

LGBTQ-Inclusive Data Collection: A Lifesaving Imperative



• •

• • • • • •

.

• • • • •





.

....















• •

• • • • •

.

• • • • • •

• •

. . .

• •

• • • • • • • • • • •



• • • • •







Table of Contents

I. (Executive Summary	2
н. т	ntroduction	4
	The Importance of LGBTQ-Inclusive Data Collection	5
IV. ı	egal Landscape	7
Α. 9	STATE LAWS AND POLICIES	7
B. I	EDERAL LAWS AND POLICIES	7
FE	ATURE: DATA DESERT BY DR. RANDALL SELL	10
V. 9	Survey of Current Data Collection Efforts	11
Α. 9	STATE-ADMINISTERED INSTRUMENTS	11
B. I	EDERALLY-ADMINISTERED INSTRUMENTS	13
VI. 1	Recommendations	14
	ST PRACTICES: ASKING QUESTIONS ON SEXUAL ORIENTATION D GENDER IDENTITY	16
VII. d	Conclusion	18

Executive Summary

LGBTQ Americans remain largely invisible to the local, state, and federal officials charged with ensuring their health, safety, and wellbeing. This is because state and federal officials have failed the LGBTQ community when it comes to ensuring equal treatment in government data collection efforts.

Countless sweeping legislative and regulatory proposals, as well as decisions directing public funding to the tune of hundreds of billions of dollars, are based on data collection instruments that include demographic data. Since the vast majority of data collection surveys fail to include sexual orientation and gender identity metrics alongside other demographic metrics, LGBTQ people are continuously left out of policy and funding decisions that carry lifesaving potential. Moreover, the lack of LGBTQinclusive data significantly impairs advocacy organizations' ability to press for LGBTQ policy and funding priorities, creating a cycle that perpetually harms LGBTQ Americans and their families.

Currently, no state or the federal government has a comprehensive law that requires all government and government-funded data collection endeavors to include sexual orientation and gender identity data alongside other demographic data like race, ethnicity, and sex. Only four states—New York, California, Oregon, and New Jersey—and the District of Columbia have narrower laws or regulations mandating LGBTQ-inclusive data collection in specific areas other than hate crimes. What's more, since the start of Donald Trump's presidency in 2017, the federal government has engaged in a concerted effort to stymie and roll back existing LGBTQ-inclusive data collection.

Comprehensive laws on every level of government are the most effective first step in ensuring that LGBTQ people are recognized and that their unique needs are adequately addressed. Municipalities, states, and the federal government can and should promulgate laws and policies that require their respective data collection undertakings to be fully inclusive of the LGBTQ community. Ultimately, it is incumbent on the federal government to lead by example. The Office of Management and Budget, as the federal agency charged with coordinating the efforts of the vast and complex federal statistical system, should act quickly in issuing a statistical directive that requires sexual orientation and gender identity measures where data on sex is collected. Moreover, Congress should swiftly consider and pass the LGBTQ Data Inclusion Act.

Given the central role that data collection occupies in virtually every aspect of government decision-making and resource allocation, failure to include sexual orientation and gender identity in surveys that collect demographic data brings about very real and dire consequences for LGBTQ Americans.

It is long past time that officials on every level of government equally include all marginalized communities, including LGBTQ Americans, in all relevant data collection endeavors.



"One of the greatest threats to the health of [LGBTQ] Americans is the lack of scientific information about their health."

-Am J Public Health. 2001;91: 876-8821



LGBTQ-INCLUSIVE DATA COLLECTION: A LIFESAVING IMPERATIVE

Introduction

Demographic data, or statistics on the characteristics of a population, is of great import to virtually every sector of society. In fact, we interface with many systems in our daily lives that are shaped in no small part by demographic data.

Corporations rely on demographic data to inform and direct their business and advertising decisions. The problems medical and other researchers set out to tackle are often informed by demographic data, and research methodology often necessarily begins with and centers around demographics. Advocacy organizations depend on demographic data to illustrate the existence and severity of their issues to the public and decision-makers. And governments regularly collect demographic data to inform all manner of business including electoral districting, zoning, taxation, grantmaking, and policy-making.

It is in this latter realm—the public sector—where the collection of demographic data is most fundamental. Governments of every tier—local, state, and federal— and their constituent bodies would be significantly stymied without the ability to assess demographic information related to the people they serve. Core, vital government functions like demarcating school districts, setting budget priorities, and identifying and responding to health crises when or if they occur rely on population statistics. Essentially, current and comprehensive demographic information enables governments to effectively execute their foremost duty of ensuring the health, safety, and wellbeing of the population.

This report highlights the imperative of ensuring that all relevant government data collection instruments include metrics on

sexual orientation and gender identity (SOGI) and identifies the serious harms that result from the failure to do so.

It presents an overview of existing state and federal laws and policies that expressly mandate LGBTQ-inclusive data collection as well as past and current legislative and policy proposals on the subject. This report also examines the extent to which existing state and federal data collection efforts incorporate lesbian, gay, bisexual, transgender, and queer (LGBTQ) people. Finally, this report offers legislative and policy recommendations to ensure fullyinclusive government data collection undertakings and identifies best practices on incorporating LGBTQ metrics in data collection instruments.

The Importance of LGBTQ-Inclusive Data Collection

Ensuring that LGBTQ people are fully incorporated in local, state, and federal data collection efforts carries life-saving potential.

This is most directly illustrated in the context of public health efforts. Consider, for example, the Centers for Disease Control and Prevention's (CDC) Youth Risk Behavior Surveillance System (YRBSS), which includes a national Youth Risk Behavior Survey (YRBS) conducted by the CDC as well as a standard YRBS conducted by states and school districts. ² The YRBSS was developed in 1990 to monitor health risk behaviors that significantly contribute to the leading causes of death, disability, and social problems among youth and adults in the United States.3 From 1991 through 2017, the YRBSS collected data from more than 4.4 million high school students in more than 1,900 separate surveys.⁴ But it wasn't until 2015 that the YRBSS formally added questions on sexual orientation and gender of sexual contacts to both the national and standard YRBS.⁵ The prior lack of standard inclusion of these data points severely limited analysis on the health and safety risks among lesbian, gay, and bisexual (LGB) youth nationwide. Based on this more robust sexual orientation data collection, the CDC issued a milestone report in 2016 that provided the first national estimates of high school students who are LGB and identified specific health disparities between LGB high school students compared with their non-LGB peers, including a disproportionately higher risk of suicidality.6 The landmark federal report went on to recommend action state agencies and schools can take to address these alarming disparities, including implementing inclusive school anti-bullying policies, ensuring that health classes are inclusive of and relevant to LGB students, and easing student access to LGB competent health care providers.7 Moreover, the report highlighted specific steps numerous school districts and states have taken as a result of the sexual orientation data they collected through their YRBS.8 The Massachusetts Department of Elementary and

Secondary Education, for instance, used its data to help schools make their sexual health curricula more LGBinclusive and train school counselors, social workers, and nurses on the unique risks faced by LGB youth.⁹

As illustrated in the above example, demographic data informs important policy decisions and directs the resources required to implement and execute these policies. Local, state, and federal officials base many sweeping legislative and regulatory proposals on data collection instruments that include demographic data, and demographic data is utilized to direct public funding and grantmaking to the tune of hundreds of billions of dollars. At the federal level alone, U.S. Census Bureau data was employed in whole or in part to distribute more than \$675 billion dollars across 132 programs during the 2015 fiscal year.¹⁰ Excluding sexual orientation and gender identity measures from taxpayer-funded data collection efforts is fundamentally unjust and renders LGBTQ constituents invisible to the officials that represent them.

Finally, LGBTQ-inclusive data collection equips pro-equality advocates with authoritative statistics to demonstrate the unfortunate reality that anti-LGBTQ discrimination is still all too common, helping dispel a commonly employed falsehood by anti-equality activists that discrimination is a bygone issue undeserving of government officials' attention. This is especially important in today's legal and political landscape in which thirty states lack fully-inclusive comprehensive statewide nondiscrimination protections and many states and the federal government are actively working to rollback existing protections. Moreover, mandatory LGBTQ-inclusive hate crimes data collection and reporting is imperative to law enforcement's ability to accurately gauge the scope of biasmotivated crimes and effectively address them.¹¹ Countless sweeping legislative and regulatory proposals, as well as decisions directing public funding to the tune of hundreds of billions of dollars, are based on data collection instruments that include demographic data.

• • • • • • •

••

Legal Landscape

STATE LAWS AND POLICIES

Currently, no state has comprehensive laws or regulations requiring all state data collection efforts to include sexual orientation and gender identity alongside other demographic data like race, ethnicity, and sex.

Four states—New York, California, Oregon, and New Jersey—and the District of Columbia have more limited laws or regulations that require SOGI-inclusive data collection in areas other than bias-motivated crimes. Though, 21 states plus the District of Columbia require law enforcement agencies to collect and report data on hate crimes based on sexual orientation and/or gender identity.¹²

In 2014, New York Governor Andrew M. Cuomo announced a multi-agency effort to strengthen data collection for LGBTQ New Yorkers.13 In 2015 and 2017, California enacted laws that together require the state health, human services, education, and employment agencies to include SOGI data along with other voluntarily-provided demographic information on race and gender.¹⁴ Both Oregon¹⁵ and New Jersey¹⁶ have laws requiring public higher education institutions to allow students and faculty to identify their sexual orientation and gender identity on any form that collects demographic information on gender, race, or ethnicity. Additionally, the District of Columbia recently passed a bill requiring the inclusion of LGBTQ questions on the federally-coordinated health surveys discussed below.¹⁷ It should also be noted that Rhode Island's¹⁸ Department of Health has undertaken department-level initiatives to incorporate LGBTQ data collection.

Efforts to expand both this list of states and the scope of laws on this subject have been ongoing in recent years. Since 2011, legislation that would codify and expand New York's aforementioned regulations by requiring a uniform statewide data collection system to identify health disparities based on sexual orientation, among other demographic factors, has been introduced.¹⁹ A more expansive bill that would require all New York state agencies that engage in data collection to include questions on sexual orientation and gender identity alongside ancestry or ethnic origin was introduced this year.²⁰ In total, at least twelve bills in eight states seeking to expand SOGI data collection have been introduced in the 2019 legislative session.²¹

FEDERAL LAWS AND POLICIES

The federal government has a highly decentralized statistical system. Currently, 107 federal agencies engage in data collection to varying degrees.²²

Adding to the complexity of the federal statistical system is the fact that no single federal statute or regulation sets a governing standard for what demographic information must be collected by these agencies. Rather, piecemeal laws, regulations, and non-binding guidance create a patchwork of varied requirements and practices from agency to agency.

Decentralized structure notwithstanding, one agency occupies a unique and farreaching role in the federal statistical system: the U.S. Office of Management and Budget (OMB).²³

The Office of Information and Regulatory Affairs (OIRA) within OMB is charged with coordinating the efforts of the nation's thirteen principal statistical agencies, which include the Bureau of the Census, the National Center for Education Statistics, and the National Center for Health Statistics.²⁴ Further, pursuant to the Budget and Accounting Procedures Act of 1950 and the Paperwork Reduction Act of 1995, OMB possesses the authority to issue Statistical Policy Directives to ensure the "efficiency and effectiveness" and the "objectivity, impartiality, [and] utility" of information collected by the federal government.²⁵ OIRA has issued Statistical Policy Directives relatively sparingly. Of particular pertinence is Statistical Directive No. 15, which sets the minimum categories that must be included in federal data collection on race and ethnicity.²⁶

Since the start of Donald Trump's presidency in 2017, the federal government has engaged in a concerted effort to roll back LGBTQ-inclusive data collection. The Trump administration's first such action came in March of 2017 when the U.S. Department of Health and Human Services (HHS) announced it would be removing questions on sexual orientation and gender identity from the National Survey of Older Americans Act Participants.²⁷ Fortunately, the questions were restored after outcry from LGBTQ advocates and allies.²⁸ Shortly thereafter, however, HHS renounced its plans to include questions on sexual orientation and gender identity in its Annual Program Performance Report for



Current U.S. federal statistical system

SOURCE: National Center for Health Statistics, CDC

Centers for Independent Living;²⁹ the U.S. Department of Housing and Urban Development withdrew its request for comments on a proposed LGBTQ youth homelessness survey;³⁰ and the U.S. Census Bureau reversed its plans to include sexual orientation and gender identity on the American Community Survey.³¹

In October 2017, HHS published its Strategic Plan for 2018-2022, which excluded any mention of sexual orientation and gender identity.³² This onslaught of federal administrative rollbacks continued into 2018 when the Department of Justice announced that it would stop asking sixteen and seventeen year olds voluntary and confidential questions on their sexual orientation and gender identity in the National Crime Victimization Survey.³³ Moreover, on April 19, 2019, HHS published a proposed rule change that would abandon data collection on the sexual orientation of foster youth and foster and adoptive parents and guardians in the Adoption and Foster Care Analysis and Reporting System.³⁴

First introduced in 2016, the LGBTQ Data Inclusion Act would require all federal agencies to include voluntary SOGI questions in data collection instruments that include demographic data.³⁵ The Act would also require reports that rely on these surveys to include analysis of the SOGI data collected while maintaining participant privacy and confidentiality.

Though this bill has been introduced in every Congress since 2016, it has yet to have a committee hearing. Moreover, the LGBTQ Essential Data Act,³⁶ which would strengthen SOGI data collection in the National Violent Death Reporting System, has also been introduced annually since 2016 and has failed to advance to committee.³⁷

Mandatory Inclusion vs. Voluntary Participation

It is important to distinguish between the mandatory inclusion of SOGI questions in data collection instruments and ensuring that SOGI questions are non-mandatory for respondents. While laws and policies should require that relevant government data collection efforts include SOGI measures, questions regarding sexual orientation and gender identity should, like all other demographic questions, be voluntary for the participant.

FEATURE:

A Data Desert

Dr. Randall Sell

Director of LGBT Health Program and Professor, Drexel University Dornsife School of Public Health

Government officials and scientists that control data production, analysis, and dissemination hold extraordinary power to influence laws, policies, and programs that impact people's lives in profound ways. Sexual and gender minority (SGM) communities have been denied this power for far too long. While SGMs are seldom physically excluded from participating in data collection efforts, their identities as SGMs have rarely been considered important enough to be recognized within the actual data collected.¹ The resulting data desert has caused immeasurable harm not just to SGMs, but to their friends, families, and their larger communities.²

The laws and policies promoted in this report will go a long way toward eliminating this data desert by mandating data collectors recognize the SGM identities (e.g. lesbian, gay, bisexual, and transgender) of the people they engage in their work. This is most easily done by adding questions assessing sexual orientation and gender identity to existing data collection systems.² There are many examples of how data collection has benefited SGMs through the simple addition of these variables to extant protocols. Perhaps the richest examples come from the Youth Risk Behavior Surveillance System (YRBSS).

As discussed elsewhere in this report, the YRBSS is comprised of individual Youth Risk Behavior Surveys (YRBS) implemented by states and cities. While the Centers for Disease Control, for political reasons (not scientific or methodological), long avoided adding these variables to the core set of required questions, they allowed and at times facilitated the addition of SGM variables at the state and city level. This has resulted in an uncoordinated and haphazard yet rich collection of sexual orientation and gender identity data across the country.

The data repeatedly (across locations and time) has shown LGBTQ youth at risk for most health outcomes measured

on the survey including bullying, drug and alcohol use, suicide, and homelessness.³⁻⁷ Advocates for LGBTQ youth have used this data to lobby for the creation of safe schools programs in Massachusetts, Vermont, Maine, and in virtually every state and city where sexual orientation and/ or gender identity data has been collected.[8-10] While the primary outcome of the survey is the quantification of risk, the data is also used to inform professional development in schools and health centers, propose, lobby for, and pass legislation, inform and fund programs to address survey findings, and to monitor change.¹¹⁻¹⁴

If YRBS data alone can have this impact, just imagine the influence there would be on the lives of SGMs if the thousands of data collection systems funded wholly or in part by our state and federal governments simply added sexual orientation and gender identity variables. The data desert would disappear and from the newly created data SGM people would be given the power to better describe their lives and tell their stories in ways presently unavailable.

Appendix begins on page 23

Survey of Current Data Collection Efforts

STATE-ADMINISTERED INSTRUMENTS

States currently have the opportunity to collect SOGI data through two critical health surveys coordinated by the U.S. Centers for Disease Control and Prevention (CDC): the Behavioral Risk Factor Surveillance System (BRFSS)³⁸ and the Youth Risk Behavior Surveillance System (YRBSS).³⁹

The BRFSS is the world's largest continuously conducted health survey system in the world and collects behavioral health risk data in all 50 states, the District of Columbia, and five U.S. Territories.⁴⁰ Due to the sheer breadth of this surveillance system, it is considered the premier source of health data and is used by every state to establish and track local health objectives, plan health programs, implement disease prevention and health promotion activities, and monitor trends.⁴¹ Additionally, nearly twothirds of states use BRFSS data to support health-related legislative efforts.⁴²

In 2013, the CDC developed a BRFSS optional question module on sexual orientation and gender identity. Although the BRFSS is federally-coordinated, states have the freedom to pick and choose which question modules to include and may add questions of their own.⁴³ According to the Human Rights Campaign's review of the latest BRFSS data, only 25 states and one U.S territory incorporated the CDC-approved optional SOGI question

module,⁴⁴ and at least 6 other jurisdictions asked questions on sexual orientation that differed from the CDC SOGI optional question module.⁴⁵ If every state and participating territory incorporated the CDC-approved optional SOGI question module as-is, the BRFSS would be an even more comprehensive tool, allowing for new insights on the health of America's LGBTQ population.

The YRBSS was developed in 1990 and focuses on health-risk behaviors among youth and young adults.46 This data collection effort is comprised of both a national Youth Risk Behavior Survey (YRBS) conducted by the CDC as well as a standard YRBS conducted by states and localities. Although the CDC formally added questions on sexual orientation and gender of sexual contacts to both the national and standard YRBS in 2015, states retain the option of not including these sexual orientationrelated questions in their YRBS. States should ensure that their YRBS questionnaires include these vital measures on sexual orientation. It is also important to note that the national and standard YRBS does not formally include a gender identity measure. However, in the 2017 YRBS cycle, the CDC allowed states and local urban school districts to pilot a question on transgender identity.⁴⁷ 10 states and nine large urban school districts (including District of Columbia Public Schools) piloted this question and the CDC recently released an analysis of this data.48 The CDC should work to ensure that its recently-piloted measure on gender identity remains on track for formal addition to both the national and state YRBS as soon as possible.

The above discussion reiterates the alarming reality that state laws, state regulations, and state participation in federally-coordinated data collection efforts fall disturbingly short of comprehensively including LGBTQ people.



•••	•••
•••	•••
•••	•••
•••	•••
•••	••
•••	••
•••	•••

Failure to include sexual orientation and gender identity in surveys that collect demographic data brings about very real and dire consequences for LGBTQ Americans.

• •	••
• •	••
• •	••
• •	••
• •	••
• •	••
• •	••





12 | HRC.ORG

.

• • • • • • • •

LGBTQ-INCLUSIVE DATA COLLECTION: A LIFESAVING IMPERATIVE

FEDERALLY-ADMINISTERED INSTRUMENTS

Data collection instruments administered directly by the federal government are many and wide-ranging.

In order to help make sense of the federal data collection landscape as it relates to LGBTQ Americans, the Office of Management and Budget (OMB) convened the Federal Interagency Working Group on Measuring Sexual Orientation and Gender Identity (Working Group) in April of 2015.⁴⁹ Apart from the BRFSS and YRBSS discussed in the previous section, the Working Group identified nine federally-administered surveys⁵⁰ and one study that included measurements on sexual orientation and/or gender identity as of 2016.⁵¹ These include the:

- Health Center Patient Survey;
- National Adult Tobacco Survey;
- National Health and Nutrition Examination Survey;
- National Health Interview Survey;
- National Inmate Survey;
- National Crime Victimization Survey;
- National Survey of Family Growth;
- National Survey on Drug Use and Health;
- National Survey of Older Americans Act Participants; and
- Population Assessment of Tobacco and Health.

All of these data collection efforts include measurements on sexual orientation, but only five collect gender identity information.⁵³ As noted earlier, the Trump administration has limited SOGI data collection in the National Crime Victimization Survey and attempted to eliminate SOGI measures from the National Survey of Older Americans Act Participants since the Working Group report. Furthermore, although not mentioned in the Working Group report, the Federal Bureau of Investigation annually collects data voluntarily submitted by states and localities on SOGI-based hate crimes.⁵⁴

The above list of SOGI-inclusive federal data collection efforts represent a paltry portion of existing federal surveys that include demographic data.

It is particularly harmful that SOGI measures are omitted from the country's largest demographic data collection endeavors—the decennial U.S. Census and the American Community Survey.⁵⁵

Recommendations

It is clear that government officials have failed the LGBTQ community when it comes to ensuring equal treatment in data collection efforts.

Comprehensive laws on every level of government are the most effective first step in ensuring that LGBTQ people are recognized and that their unique needs are adequately addressed. In general, municipalities, states, and the federal government can and should promulgate laws and policies that require their respective data collection efforts to be fully inclusive of the LGBTQ community. At a minimum, such laws should:

- Mandate that SOGI data be collected alongside other demographic data in relevant existing and new surveys administered by the government, its constituent bodies, and all recipients of public funds;
- Require that all government reports analyzing survey data appropriately include assessments on SOGI data;
- Ensure that SOGI questions, like other demographic measures, are non-mandatory in nature for respondents;
- Protect the privacy and confidentiality of participants who respond to SOGI questions and ensure anonymity where possible;
- Direct law enforcement agencies to report SOGIinclusive hate crime data to the FBI annually;
- Require periodic review of SOGI data collection practices to ensure conformance with evolving best practices; and
- Allocate sufficient resources for government entities to achieve the aforementioned goals.

City, state, and federal officials should consider regulatory action to achieve the above objective to the greatest possible extent if comprehensive legislation is not in effect.

Ultimately, it is incumbent on the federal government to lead by example.

Executive action should be taken to require recipients of federal funds to include LGBTQ populations in publicly-funded data collection efforts. Importantly, as the federal agency charged with overseeing and ensuring the inclusivity and efficiency of all federal statistical efforts, OMB should issue a statistical directive requiring the inclusion of sexual orientation and gender identity measures where data on sex is collected. This directive should outline the best practices for asking SOGI questions as outlined below. Last but not least, comprehensive legislation like the LGBTQ Data Inclusion Act should be swiftly enacted to augment and solidify these regulatory steps. Municipalities, states, and the federal government can and should promulgate laws and policies that require their respective data collection undertakings to be fully inclusive of the LGBTQ community.

Best Practices: Asking Questions on Sexual Orientation and Gender Identity

While it is imperative to include LGBTQ metrics in data collection efforts, information regarding sexual orientation and gender identity is highly personal in nature. The following principles should be kept in mind when incorporating LGBTQ metrics in data collection instruments.

Framing

An individual's sexual orientation and gender identity is only ascertainable and identifiable by that individual. This is why it is important to frame questions in a way that emphasizes self-identification:



Open-Ended Options

As demonstrated in the examples above, individuals vary greatly in the labels they assign to describe their sexual orientation and gender identity. To the extent compatible with your study or data collection needs, allowing an open-ended response for those that utilize a different label—or no label at all—can elicit a more accurate and honest response.

Self-Administration

Whenever possible, questions relating to sexual orientation and gender identity should be placed in self-administered portions of data collection instruments. This allows respondents to feel more comfortable in answering these questions candidly.

Privacy, Confidentiality, and Anonymity

Privacy, confidentiality, and anonymity are central principles that should be kept in mind when eliciting information on survey respondents' sexual orientation and gender identity. LGBTQ individuals may not feel safe being open about their sexual orientation or gender identity. Accordingly, assurances of privacy, confidentiality, and anonymity (wherever possible) both on the data collection instrument itself as well as through the process of the survey administration (e.g., privacy booths for surveys administered physically in a central space) carry a high premium.

Voluntary Response

Because of the deeply personal nature of sexual orientation and gender identity, and due to continued discrimination against LGBTQ people, questions relating to one's sexual orientation or gender identity should be non-mandatory for the respondent, like other demographic measures.

Intersectionality

It is important to be keenly aware of intersectionality when collecting and analyzing data on LGBTQ populations. LGBTQ people hail from every walk of life, representing every race, ethnicity, religion, age, ability, and socioeconomic background. Implications of these layered identities should be built into data collection instruments' composition and methodology. It is vital to know, for instance, that some racial or ethnic groups may utilize different terminology to describe being LGBTQ.⁵⁸

Moreover, socioeconomic considerations should factor into how information on sexual orientation and gender identity is gathered, assessed, and reported. The unfortunate reality is that LGBTQ people face disproportionately high levels of social and economic marginalization. One primary way in which this reality manifests is in the disproportionately high representation of LGBTQ people among those experiencing homelessness. It is therefore imperative that data collection efforts incorporate sampling strategies that reach people experiencing homelessness in order to avoid selection bias. Additionally, the unique circumstances and difficulties faced by older LGBTQ adults and LGBTQ people living with disabilities should be factored into survey design, administration, and analysis.

TERMINOLOGY

Sexual Orientation

An inherent or immutable enduring emotional, romantic or sexual attraction to other people.

Gender Identity

One's innermost concept of self as male, female, a blend of both or neither—how individuals perceive themselves and what they call themselves. One's gender identity can be the same or different from one's sex assigned at birth.

Gender Expression

External appearance of one's gender identity, usually expressed through behavior, clothing, hairstyle or voice, and which may or may not conform to socially defined behaviors and characteristics typically associated with being either masculine or feminine.

Transgender

An umbrella term for people whose gender identity and/or gender expression is different from cultural expectations based on the sex they were assigned at birth. Being transgender does not imply any specific sexual orientation. Therefore, transgender people may identify as straight, gay, lesbian, bisexual, etc.

Gender Non-Conforming

A broad term referring to people who do not behave in a way that conforms to the traditional expectations of their gender, or whose gender expression does not fit neatly into a category.

Gender Transition

The process by which some people strive to more closely align their internal knowledge of gender with its outward appearance. Some people socially transition, whereby they might begin dressing, using names and pronouns and/or be socially recognized as another gender. Others undergo physical transitions in which they modify their bodies through medical interventions.

Conclusion

As aptly stated in the 2018 OMB annual federal statistical programs report, "statistical agencies and programs play a vital role in generating the data that the public, businesses, and governments need to make informed decisions.

Timely, accurate, and relevant statistical data are the foundation of evidence-based decision-making."⁵⁹ Given the central role that data collection occupies in virtually every aspect of government decision-making and resource allocation, failure to include sexual orientation and gender identity in surveys that collect demographic data brings about very real and dire consequences for LGBTQ Americans. Because the vast majority of states and the federal government do not currently mandate SOGI-inclusive data collection, LGBTQ Americans remain largely invisible to local, state, and federal officials who make decisions that directly affect their health, safety, and wellbeing. And since LGBTQ advocates and allies do not have access to thorough LGBTQ-inclusive data, their ability to effectively identify the most pressing issues facing LGBTQ Americans and hold the government accountable for addressing those issues is significantly impaired. It is long past time that officials on every level of government equally include all marginalized communities, including LGBTQ Americans, in all relevant data collection endeavors.

About the Author

Xavier Persad serves as senior legislative counsel at the Human Rights Campaign.

His work focuses on state and local law and policy, including legislation related to conversion therapy, data collection, hate crimes, and non-discrimination. Xavier is also the author of HRC's annual Municipal Equality Index publication.

Xavier earned a Bachelor of Social Work from the University of Central Florida and obtained his law degree from Florida A&M University College of Law. Xavier also holds a Master of Laws degree in Human Rights Law from the London School of Economics and Political Science. He is admitted to the Florida Bar.

©2019 BY THE HUMAN RIGHTS CAMPAIGN FOUNDATION

ISBN-13: 978-1-934765-52-4

The Human Rights Campaign Foundation owns all right, title and interest in and to this publication and all derivative works thereof. Permission for reproduction and redistribution is granted if the publication is (1) reproduced in its entirety and (2) distributed free of charge. The Human Rights Campaign name and the Equality logo are trademarks of the Human Rights Campaign. The Human Rights Campaign Foundation and design incorporating the Equality logo are trademarks of the Human Rights Campaign Foundation. When referencing this document, we recommend the following citation:

Persad, X. LGBTQ-Inclusive Data Collection: A Lifesaving Imperative. Washington, DC: Human Rights Campaign Foundation (2019).

Appendix

- Randall L. Sell & Jeffrey Blake Becker, Sexual Orientation Data Collection and Progress Toward Healthy People 2010, 91 Am. J. OF PUB. HEALTH 876, 876-882 (2010).
- ² Centers for Disease Control and Prevention, Youth Risk Behavior Surveillance System (YRBSS), CDC. Gov, https://www.cdc.gov/healthyyouth/ data/yrbs/index.htm (last visited Aug. 14, 2019).
- з *Id.*
- 4 *Id.*
- The YRBS questionnaire uses the 5 term sexual identity instead of sexual orientation. Additionally, it is important to note that before questions on sexual orientation and gender of sexual contacts were added to both the national and standard YRBS in 2015, states were free to add their own questions on sexual orientation to their YRBS or utilize an optional question proffered by the CDC in 1997. See Laura Kann, et al., Sexual Identity, Sex of Sexual Contacts, and Health Related Behaviors Among Students in Grades 9-12 - United States and Selected Sites, 2015, 65 CDC Surveillance Summaries 1, 20 (2016), http://dx.doi.org/10.15585/mmwr. ss6509a1 (last visited Aug. 14, 2019).
- 6 *Id.* at 20.
- 7 Id. at 79.
- As mentioned supra note 5, states were free to add their own sexual orientation-related questions before 2015. Massachusetts began adding its own sexual orientation-related questions in the early 1990s. Id. at 80.
- 9 *Id.* at 80.
- 10 MARISA HOTCHKISS & JESSICA PHELAN, USES

OF CENSUS BUREAU DATA IN FEDERAL FUNDS DISTRIBUTION 8 (United States Census Bureau, 1st ed. 2017).

- For more information, see HUMAN RIGHTS CAMPAIGN, The Imperative of Responsible Hate Crimes Reporting, in 2017 MUNICIPAL EQUALITY INDEX (2017), available at www.hrc.org/mei.
- California, Connecticut, the District 12 of Columbia, Hawaii, Illinois, Maine, Massachusetts, Minnesota, New Jersey, New Mexico, New York, Oregon, and Washington all have laws that mandate the reporting of hate crimes based on sexual orientation and gender identity. Arizona, Florida, Iowa, Louisiana, Maryland, Michigan, Nebraska, Rhode Island, and Texas have laws that require the reporting of hate crimes based on sexual orientation only. See HUMAN RIGHTS CAMPAIGN, 2018 STATE EQUALITY INDEX (2018), which can be found at www.hrc.org/sei.
- When this effort was announced, eight 13 New York state agencies collected or were updating their systems to collect LGBTQ demographic information in their clinical and survey instruments: the Department of Corrections and Community Supervision, the Department of Health, the Office for the Aging, the Office of Mental Health, the Office of Alcohol and Substance Abuse Services, the Office of Temporary and Disability Assistance, the Office of Children and Family Services, and the Office for People with Developmental Disabilities. Governor Cuomo Announces Multi-Agency State Effort to Address LGBT Disparities, NY.gov (July 23, 2014), https://www.governor.ny.gov/news/ governor-cuomo-announces-multiagency-state-effort-address-lgbtdisparities.
 - A.B. 959, 2015-2016 Reg. Sess. (Cal.

2015); A.B. 677, 2017-2018 Reg. Sess. (Cal. 2017).

- S.B. 473, 78th Leg. Assemb., Reg. Sess. (Or. 2014) (signed July 2015, effective Jan. 1, 2016). Though the bill only covers "sexual orientation," the term is defined to include gender identity. See ORS § 174.100.
- A. 3739, 217th Leg. (N.J. 2018) (passed in 2018).
- ¹⁷ C.B. 22-0840, 22nd Council, Reg. Sess. (D.C. 2019).
- Sexual Orientation and Gender Identity Equity Group (SOGI Equity), State of Rhode Island Department of Health, http://www.health.ri.gov/programs/ detail.php?pgm_id=1106 (last visited Oct. 15, 2018) (listing one of the group's tasks as "[e]nsur[ing] that [Rhode Island's] health surveillance systems include questions about sexual orientation and gender identity.")
- ¹⁹ See A.B. 2227, 202nd Leg., 2017-2018 Reg. Sess. (N.Y. 2017).
- A.B. 7929, 203rd Leg., 2019-2020
 Reg. Sess. (N.Y. 2019); S.B. 6321,
 203rd Leg., 2019-2020 Reg. Sess. (N.Y.
 2019).
- A.B. 650, Reg. Sess. (Cal. 2019); H.B. 0928, 101st Gen. Assemb, (III. 2019);
 A. 4870, 218 Leg. (N.J. 2019); S. 3383, 218 Leg. (N.J. 2019) , A. 4877, 218 Leg. (N.J. 2019) ; H.B. 320, Gen. Assemb. (Md. 2019); S.B. 0455, Gen. Assemb. (Md. 2019); H.B. 2648, 57 Leg., 1st Sess. (Okla 2019); S. 905, 191st Gen. Court (Mass. 2019); H. 2141, 191st Gen. Court (Mass. 2019); S.B. 430, 54 Leg., 1st Sess. (N.M. 2019); S. 47, Reg. Sess. (N.Y. 2019).
- 22 Office of Management and Budget, Statistical Programs of the United

STATES GOVERNMENT: FISCAL YEAR 2018 REPORT 6 (2018), https:// www.whitehouse.gov/wp-content/ uploads/2018/05/statisticalprograms-2018.pdf.

- Office of Management and Budget, Statistical Program & Standards, WHITEHOUSE.GOV (last visited April 12, 2019), https://www.whitehouse.gov/omb/ information-regulatory-affairs/statisticalprograms-standards/.
- The thirteen principal statistical agencies 24 are: the Bureau of the Census, Bureau of Economic Analysis, Bureau of Justice Statistics, Bureau of Labor Statistics, Bureau of Transportation Statistics, Economic Research Service, Energy Information Administration, National Agricultural Statistics Service, National Center for Education Statistics. National Center for Health Statistics, National Center for Science and Engineering Statistics, Office of Research, Evaluation, and Statistics, and the Statistics of Income. See Office of MANAGEMENT AND BUDGET, STATISTICAL PROGRAMS OF THE UNITED STATES GOVERNMENT: FISCAL YEAR 2018 REPORT (2018).
- 25 31 U.S.C. 1104(d); 44 U.S.C. 3504(e).
- Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity, 62 Fed. Reg. 58782 (October 30, 1997), https://www. govinfo.gov/content/pkg/FR-1997-10-30/ pdf/97-28653.pdf.
- 27 Gary J. Gates, LGBT Data Collection Amid Social and Demographic Shifts of the US LGBT Community, NCBI (Aug. 2017), https://www.ncbi.nlm.nih.gov/ pmc/articles/PMC5508189/#bib2.
- Administration for Community Living (ACL) Notice, 82 Fed. Reg. 28491 (June 22, 2017), https://www.federalregister. gov/documents/2017/06/22/2017-13030/ agency-information-collection-activitiessubmission-for-omb-review-commentrequest-revision-of-a.
- Madd Sedensky, Federal Surveys Trim LGBT Questions, Alarming Advocates, APNEWS.COM (March 20, 2017), https:// apnews.

- Housing and Urban Development (HUD)
 Department Notice, 82 Fed. Reg.
 13359 (March 10, 2017), https://www.
 govinfo.gov/content/pkg/FR-2017-03-10/
 pdf/2017-04788.pdf; Alec MacGillis,
 Is Anybody Home at HUD?, New York
 MAGAZINE (August 21, 2017), http://
 nymag.com/intelligencer/2017/08/
 ben-carson-hud-secretary.
 html?gtm=bottom>m=bottom.
- Hansi Lo Wang, U.S. Census To Leave Sexual Orientation, Gender Identity Questions Off New Surveys, NPR (Mar. 29, 2017), https://www.npr.org/sections/ thetwo-way/2017/03/29/521921287/us-census-to-leave-sexual-orientationgender-identity-questions-off-newsurveys; UNITED STATES CENSUS BUREAU, SUBJECTS PLANNED FOR THE 2020 CENSUS AND AMERICAN COMMUNITY SURVEY (2017), https://www2.census.gov/library/ publications/decennial/2020/operations/ planned-subjects-2020-acs.pdf.
- ³² Coalition Comments HHS Strategic Plan, ALCU (Oct. 26, 2017), https:// www.aclu.org/sites/default/files/ field_document/2017-10-26_coalition_ comments_hhs_strategic_plan.pdf; Assistant Secretary for Planning and Evaluation (ASPE), Strategic Plan FY 2018-2020, HHS.gov (last updated February 28, 2018), https://www.hhs. gov/about/strategic-plan/index.html.
- OMB approved this change in February 2019. See Comments Requested: National Crime Victimization Survey (NCVS), 83 Fed. Reg. 15634 (April 11, 2018), https://www.govinfo.gov/content/pkg/FR-2018-04-11/pdf/2018-07448.pdf; see also Office of Mgmt and Budget, View ICR--OIRA Conclusion: OMB Control No. 1121-0111, REGINFO. Gov, https://www.reginfo.gov/public/do/PRAViewICR?ref_nbr=201803-1121-001# (last visited July 10, 2019).
- Adoption and Foster Care Analysis and Reporting System, 84 Fed. Reg. 16,572 (April 19, 2019) (to be codified at 45 C.F.R. pt. 1355).
- ³⁵ H.R. 5373, 114th Cong. (2016); S. 3134, 114th Cong. (2016); H.R. 3273, 115th Cong. (2017); S. 1570, 115th Cong. (2017); S. 1980, 116th Cong., 1st Sess.

(2019).

- ³⁶ H.R. 3280, 116th Cong., 1st Sess. (2019).
- This bill was first introduced as the LGBT Pride Act. H.R. 5855, 114th Cong., 2nd Sess. (2016).
- Centers for Disease Control and Prevention, About RFSS, CDC.gov (last visited Feb. 27, 2019), https://www.cdc. gov/brfss/about/index.htm
- ³⁹ Centers for Disease Control and Prevention, Youth Risk Behavior Surveillance System, CDC.gov (last visited Feb. 27, 2019), https://www.cdc. gov/healthyyouth/data/yrbs/index.htm
- 40 Centers for Disease Control and Prevention, BRFSS Today: Facts and Highlights, CDC.gov (last visited Feb. 27, 2019), https://www.cdc.gov/brfss/ about/brfss_today.htm. These territories include Puerto Rico, the U.S. Virgin Islands, Guam, American Samoa, and Palau.
- 41 Centers for Disease Control and Prevention, BRFSS Frequently Asked Questions: 4. What is Done With This Information?, CDC.gov (last visited Feb. 27, 2019), https://www.cdc.gov/brfss/ about/brfss_faq.htm.
- 42 Id.
- 43 Behavioral Risk Factor Surveillance System: BRFSS Questionnaires, CTR. FOR DISEASE CONTROL AND PREVENTION (last reviewed Feb 5, 2019), https://www.cdc. gov/brfss/guestionnaires/index.htm.
- ⁴⁴ Centers for Disease Control and Prevention, 2016 BRFSS Modules Used by Category, CDC.gov (last visited Feb. 27, 2019), https://www.cdc.gov/brfss/ questionnaires/modules/category2016. htm; California, Connecticut, Delaware, Georgia, Guam, Hawaii, Idaho, Illinois, Indiana, Iowa, Kentucky, Louisiana, Massachusetts, Minnesota, Mississippi, Missouri, Nevada, New York, Ohio, Pennsylvania, Rhode Island, Texas, Vermont, Virginia, Washington, Wisconsin.

- ⁴⁵ Alaska, Colorado, Michigan, North Carolina, Utah, and New Mexico.
- 46 Nancy D. Brenner, et al., Methodology of the Youth Risk Behavior Surveillance System – 2013, 65 CDC RECOMMENDATIONS AND REPORTS 1, 13 (2013).
- 47 Kellan Baker & Margaret Hughes, Sexual Orientation and Gender Identity Data Collection in the Behavioral Risk Factor Surveillance System, CENTER FOR AMERICAN PROGRESS (March 29, 2016), https://www.americanprogress.org/ issues/lgbt/reports/2016/03/29/134182/ sexual-orientation-and-gender-identitydata-collection-in-the-behavioral-riskfactor-surveillance-system/.
- 48 Id.
- 49 Id.
- 50 These ten states are: Colorado, Delaware, Hawaii, Maine, Maryland, Massachusetts, Michigan, Rhode Island, Vermont, and Wisconsin. See HUMAN RIGHTS CAMPAIGN, 2018 STATE EQUALITY INDEX (2018), which can be found at www.hrc.org/sei.
- Shaun Donovan, Prepared Remarks of OMB Director Shaun Donovan, Williams Institute Spring Reception, President Barack Obama Archive on TheWhiteHouse.gov: Blog, (Jun. 18, 2015 1:42 PM), https:// obamawhitehouse.archives.gov/ blog/2015/06/18/prepared-remarksomb-director-shaun-donovan-williamsinstitute-spring-reception.
- 52 Current Measures of Sexual Orientation and Gender Identity (Federal Interagency Working Group Working Paper, 2016), https:// s3.amazonaws.com/sitesusa/wp-

content/uploads/sites/242/2014/04/ WorkingGroupPaper1_

CurrentMeasures_08-16.pdf. The report identified 11 total surveys, which included the YRBSS and BRFSS. Since these are administered by the states (though coordinated by the federal government) and since these surveys were discussed in the preceding *State-Administered Instruments* section of this report, they were not included in this count.

ld. at 5.

53

- This is a study as opposed to the aforementioned surveys. It is a national longitudinal study of tobacco use and how it affects the health of people in the United States. National Institutes of Health (NIH), PATH Study Info, NIH.gov (last visited March 1, 2019), https://pathstudyinfo.nih.gov/UI/ HomeMobile.aspx
- ⁵⁵ The five surveys that include gender identity are PATH, HCPS, NATS, NIS, and NCVS. The BRFSS also collects information on gender identity, but is excluded from this count since it is addressed in the preceding section.
- ⁵⁶ 34 U.S.C. § 41305(b)(1) ("the Attorney General shall acquire data, for each calendar year, about crimes that manifest evidence of prejudice based on race, gender and gender identity, religion, disability, sexual orientation, or ethnicity").
- 57 U.S. CENSUS BUREAU, AMERICAN COMMUNITY SURVEY: INFORMATION GUIDE (2017), https://www.census.gov/ content/dam/Census/programs-surveys/ acs/about/ACS_Information_Guide.pdf.
- 58 SEXUAL MINORITY ASSESSMENT RESEARCH TEAM (SMART), BEST PRACTICES FOR ASKING QUESTIONS ABOUT SEXUAL ORIENTATION ON SURVEYS 7-9 (2009),

https://williamsinstitute.law.ucla.edu/ wp-content/uploads/SMART-FINAL-Nov-2009.pdf.

59 GENDER IDENTITY IN U.S. SURVEILLANCE (GENIUSS), BEST PRACTICES FOR ASKING QUESTIONS TO IDENTIFY TRANSGENDER AND OTHER GENDER MINORITY RESPONDENTS ON POPULATION-BASED SURVEYS 16 (2014), https://williamsinstitute.law.ucla.edu/ wp-content/uploads/geniuss-reportsep-2014.pdf.

More research is needed to determine 60 whether community-level variances in the way people of color selfidentify affect the accuracy of data collection instruments that utilize "sexual orientation." "gender identity." and common associated terms. WILLIAMS INSTITUTE, LESBIANS, GAYS, BISEXUALS, AND TRANSGENDERS OF COLOR SAMPLING METHODOLOGY: STRATEGIES FOR COLLECTING DATA IN SMALL, HIDDEN. OR HARD-TO-REACH GROUPS TO REDUCE TOBACCO RELATED HEALTH DISPARITIES 19 (2008), https://williamsinstitute.law.ucla. edu/wp-content/uploads/LGBTReport-Dec-2008.pdf.

61 OFFICE OF MANAGEMENT AND BUDGET (OMB), STATISTICAL PROGRAMS OF THE UNITED STATES GOVERNMENT: FISCAL YEAR 2018 REPORT 3 (2018), https:// www.whitehouse.gov/wp-content/ uploads/2018/05/statisticalprograms-2018.pdf.

Appendix

Feature: A Data Desert

- Sell RL, Holliday ML. Sexual orientation data collection policy in the United States: public health malpractice. American journal of public health. 2014;104(6):967-9. Epub 2014/05/16. doi: 10.2105/ajph.2013.301814. PubMed PMID: 24825192; PubMed Central PMCID: PMCPMC4061997.
- Sell RL. Challenges and Solutions to Collecting Sexual Orientation and Gender Identity Data. American journal of public health. 2017;107(8):1212-4. Epub 2017/06/29. doi: 10.2105/ ajph.2017.303917. PubMed PMID: 28657779; PubMed Central PMCID: PMCPMC5508182.
- Fish JN, Turner B, Phillips G, 2nd, Russell ST. Cigarette Smoking Disparities Between Sexual Minority and Heterosexual Youth. Pediatrics. 2019;143(4). Epub 2019/03/14. doi: 10.1542/peds.2018-1671. PubMed PMID: 30862728; PubMed Central PMCID: PMCPMC6565340 conflicts of interest to disclose.
- Pistella J, Ioverno S, Russell ST. The role of peer victimization, sexual identity, and gender on unhealthy weight control behaviors in a representative sample of Texas youth. The International journal of eating disorders. 2019;52(5):597-601. Epub 2019/02/26. doi: 10.1002/ eat.23055. PubMed PMID: 30805974.
- Johns MM, Lowry R, Andrzejewski J, Barrios LC, Demissie Z, McManus T, et al. Transgender Identity and Experiences of Violence Victimization, Substance Use, Suicide Risk, and Sexual Risk Behaviors Among High School Students - 19 States and Large Urban School Districts, 2017. MMWR Morbidity and mortality weekly report. 2019;68(3):67-71. Epub 2019/01/25. doi: 10.15585/ mmwr.mm6803a3. PubMed PMID: 30677012; PubMed Central PMCID: PMCPMC6348759 potential conflicts of

interest. No potential conflicts of interest were disclosed.

- Cutuli JJ, Treglia D, Herbers JE.
 Adolescent Homelessness and
 Associated Features: Prevalence
 and Risk Across Eight States. Child
 psychiatry and human development.
 2019. Epub 2019/07/05. doi: 10.1007/
 s10578-019-00909-1. PubMed PMID:
 31270658.
- Fish JN, Schulenberg JE, Russell ST.
 Sexual Minority Youth Report High-Intensity Binge Drinking: The Critical Role of School Victimization. The Journal of adolescent health : official publication of the Society for Adolescent Medicine.
 2019;64(2):186-93. Epub 2019/01/21.
 doi: 10.1016/j.jadohealth.2018.07.005.
 PubMed PMID: 30660247.
- Olcon K, Kim Y, Gulbas LE. Sense of Belonging and Youth Suicidal Behaviors: What Do Communities and Schools Have to Do with It? Social work in public health. 2017;32(7):432-42. Epub 2017/07/21. doi: 10.1080/19371918.2017.1344602. PubMed PMID: 28723310.
- Coulter RW, Birkett M, Corliss HL, Hatzenbuehler ML, Mustanski B, Stall RD. Associations between LGBTQ-affirmative school climate and adolescent drinking behaviors. Drug and alcohol dependence. 2016;161:340-7. Epub 2016/03/08. doi: 10.1016/j. drugalcdep.2016.02.022. PubMed PMID: 26946989; PubMed Central PMCID: PMCPMC4792759.
- Perrotti J, Westheimer K. When the drama club is not enough : lessons from the Safe Schools Program for Gay and Lesbian Students. Boston: Beacon Press; 2001. 227 p. p.
- Foti K, Balaji A, Shanklin S. Uses of Youth Risk Behavior Survey and School

Health Profiles data: applications for improving adolescent and school health. The Journal of school health. 2011;81(6):345-54. Epub 2011/05/20. doi: 10.1111/j.1746-1561.2011.00601.x. PubMed PMID: 21592130.

- Meyer IH, Luo F, Wilson BDM, Stone DM. Sexual Orientation Enumeration in State Antibullying Statutes in the United States: Associations with Bullying, Suicidal Ideation, and Suicide Attempts Among Youth. LGBT health. 2019;6(1):9-14. Epub 2019/01/15. doi: 10.1089/ Igbt.2018.0194. PubMed PMID: 30638436; PubMed Central PMCID: PMCPMC6555145.
- Seelman KL, Walker MB. Do Anti-Bullying Laws Reduce In-School Victimization, Fear-based Absenteeism, and Suicidality for Lesbian, Gay, Bisexual, and Questioning Youth? Journal of youth and adolescence. 2018;47(11):2301-19. Epub 2018/08/18. doi: 10.1007/s10964-018-0904-8. PubMed PMID: 30117086.
- Proulx CN, Coulter RWS, Egan JE, Matthews DD, Mair C. Associations of Lesbian, Gay, Bisexual, Transgender, and Questioning-Inclusive Sex
 Education With Mental Health Outcomes and School-Based Victimization in U.S.
 High School Students. The Journal of adolescent health : official publication of the Society for Adolescent Medicine. 2019;64(5):608-14. Epub 2019/01/30. doi: 10.1016/j.jadohealth.2018.11.012.
 PubMed PMID: 30691941; PubMed Central PMCID: PMCPMC6478545.



