Exploring Tribal Public Health Infrastructure and Capacity Webinar Series

Tribal Capacity for Public Health Data

Nina Martin
Public Health Program Manager
National Indian Health Board
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Presentation Overview/Agenda

- Data for Tribal Public Health
- PHICCS I and Tribal public health data activities
- Guest Presentation – NPAIHB NativeDATA
Mission Statement:

Established by the Tribes to advocate as the united voice of federally recognized American Indian and Alaska Native Tribes, NIHB seeks to reinforce Tribal sovereignty, strengthen Tribal health systems, secure resources, and build capacity to achieve the highest level of health and well-being for our People.
Meet the PHICCS team!

Moones Akbaran
Program Coordinator

Tyler Dougherty
Director

Jessica Dean
Program Coordinator

Karrie Joseph
Deputy Director

Nina Martin
Program Manager

Johns Hopkins Center for American Indian Health
Survey Design Consultant
What do you think of when you think of “Data”?
Data for Tribal Public Health
Tribal Public Health

• Tribes have an inherent right to promote and protect the health and welfare of their citizens, using the methods most relevant for their communities.
• Public health systems that are managed by Tribes for Tribes
• Highly varied across Tribes/organizations
• “Community health”
Players in Tribal Public Health

Tribes

Federal Government (e.g. IHS)

National Indian Organizations (e.g. NIHB)

Regional Indian Organizations (e.g. AIHBs)

State and local health departments

Urban Indian Health Programs

Private/Nonprofit organizations
Tribal Public Health Data

• Data systems allow for the dissemination of vital information between Tribal and non-Tribal partners and stakeholders

• Provide timely information, develop the evidence base, and evaluate ongoing programs and activities.
Tribal Public Health Data

Processes to communicate information to community

Evaluation

Data collection, analysis, and dissemination
Current Tribal PH Data Sources

• Tribal nations may access data related to their peoples at numerous levels
  • **Tribal** (i.e. internal data systems)
  • **National/Federal** (i.e. IHS National Data Warehouse)
  • **Regional/State** (i.e. state registries, injury surveillance databases, **TECs**)
  • **Local** (i.e. city or county health records)
Tribal Epidemiology Centers

- 12 TECS
- Authorized in 1996 via Indian Health Care Improvement Act
  - Public health authority
- Provide important support and services to advance Tribal health and public health
Key Issues for Tribal Public Health Data

• Recognition of Tribal (data) sovereignty
• Representation in data
  • Racial misclassification
  • Invisibility in aggregate data
• Access, use, and contribution to relevant datasets
  • Data sharing partnerships
What is a Public Health Authority?

**CDC Definition:** A public health authority is broadly defined as including agencies or authorities of the United States, states, territories, political subdivisions of states or territories, **American Indian tribes**, or an individual or entity acting under a grant of authority from such agencies and responsible for public health matters as part of an official mandate. Public health authorities include:

- Federal public health agencies (e.g., CDC, IHS, HRSA, etc.)
- **Tribal health agencies**
- State public health agencies
- Local public health agencies
What is a Public Health Authority – Continued

• As sovereign governments, Tribal Nations are *inherent* public health authorities
  
• Under Section 214 of the Indian Health Care Improvement Act, Tribal Epidemiology Centers (TECs) gained designation as public health authorities.
  
• Tribal Nations and TECs have the authority to access personal health information (PHI) for public health purposes
Tribal Data Sovereignty

Spotlight during COVID-19

• The COVID-19 pandemic has shed a direct spotlight on the undue challenges faced by Tribes and TECs in exercising their public health authority.

• During a June 2020 hearing before the House Energy and Commerce Committee, bipartisan members pressed the CDC on media reports that the agency had failed to share data with Tribes and TECs.

• In early July 2020, 26 bipartisan members of the House and Senate sent a letter to CDC Director Redfield demanding answers as to why Tribes have been thwarted in data access.
PHICCS: INFORMATION FOR TRIBAL PUBLIC HEALTH
What is “PHICCS”

- **Public Health in Indian Country Capacity Scan**
- Periodic scan to assess Tribal public health infrastructure and capacity needs and priorities
- Informed by Tribes
- National scope
PHICCS I Respondents

- 134 respondents
- All 12 IHS service Areas represented
- Compared to IHS’s lists of direct service and self-governance Tribes:
  - 52% are self-governance compacting
  - 48% are self-determination contracting
- 90% respondents are federally-recognized Tribes
  - 9% represent Tribal Health consortia
Public Health in Indian Country Capacity Scan (PHICCS) Report

• Culminating in 2019 PHICCS Final Report
  ➢ Support and guide essential public health work in Indian Country
  ➢ Strengthen efforts to educate Legislators, federal agencies, private foundations, and policy makers on needs for building the capacity of Tribal public health

*Funded by Centers for Disease Control and Prevention (CDC)*
(CDC OT18-1802, #NU38OT000302)
Tribes Own the Data!

- NIHB wants to return your individual data
  - By request from the authorized official
  - Returned via encrypted email
  - To date, have returned data to 12 Tribes

- To request your own data, contact:
  Nina Martin
  nmartin@nihb.org
  202-548-7299
# Tribal Public Health Data Activities

**Figure 17** DATA COLLECTION, EPIDEMIOLOGY, AND/OR SURVEILLANCE (DES) ACTIVITIES

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Disease (n=84)</td>
<td>63%</td>
</tr>
<tr>
<td>Behavioral Risk Factors (n=75)</td>
<td>58%</td>
</tr>
<tr>
<td>Other Communicable/Infectious Disease (n=77)</td>
<td>57%</td>
</tr>
<tr>
<td>Vital Statistics (n=71)</td>
<td>54%</td>
</tr>
<tr>
<td>Injury (n=55)</td>
<td>42%</td>
</tr>
<tr>
<td>Other Morbidity (n=53)</td>
<td>41%</td>
</tr>
<tr>
<td>Environmental Illness (n=46)</td>
<td>35%</td>
</tr>
<tr>
<td>Foodborne Illness (n=44)</td>
<td>33%</td>
</tr>
<tr>
<td>Syndromic Surveillance (n=32)</td>
<td>24%</td>
</tr>
</tbody>
</table>

Percentage of THO Service Areas
Figure 18  PHYSICAL HEALTH DATA COLLECTION, EPIDEMIOLOGY, AND/OR SURVEILLANCE (DES) A PROVIDER TYPE

Percentage of THO Service Areas by Type of Organization:

- THO: 82%
- IHS: 59%
- Other Tribal Dept/Org: 69%
- Local Health Department: 55%
- State Health Department: 53%
- Private/Nonprofit: 40%
- Other: 34%

Legend:
- Chronic Disease (n=84)
- Foodborne Illness (n=44)
- Injury (n=55)
- Other Communicable/Infectious Disease (n=77)
- Other Morbidity (n=53)
Figure 19  SOCIAL/EMOTIONAL HEALTH & OTHER DATA COLLECTION, EPIDEMIOLOGY, AND/OR SURVEILLANCE (DES) ACTIVITIES BY PROVIDER TYPE

- **THO**
  - Behavioral Risk Factors (n=75)
  - Environmental Illness (n=46)
  - Syndromic Surveillance (n=32)
  - Vital Statistics (n=71)

- **IHS**
  - Behavioral Risk Factors (n=75)
  - Environmental Illness (n=46)
  - Syndromic Surveillance (n=32)
  - Vital Statistics (n=71)

- **Other Tribal Dept/Org**
  - Behavioral Risk Factors (n=75)
  - Environmental Illness (n=46)
  - Syndromic Surveillance (n=32)
  - Vital Statistics (n=71)

- **Local Health Department**
  - Behavioral Risk Factors (n=75)
  - Environmental Illness (n=46)
  - Syndromic Surveillance (n=32)
  - Vital Statistics (n=71)

- **State Health Department**
  - Behavioral Risk Factors (n=75)
  - Environmental Illness (n=46)
  - Syndromic Surveillance (n=32)
  - Vital Statistics (n=71)

- **Private/ Nonprofit**
  - Behavioral Risk Factors (n=75)
  - Environmental Illness (n=46)
  - Syndromic Surveillance (n=32)
  - Vital Statistics (n=71)

- **Other**
  - Behavioral Risk Factors (n=75)
  - Environmental Illness (n=46)
  - Syndromic Surveillance (n=32)
  - Vital Statistics (n=71)
## Workforce – Data Positions Needed

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Funded FTE Filled</th>
<th>Additional Funded FTE Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epidemiologists/Statisticians</td>
<td>0.2</td>
<td>0.4</td>
</tr>
<tr>
<td>Public Health Informatics Specialist</td>
<td>0.1</td>
<td>0.3</td>
</tr>
<tr>
<td>Public health information specialists</td>
<td>0.2</td>
<td>0.3</td>
</tr>
</tbody>
</table>
## Workforce Development Needs

<table>
<thead>
<tr>
<th>Category</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Training</strong></td>
<td>Technical skills (data collection/analysis), and general training on public health</td>
</tr>
<tr>
<td><strong>Professional development</strong></td>
<td>Certification and licensing</td>
</tr>
<tr>
<td><strong>Staffing</strong></td>
<td>Including hiring and retention</td>
</tr>
<tr>
<td><strong>Improvement-related</strong></td>
<td>Assessment, performance improvement, and accreditation</td>
</tr>
<tr>
<td><strong>Technical assistance</strong></td>
<td>Assistance with epidemiology, data analysis, and public health informatics</td>
</tr>
</tbody>
</table>
### Table 8: THO Public Health Needs

<table>
<thead>
<tr>
<th>Need</th>
<th>Additional Resources (n=86)</th>
<th>CDC % (n=89)</th>
<th>Other Federal Agencies (n=84)</th>
<th>States % (n=77)</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding support</td>
<td>34 (40%)</td>
<td>36 (40%)</td>
<td>33 (39%)</td>
<td>34 (44%)</td>
<td>137</td>
</tr>
<tr>
<td>Training (including technical assistance)</td>
<td>7 (8%)</td>
<td>27 (30%)</td>
<td>12 (14%)</td>
<td>8 (10%)</td>
<td>54</td>
</tr>
<tr>
<td>Partnership support</td>
<td>3 (3%)</td>
<td>2 (2%)</td>
<td>9 (11%)</td>
<td>21 (27%)</td>
<td>35</td>
</tr>
<tr>
<td>Public health education/materials support (culturally relevant, including public health education, public health law; communication)</td>
<td>13 (15%)</td>
<td>14 (16%)</td>
<td>3 (4%)</td>
<td>3 (4%)</td>
<td>33</td>
</tr>
<tr>
<td>Staffing support</td>
<td>26 (30%)</td>
<td>2 (2%)</td>
<td>2 (2%)</td>
<td>8 (10%)</td>
<td>32</td>
</tr>
<tr>
<td>Data support</td>
<td>10 (12%)</td>
<td>10 (11%)</td>
<td>2 (2%)</td>
<td>8 (10%)</td>
<td>30</td>
</tr>
<tr>
<td>Honoring the federal trust responsibility through consultation and respecting Tribal sovereignty</td>
<td>3 (3%)</td>
<td>6 (7%)</td>
<td>5 (6%)</td>
<td>14</td>
<td>14</td>
</tr>
<tr>
<td>IT support (including equipment and telehealth)</td>
<td>14 (16%)</td>
<td>6 (7%)</td>
<td>5 (6%)</td>
<td>14</td>
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</tr>
<tr>
<td>Infrastructure support</td>
<td>10 (12%)</td>
<td></td>
<td></td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Public health accreditation support</td>
<td>1 (1%)</td>
<td>2 (2%)</td>
<td>1 (1%)</td>
<td>3 (4%)</td>
<td>7</td>
</tr>
<tr>
<td>Transportation support</td>
<td>7 (8%)</td>
<td></td>
<td></td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Loan repayment/forgiveness</td>
<td>1 (1%)</td>
<td>1 (1%)</td>
<td>1 (1%)</td>
<td>4 (5%)</td>
<td>6</td>
</tr>
<tr>
<td>Public Health Associate Program (PHAP, CDC-specific program) support</td>
<td>4 (4%)</td>
<td></td>
<td></td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Reimbursement for non-clinical services</td>
<td></td>
<td></td>
<td></td>
<td>4 (5%)</td>
<td>4</td>
</tr>
</tbody>
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*This table is not an exhaustive list of all needs identified by THOs, but a summary of the most frequently identified needs across respondents.*
### Other Data Priorities and Needs

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SUPPORTING TRIBAL PUBLIC HEALTH DATA IN ACTION
Questions?
• What have been your experiences with any of the key Tribal public health data issues?
What are the key barriers to Tribal public health data infrastructure and capacity?
• What is needed to reinforce Tribal data sovereignty?
Over the next 5-10 years, what do you see as the key issues for the future of Tribal public health data?
COMING SOON!!

PHICCS II

Public Health in Indian Country Capacity Scan

National Indian Health Board
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Thank you!

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