Acknowledgements: UNMC Partners

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- Athena Ramos
- Bev Luma
- Krishtee Napit
- Jordan Ranta
- Tatiana Tchouankam
- Marcela Carvajal-Suarez
- Natalia Trinidad
Outline

1. FPBCC Nebraska Community Cancer Needs Assessment
2. Cancer Burden in Nebraska
3. Listening Sessions: Cancer Care
4. Listening Sessions: Colorectal Cancer Screening
FPBBC Community Outreach & Engagement
Cancer Needs Assessment
FPBCC Catchment Area – State of Nebraska

Non-Hispanic White: 78.7%
Hispanic: 11.1%
African American: 4.7%
Asian: 2.1%
American Indian: 1.0%

State is home to 4 federally recognized tribes:
Santee Sioux Nation, Omaha, Ponca and Winnebago Tribes

77,348 square miles
1.9 million population
48 rural
31 frontier (<7 people/mi²)
14 urban
93 total counties
Revised Specific Aims

1. **Improve** understanding of cancer burden and needs of Nebraskans especially under-represented populations

2. **Engage** with community, health care and public health partners to promote evidence-based interventions and policies to prevent and control cancer in Nebraska

3. **Promote** cancer clinical trials and community-engaged research that address cancer issues affecting Nebraskans
FPBCC State-Wide Cancer Needs Assessment

• Collaboration with
  • Nebraska Comprehensive Cancer Control Program
  • Nebraska Cancer Coalition (NC2)
  • Cancer centers in Nebraska

• Describe cancer burden in Nebraska
  • Secondary data analysis
  • Listening sessions

• Set priorities for cancer prevention and control activities in Nebraska
  • Community Advisory Board
  • Internal Advisory Board
  • FPBCC Leadership
  • FPBCC COE External Advisors
Cancer Burden in Nebraska
### Estimated new cancer cases in Nebraska in 2022

<table>
<thead>
<tr>
<th>Cancer Site</th>
<th>Cases</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Prostate</td>
<td>1,680</td>
<td>14.9%</td>
</tr>
<tr>
<td>Breast (female)</td>
<td>1,600</td>
<td>14.2%</td>
</tr>
<tr>
<td>Lung and bronchus</td>
<td>1,330</td>
<td>11.8%</td>
</tr>
<tr>
<td>Colorectum</td>
<td>960</td>
<td>8.5%</td>
</tr>
<tr>
<td>Melanoma of the skin</td>
<td>630</td>
<td>5.6%</td>
</tr>
<tr>
<td>Urinary bladder</td>
<td>480</td>
<td>4.3%</td>
</tr>
<tr>
<td>Kidney and renal pelvis</td>
<td>460</td>
<td>4.1%</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>460</td>
<td>4.1%</td>
</tr>
<tr>
<td>Leukemia</td>
<td>380</td>
<td>3.4%</td>
</tr>
<tr>
<td>Uterine corpus</td>
<td>360</td>
<td>3.2%</td>
</tr>
<tr>
<td>Oral cavity and pharynx</td>
<td>330</td>
<td>2.9%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>330</td>
<td>2.9%</td>
</tr>
<tr>
<td>Thyroid</td>
<td>240</td>
<td>2.1%</td>
</tr>
<tr>
<td>Myeloma</td>
<td>160</td>
<td>1.4%</td>
</tr>
<tr>
<td>Brain and other nervous system</td>
<td>150</td>
<td>1.3%</td>
</tr>
<tr>
<td>Liver and intrahepatic bile duct</td>
<td>150</td>
<td>1.3%</td>
</tr>
<tr>
<td>Esophagus</td>
<td>130</td>
<td>1.2%</td>
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<tr>
<td>Stomach</td>
<td>120</td>
<td>1.1%</td>
</tr>
<tr>
<td>Ovary</td>
<td>100</td>
<td>0.9%</td>
</tr>
<tr>
<td>Cervix</td>
<td>70</td>
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<tr>
<td>Larynx</td>
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<tr>
<td>Testis</td>
<td>60</td>
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</tr>
<tr>
<td>Hodgkin lymphoma</td>
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### Estimated cancer death in Nebraska in 2022

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<thead>
<tr>
<th>Cancer Site</th>
<th>Deaths</th>
<th>Death Rate</th>
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<tr>
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<td>670</td>
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<tr>
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<td>320</td>
<td>9.0%</td>
</tr>
<tr>
<td>Pancreas</td>
<td>290</td>
<td>8.2%</td>
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<tr>
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<td>250</td>
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</tr>
<tr>
<td>Leukemia</td>
<td>170</td>
<td>4.8%</td>
</tr>
<tr>
<td>Prostate</td>
<td>170</td>
<td>4.8%</td>
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<tr>
<td>Brain and other nervous system</td>
<td>120</td>
<td>3.4%</td>
</tr>
<tr>
<td>Esophagus</td>
<td>120</td>
<td>3.4%</td>
</tr>
<tr>
<td>Kidney and renal pelvis</td>
<td>110</td>
<td>3.1%</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>110</td>
<td>3.1%</td>
</tr>
<tr>
<td>Liver and intrahepatic bile duct</td>
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<td>Urinary bladder</td>
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<tr>
<td>Oral cavity and pharynx</td>
<td>70</td>
<td>2.0%</td>
</tr>
<tr>
<td>Ovary</td>
<td>70</td>
<td>2.0%</td>
</tr>
<tr>
<td>Melanoma of the skin</td>
<td>60</td>
<td>1.7%</td>
</tr>
<tr>
<td>Myeloma</td>
<td>60</td>
<td>1.7%</td>
</tr>
<tr>
<td>Uterine corpus</td>
<td>60</td>
<td>1.7%</td>
</tr>
<tr>
<td>Stomach</td>
<td>50</td>
<td>1.4%</td>
</tr>
<tr>
<td>Thyroid</td>
<td>50</td>
<td>1.4%</td>
</tr>
</tbody>
</table>
## Nebraska Compared to United States: 2015-2019

**Incidence significantly higher in NE**
NE: 467.7 vs. US: 449

**Mortality**
NE: 152.6 vs. US: 152.4

---

### Cancer Burden Within Nebraska

#### Cancers with Highest Mortality

<table>
<thead>
<tr>
<th>Cancer</th>
<th>NE</th>
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<tbody>
<tr>
<td>Lung</td>
<td>36.2</td>
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<tr>
<td>Breast</td>
<td>19.8</td>
</tr>
<tr>
<td>Prostate</td>
<td>17.8</td>
</tr>
<tr>
<td>Colon/Rectum</td>
<td>14.5</td>
</tr>
<tr>
<td>Pancreas</td>
<td>11.3</td>
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</table>

#### Cancers with Racial Disparities (Mortality)

<table>
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<th>White</th>
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<td>47.6</td>
</tr>
<tr>
<td>Colon/Rectum</td>
<td>17</td>
<td>23.9</td>
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</table>

Incidence rate for Childhood CNS tumors higher in NE than in US (RR=1.2)
Higher Cancer Burden in African Americans & Native Americans in Nebraska
Risk Behavior Prevalence from BRFSS 2020

Colonoscopy Use

- NE Hispanic: 34.9%
- NE AI/AN: 70.10%
- NE White: 70.00%
- US White: 55.8%

Adult Obesity

- NE AA: 40.10%
- NE White: 70.10%
- US White: 34.9%

Adult Smoking

- NE AI/AN: 40.20%
- NE White: 13.20%
- US White: 14.90%
Nebraska Cancer Incidence and Mortality Maps

Incidence

Age-Adjusted
Annual Incidence Rate
(Cases per 100,000)

Quantile Interval

- 267.9 to 396.0
- > 396.0 to 439.0
- > 439.0 to 467.8
- > 467.8 to 489.8
- > 489.8 to 739.4
- Suppressed * / **

Many rural counties have very high cancer incidence and mortality

Mortality

Age-Adjusted
Annual Death Rate
(Deaths per 100,000)

Quantile Interval

- 73.0 to 131.4
- > 131.4 to 148.2
- > 148.2 to 162.4
- > 162.4 to 171.8
- > 171.8 to 197.3
- Suppressed *
Pediatric Cancer in Nebraska

- Nebraska has higher annual percentage change in incidence rate compared to US SEER (2008-13)
- Most of the areas with higher incidence are rural areas
- Incidence rates for pediatric lymphoma and CNS are higher in Nebraska compared to US SEER
- Higher rate both for malignant and benign brain tumors

Listening Sessions: Cancer Care
Listening Session Methods

- Facilitation guide developed based on literature review and partner input
- In-person / Zoom sessions
- Recruitment through partner organizations
- Broad initial codes developed deductively, subthemes added inductively, and triangulation achieved via check-in with extended research team
Listening Session Questions

1. What is the overall community health status perceived by cancer survivors and caregivers?
2. What are sources of information for cancer and cancer prevention?
3. What was the experience (positive and negative) of cancer survivors and their caregivers during diagnosis and treatment?
4. What were the barriers to receiving cancer care?
5. What factors impact colorectal cancer (CRC) screening?
6. What are suggested strategies to improve CRC screening?
# Listening Session Participants

<table>
<thead>
<tr>
<th></th>
<th>Rural</th>
<th>African American</th>
<th>Hispanic</th>
<th>Native American</th>
<th>LGBTQ</th>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
<td>3</td>
<td>0</td>
<td>3</td>
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<tr>
<td>Female</td>
<td>16</td>
<td>4</td>
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<td>23</td>
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<td><strong>Role</strong></td>
<td></td>
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<td>5</td>
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<td>Hispanic</td>
<td>Native American</td>
</tr>
<tr>
<td>------------------</td>
<td>-------</td>
<td>-------</td>
<td>------------------</td>
<td>----------</td>
<td>-----------------</td>
</tr>
<tr>
<td>Breast</td>
<td>28</td>
<td>11</td>
<td>4</td>
<td>7</td>
<td>6</td>
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</tr>
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<td>Brain</td>
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<td></td>
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<td>Thyroid</td>
<td>4</td>
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<td>Leukemia</td>
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<td></td>
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<td>Liver</td>
<td>2</td>
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<tr>
<td>Myeloma</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
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<td>Pancreas</td>
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<td></td>
<td></td>
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</tr>
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<td>Uterus</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Bladder</td>
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<td></td>
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</tr>
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<td></td>
<td></td>
</tr>
<tr>
<td>Kidney</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tongue &amp; throat</td>
<td>1</td>
<td></td>
<td></td>
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<td></td>
</tr>
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Overall Health Status of the Community

<table>
<thead>
<tr>
<th>Status</th>
<th>Rural</th>
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<th>Hispanic</th>
<th>Native American</th>
<th>LGBTQ+</th>
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<tbody>
<tr>
<td>Poor</td>
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<td>13%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
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<tr>
<td>Fair</td>
<td>0%</td>
<td>38%</td>
<td>33%</td>
<td>26%</td>
<td>67%</td>
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<tr>
<td>Good</td>
<td>39%</td>
<td>13%</td>
<td>13%</td>
<td>8%</td>
<td>0%</td>
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<tr>
<td>Very Good</td>
<td>44%</td>
<td>13%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
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<tr>
<td>Excellent</td>
<td>38%</td>
<td>13%</td>
<td>11%</td>
<td>13%</td>
<td>4%</td>
</tr>
</tbody>
</table>
Importance of Cancer as a Community Concern

Don’t know | Not at all important | Slightly important | Moderately important | Very important

- Rural
- African American
- Hispanic
- Native American
- LGBTQ+
Sources of Information about Cancer

- Health care provider: 75%
- Family or friend: 68%
- Internet: 100%
- TV: 60%
- Social media: 60%
- Radio: 5%
- Newspaper: 10%
- Health fair: 0%
- Pamphlet: 0%
- Nowhere: 0%

Rural, African American, Hispanic, Native American, LGBTQ+
Cancer Diagnosis

- Routine Health care or Screening:
  - Rural: 37%
  - African Americans: 29%
  - Hispanic: 29%
  - Native American: 33%
  - LGBTQ+: 33%

- Care for Symptom not initially suspected as cancer:
  - Rural: 21%
  - African Americans: 42%
  - Hispanic: 14%
  - Native American: 33%
  - LGBTQ+: 14%

- Self-identification:
  - Rural: 42%
  - African Americans: 33%
  - Hispanic: 33%
  - Native American: 33%
  - LGBTQ+: 33%
Care Coordination

• **Primary care** set up appointment with cancer specialist (Rural)

• **Patient navigator** helped, and the cancer center “gave me…this manual that I always carried with me to keep track of tests, procedures, doctors’ cards, and so forth” (Hispanic)

• **Nurse navigator** helped set up appointments and functioned as a coordinator (Rural)

• “There were a lot of things **not connected well from [primary care] to the Cancer Center.**” (Rural)

• Doctors “**don’t coordinate with each other**” making treatment “very complicated” (Hispanic)
Communication

• **Shared decision-making:** “...her mother-in-law when she was diagnosed did receive enough information, and she was able to make the decision on her own to refuse treatment” (Native American)

• Wished there was a way to “talk to doctors and just tell them what it feels like, especially that first diagnosis. *I don’t think they always realize how traumatic* it is” (Rural)

• “My dad can die.” The patient *had to rely on her young son to translate* to learn about her husband’s cancer diagnosis (Hispanic)

• “That's not what the doctor said” *Interpreter issues* - “You don't know how many times patients don't really understand what they're communicating (Hispanic)
Finance

- **Cancer centers, foundations and a pharmacy that give out financial assistance**, gas cards, hotel discount, money for meals, housekeeping assistance and medication assistance (Rural)

- “**Everything was denied to me**” in Nebraska because the patient did not qualify for help due to residency requirements (she had been in the state less than 5 years) so she went back to Mexico and California for treatment. (Hispanic)

- “There are a lot of **limitations for the illegal community**” (Hispanic)

- “Not everybody maybe has **health insurance** coverage or is aware of how to apply for Medicaid or any those other things” (African American)
Distance

- “I am grateful that we have the radiation here in town so she didn’t have to travel for it” (Rural)
- People in western Nebraska have to travel for treatment. It is especially problematic for (radiation) therapy (Rural)
- It was difficult with 30 radiations, the patient had to drive to get the treatment.
- “it was difficult...because she always had to travel, like, I think it’s about 3-1/2 hours to Sioux Falls...every chemo treatment, radiation, specialist visit...all the testing, everything, you know, she had to travel for.” (Native Tribe)
Support Services

• “One of the big advantages to living in a small town is that your community is kind of your support” (Rural)

• Spiritual support from church (Hispanic)

• My Sister’s Keeper (African American)

• Delayed own [cancer] treatment to be caretaker while the spouse was dying of cancer (Rural)

• “There is no service to educate people about how to cope with cancer” (Hispanic)

• “There is a lot of help for women with cancer but not for men” (Hispanic)
Discrimination

• "My other grandfather was not Native, um, but he seemed to go right smoothly. Everything went smoothly for him, but it was always a struggle for my other grandparents [who are Native]. So, I know there was a difference." (Native American)

• Hispanic caregiver described the check-in staff as “treating us badly” as perceived by the couple and their interpreter. (Hispanic)

• Provider’s “demeanor changed like that...like a switch flipped” as soon as she knew the patient was lesbian. “No more smiles. No more eye contact, and...cold towards me.”(LGBTQ+)
Mistrust

• “A lot of *historical angst.*” (African American)
• “I don’t think that Black people *trust the health system*” (African American)
• Don’t trust *doctors who don’t look like them* (African American)
• “I’m used to, like, finding out who’s the queer friendly [provider] so the idea of being operated on by someone who I knew nothing about was, like, really terrifying.” (LGBTQ)
Cultural Aspect

• Prefer traditional healings as they are not invasive. “If it’s on the outside, fine. If it’s on the inside they then…go back to traditional…” (Native American)

• “A lot of people don’t talk about cancer. You know, a lot of our elders…feel like…it’s secretive, you don’t talk about things like that.” (Native American)

• You don’t go to the doctors. You know, we can take care of ourselves…If you go to the doctor, you’re gonna end up dying.” (Native American)

• Don’t want to be treated by Western doctors (Native American)
Listening Sessions: CRC Screening
Colorectal Cancer Screening Awareness

![Bar chart showing colorectal cancer screening awareness by method and demographic group. The chart compares FOBT, FIT, FIT-DNA, Sigmoidoscopy, Colonoscopy, and None, categorized by Rural, African American, Hispanic, Native American, and LGBTQ+.](image)
Perception of CRC

• “A disease that kills” (Native American)
• “It’s something that nobody likes to talk about” (Rural)
• “Cancer, oh... we’re scared” (Hispanic)
• Denial – “I don’t have it.” (Hispanic)
• “They would rather not know.” (Native American)
• “I don’t think a lot of Natives get that type of cancer, do they?...I’ve never heard of it until now.” (Native American)
• “Probably not a risk for me...I’ll get [screening] later” (Rural)
• Perception of “old person disease” (Rural)
Perception of CRC Screening

• **Men not as apt to do** it due to “I’m fine” attitude (Rural)

• “The Latino community is more closed minded and especially the men, they are very macho and don’t get those types of screenings.” (Hispanic)

• People’s perception of **manhood**” (Native American)

• Embarrassment (Rural)

• “…black people…[have] **bias against the recommended testing**. So you know nobody likes a colonoscopy.” (African American)

• “Like it’s a joke” (Rural, LGBTQ)
CRC Screening Awareness

• “I haven’t even thought about it to tell you the truth.” (African American)
• “What is that?” (Native American)
• *Unfamiliar* with other options besides colonoscopy (Rural)
• Uncertainty about the *accuracy* of stool-based tests (Rural)
• *Unfamiliar with all available options* of CRC screening (Native American)
CRC Screening Barriers

• “They don’t want to lose work to get a medical exam…The day I miss work is the day I need to put food on my table” (Hispanic)

• “Inconvenience in having a day or two of discomfort before, during and the time of being busy” (Rural)

• Scared of colonoscopy prep and procedure (Native American)

• “Horror stories about the prep” (Rural)

• Cost or insurance coverage; Financially can’t afford it, even with insurance (Rural)
Role of Health Care Providers

- Participants decided to get colonoscopy because the PCP “insisted” on it (Rural)
- Some doctors don’t recommend their patients to get CRC screening (Rural)
- The doctor must tell patients forcefully or they will not do it. (Hispanic)
Community and Provider Education

- **Education is needed for Black community** to improve trust. (African American)
- “Like it literally has to be **people that look like them**, advocating and sharing information for them…to hear stories and testimonies and to buy into them.” (African American)
- **Messaging from “cancer survivors** or going through treatment at the same time.” (African American)
- “**Group services**…do meetings, do talks…send information to churches, schools, centers.” (Hispanic)
- **Involvement of community** in educational awareness programs (Native American)
- **Social Media** (African American, LGBTQ)
Community and Provider Education

• “There is also some physician bias for additional resources like Cologuard in that they don’t trust that, so maybe education from the physician perspective as well” (African American)

• Navigators (African American)
Community Outreach & Health Fairs

- Great Plains Colon Cancer Taskforce
- Bridge to Care Refugee Health Clinic
- Black Family Health Fair
- My Sister’s Keeper
- Cancer screening at annual Cattlemen’s Ball fundraiser for FPBCC
- Rural Health Network Mobile Van – Cancer Education
iCaRe² – Promotion of Research in Rural Nebraska

- Web-based multicenter registry with standardized comprehensive cancer-related data and biospecimens
- 87 sites - 23 states - 5 NCI Comprehensive Cancer Centers - 1 site Italy
- 29,443 patients - 13,709 patients from Nebraska (Catchment Area) 8,683 patients from rural areas
- 33,363 biospecimens (tumor, serum, plasma, germline DNA)
- Cancer genome study – breast cancer / precision medicine program (700+ patients) rural community patients with breast cancer.
Pediatric Cancer Watersheds Study

Birth defect incidence rates per 100,000 live births among Nebraska's watersheds, 1995-2014
Hydrological Unit Level 4, 8-digit coding

Birth Defect Incidence Rate

Incidence rate calculated using count of live birth defects and Nebraska's live birth addresses in each watershed per 100,000.

Dr. Eleanor Rogan of Environmental, Agricultural and Occupational Health Department conducts a study of watersheds in Nebraska
COE Reports and Infographics

https://www.unmc.edu/cancercenter/outreach/coeo/coeo-reports.html
Thank You