

California Department of Public Health

It Has Missed Opportunities to Collect and Report Sexual Orientation and Gender Identity Data

April 2023

REPORT 2022-102





CALIFORNIA STATE AUDITOR
621 Capitol Mall, Suite 1200 | Sacramento | CA | 95814



916.445.0255 | TTY 916.445.0033

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April 27, 2023 **2022-102**

The Governor of California President pro Tempore of the Senate Speaker of the Assembly State Capitol Sacramento, California 95814

Dear Governor and Legislative Leaders:

As directed by the Joint Legislative Audit Committee, my office conducted an audit of the California Department of Public Health's (Public Health) role in collecting, reporting, and using sexual orientation and gender identity (SOGI) data. We determined that Public Health has been slow to adopt and enforce standardized guidelines to ensure the consistent collection and reporting of SOGI data, which has limited its ability to identify and address health disparities among those in the lesbian, gay, bisexual, transgender, and queer or questioning population.

Public Health collects health-related demographic data using a variety of reporting forms, questionnaires, and surveys (forms), but the department has not had clear and consistent policies regarding how such forms should collect SOGI data. Of the 129 forms we reviewed, 105 were exempt from the requirement to collect SOGI data but were not prohibited from doing so, and only 17 of the remaining 24 forms collect complete SOGI data. The lack of consistent SOGI data collection procedures, and ultimately the low number of Public Health forms that currently collect SOGI data, indicate that changes to state law may be warranted to compel more consistent and useful SOGI data collection practices.

Public Health also has a limited ability to analyze and use the SOGI data that it does collect to implement and deliver critical services. It is unable to collect or export SOGI data for the majority of reportable communicable diseases in California because it has not resolved technical barriers that limit its electronic communicable disease surveillance system from collecting SOGI data. Instead of resolving the technical issues, the department plans to replace its current system with a new surveillance system in 2025. Finally, local health jurisdictions and health care providers reported that they needed guidance from Public Health regarding the collection of SOGI information and standardized SOGI definitions. However, Public Health has not provided them with such guidelines, training, or resources.

Respectfully submitted,

GRANT PARKS
California State Auditor

Selected Abbreviations Used in This Report

CalREDIE	California Reportable Disease Information Exchange
CDC	Centers for Disease Control and Prevention
DOIT Subcommittee	Department Operations Improvement Team Subcommittee on Demographic Data Collection
ECR	electronic case reporting
LGBTQ	lesbian, gay, bisexual, transgender, and queer or questioning
SOGI	sexual orientation and gender identity
STD	sexually transmitted diseases

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Summary

Results in Brief

The California Department of Public Health (Public Health) has been slow to adopt and enforce standardized definitions, guidelines, and training to ensure the consistent collection, analysis, and reporting of demographic data that details sexual orientation and gender identity (SOGI). As a result, the department and its branches, units, sections, programs, and divisions (branches) have limited ability to identify and address health disparities that exist among those in the lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ) population. The Legislature has said that it is in the best interests of the State to understand the full diversity of its residents and to collect accurate data to effectively implement and deliver critical services. Recent studies have found that consistent SOGI data collection and analysis allow organizations and agencies to identify groups within the LGBTQ population that are disproportionately underserved and to direct specific outreach and services to those groups. Beginning no later than July 2018, state law required certain state departments, including Public Health, to collect and report voluntarily provided self-identification about SOGI when they collect ancestry or ethnic origin information. Although Public Health made some initial efforts to implement the law by developing departmentwide guidance, it has not ensured that its various branches have consistently collected or reported SOGI data as state law intends.

Public Health collects health-related demographic data using a variety of reporting forms, questionnaires, and surveys, and we refer to these data collection methods as forms. The forms we reviewed covered a wide range of topics, from communicable diseases, such as foodborne illnesses and sexually transmitted diseases, to vaping-related chemical exposures and healthy eating. We identified 129 Public Health forms that collect ancestry or ethnic origin information and therefore may be required by law to collect SOGI data. However, after we informed Public Health that its branches were not collecting SOGI data for most of these forms, Public Health clarified its position on the particular forms required to collect SOGI data, asserting that 105 of the 129 forms fall under exemptions from the law that requires SOGI data collection. One exemption in state law permits, but does not require, Public Health to collect SOGI when the information is collected by a third-party entity, such as a local health jurisdiction or health care provider. Most of the forms that Public Health asserts are exempt from state law fall under this third-party exemption. This exemption severely limits the amount of SOGI data the department is required to collect and analyze.

The remaining 24 forms are required by law to collect SOGI data, yet seven do not collect complete SOGI data because of a lack of clear and consistent policies regarding SOGI data. Public Health created

Audit Highlights ...

Our audit of Public Health's role in collecting, reporting, and using sexual orientation and gender identity (SOGI) data highlighted the following:

- » The California Department of Public Health (Public Health) has been slow to adopt and enforce standardized definitions, guidelines, and training to ensure the consistent collection, analysis, and reporting of demographic data that details sexual orientation and gender identity (SOGI).
 - As result, Public Health has limited its ability to identify and address health disparities among those in the lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ) population.
- » Public Health collects SOGI data on only a small portion of the forms it uses to gather demographic data.
 - Of the 129 forms we reviewed, 105 were exempt, but not prohibited, from collecting SOGI data. Most of these forms were exempt because the data is collected by a third party, such as a local health jurisdiction. This exemption severely limits the amount of SOGI data the department is required to collect.
 - Lack of clear and consistent policies and procedures have also hindered the department's collection of SOGI data. Of the remaining 24 forms required to collect SOGI data, only 17 do so in a complete manner.

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- » Public Health's system for collecting and reporting data on communicable diseases, CalREDIE, is inadequate for collecting and reporting SOGI data.
 - Because of resource and technical limitations, Public Health cannot export the SOGI data it collects for over 100 of the 128 reportable disease conditions in CalREDIE.
 - Three of the largest local health jurisdictions in the State the counties of Los Angeles, San Francisco, and San Diego do not use CalREDIE to report certain diseases.
 - Instead of resolving the technical issues, the department plans to replace its current system with a new surveillance system in 2025.
- » Public Health has only made SOGI data available to the public from 17 of the forms we reviewed, and it has not reported directly to the Legislature any SOGI data from the forms we reviewed.
- » Despite their critical role in collecting SOGI information, Public Health has not provided guidelines, training, or resources to local health jurisdictions or health care providers regarding definitions for collecting SOGI information or for recommended questions and response fields.

guidance on the questions and responses that its forms should use to collect SOGI data, and the department initially stated that adherence to this guidance was mandatory. However, when we presented the initial results of our audit, Public Health then explained that its guidance was not mandatory and that Public Health forms could comply with state law in collecting SOGI without complying with the department's own guidance. Even so, absent any other criteria, we found it reasonable to use the departmentwide guidance to determine whether Public Health's forms were collecting complete SOGI data.

We also found that Public Health's system for collecting and reporting data on communicable diseases is inadequate for collecting and reporting SOGI data. In 2010 Public Health created the California Reportable Disease Information Exchange (CalREDIE), a statewide database and surveillance system for reporting communicable diseases. Laboratories, health care providers, and local health jurisdictions use CalREDIE to report communicable diseases to Public Health, and in fact, Public Health has said that laboratories report most new communicable disease cases in CalREDIE. However, state law does not require laboratories to collect and report SOGI data to Public Health when reporting certain diseases, and even if such a requirement existed, it is unlikely that laboratories would be able to report much SOGI data because laboratories rarely interact directly with patients and do not have the opportunity to solicit SOGI information from them. In 2022 Public Health launched a new reporting method to facilitate the transfer of data from health care providers directly to Public Health. However, this new reporting method is only limited to cases of COVID-19 and is unable to report SOGI data to CalREDIE because of technological barriers.

Further, three local health jurisdictions in the State—the counties of Los Angeles, San Francisco, and San Diego—do not use CalREDIE for some of their communicable disease reporting. Although those local health jurisdictions use other methods of data transfers to report communicable disease, we found in our review that Public Health was not receiving SOGI data from all of these local health jurisdictions. Finally, because of resource and technical limitations, Public Health can export from CalREDIE the SOGI data for only 27 of the 128 reportable disease conditions that CalREDIE tracks and is therefore limited in its ability to analyze and use the data in the system. Because Public Health has begun the process to replace CalREDIE, the department has not dedicated the resources to update CalREDIE.

Subject to certain limitations, Public Health has a legal requirement to report to the Legislature the SOGI data it collects and to make that data available to the public. However, Public Health has only made SOGI data from 17 of the forms we reviewed available to the public, and it has not reported directly to the Legislature any SOGI data related to these forms. Public Health's technical limitations prevent its branches from efficiently extracting and analyzing the SOGI data Public Health has collected,

and Public Health's branches explain that the insufficient amount and quality of SOGI data that they do receive prevents their analysis and reporting. Nevertheless, Public Health has not taken the necessary steps to improve its SOGI data collection processes, despite having the authorization to do so. For example, Public Health is permitted, but not required, to collect SOGI data when the data is collected by third-party entities. When surveyed, the local health jurisdictions and health care providers indicated that they needed guidelines from Public Health regarding the collection of SOGI information and standardized SOGI definitions. However, Public Health provides no guidelines, training, or resources to local health jurisdictions or health care providers regarding recommended questions and response fields or definitions for collecting SOGI information.

Agency Comments

Public Health generally agreed with the findings and recommendations in our report and indicated that it will work to improve its efforts in this area.

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Recommendations

The following are the recommendations we made as a result of our audit. Descriptions of the findings and conclusions that led to these recommendations can be found in the Audit Results section of this report.

Legislature

To ensure that Public Health's branches use the SOGI data it collects to identify and address disparities in health outcomes, and to provide Public Health with an efficient mechanism to fulfill its current reporting requirements, the Legislature should require Public Health to provide an annual report to the public and to the Legislature that includes descriptions of the following:

- Public Health's efforts to collect, analyze, and report SOGI data, including a comprehensive list of forms that are required to collect SOGI data, the level of compliance with SOGI data requirements for those forms, the forms exempt from these requirements, and the reasons for such exemptions.
- The status of any improvement or replacement of CalREDIE—Public Health's database used for statewide reporting of communicable diseases.
- The outcomes of data analyses that Public Health has performed or has allowed other qualified researchers to perform using the SOGI data it has collected.
- The steps Public Health has taken or has caused to be taken to improve services or program outcomes for underserved LGBTQ populations.
- Until fully implemented, the progress Public Health has made in implementing recommendations from this audit report.

To ensure that Public Health collects sufficient data to effectively implement and deliver critical services, the Legislature should amend the SOGI data collection law to require Public Health to collect SOGI data from third-party entities, including local health jurisdictions, on any forms or electronic data systems unless prohibited by federal or state law.

The Legislature should amend state law to allow voluntarily provided sexual orientation and gender identity data to be included with the immunization data that is reported to Public Health.

Public Health

To consistently collect accurate SOGI data, Public Health should do the following:

- Standardize its definitions and provide guidance on how its forms should ask
 questions related to sexual orientation and gender identity, guidance on the
 minimum categories or response options to be collected, and guidelines on how to
 aggregate and report responses.
- Complete and implement the goals of its 2022 SOGI workgroup.
- Periodically identify all of its forms and review whether the forms are required to collect SOGI data or whether a statutory exemption applies.
- Develop and implement procedures to review and approve its branches' SOGI data collection processes, including a review of branches' reasons for not collecting SOGI data.

Public Health should develop a process to verify that all local health jurisdictions that do not use CalREDIE are reporting SOGI data to Public Health and are complying with SOGI data reporting requirements by October 2023.

Public Health should develop an action plan to ensure that CalREDIE users and Public Health programs can extract SOGI data for all of the reportable disease conditions currently in CalREDIE by October 2023.

Public Health should work with local health jurisdictions and the future vendor of the new surveillance system by October 2023 to ensure that the system will be able to receive SOGI data from local health jurisdictions, and be able to extract and report SOGI data for all reportable disease conditions.

To ensure that its programs are using SOGI data to identify and address disparities in health outcomes, and to provide required information to the Legislature, Public Health should require regular reports from its branches that collect SOGI data; these reports should include the branches' efforts to record and report SOGI data, the outcomes of their SOGI data analyses, and the steps they have taken to improve their services or program outcomes for underrepresented populations.

To improve Public Health's ability to collect SOGI data, it should make the following available to local health jurisdictions and health care providers:

- A standardized definition, wording, and format of SOGI data questions and response fields.
- Direction for soliciting SOGI information and education in the importance of doing so.

Introduction

Background

In 2016 the National Institutes of Health designated sexual and gender minorities as a health disparity population, which means a population that disproportionately experiences differences in health outcomes that are often preventable. According to the Public Policy Institute of California, approximately 9 percent of adults in California, or 2.7 million people, identified in 2022 as lesbian, gay, bisexual or transgender, which the text box defines. In 2015 the State enacted a law requiring certain state agencies to collect and report sexual orientation and gender identity (SOGI) data under specified conditions. As a state department focused on improving health outcomes and decreasing health disparities in California, the California Department of Public Health (Public Health) the focus of this particular audit—is subject to this state law requiring SOGI data collection and reporting.

Health Disparities Among Those in the LGBTQ Population

Although SOGI data is not yet widely available to perform health outcome analyses, some studies have already established that individuals who identify as lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ) face significantly higher risks of a variety of health problems, including the leading causes of death in California in 2020: cancer, heart disease, and COVID-19. For example, the American Association for Cancer Research highlighted a study that analyzed data from the National Health Interview

CDC Definitions for Sexual Orientation and Gender Identity Terminology

Sexual Orientation: A person's sexual and emotional attraction to another person and the behavior and social affiliation that may result from this attraction.

Gender Identity: An individual's sense of self as man, woman, transgender, or other.

Gender Expression: How an individual chooses to present their gender to others through physical appearance and behaviors, such as style of hair or dress, voice, or movement.

LGBTQ: Acronym that refers to those who identify as lesbian, gay, bisexual, transgender, and queer or questioning.

Lesbian: A woman who is primarily attracted to other women.

Gay: A person who is attracted primarily to members of the same gender, often used to describe men who are attracted primarily to other men.

Bisexual: A person who is attracted to both people of their own gender and other genders.

Transgender: An individual whose current gender identity differs from the sex they were assigned at birth.

Queer: An umbrella term sometimes used to refer to the entire LGBTQ community.

Questioning: A person still discovering his or her or their sexual orientation, gender identity, or gender expression.

Cisgender: An individual whose current gender identity is the same as the sex they were assigned at birth.

Heterosexual or Straight: A man who is primarily attracted to women or a woman who is primarily attracted to men.

Source: CDC.

Survey from 2013 through 2016 and found that gay men had greater than 50 percent increased odds of a reported cancer diagnosis, and bisexual women had 70 percent increased odds of a reported cancer diagnosis, when compared to their respective heterosexual counterparts.¹

¹ American Association for Cancer Research, AACR Conference Examines Cancer Disparities in the LGBTQ Population, January 26, 2021, https://www.aacr.org/blog/2021/01/26/aacr-conference-examines-cancer-disparities-in-the-lgbtq-population, accessed on December 29, 2022.

Likewise, the American Heart Association reported in 2020 that adults in the LGBTQ population experience worse cardiovascular health relative to their cisgender heterosexual peers. Significantly, this report noted that current studies are limited because they rely on self-reported data from population-based surveys, so they do not capture the sociocultural and clinical factors relevant to understand the population's cardiovascular health. Further, a 2021 study from the Centers for Disease Control and Prevention (CDC) found that adults in the LGBTQ population experience a high prevalence of several health conditions that have been associated with severe COVID-19, such as cancer, kidney or heart disease, breathing issues, obesity, diabetes, hypertension, and stroke. The CDC study also acknowledged that COVID-19 surveillance systems have not captured SOGI data and that doing so would improve knowledge about disparities in infection and adverse outcomes that could have informed a more equitable response to the pandemic.

The Potential Benefits of Collecting and Analyzing SOGI Data

Several recent efforts demonstrate that collecting and analyzing SOGI data can help identify and understand the health and other disparities that people who identify as LGBTQ face and can offer direction to public health officials working to resolve these disparities. The UCLA Williams Institute has performed studies regarding the LGBTQ population using SOGI data from the California Health Interview Survey—an annual survey based on interviews, conducted continuously throughout the year, of approximately 20,000 California households—which has included SOGI data since 2015. Using surveys from 2015 through 2017, one UCLA Williams Institute study found that one in seven Californians who identify as gay or lesbian delayed or went without the prescription medications they needed, a higher incidence than the one-in-ten rate found in the heterosexual population. The study noted that the California Health Interview Survey asks respondents why they delayed or went without medical care in general, and that individuals who identified as lesbian, gay, or bisexual were more likely to report the main reason as "cost, lack of insurance, and other insurance reasons."

Analyzing SOGI data also allowed the nonprofit organization WestEd to delve deeper into the mental health disparities of students in the LGBTQ population.⁵ WestEd used the California Healthy Kids Survey to analyze the relationship between students' sexual orientation, gender identity, experiences of bullying and harassment, emotional well-being, and school climate in academic years 2017–19. The study

² Billy A Caceres et al, Assessing and Addressing Cardiovascular Health in LGBTQ Adults: A Scientific Statement From the American Heart Association, Circulation, October 2020, <doi:10.1161/CIR.00000000000014>.

³ Kevin C. Heslin, PhD; Jeffrey E. Hall, PhD; Centers for Disease Control and Prevention, Sexual Orientation Disparities in Risk Factors for Adverse COVID-19-Related Outcomes, by Race/Ethnicity—Behavioral Risk Factor Surveillance System, United States, 2017-19; Morbidity and Mortality Weekly Report, Vol.5, No.5, February 5, 2021; accessed on December 28, 2022, http://dx.doi.org/10.15585/mmwr.mm7005a1.

⁴ Brad Sears and Kerith Conron, *LGBT People & Access to Prescription Medications*, The Williams Institute, December 2018, accessed on December 2022, < https://williamsinstitute.law.ucla.edu/wp-content/uploads/LGBT-Access-Prescription-Meds-Dec-2018.pdf>.

⁵ T. Hanson et al., Understanding the Experiences of LGBTQ Students in California, WestEd, San Francisco, CA, 2019; accessed on December 28, 2022 from < https://www.wested.org/wp-content/uploads/2019/10/Understanding-Experience-of-LGBTQ-Students-in-California.pdf>.

found that students in the LGBTQ population lack strong school supports, such as opportunities for meaningful participation, promotion of parental involvement, and caring adult relationships, and that their greater exposure to violence and harassment may account for the disparities in their mental health, school engagement, and academic performance when compared with their heterosexual cisgender peers. These findings could help target services that will significantly reduce the challenges that these students face.

In addition to academic and nonprofit organizations' efforts to identify and address the challenges that people in the LGBTQ population face, some government entities have also worked to address some of these concerns through the evaluation of SOGI data. The San Francisco Department of Homelessness and Supportive Housing has gathered substantial SOGI data and has implemented LGBTQ-targeted initiatives. These initiatives have led to a 33 percent increase, from the previous year, in LGBTQ households accessing permanent housing solutions. Public Health's Office of AIDS has also used SOGI data to identify vulnerable populations, and as a result, Public Health has implemented the PrEP/PEP Navigator Project to provide direct services to people in these specific priority populations, including transgender women. Navigator Projects allow physicians, health educators, and outreach workers to collaborate in identifying and addressing barriers to successful treatment.

Public Health's Efforts to Implement State Law Requiring the Collection and Reporting of SOGI Data

The Legislature has acknowledged the need to collect accurate SOGI data to understand. report, and apply that data for the enhancement and improvement of public services. Accordingly, in 2015 state law required certain state agencies to collect and report voluntarily provided SOGI information when they collect demographic data directly or by contract regarding the ancestry or ethnic origin of Californians. For Public Health, this collection was to begin no later than July 2018, and the text box lists exemptions to this requirement. State law also requires that any electronic tool that a county, city, or district health officer uses to report cases of certain communicable diseases to Public Health include the capacity to collect and report any SOGI data it receives from health care providers.

Public Health further requires health care providers and local health jurisdictions to report SOGI data when reporting on certain diseases

Exemptions to SOGI Data Collection

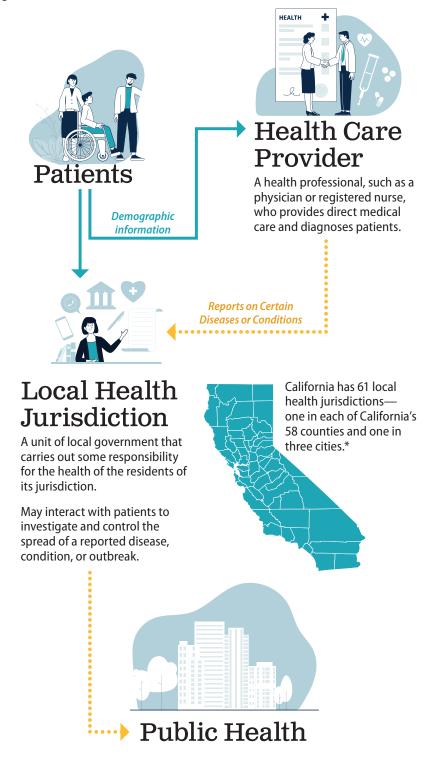
Public Health may, but is not required, to collect SOGI demographic data under any of the following circumstances:

- When demographic data collection categories are pursuant to and defined by a federal program or survey.
- When demographic data is collected by other entities, including the following:
 - State offices, departments, and agencies not required to collect SOGI data.
 - Third-party entities, including, but not limited to, private employers who provide aggregated data to a state department.
 - Surveys administered by third-party entities and where Public Health is not the sole funder.

Source: State law.

or conditions, as Figure 1 demonstrates. Specifically, Public Health's regulation requires that health care providers report to the local health officer for the jurisdiction

Figure 1Roles and Responsibilities in the Collection and Distribution of Key Demographic Information When Reporting Certain Diseases or Conditions



Source: State law, CDC, Public Health.

^{*} The cities of Berkeley, Long Beach, and Pasadena have local health jurisdictions.

where the patient resides certain demographic information about the patient, including the following: the name of the disease or condition, the date of onset and diagnosis, and the patient's Social Security number, race, ethnicity, current gender identity, sex assigned at birth, and sexual orientation, if known. Further, Public Health requires every local health officer to report to Public Health both a summary report regarding the weekly number of cases and an individual case or outbreak report of a listed disease. In general, the individual case report must contain SOGI information.

Public Health collects demographic data to fulfill its mission to advance the health and well-being of California's diverse people and communities. Public Health's almost 4,000 employees work in 20 centers, divided into branches, units, sections, programs, and divisions (branches) that implement numerous programs related to health and well-being, such as disease education and prevention, food safety, vital records management, and oversight and licensing of health care facilities and laboratories. Public Health gathers demographic data from many sources, including local health jurisdictions, laboratories, health care providers, and contractors, using a variety of reporting forms, questionnaires, and surveys; we refer to these data collection methods as forms.

In response to the state law requiring changes to the collection and reporting of demographic information, including the collection of voluntarily provided SOGI information, Public Health's Department Operations Improvement Team Subcommittee on Demographic Data Collection (DOIT subcommittee) began meeting in 2016. Its purpose was to identify and address operational issues, to develop a common approach and solution across Public Health, and to coordinate the implementation of this additional demographic data collection. In 2017 the DOIT subcommittee provided guidelines for SOGI questions and response fields to collect data, as the text box shows. The DOIT subcommittee delegated the responsibility to Public Health's individual branches to complete the implementation of the SOGI questions and response fields on the department's many forms. However, in 2022



Public Health concluded that its implementation had not been sufficient, and it formed another internal workgroup to better implement state law in its collection of SOGI data.

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Audit Results

Public Health Collects SOGI Data in Only a Small Portion of the Forms It Uses to Gather Demographic Data

Public Health has the opportunity to collect SOGI data that can be used to potentially improve health outcomes for California's LGBTQ population. However, because of state law exemptions that in many circumstances permit Public Health to collect SOGI data but do not require it to do so, and because of inconsistent SOGI data collection policies or processes, Public Health often does not collect SOGI data on the forms that already collect ancestry and ethnic origin data. We identified 129 forms that collect ancestry or ethnic origin information and therefore may be required by law to collect SOGI data. However, 105 of the 129 forms fall under exemptions from the law requiring SOGI data collection. As a result, only 24 of the 129 forms were required by state law to collect SOGI data. Of these 24 forms, seven do not collect complete SOGI data because Public Health lacks clear and consistent policies regarding SOGI data collection. This lack of consistent SOGI data collection procedures, and ultimately the low number of Public Health forms that actually collect SOGI data collection practices.

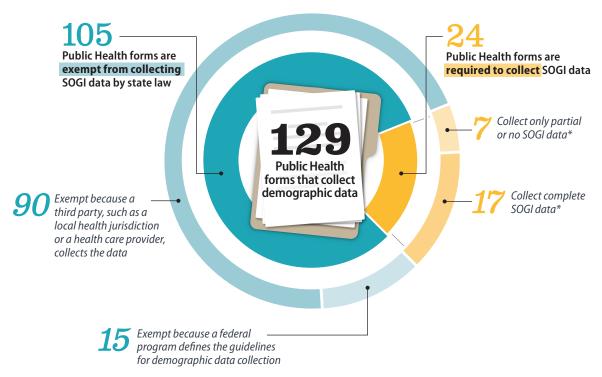
Public Health's Lack of Consistent SOGI Data Policies and Procedures Has Hindered Its Ability to Collect SOGI Data

Public Health has not ensured that some forms required to collect SOGI data contain the questions necessary to do so, in part because it lacks clear and consistent policies regarding collecting such data. State law requires that Public Health collect voluntarily provided SOGI data in the course of collecting ancestry and ethnic origin data, and the law was drafted to give Public Health the flexibility to implement its overall goal. As Figure 2 shows, we identified 129 Public Health forms that collect ancestry or ethnic origin data, of which only 24 are required to collect SOGI data, according to Public Health. The 129 forms we reviewed covered a wide range of topics, from communicable diseases, such as foodborne illness and sexually transmitted diseases, to vaping-related chemical exposures and healthy eating for children. Such forms, created and updated by Public Health, reach a broad cross-section of the State's residents.

Of the 24 forms that are required to collect SOGI data, seven do not collect complete SOGI data, as Figure 2 shows. Since the state law requiring SOGI data collection does not dictate the exact questions or responses that are required to collect SOGI data, we turned to Public Health's internal efforts to define complete SOGI data. In May 2017, Public Health's DOIT subcommittee issued guidance that proposed three specific questions and response fields when collecting SOGI data, in order to have a common approach across the department. Although Public Health's director's office stated in December 2022 that this guidance was mandatory, the department later asserted that the guidance was not mandatory and that forms may comply with law even if they do not ask all three questions. This example demonstrates Public Health's lack of clarity and consistency in its SOGI data collection approach.

Figure 2

Most of Public Health's Forms May, But Are Not Required to, Collect SOGI Data



Source: State law and Public Health guidelines and documentation provided by Public Health.

Nevertheless, in the absence of clear and consistent requirements from Public Health, we determined that the DOIT subcommittee's guidance was reasonable for assessing whether a form is collecting complete SOGI data. Of the 24 forms required by law to collect SOGI data, seven forms do not include all three of the subcommittee's SOGI questions. According to the chief deputy director of operations, Public Health has not yet developed a departmentwide policy or guidelines for how it will collect SOGI data. Instead, the department relies on each of its centers to implement the recommendations of the subcommittee and relies on the individual programs to monitor compliance with state law. Without a departmentwide policy, and without monitoring compliance with that policy, Public Health cannot ensure consistent compliance with the law or ensure the consistent collection of SOGI data.

Public Health's regulations generally require that case report forms, which collect additional demographic and disease-specific information from individuals experiencing certain infectious diseases, collect SOGI data. These case report forms comprise 75 of the 129 forms we reviewed in the course of this audit. In October 2022, and again in February 2023, Public Health's legal counsel affirmed to us that the department's regulations required these case report forms to collect SOGI data.

We determined that to collect SOGI data, the forms must comply with state law and include the DOIT subcommittee's three questions: sex assigned at birth, sexual orientation, and gender identity.

Accordingly, we had initially determined that nearly all the case report forms we reviewed did not comply with Public Health's regulations. However, when we presented this list of forms to Public Health in February 2023, the department clarified its position to assert that only one form, the Confidential Morbidity Report Form, was required to collect SOGI information to comply with the department's regulations. The Confidential Morbidity Report does request demographic information, including complete SOGI information, and health care providers complete it when dealing with cases of certain diseases or conditions. According to the assistant chief legal counsel, Public Health does not believe that additional information, including SOGI information, needs to duplicate the demographic identification information already captured on the Confidential Morbidity Report. However, we found that the Confidential Morbidity Report did not consistently gather SOGI data. Specifically, we reviewed 100 electronic case files reports and found only 17 instances that included complete SOGI data. As a result, Public Health's reliance solely on the Confidential Morbidity Report to collect SOGI data limits the amount of SOGI data available to Public Health, and the additional case report forms—as discussed further in the next section—offer additional opportunities to collect SOGI information about individuals.

Public Health has begun to take steps to standardize its SOGI data collection through a new committee and a proposed reorganization. In 2022 Public Health determined that, despite the efforts of its DOIT subcommittee, there was still no consensus on how to collect SOGI data, so it created the SOGI data standardization workgroup (SOGI Workgroup) in February 2022. The SOGI Workgroup has three goals:

- To develop a document and data dictionary of best practices for collecting SOGI data, including direction about the wording of SOGI questions and response fields.
- To document best practices for displaying SOGI data.
- To develop a reference document detailing SOGI data standards for organizations outside of Public Health, including local health jurisdictions.

Although the SOGI Workgroup is reviewing a preliminary recommendation related to its first goal, Public Health does not have a time frame for completing or implementing these recommendations or for addressing the remaining two goals. Additionally, Public Health informed us that it was in the early stages of a restructure that would allow its Center for Health Statistics and Informatics to oversee a temporary task force that will focus on SOGI data collection and reporting across the department. However, Public Health could provide neither a clear timeline for the restructure nor any specifics about the goals and responsibilities of this task force. Completing the efforts of the SOGI Workgroup, even without the proposed new task force, would likely result in more and better SOGI data collection and reporting.

Exemptions in State Law Limit the Collection of SOGI Data

The state law exempting Public Health from collecting SOGI data when the data is collected by third parties permits Public Health to forgo additional opportunities to collect SOGI data and limits the amount of SOGI data the department is required to collect and analyze. According to Public Health, 15 of the 105 forms are exempt from collecting SOGI data because a federal program defines the guidelines for demographic data collection in those forms. The remaining 90 forms are exempt because a third party, such as a local health jurisdiction or a health care provider, collects the data, even though Public Health is responsible for creating and providing these forms. In fact, such forms as the California Cancer Registry, the Adult HIV/AIDS Case Report Form, and most infectious disease case report forms are all examples of forms that neither solicit nor are required to solicit SOGI information because the data is collected by local health jurisdictions or health care providers, as Figure 3 shows. According to several legislative analyses of the bill requiring SOGI data collection, the legislation was drafted to give the department flexibility in implementing its overall goal, authorizing Public Health to take necessary steps to expand its data collection. However, Public Health includes two critical categories of data collectors—health care providers and local health jurisdictions—under the "third-party" exemption, effectively applying the SOGI data collection requirements only to Public Health itself. Thus, while Public Health is permitted, but not required, to pursue many additional ways of obtaining SOGI data, in general it is not doing so.

Figure 3

State Law Does Not Require Public Health to Collect SOGI Data When the Data Is Collected by Third-Party Entities

Examples of Public Health forms that are **not required** to solicit SOGI information because the information is collected by:

Local Health Jurisdictions* or Health Care Providers*

Some forms **NOT** required to solicit SOGI data include:

- · California Cancer Registry
- HIV/AIDS Intake Form
- · COVID-19 Border Survey
- Other Infectious Diseases Case Report Forms, including:
 - Hepatitis
 - Anthrax

Examples of Public Health forms that are **required** to solicit SOGI information because it is directly collected from individuals by:

Public Health or Public Health Contractors

Some forms required to solicit SOGI data include:

- · Youth Marijuana Survey
- Adult Role Models Community Needs Survey
- · Online California Adult Tobacco Survey
- · Delayed Registration of Birth Form

Source: State Law, and Public Health policy.

* The state law requiring Public Health to collect SOGI data in the course of collecting ancestry or ethnic origin data permits, but does not require, it to collect SOGI data when the data is collected by third parties, such as local health jurisdictions and health care providers.

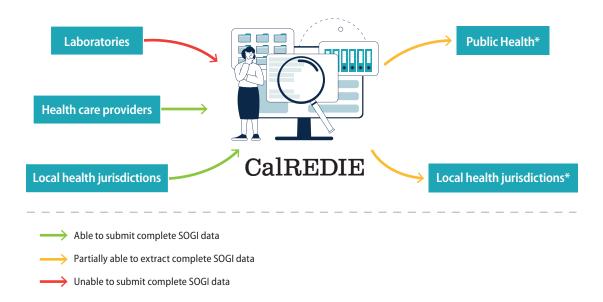
Public Health has asserted that existing regulations do not require that the additional case report forms it created to collect disease-specific information also collect SOGI data. As we note above, Public Health has developed 75 case report forms that supplement the Confidential Morbidity Report, obtain additional information on specific diseases, and request demographic information. According to Public Health, the Confidential Morbidity Report is sufficient to meet its regulatory reporting requirements and therefore there are no statutory or regulatory requirements for the case report forms to collect SOGI data.

Nevertheless, these case report forms offer an important, additional opportunity to collect SOGI data. As indicated earlier, we found that the Confidential Morbidity Reports that health care providers complete do not consistently contain SOGI information. Further, the local health jurisdictions of Sacramento County, Contra Costa County, and the city of Pasadena stated that they use additional case report forms when performing contact tracing and other follow-up with individuals. Moreover, the chief of the Policy and Viral Hepatitis Section at the Sexually Transmitted Diseases Control Branch (STD Control Branch) confirmed that these "supplemental" forms may be used to guide the questions that local health jurisdictions and health care providers ask when interacting with individuals and patients. Of the 54 local health jurisdictions that responded to our survey, 50 indicated that they collected SOGI information during contact tracing for communicable diseases or other follow-up with individuals. In contrast, only 36 of 54 local health jurisdictions responded that the SOGI information they collect was received from health care providers.

Public Health's reliance on the third-party exemption to assert that many of its forms do not need to collect SOGI data suggests that the exemption may be too broad. While it is sensible to continue to exclude programs from collecting SOGI data when federal requirements limit such collection, the third-party exemption gives Public Health an opportunity to forgo collecting SOGI data from the very entities central to obtaining the data. Thus, until Public Health is required to include SOGI data on its forms that collect other demographic data, regardless of who is using the form, Public Health will continue to miss opportunities to obtain complete SOGI data.

Unresolved Technical Issues Prevent SOGI Data Collection and Analysis

Public Health is unable to collect SOGI data for the majority of reportable communicable diseases in California because it has not resolved technical barriers that limit its electronic communicable disease surveillance system, the California Reportable Disease Information Exchange (CalREDIE), from collecting SOGI data. However, Public Health is currently also unable to analyze or extract complete SOGI data from that system, as Figure 4 shows. Public Health has not completed updates to the system, impeding its ability to analyze or report on health outcome disparities in the State's LGBTQ population.



Source: Public Health staff and auditor analysis of Public Health website and documentation provided by Public Health.

* Public Health and local health jurisdictions cannot access SOGI data for approximately 79 percent of the communicable diseases reported to CalREDIE.

Public Health implemented CalREDIE as a statewide database for electronic disease reporting and surveillance in 2010. Public Health makes CalREDIE available for local health jurisdictions, health care providers, and laboratories to provide information on cases of reportable diseases. Beginning in 2020, state law required that electronic reporting tools that county, city, or district health officers use to report cases of certain communicable diseases to Public Health should be able to collect and report SOGI data. Public Health updated CalREDIE in 2020 to allow the database to collect SOGI information. However, data protocols and other factors limit Public Health's ability to collect SOGI data from other systems.

Laboratories Are Not Required to Submit SOGI Data to Public Health and Are Unable to Do So

According to Public Health, laboratories generate nearly all new case reports in CalREDIE, but there are limitations to the demographic data that laboratories are able to provide. Although test requisitions that accompany specimens submitted for laboratory tests for certain diseases or conditions must include certain demographic information, such as gender and race, they are not required to contain SOGI information. In addition, although laboratories are required to include certain demographic information, including the patient's gender and race, when reporting cases of certain diseases to the local health jurisdiction and Public Health, laboratories are not required to report SOGI information in those instances. Further, even if laboratories were to receive SOGI information from health care providers,

they would be unable to report that data to Public Health because laboratories electronically transmit information to Public Health through CalREDIE using an international data standard called Health Level 7 (HL7). HL7 does not currently contain a standard for transmitting SOGI data.

For example, although Public Health worked with COVID-19 testing sites to use a registration form that includes SOGI questions, the data collected from those forms is not readily available to the department. Specifically, Public Health contracted with technology vendors to create online registration forms for patients to use when requesting COVID-19 tests from the community-based testing sites, and Public Health requires the community-based testing sites that it sponsors to use the online registration forms. The registration forms ask patients for identification information such as name, date of birth, and contact information, and demographic information such as race, ethnicity, and SOGI information, including questions about sex at birth, gender identity, and sexual orientation. However, Public Health is unable to automatically receive SOGI data from COVID-19 tests because all laboratories, including community-based drive-through sites, use HL7. As a result, when we requested reports to demonstrate the demographic data that the COVID-19 testing sites had collected, Public Health said it would need to ask its vendors for the data. Thus, while it has access to the data, it does not maintain it at Public Health.

Although there is a temporary solution to communicating SOGI data through HL7, neither Public Health nor laboratories are ready to use it. In June 2022, HL7 International—the organization that develops the HL7 standard—published a short-term solution that would allow laboratories to transfer SOGI data. However, according to CalREDIE's program manager, Public Health does not plan to adopt this short-term solution because it is incompatible with CalREDIE's current structure. The program manager explained that because Public Health plans to launch a new disease surveillance system that will replace CalREDIE in 2025, the department does not want to invest time and resources in updates to CalREDIE as it prepares to decommission it.

Furthermore, laboratories are not necessarily in a position to adopt the short-term solution. We spoke with three laboratories—a public health laboratory for a local health jurisdiction, a private laboratory that does business in California, and a private laboratory that does business across the nation. All three cited the need for significant investments of time and money to reconfigure their systems to obtain SOGI data. They also noted that laboratories rarely interact directly with the patient and that the most direct route for Public Health to receive data would be from the health care providers who directly communicate with the patient.

Public Health has recently instituted a new process to give health care providers a more direct means of reporting cases to Public Health, but the new process also uses HL7. In August 2022, Public Health launched electronic case reporting (ECR) for health care providers to report cases of COVID-19. ECR automatically generates a case report and sends it to CalREDIE from the patient's electronic health record. Public Health intends for ECR to replace paper-based methods of reporting from health care providers. According to the chief of the CalREDIE Surveillance Section, COVID-19 is the only reportable disease that ECR currently reports to CalREDIE as of February 2023.

The chief further confirmed that Public Health is currently in the process of developing a timeline for including additional reportable disease conditions to ECR. However, ECR uses a version of the HL7 standard that is specific to ECR but does not have the capacity to transmit complete SOGI data. In July 2022, HL7 published a newer version of the HL7 standard for trial use that would allow ECR to transmit data on gender identity and sex assigned at birth, but not sexual orientation. This means that even if Public Health were to update CalREDIE to the newer HL7 standard, it would still be unable to receive data on sexual orientation through ECR. According to the chief of the CalREDIE Surveillance Section, the lack of an HL7 standard for transmitting complete SOGI data prevents CalREDIE from collecting complete SOGI data from ECR, and Public Health has no plans to develop a solution to the technological issue because HL7 is the industry standard for health data exchange.

The lack of a complete HL7 SOGI standard is likely to remain a roadblock to the collection of SOGI data from laboratories or electronic health records for at least the next several years. Because HL7 is an international standard broadly used for electronic laboratory and case reporting, it is unlikely that Public Health will be able to abandon its use in favor of an alternative. According to the chief of the CalREDIE Stakeholder Support section, Public Health will continue to need to use HL7 to communicate with laboratories and electronic health records, even when it adopts its new surveillance system. Thus, it is even more imperative that Public Health avail itself of every opportunity to collect SOGI data outside of those two pipelines if it is to collect sufficient SOGI data to be usable. In particular, Public Health must ensure that its forms include SOGI data to allow health care providers and local health jurisdictions additional opportunities to collect and report SOGI data.

Some Local Health Jurisdictions Do Not Submit Data to Public Health Using CalREDIE

CalREDIE has additional system incompatibilities with other local health jurisdictions' data systems that limit the department's ability to access statewide SOGI data on communicable diseases. Public Health requires health care providers to report information on cases or suspected cases of certain diseases or conditions—such as anthrax, syphilis, and Lyme disease—to their local health officers, including SOGI information, if known. Public Health also requires local health officers to report information on certain diseases to Public Health, including SOGI information. Local health officers at 58 of the State's 61 local health jurisdictions report cases of all notifiable communicable diseases to Public Health using CalREDIE. According to the program manager of CalREDIE, the remaining three jurisdictions do not use CalREDIE in some cases:

- Los Angeles County does not use CalREDIE to report infectious diseases or some sexually transmitted diseases (STDs).
- San Francisco County does not use CalREDIE to report some STDs.
- San Diego County does not use CalREDIE to report infectious diseases.

A CalREDIE program manager explained that these three local health jurisdictions' data systems should exchange data with CalREDIE but that the counties lack the resources required to implement and maintain a data exchange. Public Health instructs local health jurisdictions that do not use CalREDIE to submit case reports to the department electronically or to send hard copy case report forms. The department manually consolidates the local health jurisdictions' data with CalREDIE data, which is a time-consuming process. For example, according to the chief of the Data Processing and Informatics Section for Public Health's COVID/MPX response team, the process to consolidate case information for just one disease condition, COVID-19, takes Public Health approximately 24 staff hours per week. Because of the manual process that Public Health must undertake to produce a statewide review for communicable diseases, the department does not have immediate access to information about communicable diseases for Los Angeles, San Diego, or San Francisco counties—three counties that together account for approximately 36 percent of the State's population, according to the 2020 U.S. Census.

As a result of the data exchange problems, local health jurisdictions are not supplying Public Health with complete SOGI data. Despite the assertion from Public Health's assistant chief counsel that local health jurisdictions that do not use CalREDIE are fulfilling their regulatory reporting requirements, we found that Public Health did not receive the SOGI data from some local health jurisdictions. For example, the STD Control Branch at Public Health does not receive complete SOGI information from Los Angeles or San Francisco counties for any cases of STDs. According to the chief of the Policy and Viral Hepatitis Prevention section at the STD Control Branch, the branch does not receive SOGI data from those counties because of a formatting issue in the data transfer. The chief further confirmed the branch has not resolved the technological issues preventing SOGI reporting because of multiple factors, including competing priorities such as Mpox epidemiology and surveillance.

Public Health Programs Cannot Readily Access SOGI Data Contained in CalREDIE

Public Health programs access data exports and reports from CalREDIE using the Data Distribution Portal (data portal), a web-based system to help users access data reports. According to the CalREDIE program manager, CalREDIE staff must manually update the data portal for each disease condition to extract complete SOGI data. As of February 2023, CalREDIE staff have updated only 27 of the 128 reportable disease conditions in the data portal to enable the system to extract complete SOGI data for those conditions. This means that Public Health cannot extract complete SOGI information for more than 100 communicable diseases—including anthrax, malaria, and Zika virus. This also means that Public Health programs are unable to access SOGI information for most of the disease conditions they oversee. For example, the Infectious Diseases Branch oversees approximately 50 communicable diseases listed in regulation yet cannot extract SOGI data for each of those diseases. In fact, the Infectious Diseases Branch could not even tell us the number of diseases for which it is able to extract SOGI data. According to the chief of the CalREDIE Stakeholder Support Section, Public Health lacks the time and resources to update

records for all diseases. However, the CalREDIE program manager added that it has prioritized updating the data portal for disease conditions that are current public health concerns, such as COVID-19 and Mpox.

Although Public Health has acknowledged the technical shortcomings of CalREDIE, CalREDIE's program manager confirmed that the department has not prioritized the time or resources to resolve the technical issues because some issues are impossible to resolve. This is because of the system's design and because the department plans to retire CalREDIE and replace it with a new surveillance system, the Future Disease Surveillance System (surveillance system), in October 2025. As of January 2023, the California Health and Human Services Agency and California Department of Technology have approved the first stage of Public Health's proposal to develop the new surveillance system. Public Health plans to start the procurement process to select a vendor to build the new system in May 2023 and should complete the procurement process in October 2023. Public Health estimates that the total cost of the new system will be about \$168 million. CalREDIE's program manager said Public Health plans to work with all local health jurisdictions for input on the new system in order to address the technological challenges that currently exist between CalREDIE and the local health jurisdictions that do not use CalREDIE to report all communicable diseases. When the system is complete, it will allow Public Health to have timely access to all local health jurisdictions' information on cases of reportable communicable diseases, including SOGI information, according to the chief of the CalREDIE Stakeholder Support section; however, completion is at least two years away.

Public Health Has Performed Little Analysis of or Reporting on the SOGI Data It Does Collect

State law requiring Public Health to collect SOGI data in the course of collecting ancestry or ethnic origin data also requires Public Health to report the SOGI data to the Legislature and make it available to the public, except for data that would permit identification of individuals or would result in statistical unreliability. Yet Public Health has made SOGI data available to the public from only 17 of the forms we reviewed, and it has not directly reported any SOGI data related to these forms to the Legislature. Additionally, Public Health has only performed internal analyses of SOGI data for four of the forms that we reviewed. Public Health's technical limitations prevent its branches from efficiently extracting and analyzing the SOGI data Public Health has collected, and its branches explain that they have not performed analysis or reporting of SOGI data because they lack a sufficient amount of SOGI data to report. For example, the Occupational Health Branch said that it would like to perform analysis using SOGI data but that it had not received enough data to perform quality analysis. Nevertheless, Public Health can do more, including maintaining a functioning electronic reporting system, to ensure that it receives a sufficient amount of quality SOGI data to analyze and report.

Although Public Health is both analyzing and publishing SOGI data from four of its forms, it has not reported any of this data directly to the Legislature. Three of these forms belong to the California Tobacco Control Branch, which collects SOGI data

on several of its surveys. For example, the California Tobacco Control Branch funded a UCLA study that analyzed and reported SOGI data collected from its California Native Hawaiian and Pacific Islander and LGBTQ Tobacco Survey. The analysis found that adults in the LGBTQ population reported higher exposure to secondhand tobacco smoke than the California adult population as a whole. This analysis, demonstrating how SOGI data can be used to identify specific disparities, may also contribute to the efforts to address those disparities. In fact, the chief of the Tobacco Control Branch stated that its analysis could be used to inform future projects and be part of presentations at conferences or in academic journals. Although the California Tobacco Control Branch makes SOGI data available to the public, it has not reported this data to the Legislature.

In contrast to conditions at Public Health, the city and county of San Francisco has taken significant steps to collect, analyze, use, and report on SOGI data. In 2016 San Francisco amended its administrative code to require certain departments and contractors that provide health care and social services to collect and record data concerning the sexual orientation and gender identity of the clients they serve, and further, require the covered departments to analyze and report to the city administrator the SOGI data that it collects, including SOGI data collected by contract or through grantees. To comply with this requirement, San Francisco departments—including the San Francisco Department of Public Health (SFDPH) publish annual reports on their collection of SOGI data. For example, reports from the San Francisco Department of Homelessness and Supportive Housing (SFHSH) include updates on efforts to record and report SOGI data due to COVID-19, the outcomes of SOGI data analysis, and the impact of initiatives to increase the LGBTQ populations' access to services. SFHSH's most recent annual report noted that its collection of SOGI data allowed it to identify disadvantaged LGBTQ groups and increase LGBTQ outreach and participation in its services.

Local Health Jurisdictions and Health Care Providers Need SOGI Data Collection Guidelines and Training

Public Health requires local health jurisdictions and health care providers to include SOGI information when reporting certain diseases or conditions, such as tetanus or syphilis. Despite the fact that local health jurisdictions and health care providers are responsible for collecting the data for the majority of Public Health's forms, Public Health's Director's Office acknowledged that the department has not provided departmentwide guidelines to local health jurisdictions or to health care providers on standardized language for SOGI questions and answers, on how to solicit SOGI information, or on the importance of collecting SOGI information.

In fact, some local health jurisdictions specifically cited a need for more guidelines and training. We surveyed the 61 local health jurisdictions regarding their SOGI data collection processes, and 54 (89 percent) completed the survey. Approximately one-third of local health jurisdictions responding to our survey had not received

⁶ Appendix A includes a summary of responses to selected survey questions.

guidelines or training from any federal, state, or local entity on SOGI data collection. In its survey response, the city of Berkeley suggested that Public Health should provide more outreach and training to both local health jurisdictions and health care providers, including support on how to standardize SOGI questions across all programs and departments. San Bernardino County said that allowing local health jurisdictions to develop their own SOGI questions and response fields produces inconsistency and confusion, and makes the data difficult to reconcile among different datasets. Without direction from Public Health, local health jurisdictions are unlikely to produce consistent and usable data. Nearly three-quarters of the local health jurisdictions responding to our survey noted that they do not have a standard set of questions, answers, or consistent language that they used across programs to collect SOGI data.

Similarly, Public Health has not provided health care providers with the guidelines and training they need. We conducted a survey of more than 1,900 CalREDIE users—primarily health care providers—regarding their challenges in collecting and reporting SOGI data. While only 119 (6 percent) responded, in our judgment the responses bear reporting. Only 11 of the responding health care providers replied that they had received guidelines from Public Health regarding SOGI data collection.⁷ Further, 44 of the health care providers' responses indicated that they would benefit from Public Health training and guidelines on SOGI data collection. For instance, several health care providers asked that Public Health provide training that explains the importance of collecting this information and how to ask patients these questions. In contrast, 16 of the health care providers responded that reporting SOGI information of patients was not relevant for communicable diseases. An infection control practitioner and a registered nurse said that they do not collect SOGI data for persons with communicable diseases because it is not relevant. One physician expressed concerns that collecting this information promotes discrimination. These health care providers' responses also demonstrate the need for Public Health to provide education on the significance of SOGI data collection and its benefit to patients.

Finally, some responders reported reluctance within their communities to asking questions related to sexual orientation and gender identity. For example, in our survey of local health jurisdictions, Calaveras and Sutter counties explained that they are rural communities where there is often sensitivity around answering questions regarding gender identity and sexual orientation. Likewise, Shasta County reports that its community is socially conservative, so asking SOGI questions is taboo and incites fear, confusion, and disagreement. Calaveras County noted that race and ethnicity are often easily identifiable for individuals but that new concepts related to SOGI require careful education when asking these questions of clients. Similarly, Sutter County replied that its community is more reluctant to share SOGI information than information about race and ethnicity. Likewise, Shasta County said that SOGI data is more stigmatizing than race and ethnicity data and that clients have greater fears in sharing that information. Although education and training will not overcome social perceptions overnight, it is nevertheless critical to help make

⁷ Appendix B includes a summary of responses to selected survey questions.

those who are asking the questions—both public health officials and health care providers—more comfortable with doing so and more knowledgeable about the value of such questions, and in turn make patients feel comfortable providing SOGI data.

By not providing consistent guidelines and training to local health jurisdictions and health care providers, Public Health misses opportunities to ensure that SOGI data is collected effectively or appropriately. There is training available from other entities such as the CDC and the SFDPH that Public Health could use as a starting point for developing its own. Additionally, given that Public Health has issued regulations for reportable communicable diseases requiring local health jurisdictions and health care providers to report complete SOGI data, it should do more to facilitate that reporting requirement.

Please refer to the section beginning on page 5 to find the recommendations that we have made as a result of these audit findings.

We conducted this performance audit in accordance with generally accepted government auditing standards and under the authority vested in the California State Auditor by Government Code section 8543 et seq. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on the audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

Respectfully submitted,

GRANT PARKS California State Auditor

April 27, 2023

Staff: John Lewis, MPA, CIA, Audit Principal

Ralph M. Flynn Aren Knighton, MPA

Maria Cecilia White, MPPA, CFE

Christopher P. Bellows

Robert J. Evans Sunny Yan

Legal Counsel: David King

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Other Areas We Reviewed

To address the audit objectives approved by the Joint Legislative Audit Committee (Audit Committee), we also reviewed Public Health's efforts to collect SOGI data from the administration of the COVID-19 vaccines and to engage in contracts for services. Additionally, we contacted other state entities in California to learn about their efforts to collect SOGI data but did not draw conclusions about the quality of their efforts because we did not audit them.

State Law Does Not Require Public Health to Collect SOGI Data Related to Immunizations

Public Health is not collecting SOGI data for the administration of vaccines—including the COVID-19 vaccine—because state law does not require it. State law allows local health officers, in conjunction with Public Health, to operate an immunization information system. Public Health's California Immunization Registry (immunization registry) is its statewide computerized immunization information system for California residents that health care providers can access online to track patient immunization records. However, state law specifies the demographic information that must be reported to Public Health—including the patient's name, gender, and birth date—and the law does not include reporting SOGI data.

However, recent changes to state law expanded the demographic data that must be reported to Public Health. Specifically, beginning January 2023, health care providers and others must report an individual's race and ethnicity to Public Health. According to the author of the bill creating this requirement, the lack of race and ethnicity data fields puts health officials at a disadvantage in targeting resources to communities that need them the most, and these changes will bolster data submissions to support health equity and accuracy. As we discussed in the Introduction, there are similar benefits to analyzing SOGI data to determine whether certain populations are experiencing health disparities. According to a section chief in Public Health's Immunization Branch, the immunization registry is capable of storing SOGI data should the law require it.

Including SOGI data in the immunization registry may decrease the information that patients are willing to share but could improve Public Health's ability to identify health disparities. For example, state law allows certain individuals and groups—including health care providers, health plans, schools, childcare centers, and foster care agencies—to use the registry to check the immunization status of the individuals that they serve and determine which immunizations are due, among other purposes. However, according to the chief of Public Health's Immunization Branch, individuals might be less likely to allow access to their immunization records and might hesitate to share other demographic information with the immunization registry if they have concerns about answering SOGI questions. Nevertheless, without collecting SOGI data, Public Health will be unable to fully measure whether there are immunization-related health disparities among certain populations. Public Health could include SOGI data as voluntary data elements in the immunization registry for patients to provide.

The Public Health Contracts We Reviewed Were Appropriate

The Legislature also requested that we identify the number of entities who contract with Public Health and are required to collect SOGI data, as well as the methodologies used to negotiate these contracts. Public Health identified more than 350 entities under contract that collected demographic data and should collect SOGI data. We reviewed a selection of 10 contracts and found that Public Health appropriately entered into those contracts.

Public Health contracts with local health jurisdictions and other entities to perform services; to research, develop, and implement educational campaigns; and to create and administer surveys, among other activities. Our selection of contracts to review included contracts with local health jurisdictions to implement HIV/AIDS programs, and contracts to develop and lead educational campaigns for gambling and cannabis use, among others. Public Health used interagency agreements with the University of California or with California State University; cooperative agreements with a local government entity or nonprofit organizations; and standard agreements with enrollment sites—such as nonprofit organizations, clinics, or medical providers that provide local AIDS services—to enter into contracts. For example, the Women, Infants and Children program uses a standard agreement to contract with local governments or private nonprofit organizations to provide direct services at the local level. In addition, Public Health engaged in an emergency contract related to COVID-19 disease investigators.

Public Health used competitive bidding practices for three of the 10 contracts we reviewed. The remaining seven all used other appropriate procurement instruments and processes. Because of the scope of work, which often requires many established local governments or local medical providers to implement public health programs at the local level, we would expect Public Health to use cooperative agreements with standardized language to simplify requirements, eliminate unnecessary paperwork, and ensure fiscal accountability, as state law allows.

The Legislature also requested that we evaluate Public Health's monitoring of the SOGI data its contractors collect and the methods Public Health uses to communicate changes in law relating to SOGI data collection. Managers of multiple Public Health branches explained that Public Health is involved in the final approval of the forms that contractors use to collect demographic information, so it has the opportunity to ensure that the forms comply with current state law without having separate processes to communicate changes in law relating to SOGI data collection. As we noted earlier, Public Health often does not collect SOGI data on the forms that already collect ancestry and ethnic origin data. However, we determined that this issue is not related to its contracting decisions or processes, but is rather the result of decisions and inconsistencies already described in the Audit Results.

Some Other State Entities Are Collecting SOGI Data

To identify potential best practices, we reached out to other state entities that state law specified should collect SOGI data. State law requires 11 state entities, including Public Health, to collect voluntarily provided self-identification information about SOGI in the course of collecting demographic data regarding the ancestry or ethnic

origin of Californians. We have listed those entities in the text box. We contacted each of the remaining 10 entities and determined that seven collect complete SOGI data, one collects gender identity data but not sexual orientation data, and two stated that they do not collect SOGI data. Because we did not audit these entities, we cannot draw conclusions about the quality of their efforts or whether the three entities not collecting complete SOGI data should have been doing so, but we were informed by their efforts.

The California Department on Aging's (Aging) efforts serve as a potential best practice. Despite recognizing that there is no new funding available for developing training or updating local data management systems, Aging coordinated with local agencies and their data system vendors to develop and implement standard SOGI questions statewide. Similar to Public Health's collecting data from local health jurisdictions, Aging collects data from 33 local Area Agencies on Aging (local agencies). In response to state law requiring it to collect SOGI data, Aging established a workgroup

State Entities Required, Under Certain Conditions, to Collect SOGI Data

- 1. California Department of Public Health
- 2. California Department of Health Care Services
- 3. California Department of Social Services
- 4. California Department of Aging
- California Department of Education and the Superintendent of Public Instruction, with the exception of the California Longitudinal Pupil Achievement Data System
- 6. Commission on Teacher Credentialing
- 7. Civil Rights Department
- 8. California Labor and Workforce Development Agency
- 9. Department of Industrial Relations
- 10. Employment Training Panel
- 11. Employment Development Department, with the exception of the Unemployment Insurance Program

Source: State law.

with a selection of local agencies to develop standard questions for all local agencies to use, to develop training, and to work with data management providers to update their local data collection systems to collect SOGI data. In addition, because the local agencies used six different data system providers, Aging notified the data system providers of the need to modify their systems and provided them with the standard questions to add. Further, the workgroup identified the need for statewide and local training to conduct training specific to LGBTQ emerging issues and training in respectfully asking the new SOGI questions. To inform the other local agencies of the changes, Aging issued a program memo summarizing the reasons for the changes and offering instruction for implementing the changes. Likewise, we make recommendations to Public Health to improve its collection of SOGI data by standardizing definitions and providing guidance.

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Appendix A

Results of Our Survey of Local Health Jurisdictions

The Audit Committee requested that we assess Public Health's role in collecting, reporting, and using SOGI data. To gain an understanding of the challenges that local health jurisdictions experience, we surveyed the local health jurisdictions. We notified the local health jurisdictions about this survey by email and collected their electronic responses. Of the 61 local health jurisdictions that we surveyed, 54 (89 percent) completed the survey. In Table A we present aggregated responses to selected questions.

Table ALocal Health Jurisdictions' Responses to Selected Questions From Our Survey

	PERCENTAGE (OF RESPONSES
QUESTIONS	YES	NO
Questions regarding collection of sexual orientation and gender	identity inform	ation
Does your local health jurisdiction collect information on sexual orientation for the individuals participating in its programs and services?	98%	2%
Does your local health jurisdiction currently have a standardized set of questions, answers, and language that is used across all programs to collect sexual orientation data?	26	74
Does your local health jurisdiction collect information on gender identity for the individuals participating in its programs and services?	94	6
Does your local health jurisdiction currently have a standardized set of questions, answers, and language that is used across all programs to collect gender identity data?	26	74
Does your local health jurisdiction collect SOGI data for reportable communicable diseases, as required by Title 17 of the California Code of Regulations?	91	9
Does your local health jurisdiction collect SOGI data when collecting data about COVID-19 cases?	76	24
Percentage of local health jurisdictions identifying Public Health as an entity that has provided guidance or training regarding SOGI data collection to it.	44	1%

Questions regarding improvements to Public Health's guidance

PERCENTAGE OF RESPONSES

What can the California Department of Public Health do to improve its guidance in terms of method, quality, and sufficiency for collecting, reporting, and using SOGI data?*

Increase guidance or training	72%
Standardize SOGI definitions, language, or questions	35
Increase or clarify SOGI data requirements	20
Clarify the purpose of SOGI data for local health jurisdictions, health care providers, and the public	17
Reach out to providers	13

Source: Auditor's survey of local health jurisdictions.

Note: We surveyed 61 local health jurisdictions and 54 (89 percent) completed the survey.

* We analyzed the local health jurisdictions' comments to identify common themes and we list some of those themes here.

We invited the respondents to our survey to provide written comments to give context to selected answers, although only some opted to do so. In the survey, we asked questions about the local health jurisdictions' methods for collecting and reporting SOGI data and about what Public Health can do to improve its directions. Most of the local health jurisdictions responded that they do collect sexual orientation and gender identity information for the individuals participating in their programs and services. However, only about a quarter of them use standardized questions, answers, or language across all their programs. Comments about improving Public Health's guidelines generally focused on a need for more training and for standardized SOGI questions and response field definitions. Local health jurisdictions specifically requested standard definitions and tools for collecting SOGI information, and they identified challenges to educating their communities on the importance and purpose of asking for SOGI information. Some local health jurisdictions expressed frustration with using multiple systems for storing data rather than having a central information exchange. Several local health jurisdictions stated that Public Health could assist with SOGI data collection and reporting by encouraging health care providers and laboratories to include SOGI data in medical systems reports. The results of the survey suggest that Public Health could improve its directions and guidance to local health jurisdictions and provide training.

Appendix B

Results of Our Survey of Health Care Providers

The Audit Committee requested that we assess Public Health's role in collecting, reporting, and using SOGI data. To gain an understanding of the challenges that health care providers experience, we surveyed CalREDIE users identified by Public Health as using its CalREDIE system since July 2021. We notified these CalREDIE users about this survey by email and collected their electronic responses. Of the 1,901 CalREDIE users that we surveyed, 160 (8 percent) responded. We excluded 41 responses for not coming from health care providers. In Table B we present aggregated responses from the remaining 119 survey respondents to selected questions.

Table BHealth Care Providers' Responses to Selected Questions From Our Survey

QUESTIONS	PERCENTAGE OF RESPONSES IDENTIFYING EACH AS BARRIER	
What are the barriers to collecting complete SOGI data on communicable disease?		
Individuals are reluctant to provide SOGI information when asked	39%	
There is no standard definition or guidance on which information should be collected when requesting information about a person's sexual orientation or gender identity	31	
There are no standard questions or guidance on which questions to ask to obtain a person's SOGI information	28	
SOGI information is not relevant to report	18	
You or your staff are reluctant to solicit SOGI information	11	

		TAGE OF DNSES
Has your local health jurisdiction provided any guidance or	YES	NO/UNSURE
training regarding SOGI data collection to you?	12%	88%

Has another entity provided any guidance or training regarding SOGI data collection to you?	PERCENTAGE OF RESPONSES
I have not received any guidance regarding SOGI data collection	41%
California Department of Public Health	13
Not sure	25

Percentage of open-ended responses indicating that health care providers would benefit from Public Health providing guidance or training about collecting and reporting SOGI data.	
Has the California Department of Public Health provided you with	

a standardized set of questions, answers, or language that is used

52%

PERCEN RESPO	TAGE OF DNSES
YES	NO/UNSURE
35%	65%
28	72

Source: Auditor's survey of health care providers.

Sexual orientation

Gender identity

to collect the following from patients?

Note: We surveyed 1,901 CalREDIE users and 160 responded. We excluded 41 responses for not being health care providers. In this table we present aggregated responses from the remaining 119 survey respondents to selected questions. Some questions did not receive a 100 percent response rate, and these figures reflect only the responses for each question.

We invited the respondents to our survey to provide written comments to give context to selected answers, although only some opted to do so. In the survey, we asked questions regarding the barriers to collecting SOGI data, the different methods health care providers use to collect SOGI data, and the guidance that providers have received regarding SOGI data collection. More than half of respondents said that they either did not receive or were unaware of whether they had received information from Public Health on standardized questions and answers for collecting SOGI information. Further, the health care providers who said that they had received standardized information from Public Health were more likely to collect SOGI information than health care providers who said that they had not. In addition, some health care providers were unaware of reporting requirements for communicable diseases and the reasons for collecting SOGI information or otherwise said that SOGI is not relevant to collect. Further, one health care provider expressed concerns that collecting SOGI information is discriminatory. The results of the survey suggest that without more guidelines from Public Health, there will continue to be confusion about the purposes and benefits of collecting and reporting SOGI data from local health care providers, and Public Health will be unable to obtain full participation from these individuals to collect and report SOGI information.

Appendix C

Scope and Methodology

The Audit Committee directed the California State Auditor to conduct an audit of Public Health regarding its role in collecting, reporting, and using SOGI data. Table C lists the objectives that the Audit Committee approved and the methods we used to address them.

Table CAudit Objectives and the Methods Used to Address Them

	AUDIT OBJECTIVE	METHOD
1	Review and evaluate the law, rules, and regulations significant to the audit objectives.	Reviewed and evaluated laws and regulations related to Public Health, SOGI data collection for local health jurisdictions, laboratories, and health care providers.
2	Identify the programs within Public Health that are actively collecting SOGI data and determine the following:	 Interviewed key personnel at Public Health and reviewed documentation to identify the programs that are collecting demographic data and therefore may be required to collect SOGI data.
	The process each program used to establish data collection methodologies.	 Public Health programs collect SOGI data in many ways, including intake forms, surveys, and electronic databases, and some programs collect SOGI data using multiple forms or surveys. As a result, we focused our review on the forms, surveys, or electronic databases Public Health used to collect demographic data.
	 The extent to which the programs have different methodologies for collecting and tracking the data. 	 Reviewed the forms used by Public Health to collect demographic data to determine which are required to collect SOGI data.
	 c. Public Health's compliance with AB 959, including its use of SOGI data. 	 Analyzed those forms to determine whether they complied with law and other relevant criteria. Interviewed key Public Health officials and reviewed relevant documentation to determine
	d. The extent to which each program performs monitoring to ensure the appropriateness of the data collection.	 whether Public Health tracked, monitored, or published SOGI data from the forms that collect SOGI data. Interviewed key personnel at Public Health and reviewed documentation to identify any departmentwide guidance or initiatives to standardize SOGI data collection.
3	Identify the following information regarding entities whose contracts with Public Health require collecting SOGI data:	 Interviewed key personnel at Public Health and reviewed documentation for the forms in Objective 2 that collect SOGI data. Requested Public Health to identify any contractors it engaged with to collect demographic information through these forms.
	a. The total number of contracted entities.	 Reviewed a selection of 10 contracts to determine the methodologies used to enter into those contracts and requested Public Health provide information on any processes it used to monitor SOGI data collected by the contracted entities and to communicate changes in law.
	b. To the extent possible, the methodologies Public Health used to negotiate these contracts.	
	c. Whether Public Health established and followed specific processes to monitor the data collected by these entities.	
	d. The methods by which Public Health communicates changes in law relating to SOGI data collection.	

AUDIT OBJECTIVE

- 4 Determine the following information regarding health care providers and laboratories:
 - a. Identify the procedures that Public Health has in place to ensure and facilitate the solicitation of SOGI data from health care providers and laboratories.
 - Identify the barriers that the State experiences when attempting to collect SOGI data from health care providers and laboratories.
 - c. Identify the current limitations or deficiencies related to SOGI data collection within electronic disease reporting systems used by both health care providers and laboratories and determine how these systems can be improved.

 Reviewed documentation to identify and review any departmentwide regulations, polices, and procedures to ensure and facilitate the solicitation of SOGI data from health care providers and laboratories.

METHOD

- Interviewed key personnel at Public Health to identify barriers the State experiences when attempting to collect SOGI data.
- Conducted a survey of health care providers that input data into CalREDIE to identify barriers in collecting and reporting SOGI data to Public Health.
- Conducted a survey of the local health jurisdictions in the State to identify barriers in collecting and reporting SOGI data to Public Health.
- Interviewed key personnel at Public Health and local health jurisdictions and reviewed documentation and data files to identify limitations or deficiencies in CalREDIE's SOGI data collection and reporting abilities.
- 5 Identify the following information regarding health care providers collecting SOGI data from patients with reportable communicable diseases:
 - a. The measures Public Health has taken to ensure that all health care providers are collecting and reporting SOGI data in compliance with SB 932 and how these measures can be improved.
 - To the extent possible, the different methods used to collect SOGI data and how these methods can be improved.

- For a selection of forms collecting SOGI data, identified and evaluated the methods through
 which Public Health provides guidance to health care providers and assists them in reporting
 SOGI data.
- As part of the survey of health care providers noted in Objective 4, solicited feedback on the challenges that exist to collecting SOGI data, the different methods used to collect SOGI data, and what Public Health should do to assist health care providers.
- Our office did not identify any provision of state law requiring providers to ask patients for their SOGI information. We discuss the methods of how health care providers report SOGI data in our response to Objective 2 above.
- 6 Review and assess the processes by which Public Health interacts with laboratories that receive SOGI data from health care providers and determine whether there are challenges in those interactions related to the collection of data and, if so, determine how these challenges can be addressed.
- Reviewed the requirements for health care providers to report SOGI data to laboratories to identify any shortcomings.
- Interviewed key personnel at Public Health and reviewed documentation to identify barriers in laboratories' reporting SOGI data to Public Health and identify potential solutions.
- Interviewed staff at selected laboratories to determine what barriers exist to collecting and reporting SOGI data.
- 7 Review and assess the processes by which Public Health interacts with drive-through or pop-up COVID-19 testing sites that collect SOGI data and determine whether there are challenges in those interactions related to the collection of data and, if so, determine how these challenges can be addressed.
- Interviewed key personnel at Public Health and reviewed documentation to assess the extent to which Public Health interacts with community-based COVID-19 testing sites.
- Reviewed the contracts Public Health has with its vendors for COVID-19 data collection as well
 as the forms used by those vendors to collect SOGI data to identify any challenges in data
 collection.

	AUDIT OBJECTIVE	METHOD
8	Determine the extent to which Public Health provides uniform guidance to local county health departments, laboratories, and contractors regarding the collection of SOGI data, including whether specific guidance is provided to laboratories regarding action to take after they receive SOGI data from health care providers. Identify the reasons for any lack of guidance. Further, identify examples of unified guidance that sources outside of Public Health use that could become a model for the entities that the law requires to collect SOGI data.	 Interviewed key personnel at Public Health and reviewed relevant documentation regarding the lack of departmentwide guidance to local health jurisdictions, laboratories, and contractors. Surveyed the 61 local health jurisdictions and interviewed key personnel at some local health jurisdictions to identify best practices for SOGI data collection practices and guidance. Reviewed guidance for SOGI data collection published by other entities, including the CDC to identify best practices.
9	Determine whether any efforts are being made to collect SOGI data for the administration of the COVID-19 vaccine. If no efforts have been taken, determine the reasons why.	Reviewed relevant laws and interviewed key personnel to evaluate the requirements for collecting SOGI data for the administration of vaccines.
10	Review and evaluate the following: a. The collection of SOGI data compared to the collection of data on race and ethnicity to determine whether similar difficulties exist. b. The collection of SOGI data in rural areas compared to the collection of SOGI data in urban areas to determine whether major differences exist.	Surveyed the 61 local health jurisdictions regarding common challenges to collecting SOGI data and whether they had similar challenges to collecting data on race and ethnicity. We also surveyed the local health jurisdictions to identify differences in collecting SOGI data in urban and rural areas.
11	Determine whether any Public Health programs or other state agencies are conducting SOGI data collection particularly well. Further, identify any local jurisdictions that report SOGI data to Public Health particularly well and determine whether other entities that collect these data could adopt these best practices.	 Reviewed state law and identified the 11 state entities, including Public Health, which must comply with SOGI data collection requirements. Contacted the 10 other state entities that state law named related to SOGI data to determine the extent to which they implemented the requirements in state law and identify best practices. Interviewed key personnel at most of the departments that were collecting SOGI data and reviewed documentation to identify best practices. Interviewed staff at some local health jurisdictions to learn about their experiences with Public Health's guidelines.
12	To the extent possible, review and compare SOGI data retained before and after the passage of AB 959 to determine if a quantifiable difference can be identified.	 Obtained and reviewed data reports from a selection of Public Health programs that collected SOGI data prior to 2015. Our analysis identified few Public Health programs that collected SOGI data prior to 2015. Of those programs, we found limited changes when compared to current SOGI data collection processes. This further corroborated our concerns related to Public Health's lack of departmentwide guidance for SOGI data collection and Public Health's lack of analysis of SOGI data.
13	Review and assess any other issues that are significant to the audit.	No other issues identified.

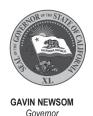
Source: Audit workpapers.

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State of California—Health and Human Services Agency California Department of Public Health



April 7, 2023

Grant Parks California State Auditor 621 Capitol Mall, Suite 1200 Sacramento, CA 95814

Dear Mr. Parks:

The California Department of Public Health (Public Health) thanks the California State Auditor for its draft audit report on sexual orientation and gender identity (SOGI) data collection titled "The California Department of Public Health: It Has Not Collected and Reported Sexual Orientation and Gender Identity Data as State Law Intended."

We believe in the importance of collecting SOGI data to identify disparities and acting to change inequities in California's health systems. Best practices related to SOGI data collection are evolving. Public Health will continue to strive to achieve and improve compliance in our data collection efforts and overall use of data to advance health equity in California.

We acknowledge and appreciate the insights shared in the audit report. Public Health will both work to improve our own efforts, as well as support local health jurisdictions and health care providers to collect this data. Although Public Health substantially complied with AB 959 provisions, implemented SOGI questions in the Confidential Morbidity report, and updated CalREDIE to receive data from local health jurisdictions, we acknowledge that the report highlights areas that go beyond the requirements of the law. We commit to reviewing the recommendations proposed by the Auditor and look forward to reporting our progress 60 days, 6 months, and one year from the final report release.

Thank you for the opportunity to respond to the audit. If you have any questions, please contact Mónica Vázquez, Deputy Director, Office of Compliance, at (916) 306-2251.

Sincerely,

Tomás J. Aragon, MD, DrPH

Director and State Public Health Officer

