THE UNIVERSITY OF KANSAS
CANCER CENTER

2018 Cancer Program Annual Report

Incorporating the 2017 Cancer Registry statistical review

NCI
Designated Cancer Center

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Chairman's report

Joshua M.V. Mammen, MD, PhD, FACS

I am pleased to share our 2018 Cancer Center Annual Report. The American College of Surgeons Commission on Cancer (CoC), which was established in 1922, has more than 1,500 participating hospitals in the United States and Puerto Rico. This represents only 30 percent of all healthcare institutions but more than 70 percent of all new cancer patients. The CoC provides important metrics and tools for cancer centers to improve quality and personalize cancer care.

CoC accreditation signals to patients access to the full scope of subspecialty care and services. For patients and their families, accreditation is an important measure of quality care and a commitment by The University of Kansas Cancer Center to continually improve the care provided to cancer patients. The CoC accredited The University of Kansas Cancer Center for three years with commendation during the most recent evaluation (we look forward to a site visit in late 2019). In addition, the U.S. News & World Report rankings once again listed The University of Kansas Cancer Center as one of the nation's best cancer programs for the seventh consecutive year. The University of Kansas Health System is also accredited by the National Accreditation Program for Breast Centers. Lastly, we received renewal of our National Cancer Institute designation for five years and an overall score of outstanding. Our cancer center is one of 70 NCI-designated cancer centers in the country.

As the number of patients we care for continues to increase, the need for additional facilities grows. The new inpatient facility, Cambridge Tower A, opened in November 2017 and has operated at full steam from day one. The new tower features the latest surgical, interventional and diagnostic facilities to enable our physicians to continue to provide the most advanced care for our cancer patients. Additionally, the tower will include expanded inpatient treatment facilities for blood and marrow transplant patients to receive groundbreaking and individualized care. New facilities also opened at our Indian Creek campus, where The Women's Cancer Center has expanded access to cancer care to patients who reside in Johnson County.

The University of Kansas Cancer Center is dedicated to the eradication of cancer. We continue to offer our patients many new options for cancer treatment and prevention. As we pursue this goal together, we will conduct new research, translate our findings into innovative therapies and investigate new ways to prevent and diagnose cancer. Together, we will continue to ensure that the patients and families we serve receive the highest level of care from diagnosis through treatment and survivorship.

Joshua M.V. Mammen, MD, PhD, FACS

The University of Kansas Cancer Center

Cancer Committee Chair

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NATIONAL CANCER
2018-19

Cancer Registry Report

The University of Kansas Cancer Registry operates under the direction and guidance of the Cancer Committee and is located within Health Information Management. The Cancer Registry at our facility became accredited by the American College of Surgeons in 1934, and has maintained accreditation since. The reference date for the organization is 2004; however, the current electronic database contains data pertaining to patient demographics, cancer diagnoses, treatment information, staging and outcomes that go back to 1947. More than 107,000 cases have been added to the electronic registry for the accession years of 1947 through 2017. The registry participates in the American College of Surgeons Commission on Cancer Approvals Program. The Commission on Cancer, or CoC, provides standards and program review of healthcare facilities participating in its program.

The Cancer Registry has a staff of 20 certified tumor registrars. Cancer registrars collect and analyze all reportable and supplemental data; document Cancer Committee attendance and provide a cancer registry report for each meeting; document tumor conference information; supply reports of database information to medical and administrative staff; and report all cases to the Kansas Cancer Registry. Missouri cases are sent to the Missouri Cancer Registry. The registry also follows patients annually to determine health changes and provide information for survival and outcomes data.

The registrars collectively are members of the National Cancer Registrars Association, the Kansas Cancer Registrars Association and the Missouri State Tumor Registrars Association. All participate in educational events annually to maintain certification status, and the CTRs also attend a regional or national cancer conference at least every three years.

In 2017, 6,572 new cases were added to the registry and 5,871 were analytic (cases diagnosed and/or treated by one of the facilities of The University of Kansas Cancer Center for the patient's first course of treatment).

Cancer Registry data is available for multiple uses, including reporting results and evaluating quality care, as well as for research and educational purposes. Periodic follow-up is an important function of the registry. It increases the likelihood that patients will receive appropriate medical care for early detection and treatment of recurrent or new cancers. Early detection can potentially improve survival. Information obtained through follow-up provides researchers and clinicians with a means to study the disease process and efficacy of treatment modalities.

The follow-up rate for all analytic patients from the Cancer Registry reference date of 2004 is 85.24%. The CoC requires this rate to be at least 80%. The follow-up rate for analytic patients diagnosed within the last five years is 91.13%, which also meets CoC requirements for the five-year rate.

The Cancer Registry assists in the collection of the cancer conference data. Tumor conferences were presented on a weekly, bimonthly or monthly basis by an interdisciplinary team consisting of physician representatives from many different departments. The University of Kansas Cancer Center had 13 different cancer conferences in 2017. These events were tracked to provide consultative services to patients and help educate the medical staff and other healthcare professionals. National treatment guidelines, staging, prognostic indicators and clinical trial options are also discussed at these conferences. There were 394 tumor conferences held in 2017, which included multidisciplinary, breast, gastrointestinal, lymphoma and myeloma, head and neck, thoracic, bone marrow, thyroid, neuro-oncology, genitourinary, melanoma, sarcoma and gynecologic oncology. A total of 1,971 cases was presented at these various conferences.

The Cancer Registry is staffed by the following Health Information Management personnel:

Management

Theresa Jackson, RHIA – HIM director
Tim Metcalf, BS, CTR – manager
Ashley Wagner, CTR – lead registrar

Registrars

Kerry Barkman, RHIT, CTR
Christine Bartlett, RHIT, CTR
Elaine Casper, RHIT, CTR
Cari Dobosz, RHIT, CTR
Ian Duff, BS, RHIA, CTR
Kathrine Greene, RHIT, CTR
Sandra Haenchen, RHIT, CTR
Marsha Klein, BS, CTR
Joyce Knapp, RHIT, CTR
Julie Mammen, CTR
Garrett Neiss, RT, CTR
Mary Beth Piranio, BA, RHIT, CTR
Andrea Reynolds, RHIT, CTR
Marcelo Saculles, RHIT, CTR
Erin Salmon, RN, CTR
Terry Sigmund, CTR
Marji Smith, RHIT, CTR
Danielle Steele, RHIT, CTR

CP3R – Cancer Program Practice Profile Reports and RQRS – Rapid Quality Reporting System

Annually, Commission on Cancer CP3R Standards 4.4 and 4.5, plus monthly RQRS Standard 5.2, require The University of Kansas Health System performance rates for the measures listed below (Table 1), which reflect our benchmark compliance rates. This offers the opportunity to review data to ensure our performance rates reflect the quality care that we provide. The Cancer Committee reviews and has the opportunity to modify treatment strategies to benchmark our alignment with national quality guidelines and recommended best practices, which will allow us to ensure optimal patient outcomes.

Below are the retrospective measures we have reviewed through 2014. Measure types indicated as "surveillance treatment" are not yet a requirement for full assessment, but rather a vehicle to observe and assess patient care and outcomes. We have met and exceeded all accountability and quality improvement goals. RQRS monthly reviewed cases are indicated below by a single *. RQRS represents cases in certain measures for which we concurrently observe and submit patterns and trends of care.

Table 1

Bladder	Measure type	CoC std/ goal	2012	2013	2014
At least 2 lymph nodes are removed in patients under the age of 80 undergoing partial or radical cystectomy.	Surveillance	Not applicable	100.00	100.00	100.00
Radical or partial cystectomy or trimodality therapy (local tumor destruction/excision with chemotherapy and radiation) for clinical T234N0M0 patients with urothelial carcinoma of the bladder, first treatment within 90 days of diagnosis.	Surveillance	Not applicable	75.00	89.30	83.30
Neoadjuvant or adjuvant chemotherapy recommended or administered for patients with muscle invasive cancer undergoing radical cystectomy.	Surveillance	Not applicable	85.00	73.90	65.20
Breast					
Breast conservation surgery rate for women with AJCC clinical stage 0, 1 or 2 breast cancer.	Surveillance	Not applicable	45.90	44.00	41.70
Combination chemotherapy is recommended or administered within 4 months (120 days) of diagnosis for women under the age of 70 with AJCC T1cN0 or stage 1B-3 hormone-receptor-negative breast cancer. *Only monitored in RQRS – not officially held to a standard percent.	Surveillance	Not applicable	96.10	97.90	91.70
Image- or palpation-guided needle biopsy to the primary site is performed to establish diagnosis of breast cancer.	Quality improvement	4.5/ 80%	96.10	99.10	99.00
Radiation is administered within 1 year (365 days) of diagnosis for women under the age of 70 receiving breast conservation surgery for breast cancer. *RQRS	Accountability	4.4 & 5.2/ 90%	98.10	94.50	98.00

Breast (continued)	Measure type	CoC std/ goal	2012	2013	2014
Radiation therapy is recommended or administered following any mastectomy within 1 year (365 days) of diagnosis of breast cancer for women with >= 4 positive regional lymph nodes. *RQRS	Accountability	4.4 & 5.2/ 90%	95.70	94.20	92.00
Tamoxifen or third-generation aromatase inhibitor is recommended or administered within 1 year (365 days) of diagnosis for women with AJCC T1c or stage 1B-3 hormone-receptor-positive breast cancer. *RQRS	Accountability	4.4 & 5.2/ 90%	96.20	95.10	98.90
Cervix					
Radiation therapy completed within 60 days of initiation of radiation among women diagnosed with any stage of cervical cancer.	Surveillance	Not applicable	100.00	100.00	91.70
Use of brachytherapy in patients treated with primary radiation with curative intent in any stage of cervical cancer.	Surveillance	Not applicable	100.00	87.50	85.70
Chemotherapy administered to cervical cancer patients who received radiation for stages IB2-IV (Group 1) or with positive pelvic nodes, positive surgical margin and/or positive parametrium (Group 2)	Surveillance	Not applicable	85.70	80.00	100.00
Colon					
Adjuvant chemotherapy is recommended or administered within 4 months (120 days) of diagnosis for patients under the age of 80 with AJCC stage 3 (lymph-node-positive) colon cancer. *Only monitored in RQRS – not officially held to a standard percent.	Surveillance	Not applicable	93.80	90.00	97.30
At least 12 regional lymph nodes are removed and pathologically examined for resected colon cancer. *RQRS	Quality improvement	4.5 & 5.2/ 85%	100.00	93.00	97.20
Endometrium					
Chemotherapy and/or radiation administered to patients with stage 3C or 4 endometrial cancer.	Surveillance	Not applicable	80.00	80.80	100.00
Endoscopic, laparoscopic or robotic surgery performed for all endometrial cancer (excluding sarcoma and lymphoma) for all stages, except stage 4.	Surveillance	Not applicable	68.30	67.50	67.30
Gastric					
At least 15 regional lymph nodes are removed and pathologically examined for resected gastric cancer.	Quality improvement	4.5/ 80%	25.00	87.50	90.00
Kidney					
At least 1 regional lymph node is removed and pathologically examined for primarily resected unilateral nephroblastoma.	Surveillance	Not applicable	No data existed	100.00	100.00

Continued

Lung	Measure type	CoC std/ goal	2012	2013	2014
Systemic chemotherapy is administered within 4 months to the day preoperatively or day of surgery, to 6 months postoperatively, or it is recommended for surgically resected cases with pathologic lymph-node-positive (pN1) and (pN2) NSCLC.	Quality improvement	4.5/ 85%	100.00	100.00	90.90
Surgery is not the first course of treatment for cN2, M0 lung cases.	Quality improvement	4.5/ 85%	93.30	96.30	88.10
At least 10 regional lymph nodes are removed and pathologically examined for AJCC stage 1A, 1B, 2A and 2B resected NSCLC.	Surveillance	Not applicable	23.30	33.30	25.00
Ovary					
Salpingo-oophorectomy with omentectomy, debulking/cytoreductive surgery or pelvic exenteration in stages 1-3C ovarian cancer.	Surveillance	Not applicable	84.40	89.60	80.50
Rectum					
Preoperative chemotherapy and radiation are administered for clinical AJCC T3N0, T4N0 or stage 3; or postoperative chemotherapy and radiation are administered within 180 days of diagnosis for clinical AJCC T1-2N0 with pathologic AJCC T3N0, T4N0 or stage 3; or treatment is recommended for patients under the age of 80 receiving resection for rectal cancer.	Quality improvement	4.5/ 85%	89.20	93.50	84.40

Patient-Centered Outcomes Research Initiative 2018

A Commission on Cancer Special Study was released in spring 2018 to investigate outcomes from ductal carcinoma in situ treatment in which The University of Kansas Health System's Cancer Division was a participant. The study was designed as a component of the Comparison of Operative to Monitoring and Endocrine Therapy clinical trial. The study examines the risks and benefits of active surveillance compared to usual care for patients diagnosed with low-risk ductal carcinoma in situ, commonly known as stage 0 breast cancer.

2017 research roundtables

The University of Kansas Cancer Center and the Kansas Masonic Cancer Research Institute conduct a variety of educational activities. These include research roundtables, tumor conferences, symposia and interdisciplinary conferences. In addition to providing supplemental education to our students, physicians and researchers, the purpose of these activities is to achieve a greater level of collaborative research and multidisciplinary interaction.

February 4

James Ford, MD
Seema Khan, MD
Priyanka Sharma, MD
Joyce O'Shaughnessy, MD
Jennifer Klemp, PhD, MPH, MA
Qamar Khan, MD
"San Antonio Breast Cancer Symposium 2017"

February 11

Rafael Bejar, MD, PhD
Barry Skikne, MD
Ronald Hoffman, MD
Tara Lin, MD
Al-Ola Abdallah, MD
Sid Ganguly, MD
Richard Mundis, MD
Abdulraheem Yacoub, MD
"ASH Review: Current Updates in Hematologic Diseases"

March 31

Joe Chang, MD, PhD
"Advanced Radiotherapy for Lung Cancer Treatment"

March 31

Gary Doolittle, MD
"Midwest Cancer Alliance Annual Meeting"

April 1

Chao Huang, MD
Rajib Bhattacharya, MD
Joe Chang, MD, PhD
Allen Chen, MD
Alexander Chiu, MD
Prakash Neupane, MD
"Lung and Head and Neck Symposium"

April 22

Joseph McGuirk, DO
Parameswaran Hari, MD
Linda Burns, MD
Christopher Bredeson, MD
Navneet Majhail, MD
Sid Ganguly, MD
Elizabeth Muenks, PhD
Tara Lin, MD
"Advances in Blood and Marrow Transplantation 2017 Symposium"

September 16

Priyanka Sharma, MD
Prakash Neupane, MD
Weijing Sun, MD
Ossama Tawfik, MD, PhD
Raed Al-Rajabi, MD
Chao Huang, MD
Abdulraheem Yacoub, MD
Joaquina Baranda, MD
"ASCO Review 2017"

October 28

Douglas Yee, MD
John Wright, MD, PhD
Janice Mehnert, MD
Andrew Brenner, MD, PhD
Mark Albertini, MD
Byron Gajewski, PhD
Neil Dunavin, MD
Priyanka Sharma, MD
Weijing Sun, MD
"Bohan Early Phase Program"

December 2

Gastric Cancer
Anwaar Saeed, MD
Christopher Lominska, MD
Peter DiPasco, MD
Weijing Sun, MD
Colon Cancer
Anup Kasi, MD
Andrew Hoover, MD
Benjamin Martin, MD
Breast Cancer
Anne O'Dea, MD
Melissa Mitchell, MD, PhD
"Multidisciplinary Symposium"

2017 tumor conferences

Type of conference	Interval	Number of conferences	Number of analytic cases presented
Departmental: ENT	Weekly	36	308
Departmental: Genitourinary	Bimonthly	20	55
Departmental: Gynecologic	Weekly	50	233
Departmental: Sarcoma	Bimonthly	17	72
Departmental: Thoracic	Weekly	44	300
Multidisciplinary	Weekly	31	58
Site-focused: Bone marrow/BMT	Weekly	39	228
Site-focused: Breast	Weekly	46	160
Site-focused: Gastrointestinal	Weekly	39	246
Site-focused: Hemepath	Weekly	26	60
Site-focused: Melanoma	Monthly	12	35
Site-focused: Neuro-oncology	Bimonthly	22	99
Site-focused: Thyroid	Monthly	12	117
Totals		**394**	**1,971**

2017 county distribution

Kansas by place of residence at diagnosis	Missouri by place of residence at diagnosis
Johnson: 19.29%	Jackson: 17.92%
Wyandotte: 7.84%	Clay: 9.39%
Shawnee: 3.65%	Platte: 3.83%
Leavenworth: 2.75%	Cass: 2.27%
Douglas: 2.51%	Buchanan: 1.52%
Sedgwick: 1.51%	Other Missouri: 9.41%
Other Kansas: 14.92%	**Total Missouri: 44.34%**
Total Kansas: 52.47%	

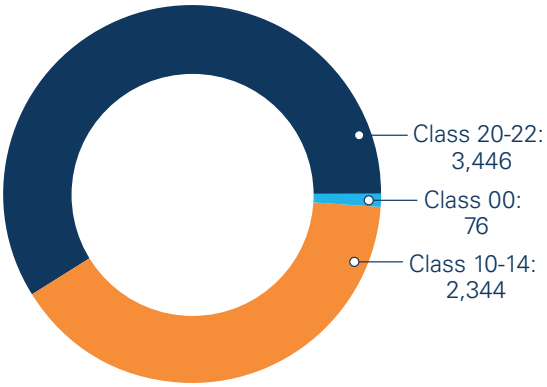
All other states: 2.82%
Unknown county or state: 0.29%
Foreign residents: 0.08%

2017 primary site table

Primary site	Analytic	Nonanalytic	Total
Oral cavity	234	20	254
Lip	5	0	5
Tongue	72	9	81
Oropharynx	8	0	8
Hypopharynx	1	0	1
Other	148	11	159
Digestive system	897	92	989
Esophagus	71	2	73
Stomach	60	2	62
Colon	209	32	241
Rectum	102	14	116
Anus/anal canal	23	2	25
Liver	177	14	191
Pancreas	168	11	179
Other	87	15	102
Respiratory system	604	65	669
Nasal/sinus	17	5	22
Larynx	44	15	59
Other	7	2	9
Lung/bronc-small cell	85	7	92
Lung/bronc-nonsmall cell	425	34	459
Other bronchus/lung	26	2	28
Blood & bone marrow	476	90	566
Leukemia	266	49	315
Multiple myeloma	135	29	164
Other	75	12	87
Bone	38	5	43
Connect/soft tissue	108	6	114
Skin	392	47	439
Melanoma	363	43	406
Other	29	4	33
Breast	1,038	64	1,102
Female genital	339	24	363
Cervix uteri	34	2	36
Corpus uteri	198	7	205
Ovary	84	13	97
Vulva	15	0	15
Other	8	2	10
Male genital	457	84	541
Prostate	418	80	498
Testis	28	4	32
Other	11	0	11
Urinary system	491	86	577
Bladder	192	47	239
Kidney/renal	279	34	313
Other	20	5	25
Brain & CNS	256	21	277
Brain (benign)	16	2	18
Brain (malignant)	114	9	123
Other	126	10	136
Endocrine	178	35	213
Thyroid	137	17	154
Other	41	18	59
Lymphatic system	265	50	315
Hodgkin lymphoma	27	6	33
Non-Hodgkin lymphoma	238	44	282
Unknown primary	63	3	66
Other/ill-defined	30	14	44
All sites	**5,866**	**706**	**6,572**

2017 statistical graphs – analytic cases

Class distribution

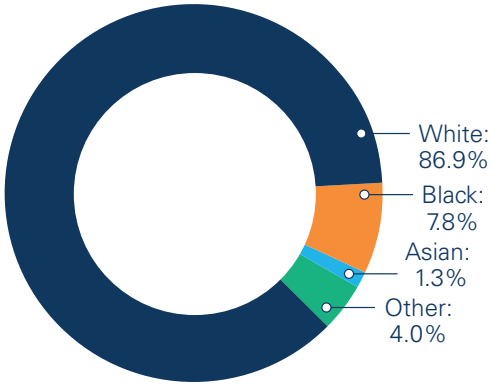


Class 00: Diagnosed here, all treatment elsewhere.

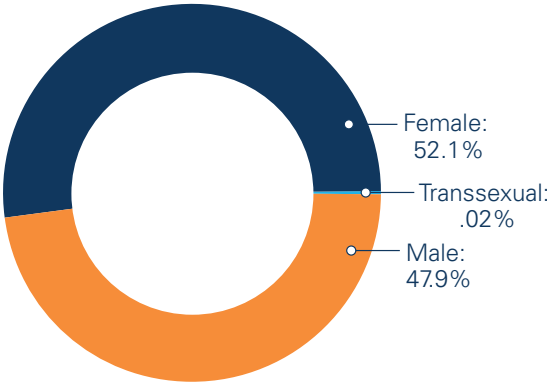
Class 10-14: Diagnosed here, all or part of first-course treatment here.

Class 20-22: Diagnosed elsewhere, all or part of first-course treatment here.

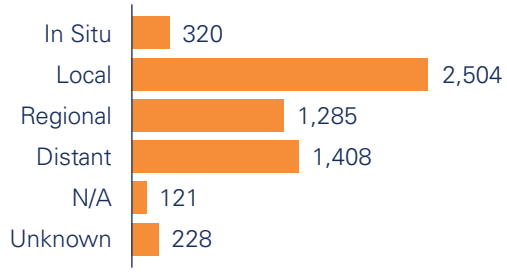
Race distribution



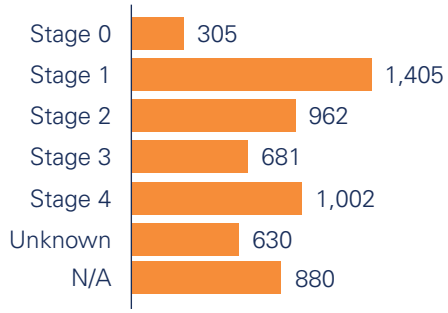
Sex distribution



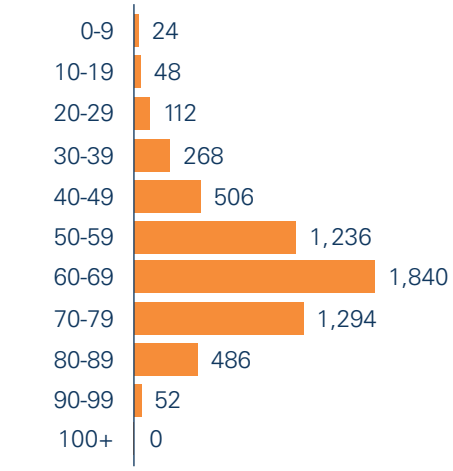
SEER summary stage at diagnosis (n=5,831)



AJCC stage group at diagnosis (n=5,831)

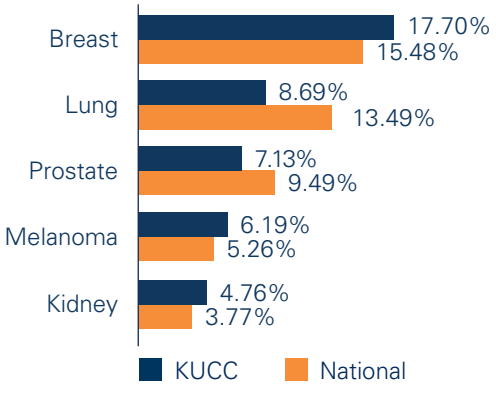


Age at diagnosis (n=5,831)



Top five primary sites

American Cancer Society statistics



Ensuring same-day, next-day appointments for newly diagnosed cancer patients essential to patient-centered care

Teri Banman, RN, OCN
Director, Nurse Navigation
Cancer Center Navigation

There's nothing quite like hearing the words, "You have cancer."

At a time when newly diagnosed patients are understandably anxious and emotional, there is no substitute for sitting down with a physician face-to-face to discuss the possibilities. The rapid access program at The University of Kansas Cancer Center, the region's only National Cancer Institute-designated cancer center, is designed to help allay patient anxiety by making appointments faster with our nationally renowned cancer specialists.

The new program is for patients with a cancer diagnosis or a high probability of cancer. The program is being phased in, starting with breast cancer and gynecologic cancer physicians at The Women's Cancer Center at the Indian Creek Campus in Overland Park, Kansas, and the Richard and Annette Bloch Cancer Care Pavilion in Westwood, Kansas.

Our program is the only one in the region that offers same-day or next-day appointments with a disease-specific physician who specializes in the patient's particular cancer.

Lessening anxiety

Every cancer patient's experience will likely be challenging, frightening and worrisome. Unfortunately, we can't take that away from our patients. But with a rapid access visit, we can take away some of the anxiety about whether they receive quality care in a timely way.

During the initial visit, we talk with a patient about the specialty physicians they will likely see, such as a surgeon, medical oncologist and radiation oncologist, tests they will need, and how and when they will be scheduled. We may not be able to tell them everything at their initial visit, but we can answer their questions, educate them on their diagnosis and ensure they have some understanding of how their care and treatment will unfold.

Program at a glance

Initially, select breast cancer and gynecologic cancer physicians reserve time in their schedule for same-day or next-day appointments. When a patient calls, our nurse navigators inform them of the same-day, next-day appointment option and offer the first available opening.

Before the rapid access appointment is confirmed, the nurse navigator informs the patient that to develop a full treatment plan, physicians need the patient's medical records, including imaging. Obtaining these records from an outside provider in less than 24 hours may not be possible in every instance.

The nurse navigation team works diligently to gather a patient's records as quickly as possible. In the event the nurse navigator is unable to obtain this vital information, a patient may choose to wait for their records to ensure they leave their first appointment with a full treatment plan.

An opportunity to choose

Whether a patient chooses a rapid access appointment or decides to wait, we know that being able to promote swift appointments for cancer patients has multiple benefits.

Patients and referring physicians appreciate knowing we prioritize rapid appointments whenever possible. Most important, the program reinforces our commitment to patient-centered care.

Offering the program also helps patients know The University of Kansas Cancer Center is committed to doing all we can to help them get access to the very best care as quickly as possible. Since the program launched, disease-site specialists in genitourinary and gastrointestinal cancers have been added. By early 2019, oncology specialists in head and neck, malignant hematology and blood and marrow transplant will also offer rapid appointments.

Having a cancer center physician available to talk with patients within 24 hours of receiving a cancer diagnosis is tremendously reassuring for patients because we can offer expertise, care and support. Providing same-day or next-day appointments doesn't mean we rush care and treatment that compromises quality. But it allows us to relieve some of the anxiety associated with decision-making about cancer care and treatment – and that enhances the quality care we provide.

Monitoring compliance with evidence-based guidelines, hepatocellular carcinoma of liver, 2017 case analyses

Liver cancer cases

Raed Al-Rajabi, MD
Associate Professor, Medical Oncology
Department of Internal Medicine, University of Kansas Medical Center

In 2017, there were an estimated 40,710 new cases of liver cancer in the United States (per American Cancer Society 2017 Facts and Figures). Approximately three out of four primary liver cancers were hepatocellular carcinoma (HCC). HCC is the sixth most common type of cancer, with a high mortality rate and an increasing incidence worldwide.

Liver cancer is three times more common in men than in women. Since 1980, the incidence of liver cancer has tripled, and, in fact, risen about 4% per year from 2004 to 2013. The number of deaths resulting from liver cancer also increased about 3% per year since 2000. The disease claimed the lives of an estimated 28,920 people in the United States in our year of focus – 2017.

Symptoms at presentation

Unfortunately, liver cancer does not typically present notable symptoms until it reaches an advanced stage. At an advanced state, liver enlargement often causes or exacerbates symptoms, including loss of appetite, unintentional weight loss, jaundiced skin and eyes, fever and abdominal pain.

Risk factors

In the United States, the most common risk factors for the disease include chronic infections from the hepatitis B virus (HBV) or the hepatitis C virus (HCV), heavy alcohol consumption, smoking, obesity, fatty liver disease and diabetes. Rare genetic disorders, such as hemochromatosis, also have been associated with risk factors for the disease. Being male is also a risk factor, as men are three times more likely to develop the disease than women.

Early detection

Research shows that screening does not reduce the risk of liver cancer mortality; however, high-risk patients such as those with liver cirrhosis or chronic HBV or HCV, can have liver cancer testing with ultrasound. Since the disease is usually asymptomatic in its early stages, the main preventive measures are maintaining a healthy weight, not smoking or drinking to excess, and having the hepatitis B vaccine, which helps prevent HBV. Currently, there is no vaccine for HCV.

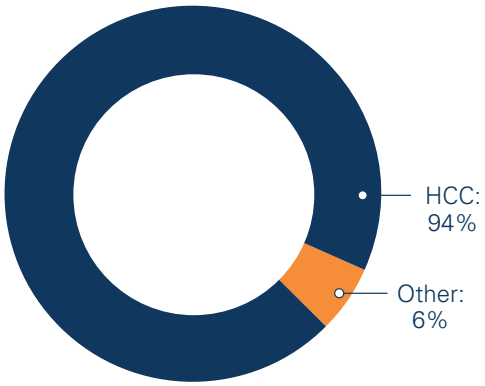
National guidelines for treatment

The University of Kansas Cancer Center follows evidence-based clinical guidelines for determining treatment based on disease stage as found in the National Comprehensive Cancer Network (NCCN). These guidelines are site-specific and based on multiple presenting factors and cancer stage at presentation and recurrence. NCCN treatment guidelines for liver cancers are specifically outlined within the hepatobiliary category. For early disease, surgery, radiation or transplant may be an option. Since early detection is rare, there may not be enough healthy liver tissue to allow locoregional treatment. Performance status and overall health also factor into treatment, as does the location of the tumor within the organ. If a tumor is located near vital blood vessels, surgery may not be an option.

The University of Kansas Cancer Center liver patient population

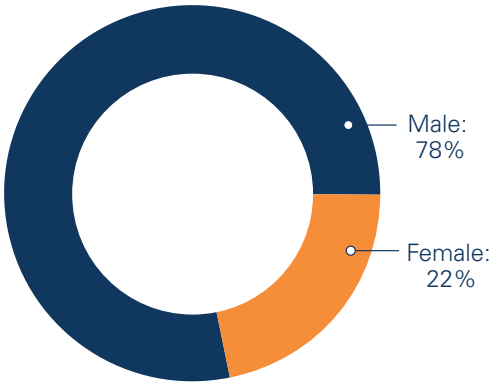
Histologies

In 2017, The University of Kansas Cancer Center had 156 cases of primary liver cancer. For the purposes of this study, we focus on the 146 analytic liver cancer cases of HCC. The other nine cases that were not HCC included lymphoma, adenocarcinoma, clear cell carcinoma, mixed cell histology and cholangiocarcinoma.



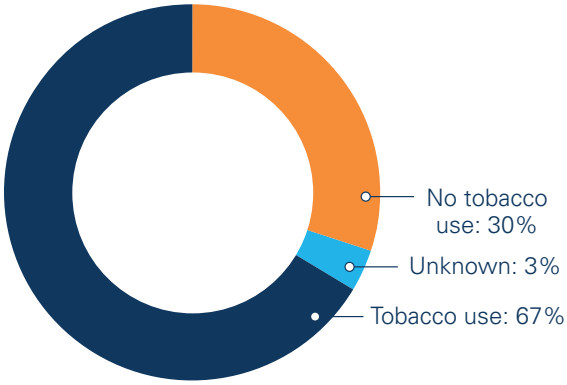
Distribution by sex

Sex distribution is statistically similar to nationally published data. Liver cancer is more prevalent in men, as seen in the below chart.



Tobacco use

Of the 146 patients presenting with HCC, 67% were former or current tobacco users, as expected per national statistics. This shows tobacco use as a causative factor for the disease.



Summary of HCC treatment – clinical American Joint Committee on Cancer stage at diagnosis (n=146)

Treatment	Stage I	Stage II	Stage IIIA	Stage IIIB	Stage IIIC	Stage IVA	Stage IVB	Unknown	Totals
TACE	12	4	2	2		1	2	1	24
TACE/Radiation	3				2				5
TACE/RFA	22	12	2					1	37
TACE/ Hepatectomy (partial)	1	1	2						4
TACE/Transplant	1	1							2
RFA	8	4					1		13
RFA/Nexavar		1							1
Hepatectomy (partial)	5	4					1		10
Transplant	1	2							3
Surgery/TACE/ Radiation			1	2					3
Radiation Only	1	4	2	4		2	1		14
Radiation/ Immunotherapy							1		1
Nexavar/Radiation				1			1		2
Nexavar			1	2		1	2		6
Immunotherapy	1			1					2
Nexavar/ Immunotherapy						1			1
No Treatment	2	3		5	1	1	4	2	18
Totals	**57**	**36**	**10**	**17**	**3**	**6**	**13**	**4**	**146**

Early-stage disease can at times be treated surgically with partial hepatectomy. This option involves removal of part of the liver and depends on the amount of healthy liver tissue. Transplantation from an autologous liver is also possible for patients with small tumors who are not candidates for partial hepatectomy. Tumor ablation or embolization are also procedures we apply to destroy the tumor.

Given the nationwide statistics, we had a surprising 73 cases within our population that received surgery as part or all of their first course of cancer-directed treatment. That is almost half of our population being examined.

Transarterial chemoembolization

Sixty-nine patients received TACE or chemoembolization as part or all of their treatment.

Radiofrequency ablation

Fifty patients were treated with RFA. This treatment uses soundwaves directed toward the lesion(s) to destroy the tumor.

Partial hepatectomy

Fifteen patients had partial or total hepatectomy to surgically remove the diseased part of the liver.

Liver transplant

Seven patients had liver transplants as their first course of cancer-directed treatment. All were AJCC stage I or stage II. An additional stage I patient had a transplant after a delayed first course of treatment.

Radiation

Twenty-three patients were treated with SIR-Spheres® Y-90; one stage IVB case had palliative radiation to brain metastasis.

Oral chemotherapy

If severe cirrhosis is not present, sorafenib (Nexavar®) or lenvatinib (Lenvima®) can be used for more advanced disease. One patient declined treatment, one received treatment as a subsequent course of cancer care and it was recommended for an additional seven patients, but their poor functional status disallowed the treatment.

Immunotherapy

Five patients received immunotherapy with nivolumab (Opdivo®). Pembrolizumab (Keytruda®) has recently been approved for treatment of advanced hepatocellular carcinoma.

No cancer treatment

One stage I patient identified as "no treatment" had subsequent, second-course treatment with a liver transplant. The other four early stage cancers had comorbid conditions that disallowed cancer-directed treatment.

Summary

In summary, after careful analysis and review of the 146 HCC patients, all treatment, or lack thereof, was in accordance with NCCN and other national guidelines for cancer-directed care.

National Cancer Institute designation

Through world-class research and patient care, The University of Kansas Cancer Center is working toward a world without cancer. As one of only 70 National Cancer Institute-designated cancer centers in the country, The University of Kansas Cancer Center is committed to providing the highest level of research, treatment, prevention and survivorship services available.

Why NCI designation is important

NCI designation is only awarded to the nation's premier cancer research and treatment centers. NCI-designated cancer centers are pioneers in cancer research, recognized for scientific leadership, resources and depth of research in basic, clinical and population science.

NCI designation transforms our region

Each year, approximately 14,500 Kansans are diagnosed with cancer. The University of Kansas Cancer Center's NCI designation allows these patients to remain close to home while receiving the most advanced cancer care from a deep bench of specialists.

- Patients treated at NCI centers have a 25% greater chance of survival.
- 22,000-plus individuals enrolled in clinical trials since 2010.
- More than 90% of Kansas City patients now receive lifesaving cancer treatments close to home.
- Economic driver – more than 3,600 jobs created and $2.5 billion in economic development as of 2018.

Joining forces to fight cancer

Our cancer efforts are bolstered by our NCI-recognized consortium partners, Stowers Institute for Medical Research and, more recently, Children's Mercy Hospital. Together, we represent more than 350 cancer researchers and clinicians.

Partnering with Children's Mercy further strengthens our collective efforts, particularly in addressing pediatric cancer. The NCI has identified children as an underserved population in cancer research. With the physicians and researchers at Children's Mercy focused entirely on pediatrics, this partnership makes a meaningful impact on pediatric cancer research. Together, our research and clinical care program spans the entire spectrum of patients, from infants and children to adults.

Focused prevention and treatment efforts

As an NCI-designated cancer center, we disseminate cancer prevention methods and provide early detection screenings to the diverse and far-reaching communities we serve by:

- Improving access to prevention services and cancer treatment for underserved, high-risk and minority communities
- Decreasing smoking rates, increasing human papillomavirus vaccinations and reducing obesity rates through public education and outreach programs
- Identifying new therapies and prevention strategies, and improving cancer patient/survivor quality of life with innovative clinical trials
- Informing national research and treatment priorities through evidence-based work with specific populations

Our journey continues

NCI centers like ours pioneer improved cancer treatments that contribute significantly to the 15 million-plus cancer survivors in the U.S. But there is more work to be done.

- New cancer cases diagnosed annually in the United States will increase nearly 50% by 2030.
- Cancer is the No. 1 cause of death in Kansas and the No. 2 cause of death in Missouri.
- 1 in 2 men and 1 in 3 women will be diagnosed with cancer in their lifetime.

The future in cancer treatment

The NCI Cancer Centers Program is one of the anchors of the nation's cancer research effort. This means our patients have more opportunities to take part in clinical trials that test the latest treatment advancements. We envision a cancer-free Kansas and beyond, and that is only possible when we put forward our best efforts.

- Highly personalized cancer treatments for each unique patient
- Newest, most promising therapies and laboratory discoveries
- Highly trained, multidisciplinary team, including physician-scientists
- Innovation in drug discovery and development

The University of Kansas Cancer Center is committed to elevating standards in cancer care, and we are moving furiously to translate laboratory discoveries into clinical patient care.

Next leg of the journey: NCI Comprehensive Cancer Center designation

In 2017, the NCI renewed The University of Kansas Cancer Center's designation, elevating our score from "excellent" to "outstanding." Equally significant, Children's Mercy joined Stowers Institute for Medical Research as a formal NCI consortium partner.

December 2018 marks approximately 1,000 days until the next application due date. Cancer center leaders are developing a strategic plan and outlining the roadmap for 2021 when we will reapply for Comprehensive Cancer Center status. The roadmap includes the core features that make up all NCI Comprehensive Cancer Centers:

- Drive scientific discovery
- Translate discovery to benefit patients
- Change the practice of medicine
- Impact public policy
- Train the next generation of medical staff

Cancer patient support services

Nurse navigation services

Our nurse navigators guide patients from their first call through their treatment process and follow-up. They answer questions and offer emotional support every step of the way. Nurse navigators make sure patients are prepared to meet with specialists and their cancer care team by collecting medical records, getting orders for tests when needed and identifying support services for patients and their caregivers.

Social services

Our social workers assist patients in both inpatient and outpatient settings. In addition to helping patients and their loved ones cope with distress related to their cancer diagnosis and treatment, our social workers provide resources for lodging, transportation, home care services and financial concerns, including medication assistance programs. They also provide information on Social Security disability and Medicaid and make referrals to community resources that offer numerous classes and programs.

Onco-psychology services

Our licensed psychologists provide patients and their caregivers support for the mental, emotional and behavioral aspects of the cancer experience. They provide assessment, consultation and evidence-based therapeutic interventions and counseling for individuals, groups, families and couples. They also help patients adjust to the lifestyle and behavior changes that accompany cancer diagnosis, treatment and survivorship. Short-term crisis resolution and grief counseling for caregivers and family members are also available.

Nutrition services

Our dietitians provide individualized nutrition care to patients and work with caregivers in helping patients achieve optimal nutrition at home. Our dietitians work closely with each patient's healthcare team to provide comprehensive care, with the goal of keeping patients strong, maintaining muscle mass, promoting healing, treating nutritional deficiencies and minimizing complications and side effects of cancer. Ultimately, the dietitian's goal is to promote overall better quality of life before, during and after cancer diagnosis and treatment through good nutrition.

Spiritual services

We offer pastoral care/spiritual services for our patients and hospital visitors to help them meet their spiritual needs. Members of our spiritual care team are available on request to everyone. All of our spiritual care team members are ordained ministers and able to offer prayer, pastoral counseling and worship services.

Financial counseling services

Our financial counselors help patients navigate the cancer journey by understanding the costs of cancer and insurance implications, and the complex application process for Medicaid and other financial assistance programs. They also assist patients in securing financial benefits from these programs and from private health insurance. The Patients in Need Fund at Missys' Boutique at our Westwood campus helps uninsured and underinsured patients receive the boutique's cancer-related services and products at no charge.

Educational resource services

Our patient resource centers provide answers, resources and support for cancer patients, their families and the community. Staffed by an experienced oncology nurse, each center offers information about specific types of cancer, treatments, clinical trials and other cancer-related issues. A variety of cancer-related programs and educational classes is offered throughout the community as well. Others are available through televideo.

Practical and emotional support groups

Our staff facilitates support groups and educational programs for patients and families affected by gynecologic, breast, renal cell, head and neck, prostate and other cancers, along with groups for caregivers. Patients and families also receive information about community cancer support groups and agencies that provide practical and emotional support.

Turning Point: The Center for Hope and Healing in south Kansas City, a program of The University of Kansas Health System, provides educational programs at different locations throughout the greater Kansas City area at no charge. Topics include mind/body, movement, nutrition, art and more for all patients with chronic illnesses. It also offers programs for children of all ages and their family members.

Onco-rehabilitation services

Our onco-rehabilitation physiatrist works with cancer patients and caregivers in inpatient and outpatient settings to help them maintain and improve their functional abilities, alleviate pain, minimize fatigue and improve quality of life. Occupational therapists focus on helping patients with activities of daily living, and speech pathologists help patients who have difficulty with communication, cognition or swallowing.

Personal appearance services

Missys' Boutique, located at our Westwood Campus, is an accredited appearance center dedicated to helping patients overcome appearance obstacles with dignity and style. Services include bra and wig fittings. Products include breast forms, postsurgery bras and camisoles and a wide assortment of clothing and accessories.

Survivorship services

Surviving cancer begins the day of diagnosis and continues every day after. Survivorship services include:

- Providing patients with treatment summaries
- Providing ongoing care of survivors and their caregivers
- Scheduling follow-up appointments
- Referring patients to appropriate support services to address late effects such as energy balance or cognitive concerns

Fertility preservation services

Cancer treatments result in fertility challenges following treatment. We provide fertility preservation services in which eggs and sperm are harvested from the body, preserved through freezing and transplanted back after treatment.

Palliative care

Palliative care focuses on how well patients with a terminal illness can live better every day. We provide for the medical, emotional and spiritual needs of patients of all ages with illnesses at any stage. Outpatient services are offered through the Allen J. Block Outpatient Palliative Care Program.

Genetic counseling

Through genetic consultation, we are able to help patients proactively. With a full assessment of risk factors and family history, we can better understand the underlying cause of a patient's disease. This allows us to more accurately predict the patient's response to treatment and create a highly individualized treatment plan.

Pharmacy patient advocate services

We provide pharmacy patient advocates, or PPAs, who answer patients' questions or concerns, reorder medications and streamline payment processing.

Second opinion services

We offer second opinions to provide patients and referring physicians the opportunity to receive multidisciplinary opinions and the confidence to begin treatment.

National Cancer Institute Cancer Information Service

The NCI Cancer Information Service provides the latest and most accurate information to patients, their families, the public and healthcare professionals. This national information and education network is a free public service of the NCI. Call toll-free 800-4-CANCER.

Biospecimen Bank

The Biospecimen Bank at The University of Kansas Cancer Center supports cancer research by serving as a bank for human tissues and fluids. Researchers use these biospecimens to study causes, prevention, detection, diagnosis and treatment of cancer. Find out how you can make a tissue or fluid donation by calling toll-free 855-211-1475.

Glossary of terms

Accession number: A unique number assigned to each patient entered into The University of Kansas Health System's Cancer Registry. The first four digits specify the year of diagnosis. The last four numbers are the numeric order in which the case was entered into the database.

Adjusted (observed) survival rate: Whenever reliable information on cause of death is available, an adjustment can be made for deaths due to causes other than the disease under study. Patients who died without disease are treated in the same manner as patients "last seen alive during the year."

AJCC stage: A staging system developed by the American Joint Committee on Cancer and the International Union Against Cancer. It takes into account the tumor size (T) and/or depth of invasion, lymph node involvement (N) and distant metastases (M). A combination of T, N and M elements gives an overall classification of stage 0, 1, 2, 3, 4 or unknown stage.

Analytic case: A case that is first diagnosed and/or receives all or part of the first course of treatment at The University of Kansas Cancer Center.

Distant: A malignant neoplasm that has spread to parts of the body remote from the primary tumor either by direct extension or by discontinuous metastasis to other organs, tissues or lymph nodes.

In situ: A neoplasm that fulfills all microscopic criteria for malignancy without invasion.

Localized: A locally staged neoplasm that is restricted to the organ of origin.

Nonanalytic case: A case that was diagnosed elsewhere and received all the first course of treatment at another institution, presenting here for recurrence or progression of disease.

Regional: A neoplasm that has spread by direct extension to immediately adjacent organs or tissues and/or regional lymph nodes.

Systemic: A neoplasm that is disseminated throughout the body or found in blood and/or bone marrow.

Unknown: A neoplasm whose stage cannot be determined by a medical authority or indeterminate stage from the medical record.

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2017 Cancer Committee members

Joshua Mammen, MD, PhD
Committee Chair
Division Director
Surgical Oncology

Sunil Abhyankar, MD
Hematology/Oncology

Mazin Al-kasspooles, MD
Surgical Oncology

Raed Al-Rajabi, MD
Medical Oncology

Hobs Apell
Senior Executive Director
Clinical Trials Office

Paul Arnold, MD
Neurosurgery

Teri Banman, RN, OCN
Director, Nurse Navigation
Cancer Center Navigation

BJ Broome
Senior Director
Clinical Trials Office

Rhonda Cherry, LMSW
Social Work

Carol Cleek, RN, MSN, CCNS, CCRN
Senior Director of Nursing

Debra Collins, MS, CGC
Genetic Counseling

Meredith Cooper, BA
Quality Analysis Coordinator

Devin Cox, MS, CGC
Genetic Counselor

Pam Crawford
Strategic Marketing
Program Manager

Peter DiPasco, MD
Surgical Oncology

Gary Doolittle, MD
Hematology/Oncology

Meagan Dwyer, PhD
Onco-psychology
Program Director

Debbie Fernandez, LMLP, MHSA, CPHQ
Director, Oncology
Service Line Quality
Cancer Center

Timothy Fields, MD, PhD
Pathology and Laboratory Medicine

Tanya Folker
Information Technology
Pharmacist

Julie Ginter, MS, L/CCC-SL PT, MS, MBA
Director, Rehabilitation Services

Douglas Girod, MD
Otolaryngology

Jessica Hamilton, PhD
Onco-psychology

Jeffrey Holzbeierlein, MD
Chair, Urology

Ashley Huber
Chaplain

Marc Inciardi, MD
Radiology

Theresa Jackson, RHIA
Director, Health Information Management

Thu Janes, RN
Assistant Director of Nursing

Roy Jensen, MD
Director, The University of Kansas Cancer Center

Andrea Jewell, MD
Gynecologic Oncology

William Jewell, MD
General Surgery

Ed Johnson
Representative for
American Cancer Society

Marsha Klein, BS, CTR
Cancer Registrar

Jennifer Klemp, PhD, MPH
Breast Cancer Prevention Center

Janet Kliethermes, MA
Assistant Director, Pathology and Laboratory Medicine

Hope Krebill, BSN, RN, MSW
Executive Director,
Midwest Cancer Alliance

Christopher Lominska, MD
Radiation Oncology

Joseph McGuirk, DO
Division Director, HMCT
Hematology/Oncology

Tim Metcalf, BS, CTR
Manager, Cancer Registry

Kirk Miller, DO
Radiology

Melissa Mitchell, MD, PhD
Radiation Oncology

Mark Myron, MD
Medical Oncology

Michele Park
BRCF Database Manager

Rachel Pepper, RN
Chief Nursing Officer,
Kansas City Operations

Tammy Peterman, MS, RN
Executive VP, COO, CNO
and President
Kansas City Operations

Sonja Pittrich
Rehabilitation Manager

Karin Porter-Williamson, MD
Division Director,
Palliative Medicine

Van Rickard, LMSW, CCM
Social Work Case Manager

Michael Salacz, MD
Medical Oncology

Leigh Anne Scott, PharmD
Director of Pharmacy

Lisa Serig, MBA
Director of Operations
Cancer Center

Maureen Sheehan, MD
Hematology/Oncology

Xinglei Shen, MD
Radiation Oncology

Christian Sinclair, MD, FAAHPM
Palliative Medicine

Laura Smith
Clinical Dietitian

Terri Thompson, MBA
RT Director, Radiation Oncology

Terance Tsue, MD
VP, Physician Services
VP, Physician in Chief,
Cancer Center

Nirmal Veeramachaneni, MD
Cardiothoracic Surgery

Ashley Wagner, CTR
Lead Cancer Registrar

Jamie Wagner, DO
Division Director, Breast Surgery

Jeff Wright
Vice President, Cancer Services

Hadley Wyre, MD
Urology Surgery

Da Zhang, MD
Pathology and Laboratory Medicine

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