM Measuring Sexual Orientation and Gender Identity Research Group (**SOGI RG**)

HHS Sexual Orientation and Gender Identity Data Action Plan signed by HHS Secretary and approved by the White House (June 2023)

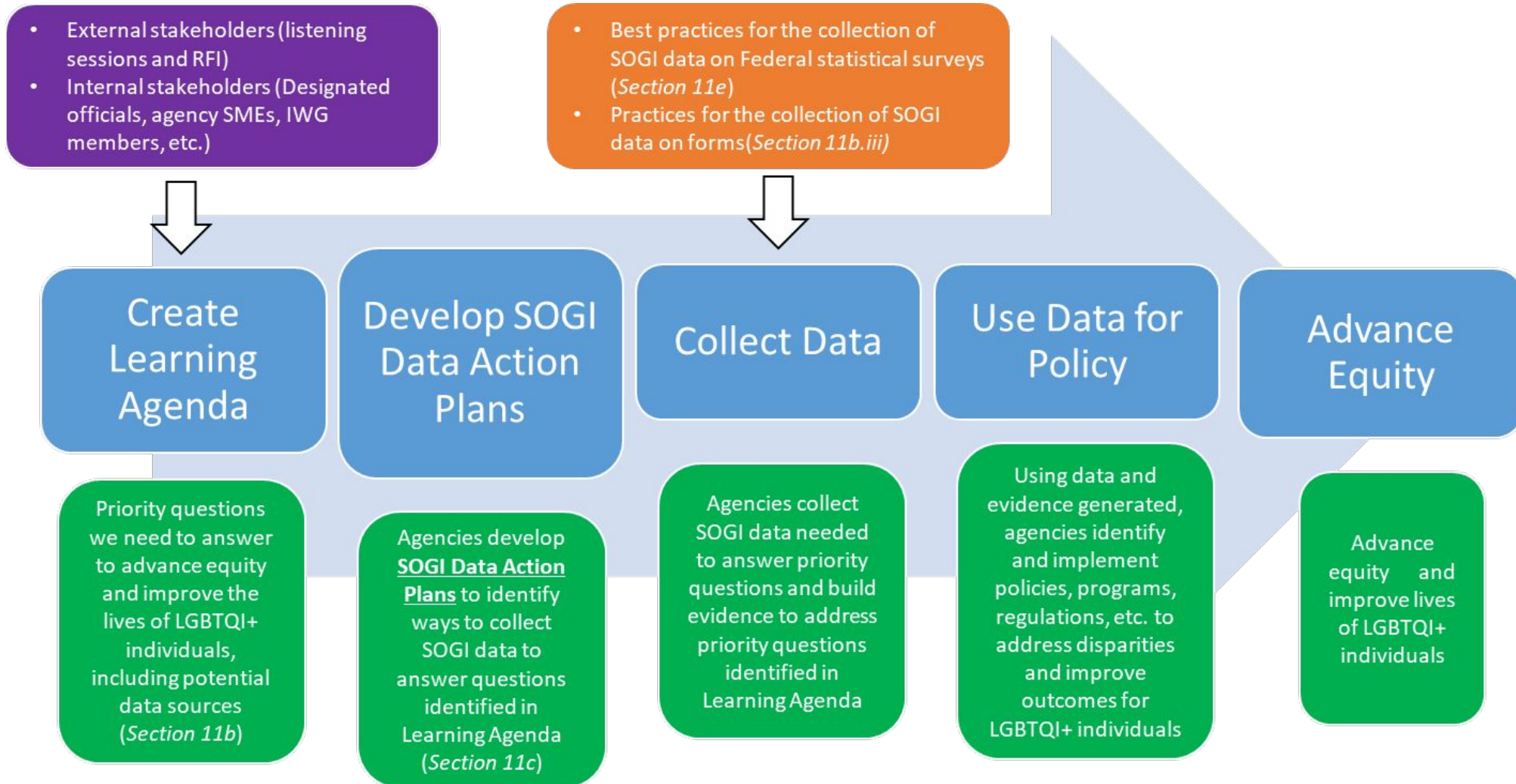


Interagency Working Group on Measuring Sexual Orientation and Gender Identity (**SOGI IWG**)

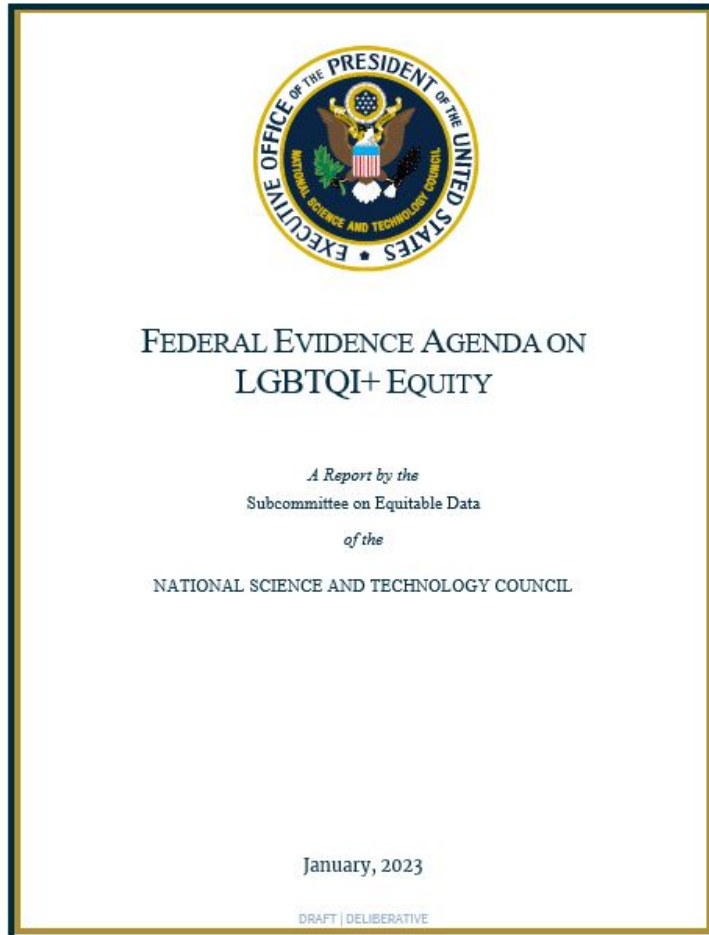
Interagency Working Group on EO 14075 Federal Evidence Agenda on LGBTQI+ Equity (January 2023)

Nearly exclusive focus on developing and testing questions for federal statistical surveys

Building Equitable Data Evidence Base



Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals (LGBTQI+)



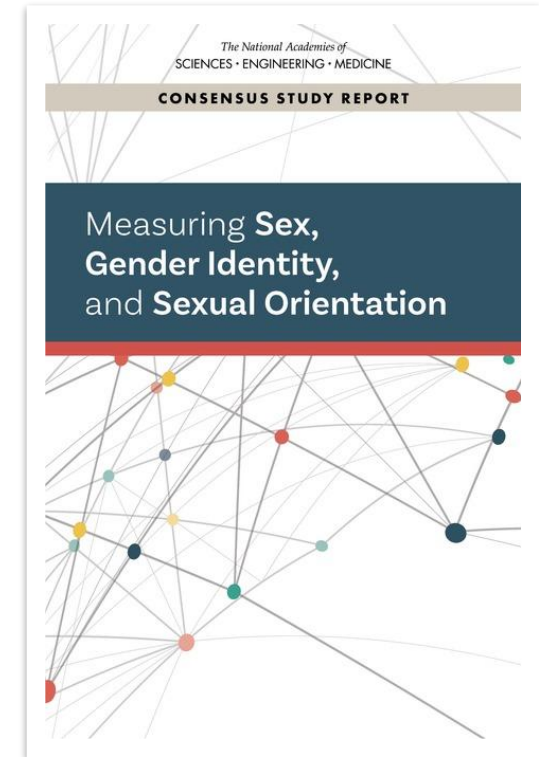
- Wide-ranging EO with many components and requirements
- Recognition that advancing equity and full inclusion requires improvements in data collection and evidence use
- Emphasis on promoting inclusive and responsible Federal data collection practices (Section 11):
 - Development of Federal Evidence Agenda on LGBTQI+ Equity
 - Development and implementation of agency SOGI Data Action Plans
 - Recommendations for agencies on the best practices for collection of SOGI data on Federal statistical surveys

OMB Report: Recommendations on the Best Practices for the Collection of SOGI Data on Federal Surveys

- It is not the intent of this report to limit the continued evolution and improvement of SOGI data collection methods.
- This report does not mandate any particular approach or create any new requirements for agencies. In the future, Federal agencies may need to diverge from the recommendations in this report to reflect new, evidence-based best practices.
- Data should only be collected if there are plans to publish statistics, release data to the public or researchers, or to otherwise support the mission of the agency.
- SOGI measures need to be flexible and adapt over time to maintain usefulness.
- There's no best practice for the minimum survey sample size needed to collect SOGI data.
- Current surveys collecting SOGI data show that respondents are unlikely to skip SOGI questions (low item nonresponse), especially compared to other sensitive data items.
- There is no single, best practice set of questions for soliciting information about a person's sexual orientation or gender identity.

Guiding Principles for the Agenda

- **Inclusiveness**
 - People deserve to count and be counted
- **Precision**
 - Use precise terminology that reflects the constructs of interest
- **Autonomy**
 - Respect individual identity and self-reporting
- **Parsimony**
 - Collect only necessary data
- **Privacy**
 - Use data in a manner that benefits respondents and respects their privacy and confidentiality



Federal Evidence Agenda: Process

- 45+ IWG members
- 20+ Federal agencies
- 70+ RFI responses representing 200+ community members and subject matter experts
- 9 listening sessions with 50+ community members and subject matter experts
- Input from Evaluation Officers, CDOs, Statistical Officials, USG researchers
- Chapter 1: An Overview of LGBTQI+ Data Needs – This chapter provides an overview of the SOGI-related data needs throughout the Federal Government that, if addressed, could improve the Federal Government’s ability to make data-informed, evidence-based decisions to improve the health and well-being of LGBTQI+ individuals.
- Chapter 2: Learning Agenda to Advance LGBTQI+ Equity – This Learning Agenda identifies a series of overarching and illustrative questions that will guide the Federal Government’s efforts to understand, support, and improve the lives of LGBTQI+ individuals and families.
- Chapter 3: Guidelines for Collecting SOGI Data on Federal Administrative Forms – This chapter identifies important guidelines for collecting SOGI data on Federal administrative forms, like applications for benefits and services.

Federal Evidence Agenda: Key Takeaways

Data Needs

- SOGI data are demographic data
- Data collection must start immediately
- SOGI data have the most utility when they are disaggregated
- SOGI data must be used to serve LGBTQI+ people
- The value of SOGI data is unlocked by analysis
- Integrate the needs of LGBTQI+ people in privacy, training, and public trust work

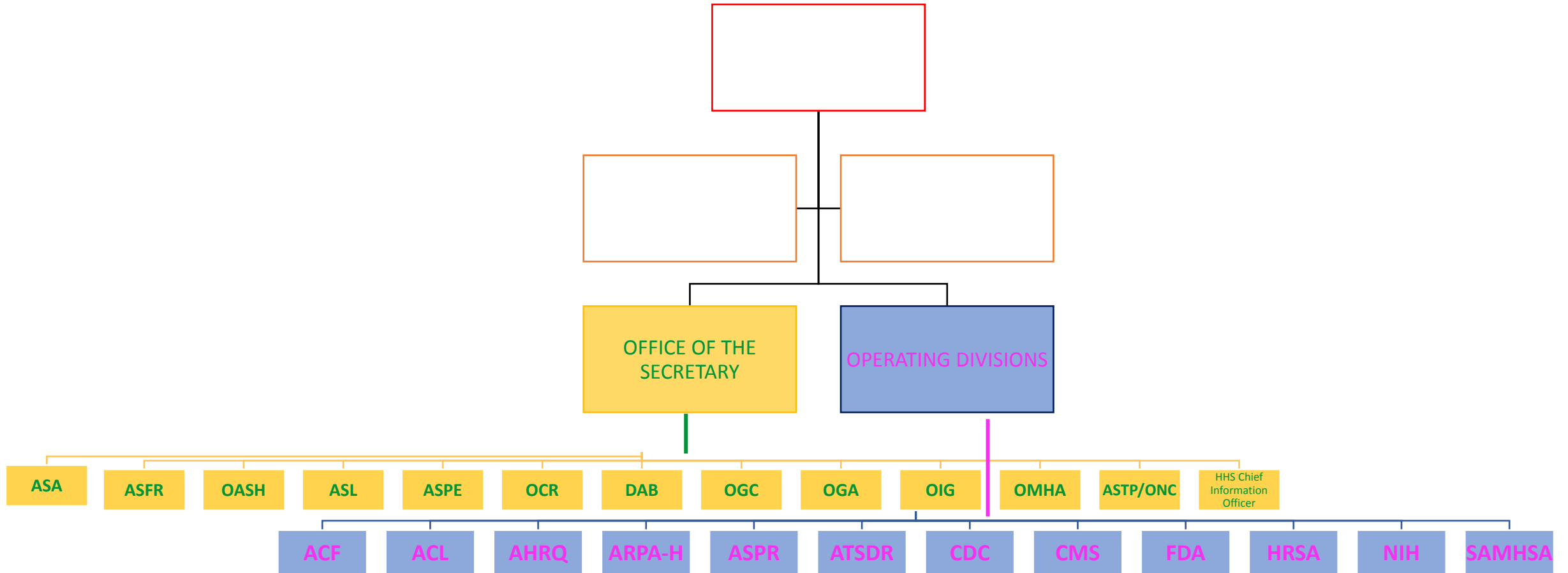
Learning Agenda Topics

- Health, Healthcare, and Access to Care
- Housing Stability and Security
- Economic Security and Education
- Safety, Security, and Justice

Administrative Forms

- Ensure relevant data are collected and privacy protections are properly applied
- Prevent adverse adjudication
- Make responses voluntary
- Rely on self-attestation
- Be consistent and intentional

Overview: HHS



HHS SOGI Data Action Plan

Evidence Building Infrastructure

- Building infrastructure through policies, processes, staff, and resources
- Develop and implement a process for tracking both survey and administrative data implementation of SOGI data across HHS
- Additional research related to SOGI data measurement

Evidence Use Activities

- Review of areas where other demographic data are utilized in programmatic decision-making, but SOGI data are not collected
- Deidentified data sharing as applicable

Monitoring Progress

- Updates ongoing basis regarding major progress & annually
- Division-level workplans as living documents to assist with tracking and monitoring, adding new items, and reporting up to HHS and the White House

HHS Action Plan: High Priorities

- Action Item 1: Developing Division-level (HHS Component) Workplans
- Action Item 2: Addressing Prioritized Data Instruments
- Action Item 3: Exploring SOGI Data in Contractor and Grantee Datasets
- Action Item 4: Reviewing Current Usage of Binary Gender and Sex Questions

Review all data instruments by their division and catalog to assess whether data collected include any demographic information.

Develop timelines to add SOGI data elements to all public health surveillance, epidemiology, and laboratory collections of adults

Across HHS, many datasets are collected by contractors and grantees. At the next opportunity to modify or negotiate contracts, include SOGI data.

Identify continued research in best practices for administrative SOGI data collection, following Federal Evidence Agenda guidelines.



Sexual Orientation and Gender Identity (SOGI) Data Action Plan

The U.S. Department of Health and Human Services (HHS) mission is to enhance the health and well-being of all Americans by providing effective health and human services and by fostering sound, sustained advances in the sciences underlying medicine, public health, and social services. Healthy People 2030 defines 'health equity' as "the attainment of the highest quality of health for all people." Demographic data collection on sexual orientation and gender identity (SOGI) metrics helps HHS achieve its mission and its Healthy People 2030 goals by identifying disparities in health and human services. As identified in the Federal Evidence Agenda on LGBTQI+ Equity, this departmental SOGI Data Action Plan seeks to *improve the health and well-being of lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI+) people.*

The National Academies of Sciences, Engineering, and Medicine (NASEM)¹ considered measures across three broad categories of SOGI data: data collection in surveys and research settings, clinical and medical settings, and administrative settings. All three categories are necessary to better understand the needs, care, and services of people of all identities and the extent to which there may be disparities in health, services, and access to care challenges across LGBTQI+ populations. Precision public health is the emerging practice of utilizing specific data elements about targeted populations to ensure that HHS responses are directed where they are most needed. SOGI data collection is a necessary foundational element in the use and expansion of precision public health. It ensures intersectional understanding of how disparities are present in race, age, gender identity, and sexual orientation, for example how cancer screening disparities may be increased for people of color who are also LGBTQI+. It also ensures that health promotion efforts and human services for LGBTQI+ people are more accurately targeted.

For the purposes of this action plan, SOGI data means self-reported sexual orientation and gender identity demographic data and sex characteristics data as outlined in the Federal Evidence Agenda on LGBTQI+ Equality, when appropriate, and always on a voluntary basis (when not otherwise required by law or to carry out operations). This includes in Federal Statistical Surveys, as outlined by the Office of Management and Budget (OMB).² While research is still needed in some areas like proxy reporting, youth, and language other than English, evidence-based measures that work in a variety of contexts exist for adults whose primary language is English. To encourage interoperability of SOGI data, agencies should consult recent publications that outline best practices guidance in SOGI data collection. These include the OMB Best Practices for Collecting SOGI Data in Federal Statistical Surveys,² the Federal Evidence Agenda on LGBTQI+ Equity (for administrative data systems),³ and the 2022 NASEM report,

¹ National Academies of Sciences, Engineering, and Medicine. 2022. *Measuring Sex, Gender Identity, and Sexual Orientation*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26424>.

² RECOMMENDATIONS ON THE BEST PRACTICES FOR THE COLLECTION OF SEXUAL ORIENTATION AND GENDER IDENTITY DATA ON FEDERAL STATISTICAL SURVEYS, OMB, available from: <https://www.whitehouse.gov/wp-content/uploads/2023/01/SOGI-Best-Practices.pdf>

³ Federal Evidence Agenda on LGBTQI+ Equity, National Science and Technology Council, 2023. Available from: <https://www.whitehouse.gov/wp-content/uploads/2023/01/Federal-Evidence-Agenda-on-LGBTQI-Equity.pdf>

HHS ACCOMPLISHMENTS



HHS SOGI Data Action Plan: First Year Impact

Incorporating LGBTQI+ populations in federal surveys and data collection efforts is an important step in improving understanding of this community, promoting data-based policymaking, and addressing health equity broadly. In response to President Biden's 2021 Executive Order 14075, Advancing Equality for Lesbian, Gay, Bisexual, Transgender, and Intersex Individuals, the U.S. Department of Health and Human Services (HHS) developed a Sexual Orientation and Gender Identity (SOGI) Data Action Plan approved by Secretary Xavier Becerra in June 2023. The plan seeks to identify disparities in that may have long existed but weren't measured in Federal data collection. All divisions of HHS have reviewed their data instruments and initiated determinations and have started incorporating SOGI data measures where possible. Examples of data instruments that have incorporated or improved SOGI data measures in response to the plan include:

Administration for Children & Families

- Annual Survey of Refugees
- Temporary Assistance for Needy Families (TANF) Data Report

Administration for Community Living

- Alzheimer's and Dementia Data Reporting Tool
- National Survey of Older Americans Act (OAA) Participants
- State Health Insurance Assistance Program (SHIP) Client Contact Forms

Agency for Healthcare Research & Quality

- Consumer Assessment of Healthcare Providers and Systems
- Medical Expenditure Panel Survey

Centers for Disease Control & Prevention

- National Health and Nutritional Examination Survey (NHNES)
- STI, HIV, Hepatitis, and MPOX case reports
- Minimum standards for case reports in the event of a future public health emergency
- SOGI Core Surveillance Data Standardization Recommendations

Centers for Medicare & Medicaid Services

- Healthcare.gov enrollment application for Affordable Care Act (ACA) plans
- Medicare Parts C and D enrollment applications
- Medicaid Information Bulletin with guidance to States to voluntarily add SOGI measures on State Medicaid enrollment applications
- Model Medicare Advantage and Medicare Prescription Drug Plan Individual Enrollment Request Form
- CMS Resource of Health Equity-related Data Definitions, Standards, and Stratification Practices
- CMS Innovation Center's Enhancing Oncology Model
- Current Medicare Beneficiary Survey

Indian Health Service

- IHS patient records

National Institutes for Health

- Clinical Center Blood Bank Screening Form

Office of the National Coordinator for Health IT

- US Core Data for Interoperability (USCDI)

Substance Abuse & Mental Health Services Administration

- National Survey on Drug Use and Health (NDSUH)
- Drug and Alcohol Warning Network

HHS will continue to prioritize LGBTQI+ health equity, including by continuing to build the SOGI data evidence base. The Department will continue to identify other opportunities to incorporate SOGI measures in additional surveys and administrative forms, will test data measures in languages other than English and for specific populations such as youth, and adopt promising practices to increase SOGI measure response rates in surveys.



- Driving conversations to action
- Clinical Trial Diversity FDA and NIH collaborations
- Continued support of Healthy People 2030

- Agency SOGI Data Action Plans
 - US Census Bureau: [Sexual Orientation & Gender Identity](#)
 - Department of Health and Human Services: [HHS SOGI Data Action Plan](#)
 - National Science Foundation: [National Science Foundation Sexual Orientation and Gender Identity Data Action Plan](#)
 - Department of Housing and Urban Development: [Sexual Orientation and Gender Identity \(SOGI\) Data Action Plan for the Department of Housing and Urban Development](#)
 - Department of Education: [Department of Education Equity Action Plan | U.S. Department of Education](#)
- Advances in Clinical Research and Diversity
 - [SACHRP Recommendations for the Ethical Review and Inclusion of LGBTQI+ Participants in Human Subjects Research | HHS.gov](#)

Continued Research to Improve Measurement

Sexual Orientation

- Alternate wording for the “straight” response option
- Ordering of response categories
- Guidelines for measures that capture other dimensions of sexual orientation (i.e., attraction, behavior)
- Evaluation of existing measures and identification of best practices for collecting data among sexual minority adolescents
- Impact of proxy reporting of sexual orientation identity

Gender Identity

- Testing of current gender-specific response categories and optimal response ordering
- Inclusion of “nonbinary” in gender identity response categories
- Utility of including a nonbinary response when asking about sex assigned at birth and how to count responses in terms of gender
- Evaluation of a “select all that apply” option for current gender
- Expanding testing of the two-step measure beyond general population assessments of English-speaking adults

Intersex Status

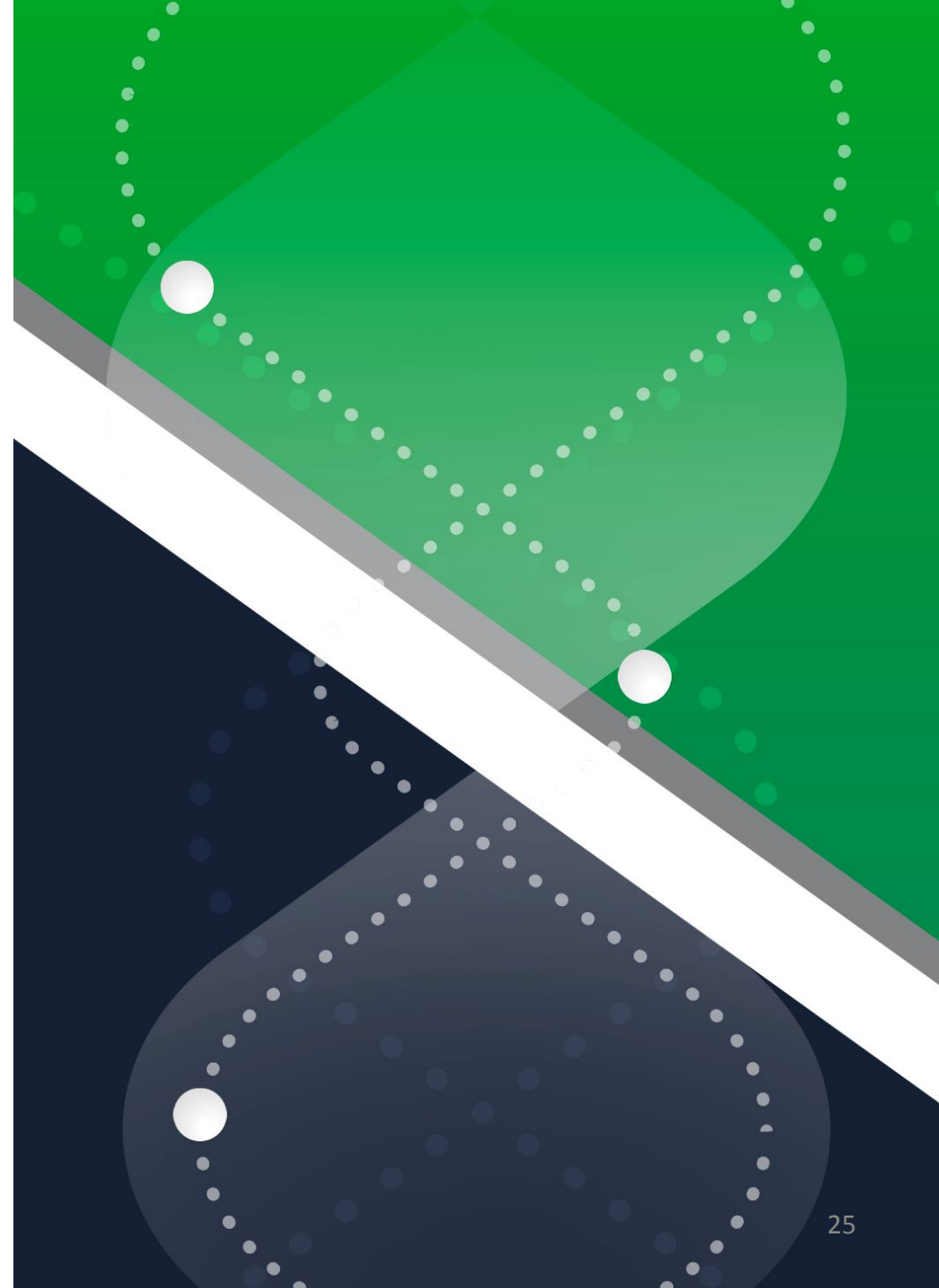
- Additional testing of single-item intersex/DSD status questions
- Effects of including definitions and examples of terms used in intersex status questions, such as “intersex,” “DSD,” and specific intersex variations
- Effects of proxy reporting of intersex/DSD status, particularly of caregivers reporting their children’s status

Moving Forward

- Robust SGM population data collection will greatly improve visibility and access for LGBTQI+ people
- Adding SOGI measures to the ACS will help reduce our reliance on cobbled together estimates and third-party data collection
- Paving the way for expansive and inclusive representation in data collection is critical for continuing to support a thriving democratic country
- Critical data collection for health, social determinants of health, economic, and social well-being must be prioritized
- These efforts don't, and haven't happened over night

THANK YOU!

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Resources for Reference: SOGI IWG & Research Group Reports

FCSM SOGI Resources:

- <https://www.fcsm.gov/groups/sogi/>
- [Why Do Federal Agencies Ask About Sexual Orientation and Gender Identity \(SOGI\) on Surveys? \(2021\)](#)
- [Updates of Terminology of Sexual Orientation and Gender Identity Survey Measures \(2020\)](#)
- [Current Measures of Sexual Orientation and Gender Identity in Federal Surveys \(2016\)](#)
- [Evaluations of Sexual Orientation and Gender Identity Survey Measures: What Have We Learned? \(2016\)](#)
- [Toward a Research Agenda for Measuring Sexual Orientation and Gender Identity in Federal Surveys: Findings, Recommendations, and Next Steps \(2016\)](#)

Other Federal Resources:

- [SACHRP Recommendations for the Ethical Review and Inclusion of LGBTQI+ Participants in Human Subjects Research](#)
- [HHS SOGI Data Action Plan: First Year Impact](#)
- [HHS SOGI Data Action Plan](#)
- [Federal Evidence Agenda on Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex \(LGBTQI+\) Equity \(Factsheet\)](#)
- [Recommendations on the Best Practices for the Collection of SOGI Data on Federal Statistical Surveys](#)
- [Measuring Sex, Gender Identity, and Sexual Orientation \(NASEM\)](#)
- [NIH Sexual & Gender Minority Research Office](#)
- [Healthy People 2030](#)
- [SOGI on the Census Bureau's Household Pulse Survey](#)

Resources!

About SGMRO Collaboration Events Reports Resources

COVID-19
• Get the latest public health information from CDC » • Get the latest research information from NIH » | Español » • NIH staff guidance on coronavirus (NIH Only) »

New Reports Released!
FY 2020 Annual Report & FY 2019 Portfolio Analysis
[Learn more »](#)

Sexual & Gender Minority Research
PORTFOLIO ANALYSIS
Fiscal Year 2019

Sexual & Gender Minority Research Office
ANNUAL REPORT
Fiscal Year 2020

DPCPSI » About SGMRO

The National Institutes of Health

Strategic Plan to Advance Research on the Health and Well-being of Sexual & Gender Minorities

Fiscal Years 2021 – 2025

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Sign-up for the SGM Health SIG Listserv:
https://tinyurl.com/SGMGROUP