

Meeting Report: Increasing Colorectal Cancer Screening for American Indians and Alaska Natives

November 2017



Table of Contents

Overview	3
Background	3
Presentations & Discussion.....	7
Post Meeting Actions.....	13
Acknowledgements.....	14
Appendices.....	15
A. Agenda	15
B. Planning Committee Roster	18
C. Meeting Roster	19
D. Framework for Change	22
E. Suggested Reading List.....	30

Acronym Guide

ACS – American Cancer Society
AI/AN – American Indian and Alaska Native
CDC – Centers for Disease Control and Prevention
CRC – colorectal cancer
IHS – Indian Health Service
NCCRT – National Colorectal Cancer Roundtable

Overview

This report summarizes the presentations, discussions, and strategic planning that took place during the American Cancer Society (ACS) and National Colorectal Cancer Roundtable (NCCRT) co-sponsored meeting to discuss increasing colorectal cancer (CRC) screening in American Indian and Alaska Native (AI/AN) communities that took place on April 25th, 2016 in Traverse City, Michigan. This day-long meeting, “Increasing Colorectal Cancer Screening for American Indians and Alaska Natives”, was co-moderated by Richard Wender, MD, ACS Chief Cancer Control Officer and NCCRT Chair, and Kris Rhodes, MPH, Executive Director of the American Indian Cancer Foundation (AICF). The meeting was held as a pre-meeting to the Centers for Disease Control and Prevention’s (CDC’s) summit on cancer control in AI/AN communities that began the following day.

The purpose of the meeting was to bring together AI/AN health leaders, public health specialists, and individuals/programs involved in CRC screening to discuss the challenges and potential solutions to improving access to quality CRC screening in this population.

Meeting goals included:

1. Examine the opportunities and barriers related to delivering quality CRC screening and follow-up care in health care settings serving AI/AN communities.
2. Develop guidance that can be used by involved organizations to enhance delivery of effective, efficient cancer screening in AI/AN-serving health care settings, to include:
 - Integrating with existing structures
 - Aligning resources in the public and private spheres
 - Strengthening channels of communication
 - Working across organizational goals and priorities
3. Examine the existing tools and resources that support cancer screening in practice and identify dissemination strategies and additional needs.

Background

Colorectal Cancer in AI/AN Populations

According to the CDC, AI/AN men and women have some of the highest rates of CRC in the United States, but among the lowest screening rates.¹ The American Indian Cancer Foundation notes that CRC is the second most common cancer among American Indians (following lung cancer), and is the second

¹ James AS, Filippi MK, Pacheco CM, Cully L, Perdue D, Choi WS, et al. Barriers to Colorectal Cancer Screening Among American Indian Men Aged 50 or Older, Kansas and Missouri, 2006–2008. *Prev Chronic Dis* 2013;10:130067. DOI:<http://dx.doi.org/10.5888/pcd10.130067>

leading cause of cancer death.² From 2005 to 2009, the AI/AN CRC incidence was 21% higher and mortality 39% higher than in Whites. AI/AN CRC incidence and mortality rates varied regionally, with significantly higher rates in four regions (Alaska, Northern Plains, Southern Plains and Pacific Coast). AI/AN had a higher incidence of CRC than Whites in all ages and were more often diagnosed with late stage CRC than Whites.³

Further, between 1990 to 2009 there was a statistically significant decrease in the death rate from CRC among male and female Non-Hispanic Whites, but the CRC death rate among AI/AN men and women has not decreased, illustrated in the graphs below.

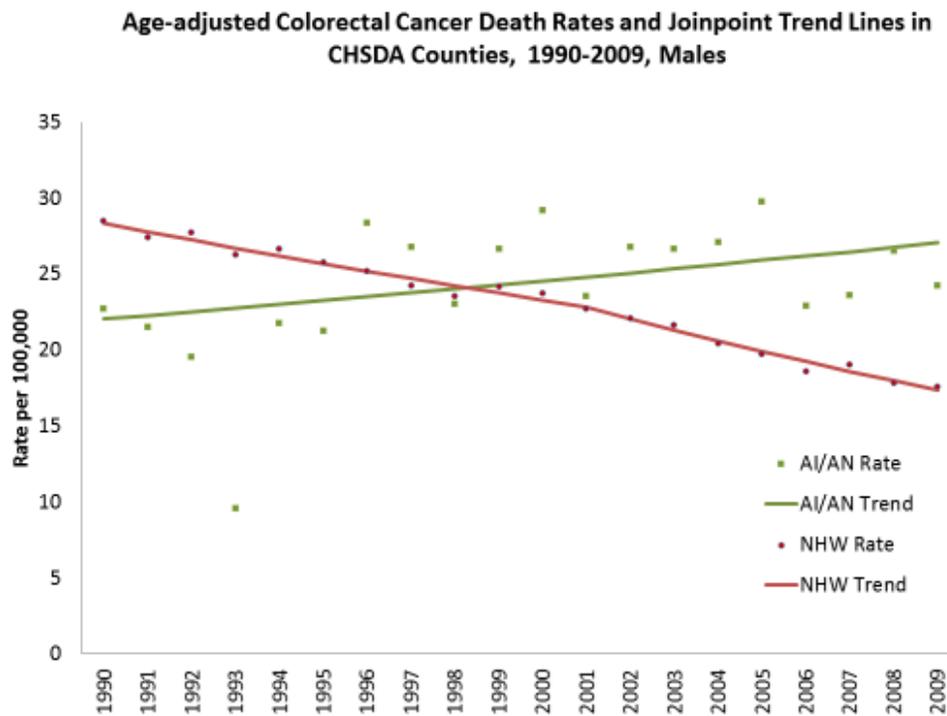


Chart prepared by Don Haverkamp, MPH, CPH, Epidemiologist, Division of Cancer Prevention and Control, CDC. Source: White, M. C., et al. (2014). "Disparities in cancer mortality and incidence among American Indians and Alaska Natives in the United States." *Am J Public Health* 104 Suppl 3: S377-387.

² <https://www.americanindiancancer.org/colon>

³ Perdue DG, Haverkamp DS, Perkins C, Makosky Daley C, and Provost E. Geographic Variation in Colorectal Cancer Incidence and Mortality, Age of Onset, and Stage at Diagnosis Among American Indian and Alaska Native People, 1990-2009. *Am J Public Health*. 2014; 104(Suppl 3): S404–S414.

Age-adjusted Colorectal Cancer Death Rates and Joinpoint Trend Lines in CHSDA Counties, 1990-2009, Females

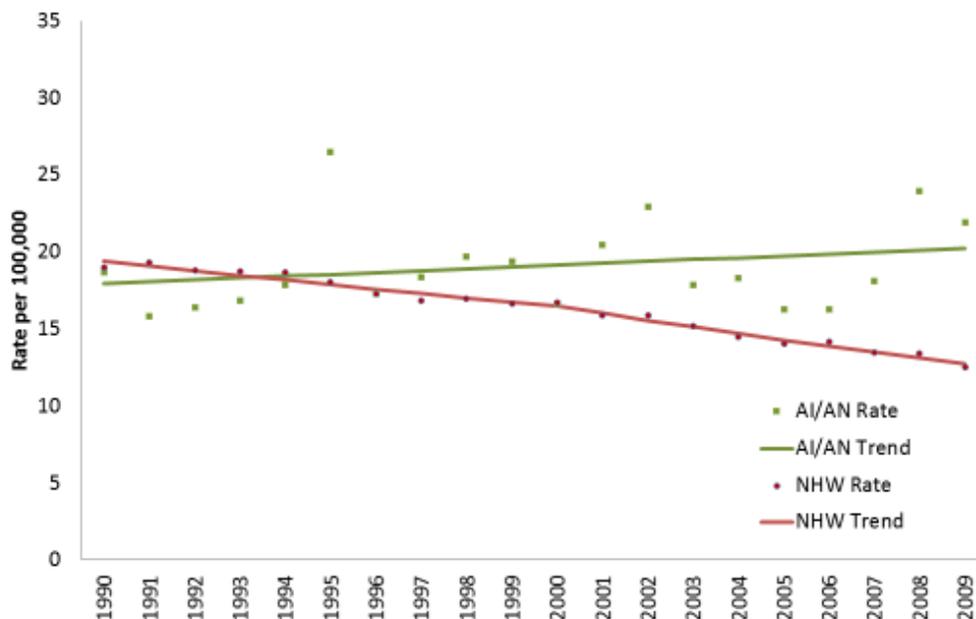


Chart prepared by Don Haverkamp, MPH, CPH, Epidemiologist, Division of Cancer Prevention and Control, CDC. Source: White, M. C., et al. (2014). "Disparities in cancer mortality and incidence among American Indians and Alaska Natives in the United States." *Am J Public Health* 104 Suppl 3: S377-387.

CRC is one of the few cancers that can be prevented through regular screening, however screening rates remain distressingly low in most regions despite the disproportionate impact of the disease on the AI/AN population. According to 2016 Behavioral Risk Factor Surveillance System (BRFSS) survey data, 59.5% of AI/AN respondents ages 50-75 years reported being up-to-date with CRC screening compared to 69.7% of Non-Hispanic Whites.⁴ Further, according to the 2015 National Health Interview Survey, among AI/AN adults 50 years of age and older, 54.3% reported being up-to-date with CRC screening compared to 65.4% of Whites.⁵ Another source of data on AI/AN populations is the Government Performance and Results Act (GPRA) measure set, which collects CRC screening rates by Indian Health Service (IHS) region (see chart below).

⁴ Centers for Disease Control and Prevention (CDC). Behavioral Risk Factor Surveillance System Survey Data. Atlanta, Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, [2016].

⁵ Cancer Prevention & Early Detection Facts & Figures. American Cancer Society. 2017-2018. <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/cancer-prevention-and-early-detection-facts-and-figures/cancer-prevention-and-early-detection-facts-and-figures-2017.pdf>.

Colorectal Cancer Screening: GPRA 2016 results, by IHS Area

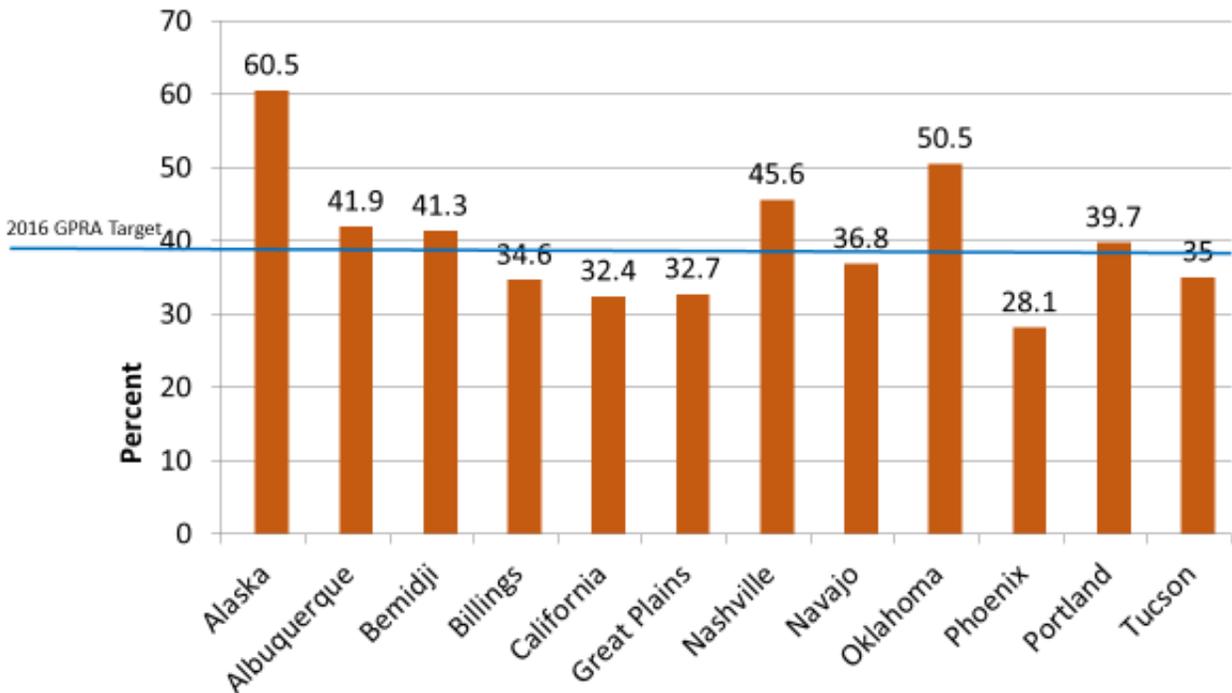


Chart prepared by Don Haverkamp, MPH, CPH, Epidemiologist, Division of Cancer Prevention and Control, CDC.
Source: Indian Health Service. Government Performance and Results Act. [2016]
<https://www.ihs.gov/crs/gprareporting/>

ACS, NCCRT and Partners Convene to Address Disparities

While we recognize important work was already taking place in many AI/AN communities to address these disparities in CRC screening and outcomes, the ACS and the NCCRT convened the “Increasing Colorectal Cancer Screening for American Indians and Alaska Natives” meeting to stimulate additional information sharing and action planning and to augment the efforts already under way.

The ACS is a nationwide community-based volunteer health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer, through research, education, advocacy, and service. To support this mission, the ACS is committed to reducing cancer incidence and mortality rates, increasing quality of life for its constituents and decreasing health disparities.

The ACS work to support cancer prevention and control in AI/AN communities is not new. Since 1991, the ACS has been formally working with AI/AN communities to increase cancer awareness through the Circle of Life Initiative (COL). The COL initiative is a holistic, culturally sensitive, and interactive means for

individuals, families, and tribal communities to make healthy choices and stay well. COL also focuses on providing Community Health Representatives (CHRs) employed by the IHS or AI/AN communities with up-to-date and accurate cancer information that they can utilize to educate their communities. Through this work, the ACS has been able to work with many tribes and organizations to lay a foundation for a network of partnerships.

In the last few years, the ACS Cancer Control Department has deployed state-based health systems staff to improve local systems of care. ACS Primary Care staff in each state provide support and technical knowledge to assist health care centers (primarily Federally Qualified Health Centers and AI/AN-serving clinics) to increase cancer screening rates. These staff collaborate with local clinics and networks to develop cancer screening policies, implement evidence-based interventions, provide culturally and linguistically appropriate outreach, and other support for improvement and systems change.

The NCCRT, established by ACS and the CDC in 1997, is a national coalition of more than 100 membership organizations, including public organizations, private organizations, voluntary organizations, and invited individuals, dedicated to reducing the incidence of and mortality from CRC in the United States, through coordinated leadership, strategic planning, and advocacy. The ultimate goal of the NCCRT is to increase the use of recommended CRC screening tests among the entire population for whom screening is appropriate. Addressing disparities in cancer screening, incidence, and mortality has been a longtime focus of the NCCRT's work.

Presentations & Discussion

The one-day “Increasing Colorectal Cancer Screening for American Indians and Alaska Natives” meeting agenda was developed to address the following meeting goals:

1. Examine the opportunities and barriers related to delivering quality CRC screening and follow-up care in health care settings serving AI/AN communities.
2. Develop guidance that can be used by involved organizations to enhance delivery of effective, efficient cancer screening in AI/AN-serving health care settings, to include:
 - Integrating with existing structures
 - Aligning resources in the public and private spheres
 - Strengthening channels of communication
 - Working across organizational goals and priorities
3. Examine the existing tools and resources that support cancer screening in practice and identify dissemination strategies and additional needs.

The complete meeting agenda can be found in Appendix A of this report.

Opening Prayer, Welcome & Introductory Remarks

The meeting commenced with an opening prayer led by Ruth Bussey of the Grand Traverse Band. The meeting co-chairs Kris Rhodes, MPH, (Bad River Chippewa & Fond du Lac Chippewa) Executive Director

of the American Indian Cancer Foundation and Richard Wender, MD, ACS Chief Cancer Control Officer and NCCRT Chair, then shared an overview of the agenda and goals for the day. [Dr. Wender shared an overview of the 80% by 2018 initiative](#), which aims to engage partners and the public in reaching an 80% CRC screening rate by 2018. [Don Haverkamp, MPH, of the CDC then provided an overview of CRC incidence and mortality and CRC screening in AI/AN populations](#). Highlights from this presentation are shared in the Background above.

Barriers, Promising Practices, and Tools to Improve CRC Screening

During this section, several meeting attendees shared seven to eight minute presentations on barriers to CRC screening and corresponding successful efforts to increase CRC screening. Presentations included:

- **Diane Fuller, RN, Warm Springs Health and Wellness Center**
 - Ms. Fuller shared an overview of efforts to increase CRC screening at the Warm Springs Health and Wellness Center in Northern Oregon, which serves members of the Confederated Tribes of Warm Springs, Wasco and Paiute. The Center has seen steady increases in their CRC screening rate following the implementation of several interventions, including improvements to the electronic health record system, reminder systems, and videos and PSAs to increase awareness in the community.
- [Dan Tadgerson, MPH, \(Bay Mills Indian Community\) Bay Mills Health Center](#)
 - Mr. Tadgerson described how the Bay Mills Health Center of the Upper Peninsula of Michigan used evidence-based systems changes, including patient reminders and screening navigation, to increase CRC screening from below 40% to nearly 70% between 2012 to 2016.
- **Virginia Warren, Arizona Department of Health Services**
 - Ms. Warren shared how the Arizona Department of Health Services and Hopi Cancer Support Services have developed a longstanding partnership to increase screening among the Hopi Tribe in Arizona, highlighting the successes of the patient navigator program.
- [Jen Olson, MS, MA, South Puget Intertribal Planning Agency \(SPIPA\)](#)
 - Ms. Olson shared how SPIPA has used patient reminders, patient navigation, and culturally appropriate outreach to increase CRC screening from 56% in 2008 to 82% in 2015 among AI/AN populations in Southwest Washington State.
- **Anne Walaszek, MPH, (White Earth Band of Ojibwe) American Indian Cancer Foundation (AICAF)**
 - Ms. Walaszek described AICAF's work to increase CRC screening in AI/AN populations, including available education and support tools, the Improving Northern Plains American Indian Colorectal Cancer Screening (INPACS) initiative assessment of CRC screening practices, and the work of the Clinical Cancer Screening Network (CCSN) to implement systems changes to increase CRC screening.
- [Kevin English, DrPH, Albuquerque Area Southwest Tribal Epidemiology Center, Albuquerque Area Indian Health Board](#)
 - Dr. English shared the results of a randomized clinical trial that resulted in increased screening CRC in the IHS Albuquerque Area with the addition of mailed fecal

immunochemical tests (FITs) and navigation by Community Health Representatives (CHRs) to standard care.

- **Diana Redwood, PhD, MPH, Alaska Native Tribal Health Consortium and Statewide Alaska Colorectal Cancer Partnership**
 - Dr. Redwood described the results of research and programs to increase CRC screening among Alaska Native communities, including promising results from a screening navigation program and a first-degree relative notification program.

Presentations were followed by a question and answer and discussion session.

AI/AN-serving Organizations and Institutions: Policy and Systems Change

During this section, meeting attendees shared brief seven to eight minute presentations to explore the national policy and coverage landscape that impacts CRC screening in AI/AN communities. Presentations included:

- **Impact of ACA, Medicaid expansion and other health care financing issues on AI/AN communities – Eric Vinson (Cherokee Nation), Northwest Portland Area Indian Health Board Indian Health Service**
 - Mr. Vinson shared a brief overview of the national impact of the Affordable Care Act and Medicaid Expansion on AI/AN communities, and shared how these policies have impacted tribes in Oregon, Washington, and Idaho.
- [Indian Health Service – Susan V. Karol, MD \(Tuscarora Indian Nation\)](#)
 - Dr. Karol, Chief Medical Officer at IHS,⁶ described IHS's role in supporting CRC screening, including how the Improving Patient Care (IPC) Program is supporting clinical quality improvement in primary care settings.
- **Centers for Disease Control and Prevention – Nikki Hayes, MPH**
 - Ms. Hayes, Chief of the Comprehensive Cancer Control Branch within the Division of Cancer Prevention and Control at CDC, described CDC grants and programs that support CRC screening in AI/AN communities.
- [Great Plains Tribal Chairmen's Health Board – Richard Mousseau, MS \(Oglala Sioux Tribe\)](#)
 - Mr. Mousseau, Director of Community Health Prevention Programs, shared GPTCHB's planned work as a new CDC Colorectal Cancer Program grantee.
- **American Cancer Society – Dave Egli, MA, MBA**
 - Mr. Egli, Health Systems Manager, Primary Care, described the ACS's health systems staff and their role in supporting cancer screening work in primary care systems.

Presentations were followed by a question and answer and discussion session.

⁶ Dr. Karol has transitioned to a new role at the Centers for Medicare and Medicaid Services.

Findings from Pre-meeting Survey

During this session, Emily Bell, MPH, NCCRT Associate Director, shared the findings from a pre-meeting survey of meeting attendees that sought to generate ideas for the key barriers to screening and most promising solutions, which were used to set the stage for the following action planning session. Survey responses are reflected in the Framework for Change described in the next section.

Framework for Change

The purpose of this session was to draw from meeting attendees' knowledge and experience and consider all that the group learned in the previous sessions to begin to think about ways that we might be able to collaborate to arrive at solutions. During and after the meeting, the group worked collaboratively to populate ideas in a "Framework for Change" tool, which outlined the key goals, priority tactics, barriers, and potential community of solution and roles for four strategic drivers: patients, providers, systems, and policy. A detailed version of this Framework can be found in Appendix D. Following is a summary of this discussion.

Strategic Driver 1: Patients

Meeting attendees identified several key goals related to patients, including increasing CRC screening among AI/AN, increasing awareness of and access to CRC screening options, normalizing CRC screening among AI/AN and encouraging open dialogue throughout the AI/AN community, expanding colonoscopy service availability, increasing timely receipt of screening results, and increasing understanding of AI/AN motivations to screen.

The group cited numerous barriers to achieving these goals, including patient-level barriers such as lack of knowledge about the risk of CRC and the importance of screening, embarrassment, and lack of trust in providers and/or the health care system. Systems barriers included suboptimal provider recommendations, colonoscopy access, and affordable health insurance coverage.

Attendees cited several priority tactics needed to address these barriers and achieve these goals, with the highest priority given to the following:

Priority Tactics (bold indicates meeting attendee selection for highest priority)	
<ul style="list-style-type: none">• Provide patient navigation to identify and address barriers• Collect qualitative data on the "never" and "rarely screened" to identify additional strategies to increase screening in these groups• Develop dissemination strategies to improve use of materials (e.g. build into EHR)	<ul style="list-style-type: none">• Inventory existing educational materials (e.g. link to repositories such as National Native Network and Native CIRCLE) Evaluate existing materials for cultural appropriateness and literacy level• Disseminate culturally appropriate materials• Use client reminders• Support community health to clinic linkages (e.g. invite community members to clinic meetings)

<ul style="list-style-type: none"> Identify and leverage community champions to encourage screening/change cultural norms 	
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Attendees identified numerous organizations and associations that could play a role in implementing the priority tactics, and began outlining the available and needed resources and the metrics and data sources needed to conduct the work. Visit Appendix D for more information.

Strategic Driver 2: Providers

Meeting attendees identified several key goals related to providers, including increasing providers’ CRC recommendations, increasing provider knowledge about FIT, stool DNA testing, and the importance of offering screening test choices, training more providers to perform quality colonoscopies, and improving providers’ cultural competence and communication skills specific to AI/ANs.

The group cited numerous barriers to achieving these goals, including knowledge and skills of the provider, such as lack of knowledge (e.g. guidelines, impact of family history, higher risk in AI/AN), lack of knowledge about FIT and other screening tests, use of older, less effective guaiac FOBT and in-office DRE, and extraneous barriers, such as provider turnover, limited time with patient, under-staffing, poor EHR reminder and tracking systems, lack of qualified staff, lack of awareness of screening rates among providers, and unreliable screening data.

Attendees cited several priority tactics needed to address these barriers and achieve these goals, with the highest priority given to the following:

Priority Tactics (bold indicates meeting attendee selection for highest priority)	
<ul style="list-style-type: none"> Increase ongoing training and professional development opportunities available for providers and CHR/patient navigators Improve provider skills in communicating CRC risk and screening to patients (e.g. motivational interviewing, easy-to-understand/low-literacy phrasing) Increase collaboration between providers and respective community outreach personnel, including patient navigators (Native Sisters), CHAPS, CHR, CHWs, peer educators, lay health advisors 	<ul style="list-style-type: none"> Support effective EHR solutions, including provider reminders Use patient navigators in concert with providers to conduct CRC screening outreach Link CRC screening to existing organizational priorities (i.e. diabetes management) Implement provider feedback and assessment to report and monitor individual provider rates Use team-based approaches to increase screening

Attendees identified numerous organizations and associations that could play a role in implementing the priority tactics, and began outlining the available and needed resources and the metrics and data sources needed to conduct the work. Visit Appendix D for more information.

Strategic Driver 3: Systems

Meeting attendees identified several key goals related to providers, including increasing EHR capacity, functionality, and interoperability, utilizing team-based care, developing incentives for hospitals/health systems to increase screening rates, funding and sustaining patient navigation.

The group cited numerous barriers to achieving these goals, including insufficiencies in EHR and reminder and tracking systems, resource and capacity issues (e.g. colonoscopy not available, long wait times, lack of funding), lack of provider assessment and feedback, lack of care coordination, lack of clear workflows, screening protocols, and policies, and the observation that prevention is not a priority.

Attendees cited several priority tactics needed to address these barriers and achieve these goals, with the highest priority given to the following:

Priority Tactics (bold indicates meeting attendee selection for highest priority)	
<ul style="list-style-type: none"> • Develop and provide tailored TA to implement clinic policies and procedures, including EHR improvements • Develop tutorials on documenting/pulling data from EHRs • Centralize population outreach on CRC screening (e.g. automated reminders, mailed FIT) • Implement phone-based patient navigation 	<ul style="list-style-type: none"> • Develop and implement CRC policy and procedure templates for clinics • Negotiate bulk pricing for evidence-based screening tests (e.g. FIT, stool DNA) and prep (e.g. through IHS and community based clinic settings) • Implement Flu-FIT (to emphasize annual screening)

Attendees identified numerous organizations and associations that could play a role in implementing the priority tactics, and began outlining the available and needed resources and the metrics and data sources needed to conduct the work. Visit Appendix D for more information.

Strategic Driver 4: Policy

Meeting attendees identified several key goals related to policy change, including expanding grant assistance, coverage for the uninsured, increasing access to CRC screening, diagnosis and follow-up care to the under- and uninsured, patient navigation reimbursement and certification, and improving the full continuum of care (screening to end of life).

The group cited numerous barriers to achieving these goals, including variability in coverage between health plans, variability in access to coverage between states, variability in access to services between different I/T/U programs, insufficient funding for IHS-contracted preventive care throughout the calendar year, costs to patient for colonoscopy (Medicare loophole, colonoscopy following positive stool test), health plan “churn” (frequent change of health plan), and a lack of focus on preventive care.

Attendees cited several priority tactics needed to address these barriers and achieve these goals, with the highest priority given to the following:

Priority Tactics (bold indicates meeting attendee selection for highest priority)	
<ul style="list-style-type: none"> • Advocate for increased funding for tribal, urban and AI/AN organization specific CRC interventions • Workforce development for AI/AN patient navigators, CHRs, Primary Care Physicians and support staff to aid in increasing CRC screening rates and follow-up 	<ul style="list-style-type: none"> • Implement and evaluate CRC interventions for high-risk AI/AN community members. (post meeting suggestion) • Advocate for increase in GPRA target from 39%

Finally, attendees identified numerous organizations and associations that could play a role in implementing the priority tactics, and began outlining the available and needed resources and the metrics and data sources needed to conduct the work. Visit Appendix D for more information.

Taking Action & Closing Prayer

During this closing session, the meeting attendees each shared the role that their organization could potentially play in future work and their intention to engage and contribute in future collaborations. The meeting adjourned with a closing prayer led by Ruth Bussey of the Grand Traverse Band.

Post Meeting Actions

The American Cancer Society (ACS) and the National Colorectal Cancer Roundtable (NCCRT) have taken steps to build on the discussion and strategic planning that took place in the “Increasing Colorectal Cancer Screening for American Indians and Alaska Natives” meeting.

In February 2017, the ACS announced a new funding opportunity to support increased colorectal cancer (CRC) screening in AI/AN communities through the Community Health Advocates implementing Nationwide Grants for Empowerment and Equity (CHANGE) Grant Program, with applications due in May 2017. Through this opportunity, the ACS awarded five grants in amounts up to \$100,000 (\$50,000/year for two years) to eligible tribal health organizations and organizations serving the health needs of AI/AN communities to support the implementation of CRC screening projects. The funding supports the grantee’s efforts to improve colorectal cancer outcomes and decrease disparities. Current grantees include:

- Arctic Slope Native Association in Barrow/Utquiagvik, Alaska
- Fond du Lac Services Division in Cloquet, Minnesota
- Keweenaw Bay Indian Community in Baraga, Michigan
- Native Americans for Community Action in Flagstaff, Arizona
- Riverside San Bernardino County Indian Health Inc. in Grand Terrace, California

The NCCRT is working to advance understanding of the unique barriers to CRC screening and the promising interventions to increasing CRC screening in AI/AN communities among NCCRT members and partners. In November 2016, NCCRT hosted a workshop at the 2016 NCCRT Annual Meeting titled

“American Indians/Alaska Natives and Colorectal Cancer Screening: Understanding the Challenge, Real Life Solutions and the Path Ahead,” featuring several April 2016 meeting attendees. Additionally, NCCRT plans to host a webinar on CRC screening in AI/AN communities on Tuesday, November 28th, 2017. A replay of this webinar will be available in the [NCCRT Resource Center](#) in early December 2017.

The ACS and the NCCRT intend to continue to explore additional opportunities to address the unique barriers to CRC screening and support promising interventions to increasing CRC screening in AI/AN communities. We will utilize the recommendations included in this report to shape strategies for enhanced ACS and NCCRT engagement with AI/AN populations. We invite the many partners involved in this meeting or named in this report to continue to work individually and collectively to make a positive impact on the health of AI/AN populations, and to collaborate with us in this work.

Acknowledgements

The NCCRT and the ACS would like to thank the many individuals who generously offered their time and expertise in planning the meeting agenda, participating in the meeting, and in developing this meeting report. See Appendices B and C to find a list of these individuals. The NCCRT and the ACS would also like to thank the CDC for their gracious cooperation in allowing us to hold this meeting as a pre-meeting to the CDC’s summit on cancer control in AI/AN communities.

Appendices

Appendix A

Increasing Colorectal Cancer Screening for American Indians and Alaska Natives

Monday, April 25th, 2016 – Traverse City, MI

Grand Traverse Resort and Spa – Director’s Room (Lobby Level)

Summit Goals:

1. Examine the opportunities and barriers related to delivering quality colorectal cancer (CRC) screening and follow-up care in health care settings serving American Indian/Alaska Native (AI/AN) communities.
2. Develop guidance that can be used by involved organizations to enhance delivery of effective, efficient cancer screening in AI/AN-serving health care settings, to include:
 - Integrating with existing structures
 - Aligning resources in the public and private spheres
 - Strengthening channels of communication
 - Working across organizational goals and priorities
3. Examine the existing tools and resources that support cancer screening in practice and identify dissemination strategies and additional needs.

7:15 am **Continental Breakfast**

8:00 am **Summit Opening**

Opening Prayer

- Ruth Bussey (Grand Traverse Band)

Welcome & Introductions

- Kris Rhodes, MPH, (Bad River Chippewa & Fond du Lac Chippewa) American Indian Cancer Foundation

- Richard Wender, MD, American Cancer Society

80% by 2018 initiative

- Richard Wender, MD, American Cancer Society

8:45 am Setting the Stage

Overview of CRC and CRC screening in AI/AN populations

- Don Haverkamp, MPH, Centers for Disease Control and Prevention

9:05 am Barriers and Promising Practices and Tools to Improve CRC Screening

“Deeper dive” presentations into barriers to CRC screening and corresponding successful efforts to increase CRC screening

(7-8 minutes each)

- **Diane Fuller, RN**, Warm Springs Health and Wellness Center
- **Dan Tadgerson, MPH, (Bay Mills Indian Community)** Bay Mills Health Center
- **Virginia Warren**, Arizona Department of Health Services
- **Jen Olson, MS, MA**, South Puget Intertribal Planning Agency
- **Anne Walaszek, MPH, (White Earth Band of Ojibwe)** American Indian Cancer Foundation
- **Kevin English, DrPH**, Albuquerque Area Southwest Tribal Epidemiology Center, Albuquerque Area Indian Health Board
- **Diana Redwood, PhD, MPH**, Alaska Native Tribal Health Consortium and Statewide Alaska Colorectal Cancer Partnership

10:15 am BREAK

10:30 am Cancer Screening Barriers and Solutions for AI/AN Communities

Q&A and Discussion

- What are the critical issues that affect efficient and effective CRC screening in AI/AN populations?
- Identifying strategies to overcome barriers
- What are the primary management challenges with screening delivery within these environments?

11:15 am AI/AN-serving Organizations and Institutions: Policy and Systems Change

Presentations (7-8 minutes each)

- **Impact of ACA, Medicaid expansion and other health care financing issues on AI/AN communities** – Eric Vinson (Cherokee Nation), Northwest Portland Area Indian Health Board

- **Indian Health Service** – Susan V. Karol, MD (Tuscarora Indian Nation)
- **Centers for Disease Control and Prevention** – Nikki Hayes, MPH
- **Great Plains Tribal Chairmen’s Health Board** – Richard Mousseau, MS (c) (Oglala Sioux Tribe)
- **American Cancer Society** – Dave Eggli, MA, MBA

Q&A and Discussion

- How can we take advantage of the changes in care delivery that are already underway?
- How do we connect screening delivery, including follow-up care, with the rest of the healthcare system?
- What are the critical issues that affect integration with 80% by 2018 and other state and national screening efforts?

12:30 pm LUNCH

1:30 pm Findings from pre-meeting survey

Presentation of challenges and proposed solutions to low CRC screening rates as described by meeting participants

- Emily Butler Bell, MPH, National Colorectal Cancer Roundtable

1:50 pm Framework for Change

Collaborative Discussion

- Discussion of Recommendations/Strategies for Addressing Change (based on pre-meeting survey and morning discussion)
- Brainstorm on potential roles and responsibilities for involved organizations in implementing identified strategies and approaches

Break as Needed

3:30 pm Taking Action

Open Discussion

- As we move forward, what is the role that each of our organizations can play?
- Are there other groups or individuals that need to be contacted and involved?
- Clarify next steps and implementation needs.

4:00 pm Closing Prayer

- Ruth Bussey (Grand Traverse Band)

ADJOURN

Appendix B

AMERICAN CANCER SOCIETY & NATIONAL COLORECTAL CANCER ROUNDTABLE Increasing Colorectal Cancer Screening for American Indians and Alaska Natives Monday, April 25th, 2016 – Traverse City, MI

PLANNING COMMITTEE ROSTER

Emily Bell, MPH

Associate Director, National Colorectal Cancer Roundtable,
American Cancer Society, Inc.

Durado Brooks, MD, MPH

Managing Director, Cancer Control Intervention, American Cancer Society, Inc.;
National Colorectal Cancer Roundtable Chair Steering Committee

T'Ronda Flagg, MPA, MCHES

Division of Cancer Control and Prevention, Program Services Branch,
Centers for Disease Control and Prevention

Don Haverkamp, MPH, CPH

Epidemiologist, Division of Cancer Prevention and Control,
Centers for Disease Control and Prevention

Judith Muller, MHA

Alaska Native Tribal Health Consortium CCC Program;
Chair, Statewide Alaska Colorectal Cancer Partnership

Noel Pingatore, BS, CPH

Health Education and Chronic Disease Department,
Inter-Tribal Council of Michigan

Kris Rhodes, MPH (Bad River Chippewa & Fond du Lac Chippewa)

Executive Director, American Indian Cancer Foundation

Ena Wanliss, MS

Associate Director, Program and Policy Information, Comprehensive Cancer Control Branch, Division of
Cancer Prevention and Control, Centers for Disease Control and Prevention

Appendix C

AMERICAN CANCER SOCIETY & NATIONAL COLORECTAL CANCER ROUNDTABLE Increasing Colorectal Cancer Screening for American Indians and Alaska Natives Monday, April 25th, 2016 – Traverse City, MI

MEETING ROSTER

Michael L. Bartholomew, MD, FAAP

CDR, United States Public Health Service, Deputy Director (Acting),
Office of Public Health Support, Indian Health Service

Emily Bell, MPH

Associate Director, National Colorectal Cancer Roundtable,
American Cancer Society, Inc.

Durado Brooks, MD, MPH

Managing Director, Cancer Control Intervention, American Cancer Society, Inc.;
National Colorectal Cancer Roundtable Chair Steering Committee

Linda Burhansstipanov, MSPH, DrPH (Cherokee Nation of Oklahoma)

Founder, Native American Cancer Research Corporation;
President, Native American Cancer Initiatives, Incorporated

Margie Burkhart

Program Manager, Cherokee Nation

Dave Egli, MA, MBA

Health Systems Manager, Primary Care,
American Cancer Society, Inc.

Kevin English, DrPH

Director, Albuquerque Area Southwest Tribal Epidemiology Center,
Albuquerque Area Indian Health Board, Inc.

DeAnna Finifrock RN, PHN, MSN (Fond du Lac Reservation)

Fond du Lac Human Services Division, Community Health Services Department

Diane Fuller, BSN, RN

Quality Improvement/Risk Management,
Warm Springs Health and Wellness Center

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Appendix D

AMERICAN CANCER SOCIETY & NATIONAL COLORECTAL CANCER ROUNDTABLE Increasing Colorectal Cancer Screening for American Indians and Alaska Natives Monday, April 25th, 2016 – Traverse City, MI

Framework for Change

During and after the meeting, meeting attendees worked collaboratively to populate ideas in the following “Framework for Change” tool, which outlines the key goals, priority tactics, barriers, and potential community of solution and roles for four strategic drivers: patients, providers, systems, and policy.

Priority tactics that group members identified as being of high priority are shown in purple font. Highest priority tactics are bolded.

Acronym Guide

ACS – American Cancer Society
AI/AN – American Indian and Alaska Native
AICAF – American Indian Cancer Foundation
CDC – Centers for Disease Control and Prevention
CHR – Community Health Representatives
CRC – colorectal cancer
EHR – electronic health record
FIT – fecal immunochemical test
FOBT – fecal occult blood test
GPRA – Government Performance and Results Act
IHS – Indian Health Service
I/T/U – IHS/Tribal/and Urban
NACR – Native American Cancer Research
NCCRT – National Colorectal Cancer Roundtable?
NIHB – National Indian Health Board
RPMS – Resource and Patient Management System

American Indian and Alaska Native Collaborative Colorectal Cancer Screening Strategic Framework

Strategic Driver	Goals	Priority Tactics	Barriers	Potential Community of Solution & Roles
Patient	<ul style="list-style-type: none"> • Increase CRC screening among AI/AN • Increase awareness of CRC screening options • Increase access to CRC screening options • Normalize CRC screening among AI/AN and encourage open dialogue throughout the AI/AN community • Expand colonoscopy service availability • Increase timely receipt of screening results and any needed follow up • Increase understanding of AI/AN motivations to screen 	<ul style="list-style-type: none"> • Provide patient navigation to identify and address barriers • Collect qualitative data on the “never” and “rarely screened” to identify additional strategies to increase screening in these groups • Develop dissemination strategies to improve use of materials (e.g. build into EHR) • Identify and leverage community champions to encourage screening/change cultural norms • Inventory existing educational materials (e.g. link to repositories such as National Native Network and Native CIRCLE) • Evaluate existing materials for cultural appropriateness and literacy level • Disseminate culturally appropriate materials • Use client reminders • Support community health to clinic linkages (e.g. invite community members to clinic meetings) • Provide transportation (e.g. via Community Health Aide Program (CHAP)/CHR, bus and gas cards) • Identify effective media channels (text messages, Facebook, etc.) and integrate into dissemination strategy • Provide patient education in both clinic and community settings • Educate patients about all opportunities for screening (e.g. local health departments) • Educate patients about all recommended screening modalities 	<ul style="list-style-type: none"> • Embarrassment • Fear (colonoscopy, cancer, cost) • Fatalism • Lack of discussion about cancer • Lack of knowledge: risk of CRC, importance of screening, how to complete stool test, how to conduct stool test without violating cultural modesty mores • Transportation/distance • Difficulty in taking time off (caregiving, work) • Language barriers • Cultural issues w/ stool testing • CRC screening is not a cultural norm • Unpleasantness of the prep • No prep or poor prep • Lack of trust in providers and/or health care system • Unable to establish rapport with health system staff due to high staff turnover • Negative patient experience stories that spread to others • Historical trauma related to past abuse impacts trust (boarding school, etc.) • No provider recommendation • Access to colonoscopy • Confusion regarding screening options and the timing for each • Worry about cost if polyps are detected • Scheduling and coordinating with endoscopy centers 	<ul style="list-style-type: none"> • National Native Network and Native CIRCLE to host and inventory resources • AICAF to offer technical assistance and serve as a liaison to expert AI/AN community members • Patient navigators (e.g. Native Sisters) • I/T/U and AI/AN community organizations • Partnerships between endoscopy and treatment settings and I/T/U and AI/AN organizations • NCCRT/ACS resources and tools • Public Health Nurses, Community Health Nurses • National Association of City and County Health Organizations

	<ul style="list-style-type: none"> • Increase awareness of the increased risk for CRC among some AI/AN populations, the value of screening at lowering this risk, and the importance of prompt medical attention for symptoms – regardless of patient age • Encourage eligible patients to enroll in affordable, high quality insurance 	<ul style="list-style-type: none"> • Confusion regarding insurance coverage • Lack of free coverage and services for individuals between 45 and 49 years of age • Lack of access to treatment and/or social/emotional support for a cancer diagnosis 	
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Resources

<p>Available:</p> <ul style="list-style-type: none"> • Existing AI/AN materials – use as a starting point to develop new community-specific materials • NCCRT’s 80% by 2018 Communications Guidebook • CDC’s Screen for Life campaign tested messages • MIYO (Make It Your Own) custom educational materials • University of Colorado patient navigation and motivational interviewing materials • Validated AI/AN-specific CRC curricula ("Get on the Path to Colon Health", CRC excerpt from Native Cancer 101 Module 10 "Preventing and Early Cancer Detection (Screening); CRC excerpt from ACS Circle of Life, Alaska Community Health Aide training modules on cancer (<i>post meeting suggestion</i>)) 	<p>Needed:</p> <ul style="list-style-type: none"> • Study effective messaging and the best channels to reach AI/AN populations about CRC screening options • Funding for I/T/U and AI/AN community organizations to train and hire patient navigators/Native Sisters for CRC screening and education (e.g. train existing IHS-funded CHRs) • Funding for subcontracts from CRC clinical settings and I/T/U and AI/AN community organizations for recruitment of community members to screening • Explore development of a clearinghouse for tested patient education materials (CRC specific or for multiple cancers)
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<p>Data:</p> <p>Metric:</p> <ul style="list-style-type: none"> • Documentation (see NACR’s online evaluation program; login with username “train” and password “choochoo”), which allows for tracking type of CRC screening recommended, date when recommended for screening (e.g. by Native Sister), date when screening scheduled, date when screening completed, etc. (<i>post meeting suggestion</i>) 	<p>Data Source(s):</p> <ul style="list-style-type: none"> • EHR • NACR tracking form for the Native Cancer 101 Module could be modified (see link to online evaluation program at left) (<i>post meeting suggestion</i>) • Excerpt from “navigation” tab within NACR’s online evaluation program (<i>post meeting suggestion</i>)
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Strategic Driver	Goals	Priority Tactics	Barriers	Potential Community of Solution & Roles
Provider	<ul style="list-style-type: none"> • Increase providers' CRC recommendations (guidelines-informed) • Increase provider knowledge about FIT, DNA stool testing, and importance of offering choices • Train more providers to perform quality colonoscopies • Improve providers' cultural competence and communication skills specific to AI/ANs 	<ul style="list-style-type: none"> • Increase ongoing training and professional development opportunities available for providers and CHR/patient navigators • Improve provider skills in communicating CRC risk and screening to patients (e.g. motivational interviewing, easy-to-understand/low-literacy phrasing) • Increase collaboration between providers and respective community outreach personnel, including patient navigators (Native Sisters), CHAPS, CHR, CHWs, peer educators, lay health advisors • Support effective EHR solutions, including provider reminders • Use patient navigators in concert with providers to conduct CRC screening outreach • Link CRC screening to existing organizational priorities (i.e. diabetes management) • Implement provider feedback and assessment to report and monitor individual provider rates • Use team-based approaches to increase screening 	<ul style="list-style-type: none"> • Lack of knowledge (guidelines, impact of family history, higher risk in AI/AN) • Preference for colonoscopy, lack of knowledge about FIT and other screening tests • Use of guaiac FOBT and in-office digital rectal exam (DRE) • Provider turnover • Limited time with patient • Under-staffing • Poor EHR reminder and tracking systems • Lack of qualified staff • Lack of awareness of screening rates among providers • Unreliable screening data 	<ul style="list-style-type: none"> • GPRA • AICAF CME Opportunities for CRC Best Practices • Association for American Indian Physicians • AI/AN nurses associations • American Academy of Family Physicians • Primary care associations • ACS Primary Care and Health Systems staff • NCCRT tools and resources • Explore IHS policy changes (e.g. mandatory directives for CRC screening)

Resources	
<p>Available:</p> <ul style="list-style-type: none"> • Strong existing models in diabetes, immunization and HIV • NCCRT's Steps For Increasing Colorectal Cancer Screening Rates: A Manual For Community Health Centers 	<p>Needed:</p> <ul style="list-style-type: none"> • Funding to support training of healthcare professionals (physicians, NPs, PAs, nurses, social workers, navigators, CHWs, etc.)

Data	
Metric: <ul style="list-style-type: none"> TBD 	Data Source(s): <ul style="list-style-type: none"> EHR GPRA BRFSS (in some states/tribes) Other

Strategic Driver	Goals	Priority Tactics	Barriers	Potential Community of Solution & Roles
System	<ul style="list-style-type: none"> Increase EHR capacity and functionality (to ensure data capture, reminders, etc.) Increase EHR interoperability Optimize and increase accuracy of RPMS (Resource and Patient Management System) Develop capacity for 3rd party billing for patient navigation Utilize team-based care Increase use of stool tests (FIT, stool DNA) Develop incentives for hospitals/health systems to increase screening rates Develop incentives for public health programs to increase screening rates Fund and sustain patient navigation Train a range of health workers [CHAPS, Patient Navigators (Native Sisters), CHWs] on how to conduct effective CRC education 	<ul style="list-style-type: none"> Develop and provide tailored TA to implement clinic policies and procedures, including EHR improvements Develop tutorials on documenting/pulling data from EHRs Centralize population outreach on CRC screening (e.g. automated reminders, mailed FIT) Develop and implement CRC policy and procedure templates for clinics Negotiate bulk pricing for evidence-based screening tests (e.g. FIT, stool DNA) and prep (e.g. through IHS and community based clinic settings) Implement Flu-FIT (to emphasize annual screening) Implement phone-based patient navigation Create patches for RPMS to eliminate duplicate entries Harmonize CHR notes/documentation with EHR Measure and track colonoscopy quality indicators (e.g. adenoma detection rate) in the EHR Leverage a range of health workers as advocates 	<ul style="list-style-type: none"> Resource/capacity issues (colonoscopy not avail., long waits, lack of funding) Insufficient EHRs, reminder and tracking systems Lack of time to clean data in EHRs Lack of provider training on correct data entry procedures Lack of provider assessment and feedback (no individual provider rates) Lack of care coordination Lack of clear workflows/ screening protocols and policies Prevention is not a priority Lack of support for systems change RPMS, insufficient templates Lack of collaboration with IT staff Evidence-based interventions require time for cultural adaptation 	<ul style="list-style-type: none"> NCCRT work on EHRs (guides for NextGen and eClinicalWorks) IHS could explore prioritizing and incentivizing CRC screening and follow up IHS support for RPMS/EHR optimization and training IHS to address FIT uptake/selection AICAF to provide system support to unify clinic and community health programs for increased CRC screening

	<ul style="list-style-type: none"> • Conduct community education using validated AI/AN curricula • Enable other providers (e.g. dentists, optometrists, pharmacists) to recommend screening • Improve care coordination between primary care and specialists (e.g. streamline referrals for diagnostic services) 		
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Resources

<p>Available:</p> <ul style="list-style-type: none"> • NCCRT’s Steps For Increasing Colorectal Cancer Screening Rates: A Manual For Community Health Centers • National Supply Service Center in Oklahoma • Tracking system for Patient Navigator/CHW and specially trained CHR’s time and services • Kalispel’s clinic data management system (Ron Poplawski) <i>(post meeting suggestion)</i> • Melany Cueva’s CHAP training materials <i>(post meeting suggestion)</i> 	<p>Needed:</p> <ul style="list-style-type: none"> • RPMS operability with other EHRs • More effective use of EHR and related tools to assist with CRC screening
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Data

<p>Metric:</p> <ul style="list-style-type: none"> • TBD 	<p>Data Source(s):</p> <ul style="list-style-type: none"> • TBD
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Strategic Driver	Goals	Priority Tactics	Barriers	Potential Community of Solution & Roles
Policy	<ul style="list-style-type: none"> Expand CDC CRC programs to AI/AN programs in all 50 states or in each IHS regional tribal epidemiology center Expand tribal-specific BRSS Provide CRC screening, diagnosis and follow-up care to the under- and uninsured Cover the uninsured Increase GPRA target from 39% Include a focus on other targets such as Healthy People 2020 (2020 target is 70.5%) Advocate for cancer-specific IHS/tribal/urban CRC program Advocate for patient navigation reimbursement and certification Improve continuum of care (screening to end of life) 	<ul style="list-style-type: none"> Advocate for increased funding for tribal, urban and AI/AN organization specific CRC interventions Workforce development for AI/AN patient navigators, CHRs, Primary Care Physicians and support staff to aid in increasing CRC screening rates and follow-up Implement and evaluate CRC interventions for high-risk AI/AN community members. (post meeting suggestion) Advocate for increase in GPRA target from 39% Advocate for increased funding for tribal-specific BRSS (e.g. fund individual tribes) Develop a CRC-specific overarching screening policy supported by IHS headquarters 	<ul style="list-style-type: none"> Costs to patient for colonoscopy (Medicare loophole, colonoscopy following positive stool test) Insufficient funding for IHS-contracted preventive care throughout the calendar year Low prioritization of preventive care in IHS funding (limited resources beyond acute care) Health plan “churn” (frequent change of health plan) Patients opt out of ACA plans for care through IHS Variability in coverage between health plans Variability in access between states (Medicaid Expansion) Variability in access to services b/w different I/T/U programs Screening recommendations do not emphasize AI/AN high risk, promote early screening Lack of focus on preventive care Insufficient I/T/U leadership prioritizing cancer prevention and control 	<ul style="list-style-type: none"> ACS Cancer Action Network (ACS CAN) ACS NCCRT CDC IHS NIHB

Resources:	
Available: <ul style="list-style-type: none"> Patient navigator/CHW training (online, in-person) 	Needed: <ul style="list-style-type: none"> Enhanced funding for CRC screening and follow up via contracted health services Funding to support patient navigator salaries Funding to support I/T/U and AI/AN organizations to conduct and evaluation CRC interventions specific to AI/AN communities

	<ul style="list-style-type: none">• Improved CRC screening data
Data	
Metric: <ul style="list-style-type: none">• TBD	Data Source(s): <ul style="list-style-type: none">• TBD

Appendix E

AMERICAN CANCER SOCIETY & NATIONAL COLORECTAL CANCER ROUNDTABLE Increasing Colorectal Cancer Screening for American Indians and Alaska Natives Monday, April 25th, 2016 – Traverse City, MI

SUGGESTED READING LIST

Meeting attendees provided the following recommendations in advance of the meeting.

HIGHLY SUGGESTED READING

Articles/Publications

- The *American Journal of Public Health* article: [Geographic Variation in Colorectal Cancer Incidence and Mortality, Age of Onset, and Stage at Diagnosis Among American Indian and Alaska Native People, 1990–2009](#)
- The American Indian Cancer Foundation's [Improving Northern Plains American Indian Colorectal Cancer Screening \(INPACS\) Project Report](#)
- A NCCRT article published in *the ACS journal CA*: [Strategies for Expanding Colorectal Cancer Screening at Community Health Centers](#). Our goal is to produce a post-meeting report along these lines outlining strategies for improving AI/AN screening.

SUGGESTED READING

Articles/Publications

- Annual Report to the Nation on the Status of Cancer, 1975-2004, Featuring Cancer in American Indians and Alaska Natives. *Cancer*. 2007. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.23044/pdf>
- Supplement: An Update on Cancer in American Indians and Alaska Natives, 1999–2004. *Cancer*. 2008. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.v113:5%2B/issuetoc>
- *American Journal of Public Health*: June 2014, Vol. 104, No. S3. (Supplement issue on American Indian and Alaska Native health.) <http://ajph.aphapublications.org/toc/ajph/104/S3>
- Petersen, Paneen S., "[Colorectal cancer survival among American Indian and Alaska Native people in the Pacific Northwest](#)" (2011). Scholar Archive. Paper 664.
- Native JourneyWoman books

Websites

- www.alaskacolorectalhealth.org
- www.americanindiancancer.org/colon
- www.cancer.org
- www.cancer.org/circleoflife
- www.nccrt.org/80by2018
- www.tribalcolorectalhealth.org