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# Collection of Gender Identity in National Case Notifications of Chlamydia, Gonorrhea, and Primary and Secondary Syphilis, 2018

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## Abstract

In 2018, 21 (41%) jurisdictions had begun reporting gender identity for sexually transmitted disease case notifications sent to the Centers for Disease Control and Prevention. Among jurisdictions with ≥70% of cases with reported gender identity and sex, 1.0% of primary and secondary syphilis cases were identified as transgender and 71% of transgender women with syphilis were concurrently coded as being male sex.

Transgender men and transgender women may be particularly vulnerable to acquiring sexually transmitted diseases (STDs) because of stigma and real or perceived discrimination, which can result in risk behaviors that increase exposure to STDs (such as sex under the influence of drugs or alcohol), as well as in reduced access to quality sexual health care.[1] In addition, transgender individuals may face lower levels of social support[2] and higher levels of poverty, substance abuse, and mental health issues than cisgender (not transgender) men and women, which can significantly increase barriers to effective STD prevention.[3,4]

There are limited national data on the burden of STDs among transgender men and women; however, clinic-based studies suggest that transgender women have substantial STD rates[5,6] that can be higher than STD rates among cisgender women. For example, in one study in a federally qualified health center, 11% of cisgender women tested positive for chlamydia, gonorrhea, or syphilis compared with 25% of transgender women.[7] Few jurisdictions routinely present STD case data separately for transgender persons in annual surveillance reports[8]; however, in those that do, up to 1% of reported cases of primary and secondary (P&S) syphilis, the stages of infection indicating recent acquisition, were among transgender persons in 2017.[9]

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Collection of gender identity in state and national surveillance systems, and the ability to report these data routinely for public health purposes can improve understanding of health disparities and inform interventions and policies to improve the health of transgender individuals.[10] Before 2018, case notifications provided to the Centers for Disease Control and Prevention (CDC) through the National Notifiable Disease Surveillance System (NNDSS) did not allow for transmission of a case-level variable identifying gender identity, with only a "current sex" variable collected, coded as male, female, or unknown. In addition to not fully capturing case demographics to allow for a better description of STD epidemics, only being able to report a single current sex variable forced jurisdictions that do collect gender identity in addition to sex to map to a single sex variable in their NNDSS reporting.

To help inform national STD surveillance, CDC obtained Office of Management and Budget approval in mid-2017 to collect gender identity for case notifications of STDs provided to CDC and modified the case notification structure for nationally notifiable STDs.[11,12] Beginning in January 2018, CDC was able to receive STD case notifications that included a variable for gender identity. We reviewed 2018 case notifications sent to CDC through NNDSS to describe progress toward the collection of gender identity and use these initial data to estimate the distribution nationally notifiable STDs by gender identity.

## METHODS

We reviewed cases of chlamydia, gonorrhea, and P&S syphilis diagnosed and reported to CDC in 2018. For each case notification, current sex (male, female, unknown) continued to be reported, along with gender identity able to be reported with the following response options: 1, transgender, male-to-female; 2, transgender, female-to-male; 3, transgender, unspecified; 4, cisgender; and 9, unknown.

We reviewed case records received at CDC from 51 jurisdictions (50 states and the District of Columbia) and identified jurisdictions that had sent at least one case notification coded with a nonmissing/unknown gender identity (considered to "have begun reporting" gender identity). Among jurisdictions that had begun reporting, we calculated the proportion of cases coded with a nonmissing/unknown response value (i.e., coded as 1, 2, 3, or 4) and identified jurisdictions with ≥70% of case notifications with nonmissing response values (considered "complete reporting"). In jurisdictions with complete reporting for the gender identity variable, we estimated the distribution of cases by gender identity. Determination of reporting completeness and distribution of gender identity was completed separately for each STD and for each jurisdiction. Finally, among jurisdictions with complete reporting for P&S syphilis, we compared the reported value for the current sex variable to the value for the gender identity variable.

As reporting completeness may have improved throughout the calendar year, as a sensitivity analysis, we repeated all analyses using data from the last 6 months and last 3 months of 2018. In addition, we investigated the impact of using a 70% threshold to categorize jurisdictions as having complete reporting by repeating all analyses using 50% and 90% thresholds. Data analyses were conducted using SAS version 9.4 (SAS Institute, Inc, Cary, NC).

## RESULTS

In 2018, 1,758,668 cases of chlamydia, 583,405 cases of gonorrhea, and 35,063 cases of P&S syphilis were reported in the United States. Overall, 18 (35%) of the 51 jurisdictions reported at least one case of chlamydia with a value for the gender identity variable that was not coded as missing or unknown and were considered to be jurisdictions who had begun reporting gender identity for chlamydia, with a few more jurisdictions reporting gender identity for gonorrhea (n = 20; 39%) and P&S syphilis (n = 21; 41%; Supplemental Figs. A–C, http://links.lww.com/OLQ/A527).

Among the jurisdictions that had begun reporting gender identity, 41.6% (291,908/702,168) of chlamydia cases were coded as missing or unknown (range by jurisdiction, 0.3%–99.9%), 43.7% (113,164/258,858) of gonorrhea cases were coded as missing or unknown (range by jurisdiction, 0.3%–99.9%), and 15.5% (2,314/14,934) of P&S syphilis cases were coded as missing or unknown (range by jurisdiction, 0%–99%).

Few jurisdictions reported ≥70% of cases with nonmissing or unknown values for gender identity (5 jurisdictions for chlamydia, 6 for gonorrhea, and 13 for P&S syphilis; Table 1). In these jurisdictions, 0.09% of chlamydia cases were reported as being diagnosed in a transgender person (0.07% among transgender male-to-female, 0.02% among transgender female-to-male, and 0% among transgender unspecified). The proportion of chlamydia cases reported among transgender persons varied across jurisdictions but was consistently less than 0.2%. Similar patterns were seen for gonorrhea; however, the proportion of cases identified as transgender was slightly higher at 0.3%. For P&S syphilis, 1.0% of cases were reported among transgender persons (0.84% among transgender male-to-female, 0.11% among transgender female-to-male, and 0.05% among transgender unspecified). In the 13 jurisdictions with complete reporting for P&S syphilis, among the 102 transgender women reported with P&S syphilis, most (71%) were concurrently reported as male sex, and among the 13 transgender men with P&S syphilis, 5 (39%) were reported as female sex (Table 2).

## DISCUSSION

In the first year of collecting gender identity for STD case notifications provided to CDC, more than one-third of jurisdiction had begun sending gender identity data; however, in these jurisdictions, approximately 40% of chlamydia and gonorrhea cases and 15% of P&S syphilis cases were coded as unknown or missing gender identity. In the few jurisdictions with more complete reporting of gender identity, the proportion of cases identified as transgender was relatively low (<0.4% for chlamydia and gonorrhea and 1% for P&S syphilis); however, if these proportions were applied to all reported cases, almost 3900 STD cases would have been reported among transgender persons in 2018. In addition, for cases of P&S syphilis, there was often discordance between the reported current sex and gender identity, with 70% of transgender women coded as being male sex.

To begin sending data on gender identity in case notifications to CDC, jurisdictions may have had to make several different types of modifications to their local and state surveillance systems. If a jurisdiction was not already collecting gender identity, modifications to data

collection forms (e.g., case report forms) and systems (e.g., online entry systems for local reporting to the state) could be required, as well as changes to their surveillance information system to ensure data were able to be stored in appropriate data formats separate from current sex. In addition, data must be mapped to CDC's case notification message layout, extracted, and sent to CDC weekly. These types of changes often take time and may require resources to implement.

Even among jurisdictions that had begun reporting the gender identity variable, approximately 40% of chlamydia and gonorrhea cases were coded as missing or unknown gender identity. Given the disease burden (>2 million cases reported annually), most jurisdictions are not able to conduct patient or provider follow-up on cases of chlamydia and gonorrhea. As such, chlamydia and gonorrhea case data often only reflect information available on laboratory reports, which likely do not include gender identity. Most cases of P&S syphilis are targeted for disease investigation, and more complete information of gender identity likely reflects patient follow-up.

In addition, it is possible that jurisdictions with a high proportion missing had made modifications to their surveillance practices in 2018 and had more complete reporting in later months; however, we conducted a sensitivity analysis using data from the last 6 months and then last 3 months of the year, and findings were similar to those using the whole year of data (data not shown). Similarly, a sensitivity analysis to investigate the impact of the 70% threshold to determine complete reporting revealed that, although the absolute number of jurisdictions and cases included varied by threshold, the overall findings were similar (e.g., overall proportion of cases identified among transgendered persons did not change; data not shown).

In jurisdictions meeting our criteria for complete reporting, the overall proportion of cases among transgender persons was similar to reports from local jurisdictions where the data are routinely ascertained and published.[9] In jurisdictions with complete reporting for P&S syphilis (≥70% of cases reported with a nonmissing value for gender identity), there was not concordance between the reported value for current sex and for gender identity, with most transgender women coded as being male sex. It is likely that transgender women have different STD prevention needs than cisgender men. Being able to disentangle sex from gender may be useful to designing and targeting effective prevention interventions.

This is first report of the distribution of reported gender identity in national STD case notifications; however, it is important to interpret these findings in light of several limitations. First, the distribution of gender identity of cases was limited to a subset of jurisdictions that were considered to have complete reporting of gender identity and is not representative of the entire United States. Additional investigation into barriers and facilitators of collecting and reporting gender identity will help improve national surveillance efforts. Second, methodology for coding of gender identity in local surveillance systems likely varies and may have biased results. For example, if the default coding for the gender identity variable was cisgender and only overwritten if transgender identity was known, the proportion that was coded as transgender would be an underestimate. Alternatively, if the default coding was unknown and only updated when gender identity

was reported, the proportion of cases that were identified as transgender could be an overestimate if transgender persons were more likely to have their gender identity noted. A better understanding of how gender identity is collected and stored will help improve understanding of national trends. Finally, there are no state-level population estimates for transgender populations; high-quality population data would facilitate the estimation of rates of reported disease, which may be more useful than comparing the distribution of case counts.

Jurisdictions that routinely collect gender identity for cases of nationally notifiable STDs are encouraged to send these data to CDC in their STD case notifications. These data are critical to inform efforts to monitor and improve the health and well-being of transgender individuals. In addition, for case data based solely on laboratory reporting, enhanced surveillance strategies such as random sample methodology could be used to better estimate distributions of disease by gender identity. Finally, data could be used to inform programmatic action and disease intervention. Promising strategies to prevent STDs among transgender individuals include ensuring providers provide culturally competent sexual health care[13,14] and interventions that address multiple health issues, such as stigma and discrimination, and utilize community mobilization strategies.[15,16]

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Disclosure:

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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**TABLE 1.**

Gender Identity Among Reported Cases of Chlamydia, Gonorrhea, and Primary and Secondary Syphilis, 2018

| | Chlamydia | | | Gonorrhea | | | Primary and Secondary Syphilis | | |
|---|---|---|---|---|---|---|---|---|---|
| | | (%) | | | (%) | | | (%) | |
| | n | Overall | Range by State | n | Overall | Range by State | n | Overall | Range by State |
| States that reported gender identity for ≥1 case * | 18 | 35.3 | — | 20 | 39.2 | | 21 | 41.2 | |
| Total cases reported | 702,168 | — | — | 258,858 | — | — | 14,934 | — | — |
| Missing or unknown | 291,908 | 41.6 | 0.34–99.9 | 113,164 | 43.7 | 0.28–99.9 | 2,314 | 15.5 | 0–98.7 |
| States that reported gender identity for ≥70% of cases * | 5 | 9.8 | — | 6 | 11.8 | — | 13 | 25.5 | |
| Total cases reported | 298,640 | — | — | 134,930 | — | — | 12,815 | — | — |
| Missing or unknown | 19,995 | 6.7 | 0.34–21.9 | 12,923 | 9.6 | 0.28–21.2 | 600 | 4.7 | 0–20.9 |
| Not missing or unknown | 278,645 | 93.3 | 78.1–99.7 | 122,007 | 90.4 | 78.7–99.6 | 12,215 | 95.3 | 79.1–100 |
| Transgender, male to female | 184 | 0.07 | 0.03–0.13 | 224 | 0.18 | 0.07–0.43 | 102 | 0.84 | 0.38–1.64 |
| Transgender, female to male | 47 | 0.02 | 0.01–0.04 | 134 | 0.11 | 0.02–0.37 | 13 | 0.11 | 0.10–0.34 |
| Transgender, unspecified | 6 | 0.00 | 0–0.02 | 54 | 0.04 | 0–0.17 | 6 | 0.05 | 0.03–0.21 |
| Cisgender | 278,408 | 99.9 | 99.9–100 | 121,595 | 99.7 | 99.0–99.9 | 12,094 | 99.0 | 98.4–100 |

* Reported case(s) with the gender identity variable coded as not missing or unknown.

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**TABLE 2.**

Distribution of Primary and Secondary Syphilis Cases by Sex and Gender Identity, 13 States*, 2018

| | Missing | Transgender M/F | Transgender F/M | Transgender Unspecified | Cisgender | Unknown | Total |
|---|---|---|---|---|---|---|---|
| Male | | | | | | | |
| n | 1 | 72 | 8 | 6 | 10,361 | 493 | 10,941 |
| (Row %) | (0.01) | (0.7) | (0.07) | (0.05) | (94.7) | (4.5) | |
| (Column %) | (100) | (70.6) | (61.5) | (100) | (85.7) | (82.3) | |
| Female | | | | | | | |
| n | 0 | 30 | 5 | 0 | 1733 | 106 | 1874 |
| (Row %) | (0) | (1.6) | (0.3) | (0) | (92.5) | (5.7) | |
| (Column %) | (0) | (29.4) | (38.5) | (0) | (14.3) | (17.7) | |
| Total | 1 | 102 | 13 | 6 | 12,094 | 599 | 12,815 |

*States that reported gender identity for ≥70% of cases.