

Nebraska Cancer Needs Assessment: Listening Session Outcomes

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Great Plains IDeA-CTR Seminar

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Outline

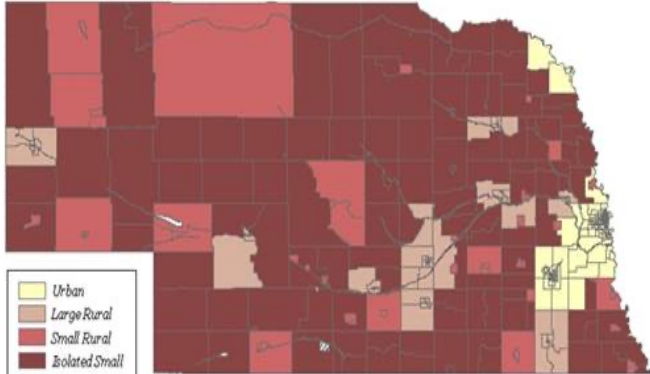
1. FPBCC Nebraska Community Cancer Needs Assessment
 2. Cancer Burden in Nebraska
 3. Listening Sessions: Cancer Care
 4. Listening Sessions: Colorectal Cancer Screening
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FPBBC Community Outreach & Engagement Cancer Needs Assessment



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%

77,348 square miles

1.9 million population

48 rural

31 frontier (<7 people/mi²)

14 urban

93 total counties

**State is home to 4 federally
recognized tribes:**

**Santee Sioux Nation, Omaha,
Ponca and Winnebago Tribes**



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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

Prostate	1,680	14.9%
Breast (female)	1,600	14.2%
Lung and bronchus	1,330	11.8%
Colorectum	960	8.5%
Melanoma of the skin	630	5.6%
Urinary bladder	480	4.3%
Kidney and renal pelvis	460	4.1%
Non-Hodgkin lymphoma	460	4.1%
Leukemia	380	3.4%
Uterine corpus	360	3.2%
Oral cavity and pharynx	330	2.9%
Pancreas	330	2.9%
Thyroid	240	2.1%
Myeloma	160	1.4%
Brain and other nervous system	150	1.3%
Liver and intrahepatic bile duct	150	1.3%
Esophagus	130	1.2%
Stomach	120	1.1%
Ovary	100	0.9%
Cervix	70	0.6%
Larynx	70	0.6%
Testis	60	0.5%
Hodgkin lymphoma	50	0.4%



Estimated cancer death in Nebraska in 2022

Lung and bronchus	670	18.9%
Colorectum	320	9.0%
Pancreas	290	8.2%
Breast (female)	250	7.0%
Leukemia	170	4.8%
Prostate	170	4.8%
Brain and other nervous system	120	3.4%
Esophagus	120	3.4%
Kidney and renal pelvis	110	3.1%
Non-Hodgkin lymphoma	110	3.1%
Liver and intrahepatic bile duct	100	2.8%
Urinary bladder	100	2.8%
Oral cavity and pharynx	70	2.0%
Ovary	70	2.0%
Melanoma of the skin	60	1.7%
Myeloma	60	1.7%
Uterine corpus	60	1.7%
Stomach	50	1.4%
Thyroid	50	1.4%



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

Cancer	<u>NE</u>
Lung	36.2
Breast	19.8
Prostate	17.8
Colon/Rectum	14.5
Pancreas	11.3

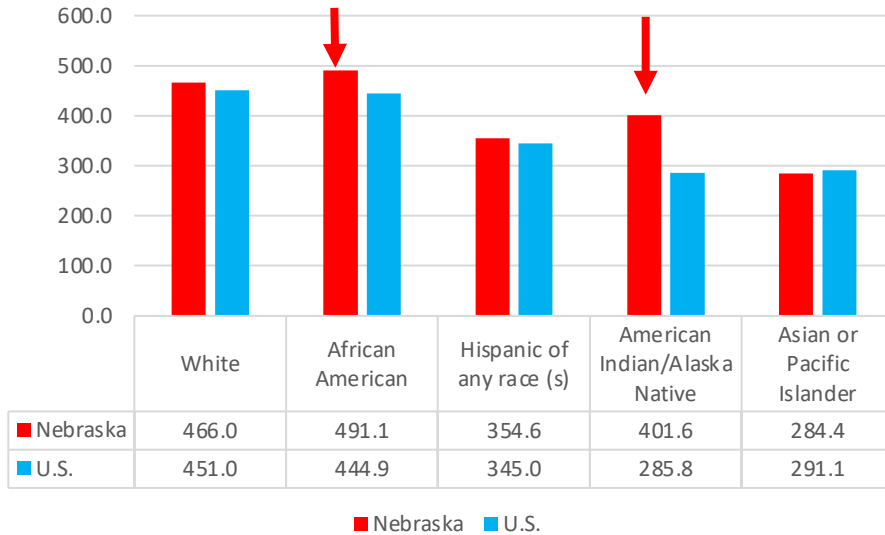
Cancers with Racial Disparities (Mortality)

Cancer	<u>White</u>	<u>AA</u>
Prostate	17.1	47.6
Colon/Rectum	17	23.9

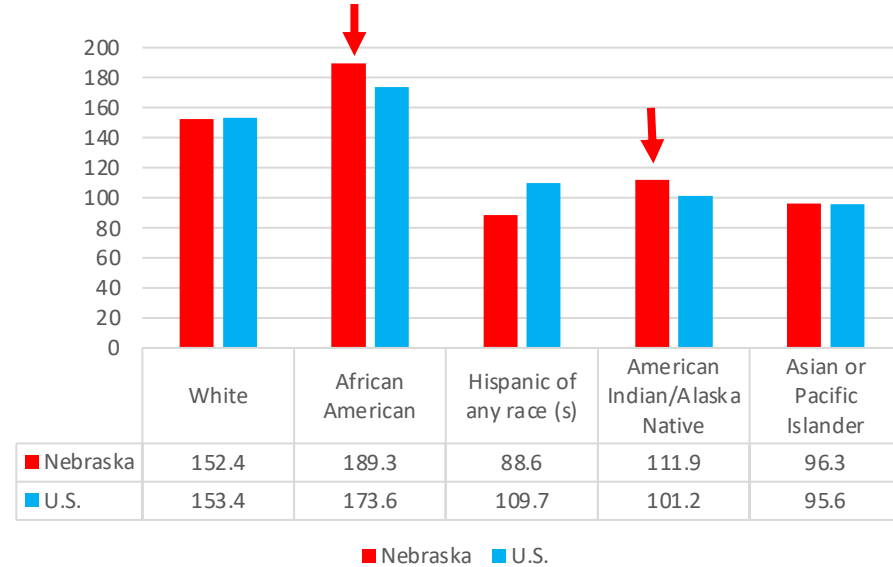
Incidence rate for Childhood CNS tumors higher in NE than in US (RR=1.2)

Cancer Incidence & Mortality Rates per 100,000 Nebraska & USA

Incidence (2014-2018)



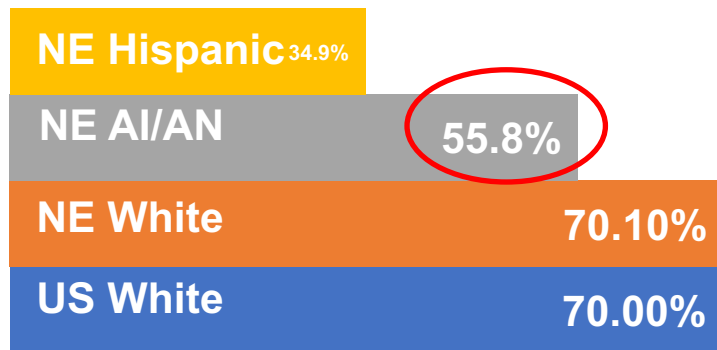
Mortality (2015-2019)



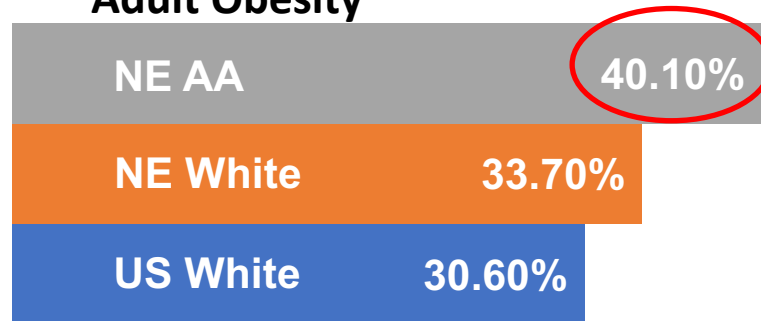
Higher Cancer Burden in African Americans & Native Americans in Nebraska

Risk Behavior Prevalence from BRFSS 2020

Colonoscopy Use



Adult Obesity

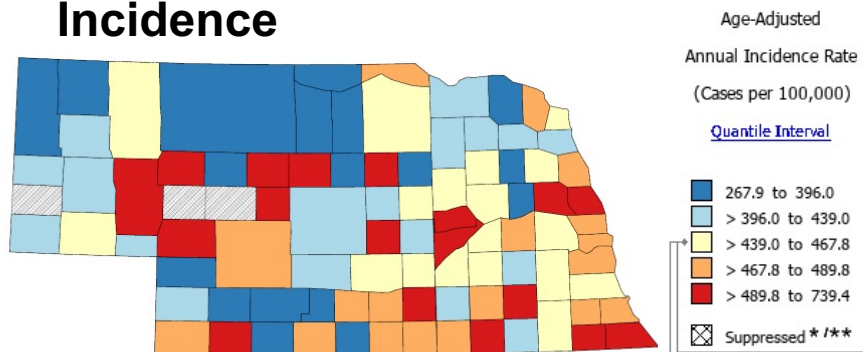


Adult Smoking



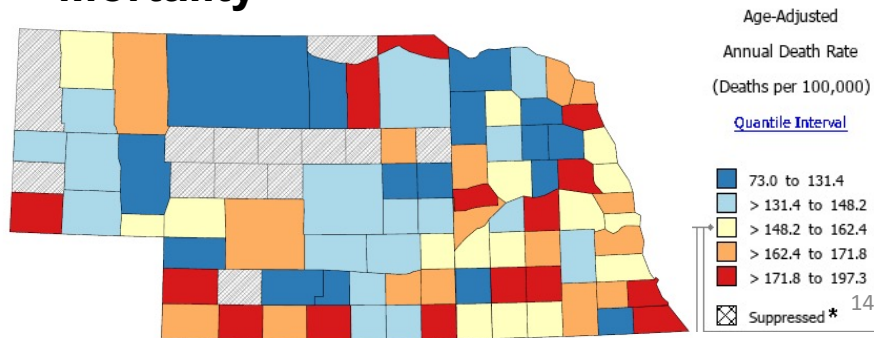
Nebraska Cancer Incidence and Mortality Maps

Incidence



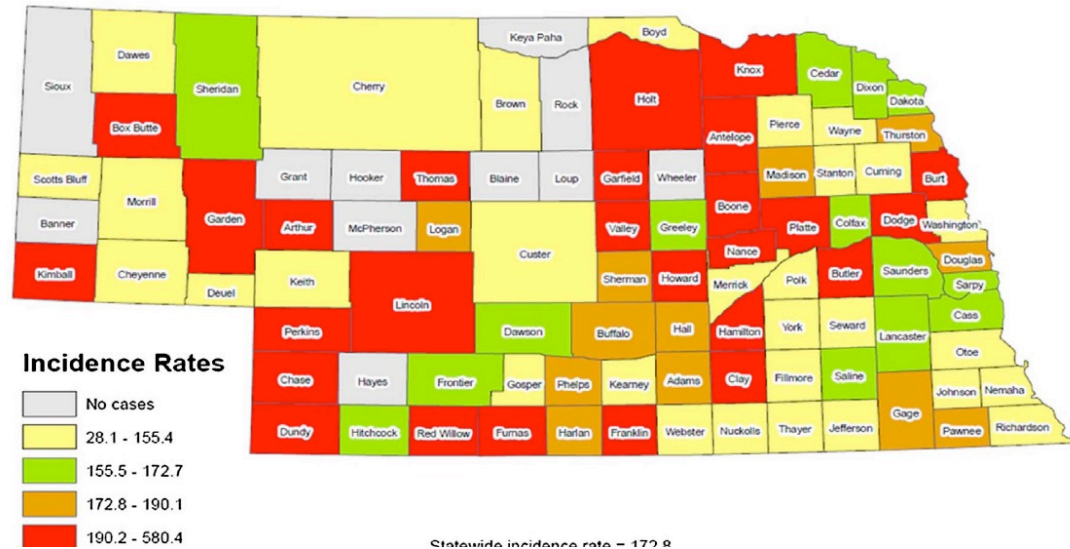
Many rural counties have very high cancer incidence and mortality

Mortality



Pediatric Cancer in Nebraska

Pediatric Cancer Incidence Rates per 100,000



- 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

Source: Farazi, Watanabe-Galloway...Coulter, 2018. Temporal and geospatial trends of pediatric cancer incidence in Nebraska. Cancer Epidemiology, 2018. 52:83-90.



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

	Rural	African American	Hispanic	Native American	LGBTQ
Sex					
Male	4	3	0	3	0
Female	16	4	12	23	2
Transgender	0	0	0	0	1
Role					
Survivor	16	2	9	4	3
Caregiver	5	5	5	22	0
Cancer Types(All)	19	11	16	27	3

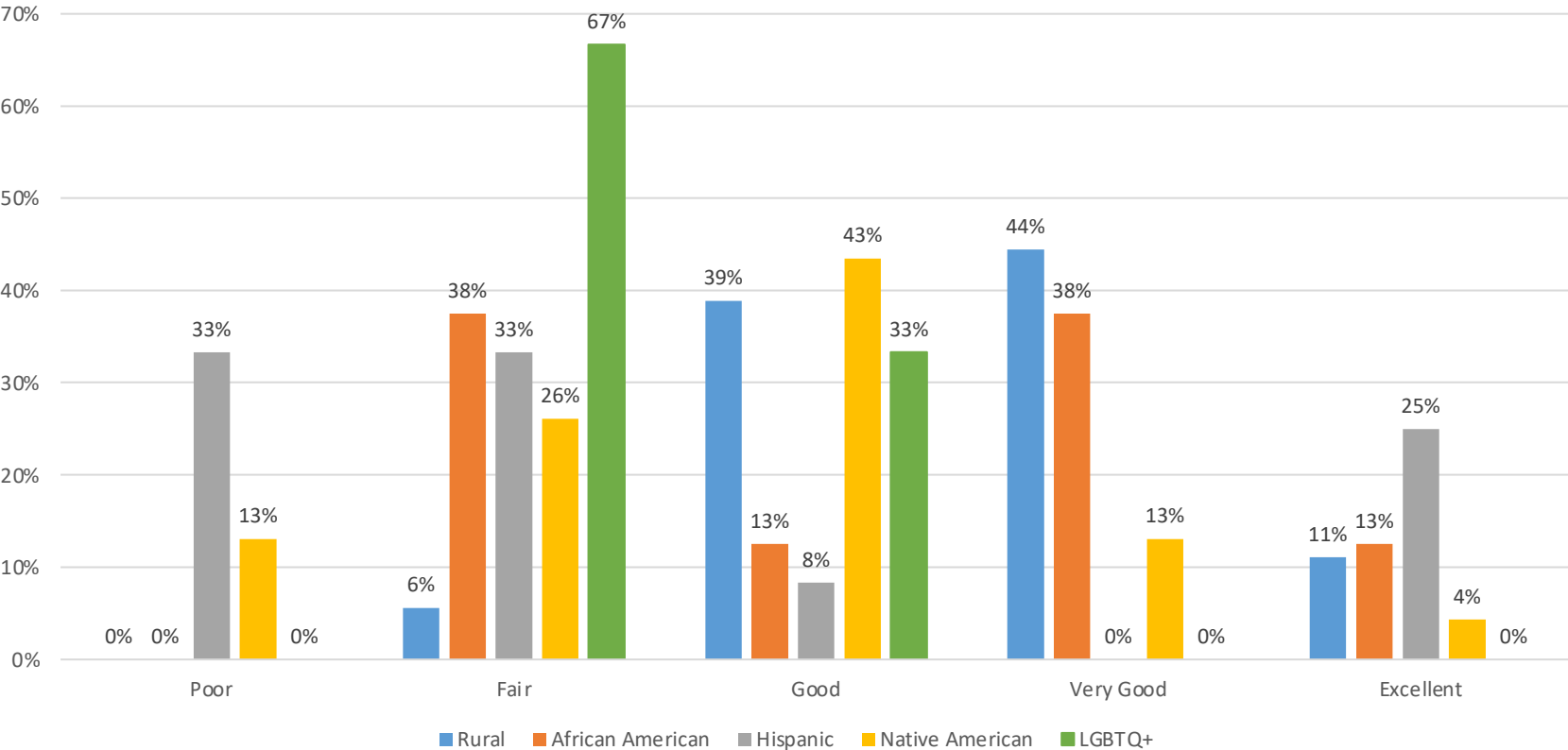


Listening Session Participants Cancer Types

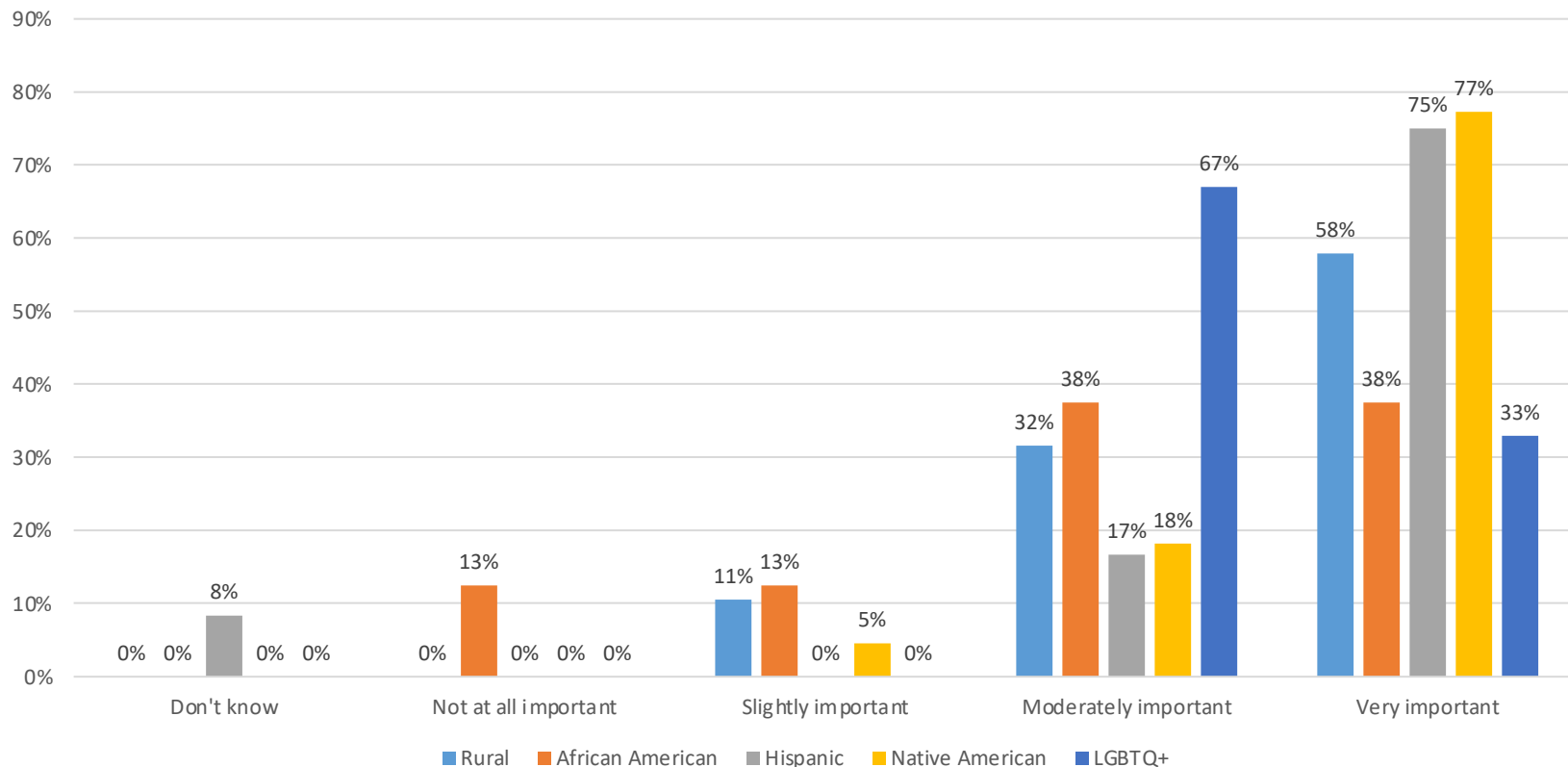
Cancer Type	Total	Rural	African American	Hispanic	Native American	LGBTQ
Breast	28	11	4	7	6	
Colorectal	6			3	2	1
Lung	6	2		1	3	
Lymphoma	5	2	1	1	1	
Ovarian	5		2		3	
Brain	4			1	3	
Thyroid	4		1	2		1
Leukemia	2				2	
Liver	2				2	
Myeloma	2	2				
Pancreas	2		2			
Prostate	2	1	1			
Uterus	2				1	1
Bladder	1	1				
Cervix	1			1		
Endometrial	1				1	
Kidney	1				1	
Skin	1				1	
Tongue & throat	1				1	



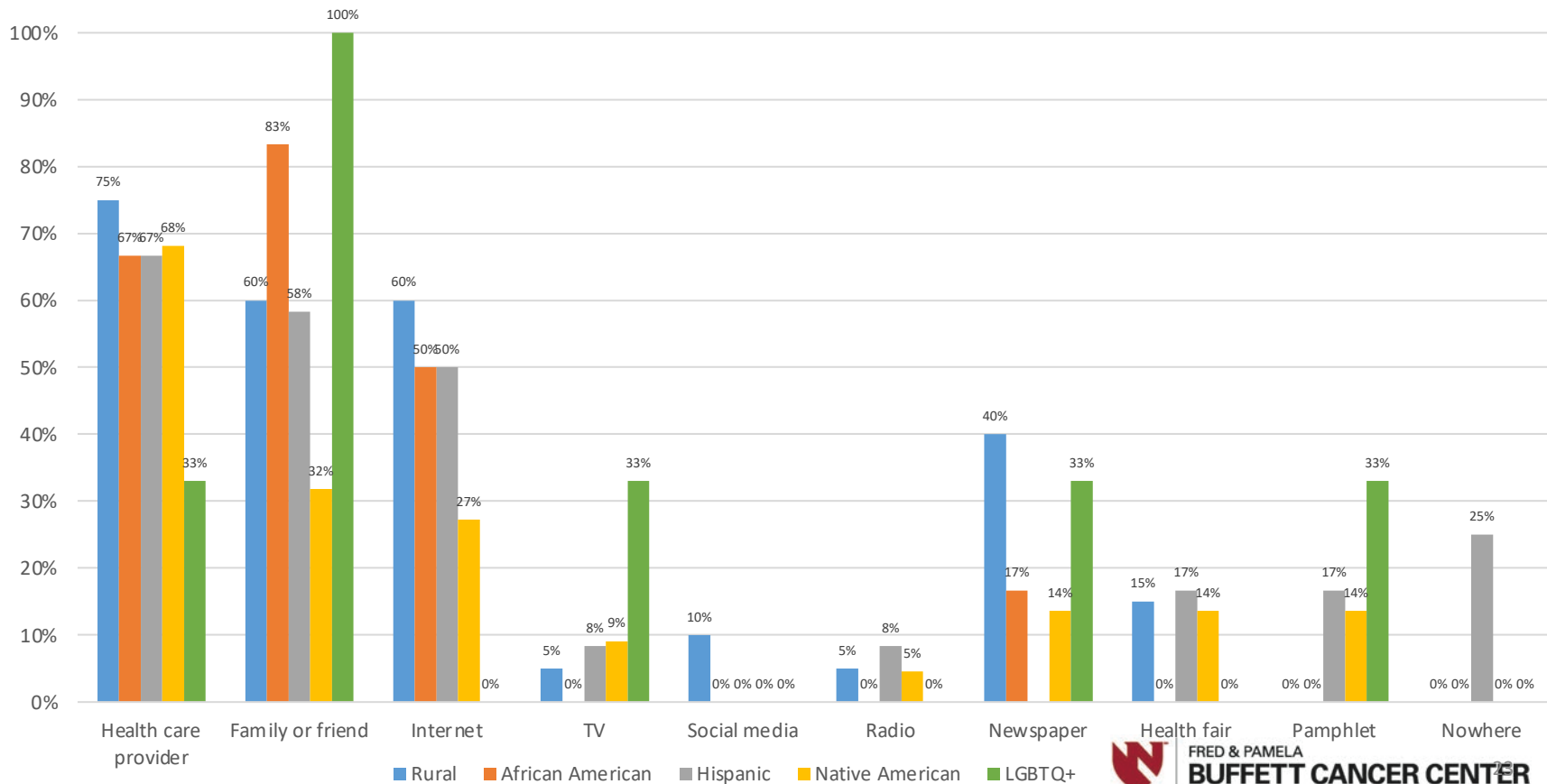
Overall Health Status of the Community



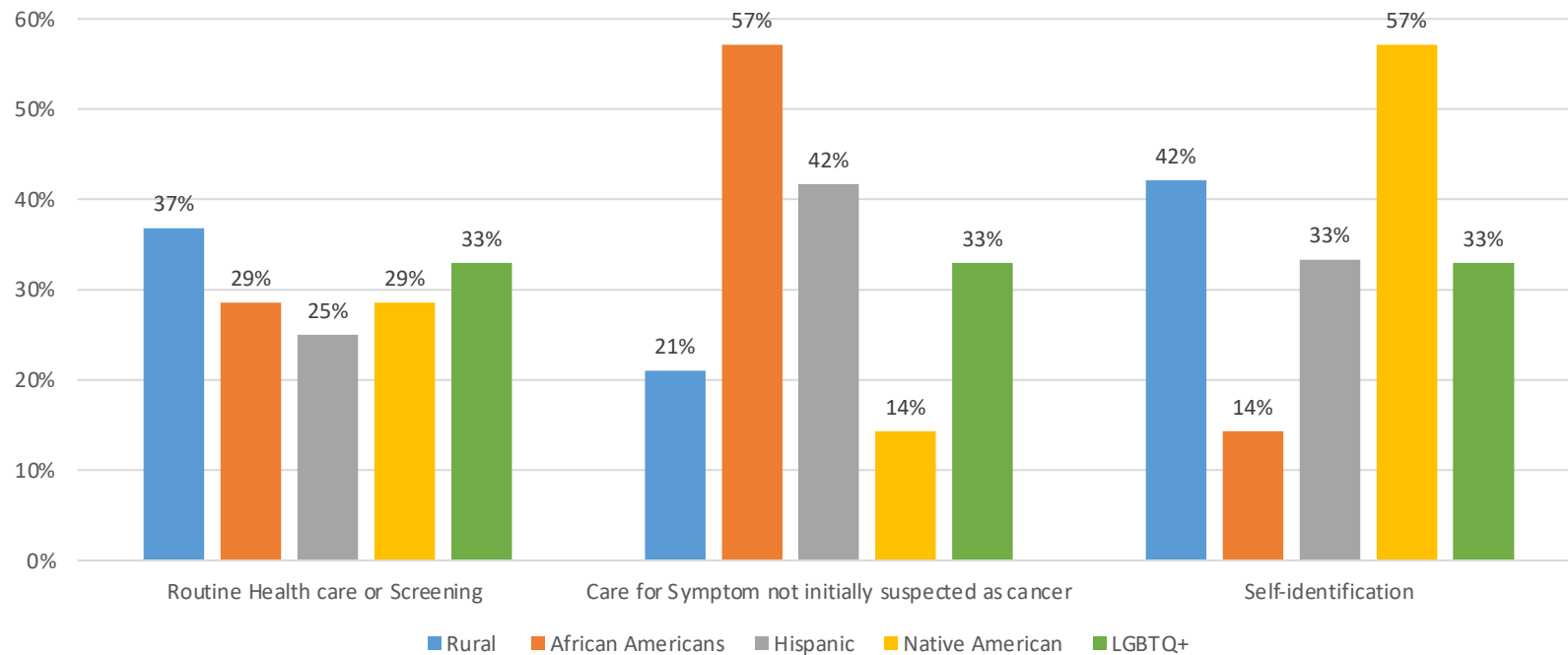
Importance of Cancer as a Community Concern



Sources of Information about Cancer



Cancer Diagnosis



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)

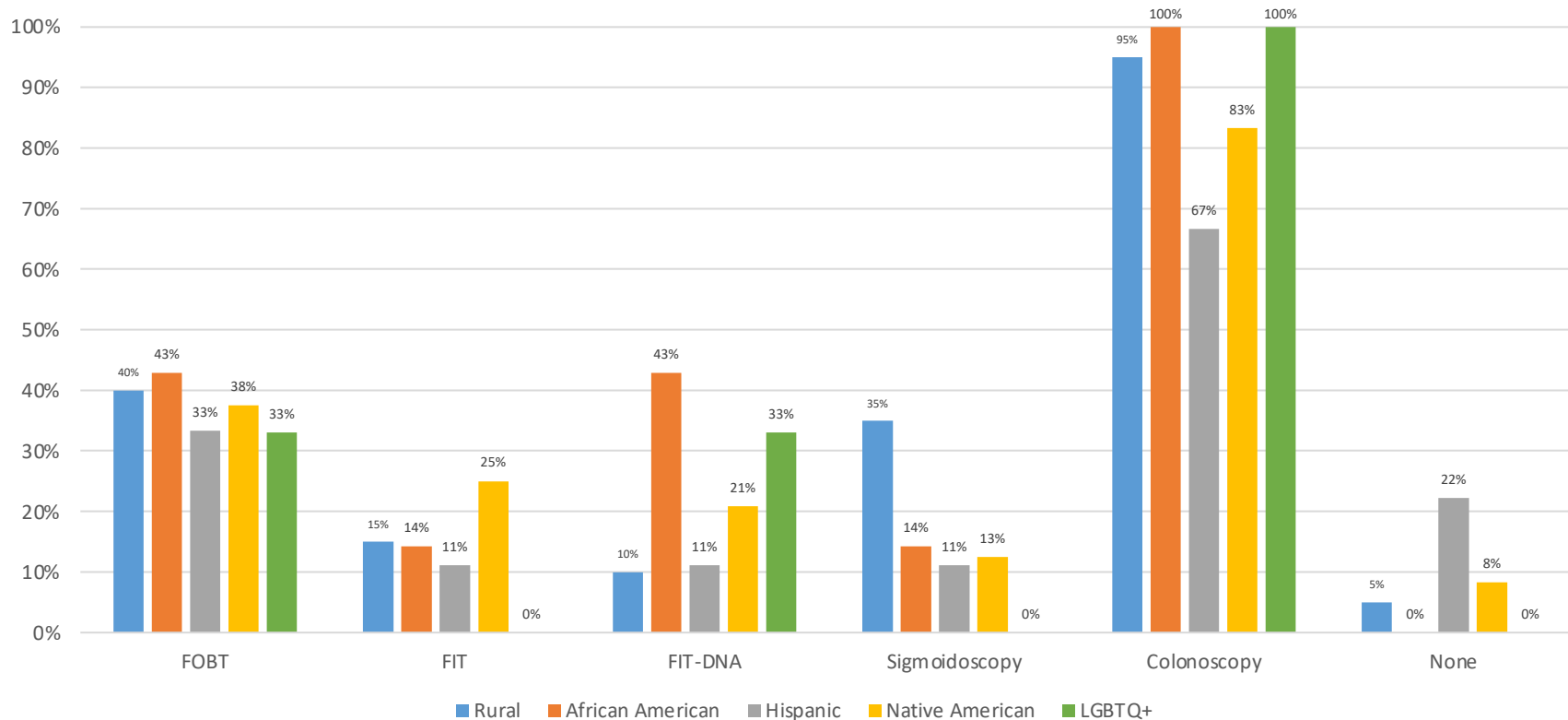




Listening Sessions: CRC Screening



Colorectal Cancer Screening Awareness



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



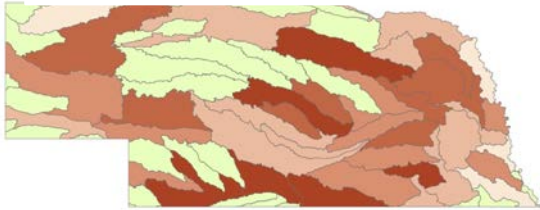


iCaRe² – Promotion of Research in Rural Nebraska

- **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

Pediatric Cancer incidence 1995-2014

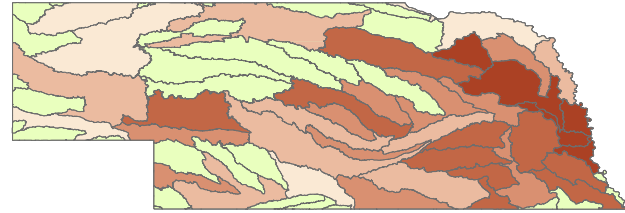


Pediatric cancer incidence rate

7.45 - 12.39	16.11 - 19.80	21.84 - 26.68
12.40 - 16.10	19.81 - 21.83	Population < 1000

Incidence rate averaged over 27 years using 2010 U.S. Standard Population for those under 19 years of age.

Birth defect incidence 1995-2014



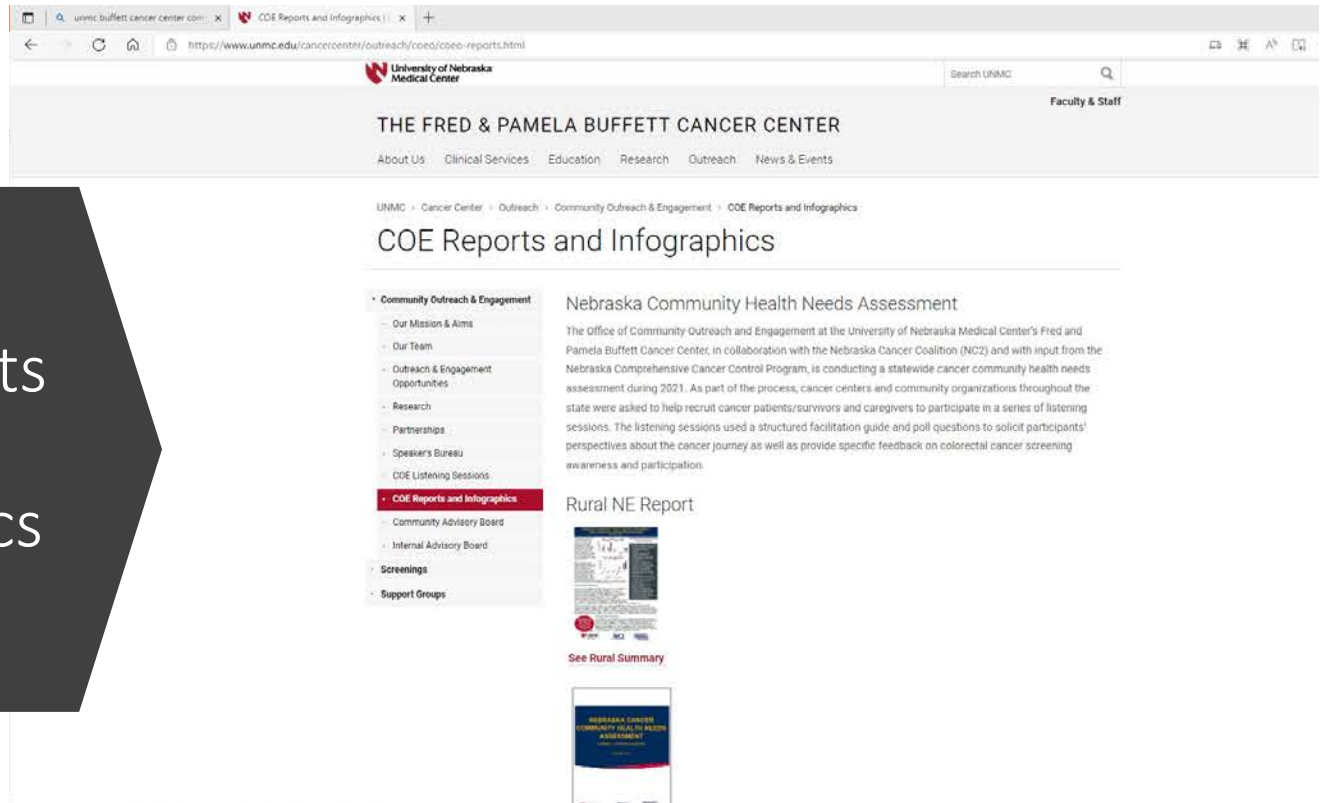
Birth Defect Incidence Rate

1399 - 2479	3478 - 4073	4727 - 6277
2480 - 3477	4074 - 4726	Population at risk < 1000

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



The screenshot displays the University of Nebraska Medical Center (UNMC) website. The header includes the UNMC logo and navigation links: About Us, Clinical Services, Education, Research, Outreach, and News & Events. The main content area is titled "THE FRED & PAMELA BUFFETT CANCER CENTER" and features a search bar and a "Faculty & Staff" link. Below the header, a breadcrumb trail reads: UNMC > Cancer Center > Outreach > Community Outreach & Engagement > COE Reports and Infographics. The main heading is "COE Reports and Infographics". A left sidebar lists various categories under "Community Outreach & Engagement", with "COE Reports and Infographics" highlighted in red. The main content area contains two sections: "Nebraska Community Health Needs Assessment" and "Rural NE Report". The "Nebraska Community Health Needs Assessment" section includes a paragraph about the assessment process and a link to "See Rural Summary". The "Rural NE Report" section features a thumbnail image of a report cover titled "NEBRASKA CANCER COMMUNITY HEALTH NEEDS ASSESSMENT RURAL NE REPORT".

UNMC > Cancer Center > Outreach > Community Outreach & Engagement > COE Reports and Infographics

COE Reports and Infographics


- Community Outreach & Engagement
 - Our Mission & Aims
 - Our Team
 - Outreach & Engagement Opportunities
 - Research
 - Partnerships
 - Speakers Bureau
 - COE Listening Sessions
 - COE Reports and Infographics**
 - Community Advisory Board
 - Internal Advisory Board
 - Screenings
 - Support Groups

Nebraska Community Health Needs Assessment

The Office of Community Outreach and Engagement at the University of Nebraska Medical Center's Fred and Pamela Buffett Cancer Center, in collaboration with the Nebraska Cancer Coalition (NC2) and with input from the Nebraska Comprehensive Cancer Control Program, is conducting a statewide cancer community health needs assessment during 2021. As part of the process, cancer centers and community organizations throughout the state were asked to help recruit cancer patients/survivors and caregivers to participate in a series of listening sessions. The listening sessions used a structured facilitation guide and poll questions to solicit participants' perspectives about the cancer journey as well as provide specific feedback on colorectal cancer screening awareness and participation.

[See Rural Summary](#)

Rural NE Report



<https://www.unmc.edu/cancercenter/outreach/coeo/coeo-reports.html>

Thank You



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