



WALKING FORWARD

**Collaborating at the Community Level
To Advance Cancer Control**

**NASEM Workshop
November 12, 2019**

**Daniel G Petereit, MD, FASTRO
Avera Cancer Care Institute, Sioux Falls, SD
Regional Cancer Care Institute, Rapid City, SD**





Walking Forward Community Model for Cancer Control



SCREENING • NAVIGATION • CLINICAL TRIALS • GENOMICS • PALLIATION



Walking Forward's Vision

To improve the quality of life for AI cancer patients from early detection, successful treatment and survivorship - including end of life care

Walking Forward's Mission

This has been and will continue to be accomplished through access to screening, state of the art cancer treatments and clinical trials, and comprehensive patient navigation

Expansion into the entire Frontier population



Objectives

- **Discuss American Indian History and historical trauma**
- **Discuss the National Cancer Institute (NCI) Cancer Disparity Research Partnership (CDRP) Program**
- **Phase I and II: Discuss objectives and 10 year results
2002-2011**
- **Phase III: Mobile health smoking cessation program
2011-2017**
- **Phase IV: Lung Cancer Screening Project (LDCT)
2018-2022**
- **Phase V: RO1 Palliative Care Grant
2019-2024**



Disclosures

- **Bristol Myers Squibb Foundation**
- **Pink Pony Ralph Lauren Foundation**
- **Irving A Memorial Hansen Foundation**
- **NCI Funding**
- **President of the American Brachytherapy Society**



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- **From South Dakota!**

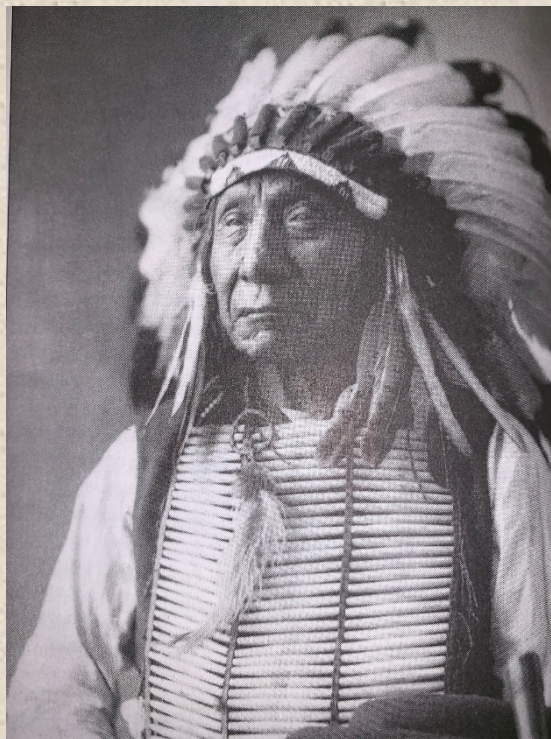


RED CLOUD (Maḥpíya Lúta)





RED CLOUD (Maŋpíya Lúta)



“They made us many promises, more than I can remember. But they kept but one – They promised to take our land...and they took it”



Crazy Horse (Tashunka Witco)





Crazy Horse (Tashunka Witco)

"My lands are where my dead lie buried"





MASSACRE OF WOUNDED KNEE

Dec. 29, 1890, Chief Big Foot, with his Minneconjou and Hunkpapa Sioux Band of 106 warriors, 250 women and children, were encamped on this Flat, surrounded by the U.S. 7th Cavalry (470 soldiers), commanded by Col. Forsythe.

The "Messiah Craze" possessed many Indians, who left the vicinity of the Agencies to "Ghost Dance" during the summer and fall of 1890. "Unrest" on the Pine Ridge Reservation was partly due to the reduction of beef rations by Congress, and to the "Ghost Dancing" of Chiefs Sitting Bull, Hump, Big Foot, Kicking Bear, and Short Bull. The Sioux were told by Kicking Bear and Short Bull that by wearing "Ghost Shirts," the ghost dancing warriors would become immune to the whiteman's bullets and could openly defy the soldiers and white settlers, and bring back the old days of the big buffalo herds.

On Nov. 15, 1890, Indian Agent Royer (Lakota Wokokpa) at Pine Ridge called for troops, and by Dec. 1, 1890, several thousand U.S. Regulars were assembled in this area of Dakota Territory.

On Dec. 15, 1890, Chief Sitting Bull was killed by Lt. Bullhead of the Standing Rock Indian Police. Forty of Sitting Bull's braves escaped from Grand River, and joined Chief Big Foot's band on Deep Creek, to camp and "Ghost Dance" on the south fork of the Cheyenne River. Chief Big Foot was under close scrutiny of Lt. Col. Sumner and his troops, and on Dec. 23, 1890, they were ordered to arrest Big Foot as a hostile. However, the Big Foot band had already silently slipped away from the Cheyenne country, into the Badlands, heading for Pine Ridge.

On Dec. 28, 1890, without a struggle, Chief Big Foot surrendered to the U.S. 7th Cavalry (Maj. Whitesides) at the site marked by a sign five miles north of here. The Band was then escorted to Wounded Knee, camping that night under guard.

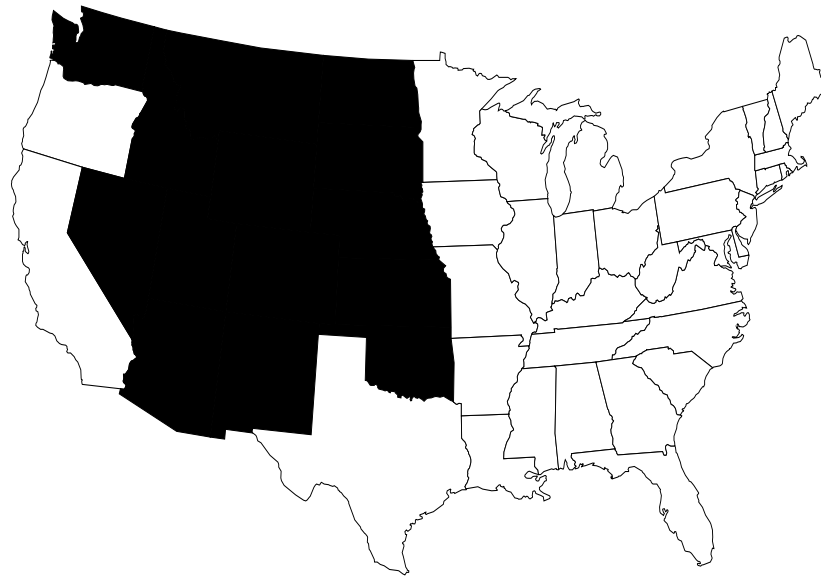
Reinforcements of the U.S. 7th Cavalry (including one company of Indian Scouts) arrived at Wounded Knee from Pine Ridge Agency the morning of Dec. 29, 1890. Col. Forsythe took command of a force of 470 men. A battery of four Hotchkiss guns was placed on the hill 400 feet west of here, overlooking the Indian encampment. Big Foot's Band was encircled at 10:00 P.M.

By — Stanley S. Walker Sup. Highway Engr.

Delineator — Irving R. Pond and Herbert H. Clifford

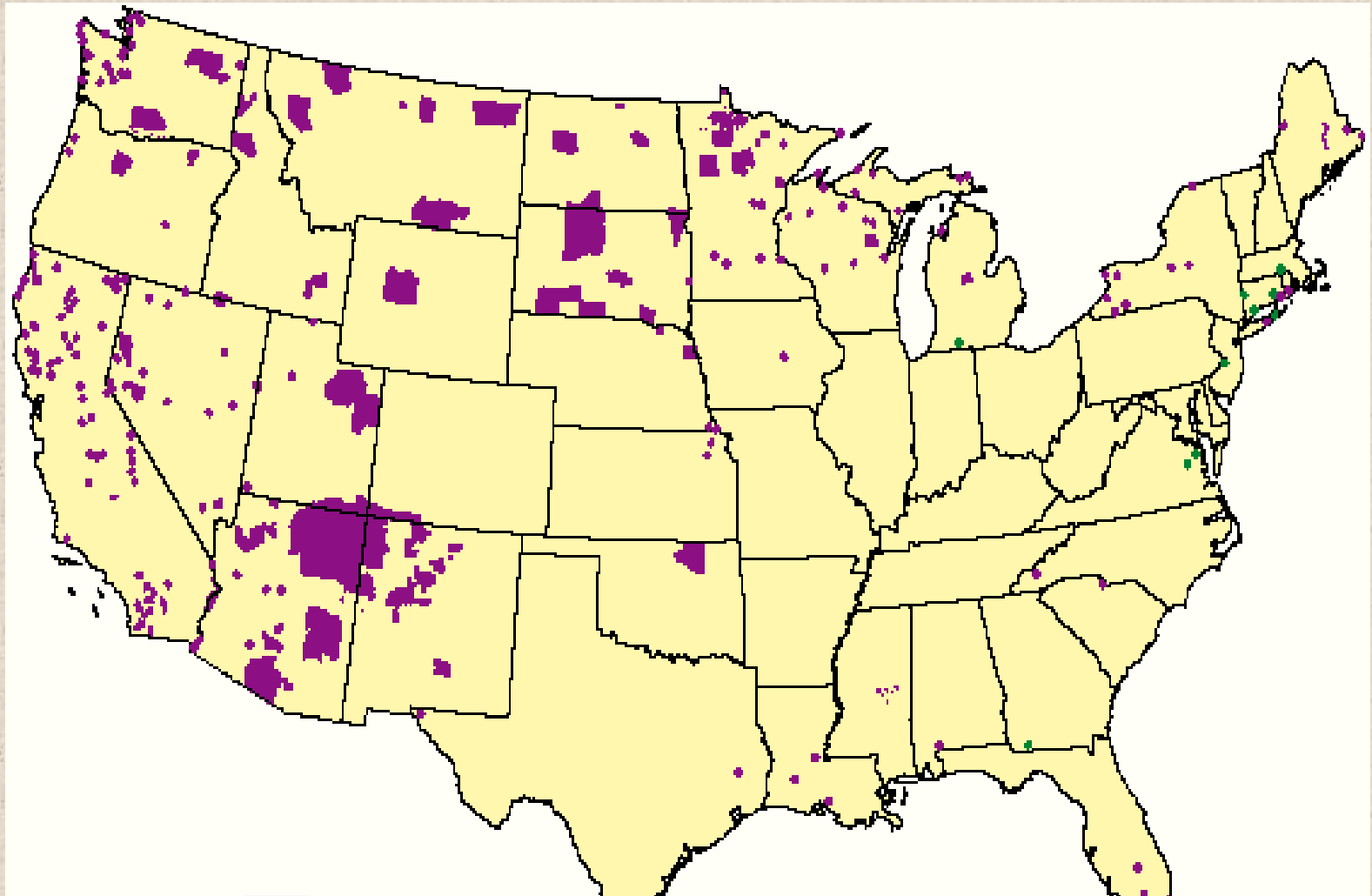


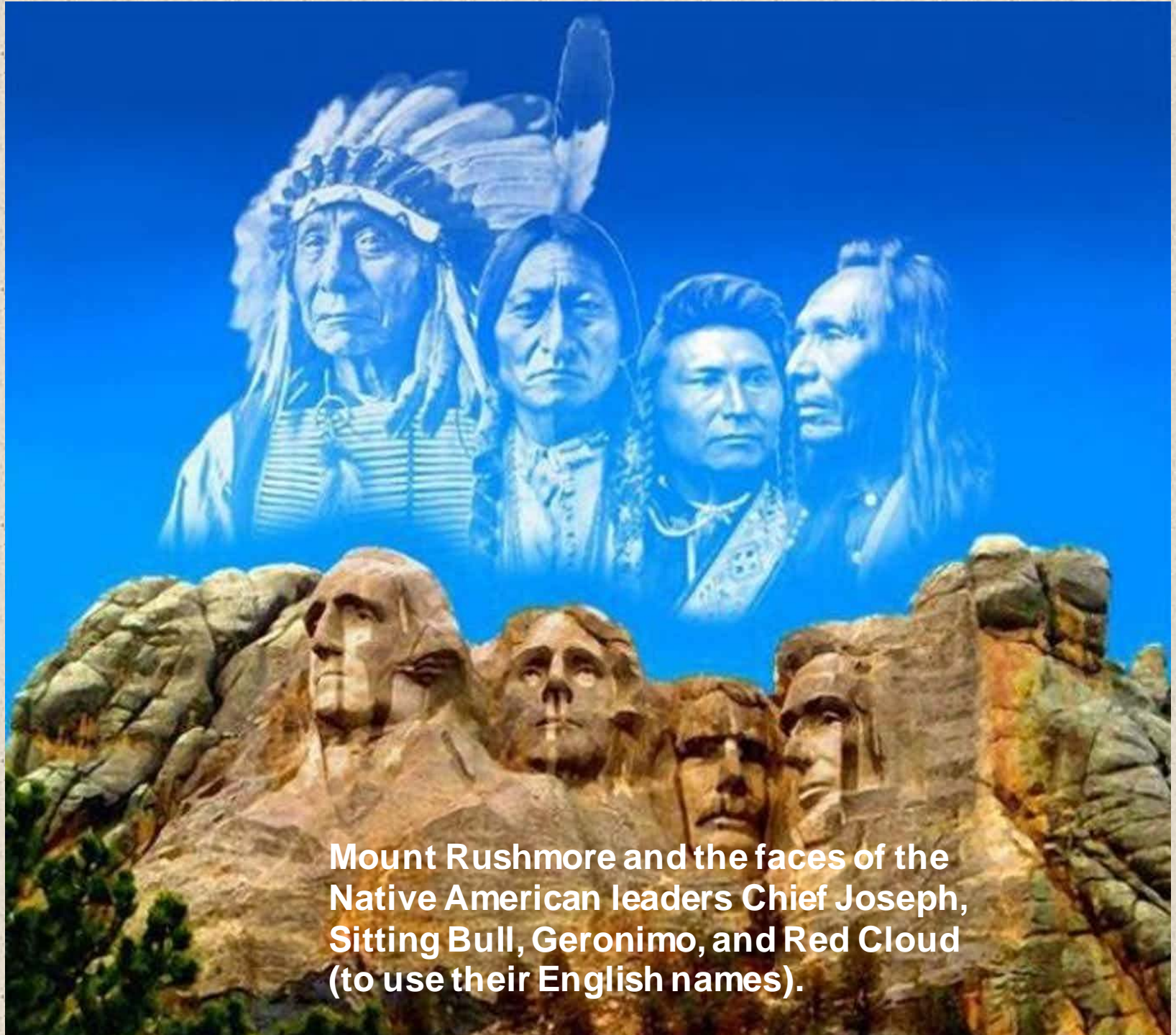
Indian Lands within the U.S.: 1492 to ...?



1860

Indian Lands: 1492 to Present





Mount Rushmore and the faces of the Native American leaders Chief Joseph, Sitting Bull, Geronimo, and Red Cloud (to use their English names).

How May Historical Trauma Affect AIANs Use Of The Healthcare System?

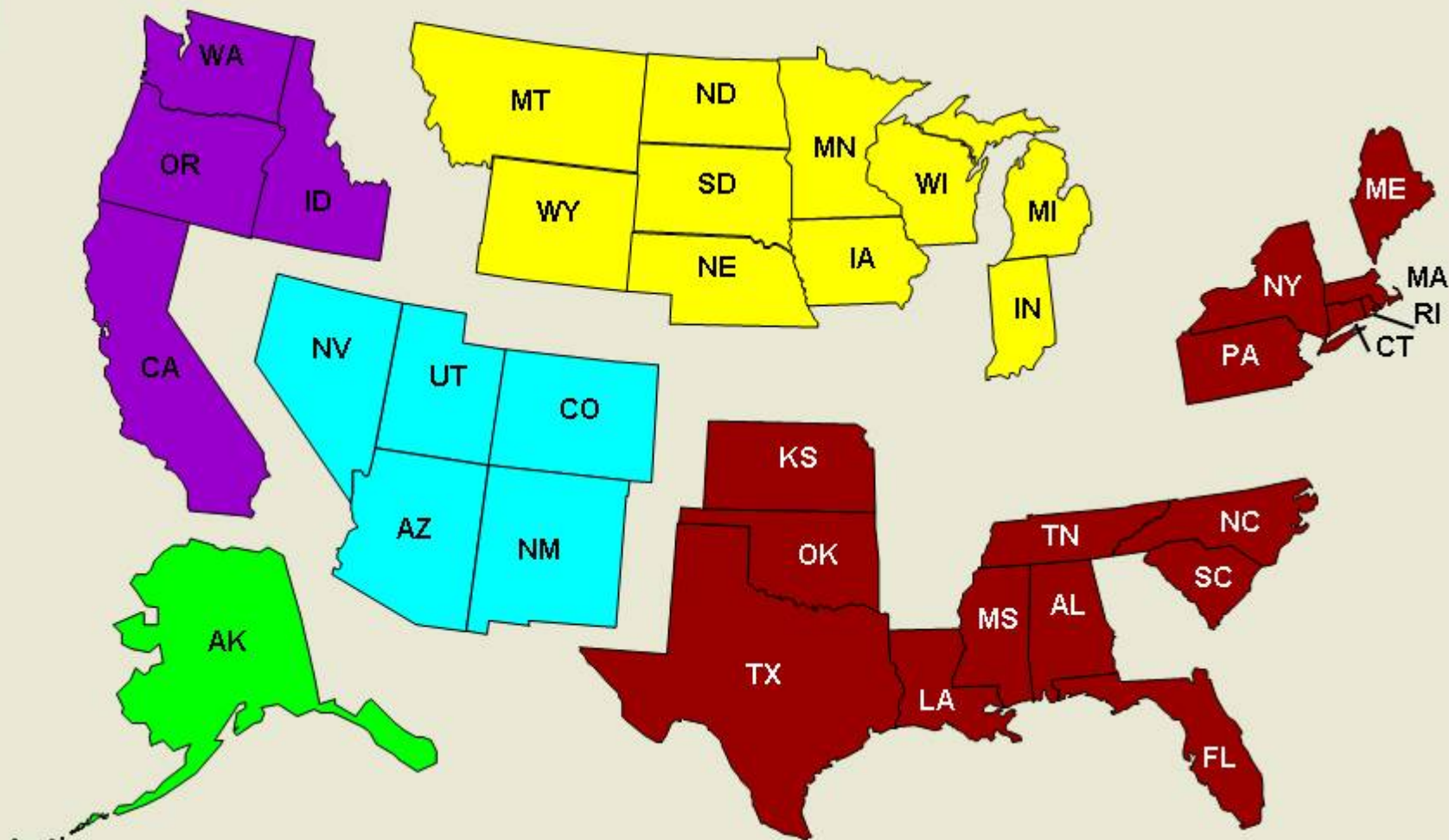
- Example: distrust = avoid Western medicine

What are specific examples related to cancer?

- Cancer clinical trials
- Cancer genetic studies
- Petereit: PI of Walking Forward???



Five Geographic Regions



ALASKA



NORTHERN PLAINS



EAST



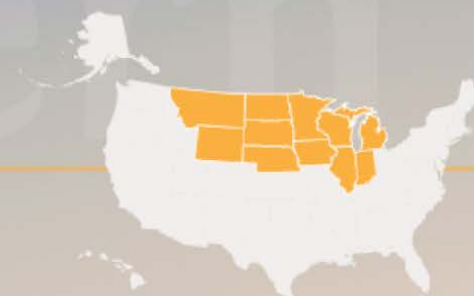
PACIFIC COAST



SOUTHWEST

Northern Plains

AI/AN in the Northern Plains experience some of the **highest** cancer diagnoses and death rates in the United States.

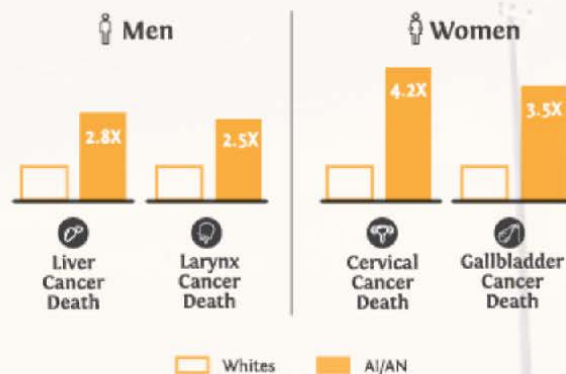


Most Common Cancers: Northern Plains

Cancer Diagnosis	Women	Cancer Deaths
#1 Breast		#1 Lung *
* #2 Lung		#2 Breast
* #3 Colorectal		#3 Colorectal *
Cancer Diagnosis	Men	Cancer Deaths
#1 Prostate		#1 Lung *
* #2 Lung		#2 Colorectal *
* #3 Colorectal		#3 Prostate *

* Indicates higher rate for AI/AN than whites

Cancer Disparities for AI/AN vs. Whites: Northern Plains



Prevention

Lung cancer is the leading cause of cancer death in the Northern Plains. Improved access to tobacco cessation services like quit lines, medications, and counseling can help AI/AN people quit commercial tobacco and reduce their risk for lung cancer.

Cancer in Native America

Guadagnolo, Petereit Sem in Rad Oncol, 2017

McClelland, Leberknight, Petereit Advances in Radiation Oncology 2017

- High rates of high risk health behaviors and comorbidities (social stressors)
- Low screening rates (resources, trust, remoteness, health literacy)
- AI/ANs more likely to have advanced-stage cancer at diagnosis than other racial groups
- AI/ANs less likely to get cancer-directed therapies after cancer diagnosis than non-Hispanic whites
- Pine Ridge Indian Reservation Data
 - Median age: 25
 - 51% live below poverty
 - Life expectancy lowest in the US: 48 males, 52 for females



Stage of Cancer at Presentation

Site	Native American Population					Non-Native American Population				
	Total Patients	Stage 1&2	Stage 3	Stage 4	Total % 3 & 4	Total Patients	Stage 1&2	Stage 3	Stage 4	Total % 3 & 4
Lung	304	85	92	127	72%	2438	780	669	989	68%
Breast	544	457	12	75	16%	12380	11142	111	1127	10%
Colorectal	167	87	26	54	48%	2593	1556	298	739	40%
Prostate	164	92	22	50	44%	4087	2861	281	945	30%
Cervix	43	20	8	15	53%	246	182	13	51	26%
TOTAL:	1222	741	160	321	50%	21744	16521	1372	3851	36%

Petereit et al JCO 22:4452-4455, 2004



CDRP (Cancer Disparity Research Partnership)



Build and stabilize independent and collaborative clinical research capabilities of institutions providing radiation oncology care to populations experiencing the negative consequences of cancer-related health disparities.

- C. Norman Coleman, MD, FASTRO
- Frank Govern, PhD
- Bhadrasain Vikram, MD, FASTRO
- Rosemary Wong, PhD



Radiation Research Program
Division of Cancer Treatment and Diagnosis
National Cancer Institute: 2001

When we look into the eyes
of our relatives, we know
how precious life is.

WALKING FORWARD
To'katakiya zanniyan omani pi ye/yo.

Walking Forward, a program of Rapid City Regional Hospital (in partnership with the National Cancer Institute), seeks ways to help families and communities protect life and health. By working together, doctors, other health care workers, and people in the community can address cancer prevention, detection, and early treatment. We are committed to walking forward toward a healthier life for all the people we serve.

Mitakuye oyasin!

Hear more about the Walking Forward program on KILI Radio every other Wednesday from 10-11 a.m.

For more information call 800-232-0115 ext.2305 | E-mail: walkingforward@rcrh.org

 **RAPID CITY REGIONAL HOSPITAL**
353 Fairmont Blvd., Rapid City, SD

 Cancer Disparities Research Partnership



Addressing Cancer Disparities

- Behavioral research: assessing barriers to early cancer detection
- Culturally appropriate community education
- Comprehensive patient navigation program
- Recruitment to clinical trials
- Shorter treatment schedules for prostate and breast cancer: brachytherapy and IMRT (geographic distance)

Primary Hypothesis: these interventions would lead to patients presenting with earlier stages of cancer

Petereit et al. Addressing Cancer Disparities among American Indians, *Frontiers in Radiation Oncology* 6/22/11



Founding Partners: UW - Minesh Mehta, Mayo – Judith Kaur



SCREENING • NAVIGATION • CLINICAL TRIALS • GENOMICS • PALLIATION

Sept 2002: Grant Awarded



JOHN T. VUCUREVICH

REGIONAL
CANCER CARE INSTITUTE



Cancer Disparities Research
Partnership Program



CDRP Award Recipients

Rapid City Regional Hospital
Rapid City, SD

University of Wisconsin
Madison, WI

UPMC McKeesport
McKeesport, PA

- Center for
- Clinical O
- National
NIH, Beth
- Walter R
- Children
- Washing

Nation
Bethes

Wheeling
Wheeling

Washington University
St. Louis, MO

UNC Hospitals
Chapel Hill, NC

New Hanover Regional
Medical Center
Wilmington, NC

University of Southern California
Los Angeles, CA

Daniel Freeman Memorial Hospital
Inglewood, CA

University of Alabama
Birmingham, AL

Singing River Hospital
Pascagoula, MS

University of Texas
Health Sciences Center
San Antonio, TX

Laredo Medical Center
Laredo, TX

Holy Cross Hospital
Ft. Lauderdale, FL

★ - CDRP Awardee

● - CDRP Mentor

★ - Other Sites



Western South Dakota

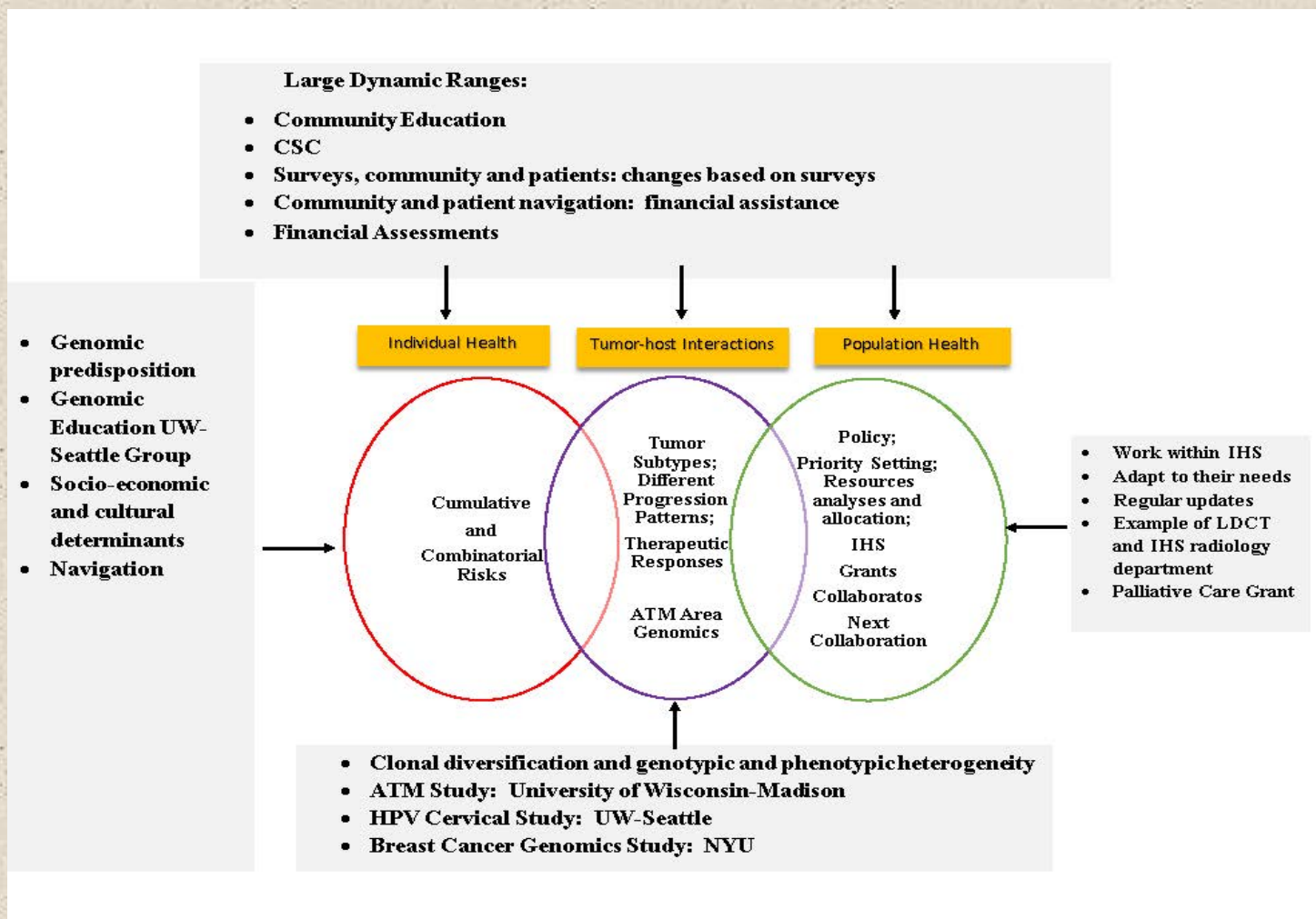
Pine Ridge

Rosebud

Cheyenne River

Rapid City

Cancer Control As a Complex Adaptive System





Walking Forward Critical Outcomes

- **Accrual rate of 10% of AIs to clinical trials**



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- **Successful completion of a genetic study (ATM)**



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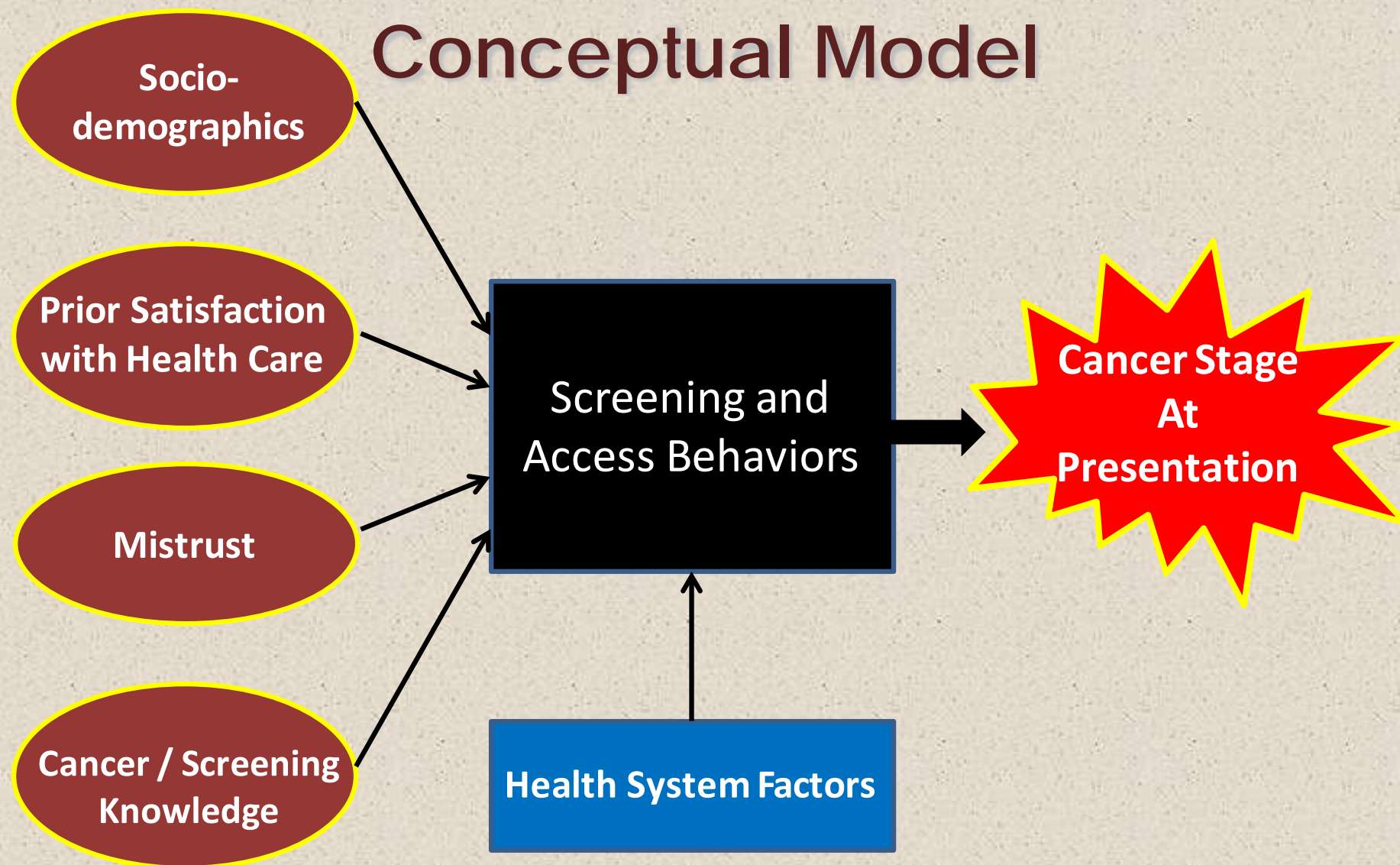


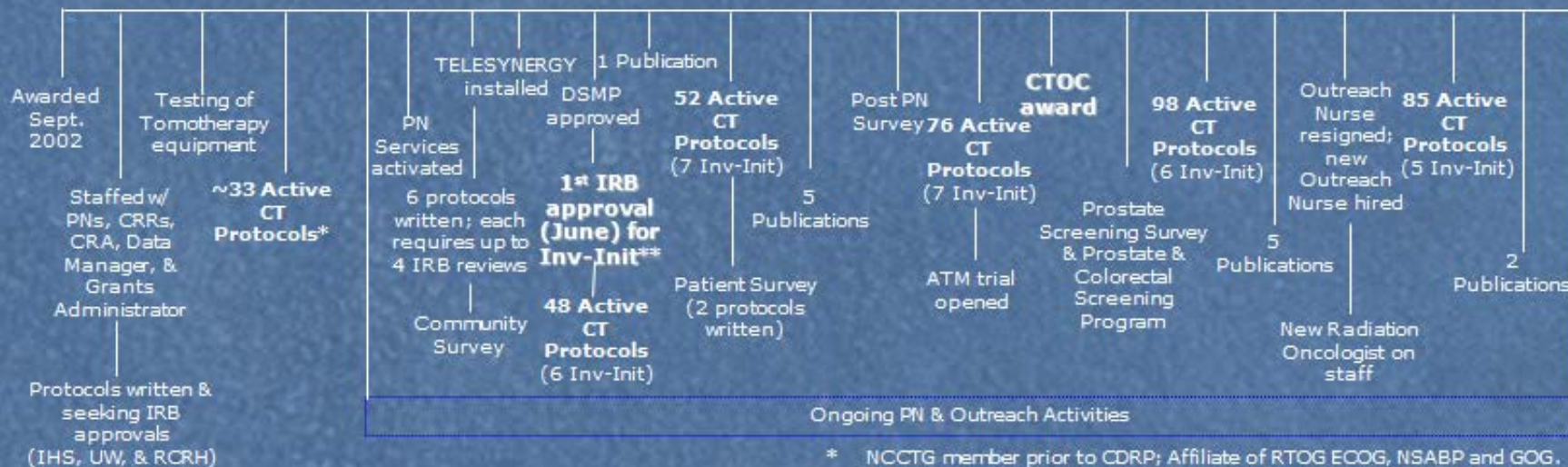
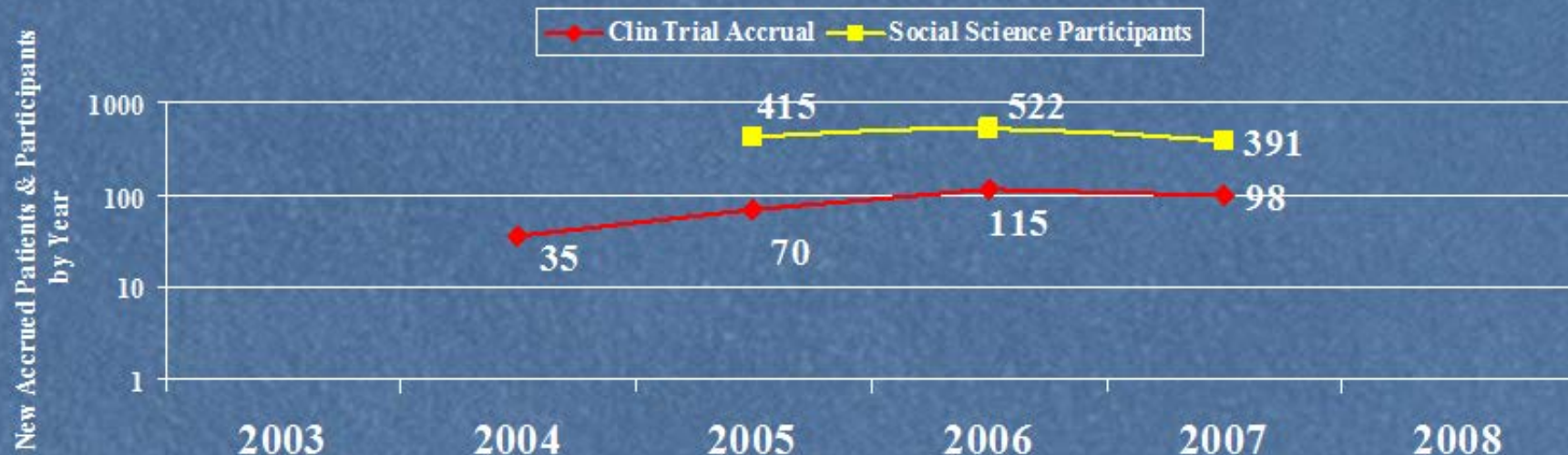
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- **60 manuscripts, 16M grants (NIH and foundations)**



Conceptual Model





* NCCTG member prior to CDRP; Affiliate of RTOG ECOG, NSABP and GOG.

** Inv-Init = Investigator-initiated studies.



Patient Navigation Program

Two Navigation Programs:

1. Community Navigation Program

- Community Research Representatives (CRRs)
- Assessment of barriers to early cancer detection
- Goal: promote education, outreach networking

2. Cancer Navigation Program

- RN navigators
- Identify barriers during cancer treatment
- Goal: assist cancer patients during cancer treatment



Patient Navigation Objectives

- Education: Cancer 101 Modules
- Community surveys
- Cancer surveys
- Patient Navigation Surveys
- Networking
- Foundation and trust for entire project



Patient Navigation Impact


- Reduction treatment interruptions: Yes
- Overall experience during treatment enhanced: Yes
- Change in trust towards healthcare system: No
- Cultural Competency: Yes

Molloy, K, Petereit, D et al. Developing and Implementing a Culturally Competent Patient Navigator Program in American Indian communities in Western, South Dakota. Association of Community Cancer Centers Oncology Issues, 22 (5);38-41, Sept/Oct 2007.

Guadagnolo BA, Cina K, Koop D, Brunette D, Petereit DG. A pre-post survey analysis of satisfaction with health care and medical mistrust after patient navigation for American Indian cancer patients in the Northern Plains. *Journal of Health care for the Poor and Underserved*. 22(4), 2011;1331-13433

Yearly Mileage for *Walking Forward* Team

September 2006 – August 2007

	OST	RST	CRST	RC	Kevin	Total by Month
Sept. 06	557	604	688		1358	3207
Oct. 06	446		799			1245
Nov. 06		720	850		68	1638
Dec. 06		456	486			942
Jan. 07			808	94		902
Feb. 07			342		384	726
Mar. 07	1601	900	1738		518	4757
Apr. 07	1614		1160		238	3012
May. 07	442	1630	1210		330	3611
Jun. 07	328	360	1092		100	1880
Jul. 07	172	360	1077		230	1839
Aug. 07		720	712			1432
TOTALS	5160	5750	10959	94	3226	25189





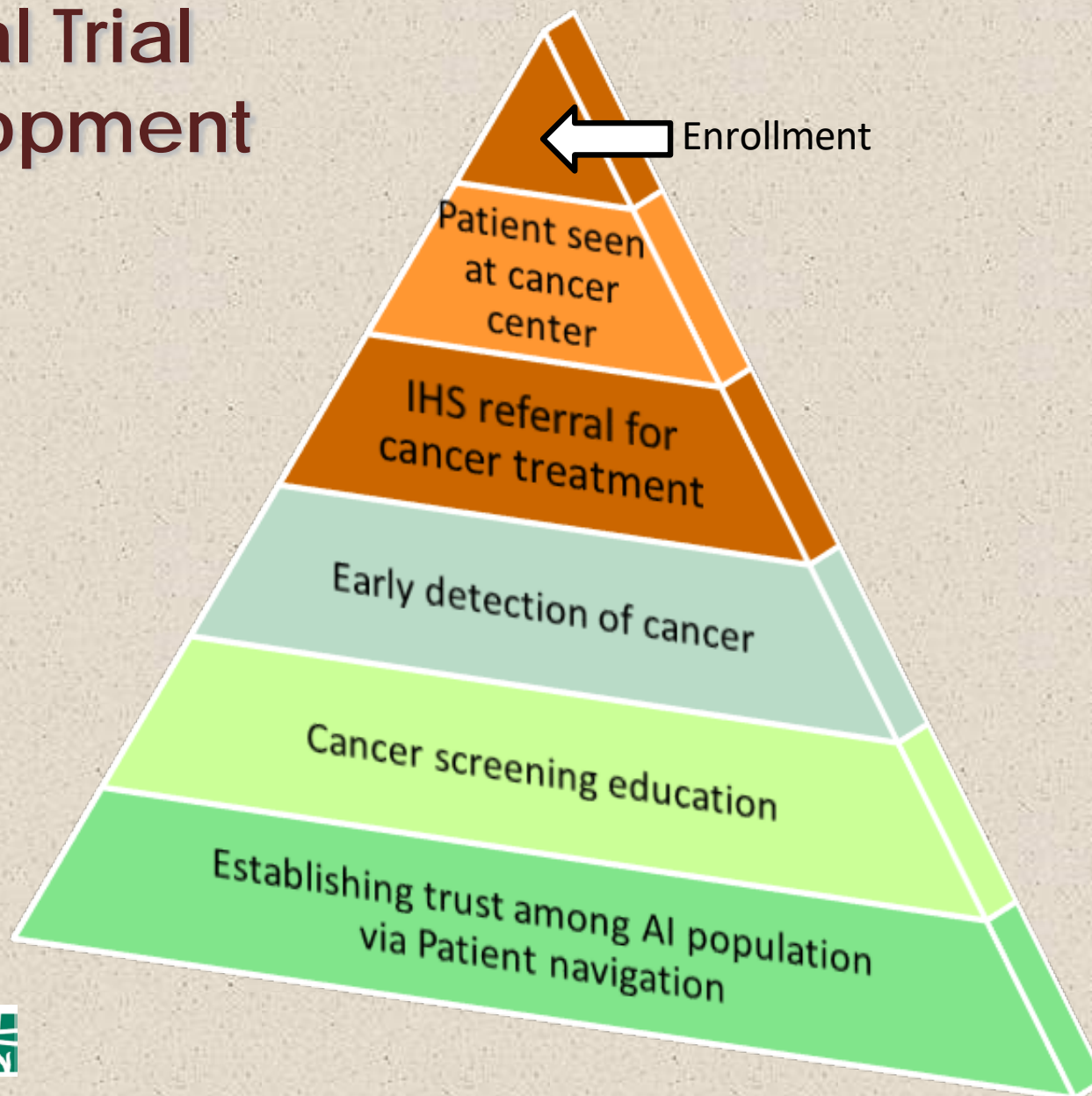


Clinical Trials Rationale

- Emerging technologies often only available and early in implementation are best administered through clinical trials:
- Nationally, minority participation rates in clinical trials are low (approximately 3%)
- Racial discrepancies in clinical trial participation rates may contribute to cancer-related disparities



Clinical Trial Development





Successful Recruitment Clinical Trials

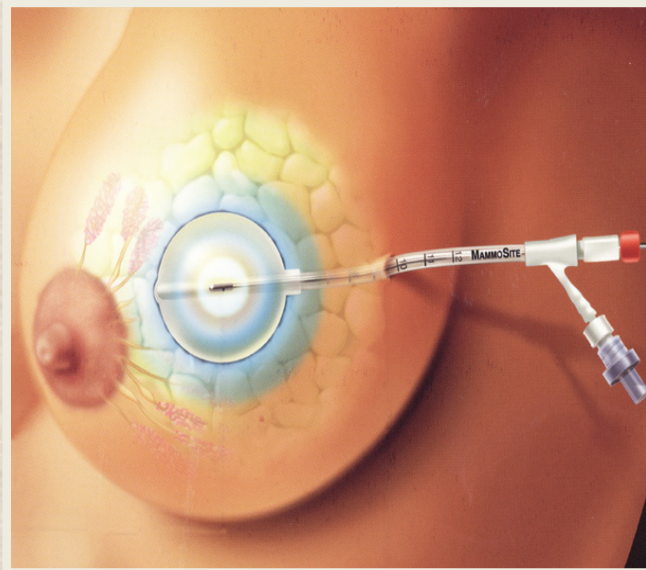
- **225 AIs with patient navigation during radiation enrolled on a clinical trial**
- **Reasons for non-participation in clinical treatment trials for AIs:**
 - **29% Advanced stage and/or poor performance status**
 - **16% No trial available for cancer site**
 - **15% Ineligible for other reasons after evaluation**

Guadagnolo B, Petereit D, Helbig P, et al, Involving American Indians and Medically Underserved populations in Cancer Clinical Trials. *Clinical Trials: Journal of the Society for Clinical Trial*, 6(6), Dec 2009; 610-617.



Clinical Trials – Breast Brachytherapy

•





Clinical Trials – Intensity Modulated Radiotherapy (IMRT)

Rapid City was the first community site and the fourth unit worldwide – installed 2001





Phase I/II Prostate Hypofractionation (continued)

Low-Risk Disease (early-stage disease)

320 patients accrued - 50 patients enrolled from Rapid City

<i>Fract. Level</i>	<i>Dose per Fx (Gy)</i>	<i># Fxs</i>	<i>Total dose (Gy)</i>	<i>Tumor NTD (alpha/beta =1.5)</i>
I	2.94	22	64.68	82.6
II	3.63	16	58.08	85.1
III	4.3	12	51.6	85.5

Predicted late toxicities equivalent to 76 Gy in 2 Gy fractions

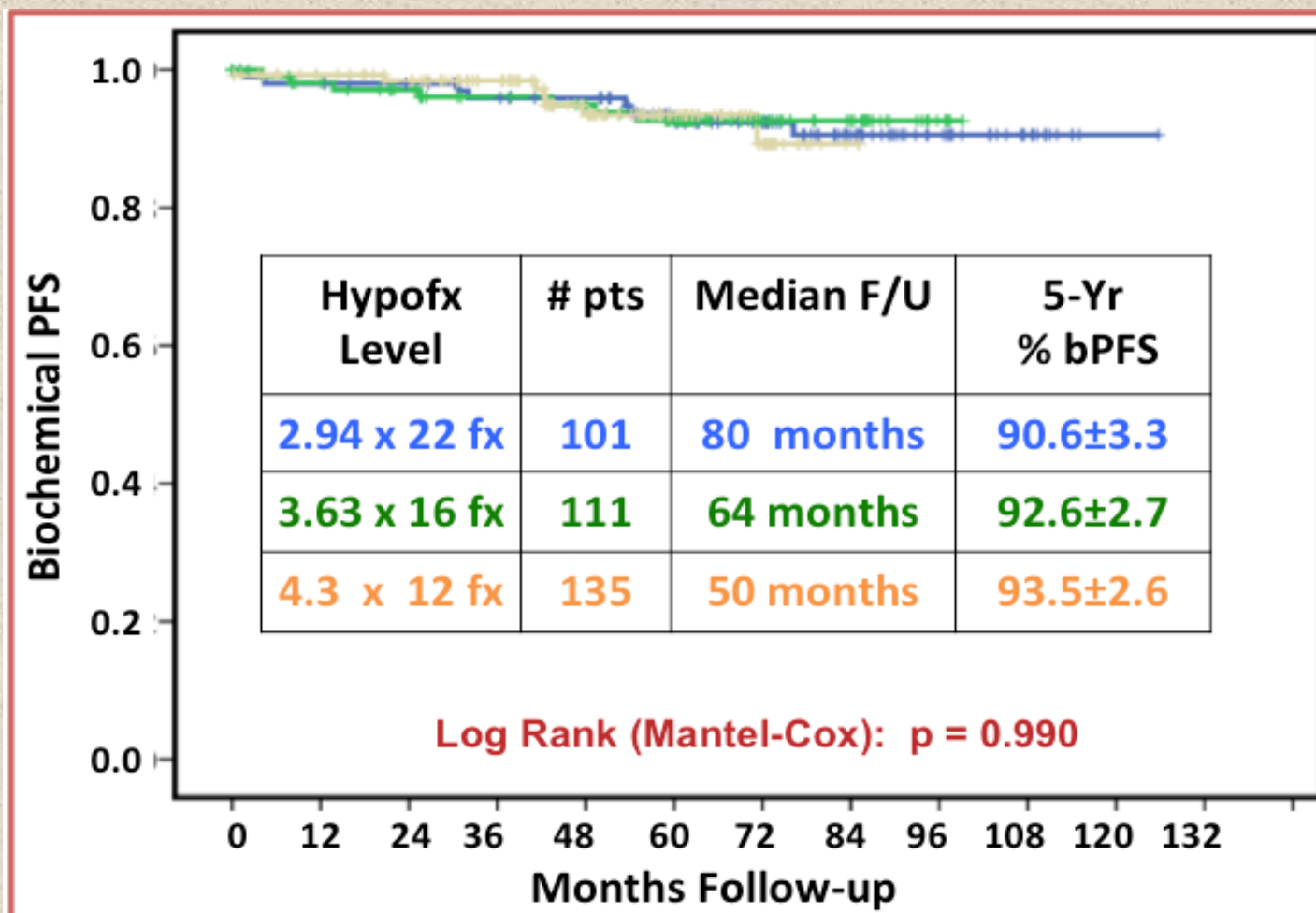
Ritter, MA, et al, International Journal of Radiation Oncology • Biology • Physics, 2009





Phase I/II Prostate Hypofractionation (continued)

Biochemical PFS versus Hypofractionation Level





ATM Mutations in American Indians

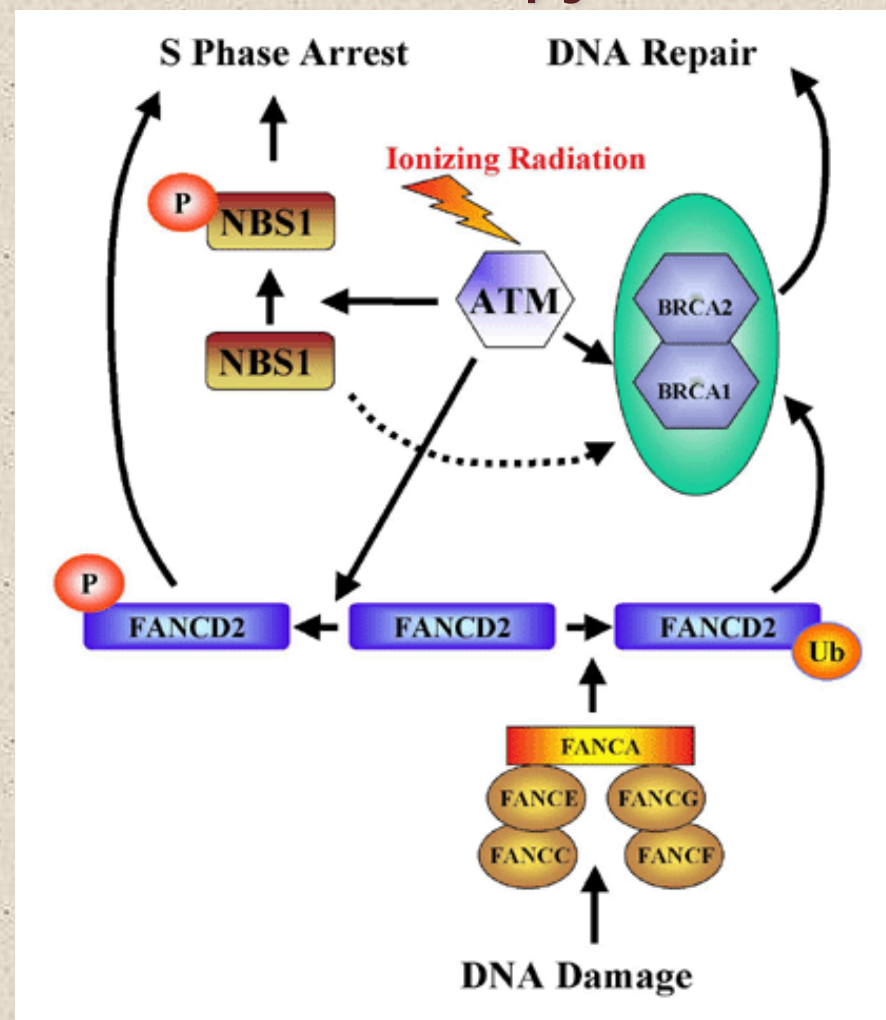
Possible Association with Cancer and Radiotherapy Toxicities

Determine the association between ATM heterozygosity and sensitivity to radiation

Amy Moser, PhD, UW
Gene sequencing

Enrollment:

- 100 Native Americans
- 100 non-Native Americans





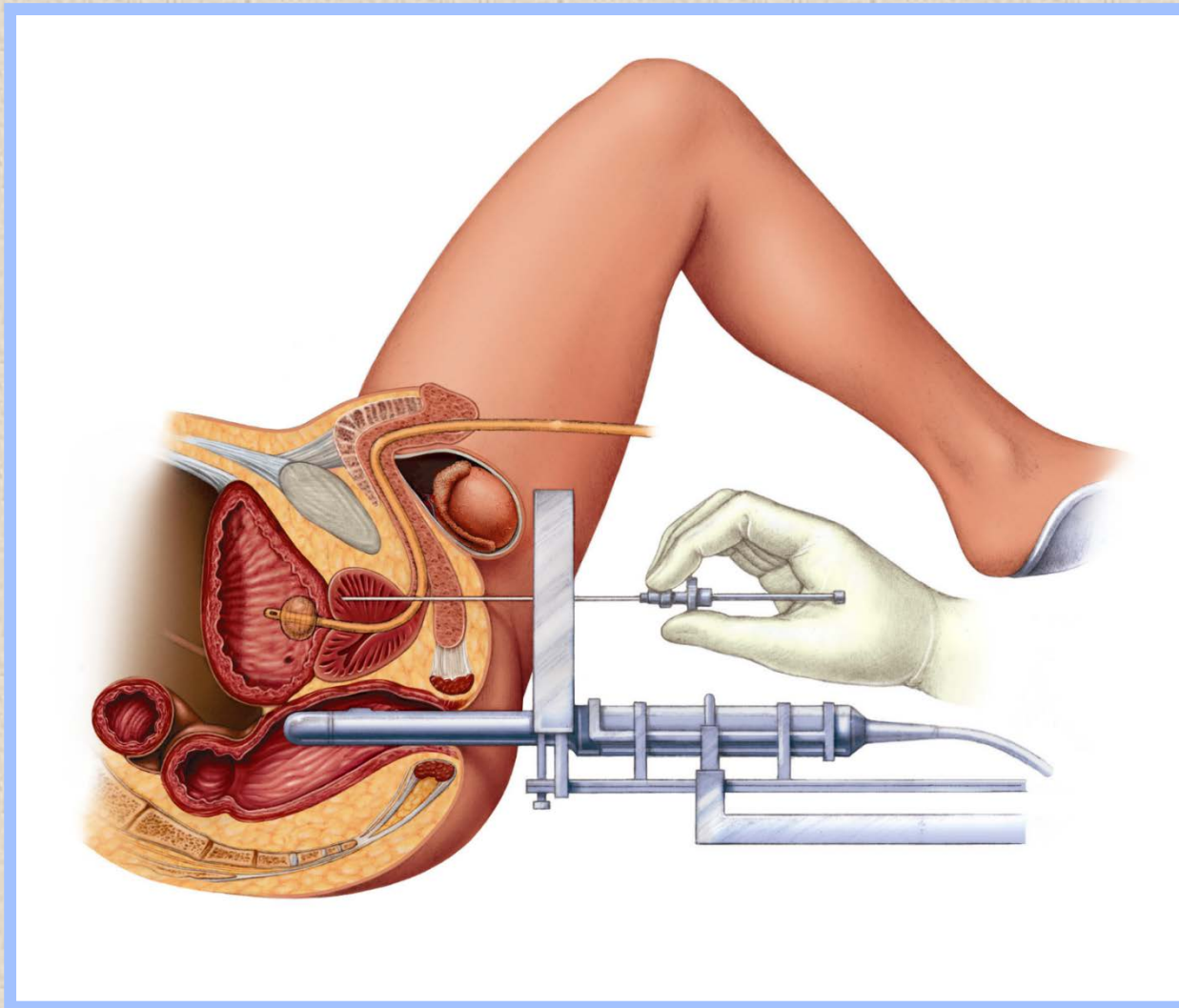
ATM Mutations in American Indians

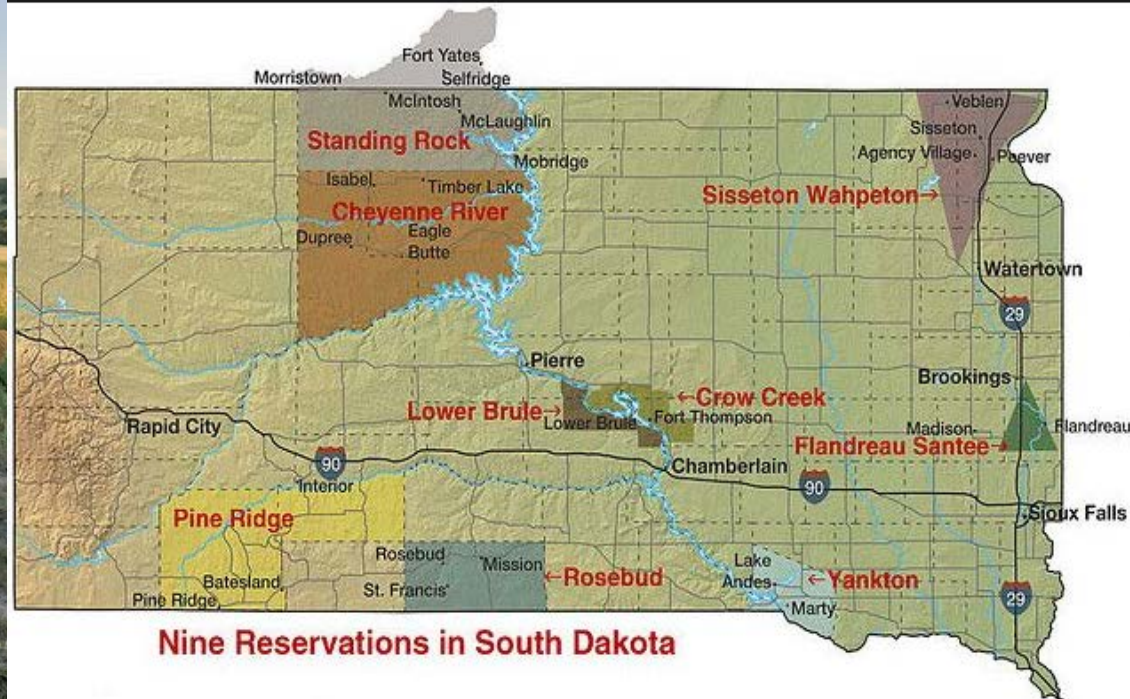
Conclusions:

- No higher prevalence in AIs versus non-AIs
- Success of recruiting AIs to genetic study (low refusal rate)
- Identified common variants and possibly some new ones
- Community/academic collaboration
- **ALL SAMPLES DESTROYED AT END OF STUDY**

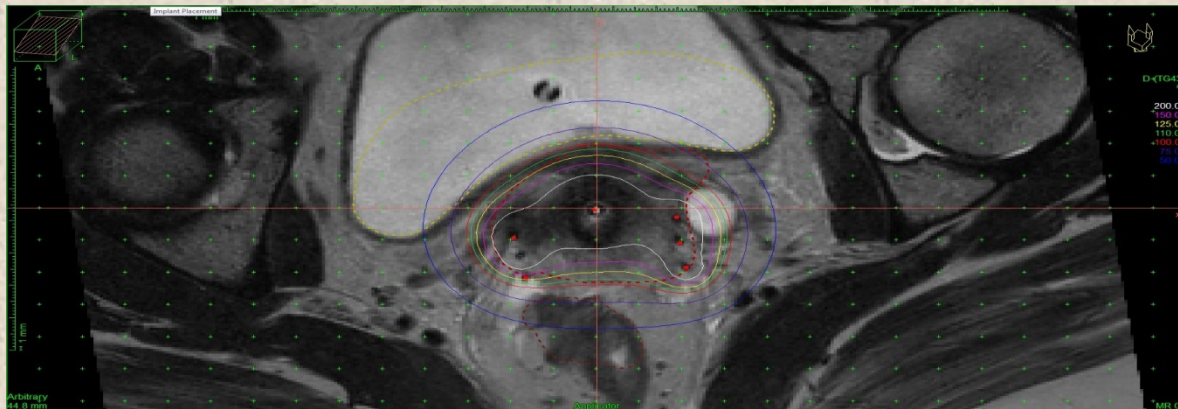
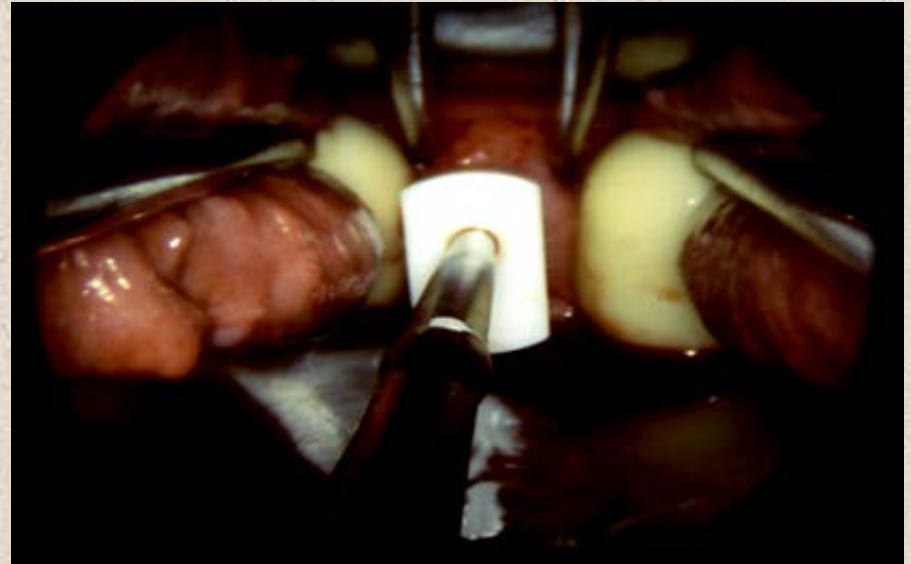
Petereit, D G; Hahn, L J; Kanekar, S; Boylan, A; Bentzen, S M; Ritter, M; Moser, A R. Prevalence of ATM Sequence Variants in Northern Plains American Indian Cancer Patients. *Frontiers in Oncology*. 3(319):1-5. Dec 30, 2013.

Transperineal Interstitial Permanent Prostate Brachytherapy





Brachytherapy For Cervical Cancer



Cervical cancer cure rates are markedly compromised if omitted



NASEM CONSENSUS REPORT

- Advances in cancer therapies, page 30, BOX 1-3
- *“Advances in radiation therapy, such as intensity-modulated radiation therapy, stereotactic radiotherapy, and proton therapy, have allowed highly precise and conformal delivery of radiation therapy to tumors while minimizing normal tissue exposure and its accompanying side effects” (Jawerth, 2018)*
- **No mention of brachytherapy!**
- Brachytherapy is the most conformal method of delivering radiation while sparing the normal tissues
 - Critical role in curing gynecologic and prostate cancers

ABS Initiative

300 in 10

Train 30 competent brachytherapists
per year over the next 10 years
through a multi-faceted approach



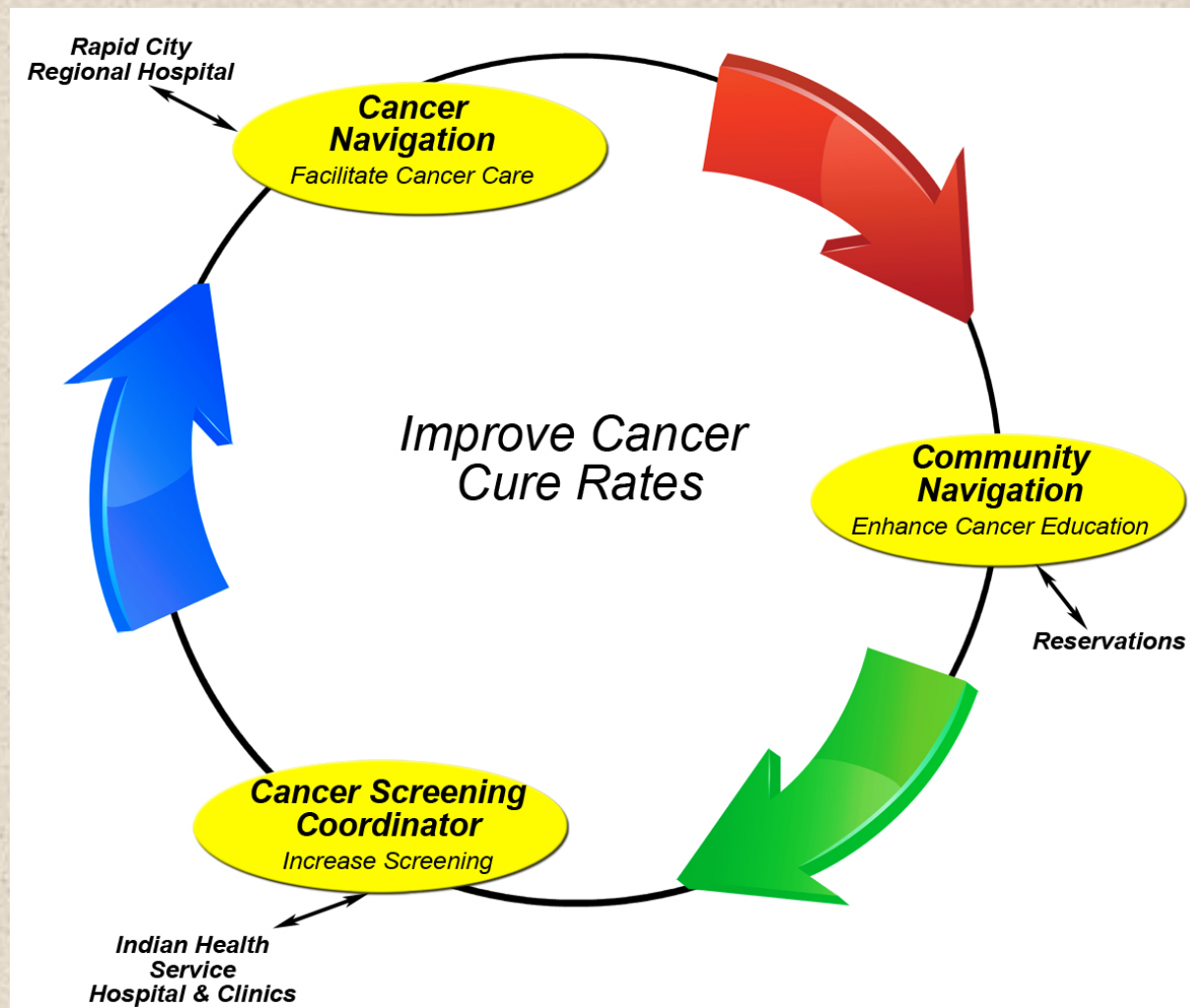


Walking Forward II Objectives 2007-2012

- **Increased efforts cancer screening and education**
- **Placement of cancer screening navigators within the Indian Health Services (IHS) Hospitals**
- **Continuation of Patient Navigation**
- **Enrollment clinical trials**
- **Partnerships with other national disparity programs**



Model for Expanding Patient Navigation Walking Forward II (2007-2012)





Cancer Screening Coordinators





METHFREE
ZONE
DONT METH AROUND





Walking Forward: Screening Initiatives

- Totals for Rapid City, Pine Ridge, Rosebud, and Cheyenne River
- Breast, cervix, colorectal, and prostate: 1,781
- **As of November 2019: 3,200**

Cancer Screening Among American Indians by Walking Forward Program				
Site	# of Screens	Abnormal Test Results	Cancer Diagnosis	Pending Results
Breast	721	91	4	1
Cervix	480	33	1	0
Colorectal	444	78	2	0
Prostate	136	1	0	0
Total	1781	203	7	1



American Indian Stage at Cancer Presentation

Potential Impact of Walking Forward Interventions

Cancer Stage at Presentation	1990-2000	2001-2012 (WF era)
In situ	13 (8%)	18 (4%)
Localized	48 (29%)	187 (45%)
Regionalized	41 (25%)	126 (30%)
Distant	63 (38%)	89 (21%)
Total	165	420

P < 0.001



mHealth Smoking Cessation Study (WF Phase III)

Study Timeframe: October 2012 to July 2017

Principal Investigator: DG Petereit

Co-Investigators / Research Team

- L. Burhansstipanov, MSPH, DrPH
- Linda U. Krebs, PhD, RN, AOCN, FAAN
- Sheikh Iqbal Ahamed, PhD
- Mark Dignan, PhD
- Stevens Smith, PhD

CDRP “Phased Out”



Research Question / Hypotheses

- Primary H₀: “Why don’t more Northern Plains American Indians alter tobacco use behaviors known to increase the risk of cancer?”



Mobile Health Smoking Cessation Study

Four Interventions: minimal versus intense (RCT)

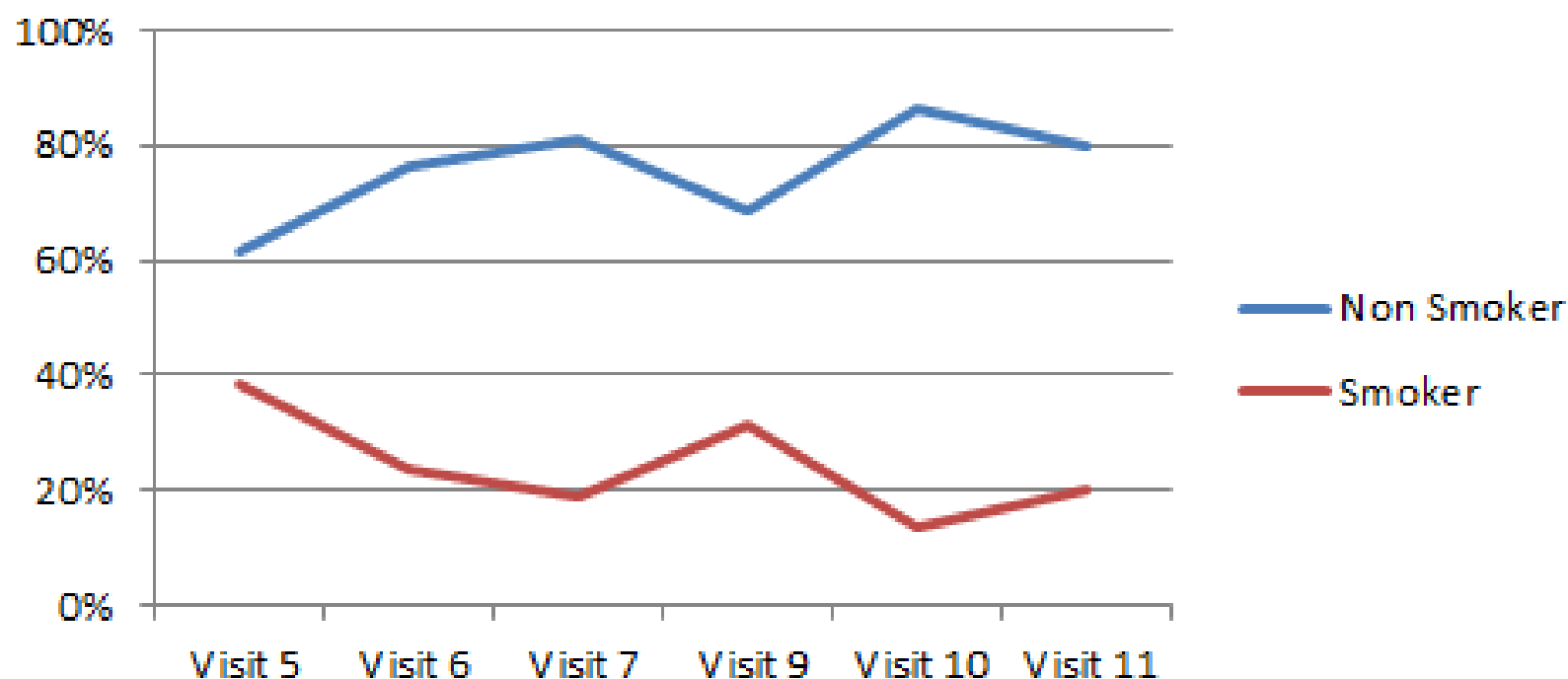
1. Nicotine replacement therapy (NRT): patch and/or oral
2. Pre-cessation counseling
3. Post-cessation counseling
4. Smart phones (mHealth): text messaging

Contemporary Clinical Trials 81 (2019) 28–33



Smoking Status by Visit

Smoking status of mHealth participants

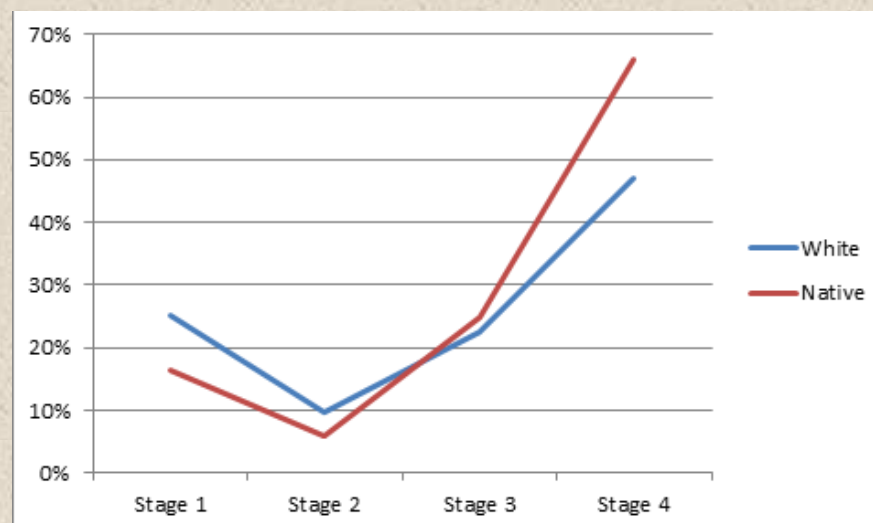




Smoking and Lung Cancer in South Dakota

- High smoking rates: State average 20-40% High lung cancer mortality rates:
 - American Indian: 95 per 100,000
 - Whites: 55 per 100,000
 - **Northern Plains Als: highest lung cancer mortality rate in the US**

New diagnosis of Non-Small-Cell Lung cancer 2009-2015 Rapid City



Increasing Lung Cancer Screening for High Risk Smokers in a Frontier Population (Phase IV)

- **Research Question:**

- will provider and/or individual level interventions increase low dose computerized axial tomography (LDCT) lung cancer screening among high risk smokers living in western South Dakota?

- **Project Goal:**

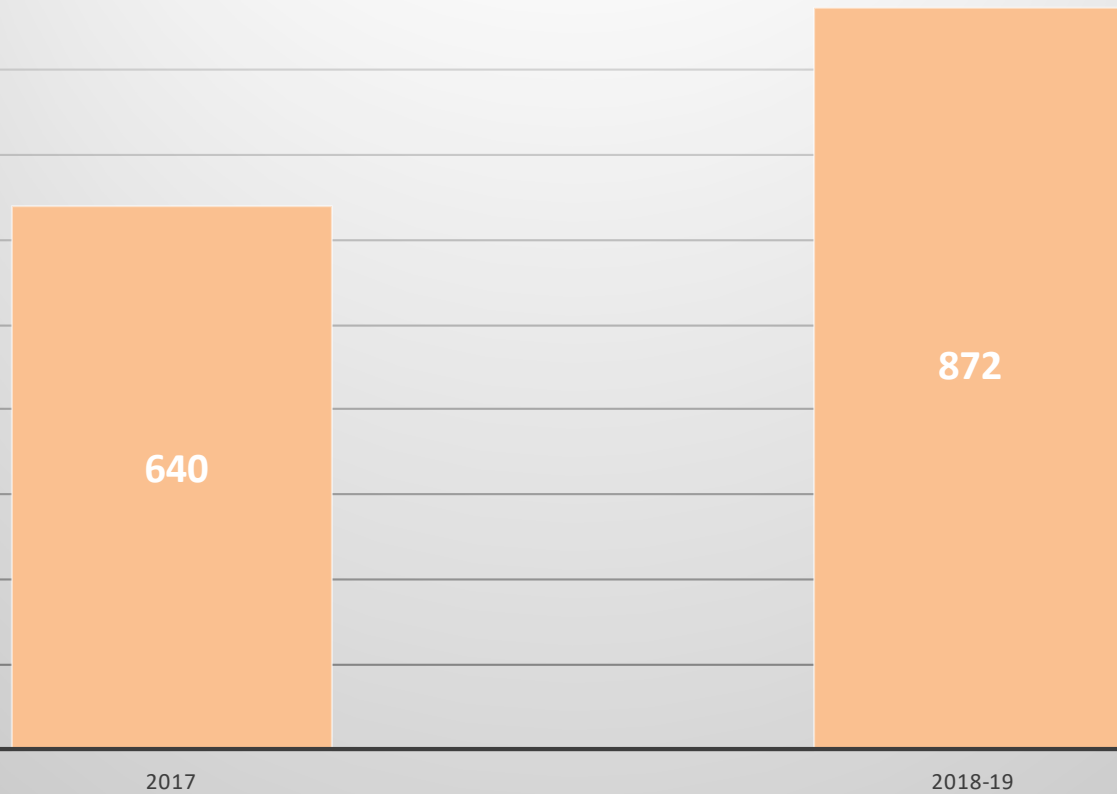
- To increase lung cancer screening rates by educating primary care providers and their clinic staff as well as community members in western South Dakota.



Bristol-Myers Squibb
Foundation



Year 1 LDCT Results



2017 Baseline LDCT #'s



NEXT CHALLENGE

- Indian Health Service will not cover the cost of LDCTs for contract health
- **Foundations from the Irving A. Hansen Memorial Foundation for 105K**
 - Will allow us to screen 500 American Indians







Advancing Palliative Care Northern Plains American Indians (NPAIs) RFA-CA-18-026 (Phase V)

- Palliative care is one of the greatest cancer needs for NP AIs
- Palliative care is almost non-existent
- Root causes
 - Distant to the cancer center
 - Lack of transportation
 - Lack of community based palliative care
- Majority patients die at home with inadequate palliation
- Early application of palliative care has been demonstrated to improve outcome for several cancers



Advancing Palliative Care in Northern Plains American Indians

RFA-CA-18-026

- **PIs:** Katrina Armstrong, MD (HMS/MGH), Daniel Petereit, MD
- **Investigator Team:** Mary Isaacson, Francine Arneson, JR
- **8 Partners:** MGH/Harvard, Walking Forward Avera, SDSU, Great Plains Tribal Chairmen's Health Board, 3 SD reservations
- **MGH/Harvard Team**
- **Overarching project goal:** to develop and test a multi-prong strategy for the delivery of palliative care to NPAIs
- **All phases of the project will be guided by a community advisory board composed of tribal health leaders and representative enrolled members from the three tribes**





From Conflict to Resolution

- Alignment of goals
- “Silos” of research
- Patients, hospitals, tribes, IHS, state of South Dakota, researchers/universities, NCI
- Examples
 - Hospital administration
 - ACS WF navigator
 - Pine Ridge IHS & LDCTs
 - NCI CDRP program, almost shut down in 2008
- How do you align all of these?



Walking Forward: Pathways to Sustainability

- CDRP: (Last program remaining)
- Staff who are AI and part of the community/CBPR
- Patient navigation: Walking Forward foundation
 - Not a NCI funding priority after 2012
- Constant communication with staff
- Staff adapting and changing over time: “community signals”
 - Very resourceful staff: HPV cervical project
- Community presence to nurture ongoing trust
- WF is a known entity: other programs approach us
- Flexibility: moving the program administratively to ↑ sustainability



Walking Forward: Pathways to Sustainability

- **Extensive collaborations:**
 - **South Dakota Community**
 - SD hospitals, Indian Health Service, Tribal Health
 - **Academic Centers:** University Wisconsin/ Washington/South Dakota, Mayo Clinic, MGH/Harvard, NYU, Cooperative Groups
 - **Political**
 - SD Congressional Delegation, ASCO, ASTRO, ABS, NCI
 - **Other:** BMSF, Irving Memorial Foundation, Polo Ralph Lauren
 - **Individuals:** Minesh Mehta, Norm Coleman, Frank Govern, Judith Kaur, Linda Burhansstipanov, Ashley Guadagnolo, Sunshine Dwojak, Katrina Armstrong, many others
 - **Margaret O'Conner (Rosebud) & Dr. Katrina Armstrong (MGH)**
 - **Lead to successful submission palliative care RO1**



Walking Forward: Pathways to Sustainability

- Absolute persistence
- Motivation to help the underserved
- **END RESULT: SUSTAINABLE PROGRAM THAT HAS GONE FROM 5 YEARS TO 22 YEARS**



Lessons Learned

- **Patience / time – implementation science**
- **Essential that PI is part of the community/region**
- **Dedicated research time (funding)**
- **Challenges: workload primary care MDs**
- **IHS inertia**





06/12/2009



Walking Forward's Vision

To improve the quality of life for AI cancer patients from early detection, successful treatment and survivorship - including end of life care

Walking Forward's Mission

This has been and will continue to be accomplished through access to screening, state of the art cancer treatments and clinical trials, and comprehensive patient navigation

Expansion into the entire Frontier population



Walking Forward Team



Walking Forward Collaborations

MD Anderson Cancer Center – since 2004



B. Ashleigh Guadagnolo, MD, MPH

- **Enrolled member of the Choctaw Nation of Oklahoma**
- **Professor, Radiation Oncology, M.D. Anderson Cancer Care Center**



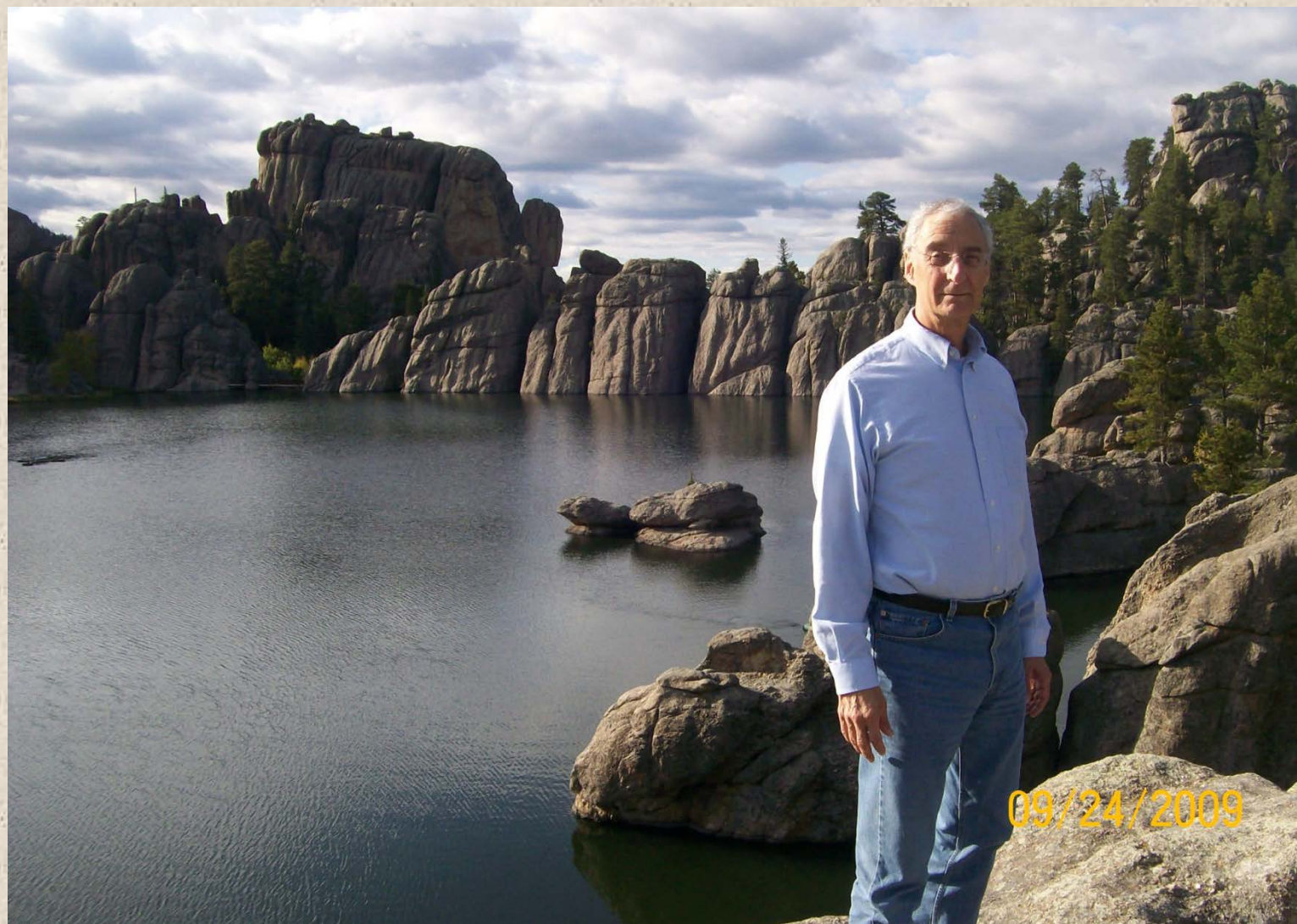
Mobile Health Smoking Cessation Study

Walking Forward Collaborator

Linda Burhansstipanov, MSPH, DrPH

- Cherokee Nation of Oklahoma
- Founder, Native American Cancer Research Corporation
- Founder, Native American Cancer Initiatives, Inc.





Walking Forward “Tree” Complex Adaptive Systems





Life's most persistent and urgent question is,
'what are you doing for others'

Martin Luther King, Jr



