

NEBRASKA CANCER COMMUNITY HEALTH NEEDS ASSESSMENT

Rural Listening Sessions

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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 (hereafter referred to as "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 did not necessarily receive treatment at the cancer center closest to their residence, traveling due to preferences about health care providers and to receive specialized cancer treatment services. Participants identified barriers to cancer care that are well known in the cancer literature, including financial and travel burdens. While some supportive services are available to address these issues, they are not universally known or used and do not adequately address all the needs of rural cancer patients. In general, participants indicated that breast cancer awareness and support was better-known compared to other types of cancer.

OVERVIEW

Three listening sessions were held with rural Nebraskans. A 90-minute virtual listening session was held on February 26, 2021, with 8 participants recruited from Grand Island, Nebraska. The session consisted of one male caregiver and seven female survivors, one of whom also served as a caregiver. Cancer types represented included breast (n=7), bladder (n=1), and lung (n=1). Six of the participants lived in Grand Island, and two were from outlying communities but received care in Grand Island.

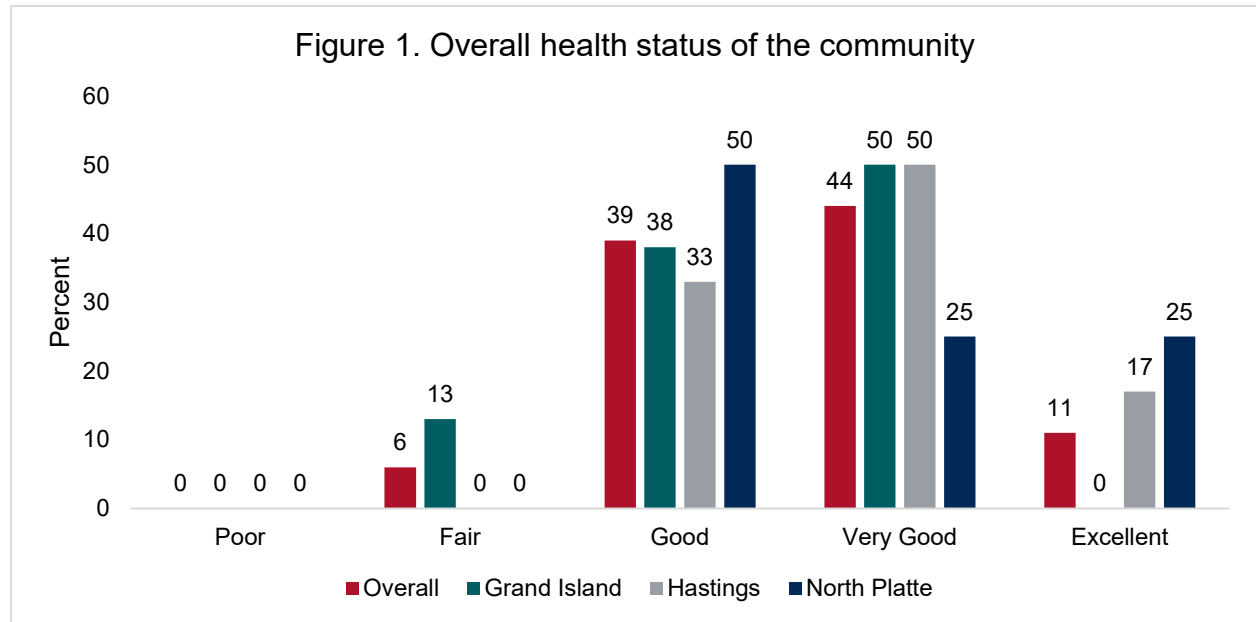
A 75-minute virtual listening session was held on April 8, 2021 with 6 participants recruited primarily from Hastings, Nebraska. The session consisted of 1 female caregiver, 1 male survivor, and 4 female survivors. Cancer types represented included breast (n=1), myeloma (n=2), lymphoma (n=1) and lung (n=1). One survivor lived in Grand Island and received care in Omaha, one lived in Hastings but received care in Omaha, one lived in Kearney but received care in Hastings, one traveled about an hour to receive care in Hastings, and one lived west of Lincoln and received care in Lincoln and Omaha.

A 75-minute virtual listening session was held on May 28, 2021, with 6 participants recruited from North Platte, Nebraska. The session consisted of two female caregivers, two male survivors, and two female survivors. Cancer types represented included breast (n=3), prostate (n=1), and lymphoma (n=1). One of the caregivers was the spouse of a survivor also participating in the group. Five of the participants lived in North Platte, and one traveled approximately an hour to receive care in North Platte. One received treatments locally but traveled to Omaha for specialist care.

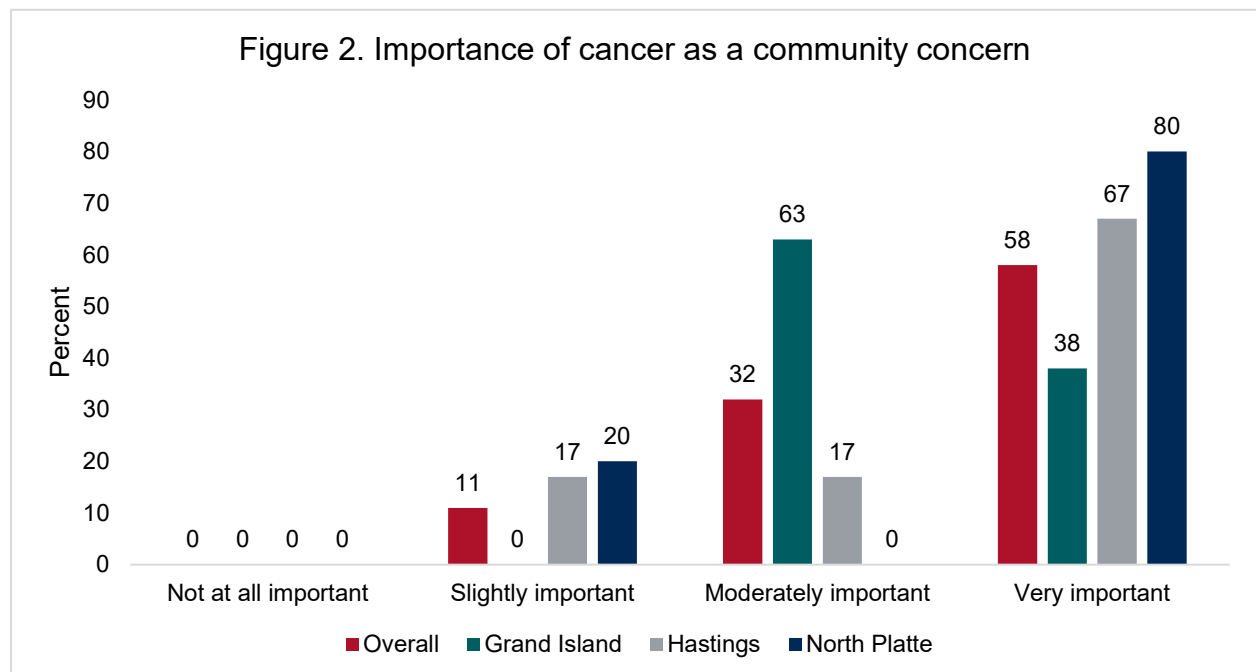
The listening sessions utilized a structured facilitation guide and included built-in Zoom polling questions. Topics covered included overall community health status as well as sources of cancer-related information, experience with diagnosis and treatment, and colorectal cancer (CRC) screening.

COMMUNITY HEALTH STATUS

Overall, the perception of the community health status ranged from fair (6%) to excellent (11%), with most responses in the good (39%) and very good (44%) range (Figure 1). The only “fair” response was from the Grand Island listening session, whereas Hastings and North Platte both had “excellent” ratings.

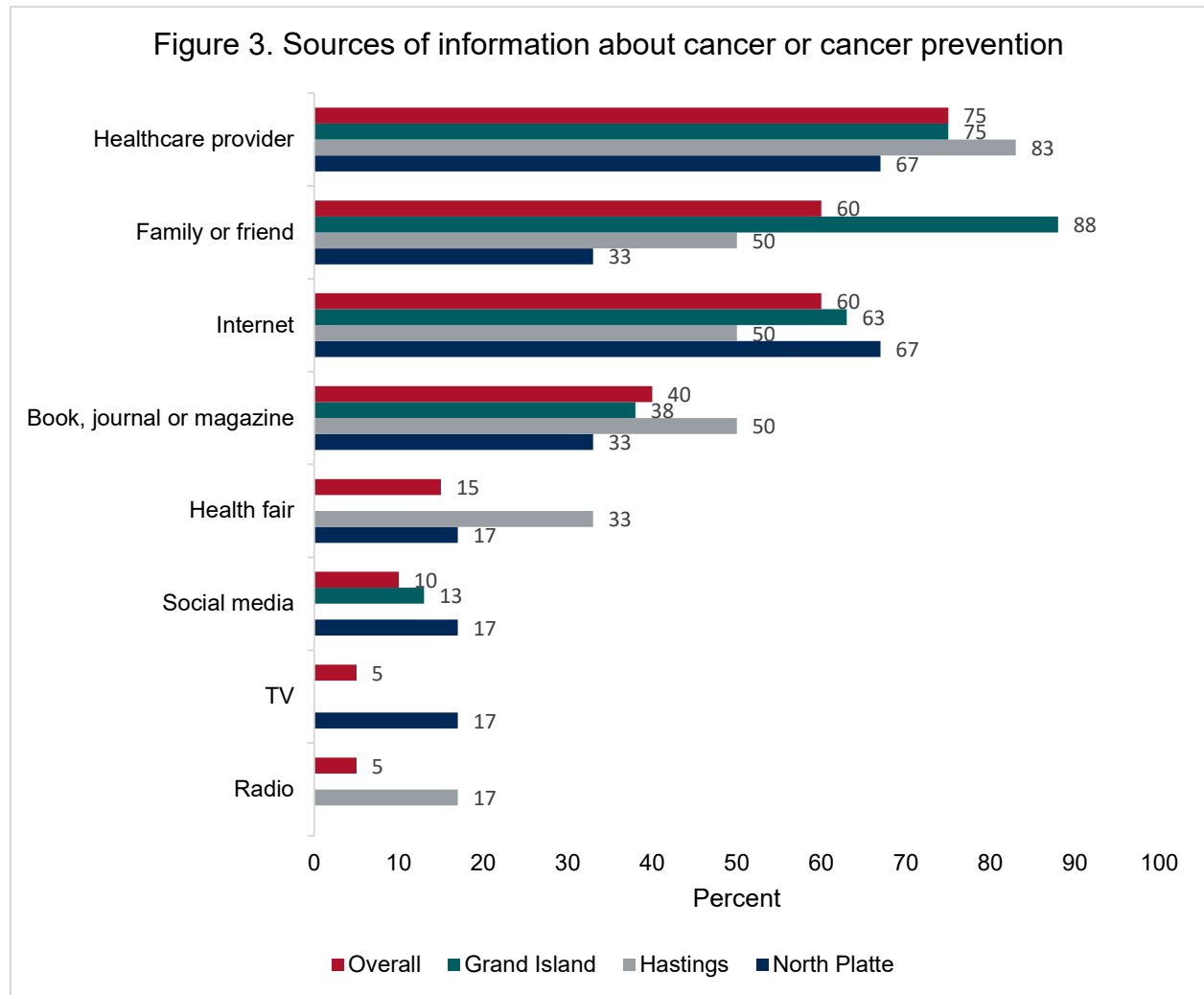


Overall, most participants (58%) indicated that cancer was a very important community health concern (Figure 2). The majority of participants from Grand Island viewed cancer as a moderate concern (63%).



SOURCES OF INFORMATION ABOUT CANCER AND CANCER PREVENTION

Participants received cancer-related information from a variety of sources, and often from multiple sources. Overall, the most common source of information about cancer or cancer prevention was from physicians or other healthcare providers (75%), followed by family member or friend (60%) and the internet (60%) (Figure 3). Sources of cancer information varied slightly by community, with participants from Grand Island most reliant on family members or friends. Relatively few participants received cancer-related information from mass media sources such as TV or radio.



Note: Participants could select multiple responses.

In addition to receiving information directly from physicians, one participant noted the role of the nurse care coordinator at the start of treatment. Participants also received books and brochures from the cancer center, and shared information from cancer support groups. They valued information provided by people who were going through a similar experience because “you can talk to someone that has gone through it as well.” Some survivors relied on the spousal caregiver to research cancer and share

information. Internet searches primarily utilized search engines such as Google and trusted sites such as the American Cancer Society, sites by nonprofit organizations focusing on specific cancer types (e.g., Lymphoma and Leukemia Society), and sites recommended by physicians. Participants indicated that they often used search engines to research drug information related to cancer treatment.

When asked about the most trusted source of cancer-related information, 95% of participants indicated physician or healthcare provider. The exception was a male survivor in North Platte who relied on his wife/caregiver to research information.

CANCER DIAGNOSIS AND TREATMENT

Nearly half the reported cancer diagnosis resulted from routine healthcare or cancer screening (breast, prostate) and were characterized by referral for follow-up diagnostic testing with timely notification of biopsy results (often within days) and smooth transition to specialists for cancer treatment. Regarding cancer screening, a female survivor indicated reliance on reminder postcards from the mammography center to know when to be re-screened. One year she did not receive the postcard, so she followed up with her primary care provider (PCP). She was informed that mammography had moved to the local hospital and the PCP connected her to the new location. Another participant said she had not received a mammogram for several years until she switched to a new PCP who “insisted” she get a mammogram. She did so and was diagnosed with metastatic breast cancer.

Several other individuals received care for symptoms not initially suspected as being cancer-related. For example, a female survivor went to her PCP for a urinary tract infection but was told “everything is clear.” She was soon hospitalized for sepsis and had a biopsy, identifying bladder cancer. A caregiver’s husband had been sick for more than a year with numerous tests and multiple doctors before a chest x-ray revealed advanced lung cancer. A male was hospitalized for pneumonia and was diagnosed with lung cancer following a biopsy. A female reported being “misdiagnosed” for two and a half months related to stomach pain before having a CT scan, which found a blood clot in her portal vein. She was then referred to a hematologist, had a bone marrow biopsy, and was diagnosed with multiple myeloma. A female with a history of osteoporosis had been seeing a physical therapist. The therapist recommended she see an osteoporosis specialist, who saw abnormalities in lab values and referred her to a hematologist. The participant was diagnosed with multiple myeloma within a month.

The remainder of the represented cancer cases were self-identified by noticing a lump or pain. They reported waiting one to four weeks to see if the symptoms resolved before seeing a physician. For example, one female had a history of benign brain tumor that caused her to be more attentive to her body. She later noticed a site in her mouth that started growing and was eventually diagnosed with MALT lymphoma.

Not all participants had positive experiences with diagnosis and referral for follow-up testing, results notification, and transition to specialist care. A female survivor from an

outlying community reported numerous problems with care coordination and communication. This patient's initial appointment for breast pain was with an on-call doctor rather than her PCP. The patient was referred for a mammogram and ultrasound; she indicated that the doctor then referred her for biopsy while downplaying the possibility of cancer. After nearly two weeks, the patient had not received the test results but did not know which provider to call for the results (biopsy provider, on-call, or PCP). After multiple calls, the referring doctor called back and apologized, informing the participant that the results had been received more than a week ago but had been overlooked. This survivor also reported poor care coordination with subsequent referral to cancer specialists.

One of the female survivors reported being diagnosed with Paget's disease (of the breast) during a routine diabetes check-up. She was referred for follow-up testing but did not receive the results within the expected timeframe. She repeatedly called her provider. Eventually a nurse "told me over the phone [that it was cancer]...It was hard to get that news over the telephone...So I had that news and I had to drive [an hour] home [from work]" alone with the emotional burden of the diagnosis. This survivor also reported numerous issues with care coordination and patient-provider communication.

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

Table 1. Positive and Negative Experiences with Cancer Treatment

Theme	Positive examples	Negative examples
Care coordination	<ul style="list-style-type: none"> • Primary care providers set up appointment with cancer specialists and coordinated care • "My care was coordinated and it is still being coordinated now that I am in maintenance phase" • Nurse navigator helped set up appointments and functioned as a coordinator • Referrals to support services • Care transferred to a local center more convenient for the patient • "When I get [to the cancer center], back in the treatment room usually within 3 to 4 minutes and on my way home." 	<ul style="list-style-type: none"> • "There were a lot of things not connected well" from primary care to cancer center • Lack of connection between providers resulting in delayed reporting of test results • Confusion about order to see specialists (surgeon, oncologist) • Went through several different radiation oncologists during course of treatment • Physician "hadn't read through the report fully" and "fumbled through all the papers...and the nurse knew more about it than [physician]"
Patient-provider communication	<ul style="list-style-type: none"> • Initial meeting with care team involved patient and family, where the patient received "care bag" with notepad, brochures, etc. 	<ul style="list-style-type: none"> • 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." • Patient not allowed to ask questions

	<ul style="list-style-type: none"> • “I have received the information I’ve needed and am always encouraged to ask questions” • “Kept us all involved and never rushed those kinds of things” • Shared decision-making, gave “options” to patient • The patient was able to make a decision about mastectomy vs. lumpectomy based on the survival information provided by the provider • “I had four options” and discussed with the physician the pros and cons; patient made decision based on survival rates 	<ul style="list-style-type: none"> • Doctor made assumptions about what patient already knew; patient not given enough information • Lack of alternative provider options • Provider seemed unprepared, appeared he hadn’t reviewed the chart, which patient found frustrating • Surgeon’s explanation to patient was overwhelming and surgeon “had no desire to listen to what I was telling him, and I did not have a good experience with my surgeon” who “thought he knew it all...was just really rude” and downplayed mastectomy saying “It is just a breast...it’s no big deal.”
Provider interpersonal skills	<ul style="list-style-type: none"> • “Really considerate” • “They just showed me such care and concern. I mean, I was connected with everybody...” • “They would call and check on you” • Compassionate • Straightforward 	<ul style="list-style-type: none"> • Specialist seemed “proud” • “Very good doctor but not very personable, and I think he thought he was a little God.” • “No compassion...He just didn’t care and he thought he was right and they didn’t do any treatments or anything and it came back quickly and with a vengeance” • Current radiation oncologist “lacks just any sort of compassion, understanding, caring, human interaction, is strictly all business” • Aggressive, demeaning, “in my face” • Oncologist “called me a crybaby. He yelled at my husband in the office.”
Staff	<ul style="list-style-type: none"> • “Nothing short of wonderful” • “Like family”; “they celebrated all of the holidays with us.” • Supportive and welcoming • Regular follow-up • Nurse navigators “an incredibly valuable piece to what is going on...because they are wonderful.” • “Everybody there is great to work with” • Her mother “did comment on how nice the therapists were” 	
Support system and services	<ul style="list-style-type: none"> • “Biggest support I got was from church, family and friends” • “One of the big advantages to living in a small town is that your community is kind of your support” – examples included 	<ul style="list-style-type: none"> • Delayed own cancer treatment to be caretaker while the spouse was dying of cancer • Lack of support from spouse: “My wife told me with her anxieties, she couldn’t handle [my cancer diagnosis] so I was on my own and it

	<p>help with yard work, T-shirts in support of cancer battle</p> <ul style="list-style-type: none"> • Cancer centers, foundations and a pharmacy that give out financial assistance, gas cards, hotel discount, money for meals, housekeeping assistance and medication assistance • “Full time social worker...really great on trying to find assistance with gas cards” • Cancer support group: “We get questions answered and we are armed with information that we ask our doctors, so that is what I would recommend” • Local organizations help fundraise to support cancer treatment costs 	<p>was kind of rough.” “My wife dumped me as soon as I had the diagnosis and was discharged from the hospital.”</p> <ul style="list-style-type: none"> • Unaware of support groups in local community • More cancer support groups (other than breast cancer) are needed • More linkage to financial support services and reminders that it’s there if the survivor and caregiver need it (some people reluctant to ask for help)
Treatment	<ul style="list-style-type: none"> • Keytruda working • Excellent care • “My treatment went really well... went really smooth for me.” • “Impeccable credentials that was an absolutely fantastic radiation oncologist throughout my course of treatment” • Helped manage side-effects • “Had no side effects” 	<ul style="list-style-type: none"> • “Almost died from the chemo.” <ul style="list-style-type: none"> ▪ “It was stage 0 and they said it would never come back. No treatments were needed; then 17 months later...stage 4” • “Two lumpectomies because they didn’t get it the first time. I’m in radiation and probably be on medication for about 5-10 years...I just had an ultrasound and they just found a nodule on my chest cavity...hopefully that’s nothing, but we’ll see.” • More mental health support needed—and more use of the mental health support that’s available—by having care team integrate it more, especially at time of diagnosis • More physician education about psychology of cancer diagnosis needed
Distance	<ul style="list-style-type: none"> • “I am grateful that we have the radiation here in town so she didn’t have to travel for it” • “Thank goodness I don’t have to drive” 	<ul style="list-style-type: none"> • Had to drive two hours every day for treatment • People in western Nebraska have to travel for treatment. It is especially problematic for (radiation) therapy

BARRIERS TO CANCER CARE AND SUPPORT SERVICES

As suggested by themes presented in Table 1, some cancer survivors experience obstacles with cancer treatment and services. Cancer treatment can be costly, even with insurance. Finances are also related to transportation in terms of gas, vehicle

upkeep, and potentially the need for overnight stays at distant treatment centers. Barriers identified by the listening session participants are summarized in Table 2. In addition to identifying barriers, participants also identified existing services in the community and through the cancer center (Table 3), as well as additional services that are needed (Table 4). In some cases, support services are available to those living near the cancer center but not in outlying communities (limited geographical availability).

Table 2. Barriers to Cancer Care

Barrier	Example
Financial	<ul style="list-style-type: none"> • Lost insurance early in cancer journey • Cost of medications (\$50,000 every 3 weeks) • Thankful for Medicare and good insurance but still have deductibles • Debt
Access to Service	<ul style="list-style-type: none"> • Support groups limited geographically • Support groups limited to specific types of common cancers
Transportation	<ul style="list-style-type: none"> • Traveling to/from daily treatment (time and distance) • Multiple treatment trips, “gas was quite costly”
Physician Turnover	<ul style="list-style-type: none"> • “It seems like we have trouble keeping like our oncologists and our radiation oncology doctors”
Other	<ul style="list-style-type: none"> • Reluctance to ask for/use available services because “it just seems like I’m always asking for help” • Entry into medical world – for those without a PCP for annual check-ups, who do you see when something is wrong

Table 3. Support Services Available

Service	Example
Financial	<ul style="list-style-type: none"> • Cancer center provided gas cards (mentioned by several) • Local organization (Hope Cancer Foundation) can help pay bills/utilities, etc. • Local organizations (Concrete Cares & Forever Pink) help fundraise to support cancer treatment costs
Support Service	<ul style="list-style-type: none"> • Cancer center helped fill out paperwork for support services • Local organization can assist with housekeeping services • Cancer support group – “COVID messed a lot of that stuff up, but it’s getting better”

Table 4. Other Cancer Services Needed

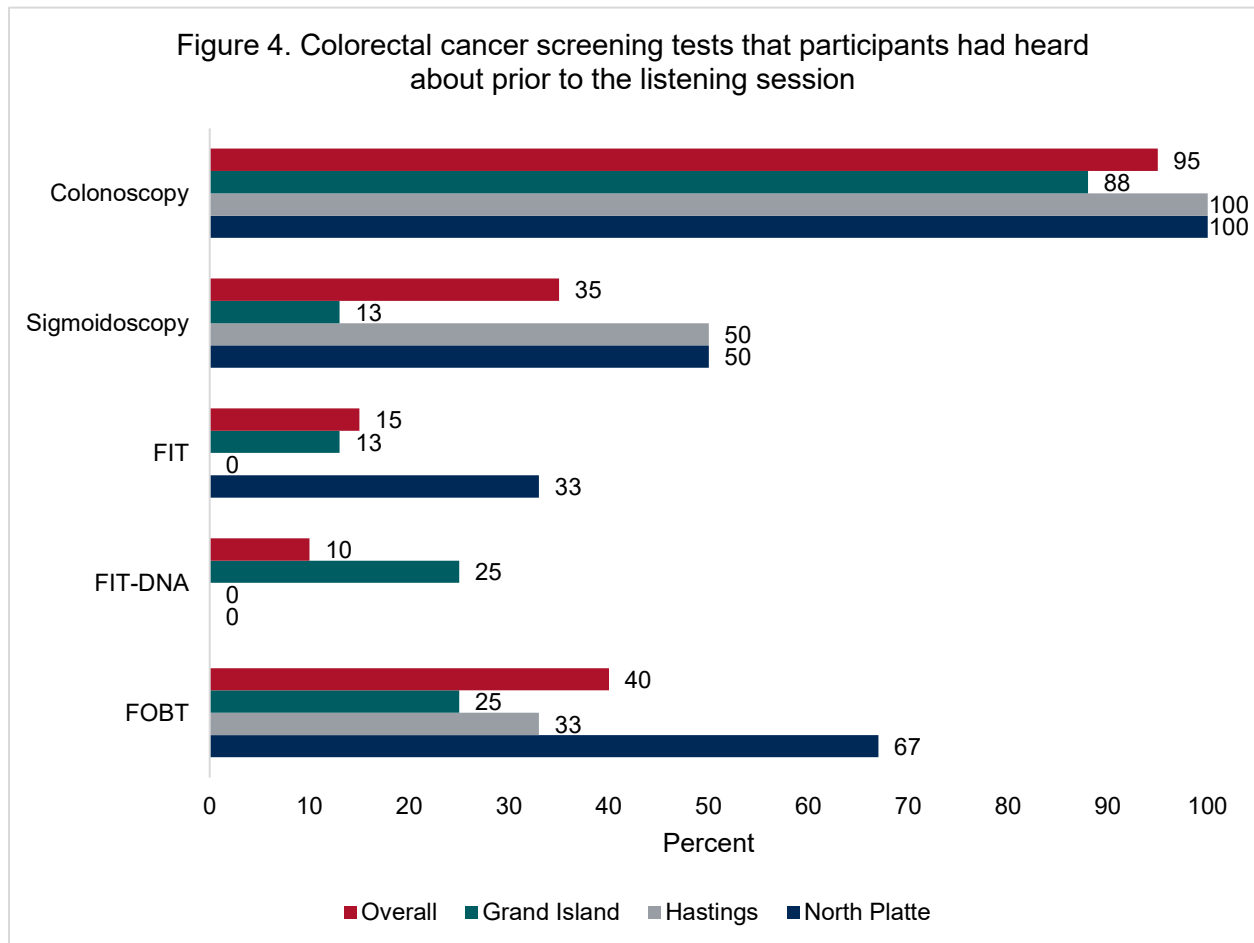
Service	Example
Support Groups	<ul style="list-style-type: none"> • Cancer support groups (other than for breast cancer)
Financial	<ul style="list-style-type: none"> • More linkage to financial support services and reminders that it’s there if you need it (some people reluctant to ask for help)
Psychosocial	<ul style="list-style-type: none"> • More physician education about psychology of cancer diagnosis • More mental health support – and more use of the support that’s available—by having care team integrate it more, especially at time of diagnosis

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?

Overall, nearly all participants (95%) knew about colonoscopy (Figure 4). Stool-based tests were less familiar. During follow-up discussion, participants specifically identified Cologuard by name, which is the only FDA-approved stool DNA screening test for CRC currently available in the US market. Although some had seen ads on TV for Cologuard, they did not know which type of stool-based test it was. In some sessions, Cologuard was incorrectly identified as FOBT rather than FIT-DNA. Misunderstanding of



Note: Participants could select multiple responses

the type of test likely resulted in some misclassification in the poll results. Participants also expressed uncertainty about the accuracy of stool-based tests, including Cologuard.

Participants primarily received information about CRC screening from doctors. They described physician reminders or insistence about being screened as “harping” or “harassing” but indicated that they eventually complied with the recommendation. Those with a family history of colon problems were also more aware of and valued the importance of screening. Reluctance about the bowel preparation and the colonoscopy procedure were cited by several participants, who viewed the home-based stool testing as a positive alternative. In addition to name familiarity from television advertising, participants had also heard TV celebrities such as Al Roker talk about colorectal cancer during CRC Awareness Month.

Participants had many thoughts about factors that impact CRC screening, which have been thematically organized in Table 5. Most focused on negative aspects, although they did identify some positive factors that promote screening, such as knowing someone who has experienced CRC.

Table 5. Factors Impacting Colorectal Cancer Screening

Theme	Example
Perception and Emotion	<ul style="list-style-type: none"> • Perception of “old person disease.” • Men not as apt to do it due to “I’m fine” attitude • Generational attitude: older people less likely to be screened “Mom said walk it off” • Low perceived personal risk: “probably not a risk for me...I’ll get it later” • Embarrassment • Scared of colonoscopy preparation and procedure
Information and Awareness	<ul style="list-style-type: none"> • “It’s something that nobody likes to talk about” • The rural area may have more people who are not aware of the need for CRC screening • “You don’t hear about that you should, it’s not...like mammograms.” • Don’t know the recommended age for screening • Unfamiliar with other options besides colonoscopy (e.g., Cologuard) • Uncertainty about the accuracy of stool-based tests (e.g., Cologuard) • Misinformation (about causes, relationship to other cancers) • Patients wait to be told it is needed • Older people may be more aware because providers tell them to get CRC screening done • Knowing someone with CRC increases screening uptake • Family history of colon problems (CRC, Crohn’s disease) • Family history of colon cancer so “probably something in ...future to get screened for” once patient reaches age 45
Health Care Providers	<ul style="list-style-type: none"> • The daughter insisted her mother receive colonoscopy but it seemed that her mother was never recommended by the PCP to get colonoscopy “so she didn’t think it was necessary” • Participants decided to get colonoscopy because the PCP “insisted” on it • Some doctors don’t recommend their patients to get CRC screening

	<ul style="list-style-type: none"> • Older doctors may not have much focus on any preventive care, including cancer screenings, and may be less likely to recommend it than younger doctors
Colonoscopy	<ul style="list-style-type: none"> • Invasive procedure, need to go to the hospital • “Horror stories about the prep” • “Inconvenience in having a day or two of discomfort before, during and the time of being busy” • Cost or insurance coverage; Financially can’t afford it, even with insurance
Cologuard	<ul style="list-style-type: none"> • Patient decided to get Cologuard when he found out that it was 90% effective • “A lot of people also like the convenience of the Cologuard because they’re at home and it is more private”

Participant suggestions for improving CRC screening and needed resources included education, delivery method, messaging, and accessibility and utilization of healthcare services (Table 6).

Table 6. Suggestions to Improve CRC Screening

Theme	Example
Information and Awareness	<ul style="list-style-type: none"> • Doctor’s office –have brochures or posters in the waiting and exam rooms • “Jenny’s Stall Stories” (short health education messages posted in restrooms at Women’s Healing Center, physical therapy, etc.) “are great” • Use church groups to spread the word • Senior Citizen monthly informational dinners (guest speakers on different topics) • Mini health fairs and in-person education from those with personal experience of CRC • Need for general education and awareness of CRC screening recommendations, so patients aren’t relying solely on doctors to tell them when to screen • Need to increase awareness among Hispanic population and those of other cultures • Need to increase awareness – compared to breast cancer & mammogram • Cancer awareness month • Use media preferred by target age group– radio blitz • Targeted media during colorectal cancer awareness month • Billboards
Messaging	<ul style="list-style-type: none"> • Somehow convey that CRC is not a joking matter, remove sexual connotations • Reminders to do it on your birthday: “Give yourself a birthday present so that you have time for family and grandkids” • Educational campaign – better programs, test options (colonoscopy OR stool-based tests), and strategies for colonoscopy preparation are now available; newer colonoscopy bowel preparation is better tolerated than in past
Providers	<ul style="list-style-type: none"> • Need for increased awareness and recommendation from primary care - comparison to military doctors who tell their patients about preventive care services

GENERAL COMMUNITY NEEDS

In the discussion about ways to improve colorectal cancer screening, some listening session participants identified community needs related to general medical care. They indicated that lack of regular medical care and preventive care impacts cancer care as well. For example, participants in Grand Island identified the need for more bilingual PCP and free or low-cost primary care clinics, even if they were only offered on a limited basis. Other suggestions included expanding the service area of a local community organization, the Grace Foundation, so cancer survivors from more distant areas could have access to the support services.

CONCLUSION

Listening session participants appreciated the opportunity to share their experiences. Results from these sessions highlight the need for continuing efforts to address gaps in cancer care services, including colorectal cancer screening, in the state of Nebraska, as well as the need for improved access to general health care for rural minority populations. The sessions also highlighted the important work that is being done by local community organizations to support cancer patients and their caregivers emotionally and financially.