

# **CANCER BURDEN OF THE HOPI TRIBE: AN [EXPERIENTIAL] MODEL FOR COLLABORATION**

**A Joint Presentation by  
Lori Martin & Sylvia Brown  
APHA, November 5, 2007**

# TOPICS

- ◆ **PARTNERSHIP MEMBERS: WHO'S WHO?**
- ◆ **MORE ABOUT HOPI!**
- ◆ **HOW HAS THE PARTNERSHIP DEVELOPED?**
- ◆ **HOW HAS THE PARTNERSHIP EXPANDED?**
- ◆ **PROJECT: CURRENT STATUS**

# CURRENT PARTNERS

- ◆ **Hopi Tribe and Hopi Women's Health Program (HWHP)**

  - Lori Martin

  - Delores Ami

- ◆ **University of Arizona (UA) and Arizona Cancer Center (ACC)**

  - Robin Harris

  - Sylvia Brown

  - Kathryn Coe

  - Tomas Nuno

- ◆ **Northern Arizona University (NAU)**

  - Charlotte Goodluck

  - R. Cruz Begay

- ◆ **Arizona Cancer Registry (ACR) of the Arizona Department of Health Services (ADHS)**

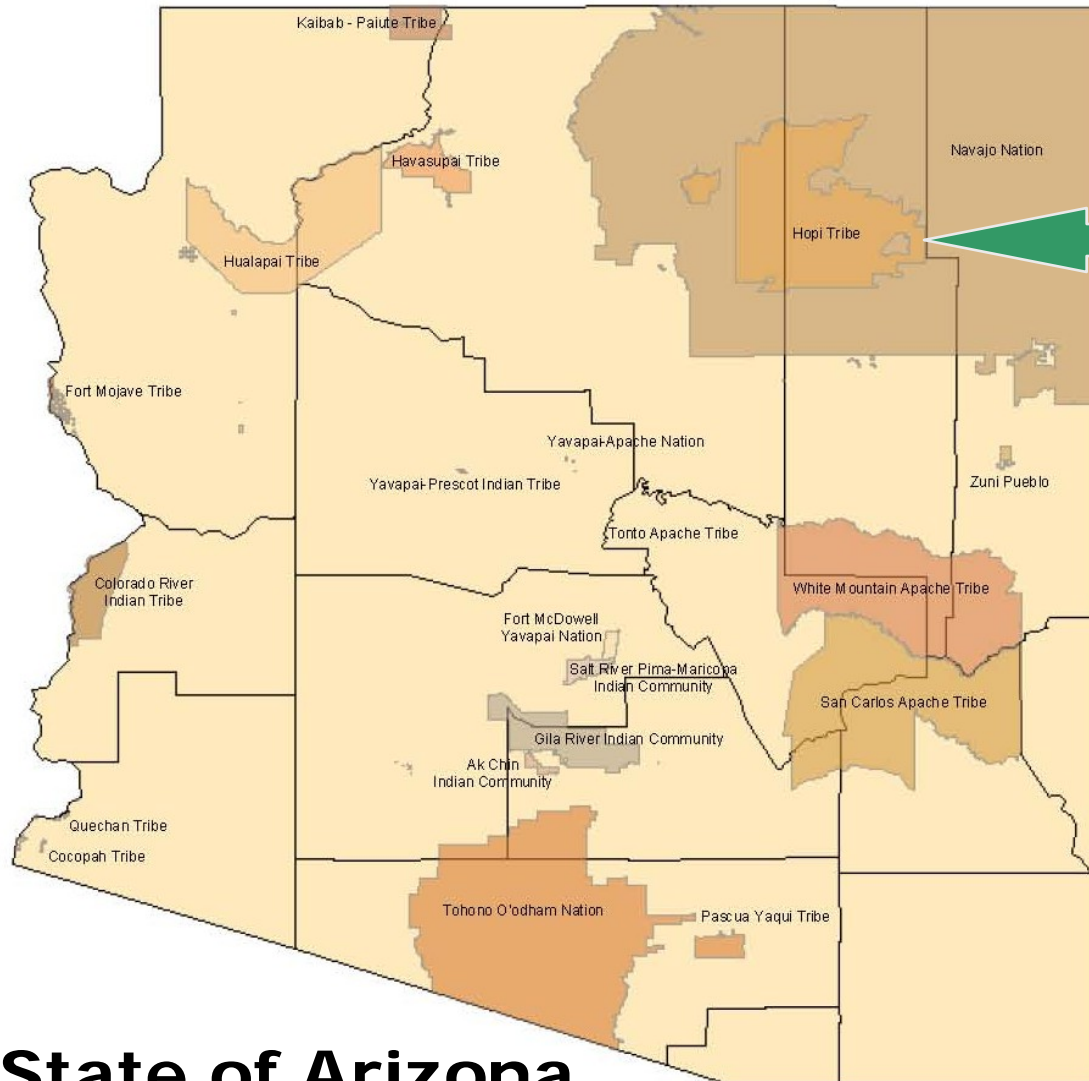
  - Tim Flood

# FUNDING SOURCES

## NATIONAL CANCER INSTITUTE

1. Native American Cancer Research Partnership (NACRP)
2. Southwest American Indian Collaborative Network (SAICN)

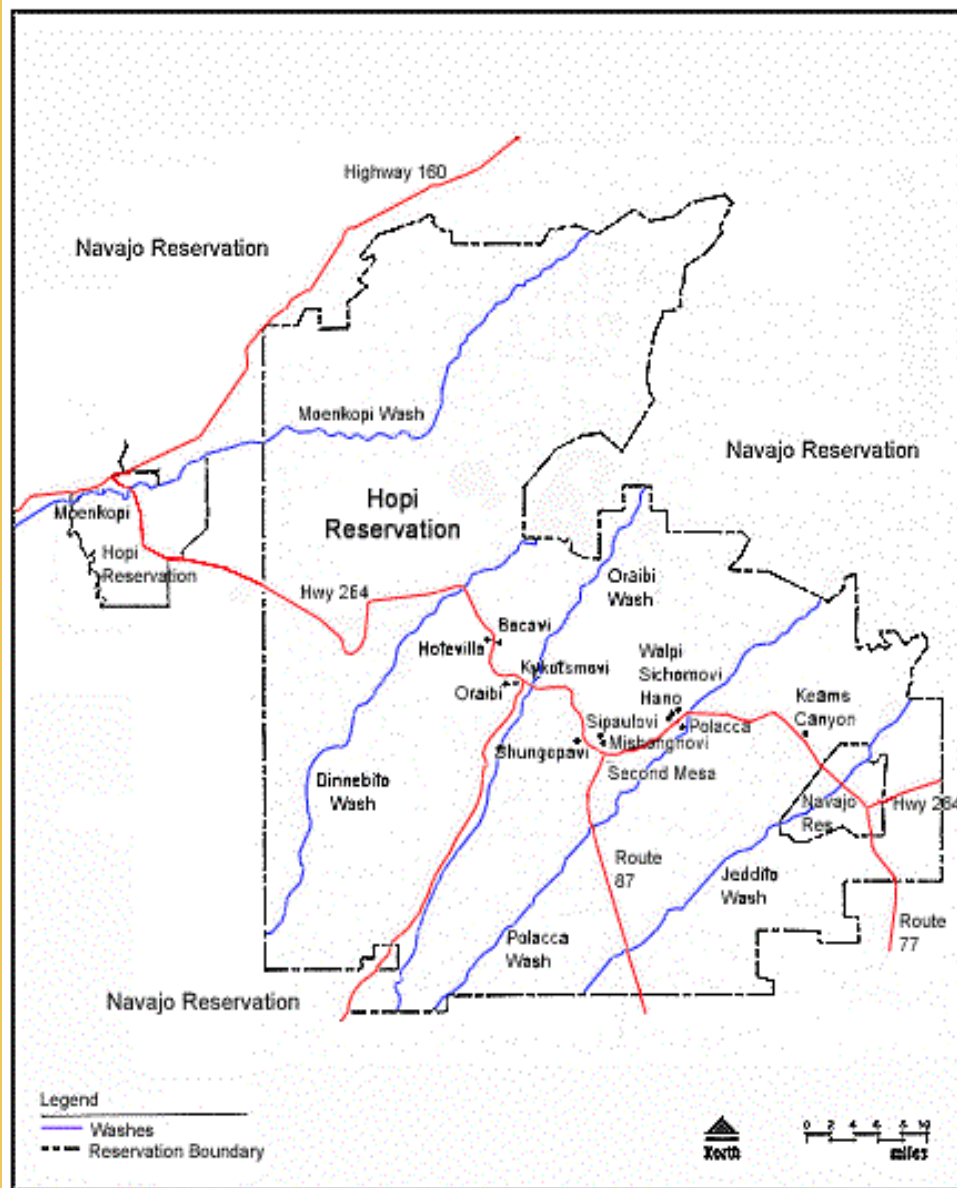
# \*\* THE HOPI TRIBE \*\*



**State of Arizona**

<http://www.hopi.nsn.us/visitors.asp>

# \*\* HOPI \*\*



- Historically resident in area > 8000 years
- >2,500 sq miles
- Population  
On Rez: 7,299  
Off Rez: 5,143
- Tribal Government +  
11 autonomous villages
- 2.7 persons per sq  
mile

# HOPI VILLAGES

**First Mesa:**        *Waalpi* (Walpi)  
                          *Hanoki* (Hano or Tewa)  
                          *Sitsomovi* (Sichomovi)

**Second Mesa:**    *Songoopavi* (Shongopavi)  
                          *Musungnuvi* (Mishongnovi)  
                          *Supawlavi* (Shipaulovi)

**Third Mesa:**        *Hoatvela* (Hotevilla)  
                          *Paaqavi* (Bacavi)  
                          *Munqapi* (Moencopi)  
                          *Kiqotsmovi* (Kykotsmovi)  
                          *Orayvi* (Oraibi)

# WALPI - FIRST MESA





# COLLABORATION

**HOPI:UA**



1993  
SURVEY

# 1993 KABB SURVEY

- Hopi: UA Joint effort
- Research team led by Leon Nuvayestewa from Hopi and Anna Giuliano from the Arizona Cancer Center at the UA
- Survey of Knowledge, Attitudes, Beliefs and Screening History of Breast and Cervical Cancer among Hopi Women

# COLLABORATION

**HOPI:UA**



1993  
SURVEY

1996

**HOPI BCCP**

# HISTORY OF HWHHP

- Breast and Cervical Cancer Program (BCCP) Funded in 1996 - program is in its 11th year
- Approximately two years to set up the program – breast screening 1998, cervical screening 2000
- Staff
  - Director
  - Case Managers (3)
  - Data Entry Specialist
  - Health Educator
  - Outreach worker
  - Secretary
  - Transportation Driver

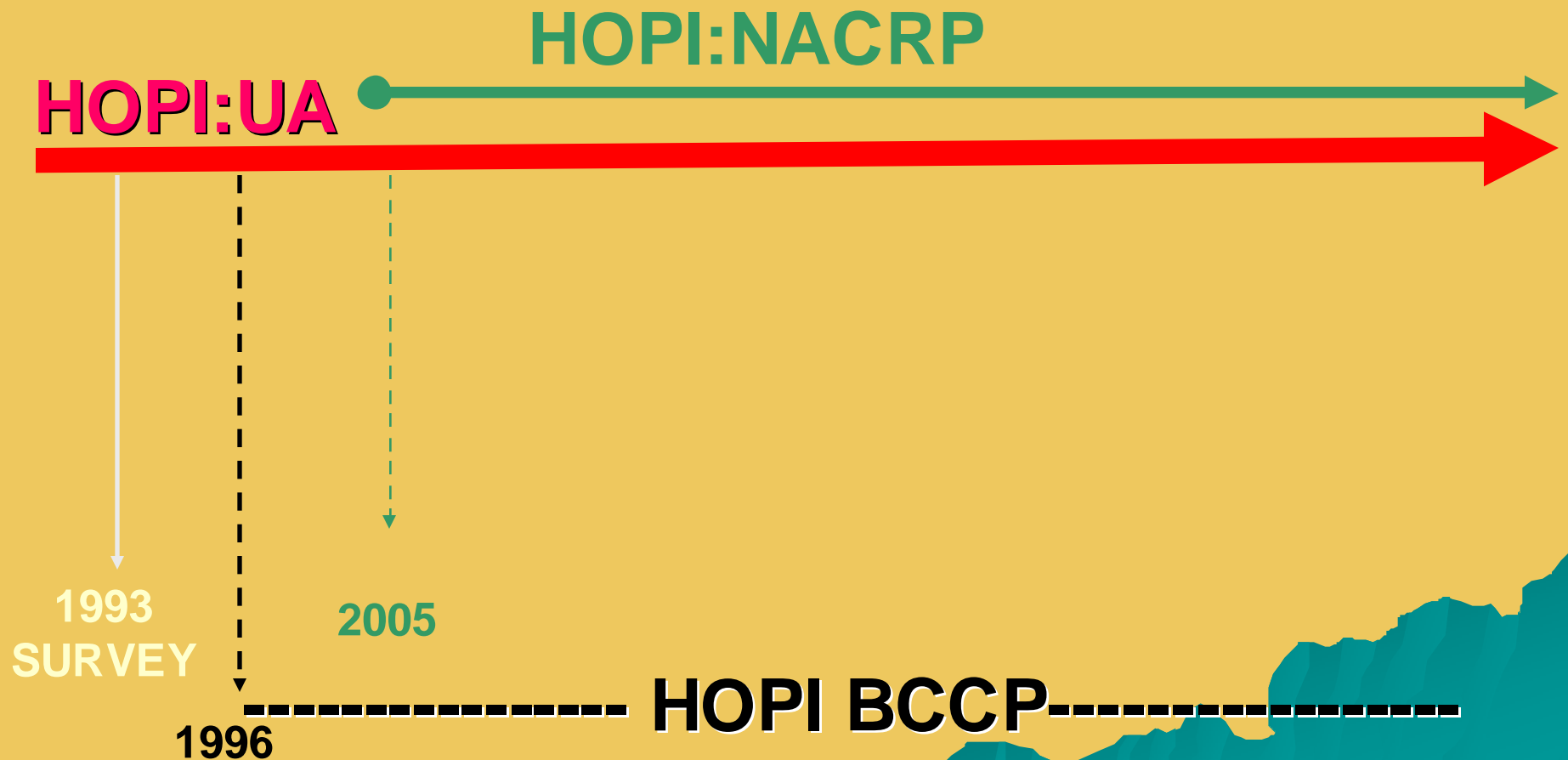


# HWHP: MISSION

**“to provide early detection of breast and cervical cancer through prevention and education to reduce morbidity and mortality from these diseases.”**



# HOPI:NACRP COLLABORATION



# HOPI:NACRP COLLABORATION

**2005:** HWHP contacted NACRP to request a) assistance with evaluation of BCCP program and b) update of 1993 survey

**2005-2006:** Meetings with HWHP, Focus groups and Community Meetings held to discuss content of updated survey. The question as to how much cancer exists on Hopi was frequently asked by community members.

# HOPI:NACRP STATUS

## ◇ 2006 SURVEY

- Field Test Completed May 2006 (n=25)
- Full Survey Completed Dec 2006 (n=224)
- Report to Tribe 10/31/07
- Publication analysis/writing underway

## BCCP EVALUATION

- Reports Issued to Tribe December 2006
- Results Presented to Tribe Feb 2007
- HWHP refunded for 5 more years

## – SEE APHA POSTER PRESENTATION

*5009.0: Wednesday, November 07, 2007 - Board 8 -Abstract #151657- Cancer prevention in Indian Country: An evaluation of breast cancer screening efforts of the Hopi Women's Health Program*



# HOPI:SAICN COLLABORATION

HOPI:ACR

HOPI:SAICN

HOPI:NACRP

HOPI:UA

1993  
SURVEY

1996

2005

2006

- Ongoing communication with HWHP
- Focus Groups
- Community Meetings

--- SURVEY ---

HOPI BCCP

# HOPI:SAICN COLLABORATION

**GOAL: To Ascertain the Cancer Burden of Hopi People Living both On and Off the Hopi reservation**

INCIDENCE: Those getting cancer

PREVALENCE: Those living with cancer

MORTALITY: Those dying from cancer

PATTERNS: Age, Stage, Geography

# HOPI:SAICN COLLABORATION

Dec 2005: TALKS BEGAN in Kykotsmovi: Lori Martin, Kathryn Coe, Sylvia Brown

Jan 2006: TALKS EXPANDED to include Tim Flood (ACR)

2006-2007: Ongoing email and in-person meetings

March 2007: TRIBAL RESOLUTION

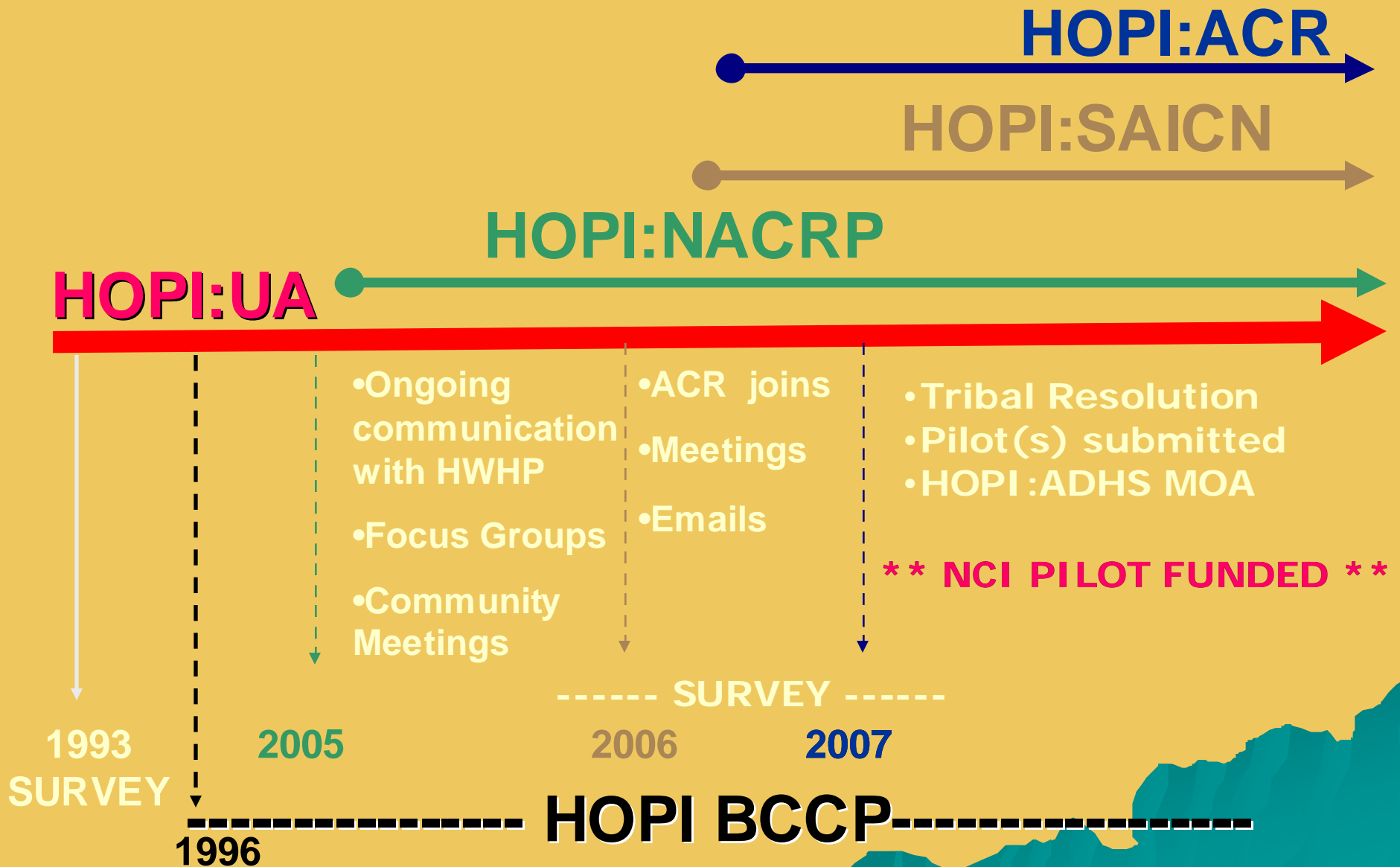
April 2007: SAICN STARTUP money provided

June 2007: Presentation to Hopi Officials & Health Workers

July 2007: MOA between the State of Arizona and Hopi Tribe on data exchange

Sept 2007: NCI PILOT AWARD NOTIFICATION

# COLLABORATION



# CURRENTLY AVAILABLE HOPI CANCER DATA

## ACR DATA

- **GEOCODED**
- Grouped into **COMMUNITY HEALTH ANALYSIS AREAS (CHAAs)**

**Purpose:** Convey Community Cancer Burden

**Aggregation:** Block Group

**Number:** 126

**Reporting:** All Races Combined

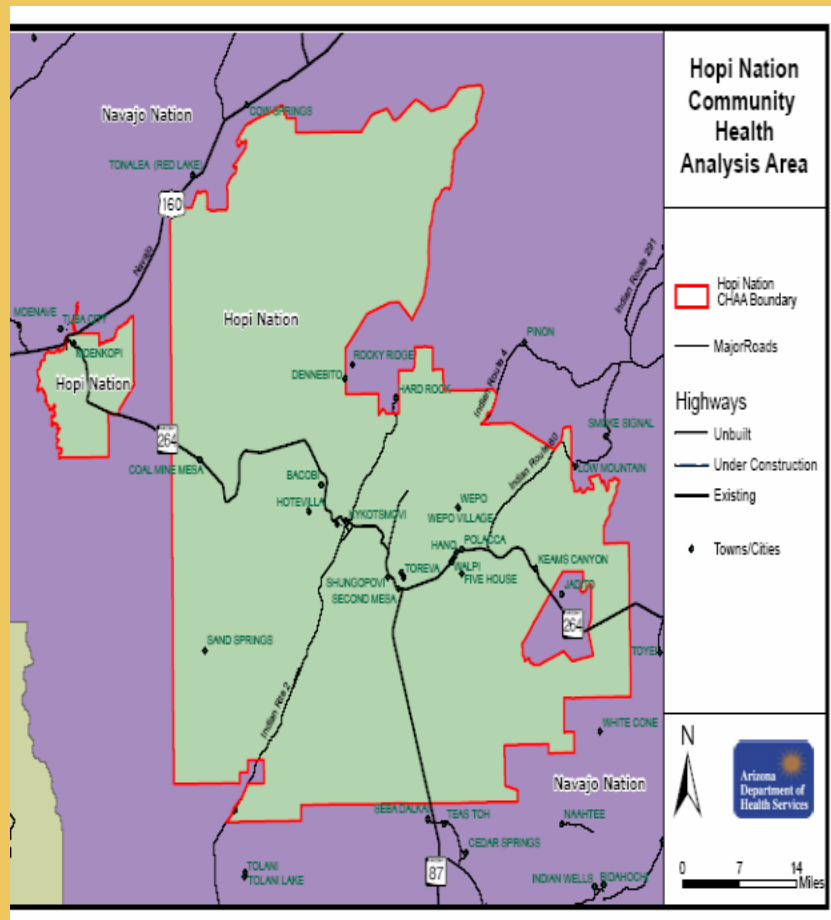


[http://www.azdhs.gov/phs/azchaa/chaa\\_base\\_map.pdf](http://www.azdhs.gov/phs/azchaa/chaa_base_map.pdf)

# HOPI CHAA

## Limitations

- Small numbers: cannot be publicly reported due to
  - rate instability
  - possible breach of confidentiality
- Hopi CHAA reports all providing Hopi address at time of diagnosis
- Not limited to Hopi people
- Does not reflect Hopi living off reservation

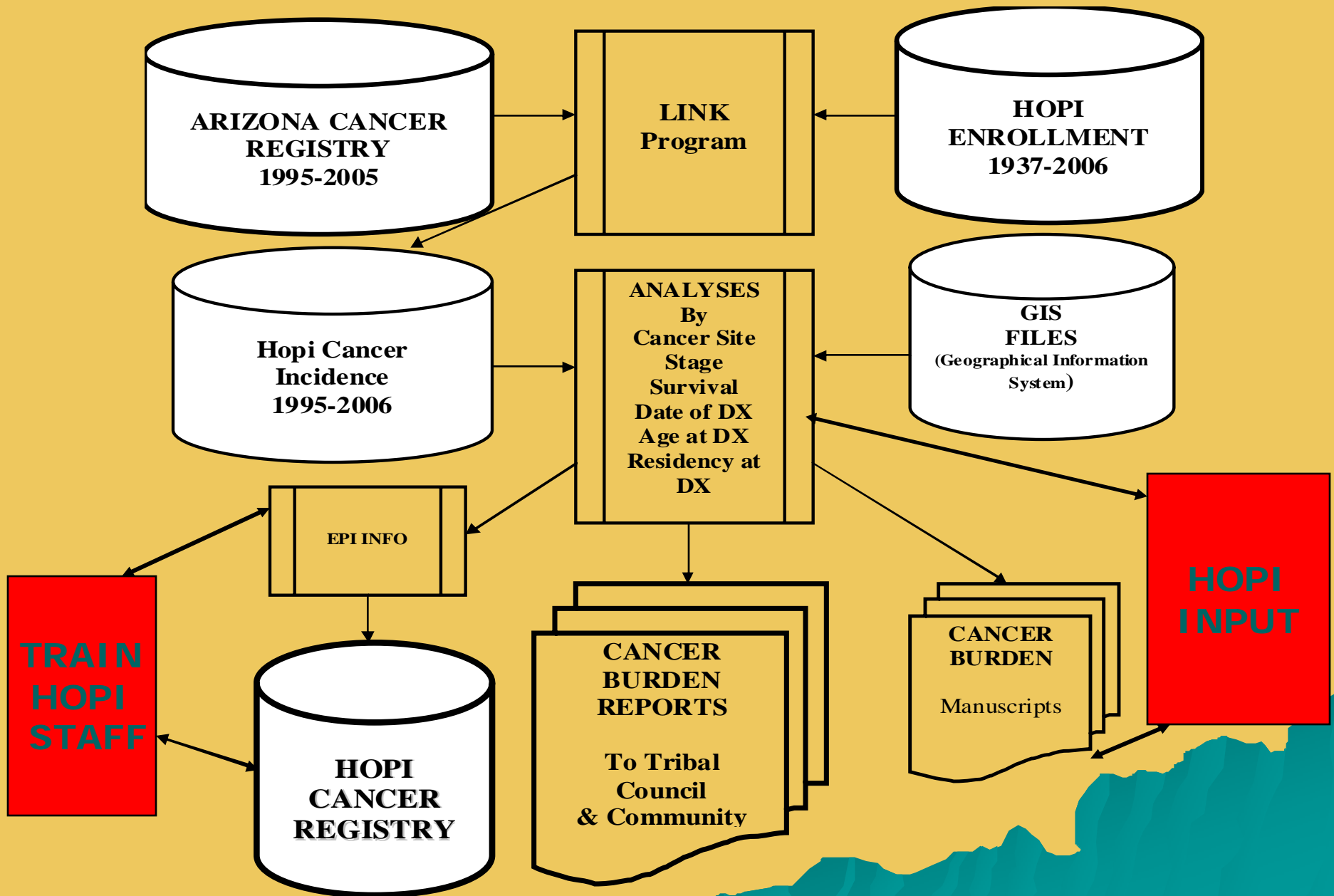


[http://www.azdhs.gov/phs/azchaa/maps/chaa\\_hopination.pdf](http://www.azdhs.gov/phs/azchaa/maps/chaa_hopination.pdf)

# SOLUTION

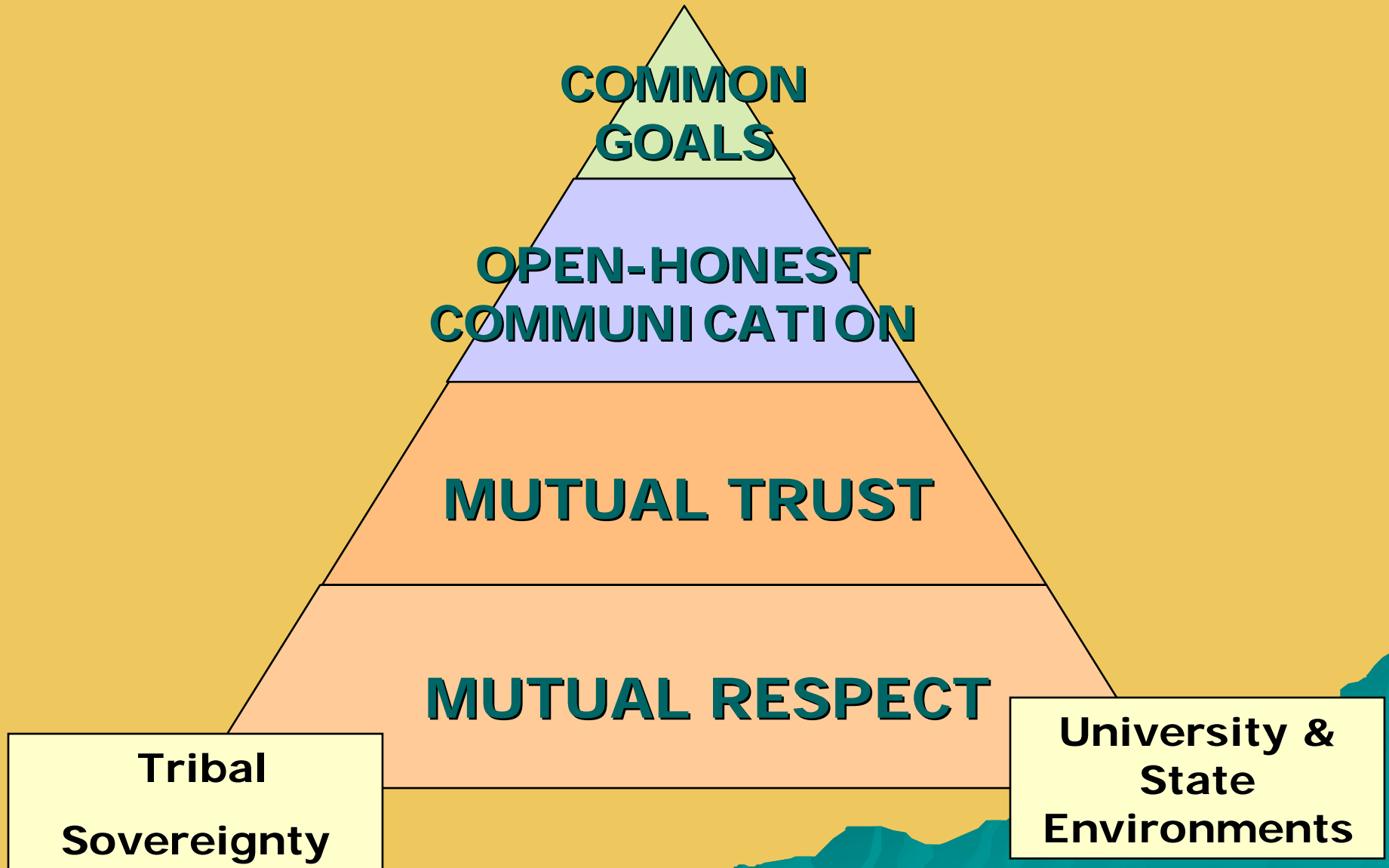
## **Link ACR data to Hopi Enrollment Data**

# HOPI PILOT DESIGN





# SECRET TO OUR SUCCESS





# THANK YOU

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The contents herein are solely the responsibility of the authors and do not necessarily represent the official views of the NIH/NCI