

K A N S A S



Kansas Comprehensive Cancer Control & Prevention Partnership Survey of Cancer Centers

Introduction

The Kansas Comprehensive Cancer Control and Prevention (CCC) Partnership is a collaborative group of more than 200 members across Kansas working to reduce the risk and burden of cancer in the state. The Partnership published the Cancer Plan in March 2005 and immediately began working on the goals and objectives outlined in the document to make an impact on the problems and issues faced by cancer patients, survivors, caregivers and families. Each year in Kansas more than 13,000 individuals are diagnosed with cancer, beginning the process of making major health decisions, seeking quality care and accessing the many and varied services available to patients. One of the issues identified in the Plan was the need for a patient navigator or advocate that could assist in the continuum of cancer care.

In March 2009 the CCC Partnership invited 43 Cancer Centers, identified as providing cancer patient services across the state of Kansas, to complete a survey to help identify needs, gaps and barriers to quality services in the state. The survey focused on gathering information about patient services pertinent to those affected by cancer as they navigate their way through the health care system. The ultimate goal of the survey is to work toward establishing Patient Navigator programs in Kansas' health care centers statewide.

The objectives of the survey were:

- To assess the level of coverage of cancer diagnosis and treatment services in Kansas,
- To identify strengths and weaknesses of the current cancer care delivery system,

- To inform the cancer centers about the existing services, and
- To generate pertinent information that could support a patient navigation program in Kansas in the future.

Methodology

A web-based 33 question survey was sent to the administration of 43 Cancer Centers in Kansas during summer of 2009. The survey monkey, a web based survey tool, was used for the administration of this survey. The data and research work group members drafted the questionnaire. Survey questionnaire was finalized after incorporation of feedback from the CCC partnership members. A total of 19 Centers returned the survey, a 44 % response rate. This report is summarizing the responses obtained from these 19 centers. The categories on which data were collected through this survey are as follows:

- 1- Availability of cancer screening services at the facility
 - Availability of onsite screening services
 - Availability of satellite screening services
- 2- Location of screening services
- 3- Cancer diagnosis and treatment at the facility
 - Access to specialist by cancer centers for cancer diagnosis and treatment
 - Availability of cancer diagnosis procedure
 - Availability of cancer treatments/services at the facility
 - Location to receive radiation therapy
- 4- Support services for cancer patients at the facility
 - Financial assistance
 - Transportation assistance
 - Translation assistance
 - Disability friendly access to centers
 - Resource assistance
 - Access to information
 - Referral of terminally ill patients to hospice services
 - Opportunity to participate in clinical trials
 - Access to palliative care
 - Access to patient navigator
- 5- Patient navigation for cancer patients at the facility
 - Number of patient navigator
 - Qualification of patient navigator
 - Employment status of patient navigator
 - Amount of time dedicated to patient navigation

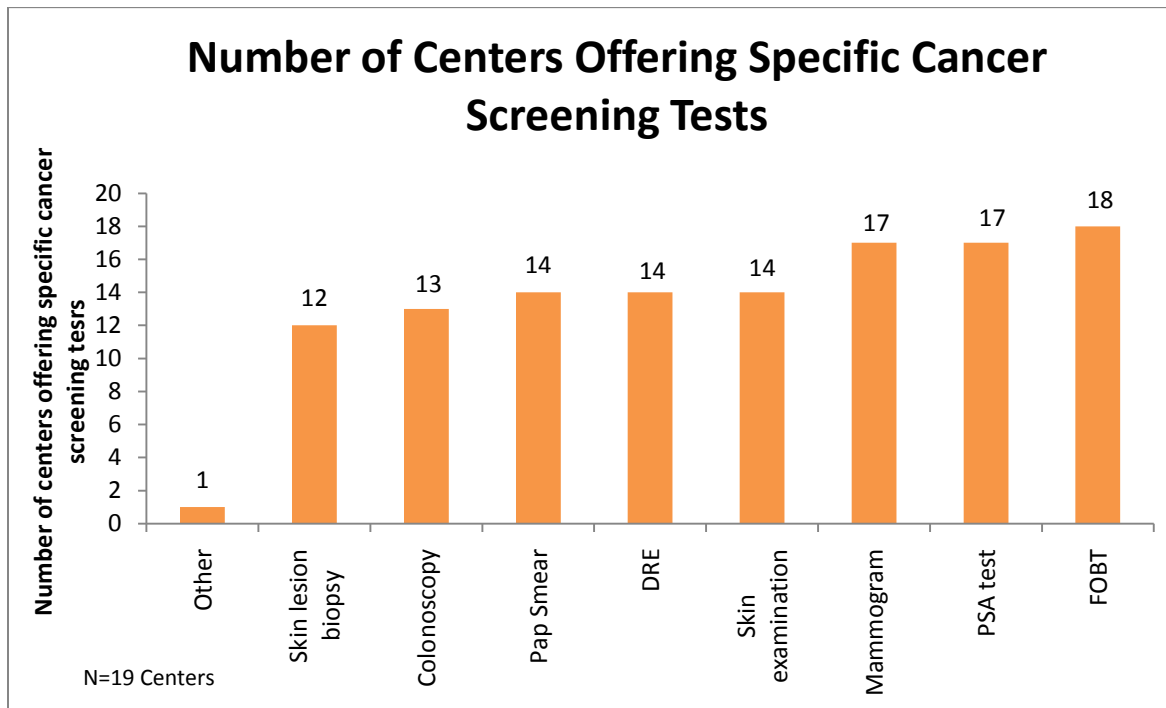
- 6- Availability of cancer related support groups
 - Types of cancer addressed by the support groups

Summary of the responses provided by the centers participating in the survey:

SCREENING SERVICES FOR CANCER (N=19)

This section evaluates the availability of screening services in Kansas. Based on this survey it is estimated that:

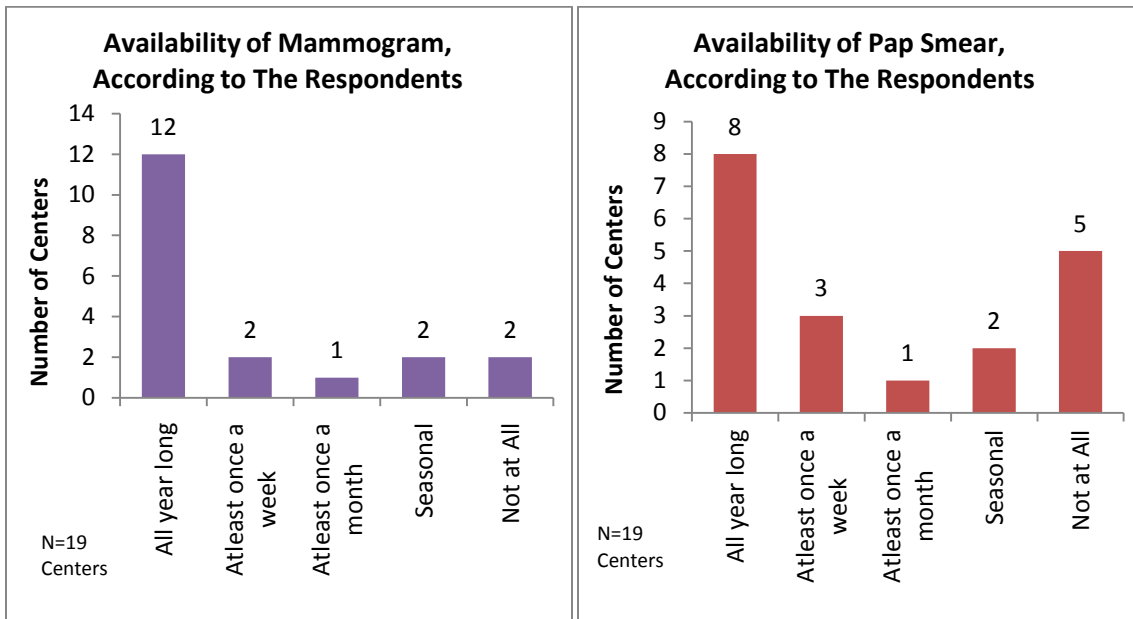
- Mammography is offered by 17 of 19 centers participated in the survey (89.5%)
- Pap test is offered by 14 of 19 centers participated in the survey (73.7%)
- Prostate Specific Antigen test is offered by 17 of 19 centers participated in the survey (89.5%)
- Digital Rectal Exam is offered by 14 of 19 centers participated in the survey (73.7%)
- Fecal Occult Blood Test is offered by 18 of 19 centers participated in the survey (94.7%)
- Colonoscopy is offered by 13 of 19 centers participated in the survey (68.4%)
- Skin examination is offered by 14 of 19 centers participated in the survey (73.7%)
- Biopsy of skin lesions is offered by 12 of 19 centers participated in the survey (63.2%)
- One out of 19 centers participated in the survey responded that they offer other tests such as genetic counseling and cancer survivorship.



All 19 Cancer Centers that participated in the survey offered some cancer screening services. FOBT, PSA test, and Mammogram are the most frequently offered screening tests. Advanced screening tests, skin lesion biopsy, and colonoscopy are among the least offered screening tests.

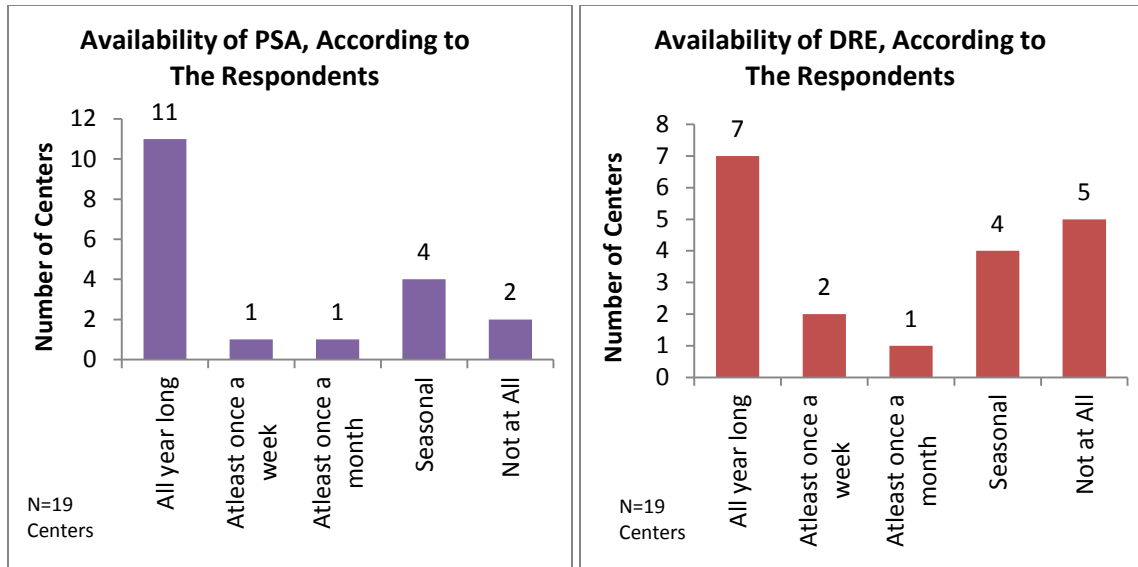
Availability of Onsite Screening Services (N=19)

Out of 19 centers that participated in the survey, mammogram was offered every working day, all year long at 12 centers (63%); at least once a week, but not every day at 2 centers (11%); at least once a month, but less than once a week at one center (5%); on a seasonal basis at two centers (11%); and not at all at two centers (11%).



Out of 19 centers that participated in the survey, pap smear tests was offered every working day, all year long at eight centers (42%); at least once a week, but not every day at three centers (16%); at least once a month, but less than once a week at one center (5%); on a seasonal basis at two centers (11%); and not at all at five centers (26%).

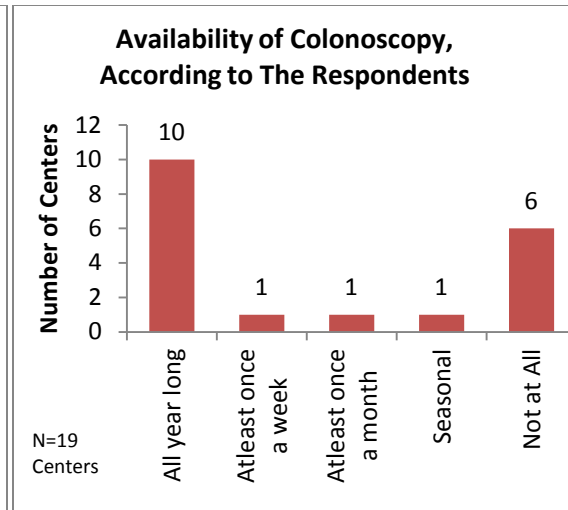
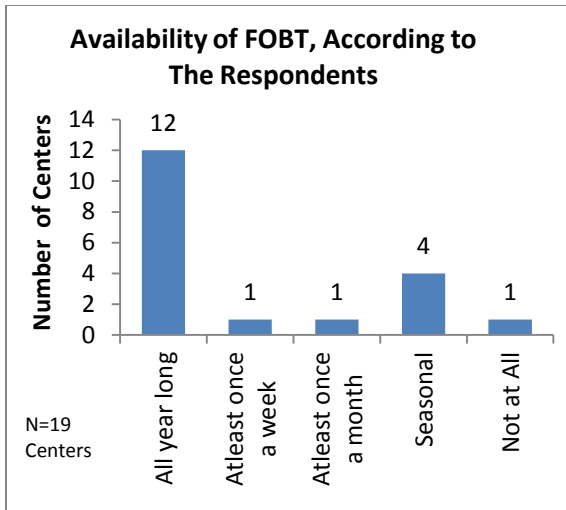
Out of 19 centers that participated in the survey, Prostate Specific Antigen (PSA) test was offered every working day, all year long at eleven centers (58%); at least once a week, but not every day at one center (5%); at least once a month, but less than once a week at one center (5%); on a seasonal basis at four centers (21%); and not at all at two center (11%).



Out of 19 centers that participated in the survey, Digital Rectal Exam (DRE) was offered every working day, all year long at seven centers (37%); at least once a week, but not every day at two centers (11%); at least once a month, but less than once a week at one center (5%); on a seasonal basis at four centers (21%); and not at all at five centers (26%).

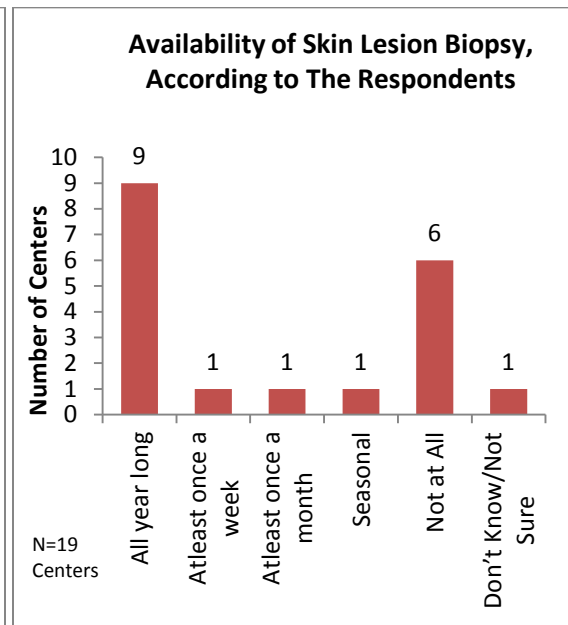
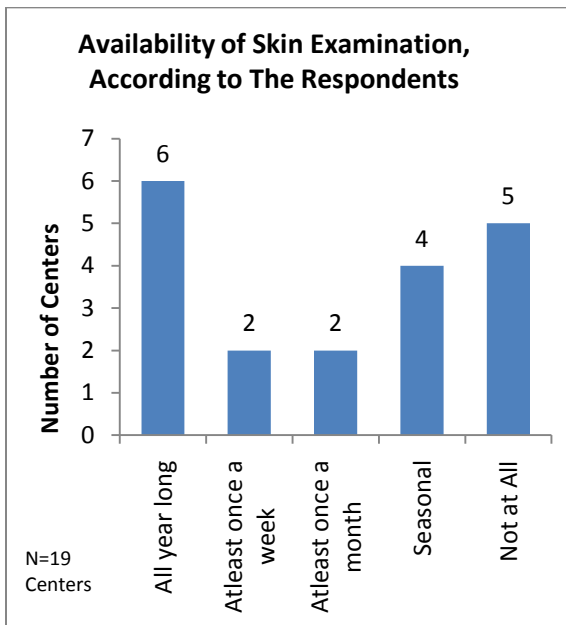
Out of 19 centers that participated in the survey, Fecal Occult Blood Test (FOBT) was offered every working day, all year long at twelve centers (63%); at least once a week, but not every day at one center (5%); at least once a month, but less than once a week at one center (5%); on a seasonal basis at four centers (21%); and not at all at one center (5%).

Out of 19 centers that participated in the survey, Colonoscopy was offered every working day, all year long at ten centers (53%); at least once a week, but not every day at one center (5%); at least once a month, but less than once a week at one center (5%); on a seasonal basis at one center (5%); and not at all at six centers (32%).



Out of 19 centers that participated in the survey, Skin examination was offered every working day, all year long at six centers (32%); at least once a week, but not every day at two centers (11%); at least once a month, but less than once a week at two centers (11%); on a seasonal basis at four centers (21%); and not at all at five centers (26%).

Out of 19 centers that participated in the survey, Skin lesion biopsy was offered every working day, all year long at nine centers (47%); at least once a week, but not every day at one center (5%); at least once a month, but less than once a week at one center (5%); on a seasonal basis at one center (5%); not at all at six centers (32%); and one center (5%) was not sure or did not know.



Availability of Satellite Screening Services (N=5)

Out of 19 Centers participated in the survey; five centers have satellite screening services.

These responses are based on responses provided by the five facilities.

Mammogram was offered every working day, all year long at three out of five centers; not at all at one center; and one center did not respond to this question.

Pap smear test was offered every working day, all year long at two out of five centers; not at all at two out of five centers; and one center did not know or was not sure.

Prostate Specific Antigen (PSA) test was offered every working day, all year long at four out of five centers; and not at all at one out of five centers.

Digital Rectal Exam (DRE) was offered every working day, all year long at three out of five centers; not at all at one out of five centers; and one center did not know or was not sure.

Fecal Occult Blood Test (FOBT) was offered every working day, all year long at four out of five centers; and not at all at one out of five centers.

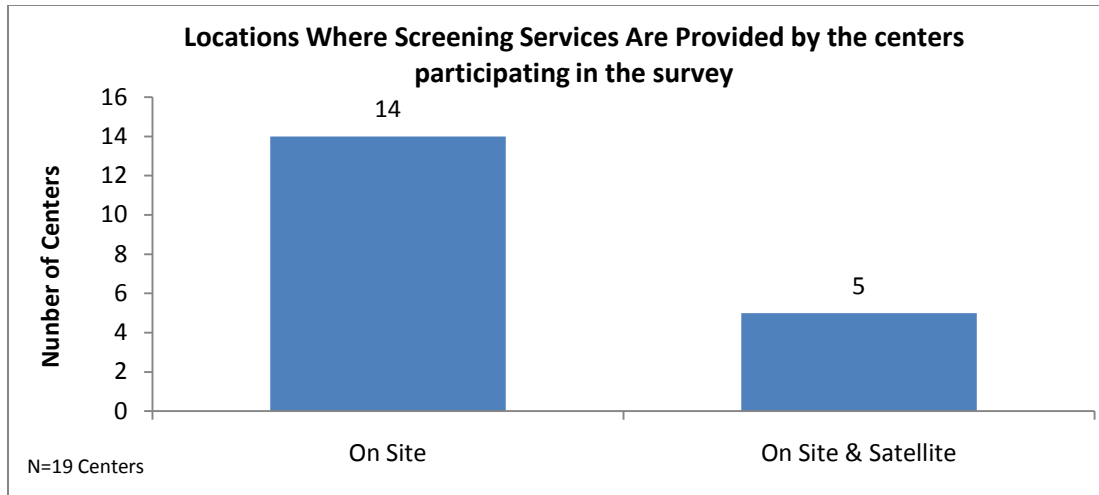
Colonoscopy was offered every working day, all year long at three out of five centers; not at all at one out of five centers; and one center did not know or was not sure.

Skin examination was offered every working day, all year long at two out of five centers, not at all at two out of five centers; and at least once a month, but less than once a week at one out of five centers.

Skin lesion biopsy was offered every working day, all year long at three out of five centers; and not at all at two out of five centers.

Location of Screening Services (N=19)

Nineteen centers responded to these question related to location of screening services. Fourteen out of nineteen centers (74%) surveyed provide their services on site only; while five out of nineteen centers (26%) provide services at both on-site and at satellite locations.



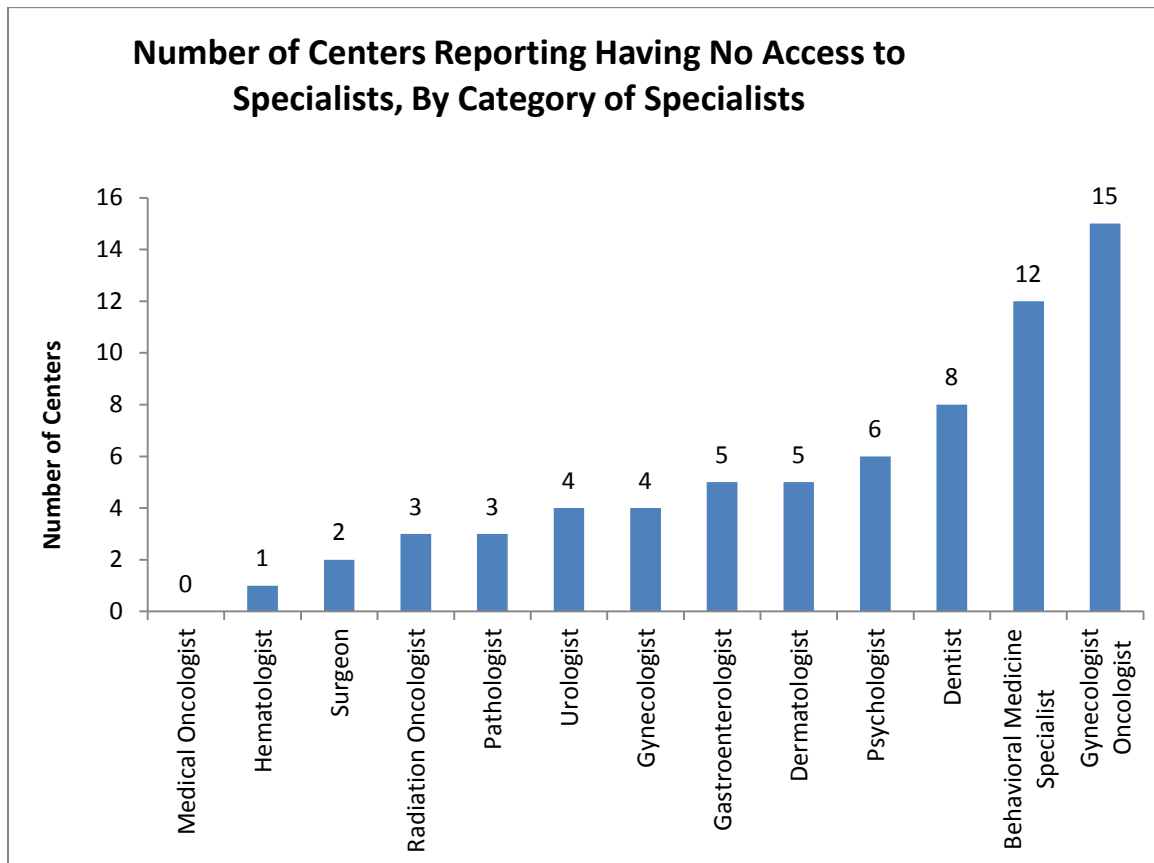
Access to Specialists by Cancer Centers for Cancer Diagnosis and Treatment:

Table 1: Level of access to specialists as reported by survey respondents (N=19)

	On Staff	Visiting Regularly	Visiting Sporadically	No Access
Hematologist	13 (68.4%)	5 (26.3%)	0 (0.0%)	1 (5.3%)
Urologist	10 (52.6%)	5 (26.3%)	0 (0.0%)	4 (21.1%)
Surgeon	16 (84.2%)	1 (5.3%)	0 (0.0%)	2 (10.5%)
Medical Oncologist	14 (73.7%)	5 (26.3%)	0 (0.0%)	0 (0.0%)
Radiation Oncologist	13 (68.4%)	3 (15.8%)	0 (0.0%)	3 (15.8%)
Gynecologist	12 (63.2%)	3 (15.8%)	0 (0.0%)	4 (21.1%)
Gynecologist Oncologist	2 (10.5%)	1 (5.3%)	1 (5.3%)	15 (78.9%)
Pathologist	12 (63.2%)	3 (15.8%)	1 (5.3%)	3 (15.8%)
Dentist	6 (31.6%)	3 (15.8%)	2 (10.5%)	8 (42.1%)
Gastroenterologist	7 (36.8%)	4 (21.1%)	2 (10.5%)	6 (31.6%)
Dermatologist	7 (36.8%)	5 (26.3%)	1 (5.3%)	6 (31.6%)
Psychologist	8 (42.1%)	3 (15.8%)	1 (5.3%)	7 (36.8%)
Behavioral Medicine Specialist	4 (21.1%)	1 (5.3%)	2 (10.5%)	12 (63.2%)

Nineteen centers reported to question related to access to specialist by cancer centers for cancer diagnosis and treatment.

Access to gynecologist oncologists and behavioral medicine specialist seems to be most difficult for the centers. Only four out of nineteen centers have access to gynecologist oncologist and seven out of nineteen centers have access to behavioral medicine specialist. On the other hand, they reported having the greatest access to medical oncologist and hematologist.



Availability of Breast cancer diagnostic procedures at cancer centers (Stereotactic breast cancer needle biopsy and ultra sound guided breast core needle biopsy) N=19

According to the nineteen centers participating in the survey, 11 centers (57.9%) perform stereotactic breast cancer needle biopsy for diagnosis at their facility and 6 centers (31.6%) do not perform the procedure. The respondents from two centers (10.5%) were not sure or did not know whether their facilities perform the procedure or not.

Fourteen centers (73.7%) perform Ultrasound guided breast core needle biopsy for diagnosis and four centers (21.1%) do not perform this procedure. The respondent from one center did not know whether the center perform the procedure or not.

Availability of Cancer Treatments (N=19)

Nineteen centers responded to the question regarding availability of Cancer treatment at their centers.

According to the respondents, chemotherapy was available at 18 out of 19 centers (94.7%). Chemotherapy was not available at one center.

Radiotherapy was available at 13 out of 19 centers (68.4%). Five centers did not provide the radiotherapy treatment and respondent from one center did not know whether the center provides the radiotherapy treatment or not.

Nutrition services were available at 17 out of 19 centers (89.5%). One center did not provide the service and respondent from one center did not know whether the center provides nutritional services or not.

Surgery was available 16 out of 19 centers (84.2%). Three centers did not provide surgical treatment.

Social Services were offered at 15 out of 19 centers (78.9%). Three centers did not provide social services and respondent from one center did not know whether their center provides social services or not.

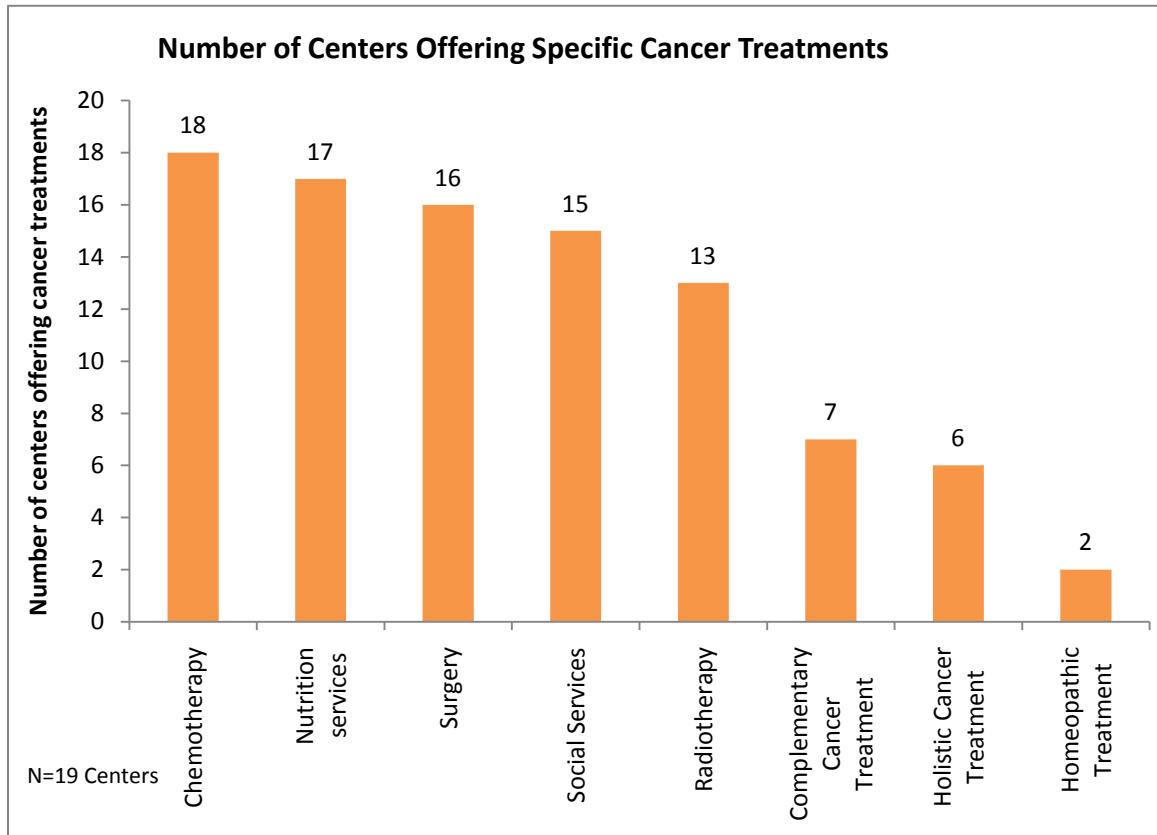
Complementary cancer treatment was offered at 7 out of 19 centers (36.8%). Eleven centers out of nineteen did not provide complementary cancer treatment and respondent from one center did not know whether the center provides complementary cancer treatment or not.

Holistic cancer treatments were offered at 6 out of 19 centers (31.6%). 13 centers did not provide holistic cancer treatment.

Homeopathic treatments were offered by 2 out of 19 centers (10.5%). 16 centers did not provide homeopathic treatment and one center did not know if their center provided homeopathic treatment.

When asked about treatments offered at the centers other than the one listed, 13 centers skipped the question and six responded. Other treatments like lymphedema massage, lymphedema management, lymphedema therapy, and physical therapy were offered at four out of six centers that responded. One center responded that they did not provide any other treatment than listed and respondent from one center did not know whether the center provided any other treatment or not.

Assistance to Cancer Patients (N=19)



Radiation Therapy (N=19)

Out of 19 centers that participated in the survey, 13 centers provide the patients with radiation therapy on site at their centers. Patients from the four centers who need radiation therapy receive it at in-state, non-affiliated facilities. And patients from the two centers receive it from other locations that have radiation therapy facilities.

Financial Assistance (N=19)

Nineteen centers responded to the questions regarding provision of financial assistance to the patients.

When asked about the availability of financial resources at their facility for patients in need of care with no insurance or with high, unmet deductibles, respondent from 14 centers (73.7%) reported “yes”; and respondents from 2 centers (10.5%) reported “no”; respondents from three centers (15.8%) responded don’t know or not sure.

Transportation Assistance (N=19)

Nineteen centers responded to the questions regarding provision of transportation services to the patients.

Respondents from 15 centers (78.9%) reported their patients have access to taxi services.

Respondents from 13 centers (68.4%) reported their patients have access to public city bus services.

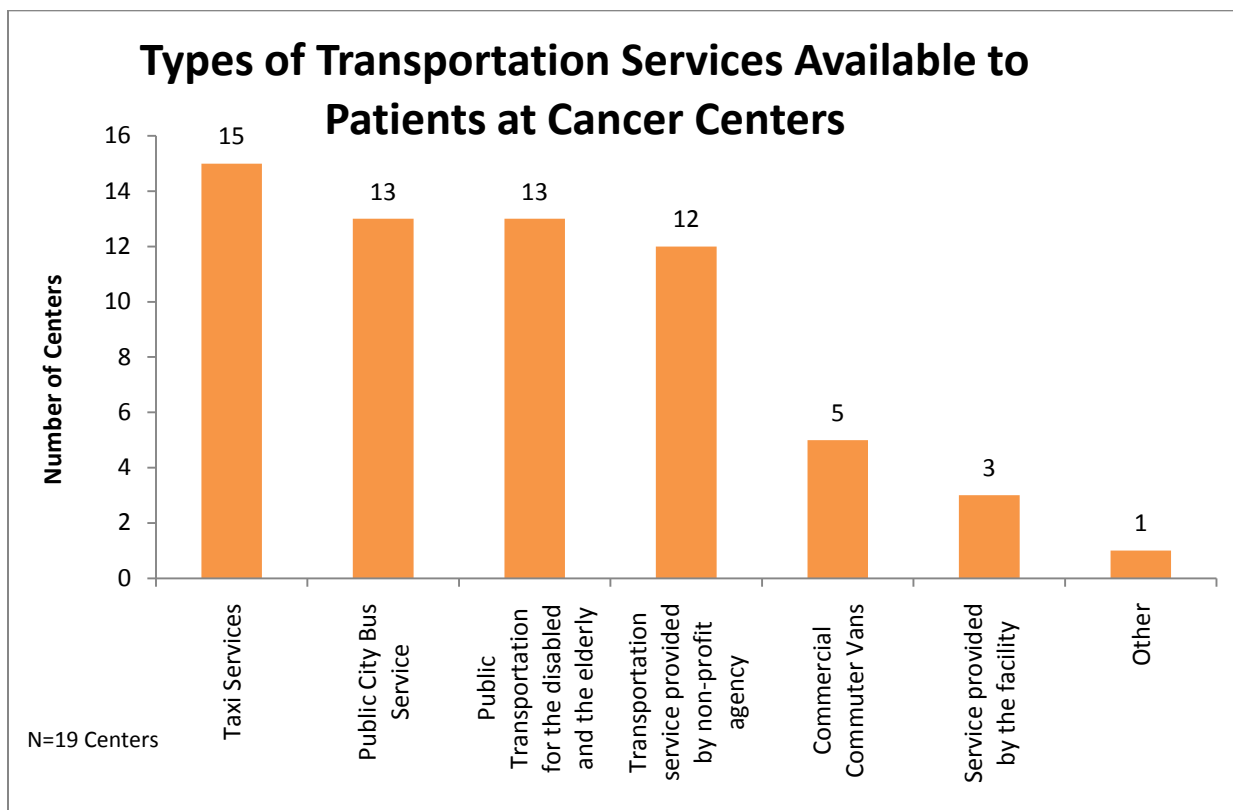
Respondents from 13 centers (68.4%) reported their patients have access to public transportation for the disabled and the elderly.

Respondents from 12 centers (63.2%) reported their patients have access to transportation services provided by non-profit agency.

Respondents from 5 centers (26.3%) reported their patients have access to commercial commuter vans.

Respondents from 3 centers (15.8%) reported their patients have access to services provided by their facility.

Other types of services offered at one of the centers were for profit transportation services and services offered by American Cancer Society.

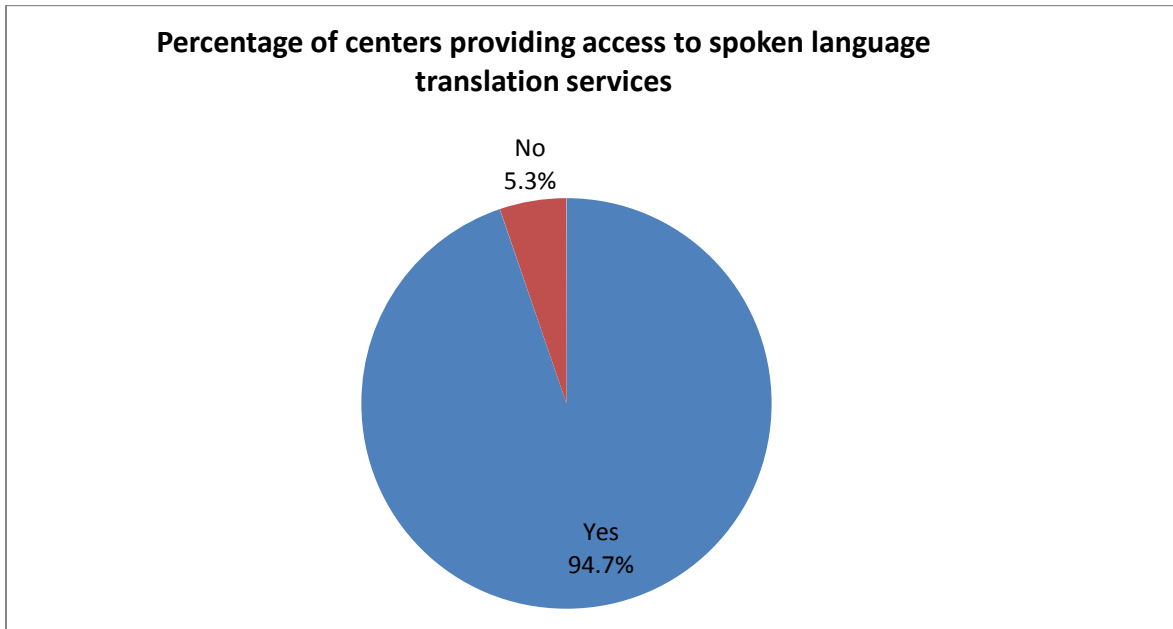


Translation Assistance (N=19)

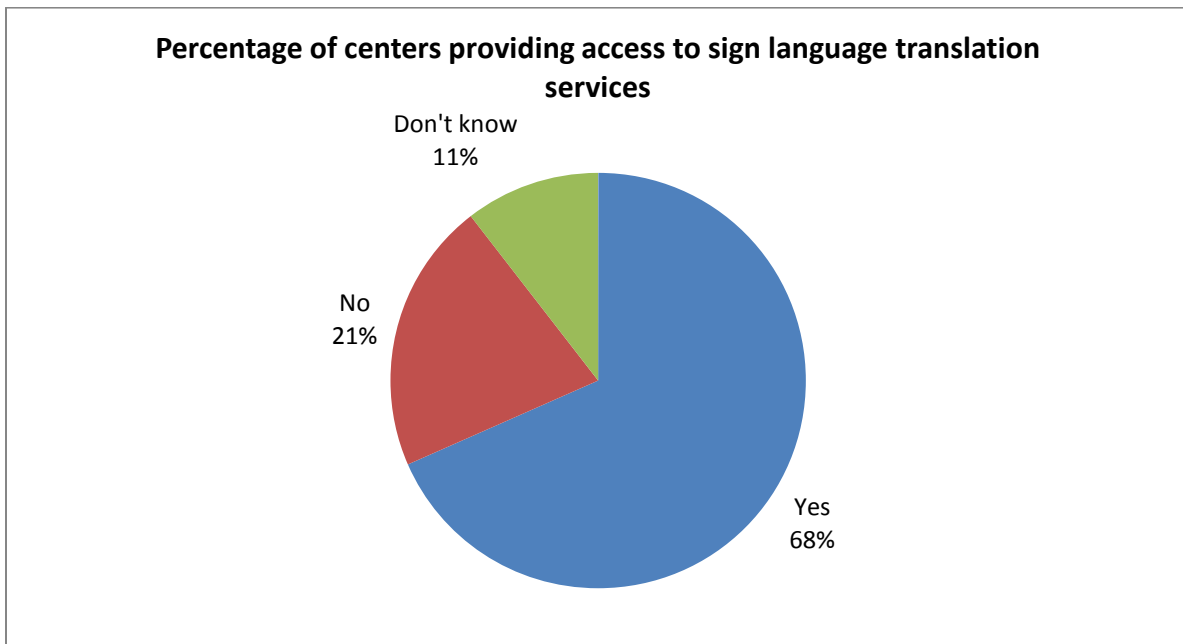
Nineteen centers responded to the questions regarding provision of translation assistance to the patients.

When asked if patients receiving care at their facility have access to translation services that they have available, 18 centers (94.7%) reported that their patients use the spoken

languages while one center (5.3%) reported that it does not have access to spoken language translation services.



Thirteen centers (68.4%) reported that their centers had sign language translation services available to the patients whereas four centers (21.1%) reported they do not have this service. The respondents from two centers (10.5%) did not know about the status of this service available at their centers.



Disability friendly access (N=19)

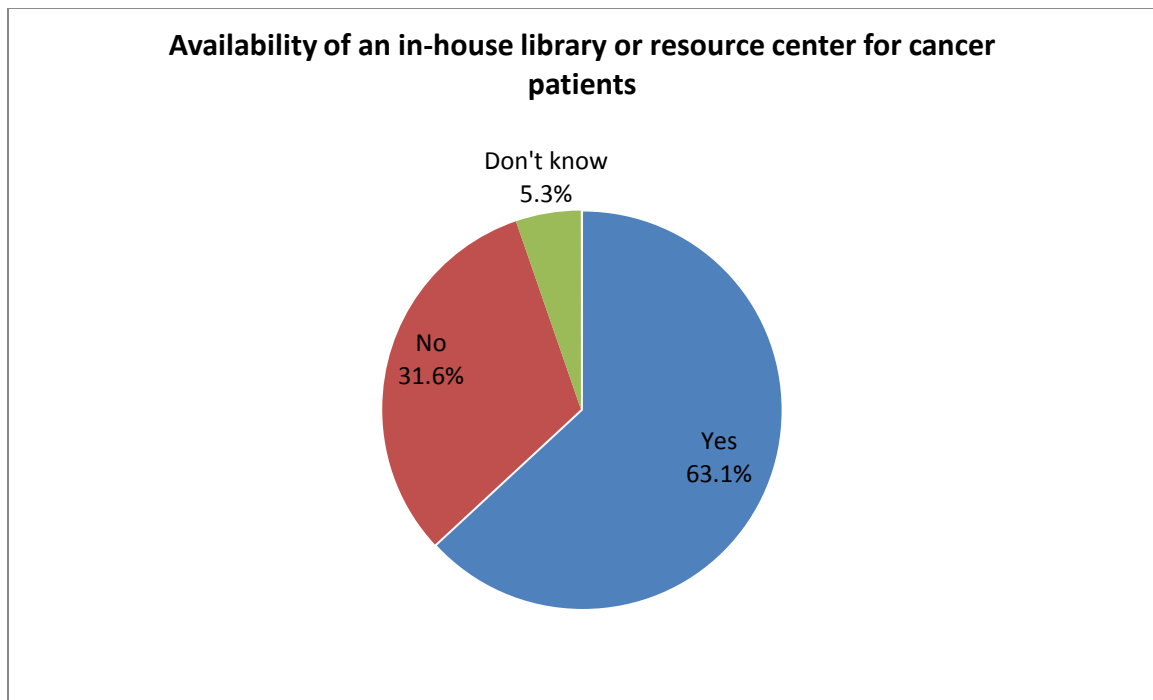
Nineteen centers responded to the questions regarding provision of disability friendly access to the centers for the patients.

When asked if they have facility easily accessible for someone who uses a mobility device (e.g., wheelchair, scooter, cane) or who has mobility limitations, all nineteen centers reported that their facility has easy access for someone who has mobility limitations.

Resource Assistance (N=19)

Nineteen centers responded to the questions regarding provision of in-house library or resource center to the patients.

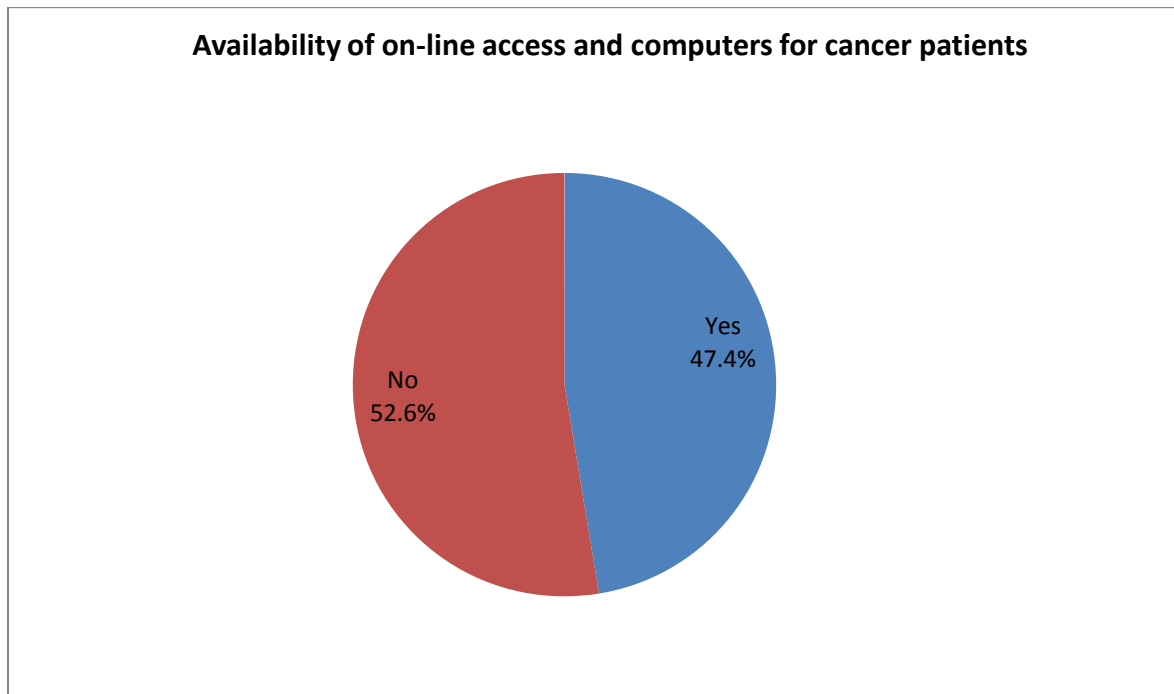
When asked if they have an in-house library or resource center where cancer patients can have access to information, 12 centers (63.1 %) responded that they have an in-house library, 6 centers (31.6%) responded they do not have the library and resource center and respondent from one center (5.3%) was unsure or did not know about availability of this assistance at the center.



Access to Information (N=19)

Nineteen centers responded to the questions regarding provision of on-line access and computers to the patients.

When asked if they have on-line access and computers for cancer patients to use, 9 centers (47.4%) reported they do have on-line access for patients and 10 centers (52.6%) reported that they do not have internet access for patients.



Enrollment in Clinical Trials (N=19)

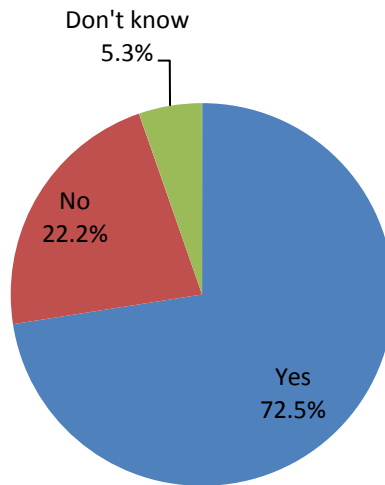
Nineteen centers responded to the questions regarding provision of enrollment in clinical trials to the patients.

When asked if patients have an opportunity to enroll in cancer treatment clinical trials at their facility, 8 centers (42.1%) reported that they routinely offer patients to participate in cancer treatment clinical trials, whereas 11 centers (57.9%) reported they don't routinely enroll patients in cancer treatment clinical trials.

When asked if patients have an opportunity to enroll in cancer control/ symptom management trials at their facility, 6 centers (31.6%) reported that they routinely offer patients to participate in cancer control/ symptom management trials whereas 13 centers (68.4%) reported that they don't routinely enroll patients in cancer control/ symptom management trials.

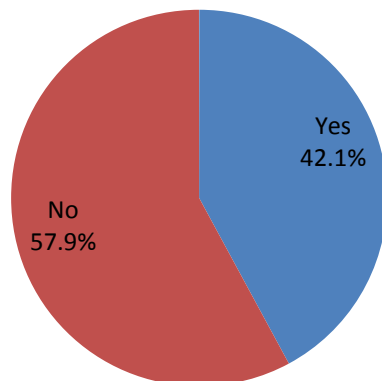
When asked if patients have an opportunity to enroll in non-cancer related clinical trials at their facility, 4 centers (22.2%) reported that they routinely offer patients to participate in non-cancer related clinical trials whereas 13 centers (72.5%) reported that they don't offer patients to participate in non-cancer related clinical trials. The respondent from one center did not know that their facility routinely enroll patients in non-cancer related clinical trials or not.

Availability of an opportunity to enroll in cancer-related clinical trials



When asked if their facility has staff dedicated to the management of cancer-related clinical trials, eight out of nineteen centers (42.1%) reported that their facility has staff dedicated to the management of cancer-related clinical trials; and 11 centers (57.9%) reported that their facility does not have the staff dedicated to the management of cancer-related clinical trials.

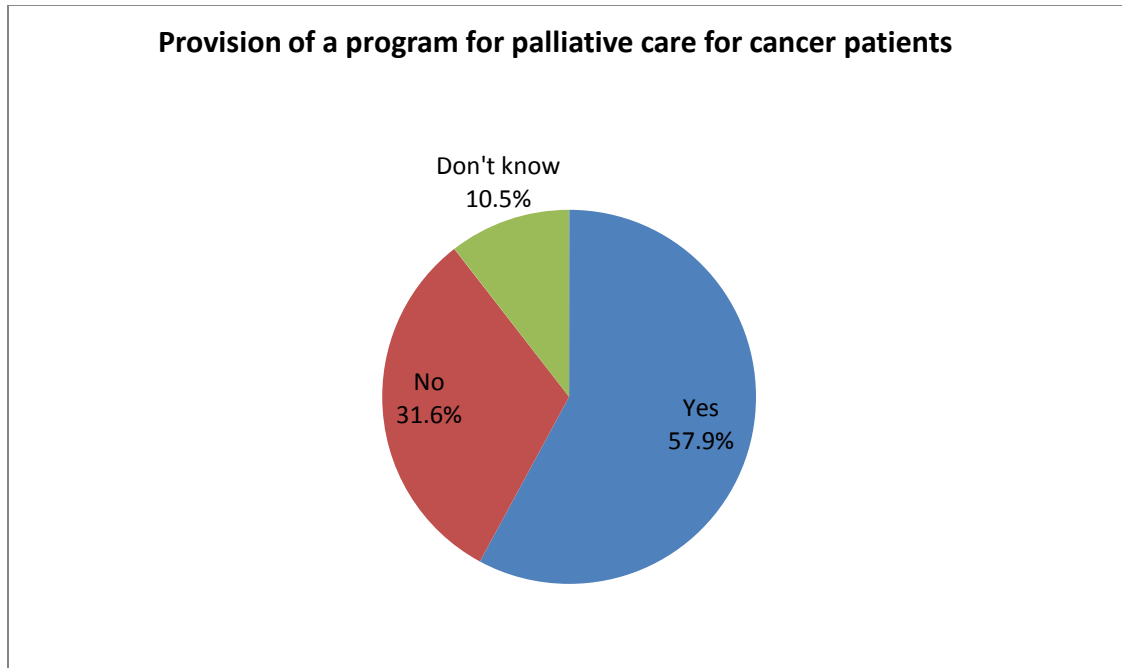
Management of cancer-related clinical trials at the center



Access to Palliative Care (N=19)

Nineteen centers responded to the questions regarding availability of a program for palliative care for cancer patients.

When asked if their facility has a program for palliative care for cancer patients, 11 centers (57.9%) responded that their facility has a program for palliative care for cancer patients, six centers (31.6%) reported they don't have such a program; respondents from two centers (10.5%) were unsure or did not know if their facility have palliative care programs.



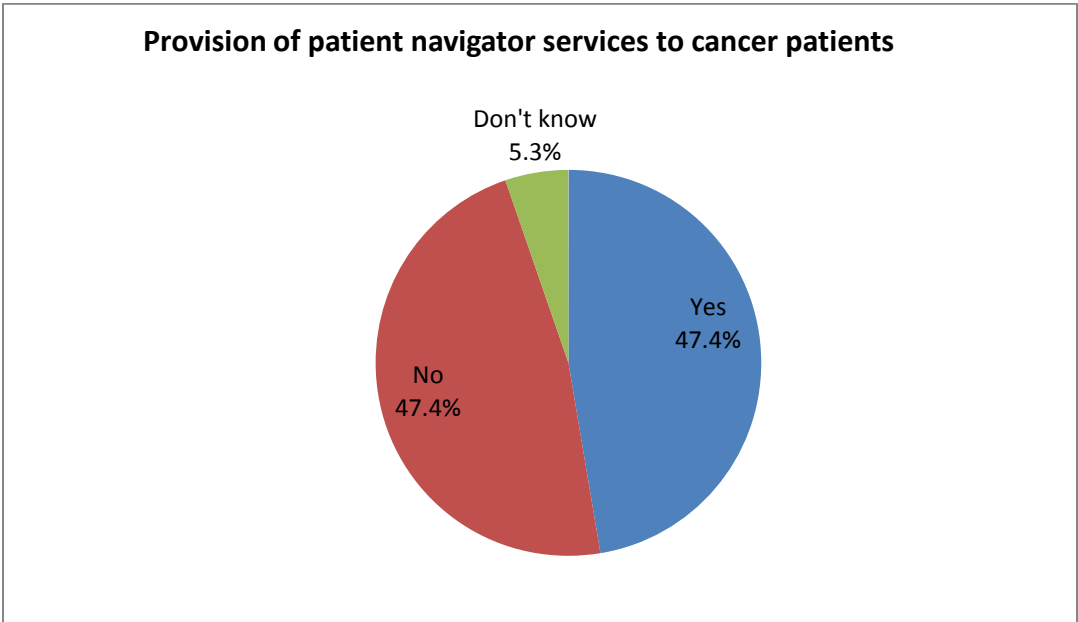
Survey participants were further asked if their facility refer terminally ill patients to hospice services. All 19 centers (100%) reported referring terminally ill patients to hospice services.

Access to Patient Navigation Program (N=19)

Patient navigators are health care professionals whose primary focus is to assist cancer patients, caregivers and families in “bridging the gaps” within the health care system and decreasing barriers to care by utilizing resources.

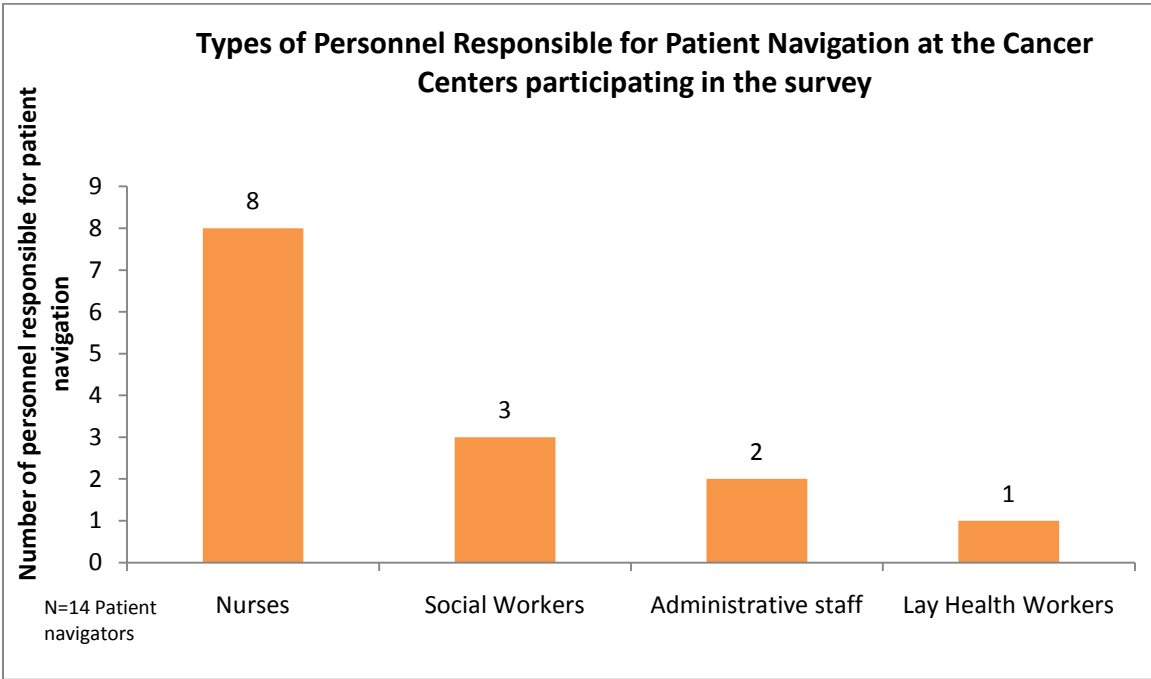
Nineteen centers responded to the questions regarding availability of the patient navigator services to cancer patients.

Nine centers (47.4%) reported that their facility provides patient navigator services to cancer patients whereas 9 centers (47.4%) said they do not provide such services. The respondent from one center (5.3%) was unsure or did not know if the facility provides patient navigation services or not.

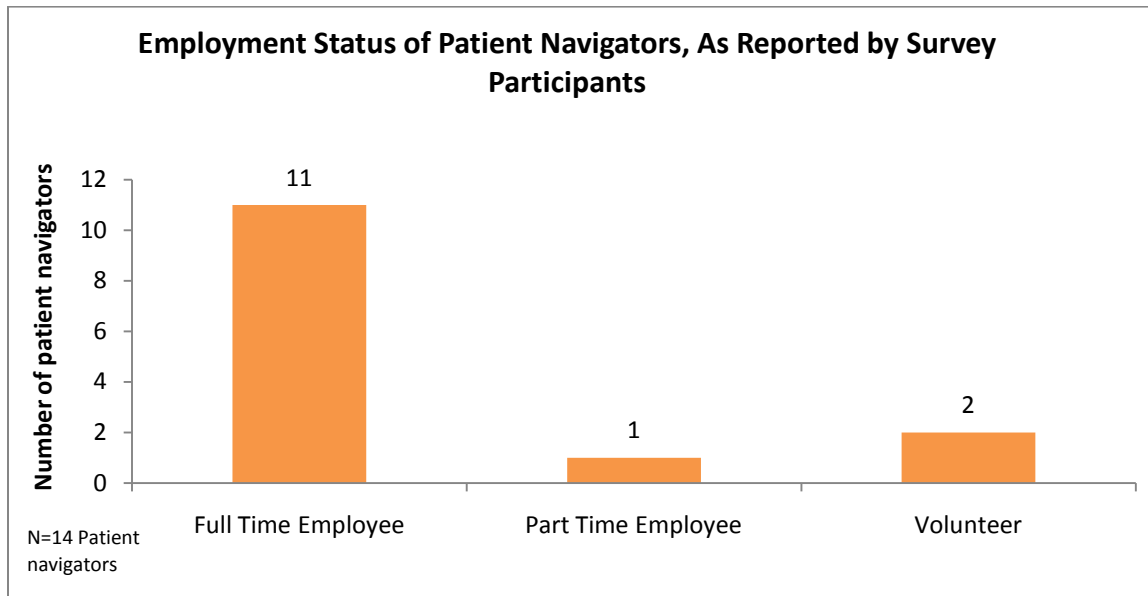


Out of those nine centers that reported having patient navigators, one center had three staff patient navigator, three centers had two patient navigators and five centers had one patient navigator. Thus in nine centers there were 14 patient navigators.

Those nine centers that reported that their facility provided patient navigator services to cancer patients were further asked about the qualifications of the patient navigators. Out of 14 patient navigators eight were nurses, three were social workers, two were administrative staff and one was a lay health worker.



Those who reported having patient navigation services at their facility were also asked about the employment status of the current patient navigators. They responded that eleven patient navigators were full time employee. One patient navigator was a part time employee. Two patient navigators' were volunteers.



When asked about the time dedicated to patient navigation, survey showed that out of fourteen patient navigators, five patient navigators dedicated 100% of their time; three patient navigators dedicated 90% to 99% of their time; one patient navigator dedicated 70% to 79% of the time; one patient navigator dedicated 30% to 39% of the time; one patient navigator dedicated 20% to 29% of the time and three patient navigators dedicated 10% to 19% of their time in patient navigation.

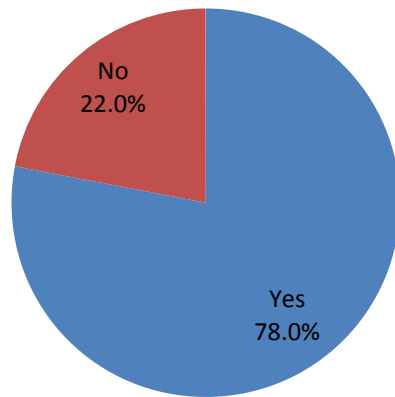
When asked if the facility staff providing patient navigation, had a “Patient Navigator” as their title, three centers reported they had a staff with a “Patient Navigator” as their title and six centers reported they do not have a staff with a “Patient Navigator” as their title.

One out of six centers that reported they do not have a staff with a “Patient Navigator” as their title refer them as “Patient Advocate”.

Availability of Cancer-Related Support Groups (N=9)

Survey respondents were asked if they provide support groups led by health professionals for the cancer patients at their facility. Nine centers responded to this question, seven centers (78%) stated that they provide support groups at their facility, two centers (22.2%) said they don't offer support groups led by health professionals at their facility.

Provision of support groups led by health professionals for cancer patients

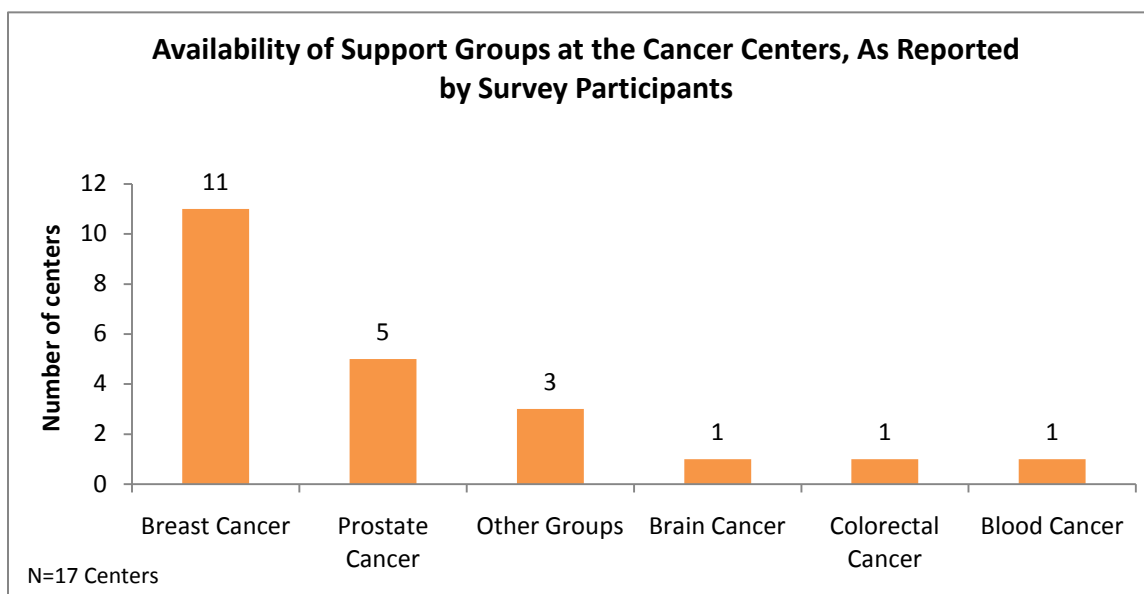


Type of cancer addressed by the support groups (N=17)

Seventeen centers responded to the questions regarding availability of a support groups for different cancer patients receiving care at their facility.

Out of seventeen centers, 14 centers (82.4%) reported that they offer general support groups at their centers. Out of seventeen centers, breast cancer support groups were offered at 11 centers (64.7%); prostate cancer support groups at 5 centers (29.4%); brain cancer support groups at one center (5.9%), colorectal cancer support groups at one center (5.9%) and other groups such as ovarian cancer, head and neck cancer and blood and marrow cancer at three centers (17.6%).

Availability of Support Groups at the Cancer Centers, As Reported by Survey Participants



That completes the survey report of the Cancer Centers located in the state of Kansas. If you would like further details or have any questions about the report, please feel free to contact the Kansas Cancer Partnership at 785-296-1228 or e-mail BVanCortlandt@kdheks.gov

Additional information and resources about cancer in Kansas can be obtained on the Cancer Partnership web site www.cancerkansas.org