

# NEBRASKA CANCER COMMUNITY HEALTH NEEDS ASSESSMENT

African American Listening Sessions

November 2021



## RESEARCH TEAM

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## EXECUTIVE SUMMARY

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 sessions used structured interviews and poll questions to solicit participants' perspectives about the cancer journey from diagnosis through treatment, as well as input specifically focusing on colorectal cancer screening awareness and participation.

Participants were open about the positive and negative aspects of their journey from cancer diagnosis through treatment. The need to feel supported in the journey – from family, friends, community, and treatment providers—was a central theme. Participants identified barriers to cancer care that are well known in the cancer literature, including financial burdens and accessibility. However, participants also identified factors specific to the African American community that impact cancer care as well as general health status. The community as a whole, but males in particular, need continued outreach and education to promote routine medical care rather than waiting until symptoms develop. In general, participants indicated that breast cancer awareness is strong within the African American community but less so for other types of cancer including colorectal cancer. In general, participants indicated the importance of cancer support groups to have hope for the future and not view a cancer diagnosis as a death sentence. As one participant clearly indicated, “words matter” and how the diagnosis and prognosis are presented can have lasting impact on treatment decisions and survivorship.

## OVERVIEW

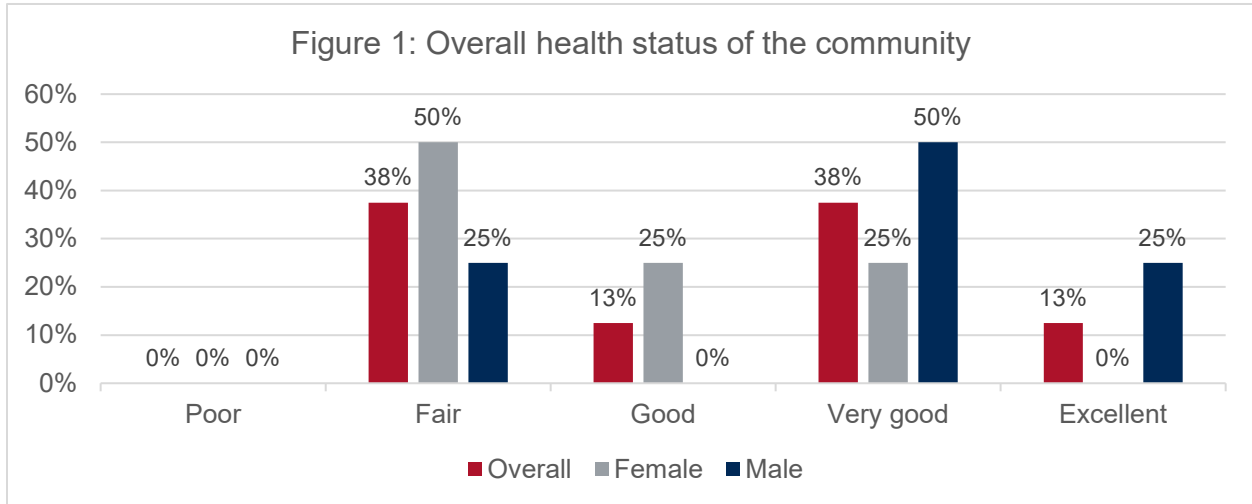
A 60-minute virtual listening session with four African American women recruited from the Omaha metro area was held on 29 April 2021. A 75-minute virtual listening session with three African American men was held on 13 August 2021. Both groups met via Zoom and used the same structured facilitation guide and included built-in Zoom polling questions. The groups were facilitated by an African American faculty member from the University of Nebraska Medical Center (UNMC) who is active in cancer outreach activities, with support from additional research personnel to serve as notetaker and technology assistance. Topics covered in the listening sessions included polls related to overall community health status as well as sources of cancer-related information, experience with diagnosis and treatment, and colorectal cancer (CRC) screening.

The female group consisted of 1 breast cancer survivor and 3 caregivers. One woman cares for her mother who recently had a recurrence of breast cancer. Another woman cared for her mother (ovarian and breast cancer), father (pancreatic cancer), and stepmother (pancreatic cancer) until they passed away. The remaining participant cared for her friend, now deceased, who was originally diagnosed with Hodgkin's lymphoma and after four years of remission was diagnosed with ovarian cancer. Thus, types of cancer represented included breast (n=3), ovarian (n=2), pancreatic (n=2), and Hodgkin's lymphoma (n=1). The cancer patients represented received care in Omaha at UNMC (Buffett Cancer Center, Village Pointe), Catholic Health Initiatives (CHI), and Children's Hospital, as well as the cancer center in Hastings.

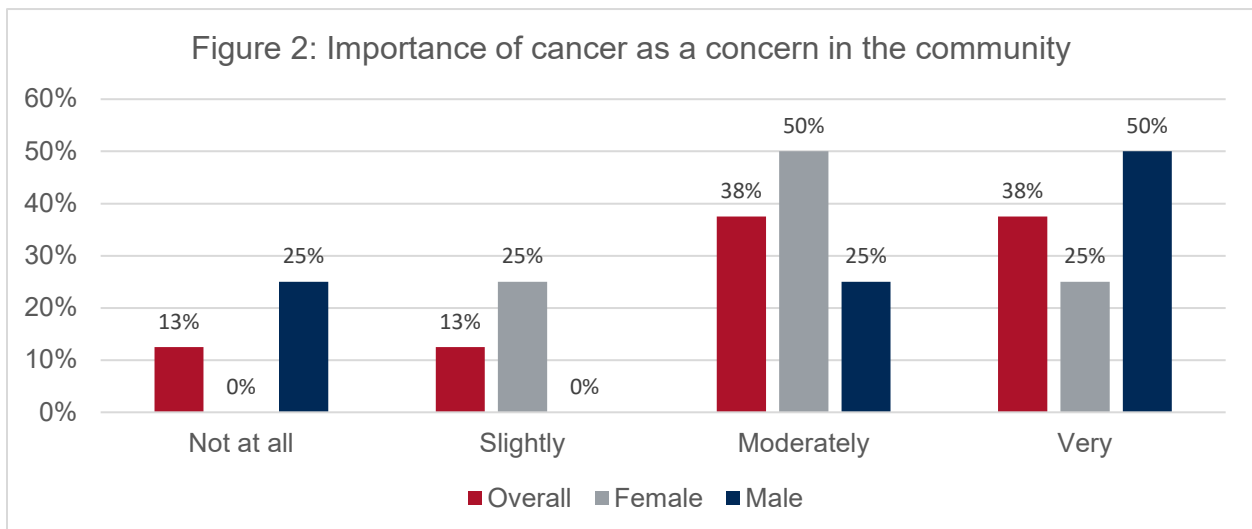
The male group started with four participants, but one had a bad connection and left the group after the first two polling questions. Participants included a thyroid cancer survivor, a male caregiver of his wife with breast cancer, and a male caregiver of his grandfather with prostate cancer. The thyroid cancer patient was diagnosed and received treatment at UNMC. The breast cancer patient was initially treated at UNMC, transferred care to Chicago, and is currently receiving care in Omaha at CHI Health Creighton University Medical Center—Bergan Mercy Hospital (Bergan Mercy). The prostate cancer patient was diagnosed and treated in Texas but moved to Nebraska where he receives follow-up care (location unspecified).

### COMMUNITY HEALTH STATUS

The perception of the community health status ranged from fair to excellent, with fair and very good being the most common responses (37.5%) (Figure 1). Perceptions differed between the female and male groups. Half the female participants indicated that the overall health status of the community was fair, while half of the male participants indicated it was very good.

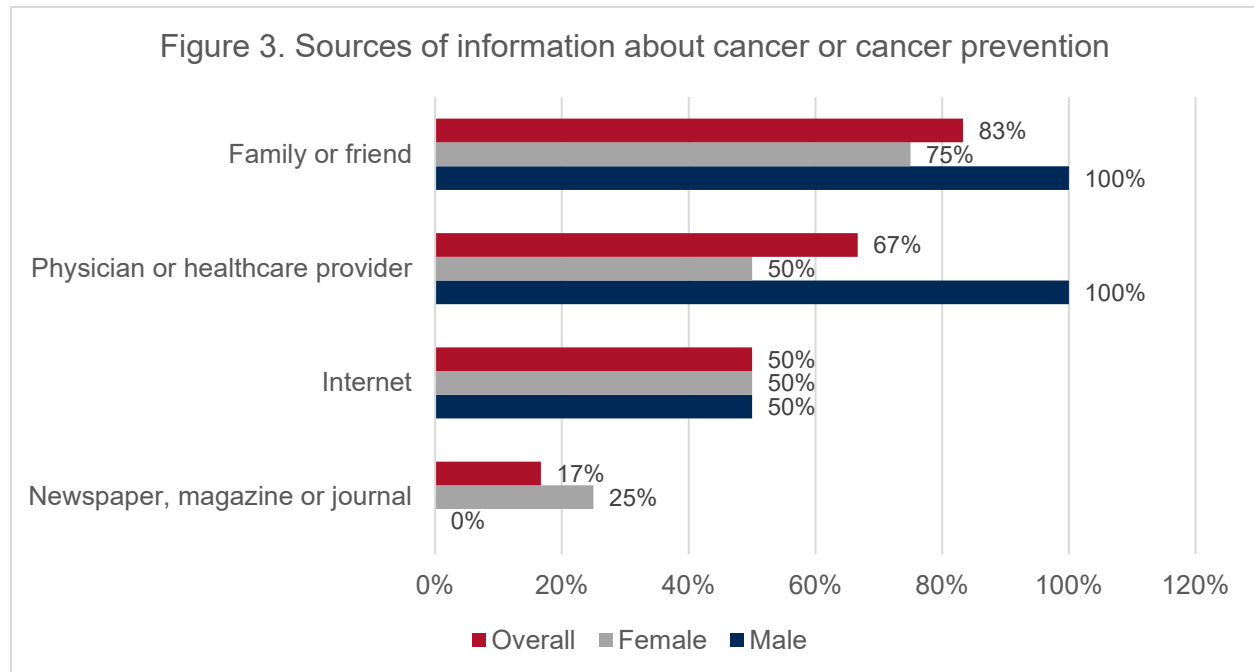


Most participants indicated that cancer was moderately (37.5%) or very (37.5%) important health concern in their community (Figure 2). Half the female participants indicated moderately important, while half of the male participants indicated very important.



## SOURCES OF INFORMATION ABOUT CANCER AND CANCER PREVENTION

Participants received cancer-related information from a variety of sources, and often from multiple sources. The most common source of information about cancer or cancer prevention was family member or friend, followed by physician or healthcare provider and the internet (Figure 3). One female participant also selected book/journal article.



*Note: Participants could select multiple responses, and only 2 of the 3 male participants completed the poll. Included in the poll but not receiving any responses were health fairs, social media, TV, and radio.*

One survivor's brother was a physician, whom he relied on heavily for information. One caregiver's mother had been a navigator at Buffett Cancer Center and had also been very involved in My Sister's Keeper, an Omaha-based breast cancer support organization for African Americans, so some family members were very informed about breast cancer and actively encouraged participation in community support groups. Although not reflected in the poll results, two male participants were also familiar with breast cancer educational outreach through My Sister's Keeper and one described a community health fair.

Internet searches used search engines such as Google and trusted websites such as the Susan G. Komen website, WebMD, UNMC, Mayo Clinic, Chicago Cancer Center, and Physiopedia. One participant specifically mentioned that "I kind of look at all of it because I tend to want to see if there's similarities or extreme differences in what is being provided." This participant also looked up online medical journals. The husband and caregiver of a breast cancer survivor indicated that his wife is highly educated and "she loves researching and educating herself...she just kept doing more and more and more research" about her symptoms before she received her (delayed) diagnosis. When discussing colorectal cancer (CRC) information specifically, participants also

indicated that they trust internet sources with URLs ending in “.edu”, and medical journals. Female participants also asked physicians and medical colleagues directly, attended medical or professional conferences, and preferred information containing statistics.

One participant said that in general there is lack of data for African American populations and research should focus on gathering data to disseminate among African American community members.

When asked about the most trusted source of cancer-related information, most participants (85.7%) indicated physician or healthcare provider (85.7%), with one male participant selecting family member or friend (14.3% of combined responses).

## **CANCER DIAGNOSIS AND TREATMENT**

One caregiver of a deceased female friend reported that she first noticed enlarged lymph nodes on her friend’s neck. The friend had a biopsy and was informed of Hodgkin’s lymphoma, receiving care at UNMC and Children’s Hospital. This patient was in remission for four years before being diagnosed with ovarian cancer, which was diagnosed more quickly than the initial cancer had been. The friend was initially treated at UNMC before transferring care to her local cancer center in Hastings. The patient was eventually transferred to hospice services and finished her treatments at home. The caregiver said the staff were very kind and helpful, but that her friend was very isolated due to COVID-related visitation limitations.

The breast cancer survivor self-identified signs of cancer by noticing a lump. She noted in her phone to schedule an appointment with her physician in a month if not resolved. Once she saw her physician, she was immediately referred for a mammogram and biopsy. This participant indicated that she had the mammogram at Nebraska Medicine Village Pointe, which was further from where she lived, because they could schedule her sooner. The biopsy and remainder of care were at UNMC, which is conveniently located to where she lives and works. Her job allowed her the flexibility to take time off during the day for cancer treatments. She is pleased with the care she receives and would recommend the facility to others.

A caregiver reported her mother, who was a 35-year ovarian cancer survivor, became unable to keep food down and was later diagnosed with stage 4 breast cancer. She was treated at Nebraska Medicine Village Point and UNMC main campus, receiving chemotherapy and radiation treatments.

A caregiver reported that her father was diagnosed with Stage 3 pancreatic cancer and was treated at CHI with a Whipple procedure. The father was “okay for a little while and then it resurfaced.”

A female caregiver’s mother was a 20-year breast cancer survivor who had received a mastectomy. The mother developed knee pain and was treated for a long time by her

primary care provider without having any tests ordered. Eventually, the mother was diagnosed with stage 4 breast cancer that had metastasized to the bones. The mother is in her 70s and opted to not actively seek treatment. The caregiver expressed frustration that her mother's diagnosis was delayed, saying, "So, you know years ago had some due diligence been done we could have caught this a little earlier than where we are now."

The husband of the 11-year breast cancer survivor who has had five recurrences indicated that his wife had done a breast self-examination and noticed lumps. She went to her primary care provider who "said she was too young, and it was fatty tissue" and dismissed the concerns. Nothing was done further until nine months passed and the woman's breasts started hurting. She went to a different doctor and was diagnosed with breast cancer and had a double mastectomy. At the first recurrence, she had lymph nodes removed. Additionally, the wife "always had nodules in her lungs, but then [the physicians] wrote them off and said oh, we live in the Midwest so because of all the agriculture, everyone has nodules in their lungs." At the second recurrence, the doctors ordered a lung biopsy and discovered the cancer had metastasized to the lungs. The patient was told they didn't take out enough lymph nodes previously, and said she had 3 years to live. The patient and her husband were very hurt by this statement because "Words have power and you can't just tell me I've only got three years to live." They decided to transition care to Chicago Cancer Center, and the process took a few months. They loved the holistic approach in Chicago and traveled there every 6 weeks for 3-4 days of treatment. During that time, the cancer center opened a new hotel and cafeteria and the couple no longer received the travel support they had previously received, such as free/discounted food and hotel rates and mileage assistance. The husband was disillusioned about "how much a lucrative business cancer can be." Due to the costs, they transferred care back to Omaha (Bergan Mercy) where the wife continues to be seen.

As reported by the grandson caregiver, his grandfather noticed symptoms including pain while urinating which progressed to blood in the urine and semen. The family urged him to seek medical services at which time he was screened for cancer and a diagnosis was made of stage 2 prostate cancer. It took about 5 months from the start of the symptoms to diagnosis. The patient was given good care in the Texas hospital "because the medical practitioners really wanted to see him get well so fast." However, within the Haitian immigrant community, the grandfather faced stigmatization and was "like an outcast" due to lack of knowledge about prostate cancer. The grandson (who is a student and was the sole caregiver) felt isolated and it was difficult for him to take his grandfather to clinic visits without community support. Three months ago, the grandfather moved to Nebraska where there is more family support. He receives follow-up care in Nebraska, although the grandson lacked details of his grandfather's care.

The thyroid cancer survivor's mother died of breast cancer at age 60 so he has been very mindful about getting routine semi-annual checkups and colonoscopies every five years. At a routine visit he had bloodwork done that came back with abnormal results, so his primary care physician referred him to a thyroid specialist who did x-rays and a



biopsy. It took about 1 month from the physical before he received a thyroid cancer diagnosis. He had a very positive experience at UNMC (surgeon and thyroid expert). The physicians gave him the choice of complete or partial thyroid removal, and he opted for partial because he did not want to be on thyroid medication. The surgery went well and the scar has virtually disappeared. He did not have any additional treatment.

Participants who were familiar with the timing of diagnostic workups indicated that they or their loved ones received biopsy results within 2 weeks and were satisfied with the time to receive results and the method in which results were communicated. Despite the timely receipt of results, one participant expressed that “when you are waiting for that news, every day is just treacherous.”

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

**Table 1. Positive and Negative Experiences with Cancer Treatment**

Theme	Positive examples	Negative examples
Shared decision making	<ul style="list-style-type: none"> <li>• Choice of local vs radical surgery with discussion of side effects (male survivor)</li> </ul>	<ul style="list-style-type: none"> <li>• “Words have power and you can’t just tell me I’ve only got three years to live.” (male caregiver)</li> </ul>
Patient-provider communication	<ul style="list-style-type: none"> <li>• “The doctors were clear and you know [stepmother] had already made those connections and those relationships with those physicians that knew her.” (female caregiver)</li> <li>• “I was able to communicate with the nurse for the oncologist fairly easy.” (female caregiver)</li> <li>• “The nurse will reach out to me and keep me updated...so I appreciate that.” (female caregiver)</li> </ul>	<ul style="list-style-type: none"> <li>• “I didn’t feel like [local providers] listened and I didn’t feel like they heard us as a family.” (female caregiver)</li> <li>• When being informed of dad’s cancer treatment, “we were kind of herded into a large room and the physician there pulled my stepsister aside and kind of treated her like, you know, almost like a student who was being grilled.” (female caregiver)</li> </ul>
Nurses and Staff	<ul style="list-style-type: none"> <li>• At Buffett “everybody was so friendly and understanding there.” (female caregiver)</li> <li>• “They were able to bring...a sense of peace for lack of better terms, in a sense of they are going to fight for you and I think that meant a lot to both of us and her family because it was a very discouraging time, but the way they are real and honest with you about the situation and hopeful.” (female caregiver)</li> <li>• “They treated my mom with value and they actually cared</li> </ul>	

	<p>about her well-being.” (female caregiver)</p> <ul style="list-style-type: none"> <li>• Mother’s nurses “were no joke at all.” (female caregiver)</li> <li>• “Staff was so kind and generous...They were actually helping plan her wedding...They really went above and beyond to make sure that every day was as normal as possible.” (female caregiver)</li> </ul>	
<p>Support Services</p>	<ul style="list-style-type: none"> <li>• Cancer center helped with Family Medical Leave Act (FMLA) paperwork. (female caregiver)</li> <li>• Social worker “said if you ever need anything, just let me know...She kept checking in on me...and helped me with my rent because I had missed a lot of days of work that month.” (female survivor)</li> <li>• Grocery card (female survivor)</li> <li>• Social worker linked cancer patient to resources for her child who was “struggling, thinking I was going to die” (female survivor)</li> <li>• Wholistic approach (male caregiver)</li> </ul>	<ul style="list-style-type: none"> <li>• Initially received travel assistance (discounted hotel, food, mileage) but it was reduced or eliminated over time (male caregiver)</li> </ul>
<p>Community Support</p>	<ul style="list-style-type: none"> <li>• My Sister’s Keeper “is kind of how we get through the process.” (female caregiver; mentioned by several)</li> <li>• “My job was really flexible and let me miss days or come in late.” (female survivor)</li> </ul>	<ul style="list-style-type: none"> <li>• Within Haitian immigrant community, prostate cancer patient was stigmatized, isolated, and treated “like an outcast” (male caregiver)</li> </ul>
<p>Treatment Side Effects</p>	<ul style="list-style-type: none"> <li>• Surgery scar virtually disappeared; no need for medication because thyroid only partially removed (male survivor)</li> </ul>	<ul style="list-style-type: none"> <li>• “They told us that there was nothing else they could do. [The mother] had been through rounds and rounds of chemo. She had lost considerable weight.” (female caregiver)</li> <li>• “She would have a reaction to a medicine, and we didn’t what know what it was because so much happened that day” [during different treatments]. (female caregiver)</li> </ul>

		<ul style="list-style-type: none"> <li>• Lack of energy/exhaustion (mentioned by several)</li> <li>• Hair loss (mentioned by several)</li> <li>• “chemo brain, like I can’t remember things very much.” (female survivor)</li> <li>• Bone pain; “It hurt to walk.” (female survivor)</li> <li>• Changes in sleep patterns (female survivor)</li> <li>• Anxiety (female survivor)</li> <li>• Felt isolated going through treatment in midst of COVID; “only allowed 30-minute visits so I think that was hard when you are having to be alone and go through all of those things.” (female caregiver)</li> <li>• “Lack of time and closeness with family members.” (female caregiver)</li> </ul>
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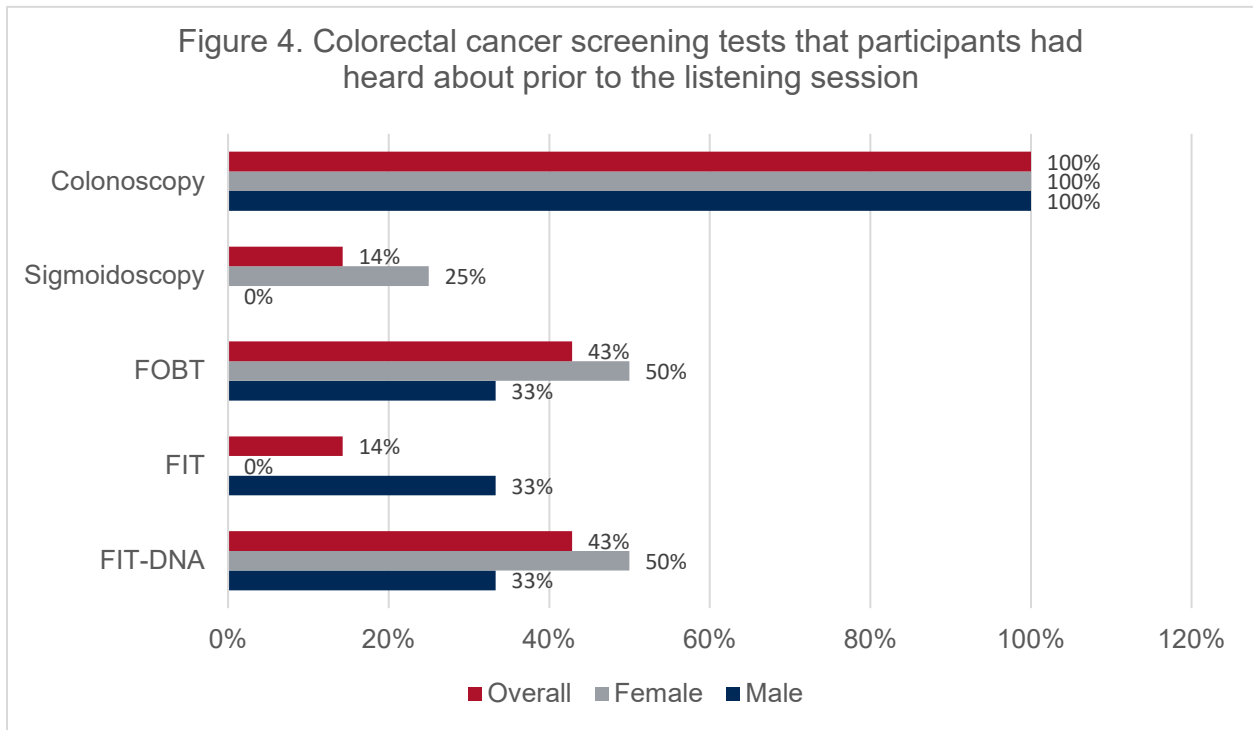
**COLORECTAL CANCER (CRC) SCREENING**

As an introduction to the CRC screening discussion, participants were read the following statement and asked to respond to a poll question in which they could select multiple responses:

There are several different colorectal cancer screening methods available. Stool or poop-based tests include the fecal occult blood test or FOBT, the fecal immunochemical test or FIT, and FIT-DNA tests. Other tests insert a long, thin, flexible tube into the rectum or even the entire colon to look for small growths called polyps, and cancer. These tests are known as sigmoidoscopy and colonoscopy. Which of these tests have you heard about prior to today?

Cologuard, the only FDA-approved stool DNA screening test for CRC currently available in the US market (FIT-DNA), was mentioned by name by only one (female) participant.

All participants had heard of colonoscopy, few had heard of sigmoidoscopy, and familiarity with the fecal tests varied by group (Figure 4). Two of the four female participants and one of the three male participants had heard of FOBT and FIT-DNA. Colonoscopy was the only screening method discussed during the male listening session, as the two younger men expressed concerns about colonoscopy such as fear and stigmatization.



*Note: Participants could select multiple responses*

Participants had many thoughts about factors that impact CRC screening, grouped into the themes of mistrust, bias, access, lack of awareness, and fear and avoidance (Table 2). The Haitian participant indicated that his grandmother had CRC and his entire family was recommended to be screened. “Not all of them were okay with screening. Some of them forego the screening.” When asked if he had been screened, he initially said yes then chuckled and admitted that he had not.

**Table 2. Factors that Impact CRC Screening**

Theme	Example
Mistrust	<ul style="list-style-type: none"> <li>• “I don’t think that Black people trust the health system.”</li> <li>• “A lot of historical angst.”</li> <li>• “They are not going to right away listen to information from the doctor or the public.”</li> <li>• Don’t trust doctors who don’t look like them.</li> </ul>
Bias	<ul style="list-style-type: none"> <li>• “...black people...[have] bias against the recommended testing. So you know nobody likes a colonoscopy.”</li> <li>• “Some physician bias for additional resources like Cologuard in that they don’t trust that.”</li> </ul>
Access	<ul style="list-style-type: none"> <li>• “Not everybody maybe has health insurance coverage or is aware of how to apply for Medicaid or any those other things.”</li> <li>• “There is that gap of when you lose health insurance. It is so expensive to have health insurance, so I think that accessibility is a huge issue.”</li> </ul>
Lack of awareness	<ul style="list-style-type: none"> <li>• General lack of awareness.</li> <li>• “Lack of importance regarding education of regular screening.”</li> <li>• Irregular use of medical services (only go when really ill, lack of regular check-ups). (mentioned by several)</li> <li>• “I haven’t even thought about it to tell you the truth.”</li> </ul>
Fear and avoidance	<ul style="list-style-type: none"> <li>• [Colonoscopy] “kind of scares you away from even having to go get checked out.”</li> <li>• “I’m 33 years old and I’m not looking forward to it...I hope they keep that age up and I’m hoping I can stay healthy.”</li> </ul>

Participant suggestions for improving CRC screening and needed resources included education, delivery method, messaging, and accessibility and utilization of healthcare services (Table 3).

**Table 3. Suggestions to Improve CRC Screening**

Theme	Example
Education	<ul style="list-style-type: none"> <li>• Education is needed for Black community to improve trust. “Initially I don’t think that Black people trust the health system. Um there is a lot of historical angst and I think there needs to be – I think it is an opportunity for education and, I don’t know, education... I think the Black people or whoever is like not getting the recommended screenings. There is also a lot of...bias against the recommended testing. So you know nobody likes a colonoscopy.”</li> <li>• Education is needed for physicians. “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.”</li> </ul>
Delivery method	<ul style="list-style-type: none"> <li>• “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.”</li> <li>• Messaging from “cancer survivors or going through treatment at the same time.” (mentioned by several)</li> <li>• “You just have to have that relationship and that connection and that cultural buy-in to make it successful and to make people to like, take the next step.”</li> <li>• Navigators</li> <li>• Social media</li> <li>• Group message texts</li> <li>• Primary care physician</li> </ul>
Messaging	<ul style="list-style-type: none"> <li>• “Advocate for going to the doctor.”</li> <li>• Need for increased general community education about regular physicals/check-ups (not specific to cancer), to not just go to the doctor when you’re sick. (mentioned by several)</li> <li>• “Diagnosis is not a death sentence. Diagnosis is taking that step to live.”</li> <li>• There are resources available, including financial resources.</li> <li>• Support is available in the community.</li> <li>• Knowing your family history is important. “If you have a history of cancer in your family, you should get that checked as often as possible.”</li> </ul>
Healthcare Access and Utilization	<ul style="list-style-type: none"> <li>• Regarding navigating the healthcare system and health insurance coverage: “Need to make improvements in our health care system so that everyone has access or knowledge of how to attain those helpful pieces of information.”</li> </ul>

## COMMUNITY NEEDS

The discussion about CRC cancer screening broadened into some general community health needs, outlined in Table 4.

**Table 4. General Community Needs**

Theme	Example
Building Trust	<ul style="list-style-type: none"> <li>• Focus on building trust between the medical community and the Black community.</li> <li>• Doctors that look like the population they serve.</li> <li>• UNMC needs to be more visible and network more with minority communities, linking to trusted medical professionals, to hold seminars (but with a “hook” such as free food or giveaways to encourage participation). Suggested partnerships included the North Omaha Area Health Clinic and Charles Drew Health Center, Inc.</li> <li>• UNMC should host a booth at community events such as Juneteenth.</li> </ul>
Regular Medical Care	<ul style="list-style-type: none"> <li>• Normalize routine check-ups for males and females, even at a young age, to catch and treat health conditions when they are more treatable.</li> <li>• “I didn’t start doing that until I graduated from college to be honest with you because I didn’t realize how important it was to get checked regularly....I wished I had caught [anemia] earlier. I almost had to get a blood transfusion.”</li> <li>• “The fact is that we don’t always want to – as males – address issues of our health. And oftentimes that is a key problem and indicator, and it becomes too late in many cases when in fact the symptoms become so overwhelming or so obvious that it’s necessary for somebody to go in and see a physician.”</li> </ul>
Sense of Community	<ul style="list-style-type: none"> <li>• Support network “knowing you’re not alone is really important, you know, when you are dealing with grief like this.”</li> <li>• Support network is also avenue for education, sharing resources</li> <li>• Sense of community</li> </ul>
Overcome Disease Fatalism	<ul style="list-style-type: none"> <li>• Need for sense of hope</li> <li>• “Diagnosis is not a death sentence. One thing that sticks out with me is that [mother, who was a cancer care navigator and involved with My Sister’s Keeper, was] able to convince at least 7 to 10 women not to kill themselves.”</li> <li>• “It is important that people understand that regardless of not just cancer, but a lot of the diseases that plague the African-American community, that diagnosis is not a death sentence.”</li> </ul>

## **CONCLUSION**

Listening session participants appreciated the opportunity to share their experiences. These listening sessions highlighted the need for continuing efforts to provide education about the importance of routine medical care. Comments about disease fatalism, and the need for hope in life after a cancer diagnosis, highlight the need for social and emotional support at the time of diagnosis and throughout treatment. My Sister's Keeper was identified as an important support organization within the community. They also identified gaps in both general health care and cancer care services including colorectal cancer screening in the African American community within Nebraska.