

# Development of a Statewide Survey of Transgender Health Needs

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# Disclosures

Presenter(s) has no financial interest to disclose.

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# Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. Understand how to design data collection instruments to ensure experiences of transgender population are effectively captured
2. Have knowledge of respondent-driven sampling methods
3. Understand issues about transgender health needs

# Background

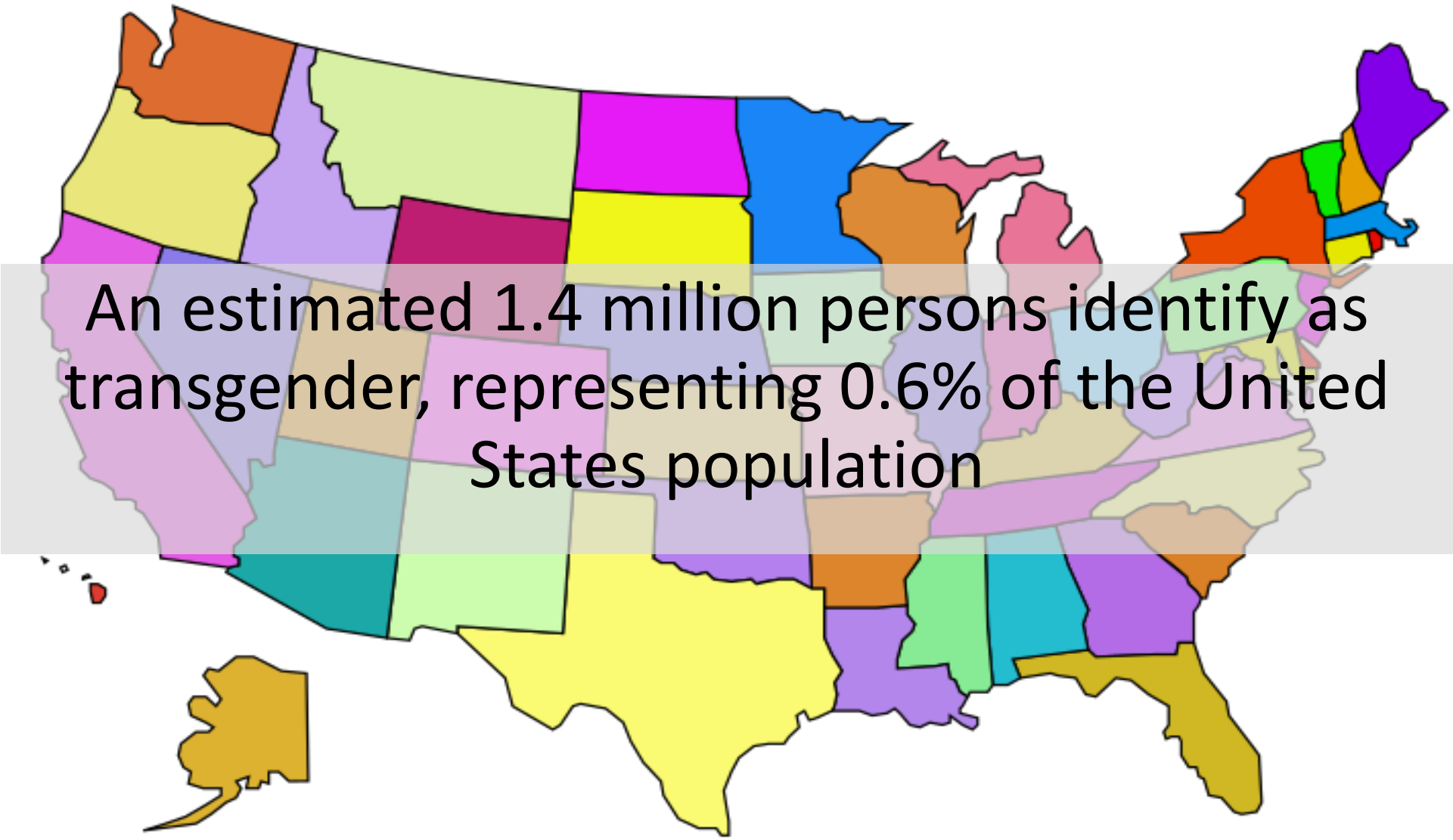
- Data on transgender persons and health needs are lacking in national datasets
- Transgender women in the United States are at high risk for acquiring HIV. According to current estimates, around a quarter ([22-28%](#)) of transgender women are living with HIV
- More than half ([an estimated 56%](#)) of black/African American transgender women are living with HIV.
- Among the 3 million HIV testing events reported to CDC in 2015, the percentage of transgender people who received a new HIV diagnosis was more than 3 times the national average.

Source: <https://www.hiv.gov/blog/dear-colleague-cdc-observes-national-transgender-hiv-testing-day-2018>

# You can't count if you aren't counted

Judy Bradford, Virginia Commonwealth University, Fenway Institute

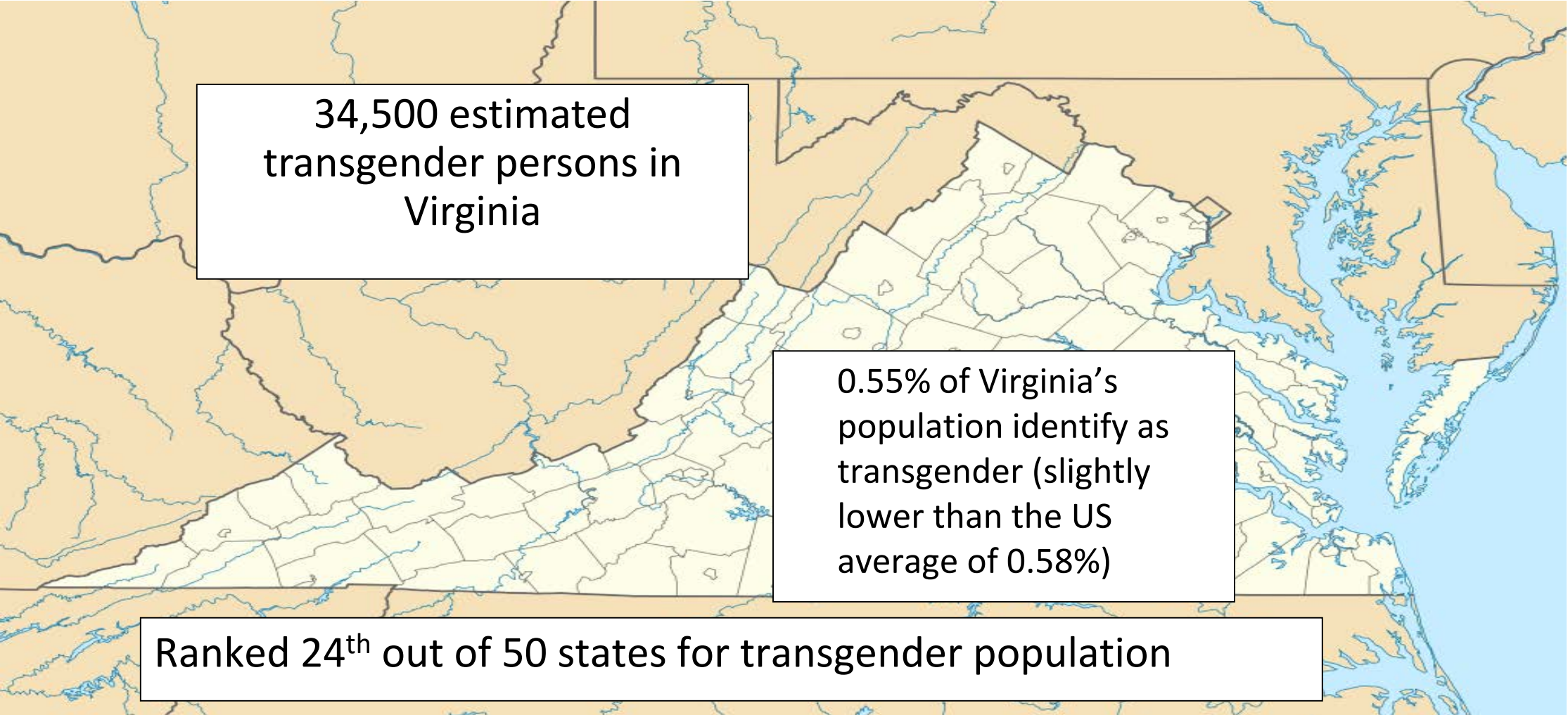




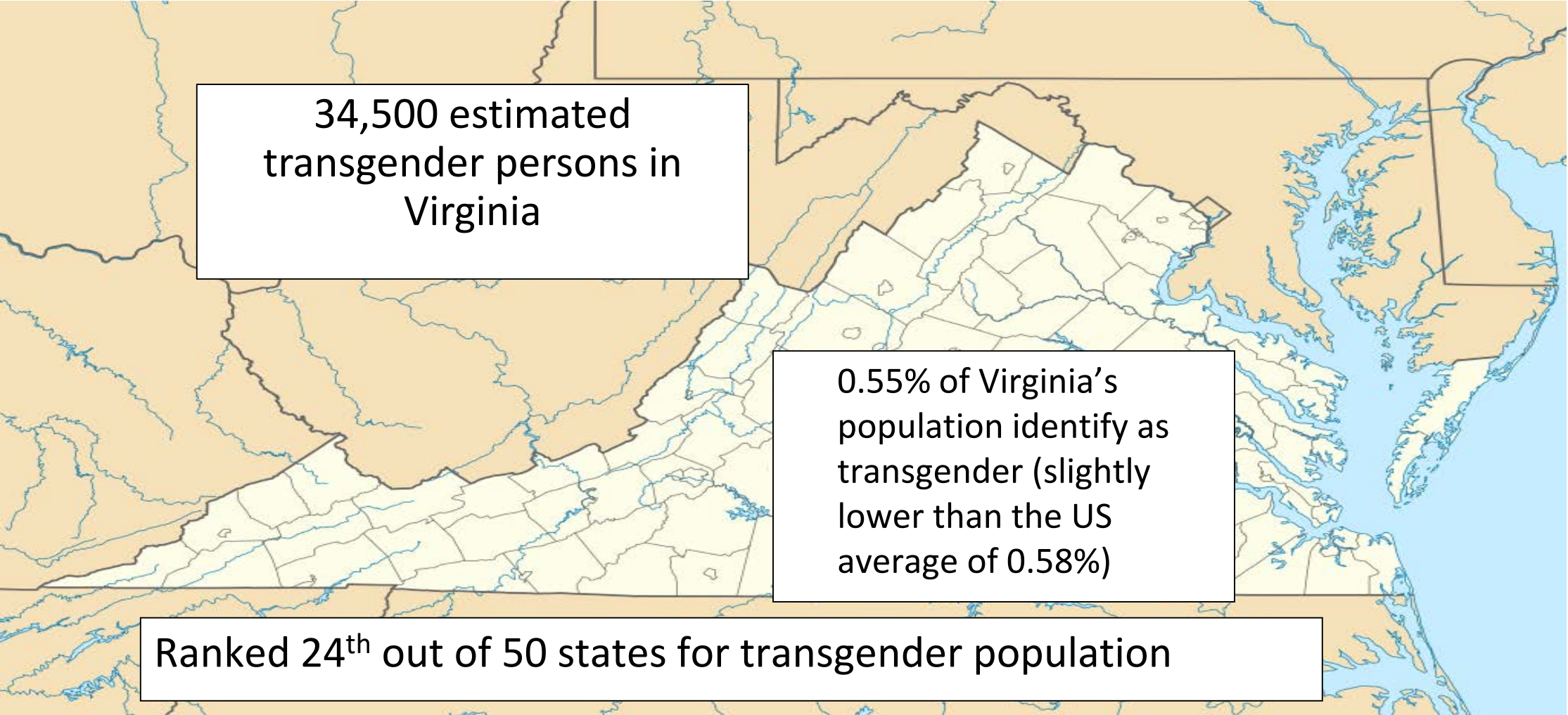
An estimated 1.4 million persons identify as transgender, representing 0.6% of the United States population



# Transgender Persons in Virginia

A map of Virginia showing county boundaries. A white callout box with a black border is positioned in the upper left quadrant of the map. The text inside the box is centered and reads: "34,500 estimated transgender persons in Virginia".

34,500 estimated transgender persons in Virginia

A map of Virginia showing county boundaries. A white callout box with a black border is positioned in the lower right quadrant of the map. The text inside the box is centered and reads: "0.55% of Virginia's population identify as transgender (slightly lower than the US average of 0.58%)".

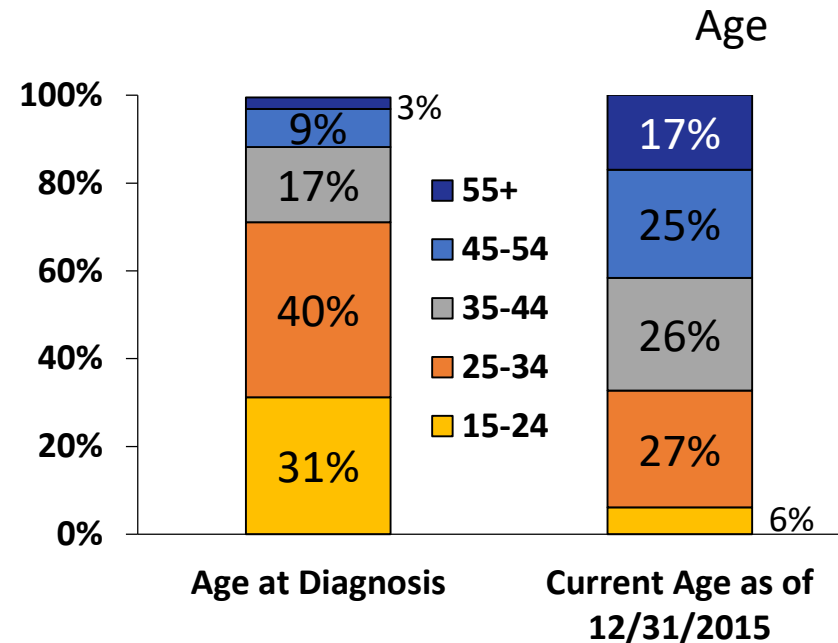
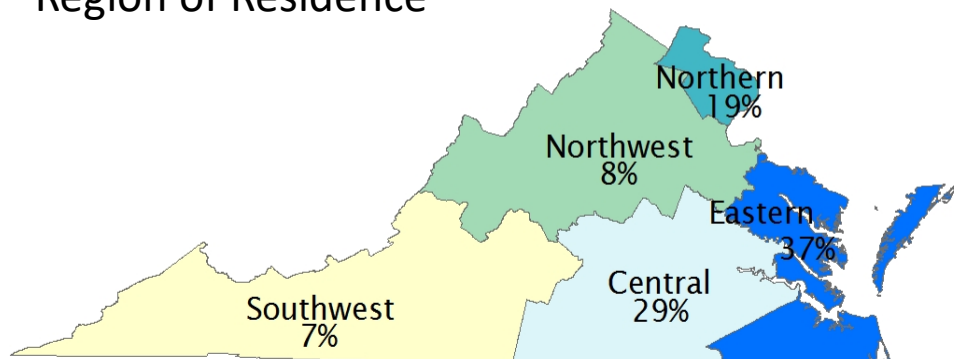
0.55% of Virginia's population identify as transgender (slightly lower than the US average of 0.58%)

A map of Virginia showing county boundaries. A white callout box with a black border is positioned at the bottom center of the map. The text inside the box is centered and reads: "Ranked 24<sup>th</sup> out of 50 states for transgender population".

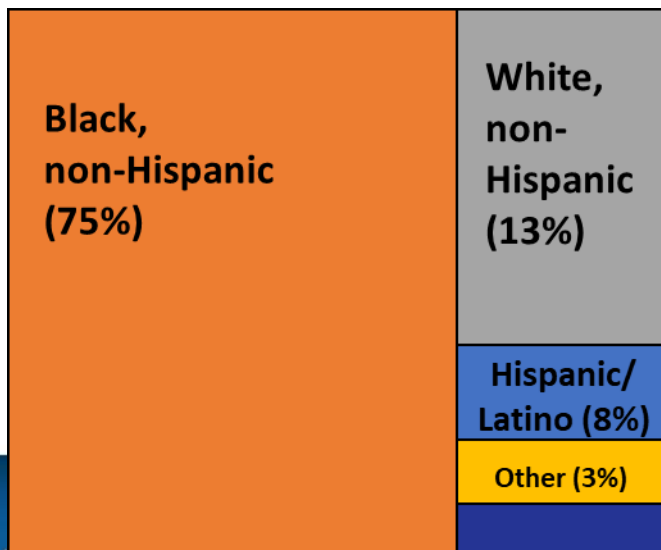
Ranked 24<sup>th</sup> out of 50 states for transgender population

# Transgender Persons Living with HIV in Virginia as of December 31, 2015 (N=346)

Region of Residence



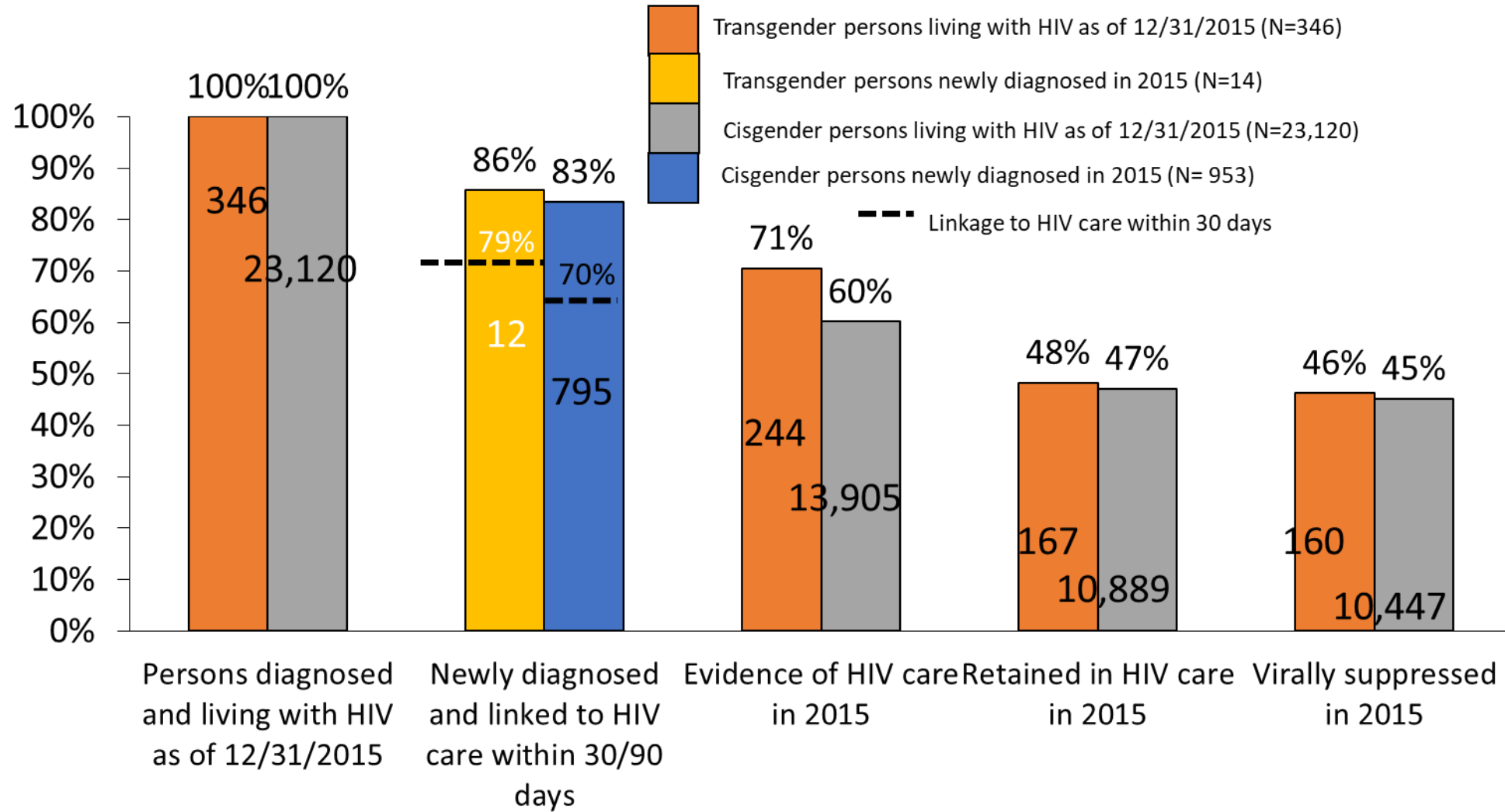
Race/Ethnicity



Transmission Risk	% of PLWH
Men who have sex with men (MSM)	66%
No reported or identified risk (NIR/NRR)	13%
Heterosexual contact	12%
MSM with history of injection drug use (IDU)	5%
IDU	4%
Other (mother-to-child and receipt of blood products)	0%



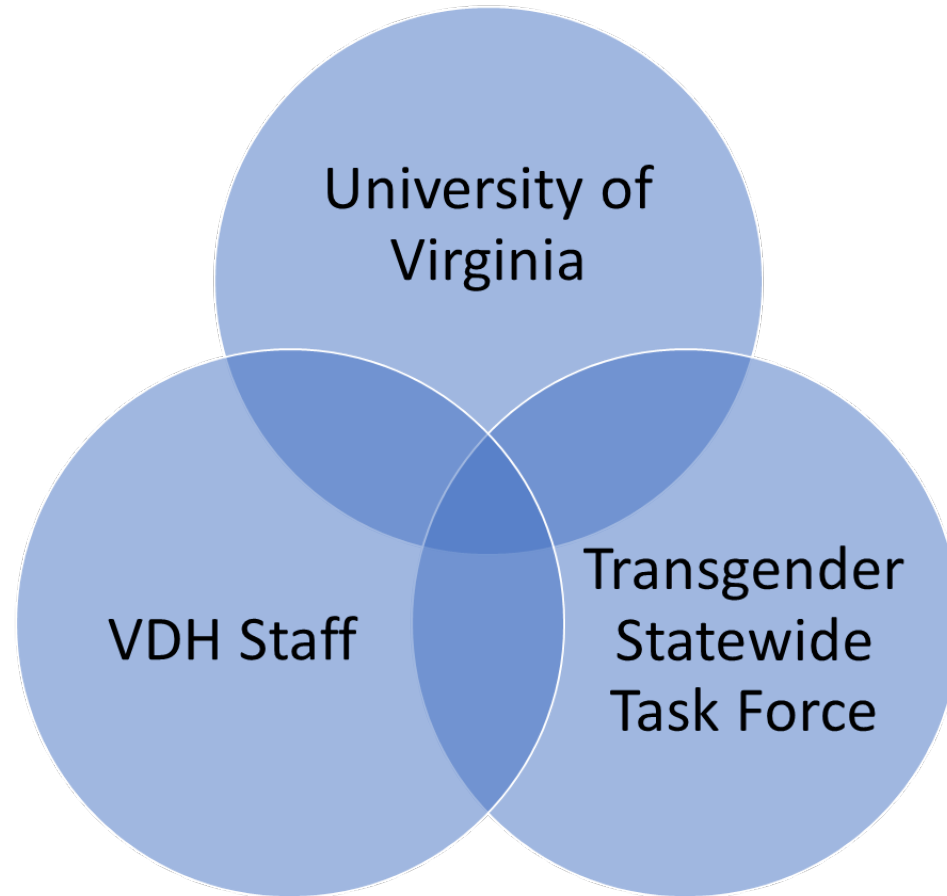
# HIV Continuum of Care in Virginia by Transgender Identity, 2015



# Study Overview – Legacy Study

- 2005 statewide study conducted (Virginia Transgender Health Initiative Study (THIS), 2005-2006)
- Focused on transgender health experiences and discrimination
- 387 self-identified transgender persons completed the survey
- Overall findings concluded that transgender Virginians (41%) experienced widespread discrimination in health care, employment, and housing

# 2017 Update



# Study Overview – What's in the current survey?

## Current Study Topics:

- Demographics
- Transgender Experiences and Discrimination
- Social and Relational Support
- Substance Use
- Mental Health
- General Health Care
- Transgender Health Care
- Sexual/Health Behaviors

## Sub-Topics:

- HIV Testing/Status & PrEP
- Access to HIV, STD, HCV prevention & education
- Access to HIV treatment and care

# Study Timeline

- \*Develop study questions and project design.

- \*Hold community advisory meetings.

## **Summer 2017**

- \*Finalize study questions and project design including IRB approval.

- \*Hold second community advisory meeting.

## **Fall 2017**

- \*Obtain IRB approval.

- \*Begin study recruitment.

- \*Launch study.

## **Winter-Spring 2018**

# Study Overview – Community Input

## Major Themes from First Community Meeting (June 2017)

- Social & Relational Support
- Mental Health
- Substance Use
- End of Life Care
- Sex Work
- Adoption and Child Rearing

# Themes from Pilot

- Ability for persons to provide details, stories rather than just answer specific question
- Wanted questions on experiences of violence
- Strong feeling that no one else is asking for this type of data and we are trying to represent trans people across the state and unearth these experiences that they think are quite common
- Change the title of the survey- not to isolate people that think they are not transgender – ie gender non-conforming
- Did not like knowledge questions – felt like they were not helpful



# Respondent-Driven Sampling

- Utilized for difficult to reach populations. Survey enrollment is driven by “seeds”.
- Community based organizations and members share information about the study to their well-connected members. If individuals are interested in becoming a seed for the project they will contact UVA or provide permission for UVA to contact them.
- Upon completion of the survey, seeds will be given coupons and directions to invite others to participate. When individuals redeem a coupon and take the survey they will also be provided with recruitment coupons that grow the recruitment chain. This method allows us to reach individuals who otherwise may not be reached by the study.

# Sample Selection

Health Planning Region	Estimated Transgender Population (0.55%)	Sample Size
1 – Northwest	7163	143
2 – Northern	13462	269
3 – Southwest	7459	149
4 – Central	7821	156
5 – Eastern	10201	204
<b>Total</b>		<b>922</b>

# Where are We?

- Launching survey in two areas of Virginia
- Found a few initial issues with survey questions in first interviews and submitted an IRB modification to update the survey
- Plan to launch full survey in December and to rest of state in 2019

# Acknowledgements



University of Virginia: Jessica Xavier, Rebecca Dillingham, Karen Ingersoll, Sarah Knight, Tabor Flickinger, Chelsea Canan, Kate McManus

Virginia Department of Health: Lauren Yerkes, Kathryn Gilmore, River Pugsley, Ted Heck, Bruce Taylor, Diana Jordan

Statewide Transgender Task Force

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