Increasing Access to Lung Cancer Screening for American Indians in South Dakota

2021 Prevent Cancer Dialogue
Prevent Cancer Foundation

Daniel G Petereit, MD, FASTRO
PI of Walking Forward

Avera Cancer Care Institute, Sioux Falls, SD
Regional Cancer Care Institute, Rapid City, SD
Disclosures

- Bristol-Myers Squibb Foundation
- Pink Pony Ralph Lauren Foundation
- Irving A Memorial Hansen Foundation
- NCI Funding
- All funding supports Walking Forward staff and objectives to complete research goals
- Past President of the American Brachytherapy Society (2019-2020)
Objectives

• Challenges of providing health care to tribal and rural communities in western, SD
• Summary of 18 year results on efforts to reduce cancer disparities through innovative technologies and patient navigation
• Challenges to lung cancer screening in western, SD
• How challenges were previously and continue to be addressed
• Lessons learned
Cancer in Native America/Challenges

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
Cancer in Native America/Challenges

• AI/ANs with cancer dx more likely to be admitted for non-elective procedures and more likely to undergo emergent procedures (ACS NSQIP database)

• SEER analysis demonstrate AI/ANs less likely to undergo any cancer surgery at all compared to other racial groups
  – Perception that cancer is a death sentence

• Less likely to receive chemotherapy and radiation for breast, colon and prostate cancer

• Lower rates of hospice use than whites among AI/ANs dying of cancer

• Poverty is not the only issue: poorer cancer-related survival persists among AI/ANs, even when adjustments are made for influence of poverty. Ward et al Cancer J Clin 2004;54;78-93
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**

<table>
<thead>
<tr>
<th>Cancer Diagnosis</th>
<th>Women</th>
<th>Cancer Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1 Prostate</td>
<td>![Prostate Icon]</td>
<td>![Prostate Icon]</td>
</tr>
<tr>
<td>#2 Lung</td>
<td>![Lung Icon]</td>
<td>![Lung Icon]</td>
</tr>
<tr>
<td>#3 Colorectal</td>
<td>![Colorectal Icon]</td>
<td>![Colorectal Icon]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cancer Diagnosis</th>
<th>Men</th>
<th>Cancer Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1 Prostate</td>
<td>![Prostate Icon]</td>
<td>![Prostate Icon]</td>
</tr>
<tr>
<td>#2 Lung</td>
<td>![Lung Icon]</td>
<td>![Lung Icon]</td>
</tr>
<tr>
<td>#3 Colorectal</td>
<td>![Colorectal Icon]</td>
<td>![Colorectal Icon]</td>
</tr>
</tbody>
</table>

---

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

- **Men**
  - Liver Cancer Death: 2.8X
  - Larynx Cancer Death: 2.5X

- **Women**
  - Cervical Cancer Death: 4.2X
  - Gallbladder Cancer Death: 3.5X

---

**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.
Pine Ridge IHS Hospital
Geographic Distance

For American Indians: average distance is 140 miles to Rapid City
Walking Forward
Community Model for Cancer Control

SCREENING • NAVIGATION • CLINICAL TRIALS • GENOMICS • PALLIATION

Avera
Walking Forward Phases

• Phase I and II: Community education, screening, patient navigation enrollment clinical trials
  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

Overarching goal: reduce cancer mortality rates
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


**Founding Partners:** UW - Minesh Mehta, Mayo – Judith Kaur
Walking Forward: 2002-2011

- Socio-demographics
- Prior Satisfaction with Health Care
- Mistrust
- Cancer / Screening Knowledge

Screening and Access Behaviors

Health System Factors

Cancer Stage At Presentation
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 for Native Americans Undergoing Cancer Treatment

- Analysis of 332 NAs navigated February 2004 through September 2009
  Historical comparison to 70 NAs not navigated

- Treatment interruptions during XRT, curative intent:
  1.7 days navigated patients vs. 4.9 days non-navigated

- 22% of navigated patients enrolled in a clinical trial

Patient Navigation Impact

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


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

- Rapid City Regional Hospital
- Cancer Navigation: Facilitate Cancer Care
- Improve Cancer Cure Rates
- Community Navigation: Enhance Cancer Education
- Cancer Screening Coordinator: Increase Screening
- Indian Health Service Hospital & Clinics

Avera
Cancer Screening Coordinators
Walking Forward: Screening Initiatives

- Totals for Rapid City, Pine Ridge, Rosebud, and Cheyenne River
- Breast, cervix, colorectal, and prostate:
- As of November 2020: 3,200

<table>
<thead>
<tr>
<th>Site</th>
<th># of Screens</th>
<th>Abnormal Test Results</th>
<th>Cancer Diagnosis</th>
<th>Pending Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>721</td>
<td>91</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Cervix</td>
<td>480</td>
<td>33</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Colorectal</td>
<td>444</td>
<td>78</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Prostate</td>
<td>136</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>1781</td>
<td>203</td>
<td>7</td>
<td>1</td>
</tr>
</tbody>
</table>
Walking Forward 18 year Results

- Accrual rate of 10% of AIs to clinical trials
- Nearly 4,500 American Indians enrolled research studies
- Increased compliance with cancer treatment
- Identification of specific barriers to effective cancer screening and cancer care
- Coordination of 3,200 cancer screenings
- Successful completion of a genetic study (ATM)
- Completion of a randomized smoking cessation trial
- Establishment of trusting partnerships with AI communities
- Creation of research infrastructure to address new research questions
- Continuation and creation of partnerships for sustainability
- Current collaborative palliative care project
Clinical Trials – Brachytherapy
Clinical Trials – Intensity Modulated Radiotherapy (IMRT)

Rapid City was the first community site and the fourth unit worldwide – installed 2001
## American Indian Stage at Cancer Presentation

### Potential Impact of Walking Forward Interventions

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

P < 0.001
Smoking and Lung Cancer in South Dakota

- High smoking rates: State average 20%, 7 counties over 30% (Todd County highest at 41%)
- High lung cancer mortality rates:
  - American Indian: 95 per 100,000
  - Whites: 55 per 100,000
  - Northern Plains AIs: highest lung cancer mortality rate in the US

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

- Only 2-4% screened nationally (historically)
- Potentially 30,000 screen eligible South Dakota
  - 14,000 western part of SD
- Limited use of LDCTs by primary care providers (PCP)
- High risk individuals: many unaware
- Higher cure rates and good treatment options: surgery or SRS (stereotactic radiosurgery)
Limited Access to Lung Cancer Screening in South Dakota

- Population density in SD: 11 people per square mile
- Only 16 cities with screening centers in SD (~77,000 square miles or 49 million acres)
- 1 screening center per 4,800 square miles (3 million acres)
Increasing Lung Cancer Screening for High Risk Smokers in a Frontier Population

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.
Increasing Lung Cancer Screening for High Risk Smokers in a Frontier Population

• **Aim 1: Screening awareness**
  • Build on previous research to improve provider and individual awareness of LDCT lung cancer screening
    • Initial and follow-up surveys at baseline and 6 months

• **Aim 2: Evaluate the efficacy of two interventions with PCPs and community members to increase awareness of LDCTs**
  • Main outcome measure: number of LDCTs completed

• **Aim 3: Policy Symposium and Lung Health Forum**
  • Partnership with Georgetown University: Bette Jacobs, PhD
  • Engage community members, state and tribal leaders, primary care MDs
  • Develop sustainable, evidence-based, culturally- and regionally-appropriate practice and policy recommendations
Increasing Lung Cancer Screening for High Risk Smokers in a Frontier Population

Bristol-Myers Squibb Foundation - Funded February 2017

• 2 x 2 study design to evaluate provider (n=135) and individual level (n=1000) interventions

• Both interventions include education and introduction to the online resource

• Metric will be increase in screening LDCTs

• 14,000 patients at risk in Western, SD

**First WF Project to include all of western SD
Challenge: Limited access to screening LDCT

2 X 2 Design

<table>
<thead>
<tr>
<th>Intervention:</th>
<th>Study Groups:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td>Provider</td>
<td>No*</td>
</tr>
<tr>
<td>Individuals</td>
<td>No*</td>
</tr>
</tbody>
</table>

*delayed intervention based on study findings
Education sessions

Provider Workshops/CME sessions
  Began September 2018
  13 clinic sites completed
  Provider accrual 95
  Target goal: 135

Community Workshops/Education sessions
  Began August 2018
  460 participants

To date: 100 LDCT referrals have been obtained with 81 completed
Year 2 LDCT Results

Baseline: 640
Year 1: 872
Year 2: 1209
### LDCTs by Site and Quarter

<table>
<thead>
<tr>
<th>Quarter</th>
<th>Total</th>
<th>RCRH</th>
<th>Lead/DW</th>
<th>Spearfish</th>
<th>Custer</th>
<th>Dakota Radiology</th>
<th>RCMC</th>
<th>Philip</th>
<th>Sturgis</th>
<th>Avera St. Marys</th>
</tr>
</thead>
<tbody>
<tr>
<td>July - Sept 2018</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oct - Dec 2018</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jan - March 2019</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apr - June 2019</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>July - Sept 2019</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oct - Dec 2019</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jan - March 2020</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apr - June 2020</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Negative Impact of COVID**
OVERCOMING CHALLENGES

• Indian Health Service is not currently covering the cost nor providing LDCTs
  • Recent update: Rosebud IHS providing LDCTs
• Indian Health Service (IHS): “life and limb” policy
• COVID pandemic
• Grant received from the Irving A. Hansen Memorial Foundation for 152K
  • Will allow us to screen about 400 American Indians at no cost to the patient
Education sessions
Increasing Lung Cancer Screening for High Risk Smokers in a Frontier Population

• **Aim 1: Screening awareness**
  • Build on previous research to improve provider and individual awareness of LDCT lung cancer screening
  • Initial and follow-up surveys at baseline and 6 months

• **Aim 2: Evaluate the efficacy of two interventions with PCPs and community members to increase awareness of LDCTs**
  • Main outcome measure: number of LDCTs completed

• **Aim 3: Policy Symposium and Lung Health Forum (May 2021)**
  • Partnership with Georgetown University: Bette Jacobs, PhD
  • Engage community members, state and tribal leaders, primary care MDs
  • Develop sustainable, evidence-based, culturally- and regionally-appropriate practice and policy recommendations
Chicago Race/Gender Eligibility for Screening Cohort (CREST)

Mary M. Pasquinelli, DNP, FNP-BC, APRN
Nurse Practitioner: Pulmonary and Thoracic Medical Oncology
University of Illinois Hospital and Health Science System (UI Health

Walking Forward: Pathways to Sustainability

- Community based participatory research (CBPR)
- Patient navigation: the foundation of Walking Forward
- Constant communication with staff and community
- Staff adapting and changing over time: “community signals”
- Community presence to nurture ongoing trust
- WF is a known entity: other programs approach us
  - WF community staff are tribal members living on the reservations
Walking Forward: Pathways to Sustainability

- Extensive collaborations:
  - South Dakota Community
  - Academic Centers: Universities of Wisconsin/Washington/South Dakota, Mayo Clinic, MGH/Harvard, NYU, Cooperative Groups
  - Political
    - SD Congressional Delegation, ASCO, ASTRO, ABS, NCI
  - Other: GPTLHB, BMSF, Irving A Hansen, Memorial Foundation, Pink Pony-Polo Ralph Lauren
  - Individuals: Minesh Mehta, Norm Coleman, Frank Govern, Judith Kaur, Linda Burhansstipanov, Ashleigh Guadagnolo, Sunshine Dwojak, Katrina Armstrong, Bette Jacobs and many others
Walking Forward: Pathways to Sustainability

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

Through lessons learned

- Patience / time
- Essential that PI is part of the community/region
- Dedicated research time (funding)
- Challenges: workload primary care MDs
- Indian Health Service (IHS) is underfunded: per capita funding for IHS in 2017= $3,851, general population=$10,224
Future Funding for LDCT Program

• Goal: to extend lung health prevention research to enable the momentum to continue
• Significant progress, despite COVID
• Funding for community staff ends in August 2021
• BMSF continuation?
• Other foundations
• Annual budget to continue: $150,000
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