

NEBRASKA CANCER COMMUNITY HEALTH NEEDS ASSESSMENT

NATIVE AMERICAN LISTENING SESSION REPORT

Summer 2022



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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 the Nebraska Comprehensive Cancer Control Program (NECCCP), is conducting a statewide cancer community health needs assessment during 2021-2022. 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 or survey questions to solicit participants' perspectives about the cancer journey as well as provide specific feedback on colorectal cancer screening awareness and participation.

Three listening sessions focused on the perspectives of Native American community members recruited from two Urban Indian Program clinics and the Ponca Tribe. Participants shared their positive and negative aspects of the journey from cancer diagnosis through treatment. Several caregivers had limited knowledge about their family member's cancer experiences, in part due to elders being very private about health concerns in general and cancer in particular. Along with well-known barriers such as cost and travel, participants identified lack of support services (such as local cancer support groups), older adults' hesitancy to seek medical care, and the stigma of cancer as other major barriers to treatment. Lack of information on colorectal cancer and colorectal cancer screening options and the concept that "colorectal cancer is not common among Native Americans" are some important contributors to low screening rates among the Native Americans living in the Omaha and Lincoln areas. Perception of being 'macho' and embarrassment related to the colonoscopy procedure are some important contributors to low screening rates among the Ponca Tribe community members. Cancer is perceived as a death sentence, so some people would prefer not to know (leading to low screening). Additionally, preference for traditional non-invasive treatment measures are challenges to cancer care and treatment services which often involve biopsy for diagnosis and surgery as a frontline cancer treatment. Efforts to increase awareness, partnership with UNMC, and addressing community needs are some suggestions made by participants to improve CRC screening.

OVERVIEW

Three listening sessions were held. A 75-minute in-person listening session was held on October 25, 2021, with six participants recruited from the Nebraska Urban Indian Health Coalition, Inc. in Lincoln, NE (referred to hereafter as UI-Lincoln). The listening session consisted of six female family members with differing levels of involvement with caregiving. Cancer types represented included breast (n=2), ovary (n=1), brain (n=1), leukemia (n=1), liver (n=2), tongue and throat (n=1), and lung (n=1).

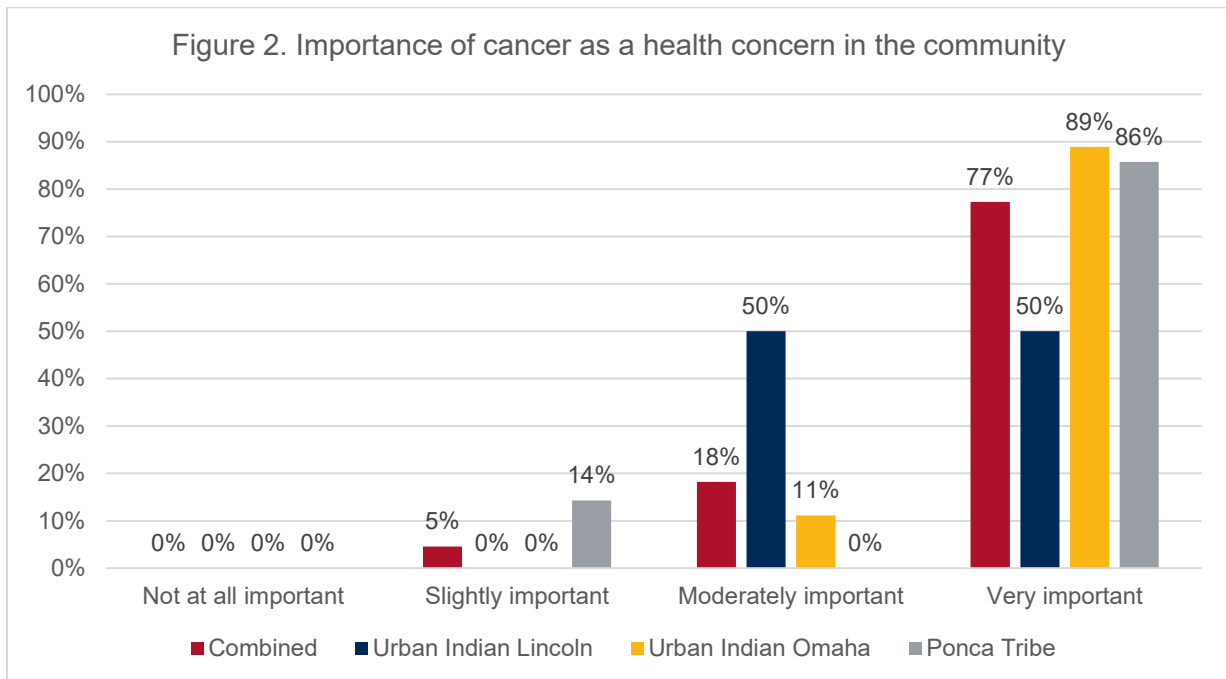
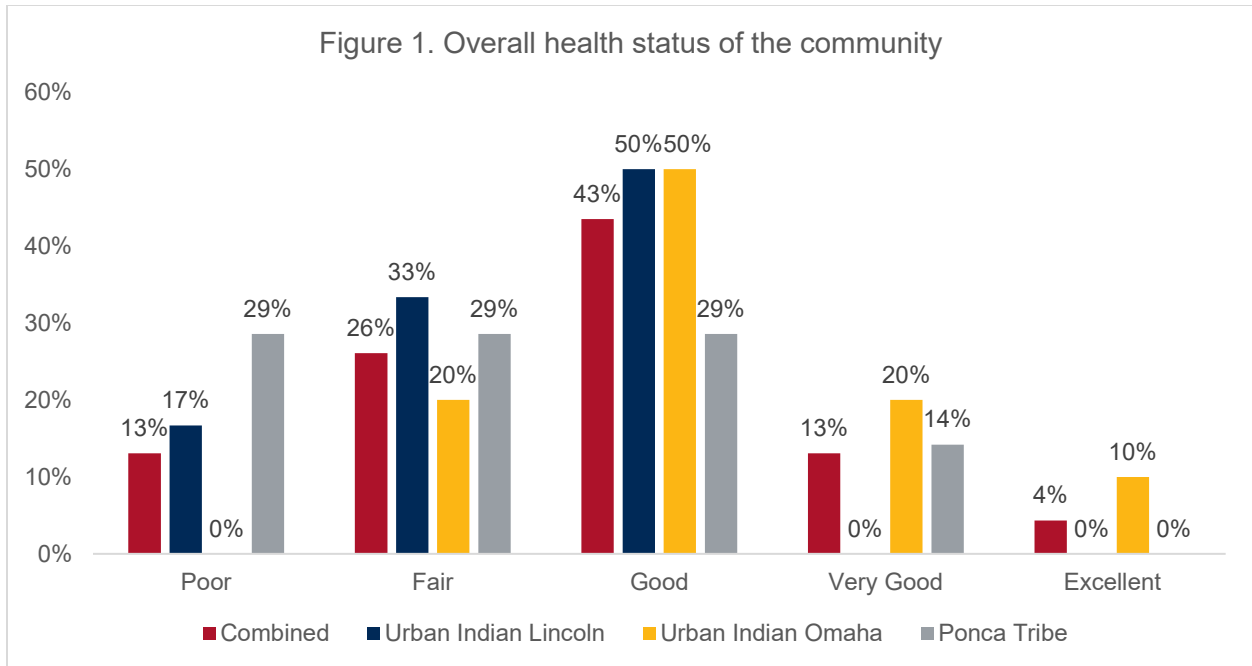
A 75-minute in-person listening session was held on December 2, 2021, with eleven participants recruited from Nebraska Urban Indian Health Coalition, Inc. in Omaha, NE (referred to hereafter as UI-Omaha). The listening session consisted of two male caregivers, seven female caregivers, and two female cancer patients/survivors. One of the female caregivers had suspected lung cancer which was not formally diagnosed. Three caregivers were unable to identify their relatives' cancer sites. Cancer types represented included breast (n=2), uterus (n=1), Non-Hodgkin's Lymphoma (n=1), ovarian (n=1), brain (n=1), kidney (n=1) and skin (n=1).

A 75-minute virtual listening session was held on December 22, 2021, with nine participants recruited from the Ponca Tribe of Nebraska. One participant joined part way through the session. The listening session consisted of seven female family members or friends with differing levels of involvement with caregiving, one male survivor, and one female survivor. Three caregivers also worked as community health workers for the Ponca Tribe. Cancer types represented included breast (n=2), lung (n=2), colon (n=2), ovary (n=1), brain (n=1), Adult Philadelphia Positive Acute Lymphoblastic Leukemia (ALL, n=1), and endometrial (n=1).

The listening sessions utilized a structured facilitation guide and a survey instrument for polling questions. Some participants did not answer the poll questions resulting in some missing data. Data presented below represent percent based on the number of people who responded to each question. Topics covered in the listening sessions included overall community health status, sources of cancer-related information, experience with diagnosis and treatment, and colorectal cancer (CRC) screening. During the listening session of UI-Omaha, participants also discussed some potential exposures to cancer-causing agents, such as the use of baby powder, pesticides, and smoking.

COMMUNITY HEALTH STATUS

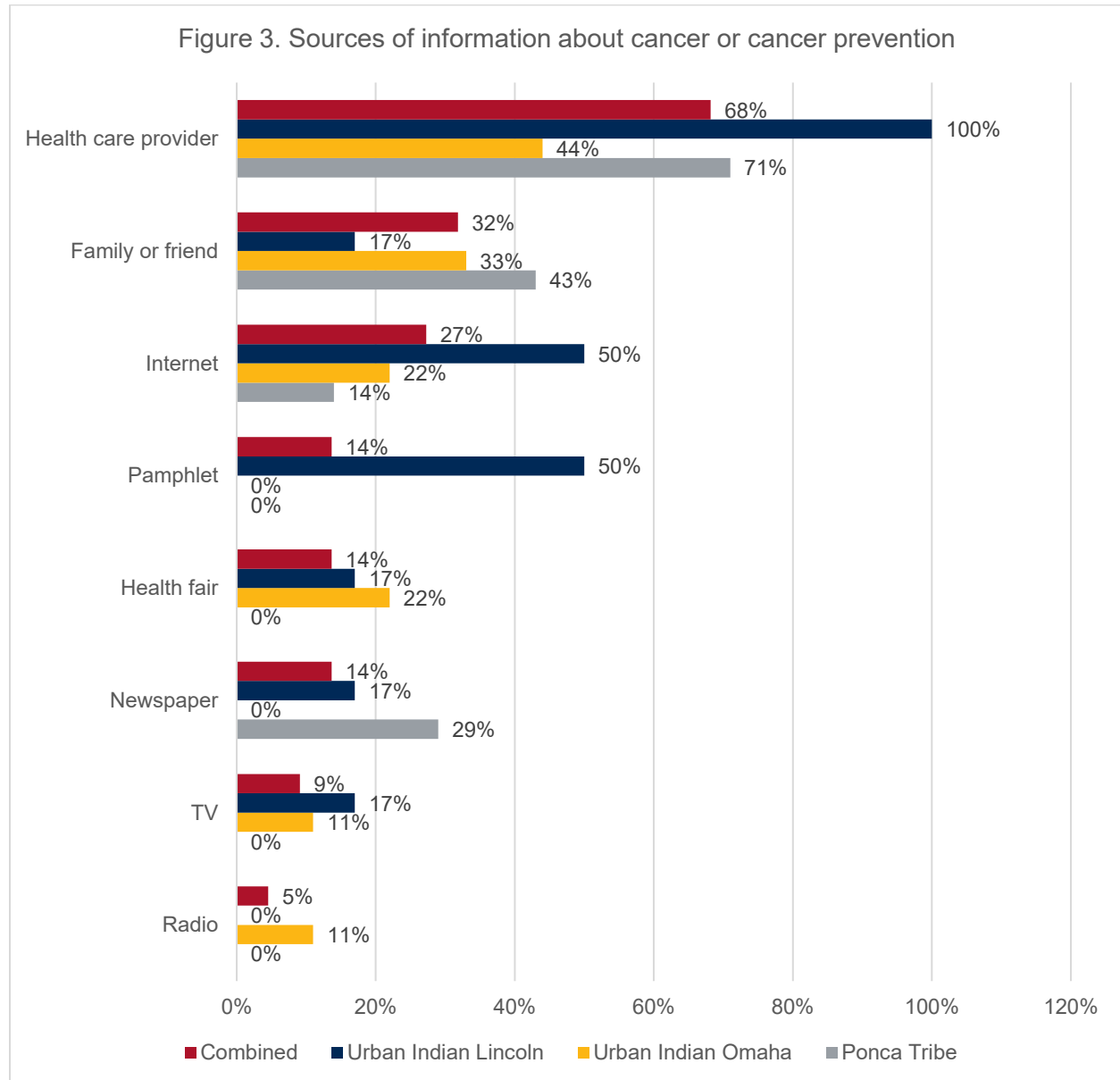
Perceptions of the overall health of the community were mixed. Overall, most participants thought the community's health was good (43%) or fair (26%) (Figure 1). Only 4% of the total participants and 10% of UI-Omaha rated the community's health as excellent. None of the participants of UI-Lincoln and Ponca rated overall health as excellent. Regarding the importance of cancer as a community health concern, most rated it as very important (77%) (Figure 2). UI-Omaha and Ponca Tribe were leaning toward very important (89% and 86%, respectively), while UI-Lincoln participants were evenly split between moderately and very important.



SOURCES OF INFORMATION ABOUT CANCER AND CANCER PREVENTION

Participants utilized a variety of sources of cancer information, with information source preferences varying by group. Overall, doctor or healthcare provider (68%), family

member or friend (32%), and the internet (27%) were cited most frequently (Figure 3). Other sources included pamphlets, health fairs, newspapers, TV, and radio.



Note: Participants could select multiple responses

UI-Lincoln participants explained that internet involved search engines such as Google to learn more about cancer diagnosis. One participant mentioned that her grandmother used the library to get cancer information before the internet was widespread. In the Ponca Tribe listening session, a participant got information about treatment from pamphlets provided by the hospital and preferred credible sources. He avoided the internet because he did not consider it to be credible. In the same session, one caregiver mentioned that her mother did research by herself to learn about treatments and the disease but did not specify how her mother conducted the search.

Participants were also asked which source of cancer information is the most trusted. Most participants indicated health care providers are the most trusted sources of cancer information, but frequency of response varied by listening session (100% UI-Lincoln, 88% Ponca, and 44% UI-Omaha).

CANCER DIAGNOSIS AND TREATMENT EXPERIENCES

Cancer diagnosis can generally be grouped as discovering suspected cancer through routine medical care such as annual check-ups or screening without symptoms, or self-identification of symptoms which may or may not be suspected as being cancer-related.

In both the UI-Lincoln and UI-Omaha groups, it was common for caregivers to lack details about the process leading to the cancer diagnosis, although some caregivers mentioned that cancer was discovered through medical care. For example, one caregiver indicated that her family is very private about health issues, and she did not know about her grandparents' cancers until years later. However, she said her grandparents had "great insurance" and went "to the doctors regularly...getting healthy check-ups and stuff like that," so she assumed they had regular cancer screening. A caregiver lacked details about her grandmother's breast cancer but knew that the grandmother had annual mammograms. Another grandmother also underwent routine screening, identifying ovarian cancer via Pap smear and follow-up biopsy.

Many survivors and caregivers indicated that they or their family members initially received treatment for symptoms or other conditions before cancer was diagnosed. They may or may not have suspected cancer as the cause.

- A sister had backaches which she self-treated with over-the-counter pain relief. The sister was later hospitalized for a heart attack, at which time she was diagnosed with liver cancer that had spread to the kidneys.
- An uncle was a heavy smoker who had emphysema and pneumonia, which led to chest X-rays discovering lung cancer.
- A mother was a heavy smoker. The mother thought she burnt her tongue and waited a few weeks to see if it resolved before seeing a doctor about it. A biopsy revealed tongue and throat cancer.
- A mother was hospitalized for stomach pain. After a few days, test results showed liver cancer.
- A brother was having speech problems, which led to a brain tumor diagnosis.
- A survivor indicated that she "was losing a lot of weight," so she went to "get checked out." At the hospital, she had an x-ray and was diagnosed with kidney cancer. Following this initial cancer, she had "normal check-ups," including colonoscopy every 3 years to check for colorectal cancer due to previous polyps.
- A survivor described going to the emergency room after experiencing "chest pains for a couple of weeks that I thought was skeletal...arthritis or something." While in the emergency room, he was diagnosed with ALL.
- A survivor described going to the emergency room when she was 28 because she had "very, very heavy" menstrual bleeding, which "would stop for a few days

and then get back on.” This had been occurring for “a long time” and “I hadn’t gone to the gynecologist ever.” She then went to a gynecologist and was “put on hormones...it didn’t work,” so she had a dilation and curettage (D&C) procedure done. During her follow-up visit, the gynecologist stated that “they found cancer cells in the D&C tissues and blood.”

- A mother was flown from the reservation to a hospital because “she thought she had pneumonia.” The mother was later diagnosed with stage IV lung cancer. The caregiver daughter explained that her mother had been exposed to asbestos while working at an old hospital. “So, apparently, it traces back to that, that it had, like, formed in her lungs.”
- A mother was diagnosed with colon cancer at age 75 after “four or five years with bowels...being bound up.” The mother’s bowel problems would cause her to “go in the hospital because it would send the toxic poison to her brain,” but the mother resisted getting surgery because “she never wanted to have a colostomy bag.” The daughter said that old people are stubborn not to go to the hospital “...these older people are harder to get them to the doctor than it is...” The daughter and her father kept insisting her mother to go to the hospital and finally, her mother did so. Neither the mother nor the doctor ever told the family about her colon cancer. “We didn’t find out from [the doctor] ‘till after the surgery was over and after she passed.”
- A mother “went in to take her fibroids out, I guess, but what they saw, they just did the full hysterectomy” and “then the pathologist found” ovarian cancer. The caregiver considered the cancer was found accidentally.
- A participant described her own experience with a potential cancer diagnosis. She was invited to participate in a clinical study of longtime smokers. As part of the study, she received specialized x-rays and was informed she had nodules on her lungs. A repeat x-ray confirmed the initial findings, but she did not report receiving a biopsy. Rather, when she went back for a re-check 3 months later, the nodules had disappeared and/or calcified. For those 3 months between scans, she thought she had lung cancer, and “it was a sad time.”
- A sister was diagnosed with non-Hodgkin’s Lymphoma (NHL). The caregiver did not provide details about the initial diagnosis, but the sister survived 35 years before being involved in a car accident. When receiving treatment for related chest pain, she had an x-ray that revealed a tumor.

The cancer diagnosis notification method varied. Presumably, those who were already hospitalized were informed in person. Others had in-person visits with primary care providers to discuss the results. One participant was not satisfied with how her grandmother received a phone call from the doctor with the biopsy results, telling her to come in for an appointment to get more information. The participant called the notification method “piss poor...like it was nothing” because “it still leaves you at nighttime – 3 days to get to your doctor’s appointment thinking ‘what’s ovarian cancer?’” She stated that those three days were very stressful for her family. She spent the time Googling to find details of the disease. She suggested a better notification method would be to set up an appointment for an in-person visit to give detailed information rather than notifying just by phone.

PERCEPTIONS OF CANCER DIAGNOSIS AND TREATMENT

Themes related to the participants’ experiences from diagnosis through treatment and maintenance are presented in Table 1 with selected quotations to illustrate concepts related to both positive and negative aspects of the themes.

Table 1. Positive and Negative Experiences with Cancer Treatment

Theme	Positive examples	Negative examples
Care Coordination	<ul style="list-style-type: none"> • Caregiver’s mother was accepted into a clinical trial at UNMC and “from the time she was diagnosed, I mean they immediately – she had someone who took care of everything with all her appointments.” 	<ul style="list-style-type: none"> • Caregiver had to manage all the appointments. “They were supposed to get the appointments going and they had done nothing. And so I had to...call around.” • “It took about a month before she could see an oncologist and stuff and get the ball rolling.”
Patient-Provider Communication	<ul style="list-style-type: none"> • Doctor explained about the disease and treatment • Care team focused on fulfilling patients need such as pain relief and nutrition; “the doctors were great about things, explaining things and willing to go the distance to meet her needs” • “My oncologist, she was always willing to listen to me if I had any concerns or questions, which was great... So, that really helped me out a lot.” • “They were really good at answering [questions].” • 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.” • Providers maintained the confidentiality of the patient: “If she didn’t want him to tell us or what, you know. You know, they go through that confidentiality.” 	<ul style="list-style-type: none"> • Lack of communication skills • Notification of diagnosis by phone call led to panic moments for patient and caregivers • Three days for an appointment from diagnosis was a scary period for the patient and family: “The problem was just communication. I just could not get nobody to communicate with me.” • Doctors did not provide much information: “But then the doctors – I didn’t really have any information and stuff.” • “It just depends on what clinic you go to or what hospital you go to how, well, how professional they’re going to be.” • Provider needs better bedside manner. Sister loved dancing, and when she awoke from surgery the doctor told her, “Well, your dancing days are over.”
Discrimination		<ul style="list-style-type: none"> • Different treatment of Native Americans by the health care system: “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. So, I know there was a difference."
Staff	<ul style="list-style-type: none"> • "I know she really loved the staff there...She went there forever and just got, you know, to be on a personal level with all of them." • "The staff is unbelievably polite, and considerate, and caring." • "Just the caring people, you know..." • "The workers were so not down and depressed. I mean, they walked around happy, which keeps you happy." • "All the house staff that I worked with when I went through treatment, they just had a great attitude, positive attitude." • "Just the caring people, you know." • "I just rode their, their good vibes." 	
Support System	<ul style="list-style-type: none"> • Family members "tried to change our diets" to eat healthier when grandmother had trouble eating due to chemotherapy • "I would sit up in the night to rub her feet, rub her legs, just try to give her comfort even though that's not where the pain was at...to know she wasn't alone." • Had a sister move in to facilitate providing care and getting her to appointments • Boss encouraged her to "go to the doctor. Go. Go. Find out what's going on. We don't want you to be sick." • Siblings • Family members • "She had a lot of family support." • The support from the doctors and his staff, plus her family 	<ul style="list-style-type: none"> • "I think some people don't have family support, you know, to help encourage your elders...they just don't have that support to help encourage them or to go with them."
Support Services	<ul style="list-style-type: none"> • Nutrition support • Counseling services • Survivor support groups • Patient was involved in providing support service to other cancer patients 	<ul style="list-style-type: none"> • No supportive services - "Should have had more supportive people." • Support services (survivor groups) are limited

	<ul style="list-style-type: none"> • “I don’t remember her really ever taking time off. And then she started a cancer group back home on our reservation for other cancer patients so they could help each other, like, get through it.” • “Being there for each other, knowing you’re not alone.” 	<p>geographically (mostly in Omaha, not in Lincoln)</p> <ul style="list-style-type: none"> • Support groups not available • “There wasn’t, you know, a big survivor community around here.” • Support group members not of same age: “The majority of the support groups, they were all, you know, way, at least 20 years older than me. So, I never went.”
<p>Treatment</p>	<ul style="list-style-type: none"> • Pain medicine was available • “They just removed that kidney that had the cancer, and I didn’t go through chemo or anything...So far so good.” • Participation in a clinical trial: “She also joined, like a, it was like a study; so, they would try different medications on her pretty much.” • “Thankfully, both [grandma and aunt] had multiple surgeries and are still with us today.” • “Got my [stem cell] transplant in June, and been cancer free since.” • “My treatment’s been top notch.” • Patients were cancer-free for a long period after the treatment • “With her cancer treatment, and she, you know, she’s in remission; so, she’s doing really good.” • “That she’s been in remission for like, what, 13 years now.” • “Decided to not do any chemo or radiation and was on hospice for about nine months until she passed at home... Kept her on her morphine until her last breath.” • “So, they pretty much took the whole thing out in one shot. They had the whole chemo, a round of chemo just to make sure they got everything” • “She also did like a lot of herbal-like native ceremonies and such along the way, too. So, it was a long haul.” 	<ul style="list-style-type: none"> • Pain medication “can’t take that pain away” • Grandfather “was in a lot of pain” • “Yeah, she suffered with it.” • “Very painful.” • “Pain medicines, and stuff like that, but she didn’t take ‘em, ‘cause they bound her up, you know. Make her sick.” • “She didn’t die due to the cancer, but from the after-effects after it.” • “The radiation, it did burn her skin” • “Radiation before my stem cell transplant was horrible. That was like the worse three or four days of my life” • Chemotherapy – “the worst part is like, she couldn’t eat” • “There were times where she couldn’t even hold her own bowel movements.” • Some patients died within months of diagnosis and it was “shocking” to family • Recurrence was more aggressive “each time that it came back” • Recurrence: “Over the length of eight years just moved all over. It was in her lymph nodes. In the last two years, it had moved to her brain. ... she had like four brain tumors; so, she did radiation at that point.” • Treatment experience was “scary” • Side effects of chemo: hair loss, weight loss, unable to eat, “very, very sick”

		<ul style="list-style-type: none"> • Sister tried to commit suicide because “the treatment was too hard for her” and “I don’t know if they addressed the mental health side of it.” • Frustrated, “...Why do I have to die?” • “I had some challenges healing up from my hysterectomy, and then I had to get put on a wound vac, and then that got infected, and I couldn’t start chemo when I was supposed to start chemo” • “It was a long, hard road for her.” • “She never wanted to have a colostomy bag put on, you know, ‘cause they had to move her bottom to the side, you know. And she didn’t want to do that ever, and I think that just caused her to give up ‘cause she died, but they did put colostomy bag on her, but she never regained consciousness after that.” • Side effect of the treatments • “My memory is so bad from all the other stuff, radiation. I have hard times remembering anything anymore.”
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BARRIERS TO RECEIVING CANCER CARE

Participants identified a few specific obstacles to care in the discussion of experiences with cancer treatment and services, as reported in Table 2.

Table 2. Barriers/Obstacles to Cancer Care

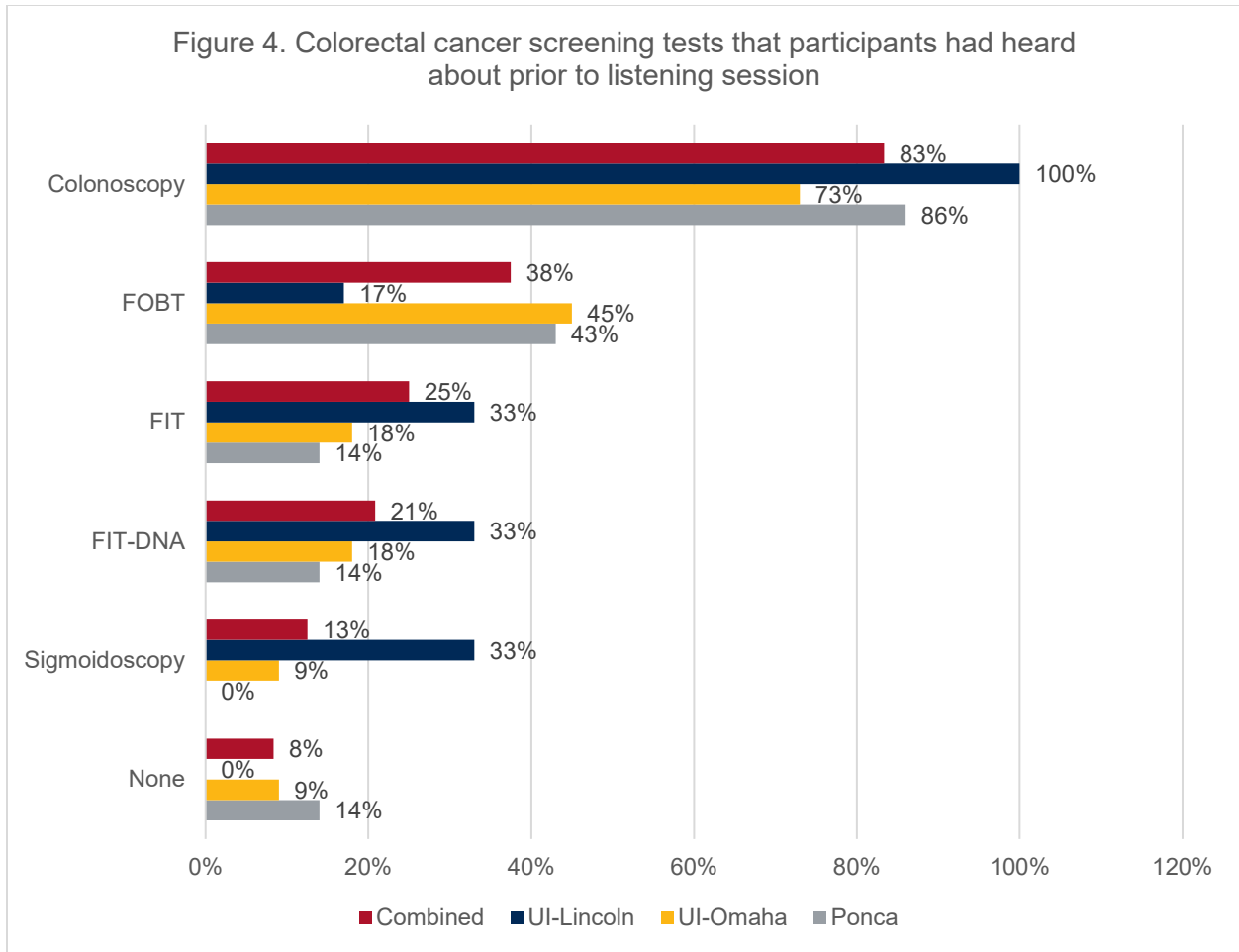
Barrier	Example
Cost and Insurance	<ul style="list-style-type: none"> • Hard to deal with some hospitals (struggle with insurance) • “We had to apply for Medicaid because she didn’t have insurance.” • Grandparents “always having to struggle with insurance issues. So I think it made it a lot harder.” • “She was going to school and on a kinda fixed income; so, she, she was not able to travel outside, you know, to a bigger facility.”
Transportation	<ul style="list-style-type: none"> • Grandmother would “get a ride there and go by herself” • Distance and time burden traveling to/from treatment (cited by multiple people) • Treatment services are limited geographically (mostly in Omaha, fewer in Lincoln) • “But yeah, I mean, it was difficult that part, too, because she always had to travel, like, I think it’s about 3-1/2 hours...so, every chemo treatment, radiation, specialist visit, you know, EK[G, electrocardiogram], all the testing, everything, you know, she had to travel for.” • “The stories of people having to drive three or four hours just to go to a clinic, and to go to a hospital, it could be even further.”
Cultural	<ul style="list-style-type: none"> • “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.” • Cultural stigma about medical care in general: “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.” • Perception of “we can take care of ourselves” • Scared of diagnosis • “Stigma” of cancer diagnosis • Don’t want to be treated by Western doctors • Fear and perception that ultimately people will die if diagnosed with cancer. “You know, you’re diagnosed with cancer, that’s a death wish” because so many people are diagnosed with late-stage cancer and die quickly that it reinforces the community fear of diagnosis. “A lot of problem is, uh, you know, people are scared of cancer, right? So they put off getting tested and then by the time they have symptoms, unfortunately, it’s too late.” • 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...” • Interest in traditional ‘peyote’ used by Native Americans for treatment • “Do you know if there’s any studies being done whether the peyote is more harmful or beneficial or what?” • Stigma related to disease: “...they didn’t talk about health issues or, you know, it was kind of a taboo thing to talk about...”

	<ul style="list-style-type: none"> • “Natives are stubborn anyway when it comes to going to the doctor, but a lot of people don’t go, get regular check-ups, unless they have something wrong.” • “The elders...they don’t show too much pain and hurt, they just kind of deal with it. They don’t really talk about it too much” so it’s hard for family members to know what is really going on
Support Services	<ul style="list-style-type: none"> • Support services are limited geographically (mostly in Omaha not in Lincoln)
Aging	<ul style="list-style-type: none"> • Elderly do not understand medical terms and are not able to comprehend information. Need volunteers who can explain in detail • Elderly are overwhelmed with many diseases so ignore cancer. • Older people don’t like to go to hospital and undergo invasive procedures; younger people “they wanna get fixed, you know, they wanna go to the hospital and do this and that. Well, older people are not like that.” • Older people don’t want to visit hospital • “But you know, these older people are harder to get them to the doctor than it is, you know. They’ll say, ‘Ohh, I’m alright,’ you know. They don’t want to go to the hospital or anything.” • “I’ll be 74; so, it’s hard to get us to the doctor. I would say, ‘ohh, yeah, I’ll go, I’ll go,’ but I don’t like going to the doctor either, you know. It’s just, even when I’m real sick, I have to be, I pretty near smothered to death one night before I went to the doctor here in Creighton.”
Treatment Services	<ul style="list-style-type: none"> • “The only thing that could, it would be if they had more options for what I had.”

COLORECTAL CANCER (CRC) SCREENING

Participants were asked what types of CRC screening methods they had ever heard about (Figure 4). Of those who had heard of CRC screening methods, colonoscopy and FOBT were the most commonly recognized methods. All UI-Lincoln participants have heard about at least one screening method, but 9% of UI- Omaha and 14% of Ponca participants had not heard about any methods. During the follow-up discussion, participants specifically identified Cologuard®, which is the only FDA-approved stool DNA screening test for CRC currently available in the US market.

Participants primarily received information about CRC screening from doctors but also received information from health centers such as Ponca Health Center, social media, their job, TV, community health workers and knowing someone who had received a CRC diagnosis. Information from the health care system included flyers and brochures at the clinic. One UI-Lincoln said she “knew nothing about it” until she took a new work position and was assigned to contact patients to schedule CRC screening. Several UI-Omaha participants commented on the Ponca Health Center’s monetary incentives to encourage CRC screening with FOBT, with statements such as “The Ponca Tribe always makes sure that everybody does go for rectal – what do you call – hema test. And then as an incentive, they give you like a \$30 gift card. So I mean I do that every year with the Ponca.”



Note: Participants could select multiple responses

Factors that impacted CRC screening (both positive and negative) are presented in Table 3.

Table 3. Factors that Impact CRC Screening

Theme	Example
Perception and Emotion	<ul style="list-style-type: none"> • Elders say they could take care of themselves • Stigma that there is no need for a doctor • “I think you have to take in consideration of, you know, the elders. That’s a whole different generation. They have a different way of thinking” • Fear of diagnosis: “They’re fearing what they’re gonna find out.” • Afraid of diagnosis (a disease that kills) • “Too scared...” • “They would rather not know.” • Positive experience of colonoscopy: “The prep is the worst, but the colon test itself is so easy. You just go to sleep and it’s done.” (supported by 2 other people) • Prep “not that bad...they’ve changed it a little bit now.” • Scared of colonoscopy prep and procedure • Embarrassed with the stool testing “Because I don’t wanna be digging in my poop” and “I wouldn’t even do it for money.” • “I think, you know, I got a little older brother and I almost can guarantee that’s what it [embarrassment] is.” • “People’s perception of manhood” • “Being too macho.” • “I think a lot of times people don’t think that it can happen to them.” • “The stubbornness of some people. They don’t want to do it themselves, I guess, those colorectal tests.” • “He kinda talks it as a joke... He’ll say something like he’ll get pink eye or something doing those tests.”
Information and Awareness	<ul style="list-style-type: none"> • Lack of information on colorectal cancer and screening. “What is colorectal cancer? What is that actually? Can you tell me how do they screen them? What is the screening for colorectal cancer?” • “I don’t think a lot of Natives get that type of cancer, do they?...I’ve never heard of it until now.” • Some participants have never heard about CRC screening: “What is that? What is that?” • “I have to say that before [new job calling to schedule CRC screening] last year, I had knew nothing about it.” • “Not informed enough maybe.” • Information event on a recent update in screening recommendation • Ponca Health Center conducting regular stool-based screening test • Physician recommendation • Informal talk with neighbors: participant mentioned to neighbor that she had just done a colonoscopy and neighbor replied “Good, I just hate doing that prep...but I’ve been having some bleeding” so participant told neighbor to get it checked; neighbor was diagnosed with stage 4 CRC and is now on chemotherapy • Unfamiliar with all available options of CRC screening
Aspects of Colonoscopy Procedure	<ul style="list-style-type: none"> • Colonoscopy: “I think it’s uncomfortable for them and a lot of them just don’t wanna do it.”

	<ul style="list-style-type: none"> • Invasive procedure: “Seeing their body and, you know, especially back there. They’ll just like, ‘Oh, no, I can’t do that. No, no, you can’t go there.” • “Camera is a red flag that put me off.” • “A lot of people don’t want to do the prep.” • “I don’t think anything came of it, but I have had a colonoscopy two times, and they’re not fun.”
Lack of Support Services	<ul style="list-style-type: none"> • “Think some people don’t have family support, you know, to help encourage your elders” • “To go with them to be that other listening person. Just in case, you know, ‘cause if they’re gonna go, they hear some bad news, they’re not gonna retain all the information.”
Cost and Insurance	<ul style="list-style-type: none"> • “They don’t make enough for insurance to, from their work, or they make too much to get help from the state, so, they’re just kinda stuck in this gray area where they have lack of insurance so then, a lot of times, they won’t go unless they really need it.”
Lack of Physician Recommendation	<ul style="list-style-type: none"> • “My doctor hasn’t really pushed too much of the colon testing stuff on me quite yet.”

Participant suggestions for improving CRC screening are presented in Table 4. These included ideas about increasing public awareness of CRC.

Table 4. Suggestions to Improve CRC Screening

Theme	Example
Information and Awareness	<ul style="list-style-type: none"> • Sending flyers/ brochures in the mailbox (similar to receiving coupons from restaurants) (L) • Flyers or brochures with pictures as older people don't have social media or access to internet (P) • Use of billboards to convey information: "Big ole colon picture would get people's attention." (P) • "For them to make [billboards], I mean, goofy. That way, people don't take it so seriously. They ain't so scared all the time about it. That way, they can kinda laugh at the ad, and hopefully, not be so nervous if they had to go and take a check." (P) • Educational materials in waiting rooms (L) • Posters in clinic (O) • Visual materials which will help to understand CRC and CRC screening (L) • Use of social media, particularly Facebook (L) • Health fair (L, O) • Sharing success stories (O) • "Public meetings every now and then." (P) • Health education from nursing students to "come in and teach the elderly about these diseases so that they will be able to be more self-aware" (O) • Involvement of Native Americans Centers in awareness programs that know the history of Native Americans (L) • Involvement of community in educational awareness programs (O) • Convey information to others from "regular people from the community that already had it before" (friends, neighbors, etc.) (O) • "If you get a chance, maybe you can come and talk to us and explain that to them because it is impossible to get these older people, I'm old, too, you know. I'll be 74; so, it's hard to get us to the doctor." (P) • Continuous counseling, especially elders, until they agree to test. "Pushed one of our elders because she kept ignoring me. She kept saying, I'll do the test, I'll, do the test, I'll do the test, and we finally, I finally got her to do the test. And when she brought it back, it was positive." (P) • "Stressing the importance of getting checked. I mean Natives are stubborn anyway when it comes to going to the doctor." (P) • Better explanation about the anesthesia, that the actual colonoscopy procedure "doesn't hurt, no aftereffects" (L) • Need to talk more about the screening measures to bring awareness (P) • Formation of elders committee where the members can be involved in awareness (P) • Provision of food can encourage people to participate in the awareness program. "If you feed them, they will come." (P)
Messaging	<ul style="list-style-type: none"> • Let people know that cancer is like other diseases, it can be treated if diagnosed early (L) • "It's good to be checked...You get to a certain point in your life, you've got kids, you want to see them graduate." (L) • CRC is treatable "if they catch it in time" – so need to do screening (O)

	<ul style="list-style-type: none"> • “If you get checked, your mind rests too if you know you don’t have it.” (O)
Providers	<ul style="list-style-type: none"> • Physician reminder during appointments (L) • Need better explanation about procedures during the visit (L) • Support from doctors, especially for elderly people, need to clearly explain what to expect (L) • Need for increased awareness and recommendation (O) • Better communication between providers and patients (O)
Community Needs	<ul style="list-style-type: none"> • Involvement of Native Americans Centers in awareness programs that know the history of Native Americans (L) • Transportation services (L) • Having family members attend the appointments (L) • Social worker services: who will be able to talk (provide information), attend elderly people’s appointments, and identify the needs of elderly people (L) • Financial counselors (L) • Need of support groups for patients (O) • Prevention education, including education about diet to promote colon health (O) • Like travelling mammogram, mobile services for CRC screening tests especially targeting Native Americans (P) • CRC screening test should be made available in the rural area. “More services are needed, something more close by to reservations and the rural areas, not just the cities.” (P) • Community health workers should reinforce elders to test. “...pushing sometimes your elders to do the tests” (P) • Free physical therapy services to be healthy and strengthen body after treatment (P) • Support groups that follow more Native American culture, traditional medicine as well as modern medicine (P) • Availability of facilities nearby reservations (P)
Partnership	<ul style="list-style-type: none"> • “We’re hoping to, we’re hoping to have a partnership with UNMC, and with that partnership, you know, hopefully, could come great things” (P)

L = UI-Lincoln participant
 O = UI-Omaha participant
 P = Ponca Tribe participant

CONCLUSION

Listening session participants appreciated the opportunity to share their experiences and hoped to have similar opportunities in the future for support and educational groups. Participants identified some general community needs, including the need for general health education outreach, cancer support services including mental health services, and cultural sensitivity to generational differences in attitudes toward health care. The community also needs a sense of hope – that cancer is not a death sentence - to promote screening and treatment. Participants were also interested in research about environmental exposures (such as pesticides), as well as research on the possible effects of traditional practices such as peyote. Results from this listening session highlight the need for continuing the efforts to address gaps in cancer care services, including colorectal cancer screening for Native Americans in the state of Nebraska.