The Tohono O'odham Nation (TON) Comprehensive Cancer Planning Grant “Data” Experience

Joseph B. Hawes MD, MPH
TON Comprehensive Cancer Planning (CCP) Grant

• Overarching Goal – decreasing the burden of four selected cancers; breast, cervix, prostate and colorectal, on the Tohono O'odham Nation (TON) population

• Data needs - data sources reporting on, screening, stage at diagnosis, treatment and management of cancer cases
“Finding and Using Data to Serve Disparate Populations”

2009 Collaborative NCCCP & NPCR Conference
April 15-17, CDC, Atlanta, GA.
Data and Decision Making

• Science based information – key to the decision making process

• Data - key component that drives the information generating process

• Surveillance system – mechanism that moves the data through the process
Surveillance System Mechanism

- Data collection
- Data Analysis
- Dissemination of Findings
- Action activities
Finding and Using Data to Serve Disparate Populations.

“The Data Maze”

2009 Collaborative NCCCP & NPCR Conference
April 15-17, Atlanta, GA.
Finding and Using Data to Serve Disparate Populations

Disparate – distinct, dissimilar, different from main stream

• What constitutes a disparate population?

• Distinct populations?

• Main stream/Traditional – Data sets?
Finding Cancer Data for Distinct Populations in “Traditional” Data Sets

**Objectives:**

- Adequacy of mainstream/traditional cancer data sets
- A process for identification of TON population in existing data sets
- Highlight challenges to success
- Recommendations
Health Status Information on The Distinct Population - TON

National Cancer Information Sources

• National Program of Cancer Registries (NPCR)
• *The SEER Program Cancer Registry
• New Mexico Tumor Registry

*Operates and maintains a population-based cancer registry for the entire state of New Mexico and the American Indian population of Arizona
Finding Cancer Status Information on TON population

*BRFSS

Hospital Discharge

State Cancer Registry

Vital Statistics

New Mexico Tumour Registry

Indian Health Services

TON population

Tribal Registry
Cancer Information Generating Status

- Cancer screening
- Incidence and prevalence count
- Stage at diagnosis
- Management & treatment
Challenges to the Tohono O'odham Nation’s CCP Data Effort

- Accessing data sources identified
- Extracting information from accessible data sources
- Obtaining accurate numerators and denominators
- Dissemination of information on cancer status of Arizona’s American Indian population
Challenges to the NCCCP & NPCR Collaborative

- Representation of non SEER American Indian populations in national statistics on Cancer status in American Indians

- Building the capacities of tribes to generate BRFSS like information
Recommendations

- Use of demographic identifiers, similar to those on Birth and Death certificates, on all state and IHS health data reporting forms
- Create a unit within the Tribe’s health system with the functional capacity of the state’s local health department
Getting out of the Data Maze

The End

Thank You!