



# ***Evidence to Action:*** EO14075 and Advancing Equitable SGM Data at HHS

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# Definition of SGM

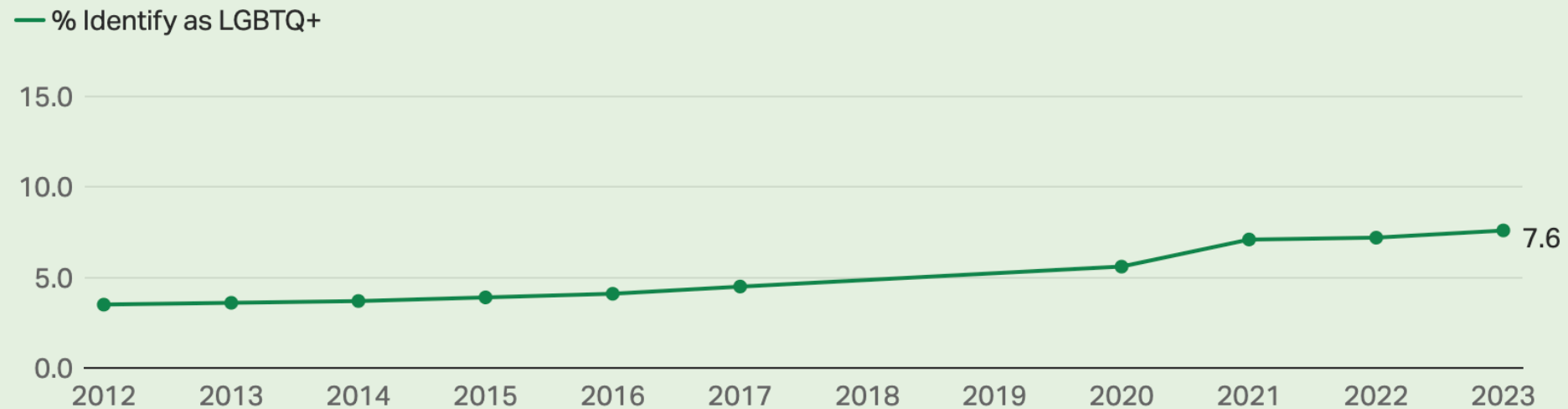
*Sexual and gender minority (SGM) populations may include, but are not limited to, individuals who identify as lesbian, gay, bisexual, asexual, transgender, non-binary, Two-Spirit, queer, and/or intersex. Individuals with same-sex or same-gender attractions or behaviors and those with a variation in 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)

# 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

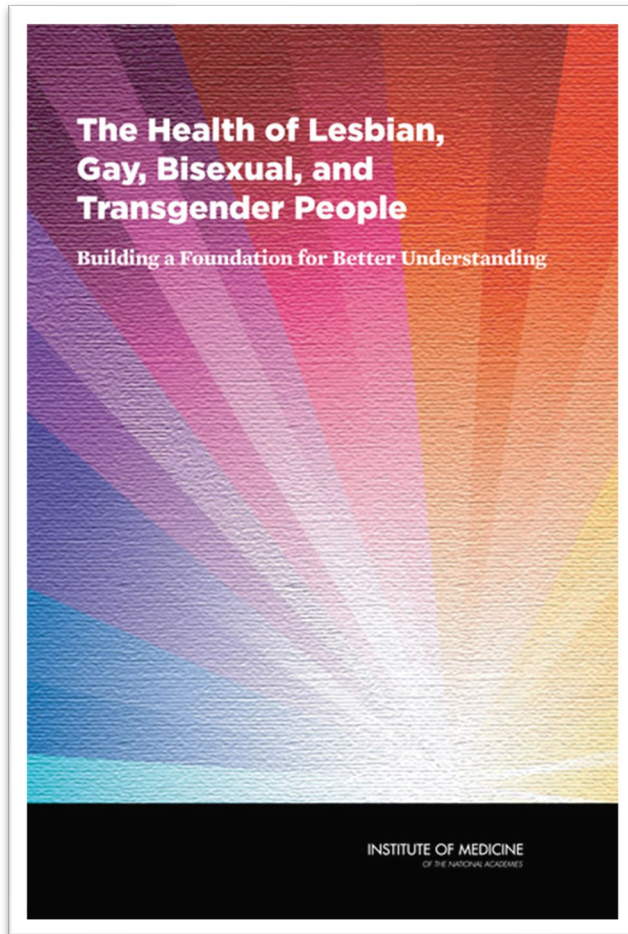


Respondents who volunteer another identity (e.g., queer; same-gender-loving; pansexual) are recorded as "Other LGBTQ+" by interviewers. These responses are included in the LGBTQ+ estimate.

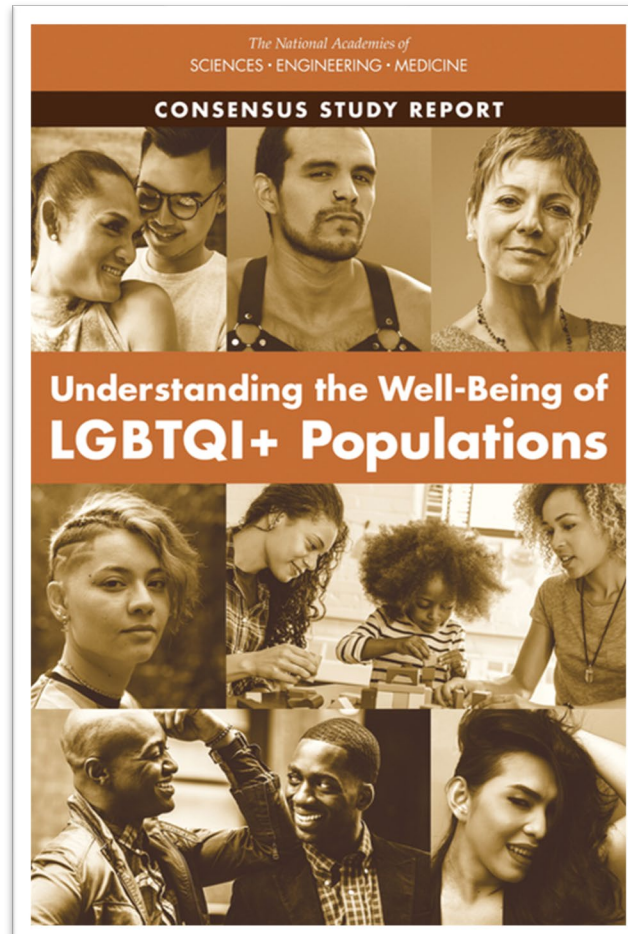
Data were not collected in 2018 and 2019.

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

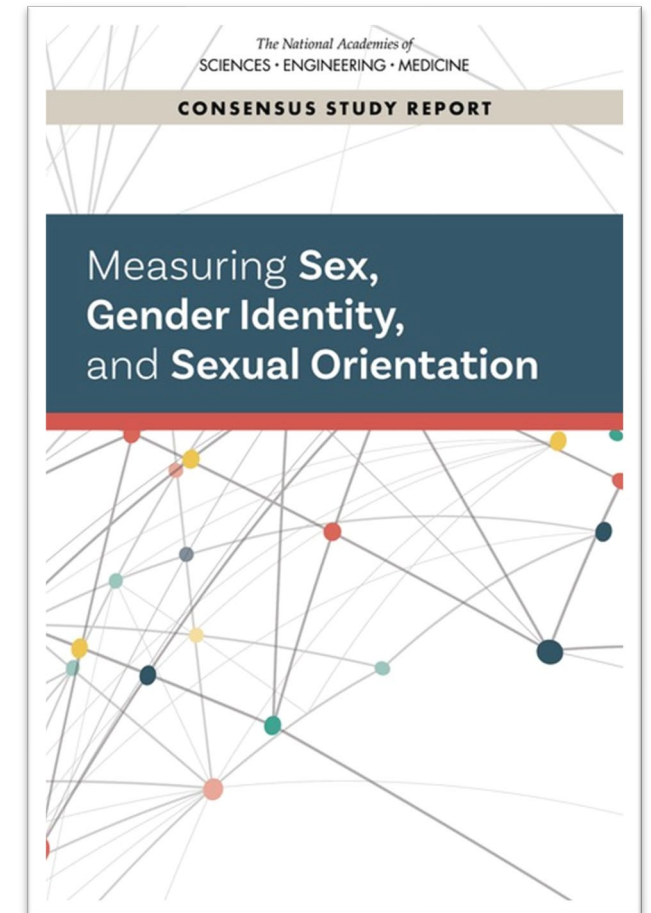
# NASEM Reports: Evidence-Based



2011

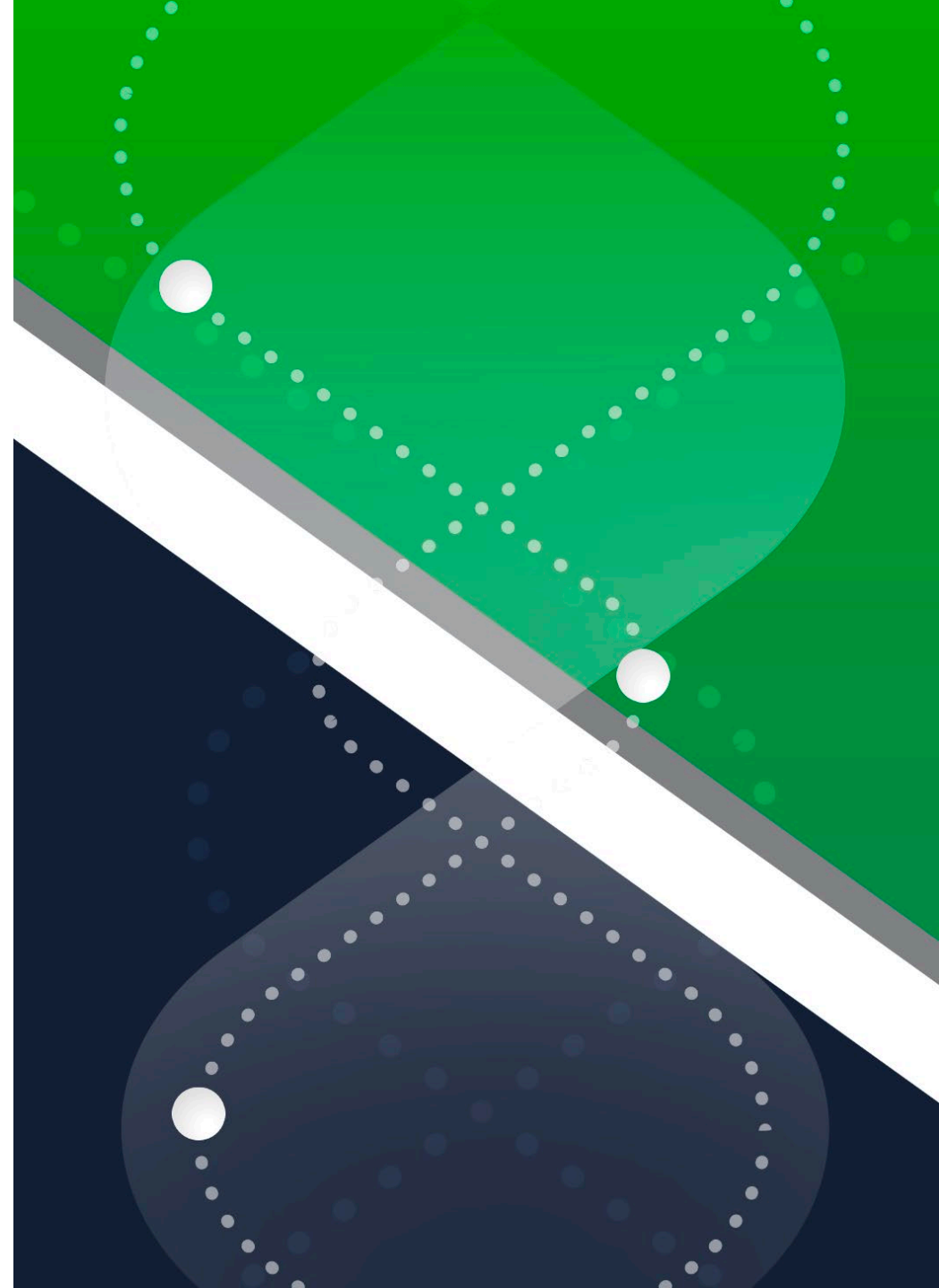


2020



2022

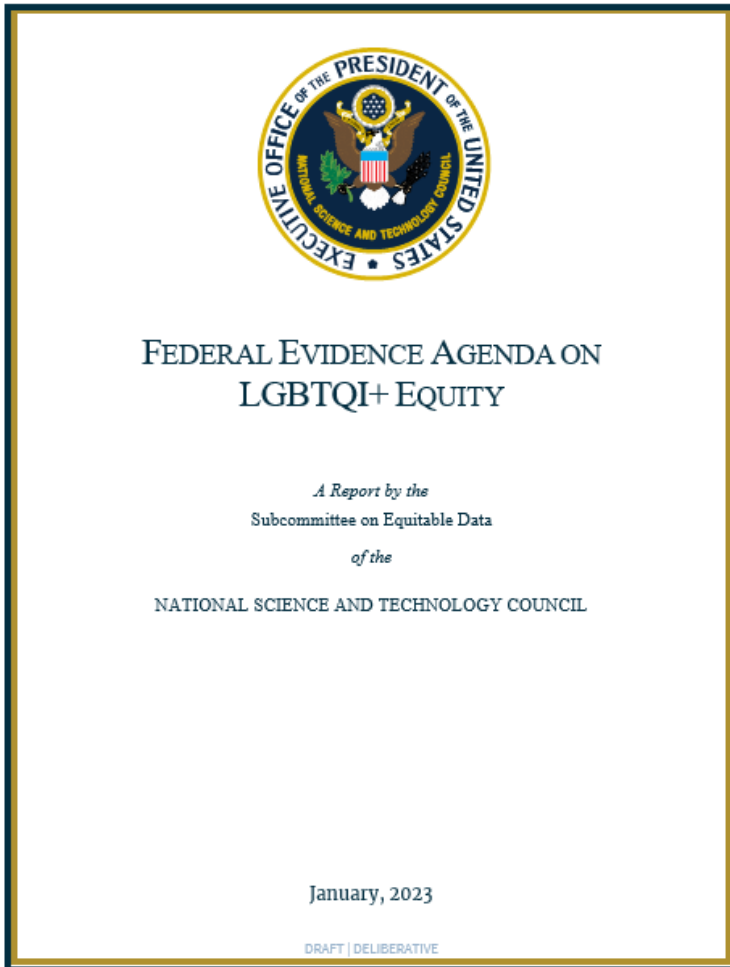
**EXECUTIVE ORDER 14075:  
Advancing Equality for Lesbian,  
Gay, Bisexual, Transgender,  
Queer, and Intersex Individuals  
(LGBTQI+)**



# Executive Order 14075

- 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:
  - Development of Federal Evidence Agenda on LGBTQI+ Equity
  - Recommendations for agencies on the best practices for collection of SOGI data on Federal statistical surveys
  - Development and implementation of agency SOGI Data Action Plans

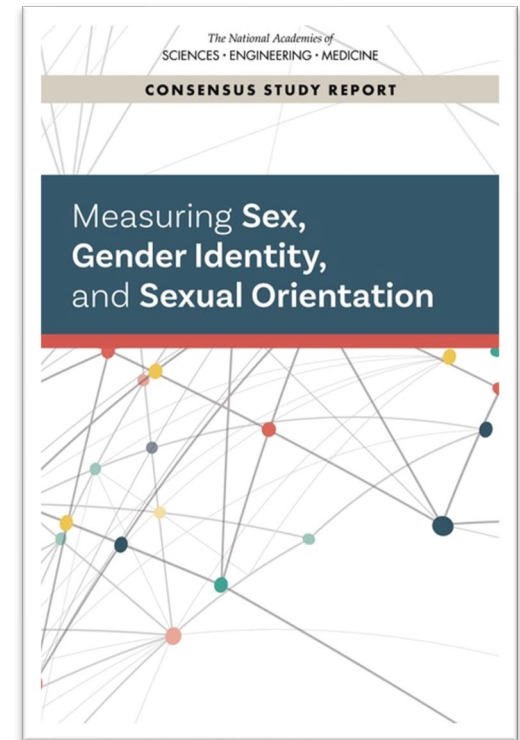
# Federal Evidence Agenda



- Foundational document for building department level SOGI Data Action Plans
- 9 community engagement listening sessions with over 150 participants, including one session focused on intersex and variations in sex characteristics
- Resource for:
  - Administrative SOGI data collection
  - Rational and data needs for collecting SOGI and sex characteristics data, where appropriate
  - Context specific data collection capture

# Guiding Principles

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





# 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

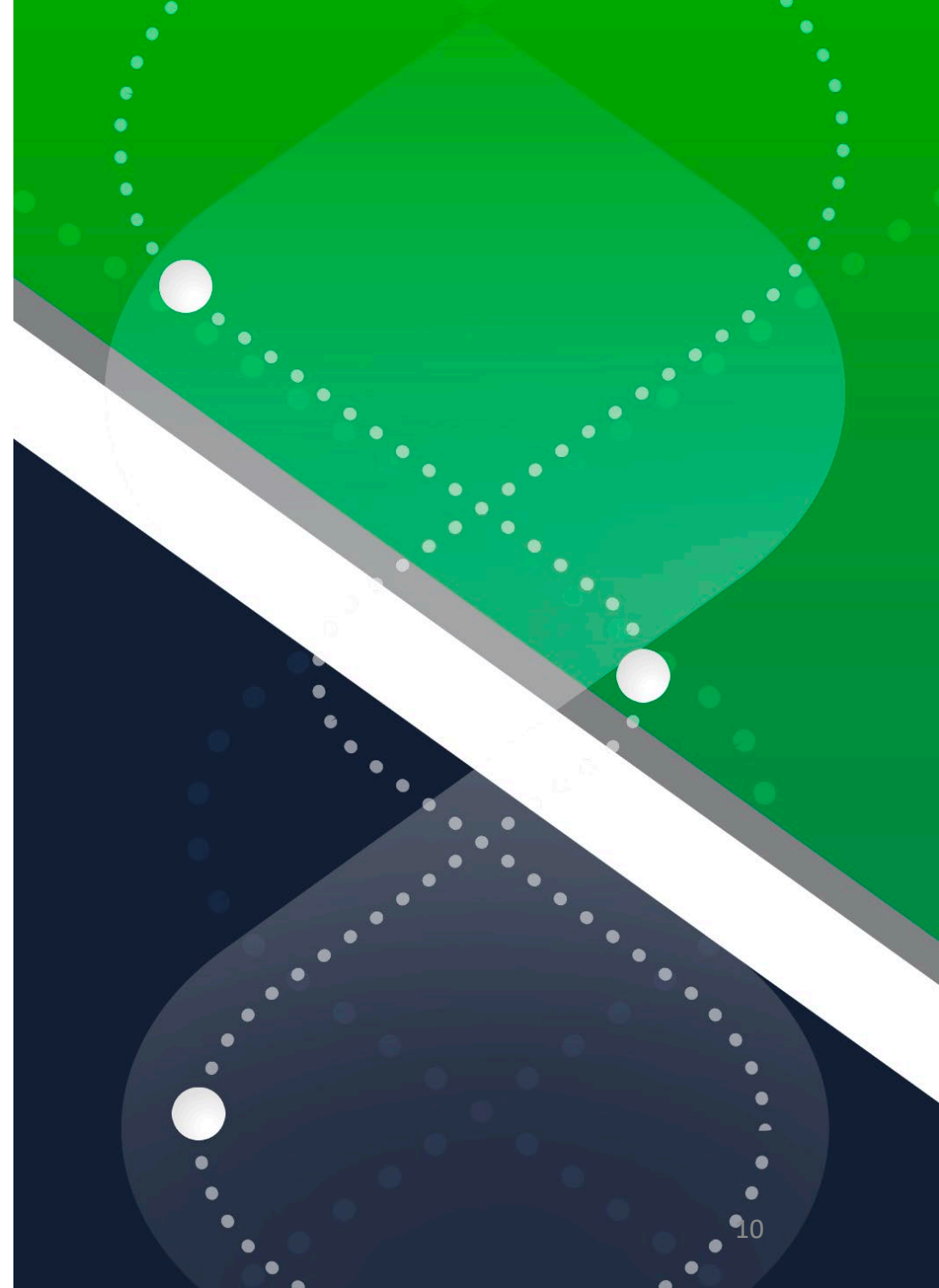
## Learning Agenda Topics

- 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

# HHS SOGI DATA ACTION PLAN



# HHS 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

OMB has praised HHS, writing “*HHS has taken a broad and cross-cutting approach to their SOGI Data Action Plan, integrating concrete steps to make SOGI data collection the norm in public health surveys and data collections.*”

# 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, should include SOGI.

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)<sup>1</sup> 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).<sup>2</sup> 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,<sup>2</sup> the Federal Evidence Agenda on LGBTQI+ Equity (for administrative data systems),<sup>3</sup> and the 2022 NASEM report,

<sup>1</sup> 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>.

<sup>2</sup> 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>

<sup>3</sup> 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>

# 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

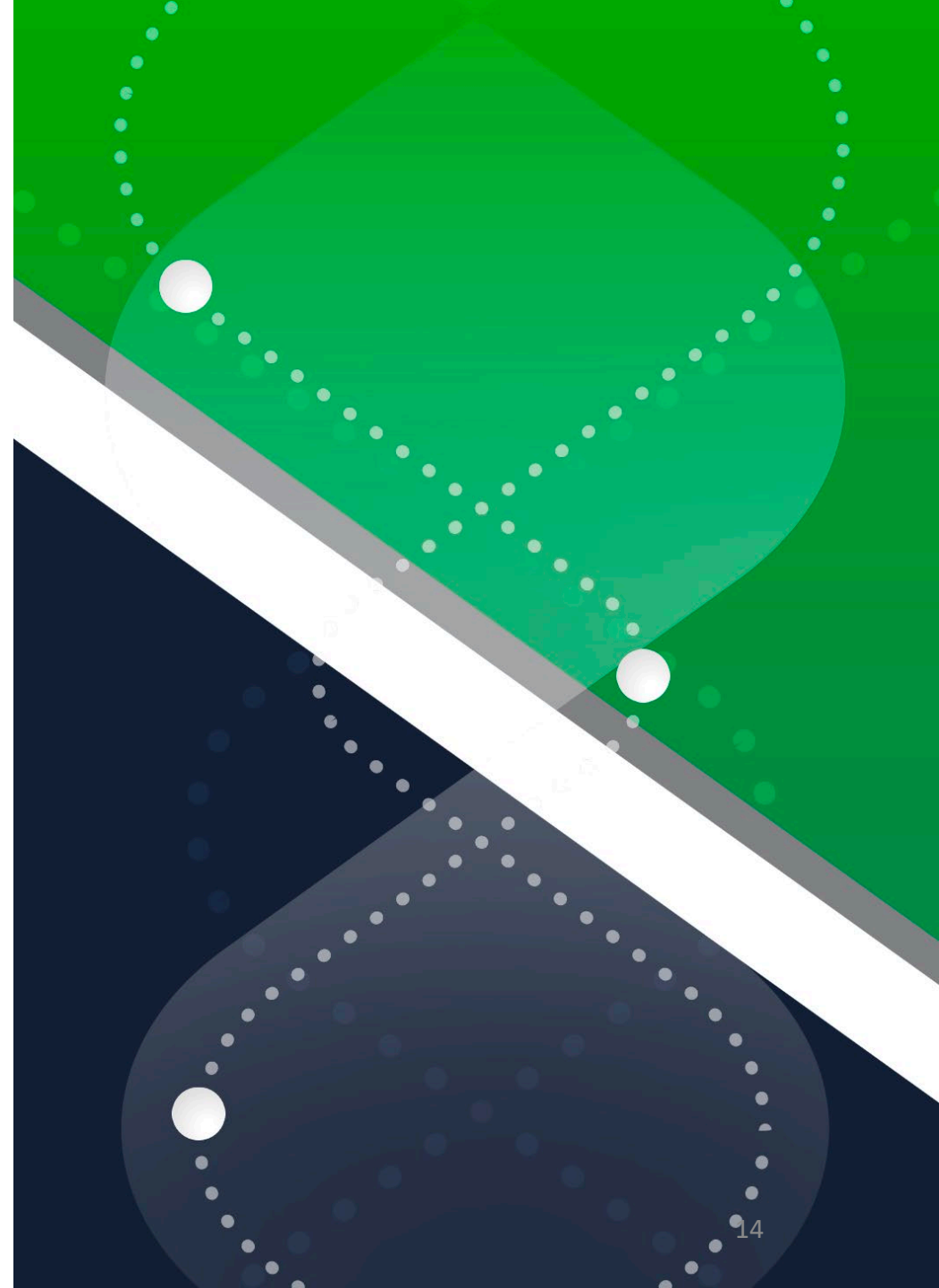
HHS will continue to prioritize LGBTQI+ health equity, including by continuing to build the SOGI data evidence base. The Department will continue to identify other opportunities to incorporate SOGI measures in additional surveys and administrative forms, will test data measures in languages other than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



- Driving conversations to action
- SACHRP Recommendations for the Ethical Review and Inclusion of LGBTQI+ Participants in Human Subjects Research
- Clinical Trial Diversity FDA and NIH collaborations

# THANK YOU!

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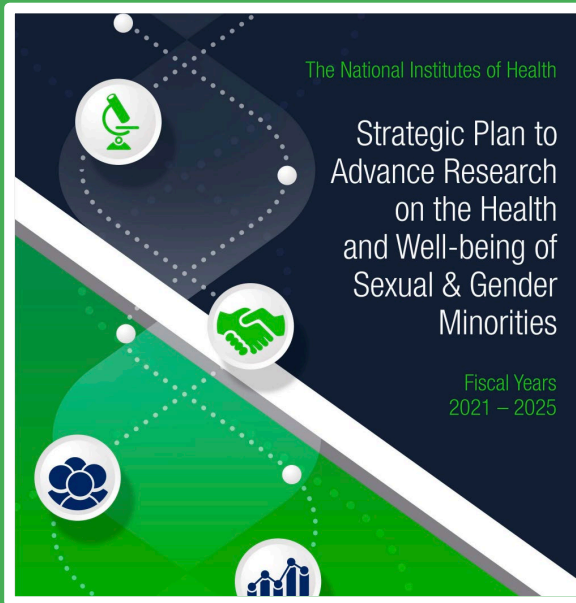
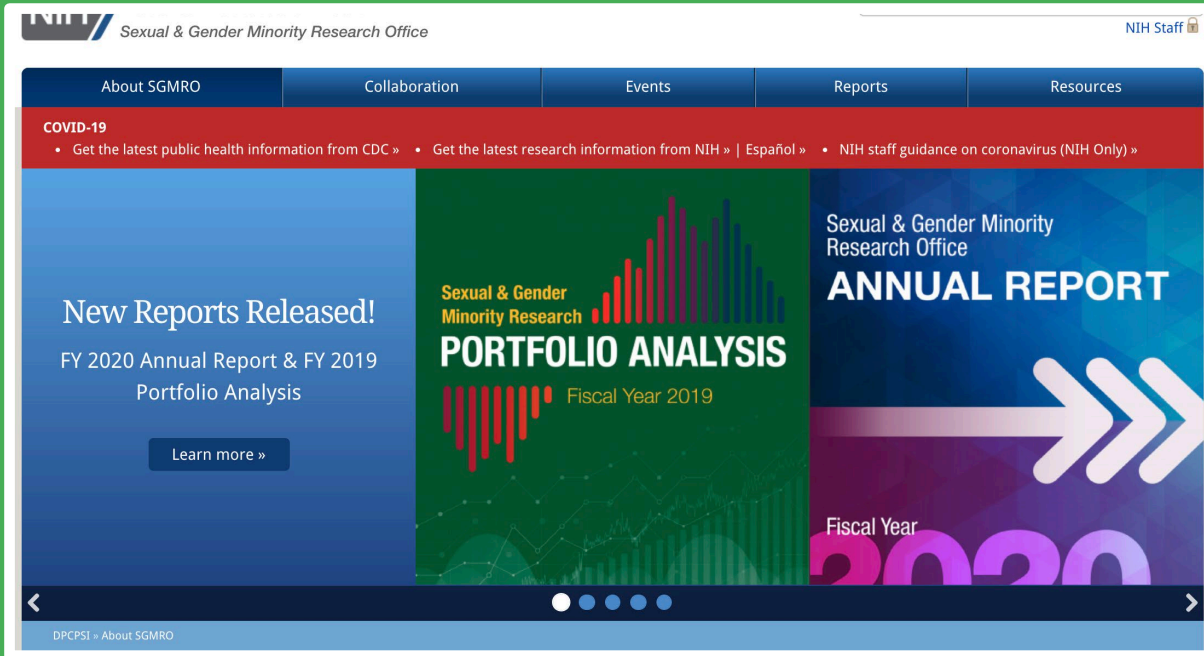
# Resources for Reference: SOGI IWG & Research Group Reports

## 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](#)



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