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## IDENTIFICATION AND REPORTING OF GENDER IDENTITY AMONG INDIVIDUALS DIAGNOSED WITH HIV IN THE DEEP SOUTH

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November 2019

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## INTRODUCTION |

The Southern United States has been disproportionately affected by HIV with the region consistently having the highest HIV diagnosis rates of any US region (2016).<sup>1</sup> The Deep South region of the US South (defined herein as Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, and Texas) has borne a particularly high HIV disease burden and is a significant driver of the US HIV epidemic.<sup>2</sup> The Deep South has experienced the highest HIV diagnosis rates and number of people diagnosed with HIV over the last decade along with the highest number of individuals living with HIV and the highest HIV death rates of any US region.<sup>1,3,4</sup>

Transgender people, particularly transgender women, have been identified as being at higher risk for HIV.<sup>5,6</sup> A recent systematic review found that 14% of transgender women are living with HIV and among African American transgender women, an estimated 44% are living with HIV.<sup>6</sup> A study using HIV surveillance data found that approximately half of transgender people (43% of transgender women; 54% of transgender men) who received an HIV diagnosis from 2009 to 2014 lived in the South.<sup>5,7</sup> This study likely far underestimated the number of individuals diagnosed with HIV who were transgender due to underreporting of gender identity information in surveillance data.

Transgender people often face challenges and barriers that affect their health and place them at increased risk for HIV and other sexually transmitted infections. These barriers include discrimination in housing, health care, employment, and law enforcement settings as well as difficulty accessing basic necessities such as affordable housing.<sup>8</sup> The bias, discrimination, and violence faced by transgender people often forces them into potentially dangerous circumstances including homelessness and survival sex work.<sup>9</sup> Black and Latina transgender women are at particular risk for stigmatizing and discriminatory experiences due to the additional burdens of racism, ethnocentrism, and xenophobia. For transgender people living with HIV (PLWH) in the South, transphobia, stigma, and violence are often magnified due to the conservative culture of the region.<sup>10</sup> At least 26 transgender people were killed in the United States in 2018 – half resided in the US Deep South.<sup>11</sup> By October 2019, 22 transgender women had been documented as being violently killed, fifteen of whom resided in the Deep South.<sup>9</sup>

To inform interventions to address the critical need for HIV prevention and HIV medical and social services for transgender individuals living with or at higher risk for HIV, it is imperative to accurately collect data on numbers, locations, and demographics of the transgender population, both as a population overall and specifically those who are diagnosed with HIV.<sup>10</sup>

Unfortunately, this information is not currently available in national HIV surveillance data reports. The most current CDC HIV Surveillance Report, which includes data from 2017, states that “data for transgender persons are not presented in this report because information on gender identity...is not consistently collected or documented in the data sources used by HIV reporting jurisdictions. HIV surveillance personnel collect data on gender identity, when available, from sources such as case report forms submitted by health care or HIV testing providers and medical records, or by matching with other health department databases (e.g., Ryan White program data).”<sup>12</sup> However, some state surveillance data do report information on gender identity beyond the categories of male and female, indicating that these states are attempting to gather and make available information on HIV among transgender individuals.

This study focuses on gender identity data collection in HIV surveillance data in the US Deep South, a region that has been disproportionately affected by HIV and where stigma and discrimination regarding gender identity is high. To gather this information, study staff interviewed leadership staff at the state offices of epidemiology about their practices regarding gender identity documentation in HIV surveillance data. This information can be used to identify current surveillance data collection practices and related gaps in knowledge and resources with the goal of developing strategies to obtain more specific and accurate gender identity information among those diagnosed with HIV. Accurate epidemiologic data is essential to inform interventions for transgender individuals living with HIV in the region and to better tailor allocation of limited resources for transgender people.

## **METHODS |**

Multiple phone interviews and email follow-ups were conducted with HIV surveillance branch staff from eight southern states from August 2018 to March 2019. The leadership of one Deep South state’s surveillance branch, Alabama, could not be reached after multiple attempts. A local provider who worked in HIV prevention and care provided information on his understanding of HIV surveillance in Alabama. Staff interviewed for the study included Directors of Surveillance, Epidemiologists, HIV/STD Prevention Staff, and HIV/AIDS Community Based Organization Staff.

Interviews utilized a semi-structured interview format and included the following questions:

- How does the state collect data on individuals diagnosed with HIV
- What questions do states ask about gender identity for surveillance reporting
- In what ways do they obtain and verify gender identity information
- Do staff believe numbers of transgender PLWH are underreported
- What are the successes and barriers for collecting data on transgender PLWH
- What other information would staff like to share related to HIV surveillance and better interventions and services for transgender PLWH

In addition, research staff searched relevant literature regarding the collection of gender identity data as part of HIV surveillance monitoring. All recent HIV surveillance reports for the

nine Deep South states that were published online were reviewed to examine their reporting of gender identity information among individuals diagnosed with HIV. Finally, email and phone contacts with CDC surveillance leadership were completed to better understand CDC collection and reporting of gender identity data among individuals diagnosed with HIV.

## **FINDINGS |**

### **Federal recommendations regarding collection of gender identity information for HIV surveillance**

The CDC case report form includes fields to report sex at birth and gender identity. However currently, the CDC does not include information regarding gender identity in HIV surveillance reports. According to the CDC, gender identity information in HIV surveillance data is limited because some state and local agencies do not collect or have complete data about gender identity.<sup>12</sup> The Department of Health and Human Services (HHS) included an objective in their “Healthy People 2020” to increase the number of states that are collecting gender identity information in state surveys and data collection in an attempt to address the lack of comprehensive data for this population.<sup>13</sup>

The CDC suggests that states adopt a two-step data collection method to determine gender identity by asking for sex assigned at birth and current gender identity to increase the likelihood that transgender people are correctly identified for HIV reporting.<sup>5</sup> The two-step data collection method recommended by the CDC involves asking two questions instead of one in order to both validate a person's present gender identity and understand their history. The questions are as follows:

**1. What is your sex or current gender? (Check all that apply)**

- ☐ Male
- ☐ Female
- ☐ TransMale/Transman
- ☐ TransFemale/Transwoman
- ☐ Genderqueer
- ☐ Additional Category (Please Specify): \_\_\_\_\_
- ☐ Decline to State

**2. What sex were you assigned at birth?**

- ☐ Male
- ☐ Female

This two-step method was recommended by the UCSF Center of Excellence for Transgender Health. A report from the UCSF Center described the critical need for accurate data collection on gender identity, stating that “outdated methods are too simplistic and binary to accurately and effectively collect critical information to assess HIV incidence and prevalence, identify

emerging trends, allocate resources, improve health care services, and address service gaps among populations of individuals.”<sup>10</sup>

In 2017, the Council of State and Territorial Epidemiologists also called for improving the accuracy of HIV surveillance information on gender identity stating that “the current hierarchy for identifying transmission category in the National HIV Surveillance System (NHSS) does not take into account transgender status. This results in most transgender women living with HIV/AIDS being categorized as MSM. The MSM classification misrepresents the identities and risk factors of transgender women and overestimates, to an unknown extent, the prevalence of HIV among MSM. Furthermore, variability and incompleteness of data on transgender people makes this population less likely to benefit from partner services, data-to-care activities, and record linkage programs, which depend on accurate surveillance data to compare databases. Inaccurate data categorization may cause these surveillance mechanisms to be attuned to serving MSM rather than transgender women. A unified approach to transgender data collection and analysis is needed on a national level.”<sup>14</sup>

Although not specific to collection of HIV surveillance data, Human Rights Watch, in their related policy brief, discussed the imperative need to collect data on sexual orientation and gender identity as part of health-related data in order to maximize health and address prevention needs.<sup>15</sup> They recommend mandating that sexual orientation and gender identity data be collected “alongside other demographic data in relevant existing and new surveys administered by the government, its constituent bodies, and all recipients of public funds”. This report also recommended that essential aspects of such data collection include that this information is non mandatory in nature for respondents (similar to collection of other demographic information) and that privacy and confidentiality of respondent information is protected.

### **CDC guidance for states on gender identity data collection**

According to CDC correspondence,<sup>16</sup> the CDC requires that the fields of race/ethnicity and sex at birth be completed on the Adult HIV Confidential Case Report Form (ACRF) and sets a standard that 97% of cases have no missing race/ethnicity and sex at birth data. Gender identity is not a required field since this data is not consistently collected and reported in medical records. CDC guidelines provided by CDC staff state that the CDC defers to local jurisdictions to decide how and if they will complete gender identity reporting.<sup>17</sup> CDC’s HIV Incidence and Case Surveillance Branch (HICSB) revised HIV surveillance and data collection methods for transgender people in 2011 to align them with the afore described two-step model. During 2011, the variable “current gender identity” was added to the Adult HIV Confidential Case Report Form (ACRF),<sup>17</sup> which is the form often used to compile HIV testing data and to report HIV status and demographic information of individuals who are tested for HIV. However, the response category “genderqueer” that appears in the two-step method was not included as an option in the gender identity question on the ACRF nor was there any other non-binary option apart from “additional gender identity.”

### **Deep South State collection of gender identity data:**

States use the CDC Enhanced HIV/AIDS Reporting System (eHARS), which is a “browser-based, CDC-developed application that assists health departments with reporting, data management, analysis, and transfer of data to the CDC. Each surveillance program maintains a separate eHARS installation and submits de-identified data monthly to CDC through a secure data network.”<sup>18,19</sup> Data collected during the HIV testing process or at a later date is used to populate the eHARS data system including sex at birth and current gender identity information. Collecting accurate data on gender identity for individuals receiving a positive HIV test was described as challenging in the Deep South states.

State health department respondents reported that one of the challenges to collecting gender identity information was a lack of standardized data collection tools and computer database platforms within and across states. The states are currently using a variety of ways to obtain data to populate gender identity fields in eHARS including utilizing the CDC recommended ACRF.<sup>20</sup> However, interview participants reported encountering significant barriers to reporting accurate gender identity data on the ACRF including incomplete gender identity information and delays in submission of the ACRF forms to the state health departments. Some participants discussed not wanting to mandate the use of ACRF, since inputting these paper documents into electronic form creates additional data entry tasks. One interview participant reported that many of the medical providers in their state will not complete the ACRF, rather these forms are primarily completed by Disease Intervention Specialists (DIS), professionals who are charged with providing information and partner notification services for individuals testing positive for HIV. In another state, field epidemiologists routinely complete the ACRF by contacting providers and/or accessing medical records. Additional paper and electronic data collection forms are being used to capture information regarding individuals who receive HIV testing services. Similar barriers including delays and incomplete information on forms were also reported with these data formats. In addition, some of the forms used by medical providers and/or other entities providing HIV testing or testing follow-up do not include the information needed to use the two-step method of gender identity determination. For example, while the states often receive surveillance information through Electronic Lab Reporting (ELR) systems, most ELR were reported not to have the gender identity fields necessary for the two-step method.

### **Supplementing missing gender identity data:**

To address the lack of consistently reported gender identity information, the Deep South states are using various methods to attempt to supplement this data. These methods differ across states and sometimes within states. For example in North Carolina, the data on a positive HIV test may be first reported to the state through a lab rather than through the testing provider so state surveillance staff do not wait to receive the ACRF from the medical provider, which may be delayed or never arrive. Rather the data regarding the individual receiving a positive test are entered into the surveillance system (NC EDSS) after verifying it via an initial call to the provider by a state surveillance coordinator. Additional information that is not available from the

provider call is obtained, when possible, through an interview with the newly diagnosed individual conducted by a DIS.

Interview participants reported that in addition to the information collected for HIV surveillance and put into eHARS, their states often use data sources that include information about gender identity to complete these fields. For example, web-based systems used for STD surveillance, partner tracking, and partner notification such as Patient Reporting Investigation Surveillance Manager (PRISM) (STD surveillance and contact tracking)<sup>21</sup> and Maven Disease Surveillance and Outbreak Management System (provides a system of STD reporting and data management)<sup>22</sup> also collect gender identity data and may be of use in instances where individuals are missing gender identity data in the HIV surveillance system. In addition, states use lab reports from companies such as Lab Corp and physician notes to track gender identity. Finally, states were reported to use systems for collecting data on individuals living with HIV including CAREWare, the system for collecting data for the Ryan White Care Act program, to supplement missing gender identity data.<sup>23</sup> HIV case managers and other Ryan White care providers enter information, including gender identity, into CAREWare and these data are matched with existing surveillance information to gather gender identity responses for individuals missing this information in the HIV surveillance database. In Texas, the AIDS Regional Information and Evaluation System (ARIES) is used for data collection, which is similar to CAREWare. State surveillance staff also reported using gender identity indicators in AIDS Drug Assistance Program data to supplement HIV surveillance data.

Another method of obtaining gender identity information involves medical practices allowing surveillance staff to access their electronic medical records to search for gender identity. However, the electronic medical records do not always contain the necessary gender identity fields or the information may not be complete. In these cases, the record abstractor must look through the provider notes for any information about gender identity. In the case where a provider does not report new diagnoses on their own, or allow access to their EMR, sometimes they will provide information for a list of patients when asked. It was reported that providers often do not collect gender identity information in any uniform way.

Information regarding gender identity is also captured or verified through DIS. In some states this information flows to the surveillance systems; in others, there are barriers to data sharing. In Tennessee, DIS attempt to collect data regarding gender identity; however, interview forms used by DIS are often developed at a local level; at least six unique forms are currently utilized throughout the state. The DIS are trained to ask the questions necessary to collect gender identity information but are not using forms/questions consistently across localities. Use of multiple forms was reported to make compiling and comparing data less efficient. Additional barriers to obtaining gender identity data through this method are that not all individuals diagnosed with HIV are interviewed by a DIS worker and for those who are interviewed, the gender identity information may still be incomplete.

To further attempt to report complete gender identity information on individuals diagnosed with HIV, several states reported that the care coordinators who search for individuals living

with HIV who have fallen out of HIV medical care attempt to capture information on these individuals' gender identity when they are located.

State surveillance staff in Alabama were unavailable for comment on collection of gender identity data among individuals diagnosed with HIV. Respondents from an AIDS service organization that is involved in care coordination across the state reported that there were many barriers to testing and that transgender people living with HIV are most likely being undercounted.

### **Additional barriers to identifying gender identity among individuals testing positive for HIV:**

When asked about further barriers to obtaining information about gender identity, state interviewees identified the following:

#### ***Accessibility and acceptability of HIV testing among gender minorities per the perceptions of interview participants:***

- People who are transgender are not as likely to go to a health department or medical provider for HIV testing because they may fear they will be discriminated against or their confidentiality will be breached.
- HIV testing may not be offered in places where transgender people frequent or they may not know about testing options.
- HIV testing may not be a priority in cases where basic needs such as housing and employment are not being met and HIV criminalization and safety are concerns.

#### ***Cultural sensitivity***

Barriers to collecting complete information on gender identity were also reported to include a lack of understanding of gender identity categories for reporting. One related example was provided by a study participant, who said, "One factor I recently became aware of is that some reporters may not be sure at what point they should check a person off as transgender on the case report form. Our staff have encountered office staff who may think, for example, that a person needs to have had gender reassignment surgery, which could limit who they identify as transgender. This highlights the fact that an inherent challenge is that case report forms are completed by providers, not by patients." In addition, gender identity is a more encompassing issue than just transgender identity and many reporting systems do not have a breadth of options such as genderqueer or nonbinary which also leads to undercounting of individuals with diverse gender identities.

It was frequently reported that some staff have an inadequate understanding of social determinants that affect transgender health such as discrimination in health care and employment, lack of adequate housing, and increased risk of violence. This lack of knowledge may result in less compassion and understanding of the challenges faced by transgender people and lowered investment in determining accurate gender identity.



In the interviews, it was also reported that some staff, including DIS, who are often charged with partner notification and linkage to care, may lack important communication skills around transgender issues or are uncomfortable asking questions about a person's gender identity, making it difficult to ascertain true gender identity when they follow-up with persons who are newly diagnosed with HIV. This factor can further be exacerbated by transgender people having distrust toward service providers because of the way they may have been treated previously.

In addition, because transgender issues are politicized and deemed controversial by some at the local and state policy/governmental level, it can be challenging to change a simple HIV-related data collection form or to ask more questions of an individual receiving HIV testing. Bureaucratic processes were reported to act as barriers to making changes to forms or systems that could improve gender identity reporting.

The present day divisive political climates in many states can make it difficult for state staff to push more gender identity inclusive measures for data collection and programming forward. These political climates are particularly exemplified by legislation that inherently discriminates against the transgender population such as "bathroom bills," which require individuals to use the public bathroom that matches their sex assigned at birth. Three Deep South states have introduced legislation restricting restroom access. So far, North Carolina is the only state to sign into law this discriminatory legislation (HB 2 later replaced by HB 142). Additionally, North Carolina and Tennessee have passed laws that specifically prohibit municipalities from passing local non-discrimination ordinances that would protect transgender people.<sup>24</sup>

### **Gender identity reporting in state epidemiologic profiles:**

Two-thirds of Deep South States reported information on gender identity in their online state HIV epidemiology reports. Of the six Deep South states that included information about gender identity in their most recently released online surveillance reports, there was not consistency in the language and categories used for reporting (Table 1).

Examination of each of the six Deep South States' HIV surveillance reports that had data on transgender people identified that the percentage of HIV diagnoses among transgender people fell below 1% (with the exception of Louisiana) (Table 1). These levels are slightly below the national estimate of 1%, which is already thought to be an underestimate according to the CDC, due to inconsistency in transgender reporting.<sup>7</sup>

**Table 1: State Collection of Gender Identity Data**

State	How gender identity data is collected	Gender identity information included in State Surveillance Report	Classification categories in report	Percent of total reported HIV diagnoses that were transgender
AL <sup>25</sup>	No documentation	No (2016)		No documentation
FL <sup>26</sup>	Adult Case Report Form (starting in 2011) STARS (Surveillance Tools and Reporting System)	Slide set – provided prevalence information (2017)	Transgender women Transgender men	0.457%
GA <sup>27</sup>	Adult Case Report Form CAREWare	Yes (2017)	Transgender	0.815%
Louisiana <sup>28</sup>	Adult Case Report Form – modified version CAREWare PRISM	Yes (2017)	Transgender women Transgender men	2.33%
Mississippi <sup>29</sup>	Adult Case Report Form PRISM	No (2015)		No documentation
North Carolina <sup>30</sup>	Adult Case Report Form MAVEN CAREWare ADAP Medicaid	Yes (2017)	Transgender	0.568%
South Carolina <sup>31</sup>	Adult Case Report Form ACCESS MAVEN	No (2018)		No documentation
Tennessee <sup>32</sup>	Adult Case Report Form PRISM CAREWare	Yes (2017)	Transgender person	0.916%
Texas <sup>33</sup>	Adult Case Report Form (adapted version) ARIES STD MIS	Yes (2017)	Transgender women Transgender men	0.883%

### **Respondent ideas for improving data collection related to gender identity:**

The consensus of interview participants was that having accurate information on gender identity in HIV surveillance data would be very beneficial to planning for HIV prevention and care needs. When asked their opinions on what would be needed to obtain more optimal completion and accuracy of this data, there were two primary areas of intervention: data collection and cultural sensitivity. In each category, they identified strategies that could assist with collecting more accurate data on gender identity but noted that these strategies would require leadership, funding, staff buy-in, and commitment to change from multiple types of entities.

#### ***Gender identity data collection:***

Notably, all interview respondents were interested in changes to improve data collection related to gender identity. Most interview respondents reported that changes to surveillance forms and data systems used for testing and testing follow-up were needed so that they could more accurately capture the information necessary to determine gender identity. Specific suggestions included:

- Assistance with/additional funding for provider education regarding data capture - a respondent stated that “more education to providers is needed to encourage them to document the transgender information in case notes, and to record the current gender when known on the ACRF when reporting new and/or updated HIV/AIDS cases to the local HIV/AIDS surveillance staff.”
- Support for states to make changes that would increase their ability to capture gender identity data including mechanisms for the various data systems that collect information on gender identity to be able to sync with one another.
- Related to the above suggestion was a recommendation for assistance with data collection programming: A participant stated that “SAS (data management analysis software) programs need to be written to incorporate database matching of eHARS and the HIV care databases to identify any undocumented transgender cases in eHARS. Once written, matches for these variables will become routine.” This type of data streamlining could assist states to more rapidly and efficiently identify gender identity for individuals receiving a new HIV diagnosis. It was reported that CDC has assisted with this type of data streamlining in the past, as they released standardized SAS code for states to help identify who might have discrepant gender and sex assigned at birth information. For instance, a person might have demographic information indicating they are transgender and lab information with a different sex indicated so this would be flagged for further determination.
- Assistance with encouraging/requiring health care facilities and laboratories to build their Electronic Health Records to include gender identity questions. “The results of the questions could be reviewed by individuals doing chart abstractions and also could be

electronically submitted to the health department. In addition, it would be beneficial to improve training of staff who do chart abstractions to look for gender identity information in records.”

**Cultural sensitivity:** Cultural sensitivity trainings for medical staff and social services providers (including testing professionals and DIS) were also suggested as beneficial strategies to better capture the number of transgender people living with HIV. Specific issues and suggestions included:

- Technical assistance and funding support to enhance LGBTQ cultural sensitivity for individuals involved in testing, DIS, and related data collection. This would include providing routine in-person and web-based training on transphobia, homophobia and undoing racism for individuals involved in collecting gender identity data. There are some examples of existing programs that could be more widely disseminated such as the CDC training on patient-centered health care for transgender individuals.<sup>34</sup>

The CDC also provides the opportunity to request technical assistance on HIV prevention related issues through the capacity building branch.

(<https://www.cdc.gov/hiv/programresources/capacitybuilding/index.html>), which could potentially offer these types of cultural sensitivity trainings. In addition, according to a CDC leadership contact, CDC regional technical assistance (TA) providers can provide a tailored training/TA training on cultural sensitivity related to a prevention or treatment activity at the request of a health department or CBO.<sup>16</sup> Furthermore, the group HealthHIV created a cultural competency training under the funding opportunity, PS15-1510, and will start conducting this training in 2020.<sup>16</sup>

- Some interview respondents suggested that asking questions about a person’s comfort level with and understanding of transgender issues when conducting employment interviews for DIS or other related positions would also assist in identifying knowledge levels and the need for gender identity training.
- Interview participants said that many medical providers, especially at university and HIV specialty clinics seem skilled and sensitive when asking questions about gender identity. However, respondents also reported that there are some providers who do not even ask basic questions about gender identity thus training is needed to increase cultural sensitivity among medical providers. One respondent said, “We need cultural competence with medical providers.”
- Interview participants reported that medical care providers/staff in rural areas are often less knowledgeable about transgender issues. It was reported that in some cases, providers had culturally inappropriate responses to transgender people and created mistrust that lingered. When asked how cultural sensitivity can be improved in rural areas, interview participants suggested trainings for smaller, rural clinics on gender identity would be beneficial. One respondent noted that this information needs to be

reinforced repeatedly, saying, “It will take more than one training to change attitudes about transgender issues.”

- Several respondents suggested that ongoing engagement of transgender people in the development of surveillance systems will support adequate data collection. Input from members of the transgender community could also assist in guiding interventions and services to better serve this population and other gender minorities. This guidance is also essential in developing cultural sensitivity programming that both educates and assists providers to create environments that are safe for transgender individuals to disclose their gender identity and receive the care they need.

State surveillance interview respondent suggestions were consistent with recommendations issued by the UCSF Center of Excellence for Transgender HIV Prevention to improve gender identity data collection. One step recommended by the Center was to update data collection methods to maximize accurate collection of information for the two-step method. Secondly, the recommendation was to train staff and health professionals to ask questions about gender identity correctly and consistently. Training regarding transgender issues was an essential part of this step. Respondents echoed this sentiment and said that training for health care personnel would build trust with transgender communities and reduce stigma. In addition, the Center recommended that information gathered regarding gender identity should be used to identify emerging trends and inform allocation of resources.<sup>10</sup>

### **State spotlight: Louisiana cultural competency training as a best practice model**

Surveillance staff from all Deep South states said that training on transgender issues is needed and vital, especially for those working directly with transgender PLWH (DIS, HIV counselors, medical providers), but many programs do not have enough training available to them. Louisiana surveillance staff, however, reported that they consistently were able to offer exceptional training for staff on issues affecting transgender people, namely deconstructing transphobia and undoing racism. Training was initially funded through a demonstration project. The lack of this type of funding in other states appeared to hamper their ability to offer this level of training.

Louisiana staff reported that they also discussed LGBT issues when interviewing candidates for all positions. This included DIS, HIV testers and counselors, epidemiologists, and front office staff. Of particular note in interviews with LA state staff was the motivation across the board, from leadership to front line staff, to make the transgender population a priority.

Furthering the state of Louisiana’s commitment to transgender PLWH, in 2017, Louisiana’s HIV/STD/Viral Hepatitis Surveillance Manager co-authored a position paper on *Transgender HIV Surveillance* with an Epidemiologist and Medical Director from the Public Health Department in Philadelphia, PA. This paper clearly defined the barriers to obtaining accurate HIV surveillance data among transgender people, examined the impact on public health and offered action steps to begin the process of changing how surveillance is working at the present time.<sup>35</sup>

## CONCLUSIONS |

The United States Healthy People 2020 goals for the LGBT population state the importance of increasing the number of states, territories, and the District of Columbia that include questions that identify sexual orientation and gender identity in state level surveys and data systems.<sup>13</sup> Other policy research organizations, such as USCF and Council of State and Territorial Epidemiologists, have also reported the necessity of having these data for HIV prevention and care planning. Despite this goal, it is not clear how gender identity data can be reliably and consistently collected for individuals testing positive for HIV within the current systems of HIV testing data collection.

The CDC recommends that states capture data on gender identity using a two-step method that asks about sex assigned at birth and current gender identity. According to most Deep South state government representatives interviewed for this project, the gender identity information that is currently being collected is not complete and a number of steps would be necessary to more accurately capture and present this information. These steps include support for improving data collection mechanisms, funding for LGBTQ-related sensitivity training for staff and providers, offering testing, working with individuals living with HIV, and commitment from labs, healthcare organizations, and other entities collecting data on individuals testing for HIV to include and sensitively collect information regarding gender identity.

Gender identity information has not been included in the CDC HIV Surveillance report to date; however, per conversation with the CDC,<sup>16</sup> this information is expected to be released in 2020 with the caveat that it is likely to be incomplete due to the aforementioned barriers to gender identity data collection. A CDC report on HIV and transgender communities describes barriers to accurate reporting of gender identity and presents information on CDC efforts to improve data on HIV among transgender populations including revising the data fields to include gender identity information and issuing “recommendations and statistical tools for health departments to collect information on current gender identity”.<sup>5</sup>

A significant barrier to collecting gender identity data is a lack of availability of this information in medical databases including at laboratories. In an effort to improve electronic data collection of gender identity information by health care organizations, this issue is being addressed as a part of a larger endeavor labeled “Meaningful Use,” which is led by the Centers for Medicare and Medicaid Services (CMS) and the Office of the National Coordinator for Health Information Technology (ONC). This program designation was renamed as Promoting Interoperability (PI) in April 2018. Meaningful Use has been defined as “the use of Electronic Health Record (EHR) technology in a meaningful manner (for example electronic prescribing); ensuring that the certified EHR technology connects in a manner that provides for the electronic exchange of health information to improve the quality of care.”<sup>36</sup> To address the lack of routinely collected and standardized gender identity information, in 2018, CMS made instituting a system of gender identity reporting a mandatory part of receiving a Meaningful Use Stage 3 designation (the final stage of the Meaningful Use designation process, which focuses on using certified

electronic health record technology (CEHRT) to improve health outcomes).<sup>37</sup> Organizations participating in meaningful use must adhere to the rigorous privacy and confidentiality policies required through the meaningful use designation process. In October 2018, more than 642,600 eligible professionals, eligible hospitals, and critical access hospitals were actively registered in the Medicare and Medicaid Promoting Interoperability program (CMS.gov, 2019). However, though sexual orientation and gender identity were required to be made available fields for providers who wish to collect this information, collection of this data from patients is not required.<sup>38</sup> Thus even for organizations that have decided to enter the process for Meaningful Use designation, many organizations may not be routinely and uniformly collecting gender identity data.

Study participants reported that identifying ways to effectively motivate these organizations to collect gender identity data is a critical component of comprehensive gender identity data collection among individuals testing positive for HIV. However, previous studies have found that many healthcare organizations perceived barriers to incorporating a systematic data collection approach for gender identity and sexual orientation. Perceived barriers included making staff and patients uncomfortable, the inability to record the data in the EHR platform, and inadequate dissemination of best practices.<sup>39</sup> Researchers found that 77.9% of providers felt patients would be offended by or refuse questions about sexual orientation and gender identity; however, only 10.3% of patients actually reported this.<sup>40</sup> Instituting culturally sound systems of data collection and service providers at all levels of care that are culturally sensitive and provide safe environments for care can assist in maximizing individuals' comfort in sharing gender identity information. However, self-determination is critical; thus, systems that appear or are coercive in acquiring this information must be strictly avoided so that individuals perceive that they maintain the right to withhold this information if they prefer. Because of this self-determination requirement, the data can never be fully complete; similar to collection of any type of sensitive data.

## RECOMMENDATIONS |

Based on the information and recommendations provided by state interview participants (and input from transgender people in the Deep South), the following is recommended:

The federal government should take the following steps to improve the consistency, accuracy and availability of gender identity information in HIV surveillance reporting:

- To ensure more complete gender identity collection, the US Department of Health and Human Services, through the CDC, HRSA, and other relevant divisions and agencies, should provide financial and technical assistance support to states and localities to improve data collection mechanisms and create systems for relevant databases to efficiently communicate with each other.
- Provide increased federal funding through CDC and/or other federal agencies to support gender identity cultural sensitivity training for health department staff and

providers working with individuals being tested and treated for HIV. Training should be focused on sensitivity around transgender-related issues, including medical issues, and funded training should provide meaningful involvement for members of the transgender community.

- Develop formal guidance and provide technical assistance through the CDC that targets and educates laboratories and other medical organizations on best practices to develop and implement systems of data collection that routinely capture gender identity data while also guaranteeing that respondent privacy and confidentiality are protected and non-discrimination provisions are in place.
- Once the foregoing technical assistance and training is in place but no later than 2023, the CDC should establish benchmarks for completion of gender identity information on the ACRF.

## **ACKNOWLEDGEMENTS |**

This report was supported by the Ford Foundation. We also wish to acknowledge and express our deep gratitude to the state health department representatives for their time and willingness to participate in the interviews and multiple follow-up clarifications and to those members of the transgender community who provided feedback and technical assistance for this report. Finally, we thank the leadership and policy team at the Southern AIDS Coalition for their support and policy guidance.



## REFERENCES |

1. NCHHSTP Atlas. 2019. <http://www.cdc.gov/nchhstp/atlas/>. Accessed April 2019.
2. Reif S, Safley D, Wilson E, Whetten K. HIV/AIDS in the U.S. Deep South: Trends from 2008-2013. <https://southernaids.files.wordpress.com/2011/10/hiv-aids-in-the-us-deep-south-trends-from-2008-2013.pdf>. Published 2016. Accessed.
3. Reif S, Wilson E. Interventions to address HIV-related stigma: Literature Summary. <https://southernaidsstrategy.org/hiv-related-stigma-research/>. Published 2017. Accessed 2019.
4. Reif S, Whetten K, Wilson E, et al. HIV/AIDS in Southern USA: A disproportionate epidemic. *AIDS Care*. 2014;26(3):351-359.
5. Centers for Disease Control and Prevention. *HIV and transgender people*. Atlanta: Division of HIV/AIDS Prevention, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, Centers for Disease Control and Prevention; 2019.
6. Becasen J, Denard C, Mullins M, Higa D, Sipe T. Estimating the prevalence of HIV and sexual behaviors among the US transgender population: A systematic review and meta-analysis, 2006-2017. *American Journal of Public Health*. 2018:e1-8.
7. Clark H, Babu A, Wiewel E, Opoku J, Crepaz N. Diagnosed HIV infection in transgender adults and adolescents: Results from the national HIV Surveillance System. *AIDS and Behavior*. 2017;21(9):2774-2783.
8. National Center for Transgender Equality. *Issues: Housing & Homelessness*. 2019.
9. Human Rights Campaign. A national epidemic: Fatal anti-transgender violence in America in 2018. <https://www.hrc.org/resources/violence-against-the-transgender-community-in-2019>. Published 2018. Accessed.
10. Sausa L, Sevelius J, Keatley J, Iniguez J, Reyes M. *Policy recommendations for inclusive data collection of trans people in HIV prevention, care & services*. University of California, San Francisco; 2009.
11. Human Rights Campaign. Violence Against the Transgender Community in 2018. <https://www.hrc.org/resources/violence-against-the-transgender-community-in-2018>. Published 2018. Accessed.
12. Center for Disease Control and Prevention. *HIV Surveillance Report, 2017*. 2018.
13. Healthy People 2020. Lesbian, gay, bisexual and Transgender Health. <https://www.healthypeople.gov/2020/topics-objectives/topic/lesbian-gay-bisexual-and-transgender-health>. Published 2019. Accessed.
14. Nassau T, Brady K, Fridge J. Transgender HIV Surveillance. Council of State and Territorial Epidemiologists. <https://cdn.ymaws.com/www.cste.org/resource/resmgr/2017PS/2017PSFinal/17-ID-06.pdf>. Published 2017. Accessed 2019.
15. Human Rights Campaign. Human rights campaign report: State and federal officials failing LGBTQ community in data collection. <https://www.hrc.org/press/human-rights-campaign-report-state-and-federal-officials-failing-lgbtq-comm>. Published 2019. Accessed November, 2019.
16. Hall I. Skype Conversation 2019.
17. Balagi A. Email Correspondence. 2019.
18. Cohen S, Gray K, Ocfemia M, Johnson A, Hall H. The status of the national HIV surveillance system, United States, 2013. *Public Health Reports*. 2014;129(4):335-341.

19. Centers for Disease Control and Prevention. Enhanced HIV/AIDS reporting system. <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published 2009. Accessed.
20. Centers for Disease Control and Prevention. Adult HIV Confidential Case Report. <https://www.cdc.gov/hiv/pdf/guidelines/cdc-hiv-adult-confidential-case-report-form-2018.pdf>. Published 2018. Accessed.
21. Shiver S, Schmitt K, Cooksey A. Use of a Business Approach to Improve Disease Surveillance Data Management Systems and Information Technology Process in Florida's Bureau of STD Prevention and Control. *Public Health Reports*. 2009;124:98-102.
22. Conduent. Maven Disease Surveillance and Outbreak Management System. <https://downloads.conduent.com/content/usa/en/brochure/maven-outbreak-management.pdf>. Accessed September, 2019.
23. HRSA. CAREWare. <https://hab.hrsa.gov/program-grants-management/careware>. Published 2019. Accessed July, 2019.
24. Kralik J. "Bathroom bill" legislative tracking. <http://www.ncsl.org/research/education/-bathroom-bill-legislative-tracking635951130.aspx>. Published 2017. Accessed.
25. Alabama Division of STD Prevention and Control HIV Surveillance Branch. State of Alabama HIV surveillance 2017 Annual Report. [https://www.alabamapublichealth.gov/hiv/assets/hivsurveillanceannualreport\\_2017.pdf](https://www.alabamapublichealth.gov/hiv/assets/hivsurveillanceannualreport_2017.pdf). Published 2018. Accessed 2019.
26. Florida Department of Health. State of epidemic, 2017, State HIV slide sets. <http://www.floridahealth.gov/diseases-and-conditions/aids/surveillance/epi-slide-sets.html>. Published 2019. Accessed 2019.
27. Georgia Department of Public Health HIV/AIDS Epidemiology Section. HIV Surveillance Summary, Georgia 2017. [https://dph.georgia.gov/sites/dph.georgia.gov/files/HIV\\_EPI\\_2017\\_Surveillance\\_Summary\\_20190128.pdf](https://dph.georgia.gov/sites/dph.georgia.gov/files/HIV_EPI_2017_Surveillance_Summary_20190128.pdf). Published 2019. Accessed 2019.
28. State of Louisiana Department of Health. 2017 STD/HIV surveillance report. [http://ldh.la.gov/assets/oph/HIVSTD/std/STDAnnualReports/2017\\_STDHIV\\_SURVEILLANCE\\_REPORT.pdf](http://ldh.la.gov/assets/oph/HIVSTD/std/STDAnnualReports/2017_STDHIV_SURVEILLANCE_REPORT.pdf). Published 2019. Accessed 2019.
29. Department of Health SHO. State of Mississippi 2015 STD/HIV epidemiologic profile,. [https://msdh.ms.gov/msdhsite/\\_static/resources/7543.pdf](https://msdh.ms.gov/msdhsite/_static/resources/7543.pdf). Published 2017. Accessed August, 2019.
30. HIV/STD/Hepatitis Surveillance Unit NC Department of Health and Human Services. North Carolina HIV/STD/Hepatitis surveillance report 2017. [https://epi.dph.ncdhhs.gov/cd/stds/figures/std17rpt\\_rev12142018.pdf](https://epi.dph.ncdhhs.gov/cd/stds/figures/std17rpt_rev12142018.pdf). Published 2019. Accessed 2019.
31. DHEC SC. Surveillance Report. [https://epi.dph.ncdhhs.gov/cd/stds/figures/std17rpt\\_rev12142018.pdf](https://epi.dph.ncdhhs.gov/cd/stds/figures/std17rpt_rev12142018.pdf). Published 2017. Accessed 2019.
32. Tennessee Department of Health. Tennessee HIV epidemiologic profile. [https://www.tn.gov/content/dam/tn/health/program-areas/hiv/2017\\_HIV\\_Epi\\_Profile.pdf](https://www.tn.gov/content/dam/tn/health/program-areas/hiv/2017_HIV_Epi_Profile.pdf). Published 2018. Accessed 2019.
33. TB/HIV/STD Epidemiology and Surveillance Branch. Texas HIV surveillance report, 2017 annual report. <https://www.dshs.texas.gov/hivstd/reports>. Published 2018. Accessed 2019.

34. Centers for Disease Control and Prevention. Patient-Centered Care for Transgender People: Recommended Practices for Health Care Settings. <https://www.cdc.gov/hiv/clinicians/transforming-health/health-care-providers/affirmative-care.html>. Published 2019. Accessed November, 2019.
35. Council of state and territorial epidemiologists. Transgender HIV Surveillance. <https://cdn.ymaws.com/www.cste.org/resource/resmgr/2017PS/2017PSFinal/17-ID-06.pdf>. Accessed 2019.
36. Centers for Disease Control and Prevention. Public health and promoting interoperability programs (formerly , known as Electronic Health Records Meaningful Use. <https://www.cdc.gov/ehrmeaningfuluse/introduction.html>. Published 2019. Accessed September, 2019.
37. CMS.gov. Certified EHR technology. . Published 2019. Accessed September, 2019.
38. HealthIT.gov. 2015 edition test method resources: . Published 2017. Accessed September, <https://www.healthit.gov/test-method/demographics>.
39. Grasso C, McDowell M, Goldhammer H, Keuroghlian A. Planning and implementing sexual orientation and gender identity data collection in electronic health records. *Journal of the American Medical Informatics Association*. 2019;26(1):66-70.
40. Haider H, Schneider E, Kodadek L. Emergency department query for patient-centered approaches to sexual orientation and gender identity: the EQUALITY Study. *JAMA Internal Medicine*. 2017;177(6):819-828.