Memorandum of Understanding
Cancer Incidence in American Indian populations in

MEMORANDUM OF UNDERSTANDING

Between the and The to support the activities under the Cancer Data Analysis Project funded by the Department of Community Health – Cancer Registry Department.

Period of Agreement: through

PURPOSE

The purpose of this document is to describe the roles, responsibilities, and procedures with respect to the research project entitled: Cancer Incidence in American Indian Populations in . This project is funded by the under a contract from the Department of Community Health – Cancer Section.

BACKGROUND

According to national cancer registries, the all-cancer incidence rate for American Indians and Alaska Natives (AI/AN) is nearly half that of the total U.S population.[1] However, research has shown that, when linked with more accurate sources of race (such as Indian Health Services patient files) the cancer incidence rate of AI/AN can increase by more than 100%.[2] Racial misclassification of minorities presents problems for cancer surveillance and research, as well as public health practice. Cancer incidence statistics are used to determine need and, therefore, funding. Obtaining a more accurate estimate of cancer incidence in AI/AN populations will better inform public health decision-making.

The effect of racial misclassification in cancer registries has proven difficult to study due to the lack of accurate sources of population-based racial identity information. Even Indian Health Services (IHS) patient files cover only a fraction of American Indians, as many who identify as American Indian are ineligible for services through IHS. Tribal rosters promise a more comprehensive list of those who identify as American Indian. There are nearly American Indians and Alaska Natives living in the state of [3] The ists nearly members. Cooperation between tribes, cancer registries, and research professionals is necessary to obtain a more accurate estimate of cancer burden in AI/AN.

We hypothesize that the estimate of cancer incidence rate of AI/AN populations is an underestimate due to misclassification of AI/AN cancer cases an non-AI/AN. We expect to find that the incidence rate of all cancer will be significantly higher after matching with the tribal membership roster than before. Secondarily, we hypothesize that those who are misclassified are different in terms of age, cancer type, and stage at diagnosis, and urban/rural status from those who are currently classified as AI/AN.

PROCEDURE

The organization devoted to serving the needs of tribes: They will provide coordination services for Epidemiologist,

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[1] (Swan J, 2003;98)
[2] (Puukka & Stehr-Green, 2005;95)
[3] (U.S. Census 2005 American Community Survey (ACS), 2005)

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to conduct the linkage and prepare reports for the . has received training by Indian health Service (I.H.S./CDC) in Registry Plus ™ LinkPlus, a probabilistic record-linkage software developed by the Centers for Disease Control, designed specifically for record linkages with cancer registries.

W will conduct the linkage of the records, which will result in the creation of a de-identified dataset. director of the Cancer registry, will bring identified Cancer Registry records (1985 – 2010) to the y tribal center in on an external hard drive provided by . The will allow access to an electronic version of identified membership records (1975-current). Both and ative staff will be present for the entire linkage process to ensure confidentiality of their respective datasets. conduct the linkage process.

The dataset created through this linkage process will contain cancer cases that were identified as AI/AN as well as cases that were misclassified as non-AI/AN. Identifiers will be removed or transformed into confidential forms, including the following: age group at diagnosis (10-year intervals) instead of age at diagnosis, Beale Code (a measure of urban/rural) instead of zip code of residence, and year at diagnosis instead of age at diagnosis. Personal identifiers (first, middle, and last name; address; SSN) will be removed from the dataset altogether.

The de-identified dataset will be jointly owned by the , and the It will be copied to two CDs-one to be kept by each party. The external hard-drive will be wiped clean using appropriate shredding software as soon as linkage is completed. The CDs will be stored in locked file cabinets in locked offices. Access to the data will require approvals by the Community Department of Health and Human Services Health Administrator or Director of Cancer Registry. and will also take a list of all AI/AN cancer cases who were misclassified as non-AI/AN back to in order to update Cancer registry. These cases will be listed by their cancer registry record number, not by any identifiers. The list will be shredded using appropriate software when the Cancer Registry has been updated.

The incidence rate for all cancers will be estimated according to the new, merged dataset, containing both cases that were correctly identified as AI/AN as well as cases that were incorrectly misclassified as non-AI/AN. This new estimate will be compared to the pre-linkage estimate to see if the two are significantly different from each other and, if so, by how much. Misclassification and correctly classified individuals will be compared and contrasted with respect to relevant characteristics (stage at diagnosis, age group at diagnosis, year of diagnosis, cancer site, urban/rural status, survival, gender, and report source) and any differences will be statistically analyzed for significance.

PUBLICATION & DISSEMINATION

All requests for publication will be presented in-person before the , or its designee and for approval before submission. Any future requests to use this data for research will require approval from the same sources listed above. Confidentiality and privacy of the cancer cases will be protected with fidelity. If desired, publications will not identify the by name, instead referring to them as a Tribe." Efforts will be made to recruit co-authors from the tribe. . In addition, a short report will be made available to the containing relevant results for use in grant applications and other research. If the

Community consents, we may provide this report to other Tribal and/or Federal agencies, describing the processes we used and the potential value of such research to their organization.

AGREEMENT

By signing this document, each participant is evidencing its intent to abide by the terms outlined above. This is a non-binding agreement.

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State Registrar Date

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Health Director Date

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Date