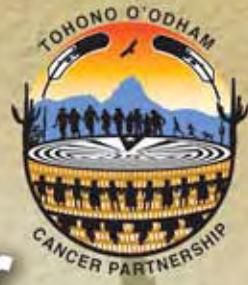




Tohono O'odham Nation



# Comprehensive Cancer Prevention and Control Plan

2010-2015



# TABLE OF CONTENTS

A THANK YOU TO OUR PARTNERS	3
DEDICATION	4
LOGO AND VISION	5
EXECUTIVE SUMMARY	6
INTRODUCTION	11
The Tohono O'odham Nation	11
Cultural Considerations	14
Health Care	15
Cancer on the Tohono O'odham Nation	18
Two Types of Data	27
Data Surveillance System	27
Evaluation	28
CHAPTER 1-Prevention	29
CHAPTER 2-Early Detection	41
CHAPTER 3-Diagnosis and Treatment	53
CHAPTER 4-Quality of Life	63
CHAPTER 5-Survivorship	67
CHAPTER 6-Children and Cancer	74
CHAPTER 7-Environment and Cancer	81
June 2009 Cancer Awareness and Education Day	87
A Special Thanks....	89
Table of Acronyms and Definitions	91
Appendix 1 TODHHS Organizational Chart	92
Appendix 2 TON Cancer Screening Report	93
Appendix 3 ACR TON Tribe Analysis	110
Appendix 4 Children and Cancer Educational Information	133

**The Tohono O'odham Nation  
would like to thank the following organizations  
for their commitment, hard work and assistance  
in the development of this plan.**

- Arizona Cancer Center
- Arizona Department of Health Services
- Department of Health and Human Services, Tohono O'odham Nation
- Indian Health Services-Tucson Area Office and Sells Service Unit
- Leukemia and Lymphoma Society
- Members, Tohono O'odham Nation
- MEZA College of Public Health, University of Arizona
- Native American Cancer Research Partnership
- Southwest American Indian Collaborative Network
- Tohono O'odham Hospice
- University of Arizona Center of Excellence in Women's Health

This publication was supported by Cooperative Agreement Number 5U58DP000840 from the Centers for Disease Control and Prevention. The contents of this document are solely the responsibility of the authors and do not necessarily reflect the official viewpoints of the Centers for Disease Control and Prevention.

# DEDICATION

*Sharing Our Stories of Hope*



The Tohono O'odham Nation Comprehensive Cancer Prevention and Control Plan is dedicated to cancer survivors Marian Manuel, Nelson Miguel (standing) and Gerard Norris, for the courage, wisdom and willingness to share their cancer stories of hope during the 2009 Cancer Awareness and Education Day.

# *The Vision Statement*

Tohono O'odham 'o tas s-doda kc pi 'edagid g mumkidag nopi  
s-ap 'am 'oidahim g 'e-himdag kc 'e-duakadag.

Tohono O'odham living long, cancer-free, and fulfilling lives  
through cultural and healthy lifestyle practices.



## *Executive Summary*

The Cancer Planning Committee (CPC) comprised of varied partners listed on page three met over 2008 and 2009 to complete this comprehensive cancer prevention and control plan for the Tohono O'odham Nation (TON). The purpose of this plan is to reduce the cancer burden for tribal members, as well as enhance the quality of life of cancer victims and their families.

From the beginning of the planning process, the CPC thought it crucial that we hear from the Nation members. During the summer of 2008, focus group interviews were conducted in order to gain an understanding of cancer prevention, screening, treatment and quality of life issues on the Tohono O'odham Nation. Information from the Nation members was also gathered during the 2009 Cancer Education and Awareness Day held in June. The following are a list of challenges that cancer patient's deal with after they are diagnosed with cancer and other concerns expressed by Nation members at the Education and Awareness Day.

## *Challenges of Having Cancer*

- Losing their jobs and ending up on Social Security.
- Can't eat certain foods.
- Not as active.
- Fear of cancer coming back...the person may feel careful.
- Treatment side effect...Cancer patients lose hair, sleep a lot.
- Transportation to doctors.
- Lodging assistance if staying overnight.
- Support groups would help those who are going through treatment. Need support for families. Education on treatment for family members, need advocates.
- CHS or Social Service can provide a paid position or a regular job to be a navigator.
- Elders and those who have cancer do not want to be a burden to family members.
- Caregivers take care of the family member.
- Palliative, end-of-life, if they are end stage then need hospice, which can provide 24/7 care.
- Need help with cancer pain.

# *Other Concerns of Having Cancer*

- Hospital appointment - sent here and there
- Hours of sitting in the hospital
- Referral
- Medication questions
- First follow up
- Lab work
- Billing
- Explaining what you are supposed to do
- Medical words used
- Spirituality changes
- No one to talk to
- Understanding therapy-chemo etc.
- Diagnosed-time lapse-before surgery

The CPC has laid out a comprehensive cancer plan that covers five years, 2010 – 2015, contains seven goals and 34 objectives. It would be unrealistic to believe that the committee who oversees the implementation of this plan could be responsible for meeting all the named objectives. As a result, the committee will decide early on, through a consensus process, on the top three to five goals to implement, keeping in mind this is a “living” plan, meaning the plan can change based upon the most urgent needs of the Tohono O’odham Nation members. cancer patient’s deal with after they are diagnosed with cancer and other concerns expressed by Nation members at the Education and Awareness Day.

## *Plan Goals and Objectives*

**GOAL 1:** Promote cancer risk reduction for the Tohono O’odham Nation through primary prevention.

**Objective 1.1:** Reduce obesity by increasing the availability of quality fresh fruits and vegetables within schools and the community.

**Objective 1.2:** Reduce obesity by enhancing nutrition education in all grade levels and local schools within the community.

**Objective 1.3:** Reduce obesity by increasing the number of O’odham children who participate in daily moderate physical activity for at least thirty minutes per day.

**Objective 1.4:** Reduce obesity by increasing the number of Tohono O'odham who participates in daily moderate physical activity for at least thirty minutes per day.

**Objective 1.5:** Increase community awareness of alcohol as a risk factor for cancer.

**Objective 1.6:** Increase the number of Tohono O'odham who regularly use effective sun protection.

**Objective 1.7:** Increase knowledge and awareness about the links between environmental contaminants and cancer.

**Objective 1.8:** Increase knowledge and awareness about the HPV and Hepatitis B vaccines.

**Objective 1.9:** Increase the number of youth and adults who do not use cigarettes and smokeless tobacco.

***Objective 1.10: Develop and enforce a non-smoking policy in workplaces and other public areas.***

---

***GOAL 2: Maximize community acceptance and timely utilization of available cancer screening to increase the likelihood of early diagnosis and positive outcomes.***

**Objective 2.1:** Begin discussions with the Arizona Department of Health Services about including TON in the state Behavioral Risk Factor Surveillance System.

**Objective 2.2:** Begin discussions with the Tohono O'odham Department of Health & Human Services (TODHHS) about including additional questions related to cancer in the Community Health Assessment (CHA).

**Objective 2.3:** Begin discussions with the Indian Health Services about receiving comprehensive cancer screening data on a regular or on an as-needed basis.

**Objective 2.4:** Obtain more information from the Nation's members about cultural and other considerations needed to enhance acceptance of cancer screenings.

**Objective 2.5:** Conduct regular breast, cervical, colorectal and prostate cancer screening awareness campaigns throughout the Tohono O'odham Nation.

***GOAL 3: Increase access to appropriate and effective diagnosis and treatment services.***

---

**Objective 3.1:** Review information contained in mapping project report.

**Objective 3.2:** Review information contained in Analysis of TON Cancer Cases Diagnosed From 1995-2006.

**Objective 3.3: Secure authorization from the TON council for the Tohono O'odham Cancer Program (TOCP) to ask the ACR for periodic TON-level cancer data.**

**Objective 3.4: Decide on and begin first steps to institutionalize receipt of diagnosis data on a regular basis**

---

***GOAL 4: Improve the quality of life for Tohono O'odham Nation members whose lives are shortened by cancer.***

**Objective 4.1: Increase awareness of Nation members and health care providers about what types of patients are appropriate referrals for hospice services, including cancer patients.**

**Objective 4.2: Explore options for providing respite for caregivers of cancer patients.**

**Objective 4.3: Explore options for providing childhood cancer hospice services on the Nation.**

**Objective 4.4: Explore options for palliative (pain reduction) care availability at the Indian Health Services Sells Hospital.**

---

***GOAL 5: Improve support available to cancer survivors and their family members as co-survivors.***

**Objective 5.1: Develop a resource directory for both patients and providers that will provide information about cancer diagnosis and treatment, community resources, internet resources and access to counseling and support for cancer survivors and their families.**

**Objective 5.2: Develop cancer survivor support groups to provide information and emotional support to survivors and families.**

**Objective 5.3: Develop a local database of Tohono O'odham members with an identified cancer diagnosis.**

**Objective 5.4: Develop a case management process to coordinate cancer care that will ensure prompt access to specialists and communication between them and a patient's primary care provider, and to facilitate navigation across systems to ensure that all healthcare needs are met.**

---

***GOAL 6: Increase Educational and Support Services for Children Affected by Cancer.***

**Objective 6.1: Develop a list of resources for parents affected by a childhood cancer.**

**Objective 6.2: Document how TON schools deal with children with cancer returning to school.**

**Objective 6.3: Develop bereavement support for children who lost a parent or loved one to cancer.**

**GOAL 7: To improve knowledge of known environmental risk factors.**

**Objective 7.1: Develop an arsenic water and soil Geographical Information System (GIS) database.**

**Objective 7.2: Develop a baseline for arsenic on the Nation.**

**Objective 7.3: Conduct an environmental health consultation with Agency for Toxic Substances and Disease Registry (ATSDR).**

**Objective 7.4: Determine the health risk of arsenic on the Nation.**



# *Introduction*



## The Tohono O'odham Nation

Historically, the O'odham inhabited an enormous area of land in the southwest, extending south to Sonora, Mexico, north to Central Arizona (just north of Phoenix, Arizona), west to the Gulf of California, and east to the San Pedro River. This land base was known as the Papagueria and it had been home to the O'odham for thousands of years.

From the early 18th Century through to the present, foreign governments occupied the O'odham land. First, the O'odham came under Spanish rule in what was then New Spain. With the independence of Republic of Mexico, O'odham fell under Mexican rule. Then, in 1853, through the Gadsden Purchase or Treaty of La Mesilla, O'odham land was divided almost in half, between the United States of America and Mexico.

According to the terms of the Gadsden Purchase, the United States agreed to honor all land rights of the area held by Mexican citizens, which included the O'odham, and O'odham would have the same constitutional rights as any other United States citizen. However, the demand for land for settlement escalated with the development of mining and the transcontinental railroad. That demand resulted in the loss of O'odham land on both sides of the border.

Following the Plan de Iguala, O'odham lands in Mexico continued to decrease at a rapid rate. In 1927, reserves of lands for indigenous peoples were established by Mexico. Today, approximately nine O'odham communities in Mexico lie proximate to the southern edge of the Tohono O'odham Nation, a number of which are separated only by the United States/Mexico border.

On the U.S. side of the border, the Gadsden Purchase had little effect on the O'odham initially because they were not informed that a purchase of their land had been made, and the new border between the United States and Mexico was not strictly enforced. In recent years,

however, the border has come to affect the O'odham in many ways, because immigration laws prevent the O'odham from crossing it freely. In fact, the U.S.-Mexico border has become "an artificial barrier to the freedom of the Tohono O'odham. . . to traverse their lands, impairing their ability to collect foods and materials needed to sustain their culture and to visit family members and traditional sacred sites." O'odham members must produce passports and border identification cards to enter into the United States.

On countless occasions, the U.S. Border Patrol has detained and deported members of the Tohono O'odham Nation who were simply traveling through their own traditional lands, practicing migratory traditions essential to their religion, economy and culture. Similarly, on many occasions U.S. Customs have prevented Tohono O'odham from transporting raw materials and goods essential for their spirituality, economy and traditional culture. Border officials are also reported to have confiscated cultural and religious items, such as feathers of common birds, pine leaves or sweet grass.

The division of O'odham lands has resulted in an artificial division of O'odham society. O'odham bands are now broken up into four federally recognized tribes: the Tohono O'odham Nation, the Gila River Indian Community, the Ak-Chin Indian Community and the Salt River (Pima Maricopa) Indian community. Each band is now politically and geographically distinct and separate. The remaining band, the Hia-C'ed O'odham, is not a federally recognized tribe, and resides throughout southwestern Arizona. All of the groups still speak the O'odham language, which derives from the Uto-Aztec language group, although each group has varying dialects.

The Tohono O'odham Nation is a federally recognized Indian Tribe. The Nation has the second largest reservation land base in the United States that is located in three counties in south-central Arizona, west of Tucson. Its four non-contiguous segments total more than 2.8 million acres (4,336 square miles), roughly comparable in size to the state of Connecticut. The Nation shares more than seventy miles of international boundary with the Republic of Mexico.

# The Tohono O'odham Nation Location

The Tohono O'odham Nation has 27,297 enrolled tribal members (Enrollment Office, 2008).

Approximately one-half of these members reside on the reservation, scattered among eighty-three rural and remote tribal villages. Those tribal members who live in nearby Tucson, Phoenix and other cities still return home regularly and/or utilize reservation-based services. Some reservation villages are more than two hours from Sells, the tribal government capital, or other off-reservation towns and cities, where health care, stores and advanced education are located. The Nation has no public transportation system.



# Cultural Considerations

During the summer of 2008, focus group interviews were conducted with members of the Tohono O'odham community in order to gain an understanding of cancer prevention, screening, and treatment and quality of life issues on the Tohono O'odham Nation. Some participants talked about the utilization of medicine men that were consulted for a health problem and then were referred to western medicine because the traditional medicine could not help the specific illness.

"The Medicine Man saw the point where the medicine could not help...there are things I can't do... so you need to see the white man."

The Tohono O'odham Himdag, "our path," refers to a "way of life inclusive to culture, heritage, history, values, traditions, customs, beliefs and language. This way of life includes a crucial balance between the mental, physical, and spiritual health of an individual, family, and community. Himdag incorporates everything in life that makes us unique as individuals and as a people. It is a lifelong journey.

The following are elements of Himdag:

- Arts
- Beliefs
- Community
- Games
- Harvesting
- Language
- Land
- Medicine
- Mobility
- Past, future, journey in life...
- Relatives
- Songs
- Storytelling
- Spirituality
- Sensitivity
- Value



When a family member is diagnosed with cancer, the family comes together to provide each other with spiritual, emotional and psychological support. During this time of need, the Tohono O'odham rely on "Himdag," to guide us on the cancer journey. Some rely on traditional cultural practices while others follow western medical and spiritual practices.

Tohono O'odham people are sensitive and respectful of disease(s) in person and therefore are considerate of the privacy needs of families during their cancer journey.

## Health Care

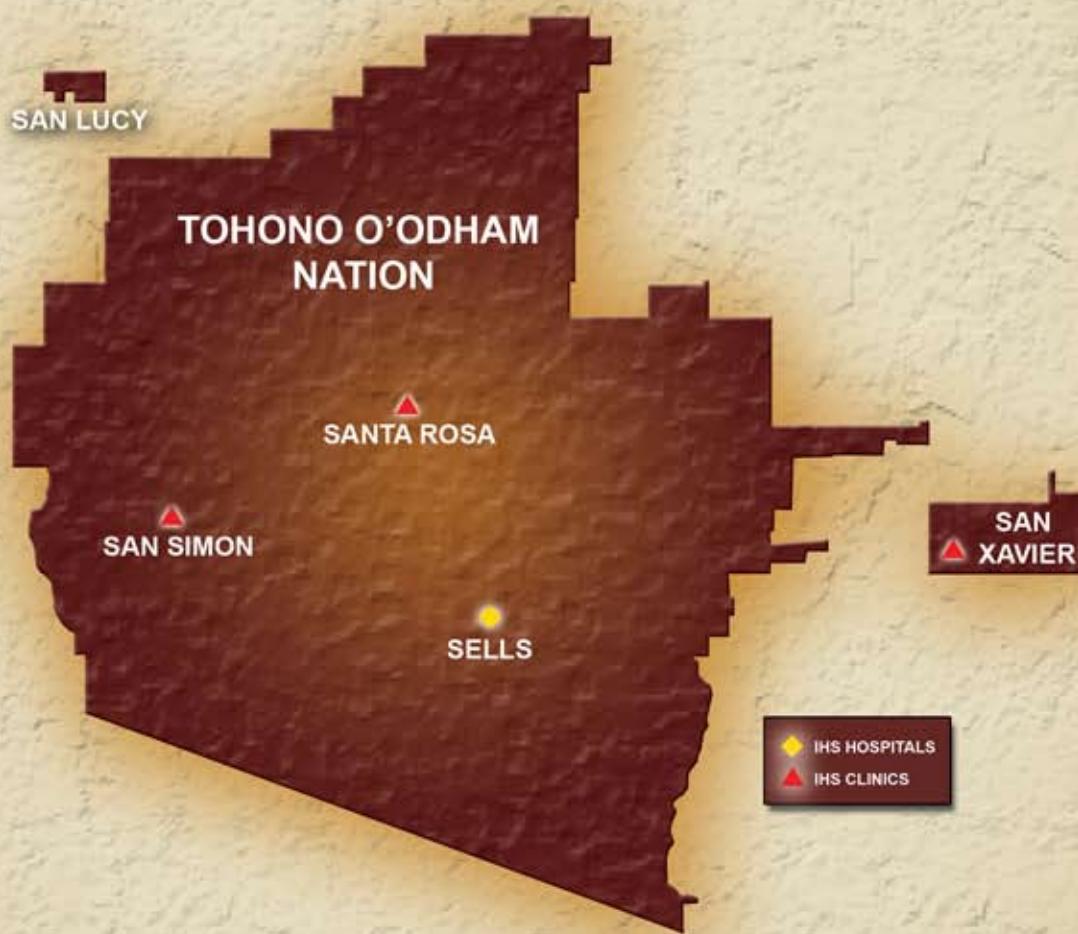
Health care for the Tohono O'odham Nation members is provided by the Tribe's Department of Health and Human Services (TODHHS) and the federal Indian Health Service (IHS).

### The Indian Health Service

The provision of health services to members of federally recognized tribes grew out of the special government-to-government relationship between the federal government and Indian tribes. This relationship, established in 1787, is based on Article I, Section 8 of the Constitution, and has been given form and substance by numerous treaties, laws, Supreme Court decisions, and Executive Orders. Originally, health services to Native Americans were provided in response to protect soldiers from infectious diseases and that responsibility resided with the War Department. Over time, administration of health care passed from the War Department to the Department of the Interior (DOI), Bureau of Indian Affairs (BIA). In 1955, responsibility for health services transferred to the U.S. Public Health Service, formally establishing the Indian Health Service. The IHS is the principal federal health care provider and health advocate for Indian people and its goal is to raise their health status to the highest possible level. The IHS provides a comprehensive health service delivery system for approximately 1.9 million American Indians and Alaska Natives who belong to 562 federally recognized tribes in 35 states.

Primary health care on the Tohono O'odham Nation is delivered through the Tucson Area IHS with direct care services being provided by the Sells Service Unit. The service unit is an 18-bed hospital and ambulatory care clinic located in Sells, AZ and three other sites: San Xavier Health Center, San Simon Health Center and Santa Rosa Clinic. Patients may sometimes be referred to Tucson, 60 miles east of Sells, or to Phoenix, 120 miles north of Sells.

## Map of Sells Hospital and clinic locations



The TODHHS began to strategically and systematically develop its capacity to address cancer, building upon a strategic plan developed in 2000 that focused on three health priorities: diabetes; substance use and violence; and injuries. The strategic plan, in 2005, added cancer. Based on the successful experience addressing other public health issues, TODHHS staff knew that a good planning and assessment process was needed to build the foundation for comprehensive cancer services over time.

TODHHS also pursued funding to support incremental steps toward cancer prevention and control capacity building. Two small cancer grants, one from the Arizona Department of Health Services Assessment to conduct focus groups with target groups of community members to learn more about beliefs about, attitudes toward and experiences with cancer screening, illness, treatment and survival, and the second from the Susan G. Komen for the Cure to train Community Health Representatives to promote breast health awareness among women over age 40, were successfully implemented and provided valuable groundwork for comprehensive cancer prevention and control. (Appendix 1 contains an organizational chart of TODHHS.) .

*“Cancer is here”, spoken by a survivor at the 2009  
Cancer Education and Awareness Day*

## Cancer on the Tohono O’odham Nation

### Methodology of Tribal Case Identification

For this analysis, the Arizona Cancer Registry (ACR) generated data from the state’s central registry. The ACR presumed a case was a Tohono O’odham cancer case if it carried a TO tribal affiliation code; or had a race code of “American Indian” with an “unknown tribe” code and lived within five zip codes likely to have high proportion of TO members. A presumed TON case could live in a TON community or anywhere in Arizona. The ACR did not have access to tribal rolls that would have allowed definitive identification of TON membership. The following data are for the years 1995-2006. It is best to consider the data as a reasonable estimate of the TON cancer incidence.

# Tohono O'odham Nation Cancer Incidence

While the count of cases reported to the central registry varies from year to year, over the 12-year period, 1995-2006, an average of 28 cases among TON members were diagnosed and reported each year.

## A Comparative Analysis of Primary Site Incidence between TON Members and All Arizona

### Resident Invasive Cancer Cases - All Cancer Cases Combined:

When comparing cancer cases among the TON members with all Arizonans the sex ratio differs between the two groups. TON has more female cases than male cases (52% to 48%) while Arizona has more male cases than female cases (53% to 47%).

TOHONO O'ODHAM NATION



**WOMEN 52%**

**MEN 48%**

ARIZONA



**MEN 53%**

**WOMEN 47%**

Analysis of primary sites also shows differences. Kidney cancer (14% of all malignancies) is the leading type of cancer for TON members. Among all Arizonans, kidney cancer ranks ninth (3% of all cases).

TOHONO O'ODHAM NATION

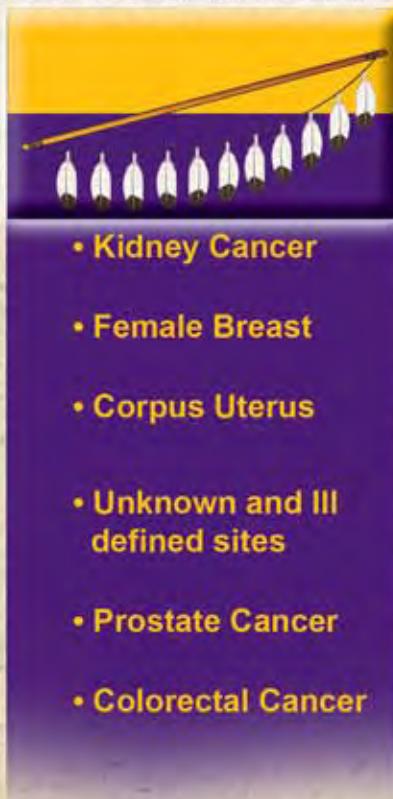
**14%**

ARIZONA

**3%**

Following kidney cancer the next most common cancers among TON members are female breast (11% of all cases), corpus uterus (8%), unknown & ill defined sites (7%), prostate (7%), and colorectal cancer (6%). When cancer in all Arizonans is analyzed prostate cancer (15%) led the way; while lung (14%), female breast (14%), colorectal (11%), and bladder cancer (5%) round out the top five cancers.

#### TOHONO O'ODHAM NATION



#### ARIZONA



Although prostate, female breast and colorectal cancer are in the top cancers for both groups, a smaller percentage of each of these types is found among the TON cases. TON also has a smaller percentage of lung cancer cases than Arizona overall as lung cancer is in tenth place at 3% of TON cases while it is in second place with 14% for all Arizonans.

## Lung Cancer Cases



Uterine cancer comprises a greater percentage of all TON cases (8%) than it does for Arizonans (2%), and TON cases have double the number of unknown & ill defined cancer cases (7%) compared to all Arizonans (3%). (See Appendix 2, Figure 1 and Figure 2.)

### Uterine Cancer Cases



### Unknown & ILL Defined Cancer Cases



### Male Cancer Cases:

When comparing TON male members against all Arizona males, kidney cancer stands out as a large burden for TON males: 20 percent of male TON cases are kidney cancer cases. For all Arizona males, kidney cancer cases comprise only 3% of cases. Prostate (14%), liver (10%), ill defined and unknown (9%), colorectal (7%) and stomach cancer (6%) are the next most frequent sites for TON males. Prostate cancer among Arizona males is by far the most common type of cancer at 28 percent. Prostate cancer is followed by lung, colorectal, bladder, and melanoma. (See Appendix 2, Figure 3 & Figure 4.)

## TOHONO O'ODHAM NATION MALES



## ARIZONA MALES



### Female Cancer Cases:

TON females and all Arizona females are most likely to be stricken with breast cancer (21% and 32% respectively). The next most common cancers for TON females are: uterus (15%), kidney (7%), colorectal (6%), ill-defined sites (6%) and stomach (5%). For Arizona females the most frequent cancers diagnosed after breast cancer are: lung (14%), colorectal (10%), uterus (5%), non-Hodgkin lymphoma (4%), and ovarian (4%). (See Appendix 2, Figure 5 and Figure 6.)

## TOHONO O'ODHAM NATION FEMALES



## ARIZONA FEMALES



## Analysis of Selected Primary Sites by Age Group and Sex for TON Cancer Cases

Table 11 and Table 12 provide the counts by age groups for certain cancer sites. The median age of diagnosis of cancer was 63 years for TON males and 57 years for TON females. In comparison, the median age at diagnosis for all Arizona resident males is 69 years and 67 years for Arizona females. For TON members, childhood and adolescent cancer aged 0 to 19 years (6 males and 7 female cases) totaled 13 cases (3.8%). TON young adults aged 20 to 39 years represent 37 cases (10.9%) of all cases. No individual cancer type stood out for the 11 male cases in this age group. However, uterine (7 cases) and breast cancer (6 cases) represented half of the 26 female cases of this age group. For TON males, kidney cancer (8 cases) begins to appear in the 40 to 49 year old age group. For TON females, the 50 to 64 year age group shows the most cases of all female age groupings (62 cases). Almost half these cases are breast and uterine cancer cases. For TON males most cases are diagnosed in the oldest age category, 65 years and older (74 cases). For TON males in this category, 38% of cases are diagnosed in the prostate or kidney.<sup>2</sup>

TABLE 11

Case Count: Site by Age Group for Male TON Cases, 1995-2006							
Primary Site	0-19 yrs	20-29 yrs	30-39 yrs	40-49 yrs	50-64 yrs	65 yrs and older	Total
Colorectal	0	0	2	1	4	4	11
Lung	0	0	0	0	1	7	8
Prostate	0	0	0	0	6	17	23
Kidney	0	0	0	8	15	11	34
All Other Cases	6	2	7	8	30	35	88
Total	6	2	9	17	56	74	164

TABLE 12

Case Count: Site by Age Group for Female TON Cases; 1995-2006							
Primary Site	0-19 yrs	20-29 yrs	30-39 yrs	40-49 yrs	50-64 yrs	65 yrs and older	Total
Colorectal	0	0	0	2	5	4	11
Lung	0	0	0	0	3	0	3
Breast	0	0	6	4	17	10	37
Cervix	0	1	2	3	1	0	7
Uterus	0	1	6	4	13	2	26
Kidney	1	0	1	2	5	3	12
All Other Cases	6	2	7	7	18	41	81
Total	7	4	22	22	62	60	177

<sup>2</sup> Analysis of Tohono O'odham Nation Cancer Cases Diagnosed From 1995-2006, Appendix 3

## **Review of Vital Status of TON Members with Cancer**

**Between 1995 and 2006 there were nineteen persons among 322 TON members who had more than one primary cancer diagnosed, resulting in 341 cancer cases. One hundred and thirty one (40.7%) of the TON members with cancer were alive and 191 (59.3%) had died as of June of 2008.**

**Eighty of the living TON members live in TON designated zip codes.**

Place of Residence	Vital Status		
	Alive	Dead	Total
Live In TON Zip Codes	80	141	221
Live Outside of TON zip codes	51	50	101
Total TON persons with Cancer	131	191	322

The following table includes the vital status on selected primary sites that may include persons with multiple cancers. Of the breast cancers, three of the 34 persons had an additional breast cancer resulting in 37 cases. Cervix and female breast had the greatest number of survivors (57.1% & 58.8% respectively).

Primary Site	Vital Status			
	Alive	Dead	Pct Alive	Total
Colorectal	9	13	40.9	22
Female Breast	20	14	58.8	34
Cervix	4	3	57.1	7
Prostate	10	13	43.5	23

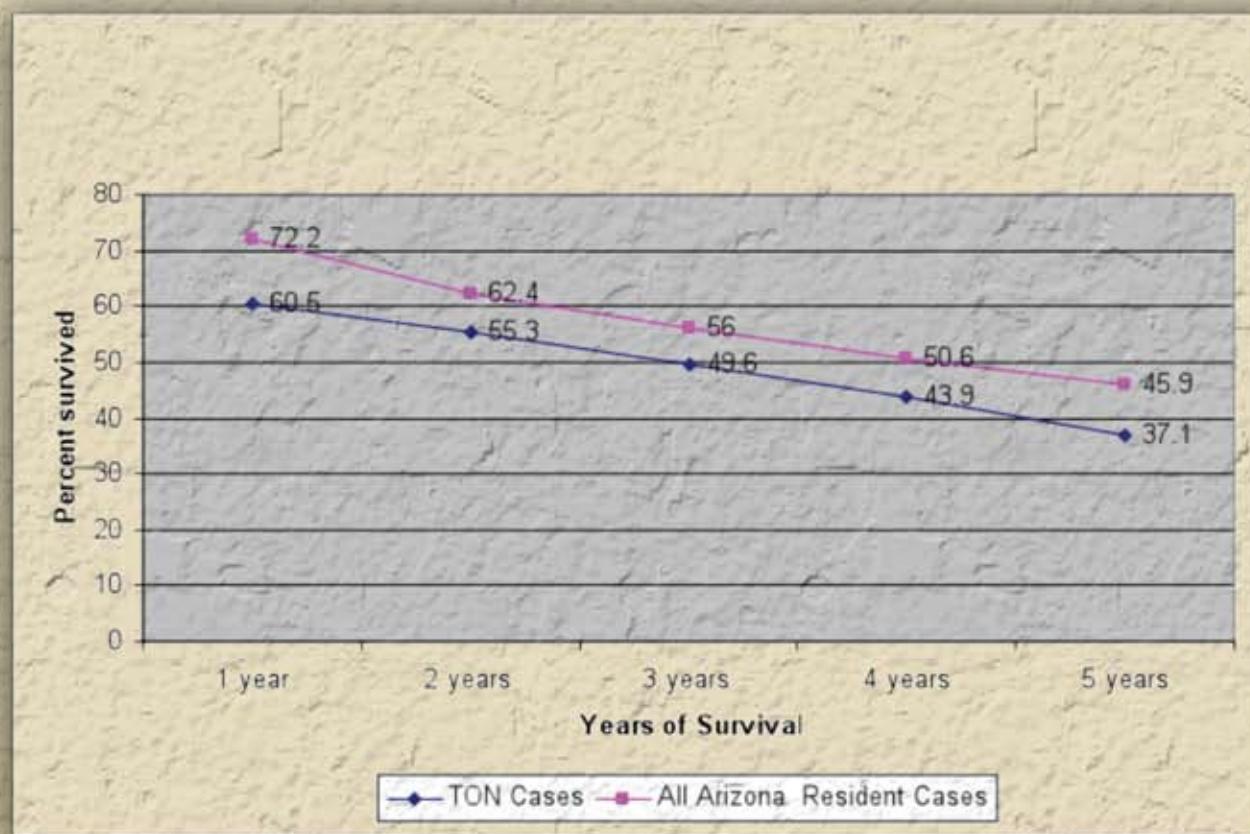
## Analysis of TON Cancer Survival as Compared with All Arizona Residents

### Cancer Survival

This analysis presents the survival of all cancer sites, regardless of any specific factors that may affect survival, between the TON member cancer cases and all Arizona cancer cases.

For this survival analysis, cases with multiple primaries were excluded. TON member observed actuarial<sup>3</sup> survival varies between 11.7% and 6.4%, lower than the survival of all Arizonan cancer cases (See Figure 19). However, survival is affected by factors such as primary site, stage of disease, and age of patient. These factors are not included in this analysis.

Figure 19



<sup>3</sup> Observed actuarial survival is used for this analysis. The observed rate indicates that age was not taken into account.

Actuarial survival defines survival at specific time intervals at which all cases dropping out since the last defined time point is analyzed. "The Actuarial method assumes that only half of those individuals were at risk at the time of the deaths". The Actuarial method was developed for grouped data. SEER Cancer Website. Retrieved 8/14/09 from [http://seer.cancer.gov/seerstat/508\\_WebHelp/Method\\_of\\_Calculation\\_for\\_a\\_Survival\\_Session.htm](http://seer.cancer.gov/seerstat/508_WebHelp/Method_of_Calculation_for_a_Survival_Session.htm).

## **Two Types of Data**

In order to put together a comprehensive cancer prevention and control program for the TON, two different types of data are needed to track the disease of cancer: 1) cancer screening data and 2) cancer diagnosis and treatment data. The IHS data system, while not providing a complete picture of all TON members, can provide data on cancer screenings performed at the IHS hospital and clinics located on the TON. The IHS is required through the Government Performance Results Act (GPRA) to routinely track and report on three of the four cancers addressed in the Early Detection chapter of this plan. In addition, the Tucson Area Director's performance is measured by how well the GPRA measures are met.

According to the Medical Epidemiologist consultant, "the state's cancer registry, with its registration of all cancer cases diagnosed in the state, offers the best opportunity for obtaining the number of diagnosed cancer cases for the Tohono O'odham Nation."

There are several options to be considered for obtaining cancer diagnosis data and these will be discussed in the chapter on Diagnosis and Treatment.

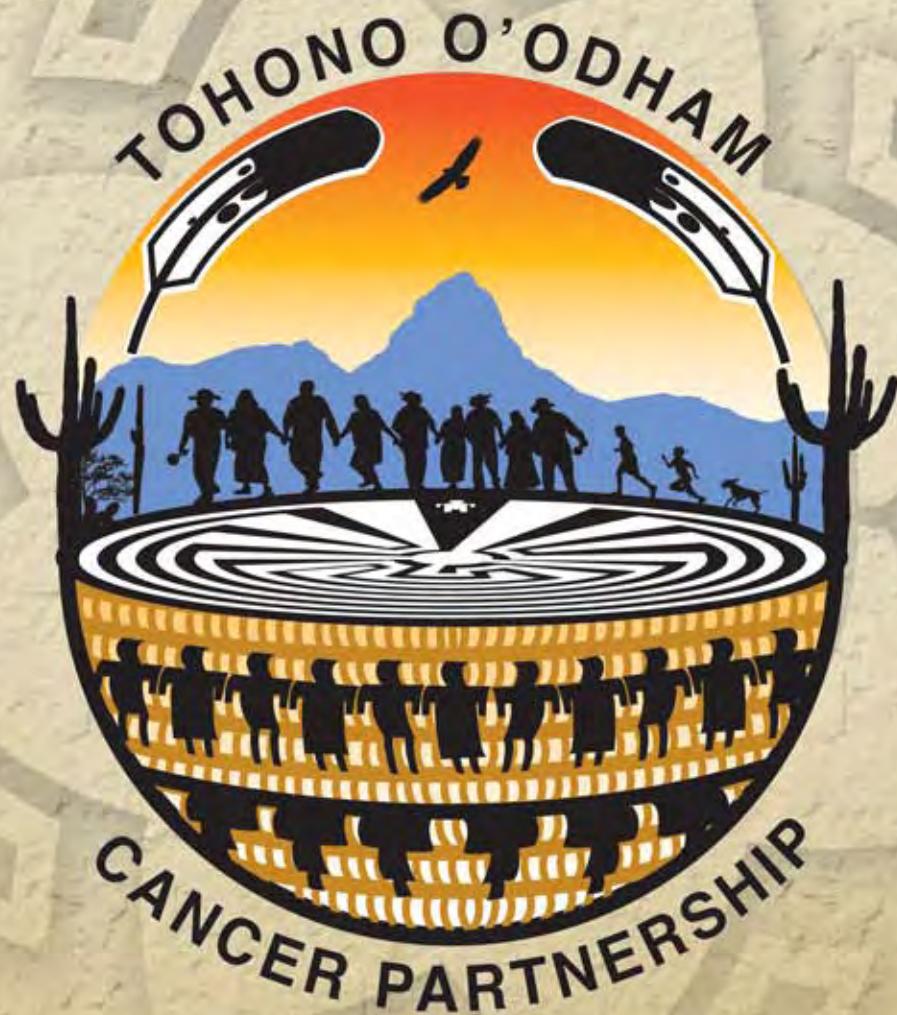
## **Data Surveillance System**

Data surveillance is an important component of any disease management, prevention, or public health program. Under the TON grant, it is anticipated that the Sells Service Unit/Tucson Area Indian Health Service information management system called RPMS (Resource Patient Management System), and appropriate Service Unit, Area and Tribal staff will be utilized for Cancer Surveillance Data and actions taken based on the data. Data will be retrieved from the RPMS system as it pertains to specific cancer screening performance (Government Performance Results Act indicators), referrals for specific cancer screening, diagnosis, and treatment (Referred Care Information System module within RPMS), eventual outcomes measurement, and potentially the establishment and maintenance of a "core group" of health staff to analyze and carry out the functions of cancer surveillance.

## Evaluation

The CPC has laid out a comprehensive cancer plan that covers five years, 2010 – 2015, contains seven goals and 34 objectives. It would be unrealistic to believe that the committee who oversees the implementation of this plan could be responsible for meeting all the named objectives. As a result, the committee will decide early on, through a consensus process, on the top three to five goals to implement, keeping in mind this is a “living” plan, meaning the plan can change based upon the most urgent needs of the Tohono O’odham Nation members. As the committee works toward goal attainment, the project will have access to an experienced evaluator who will utilize the following:

- Process evaluation - used to determine if activities are being implemented as proposed.
- Formative evaluation – used to discover what is working and what is not so the project can use this information for improvement.



# CHAPTER 1

**Agnes Attakai, M.P.A.- CHAIR**  
Mel and Enid Zuckerman  
College of Public Health  
University of Arizona

**Francisco Garcia, M.D., M.P.H.**  
Women's Center of Excellence  
Arizona Cancer Center  
University of Arizona

**Peter Lance, M.D.**  
Arizona Cancer Center  
University of Arizona

**Kendra Sabol, M.Ed., M.S.**  
Program Director  
Comprehensive Cancer Control  
Arizona Department of Health Services

**Marlene Saraficio, B.A.Ed., M.A.Ed.**  
Health Educator  
San Simon Health Center  
Sells Service Unit  
Indian Health Service

## PREVENTION

## **Introduction**

### **Cancer Prevention and the Tohono O'odham Nation**

The Prevention Chapter of the Tohono O'odham Nation Comprehensive Cancer Control Plan documents how the Nation can increase its capacity to address primary cancer prevention at both the individual (lifestyle) and community levels. By addressing preventable risk factors (i.e., obesity, commercial tobacco use, excessive alcohol use, unprotected sexual intercourse, etc.) individuals and the Nation as a whole can take action and not only reduce their risk for cancer, but for most chronic diseases, including diabetes, cardiovascular disease, cerebrovascular disease, and chronic respiratory diseases.

### **Why Prevention?**

The ultimate goal of prevention is to promote healthy behaviors and risk reduction for a variety of diseases including cancer. Cancer is caused by changes in genes that normally control the growth and death of cells. Certain lifestyle and environmental factors can change some normal genes into genes that allow the growth of cancer. Many gene changes that lead to cancer are the result of tobacco use, alcohol use, diet, obesity, lack of physical activity, exposure to ultraviolet (UV) radiation from the sun, or exposure to carcinogens (cancer-causing substances) in the workplace or in the environment. In addition, viruses, such as the human papilloma virus (HPV), and hepatitis B (HepB) increase the risk of some types of cancer. When the above risks are avoided, a healthy individual can reduce their cancer risk by more than half. According to the American Cancer Society, lifestyle factors such as cigarette smoking, lack of physical activity, poor nutrition and obesity contribute to about one-third of U.S. cancer deaths each year<sup>4</sup>.

<sup>4</sup> American Cancer Society Facts and Figures 2007 <http://www.cancer.org/downloads/STT/CAFF2007PWSecured.pdf>

For American Indians, cancer and other leading causes of death such as heart disease and diabetes-related complications are usually linked to the previously mentioned preventable risk factors. Knowledge, attitudes, and health behaviors related to environmental exposures are also important considerations for preventable cancer risk among American Indian people. .

## **Obesity: the Nutrition and Exercise cancer connection**

Until the second half of the 20th century, the Tohono O'odham were almost entirely food self-sufficient utilizing agricultural practices that date back over one thousand years. The causes for the decline in subsistence farming/gathering are complex and multifaceted. Many Tohono O'odham worked away from the homelands taking jobs as field labor for cotton growers, with the railroad, in construction, or they joined the military or attended boarding schools or training schools. Living and working away from Tohono O'odham lands reduced the opportunity to plant, harvest and hunt, and increased the consumption of commercial foods.

Today, the diet of most American Indian families, including the Tohono O'odham is high in refined carbohydrates, fat, and sodium. This is due to the high consumption of foods such as bread, potatoes, and meat that have been fried and a low consumption of lean meat, dairy products, vegetables, and fruits. This "westernized" diet has led to high rates of obesity among most Americans, but especially among the O'odham. According to the American Cancer Society more American Indian/Alaska Native (AI/AN) than non-Hispanic White (NHW) men and women aged over 20 years reported being obese; and, correspondingly, more AI/AN than NHW persons aged over 18 years reported no leisure time physical activity.<sup>5</sup>

<sup>5</sup>American Cancer Society. <http://www3.interscience.wiley.com/cgi-bin/fulltext/116330621/PDFSTART>

With such a diet and lack of physical activity, obesity has become an increasing problem for American Indian people. Obesity increases the risk for cancers of the breast, endometrium, colon, and kidney. A diet that is high in red meats (beef, lamb, or liver) and processed meats (hot dogs, bologna, and luncheon meat) can increase colorectal cancer risk. Methods of cooking meats at very high temperatures (frying, broiling, or grilling) create chemicals that might increase cancer risk. Men who eat a lot of red meat or fatty foods seem to have a greater chance of getting prostate cancer and possibly kidney cancer. These men also tend to eat fewer fruits and vegetables. Physical activity is associated with a reduced risk of cancers of the colon, breast, prostate, lung and endometrium (lining of the uterus).

The American Cancer Society and National Cancer Institute suggest eating less red meat and fat, eating whole grains and eating five or more servings of vegetables, fruits, each day. These guidelines provide a healthful approach to eating that may help lower your risk for some other types of cancer, as well as other diseases.

### **Substance Abuse and Other Behaviors as Risk Factors**

**Commercial Tobacco Use:** Smoking (particularly cigarettes) exposes the body to many cancer-causing chemicals (carcinogens) that affect more than the lungs. These harmful substances are absorbed by the lungs and are carried in the bloodstream throughout the body. Smoking is the leading risk factor for lung cancer. In addition to increasing lung cancer risk, women who smoke are about twice as likely as non-smokers to get cervical cancer. While smoking is a well-known cause of lung cancer, some of the cancer-causing substances are swallowed and can cause digestive system cancers, such as colorectal cancer. People who don't smoke but who breathe the smoke of others (environmental tobacco smoke) may also be at a higher risk for lung cancer. Non-smoking spouses who live with a smoker, for example, have about a 20% to 30% greater risk of developing lung cancer than do spouses of non-smokers.

Non-smokers exposed to tobacco smoke in the workplace are also more likely to get lung cancer. There appears to be wide variation among tribes and regions in the extent of tobacco use. Compared to other tribal communities, the Nation has low commercial tobacco usage and low lung cancer cases (see Diagnosis and Treatment Chapter).

In addition to cigarette smoking and alcohol use, smokeless tobacco (chewing tobacco and snuff) is popular in many American Indian communities, especially among young people. Oral and nasopharyngeal cancers, which are closely associated with smokeless tobacco use, are much more common among males than among females (Horm and Burhansstipanov, 1992).

For both men and women, smokeless tobacco use often begins during adolescence. Current smoking prevalence among persons aged over 18 years was higher among AI/AN persons overall than among NHW persons, however was less in Southwest.<sup>6</sup>

Few tribes and tribal communities have passed and implemented comprehensive tobacco policies. Currently only two tribes, the Black Feet and Fort Peck have such policies. The challenges of passing tobacco policies in tribal communities include the issue of sovereignty, lack of funds, lack of tobacco advocates, the selling of tobacco products in the gaming industry and by tribal enterprises. Currently on the Nation, the Nation does not have a no-smoking policy for tribal departments, programs and schools. However, the Indian Health Service does have a smoking policy. The proposed strategies focus on preventing or reducing the number of young people who begin smoking. The state of Arizona recently became a smoke free state, passing a law that prohibits smoking in all enclosed public places, including bars and bowling allies.

<sup>6</sup> American Cancer Society. <http://www3.interscience.wiley.com/cgi-bin/fulltext/116330621/PDFSTART>

**Heavy alcohol use:** Long term and heavy drinking increases the risk for cancers of the colon and rectum, esophagus, mouth, throat and larynx. Alcohol use should be limited to no more than two drinks a day for men and one drink a day for women. The United States Preventive Services Task Force (USPSTF) recommends that adults be screened and receive behavioral counseling in a primary care settings to reduce alcohol misuse. Heavy drinking not only increases social problems but also has other serious consequences, such as suicide, homicide, and accidents, which contribute significantly to disability and early death. For American Indian women who drink during pregnancy, there is the additional risk of having babies with severe developmental disabilities—fetal alcohol syndrome or milder forms of disabilities associated with fetal alcohol effects.

Whereas heavy drinking was more common among men than among women, in both populations, the percentage of AI/AN persons aged over 18 years who consumed more than five drinks on one occasion was higher overall than that of Non-Hispanic White adults.<sup>7</sup>

**Human papilloma virus infection:** The most important risk factor for cervical cancer is infection by the human papilloma virus (HPV). HPV is a group of more than 100 related viruses. Low risk papilloma viruses cause benign growths called papillomas or warts that have almost no malignant potential. HPV is passed from one person to another during skin-to-skin contact during sex - including vaginal intercourse, anal intercourse, and possibly even during oral sex. High risk HPV viruses are associated with pre-cancer and cancer of the cervix, as well as the vulva and vagina. Persistent high-risk HPV infection is required for the development of cancer. The prophylactic HPV vaccine protects against the two viral types associated with 65% of all cervical cancers and the two viral types associated with 95% of all genital warts. The vaccine is optimally effective when given to girls before they become sexually active. The most important aspect of preventing cervical cancer is regular, age appropriate screening

<sup>7</sup> American Cancer Society <http://www3.interscience.wiley.com/cgi-bin/fulltext/116330621/PDFSTART>

(per recommended guidelines), Pap tests with or without high-risk HPV testing, and timely follow up to a positive test.

**Chronic infection with hepatitis B virus (HepB) is a common cause of death associated with liver failure, cirrhosis, and liver cancer. HepB is transmitted by exposure to infectious blood or body fluid such as semen and saliva. Those most susceptible to HepB infection are hemodialysis patients, pregnant women, and people known or suspected of having been exposed to HepB (i.e., infants born to HepB-infected mothers, household contacts and sex partners of infected persons, and persons with known occupational or other exposures to infectious blood or body fluids). Hepatitis B vaccination is highly effective in preventing infection with HepB and consequent acute and chronic liver disease.<sup>8</sup>**

## **Skin Cancer and Sun Safety**

Ultraviolet (UV) radiation from the sun is the main cause of skin cancer. Energy from the sun actually is a form of radiation. It consists of visible light and other rays that people can't see. Invisible infrared radiation, for instance, makes sunlight feel hot. UV also is invisible, and causes sunburn and sun tan.

UV rays damage the skin's deoxyribonucleic acid (DNA), which is the genetic material that makes up genes. Genes control the growth and overall health of skin cells. If the genetic damage is severe, a normal skin cell may begin to grow in the uncontrolled, disorderly way of cancer cells. UV also can cause sunburn, and other damage that makes the skin look prematurely old and wrinkled.

<sup>8</sup> American Cancer Society <http://www3.interscience.wiley.com/cgi-bin/fulltext/116330621/PDFSTART>

**Two kinds of rays exist in ultraviolet radiation:**

- Ultraviolet A (UVA)
- Ultraviolet B (UVB)

Scientists once thought that excessive exposure to UVB rays was the main cause of skin cancer. Now they think that UVA also is involved. That's why it is important to use a sunscreen product that protects against both UVA and UVB rays. In addition to sun screen, it is recommended to cover up (wide brim hats, long sleeve shirts, pants), and if possible avoid outdoor activity during the highest exposure times (10am to 3pm).

Anyone can get skin cancer. Although most cases occur in people over age 50 with fair skin, it can develop in younger people, those who work outdoors and those with dark skin. In general, an individual's lifetime exposure to UV light determines her/his risk. Evidence shows that sunburns during childhood increase the risk for skin cancer. Skin cancer is one of the top five cancers among American Indians at the Phoenix Indian Medical Center.<sup>9</sup>

### **Challenges: Where is the data?**

To develop prevention programs and track the progress towards reducing the risk factors for cancer, research and statistical data are needed. Unfortunately, among the Tohono O'odham people, there are very limited and incomplete data on cancer-related knowledge, attitudes and behaviors as well as cancer prevalence for the Nation. Our committee reviewed the Tohono O'odham Community Health Assessment conducted 2000-2001 and the Tohono O'odham 2007 Youth Risk Behavior Survey to obtain baseline information to measure the effectiveness of the proposed interventions. Both provided small numbers of respondents and therefore any evaluation would be difficult. The Guide to Community Preventive Services<sup>10</sup> and the Healthy People 2010 Leading Health Indicators were reviewed in creating the prevention chapter because they were cancer related or had the capability to track interventions.

<sup>9</sup> Arizona Republic <http://www.azcentral.com/arizonarepublic/local/articles/1029nativecancer29.html>

<sup>10</sup> <http://www.thecommunityguide.org/>

# **What can I do to reduce my community's risk for developing cancer?**

## **Prevention Goal, Objectives and Strategies**

**GOAL 1: Promote cancer risk reduction for the Tohono O'odham Nation through primary prevention.**

**Objective 1.1: Reduce obesity by increasing the availability of quality fresh fruits and vegetables within schools and the community.**

**Strategies:**

1. Advocate for nutritious and healthy meals within the local schools. Find alternatives to current school meal vendors to increase the health quality of school meals.
2. Advocate for commercial business to provide more fresh fruits and vegetables and healthier food choices.
3. Collaborate with Tohono O'odham Community Action (TOCA) and other organizations to develop and promote community gardens to increase the availability of fresh vegetable and fruit.
4. Develop community cooking and nutrition classes to teach healthy recipes.

**Objective 1.2: Reduce obesity by enhancing nutrition education in all grade levels and local schools within the community.**

**Strategies:**

1. Modify the school health curriculum to integrate nutrition education into the mathematics, reading, writing and science curriculum.
2. Develop and provide training to school staff, school board leadership, districts and community members who can influence healthy eating and nutritional habits.
3. Develop household education session on nutrition, cooking and shopping.

**Objective 1.3: Reduce obesity by increasing the number of O'odham children who engage in daily moderate physical activity (30 minutes) at school.**

**Strategies:**

1. Implement physical education (PE) time in all eight schools on the Nation.
2. Educate tribal leaders, school board, parents and community members on the benefit of physical activity.
3. Provide physical activity programs for youth.

**Objective 1.8: Increase knowledge and awareness about the Human Papilloma Virus (HPV) and Hepatitis B Virus (HepB) vaccines.**

**Strategies:**

1. Develop partnerships between health department and community organizations to develop a community education plan and educational materials on the HPV and Hepatitis vaccines.
2. Initiate patient education in primary care settings on HepB/HPV using bilingual, bicultural health professional staff.
3. Coordinate with IHS, clinics, health department and school programs on the availability of the HPV and or Hepatitis B vaccines.

**Objective 1.9: Increase the number of youth and adults who do not use cigarettes and smokeless tobacco.**

**Strategies:**

1. Develop a media campaign to reduce tobacco initiation and motivate youth and adults to remain tobacco free.
2. Collaborate with existing tobacco prevention programs to increase education on the harmful effects of tobacco use.
3. Develop work-based tobacco cessation programs.
4. Encourage community events to be commercial tobacco free.

**Objective 1.10: Develop and enforce a non-smoking policy in workplaces and other public areas.**

**Strategies:**

1. Assess leadership regarding a non-smoking policy.
2. Assess the community regarding a non-smoking policy.
3. Educate community and leadership on the challenges and benefits of a non-smoking policy.
4. Collaborate with organizations, advocates, districts, committees and leadership to develop resolutions and legislation on a comprehensive no-smoking policy.
5. Pass and enforce a non-smoking policy.

**Objective 1.4: Increase the number of Tohono O'odham who participates in daily moderate physical activity for at least 30 minutes per day.**

**Strategies:**

1. Promote programs that encourage traditional and social physical activity such as toka, rodeo, running and gardening.
2. Collaborate with Healthy O'odham Prevention Program (HOPP) recreation center and other organizations to provide physical activity opportunities within the community.
3. Increase the number of worksites that provide opportunities and policies that promote physical activity.
4. Collaborate with the Indian Health Service (IHS) and Health departments to develop physical activity programs for people of all ages.

**Objective 1.5: Increase community awareness of alcohol as a risk factor for cancer.**

**Strategies:**

1. Develop an educational campaign to increase awareness of the relationship between excessive alcohol use and cancer.
2. Train health care providers, Community Health Representatives (CHRs), and Health Educators on the appropriate ways to identify, counsel and refer adults for alcohol use.

**Objective 1.6: Increase the number of Tohono O'odham who regularly use effective sun protection.**

**Strategies:**

1. Educate the community on the application of sunscreen with a sun-protective factor (SPF) of 15 or higher before outdoor activities and continual reapplication while outdoors for extended periods.
2. Advocate scheduling outdoor activities to avoid peak sun hours between 10:00 a.m. and 4 p.m.
3. Provide and encourage ample shade at outdoor events.
4. Encourage children and adults to wear sun-protective clothing when exposed to sunlight.

**Objective 1.7: Increase knowledge and awareness about the links between environmental contaminants and cancer.**

**Strategies:**

1. Collaborate with environmental programs to identify and address potential carcinogens on the Nation.
2. Educate the tribal leaders and the community about the links between environmental contaminants and cancer.

# CHAPTER 2

John Kittredge, M.D., FAAFP-CHAIR  
Chief Medical Officer  
Tucson Area  
Indian Health Service

Joseph B. Hawes, M.D., M.P.H.  
Medical Epidemiologist  
Consultant

## EARLY DETECTION

# What is Early Detection?

Early detection or cancer screening is the method used to test for cancers. The more common screening methods are the mammogram, Pap smear, colonoscopy and PSA blood test. These four cancer screenings are routinely completed on thousands of people daily and can detect the most treatable types of cancers.

A screening mammogram is an x-ray of a woman's breasts to look for tumors within the breast tissue (breast cancer). If tumors are seen on the mammogram, further testing or treatment will be encouraged. Mammograms are performed annually on women over the age of 40 or earlier if there are other risk factors.

A pap smear is a test for cancer in the uterine cervix (cervical cancer) of a woman.

Pre-cancerous or cancerous cells within this smear can be seen through a microscope. If the test comes back positive, more verification testing can be done before a treatment plan is started. All females starting at age 18 or at initiation of sexual activity are encouraged to have an annual pap smear.

Colonoscopy is a screening test for men and women over the age of 50. This test for colon cancer requires complete emptying of the bowel so that a flexible tube can be inserted to look for masses. If a polyp is seen it can be removed then. Polyps are small growths that can become cancerous. It is recommended to have a colonoscopy every ten years. Sigmoidoscopy is similar to the colonoscopy although only the lower segment of the bowel is observed in this test. It is recommended every five years. Another test for colon cancer is the Fecal Occult Blood Test (FOBT). The annual FOBT tests for blood in the stool. A series of three cards for collection of stool samples are given to the patient with instructions to limit certain foods and medications from the diet prior to and during collection of the stool. The stool samples are collected at home and must be returned to the laboratory within a certain period of time for proper interpretation.

Prostate cancer screening for men involves a blood test and a Digital Rectal Examination (DRE). The prostate-specific antigen (PSA) blood test can measure if a particular protein is higher than normal. If so, this will indicate that further testing is needed. A DRE can detect an enlarged prostate. Although the science behind the soundness of these screening tests is not strong, all men over 45 years of age are encouraged to talk to their healthcare provider about screening for prostate cancer.

National standards for cancer screening are developed by a select group of experts in the field. The following table depicts the recommendations of the U.S. Preventive Services Task Force on cancer screenings.

## Cancer Screening Recommendations

### Breast Cancer 2002

- Screening mammography, with or without clinical breast exam (CBE), every 1-2 years for women aged 40 and over

### Cervical Cancer 2003

- Strongly recommends screening for cervical cancer in women who have been sexually active and have a cervix.

### Colorectal Cancer 2008

- Recommends screening for colorectal cancer (CRC) using fecal occult blood testing, sigmoidoscopy, or colonoscopy, in adults, beginning at age 50 years and continuing until age 75 years. The risks and benefits of these screening methods vary.

### Prostate Cancer 2008

- Concludes that the current evidence is insufficient to assess the balance of benefits and harms of prostate cancer screening in men younger than age 75 years.



# Available Cancer Screenings

The IHS, Sells Service Unit provides early detection (screening) services. The recent conversion to the Electronic Medical Record has enhanced the service unit physician's ability to discuss cancer screenings with patients. A reminder is generated when the appropriate time or age interval is reached for breast, cervical or colon cancer screening. Prostate cancer screening is not part of the reminder package; as mentioned there is disagreement within the scientific community about the validity of the PSA blood test.

Mammograms for breast cancer screening are available in the mobile mammography unit.

Testing at the Sells hospital and three clinics varies based on dates the mobile mammography unit is scheduled to be available at each location.

Cervical cancer testing (pap smears) can be performed during well-woman exams or prenatal appointments at all three clinic sites and the Sells Hospital. Female physicians are available upon request. According to focus group participants, all the women preferred female providers at Women's clinic and recommended that women ask for one and advocate for more female providers.

Colonoscopies and the FOBT are discussed with patients at the appropriate age. If a patient chooses to have a colonoscopy, it is scheduled in Tucson with one of two gastroenterologists. This requires patients to make two trips to Tucson; the first trip is for consultation, then a return trip for the colonoscopy procedure. Prior to the procedure, the patient has to complete the colonoscopy preparation procedure available from the Sells pharmacy. When the construction of a new Indian Health Service hospital is completed, it is anticipated that colonoscopies could be performed in Sells.

The FOBT instruction sheet and card can be given out after the clinic visit and performed at home. The test cards must be returned to the hospital laboratory for evaluation. Although

not part of the Electronic Health Record (EHR) screening reminders, all men over 45 years of age are encouraged to talk to their healthcare provider about prostate screening.

## Tohono O'odham Cancer Screening Data

### BACKGROUND

The collection and reporting of National and State cancer screening data in the United States is heavily dependent on information generated through the Behavioral Risk Factor Surveillance System (BRFSS) self reported data set. A review of the 2002 – 2006 Arizona BRFSS report revealed no information on TON members. This meant that at the state level, there was no data set available as a source for identifying TON cancer screening cases.

The New Mexico Tumor Registry (NMTR), a regional data source, has been contracted by National Institutes of Health (NIH), Surveillance Epidemiology and End Results (SEER) program to collect and abstract cancer cases from Indian Health Service facilities within Arizona and New Mexico. This registry operates and maintains a population-based cancer registry for the entire state of New Mexico and the American Indian population of Arizona. Its registry routinely collects health information from the Sells, San Xavier and Santa Rosa clinics. Review of the New Mexico Tumor Registry data set revealed that there was no published information (including cancer screening) available on Native American Indians living in Arizona.

The Tohono O'odham Nation Indian Health Service system provides only primary care services (including some screening services) through its clinics of Sells, San Xavier, Santa Rosa and San Simon. Not all TON members utilize the services provided through this health care system, as some, with private insurance and public insurance, often opt to use the services of private non-IHS providers. In addition, the TON IHS contracts out all medical care services associated with cancer diagnosis, treatment and management, to medical facilities operating within the state. All contract service providers ultimately bill the IHS according to the type of service

provided. This makes administrative data sets a potential source for enhancing surveillance capacity for identifying screening cases outside of the IHS medical service system.

Given the lack of TON cancer screening information in the available state and regional data sources, the decision was made to use the service provision records of the IHS system as the data source for finding TON members receiving cancer screening services. The following results represent the first stage of an analytic review of the screening data presented by three service unit sites: San Xavier, Santa Rosa clinic, and Sells Hospital. The San Simon clinic is not included since the data reviewed for this report is from 2005-2007. Since screening rates could not be generated, percentages were used instead to display available screening data.

## Screening Percentages

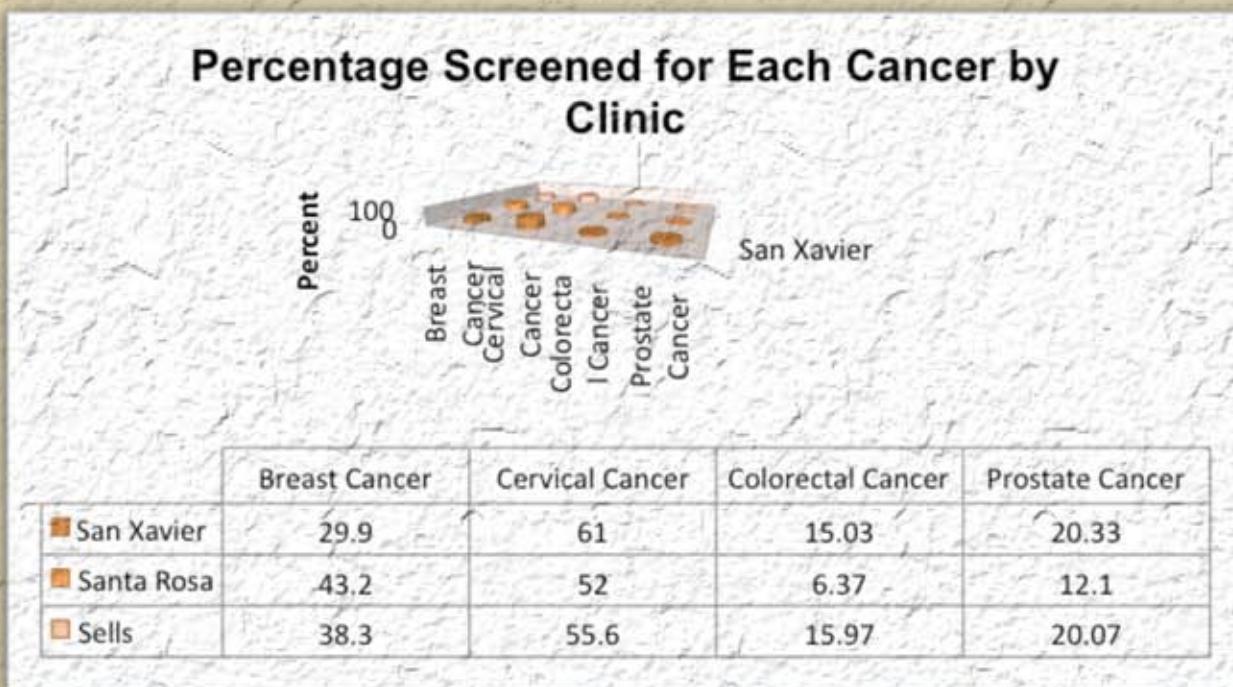
First, the following chart shows the percentage of individuals who were screened throughout the Sells Service Unit in 2005, 2006 and 2007 for the four types of cancer: breast, cervical, colorectal, and prostate. For the years 2005, 2006 and 2007, there was a yearly decrease for two of the cancers: breast and cervical. Colorectal and prostate screenings show an increase then a decrease, especially noticeable for prostate screening.

**Percent Screened for Each Cancer by Year**



	Breast Cancer	Cervical Cancer	Colorectal Cancer	Prostate Cancer
2005	37.51	62	10.37	17.97
2006	35	57.84	16.91	21.45
2007	32.41	55.02	16.25	18.67

In the interpretation of these findings, please keep in mind the percentages do not include members of the TON population who may have received screenings elsewhere. This could have occurred if the TON member had private health insurance or was enrolled in AHCCCS. Overall, the percentage of the eligible population screened was highest for cervical cancer while prostate and colorectal cancer screenings were lowest.



## DISCUSSION

The findings in the Report on Breast, Cervix, Prostate and Colon/Rectal Cancer Screening in the Tohono O'odham Nation Population [See Appendix 2 for entire report] represent an analytic snapshot of a first phase data extraction effort. However, the findings also provide the opportunity for making some comments in terms of their potential implications for: cancer screening rates in the Tohono O'odham Nation population; the development of cancer prevention efforts; and the determination of the magnitude of the existing cancer burden.

In the interpretation of these findings, keep in mind they do not represent members of the TON population residing in Arizona who do not use IHS medical care services, nor do they represent the population of TON members residing in Mexico.

The findings of this report are generated from a review of patients recorded as having received a cancer screening test and consist of two distinct categories of patients. One category is made up of asymptomatic individuals self referring or referred by the medical officer because of age or family history for screening test (true number of patients screened). The other category consists of individuals reporting to the medical services provider with suspected early symptoms or signs of cancer who were then subjected to a diagnostic screening test.

In order to realize the preventive benefits of screening and early intervention, and make meaningful prediction for targeted screening goals for the planning and development of intervention strategies to improve screening rates, it is imperative to be able to distinguish between these two categorical populations of patients. The first step toward decreasing the morbidity burden of cancer is to increase the population of patients in the category of asymptomatic screening pool, while decreasing the category of patients receiving diagnostic screening tests.

By only analyzing patients using the IHS services, this effort will miss counting patients receiving the screening tests outside of the IHS clinical care services as well as individuals who are eligible for consideration in the denominator of the rates generated. The cancer screening rates in this report, as well as those in the Government Performance and Results Act (GPRRA) reports, do not represent the true screening rates for the Tohono O'odham Nation population. In addition, these rates are more representative of a measure of the IHS clinical care services function, rather than the capacity of its existing primary care services of health education and health promotion to provide primary care preventive services.

Notwithstanding these shortcomings, the findings indicate a much smaller number of males in the clinic user population when compared to the female users, suggesting a need to develop strategies that will increase the number of male users of the medical care services. In addition to a low clinic utilization rate for males, the fact that less than 20% of the male population seen at the clinic was screened for prostate cancer suggests that there is room for improvement both in terms of the number of males using the clinics, as well as the percentage of male patients receiving screening tests. Given that GPRA data reflects all patients who received or refused screening tests, and there were no recorded cases of refusal, it can be assumed that all patients who were offered a screening test accepted. This suggests that caregivers can play a meaningful part in increasing the number of patients who receive screening tests.

The colorectal cancer screening findings provide us with an opportunity to make some assumptive comparisons on the rate of cancer screening for a given cancer based on gender. The finding in colorectal results is that while the population of female clinic users was almost twice that of the male users, the average percentage screening rate for males was twice that of females. Based on clinical practice and public health practice experience, a plausible explanation of this finding is that male clinic visits were for suspected symptoms, which required diagnostic screening testing.<sup>11</sup>

<sup>11</sup> Report on Breast, Cervix, Prostate and Colon/Rectal Cancer Screening in the Tohono O'odham Nation Population; Report to the Tohono O'odham Nation, Joseph B. Hawes MD, MPH, Senior Medical Epidemiology Consultant

## **GOAL 2 – Increase the acceptance and utilization of available cancer screenings**

**Objective 2.1:** Begin discussions with the Arizona Department of Health Services (ADHS) about including TON in the state Behavioral Risk Factor Surveillance System (BRFSS).

**Strategies:**

1. Meet with ADHS to determine requirements for including TON in the BRFSS.
2. Educate TODHHS leadership, TON Health Oversight and Legislative Council on the benefits of participating in the BRFSS.

**Objective 2.2:** Begin discussions with the TODHHS about including additional questions related to cancer in the Community Health Assessment (CHA).

**Strategies:**

1. Meet with TODHHS to determine requirements for including additional cancer related questions in the CHA.

**Objective 2.3:** Begin discussions with the IHS about receiving comprehensive cancer screening data on a regular or on an as-needed basis.

**Strategies:**

1. Meet with IHS in order to discuss methodology for compiling comprehensive cancer screening data.

**Objective 2.4:** Obtain more information from the Nation's members about cultural and other considerations needed to enhance acceptance of cancer screenings.

**Strategies:**

1. Conduct group discussions throughout the TON.
2. Obtain information at annual cancer summit and other large gatherings throughout the TON.

**Objective 2.5:** Conduct regular breast, cervical, colorectal and prostate cancer screening awareness campaigns throughout the Tohono O'odham Nation.

**Strategies:**

1. Develop culturally relevant cancer screening campaigns.
2. Increase use of IHS cancer screening sites.

# CHAPTER 3

John Kittredge, M.D., FAAFP-CHAIR  
Chief Medical Officer  
Tucson Area  
Indian Health Service

Tim Flood, MD  
Medical Director  
Public Health Statistics  
Arizona Department of Health Services

Chris Newton, M.P.A.  
Arizona Cancer Registry  
Arizona Department of Health Services

Agnes Attakai, M.P.A  
Consultant

## DIAGNOSIS AND TREATMENT



Photo Courtesy: AZHIST051b

In the best of all health care worlds, persons are born, delivered by the local doctor, and grow up being cared for by that same doctor throughout much of adulthood. This doctor would know a lot about her patients. This is somewhat true for the Indian Health Services. Unfortunately, this is not how health care is delivered in most of the health care systems outside the IHS to which many Native American patients are referred. Health care has become an increasingly complex system that requires navigation, time, personal finances, and advocacy.

## Mapping the Cancer Diagnosis and Treatment Network

Unlike the early detection (screening) of cancer, the Indian Health Service does not provide diagnosis and treatment of cancer. For diagnosis and treatment of cancer, patients within the Sells Service Unit are referred to cancer specialists (oncologists) as far away as 120 miles in Phoenix. The majority of service unit patients are referred to oncologists in Tucson, still, a fifty-mile drive from Sells. The IHS physician who made the referral may never see that patient again for months or years.

With the purpose of examining this network, the CPC needed additional information about the IHS referral process for TO members diagnosed with cancer; for example, what type of cancers were being diagnosed, where patients were being referred, how patients were transported to the place of referral, to list a few.

A consultant was contracted to obtain information from the IHS contract health services and then visit each of the cancer referral centers to find out the answers to the questions depicted in the following diagram. The final report of the consultant will document four key areas:

- 1) The “patient journey”—booking diagnostic tests, starting treatment,
- 2) The experiences of patient and cancer—providing better information,
- 3) Delivery of care—strengthening the multidisciplinary approach to treatment and follow up,
- 4) Capacity and demand—

understanding the dynamics of waiting times, contract health services and access to health services.

## Focus Group Information

The information obtained during the 2008 focus groups provided a glimpse of real life experiences of TO members' personal or family member's experiences after a cancer diagnosis. One response is worth listing here.

*Getting to treatment sites can be difficult for families due to the length of travel, the time to get to off reservation sites, the time commitment away from employment, the cost of gas and the condition of the cancer patient.*

## Cancer Diagnosis and Treatment Data

Discussions with the Chief Medical Officer of the Tucson Indian Health Service Area Office revealed several issues related to tracking patients who leave the IHS health care system and receive cancer care at other facilities. First, the inability of the IHS information management system to track patients once they leave the IHS health care system. Second, a lack of complete cancer diagnosis and treatment data exists. This is similar to the issue of lack of cancer screening data mentioned in the previous chapter whereby Nation members receive treatment for cancer through their employee health insurance plan or the Arizona Health Care Cost Containment System (AHCCCS). These patients may never enter the IHS health care system for the entire period they are being treated for cancer. All of this results in fragmented patient care, with cancer treatment information going out from the IHS while no information comes back.

Due to time limitations, the CPC had to alter plans to match IHS data and Arizona Cancer Registry data and use existing data from the Arizona Cancer Registry. Unfortunately, this cancer data includes members of other tribal groups who may be living within the Tohono O'odham boundaries of the Tohono O'odham Nation, cancer data must be specific to the TON.

The current inability of the TON to acquire cancer data specifically for Nation members who live within the boundaries of the Tohono O'odham Nation is of great concern. There is the possibility of obtaining a more accurate count of TON members who have been diagnosed and treated for cancer. There are several options that the TON can consider:

*Linking data between the IHS patient record database and the records contained in the Arizona Cancer Registry (this would require a Memorandum of Understanding between the two agencies).*

*Utilize the Sells Service Unit/Tucson Area Indian Health Service information management system, RPMS (Resource Patient Management System).*

*Enter into a negotiated Memorandum of Understanding between the TON and the Arizona Cancer Registry. The MOU would specify an authorizing agent of the TON to request data and assure the TON is accountable for its confidentiality.*

*Model the approach two other Arizona Tribes have taken: to enter into a Data Sharing Agreement with the Arizona Cancer Registry. This would require matching TON enrollment data with Arizona Cancer Registry data.*

## Establishing the Stage at Diagnosis

Determining what Stage cancer is in at the time of diagnosis is an indirect measure of the quality of early detection services (see Chapter 2). It also is useful in documenting the challenges faced by the systems-of-care. For example, early stage breast and colon cancers are potentially curable through surgical excision. Late stage cancer sometimes is managed by trying to delay further spread of the cancer. The low yearly counts of TON cancer cases results

in wide year-to-year variability in the proportion diagnosed in early stage, especially when the analysis splits out the counts for cancer types.

**SEER Summary Stage**<sup>12</sup> is used to show the extent cancer has spread from its original starting point to its point at time of diagnosis. Early stage identifies cases that are confined to the site from which the cancer started (in situ stage) or has spread to only surrounding tissue in the organ of origination (local stage). These cancers are usually curable and have a high five year survival rate. Late stage identifies cases that have spread to other organs or to the lymph system (regional stage) or spread to organs far from the site of origination in the body (distant stage). Late stage cancers have a poor five-year survival rate.

## SEER Summary Stage

STAGE AT DIAGNOSIS		CURABLE	FIVE-YEAR SURVIVAL RATE
Early	Spread from site where started to surrounding tissue within same organ	Maybe	Depending upon cancer type may be good.
Late	Spread from site where started to other organs or lymph system	Not likely	Poor

Summary stage is a good tool to identify the need and effectiveness of screening programs (for cancers that can be screened) and the potential need for treatment and support services for all cancer. The following analysis compares the proportion of cases from six cancer sites between TON cancer cases and all Arizona resident cases.

<sup>12</sup> The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) is an authoritative source of information on cancer incidence and survival in the United States. SEER currently collects and publishes cancer incidence and survival data from population-based cancer registries covering approximately 26 percent of the US population. SEER coverage includes 23 percent of African Americans, 40 percent of Hispanics, 42 percent of American Indians and Alaska Natives, 53 percent of Asians, and 70 percent of Hawaiian/Pacific Islanders. (<http://seer.cancer.gov/about/>)

# Limitations of Analysis

The comparative analysis between TON cancer cases and Arizona resident cancer cases is limited by the small number of TON cases per cancer site. Inferences can be drawn for the sites of colorectal, female breast, prostate, and kidney. TON lung cancer and cervical cancer cases have too few cases to compare with Arizona resident cancer cases.

(See Table 8 and Table 9 below.)

**Table 8**

TON Tribe Cases Primary Site by Summary Stage For Dx Years: 1995 - 2006				
Primary Site	Early Stage	Late Stage	Unknown	Total
Colorectal	7	10	5	22
Lung	0	7	4	11
Female Breast	17	15	5	37
Cervix	3	2	2	7
Prostate	7	7	9	23
Kidney	25	17	4	46

**Table 9**

All Arizona Resident Cases Primary Site by Summary Stage For Dx Years: 1995-2006				
Primary Site	Early Stage	Late Stage	Unknown	Total
Colorectal	9,573	14,884	3,431	27,888
Lung	6,064	23,253	9,076	38,393
Female Breast	22,456	12,650	3,246	38,352
Cervix	1,063	980	326	2,369
Prostate	24,823	5,606	8,162	38,591
Kidney	4,126	2,386	859	7,371

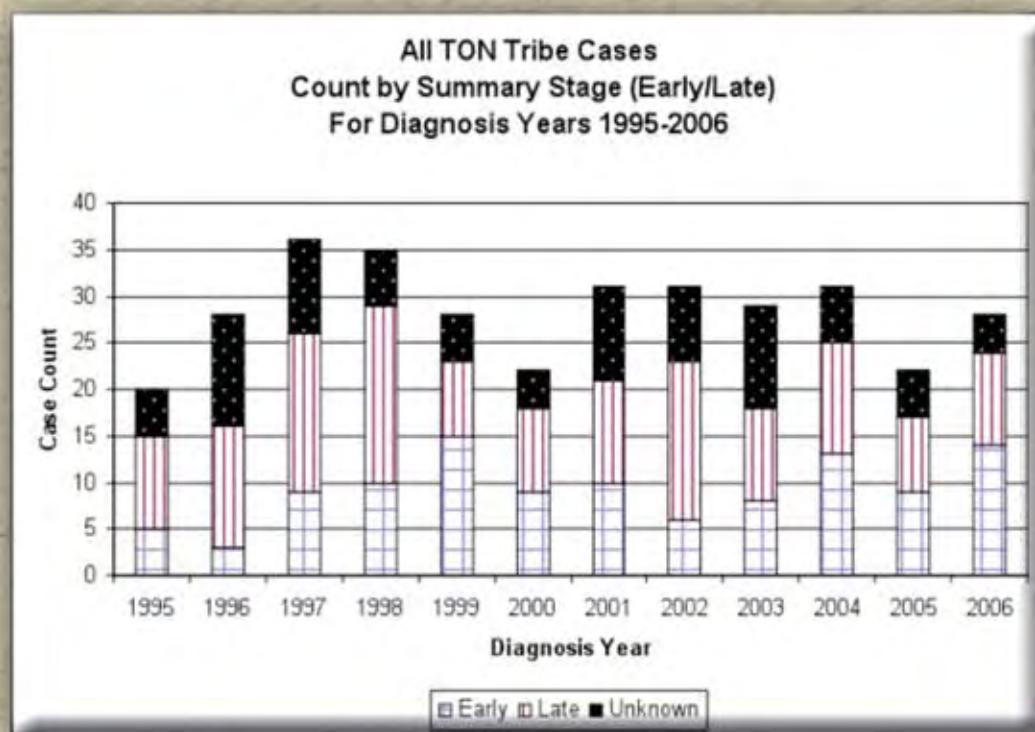
## Comparing TON to Arizona

Colorectal cancer staging shows the TON percent of cases staged at an early stage very similar to the Arizona resident percentage of cases staged at an early stage (32 % to 34% respectively). Both populations show a need for increased screening to find colorectal cancer at its earliest stage. [See Appendix 3, Figure 7a and Figure 7B.] A comparison of kidney cancer cases between TON and Arizona residents also show a similarity in the percentage of cases staged in an early stage (54% to 56% respectively). [See Appendix 3, Figure 8A and Figure 8B.] Female breast cancer comparisons show a greater need for screening of TON women as ten percent fewer cases than Arizona resident women were diagnosed in an early stage (49% to 59% respectively).

[See Appendix 3, Figure 12A and Figure 12B.] Whether prostate screening saves lives is still under intense debate.

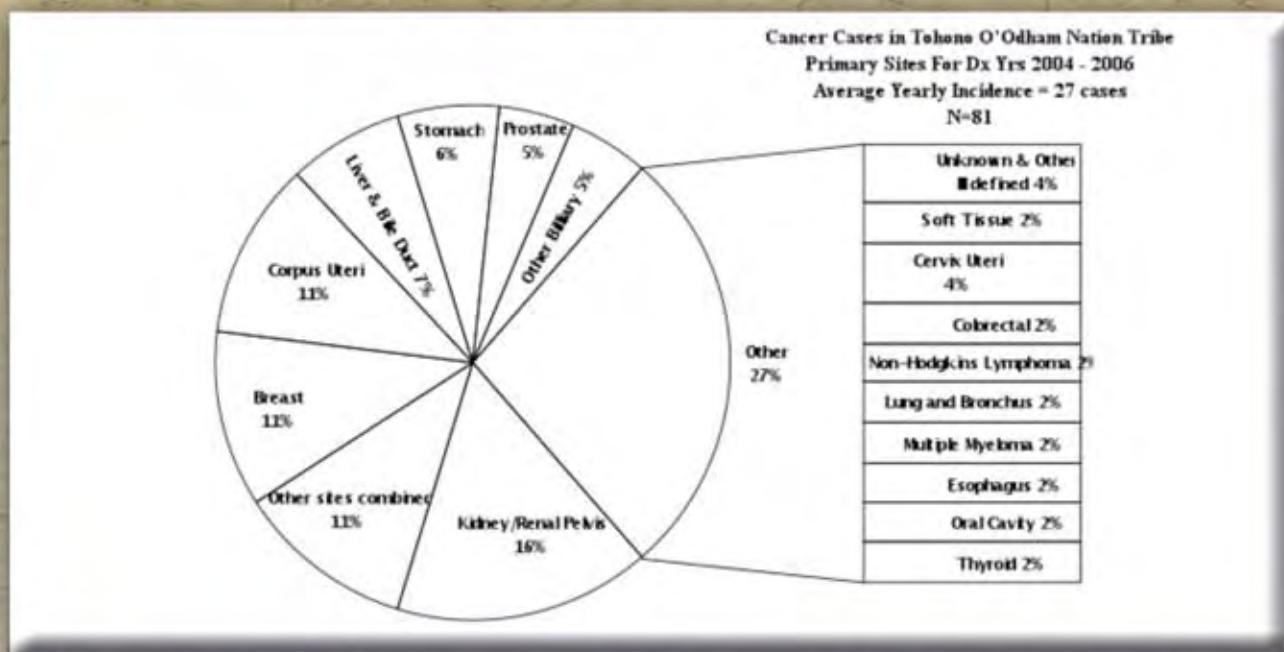
## TON Staging

An early stage diagnosis cancer has varied greatly year to year amongst the TON tribe. The lowest number of early stage cases is found in 1996 with three cases (10.7% of cases that year), while the highest number of cases is counted in 1999 with 15 cases (53.6% of cases that year). The average number is nine early staged cases per year.



## TON Cancer Cases Diagnosed in Years 2004 – 2006

Eighty-one cancer cases were diagnosed among TON tribal members. Most cases are female (56.8%). Kidney cancer led the primary site categories with 16% of the cases (13 cases) (See Figure 20). It is followed by female breast (11%), uterus (11%), liver (7%) and stomach (6%).

**Figure 20**

The top five TON female cancer cases are: female breast (19.6%), uterus (19.6%), kidney (10.9%), other billiary (8.7%), and cervix (6.5%) (See Table 17). The top five cancer sites for TON males is kidney (22.9%), liver (17.1%), prostate (11.4%), stomach (8.6%), and lymphoma (8.6%). (See Table 18.) Refer to page 18 of this plan for comparison with Arizona cancer cases.

**Table 17**

Top Five Primary Sites for Female TON Cases Diagnosed 2004 – 2006		
Primary Site	Case Count	Pct of Cases
Breast	9	19.6
Corpus Uteri & Uterus NOS	9	19.6
Kidney	5	10.9
Other Billiary	4	8.7
Cervix Uteri	3	6.5
All Other Sites	16	34.8
Total	46	100.0

**Table 18**

Top Five Primary Site for Male TON Cases Diagnosed 2004 - 2006		
Primary Site	Case Count	Pct of Cases
Kidney & Renal Pelvis	8	22.9
Liver	6	17.1
Prostate	4	11.4
Stomach	3	8.6
Lymphoma	3	8.6
All Other Sites	11	31.4
Total	35	100.0

# **Diagnosis and Treatment Goal, Objectives and Strategies**

**GOAL 3: Increase access to appropriate and effective diagnosis and treatment services**

**Objective 3.1: Review information contained in mapping project report.**

**Strategies:**

1. Disseminate report to cancer committee for review.
2. Provide overview of report to cancer committee to encourage discussion.
3. Decide what report recommendations the cancer committee ought to address.

**Objective 3.2: Review information contained in Analysis of Tohono O'odham Nation Cancer Cases Diagnosed From 1995-2006.**

**Strategies:**

1. Disseminate report to cancer committee for review.
2. Diagnosis and Treatment Subcommittee to provide overview of report to cancer committee to encourage discussion.
3. Decide what report recommendations the cancer committee ought to address.

**Objective 3.3: Secure authorization from the TON council for the Tohono O'odham Cancer Program to ask the ACR for periodic TON-level cancer data.**

**Strategies:**

1. Meet with ADHS Arizona Cancer Registry to determine requirements for receiving ACR data.
2. Educate DHHS leadership, TON Health Oversight and Legislative Council on method for receiving ACR data.

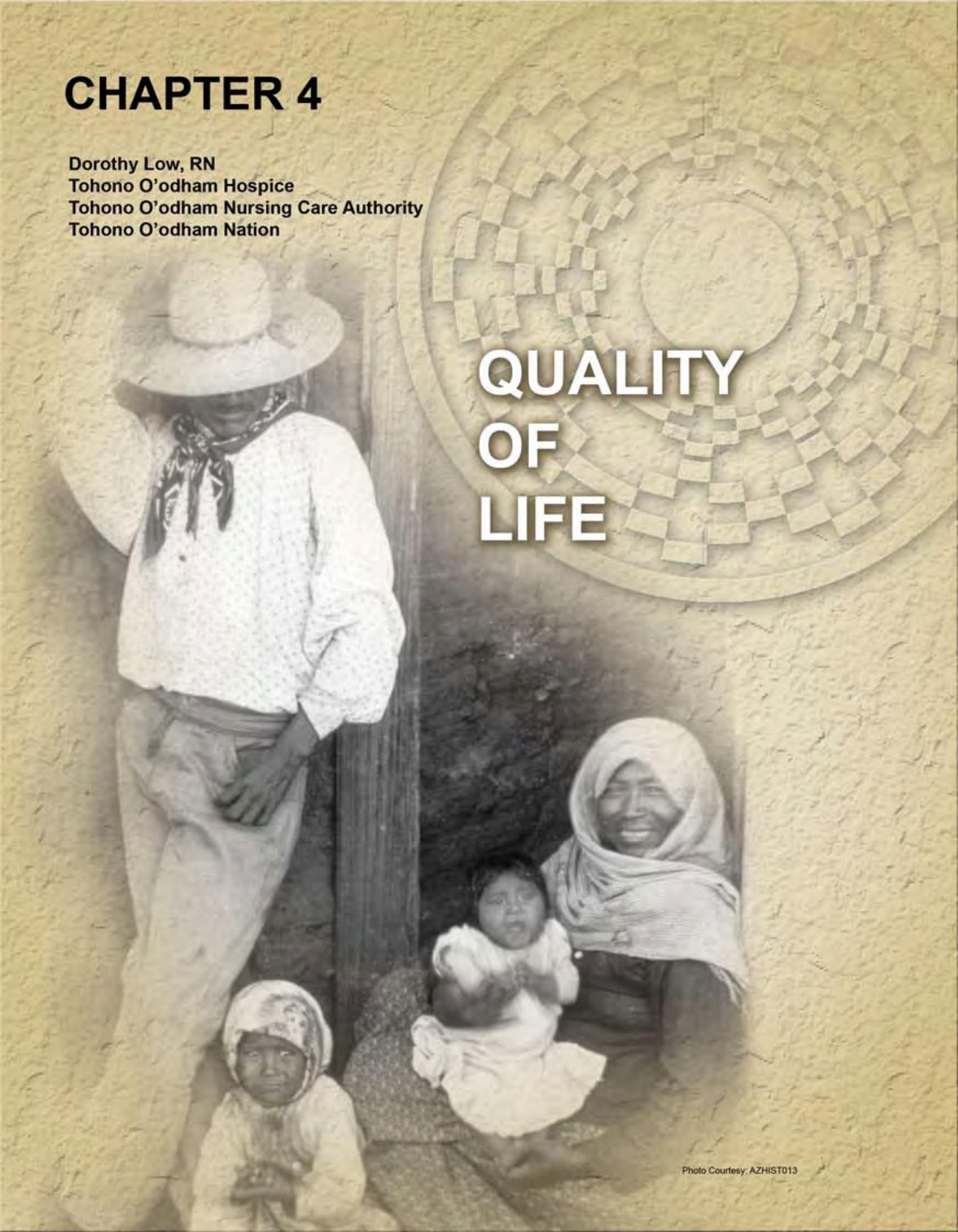
**Objective 3.4: Decide on and begin first steps to institutionalize receipt of diagnosis data on a regular basis.**

**Strategies:**

1. Educate cancer committee on the various options available for receiving diagnosis data.
2. Decide what option the cancer committee will recommend to the DHHS leadership, TON Health Oversight and Legislative Council for receiving diagnosis data on a regular basis.

# CHAPTER 4

Dorothy Low, RN  
Tohono O'odham Hospice  
Tohono O'odham Nursing Care Authority  
Tohono O'odham Nation



QUALITY  
OF  
LIFE

# **Impact on Quality of Life**

While the numbers of cancer survivors increases each day, there are others whose disease will be too aggressive. For these individuals, the continuum of care for cancer must include comfort and pain relief at the end of life. Knowing their family member could receive this type of care would be comforting to the family, as well. All of us hope for a pain free and easy ending to our life's journey. Many of us believe this is not possible with cancer.

Great progress has been made within the medical community and it is now likely we can face even our last days with strength, hope and courage. Hospices provide palliative care for those who are in their last stages of life. Palliative care is the active, total care of a person when cure is not possible. Hospice assists all types of patients, including cancer patients, transition into death with as much dignity as possible.

In November 2007, the Tohono O'odham Hospice, a program of the Tohono O'odham Nursing Care Authority, was opened, housed within the sixty-bed Archie Hendricks Sr. Skilled Nursing Facility, located in the Santa Rosa District, approximately 30 miles northwest of Sells. The Tohono O'odham Hospice provides, with cultural sensitivity, flexible services to meet the physical, psychological, emotional, and spiritual needs of the individual and family. A range of end-of-life services in the most appropriate setting (at home or in alternative residential settings) is offered. A team of traditional healers, physicians, nurses, social workers, chaplains and volunteers coordinate these services.

The federal agency that certifies hospice programs, Centers for Medicare and Medicaid Services (CMS), requires separate certification for hospice care of children and requires training of staff and maintaining certification. Currently, official hospice services for Nation members eighteen years and younger are not available on the Nation. These services are available in Tucson, although none exists in the Casa Grande area. The Tohono O'odham Hospice Board

has approved informal support services to families who need childhood hospice services if the symptom management isn't difficult.

The Cancer Planning Committee (CPC) commends the Tohono O'odham Nursing Care Authority for the wisdom and foresight to establish a hospice program for members over the age of eighteen. The Tohono O'odham Cancer Planning Committee would like to see hospice services established for children with cancer. This would be a positive step towards the comprehensive cancer control program that the Tohono O'odham Nation is seeking.

An additional need identified by a 2008 focus group participant, requested respite care for caregivers of cancer patients.



# **Quality of Life Goals, Objectives and Strategies**

**GOAL 4: Improve the quality of life for Tohono O'odham Nation members whose lives are shortened by cancer.**

**Objective 4.1: Increase awareness of Nation members and health care providers about what types of patients are appropriate referrals for hospice services, including cancer patients.**

**Strategies:**

1. Educate Nation members in order that appropriate referrals for hospice care can be made.
2. Educate health care providers in order that appropriate referrals for hospice care can be made.

**Objective 4.2: Determine options for providing respite for caregivers of cancer patients.**

**Strategies:**

1. Obtain information about available respite opportunities on the TON.
2. Educate the cancer committee on availability of respite opportunities.
3. Determine next steps based on information.

**Objective 4.3: Determine options for palliative care availability at the Indian Health Services Sells Hospital.**

**Strategies:**

1. Obtain information about palliative care programs available at other IHS facilities.
2. Educate the cancer committee on availability of palliative care programs.
3. Determine next steps based on information.

**Objective 4.4: Explore options for providing childhood cancer hospice services for the Nation.**

**Strategies:**

1. Obtain information about available childhood cancer hospice service opportunities on the TON and off the TON.
2. Educate cancer committee on available childhood cancer hospice service opportunities.
3. Determine next steps based on information.

# CHAPTER 5

Darlene Lopez, LPN-CHAIR  
Home Health  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

Michael Flood, LISW, BCD  
Director, Social Work Program  
Indian Health Service  
Sells Service Unit

Nancy Harvey  
Home Health  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

Patricia Leibensohn, Ph. D.  
Arizona Cancer Center

Marilynne Loonsfoot, BSW  
Hospice Social Worker  
Tohono O'odham Hospice

## SURVIVORSHIP



# **Addressing Survivorship on the Nation**

A small subcommittee was formed to explore the thoughts, beliefs, and activities of Tohono O'odham cancer patients and elders with respect to cancer and its impact on their lives and families. In addition, various providers both within the Nation's health care infrastructure and external to it, such as the Indian Health Service Hospital, were surveyed to determine available resources and programs that specifically addressed the medical and psychosocial needs of cancer survivors. That information has been instrumental in leading to the development of the recommendations at the end of this chapter.<sup>13</sup>

There are a number of issues that come with being a cancer survivor. The subcommittee wanted to identify factors to enhance a survivor's ability to navigate through the medical system at IHS as well as medical facilities and other specialty resources utilized by IHS in the surrounding area.

The Indian Health Service hospital at Sells was surveyed to determine available resources and programs that specifically address the medical and psychosocial needs of cancer survivors. The results are:

- A. No defined programs exist.** The IHS hospital at Sells is focused upon primary care and family practice; there is no one program dedicated to patients with a cancer diagnosis.
- B. Many patients** that are later diagnosed with cancer are not often seen on a regular basis in the clinic, and usually come to the emergency department only during a medical crisis, only to be sent to care outside of the IHS medical system. They are often lost to primary care follow up. Other patients, seen in primary care clinic identified with a possible cancer diagnosis, are sent to specialists who in essence take over the medical

<sup>13</sup> From Cancer Patient to Cancer Survivor: Lost in Transition  
<http://iom.edu/Reports/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition.aspx>

management of the patient and may not always be in complete communication and coordination with IHS with respect to post-treatment management and surveillance.

**C. There are no support groups for cancer survivors on the TON.**

**Critical areas that the subcommittee decided to focus on were:**

- A. The need for an accessible survivor data base and determination as to who maintains the data - Tohono O'odham Nation, State of Arizona or Indian Health Service; [See page 23 in introduction for cancer survivor data.]**
- B. The need for a provider resource directory that contains, education information and resources;**
- C. The need to establish support groups; and**
- D. The need to promote Indian Health Service care coordination.**

The Survivorship Subcommittee also visited a support group in the Gila River Indian Community and found the sole support of the group came from the donations that were gathered at the end of their meetings. To better understand the thoughts and beliefs of elders from the Nation, a presentation was done with Congregate Meals for Seniors from the south area of the reservation. The question was asked, "What comes to mind when you hear the word cancer?" Responses were:

- 1) Death;**
- 2) Surgery;**
- 3) Relatives dying.**

The elders wanted more information about education, screenings, and treatment. Participants felt they lacked support and had no one to go to when cancer was diagnosed. They felt the lack of knowledge pertinent to cancer - that it can be cured for some and not for others.

They also expressed the need to know where to get the proper medications. This pointed to the inability to navigate through the various and complex medical systems involved with the care and treatment of their cancer diagnosis.

## Recommendations and Goals

Based on the information obtained from focused interviews with members of the Nation, some of whom are cancer survivors, as well as interviews with local health care program providers the Survivorship Subcommittee is suggesting the following recommendations and goals:

1. Develop a local database of Tohono O'odham members with an identified cancer diagnosis.

It has been determined that it is difficult to identify our Nation's members that have a cancer diagnosis. The Arizona Department of Health Services (ADHS) maintains a directory of all Native Americans Cancer patients in Arizona. It however, does not provide the ability to sort by tribal affiliation, only by postal zip code. The Indian Health Service Resource Program Management System (RPMS) is able to sort on those patients sent for specialty care, but does not comprehensively identify and record confirmed diagnoses. Goal: To establish within the IHS data system a user friendly tool that will easily identify cancer patients who obtain their healthcare at Sells Service Unit to coordinate care and to maintain surveillance of those persons having completed treatment in order to prevent new or recurring illness.

2. Develop a case management process to coordinate cancer care that will ensure prompt access to specialists and communication between them and a patient's primary care provider, and to facilitate navigation across systems to ensure that all healthcare needs are met. Often, patients identified with possible cancer diagnoses are referred to specialty providers outside of the IHS health care

system. Communication and coordination is sometimes inconsistent or untimely leading to delay of critical follow up and specialty care. Other times, the coordination and delivery of specialty care begins, bypassing the primary care setting. Both instances can have devastating consequences for patients and their families; impacting treatment and related activities such as access to medications and durable medical equipment, making and keeping appointments, transportation, insurance and payment issues. **Goal:** To establish a cancer patient navigation system to ensure access to specialty services, and to facilitate primary care internal coordination and communication with specialty care systems.

**3. Develop a resource directory for both patients and providers that will provide information about cancer diagnosis and treatment, community resources, internet resources and access to counseling and support for cancer survivors and their families.** As pointed out in our focus groups and interviews with individuals, the Nation's members have identified a need for more information about cancer diagnoses and terminology, about treatment and care, and access to specialty pharmaceuticals. Another identified issue is the need for interpretation services, not just with respect to language but also to communicating information in a clear and culturally effective manner. **Goal:** To establish a user friendly information resource to help cancer survivors answer questions related to their illness and to access resources and service providers.

**4. Develop cancer survivor support groups to provide information and emotional support to survivors and families.** The subcommittee's survey of individuals and providers pointed out that there was no structured group devoted to discussion of the consequences of treatment – physical, emotional, financial, or spiritual. A survivors . group could provide a safe and comfortable setting to share experiences, explore feelings and provide support to persons in the various stages of their treatment and ongoing management.

**Goal: To establish two support groups, one for Sells area cancer survivors and one for San Simon area cancer survivors to address the biopsychosocial<sup>14</sup> and educational needs of persons either currently undergoing cancer diagnosis related treatment or who have completed treatment and are in a surveillance and remission stage of care.**



<sup>14</sup> The biopsychosocial approach advocates that health is best understood in terms of a combination of biological, psychological, and social factors all of which play a significant role in how people cope with disease or illness. The biological component seeks to understand how the cause of the illness stems from the functioning of the individual's body. The psychological component looks for related influences on a health problem such as negative thoughts, emotion turmoil, or destructive behaviors. The social component examines how factors such as socioeconomic status, culture, poverty, technology, and religion can influence health. Santrock, J. W. (2007). A Topical Approach to Human Life-span Development (3rd Ed.). St. Louis, MO: McGraw-Hill.

# CHAPTER 6

Victor Carrasco, MHSA, CHAIR  
Patient Services Manager  
The Leukemia & Lymphoma Society  
Desert Mountain States Chapter  
Desert Mountain States Chapter

Phoenix, AZ  
Albert Adler, MD  
Pediatrician  
Sells Service Unit  
Indian Health Services

Mary Antone-CHR  
Community Health Representative Program  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

Loriann Cruz-CHR  
Community Health Representative Program  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

Barbara Juan-CHR  
Community Health Representative Program  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

Loretta Ortega-CHR  
Community Health Representative Program  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

Polly Osife-CHR  
Community Health Representative Program  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

Marlene Saraficio, B.A.Ed., M.A.Ed.  
Public Health Educator  
San Simon Health Center  
Sells Service Unit  
Indian Health Services

## CHILDREN AND CANCER



Photo Courtesy: AZHIST036

# Introduction to Childhood Cancer

Cancer is often thought of as an adult disease and many institutions and organizations dedicate large amounts of resources for this population. Children are often not thought of as being at risk for developing cancer or to having risky behaviors, such as smoking. Although this is true for the most part, more attention needs to be given to childhood cancer as a possible disparity. Being able to recognize early symptoms and developing awareness about childhood cancer can empower all parents to make the right choices for their children. The Childhood Cancer Committee felt that this issue needed to be included in the Cancer Plan for the Tohono O'odham Nation. If ignored, the incidence and mortality rate may increase due to poor recognition of signs and symptoms leading to late stage diagnosis and poor survivorship among the Tohono O'odham people. The future of the Tohono O'odham Nation rests on keeping the youth healthy and recognizing the need for prevention of disease.

Childhood cancer is a group of many related diseases that begin in cells, the body's basic unit of life. As the body needs cells, they grow and divide in an orderly fashion. However, there are times when the cells keep dividing even if the body does not need them. When an abnormal over-growth of cells occurs a mass is formed, called a growth or tumor. Tumors can be benign (non-cancerous) and malignant (cancerous). If these cancer cells break away from the tumor and enter the blood stream or lymphatic system and invade vital organs, it's said to be metastatic cancer.

Children develop cancer in the same body parts as adults. However, there are some common types in children. These more common types of childhood cancers are listed on the following page. [See Appendix 4 for a more detailed list with signs and symptoms of selected childhood cancers]

**Leukemias** are the most common

**Brain and other nervous system cancers** are the second most common

**Neuroblastoma** starts in certain types of nerve cells and occurs in infants and young children

**Wilms tumor** starts in one, or rarely, both kidneys and is most often found in children about 3 years old

**Non-Hodgkin and Hodgkin lymphomas** account for about 8% of childhood cancers. Hodgkin lymphoma is more common and occurs in early adulthood, usually people in their 20s

**Rhabdomyosarcoma** is the most common soft tissue tumor and accounts for about 3% of childhood cancers

**Primary bone cancers** occur most often in children and adolescents. Osteosarcoma is uncommon, accounting for almost 3% of all new childhood cancer cases. Ewing sarcoma is a less common primary bone cancer found in adolescents. It accounts for a little more than 1% of childhood cancer

# Childhood Cancer in the Tohono O'odham Nation

While examining cancer registry data for the Tohono O'odham Nation Cancer Plan it was discovered that data for childhood cancers was available for few cancer sites. The Cancer Planning Committee decided to address Children and Cancer as part of the overall plan. One of the major goals to put forward in relation to cancer and children is to increase the tracking of childhood cancers in the Tohono O'odham Nation. This goal will highlight future efforts to better understand the incidence of childhood cancer in the Tohono O'odham Nation youth. The following table explains the breakdown of the cancer sites in Tohono O'odham Nation children from 1995-2006.

Cancer In TON Children & Adolescents (less than 20 years) For Diagnosis Years 1995 - 2006			
Primary Site	Histology	Case Count	Cancer Type
Bone Marrow	Leukemia	3	Leukemia
Eye	Retinoblastoma	1	Retinoblastoma
Kidney	Nephroblastoma	1	Nephroblastoma
Brain	Meduloblastoma	1	Meduloblastoma
Foot	Sarcoma	1	Sarcoma
Lymph Node	Non-Hodgkin Lymphoma	1	Non-Hodgkin Lymphoma
Pancreas	Solid Carcinoma NOS	1	Pancreas
Skin	Melanoma	1	Melanoma Skin
Oral Cavity	Mucoepidermoid Carcinoma	1	Mucoepidermoid Carcinoma, Oral Cavity
Ovary	Serous Cystadenoma; Sertoli Cell	2	Ovary

## Youth Concerns

Youth are the future of the Tohono O'odham Nation and in the 2009 Cancer Education and Awareness Day the youth (mostly teenagers), attending this conference had a chance to

express their concerns surrounding cancer. Some concerns included limited access to cancer information, though access to the internet is available. However, some places in the Nation still do not have access to the internet. The attendees agreed that there is little cancer information in the schools and hardly any health information. The exception is STDs (Sexually Transmitted Diseases). Some teens mentioned that a good way to increase cancer awareness is through role-playing. There was a concern regarding general health and cultural factors among teens that affected their behavior. One example was that teens and pre-teens can stay physically fit by playing outside; however, other teen ‘peers’ perceive them as ‘kids’ and therefore many don’t continue their physical activities. Some of the most predominant health issues included diabetes, STDs, and early pregnancies, which are all risk factors to developing specific types of cancer in adult life.

The youth are also interested in getting more information of age-specific diseases and the type of support services that exist in their community. Teens expressed getting involved as health educators if incentives were offered. One of the key issues these teens had was how to best support a family member or parent when diagnosed with cancer or other disease.

## Emotional and Social Aspects of Childhood Cancer

Helping children to understand their feelings either as a cancer patient or as a family member is an important factor when an individual is newly diagnosed. It is also important to remember family values around coping, as each family is different; some traditional in the O'odham way, others believe in organized religion, or there may be other beliefs that people have.

[See Appendix 4 for general guidelines to follow to help children cope with a cancer diagnosis.]

Siblings of childhood cancer patients can feel lost or overlooked. Sometimes one or both parents may spend a lot of time in the hospital with the sick child. Sometimes siblings feel guilty about being healthy, feel resentful at their sibling for getting all of the parent's attention or feel angry, sad, anxious or lonely. Siblings should continue their daily school and other activities. It is important for parents to communicate with school personnel, friends, teachers, and coaches about the situation so they can provide support where appropriate.

[See Appendix 4 for general guidelines to help siblings cope with a brother or sister with cancer.]

## School Re-Entry

Returning to school may bring up fears from friends, teachers and other children. These fears may be due to missed schoolwork, social activities, changes in abilities and appearances, and a new routine.

Discuss any fears with the child before the beginning of school. Many hospitals or organizations provide re-entry school programs for children returning back to school after cancer treatment. Ask your treatment team if they know of such programs. Additionally, in order to reduce anxieties meet with school administrators to talk about your child's challenges and develop a re-entry plan. A parent or guardian is the most powerful advocate for a child. If necessary, ask your physician to write a letter outlining the child's physical limitations or physical needs.

# **Children and Cancer Goal, Objectives and Strategies**

**GOAL 6: Increase educational and support services for children affected by cancer.**

**Objective 6.1: Develop a list of resources for parents affected by a childhood cancer.**

**Strategies:**

1. Reach out to the community for current resources.
2. Interview human services agencies serving the TON.
3. Contact national cancer organizations for local access to their resources.

**Objective 6.2: Document how TON schools deal with children with cancer returning to school.**

**Strategies:**

1. Contact school administrators to see if there is a set policy or procedure for these events.
2. Contact school counselors or nurses to speak about their experiences of children with cancer re-entering school.
3. Document what each school is doing and note best practices that others can emulate.

**Objective 6.3: Develop bereavement support for children who lost a parent or loved one to cancer.**

**Strategies:**

1. Obtain information about establishing bereavement support.
2. Educate the cancer committee about bereavement support best practices.
3. Outline the components to be included in a bereavement support program.
4. Determine which agency will be responsible for providing bereavement support.

# CHAPTER 7

Selso Villegas, PhD-CHAIR  
Director  
Water Resources  
Tohono O'odham Nation

Sylvia Brown, PhD  
Native American Cancer Research Partnership  
Arizona Cancer Center  
University of Arizona

## ENVIRONMENT AND CANCER

*"Environmental health comprises those aspects of human health, including quality of life, that are determined by physical, chemical, biological, social, and psychosocial factors in the environment. It also refers to the theory and practice of assessing, correcting, controlling, and preventing those factors in the environment that can potentially affect adversely the health of present and future generations." -- World Health Organization*

Environmental health to the Tohono O'odham (O'odham) is the concept that if the Creation (the world we live in) and everything in it (the land, water, animals and plants) are healthy, then the O'odham are healthy.

Because there are very few documented Environmental Health assessments conducted on the Tohono O'odham Nation, the O'odham have used the "feeling of sickness" to explain their concerns about impacts on the lands and water.

For example, in 1995, the Nation requested assistance from the Agency for Toxic Substances and Disease Registry (ATSDR) to determine whether asphalt and petroleum products dumped in and around the Choulic gravel pit were health hazards. The O'odham in the area were scared that the cattle and wildlife in that area would become sick and in turn, the O'odham would get sick if they ate those animals. A road contractor dumped and covered about 17,000 cubic yards of asphalt and oil into the gravel pit area. Soil samples recovered in this area also revealed that diesel fuel was dumped with total petroleum hydrocarbons levels up to 2120 parts per million (ppm).<sup>15</sup> A consultant for the Nation estimated that it would take about five years for the pollution at the gravel pit to reach the groundwater.<sup>16</sup>

<sup>15</sup> Agency for Toxic Substances and Disease Registry. November 4, 1998. Petitioned Health Consultation, Choulic Gravel Pit (aka Baboquivari District), Tohono O'odham Nation, Pima County, Arizona, CERCLIS No. AZXCR167000.

<sup>16</sup> C.W. Stockton and Associates, Incorporated. August 4, 1994. A Preliminary Evaluation of possible ground water pollution from hydrocarbons suspected to be buried in a gravel pit located 2.8 miles east, southeast, of Choulic, Arizona, Tohono O'odham Nation.

The Tohono O'odham Utility Authority (TOUA) also found elevated levels of methylene chloride in surface water samples. Remediation involved the placement of fencing around the gravel pit area to keep the cattle and most wildlife out. The local O'odham considers the Choulic gravel pit area "a sick area".

The O'odham have endured a growing list of environmental concerns. The two active copper mines (Cyprus Tohono and ASARCO Mission) have caused the U.S. Environmental Protection Agency (EPA) to monitor impacts to the Nation's water resources and air quality. Archaic and unsafe mining practices have produced uranium and sulfate in the groundwater at Cyprus Tohono and adjacent areas. Dust pollution, sulfate contamination of groundwater, and the erosion of the tailing and dump structures are prevalent at ASARCO.

Although there are many examples of threats to the environment and the wellness of the O'odham, the focus of the Environment and Cancer Committee will be on the threat of arsenic in the public water systems on the Nation.

Arsenic concentrations in the water on the Nation range from a trace amount to 1000 parts per billion (ppb).<sup>17</sup> Most of the arsenic is incorporated in thick clay-rich basin-fill deposits throughout the Nation. Arsenic is a cumulative poison and is a carcinogen. The EPA maximum contaminant level (MCL) is 10 ppb. There are at least 23 communities on the Nation that have elevated levels of arsenic in their drinking water.

According to the TOUA, 17 of the 35 public water systems have arsenic levels at 10 ppb or higher.<sup>18</sup> The range of arsenic in these public water systems is from 10 ppb to 32 ppb. Although the range of arsenic on the Nation may be considered low when compared to other areas in the U.S. and Arizona, it is the opinion of the Environment and Cancer Committee that these levels may be linked to gastro-intestinal sickness and skin lesions and may be a precursor to cancer.<sup>19</sup>

<sup>17</sup> Kenneth J. Hollett and Joanne M. Garrett. 1984. Geohydrology of the Papago, San Xavier, and Gila Bend Reservations, Arizona 1978-81. Hydrologic Investigations Atlas HA-660. US Geological Survey.

<sup>18</sup> C.W. Stockton and Associates, Incorporated. August 4, 1994. A Preliminary Evaluation of possible ground water pollution from hydrocarbons suspected to be buried in a gravel pit located 2.8 miles east, southeast, of Choulic, Arizona, Tohono O'odham Nation.

<sup>19</sup> Personal Communication. July 2009. Jennifer Botsford, Office of Environmental Health, Bureau of Epidemiology and Disease, Arizona Department of Health Services. Phoenix, Arizona.

Additionally, a study has correlated arsenic exposure through drinking water with a higher prevalence of Type 2 diabetes.<sup>20</sup>

It is also the opinion of the Environment and Cancer Committee that all Americans, including the O'odham, are entitled to clean water under the Safe Drinking Water Act. Whether arsenic is linked to illness or cancer is not as critical as the fact that low-level chronic exposure to the human body is not a healthy thing. The Environment and Cancer Committee also has concerns about O'odham drinking water from private wells (not serviced by TOUA) in areas where the arsenic concentration in groundwater is over 10 ppb.

Currently, the TOUA and the EPA are using an arsenic pilot treatment plant at the public water system with 33 ppb. The iron oxide adsorption water treatment at this public water system has reduced the arsenic level to less than 1 ppb.<sup>21</sup> This type of remediation or an alternate source of water that complies with the arsenic standard is needed at the seventeen other public water systems. The Nation's Department of Water Resources (DWR) and the IHS are actively searching for water sources with arsenic concentrations below 10 ppb to supply the arsenic affected areas.

It is the recommendation of the Environment and Cancer Committee that the Centers for Disease Control and Prevention (CDC) and its sister agency the ATSDR conduct an environmental health consultation with the Nation concerning the arsenic in the drinking water. It is also recommended that the CDC and ATSDR use their public health authority and influence to help the Nation obtain federal funding for well drilling, pipeline construction, and the purchase of additional arsenic water treatment facilities so all public water systems have drinking water that meets EPA's standard for arsenic.

<sup>20</sup> Ana Navas-Acien, Ellen K. Silbergeld, Roberto Pastor-Barriuso, and Eliseo Guallar. 2008. Arsenic exposure and prevalence of Type 2 diabetes in US adults. Journal of the American Medical Association 2008;300(7):814-822.

<sup>21</sup> Personal Communication. July 2009. Myrt McIntyre, Water and Wastewater Department, Tohono O'odham Utility Authority, Sells, Arizona.

# **Environment and Cancer Goal, Objectives and Strategies**

**GOAL 7: To enhance the knowledge of the O'odham about environmental risk factors.**

**Objective 7.1: Develop an arsenic water and soil Geographic Information System (GIS) database.**

**Strategies:**

1. Analyze the soil for arsenic at selected sites with elevated levels of arsenic in the groundwater.
2. Analyze the soil for arsenic at selected sites with little or no levels of arsenic in the groundwater.
3. Enter arsenic groundwater and soil data into the GIS database.

**Objective 7.2: Develop a baseline for arsenic in the groundwater and soil on the Nation.**

**Strategies:**

1. Develop an average baseline measure for arsenic in the groundwater on the Nation.
2. Develop an average baseline measure for arsenic in the soil on the Nation.

**Objective 7.3: Conduct an environmental health consultation with the ATSDR.**

**Strategies:**

1. Support the cooperation between the Nation's DWR and the ATSDR to conduct an environmental health consultation for the Nation.
2. Help the DWR draft a letter of request for an environmental health consultation from the Nation's Executive Office to the ATSDR.

**Objective 7.4: Determine the health risk of arsenic on the Nation.**

**Strategies:**

1. Obtain a health risk assessment on arsenic on the Nation from the ATSDR after the environmental health consultation is completed.

**2009 CANCER EDUCATION & AWARENESS DAY**



*Sharing Our Stories of Hope*

**JUNE 13, 2009**

10:00 a.m. to 5:00 p.m.

**Sells Recreation Center**

**Registration starts @ 9:15 a.m.**

Please contact your districts for transportation.

For questions related to this event, please contact Teresa Wall @ (520) 383-6200.



**The Leukemia &  
Lymphoma Society**  
Fighting Blood Cancers

**ARIZONA  
CANCER  
CENTER**

A Special Thanks to the  
Tohono O'odham Nation's Districts  
for their support.



ARIZONA CANCER COALITION



**SUSAN G.  
KOMEN  
FOR THE CURE**  
SOUTHERN ARIZONA



# 2009 CANCER EDUCATION & AWARENESS DAY



**Sharing Our Stories of Hope**



# A Special Thanks to the Following:

**Dr. Louise Canfield**  
Representing the Director  
Arizona Cancer Center/University of Arizona  
Tucson, AZ

**Juana Casillas**  
Manager  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

**Annie Fair, MSW, MPH**  
CAPT, U.S. Public Health Service  
Tribal Liaison, CDC/NCCDPHP/DCPC  
Phoenix, AZ

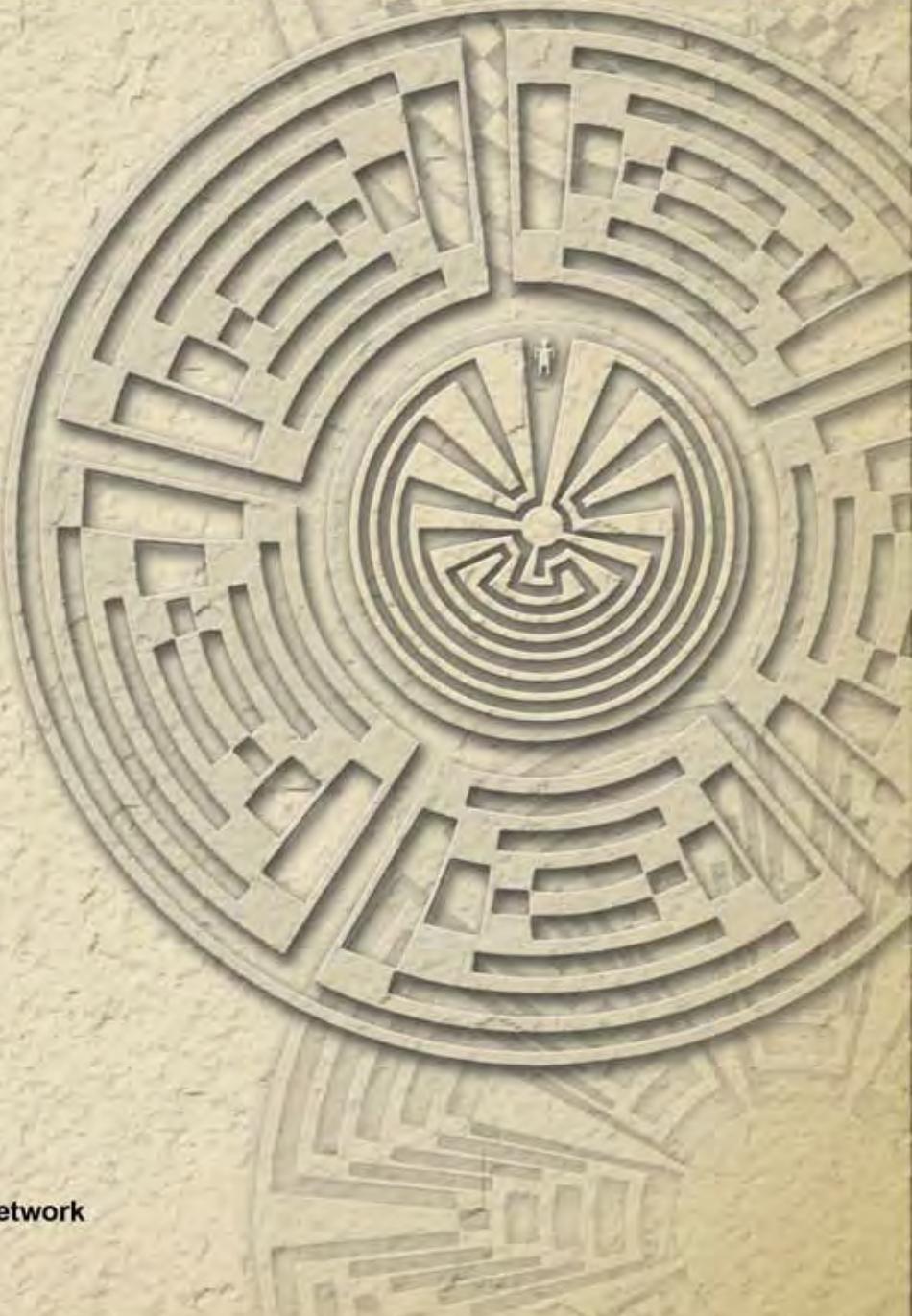
**Julie Encinas-CHR**  
Community Health Representative Program  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

**Norma Gonzales-CHR**  
Community Health Representative Program  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

**Mary Hoffman-CHR**  
Community Health Representative Program  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

**Kenton Laffoon**  
Program Director  
Southwest American Indian Collaborative Network  
Inter Tribal Council of Arizona  
Phoenix, AZ

**Rosemary Lopez**  
Deputy Director  
Department of Health and Human Services  
Tohono O'odham Nation



## A Special Thanks to the Following:

**Andrew Lorentine**  
Assistant Manager  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

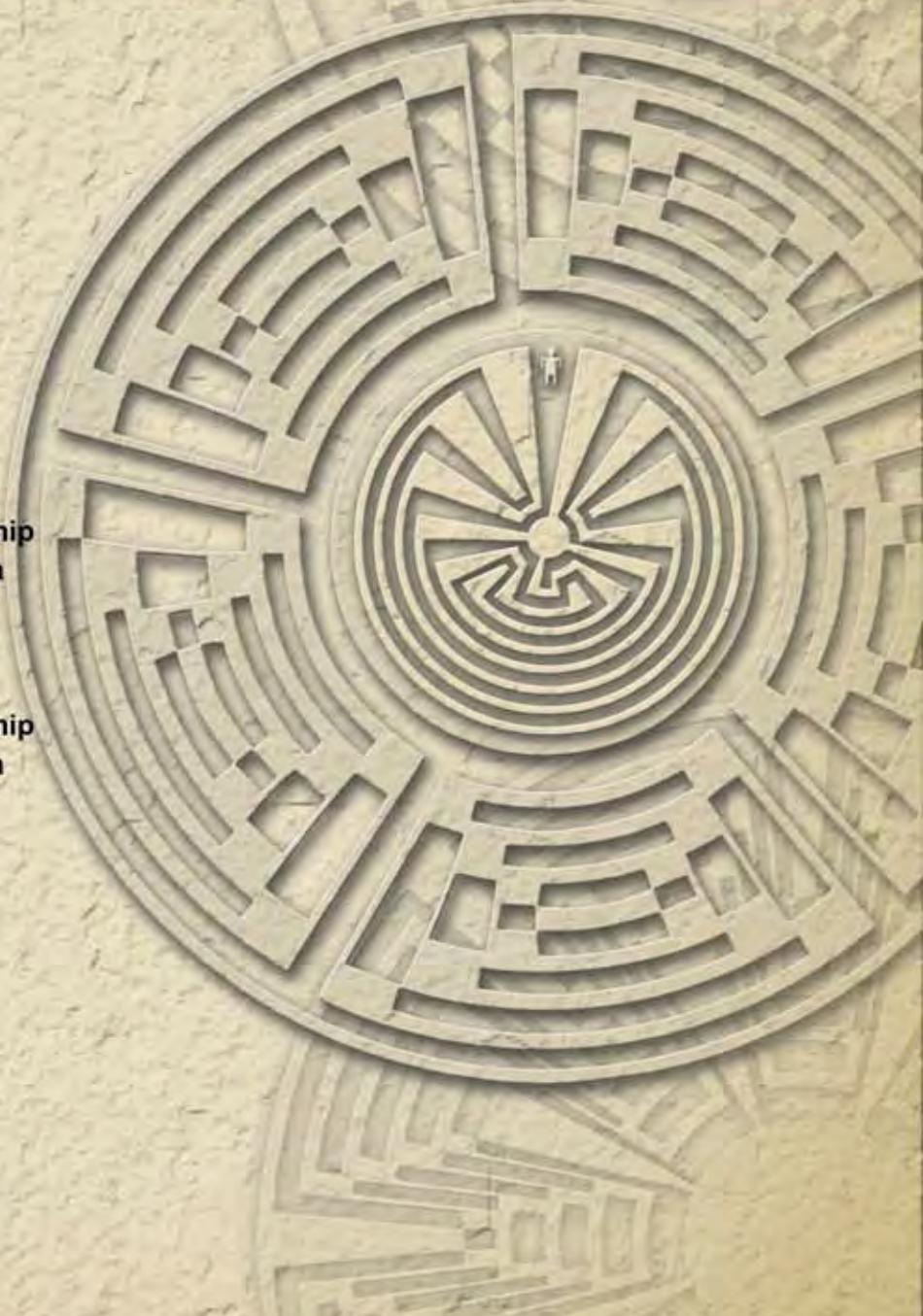
**Marietta Martin**  
Program Development Manager  
Department of Health and Human Services  
Tohono O'odham Nation

**Stewart Noceo-CHR**  
Community Health Representative Program  
Division of Community Health Services  
Department of Health and Human Services  
Tohono O'odham Nation

**Dr. Jesse Nodora**  
Native American Cancer Research Partnership  
Arizona Cancer Center/University of Arizona  
Tucson, AZ

**Jennifer Prissel**  
Native American Cancer Research Partnership  
Arizona Cancer Center/University of Arizona  
Tucson, AZ

**Virginia Warren**  
Community Services Office Chief  
Bureau of Health Systems Development  
Arizona Department of Health Services  
Phoenix, AZ

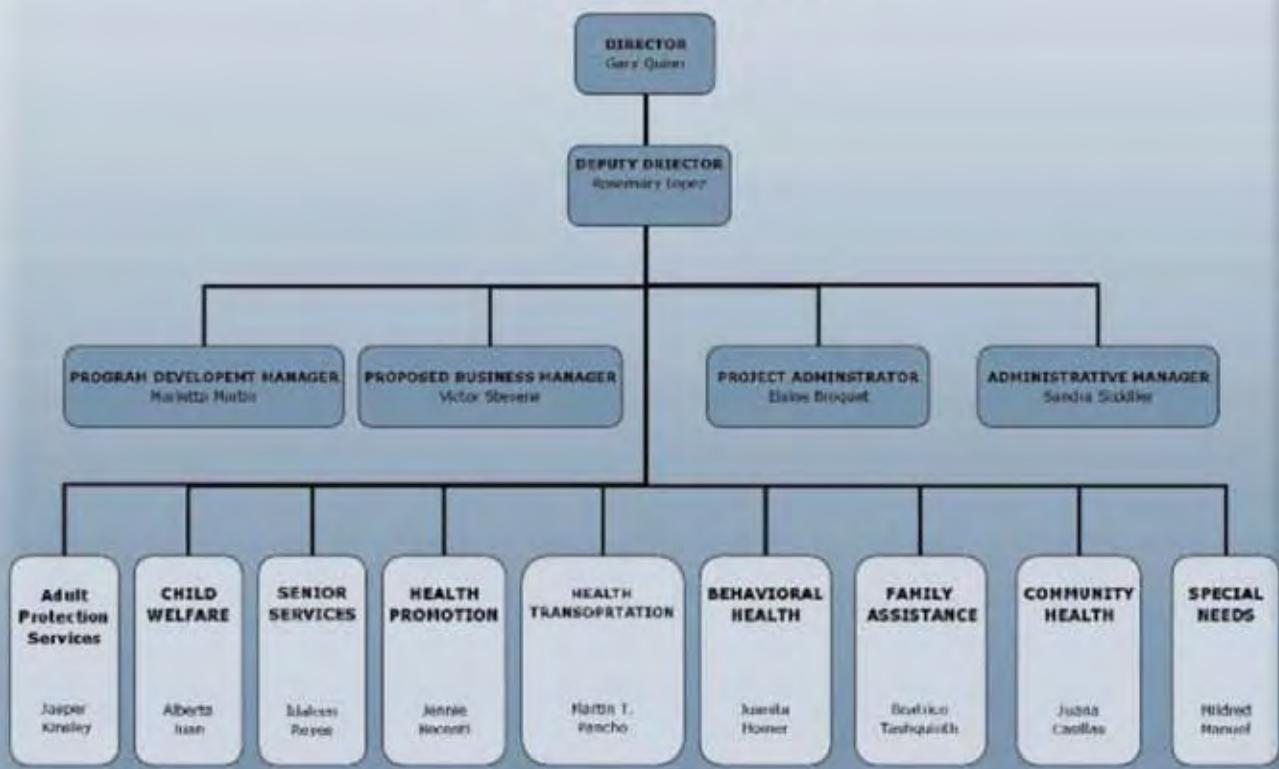


# Table of Acronyms and Definitions

Acronym	Definition
ACCCP	Arizona Comprehensive Cancer Control Plan
ACR	Arizona Cancer Registry
ACS	American Cancer Society
ADHS	Arizona Department of Health Services
AHCCCS	Arizona Health Care Cost Containment System
AI/AN	American Indian/Alaska Native
ATSDR	Agency for Toxic Substances and Disease Registry
BRFSS	Behavioral Risk Factor Surveillance System
CDC	Centers for Disease Control and Prevention
CHA	Community Health Assessment
CMS	Centers for Medicare and Medicaid Services
CPC	Cancer Planning Committee
DNA	Deoxyribonucleic Acid
DRE	Digital Rectal Examination
DWR	Tohono O'odham Nation Department of Water Resources
EHR	Electronic Health Record
EPA	Environmental Protection Agency
FOBT	Fecal Occult Blood Test
GIS	Geographical Information System
GPRA	Government Performance and Results Act
HepB	Hepatitis B Virus
HOPP	Healthy O'odham Prevention Program
HPV	Human Papilloma Virus
IHS	Indian Health Service
IPC	Innovations in Patient Care
MCL	Maximum Containment Level
NMTR	New Mexico Tumor Registry
NHW	Non-Hispanic- White
NIH	National Institutes of Health
PPB	Parts per Billion
PSA	Prostate-specific Antigen
RPMS	Resource Patient Management System
SEER	Surveillance Epidemiology & End Results program, National Institute of Health
SPF	Sun-protective Factor
TOCA	Tohono O'odham Community Action
TODHHS	Tohono O'odham Department of Health & Human Services
TON	Tohono O'odham Nation
TOUA	Tohono O'odham Utility Authority
USPST	United States Preventive Services Task
UVA	Ultraviolet A
UVB	Ultraviolet B
UV	Ultraviolet Radiation
USPSTF	United States Preventive Services Task Force

# Appendix 1

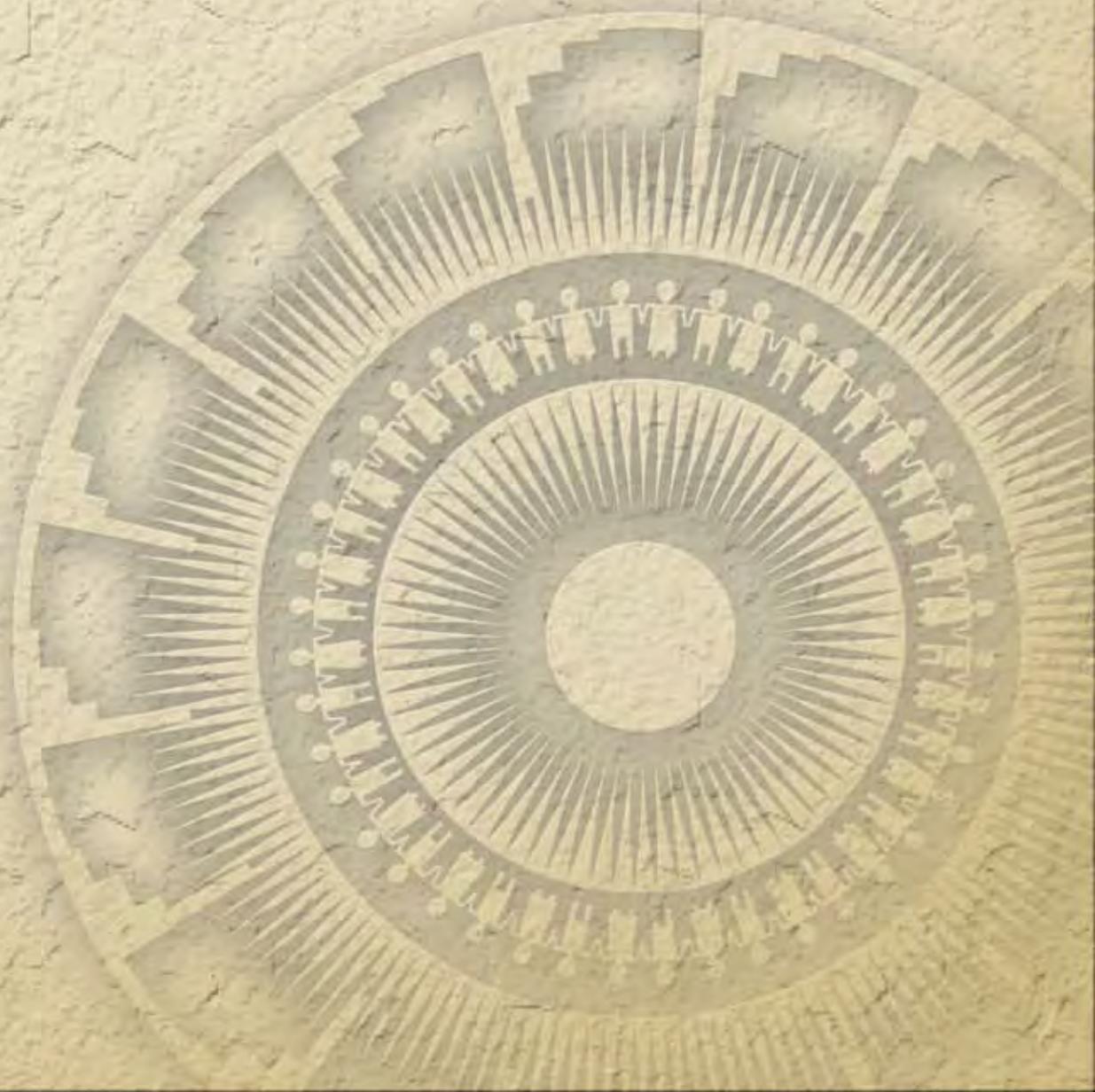
## Tohono O'odham Nation Department of Health and Human Services Management of Health



## Appendix 2

# Report on Breast, Cervix, Prostate and Colon/Rectal Cancer Screening In the Tohono O'odham Nation Population

Report to the Tohono O'odham Nation  
Joseph B. Hawes MD, MPH  
Senior Medical Epidemiology Consultant



# **TON CANCER SCREENING CASE - IDENTIFICATION**

## **INTRODUCTION:**

The Tohono O'odham Nation (TON) obtained a Cancer Planning grant in June 2007 to evaluate the burden of four selected cancers; breast, cervix, prostate and colorectal on the TON population. The principal objectives of this planning exercise were to: determine the screening rates for breast, cervical, colorectal and prostate cancer for the period 2005-2007; determine the prevalence of these four cancers within the Tohono O'odham Nation population for this period and establish the stage at diagnosis of these cancers and outcomes as they relate to the treatment and management of these cancer patients. This is a report on the exercise at determining cancer screening rates only.

Decision-makers who set health policies and manage prevention and cancer control programs are committed to the goals of reducing cancer-related morbidity and mortality and improving the populations' health and quality of life. Primary prevention, through health education and health promotion, and intervention through early detection and treatment represent the most appropriate approach to preventing the morbidity and mortality associated with cancer occurrence. Screening for the presence of cancer is the fundamental methodology applied to early detection.

This document reports the findings of a preliminary effort to utilize available data from Indian Health Services to identify TON patients screened for breast, cervical, colorectal and prostate cancer with the objective of determining the screening rate for each cancer. Of importance, approximately nine O'odham communities exist in Mexico, proximate to the southern edge of the Tohono O'odham Nation, separated by the United States/Mexico border. Thus, in the consideration of researching health outcomes and the planning of efforts to promote prevention and control for the Tohono O'odham Nation population, TON communities residing in Mexico should be included.

## **BACKGROUND:**

The collection and reporting of National and State screening counts and rates in the United States are heavily dependent on information generated through the Behavioral Risk Factor Surveillance System (BRFSS) self report data set. A review of the 2002 – 2006 Arizona BRFSS report revealed no information on TON members. This meant that at the state level, there was no data set available as a source for identifying TON cancer screening cases.

The New Mexico Tumor Registry (NMTR), a regional data source, has been contracted by National Institutes of Health Surveillance Epidemiology and End Results (SEER) program to collect and abstract cancer cases from Indian Health Service (IHS) facilities within Arizona and New Mexico. This registry operates and maintains a population-based cancer registry for the entire state of New Mexico and the American Indian population of Arizona. Its registry routinely collects health information from the Sells, San Xavier and Santa Rosa clinics. Review of the New Mexico Tumor Registry data set revealed that there was no published information (including cancer screening) available on Native American Indians living in Arizona.

The Tohono O'odham Nation (TON) IHS system provides only primary care services (including some screening services) through its clinics of Sells, San Xavier, Santa Rosa and San Simon.

Not all TON members utilize the services provided through this health care system, as some, with private insurance and public insurance, often opt to use the services of private non-IHS providers. In addition, the TON Indian Health Service contracts out all medical care services associated with cancer diagnosis, treatment and management, to medical facilities operating within the state. All contract service providers ultimately bill the IHS according to the type of service provided. This makes administrative data sets a potential source for enhancing surveillance capacity for identifying screening cases outside of the IHS medical service system.

- 2. Must be alive on the last day of reporting period**
- 3. Must be American Indian or Alaska Native**
- 4. Must have had two visits to medical clinics in the past three years. At least one visit must be to one of the following core medical clinics: 01 General, 24 Well Child, 06 diabetic, 28 Family Practice, and 10 GYN, 57 EPSDT, 12 Immunization, 70 Women's Health, 13 Internal Medicine, 80, Urgent Care, 20 Pediatrics, 89 Evening.**

The second visit is either to one of the core medical clinics listed above or to one of the following additional medical clinics: 02 Cardiac, 37 Neurology, 03 Chests And TB, 38 Rheumatology, 05 Dermatology, 49 Nephrology, 07 ENT, 50 Chronic Disease, 08 Family Planning, 69 Endocrinology, 16 Obstetrics , 75 Urology , 19 Orthopedic , 81 Men's Health Screening, 23 Surgical, 85 Teen Clinic, 25 Other , 8 Sports Medicine , 26 High Risk , B8 Gastroenterology – Hepatology, 27 General Preventive, B9 Oncology – Hematology, 31 Hypertension , C3 Colposcopy, 32 Postpartum.

### **General Clinic User Population**

- 1. As is stipulated in 1-3 above**
- 2. Must have been seen at least once in the three years prior to the end of the report period at any one of the three clinics, regardless of visit type.**

In the determination of cancer screening cases for breast, cervical and colorectal cancer, the GPRA Active Clinical population requirement was used and not the general clinic user population. The general clinic user population counts random visits for minor ailments and non-medical care and it was felt that such type of visits seldom represent an opportunity to provide primary care prevention services.

## Procedure:

The IHS Resource and Patient Management System (RPMS) is a comprehensive integrated health information system that supports the patient care service provided through the IHS system. The decision was made to develop a methodology for identifying the subset of patients within this system who received cancer screening care services for breast, cervical, colorectal and prostate cancer over the period 2005-2007.

In conjunction with IHS program personnel, first with Mr. David Hatton, and later with Dr. Karen Higgins a data extraction program was developed to identify patients receiving cancer screening services within the IHS clinical care service system. Due to confidentiality issues associated with the use of patient records all aspect of the identification process that involved patient information was handled by the IHS data personnel. Data without patient identifiers were generated and this was reviewed to identify potential patients that received cancer screening services.

The queries run were patterned after Government Performance and Results Act (GPRA) queries, using ICD9 diagnostic classification codes, CPT procedure codes, and selected Lab codes to capture all cancer-screening visits made to the Sells, San Xavier and Santa Rosa clinics. Because this review process focuses on cancer screening cases identified for the period 2005- 2007, the San Simon clinic, established after 2007, was not included. Unfortunately prostate cancer is not covered in GPRA performance report guidelines. For the identification of prostate cancer screening cases, a QMN search was carried out using PSA codes in CPT and diagnostic codes in ICD9 systems. The logic implemented was designed to closely mirror GPRA logic.

Data generated through these queries were reviewed to determine completeness and capacity to generate information on cancer screening cases for TON population.

Because of time constraints it was not possible to refine the data extraction tool, thus, the data used in this analytic process represent those data generated through phase 1 of the 5 phase methodological process described above. Potential cancer screening patients identified were tabulated and analyzed to determine the percentage of patients eligible for screening that were seen at the clinic and actually received a screening test. The findings of this exercise are presented below.

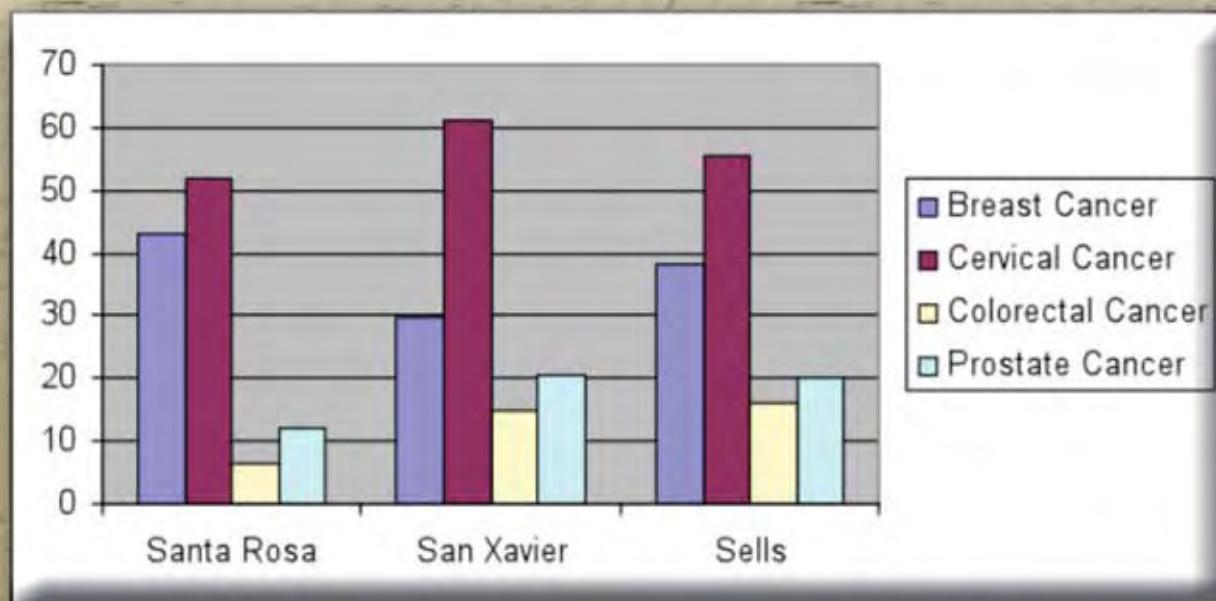
#### FINDINGS:

##### General Findings:

The percentage of eligible population screened was highest for cervical cancer at all clinics while the percentage screening rates for prostate and colorectal cancer were low at all clinics (Fig. 1).

Fig. 1

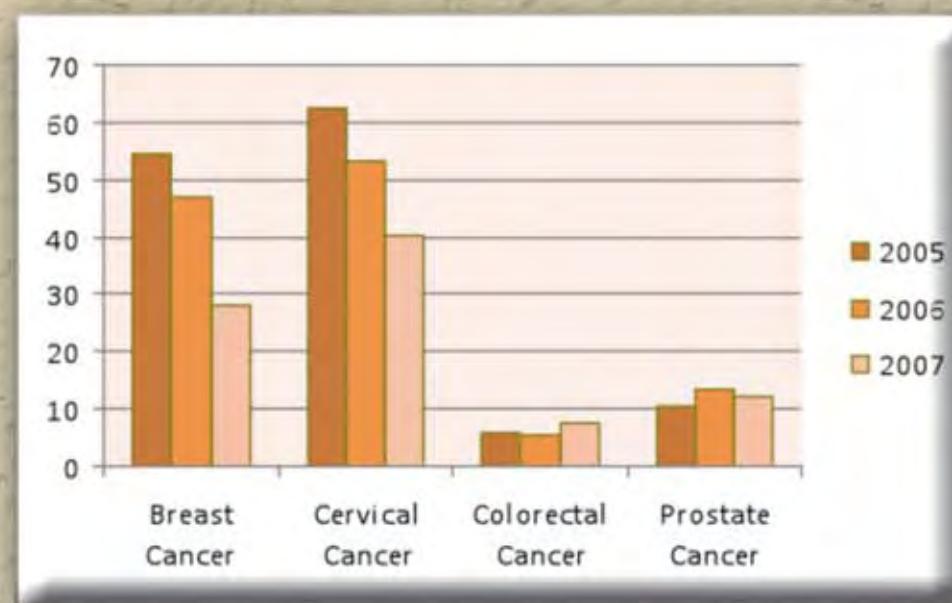
Percentage of Eligible Population Screened for Each Cancer by Clinic



**Findings for individual cancers:**

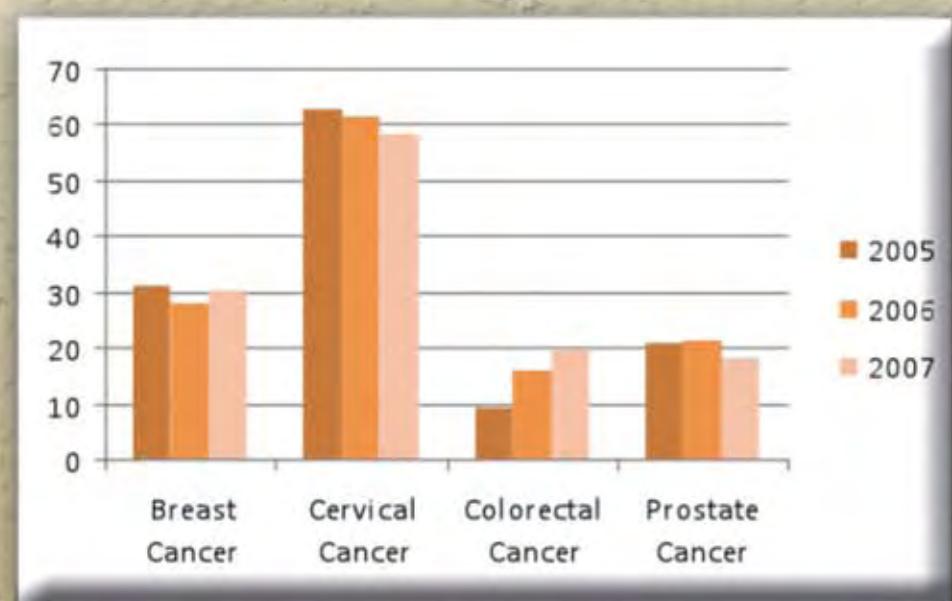
**Percentage of Eligible Population Screened for All Cancers at Santa Rosa Clinic by Year**

**Fig. 2 Santa Rosa Clinic**



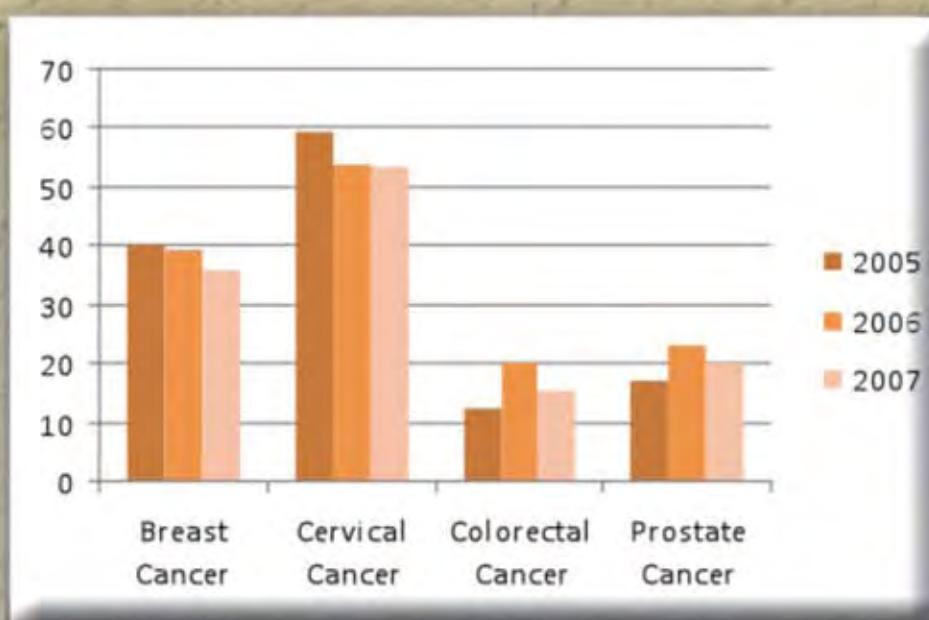
**Percentage of Eligible Population Screened for All Cancers at San Xavier Clinic by Year**

**Fig.3 San Xavier Clinic**



**Percentage of Eligible Population Screened for All Cancers at Sells Clinic by Year**

**Fig. 4 Sells Clinic:**



**Breast and Cervical cancer screening;**

Breast cancer screening (Fig.1-4 above and Table 1 in appendix ), using 2005 as the base year, shows that 54%, 31% and 40% of patients eligible for screening received screening test from the Santa Rosa, San Xavier and Sells clinics, respectively. For 2007, while the percentage screening rate of the San Xavier and Sells clinics remained about the same, the value for Santa Rosa showed a 16% decline; approaching a value comparable to that seen at the San Xavier and Sells clinic. According to a 2008 GPRA report, 40% of overall eligible clinic patients received a Mammogram screening test.

Cervical cancer screening (Fig.1-4 and Table 2), again using 2005 as the base year, shows that on the average 60% of patients eligible for screening received screening test from Santa Rosa, San Xavier and Sells clinics. As was the case with breast cancer, the 2007 percentage screening rate at the Santa Rosa Clinic declined 20%. According to a 2008 GPRA report, 54% of overall eligible clinic patients received a screening test.

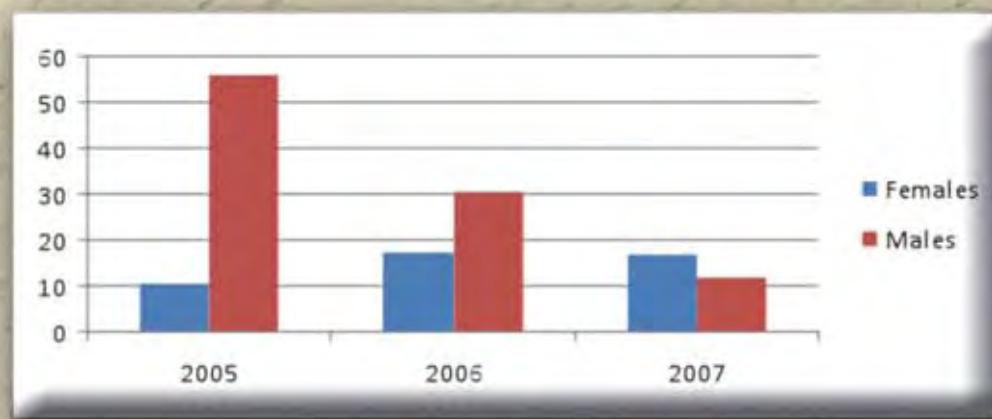
## **Prostate cancer screening**

### **Prostate Cancer**

As indicated above, the methodology used in the identification of cancer screening for prostate cancer was different from that applied in the case of our other cancers. The finding here reflects a low population of male clinic users when compared to female clinic user population recorded for cervical and breast cancers. The number of patients screened ranged from 10% to 20% of the male population seen at the clinic. (Fig. 1-4 and Table 5)

**Percentage of Eligible Population Screened  
For Colo/Rectal Cancer Each Year by Gender**

**Fig. 5**



### **Colo/Rectal cancer screening;**

Screening for colo/rectal cancer provides us with a window of opportunity for comparing cancer screening test rates between male and female users of the clinic services (Fig. 5).

For colorectal cancer, the value of the percentage of eligible patients that received a screening test was the lowest for all cancers reviewed. Colorectal cancer screening test rates for the Santa Rosa, San Xavier and Sells clinics ranges from a high of 15% to a low of 6% (Fig.1- 4). While the overall active female clinic population users was almost twice the number of males, the average percentage screening rate for males was twice that of females (Fig.1-5 and Table 3 &4).

## **DISCUSSION:**

Although these findings represent an analytic review of the first phase data extraction effort, they nonetheless provide the opportunity for making some comments in terms of their potential implications for: cancer screening rates in the Tohono O'odham Nation (TON) population; the development of cancer prevention efforts; and the determination of the magnitude of the existing cancer burden. In the interpretation of these findings one must be cognizant of the fact that they do not represent members of the TON population residing in Arizona who do not use IHS medical care services, nor do they represent the population of TON members residing in Mexico.

The findings of this report are generated from a review of patients recorded as having received a cancer screening test and really consist of two distinct categories of patients. One category is made up of asymptomatic individuals self referring or referred by the medical officer because of age or family history for screening test (true number of patients screened). The other category consists of individuals reporting to the medical services with suspected early symptoms or signs of cancer who were then subjected to a diagnostic screening test.

In order to realize the preventive benefits of screening and early intervention, to make meaningful prediction for targeted screening goals, and for the planning and development of intervention strategies to improve screening rates, it is imperative to be able to distinguish between these two categorical populations of patients. The first step toward decreasing the morbidity burden of cancer is that of increasing the population of patients in the category of asymptomatic screening pool while decreasing the category of patients receiving diagnostic screening tests.

By only analyzing patients using the IHS services one will miss counting patients receiving the screening tests outside of the IHS clinical care services as well as miss counting individuals who are eligible for consideration in the denominator of the rates generated.

The cancer screening rates in this report, as well as those in the GPRA reports, do not represent the true screening rates for the Tohono O'odham Nation population. In addition, these rates are really more representative of a measure of the IHS clinical care services function rather than the capacity of its existing primary care services of health education and health promotion to provide primary care preventive services.

Notwithstanding these shortcomings the findings of a small male clinic user population when compared to the female users, suggest a need to develop strategies that will increase the number of male users of the medical care services. Despite the presence of a low male clinic utilization rate the fact that only a low of 10% to a high of 20% of the male population seen at the clinic were screened for prostate cancer suggests that there is room for improvement both in terms of the number of males using the clinics as well as the percentage of male patients receiving screening tests. Given that GPRA data reflects all patients who received or refused screening tests, and there were no recorded cases of refusal, one can assume that all patients who were offered a screening test accepted. This suggests that care givers can play a meaningful part in increasing the number of patients who receive screening test.

The colorectal cancer screening findings provide us with an opportunity to make some assumptive comparisons on the rate of cancer screening for a given cancer based on gender. The finding in colorectal results is that while the population of female clinic users was almost twice that of the male users, the average percentage screening rate for males was twice that of females. Based on clinical practice and public health practice experience, a plausible explanation of this finding is that perhaps male clinic visits were for suspected symptoms which required diagnostic screening testing.

## **Conclusion:**

It is recommended that this review process be carried forward in order to improve its accuracy as well as the adequacy of information on breast, cervical, colorectal and prostate cancer screening rates in the Tohono O'odham Nation (TON) population. Consideration should be given to conducting inter- IHS data set linkages and cross tabulation matching with TON tribal population demographic data. The information generated through this kind of a review process should focus on the identification of needs within the existing IHS primary health care system.

## **Appendix 1**

### **TABLES**

#### ***Tabulated data of results:***

**Table 1 Breast Cancer Screening**

#### **Santa Rosa**

Year	Population	# Screened	Percentage screened
2007	216	61	28.2
2006	211	99	46.9
2005	223	121	54.3
Total	650	281	*43.2

#### **San Xavier**

Year	Population	# Screened	Percentage screened
2007	1,051	317	30.2
2006	1,007	285	28.3
2005	971	303	31.2
Total	3,029	905	*29.9

#### **Sells**

Year	Population	# Screened	Percentage screened
2007	998	356	35.7
2006	971	381	39.2
2005	939	376	40.0
Total	2908	1113	*38.3

#### **Population identification**

**GPRA Population denominator:** All females 40 years and over without a documented history of mastectomy. **GPRA Population numerator:** All patients without a mammogram in past two years and patients with a documented refusal.

\* Average percentage

**Table 2 Cervical Cancer Screening****Santa Rosa**

Year	Population	# Screened	Percentage screened
2007	323	130	40.2
2006	321	171	53.3
2005	344	215	62.5
Total	988	516	*52

**San Xavier**

Year	Population	# Screened	Percentage screened
2007	2,062	1,208	58.6
2006	2,062	1,269	61.5
2005	2,021	1,272	62.9
Total	6,145	3,749	*61

**Sells**

Year	Population	# Screened	Percentage screened
2007	1,628	870	53.4
2006	1,569	846	53.9
2005	1,554	925	59.5
Total	4,751	2641	*55.6

**GPRA Population denominator:** All active female clinic patients aged 21 through 64 years without a documented history of hysterectomy. **GPRA Population numerator:** Patients with Pap smears documented in past 3 years including refusals in past year.

**Table 3 Colo/Rectal Cancer Screening****Santa Rosa**

Year	Population	# Screened	Percentage screened
2007	222	17	7.7
2006	221	12	5.4
2005	232	14	6.0
Total	675	43	*6.37

**San Xavier**

Year	Population	# Screened	Percentage screened
2007	775	152	19.6
2006	729	118	16.2
2005	679	63	9.3
Total	2183	333	*15.03

**Sells**

Year	Population	# Screened	Percentage screened
2007	991	154	15.5
2006	937	189	20.2
2005	931	114	12.2
Total	2859	457	*15.97

**GPRA Denominator (population): All active clinical patients 50 years and over without a documented history of colorectal cancer or total colectomy.**

**GPRA Numerator:** Patients who have had any of the following CRC screening, defined as: 1) Fecal Occult Blood test (FOBT) during the Report period; 2) flexible sigmoidoscopy (FSC) or double contrast barium enema (DCBE) in the past 5 years; or 3) colonoscopy (CS) in the past 10 years; or 4) a documented refusal in the past year.

**Table 4 Colo/Rectal Cancer Screening by Gender****Females**

Year	Population	# Screened	Percentage screened
2007	1272	216	16.9
2006	1227	214	17.4
2005	1180	122	10.3
Total	3679	552	*15.0

**Males**

Year	Population	# Screened	Percentage screened
2007	716	85	11.8
2006	660	200	30.3
2005	662	377	56.9
Total	2038	662	*32.5

**GPRA Denominator (population): All active clinical patients 50 years and over without a documented history of colorectal cancer or total colectomy – broken out by gender.**

**GPRA Numerator: Patients who have had any of the following CRC screening, defined as: 1) Fecal Occult Blood test during the Report period; 2) flexible sigmoidoscopy or double contrast barium enema in the past 5 years; or 3) colonoscopy in the past 10 years; or 4) a documented refusal in the past year - broken out by gender.**

**Table 5 Prostate Cancer Screening**

Santa Rosa	Year	Population	# Screened	Percentage screened
	2007	146	18	12.3
	2006	149	20	13.4
	2005	151	16	10.6
	Total	446	54	*12.1

San Xavier	Year	Population	# Screened	Percentage screened
	2007	227	42	18.5
	2006	204	44	21.5
	2005	200	42	21.0
	Total	631	128	*20.33

Sells	Year	Population	# Screened	Percentage screened
	2007	677	136	20.1
	2006	682	158	23.2
	2005	695	130	16.9
	Total	2054	424	*20.07

Denominator: TON males > 49 years seen at least 1 time in the calendar year. Numerator: Tohono O'odham male age greater than 49 years screening by: PSA, CPTS & ICD9 codes

## **Appendix 3**

# **Analysis of Tohono O'odham Nation Cancer Cases Diagnosed From 1995-2006**



**Arizona Cancer Registry  
Office of Health Registries  
Bureau of Public Health Statistics  
150 North 18th Avenue Suite 550  
Phoenix, Arizona 85007  
(602) 542-7320**



**Janice K. Brewer, Governor  
State of Arizona**

**Will Humble, Interim Director  
Arizona Department of Health Services**

**Permission to quote from or reproduce materials from this publication is granted when  
due acknowledgement is made.**

## **Analysis of Tohono O'odham Nation Cancer Cases**

**Diagnosed From 1995-2006**

### **Co-Authors:**

**Chris Newton, MPA  
Epidemiologist  
Arizona Cancer Registry**

**Timothy J Flood, M.D.  
Medical Director  
Bureau of Public Health Statistics**

**We wish to acknowledge the New Mexico Tumor Registry and the Indian Health Service for providing the data from Indian Health Service facilities through a trilateral data exchange agreement with the Arizona Cancer Registry.**

**We also thank Georgia Yee, Chief of the Office of Health Registries, Bureau of Public Health Statistics, Arizona Department of Health Services, for help with the editing of this report.**

**The Centers for Disease Control and Prevention provides enhancement funds under cooperative agreement 5U58DP000796 awarded to the Arizona Cancer Registry. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention.**

**Notice: The Arizona Department of Health Services does not discriminate on the basis of disability in the administration of its programs and services as prescribed by Title II of the Americans with Disabilities Act of 1990 and Section 504 of the Rehabilitation Act of 1973.**

**If you need this publication in an alternative format, please contact the ADHS Arizona Cancer Registry at (602) 542-7320.**

## Introduction

To identify and describe Tohono O'Odham Nation (TON) cancer cases, this analysis reviews all invasive cancer cases<sup>22</sup> classified as Arizona residents and American Indians diagnosed in the years 1995 through 2006. A total of 4,480 American Indian invasive cases are identified. From this total, TON cases were selected. As described below, in Table 1, the estimate of TON cases totaled 341 (7.6% of all American Indian cases). This analysis will: 1) Compare primary site incidence for all cases combined and all male and female cancer cases between TON member cases and all Arizona resident cases; 2) Analyze selected primary sites by age group and sex for TON member cancer cases; 3) Compare SEER summary stage between TON members and all Arizona resident cancer cases; 4) Analyze TON member cancer vital status; 5) Compare TON cancer survival with all Arizona residents cancer survival; and 6) Review the last three years of available cancer data for primary site incidence of cases diagnosed in the years 2004 -2006 for all cancer cases combined and the top 5 male and female cancer sites.

**Table 1**

Tribe Affiliation (TON or Other) of Arizona Resident American Indian (AI) Cases		
Tribe Affiliation	Case Count	Pct of AI Cases
Presumed Tohono O'Odham	341	7.6
Other or Unknown Tribe	4,139	92.4
Total	4,480	100.0

### Sources of TON Cancer Cases

The Arizona Cancer Registry (ACR) receives most of its case reports from Arizona licensed hospitals, clinics, doctors, and pathology laboratories. State statute requires that all cancer cases from these facilities be reported. Case reports are also received from New Mexico Tumor Registry (NMTR). The NMTR has been contracted by National Cancer Institute's Surveillance

<sup>22</sup>Invasive cancer cases include in situ bladder cases

the NMTR to share IHS cancer cases with the ACR. The NMTR also does linkages between the ACR data and IHS enrollment data to provide tribe information for cases with no tribal identification. This agreement also allows the ACR to share American Indian cancer cases seen at Arizona health care facilities with the IHS and NMTR for their analysis of the complete American Indian cancer burden in Arizona and New Mexico. NMTR case collection helps to provide a more complete picture of cancer among the TON specifically and American Indians generally. Other sources of case reports are death certificates, military installations in Arizona and case exchanges with 21 state central registries throughout the United States. In the past Veterans Administration (VA) hospitals have been a source of cases for the ACR. At present the ACR is not receiving cases from VA hospitals in Arizona. As a result case counts for American Indians and non-American Indians alike, during the years 2005 and 2006, may be affected.

### **Methodology of Tribal Case Identification**

For this analysis, Tohono O'Odham (TON) member cancer cases were defined by identified tribal affiliation or place of residence as TON members live both in-TON tribal communities as well as outside of them. The ACR did not have access to tribal rolls that would have allowed definitive identification of TON membership. Instead, the ACR makes the presumption that persons meeting the criteria listed in the following three paragraphs are TON members.

The ACR master data contains tribal affiliation on 59 percent of American Indian cases (See Table 2). Tribal affiliation was used to identify 289 (84.8%) of the 341 TON member cases (See Table 3). The tribal identification was abstracted from IHS medical records and coded by the New Mexico Tumor Registry abstractors when available in the IHS medical record or abstracted from Arizona death records when tribal affiliation was listed.

If a case lacked tribal affiliation, the ACR counted the case as a TON member if it had an American Indian race code, unknown tribal code, and resided in one of five zip code areas. These five zip codes were identified as areas in which cancer cases with an American Indian race code would most likely be TON members. These zip codes were: 85321 – Ajo; 85337 – Gila Bend; 85634 – Sells; 85639 – Topawa; and 85746 – San Javier. Cases from these zip codes with an unknown tribal affiliation accounted for 15.2 percent (52 cases) of total TON member cases. The TON member case count included 289 cases with a tribe code indicating TON and 52 cases with an unknown tribe affiliation that lived in one of the five identified TON zip codes (See Table 3). When the tribal code identified cases that were a tribe other than TON and living in the five identified TON zip codes (38 cases), the cases were excluded from the analysis.

**Table 2**

Tribe Affiliation (known or unknown) For Arizona Resident American Indian (AI) Cases		
Tribe Identified	Case Count	Pct of AI Cases
Known Tribe ID	2,644	59.0
Unknown Tribe ID	1,836	41.0
Total	4,480	100.0

**Table 3**

Tribe Affiliation of TON Study Population Cancer Cases		
Tribe Type	Tohono O'Odham	
	Count	Pct of TON
Tohono O'Odham	289	84.8
Unknown Tribe	52	15.2
Total	341	100.0

Tribal codes were used to identify cancer cases of TON members living outside TON tribal designated zip codes. Almost one third (31.9%, 109 cases) of the 341 TON member cases live outside the five TON zip code areas. Females account for a majority of cases (61.5%, 67 cases) living outside TON designated zip codes (See Table 4). Most TON members living outside TON designated zip code areas resided in Pima County (51.4%). (See Table 5)

**Table 4**

Tribal Designated Zip Code Residence by Sex of TON Member Study Population Cancer Cases						
Sex	Live on Tribal Lands		Live off Tribal Lands		Total	
	Case Count	Case Pct	Case Count	Case Pct		
Male	122	52.6	42	38.5	164	
Female	110	47.4	67	61.5	177	
Total	232	100.0	109	100.0	341	

**Table 5**

County of TON Member Cancer Cases Living Outside TON Designated Tribal Zip Codes		
County	Case Count	Pct
Pima	56	51.4
Maricopa	22	20.2
Pinal	19	17.4
All Other Counties	8	7.3
Unknown County	4	3.7
Total	109	100.0

## Limitations

Using this method of identification of TON member cases as described above, is subject to both under-counting and over-counting. The true count of TON member cases might be over-estimated if the ACR data shows the case lives in the TON zip codes and the tribe affiliation is "unknown" but the case is not a member of the TON. In this situation we falsely presume that they are members of the TON and the count is inflated. On the other hand, the count of true TON member cases might be under-estimated if the ACR data has no tribal affiliation and the case lives outside the TON zip codes. In this situation, there would be no way to know that such cases are indeed TON members and we would fail to include them in the count.

## **Characteristics of Cases Reviewed**

TON member cancer case counts greatly vary from year to year ranging from a low of 20 in 1995 to a high of 36 in 1997 (See Table 6). The average yearly case count for TON tribe cases is 28 cases per year. Cases with a known tribe code living in TON zip codes fluctuated from 10 in 1995 and 2005 to 22 in 2002. Cases with an unknown tribe code living in TON zip codes varied from 1 case to 7 cases per year from 1995 to 2005. There were 16 cases with an unknown tribe in 2006 as NMTR linkages with IHS tribe designations were not complete possibly overstating the number of TON members in TON designated zip codes. (See Table 7). The lack of IHS tribal linkage may also affect the number of total 2006 TON cases. No cases of TON were identified outside of TON zip codes, in the 2006 diagnosis year, possibly lowering the total number of TON member cases for that year (See Table 8).

**Table 6**

Tohono O'Odham Tribe Cancer Cases For Dx Year by Sex			
Dx Year	Sex		Total Cases
	Male	Female	
1995	12	8	20
1996	11	17	28
1997	18	18	36
1998	14	21	35
1999	13	15	28
2000	12	10	22
2001	15	16	31
2002	16	15	31
2003	18	11	29
2004	11	20	31
2005	12	10	22
2006	12	16	28
Total	164	177	341

**Table 7**

Tohono O'Odham Tribe Cancer Cases in TON Zip Codes for Known & Unknown Tribe by Dx Year		
Dx Year	Known Tribe Counts	Unknown Tribe Counts
1995	10	1
1996	15	4
1997	18	7
1998	17	7
1999	13	5
2000	13	1
2001	18	0
2002	22	1
2003	18	1
2004	14	5
2005	10	4
2006	12	16
Total	180	52

**Table 8**

Tohono O'Odham Tribe Cancer Cases for Dx Year by Residence Outside of Tribal Zip Codes	
Dx Year	Residence Outside of Tribal Zip Code Counts
1995	9
1996	9
1997	11
1998	11
1999	10
2000	8
2001	13
2002	8
2003	10
2004	12
2005	8
2006	0
Total	109

The number of TON members living outside of tribal identified zip codes could only be found if a tribal code was given for the case. These cases with a tribal code identified ranged from 8 cases to 13 cases yearly from 1995 – 2005 (See Table 8). Because 41 percent of American Indian cases had no tribal affiliation listed, these counts are affected by American Indian cases with an unknown tribal affiliation. However, the effect of unknown tribal affiliation is minimized in TON designated zip codes as only 15.2 percent of cases had an unknown tribal affiliation. Because of the way TON tribe is defined in this analysis, the ACR is unable to create rates of cancer as no reliable population denominator is available on which the rates would be based.

The ACR received 450 case reports for the 341 TON member cases. Multiple case reports are sent to the ACR when a person is seen at more than one facility for their diagnosis and treatment. For the TON member cases, 93 (27.3%) received diagnosis or treatment from more than one facility (See Table 9). NMTR is one of the reporting facilities on 71 of the 93 TON member cases with multiple case reports. For TON member cancer cases with one facility reporting, Arizona hospitals account for 180 (72.6%) of the 248 cases. Cases from NMTR (44) represent 17.7% of the total cases (See Table 10). The 14 cases (4.1% of 341 cases) found through a review of death certificates (DCO) can provide a gauge of completeness of case ascertainment.

**Table 9**

Multiple Facilities Reported Per Case		
Facility Type	Case count	Case Pct
NMTR & AZ Facility	71	76.3
Two or More AZ Facilities	18	19.4
Az Facility & Other	4	4.3
Total	93	100.0

**Table 10**

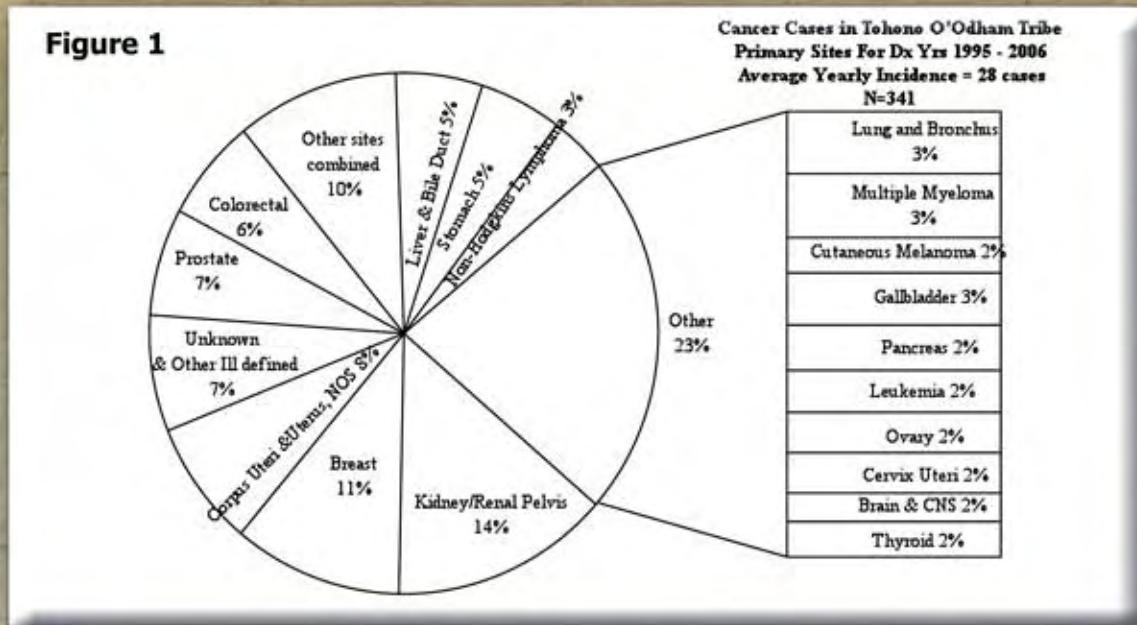
One Facility Reported Per Case		
Facility Type	Case Count	Case Pct
Hospitals	180	72.6
NMTR (IHS)	44	17.7
Physician	6	2.4
Death Certificate	14	5.6
Path Lab	2	0.8
VA Cases	2	0.8
Total	248	100.0

## A Comparative Analysis of Primary Site Incidence between TON Members and All Arizona Resident Invasive Cancer Cases

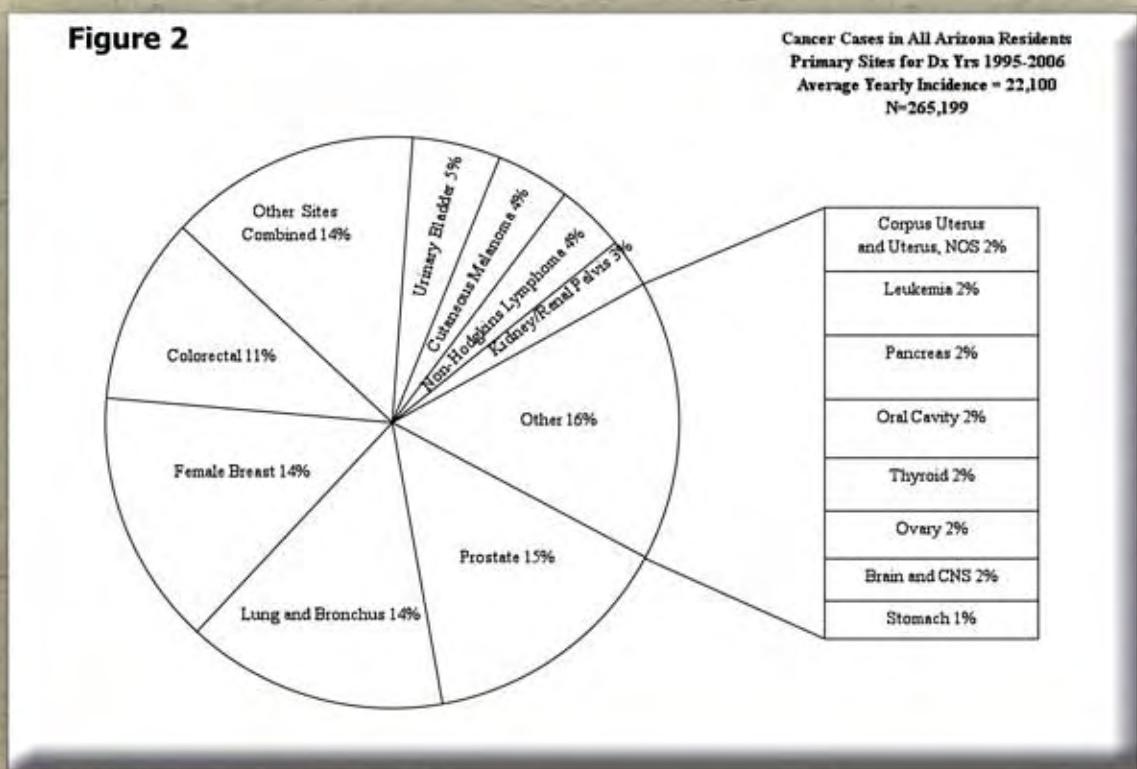
### All Cancer Cases Combined:

When comparing cancer cases among the TON members with all Arizonans the sex ratio differs between the two groups. TON has more female cases than male cases (52% to 48%) while Arizonans has more male cases than female cases (53% to 47%). Analysis of primary sites also shows differences. Kidney cancer (14%) is the leading type of cancer for all TON members. Amongst all Arizonans, kidney cancer ranks ninth at (3%). Following kidney cancer the next most common cancers among TON members are female breast (11%), corpus uterus (8%), unknown & ill defined sites (7%), prostate (7%), and colorectal cancer (6%). When cancer in all Arizonans is analyzed prostate cancer (15%) led the way; while lung (14%), female breast (14%), colorectal (11%), and bladder cancer (5%) round out the top five cancers. Although prostate, female breast and colorectal cancer are in the top cancers for both groups, a smaller percentage of each of these cancer types of all cancers is found amongst the TON cancer cases. TON also has a smaller percentage of lung cancer cases than Arizonans overall as lung cancer is in tenth place at 3% of cases while it is in second place with 14% for all Arizonans. Uterine cancer has a greater percentage of all TON cases (8%) than it does for Arizonans (2%) and TON cases have double the number of unknown & ill defined cancer cases (7%) compared to all Arizonans (3%). (See Figure 1 and Figure 2)

**Figure 1**



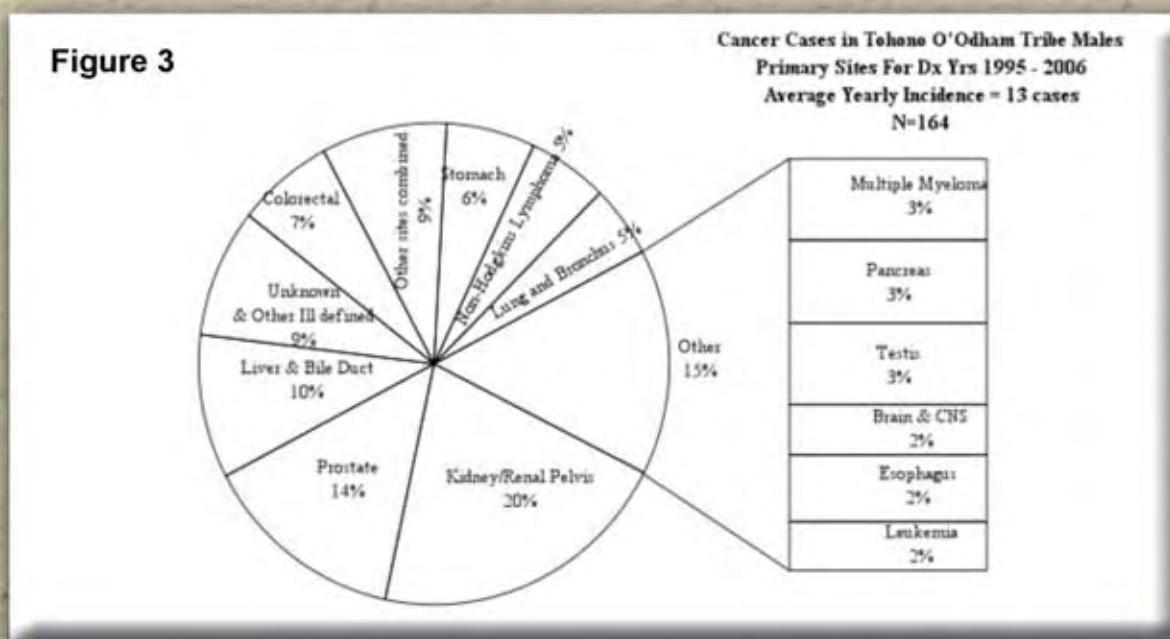
**Figure 2**



## Male Cancer Cases:

When comparing TON male members with all Arizona resident males, kidney cancer stands out as a large burden for TON males as 20 percent of male TON cases are kidney cancer cases. For all Arizona males, kidney cancer cases comprise only 3% of cases. Prostate (14%), liver (10%), ill defined and unknown (9%), colorectal (7%) and stomach cancer (6%) are the next sites of higher incidence for TON males. Prostate cancer amongst Arizona males is by far the largest type of cancer at 28 percent. Prostate cancer is followed by lung, colorectal, bladder, and melanoma (See Figure 3 & Figure 4).

Figure 3



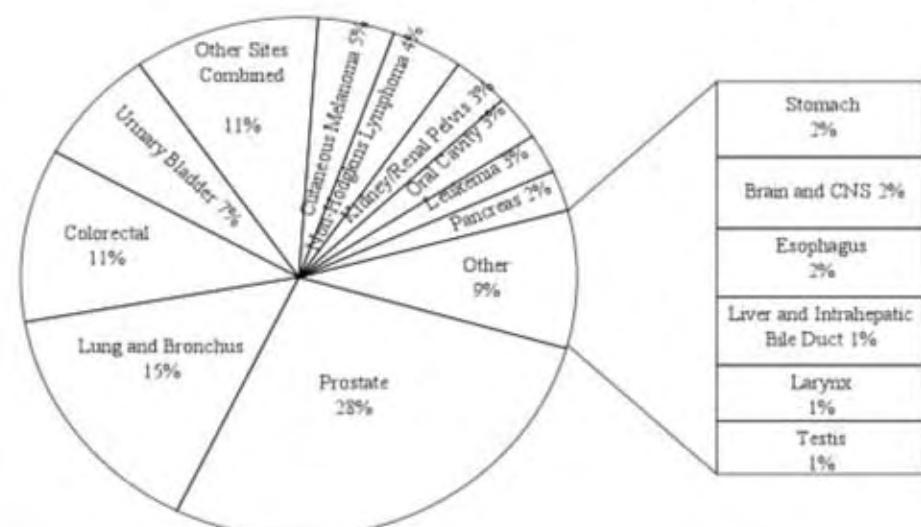
**Figure 4**

Cancer Cases in All Arizona Male Residents

Primary Sites for Dx Yrs 1995-2006

Average Yearly Incidence = 11,650

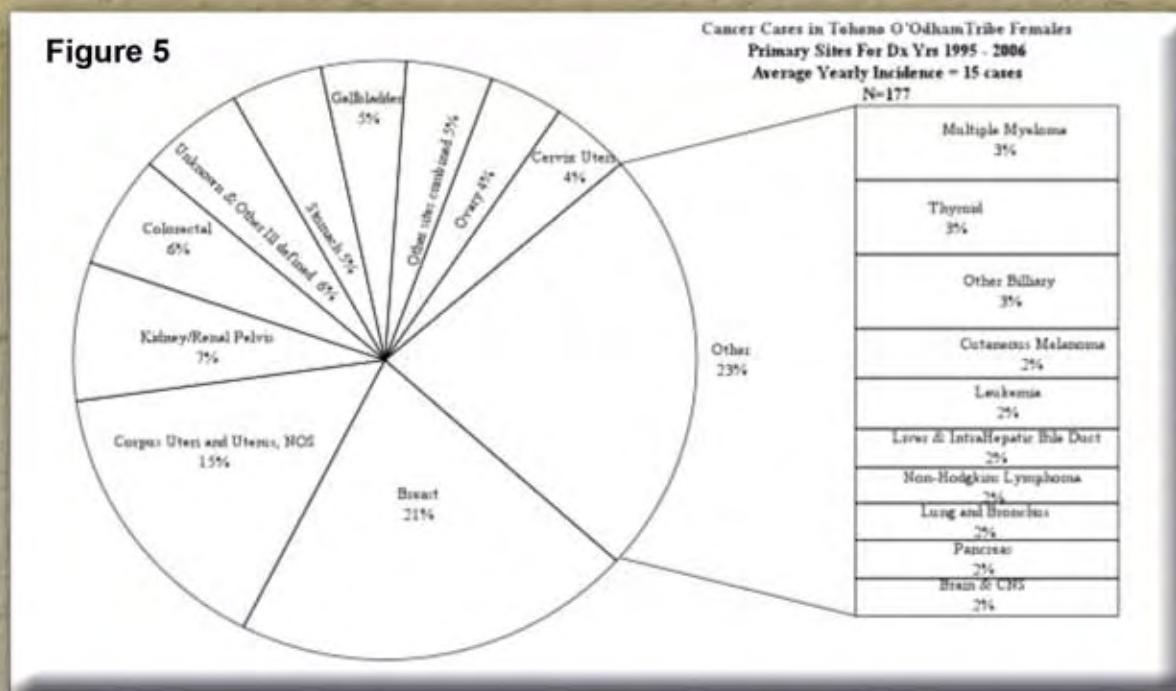
N=139,794



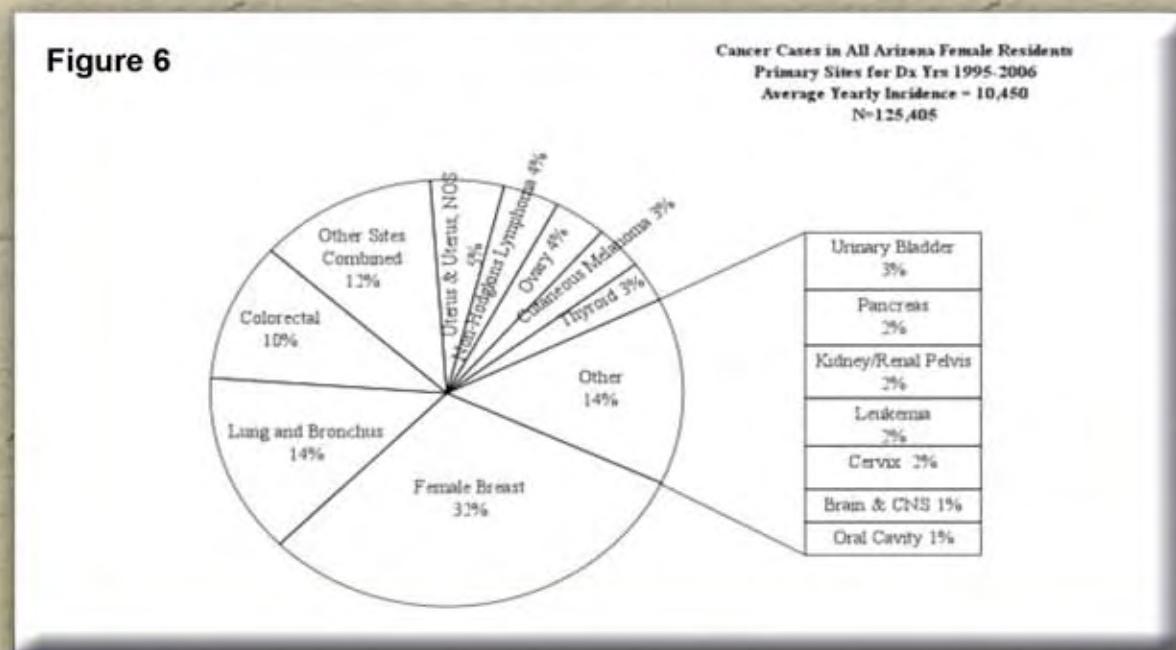
### Female Cancer Cases:

TON female members and all Arizona females are most likely to be stricken with breast cancer (21% and 32% respectively). The next most common cancers for TON females members are: uterus (15%), kidney (7%), colorectal (6%), ill-defined sites (6%) and stomach (5%). For Arizona females the most frequent cancers diagnosed after breast cancer are: lung (14%), colorectal (10%), uterus (5%), non-Hodgkin lymphoma (4%), and ovarian (4%). (See Figure 5 and Figure 6)

**Figure 5**



**Figure 6**



## **Analysis of Selected Primary Sites by Age Group and Sex For TON Cancer Cases**

Table 11 and Table 12 provide the counts by age groups for certain cancer sites. The median age of diagnosis of cancer was 63 years for TON males and 57 years for TON females. In comparison, the median age at diagnosis for all Arizona resident males is 69 years and 67 years for Arizona resident females. For TON members, childhood and adolescent cancer aged 0 to 19 years (6 males and 7 female cases) totaled 13 cases (3.8%). TON young adults aged 20 to 39 years represent 37 cases (10.9%) of all cases. No individual cancer type stood out for the 11 male cases in this age group. However, uterine (7 cases) and breast cancer (6 cases) represented half of the 26 female cases of this age group. For TON males, kidney cancer (8 cases) begins to appear in the 40 to 49 year old age group. For TON females, the 50 to 64 year age group shows the most cases of all female age groupings (62 cases). Almost half these cases are breast and uterine cancer cases. For TON males most cases are diagnosed in the oldest age category, 65 years and older (74 cases). For TON males in this category, 38% of cases are diagnosed in the prostate or kidney.

**Table 11**

Primary Site	Site by Age Group for Male TON Tribe Cases						
	0-19 yrs	20-29 yrs	30-39 yrs	40-49 yrs	50-64 yrs	65 yrs and older	Total
Colorectal	0	0	2	1	4	4	11
Lung	0	0	0	0	1	7	8
Prostate	0	0	0	0	6	17	23
Kidney	0	0	0	8	15	11	34
All Other Cases	6	2	7	8	30	35	88
Total	6	2	9	17	56	74	164

**Table 12**

Primary Site	Site by Age Group for Female TON Tribe Cases						Total
	0-19 yrs	20-29 yrs	30-39 yrs	40-49 yrs	50-64 yrs	65 yrs and older	
Colorectal	0	0	0	2	5	4	11
Lung	0	0	0	0	3	0	3
Breast	0	0	6	4	17	10	37
Cervix	0	1	2	3	1	0	7
Uterus	0	1	6	4	13	2	26
Kidney	1	0	1	2	5	3	12
All Other Cases	6	2	7	7	18	41	81
Total	7	4	22	22	62	60	177

## A Comparative Analysis of SEER Summary Stage between TON members and All Arizona Resident Invasive Cancer Cases

SEER Summary Stage is used to describe the extent cancer has spread. Early stage identifies cases that are confined to the site from which the cancer started (*in situ* stage) or has spread to only surrounding tissue in the organ of origination (local stage). These cancers are usually curable and have a high five year survival rate. Late stage identifies cases that have spread to other organs or to the lymph system (regional stage) or spread to organs far from the site of origination in the body (distant stage). Late stage cancers have a poor five year survival rate. Summary stage is a good tool to identify the need and effectiveness of screening programs (for cancers that can be screened) and the potential need for treatment and support services for all cancer. The following analysis compares the proportion of cases from six cancer sites between TON cancer cases and all Arizona resident cases.

The comparative analysis between TON member cancer cases and Arizona resident cancer cases is limited by the small number of TON member cases per cancer site. TON member lung cancer and cervix cancer cases have too few cases to compare with Arizona resident cancer cases (See Table 13 & Table 14). Colorectal cancer staging shows the TON member percent of cases staged at an early stage very similar to the percentage of Arizona resident cases (32 % to 34% respectively) (See Figures 7 and 8). The comparison of kidney cancer cases between TON members and Arizona residents also exhibit similarities in the percentage of cases staged in an early stage (54% to 56% respectively) (See Figures 9 & 10). Female breast cancer comparisons demonstrate that TON women have ten percent fewer cases diagnosed at an early stage than Arizona resident women (49% to 59% respectively) (See Figures 11 & 12). The percentage of prostate cancer cases in TON men identified at an early stage of diagnosis is less than half that of Arizona resident men (30% to 64%) (See Figures 13 & 14).

Both the TON members and all Arizona residents show a need for increased screening to find colorectal cancer in early stages as only one third of cases are diagnosed in an early stage. TON female breast cancer and TON male prostate cancer comparisons also demonstrate a greater need for screening among the TON as a much smaller percentage of TON members are diagnosed in an early stage for these sites (10% less for female breast cancer & 34% less for prostate cancer).

**Table 13**

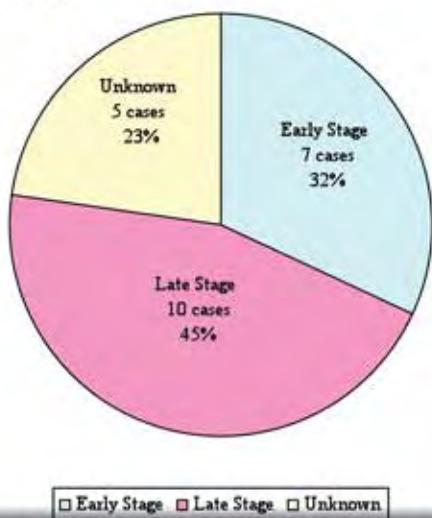
TON Tribe Cases Primary Site by Summary Stage For Dx Years: 1995 - 2006				
Primary Site	Early Stage	Late Stage	Unknown	Total
Colorectal	7	10	5	22
Lung	0	7	4	11
Female Breast	17	15	5	37
Cervix	3	2	2	7
Prostate	7	7	9	23
Kidney	25	17	4	46

**Table 14**

All Arizona Resident Cases Primary Site by Summary Stage For Dx Years: 1995-2006				
Primary Site	Early Stage	Late Stage	Unknown	Total
Colorectal	9,573	14,884	3,431	27,888
Lung	6,064	23,253	9,076	38,393
Female Breast	22,456	12,650	3,246	38,352
Cervix	1,063	980	326	2,369
Prostate	24,823	5,606	8,162	38,591
Kidney	4,126	2,386	859	7,371

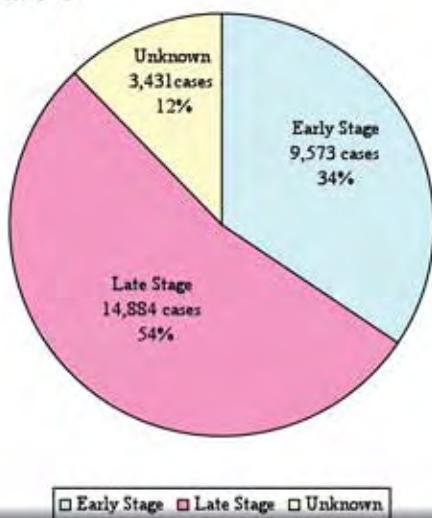
TON Tribe Colorectal Cancer Cases

**Figure 7**



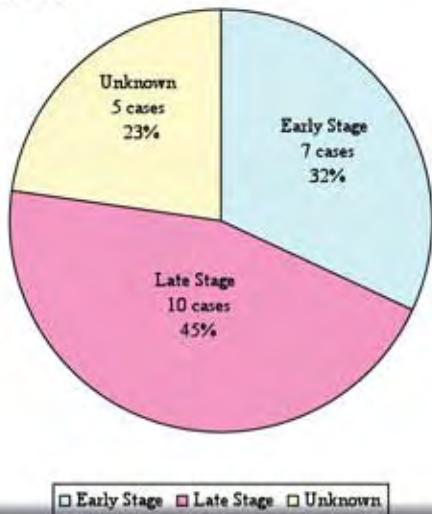
Arizona Resident Colorectal Cancer Cases

**Figure 8**



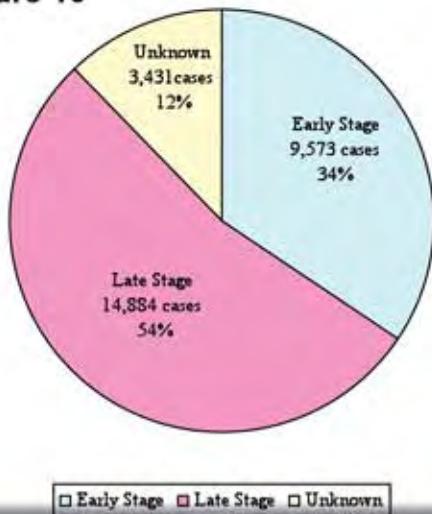
TON Tribe Colorectal Cancer Cases

**Figure 9**



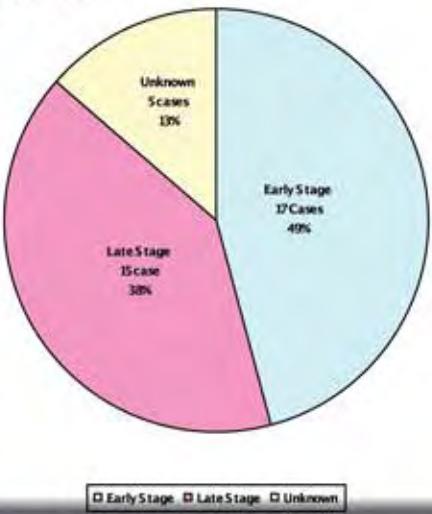
Arizona Resident Colorectal Cancer Cases

**Figure 10**



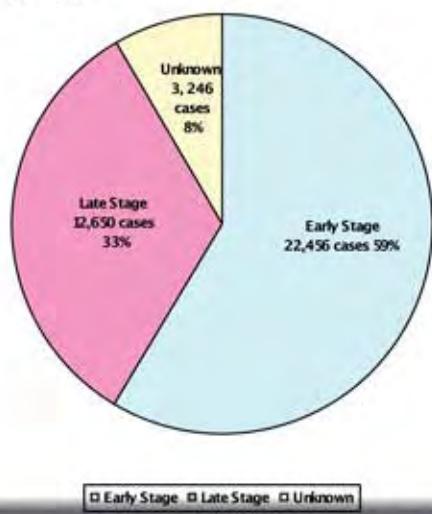
TON Tribe Female Breast Cancer Cases

**Figure 11**



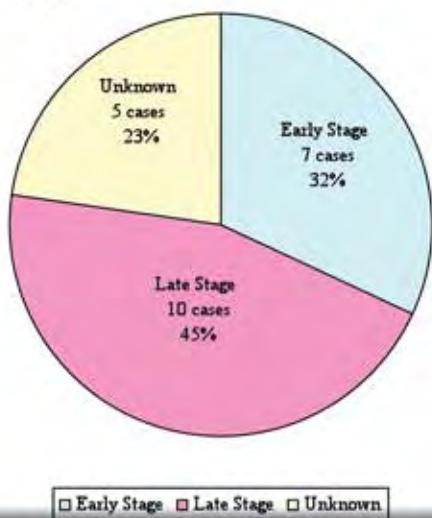
Arizona Resident Female Breast Cancer Cases

**Figure 12**



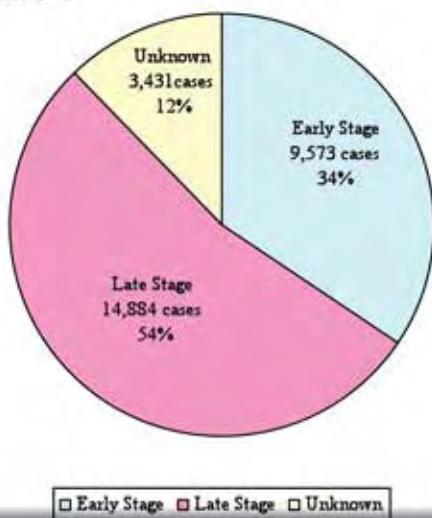
TON Tribe Colorectal Cancer Cases

**Figure 7**



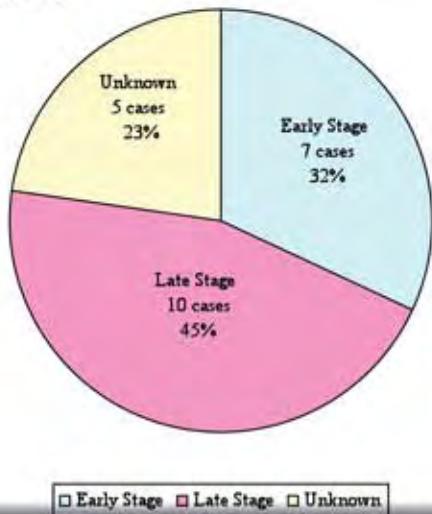
Arizona Resident Colorectal Cancer Cases

**Figure 8**



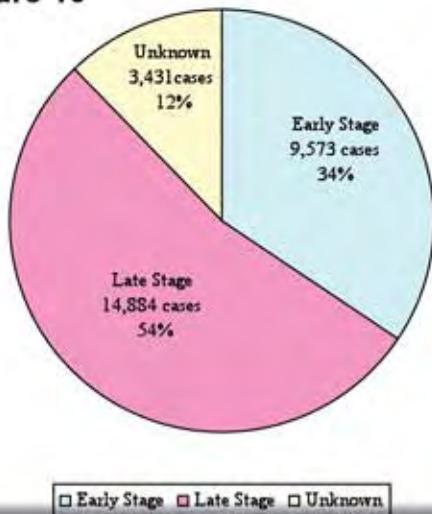
TON Tribe Colorectal Cancer Cases

**Figure 9**



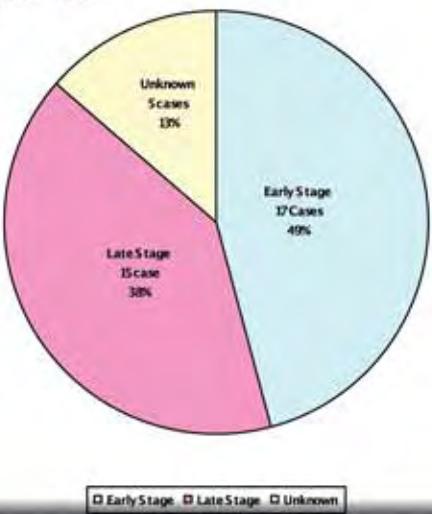
Arizona Resident Colorectal Cancer Cases

**Figure 10**



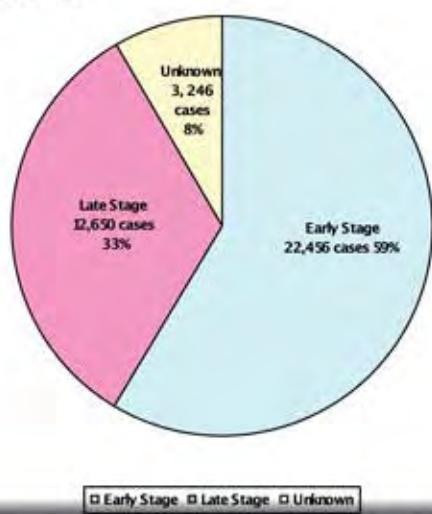
TON Tribe Female Breast Cancer Cases

**Figure 11**



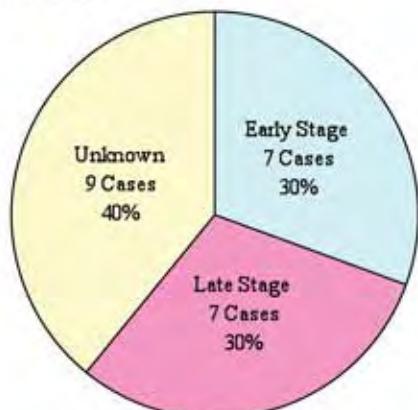
Arizona Resident Female Breast Cancer Cases

**Figure 12**



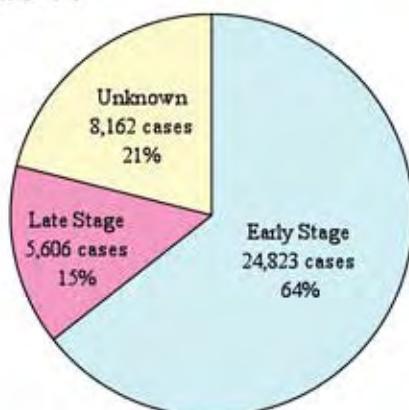
TON Tribe Prostate Cancer Cases

**Figure 13**



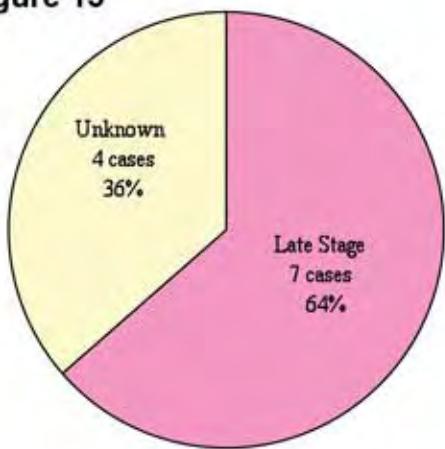
Arizona Resident Male Prostate Cancer Cases

**Figure 14**



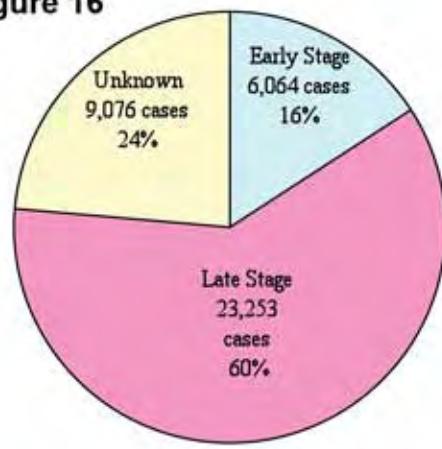
TO Tribe Lung Cancer Cases

**Figure 15**



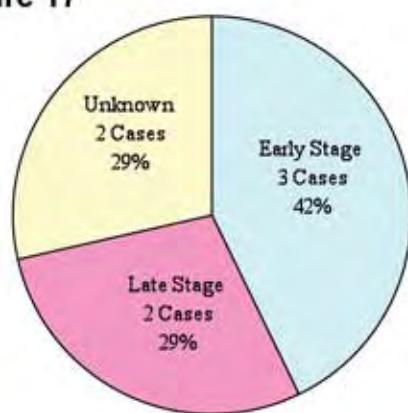
Arizona Resident Lung Cancer Cases

**Figure 16**



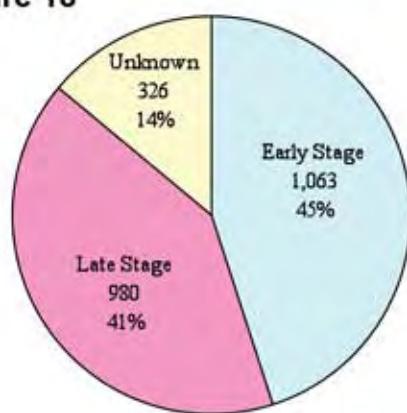
TO Tribe Cervix Cancer Cases

**Figure 17**



Arizona Resident Female Cervix Cancer Cases

**Figure 18**



## **Review of Vital Status of TON Members with Cancer**

Between 1995 and 2006 there were nineteen persons among 322 TON tribe members that had more than one primary cancer diagnosed resulting in 341 cancer cases. One hundred and thirty one (40.7%) of the TON members with cancer were alive and 191 (59.3%) had expired as of June of 2008. Eighty of the living TON members live in TON designated zip codes (See Table 15).

**Table 15**

Place of Residence	Vital Status		
	Alive	Dead	Total
Live In TON Zip Codes	80	141	221
Live Outside of TON zip codes	51	50	101
Total TON persons with Cancer Diagnosis cancer	131	191	322

Table 16 includes the vital status on selected primary sites that may include persons with multiple cancers. Of the breast cancers, three of the thirty four persons had an additional breast cancer resulting in thirty seven cases. Cervix and female breast had the greatest number of survivors (57.1% & 58.8% respectively).

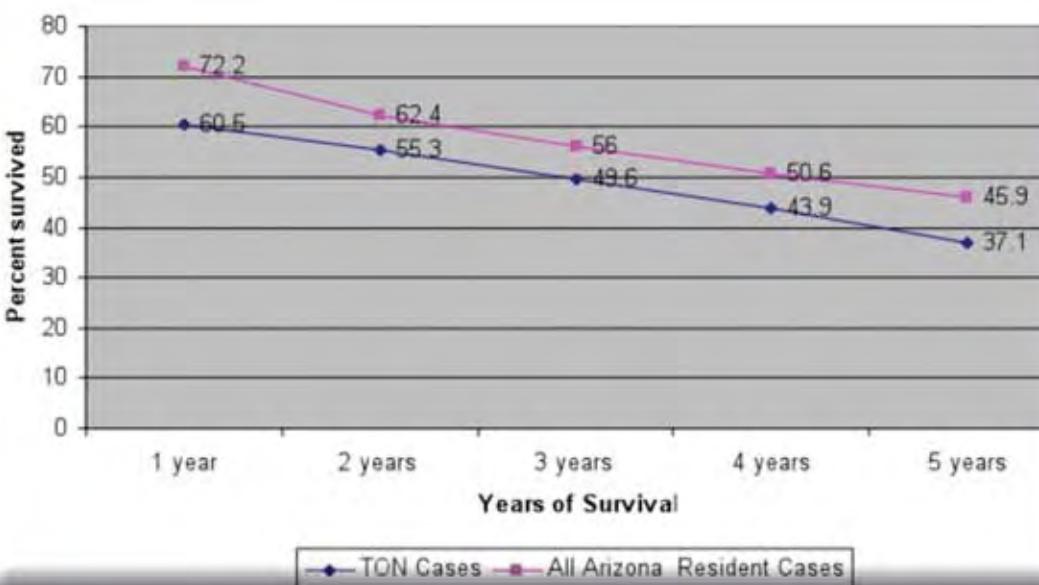
**Table 16**

Primary Site	Vital Status		
	Alive	Dead	Pct Alive
Colorectal	9	13	40.9
Female Breast	20	14	58.8
Cervix	4	3	57.1
Prostate	10	13	43.5

## Analysis of TON Cancer Survival as Compared with All Arizona Residents Cancer Survival

This analysis presents the survival of all cancer sites, regardless of any specific factors that may affect survival, between the TON member cancer cases and all Arizona cancer cases. For this survival analysis, cases with multiple primaries were excluded. TON member observed actuarial<sup>23</sup> survival varies between 11.7% and 6.4%, lower than the survival of all Arizonan cancer cases (See Figure 19). However, survival is affected by factors such as primary site, stage of disease, and age of patient. These factors are not reviewed for this analysis.

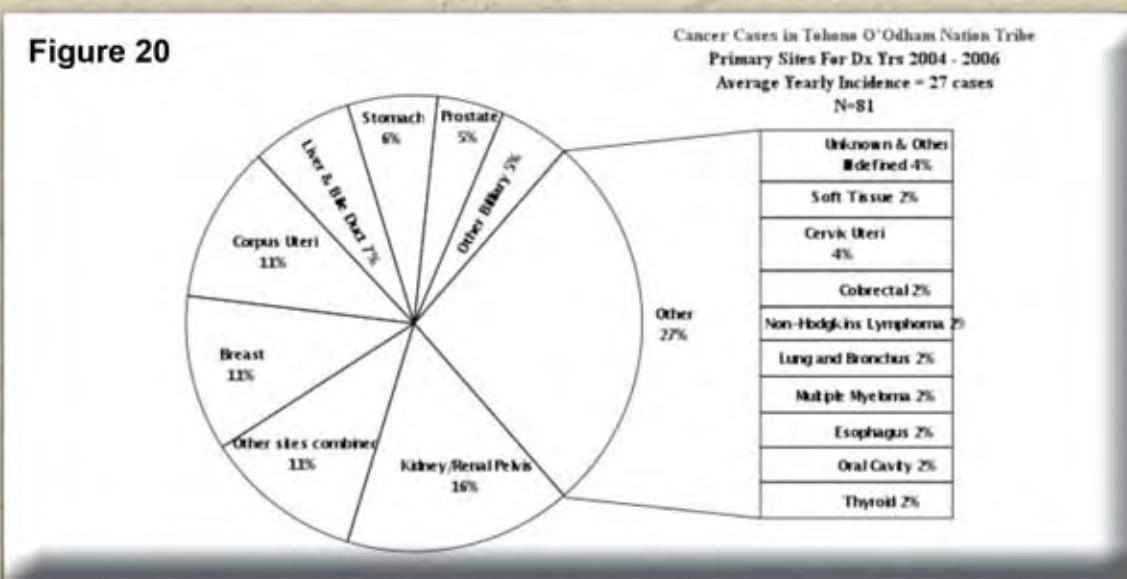
Table 19



<sup>23</sup> Observed actuarial survival is used for this analysis. The observed rate indicates that age was not taken into account. Actuarial survival defines survival at specific time intervals at which all cases dropping out since the last defined time point is analyzed. "The Actuarial method assumes that only half of those individuals were at risk at the time of the deaths". The Actuarial method was developed for grouped data. SEER Cancer Website. Retrieved 8/14/09 from [http://seer.cancer.gov/seerstat/508\\_WebHelp/Method\\_of\\_Calculation\\_for\\_a\\_Survival\\_Session.htm](http://seer.cancer.gov/seerstat/508_WebHelp/Method_of_Calculation_for_a_Survival_Session.htm).

## TON Cancer Cases Diagnosed in Years 2004 – 2006

This final section reviews cases diagnosed in the years 2004 to 2006 as requested by the TON Cancer Planning Committee. Eighty-one cancer cases were diagnosed among TON tribal members. Most cases are female (56.8%). Kidney cancer led the primary site categories with 16% of the cases (13 cases) (See Figure 20). It is followed by female breast (11%), uterus (11%), liver (7%) and stomach (6%). The top five TON female cancer cases are: female breast (19.6%), uterus (19.6%), kidney (10.9%), other billiary (8.7%), and cervix (6.5%) (See Table 18). The top five cancer sites for TON males is kidney (22.9%), liver (17.1%), prostate (11.4%), stomach (8.6%), and lymphoma (8.6%). (See Table 19)



**Table 17**

Top Five Primary Sites for Female TON Cases Diagnosed 2004 – 2006		
Primary Site	Case Count	Pct of Cases
Breast	9	19.6
Corpus Uteri & Uterus NOS	9	19.6
Kidney	5	10.9
Other Billiary	4	8.7
Cervix Uteri	3	6.5
All Other Sites	16	34.8
Total	46	100.0

**Table 18**

Top Five Primary Site for Male TON Cases Diagnosed 2004 - 2006		
Primary Site	Case Count	Pct of Cases
Kidney & Renal Pelvis	8	22.9
Liver	6	17.1
Prostate	4	11.4
Stomach	3	8.6
Lymphoma	3	8.6
All Other Sites	11	31.4
Total	35	100.0

## **Appendix 4**

### **COMMON TYPES OF CHILDHOOD CANCERS and SIGNS AND SYMPTOMS**

**Leukemias** are the most common childhood cancers. They account for about 33% of all childhood cancers. Acute lymphocytic leukemia (ALL) and acute myelogenous leukemia (AML) are the most common types of leukemia in children.

**Brain and nervous system cancers** are the second most common cancers in children, making up about 21% of childhood cancers. Most brain cancers of children involve the cerebellum or brain stem. Spinal cord tumors are less common than brain tumors in both children and adults.

**Neuroblastoma** is a form of cancer that starts in certain types of nerve cells found in a developing embryo or fetus. This type of cancer occurs in infants and young children. It is most often found during the first year of life. It is rarely found in children older than 10. This tumor can start anywhere but usually occurs in the belly (abdomen) and is noticed as swelling. It accounts for about 7% of childhood cancers.

**Wilms tumor** is a cancer that starts in one, or rarely, both kidneys. It is most often found in children about 3 years old, and is uncommon in children older than age 6. It can show up as a swelling or lump in the belly (abdomen). Sometimes the child may have other symptoms, such as fever, pain, or poor appetite. Wilms tumor accounts for about 5% of childhood cancers.

#### **Lymphoma**

**Non-Hodgkin lymphoma** and **Hodgkin lymphoma** (sometimes called **Hodgkin disease**, **Hodgkin's disease**, or **Hodgkin's lymphoma**), are cancers that start in lymph tissues, such as the tonsils, lymph nodes, and thymus. These cancers may spread to bone marrow and other organs, which can cause different symptoms depending on where it is growing.

Hodgkin lymphoma can occur in both children and adults, and accounts for about 4% of childhood cancers. It is more common, though, in 2 age groups: early adulthood (age 15 to 40, usually people in their 20s) and late adulthood (after age 55). Hodgkin lymphoma is rare in children younger than 5 years of age. About 10% to 15% of cases are diagnosed in children and teenagers.

Non-Hodgkin lymphoma makes up a little more than 4% of childhood cancers, and can cause symptoms much like those of Hodgkin lymphoma.

Rhabdomyosarcoma is the most common soft tissue sarcoma in children. It makes up a little more than 3% of childhood cancers. This tumor starts in the same embryonic cells that develop into striated (voluntary) muscles. It can happen in the head and neck, groin, abdomen, pelvis, arms and legs. It may cause pain, swelling (a lump), or both.

Retinoblastoma is a cancer of the eye. It is rare, accounting for just under 3% of childhood cancers. It usually occurs in children under the age of 4, and is seldom found in children older than 6.

#### Bone cancers

Primary bone cancers (cancers that start in the bones) occur most often in children and adolescents. Metastatic bone cancer is more common than primary bone cancer because many types of cancer can spread to the bone. Two types of primary bone cancers occur in children: Osteosarcoma is uncommon, accounting for almost 3% of all new childhood cancer cases in the United States. It often causes no pain or symptoms until swelling starts, but sometimes there is bone pain that keeps getting worse. Ewing sarcoma is a less common primary bone cancer which can cause bone pain. It is mostly found in adolescents. It accounts for a little more than 1% of childhood cancers.

## Signs and Symptoms of Cancer in Children

The following list of cancers contains some of the most common types of cancers found in children, their associated signs/symptoms and risk factors. Please note other conditions may cause the same symptoms. A doctor should be consulted if any of problems listed below occur.

Any factor that increases the risk of getting a specific type disease is referred as a risk factor.

Having a risk factor does not mean that you will get cancer; not having risk factors doesn't mean that you will not get cancer. People who think they may be at risk should discuss this with their doctor.

### Non-Hodgkin Lymphoma

- The following signs and symptoms may be caused by childhood **non-Hodgkin lymphoma**. Other conditions may cause the same symptoms. A doctor should be consulted if any of the following problems occur:
  - Shortness of breath, trouble breathing, wheezing, high-pitched breathing sounds, swelling of the head or neck, trouble swallowing, painless swelling of the lymph nodes in the neck, underarm, stomach, or groin, fever for no known reason, weight loss for no known reason, and night sweats.
  - Risk Factors-Being infected with the Epstein-Barr virus; certain types of bacteria such as Helicobacter pylori is associated with mucosa-associated lymphoid tissue (MALT) lymphoma in the stomach wall.

### Non-Hodgkin Lymphoma

- The following signs and symptoms may be caused by childhood **non-Hodgkin lymphoma**. Other conditions may cause the same symptoms. A doctor should be consulted if any of the following problems occur:
  - Shortness of breath, trouble breathing, wheezing, high-pitched breathing sounds, swelling of the head or neck, trouble swallowing, painless swelling of the lymph nodes in the neck, underarm, stomach, or groin, fever for no known reason, weight loss for no known reason, and night sweats.
  - Risk Factors-Being infected with the Epstein-Barr virus; certain types of bacteria such as Helicobacter pylori is associated with mucosa-associated lymphoid tissue (MALT) lymphoma in the stomach wall.

## Brain and Spinal Cord Tumors

- Headaches and other symptoms may be caused by childhood brain and spinal cord tumors. Other conditions may cause the same symptoms. A doctor should be consulted if any of the following problems occur:
  - **Brain Tumors**-Morning headache or headache that goes away after vomiting, frequent nausea and vomiting. Vision, hearing, and speech problems. Loss of balance and trouble walking. Unusual sleepiness or change in activity level. Unusual changes in personality or behavior. Seizures. Increase in the head size (in infants).
  - **Spinal Cord Tumors**-Back pain or pain that spreads from the back towards the arms or legs. A change in bowel habits or trouble urinating. Weakness in the legs. Trouble walking.
- **Risk Factors**-The cause of most spinal cord and brain tumors is unknown

## Childhood Leukemias

- These and other symptoms may be caused by childhood Leukemias. Other conditions may cause the same symptoms. A doctor should be consulted if any of the following problems occur:
  - Fever with or without an infection; night sweats; shortness of breath; weakness or feeling tired; easy bruising or bleeding; petechiae (flat, pinpoint spots under the skin caused by bleeding); pain in the bones or joints; pain or feeling of fullness below the ribs; painless lumps in the neck, underarm, stomach, groin, or other parts of the body. When seen in childhood AML, these lumps, called leukemia cutis, may be blue or purple. Painless lumps that are sometimes around the eyes. These lumps, called chloromas, are sometimes seen in childhood AML and may be blue-green; an eczema -like skin rash.

Source: National Cancer Institute, 2009.

## **General guidelines to follow to help children cope with a cancer diagnosis**

Ask for professional assistance to help your child if he or she is having a especially difficult time adjusting to the diagnosis and treatment.

Arrange for your child to stay connected to their friends. Inform your child's friends of the disease to decrease misinformation.

If appropriate, get the school involved and arrange for a classroom presentation by a pediatric healthcare professional/counselor to explain the child's diagnosis and treatment. Ask the child if they would like for this to be done, prior to making the presentation.

Provide structure to increase the child's sense of control. Make things as consistent as possible. Recognize that giving your child gifts all the time, or stopping all previous form of discipline, is confusing ot the child.

Let your child make choices on their own (when appropriate)

At times your child may express behavior of "acting out" Set limits for your child (whether they are sick or not) yet show respect for their feeling of anger, worry, sadness or fear. Children will have a more difficult time returning back to school, following rules and relating to peers if they are able to do whatever they want.

Acknowledge and praise your child when he or she is doing things that are difficult (receiving treatment). This will reinforce positive behaviors.



## **General guidelines to help siblings cope with a brother or sister with cancer**

Be honest with your children about the diagnosis and treatment of their sibling. If appropriate, introduce the siblings to the medical team who can give medical information and make siblings feel special too.

Give siblings information that is age-appropriate and dissolve misinformation such as if cancer is contagious.

Be open and willing to answer questions as their sibling's treatment continues and involve the sibling in the treatment if possible and arrange for them to visit the hospital.

Remember that all children have problems and may require the attention of the parent; provide consistent and fair discipline.

Let siblings know that you love them and that you are proud of them.

