



*Exploring Tribal Public Health Infrastructure and  
Capacity Webinar Series*

# **Tribal Capacity for Public Health Data**

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# Presentation Overview/Agenda

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



# National Indian Health Board

## 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

AAAA  
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of PUBLIC HEALTH

**Johns Hopkins Center for  
American Indian Health**  
Survey Design Consultant

National Indian  
Health Board



What do you think of when you  
think of “Data”?





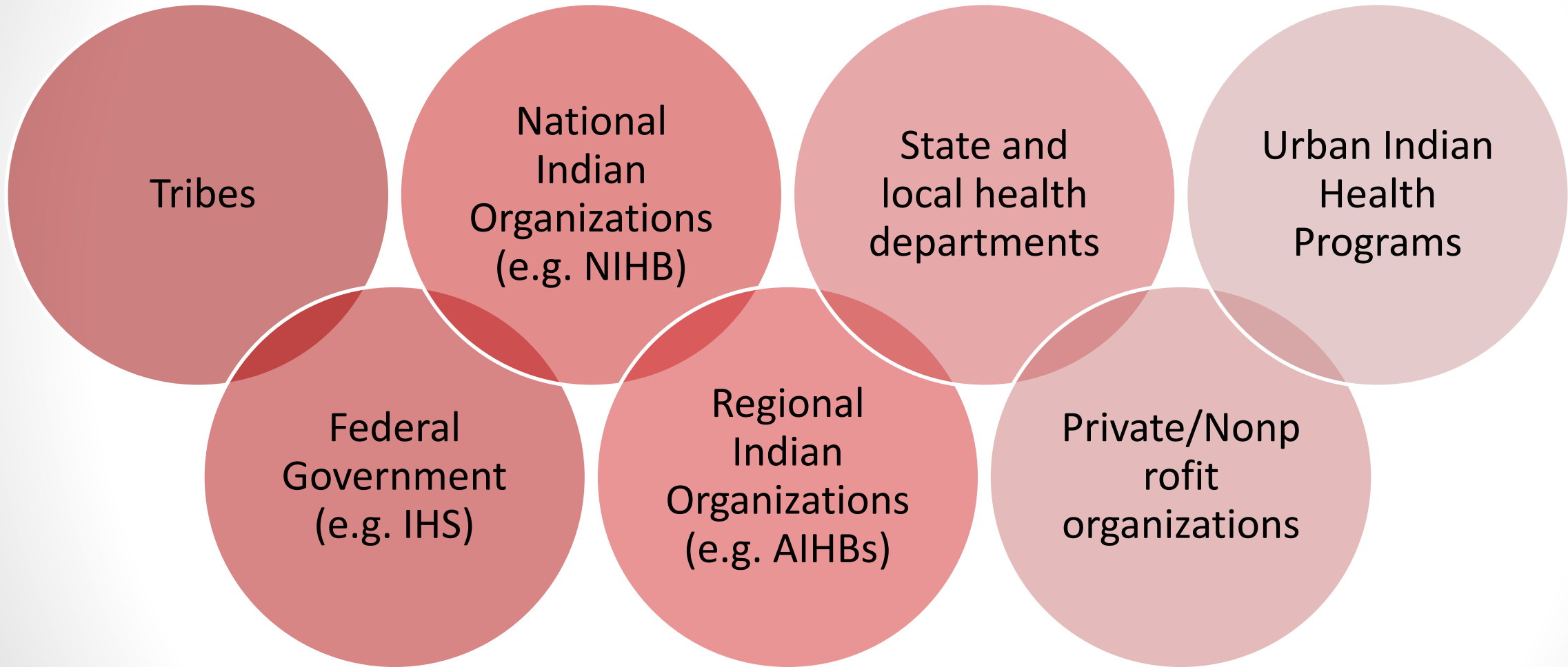
# Data for Tribal Public Health

# 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





# 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



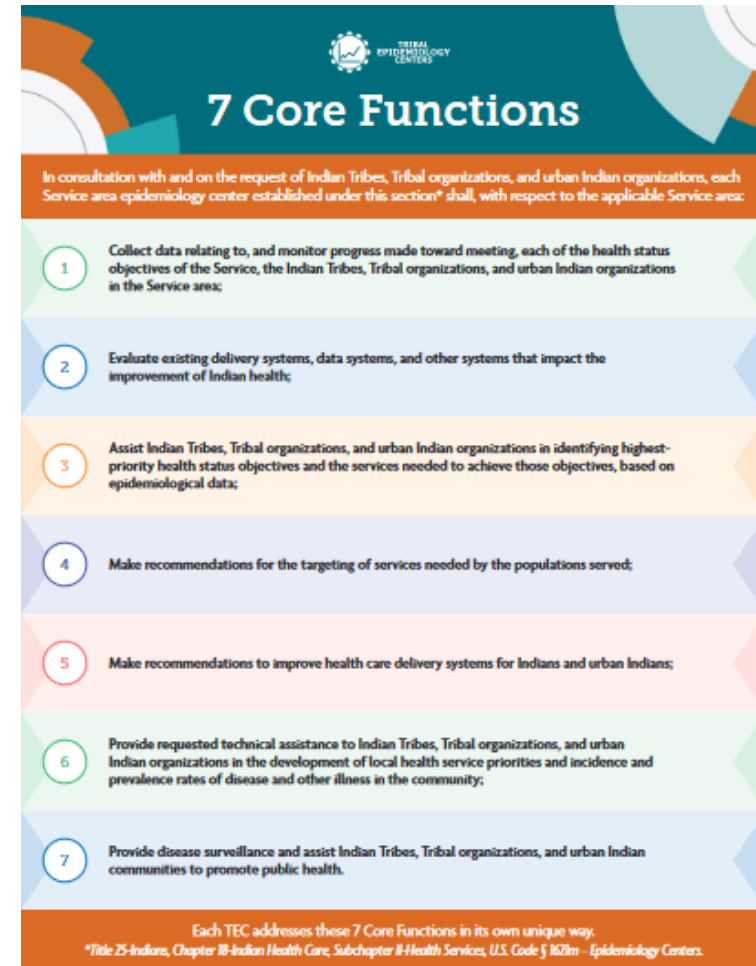
# Current Tribal PH Data Sources

- 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 under 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

The screenshot shows the CDC website page for "HIPAA Privacy Rule and Public Health". The page includes a navigation bar with "About CDC", "Announcements", "Funding", "Publications", and "Contact Us". The main heading is "HIPAA Privacy Rule and Public Health" followed by "Guidance from CDC and the U.S. Department of Health and Human Services" and "MMWR, Volume 52, Early Release". A sub-heading reads "The Privacy Rule and Public Health". The main text states: "The Privacy Rule recognizes 1) the legitimate need for public health authorities and others responsible for ensuring the public's health and safety to have access to PHI to conduct their missions; and 2) the importance of public health reporting by covered entities to identify threats to the public and individuals. Accordingly, the rule 1) permits PHI disclosures without a written patient authorization for specified public health purposes to public health authorities legally authorized to collect and receive the information for such purposes, and 2) permits disclosures that are required by state and local public health or other laws. However, because the Privacy Rule affects the traditional ways PHI is used and exchanged among covered entities (e.g., doctors, hospitals, and health insurers), it can affect public health practice and research in multiple ways. To prevent misconceptions, understanding the Privacy Rule is important for public health practice. Some illustrative examples are presented in this report (Box 4). Also provided are sample letters that might prove useful in clarifying relationships involving public health and the Privacy Rule (Appendix B)." A sidebar on the left contains a table of contents with items like "Contents", "Summary", "Introduction", "Overview of the Privacy Rule", "The Privacy Rule and Public Health", "The Privacy Rule and Public Health Research", "The Privacy Rule and Other Laws", "Online Resources", "Acknowledgments", "References", "Appendix A", "Appendix B", "Privacy Rule Home", and "Guidance for".

# What is a Public Health Authority – Continued

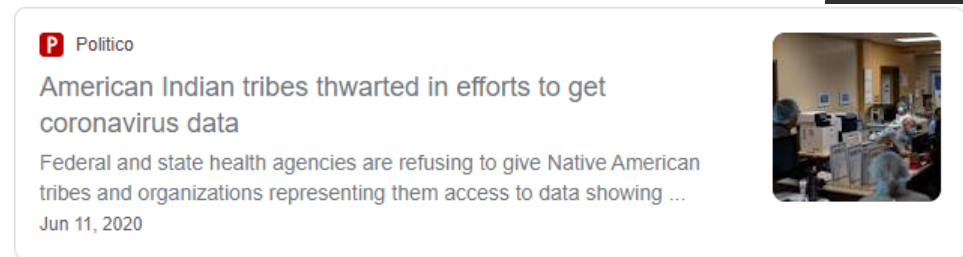
- As sovereign governments, Tribal Nations are inherent public health authorities
  - Under Section 214 of the Indian Health Care Improvement Act, Tribal Epidemiology Centers (TECs) gained designation as public health authorities.
- Tribal Nations and TECs have the authority to access personal health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

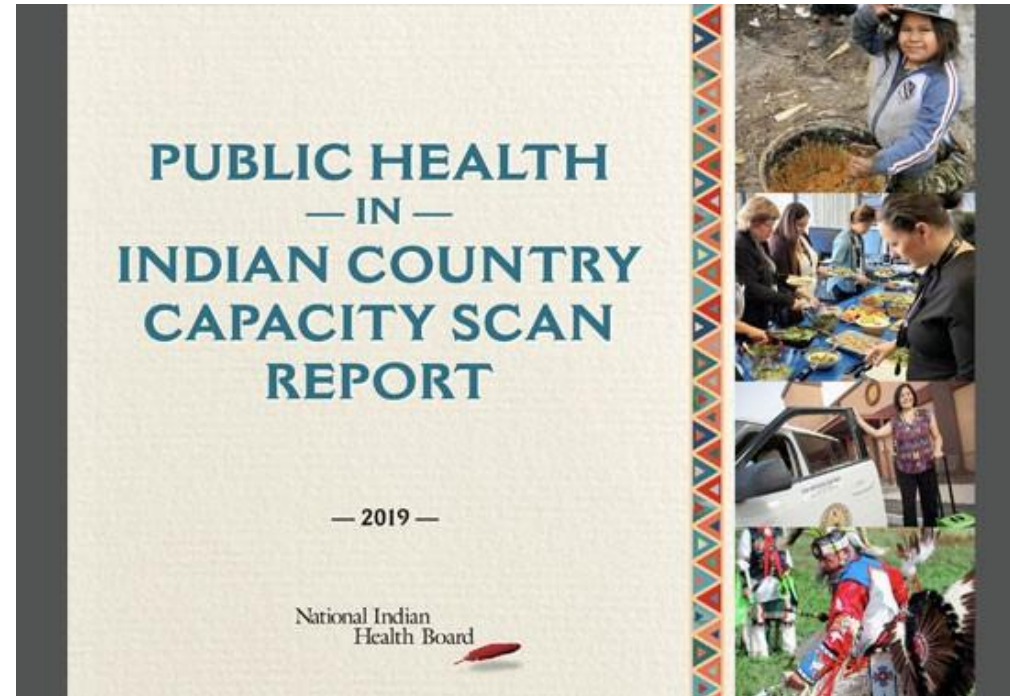


# PHICCS I Respondents

- 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

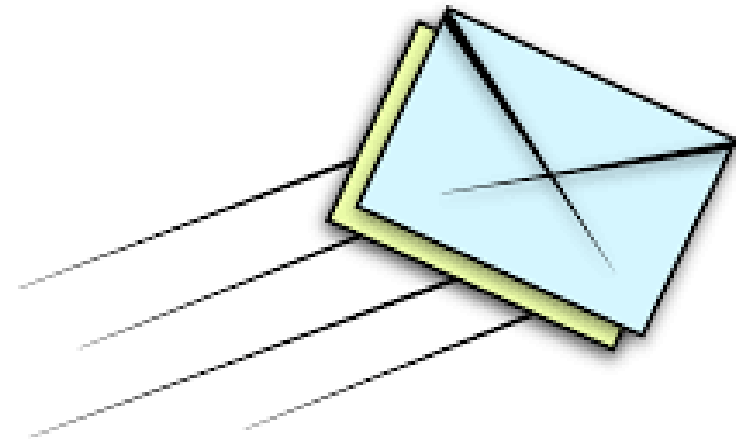
- Culminating in 2019 PHICCS Final Report
  - Support and guide essential public health work in Indian Country
  - Strengthen efforts to educate Legislators, federal agencies, private foundations, and policy makers on needs for building the capacity of Tribal public health



\*Funded by Centers for Disease Control and Prevention (CDC)\*  
(CDC OT18-1802, #NU38OT000302)

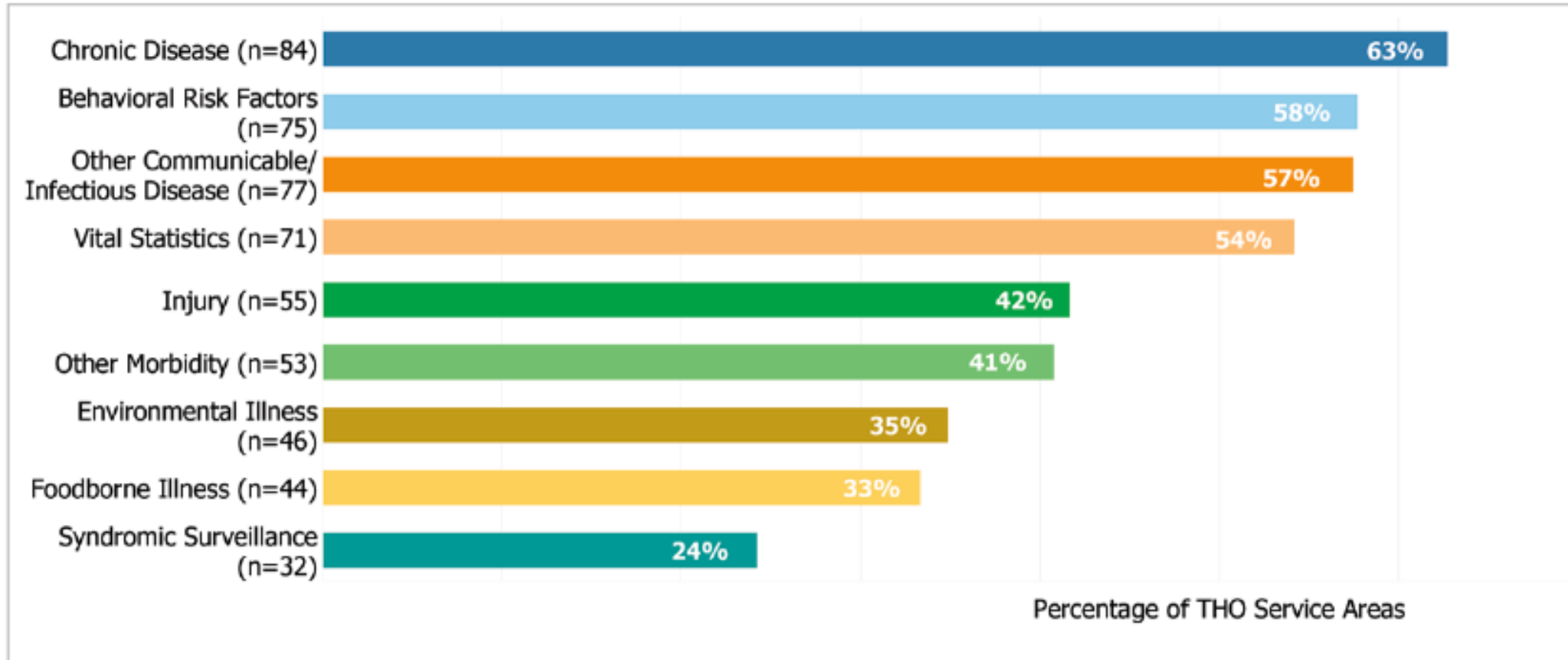
# Tribes Own the Data!

- 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](mailto:nmartin@nihb.org)
  - 202-548-7299

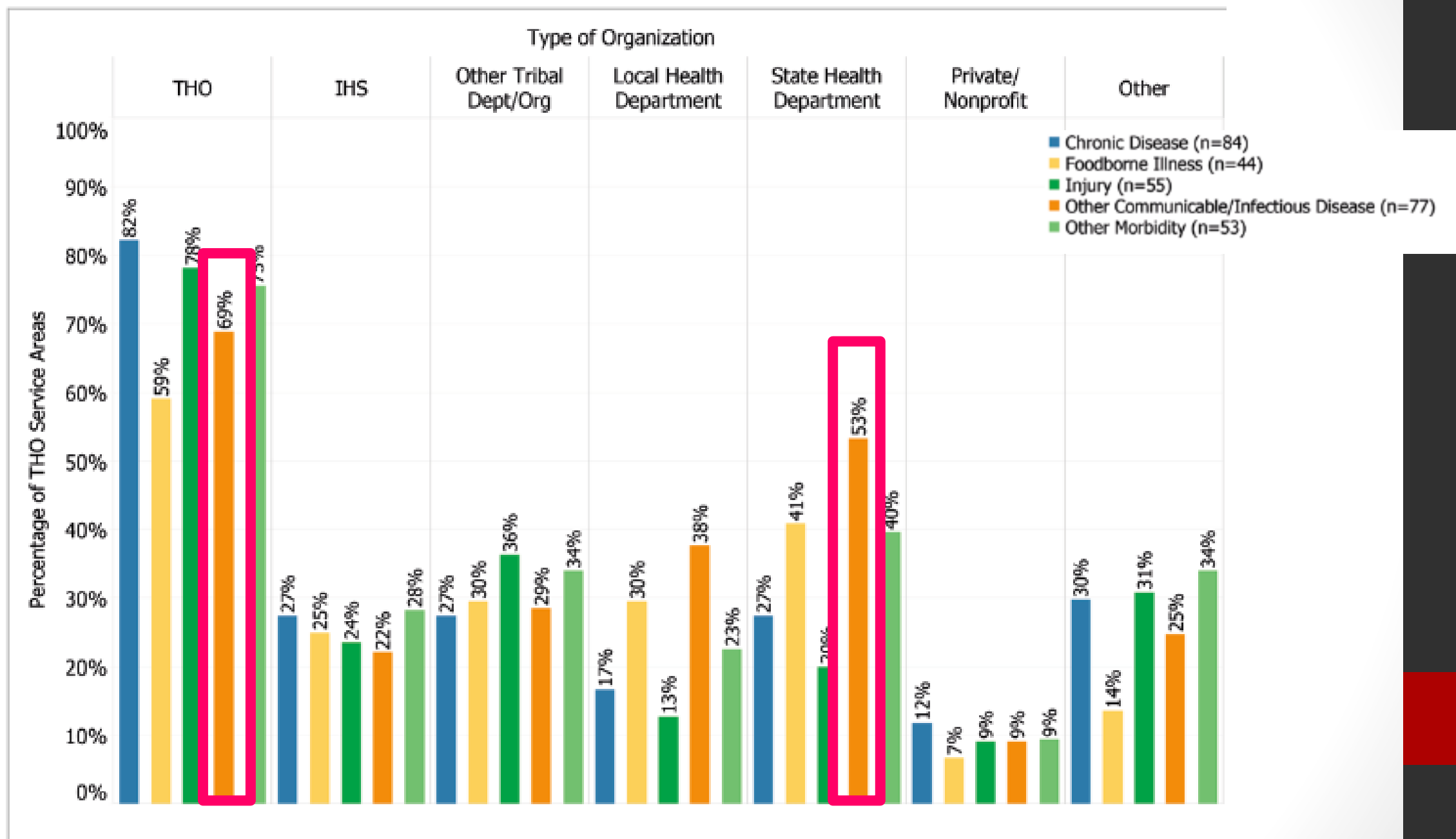


# Tribal Public Health Data Activities

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



**Figure 18 PHYSICAL HEALTH DATA COLLECTION, EPIDEMIOLOGY, AND/OR SURVEILLANCE (DES) A PROVIDER TYPE**



**Figure 19 SOCIAL/EMOTIONAL HEALTH & OTHER DATA COLLECTION, EPIDEMIOLOGY, AND/OR SURVEILLANCE (DES) ACTIVITIES BY PROVIDER TYPE**





# Workforce – Data Positions Needed

<b>Occupation</b>	<b>Funded FTE Filled</b>	<b>Additional Funded FTE Needed</b>
Epidemiologists/Statisticians	0.2	0.4
Public Health Informatics Specialist	0.1	0.3
Public health information specialists	0.2	0.3



# Workforce Development Needs

## Training

Technical skills (data collection/analysis), and general training on public health

## Professional development

Certification and licensing

## Staffing

Including hiring and retention

## Improvement-related

Assessment, performance improvement, and accreditation

## Technical assistance

Assistance with epidemiology, data analysis, and public health informatics

# Other Data Priorities and Needs

**Table 8 THO PUBLIC HEALTH NEEDS**

Need	Additional Resources (n=86)		CDC % (n=89)		Other Federal Agencies (n=84)		States % (n=77)		TOTAL
	N	%	N	%	N	%	N	%	N
Funding support	34	40%	36	40%	33	39%	34	44%	137
Training (including technical assistance)	7	8%	27	30%	12	14%	8	10%	54
Partnership support	3	3%	2	2%	9	11%	21	27%	35
Public health education/materials support (culturally relevant, including public health education, public health law; communication)	13	15%	14	16%	3	4%	3	4%	33
Staffing support	26	30%	2	2%	2	2%	2	3%	32
Data support	10	12%	10	11%	2	2%	8	10%	30
Honoring the federal trust responsibility through consultation and respecting Tribal sovereignty			3	3%	6	7%	5	6%	14
IT support (including equipment and telehealth)	14	16%							14
Infrastructure support	10	12%							10
Public health accreditation support	1	1%	2	2%	1	1%	3	4%	7
Transportation support	7	8%							7
Loan repayment/forgiveness			1	1%	1	1%	4	5%	6
Public Health Associate Program (PHAP, CDC-specific program) support			4	4%					4
Reimbursement for non-clinical services							4	5%	4

*\*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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Staffing support	24	28%	2	2%	2	2%	2	3%	30
Data support	10	12%	10	11%	2	2%	8	10%	30
Honoring the federal trust responsibility through consultation			7	7%	4	7%	5	6%	16



# 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*

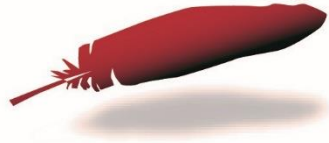
**Public Health in Indian  
Country Capacity Scan**



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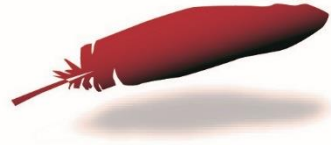


# National Indian Health Board



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Thank you!

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