

2013 Northwest Tribal Epidemiology Center Survey

Introduction

This survey is for NPAIHB Delegates and Tribal Health Directors. We appreciate your responses, which will help NPAIHB and the Northwest Tribal EpiCenter to serve the tribes' needs. You can either complete the paper version of the survey or take it online at:

<https://www.surveymonkey.com/s/2013EpiCenterSurvey>

In this survey, we will ask about your tribe's public health priorities, your preferences for the creation of tribal health profiles, tribal data and technical assistance needs, some basic info about you and your community, and your opinion of the EpiCenter's work.

If you would like to receive a summary copy of the report results, please provide your name, tribe and contact information on the last page of the survey. **NPAIHB will not include personal or tribal identities in any reports.**

Thank you for taking the time to complete this survey. Your responses are very important to us.

If you have any questions about the EpiCenter or this survey, please contact Victoria Warren-Mears, EpiCenter Director, at 503-416-3283 or vwarrenmears@npaihb.org.

If you need technical assistance with this survey, please contact Bridget Canniff, Project Director, Tribal EpiCenter Consortium, at 503-416-3302 or bcanniff@npaihb.org.

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Tribal Health Priorities

Please help guide NPAIHB's future work and grant applications by telling us which health topics are most important to you.

1. Please take a minute to check off the TOP THREE priority areas that you would like to see NPAIHB address. Not all delegates and tribal health directors will have the same priorities, so please list YOUR tribe's most pressing topics. If we did not include any of your priority concerns, please list them below.

- | | |
|---|--|
| <input type="checkbox"/> Arthritis and joint diseases | <input type="checkbox"/> Mental health |
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Nutrition and availability of healthy food |
| <input type="checkbox"/> Cancer | <input type="checkbox"/> Occupational Health |
| <input type="checkbox"/> Commercial tobacco use | <input type="checkbox"/> Overweight and obesity |
| <input type="checkbox"/> Dental health | <input type="checkbox"/> Sexual health and sexually transmitted infections |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Substance abuse |
| <input type="checkbox"/> Environmental health | <input type="checkbox"/> Suicide |
| <input type="checkbox"/> Heart health and cardiovascular disease | <input type="checkbox"/> Unintentional injury (traffic crashes, falls) |
| <input type="checkbox"/> Immunizations | <input type="checkbox"/> Violence and abuse |
| <input type="checkbox"/> Infectious diseases | <input type="checkbox"/> Vision or hearing loss |
| <input type="checkbox"/> Maternal and child health | |
| <input type="checkbox"/> Other priority area(s) not listed above: | |

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Tribal Health Priorities, continued

2. If there are any issues which are NOT of high interest or concern for your tribe at this time, please check them off below.

- | | |
|--|--|
| <input type="checkbox"/> Arthritis and joint diseases | <input type="checkbox"/> Mental health |
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Nutrition and availability of healthy food |
| <input type="checkbox"/> Cancer | <input type="checkbox"/> Occupational Health |
| <input type="checkbox"/> Commercial tobacco use | <input type="checkbox"/> Overweight and obesity |
| <input type="checkbox"/> Dental health | <input type="checkbox"/> Sexual health and sexually transmitted infections |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Substance abuse |
| <input type="checkbox"/> Environmental health | <input type="checkbox"/> Suicide |
| <input type="checkbox"/> Heart health and cardiovascular disease | <input type="checkbox"/> Unintentional injury (traffic crashes, falls) |
| <input type="checkbox"/> Immunizations | <input type="checkbox"/> Violence and abuse |
| <input type="checkbox"/> Infectious diseases | <input type="checkbox"/> Vision or hearing loss |
| <input type="checkbox"/> Maternal and child health | |

Comments:

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Tribal Health Profiles

The EpiCenter at NPAIHB is in the process of developing a tribal health profile for each of the 43 Northwest Tribes. Tribal or community health profiles (THPs) are a way of documenting the current status of health of the community, in order to give the community an accurate picture upon which to base their future health planning.

The NPAIHB THPs will present tribal, county and/or state data on a variety of key health topics. Each tribe will receive their own tribal report, as well as statewide or regional reports.

We would like to get your input on how to format and present the profile reports to make them most useful to the tribes and their health programs. Please give us your feedback and thoughts below.

***3. In what format(s) would your tribe like to receive your Tribal Health Profile?**

(Mark all that apply.)

- ☐ Printed copy
- ☐ Electronic (PDF) copy
- ☐ Full report
- ☐ Summary report (1-2 pages)
- ☐ Full report AND shorter summary report
- ☐ No preference

Other (please specify):

Tribal Health Profiles, continued

***4. How would you MOST prefer we organize the content of the Tribal Health Profiles? (Choose one)**

- ☐ Separate section for each health topic, in rough order of priority for Northwest Tribes
- ☐ Health information grouped in the following way (or similar): healthy spirit, healthy mind, healthy body, healthy community
- ☐ Related health topics grouped together in broader sections: chronic disease, behavioral health, etc.
- ☐ Health data grouped by age or population group: maternal & child health, youth health, adult health, elder health
- ☐ No preference
- ☐ Other (please specify):

5. General comments, suggestions or questions about Tribal Health Profiles:

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Data Policies and Needs

The following information will help NPAIHB and the EpiCenter better understand the tribes' data practices and any technical assistance needs.

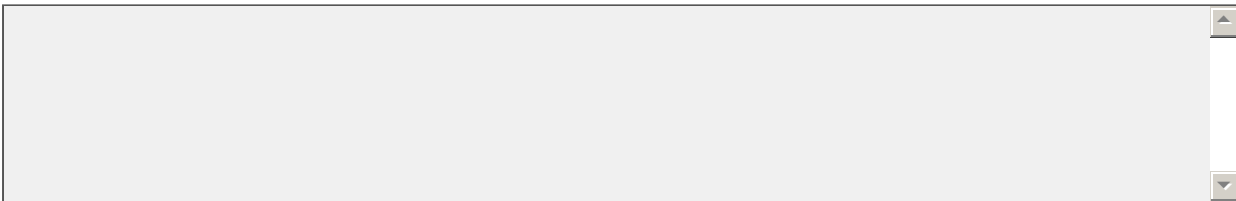
***6. Proposed health research that involves information on or interaction with people is subject to careful scrutiny, in order to protect the rights, privacy, and welfare of the people from potential harms.**

Before any institution can receive Federal support for research involving human subjects, the US government requires a declaration known as a Federalwide Assurance (FWA) for the Protection of Human Subjects. The FWA must designate at least one Institutional Review Board (IRB), which is a committee that performs ethical review of proposed research. FWAs must be renewed every 5 years, even if no changes have occurred.

To the best of your knowledge, is there is currently an FWA in place for your tribe?

- ☐ Yes, we have a current FWA
- ☐ No, we have never had an FWA
- ☐ No, our FWA has expired and/or was not renewed
- ☐ Don't know
- ☐ Prefer not to answer

Comments or questions:



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Data Policies and Needs, continued

*7. Are you aware of whether or not your tribe has a current, signed data sharing agreement (DSA) with NPAIHB?

- ☐ Yes, we have a DSA with NPAIHB
- ☐ No, we don't have a DSA with NPAIHB
- ☐ Don't know

Comments or questions:

*8. Does your tribe have a written policy on the sharing, release, or publication of tribal health data, such as with the state, counties, colleges and universities, or other institutions?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Prefer not to answer

Comments or questions:

9. Would your tribe like any technical assistance or more information related to data sharing, or research and data policies?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Prefer not to answer

Comments, questions or technical assistance needs:

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Data Literacy

***10. How would you rate your personal understanding of statistics and data interpretation, as needed for your job?**

Please rate your knowledge level on a scale of 1-10, where 1 is no understanding, and 10 is perfect understanding.

	1 - No understanding	2	3	4	5	6	7	8	9	10 - Perfect understanding
My understanding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

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***11. How would you rate the average understanding of statistics and data interpretation of other key people working for your tribe, as needed for their jobs?**

For each listed position (which may include more than one person), rate the average understanding of data and statistics of that person or group of people on a scale of 1-10, where 1 is no understanding, and 10 is perfect understanding. If you yourself hold one or more of these positions, include yourself in the rating, even if you include yourself in several categories. If there is no one with that role at your tribe, choose N/A. You can also choose "Don't know" if you have no knowledge of that person or group of people's understanding of data.

	1 - No understanding	2	3	4	5	6	7	8	9	10 - Perfect understanding	N/A	Don't know
NPAIHB Delegate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NPAIHB Alternate Delegate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tribal Health Director	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinic Director	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Primary Health Care Providers (doctors, nurses, PAs, dentists, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community Health Representatives (CHRs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Healthcare Promotion/Disease Prevention Staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Data Entry/Clinical Records Staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Administrative Staff (CHS, Billing, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tribal Council / Elected Tribal Leaders	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tribal Health Committee Members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments or additional information: If others at your tribe are familiar with data and statistics, but are not listed above, please tell us their job title(s) and level of knowledge:

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The EpiCenter

The Northwest Tribal Epidemiology Center (The EpiCenter), established in 1997, is a part of the Northwest Portland Area Indian Health Board (NPAIHB).

Past and current EpiCenter projects include:

- Comprehensive Cancer Tribal BRFSS Project
- Improving Data & Enhancing Access (IDEA-NW)
- Improving Health Research Skills for AI/AN Students
- Indian Community Health Profile Project
- Injury Prevention Project
- Monitoring the Abuse of Drugs (MAD NARCH)
- Native CARS (Children Always Ride Safe)
- Native Nutrition and Physical Fitness Project
- Northwest Tribal Cancer Control Project
- Northwest Tribal Cancer Navigator Project
- Northwest Tribal Dental Support Center
- Northwest Tribal Registry Project
- Northwest Native American Research Center for Health (NW NARCH)
- Portland Area IHS Institutional Review Board (IRB)
- Project Red Talon, VOICES Project, and It's Your Game
- Suicide Prevention Project - THRIVE
- Toddler Obesity & Tooth Decay Prevention Project (TOTS)
- Tribal Epidemiology Center Consortium
- Western Tribal Diabetes Project

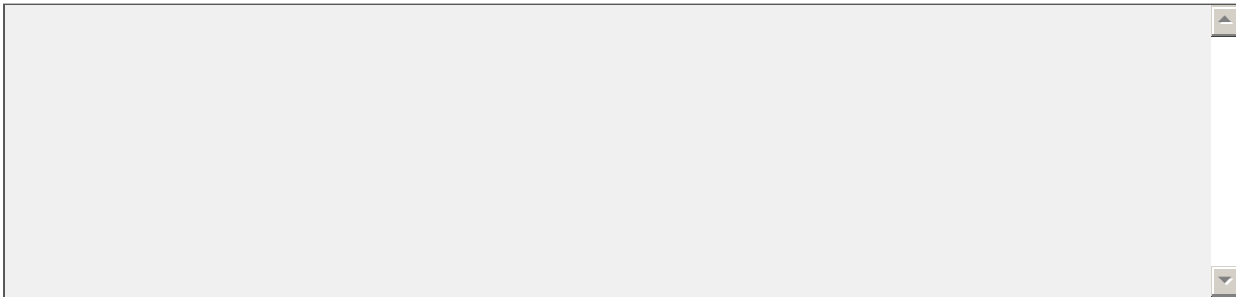
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The EpiCenter, continued

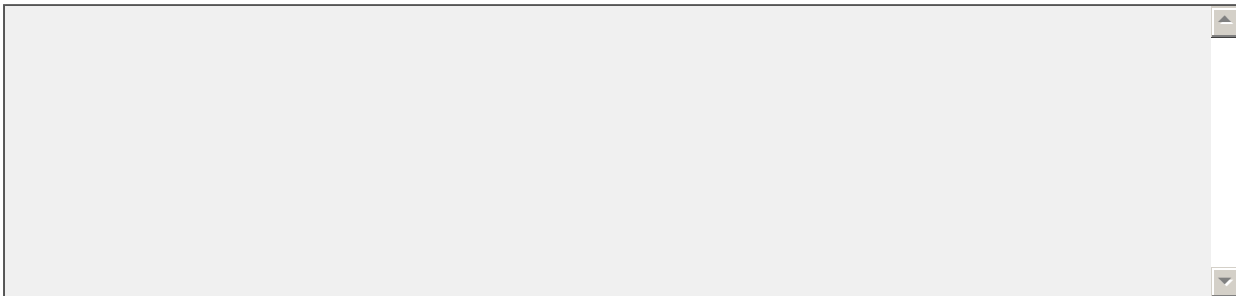
12. What do you think are the greatest STRENGTHS of the EpiCenter?

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13. How could the EpiCenter provide better assistance to your tribe?

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14. Do you have any other questions or comments to share with us?

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Demographics

***15. Which of the following describes your position(s) or role(s) at your tribe? (Choose all that apply.)**

- ☐ NPAIHB Delegate or Alternate
- ☐ Tribal Health Director
- ☐ Clinic Director
- ☐ Primary Health Care Provider
- ☐ Community Health Representative (CHRs)
- ☐ Healthcare Promotion/Disease Prevention Staff
- ☐ Community/Social Service Program Staff
- ☐ Administrative Staff
- ☐ Tribal Council Member / Elected Tribal Leader
- ☐ Tribal Health Committee Member
- ☐ Tribal Member / Community Member
- ☐ Other (please specify)

***16. Approximately how many people are included in your tribal community?**

- ☐ Under 500
- ☐ Between 500 and 2,000
- ☐ 2,000 or more
- ☐ Prefer not to answer

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Contact Info

The following information is **optional** and will not be shared in any survey reports.

17. Which tribe do you represent?

18. If you would like to receive a summary report, or if you would like NPAIHB to respond directly to you about your questions and needs, please provide us with your contact information.

Name:

Email Address:

Phone Number:

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THANK YOU!

Thank you for taking this survey!

Please give your completed survey to any NPAIHB staff member, or send it to:

Bridget Canniff
NPAIHB
2121 SW Broadway, Suite 300
Portland, OR 97201

Email: bcanniff@npaihb.org
Fax: 503-228-8182