Process for Determining the Cancer Burden of the Hopi Tribe

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SYNOPSIS

The Hopi Tribe is located in the northeastern part of Arizona on more than one million acres of federally reserved land. Tribally based community research, conducted in collaboration with University of Arizona researchers, has been successfully implemented on Hopi beginning with a cross-sectional community survey in 1993 and continuing with a second survey in 2006. Both surveys identified a strong community interest in cancer.

This article reports on the process involved in a third study, in which official Hopi enrollment data were matched with Arizona Cancer Registry data. The process involved bringing in a new partner and obtaining tribal, state, and university approvals, as well as a signed data exchange agreement between the state and the Hopi Tribe. Technical implementation of the data match required computer programming and epidemiologic expertise, as well as an understanding of the community and the culture. Close collaboration among Hopi residents and university epidemiologists was critical.

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The purpose of this article is to describe, in detail, the collaborative and technical processes undertaken by the Hopi Tribe, University of Arizona (UA) researchers, and the Arizona Cancer Registry (ACR) to provide the Hopi Tribe with Hopi-specific cancer data needed to assess the tribe's cancer burden. These processes—jointly referred to as “the data match”—involved sharing highly confidential tribal enrollment data with university researchers and state health professionals. The data match was accomplished after years of tribally based participatory research and trust building.

The data match was a rare event. While numerous studies link Indian Health Service (IHS) data to cancer registry data, only a few epidemiologic studies in the extant literature point to the use of tribal enrollment data to examine the cancer burden of a specific American Indian/Alaska Native (AI/AN) tribe or nation.^{1–3} Moreover, to our knowledge, no previous study has described this collaborative process in such detail. We suggest a roadmap upon which such efforts can be accomplished within the context of tribal sovereignty. AI/AN tribes are recognized as sovereign nations by the U.S. government. They have the right to govern themselves; only Congress can limit these rights and must do so directly, not by implication.⁴ Therefore, working with American Indian (AI) tribes requires understanding, appreciation, recognition, and respect of this special status on the part of researchers and other collaborators. This necessarily results in additional procedural requirements for the introduction and completion of any research and/or service project. As such, the data match required not only collaboration for technical reasons but also tribal, state, and university approvals, and a signed data exchange agreement between the state and the Hopi Tribe.

THE HOPI TRIBE

The Hopi Tribe is one of the 22 federally recognized AI tribes in Arizona. Tribal members live on more than a million and a half acres of federally reserved land in the northeastern part of the state and represent approximately 5% of all AIs in Arizona. According to the 2000 U.S. Census, there were approximately 2,000 households on the Hopi reservation.⁵ The per capita income was about \$8,500 per year, with a median household income of less than \$21,000. Thirty-six percent of all families and 41% of all people were below the poverty level in 2000. Additionally, approximately 32% of occupied housing units had no telephone service; 64% of the population older than 5 years of age spoke a language other than English at home, 33% of whom

spoke English less than very well; and 25% of the occupied housing units had no vehicle.

Through the Office of Health Services, the Hopi Tribe participates in the Centers for Disease Control and Prevention's (CDC's) Breast and Cervical Cancer Early Detection Project. This program is referred to as the Hopi Women's Health Program (HWHP). Until 2009, this program was the only Hopi tribal program engaging in any type of cancer screening. The HWHP works closely with IHS and is currently working to expand its scope to serve the entire community, including men, with other cancer screenings and cancer planning for the Hopi Tribe.

TRIBALLY BASED PARTICIPATORY CANCER RESEARCH ON HOPI

Tribally based community research, conducted in collaboration with the university researchers in Arizona, has a history of being successfully implemented with the Hopi Tribe. This positive history provides a critical backdrop to the success of the collaboration required to implement the data match project. In 1993, a cross-sectional community survey of Hopi women was performed in collaboration with the Office of Health Services of the Hopi Tribe and the Arizona Cancer Center of UA. This survey assessed the prevalence of and predictors for breast and cervical cancer screening⁶ and provided the funding justification for HWHP. Between 2003 and 2006, HWHP and faculty from UA, the Arizona Cancer Center, and Northern Arizona University partnered in an evaluation of HWHP and the implementation of a follow-up survey.

In the course of developing the 2006 survey, community meetings and focus groups were held during which Hopi community members raised concerns about the cancer burden of their people beyond that of breast and cervical cancer. This concern was echoed in the high participation rate (86%) in the 2006 survey and by community members at the Hopi Health Summit held in November 2007.

CANCER AND NATIVE AMERICANS OF THE SOUTHWEST

Aggregate data spanning several decades (1975–2004) on cancer incidence and survival among Native Americans were recently published in great detail.⁷ These data indicate that cancer rates are generally lower among AI/AN compared with non-Hispanic white (NHW) people, but that this pattern has not been found for all cancer sites. In the southwest region of

the U.S., which includes Arizona, the three leading cancers among AI men are prostate (67.0 per 100,000 population), colon and rectum (26.7 per 100,000 population), and kidney (25.1 per 100,000 population), while the three leading cancers among AI women are breast (50.4 per 100,000 population), lung (10.3 per 100,000 population), and uterine (19.8 per 100,000 population). These findings about colorectal cancers (CRCs) are consistent with reports from IHS, such as the 2005 Navajo community health status assessment, wherein a steady increase in CRCs among its patients in the last decade was reported.

In addition, age-specific incidence data for AI/AN in the southwest region⁷ indicate that cancers continue to be diagnosed at later stages among AI/AN compared with NHW people. For example, 62.7% of all AI/AN CRCs in the southwest region were diagnosed at the regional/distant stage compared with 53.6% of all CRCs among NHW people. Similarly, 40.3% of all AI/AN breast cancers in the southwest region were diagnosed at the regional/distant stage compared with 31.8% of all breast cancers among NHW people. These patterns are also observed when comparing the NHW vs. AI populations in the percentage of late-stage diagnoses for both CRC (38% vs. 44%) and prostate (14% vs. 23%) cancer. As late-stage diagnosis impacts mortality, it is not surprising that even though overall cancer death rates between 1995 and 2004 declined for most racial/ethnic populations, they remained stable for AI/AN men and women. In Arizona, in 2006, cancer was the second leading cause of death for AI females and the third leading cause of death for AI males, based on rates age-adjusted to the 2000 standard.⁸

Whether the aggregate data reported accurately reflected the cancer burden of the Hopi people was a concern to the Hopi Tribe. As such, the tribe desired tribal-specific cancer data to address the causes and specific health-care needs of its own population. The aggregate data are limited by the assumption of intertribal homogeneity and racial misclassification^{9–13} and contain no tribal-specific information. In response to this desire, the director of HWHP and UA researchers extended and strengthened their partnership to include representatives of the ACR of the Arizona Department of Health Services (ADHS) to more fully address this tribally identified need.

The ACR is a state-mandated “population-based surveillance system that collects, manages, and analyzes information on the incidence, survival, and mortality of persons having been diagnosed with cancer.”¹⁴ Mandatory reporting began in 1992 with enactment of the

Arizona cancer reporting rules. Congressional enactment of the National Program of Cancer Registries also facilitated the reporting. Arizona data are considered complete statewide beginning in 1995. The ACR receives non-IHS data directly from Arizona’s non-IHS facilities and Arizona IHS data from the New Mexico Tumor Registry. The ADHS encourages the sharing of cancer registry data with the tribes and is implementing the National Standards for Culturally and Linguistically Appropriate Services in Health Care.¹⁵ Standard #11 is particularly relevant and explicit in advocating community involvement in creating an epidemiologic profile and needs assessment. The Hopi-ACR agreement was built upon a successful data-sharing agreement with the designated health officer at the Gila River Indian Community and an IHS agreement for matching data files, obtained from the IHS cancer epidemiology unit in Albuquerque, New Mexico.

The ACR currently provides community-specific cancer incidence data cartographically by Community Health Analysis Area (CHAA). CHAAs are based on the census block group of the residential address at the time of diagnosis of the reported cancer case. In the case of the tribes, CHAAs are geographically congruent with individual reservations. Rates and counts for each of the 126 CHAAs are reported in a statewide map.¹⁶ However, several limitations associated with CHAA data precluded our ability to obtain Hopi-specific cancer data using this mechanism. First, CHAA data have only been reported for “all races combined” and are not specific for AI tribes or nations. Secondly, CHAAs do not differentiate between AIs living off reservation and others in the same community, nor do they identify the tribal affiliation of off-reservation residents. Finally, CHAA data require the geocoding of all addresses at diagnosis and, due to financial limitations, that geocoding was not complete beyond 2002.

Given the breadth of coverage of the ACR but its lack of tribal specificity, the Hopi Tribe, university researchers, and ACR identified a process to link Hopi tribal enrollment data to ACR data. In September 2007, National Cancer Institute funding was received to implement this process and analyze the matched data. We describe the steps necessary to successfully implement the data match between the ACR and the Hopi enrollment data for the purpose of ascertaining Hopi’s cancer burden. Although the results of the analysis are not yet complete, and will be presented elsewhere, we feel that the process of ascertaining Hopi’s cancer burden is critical and provides a successful model for other AI tribes to obtain their own cancer data.

MATCH PROCESS

During the week of May 26, 2008, data from the ACR were matched to the Hopi enrollment data obtained directly from the Hopi Office of Tribal Enrollment to provide the Hopi Tribe with an analytic dataset that could be used to assess the burden of cancer in the Hopi people. This analytic dataset will be used to assess the incidence of cancer among Hopi people, stratified by age, gender, village of enrollment, cancer site, and residency at time of diagnosis. The results of these analyses will be presented to the Hopi Tribe in report format and also orally to Hopi tribal and health officials at the Hopi tribal offices in Kykotsmovi, Arizona.

The data match took place in the offices of HWHP on the Hopi reservation, in Kykotsmovi. This effort represented a joint collaboration among the Hopi Tribe, the Arizona Cancer Center, the Mel and Enid Zuckerman College of Public Health at UA, and ACR of ADHS. While many individuals participated in this effort, the four key players were the Director of the HWHP, the Director of the Hopi Office of Tribal Enrollment, the Medical Director of the ADHS Bureau of Public Health Statistics, and a UA epidemiologist/researcher. Underlying this entire effort was the establishment of trust and mutual respect, built during years of close collaboration between and among all participants within and outside the Hopi tribal community.

Linking the ACR 1995–2005 data to the Hopi Enrollment Data was accomplished in three distinct phases. The first phase consisted of the prerequisites to the preparation for the match. The second phase consisted of the steps required to prepare for the successful implementation of the match. The third phase was the actual data match.

Phase I: prerequisites

This phase consisted of five specific efforts:

1. Identification of community need: As noted previously, the need to assess the Hopi cancer burden was first identified by Hopi Tribe members at community meetings and focus groups held to assess knowledge, attitudes, beliefs, and behaviors about breast and cervical cancer. This need was further highlighted by cancer health issues expressed at a Health Summit on November 15, 2007. After the concerns were first identified, meetings were held among university researchers, members of HWHP, the Office of Health Services of the Hopi Tribe, and the Hopi Office of Tribal Enrollment to identify a strategy to meet those tribal needs. This led to the second effort in this phase.
2. Expansion/development of relationships: The strong relationship that existed between UA researchers and HWHP was expanded to personnel from the ACR. This three-part collaboration began in early 2006 and continues to this day. It is fostered by frequent meetings, e-mails, phone conversations, and in-person meetings. Early on, the support of tribal leadership was sought and, in March 2007, the Hopi Tribal Council passed a Tribal Resolution (H-026-2007) supporting the project and its participants.
3. Independent funding: While the first three efforts were underway, three additional tasks were undertaken. The partners worked collaboratively to obtain independent funding for this project, which was realized as a National Cancer Institute pilot project through the Southwest American Indian Cancer Network. Additional funding was also obtained from the Comprehensive Minority Institute/Cancer Center Partnership of the National Cancer Institute funded through the UA-Northern Arizona University Comprehensive Arizona Cancer Center Cancer Research Partnership.
4. Data exchange agreement: A data exchange agreement between the sovereign Hopi Tribe and the state of Arizona was negotiated by attorneys of the respective parties in 2006–2007 and signed in July 2007.
5. Institutional Review Board approval: Finally, because UA researchers were involved in this project, we obtained UA Institutional Review Board approval in October 2007.

Phase II: preparation for match

The specific efforts undertaken to prepare for the actual match can be summarized in three parts. First, the UA epidemiologist, a former computer programmer, spent time with ACR computer personnel to acquire technical training on Registry Plus™ Link Plus, the software used to implement the data match. Link Plus is a probabilistic record linkage program developed at CDC's Division of Cancer Prevention and Control in support of the National Program of Cancer Registries.¹⁷ This step was critical to ensure that the match could be correctly implemented and to assure the ACR that its data would be handled properly.

The second effort included the identification of security requirements. An overriding concern in this entire effort was to maintain the confidentiality of both ACR and Hopi enrollment data. To this end, it was determined that a secured, password-encrypted

laptop would be used for the data match and that upon completion of the matching process, all confidential files would be permanently deleted.

Finally, to perform a successful data match, consistency in data format between the ACR data and Hopi enrollment data was essential. Therefore, it was necessary to communicate technical requirements to Hopi Management Information Systems and Enrollment departments and their contract programmers. The UA epidemiologist drew on her background in computer programming to identify the specific format needs for the files to be matched and to communicate these requirements in detail to the Hopi Management Information Systems department and the computer programming contractors who maintain the Hopi enrollment data.

Phase III: implementation of match

Phase III consisted of 17 steps, which are presented from two perspectives. The first identifies the tasks undertaken to implement the match (Figure 1). The second identifies the personnel needed to implement the tasks and their respective responsibilities (Figure 2). We discuss Figure 1 in detail, but emphasize that both perspectives, while providing the same information, are critical to the success of this project.

The first two steps—extracting data from the ACR master file and loading the secured laptop—took place in the ACR offices in Phoenix, Arizona. ACR provided a file of 260,173 registered cases diagnosed between 1995 and 2005 and whose residence at diagnosis was listed as Arizona. The file for matching excluded cases of nonreportable cervix uteri, nonreportable skin, and benign brain/central nervous system cancers. All other neoplasms with malignant behaviors were included.

The remaining steps took place in Kykotsmobi. All partners were present for the completion of steps 4–16, and each partner undertook specific roles commensurate with their levels of expertise and community knowledge. The file extracted from the Hopi enrollment database consisted of 18,744 records, representing 16,272 unique people ever enrolled in the Hopi Tribe. These highly confidential denominator data were obtained directly from the Hopi Office of Tribal Enrollment.

The technical steps undertaken to perform the match are shown in Figure 1. The Hopi enrollment data and ACR data were examined, and variables were modified, as necessary, so that the data elements on which the match was to occur were formatted in the same manner (steps 3–5). This was accomplished using SAS® version 9.1.¹⁸ Link Plus 2.0 probabilistic record linkage software¹⁹ was used to match the data on the

following parameters: last name, first name, middle initial, date of birth, social security number, and gender. The phonetic algorithm Soundex was used to match names by sound, not just spelling.

Last name was also identified as a blocking factor to maximize the efficiency of the match process. Link Plus produces a linkage score to identify the strength of any given match. We used a cutoff score of 5 to identify possible matches and the Direct Method with default M-probabilities (sensitivity). In this approach, U-probabilities (specificity) are derived from the data.

To account for variation in names recorded in both files, two matches were performed (steps 6 and 8). On the first match attempt, the current first and current last name were used as recorded in the enrollment file. In the second attempt, the alternative first and alternative last name were used. With this approach, one additional case was identified that would not have been identified if the match was completed on current names only. Link Plus generates listings of potential matches. Members from the Hopi Office of Tribal Enrollment and HWHP manually reviewed all potential matches (steps 7 and 9). With input from ACR and UA collaborators, Hopi participants manually reviewed each possible match and identified the true matches based on a combination of cutoff value, Hopi name recognition, gender, and similarities in birth dates and social security numbers.

These data were then exported from Link Plus (step 10) and entered into an analytic file, which was reviewed for consistency with the exchange agreement (steps 11–13). This match file, along with denominator data, was then written to CD-ROM and transferred from the ACR primary partner to the Hopi primary partner. The Hopi primary partner then gave the UA epidemiologist a copy of the data (steps 13–15) for analysis, and we deleted the input files containing confidential information from the secure laptop (step 16). Finally, on April 30, 2009, we reported the details of the match process to the Hopi Tribe, the UA, and the ACR, in a report jointly created by all collaborators (step 17).

CONCLUSION

The data match between the Hopi enrollment data and the ACR data was a tribally identified and driven project undertaken to identify the Hopi tribal-specific cancer burden. The data match is an example of the successful collaboration among the Hopi Tribe, UA researchers, and the state of Arizona. The need to identify the Hopi cancer burden was identified by tribal members at multiple venues at different times. That need was

Figure 1. Steps to implement a data match between the Hopi Tribe and the Arizona Cancer Registry, May 2008

Step	Objective	Tasks	Primary responsibility		
			Hopi Tribe	ACR	UA
1.	Extract ACR data for data match	Pull database of Arizona cancer cases eligible to be matched		X	
2.	Load secure laptop	Load ACR data and software onto secure laptop		X	
3.	Verify ACR data ready for match	Set up and review ACR data/reformat dates to YYYYMMDD		X	X
4.	Export Hopi Office of Tribal Enrollment file	<ul style="list-style-type: none"> Meet with Hopi personnel Export Hopi Office of Tribal Enrollment file based on file specifications provided to contract programmers 	X		
5.	Verify Hopi data ready for match	<ul style="list-style-type: none"> Review data Create two files: one for match using current names and one for match using alternative names 			X
6.	Run Registry Plus™ Link Plus for current name match	Run Link Plus to match on names, date of birth, social security number, and gender			X
7.	Identify true matches	<ul style="list-style-type: none"> Examine match pairs output from Link Plus run Identify true matches 	X	X	X
8.	Run Link Plus for alternative name match	Run Link Plus to match on also-known-as names, date of birth, social security number, and gender			X
9.	Identify true matches	<ul style="list-style-type: none"> Examine match pairs output from Link Plus Identify true matches 	X	X	X
10.	Export true matches	Export true matches from both Link Plus runs			X
11.	Create analytic file	<ul style="list-style-type: none"> Import true matches Combine files, create one unduplicated file Merge unduplicated matched file with enrollment file to identify village of enrollment and death date Merge unduplicated file with ACR data to make sure all cancer cases for each person with cancer are captured Create final analytic file according to agreement 			X
12.	Verify analytic file conforms to state-tribal agreement	Examine all data elements in file to ensure compliance with data exchange agreement between Hopi Tribe and state of Arizona	X	X	X
13.	Create Hopi denominator data	Create file to be used in analysis excluding names and social security numbers			X
14.	Transfer data to Hopi	Analytic file and denominator data file and computer programs transferred to Hopi from ACR representative on CD-ROM: two copies made	X	X	
15.	Transfer data from Hopi to UA	Analytic file and denominator data file transferred to UA researcher for analysis	X		X
16.	Final security	All enrollment files wiped from laptop: only the non-confidential analytic file remains on laptop for ACR use	X	X	X
17.	Process report	Process report created and disseminated	X	X	X

ACR = Arizona Cancer Registry

UA = University of Arizona

translated into action through the joint collaboration of the state of Arizona, UA, and Hopi tribal members. Multiple areas of expertise were required to complete the data match, and each role undertaken by each collaborator was a necessary component of the data match. None of the roles alone was sufficient to achieve a successful result. The partners believe that the first

step in addressing the needs of the Hopi people was to identify their cancer burden. We also believe that our work has established a successful collaborative model for obtaining tribal-specific cancer data that can be used by other federally recognized tribes in the state of Arizona and beyond.

Finally, this collaborative process and data linkage

Figure 2. Personnel needed to implement Hopi data match and their responsibilities, May 2008

Organization	Key partner(s)	Role(s)
Hopi Tribe	HWWP director	<ul style="list-style-type: none"> Serves as Hopi liaison for the match Sets up/oversees communication among ADHS, UA, and Hopi tribal participants Reviews match pairs/identifies matches Verifies contents of analytic files Verifies deletion of Hopi files from secure laptop Receives Hopi matched files
	Hopi lawyers	Work with ADHS lawyers to develop a data exchange agreement between the Hopi Tribe and the state of Arizona
	Programming contractor to Hopi MIS Department	Writes program to extract Hopi enrollment data from tribal database according to specifications
	MIS Department	Extracts Hopi enrollment data from tribal database
	Hopi Office of Tribal Enrollment	<ul style="list-style-type: none"> Acts as liaison for entire process Reviews match pairs/identifies matches (two people)
ADHS	ACR medical director	<ul style="list-style-type: none"> Acts as ACR liaison for the match/holder of secured laptop Oversees the match process Reviews match pairs/helps identify matches Verifies contents of analytic file created Verifies compliance with data exchange agreement Oversees deletion of Hopi data and personal identifiers from secured laptop
	ACR manager	Reviews and approves use of confidential data during the match process
	ACR computer programmer	Provides technical training to university researcher on Registry Plus™ Link Plus
	State lawyers	Work with Hopi tribal lawyers to develop a data exchange agreement between the Hopi Tribe and the state of Arizona
UA	Mel and Enid Zuckerman College of Public Health researcher and programmer	<ul style="list-style-type: none"> Act as UA liaisons for the match Maintain communication among main parties Receive training on Registry Plus Link Plus Provide file specifications to the Hopi MIS Department Interface with programming consultant on file specifications Verify/enforce consistent formatting of ACR and enrollment data files Create two Hopi files, allowing for matches on also-known-as names Set up Registry Plus Link Plus for matches and run program Review match pairs/help identify matches Create final match files from Registry Plus Link Plus Create analytic file Verify analytic file in compliance with data exchange agreement Oversee deletion of files Receive matched data for analysis Create and disseminate report on data linkage process

HWWP = Hopi Women's Health Program

ADHS = Arizona Department of Health Services

UA = University of Arizona

MIS = Management Information Systems

ACR = Arizona Cancer Registry

technology might be used in the future to address other tribal-specific health needs. For example, much epidemiologic research utilizes administrative databases to assess birth outcomes. However, these databases—birth certificate data, congenital anomaly registries, and fetal death data—commonly capture race but not tribal affiliation. Linking tribal enrollment data to these databases would allow for tribal-specific assessments of their birth outcomes to develop interventions to reduce the incidence of adverse birth outcomes.

The authors acknowledge the participation and support of the following individuals: Mary Polacca and Gladys Sosnewa, Hopi Office of Tribal Enrollment; Merwin Lomayestewa, Hopi Management Information Systems (MIS) Department; Rita Romano, Programming Contractor to the Hopi MIS Department; Georgia Yee and Keith Laubham, Arizona Cancer Registry (ACR); and Louise Canfield, Arizona Cancer Center of the University of Arizona (UA).

Funding was provided primarily by the Southwest American Indian Cancer Network (SAICN), which is supported by grant #U01 CA114696 from the National Institutes of Health/National

Cancer Institute (NCI). SAICN is administered through the Inter Tribal Council of Arizona, which was awarded pilot funding for this match effort by NCI on September 20, 2007 (#3U01 CA114696-03S2). Funding was also provided in part by the Comprehensive Minority Institute/Cancer Center Partnership of NCI funded through the UA-Northern Arizona University Comprehensive Cancer Research Partnership (#U54 CA096281-5). The Centers for Disease Control and Prevention also provided support to the ACR under cooperative agreement #5U58DP000796.

The contents of this article are solely the responsibility of the authors and do not necessarily represent the official views of the funding agencies.

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