

Leveraging Data to Advance Equity for LGBTQI+ People

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Disclaimer

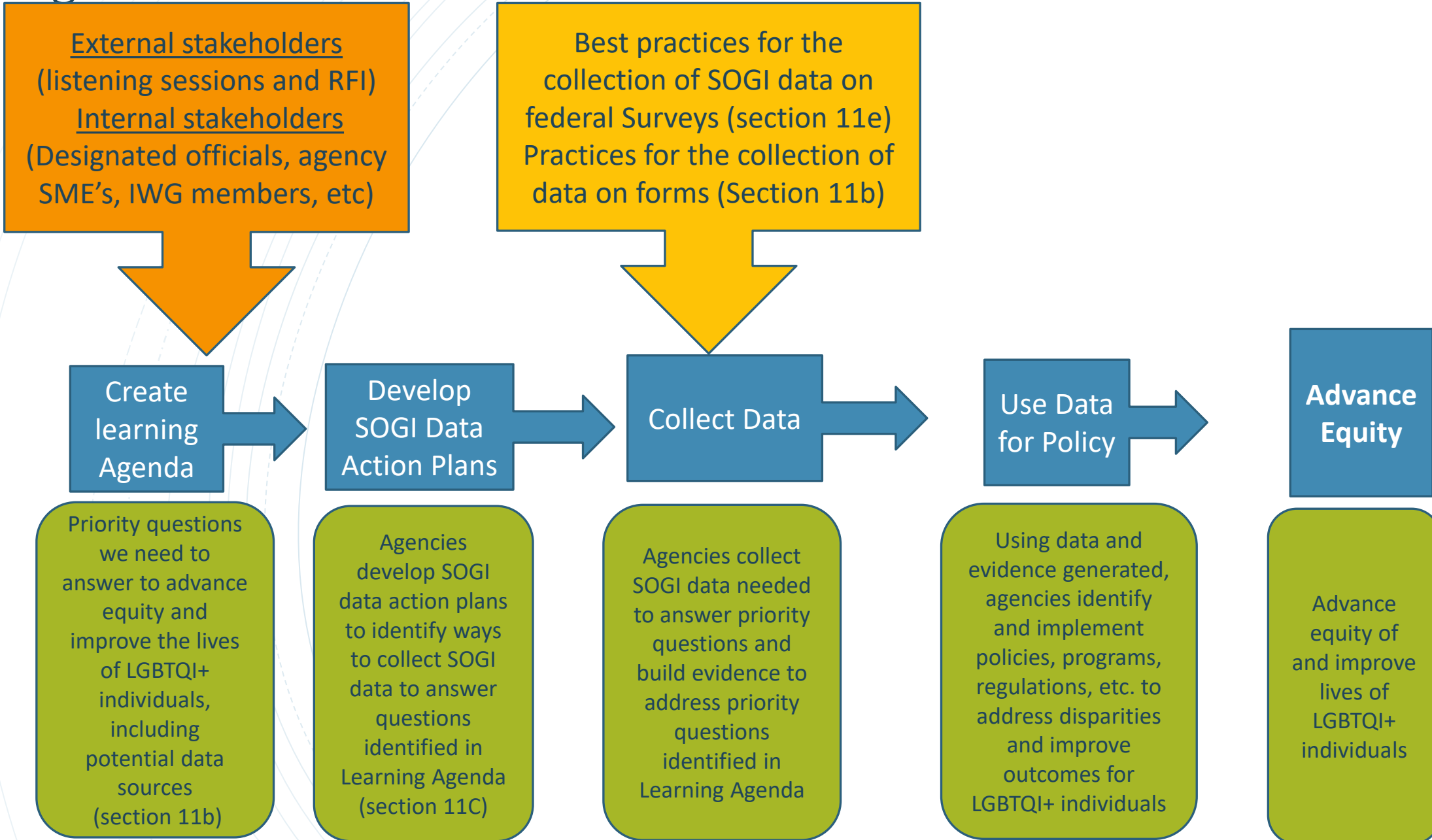
This presentation is released to inform interested parties of research and to encourage discussion. The views expressed are those of the authors and not necessarily those of the U.S. Census Bureau, NIH, Office of Management and Budget, or Federal Government.

Overview of Presentation

- Definitions
- Background
- Federal Resources
- EO 14075:
 - OMB Report
 - Federal Evidence Agenda
 - SOGI Data Action Plans
- Data for collaborations
- Resources



Big Picture



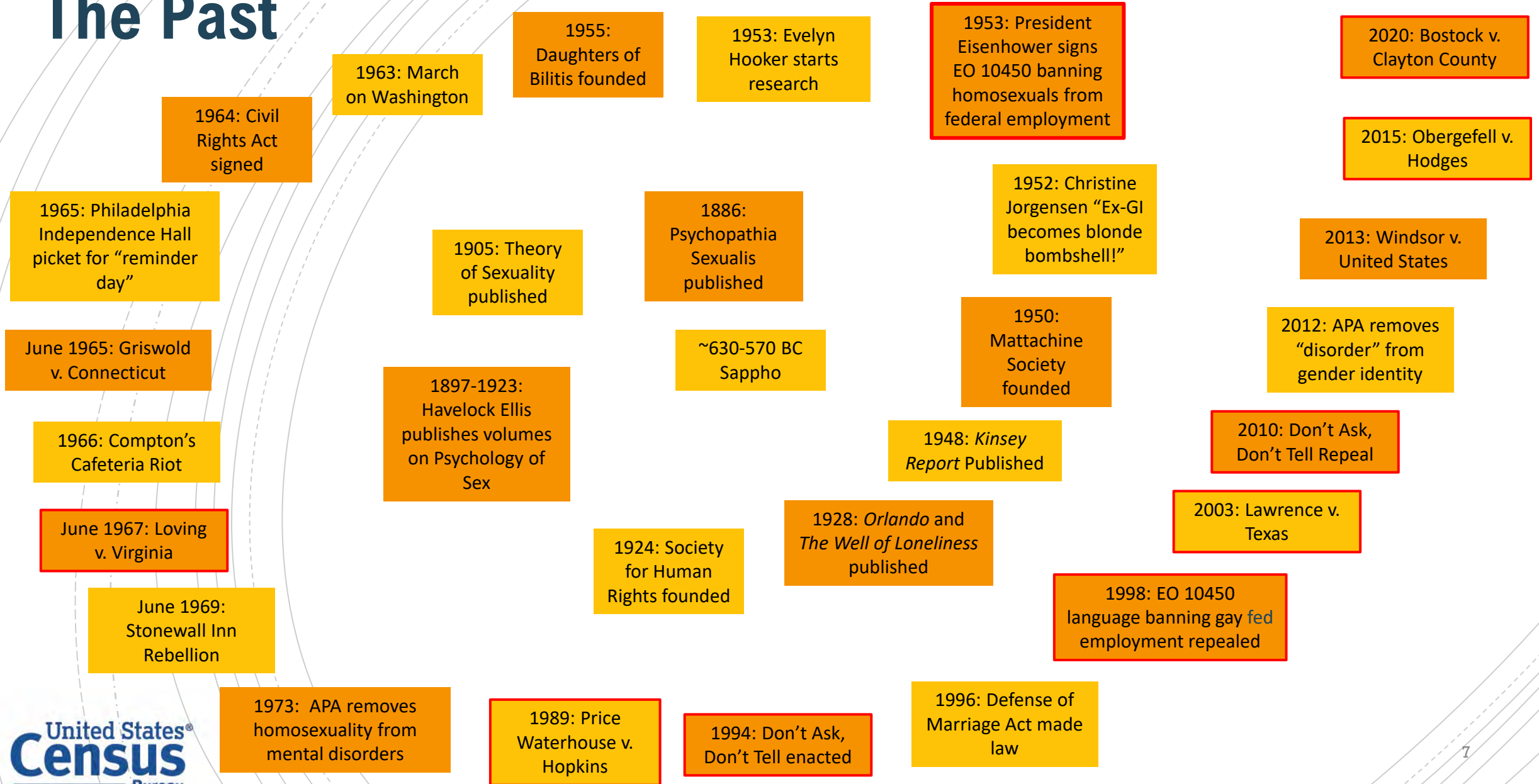
Definitions

Sexual and gender minority (SGM) populations include, but are not limited to, individuals who identify as lesbian, gay, bisexual, asexual, transgender, Two-Spirit, queer, and/or intersex. Individuals with same-sex or -gender attractions or behaviors and those with a difference in sex development 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 reproductive development is characterized by non-binary constructs of sexual orientation, gender, and/or sex.

[NIH Sexual & Gender Minority Research Office](#)

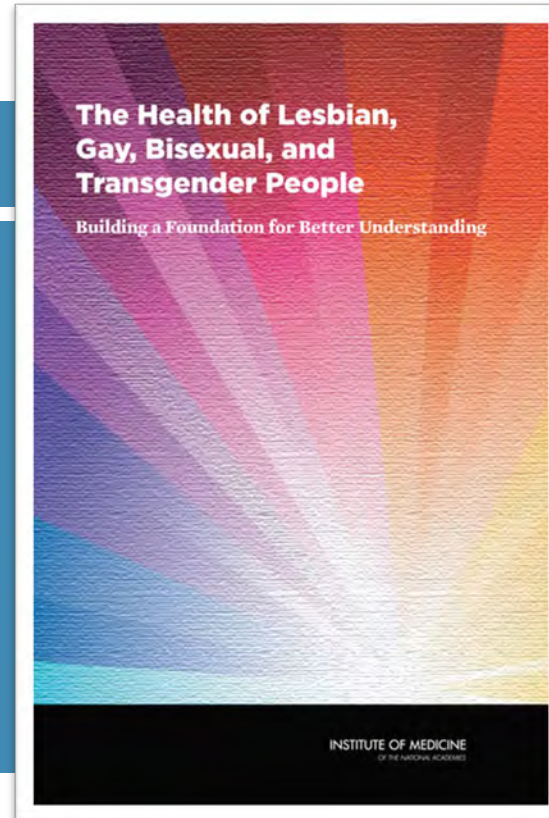
Background

The Past



Highlights from the 2011 Recommendations:

2011 National Academies of Science Engineering and Mathematics (NASEM) Report



- Data on sexual orientation and gender identity should be collected in federally funded surveys administered by the Department of Health and Human Services and in other relevant federally funded surveys.
- NIH should support the development and standardization of sexual orientation and gender identity measures.
- Critical in driving development of Healthy People 2020 measures.

Being Counted?



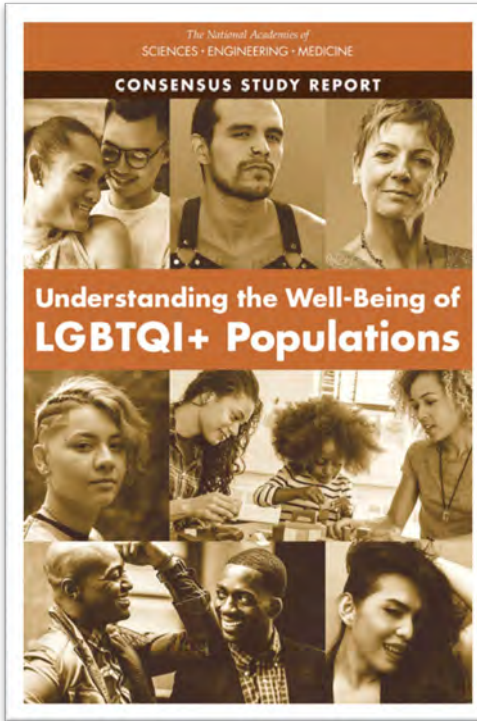
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measurable
LGBT
objectives



7
measurable
LGBT
objectives

- 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.

2020 NASEM Report



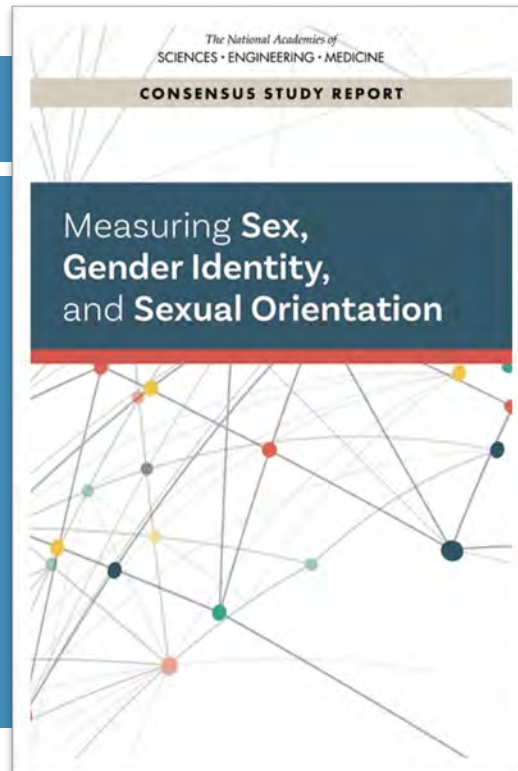
Highlights from the 2020 Recommendations: 10

- ...consider adding measures of sexual orientation, gender identity, and intersex status to all data collection efforts and instruments, such as population-based surveys, administrative records, clinical records, and forms used to collect demographic data.
- ...fund and conduct methodological research to develop, improve, and expand measures that capture the full range of sexual and gender diversity in the population—including but not limited to intersex status and emerging sexual and gender identities, sexual behaviors, and intersecting identities—as well as determinants of well-being for sexual and gender diverse populations.
- The U.S. Office of Management and Budget should convene federal, state, and private funders, as well as other relevant stakeholders, to address significant problems in linking data from different datasets to facilitate research on the health status and well-being of sexual and gender diverse people.

Persisting Measurement challenges

- No official standards
- Labels/definitions are fluid and rapidly changing
- Many terms are unfamiliar to sexual majorities and cisgender populations
- Official statistics require time-series, repeated measures over time
- Lack of production survey vehicles to conduct experiments
- Need for translations into languages other than English
- Questions must work for interviewer and self-administered response modes, as well as when asking proxies to respond for other household members
- Dearth of research on variations in sex characteristics or intersex people

2022 NASEM Report



Report Highlights:

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- NIH commissioned the National Academies of Sciences, Engineering, and Medicine (NASEM) to convene a panel of experts to review the existing knowledge base related to SGM-related measurement, make recommendations for specific measures, and provide guidance for their use

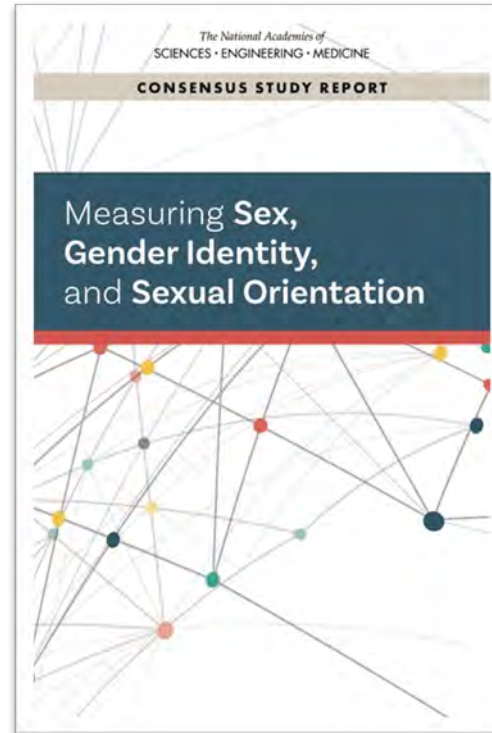
Measures that can be used in the U.S. English-speaking adult population

- More detailed response options may be necessary for measures used within LGBTQI+ populations
- Modifications to recommendations may be needed if they are used within younger populations
- Prioritizes representation of indigenous sexual and gender minorities

Focus solely on measures of identity for counting and identifying members of sexual minority populations

- Identity dimension is most relevant for measuring disparities in treatment and outcomes
- Greater effort has been spent on developing and deploying measures of identity than for other dimensions

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 Resources

National Academies Consensus Studies drive and focus LGBTQI+ Data Efforts Across Time

OMB Report: *Recommendations on the Best Practices for the Collection of SOGI Data on Federal Surveys* – Report released early January 2023

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

2010–2014

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

2018 to present

2015–2016

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

2022 to present

Interagency Working Group on EO 14075 Federal Evidence Agenda on LGBTQI+ Equity – Report released late January 2023

FCSM SOGI SOGI Research Group

The Measuring Sexual Orientation and Gender Identity (SOGI) Research Group explores the best practices of the measurement of SOGI in the context of Federal information collections.

The Group provides ongoing opportunities for individuals interested in statistical methods or data quality related to SOGI to interact, exchange information, and explore issues related to this topic.

There are five subgroups that focus on specific critical topics including:

- Proxy measurement
- Terminology
- Translation
- Youth
- Outreach and communication



FCSM SOGI Research Group Membership

Department of Justice
(DOJ)

Department of Health
and Human Services
(HHS)

Department of
Commerce (DOC)

Department of
Housing and Urban
Development (HUD)

Department of Labor
(DOL)

Office of Personnel
Management (OPM)

Department of
Education,
Department of
Veterans Affairs (VA)

Department of
Defense (DOD)

United States Agency
for International
Development (USAID)

Environmental
Protection Agency
(EPA)

National Science
Foundation (NSF)

Executive order 14075

JUNE 15, 2022

Executive Order on Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals

[BRIEFING ROOM](#)[PRESIDENTIAL ACTIONS](#)

Executive Order 14075

Advancing Equality for Lesbian,
Gay,
Bisexual, Transgender, Queer,
and Intersex Individuals

Sec. 11. Promoting Inclusive and Responsible Federal Data Collection Practices. (a) Advancing equity and full inclusion for LGBTQI+ individuals requires that the Federal Government use evidence and data to measure and address the disparities that LGBTQI+ individuals, families, and households face, while safeguarding privacy, security, and civil rights.

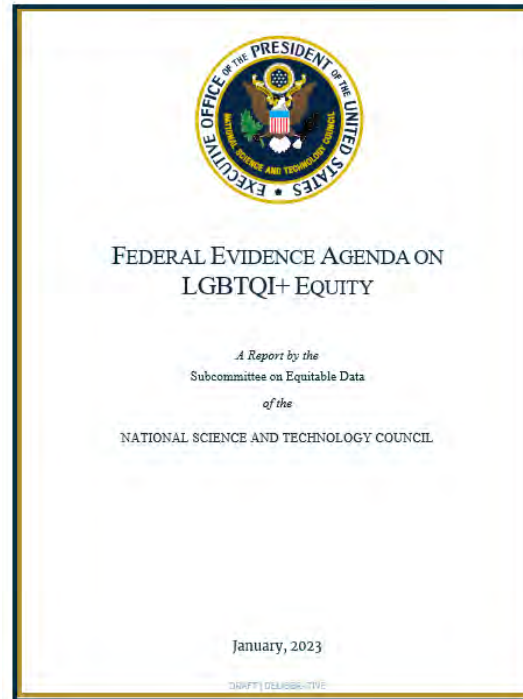
Section 11: Promoting
Inclusive and
Responsible
Federal Data Collection
Practices

- Recommendations on the Best Practices for the Collection of Sexual Orientation and Gender Identity Data on Federal Statistical Surveys
- Federal Evidence Agenda on LGBTQI+ Equity
- Federal Agency SOGI Data Action Plans

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.

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

Federal Evidence Agenda Content

- 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

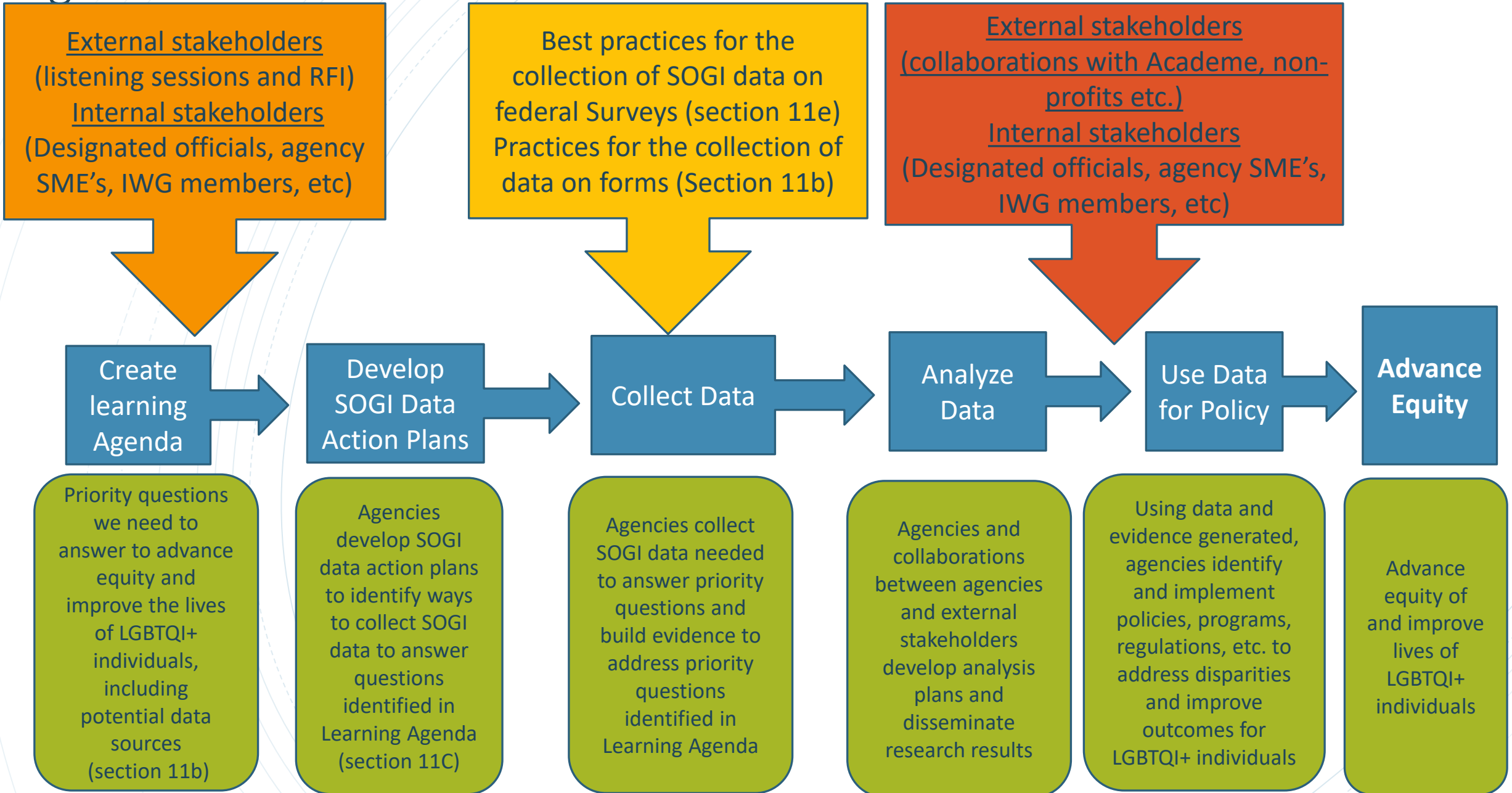
SOGI Data Action Plans

(c) Within 200 days of the date of this order, the head of each agency that conducts relevant programs or statistical surveys related to the Federal Evidence Agenda on LGBTQI+ Equity shall submit to the Co-Chairs of the Interagency Working Group on Equitable Data a SOGI Data Action Plan, which shall detail how the agency plans to use SOGI data to advance equity for LGBTQI+ individuals and shall identify how the agency plans to implement the recommendations in the Federal Evidence Agenda on LGBTQI+ Equity.

Some Highlights of data collection efforts at a few federal agencies

- ACS survey methods panel: 2024 Sexual Orientation and Gender identity test
- Agency for Healthcare research and Quality proposed changes including the addition of SOGI questions. Federal Register public comment open until Nov 28.
- CMS proposed collection of SOGI for Medicare parts C and D. Federal Register public comment is open until Nov 28.
- OPM is rolling out new forms for collection of Sexual orientation and Gender Identity for the federal workforce

Big Picture



SOGI IWG & Research Group Reports

FCSM SOGI Resources:

- [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:

- [Federal Evidence Agenda on Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex \(LGBTQI+\) Equity \(Factsheet\)](#)
- [Recommendations on the Best Practices for the Collection of Sexual Orientation and Gender Identity Data on Federal Statistical Surveys \(whitehouse.gov\)](#)
- [Learning Agenda Dashboard \(on Evaluation.gov\)](#)
- [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](#)
- [SOGI Data Action Plan for the Department of Housing and Urban Development \(huduser.gov\)](#)

Thank you

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