Surveillance and Evaluation Webinar Series Presents:

ADVANCING HEALTH EQUITY THROUGH THE POWER OF DATA

WEDNESDAY, MAY 20, 2020

The findings and conclusions in this presentation are those of the author and do not necessarily represent those of the Centers for Disease Control and Prevention.

ADVANCING HEALTH EQUITY THROUGH THE POWER OF DATA

Hosted by: National LGBT Cancer Network & National Behavioral Health Network and National Native Network

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I run one of eight CDC-funded tobacco and cancer disparity networks. In this capacity I spend a lot of my time helping invoke system changes that build capacity of CDC grantees and health care groups to reach and serve sexual and gender minorities.
Why COVID-19 is decimating some Native American communities

As Coronavirus Spreads, Racism And Xenophobia Are Too

March 11, 2020 • 4:00 AM ET
Our number one health risk

LGBT people use tobacco at rates higher than the general population. 50%
LGBT youth smoking rates

Current cigarette smoking?

8.1% 16.2%
Hetero LGB
2017 YRBS

LGBT youth smoking rates

Current vape use?

13.2% 17.5%
Hetero LGB
2017 YRBS
Worse survivorship outcomes

When compared to the general population of cancer survivors...

Lesbians were 2x as likely to report poor health.

Bi women were 2.3x as likely to report poor health.

We want to disclose

In one study of emergency room patients,

90% of LGB people wanted to disclose sexual orientation.

78% of providers worried about asking.
Advancing Sexual Orientation/Gender Identity (SOGI) Measures in the Behavioral Risk Factor Surveillance System (BRFSS)

The number of Americans who identify as lesbian, gay, bisexual, and transgender (LGBT) is increasing. According to the 2018 Gallup and PNA Research Center report, (i) at least 11 million U.S. adults identify as LGBT (4.5% of the U.S. adult population). This represents a modest but substantial increase from the 9 million U.S. adults (3.5% of U.S. adult population) who identified as LGBT in 2012. (ii) This growth may be in part due to increased disclosure of LGBT status following progress in societal acceptance and legislative protections (e.g., the 2013 U.S. Supreme Court ruling on marriage for same-sex couples). As the number of Americans who identify as members of the LGBT population increases, the role of surveillance systems, like the BRFSS, (iii) becomes even more critical in measuring health disparities.

Use of the Optional BRFSS SOGI Module is Rapidly Becoming a Norm for States.

In 2006 no states were collecting sexual identity and none were collecting gender identity data. Over the span of 2013-2018, 35 states used the standardized BRFSS SOGI module. (v)

Pooled datasets are providing leading edge information. The BRFSS SOGI module has resulted in the publication of more than 120 peer reviewed articles, focusing on a range of health behaviors among U.S. LGBT adults. Pooled datasets are providing particularly valuable information about a range of health behaviors. As the BRFSS has the largest sample size of any surveillance instrument, these pooled datasets have long been identified as having the greatest potential to allow researchers to investigate subpopulations such as LGBT people of color. (v)

SOGI Adoption

Number of States with Same-Sex Sexual Behavior, Sexual Orientation, and Gender Identity Items in BRFSS, 1995-2017
Shifting demographics

Gen Z more familiar with gender-neutral pronouns

% saying they personally know someone who prefers that others refer to them using gender-neutral pronouns

- Gen Z: 35
- Millennials: 25
- Gen X: 16
- Boomers: 12
- Silent: 7


Shifting demographics - 14.7M

http://www.tacenters.emory.edu/resources/SEwebinars/
Models for Dissemination

Government of the District of Columbia
Department of Health

EHR Campaign

http://www.tacenters.emory.edu/resources/SEwebinars/
Electronic Health Records and LGBTQ Data Collection

For Immediate Release

April 21, 2020

Contact:
Scout, 401-267-8337, scout@lgbtcan.org or Jewel Adity, 402-204-5137, jewel@lgbtcan.org

LGBTQ+ AND ALLIED ORGANIZATIONS ISSUE SECOND OPEN LETTER URGING DECISIVE ACTION TO PREVENT COVID-19 DISCRIMINATION

170 Organizations Highlight Need for Nondiscrimination, Sexual Orientation & Gender Identity Data Collection, and More Help for Economically Devastated Communities

Health care providers and public health authorities to collect sexual orientation and gender identity data for COVID-19 cases in addition to data on race, ethnicity, age, sex and disability, in order to document and address the pandemic’s impact on minority communities. The signing organizations also emphasize the urgent need for more robust relief for lower-income individuals and families, and for persons who are dependent on lower-paying jobs in hospitality and other industries which are being devastated by the pandemic.

“We are in the middle of an unprecedented global health crisis - and we cannot afford to leave anyone behind,” said Rep. Barbara Lee, Vice Chair of the Congressional LGBTQ+ Equality Caucus. “As our work continues to get families and communities the resources they need to survive, we must ensure that protecting LGBTQ+ communities is a core part of our country’s response to COVID-19. Ensuring non-discrimination has and always will be a priority for me, and I will continue to work with my colleagues to make that a reality.”

“LGBTQ+ people have increased risk factors for COVID-19, including higher HIV and cancer rates, higher rates of smoking, and increased risk of homelessness,” said Senator Scott Wiener (D-San Francisco), who serves as Chair of the California Legislative LGBTQ Caucus and recently led a letter urging data collection. “We must ensure that the LGBTQ community has access to the resources it needs to face this pandemic, including quality, non-judgmental, and affordable healthcare, as well as unemployment benefits for every impacted industry, including the service and entertainment sectors. We also must collect data to understand how the LGBTQ+ community is being impacted by COVID-19.”

http://www.tacenters.emory.edu/resources/SEwebinars/
COVID-19: LGBTQ community kept in closet by public health officials

April 27, 2020  •  by Scout

Data collection important

What does that mean?

We use tobacco at rates that are 50% higher than the general population, and ½ of all cancers are caused by tobacco use. But can I give you an overview of our disproportionate cancer impact as a result? No.

Let's switch to our current public health crisis, the COVID-19 pandemic. An estimated 2.3 million LGBTQ+ people are cigarette smokers. An early study out
Dr. Rachel Levine  
Secretary of Health  
625 Fostler St  
Harrisburg, PA 17120

Secretary Levine:

The 26 undersigned organizations write to you with profound gratitude for your historic leadership during this crisis. The global COVID-19 pandemic is causing incredible challenges for the health of all Pennsylvanians, including LGBT Pennsylvanians. Due to LGBT population disparities in tobacco use, HIV incidence, and cancer diagnosis, as well as a history of barriers to care and discrimination, LGBT Pennsylvanians live with increased risk factors and vulnerabilities for COVID-19 infection.

Early epidemiological analyses have spotlighted disparities in death rates for both African American and Latinx populations; these are exactly the type of analyses that also need to be conducted for the LGBT population. In order to do so, it is critical that hospitals and testing sites collect LGBT demographic data from COVID-19 patients (testing results, hospitalizations, and mortality). Without these data, efforts to limit exposure for the LGBT community through behavioral change (including community adherence to the sound direction from PA Department of Health and the CDC), as well as clinical efforts to improve care for adversely impacted populations, will be limited.

We understand that many hospitals and clinics are overwhelmed. And we know that some have not complied with your mandate regarding data collection efforts for other adversely impacted populations. However many hospitals are complying. We are asking that you utilize your power as Secretary of...
Action Steps

1. Do your evaluation activities routinely collect SOGI as part of demographic measures?
2. Are you analyzing and disseminating those findings?

Thank you.

For more information contact us at info@cancer-network.org.
National Behavioral Health Network

Meet NBHN

The National Behavioral Health Network for Tobacco & Cancer Control is operated by the National Council for Behavioral Health.

NBHN serves as a resource hub for professionals seeking to combat disparities specifically impacting people with mental illnesses and addictions.

www.bhthechange.org
Meet NBHN

NBHN Staff

Taslim van Hattum, LCSW, MPH Director
Margaret Jaco Manecke, MSSW Project Manager
Dana Lange
Project Manager
Samara Tahmid
Project Coordinator

NBHN Core Partners

UCSF Smoking Cessation Leadership Center
MPHI
School of Medicine
UNIVERSITY OF COLORADO ANSHUTZ MEDICAL CAMPUS
Behavioral Health & Wellness Program

Data-Integrated Strategies to Assist States

Communities of Practice
- 10-15 small state teams
- SMEs & faculty
- Focused action planning
- Peer to peer sharing
- Ongoing coaching

State Strategy Sessions
- Readiness
- Leadership participation
- Cross-sector partners
- Expert facilitators
- State Action Plan

Consultation & Integration
- State needs assessment & outreach
- Educational sessions
- EBI-specific trainings
- Bridging relationships

http://www.tacenters.emory.edu/resources/SEwebinars/
Spotlight: 2019 Tobacco-Free Facilities Training

IMPACT OF THE TRAINING

How did the training help enhance your ability to engage in tobacco-free activities?

**Content, Presentations and Resources**
Attendees said the training provided them with:

- Data and resources needed to begin their work around tobacco-free facilities and activities
- Training around communicating organizational change to leadership
- Language to frame messaging to staff and clients
- Assistance setting goals and targets that increased confidence in ability to carry out the work

**Tobacco-Free Policy Planning and Leadership Buy-in**
Attendees said the training provided them with:

- Training on how to engage in conversations about enhancing tobacco control activities with their leadership
- Resources on how to implement additional policies regarding different tobacco types
- Strategies on working with external partners to enhance referral services
- Strategies on how to evaluate tobacco control activities

Spotlight: Impact of Training

**Organizational Changes Made Since Attending the Training**

Overall, participants have generally implemented practice change(s) following the trainings. The top 3 changes participants said they have made included:

- Enhancing tobacco screening and cessation supports to clients/patients: 57%
- Engaging leadership around tobacco control activities: 45%
- Training staff, leadership, or clients/patients: 42%

9 organizations had follow up coaching calls around going tobacco-free

1,123 staff impacted
*estimate with only one-third reporting

58,000 clients impacted
*estimate with only one-third reporting
Tips for State Evaluators

JOIN THE NETWORK!

- Improve data captured to better define priority population & measure outcomes (BRFS, Outline)
- Strengthen relationships with Medicaid, Behavioral Health Depts. and Treatment Centers
- Learn how to access existing (B.A.D.) datasets (e.g. SAMHSA State Survey)

National Native Network (NNN)
Coordinated by the Inter-Tribal Council of Michigan
PI: Noel Pingatore
Program Director: Joshua Hudson
www.keepitsacred.org
National Native Network

A ‘Network of networks’ of Tribes, tribal organizations and health programs working to decrease commercial tobacco use and cancer health disparities among American Indians and Alaska Natives (AI/AN) across the U.S.

www.keepitsacred.org

Working with Partners

The NNN Tobacco Network is made up of 122 organizations, connected by 780 relationships
### 2019: Top 10 Areas of T/TA Needs Identified

<table>
<thead>
<tr>
<th>Area</th>
<th>Tribal</th>
<th>Non-tribal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessing existing data for AI/AN population</td>
<td>34%</td>
<td>30%</td>
</tr>
<tr>
<td>Collecting new or improved data on AI/AN people's use patterns</td>
<td>37%</td>
<td>30%</td>
</tr>
<tr>
<td>Current research on emerging topics in tobacco or cancer</td>
<td>37%</td>
<td>30%</td>
</tr>
<tr>
<td>Communication or messaging about tobacco and cancer-related health disparities experienced by AI/AN people</td>
<td>37%</td>
<td>30%</td>
</tr>
<tr>
<td>Best practices for tobacco prevention and control for AI/AN communities</td>
<td>34%</td>
<td>30%</td>
</tr>
<tr>
<td>Best practices for cancer prevention and control for AI/AN communities</td>
<td>37%</td>
<td>30%</td>
</tr>
<tr>
<td>Practical tools and strategies to barriers for practitioners trying to address cancer/tobacco health issues within health care settings</td>
<td>43%</td>
<td>40%</td>
</tr>
<tr>
<td>Practical tools and strategies to barriers for practitioners trying to address cancer/tobacco health issues within non-health care settings</td>
<td>43%</td>
<td>40%</td>
</tr>
<tr>
<td>Misperceptions and myths about tobacco/cancer prevention and control within your organization</td>
<td>45%</td>
<td>40%</td>
</tr>
<tr>
<td>How to design and implement media and marketing targeting commercial tobacco for AI/AN audience</td>
<td>70%</td>
<td>40%</td>
</tr>
</tbody>
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### Strategies to Support States with Data

- **Connect with regional/local tribal organizations**
- **Tailored consultation on doing things in a ‘good way’ in Indian Country**
- **Culturally-relevant trainings & toolkits**
Spotlight

NNN disseminates successful practices for data collection partnerships with tribes.

Example: MI BRFSTribal Oversample
N=563+state sample

Tips for States

Meaningful engagement & relationships

Long-term commitment

Data Use Agreements, Tribal Data Ownership

Realistic pace & expectations