S&E Webinar Series:
National Networks Spotlight Part 2 — Evaluating through a Health Equity and Disparities Lens

Tuesday, August 24, 2021
3:30 p.m. – 4:30 p.m.

Having trouble connecting?
Dial into the session by calling: +1 929 205 6099
Meeting ID: 878 1291 4333
Passcode: 963819
Announcements and Introductions
National Native Network

Noel Pingatore, MPH, Department Director

Hannah Bartol, B.S., Program Manager

Richard Mousseau, M.S., Program Coordinator/Data Manager

Chiharu Kato, PhD, Evaluator, Michigan Public Health Institute

National Native Network
Introduction to the National Native Network

- We offer technical assistance, culturally relevant resources, and a place to share up-to-date information and lessons learned, as part of a community of tribal and tribal-serving public health programs. The Network is intimately connected to the communities we serve and brings a wealth of knowledge of culturally based approaches for commercial tobacco and cancer prevention and control.

- The strength of our Network lays in partnerships between Tribes and tribal, national, state, and local organizations across Indian Country.

- The Network is administered by the Inter-Tribal Council of Michigan and directed by a board composed of three partner tribal organizations:
  - California Rural Indian Health Board
  - Great Plains Tribal Leader’s Health Board
  - Southeast Alaska Regional Health Consortium

- For more information visit us at https://keepitsacred.itcmi.org
Evaluation of NNN
Hitting the Sweet Spot; Network Survey
State BRFSS rarely captures enough AI/AN respondents to produce a sample size large enough for analysis - often requires combining multiple years of data, which provides outdated information and may not represent geographies where tribal communities are located.

A Tribal BRFSS is often tribally owned and can be shared with the State; tribes may select optional modules, based on their needs.

Incorporates Tribal Government and utilizes CBPA, yielding high response rates - often enough to produce tribal specific reports, as well as the aggregate report.

Comparable to State BRFSS - useful to identify disparities and can be used for surveillance and program evaluation.

**Cultural Context and Language Training for State BRFSS Interviewers**

(Michigan State University)

**Tribal Council Approval to Conduct the Survey; share tribal roster/phone numbers; confidentiality agreements**

Articles in Tribal Newsletters, and other media outlets - informs tribal members of the survey and its purpose, as well as what to expect from a phone call

Letters from Tribal Administration to members selected to participate

Report back to the Community with results and recommendations

Sample Success Story with Michigan

NaBRFS_Success_Story_706600_7.pdf (michigan.gov)
The American Indian Adult Tobacco Survey (AI ATS) is a survey that was designed as a surveillance and evaluation tool that can be used by American Indian tribes, tribal organizations, other organizations, and National Tobacco Control Partners to provide tribal-specific information on commercial tobacco use, cessation efforts, exposure to secondhand smoke, workplace policies, tobacco-related knowledge and practices among American Indian adults aged 18 years or older.
# American Indian Adult Tobacco Survey Timeline

<table>
<thead>
<tr>
<th>Quarter:</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<tbody>
<tr>
<td><strong>Selection &amp; Training of Research Team</strong></td>
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<tr>
<td>• Field Site Preparation</td>
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<tr>
<td><strong>Data</strong></td>
<td></td>
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<td></td>
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<tr>
<td>• Mailing to Selected Participants</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
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<tr>
<td>• Face-to-Face Interviews</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>• Quality Assurance Review of Data Collection</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>• Surveys Entered into Statistical Database</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>• Received ATS Data will be Analyzed</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
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<tr>
<td><strong>Reporting</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>• Generate Comprehensive Report on ATS Data (1st Draft)</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Finalization of ATS Report</td>
<td></td>
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<td>X</td>
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**Problem:** Cancer registries around the nation realize that their cancer statistics for American Indians underestimate the burden of cancer in these communities. This is because American Indian individuals with cancer are frequently reported as white by their doctors.

**Solution:** A data linkage between the state cancer registry and a Tribe’s enrollment roster looks for records in both files that are the same person; in short, we identify all Tribal members who are diagnosed with cancer in the state. This information is used to provide the Tribe with Tribe-specific cancer data and to correct the state’s cancer registry. Can be used to establish baseline and surveillance data.

**Sample Results:** Age-adjusted incidence rates among AI/ANs increased substantially due to linkage (119.30 per 100,000 vs. 405.41 per 100,000).

<table>
<thead>
<tr>
<th></th>
<th>Age-adjusted incidence rate (per 100,000)</th>
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<tbody>
<tr>
<td>AI/AN Cancer Registry Only</td>
<td>119.3</td>
</tr>
<tr>
<td>AI/AN Complete Link</td>
<td>405.41</td>
</tr>
<tr>
<td>NHW</td>
<td>421.46</td>
</tr>
</tbody>
</table>

[https://keepitsacred.itcmi.org/resources/tribal-data-toolkit/]
Table 2

Most Commonly Diagnosed Cancers by Tribal Community according to the 2012 Michigan State Cancer Registry

<table>
<thead>
<tr>
<th>Tribe A</th>
<th>Tribe B</th>
<th>Tribe C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>19.9%</td>
<td>Lung</td>
</tr>
<tr>
<td>Colon</td>
<td>18.7%</td>
<td>Colon</td>
</tr>
<tr>
<td>Prostate</td>
<td>12.7%</td>
<td>Prostate</td>
</tr>
<tr>
<td>Cervical</td>
<td>9.6%</td>
<td>Lung</td>
</tr>
<tr>
<td>Lung</td>
<td>7.8%</td>
<td>Thyroid</td>
</tr>
<tr>
<td>Other</td>
<td>31.3%</td>
<td>Other</td>
</tr>
</tbody>
</table>

Note. Other cancers included bladder, kidney, lymphocytic leukemia, multiple myeloma, myeloid leukemia, other gastrointestinal tract, lip, oral and pharynx, other genital, other central nervous system, other respiratory, and refractory anemia.

https://keepitsacred.itcmi.org/resources/tribal-data-toolkit/
Talking Circles and Focus Groups

- The purpose of the less formal talking circle is to create a safe environment in which individuals can share their point of view with others.
  - In a Talking Circle, each one is equal and each one belongs.
  - Participants in a Talking Circle learn to listen and respect the views of others.
  - The goal is to open hearts to recognize and connect with one another.
  - Taking time to share stories, build relationships, explore values, and create guidelines for participation helps everyone feel physically, psychologically, and emotionally safe in the circle and creates a foundation for courageous acts of sharing.
Talking Circles and Focus Groups

Protocols
- Respecting the circle is sacred and understanding, “who you see, what you hear, when you leave here, let it stay here.”
- Review ground rules
- Respect the differing comfort zones of participants

The Process
- Participants sit in a circle. It symbolizes completeness.
- Everyone’s contribution is equally important.
- Practice active listening by letting others complete their thoughts
- State what you feel or believe starting with “I-statements,” e.g., “I feel …”
- Sometimes an object (sacred or everyday) can be used as a talking ‘item’
WHAT IS THE NATIONAL NATIVE NETWORK?
The National Native Network is a network of Tribes, tribal organizations, and tribal-serving programs across the U.S. working to decrease the burden of cancer and commercial tobacco health disparities in American Indian and Alaska Native (AI/AN) communities. The Network is funded by the U.S. Centers for Disease Control and Prevention and administered by the Inter-Tribal Council of Michigan, with the following partner agencies: California Rural Indian Health Board, Great Plains Tribal Chairmen’s Health Board, and Southeast Alaska Regional Health Consortium.

WHAT WE DO
The National Native Network seeks to serve all 573 federally recognized Tribes, 68 state recognized Tribes, urban AI/AN communities, and tribal-serving agencies with training, resources, and technical support for AI/AN cancer and commercial tobacco use prevention and control efforts.

WHAT WE DO
We provide culturally relevant, evidence-based training and technical assistance.

Produce culturally relevant, evidence-based training and technical assistance.

Develop and strengthen partnerships to remove barriers.

Support and implement tribal public health policies.

Leverage media to increase awareness and deliver culturally appropriate health messages.

WHY THIS WORK IS IMPORTANT
AI/AN populations face inequities in cancer incidence and mortality. Culturally competent strategies for health systems interventions and educational-based resources, increased program evaluation and documentation of干线 and funding practices, and increased collaboration among tribal, federal, state, and local agencies are needed to address these inequities.

For more information you can find us here: https://keepitsacred.itcmi.org

Thank You
Evaluating through a Health Equity Lens

August 24, 2021
Surveillance & Evaluation Webinar Series
Michelle Veras, MPH  
Projects Director  
National LGBT Cancer Network  
She/her

Reece Lyerly, MS, MPH  
Project Evaluator  
National LGBT Cancer Network  
He/him
Agenda

○ Network overview
○ Data
○ Best practices
○ Action steps
Who we are
EDUCATING

our communities about our increased cancer risks and the importance of screenings

ADVOCATING

for LGBTQI+ engagement in mainstream cancer organizations, the media, and research

TRAINING

public health and health care providers to be more welcoming to us
As one of eight disparity networks

- We assess the field to ID knowledge gaps
- We offer trainings to all
- We create and find knowledge pieces to disseminate
- We build partnerships & connections between members
- We offer technical assistance to members
- We create and advise on media strategies
Newsletters

Celebrating Black History

Friends,
As February comes to a close, we move forward remembering Black History Month is every month of the year. Every day we renew our commitment to Black LGBTQ+ communities across the country. We honor and celebrate the contributions and legacies of our Black LGBTQ+ family. It is not enough to celebrate Black History, our history, just one month each year. The foundational teachings, writings, and gifts that folks like James Baldwin, Audre Lorde, and Marsha P. Johnson have given the world are carried on today through the work and life of Black LGBTQ+ activists.

Webinar Announcement
In partnership with HRC, we are excited to present: Equality in the Air We Breathe: COVID-19, HIV, Smoking and the Black Community

I VALUE MY HEALTH too much to continue smoking
Smoking is a top health threat to people living with HIV.
Talk to your medical provider.

Webinar: LGBTQ+ Pride 2021

Pride Webinar
The webinar is better than anything we can practice for leading and caring control partners to engage with LGBTQ+ communities.
Joining a variety of local LGBTQ+ organizations and health programs highlighting the importance of tobacco control efforts.
Thursday, April 29th at 2pm EDT.
Register here!

Community Survey - Tell us what you think!
Online Resource Library

HIV & Smoking Graphics
HRC Campaign, on the impact of smoking has on the health of people living with HIV, is simply brilliant!

Cancer Cards
These cards aim to raise awareness about colorectal, breast, lung, and cervical cancer among members of the LGBTQ+ community. There are also cards that address the need for taking care of an individual's physical and mental health. Each bundle includes the front and the back of the cards in JPEG format.

Forgetting Something: Anal Cancer Screening Campaign
Take a look at Forgetting Something, our anal cancer screening campaign.

Cancer in LGBT Communities
Our Fact Sheet gives you an idea of some of the challenges facing LGBT community members. Available in English and Spanish!

¿Por qué?
Nuestra campaña que demuestra algunas razones para hacer pruebas de detección de cancer. English versions coming soon.

Out Proud (Smoke/Vape) Free Series
Check out our Out Proud Free Logo over the seven different pride flags! The possibilities are endless. Contact us to learn about co-branding!

Cancer-network.org/resource-library
Join Our Network

❖ Training & technical assistance
❖ Connecting & capacity building with your local LGBTQ+ organization
❖ Opportunities for networking with state health departments, LGBTQ+ orgs, and more
❖ Tailored media & educational resources
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State Needs Assessment Tool

❖ Based on our Best & Promising Practices
❖ State cancer & tobacco program evaluation
❖ Other applications - LGBTQ+ orgs, community partners, healthcare organizations
❖ Can help identify opportunities for growth & collaboration
Our Best & Promising Practices

1. Promote LGBTQ+ professional safety & leadership in public health.
2. Include LGBTQ+ community members in policy planning.
3. **Monitor the impact of tobacco/cancer on LGBTQ+ populations.**
4. Establish LGBTQ+ cultural competency standards.
5. Fund community-based programs.
6. Routinely integrate LGBTQ+ tailored materials into mass media campaigns.
7. Disseminate findings & lessons learned.
State Needs Assessment Tool

- Administered 3 times over a 5 year project period
- State cancer & tobacco program directors & staff
- Administered online via Qualtrics
- Poll Questions
State Scorecard Examples

Baseline

Best practices that Rhode Island needs improvement on include: establishing LGBTQ cultural competency programs for statewide programs.

Midpoint

Best practices that Rhode Island needs improvement on include: promoting LGBTQ professional safety & leadership in public health.
What is SOGI Data?

SO = Sexual Orientation (LGB)

Which of the following best describes how you think of yourself?

- Lesbian or Gay
- Straight, that is, not gay
- Bisexual
- Something else
What is SOGI Data?

GI = Gender Identity (T+)

What sex were you assigned at birth?
● Male
● Female
● Intersex

Do you consider yourself to be transgender?
● Yes, transgender, male-to-female
● Yes, transgender, female-to-male
● Yes, transgender, gender nonconforming
● No
Evolving Definitions for LGBTQ+ Populations

- Standard SOGI module on BRFSS tested for validity and reliability
- Continuity of longitudinal data
- Small sample sizes
Lack nationally representative data

BRFSS 2021
1. Increase the number of states, territories, and DC that include sexual orientation and gender identity questions in the BRFSS

1. Increase the number of states, territories, and DC that use the standard module on sexual orientation and gender identity in the BRFSS
Importance of SOGI Data Collection

- Identify & measure health disparities among LGBT populations at state and national level
  - Shifting demographics
- Tailored health promotion programs and services
- Inform competitive grant proposals
In 2018, almost 30% of lesbian, gay, or bisexual adults used tobacco products.

“We have collected SOGI data for over 10 years. Actually, the tobacco control program initially requested and subsequently paid for the BRFSS questions to assure inclusion. In so doing, not only tobacco but all DOH programs have years of data.” - Hawaii TCP

“We used SOGI data to assess the burden of tobacco use among individuals identifying as LGBTQ for the first time in Tennessee in 2018, and again in 2019. These findings have been used to not only monitor tobacco use among LGBTQ populations, but also to inform our strategic plan and programmatic activities under the new CDC-funded cooperative agreement.” - Tennessee TCP
Midpoint Evaluation Results

**Analyzed findings specific to LGBTQ populations**

- Cancer: Baseline 14, Midpoint 13
- Tobacco: Baseline 30, Midpoint 38
- Overall: Baseline 44, Midpoint 51

**Disseminated findings specific to LGBTQ populations**

- Cancer: Baseline 11, Midpoint 12
- Tobacco: Baseline 21, Midpoint 28
- Overall: Baseline 32, Midpoint 40

# of programs
Common Misconceptions

- Including SOGI measures negatively impacts response rates and data accuracy.
- SOGI measures are ‘sensitive’ questions, especially for youth populations.
Recommendations

- Talk to your BRFSS coordinator
  - Start planning for 2022 BRFSS cycle
- Request SOGI data for your work
  - Utilize available data and identify gaps
- Understand the priorities (and concerns) of your partners
- Engage LGBTQ+ community partners early
Community-Based Surveys

- Standardize including SOGI questions on surveys & forms
  - Quitlines
  - Cancer Registries
  - Intake forms
“For the past couple of years I have elevated our state's desire for CDC cancer registry software to be modified to collect SGM data so that we can one day begin to use the state cancer registry as a tool to study health disparities impacting LGBTQ+ populations. Tobacco use history is something currently noted in the registry software for relevant cancers, but SGM demographic data isn't.” - Rhode Island CCP
LGBTQ Needs Assessment

LGBTQ Needs Assessment

- Personal background & demographics
- Health care coverage & access
- LGBTQI+ identity & interactions
- Overall health status & mental health
- Sexual health
- Tobacco, alcohol & other drug use
- Cancer risk & screenings

Contact us for a copy!
Recruiting LGBTQ+ Populations

- Seek community advisors
- Engage diverse partners
- Include a call to action
- Consider a media buy for targeted recruitment ads
Media Buys

- 1st buy: LGBTQ population in 10 cities
- 2nd buy: Black and Hispanic communities in 10 cities to increase BIPOC representation
Key Takeaways

1. Regularly collect SOGI data
2. Encourage adoption of the standard SOGI module on BRFSS in your state
3. Foster LGBTQ+ employee leadership
4. Engage LGBTQ+ community partners and seek feedback regularly
Thank you. For more information contact us at info@cancer-network.org or visit cancer-network.org
Q & A
Thank you for joining us!

Please share your feedback in the post-webinar evaluation survey that will pop up when you leave the webinar.