



## Strengthening Data Sovereignty: Teachings from the Eel Life Cycle

Wabanaki Public Health and Wellness (WPHW) serves four federally recognized tribes located in five communities: the Houlton Band of Maliseet Indians, the Aroostook Band of Micmacs, the Passamaquoddy Tribe at Indian Township, the Passamaquoddy Tribe at Pleasant Point, and the Penobscot Nation. Our mission is to provide community-driven, culturally centered, public health and social services to all Wabanaki communities and people while honoring Wabanaki cultural knowledge, cultivating innovation, and fostering collaboration.

WPHW values include inclusivity, balance, and cultural centeredness. Wabanaki traditions, language, and culture guide our approach and describe the ways we live in harmony with each other and the land we collectively share. Our services are available to community members living on and off reservation across the state of Maine. Wabanaki Public Health and Wellness organizes its services under three departments: Wabanaki Public Health, Wabanaki Health and Wellness, and Wabanaki Health and Recovery.

Wabanaki Public Health was formed as a Tribal Public Health Unit in 2008 in partnership with the Maine Center for Disease Control and in 2011 was established in statute as the Wabanaki Public Health District. Wabanaki Public Health's work focuses on planning and development of Tribal Public Health Infrastructure, implementation of disease prevention, and health promotion activities for Tribal citizens in Maine.

Wabanaki Health and Wellness provides mental and behavioral health and wellness services to Wabanaki people in Maine, including case management services, HIV testing, housing security, and behavioral and substance use treatment services.

Wabanaki Healing and Recovery provides outpatient services to include MAT, substance use recovery residence, workforce development, and cultural healing services to Tribal citizens.



# SUCCESS STORY REVITALIZING INHERENT ALIGNMENT WABANAKI PUBLIC HEALTH AND WELLNESS



## THE SITUATION

WPHW has prioritized creating an Indigenous public health surveillance system to ensure Tribal health data is accurate and representative of Indigenous people in Maine. Accurate and representative Tribal health data is vital to assess Tribal health needs and priorities, plan Tribal public health programs for health improvement, and justify resources and funding to improve the health of Tribal citizens in Maine. Tribal health data is historically difficult to obtain and separate from state and national public health databases. It historically lacks involvement and input from Tribal leadership with regard to how Tribal health data is collected, by whom, and for what purpose.

To advance the goal of Wabanaki data sovereignty and to build a system of Wabanaki health data wholly owned and controlled by Tribal citizens, WPHW created the Center for Wabanaki Research, Knowledge, and Innovation. With representation, leadership, and health system expertise from all four federally recognized tribes in Maine, as well as Non-Indigenous public health and science specialists, the Center for Wabanaki Research, Knowledge, and Innovation represents a collaboration between western evidence-based health science with Indigenous knowledge and values.

This project helped support WPHW's efforts to provide training, discussion, and engagement; empowering Tribal leadership to be active partners in the pursuit of Wabanaki data sovereignty. It is also the basis to develop a surveillance infrastructure to collect and house Indigenous data to promote data sovereignty. Data sharing agreements have been developed and shared with Tribal leadership, along with education about data sovereignty and the importance of leveraging Indigenous health data.





## IMPLEMENTATION HIGHLIGHT

One of our main priorities was to conduct a comprehensive review of available Indigenous data sources. The review included current state and national surveillance systems as well as other demographic, economic, and epidemiological data sources. The review found the limitations in how these data are collected and aggregated made them unreliable and not representative of the Indigenous communities of Maine. The lack of data sharing agreements between Tribal communities of Maine and the collectors of these data indicated a clear need for the creation of a surveillance system that is integrated into Indigenous culture, is responsive to Tribal needs, and respects Tribal data sovereignty.

Another goal was to generate diverse participation and support within WPHW and Tribal leadership. The surveillance system development process enhanced existing priorities to develop data protocols, convene a data oversight team, and develop Tribal data use agreements between WPHW and Tribal leadership. These elements served as a baseline infrastructure to support future developments to Indigenous data management capacity. Data sharing agreements have been a WPHW priority since January 2019, and this grant built the necessary capacity for regular meetings, increased visibility and awareness of data sharing agreements, and helped communicate why these agreements are important. We formed a Tribal Transformation Team (T3) with representation from WPHW leadership, administration, IT staff, and program staff; Tribal communities, leaders, Elders, and youth; and the Public Health Research Institute.

We are committed to formalizing data sharing partnerships. The development of Tribal data sharing agreements, combined with an overhaul of WPHW data-related infrastructure, policies, and procedures, laid the groundwork to build the relationships necessary to facilitate access to and use of current and future Tribal data.





## SUCCESSSES

One of our early successes in this project was the creation of a visual tool to help us understand how data might be processed and valued through an Indigenous lens. Our T3 team used the life cycle of the eel to represent how data might flow within our organization. We were able to share this model with the other T3 partners in our grantee meetings and we have also shared this concept within our organization.

Data sharing agreement meetings were recently held with the WPHW co-CEOs and Tribal leaders to discuss, sign, and implement the agreements. WPHW forged partnerships with the leaders from all five of the Wabanaki communities in Maine. The process helped to develop relationships, trust, and shared expectations around using and sharing Indigenous health data.

WPHW data protocols, procedures, and policies were also reviewed and revised as a result of this project.

We created and improved organizational infrastructure to support surveillance systems. As a result of this project, WPHW has clarified its organizational data vision and intent, and has established a position to oversee the creation of the surveillance system. The system and the individual responsible for its creation and maintenance will enable syndromic surveillance activities and will provide support to scale up the system over time for use with other sources of Wabanaki Indigenous data. The surveillance system will enable WPHW and Tribal leaders to monitor, understand, and respond to changes in demographics, health status, health risk and protective factors, and environmental health hazards. Specifically, the surveillance system will serve as a platform to house and analyze trends in health data from the Waponakhi Health Needs Assessment, administered every ten years to a sample of Tribal citizens across the state of Maine.

WPHW successfully engaged Tribal communities and leaders despite significant barriers, challenges, and logistical roadblocks due to COVID-19. The pandemic has significantly impacted Indigenous communities in Maine, resulting in frequent changes in the status of Tribal governments and the accessibility of Tribal community spaces. We worked hard to overcome these challenges, maintain dialogue with Tribal leaders, and make progress toward data sharing agreements.

## LESSONS LEARNED

Planning the purchase and use of technology to support the new surveillance system required input from a skilled and experienced IT professional. Information systems necessary to the surveillance system are complex and nuanced. It was apparent early on that specialized input was necessary to build shared expectations and a clear understanding of capabilities and limitations.

COVID-19 added a level of complexity, delaying our completion of the Opioid Strategic Planning project and the installation of the surveillance system in accordance with the original timeline.

Full implementation and ongoing monitoring of the surveillance system will require additional work and funding, but a solid foundation exists to enable this work in the future.

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## KEY RESOURCES USED

The Center for Wabanaki Research, Knowledge, and Innovation team referred primarily to the Ownership, Control, Access, and Possession (OCAP) Model from the First Nations Information Governance Centre to articulate values and priorities for data collection, storage, stewardship, distribution, and access of current and future Wabanaki health data.

Additionally, the team referenced the Global Indigenous Data Alliance's FAIR and CARE principles for Indigenous Data Governance to ensure Wabanaki values, worldviews, interests, and sovereignty were emphasized throughout the development of Data Sharing Agreements. FAIR (Findable, Accessible, Interoperable, Reusable) and CARE (Collective benefit, Authority to control, Responsibility, and Ethics) reinforce the need for Indigenous rights, empowerment, and decision-making to ensure data collection, analysis, and interpretation practices maximize data utility to Tribal citizens and leaders while eliminating harm.

The team also referenced templates and tools from the Digital Curation Centre in Edinburgh, Scotland to update a WPHW Data Management Plan to guide organizational practices and procedures to collect, manage, analyze, and store Tribal health data.

The team referred to and adapted concepts from data sharing agreement examples and templates of other Tribal organizations, as well as partners in academia.

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## NEXT STEPS

Our primary goal is to ensure that Wabanaki people have access to, and understand the power of, having accurate and representative health data to make decisions for their future. We will use existing Wabanaki data sets and results from the 2010 and 2020 Waponahki Health Needs Assessments to populate the surveillance system with health data. This data will be cleaned and analyzed by WPHW to prepare Wabanaki-wide reports for each Tribal community, packaged with discussion and guidance for how to use Tribal health data for local planning. We will use data from existing external sources and from our own Recovery and Healing programs to pilot our surveillance efforts to Tribal leaders and to build Tribal data capacity in each Tribal community.

## FOR MORE INFORMATION

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Led by Seven Directions, A Center for Indigenous Public Health at the University of Washington, ***Indigenous Systems: Revitalizing Inherent Alignment*** is a practice-based research study of how health care delivery, public health, and social services sectors work together to achieve shared goals.

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