Yurok Tribe Environmental Community Health Profile 2004-2011

California Tribal Epidemiology Center
&
Yurok Tribe Environmental Program

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SUMMARY

The Yurok Indian Reservation is located along the lower 44 miles of the Klamath River and extends one mile on each side of the River. The River is a source of subsistence and traditional/cultural practices for the Yurok people. Recent perceived increases in adverse health conditions of Tribal Members along with declines in the Klamath River fisheries have intensified interest and concern among Yurok Tribal Members about the environmental condition of the Yurok ancestral territories.

The Yurok Tribe Environmental Program (YTEP) is committed to protecting the environment of the Yurok Indian Reservation. It consists of three Divisions: Water, Pollution Prevention, and Community and Ecosystems. YTEP is investigating the potential presence of selected contaminants and toxins in the local environment that are known to be associated with the adverse health outcomes listed in Table 3 on page 10 of the Appendix. This project is being conducted under a grant from the U.S. Environmental Protection Agency's National Center for Environmental Research (EPA-STAR Grant #RD-83370801-0), "Understanding the Cumulative Affects of Environmental and Psycho-Social Stressors that Threaten the Pohlik-lah and Ner-er-ner Lifeway: The Yurok Tribe's Approach. The California Tribal Epidemiology Center (CTEC), under contract with YTEP for their study, developed this report to identify health outcomes of the Yurok Tribal Members which may have an association with the contaminants and toxins in the environment of the Yurok ancestral territories.

This report is on the health outcomes of 2,677 Yurok Tribal Members who have utilized services at United Indian Health Service (UIHS) at least once since 2004, when the clinic started utilizing electronic health records. Health outcome data sets were selected based upon known adverse health outcomes associated with exposure to specific contaminants and toxins that are potentially present in the environment. Results are categorized into cancer, diabetes related, perinatal, and endocrine related health outcomes which are potentially associated with select environmental contaminants.

Data were requested on over 90 health conditions, although, to maintain privacy, data are only reported for conditions with 20 or more individuals diagnosed between 2004 and 2011, of which there are 23 health conditions which meet this criteria. This is a very small number when determining rates of disease; therefore some of the data may lead to unstable and inaccurate results. Comparison data are from national sources and were usually collected through surveys, which are completed by a general sample of the population whereas UIHS data is for those that visited the clinic and are more likely to be sick, therefore interpretation of results should be done with caution. The results should be used to determine areas for further studies.

The results of the analysis show that Yurok Tribal Members may have higher rates of cancer and proteinuria than are seen nationally, therefore these may be areas for further research. The rate of cancer in Yurok Tribal Members who visited UIHS is 683.5 per 100,000 people, in comparison to 190.4 per 100,000 American Indian/Alaska Native (AIAN) people nationally and 484.0 per 100,000 for all races combined.[6] The diabetes, heart disease, and obesity health outcome analyses reported lower or comparable results to national data. Approximately 12.8% of the Yurok population aged 20 years or older who visited UIHS had been diagnosed with diabetes, in comparison to 14.2% of AIAN aged 20 years or older who received care from IHS-funded facilities.[8]

While CTEC is unable to make any deterministic or epidemiological links between known contaminants in the Klamath River environment and the health outcomes of the Yurok Tribal Members, we hope this report will assist YTEP and the Yurok Tribal Council in identifying future directions for studies that aim to examine potential links between adverse health outcomes and environmental contaminants.

BACKGROUND AND PURPOSE

The Yurok people reside on the Lower Klamath River and territories along the Pacific Coast. Those who reside along the River are traditionally known as Pohlik -lah and Yurok who live along the coast as Ner-er-ner. The Yurok Reservation lies within the Lower Klamath Sub-Basin and extends one mile on each side of the lower 44 miles of the Klamath River. In addition to lands along the river, ancestral lands include a strip along the ocean together with all usual and customary off-shore fishing areas[1] (see Figure 1). The Yurok people maintain cultural, economic, and spiritual ties to these ancestral lands through subsistence use and management of traditional resources.

Figure 1. Yurok Lands showing the Klamath River

Recent perceived increases in adverse health conditions of Tribal members along with declines in the Klamath River fisheries have intensified interest and concern among Yurok Tribal members about the environmental conditions of the Yurok ancestral territories. The Yurok Tribal Council and membership have identified the health of the Klamath River, its fishery, and the continued dependence on key subsistence species as a primary concern for the Tribe and its future.[2-4]

The Yurok Tribe has an Environmental Program (YTEP) that is committed to protecting the environment of the Yurok Reservation. It consists of three Divisions: Water, Pollution Prevention, and Community and Ecosystems. This project is being conducted under a grant from the U.S. Environmental Protection Agency's National Center for Environmental Research (EPA-STAR Grant #RD-83370801-0), "Understanding the Cumulative Affects of Environmental and Psycho-Social Stressors that Threaten the Pohlik-lah and Ner-er-ner Lifeway: The Yurok Tribe's Approach. The goal of this YTEP's study is to answer questions about the environmental conditions of the Lower Klamath River and coastal areas and the key aquatic species that are critical to the continuation of Yurok subsistence, traditions, ceremonies and life. To achieve this YTEP is conducting a screening study on the presence of selected contaminants and toxins in the aquatic environment (riverine and coastal/marine) that are known to be associated with adverse health outcomes that are listed in Table 3 on page 10.

The California Tribal Epidemiology Center's (CTEC) goal is to improve the health of American Indians in California. CTEC aims to achieve healthier Indian communities by providing timely and accurate health information. To identify the adverse health outcomes that are potentially associated with contaminants in the Yurok ancestral territories, CTEC was contracted by YTEP to obtain health information from the Tribal Health Program which serves the Yurok Tribe, United Indian Health Service (UIHS). Toxins and contaminants of interest include: organochlorines, organophosphates, PCBs, PAHs, PCPs/TCPs, microcystins, carbamates, diaxin/furans, triazines, mercury and trace elements. The results will assist YTEP in informing Tribal policy and in determining which areas may warrant further examination of the potential links between the adverse health outcomes and the contaminants.

METHODS

This project was approved by the Yurok Tribe, United Indian Health Service (UIHS), and the California Rural Indian Health Board (CRIHB) Institutional Review Board (IRB). Staff involved in the project signed a Data Use Agreement to ensure confidentiality of data. Additionally, data were kept on a secure server in a password protected file.

UIHS utilizes Electronic Health Records, therefore CTEC staff reviewed International Statistical Classification of Diseases and Related Health Problems codes, 9th edition (commonly known as ICD-9 codes) to develop a list of diseases and health outcomes that are possibly associated with environmental contaminants in the Yurok ancestral territories, page 10 of the Appendix. Please see Appendix pages 12-13 for the list of health outcomes and ICD-9 codes that were submitted to the Electronic Health Records Manager at UIHS. For ease, CTEC grouped the ICD-9 codes into five broad categories of health outcomes: cancer, diabetes, endocrine disorders, perinatal and miscellaneous.

Only data from 2004 – 2011 patient medical visits were requested, since Electronic Health Records did not go into effect at UIHS until 2004. Only records for Yurok Tribal Members were requested in the dataset, which included those identified in the dataset as being enrolled in the Yurok Tribe, which are UIHS tribal codes: 410 and 178. There were 2,677 Indian Registrants included in these two tribal codes who received services at UIHS.

Variables requested for Yurok Tribal Members included:

- Unique Patient ID
- Date of Birth
- Date of Death
- Gender
- Height - most recent
- Weight - most recent
- Zip Code - most recent
- Encounter Date - most recent
- Health Condition Diagnosis Date

Additional data for perinatal health outcomes:

- Number of Births per Delivery (received if Multiple Births Diagnosis code recorded)
- Live Birth or Not, per Delivery (received if Live Birth or Fetal Death Diagnosis code recorded)

Data were received from UIHS in Excel format and cleaned (deleted outcomes not requested) for analysis and analyzed in both Excel and SAS. Data were requested on over 90 health conditions, although, to maintain privacy, data are only reported for conditions with 20 or more individuals diagnosed between 2004 and 2011, of which there are 23 health conditions which meet this criteria. For each of five broad categories of disease (cancer, diabetes, endocrine disorders, perinatal and miscellaneous), several adverse health conditions of interest were defined by ICD-9 codes, and the total number of new diagnoses of each of these conditions was calculated, by sex and for the population overall. Due to such a small number of people diagnosed, and to ensure privacy, an average rate is reported from approximate annual rates of disease diagnosis, calculated using as the denominator the number of individual Yurok people who visited the UIHS clinic during 2005 to 2010. Rates by sex are not always reported, due to small numbers. The adverse health conditions with 20 or more individuals diagnosed at the UIHS clinic between 2004 and 2011 are reported in the following table:

Table 1: Adverse Health Conditions with 20 or more diagnoses

Disease or Condition	ICD-9 Codes
Cancer Outcomes	
Cancer - any type	141.9-239.9
Skin Cancer - uncertain behavior	238.2
Diabetes Related Outcomes	
Cerebrovascular Accident	436
Cholesterol Disorders	272, 272.1, 272.2, 272.4
Chronic Kidney Disease (any stage)	585.1-585.9
Coronary Atherosclerosis	414, 414.0
Diabetes Mellitus (not otherwise specified)	250, 250.0
Diabetic Neuropathy (not otherwise specified)	357.2
Diabetes Type 2 with Nephropathy	250.40, 250.42
Diabetes Type 2 with Neuropathy	250.6, 250.60, 250.62
Diabetes Type 2 Uncontrolled	250.02
Dysmetabolic Syndrome X	277.7
Hypertension	401, 401.1, 401.9
Morbid Obesity	278.01
Obesity	278
Overweight	278.02
Pre-Diabetes (abnormal fasting glucose)	790.21, 790.22, 790.29
Proteinuria	791, 791.0
Endocrine Related Outcomes	
Hypothyroidism	244, 244.8, 244.9
Perinatal Outcomes	
High Risk Pregnancy	646.9, V23.89
Fetal Loss/Abortion	656.4/632-634
Multiple Pregnancy and/or Delivery Complications	640-648 or 660-669
Fetal/Infant Anomaly	653.6, 655-656/740-759

Limitations

There are various limitations in this analysis of UIHS data. First, there is no way to determine a causal link between the toxins in the Yurok ancestral territories and the health outcomes in this report since we can not determine if or when there was exposure to potential contaminants and toxins. Second, UIHS informed CTEC that some of the data requested may not be accurate. For example, death information is often not reported to the clinic, health condition diagnosis date was sometimes missing and data from 2004, the first year of electronic record use, seems incomplete. Additionally, the findings are not representative of all Yurok Tribal Members; it is representative of Yurok Tribal Members who are enrolled and who visited a UIHS clinic at least once since 2004. Thus, interpretation of these results should consider that the following groups were not included in the analysis: Yurok people who are not enrolled in the Tribe, Yurok enrolled members who did not utilize services at UIHS (and received services at another clinic or hospital), and Yurok Tribal Members who received services from UIHS prior to 2004. Furthermore, data are only reported for

conditions with 20 or more individuals diagnosed between 2004 and 2011. This is a very small number when determining rates; therefore some of the data may lead to unstable and inaccurate results. Additionally, comparison data are from national sources and was usually collected through surveys, instead of health records, therefore interpretation should be done with caution since surveys are distributed to a general sample of the population whereas medical record data is for those that visited the clinic and are more likely to be sick.

RESULTS

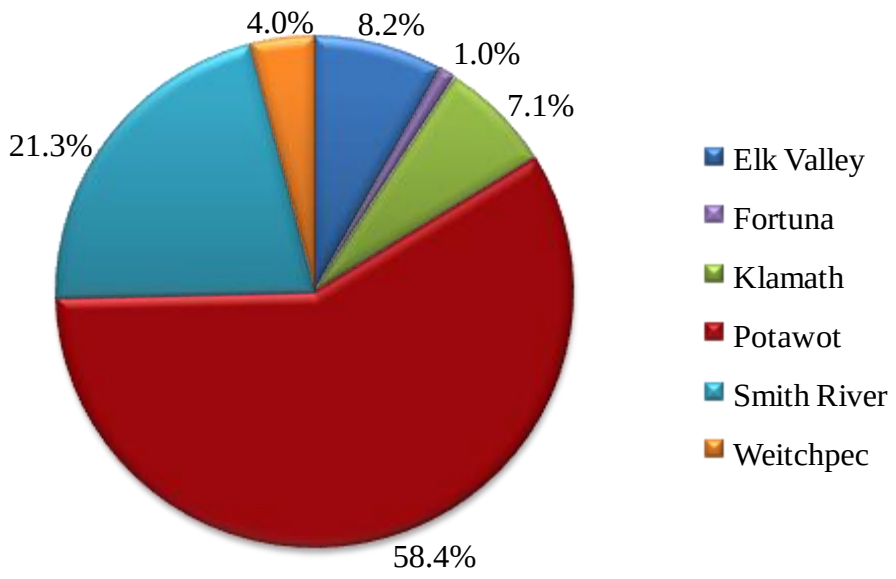
Demographic Characteristics

The data includes 2,677 people from the Yurok Tribe, of which 50.7% (n=1,357) are female. Year of birth ranges from 1908 to 2010. Data on age is not reported, since mortality information is inaccurate, therefore it cannot be determined who is still living. Yurok Tribal Members included in the data reside at various zip codes, see Table 2 for the top four areas.

Table 2. Top reported Zip Codes

Zip Code	Number	Percentage
95501	320	12.0%
95531	522	19.5%
95546	411	15.4%
95548	365	13.6%

Chart 1. Percent of patient visits by UIHS Facility



More than half (59.6%, n=1,595) of the people visited the clinic within the past year. On average, there are approximately 15,400 visits per year from Yurok Tribal Members to UIHS facilities, for an average of six visits by a Tribal Member each year. The majority of visits were at Potawot (58.4%), and Smith River (21.3%), see Chart 1.

Cancer Outcomes

Cancer is the second leading cause of death in American Indians and Alaska Natives (AIAN).[5] The data shows that 90 Yurok Tribal Members seen at UIHS were diagnosed with cancer since 2004, with an average of 14 people per year for a rate of 683.5 per 100,000 people. The United States Cancer Statistics invasive cancer incidence rates from 2003-2007 is 190.4 per 100,000 AIAN people and 484.0 per 100,000 for all races combined.[6] The rate of cancer for those at UIHS compared to national data, may differ due to the small sample size at UIHS and racial misclassification of AIAN in national data, therefore further studies would need to be done to determine if there is an increased rate of cancer in the Yurok Tribal Members.

Skin cancer was the most common type of cancer in the Yurok people, with 27 people being diagnosed (average = 4 per year); the rate is 196.5 per 100,000 people. The United States Cancer Statistics skin cancer incidence rates are calculated by excluding Basal and Squamous types of skin

cancer. We are unable to differentiate this information from the data, therefore, there is no comparison data for skin cancer rates.

Diabetes Related Outcomes

Diabetes

Statistics also show the high prevalence of diabetes in Indian Country; it is the fourth leading cause of death for AIANs in the United States.[5] Diabetes is also approximately three times higher in American Indians and Alaskan Natives than in the general United States population.[7] The data shows that 259 Yurok Tribal Members were diagnosed with diabetes since 2004 at UIHS, with an average of 41 people per year for a rate of 2,061.0 per 100,000 people. Data indicates that 12.8% of the Yurok population aged 20 years or older who visited UIHS had been diagnosed with diabetes, in comparison to 14.2% of AIAN aged 20 years or older who received care from IHS funded facilities.[8]

Prediabetes is a condition in which individuals have blood glucose or A1c levels higher than normal but not high enough to be classified as diabetes. People with prediabetes have an increased risk of developing type 2 diabetes, heart disease, and stroke.[8] The data shows that 205 Yurok Tribal Members were diagnosed as pre-diabetic since 2004, with an average of 30 people per year for a rate of 1,470.3 per 100,000 people. Of those Yurok Tribal Members 15 years of age and older seen at UIHS (n = 2,247), 9.0% were prediabetic, compared to 20% of American Indians in the United States aged 15 years or older had prediabetes in 2001–2004.[8] Based on the available data from UIHS, pre-diabetes is more common in Yurok women, with an average number of 19 new cases per year compared to 11 new cases per year in Yurok men.

Of those Yurok Tribal Members seen at UIHS with diabetes, 98 had uncontrolled type 2 diabetes. Complications due to diabetes are often a concern. Among those with type 2 diabetes, the most common complications were nephropathy/kidney disease (n=47) and neuropathy/eye disease (n=29).

Heart Disease

Heart disease is the leading cause of death for AIANs.[5] High blood pressure and cholesterol, smoking, a lack of physical activity, and obesity all contribute to the development of heart disease and stroke. High blood pressure is also defined as hypertension, among Yurok Tribal Members, there are approximately 81 new cases per year of hypertension (504 cases total since 2004) with 23.7% of adults having high blood pressure. About one out of three U.S. adults (31.3%) has high blood pressure.[9]

The data shows that 39 adult Yurok Tribal Members seen at UIHS (2%) have been diagnosed with coronary atherosclerosis, with an average of 6 new cases per year. Atherosclerosis is a disease in which plaque builds up inside the arteries. This limits the flow of oxygen-rich blood to the organs and other parts of the body and can lead to serious problems, including heart attack, stroke, or even death.[10] Nationally, 12% of adults are diagnosed with heart disease.[11]

Cholesterol is a fat (also called a lipid) that is needed by the body to work properly. Cholesterol levels that are too high can increase the chance of getting heart disease, stroke, and other problems. There were 452 diagnoses of cholesterol disorders (average = 69 per year). Cholesterol disorders are more common in Yurok men seen at UIHS, with an average number of 37 new cases per year compared to 32 new cases per year in Yurok women.

Kidney Disorders

Proteinuria, also called albuminuria or urine albumin, is a condition in which urine contains an abnormal amount of protein. Proteinuria is a sign of chronic kidney disease, which can result from diabetes, high blood pressure, and diseases that cause inflammation in the kidneys.[12] There were 64 cases of proteinuria, with an average of nine new cases per year, resulting in 2.6% of adult Yurok Tribal Members having a diagnosis of proteinuria. The national prevalence of proteinuria is 1.1%.[13]

Chronic kidney disease is a condition in which the kidneys are damaged and cannot filter blood as well as possible. This damage can cause wastes to build up in the body and lead to other health problems, including cardiovascular disease, anemia, and bone disease. There were 59 cases, or 2.9% of those over 20 years of age with chronic kidney disease. More than 10% of people aged 20 years or older in the United States have chronic kidney disease.[14]

Further studies would need to be done to determine if there is a disparity in proteinuria and chronic kidney disease in the Yurok Tribal Members.

Obesity

The data shows that 335 Yurok Tribal Members are categorized as being obese. Obesity is found to be more common in Yurok women, with an average number of 29 new diagnoses per year compared to 22 new cases per year in Yurok men. Additionally there are approximately 13 new diagnoses per year of morbid obesity. Approximately 17.0% of Yurok adults age 20 years and over are obese, compared nationally to 33.9% of adults age 20 years and over.[15]

Stroke

There were 20 Yurok Tribal Members who had stroke or cerebrovascular accident, this is approximately three people having a stroke each year (about 1% of adults). Approximately 2.6% of adults in the U.S. have had stroke.[16]

Endocrine Related Outcomes

Thyroid Disorders

Hypothyroidism is a condition in which the thyroid does not make enough thyroid hormone which controls the metabolism. It is most common in women and those over the age of 50 years. Between 2004 and 2011, 82 Yurok people were diagnosed with hypothyroidism, which is approximately 3.1% of the Yurok population that utilize UIHS clinics. As typical in the general U.S. population, hypothyroidism is more common in Yurok women, with an average number of nine new cases per year compared to three new cases per year in Yurok men. The National Health and Nutrition Examination Survey (NHANES 1999-2002) reported hypothyroidism (defined as TSH levels >4.5 mIU/L) in 3.7% of the U.S. population.

Perinatal Outcomes

Perinatal refers to the period immediately before and after birth. There were 289 pregnancies from 244 Yurok women seen at UIHS with 27 of the pregnancies resulting in spontaneous abortion or fetal loss (average = 4 per year), for a rate of 78.9 per 1,000 pregnancies or 9.3% of pregnancies. In addition, 24 (average = 4 per year, 8.3%) of the pregnancies resulted in a fetal malformation or infant anomaly. There is no national data available for comparison, thus more information would need to be gathered to determine if there is a disparity in perinatal outcomes.

DISCUSSION

As previously mentioned, there are various limitations in this analysis of UIHS data. First, there is no way to determine a causal link between the toxins in the Klamath River and coastal areas and the health outcomes in this report. Additionally, the findings are only representative of Yurok Tribal Members who are enrolled and who visited a UIHS clinic at least once since 2004. Data are reported for conditions with 20 or more individuals diagnosed between 2004 and 2011 which is a very small number when determining rates; therefore some of the data may lead to unstable and inaccurate results. Additionally, comparison data are from national sources and was usually collected through surveys, instead of health records, therefore interpretation should be done with caution since surveys are distributed to a general sample of the population whereas medical record data is for those that visited the clinic and are more likely to be sick.

The results of the analysis show that Yurok Tribal Members may have higher rates of cancer and proteinuria than are seen nationally, therefore these may be areas for further research. The rate of cancer in Yurok Tribal Members who visited UIHS is 683.5 per 100,000 people, in comparison to 190.4 per 100,000 American Indian/Alaska Native (AIAN) people nationally and 484.0 per 100,000 for all races combined.[6] There prevalence of proteinuria is 2.6% of adult Yurok Tribal Members compared to the national prevalence of proteinuria of 1.1%.[13] proteinuria is a sign of chronic kidney disease, although the rate of chronic kidney disease among Yurok Tribal Members at UIHS was determined to be lower than the national average. The diabetes and endocrine related health outcome analyses reported lower or comparable results to national data.

Recommendations

While we are unable to make any deterministic or epidemiological links between known contaminants in the Klamath Basin aquatic subsistence species and the health outcomes of the Yurok Tribal Members, this report will assist YTEP and the Yurok Tribal Council in identifying future directions for studies that aim to examine potential links between adverse health outcomes and environmental contaminants. Potential increases in adverse health conditions were determined for rates of cancer and proteinuria, and further research needs to be in perinatal outcomes since there is no comparison data available. Further studies should be performed to determine if there are actually disparities in these conditions and if it is due to environmental exposures.

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APPENDIX

Table 3. List of Target Toxins and Associated Adverse Health Outcomes

Table 4. List of ICD-9 Codes Requested

Data Use and Distribution Agreement

Table 3. Target Toxins and Associated Adverse Health Outcome

Toxins	Symptoms
(N-Methyl) Carbamates	overstimulation of nerves causing malaise muscle weakness dizziness central nervous system depression pulmonary edema in serious cases headache salivation sweating nausea vomiting abdominal pain diarrhea
Dioxins/ Furans	skin damage neurological and immune system impairments in infants endocrine system disruption and associated insulin resistance obesity and type II diabetes increased cancers of breast, testes, prostate and thyroid attention deficiencies lowered IQ
Mercury	damage the gastrointestinal tract and kidneys impaired neurological development and reduced peripheral vision "pins and needles" sensations muscle weakness including impairment of speech hearing and walking
Mycrocystins	rash hepatotoxicity with associated vomiting, diarrhea, abdominal pain, malaise muscle fasciculations abdominal breathing convulsions
Organochlorine Pesticides (1st group)	neurotoxicity and associated hyperexcitable state in the brain tremors seizures convulsions possible human carcinogen with increased liver tumors and breast, testes, prostate and thyroid cancers immune disruption and associated non-Hodgkin lymphoma endocrine system disruption insulin resistance obesity and type II diabetes attention deficiencies lowered IQ
Organophosphate Pesticides (2nd group)	neurotoxicity and associated muscle weakness paralysis of the extremities headache muscle twitching seizures loss of consciousness nausea and diarrhea respiratory depression and failure hypersecretion with increased sweating, salivation, lacrimation and rhinorrhea increased incidence of Parkinson's disease reduced levels of testosterone
Phenols PCP & TCP's	thyroid endocrine system disruption with associated insulin resistance obesity and type II diabetes increased cancers attention deficiencies lowered IQ

Toxins	Symptoms
Polybrominated diphenyl ethers/ PBDE	impairs development of nervous system and increases frequencies of hyperactivity attention deficiencies lowered IQ endocrine system disruption with associated insulin resistance obesity and type II diabetes increased cancers of breast, testes, prostate and thyroid
Polychlorinated biphenyls/ PCB	serious and disfiguring dermatitis probable human carcinogens with increased cancers of breast, testes, prostate, thyroid, liver and biliary tract irregular menstrual cycles lowered immune response endocrine system disruption with insulin resistance obesity and type II diabetes attention deficiencies lowered IQ
Polycyclic aromatic hydrocarbons/ PAH	highly carcinogenic with increased incidences of lung, skin and bladder cancers genotoxic
Trace mineral elements	fatigue skin lesions gastrointestinal distress anemia neuropathy muscle contractions growth reduction liver cirrhosis necrosis in kidneys and the brain pulmonary edema congestion most become carcinogens, teratogens and possible mutagens associated with a wide range of problems including: cardiovascular, developmental, immunological, respiratory, liver, thyroid and kidney functions adverse neurological effects hematological effects (blood problems) pancreatic effects reproductive effects
Triazines	irritating to eyes, skin and respiratory tract neuroendocrine toxicity adverse developmental and reproductive effects endocrine system disruption

Table 4. List of ICD-9 Codes Requested

Diseases List	Codes	Include		Subset of Codes
Infectious and Parasitic Diseses	001-139	NO		
Neoplasms	140-239	Partial		
Malignant Neoplasm of Lip, Oral Cavity, and Pharynx	*140-149*	*YES*		
Malignant Neoplasm of Digestive Organs and Peritoneum	*150-159*	*YES*		
Malignant Neoplasm of Respiratory and Intrathoracic Organs	*160-165*	*YES*		
Malignant Neoplasm of Bone, Connective Tissue, Skin, and Breast	*170-176*	*YES*		
Malignant Neoplasm of Genitourinary Organs	*179-189*	*YES*		
Malignant Neoplasm of Other and Unspecified Sites	*190-199*	*YES*		
Malignant Neoplasm of Lymphatic and Hematopoietic Tissue	*200-208*	*YES*		
Nueroendocrine Tumors	*209*	*YES*		
Benign Neoplasms	*210-229*	*NO*		
Carcinoma In Situ	*230-234*	*YES*		
Neoplasms of Uncertain Behavior	*235-238*	*YES*		
Neoplasms of Unspecified Nature	*239*	*YES*		
Endocrine, Nutritional and Metabolic Diseases, and Immunity Disorders	240-279	Partial		
Disorders of Thyroid Gland	*240-246*	*YES*	*Partial*	*240.0-242.3, 242.8, 242.9, 243, 244.2-244.9, 246.1*
Diseases of the Endocrine Glands	*249-259*	*YES*	*Partial*	*250, 253.1-253.8, 256.0-256.1, 256.3-256.9, 257.0, 257.2-257.9, 259.0-259.1*
Nutritional Deficiencies	*260-269*	*NO*		
Other Metabolic and Immunity Disorders	*270-279*	*YES*	*Partial*	*272, 277.7, 278.0-278.1, 279.0-279.03, 279.3, 279.4, 279.9*
Diseases of the Blood and Blood Forming Organs	280-289	YES	*Partial*	*284*
Mental Disorders	290-319	Partial		
Organic Psychotic Conditions	*290-294*	*NO*		
Other Psychoses	*295-299*	*YES*	*Partial*	*299*
Neurotic Disorders, Personality Disorders, and Other Nonpsychotic Mental Disorders	*300-316*	*YES*	*Partial*	*313-315*
Mental Retardation	*317-318*	*YES*		
Diseases of the Nervous System and Sense Organs	320-389	Partial		
Inflammatory Diseases of the Central Nervous System	*320-326*	*NO*		
Organic Sleep Disorders	*327*	*NO*		
Hereditary and Degenerative Diseases of the Central Nervous System	*330-337*	*YES*	*Partial*	*332*
Pain	*338*	*NO*		
Other Headache Syndromes	*339*	*NO*		
Other Disorders of the Central Nervous System	*340-349*	*YES*	*Partial*	*343*
Disorders of the Peripheral Nervous System	*350-359*	*YES*	*Partial*	*357.2-357.3*
Disorders of the Eye and Adnexa	*360-379*	*YES*	*Partial*	*362.00-362.07*
Diseases of the Ear and Mastoid Process	*380-389*	*NO*		
Diseases of the Circulatory System	390-459	Partial		
Acute Rheumatic Fever	*390-392*	*NO*		
Chronic Rheumatic Heart Disease	*393-398*	*NO*		
Hypertensive Disease	*401-405*	*YES*		
Ischemic Heart Disease	*410-414*	*YES*		
Diseases of Pulmonary Circulation	*415-417*	*NO*		
Other Forms of Heart Disease	*420-429*	*NO*		
Cerebrovascular Disease	*430-438*	*YES*		
Diseases of the Arteries, Arterioles, and Capillaries	*440-449*	*YES*	*Partial*	*440-442*
Diseases of the Veins and Lymphatics, and Other Diseases of Circulatory System	*451-459*	*YES*	*Partial*	*457.0*
Diseases of the Respiratory System	460-519	NO		
Diseases of the Digestive System	520-579	NO		

Diseases List	Codes	Include		Subset of Codes
Diseases of the Genitourinary System	580-629	Partial		
Nephritis, Nephrotic Syndrome, and Nephrosis	*580-589*	*YES*	*Partial*	*583-587, 588.1*
Other Diseases of Urinary System	*590-599*	*NO*		
Diseases of the Male Genital Organs	*600-608*	*YES*	*Partial*	*606.1*
Disorders of Breast	*610-612*	*YES*	*Partial*	*611.72*
Inflammatory Disease of Female Pelvic Organs	*614-616*	*NO*		
Other Disorders of Female Genital Tract	*617-629*	*YES*	*Partial*	*617.1-617.9, 622.1, 628.2-628.4*
Complications of Pregnancy, Childbirth, and the Puerperium	630-679	YES		
Diseases of the Skin and Subcutaneous Tissue	680-709	Partial		
Infections of Skin and Subcutaneous Tissue	*680-686*	*NO*		
Other Inflammatory Conditions of Skin and Subcutaneous Tissue	*690-698*	*NO*		
Other Diseases of Skin and Subcutaneous Tissue	*700-709*	*YES*	*Partial*	*707.1*
Diseases of the Musculoskeletal System and Connective Tissue	710-739	NO		
Congenital Anomalies	740-759	YES		
Certain Conditions Originating in the Perinatal Period	760-779	*YES*	*Partial*	*exclude 760.71-760.72, exclude 771*
Symptoms, Signs, and Ill-Defined Conditions	780-799	Partial		
Symptoms	*780-789*	*YES*	*Partial*	*783.4*
Nonspecific Abnormal Findings	*790-796*	*YES*	*Partial*	*790.2, 790.93, 791, 793.8, 796.0*
Ill-Defined and Unknown Causes of Morbidity and Mortality	*797-799*	*NO*		
Injury and Poisoning	800-999	Partial		
Fractures	*800-829*	*NO*		
Dislocation	*830-839*	*NO*		
Sprains and Strains of Joints and Adjacent Muscles	*840-848*	*NO*		
Intracranial Injury, Excluding Those with Skull Fracture	*850-854*	*NO*		
Internal Injury of Thorax, Abdomen, and Pelvis	*860-869*	*NO*		
Open Wounds	*870-897*	*NO*		
Injury to Blood Vessels	*900-904*	*NO*		
Late Effects of Injuries, Poisonings, Toxic Effects, and other External Causes	*905-909*	*YES*	*Partial*	*909*
Superficial Injury	*910-919*	*NO*		
Contusion with Intact Skin Surface	*920-924*	*NO*		
Crushing Injury	*925-929*	*NO*		
Effects pf Foreign Body Entering Through Orifice	*930-939*	*NO*		
Burns	*940-949*	*NO*		
Injury to Nerves and Spinal Cord	*950-957*	*NO*		
Certain Traumatic Complications and Unspecified Injuries	*958-959*	*NO*		
Poisonings by Drugs, Medicinal and Biological Substances	*960-979*	*YES*		
Toxic Effects of Substances Chiefly Nonmedicinal as to Source	*980-989*	*YES*		
Other and Unspecified Effects of External Causes	*990-995*	*NO*		
Complications of Surgical and Medical Care, Not Elsewhere Classifiea	*996-999*	*NO*		
Supplementary Classification of Factors Influencing Health Status and Contact with Health Services	V01-V89	Partial		
Persons with Potential Health Hazards Related to Communicable Diseases	*V01-V06*	*NO*		
Persons with Need for Isolation, Other Potential Health Hazards and Prophylactic Measures	*V07-V09*	*NO*		
Persons with Potential Health Hazards Related to Personal and Family History	*V10-V19*	*YES*	*Partial*	*V10, V13.2, V13.6-V13.9, V15.86, V16, V17.1, V17.3, V17.4, V18.0, V19.5, V19.8*
Persons Encountering Health Services in Circumstances Related to Reproduction and Development	*V20-V29*	*YES*	*Partial*	*V21.3, V22-V23.2, V23.4-23.5, V23.89-V23.9, V27-V28.4, V28.6-V29*
Liveborn Infants According to Type of Birth	*V30-V39*	*YES*		
Persons with a Condition Influencing Their Health Status	*V40-V49*	*YES*	*Partial*	*V43.82, V45.0-V45.1 V49.3, V49.7*
Persons Encountering Health Services for Specific Procedures and Aftercare	*V50-V59*	*YES*	*Partial*	*V58.67*
Persons Encountering Health Services in Other Circumstances	*V60-V69*	*YES*	*Partial*	*V61.5-V61.7, V65.3*
Persons Without Reported Diagnosis Encountered During Examination and Investigation of Individuals and Populations	*V70-V82*	*YES*	*Partial*	*V72.4, V76, V77.1*
Genetics	*V83-V84*	*YES*	*Partial*	*V84.0*
Body Mass Index	*V85*	*YES*		
Estrogen Receptor Status	*V86*	*YES*		
Other Specific Personal Exposures and History Presenting Hazards to Health	*V87*	*NO*		
Acquired Absence of Other Organs and Tissue	*V88*	*NO*		
Other Suspected Conditions Not Found	*V89*	*NO*		
Supplementary Classification of External Causes of Injury and Poisoning	E000-E999	Partial		*E980*
Family PACT Diagnosis	S101-S902	Partial		*601, 602, 901, 902*

CALIFORNIA TRIBAL EPIDEMIOLOGY CENTER (CTEC)
CALIFORNIA RURAL INDIAN HEALTH BOARD, INC. (CRIHB)
SACRAMENTO, CA

YUROK COMMUNITY HEALTH PROFILE PROJECT (515)

DATA USE AND DISTRIBUTION AGREEMENT FOR EMPLOYEES AND CONTRACTORS

INTRODUCTION

The **Yurok Community Health Profile Project** is sponsored by the Yurok Tribe Environmental Health Program (YTEP) via funding from the United States Environmental Protection Agency (EPA) STAR Grant # RD-83370801-1. CTEC is working as a subcontractor to YTEP to develop a community health profile for Yurok Tribal members who utilize United Indian Health Service (UIHS) clinics using NextGen patient data for all years available. The project will be completed over a 12 month period: January 2011 to December 2011. The final product will be a lay report that will present data on various health outcomes, described below, that have been linked to environmental contaminants being studied in the Klamath River. Tasks associated with this project include:

- Researching and collecting ICD-9 codes for all variables of interest, with respect to health outcomes associated with contaminants found in the Klamath River (including but not limited to diabetes, obesity, cancers, and prenatal & birth outcome data). The list of ICD-9 codes to be used will be collected by the CTEC Research Associate in conjunction with the CRIHB Health Information Manager. ICD-9 codes will be selected by cross-referencing health outcomes that are associated with contaminants found in the Klamath River.
- Requesting and receiving a NextGen dataset from UIHS dating back to the inception of the NextGen system (2004) for all Yurok tribal members who have visited the clinic at least once, including all ICD-9 codes variables of interest.
- Cleaning and analyzing the data obtained from this NextGen dataset.
- Compiling findings in a Yurok Community Health Profile Report.

To protect the confidentiality and privacy of the UIHS Yurok patients, investigators granted access to the Yurok NextGen data and materials must adhere to the requirements of this Data Use and Distribution Agreement. Failure to comply with this Data Use and Distribution Agreement could result in its termination, denial of further access to the Yurok NextGen data, and may leave violators liable to legal action.

TERMS AND CONDITIONS

1. **Data:**
   CTEC agrees to provide the Recipient with Data described as follows:

   The Recipient understands that the data are owned by the Yurok Tribe, housed by CTEC, and he or she agrees to the following:

   a. The Recipient will not use the data for *any other project or investigation unless he or she receives written permission* from the data's owner (Yurok Tribe). The Recipient will abide by project guidelines, where they are specified, in the preparation and presentation of reports, manuscripts, and abstracts.

b. The Recipient will cite the data's source (as specified by CTEC and the Yurok Tribe) in all publications and academic work based on this data. The Recipient will submit all articles, manuscripts and other publications for review according to the terms established by the CRIHB Institutional Review Board (IRB) policy.

c. The Recipient will not allow any access to the information without written consent from the Yurok Tribe and the study's Principal Investigator from CTEC. This includes, but is not limited to, individuals within CRIHB (including those working on this project, who do not yet have written permission to use the data), as well as other institutions, organizations and commercial enterprises that may be contracted for the Yurok Community Health Profile Project.

d. The Recipient will guard these data carefully, understanding that he or she is responsible for preventing others from accessing this information without his or her permission. No Yurok Community Health Profile Project data shall be stored on portable storage devices. The Recipient will ensure that the computers, data files, laboratory logs and notebooks, archival files, and other materials containing the data will be secure at all times. Data security will be in accordance with the current standards for data security. This data use agreement may authorize the Yurok Community Health Profile Project Principal Investigator or CTEC to verify that the information is secure. The Recipient agrees to allow such verification of the data's security when the Principal Investigator/Yurok Tribe is acting in accordance with the aforesaid agreement.

e. The Recipient realizes the information may be disclosed under special circumstances (i.e. a governmental authority lawfully requests access to this information). However, the Recipient will not disclose any of the data and instead will ask the Principal Investigator to address any requests for disclosure of this information.

f. The Recipient will comply with and agree to the following:

    i. He or she will not use the data for any purpose other than those explicitly authorized by the Yurok Tribe.
    ii. Protected health information is provided in the dataset, and as part of this agreement, their use and safekeeping are governed by the provisions of the IRB of CRIHB.
    iii. The Recipient will not publish, share, disclose or release any identifiable information (also known as identifiers) of the study participants. This implies that only summary statistics will be used in reports and publications.
    iv. The Recipient will not attempt to link records included in the data to any other identifiable information without written authorization from the Yurok Community Health Profile Project Principal Investigator and the data's owner (Yurok Tribe).
    v. The Recipient will not attempt to determine the study participants' individual identities.

g. The Recipient will comply with the IRB requirements of CRIHB.
h. Within one year of receiving the data, the Recipient will either return all data to CTEC, or destroy all data in accordance with the Principal Investigator's instructions. If at that time, the data are still needed for completion of the originally approved project, please notify the study Principal Investigator.

2. **Non-transferability.**
   This Data Use and Distribution Agreement is not transferable. The Recipient will agree that substantive changes made to the Research Project, and or appointment by him or her of another Recipient, and/or my transfer to another institution or other entity to complete this Research Project, will require a separate Data Use and Distribution Agreement.

3. **Publication**
   The Recipient agrees to promptly publish the results of this Research Project and to comply with the rules of the CRIHB IRB, the UIHS Publications Committee, and the Yurok Tribal Council. Specifically, the Recipient agrees to provide each Committee with a copy of any report within thirty (30) days in advance of submission for publication.

4. **Acknowledgements:**
   The Recipient agrees to acknowledge the contribution of the Yurok patients and CTEC staff in all oral and written presentations, disclosures, and publications resulting from any and all analyses of Data.

   The present document will be governed under the law of the US state that has jurisdiction over the forms authorizing the principal investigator and this study to use the data. In the event that the governing state is not specified, this document shall fall under California law.

Recipient: The undersigned individual hereby attests that he or she is authorized to enter into this Agreement and agrees to all terms specified herein.

_____
Recipient name and title

_____
Recipient Institution/Organization

_____
Street Address

_____
City/State/Zip Code

_____
Phone Number

_____
Email address

_____
Signature Date

Yurok Community Health Profile Project Principal Investigator: The undersigned individual will be the custodian of the database and agrees to comply with all provisions of this Agreement.

Kristal Chichlowska, PhD, MPH
Name and Title of Yurok Community Health Profile Project Principal Investigator

_____
Signature Date

Please return to:
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