#### **Breast cancer in Indian Country**

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National Center for Chronic Disease Prevention and Health Promotion Division of Cancer Prevention and Control

#### **Learning Objectives**

- Discuss overall patterns of breast cancer incidence and mortality in American Indian and Alaska Native (AI/AN) women
- Describe regional variation in breast cancer mortality in AI/AN women
- Summarize the role and leverage the resources of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) in addressing the burden of breast cancer in AI/AN women

## **Overview**

- Background on breast cancer
- Breast cancer mortality
- National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

## What is Breast Cancer?

- Cancer begins in breast tissue
  - Noninvasive
  - Invasive

U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2010 Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2013. Available at: <a href="http://www.cdc.gov/uscs">www.cdc.gov/uscs</a>

## **Risk Factors**

#### Modifiable

- Obesity
- Alcohol use
- Cigarette use
- Hormone replacement therapy
- Pregnancy at later age
- Not breastfeeding

#### Non-modifiable

- Age
- Early menarche
- Late menopause
- Family history
- Inherited genetic mutations (BRCA1, BRCA2)

## **Cigarette Smoking**

New risk factor by recent studies:

- Smoking at early ages
- Smoking for long duration
- Second-hand smoke
- Data inconclusive, but showing strong associations

Gaudet, M.M., Gapstur, S.M., Sun, J., Diver, W.R., Hannan, L.M. Thun, M.J. Active smoking and breast cancer risk: original cohort data and metaanalysis. Journal of the National Cancer Institute. 2013 Apr 17; 105(8): 515-525.

Johnson, K.C., Miller, A.B., Collishaw, N.E., Palmer, J.R., Hammond, S.K., Salmon, A.G., Cantor, K.P., Miller, M.D., Boyd, N.F., Milar, J. & Turcotte, F. Active smoking and secondhand smoke increase breast cancer risk: the report of the Canadian Expert Panel on Tobacco Smoke and Breast Cancer Risk (2009). Tobacco Control. 2011 Jan;20(1):e2.

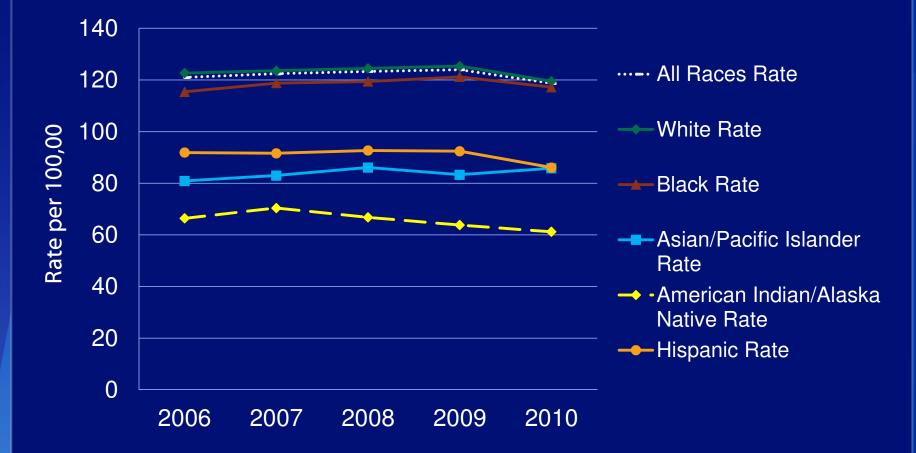
Terry, P.D., & Rohan, T.E. Cigarette smoking and the risk of breast cancer in women: a review of the literature. Cancer Epidemiology Biomarkers Prevention. 2002. 11(10 Pt 1): 953-71.

#### **Breast Cancer**

- Most commonly diagnosed cancer among women
- Second leading cause of cancer deaths
- 206,966 women diagnosed
- 40,996 women died

U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2010 Incidence and Mortality Web-based Report.* Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2013. Available at: <u>www.cdc.gov/uscs</u>

# Breast Cancer Incidence Rates by Race/Ethnicity, United States, 2006-2010



Rates are age-adjusted to the 2000 US Standard Population.

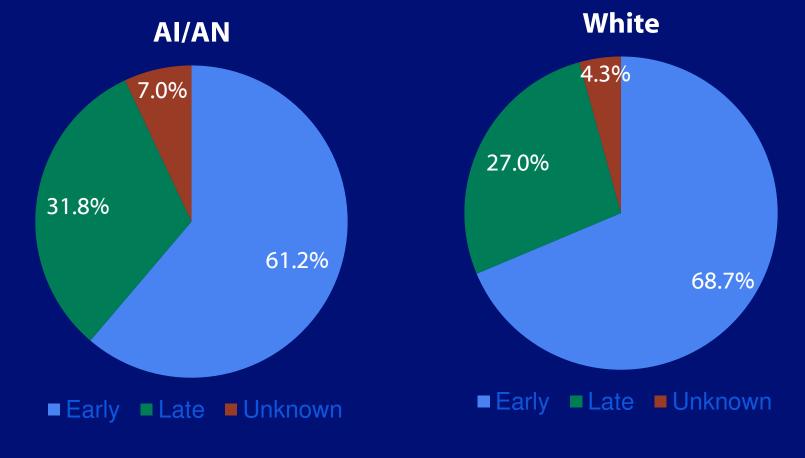
U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2010 Incidence and Mortality Web-based Report.* Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2013. Available at: <u>www.cdc.gov/uscs</u>

# **Breast Cancer in AI/AN**

- Most frequently diagnosed cancer
- Diagnosed at younger age
  - Al/AN: 57.5 years
  - NHW: 63.4 years
- Diagnosed at later stage

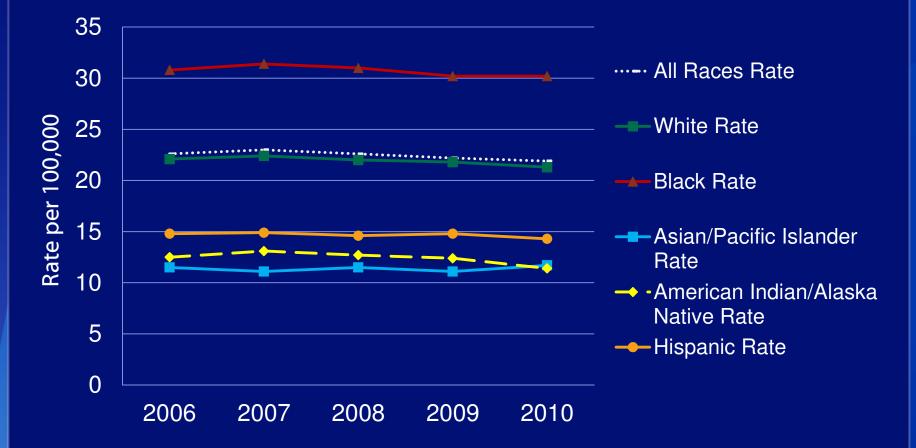
Wingo, P.A., King, J., Swan, J., Coughlin, S.S., Kaur, J.S., Erb-Alvarez, J.A., Jackson-Thompson, J., & Solomon, T.G. Breast Cancer Incidence Among American Indian and Alaska Native Women: US, 1999–2004. Cancer 2008;113(5 suppl):1191–202.

Invasive and In Situ Breast Cancer, Summary Stage Distribution for American Indian/Alaska Natives and White Women in Contract Health Service Delivery Area Counties: United States, 1999-2003



Wingo, P.A., King, J., Swan, J., Coughlin, S.S., Kaur, J.S., Erb-Alvarez, J.A., Jackson-Thompson, J., & Solomon, T.G. Breast Cancer Incidence Among American Indian and Alaska Native Women: US, 1999–2004. Cancer 2008;113(5 suppl):1191–202.

# Breast Cancer Death Rates by Race/Ethnicity, United States, 2006-2010



Rates are age-adjusted to the 2000 US Standard Population.

U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2010 Incidence and Mortality Web-based Report.* Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2013. Available at: <u>www.cdc.gov/uscs</u>

# BREAST CANCER MORTALITY REGIONAL VARIATION

Breast cancer mortality among American Indian and Alaska Native Women, 1990-2009

White, A., Richardson, L.C., Li, C., Ekwueme, D.U., and Kaur, J.S. Breast Cancer Mortality Among American Indian and Alaska Native Women, 1990–2009. American Journal of Public Health. Supplement 3, 2014, Vol 104, No. S3.

#### Background

#### Breast cancer incidence varies across the United States

- 1999-2004
- AI/AN women in Alaska have similar rates as NHW women
- AI/AN have lower rates in all other regions

#### Death rates exhibit similar patterns in regional variation

- 1990-2001
- AI/AN women in Alaska & Southern Plains have similar rates as NHW women
- AI/AN have lower rates in all other regions

Wingo, P.A., King, J., Swan, J., Coughlin, S.S., Kaur, J.S., Erb-Alvarez, J.A., Jackson-Thompson, J., & Solomon, T.G. Breast Cancer Incidence Among American Indian and Alaska Native Women: US, 1999–2004. Cancer . 2008. 113(5 suppl):1191–202. Espey, D., Paisono, R., Cobb, N. Regional patterns and trends in cancer mortality among American Indians and Alaska Natives, 1990-2001. Cancer. 2005 Mar 1;103(5):1045-53.

#### **Data Sources**

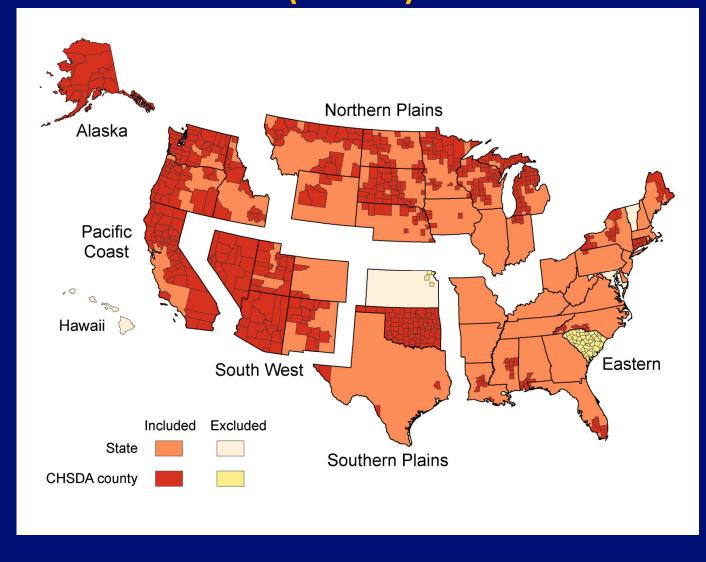
#### Death data

- National Center for Health Statistics
- Death certificates linked with Indian Health Service patient registration data
  - o 1990-2009

#### Population data

- US Census Bureau
- National Center for Health Statistics

# Indian Health Service Contract Service Delivery Areas (CHSDA)



# **Statistical Analysis**

- Mortality rates
  - Age- and race-specific
- Joinpoint analysis
  - Annual percentage change in breast cancer death rates

Death Rates for Breast Cancer by Indian Health Service Region for American Indian/Alaska Native Compared with White Women, All Ages, Contract Service Delivery Area Counties United States, 1990-2009

IHS Region	AI/AN	AI/AN Rate	White Rate	AI/AN: White
	Count			Rate Ratio (95% CI)
Northern Plains	376	26.6	25.6	1.04 (0.93, 1.16)
Alaska	178	27.9	24.9	1.12 (0.94, 1.33)
Southern Plains	475	29.3	25.2	*1.16 (1.06,1.28)
Pacific Coast	410	13.9	25.6	*0.54 (0.49, 0.60)
East	407	22.5	27.2	*0.83 (0.75, 0.92)
Southwest	124	17.6	26.9	*0.65 (0.54, 0.78)
Total	1970	21.6	26.5	*0.82 (0.78, 0.85)

Breast Cancer Death Rates by Indian Health Service Region for American Indian/Alaska Native and White Women, *Aged 0-39 years*, Contract Service Delivery Area Counties, United Sates, 1990-2009

IHS Region	AI/AN	White	RR
Northern Plains	1.8 (1.2, 2.7)	1.7 (1.5, 1.8)	1.1 (0.67, 1.60)
Alaska	2.8 (1.6, 4.6)	1.5 (1.0, 2.0)	1.9 (0.98, 3.50)
Southern Plains	1.8 (1.1, 2.8)	1.8 (1.5, 2.1)	1.0 (0.62, 1.60)
Southwest	1.4 (1.0, 2.0)	1.6 (1.4, 1.7)	0.9 (0.62, 1.30)
Pacific Coast	0.9 (0.5, 1.5)	1.6 (1.6, 1.7)	*0.5 (0.29, 0.92)
East	-	1.7 (1.6, 1.8)	-
Total	1.6 (1.3, 1.9)	1.7 (1.6, 1.7)	0.9 (0.77, 1.10)

Breast Cancer Death Rates by Indian Health Service Region for American Indian/Alaska Native and White Women, Aged 40-49 years, Contract Service Delivery Area Counties, United Sates, 1990-2009

IHS Region	AI/AN	White	RR
Northern Plains	19.0 (14.5, 24.6)	18.8 (18.1, 19.6)	1.0 (0.77, 1.30)
Alaska	27.3 (19.0, 38.0)	14.8 (12.2, 17.8)	*1.9 (1.20, 2.70)
Southern Plains	23.5 (18.2, 29.8)	19.0 (17.5, 20.6)	1.2 (0.95, 1.60)
Southwest	14.3 (11.4, 17.8)	19.7 (18.8, 20.6)	*0.7 (0.58, 0.91)
Pacific Coast	15.1 (11.5, 19.5)	20.8 (20.2, 21.5)	*0.7 (0.55, 0.93)
East	10.1 (5.5, 16.9)	20.5 (19.9, 21.2)	*0.5 (0.27, 0.83)
Total	17.4 (15.5, 19.4)	20.1 (19.7, 20.4)	*0.9 (0.77, 0.97)

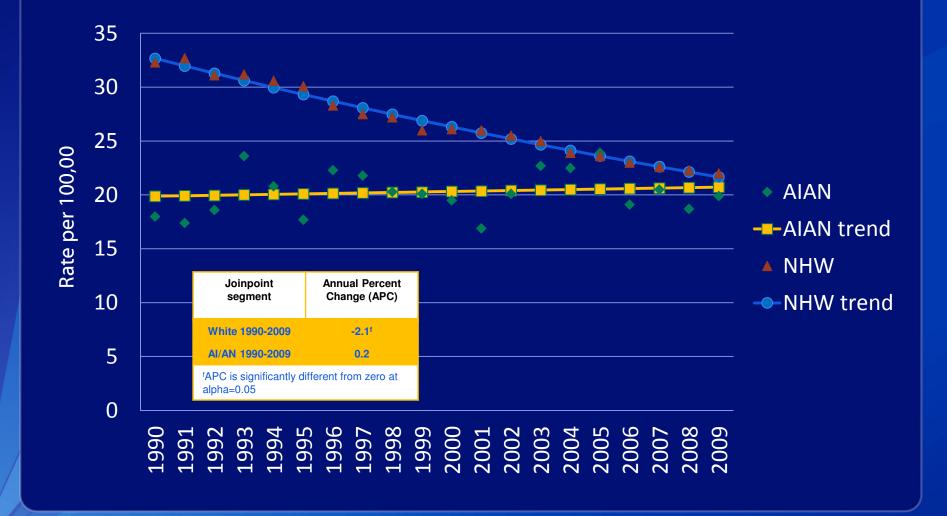
## Breast Cancer Death Rates by Indian Health Service Region for American Indian/Alaska Native and White Women, Aged 50-64 years, Contract Service Delivery Area Counties, United Sates, 1990-2009

IHS Region	AI/AN	White	RR
Northern Plains	47.6 (39.8, 56.6)	47.1 (46.0, 48.3)	1.0 (0.84, 1.20)
Alaska	58.1 (44.9, 73.9)	44.7 (39.5, 50.3)	1.3 (0.98, 1.70)
Southern Plains	55.2 (47.0, 64.5)	48.2 (46.0, 50.5)	1.2 (0.97, 1.30)
Southwest	28.0 (23.6, 32.9)	48.5 (47.2, 49.9)	*0.6 (0.48, 0.68)
Pacific Coast	42.2 (35.7, 49.4)	51.1 (50.2, 52.0)	*0.8 (0.70, 0.97)
East	41.0 (30.7, 53.6)	50.8 (49.9, 51.7)	0.8 (0.60, 1.06)
Total	42.0 (39.0, 45.2)	49.7 (49.2, 50.3)	*0.8 (0.78, 0.91)

Breast Cancer Death Rates by Indian Health Service Region for American Indian/Alaska Native and White Women, Aged <u>>65</u> years, Contract Service Delivery Area Counties, United Sates, 1990-2009

IHS Region	AI/AN	White	RR
Northern Plains	124.5 (105.9, 145.5)	115.6 (113.7, 117.4)	1.1 (0.92, 1.30)
Alaska	106.4 (81.1, 137.0)	120.4 (107.4, 134.5)	0.9 (0.66, 1.20)
Southern Plains	130.5 (114.0 , 148.8)	110.3 (106.9, 113.7)	*1.2 (1.00, 1.40)
Southwest	52.7 (44.6,61.9)	113.5 (111.5,115.6)	*0.5 (0.39, 0.55)
Pacific Coast	105.6 (90.5, 122.5)	121.3 (119.8, 122.7)	0.9 (0.75, 1.00)
East	71.5 (52.7,94.9)	119.2 (117.9, 120.5)	*0.6 (0.44, 0.80)
Total	93.5 (87.2, 100.1)	118.0 (117.2, 118.8)	*0.8 (0.74, 0.85)

#### Trends in Age-Adjusted Breast Cancer Death Rates: Contract Health Service Delivery Area counties, United States, 1990–2009



# Limitations

- Restricted to women residing in CHSDA areas
- Exclusion of Hispanic AI/AN women
- Use of death certificates

# Conclusions

- No improvement in death rates among AI/AN women
- Interventions:
  - Targeted screening
  - High-quality treatment

THE ROLE OF CDC IN ADDRESSING THE BREAST CANCER BURDEN AMONG AI/AN WOMEN



SCREENING WOMEN, SAVING LIVES

## Breast and Cervical Cancer Mortality Prevention Act of 1990

- Authorized CDC to address breast and cervical cancer screening among low-income, underserved women
- Requirements
  - public education
  - treatment referral
  - professional development
  - program monitoring
  - quality assurance
  - matching funds
  - 60/40 requirement
  - reimbursement at Medicare rate
  - Payor of last resort (exception to IHS)

### **Preventive Health Amendments of 1993**

- Authorized CDC to initiate a program with AI/AN tribes and tribal organizations to improve screening in tribal communities
- NBCCEDP was first CDC program to fund tribes directly
- Initial cooperative agreements with
  - Arctic Slope Native Association Limited
  - Cherokee Nation
  - Cheyenne River Sioux
  - Southcentral Foundation
  - South Puget Intertribal Planning Agency

#### **NBCCEDP** grantees



# **Clinical Services**

- Clinical breast examinations
- Mammograms
- Breast MRI
- Pap testing
- HPV testing
- Pelvic examinations
- Diagnostic testing if results are abnormal
- Referrals to treatment

# **Non-clinical Support Services**

- Program management
- Data management
- Quality assurance / quality improvement
- Professional development
- Case management
- Recruitment and outreach

## **Eligibility Criteria**

- CDC policies established eligibility criteria for women
  - ≤250 % federal poverty level
  - Uninsured or underinsured
  - Age parameters
    - 40-64 years old for breast cancer screening
    - 21-64 years old for cervical cancer screening
- Grantees can modify these criteria as needed

#### **NBCCEDP** Policies

- CDC does not develop screening guidelines
- Policy identifies what can be covered
- Generally follow the US Preventive Services Task Force guidelines for screening; the American College of Obstetrics and Gynecology and American Cancer Society for topics not addressed such as high risk women
- Follow National Comprehensive Cancer Network guidelines for follow up to abnormal screening results

#### **Clinical Services and Outcomes**

#### Since Inception in 1991

- 4.6 million women served
- 11.6 million screenings
- 64,718 breast cancers
- 3,576 cervical cancers
- 167,169 premalignant cervical lesions (40% high grade)

#### Program Year 2013

- 561,306 women served
- 589,409 screenings
- 5,982 breast cancers
- 269 cervical cancers
- 11,381 premalignant cervical lesions

# **Clinical Surveillance Dataset Minimum Data Elements (MDEs)**

- Each record describes a clinical visit
- Data include
  - Patient demographics
  - Screening location
  - Screening history
  - Screening tests and results
  - Diagnostic tests and results
  - Date of treatment initiation

- Nationwide data
- Submitted twice/year
- Monitors screening, follow-up, and clinical outcomes
- Assists with program management, quality assurance, and evaluation
- Used for program relevant research

# **Core Quality Indicators for Program Performance**

Туре	Indicator	Target
Screening Priority Population	Mammography screening age 50 and older	
	Women rarely/never screened for cervical cancer	<u>&gt;</u> 20%
Timely and complete Diagnostic follow-up of	Breast diagnosis completed	<i>≥90%</i>
abnormal screening results	Breast diagnosis completed within 60 days	<u>&gt;</u> 75%
	Cervical diagnosis completed	<i>≥90%</i>
	Cervical diagnosis completed within 90 days	<u>&gt;</u> 75%
Timely and complete Treatment initiated for	Breast treatment initiated	<u>≥</u> 90%
cancers diagnosed	Breast treatment initiated within 60 days	<u>&gt;</u> 80%
	Cervical treatment initiated	<u>≥</u> 90%
	Cervical treatment initiated within 60 days (Invasive)	<u>&gt;80%</u>
	Cervical treatment initiated within 90 days (CIN2/3)	<u>&gt;80%</u>

# Breast and Cervical Cancer Prevention and Treatment Act of 2000

- Allowed states the option to offer women treatment through Medicaid
- Each state establishes guidelines for treatment eligibility

## Native American Breast and Cervical Cancer Treatment Technical Amendment Act of 2001

 Extends Medicaid treatment services to American Indians and Native Alaskans who received their care through the Indian Health Service.

#### Women Screened in the NBCCEDP by Race/Ethnicity, 1991 to 2012

Race/ethnicity	Women screened for breast cancer		Women	screened
	n	%	n	%
Black	467,943	16.4	679,262	15.3
AI/AN	113,140	4.0	206,238	4.6
A/PI	156,718	5.5	234,905	5.3
Hispanic <sup>a</sup>	737,258	25.9	1,206,767	27.2
Multi/unk	66,938	2.4	106,122	2.4
Total	2,848,176		4,443,975	

Source: National Breast and Cervical Cancer Early Detection Program, October 2013 submission of the Minimum Data Elements NBCCEDP indicates National Breast and Cervical Cancer Early Detection Program; AI/AN, American Indian and Alaska Native <sup>a</sup> Regions defined per previous analyses and standard definitions used within the community and based on state boundaries

# Characteristics of Women Screened for Breast Cancer in the NBCCEDP, 1991 to 2012

Characteristics	No. (%) AI/AN	No. (%) Overall
Women screened	113,140 (100)	2,848,176 (100)
Age		
<40	4,769 (4.2)	83,201 (2.9)
40-49	45,397 (40.1)	783,352 (27.5)
50-64	55,886 (49.4)	1,837,672 (64.5)
<u>&gt;</u> 65	7,088 (6.3)	143,951 (5.1)
Residence		
Metro	51,949 (45.9)	2,125,012 (74.6)
Urban	50,827 (44.9)	608,764 (21.4)
Rural	10,196 (9.0)	106,345 (3.7)
Unknown	168 (0.1)	8,055 (0.3)
Region <sup>a</sup>		
East	11,335 (10.0)	1,277,564 (44.9)
Alaska	14,689 (13.0)	27,048 (0.9)
Southwest	39,873 (35.2)	230,900 (8.1)
Pacific Coast	14,407 (12.7)	556,322 (19.5)
N. Plains	18,696 (16.5)	480,679 (16.9)
S. Plains	13,982 (12.4)	215,006 (7.5)
Other/Unknown	158 (0.1)	60,657 (2.1)

Source: National Breast and Cervical Cancer Early Detection Program, October 2013 submission of the Minimum Data Elements NBCCEDP indicates National Breast and Cervical Cancer Early Detection Program; AI/AN, American Indian and Alaska Native <sup>a</sup> Regions defined per previous analyses and standard definitions used within the community and based on state boundaries

# NBCCEDP Eligible Population for Breast Cancer Screening

Race/ethnicity	All women age 40-64		Women eligible <sup>a</sup> for NBCCEDP mammography screening			
	Number (thousand)	Percent distribution <sup>b</sup>	Number (thousand)	90% CI	Percent <sup>c</sup>	90% CI
Total	46,899	100	4,007	3,806-4,208	8.5	8.1-9.0
Non-Hispanic	42,504	90.6	2,991	2,817-3,166	7.0	6.6-7.4
White	34,403	73.4	1,972	1,835-2,109	5.7	5.3-6.1
Black	5,439	11.6	714	629-799	13.1	11.6-14.6
AI/AN	225	0.5	45	23-66	19.8	11.3-28.4
A/NH/OPI	1,977	4.2	221	173-268	11.2	8.9-13.4
Multiracial	460	1.0	41	20-61	8.9	4.6-13.2
Hispanic	4,395	9.4	1,016	909–1,122	23.1	20.9-25.3

Source: Tangka FK, Dalaker J, Chattopadhyay SK, Gardner JG, Royalty J, Hall IJ, DeGroff A, Blackman DK, Coates RJ.. Meeting the mammography screening needs of underserved women: the performance of the National Breast and Cervical Cancer Early Detection Program in 2002-2003 (United States). Cancer Causes Control. 2006 Nov;17(9):1145-54.

# NBCCEDP Reach to Eligible Population for Breast Cancer Screening

Race/ethnicity	Number of women screened	Percentage of U.S. women screened <sup>a</sup>	Percentag NBCCED women sc	P-eligible
			%	90% CI
Total	528,622	1.1	13.2	12.5-13.9
Non-Hispanic	349,655	0.8	11.7	11.0-12.4
White	221,433	0.6	11.2	10.4 - 12.0
Black	74,259	1.4	10.4	9.2-11.6
AI/AN	21,882	9.7	49.2	25.5-72.9
A/NH/OPI	30,687	1.6	13.9	10.9-16.9
Multiracial	1,394	0.3	3.4	1.7-5.2
Hispanic	166,314	3.8	16.4	14.7-18.1

Source: Tangka FK, Dalaker J, Chattopadhyay SK, Gardner JG, Royalty J, Hall IJ, DeGroff A, Blackman DK, Coates RJ.. Meeting the mammography screening needs of underserved women: the performance of the National Breast and Cervical Cancer Early Detection Program in 2002-2003 (United States). Cancer Causes Control. 2006 Nov;17(9):1145-54.

# **AI/AN Community Challenges**

- Geographic barriers
- Language barriers
- Fear and lack of knowledge
- Traditional medicine and Western medicine

# **NBCCEDP Interventions for AI/AN**

- Mobile mammography and clinics
- Screening events
- Bi-lingual educators
- Cancer dictionaries
- Home visits education and case management
- Culturally appropriate events
- Flexibility and coordination with traditional medicine

#### **Contact information:**

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

National Center for Chronic Disease Prevention and Health Promotion Division of Cancer Prevention and Control

