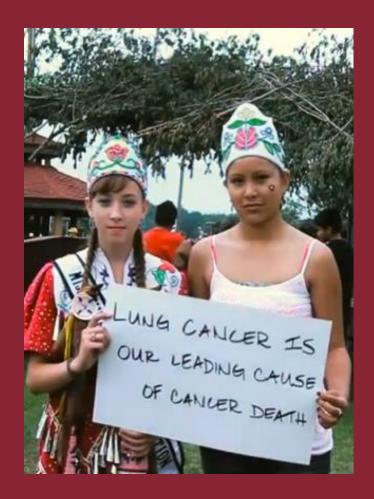
# Reclaiming Indigenous Health by Centering Kinship within Cancer Survivorship Programming





# American Indian Cancer Foundation (AICAF)



American Indian Cancer Foundation (AICAF) is a national non-profit organization established to address tremendous cancer inequities faced by American Indian and Alaska Natives.

## Mission:

Eliminate cancer burdens on American Indian and Alaska Native people through education and improved access to prevention, early detection, treatment and survivor support.



## **AICAF Approach**



We believe Native communities have the wisdom to find the solutions to cancer inequities, but are often seeking the organizational capacity, expert input, and resources to do so.

We support innovative, community-based interventions that engage Native populations in the discovery of their own cancer best practices.

We strive to be a partner trusted by tribal and urban community members, leaders, health care providers, and others working toward effective and sustainable cancer solutions.



## Relations

- Lindsey Petras, MSN, RN
- Cancer Programs Project Manager
- Located in Wisconsin, on Ojibwe land
- Misha LaPlante
- Cancer Programs Project Manager
- Bay Mills Ojibwe/Blackfeet
- Located in Mni Sota; on Dakota land

If you would like to share, please provide in the chat:

- Name
- Role
- Who stewards the land you are on?
- Who do you dedicate your work to?



Gnoozhekaaning; Bay Mills, MI w Nookomis



## **Learning Objectives**

By the end of the presentation, attendees will be able to:

- 1. Define kinship in relation to public health programming and services, specifically cancer survivorship programming.
- 2. Understand ways to reclaim and revitalize Indigenous health and sovereignty by centering kinship.
- 3. Strategize several ways to support cancer survivors in leading the movement to reclaim Indigenous health.



# **Survivorship Definition**

Cancer survivorship begins at diagnosis and lasts throughout one's lifespan. Survivors can be community members, caregivers, and/or other loved ones intimately impacted by a cancer diagnosis, such as a child, other dependents, or a relative.



## Kinship

An intentional act to honor the sacredness of relationships, including acknowledging, uplifting, and celebrating the shared responsibilities and interconnectedness of these connections

How do we honor our relationships so that they support each person in being the relative and ancestor they are meant to be?



# Healing with Culture. Reclaiming Indigenous Health.

#### **Health System Partnerships:**

- Champion inter-tribal collaborations to define cancer barriers and solutions in and across native communities
- Assist health systems to identify gaps and find solutions to effective cancer prevention and care
- Offer systems support to improve cancer screening and tracking systems
- Conduct health care provider education to increase awareness of the importance of the provider role in recommending the right screening, referrals, and treatment for every native patient

#### Community Education And Outreach:

- Perform community education and outreach to raise awareness of cancer prevention, promote early detection, and encourage positive health behaviours that can aid in healing our families
- Deploy community health workers to help men and women overcome screening barriers

#### Community-Based Research:

- Work with communities to identify research questions, methods, and funding opportunities
- Support the collection and use of population-specific data to guide efforts
- Make sure our findings are shared and published so all Native communities can benefit from new health ideas, knowledge, and methods



## **AICAF Guideposts for Collaboration**

- Prioritize
  - Relatives
  - Tribal & Community Sovereignty & Self-Determination
  - Indigenous Lifeways/Ways of Knowing
- > Trust that the community has the wisdom and solutions to address health disparities which affect their community
- Seek input early on from the community
- Change organizational practices
- Actualize change through strategies that are conceived through community member engagement and conversation



# Cancer in Indian Country

## Cancer is the...

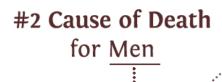
#1 Cause of Death for Women

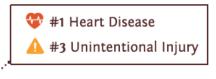


The most commonly diagnosed cancers are...









Lung cancer is the leading cause of cancer death for men and women.

Other leading causes of cancer death are...



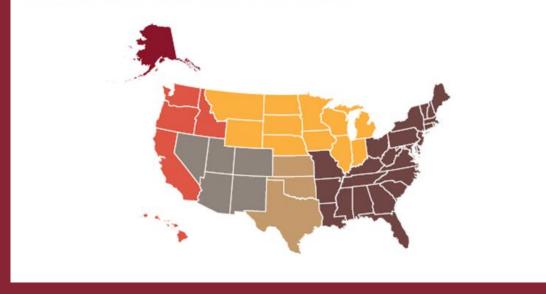






# **Cancer in Indian Country**

Distinct patterns in Al/AN cancer rates are observed across six geographic regions defined by the Indian Health Service.



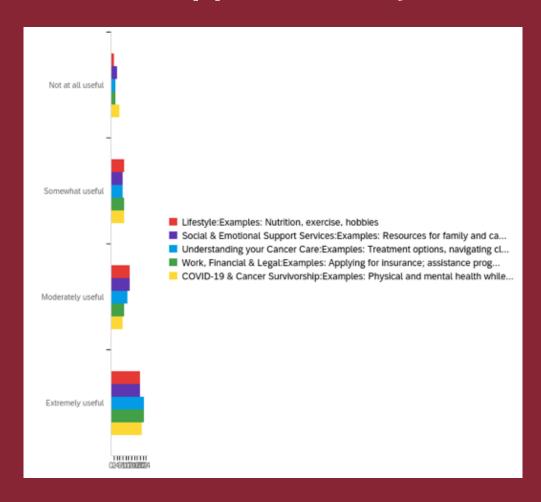


# **AICAF Survivor Support Survey (2022)**

- Results collected so far in 2022...
- Demographics:
  - Diagnosed >50
  - Representation from
  - Most responded as cancer survivors
  - Most were in remission
  - Mostly female respondents
  - Most were diagnosed in stage 4, with a range between 0-3
  - Nearly half lived in rural areas, with the other half in urban settings



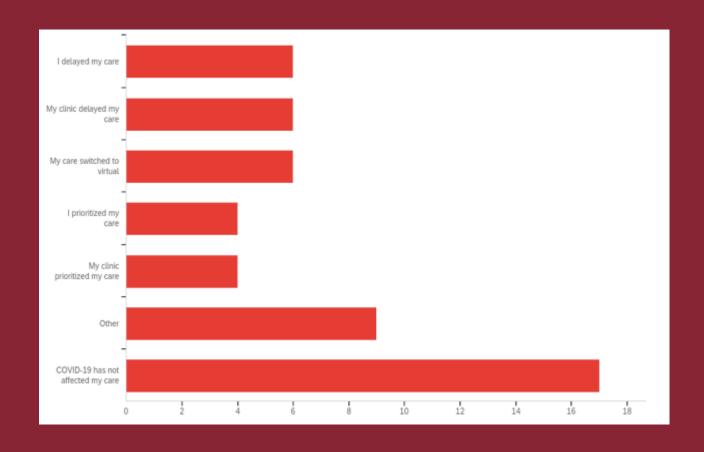
## **Survivor Support Survey Results**





# Cancer in Indian Country During COVID-19

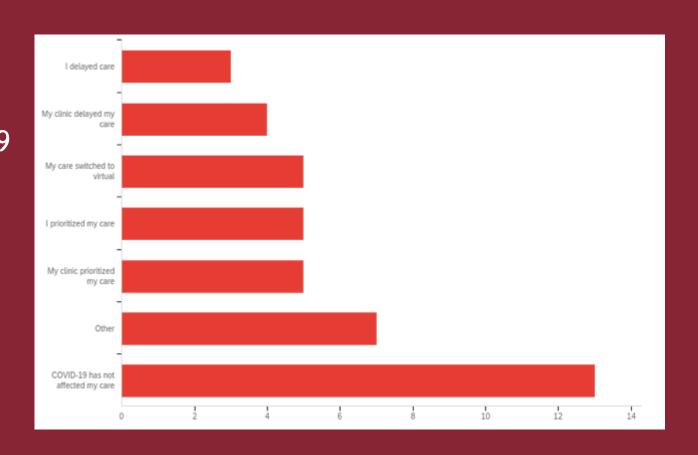
How has COVID-19 impacted your traditional medicine cancer treatment?





# Cancer in Indian Country During COVID-19

How has COVID-19 impacted your non-traditional/commercialized medicine cancer treatment?





## Additional Takeaways

- Some of the biggest challenges:
  - Barriers: finances, transportation, culturally-responsive health care team, etc.
  - Treatment & side effects
  - Dealing with the day-to-day feelings
- More support is needed:
  - o Barriers to care: finances, transportation, culturally-responsive health care team, etc.
  - Clinical Trials
  - Social-Emotional Support
  - Financial Support
- Native cancer survivors can participate throughout 2022. The survey will close on December 30, 2022.
  - Survey Link: https://bit.ly/AICAF-Survivorship-Survey

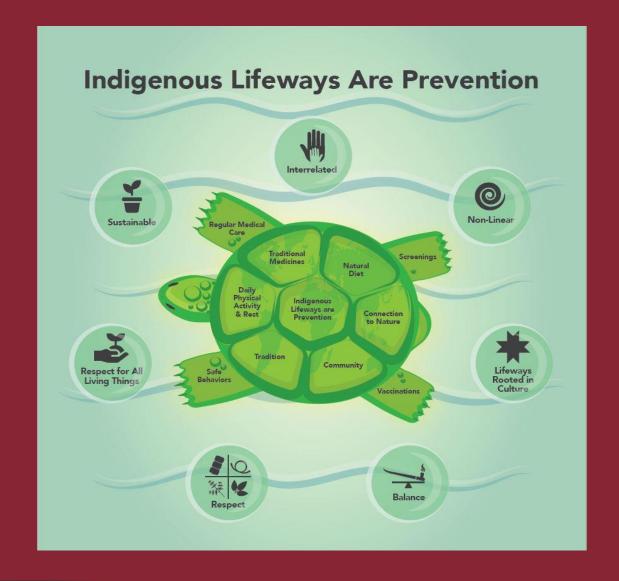


# Reclaiming And Revitalizing Indigenous Health And Sovereignty By Centering Kinship



How do we support the patient/relative/community member to make decisions on their health that best reflect the person/relative/ancestor they are and want to be?







## Indigenous Lifeways















- Ancestral life addressed the many potential root causes of cancer.
- Adopting many ancestral principles are intuitively, as well as scientifically, supported to reduce cancer risk and bolster natural defenses at all stages along the disease continuum.
- The reductionist approach undermines Indigenous wisdom.
  - The interconnectedness of the whole, rather than focusing on just one aspect of the person, is true medicine.
- Our interconnectedness is our relationships.



## Trauma-Informed Care

Experience of trauma can remove a person from their bodies



Guiding Principles to Trauma-Informed Care (TIC):

- Safety
- Choice
- Collaboration
- Empowerment
- Trustworthiness

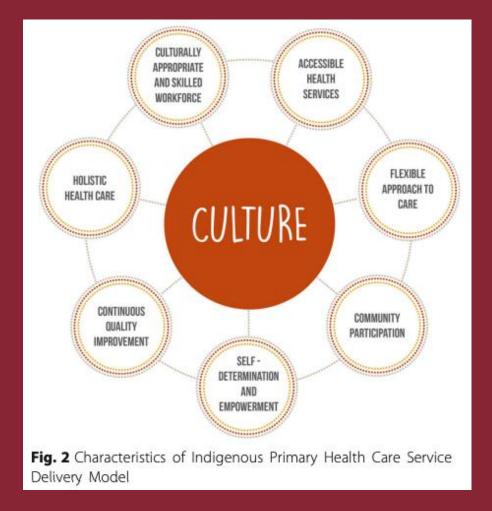
Recognizes the connection to adverse childhood experiences (ACEs)

Cancer is an experience that can be traumatizing

- Preventative screenings come with the potential risk of additional trauma
- Normalizing screenings will take time



"Characteristics of Indigenous primary health care service delivery models" -Stephen Harfield, Carol Davy, Alexa McArthur, Zachary Munn, Alex Brown, and Ngiare Brown



Harfield et al. Globalization and Health (2018) 14:12 DOI 10.1186/s12992-018-0332-2



## **Root Causes of Chronic Disease**



## Adverse Social Determinants of Health

- **Historical & Intergenerational Trauma**: colonization, genocide, stress, disruption of childhood development
- **Poor Access To:** healthy foods, health & human services, employment, education, transportation

## **Adverse Childhood Experiences**

- **Household Dysfunction**: divorce/separation, alcohol abuse, drug use, incarceration, mental illness, domestic violence
- Abuse: physical, sexual, verbal, emotional
- Neglect: physical, emotional

### **Behavioral Risk Factors**

- Behavior: lack of physical activity, unhealthy eating & commercial tobacco use
- Addiction: commercial tobacco, alcoholism, drug use, unsafe sex

## **Poor Health Outcomes**

- Mental Health: depression, post traumatic stress disorder, suicide
- **Physical Health**: cancer, obesity, diabetes, heart disease, sexually transmitted diseases, chronic obstructive pulmonary disease, HIV, Hep C, cirrhosis



**Early Death** 







# Health Equity

# Achieving full health potential



## **Balanced Health**

- Physical: exercise, eat nutritious meals, get adequate sleep, avoid alcohol and processed foods
- Mental: practice mindfulness, seek help when needed, learn how to manage stress, maintain a healthy work and life balance
- **Emotional**: build healthy relationships, value yourself, stay connected with your community, express gratitude
- Spiritual: participate in ceremonies, offer prayers, learn your language, connect with elders

## **Breaking the Cycle of Trauma**

- Protective Factors: cultural connection, belonging, resilience, safety, healthy coping skills
- Preventing Adverse Childhood Experiences: nurturing stable relationships, culturally tailored family education, breastfeeding, connecting families to community system resources

## Social Determinants of Health

- Social and Economical: supportive government, financial institutions, safe transportation routes, cultural activities
- **Increased Access to**: healthy foods, safe physical activity spaces, sacred medicines, health care, education, housing, modes of transportation, internet



Possible perspective: choosing a screening, if the results are abnormal, can be choosing to experience trauma

• "Applying a diagnosis all too often pathologizes the person rather than the process that they experienced, which brought about the injuries. Furthermore, diagnoses complicate identity development. Given these issues, and the fact that most of the imbalance and disharmony experienced by Indigenous people is a result of external colonial focus, it is important to reframe current realities in ways that support healing and wellness." (Linklater, 2014)



## Relationships/Kinship

- The foundation of our lives is our deep relationships with
  - One another
  - The earth, animal, plant nations
  - Ancestors
- Building
   relationships/kinship is
   more than just building
   rapport. It is deepening
   relationships for
   collective collaboration



### Kinship

- Reciprocity
  - Collaboration
  - Trustworthiness
  - Community Participation
  - Continuous QualityImprovement
- Respect
  - Safety
  - Culturally-Appropriate & Skilled Workforce
  - Flexible Approach to Care
- Self-Determination
  - Empowerment
- Freedom/Sovereignty
  - Choice
  - Accessible Health Services
  - Holistic Health Care



## Kinship with Patients & Survivors

What is the health story (or stories) they are sharing?

- Oral Storytelling is a traditional, ancestral practice
- What do they value?
- Opportunities for Connection:
  - Tribal Nation Connection
  - Family/Loved Ones
  - Traditional Medicine/Healing
  - Traditional/Ancestral Lifeways



How do we support the patient/relative/community member to be leaders and make decisions on their health that best reflect the person/relative/ancestor they are and want to be?



# **Cancer Survivorship Programming**



# **AICAF Cancer Survivorship Programming**

- Cancer Survivors Leadership Advisory Council
- Cancer Support Circle
- 1:1 Check-Ins
- Celebrate Indigenous Life Campaign
- Surveys
- Survivor/Caregiver Resources
  - Interviews
    - Webinars
    - Podcasts
    - Articles
  - Print/Digital
  - Policies and Protocols



# Cancer Survivors Leadership Advisory Council

- Overall AICAF programming
  - Themes that emerged:
    - Listening, non-judgment, acceptance
    - Support needed for:
      - Survivor
      - Families/Loved Ones
      - Health Care Team
- Projects
  - Cancer Plan
  - Resources
    - Finding Trusted Resources
    - How to Use the Family History Tree
    - Enhancing Your Time with Patients
    - Resources for Cancer Patients
  - Celebrate Indigenous Life Campaign
- Ribbon Work Evaluation





## **AICAF Cancer Support Circle**

- IHS Cancer Support Leadership training
- Restorative Practices/Justice
- Circle creation was informed by a 2021 Cancer Support
   Circle Evaluation
- Meets twice a month on Thursdays at 6 PM CT





Looking for support in your experiences with cancer?

Join the

### American Indian Cancer Foundation (AICAF) Virtual Cancer Support Circle!

The support group will offer a space to meet others who are experiencing similar situations. You will be able to tell your story, share your fears, and offer support to others on their cancer journey. Activities during the group include story sharing, guest speakers, and other opportunities. These groups are open to all Native survivors, caregivers, and relatives who have been affected by cancer. Please contact health@aicaf.org to learn more about the circle and other survivorship programming, including support circle facilitation trainings.



#### Date:

Thursdays Jan 27 Feb 10 Feb 24 Mar 10
Mar 24 Apr 14 Apr 28 May 12 May 26 Jun 9
Jun 23 Jul 14 Jul 28 Aug 11 Aug 25 Sept 8
Sept 22 Oct 13 Oct 27 Nov 10 Nov 17 Dec 15

#### Time:

2 PM HT / 3 PM AKT / 4 PM PT / 5 PM MT / 6 PM CT / 7 PM ET

#### Registration:

bit.ly/AICAFcircle2022

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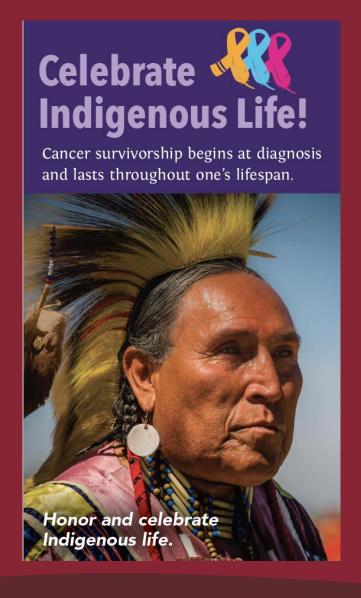


## 1:1 Check-Ins

- Building Kinship with
   AICAF Interview Survey
- Brief check-ins to review AICAF's survivorship opportunities and programming







## Our ancestral traditions keep us healthy.

1

Use traditional medicines



Consume natural nonprocessed foods



Maintain daily physical activity & rest



Engage with the community in traditional activities



Connect with nature



Maintain regular medical care



Schedule screenings



Stay up to date on vaccinations



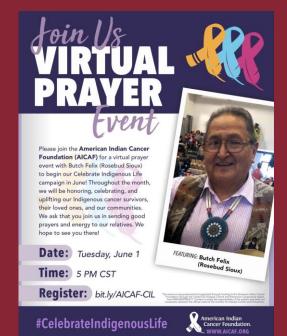
Practice safe behavior

Support and celebrate the strength and resilience of Indigenous cancer survivors everywhere!

#CelebrateIndigenousLife











Please join the American Indian Cancer Foundation (AICAF) and our partners throughout the month of June for our Celebrate Indigenous Life webinars! These events will provide opportunities for our beloved relatives impacted by a cancer diagnosis (and those who support them) to participate and learn from our panelists. All webinars held on Tuesdays, 2 PM AKT/3 PM PT/ 4 PM MT/5 PM CT/6 PM ET

#### Food as Comfort - JUNE 8

Join us for a discussion panel with Indigenous chefs on how food plays a role in healing. Register: bit.ly/AICAF68

**Holistic Approaches to Support Pain Management from Treatment Onset** Through Survivorship - JUNE 15

Listen in on a discussion on various approaches that can help support your pain management journey. Register: bit.ly/AICAF615

#### Celebrating Sacred Indigenous Life: Cancer Survivors Panel - JUNE 22

Join AICAF for a survivor-led panel discussion on living with cancer and celebrating Indigenous life, which includes the healing art of storytelling. Register: bit.ly/622CILpanel

#### Latseen: Everyday Strength - JUNE 29

Góok dé (Get moving)! This webinar features stretches for every day movement, and an Alaska Native Youth Olympic event demonstration. Register: bit.ly/AICAF629



#CelebrateIndigenousLife









Please join the American Indian Cancer
Foundation (AICAF) on June 26 for our Celebrate
Indigenous Life Prayer Walk! We encourage
everyone to honor our relatives impacted by a
cancer diagnosis by participating in this special
community walk and reflection event.

You can help us honor cancer survivors by going for a prayer walk or any other form of meditative physical activity on this special day.

All relatives can take part in this prayer and movement ceremony at any point during

June 26!

You will be entered into a drawing by tagging AICAF or using #CelebrateIndigenousLife in your photos and videos on your social media.

#### When:

ALL DAY June 26th. Join us in movement and prayer whenever you have time.

#### Where:

You can participate from anywhere!

This resource was produced and supported through funding to the American Indian Center Foundation through the Centers for Disease Control and Prevention Cooperative Agreement #NUSBDP006

#CelebrateIndigenousLife



Tell your friends!

Bring your whole family!



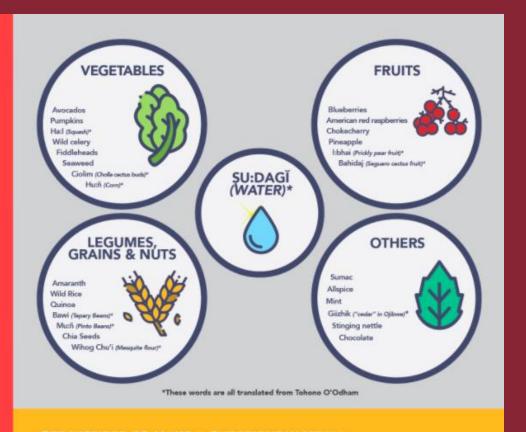


# INDIGENOUS FOOD FOR YOUR (GUT) HEALTH

FOOD IS MEDICINE. Our ancestors had access to many foods that are important for maintaining a healthy gut. Each of these foods is Indigenous to the North and South American continents. They provide us with several nutrients that fortify our gastrointestinal systems and may help reduce the risk of certain diseases, like colorectal cancer.

Research shows that eating a diet low in processed foods and meats, and including more plant-based meals is beneficial to preventing cancer. In addition to increasing your intake of these foods, make sure to drink plenty of Şu:dagī (water)\*.





## **GET INSPIRED TO MAKE A GUT-FRIENDLY MEAL!**

### Use these foods to make:

- Mixed green salad with roested pumpkin, squash, chia seeds, celery, and corn-
- Fruit salad with fresh blueberries, raspberries, and pineapples
- Burrito bowl with quinoa, wild rice, squash, black beans, and avocado
- Chocolate avecado pudding
- Cedar & mint tea
- Water infused with prickly pear fruit

There are many foods that can help reduce the risk for cancer. Keep your gut healthy by incorporating nutrient-dense foods local to your community.



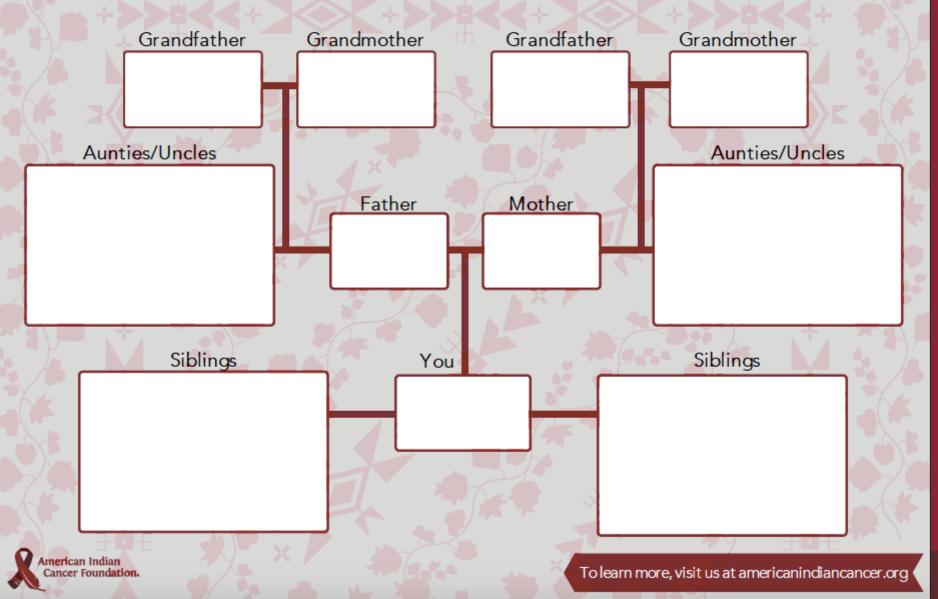


Make copies for family members and share this information with your healthcare provider

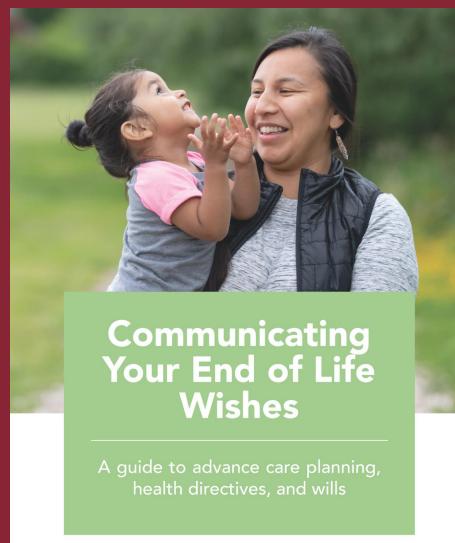
Family History Tree

For each blood relative (parents and grandparents, sisters and brothers, children, aunties and uncles, nieces and nephews) write in cancer type and age of diagnosis

Family history of breast, ovarian, uterine, colorectal cancer can increase you and your family's risk of occurrence.







# Advancing Care

## What are advance directives?

Any document that provides instructions for your health care and/or appoints someone to make medical decisions on your behalf is an advance directive. The most common advance directives include:

- 1. Living wills
- Durable power of attorney for health care (also know was the medical durable power of attorney)
- 3. CPR (cardiopulmonary resuscitation) or DNR (do not resuscitate) Directive

## What is a POLST?

The Provider Orders for Life Sustaining Treatment (POLST) is a legal document that guides health care professionals on your treatment during emergency medical situations. The POLST includes do not resuscitate orders, and further specifies additional medical interventions that may be performed, such as hospitalizations, hydration, and artificial nutrition. Learn more at POLST.org

## What is a living will?

A living will is a legal document that states your wishes about life-sustaining medical treatment. It is used when you are unable to state your own wishes because of permanent unconsciousness or terminal illness. Throughout your lifetime, you can update or change your living will.

## Who should have a living will?

Everyone 18 years and older should have a living will. It is the best way to ensure that your health care wishes are upheld.

## How does a living will work?

After physicians confirm that you are unable to make your own medical decisions, a living will is used to direct your medical care. If you do not have a living will, your relatives will have to



# **Survivorship Policy & Protocol**

Why policies and protocols?





# What's the difference?

Policy is not immediate- it grows overtime with an organization.

Protocol- a defined set of procedures- what are the steps



# **Survivorship Policy & Protocol**

# AICAF's survivorship protocol





# **Survivorship Policy & Protocol**

How do we start?





# Cultural & Literacy Tailored Materials





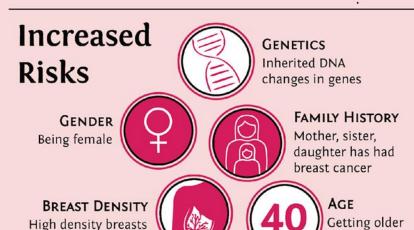
The goal of the AICAF Indigenous Pink national campaign is to spread awareness, educate all Indigenous people on the importance of early detection, and remind our relatives to keep up to date on their breast cancer screenings.



# **Indigenous Pink**

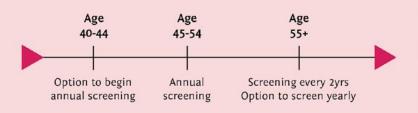
▶▶▶▶▶ Breast Health

women will get breast cancer in their lifetime



Breast cancer usually has no symptoms when the tumor is small and most treatable.

## Screening Guidelines/Recommendations





Breast cancer is the 2nd leading cause of cancer death for American Indian women. A mammogram may save your life.

# What can I do?

## **BREASTFEED**

Breastfeeding reduces estrogen exposure that helps prevent breast cancer

REGULAR MAMMOGRAMS

Women 40+ should have

mammogram once a year

**REGULAR BREAST EXAMS** 

Speak to your health care

provider for options

the option to have a

## WEIGHT CONTROL

Overweight or obese women are at a higher risk

## EXERCISE

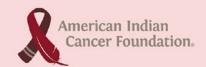
Exercising 3 days/week may lower your risk



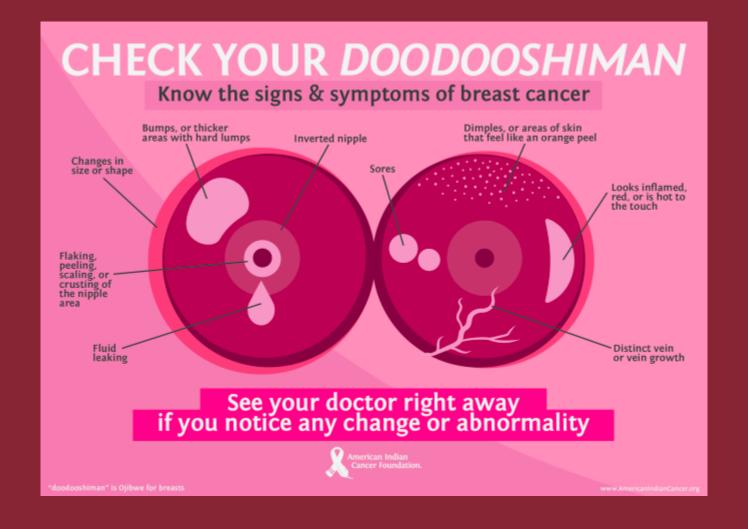
## LIMIT ALCOHOL USE



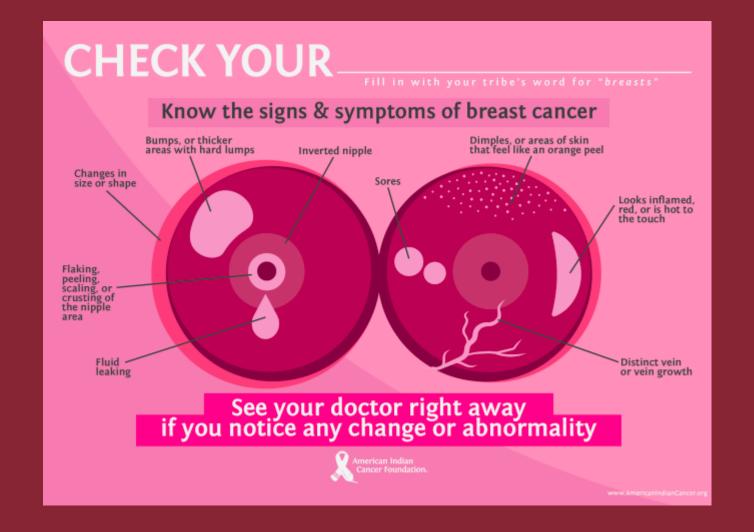
Alcohol can increase estrogen which can increase risk













# Turquoise Thursday

Turquoise Thursday is a national cervical cancer awareness campaign for Native people. Our team invites Indigenous people of all ages to join us by wearing turquoise clothing and jewelry, and sharing photos on social media using the hashtag #TurquoiseThursday. Native women are nearly twice as likely to develop cervical cancer compared to White women. Turquoise Thursday aims to educate people about the importance of early detection, and remind women to stay up to date on their cancer screenings.



# SURVIVOR SOVEREIGNTY

Native people face high rates of sexual assault, sexual abuse, child abuse, and domestic violence. According to the National Institute of Justice, more than four in five Native men and women have experienced violence in their lifetime. We understand that scheduling and receiving preventive health care can feel daunting while recovering from traumatic events. We also know that life-saving cancer screenings are essential in honoring your long-term health.

Cancer is the leading cause of death for Native women and the second leading cause of death for Native men.

Early cancer detection improves survival rates, meaning that #CancerScreeningSavesLives. We understand that for survivors, certain cancer screenings may be triggering. To help with this, we have compiled tips for making screening and preventive health care more comfortable.

## YOUR BODY IS YOUR OWN. YOU HAVE BODY SOVEREIGNTY.

Here are some ways to advocate for your emotional and physical health:

## Know what to expect:

- Talk to your health care team about what cancer screenings are recommended for your age and health history, and what each one entails
- Colonoscopies, mammograms, pap smears, and other screenings may feel invasive, but your health care team can help make them more comfortable
- Ask your health care provider to explain why each step of the screening process is necessary. Your health care provider should explain why they are performing certain exams and what these test results tell them about your health.
- Knowledge is empowering. Asking questions helps to mentally, emotionally, and physically prepare for screening, and is a great way to feel more confident in each step of the process

## Advocate for your physical sovereignty:

- Talk to your health care provider about your survivor history if you feel comfortable doing so
- Request that your health care provider narrates each step of the exam as it is performed
- Invite a friend or family member to serve as an emotional support person during the screening
- lt is okay to slow or stop an exam or screening at any time
- Inform your health care provider if any part of the
- screening is uncomfortable or triggering
  Remind yourself that taking care of your health is another
  way to celebrate your body sovereignty

## After your screening:

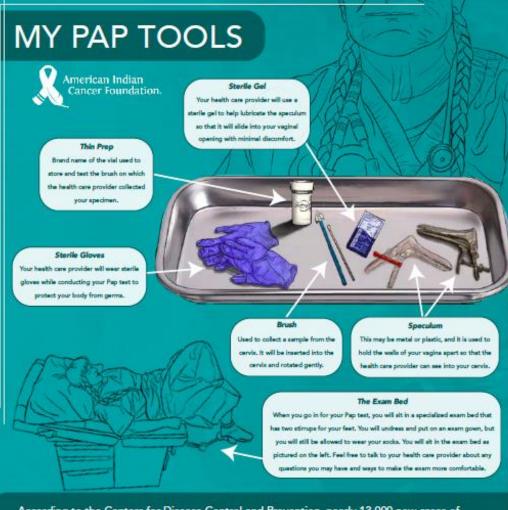
- Debrief with your health care provider about the exam/screening process. Let them know what did and didn't work for you. This is an opportunity for the provider to document what is most helpful for future exams
- Come up with a screening plan. Know what other preventive screenings are recommended and when you should receive them



Cancer screening is an important way to honor yourself, your body, and your future as a resilient survivor. You deserve long-term health and well-being. It is perfectly normal to feel nervous about other people touching your body, but you have complete control over how and when that happens. We celebrate every Indigenous survivor and pray for your mental, physical, and spiritual well-being.







According to the Centers for Disease Control and Prevention, nearly 13,000 new cases of cervical cancer were reported in 2018. When found early, cancer is typically easier to treat and health outcomes tend to be better. Getting a Pap test can help prevent cervical cancer or catch it in its earliest stages.

From the age of 21 to 29, it is recommended that women receive a cervical cancer screening every three years with a Pap test alone.<sup>2</sup> From the age of 30 to 65, it is recommended that women continue receiving screening every three years with a Pap test alone, OR every five years with high risk HPV testing alone, OR every five years with high risk HPV testing plus a Pap test. Most women younger than 21 years and older than 65 years, or those who have had a hysterectomy, do not need a screening for cervical cancer.<sup>2</sup>

Above, you will find the tools used in a Pap test and a brief description of how they are used.



# Blue Beads Awareness Campaign

The idea for the name came from the traditional and spiritual art form of beadwork. While there are multiple meanings behind the symbolism in beadwork, Blue Beads at the American Indian Cancer Foundation symbolizes the acknowledgment and honoring of Native relatives whose life has been affected by a colorectal cancer diagnosis and contains prayers for reducing the impact of colorectal cancer in Indigenous communities.





Our family history provides a blueprint for our life, including insight into our healing journey.

- \* A family history of colorectal cancer (CRC) can increase the risk of an individual developing CRC over their lifetime
- ★ 1 in 4 people diagnosed with CRC have a family history





Knowing your family health history of CRC can help you take steps to lower your risk. A family history of CRC means having:

- \* At least one immediate family member (parents, siblings, and children) diagnosed under the age of 60
- ★ Multiple second-degree relatives (aunts, uncles, grandparents, grandchildren, nieces) and/or at least one immediate family member (parents, siblings,children) diagnosed under the age of 60
- \* Multiple second-degree relatives (aunts, uncles, grandparents, grandchildren, nieces, nephews) who were diagnosed with CRC or advanced colon polyps





COVID-19 Has Not Stopped Colorectal Cancer:

**GET SCREENED** 



Due to the COVID-19 pandemic, CRC screening rates have drastically declined. According to the American Cancer Society, there was an estimated 90% drop in colonoscopies and biopsies last spring compared to the same time period in 2019.

CANCER

SCREENING

SAVES

LIVES



serious Carcer Society (2020, October). Promoting Colorectal Carcer Screening During the COVID-19 Pandemix

learn more about colorectal cancer and screening options at AmericaninclanCancer.org

This records and produced and appareted through burding to the American Sulter Corone Foundation through the Centers for Disease Control and Reviewton Corporative Agreement #5 16/00/P006277. Content to adult the responsibility of the authors and chair not recorded an apparent the official vision of the Centers for Disease Control and Provention.





# **Empowering Traditional Wisdom in Public Health**

- Relationships are central to our work
- Holistic approach to care
  - Individual, family, community, ancestors, earth
- Community participation & active, ongoing, reciprocal engagement
- Self-determination/body sovereignty
- Look to the land







# How do you envision supporting, celebrating, honoring the cancer survivor leaders in your community?



# **Questions?**

**Contact AICAF** health@aicaf.org 612-484-9670

Miigwech/Pidamaya!







