Comprehensive Cancer Planning by states and tribal groups: An Analysis of five states Brenda Seals, PhD Eastern Band Cherokee Native American Cancer Research Linda Burhansstipanov, DrPH, MSPH Cherokee Nation of Oklahoma Native American Cancer Research Doris Cook, PhD, MPH Akwesasne Mohawk Retired Delight Satter, MPH

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#### **Disclaimer and Disclosure**

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#### Background

- Comprehensive Cancer Control (CCC) is a CDC funded activity for states.
- CCC planning is a developed process involving states, communities and health care providers, many as volunteers
- CCC identifies gaps, prioritize needs, and create goals and objectives for 3-5
- Many states and tribes are now revising and updating their plans

# Tribal CCC Planning

- The over 560 federally recognized tribal nations in the US have little participation in CCC.
- Currently the CDC funds seven tribal groups for CCC planning
- Urban and reservation based tribal groups need information, training, resources and encouragement to fully engage in CCC

### Goal

- This analysis seeks to describe:
   Common and unique components of state and tribal CCC plans
  - Levels of acknowledgment for tribes in state plans and for state partners in tribal plans
  - The value of epidemiological and needs assessment date for CCC plans
  - The incorporation of the top five cancers in CCC goals and objectives

#### Selection of state and tribal plans

- Publicly available plans reviewed from: http://cancercontrolplanet.cancer.gov/state\_plans.jsp
- Some tribal plans covered more than one state. For these, the selected state was where the agency was located.
- One multi-state plan was excluded as it did not provide state specific information.

# Coding

- Plans were coded for:
  - Explicit representation of
    - Tribes, tribal organizations, or community status in state plans
    - State, federal or regional Department of Health representation in tribal plans

# More Coding

- -AIAN specific epidemiological data
  - cancer incidence, prevalence or mortality
    demographics (Census or other)
  - ◆BRFSS/YRBS indicators for cancer mortality.
- Objectives:
  - Prevention and special issue
  - Five screenable car
  - Addressing the top five types of cancer from mortality tables

### Planning Representation

- Some states had:
  - 1+ AIAN representative on steering and each working group.
  - No explicit AIAN representatio
- Some tribal groups had:
  - 3 people from state DOH (CCC, Epi)
  - 1 person from federal orgs. (CDC, IHS)
  - No representation (Tribal plans that recognized organizations no individuals)

#### AIAN Epidemiological Data

- All states & tribes presented some AIAN data;
  - Census (1990 & 2000)
  - Insurance coverage
  - BRFSS & cancer incidence & mort
  - None provided YRE
- AIAN data usually pooled across 4-6 yrs
- A few states & tribes mentioned ATAN racial misclassification, linkage data &/or data quality issues

### Top Five AIAN Cancer Mortality

- Some state plans included
- Others did not provide AIAN data
- Almost all tribal groups included

# State Plan Objectives

- All included cancer prevention

   mostly tobacco and obesity/physical activity
  - skin cancers, environmental factors, childhood cancer, health disparities and/or palliative carc
- All addressed the five screenable cancer
- Melanoma, pancreatic and bladder cancer were listed in top five cancer mortality but not in objectives.
- Did not provide objectives for ethnic groups including AIAN except some mention of health disparities

# **Tribal Plan Objectives**

- All covered both prevention and screenable cancers
- Lung and cervical cancer not in all plans
- Stomach, Kidney, Bladder and Leukemia/Lymphoma were listed in some tribal top five cancer mortality but not in objectives.

### Conclusions

- State & tribal groups benefit from cross participation
- Where tribes are not directly funded, efforts may be needed to improve tribal "readiness" to fully participate in planning efforts
- States need to initiate efforts to increase participation of tribal groups & AIAN living in urban areas

### Epidemiological data

- State provided BRFSS, YRBS, morbidity and mortality data is critical for goals and objectives

   requires dedicate the staff time and skills for merging data across years
- Misclassification and other limits to providing accurate data need to be acknowledged and addressed.

# Objectives

- Unique objectives developed may be good models for CCC planning
- Many plans need to expand lung and skin cancer sections.
- Non-screenable cancers that contribute to top cancer mortality should be addressed.

### Discussion

- Comprehensive cancer planning may be more important than ever
- AIAN groups, funded or not, also benefit from such planning efforts
- States can play a critical role by partnering with tribal groups