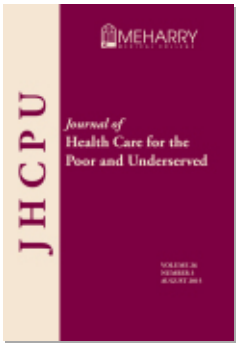
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The Waponahki Tribal Health Assessment: Successfully Using CBPR to Conduct a Comprehensive and Baseline Health Assessment of Waponahki Tribal Members



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The Waponahki Tribal Health Assessment: Successfully Using CBPR to Conduct a Comprehensive and Baseline Health Assessment of Waponahki Tribal Members

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Abstract: **Objective**. Describe a community-based participatory research effort between Tribal Health Departments in Maine and the University of Nebraska Medical Center (UNMC), College of Public Health to conduct a modified behavioral risk factors surveillance system with five Tribal communities in Maine. **Methods**. The study incorporated a long-distance community-based participatory research approach where Tribal Health Directors selected domains for the survey, modified the questions as needed, and advertised/recruited for the survey. Tribal interviewers trained via UNMC College of Public Health webinars conducted the surveys *via* computer assisted personal interviews at Tribal health centers or other Tribal facilities. Tribal interviewers uploaded surveys from the sites into a UNMC firewall protected data base. **Results**. 1,127 Tribal members completed the survey. **Conclusions**. The methodology of this study can be adapted to other communities who wish to work long-distance with academic institutions to conduct community-based participatory research.

Key words: Community-based participatory research, American Indian, tribes, health disparities.

While national data indicate that American Indians and Alaska Natives (AI/AN) experience worse health conditions and outcomes than White Americans in the form of higher mortality rates from diabetes, suicide, unintentional injuries, sudden infant death syndrome, and alcohol related injuries, in many states, the relatively small proportion of AI/AN who participate in state-wide surveys such as the Behavioral Risk Factors Surveillance System (BRFSS) often prevents the analysis of data at the level of individual tribes that will yield meaningful results.[1]

The BRFSS, the nation's leading telephone survey, allows states to identify emerging health problems, establish and track health objectives, develop and evaluate public health policies and programs, and to support health-related legislative efforts.[2] According to

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the 2010 census, 1.4% of Maine's population, or 18,482 individuals identified themselves as AI/AN alone or in combination;[3] however, the State of Maine BRFSS does not list AI/AN participation. Limited and perceived inaccuracies in State level data on the health status of AI residing in Maine has been a long-standing concern of Maine Tribal health directors.[4] In order to address the lack of existing data on the health of Tribes of Maine: the Aroostook Band of Micmacs, the Houlton Band of Maliseet Indians, the Passamaquoddy Tribe—Indian Township and Pleasant Point, and the Penobscot Nation, identified the need for a multi-Tribal health assessment based on the BRFSS. Employing a community-based participatory research (CBPR) approach in collaboration with researchers from the University of Nebraska Medical Center (UNMC) College of Public Health, 2010–2011, the Maine Tribal health departments conducted the Waponahki Tribal Health Assessment, the first-ever multi-Tribal health assessment in Maine. The Waponahki Tribal Health Assessment represents the first time that the Maine Tribes have collaborated together on a health assessment. The objective of this paper is to examine the CBPR components of the study that contributed to the high number of participants in this community health assessment. We believe this CBPR methodology can provide a model for CBPR in rural and remote communities in the absence of a local academic partner.

Methods

Approach. As sovereign nations, AI/AN communities have full authority to regulate research conducted with their citizens. Furthermore, federal law Public Law 93-638, the Indian Self-Determination and Education Assistance Act of 1975, as well as the federal doctrine of Self-Governance, provides AI/AN communities with a legal basis for taking over the administration of health and social services provided to their citizens. These services would include research related to health and social issues.[5] In the context of Tribal sovereignty, CBPR has been hailed by many as a successful method by which academic institutions should conduct research with AI/AN communities.[6–12] Community-based participatory research entails collaborating and striving for equitable partnerships between community members, practitioners, and academic researchers in all phases of the work. By engaging local knowledge and theory based on the lived experience of the people involved, CBPR benefits include improved quality, validity, and relevance of the research to all parties.[13] Core principles of CBPR include building on existing strengths and resources to promote co-capacity-building and co-learning, fostering action-oriented research, and social change that addresses community priorities.[13] The National Congress of American Indians endorses CBPR as a methodology, particularly because the approach provides an effective means to facilitate community capacity-building.[14,15] Burhansstipanov and Christopher indicate that many Native American communities are strongly supportive of CBPR because the methodology engages communities in research initiatives.[6,7,16] Features of the CBPR conducted in the Waponahki Tribal Health Assessment that align with recommendations made by Christopher, Bharadwaj, Burhanstippanov, and others regarding conducting CBPR with AI/AN communities, included:

- being present in the community and listening to community members to build trust
- acknowledging personal and institutional histories
- acknowledging the expertise of all partners
- recognizing the historical context of the research
- ensuring equitable distribution of resources for salary support, including for Tribal staff who worked on the project
- implementing active effective communication among all CBPR partners,
- creating partnerships with leaders with decision-making responsibility within each Tribal health department
- sharing raw and summary data related to the project to stakeholders
- following both Tribal and researchers' protocols for disseminating and publishing the findings[6,7,11,16–19]

The proximity paradox articulated by Ritchie *et al*. suggests the need for increased application of CBPR principles in distal partnerships with remote indigenous communities while paradoxically these principles are much easier to apply in proximal partnerships.[20] Separated by 1,600 miles, the UNMC and University of Nebraska Lincoln faculty, staff, and students representing the academic members of the research team remained minimally present in the community. However, the continuous presence of the Waponahki members of the research team which included a Tribal principal investigator (PI), Tribal health directors, and Tribal interviewers, who already had earned community trust negated the need for continuous on-site engagement by academic members of the research team.

Participants. *Waponahki Confederacy's historical and present relationship*. The four Maine federally recognized tribes have a long history of working together to improve the quality of life in the Tribal communities. Historically, the Maine Tribes have endorsed the view that there is strength in numbers and working together for a common goal benefits everyone. This can be documented back to the formation of the Waponahki Confederacy. The Waponahki Confederacy joined the Micmac, Maliseet, Passamaquoddy, and Penobscot Nations (including the bands in the United States and Canada) and allowed the Tribes opportunities to work together as allies. The Confederacy would meet periodically and continues to meet annually to exchange information, share ideas and concerns, and work together to resolve common difficulties.[21,22] The Maine Tribes continue to provide political support throughout the year and other resources during crises. In the past four decades, the Maine Tribes have worked together on land claims, federal recognition, contracting with the federal government for services provided by the U.S. Indian Health Service and Bureau of Indian Affairs, in addition to matters relating to Tribal sovereignty in relation to the State of Maine.

The Aroostook Band of Micmacs. The majority of the more than 1,240 members of the Aroostook Band of Micmacs live in Aroostook County, in northern Maine. The Micmacs continue to speak their native language, which is part of the Algonquian linguistic group and related to Maliseet, Passamaquoddy, and Penobscot. The Aroostook Band of Micmacs is governed by the Micmac Tribal Council consisting of a Tribal Chief,

Vice-Chief and nine Tribal Council members. The Micmacs have no reservation, but currently possess approximately 1,350 acres of land in northern Maine.[23,24]

The Houlton Band of Maliseet Indians. With some 1,400 Tribal members the Houlton Band of Maliseet Indians is located in Houlton in Aroostook County in northern Maine and is part of the Maliseet Nation, which also has Tribal communities based in Canada. The governmental structure of the Tribe consists of a six-member Council and one Tribal Chief.[25]

The Passamaquoddy Tribe: Indian Township and Pleasant Point. The Passamaquoddy Tribe has two separate reservation communities on the U.S. side of the border, located 50 miles apart: Indian Township and Pleasant Point. A total of 3,575 Tribal members are listed on the Tribal census rolls with 2,148 listed on Pleasant Point census and 1,427 on the Indian Township census. Indian Township and Pleasant Point maintain separate health programs and Tribal Councils; however, the Tribal Chiefs and Tribal Councils meet jointly to decide on matters that affect the Tribe as a whole.[26]

The Penobscot Nation. According to the 2014 Penobscot Tribal Census, the total population of the Penobscot Nation is 2,398 members, with 414 residing on the Penobscot Nation Reservation and 1,395 residing in Maine. A large percentage of the Tribal population lives with-in a 50-mile radius of reservation, Indian Island. The Penobscot Nation is led by an elected Chief, Vice Chief, and a 12-member Tribal Council.[27]

The Maine Tribal health directors. The four Tribes' collaborative efforts through the Waponahki Confederacy have carried over into the Tribal health departments, manifested in jointly held standing quarterly inter-Tribal meetings. The Maine Tribal health directors (MTHD) have supported each other by sharing best practices, providing information to help resolve common problems, sharing staff and helping to train employees. This long history of successfully working together also stems from the fact that MTHD face many similar challenges, resulting in mutual understanding. Alike in design, the Health Departments receive the majority portion of their operating budgets through federal contracts with Indian Health Services and therefore follow many of the same federal laws and regulations that govern these contracts. At the time of the Waponahki health assessment, four of the five MTHD were Tribal members, had significant experience in working in the Health Programs, were sensitive to the culture in the communities in which they work, and were very familiar with the families in their respective communities. All these factors helped build widespread, strong community acceptance of and trust for the Waponahki health assessment. When the MTHD selected the Tribal Principal Investigator, they chose the most senior and experienced Health Director, Patricia Knox-Nicola, a Penobscot Nation Tribal member who resides in the Penobscot community. At the time of the survey Ms. Knox-Nicola had worked in the Health Department for 33 years, and had a long history of collaborating with the other MTHD directors. MTHD primary roles included:

- obtaining Tribal Council permission to conduct the survey
- developing the survey instrument used in the health assessment in collaboration with UNMC
- conducting the pilot test of the survey
- identifying Tribal interviewers

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- coordinating the training of Tribal IT staff and Tribal interviewers in preparation for the survey
- identifying subjects eligible to participate in the survey
- supervising survey Tribal IT staff and Tribal employees who conducted the survey
- promoting the survey
- developing their individual Tribal survey result dissemination plans.

Tribal Chiefs and Tribal Councils. The primary role of each Tribal Council was to approve the survey and assist in promoting the survey by having the Tribal Chairperson/Chief sign the initial recruitment letter. In individual Waponahki Tribal communities, which are sovereign nations within the United States, Tribal citizens have direct access to the Tribal Chief. The Chief in each community generally maintains an open-door policy where Tribal members can walk in and speak directly to the Chief. Tribal members in turn, maintain a similar relationship with the Tribal health directors. The Tribal health directors in turn, are directly hired and supervised by the Tribal Chief. Because of the direct supervision, the Tribal Chiefs are familiar with the Directors and have an opportunity to build a trusting relationship with the Health Directors. The relationship between the Chief, Tribal health director, and the community helps foster a perception of community ownership of the Health Department which facilitated the willingness of community members to participate in the Health Department-implemented Waponahki Tribal Health Assessment.

Tribal IT staff. Tribal IT staff responsibilities included installing the survey application on laptops which interviewers employed in surveying participants. Furthermore, the IT staff assisted interviewers with uploading survey data into a secure website that encrypted the data, and then converted to SAS (SAS Institute, Cary NC) for analysis by the UNMC biostatisticians.[28]

Tribal interviewers. The interviewers contacted survey participants to schedule time for them interview participants.

The University of Nebraska. In addition to choosing a Tribal PI, the Tribal health directors also identified an academic PI who had conducted health assessments with Tribal communities and worked as a clinician in a primary care clinic that served Waponahki Tribal members. The academic PI was based at the UNMC, College of Public Health, Department of Health Promotion, Social and Behavioral Health in Omaha, Nebraska, which necessitated the presence of an on-site Tribal PI in Maine and MTHD who supervised the survey in each community. Additional participants from the UNMC College of Public Health included a lead statistician and statistical coordinator who conducted all the analyses, and a programmer who developed the survey application and provided technical assistance to Tribal IT staff. A graduate student from the University of Nebraska Lincoln, Sociology Department conducted the qualitative data analysis for the open-ended questions.

Project steps. Two years prior to the survey, the Maine Office of Health Equity Director, a Passamaquoddy Tribal member, introduced the academic PI individually to the MTHD during a trip to Maine as a candidate for conducting the health assessment. The MTHD were interested in having an academic PI who was known, trusted, and had worked in Native American communities previously. The academic PI had

worked as clinician in a health system that cared for Waponahki Tribal members with the Maine Office of Health Equity Director. In addition, the academic PI had conducted a similar assessment with another New England Tribe.[29]

These introductions resulted in sustainable patterns of communication that included three MTHD teaching in courses that the academic PI taught to master of public health students. The Maine Office of Health Equity Director facilitated introductions of the MTHD to funding opportunities in the philanthropic sector. The MTHD then proceeded with collaborating with the academic PI who was housed at the UNMC, College of Public Health on a grant proposal to a private foundation, which ended up funding the majority of the health assessment. A former MTHD represented the interest of MTHD in developing the grant proposal with the academic PI. The Tribe of the Tribal PI, Penobscot Nation, served as the principal investigator on the grant application. See Table 1 for timeline of project steps.

Partnership agreements. The UNMC-College of Public Health served as a subcontractor to the Penobscot Nation. Subsequently, the academic PI reported directly to the Tribal PI.

Duties. The Tribal PI reported directly to the four other Tribal health directors who constituted a decision-making board and who supervised interviewers and IT staff. See Figure 1. Tribal data ownership and expectations for the scope of work by UNMC employees were described in the initial grant application, which was developed jointly between the academic PI and MTHD. The subcontract with the UNMC College of Public Health built on the language in the grant; therefore, the contract between UNMC and the Penobscot Nation required very little negotiation.

Due to previous negative experiences including situations in which survey results were used to support legal claims that did not benefit the Tribes and a history of researchers not sharing survey results with the participants, there existed an overall reluctance among Waponahki Tribal members to participate in surveys. Therefore, from the project's inception, the MTHD determined the need for Tribal ownership of the data. In the grant proposals that supported the survey and in the final contract between the UNMC College of Public Health and the fiscal agent, Penobscot Nation, MTHD articulated that each tribe must maintain ownership of their Tribal data and that no data could be shared for use or publication without express written permission from the designated Tribal authority. Tribal ownership of the data was also necessary to enhance community member participation in the survey. The UNMC College of Public Health agreed to the condition of Tribal ownership as this is the institution's practice. The UNMC Institutional Review Board and each Tribal Chief and Tribal Council approved the study.

Survey design. Tribal health directors selected domains for the survey while UNMC College of Public Health research team members identified validated survey instruments to match the domains the health directors identified as being of high priority. To allow for comparability of health statistics and possible identification of health disparities in comparison with other populations in the State of Maine, MTHD selected the majority of the domains from the 242-item survey from the BRFSS.[30] Topic areas on the BRFSS of interest to the MTHD included the prevalence of self-reported chronic diseases, cancer,

Table 1.

KEY MILESTONES AND TIMELINE

Key Milestones and Timeline (Month 1, July 1, 2007–Month 60—July 1, 2012)

	Months			
Milestone	**1–24**	**25–36**	**37–44**	**45–60**
Initial contact • Introduction by Waponahki Tribal member of academic PI to individual Maine Tribal Health Directors • Tribal Health Directors guest lecturing to MPH students in academic PI's class for MPH students	⟶			
Partnership agreements and grants • Tribal data ownership agreement made between Waponahki Tribes and the University of Nebraska Medical Center, College of Public Health • Development and completion of proposal to philanthropic organizations to support survey		⟶		
Survey design • Obtaining of Tribal Council resolutions to support survey • Training of Tribal Interviewers • IRB submission for pilot test • Implementation of pilot test		⟶		
Survey implementation • IRB approval of final survey • Advertising and marketing of survey • Conducting of survey			⟶	
Quantitative and qualitative data analysis • Conducted by the University of Nebraska Medical Center College of Public Health Departments of Biostatistics and Health Promotion, Social and Behavioral Health				⟶
Dissemination • Presentation to Tribal Leadership and Funders • Tribal community dissemination planning initiated by Maine Tribal Health Directors				⟶

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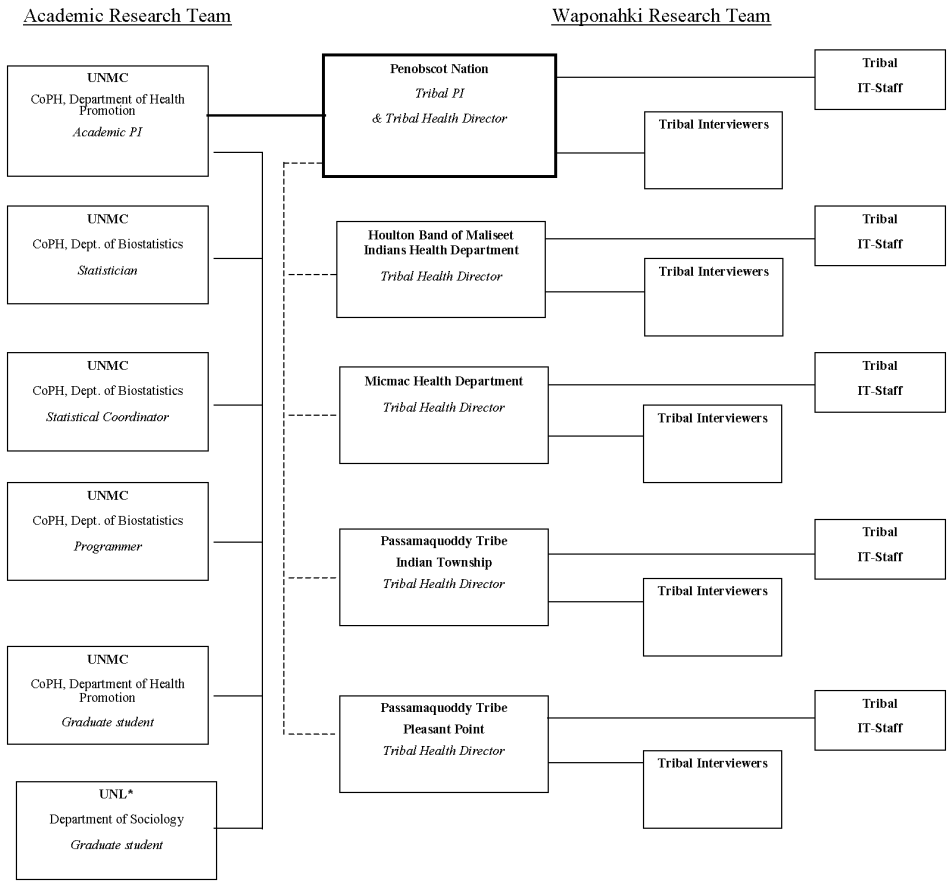


Figure 1. Waponahki Tribal Health Assessment organizational chart.

Legend:

CoPH	College of Public Health
IT	Information Technology
UNMC	University Nebraska Medical Center
UNL	University Nebraska Lincoln

For the qualitative data analysis eth academic included a graduate student fom the Sociology Department of UNMC's sister campus UNL.

diabetes, heart disease, and their associated risk factors, and participant engagement in clinical and preventive services such as health screenings for cancer and heart disease.

Tribal health directors and the UNMC members of the research team also developed Tribe-specific open-ended questions on community matters including sources of pride, community strengths, and elder health care needs. In addition, the survey included questions on perceived discrimination, historical loss, domestic violence, substance abuse and prescription drug use, adverse childhood events, and mental health. The questions about these sensitive topics were drawn from validated surveys, including the perceived discrimination scale developed by Williams *et al.*,[31] Whitbeck's historical loss scale,[32] the Maine Youth Drug and Alcohol Survey,[33] the BRFSS,[30] and the Center

for Epidemiological Studies Depression Scale.[34] MTHD initially desired conducting surveys in the homes of participants, in order to reach disabled and home bound Tribal members; however, due to safety and confidentiality concerns stemming from questions on domestic violence and sensitive topics, Tribal health departments or another Tribal site were designated as locations to conduct the surveys. In the Passamaquoddy tribes, some elders' first language is Passamaquoddy. In this population survey, interviewers fluent in Passamaquoddy translated the survey into the first language of participants as needed.

Previous surveys completed by the Tribal health departments included mail-out surveys, in-person surveys, and telephone surveys, in addition to the voluntary completion of surveys left in the waiting areas of the Health Department. Tribal health directors now chose to use computer-assisted personal interviews, as face-to-face interviews previously had provided the highest rates of survey completion. Tribal health directors identified trusted members of their communities to conduct the interviews as a means to garner the best possible response rate. We pilot-tested the survey with four participants from each community (N=20) and learned the following: the survey (including informed consent) took an hour, participants should have the option to complete the section on sensitive topics by themselves rather than having the interviewer key in the responses, and participants did not have much difficulty understanding the questions. Therefore, we did not modify the BRFSS questions or other questions taken from validated instruments.

Sample size. The Waponahki Tribal Health Assessment sample included randomly selected male and female Tribal members 18 years and above, who lived within each Tribe's respective health service delivery area. There were 3,014 male and female and male Tribal members 18 years and older who resided within each respective Tribe's health service delivery area at the time of the survey. Each Tribe's sample size was calculated using NCSS/PASS.[35] Sample size was calculated for estimation of a proportion and a 95% confidence interval with a precision of 4% using a finite population correction to account for the small and differing size of each tribe.[36–38] Using Tribal rolls, all eligible participants were assigned a number, and these numbers were randomly selected to obtain the sample. Tribal health directors contacted potential participants in order of their selection. After potential participants had been contacted, additional participants were randomly selected until the target sample was achieved or until the list of eligible participants was exhausted (which occurred in some cases).

Advertising the survey. The MTHD used several strategies to raise awareness of the survey and notify the Tribal members that the Tribal health departments would be conducting the survey:

- the Tribal health directors placed notices regarding the survey in the bi-monthly joint community newsletter
- the Tribal Public Health District produced large posters advertising the survey and placed them in the waiting areas of each health department
- Tribal health departments promoted the survey at health fairs
- the Tribal Chief or Tribal health director sent a recruitment letter to participants randomly selected to take part in the survey

- interviewers attempted to contact prospective participants up to three times before contacting the next participant
- word-of-mouth played an important role in promoting the survey
- participants who completed the survey received a $25 Walmart gift-card. In addition, participants received gas cards if they had to travel 30 or more miles roundtrip to complete the survey.

The public advertising of the survey caused some confusion. Although all the advertising materials explained that some Tribal members might receive a letter asking them to participate, individuals who were not selected came to the Health Directors and interviewers asking if they could take part in the survey. In these instances the Health Directors and interviewers explained that only individuals selected from a scientifically-based list could participate. However, if more participants were needed, individuals who met inclusion criteria might be contacted to participate in the survey. This explanation sufficed.

In advertising the survey the MTHD consistently communicated the purposes of the use of the survey results to Tribal citizens in publications, recruitment letters, and conversation:

- health program planning
- development of health services
- education and research
- seeking future funding.

Survey implementation

A UNMC programmer wrote the survey delivery application using Census and Survey Processing (CSPro) software, developed by the U.S. Census Department for creating complex surveys.[39] Handling complex skip patterns and the bundling of all files needed to run the application/output the data set made CSPro the ideal software to develop this type of application. The entire survey application, including supporting files, was bundled in a self-extracting executable file and emailed to IT contacts at the five different Tribal health departments, who in turn loaded the survey onto laptops. The survey consisted of a laptop-based questionnaire, which interviewers administered to participants. Participants had the option to complete the section on sensitive questions by themselves. The UNMC programmer provided technical assistance to Tribal IT contacts in completing any of these tasks. Answers keyed into the application populated a text file on an encrypted laptop hard-drive (one record per interview). That data file was loaded to a pre-determined secure website that encrypted the data, and then converted to SAS (SAS Institute, Cary, NC) for analysis by the statisticians.[28]

The MTHD and all 19 interviewers completed human subjects training through the on-line Collaborative IRB Training Initiative (CITI) training *via* the UNMC web-site. In addition, members of the research team from UNMC trained Tribal interviewers *via* webinars conducted in Adobe Connect on: confidentiality/consent, sampling and survey topics, prepping for survey and application, and interview techniques. Each interviewer practiced the completion of the survey with the relevant MTHD. At the

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time of the survey, the interviewer provided a consent form that reassured participants that:

- their personal health information was protected
- answers could not be traced back to any individual
- summary results would not be shared without approval from Tribal authorities.

In addition, all interviewers carried a signed oath of confidentiality form to each of their interviews. Interviewers conducted computer-assisted interviews, an approach that had been employed in a Northeastern community by the academic PI to attain a higher response rate in a northeastern Tribal community than achieved when health surveys were disseminated in the waiting room of the Tribal health department.[29] Following the completion of the survey, the interviewer offered a list of resources including 24-hour hot-lines that addressed the sensitive topics in the survey. Due to the sensitive nature of several questions (e.g., HIV risk factors, substance abuse, domestic abuse and suicide) respondents had the option to answer these questions in a self-administered portion of the survey (which also enhanced standardization). The application included all the sensitive questions in an isolable segment of the survey.

During the duration of the project, the academic PI traveled to Maine from Nebraska four times for the following reasons:

- to meet with Tribal health directors to review survey questions
- to conduct an in-person tutorial of the application
- to review findings from the survey
- to present results from the survey to Tribal health directors, Tribal leadership, and funders.

All other communication was handled *via* e-mail, conference calls, and webinars. During the regularly scheduled MTHD quarterly meetings, time was set aside for a call with the Academic and Tribal PIs. In addition to these quarterly calls, the Tribal PI had regularly scheduled calls with the Academic PI and MTHD (both jointly and separately), in addition to communication with individual Tribal health departments. The Academic PI communicated directly with the Tribal PI, who coordinated the flow of information between UNMC and the individual MTHD. All decisions affecting the surveys were made jointly by the MTHD in consultation with the Tribal and Academic PIs.

Results

For the qualitative data, the academic PI, a UNMC College of Public Health graduate student, a University of Nebraska Lincoln graduate student in the Department of Sociology, and the Tribal PI collaborated on the analysis of the open-ended questions. The research team used a randomly selected set of 200 de-identified responses to each of the six qualitative, open-ended questions to develop the codes. The six open-ended questions were populated for review and categorical responses were generated for each question. Because the cases for each question were randomly and independently selected for review, cases from each of the tribes were considered. Open coding proceeded in two

phases. In phase one, each of the five members of the research team reviewed 40 cases across the 200 cases per question. In phase 2, all categories that defined a particular question were reviewed by the team with questions posed as to terminology, overlapping constructs, and precision of measurement (e.g., heart/cardiac problems generally or heart disease and high cholesterol specifically). A list of codes with operational definitions was developed for final review by the team. We then coded the data and determined the frequency with which each code was applied.

In the quantitative portion of the study, descriptive statistics of individual Tribes and for the total Waponahki sample were presented to the MTHD. A descriptive summary of all survey questions was completed for each individual Tribe including the number responding, mean, and range for all questions with a numeric response, and frequency and percent for all questions with a categorical response. In addition, each Tribe received an aggregate summary of the responses from all five Waponahki Tribes. The two Passamaquoddy Tribes also received aggregate Passamaquoddy data. With the data summary, each Tribe received a written executive summary that described the survey, summarized the Tribe's demographics, and compared Tribal data (e.g., use of preventive services such as various cancer screening modalities and vaccinations) with *Healthy People 2020* objectives.[40] In addition, based on survey data, MTHD identified areas of concern which were included in the executive summary, which also gave information on the open-ended questions asked, historical loss and depression, and social determinants of health.

Based on the calculated sample size for each tribe, response rates were between 68% and 97%. Overall 78% (1,127/1,445) completed the survey resulting in a precision for estimation of 2% for all of Waponahki. To protect the anonymity of the Tribes, the MTHD decided not to publish data which identified survey completion rates by individual Tribe.

Table 2.

SAMPLE SIZE OF MAINE TRIBAL POPULATIONS AGE 18 AND ABOVE

Tribe	Adult Tribal population residing within Tribe's health service delivery area[a]	Sample size by Tribe
Aroostook Band of Micmacs	336	216
Houlton Band of Maliseet Indians	339	217
Passamaquoddy Tribe—Indian Township	644	311
Passamaquoddy Tribe—Pleasant Point	966	371
Penobscot Nation	729	330
Total	3014	1,445

[a]As provided by each Tribe at the planning stage.

Discussion

With 1,127 completed surveys, to our knowledge the Waponahki Tribal Health Assessment represents one of the largest comprehensive health needs assessment of American Indians/Alaska Natives east of the Mississippi River. We could not identify any other study that compares survey response rates between long-distance CBPR employing the technology described in the Waponahki health assessment and CBPR where the community is located more proximally to the academic PI. Ritchie *et al.* indicate that CBPR principles are easier to apply in proximal partnerships due to them affording an environment "where collaborative partnerships can be developed and sustained."[20] [183] This finding is also supported by the work of Earle-Richardson *et al.*[18] The long distance CBPR approach described in this study focused on a Tribally driven, multi-Tribal health assessment in five communities with: a long history of collaboration, information technology infrastructure, experienced Tribal health directors, a partnership with an academic institution where the Tribal partner served as the fiscal agent, and significant trust between Tribal health directors, Tribal leadership, and community. However, we believe that the principles from this study can be adapted to other communities nationally and globally who wish to work long-distance with an academic institution. While we did not measure individual factors affecting the number of completed surveys we believe that several factors contributed to the high number of completed surveys.

Trust between partners. The success of the health assessment, measured in number of completed surveys, relied on a foundation for collaboration present at each Tribal site, manifested in several layers of trust between parties, grounded in the historic Waponahki Confederacy collaborative relationship between the five participating communities in addition to:

- trust between the Tribal health directors
- the Tribal leadership's trust in the Tribal health directors
- the community members' trust in: Tribal leadership, Tribal health departments, and Tribal members and Tribal employees who conducted the surveys.

A telling finding of the survey concerning trust was that—among all branches of Tribal organizations—the Tribal health department ranked the highest in terms of participants' perceptions of strengths in the community. Support from Tribal leadership may also explain the high number of survey participants. For example, when one group of survey participants did not receive the introductory letter to the survey from the Tribal Chief, the participation-level in this group appeared to be less in comparison to other groups who received the letter. The introductory letter indicated endorsement of the survey by Tribal resolution and encouraged Tribal members to participate. In addition the letter included the provision which stated that the Tribe maintained ownership of the data.

Having interviewers who were members of each specific community also was important in the success of this project as the Tribal health directors indicated that there would be an increased willingness for participants to be interviewed by someone who was known and trusted in their community. The interviewers providing a signed confidentiality statement to participants also encouraged participation. In the Passama-

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quoddy tribes, the ability to complete the survey in the Tribe's language demonstrated the importance placed on having the elders' voice in the study and encouraged survey participation.

Tribal data ownership. The Tribal health directors articulated a need for Tribal ownership of data which was explicitly stated in the contract with UNMC and in communications marketing the health assessment in each Tribal community. The clause regarding Tribal ownership of data, data use, and data dissemination, added a layer of trust between the academic institution and the Tribal health departments; furthermore, the communication through publications, recruitment letters, and word of mouth to Tribal citizens regarding Tribal ownership of the data provided an incentive for individuals to participate in the survey.

Tribal partner as fiscal agent

Having a contractual agreement where a Tribal Nation served as the fiscal agent for the study the academic PI reported directly to the Tribal PI, allowed for a balance of power and shared decision-making that CBPR seeks to accomplish. Often, in CBPR projects, academic institutions yield fiscal control over grants, leading to an uneven distribution of power with their community partner.[18,41] Having a Tribal Nation as the primary fiscal agent ameliorated this fact. In addition, having a respected and known senior Tribal PI, minimized the need for the continuous presence of an academic PI in the communities. We identified one long distance CBPR study addressing farmworker health in Maine and upstate New York, where the PI was based at a distance from both sites, and the main concern among participants was long-distance project coordination. Farmworker participants felt that the research coordinator rather than the local site coordinator served as the main driver of the study.[18] The PI indicated that this perception might stem from having the research coordinator based at the academic institution due to accountability to funding agencies, in effect limiting control of the site coordinator.

Advertising and timing of study. According to the Tribal health directors, advertising the survey in the communities played a significant role in the high rates of survey completion. Community members were informed about the survey in advance and updated on the survey through the community newsletter, information posted in the waiting rooms at the Health Departments, and an introductory letter from the Tribal Chief describing the survey. The Tribal health directors indicated that having the survey coincide with the Christmas holiday season encouraged individuals to participate in the study due to the $25 Walmart gift card incentive.

User-friendly technology. In addition to providing a secure, user-friendly, and reliable means to upload data, the employment of CSPro software to conduct the survey allowed for the handling of complex skip patterns which would have been difficult to manage if the survey were pen-to-paper. Each Tribal health department also had information technology (IT) staff who worked closely with the UNMC programmer on installing the survey on laptops and uploading the survey to a UNMC secure website. Supplemental webinars via Adobe Connect and on-line modules allowed for the training and education of interviewers to obtain the necessary and required skills to conduct

the surveys in a manner consistent with IRB guidelines. Tribal health directors underwent the education/training sessions prior to the interviewers and conducted the pilot tests in each community before the launching of the survey. Subsequently, in addition to providing overall supervision at each site, they became experts in conducting the surveys and could provide technical assistance to the interviewers.

Funding from philanthropic organizations. As Tribal ownership and control of the publication and distribution of the resulting data played a significant role in the decision to move forward to conduct the survey, the source of the funding played a critical role. Tribal health directors found that state and federal grant funding guidelines often dictated that data collected from surveys are public information and therefore examined other sources for funding to maintain data ownership. They sought and received funding from philanthropic organizations, which provided them with the flexibility to complete the survey and protect Tribal ownership of the data. The philanthropic organizations agreed to terms where access to data from the survey supported by their organization would only be shared on conditions where designated Tribal authorities approved the dissemination of data.

Limitations. Study limitations included the following:

- The research team could not accommodate Tribal members who were unable to travel to the areas designated confidential and secure areas to partake in the survey.
- Elders were not familiar/not comfortable with using the computer during the self-administered portions of the computer.
- In selecting participants 18 years and older we did not obtain substance abuse data on the youth population, defined by Tribal Health Directors as anyone 17 years old or younger. Based on patient visit data and referrals to substance abuse treatment programs, the Tribal health directors believed this age group to have the highest prevalence of substance abuse among all age cohorts.
- Using computer-assisted face-to-face interviews does not allow for an exact comparison with the BRFSS which is a random-digit dial telephone survey.

Implications. The results from the assessments, that the Tribal leaders have agreed to make public, have been compiled into community profiles for each Tribe. The Passamaquoddy Tribe decided to complete only one profile for the two Passamaquoddy communities. The profiles will be:

- available at each health department for community members,
- distributed to the Tribal leaders,
- available at annual community health fairs,
- distributed to the agencies who provided funding for the assessment project, and
- available upon request as appropriate.

Data not contained in the community profiles may be made available upon written request to Tribal leadership.

Future directions. The Wabanaki Public Health District (WPHD) will play a primary role in addressing findings from the health assessment. The WPHD has the responsibility of providing public health education to each of the five Tribal communities. In line

with the National Prevention Strategy which calls for interdepartmental collaboration to address public health matters in an evidence-based fashion, the WPHD will create a committee sanctioned by the Tribal leaders composed of representatives from different departments and programs in each community.[42] The committee will address the need for a broader, community-wide approach to improve the health of the community. Based on data from the health assessment, the committee will develop a Waponahki health improvement plan which will address the prevention, education, and health promotion needs of each community.

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